

Reading with early-stage Alzheimer's disease.

Modifications to book design as a way of  
supporting preserved literacy skills

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## **Abstract**

Little attention has been paid by publishers of accessible texts to the needs of readers who have early-stage Alzheimer's disease but who want to continue to read for pleasure. The aim of this thesis is to explore the effect on reading of the specific memory impairment that is characteristic of this form of dementia and to investigate whether there are modifications to text design or content that would be beneficial. A qualitative approach involving iterative testing was taken to the research. An initial scoping study established the nature of the condition and assessed the feasibility of volunteer recruitment. Collaboration with established organisations was chosen to ensure consistency of participant diagnosis and adherence to strict ethical guidelines. Three small-scale participant-centred studies were carried out involving both one-to-one interviews and group meetings. A reflexive approach ensured that the research findings were constantly reviewed. Sample materials were devised to simulate the experience of reading a printed book. Using a combination of published texts and improvised visual materials, the samples highlighted specific problems with content and presentation that had been identified in the published literature and by informants during the scoping study. With careful questioning by the researcher, participants were able to choose between contrasting memory-supporting features and to articulate their further needs. A favourable response was received to the addition of descriptive illustrations to works of fiction, providing plot summaries at the start of each new chapter, and printing a list of characters in the prelims or on a jacket flap. Visualisation skills were also reported by a number of informants as being unaffected by a cognitive impairment. The studies confirm the contribution made by multidisciplinary research to the field of dementia studies. Participant involvement in the research combined with medical knowledge and publishing heuristics produced an innovative approach to a multifaceted problem.

**Declaration**

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Marie Leahy

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The poem by Muriel Spark, 'Authors' Ghosts' (p. 11), is quoted by permission of David Higham Associates. It is included in *Muriel Spark: All the Poems*, published by Carcanet Press (2004).

I am grateful to all the publishers who have given me permission to include images from their books. Particular thanks are due for Figs 3 and 4 – Younger People with Dementia (Berkshire); Figs 5 and 28 *Dear Zoo* copyright © Rod Campbell 1982, 2007 – Macmillan Children's Books; Figs 8a, 8b and 31 – Simon & Schuster (UK) Ltd; Figs 30, 33, 35 and 36 – Jamie Stonebridge; Fig. 37 – Jonathan Friedman, Rainbow Ridge Books, Virginia Beach, VA.

In order to comply with current copyright regulations, certain images have been withdrawn from this public version of the thesis. The images concerned are Figs 6a, 6b, 26, 27, 32 and 34.

## **Authors' Ghosts**

I think that authors' ghosts creep back  
Nightly to haunt the sleeping shelves  
And find the books they wrote.  
Those authors put final, semi-final touches,  
Sometimes whole paragraphs.

Whole pages are added, re-written, revised,  
So deeply by night those authors employ  
Themselves with those old books of theirs.

How otherwise  
Explain the fact that maybe after years  
Have passed, the reader  
Picks up the book – But was it like that?  
I don't remember this ... Where  
Did this ending come from?  
I recall quite another.

Oh yes, it has been tampered with  
No doubt about it –  
The author's very touch is here, there and there,  
Where it wasn't before, and  
What's more, something's missing –  
I could have sworn ...

Muriel Spark (1918–2006)

# **1 Introduction**

## **1.1 Reading printed books**

Despite the competition offered by television, cinema and digital media, reading remains a popular pastime for much of the UK population. A surprisingly large number of readers also appear to enjoy printed books. In fact, a recent report by Nielsen BookScan (2020) states that 191.6 million books were sold in 2019, making this the print market's fifth consecutive year of growth. Only a proportion of these titles will have been bought for recreational reading, but the habit of reading for pleasure still seems to be firmly established in the UK. A similar conclusion was reached by the survey of the Royal Society of Literature carried out in 2019 (RSL 2019), which questioned a representative sample of participants about their attitude to 'literature'. The term was deliberately not defined, and respondents were invited to interpret it as they wished, but the answers they gave indicated that a large proportion of the public valued the written works of published authors. Sadly, the report did not distinguish between audio books and printed and electronic texts, so the report's findings cannot be taken as evidence purely of reading the written word; however, they do suggest that narrative has an important part to play in the cultural life of a large number of individuals. A review of the report by Professor Dame Hermione Lee provides an insight into the significance of the findings:

Literature matters: to society, to education, to future generations. It matters for our minds, brains and hearts; it matters because it widens our scope of life and intensifies our perceptions; it takes us on journeys, invites us to share our lives with strangers, challenges and threatens, moves and changes us. It matters to every one of us; and it matters to me. (RSL 2019)

This thesis takes as its premise that there are a number of individuals living in the UK who have enjoyed books for many years but who have developed Alzheimer's

disease and are beginning to experience difficulties with reading. The thesis seeks to explore the particular issues that such readers encounter and to suggest design modifications that might help to alleviate the problems. It makes no claim for the benefits of reading ('bibliotherapy'), or for the advantages of shared reading, though these will be considered below; instead, it aims to explore the views and the personal experience of individuals whose literacy skills have been affected by dementia and to make positive suggestions for improvements to the material attributes of printed books for reading. The 'What if?' strategy adopted by designer and academic Graham Pullin is put to the test here in the context of book design (Pullin 2009).

## **1.2 Outline of the context and aim of the thesis**

The context of the thesis is the growing awareness of the potential for accessible publishing to meet the needs of different readerships. The aim of the thesis is to investigate the ways in which design might help readers who have Alzheimer's disease. Each of these aspects is considered below.

### **1.2.1 The context of the thesis**

The experience of reading for pleasure by individuals who have early-stage Alzheimer's disease is a relatively new area of research. The reasons why investigation has so far been limited are complex, but a significant issue would seem to be that the study of reading with a cognitive impairment does not fit naturally within any single discipline. The work of gerontologists (Salthouse and Craik 2008/2016) is mainly concerned with describing the aetiology of the disease and its physical manifestations; clinical psychologists (Patterson and Hodges 1992; Bayles and Tomoeda 2014) have analysed the effect of a memory impairment on literacy skills, though not on the continuous reading of narrative prose; healthcare workers may be trained to see apathy and a reduced capacity to initiate as typical manifestations of Alzheimer's disease (Starkstein, Jorge and Mizrahi 2006) even though recent research suggests that psychological accommodation may be a response to a lack of visual stimulus (Newman, Goulding, Davenport and Windle

2019). Furthermore, the published literature on the recreational reading habits of individuals who have early-stage Alzheimer's disease is not extensive. A few small-scale publishing initiatives have taken steps to produce books especially for this readership, but their output is limited, and the design of their books is relatively unsophisticated (see Discussion, p. 204). Reading with dementia poses a number of complex, multi-faceted questions.

The current understanding of the disease is summarised on the website of the Alzheimer's Society. Here the Society confirms that, 'More than 520,000 people in the UK have dementia caused by Alzheimer's disease and this figure is set to rise' (Alzheimer 2020a). Information is constantly being reviewed and, drawing on the latest published literature, the website states that change to the hippocampus (located on each side of the brain) is implicated in the memory impairment that is characteristic of the condition. Both episodic and semantic memory may be affected, and the retrieval of recently experienced incidents is particularly vulnerable. Successful extended reading relies on the interplay of newly decoded information being blended with information that is stored in long-term memory to produce a coherent whole. Alzheimer's disease would seem to affect precisely this intricate comprehension process.

Relatively little attention has been paid to the experience of the reader during the early stages of the disease. This may in part be due to a misapprehension of the gradual nature of its onset and a tendency to focus only on the effects of the disease in its advanced stages. However, with the re-describing of dementia as a longer-term disability (Equality Act 2010; APPG 2019) it is possible that this may change. The social model of disability states that individuals have the right to written information (CRPD 2006; Thomas and Milligan 2018), and online information must be designed with this in mind (Gov.uk Design System 2020). This right to access is gradually being extended to areas that are not just concerned with activities of daily of living, but which make a contribution to a person's quality of life. Reading is known to be a source of enrichment and pleasure to many. However,

the UK publishing industry has been slow to meet the needs of non-typical readers, perhaps because this sector of the market is not regarded as significant source of revenue. Even a comprehensive study such *The Oxford Handbook of Publishing* (Phillips and Bhaskar 2019) makes no mention of the needs of readers with dyslexia let alone a cognitive impairment; the topic of diversity is confined to a discussion of employee numbers and the need for a more inclusive approach in subject matter (le Roux 2019, pp. 86–95).

The present study has grown out of earlier research (Leahy 2013) which looked at the issues raised in the design of illustrated books for readers with later stage dementia. The books available for these individuals are growing in number and are limited to shared reading (e.g., Pictures to Share 2020). The design requirements of publications such as this fall into two categories: first, the typeface, page layout, and the choice and cropping of illustration must be particularly clear, engaging and unambiguous; second, the text and the format of the book must be appropriate for two people to read simultaneously, with both the content and the illustration providing natural stimulus for conversation. The needs of this readership are gradually being met, and it is the needs of individuals whose diagnosis of Alzheimer's disease is more recent and who prefer to read on their own (Pugh 1978) that still require attention.

The memory impairment that is a feature of Alzheimer's disease has a particular impact on the act of sustained reading. The experience of extended narrative prose relies heavily on the synchronised activity of separate areas of the brain (Rayner, Pollatsek, Ashby and Clifton 2012; Dehaene 2009). Decoding the words, comprehending their sense and drawing on relevant individual experience is a sophisticated skill that can take many years to develop. A capacity for sustained silent reading is only gradually accomplished and it may gradually decline if an individual's circumstances change; the onset of a serious illness might certainly constitute such a change.

The present study is concerned only with the experience of reading for pleasure. As outlined below (Field Study, p. 94), readers derive pleasure from a wide variety of texts; it has therefore been important to consider not the specific genres of text but the readers' experience of them when analysing the issues raised. Understanding the obstacles to engagement with the author's intentions has been the starting point for the research. Issues such as retaining a description or a plot in memory, remembering who the characters are in a story, and relating illustrations to accompanying text draw on a range of cognitive skills that are likely to be affected by Alzheimer's disease. The thesis considers the problems raised by each of these aspects of reading and makes positive design suggestions to support the reader's memory.

While acknowledging the extreme complexity of the issues involved, the current study adopts a solutions-focussed approach that is firmly based on the lived experience of affected individuals. Their first-hand accounts form the basis of the study.

### **1.2.2 The aim of the thesis**

The aim of this thesis is to explore the ways in which book design interventions can help readers who have Alzheimer's disease. An initial search of the published literature highlighted the areas of reading that are susceptible to memory loss; subsequent contact with affected individuals allowed the researcher to corroborate and occasionally question the published accounts. Through informal and often unstructured conversations a general impression was formed of those difficulties that could not be remedied – for example, access to libraries and public transport – and of those that could if professional design expertise were to be applied.

The aim of the studies that were carried out was to ascertain whether specific design interventions could help to overcome some of the barriers that the informants reported. Published accounts have noted that book design is based on a number of conventions (Williamson 1956, p. xii; Bateman 2017, p. 227) and that many of these

practices are a consequence of the long history of book making and of the technological limitations imposed by production techniques. Book readers gradually absorb these conventions as they become more experienced and then learn to accommodate and even to appreciate small modifications to content and presentation. The research carried out for this thesis aimed to reconsider genre-specific practices, to retain any that served an explicit purpose and to supplement them with borrowings from different genres if it was felt that these might be beneficial. Book making of any kind involves a detailed consideration of every aspect of content, presentation and distribution, with the contribution of each carefully monitored in the context of the whole. In the case of the studies described below (pp. 94ff.) a marginal gains approach was adopted (Corley, Cox and Deary 2018) in order to analyse the cumulative effect of a number of small, carefully targeted modifications. In fact, in order to construct effective sample material, information had to be gathered from a wide range of sources, some of which are not traditionally associated with book design. These sources are discussed in some detail in the survey of the research literature (pp. 30ff.).

The thesis sets out to answer two basic questions, namely:

- i. What impact does early-stage Alzheimer's disease have on an individual's capacity to read for pleasure?
- ii. What can be done by book editors and designers to mitigate this?

Inevitably these questions raise several sub-questions, and these had to be addressed when surveying the published literature and devising the research studies. A major issue, for example, concerned the feasibility of seeking opinions from participants given the limiting effects of a cognitive impairment on communication. However, the need to involve affected individuals as expert witnesses has been clearly made (Brooks, Savitch and Gridley 2017; Gove et al. 2018; Waite, Poland and Charlesworth 2019). The question therefore became one of establishing the sort of enquiry that would be appropriate given the medical and psychological constraints imposed by the condition.

### **1.3 The areas in need of research**

In formulating the research questions, it became clear that reliable, up-to-date information was not available on key subjects. Work is currently being carried out in the four areas listed below, but each topic requires expansion. An appraisal of the available published information is given in the survey of the research literature (pp. 30ff.).

#### **1.3.1 Alzheimer's disease**

The findings of published studies involving participants with Alzheimer's disease need to be monitored carefully as the medical understanding of Alzheimer's disease is constantly evolving. There is currently no cure for the condition, so early diagnosis is being pursued as a research aim and contributions are being made by less obvious disciplines, e.g., ophthalmology (Lueck, Mendez and Perryman 2000; Fraser, Lundholm Fors, Kokkinakis and Nordlund 2017). The increased understanding of the long prodromal stage has led to a revised view of the condition: individuals are now to be described as 'living with' rather than 'suffering from' dementia.

There is an ongoing interest in ways of maintaining an optimum cognitive performance, although it is not at all certain that therapy can offer long-term improvements to impaired capacities (Orgeta, Leeung, Yates et al. 2015). To this extent, Alzheimer's disease differs from stroke and autistic spectrum conditions, which may respond to intensive rehabilitation and training. Nevertheless, living well with dementia is the currently favoured approach and there is a growing rejection of what Davis and Guendouzi (2013) term a 'defectological' attitude in favour of an approach which is chiefly concerned with 'preserved abilities' (p. 273). Attention is increasingly being paid to products and experiences that enhance daily life.

### **1.3.2 Reading with Alzheimer's disease**

There is a need for research into the loss of the ability to read for pleasure that is experienced by individuals who have hitherto been proficient readers. Information is available in the form of anecdotal observations made in texts published by writers who have dementia (Bryden 2005 and 2012; Swaffer 2016; Mitchell 2018). The reading described by such writers goes beyond word lists and tests for timed recall and describes instead an engagement with extended prose and the consequences of memory loss. The personal strategies devised by the writers to support their reading memory provided valuable suggestions for possible design solutions to particular difficulties such as retaining a plot and remembering who the characters were.

### **1.3.3 Accessible publishing and Alzheimer's disease**

Readers with Alzheimer's disease are not formally catered for by accessible publishing. Given that the aim of accessible (inclusive) publishing is to provide freedom of access to as wide a public as possible, it would seem appropriate to extend the term to cover the needs of this section of the reading public. At present, accessible publishing is primarily concerned with digital or online texts, but the underlying principle of making reading-matter appropriate for non-typical readers could easily extend to printed matter. Certainly, the term accessible publishing is preferable to the label 'special needs' publishing since it draws attention not to the disability – dyslexia, low vision, macular degeneration, etc. – but to the solutions offered by the text.

There is a need for research into the publishing model for texts for minority readerships. The academic publisher Elsevier is a leader in the provision of works for readers who are 'print disabled'. The company's aim, summarised by Gies, Boucherie, Narup et al. (2016), provides a template for producers of reading matter of all kinds:

We believe that accessibility is a convergence of quality and usability applicable to all editors and publishers, and, as such, progress in this area will benefit from an industry-wide awareness and approach to finding solutions for these gaps.  
(p. 66)

The composition and presentation of an accessible text requires a significant contribution from both editors and book designers. This working method is therefore quite different from the author-centred approach of mainstream publishing in which the author's individuality is the unique selling point and publishing by consensus would seem to be an alien concept. Indeed, the current approach to trade publishing stresses the function of 'amplification' (Phillips and Bhaskar 2019, p. 5) and the maximising of sales. Mainstream publishing has traditionally relied on heuristics rather than theoretical knowledge. However, a form of less explicit user-testing has always been part of the publishing cycle. Seeking expert opinions on book proposals, soliciting reports from external readers on early drafts of texts, and in-house discussion of sample chapters and layouts are all intended to anticipate the reactions of readers; authors themselves often circulate their drafts informally and may note the helpfulness of colleagues' feedback in their acknowledgements; reviews in the press are scrutinised in order to learn from the weaknesses found in the finished product.

#### **1.3.4 Insights offered by product design**

Formal research is required into the design of household products for people who have dementia. The few written sources that are available offer important insights into ways of combining theoretical and practical knowledge to improve accessibility. Best-selling items such as the simple clock (Fig. 1) and the music player offered by Live Better With Dementia (2020) are the result of extensive, systematic consultation with design professionals.<sup>1</sup> Similarly, the Dementia Services Development Centre at the University of Stirling (DSDC 2020) is a leading example of the application of design skills to living accommodation for individuals with dementia. The principles adopted by the Centre contributed to the groundwork for the current research.

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<sup>1</sup> Email exchange with the Head of New Product and Innovation at Unforgettable (now Live Better With Dementia), 14.10.2018. The product is available online at <https://dementia.livebetterwith.com/products/unforgettable-2-in-2-calendar-day-clock-8>. Accessed 4.05.2019.



Fig. 1 Calendar day clock.

This clock has been designed for individuals who may have a variety of impairments including low vision and dementia.

The use of a sans serif typeface and lining figures ensures that the display is simple and clear. The initial capital in the word 'Morning' was a deliberate design decision based on research into road signs.<sup>2</sup> It thus provides an example of a design that is willing to set aside standard practice in order to accommodate the specific, stated needs of the user.

Furthermore, in appraising accessible products, it is common to conflate the views of individuals who have dementia with the views of carers, both professional and non-professional (e.g., Giebel, Burns and Challis 2016, quoted above). There is a need for new research directly and exclusively involving participants who have dementia (Sanders and Scott 2020). Overall, this thesis endorses the approach recommended by Innovations in Dementia (Brooks, Savitch and Gridley 2017) in seeking the opinion of potential users of a product.

## 1.4 The scope of the research topic

Given the breadth of the subject area, the specific topic addressed by this thesis has been narrowly defined. An indication of the deliberate choices made in formulating the range of issues that would be included is given below.

### 1.4.1 Alzheimer's disease

The present research is centred on the experience of individuals who have a form of dementia that has been attributed to Alzheimer's disease. There were three main reasons for taking this decision:

- i. Alzheimer's is the most commonly diagnosed form of dementia and accounts for about two-thirds of the cases identified (Alzheimer 2020a)

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<sup>2</sup> Confirmed in an email from the Head of New Product and Innovation at Unforgettable (now Live Better With Dementia) dated 14.10.2018.

- ii. a sufficient number of volunteers was more likely to be found if the studies were restricted to this form of dementia
- iii. there is evidence to suggest that certain individuals have a retained capacity for reading (Snowdon 2003; Stern 2006).

#### **1.4.2 Alzheimer's disease in its early stages**

The present research is concerned only with early-stage Alzheimer's disease. This term is recognised by the medical profession and marks the progression of the disease from a more general mild cognitive impairment (MCI: Bayles and Tomoeda 2013, p. 86). The diagnosis may be based on a scoring system involving case history notes, blood tests, MRI scans and questionnaires. It is to be distinguished from early-onset or young-onset dementia, which is the term used when an individual is less than 65 years of age. Informants who had early-stage young-onset dementia contributed to the Fieldwork Study (p. 99). Reading difficulties that are the result of later stage Alzheimer's are a quite separate topic and reference has already been made to the solutions offered by illustrated books that have been specially devised for shared reading.

#### **1.4.3 Self-identified readers**

The research studies solicited the opinions solely of self-declared readers who had early-stage dementia. The views of family members, carers and professionals were noted, particularly during the Fieldwork Study (pp. 94ff.), but they are not the main concern of this thesis.

#### **1.4.4 Private reading**

The research is concerned with sustained silent reading (Rayner and Pollatsek 2012, chapter 7 passim). It is therefore to be distinguished from the extensive dementia literature on shared reading in groups (Billington et al. 2013; Longden et al. 2016) and reminiscence therapy involving texts (Woods, Aguirre, Spector and Orrell 2012). Both forms of supported reading have been reported to have beneficial effects, but it is not clear from the accounts of the studies how much of the benefit is attributable to reading and how much to the additional attention and support

offered by both the researchers and the carers who supported the studies. Literacy interventions of any kind may be advantageous, but it was not the purpose of the present research to quantify these effects.

#### **1.4.5 Recreational reading**

The thesis takes as its subject reading for pleasure. Proficient readers may read serious non-fiction texts for pleasure, so their recreational reading is likely to encompass a wide variety of genres. A recent report commissioned by The Reading Agency (Demos 2018, p. 10) distinguishes between reading for pleasure and reading for empowerment and information. This thesis takes the view that such a distinction is too stark and does not reflect the preferences of experienced readers. The informants who described their recreational reading mentioned works of literary biography as well as historical fiction. The studies therefore included texts from a range of genres.

#### **1.4.6 Print medium**

Reading from printed books is the subject of the current research. This is not to deny the increasing significance of reading with electronic devices (Maxwell 2019) but restricting the scope to works on paper was felt to be a necessary delimitation. The general use of kindles and iPads by individuals with dementia is an area of research that is rapidly expanding (Jamieson, Cullen, McGee-Lennon et al. 2014; Harris, Boyd, Evans et al. 2020; Sanders and Scott 2020). Further studies are needed to clarify what the potential may be for the independent use of electronic devices by individuals who have a cognitive impairment.

#### **1.4.7 Reading not listening**

Audiobooks are not included in the study. Listening to texts constitutes an alternative activity to reading. Reading texts involves both decoding and comprehending an author's words; the reader has therefore to 'become both the teller ... and the told' (Meek 1988, p. 10).

#### **1.4.8 Published fiction**

The thesis examines the small amount of published fiction that is currently available for readers who have an early-stage cognitive impairment.

#### **1.4.9 Limitations of scope**

The scope of the topic is deliberately restricted in order to focus attention on the two research questions mentioned above (p. 17). The topic is also relatively unexplored, and it was therefore considered wise to build on a secure foundation of existing literature.

### **1.5 The research approach and method**

The thesis is written from the perspective of a publisher's editor who not only has extensive experience of working with authors, copyeditors, photographers and designers to produce illustrated texts, but who also has recent family experience of Alzheimer's disease. Such a perspective inevitably reflects a belief in the value of collaborative work but at the same time acknowledges the ambivalence of the researcher's position with regard to study participants. While remaining an outsider to their experience, the adoption of a reflexive approach meant that the researcher's understanding of the participants' needs deepened as the investigation progressed.

The studies took place at the intersection of three distinct areas of research: first, the current understanding of the complex nature of Alzheimer's disease, which differs in expression from individual to individual; second, an examination of the difficulties with substantial private reading which may be attributable to this condition; and third, the testing of design solutions by appropriate users. The research therefore combines theoretical knowledge with applied research findings and publishing heuristics.

The thesis is constructed on the basis that certainty resides only in the medical description of Alzheimer's dementia in accordance with established clinical criteria for categorisation. The criteria for diagnosis are described in the International

Classification of Diseases (ICD-10 2016). An individual diagnosis is based on an analysis of symptoms and signs using verifiable tests combined with clinical experience. It is therefore interpretative and essentially provisional. Ontologically, the link between the symptoms associated with Alzheimer's disease and dementia may be described as an empirical association (Sadegh-Zadeh 2015, p. 466), that is to say that Alzheimer's disease does not in all cases lead to dementia and there are several types of dementia other than Alzheimer's disease.

The currently accepted clinical categorisation of Alzheimer's disease was used as the basis for the selection of participants for the Interview Study (p. 111). Individuals who had registered their interest in volunteering for research, and who had no symptoms of co-morbidity, were contacted by specialist staff at a local memory clinic and invited to take part in the study.

A wider clinical categorisation of dementia was used in sourcing participants for the two studies that followed. This was partly due to time constraints, but also because of the availability of volunteers through a local Dementia Engagement and Empowerment Project (DEEP). Members are regularly invited to comment on research projects.

Only volunteers who were self-declared readers were invited to take part in discussions, and care was taken to distinguish between the views of people who had dementia and the views of professionals and carers. The approach of the research from the start was to consider only the opinions of individuals who had dementia. Where members themselves mentioned that their dementia was of the Alzheimer's type, this would be noted as having particular relevance to the studies.

Well-established theories that are defined in the literature of medicine and psychology were referred to where relevant when describing the reading difficulties experienced by participants. Applied research in the area of typography and book design was drawn on wherever findings indicated possible solutions to specific

problems. Knowledge of current publishing conventions together with editorial and design experience provided a framework for the creation of sample study materials.

By combining the different types of knowledge described above, a basis was established for empirical, small-scale qualitative research studies. The studies adopted a user-testing method and were carried out with a representative sample of informants. In addition, and in view of the sensitive nature of the enquiry, a reflective approach was at times adopted for the questioning in order to allow a deeper exploration of the issues with the participants and to encourage a sense of collaboration (Schön 1996, p. 40; Pontis 2018, p. 44).

It was hoped that the results would be of use to editors and designers involved with preparing accessible texts. It was also hoped that the findings would be transferable and would be useful to readers with other forms of memory impairment. Individuals who have suffered a stroke, for example, or serious brain injury are reported to have similar cognitive issues.

### **1.5.1 Reflections on the approach**

The thesis acknowledges that the approach outlined above is not without problems. An investigation that sets out to assess the impact of Alzheimer's disease on reading and then to evaluate possible design solutions raises a number of complex and subtle issues; these derive at least in part from the nature of reading itself and from concerns about participant collaboration in a medical context. The concerns may be summarised as follows.

Reading for pleasure is both individualistic and unquantifiable. Following the example of the Royal Society of Literature mentioned above (p. 12), a purely pragmatic approach was adopted, with prolonged periods of private reading constituting a defining feature of the activity. Participants in the research studies contributed on this basis.

The design of printed books is heavily dependent on convention. Design itself cannot be neutral and it has connotations of which the reader may be unaware. The research was therefore based purely on an assessment of usefulness to the informant and did not dwell on aesthetic considerations.

It is now firmly established that affected individuals should be involved as expert witnesses in research studies (Brooks, Savitch and Gridley 2017; Gove 2018; Waite, Poland and Charlesworth 2019). However, ethical considerations impose a substantial constraint on many forms of dementia research. The NHS and, in particular, the Health Research Authority (HRA.NHS 2020) implement a rigorous screening of research proposals as part of their remit to safeguard vulnerable individuals (see letter of approval Appendix IV, p. 289ff.). Even a proportionate review requires the early submission of proposals, and this means that the choice of materials and methods is circumscribed. Further testing would therefore be necessary to guarantee the generalisability of the results described in this thesis.

The relationship of researcher and informant is coming under increasing scrutiny in the field of disability studies (DEEP 2013d). The research carried out for this thesis involved interacting with a wide variety of individuals. It is not the purpose of this thesis to examine the nature of this interaction or to explore the delicate and at times painful conversations which took place. A reflective approach was taken throughout (Schön 1996), with a disclosure of family experience of learning difficulties and Alzheimer's disease made only when necessary to deflect possible concerns about academic opportunism. Cheston, Hancock and White (2019) draw attention to the results of exposure to dementia on previously non-affected families.

### **1.5.2 Reflections on the research method**

The qualitative approach taken to the studies (Angen 2000) required the application of strict criteria for participant selection in order to eliminate the possibility of reaching unsound conclusions because of differing diagnoses or co-morbidity. Both the formal testing and the informal meetings with people with dementia provided

relevant and constructive information. In some cases, the findings confirmed the expectations set up by the literature, in others the findings offered unexpected insights. A few of these insights challenged preconceptions about the reading experience of individuals with dementia.

A full account of the research methods adopted is given in the Methodology section (pp. 80ff.).

## **1.6 The significance of the research**

The studies carried out for this thesis were small in scale and exploratory in nature. Full details of the contribution made by the research are given below in the Conclusion (pp. 231ff.). The broader significance of the work may be said to lie in the fact that:

- i. it identifies a readership that has not yet been formally studied
- ii. it is timely since the active participation of affected individuals is now a prerequisite for many forms of dementia studies (Gove 2018)
- iii. it demonstrates the value of interdisciplinary teamwork: accessible publishing depends on contributions from writers, healthcare professionals and, in particular, from designers who have both the skills and the imagination to solve problems with which they are not familiar.

The research has shown that the ability to learn from the experience of others and to build on their methods and achievements is of particular importance in the area of dementia studies.

## **1.7 The structure of the thesis**

The structure of the thesis is simple and conventional. It is divided into:

The **Literature survey** discusses the texts upon which the thesis is constructed. Some of the sources listed are well established in their field; others are more exploratory and provide an indication of the way in which different aspects of the subject are evolving. The understanding of dementia is rapidly developing, and the questions posed by ethical research in this area are much debated.

The **Methodology** section presents the rationale for the approach taken by the thesis. The issues raised by combining different kinds of research knowledge are described and the reasons for the decisions made are explained.

The **Research studies** are then presented individually. There are four studies, and these are described in the order in which they were carried out; each represents a development of the previous study and builds on the results obtained. As described above, the four studies consisted of a field study, a one-to-one interview study, a textual additions group study, and a book-cover group study.

The **Consultation with Book-Making Professionals** section provides an account of discussions that were held with practising book designers and a book illustrator. Their views validate the approach taken in the sample materials used in the studies and at the same time suggest new ways of tackling the questions raised by the design of texts for a memory impairment.

The **Discussion** section situates the studies and the consultation in a broader context and considers a number of significant points raised by the research. It discusses issues such as current trends in publishing, the inroads being made into accessible publishing by independent book producers and the need for user involvement at all stages of commissioning and production.

The **Conclusion** provides a summary of the findings of the four studies. It also describes the contribution to knowledge made by the thesis and indicates the specific areas which would repay further investigation.

The overall approach of the thesis is to concentrate on a carefully delimited area of research and to examine it in an objective way. The reasons for the particular effects of Alzheimer's disease on reading, the first-hand evidence provided by the growing number of published autobiographical accounts, and the appropriate design of texts are discussed in the literature survey which follows.

## **2 Research Literature in Context**

### **2.1 Introduction**

No single discipline encompasses the full scope of the present research study. Attempts have therefore been made to seek out relevant information from a number of separate areas and bring them to bear on the study's central topic, namely the ways in which design might help readers who have Alzheimer's disease. Insights into the behaviour of such readers have been gleaned from a wide range of written sources, and it is on the basis of these findings, coupled with the verbal accounts of volunteer participants and the guidance of professional designers that the studies were constructed.

The research project is underpinned by three broad subject areas, namely:

- i. Alzheimer's disease
- ii. reading with Alzheimer's disease
- iii. accessible book design

Each subject area has additional subcategories, and these are outlined below.

### **2.2 Alzheimer's disease**

The literature on Alzheimer's is extensive. The rise in incidence of the disease in an ageing population together with a broadening of the range of diagnostic techniques has resulted in a constant flow of publications in academic journals and online sources of varying reliability. Perceiving a growing market for reliable information, several publishers have invested in issuing updated versions of established texts. When the reputation of the author is a particularly important asset to a publisher, the book continues to appear under their name with new contributors brought in to

widen the scope of the text. The content is sometimes completely revised and ground-breaking new chapters are added to guarantee that the text reflects the most up-to-date findings.

### **2.2.1 Defining Alzheimer's disease**

It was necessary to base the investigation on the secure footing of an acceptable definition of Alzheimer's disease to ensure that any findings might be reliable. The definition of Alzheimer's disease by the medical profession is the subject of much debate. An understanding of the current conceptualisation of the disease was needed in order to communicate both with the Health Research Authority and with the professional bodies that oversee participant recruitment. An important distinction was to be drawn, for example, between early-stage Alzheimer's and young-onset Alzheimer's (Alzheimer 2020b, see below). It was the stage of the progression of dementia not the age of the individual that was a defining condition for recruitment to the user-testing studies.

The definition of the disease that is offered on the website of the Alzheimer's Society is carefully worded: 'Alzheimer's disease is a physical disease that affects the brain' (Alzheimer 2020a). The text also describes the biological changes implicated in the disease:

Alzheimer's disease is thought to be caused by the formation of abnormal deposits of protein in the brain. These are called plaques and tangles and they are made up of two key proteins, amyloid and tau. Amyloid and tau are present in healthy brains but in Alzheimer's disease they function abnormally. Amyloid forms plaques outside cells and tau forms tangles inside them. (Alzheimer 2020a)

A full account of the issues surrounding the defining of Alzheimer's disease is to be found in the wide-ranging *Dementia*, edited by Ames, O'Brien and Burns (2017). Now in its fifth edition, the book is over 900 pages in length and has been 'updated and revised to reflect recent advances in this fast-moving field' (back of cover). The book's 77 chapters have been contributed by 146 authors with a wide range of nationalities and professional backgrounds. The previous (fourth)

edition included the preface of each of the three earlier editions, providing silent evidence of the ways in which the subject has evolved since the book first appeared.

Current attitudes to dementia have a history and this is outlined in the first chapter of the book (Berrios 2017, pp. 3–18). The interpretation of disease also has a history, and this is examined in a later chapter entitled, ‘What is dementia, and how do you assess it?’ (Kane and Thomas 2017, pp. 33–43). The authors describe the relatively recent advent of classification and introduce the three main diagnostic tools currently in use:

- i. Diagnostic and Statistical Manual of Mental Disorders (DSM-5 2013)
- ii. International Classification of Diseases (ICD-10 2016)<sup>3</sup>
- iii. National Institute on Aging and Alzheimer's Association (NIA-AA 2018)

Subtle but important distinctions are to be found between the three frameworks, and while there is a general a consensus that dementia is a multifaceted condition, there is substantial disagreement about the way Alzheimer’s disease is to be conceptualised. In 2018 the National Institute on Aging and Alzheimer's Association (NIA-AA) declared that diagnosis was to be based on demonstrable biological evidence:

The diagnosis is not based on the clinical consequences of the disease (i.e., symptoms/signs) in this research framework, which shifts the definition of AD in living people from a syndromal to a biological construct.

The approach has received a critical response from the influential Cochrane Dementia and Cognitive Improvement Group<sup>4</sup> and they write that ‘These recommendations are contentious and have important implications for patients,

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<sup>3</sup> The ICD is administered by the World Health Organisation. The WHO states that, ‘following endorsement, Member States will start reporting using ICD-11 on 1 January 2022’ (<https://www.who.int/classifications/icd/en/>). Accessed 18.11.2019.

<sup>4</sup> Cochrane is an international not-for-profit organisation. Its stated aim is ‘To produce high-quality, relevant, up-to-date systematic reviews and other synthesized research evidence to inform health decision making’ (Cochrane 2019). Both the National Institute for Health and Care Excellence (NICE 2019) and the National Institute for Health Research (NIHR 2019) draw on reviews made available by Cochrane.

clinicians, policy makers and the pharmaceutical industry' (McCleery et al. 2018). While acknowledging the far-reaching consequences of these distinctions, the research carried out for this thesis is based on the classification made by ICD-10 (F00 and G30). This distinguishes between dementia in Alzheimer disease and both early-onset (Alzheimer 2020b) and late-onset dementia and provides a working definition:

Alzheimer disease is a primary degenerative cerebral disease of unknown etiology with characteristic neuropathological and neurochemical features. The disorder is usually insidious in onset and develops slowly but steadily over a period of several years. ICD-10 (F00 and G30)

The individuals who contributed to the studies all had early-stage dementia.

### **2.2.2 Describing Alzheimer's disease**

Alzheimer's disease is a multifaceted condition and the large teams of contributors to medical and psychology textbooks are an indication of the variety of disciplines involved in adequately capturing its complexity. Such accounts are for the most part generalised and impersonal. A different approach is seen in the case studies or clinical vignettes written with a didactic purpose; their focus on the individual is similar to the accounts written by carers and they may be seen as observer accounts. A third angle is covered by the descriptions offered by individuals who themselves have dementia. The current research drew on all three sources both for the fieldwork study and for the testing of the sample materials.

**Formal accounts:** standard textbooks provide details of the specific features that characterise Alzheimer's disease. Such accounts were referred to when drawing up the test materials in order that issues that are not normally associated with this form of dementia could be excluded (e.g. the muscular disorders associated with dementia with Lewy bodies (Alzheimer 2020b)). The definitive texts by Ames, O'Brien and Burns (2017), referred to above, and by Salthouse and Craik (eds, *The Handbook of Aging and Cognition*, 2008/2016) are complemented by the concise statement offered in *Alzheimer's Disease*, edited by Waldemar and Burns (2017). This short text offers an up

to date, more nuanced approach to the cognitive and behavioural features of the illness. The idiosyncratic presentation of Alzheimer's disease meant that it was necessary to meet and learn from a wide variety of informants.

The design of the study materials focused on the memory impairment that is a defining feature of Alzheimer's disease. Budson and Solomon's *Memory Loss, Alzheimer's Disease and Dementia* (2016) takes a person-centred approach to the subject, and their work on visual memory will be returned to below. The design recommendations that are based on the studies (see Conclusion pp. 231ff.) would also be relevant to readers who have a mild cognitive impairment (MCI). The two conditions are discussed by Bayles and Tomoeda in *MCI and Alzheimer's Dementia* (2013) and among the issues described as being characteristic of the two disorders are an impaired comprehension of instructions and a failure to recognise humour (Bayles and Tomoeda 2013, p. 63). These two features have a particular relevance for the present research and reference will be made again to the work of these two influential authors (see below, Specific reading difficulties associated with early-stage Alzheimer's disease, p. 50).

The thesis has also drawn on the regularly updated information provided by the Alzheimer's Society. The Society adopts a clear, user-centred approach and information is available as printed fact sheets, online text, and as a signed video (Alzheimer 2020d). The stated aim is for the information to be clearly written, accurate, reliable and independent. This last is of particular importance and the Society states that 'our policies and principles help keep our content free from bias or undue external influence'. Evaluations of claims made by recent research projects appear regularly on the Society's website.

The perceptible shift of focus in some formal accounts of Alzheimer's disease would seem to fit well with the aims of this thesis. For example, the epilogue to Davis and Guendouzi (eds) *Pragmatics in Dementia Discourse* (2013) refers to a

‘defectological’ view of the disease vs. a ‘preserved abilities’ view’ (p. 273) and continues:

The work in this volume clearly shows a preference for finding and identifying preserved abilities over cognitive defects, and it may be one of the signal strengths of discursivity work on Alzheimer’s disease to contribute to this badly needed corrective. From a scientific viewpoint, however, it is important that we integrate a careful understanding of the actual nature of cognitive compromise with an equally careful understanding of preserved abilities. (p. 274)

Clark and Maguire (2016, p. 53) likewise suggest that research has hitherto focussed, unhelpfully, on ‘unearthing impairments’.

**Observer accounts:** these accounts take the form of closely observed summaries presented by clinical practitioners or more personal accounts written from the point of view of a family member or carer. Both help to broaden the understanding of the effects of the illness.

It is not easy to separate Alzheimer’s disease from the manifestation of the illness in the individual. One of the teaching methods in medical practice is therefore the use of case studies or clinical vignettes. These written accounts, sometimes quite brief, demonstrate the complex interplay between medical symptoms and the individual’s life history. The person-centred approach first advocated in Kitwood’s *Dementia Reconsidered: The Person Comes First* (Kitwood 1997) is now widely adopted in medical care and in accessible design.

Of particular relevance to the current research are the four ‘case vignettes’ that constitute the final chapter of Waldemar and Burns overview of Alzheimer’s disease (2017, pp. 117–120). Case 1 ‘Managing behavioural and psychological symptoms in AD: apathy’ serves as a reminder that an individual’s skills (e.g. reading) may be preserved and that a lack of initiating behaviour should not always be interpreted as a lack of interest (Manera et al. 2017); Burns further emphasizes the point in a collaborative article entitled ‘Taking a positive spin’ (Giebel, Burns and Challis 2017). A clinical vignette also features in the appendix to Marilyn Albert’s chapter in

Salthouse and Craik (Albert 2008/2016, pp. 119–120). A justification for the use of the vignette is made by Budson and Solomon (2016) in the Preface to the second edition: ‘In Section II we have also added a case vignette at the beginning of each chapter to provide an example of how a patient with each disorder might present’ (p. xi). A similarly significant change may be noted between the third and the current (fifth) edition of Ames, O’Brien and Burns (2017), where Shirley Nurock’s frank description of her GP husband’s terminal early-onset Alzheimer’s now appears as the second of 77 chapters (Nurock 2017).

Shirley Nurock’s experience is typical of the accounts of caring in its many forms that constitute a growing literature. The current research has drawn on the experience of carers whenever information about reading behaviour was provided, but it does not discuss the complex question of the nature of care itself. The influence of carers as gatekeepers is increasingly being questioned (Brooks, Savitch and Gridley 2017), but the practical research carried out for this thesis confirmed that many carers wish to support the individual in their illness. Given that family members and carers may be involved in the purchase of reading material, particular attention was paid to the book covers that were used in the Book Cover Study (pp. 171ff.). The effect on carers of an unforeseen exposure to dementia is surveyed in Cheston, Hancock and White (2019), and the reported increase in awareness and sensitivity could no doubt be replicated in the context of other disabilities.

**Autobiographical accounts:** accounts written by individuals who have dementia are as yet relatively few in number, but they constitute a valuable source of information for research into Alzheimer’s disease and literacy. Martina Zimmermann examines dementia narratives as a genre in *The Poetics and Politics of Alzheimer’s Disease Life-Writing* (2017) and argues strongly that the written evidence of the individual, however fragmented, is always significant. This contrasts with Ames, O’Brien and Burns (2010, Preface, p. xviii), who suggest that such accounts cannot be regarded as a reliable source.

The ownership of a written text is discussed by Bouchard Ryan, Bannister and Anas (2009) in their exploration of the genre of autobiographical narratives of dementia. Examples are found in two published collections: *Welcome to Our World* (Jennings 2014) and *People with Dementia Speak Out* (Whitman 2016). In each case the stated aim of the editors has been to ensure that the thoughts and ideas expressed by the individuals have been retained. The value of the first-person patient narrative as a diagnostic tool in general practice is highlighted by Greenhalgh and Hurwitz (1999).

Reference will be made in the second section of this survey (Reading with Alzheimer's disease) and in the third section (Accessible book design) to the specific observations on reading made by authors who are living with Alzheimer's disease. The writings of Thomas DeBaggio (2002), Marilyn Truscott (2003), Christine Bryden (2012), Kate Swaffer (2016), Wendy Mitchell and Anna Wharton (2018), and Keith Oliver (2019) are amongst the most frequently quoted. While allowing for the stylistic input of a publisher's ghost writer (e.g. Wharton 2019), the insights offered by autobiographical texts are often of a practical nature, and they frequently echo comments made by participants in the interview studies.

### **2.2.3 Overview of the effects of early-stage Alzheimer's disease**

The link between brain disease and loss of memory function was firmly established by the multidisciplinary work carried out by Karalyn Patterson (Royal Society 2020). The particular characteristics of early-stage Alzheimer's disease are identified by Stuart-Hamilton (2012, pp. 222–223) as severe memory failure, apraxia (the inability to perform skilled movements), visual agnosia (the inability to recognise by sight) and impoverished verbal skills. The factors that connect this disparate group of impairments will be discussed below. However, in summarising the effects of the disease in its early stages, Bayles and Tomoeda introduce the term 'Activities of Daily Living' (Bayles and Tomoeda, 2014, p. 48; Waldemar and Burns, 2017, p. 50). An individual's reduced efficiency in servicing their daily life was a constant consideration in preparing the study materials.

### 2.2.4 Memory impairment

Self-reported memory impairment is a primary feature of early-stage Alzheimer's disease. Indeed, 'The cardinal symptom of AD is an insidious and progressive loss of episodic memory' (Waldemar and Burns 2017, p. 28). Baddeley, Eysenck and Anderson's account of episodic memory (2015, pp. 137ff.) dates the use of the term to Tulving (1983), who used it as a way of distinguishing between the recollection of specific events and the more generalized knowledge of the world which he described as semantic memory. Waldemar and Burns further observe that, 'The type of memory deficit in AD is specific and is the manifestation of hippocampal dysfunction: patients have difficulty acquiring new information and rapidly forget the information they were able to learn' (2017, p. 28).

It is the multiple difficulties caused by the dysfunction of the hippocampus that characterise Alzheimer's disease. In a paper entitled 'The cognitive revolution: a historical perspective' Miller (2003) describes the progress being in this area by a collaboration between the disparate disciplines of psychology, linguistics, neuroscience, computer science, anthropology and philosophy:

Each, by historical accident, had inherited a particular way of looking at cognition and each had progressed far enough to recognize that the solution to some of its problems depended crucially on the solution of problems traditionally allocated to other disciplines. (Miller 2003, p. 143)

This collaboration has been significant in the study of literacy in individuals who have Alzheimer's disease. On the subject of orientation, psychologists O'Keefe and Nadel (1978) suggested that place cells in the hippocampus created a cognitive map which, to quote Clark and Maguire, allowed the individual to locate themselves in 'a world-centered or allocentric spatial framework as opposed to a framework where space is egocentric and represented relative to the observer him/herself' (Clark and Maguire 2016). The part played by the hippocampus in physical and mental navigation was investigated by Maguire et al. in a study of London taxi drivers (2000) and later by Maguire, Woollett and Spiers (2006) in a study of London bus drivers. More recently, Maguire and Mullally (2013) have

argued for the inclusion of imagination and scene creation as one of the functions of the hippocampus. An ambitious publication by Ekstrom, Spiers and Bohbot, *Human Spatial Navigation* (2018) re-purposes earlier ethnographic research to explain the disorientation caused by damage to the hippocampus in Alzheimer's disease (Preface, p. ix).

Research by Eichenbaum (Eichenbaum and Cohen 2014; Howard and Eichenbaum 2014) suggested that the hippocampus was also involved in the computation of time:

The memory and spatial functions of the hippocampus can be reconciled by extending hippocampal function beyond navigation in allocentric space to the organization of events in spatial contexts, to nonspatial organizations including time and more, and to the larger sense of 'navigation' through a memory space. (Eichenbaum and Cohen 2014, p. 766)

The studies by Olsen et al. (2012), which involved amnesiac as well as healthy participants, suggested that the hippocampus was implicated in the binding and comparison of new and previously encountered information. Rubin et al. (2014) propose a wide role for the hippocampus:

The hippocampus supports the ability to bind and flexibly represent discrete elements of an experience and, through its interconnections with other neural systems, permits the expression of flexible and adaptive behaviour. (p. 742)

Reading requires a sense of place, time and organisation. The mental agility needed to read and enjoy a piece of prose is likely to be hampered by a dysfunction of the hippocampus (Duff and Brown-Schmidt 2012); creativity may also be reduced (Duff et al. 2013). Also affected may be gist memory (Sekeres, Winocur and Moscovitch 2018) and inferential reasoning (Zeithamova, Schlichting and Preston 2012), both of which are essential requirements when reading normal prose. The involvement of the hippocampus in sequence learning, whether through multiple repetitions or through rapid novel episodic events is proposed by Davachi and DuBrow (2015). Sequence memory is a pre-requisite for successful reading, and this was a factor in devising and suggesting design approaches to supporting this function.

The crucial role of the hippocampus in memory consolidation (Squire 1992; McClelland, McNaughton and O'Reilly 1995; Baddeley, Eysenck and Anderson 2015, p. 447) has been re-examined by Hardt, Nader and Nadel (2013), who draw attention to the perhaps underestimated significance of the discarding of memories for normal brain activity. Similarly, Richards and Frankland (2017) refer to the 'fledgling literature' on the neurobiology of the transience of memory (forgetting), contrasting it with the mature study of the persistence of memory (remembering). The role of memory in the reading process is highlighted in Muriel Spark's poem 'Authors' Ghosts' and will be returned to below (pp. 48ff.).

### **2.2.5 Preserved aspects of memory**

Alzheimer's disease in its early stages does not affect all areas of the brain equally, nor does it affect all individuals in the same way. The user-testing studies carried out for this thesis (pp. 111ff.) were based on the observation that Alzheimer's disease in its early stages leaves certain capacities functioning adequately, if not optimally, and that individuals may continue to derive pleasure from habits formed earlier in their lives. This is in line with Baddeley's observation that semantic memory and procedural memory are often preserved rather longer than episodic memory (Baddeley, Eysenck and Anderson 2015, pp. 450–455).<sup>5</sup> An explanation for the preservation of certain memory functions may be offered by cognitive reserve theory. Stern (2002) defined cognitive reserve as, 'the ability to optimize or maximize performance through differential recruitment of brain networks, which perhaps reflect the use of alternate cognitive strategies.' Stern (2006) examined cognitive reserve in Alzheimer's disease and suggested the presence of two mechanisms:

neural reserve which emphasizes pre-existing differences in neural efficiency or capacity, and neural compensation, which reflects individual differences in the

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<sup>5</sup> Baddeley writes, 'AD is basically characterized by a single overall feature, namely that of defective episodic memory. It is important to note, however, that a memory deficit is necessary for diagnosis, so this is perhaps unsurprising' (Baddeley, Eysenck and Anderson 2015, p. 451).

ability to develop new, compensatory responses to the disabling effects of pathology. (p. 115)

More recently, Stern (2012) and Barulli and Stern (2013) have suggested the possibility of two possible sorts of reserve: ‘brain reserve, which refers to differences in the brain structure that may increase tolerance to pathology, and cognitive reserve, which refers to differences between individuals in how tasks are performed’ (Stern 2012).

Support for Stern’s hypothesis is provided by Wilson et al. (2000 and 2019), who suggest a possible link between number of years of education and the delayed onset of Alzheimer’s disease. Similarly, Keage et al. (2010) draw on the results of large, population-based cohort studies to demonstrate the possible correlation of years of education with resilience in the face of dementia. However, the number of years of education (which may in any case be a proxy for some notion of IQ) was not taken into consideration in recruiting for the studies carried out for this thesis; rather it was the current interest in reading that was the defining requirement for participation.

Further evidence for the possible role of resilience in the face of dementia comes from the Nun Study (Snowdon 2003). This longitudinal study is based on the experiences of 678 members of the School Sisters of Notre Dame aged from 75 to 107. Snowdon writes:

These case histories provide examples of how healthy aging and dementia relate to the degree of pathology present in the brain and the level of resistance to the clinical expression of the neuropathology. (p. 450)

While such case histories may provide living examples of cognitive reserve, it is perhaps also relevant that the nuns joined a teaching order and may therefore have had a predisposition to extroversion and effective communication. Certainly, Stuart-Hamilton (2012, p. 226) advises caution when considering possible links between lifestyle and cognitive degeneration.

It has been suggested that creativity may be affected by the loss of hippocampal function (Rubin et al. 2014). However, participants who had early-stage Alzheimer's disease reported a continued ability to visualise a place or an object that is described verbally in print (see below, p. 165). Exercising this particular form of imagination is a constitutive part of reading.

### **2.2.6 Visual and perceptual issues in Alzheimer's disease**

Difficulties with perception and visual identification may be linked to Alzheimer's disease (Alzheimer 2020e), and the drive towards ever earlier diagnosis has led to a rapidly growing literature in the field of ophthalmology. A by-product of this research has been a clarification of the effects of Alzheimer's disease on reading (see also below, p. 50).

A review article by Tzekov and Mullan (2014), aimed specifically at ophthalmologists who may not be familiar with Alzheimer's pathology, lists the major effects of the disease on vision; these include irregularities of saccadic eye movement, reduced sensitivity to contrast, reduction to the field of vision, and altered perception of colour that may occur. Molitor, Ally and Ko (2015) focus on eye movements in Alzheimer's disease and usefully comment on the role that apathy may play in a subject's reduced capacity to explore a scene or fixate an area of interest. The link between vision and behaviour is discussed by Spierer et al. (2016), and they draw attention to the impact of visual impairment on reading and other mentally stimulating activities.

A colour vision deficiency could have an impact on the reader's appreciation of an illustrated text. This visual impairment was investigated by Pache et al. (2003) using colour plates (the Ishihara test) and coloured disks (the PV-16 choice test) and led to the conclusion that, 'Alzheimer's disease patients have an unspecific colour vision deficiency independent of the severity of the disease.' The likelihood of pre-existing colour vision issues is not addressed even though the incidence in the general population is not negligible (Colour Blind

Awareness 2019). Furthermore, various studies (e.g. Pache et al. 2003; Tzekov and Mullan 2014; Spierer et al. 2016) comment on the difficulty of obtaining reliable results from individuals who are affected by later-stage Alzheimer's.

### **2.2.7 Alzheimer's disease as a disability**

There is a growing literature in the areas of healthcare and disability studies about the ambivalent status of dementia. Advances in neurobiology and digital technology have extended the prodromal stage of dementia and this has led to a reconceptualization of dementia as a condition or a disability rather than as a disease. The relevance of the disease/disability debate to the current research lies in the fact that an acknowledgement of disability confers rights on the individual, including the right of access to written material.

The status of dementia as a disability was confirmed in The Equality Act (2010) and is supported by the United Nations Convention on the Rights of Persons with Disabilities (CRPD 2006), which adopts a social model of disability. This developing concept is summarised by Thomas and Milligan (2018) in 'Dementia, disability rights and disablism', where they locate the issues in the context of the challenge to the status quo made by other minority groups (p. 118). The authors single out J.I. Charlton for advancing the theory of socially constructed disability in his landmark work *Nothing About Us Without Us* (Charlton 1998). They also highlight the work of Shakespeare, Zeilig and Mittler (2017), who likewise frame the disease/disability debate in terms of their own lived experience. Aspects of this ongoing discussion appear in many areas of this thesis.

The report produced by the Mental Health Foundation, 'Dementia, rights, and the social model of disability' (2015) was based on a wide-ranging consultation, with experts by experience being supported by Innovations in Dementia. To its credit, the report includes the views of non-activists, who state that 'it is their dementia (i.e. the condition) that is the cause of their withdrawal from and disengagement in community life and not the "disabling barriers" that exist in these communities (p.

28; Innovations in Dementia 2011)'. The 2019 report by the All-Party Parliamentary Group on Dementia entitled 'Hidden no more: dementia and disability' (APPG 2019) takes a more robust position and argues for wide societal recognition of the often subtle needs of affected individuals.<sup>6</sup>

However, it is not easy to collect first-hand evidence of the changes caused by Alzheimer's disease. The frequent occurrence of apathy in affected individuals is highlighted by Waldemar and Burns (2017, p. 117–118). Starkstein (2006) emphasises the important distinction between apathy and depression, and suggests that individuals with Alzheimer's may manifest symptoms of both conditions, either condition, and indeed neither condition. Starkstein (2014) also reports that individuals may show a lack of awareness of their condition (anosognosia).

### **2.2.8 Concluding comments on Alzheimer's disease**

The description and diagnosis of Alzheimer's disease is an area of continuing debate. The development of the condition varies in ways that are complex and not yet fully understood. It has therefore become important to focus support on the precise expression of the disease in the individual. Genetics, co-morbidity and life opportunity all contribute to the ways in which Alzheimer's is experienced and each of these factors will have a bearing on an individual's capacity to continue to read. The possible effects of the condition on reading skills are considered in the following section.

## **2.3 Reading with early-stage Alzheimer's disease**

The pathology associated with Alzheimer's leads to characteristic interruptions in the reading process and it is the purpose of this study to investigate possible ways of remediating these problems.

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<sup>6</sup> The blue badge parking scheme was finally extended to people with dementia on 30.08.2019 (Alzheimer 2020g).

### 2.3.1 Related topics that are beyond the scope of this study

There are a number of parallel areas of investigation which throw light on individual aspects of reading, and findings in these areas have been included where relevant. A full account of the following topics is, however, beyond the scope of the present study.

**Medical information:** the written presentation of information for individuals who have dementia and their carers has been studied by the healthcare profession. Issues such as the appropriate labelling of medications (MHRA 2014), leaflet and questionnaire design (e.g. Abraham and Kools 2012; Black et al. 2013) and the presentation of supporting material for carers (Black et al. 2019) have been closely examined by information designers, often in consultation with focus groups.

**Cognitive stimulation therapy:** this thesis makes no claim for the therapeutic value of reading. Cognitive improvement and Alzheimer's disease is an area of much debate and one that is of considerable interest to private companies. The NICE guidelines (NICE 2018) support *group* cognitive stimulation (1.4.2) and give a cautious recommendation to functional cognitive rehabilitation (1.4.4); they do not recommend cognitive training (1.4.7). Similarly, a major randomised controlled trial carried out for the NIHR (Orgeta et al. 2015) found that there were no long-term benefits for individual cognitive stimulation therapy. Spector, who took part in the trial, also contributed to the Cochrane Report (Woods 2012) and to a synthesis of systematic reviews of psychosocial interventions in dementia (McDermott et al. 2018). While the participants' quality of life may have been temporarily enhanced, Stine-Morrow is critical of over-optimistic claims for significant functional outcomes (Stine-Morrow, Hussey and Ng 2015). In general, methodological issues concerning recruitment and the accuracy of comparisons would seem to be problematic.

**Wayfinding and way-showing:** The signage in public places such as tourist attractions, shopping precincts and airports is constantly being re-evaluated in the

light of dementia studies (e.g. National Trust 2020), and attention is increasingly being paid to the presentation of colour and visual cues in residential homes (Fleming et al. 2012; Pollock and Fuggle 2013; DSDC 2020). Guidelines offered by Mollerup (2013, p. 70) on the use of simplicity and redundancy were adhered to in designing the research materials.

**Bibliotherapy:** the survey by Canty (2017) summarises why reading may offer benefits to the individual's health and overall well-being. Two studies published by The Reader Organisation in collaboration with the University of Liverpool's English department (Billington et al. 2013; Longden et al. 2016) suggest (but do not indicate conclusively) that shared reading with groups of individuals who have dementia can have a beneficial effect.

Self-help was certainly the rationale for the Arts Council funded Books on Prescription Scheme, which includes titles on a range of health topics (The Reading Agency 2019a).

**Bilingualism:** the beneficial effects of bilingualism have been studied by Craik, Bialystok and Freeman (2010) and by Bialystok (2017). Their research suggests that lifelong bilingualism is likely to contribute to cognitive reserve, which is thought to play a part in delaying the expression of symptoms of Alzheimer's disease (Stern 2012; Stine-Morrow et al. 2015). Bak and Robertson (2017) report biological evidence that would support this view.

**Digital media:** the significance of e-publishing is discussed by Maxwell in a chapter entitled 'Publishing and Technology' in *The Oxford Handbook of Publishing* (Maxwell 2019). The potential of digital media to contribute to the reading experience of those with Alzheimer's disease is beyond the remit of the present study. However, the close examination of the affordances of both print and electronic media has drawn attention to the physical aspects of books that can easily be overlooked because of their familiarity. Mangen (2017, p. 278ff.) and Mangen

and Schilhab (2012) discuss attributes of the printed page that are of undoubted significance to readers with particular literacy needs. Waller (2012) draws attention to the essential role of layout in facilitating the navigation of a text by typical readers. Wright is positive about the evolution of the design of digital tablets to support older readers (Wright 2017, pp. 391–404). Wright discusses the situation of individuals who have a memory impairment caused by brain injury and reports their success in learning to use an electronic diary. However, she makes no mention of dementia. It is important to distinguish between brain trauma and brain disease since the latter (e.g. Alzheimer’s disease) is known to affect the ability to learn new skills.

### **2.3.2 Cognitive issues raised by reading with early-stage Alzheimer’s disease**

The review article by Stine-Morrow, Hussey and Ng entitled, ‘The potential for literacy to shape lifelong cognitive health’ (2015) brings together a number of the key issues that are relevant to the current research. In outlining their policy recommendations, the authors make two important points concerning the nature of reading and the nature of the professional study of reading. Their first point describes the complexity of the act of reading:

Reading is characterized by a complex cascade of operations that allow us to decode the surface form (i.e., the printed word or acoustic signal) into meaningful words to form syntactically licensed sentences, which ultimately fit into a broader discourse, or conceptual theme. As such, comprehension requires the generation of inferences to link the ideas from the text to those in the existing base of knowledge ... . Reading can engender thought and imagination, affording access to worlds that we may not be able to directly experience, so that it can be a highly active form of mental engagement ... (pp. 94–95).

The authors’ second point follows on from their first. Given the complexity of reading and the wide variety of issues raised by literacy, they advocate a new approach to research:

Historically, the study of reading (as mental computations, neural processes, and their products) and the study of literacy practices and their effects have been largely independent. There is need for a literacy science that bridges this gap. (Stine-Morrow et al. 2015, p. 97)

Bringing together insights from diverse but related disciplines might allow progress to be made in understanding a broader range of reading profiles.

The difficulties that readers with Alzheimer's disease experience in negotiating the printed word are partly explained by the neurophysiology and by the cognitive psychology of reading. In order to identify and analyse the problems encountered by readers with Alzheimer's disease it was important to compare their experience with that of non-affected readers. The complex and interdependent skills required for successful reading are described by Rayner, Pollatsek, Ashby and Clifton in *Psychology of Reading* (2012). A useful overview is offered by Dehaene (2009) in *Reading in the Brain. The New Science of How We Read*. This is a text that needs to be read in conjunction with the author's replies to criticism of its overemphasis on the visual word form area (Szwed et al. 2011). Snowling and Hulme's *The Science of Reading. A Handbook* (2007) presents a wide-ranging discussion of the reading process but mentions Alzheimer's disease only briefly (p. 601, 604), since the focus of the text is on dyslexia and non-acquired literacy disorders.

