

‘Life goes through in a book’: A case study of a co-creative narrative enquiry involving older adults living with early-stage dementia

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Abstract:

Arts participation and life review are recognised methods for improving the psychosocial wellbeing of older adults, particularly those facing challenges such as cognitive impairment. Many creative interventions taking this approach in care settings focus on large-group activities and often centre on visual arts, dance, theatre or music. This article reflects on the benefits that might emerge from a more intimate creative collaboration based on early experiences of private reading and continuing personal connections to childhood stories. It also proposes an innovative approach to life review, grounded in narrative enquiry that decouples storytelling from linear chronology or factual truths about the past. We discuss the project ‘Lifelong Reading: New Stories’, which allowed a small creative research team to work with two individuals living with early-stage dementia to produce *fictional* life-story books. We explore how this project encouraged co-creativity and created new story objects that disrupt conventional ideas about life review.

Keywords: childhood books; co-creative; life review; memory; narrative

Introduction

‘Life goes through in a book’, says one of the participants in the co-creative project, ‘Lifelong Reading: New Stories’ (subsequently referred to as ‘New Stories’). Life-story books have

become a commonly used intervention for improving the psychosocial wellbeing of older adults, particularly those facing challenges such as cognitive impairment. The creation of these books is usually considered to be a therapeutic procedure (Subramaniam, Woods & Whitaker, 2014), or a means for enhancing care practices (Thompson, 2009). The process is rarely viewed primarily as a creative opportunity for the remembering subject or the practitioners involved in helping them gather and shape the raw material of autobiographical memory. Moreover, the nature of narrative itself is not usually interrogated in studies of literary arts participation or narrative based life-review interventions.

This article reflects on the processes and outcomes of *New Stories*, focusing on the shared value for professional practitioners, researchers, and lay individuals of immersing in childhood stories in the broadest sense. The project's tangible end product was a *fictional* life-story book co-created by and for each of the two participants in a day centre specialising in early-stage dementias. We explore ways that *New Stories* 1) encouraged co-creativity through the exploration of memories of childhood stories and stories about memories, and 2) created new objects that disrupted accepted linear and sense-making ideas about life review.

Context

Remembering Childhood Stories & the Narrative Self

In his bibliomemoir, *The Child that Books Built* (2002), Francis Spufford records his memories of the books he read from 'babyhood to the age of nineteen', creating what he calls his 'inward autobiography' (p. 21). His argument, that 'the words we take into ourselves help to shape us' (p. 21), acts to frame *New Stories* and its concern with remembered childhood books and stories. The importance of reading in the early years is well established amongst educational bodies and scholars of literacy as a means of increasing academic and socioeconomic achievement (Clark and De Zoysa, 2011; Mol and Bus, 2011), but there is also a growing body of evidence for the value of books encountered in infancy and youth in terms of social and personal wellbeing (Clark and Rumbold, 2006; Cremin et al., 2014). Moreover, early reading or being read to may continue to have an impact on individual subjectivity well into later life, through the functions of memory and affective traces (Waller, 2019). The link between early literary matter and selfhood claimed by Spufford has been explored by numerous other bookish memoirists and critics (see for example Crago, 1990; Mackey, 2016; Mangan, 2018). Most of these writers have an investment in the written word as an integral part of their own professional identity that goes beyond most lay experiences; nevertheless, a case has also been made for the importance of reading in many ordinary lives (The Reading Agency, 2015; Billington, 2019).

These various links between books, reading, memory and subjectivity can be theorised using the broad notion of narrative identity: the sense, as William Randall and

Elizabeth McKim put it, that our lives are ‘quasi-literary works’ (2008, p. viii; see also Hunt & Samson, 1998; Bruner, 2004). The basic premise of this theoretical positioning is that each one of us moves from a state of narcissistic egotism into full selfhood through the process of ‘narrating our own story’ (Ricoeur, 1991, p. 437). Furthermore, writing and reading or telling and listening to stories provides us with intimate knowledge of the internal lives of others, thus contributing to an understanding of our own subjectivity as socially constructed (Hardy, 1968; Ricoeur, 1991). This kind of narrative work has been recognised as of particular value to ageing and older individuals as they seek to find meaning into later life (Hepworth, 2000). Work in literary gerontology has mostly concentrated on the role that fictions of ageing or books read in older age can play in consolidating a coherent sense of selfhood (Hepworth, 2000; Hubble, and Tew, 2013; Small, 2007) but *New Stories* has shifted focus to childhood books and remembered stories as a source of narrative identity carrying equal weight. The concept of the ‘lifelong reading act’ helps to explain the thinking underpinning this move:

The kernel of the lifelong reading act is a first encounter with a book, but this act spreads beyond the initial moment of reading (or being read to) into other points of engagement in the following hours, days, months, years, and decades. (Waller 2019, p. 190)

By focusing on the influence of books encountered early in life, rather than on continuing literary engagement, the lifelong reading act touches most lives, and not just those of bookish adults. It also involves a variety of cognitive and social activities beyond reading itself: these can include reminiscing about books, as well as imaginative re-working of stories from the past into new creative artefacts or new narratives of the self. So far, tentative work has been undertaken exploring the potentially beneficial results of introducing children’s literature to an older adult living with a dementia, where simple episodic storylines, bold characterisation, and linguistic repetition help maintain interest (Pinsent, 2017). *New Stories* aimed instead to explore the possibilities that open up when childhood stories and the lifelong reading act are used as a starting point for narrative inquiry; in particular, as a new form of life review.

