‘As I cannot write’: Transforming perceived barriers to autobiographical writing through the use of experimental writing practices.

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Abstract

Conventional approaches to autobiography assume access to memory, personal history and a coherent sense of self which is stable through time. These assumptions disadvantage those who have difficulties with writing for reasons such as cognitive impairment, mental health problems, physical disabilities, or literacy issues. Such disadvantages can be a barrier to their ability to engage with writing activities which promote wellbeing, as current approaches rely heavily on the ability to write about difficult memories.

The research comprises two interrelated elements: a critical thesis considering the barriers to writing autobiography and how the perception of these barriers might be transformed through the use of experimental writing techniques, and an innovative autobiography.

The creative project consists of an innovative autobiography, formed from linked sequences of quilts, which are embellished and embroidered with experimental and conceptual writing. The basis of the pieces will be found texts, rather than memoir, in order to investigate the potential of experimental writing techniques to construct and transform notions of identity for people who have issues with access to memory, or personal history, or with their sense of self.

Bridging the two aspects of the research will be autobiographical passages exploring the conventional approach to writing autobiography, through the practice of writing in this style.

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Acknowledgements

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To Lorina and Elizabeth, for the inspiration.

This is for nana, who couldn’t write. Inþobbok.

Introduction

At some point during my MA in Creative Writing: Innovation and Experiment, I began to write with thread.

I had discovered the work of Lorina Bulwer (Fleming, 2014) and Elizabeth Parker (1830) who had both created vast sewn pieces of writing which reminded me of my own experiments.

I made a small story quilt and took it to a symposium about using the arts in health, held at the University of Salford. I named it *Healing Stitches* and watched in dismay as a group of student midwives gathered around it and mocked it.

During the symposium the germ of this project was planted. In one workshop, we were invited by a storyteller with a singing bowl to revisit our childhoods, with the assumption that this would be a pleasant experience for all participants in a big room full of strangers.

In a later workshop, about writing for wellbeing, we wrote letters to ourselves. The act of writing out our thoughts seemed to offer no special benefit, it was a kind of counselling, redirected onto paper. As a budding experimental writer I wondered how the creative act of writing might be used, for good.

Although the focus of the thesis is dementia, its ideas are not limited to use with any one condition. At present I am working in a school for children with Special Educational Needs. Many of them struggle with writing, due to dyslexia, or problems with their fine motor skills. They write by typing, or getting me to transcribe, use fridge magnet letters to build words, or make their initials from play dough.

Atkinson and Hunt (2020, p.3) identify a 'growing enthusiasm for exploration and experimentation in how and what we produce as research outputs, including in and beyond the conventions of our written outputs'. The writing in this thesis is as much of an experiment as the creative pieces I have made. I offer it not in chapters, but in colour coded threads. Extracts from other writers are offered in

conversation with my own, connecting and contrasting with each other like the fabrics in a patchwork quilt.

In order to take this approach, I have had to embrace a paradoxical state of 'not-knowing' (Flint, 2004, p.152) at odds with the process of writing a doctoral thesis which needs to demonstrate 'the creation and interpretation of new knowledge' (University of Salford, 2021, p.30).

Flint identifies that allowing the 'not-knowing' and 'trusting the process' are the two precepts which form the basis of therapy; 'there is the possibility of healing […] in the process of going to the inner world to creatively make something that had no previous existence and bring it back to the here and now, changing the world' (2004, p.152). My textile pieces, written with thread, clearly resonate with the concept of creatively bringing something into existence. However, the words they feature are drawn not from my inner world, but from found texts or scavenged words, presenting a challenge to the assumption that to write in a healing way, we must harvest our most difficult thoughts.

'Not-knowing' may also be part of the experience of living with dementia, which manifests through 'problems with memory, thinking or language, and changes in mood, emotions, perception and behaviour' (Alzheimer's Society, 2022, para.3). This kind of 'not-knowing' represents a loss of that which was previously known. Dementia is a touchstone for me. My nana, who never learned to write, had dementia for many years.

Patches with a black outline present traditional style academic prose, presented in a way which moves beyond the conventional. They draw upon a range of academic literature on autobiography, textile making as a response to trauma and creative approaches to therapy for dementia. They provide a context in which to situate my creative practice and experimental approaches. In doing so, they serve as a grounded, jumping-off point for the more experimental patches which make up the thesis.

Patches with a blue outline contain passages of autobiography. These are written in a largely conventional style but are not presented in chronological order.

Instead, they are positioned by theme within the patchwork. They are offered as another way of knowing me, in contrast to the experimental autobiography formed by the creative pieces. Many of the memories shared reflect the type of experiences which people are expected to share in therapeutic writing exercises.

Patches with a green outline contain decontextualised quotes which would usually be found in more conventional academic writing. Taken out of their usual contexts they function instead as found texts, like those used in my creative work. They allow for ‘not-knowing’, providing a space for readers to form connections between the quotes and the surrounding patches. They reflect a popular way of writing poems with people who are living with dementia, where their words are transcribed and tidied but never added to. Killick describes this as an integral element of his own work writing poems with people with dementia, stating, ‘a rule I have set myself and never broken is not to add a word to the original but only to make use of exactly what is given by the person’ (2004, p.57).

Patches with an orange outline present sewing superstitions taken from folklore. They form a playful sociocultural commentary on the ‘cult of domesticity’ and the notion of ‘true womanhood’ (Hedges, Ferrero and Silber, 1996, p.22) associated with sewing throughout history. My creative work further explores these themes, subverting ideas of what it means to be a woman, a maiden, a mother, or a crone.

Discussion

It starts with writing poems for boy who will not love me. It starts with Lorina Bulwer and Elizabeth Parker. It starts with my dad having a fight with my brother. It starts with my friend telling me I should learn to write. It starts with leaving my husband, and wanting to keep busy when the children aren't there. It starts with writing poems for my friends (most of them are rude). It starts with my dad having a fight in the dry cleaners. It starts with googling Scott Thurston and finding a poem in the shape of window panes. It starts with asking a nursing home manager about the person I've come to see, and her having to read what someone else has written. It starts with a proposal. It starts with writing a letter to myself that nobody else will see. It starts in infant school, learning stitches in the shape of turrets. It starts with Nana not knowing my name.

Start with two light and two dark squares of fabric, half the length of your finished block plus ½ inch seam allowance on each side.

It starts in more than one place. It starts in places which aren't the beginning. I can't remember where it starts.

The four patch block is one of the simplest pieced quilt blocks. It is made by sewing 4 squares the same size together to make a larger square. Four patch blocks can be made using 2, 3 or 4 different fabrics depending on the effect you are after.

Step 1: Requirements

4 squares of cotton fabric the same size
sewing machine
thread
or needle and thread if you hand piece (i.e. no sewing machine)
Iron
Ironing board
Scissors
Rotary cutter (not absolutely necessary, but makes cutting squares much faster)

(Instructables Craft, n.d., para.1)

Witty

Clever

Sympathetic

Adaptable

Knowledgeable

Caring

Quiet

Tense

Empathetic

Wise

Complex

Independent

Able

Reflective

Patient

Sensible

Searching

Ingenious

Responsive

Self-conscious

Nervous

Intelligent

Observant

Silly

Proud

Logical

Dependable

Introverted

Brave

Giving

Bold

Dignified

Shy

Spontaneous

Helpful

Self-assertive

Loving

Trustworthy

Idealistic

Mature

Accepting

Powerful

Kind

Modest

Cheerful

Calm

Energetic

Confident

Sentimental

Religious

Relaxed

Friendly

Extroverted

Warm

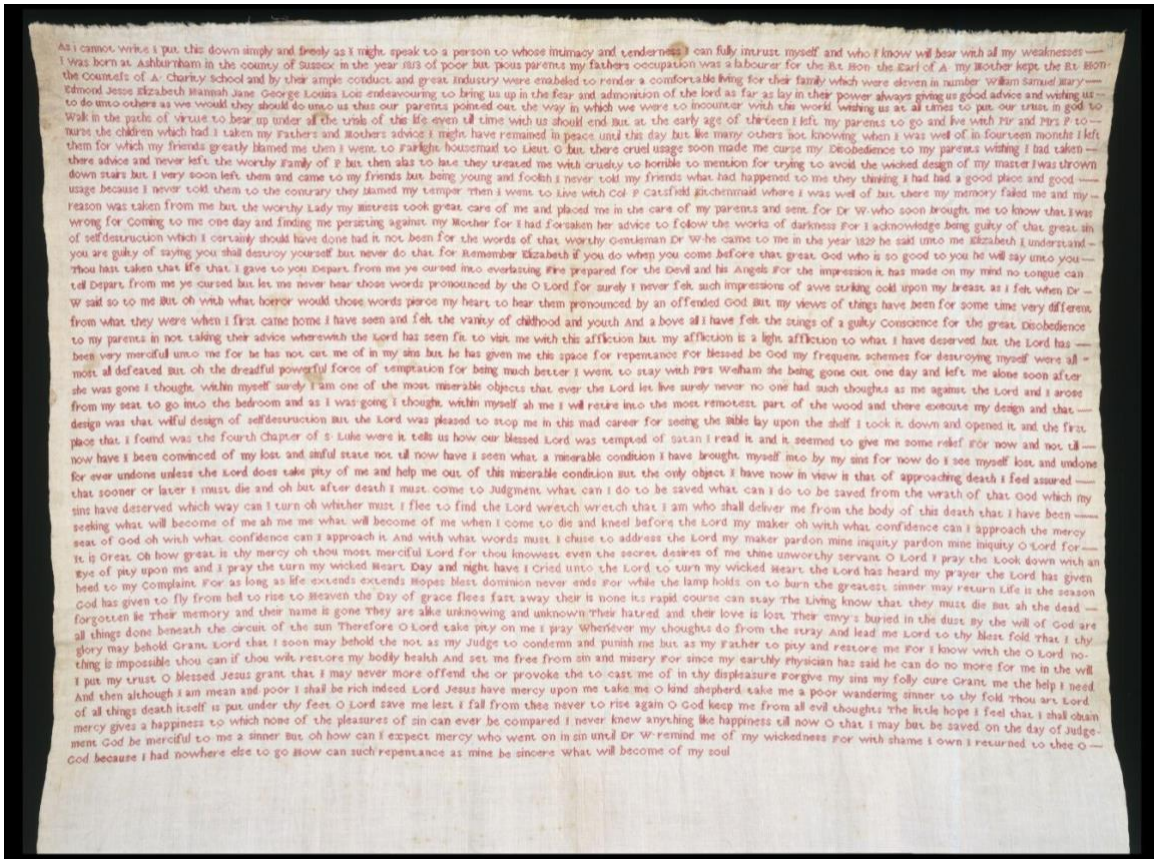
Organised

Happy

I cannot write because I don't know where to start. I cannot write because I need to put the dinner on. I cannot write because I don't have anything to say. I cannot write because I want my writing to be perfect, and it never is. I cannot write because somebody might read it. I cannot write because I never learned to write. I cannot write because I danced till dawn. Trembling of the hands disturbs her very much in writing. I cannot write because I can't find my favourite pen. I cannot write because I have a headache. I cannot write I need to walk the dog. Everything I write is a lie. I cannot write because I don't want you to know me.

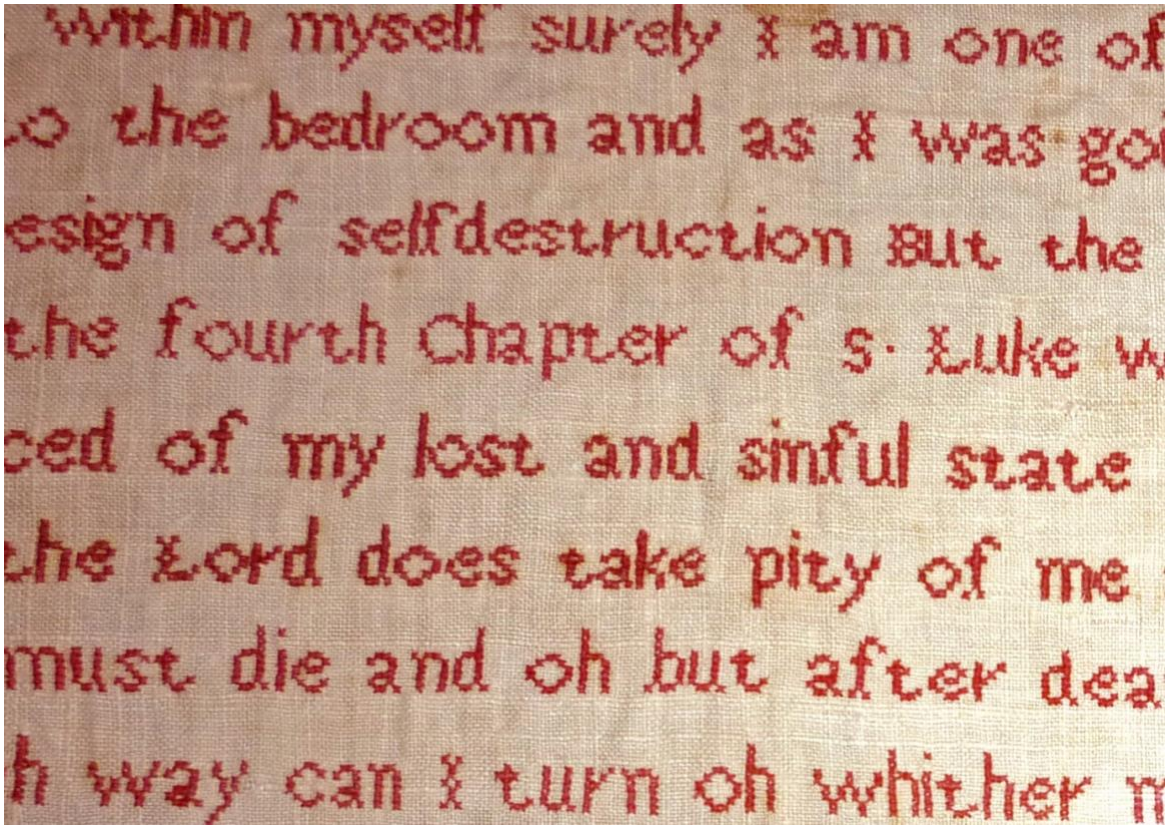
The clause 'As I cannot write' is taken from the opening of Elizabeth Parker's *Sampler* (1830) from the Victoria and Albert Museum's collection. I have chosen this sampler's phrase to encourage an inclusive way of thinking about those who have difficulties with writing, and because the sampler has had a formative influence on my own textile-based writing practice. Although Parker protests that she cannot write, this is not literally true. Her sampler attests to the fact that she was literate, and capable of fluent expression in writing, leaving her declaration, that she cannot write, open to interpretation.

'As I cannot write I put this down simply and freely as I might speak to a person to whose intimacy and tenderness I can fully intrust myself and who I know will bear all my weaknesses .... I was born at Ashburnham in the county of Sussex in the year 1813 of poor but pious parents my fathers occupation was a labourer for the Rt Hon the Earl of A my mother kept the Rt Hon the Countefs of A Charity School and by their ample conduct and great industry were enabeled to render a comfortable living for their family'.



As I cannot write I put this down simply and freely as I might speak to a person to whose intimacy and tenderness I can fully intrust myself and who I know will bear with all my weaknesses —
I was born at Ashburnham in the county of Sussex in the year 1813 of poor but pious parents my fathers occupation was a labourer for the Rt Hon the Earl of A my Mother kept the Rt Hon
the Countess of A Charity School and by their ample conduct and great industry were enabled to render a comfortable living for their family which were eleven in number William Samuel Mary —
Edmond Jesse Elizabeth Hannah Jane George Louisa Lot endeavouring to bring us up in the fear and admonition of the lord as far as lay in their power always giving us good advice and wishing us —
to do unto others as we would they should do unto us thus our parents pointed out the way in which we were to encounter with the world wishing us at all times to put our trust in god to
Walk in the paths of virtue to bear up under all the trials of this life even till time with us should end But at the early age of thirteen I left my parents to go and live with Mr and Mrs P to —
nurse the children which had I taken my Fathers and Mothers advice I might have remained in peace until this day but like many others not knowing when I was well of in fourteen months I left
them for which my friends greatly blamed me then I went to Farlight housemaid to Lieut. O but there cruel usage soon made me curse my Disobedience to my parents wishing I had taken —
there advice and never left the worthy Family of P but then alas to late they treated me with cruelty so horrible to mention for trying to avoid the wicked design of my master I was thrown
down stairs but I very soon left them and came to my friends but being young and foolish I never told my friends what had happened to me they thinking it had had a good place and good —
usage because I never told them to the contrary they blamed my temper then I went to Live with Col P Catsfield Kitchenmaid where I was well of but there my memory faled me and my —
reason was taken from me but the worthy Lady my mistress took great care of me and placed me in the care of my parents and sent for Dr W who soon brought me to know that I was
wrong for coming to me one day and finding me persisting against my Mother for I had forsaken her advice to follow the works of darkness For I acknowledge being guilty of that great sin
of self destruction which I certainly should have done had it not been for the words of that worthy Gentleman Dr W-he came to me in the year 1829 he said unto me Elizabeth I understand —
you are guilty of saying you shall destroy yourself but never do that for Remember Elizabeth if you do when you come before that great God who is so good to you he will say unto you —
Thou hast taken that life that I gave to you Depart from me ye cursed into everlasting fire prepared for the Devil and his Angels For the impression it has made on my mind no tongue can
tell Depart from me ye cursed but let me never hear those words pronounced by the O Lord for surely I never felt such impressions of awe striking cold upon my breast as I felt when Dr —
W said so to me But oh with what horror would those words pierce my heart to hear them pronounced by an offended God But my views of things have been for some time very different
from what they were when I first came home I have seen and felt the vanity of childhood and youth And above all I have felt the stings of a guilty Conscience for the great Disobedience
to my parents in not taking their advice wherewith the Lord has seen fit to visit me with this affliction but my affliction is a light affliction to what I have deserved but the Lord has —
been very merciful unto me for he has not cut me of in my sins but he has given me this space for repentance For blessed be God my frequent schemes for destroying myself were all —
most all defeated But oh the dreadful powerful force of temptation for being much better I went to stay with Mrs Welham she being gone out one day and left me alone soon after
she was gone I thought within myself surely I am one of the most miserable objects that ever the Lord let live surely never no one had such thoughts as me against the Lord and I arose
from my seat to go into the bedroom and as I was going I thought within myself ah me I will retire into the most remotest part of the wood and there execute my design and that —
design was that wilful design of self destruction but the Lord was pleased to stop me in this mad career for seeing the Bible lay upon the shelf I took it down and opened it and the first
place that I found was the fourth Chapter of S Luke were it tells us how our blessed Lord was tempted of Satan I read it and it seemed to give me some relief For now and not till —
now have I been convinced of my lost and sinful state not till now have I seen what a miserable condition I have brought myself into by my sins for now do I see myself lost and undone
for ever undone unless the Lord does take pity of me and help me out of this miserable condition but the only object I have now in view is that of approaching death I feel assured —
that sooner or later I must die and oh but after death I must come to Judgment what can I do to be saved what can I do to be saved from the wrath of that God which my
sins have deserved which way can I turn oh whither must I flee to find the Lord wretch wretch that I am who shall deliver me from the body of this death that I have been —
seeking what will become of me ah me me what will become of me when I come to die and kneel before the Lord my maker oh with what confidence can I approach the mercy
seat of God oh with what confidence can I approach it And with what words must I chuse to address the Lord my maker pardon mine iniquity pardon mine iniquity O Lord for —
it is Great Oh how great is thy mercy oh thou most merciful Lord for thou knowest even the secret desires of me thine unworthy servant O Lord I pray the look down with an
Eye of pity upon me and I pray the turn my wicked Heart Day and night have I cried unto the Lord to turn my wicked Heart the Lord has heard my prayer the Lord has given
heed to my Complaint For as long as life extends extends Hopes blest dominion never ends For while the lamp holds on to burn the greatest sinner may return Life is the season
God has given to fly from hell to rise to Heaven the Day of grace flees fast away their is none its rapid course can stay The Living know that they must die But ah the dead —
forgotten lie Their memory and their name is gone They are alike unknowing and unknown Their hatred and their love is lost Their envy's buried in the dust By the will of God are
all things done beneath the circuit of the sun Therefore O Lord take pity on me I pray Wherever my thoughts do from the stray And lead me Lord to thy blest fold That I thy
glory may behold Grant Lord that I soon may behold the not as my Judge to condemn and punish me but as my Father to pity and restore me For I know with the O Lord no-
thing is impossible thou can if thou wilt restore my bodily health And set me free from sin and misery For since my earthly physician has said he can do no more for me in the will
I put my trust O blessed Jesus grant that I may never more offend the or provoke the to cast me of in thy displeasure Forgive my sins my folly cure Grant me the help I need
And then although I am mean and poor I shall be rich indeed Lord Jesus have mercy upon me take me O kind shepherd take me a poor wandering sinner to thy fold Thou art Lord
of all things death itself is put under thy feet O Lord save me lest I fall from thee never to rise again O God keep me from all evil thoughts The little hope I feel that I shall obtain
mercy gives a happiness to which none of the pleasures of sin can ever be compared I never knew anything like happiness till now O that I may but be saved on the day of Judge-
ment God be merciful to me a sinner But oh how can I expect mercy who went on in sin until Dr W remind me of my wickedness For with shame I own I returned to thee O —
God because I had nowhere else to go How can such repentance as mine be sincere What will become of my soul

Figure 1: 'Sampler' (Parker, 1830)



within myself surely I am one of
o the bedroom and as I was go
esign of selfdestruction But the
the fourth Chapter of S. Luke w
ced of my lost and sinful state
the Lord does take pity of me
must die and oh but after dea
h way can I turn oh whither m

Figure 2: Close-up of 'Sampler' (Parker, 1830)

Despite her abilities, Elizabeth Parker perceived barriers to being able to write her own story. People can have difficulty with writing for diverse and sometimes complex reasons. Cognitive impairment, mental health problems, physical disabilities, chronic pain, poor literacy skills or lack of confidence can act as barriers to writing.