Memory plays a central role in reading comprehension. The research carried out for this thesis investigated possible ways of supporting or compensating for memory deficits; it therefore had to take account of the role of schemas in the encoding, storage and retrieval of memories. Schema theory was outlined in general terms by Bartlett (1932) and was later applied to reading. Work by Bransford and Johnson (1972) and by Rumelhart (1975) on the reader's comprehension of written narrative demonstrated the structures that underpin stories and the ways in which readers use schemas to comprehend texts. Schank and Abelson (1977, p. 423) drew attention to the causal chains that link paragraphs and to the inferences that readers make to follow a text. Kintsch and van Dijk (1978) link the application of appropriate schemas to successful text comprehension and give stories or psychological research reports as examples of well-established schemas. In their much later study of reading, Rayner et al. (2012) note the contribution made by schema theory to studies of discourse comprehension. An influential article by Tse

et al. (2007) draws on the work of psychologists for a neuroscientific investigation of the role of schemas in memory consolidation. Reconciling the two approaches is now an area of intense activity and the integration of new information into existing schemas has been explored by Eichenbaum and colleagues (McKenzie 2013).

A bridge between memory research and research into reading is suggested in a much-cited article by educational psychologists Sweller, van Merriënboer and Paas (1998) in which the authors describe the ‘active, constructive process’ by which schemas are formed and used in reading. Drawing on Baddeley’s account of working memory (1992) and earlier work by Sweller (1988), the authors propose cognitive load theory as an explanation of the interdependence of schemas and working memory and suggest ways of presenting information to optimise this system. The psychology of learning instruction for younger people has since expanded this initial work (see review article Kirschner 2002 and Paas, Renkl and Sweller 2003) but, importantly for the present research, the conclusion to the original article draws attention to the specific needs of older readers:

Instructional methods based on cognitive load theory, which can be argued to be more cognitive-capacity efficient, could be expected to compensate for these age-related declines. (Sweller, van Merriënboer and Paas 1998, p. 292)

The theory of perceptual load, first proposed in a highly influential paper by Lavie (1995), focussed on the role of selective attention and perception. Load theory would seem to be an expanding area of research and highlights the issue of distraction in designing for real-world experience. Inhibiting distraction is a particularly important aspect of the design of books for readers with any cognitive impairment or learning difficulty. Baddeley, Eysenck and Anderson (2015, p. 56) write of the limiting effects of increased memory load while Wingfield et al. (1988) note that age is a factor in the reduction of working memory capacity. With the added burden of Alzheimer’s disease, a number of the information processing skills involved in reading are known to be compromised.

Schemas also play a part in the perception of images (Gombrich 1960, *Art and Illusion*, p. 246). A memory impairment may affect a reader's access to previously formed mental images, so illustrations have a particularly important role to play in accessible book design. The implications for the commissioning of new artwork are discussed below (p. 73).

### **2.3.3 Specific reading difficulties associated with early-stage Alzheimer's disease**

A number of specific communication difficulties are outlined by Bayles and Tomoeda (2013, p. 61; 2014, p. 53). Their findings are based on case studies and their conclusions played a significant role in the conceptualising of the Interview Study (p. 111). Amongst the problems they list are an impaired comprehension of texts, an impaired recall of text, and a failure to recognise humour (perhaps mistaking it for sarcasm). However, in a much earlier paper on behavioural intervention, Bayles and Kim (2003) are notably optimistic about supporting the spared aspects of memory and write that, 'For example, many investigators demonstrated that AD [Alzheimer's Disease] patients could recognize that which they cannot recall.' This observation, which is repeated by Hudon et al. (2006, see below), is of great importance in the context of the current research project.

New insights into reading difficulties may result from seemingly unrelated studies on the early diagnosis of dementia. As noted above (p. 42), research in the field of ophthalmology has provided both new and confirmatory evidence for the designer. For example, a survey article by Valenti (2010) recommends the use of high-contrast materials, tactile media and the enlargement of print as ways of supporting reading and other routine tasks included in Bayles and Tomoeda's *Activities of Daily Living* (2014). Similarly, Tzekov and Mullan (2014) note that, 'The majority of the published studies find the CS [contrast sensitivity] function to be affected in AD patients' and suggest that this may explain problems with letter identification, word reading, picture naming and face discrimination.

Research involving eye-tracking (Lueck, Mendez and Perryman 2000) demonstrated that subjects with mild to moderate Alzheimer's and control subjects could understand material of similar difficulty but that subjects with the disease demonstrated slower reading times and irregular eye movements. These results were confirmed by Fernandez et al. (2013); subjects with Alzheimer's were found to show more fixations, more regressions, and shorter outgoing saccades than controls; however, word frequency, word length and word predictability were not found to affect the length of outgoing saccades. Fraser et al. (2017) found significant changes to reading patterns even in subjects who had only a mild cognitive impairment and they write of informants demonstrating a 'somewhat disorganised and non-linear path through the text' (p. 1023, Fig. 2). Findings such as these confirm that particular attention needs to be paid to the typography of texts intended for this readership.

### **2.3.4 Alzheimer's disease and general text comprehension**

Two important findings by Cummings, Houlihan and Hill (1986) influenced the preparation of the study materials. The first was that in the early stages of Alzheimer's disease, reading with comprehension was still possible, although there was a strong correlation with decline in the score noted in the Mini Mental State Examination (Alzheimer 2020f). The second was the finding that, 'The reading pattern is dissimilar to that exhibited by children learning to read.' The importance of this statement cannot be overemphasized, particularly in the context of commissioning adult texts.

Early research by Patterson, Graham and Hodges (1994) examined the specific role of semantic memory in Alzheimer's disease. The tests carried out used word lists rather than narrative prose, but authors write that 'in DAT [dementia of the Alzheimer's type] there is partial damage to two cognitive subsystems or processes, neither of which is uniquely dedicated to reading but both of which are crucial to skilled oral reading.' Significantly, 'the reading of regular words, which is supported

by both processes, remains relatively intact'. This spared ability ought to influence the lexical range of any text prepared for readers with early-stage Alzheimer's.

In a study of the effects of Alzheimer's disease, Kempler et al. (1998) suggest that the impairment with sentence comprehension is related to deficits in verbal working memory and not to an impaired grasp of syntax. They conclude that any language-based interventions 'should therefore focus on techniques that compensate for memory deficits rather than focus on linguistic structure.' The same conclusion is reached by Kempler, Almor and MacDonald (1998) in an accessible article in the *American Journal of Speech–Language Pathology*, which suggests that speaking slowly may tax working memory. Further work by Almor et al. (1999) draws attention to the extra load placed on working memory by the use of pronouns instead of noun phrases (grammatical anaphora). On this point Mitzner and Adams (2008) agree, and they single out left-branching sentences and temporary closure ambiguities as further examples of grammatical constructions in English that make particular demands on memory. Rayner et al. (2012, p. 224) indicate why such 'garden path' sentences can be generally problematic. Avoiding unnecessarily complex grammatical structures was particularly important in writing the texts for the Book Cover Study (p. 171).

The role of clause and sentence 'wrap-up' in retaining written information is examined by Payne and Stine-Morrow (2016) in their investigation of mild cognitive impairment. Crucially, the authors observe an effect that is characteristic of the condition, namely that individuals are unable to improve their reading performance even by 'allocating disproportionate effort'. The authors liken this finding to the 'labor in vain' effect noted in college students by Nelson and Leonesio (1988), although the similarities in outcome would seem to be unrelated to the causes. Taking an unusually practical approach, the authors draw attention to the implications of their findings for the design of healthcare information.

A read-aloud procedure was used by Creamer and Schmitter-Edgcombe (2010) to highlight the difficulties in using inference to comprehend written texts. The authors suggest that the particular memory impairment associated with Alzheimer's disease interferes with the ability to 'integrate story events through the use of inferences and to create a global coherence to support text comprehension.' Tse et al. (2007) and Zeithamova, Schlichting and Preston (2012) discuss the role of the hippocampus in inference, and Stine-Morrow, Hussey and Ng (2015) regard inference as a constitutive activity of immersive reading. Particularly relevant to the current research is the observation by Kintsch and van Dijk (1978) that writers normally omit anything that readers may be expected to infer either from the text or from their world knowledge. Expert readers who go on to develop Alzheimer's disease may now need information to be presented explicitly and not left to inference.

An inability to remember what happens in a story or who the characters are was reported repeatedly by readers who had early-stage Alzheimer's disease. The difficulty would seem to be related to an impairment of gist memory. Kintsch and van Dijk (1978) propose a model for the way in which 'the meaning elements of a text become organized into a coherent whole' and the whole is then condensed into a gist. Reyna and Brainerd (1995) in a lengthy and frequently cited article draw an important distinction between verbatim memory and gist memory. The gradual loss of gist memory as a result of Alzheimer's disease was suggested by Chapman et al. (2002) in a study involving individual word reading. The loss of both gist memory and detail memory is related to the advancing of the disease according to Hudon et al. (2006). A picture identification task was used by Budson, Todman and Schacter (2006) to demonstrate the effect that Alzheimer's disease can have on gist memory. Their work on images and memory will be returned to below (p. 57).

The ability to remember individual events and the order in which they occur is a prerequisite for successful reading of narrative prose. Zacks et al. (2006) suggest that Alzheimer's disease affects the ability to encode activity as a series of discrete

events. They conclude that, ‘parsing the activity at the right moments is likely to be critical for later memory.’ It is therefore possible that the careful structuring of a story might enhance recall.

Zacks et al. draw on the work of Radvansky, one of the authors of the much-cited article, ‘Walking through doorways causes forgetting’ (Radvansky and Copeland 2006). This article explores ideas on event boundaries and event segmentation; a later article (Radvansky, Pettijohn and Kim 2015) applied these theories to younger and older adults. A full account is available in *Event Cognition* (2014), co-authored by Radvansky and Zacks, which refers to the difficulties experienced by individuals who have Alzheimer’s disease (p. 13). A practical example of experiencing an event boundary might be turning the page of a printed book. This important aspect of page layout was raised during the interviews (e.g. Appendix II, p. 279).

Corroborating evidence of the difficulties readers may experience with text comprehension is provided by the published accounts of individuals who have dementia. Not every author has Alzheimer’s disease, but their comments, though anecdotal, are too consistent to be ignored. Bryden (2005, p. 120) singles out the problems caused by turning the page. The same author (Bryden 2012, pp. 86, 90–91) describes writing notes about characters and the difficulty of holding a plot in memory. Swaffer (2016, p. 293) writes of a similar experience: ‘I read, then I forget ... I read and take notes, then I forget.’ Mitchell (2018, p. 120) refers to the difficulty of retaining a plot and her discovery of the advantages of shorter works of fiction. A nursing home resident writes that she annotates her copies of books and adds summaries that she can consult when resuming reading (Healthcentral 2007). Davis (1989, p. 21) notes with regret that he can no longer read substantial magazine articles. The ways in which this sort of user experience can guide design is discussed in the third part of this literature survey (pp. 60ff.).

### **2.3.5 Reading for pleasure with early-stage Alzheimer's disease**

The current research investigates the pleasure that individuals with early-stage Alzheimer's derive from recreational reading. Underpinning this enquiry is a search for the aspects of reading that seem to be spared and an exploration of ways in which can texts be designed to capitalize on these spared skills.

Recreational reading is reading that is not obligatory and it may therefore encompass fiction and non-fiction, poetry and illustrated texts. Shared reading is not included in the current research project, but the findings of a collaboration between The Reading Agency and the department of English at the University of Liverpool (Billington et al. 2013) offer important insights. The summarising report entitled 'A literature-based intervention for older people living with dementia' reaches positive if tentative conclusions. The methodology of the intervention may be less than ideal (e.g. the participants' comorbidity is not taken into account, the opinions of carers and affected individuals are mixed, and the gathering of information is erratic), but there are telling details that reflect the powerful effect of the written word; the insights offered in the three case studies included in the appendix are particularly noteworthy. Similarly affecting are the accounts provided in the 'What Literature Can Do' report (Davis et al. 2016), which describes a shared reading scheme for non-typical readers. Pleasure in reading does not seem to be dependent on reading fluency.

Fiction will be a familiar genre for once-fluent readers. Mar and Oatley (2008) draw attention to the schema/story relationship and discuss the ways in which fiction is made recognisable to the reader by the author's subtle manipulation of expectation and surprise. This point is also made by Sullivan et al. (2015), who draw on the results of fMRI scanning to conclude that, 'The experienced reader, like the well-functioning individual, is aware of multiple meaning threads and iteratively updates meaning within holistic plots and schemata' (p. 154).

Recent work in neuropsychology has revealed the complexity of the activity involved in reading rich texts. In an experiment which involved volunteers reading Robert Harris's novel *Pompeii* while in a scanner, Berns et al. (2013) demonstrated the regions of the brain that were involved in following the dramatic twists of the plot. Also using fMRI imaging, Wehbe et al. (2014) investigated the pattern of brain regions involved in reading stories and suggest that areas associated with theory of mind may be activated; a suggestion that is also raised by Stine-Morrow, Hussey and Ng (2015).

In a similarly interdisciplinary study, Keidel et al. (2013) investigated the parts of the brain that respond to literary devices such as simile and metaphor, features of a writer's work that are known to enhance the reader's engagement. Following a similar collaboration between neuroscience and literary studies, Zeman et al. (2013) suggested a link between the response to emotional texts, such as poetry, and the response to music. Such a finding may be significant in the context of the current research as the enjoyment of music is known to be less affected by Alzheimer's disease (Dowson, McDermott and Schneider 2019) and it may suggest the value of heightened language to those with a cognitive impairment.

Neuroscientists Zeman, Dewar and Della Sala (2015 and 2016) coined the term 'aphantasia' to describe the general inability to visualise. In the context of the written word, Brosch (2015 and 2018) writes that visualisation may also occur in the production of mental images in the process of reading. Writers use verbal description to guide their reader's visualization of a story and it is possible that experienced readers who develop Alzheimer's disease may retain this capacity (see p. 132). Texts might therefore be commissioned that deliberately paint a vivid picture in the mind's eye.

The effect of curiosity and interest on memory in both younger and older healthy adults is explored by McGillivray, Murayama and Castel (2015). The authors conclude that 'Interest might serve to rally and direct attentional resources or lead

one to engage in more elaborative encoding, benefiting memory. This effect of subjective interest is particularly important for older adults given declines within certain cognitive domains' (p. 839). This view would seem to be supported by Sakakia, Yagib and Murayama (2018). They describe the biological processes involved in stimulus and interest in healthy individuals and conclude that, 'In addition, one's chronic tendency to experience curiosity has a life-long impact on memory, general cognitive functioning, wellbeing, and physical health both by changing behaviours and altering the brain function or structure' (p. 111). Hess (2014) adds another determinant, namely motivation, and suggests that older adults may naturally adapt to the increased cognitive effort in tasks such as reading by focussing only on the most significant information. Working with this wide range of issues is the focus of the section dealing with accessible book design below (pp. 60ff.).

### **2.3.6 Reading illustrated texts with Alzheimer's disease**

Preliminary fieldwork suggested that illustrated books continue to be enjoyed by life-long readers who have early-stage Alzheimer's disease. The subjective, aesthetic response to such reading material is not considered in the present context; rather it is the usefulness of pictures as an aid to text comprehension and as a prompt to memory that has been explored in the current research. The ways in which design might capitalise on these findings are discussed in section three below.

The literature on the design of illustrated books for readers who have early-stage Alzheimer's disease is limited. The publication by Bate (2014) entitled *Too Late to Learn to Drive: Dementia, Visual Perception and the Meaning of Pictures* is slight, but it is firmly based on the academic research carried out by the author and marks out new territory. The effect of Alzheimer's disease on the memory for images is surveyed by Ally, Gold and Budson (2009). Budson, Todman and Schacter (2006) suggested that Alzheimer's disease affects gist memory for both words and pictures. However, in a review article, Ally (2012) singles out for mention a study carried out by Embree, Budson and Ally (2012) and states:

This study provided convincing evidence that familiarity remains intact for pictures but not for words in patients with a[mnestic]MCI. Further, this study also provided solid evidence that the picture superiority effect is greater in magnitude than in healthy older adults. (p. 691)

In his review article, Ally lists the ‘dual-coding account’ as one of the three theories that would explain the ‘picture superiority effect’. This theory, which was proposed by Paivio (1971) and expanded in his *Mental Representations: A Dual Coding Approach* (1986), is beyond the scope of the present research. However, the author’s exploration of the two symbol systems and their interconnectedness has been highly influential in the field of textual communication. The seminal work by Gestalt psychologist Rudolf Arnheim (1954/1974) *Art and Visual Perception* explored this subject in a systematic way, while his later work, *Visual Thinking* (1969), offers a historically wide-ranging account of the complex relationship between the visual and the verbal. Taken together, the texts map out a subject area which brings together memory, perception and the role of illustration. Arnheim does not refer to schemata (compare Gombrich 1960) but instead describes the very personal and idiosyncratic way that images are stored in memory, concluding that ‘Innumerable thought operations have formed these patterns of shapes and continue to form them’ (Arnheim 1969, p. 84).

Arnheim is one of the many sources referred to in Bateman’s *Text and Image. A critical introduction to the visual/verbal divide* (2014), which offers a detailed, up-to-date account of the complementary roles of words and illustrations. Early in his text Bateman introduces the word ‘multimodality’ (p. 31) and draws on the earlier work by Kress and van Leeuwen (1996 and 2006) to emphasise the growth in interest in combining images and text. Bateman’s examination of multimodality is deeply informative, and it is relevant to the design of materials for readers who rely on two or more modalities to construct meaning. Furthermore, Unit 13 presents possibilities for future research into text and image comprehension, and while an average, neurotypical reader is clearly envisaged, the chapter (p. 239ff.) includes a mention of eye-tracking, scaffolding and the functions performed by images in instructional books. Bateman explores the topic further in ‘Multimodality and

genre' (Bateman 2017), but here the database approach to information analytics is less relevant to the research on which this thesis is built.

A taxonomy of illustration is provided by Goldsmith in her *Research into Illustration. Approach and a Review* (1984) and is returned to in her chapter on the analysis of illustration in Houghton and Willows (eds) *The Psychology of Illustration* (1987). Goldsmith acknowledges the influence on her research of Twyman, whose seminal work on verbal graphic language (Twyman 1982) is similarly descriptive and analytical. Both authors have provided a framework and a vocabulary for the effective appraisal or commissioning of illustrations for new printed works.

The work of A.L. Yarbus has informed the current research into reading illustrated texts with Alzheimer's disease. Goldsmith draws on the then relatively recent translation of his *Eye Movements and Vision* (Yarbus 1967) for her own work (p. 297ff.). Yarbus's research into attention, and his pioneering study using eye-tracking equipment, demonstrated the influence that a preceding textual description may have on a reader's scanning of an illustration. Yarbus's work was replicated and extended by Tatler et al. (2010) and his findings were drawn on for the layout of the pages in the Participant Interview Study (p. 112).

Adult readers who have cognitive issues constitute a discrete readership and, unlike younger readers, they are likely to have a wide range of cultural and intellectual experience. Works on images and texts have been also used as a benchmark against which to test the reaction of informants. The chapter by Peeck entitled 'The role of illustrations in processing and remembering illustrated text' in *The Psychology of Illustration* (Willows and Houghton 1987) includes a number of relevant observations about comprehension, retention and motivation (pp. 116–119). Particularly helpful in the investigation of the pleasure of illustrated books is Rock's *Perception* (1984). The author's discussion of the enjoyment of the viewing experience is an aspect that is often missing from purely psychological accounts.

### **2.3.7 Concluding comments on reading with Alzheimer's disease**

In concluding this section of the survey, it is important to emphasise that building up an understanding of the effect of Alzheimer's disease on reading involves drawing on the literature of a number of separate disciplines. An attempt has therefore been made to identify key elements of the research carried out in each area and bring this knowledge to bear on the central issue, namely the experience of the habitual reader whose cognitive skills are affected by a particular form of dementia.

## **2.4 Accessible book design**

As noted in the Introduction, there is not yet a cohesive body of literature on accessible book design for readers who have Alzheimer's disease. The research carried out for this thesis had therefore to draw on information in the area of conventional book design and to supplement it with findings on design for specific literacy needs.

A major difference from conventional book design is the importance attached to user-testing in the preparation of content and presentation. The more routine aspects of user-testing are included in the Methodology section (p. 85). The ethical issues raised by the involvement of volunteers who have a cognitive impairment are discussed below (pp. 77ff.).

### **2.4.1 The accessible design context**

Accessible book design is an aspect of user-centred design, which is itself related to inclusive or universal design. Clarkson and Coleman outlined the importance of the inclusive design concept in their editorial 'Designing for our future selves', before going on to describe the possible economic and societal benefits of the approach in the opening article, 'History of inclusive design in the UK' (Clarkson and Coleman 2013/15). A brief summary of the emergence of user-centred design is offered by Kelly and Matthews (2014) as part of their argument for the broadening of the concept of 'user' to include individuals who facilitate the use of an object; this is

particularly relevant in the context of dementia design, where the purchaser is not likely to be the end user. The ethical need to involve users in design is also being recognised. This was noted by Frascara in *Information Design As Principled Action*, where he writes that, ‘Information design is of necessity user-centred. It is ethical because it recognizes “the others” as different from the designer and deserving respect in their difference’ (Frascara 2015, p. 5).

The current research examines the needs of a specific section of the population, but it also anticipates that other readers may benefit from its findings. Farage (2012) and her colleagues at the US based Procter & Gamble make a strong business case for meeting all market needs, and their informative article ends with ten pages of tabulated analysis of universal design, the effects of ageing, and possible design remedies. Under a final heading ‘The Importance of Respectful Inclusion’, they make the following observation:

Aging should be viewed not as a liability or a form of pathology but as the common destiny of the fortunate. (p. 9)

From this viewpoint, accessible design needs to be open minded and innovative; on occasion, it may also need to challenge accepted ideas. Consciously disruptive approaches to design are a recurrent theme in the work of Paul Rodgers (2018), while Graham Pullin adopts a gently confrontational tactic in his *Design Meets Disability* (2009) in which high-profile designers are challenged with unfamiliar problems. The presentation of this small book is understated but printed on the front cover is a comment by Donald Norman: ‘A powerful, important book’. Supporting this view, Clarkson and Coleman (2013/2015) include extensive discussion of Pullin’s text in the closing section of their article entitled, ‘Where next’. Pullin’s belief in the resourcefulness of designers when faced with a constraining specification (p. 79) was put to the test when commissioning test materials for this thesis. Pullin also favours going beyond a diagnosis-and-solution approach to design and, in this context, he mentions the work of Bill Gaver (p. 151), in particular his interest in ‘ludic design’. Gaver had observed in his article ‘Designing for homo ludens’ (2002) that ‘pleasure comes before performance, and

engagement before clarity'. This challenging view was one that had to be considered when designing books for readers living with dementia.

#### **2.4.2 Accessible design and publishing convention**

The studies devised for this thesis were based on findings from the field study which suggested that early-stage Alzheimer's disease need not be a barrier to recreational reading. There are two reasons that may explain this finding: first, experienced readers may retain enough preserved skills and memory function to comprehend a text (Stine-Morrow, Hussey and Ng 2015); second, printed texts (and bound books in particular) draw on conventions that make the textual content and presentation to some degree predictable.

Accessible book design explicitly capitalises on both of these characteristics. The current research also takes advantage of the fact that accessible book design takes a pragmatic approach to the conventions of publishing and makes adjustments in the light of the user's needs. Publishing is regarded as one of the UK's creative industries (DCMS 2016) and the complexity of this hybrid business is captured by Greco in 'Economics of publishing' (Greco 2019, chapter 5, pp. 165–187). The larger companies are able to combine different kinds of knowledge in producing their products: data-driven information for production costs, book sales and projected income; craft knowledge and applied research for design, printing and binding; and subject knowledge for authorship. Many judgements, though, also rely on heuristic knowledge and draw heavily on experience in each separate area.

Each newly published work is a unique combination of multiple factors. The Field Study (pp. 94ff.) suggested that taking a marginal gains approach to individual factors might be fruitful. This would involve manipulating the different aspects of conventional page design to see what provided the reader with the most successful outcome. Although marginal gains as a concept is normally associated with economics and elite sports, it has also been used in a medical context to describe the interdependent factors that contribute to healthy cognitive ageing

(Corley, Cox and Dearly 2018). In a book publishing context, it is recognised that individual features cannot be taken in isolation. Dyson, for example, notes in her recent publication *Legibility: how and why typography affects ease of reading* (2019) that typographical variables interact and that the overall effect may be perceived as ‘other than the sum of the parts’ (p. 99).

### **2.4.3 Accessible design for readers who have Alzheimer’s disease**

Specific aspects of book design were investigated in the studies carried out for this thesis. These aspects are described below and the literature surrounding each of the design decisions made is discussed.

**The conventions of text preparation:** Experienced readers who develop Alzheimer’s disease continue to be aware of the conventions of book design. This was clear from the findings of the Field Study (p. 94ff.). The sample materials were designed to fit within existing publishing conventions and to meet the expectations of the genre. Texts were designed to suggest works of fiction, illustrated fiction and illustrated non-fiction, and the content of the texts were appropriate in each case.

Conventions within publishing are reflected both in the existence of publishers’ lists, which divide authors’ works into categories by genre (scholarly monographs, literary fiction, popular fiction, etc.) and in the traditions of the presentation of texts within those lists. The expectations of specific genres are made explicit in the detailed style-guides issued by major academic presses such as *The New Oxford Style Manual* (Oxford University Press 2016) and *The Chicago Manual of Style* (University of Chicago Press 2017), while Butcher, Drake and Leach’s *Copyediting* (Cambridge 2006) offers a succinct and realistic account of the copyeditor’s role.

The research carried out for the thesis took place within the context of contemporary book publishing. It also considered the historical background to

the current conventions governing the preparation and the presentation of printed text. Ong's *Orality and Literacy. The Technologizing of the Word* (1982) explains why such conventions evolved and describes the changing attitudes to writing, authorship and publishing.

**The conventions of book design:** the design of the sample materials aimed to address individual problems that books can pose for the reader who has a cognitive impairment. In each of the areas discussed below, the specific difficulty is considered in the context of the relevant design literature.

i. The overall style of the book

Every published book is the result of numerous decisions. To achieve a coherent overall design, every aspect of presentation needs to be considered in the context of the whole. Readers may be only subliminally aware of the style of a book, but it will have been carefully constructed to serve the book's purpose.

In the case of habitual readers who have a cognitive impairment, the choice of a traditional design has the advantage of offering predictability. Whereas novelty may interfere with the reader's absorption of the text, an unobtrusive, conventional design presents no distractions. This choice was in line with the guidelines issued by the Dementia Engagement and Empowerment Project (DEEP 2013a). Typical features of a conventional design for fiction would include a generous use of white space, wide margins, an unexceptional typeface that is clear and readable, and a text that flows through the book in an unhurried fashion. The sample materials drew on a number of standard texts that define and describe this approach. Books written by designers were particularly helpful in demonstrating the close relationship between clarity of thought and clarity of presentation; they also reflected the often quite subtle interplay of image and text.

Hugh Williamson notes in his preface to *Methods of Book Design. The Practice of an Industrial Craft* (1956, p. 8) that 'In Britain at least, convention is the most

powerful single influence on style in book design.’ Academic publishers such as Oxford University Press, who published the original text, and Yale, who published a revised edition in 1983, have played a significant role in establishing norms of typography and layout. Their texts are presented in a timeless style reflecting the investment made by the presses and their expected long-term contribution to the canon. Yale University Press is also the publisher of Richard Hendel’s *On Book Design* (1998) and Derek Birdsall’s *Notes on Book Design* (2004). Hendel’s *Aspects of Contemporary Book Design* (2013), referred to below, is published by the University of Iowa Press.

A traditional design offered readers a carefully regulated presentation of ideas and expression. Robert Bringhurst’s *The Elements of Typographic Style* (1992) was particularly relevant in considering the overall ‘feel’ of the sample texts.

Bringhurst, who is a poet and translator as well as a typographer, states as his first principle that ‘Typography exists to honor content’ (p. 17). This view influenced the design choices made in the sample material and, where it was necessary to be innovative, the designer broke the rules, as Bringhurst recommends, ‘beautifully, deliberately and well’ (p. 10). Hendel (2013) makes the same point and advises that the rules of conventional typography, ‘should not be slavishly followed, but neither should they be ignored’ (p. 8).

Adopting a classic design meant that readers could move through a text smoothly. Beatrice Warde argues in ‘The Crystal Goblet, or Printing Should Be Invisible’ (Warde 1930) that typography should be transparent and at the service of the text. Warde is no idealist and she writes:

I beg you to remember that thousands of people pay hard-earned money for the privilege of reading quietly set book-pages, and that only your wildest ingenuity can stop people from reading a really interesting text. (p. 4)

Both the fieldwork and the interview studies supported her view that readers are willing to struggle with poorly designed texts if the content makes it worth their while.

A classic design also avoided producing sample materials with a ‘remedial’ feel. Accessible design need not be unsophisticated, a point that is stressed by Barker in his contribution to *Aspects of Contemporary Book Design* (Hendel 2013). Barker devotes several pages of his essay ‘Backwards and in high heels: the glamorous work of book design’ to a consideration of designing for disability (Barker 2013, pp. 17–100). Cognitive impairment is explicitly referred to, together with an appreciation that, ‘accessible versions of documents should not be regarded as poor relatives’ (p. 32).

ii. The layout of the page

The layout of the page is particularly important for the reader with a cognitive impairment. The published literature in this specific area is not extensive. Information had therefore to be combined from three areas, namely general texts on current design practice, applied research literature on instructional texts, and a small number of specialist sources.

An impaired memory may be supported by a regular and predictable page design. The use of a grid allows a systematic positioning of the text block, running heads and page numbers within the white space of margins. The fundamental importance of an appropriate grid is stressed in many guides to book design. Bringham (1992) refers to shaping the page (p. 150–151) and Barker (2013) describes the devising of grids to accommodate difficult copy (pp. 32–33). The detailed analysis by Birdsall (2004, p. 212ff.) is beyond the scope of the present research. Schriver addresses the construction of the page in more general terms in *Dynamics of Document Design. Creating Texts for Readers* (1997). Here the reader is put firmly at the centre of design.

An effective use of the text block may help to reduce excessive cognitive load on the part of the reader. To reduce the demands made on memory, the newly commissioned texts used for the sample materials were written in short paragraphs; for existing tests, the denotation of the authors’ paragraphs was emphasised.

Lonsdale (2014, Ch. 4.3.4) reviews the evidence for the merits of indentation and extra line spacing and notes Schriver's preference (p. 356ff.) for using both features despite the inevitable increase in text extent. Hartley (2004) discusses the evidence in an instructional context, but his comments on breaking the reader's flow are particularly relevant to the study of cognitive impairment. Waller (2012) draws attention to the advantages of breaking the text down into visually differentiated parts, commenting that 'These are instances of documents as memory tools, reducing the need for readers to construct and refer to mental representations of content structure' (p. 261). Similarly, Graesser, McNamara and Louwerse (2003) analyse the reader's experience of both narrative and expository text and emphasise that good comprehension depends on good coherence relations within a text. Such relations need to be made visually explicit. The interplay of the visual and the verbal is the subject of Moys's 'Visual rhetoric in information design' (Moys 2017). The subtle impact of the presentation of the text on the reader is demonstrated in Black and Stanbridge (2012), with particular emphasis on the function of the structure of text and ideas in successful communication.

### iii. Typography

Immersive reading is facilitated by legible type. The literature on the legibility of printed text is reviewed by Lonsdale (2014), and she follows Twyman (1982) in distinguishing between the intrinsic features of type (the typeface, different fonts, upper and lowercase, etc.) and the extrinsic features (letter spacing, colour, line spacing, etc.)

Legge and Bigelow (2011) approach legibility from their respective disciplines of psychology and typography, writing that 'The legibility of print depends on physical characteristics of text and also on task demands, viewing conditions, and the vision status of the reader' (p. 5). The authors discuss the findings of Tinker, which were published in his influential *Legibility of Print* (1963). Tinker is of the opinion that, 'A legible type is one that can be read rapidly and easily' (p. 66); he also recommends a generous type size for less fluent readers (p. 38). Legge and Bigelow

also draw attention to the ‘important and deep insight’ provided by psychologists Pelli et al. (2007) who demonstrated the effect of crowding on perception and the consequent need for optimal letter-spacing for maximum reading efficiency. All of these writings are skilfully contextualised in Dyson’s *Legibility*, a book that has already been mentioned and one that offers the non-specialist reader a clear and concise summary of all relevant issues (Dyson 2019).

Recommendations for optimising the legibility of texts for readers who have dementia are limited. Mention has already been made of the DEEP guide ‘Writing dementia-friendly information’ (2013a), which was co-produced with members of the group and uses the typeface, type size and layout that it endorses. Continuous text, however, makes different demands on the reader, although recommendations made by Luna in ‘Choosing type for information design’ (2017) would be relevant to the design of narrative prose. Luna draws particular attention to the work of type designer Sophie Beier, author of *Reading Letters: designing for legibility* (2012). In a collaborative paper Beier and Larson (2013) assess the part played by familiarity of type design convention and exposure to a particular typeface. Two points are of relevance to the current research: first that all the participants had good literacy skills, and secondly that readers are not indifferent to typefaces; indeed, ‘In a normal reading situation, outside of the laboratory setting, readers will simply stop reading if the situation is uncomfortable ...’. An unwillingness to struggle with hard-to-read type would be particularly understandable in readers who have Alzheimer’s disease.

Reading for pleasure requires an ease with the typeface chosen for a text not just its basic legibility. The influential text by Pelli and Tillman (2007) on parts, wholes and context states that, ‘mechanistic letter decoding, L, accounts for the lion’s share (62%) of the adult reading rate’. This is a very high proportion and while it may reflect only the experience of average readers, it does suggest that the choice of typeface is of some significance. Crowding and ambiguity need to be avoided if the reader is to perceive each word correctly at first pass. The 22% average contribution

made by contextual sentence recognition is described as ‘variable across readers, which may reflect individual differences in print exposure’ (Pelli and Tillman 2007). The beneficial effects of a habit of reading are a recurrent theme in the research carried out for this thesis.

The DEEP (2013a) guide recommends a sans serif typeface for conveying information, but it makes no mention of recreational reading. The contribution that serifs may make to legibility is summarised by Dyson (2019, pp. 64–74) although, interestingly, her text is set in a sans serif face. Lonsdale (2014) is also equivocal, noting that ‘some studies have found a significant difference between sans serif typefaces, despite there being no significant difference between serif and sans serif typefaces’ (p. 4). Particular care was needed in choosing two sympathetic but contrasting typefaces when preparing the sample materials. The status of different parts of the text was indicated to the reader by the use of a serif typeface (for narrative) and a sans serif typeface (for instructions, summaries and supporting material).

Interdisciplinary work carried out by Thiessen (Thiessen, Kohler, Churches, Coussens and Keage 2015) found a difference in the speed at which the brain processed harder to read and easier to read typefaces; the write-up of the experiment that appeared in *Brain and Cognition* (Keage et al. 2014) highlights the differences in approach of the various disciplines. The value of collaborative research in investigating reading and typography has long been emphasised by Dyson (1999, 2013).

Punctuation was mentioned by individuals at the scoping stage of the research and it is likely that clearly distinguishable marks help to make the structure of a text intelligible. This is borne out by the advice provided by the RNIB: ‘Remember that punctuation is harder to see with vision impairment and is essential to understanding’ (RNIB 2017). This point is also highlighted by Spencer in *The Visible Word* (1969, p. 34). In *The Oxford Manual of Style* (Ritter, 1992, p. 112) it

is clearly stated that, ‘Punctuation exists to clarify meaning in the written word and to facilitate reading.’ This often-overlooked aspect of text design is fully catered for in Barrington Stoke publications. These titles are especially prepared for readers who have dyslexia (Barrington Stoke 2019) and have conspicuous punctuation marks to help the reader to parse each sentence correctly.

The full range of ‘alphabetic furniture’ is demonstrated by Bringhurst (1992, p. 73ff.) in a discussion of commas, parentheses, quotation marks, hyphens and numerals (pp. 44–45). Bringhurst’s use of clear but elegant numerals and his instruction to ‘Use the best available ampersand’ (p. 76) were followed in the sample materials. Jost Hochuli’s *Detail in Typography* (2008) is concerned with the smaller points of typographical design, though not obsessively so. The author’s stated aim is to achieve maximum legibility and readability (p. 6) but not at the expense of editorial sense; eschewing the use of italic punctuation after a book title indicates that the designer is putting the reader’s needs first (p. 37). Barker (2013) is similarly concerned to use punctuation conventions as a notation system to communicate with the reader (p. 94ff.). Waller (2011) takes a relaxed view of punctuation but appreciates the need to tailor it to the needs of a particular readership. In a later paper, Waller (2012) introduces the work of bibliographer Paul Saenger. Saenger’s scholarly text *Space Between Words: The Origins of Silent Reading* (1997) is beyond the scope of the present research, but it provides a vital historical context for current typographical conventions; it also cautions against regarding western reading practices as the norm. Saenger’s assertions on word shape (p. 18) may be regarded with caution. The earlier work by Pugh on silent reading is more relevant since it discusses the inherent difficulty of testing silent reading and assessing comprehension (Pugh 1978, p. 94).

Vision research into reading with dementia (e.g. Fraser et al. 2017) highlights the problem of the return sweep. Line length was therefore considered in the context of type size and typeface. The flexibility offered by unjustified text was used in the

sample materials to avoid hyphens and to control line breaks for sense. Early work by Raban (1982) draws attention to the importance of judicious line breaks when laying out texts for young readers. Raban's findings are referred to by Walker in her historical account of the pedagogical requirement to relate line breaks to the sense of a text (Walker 2013, p. 44). An overview of the issues raised by the production of materials for non-fluent readers is provided by Walker et al. (2018, pp. 31–67) in Barzillai, Thomson, Schroeder and van den Broek (eds), *Learning to Read in a Digital World* (2018). Of particular relevance to the research for this thesis is the emphasis placed on user testing, with the various options available for eliciting feedback helpfully listed (p. 59). The typographic features that are likely to benefit children's reading (Table 1, p. 62) also need to be considered when designing for an adult cognitive impairment.

#### iv. Navigation

The DEEP (2013a) guidelines specifically mention the use of headings to assist the absorption of text by readers who have a cognitive impairment. This recommendation is supported by a body of applied research into the helpfulness for unimpaired readers of a hierarchy of headings as an aid to comprehension and recall. However, within the literature there is a wide variation in the age and literacy level of participants, the materials used and the testing context. There would seem to be a general agreement, though, that advance organisers can help the reader by making the structure of information explicit.

The use of side headings in a classroom context was investigated by Hartley and Trueman (1983). Their observation that 'Headings thus proved effective for aiding recall, search and retrieval' (p. 213) suggests that headings have a general memory-supporting function. Lorch (1989) proposed that the use of text-signalling devices helps to focus attention while reading and thus aid comprehension. Importantly, Lorch and Puzles Lorch (1996) distinguish between narrative and expository text, writing that 'The tight causal structure of narratives generally makes them relatively easy to recall, perhaps in part because the transitions between episodes are

relatively easy to reconstruct.’ The use of signals in expository text may alert the reader to the writer’s intentional structuring of the text and guide the reader to building an effective topic structure representation.

A study by Kardash and Kent Noel (2000) introduced further variables into the testing method. By adding in ‘need for cognition’, the authors indicated that motivation and reader competence may affect the usefulness of headings. Habitual readers and those who read for pleasure may respond differently from readers who have low literacy skills.

Eye-tracking equipment was used by Hyönä and Lorch (2004) and the authors noted that ‘signalling devices’ affected the way the text was processed at first reading. The more recent eye-tracking study by Fraser et al. (2017) suggests that readers with dementia might benefit from a strategy to control the amount of text to be processed at any one time.

The research by the Dementia Services Development Centre at Stirling University suggests that appropriately designed signage may help with orientation in residential settings (DSDC 2020). The findings have relevance for the design of texts for both strategic and receptive reading.

The benefits of text summaries in an instructional context are included in the overview by Lorch (1989) mentioned above. Summaries are listed by Hartley (2004) as a way of supporting the processing and memory load of older readers, although Hartley also notes the problem of testing heterogeneous groups of such informants. Working in an educational context, Hartley, Goldie and Steen (1979) compared the effect on recall of positioning summaries either before or after a text and noted that ‘the end summary led to significantly better recall scores’. End summaries may identify the key points that the writer intends the reader to recall. Positioning the summary at the start of the following section would serve as a recapitulation before new information is presented. This is the

function of the recap sequence in television convention. Jason Mittell in *Complex TV: The Poetics of Contemporary Television Storytelling* (2015, p. 187ff.) describes the recap sequence as a narrative device that is used to remind the viewer of key events in preceding episodes of a drama. It is brief and selective, and, like a text summary, it helps to set up the correct representation in the mind of the viewer.

#### v. Illustration

The DEEP (2013a) guidelines include advice on the handling of images. The instructions are specific and are based on specially commissioned user-evaluation carried out by Innovations in Dementia (Litherland 2008). The evaluation involved participants who were more incapacitated than the informants who contributed to the present research but, in the absence of other user-centred studies, the findings had at least to be considered. Issues raised included ensuring that the content of an image was unambiguous and not distressing and that its message was not made unintelligible by harsh cropping and conflicting juxtaposition.

A distinction is to be made between commissioned artwork and the use of existing images. The styling of commissioned artwork in a medical context was tested by Black (2019) and the results highlighted the emotional effect that drawings may have on the typical reader; further user-testing would indicate if the findings held good for readers who have dementia. In a wide-ranging text, Barbara Tversky (2011) notes that diagrams have conventions that have been refined over time and that it would be helpful, ‘to formalize the natural user testing cycle – produce, use, refine – and bring it into the laboratory by turning users into designers.’ The research carried out for this thesis suggests that commissioned illustration would also need to be tailored to the specific needs of the reader.

Good practice in the handling of existing images is exemplified in Haslam’s *Book Design* (2006). The publishers, Laurence King, are known for their illustrated

reference list and it is no surprise that Haslam acknowledges, 'A printed book is the result of a collaborative process' (p. 13). Derek Birdsall's *Notes on book design* (2004, mentioned above) also notes the particular questions posed by the reproduction of works of art. Pages from publications of major museums and galleries demonstrate the design skills required when text and images are juxtaposed in a delicate balance, the author's meaning lying in the combination of words and pictures. Birdsall notes in his Preface that his aims are 'the decent setting of type and the intelligent layout of text and pictures based on a rigorous study of content' (p. vii).

A valuable section of Schriver's *Dynamics in Document Design* (1997, already mentioned), includes more general guidelines for the integrating of words and pictures (p. 440ff.). A number of the suggestions are especially relevant to design for readers who have a memory impairment, in particular the use of deliberate redundancy and the recommendation to 'Strengthen and constrain the meaning for readers by using complementary prose and graphic combinations' (p. 441). The positioning of illustrations was investigated in the sample materials, putting to the test another of the author's guidelines: 'Display graphics shortly after they are referred to in the text' (p. 441). The recommendation to avoid images and text that lack content would be relevant to any reader who may be at risk of cognitive overload.

#### **2.4.4 The book as object**

The physical attributes of the bound book are of particular importance for readers who have Alzheimer's disease. It is also likely that the tactile qualities of paper and the pleasure of ownership contribute to the general public's continued interest in reading printed books even when an identical text is readily available in a digital format.

The book-as-object is emphasised by Hartley (2004), referred to above, and he works inwards from the format to the typographical details. In an article that has

particular relevance to the current research Mangen and Schilhab (2012) draw attention to the way that printed pages allow the reader to process an author's ideas by relating them spatially and locating them sequentially. Mangen (2017, p. 286) also suggests that recall of narrative prose is enhanced when the text is in a printed form. Mangen's use of the theory of embodied cognition opens up areas of research that would be highly relevant to a study of the presentation of text for different readerships. She references the extensive work of psychologist Barsalou on grounded cognition. Barsalou (2008) explains the relationship between the two descriptions of cognition, and although his work goes far beyond the scope of the present thesis, an indication of the direction further work might take is provided in a recent but little-cited review entitled, 'Define design thinking' (Barsalou 2017). Here Barsalou describes the part played by Gestalt theories and by grounded cognition in the formation of practising designers; he goes on to recommend that they remain cognisant of developments in the field of psychology:

Because design thinking draws on the full scope of cognitive and affective processes in humans, new insights in cognitive science are likely to percolate into the design community. Rather than being surprised by the co-evolution of cognitive science and design thinking, we should expect it. (p. 104)

It was the insights provided by these texts which suggested that the exploitation of the physical properties of the printed book might be the starting point for the current research.

#### **2.4.5 The content of text**

The literature on text design focuses largely on the presentation of existing material rather than on its creation. Since the current research touches on the composition of texts, the article by Armbruster and Anderson entitled, 'Producing "considerate" expository text: or, easy reading is damned hard writing' (Armbruster and Anderson 1984) is particularly relevant. The authors compare drafting a text to preparing a computer simulation and note that:

In doing computer simulations, a simulation is not complete until we have run the program and determined how well it fits human performance. (p. 45)

An iterative approach was employed for the research studies to check the validity of the conclusions drawn.

The commissioning of texts lies beyond the scope of the present research. However, literary historian John Mullan's elegant *How Novels Work* (2006) serves as a reminder that works of fiction have to be constructed just as much as works of non-fiction. David Lodge neatly explains the difference between story and plot (Lodge 1990, pp. 141–153), and practical examples of this distinction are evident in the texts prepared for readers who have a memory impairment (see Discussion, pp. 210 ff.). The editorial policy of publishers of accessible texts is not widely circulated; excerpts from emailed exchanges have therefore been included as supporting evidence in the accounts of the studies carried out for this thesis.

#### **2.4.6 Existing publications for readers who have early-stage dementia**

Attention has been paid to the small but growing list of publications aimed at readers who are elderly or who have health issues. In the US, these are referred to as books for seniors, to distinguish them from books for adults, young adults and children. In the past five years, there has been a discernible increase in books that have been specially commissioned to interest readers who have cognitive issues such as dementia. Three levels of publication are generally distinguished to match the needs of readers with various degrees of impairment: illustrated fiction with a short text, illustrated non-fiction with simple labels as text, and illustrated non-fiction without text. It is the first of these categories that is relevant to the present research as these books are intended for private rather than shared reading.

There are currently two series of texts, both independently published in the US, that are of interest. The first is a series of six titles written by a female author under the name of Emma Rose Sparrow. An appraisal of the choices made concerning format, page layout and illustration is included in the Discussion section of this thesis (pp. 212ff.). The second series represents a more developed form of the genre. The eight titles are published by Jamie Stonebridge and are

written, ‘in collaboration with people who have direct, positive experience of working with loved ones and patients that have dementia’ (Stonebridge 2020). The stories have been commissioned from experienced writers of fiction, with each narrative carefully crafted to supply ‘a satisfying ending’. The sophistication of the concept is similar to that of the Quick Reads series, which also aims to provide relevant, page-turning stories written in a style deliberately chosen to attract the designated reader (The Reading Agency 2019b).

Both series are a useful point of reference in the current research context. For example, the stated aim of the two series is to be indistinguishable from other trade titles. No mention is made of dementia in any part of the books and this decision is praised in Amazon’s online reviews. However, reviewers of the Sparrow series comment that their purchased book is slight and has the feel of a pamphlet or a children’s book; that it is expensive, and the paper is of poor quality; and that the intended reader found the story boring and would have liked more of a plot. Such deficiencies might well have been anticipated had the books been user-tested and produced by a conventional trade publisher.

#### **2.4.7 Ethical issues raised by user-involvement in dementia research**

This thesis draws explicitly on the opinions expressed by individuals who have early-stage dementia. The reasons for adopting this user-centred approach are outlined in the Methodology section that follows (p. 86). However, a number of published texts raised questions about the broader ethical context for the research and the appropriate study design. A brief discussion of their contribution is included here.

The importance of public and patient involvement (PPI) in dementia research is increasingly being emphasised in the academic literature. Alzheimer Europe offers a simple rationale for greater involvement stating that, ‘PPI can promote the transparency, validity and legitimacy of research projects’ (Gove et al. 2018). This is endorsed by Brooks, Savitch and Gridley (2017), who argue strongly for the direct

consultation of individuals rather than their carers. Certainly, the early diagnosis of Alzheimer's disease has meant that individuals are increasingly able to opt to take part in research studies, and active participation is a key aim of the DEEP organisation: 'DEEP engages and empowers people living with dementia to influence attitudes, services and policies that affect their lives' (Dementia Voices 2020). However, in order to avoid any possibility of exploitation or malpractice, user involvement in medical research is subject to strict ethical control. The Health Research Authority requires all generalisable research or research involving NHS patients to be carried out according to specific guidelines (HRA 2019a; HRA 2019b).

Design research in a healthcare setting raises a number of new ethical issues. Anthropologist C.Z. Miller (2014) refers to a far-sighted article by Wasson (2000) and draws attention to the need for designers to understand the ethical framework within which anthropologists and ethnographers have always worked. The important difference between the fieldworker's purely observational study and the designer's intervention/problem-solving approach is noted, and the ideas are expanded in *Design and Anthropology. Converging Pathways in Anthropology and Design* (Miller 2018). The need for the development of new skills by the designer is also referred to by Pontis (2018), and her emphasis on empathy and on the need for imagination has a particular relevance in the context of accessible design for dementia. The use of 'thick description' in making observational notes is advocated by Geertz in *The Interpretation of Cultures* (1973), and a clarification of this influential text is provided by Ponterotto (2006). Meeting the ethical requirements for this approach is discussed by Jorgensen in *Participant Observation: A Methodology for Human Studies* (1989).

The ethical case is increasingly being made for adopting a participatory or a co-research approach to studies that have a direct bearing on individuals who have dementia. An article by Rivett (2017) suggests that engaging with individuals as co-participants rather than as subjects or informants allows them to retain a sense of

control and autonomy. This is in line with the recommendations of Waite, Poland and Charlesworth (2019), although the authors also highlight the potential problems of tokenism, the protective attitudes of carers, and the need for researcher training. A realistic account by Hendricks et al. (2014) lists seven challenges that are posed by a participatory approach. In the context of book design for early-stage Alzheimer's disease, a simple user-testing approach was considered to be both respectful and productive.

## **2.5 Conclusion**

Three quite separate areas of study contributed to the present research: the nature of Alzheimer's disease, the impact of early-stage Alzheimer's on reading, and the role of accessible design in the preparation of printed books for readers affected by the disease. Despite the extensive literature in each of the areas, there appears to have been little research into the real-world experience of recreational silent reading by individuals who have early-stage Alzheimer's disease.

The studies described below represent an attempt to clarify a number of specific points that are raised by the research questions. The preparation of the sample materials and their presentation to informants drew largely on a careful combining of widely available medical knowledge, design expertise, published instructional research and current publishing practice, none of which, on their own, would have sufficed to probe the complex issues involved.

## **3 Methodology**

### **3.1 Introduction**

The research carried out for this thesis sought to address two main questions: first, what impact does early-stage Alzheimer's disease have on an individual's capacity to read for pleasure? Second, what can be done by book editors and designers to mitigate this? The specific focus of the current study was the experience of life-long readers who have received a recent diagnosis of Alzheimer's disease. To investigate the issues raised, a qualitative approach was taken which involved participant evaluation in three separate, small-scale studies. The general approach to the research is outlined below, followed by an overview of the materials that were prepared for the studies and the methods that were implemented in their testing. Details of the typographical and design decisions made in the course of the preparation of the materials are included in the separate accounts of each of the three question-and-answer studies (see Sections 5, 6 and 7).

### **3.2 Research approach**

The decision to adopt a qualitative approach was made during the early stages of the Field Study, when the sensitive nature of the enquiry became apparent. Since the aim of the research was to gather first-hand information from volunteer informants, it was decided that a method involving thoughtful questioning on an individual or small-scale basis would offer the best chance of drawing out participants' opinions and ideas. Furthermore, since the effects of Alzheimer's disease are known to differ from person to person, the method could be adapted to suit each new encounter.

A qualitative approach proved to be appropriate for an investigation of the personal response to reading books for pleasure. The credibility of the research findings is supported by the small-scale but expert recruiting offered by the BMCRC and by the strong framework provided by the group facilitators at the DEEP meetings.

Verbatim transcriptions of all relevant opinions expressed by informants are provided (see Appendices VI, VIII and IX) to ensure transparency and to allow for checking for researcher bias. The formal description of the materials and methods used in each of the studies offers consistency and allows for the possibility of further examination. The transferability of findings is outlined in the Discussion section of the thesis (p. 204ff.), which draws on the detailed notes made by the researcher at each stage of the investigation. Within each of the individual studies a carefully considered discussion section serves to describe the researcher's reflexive approach to the findings, and to record the changes made as the project evolved.

Throughout the research, theoretical and empirical knowledge has been combined, with the findings of relevant published studies being tested against the real-world experience of affected individuals. The advantages of blending published information from different research disciplines has already been noted (Introduction p. 25). Caution is, however, necessary as dementia studies is a relatively new subject area and the published research lacks the cohesion of more established disciplines (Sanders and Scott 2020). The validity of small-scale investigative research in a healthcare setting is, however, strongly defended by Angen (2000) and is endorsed by Pope, Ziebland and Mays (2000) in a frequently cited article in the *British Medical Journal*.

Qualitative research that brings together the findings of a number of different disciplines has a precedent in publishing for particular needs. Progress has been made in the preparation of books for young readers who have dyslexia by building on research into the psychology of reading (Rayner, Pollatsek, Ashby and Clifton 2012; Snowling and Hulme 2007) and combining it with an insight

into the reader's lived experience (Wolf 2008) and the skills of publishers who have a background in primary education (Barrington Stoke 2019).

The focus of the present research was deliberately narrowed in order to clarify specific issues. Aspects of the reading experience that were widely thought to be problematic in the target population were isolated and matched against the accounts of preferences expressed by members of that target population.

The approach adopted for the current study involved:

- i. a scoping study of individuals' experience of dementia and their interest in printed books
- ii. a close examination of the published literature in relevant subject areas, including the pathology of Alzheimer's disease, the effects of a cognitive impairment on reading, and designing for particular literacy needs
- iii. the testing of pairs of sample book layouts by readers who had early-stage Alzheimer's disease
- iv. the appraisal by individuals who had early-stage dementia of sample layouts offering memory-supporting additions
- v. the appraisal of contrasting treatments of sample book covers by informants who had early-stage dementia
- vi. the appraisal of the sample text layouts (iii and iv above) by three practising book designers and a book illustrator

The reasons for adopting this approach are discussed below.

### **3.2.1 Scoping study**

The effects of Alzheimer's disease in its early stages can vary considerably. The initial field study therefore sought to clarify the problems the condition might raise in reading for pleasure. Conversations with informants revealed that these individuals represented a discrete group defined by their diagnosis, which suggested that approaches used in design ethnography would be relevant to the research study. Focussing on the members' specific stated needs allowed the researcher to set aside considerations that were less relevant: for example, low vision, intellectual disability and physical immobility.

The personal but informal accounts provided by individuals and groups from a range of backgrounds constituted an important information-gathering exercise which made a substantial contribution to the formulation of the sample materials used in the studies. The accounts also provided the researcher with an opportunity to measure the informants' lived experience against the generalisations that are made about the condition in the literature. Individual contributions suggested that certain generalisations were questionable and needed further investigation.

### **3.2.2 Published literature**

The issues raised by the research studies involved current medical descriptions of Alzheimer's disease, theoretical contributions from psychology and educational psychology, and applied research carried out in the field of book design, legibility and user-testing.

**Medicine:** in order to construct a framework within which to set the investigation, the studies drew on the medical literature concerning dementia and, in particular, on up-to-date accounts of prodromal and early-stage Alzheimer's disease (Ames, O'Brien and Burns 2017, p. 418ff.; Waldemar and Burns 2017).

**Psychology:** three recognised areas of psychology research contributed to the design of the study materials. The first was the current model of working memory (Baddeley, Eysenck and Anderson 2015), which provides an insight into the specific memory deficits that occur as a result of Alzheimer's disease (Baddeley 1991). Secondly, Stern's theory of cognitive reserve (Stern 2006), which suggests that the differential effects of Alzheimer's disease may in part be due to personal education and life experience. The particular relevance was the account this theory provides of the range of preserved skills that may be noted despite an individual's evidence of pathology. Thirdly, cognitive load theory (Sweller 1988 and Sweller, Marrienboer and Paas 1998), which draws on the

well-established schema theory originally proposed by Bartlett (1932) and suggests that accomplishing a task is related to the concurrent demands of specific aspects of the task. The notion that some activities – e.g. reading – are intrinsically complex and require simultaneous manipulation of schemas and skills has important implications for the design of books for a reader who has a cognitive impairment.

The published literature also provided evidence of the effects of early-stage Alzheimer's disease on literacy (Bayles and Tomoeda 2014) and the decline in semantic memory (Patterson, Lambon Ralph, Jefferies et al. 2006). However, the extensive literature on reading with dementia focusses largely on word recognition and word recall, and few academic papers describe studies involving narrative prose. Furthermore, many of the tests were carried out in laboratory conditions, which limits their external validity and thus their relevance to the present research. More indicative, perhaps, are the findings of recent studies using eye-tracking to diagnose dementia in its very early stages (Fraser, Lundholm Fors, Kokkinakis and Nordlund 2017); the effects of the condition on reading continuous prose are immediately apparent. Findings of studies that are pursuing different but related goals have frequently contributed to the present research, as have insights gained from autobiographical accounts of reading with Alzheimer's disease (Bryden 2012; Swaffer 2016).

**Design for accessibility:** particular attention was paid to the growing literature on the need to involve informants with cognitive impairments in research. The advantages of such an approach are made, for example, by Brooks, Savitch and Gridley, (2017) and by Waite, Poland and Charlesworth (2019).

Possible approaches to clarifying the needs of a specific reader group were provided by accounts of design for emergent readers (Walker, Black, Bessemans et al. 2018) and for readers who have literacy difficulties. A problem-solving approach involving close collaboration with specially recruited volunteer readers

has been demonstrated to produce useful outcomes. An example is provided by the study carried out by Thiessen and Dyson (2010) which investigated the typographical and illustrative preferences of children who have dyslexia. Here a theoretical framework was combined with user-centred design.

Research into specific reading needs also depends upon collaboration by individuals with different areas of expertise. A model of a multidisciplinary team was provided by the investigation into the cognitive processing of typographic information by Thiessen, Kohler, Churches et al. (2015). The combining of skills was also in evidence in the work by type designer Bessemans, which investigated the effect of typefaces on young readers with low vision (Bessemans 2016a, pp. 19–36). Dyson had for some time been advocating collaboration between typographers and psychologists (e.g. Dyson 1999, Dyson 2013), and Bessemans (2016b) restates Dyson's call for interdisciplinary work. There would seem to be an advantage in adopting the pragmatic approach advocated by Dillon (2017, p. 297) as a way of bridging the gap between the scientific understanding of reading and the designer's problem-solving brief.

Applied research on information design was heavily drawn on in the preparation of sample materials for the studies, in particular the recommendations for typography and the presentation of continuous text (Bringhurst 1992; Barker 2013; Hartley 2004) and the layout of text and images (Waller 2012; Schriver 1997). The increasingly studied area of healthcare design provided examples of good practice in presentation which were based on empirical evidence gathered in a healthcare setting (e.g. Abraham and Kools 2012; Black, Carey, Matthews and Solomons 2019; Black 2019; Dickinson and Gallina 2017).

### **3.2.3 Testing of sample materials**

The research findings of the scoping study suggested that a particularly rigorous approach would need to be taken both to the recruitment of study participants

and to the preparation of test material in order to ensure an acceptable degree of internal validity.

**User-testing:** the context of user-based investigation was established by Jones's *Design Methods* (1992) and by Norman's two texts, *The Design of Everyday Things* (reissued 2013) and *Emotional Design* (2005). An iterative approach to user-testing was followed, as described by Rubin in the *Handbook of Usability Testing* (2008), although the attitude to the involvement of people with disabilities (p. 294) is rather dated. More relevant was the discussion of ethical accountability in Robson's *Real World Research: a Resource for Users of Social Research Methods in Applied Settings* (2016, chapter 5, p. 205ff.)

User-testing in a text design context is addressed by DEEP in 'Tips for organisations wanting to consult people with dementia about written documents' (DEEP 2013c). The need for graphic designers to engage with potential users is made by Walker (2017), and the recommendation that designers of healthcare materials adopt a working method of 'user input, iteration and consideration of circumstances of use' (Walker 2019, p. 1) is particularly relevant to accessible page design.

**Recruiting study participants:** strict ethical guidelines apply to user research involving individuals who have Alzheimer's disease, so recruitment and user involvement was carried out through formal channels. The initial interview study required permission from the Health Research Authority. The advantage was that the exact nature and degree of the individual's dementia were medically documented, and each participant was a self-declared reader. It also eliminated individuals who had health issues and vision issues that affected their literacy skills. Participants in the two subsequent studies had all received a medical diagnosis of dementia. However, not only were the informants well enough to give their consent to taking part in the research, but their opinions were given without the involvement of intermediaries. A key aspect of the studies was that they were to be limited to first-hand participant experience.