Life Review

Since Robert Butler’s discussion of ‘life review’ in 1963, the social, cultural and psychological benefits of narrative forms of thinking in making sense of lived experience and aiding the process of ageing have been widely debated. As an evaluative form of memory work, in which events and relationships, both positive and negative, are explored and integrated into a sense of identity, it has a clear connection with narrative approaches to gerontology and care practice. According to Gerben, Westerhof & Bohlmeijer, narrative gerontology ‘sees aging [sic] and development as processes of construction and reconstruction of stories that serve to interpret and guide the aging process’ (2014, p. 211). Life review can take place at any stage of life, with multiple benefits, including social gains (such as bonding between

individuals) and instrumental functions (such as helping an individual deal with current problems or losses). However, it is often considered particularly crucial in later life, as individuals come to terms with their decreasing life span and want or need to assess the kind of life they have led or person they have become (Haight & Webster, 1995; Small, 2007). As noted above, the creation of life-story books as part of life review is usually understood to be a therapeutic procedure aimed at improving mental health in older adults facing challenges, including dementias (Subramaniam, Woods & Whitaker, 2014), or as an activity that can help improve interactions between care providers and their clients (Thompson, 2009). Organisations such as the Life Story Network, inaugurated in 2011 and partnered with the NHS, explicitly link life review to narrative through guided activities and policy development (Kaiser and Eley, 2016).

While life review is most often understood as a very structured process that paves the way for a person living with dementias to create a chronological account of their past (Woods et al., 2005; Subramaniam, Woods & Whitaker, 2014), for this project the narrative framework for the life-story books (and thus the lives) was intentionally more fluid and flexible. Accurate chronology is just one aspect of evaluating a life, and arguably not the most appropriate one for individuals with cognitive impairments that often result in confusion and anxiety around remembering the past. Moreover, simple linear chronology is not the only, or even the most common, structure for stories. Contemporary fiction, in particular, is often characterised by its non-linear plots and other postmodern qualities, which include temporal distortion and fragmentation (McHale, 1987; Waugh, 1995). Postmodern narrative therapy offers an alternative framework for understanding the self in these terms (Polkinghorne, 2004). In his outline of Narrative Social Work, Clive Baldwin (2013) argues that narrative enquiry such as life review needs to be 'repossessed' for marginalised groups such as those living with dementias. This repossession involves placing less emphasis on linearity and conventional plot, and focusing instead on 'small stories' and 'a sort of patchwork of fragments' (Baldwin, 2013, p. 38). Similar tactics are suggested by Moore and Davis, who use the idea of 'narrative quilting' to suggest that 'repetition techniques' (2009, p. 263), such as speaking familiar utterances back to individuals in order to piece 'blocks of the quilt together' (2009, p. 266), are often a more valuable approach in life-review work with older people than attempting to find a coherent and teleological life history. New Stories offered a chance to test these insights about the self, memory and narrative through talk based on familiar and accessible books and narratives from childhood. The intention was not primarily therapeutic, although the potential benefits for the health and wellbeing of individuals in such an intervention are relatively clear (Staricoff, 2004). As Sara Houston notes in setting out her approach to research into dance-based community arts projects, creative endeavours do not produce 'standardized, goal-orientated content that might be boxed and certified as clinically effective' (2019, p. 14). New Stories was also interested in broader implications arising from the shared creative context in which such stories are spun.

Co-creativity

Arts participation among older people has been recommended by the All Party Parliamentary Group into Arts, Health and Wellbeing Creative Health Inquiry Report (2017) as a key activity for stimulating cognitive abilities such as memory, as well as for promoting social interaction and allowing creative expression; however, according to the Department for Digital Culture, Media and Sports (Taking Part Adult Annual Report, 2018/19), arts participation is lower for people aged over 75 than for any other age group. The value of engaging with the arts is considered to have particular gains for those who are socially isolated or who face cognitive challenges. Arts-participation interventions in care contexts for older individuals and those living with dementias, especially group workshops led by a single practitioner, are therefore often seen as relatively efficient and low-cost public health resource (Clift, 2012; Noice et al., 2014; de Medeiros & Basting, 2014). However, the model of a one-to-many workshop has certain limits in terms of allowing a sense of agency and ownership.

Collaboration at a more granular level brings additional general benefits to the lived experiences of older people and those living with dementias, in particular in the context of what can be called ‘co-creation’. Camic et al. note that ‘co-creativity using the arts extends an invitation to participate in an aesthetic process and allows unique opportunities for communication and expression’ (2018, p. 4). Co-creativity approaches thus promote and sustain wellbeing and other social and personal goods through both an increased participation in the arts and through meaningful social exchange and active engagement. They also chime with the landscape of current constructivist theory and practice in gerontology, dementia research and care studies, in which research *with* rather than *on* or *about* people living with dementia is a cornerstone (Sterin, 2002). A range of research methods emerging from narrative and performance paradigms, including Co-Constructed Inquiry (CCI) (Keady et al., 2007) and Narrative Care (Berendonk et al., 2019), have been developed to ensure that understanding emerges from ‘a mutual creation of knowledge by the viewer and viewed’ (Charmaz, 2000). Creative arts projects such as the TimeSlips programme (Thompson, 2009) and Living Words (*Living Words*, n.d.) recognise participants as agents in arts production, for instance.

Co-creative approaches value social forms of creativity that to some degree counter conventional, individualistic ideas of artistic genius (Camic et al., 2018). Although projects may still aim to create a ‘high quality work of art’ as part of their remit (Zeilig, Killck & Fox, 2014, p.13), as a shared *process* and through shared *ownership*, co-creation offers a socially entwined and embodied approach to arts participation that goes beyond the final artwork. In this sense, co-creativity is especially important in the field of dementia care, since it recognises that self-expression does not have to rely on intact cognitive faculties, especially when creative acts can be gently facilitated by others (Zeilig et al., 2018; 2019). Co-creative practitioners and facilitators also acknowledge that people living with and people living without a dementia have a common need for social interaction in order to fulfil the basic requirements of personhood (Kitwood & Bredin, 1992).