Does Parker refer to a self-perceived lack of eloquence, or an inhibiting fear of how her writing will be received? Perhaps her barriers more practical. Daly Goggin points out that Parker was employed as a nursery maid, and in this era would not be 'of a social class that would have the luxury of keeping personal papers or other artifacts' (Daly Goggin, 2017, p.42). I wonder how it is possible for the creation of textile artefact, embroidered with over 1600 words, to not feel like an act of writing.

My nana never learned to read or write. I remember wanting to teach her, when I was little, but she would always distract me by trying to teach me to count to ten, in Maltese, on my fingers. I realise now that I wasn't the first to try. My uncle had tried when he was still a boy. By the time that I had learned to read, Nana had been diagnosed with dementia. She never remembered my name and always called me Angela, after my cousin.

I have worked with people who are living with dementia, as a nurse, an advocate, and a carer. The cognitive decline associated with dementia can make writing a lost skill. Often there are compounding factors associated with old age, for example, poor eyesight, or inability to control a pen due to arthritis or essential tremor. These difficulties can prevent people from being able to participate in writing activities which aim to promote wellbeing, as these are often based on writing about difficult memories, with the idea that putting them into writing is a transformative experience.

Imagine a talking therapy in which you are expected, without any support or building of trust, to immediately divulge your worse experiences, and describe your deepest feelings. Then these are not discussed, explored, or even remarked upon, and then the therapy is ended.

The National Institute of Health Research's *Health Technology Assessment (HTA) Programme* provides funding for independent research about the effectiveness, costs and broader impact of healthcare treatments and tests for those who plan, provide or receive care in the NHS. The programme published a systematic review and realist synthesis of the effectiveness, and clinical cost of, therapeutic writing for people with long-term mental and physical health conditions (Nyssen et al., 2016).

The review considered 64 studies, 59 of which examined unfacilitated therapeutic writing, defined as being 'completed without any assistance, feedback, comment, or any other form of support' (ibid, p.2). The remaining five studies examined facilitated therapeutic writing, which took place with the support of a facilitator.

The most frequent approach to evaluation was to compare results from a treatment group, engaged with writing in a way which expressed emotion or explored difficult thoughts, with a control group asked to write about non-emotional topics.

The review recognised that the techniques examined within the studies did not reflect contemporary writing therapy practice. As a result, it is suggested that further research needs to take place and concluded that ‘an audit of the types of TW currently being used in the NHS in both primary and secondary care would be very useful’ and recommends ‘further, robust research into the facilitated TW interventions that are used in clinical practice and the voluntary sector’ (ibid, p.192).

The review also identified a lack of theory underpinning the therapeutic writing techniques used in the studies, calling for further research ‘theorising why it might be that such an intervention type would even work in the first place’ (ibid, p.191).

'It is important to note that while current research demonstrates the effectiveness of expressive writing as a complementary form of treatment for those who have suffered trauma, it is unable, within the limits of quantitative method, to show how the practice of expressive writing works, in particular cases, to help people to confront trauma.' (Hagi-Mohamed, 2022, p.40).

‘During each of the 3 writing days, I want you to write about the most traumatic and upsetting experiences of your entire life. You may write on different topics each day or about the same topic for all 3 days. The important thing is that you write about your deepest thoughts and feelings. Ideally, whatever you write about should deal with an event or experience that you have not talked with others about at all or in very little detail.’ (Richards et al., 2000, p.157).

‘Through the act of arranging words on paper, we forge new meaning out of the feelings, images and memories that shape us’ (Chavis, 2011, p.12).

‘Give sorrow words; the grief that does not speak knits up the o-er wrought heart and bids it break’ (Shakespeare, 1606/1997, 4.3.211).

'It is important to note that while current research demonstrates the effectiveness of expressive writing as a complementary form of treatment for those who have suffered trauma, it is unable, within the limits of quantitative method, to show how the practice of expressive writing works, in particular cases, to help people to confront trauma' (Hagi-Mohamed, 2022, p.40).

‘If the thread breaks, it will bring bad fortune’ (Harding, 1987, p.62)

‘Those in the trivial writing control group were asked to write about an assigned topic during each of the 3 writing days, such as how they manage their time. The experimenter emphasized that they were to describe specific objects or events of their day without discussing their feelings or thoughts on the subject.’ (Richards et al., 2000, p.157)

As an experimental creative writer I question the characterisation of the kind of non-emotional writing undertaken by control group subjects as a neutral, or trivial act. Kenneth Goldsmith’s book length work, *Fidget* (1994) is a real-time documentation of all his movements over a thirteen hour period, which contains no emotional content or material drawn from memory. It is, nonetheless, a text which is inextricably linked with the selfhood of its author. In *Being Boring*, Goldsmith describes the reactions of students asked to carry out the uncreative task of retyping five pages of text as being ‘varied and full of revelations’, including finding it ‘an act of performance’, ‘zen-like’ or ‘amnesia inducing’ (2004, para.18). Michael Jauchen (2013) observes that for his students, uncreative writing exercises offer up more moments of renewal and surprise than traditional writing exercises. The assumption that it is necessary to access difficult thoughts and feelings in order for the writing process to be beneficial to the writer needs to be challenged. Experimental approaches can facilitate this by placing emphasis on other aspects of the writing process such as creativity and connection.

‘When we are working towards making a story of someone’s life, the process of making is important. It does not matter how adept we are, what matters is the connection between us. Sitting with someone, quietly making is a healing experience. Sometimes we talk and sometimes not. Sometimes the person with dementia joins in and sometimes not. When we are being creative time slows down, we feel peaceful and we make time for the other to be. We exchange presence. We are contentedly immersed in our activity in the present moment. We can use whatever craft skills we have: it may be knitting, crocheting, quilting, to make something which represents the person’s life’ (Hayes and Povey, 2011, p.97).

Dementia stories can be created using prose, poetry or comics, or beyond the page in song, dance, art, performance and textile making. The stories can focus on one individual, or a group, and may include the voices of people who living with dementia or their families, friends and carers.

Hayes and Povey describe the importance of working in a wide variety of creative ways, including 'dance, singing, image and story' as methods of creative expression which appeal to the people living with dementia (2011, p.16). In these approaches, the process is as important as the outcome, and offers an opportunity for healing, since creativity is a 'multi-layered process in which feelings surface, evolve and come to rest in a more peaceful place' (ibid, p.45). The positive effects of creative approaches also extend to improving the 'relationship[s] between people with dementia and their families and their staff' (ibid, p.63) who may get involved in this process and find new ways to communicate.

'How does creativity relate to dementia? I am suggesting that the creative arts make three distinct contributions to the wellbeing of people with dementia and those around them. First, the creative arts provide a most necessary vehicle for the self, isolated by forgotten language, to step back in contact with life. Second, the creative arts form a relational bridge between people with dementia and those who care for them; that they aid communication and understanding. Finally, that the creative arts contribute to healing, to making whole through both of the above and through profound reunion with spirit' (Hayes and Povey, 2011, p.16).

In this thread I will reflect on several approaches to telling dementia stories, to provide a contextual basis for my own creative practice. I have selected examples which utilise a range of media to develop innovative visual, embodied and textual approaches to storytelling.

Wendy Mitchell's *Somebody I Used To Know* (2018) is a rare example of a book length memoir written by somebody living with dementia. Gerrard (2018a, para.4) describes the book as a 'narrative about the loss of narrative', formed of an account of Mitchell's life after diagnosis, intercut with 'what read like wistful love-letters to her previous self' (ibid, para.13). The level of Mitchell's cognitive difficulties meant that she was unable to write her memoir independently, therefore it was co-written with journalist Anna Wharton. This, according to Gerrard, creates a 'ventriloquised, ghostwritten "I"' (2018b, para.13) within a text in which identity is already muddled. 'And who is "I", anyway? Pre-dementia Wendy? Today Wendy, who is different from tomorrow Wendy?' (ibid, para.13).

In an interview in Granta, Wharton and Mitchell discuss the challenges of the writing process; 'usually when I work as a ghostwriter, I rely heavily on my subject's memory, so this posed a huge challenge, as you "had no memory"' (2019, para.1). The writing took place using WhatsApp messages, with the blog Mitchell began after her diagnosis providing a foundation. Missing details from before Mitchell's diagnosis were pieced together from hospital notes and her daughter's diary.

Wharton and Mitchell describe the challenges of 'foggy days' (ibid, para.15) and the telling of different versions of the same event. Interestingly, Mitchell is unable to remember the contents of the memoir but still feels connected to the writing. 'I still couldn't tell you what's in my book. But if you read me a piece I would instantly know that it was me' (ibid, para.17).

‘The memoir is, at its core, an act of resurrection. Memoirists recreate the past, reconstruct dialogue. They summon meaning from events that have long been dormant. They braid the clays of memory and essay and fact and perception together, smash them into a ball, roll them flat. They manipulate time; resuscitate the dead. They put themselves, and others, into necessary context’ (Machado, 2019, p.5).

The experiences of Wharton and Mitchell illustrate the difficulties of writing memoir, for people with memories that are unreliable or missing altogether. This method of writing is a kind of reconstruction, relying on a person having kept a record of events during their lives and the support of another writer.

Comic books offer a different way of storytelling. Dr Ian Williams coined the term graphic medicine to describe the role that comics can play in healthcare including 'graphic memoirs of illness, educational comics for both students and patients, academic papers and books, gag strips about healthcare, graphic reportage and therapeutic workshops involving comic making, as well as many other practices and source material, both fictional and non-fictional' (n.d., para.1)

Dana Walrath argues that graphic storytelling 'captures the complexity of life and death, of sickness and health. Going back and forth between the subconscious and conscious, between the visual and the verbal, lets us tap into our collective memory, an essential element of storytelling' (2016, p.3). Her book, *Aliceheimer's: Alzheimer's through the looking glass* (ibid), has elements of graphic novel, essay, drawing, collage and embroidery, and tells the story of her mother Alice's experiences with dementia.

Graphic novels about dementia are often written by authors reflecting on their experiences of having a parent who is living with dementia, rather than by someone with dementia themselves. Further examples include *Tangles: A story about Alzheimer's, my mother and me* (Leavitt, 2010), *Dad's not all there any more: A comic about dementia* (Demetris, 2015) and *Wrinkles* (Roca, 2016).

The most traumatic and upsetting experience of my life was when my dad attacked my brother and threatened to kill him. My dad, a police sergeant, was recovering from an assault at work in which he'd been left for dead after being kicked repeatedly in his head. He is not a calm or patient man, and things at home were more difficult than usual. My younger brother was full of teenage mischief and had managed to get into minor trouble with the police, embarrassing Dad in front of his colleagues and triggering a row, which turned into a physical fight. Mum and I both intervened. My mum got hurt, and I got hurt, but it bought my brother enough time to jump out of the window and run away.

We didn't talk about it after, or since. It had such an impact on me that I left school, abandoning my A levels and my chance to escape to university. I sometimes feel like I'm always trying to get back to that point, to have my chance to go to university and start my life.

A cartoon in Jacky Fleming's recent book, *The Trouble with Women* (2016, p.39), which takes a playful look at women's role in history, jokes that 'Once girls had learned sixty different embroidery stitches there was no more room to learn anything else'.

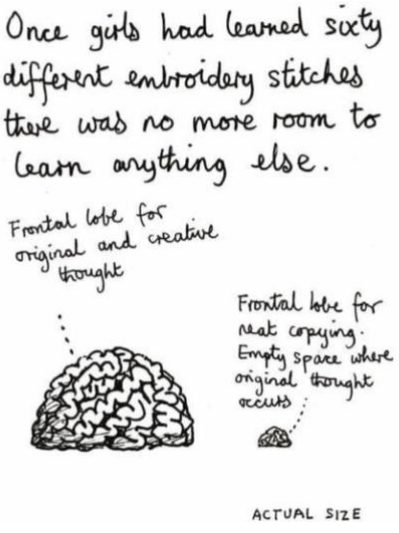


Figure 3: Cartoon (Fleming, 2016)

Figure 2: Fragment from Tangles *(Leavitt, 2010, p.89)*

Tangles (Leavitt, 2010) features experimental elements, although the story is largely told as a cohesive narrative, it features fragmented asides containing transcribed conversations or phrases, or lists. Reading it I often felt that these fragments were more revealing than the neatly ordered story they interrupt.

Aliceheimer's (Walrath, 2016) is fragmented into short passages and designed to be read either as a complete narrative or as individual vignettes suitable for a reader with dementia.

There's No Map For Dementia (McNicol and Leamy, 2020a) is a graphic illness narrative, created during a project which aimed to 'pilot a collaborative, patient-led approach to comics creation by developing an artistic process that allows people living with dementia to communicate their experiences and express their opinions' (McNicol and Leamy, 2020b, p.267).

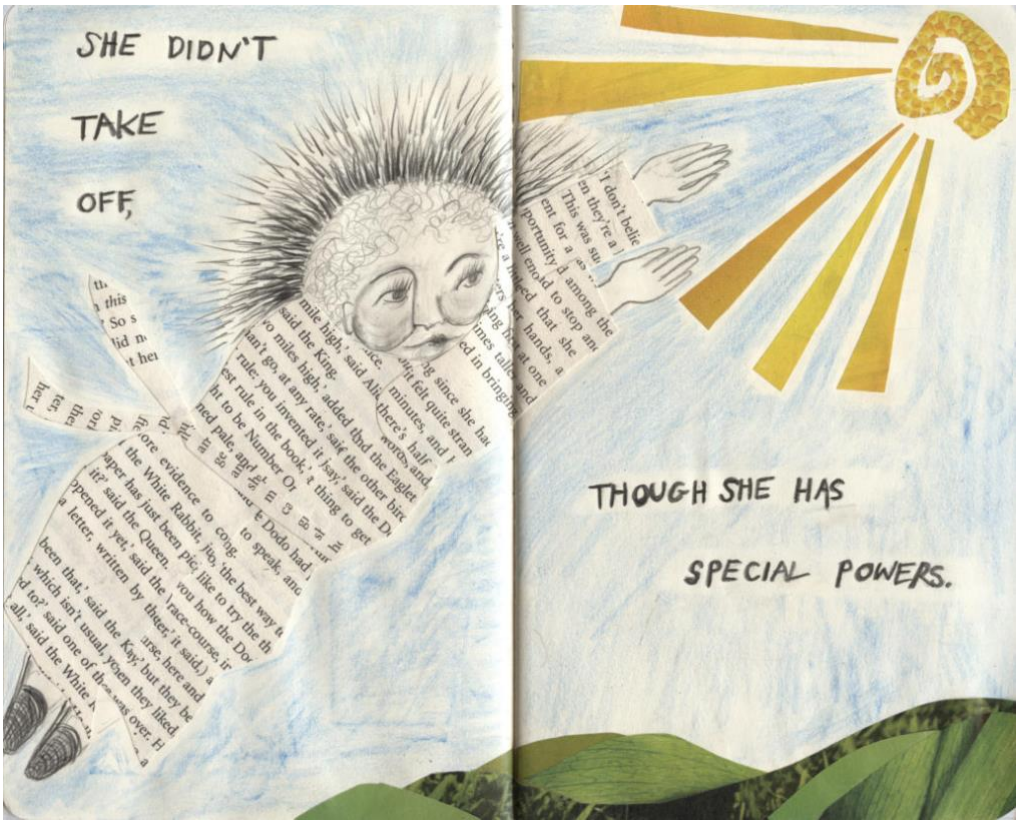


Figure 3: Vignette from Aliceheimer's *(Walrath, 2016, p.18)*

Participants considered existing graphic novels to be 'quite negative' (McNicol and Leamy, 2020b, p.271) and not reflective of their own experiences of living with dementia. They identified several tropes within existing graphic novels that they wished to challenge; the stories were usually written from the perspective of a carer or family member, were often focused on someone in the advanced stages of dementia and were not presented in a format that felt accessible for people with dementia to engage with. For these reasons, participants wanted their own comic to be accessible, with short narratives, limited text on each page and an easy-to-follow layout, with a hopeful message for people who had been recently diagnosed. The process of co-creating the comic took place with the assistance of a supporting artist and two dementia advocates who were available to offer emotional support for any issues arising during the sessions.

The finished comic has been widely distributed, free of charge, to organisations including those which support people living with dementia, libraries, health and social care workers and people living with dementia and their carers (McNicol and Leamy, 2020b). This demonstrates the possibilities for collaborative projects to benefit not only the participants, but also the wider community who may engage with the project's outcome. The project also highlights that people who are living with dementia are sensitive to their depiction in media and are able to advocate for alternative forms of self-representation that challenge dominant narratives.

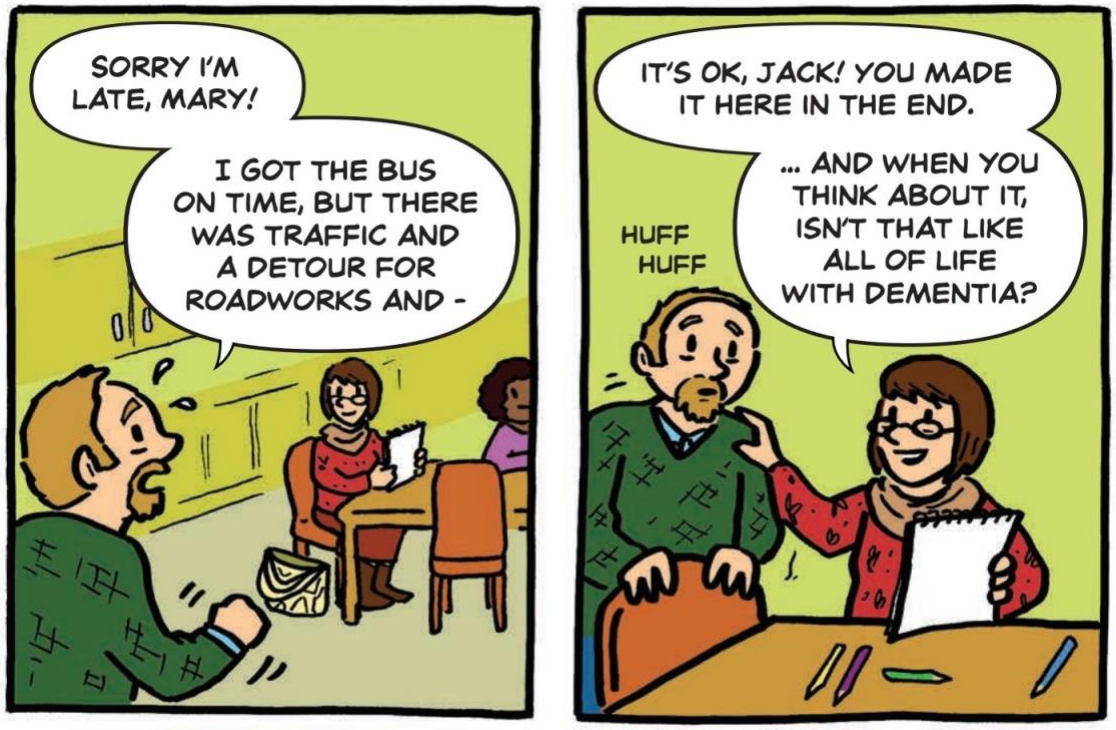


Figure 4: (McNicol and Leamy, 2020a, p.14)

Another accessible form of writing for people who are living with dementia is song writing, facilitated by music therapists, musicians or composers. In their study of Therapeutic Song Writing (TSW), Clark et al. (2021) used song parody and song collage to create original lyrics in workshops attended by people with dementia and their carers. Participants worked in pairs, referred to in the study as dyads, consisting of husband and wives, parents and children, or other family relationships.

The researchers identified a number of positive outcomes, for both members of the dyad.

‘Recurrent Theme 1. Group TSW was an overwhelmingly positive shared experience, benefiting both members of the dyad and motivating further engagement with music’ (Clark et al., 2021, p.7).

‘Recurrent Theme 2. TSW was engaging and valuable as it stimulated mental processes and reignited participants’ interests, skills and memories’ (ibid, p.8).

‘Recurrent Theme 3. TSW provided meaningful opportunities for reflection and connection with memories and life experiences’ (ibid, p.9).

‘Recurrent Theme 4. TSW prompted interaction and collaboration, leading to social connections, empathic relationships and experiences of inclusion’ (ibid, p.10).

‘Recurrent Theme 5. Group TSW included diverse challenges, however, the facilitated process supported participants to engage, highlighting abilities and challenging doubts’ (ibid, p.10).

Song writing projects are an ideal medium for telling dementia stories containing many voices. In 2017, *So Many Beauties*, a new oratorio by Holly Marland and people with dementia, had its world premiere in Manchester Cathedral. Working with over 100 participants, Marland 'recorded over 80 hours of creative material from people living with dementia and all their remarks and tunefulness weaved into this mesmerizing musical tapestry' (Keaney, 2017, para.5).

Feedback from audience members praised the arrangement of the oratorio, feeling its pieced together structure of original passages and familiar songs, was truly reflective of their experiences of supporting people living with dementia.

'The pieces were far more emotive than I had expected (sad/happy/haunting/beautiful). I had expected a 'whole' piece. The separate shorter pieces woven into the whole evening reminded me of time with my relative (sister in law with dementia) moving from happy/sad/anxious/beautiful all in the same moment.' (Musicforhealth, 2017, para.6)

People with advanced dementia, who might be unable to be involved in writing their own songs, can still benefit from engagement with music, including lyrics written by others. Marchant (2011, as cited in Hayes and Povey, 2011), a registered dance movement psychotherapist, describes using music and movement to facilitate connection between people living with dementia and their families and friends.