**Selecting a study approach:** a ‘Better like this, or like this?’ approach was decided upon for each of the studies. This forced-choice method asked participants to indicate which of two design options they considered to be more useful. It was felt that making simple, clear-cut choices would be a straightforward and non-threatening experience for individuals who had an early-stage cognitive impairment. Participants would also be encouraged to expand on their answers and give reasons for their choices.

**Devising the sample materials:** the focus on reading for pleasure did not limit the range of possible test material since informants clearly enjoyed both fiction and non-fiction texts. Sample materials therefore tested approaches to illustration, text layout and cover design for different genres. Much of the user-testing that has been carried out into reading with dementia has focussed on vital issues such as medical information, patient leaflets, labelling of medicines (DEEP 2013a, DEEP 2013b, DEEP 2013c). As noted above, research findings in this area were drawn on where appropriate.

#### **3.2.4 Consideration of test materials**

The test materials for the first two studies were commissioned by the researcher from a professional designer whose work was well known within the Department of Typography and Graphic Communication. The brief for each study was carefully drawn up by the researcher (see Appendix III, pp. 284ff.) but was also intended to allow scope for the designer’s interpretation and typographical experience. In order to check the validity of the researcher’s brief for each study, and the appropriateness of the designer’s implementation of the briefs, an impartial evaluation of the completed sample layouts for the first two studies was sought from three practising designers. Each of the designers was engaged in postgraduate study within the Department and all agreed to act as volunteer participants in an evaluation. A practising professional book illustrator was invited separately to comment on the line drawings used in the first study.

### 3.3 Research method

The results of the field study together with a survey of the literature on the effects of early-stage Alzheimer's disease suggested that there might be scope for adjusting the presentation of texts and images in order to reduce the effects of a cognitive impairment. Three separate, small-scale studies were therefore set up with a number of volunteers to investigate readers' views on a number of specific modifications. An iterative approach was taken to devising the materials with each study building on the results of the preceding one. Insight was also to be sought into the readers' interaction with the book as a material object.

The three studies may be characterised as:

- i. participant interview study
- ii. textual additions study
- iii. book cover study

The interview study was held on a one-to-one basis, and group discussions were held for the following two studies. Different volunteers took part in the three sessions. The materials used and the methods adopted are summarised below.

#### 3.3.1 Materials prepared for the studies

Illustrations of the sample layouts are included in the account of each of the three studies provided in Sections 5–7. Each account also includes a full description of the typographical characteristics of the test materials. The main features of each study are summarised below.

**Participant Interview Study:** for the first study (pp. 111ff.), four pairs of contrasting page layouts were prepared to test individuals' preferences for different aspects of design. The four aspects highlighted were:

- the positioning of an illustration in the text or on a facing page
- the including of speakers' names in prose dialogue
- the use of side headings in expository text
- the use of simplified text in a prose narrative

The layouts were prepared by a professional designer using text and images gathered by the researcher from published sources. The layouts were presented as pages from printed books and a clear, serified typeface was chosen in order to suggest familiarity and even straightforwardness in the textual content (Song and Swartz 2008 and 2010). The current conventions of book design for the handling of images were also followed.

**Textual Additions Study:** building on the responses provided in the interview study, three text layouts were prepared to simulate pages from a novel (pp. 148ff.). Each layout offered a memory-supporting feature. These were:

- a list of characters opposite the title page
- a summary at the end of a chapter
- a plot summary of a new chapter

Examples of printed works of fiction with ribbon markers were also provided.

**Book Cover Study:** the test materials used in this study consisted of two variations on a design for the cover of a paperback novel and two designs for a sticker for the cover (pp. 172ff.). The two cover designs were:

- a cover featuring an attached bookmark on which were printed a list of characters (face) and a chapter-by-chapter plot summary (reverse)
- a cover with wide flaps, the front flap incorporating a detachable bookmark with a list of characters (face) and a plot summary (reverse).

The sticker designs were:

- an image of a small elephant reading a book, together with a working series title READ + REMEMBER
- a symbolic image featuring an open book together with a working series title READ + REMEMBER
- an alternative version of the title featuring an ampersand (READ & REMEMBER) printed out on separate slips of paper for separate consideration.

### 3.3.2 Methods used in carrying out the studies

The studies were carried out in a number of stages. The methods used are described below.

**One-to-one interviews:** ten informants were selected from a database of volunteers managed by the Berkshire Memory & Cognition Research Centre. The researcher was not involved in the selection. Confidentiality was ensured at all times, with participants' personal details and any information they provided fully anonymised. Permission was granted by the participants for their behaviour to be observed.

The interviews took place in the participants' homes. The visits lasted about an hour with the interview itself taking between 15 minutes and 40 minutes. The interviews were semi-structured and were based on a number of scripted, forced-choice questions about the sample materials. The questions were repeated or reworded as necessary, and the participants' responses were confirmed by the researcher if there was any doubt that they had been correctly understood. The question-and-answer session was followed by a wider discussion of points arising from the materials.

The interviews were audio-recorded and were transcribed in full after the meeting. A summary outline of preferences was entered on a spreadsheet. The researcher also noted the way the participants interacted with the material and produced a summary account after the meeting using the detailed, observational method (thick description) favoured by ethnographic designers.

**Group question-and-answer sessions:** two formal sessions with members of the Dementia Engagement and Empowerment Project (DEEP) were held. The first formal meeting took place in a community centre in Calcot, Reading, and the second in the office of the Alzheimer's Society in the centre of Reading.

The agenda was sent by post to all DEEP members in advance of each meeting. Three informants took part in the first DEEP session and six in the second session. Members of administrative staff were present, but the focus was on the views of the DEEP members. Permission was granted by the participants to observe their behaviour. The first discussion lasted for over 90 minutes and took up the entire DEEP meeting; the second was allocated a brief (30-minute) slot in a crowded agenda.

A semi-structured approach to the discussion was adopted on each occasion. The materials were handed round, and participants were invited to answer a number of simple, open-ended questions that had been scripted by the researcher (see Appendix VIII, pp. 317ff. and Appendix IX, pp. 325ff.). Participants were invited to express opinions on the contrasting sets of sample materials and, if they wished, to give reasons for their preferences.

The discussion at both DEEP sessions was audio-recorded and comments that had a direct bearing on the questions were transcribed by the researcher. Relevant observations made by the researcher in the course of the meetings were written up separately using a thick description approach.

**Summarising the findings:** the response given by participants to each question was carefully noted by the researcher and all relevant information was immediately extracted. A thematic review was carried out to highlight the issues raised both in response to the forced-choice tasks and to the more general topic of reading. This review was carried out by the researcher. The small scale of the studies, the inherent complexity of the medical condition, and the difficulty of expressing verbally the subtlety of the individual reading experience suggested that a more reflective approach would be the most productive. Common topics in participants' replies were identified: these included a continued desire to read for pleasure, the overwhelming difficulty of retaining details of a plot in works of fiction, the benefit of illustrations used as landmarks in a text, and an

appreciation for clear and unambiguous design. Re-checking the findings at each stage with a second group was not feasible given the nature of the cognitive impairment and the constraints under which the studies were carried out. Instead, repeated questioning of the different groups provided some indication of the validity of the researcher's conclusions at each stage.

**Consultation with external experts:** in order to broaden the discussion and to uncover any significant problems with the approach, three practising designers and a professional book illustrator were invited to comment on various aspects of the first two research studies. None of those invited had worked on material for readers who had dementia, but two of the designers had a particular awareness of the literacy difficulties caused by dyslexia.

The designers were asked to draw on their professional experience and give their views on the proposed solutions to the issues with typography and layout that had been reported by readers who had dementia. The discussions with the designers were audio-recorded and significant sections were transcribed. Their observations form the basis for the Consultation section below (pp. 188ff.).

The professional book illustrator was sent a copy of the sample layout that included a line drawing and was asked to comment on its suitability for the target readership and to make suggestions for its improvement. The illustrator provided a written response, and her comments are also discussed in the Consultation section (p. 188 and Appendix X).

### **3.4 Conclusion**

The different strategies employed in the Field Study and the three question-and-answer studies proved to be both workable and productive. A more detailed description of the possibilities offered by the research methods adopted and the constraints they imposed is offered in the account of each study.



## **4 Field Study: gathering information from experts-by-experience**

### **4.1 Introduction**

The need to gather information about real-world experience led to a series of scheduled encounters with informants who had dementia. The meetings took the form of visits to individuals' homes, group discussions, one-to-one conversations, and close observation. Overall an exploratory approach was adopted which drew on methods involved in design ethnography (Wasson 2000; Miller 2014, 2018; Pontis 2018).

The aims of this field study were twofold: first, to learn more about the reading experience of the population with early-stage dementia and, secondly, to assess the feasibility of recruiting individuals for an initial user-centred interview study. With these aims in mind, contact was made with a number of organisations and individuals who had current experience in the field of dementia. The investigation proceeded slowly at first, partly because of the difficulty of identifying potential informants (Leavy 2017, pp. 76–77), and partly because of the sensitive nature of their situation (Rivett 2017, p. 111); for example, admission was refused to a Brighton dementia café for LGBT members on the grounds that the group was newly formed and individuals were not yet ready to be approached.

### **4.2 The Field Study meetings**

Given the exploratory nature of the field study, it was important to speak to a wide range of informants in different contexts. Initial discussions were therefore held with the following eight groups and individuals:

- visitors to a Dementia Café in a local library
- Library Community Engagement Manager
- members of an Age Concern lunch club
- leader of a Cognitive Stimulation Therapy (CST) group
- members of the Younger People With Dementia (Wokingham) group
- retired school teacher
- members of a Dementia Engagement and Empowerment (DEEP) Group
- individual members of the Brighton DEEP group and the Reading DEEP group.

A description of each of these formal and informal meetings is given below. Each discussion made a contribution to the dual aims of the field study, namely to gather information about the individuals' reading habits and to assess the possibilities of recruitment. The specific contribution of each meeting is noted in each case with information summarised under the headings 'Question 1: Reading' and 'Question 2: Participation'. Where the observations made during the meetings are supported by the literature, a reference has been added in each case.

#### **4.2.1 Dementia Café**

The Dementia Café was held in a branch library in Hove on a Wednesday in the early evening. It was organised jointly by a representative of the Alzheimer's Society and the Library Community Engagement Manager for the area; a representative from Social Services and an officer from the local community centre were also present. The Library Manager gave a brief welcoming address and introduced the Books on Prescription scheme (The Reading Agency 2019a), which is widely available in public libraries, and the Pictures to Share series (2020), which does not appear in the library catalogue. About a dozen individuals who had dementia arrived during the course of the evening. Some came with friends or family members and one or two on their own. Conversation on general topics was encouraged.

Although planned with evident care, the occasion seemed rather forced, perhaps because this was only the second meeting of the Café. However, the event provided information that related to informant recruitment, the second aim of the field study, and this may be summarised as follows.

#### Question 2: Participation

- It was evident that any relationship between a researcher and an individual who has dementia would have to be handled with great care. Approaching affected individuals in a social context and asking them to contribute to a research project might be perceived by carers as opportunistic and insensitive. Patient and public involvement (PPI) is an important topic in health research (Gove et al. 2018; Waite, Poland and Charlesworth 2019).
- Carers are likely to be protective of the person they are accompanying (Brooks, Savitch and Gridley 2017).
- A researcher would need to convey that they have some insight into the situation of the person who has dementia and of their carer.
- Individuals with dementia may not readily engage in conversation (Bayles and Tomoeda 2014, p. 53).

#### **4.2.2 Library Community Engagement Manager**

The Manager was contacted initially by email. She has responsibility for several branch libraries in Brighton and the surrounding districts and readily agreed to a brief meeting. In response to general questions, the Manager provided information about the library stock, including the large-print titles and the Books on Prescription list, and the services that were offered to housebound readers; she also commented that libraries were still seen as ‘a place of trust’. It is possible that this was a factor in the choice of the library as the venue for the dementia café mentioned above.

In advance of the meeting, the Manager had sought the opinion of colleagues about the role of reading in the lives of people who have dementia. A brief written

response from a colleague who ran the Home Delivery Service was provided (see Appendix I, p. 275). The summary includes a number of points that are relevant to the first study question.

#### Question 1: Reading

- Library users are likely to have a lifelong reading habit.
- Reading may be thought of as a way of expressing one's identity. Losing the ability to read may therefore feel like losing one's identity.
- Concentration and memory for plot may become problematic.
- Short stories written for non-English speaking readers or for readers with low literacy skills may prove to be helpful.
- Familiarity with an author's work may help to support memory.
- Books may be too heavy for readers who have additional health issues.
- Readers may prefer larger print.
- Texts can provide a means of escape from everyday life.

The Manager also quoted from an email she had received which gave an insight into the preferences of a reader as expressed by her daughter:

She is interested in historical fiction, especially Dickens because *she already knows the stories and so these are easier for her to follow with her Alzheimer's* [Manager's italics].<sup>7</sup>

#### Question 2: Participation

As far as recruitment to the study was concerned, the Manager was not able to recommend any particular readers who might be willing to take part in an interview study. By way of an explanation, she quoted in an email the views of her library colleagues:

... they say the same thing, which is that they don't believe the library customers with dementia whom they know, would be able to help with your research,

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<sup>7</sup> Email from Community Engagement Manager to ML dated 10.05.2015.

owing to the effects of dementia. The staff are reluctant to ask the customers to help, because they think it would confuse/upset them.<sup>8</sup>

#### **4.2.3 Age Concern lunch club**

An email approach was made to the Dementia Care Advisor at Barkham Day Hospital. This led to an invitation to the Woodley Lunch Club, which was organised each month by a local branch of Age Concern. Attending this event proved to be mainly an information-gathering exercise with little opportunity for individual conversations. However, it contributed to the second aim of understanding potential issues surrounding recruitment.

#### Question 2: Participation

- Informal gatherings would be unlikely to allow the researcher time to identify and recruit potential participants.
- Individuals attending gatherings were likely to have a range of medical conditions and to be at different stages of their condition's progression.

The visit did, however, provide an opportunity to meet individuals in the medical and healthcare professions (see below).

#### **4.2.4 Meeting with a Cognitive Stimulation Therapy leader**

The meeting was held with a doctor and her assistant who held group Cognitive Stimulation Therapy (CST) sessions at Barkham Day Hospital for individuals with dementia. CST has been found to be helpful in the early stages of dementia and aims to maintain cognitive and social skills at an optimally functioning level (Orgeta, Leeung, Yates et al. 2015; NICE 2018). The sessions were held twice weekly and always included reading and discussion. Participants were each given an illustrated summary of a recent news story and were asked to volunteer to read it aloud; the less forthcoming participants were encouraged by the session leader to take their turn. The excerpts were always deliberately chosen to provoke comment

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<sup>8</sup> Email from Community Engagement Manager to ML dated 10.08.2015.

and opinion, and a lively debate generally ensued. The doctor also produced examples of books that were used in general dementia care.

#### Question 1: Reading

The meeting highlighted several issues that were relevant to the first question, namely the reading habits of individuals who have dementia.

- Due consideration needs to be paid to a participant's level of education and to the part that reading has played in their life before the onset of illness. The significance of an individual's educational background has been identified by Stern (2006, 2012) and by Barulli and Stern (2013).
- Participants need to have normal vision (when corrected).
- Topics that are emotive may prove to be more productive than pure reminiscence. The important role played by curiosity in maintaining cognitive skills in later life has been identified by McGillivray, Murayama and Castel (2015) and by Sakakia, Yagib and Murayama (2018).
- Childish content and a patronising tone may be regarded as off-putting.
- Participants appreciate page layouts that are uncluttered, a generous type size, large images that are linked visually to their captions, and a short summary at the start of a page of information (DEEP 2013a).

#### **4.2.5 Younger People With Dementia**

Younger People With Dementia (YPWD) Berkshire was set up in 2012 with the aim of providing support to individuals in the Berkshire West area who are diagnosed with young onset dementia (dementia that is diagnosed before the age of 65; Alzheimer 2020b). The organisation is based in Wokingham and is funded by the Clinical Commissioning Group and local charities.

Following an initial conversation with a dementia care advisor from YPWD, a flyer (Fig. 2) and a brief written summary of the aims of the research were circulated to

**Do you enjoy reading?**

**Would you be willing to help with research into book design?**



I am looking at ways of improving the layout of texts for people with memory issues.

Could you spare some time to help with this PhD research?

We would need just one session of about an hour. It could be at your home or at a place that is convenient for you.

I would ask you a number of questions about your current reading tastes and preferences.

*Please get in touch if you would like more information.*

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 University of Reading

 design star  
Arts & Humanities Research Council Centre for Doctoral Training

Fig. 2 Flyer supplied to Younger People With Dementia asking for participants for future studies.

members of staff. Subsequent meetings with the operations manager and a second advisor resulted in an invitation to participate in two meetings of the Shared Reading Group at Barkham Day Hospital. Both the preliminary meetings and the reading group provided significant information concerning individuals' reading habits (Question 1) and the issue of recruitment (Question 2).

#### Question 1: Reading

The contributions made by participants and by members of staff are summarised

separately below.

Contributions made by participants at the YPWD Shared Reading Group:

- All of the texts had been selected from the anthology of prose extracts and poetry entitled *A Little, Aloud* (Macmillan 2010). The texts were circulated as enlarged photocopies that had been stapled together for ease of handling. However, participants did not always start reading in the right place when turning the sheets over.
- Participants readily volunteered to sight read a few paragraphs of text. Sentences were frequently misconstrued because of awkward syntax or stylised language.<sup>9</sup>
- In the absence of any textual context, the participants took the prose extracts and poems at face value.<sup>10</sup>
- Poetry was appreciated, with a passage from T.S. Eliot's *The Four Quartets* being re-read by the facilitator in response to the group's evident interest.<sup>11</sup> The response to poetry has been described by Billington et al. (2013) and by Billington (2015); an interdisciplinary study led by neuroscientist Zeman (2013) noted that poetry activated particular areas of the brain.

General contributions made by YPWD staff:

- The issues raised by young-onset dementia need to be considered when providing products and services for people with dementia. There are currently over 42,000 individuals in the UK who have some form of dementia and are under the age of 65 (Alzheimer 2020b).
- Books are needed that address the interests and preferences of readers of working age.

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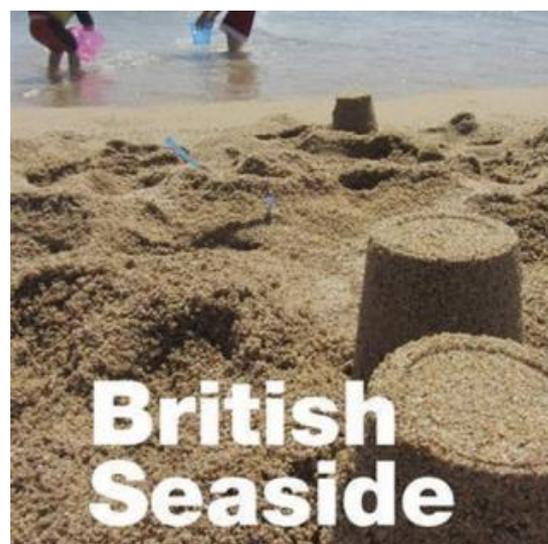
<sup>9</sup> This aspect of reading aloud was so evident that it led to the including of one of the texts in the interview study.

<sup>10</sup> Facilitators did not provide any additional information about authorship or context but used carefully phrased questions to elicit comment and further discussion.

<sup>11</sup> The readers' engagement with poetry came as no surprise to the editor of *A Little, Aloud*, Angela Macmillan, who described a similar response in her own reading groups: 'Engagement with the text is immediate and enriched by the spontaneous sharing of life stories and experience.' (Email of 9.06.2016.)

- Individuals may have different interests. In addition to their larger workshops, YWPD also organise micro-groups which may be attended by just 2, 3 or 4 members allowing them to focus on a particular interest or activity.
- YPWD have produced two illustrated books that are intended for both independent and shared reading by male and female readers (Anwar 2013; Figs 3 and 4). The approach draws heavily on reminiscence therapy, and both the illustrations and the text provide appropriate prompts. The final design and production were outsourced to Chandler Design Associates, who recommended the large, sans serif typeface and the layout.<sup>12</sup>

Further research indicated that while potential users of the books had been consulted, some design decisions appeared not to have been considered from the perspective of people with dementia (DEEP 2013a, DEEP 2013b, DEEP 2013c). Problems might be caused to readers by the reversing out of text from tints, using photographic images that show familiar objects presented in unfamiliar ways, the harsh cropping of images, and the bleeding of images into the gutter producing awkward juxtapositions. Nevertheless, the books are reported to have been well received by their target readers (Anwar 2013).



Figs 3 and 4

*Around The World In Many Ways* and *British Seaside*.

Two titles in a series produced by Younger People with Dementia (Berkshire).  
Hardback; 297 x 210mm; 48 pages; laminated cover.

<sup>12</sup> Email reply from Business Support Manager (6.06.2016).

### Question 2: Participation

The contribution of YPWD was to highlight the problem of identifying suitable participants for an interview study. The reasons for this were twofold: first, the individuals who attended the shared reading group had a wide range of impairments that would be broadly classified as dementia; and second, the seriousness of the cognitive impairment varied from individual to individual. It would therefore not be possible to put together a cohort of participants who had Alzheimer's disease that was at an early stage.

#### **4.2.6 Retired school teacher**

The informant was a retired school teacher who lived independently in a small village in Oxfordshire. The informant had studied modern languages at Cambridge and had travelled extensively before pursuing a career as a teacher of French. Books, journals and magazines were very much in evidence in her accommodation. She volunteered that she had always found it difficult to recognise faces (prosopagnosia), but that she had used classroom seating-plans to work around this issue. She did not have a formal diagnosis of dementia but acknowledged, when prompted, that her memory was impaired; she did not appear to know why and did not seem unduly concerned. A few weeks after the meeting, she moved to a nearby residential home.

The meeting with this informant provided valuable insights into both aspects of the research study.

### Question 1: Reading

- Seeing the informant in the context of her own home offered some insight into the gradual nature of the onset of dementia. There was ample evidence of a lifelong habit of reading.
- Understanding illustrated narrative sequencing may still be possible with an impaired memory. The informant read the researcher's copy of *Dear Zoo*

(Campbell 1982/1998) to herself with an adult understanding and appreciation of the author's skill (Fig. 5).

- Individuals may still respond to verbal humour in written form. On being presented with a business card, the informant was amused to note the irony of research into reading being carried out at the University of Reading. This finding was interesting given the claim by Bayles and Tomoeda (2013, p. 63) that dementia may result in the loss of a sense of humour. For a similar appreciation of written humour, see the account of the interview with the DEEP representative below (p. 108).

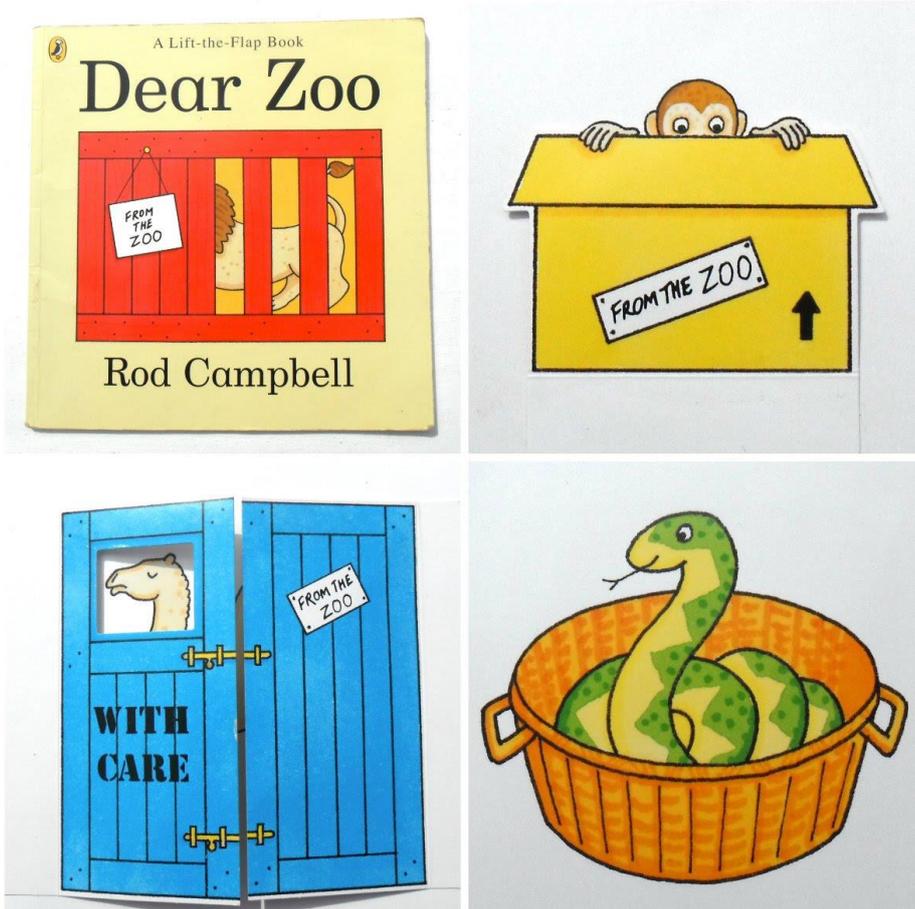


Fig. 5 Rod Campbell, *Dear Zoo* (1982, board book edition 1998). London: Campbell/Macmillan. 175 x 175mm; 18 pages.

The zoo responds to a child's request for a pet by sending seven animals each of which is declared unsuitable and sent back. The eighth animal sent is a puppy, and the final lines of the story read, 'He was perfect! I kept him.'

### Question 2: Recruitment

- Lack of insight (anosognosia) noted by Starkstein (2014) is a factor when inviting individuals to participate in research. It would be advantageous to work only with participants who had a formal diagnosis of their condition.
- Participants would need to consent or at least assent to taking part in the study to avoid any charge of exploitation by the researcher (Rivett 2017, p. 108). Such considerations would be covered by an application for ethical clearance by the University.

#### **4.2.7 Dementia Engagement and Empowerment Project (DEEP): group meetings**

Contact with Innovations in Dementia (2020) and with the Alzheimer's Society in Reading led to an introduction to the Dementia Engagement and Empowerment Project (DEEP) in Reading and in Brighton. DEEP is a nationwide organisation which aims to change and improve services and policies that affect the lives of people with dementia. Members are regularly invited to contribute to research.

An invitation was extended to attend, primarily as an observer, two of the monthly DEEP meetings in Calcot, Reading. The meetings offered a chance to discuss informally a number of sample books as a way of learning about the preferences of readers who have dementia. The samples included copies of Quick Read paperbacks (The Reading Agency 2019b), which offer adult readers lively but simply written stories, and a paperback from the Oxford Bookworms series, which provides simplified stories for adult readers who are learning English as a second language (Oxford Bookworms 2020). The participants' positive reaction to both series suggested that the books could play a part in subsequent investigations (see Section 5: Participant Interview Study and Section 6: Textual Additions Study). There was also an opportunity to listen and to note the way in which the DEEP organiser interacted with the informants and carers. Again, valuable information was provided that addressed both questions posed by the study.

### Question 1: Reading

- It was noted that the term 'dementia' was used freely by the group organisers and members.
- Not all members were – or had ever been – habitual readers. Members did not know of either the Quick Reads series or the Oxford Bookworms series but handled the samples with interest.
- Difficulties in reading conventional books were described by members. These included losing one's place in a story, forgetting who characters were, over-complex language, small type, lack of punctuation, distracting textual details and lengthy descriptive passages.
- Preference seemed to be for an episodic style of writing, and for including a list of characters at the start of the book; using illustrations to capture events described in the text and also to relieve the text; providing a summary of the events at the end of a chapter; and leaving space on the page for the reader to annotate the text. Short stories that would fit on a single page (or double-page spread) were also suggested.
- The need to be given just the gist of things was a recurrent theme.

### Question 2: Participation

As far as recruitment was concerned, the meetings did not provide any suitable leads; they did, however, provide important information about group dynamics.

- Members did not volunteer to be interviewed individually and it seemed insensitive to press them.
- Members were clearly used to taking part in research studies as a group and were confident in expressing opinions.
- Spouses and friends expressed strong feelings, often in front of the people for whom they were caring. It would be important to distinguish between the contributions of the two groups of informants.

#### **4.2.8 Dementia Engagement and Empowerment Project (DEEP): interviews**

After discussion with DEEP group leaders, the two meetings were followed up by one-to-one interviews with two DEEP members, one from Brighton (Participant 1) and one from the Calcot group (Participant 2). In contrast to the previous informal exchanges at DEEP meetings, these two conversations took the form of semi-structured interviews. Ethical approval for the study was given by the University of Reading. Permission to voice record the interviews and to observe the informants was explicitly requested on the participant consent form.

Participant 1 volunteered that he had frontotemporal dementia (Pick's disease), one of the less common types of dementia (Alzheimer 2020h). Participant 2 self-described as having Alzheimer's disease. Both participants had been obliged to stop working because of their cognitive impairment. However, as both informants were able to communicate either by email or by telephone, it was possible to explore the use of typed questionnaires as a way of gathering information. The questionnaires were sent in advance of the interviews in the hope that this would give the participants a sense of having some control over the situation; there was no premium on spontaneity and the questions could be answered in any order. Opting to interview participants in their own home or in a neutral setting (a Brighton coffee shop) was intended to reinforce their feeling of retaining control.

The interviews were recorded and a summary of the participants' verbal responses to the questions is provided as an appendix to this thesis (Appendix II, pp. 277ff.). Both informants contributed to an understanding of the issues facing readers with dementia and expressed definite views.

##### **Question 1: Reading**

- Both informants stressed the effort involved in reading and the consequent need for clarity of expression.

- Both informants could recall books they had read, and participant 2 was able to retrieve a particular book from a shelf in an adjacent room. The book was a collection of children's Nativity stories entitled *A Wayne in a Manger* (Phinn 2006). The participant commented appreciatively on the play on words in the title and on the light-hearted line drawings that illustrated the text.
- Bland texts were thought to be unappealing, and a patronising tone was considered off-putting.
- Illustrations could play a part in signposting a text and giving a book character.
- The style and content of images might also be considered patronising.
- Books may be cherished possessions.

Despite being given the opportunity, neither informant commented on the layout or the typeface of any book. One reason for this might be that the conventions of specific literary genres are deeply engrained in the expectations of habitual readers. It is also possible that habitual readers may not feel inclined to challenge the conventions of textual presentation when their own needs change.

#### Question 2: Participation

The two interviews highlighted the advantage of talking individually to volunteers who were well enough to live relatively independently and who had professed an interest in reading. Despite the difference in their diagnosis and in their experience of cognitive issues, there appeared to be some similarity in their accounts of reading with an impairment.

### **4.3 Concluding observations**

The eight encounters outlined above achieved both of their aims, which were to learn more about the reading experience of individuals with dementia and to consider the possibilities of recruitment for a user-testing study. By expanding the research methods to draw on those of design ethnography as well as user-centred

design, it was possible to define more closely the questions that needed to be investigated and to anticipate a number of the ethical issues that would be raised.

The meetings and conversations suggested that there was a genuine issue to be explored, namely that dementia could cause difficulties for individuals who wanted to go on reading for pleasure. By listening closely to informants' accounts, observing their behaviour, asking open questions and adopting an unhurried approach to each exchange, the research accumulated into a fairly nuanced appreciation of their situation (Jones 1992, p. 216; Kelly and Matthews 2014; Pontis 2018, p. 16).

One aspect of the findings seemed to be consistent, and this was that participants did not comment on the presentation of printed books. The layout of the text and the nature and style of illustration were seen as the preserve of the publisher, and the reader's choice lay in either reading the book or discarding it. Specific difficulties with current publications were mentioned by participants, and it was evident that a memory impairment lay behind a number of the problems. Four particular issues were noted which could perhaps be addressed by adjustments to design or editorial content. These were the positioning of explanatory illustrations in a text, the breaking down of texts into small sections, the building in of intentional redundancy into text, and the simplifying of grammatically complex descriptions. However, the evident strain put upon individuals' concentration by their illness suggested that a pragmatic approach to user-testing would be needed, with the use of sample materials that would offer the reader simple, contrasting options. Participant observation would be necessary (Jorgensen 1989, pp. 13–14) and permission would have to be explicitly sought for this.

The second aim of the field study, i.e. to investigate the possibility of finding and recruiting suitable volunteers, was also clarified as a result of the encounters. It quickly became evident that to improve the reliability of findings and thus the usefulness of any recommendations, the focus of the research should be on the experience of volunteers who had declared an interest in reading and who had

early-stage Alzheimer's disease. Informants who had an up-to-date medical diagnosis and who had formally consented to being interviewed were likely to provide the most compelling evidence.

## **5 Participant Interview Study: testing layouts of text and image**

### **5.1 Introduction**

The meetings and conversations carried out in the course of the field study confirmed that the effects of dementia were evident at a relatively early stage. To narrow down the field of investigation and to improve the chances of recruiting a homogeneous group of participants, the decision was taken to include only Alzheimer's disease in the study that followed. Alzheimer's is the most commonly occurring form of dementia and a description of its effects is widely available (Alzheimer 2020a). The published accounts of the early stages of the disease confirm that memory deficiencies are quickly apparent: the recall of recent events is likely to be affected (Ames, O'Brien and Burns 2017; Budson and Solomon 2016); difficulties with orientation (Clark and Maguire 2016; O'Keefe and Nadel 1978) and with the perception of time (Eichenbaum and Cohen 2014) are regularly reported. The ability to bind together events from the past and the present is also frequently affected (Rubin, Watson, Duff and Cohen 2014). All of these mental activities have a part to play in reading.

The interview study described below was designed to be easy for participants to understand and straightforward to administer. However, since the research involved individuals who were in the care of the NHS, the approval of the Health Research Authority (HRA) was essential.

### **5.2 Aim of the study**

The aim of the study was to investigate specific aspects of the reading experience of individuals with early-stage Alzheimer's disease. The study was designed to

test four features of page layout to see if any of the proposed changes would be beneficial. The four features involved the positioning of images and the presentation and content of text and were closely based on the findings of the Field Study (p. 94). The results of the tests are discussed below in relation to the literature.

### **5.3 Method**

A standard, user-centred approach was adopted for the study and a series of one-to-one qualitative interviews (Pope 2000) was carried out with informants who self-identified as regular readers and met the necessary medical criteria. The post-study requirements were also met in submitting a report to the HRA and contacting each person who had been interviewed (Appendix VII, p. 316).

#### **5.3.1 Participants**

An application to work with individuals who had early-stage Alzheimer's disease was made through the Integrated Research Application System (IRAS, see Appendix IV, p. 289ff.). The application was supported by the Berkshire Memory and Cognition Research Centre (BMCRC). The staff of the BMCRC were responsible for recruitment and for meeting the medical and ethical requirements of the study in briefing the volunteers, administering memory tests and taking written consent (Appendix V, p. 292). Because each participant had early-stage Alzheimer's disease, or dementia with an Alzheimer's component, particular care was taken to see that each printed form was fully understood. Individuals were informed that the interview study was designed for people who had issues with their memory. Further safeguards were in place in the form of a Disclosure and Barring Service (DBS) check and the issuing of a research passport.

Ten participants were recruited, all of whom self-identified as recreational readers. There were five male and five female participants ranging in age from

mid-sixties to mid-eighties. All spoke English as their first language.<sup>13</sup> A minimum of biographical details were disclosed by the Centre, but the participants often mentioned their former occupations in the course of the interview. Reference was made to hairdressing, sport, human resources, taxi driving, music teaching, academic life, publishing and the BBC monitoring service at Caversham.

Individuals were recruited in two blocks of five, but as the recruitment brief and the test materials remained the same, the participants have been treated as a single group and the results of the two sessions combined. Spouses and carers were not recruited to the study and any information they supplied was noted separately from the participants' replies. The consistent aim of the study was to capture only the views and preferences of the participants themselves.

### **5.3.2 Materials**

Four pairs of layouts were devised (Appendix III). Each pair isolated a single issue that might have an impact on the participant's experience of reading and suggested a possible alternative approach. The issues selected were developed from the views gathered in the Field Study and were supported by the published research.

The four issues that were highlighted in the research materials were:

- i. the position of an illustration on a layout and the use of captions
- ii. the use of side headings
- iii. the addition of names of speakers in a dialogue
- iv. the use of complex syntax in a piece of literary prose

Pairs of contrasting layouts were designed to test each of the four issues (Samples 1–4). A professional designer was engaged to prepare Samples 1, 3 and 4. In the

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<sup>13</sup> One of the participants had Italian immigrant parents. The participant appeared to maintain a working knowledge of Italian and spoke with the accent of a native speaker. Another participant had learned a Scandinavian language as his spouse knew no English but was no longer able to speak the language fluently. Research suggests that native bilingualism may delay the experience of the symptoms of Alzheimer's disease by contributing to cognitive reserve (Bialystok 2017; Stern 2002).

course of the interviews a dot of red ink was added to Samples 3 and 4. This was done to draw participants' attention quickly to those parts of the text that were directly relevant to the questions being asked.

**Sample 1: The position of an image and the use of captions**

Sample 1 was based on the Oxford Bookworms edition of John Buchan's *The Thirty-Nine Steps* (2008). The series is intended for readers whose first language is not English. The author's original story is described as being 'retold by Nick Bullard', and black-and-white line drawings have been added. The contrasting pairs consisted of a layout with the illustration following its reference in the text and a layout with the illustration on the facing page. The Bookworms series always has the text preceding the illustration.<sup>14</sup>

Illustrations of the two sample layouts follow on page 115.

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<sup>14</sup> The positioning of an image in the text was confirmed by an editor of the series (email exchange of 3.05.2016). [Textual matter removed.]

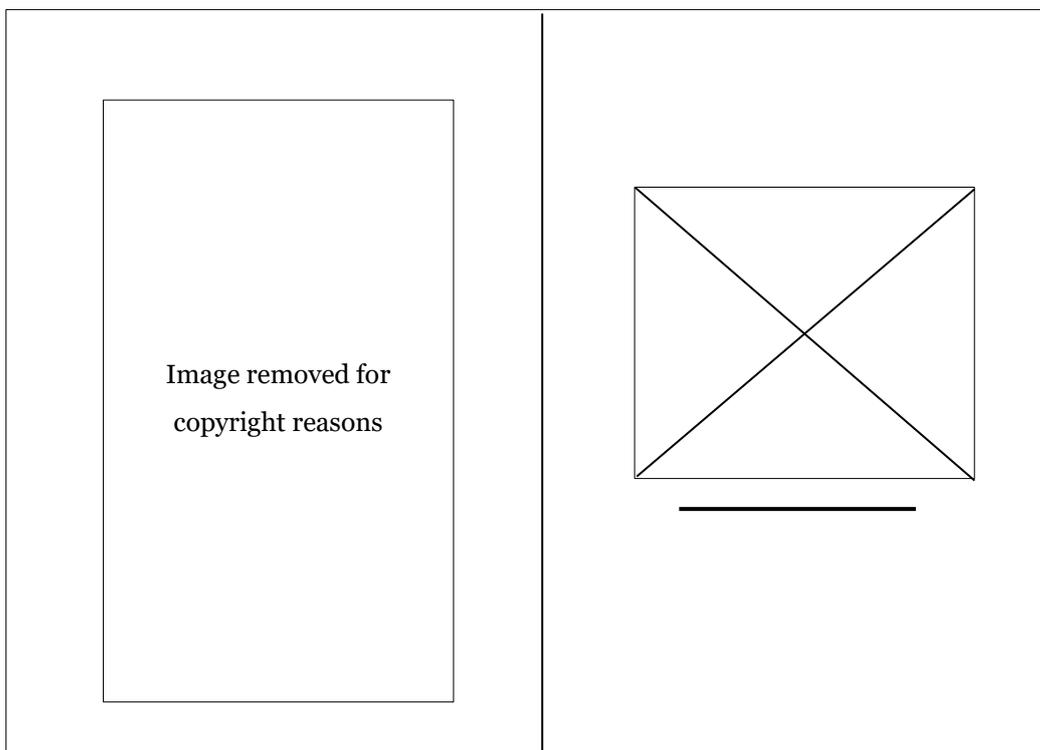
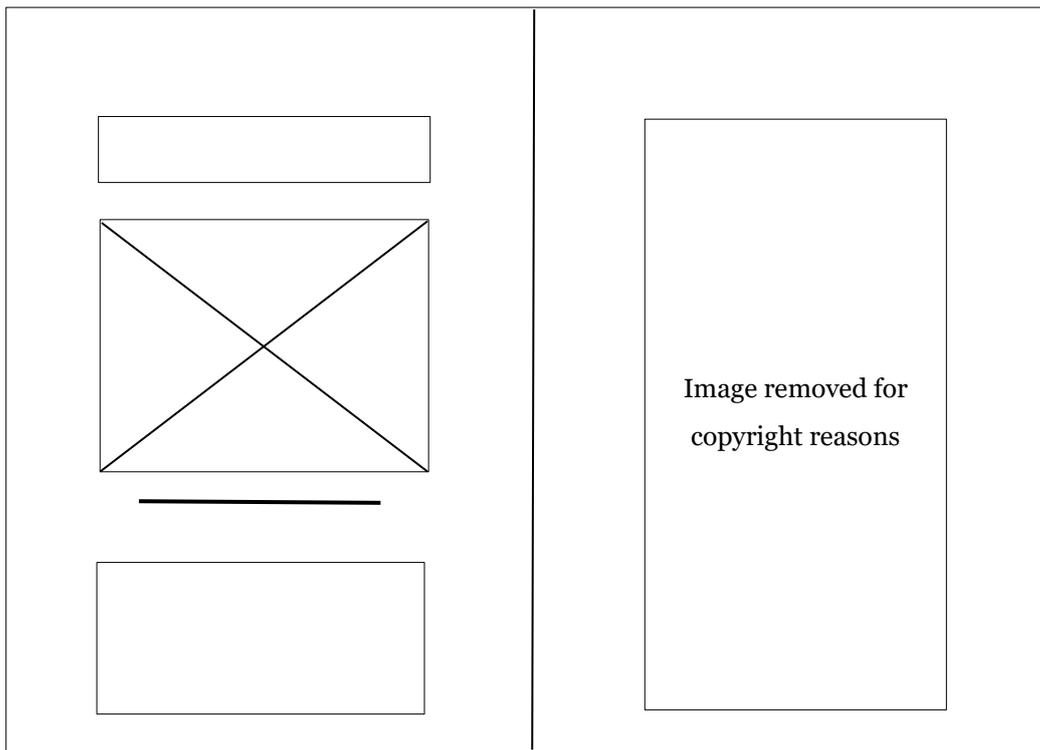


Fig. 6a Sample 1: layout based on the OUP version of John Buchan, *The Thirty-Nine Steps* (pp. 8–9), with the illustration inserted at its point of reference in the text.  
Fig. 6b Sample 1: layout with the illustration positioned on the facing page.

### **Sample 2: The use of side headings**

Sample 2 included a portrait by Rubens and a piece of descriptive text that had been compiled from a number of works of reference. The layout of the text and image followed closely the style of standard trade art books. The contrasting pair of layouts showed the text with and without added side headings. Both styles of layout are found in illustrated reference books, with the use of side headings more likely to feature in simpler texts.

Illustrations of the two sample layouts follow on page 117.



### Rubens

#### Portrait of a Woman

We do not know who the woman in the portrait is. She was once thought to be Rubens's wife, Helena Fourment, but the portrait does not seem to bear any resemblance to the other pictures of Helena that have survived. It has also been suggested that the sitter may be Elizabeth Fourment, a younger sister of Helena, who was born in 1609.

The portrait dates from around 1625–1630. It is painted in oils on a wood panel and measures 33 x 23 inches (84.8 x 59.3 cm). On the back of the panel is a rough sketch by Rubens, which is also drawn in oil paint. The sketch seems to have been part of Rubens's early thinking for another painting, but that painting has not survived.

Sir Peter Paul Rubens was a hugely successful artist and produced over 1,400 works in his lifetime. He was enormously versatile, and produced large-scale religious paintings as well as many fine portraits and drawings of exceptional clarity and skill.

Rubens's *Portrait of a Woman* is on display at Buckingham Palace in London. The painting was bought from Rubens's descendants by King George IV in 1818 and now forms part of the Royal Collection.



### Rubens

#### Portrait of a Woman

##### The subject

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##### The painting

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##### The artist

Sir Peter Paul Rubens was a hugely successful artist and produced over 1,400 works in his lifetime. He was enormously versatile, and produced large-scale religious paintings as well as many fine portraits and drawings of exceptional clarity and skill.

##### Where the painting is now

Rubens's *Portrait of a Woman* is on display at Buckingham Palace in London. The painting was bought from Rubens's descendants by King George IV in 1818 and now forms part of the Royal Collection.

Fig. 7a Sample 2: layout of a fictitious text describing a portrait by Rubens.

Fig. 7b Sample 2: the text with added side headings.

**Sample 3: The addition of the names of speakers in a dialogue**

Sample 3 was based on Lynda La Plante's *The Little One* (2012), which is a short story in the Quick Reads series of paperbacks. The contrasting pair of layouts showed the text of a dialogue as originally published and with the addition of the speakers' names.

Illustrations of the two sample layouts follow on page 119.

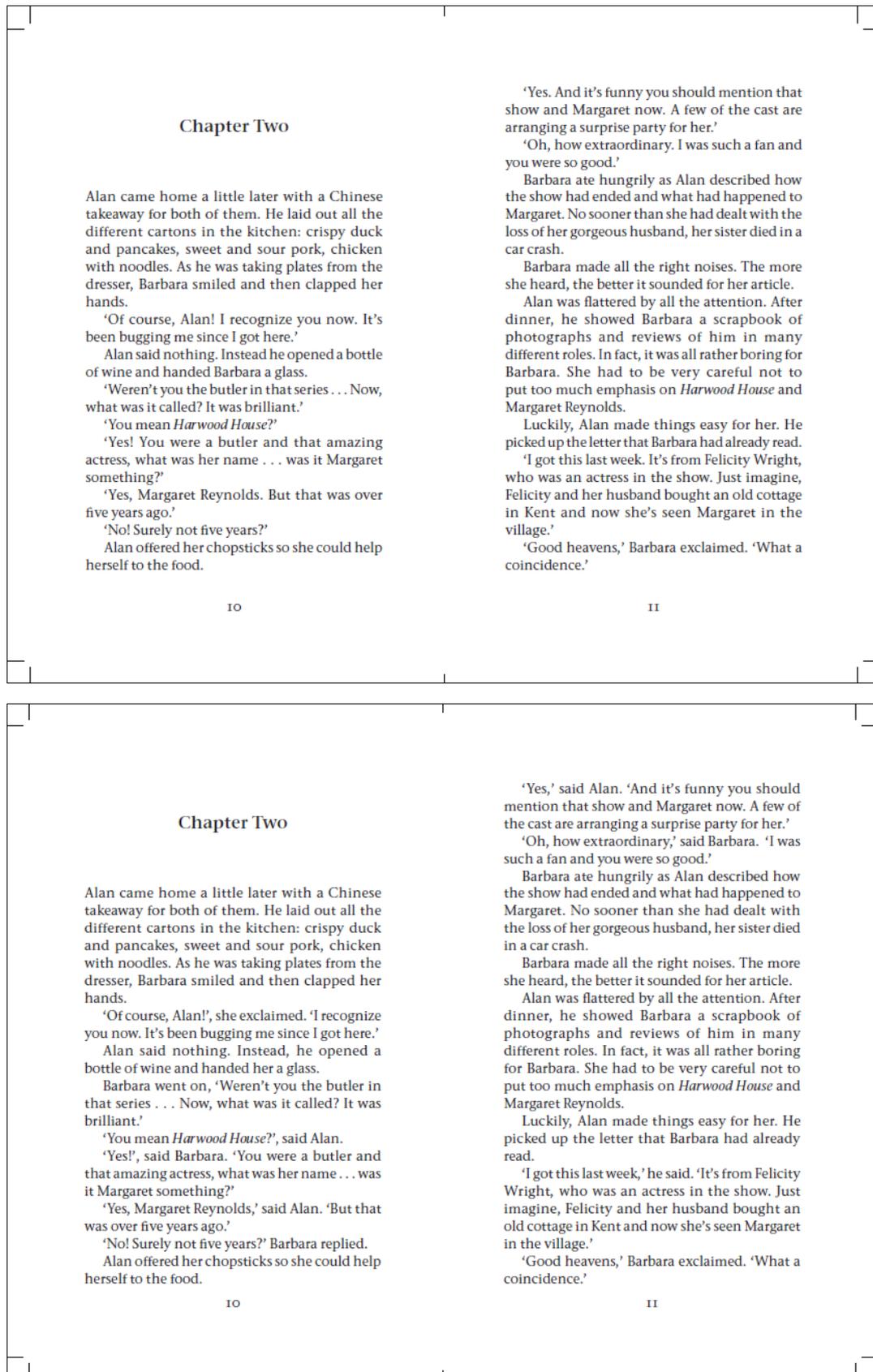


Fig. 8a Sample 3: pages of dialogue based on Lynda La Plante, *The Little One* (pp. 10–11), as published. Fig. 8b Sample 3: the text with additional references to speakers' names.

**Sample 4: The use of complex syntax in a piece of literary prose**

Sample 4 was based on a short story by Katherine Mansfield entitled *The Doll's House*. The story is included in the anthology *A Little, Aloud*, edited by Angela Macmillan (2010), and was one of the texts discussed at the Younger Persons With Dementia book group (see above, Field Study, p. 101). The typeface and the amount of vertical spacing of the text were decided upon by the designer of the original book in response to the editor's brief.<sup>15</sup> The contrasting pair of layouts showed the author's original text and a slightly edited version with some of the complexities of grammar and vocabulary reworked.

Illustrations of the two sample layouts follow on page 121.

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<sup>15</sup> Email from the editor of *A Little, Aloud* (9.06.2016).

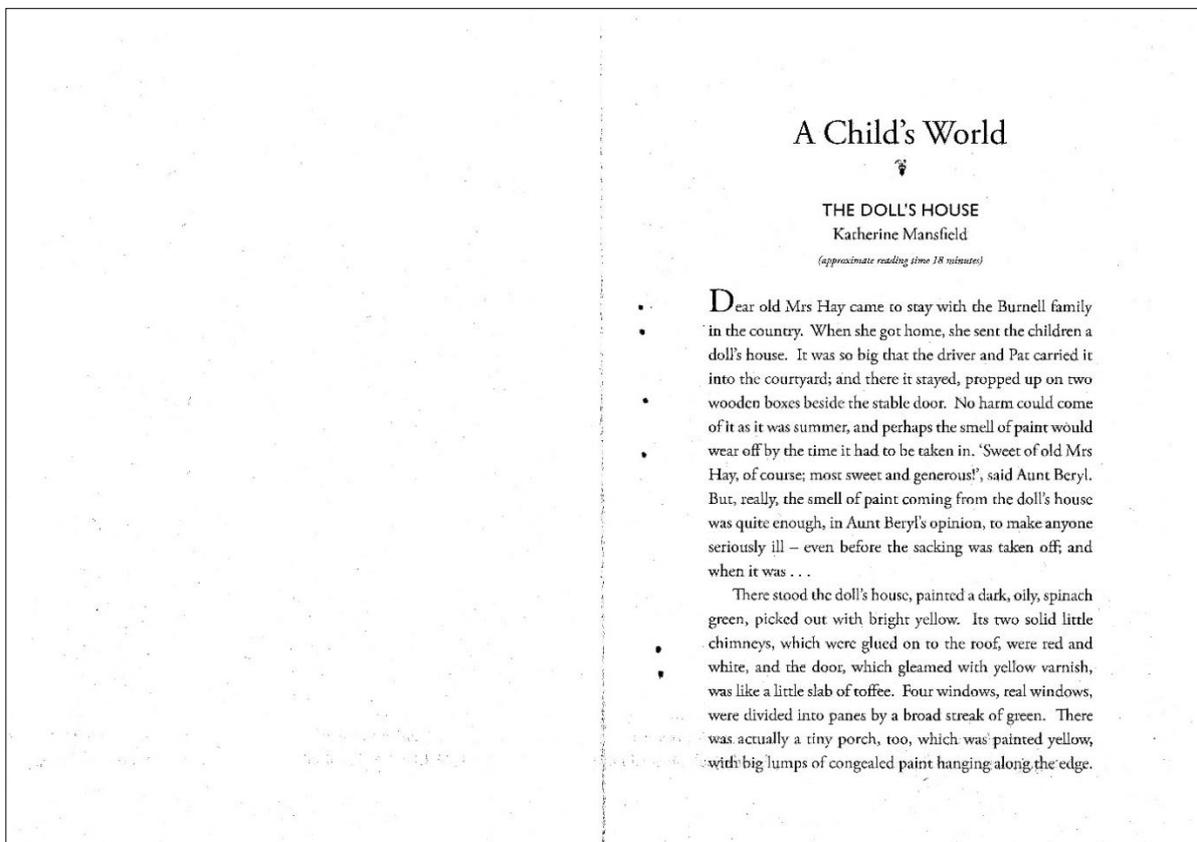
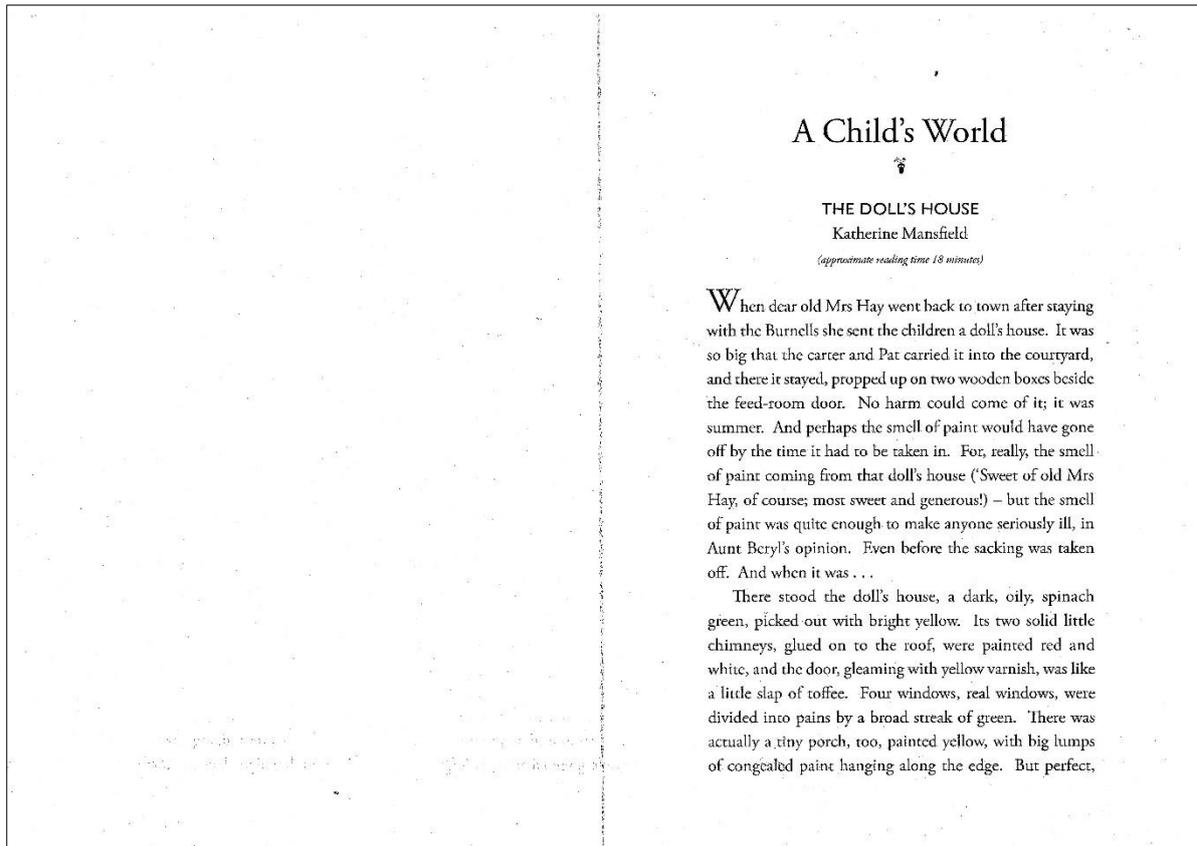


Fig. 9a Sample 4: text based on the opening page of Katherine Mansfield, *The Doll's House* (p. 25) as published in *A Little, Aloud*. Fig. 9b Sample 4: the text with editorial changes.

### 5.3.3 Procedure

At the start of the interview, a brief verbal outline of the purpose of the study was given to each participant and permission sought to switch on the voice recorder. The voice recorder was turned off when the participant had answered the questions about the final layout.

Two questions were asked about each of the four samples. The questions were:

Sample 1     John Buchan, *The Thirty-Nine Steps*

- i.    Which of the two layouts would you find more useful?
- ii.   Is it helpful to have a caption to the illustration?

Sample 2     Rubens, *Portrait of a Woman*

- i.    Do you think the headings are useful?
- ii.   Do you think the headings are the right size?

Sample 3     Lynda La Plante, *The Little One*

- i.    Is it useful to add the names of the speakers?
- ii.   If so, could you explain why?

Sample 4     Katherine Mansfield, *The Doll's House*

- i.    Which of the two opening paragraphs do you prefer?
- ii.   Are there any sentences or words that might cause you problems?

The first question in each pair invited a direct answer. The second question asked for an explanation or elucidation of the first answer. Participants often tended to think aloud in formulating their response and sometimes had to be brought back to the original point under discussion. Some of the participants were not consistently aware of their memory loss (Starkstein 2014), so questions were asked about what a notional reader with a memory impairment might prefer. In a few cases, when a participant appeared to be tired or not to understand a question, the question was passed over rather than being repeated in order to get a response. Participant 3 was not shown contrasting layouts as

intended for Sample set no. 3.<sup>16</sup> The participant was, however, able to offer a legitimate opinion even though she had to rely on a verbal explanation.

Transcriptions of the recorded interviews are provided in Appendix VI, p. 293ff. Additional points made by Participant 3 have also been transcribed as they throw light on the participant's current reading experiences.

## 5.4 Results

The views expressed by the participants are summarised below. Direct quotations are taken from the recorded interviews. Further observations on the results are included in the Discussion section of this study (p. 136).

### 5.4.1 Sample 1: The position of an image and the use of captions John Buchan: *The Thirty-Nine Steps*

Question (i) Which of the two layouts would you find more useful?

Responses: (a) Image in text – 6  
(b) Image opposite – 2  
(c) Other – 2

(a) Image in text preference

Six participants expressed a preference for the picture to appear at its point of reference in the text. Three specifically noted the usefulness of the juxtaposition.

*... just above, is the actual words of what's happening in the picture, so in that case that seems like a good arrangement ... (Participant 2)*

*If I didn't have a choice, I'd be happy with either. ... I suppose a picture sort of indicates straightaway what the subject is going to be about ... so the sooner you get that in your head the better. (Participant 7)*

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<sup>16</sup> Two versions of the unedited text were shown to Participant 2 in error. As this may also have occurred in the case of Participant 1, a photocopy of the correct pair of layouts was sent and their written preferences noted.

[if illustration is opposite] *I mean, you'd have to break off and look ... or you'd have to read it through and then the picture is sort of apropos not a lot ... whereas if you've got the shock of the picture and the immediate ... yeah ...*  
(Participant 8)

One participant explicitly endorsed the decision by Oxford University Press always to position an illustration after its point of reference in the text:

*... because it's actually talking about it above, and then you've got the picture below ... it's a bit like a comic in a way ... where it's telling you what's going on, if you like ... [reads the text] ... and there's the picture showing you it ...*  
(Participant 3)

Another participant referred specifically to the difficulty of going back to a given point in the text when one's attention had been drawn to an illustration on the facing page.

*... if you are reading here and then you go across and look at the picture ... and you look at it with any depth or anything, then you've got to go back and you've got to find it, haven't you? And you can imagine, though you think you know it was at the end of the paragraph ... it must have been this one and then you miss that and you must miss some salient points, mightn't you?*  
(Participant 10)

#### (b) Image opposite preference

Two participants expressed a preference for the image to appear opposite the text. The first observed:

*I think I prefer to read a whole page and have it there [opposite].* (Participant 4)

She later commented on using an image as a fixed point or landmark in a text.

*I think occasionally, if you've got a big book and you're reading a lot of it, I think it's probably a bit of a ... yes, I remember that, that was a couple of pages back.*

The second participant observed that there was an advantage in displaying an image away from the text.

*... it seems to be clearer, you know, more pronounced ...* (Participant 5)

## (c) Other

It was not clear whether a preference for placing the image opposite a piece of text rather than embedded in it was sometimes an expression of the participant's view that fiction for adults need not be illustrated. Two participants were of this opinion. The first referred to the part played by the reader's imagination when reading a text (see also Discussion, p. 206).

*I think, really, you don't need a picture ... I don't need [an illustration], I like my mind to work ... I don't mind illustrations, I think they're more for younger people that probably don't understand the text and it gives them an opportunity to think about it, so it promotes thinking ... (Participant 1)*

The other participant declared, perhaps with deliberate understatement, that he read 'a lot' and, on the basis of a personal copy of book shown to the researcher, his preferred reading matter was largely text-based and of a high level of complexity.