With the importance of social interaction underpinning it, alongside pressures of economy mentioned earlier, co-creativity both within and beyond care contexts is often conceived of as a large-group endeavour, usually drawing on the visual arts, dance, theatre or music, in which artists work with a community and to differing degrees give over the control they would normally wield over a project (see Young, Camic & Tischler, 2016; Zeilig, Killick & Fox, 2014 for overviews). Other projects focus on inclusion in smaller groups. For instance, the Wellcome-Trust funded 'Created Out of Mind' project, 'With all' (Exploring co-creativity, n.d.), brought together up to five individuals living with dementia with musicians, dancers and researchers in improvised workshops. The following description of the project design and methodology for New Stories outlines why more intimate, small-scale co-creation can be especially effective and may bring additional social and personal goods to participants involved.

New Stories: Methodology

New Stories brought together two individuals living with early-stage dementias (Catherine and Fay¹) and a creative research team made up of a children's literature expert (Alison), a creative writer (Gemma), and a book artist (Wallis).² Meetings were facilitated by, and held at, a London day centre specialising in early-stage dementias. The team and participating individuals met formally three times: first, to discuss remembered childhood and to explore memories of childhood stories; and second, to follow up on any childhood books or story experiences recalled with readings and further discussion. These initial meetings included an element of creative play, and the second meeting also began to collate verbal and visual material for a final fictional life-story book. The creative practitioners were involved in leading games and exercises, and also note-taking and sketching aspects of the meetings, while the children's literature academic directed and guided discussion. The creative writer and book artist then worked with the two participants and collaborated together to produce a fictional life-story book for each, based on discussion and stories told as well as the creative and craft items developed in the meetings. In the third and final meeting, these artefacts were handed back for the participants to keep and share with their families and carers. All meetings were audio recorded and transcribed, and photos recording the sessions were taken. Before the core meetings and co-creation took place, the creative research team also held an initial workshop on remembering childhood books and retelling stories for all interested clients³ of the day centre, to test out ideas and become familiar with and to the community. In addition, a pilot workshop had previously been held with volunteers and stakeholders (including students, local members of the University of the Third Age, and the day centre manager and staff member) to trial some of the project methods.

Aims and Objectives

Lifelong Reading was an exploratory project. As such, it acts as an intrinsic case study that can be examined in order to understand the particular dynamics at play in co-creating through stories in the context of early-stage dementias. Crucially, however, this was not a study of the effects of ageing or dementias; nor was it intended to provide any particular insight into the specific experiences of our two participants, although the case-study's focus on details makes it a valid methodology for understanding more about the subjective nature of living with dementias. For this reason, in this article we do not present data about the participants' ages or specific form of dementia, or about their ethnic or social background, beyond any information that arose in discussion (which may or may not be objectively accurate).⁴ We have purposefully not sought any further details about participants from the day centre or carers, since within the paradigm of a co-creative project they are not subjects but contributors.

Intrinsic case study is especially appropriate for a project concerning remembered stories and storytelling, since it relies heavily on the 'thick description' (Geertz, 1973) of narrative accounts to outline its data and offer insights into lived experiences (Stake, 1995; Hellström, Nolan & Lundh, 2005; Zeilig et al., 2019). Our initial research questions for the project were open, reflecting intrinsic case study's tendency to produce emergent ideas rather than definitive conclusions or new theories. Nevertheless, we have been able to develop some methodological tools and offer some reflections that we hope will help to influence future work in this area and contribute to the larger picture of shared creativity.

Our research questions were:

1. How can stories and illustrations encountered in childhood enrich or intersect with narrative and reflective processes of ageing for older adults living with early-stage dementia?
2. What might the collaborative process of creating a fictional life-story book add to a wider understanding of co-creative practice as an intervention for wellbeing?

Project Design

Co-creation was at the heart of the project design and New Stories worked uniquely in this context in two ways. First, it functioned on a small scale, with a model of interaction in which two members of the creative research team mostly talked with the participants while a third primarily observed and took visual or verbal notes. We met three times, and sessions were no longer than an hour, meaning that discussion was contained and focused, and the project did not disrupt other aspects of Fay and Catherine's routine. This design recognised the value of intimate methods such as John Killick's one-to-one poetry project (Killick, 1999), which allow for control and autonomy on the part of the participants. Fay and Catherine could to some degree shape the direction sessions took and also direct Gemma and Wallis's artistic visions. For instance, at one point in Meeting 1, Catherine admitted she could not remember anything about the topic we were exploring together and said she would 'have to come back to you on that'. Both participants agreed to what might be worth eventually

going in their fictional life-story books, adding details (such as the colour of a skirt) when it seemed important. The three-to-two model encouraged an atmosphere of collaborative discussion rather than intense scrutiny and felt less pressured as a creative process than one-to-one activity, especially as participants and creative research team members could pass control over to each other when ideas dried up or conversations became emotionally challenging. In particular, the creative research team used strategies of probing, affirming, re-inscribing, reiterating and repeating in order to facilitate discussion and generate ideas; dialogic tactics that promote depth and collegiality. It should also be said that both creative practitioners had experienced lone working during previous projects, and appreciated the support and dialogue made possible from a more collegiate model.

The second difference in design is in the focused art form. The project drew on narrative arts – specifically personal reading and an experimental and flexible notion of story – as its keystone for creativity. Although there are some existing reports of literary participative arts projects (Killick, 1999; Gregory, 2011; Dorrick et al., 2012), they are in the minority overall, and tend to work with poetry or shared reading aloud. Using childhood books as a starting point, *New Stories* offered an alternative set of participatory activities that focused on experiences of private reading and personal connection to books, stories and illustrations. These stimuli may well aid individuals in accessing different aspects of their pasts to other participatory arts activities. We found that childhood books certainly appealed to individuals in terms of opening up possibilities for intimate sharing and evoking memories of past pleasures. For instance, for Catherine and Fay there were direct links between the storytelling and book prompts we introduced and life themes of play, sibling relationships, and family life.