Marchant's case study describes a group intervention on a 30 bedded ward for people living with dementia, within a secure mental health hospital. In preparation for running the group she visited the ward for two weeks, making the following observations about the patient's bodies, the setting and the visiting hour.

‘• The patients’ bodies • absence of thought and expression • haunted expressions • lifelessness suggested by long periods of empty stillness • thin, fragile bodies, decaying teeth • gargling vocal sounds, shouting, verbal abuse directed towards other patients or staff • Slack jaw, loose open mouth • tired or sleeping bodies slumped on chairs lined up in a row. In one instance an individual slumped on the floor • sudden, repetitive, fidgety movements (particularly with hands) • shuffling through the space with hunched postures’ (Marchant, 2011, as cited in Hayes and Povey, 2011, p.48)

‘• The setting • institutionalized decoration, pastel and flowery patterns throughout • pungent smell of urine • chairs lined up in a row on both sides of the room • an empty dining table • wheelchairs and frames scattered around the room • doors securely locked and a doorbell occasionally ringing to indicate family, friends or staff arriving • staff members hurrying round the space • an observatory staff room overlooking the lounge area • some individuals confined to their beds in small rooms containing single beds, a wardrobe and a bedside unit’ (Marchant, 2011, as cited in Hayes and Povey, 2011, p.48-49).

‘• Family and friends visiting hour • sadness • grief-stricken individuals trying to communicate with their loved one • holding and stroking their loved one’s hand • witnessing verbal or physical abuse towards themselves or others • hearing a range of different emotions • witnessing the isolation of the loved one • witnessing the loved one asleep • terrified expressions • minimal verbal communication • sitting on a chair next to their loved one, gazing at their absent face’ (Marchant, 2011, as cited in Hayes and Povey, 2011, p.49).

Later in the session Marchant played music with poignant lyrics about loss, which the participants listened to, sang or hummed along to. ‘The lyrics of the song helped the participants to tune into their own feelings of loss and sadness, of desire to reconnect. As I witnessed the pairs coming together in movement I felt happy. The participants had been able to see themselves again, to love again, laugh again, join again in the present.’ (Marchant, 2011, as cited in Hayes and Povey, 2011, p.49)

Marchant’s observations before the session, of isolation, grief and absence, are in stark contrast to her positive observations during the sessions, in which she notes signs of laughter, joy and togetherness.

The study demonstrates that it is possible to tailor creative therapeutic activities to the needs of those with advanced dementia, who can benefit from the power of a shared experience, even if they are no longer able to co-create.

Poet John Killick also works with people in the advanced stages of dementia, who are unable to write for themselves. However, he feels it is essential to work with them on an individual basis, rather than in a group setting.

‘Not only is every person different in terms of personal characteristics and life history; but the illnesses which make up the dementia family affect each one uniquely and they display individual language features which must be respected and embodied in the resulting writing’ (Killick, 2004, p.58).

Killick’s approach is a sensitive one, which honours individuality and recognises people living with dementia as a diverse group with a variety of lived experiences. This marks a significant departure from other approaches which utilise a group workshop setting, and often involve family members and carers in the creative process. While it is important to acknowledge individual experiences, Barrett is critical of individualism in disability writing, arguing that it reinforces ‘associations between disability and isolation’ (2014, p.1569). Similarly, Walrath observes that some cultures ‘locate sickness not in individuals but instead in families or communities. As any caregiver knows, we live the sickness too’ (2016, p.4). These perspectives contrast with Killick’s approach and point towards the need to consider writing in ways which reflect not only the participant’s personhood, but their relationships and networks. The most inclusive creative approaches, Hurley argues, are ones which ‘accommodate individual expression but also highlight the disabling factors of the social context in which the cowriters are located’ (Hurley, 2018, p.293).

From 2007 to 2021, arthur+martha, co-directed by artist Lois Blackburn and poet Philip Davenport, pioneered ‘ways of working in arts and health, entwining poetry and art, to allow greater inclusion as well as deeper, richer means of self-expression for the makers — whether stitched, written, spoken or sung’ (arthur+martha, 2022a, para.2). Working with marginalised and vulnerable communities, including people living with dementia and those affected by homelessness, arthur+martha worked to document their stories and share what they describe as the ‘invisible heritage of excluded people’ (ibid, para.3).

‘We aren't running reminiscence projects, because often we confront the present as well as the past. We aren't therapists because we investigate material with an eye on the art itself, rather than trying to make the art do something that isn't artistic. And yet as artist/writer we are collaborators, not originators - and some people would dispute that we are artists at all. We aren't oral historians because our attempt is not to construct any consensus on events, only to honour personal histories however eccentric or 'wrong' they might seem. We aren't journalists because we aren't wedded to the big matters of the moment’ (arthur+martha, 2014a, para.3).

One of arthur+martha's notable projects was Stitching the Wars, a two-year long collaboration with over 700 people. Participants came together to produce two companion quilts, *A Bomber's Moon* (arthur+martha, 2017a) and *Fresh Air and Poverty* (arthur+martha, 2017b), which have since been displayed in exhibitions across the UK. The contents of the quilts include embroidered fragments of poetry, assembled from the memories collected during workshops with people living with dementia. These were later constructed into the quilts with the assistance of volunteers.

Davenport embraces an experimental approach to co-creating poems, noting 'a huge tradition of experimental writing that's often ignored as a resource for workshops, especially workshops for people who have dementia' (arthur+martha, 2014b, para.1). In his experience, 'bringing looseness and playful logic into such sessions can free up people to be more expressive of their lives' (ibid, para.1). When working in the context of dementia, embracing a more experimental approach can reduce the barriers for participation, since there are no particular expectations for the outcome, and no pressure to conform to a conventional format. This creative freedom has the potential to generate authentic and thoughtful responses, as seen in the Stitching the Wars quilts.

Anne Basting is a scholar and artist whose work focuses on the potential for the arts to transform the lives of people living with dementia and other cognitive disabilities and their communities. Basting is the Founder and Creative Strategist of TimeSlips Creative Storytelling, an international alliance of over 1000 artists and caregivers across 23 countries 'bringing meaning to late life through creativity' (Basting, 2022a, para.5). TimeSlips offers a way of engaging with people with dementia that moves away from memory and encourages imagination, through the use of photographic prompts and open questioning, a process Basting calls 'making it up together' (2013, p.1). Basting advocates the use of 'beautiful questions', which are open-ended, inspiring, and asked with a commitment that the answer will be listened to. (2020, pp.76-77). Examples include: 'What do you treasure in your home and why?' (ibid, p.79); 'What is your safe harbour?' (ibid, p.79); 'If your feet could talk, what would they say?' (ibid, p.82). Basting's approach to creating stories with people who are living with dementia is centred around imagination rather than reminiscence, therefore avoiding drawing attention to the person's memory problems.

TimeSlips facilitators invite imagination-based responses to a prompt and accept any answers that are given. Facilitators are taught to ask open-ended questions based on a prompt (an object, a question, a song, and most commonly, an image) that invite imagination, rather than dictate or guide it. Facilitators echo all responses to demonstrate that they are truly hearing every component of the storyteller's answer, its tone, emotion, pitch, wording, gesture, and facial expression. Facilitators write down all responses and read them back as the story builds' (Basting, 2013, p.2).

Stories created using this process have been used as a starting point for public facing projects celebrating the creativity of people living with dementia, including *TimeSlips (2000)* an art exhibition of photographs of the storytellers and pop-up books of the stories and *TimeSlips Art exhibit (2001)* featuring 12-foot figures from the TimeSlips stories, and *TimeSlips - the play* (2005), which was performed at Elsa Mott Ives Gallery, New York.

More recent projects have incorporated interactive elements. *Beyond Memory* (2017) is a performance that utilises animation and choreography devised by participants, to tell stories collected from 50 nursing homes. During the performances, the audience become active participants in the storytelling through their collective embodied movements (Basting, 2022b).

Figure 5: Performance of Beyond Memory *(Basting, 2022b)*

Research into the TimeSlips programme has identified numerous benefits including improved quality of life for people with mild to moderate dementia (Vigliotti et al., 2018), improved social connectedness and communicative interactions in mid to late-stage dementia (Bahlke et al., 2010), an increase in play behaviour and joy (Swinnen, et al., 2018) and improved attitudes towards older adults from healthcare students (George et. al., 2011; Heuer, 2020).

The TimeSlips project is a strong example of expressive writing that has proven therapeutic benefits, which does not rely on the participants accessing difficult memories. Basting argues that the asking of beautiful questions is an invitation 'both to selfhood and to community' (2020, p.77) which helps participants to articulate who they are. Her beautiful questions have applications *beyond* the story making process, with Basting encouraging their use by families, friends and carers to promote communication in everyday situations.

The creative approaches explored within this thread offer various ways of writing dementia stories. Some approaches attempt to represent experiences in an accurate way, using exact words and phrases spoken by the person with dementia (Killick, 2004), or recounting real events (Mitchell, 2018). Other approaches transform autobiographical fragments through their combination with other kinds of writing (arthur+martha, 2017a; 2017b), or through their manipulation, for example, by cutting them up and reassembling them to create poetry. We are all composed of many stories, some we've written ourselves, some that we've read and loved, some that people have told about us, some that we've forgotten or don't want to remember. In my own approach, I reconstitute myself from fragments, using found texts, scraps of paper, fabrics which are connected to my own history, or full of borrowed history. I feel this is a more accurate representation of how we experience and express our own identities. I don't present one version of myself but different facets in different pieces, which relate to each other but do not claim to represent a whole.

'Little has been said about what actually happens when the writing subject cobbles together a self from the material of language in an always-unpredictable experiment with the proverbial pen and paper or, moreover, keyboard and screen' (Takolander, 2017, p.372).

The most traumatic and upsetting experience of my life was when I fell in love.

I didn't really plan to be a nurse. I was miserable in sixth form, doing subjects I didn't like, with no particular goal in sight. My mum thought I'd do well in the army, because my grandad had liked his army life, and my dad wanted me to be an electrical engineer because that was his dream career. I had no sense that I could follow a career doing something that I might actually like.

Though the term ‘life writing’ has been broadly applied to encompass a range of autobiographical texts, such as diaries, memoirs, letters, journals (Rippl, Schweighauser, and Steffen, 2013, p.5), Kadar (1992, p.196) rightly identifies the exclusionary nature of the ‘formal conventions’ and ‘certain protocols’ associated with autobiographical writings. Indeed, in defining ‘life writing’ as work adhering to these restrictions, Kadar argues that an objective truth and narrative regularity is privileged, thus “leaving less room for non-linear narratives and fragments, and unpublished documents” (ibid, p.196). The designation of unpublished documents as non-traditional literature dismisses work by non-white, non-male subjects, who are often writing from a marginalized position within society (Behar, 1990). This speaks to Kraus’s question, ‘who gets to speak and why?’ (2006, p.146). But there is another question, who gets to speak, and why, and *how*?

‘Broken stories and little fragments are a more potent way to get a portrait of the person who is telling it. In a complete story, when it is told right, the person telling it almost disappears because the story takes centre stage. A fractured narrative is really about the individual in a more profound way’ (Greenberger, cited in Basting, 2009, p.127).

‘To patch or piece together suggests collecting information or things, an act of investigation. A patch can be a scrap or a remnant: a piece of material, a computer key, a torn item of clothing. Patching can also mean to mend, join together, or connect’ (Robertson, 2014, p.198).

What is quilting?

‘Quilting is a method of stitching layers of material together. Although there are some variations, a quilt usually means a bed cover made of two layers of fabric with a layer of padding (wadding) in between, held together by lines of stitching. The stitches are usually based on a pattern or design’ (Victoria and Albert Museum, n.d, para.3).

‘Quilting is a ‘mother tongue’, a visual language and culture indigenous to women. It is a medium that has enabled, and continues to enable, women to create works in which they speak the truth about their lives’ (Witzling, 2009, p.619).

What is patchwork?

‘Although closely linked to quilting, patchwork is a different needlework technique, with its own distinct history. Patchwork or 'pieced work' involves sewing together pieces of fabric to form a flat design. In Britain, the most enduring method is known as 'piecing over paper'. In this method, the pattern is first drawn onto paper and then accurately cut. Small pieces of fabric are folded around each of the paper shapes and tacked into place (also known as basting, this uses long, temporary stitches that will eventually be removed). The shapes are then joined together from the back using small stitches called whipstitches’ (Victoria and Albert Museum, n.d, para.12).

‘[Kenneth] Goldsmith believes that the Internet, with its cataract of words, made obsolete the figure of the writer as an isolated man or woman endeavoring [sic] to produce an original work. Instead of depending mainly on his or her capacity for invention, the new writer transports information. He or she retypes and recasts, archives, assembles, and cuts and pastes, passing along pieces of writing and blocks of text, the way people do on social media. The new writer transports information. He or she retypes and recasts, archives, assembles, and cuts and pastes, passing along pieces of writing and blocks of text, the way people do on social media’ (Wilkinson, 2015, para.21).

1968 Lawrence Weiner declaration of intent:

‘1. The artist may construct the piece.
2. The piece may be fabricated.
3. The piece need not be built.
Each being equal and consistent with the intent of the artist, the decision as to condition rests with the receiver upon the occasion of receivership’ (Weiner, 1968, n.p).

Conceptual artist Lawrence Weiner has attempted to create a series of text based artworks in the texts have no material form. His statements exist as text with the potential to be materialised, and have been brought into existence in diverse ways, for example as tattoos, song lyrics, or on art gallery walls.

‘The world is full of objects, more or less interesting, I do not wish to add any more. I prefer, simply, to state the existence of things in terms of time and/or place’ (Huebler, 1969, p.26).

‘Telling the truth – this is surely the most familiar of the rules we associate with autobiographical discourse’ (Eakin, 2001, p.115).

Embroider

‘If you accused me of **embroidering the truth**, you would mean that, though not quite perhaps lying, I was certainly adding a good deal of exaggeration and invention to what I was telling you. We embroiderers are a tricksy lot, and might look you straight in the eye and declare that our work literally does embroider the truth.

Anyway, what’s wrong with adding decoration, colour and texture to a bare narrative? It makes life much more fun. Embroiderers know that there are many different types of embroidery as well as vast numbers of stitches. Although many of these stitches have interesting and even exotic names, they are all derived from everyday life and not the other way round. In fact, I cannot think of any that have been used as figures of speech or become idioms in common use. Incidentally, embroidery patterns have a lot in common with tattooing, and Marco Polo described tattoos as ‘flesh embroidery’ (Kapp, 2007, p.32).

Towards the end of my lower sixth year my dad was seriously assaulted at work and left for dead. He eventually made a full recovery, but he'd been kicked in the head repeatedly, and for a while, he wasn't himself. Around the same time, my younger brother was full of teenage mischief and got in trouble with the police, which inflamed my dad to the point where he snapped. One afternoon he attacked my brother and threatened to kill him. There was a big fight, with me, and my mum, trying to intervene to stop my brother from being hurt. Mum got me to phone the police, who were, of course, my dad's colleagues, something I felt guilty about for months. My brother managed to escape through the bathroom window and run to safety. My mum must have been hurt because all her rings were bent and broken. I was hurt because I'd tried to shield my brother and my dad had pulled me off him using my head. Things in the bathroom were smashed up. Soon it was all tidied up and my mum got her rings fixed, and nobody ever talked about what had happened. I had a hard time coping with it all and decided not to go back to school.

'If quilting is often associated with warmth and protection, patchwork is more closely associated with domestic economy – a way of using up scraps of fabrics or of extending the working life of clothing. Unlike quilting, patchwork remained a predominantly domestic, rather than professional, undertaking. Not all patchwork was produced for reasons of economy, however. There's evidence that some of the patchwork quilts in our collection used significant amounts of specially bought fabrics and these quilts have been attributed to middle-class women making these objects for pleasure rather than necessity' (Victoria and Albert Museum, n.d, para.13).

Tracey Emin has produced a body of large scale, text based textile pieces of an autobiographical, confessional nature. These include her 1995 work *Everyone I Have Ever Slept With 1963-1995,* a shop bought tent in which Emin appliqued the names of every person she had ever been asleep with, including two aborted foetuses and her grandmother. Emin has produced several large, brightly coloured blankets adorned with patches of text, with some featuring fabrics with significant associations, which she calls 'high altar' fabric (Brown, 2006, p.37). Brown observes that 'implicit in preservation and conservation of these fragments is a correspondence with memory and remembrance, the fabric pieces having both public and private talismanic meanings for Emin, and containing or 'transmitting' presence, not just representing it' (ibid, p.37). Brown also notes that in using blankets as a medium, Emin plays with the associations of bedcovers, from childhood comfort blankets, to lovers' beds (ibid, p.38).

'The spare fabric that formed the checkerboard may have been from uniforms of the dead or wounded, thus adding a somber [sic] memorial to an otherwise vibrant wool quilt.

Although there is a vision of hope in making something beautiful out of horror, there's an eerie echo of the suturing of wounds in each stitch of the quilt' (Meier, 2017, para.7-8).

One of the attractions of samplers, for me, is the reflection of female history which is inherent in the form. For me there is also a resonance between sampler making as an act of imitation, the creation of a beautiful object through copying, and the act of writing using uncreative or conceptual techniques.

If a girl shakes a new quilt out the front door, the first man who enters will be her husband' (Harding, 1987, p.62).

‘Her art gives pleasure to the eye and to the mind and to the touch, if only one were allowed to touch. One wants to feel the braid and nub, to finger the frays and proud threads, the tightness and looseness and differences between It its part, but mostly all this is in the imagination. Sensuality – bordering on the sexual – and geometric rigour, variety and similarity (pleasures that demand being repeated) infuse the work of a lifetime in Albers’ show’ (Searle, 2018, para.1).

Stommel asserts that ‘all media have the potential to be (or necessarily are) haptic’, defining a haptic interface as ‘one that engages our skin before our intellect, our body before our brain’ (2014, para.2). The textile pieces I create are tangible stories. Some are designed to be playful, using strips of chenille to conceal text, inviting viewers to interact by parting the chenille in order to read the text. Others are less inviting to touch, as they are pierced with sewing pins, contrasting the soft fabric with sharp metal. By using a variety of textures and fabrics, I want to show that my textile pieces can create a sense of haptic unpredictability, where touch may be a pleasant or uncomfortable experience.

I got an interview for an apprenticeship in a local factory, in a science based role. My dad offered to drive me there, but on the morning of the interview he got into a fight at the drycleaners and I missed my appointment.

Consoling me that evening, my mum pointed out that I'd enjoyed my work experience at the local hospital, and suggested I should apply to be a nurse. Project 2000 training had recently started, so as well as getting my professional qualification I'd get a diploma, which I could later top up to a degree. I liked the sound of mental health nursing, which the brochure said needed good communication skills and an ability to connect with people. My parents weren't keen, especially dad, who'd had some negative encounters with people with mental health problems in his work role. By this stage their disapproval just spurred me on.

Lorina Bulwer was born in 1838 and produced three samplers, embroidered during her incarceration in Great Yarmouth Workhouse lunatic ward. It is thought that she was committed to the workhouse in which she created the samplers in 1907 (Crawshaw, 2016). Her three samplers are owned by the Norwich Castle Museum. They feature extraordinary, angry, unpunctuated, rambling texts, embroidered in capital letters and underlined for emphasis. Each sampler is approximately 30cm wide, but two are remarkably long, at around 3.65 metres and 4.2 metres (Norfolk Museum Collections, 2021). The content of the samplers reveal a disturbed mental state, which must have been sustained for a long period of time in order for her to be able to embroider such substantial pieces.

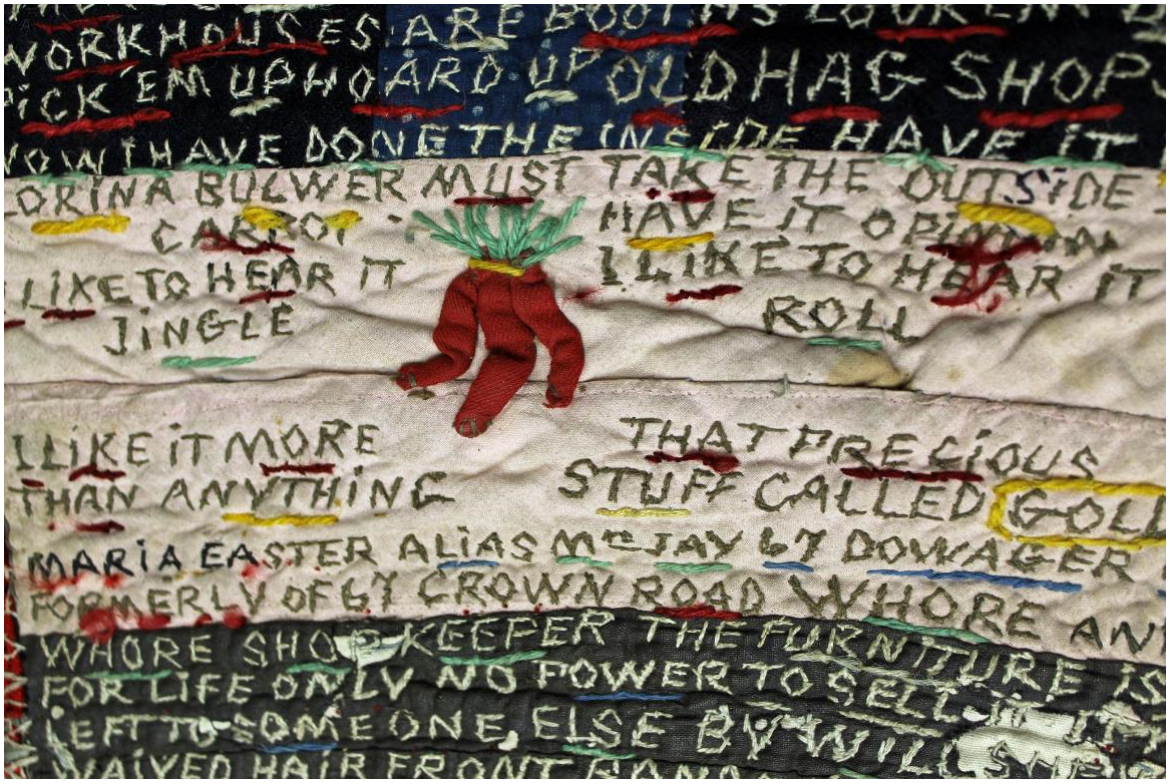


Figure 6: Close-up of Lorina Bulwer sampler (Brumby, 2014)

Figure 7: Sampler on display (Brumby, 2014)

There is a link between early samplers and memory. Clare Browne, Curator of British and European Textile at the Victoria and Albert Museum, describes samplers from the sixteenth century and earlier being stitched as ‘personal reference works for embroiderers: trials of patterns and stitches that had been copied from others; records of particular effects achieved which could then be recreated,’ creating an ‘effective memorandum’ (Browne, 2010, pp. 6-7). Browne notes that samplers derive their name from an Old French word *essamplaire,* meaning work to be copied or imitated (ibid, p.7).