*I don't think it would make any difference. ... I don't have any difficulty following the text. (Participant 6)*

Question (ii) Is it helpful to have a caption to the illustration?

- Responses: (a) Caption helpful – 3  
 (b) Caption not helpful – 5  
 (c) Other – 2

## (a) Caption helpful

Three participants said that they found captions useful in general. However, no mention was made of the repetition in a caption of information already given in the text being helpful to readers who had issues with their memory.

The first participant saw the need for captions in some but not all cases.

*... if there are to be pictures then you've got to have captions ... [but] no, I don't think I do, because if I know the story ... (Participant 1)*

The anchoring effect of captions was also remarked upon.

*... well, they've got one on both, haven't they, they've got a caption there, they've got a caption on both, but it's ... the picture looks lost on the page like that, doesn't it? [ML asks if a caption is useful when the illustration is opposite] ... no, I think the caption helps, I think the caption helps, but it's all about ... if you didn't have a caption you'd have to read that, put it that way (Participant 9)*

One participant commented that a caption was needed if the image was placed on the facing page (Participant 5).

#### (b) Caption not helpful

Four participants said that they did not find the captions helpful. The aspect of redundancy was referred to in a number of replies.

*I don't know whether it would or not, because that's actually there telling you what's there and I don't know whether you'd need that as well ... (Participant 3)*

*Well, if it's explaining, I wouldn't necessarily expect a caption because it's part of the story. I should be able to identify with it, um, going along, so long as it's on the right page ... (Participant 7)*

*No, you don't need ... not if you've got that, I mean, they've told you that, you don't want to have attention broken to look at it again. (Participant 8)*

*Well, if you've got it there [i.e. in the text] do you need it there? (Participant 10)*

Redundancy may also have been the reason why another participant commented that captions were not useful to him.

*I don't think so, not for me. [ML repeats the question] ... I don't particularly need captions. (Participant 6)*

#### (c) Other

One participant seemed unable to give a direct answer, although she hinted that an image on a facing page could benefit from a caption.

*I think it depends what the picture is about ... probably, if I started reading this one [version with illustration in the text], I'd read that, I'd skip the picture, read this and then I'd turn over ... but because it's there, you look at it as you're reading that, so yes, it probably does ... (Participant 4)*

The question was not put to Participant 2.

### 5.4.2 Sample 2: The use of side headings

#### Rubens: *Portrait of a Woman*

Question (i) Do you think the headings are useful?

- Responses: (a) Headings useful – 7  
 (b) Headings not useful – 2  
 (c) Other – 1

#### (a) Headings useful

Seven participants found the presence of headings useful. Two participants specifically mentioned the advantages the headings would offer to those who had memory issues.

*... Again, with my memory problems, I think that [participant indicates the version with the headings] because it's actually giving you a heading of what you're talking about ... the artist, the painting, plus the fact that if you want to, you know, with a memory problem, go back and say who wrote, who painted it you've just got to look there, whereas that you probably have to re-read it ... (Participant 3)*

*I think these are helpful ... [ML says, because ...] ... they encapsulate ... the thing is, I read a lot but clearly I'm beginning to have difficulties with reading ... [ML might headings be supportive?] ... I think so ... (Participant 6)*

A third participant felt that breaking the text down would help individuals with reading difficulties.

*I think this [indicating layout with headings] is good ... this isn't bad, I mean it still follows and you can still follow the description of the painting ... but that does just split it up and make it easier for anybody who might be having difficulties ... (Participant 2)*

Three other participants commented directly on the advantages that breaking up a text with side headings can have. One noted that headings can draw attention to specific aspects of an illustration.

*I don't think it helps in the reading of it, understanding it, it's something that you probably put a little bit more into because you look at the picture and you see other bits that you wouldn't look at straightaway ... You kind of look at that and you read this and you look at that and you think um, yes, that's it, and*

*you're down here and you think of something else that was in the picture, so you look at it again ... (Participant 4)*

One participant commented that headings might help to commit information to memory.

*Yes, I think so. [ML prompts participant to continue] ... it fixes it, I don't know, it does fix it more, you know, the subject ... and then you're told [pause, ML repeats, It fixes it] ... I think so ... I mean this tells, this tells everything ... well, it's as if you've got all of the same information but you're sort of going from one to the other, which fixes it a bit more ... (Participant 8)*

Another participant, who read broadsheet newspapers but not books, noted that headings made for more efficient reading.

*... well, from the point of view of learning, that's more descriptive ... well, it itemises it all, doesn't it, you don't have to read that ... [indicates version of text without headings, then reads aloud the side headings] ... now, I've done that in two seconds, now I've got to read all that [version without side headings] to find out the gist of it, but I mean that ... [ML heading useful?] ... I think they are, I do think they are, especially I emphasise I'm a non-reader and that would bring, that brings my ... brings me into view ... (Participant 9).*

#### (b) Headings not useful

One participant was undecided, but hinted that when it came to serious texts, headings might serve a purpose.

*Well, I suppose that one [without the headings] ... [ML Headings?] They're a bit superfluous ... at the same time, they could be helpful. ... I wouldn't like this on every page of a book, or anything like that, but when it comes to a document like that ... (Participant 7)*

A second participant commented that the layout with headings might be perceived as being condescending.

*I don't have very strong feelings about that, really. ... Yes, I think I might be inclined to feel spoken down to, talked down to with the headings ... (Participant 10)*

#### (c) Other

The question was not understood by Participant 1. Two participants volunteered a response to the image itself. Participant 5, who had had little to say in answer to any of the questions about the text, commented, 'Fantastic painting, isn't it?'

and, 'I wish I could paint like that.' Participant 4 noted that a reader's response to the illustration might vary: 'I think it depends on what sort of person you are, I mean I am a person's person, I mean all my working days I was a hairdresser, I was looking at people's faces ... that's why you have a different ... if there's a picture, I look at it and I look at their faces ...'.

Question (ii) Do you think the headings are the right size?

Responses: (a) Headings the right size – 8  
 (b) Headings not the right size – 0  
 (c) Other – 2

(a) Headings the right size

Eight of the participants found the headings to be appropriate in size and weight. Sometimes the question had to be clarified and supplemented with a phrase asking if the headings were too big or too small. This resulted in participants responding with an initial answer 'No' before going on to offer a positive response and explanation.

*It's the same typeface, isn't it? ... No, I think they're fine. (Participant 2)*

*No, I think that's quite good, I mean, I wear glasses, if I couldn't wear my glasses I could still, just about, see that and it's also a nice clear picture [?] that doesn't make your eyes sore ... the spacing and the dark print on the white paper, that's another good thing (Participant 4)*

*That's about right, that one ... [thinks other headings are a different size] ... that's clear ... (Participant 5)*

*No, they're very helpful ... and I think that that's good. (Participant 6)*

*No, if you're trying to point something out it's ideal. (Participant 7)*

*The Subject, The Painting, The Artist, no, I think they're fine. (Participant 8)*

*[ML too big?] ... no, not at all, done like that, it's itemised for you ... (Participant 9)*

*I wouldn't want it any bigger, but I would have thought, yes, that's perfectly satisfactory... if it was slightly smaller but still in heavy print then I suppose that would be ok. (Participant 10)*

Participant 9, who had printing experience, commented on the bold type.

*Well, I think [hesitates] some people might find that a bit harsh, these subheadings, quite harsh, I don't, I think it brings your ... head to what you're reading, doesn't it?*

(b) Headings not the right size

None of the participants said that the headings were the wrong size.

(c) Other

The question was not understood by Participant 1 and was not answered directly by Participant 3.

### **5.4.3 Sample 3: The addition of names of speakers in a dialogue**

#### **Lynda La Plante: *The Little One***

Question (i) Is it useful to add the names of the speakers?

Responses: (a) Not useful to add names – 4

(b) Useful to add names – 4

(c) Other – 2

(a) Not useful to add names

Four participants did not think that adding the speakers' names would be useful.

*I'm not sure you need 'Barbara replied' there because it's obvious it's set like dialogue ... [ML explains again, P. reads again] ... ah, there it says, 'Barbara replied', I don't think you need that ... (Participant 2)*

*... no, I think you just ... no, I don't think that makes any difference at all.*

(Participant 4)

*Just as it is, I'm fine ... [ML explains again, just to be sure] ... No, it's fine, it doesn't make no difference to me ... [ML presses again] ... [he reads] ... yes, fine, I can understand all of it ... (Participant 5)*

## (b) Useful to add names

Four participants said that they would find adding the speakers' names useful.

*... I think it probably helps a bit, because I'm all right reading a book I've read before, I still have memory of that, but a new book I do have to flick back and remember who the characters are so, I think, yes, it probably does ...*

(Participant 3)

*... I think that's a very good help, actually ...* (Participant 6)

*... Yes, I think it would be.* (Participant 8)

*... yes, but one could lose one's way, I suppose, couldn't one?* [ML reads the question aloud] *... I would think it would be better to opt for that because if you lose your reader in some way that's damage done, isn't it?* (Participant 10)

## (c) Other

The tone of the response by two participants suggested that they were ambivalent about the addition of names.

*I don't think I'm bothered about that... [reads] ... I could take either ...* [ML repeats, either?] *... yes...* (Participant 7)

*Well, I think that's very much in the reader's interest, from the point of view of the design and layout of the book ... you're emphasising the names in spades, aren't you?* (Participant 9)

## Question (ii) Could you explain why?

Responses: (a) Why better without added names – 3

(b) Why better with added names – 3

(c) Other – 4

## (a) Why better without added names

A discussion of the reasons for their preferences often involved participants thinking aloud. Three participants said that the text was acceptable as it was.

*... [adding names] stops the flow ...* (Participant 1)

*... [it's obvious] when it's set like that ...* [ML reminds participant of the question] *... there's only two of them there ...* [ML picks up participant's idea of visualising the scene] *... you don't need 'said Alan' there ... I think that makes it a bit cluttered ... where is says 'said Alan' and 'Barbara replied', I don't think*

*you need that, it's obvious it's dialogue ... [agrees with ML] ... the layout's very important ... there, I don't think you need that 'said Alan', I mean there's only two of them around, isn't there, in the scene? ... (Participant 2)*

*... I think you would of, because [they're probably in] the chapter before so you connect it ... it's if you've gone two or three chapters along and you've suddenly got names ... [ML you won't forget] ... no, I think you just ... no, I don't think that makes any difference at all. (Participant 4)*

Three readers referred to imagination and to the ability to visualise a scene described in a text. One participant commented that the omission of names would be useful:

*... to help you visualise it more, to stimulate your memory ... (Participant 1)*

Another participant, who was evidently able to picture the scene, commented that:

*... you don't need that one, nobody else has entered the scene, there's only the two of them, so some of those are superfluous ... just a bit cluttery ... (Participant 2)*

A third reader concluded with the observation:

*... when you're reading a book, you put your own imagination into it ... (Participant 4)*

#### (b) Why better with added names

Three participants said that adding the speakers' names in a dialogue would be a way of supporting memory.

*... yes, it probably does ... sometimes you can read a conversation between two people ... their names aren't mentioned at all, you know, they might have been on the previous page, but [you have to look] back to see who's talking now ... so, yeah, I think it does help to sort of throw in their names ... (Participant 3)*

*... you know, if you were reading with a little bit of difficulty, you're slower, so you need ... [ML contributes here] ... there are fast readers and slow readers, you know, I can take a book and get through it pretty quickly. [ML comments that there is no mention at all of speakers' names in some passages] ... And you'd have to know from the exclamation marks and the pause marks, which not everyone would if they had a little bit of difficulty. (Participant 8)*

*... that could be an irritation but basically ... I'm a very quick reader... so then I'd get fed up with all these extra bits and pieces ... but on the other hand you ... it's probably a matter of half [and] half, isn't it ... but you don't want, whatever*

*you do, you don't want to lose somebody's confidence, do you? [ML agrees] ... Difficult. (Participant 10)*

(c) Other

Two of the participants were able to comment on the usefulness of the addition of speakers' names for individuals who might be experiencing difficulties reading – difficulties which they implied they did not themselves have.

*Yes, I think it would be quite a good idea to have the, you know, the narrative interrupted, but it's not necessary for me [ML you are an expert reader] ... I read a lot. (Participant 6)*

*... if I read that I wouldn't consider something was missing ... [ML can you imagine that someone might want the names in?] ... yes, yes, oh yes. (Participant 7)*

The question was not fully understood by Participant 5, and in the case of Participant 9 the answer was not clear.

#### **5.4.4 Sample 4: The use of complex syntax in literary prose**

##### **Katherine Mansfield: *The Doll's House***

Question (i) Which of the two opening paragraphs do you prefer?

- Responses:
- (a) Author's original text – 3
  - (b) Edited version of original text – 3
  - (c) Other – 4

Participants were often tired by the time they tackled this sample; however, a number were willing to grapple with the unfamiliar language and complex syntax of the extract.

(a) Prefer author's original text

Three of the participants expressed a preference for the author's original text.

*[ML asks whether it is easier if the language is smoothed out a bit] ... no, because the point is that book is written by the author and it's how he's written*

*it and the way he's spoken the words that he envisaged, so it's a bit insulting if you don't follow the script ...*

[Same participant expresses a change of mind] ... *I like that better...* [Participant reads both out loud and indicates the original version] ... *that flows better, sounds better, just everything ...* [ML summarises, noting change of opinion] ... *It's better writing, if you like* [ML asks if reading good writing can be hard work] ... *I don't think good writing could ever be hard work, but then I'm a bit prejudiced ... because I read a lot ... no I don't think it would be hard work ...* (Participant 1)

*... it's funny, isn't it, what you prefer and don't prefer and you'd be hard put to say exactly why ... it's sort of to the ear, isn't it?* (Participant 2)

*... Well, I think already, this* [indicates the author's own text. ML asks if she likes to read it as the author wrote it] ... *Yes.* [ML asks if she prefers to grapple with the author's own words] ... *Yes, because they're clearer.* (Participant 8)

#### (b) Prefer edited version of original text

Three participants expressed a preference for the edited version. One participant spent some time reading each text and responded with slight awkwardness.

*... I suppose I prefer this one ...* [indicates edited version] ... *it goes straight to the heart of things without waffling ... that's too, too, it's not waffling really, but it's ...* (Participant 7)

The extra clarity of the edited version was thought to be helpful by another participant, who referred here and elsewhere to her impaired memory.

*... I think that one, to me, is clearer ... is this the adjusted one, if you like ... I think it explains things more ... to me, that's, if you like, with my memory problems, clearer than the other one ...* (Participant 3)

One reader could not explain precisely why she preferred the edited text.

*... I think I prefer that one, I don't know why... I think I prefer that one* [the edited version] ... *I don't know why, I just do, I don't know.* (Participant 4)

#### (c) Other

Four out of the ten participants could not make a decision on this sample. In the case of Participant 10, who spoke freely of her diagnosis of Alzheimer's

disease, the process of thinking aloud suggested that her indecision was not the result of issues with her memory.

*I'm sort of ambivalent about it really; it's difficult, isn't it? ... I mean, do you think that the market you're looking at could be quite off put by not quite getting the style or ... in which case you do need to work at it, don't you?... No, this is it, you don't want to lose ... some of these bits ... [reads the text and the alterations] ... Yes, it's no good being offended by that, is it? [reads the two versions] ... well, 'which was painted yellow' whereas the other one is, 'comma, painted yellow' ... Yes, I don't really mean offended but you know ... Yes, I find that quite difficult to make a ... a decision on, really. (Participant 10)*

Two other Participants (5 and 6) were unable to answer the question even when it was re-phrased in more general terms. In the case of another reader, the question drew the non-committal response of:

*no, it's words for words sake, isn't it? ... (Participant 9)*

Question (ii) Are there any sentences or words that might cause you problems?

The final question of the interview was not put to five of the participants. In some cases, this was because of the evident fatigue of the participants, in other cases it was clear that it would not be appropriate to probe any more deeply into the reader's understanding of the text.

Responses: (a) There are some difficult parts – 4  
 (b) There are no difficult parts – 1  
 (c) Other – 5

(a) There are some difficult parts

Three participants noted the slightly arch style of the author's writing:

*I'm not quite sure about the brackets, it's a speech and it's got the speech marks round it, and it's got 'Said Aunt Beryl' after it ... I think that's messier somehow with Aunt Beryl's opinion at the end ... Very subjective these things, aren't they? (Participant 2)*

[Participant reads sentence about the 'feed-room door' and reads the version mentioning 'the stable'] ... *it's more what you expect to see, that's what it is [ML*

asks if this is a question of vocabulary rather than syntax] ... *no, it's the way it's been written ...* (Participant 4)

*It's a funny first sentence, isn't it? Because it's very ... it's a bit way out.*  
(Participant 10)

(b) There are no difficult parts

Two participants said that they did not find the text difficult. One commented:

*I find the author's writing quite clear.* (Participant 8)

Participant 1 said that he had no difficulties and read with some feeling until he got to the syntactically complex sentence beginning, 'For, really, the smell of paint ...'. At this point, he stopped reading.

Other – 5

The question was not put to Participants 3, 5, 6, 7 and 9.

## 5.5 Discussion

Observations on the results of the interview study are given below, followed by a summary of additional design points that were raised by participants. A brief discussion of the experience of user-testing in this aspect of dementia research concludes the section.

### 5.5.1 The results of the interviews

Many of the participant responses are expressions of the particular memory difficulties that arise from Alzheimer's disease. This was to be expected as the sample spreads had been specifically planned to identify aspects of design that were likely to prove problematic for readers with this specific cognitive impairment. The four aspects of design under consideration were:

**(i) Position of an illustration and use of captions:** the majority of participants expressed a preference for locating an illustration on the same page as its text reference. Positioning an image in this way might reduce the

demands on working memory (Baddeley 1992) and could help to decrease the burden of memory load (Baddeley, Eysenck and Anderson 2015, p. 56; Murphy, Groeger and Greene 2016, p. 135). Schriver (1997, p. 441) emphasises the need to position images after their point of reference. The anchoring effect of a caption may be beneficial if the image is positioned alone on a facing page.

One of the two participants who preferred the image to appear on the opposite page referred to its function as a placeholder. Navigating a text may be seen as a form of wayfinding, and research into way-showing (Mollerup 2013) is a key aspect of design for dementia (Marquart 2011; DSDC 2020). Areas of the brain involved in orientation are known to be affected by Alzheimer's disease (Alzheimer 2020a).

**(ii) Use of side headings:** most participants appreciated the value of introducing side headings into a non-fiction text. Research in an educational context suggests that introducing signalling devices into a piece of continuous prose might relieve the demands placed on working memory (Hartley and Trueman 1983); it could also help to direct attention (Lorch 1989). The use of side headings might guide the reader to building an effective topic structure representation (Lorch and Lorch 1996) and consequently help with the retrieval of information. However, the potentially patronising effect of side headings should also be noted.

**(iii) Names of speakers in dialogue:** there was ambivalence about the need to introduce the speakers' names and this might reflect the preserved abilities of participants at an early stage. Too much repetition was considered unnecessary and even patronising. However, building at least a degree of redundancy into a text could reduce the need for inference, which is known to be affected by dementia (Creamer and Schmitter-Edgcombe 2010; Stine-Morrow, Hussey and Ng 2015). Inference is a constitutive part of reading comprehension (Schank

and Abelson 1977, p. 423; Kintsch and van Dijk 1978; Graesser, McNamara and Louwerse 2003).

Several participants referred to picturing the scene with the speakers in their imagination. This was a surprise finding and one that influenced the design of the following study. The work by Zeman on visualisation (Zeman, Dewar and Della Sala 2015 and 2016) suggests that expert readers may maintain this innate imaginative ability in the early stages of dementia. Publishers of accessible texts would need to brief their authors to take this preserved ability into account.

**(iv) Complex syntax in literary prose:** the responses of the participants highlighted both their personal response to literature and the severity of their impairment. It was not always possible to separate the two. A number of the replies suggested that using rich language might enhance the reader's enjoyment of narrative prose despite a cognitive impairment (Billington et al. 2013; Longden et al. 2016). The pleasure of heightened language (Zeman, Milton, Smith and Rylance 2013) had certainly been evident amongst members of the Younger Persons With Dementia reading group (p. 101). Similarly, research into the characteristics of popular works of fiction by Ashok, Feng and Choi (2013) suggested that as far as the general public was concerned, simple readability was not an accurate predictor of a novel's success.

### 5.5.2 Design issues raised by participants

A number of design issues were raised by participants in the course of conversation. Their comments did not always relate directly to the study questions, but were of a more general, observational nature.

**Typography:** the participants were all experienced readers, which may explain why a number of them showed an interest in the presentation of text. The size of type was commented on, especially in connection with Sample 3, the Lynda La Plante Quick Read, which is set in a noticeably generous 12 on 16-point Stone

serif. Participant 2 compared it to that of Sample 1, the John Buchan text, and observed that it would be helpful to readers with imperfect eye sight, but that ‘it’s the size that you’d get in your Enid Blyton books or children’s literature’. The size of type is a factor in the legibility of a text (Tinker 1963; Legge and Bigelow 2011; Lonsdale 2014), but it also contributes to the reader’s perception of a text (Barker 2013).

The weight of the typeface used for Sample 2, the Rubens portrait, which is printed on white art paper, drew a comment from Participant 4:

*... the spacing and the dark print on the white paper, that’s another good thing ... I mean, I read a book last year and it was very fine, it was dark print, but it was very fine ...*

It is unusual to remember a book because of its typeface and such observations would be of interest to a designer of accessible texts. A suitable typeface is likely to attract no comment (Bringhurst 1992) and would not distract the habitual reader from engaging with a text. As Participant 7 noted of Sample 3, ‘I’d be comfortable with that ... if it’s a good story it will keep me going.’

**Layout:** Participant 2 expressed a preference for paragraphs to finish at the foot of the page rather than being carried on to the following page. Such a layout would place demands on both the writer and the designer and would add to the book’s extent. However, allowing the pages of a text to find their own depth is a feature of the accessible titles published by Barrington Stoke: for example, *Extra Time* (Oldfield 2001), where a sense of the content of the text is reflected in the layout of the page. This supporting aspect of design is noted by Waller (2012) and it may also reflect the findings of psychologists Radvansky and Zacks (2014), who maintain that dividing experience into events is the basis of perception and understanding.

**Illustration:** two participants (7 and 9) expressed a dislike of an illustration being located on the spread following its reference in the text. Such a layout

would increase cognitive load (Sweller, van Merriënboer and Paas 1998) as information has to be maintained in working memory while the illustration is located and the correct point for resuming reading is found. This complaint may also reflect the age of the readers since colour printing throughout a text is a relatively recent development.

**Numbers:** two participants were troubled by numbers. Participant 1 and Participant 6 read aloud correctly until reaching the roman numerals in ‘George IV’ (Sample layout 2). In contrast, Participant 2 read aloud both the name of George IV and the dimensions of the painting. Reading aloud and reading silently are two separate activities (Rayner and Pollatsek, p. 208ff.), but the participants’ hesitation might signal that it would be preferable to use arabic numbers rather than roman numerals, or to spell out the numerals in words.

### **5.5.3 User-testing and Alzheimer’s disease**

There was a wide variation in the age of participants because there is no direct link between age and the severity of symptoms. However, amongst some of the volunteers in the interview study there appeared to be a link between age and educational background. Three of the older participants mentioned that they had been evacuated during the Second World War and commented that this had badly affected their education; one individual commented that he had attended five schools in his youth.

Carrying out the interviews in the individual’s home offered a number of advantages. It gave the participant a degree of control over the situation, in particular the duration of the interview; it meant that family members or carers could be present in the house while not being involved in the interview; participants were able to talk about books they had in their possession and offer examples for discussion; and participants were sufficiently relaxed to expand on the place of reading in their lives. The unhurried approach meant that questions could be

repeated and if necessary rephrased in order to ensure that the views of each individual could be accurately understood.

The participants' experience of Kindles, iPads and other devices was raised in conversation in order to explore their views. Handheld devices were available in at least three of the homes visited but were apparently unused. One participant expressed a liking for the tactile qualities of printed books, while another commented that the iPad was beyond his competence. The impact of the precise memory impairment caused by Alzheimer's disease is currently being explored in the context of electronic devices (Harris, Boyd, Evans et al. 2020) and in the broader context of emergent technology (Sanders and Scott 2020).

## **5.6 Conclusion**

The aim of the interview study was to investigate specific aspects of the reading experience of individuals with early-stage Alzheimer's disease. Four features of textual content and page layout were chosen that were likely to be problematic for such readers. A simple user-testing approach was adopted which allowed the expression of first-hand opinions. Participants were also encouraged to express their views on the broader aspects of reading suggested by the sample materials.

The study confirmed that the reading experience of individuals with early-stage Alzheimer's disease differs from that of readers who have a more advanced form of the condition (Bayles and Tomoeda 2014, p. 53). The results indicated not only that participants were interested in contributing to research into reading but also that they were able to express preferences and, in some cases at least, to give reasons for their preferences. The answers that were given suggested that images should follow their reference in a text to avoid placing extra demands on memory; that side headings might help to clarify the content of non-fiction text and thus support recall; that the judicious repetition of speakers' names in dialogue might help to avoid ambiguity; and that retaining an author's use of literary language might not prove a barrier to all readers.

A key theme emerging from the discussions was the effect of memory loss on the enjoyment of works of fiction. This commonly expressed limitation suggested that it would be profitable to investigate ways in which an accessible design might help the reader to remember a storyline. This topic became the focus of the next study.

## **6 Textual Additions Study: testing inserted chapter summaries**

### **6.1 Introduction**

The third study described below builds on the findings of the Field Study and the subsequent Participant Interview Study. An unexpected finding of the one-to-one interviews was that some participants continued to derive pleasure from reading narrative prose. Despite having a diagnosis either of Alzheimer's disease or of dementia with an Alzheimer's component, a number of the individuals continued to read for enjoyment and professed an interest in works of biography, fiction, or general information; they all commented on the difficulty of retaining textual information in their memory. This same regret at not being able to remember a storyline or a written account had been expressed by readers who had contributed to the Field Study. While individuals who have a lifetime habit of reading may develop a degree of protection due to cognitive reserve (Stern 2002, 2006, 2012), it would seem likely that gradually losing the ability to retain written information is a feature of Alzheimer's disease (Alzheimer 2020i).

The third study explored ways in which design modifications might support the reader's ability to retain a story in their memory. The precise nature of the memory loss had to be carefully considered in order to make appropriate suggestions.

### **6.2 Reading with a memory loss**

In setting up the study it was necessary distinguish between two different aspects of memory impairment and to test separate ways of supporting each. The two aspects may be described as conceptual memory loss and practical memory loss.

**Conceptual memory loss:** individuals who develop Alzheimer’s disease are likely to experience problems with episodic and semantic memory (Baddeley, Eysenck, Anderson 2015, pp. 452–454). For such individuals, the gradual fading from memory that might occur to the average person over a period of days or weeks happens over a much shorter time, making it difficult both to retain and to recall information. In the context of reading, this kind of memory loss could pose problems such as forgetting who characters are in a story and what the relationships are between them; it could also include forgetting the events of the narrative and the sequence in which they occurred.

Recent research into the transience of memory emphasises the important part that forgetting plays in the healthy functioning of the individual (Hardt, Nader and Nadel 2013). Some writers take the view that the persistence of memory is of questionable value on its own and that it is the capacity to select and to retain relevant, useful information that makes for efficient mental processing. Certainly, the ability to seek out and retain the salient points in a text is an important aspect of expert reading and it is one that may be enhanced by the purposeful design of text (Hartley 2004).

A further explanation of the difficulties experienced by the reader may be found in the literature on event segmentation and Alzheimer’s disease. Zacks and Speer draw attention to the function of an efficient memory: ‘This ability to recollect everyday experiences, termed episodic memory, is critical to a number of everyday tasks, from cooking to navigating to following a television programme.’ They continue, ‘Failing to remember what has just happened leaves one less able to keep track of what is happening right now. Accordingly, patients with dementia have difficulty remaining oriented with respect to space and time’ (Zacks and Speer 2006).

Likewise relevant to reading with dementia is the suggestion that the perception of events may affect the recollection of items that are no longer in view (Radvansky, Pettijohn and Kim 2015). Walking through doorways, which the

authors use as an instance of disruptive interference, can be seen as marking a new event in the mind of the individual. It is possible that turning the page of a book has an equivalent effect on the reader, and this might suggest that the careful positioning of text breaks and the clustering of relevant elements of a text would be beneficial to readers whose memory is under strain. This would be supported by the recommendations of Schriver (1997, p. 358). In their co-authored text *Event Cognition*, Zacks and Radvansky explore the relationship between written language and perception (Zacks and Radvansky 2014). They observe that, ‘There is a synergy between studies of discourse comprehension and event perception: Language gives us opportunities to broaden our study of event comprehension more, and event cognition provides insights into language processing’ (p. 57).

The study of gist memory is also relevant in the present context since individuals with Alzheimer’s disease are known to have an impaired ability to remember the gist of written or comparative materials (Hudon 2006; Budson 2006). A failure to encode information and to retrieve it correctly underpins this particular memory impairment. This might suggest that writers would be advised to reinforce key elements of their text so that information can be precisely encoded at the point of reference and later accurately recovered when required.

Accessible publishing requires active intervention on the part of editors and designers, and the presentation of works of fiction needs particular attention. In an article on the continuing importance of text layout Waller notes that ‘It is largely (but not entirely) absent from literature, and it is therefore correspondingly absent from literary studies of text, and absent from theories of text that originate in literary studies’ (Waller 2012). Designing a literary text for readers with particular needs may mean intervening in ways that might seem intrusive for more typical readers. However, there are two points to consider: first, the novel is a relatively recent development in the history of the book and the conventions of its layout have been partly defined by the economics of production (Littau, 2006, pp. 18–19); and

secondly, it is possible that modifications made for a particular readership could be beneficial to all.

**Practical memory loss:** this loss may be manifested in a reader's inability to navigate the book as an object. Informants at various stages of the research reported difficulties in finding their place in a text when resuming reading after a break. They also stated that they would normally try to complete a paragraph, or at least read to the bottom of a page, before stopping reading, in order to try and fix the page in their memory.

For readers with a memory impairment, the addition of a ribbon marker could act as a useful placeholder. Ribbon markers are currently added to non-fiction books such as travel guides or diaries, or to works of hardback fiction where the publisher decides to emphasise the haptic qualities of the printed book; the enhanced presentation of the bound volume is in deliberate contrast to the functional approach of the Kindle or iPad.<sup>17</sup> Furthermore, ribbons that are attached to a book would meet Donald Norman's recommendation that design should guide users towards advantageous outcomes (Norman 2013, p. 132). A ribbon that is glued to the book block would act as a constraint since it could not easily be ignored when the book is closed after reading.

An alternative to a ribbon marker would be a bookmark. On this subject, Norman writes:

Consider a bookmark, a deliberately placed signifier of one's place in reading a book. But the physical nature of books also makes a bookmark an accidental signifier, for its placement also indicates how much of the book remains. Most readers have learned to use this accidental signifier to aid in their enjoyment of the reading. With few pages left, we know the end is near (Norman 2013, p. 16).

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<sup>17</sup> An email communication with Macmillan (15.08.2017) states that ribbon markers are included in volumes of the Macmillan Collector's Library as the books are intended for the gift market. In general, books that are included in this category are designed to be aesthetically pleasing and features may therefore be added at the production stage to achieve this aim.

This form of orientation might be particularly useful when reading works of fiction since stories often unfold sequentially and their conceptual structure is reflected in the progress of the text across the pages; the story can be experienced physically in the piling up of numbered pages (Mangen 2017, p. 286).

A bookmark might be a personal possession or, as in the case of one informant, it might simply be an old envelope tucked inside the book in the appropriate place; other participants described and demonstrated similar strategies. Such improvisations may be common amongst readers in general, but they take on a special significance when reading with a memory impairment. As Jones writes, 'It is always worth paying a lot of attention to the crude adaptations that users make to their equipment and important to discover the reasons for them' (Jones, 1992, p. 216). The observations recorded by Fulton Suri demonstrate the value of close scrutiny of improvised solutions (Fulton Suri 2005).

**Other reading difficulties caused by memory impairment:** the answers given by informants during the interview study suggested that it would be worth revisiting the question of the usefulness of illustrations as a support to memory. Such an enquiry would be in addition to the discussion of the layout of text and the appraisal of published books and could only be introduced if time permitted.

### **6.3 Aim of the study**

The aim of the Textual Additions Study was to investigate the usefulness of suggested design modifications for readers who have dementia. The primary objective was to establish if any of the suggested modifications to the content, layout and presentation of a printed novel would be beneficial for readers with a memory impairment. A secondary objective was to use the sample materials to initiate a discussion about participants' experience of navigating texts with a memory impairment.

## 6.4 Method

The method adopted for the study is outlined below under four headings: content, materials, participants and procedure.

### 6.4.1 Content

Work carried out with informants in group settings and in one-to-one conversations had highlighted three difficulties that might be supported by a design intervention. The three difficulties were:

- i. remembering who the characters are in a text
- ii. remembering a storyline or a plot
- iii. remembering where to start reading again after a break

The testing of sample layouts and a discussion of existing published books meant assembling suitable material. The text for the sample layouts had to be prepared well in advance of the user-testing session. Since the aim of the discussion would be to compare three approaches to supporting the reader, and since the participants would not be required to read the text itself, Charles Dickens's *A Christmas Carol* was chosen as suitable material. The story of Ebenezer Scrooge was likely to be familiar and would be suitable for both male and female readers. Furthermore, visualisations in both film and cartoon form are often shown on television, so less experienced readers might at least have had some access to the storyline.<sup>18</sup> The fact that the text was available in digitised form on the Project Gutenberg website (Dickens 1843) and carried no copyright restrictions was also a factor in the choice.

### 6.4.2 Materials

Hendel observes that 'More than other graphic designers, those who design books need to be aware of conventions of how people read' (Hendel 2013, p. 7). A professional designer was therefore chosen who had an interest in the relationship

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<sup>18</sup> The aim was to include as many participants as possible in the discussion. The editor of *A Little, Aloud* reports the response of a reading group to an extract from *Jane Eyre*: 'One person had seen a film version; no one had read the book' (Macmillan 2010).

between the reader and a narrative text and who was sympathetic to the aims of accessible publishing. The difficulty of reading with a memory impairment calls into question existing design conventions, and an open-minded, user-centred approach was required.

The designer was supplied with pencil-drawn sketches (Appendix III) and a copy of the 2008 Oxford University Press paperback edition of *A Christmas Carol* (Dickens 2008/1843). Using this material as a guide, the designer prepared sample layouts: Sample A (Figs 10 and 11), Sample B (Fig. 12), and Sample C (Fig. 13). The purpose of each was as follows:

- Sample A aimed to remind the reader who the characters were in a story.
- Sample B provided a summary of the events of the preceding chapter.
- Sample C provided a summary of the plot up to the start of the new chapter.

Despite the vivid detail of the narrative, Dickens had a clear view of the story's shape and its proportions from the start (Dickens 2008/1843, p. xi). The internal structure of the narrative needed to be reflected in the sample layouts of the text.

No alterations were made to the original text of the story. The aim was purely to test whether any of the supporting material added to the three sample layouts would help to reinforce the reader's memory of the story. Providing a list of the characters' names and a short description of each might prove a useful source of reference, while summarising key events might help to consolidate the reader's memory of the storyline. The aim was to make explicit the inner structure of the narrative, which would involve reflecting the sequence of the author's original text (Mullan 2006, p. 156).

The intention was to give the pages of the sample layouts a modern classic feel. The typeface used for the OUP edition was Ehrhardt (Dickens 2008/1843) while the equivalent Penguin edition was set in 11/13pt Dante (Dickens 2003/1843).

For the sample layouts, the designer proposed Minion, a serif typeface offering legibility and flexibility; it is also considered to be rather more robust than Dante and has a larger appearing size.<sup>19</sup>

The text of a novel is, in design terms, an example of communication rather than pure information, but the readers' impressions were likely to be based on a number of predictable factors. Jeanne-Louise Moys lists seven possible factors that can affect a reader's opinion, and the factors of accessibility, content and value would seem to be relevant in the present case (Moys 2017, p. 214). The aim was certainly to present test materials that would not challenge the participants for the wrong reasons. The layouts had to retain the 'feel' of an adult work of fiction and, with this in mind, a page size was chosen to replicate the standard dimensions of a paperback novel.

**Sample A content:** the wording for the title page (Figs. 10 and 11) was taken from earlier editions of the novel, and the descriptions of the characters were compiled from general works of reference. The copy originally supplied to the designer listed all the characters who appear in the book. The designer's decision only to include the main characters was based on the limitation of space and a preference for legibility rather than completeness. The shortened version was used for the testing as the aim of the layout was to find out if a list would be useful and whether it should appear in the prelims. Further investigation would be necessary to ascertain whether a double-page list in the prelims would be equally useful.

**Sample A presentation:** Two versions of the layouts were prepared by the designer (Figs 10 and 11). The title page for both versions is simple and uncluttered. The story's original title is given in full, as would be expected by a reader familiar with the author's work, and the classic treatment was intended to signal to such a reader that the text is an acknowledged work of literary merit.

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<sup>19</sup> Minion is the typeface of choice for Bringhurst's *The Elements of Typographic Style* (1992).

In version 1 (Fig. 10), the list of characters faces the title page and takes the place of a conventional frontispiece to the book. The use of a tint mimics the area that would normally be assigned to an illustration and thus helps to balance the spread. The names of the characters are picked out in bold and the weight of tint is not so heavy as to make the text illegible. A grey tint was used to give the reader a realistic sense of what might be achievable. A grey tint would not add to the printing costs, whereas a second colour would have to be included in the budget for the book. The layouts were printed both on white paper and on good quality cream paper.

In version 2 (Fig. 11), the list of characters is centred and is bordered by a fine rule; on the title page, a decorative double rule separates the title and the first name. The second version of the layout, although it might be considered aesthetically more pleasing,<sup>20</sup> was thought to be less suitable for the target readership. It was felt that readers would be likely to use the list as they would an index and would therefore expect the entries to range left. In addition, the sequencing of related items (e.g. family members) is not immediately obvious when centred.

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<sup>20</sup> A centred layout may be used for copyright details on an imprint page, as in the case of Bringhurst's *Elements of Typographic Style* (1992).

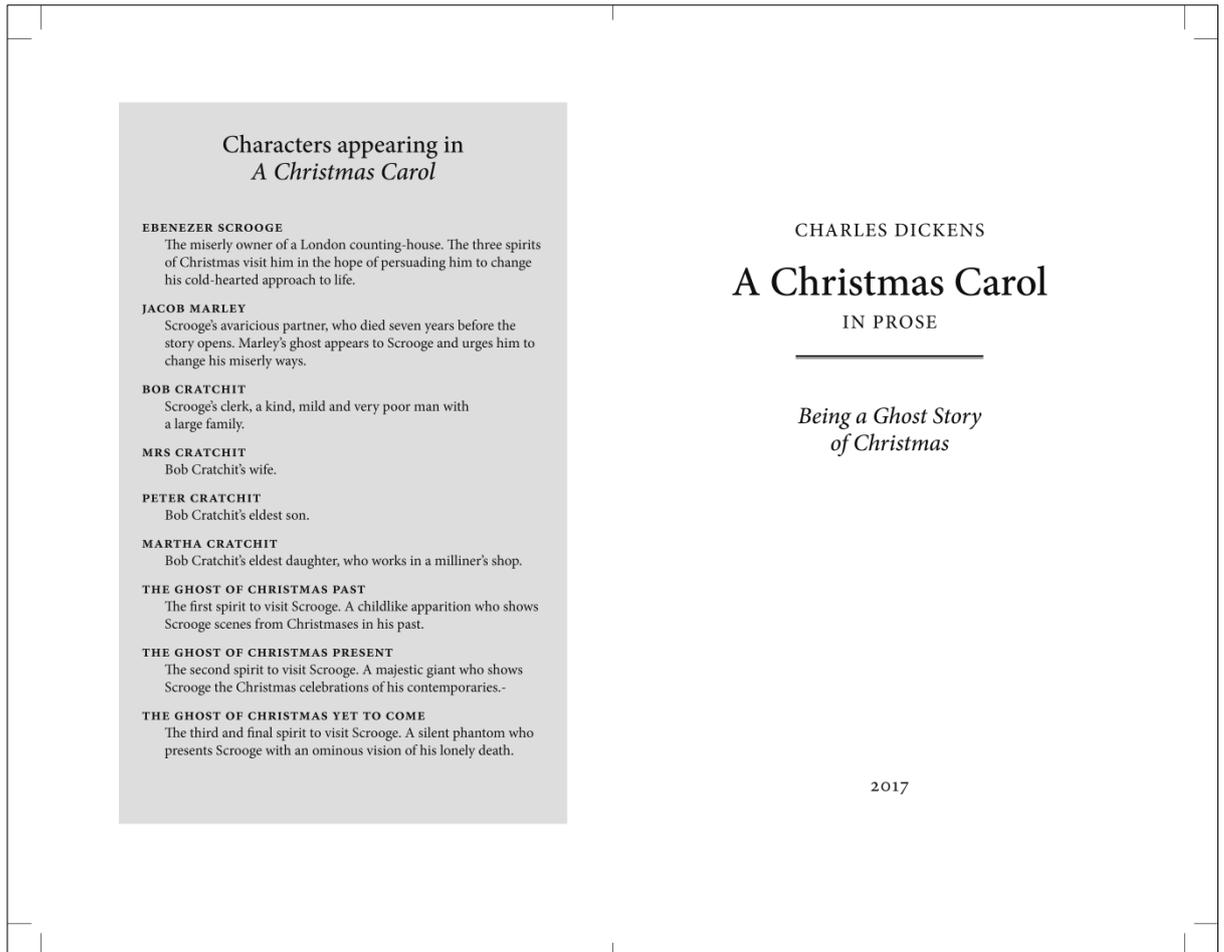


Fig. 10  
List of characters (Sample A): version 1.  
trimmed page size 195 x 125mm  
10.5/13pt Minion

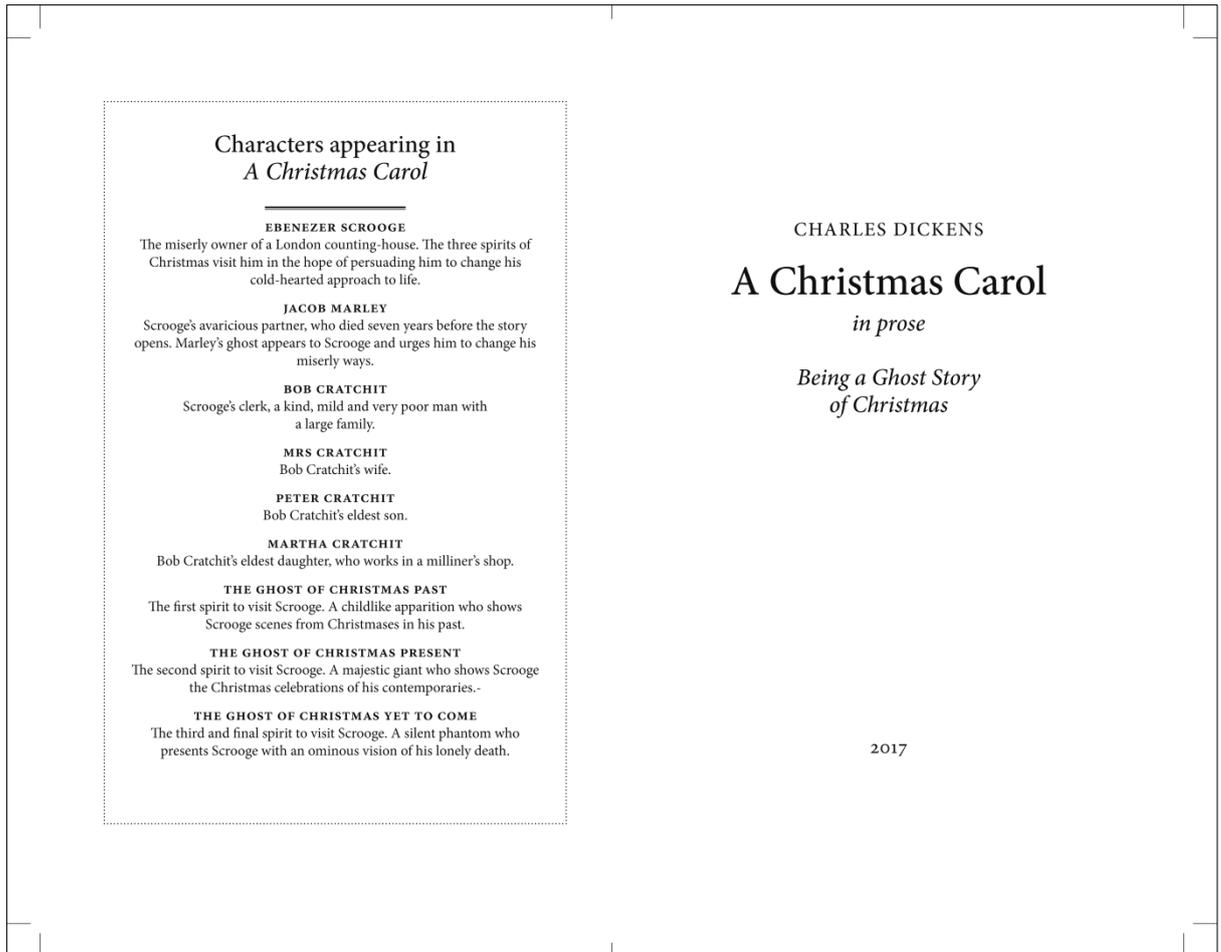


Fig. 11  
List of characters (Sample A) – version 2  
trimmed page size 195 x 125mm  
10.5/13pt Minion

Adding the list of characters to the title page spread would be a definite intervention on the part of the publisher and would be a break with convention. However, usefulness might outweigh other considerations in this special case, and justification may be found in Williamson's comments on design solutions: 'Tradition is not always a certain guide to style in typography; many of the great master-printers of history, from whose practice traditions should presumably derive, were far from patient with conventions' (Williamson 1956, p. 177).

**Sample B content:** a brief summary of the events described in the chapter is added at the end of Chapter 1 (Fig. 12). The summary is limited to the salient points of the story on which the narrative will build in subsequent chapters. Brief recapitulations of the key ideas in a chapter are frequently found in student textbooks (e.g. Baddeley, Anderson and Eysenck 2015) and their use as an aid to memory in an instructional setting is highlighted by Lorch (1989). A summary positioned at the end of a text was found by Hartley, Goldie and Steen (1979) to improve student recall the most, while the particular benefits of a summary for older readers are noted by Hartley (2004).

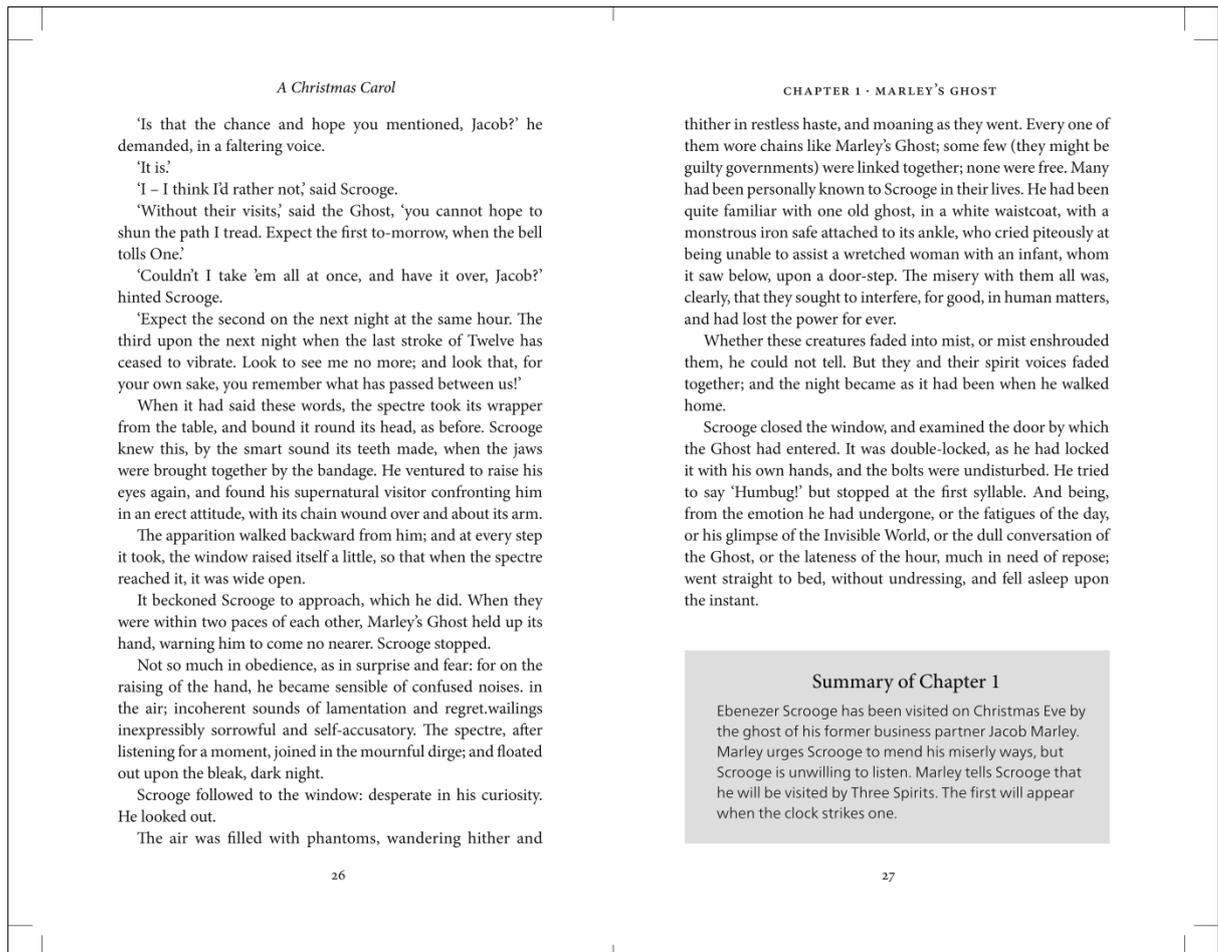
For the running head, the author's word 'stave', which builds on the conceit of the story as a form of carol with five verses, is replaced by the more familiar term 'chapter'.

**Sample B presentation:** the main text was set with a generous amount of vertical space between the lines to aid legibility (Dyson 2019, p. 95). A small amount of extra spacing was added between sentences to allow the reader both to anticipate and to pause at breaks in the sense. Care was taken, though, not to make the space too wide as the reader naturally uses parafoveal vision to detect the features of letters positioned to the right of a fixation point (Rayner et al. 2012, p. 107). Punctuation marks are large enough to be clear (Spencer 1969, p. 34; RNIB 2017) and the quotation marks that indicate dialogue are

unambiguous (Ritter, 1992, p. 112). Old style figures are a feature of Minion and make an unobtrusive but definite contribution to the design.

The conventional positioning of the book title and the chapter number and title has been used. For consistency, page numbers are centred at the foot of the page, which means that they can also appear on pages where a new chapter starts. The summary comes at the end of the chapter and is signalled to the reader by the use of a light grey tint. In contrast to the main text, the summary is set in a sans serif typeface and is unjustified; however, to give a sense of continuity, the heading to the summary is set in Minion bold.

The adjustments made in achieving a final layout for Sample B were based on a further consideration of the needs of the specified reader. The length of line was slightly increased to make it easier to break up the text into chunks of sense (Sweller 1994; Waller 2011), and the typeface was changed from Gill Sans Light to Frutiger, which blended well with the serified Minion. The size of the heading to the summary was reduced so as not to patronise the reader. The running head was enlarged to signpost the text more clearly, and a decorative double rule and square brackets around the page numbers were removed to avoid over-facing the reader.



**Fig. 12**  
**Summary positioned at the end of a chapter (Sample B)**  
 trimmed page size 195 x 125mm  
 main text 10.5/13pt Minion  
 line length 93mm, 12pt indentation

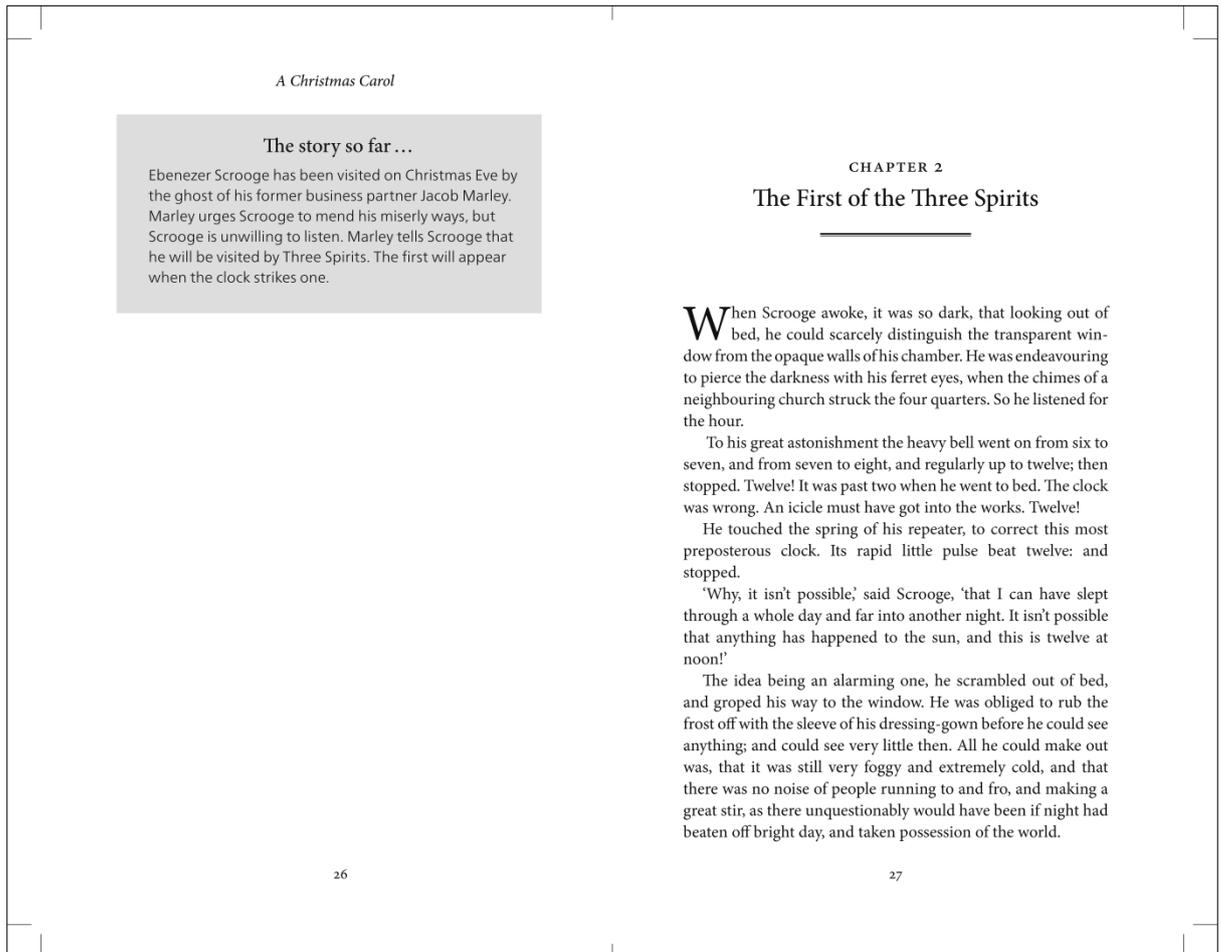
**Sample C content:** the heading ‘The story so far ...’ was added to the chapter summary that had been used for Sample B. The summary was positioned opposite the opening page of Chapter 2 making it a plot summary (Fig. 13). The wording of the heading was tentative and other possibilities were noted.

**Sample C presentation:** for the main text, the typeface, type size, line length and leading are the same as for Sample B. The design is clear, uncluttered, and carefully considered.

The chapter number and title are prominently displayed with a generous chapter drop. A double rule gives added emphasis and serves to indicate to the reader that a new section of the text is about to begin (as seen in Williamson 1956, *passim*). A drop capital, an appropriate touch for a nineteenth-century text, also serves a practical purpose in signalling the start of a new chapter.

The text in the tint box is set in Frutiger, with the heading in Minion. The designer did not act on a suggestion to use a tint over the whole of the page. Although this would have punctuated the book more definitely, it could have seemed intrusive and too much of a departure from the norms of fiction publishing.

Several changes were made in the course of preparing this sample layout. For ease of reference, the chapter number was presented as an arabic numeral, and the space between the three elements of the chapter title was increased to make it easier to distinguish each line. The optimum spacing for such a rhetorical cluster may be adjusted to the needs of the anticipated readership (Schraver 1997, p. 343).



**Fig. 13**  
 Plot summary positioned at the start of a chapter (Sample C)  
 trimmed page size 195 x 125mm  
 main text 10.5/13pt Minion  
 line length 93mm, 12pt indentation

**Ribbon markers and bookmarks:** the second part of the user-testing involved an appraisal by participants of publications that had ribbon markers and bookmarks. Examples of hardback fiction that had ribbon markers were assembled, together with a small personal diary (Fig. 14). A number of paper bookmarks were also gathered together to indicate the different kinds that are available (Fig. 15). Examples included two that were based on wallpaper designs from the Victoria & Albert Museum, some free samples from WHSmith that advertised the latest Dan Brown novel, and a bookmark calendar that provided a tear-off strip for each month of the year.

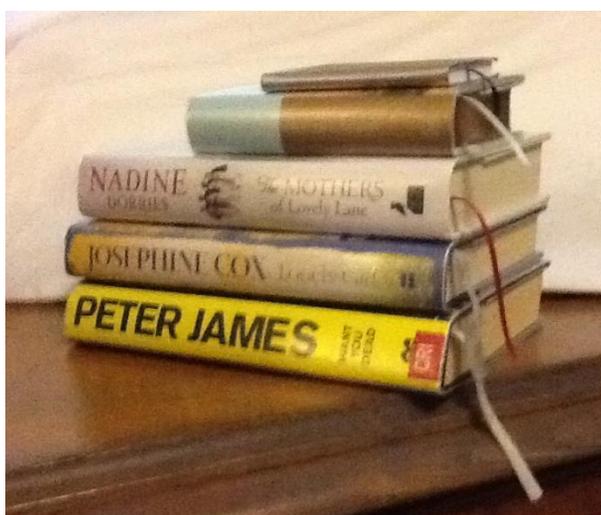


Fig. 14 (above left) Examples of library books and a diary with ribbon markers shown to the study participants.



Fig. 15 (above right) Paper bookmarks shown to the study participants.

### 6.4.3 Participants

Working in collaboration with the NHS for the previous study had meant following an exacting protocol that it would be difficult to repeat within a reasonable timescale. Contact was therefore made with the organiser of the Reading branch of the Dementia and Engagement and Empowerment Project (DEEP), who confirmed

that the research would be in keeping with the aims of the organisation. A total of eight participants were invited to the monthly meeting by the organiser but only three members attended, together with a representative of the Berkshire Alzheimer's Society. The low attendance may have been partly due to the fact that a written agenda had been sent out in advance which indicated that the entire meeting would be devoted to a discussion about reading. Such a topic might not have appealed to all members.

Compared to the volunteers who took part in the Participant Interview Study, the DEEP members formed a less homogeneous group as their dementia was both unspecified and had not been medically classified as 'early-stage'. However, two members mentioned their diagnosis of Alzheimer's disease in the course of discussion. Both had travelled alone on public transport to attend the meeting. A third participant, who was accompanied to the door, mentioned that she was also a member of the Younger Persons With Dementia group. Everyone who attended the meeting had their vision corrected by glasses; two members said that their lenses were slightly tinted to reduce glare.

The number of participants was unexpectedly small, but a decision to proceed was taken since the participants, although constituting a limited sample in themselves, had made a deliberate decision to attend. The appropriateness of purposeful sampling is discussed by Leavy, who observes that it is 'based on the premise that seeking out the best cases for the study produces the best data, and research results are a direct result of the cases sampled' (Leavy 2017, p. 79).

#### **6.4.4 Procedure**

The study was given ethical approval by the University of Reading Research Ethics Committee. At the start of the DEEP meeting, consent forms were collected from all the participants and a general agreement to the meeting being voice-recorded was obtained. The purpose of the discussion was briefly explained, and the meeting was then divided into five stages with questions being asked at each stage.

**Stage 1:** participants were given a photocopied version of Sample A, a double-page layout showing a list of characters opposite a title page. An explanation for including such a list in a work of fiction was given.

Question: Do you think it would be useful to include a list of the characters who appear in the story?

**Stage 2:** participants were given a photocopied version of Sample B, a double-page layout with a chapter summary at the end. An explanation for the design of the layout was given.

Question: Would it be useful to include a chapter summary at the end of each chapter?

**Stage 3:** participants were given a photocopied version of Sample C, a double-page layout with a plot summary at the top left-hand side.

Question: Would it be useful to include a chapter summary at the end of each chapter or a summary of the story so far at the start of each new chapter?

**Stage 4:** participants were shown examples of hardback books with ribbon markers and examples of paper bookmarks.

Question: Would you use either of these two sorts of bookmark?