We also acknowledged the importance of understanding narrative as a fluid concept. We followed the general premise of life review, in which individuals and their carers or family work together to record aspects about their lives, but also drew upon the more relaxed processes of reminiscence, which ‘depends less on the accurate remembering of the past and more on the process of exchange and listening’ (Bornat, 1989) as well as the notion of repossession of narrative and allowing small stories, fragments and repetition to guide process (Baldwin, 2013). Furthermore, we recognised that co-created narratives can help to shape and integrate memories into a new and meaningful sense of identity. ‘Bricolage’ emerged as a meaningful process in our discussions, allowing us to use the ideas and materials ‘at-hand’ in each session to fashion our activities and meaning-making (Levi-Strauss, 1966). Fay recalled the way her mother used to pick up ‘what she called oddments, in a bowl...bits of red and bits of yellow’ to make clothes for the family – a practice several of us recognised in our own families – and ‘making something from nothing’ became one of the themes of the sessions. The phrase is one that Gemma used in her introductory creative game, and reflects her conscious intention to ‘enhance creative potential of those in later life’ (Seltzer, 2016, p. 6). Interweaving of childhood fiction and autobiographical memories was encouraged in discussions and creative activities, as was repetition of key themes in new contexts, and an acceptance of non-linear forms of chronology. Collaboration in this

form came from a shared acceptance that together we could ‘make something from nothing’.

These two aspects of the project design – the three-to-two co-creative model, and the use of private and collective narrative as a creative keystone – helped to emphasise imagination over ‘true’ or ‘successful’ remembering and thus had the additional benefits of promoting creativity for its own sake and fostering a ‘failure-free atmosphere’ in a way that engagement with memory activities does not always achieve.

Ethical Considerations

The collaborative nature of the project raised specific ethical issues around co-creation and consent, which are worth outlining in some detail. We wanted participants to consider themselves as co-creators of the final fictional life-story books, not just recipients of an arts intervention. As self-employed consultants, the creative practitioners also needed to feel that the project informed their creative practice and that the final artefacts could become part of their portfolios. University policy on copyright and data sharing poses some challenges in designing a project like this one, in which the creative output is a shared collaboration but one that will be handed over to the participating individuals living with dementia. These issues were resolved through a careful consent process.

An accessible information sheet was provided for participants to read with their families and/or carers in advance of the first meeting. We followed the principles of process consent outlined by Jan Dewing (2007; 2008). By focusing on the notion of personhood, this approach moves away from universalities towards specific needs of the individuals involved. It requires five actions: 1) background and preparation; 2) establishing a basis for capacity; 3) initial consent; 4) on-going consent monitoring; 5) feedback and support. In the case of New Stories, background was provided by the day centre managers, who selected our participants based on knowledge of the project: both Fay and Catherine were identified as interested in engaging in talk and capable of sustained activity. In the initial workshop, the creative research team could establish a basis for capacity by observing Fay interacting with books and joining in with our conversations (unfortunately, Catherine did not attend this workshop). Working with individuals living with an early-stage dementia posed some additional challenges in preparation. We learned that it was useful to go and meet Fay and Catherine in the main area of the day centre and invite them into the smaller room where we were holding our discussions: this helped to avoid an initial situation in which Fay felt she had been taken away from her usual activities with no explanation.

At our first meeting, Alison talked through the project design and intentions in simple terms for initial consent. She also helped Fay and Catherine to understand the formal consent form required by my institution, explaining each clause in accessible language. After each clause and related discussion, Alison asked the participants to tick a box to show they understood. The same process took place at the beginning of every meeting. Although this formal part of proceedings felt to the research team rather heavy-handed considering the fluid and open nature of the sessions themselves, both Catherine and Fay were willing and

engaged, keen to read each statement and ask for clarity when required. Our final meeting included a further discussion about what aspects of the fictional life-story books participants were willing for us to use in research presentations and creative portfolios: Catherine and Fay were eager for the materials to be shared. We also included a summary activity and invited the day centre manager to come and see what we had been working on together. The collaborative nature of the project meant that this final element of feedback and support felt truly like a shared experience for all five of us.

Narrative enquiry opens up potentially difficult topics. Early on, both participants brought up the subject of the death of a sibling in childhood, for instance. As a team, we recognised the importance of listening to, and giving space to, all types of experiences and emotional response. It was therefore important for us to include fragments that detailed sad experiences as well as joyful ones in the final life-story book. We also stressed that our activities together had no right or wrong answers, and that Catherine and Fay could move on from painful or upsetting memories at any time. The trust built across even a relatively short period and limited intervention allowed for a rich set of interactions. In the next section, we discuss these, drawing out key themes and outcomes.

Discussion

Transcripts, research notes taken during and after the sessions, images and artwork were all treated as data. Following the analytical approach of intrinsic case study, we examined data in order to highlight significant statements, clusters of meaning, and themes (Moustakas, 1994). Drawing on Alison's expertise as a literary scholar, we also relied on methods of close reading to analyse our conversations, recognising the narrative nature of autobiographical accounts generated during the New Stories project. We selectively use the present tense from hereon, treating transcripts of the meetings as literary texts of sorts.