‘Memory is not a camera aimed at the past’ (Basting, 2009, p. 18).

‘In some ways, technology has provided us with misleading metaphors for memory. Thanks to the computer, the camera, and the museum, we have a tendency to think of a memory as a bit of information that is stored away and can be retrieved on demand, as a photograph or video that objectively captures all details of a moment, or as an artifact that, with the right care, will remain intact for centuries’ (ibid, p.18).

I am interested in autobiography and people's memories of themselves, how this ties in with their sense of identity and how this identity is lost with the cognitive decline of dementia. In addition, for people living in a care home, there is a loss of connection with the history in the environment of their own home, their own photographs and possessions, their neighbours and community, often combined with a further loss of individuality imposed upon them by institutionalised routines.

The early 90s was a horrible time to be a student mental health nurse. The transition into higher education was still a work in progress for the nursing colleges. The ward staff were suspicious of our training, believing we were only interested in book learning, rather than getting our hands dirty. At times they were openly hostile.

The hospital I trained at was a sprawling Victorian asylum, with generous grounds. In its prime it had been totally self-sufficient, with a bakery, farm and other facilities on site. My mentors were being made redundant as the changes dictated by the *NHS and Care in the Community Act 1990* started to be implemented. One by one the wards closed down, as people were relocated from long stay wards into community placements. There would be no jobs to apply for at the end of my training, so many existing staff were being made redundant that no new posts were allowed to be advertised.

One of the high points of those years was my placement at the Day Hospital. They ran a programme of activity groups and therapies, including relaxation, pottery, creative writing and art therapy. I enjoyed it so much I wanted to retrain to be an art therapist (but by then I'd met my first husband, who was adamant that I could only ever be a nurse.)

'We tend to think of autobiography as a literature of the first person, but the subject of autobiography to which the pro- noun "I" refers is neither singular nor first, and we do well to de-mystify its claims. Why do we so easily forget that the first person of autobiography is truly plural in its origins and subsequent formation? Because autobiography promotes an illusion of self-determination: *I* write my story; *I* say who I am; *I* create my self. The myth of autonomy dies hard…' (Eakin, 2019, p.43)

Autobiographical writing tends to focus on one individual. Bruss notes that 'autobiography could simply become obsolete if its defining features, such as individual identity, cease to be important to a particular culture' (1976, p.15). Usher speaks of a 'centred self' situated in time; 'Autobiographies do very often read as if they were referential of a life, representations of a prior self where the past can and does appear fixed, discrete and entire to the mind in the life as told. In other words, an autobiography predominantly *reads* as if it is an account of a centred past by a centred self' (2005, p.23). Lejeune argues that our sense of time is being altered by internet technology, yet is essential component in the generation of a life story, 'we are losing our long-term connections, our rootedness in the past, and the ability to project ourselves into the future, all of which allowed us to construct a narrative identity' (2014, p.250). In my own creative practice, I like to use time as a framework, rooting a writing practice in the present, for example, writing a list poem using the first words I hear on the radio each morning for a week, or using a daily newspaper headline as the basis for a quilt. My own identity in the finished pieces is not connected to the past, but to the things which surround me in the present. I am constructed as an ongoing experience of the world around me.

Hulstyn (2021, p.193) argues that experimental approaches to autobiography challenge readers, requiring them to link 'disparate fragments to the story of a life of a person' in order to form a mental picture of them. Textiles formed from fragments offer a further element of challenge to the reader (or viewer). They exist as multimodal texts, which as Alison Gibbons argues 'ask readers to cognize and integrate meaning from the creative synthesis of word, image, and tactility' and as such call for 'a more performative and engaged understanding of the reader's role' (2012, p.433).

Lorek-Jezińska et al. (2021, p.1) suggest that the authorial space can be opened for ‘disruptions, dispersals, redefinitions, negotiations and reconciliations of authorial presences’ through ‘questioning and transforming the practices of authorship and the process of (re)introducing alternative or marginalised authors’. Making stories about myself using found texts, sampled materials and using sewing as writing, transforms conventional practices of authorship, creating an autobiography which can be received in different ways depending on the reader (or viewers) connections with particular elements. They might recognise a particular phrase, or scrap of junk mail or feel a resonance with certain fabrics, layouts or threads. Using this way of writing with people who are living with dementia would invite them into the authorial space and allow them to be present in fragments which readers could then link to the stories of their lives.

In *Seven American Deaths and Disasters* (Goldsmith, 2013) a collection of transcriptions of reportage of iconic tragedies in American history, including the assassination of President John F. Kennedy and the World Trade Center attacks, Kenneth Goldsmith describes his selection as having an autobiographical basis: ‘all seven events depicted here were ones that I lived through which changed me, and a nation, forever’ (ibid, p.173).

I spent several months as a student on the EMI (elderly mentally ill) Unit. Half the unit carried out inpatient assessment, admitting people needing diagnosis, and either a suitable placement, or home care package, to be funded and arranged. The other half provided day care, with patient transport collecting people from their homes, and dropping them off at the unit, to spend the day doing nothing much at all.

I was 18 when I started my course and 21 when I qualified. I didn't enjoy my time on the EMI Unit at all. I liked to look after people who had a chance of getting better, and I hated being confronted with the reality of mortality. I didn't like to think of my nana having to stay somewhere similar.

There are currently 885,000 living with dementia in the UK, which is projected to increase to over 1.6 million people by 2040 (Wittenberg, Hu, Barraza-Araiza, and Rehill, 2019, p.5-6).

The total costs of dementia in the UK in 2019, £34.7 billion at 2015 prices (ibid, p.21).

Public Health England observes that the COVID-19 pandemic has had a significant impact on diagnosis rates for dementia, with over 65 year olds experiencing a lower diagnosed prevalence compared to pre-pandemic levels (Public Health England, 2021).

Age UK describes dementia as 'a progressive disorder that affects how your brain works and in particular the ability to remember, think and reason. It is not a disease in itself – but a group of symptoms that may accompany a number of diseases that affect the brain' (2019, para.1).

‘Dementia is characterized by the presence of marked impairment in two or more cognitive domains relative to that expected given the individual’s age and general premorbid level of cognitive functioning, which represents a decline from the individual’s previous level of functioning. Memory impairment is present in most forms of dementia, but cognitive impairment is not restricted to memory (i.e., there is impairment in other areas such as executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities). Neurobehavioural changes may also be present and, in some forms of dementia, may be the presenting symptom. Cognitive impairment is not attributable to normal aging and is severe enough to significantly interfere with independence in an individual’s performance of activities of daily living. The cognitive impairment is presumed to be attributable to an underlying acquired disease of the nervous system, a trauma, an infection or other disease process affecting the brain, or to use of specific substances or medications, nutritional deficiency or exposure to toxins, or the etiology may be undetermined. The impairment is not due to current substance intoxication or withdrawal’ (WHO, 2019, para.1).

Writing can be an act of paying attention, but how much can we pay attention to? Would writing in a different way make us pay attention differently?

‘In my diary I recorded what had changed since the previous day, but sometimes I wondered: What if I recorded only what hadn’t changed? *Weather still fair. Cat still sweet. Cook oats in same pot. Continue reading same book. Make bed in same way, put on same blue jeans, water garden in same order* ... Would that be a better, truer record?’ (Manguso, 2018, p.26).

‘The essential problem of ongoingness is that one must contemplate time as that very time, that very subject of one’s contemplation, disappears’ (ibid, p.72).

‘If an unmarried girl puts in the last stitch of the quilting, she will be an old maid’ (Harding, 1987, p.62).

In a study investigating the impact of cognitive deterioration and identity loss on well- being in older adults living with dementia, Jetten et al. (2010) identified that the loss of self-identity associated with memory loss was a principle cause of a compromised sense of well-being in their subjects.

However it is not clear what sense of self may be preserved in individuals with symptoms of advanced dementia. Klein and Cosmides study (2003) describes their work with a woman with a diagnosis of Alzheimer’s disease, who despite being unable to remember personal details such as the fact that her husband had died some years previously, was able to demonstrate that she retained knowledge of her own pre-morbid character. However she did not appear to have integrated her experience of dementia into her self-image.

They observe, ‘despite a striking inability to retrieve even mundane facts about the world and her surroundings KR has an intact, retrievable knowledge of her personality traits [...] however her knowledge is of her personality before the onset of Alzheimer’s dementia’ (Klein and Cosmides, 2003, p.158).

Karl Ove Knausgård, in an interview with Tim Adams in the Guardian newspaper stated that people's tolerance for honesty in his autobiography 'My Struggle' varied with time passed from the event in question. Stories from the distant past were seen as less contentious than recent ones.

'"I sent all the manuscripts out to the people I wrote about before the books were published," he says. "My friends in childhood did not change anything. But the closer it came to the present it was always, 'No it was not like that', or 'You can't say that'' (Adams, 2018, para.11).

Our relationship to our stories changes throughout our lives. Some of the stories that I have incorporated into my textile autobiography would have been too difficult to articulate if a substantial amount of time had not passed since. Some stories which are still too difficult have not been told.

In college we learned about *Orem's Self-Care Theory* (1991), to support each person to achieve maximum independence in their activities, rather than taking over and doing things for them. But life on the ward was a series of time sensitive routines, task orientated, rather than person centred. On placement on a general medical ward, I helped a man who was recovering from a stroke to shave himself. I had to track down a mirror, first, because the ward supplies hadn't been assembled with the promotion of independence in mind. The man slowly, clumsily, shaved himself using an economy NHS razor, and I left his bedside hoping I'd restored some small sense of dignity to him. A couple of minutes later, the ward sister sent in a male nursing assistant, to 'give him a proper shave' so he'd be 'nice and tidy'.

‘The twilight condition of both the zombie and the person with AD raises the thorny question of what it means to be human. When cognition has gone, is the person gone even though the body remains animated? What indeed is the connection between the brain and the body? Even the concept of 'brain death' plays into the zombie metaphor; after all, the only way to kill a zombie permanently is with either a bullet or a blow to the head, the general wisdom being, 'kill the brain, kill the zombie'. What does this mean, then, for the person whose brain is 'invaded' by tangles and plaques?’ (Behuniak, 2011, p.80).

We have an idea that people who can’t remember properly can somehow unlock their memories – fuelled by stories such as *Before I Go To Sleep* (Watson, 2011), *The Bourne Identity* (Ludlum, 1980), *The Girl on the Train* (Hawkins, 2015) which share the trope that a sudden recovery of lost memories brings about the resolution of the story. Perhaps these stories lead to a kind of cultural distrust of people with poor memories, a feeling that rather than forgetting they are holding back, with information locked away inside them just waiting for the correct key.

On the EMI Unit there was a similar divide between theory and practice. As student nurses we were often allocated practical tasks, such as helping the patients to get washed and dressed. I noticed that the people on the unit didn't seem to have their own clothes. Every morning we were faced with a jumble of communal clothing. The men would invariably be dressed in ill fitting, oversized trousers which had to be held up with braces, which would then confuse the men when they needed the toilet, resulting in increased occurrences of incontinence. It seemed to be a way of eroding their dignity and identity. There was a joke that on hairdressing day, the ladies were all given the same 'Parkside perm', named after the hospital, and it was true, there was no individuality encouraged when it came to appearance.

Jackie Kay's short story collection *Reality, Reality* (2012) contains a story called *These Are Not My Clothes*, about a woman with dementia who is upset because she is dressed in the wrong cardigan, a fiction which resonated with the truth of my experiences. By contrast, I have found fiction exploring dementia in the novel format to portray life with dementia as something extraordinary rather than addressing more prosaic concerns. The protagonists are often young, as in the 38 year old central character of *The Things We Keep* (Hepworth, 2016) or the father of a seven year old who is diagnosed with early onset Alzheimer's disease in *Forgetting Foster* (Touchell, 2016). Often the person diagnosed with dementia is particularly brilliant, for example the talented architect at the heart of *The Wilderness* (Harvey, 2010). Sometimes the protagonists are both young *and* brilliant, with Genova's *Still Alice* (2007) aged only 50, and a cognitive psychology professor and expert in linguistics at Harvard, being perhaps the prime example.

I wonder if these tropes arise as a way of increasing the perceived tragedy of a dementia narrative, as if a great intellect in decline is more dreadful that the deterioration of an average person, or if a younger life cut short is somehow more climactic than the death of an elderly person.

Deborah Levy's *Cost of Living* (2013) is frequently referred to as a 'living autobiography', but I can find no explanation for it. The idea of an autobiography as a living thing intrigues me, imagine the story of a life that is living itself, and evolves through time as the writer changes.

‘If the thread breaks, it will bring bad fortune’ (Harding, 1987, p.62)

In the latest *Diagnostic and Statistical Manual of Mental Disorders*, ‘DSM-5’ (American Psychiatric Association, 2013) a decision has been made to replace the term dementia with the terms major, or minor, neurocognitive disorder. Siberski (2012) suggests that the change is due to the stigmatising nature of the word dementia. He argues that the new terminology enables the condition of people with milder forms to now be recognised, and focuses on decline rather than deficit. However, in 2022 the word dementia appears to still be widely used and accepted. The *ICD-10: The ICD-10 Classification of Mental and Behavioural Disorders : Clinical Descriptions and Diagnostic Guidelines* (WHO, 2019) continues to use dementia as a classification.

Autobiographies are often based around a person rather than an event, yet they are reflections of cultural situations and historical events.

‘Autobiographical lives are always “relational lives” (Eakin, 1998) that is, lives that are related to other subjects as well as to real and imagined communities as small as the family or as large as the nation.’

On the day side of the EMI unit the people tended to be a bit more independent, but some of them had such advanced dementia that they couldn’t tell you their own name. One of the patients was a retired footballer from a famous Northwest football team, a kind of David Beckham of his era, and it amazed me to see him recognised by people who were unable to communicate their own identity.

When I qualified I worked on a Mother and Baby Unit, and then an acute admissions wards. Life on the wards seemed to be concentrated on firefighting rather than on any real therapy. I was lucky to be involved in a pilot study for a research project considering CBT for perinatal health, and on the acute ward we hosted a project run by an arts in health group, in which Nigerian artists worked with the patients using traditional Nigerian crafts, accompanied by drumming, singing and a riot of colour which lent a carnival atmosphere to the dismal ward.

‘Autobiography is construed here as a genre with its own evolving set of norms and codes’ (Martens, 2014, p.319).

‘WE DID NOT ROB THE TREASURY FOR OUR MONEY THE BOTH KENTS HARRIET SEARS HER BROTHER MATHEW SEARS / ARE BASTARDS FROM CHATTERIS CAMBRIDGESHIRE / MARIA TURNER MRS ANNA MARIA YOUNG AND HER MUL / TITUDE OF TRAMPS OLD MAD MOLLY HAWES WHO WAS TAKEN / TO COLNEY HATCH ASYLUM IN A TINKERS CART STRAPPED / IN SHE LOOKED AS IF THE DEVIL HAS CHASED HER THREE / TIMES THROUGH THE FLAMES OF HELL FIRE AND TURNED OUT / THIS HIDEOUS WILD BROWN EYED OLD WOMAN DIED ABOUT / TWENTY ODD YEARS AGO THIS VILE HEMAPHRODITE OLD / HAG WOULD BE NEARLY A HUNDRED YEARDS OF AGE’

Lorina Bulwer sampler transcript (Fleming, 2014)

‘I wrote so I could say I was truly paying attention. Experience in itself wasn’t enough. The diary was my defense against waking up at the end of my life and realizing I’d missed it’ (Manguso, 2018, p.3).

When I worked on an acute mental health ward in Manchester, patients were always writing. Sometimes, I'd pick up a set of medical notes and a letter, or a poem would fall out. The writing was often really raw, and full of immense energy. The writing would be filed away as a sort of evidence of a person's symptoms, rather than as a piece of communication. It reminded me of one of my favourite things I learned as a student, the Rosenhan experiment *On Being Sane in Insane Places* (Rosenhan, 1973), in which the undercover participants' note writing is identified as a symptom of their mental illness. Recently, when reading *The Shock of the Fall* (Filer, 2014), I was transported back to my time on the ward when the protagonist's writing is referred to by staff as 'writing behaviour'.

'Life writing is the most flexible and open term available for autobiographical fragments and other kinds of autobiographical seeming texts. It includes the conventional genres of autobiography, journals, memoirs, letters, testimonies, and metafiction, and in earlier definitions it included biography. It is a way of seeing literary and other texts that neither objectifies nor subjectifies the nature of a particular cultural truth' (Kadar, 1992, p.i).

I was born in Gloucester and lived in the area throughout my childhood. My dad was a police officer and we moved around a lot. It always seemed to be because of his job but since my parents retired they've kept on moving and I have realised that my mum just has itchy feet. My Aunty Cath (who was my Aunty Kath before she went to see a numerologist!) lived in a high rise council flat near to Gloucester Cathedral. In a little lane off the cathedral grounds is the Beatrix Potter museum, which is really more of a shop than a museum, modelled as a replica of the tailor's shop from Potter's story *The Tailor of Gloucester* (2002). On display, inside a glass case, is a waistcoat just like the one in the story, glossy ivory silk embroidered with an intricate lattice of tiny cornflowers and dark pink poppies. In the book, mice make the waistcoat overnight for the incapacitated tailor, but run out of thread, leaving just one buttonhole to complete, marked with a little note, 'no more twist'. Upstairs in the museum was an area where children could do colouring in, or drawing, sat on giant cotton reels instead of chairs. Mice making stitches almost too tiny to see, giant cotton reels, and a story woven from the city I lived in, seemed quite magical to me.

I left my regular job when I got divorced, and did agency work for six months while I took temporary refuge at my parent's house. I worked throughout the county in various nursing homes, with varying standards of care, some of which shocked me. I remember one home in particular, partly because it had friendly badgers who would snuffle up if you sat outside on your 4am 'lunch' break, but also because there wasn't a single pair of protective gloves in the entire place.

I also remember a school trip to Coventry cathedral, seeing the largest tapestry made in one piece in the world. The Christ in Glory tapestry ‘measures 23m high by 12m wide and is made of undyed cotton warps and dyed wool wefts with a weave count of 12 warps per inch. It is estimated to have more than 900 colours and was created by a team of 12 weavers working for two years’ (Murphy, 2016). It was so huge and unlike anything I’d ever seen. The scale of it seemed as impossible to me as the tiny stitches which embellished the tailor’s waistcoat.

As printed pattern books became more widely available, the nature of samplers evolved. During the seventeenth century they served as a means of ‘measuring and recording their makers’ attainments’ (Browne, 2010, p.8). Schoolgirls were instructed in sampler making as part of their education, sewing rows of different stitches to make narrow band samplers (like my binca) or sewing maps or mathematical designs as part of their wider education. In the eighteenth century, girls continued to learn sampler making, but the finished results were increasingly viewed as decorative objects rather than as a reference to be rolled up and later referred to, something reflected in the squarer shape of samplers of this era (ibid, p.10).

One night I arrived in a home I'd not worked in previously. One of the regular members of staff had called in sick leaving the nightshift with three staff instead of four. One of those three was also from an agency, a nursing student, who like me had never worked in that home before. The third, regular member of staff had started a month before and only worked one night a week.

I tried to give out the medication while the other two helped people to get ready for bed, but I had massive problems identifying the residents. Some of them were able to confirm who they were, but the majority couldn't. Each prescription card had an attached photograph of the person it related to, presumably taken on their day of arrival, but I couldn't match the photos to the people in front of me. They'd stopped being groomed, had lost weight, some were missing their teeth or glasses. It was almost as if their characters had withered into a kind of sameness. Their identity eroded, not only by the progress of their dementia but also from the outside, from the routines of nursing home life.

As a nursing student I studied the JoHari window, a cognitive psychology tool developed by, and named after, Joseph Luft and Harrington Ingham in 1955. The window is a simple model for interpersonal awareness, examining the relationships we have with ourselves and others, using the placement of characteristics from a set list. It consists of quadrants, stacked in a two by two formation like a window pane (or, the simplest of quilt blocks). The basic concept of the window is that there are different areas of knowing ourselves. In the 'Open Self' quadrant are characteristics which are known to ourselves and to others. In the 'Blind Self' quadrant are aspects which are known by others but which we are unaware of ourselves. What we know about ourselves but others are unaware of, forms the 'Hidden Self' quadrant. Finally the 'Unknown Self' is a quadrant which houses the unconscious parts of ourselves that are not recognised by others, or by us.