**Stage 5:** the discussion was broadened out and questions were asked about three aspects of reading, namely the experience of visualising stories, the usefulness of illustrations in works of fiction, and the addition of a sticker to the jacket of a book.

## 6.5 Results

A summary of the discussion with the DEEP participants, including a verbatim account of their response to questions, is given in Appendix VIII, p. 317ff. The explicit aims of the study were to clarify whether suggested design modifications would be beneficial to readers with dementia and to elicit further information about reading with a memory impairment. A number of findings emerged, and these are outlined below.

### 6.5.1 Sample A - List of characters

The idea of including a list of characters in works of fiction for readers with a cognitive impairment was well received. Participants shared their experiences of forgetting who the characters were in stories and commented on the added difficulties of remembering complex relationships or remembering who characters were when they were referred to by different names. Asked if a reader might find a list patronising, one participant said:

*No, it's fabulous.* (Participant 2)

The same participant described her difficulties in distinguishing between characters and commented:

*Had I been able to look at this, because it's visual, I would have been able to get it into my head.* (Participant 2)

*I actually think, I don't think it matters whether you've got any sort of difficulty remembering, I think a lot of people would be quite pleased, because a lot of people can take a few weeks to read a book and I think this is something that should become standard.* (Participant 2)

There was some discussion about where readers with a memory impairment might find it useful to have the list. Putting a list on the front flap of a jacket was suggested, and one participant used a sample hardback book to show how the list would then be available when pages of text were tucked underneath the flap.

### 6.5.2 Sample B - Chapter summary

Participants were slow to comment on Sample B, even allowing for the fact that including a summary at the end of a chapter in a work of fiction would be something out of the ordinary. Participants were reminded of the use of summaries in textbooks, but no one saw any merit in including chapter summaries in a work of fiction.

### 6.5.3 Sample C - Plot summary

Participants were invited to compare Samples B and C, and the response was quite definite. A plot summary positioned opposite the start of a new chapter was felt to be the more useful. Participant 2 referred back to the role of summaries in text books:

*They do it all the time, summaries, don't they, and they do it for a reason ... to keep the students understanding or knowing what it is that they are reading, or whether they've read that without having to read the whole chapter again. (Participant 2)*

Participant 1 commented:

*I think you're on to a damn good idea with this. ... What you might call sane people would find this a useful adjunct to a book. (Participant 1)*

Participant 1 suggested that the summary might be even more use if were placed just above the chapter number and title. When asked if readers would find such an arrangement confusing, participants said that it would not be a problem if the text was in a box; a tinted background was not thought to be necessary. Also, participants agreed that the heading ("The story so far") would make the function explicit. They did not find the wording of the heading patronising.

To make the point more clearly, Participant 1 folded up a sheet of Sample C to demonstrate the effect of positioning the plot summary above the chapter title.

*I think, if it was in a box here and all this was further down, people would quickly get the knack of it and think, well I'm not thick enough to need that, I'll go straight into the story, and other people would think, Oh, that's handy, I*

*will remind myself ... and I think this is the place for it ... and in a box.*  
(Participant 1)

Opinions differed about this approach, with one participant expressing a preference for Sample C as it stood, although there was agreement that this would not be the most economical approach. Consistency in the treatment of chapter openings was recommended.

There was a brief discussion about the typeface and the layout of Sample C.

*... this is acceptable and there's enough lined space in between ... Yes, the font is nice, I quite like a classic font but that's just my preference.* (Participant 2)

The same participant expressed a liking for the part of the text set in Frutiger, but the idea of setting the whole of the text in this typeface was not pursued.<sup>21</sup> Participant 3 confirmed that the type used for the three samples was legible.

#### **6.5.4 Ribbon markers and bookmarks**

General approval was expressed for the provision of a ribbon marker with diaries and hardback novels. One participant asked if it would be 'against copyright' for libraries to insert markers into books in their collection. Paper bookmarks were also liked and no preference for either placeholder was expressed, with one participant commenting:

*Both, because I think, how nice to receive a bookmark ... Yes, bookmarks are good.* (Participant 2)

Various suggestions for improving the design of bookmarks were also made.

These included:

- folding over the top of a paper bookmark so that it would not slide out of the book

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<sup>21</sup> Sans serif type is rarely used for published fiction. John Mullan draws the reader's attention to 'a technical peculiarity of which they might not be conscious' in discussing Mark Haddon's *The Curious Incident of the Dog in the Night-Time*. He notes that the text is set throughout in a sans serif typeface in an effort to reflect the thoughts of the narrator, who has Asperger's syndrome (Mullan 2006, p. 217).

- making the bookmark wider, perhaps up to 7–8cm wide
- supplying a blank bookmark on which readers could write notes about the text
- printing a list of characters on the bookmark and selling it separately
- printing the list of characters on the outer edge of the front flap of a book jacket so that it could be cut off and used as a bookmark.

### 6.5.5 Participant responses to further questions

As there was enough time remaining, four further questions were asked about reading books with a memory impairment.

The first question concerned participants' ability to visualise the setting or the action of a novel. Two of the participants, who had declared themselves to be life-long readers, commented:

*When I read a book, I don't see pages of print, I see pictures in my head.*  
(Participant 1)

*I think that's brilliant, isn't it? Because you just see it.* (Participant 2)

*At first, I'm reading the words and if the book's not very good, I think, this is not very good and chuck it away, and if it's a decent book, I stop seeing the words and start seeing the pictures ... and it's going on around me.*  
(Participant 1)

The second question asked whether participants felt that the addition of informative illustrations would be helpful. One informant replied that she had experienced some difficulty in visualising the setting of a story and that a simple black and white drawing would have helped. When asked if she would also like illustrations of characters, she replied with some certainty:

*I wouldn't want a character ... but a scene, just a very, very outline drawing of a house.* (Participant 1)

The third question concerned the quality of paper used for novels and was elaborated upon when one of the informants produced a paperback that she had

bought online. The paper was bleached and coarse and the ink had spread, making the text difficult to read. The benefits of a cream paper were noted, and the designer's original cream-coloured print outs were compared to the similar paper of the sample novels. The glare of white paper was considered unhelpful to the reader.

The fourth and final question concerned the addition of a sticker to a book jacket to indicate the book's suitability for readers with a memory impairment. Participants had no objection to this and did not appear to find the presence of a sticker patronising; rather they felt that it would help them to locate the book in the library or bookshop.

## 6.6 Conclusion

A number of conclusions may be drawn from the discussion of the test material with the DEEP members. These would include the following.

- A proportion of individuals with a diagnosis of dementia, including Alzheimer's disease, are still able to engage with works of fiction.
- The inclusion of a List of Characters in the early part of a novel might be helpful to readers who have a memory impairment.
- A summary of a chapter is less likely to be useful to a reader with a memory impairment than a plot summary placed at the start of a new chapter.
- A placeholder in the form of a ribbon marker or a bookmark might be particularly useful to readers who have a memory impairment.
- A bookmark might be further developed to enhance its use as an aide-mémoire.
- Bright colours and a wider than usual ribbon might be advantageous.

The four further questions asked following the user-testing also provided corroborative evidence for the findings of the previous study. Two aspects in particular were of note.

- Some individuals who have dementia appear to retain the ability to visualise the content of a text.
- Readers with dementia might find it helpful if those aspects of a story which are difficult to describe in words were presented in the form of an illustration.

The findings of this study suggested that further investigation would be both possible and productive. The DEEP group expressed a willingness to contribute to future studies and were clearly well placed to offer expert opinions. This is consistent with an observation about user-testing made by Jones: ‘There is little doubt that major weaknesses in design go uncorrected because no effort has been made to find out what users know but have no reason to pass on to other people’ (Jones 1992, p. 220).

## **6.7 Issues arising from the study**

The exploratory nature of the study meant that findings were not limited to the answers given by participants to specific questions. Insights were also gained into aspects of the research design, the research materials, and the participant experience of text visualisation. The contribution made by each of these three aspects is summarised below.

### **6.7.1 Research design**

The advantages and drawbacks of involving pre-existing groups of informants in user-testing are clearly spelled out in the DEEP guides (DEEP 2013b; DEEP 2013c). Attention is drawn to the position of the researcher as a guest rather than a leader at a meeting and also to the need to allow the convenor to control the agenda. The purpose of the present study was to collect the views of the participants directly and this was certainly allowed. However, the issue of gatekeepers in the context of

dementia research is frequently raised in the literature (Brooks, Savitch and Gridley 2017) and the role of the researcher is increasingly coming under scrutiny. The recommendations made by Leavy for ethical group-based research were certainly relevant in the DEEP context: ‘the researcher is not the authoritative voice; avoids “drive-by” scholarship; avoids voyeurism of disenfranchised communities; and works sensitively with vulnerable populations’ (Leavy 2017, p. 249). Care had to be taken to respect the capabilities of participants.<sup>22</sup>

Each of the participants at the DEEP meeting volunteered relevant and at times unexpected information. Participants were articulate and creative. Indeed, what began as a user-centred study began to develop into a participatory study as ideas about text layout and the use of bookmarks were generated by the group. There was no lack of involvement, and perhaps the rather negative experience of Hendriks et al. (2014) may be explained by the later-stage impairment of the participants. The value of co-research in combining academic findings with the real-world experience of those affected by dementia has been suggested by Rivett (2017).

### **6.7.2 Research materials**

There was no unanimous view on the positioning of the plot summary (Sample C), and a suggestion was made that it could be positioned above the chapter title. After the meeting, a rough layout was prepared to explore this option (see Fig. 16, following page). A properly designed version would need to be discussed with participants at a future date.

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<sup>22</sup> One individual justifiably objected to putting his signature on the second page of a consent form.

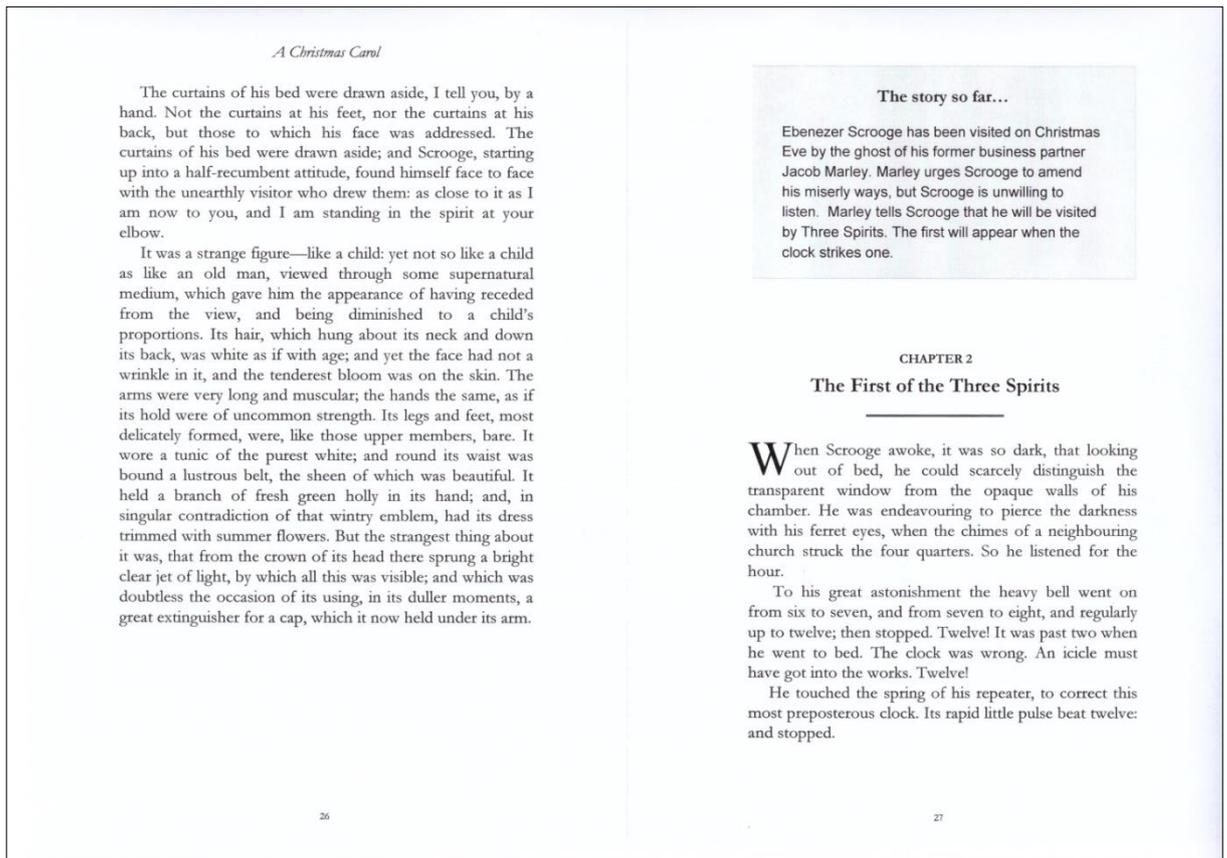


Fig. 16 Improvised alternative layout for Sample C. The text has been prepared in Word and is intended to give a visual impression of the relative position of the various components.

The advantage of this solution is that there would be no discontinuity between one chapter and the next, whereas starting a new chapter on a new spread would remove the preceding text from view. As noted above, the literature suggests that lived experience is parsed continuously and is broken down into episodes before being stored in memory (Zacks and Speer 2006). Making the episodes separate but linking them visually might help to support an impaired memory.

A further suggestion for supporting memory involved reconsidering the design of the jacket flaps of a book. If text (for example, a list of characters) were to be printed on the outer edge of the flap, it might be made detachable by perforating the join. An email exchange with a production manager confirmed that the cover of a paperback book might be printed with wide flaps to allow a detachable strip

to be incorporated.<sup>23</sup> The suggestion of using the jacket flaps or the cover itself as a memory aid was eventually carried forward to the final study (pp. 171ff.).

### **6.7.3 Participant experience of text visualisation**

The preserved ability in some participants to picture objects and events ‘in the mind’s eye’ has important implications for accessible publishing. Alzheimer’s disease in its early stages may not affect areas of the brain involved in visualisation,<sup>24</sup> and carefully targeted user-centred research might indicate which sorts of writing would be most stimulating to a reader who has dementia. Writers could then be briefed to construct texts that would capitalise on this important reading skill. This possibility will be returned to in the Discussion section of this thesis (p. 214).

However, in testing the reader’s response, it should be acknowledged that the ability to visualise is not universal and that some individuals may be described as having ‘aphantasia’ (Zeman 2016). This characteristic seems to be quite independent of any form of dementia and may be described as a natural variant.

Creative thinking may also be a problem for readers who have Alzheimer’s disease. Research suggests that damage to the hippocampus, whether through infection or accident, can result in a diminished capacity for creativity (Duff 2013). Writers of accessible texts might therefore need to focus on vivid description rather than suggestion or inference.

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<sup>23</sup> Email of 17.10.2017.

<sup>24</sup> Email exchange with Professor Adam Zeman (5.02.2018).

## **7 Book Cover Study: testing material enhancements of the book**

### **7.1 Introduction**

The Participant Interview Study and the Textual Additions Study were devised to investigate ways of supporting the reader's memory by making adjustments to the design of a book. The list of characters was felt by participants to be a useful addition to a story and providing a plot summary at the start of a chapter was considered a practical way of helping the reader to locate their place in the narrative after a break. The use of a bookmark as a placeholder also met with approval.

Discussions with individuals working in publishing suggested that it would be worth exploring ways of using the properties of the physical book as a memory aid. The cover in particular might offer possibilities beyond its usual function as a form of protection and a marketing tool for the book. Participants in the Field Study had commented on the practical usefulness of the bound book and had also mentioned the pleasure they derived from ownership (p. 108 and Appendix II). The guidelines produced by DEEP (2013a, 2013c) refer to the functionality of printed materials and the need to tailor them to the requirements of readers who have dementia. It is likely that the way a book handles and the relationship of all the parts to the whole would have to be considered in even more detail than they would for the more typical reader (Mangen and Schilhab 2012). Certainly, the affordances of the printed book may be advantageous to this particular section of the reading public.

With this in mind, a fourth study was set up to experiment with ways of using the cover of a book to support the reader's memory. By using a mock-up of a cover, it would be possible to judge the effect of the different components when it was held in the hand. The Reading DEEP group again agreed to include a user-testing session in one of their monthly meetings.

The design of the materials was exploratory in nature, which meant that it would not be possible to refer the designer to an existing precedent as a model to follow. A preliminary mock-up was therefore made to test the feasibility of the concept before involving a professional designer. A Penguin paperback edition of F. Scott Fitzgerald's *The Great Gatsby* (1975) was used as a base. This volume was chosen as it offered a familiar format, a relatively short text, a limited number of characters and a straightforward storyline. Using the simplest of materials, practical approaches to supporting the reader's memory were devised. These included a bookmark showing a printed list of characters; a bookmark with a printed list of characters attached to a ribbon marker; and a list of characters printed on the front flap of a book cover. These very basic materials were used to convey to the designer the sort of interventions that the study might explore.

## **7.2 Aim of the study**

The aim of this study was to investigate the preferences of readers who had early-stage dementia. A user-testing approach was employed to gauge participants' views on additions to the text on a book cover and on the use of explanatory selling copy.

## **7.3 Method**

The design brief and the preparation of the test materials required particular attention for this study. These are therefore discussed first and information about the participants and the procedure adopted for the user-testing then follows. The study received ethical approval from the University of Reading Research Ethics Committee.

The preliminary mock-up described above formed the basis for a discussion with a professional designer. An initial briefing meeting was held with the designer, and a reminder was given of the particular nature of the memory impairment associated with Alzheimer's disease. It was also emphasised that participants actually handling the cover and the bookmark would be an important part of the testing. It was therefore decided to prepare a book cover for a paperback edition rather than a book jacket for a hardback edition which might tear more easily.

The designer prepared a number of samples each providing a printed list of characters. However, the allotted time for discussion at the DEEP meeting was short (30 minutes maximum), so it was decided to focus on two alternative ways of offering a list of characters, namely as a bookmark attached to a ribbon marker (Sample 1) or as a printed list on the front flap of the cover (Sample 2).

### **7.3.1 Materials**

The materials used for the user-testing session consisted of two book covers (Sample 1 and Sample 2), two stickers for the front of the cover, and two versions of a notional series title 'Read + Remember'. There was no reference to dementia on any of the sample materials.

**Book cover:** the base for the sample material was Robert Louis Stevenson's *Treasure Island* (1883/1999). It was felt that participants would be aware of the novel, even if they had not read it, and would know that it was an adventure story that was considered to be of literary merit. The limited list of characters and the carefully constructed plot lent themselves to summary without undue distortion. The text was out of copyright and was available on Project Gutenberg (Stevenson 1883). The sample cover was made of heavy card and was robust enough to withstand handling by the participants.

Sample 1 was a bookmark that was attached to the spine of the book by a red ribbon marker. The words BOOKMARK and CHARACTER LIST were added to make the information explicit. The reverse of the bookmark carried a chapter-by-chapter plot summary.

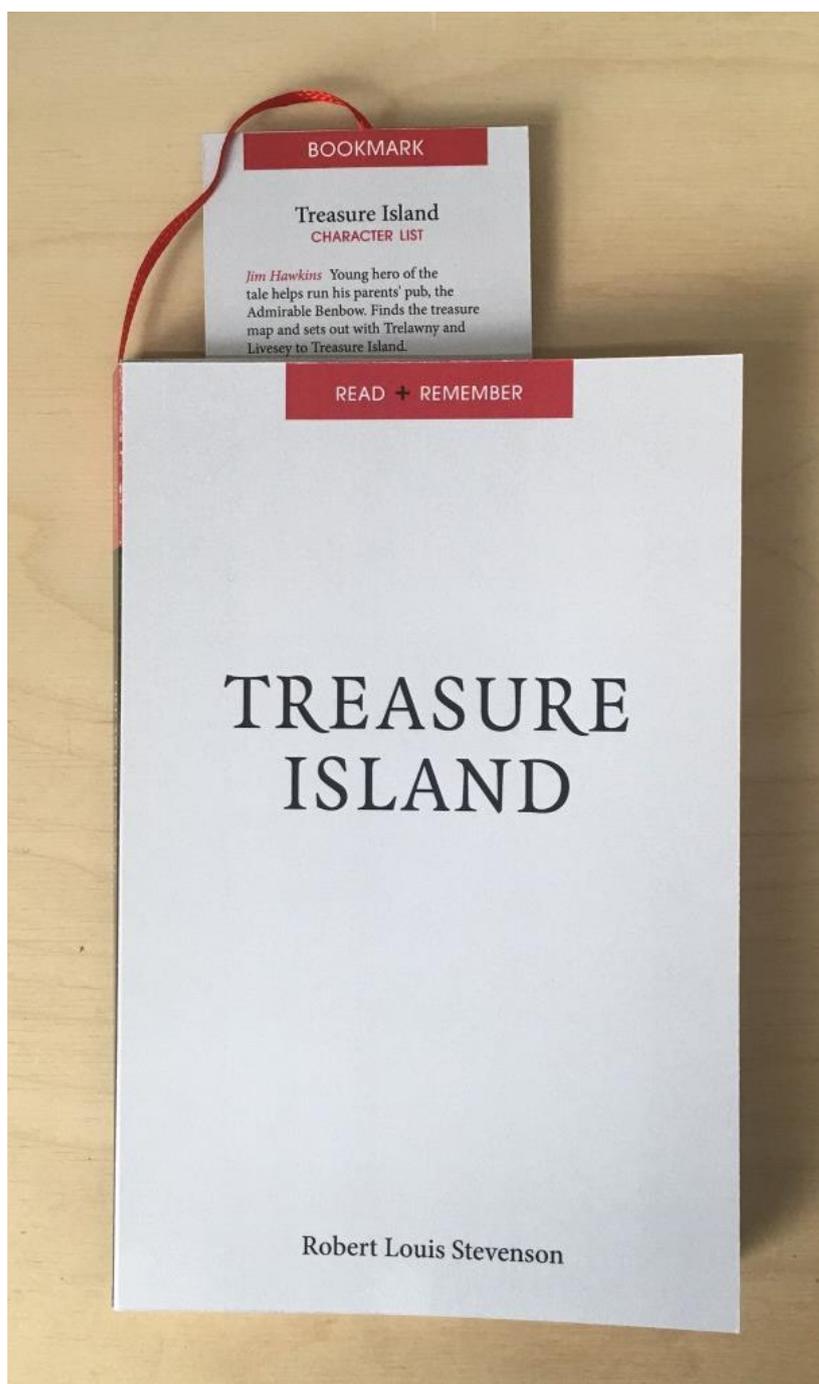


Fig. 17 **Sample 1** Bookmark attached by a ribbon and providing a list of characters .

Sample 2 (Fig. 18) was a book cover with wide flaps front and back. The front flap featured a detachable bookmark with a list of characters (face) and a plot summary (reverse). Written instructions for cutting were provided on the front flap, with a scissor motif offering deliberate redundancy. The total width of the bookmark was 72mm. The width of the remaining blank strip was 45mm, which was enough to allow it to be folded flat into the cover when the bookmark had been removed. The back flap was the same width to reduce production costs.

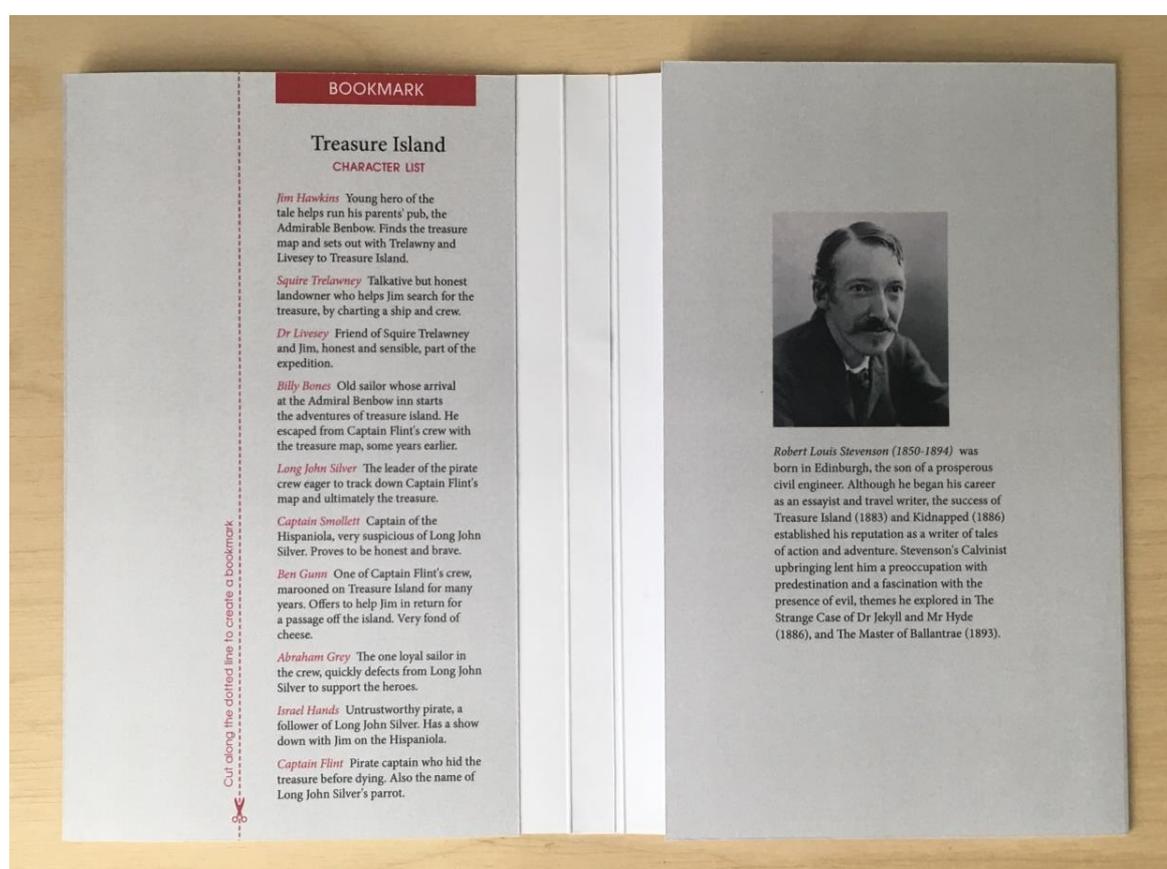


Fig. 18 **Sample 2** Bookmark provided as a detachable strip printed on the front flap.

The design for the covers for both samples (Fig. 19) was consistent in page size (198 x 129mm) and in choice of typeface so that the differing features would be immediately apparent. In each case, a serif typeface (Minion) was used for text and a contrasting sans serif typeface (Avant Garde Gothic) was used for explanatory copy. The sharp contrast between the white board and the red and black tints was

intended to enhance the visibility of the type but also to give the books a clean, sophisticated feel.

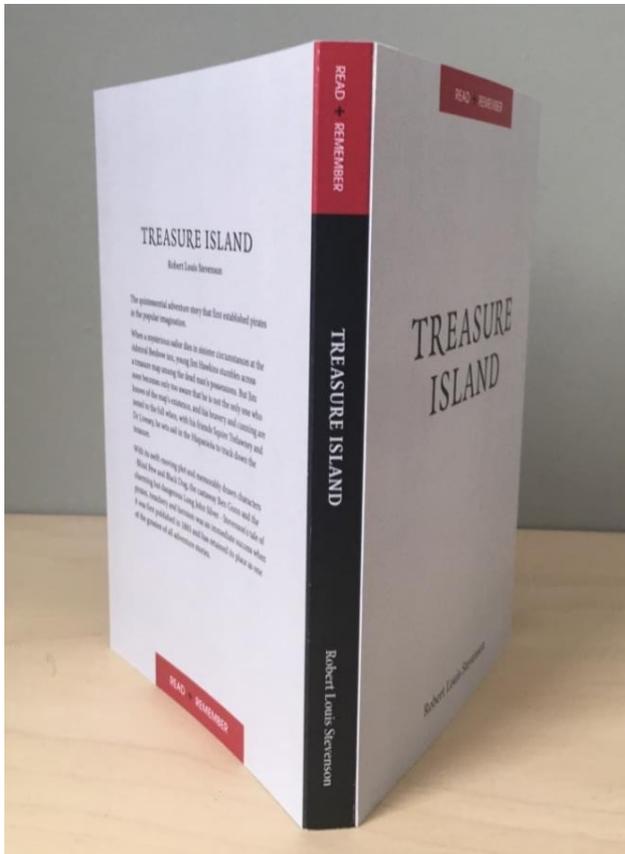


Fig. 19 **Samples 1 and 2** For each sample, the title of the book was set in Quadraat Regular black and the author and blurb were set in Minion Pro medium black.

The series title READ + REMEMBER was set in ITC Avant Garde Gothic medium.

In the course of development, minor modifications were made to remove possible obstacles to fluent reading. The designer was asked to change the setting of the cover copy so that it was unjustified at right. This was to avoid hyphenation and to allow for the adjustment of line breaks. The use of unjustified setting is supported by the literature, which suggests that line endings can affect the accuracy of young readers (Raban 1985). Since the difficulty experienced by such

readers may involve the return sweep to the beginning of the following line, the researcher felt that this simple modification might also be advantageous to other readers. The synopsis of the story on the back panel was sub-divided into three paragraphs in order to clarify the structure of the content; this accords with recommendations made by Hartley (2004) for the use of white space in instructional text.

**Sticker:** the design of the removable sticker for the front of the cover featured an eye-catching image that would attract the attention of the potential buyer. Medical imagery was avoided as being inappropriate in the context of reading for pleasure.

Two contrasting stickers were presented for testing. The first showed an open book with asterisks (representing brain synapses) emanating from the lines of text. The second showed an elephant reading a book, a reference to the adage ‘An elephant never forgets’ (Fig. 20).



Fig. 20 Alternative designs for a publicity sticker, with (left) a book motif and (right) an elephant motif. The information beneath the motif does not refer to dementia.

Above the image, a series title READ + REMEMBER was included in both designs. The words aimed to be explanatory but neutral, and the use of alliteration was intended to make the title memorable. The designer opted to use a plus sign to link the two words on the grounds that it was unambiguous and would align neatly with

the height of the capital letters. An alternative version using an ampersand (READ & REMEMBER) was printed on separate slips of paper for distribution to participants.

Under the image are printed the words ‘Memory-supporting features to aid recall’. This was a change from the designer’s original wording of ‘Memory-friendly features’, and the alteration was made to avoid the slightly patronising tone that has been referred to by individuals with dementia writing about their own experience (e.g. Swaffer 2014). Each sticker was 50mm in diameter and a sans serif typeface was used for clarity. Photocopies were made for distribution to participants.

### **7.3.2 Participants**

Participants were members of the Reading branch of the Dementia Engagement and Empowerment Project (DEEP) group, which had hosted earlier discussions. The user-testing session formed part of one of the group’s monthly meetings. Six DEEP members (3 male, 3 female) attended the meeting, but the views of only four of the members have been drawn on for the study.<sup>25</sup> The DEEP organiser and two representatives of the Alzheimer’s Society were also present.

### **7.3.3 Procedure**

The aims of the research project were briefly introduced, and the conclusions of the previous DEEP discussions summarised. The book cover with the ribbon marker, the book cover with the printed list on the front flap, the two stickers, and the typed slips with alternative versions of the series title were then passed around and questions were asked about each item in turn. The questions were brief and simple. They were:

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<sup>25</sup> Two DEEP members, a husband and wife, were unavoidably late and did not sign consent forms. This did not affect the outcome of the study as only the preferences of individuals with dementia were being noted. The unaffected partner expressed strong (though unexceptionable) views on books and reading; the other remained silent.

- i. Which of the two sorts of bookmark do you prefer?
- ii. Why do you prefer that sort of bookmark?
- iii. Which of the two stickers do you prefer?
- iv. Why do you prefer that sticker?
- v. Which version of the series title do you prefer?
- vi. Why do you prefer that version?

Time was allowed for participants to consider their answers and to expand on them if they so wished. Both the presentation and the discussion were audio-recorded, and a partial transcript is included in Appendix IX (p. 325ff.).

## 7.4 Results

The reactions of the meeting were generally positive. There was a diffuse but perceptible interest in the idea that adjustments might be made to printed books to make them more accessible. The summary that follows presents the specific observations made by participants on the two approaches to a bookmark, the two images on the stickers, and the alternative ways of presenting the series title.

### 7.4.1 Bookmark attached by a ribbon and bookmark printed on the front flap

Question (i) Which of the two sorts of bookmark do you prefer?

Question (ii) Why do you prefer that sort of bookmark?

Participants agreed on the usefulness of bookmarks and shared their experiences of improvising placeholders while reading a text. One participant commented that she regularly lost her place when reading a story:

*Yes, I do read quite a lot. ... [If I lose my place] it doesn't bother me, I'm quite happy to, to even go back to the beginning and start again if I want to.*  
(Participant 1)

The suggestion of cutting a strip off the front flap to make a free-standing bookmark was regarded as an interesting option but not necessarily an obvious benefit. There was a general preference for the list just to be printed on the front flap. It was felt that having the list here would mean that it was secure and readily accessible. The size of type used for the list was generally regarded as acceptable.

A plot summary appeared on the reverse of the bookmark and on the reverse of the front flap. This feature was not referred to in the questions asked during the session. Only the alternative ways of presenting the same information were being tested not the different possibilities for content. One participant, however, commented:

*I was thinking, basically, you've got the character list, which is quite useful, and a plot summary and I think that's useful because if they've lost their place they can look at the plot summary and find out where they start again.*  
(Participant 3)

When asked if the reader would think to consult the plot summary, the participant continued:

*Well, I think if you've got something only this big you'd search it ... if it was a huge tome ... I would say if it was something this small ... you'd remember ...*  
(Participant 3)

#### **7.4.2 Sticker**

Question (iii) Which of the two stickers do you prefer?

Question (iv) Why do you prefer that sticker?

The participants were first asked for their views on the two motifs. The elephant motif was liked by both male and female participants. Participant 3 described it as 'rather sweet' and Participant 4 commented:

*... it's very nice, it's like a little toy ... he is showing me that if he can read, I can read, thank you very much ...*

When asked if the elephant motif might be considered rather patronising, one participant noted:

*I don't, certainly, no, I don't know about everybody else ...* (Participant 1).

Question (v) Which version of the series title do you prefer?

Question (vi) Why do you prefer that version?

On being asked to consider the wording on the sticker, one participant observed:

*If I look at the READ + REMEMBER, the picture with the book and two stars above, it looks like something very holy ... the church ... it's like for little children, you see the light and you just go the way ... but I like the word memory-supporting.* (Participant 4).

The difference between the plus sign and the ampersand in the series title was fully appreciated. Participant 3 commented, 'I prefer the ampersand myself ...' and, referring to their neighbours, 'the ampersand has it over here'. When asked for an opinion, Participant 1 replied, 'I think they're all nice, I couldn't choose one, I don't think.'

Participants were also asked if they would prefer selling copy to appear on a sticker or on the cover itself. There was a strongly held opinion that copy could appear on the cover. When asked if it caused concern for the words to be seen, one participant noted:

*No, it doesn't. ... I wouldn't be too much worried about it ... [Nobody comments if] a blind man's going along with a white stick ...* (Participant 3)

This point was taken up by another participant:

*... it's my choice, because Treasure Island I know it's a story and I want to know about this story ... I don't mind ...* (Participant 4)

## 7.5 Discussion

Although the study was small in scale, the participants provided helpful opinions on possible design modifications. Also, and perhaps rather more significantly, the participants expressed views that in some cases challenged pre-existing ideas about what appropriate design solutions might be.

### 7.5.1 Bookmark attached by a ribbon or printed on the front flap

The pleasure of owning bookmarks had been commented on during a previous study (p. 164), so providing a freestanding bookmark as an option would not have been controversial. There is also a precedent for publishers using bookmarks to add value in the case of Persephone Books (p. 196) or, explicitly, Macmillan gift books (p. 146).

The discussion about the merits of the ribbon marker and the cut-off bookmark served as a reminder that ingenious, design-led ideas may not be as useful as more straightforward solutions. If more time had been allocated at the meeting, it might have been helpful to include a further two samples prepared by the designer. However, the suggested solutions to the problem of supporting the reader's memory might have proved too numerous and too subtle for participants to grasp in the time-pressured context of a group meeting. The advantages offered by the two further samples (Sample 3 and Sample 4) are outlined below.

Sample 3 (Fig. 21) provides a simple, non-detachable list of characters on the front flap. The cover in this case extends beyond the book block and is double creased to allow the front flap to tuck into the pages and act as a placeholder. The extra width of the flap has a red tint and reversed out lettering.

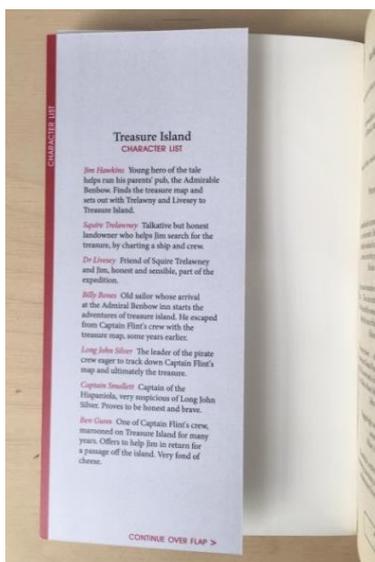


Fig. 21 Sample 3 Not shown to participants.

It is likely that Sample 3 would have been favoured by the participants as it is a simplified version of Sample 2. Further user-testing would also be needed to explore whether readers would prefer to have the list of characters within the prelims (as suggested in the Textual Additions Study (p. 162)) or printed on the front flap. A third option would be to give the list in both places. Redundancy may serve a useful purpose in the context of accessible publishing.

Sample 4 was a further development proposed by the designer. This version is identical to Sample 3 but offers a plot summary on the face and the reverse of the back flap (Fig. 22).

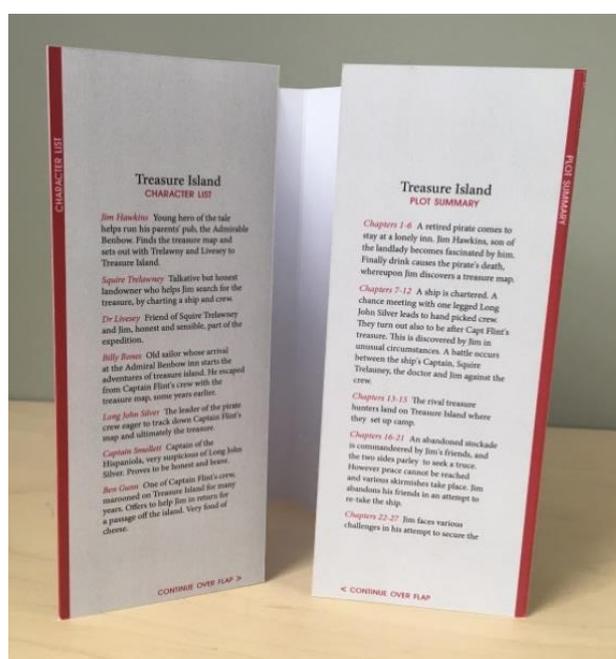


Fig. 22 **Sample 4** Not shown to participants.

Further user-testing might indicate whether readers might prefer a plot summary to be included at the start of every new chapter (see previous study, p. 163) or whether a full chapter breakdown on the back flap would be more helpful. The latter option would, of course, risk spoiling the reader's pleasure by giving away the plot.

### 7.5.2 Publicity sticker

The removable sticker was proposed as a way of indicating the special nature of the book to the purchaser. In many cases the reader and the purchaser would not be the same person and it would be helpful to know the views of each on the presence of advertising copy on the cover. It was interesting to note one participant's approval of the phrase 'memory-supporting' on the sticker.

The same participant commented on the rather liturgical feel of the book icon. This was something the designer had been aware of and had led to the rejection of images showing a book with a bookmark (Fig. 23). The use of a brain motif, which is common in visual material related to dementia, was also rejected as being too clinical in this context.

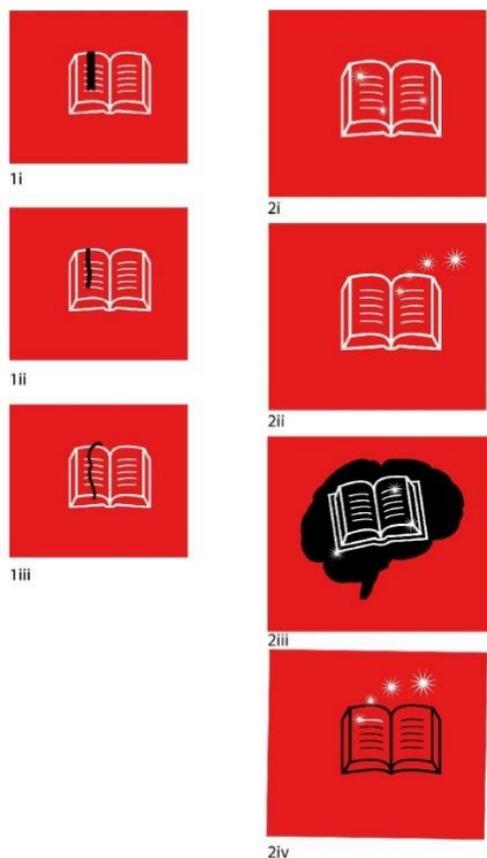


Fig. 23 Alternative suggestions made by the designer for the sticker motif.

Participants were encouraged to offer opinions as ideas occurred to them and sometimes this approach resulted in more general insights. For example, when asked if having selling copy on the back of the cover would bother readers, Participant 1 commented, 'it only bothers me when I've lost the thing ... that would be very difficult to lose, wouldn't it, because it's a nice size.' The participants passed the sample covers around and examined them with care. Such an observation might therefore be useful as it may indicate the value of a familiar format. The important question of the size and shape of books would need further investigation.

### **7.5.3 Participants**

The views of the DEEP members on advertising copy were instructive and showed a markedly 'dementia confident' approach. This was to be expected given the Project's stated aim of empowering its members and it is not possible to generalise from these opinions when gauging attitudes to publicity material. There was at times a discrepancy between the confidence expressed by the participants and the caution of the staff members who were present. The views of carers and members of staff were not included in the user-testing at the meeting.

The brevity of the discussion meant that the opinions of quieter participants could not be sought. This emphasised the value of the more relaxed, one-to-one approach taken for the Participant Interview Study. Both user-testing methods offered benefits. In each case, though, the effects of dementia on language were apparent and the opinions of participants had to be carefully drawn out. Gesture and tone of voice were used by participants to convey meaning and participants could not be expected to reply in clear, fully formed sentences.

## 7.6 Conclusion

A number of conclusions may be drawn from this small user-testing study. As regards the sample materials, there was a consensus that modifications to the presentation of the printed book could be helpful to the reader living with dementia. Providing a list of characters on the front flap of a book cover was considered to be a useful support to memory. Further testing would be needed to find out whether printing a chapter-by-chapter summary on the back flap would be similarly advantageous.

With regard to the publicity sticker, a simple, eye-catching motif met with approval and participants did not feel patronised by the light-hearted approach taken by the elephant drawing. The participants did not feel that the sticker needed to be removable to avoid embarrassment. Participants also expressed a preference for the use of an ampersand in the series title rather than a plus sign.

Two further conclusions concerning the methods adopted for the study may also be noted. The first is that producing accessible texts requires particularly close collaboration. When the needs of readers are very specific, and there is no style guide to follow,<sup>26</sup> extensive discussion is necessary at each stage to ensure that the design brief is clear and that it has been interpreted appropriately. Regular communication is needed to give the designer a free hand in making imaginative suggestions but also to ensure that any decisions made are monitored and amended as necessary. The second is that extra time needs to be allowed for user-testing sessions that involve groups of participants who have a cognitive impairment. A calm, unhurried approach is vital to allow the participants to respond fully to sample material.

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<sup>26</sup> The typography and layout of Quick Reads books follows an established style guide. According to the editor, 'that side of it is covered by a document giving guidelines to authors and their editor at their regular publisher.' Email of 4.09.2017 quoted in full in Appendix XI.

## **Concluding observations on the research studies**

The results of the four studies presented above reflect the views of a wide range of individuals. A clear consensus was not reached on every point, but a number of definite conclusions could be drawn, and ideas were forthcoming about the direction that future research might take.

In the Consultation and Discussion sections that follow a number of the issues raised by the studies are examined in more detail, with particular consideration being given to the specific challenge posed to designers by a memory impairment. These two sections are followed by the Conclusion to the thesis, which provides a summary of the recommendations for the presentation of books for readers who have early-stage Alzheimer's and offers suggestions for research topics that would merit further investigation.

## **8 Consultation with book-making professionals**

### **8.1 Introduction**

The sample layouts used in the studies described above were all commissioned from practising designers. In each case, the brief for the designer brought together information gathered from a number of different sources. It drew on findings from the formal and informal meetings with individuals who had dementia that are described in the Field Study. It was informed by personal experience of preparing texts for illustrated reference books and by discussions with publishers with non-fiction titles on their lists. It drew on examples of printed books prepared for specific markets: these included editions of classic works of fiction, stories written for adult readers with low literacy levels (Quick Reads), illustrated texts for readers whose first language is not English (Oxford Bookworms), and books especially designed for readers with dyslexia (Barrington Stoke).

### **8.2 Aim of the study**

The aim of this part of the research was to explore the practical issues that commissioning texts for non-typical readers might raise. Accessible publishing requires a successful collaboration between potential readers, editors, designers and, where necessary, book illustrators. An invitation was therefore extended to three professional designers and a practising book illustrator to comment on the text layouts that had been discussed with study participants. It was also hoped that further ideas might emerge about ways to approach the problems posed by this unusual brief.

## 8.3 Method

A relatively informal method was chosen, and the study followed a standard approach to gathering information from participants who are expert in their field.

### 8.3.1 Participants

Three designers volunteered to take part in the study. All three were graduates of the Department of Typography & Graphic Communication at the University of Reading and all had attended seminars during which the research studies had been presented. Each volunteer had a different career experience, and their views are presented anonymously but separately. The first (Designer A) had worked in theatre design and exhibition design before turning to graphic design; the second (Designer B) had ongoing experience of working on printed books and also taught on the Department's book design course; the third (Designer C) had extensive design experience and had already contributed a substantial chapter to a published text on methods of book design. While none of the designers had direct experience of working with individuals with dementia, all three were skilled in analysing design problems and generating solutions. Designers A and B did not have experience of commissioning illustrations, though Designer B had commissioned photography. Designer C had worked with publishers on a wide range of illustrative material and had commissioning experience.

A practising book illustrator, Kate Baylay, was identified through professional contacts. The illustrator had studied at the University of the West of England and had a degree in illustration. She also had recent experience of working on commissions from recognised trade publishers.

### 8.3.2 Materials

The sample layouts used for the Participant Interview Study and for the Textual Additions Study were shown to the designers. The book illustrator was sent an image of the first layout, Sample A, used for the interview study. This sample was based on the OUP Bookworms edition of Buchan's *The Thirty-Nine Steps* and

showed the black-and-white line drawing located in the text. A brief explanation of the aims of the Bookworms series was also supplied.

### **8.3.3 Procedure**

A list of six questions was sent in advance to each of the three designers. The questions were general in nature and were intended to broaden the discussion when the sample layouts had been examined. The designers' thoughts on the book as a material object were to be particularly sought. The questions were:

- i. What might be the difference between designing a typical book and a book for readers with memory issues?
- ii. What additional features could be added to make a text easy to navigate?
- iii. How might the designer avoid making a text look childish?
- iv. How might explanatory illustrations be worked into a work of fiction?
- v. What physical aspects of the bound book would need special consideration?
- vi. Given the overriding need for clarity, would the designer object to working to a brief that was quite constrained?

The interviews with the designers were audio recorded. The joint interview with Designers A and B took place on the campus of Reading University and the interview with Designer C was held at the British Library.

The book illustrator was sent a different list of six questions. The questions were informal and were intended to draw out information that would be helpful to a commissioning editor. Since book designers are trained to handle existing images, the six questions were intended to investigate the thought processes of an illustrator when presented with a publisher's brief for new illustrations. The questions were:

- i. Do you always visualise stories as you read?

- ii. Have you ever worked on a commission where your illustrations had to be life-like? Would you find such a commission unappealing?
- iii. Would you feel very limited if you had to produce only black-and-white illustrations?
- iv. Would you draw differently for an adult readership as opposed to a children's readership?
- v. What is the key information you need from a publisher in order to produce artwork that is appropriate?
- vi. How does it feel to work under pressure? Does this make your brain freeze? Does it affect your imagination?

The sixth question was intended to probe the issue of artistic imagination. A book illustrator works to a brief and has to be able to produce sketches and finished drawings to order. This is rather different from a commission for an artist, which may not impose a time constraint, and which might well allow for complete creative freedom.

The illustrator replied to the questions by email and sent a follow-up email containing further thoughts on the issues raised (see Appendix X, p. 328ff.).

## **8.4 Results**

The comments of the designers and of the book illustrator are summarised separately below.

### **8.4.1 Designers' views on the Participant Interview Study materials**

The observations made by the designers are grouped according to typographical feature.

**Chapter headings:** Designer A noted that the chapters in the *Thirty-Nine Steps* sample layout (Sample A) were run on. The designer also commented that this would have the effect of reducing the extent of the book and perhaps making it seem more manageable for the reader whereas the current practice in producing trade

editions of works of fiction would be to bulk out the text, thus justifying the book's selling-price.

**Text:** Designers A and B noted that the literary nature of the text had been respected in the choice of a serified typeface. Designer C commented that the literature on designing for impairment, whether visual, sensory or cognitive, often recommended using a sans serif typeface set in 14 point and did not distinguish between information seeking and immersive reading. Also, the different appearing sizes of individual typefaces seemed also to be overlooked in this literature (e.g. DEEP 2013a).

The use of drop capital letters was commented on by Designer C, who pointed out their usefulness as a convention to signal the start of a new chapter. This convention could be particularly advantageous if the chapter summary were to be placed beneath the chapter heading and before the start of the text. An alternative would be to have the initial capital letter resting on the baseline, as used in the *Doll's House* sample layout. In each case the letter spacing would have to be very carefully considered.

**Running headings:** Designer C pointed out that although a chapter number and a chapter title might not always be necessary, their use might be an example of a helpful redundancy. They might also be considered as an advance organiser. The designer would have to alert the editor to the maximum length of each running head to ensure that they were copyedited to fit.

**Illustrations:** the line drawing used in Sample A (John Buchan, *The Thirty-Nine Steps*) raised several issues. Particularly significant observations were as follows.

- There was general agreement that the illustrator would need to be briefed on the function of an illustration as well as on its eventual size and position. The colour and finish of the paper would also have to be taken in to account to

ensure maximum clarity of the printed illustration. As with any book, budget constraints would be a factor in determining the final number of illustrations and the quality of the paper.

- Designer A felt that illustrations might help with navigation when reading a text. Eye-catching icons might be used to signal the start of a new chapter, although care would have to be taken not to clutter the page. Designer B noted the importance of white space in guiding the reader's attention through a complex layout.
- Designer B observed that commissioned illustrations intended to clarify particular scenes in the text might become intrusive and might interfere with the direct relationship of the author and the reader.
- Designer A suggested that illustrations might be used to round off each chapter and provide a visual reinforcement of the text summary. Designer C was not in favour of this option. There might be some ambiguity as to whether the illustration referred back to the previous chapter or looked forward to the new one.
- Designer C noted the importance of the text and the illustration working together and the necessity for an illustration to be positioned at its point of reference.
- Designer C spoke of the need to avoid a simplistic style of illustration and noted the aim of giving the cognitively impaired individual the 'same rich and complex experience' as other readers. A detailed picture with a number of hooks (i.e. visual references) to the text might help to capture the reader's attention.
- Designer B referred to Sample C, which included dialogue (LaPlante, *The Little One*), and suggested including illustrations of the characters in the text. However, Designers A and B also agreed that readers might prefer to imagine the characters themselves.
- Designer A mentioned using illustrations as a prompt to reminiscence, together with the possibility of adapting the style of drawings to the period depicted – i.e. 1950s, 1960s, etc.

### 8.4.2 Designers' views on the Textual Additions material

The observations made by the designers are again grouped according to typographical feature.

**List of characters:** Designers A and B felt that the list was too functional in appearance and that the wording of the heading might be reconsidered in order to make it seem less instructional. The designers were also of the view that the page would need to be considered in the context of the jacket, the prelims, and the rest of the text to ensure that the reader was led through the material smoothly.

**End of chapter summary:** Designer C felt that the summaries were appropriate for a student textbook but would be unlikely to help someone with a memory impairment who was reading for pleasure. Such a reader might be more likely to stop reading and close the book at the end of a chapter.

**Plot summaries:** Designer C noted that positioning the summary opposite the chapter opener might pose problems if the preceding chapter ended on a verso. This would mean leaving a blank recto. Designer C favoured positioning the summary either above or below the chapter heading.

The summary was printed on a grey tint. Designer C felt that having a tinted area at the top of a page might make the page look unbalanced. When asked about the relative importance of usability and aesthetic appeal, the designer commented that top-heavy pages might have a subtle but negative effect on the reader's experience.

All three designers had reservations about the participants' own suggestion of a box for the summary instead of a tint. Designer C wondered whether a contrasting typeface would be sufficient with, perhaps, a line rule below it. This would allow the summary to use the full text measure, which would help to accommodate different lengths of summary.

Designer C noted that the chapter drop could remain consistent if the summary were to be positioned directly beneath the chapter title. Placing the two items close together might place less of a demand on working memory.

Designer C observed that the reader might not distinguish the summary from the author's own text. Using a bold weight for the summary might make the difference more obvious; a sans serif typeface alone might not be enough. The designer suggested experimenting with either a bold version of the body text or a bold version of the Frutiger sans serif typeface.

Designers A and B felt that the use of a sans serif typeface for the summary might be considered slightly functional as it might suggest either an instructional text or a text that was intended for children.

### **8.4.3 Designers' response to the list of questions**

The designers expressed a number of ideas in response to the questions that had been supplied in advance. The questions particularly addressed the issues arising from preparing accessible texts and even though none of the designers had worked on books of this kind, all were able to draw on relevant problem-solving skills. A summary of the answers to each question is given below.

**Question (i)** What might be the difference between designing a typical book and a book for readers with memory issues?

Designers A and B emphasized that every aspect of the book – from the size of page numbers to the use of colour and illustration – would have to be carefully considered with the needs of the user in mind. To this extent, even a work of fiction would become a functional book in the eyes of the designer and the brief would have to highlight the particular issues that were likely to occur with a memory impairment. Designer B spoke of the need to be given fully edited and copyedited texts in order to clarify the author's intentions.

**Question (ii)** How might the designer avoid making a text look childish?

Designer A spoke of the need to see the finished book not as a reduced version of a standard text but rather as an enriched version that had been carefully put together to give maximum pleasure. The case of Persephone Books was mentioned as an example of a brand that was confident of its own publishing aims (Persephone Books 2019). The high production values of the titles on this list make each book a desirable object as well as an inviting read. The tints and motifs used on the endpapers and matching bookmark are carefully selected for each title.

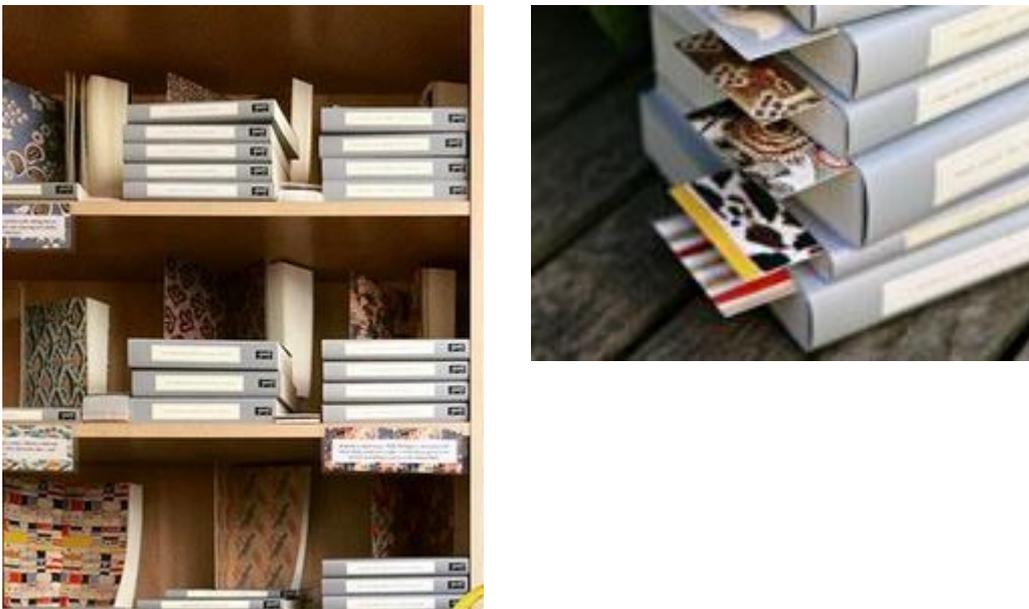


Fig. 24 (left and right) Persephone publications, with their uniform dove-grey jackets and broad, distinctive bookmarks.

**Question (iii):** What additional features could be added to make a text easy to navigate?

The use that is made of wide jacket flaps on Persephone books led to the suggestion that the list of characters might be printed on the back of the front flap so that, when the flap was unfolded, the reader would have access to it at all times. The back flap, it was suggested, could be used to provide a brief summary of the salient events of each chapter.

**Question (iv):** How might explanatory illustrations be worked into a work of fiction?

This topic was covered exhaustively in the discussion of Sample A, the layouts prepared using *The Thirty-Nine Steps* (referred to on p. 115). The designers' comments (see above pp. 192–193) drew attention to the particular function of illustration in the context of books for adult readers with acquired literacy issues.

**Question (v):** What physical aspects of the bound book would need special consideration?

Designers A and B raised the important question of branding. They commented that the jacket and spine would have to mark the books out as suitable for a particular readership if they were to be shelved alongside other trade books in a bookshop or library. The use of a distinguishing feature such as a sticker was noted, although it would be important to ensure that the sticker could be peeled off if required. A parallel was drawn with books that are produced especially for supermarkets; these often carry a removable sticker on the front of the jacket.

**Question (vi):** Given the overriding need for clarity, would the designer object to working to a brief that was quite constrained?

No direct answers were given to this question, but all three designers appeared to regard the brief for an accessible text as primarily a specific set of problems to be solved.

#### **8.4.4 Book illustrator's observations on Sample A (The Thirty-Nine Steps)**

The book illustrator acknowledged immediately that the style of her work (Fig. 25, overleaf) differed markedly from the style adopted for the OUP Bookworms series on which Sample A was based.

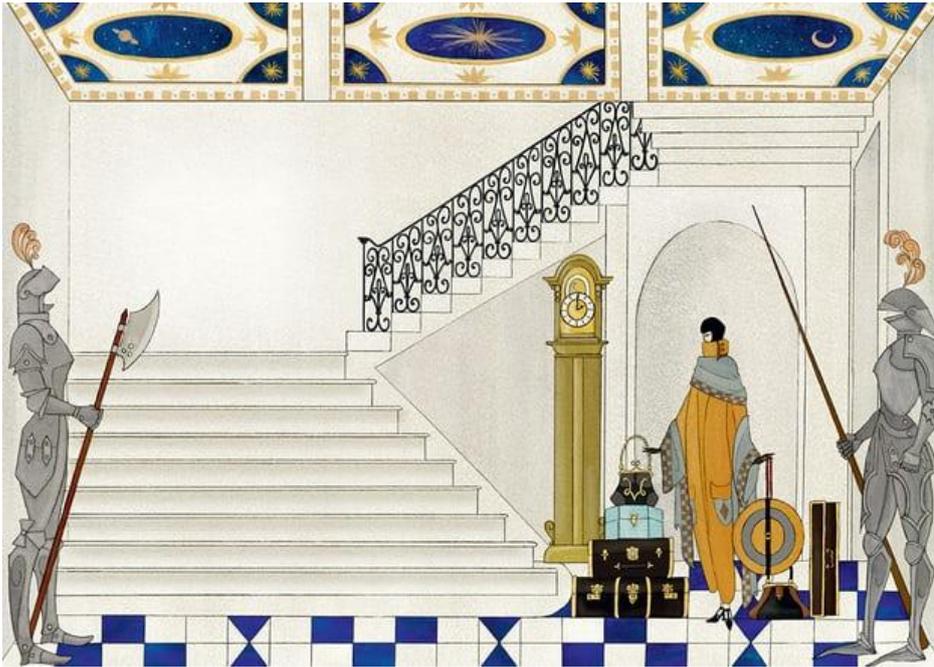


Fig. 25 Illustration by Kate Baylay for a new edition of Vita Sackville West's *A Note of Explanation* (2017/1924; illustration © Kate Baylay).

The illustrator did, however, have recent experience of producing black-and-white drawings for publishing clients (Baylay 2017). She writes:

It is certainly a different process and in many ways the process of creating the image has to be altered. For example, I have found that certain details are more difficult to define and enhance if you do not have the full colour range to utilise. ... In lots of ways it simplifies the choices you make, it is easy to spend hours playing around with different hues and there is something interesting about the way the main structure of the illustration is simplified by the limitation.