Childhood Books: Friendship and Play

The original prompt for the project was a remembered childhood book. Discussion about childhood memories was designed to lead into the identification of a significant book or books, which could in turn be used as a framework for shaping autobiographical narrative and developing creative storytelling ideas. Problems with this project design arose in the first session. When asked about the reading they did when they were young and the books they encountered as girls, neither Fay nor Catherine have much to say. As children from large and relatively poor families, in an urban, working-class part of London, they simply may not have read much children's literature, or even encountered books in general. Fay says that she was not read to when she was young because hers was a 'family with not a lot of money, so you just get what you get' and Catherine admits that she used to read at primary school but afterwards she 'put that aside because other things were happening in my life really'. Books and reading do not immediately or obviously feature in the participants' life stories in the way that they had in those of others who Alison had spoken

with in previous projects (Waller 2017; 2019): a fact that has reminded us that as researchers we need to challenge our assumptions about the central role of our subject matter based on our own autobiographical memories, background and abilities. As well as the material conditions that affected early access to books for both women, Fay implies a certain anxiety around literacy itself, noting that she ‘wasn’t very good at catching on’. Catherine in particular displays more resistance to discussion about books and reading than in any other part of our conversation in a way that suggests unease about literary culture. She repeats twice that she does not remember what she read as a girl, and also says ‘actually I can’t remember much of what I used to do in the library, thinking about it. So I think I’d have to come back to you on that’. It is possible that for individuals with early-stage dementia, books and reading represent a particular ‘mental block’, but since Alison had received similar responses from participants not living with dementia in previous projects, it is perhaps more likely that asking any direct questions about reading or, conversely, asking about childhood books in a very abstract way will evoke a certain amount of panic and ‘blanks’ in some individuals.

We had, in fact, encountered the same issue of an apparent lack of early engagement with literary culture in the initial workshop held for all of the day centre clients, and perhaps should have been more prepared. However, this workshop also gave us some clues about ways that early stories and books still have an impact on communities in which reading is not necessarily a common activity. Being read to and reading out loud in general provoked feelings of pleasure for many of the clients, as did the handling of material books, particularly ones with illustrations (see **Figure 1**).



Figure 1

For Fay and Catherine too, being read to evokes pleasure (Fay: ‘It’s nice to sit quiet and listen. It catches on, doesn’t it?’). When we reviewed the first session with Fay and Catherine, the creative research team recognised the importance of moments when these aspects of childhood reading were foregrounded. For instance, ‘prompt’ copies of classic children’s books such as Kenneth Grahame’s 1908 *The Wind in the Willows* with illustrations by E. H. Shepard, including a map of the fictional landscape, (from the 1931 edition) and

Frances Hodgson Burnett's *The Secret Garden* (1911), illustrated by Charles Robinson, elicited positive comments (Fay: 'They're beautiful aren't they?'; Catherine: 'That's a lovely piece of art work, isn't it?') and a spark of recognition from Catherine, who read the name 'Martha' in Burnett's novel and connected it to a childhood friend. Fay in particular enjoyed reading out loud from Gemma's own juvenile copy of the Grimms' fairy tale 'The Elves and the Shoemaker' (a miniature version retold by Olive Jones and illustrated by Francesca Crepsi), which had also been popular during the workshop. Acknowledging our commitment to creating a bricolage, allowing for repetition, and aiming for moments of recognition rather than full and accurate memories, we decided to build upon these fragments in the second session. We therefore planned that for this session Alison would read aloud from the chapter titled 'Martha' from the illustrated copy of *The Secret Garden* that had caught Catherine's eye, followed by the whole of *The Elves and the Shoemaker* book. We would also bring a copy of *The Jolly Postman* by Allan and Janet Ahlberg (1986), which is visually and materially very interesting and chimed with a motif of envelopes that had emerged in discussion about one of Fay's jobs packing envelopes in a factory as a young woman.

Burnett's classic tale of orphan Mary Lennox growing and thriving through coming into contact with other children and the beauty of the secret garden helped to introduce themes of friendship and play into the meetings, which integrated well with memories and stories that Fay and Catherine wanted to share. Catherine comes back again and again to the importance of 'nice friends' that she has made throughout her life, and speaks at length about a childhood friend whose house she loved visiting because it was more 'tranquil' than her own busy home. Friendship is clearly an important aspect of her personality, which is also heightened in the various affectionate exchanges we observe and join in with between her and Fay. Play featured heavily in discussions during Meeting 1, as we began with a story-making game of 'Yes, and...' that Catherine chooses to locate in an imaginary park.⁵ Sandpits and swings, and the freedom of being somewhere away from the family home where 'everyone was broke' (Catherine) connect both women to their pasts. It is worth noting that it is not always clear whether Fay is recalling her own childhood or her later experience of parenting and being a grandparent; but for her the challenges of managing big groups of children with few resources ('You never know what they'll do next!') remain a constant theme throughout our discussions in any case. In the spirit of embracing stories rather than seeking out truths, these small narratives of 'typical things with children', as Fay puts it, play a part in forming a richer understanding of her identity.

Childhood Story Structures: Poorness

The miniature edition of *The Elves and the Shoemaker* plays on the common trope of smallness in children's literature, both through its form and its narrative about the little helpers and the tiny leather shoes and knitted clothes the shoemaker creates for them to say thank you at the end of the story. After listening to it in full, Catherine finds a way to locate herself within the themes of the story, explaining that she was 'quite small amongst her sisters' and that she used to think to herself 'maybe tomorrow I won't be smaller'. For

Fay, the connection is less explicit, but emerges in discussion, as Alison makes a link between the scraps of leather used to make the elves' clothing and the 'oddments' that Fay's mother collected for sewing and mending for her children: 'my mum used to go and pick up what she called oddments, in a bowl, and it was bits of red and bits of yellow and she used to do that.' As we mentioned earlier, we found ourselves coming back to the idea of oddments in the meetings on a number of occasions, and Gemma and Wallis incorporated Fay's words and an image of the concept into the final fictional life-story book (see **Figure 2**).