I am interested in the idea that there are parts of ourselves which are never known to us or to anyone, and that some of our identity is carried in the perception of others rather than by ourselves, whether we are in good cognitive health, or not. In writing with people who are living with dementia it is tempting to address the identity as it is seen by others, and to try rekindle those aspects of identity which are remembered by others but which have become lost to the self (for example, a previous occupation). I think it might be helpful to remember that, although the progression of dementia symptoms will change the balance of what is known and not known, a person's identity can never be fully defined by how they see themselves, or by how others see them. There are always blind spots, and secrets, as well as the face we openly display to the world.

Piecing

'We speak of **piecing together** a story or puzzle. That may seem an obvious metaphor derived from sewing cloth; in fact, it's a little more complex. Piece goods were pieces of fabric of a set length, sold for a particular purpose. The Latin word pettia gave us the original piece, described as any separate portion or fragment in medieval times. However, by the 16th century the word had developed a number of more specific meanings relating to portions, including one for a length of cloth.

It's rather a shame that industrialisation did away with jobs such as that of a piecener, an apprentice in a spinning mill who filled the frames with rovings, pieced up the threads and joined the cardings and slivers for the slubber. I've only a vague idea of what he was actually doing, but it reads a bit like a poem' (Kapp, 2007, p.75, emphasis in original text).'

At the beginning of 2016 my ex-husband delivered a box, from the attic of the ‘former matrimonial home’ which had finally been sold, as ordered years before by the court as part of our divorce. It was a box full of things I only ever saw when I moved house: old school books, trinkets from my childhood bedroom, a Brownie uniform. The collection had diminished over the years, refined with each new house move. In the box, inside a folder made from two pieces of cardboard stuck together with yellowed sellotape, was a piece of ‘textile art’ I’d started to make in junior school, when I was 7 or 8 years old. A lumpen horse appliqued onto hessian with clumsy stitches. Other elements of the design are still pinned into place, waiting for stitches that I must not have had the time or inclination to make.

Autobiographies are never a complete account of an entire life. As Victorian writer Anthony Trollope observes in his own autobiography, not only is it impossible to write everything down, there is also the question of an author’s willingness to write openly about negative aspects of themselves; ‘who could endure to own the doing of a mean thing?’ (Trollope, 1999, p.11).

I stopped nursing after I remarried and had twins, the cost of sending two babies to nursery too much for my nurse's wage. When they started school I took a job as an Independent Mental Capacity Advocate, a role which hadn't existed when I was a nurse, but which had been born out of the *Mental Capacity Act 2005*. (Department of Health, 2005).

My role was to support and represent people who lacked the mental capacity to make a particular decision, usually related to medical treatment or housing, and had no friends or family who could help them. The government's *Independent Mental Capacity Advocacy Service: 7th Annual Report* (Department of Health, 2015) identified that across England and Wales 42% of people represented by the IMCA service had a diagnosis of dementia and 43% were over 65. My own caseload reflected this trend.

Despite the development of the government's national dementia strategy *Living Well With Dementia* (Department of Health, 2009) and the subsequent 2013 *Dementia* policy paper (Department of Health, 2013), statistics from the Alzheimer's Society *Dementia Report* (Dowrick and Southern, 2014) suggest that living well with dementia is not the reality for many:

- 61% felt anxious or depressed recently
- 40% felt lonely recently
- 52% don't feel they get enough support from the government
- 34% don't feel part of their community
- 28% aren't able to make decisions about how they spend their time
- 18% aren't living well with dementia

When You Are Old BY WILLIAM BUTLER YEATS

‘When you are old and grey and full of sleep,
And nodding by the fire, take down this book,
And slowly read, and dream of the soft look
Your eyes had once, and of their shadows deep;

How many loved your moments of glad grace,
And loved your beauty with love false or true,
But one man loved the pilgrim soul in you,
And loved the sorrows of your changing face;

And bending down beside the glowing bars,
Murmur, a little sadly, how Love fled
And paced upon the mountains overhead
And hid his face amid a crowd of stars.’

(Yeats, 1989, p.41)

The Whitworth Art Gallery collection includes a sampler by Frances Young, dated 1819, featuring the following verse:

With cheerful mind we yield to Men, / The higher Honours of the Pen, / The needle’s our great Care, / In this we chiefly wish to shine, / How far the art’s already mine, / This Sampler will declare.

A large part of the IMCA role is to try to find out what is important to the individual, so that this can be taken into account during the decision making process.

'ascertaining what P's wishes and feelings would be, and the beliefs and values that would be likely to influence P, if he had capacity in relation to the proposed act or decision' (Mental Capacity Act, 2005, Reg 6, 5b).

Many of my clients lived in care homes and I would arrive at a home, ask the staff what they could tell me about the person and invariably they would have to grab the person's file before they could tell me anything. Even simple facts, such as what job a person did before retirement, were not part of the picture the nurse had of the person. With no visiting family members or friends, the client's histories were no longer kept alive, but lost, separated from the person they belonged to and filed on away on a shelf.

Kitwood's *Dementia Reconsidered* (1997) focuses on the individual experience of the person with dementia. He describes a state of 'personhood' defined as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being [...] implying recognition, respect and trust.' (Kitwood, 1997, p.8) A person living with dementia's behaviour is not just a result of their physical and cognitive decline but an interplay of social and psychological factors. He suggests that people can interact negatively with people with dementia, as a result of processes he calls 'malignant social psychology' (ibid, p.4), in a way which damages their sense of personhood. He advocates the use of 'positive person work' in different forms (see Mitchell and Agnelli, 2015). One form is play in which people with dementia are able to experience enjoyment through activities which encourage fun, spontaneity and self-expression.

I wish I could say I learned to sew at my mother's knee, or that my nana had passed down her wisdom. My mum had a sewing machine but I don't remember her making anything, although she must have had some dressmaking skill, as she made her own wedding dress when she was 19. I don't remember my nana being good at anything, except winning awful trinkets at the bingo. She liked to gamble, to smoke, looking back, I suspect that she liked a swig of sherry. She lived in Gloucester, just round the corner from Fred and Rosemary West. When Margaret Thatcher appeared on her television she would erupt, shouting and swearing and shaking her fist. She would always watch the Pope's Easter message and wish she could go to see him.

In History and Memory (1992), Jacques Le Goff considers the changing cultural perception of memory in Western culture, identifying five shifts.

Le Goff suggests that during the first period, before written language, elders 'held' the memories of their tribes. Memories were shared through ritual and spoken stories.

With the advent of writing, memory could be externalised, stored and recorded outside of the human mind. Memory was personified in Greek myth in the form of Mnemosyne, mother to the nine Muses. To drink from the river of Lethe and become forgetful was to find oblivion, drinking from the water of Mnemosyne was associated with immortality, as if by being remembered, man can become immortal.

In the medieval period, Judo-Christian concerns of forgetting God's teachings become the focus. By forgetting his teachings people forget God. Saints are memorialised and therefore remembered, transgressors are 'struck from the memory books' (ibid, p.73) and therefore erased from history. In this period there is also the development of mnemotechnology, including maps and symbolic systems to assist with memory.

With the printing press, memory became more external and a wider volume of information was available to ordinary people. Memorials, museums and commemorative events became popular. The idea of collective memory emerged, for example the Tomb of the Unknown soldier, a collective remembrance of the dead. Photography was developed and memories became visual, with special events, family and individual, recorded as pictures.

'Embroidery is an Anglo-Norman word, embrouderie from the verb to embroider, which is compound of an earlier base ea for in and brouder, which is probably linked to the past participle of braid, so originally the word meant something braided, from the twisted appearance of the threads in stitching. Among the greatest artistic accomplishments of the Middle Ages are the embroideries collectively called Opus Anglicanum, which simply translates as English work' (Kapp, 2007, p.33).

‘Embroidery is all about embellishing fabric to make it look beautiful, but because of its fragility, its early history can be deduced more from myths than artefacts. For example, in the Baltic tradition, the sun is female, and as Sol or Saule, is carried across the sky in her golden chariot. She spins precious metals, and embroiders her own dazzling silken clothing all over with gold, silver and bronze threads, removing her dress at night and putting it on again at dawn. She lives on a farm in the sky, ad is seen rolling and hopping and dancing in silver shoes on Midsummer morning, which is a time of sexual licence and celebration of life in Baltic culture’ (Kapp, 2007, p.33).

Discussing her book *Hunger: A Memoir of (My) Body* (2017), Roxane Gray describes the perception of her writing, by people interviewing her during her publicity tour. Her experience has been that as a woman writing about personal matters, her writing is not taken seriously and treated as something achieved without any true craft.

‘Today, the New Yorker called me a “diarist”. The opening lines were that I came to fame as a diarist, which is just not true. I have a whole body of work. But even if it were true, there’s this smug sense that it’s just: “Oh, I’m sitting in my bed and I opened up my heart-locket diary and I’m just jotting down some thoughts!” and it’s just all emotion and that none of it is intellectual’ (West, 2017, para.11).

In current times we experience a digital flood. We seek ways to manage data. Computers have memory. We use external tools to help us to remember, mobile phone cameras, digital diaries, email reminders. We store memories in virtual clouds. There are no patterns to help us to retain information, people forget phone numbers because their phones remember them for them. We are no longer motivated to retain information which we can simply search for online, a condition dubbed digital amnesia. A second kind of amnesia occurs when our data is lost, with swathes of photographs or significant documents deleted from hard drives or clouds.

We have less control over these digital items than we do our material possessions. In a recent case, a man won a legal action Google for 'the right to be forgotten' – seeking to have sensitive information removed from search results rather than have it remain in perpetuity (France-Presse, 2019, online). Do we own our own memories?

'When you imitate someone else, something is passed on. This 'something' can then be passed on again, and again, and so take on life of its own. We might call this thing an idea, an instruction, a behaviour, a piece of information...but if we are going to study it we shall need to give it a name.

Fortunately, there is a name. It is the 'meme'' (Blackmore, 1999, p.4).

'In thinking about thinking we should remember that not all thoughts are memes. In principle, our immediate perceptions and emotions are not memes because they are ours alone, and we may never pass them on. We may imagine a beautiful scene from memory, or fantasise about sex or food, without using ideas that have been copied from someone else. We may even, in principle, think up a completely new way of doing something without using any memes from anyone else. However, in practice, because we use memes so much, much of our thinking is coloured by them in one way or another. Memes have become the tools with which we think' (ibid, p.15).

A situation is created in which, as a person becomes less able to express aspects of their selfhood, it becomes harder for those around them to then engage with their individuality. This individuality is consequently less likely to be ‘kept alive’ through the prompting and stimulation of conversations on the subject. If people in this situation could be facilitated to express themselves through autobiographical writing creating an artefact which could then be looked at by the writer and their circle, could this serve as a prompt for beneficial interactions which nurture the individual?

Autobiographical writing is subject to a series of conventions which may not be explicit, and which vary between cultures and according to who is doing the writing. Expectations of autobiographers have changed through history and continue to change as technology changes the both the way we communicate and how we see ourselves. The internet enables us to present a different version of ourselves.

‘Persons acting in the virtual environment put a lot of effort into authoring their online identity or, better put, composing a story of a life that has a credible personality.’ (Buitelaar, 2014, p.266)

One model of memory suggests that it is a three stage process. During encoding, the memory is processed into a form which can be stored during the second stage. The third stage occurs when this stored memory is retrieved (McLeod, 2007).

Basting (2009, p.18) argue that the nature of memory is mutable. ‘A memory is not an object preserved in the museum of our minds. It is a living, changeable thing that is shaped by who we are when we encode it and by who we are when we retrieve it’.

Browne observes a diminishing sense of creativity in more recent years, with samplers ‘becoming an increasingly standardised form of unambitious exercise in the early nineteenth century. Exceptions to this form draw particular attention to their makers’ (Browne, 2010, p10).

Examples of this are Lorina Bulwer’s three samplers, embroidered during her incarceration in Great Yarmouth Workhouse lunatic ward, and the Elizabeth Parker confessional sampler. Both women were able to subvert the constraints of the standard form of sampler sewing to produce radical autobiographical textiles. I have used Parker’s sampler to create an alphabet pattern which is used in some of my cross stitched work, and tried to recreate Bulwer’s style of lettering on other quilts.

Drawing on these historical aesthetics in my own creative works pays homage my original inspiration. It is a recognition that my work is descended from a long-standing tradition of radical autobiographical textiles.

I am interested to consider parallels between the changing cultural perceptions of memory identified by Le Goff (1992) and the changing forms in literature through history. For example, the oral sharing of stories, ballads and poems during the period before written language, labour intensive illuminated Holy texts in the medieval period, conceptual writers using the 'digital flood' as material rather than creating new texts which add to it.

I am also interested in the idea of where memory is held, either collectively by a community, inside yourself, in an external device. How this changes our expectations of what we need to remember. How this changes how we perceive dementia, will we be less frightened of losing our memories in future, if we are becomingly increasingly detached from memory in everyday life, outsourcing it to our computers?

'Lone Star quilts can be bad luck in certain circumstances (although so many are extant that it is hard to believe that many people took these precautions seriously) A person who starts a Lone Star quilt will never live to finish it; if a single girl makes one, she will never marry' (Harding, 1987, p.62).

‘Polk, Patty. [Cir. 1800. Kent County, Md.] 10 yrs. 16” x 16”. Stem-stitch. Large garland of pinks, roses, passion flowers, nasturtiums, and green leaves; in center, a white tomb with “GW” on it, surrounded by forget-me-nots. “Patty Polk did this and she hated every stitch she did in it. She loves to read much more.”’ (Bolton and Coe, 1921, p.210).

I learned to sew in infant school, using a placemat sized piece of yellow binca, a version of the aida fabric used for cross stitch, with a wider grid to make it easier for beginners. I made a kind of sampler, running stitches whipped with contrasting embroidery thread, or sewn in parallel lines then joined vertically to make turret shapes. Cross stitches, herringbone, row after row of neatly ordered, counted stitches. The outside rows of the binca were pulled away to leave a fringe. I kept the mat on my dressing table for years, underneath some of the ornaments now exiled to that box from the attic.

After the binca, I progressed to cushion covers made from gingham, using the pattern of the small, printed squares as a guide for the stitches. The horse on hessian was maybe too free form, too lacking a framework for me to get to grips with it. I have used this piece of childhood sewing in one of the quilts for this project. I have retained its unfinished characteristics whilst giving it new life with cross stitched words.

‘We use embroidery as a figure of speech poetically when we talk of a field as **embroidered with flowers**. Chaucer describes a fine young squire, whose clothes, embellished with floral patterns, seem so much the most important thing about him:

He was embroidered like a meadow bright,

And full of freshest flowers, red and white.

Or we can quote Yeats:

Had I the heavens’ embroidered cloths

Enwrought with golden and silver light...

I would spread the cloths under your feet’

(Kapp, 2007, p.33).

‘Think for a moment about all the thoughts you have had in the past ten minutes – let alone all day. Even while reading you have probably thought about other people, remembered things you meant to do, made plans for later in the day, or (I hope) pursued ideas sparked off by the book. Most of these thoughts will never be thought again. You will not pass them on and they will perish’ (Blackmore, 1999, p.37).

trunk leaf branch twig roots autumn blossom green tall coniferous deciduous bark oak beech sycamore conkers swaying birds canopy rainforest forest wood holly lilac cherry apple arboretum avenue oxygen thicket branching grow rings owl squirrel acorns nuts I had a little nut tree evergreen Christmas poplar pollard pinecone pine partridge in a pear tree

Everything I know about my biological father

1) His first and last names

2) What he looked like in a single photograph from the sixties – when I saw it I thought he looked a bit like a Beatle

3) His sister had worked as a nurse in the same hospital where I got my first nursing job

4) He came from Widnes or Wigan. I can never remember which. Growing up they both seemed distant, now I have a Wigan postcode.

5) He worked in the RAF. I don't know what he did

6) My mum found out, when my brother was six weeks old, that he had cheated, and the marriage broke down. I was sixteen months old

7) My mum told me that he abandoned me, he never looked back, and so I never saw him again

When my first marriage ended, my daughter was about eighteen months old. Mum advised me to stop her from seeing her dad, it would be better for everyone if there was a clean break and a fresh start.

A lack of honesty is seen as withholding. Conversely, too much honesty is seen as oversharing, or harmful to those around the writer who also form part of the story. Perhaps then there is an ideal middle ground, where the author is seen as open without being too revealing.

Hanif Kureishi's *My Ear At His Heart* (2005), a memoir about his father, was publicly criticised by his sister who said she did not recognise his portrayal of his father.

'Hanif's book presents my father, who died in 1991, as a dismal failure, a pathetic, sickly man who sat around in his pyjamas all day. It is not a portrait that I recognise at all' (Kureishi, 2004, online).

Discussing the memoir, Hanif Kureishi, acknowledges the tensions involved in writing about a parent.

'What are we doing when we're writing about our fathers? What is this act? It's an act of love, it's an act of betrayal, it's an act of mummification — it is such a complicated thing, and you feel very guilty about it [...] it's also an act of restoration' (Susheila, 2006, p.22).

'"Shaking the Cat" meant that a cat would be placed on a finished quilt and several girls (usually four) would grasp the edges and shake it; when the cat jumped out, the girl closest to it would be the next to marry' (Harding, 1987, p.62)

There have been three times in my life that I have wondered about my biological father, and wanted to know him.

When I was a teenager, I met a boy. I can't remember his name but I can picture his face. I had stared at it for hours. He was redhead with eyelashes so pale and blonde they were almost translucent. His skin had the same fragility and was glowing with suffering after a day out in the sun. We were at an awful event for young people in Gloucestershire, me with the Duke of Edinburgh's Award Scheme, the boy with the Venture Scouts. I had spent all day occasionally demonstrating, to polite but uninterested passers-by, how to pack a rucksack for an expedition. My friends from the same branch meanwhile, were attracting a crowd, cycling 'around Gloucestershire' on an exercise bike. We had been lured there with a promise of meeting Prince Edward, who eventually turned up, chatted merrily to my pals on the bike, leaving me and my rucksack and my Tupperware and camping mat ignored. I had hoped for a charming chat about working in the theatre and so was thoroughly pissed off with everything by the time I met the boy. Danny (was he a Danny? Maybe an Adam? There were so many boys) was adopted and I don't remember how the conversation started, only what it started in me.

In secondary school I learned to use a sewing machine. In Textiles lessons I made a cover for my radio, decorated with an underwater scene. I appliqued fish in sparkling metallic prints, embellished the waterline with tiny beads, and couched small pieces of twisted netting to look like seaweed. Some of them didn't catch properly in the stitching and the imperfection made me sad.

When my Mum agreed to let me experiment using her sewing machine, an old Frisch and Rosser, which was built like a tank and smelled liked engine oil, it felt like a rite of passage. I made a skirt which I never wore. I couldn't work out how to make a button hole so it stayed unfinished, not that I minded, because the cheap fabric I'd made it from had been a see through mistake.

'The trouble was that I failed to record so much.

I'd write about a few moments, but the surrounding time — there was so much of it! So much apparent nothing I ignored, that I treated as empty time between the memorable moments' (Manguso, 2018, p.4).

Blake Morrison identifies seven different motivations for writing confessional memoir, including the desire to shock others or to confess as a kind of dramatic performance.

1. Spontaneous overflow of powerful feelings (Wordsworth) or free association (Freud)
2. Confession as an apologia or self-justification, a strategic bid for sympathy and admiration
3. Confession as a desire to shock – the memoir as a screaming tabloid headline
4. Confession as the desire to redefine what is shocking; to nail the hypocrisy and shallowness of polite society
5. The drama of the ego. Confession as performance and showmanship, its natural arena not a secret cloister but a soapbox or a stage
6. The confessional memoir as a piece of truth-telling – its primary impulse being to set the record straight, to bear witness
7. Confession as catharsis, cleansing, or purgation

(Morrison, 2015, pp. 206-211).

I'd had no curiosity about my dad, or what his absence meant for me. Sometimes people would ask me about it 'Wouldn't you like to know?'. I can't remember why it ever came up in conversation. Maybe I'd said that my new dad wasn't my real dad. I had never wanted to upset my family by going digging. But people always imagined that if it was them, they would want to know, so why didn't I?

I always thought I couldn't bear to meet him. What had I missed? What if had half brothers and sisters that I'd never known, as related to me as the sister I lived with. I always wondered more about these potential brothers and sisters, who had not abandoned me. What if he was awful? Or lovely? Or dead? I sometimes allowed myself to picture myself weeping at the tragic news. But wouldn't that be a neat end to it all?

All my life my mum had told me the same story, my dad had left, he didn't care, my (new) dad 'took me on' and adopted me (I don't think of him as my new dad or my stepdad or my adoptive dad, he is just dad to me, the only one I have known). I don't know how it is possible to adopt without contacting the biological parent, but I didn't question any of it until my mum urged me to have that clean break.

In my Bunty comics there were stories about The Four Marys. Mary Field, Mary Cotter, Mary Radleigh and Mary Simpsons. They seemed to often have adventures where one of them went blind following a blow to the head, then later, following a second blow, could see all the other Marys again. Maybe it only happened once and I made it happen again and again by reading it over and over.

The big fabric shop in Cheltenham was right by my bus stop and I'd while away my waiting time perusing the shelves and imagining the possibilities of all those big rolls of fabric, choosing patterns from the fat catalogues and doing the mental arithmetic to calculate the cost of the meterage and notions. I was never very interested in fashion though, so my adventures in making my own clothes started and ended with that unfastenable, unfashionable transparent spotty skirt.

Morrison's seventh concept of confessional writing, as 'catharsis, cleansing, or purgation' (2015, pp. 206-211) seems most resonant with the style of writing exercise used in clinical trials for writing for wellbeing, the idea of getting it all off your chest, and that the more uncomfortable your confession is, the better.

Hockemeyer et al. observed that although writing for wellbeing had beneficial long term health effects, in the short term 'the immediate effect of writing about traumatic topics is negative - pre-post writing increases in negative mood, distress, and anxiety are typical' (1999, p.99).