The illustrator commented on the relationship between image, caption and text and offered her thoughts on designing layouts for readers with Alzheimer's disease.

I feel that having the line of text underneath an eye-catching illustration that quotes the exact point the illustration is based on would be helpful. It feels like these would provide a sort of check point while reading so that you're not just looking at a body of text which might be intimidating. The line of text is a good way of contextualising the illustrations as well and the two together could provide a strong support for memory. I would suggest possibly having a few of these 'check points', possibly two or three per chapter, but not so many that they sort of merge into one.

#### **8.4.5 Book illustrator's observations on illustrating accessible texts**

The illustrator's response to questions about illustrations and memory impairment gave some insight into the way this perhaps slightly unusual commission would have to be considered:

The brief of using illustration to support memory is a very new concept for me and this and similar criteria would, of course, require another level of thinking to create these illustrations. Would they need to be simplified in order to have an effect? Or be more life-like than the type of illustrations I normally work on? My main criteria as an illustrator would still be to produce illustrations that are as beautiful and interesting as possible. I would still be most interested in creating work that the audience is drawn in by and that creates an effect on the viewer.

The illustrator would seem to agree with Designer C in saying that the pleasure of looking at illustrations should not be overlooked in preparing a text and that a rewarding aesthetic experience should be offered to the reader wherever possible.

### **8.5 Discussion**

It was valuable to have the perspective of four professionals whose backgrounds were so different. Particularly instructive were the views of those professionals whose skills went beyond the high-level but routine competence required by standard trade publishing. All four experts agreed that the needs of the end-user were of paramount importance in whatever project they were undertaking and that a careful brief would be necessary to spell out the particular characteristics of the target readership.

Designers A and B observed that a multidisciplinary team, brought together in the very early stages of a project, would be vital so that any differences in the views of the author, editor, designer and illustrator could be reconciled. The normal constraints of format, word count, number of illustrations and time would have to be negotiated in order to keep within an allocated budget. Any special terms used to describe the cognitive impairment caused by Alzheimer's disease would have to be clarified, and any differences in the terminology used by the different disciplines

would need to be recognised and accommodated.<sup>27</sup> The widely varying approaches demanded by newly commissioned texts, whether illustrated or non-illustrated, and existing classic texts would need careful consideration. Whatever the genre, it became evident that a text that is intended for readers with any form of special needs would involve a heavy editorial input, and this is borne out by the experience of the editors of both the OUP Bookworms series<sup>28</sup> and the Quick Reads series (see Appendix XI, p. 332).

The designers' willingness to accept a pragmatic approach that focussed on the physical presentation of the material was also positive and the example of Persephone Books as a niche publisher was particularly telling (Cooke 2012). For this publisher, the simple grey covers give a uniformity to the appearance of the books and a reassurance as to the quality of their contents.<sup>29</sup> While the undifferentiated volumes would not be helpful for a reader who had a memory impairment, the curated nature of the texts and the confidence that this inspires in the reader are both aspects that would be relevant to an accessible publication. In the case of Persephone, the focus is very definitely on the publisher's own literary preferences,<sup>30</sup> but several study participants emphasised the need for 'a good read' to motivate them.

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<sup>27</sup> For example, Designer A used the word 'intrinsic' to refer to typographical qualities and 'extrinsic' to refer to the physical aspects of a book. To an editor, intrinsic might mean the content of a text and extrinsic the literary form in which the ideas were expressed.

<sup>28</sup> Email from OUP editor 2.05.2017. [Textual matter removed.]

<sup>29</sup> Nicola Beauman, the owner of the company, is quoted as saying, 'I like grey, and I also had this vision of a woman who comes home tired from work, and there is a book waiting for her, and it doesn't matter what it looks like because she knows she will enjoy it.' (Cooke 2012)

<sup>30</sup> Nicola Beauman comments, 'Virago was, and is, great as far it goes, and sometimes they did do books I suggested to them. But I had this inconvenient attachment to all these other books that they wouldn't publish. That's all I care about, really, you see: the text, the text, the text.' (Cooke 2012)

The need to think flexibly about the presentation of the book and in particular about its jacket or cover was expressed more than once. There would seem to be scope for re-thinking the function of a cover, as seen in the piece of student artwork illustrated below (Figs 26 and 27). Here tear-off strips added to the front



Fig. 26 Jacket design posted on Behance in the US.

and back flaps function as bookmarks, although why the reader might need two of them is not clear. In thinking about the bookmarks, the designer has opted not to draw the faces of Gatsby or of Daisy, the two major characters in the story. This

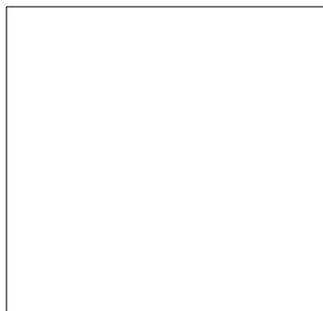


Fig. 27  
Cut-off bookmarks printed  
on the outer edges of the jacket  
flaps.

Image removed for copyright reasons

decision accords with a preference expressed by one of the participants in the DEEP discussion group. This preference seemed to strike a chord with other participants and if time had permitted, it would have been useful to explore it further.

Illustrations that are commissioned for a text need to be appropriate for the reader, the genre and the target market.<sup>31</sup> In the case of accessible texts for individuals who have early-stage Alzheimer’s disease, the retained ability of some readers to visualise people or things ‘in the mind’s eye’ could be an asset to the illustrator. Imaginative work that goes beyond purely literal depictions might prove to be both useful and an additional source of pleasure.

## 8.6 Conclusion

The primary aim of the meetings and online exchanges was to consider the sample texts layouts used in the Participant Interview Study and the Textual Additions Study. A secondary objective was to elicit ideas for further interventions from a group of experts currently working in book publishing.

There was general agreement that the design of the layouts shown was competent, but that further work might reveal the relative usefulness of different typographical adjustments. The positioning of individual elements and the removal of conventional but inessential features would need further exploration. New suggestions for modifications were offered as the discussions continued, and the value of the ‘What if ...?’ approach to generating ideas<sup>32</sup> was clearly demonstrated.

Discussion with the book designers and the book illustrator also confirmed the view that the determining factors in preparing a book for readers with a memory impairment would be the same as for any publishing project, namely the strength of the concept and the quality of the brief. The professionals were clearly resourceful and were very willing to bring their experience to bear on a new idea. What they needed above all was clear information about the precise requirements of potential readers. Such information can only be provided by the readers themselves.

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<sup>31</sup> Email from OUP editor 3.05.2016. [Textual matter removed.]

<sup>32</sup> Graham Pullin’s *Design meets disability* (2009), suggests an innovative approach to eliciting thoughtful solutions to design problems.

However, a careful design briefing would be needed in order to ensure that any preferences the readers might have for usefulness over aesthetics would be considered and that designers and illustrators would be willing to override convention in order to achieve a user-appropriate presentation. This flexibility of approach was particularly needed in the Book Cover Study and, as already noted, the designer who volunteered to work on those materials had a particular interest in texts for non-typical readers.

## **9 Discussion**

### **9.1 Introduction**

The needs of readers who have early-stage Alzheimer's disease is a relatively unexplored area of study. It is closely related to investigations into literacy interventions in care homes (Billington et al. 2013), reading groups and groups for individuals with low literacy skills (Demos 2008), but it is also quite distinct. The current research, drawing on theoretical knowledge and practical testing, challenges a number of preconceptions about this reading population and draws a number of conclusions.

This Discussion offers a consideration of the main issues raised by the research. It opens with a brief outline of the ways in which each of the four studies contributed to the development of the project. This is followed by a summary of the outcomes of the research, with the less predictable findings listed first followed by the more confirmatory information. These research findings serve to highlight the particular challenge that early-stage Alzheimer's disease poses to book designers. The medical reasons for this unique challenge are briefly outlined. A comparison then follows of the design decisions taken in the user-centred studies with the decisions made by two series of paperbacks published in the US. Both of these series are intended for individuals who have early-stage dementia and, in each case, the design solutions serve to highlight the issues raised by books for this particular readership. Points of similarity and contrast with the materials used for the research studies are noted and discussed. More general observations on the publishing issues raised by the study findings conclude this Discussion section.

## **9.2 The progression of the research studies**

The four studies presented chronologically in Sections 4–7 (pp. 94–186) mark a gradual defining of the problem of designing for Alzheimer’s disease. The information that was gathered from individuals during the informal Field Study suggested that problems with working memory did not prevent informants from taking a continued interest in reading. This finding led to the setting up of the Participant Interview Study, which examined key points that had emerged during conversations with informants and which found that readers reacted positively to a range of design interventions and strategies. The participants’ own suggestions for improvements to the design modifications for works of fiction were carried forward in the Textual Additions Study and into the Book Cover Study. The development of the research may therefore be described as having been both incremental and user centred. It was driven by the participant contribution at each stage of the research project and was shaped by the information available in recent academic literature and by personal experience of book publishing. The insights offered by the practising designers and the book illustrator during the formal Consultation expanded the range of imaginative strategies that would be available to professionals working in this area.

In a number of cases the findings of the studies were quite nuanced and suggested areas where knowledge is not yet secure and where further investigation is necessary. It is possible that these unanticipated findings will have a particular part to play in building up a complete picture of the reading experience. The continuing appreciation of humour, for example, was an unexpected and happy finding of the studies.

The involvement of individuals who were used to taking part in formal research projects helped to smooth the progress of the studies. The volunteers recruited by the memory clinic and the members representing the DEEP organisation came from a range of professional backgrounds and all brought their personal experience to bear on the questions that were asked. The recording of the

interviews and the relative formality of the format did not appear to inhibit the speakers unduly, and although their answers were not as fluent as they might once have been, individuals were none the less keen to make a personal contribution to the research.

### 9.3 Summary of findings from the studies

Noteworthy information was provided by the studies in several distinct areas:

- The literary preferences of participants were a key element in discussions and their choice of reading matter was at times surprising. The initial research had been predicated on the notion that readers would not be able to engage with texts and would need supporting illustrations. However, while illustrations evidently have a role to play, it became clear that individuals were keen to continue to read unillustrated, continuous prose. Memory was mentioned as an issue, but the pleasure of engaging with authors and with their writing did not seem to depend entirely on the ability to recall the content of texts.
- A number of informants appeared to have a preserved capacity to imagine and were able to visualise the people, objects and scenes described by an author (Zeman 2015 and 2016). Furthermore, the view was also expressed that these visualisations could be preferable to pictures contributed by book illustrators.
- Participants were aware that publishers could patronise readers. One informant in the Participant Interview Study drew attention to the negative effect of specific aspects of textual presentation.<sup>33</sup> Members of the DEEP group rejected the notion of dementia being unmentionable and were willing

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<sup>33</sup> Participant 10 in the Participant Interview Study said of Sample 2: 'Yes, I think I might be inclined to feel spoken down to, talked down to with the headings'. The same participant, speaking of Sample 3, commented: 'You don't want to hold them by the hand too much, you don't want them to feel condescended to, but none the less ...'. See Appendix VI.

to allow obvious modifications to the text and an explicit mention of dementia on the book cover if this would be beneficial to the reader.

- The notion of Alzheimer's being an older person's disease was contradicted by the presence of a number of the study participants. Several informants had taken early retirement and the majority seemed physically well apart from evident memory issues. The men and women in the Younger Persons With Dementia reading group had had their diagnosis confirmed because of recent advances in medical technology.

The studies also confirmed a number of key points:

- Volunteers could be found who were willing to take part in formal studies. Participants retained their ability to handle printed texts and were able to express personal opinions when faced with forced-choice questions. Those participants who showed signs of anosognosia (lack of insight into their condition) nevertheless made helpful contributions to the studies.
- Supporting textual features were acknowledged and welcomed. Such features were borrowed from instructional texts and included advance organisers, the insertion of textual summaries, the positioning of informative illustrations and the addition of memory-supporting material on the flaps of a book cover.

These findings help to clarify the issues involved in preparing appropriate texts. Some observations on the special nature of such a design commission are discussed next.

#### **9.4 The challenge of Alzheimer's disease to book designers**

The difficulties experienced by readers with Alzheimer's are due to the physical changes to the brain caused by the disease. A defining characteristic of Alzheimer's disease is the alteration to the parts of the brain centred on the hippocampus. The general information provided by the Alzheimer's Society now states that, 'a brain scan may show that the hippocampus and surrounding brain tissue have shrunk' (Alzheimer 2020j). Since the hippocampus plays a vital role

in normal memory and perception, it is likely that the difficulties readers experience may be in part related to this particular loss.

Two aspects of this loss are particularly relevant to the design of printed books. The first is that the hippocampus is involved in the transition of information from working memory into long-term memory (Waldemar and Burns 2017, p. 28). A defect in this specific function may mean that readers cannot store ideas and retrieve them effectively at a later time. It is therefore likely that remembering plots and characters would be problematic and this may be why the solutions offered by the Textual Additions Study (a plot summary) and the Book Cover Study (a character list printed on the front flap) met with the approval of the participants. This form of forgetting is an accelerated version of the average reader's experience and the provision of added support may be of benefit to a wide range of individuals. It is possible that an episodic style of narrative might be particularly helpful to readers who can no longer store a complex plot in memory. A series of separate, vividly described incidents that are strung together into a narrative was the basis for much early storytelling (Ong 1982, p. 140). This is the approach taken by the few books prepared for readers with early-stage dementia (see Figs 29–36 below). It is likely that more complex literary devices would confuse the narrative. These might include flashbacks, multiple viewpoints, and stories told in the epistolary form.

The second aspect of memory loss that can affect reading derives from the role of the hippocampus in the perception of space and time. Research on the involvement of the hippocampus in a wide range of brain functions suggests that its role may be wider than previously thought. The original theory proposed by O'Keefe and Nadel (1978) that the hippocampus was involved in computing space has now been broadened to explore the relationship between space and time in memory. The copious and wide-ranging work published by neuroscientist Eichenbaum and his associates has important implications for designers. He writes:

Hippocampal networks also map memories across a broad range of abstract relations among events, suggesting that the findings on spatial and temporal organization reflect a generalized mechanism for organizing memories (Eichenbaum 2017, p. 1007).

The formation of ‘relational memory representations’ and the binding together of comparisons across space and time are described by Olsen as being a key function of the hippocampus. The research by Maguire into the navigation skills of London taxi drivers would seem to confirm the role of the hippocampus in visual orientation (Maguire 2000).<sup>34</sup>

The implications of such a notion of relativity will not pose problems for designers. Many aspects of book design such as the size of type, the spacing of text, the sizing and positioning of illustrations, and the colour reproduction of images are to be considered in relation to each other (Schriver 1997, p. 358). It is possible that a designer may be able to compensate for a reader’s impaired perception by clarifying and stressing the relationships between the parts. Providing a consistency in spacing and in the positioning of individual elements such as chapter titles, running heads and page numbers may help to orientate the reader through the text. On a more abstract level, mapping a narrative in space and time is a primary aspect of the written novel. As the story evolves it moves forward through the physical pages of the book. Ong describes the ‘word-in-space’ of printed books (1982, p. 122) and, in the case of the impaired reader, the expression of ideas in a material form may prove to be a way of reinforcing memory. The work done by Mangen on grounded cognition would seem to support the view that the experience of reading a text across the printed page can help to form a memory for the relationship of the individual parts (Mangen and Schilhab 2012). It is possible that consistently positioning an illustration just after its point of reference in the text helps to reinforce the idea and strengthen the memory formation; positioning the image on

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<sup>34</sup> One of the participants recruited for the Participant Interview Study had been a London taxi driver. The link between preserved reading skills and an enlarged hippocampus due to intense spatial memory use has yet to be examined. A study involving participants with multiple sclerosis suggested that reading and writing are favourably linked to hippocampal volume and memory (Sumowski et al. 2016).

the facing page could interrupt the sequence, as a number of individuals in the Participant Interview Study pointed out (p. 123). A simple example of a schema being used to reinforce the reader's memory is provided by the children's book used in the Field Study (Figs 3 and 28). The experienced reader who acted as an informant (p. 104) appreciated the author's consistency in the repetition of words and in the use of white space and was able to anticipate the event described on the following spread.

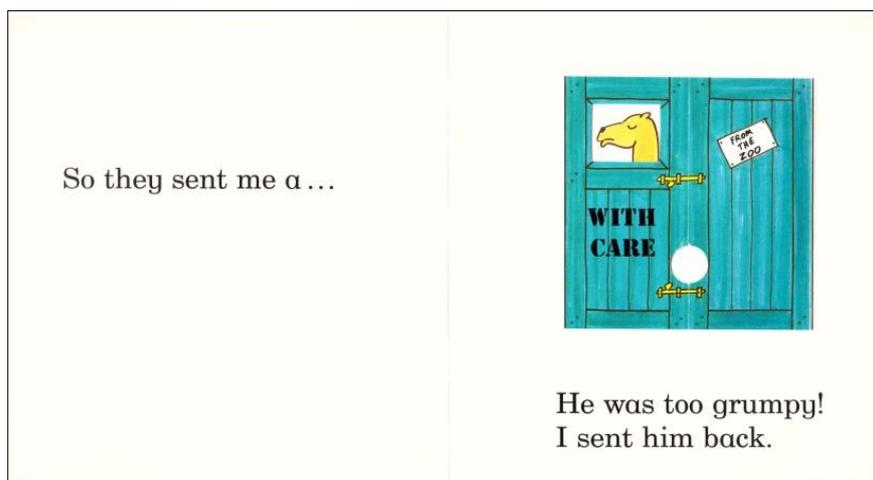


Fig. 28 Rod Campbell, *Dear Zoo* (n.p.) The book has sold over 8 million copies since it was published in 1982 and has been translated into 20 languages.

Designing books for readers with early-stage Alzheimer's disease requires an in-depth knowledge of subjects that are beyond the range of individuals employed in traditional publishing. An interdisciplinary approach involving the latest medical research might prove to be highly productive. The consequences of publishing without a full team of experts are included in the consideration of existing publications that follows.

## 9.5 Comparing the findings with evidence from existing publications

A pragmatic and solutions-focussed approach was adopted for the user-testing studies that involved participants. This is in line with the 2018 report of the 'What Works Network', which suggests that evidence-based research has a significant

role to play in the improvement of services for particular sections of society (What Works 2018). The policy of ‘test, learn, and adapt’ that is recommended in the conclusion of the report provides support for this approach.

Opportunities for gathering evidence from existing publications are limited since there are very few works of fiction designed for readers who have early-stage Alzheimer’s disease. Information has therefore been brought together from both formal and informal sources in an effort to map out this area of study. Some evidence may be anecdotal, but it has a part to play in challenging and perhaps even falsifying the claims that are routinely made based on existing practice.

Tangible evidence of a publishing effort to meet the needs of the reader with early-stage dementia is provided by two series of books produced recently in the US (Figs 29 and 30). The series are produced by Emma Rose Sparrow (Sparrow 2014a)<sup>35</sup> and by Jamie Stonebridge (2018a),<sup>36</sup> and the solutions adopted by these publishers provide an important point of comparison with the proposals being tested in the research studies. The books were independently published and are only available for purchase online. One advantage of this style of retail is that supplementary evidence of user response is available in the online reviews written by book purchasers. While positive reviews may be disregarded as unreliable since there is no way of verifying their origin, negative reviews can provide useful insights. No publisher would criticise their own product online, so there is a chance that the critical comments posted on the publishers’ websites are written by genuine purchasers. Reviews in general can serve as a crude form of user-testing and may highlight particular issues that purchasers and readers have identified, and which might repay further attention.

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<sup>35</sup> The six titles in the Sparrow series are: *What the Wind Showed to Me* (2014a), *The Sandy Shoreline* (2014b), *A Dusting of Snow* (2014c), *Three Things* (2015a), *Autumn’s Display* (2015b) and *Down by the Meadow* (2015c).

<sup>36</sup> The eight titles in the Stonebridge series are: *Trip to the Lake* (2018a), *A Visit to the Farm* (2018b), *A Day at the Park* (2018c), *A Day at the Beach* (2018d), *An Autumn Adventure* (2018e), *A Visit to the Library* (2018f), *A Summer Walk* (2019a) and *Family Thanksgiving* (2019b).

## 9.6 Comparison of the research studies with the Sparrow and Stonebridge series

There are a number of points of similarity and difference between the materials used for the studies carried out for this thesis and the two series of paperbacks produced by Sparrow and Stonebridge.

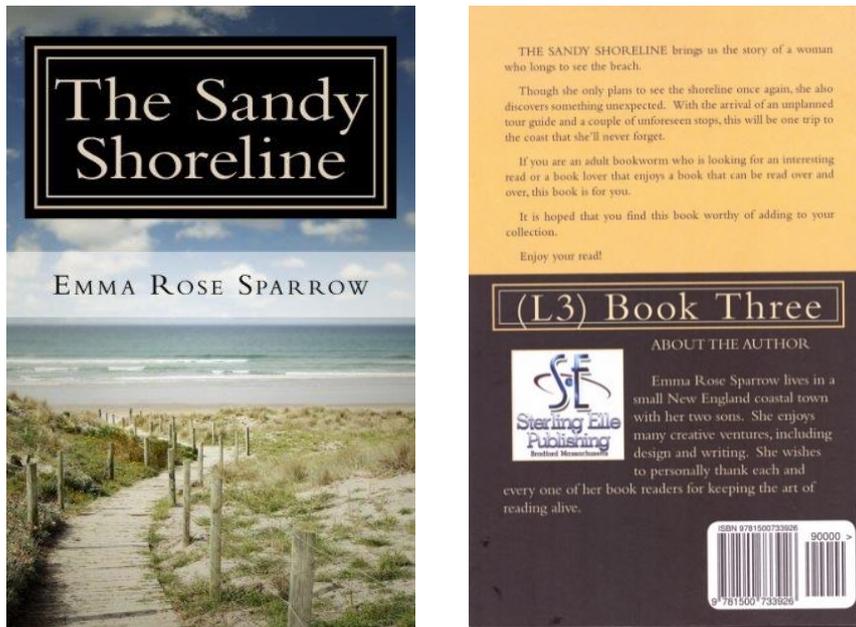


Fig. 29 The cover of the second (2014) title in the series of books by Emma Rose Sparrow. The trimmed page size is 216 x 140mm.

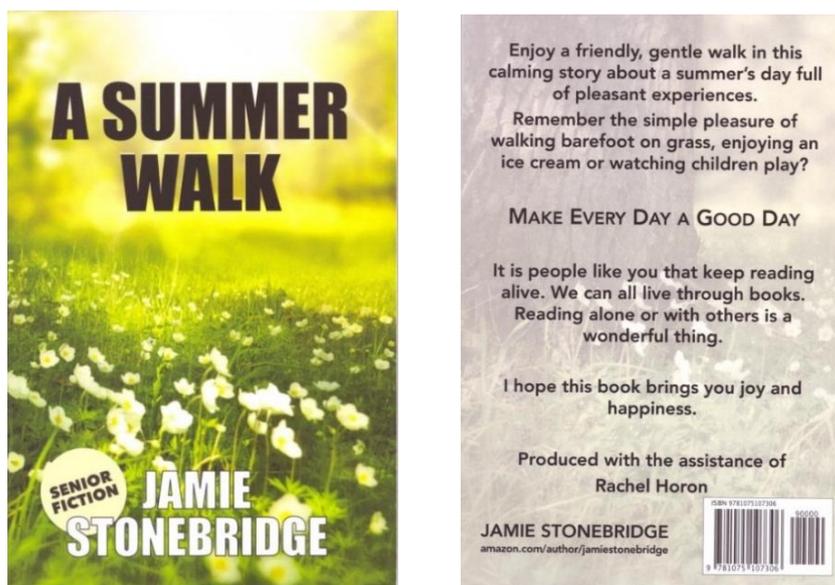


Fig. 30 The cover of a 2019 title in the series of books by Jamie Stonebridge. The trimmed page size is 229 x 152mm.

### **9.6.1 The concept**

The research sought to identify the needs of individuals who wanted to continue to read for pleasure despite early-stage Alzheimer's disease and to test possible design solutions to the problems they identified. Both the Sparrow and the Stonebridge series are based on the premise that there are such readers and that they have particular needs. The two series therefore validate the concept that underpins the research.

However, there is an important difference in the position adopted by the research and by the publishers of the series. The Sparrow paperbacks are described by Amazon as 'books for dementia or Alzheimer's patients, seniors with trouble reading and others who would benefit with "easy read" books that are formatted for adults.' They are said to offer, 'self-esteem and self-confidence to former bookworms who now struggle with 'normal' books' (Amazon advertisement for Sparrow 2015c). The Stonebridge books are described by Amazon as 'specially written for people with Dementia, Alzheimer's, Parkinson's, or rehabilitating after a Stroke' and they are 'Presented as a "normal" 6 x 9-inch paperback' (Amazon advertisement for Stonebridge 2018a).

While accepting that there is a need for the careful presentation of content and design, the present research seeks to challenge the view that there is such a thing as a 'normal' book and to suggest rather that there are different books for different readerships. This is a fundamental principle of accessible publishing.

### **9.6.2 Participant consultation**

The research for this thesis was informed and guided by the views of the readers themselves. This is in accordance with current attitudes to patient and public involvement (Gove et al. 2018, p. 725). In contrast, the Stonebridge books are described as having been produced with the help of carers and family members. Neither they nor the Sparrow series mention explicit consultation with individuals who have dementia.

### 9.6.3 Content

The present research was based on the premise that a well-constructed story is a way of holding the reader's attention. Curiosity is known to be a continuing and powerful motivator (Sakakia, Yagib and Murayama 2018), and excitement and jeopardy are intrinsic to the pleasure of reading. Participants who took part in the studies did not express a desire for more muted content because of their cognitive issues, nor did they express a wish to read texts that were explicitly reassuring or uplifting.<sup>37</sup> Participants in fact appeared to have a wide range of interests and tastes.

In contrast, the specially commissioned stories in the Sparrow and Stonebridge books are deliberately positive in their outlook. According to the advertising on Amazon, the Sparrow series presents, 'an enjoyable and uplifting story' (Sparrow 2014b), while the Stonebridge series states that, 'An enjoyable and relevant story is told of experiences that help the reader smile' (Stonebridge 2018d). The narratives have no plot and are based on a sequence of vividly described minor events that is brought to a natural close in the final paragraph. The stories in both series are written in the first person, with the gender of the narrator left unspecified.

The present research reflects the findings of the published academic literature, which suggest that the complex grammatical structure of sentences may overload the reader's working memory (Kempler, Almor, Tyler et al. 1998). The texts of the two series appear to endorse the approach adopted in the studies since the sentence structure used in the stories is straightforward and clear; the vocabulary is precise and frequently demanding, with polysyllabic words and individually challenging phrases. This is in line with the researcher's impression, and the published research evidence, that word meaning is not lost in the early stages of Alzheimer's disease (Harnish and Neils-Strunjas 2008). As already noted, some

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<sup>37</sup> This accords with the views of Professor Philip Davis, Centre for Research into Reading, Literature and Society (CRILS), who writes: 'The key issue is not to infantilise readers in terms of too nice or safe a subject-matter, texts made simple or childish texts without a strong vocabulary, and texts that do not require extended working memory of course.' Email of 12.06.2018.

participants were able to respond to rich descriptions that called up images ‘in the mind’s eye’.

The materials used in the present research studies suggested deliberate additions (‘prostheses’) to the conventional presentation of a story as a way of supporting memory. These additions included a list of characters, plot summaries and working illustrations. Further additions such as captions to illustrations and a contents page even for a work of fiction might prove to be beneficial. Perhaps with this aim in mind, the Sparrow books provide a contents page and running heads. The running heads do not consist of the chapter titles but give (perhaps less helpfully) the book title (recto) and the author’s name (verso).

#### **9.6.4 Presentation**

The sample layouts and covers used in the research studies were designed to match the standard B-format of a paperback novel (198 x 129mm). The typography and layout of the sample materials drew extensively on the designers’ knowledge and experience, and decisions were made in the light of the published literature. The marginal gains offered by a number of individual features were adopted to encourage smooth, error-free reading. The typeface (Minion) was chosen for its extended character set and its classic simplicity; ligatures were used to avoid the unnecessary distraction of juxtaposed letters; hyphenation was not used in the text to avoid making extra demands on working memory; the selling copy on the back of the sample cover was ranged left and unjustified at right to allow the judicious breaking of lines according to sense. Wide spacing between words was avoided to allow for ‘chunking’ of sense within a sentence; similarly, extra wide spacing between sentences was avoided to allow for the detection of features of letters positioned to the right in parafoveal vision. Overall, attention was paid to the ‘parts, wholes, and context’ referred to by Pelli and Tillman (2007) in their analysis of efficient reading.

Both the Sparrow and the Stonebridge books adopt a larger page size (216 x 140mm and 229 x 152mm respectively). This, when taken together with the narrow spine (3mm), distances the books from the typical format for fiction. The text in both series is justified and is set in a 16-point serif typeface, which is clear and functional. There are conspicuously wide spaces between words, and this may be a function of the justified text and the relatively narrow measure, combined with the generous type size and the absence of end-of-line word breaks. The Sparrow series has extra spacing between sentences. This is deliberate and the advertising copy states that the text has, ‘One extra space between each sentence to encourage the mind to take [a] pause’ (Sparrow 2014b). This is an explicit departure from conventional typography and signifies a difference in approach to textual content. Although between-sentence spacing normally indicates the end of one complete expression of an author’s thought and the start of a new one, the space is usually not so great as to place extra demands on working memory. Holding the ideas expressed in one sentence and carrying them forward correctly to the next sentence requires an efficient memory system. To allow for less-than-optimal remembering, the Sparrow narratives are instead constructed on the basis of a series of independent sentences linked into a topic-based paragraph. Each sentence contributes to the paragraph but may be enjoyed on its own.

In both the Sparrow and the Stonebridge books the space between paragraphs is consistent but the text is not vertically justified and has been allowed to find its own depth. Widows occur relatively frequently, which perhaps suggests that they have been deliberately tolerated since careful editing would have ensured that they were eliminated. It is impossible to say whether the aesthetic considerations of conventional typography have in this case been outweighed by functional clarity. The same may also be true of the occasional blank pages that face chapter openings.

The two series do, however, provide supporting evidence for the approach to dialogue taken in the Participant Interview Study (p. 119). The words spoken are always enclosed in unambiguous, double quotation marks and, in conversation, an indication is always given of the identity of the speaker. There are no unattributed lines of dialogue.

### 9.6.5 Cover

User-testing carried out for the Book Cover Study (pp. 180–181) indicated that members of the DEEP group had no objection to mentioning dementia in the selling-copy printed on the sample covers. However, by limiting the information to a removable sticker the choice of disclosure was offered to both purchaser and reader.

A different approach is taken by the two US series. The Sparrow titles are described as ‘camouflaged as a “real” book’, while the Stonebridge series indicates that, ‘There is no mention of dementia anywhere on the cover or inside the book, so no indication to the reader that this is in anyway a “special needs” book.’ This is in line with the Quick Reads covers (Fig. 31), which are presented without any indication of the particular nature of the books’ content.<sup>38</sup>

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<sup>38</sup> The Quick Reads books in the library of a local secondary school were deliberately shelved alongside other works of fiction to avoid causing unnecessary embarrassment to readers. (Information supplied by school librarian.) The stigma experienced by individuals who have dyslexia is described in Maryanne Wolf’s *Proust and the Squid* (2008).

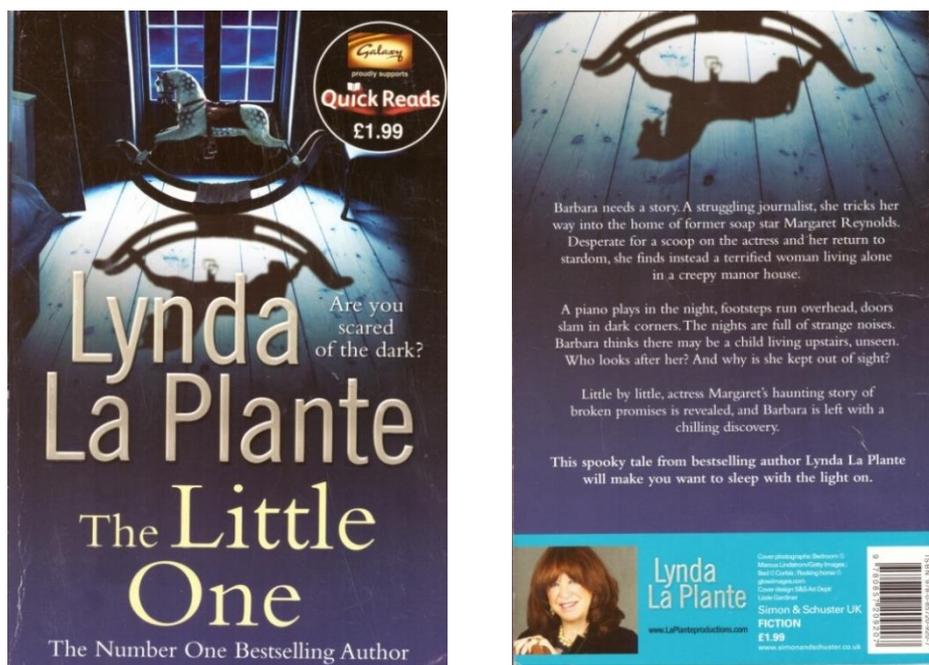


Fig. 31 The cover of Lynda La Plante's *The Little One*, the Quick Reads title used in the Participant Interview Study. A mock label gives the name of the sponsor and the price of the book.

The Stonebridge covers carry an indication that the books fit into the 'senior fiction' category. In the UK, the word 'senior', which is used to distinguish this category from adult or young adult fiction, is not without overtones and may suggest a simplified text or a larger type size. The styling of the covers of the series might well confirm this view.

### 9.6.6 Illustrations

Discussions held during the Participant Interview Study (pp. 123ff.) indicated that participants welcomed the inclusion of clear, hand-drawn illustrations as a way of reinforcing information in the text. The importance of unambiguous images is highlighted in the DEEP literature (Litherland 2008). Participants expressed a preference for an illustration to be positioned just after its point of reference in the text rather than displayed on the page opposite.

Both the Sparrow and the Stonebridge series are illustrated with photographs. A number of design problems are evident both in their location and content.

Illustrations are often positioned at some distance from their point of reference in the text; harsh cropping and the photographing of objects from uncharacteristic angles result in images that are not immediately recognisable; the use of off-white paper has not been taken into account in commissioning the original black and white photographs.

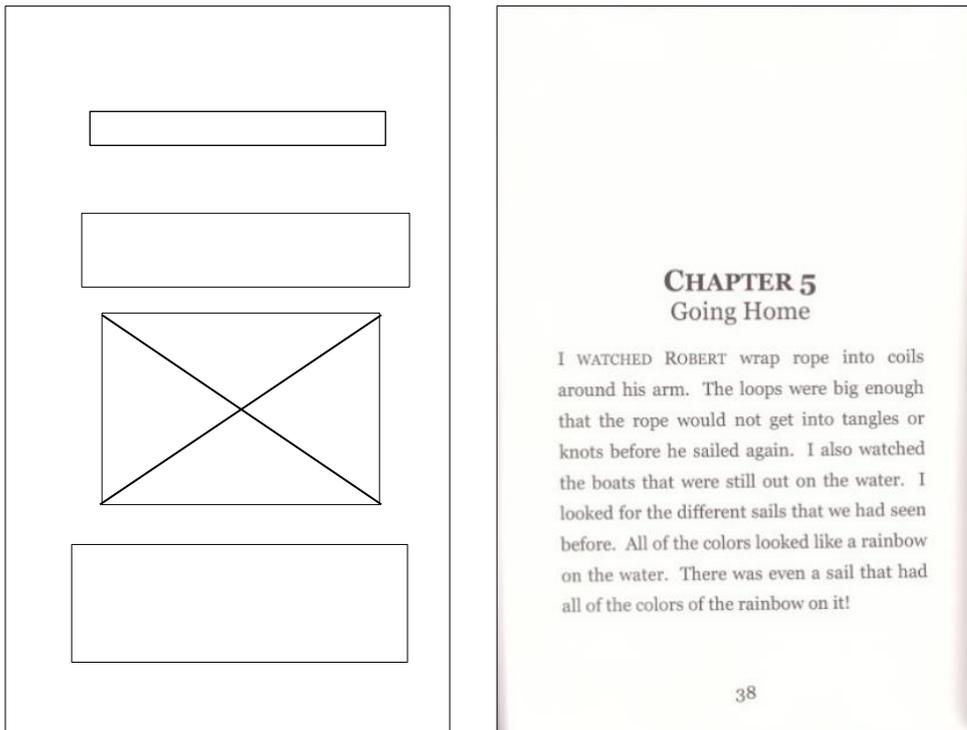


Fig. 32 (above left) Sparrow chapter opener set in bold caps over two lines with a running head that appears on every page. The seagull is not shown from an easily identifiable angle. [Image removed for copyright reasons.]

Fig. 33 (above right) Stonebridge chapter opener. The number and title are set close together, with the non-lining figure 5 encroaching on the space beneath. The chapter opens on a verso with the referring full-page illustration on the preceding recto.

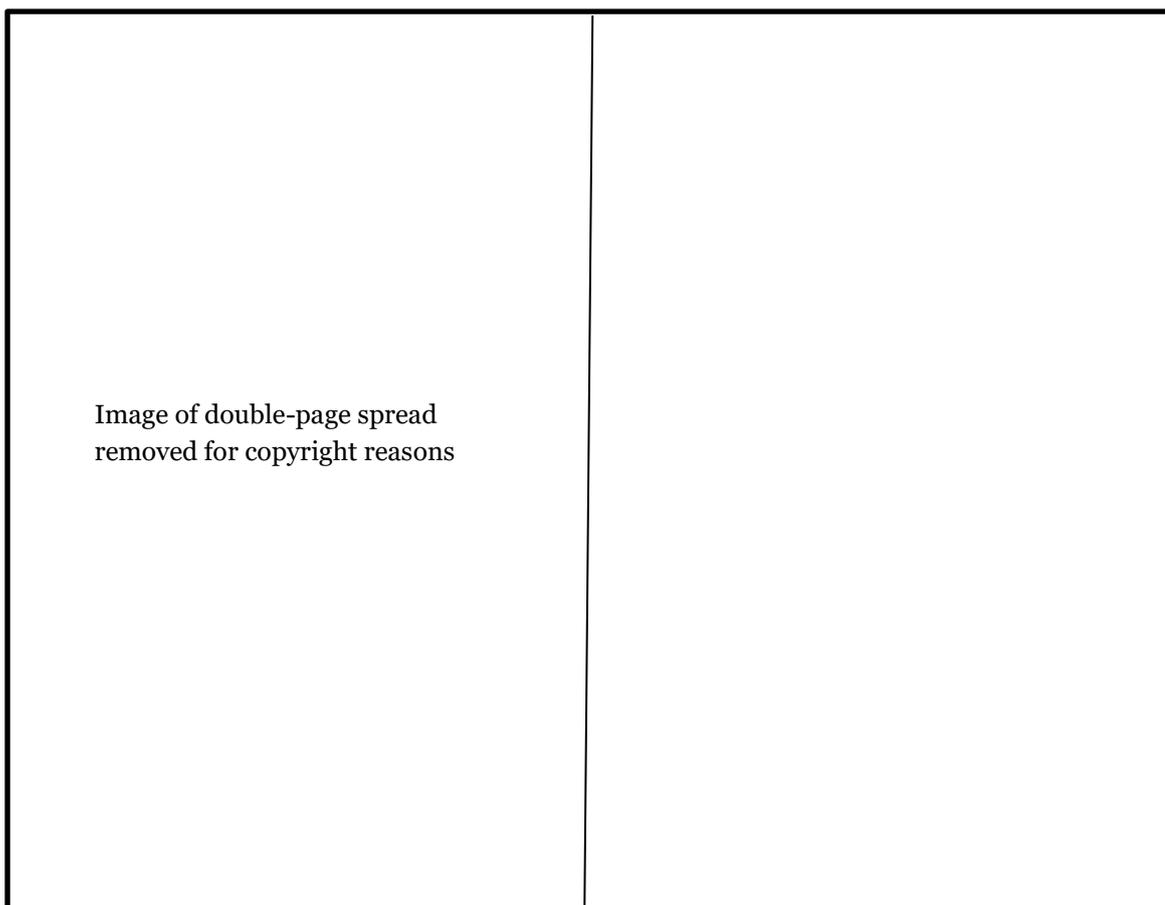


Fig. 34 Sparrow, *The Sandy Shoreline* (2014), pp. 6–7. The variation in word spacing is a result of justifying the text without hyphenation. Double quotation marks are used both to indicate imagined dialogue and to single out words and phrases for particular elaboration.

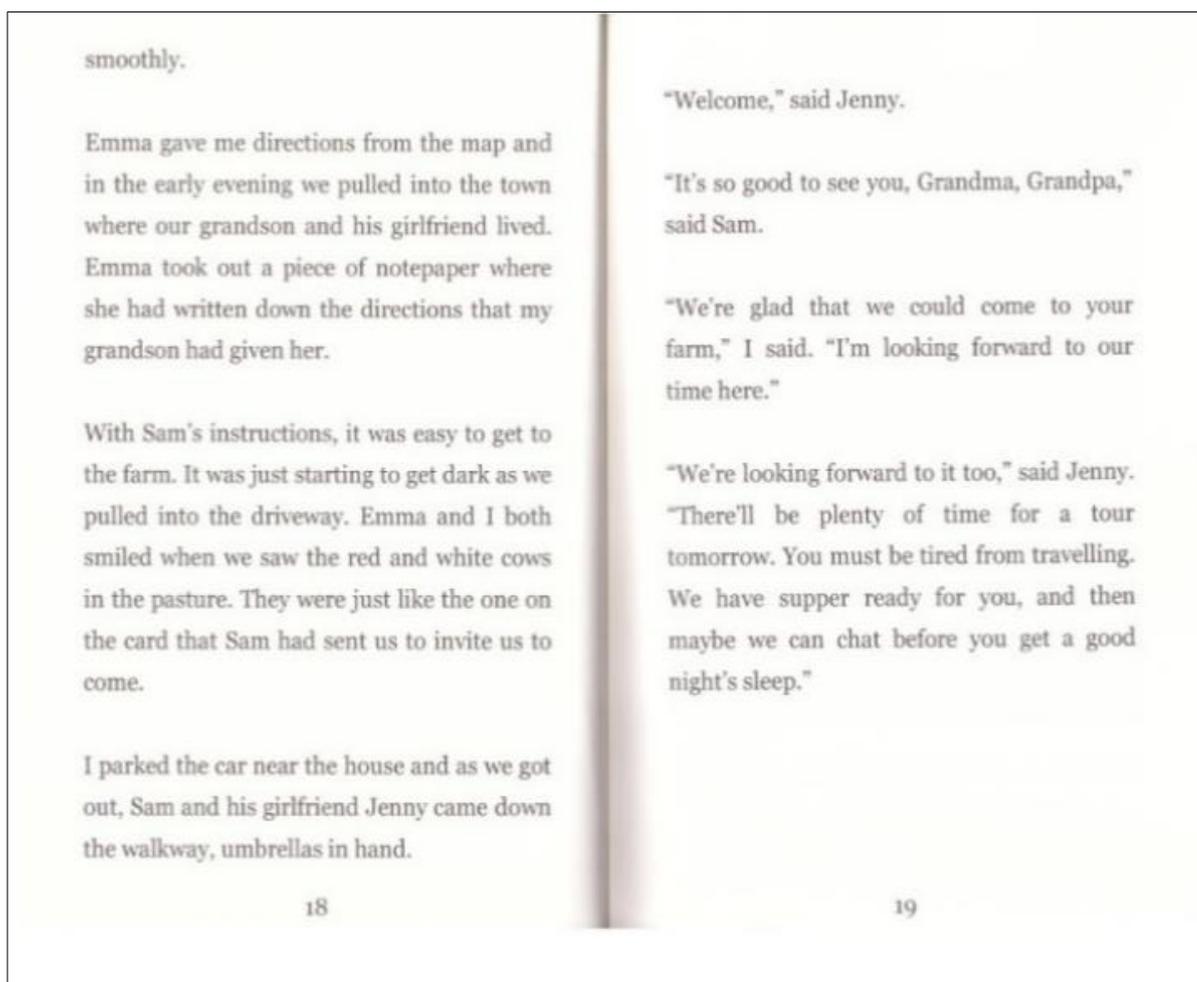


Fig. 35 Stonebridge, *A Visit to the Farm* (2018). The books have a narrow top margin which is not consistently applied. Widows occur frequently. The word spacing is wide because the text has been set without hyphenation. The double quotation marks are intentionally prominent.

### 9.6.7 The book as object

Each of the studies carried out with participants confirmed that books retained their cultural significance despite issues with memory. Readers were sensitive to the tactile qualities of books and also to the pleasure of ownership. The study materials aimed to present clear texts and simple, stylish covers. Every attempt was made to avoid the reader feeling patronised.

The publishers of both the Sparrow and the Stonebridge series allude to the significance of the ownership of printed books and both address the reader personally. Sparrow observes in her Acknowledgements that, 'In today's busy world, which is filled with all sorts of loud electronic devices, it is nice to be able to sit with

a good book' (Sparrow 2014, p. ix). On the back cover she adds, 'It is hoped that you find this book worthy of adding to your collection.' The Stonebridge series also praises the reader's discernment and invites them to feel part of a special group: 'It is people like you that keep reading alive. We can all live through books. Reading alone or with others is a wonderful thing.' None of the reviews mentions readers reacting negatively to this form of address. There are, however, several comments about the books being slight, lacking in substance both in their content and in their material presentation, and representing poor value for money.

Comparing the research findings with the evidence of the Sparrow and Stonebridge books highlighted a number of significant design issues in the two series. However, the number of titles suitable for individuals who have early-stage Alzheimer's disease is limited, and stories that are designed for private reading rather than shared reading are even rarer, so any text that appears in a published form marks a new contribution to the field. Taken together, the Sparrow and the Stonebridge books provide corroborating evidence for the existence of a specific sector of the reading public.

## **9.7 The research findings in the broader publishing context**

The research studies raised a number of issues that reflect the broader publishing context. The potential for each of these areas for expansion in future research will be alluded to in the Conclusion, but the most significant points raised by the studies are summarised below.

### **9.7.1 Accessible publishing**

Texts that are prepared for readers with low vision, dyslexia, macular degeneration and learning disabilities are now considered to be a form of accessible publishing rather than special needs publishing. The digitisation of texts and the expansion of print on demand have made access to content possible for a wide range of readers. Books prepared for readers with dementia would naturally fit into the category of

accessible publishing, although the problems caused by a memory impairment would be a new challenge to editorial, design and production departments.

The example of the Sparrow and the Stonebridge books provides evidence that small-scale publishers may choose to cater for limited but specific market segments. As with any form of publishing, the expertise of the developer lies in building a list of titles for a clearly defined group of readers in an appropriate format and at an acceptable price.<sup>39</sup> The ability to reach target readers and purchasers through an online advertising presence has opened up possibilities even to quite modest book publishers.

### **9.7.2 Multidisciplinarity**

The research studies drew on the experience of a wide range of individuals. In their overview of the publishing industry, Phillips and Bhaskar describe making and selling books as a ‘plural, variegated entity’ (2019, p. 5). It is certainly the case that accessible publishing requires many distinct areas of expertise. Working with professional designers on the research materials suggested that the disruptive approach to innovation advocated by Pullen (2009) could make a valuable contribution to this specialist area of book publishing. Asking expert designers to become involved in unfamiliar projects might yield imaginative results; it would certainly reduce the number of errors of design judgement that tend to be a feature of independently produced books. The designer’s task would be to address the specific demands of a cognitive impairment without reducing the quality of the design. As Barker writes, ‘there is absolutely no reason for alternative versions to be in anyway diminished or reduced in order to accommodate the demands of the disability’ (Barker 2013, p. 30).

The research studies drew on published works of fiction by authors who were likely to be familiar to the participants. The commissioning of fictional narratives

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<sup>39</sup> Any niche product may become mainstream if it succeeds in meeting a hitherto unfulfilled need. Gluten-free foodstuffs and clothing for fashion-conscious Muslim women (Vogue 2018) are recent examples of this business model.

for readers with dementia is a particularly challenging problem and one which, though beyond the scope of the present investigations, will be returned to briefly in summing up the research (Conclusion, pp. 238–239). Many of the Quick Reads stories are of a high quality and the series is made possible by well-known authors contributing small-scale stories for a minimal fee. The texts are short, but the plots have been expertly constructed by experienced writers before being submitted for editing and copyediting.<sup>40</sup> In contrast, neither of the two US series discussed above offers a plot-driven narrative but opt instead for a text-to-self and a text-to-world approach that does not place particular demands on recall. The Sparrow texts repay close examination as they are sophisticated and subtle, weaving together images, curious facts and an imaginative setting; the Stonebridge stories appear laboured in contrast.

### 9.7.3 Transferability

The findings of the research studies may also have a value for readers who do not have dementia but who nevertheless find conventionally designed books too challenging. The factors affecting legibility (and hence readability) have been described by Dyson (2019), and page layouts that attend to these specific points are likely to benefit many readers; generously spaced pages with clear type and extra signposting can help to support errorless reading. Books may also find unintended markets: adult readers who do not have dyslexia may appreciate the clarity of Barrington Stoke's characteristic typeface when tackling full-scale novels. Recent additions to this publisher's list are unabridged versions of John Steinbeck's *Of Mice and Men* (2016), Charles Dickens's *A Christmas Carol* (2017), R.L. Stevenson's *Dr Jekyll and Mr Hyde* (2017), Muriel Spark's *The Prime of Miss Jean Brodie* (2020) and George Orwell's *Animal Farm* (2021).

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<sup>40</sup> A brief account of the commissioning and editing process is provided by the Quick Reads editor in an email of 14.09.2017 (Appendix XI). The text specification was also supplied on request and gives detailed instructions for all aspects of layout, typography and cover typography (email from the Quick Reads programme manager 13.06.2016).

#### **9.7.4 Feminisation**

The research studies were facilitated by members of staff from the NHS and from charitable organisations; a large proportion of these individuals were female. It is important for those researching the needs of individuals who have Alzheimer's disease to consider the high numbers of female employees in the social care sector (Skills for Care 2019), the school education sector (Gov.UK 2018), and the UK publishing industry (Publishers Association 2018). Particular attention would need to be paid to possible bias or over-generalisation in the opinions expressed by care workers and in the judgements made by authors, editors and designers. Both male and female informants participated in the studies and care was taken to prepare materials that would suit a range of tastes. The Sparrow and the Stonebridge texts minimise references to the gender of the narrator, and the events in the stories are not gender specific; the texts, however, have all been written by female writers. Some of the writers have a background in teaching and this may have contributed to the slightly didactic quality of the stories.

#### **9.7.5 Diversity**

The individuals who took part in the studies were from a relatively narrow section of society. Attention has been paid to the lack of diversity in the publishing industry in the UK (le Roux 2019), and the findings of a recent survey (Publishers Association 2018) confirm that the majority of publishing employees are British and are based in the south east of England. Authors who are commissioned to write texts for readers who have early-stage Alzheimer's need to be reminded that the disease affects individuals of all ethnicities (House of Commons 2013). Care therefore needs to be taken not to unwittingly exclude certain sections of the reading public.

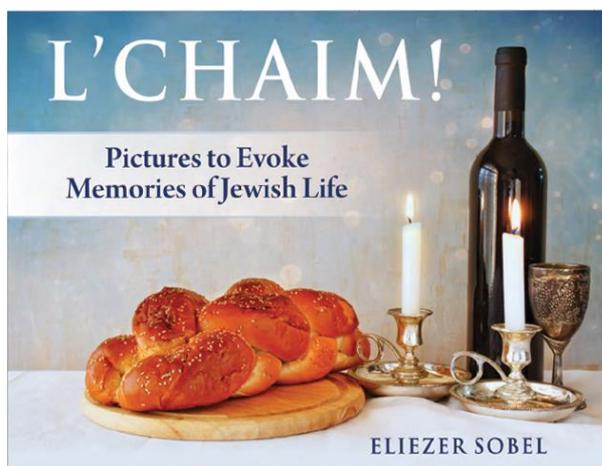
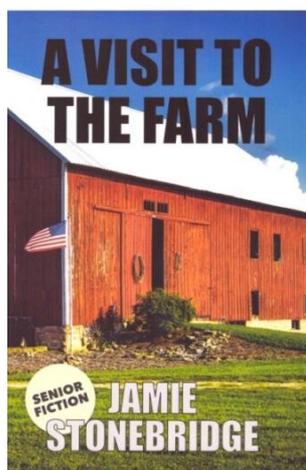
In this regard, particular attention needs to be paid to the selection of images. The large-format *Pictures to Share* series adopts a positive approach to diversity in the choice of illustrative material. The endpapers to *A Family Life in Pictures*

(Bate 2010) show a family sitting down for a meal. When asked about the illustration, the editor replied:

We always try to include images that show ethnic minority groups – we get people saying we should include more all the time – and the extended family is a big part of the Asian culture in the UK (Leahy 2013).

In the context of inclusivity, the advantages of line drawings over photographs are spelled out by Wright (2012). Noting the importance of careful selection, she writes: ‘Because the omitted information can relate to age, race and gender, line drawings can be more suitable than photographs when texts are intended for a wide audience’ (Wright 2012, p. 73).

However, illustrations used in books may have emotional or cultural overtones (Goldsmith 1987, pp. 69–70), and work done by Black (2019) on the perhaps surprising sensitivity of readers to commissioned drawings is relevant in this context. Deliberately adjusting the style and content of illustrations in order to allude to the reader’s lived experience may be particularly important ways of supporting memory loss. The cover of Stonebridge’s *A Visit to the Farm* (Fig. 36) suggests that the book is explicitly aimed at a US reader, with the image (and flag) having a specific cultural relevance. Similarly, the photographically illustrated



(Above left) Fig. 36 Front cover of Jamie Stonebridge, *A Visit to the Farm* (2018).

(Above right) Fig. 37 Front cover of Eliezer Sobel, *L'Chaim! Pictures to Evoke Memories of Jewish Life* (2016).

book *L'Chaim! Pictures to Evoke Memories of Jewish Life* by Eliezer Sobel (Fig. 37) has the intentionally restricted target readership of Jewish readers who have dementia (Sobel 2016).

Readers who develop Alzheimer's may continue to be sensitive to good quality reproductions of works of art. A portrait by Rubens was used as the illustration to the third of the sample layouts in the Participant Interview study (Figs 7a and 7b). Although the purpose of the layout was to explore the usefulness of side headings in a factual text, the image extended the scope of the investigation as it offered the reader an opportunity to comment on a work of recognised artistic quality. Only one participant remarked on the illustration. This was an individual whose capacity for reading had become quite limited but whose home was full of original works of art.

The enduring nature of aesthetic pleasure may well have been a factor in the National Trust announcing a three-year partnership with Alzheimer's Society in 2019 (National Trust 2020). Many museums and galleries have now followed the early example set by the Access Programme at the Museum of Modern Art in New York (MoMA2020). In the UK, Arts4Dementia is taking a proactive role in encouraging access to participation (Arts4Dementia 2020). The presence of patrons who are involved in the arts at the highest level marks a change in attitude towards the illness, perhaps resulting from family experience of dementia (Cheston, Hancock and White 2019).

## **9.8 Reflections on the research approach**

The approach adopted for the research may be seen as making a contribution to the field of dementia studies. The small-scale qualitative studies described in Sections 4–7 above proved to be both manageable and productive. Although their aim was to define the reading problems caused by Alzheimer's disease and to explore possible solutions, the studies were not designed to lead to broad generalisations but sought instead to contribute to a more nuanced understanding of the reader's experience.

In an effort to gain a wide variety of opinions, exploratory conversations and formal discussions were carried out with range of individuals in a number of different locations including a public library, a community centre, coffee shops, small office spaces and participants' homes. The approach was designed to be flexible and friendly while at the same time remaining within strict ethical guidelines.

Information was gathered slowly in detailed one-to-one conversations and in group discussion, and by reporting it accurately and transparently, it was hoped that the formal accounts and faithful transcriptions could provide a trustworthy resource for other researchers.

Adopting a practical approach to the materials that were shown to participants meant that the researcher could draw on experience gained as a professional book editor. Producing sample spreads based on existing publications and commissioning mock-ups of book covers meant that participants were able to handle tangible objects and use them to stimulate their thoughts. Adopting a 'show and tell' approach helped to break down barriers between researcher and informant and often led to both parties articulating ideas that had had hitherto been only partially formulated.

The individual studies particularly demonstrate the value of bringing together multidisciplinary teams when targeting complex problems. The pooling of complementary skills is normal practice in the creative industries and commissioning a book, or putting on a play, or producing a television drama all require close collaboration. The research carried out for this thesis indicates that even a small-scale study can have a number of overlapping aspects and can require the consideration of information emanating from several separate disciplines. It is by bringing together pertinent information, subjecting it to rigorous examination and considering all aspects separately and together that new insights may be found. A transdisciplinary solution that lies outside the competence of any individual field of expertise may be forthcoming if each of the components is evaluated as part of a

complex nexus of considerations. Accessible publishing in the field of dementia studies promises to be an area that will benefit from a significant input from a range of professions and, equally importantly, from experts-by-experience.

### **9.9 Concluding observations**

The research studies adopted a user-centred approach to design solutions for readers with early-stage Alzheimer's disease. The findings were compared with solutions offered by existing publications as a way of testing assumptions about the reader and about the design decisions made. The user-testing involved a forced-choice approach which at times was felt to be unnatural and restrictive, but which was also felt to be the most appropriate method given the particular nature of informants' cognitive issues.

The design of the sample materials was informed by opinions gathered both during the Field Study and during the informal conversations that were held outside of the formal testing sessions. Testing specific aspects of design meant letting go of ideas which had seemed promising, but which were ultimately passed over by potential users. In the case of the studies, the use of chapter summaries and the practical suggestion of combining a ribbon marker with a printed list of the cast of characters were both rejected in favour of alternative solutions. Testing the suitability of the textual content of a work of fiction was regarded as beyond the scope of the present research. User-testing in the context of fiction publishing would raise a number of significant editorial issues and these, along with other areas in need of further investigation, will be returned to in the concluding section of the thesis that follows.

## **10 Conclusion**

### **10.1 Introduction**

Reading is a simple pleasure. It does not require a significant financial outlay or a substantial commitment of time; it can be done anywhere and at any hour of the day or night. Reading does not involve other people; it is a purely personal pleasure that offers enrichment and entertainment in the company of great writers. It is a private act but one that brings people together.

Reading is also a complex activity. It requires the efficient synchrony of a wide range of disparate cognitive functions. Reading is not a natural process and it presses into service parts of the brain that have evolved to fulfil quite different purposes (Dehaene 2009). Reading is therefore both rewarding and demanding.

For those affected by early-stage Alzheimer's disease, reading can no longer be taken for granted. The gradual changes to memory and to concentration that are a feature of the illness may mean that the literacy skills acquired in early life begin to fail (Bayles and Tomoeda 2014, p. 53). Sustaining access to the world of books and ideas begins to be problematic and this can be a cause of regret.

The aim of this thesis has been to ascertain whether there are ways of supporting the reader's 'effort after meaning' (Johnson-Laird and Wason 1977, p. 379) through modifications to book design. The research carried out for the thesis has included seeking the views of a range of affected individuals and putting their opinions to the test in a small number of narrowly focussed studies.

The sections below consider three main aspects of the research, namely the contribution it makes to knowledge, the limitations of the work, and the areas where further research would be profitable. The thesis concludes with a few closing observations.

## **10.2 Contribution to knowledge**

Knowledge about the private reading experience of individuals who have early-stage Alzheimer's disease is not particularly extensive. Confirming existing knowledge and adding to it may therefore be considered to have been a profitable exercise. Challenging preconceptions may also prove to have been a worthwhile undertaking: even one participant displaying a characteristic thought to be incompatible with Alzheimer's disease (e.g. a sense of humour) would serve at least to guard against casual generalisations.

The contribution made by the research is summarised below under two headings, general and particular. The general findings concern the broader issues of reading and the part played by design in facilitating this activity. The particular findings concern the contribution that design and typography can make to specific aspects of the reading process by the thoughtful presentation of individual textual features.

### **10.2.1 General points confirmed**

The findings of the research into reading with early-stage Alzheimer's disease confirm a number of general points:

- some individuals who are experienced readers want to go on reading
- readers will persevere with a text if they consider that it is worth the effort
- readers continue to visualise scenes and simulate action despite incipient dementia
- expert design and typography have a specific and neglected contribution to make
- the addition of textual prostheses is helpful and acceptable

- readers continue to enjoy the material aspects of the book
- interdisciplinary research is possible and can produce results that would not be achieved by individuals working separately.

### 10.2.2 Particular recommendations

The research suggests that there are a number of interventions which might be beneficial to the reader.

**Textual modifications:** making information explicit may help the reader to navigate the text. This may be achieved in a number of ways:

- Page numbers should be visible and distinct.
- The addition of running heads that match chapter headings can help with orientation in works of fiction.
- A well-established typeface that looks solid on the page will help to make the text of a continuous narrative clear and legible.
- Conspicuously different typefaces can help to distinguish the various components of a text.
- Allowing a generous amount of vertical space within a text may help the reader to make an accurate return sweep from the end of one line of text to the start of the next.