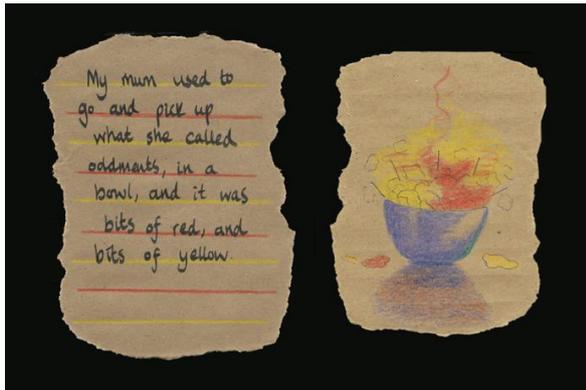


Figure 2

This was a key example of the importance of repetition in our project, which rather aptly converges with conventional fairy-tale structures (as the elves return to the shoemaker's workshop night after night to make beautiful shoes). Fay's responses reveal how this method of narrative life review is so important for personal meaning-making: she is touched to hear the word 'oddment' spoken back to her: 'you remembered!' and 'when I go home this evening all quiet, you think that yellow oddments'. This motif was meaningful for Alison as researcher too, bringing to the fore commonality of experience as she recalled her own mother and grandmother collecting oddments for sewing endeavours.

The Elves and the Shoemaker explores the common fairy-tale dilemma of poverty, as the hardworking shoemaker can hardly afford to buy enough materials to maintain his trade due to his kind and charitable nature. Poverty is a central part of Fay and Catherine's life stories and shapes the way they think of themselves and their families. From the very beginning of our first meeting, when Gemma introduces the 'Yes, and...' game to generate stories, both participants are eager to introduce their own biographical details and integrate the economic challenges they faced as girls (and possibly throughout life). Both open by explaining they are from large families, which is why the park offered such valuable space and free activities for them and their siblings ('it's a lot cheaper to look after your children' Fay points out of the park and its sandpits). Rather like the shoemaker and his wife gathering together the scraps of leather they have left and seeing what can be made, Fay recalls her parents making decisions about what to buy for the children based on how much 'club money' they could put on the table.

It seems especially important for Fay to integrate this poorness into her life story, in a way that demonstrates acceptance, resilience and gratitude. She regularly noted that ‘life is like it is’ and that you get on with it: ‘we didn’t have a lot of money and made do with what they had’. One of the most touching moments of the project came in the third and final meeting, when the participants are handed their fictional life-story books and Fay reads out loud some words she had said when we had met previously, now beautifully illustrated by Wallis (see also **Figure 3**):

Although we was very poor, and we had no money, it’s surprising how we got on, how we’ve come to be what we are today. So I thank my mum and dad for that.

She comes back to these words again and again, asking each time if she can read them out loud. She becomes slightly tearful as she reads and rereads her own words and reflects on their meaning for her life, in particular wishing that her parents could be there in front of her to thank in person. This fragment of her story represents a fictional ‘truth’ for her that can be returned to as an imaginative starting point for understanding her background and love for her family.

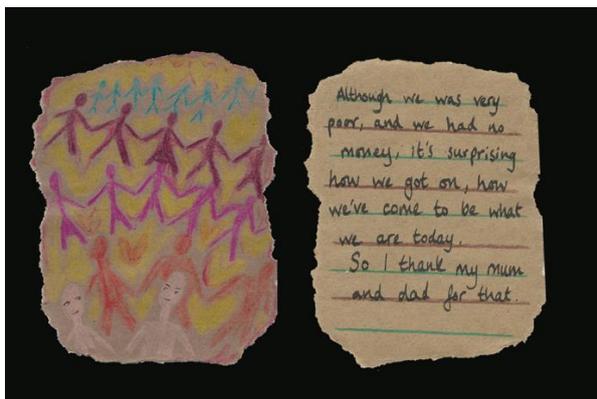


Figure 3

For Catherine, the fact of being poor generates a more amusing outcome in the process of co-creating stories. During the ‘Yes, and...’ game, she introduces a scenario that we later find out comes from life experience, in which she and her brothers and sisters were ‘quite hungry but we only had a small amount of money so we only had one ice-cream between us and we all had one lick. One lick each!’ Like Fay, she is keen to state that although they were often hungry they did always have enough food and were grateful for what they had; however, the image of the single ice-cream and multiple licks was so entertaining that we ended up exploring the idea that it could form the basis for a children’s picture book. This in turn encourages Catherine to tell us more stories of her and her siblings having to manage treats: either waiting for popcorn to blow away in order to catch it, or making do with a single chew sweet given out by their father as a bribe to get them out for a walk while their

mother prepared the family meal. Core themes merge with narrative innovation through this collaborative talk, which sometimes results in stories in a conventional sense and sometimes does not. From a starting point where mention of books and reading seems to shut down the creative aims of the project, we found a way together to unearth meaningful themes via *The Secret Garden* and *The Elves and the Shoemaker* and generate together new aspects of narrative identity.

Remembering Childhood Stories

Although testing memory was not an aim of New Stories, the project had emerged from a larger research question asking how older adults living with dementia remember and reread books from their youth, and what this might tell us more generally about lifelong reading. Considering the lack of substantial reading in Fay and Catherine's memories of childhood, this question soon became impossible to answer. Nevertheless, the connections that might be made between books and significant memories of interior life is illustrated by Catherine's response to hearing the chapter from *The Secret Garden*. Having stated in Meeting 1 that 'I can't remember, maybe I read *The Secret Garden*, I can't remember', she reflects in this second meeting;

It actually pulled me in and things like that. I had heard of *The Secret Garden* and I was thinking that was years ago. Years ago. But I kind of remember half and half. I remember actually as a child, walking through, wherever it was, with a skipping rope, all the way along, but I didn't actually read all *The Secret Garden*. At all. But I remember it. It's still there.