The creative approaches discussed earlier manage to achieve positive benefits without an interim period of distress. When creating frameworks for working with people living with dementia, the potential for distress and anxiety to occur should always be considered. Instead of focusing on difficult memories, which may be uncomfortable, creative approaches can be used to promote laughter, joy and connection instead.

When my boys were turning one we went to Butlins to celebrate their birthday. My dad had just retired and my parents were on holiday too, visiting my aunty in Malta. While they were there, my mum talked my dad into buying a flat opposite her sister's place and they never really came back after that, for years.

I recognised that this was my chance, with my parents at such a distance that I could finally look for my dad and be able to deal with any consequences without upsetting anybody else.

I didn't do it. I think now, that I won't.

Sometimes I think of the DNA testing services and how they might uncover relatives without any disloyal digging required. But I can't bear to rebuild myself.

An example of the use of textiles for remembrance is the AIDS Memorial Quilt, which is made from over 48,000 panels, each commemorating the life of an individual who has died of AIDS. The quilt is a powerful tool for awareness raising. Covering approximately 30 acres the quilt is too large to display in its entirety, but sections of the quilt tour worldwide and have been viewed by over 14 million people. The Names Project Foundation, who manage the quilt, have begun an archive project, storing digital photographs of the panels, to further develop their programmes of HIV prevention and AIDS awareness and 'to preserve the powerful images and stories contained within The Quilt' (National Aids Memorial, 2016, para.7).

For a few years, I did cross stitch instead. I liked the maths of the patterns, counting the stitches and the spaces between them, translating the symbols of the pattern into a finished motif. The pattern was more than a picture of the finished design, almost like hieroglyphics, or another language which needed translation, or a map. My mum still keeps a little cross stitch birthday card I made, tucked between her Royal Doulton in her china cabinet. I got fed up of following other people's designs and other interests (boys!) took over.

‘The poet, when his heart is weighted, writes a sonnet, and the painter paints a picture, and the thinker throws himself into the world of action: but the woman who is only a woman, what has she but her needle? In that torn bit of brown leather brace worked through and through with yellow silk, in that bit of white rag with the invisible stitching, lying among fallen leaves and rubbish that the wind has blown into the gutter or street corner, lies all the passion of some woman’s soul finding voiceless expression. Has the pen or pencil dipped so deep in the blood of the human race as the needle?’ (Schreiner, 1926, p.322-323).

I once went to a poetry workshop where we wrote poems from prompts. First we had to write down the first fifty words we could think of from the prompt ‘tree’, then write a poem about a tree which didn’t include any of them.

The second prompt was to write a poem with all the names you’ve ever been called. I have never felt settled with my name. When my dad adopted me my surname was changed to his. But sometimes, when I fill in forms, and they ask for the name on my original birth certificate, it’s a name I have no recollection of ever being known by. I have never heard it said out loud. It’s like it belongs to a different person, but it’s mine, it’s me, a version of me that I barely know.

‘My own *Much-vexed Cloths* are textiles constructed from weathered and much-used cloth: tests for mordant prints, madder-dyed linen, old damask table linen. These were left outside in my back yard for two years to be altered by the elements over time. I often take textiles outside to be weathered; naturally dyed fabrics fade with exposure, making interesting marks and textures. Fibres break down and weaken, meaning that they behave differently when cut and stitched. The printed areas, particularly when iron has been used as mordant, tend to deteriorate first, leaving patches of weakened and light-faded fabric. This presents challenges and opportunities. I backed these pieces with recycled wool blanket to reinforce them. However, as I began to stitch with silk thread over the weaker areas they continued to fray and to unravel. The more I stitched, the more I needed to repair and make good’ (Wellesley-Smith, 2021, p.19).

‘I wouldn’t dream of suggesting that I am offering a factual life of anyone, apart perhaps from myself – and there is nothing so unreliable or delicious as one’s rackety memories of oneself. Some of my recollections may be tainted by time or others’ slanted tellings or photographs, and my memories are no more and no less likely to be precisely accurate than yours or hers. I’m saying only that I was there, or was told first hand, and have remembered things thus and so, which might make what I recall a mite closer to the facts of the matter.’ (Diski, 2015, p.13)

The subversion of the traditional sampler's form and purpose, demonstrated by Bulwer and Parker's works, creates something which is not merely an aide memoire or a decoration, but which reveals and communicates the story of their distress. I wonder what other outlets for expression would have been available to them, as Parker herself says she is unable to write. Their writing brings back memories of the texts written by the patients on the acute ward and filed in their notes

Jennifer Ruth Martin Jennifer Ruth Basford Jennifer Yellow-hat Jennifer Ruth Campbell Jennifer Nennifer Jennie Jenny Jen Nennie Nen- Nens Jen Jane Ken Gemma Glenn Mrs Campbell Mrs Davies Mrs Brierley Miss Ruby's mum The twins' mum twinmum Harry and Max's mum mum mumma mum mum mum love baby babe honey darling stupid fucking bitch Mrs Crumble

There is a popular meme on social media, ‘stop comparing your behind-the-scenes with everyone’s highlight reel’ (Kerpen, 2017, para.1). In this context the behind- the-scenes perhaps refers to the mundane aspects of life, versus those which make for an interesting photo opportunity or exciting story. Perhaps though in autobiographical writing, we expect a mixture of highlights, the most tellable stories (the meme-ist ones) but also a taste from behind the scenes, of learning some of the secrets of the writer (think of celebrity autobiographies and tell-alls revealing a secret affair years ago e.g. Carrie Fisher and Harrison Ford) and these are often used as a powerful marketing tool for celebrity autobiographies. We want to learn something about the author that we didn’t already know.

Another study showed benefits for medical students who participated in poetry workshops with people with dementia. Following the workshops the students’ perception of people with dementia were positively changed, with a resulting change in attitude (Garrie et al., 2016).

It seems therefore that therapeutic writing activities can have a positive impact on the professionals involved in the care of people who are living with dementia, as well as on the participants. I have experienced something similar when working with people in my IMCA role, when clients have items they’ve created themselves (normally during organised craft activities or occupational therapy) on display in their nursing home bedroom. It reminds one of the person’s capabilities. If people produce something as part of an exercise in writing for wellbeing, the potential benefits of sharing the work should be considered.

My nana’s name was Mary and all her sisters were called Mary too.

Mary

Maria Assumpta Carmela Paulina Sophia

Mary Emma

Mary Frances Mary Josephine

‘Never quilt at all on Sundays’ (Harding, 1987, p.62).

In August 2017 I attended the Festival of Quilts at the NEC in Birmingham. Billed as Europe's leading patchwork and quilting show, the festival featured 972 competition quilts, and exhibitions from quilt artists from all over the world.

The festival's *Through Our Hands* exhibit (The Festival of Quilts, 2017) featured non-traditional portraits from a number of textile artists, including some of Jenni Dutton's (2011) *Dementia Darnings.* The displayed darnings were two portraits of Dutton's mother, who lived with dementia. Dutton describes the development of the project, from her stitching likenesses of family members, from old photographs, which her mother recognised and enjoyed, to stitching current portraits of her mother, as they sat together, as a way of coping with the challenges of caring for her mother, and recording her deterioration.

'My work is about time, I record the effects of time through the Darnings and also record the instant expression on a face when a photo is taken. Photos taken a moment apart in 2011 are translated into these two portraits made over 8 months, between 2016 and 2017. They stand as a testament to my mother and her life. Each thread sewn brings together the female body in relation to the threads that tie generations of women and makes tangible the emotional as well as biological ties between mother and daughter' (Dutton, 2017, para.2).

I was struck by the complexity of all that the darnings represented. Pleasure for the mother. Comfort for the maker. Recognition of the ties that bind generations of women. A record of something which itself was a record (the photograph) which captures both a single moment and months of togetherness. When I am making my own work I often experience a strong sense of time, of the effort of making each stitch to make a letter, instead of using a pen or hitting a key. I feel that people can look at my quilts and feel a sense of the time which was devoted to them. I have only ever thought of this as a kind of side effect of the medium but I now wonder how this aspect of the making could be used to express a sense of growing older.

In 2015, artist Cornelia Parker completed *Magna Carta (An Embroidery)* a 13 metre long textile artwork made in celebration of the 800th anniversary of the Magna Carta, depicting the document's Wikipedia entry as it had appeared on its birthday the year before. The embroidery has multiple creators, reflecting the creation of the Wikipedia page by multiple authors. Over 200 people, including celebrities and prisoners contributed to the piece, sewing words which were of particular significance to them, for example, with Jarvis Cocker, lead singer of Pulp, sewing the words Common People, the title of their signature hit (Paw, 2015).

Parker states ‘All these people have their own opinions about democracy today and I thought carefully about the words they should stitch. For instance, Baroness Warsi, Eliza Manningham-Buller, Julian Assange and numerous prisoners have all stitched the word ‘freedom’, but all have different relationships to it’ (British Library Press Office, 2015, online).

The bulk of the text was sewn by prison inmates, under the supervision of Fine Cell Work, a social enterprise which trains and pays prisoners to produce skilled needlework. Members of the Embroidery Guild, Royal School of Embroidery and embroidery company Hand and Lock created the images seen on the artwork (ibid).

Parker states ‘I love the idea of taking something digital and making it into an analogue, hand-crafted thing’ (ibid, online).

‘It often happens that we count our days, as if the act of measurement made us some kind of promise. But really this is like hoisting a harness onto an invisible horse’ (Nelson, 2009, p.37).

There seems to me to be an analogy between the progression of a narrative through a series of textile panels, using sparing text, and the pages of a graphic novel. In *The Black Project* (2013), Gareth Brookes uses embroidery and linocut techniques, in a graphic novel telling the story of a boy making life-sized dolls which he relates to as girlfriends. Brookes uses elaborately embroidered frames to border different scenes. The use of embroidery in graphic novels is unusual but this means of construction echoes the protagonist's efforts to sew his new companions together. It is interesting to consider how textile pieces can be created so that their form reflects their subject in some way, rather than being merely a 'page' for embroidered words.

Turner Prize winning artist Grayson Perry used tapestry to tell the life story of a fictional character. *The Vanity of Small Differences* (2013) is a sequence of six large tapestries using minimal text and exploring themes of taste and class in British life. The tapestries are true, woven tapestry panels created using computerised machinery to form Perry's designs.

'Of course you wouldn't dare to find a husband for yourself. He has to find you. I hear them say that the face which is kept hidden away is as valuable as gold, and the man who wants you will find you, even under the bed...' (Zarb, 1998, p.158).

I have been pregnant three times and I have three children. During each pregnancy I've had hyperemesis gravidarum – morning sickness with no boundaries that left me unable to keep water, or my own saliva in my stomach. I sometimes vomited fifty times a day.

When I was pregnant with my daughter the doctor prescribed antiemetic suppositories. Tablets would not have stayed down, nor would the water I washed them down with. The trick wasn't keeping them down, but keeping them up. If I started vomiting before one had fully melted and absorbed, the force of the retching would expel it, back out the way it went in, slimy and wasted and disgusting.

'Women are more likely to be accused of oversharing than men, no matter what the nature of their disclosures' (Sykes, 2017, p.151).

'it implies that what these woman are doing is just sort of spilling out whatever they have in their guts and that there's no art involved in the writing' (Jong, 1973, p.66)

It is notable then, that critics do not accuse male writers of oversharing with the same regularity and that contemporary male novelists, like Ben Lerner (2011), Tao Lin (2013), and Karl Ove Knausgård (2009), who write singularly autofictional accounts of their inner lives, bodies and sexuality, are celebrated.

In my second pregnancy I felt sicker. Perhaps already having a toddler to care for meant I got less rest. We had moved house, a different doctor prescribed little beige tablets that I battled with. If they stayed inside me long enough to be absorbed I might get some relief for a couple of hours.

It is a funny thing to be sick so frequently that it becomes matter of fact. To feel the sickness building inside of you and become intimately acquainted with the tipping point, the feeling or moment when it refuses to be ignored any longer and you must get up and hold yourself while you pad down the hall. To take a tablet, trying to time it so that your chances are at their best, but there is no real pattern to any of it so you don't know when is best, then try not to move, not for an hour, to know that if you are still and refuse to give in there is a chance of slight respite.

I could hardly bear for my husband to be in the same room. The motion caused by him walking on the floorboards, the smell of his breath. My sense of smell was so strong I felt like a dog. I could smell a patch of cat's piss on the stars from a cat which had died years before. I wanted to be alone, to be still, to sleep.

The *Try To Remember* programme uses poetry in dementia care, but is reminiscence based exploring and preserving memories, in co-authored poems. Gregory (2011) evaluated the programme by interviewing members of care home staff, rather than participants, and found that the poetry sessions had a positive impact on the quality of life of the participants in the opinion of the staff.
Graham Harthill, co-founder of Lapidus, the UK organisation for writing for wellbeing, describes working as a poet with people living with dementia. He is clear that he acts as a poet not a therapist (2013). He identifies the practical challenges of working with older people, such as problems with attending a group, hearing difficulties or reduced mobility (ibid).

In films women eat pickles and giggle with delight as this is the moment they realise that they're having a baby. I knew I was pregnant because I couldn't stop peeing or crying. I saw an advert on tv, a man dressed as a hotdog, dancing around and I cried because the world was full of beautiful things, and that was the moment I knew.

The hormones of early pregnancy are like those of PMT. The 4lbs of bloating that built up and made me heavy, but disappeared when my period started was never released. I was irritable, sick, hungover. My back was hurting, my bra was too tight. Before I'd missed a period my breasts were different, eager, full of veins and hot blood.

When I worked on the Mother and Baby Unit there was a mother who asked us to send off a pregnancy test for her. Her breasts felt like they had when she was first pregnant with the baby she'd been admitted with. The test came back negative but it was wrong. She knew.

Through a process of listening, scribing, transcribing, reflecting back to the participant and seeking permission to make the poem public, a poem which is then published or performed, is produced. Harthill does not see publication as an end goal for the poems but rather as a stage in the poem's life cycle: 'I suggest that everything that happens when you or the participants present a poem *is* the poem. Publication is only part of the life of the poem, reading continues the poem, the poetic process is indefinite' (2013, p.137). I had only thought of the process of writing in terms of it being used during the writing therapy exercise, not as something which carries on indefinitely after the poem has been created.

At its extremes, experimental writing can be heavily autobiographical, focusing on the minutiae of the author's life, or, can have content which seems to be very separate from it.

For example, conceptual writer Kenneth Goldsmith has produced works documenting aspects of his own life in extreme detail, and conversely, works which transcribe writing from other sources with no editing or personal stamp other than the idiosyncrasies of the transcription process.

In Fidget (Goldsmith, 2000), he documented every single movement he made on June 16th 1997 from 10am to 11pm. In Soliloquy (2001), Goldsmith recorded every word he spoke for a week, including ums, ahs, and other fillers, but omitting the responses of those in conversation with him. All other characters in Goldsmith's story are noted only by their absence, visible only in the reflected light of his responses to them.

I had imagined growing and glowing, as time went on. Not that I would feel so overtaken from the start, even without the constant puking, my body was out of control. My hair was greasy and my mouth was always full of spit. Once, on the way home from work, driving 70mph on the dual carriageway I fainted in one lane and came round in the other. A doctor at work, a nice lady I was assisting with a research project on the ward, told me that if you're a young mother it keeps you young for life, and I remember wondering why she was saying that to me, I wasn't young, I was 23.

Emck, of Fine Cell Work, describes sewing as being the slowest of all the crafts. Each prisoner spends hundreds of hours making each individual item (Chevalier and Emck, 2017, p.47). This is a particular benefit of those in prison, who have many empty hours to fill. In past times, it would've offered a similar outlet to women in the home. As Dutton (2017) describes with the making of her *Dementia Darnings*, there is something about this longitudinal aspect of textile work which is fundamental to our understanding of it. I wonder if the relationship with a finished piece of work produced in this way is the same as with something written in the usual manner. If a writer or maker spends long enough making something, does it stop being just a vehicle for delivering a story and actually become part of the story itself?

Rachel Cusk decentres the protagonist in her fictional novel *Outline* (2014) allowing her only to be seen in relation to others. She is a kind of space within her own story, sketched extremely thinly and framed by the more vibrant characters who interact with her.

Other people, or parts of our own selves, can be missing from our stories. For people who do not have a coherent sense of their selfhood, or who experience gaps in the knowledge of their own lives, these gaps can themselves become a kind of presence, showing themselves in their outline against the known. No auto/biographical story is ever complete. Nobody can document every word they say or every movement they make in a lifetime, meaning auto/biographical writing inevitably provides an edited version.

The sickness in my second pregnancy seemed to wear off more quickly and I went back to work as the second trimester started. Part way through my first shift I realised I was bleeding, and went straight home. The GP told me it was probably nothing to worry about, the worst risk of miscarriage was over by now, head to A&E if it got worse.

Later that night, on the other side of a curtain, doctors told each other that I was losing my baby, before they'd told me.

Other artists using existing texts in textile artwork are Jen Bervin, Elaine Reichek and Sylvie Franquet.

Reichek has created a series of sixteen embroideries, *Ariadne's Thread* which explore the Greek myth of Ariadne, who gave Theseus a spool of thread before he entered the maze with the Minotaur (The Whitworth, 2015).

Reichek has worked extensively with cross stitch and samplers, including her 1994 series *A Post-Colonial Kinderhood* which features traditional samplers, embroidered with quotations from her Jewish friends and family 'instead of the usual Christian homilies or the historical quotes' (ibid, p.68).

She has also produced worked exploring the idea of craft patterns as conceptual systems, 'works in which a knitting pattern appears in a variety of different linguistic systems — as word, as chart, as symbol system, as knitted wool' (ibid, p.68).

Maria Damon works with weaving and small cross stitch pieces, but does not identify herself as a fine artist, ‘I see what I’m doing as folk art, and also a somewhat bourgeois lady-work’ (Damon and Blau Duplessis, 2012, online).

Damon’s cross stitch pieces have an intimate, personal scale, from around 12 to 20cm square. She states, ‘I like the size of the x-stitches; I think of them as tokens, like Creeley poems, easily transferred from person to person, through the mail or face-to-face, fitting into a manila office folder’ (ibid).

Their text often takes the form of deconstructed words. *Open Up and Bleed: For James Osterberg, Jr (*Damon, n.d*)* made for Iggy Pop, with the needle left in the centre, features a single word, obsess. The letters look more like shapes than letters.

The next day, which was my birthday, after having a scan which showed that the baby had no heartbeat and was too small and had stopped growing a couple of weeks before (I hope to see you again, under happier circumstances, the sonographer said as I left and it was the best thing anyone said to me for weeks) I sat in an uncomfortable room with an uncomfortable doctor, who explained my options.

I could have surgery, be put to sleep and have all the ‘products of conception’ (MY BABY) sucked out. A clean break and a fresh start.

I could take medication which would hasten things along, but I’d have to stay in hospital afterwards, until it was over.

As I already bleeding, I could ‘let nature take its course’ – it would be like a bad period, she said. Then back next week for a scan to make sure everything had gone. I was a veteran of bad periods and tired of the hospital already and went home and waited.

The midwifery quilting bee

‘The quilt began in 2017 as an exploration of intimacy with midwifery students and staff. I wanted us to explore what a woman might have to give of herself during pregnancy, delivery and in the post-natal period. The head of midwifery supported the project, which included teaching staff and students. We worked with our underwear, all worn yet clean. Favourite pants, knickers, and a pair of boxer shorts belonging to the only male student. Displays of wished-for, long forgotten and literal stains, the leaking body. We unpicked them, 3D transformed into 2D, and re-pieced them. All of us mingled together – cotton, silk, polyester, elastic – a proper crazy quilt, and a complete collapsing of hierarchies. All the time we chatted in the manner of what I’ve come to think of as sideways talking. Discussion that often began at the material level, ‘how soft this feels’, ‘how difficult this is to unravel’ and soon moved into deeper territory, the impact of observing a particularly traumatic emergency caesarean section on a first labour ward placement, anxieties around learning to perform episiotomy repairs’ (Wellesley-Smith, 2021, p.57).

The next week was painful. I told my daughter that the baby had fallen out. She drew a picture of me with a fat tummy and a blob on the floor.

All week I wiped myself then examined the paper, and asked myself was that it? Was that lump a head, was there an arm, was that my baby? After one particularly fierce set of cramps and a quick inspection, I told myself that at least it was all over now.

Later that night, at 3 or 4 in the morning or a time when it is not right to be awake, I woke up and vomited so violently that it woke everyone else up. I was bent over with pain, and terrified, what was wrong, what was wrong? This wasn't like a period, the baby had already come away, was there an infection, a rupture, something?

My husband, a doctor with a high threshold for medical worry, said I'd be fine, just hold on until the scan which was later that day. He left me rocking on the toilet, the only position in which I could feel any relief from the waves of terrible pain. His mum, who was staying to help until I got back on my feet told him off LOOK AT HER and made him call 999.

'Jekk fil-qamar tħuf, issaħħan il-guf
If you wander about in the moonlight, the womb will get warm' (Zarb, 1998, p.53).

‘From winter through to summer we met, unpicked, stitched, chatted, worked it – and sometimes us – out, slowly. The backing cloth, an unpicked student uniform, and all of our names stitched at the centre, the space created by the separation of the trouser legs – a symmetry of sorts. It was displayed at the Festival of Quilts in 2017, the group’s male midwife bearing witness.

But it’s a tricky thing, this quilt made of underwear; laughable, embarrassing, amateurish’

(Wellesley-Smith, 2021, p.57).

In one of his essays on conceptual writing, Derek Beaulieu draws attention to what he describes as masculinist tendencies in conceptual writing. ‘Experimentalism (and conceptualism) is frequently criticised as a male-dominated field where the author’s works are judged not by grace or subtlety but by muscular exertion and literary “heavy lifting”’ (Beaulieu, 2001, p.37). The publications produced by the obsessive transcriptions or vast lists of items or activities can be physically huge, and hard to consider without thought of the effort involved to carry out the mechanics of the process. Writing using sewing shows a feminine side of this kind of phenomena.