**Memory support:** information may be added to various parts of the book to support the reader's memory.

- For works of fiction, a contents page and matching running heads will help to provide textual cohesion.
- Add a list of the characters in a story either in the prelims or on the front flap of a jacket or book cover.
- Consider adding brief but explicit plot summaries at the start of each chapter ('The story so far ...').
- Repeat the names of speakers in extended dialogue.

- Add unambiguous, information-rich illustrations to reinforce points made in the text and to act as signposts within the book.
- Use the captions to illustrations to repeat information if necessary.
- Use side-headings to break up the text in works of non-fiction.
- When considering book covers, use colour as a functioning part of the design not just as for a decorative effect.
- Use the flaps of a jacket or cover to provide supportive information rather than sales copy.
- Provide a conspicuous bookmark to act as a placeholder: either a wide ribbon-marker or a colourful printed bookmark.

**Memory protection:** information may also be limited to reduce the demands on the reader's attention.

- Avoid features that may prove distracting. Rules, motifs, coloured tints, etc. need to be functional rather than purely decorative.
- Avoid over-complex illustrations.
- Size the illustrations so that they fit on the page. Running an illustration across the gutter risks losing information in the fold of the pages.

**Layout considerations:** the positioning of information is an important issue when designing for readers who have a cognitive impairment.

- Use publishing conventions to support an unreliable memory. Aim for a layout that draws on the reader's knowledge and expectations.
- Use space on the page explicitly to separate and to connect.
- Position illustrations after their point of reference in the text and always on the same spread.
- Position page numbers in a conventional location.

**Reader expectations:** design can capitalise on the reader's familiarity with the printed book.

- Select a format that it is appropriate in size and weight for the expected readership.
- Enhance the reader's pleasure by emphasising the materiality of the book. Treat it as an object to be handled and enjoyed.
- Attend to the tactile qualities of the paper, the binding and a ribbon marker.

**Reader preferences:** the tastes of a discerning readership need to be taken into consideration.

- Readers expect continued respect from publishers.
- Sophistication needs to be shown in the page design, in the choice and styling of illustrations and in the quality of the typography.
- Readers may be conscious of the stigmatising effect of insensitive selling copy.

### **10.2.3 Summarising observations on the contribution**

Overall, the present research serves to extend the understanding of those aspects of page design which most affect reading with early-stage Alzheimer's disease. The value of intentional redundancy was particularly evident and suggests that a duplication of information may be useful to readers with an impaired memory; simplicity alone may not provide the reader with enough clues to allow comprehension. Furthermore, since inference is known to be affected by dementia (Creamer and Schmitter-Edgcombe 2010), explicit information is desirable. Adding textual features may in fact be a way of reducing cognitive load (Sweller, van Merriënboer and Paas 1998).

The research also contributes to the body of knowledge about user-testing involving individuals who have early-stage Alzheimer's disease. It demonstrates the value of working directly with affected informants to gain insights that would not be available even to experienced publishers. It also confirms a continuing role for the printed book when preparing texts and illustrations for readers with a

memory impairment. Designers should aim to capitalise on the affordances of the material book when producing accessible reading matter.

### **10.3 The limitations of the research**

The need to involve individuals with dementia in academic research was formally acknowledged by Alzheimer Europe in 2018 (Gove et al. 2018). Waite, Poland and Charlesworth (2019) refer to this important position statement but also draw attention to the difficulties raised by patient and public involvement (PPI). The present research indicates three particular limitations and constraints, and these are discussed below.

#### **10.3.1 Sample size**

The small size of the sample has immediately to be acknowledged. As the research progressed, it became evident that an exploratory approach using qualitative methods would be the only option given the complex issues surrounding participant recruitment (see below). Although it is not possible to make generalisable assertions based on the study findings, it has nevertheless been possible to provide first-hand accounts that challenge a number of preconceptions. The findings of the studies will also be transferable to contexts other than the reading of texts for pleasure. These opportunities for further research will be returned to below (p. 236).

#### **10.3.2 Participant recruitment**

The small sample size for both the Participant Interview Study and the two group meetings was directly related to issues of participant recruitment. For the Participant Interview Study, a detailed application had to be made to the Health Research Authority with the finalised test materials forming part of the submission. This time-consuming part of the research study limited the number of interviews that could reasonably be fitted into the schedule. It would have been advantageous to include more than ten participants, although it is possible that interviewing more participants drawn from the

same resource (i.e. the BMCRC's database of volunteers) would not have yielded significant new information. It is also possible that the test material for this first study was unduly tentative and that the responses of participants were therefore too predictable.

The number of DEEP members who attended the two discussion meetings was smaller than anticipated; a larger number of individuals had been present on earlier occasions when more general topics had been discussed. The flyer that was sent by post along with the agenda for the two meetings (p. 100) was intended to stimulate interest, but it is likely that reading as a pastime did not appeal to all members.

Recruitment may also have been affected by the gatekeepers who were involved in initially identifying informants. Gatekeepers include those individuals or organisations that protect vulnerable individuals by allowing or preventing access (Innes, Page and Cutler 2016). Gatekeepers also frame the way in which research studies are presented to possible informants. In the present context, the initial telephone calls and the wording of forthcoming agendas for meetings were not under the researcher's control.

### **10.3.3 Interdisciplinary research**

The limitations inherent in choosing an interdisciplinary research approach must also be acknowledged. This thesis draws on the knowledge, experience and practical skills of medical experts, healthcare workers and professional book designers. Methodologically this may be considered problematic since it combines established fact (e.g. the physical manifestation of a defined illness) with unquantifiable judgement (e.g. the appropriateness of a typeface or the usefulness of an illustration). Such an approach is perhaps only defensible in the light of the benefits that it may yield. There is certainly a need for a synthesis of academic research and informed design practice in tackling many of the problems associated with the activities of daily living.

The scope for the collaboration between unrelated disciplines is indicated below.

#### **10.4 Areas for further research**

The research for the thesis adopted a pragmatic, solutions-focussed approach to the problems of reading with dementia. As already noted in the Discussion section (pp. 210–211), this approach is in line with the methodology of the government’s What Works Network (2018) which seeks to learn from the successful implementation of evidence-based research and robust evaluation across a wide range of issues.

The findings of the four research studies together with the formal consultation described above suggest that there are a number of areas that would repay further investigation. By combining new medical insights into the early stages of dementia with the professional experience of designers, editors and illustrators, it is possible that novel working solutions may be found to the problem of reading with an impaired memory. Three topics in particular would benefit from further consideration, namely:

- i. the use of illustration in texts
- ii. the commissioning of works of fiction
- iii. the opportunities offered by independent publishing.

Each of these areas is considered briefly below.

##### **10.4.1 The use of illustration in texts**

In considering the relation of text and image it may be possible to extend the work of Bateman (2014). Bateman distinguishes between illustrated books and picture books (p. 87ff.) and draws a further distinction between the two roles performed by images in illustrated books, namely elaboration and enhancement. Elaboration would seem to relate to an addition of information that has been suggested as a way of supporting an impaired memory (see Contribution to

knowledge above, p. 232–232). Bateman’s analysis provides a clear basis on which to build future exploration.

A profitable area for examining the contribution that illustrations can make to books for adults would be the fiction texts prepared for English speakers of other languages (ESOL). As noted above (Participant Interview Study, p. 125), the use of illustrations in stories written for adults poses important problems of content and tone. Bateman’s categorisation of such images as elaboration is in-keeping with the editorial approach to commissioning new work. Examining the storyboarding stage of book preparation could perhaps shed new light on ways of reinforcing an impaired memory while at the same time supporting a reader’s comprehension.

A further aspect of book illustration that would bear further investigation would be the readers’ preferences for style. Such an enquiry would build on the research carried out by Helen Bate on the effects of dementia on the perception of images (Bate 2014). It would also expand on the work done by Innovations in Dementia (Litherland 2008) in establishing guidelines for what readers may find difficult or troubling in photographic images. There would be an added benefit in extending this work and examining readers’ views on commissioned book illustration, a topic that is closely related to Black’s work on the emotional content of illustrations used in medical literature (Black 2019). The observations made by a practising book illustrator on the sample layout used for the Participant Interview Study (Appendix X, p. 328ff.) suggest that professional artists may have a wide repertoire of skills at their disposal. It would be helpful to test the readers’ reactions to a broad range of depiction and illustrative styles.

#### **10.4.2 The commissioning of works of fiction**

An analysis of the characteristics of a suitable text for readers with early-stage Alzheimer’s is beyond the scope of this thesis. This important topic would involve interdisciplinary research and would require contributions from the field of

English language and literature, clinical and educational psychology, and creative writing. The research would acknowledge the material aspects of textual presentation but would build on and extend Armbruster and Anderson's notion of 'considerate' text; by this is meant, 'text that facilitates understanding, learning, and remembering' (Armbruster and Anderson 1984; Waller 2012). Drawing on literary criticism, the research would investigate the fundamentals of good story-writing, the shaping of a narrative, the components of a gripping plot, and the place of humour in fictional writing (Lodge 1990; Mullan 2006). An awareness of the constituents of a well-constructed story might lead to successful commissioning of texts for readers whose memory is unreliable. The usefulness of verbal repetition and redundancy would certainly bear testing by affected individuals.

#### **10.4.3 The opportunities offered by independent publishing**

Small-scale publishing projects have made genuine contributions to the field of books for readers with dementia. Mention has been made of the Pictures to Share series (Bate 2010), the hardback books produced by Younger People With Dementia (Anwar 2013) and the two US paperback series by Stonebridge and Sparrow. An analysis of the market for such titles is beyond the scope of this thesis, but an exploration of its extent might prove to be valuable. Accessible publishing does not offer a significant source of revenue to trade publishers, and the services they used to provide such as copyediting, proofreading and rights clearance are offered less and less. Independent, web-based publishing might offer a way of producing carefully tailored illustrated texts for a specific readership without a major financial outlay. However, it is not the place of this thesis to assess the potential viability of such a project.

#### **10.5 Closing observations**

The aim of this thesis has been to investigate ways in which book design might improve the reading experience of individuals who have early-stage Alzheimer's disease. It is based on the notion that people who have always read for pleasure

may wish to continue to do so even though their memory may be impaired and their concentration limited. The thesis suggests that judicious modifications to the design and layout of the page may make it possible for more readers to engage with an author's text, just as a ramp or a thoughtfully positioned handrail can ensure that disabled visitors have continued access to places of interest and entertainment. The thesis has sought to combine theoretical knowledge and practical skills and to test the outcome against the real-world experience of lifelong readers.

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## **Appendices**

### **Appendix I: Field Study**

The information below was provided by the Home Delivery Service, Hangleton Library, Hove. The original text was typed in Comic Sans and sent as an email attachment by the Library Community Engagement Manager (10.08.2016).

#### **Housebound clients living with dementia**

Most of the Home Delivery Service (HDS) clients living with dementia have a lifelong love of reading, so to have that pleasure denied as this disease progresses just adds to the challenges that stand in the way of keeping one's identity. Therefore it is important to find ways to nurture this dwindling flame.

Some of the HDS clients have gone from reading standard print to larger print which seems easier for them to read. 'E' has read widely and extensively all her life but at the age of 91 now finds it difficult to concentrate on books with a more complicated plot. To accommodate this need she has moved on to short stories and a selection from the Quick Reads collection.

Others have benefitted from talking books as they find the process of reading more difficult either through the additional problems of sight loss or arthritic hands which mean they are unable to hold books for any length of time. 'G's sight is very poor and he has very limited mobility caused by a stroke, leaving him really most comfortable lying on his bed. Even sitting to watch TV is uncomfortable, so talking books have been what he calls his "life savers".

As the disease progresses, other clients have benefitted from the 'Pictures to Share' collection. These attractive picture books are specially designed to appeal and

provide an alternative to the complex and confusing modern media that surrounds us. They offer opportunities to open memories and discussion between the person with dementia and their family, friends and visitors. For example 'J', is living with advance dementia and is unable to read or concentrate to listen to talking books. But she gets a lot of pleasure sitting and talking about the fashions pictured in the books and her choice of clothes in her younger days.

These are just some of the ways that libraries have helped to keep people with dementia connected with their passion for reading and provide an opportunity to escape from the everyday world.

## Appendix II: Field Study

Summary of answers given by Participants 1 and 2 during voice-recorded interviews carried out on 14.03.2016. Verbatim responses are given in italic type.

### PARTICIPANT no. 1

#### 1. Questions about reading habits

- i. Do you read for pleasure?

*Yes.*

- ii. What sort of things would you read in a week – newspapers, magazines, novels, ebooks? [Samples to be shown.]

*Two newspapers read every day, The Sun and The Argus. Friday Sussex and a motor racing magazine also read. Does not read fiction, but likes autobiographies, e.g. by Clare Balding.*

- iii. How do you come across books?

- a. Do you buy them?

*Buys them from charity shops – sometimes has made a mental note to look out for them (e.g. Clare Balding book).*

- b. Do you borrow them from friends or from the public library?

*Does not use the library. Goes on Amazon and asks his wife to ‘book’ them. Has a library card and used to go to the public library for the computer. Difficulty of ‘going back up there’ to take a book back. Too painful. May go in for a look around. It is a good, big library.*

- c. Do you receive them as presents?

*Yes. Makes a list at Christmas. Asks daughter to get them.*

- iv. Do you ever read books more than once?

*No. Gives them away, except books about football and autobiographies.*

#### 2. Questions about reading preferences

- i. Do you like particular sorts of books or magazines?

*Likes autobiographies and sporting books.*

## ii. Do you read fiction?

*No. It's not real. ... That someone's perspective, what they think. Did read [local author] Peter James, a mixture of fiction and autobiography. This preference for fact is not because of his current illness. No, I like to read things what have happened ... not so much going back through history, but things what have happened to change your life ... it's what they've done, what they've gone through, so they've combatted it. ... I couldn't sit and read a book and think there's no real end to this.*

## iii. Do you read poetry?

*No.*

## iv. Do you read non-fiction – e.g. biographies, history, art history, gardening, DIY, or cookery books?

*Yes. Bob the Cat [A Street Cat Named Bob]. It's real. Saw it in the Metro newspaper and then on television. The book tells how it all happened. It is non-fiction. Could read it again. It tells you how kids can get drugs. How easy it is to happen.*

*Biographies – Roy Keane's biography really opened my eyes. Reviewed in the Daily Mail. Participant looks at reviews and offers in newspapers. Is also given books as Christmas presents.*

*DIY – would just look at the instructions and have a go. Has looked at cookery books. Just give me a little jolt sometimes. ... What have I got to do now?*

*Gardening books – no. Went to an art class for people with dementia. Has been round Brighton Museum. Likes to visit places: I have to have guidebooks, have to have something of where I've been. Likes to share with others: Remember when we went here. Likes them all to be the same size. Uses the pictures to help his memory.*

## v. How would you choose a book either to buy or to borrow?

## a. By looking at the name of the author?

*Apart from Peter James, would choose by name of the subject not the author. Appearance is not off-putting. The book need not be attractive. If it was something I wanted, I'd have it whatever.*

## b. By looking at the front of the jacket?

*[Not answered]*

## c. By reading the description on the back of the jacket?

Participant once found a book that had been left on the bus and handled it. It quickly got him hooked.

- d. By dipping into the book?

Agreed that he could get hooked after reading a few pages.

### 3. Issues to do with reading

- i. Are there some books or magazines that you find irritating, or patronising, or too hard work to read?

Not especially, just looks out for certain titles. *I'd just put it back.* Small type would not put him off if it was a book he really wanted to read, e.g. Clare Balding's autobiography.

The Alzheimer's Society magazine: *I could find that patronising – and I'm an ambassador.* Articles say get this app, but *A lot of people with dementia don't understand what apps are. ... You've always got someone with dementia stuck on the front and it's not the best-looking picture. ... I'm the only one who's been on the front cover twice.* When he was on the cover, *It was tasteful. ... I find it a bit tacky at times.* Do you find the magazine patronising? *More so now.* The new editor had changed the front cover style. *That's not right. That's not what you need. ... Give it a bit of oomph, do you know what I mean? ... I find it quite easy. They write in silly words. ... I've just read the story. I don't want a quick read [i.e. a simplified parallel text]. ... But it just seems ... they could do something more.*

- ii. If so, what is it about these books or magazines that you find troublesome?

Question not answered.

- iii. Would you say that illustrations make a difference?

Referring to DIY books, *Not for someone with dementia.* [ML queries] *Yes, but people have to go back to where they finish. Because they've got to remember what they finished on before they start again. It's like me, I have to do at least two or three paragraphs and finish a paragraph, no matter how tired I am I've got to finish it because I can't go back the next day. ... I like the illustrations in the Express on Sunday because I get Rupert. ... Roy Keane book has pictures bunched together. When you've read it and you look at the pictures you think, oh yes, that was in that paragraph.*

### 4. General questions about reading

- i. Have you read books to young children?

*Yes, I still do, especially The Zoo. [ML produces a copy of Rod Campbell's Dear Zoo] It's the same person, the same style, the same person on the back.*

- ii. Did your paid work involve reading?  
No. *Computers really, figures.*
- iii. Do you ever get rid of books? If so, do you:
  - a. give them to friends and family
  - b. give them to charity shops
  - c. throw them out

Participant would give them away, not throw them out. *No, I just think it's a waste. ... I think you need it. I think people need to read. It's a sad world if people don't read because they can't talk properly.*

- iv. Are there any books you would not part with?

Football books. Annuals from 1994/5. *Roy of the Rovers, Beano, Dandy.*

## **PARTICIPANT no. 2**

### **1. Questions about reading habits**

- i. Do you read for pleasure?  
  
*Yes.*
- ii. What sort of things would you read in a week – newspapers, magazines, novels, ebooks? [Samples shown.]  
  
*All of these.*
- iii. How do you come across books?
  - a. Do you buy them?  
  
*Buys some (see below).*
  - b. Do you borrow them from friends or from the public library?  
  
*Occasionally borrows them from other people. Also buys book on line. Does not go to the public library. Doesn't need it, although she used to have a library card.*
  - c. Do you receive them as presents?  
  
*Yes.*
- iv. Do you ever read books more than once?

Used to, but not now. They are interesting but has so many books to read, even though she would probably not remember them. Wants to keep reading forward.

## 2. Questions about reading preferences

- i. Do you like particular sorts of books or magazines?

Science fiction, crime, quirky books.

- ii. Do you read fiction?

Yes. Likes quite deep books, not mainline; likes love-them-or-hate-them books, quite dark books. One book was quite bizarre, stuck in her mind. Likes the unusual. The writing has to be good. Books have to be quite psychologically deep, not shallow. Likes a complicated psychology.

- iii. Do you read poetry?

*Yes, absolutely.*

- iv. Do you read non-fiction – e.g. biographies, history, art history, gardening, DIY, or cookery books?

Reads books on gardening. [National Trust book on allotments is produced.] Read it on the train. Non-fiction. Very simple, has everything you could want, including drawings. Participant has an allotment and has bought three or four books on allotments. Bought it for herself. The book is small, fits into the pocket, feels it should be carried around. Just saw it on the shelf. Her type of book, how things used to be done, not chemical gardening; likes the old-fashioned feel of the book. Would read it over and over again. Has used the information because it works. No author given for the book, but the NT Jane Eastow is credited with compiling it. Cost £7.99 and is worth every penny. Participant is not a member of the NT. Bought the book in Waterstone's. She is a bookshop-goer.

- v. How would you choose a book either to buy or to borrow?

- a. By looking at the name of the author.

Looked for a book on allotments, and this had it as the title, and it was small. Dipped into it. It has no blurb, so flicked through it.

Participant is a reviewer for NetGalley. Harper send her books as they know she will enjoy them. Books that have been chosen for her. Not always right. For the last one, she read the description and looked at the picture, but could not read it at all. Stopped after five pages, the style of writing involved long descriptions of everything; she lost the plot, the sense of the plot, could not tell what the book was about. The story had time shifts. She cannot retain all of the information. Sentences were too complex.

Sometimes she reads difficult sentences out loud. They are sometimes too long, too rambling. The author skips about, taking different viewpoints. She really tried with this book because some lines were good. Normally pursues a book. Has learned to give up after a couple of chapters – but has to have a good reason. Not her kind of book. Especially dislikes romances – why are there no murders, she wonders. Modern books often include romance and relationships and that is all right. A description that is not going anywhere is pointless. Also details of family relationships. *Can't hold any of that.*

- b. By looking at the front of the jacket

Normally would look at name of the author of the book.

- c. By reading the description on the back of the jacket

Reads the blurb and reads about the author. Finds the author quite interesting. Participant is a deep researcher of books. She is a first line reader – if it gets her, she gives it a chance.

- d. By dipping into the book?

Dipped into it. Flicked through it.

### 3. Issues to do with reading

- i. Are there some books or magazines that you find irritating, or patronising, or too hard work to read?

Participant finds W.L. Ripley patronising. Patronising to women – a cowboy genre. But likes his writing and sometimes thinks *that's so good*. Women are awful, caricatures. He is still writing, and his most recent output is even worse. But she loves them. The story and the writing have quality. *I can see it.*

One book (by a different author) was so awful ... the first two were passable but the third was paedophilic. The book was already on sale. Other people found it *disturbing*. Set in Vietnam and Cambodia and a character visits a brothel. Publisher did not seem to have read the text. She felt very angry about the book.

- ii. If so, what is it about these books or magazines that you find troublesome?

Women's magazines, soap magazines [cringes]. Does not find them interesting, does not like gossip, celebrity culture. Could read them but chooses not to.

- iii. Would you say that illustrations make a difference?

Participant shows ML her bookshelves and selects an example of an illustrated text: *A Wayne in a Manger* (Gervase Phinn, 2006, Penguin).

*You would need these illustrations in here.* Treated herself to this one too. Comments that it is a nice little book, so funny. [She reads, with accents, and laughs.] Nice presentation – not childlike, definitely for adults. Draws attention to the wide line spacing and comments on pauses that allow the reader to think.

Participant had 2–3,000 books before she moved onto her boat. Kept the most precious ones.

#### 4. General questions about reading

- i. Have you read books to young children?

Read to her daughter all the time. The daughter knew ‘The Lady of Shalott’ at a very young age. Reading to her daughter was very important.

- ii. Did your paid work involve reading?

No. Her extensive book reviewing grew out of GoodReads then NetGalley. Receives advance proofs in a digital format. Submits her comments to the publisher, e.g. *I really wanted to know about that character. ... It is pure pleasure, pure escapism, and that’s really important for me.*

- iii. Do you ever get rid of books? If so, do you:

- a. give them to friends and family
- b. give them to charity shops
- c. throw them out

*Never, oh never. Never thrown a book out in my life. Books stem back from my childhood. I would escape from my childhood in a book.*

- iv. Are there any books you would not part with?

Yes. As a child, Participant read books over and over again. Did not have many. Was given book tokens at Sunday School. *It transports me into a nice feeling. That was my escape. Books were very precious. Keeps her books.*

## Appendix III: The design briefs for the research studies

The instructions and materials given to the designers of the Participant Interview Study, the Textual Additions Study and the Book Cover Study are summarised below.

### 1. Participant Interview Study

The designer was provided with a written brief (see below) and with the text for each spread prepared as a Word document. As a guide to the required layout for Samples 1, 3 and 4, images of the relevant pages from original publications were supplied. An image was also provided of a paste-up which the researcher (ML) had prepared from photocopied pages of the OUP Bookworms edition of *The Thirty-Nine Steps*.

The instructions to the designer were as follows:

#### 1. Research topic

The topic of the thesis is the content and design of books for readers with early-stage Alzheimer's disease.

#### 2. Aim

To produce four pairs of spreads to show to volunteer readers. Each of the four pairs is based on an existing publication but, in each case, one spread has been modified to isolate a particular issue. The spreads would need to be folded and trimmed to look like the original publications.

#### 3. The spreads

##### (i) Buchan, *The Thirty-Nine Steps*

The two spreads are to show the alternative positioning of an illustration:

- a) at its point of reference within the text
- b) on its own on a facing page.

For (a) the chapter number and chapter title on page 8 are to be removed and sufficient lines of text taken back from page 9 to fill the page.

For (b) the illustration currently on page 8 is to be moved to page 9. There is to be no text on page 9, but the running head, folio and rule are to be retained.

On page 8, the chapter number and chapter title are to be removed and sufficient lines of text taken back from page 9 to fill the page.

Specifications (to match the printed book):

tps 197 x 128mm  
text set in 11 on 15 point Sabon  
off-white paper

**(ii) Rubens, *Portrait of a Woman***

The two spreads are to show an image and related text on facing pages:

- a) one layout to present the text as continuous prose
- b) one layout to have subheadings.

The text for this spread is not taken from an existing publication. The spread should have the characteristics of an art book that is intended for the general reader.

(Suggested) specifications:

tps 240 x 195mm  
text set in a conventional serified typeface (e.g. Sabon, Minion), at a generous size  
headings and side-headings to be highly visible but not over-emphasized  
ligatures and non-lining figures, if available  
full-page colour image (larger than in sample)  
narrow border to be added to simulate picture frame  
wide text margins  
white, coated paper, 120 or 150gsm

**(iii) Lynda La Plante, *The Little One***

The two text spreads are to show two different treatments of dialogue:

- a) an excerpt with no indication of the identity of the speakers
- b) the same excerpt with the speakers' names added to the dialogue

The spreads are to match the original publication as far as possible.

Specifications:

tps 197 x 128mm  
text set in 12 on 16 point Stone serif, justified  
opaque off-white paper

**(iv) Katherine Mansfield, *The Doll's House***

The two text spreads are to show alternative versions of one paragraph of prose:

- a) the paragraph of text as published
- b) the paragraph of text edited in order to reduce the complexity of grammar and vocabulary

Specifications:

tps 212 x 135mm  
text set in 12 on 17 point Adobe Garamond  
headings as in original  
opaque off-white paper

#### **4. Materials**

Draft versions of all the spreads have been prepared as Word documents, and these will be provided as Word files and hard copy. Scans of images are also available. The original publications will be provided.

#### **5. Requirements**

The designer will be asked to supply each file separately.

Arrangements for printing out each spread to be discussed with the designer.

#### **6. Follow up**

The materials supplied are to be used for a pilot study [later incorporated into a single study]. Any adjustments that need to be made in the light of this study will be paid for separately.

### **2. Textual Additions Study**

The designer was provided with a written brief (see below) and with the text for each spread prepared as a Word document. As a guide to the required layout for Sample B and Sample C, a pencil sketch was prepared by ML. A photograph of the sketch was taken by the designer for reference.

The instructions to the designer were as follows:

#### **1. Sample material**

I propose taking copies of three sample layouts to the meeting and using these to prompt discussion. The layouts are:

**Sample A: title page with list of characters opposite.**

Left: list of characters

Right: title, subtitle, author's name, etc.

See suggested layout and file of text.

It is not ideal to have text on the page facing the title page, but the important thing is that readers know where to find the list of characters when they are reading the text. Somehow, the two pages need to function as a whole spread.

**Sample B: layout with a summary at the end of a chapter**

Left and right: text of end of Chapter 1.

Right: summary of Chapter 1

See suggested layout and file of text. Adjust the amount of text to fit.

The aim is to make the chapter summary visible but not conspicuous. Readers do not want to be patronised. Perhaps the chapter summary could be put on a subtle grey background.

**Sample C: layout with a plot summary opposite the chapter opener**

Left: summary of the plot so far

Right: chapter opener and text to fit.

See suggested layout and file of text. Adjust the amount of text to fit.

Again, the aim is to offer the plot summary to those who would find it helpful. Perhaps put a subtle grey tint on the whole of the left-hand page? This would distinguish these pages from the text of the story and would allow them to act as markers in the book. The aim would be to have all chapters starting on a recto with the plot summary on the facing page.

**2. Other design considerations**

As we discussed, the aim is to produce a text that will ensure smooth reading. Participants are likely to prefer:

- a serif typeface that is modern and stylish but also appropriate to the subject matter (Sabon? Minion?)
- a type size that is suitable for readers who do not have perfect vision
- generous leading
- wide margins (to allow the book to open easily)

- working running-heads and page numbers – i.e. not too discreet
- no distracting clutter, although ornaments that add to a feeling that the book has been designed – and not just put together by a computer – would be welcome.

### **3. Book Cover Study**

The designer was familiar with the purpose of the research, so a verbal briefing on the function of the book covers and bookmark was given at an initial meeting. As a guide to the required positioning of the text on the book cover and on the bookmark, ML showed the designer the simple mock-ups she had put together using *The Great Gatsby* as a base. The designer took photographs of the mock-ups to use as reference when preparing the sample materials. At ML's request, the designer also supplied a photograph of the pencil notes and sketches made during the meeting.

## Appendix IV: Participant Interview Study

Letter of 15.12.2016 confirming HRA Approval (pp. 1–3).



Ms Marie Leahy  
 Doctoral researcher  
 University of Reading  
 Department of Typography & Graphic Communication  
 University of Reading, Whiteknights, Reading  
 Hove  
 RG6 6AU

Email: hra.approval@nhs.net

15 December 2016

Dear Ms Leahy

**Letter of HRA Approval**

<b>Study title:</b>	<b>Interview study to investigate ways of improving the reading experience of people with early-stage dementia by modifying text presentation (version 1)</b>
<b>IRAS project ID:</b>	<b>208091</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>REC reference:</b>	<b>16/LO/2064</b>
<b>Sponsor</b>	<b>University of Reading</b>

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

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Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

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**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

**HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **208091**. Please quote this on all correspondence.

Yours sincerely

Catherine Adams  
Senior Assessor  
Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Dr Mike Proven, Sponsor Contact*  
*Mr Stephen Zingwe, Berkshire Healthcare Foundation Trust*

NIHR CRN Portfolio Applications Team

## Appendix V: Participant Interview Study

Participant consent form supplied by the Berkshire Memory and Cognition Research Centre.

### CONSENT FORM

Title of Project: **Improving the reading experience of people with early-stage dementia**

Name of Researcher: Marie Leahy

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information provided. Any questions I have asked have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I give my permission for the interview to be voice recorded.
5. I give my permission for the researcher to make notes based on her observations.
6. I agree to my General Practitioner being informed of my participation in the study.
7. I agree to take part in the above study.

Name of participant	Date	Signature

Name of person taking consent	Date	Signature

## Appendix VI: Participant Interview Study

Transcriptions of interviews with Participants 1 to 10. The comments of Participants (P) are given verbatim and in italic type.

### PARTICIPANT no. 1

#### Sample 1: John Buchan, *The Thirty-Nine Steps*

*I prefer this one [version with picture opposite] ... it seems more clear to me ... I can read that easily [P. reads then stops] ... [ML they've put a few pictures in just to] remind you ... I think really you don't need a picture ... I don't need [it], I like my mind to work ... actually that would suit me better, I think ... [P. reads title] ... that's a classic, isn't it? ... I don't mind illustrations, I think they're more for younger people that probably don't understand the text and it gives them an opportunity to think about it, so it promotes thinking ...*

[ML you don't really need a picture?] ... *not really, no, for me I don't ...*

#### Question 2

[at 6:28] ... *if there are to be pictures then you've got to have captions ... no I don't think I do, because if I know the story ... I did a lot of reading at school ... personally, I don't need a picture ... [discusses The Globe Theatre]*

#### Sample 2: Portrait by Rubens with accompanying text

[7–13:00 mins, P. initially takes headings to mean the main headings. Really, no response to the question and no evidence that the participant has grasped the force of the question.]

Eventually, reads the last paragraph comfortably except for 'IV'. Declares he is not a royalist. Acknowledges that this is a 'pretty lady'. Interesting amount of historical information volunteered.]

*I can see all that I want to see on the television ... if I read a book it's an insult to my intelligence, I feel, to have illustrations ... I mean, I read at school ...*

#### Sample 3: Lynda La Plante, *The Little One*

[15:07 mins] *Yes, I think you do have to have a help to visualise the story more ... [P. reads the first paragraph easily, correcting himself from 'hugging' to 'bugging' and hesitating over 'Harwood House' – given in italics] ... [ML*

comments that author omits names] ... *to help you visualise it more, to stimulate your memory* ... [ML better to have the names?] ... *I'm not sure, I can't be sure* ...

*If you're really interested you go back* ... [ML if you're reading Shakespeare] ... *you have to have a good understanding of what they're saying* ... [ML comments on the usefulness of added names] ... *well, you need to know who's who* ...

[P. reads about countries and shows knowledge of Russian history. Likes to read books] ... *where there's an element of truth* ... *I like to read stories* ... [M asks about reading fiction or non-fiction books] ... *it depends on the intellect of the person* ... *I'm not reading for information, not really, I think I've got as much information as I can contain now* ...

[ML sent photocopy of spreads with added names indicated in red. Covering letter sent and a sae (10.03.20170. Reply received. No need for added names.)]

#### **Sample 4:** Katherine Mansfield, *The Doll's House*

[26:56 mins, ML wonders whether it's easier if the language is smoothed out a bit] ... *no, because the point is that book is written by the author and it's how he's written it and the way he's spoken the words that he envisaged, so it's a bit insulting if you don't follow the script* ... [reads with some feeling until gets to the complicated part] ..

[10 minutes before the end, while spouse makes the tea] ... *I drove a London taxi* ... *I enjoyed my working life very much.*

## **PARTICIPANT no. 2**

#### **Sample 1:** John Buchan, *The Thirty-Nine Steps*

[ML shows participant the sample text from Bookworms series] ... *what are quick reads, is it a sort of abbreviated version?* ... [ML explains] ... *As it happens, it's at the end of what was presumably chapter one* ... [text does not indicate this] ... *and so that starts quite conveniently at two and, just above, is the actual words of what's happening in the picture, so in that case that seems like a good arrangement...* [ML any advantage in having it on a page of its own?] ... *no, I don't think so, it's just a waste of paper... I don't think it achieves anything, really, that's as good as it can be, really, the words of the picture happen to be just above it, and that's the end of the chapter* ... [So they've got it right] ... *much better* ...

[ML forgets to ask specifically about the captions]

**Sample 2:** Portrait by Rubens with accompanying text

[2:56, ML explains] ... *and are these aimed anybody with slight difficulties* [ML mentions memory difficulties] ... *I think you do ... if they can spare the paper, I think this* [indicating layout with headings] *is good ... this isn't bad, I mean it still follows and you can still follow the description of the painting ... um, but that does just split it up and make it easier for anybody who might be having difficulties...*

[Typeface] *It's the same typeface, isn't it?* ... *No, I think they're fine.* [ML asks if this is a book participant would browse through] *I like art books ... There you go ...* [P. reads] *it was bought by George the Fourth* [correctly read] ... [ML comments on poor quality of image] ... *perhaps it's the reproduction, sometimes* [with] *old paintings you get sort of a golden cast to it ...* [participant continues to read the text, so ML asks about bleeds] ... *you know that that's the painting, yes, I agree with that ... I think it* [bleeding] *could be misleading, yes, you need to know where the borders are ...* [ML says that's why she has given dimensions] ... *so that's the actual size of it, 33 by 23...* [ML mentions a yard and participant repeats] *a yard ...*

**Sample 3:** Lynda La Plante, *The Little One*

[7:40] ... *so this is the same down to here ...* [participant reads text out loud] ... *um, I'm not sure you need 'Barbara replied there' because it's obvious it's set like dialogue ...* [participant continues to read] ... *that's obvious that's between two people ...* [reads the text, ML repeats aim of the exercise] ... *it doesn't look terribly different ...* [reads again] ... *it doesn't look very different at all* [ML explains again, P. reads again] ... *ah, there it says, 'Barbara replied', I don't think you need that ...* [it's obvious] *when it's set like that ...* [ML reminds] ... *there's only two of them there...* [ML mentions visualising the scene] ... *you don't need 'said Alan' there ... I think that makes it a bit cluttered... where is says 'said Alan' and 'Barbara replied', I don't think you need that, it's obvious it's dialogue ...* [agrees with ML] ... *the layout's very important ... there, I don't think you need that 'said Alan', I mean there's only two of them around, isn't there, in the scene ...*

[14:07, ML compares type to Buchan] ... *well, I mean, this is ... if anybody's got a bit of an eyesight problem, this is obviously better .... But it's the size that you'd get in your Enid Blyton books or children's literature, that size, I think ...* [ML patronising?] ... *no, I don't think so, it depends on what your eyesight's like ...* [childish?] ... *no, I think, well it depends, picking a book up, whether you're buying it or at the library you make a subconscious judgement on the typeface, I think ... this would obviously make a book thicker ...* [children's book if picked up in the library?] ... *I've heard of her and she's an adult book writer anyway ... I think that was intended for somebody who with slightly visual problems ...*

[16:10, ML presses on addition of names, not necessary because 'you can visualise the scene?'] ... *you don't need that one, nobody else has entered the scene, there's only the two of them, so some of those are superfluous ... just a bit*

*clutterly ... I mean, when it's describing a scene like that, you need that in because she's eating now and it's ... filling in the scene, as it were ...*  
 [18:01] ... *there's a big margin all round ... the margins are bigger there* [ML admits that she should have trimmed the sheets] ... *but it's the same size ... the paper's all right, it's a bit coarse, thick, it's all right ...* [ML points out that it's not very white] ... *no, it isn't that white, no ... it wouldn't bother me ... it's the sort of typeface and size that you'd expect not of a child but somebody a bit older, perhaps between ten and fifteen maybe at the most ...* [P. continues to read and eventually stops].

**Sample 4:** Katherine Mansfield, *The Doll's House*

[19:52, ML shows participant the book, discussion of reading aloud] ... *it's broken up into more sentences, is it? There's a break there ...* [reads carefully] ...  
 [25:19] [ML Does it matter if you stumble?] *What, when you're reading to yourself or out loud? ... No* [with some feeling], *I don't think so ...* [ML asks which version participant would prefer] ... *Which is the original? ...* [ML confirms, participant reads closely] ... *I don't know why they've put brackets round that, really* [reads to h.s.] ... *I like that one, this one here* [indicates edited version] ... [reads 'for really, the smell of the paint etc.'] ... *It doesn't matter really, but that seems more of a flow ...* [ML comments that it is interesting that participant drew attention to the parentheses] ... *see, I'm not quite sure about the brackets, it's a speech and it's got the speech marks round it, and it's got 'Said Aunt Beryl' after it ... I think that's messier somehow with Aunt Beryl's opinion at the end ... Very subjective these things, aren't they?* [ML explains again. Participant goes on reading to h.s.] *There's not a lot of difference really, is there.* [ML repeats the question and points out where the differences are in the para.] *Yes, there's not a lot of difference, really.* [ML discussed editing] *I think that some of the old books, even our old favourite books by the classics people could have done with a bit of editing, for that very reason you've just said about going back.* [ML mentions the work of an editor] ... *I think flow is important, really* [P. goes back to reading] ... *you'd have to be really quite picky to start picking about it* [ML summarises that the difference has been noted] ...

[31:52, ML asks who the Tolkein reader is] *Oh, [spouse's name] actually. Not my favourite, I have to say.* [ML demurs] *Have you not? ... man's novel ... he just sort of took to that, he reads it periodically, every so many years...* [ML and P. laugh] ... *it doesn't do anything for me at all ... we both read a lot ...* [ML points out French dictionary] ... *yes, I enjoyed my French* [discusses French O Level, but] ... *left at 16 so didn't carry that on ...* [P. goes back to text] ... *Is there a reason that they've stopped this page there?* [ML explains] ... *end conveniently on the end of the page* [ML asks if it is better to carry the reader on to the next page] ... *like this? No, I would say that anyone who's got a bit of a problem would find that easier* [indicating paragraph ending at the foot of the page].

[35: 11, ML asks about the type] *Oh yeah, the type's fine, it's like many books, isn't it? What's the name of it? ...* [ML mentions the extra leading] ... *Oh, wide spacing between the lines ... Oh I see, it's supposed to make it easier, perhaps it*

does ... compares book to ML's layouts ... *It's got to be the same as this, isn't it? These spaces are very similar, it might be a fraction wider ... between the lines* ... [P. goes back to text, ML reminds her that the question is which one is easier] ... *I like that better...* [P. reads both out loud and indicates the original version] ... *that flows better, sounds better, just everything* ... [ML summarises, noting change of opinion] ... *It's better writing, if you like* [ML asks if good writing can be hard work] *I don't think good writing could ever be hard work, but then I'm a bit prejudiced ... because I read a lot ... no, I don't think it would be hard work* ... [P. starts reading again, especially the sentence with parentheses] ... *Don't like the brackets, I think avoid brackets if you ever can* ... [P. reads again] ... *there's been no change in this bottom bit* ... [P. notes repetition of the phrase 'the smell of paint' ... continues reading in silence] ... *yes, the edited version ... it's funny, isn't it, what you prefer and don't prefer and you'd be hard put to say exactly why ... it's sort of to the ear, isn't it* ... [ML discusses Woman's Own and whether people like to read something more substantial] ... *something a little bit that stretches you* [ML observes that P. is a reader] ... *Oh yes, voracious is putting it mildly ... we both read a lot ...different things, of course.*

[43] *I do read my Graham Greene books, over* [ML asks about re-reading books] ... *yes, I do go back and read them.* [ML comments on Dickens on the shelf, so a heavy-weight reader?] ... *no, I don't find him a heavy weight* ... [ML asks about picking up books in the library and flicking through] ... *I know, really, after a couple of pages, whether I'm going to enjoy it ... and the story should, I think, grab you, it should take you in fairly quickly* ... [ML any books P. puts down?] ... *Sometimes, yes, I do, but I usually give it a page, I'm usually in the library, I do buy the odd book but it's usually library ... if it hasn't grabbed you by page two, I think it's not going to* ... [ML asks if the library is nearby] ... *Yes, Tilehurst branch is* [P. gives directions and says she can walk there in a quarter of an hour].

*Well, that was interesting* ... [P. comments as voice recorder is switched off]

### **PARTICIPANT no. 3**

#### **Sample 1:** John Buchan, *The Thirty-Nine Steps*

*...that one* [indicates the spread with the illustration in the text] ... *because it's actually talking about it above, and then you've got the picture below ... whereas here I'd be reading it and not necessarily* ... [cat interrupts] ... *I don't know whether I would read that and then look over there ... whereas this ... it's a bit like a comic in a way ... where it's telling you what's going on, if you like* ... [P. reads the text] ... *and there's the picture showing you it* ...

[Captions] *Um., I don't know whether it would or not, because that's actually there telling you what's there and I don't know whether you'd need that as well ... there I'd be reading and I wouldn't necessarily link that ... look at that picture it's a bit like a comic, really, because you've got the picture and whatever's going on ... You're reading it and it's showing you what's going on*

*as well whereas that you're reading it and you're not necessarily looking at that at the right point ...*

**Sample 2:** Portrait by Rubens with accompanying text

[1:53] ... *Again, with my memory problems, I think that [P. indicates the version with the headings] because it's actually giving you a heading of what you're talking about ... the artist, the painting, plus the fact that if you want to, you know, with a memory problem, go back and say who wrote who painted it you've just got to look there whereas that you probably have to re-read it ... again, if you like ... so it's actually giving you headings and the information under the headings.*

[Typesize] ... *are they both the same [of the main headings] because they look it ... yeah, because it's actually, in a way, reminding you of what you're reading about, if you like, you know, who it is, who painted it, where is it now, again it's sort of like a reminder – where is that painting now and you haven't got to re-read all that again. [ends at 3:57]*

**Sample 3:** Lynda La Plante, *The Little One*

[... pauses a long time, ML explains, 05:25] ... *this one mentions his name quite a lot ... reminded of who was speaking, yeah, ... I think it probably helps a bit, because I'm all right reading a book I've read before, I still have memory of that, but a new book I do have to flick back and remember who the characters are so, I think, yes, it probably does ... sometimes you can read a conversation between two people ... their names aren't mentioned at all, you know, they might have been on the previous page, but [you have to look] back to see who's talking now ... so, yeah, I think it does help to sort of throw in their names [but do you find it irritating?] ... [10 seconds pause] ... Are these two not identical? ... Oh right, I haven't worked out where the difference is yet, let me just see [ML discovers error] ... I was going to say, they look identical to me ... sometimes ... like tv programmes, if I think something's going to be a bit complicated, I save it until I can watch it and go back on it if I want to ... and ... it's like having a reminder, if you like .. ... I see what you're saying, you're reminded of whose talking ... some books you can go on for quite a while with conversation ... initially their names are said, but ... I suppose it's also degrees of memory loss, I don't know down the line how it's going to go, but ... [ML compliments participant on spotting her error] ... I still try to read my own books and I read a paragraph and then I think, Oh, who said that, you know ...*

[ML does not ask Question 2 specifically as Participant has covered the point.]

**Sample 4:** Katherine Mansfield, *The Doll's House*

[long pause for inspection, ML repeats the question] ... *I think that one, to me, is clearer [the edited version] ... Is this the adjusted one, if you like? ... I think it*

*explains things more ... to me, that's, if you like, with my memory problems, clearer than the other one ...*

Supplementary recording 160 702\_002.mp3

[ML presses for information on stumbling and re-reading] ... *I do find now, I mean, not before ... I do find now I need more description, you know, of what's ... whereas in a book sometimes it's left to your imagination what's going on... and I do find now I probably need more information, may be put it down on paper more, what is going on other than leaving it to your imagination, because I don't know with memory problems whether you lose the use of imagination, but I can't always visualise what the what the author's probably trying to tell me, if you like, ... [ML asks about long sentences] ... I do find them a bit difficult you know ... not that they rambles ... on but by the end of it I'm thinking I'd better read that again. Because I can't always remember from one end of a sentence to the other exactly what they are trying to get at ... [ML asks about re-reading things, participant takes this to mean entire books] ... Well, before I was ill, you know, some books I've read four times over because I like them ... and if it's a story I like, for example *The Thirty-Nine Steps*, I love *The Thirty-Nine Steps*, I used to love *Geoffrey Deaver*, you know, I love a good murder ... [ML mistakenly asks about re-reading a sentence] *what, before?...* I don't know if I ever really thought about it, it never seemed to .... There probably was occasions when I had to re-read something, sometimes you can't always take in what the author's trying to tell you, if you like, and you might think, Oh, I don't really understand that and I'll go back to it whereas now I might not understand it but I've probably got to go back to it anyway because I've forgotten what they've written ... [ML you can't always get the sense of it the first time] ... no, no, because some stories are so convoluted, if you like, you've got to try and put yourself in the author's position and think what are they trying to get at without reading the last page to see who murdered ... [ML does it put you off?] ... well, I will own up, because of my memory problems I tend to, at the moment, re-read stories I've read before because I still have some memory of them, like *The Thirty-Nine Steps* or whatever it may be, or *Geoffrey Deaver* murder mysteries, I used to love ... I used to like *Jane Austen* books, you know, those sort of thing, *Pride and Prejudice*, *Sense and Sensibility*, even a bit of *Charles Dickens* ... yeah, I would sit and plough through it, I wouldn't always say I enjoyed it particularly ... I find that some books are too long, you know ... a very clever writer but ... [ML you're a reader] ... I always was a reader, I think that's the thing I miss the most with the memory problem, especially as it didn't happen to me slowly, it's what they call sudden onset ... you know, one minute I was ok and the next minute I wasn't ... and it wasn't like you'd got time to get used to not being able to read, if you like, ... yes I could read, but not remembering what I'd read, so I did try re-reading books I've read before because I still have some memory of them ...*

#### **PARTICIPANT no. 4**

**Sample 1:** John Buchan, *The Thirty-Nine Steps*

[Discussion of new technology] ... *I'm a hands person ... well, I did hairdressing from 15 to 65 [ML you're a creative person] ... and I can do it with my hands but I was never any good with my head ... [ML but you read at night ... for pleasure?] ... just for that half an hour, depending how tired I am, sometimes it's an hour, and I just read, but I never think of picking up a book during the day ... [ML too busy?] ... yes, I suppose so, yes, that's a good thing to be busy ... I have a couple of magazines that I buy each month and so I read those, but ... [ML is reading a luxury?] ... no, .. and first thing in the morning, now, I don't go to work, that's a real treat that is .. [ML fact or fiction?] ... I like a good story ... I don't like a sloppy story, you have to be a bit careful, don't you, I bought a book last month, I think it was, and I thought, this is awful... well, I did finish it but it wasn't what I would have liked ... I don't like starting a book and not finishing it [P's spouse brings in supply of paperbacks] ... oh, they're my books ... This is my favourite, this is, ... and I find that's really brilliant because my eyes get sore by the time ... by the time you get at night ... [[ML comments] ... they're nice stories ... [ML comments on Jojo Moyes text] ... that's what I like reading .. [discussion of jumble sale] ... I have daughters but they don't like reading the same things as my books [discussion of three daughters and Dubai, then spouse leaves] ... I never read a book twice ... [P. supplies more information about the source of books] ... there was one book I had, I really, really liked it, and I hadn't read it for about six months and of course ... after I'd done about three chapters, I thought, I know the end, so ... [ML asks Question 1] ... no, I think I prefer to read a whole page and have it there [opposite] than have a little bit up there and a little bit down there ...*

[ML tentatively moves on to Question 2] ... *no, but I think you take more notice of the picture if it's on a blank picture [sic] page ... there you just read that and you read that ... and you wouldn't necessarily take notice of that [the picture] ... [ML explains the books are ESOL] ... to help them know what the English understands it, yes, as you're reading that [image opposite] you're looking at that picture ... this, you read that page and you read that and you forget about it ... you don't bother to take any notice ... [ML getting back into the text again?] ... yes ... no, I don't think that would be an issue on reading the page, if I got a far as there and I looked at the picture [opposite] I might think, oh, what was all that about, so I'd start reading the page again ... just to check what it was all about ... [ML puts the case for each] ... I suppose it depends what the story's like ... [ML encourages] ... if it's a really interesting one you don't need pictures, do you? ... [ML is it patronising?] ... no ... I think occasionally, if you've got a big book and you're reading a lot of it, I think it's probably a bit of a ... yes, I remember that, that was a couple of pages back ...*

[Captions] *No ... [ML and if the picture was opposite?] ... I think it depends what the picture is about ... probably, if I started reading this one, I'd read that, I'd skip the picture, read this and then I'd turn over ... but because it's there, you look at it as you're reading that, so yes, it probably does ... I think you automatically look at it whilst you're reading ... without actually thinking about it, it's going in through your eyesight ... but that, you just read that bit then you go down and over there and you don't think ... whereas that's in your eyesight the whole time you're reading ...*

**Sample 2:** Portrait by Rubens with accompanying text

[ML explains, P. starts reading] ... *that's about the picture and that's about the artist* [ML continues] ... *I think, if it were me, I'd open it up, I'd look at the picture then I'd read this then I'd turn it over to the next page ... whereas this, because it's in separate bits, you look at the picture, so you read that and you'd look at the picture ... rather than just there's a picture there, I'll read ...* [ML it slows down the reading? Does it help?] *I don't think it helps in the reading of it, understanding it, it's something that you probably put a little bit more into because you look at the picture and you see other bits that you wouldn't look at straightaway ...* [text is the same] ... *it's just that it's in a different perspective, isn't it? You kind of look at that and you read this and you look at that and you think um, yes, that's it, and you're down here and you think of something else that was in the picture, so you look at it again ...* [ML asks about remembering it, participant indicates no] ... *not particularly ...* [ML explains about textbooks] ... *if you're reading for pleasure you remember the book and once you've finished that book you forget about it unless you make a mistake and you buy the same book in a shop and you get half way through the first chapter and you think, I've read this ...* [ML says it's the sort of book you'd keep on the shelf] ... *yes, well we keep books until we haven't got any more room ... we've got rows and rows of them ...* [ML asks about disposal of books] ... *there's a few that I still just ... especially if they're hardbacks ... I do like a hardback, not so good when you're reading in bed because they're a bit heavy ...* [ML agrees] ... *but if they've got a hardback I keep them, they're proper books* [P. laughs] ... *sounds daft, doesn't it?* ... [ML indicates the pile of books to be given away] ... *it's a paperback, like a magazine, but if it's a hardback I keep it ...* [ML returns to headings guiding the eye across] ... *yes, because you look at the picture first ...* [ML Why?] ... *because you see it first and then you look at a bit and then you'll look back again ...* [ML breaks it down?] ... *if you're reading something like that, you look at her, I think it depends on what sort of person you are, I mean I am a person's person, I mean all my working days I was a hairdresser, I was looking at people's faces ... that's why you have a different ... if there's a picture, I look at it and I look at their faces ...*

[Typesize] *No, I think that's quite good, I mean, I wear glasses, if I couldn't wear my glasses I could still, just about, see that and it's also a nice clear picture [?] that doesn't make your eyes sore ... the spacing and the dark print on the white paper, that's another good thing ... I mean, I read a book last year and it was very fine, it was dark print but it was very fine* [ML the paper?] ... *it was white ... but that's still a nice bold ...* [ML comments that the paper is heavy] ... *yes.* [ML and P. discuss of benefits of white paper] ... *and also, when you hold it like that she's still looking at you ...* [ML asks about position image on left or right] ... *I think's that's quite good because as you're reading that she's watching you .... I think it does make a difference because if you're reading this page and you see a picture there you don't really take a lot of notice of it and you just turn it over ... so if you've seen the picture and then you read it's in your mind ...* [ML true also of a flower painting?] ... *if the text was about the picture, I would, and I would go back and look at the picture and the flowers but is that because I like flowers?* [ML asks where on the spread she would look] ... *Oh, I'll look at the flowers first ... and then I read about it, but if there's something about a flower I'll look back [at the picture] ...*

**Sample 3:** Lynda La Plante, *The Little One*

[20:53, ML explains] ... [P., quietly] *I think I've read a few by her ...* [she reads] ... *I think yes, because you can connect the person with the story ...* [ML Is it useful?] ... *I think so, because you get an imagination in your head of what that person's like ... and then somebody else could read it ... they probably would tell you a completely different thing ...* [ML feels participant has not understood the question] ... *you read it as you see it ... after you've read a bit about them, you get an idea ... this one [the original] you can imagine them talking to each other ...no, you kind of think ... no, I don't think it makes any difference* [ML without 'said' would you still know who's speaking?] ... *I think you would of, because [they're probably in] the chapter before so you connect it ... it's if you've gone two or three chapters along and you've suddenly got names ...* [ML you won't forget] ... *no, I think you just ... no, I don't think that makes any difference at all.*

[ML author was right?] ... *when you're reading a book you put your own imagination into it ...*

**Sample 4:** Katherine Mansfield, *The Doll's House*

[26:04, ML explains] ... *I think I prefer that one, I don't know why... I think I prefer that one* [the edited version] ... *I don't know why, I just do, I don't know ...* [P. reads sentence about the 'feed-room door'] ... *it's more what you would expect to see, and this one* [P. reads version mentioning 'the stable'] ... *it's more what you expect to see, that's what it is* [ML suggests it is a question of vocabulary rather than syntax] ... *no, it's the way it's been written ...* [ML mentions accepting the author's prose] ... *I think it depends on what sort of reader you are, I read ... I very rarely read during the day ... I read at night and if you have bits like this, I'm inclined to miss them ... because I'm reading at night and you .... You just read on and you want to finish that bit ... you've got this in your head that you can do a chapter, or something ... Probably, if I read more during the day ...* [ML suggests she might grapple more] ... *do you know, I very rarely pick a book up during the day* [ML suggests she may be tired] ... *yes, I only retired last year so, ... yes, but I don't know, I just don't even think about picking up a book during the day, I'll read a magazine, a story in a magazine ...* [ML suggests on a train journey] ... *I would on a train, I couldn't in a car ... make you sick .... If it we go on a long journey, I take my book with me, but I often have to read some of it again because you are ... there's things going on, aren't there? You're not – like, when I read at night – you're there and you read it and that's what you listen [to] and that's what goes in, I didn't read during the day when the children were here and also then when I did child-minding, for years and years and years I didn't read during the day because I just couldn't ... I'd sit down here and I'd look at a magazine ...* [discussion about interruptions to reading and having to read bits again] ... *you have to be in the right environment and concentrate, because when you're tired you don't concentrate, but you still know what you're reading* [discussion of the effect of daytime television and computers and monitoring what the

grandchildren are watching] ... *I mean, I wouldn't pick up that piece of plastic [i.e. a Kindle] and take it to bed with me, I take a book ...*

### **PARTICIPANT no. 5**

Spouse of Participant 5 was present throughout. Both were hard of hearing.

#### **Sample 1:** John Buchan, *The Thirty-Nine Steps*

[8:00] *That one* [indicates version with image opposite] ... [ML presses] *it seems to be clearer, you know, more pronounced* ... [ML indicates the two approaches and participant repeats that he prefers version 2. ML asks about finding his way back into the text] ... *I would do* ...

[ML asks about caption, keep the caption?] ... *Yeah.*

#### **Sample 2:** Portrait by Rubens with accompanying text

[8:00, ML asks if it is useful to have headings] ... *yeah.* [ML presses, asks, gradually, if it helps to read the text] ... *yeah.*

[10:51, ML asks about type size of the headings ] *That's about right, that one* ... [thinks other headings are a different size] ... *that's clear* ... [ML asks about the paper] ... *Fantastic painting, isn't it?* [ML asks about the frame, but P. does not respond] ... *Nice, yeah ... I wish I could paint like that* ...

#### **Sample 3:** Lynda La Plante, *The Little One*

[31:34] ... *Just as it is, I'm fine* ... [ML explains again, just to be sure] ... *No, it's fine, it doesn't make no difference to me* ... [ML presses again, he reads] ... *yes, fine, I can understand all of it* ... [ML no need to be told who is speaking?] ... *no*

...

Question 2 not asked.