Remembering 'half and half' is tied directly to the experience of skipping and this kind of embodied memory linked to fictional descriptions is a fascinating area for further research for understanding the influence of reading over the life span. Moreover, Catherine's comments are provoked by listening to a chapter which does not involve skipping, and she is delighted when Alison reads out a further extract from the novel that may have inspired her recollection, which describes Mary as she 'counted and skipped, and skipped and counted, until her cheeks were quite red, and she was more interested than she'd ever been since she was born' (Burnett, Chapter 8). We are less interested in whether that fictional scene has been successfully retrieved in Catherine's memories, and more curious about the generative slippage between fictional and real worlds. Both participants are thrilled when they are shown Wallis's drawings from the first meeting, for instance, some of which illustrate the story we have created together through the 'Yes, and...' game: the pleasure comes partly from recognition of elements which seem fully embedded in a sense of themselves, even if only some are autobiographical (the single ice-cream and playing in the sandpits and on the swings) and some are completely made up (a collection of dogs in coats, which was Alison's contribution). 'There's so much in that book', states Fay, as she looks at

Wallis's drawing, demonstrating the joyful slippage we have co-created between lives, stories, and the artistic object itself.

The Fictional Life-Story Books: Book Boxes

The final element of New Stories was the fictional life-story books, co-created by Gemma, Wallis, and our participants. Our intention was to provide artefacts that Catherine and Fay could think of as their own creations, at the same time as celebrating fragmented, repeating, small stories that speak to the idea of a self as bricolage. In practice, these objects became boxes filled with the participants own words, chosen by Gemma and Wallis, and illustrated by Wallis (see **Figures 4** and **5**). In addition, the book boxes included paper-chain dolls reflecting an activity Wallis undertook with Fay and Catherine, and a poetic address to each participant written by Gemma. The last line of one of these addresses sums up the project's intention: 'So, may we present to you a book of your stories, pages from your life, moments we've loved hearing about'.



Figure 4



Figure 5

During our final meeting, we integrated a moment of reflection and feedback, all reporting on what we had enjoyed about working together. Listening was Gemma's favourite part of being involved in New Stories, and is central to her practice as creative writer. Listening and being listened to represents one of the key gains for both Catherine and Fay, who both enjoy having stories read aloud but more than anything appreciate being heard. This is particularly evident in Fay's responses. Throughout every meeting she expresses anxiety about talking: 'am I saying too much?', 'I won't say anymore', 'I don't know why I'm going on.' Having her own words repeated back to her in artistic form offers legitimacy to her talking in a way that appears in the moment to be liberating. Reading a fragment about her time working in a factory on Lavender Hill, she asks 'Can I just say that again?', and as we have already noted, she is unselfconsciously performative in rereading the fragment about her mum and dad dealing with their lack of money. Catherine also begins to speak out, having been heard. As a creative research team we chose to present her book box first, as she had been quieter than Fay in previous meetings, and she was noticeably more animated

and vocal when provided with the prompts of her own words. Reading the fragment ‘When the dogs are walking along, I always go “ahh” please can I stroke your dog’, she enthusiastically adds ‘That’s what I *do* say to everyone on the road, even now!’. Recognising her own stories, she seems to feel empowered to edit and elaborate them in a public creative act.

For Wallis, the project offered a valuable opportunity to really observe our participants while they were in conversation with Gemma and Alison. This space and time, as well as Wallis’s talent, result in similar moments of recognition for Fay and Catherine. Both respond emotionally to the sketched portraits Wallis produces of them, seeing their own mothers rather than themselves in the images. Wallis’s representation of Lavender Hill prompts Fay to use it as a kind of mapping tool, pointing out where the hill rose behind the buildings and where she used to navigate her way to work (relating back to a moment in Meeting 1 when we explored the illustrative map in *The Wind in the Willows* together). Other images, such as Wallis’s picture of children holding hands (see Figure 3), sparks a new creative act, as Fay starts to sing the nursery rhyme ‘Ring-a-Ring-a-Roses’. The combination of verbal and visual elements in the final book boxes produces effects similar to a postmodern picturebook (Sipe and Pantaleo, 2010), in which fragmented words and pictures combine to produce meaning for the individual reader. The fictional life-stories created in this project depended on both creative modes.

Although the final objects presented to Fay and Catherine took the shape of a box, we were keen to describe them as ‘book boxes’ and not ‘memory boxes’. Memory boxes or remembering boxes have mixed uses but are often used in care contexts as communication tools to help facilitate understanding between an individual and staff member or carer (Hagens, Beaman and Ryan, 2003). The centrality of books and narrative in the New Stories project results in something rather different, and the book boxes do not contain a curated selection of triggers, but instead offer fragments of a collaborative story. The distinction is underlined in the final feedback discussion between the participants and the day centre manager (who uses the term ‘memory box’ when talking with Fay and Catherine). When the manager asked ‘So you’ve enjoyed going down memory lane,’ Catherine responds ‘Well I have, yeah, and I will still, I’m sure.’ Fay adds ‘They are nice though to read, aren’t they, and to, reading them back again, isn’t it, you know?’. Both responses suggest an understanding of the narrative form of the objects, which are there to be read and to go back to; they also imply a temporal flexibility that represents something different to reminiscence and more like the literary act of rereading. Indeed, in an earlier meeting, Fay has reflected on the fact that ‘life goes through in a book.’

Implications, Limitations and Conclusions

Looking at the box we have given her for collecting remnants of the storytelling session, Fay makes the observation that ‘it’s all in there’. She elaborates that during our conversations, the memories ‘up there’ have been brought ‘down here’. During the project New Stories, the co-creative team and participants encountered a range of autobiographical memories:

some familiar from practiced life review and others surprising in their novelty in the moment. Some of the autobiographical facts are initially 'up there'. One example is the experience of poverty that is central to both participants' stories and might well be a common narrative for individuals from a certain time and place (such as mid-century Battersea) to share and bond over. While the thematic trope of 'making do' erupts again and again in structured discussions of family life, specific details also emerge in the free-flowing creative explorations of self, story and memory, and these seem to make a deep impression that is based in something felt rather than just remembered (such as Catherine's reflections on her childhood friend's house, or Fay's expression of gratitude to her mother and father). These expressions conjure the idea that fragments from the past have been captured like butterflies and, in the same way that netting beautiful creatures offers the opportunity to observe live beauty but to see it weakened through the action, there is pleasure and pain involved in the process.