The Bayeaux tapestry depicts events leading up to the Norman conquest of England in 1066. The tapestry, which is approximately 50cm high and 70 metres long, comprises of 50 panels which are largely pictorial, but feature text in the form of Latin captions (Bouet and Neveux, 2016).

Contemporary examples of this kind of epic embroidered tapestry exist. The Great Scottish Tapestry depicts the history of Scotland from the Ice Age of 8500 BC, until 2013, when the tapestry was completed. 160 panels were designed by artist Andrew Crummy, and embroidered by over a thousand needleworkers from across Scotland, with each panel taking an estimated 500 hours to complete. The completed tapestry is over twice as long as the Bayeaux tapestry at around 143 metres (The Great Tapestry of Scotland, 2016).

Jen Bervin, in *The Dickinson Composite Series* (2016), documents variant marks from Emily Dickinson's manuscripts, in a series of parchment coloured quilts, embroidered with tiny red plus signs and dashes, and short shaky lines. They represent a complex system of marks used by Dickinson throughout her life which were 'integral to her poetics', however omitted from printed editions of her work and her line breaks often overridden.

There is something appealing to me about the idea of hand crafting as an act of translation. Translating a pattern into an object, the pattern as a map or language, the possibilities of interpreting a pattern in a different way.

The dispatcher said I had to get off the toilet, I was probably about to pass the foetus. The paramedics arrived and they said it, too. At A&E, this time with solid walls around me (she needs privacy) I rocked and moaned and asked for medication. I had been hopeful of some gas and air in the ambulance, but the paramedics had not obliged.

They came back (sorry, sorry, it takes two for controlled drugs) with medication I'd told them I didn't want, I'd had it before when I was in labour and apart from making me drowsy enough for a quick nap, it hadn't helped at all. I went for a wee while they went off to change it, wanting to be comfortable and settle down once the pain had stopped, please make it stop.

I never did get any pain relief because as soon as I sat down their prediction came true. Everything that was left in my womb came out and plopped down into the toilet, a big red turd full of baby. My cervix must have dilated 5 or 6cm to let it pass. The pain and the puking had been a small sort of labour. I recognised it now and told the staff they needed to fish it out, and cried because my baby was gone.

‘This reconstitution of eight different bodies into one also occurs at a site whose most immediate referent is to another intimate space, the bed and threatens to tip the whole thing into the obscene. Perhaps, not wholly unsurprisingly, it has still to find a permanent home on the faculty walls. Yet it has a clear purpose: its legacy. It remains an unfinished thing, regularly used with seminar groups, at the transition between year one and two, at the beginning of the third-year arts and humanities module, at the International Day of the Midwife. Its continuing openness offering a way in, to come ‘to the table’, to share thoughts and ideas, find someone who might listen. Find and unmarked corner, trace a thread, leave a mark, bring the singular into dialogue with the multiple’ (Wellesley-Smith, 2021, p.57).

I am stitching.

Tilleke Schwarz works with embroidery to produce pieces which have been reminiscent of poems.

Schwarz's works are disjointed collections of small pictures and short pieces of found text, which are often mundane, for example, *Unfollow* (Schwarz, 2012) features words copied from the side of a coffee cup. The pieces show a kind of fractured narrative and combine embroidered, loose line drawings with neat cross stitch motifs. In September 2016 I attended a two day workshop with Schwarz, *Space (in your mind) for a new plan.* She spoke about her own practice, demonstrated her techniques including couched lettering, and took us through drawing and making exercise which led to a blueprint for future textile piece.

The Kendal Friends Meeting House is home to another modern tapestry, the Quaker Tapestry. Completed in 1996, it is notable for being sewn by a community of over four thousand men, women and children in fifteen countries. It uses a mixture of images and text to show Quaker events and insights across 77 panels (Greenwood, 1990).

Textile artist Aled Lewis reproduced the story of the first six Star Wars films, in a ten metre long homage to the Bayeaux tapestry. Rather than Latin captions, the tapestry is bordered with words in Aurebesh, a fictional language from the Star Wars galaxy (The Guardian, 2014).

A month later, when I was just strong enough to return to work, my GP phoned, sounding flustered and upset ‘I’m not sure I should say this on the phone. I’m not sure it’s right. I’m not sure whether I should I say this on the phone, the hospital’s been in touch...’

What now what now what now what now what now? ‘I’ve had a call from the hospital. From the obstetrician.’ What now?

‘He’d been called by the pathologist. They found your baby in the fridge. They need to know what to do with it. They can’t do anything. Because of Alder Hey.’

I am stitching together little pieces of myself.

Nobody knew what I *could* do. I phoned the hospital and got transferred from department to department, they were all very sorry, all very kind and all mentioned Alder Hey.

In 1999 it emerged that various organs had been removed from children during post-mortem examinations at Alder Hey Hospital in Liverpool, without the knowledge or consent of parents (Bauchner and Vinci, 2001). Because of guidelines put in place following the scandal, the hospital needed my permission to do anything with the remains of my pregnancy. However, nobody knew what could be done, or how I should arrange it.

There is potential for this kind of textile to be used for a more personal history. Esther Nisenthal Krinitz, a Jewish woman who grew up in Mniszek, Poland, created a series of 36 embroidered panels telling the story of her childhood and survival of the Second World War (Nisenthal Krinitz and Steinhardt, 2005). Scenes such as a death camp for Jewish boys are illustrated in pretty appliqued pictures using homely fabrics and decorative stitches, which seem at odds with the subject matter. Esther Nisenthal Krinitz's family have established a non-profit based arts and educational organisation, *Art and Remembrance*, which uses her textile art as the basis of various programmes designed to teach children about the Holocaust and to promote compassion and creativity (ibid).

A further example of the use of textile images to illustrate distressing scenes can be found in arpilleras, a traditional South American textile made from burlap and scrap fabric, featuring everyday scenes, padded figures and small found objects. During the Pinochet dictatorship in Chile, 1973 – 1990, arpilleras depicting scenes of traumatic events, such as funerals and torture, were sold by women and smuggled out of the country, raising awareness of their situation around the world.

> ‘Textiles that were originally only created as works of folk art in the Chilean countryside, became an outlet through which impoverished women in Santiago both shared their experiences with each other and described those experiences to the rest of the world’ (McCracken, 2011, para.1).

Somehow, I met up with a bereavement specialist midwife, who looked after women that had experienced a stillbirth. She fitted me in at the end of the day so I could pop across from my ward to her office in the Maternity Unit. She smiled at me benignly, told me that she usually looked after ladies who had been further along and I could feel that I was taking her away from women whose losses were greater than mine. She listed my options, a bit like that doctor had, they could put the baby (I think she was the only one who actually called it a baby) in with the clinical waste, but separately, respectfully. Or I could have it back, to do whatever I wanted with it. Some women liked to plant a tree, or have a little funeral in the garden. A proper funeral was usually for the babies who were older, stillborn not miscarried, but I was welcome to include my baby in the mass cremation and service that they held, then the ashes could be scattered on the communal garden of remembrance. Was it called that? I think it was called the snowdrop garden or something. It was something twee that I can’t remember.

Author Tracy Chevalier collaborated with Fine Cell Work to create the Sleep Quilt. Chevalier commissioned the work for her exhibition *Things We Do In Bed* (2014). Each prisoner created a ten inch square, appliqued and embroidered to reflect their feelings about trying to sleep in the prison environment. These blocks were then joined with sashing, quilted and bound into a single, large quilt measuring 7x9 feet (Chevalier, 2018, p.38).

Whilst people living with a diagnosis of dementia or who have difficulty with writing, may struggle to participate in similar projects with the level of independence shown by the prisoners, with support a person could make a block with a few words on an individual yet universal subject, to be included in a larger whole.

The only thing was, the cut off for the mass cremation was tomorrow so she'd have to know today (was that true? Did she want to get me out of her office so she could get back to the woman she'd told me had just had stillborn twins? Could I hear the woman weeping or was that me?) There was no time to discuss it with my husband. I'd have to sign something and give her a name and then it could be included. I could attend if I liked. What name should she put? I didn't even know what sex the baby would have been. We hadn't discussed surnames. I'd kept mine the same as my daughter's when I'd married again. I told her the baby was called Toby Campbell-Davies and it felt like a lie.

I am stitching together little pieces of myself.

Creative Outputs and Analysis

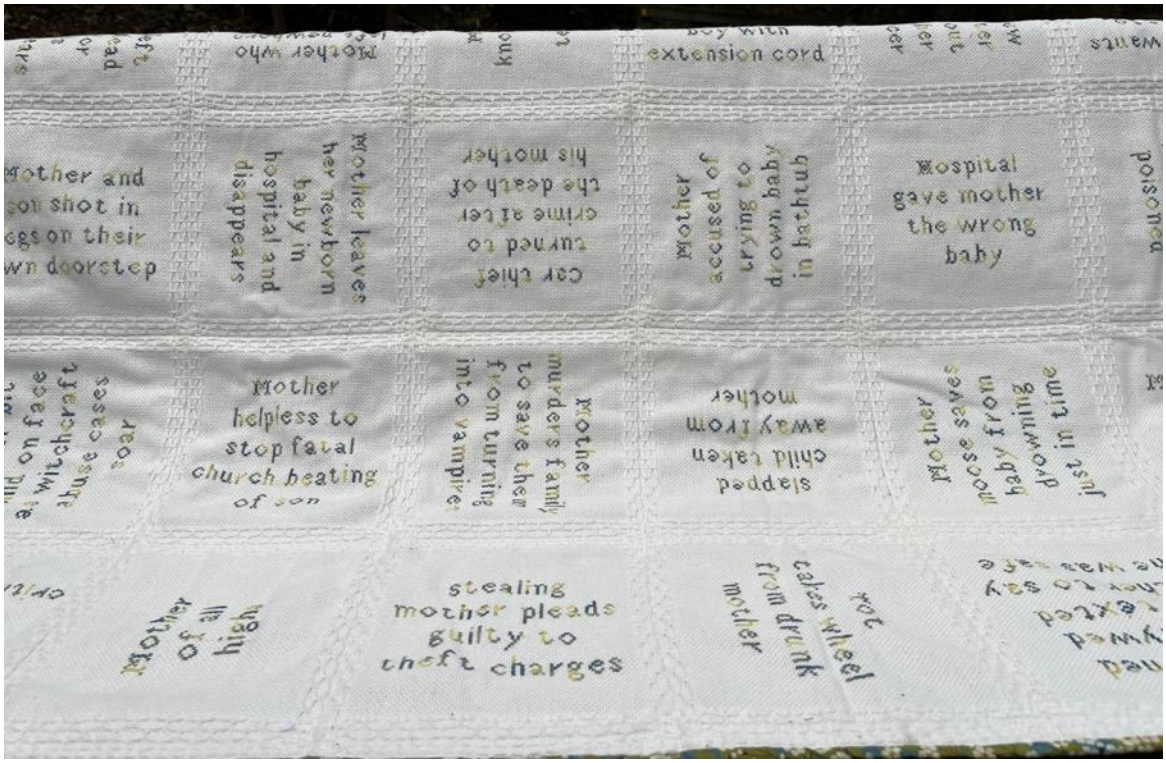


Figure 8: Mother Love

Figure 9: detail, Mother Love

Figure 10: detail, Mother Love

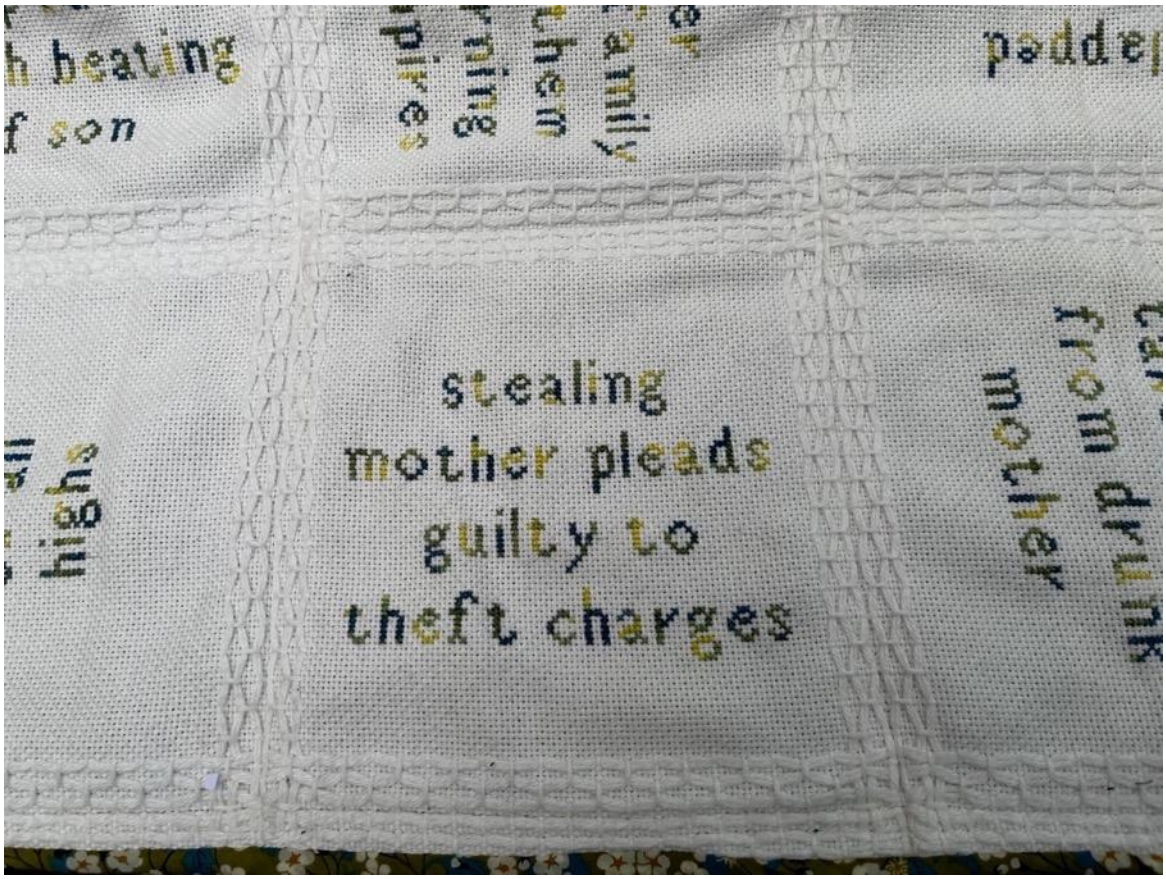


Figure 11: detail, Mother Love

Mother Love

‘Confession as a desire to shock – the memoir as a screaming tabloid headline.’ (Morrison, 2015, pp. 206-211)

Cross stitched afghan with variegated embroidery thread. Liberty print binding. Velvet backing. Machine quilted.

Mother Love is the only piece in the collection which would be of practical use as a blanket.

The cross stitch ‘typeface’ is transcribed from Elizabeth Parker’s sampler (Parker,1830). I created my own pattern using close-up photographs of her work. This offers a connection to this piece’s sampler heritage, both in the appearance of the text and the typical practice of sewing a sampler by copying alphabets and other patterns instead of creating new ones.

The text is taken from newspaper headlines featuring the word ‘mother’, taken over a month and stitched as a daily writing practice. The afghan which provides the base for the quilt top doesn’t quite have space for a whole month – only for 28 days – but this is a resonant number for a work about women.

The headlines are unaltered and taken from all over the world. I was struck by the invocation of motherhood to add weight to the stories. Tragic events were painted as being more tragic when a mother was involved, conversely, mothers were judged more harshly for their sins.

The afghan is backed with olive velvet. I had purchased the velvet intending to use it to back a quilted throw I was making to cover my new sofa, after separating from my husband. I really wanted a green velvet sofa, but with three children who were still small enough to be sticky, and a big dog, a velvet throw seemed like a sensible compromise.

The quilt I made for the other side of the throw was apprentice work. I lacked the proper rulers and cutters, and the experience to piece it all together. There were holes where the blocks refused to match up, it stood no chance against the rough and tumble of a family. So, over a decade later, I’ve never quilted it and the sofa remains naked.

Velvet is not a good backing for a quilt, the fabric is too thick and heavy for quilting stitches to easily pass through. It makes *Mother Love* feel heavy, but that feels right underneath the weight of the words.

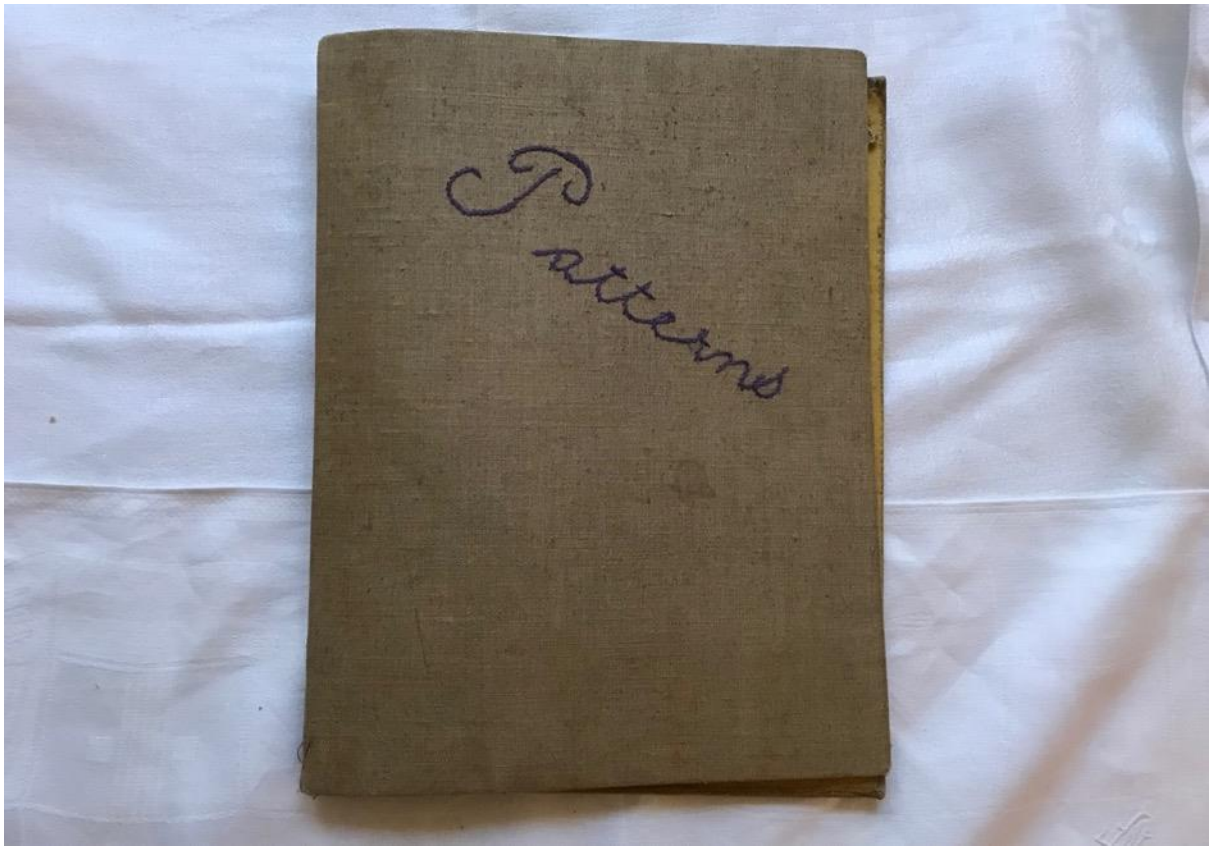


Figure 12: book of lace samples

Figure 13: inside cover with handwritten name and address

Figure 14: detail, 15, Gambier Terrace

Figure 15: 15, Gambier Terrace

15, Gambier Terrace

‘I wouldn’t dream of suggesting that I am offering a factual life of anyone, apart perhaps from myself – and there is nothing so unreliable or delicious as one’s rackety memories of oneself. Some of my recollections may be tainted by time or others’ slanted tellings or photographs, and my memories are no more and no less likely to be precisely accurate than yours or hers. I’m saying only that I was there, or was told first hand, and have remembered things thus and so, which might make what I recall a mite closer to the facts of the matter.’ (Diski, 2015, p.13)

Deconstructed lace sample pattern book with original pins and paper tags. Silk and linen. Liberty print binding. Machine pieced and hand quilted.

The main fabric of *15, Gambier Terrace* is taken from a book of lace samples. The book itself is handbound, with hemmed silk pages used to showcase lace samples. The maker's name is at the front of the book: H. S. English.

I have no idea of the age of the book. When it arrived it was filthy, thick with years of ingrained dirt that made me feel ill when I opened it. The pages needed washing and sympathetic restoration. The book was slightly unfinished, with some of the original pins still in place. I could sense the hand that made it – there was a feeling of process, not just a perfect finished piece. Not all the lace was securely attached, I have tried to improve the integrity of the pages without changing their character.

The book holds a history which I haven't been able to uncover. I can't find any evidence of the maker. When I researched the address, I discovered that John Lennon, of The Beatles, once lived on the same street, at number three.

The found texts, with words which describe different stages of womanhood (girl/woman/grandmother) were selected to illustrate the changing nature of identity throughout a life. The use of fairy tales offers a link to the childhood stage and alludes to judgemental tropes of women who appear in these stories. The pages which form the blocks offer a personal history of somebody else's making practice. This person is only known to me as a name and address, and through the work in the sample book. The pages situate my own work within wider traditions of making and beg the question, how are we remembered?