#### **Sample 4:** Katherine Mansfield, *The Doll's House*

[34:40] *Doesn't make a lot of difference to me.* [ML presses, pointing to the first sentence] ... [he reads] ... *it's ... any difference* ... [ML asks about difficult sentences in his book *The Tudor Bride*] *I just read and carry on ... I understand it* ... [ML asks about re-reading] ... *I'm reading that book, I've read it about three times, I enjoy it and I'll probably read it again* ... [ML comments on books to read in bed] ... *Well, she's not a dolly bird is she? She's a queen.*

**PARTICIPANT no. 6****Sample 1:** John Buchan, *The Thirty-Nine Steps*

[2:00, ML explains about OUP series and the need for a good story. P agrees. P. studies the layouts for a long time. ML asks if the position of the illustration makes a difference.] *No, I don't think so. I don't think it would make any difference. Because I can read and ...* [ML comments on readers losing their place] *... no, I don't have that problem. [You can hold it in your memory] ... yes, yes indeed [ML so it wouldn't matter] ... no, I don't think so. The narrative is important for me, or to me, and so I don't think I'd have any difficulty.* [ML questions whether P. would need an illustration. P. reads the text about the long knife] *... I [stammers again slightly] ... I don't have any difficulty following the text.*

[Caption? P. reads the question aloud.] *I don't think so, not for me.* [ML repeats the question] *I don't particularly need captions... [distracting?] ... yes, in some ways.*

**Sample 2:** Portrait by Rubens with accompanying text

[7:50, P. considers carefully] *I think these are [stammers] helpful [ML says because ...] ... they encapsulate ... the thing is, I read a lot but clearly I'm beginning to have difficulties with reading ...* [ML might headings be supportive?] *... I think so ...* [P. compares the two layouts and reads, though breaks off before the dates] *... I could remember that.*

[10:00, Typesize too big?] *... No, they're [stammers] very helpful ... and I think that that's good.*

**Sample 3:** Lynda La Plante, *The Little One*

[10:25, ML queries whether P. has ever read any of LLP's books] *... I've seen the television series [ML describes the QR series, P. takes the point about 'limited' exposure to literature – uses the word 'limited' which ML has just used. P. reads, ML repeats 'said Alan' etc.. P reads. ML suggests that she should have underlined the changes.] No, no, this is ... so the red dots are the ...* [ML explains again] *... Oh, right ...* [ML explains again] *... I think that's a very good help, actually ...* [ML acknowledges what P. has said, and P. reads the sentence about Alan being a butler; ML elaborates on the problem of absence of names] *... That is quite challenging ... the biography of the man I am just about to start on is [ML Palmerston?] ... Palmerston – no, Gladstone, and it was written by [ML you told me, Andrew Roberts?] ... no, it's the book by ... [searches memory] ... Roy Jenkins [ML expresses interest] ... I picked it up, cheaply ... in ... and I tend to buy all my books from the [ML supplies charity shops] ... yes ... [Do you write in them?] ... Um, possibly, the book I've got at the moment, um, which is 'Our Age' by Noel Annan ... it's by [ML apologises for not being able to help, P. goes upstairs and fetches the book]... this is the book by Noel, Lord Annan, but I couldn't remember*

*his name, but it's called 'Our Age' and, um, and I'm nearly at the end of it, but [at 17:13] what I have done is when there's a particular page that I wanted to remember, or which I thought was particularly – er - emotive, I tended to turn the page over, but obviously I've not done that ... [ML asks if it is P's own copy] ... my own copy ... [not a present, bought for h.s., people are reluctant to deface books even though they will give them away to charity] ... really?... [ML people would rather not write in them] ... right? Yes, I mean the series that I'm next start[ing] is the book by Alastair Campbell, which is ... his sort of diaries and that I will find very interesting [ML ask if it was a present? Bought it?...] no, no, I ... charity shop [ML concurs, would P. write in it?] ... no, probably not ... but books like that ... they are personal and private [19:06] [ML asks about disposing of books] The only thing that I have come to is giving them ... to the charity shop [ML recycling them?] ... yes ... [ML asks about the adding of names in a dialogue, P. reads] ... Yes, I think it would be quite a good idea to have the, you know, the narrative interrupted, but it's not necessary for me [ML you are an expert reader] ... I read a lot. I read a huge amount [ML suggests there were no problems at school], oh no, no, no ... and it's just a bit of a challenge now that I can't remember the things that I read or I [stammers] ... I learned Swedish – my wife is Swedish – but I learned that and so ... Lynda La Plante, The Little One ...*

**Sample 4:** Katherine Mansfield, *The Doll's House*

[21:40, ML explains that some people have not had any views on this question ... describes the book club for people with early onset dementia, 40 or 50 years old] ... *really, gosh, I shouldn't complain ... [ML says he should. ML explains the changes made, P. reads] ... This is different, isn't it, it's ... [ML would people be put off by complex English? P. reads. ML observes that the changes are slight] ... Yes, but it's nice to, um ... because I've got this problem and it's come as a terrible shock, but therefore I'm ... the one thing I do enjoy is reading, actually ... [ML fiction or non-fiction?] ... Um, biographies, yes, I think I find [ML inspiring], inspiring, and that's why I enjoy... I suppose why I would enjoy reading Alastair Campbell ... [ML concurs] whatever his politics are different from me but ... [ML mentions insights]... it's an insight ... [ML asks after the English prose style of Annan's work] ... it's brilliant [ML Well edited?] ... I'm sure it has been but it's a very ... it's a fascinating book and I've had it by my bedside for ... he served in the German section of military intelligence and so he was ... and elected Provost of King's at the age of 39, so he was really ... [ML and the NG?] ... and then he was chairman of the Trustees of the National Gallery and Trustee of the V&A so anything that he did, er, was extremely successful [ML asks if it is a memoir] ... No, it's *Of Our Age* and it [stammers] talks about pacifism, modernism, oh I have got [reads an excerpt from the book about not being an employment agency ... reads at length] ... It's a very long read but it's a very enjoyable book, oh and 'Richard Osborne chose another writer, John Buchan, who had a more reputable pretension to describe the manner of the governing classes because it was beyond doubt that he had joined them' and you know it's just very ... And I have, they were very different in temperament ... so it's a very interesting and, and ... for me, it is of *Our Age* and it's a book that I bought ... um ... a long time ago, but it's just an interesting ... you know, he talks about the Cambridge spies and ... [ML what a life] ... an extraordinary man, Oxford, Cambridge and the London School of Economics, so, sorry ... [ML P. prefers non-fiction really?] ... Yes, I*

*think I do, yes, because those are people who have lived and what I get enjoyment from is reading the obituaries in the Telegraph because they are potted histories of peoples [sic] whose lives I would have admired, I mean today there's an obituary of Sir Paul Judge who died at 68 which was unusual but it's a very, er, good obituary of his life ... [ML people who have made a contribution]... yes ... [ML wonders if she is asking the wrong person, not a fiction reader?] ... no, I would prefer ... but I have read fiction ... [ML left to your own devices] ... I would ... yes, it's interesting, I would go ... contemporary history, modern history, those are the books I would naturally gravitate towards ... [ML comments on television and watching the news?] ... Yes, but I don't watch it a great deal ... I mean, of an evening we would just – my wife and I – we would just sit down and say what can we anaesthetise ourselves [ML agrees, asks if they watch Morse, Poirot, etc.] ... Yes, yes ... [ML for complete relaxation] ... yes, about 8.30 or 9 ... [ML concurs and ends the interview] ... I'm sure, um, I can't think that I've helped you [ML reassures] ... and I'm very privileged to be able to read and that's why I couldn't remember the Noel Annan's name but having read his book ... and I'm just very, um, intrigued about the story he tells and I must have bought the book twenty years ago and it's been ready for me to read ... [ML asks if P. has retired] ... yes, yes ... [ML Have some time now?] ... more time ... [ML it's difficult when you're working?] ... there's less time.*

## **PARTICIPANT no. 7**

### **Sample 1:** John Buchan, *The Thirty-Nine Steps*

[1:06] ... *If I didn't have a choice, I'd be happy with either.* [ML asks if P. could say if one would be more useful than the other if the reader had a memory issue or a reading difficulty.] *I don't know, I suppose a picture sort of indicates straightaway what the subject is going to be about ... so the sooner you get that in your head the better. Does that help?* [ML observes that some people might not look at the picture if it was opposite.] *Well, no, I think I'd be ... if the story was good enough, I would carry on.* [ML if unsure of the vocabulary or story?] *Yes ... [agrees with ML] ... yes, it's bound to help. It certainly isn't a hindrance.* [ML It doesn't put you off?] ... *No.* [Would you feel patronised?] ... *I think if I was going to a library to pick up a book ... I've never thought about this before, but I think, er, yes, I think I might prefer to go with a straight print ... [mixed utterances while P. sorts out his ideas] ... Yesterday, I went to the library ... I don't always these days finish a book ... so I am back and forwards, now this time I went to the library yesterday and look what I picked up ... I've never ever read it, I opened it just like that and the print was fantastic ... [ML expresses admiration, P. laughs ... complete story?] ... Yes, I think so ... [ML inviting] ... We'll see, next time you come I'll still be reading it [laughs] ... [ML asks if it matters if the reader forgets but enjoys reading] ... Yes, that's right, you're taking something in. [ML people may re-read books for pleasure] ... Yes, and you also read books because you have to ... I can't think of any just at the moment ... [ML, Did you read for your work?] ... Only as an aid ... [ML comments on the cream paper and P. wearing glasses] ... I might need a music stand for that. [ML the books you don't finish?] ... Well, I suppose it's because it's because I've got a bit tired with the storyline or it doesn't appear to be getting*

*anywhere, or alternatively you can see what the end's going to be, so, yes, that's a terrible thing to say but ...*

[Captions] *Well, if it's explaining, I wouldn't necessarily expect a caption because it's part of the story, I should be able to identify with it, um, going along, so long as it's on the right page ...*

**Sample 2:** Portrait by Rubens with accompanying text

[7:30] *I just take it as it comes ... ML presses for a choice ... Well, I suppose that one [without the headings] ... It's saying the same thing, isn't it? Yes ... [reads it to himself] ... it's interesting ... it's worth having, it tells you, you know, what's happening now, it brings it up to date ... [ML Headings?] They're a bit superfluous ... at the same time, they could be helpful.*

[ML Size? Too big?] *No, if you're trying to point something out it's ideal. ... I wouldn't like this on every page of a book, or anything like that, but when it comes in a document like that ... [ML reminds P. that it is a spread from an art book]*

**Sample 3:** Lynda La Plante, *The Little One*

[9:40, ML explains] *... I don't think I'm bothered about that [reads] ... I could take either ... [ML either?] ... yes... if I read that I wouldn't consider something was missing ... [ML can you imagine that someone might want the names in?] ... yes, yes, oh yes.*

[ML asks about type size of text] *... I'd be comfortable with that ... [ML is it patronising?] ... No, I'm not bothered by that ... if it's a good story it will keep me going.*

**Sample 4:** Katherine Mansfield, *The Doll's House*

[12:50, P. reads for some time and responds with some hesitation] *... I suppose I prefer this one ... [indicates edited version] ... it goes straight to the heart of things without waffling ... that's too, too, it's not waffling really, but it's ...*

**PARTICIPANT no. 8**

**Sample 1:** John Buchan, *The Thirty-Nine Steps*

[ML introduces the idea of EFL, participant signals her interest] *... Yes ... [and] ... yes [as ML explains about levels of reader's vocabulary. Participant takes her time to think about the question, so ML shows her the original book. Long pause. ] ... I think, I think that's different. [ML removes the book as the heading is evidently causing problems. ML has to rephrase and ask the question again] ...*

*um, I think, I don't know, I think that's quite a sort of, um ... I mean, you'd have to break off and look ... or you'd have to read it through and then the picture is sort of apropos not a lot ... whereas if you've got the shock of the picture and the immediate ... yeah ... [Agrees with ML that the publisher has made the right decision.] It's sort of breaking ... as you follow.*

[Caption s] *No, you don't need ... not if you've got that, I mean, they've told you that, you don't want to have attention broken to look at it again. [ML says she doesn't know why they did it] ... They didn't ask you first ... [ML says they are OUP].*

### **Sample 2:** Portrait by Rubens with accompanying text

[Participant studies the layouts. ML prompts. Long pause.] *What ... I'd prefer that ... if I hadn't come across, um, it would tell me who this was ... [ML checks to be sure that the version with headings is intended] ... Yes, I think so. [ML prompts P. to explain why] ... it fixes it, I don't know, it does fix it more, you know, the subject ... and then you're told [pause, ML repeats, It fixes it] ... I, I think so ... I mean this tells, this tells everything ... well, it's as if you've got all of the same information but you're sort of going from one to the other, which fixes it a bit more ... you aren't sort of trying to get the two things ... you look and, ah, that's ... you've sort of got a while to get used to it ... whereas here, it's very lovely, but you read it through tiddly tiddly pom and tiddly tiddly pom but you're not making such a reference to her.*

[Typesize of headings] *The Subject, The Painting, The Artist, no, I think they're fine. [ML so the designer's got that right?] ... Yes.*

### **Sample 3:** Lynda La Plante, *The Little One*

[18:00, ML spells out the problem. P. takes her time to read. ML interrupts, pointing out the red spots. P. asks for help. ML asks if it's obvious who is being referred to.] *It depends who's reading. Um, what sort of reader. Now I'm getting confused about which one has got the additions. [ML explains that the red dots show where the additions are. If a person has memory issues, would it help to put the name in?] ... I think, yes. ... Yes, because if you had, um, a bit of memory problem, you'd sort of have a welter of words to go through, whereas if one doesn't, it's absolutely clear what you're following through ... [hesitates] ... you know, if you were reading with a little bit of difficulty you're slower, so you need ... [ML contributes here] ... there are fast readers and slow readers, you know, I can take a book and get through it pretty quickly. [ML suggests reading is a gift. P. laughs] ... Well, I don't know what else to call it. It's a fact. [ML talks about the difficulty of building up a story in one's memory.] ... That's such a shame. [ML comments that stories pose problems] ... Well, I don't know, you see, if they read it slowly, they probably enjoy the story too. [ML asks if adding names would be useful] ... Yes, I think it would be. [ML comments that there is no mention at all of speakers' names in some works] ... And you'd have to know from the exclamation marks and the pause marks, which not everyone would if they had a little bit of difficulty.*

[Size of type] [25:29, Is it too big?] ... *Well, no, I mean, this is fairly big type, this [the Lynda La Plante book] is bigger than this [P. indicates the first sample. ML does it strike you as too big?] ... No, I don't. I mean, presented like that, um, um, I don't know, I would find it easier to read because you've just got that much whereas here you've got ... I mean, I find this perfectly easy but the fact that it's presented like that ... it's very clear and ... [ML does it look like a child's book?] ... I'd have a feeling that perhaps ... [ML would it put you off? It's an adult story.] ... It is, it is. Yes, number one best-selling author. I mean, I'd have to look at that and think about it. Ah [indicates curiosity. The type size?] ... It's perfectly all right, it's not offensive. And you've got it all there clearly. [ML points out that it is not a low vision book] ... No, in fact it's quite a neat one, it's the sort of thing you can read easily on the train or ... .*

#### **Sample 4:** Katherine Mansfield, *The Doll's House*

[27:50, ML explains that she has simplified the text. P. reads it. Long pause.] *Well, I'm not quite sure what you, what ... [ML explains] ... Well, I think already, this [indicates the author's own text. ML asks if P. likes to read it as the author wrote it] ... Yes. [ML you prefer to grapple with the author's own words?] ... Yes, because they're clearer. [ML points out the red dots] ... I find the author's writing quite clear.*

### **PARTICIPANT no. 9**

#### **Sample 1:** John Buchan, *The Thirty-Nine Steps*

{ML thanks P.} ... *Oh no, not at all, I'm interested but ... [ML comments on difficulty of finding participants] ... and what's your objective in the end, what's the ... [ML explains] ... I see, yes ... [ML shows the book and explains] ... yes ... from my point of view, the face is legible, it's a nice size face, my eyes aren't, aren't a hundred per cent perfect but I can read that quite well with glasses, which is nice to see, it's well laid out ... [ML says it's OUP] ... they should know ... [ML comments on the work involved] ... I can well believe it, it's their names on the back of it, isn't it? [ML in print for years] ... yes ... it's history ... [ML position of picture?] ... Well, I suppose ... it depends how you're reading it ... it depends, does that picture fall on that page, or does it fall in the contents of that [i.e. a succeeding] page? [ML reads the text above the image] ... it's pretty descriptive isn't it, it's before your very eyes, so to speak, you're not transferring from one to another [ML puts the question again] ... I'm not the world's best-read man, you can well believe that ... [ML asks question again] ... well, I mean .. to me, that first line in the paragraph hits you with that picture, you haven't got to go elsewhere or ... I'd be reading it there and I'd be going over to see what ... so ... in view of content, to me, that ... to the reader that's the easiest thing to follow [ML checks it is the version with image in text] ... yes, you've got to go dancing about, I mean, I'm very ill read having been in the printing business [ML can't find way back into text?] ... yes, that's what I said, that's continuous .... Yeah, I'd go for that one.*

[Captions (out of order at 9:45)] ... *well, it depends what's there ...* [ML draws attention to image in text version] ... *well, they've got one on both, haven't they, they've got a caption there, they've got a caption on both, but it's, um, ... the picture looks lost on the page like that, doesn't it?* [ML concurs, asks if a caption is useful in this case] ... *no, I think the caption helps, I think the caption helps, but it's all about ... I mean, you might even, if you didn't have a caption, you'd have to read that, put it that way* [ML asks about the first version] ... *I think, I don't know, I think the caption, I think the picture's lost without a caption, I think it's lost, in both senses, it would be just a picture and you're searching for ... I think so, it's, it's* [ML comments that it is the voice of experience] ... *well, as somebody who never read, I just used to look at it and scan it and ...* [ML comments on P's appreciation of the structure] ... *yes, you get used to seeing so much printing* [words undecipherable] *I don't like that one, you'd better do that again, or ... well I didn't design it, I just printed it, other people ... if it wasn't right I got kicked ... we're the ones who put the ink on the paper, we're the ones who got it wrong nobody else did ...* [ML proof readers?] ... *Oh, yes, yes, all the proof reading was done before it got to us but* [ML no mistakes] ... *should have been no mistakes but we again were the people that would scan it all the time and, strangely enough, printers are incredible the way they pick them up ... you know, choom choom choom* [imitates the sound of sheets coming off the press] ... *and they'll pull a sheet out every three or four hundred sheets and scan it and ... a good print shop ... I mean, we printed Vogue and things like that ... you lived in fear of the Editor ...* [ML because?] ... *she was a formidable lady ... in the square and, er, remarkable woman* [ML she carried the whole] ... *oh yeah, she did, yes ... that's ladies' magazines but, I mean, I never did actually books, colour magazines and stuff, but books we used to do at some printers, and places like ...* [ML paperbacks?] ... *yes, we did paperbacks ...*

### **Sample 2:** Portrait by Rubens with accompanying text

[4:25, ML reads the question] ... *Yeah* [ML repeats question, P. reads the first paragraph] ... *well, from the point of view of learning, that's more descriptive* [ML with the headings] ... *well, it itemises it all, doesn't it, you don't have to read that ...* [reads aloud the side headings] ... *now, I've done that in two seconds, now I've got to read all that to find out the gist of it, but I mean that ...* [ML heading useful?] ... *I think they are, I do think they are especially I emphasise I'm a non-reader and that would bring, that brings my ... brings me into view ... the painting, and then the first thing I've got to do from the printing point of view is the painting* [words are unintelligible] ... [ML comments on the paper at 6:23] ... *well it's a ... coated paper, it's a nice paper ... and it's matt, it's not gloss* [ML a silk finish] ... *a silk finish, yes, you couldn't have gloss, hits you back, comes out at you, too bright* (at 6:41). *My personally think so, I think you've got to have a matt* [ML speculates on the weight] ... *probably 100 grams, or something like that, 120 grams ... it's a hundred years since I felt a piece of paper and said how much ...* [ML you don't lose it] ... *no, that's nice paper* [ML it is fairly white] ... *yes, it's a ... you couldn't* [words indiscernible here].

[Headings] [7:24, ML explains] ... *Yes, I see, who's it for?* [ML explains] ... *that brings your eyes to ...* [ML too big?] ... *no, not at all, done like that, it's itemised for you, exactly what you've got on the page ... I mean it's all there, but I mean*

*you've got to read all that, but there you ... [ML it's broken down] ... I think people will read phenomenal amounts, scanners they don't really take in line after line after line, I can't believe it ... I mean I've seen people, sort of people, readers who are absolutely examining printing which has been printed, to check that it's the right print, right spellings .... They scan it in no time [makes a quick sound] [ML they're looking for] ... errors ... [ML reiterates that the Rubens text is just reading for fun] ... well, I think [hesitates] some people might find that a bit harsh, these subheadings, quite harsh, I don't, I think it brings your.... head to what you're reading, doesn't it, it's itemised it for you, there you've got to read all that to find out what it's about, there you've got it ... [ML singles out the word harsh] ... yes, I think on white paper you certainly want black, you don't want grey or anything like that ... [ML will make a note] ... but I'm half blind anyhow ... no, I think that's, um, put it this way, as a student that would be the easiest thing to take on ... it's itemised for them (9:25) ... if you're a student, I wasn't a great student, I got by ... but this ... [ML for pleasure] ... for pleasure, you can read that and you know you've got all the information, there you've got to go through ...*

**Sample 3:** Lynda La Plante, *The Little One*

[13:32, ML introduces Quick Reads in the context of printing paperbacks above] *That's a nice face, a good bold face ... [ML it's cheap paper] ... but that's irrelevant to the reader, to be honest, to the reader, as long as they can see it and it's clearly black on white, um, I mean, that's not a book you'd keep for life, is it? I mean some people do ... we've got hundreds of wretched books through there ... and I'm ill read [ML like books?] ... I'm not a great reader, no, I'm a news reader, I'm for today not ... and I had an indifferent education due to my age about reading and writing ... I went to five schools during the war, 'for the benefit of the new boy we'll start at 1066' [ML five schools] ... yes, all of five schools during the war ... [other personal observations].*

*That to me is legible [ML not too big?] no, no ... well, I haven't got my glasses on, I can't read that without my glasses, no, that's all right [ML gives P. his glasses. ML explains] ... Well, I think that's very much in the reader's interest, from the point of view of the design and layout of the book ... you're emphasising the names in spades, aren't you? [reads aloud; ML too much?] ... well, that page 10 does appear too much about their names, whether it continues like that, I don't know ... [ML too many? But without any at all?] ... I mean, without reading the whole chapter and things that might well lay out what's ahead, that might be what the story's about and the subheadings you get it all there ... [ML is it helpful to be reminded who's speaking?] ... again, I emphasize I'm not well read, I would emphasize this it's... if you read this book you shouldn't come away without having the answers ... [ML the author has to take you through it] ... you've explained it all there haven't you, I mean those dotted spots ... [ML concurs] ... you don't want it on every page that sort of thing, you start the paragraph and you virtually [scrambled words and ideas] ... I might have to go back to that to find out what that was talking about, so to speak (at 19:28) because I'm not well read [ML suggests giving the reader all the info. all he needs] ... yes, and if they're going to read, they'll read and read again ... [ML adding few names?] ... I think it helps, yes, but I'm contradicting myself all the time because I keep thinking*

*myself* [ML asks again] ... *I suppose it would throughout the book ... start off with Alan and Barbara to start with instead of half-way through the book and ...* [unintelligible here] ... [ML readers don't want to have to back to the previous page] ... *I think that's quite essential (20:37) ... but of course from the point of view of studying, of exams, that's a different thing ...* [ML explains that the stories are only read for pleasure] ... *well, I think people who read that they read and they, they* [fumbles for words] ... *they flash through books, don't they ...* [ML explains they are for low literacy readers] ... *well, that's me ...* [ML speaks] ... *I mean, that's me, I'm ill read, I truly am ...* [ML counters that P. reads the newspapers] ... *yeah, but you know what I mean ... I never used to read a book ... I used to go through a magazine, I'd go through it and I'd think that's no good, that picture's bad ...* [ML mentions dyslexic people, is P. dyslexic?] ... *no, I'm not, no.*

#### **Sample 4:** Katherine Mansfield, *The Doll's House*

[22:00] *The title of the book is* [ML reads it] ... *A Child's World here, what's that?* [ML explains] ... *that's the first story, ok ...* [ML explains, explains about the mock up] ... *yes ...* [P. begins to read the author's version, ML asks which version is preferred, P. begins to read the edited version, ML points out that the text is saying the same thing] ... *it is, yes, are you ...* [ML asks question] ... [P. reads silently] ... *well, the first sentence is ...* [P. reads the edited version. ML explains the function of the red dots] ... *yes ...* [ML explains the two versions] ... *oh dear ...* [ML says it may not make any difference at all] ... *no, it's words for words sake, isn't it ...* [ML concurs, ML explains that people prefer to grapple or not] ... *Well, I'm all for* [stumbles] ... *I mean, I'd go through stuff we'd printed like that, so to speak* [indicates speed] *and look for the obvious errors, which I'd expect to be there, you know, words missed out* [ML agrees, does P. not have a view? ML rephrases the question] ... *are you in peril of offending them?* [ML says author is not alive] ... *she'll come and spook you ...* [ML admits it is a relevant consideration] ... [if you were commissioning books] ... *yes, yes ... I'm ... I don't find any of that difficult or offensive, let's put it that way ... and so I* [ML it doesn't bother you?] ... *it doesn't bother me, but then I'm not well read, I'm not somebody who sits down and ... well, that's not very well written, or that's not ...* [ML asks if P. ever feels he can't be bothered if the text is contorted] ... *if it's cluttered? No, no, I'm not a great ... I read newspapers back to front, sports page first ... and then, the City press next and then I read all across ...* [ML you read] ... *I read, I read the newspapers, yes ...* [ML well-written newspapers] ... *yes, the Daily Telegraph and we have the Mail, we have the Times sometimes ...* [stumbles] ... *The Telegraph and the Mail, of all things* [ML concurs] ... *but it's um, two extremes ...* [ML reader can make up their own mind, both well written] ... *I think the Telegraph is a good paper* [ML they win awards for sports writing] ... *well, of course, the sports people in these papers, I know most of them, or did know ...*

**PARTICIPANT no. 10****Sample 1:** John Buchan, *The Thirty-Nine Steps*

[ML explains that the text, unusually for an adult book, has illustrations.] *Oh yes, but quite rewarding, I suppose, when you're struggling with it. Oh yes, [slight mumbling here] quite a lot of thought ... an illustration like that. [ML explains how OUP commission an illustration] That's good. So, who's published them?*

[2:20, ML asks the question] *From the point of view of reading ... I would say that, but then that's not from the point of view of reading necessarily [indicates illustration in the text version] I mean, that to me is a bit of a waste of space and it's also a bit of a diversion, isn't it, because it's a change in the general pattern, whereas the other is ... but then, I suppose ... [ML shows P. the original] ...but that ... we're used to it, aren't we... [ML asks the question again] ... Yes, well when I was a child, I used to be irritated and eventually realised it was in a column ... on the part of the publisher ... I was irritated if the picture wasn't visible ... Well, to read, say that, that's all writing, to read all of that and all of that then turn over and find there's a page about what's gone is ... a kind of an insult [ML agrees and explains how OUP carefully position the illustration] ... That's good ... [ML asks the question again] I don't know... I'm probably forgetting ... so that comes in at the point that it actually happens ... we've got Scudder there .... If it were like this, he sees that then goes on, by the time he gets to the picture it's perhaps slightly irrelevant [with the illustration opposite] ... I think, I think in a way it diverts your attention there and then there is also the question that it could be that he doesn't go back correctly. He goes back to down here or turns the page ... [ML comments on reader's difficulty in finding their way back into the text] ... when you're not terribly familiar with text. [ML reiterates that this is OUP's solution] ... I would have thought so, but then, I suppose in a way that's because I can read, isn't it? [ML reiterates the question] ... If you, if you are reading here and then you go across and look at the picture ... and you look at it with any depth or anything, then you've got to go back and you've got to find it, haven't you and you can imagine, though you think you know it was at the end of the paragraph ... it must have been this one and then you miss that and you must miss some salient points, mightn't you? [ML on balance, the picture in the text?] ... It keeps the text in order.*

[Headings, at 20:25] *Well, if you've got it there [i.e. in the text] do you need it there? [P reads the caption easily] ... I suppose there's a big gap, isn't there, and I don't know exactly what there is in all of this, but ... [repetition?] ... yes, that could be irritating but if you've read it there and you go through all that would you know definitely that there's a knife through Scudder's heart – well it's in the picture, isn't it I must say, sometimes I do find it irritating when there's too much repetition and its treating you like you're a bit of an idiot ... I do get annoyed by it ... but is that the sort of thing that really can upset ...*

**Sample 2:** Portrait by Rubens with accompanying text

[7:40] *Nice face she's got, hasn't she?* [long pause, ML repeats explanation] ... *I don't have very strong feelings about that, really. No, no.* [ML rephrases the question] ... *Yes, I think I might be inclined to feel spoken down to, talked down to with the headings ...* [ML signals interest] ... *you know, let's get on with it, but then, you know, there's a question of age and maturity and that sort of thing* [participant recounts an experience with friend from U3A and losing her diaries] ... *but rubbing my nose in it doesn't actually help.* [Headings?] *I wouldn't want it any bigger, but I would have thought, yes, that's perfectly satisfactory ... if it was slightly smaller but still in heavy print then I suppose that would be ok.*

**Sample 3:** Lynda La Plante, *The Little One*

[23:20] *Lynda La Plante, I've read a couple of hers, but I haven't read ...* [ML explains] ... *I've sort of almost given up reading now, I can't retain it properly ...* [ML explains about QRs] ... *That might be quite nice ...* [ML tells P what people at book readings say, P supplies] *I could manage it ...* [ML says it's simplified not patronising ... P reads the first lines fluently ... ML says that books help reluctant readers ] ... *yes, and they manage it, and they can relate to it ... so these are available in shops, are they?* [ML indicates that they are and cheaply] ... *£1.99, yes* [ML explains, some people think it's obvious who's speaking] ... *but, you don't know what their problems are, do you?* [ML explains about the red dots] ... *you've put it in yours* [ML points and says, perhaps it's obvious, there are only two people] ... *yes, but one could lose one's way, I suppose, couldn't one?* [ML reads the question aloud] ... *I would think it would be better to opt for that because if you lose your reader in some way that's damage done, isn't it?* [ML concurs] ... *You don't want to hold them by the hand too much, you don't want them to feel condescended to, but none the less ... it's just slipped in ... mind you, I suppose it would be difficult for us to think in terms of reading when you're not very good at reading and whether they would feel condescended to, I wouldn't have thought so ...* [ML it's subtly done. P reads] ... *that could be an irritation but basically ... I'm a very quick reader... so then I'd get fed up with all these extra bits and pieces ... but on the other hand you ... it's probably a matter of half [and] half, isn't it? But you don't want, whatever you do, you don't want to lose somebody's confidence, do you?* [ML agrees.] ... *Difficult.*

[Typesize, 29:23] *It's not, sort of, it doesn't make me feel I'm being given a children's book, no ...* [ML shows P the book] ... *that's the actual feel of the book ... I suppose it is, a little bit big ... no, and quite honestly if there's ... that is like a sort of logo isn't it [on the front cover] ...and if they know they've got what they want, they want something to read, they know they've got it, they know it's right, they know it's safe, it's not going to put them on the spot, um, you've got to put up with what else there is* [ML comments that this one is a good read] ... *yes, that's important isn't it?*

**Sample 4:** Katherine Mansfield, *The Doll's House*

[35:00 ML wonders whether readers would prefer to grapple or to have problems ironed out] ... *Yes, well there will be both types of people, won't there, really?* [ML literary English is demanding] ... *And therefore, you can't anticipate ... you can't think, oh yes, that's what they're trying to say ...* [ML puts the two sides] ... *It's a funny first sentence, isn't it? Because it's very ... it's a bit way out.* [ML does reading it twice matter?] ... *Yes* [general pondering] ... *because you've got to be so careful that you haven't cut out too much because it becomes too simple to ...* [P reads the text] ... *The feed room door, the stable door ...* [ML asks if the text is losing something or is more straightforward?] ... *yes ... say that again* [ML repeats, thinking of her words] ... *Simplified too much?* [long pause] ... *I don't like that one quite so much but I'm not sure why ... reads out loud ... I don't like sentences starting with an and ...* [ML suggests author is playing around with the language] ... *yes, yes, I mean, that's fair enough, yes, yes ...* [continues to read] ... *yes, I'm sort of ambivalent about it really, it's difficult, isn't it? ... I mean, do you think that the market you're looking at could be quite off put by not quite getting the style or ... in which case you do need to work at it, don't you* [ML suggests readers might have a learning difficulty or memory problems] ... *their confidence is knocked before they start* [ML explains again] ... *isn't it difficult? ...* [reads again] ... *it says on this one, it says ... slap of toffee* [ML explains] ... *that would irritate me ... I've never come across it* [reads the text] *don't find too much significance in that, really ...* [ML draws attention to the centre part of the text, P. struggles with the text] ... *I can't clarify my mind on that.* [ML does it depend how much effort are you willing to put into reading] ... *yes, I suppose that's it, yes, because you don't want to give up on it, but on the other hand you don't ...* [ML puts the point again] ... *I really don't know...* [ML do you see the problem?] ... *yes, yes ... but of course you're never going to know exactly who your ... you, know, the circumstances of your reader ...* [ML says that some readers just skip sentences] ... *yes, I suppose so, the only thing is you don't want to do that and then find that you're caught out because you've missed a bit ... yes, I'm afraid I'm a bit ambivalent about ...* [ML comments on the pleasure of language, P. concurs] ... *No, this is it, you don't want to lose ... some of these bits ...* [reads the text and the alterations] ... *yes, it's no good being offended by that, is it?* [reads] ... *well, 'which was painted yellow' whereas the other one is, 'comma, painted yellow'...* *Yes, I don't really mean offended but you know ... Yes, I find that quite difficult to make a ... a decision on, really.*

## **Appendix VII: Participant Interview Study**

Text of a letter sent to all participants on completion of the ten interviews.

Dear Participant

### **Results of an interview study on book design**

Earlier this year you kindly volunteered to take part in a study looking at reading with a memory impairment. I visited you at home and you answered questions about four sample layouts for books.

I have now collected together the results of the interviews and I shall be including them in the research I am carrying out at the University of Reading.

All the individuals I spoke to said that they read books for pleasure. They also expressed views that would be helpful to book designers. The points they raised included:

- Readers do not want to stop reading books just because they have issues with their memory.
- Placing illustrations within a passage of text can help to reinforce the author's ideas.
- Illustrations can also seem childish, so they should be used with caution.
- Captions are not necessary if the illustration is incorporated in the text.
- Using small headings to break up blocks of text can help to support the memory.
- Adding the names of people speaking in a dialogue is not always necessary.
- Readers may prefer to read texts that are authentic and not over-simplified.
- Many participants enjoy texts that stimulate the imagination.

Several participants mentioned that they had problems with holding a story in their memory, so this is what I shall be exploring in my next study project.

Thank you very much indeed for your support with this work.

Yours sincerely,

## Appendix VIII: Textual Additions Study

Summary of a DEEP meeting on 16.10.2017. Participants' comments are given verbatim and in italic type.

Present: DEEP organiser  
 Alzheimer's Society organiser  
 Participant 1  
 Participant 2  
 Participant 3

Running time in minutes

- 1 Introduction – discussion about YPWD organiser and training assistance dogs (guide dogs)
- 3 ML introduces **Sample A**.
- 6 ML explains why a List of Characters might help. Participants' comments suggest approval – good for *every book*. ML asks if it useful, or if it might be thought patronising. (Participant 2) *No, it's fabulous.*
- 8 Participant 1 queries whether *A Christmas Carol* would be suitable for readers with dementia. (Participant 1) *My point being, would they be reading A Christmas Carol, or would they be reading a simpler book?* ML confirms she is thinking of any book. Participant 1 says some books do provide a list, at the front. ML asks if the front is the best place. ML suggests on the jacket – on the flap?
- 10 ML asks if it all right if minor characters are not included. (Participant 2) *I actually think, I don't think it matters whether you've got any sort of difficulty remembering, I think a lot of people would be quite pleased, because a lot of people can take a few weeks to read a book and I think this is something that should become standard.*
- 11 Participant 2 describes the ... twists and turns of the plot of a book she read... two brothers ... a list would have helped sort them out. (Participant 2) *Had I been able to look at this, because it's visual, I would have been able to get it into my head.*
- 13 Participant 1 suggests that a list of characters on the inner flap might be useful, or on the cover would be accessible. Participant 2 agrees that on the cover is nice but that she doesn't read hardback fiction. (Participant 1) *You don't seem to be the kind of person who would need the characters. ...* (Participant 2) *I do. I can't remember a book once I've finished reading it.* (Participant 1) *We're talking about people who need the characters while they're reading the book.* [Participant 2 explains her difficulties.] (Participant 1) *... But when you wanted to know who the characters were,*

- where did you look?* (Participant 2) *I had to keep going back.* (Participant 1) *Where did you go back to? Did you flip through the pages to find [them]?* (Participant 2) *No, I read it on my Kindle.* [No mention of the medium until this point.]
- 15 Participant 1 distinguishes between their discussion of the best place to put it and ML's query about people remembering that it is there. DEEP organiser summarises the three possibilities and Participant 2 explains that she refers back to the book summary offered at the start of the text on her Kindle. (Participant 2) *I am doing this more and more these days, I am starting to write notes about the characters ... to get them in my head.*
- 18 Participant 3 is reluctant to express a view on the list of characters but says that the type is big enough. The Alzheimer's Society organiser points out the advantages of having a brief description along with the name of the character – this might have helped Participant 2.
- 19 ML asks if it matters if the reader forgets what the book is about. (Participant 2) *It doesn't. ... For me it's only about while I'm reading a book.* (Participant 1) *It's very handy if you can read the same book again.* ML asks if it would seem familiar. (Participant 1) *Well, if you've got Alzheimer's like me, in a couple of weeks, or a couple of months anyway, you could read it again.* ML asks if anything of the story would remain. (Participant 1) *It would be there vaguely, yes.* ML suggests that it does not matter if the reader forgets. We can watch films twice – or (Participant 1) *Shakespeare.*
- 20 **Sample B** presented. ML explains use of chapter summaries in textbooks. No particular response.
- 21 **Sample C** presented. ML explains the option of a summary at the start of a new chapter. (Participant 1) *I was just thinking that very thing.* ML asks if Sample B or C would be best. (Participant 2) *I think at the beginning.* (Participant 1) *I think at the beginning – even here* [indicates above the chapter number and title]. (Participant 2) [speaking of text book summaries] *They do it all the time, summaries, don't they, and they do it for a reason ... to keep the students understanding or knowing what it is that they are reading, or whether they've read that without having to read the whole chapter again.*
- 23 (Participant 1) *I think you're on to a damn good idea with this. ... What you might call sane people would find this a useful adjunct to a book.* DEEP organiser draws attention to summaries on a tinted background in the Alzheimer's Society magazine.
- 23 ML asks about text being put on a separate page on a grey background. (Participant 1) *... the trouble is, from the printer's point of view, that wastes a page ... if it was here* [above the chapter title] *it wouldn't waste a page, would it?* (Participant 2) *If it's boxed, it doesn't matter if it's grey, brown or whatever, if it's boxed.* ML asks if it would be confusing to have a box without a tint; would the reader know where to start reading. (Participant 2) *No, because it says, 'The story so far'.* ML asks about the wording. (Participant 2)

- For me, it's ok. (Participant 1) I think, if it was in a box here and all this was further down, people would quickly get the knack of it and think, well I'm not thick enough to need that, I'll go straight into the story, and other people would think, Oh, that's handy, I will remind myself ... and I think this is the place for it ... and in a box. ML asks about having a grey background or a box. (Participant 1) I don't know about that; grey background seems a bit strong.*
- 25 ML explains about the text typeface being different from the typeface used in the box in an effort not to confuse the reader. (Participant 1) *Oh, I see ... [two conversations break out] ... ML asks if the summary should be included before every chapter. (Participant 1) If you're going to put it in at all, and also, it's less conspicuous there [i.e. on the facing page]. Maybe that's a good thing?* ML asks whether on the left or right-hand side is best. (Participant 2) *It depends, if your book is always like this and you open the page and your new chapter is always on this page, then it's ok. But if it isn't, then it would need to be above it ... [it would make] extra pages.* ML suggests starting every chapter on a new page. (Participant 2) *Yes.* ML demonstrates what it would look like with a full page of text opposite. General agreement that it would be more economical. (Participant 1) *I quite like it here [on the facing page].*
- 28 ML asks what people would think of having a label indicating that the book had been particularly designed ... (Participant 1) *... for thickos ... I'm only putting it in colloquial terms ...* ML comments that some readers would be mortified. (Participant 2) *I'm mortified.* ML quickly shows participants the Quick Reads label. (Participant 1) *I think you could be designing something that could well go into all books. ...* ML observes that reading can be hard work. (Participant 1) *... especially as reading skills are becoming, as far as I can make out, less and less used ... I don't know how to put it but ... people don't read as much as they used to, do they?* (Participant 2) *I think some kids struggle because the thought of going through a big book is too difficult, but if you've got something like this [a Quick Read], it doesn't, it feels like you don't have to read the whole book all at once.*
- 29 (Participant 1) *Make it easier for us and you'll make it easier for everybody else.*
- 30 (Participant 1) *It's hard to think what the page would look like with this above ...* ML wonders whether she should send a mock-up of revised sample. Participant 1 folds the sheet and demonstrates the layout. (Participant 1) *They'd have to lay it out better ... it doesn't look quite as bad as I thought.* ML reassures that designers can smooth things out. Participant 2 says that she prefers it opposite. ML repeats this to be sure.
- 31 (Participant 1) *Would it have to be a shaded area? I don't think it would have to be a shaded area.* (Participant 2) *I just think if you've got something in a shaded area it can be confusing to read.* (Participant 1) *Not to mention the fact that it could make it more difficult for people with, er, peculiar eyes ...* (Participant 2) *You could have it in a box, just a lined box on white with ... I mean, I like the typeface, the different typeface, that's fine ...* ML

confirms the purpose of a second typeface. (Participant 2) *I prefer that ... yes, looking at this now ...*

- 32 Participant 2 says that she has adjusted her Kindle to suit her tastes. She likes the type slightly larger ... *this [the text sample] is acceptable and there's enough lined space in between ...* ML says that legibility was the designer's aim. (Participant 2) *Yes, the font is nice, I quite like a classic font but that's just my preference*

(Participant 1) *It's all about preferences ...* ML says that if enough people find a modification useful ... (Participant 2) *I think it's the way the brain works and if you've got any sort of dementia your brain starts to work slightly differently and what you could cope with before you find you can't cope with now, so things that are plain and simple sometimes are a lot better.*

- 34 ML suggests simple with style? (Participant 2) *I think there is ... which one is this?* [ML replies that the typeface is Minion and that it could be bigger if readers preferred.] (Participant 2) *It's fine.* (Participant 1) *My guess is ... if the publisher ... accepts the ideas that we put before them they will decide on what kind of typeface to use.* ML says that publishers are likely to follow the preferences of the public if it will enhance sales.

- 35 The merits of Kindles discussed, particularly adjusting type. Participant 2 offers some criticism of Amazon ... *I do like a book, though.* The small edition of Dickens is appreciated as a gift book.

- 36 Participant 2 produces a paperback copy of Diana Gabaldon's *Outlander*. The book is printed on a bright white paper which is too absorbent causing ink spread. Participant says that she will go on reading it, though. Participant shows a piece of white card used as a placeholder.

### 38 **Sample D**

ML shows books with ribbon markers, observing that very few library books have them. (Participant 1) *Very few, it's a very good idea, isn't it?... Do you think it would be against copyright for the libraries to insert them in their books?* ML explains about the ribbon inserted by a library user in a Peter James novel. (Participant 2) *That's quite interesting, isn't it?... Sometimes the ribbons do come out.* [e.g. participant's diary]. ML asks if ribbons are useful in diaries and participants agree that they are.

- 40 ML asks which sort of bookmark would be more useful. (Participant 2) *What I quite like, I was thinking about this the other day, funnily enough, with my bookmark. I'd like something that was folded over ... and I was thinking about this because the bookmark falls out too easily sometimes. But if you've got something that's folded over it just that tiny little bit ...* (Participant 1) *All that's is a good idea but you've got to keep them and remember them, whereas just grabbing hold of any old bit of paper and*

*folding it and putting it in – it doesn't matter, does it?* Participant 2 says she could make one.

- 41 (Participant 2) *Especially if it wasn't folded over but somehow put together at the top.* ML asks if the bookmark would need to show at the bottom. The participant says not. (Participant 2) *You could possibly have something glued together [at the top] just a little bit showing at the top ...*
- 42 ML asks which sort of bookmark would be better – or both? (Participant 2) *Both, because I think, how nice to receive a bookmark ... Yes, bookmarks are good.*
- Discussion of WHS free bookmark and used for book publicity.
- 43 ML asks about having two bookmarks, especially in books with flashbacks. No request for this.
- (Participant 2) *Do we need a bookmark this thick? All bookmarks are usually quite thin* [ML misunderstands and talks about breaking the back of the book] *... I mean narrow... because that one is quite wider.* Discussion about pushing bookmarks into the spine.
- 44 (Participant 2) *This is slightly wider so you could get quite a lot on there* [shows piece of cardboard saved from packaging].
- 45 DEEP organiser suggests selling the bookmark separately. (Participant 1) *An even better idea is to have a blank bookmark and make your own notes as you go through.*
- 46 Participant 2 bought the book because it was 1940s television series/Jacobite period.
- 48 TV leaves out a lot of detail.
- 49 ML asks about visualisation. (Participant 2) *You can picture someone's face, can't you, you can picture a scene* [?], *the countryside ...* ML asks if a picture would help. (Participant 1) *When I read a book, I don't see pages of print, I see pictures in my head ...* (Participant 2) *I think that's brilliant, isn't it? Because you just see it.* ML asks if Participant 1 is a life-long reader. *Yes, it's always been like that.* Alzheimer's Society organiser asks Participant to repeat what he said. (Participant 1) *At first, I'm reading the words and if the book's not very good, I think this is not very good and chuck it away, and if it's a decent book, I stop seeing the words and start seeing the pictures ... and it's going on around me. ... But it's got to be the right kind of book. ... By that, I don't mean this kind of book, it can be cheap.* ML asks about genre. *Of course, my memory's going now, I can only go back to the really old authors that I used to read, that's what I remember. I'm ashamed to admit who they were – Denis Wheatley was one of them.*
- 51 ML comments on male and female taste.

- 52 (Participant 1) *Anyway, it's a fantastic gift to have ... to see the characters and then you look at the book and think, I never saw that tea stain on the page.* (Participant 2) *I think as well, I find sort of reading sometimes it's, it's an escape ...* (Participant 1) *Oh crikey, yes.* (Participant 2) *Because the words are there, because, like you say, you're just pictures in your head and the sentences are in the moment ...* (Participant 1) *My mother used to say to me, get your head out of that bloody book.* (Participant 2) *Because your head's in that moment, where you're reading, and not necessarily what you've read yesterday, but in that moment, it's like, there is no dementia, because you're transported into somebody else's world and everything's fine ... Am I explaining it?* ML suggests that it is not a running away sort of escapism. (Participant 2) *I get excited by words, I mean, this print is absolutely appalling [Participant's own book], however, the book is exciting, you know ... she's a really good writer.*
- 53 ML asks if Participant 2 is put off by the typeface etc. (Participant 2) *I am, definitely, but I'm really struggling through it because she can transport me out of dementia and I sometimes finish a book and I'm excited and happy ... or I can cry for hours thinking oh it was so sad and then you're back to ... and I think to myself this is just not ... I've taken my whole mood out of reality...*
- 54 ML comments on Participant 2's powerful imagination. (Participant 2) *It can be uplifting; I think it is uplifting. So, if I'm feeling down or something, I just get myself stuck into a really good book, but I like quirky books ...*
- 55 Participant 2 refers to Amor Towles's *A Gentleman in Moscow*. DEEP organiser says that she began the book and ought to give it a second chance. Opinions differ, but Participant 2 comments that a good writer makes you feel what his character is feeling.
- 57 Alzheimer's Society organiser asks about the font of Participant 2's own book. (Participant 2) *It's not just the font* [recording is faint here]. ML comments on the whiteness of the paper. Alzheimer's Society organiser mentions that the office paper supply was changed to off-white to decrease glare.
- 58 ML asks if paper for used for designer's original layouts is too yellow. No. ML mentions the Quick Reads yellow paper and dyslexic readers' preference for off-white paper. ML asks if it would be helpful to have off-white paper. (Participant 2) *Absolutely.*
- 59 Participant 2 confirms that she adjusts the contrast on a Kindle. Participant 1 states that paper is made cream [although Barrington Stoke now print a tint on the page].
- 1 hr Papers are compared, e.g. cream for OUP's *A Christmas Carol*. Participant 1 suggests that choice is a function of cost. All the books ML has brought are printed on an off-white paper.
- 1 ML asks if Participant 2 bought her book bought on Amazon. Yes.

- 2 ML comments that everyone present (herself included) is wearing glasses. Discussion follows about tints on glasses – grey or brown. ML confirms that Participant 3’s glasses are plain.
- 3 DEEP organiser mentions that her tinted glasses are an anti-migraine measure.
- 4 ML comments that eyes are not designed for reading. ML thanks participants for their helpful comments and says that people must say what they want; it is no use publishers just guessing.
- 5 Alzheimer’s Society organiser raises the issue of stickers on books and suggests that this would be an alternative to books being stocked in a reminiscence section. People need some indication of the nature of the book. ML comments on children not wanting to be seen using the Quick Reads section in the school library.
- 6 Participants agree that books would need to be distinguished in some way. ML comments that the DEEP south-east administrator had been protective of members and said that ML would have to ask them what they thought. General agreement that you cannot please everyone.
- 7 ML suggests that people want to go on doing what they do and that a general improvement in services would be better than special needs interventions. (Participant 2) *It’s routine now to have bigger font books, isn’t it?* [i.e. for low vision readers] ML comments that large print books are now better designed and suggests that publishers can increase their revenue if they get it right.
- 8 DEEP organiser points out that simple changes may benefit others, e.g. ramps for pushchairs, trollies, bikes, people who prefer not to use steps, etc.
- 9 Alzheimer’s Society organiser points out that a simple change such as printing on cream paper can make a book available to more readers. (Participant 1) *I think you’re right; I think this could easily be more restful on the eyes than plain white.* ML agrees that there is a loss of contrast with cream paper, which might mean that the type might need to be adjusted.
- 10 The different book papers are compared and relative white/off-whiteness noted. Type size, leading, ink spread are all noted in Participant 2’s book.
- 11 (Participant 1) *What determines the size of print?* ML comments on commissioning process, series, editing, pleasing the author, email from editor at Quick Reads, etc.
- 13 (Participant 1) *So the author doesn’t write a book and then say will you buy this book?*

ML comments on the creative spark of imagination.

- 14 Discussion of creative writing courses. Participant 2 says that she may do a Foundation course in textile art, which she observes is another form of storytelling.
- 16 ML speculates that electricians can be creative, can visualise things.
- 17 ML speculates that it must be in the genes ...
- 17 Participant 3 says that she enjoyed drawing and painting.
- 18 (Participant 1) *I used to write short stories ... for women's magazines ... little love stories ... I have kept most of them ... little love stories, very, very sweet.* ML asks if the stories had happy endings. (Participant 1) *Of course. ... They did print them and pay me ...* ML asks if he wrote under his own name. *I [gave them] a different name ...* ML asks at what stage he wrote the stories. (Participant 1) *When I was about thirty. ... About 8,000 words, 2,000 to 8,000 words. I can't remember what [they] paid, it wasn't very much ... I did it for the pleasure of getting it printed in a magazine ...* ML observes that people don't write for money, really, and that you don't get rich unless ... (Participant 1) *Don't encourage me because before you know it I'll bring some in to show ...*
- 23 ML asks about illustrations in books, e.g. Dickens.
- 24 Participant 2 talks about a book she had read ... *I could imagine ... because it talked about the individual houses and somehow because of the way it's written, I couldn't really imagine Valerian Road and that would be nice just to have a little black and white [picture] of a few houses ... and this was an adult book ... the house, which was the murder scene, just the front of the house, it would actually have just set the scene for you, because I could never quite imagine what the front of the houses would look like.*
- 25 Alzheimer's Society organiser comments that the illustration would need to be near the beginning of the book so that if it was of a character ... (Participant 2) *I wouldn't want a character... but a scene, just a very, very outline drawing of a house or ...*
- 26 Importance of the image on a jacket suggesting to the reader's imagination. ML asks about photographic jackets (e.g. mocked-up image of wartime scene on a book by Nadine Dorries). Discussion of the drawing of a Scottish castle on Participant 2's paperback.
- 27 Participant 3 introduces herself as a keen photographer and shows the group a photograph she has taken and used at a YPWD art class. The camera is examined.
- 1hr 29 Recorder is switched off.

## Appendix IX: Book Cover Study

Partial transcription of a discussion at a DEEP meeting held on 17.06.2019.

Participants' comments are given verbatim and in italic type.

Present: DEEP organiser and Alzheimer's Society officer (LK)

Two Alzheimer's Society organisers

Participant 1

Participant 2

Participant 3

Participant 4

[Participants 5 and 6 – consent form not submitted]

Running time in minutes:

- 1 ML thanks the meeting, explains what DEEP members had identified as difficulties when reading novels, i.e. remembering who the characters are and losing one's place in the text.
- 2 ML explains that designer has prepared two options. Pause while Participants 4, 5 and 6 arrive.
- 6 ML repeats. Combining the two solutions – useful? Printed book mark – useful? ML explains why Treasure Island chosen. Printed on the flap and cut off? Other side is plot summary – is that better? Over complicated?
- 9 People volunteer that they just shove something in between the pages (Participant A) ... *but I still sometimes have to go back ... it doesn't bother me, though, I've been doing it like that for years ...* ML comments that Participant is an expert reader ... *yes, I do read quite a lot ...* ML expands ... *It doesn't bother me, I'm quite happy to, to even go back to the beginning and start again if I want to ...* Participant describes a book mark with a photograph she was given by a granddaughter many years ago and still uses. LK interrupts to say that Participant 3 had something to say.
- 11 ... *I was thinking, basically, you've got the character list, which is quite useful, and a plot summary and I think that's useful because if they've lost their place, they can look at the plot summary and find out where they start again.* ML says that she is concerned that the plot summary would be hidden, and the reader might not remember to look for it. ... *Well I think if you've got something only this big, you'd search it ... if it was a huge tome [you wouldn't want to] ... I would say if it was something this small ... you'd remember ...*
- 12 Participant is keener on the plot summary than on the bookmark ... *Yes, it's a good idea to have this ... so that when you start reading [you've got the list of characters and the plot summary].* ML asks about the size of type, is it too small? *No, I can read that ... Too small? It might be for some people ... but not for me.*

- 13 ML asks for an honest answer about whether copy should appear on the book or on a sticker. Does that bother people? Participant 3 ... *No, it doesn't ... ML presses further explaining about selling copy ... I wouldn't be too much worried about it ... a blind man's going along with a white stick ...*
- 14 Participant 4 ... *it's my choice, because Treasure Island I know it's a story and I want to know about this story ... I don't mind ...*
- 15 Participant 1 ... *it only bothers me when I've lost the thing ... That would be very difficult to lose, wouldn't it, because it's a nice size ...* ML explains that the design is simple as it is the story that counts. ML introduces the idea of a sticker and wonders if they have already answered the question.
- 16 ML passes round photocopies and cover. She explains the two options and the fact that the elephant never forgets. Participant 4 likes the elephant and Participant 3 describes it as *rather sweet ...* Participant 4 approves ... *it's very nice, it's like a little toy ... he is showing me that if he can read I can read, thank you very much, why should I ...* ML checks, people don't feel that's patronising? ... Participant 1 ... *I don't certainly, no, I don't know about everybody else.* DEEP organiser points out that the elephant stands out because of the colour.
- 18 ML explains about the plus sign and the ampersand. Participant 3 ... *I prefer the ampersand myself ...* ML explains why the designer liked the plus sign. Participant 3 ... *the ampersand has it over here ...* ML turns to Participant 1 ... *I think they're all nice, I couldn't choose one, I don't think ...*
- 19 Participant 4 returns to the image on the sticker. *If I look at the READ + REMEMBER, the picture with the book and two stars above, it looks like something very holy ... the church ... pray God that you can ... I am not a Christian but never mind God is for everybody, who cares ... it's like for little children, you see the light and you just go the way ... but I like the word memory supporting.*
- 20 Participant 5 comments on the issue of the stability of the cover if the strip is cut off. It depends. ML explains that the flap can be tucked in, front and back.
- 22 Participant 3 ... *You used to have a little bookmark ...* ML agrees but says that they can get lost ... *but you can use a business card* (laughs) ... ML explains these are just little areas that might bear thinking about.
- 23 Participant 3 ... *One of the other things is comic book types ... that sometimes works very well ... children* [words cannot be discerned here but point is made] ... ML concurs and wonders if that is childish ... Participant 1 ... *Some people are childish* (people laugh).
- 25 What sort of stories does ML have in mind? (Participant 5 has sets of Catherine Cookson and Dick Francis.) ML mentions Quick Reads. Removing barriers is the aim.

30 Recorder is switched off.

## **Appendix X: Consultation with book-making professionals**

Text of two emails sent by Kate Baylay, book illustrator. The first was in response to the questions given below, with question no. 6 addressing a point raised in an intervening email. The second email was unsolicited and follows up a number of issues raised in the first email.

### **FIRST EMAIL**

Here are my answers to your questions. I hope they are of some help, they were very interesting to answer and have made me think carefully about my response to briefs.

#### **1. Do you always visualise stories as you read?**

Yes ever since I was a child I have always had strong visual ideas about the stories I have read, characters, places etc. This happens spontaneously as I'm reading but every now and then when I hit upon a particularly interesting scene, I stop to develop the idea in my head of what that moment would look like as an illustration. This is one of the things that has meant that I have always drawn pictures. Since becoming an illustrator and reading a lot of books with the sole purpose of going on to illustrate them, the process of keeping an eye out for a potential moment, selecting one and then visualising the style, composition, figures, colours etc. has become more habitual but it is all based on the initial impulse to visualise what I'm reading.

#### **2. Have you ever worked on a commission where your illustrations had to be life-like? Would you find such a commission unappealing?**

I admit that my life drawing is definitely not my strong point. I don't think I would ever be commissioned for such a project as I don't have any samples of such work in my portfolio. I would not enjoy such a commission because I would not be able to produce anything that I was happy with and also because I have always strongly preferred working from my imagination. Of course, I have to use reference material but the main elements of my illustration [are] formed in my imagination and this is what I have always loved about illustration and the reason why I have spent my whole life drawing pictures.

#### **3. Would you feel very limited if you had to produce only black-and-white illustrations?**

I have produced black and white images for *Vile Bodies* by Evelyn Waugh, published by the Folio Society, 2015 (<http://www.katebaylay.com/vile-bodies.html>).

It is certainly a different process and in many ways the process of creating the image has to be altered. For example, I have found that certain details are more difficult to define and enhance if you do not have the full colour range to utilise. I do usually work in colour now which I very much enjoy as I love the effect that different colours can have when put together but I do enjoy working in black and white. In lots of ways it simplifies the choices you make, it is easy to spend hours playing around with different hues and there is something interesting about the way the main structure of the illustration is simplified by the limitation.

#### **4. Would you draw differently for an adult readership as opposed to a children's readership?**

I have never done a book for young children. Titles such as *A Note of Explanation* by Vita Sackville West published by Royal Collection trust, 2017 is aimed at older children and spreads to an adult audience. I don't think I will be selected for books for young children as I have been told that my work is too "spooky" for young children! Recently, however, I have been working on a book that is definitely aimed at children, probably between the ages of 7/8 to 13/14. The author selected me because he wanted illustrations that would fit with the more traditional idea of children books. Of course there are certain aspects that I altered when working on this; I have a tendency to go a bit gruesome with my illustrations, but essentially I didn't change the way I work. I remember seeing illustrations when I was little that perplexed, fascinated and even frightened me, illustrations by such artists as Arthur Rackham and they are the ones that stayed with me. I think children enjoy being challenged and treated like adults and I, personally, as a child, didn't like book illustrations where I felt that the illustrator was holding back because it was aimed at children. I don't know anything about the research that has gone into guiding readers through text via illustrations and supporting memory in this way but I would imagine that illustrations that are visually stimulating and interesting would be helpful in engaging the reader's interest. I would have thought that the key element is the same and that people want to feel like the book that has been aimed at them is being created and designed with as much creative flare and thought as any other book.

#### **5. What is the key information you need from a publisher in order to produce artwork that is appropriate?**

The initial and probably most helpful points are the book itself and the fact that they have selected me to illustrate it. My style doesn't vary as much as some illustrators so I know that, to a certain point, the publishers know what to expect from me. However, it's important to adapt to content and to create illustrations that fit with the audience the book is being aimed and the type of book the publisher wishes to produce. I find knowing the age range helps to fine tune the style of illustration but the most informative ideas come from reading the book itself. The brief of using illustration to support memory is a very new concept for me and this and similar criteria would, of course, require another level of thinking to create these illustrations. Would they need to be

simplified in order to have an effect? Or be more life-like than the type of illustrations I normally work on? My main criteria as an illustrator would still be to produce illustrations that are as beautiful and interesting as possible, I would still be most interested in creating work that the audience is drawn in by and that creates an effect on the viewer.

**[6.] How does it feel to work under pressure? Does this make your brain freeze? Does it affect your imagination?**

For me personally I find that my stamina goes before the ideas freeze! I suppose it's like most jobs, there are areas of creating an image that are more taxing and there are times when it's fairly easy to sail through. I enjoy every part of creating an illustration and I find that I respond quite well to deadlines as it creates a structure that I find comforting. I find that if I get weary it's after I've been working on a long project for a while, such as a fully illustrated book, that's when I have to pay attention and make sure each idea is fresh and interesting. I find that looking at artwork that excites me helps massively with this, I have books of illusions that always stimulate my imagination, or I go to a gallery or museum to refresh my ideas.

**SECOND EMAIL**

I have had some thoughts about the brief as well. I don't know much about the subject of memory loss so forgive me if at any point I am off the mark. This is purely how I would respond as an illustrator.

1 - I feel that having the line of text underneath an eye catching illustration that quotes the exact point the illustration is based on would be helpful. It feels like these would provide a sort of check point while reading so that you're not just looking at a body of text which might be intimidating. The line of text is a good way of contextualising the illustrations as well and the two together could provide a strong support for memory. I would suggest possibly having a few of these 'check points', possibly two or three per chapter, but not so many that they sort of merge into one.

2 - The fact that you have said that the patients with Alzheimer's are understandably not interested in reading children's books or comics suggests that it would be important to create compositionally and stylistically sophisticated and interesting illustrations. The illustrations would be used primarily to assist and support the reader's memory but they could also be there for the reader to enjoy as images and they might have more effect if they have sparked the reader's interest. As I said, I do not know much about the subject and I'm sorry if that doesn't make sense, it's just an idea.

I hope this is helpful as the point of view of an illustrator. I think my print goals in responding to a brief such as this would be to learn all I could about the research gone into the use of illustrations to support memory loss and then, within the

guidelines necessary to such a brief, to work on creating eye catching and stimulating illustrations as I would in any other commission.

Many thanks for getting in touch and asking for my thoughts. I would be more than happy to expand on anything or answer any other questions you might have.

## Appendix XI: Discussion

Text of an email from an editor at Quick Reads, in response to an enquiry about the editorial work carried out on the texts.

You asked about the editorial work that goes into the Quick Reads. Broadly, that side of it is covered by a document giving guidelines to authors and their editors at their regular publisher (Quick Reads are published by a number of publishers, who follow design and editorial guidelines laid down by Quick Reads.) The editorial guidelines were written by two of us – both teachers of literacy to adults – and have been revised and added to over the ten years of QR’s life. I got involved because I am a book editor as well as a trained and working teacher of literacy to adults.

We ask authors to write straightforward stories or works of non-fiction of c20, 000 words. The language should be simple (for example, there are guidelines as to the frequency of three-syllable words, excluding common ones like cigarette); sentences short; paragraphs short; chapters short; punctuation and grammar conventional. The editors are expected to check their authors’ texts according to the guidelines. The text then goes through me and one other editor – and we change it if we think there is anything difficult for the intended readers. Sometimes part of the text is referred back to author and editor for clarification. I use my knowledge of what I know my literacy students can read and not read as a measure of readability. I also check the covers, titles, cover copy, cover design, legibility of cover typography etc. Interior typography also follows guidelines.

Quick Reads has a director who commissions/persuades publishers and authors to publish and write the books (the authors don’t earn much from Quick Reads, but many want to write them). Some authors find it easy to adapt their usual writing style; others find it harder. The director reads texts before they reach me – and flags anything major that bothers her.