We began our project by asking how stories and illustrations encountered in childhood might enrich or intersect with narrative and reflective processes of ageing for older adults living with early-stage dementia. Our findings suggest that there are many possibilities for memories of early encounters with story to prompt meaningful engagement with ideas of selfhood, both in relation to memories of childhood and in terms of a continuing and playful sense of identity over time. The interplay of narrative form that is central to *New Stories* – where books and storytelling from childhood shape accounts of events that took place in reality, and where remembered autobiographical episodes become part of a storytelling practice – offered a flexible way for participants and the creative research team to explore personal memories together, and meant that the rich detail of lived experience could be examined without encountering the problems inherent in formulating a coherent or chronological life story. Using childhood texts and images prompted a particular set of themes circulating around friendship and play, family, home and poverty; and these in turn allowed participants to reconnect with some of the emotional threads, both joyful and sad, that make up their ageing selves. While other iterations of this project might generate different literary stimuli and different memories, it seems likely that the feelings of familiarity and security engendered by childhood books helps to provide a safe environment for discussing all manner of moments from the past. Our bricolage approach turned to the materials to-hand, or 'oddmens' of memory, story, words, image and play, to both generate shared discussion and shape our co-creative activities. Finally, the *New Stories* book boxes have functioned differently to conventional 'memory boxes' in representing the self in a fragmentary narrative form that is meaningful for those living with dementia and the people who care for them. Somewhat to our surprise, these artefacts have stimulated an element of self-reflection or meta-narrative understanding for participants: by being able to 'read' themselves back in the objects they have helped to create, they appear to gain an element of control over the stories that used to be 'up there' and out of reach.

It would be exciting to extend the New Stories project into other centres and involve a greater number of participants and creative practitioners. Since it is a relatively expensive form of arts participation, development would be best directed at individuals most likely to be able to engage and benefit. Further developments might include research into the psychosocial gains of the intervention and a larger-scale investigation into memories of reading amongst older individuals living with early-stage dementia.

New Stories represents a starting point for exploring the potential of narrative enquiry as a co-creative form of life review. Using childhood books as a stimulus, and working with a three-to-two model that incorporates verbal and visual storytelling, the project has demonstrated the value of working from a theoretical position that decouples narrative from linear chronology or factual truths about the past. The final fictional life-story books, or book boxes, are not simple repositories of past experience, but innovative artistic creations that provoked satisfaction for all of the co-creators, whether they were professional practitioners or day centre attendees. Our findings contribute to a wider understanding of co-creative practice. We have shown that there are benefits in running intimate, small-scale projects that focus on the interior life that is produced through story from childhood onwards, and that these gains are available to those living with early-stage dementia and the practitioners who co-create with them.

Biographical Notes:

Alison Waller is Reader in Children's Literature at the National Centre of Research in Children's Literature, based at the University of Roehampton. She is an expert in the practice of remembering and rereading childhood fiction and also specialises in young adult fiction. Her current research focuses on ordinariness in British YA, and includes a project on young people reading in the time of Covid. She is author of *Constructing Adolescence in Fantastic Realism* (Routledge 2009) and *Rereading Childhood Books: a Poetics* (Bloomsbury 2019), and is General Editor of *The International Journal of Young Adult Literature*. Contact: a.waller@roehampton.ac.uk.

Gemma Seltzer is an independent writer and creative facilitator. She is author of *Speak to Strangers* (Pinned in the Margins 2011), a flash fiction book based on conversations with Londoners, and produces work for a range of media, including blogs, radio (BBC Radio 3), and virtual reality (*The Guardian*). She is an accredited coach and facilitator, supporting individuals to develop and share their creative ideas, and runs Write and Shine, a programme of morning writing workshops, events and online courses. Her short story collection, *Ways of Living*, is published by Influx Press in 2021. Contact: <http://Gemmaseltzer.com>.

Wallis Eates is a graphic narrative artist and facilitator. She is currently working on *Like an Orange* (funded by Arts Council England) about the brain injury survivors she met during a residency at Headway and her latest complete project [Wings](#) that she created with Dr.

Victoria Anderson and prisoners at HMP Wandsworth launched in Jan 2021. Wallis also co-leads the London branch of the international graphic novel forum, [Laydeez do Comics](#).

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Acknowledgements:

Ethical approval for New Stories was granted by the University of Roehampton's Ethics Committee (ECW 19/023).

The 'New Stories' project was funded by the Southlands Methodist Trust. Paperchase also kindly donated materials for the project.

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Notes:

¹ For reasons of privacy and confidentiality, these are not their real names.

² Gemma has a professional background in writing support and facilitation, along with an interest in working with older adults. This meant that her particular entry point into the project came from an urge to explore and promote co-creativity from a range of perspectives (Seltzer, 2016). Wallis describes herself as an autobiographical comics artist, and brought her memories of childhood comics reading and fascination with the relationship between memory, identity and narrative to *New Stories*. Like Gemma, she has experience of participatory and community arts projects, and was particularly keen to encourage participant-directed outcomes.

³ In correspondence and discussion with managers, we were advised to use the term 'clients' to describe individuals attending the day centre, and so use it at times in this article when not referring to specific individuals.

⁴ Some personal information about participants was self-evident or emerged during the course of the project: both participants were women over the age of 60; both were white; both came from working-class families and had lived most of their lives in south-west London; both had worked for some period of time as adults; Fay had had children and grandchildren.

⁵ This game involves a facilitator opening play by asking for an idea for a location and then making a statement about it: for example, 'Today we went to the park.' The next player is invited to respond to the statement with the words 'Yes, and...', and then add a sentence to the ongoing narrative: for example, 'Yes, and we took sandwiches'.