Figure 16: child's sewing kit with thimble, threads and sewing samples

Figure 17: To Be A Gerbil

Figure 18: detail, To Be A Gerbil - doll's handbag and sewing kit items

Figure 19: detail, To Be A Gerbil, horse panel

To Be A Gerbil

‘If a child, especially a boy, sleeps beneath a quilt displaying a pattern known as Wandering Foot, he will leave home never to return’ (Harding, 1987, p.62)

Sampler, haberdashery and doll’s items, from child’s sewing box. Primary school textile collage artist’s own. Miniature samplers, embroidery thread on evenweave, Linen. Backed with ‘Depression’ orphan quilt block made with Holly Hobbie print fabric. Liberty print binding. Machine pieced and hand quilted.

To Be A Gerbil is a collaboration through time, between me, my childhood self, and other, unknown children.

I made the horse panel at school, when I was about eight years old, but never finished it. There are hardly any stitches holding on the appliqué pieces, instead it is held together with rusty pins. I can't remember why I wanted to sew that particular scene. I was never one of those little girls who liked ponies and horses.

The panel is embellished with wishes from letters to Jim'll Fix It, transcribed from old episodes. A couple of years before I started sewing the horse, my entire class had written in to Jim (I asked to shoot J. R.) but nobody was chosen.

Other panels show items from a child's sewing kit, which contained miniature samplers (initialled M. B.), thread, needles, buttons, poppers and tiny accessories which were probably made for a doll, all housed in a little suitcase. I wonder what the child who owned it wished for.

The four remaining panels feature my own exploration of miniature samplers, using Victorian monograms and motifs (from patterns of the era), as a starting point for their wordplay.

The quilt backing features an orphan block – a single or leftover block that doesn't form part of a larger piece. The idea of a hidden orphan, in a quilt full of childhood hopes and disappointments, was irresistible.

The horse collage presented me with an opportunity to repurpose a forgotten piece of my own childhood. I have no recollection of what I felt or thought about this horse at the time of its making, so only the physical remains of it are left for me to work with. My connection to it is almost as superficial as my connection to the sewing artefacts belonging to another child, which are incorporated into the quilt. I wonder if these artefacts were precious, or if their owner had any recollection of them at all.

Figure 20: Broken Dishes

Figure 21: detail, Broken Dishes

Figure 22: detail, Broken Dishes, monogrammed table linen

Figure 23: detail, Broken Dishes

Figure 24: detail, Broken Dishes

Figure 25: detail, Broken Dishes

Broken Dishes

‘Of course you wouldn’t dare to find a husband for yourself. He has to find you. I hear them say that the face which is kept hidden away is as valuable as gold, and the man who wants you will find you, even under the bed...’ (Zarb, 1998, p.158).

Vintage table linens and linen fabric, with Liberty print binding. Sashed letters. Machine pieced and quilted.

This piece uses the Broken Dishes quilt block as its starting point. The blocks are partly made from table linen, donated to me by my ex-colleague and friend, Jeanette. As I started my PhD, Jeanette's mother died from dementia. The linens were in her belongings, and her gift of them to me adds poignancy to the piece. The monograms on the linen show in the finished quilt.

The block letters were another gift. Claire, a friend I met at the Dementia Café, at the University of Salford. After I'd visited the café to show my work, she had seen them in a charity shop and thought of me. The letters are from a vintage children's game. Their limited number placed restrictions on my ability to write with them. It was an interesting puzzle for me to form as many words as possible from them.

The name *Broken Dishes* has connotations of domestic violence and the words formed from my restricted palette of letters were chosen to echo this.

The quilt is an awkward, long, thin shape. It is almost a table runner, a repurposing of all those table linens, but the letters stop it from being flat enough to function. A glass placed onto its surface might topple and break.

The true story of this quilt is not one of broken things but of a women held up by her friends.

Figure 26: Fidget

Figure 27: Fidget

Figure 28: detail, Fidget

Figure 29: Fidget

Fidget

“Think for a moment about all the thoughts you have had in the past ten minutes – let alone all day. Even while reading you have probably thought about other people, remembered things you meant to do, made plans for later in the day, or (I hope) pursued ideas sparked off by the book. Most of these thoughts will never be thought again. You will not pass them on and they will perish” (Blackmore, 1999, p.37)

Upcycled fabrics. Buttons, ribbons, fastenings. Crochet rosette. Children’s toy.

Fidget features no text and is offered as an act of making rather than writing, a kind of curio which has informed the other pieces.

Fidget quilts are small lap quilts designed to comfort and occupy restless hands. They provide sensory stimulation to people living with dementia, with colourful embellishments, fastenings, and fiddly bits.

I made *Fidget* as an experiment, from parts of abandoned or unsuccessful projects. Its making consolidated my desire to use texture in my work, and the other pieces have echoes of techniques used in the fidget quilt within them.

Some of the textures in the other quilts are unpleasant. Crunchy fragments of paper, rusted pins. Touch is not always welcome.

Figure 30: What Great Teeth

Figure 31: detail, What Great Teeth, vintage embroidered napkin

Figure 32: detail, What Great Teeth, vintage embroidered napkin

What Great Teeth

‘If you accused me of **embroidering the truth**, you would mean that, though not quite perhaps lying, I was certainly adding a good deal of exaggeration and invention to what I was telling you.’ (Kapp, 2007, p.32)

Vintage hand embroidered napkins, reverse appliqued using modern floral fabrics. Machine pieced and quilted.

What Great Teeth uses a technique called reverse appliqué. Usually in appliqué, fabric shapes are stitched on top of a base fabric to decorate it. In reverse appliqué, shaped windows are fixed to the top of a base fabric, allowing elements of it to show through.

Behind the windows are a set of vintage hand embroideries, featuring flower baskets, songbirds, and fruit. The top fabrics are modern but based on designs from feed sacks. In 1930s America large flour and grain sacks were made in pretty cotton prints and used by thrifty mothers to make quilts and children's clothing. The windows both reveal and conceal the embroidery underneath, while forming bold letters reminiscent of those on a placard.

'Children, especially attractive, well bred young ladies, should never talk to strangers, for if they should do so, they may well provide dinner for a wolf. I say "wolf," but there are various kinds of wolves. There are also those who are charming, quiet, polite, unassuming, complacent, and sweet, who pursue young women at home and in the streets. And unfortunately, it is these gentle wolves who are the most dangerous ones of all.' (Lang, 1889, p.53)

Figure 33: Toyland

Figure 34: detail, Toyland, vintage children's fabric

Figure 35: detail, Toyland, vintage children's fabric

Figure 36: detail, Toyland, embroidered text beneath chenille

Figure 37: Figure 32 - detail, Toyland, vintage children's fabric

Toyland

‘Her art gives pleasure to the eye and to the mind and to the touch, if only one were allowed to touch. One wants to feel the braid and nub, to finger the frays and proud threads, the tightness and looseness and differences between It its part, but mostly all this is in the imagination. Sensuality – bordering on the sexual – and geometric rigour, variety and similarity (pleasures that demand being repeated) infuse the work of a lifetime in Albers’ show.’ (Searle, 2018, online)

Vintage Children’s fabric, including Noddy, Rupert the Bear, Holly Hobbie and cowboys. Hand embroidery with chenille. Liberty print binding. Machine pieced and quilted.

Toyland is a further experiment in the art of concealment, with embroidered text hidden under strips of chenille. It is impossible to read the text without touching it. Shaped like a baby's playmat, and composed from children's fabric, the quilt has a playfulness which invites you to handle it.

Fragments of text from a Rupert the Bear story are visible in the patchwork. Every Christmas I'd get a Rupert annual. I don't remember any of the stories, I was too captivated by the instructions for origami items, which sparked a lifelong love of the hobby.

Noddy, Holly Hobbie and cowboys make an appearance too. I would have liked to find fabric with the Woofits or Little Grey Rabbit.

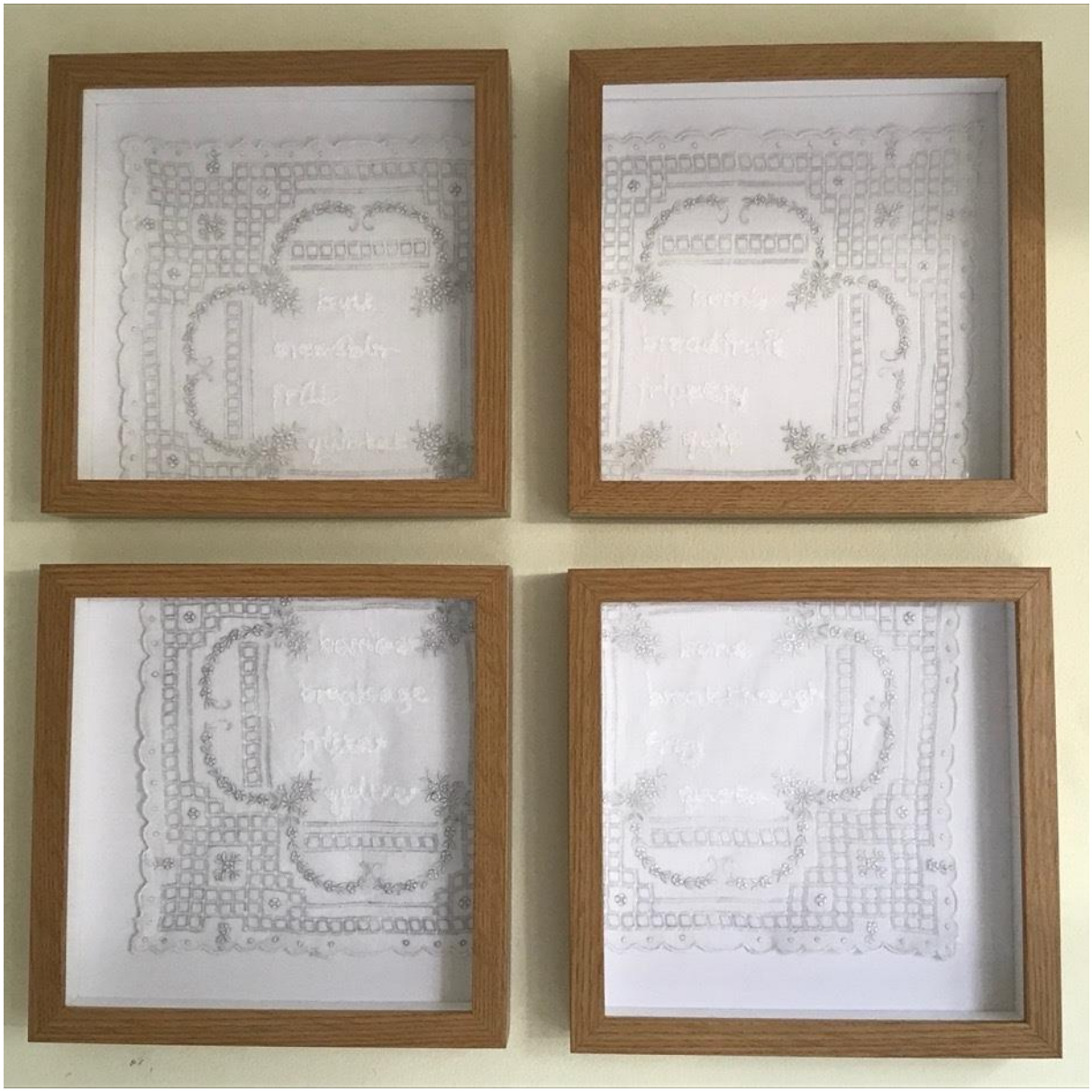


Figure 38: Tie A Knot

Figure 39: detail, Tie A Knot 1 (top right)

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Figure 40: detail, Tie A Knot 1 (bottom right)

Figure 41: detail, Tie A Knot 1 (top left)

Figure 42: detail, Tie A Knot 1 (bottom left)

Figure 43: detail, Tie A Knot, 2 of 4

Figure 44: Tie A Knot, 3 of 4

Figure 45: Tie A Knot, 4 of 4

Tie A Knot

‘To patch or piece together suggests collecting information or things, an act of investigation. A patch can be a scrap or a remnant: a piece of material, a computer key, a torn item of clothing. Patching can also mean to mend, join together, or connect.’ (Robertson, 2014, p.2)

Sequence of vintage handkerchiefs hand embroidered. Mounted and framed.

This sequence of poems features a selection from my collection of vintage handkerchiefs.

I love the symbolism of handkerchiefs. The idea of tying a knot in one to help you remember or making a sunhat out of a hankie on the beach. I think of Desdemona's handkerchief and her downfall, of women embroidering hankies to send in courtship. Handkerchiefs can be symbols of hope or be full of tears. (One of these handkerchiefs came complete with an antique bogey which rehydrated horrifically when I washed it, these handkerchiefs have stories to tell).

The starting point for these texts were words from speeches made by Donald Trump, during his presidency. The words have been heavily manipulated until signs of their origins have been erased. To treat the words, I used techniques from Oulipo (Ouvroir de Litterature Potentielle or Workshop of Potential Literature) and computerised text manipulation gizmos from https://www.languageisavirus.com .

These handkerchiefs are extremely fragile and thin, a nightmare to sew. The fabric does not want to bear the tension of the stitching through it. Because the thread is thicker than the fabric, the backs of the stitches are visible through the front, creating strange, doubled lettering which is difficult to decipher – a bit like the original speeches.

Figure 46: AprOn The Fire

Figure 47: detail, AprOn The Fire

Figure 48: detail, AprOn The Fire

Figure 49: detail, AprOn The Fire

AprOn The Fire

‘SHE LOOKED AS IF THE DEVIL HAS CHASED HER THREE / TIMES THROUGH THE FLAMES OF HELL FIRE AND TURNED OUT / THIS HIDEOUS WILD BROWN EYED OLD WOMAN DIED ABOUT / TWENTY ODD YEARS AGO THIS VILE HEMAPHRODITE OLD / HAG WOULD BE NEARLY A HUNDRED YEARDS OF AGE’

Lorina Bulwer sampler transcript (Fleming, 2014)

Mid 20th Century apron. Cross stitch and freehand embroidery.

Taken at face value, the act of throwing your apron onto the fire seems akin to burning one's bra, a defiant statement of liberation.

The text which features on *AprOn The Fire*, is cut from an old version of Little Red Riding Hood by Charles Perrault (Lang,1889, p.52). Older versions of this fairy tale are much more sinister than the story I was told as a child.

As well as being instructed to throw her apron into the fire, the grandmother-wolf coerces Red into taking off her clothing piece by piece, bodice, skirt, petticoat and stockings are all burned, with the naked Red forced to climb into bed, naked, with the wolf.

The cross stitch elements on the apron have been created using waste canvas, a starched grid which provides structure to the stitches and then is dissolved by casting it into water – an opposite act to the one it portrays.

The apron itself is well worn and threadbare in places. The ties are short, made for a more girlish waist than mine.

Figure 50: Lovely Rita

Figure 51: detail, Lovely Rita, Maltese lace

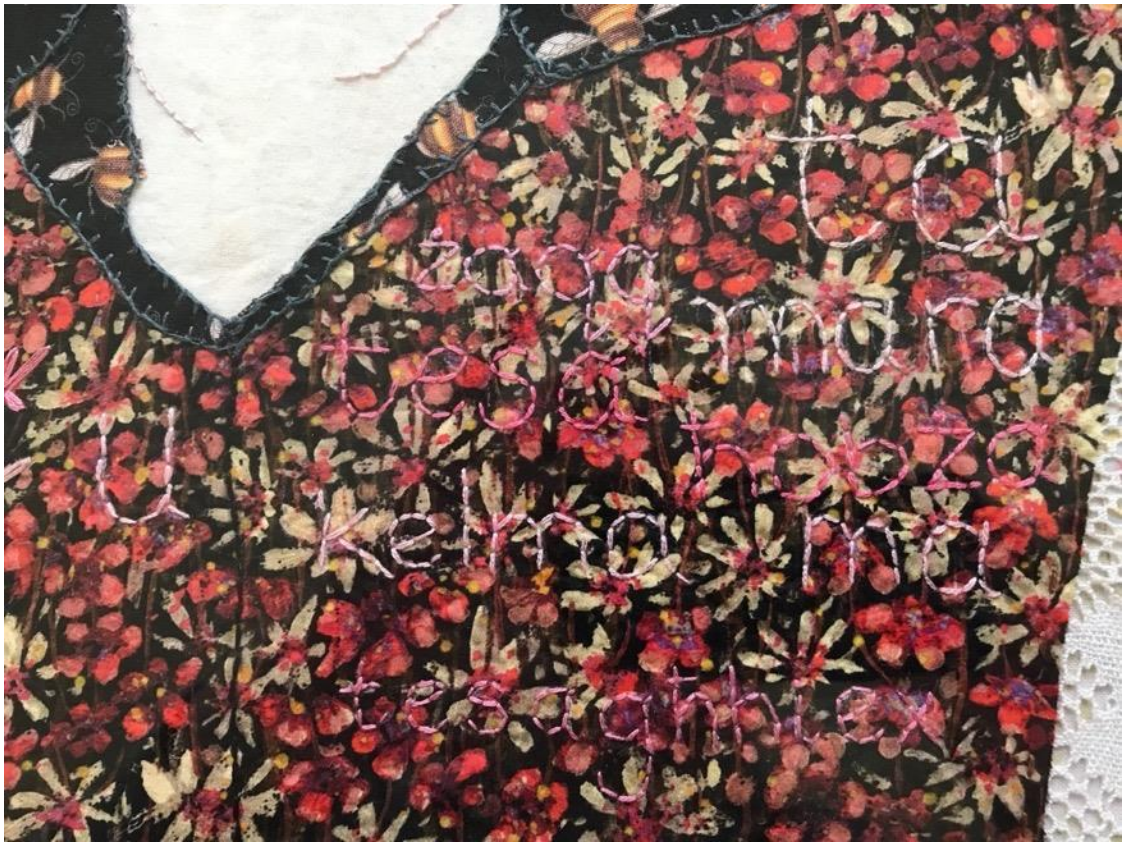

Figure 52: detail, Lovely Rita, text

Figure 53: photograph of Nana in mum's kitchen

Figure 54: photograph of Nana as a young woman

Lovely Rita

‘Memory is not a camera aimed at the past.’ (Basting, 2009, p. 18)

Liberty print and upcycled fabrics. Maltese lace frame. Hand embroidered. Mounted and framed.

I have few photographs of my nana. This portrait is based on a one that was taken in my mum's kitchen. Nana looks a bit surprised, in that nice way when you turn around and don't expect to have your photograph taken.

Another photograph I have shows Nana as a young woman, showing off her fancy dress, and looking like she is about to start dancing the flamenco. I don't know why she was all dressed up.

A third photograph is the opposite of this, one of the last ever photos of her, in her shared room in a nursing home, looking small and sunken and scared.

My mum has a grandly framed photograph of Nana getting married. It's a black and white photo which has been hand painted to add some colour. If you look closely enough, you can see that the tiniest flowers in her bouquet don't really exist. Every single time my Uncle Charlie sees the picture, he jokes that he is in it.

The lace 'frame' within the portrait is made from a piece of traditional Maltese lace. Malta has a strong lacemaking history (unlike Liverpool). I am not sure of the original purpose of the lace, other pieces I have are shaped like coasters or collars. It is shaped like a frame, but the bottom edge is gapped so it wouldn't normally function as one.

The Liberty print stripes in the background were made from fabric donated by my friend Sue, who I've known since we were student nurses together. She invited me over to go through her stash and look at some linens that her grandmother had left her. She offered me a carefully wrapped package of precious handkerchiefs, but screamed at me in horror as I went to open it. 'No, no, NO! You'll let all the goodness out!' I knew exactly what she meant.

There are not many words in *Lovely Rita*. Nana never seemed to have many words. She didn't tell me her stories or her recipes, but I know how to say 'I love you' in Maltese.

Figure 55: Home In One Piece

Figure 56: Home In One Piece

Home In One Piece

‘All these people have their own opinions about democracy today and I thought carefully about the words they should stitch. For instance, Baroness Warsi, Eliza Manningham-Buller, Julian Assange and numerous prisoners have all stitched the word ‘freedom’, but all have different relationships to it’ (British Library Press Office, 2015, online).

Linen and assorted modern fabrics. Couched lettering. Machine pieced and quilted.

Home In One Piece was inspired by social media discussions about women's safety, following the murder of Sarah Everard by a Metropolitan police officer, in 2021.

I used the quilt block Evening Star as the base. It seemed a sympathetic choice for a quilt based on the idea of women sending a text, or message, to tell their loved ones they'd arrived home safely after walking in the dark.

The idea of arriving home in one piece called for unbroken pieces of thread. The words are formed using an embroidery technique known as couching. Long sections of floss are manipulated into letter shapes then tethered with tiny stitches of thin sewing thread. It gives a strange kind of 'handwriting' as if one had written without ever taking their pen off the paper.

Inn contrast to the tightly bound letters, the ends of each section of floss have been left free, forming new shapes and interfering with the more deliberate lettering.

The quilt is small and offers little comfort.

Figure 57: Show Your Working, 1 of 3, side A

Figure 58: detail, Show Your Working, 1 of 3, side A

Figure 59: detail, Show Your Working, 1 of 3, side A

Figure 60: Show Your Working, 1 of 3, side A

Figure 61: Show Your Working, 1 of 3, side B

Figure 62: Show Your Working, 1 of 3, side B

Figure 63: Show Your Working, 2 of 3, side A

Figure 64: detail, Show Your Working, 2 of 3, side A

Figure 65: detail, Show Your Working, 2 of 3, side A

Figure 66: detail, Show Your Working, 2 of 3, side A

Figure 67: detail, Show Your Working, 2 of 3, side B

Figure 68: Show Your Working, 3 of 3, side A

Figure 69: detail, Show Your Working, 3 of 3, side A

Figure 70: detail, Show Your Working, 3 of 3, side A

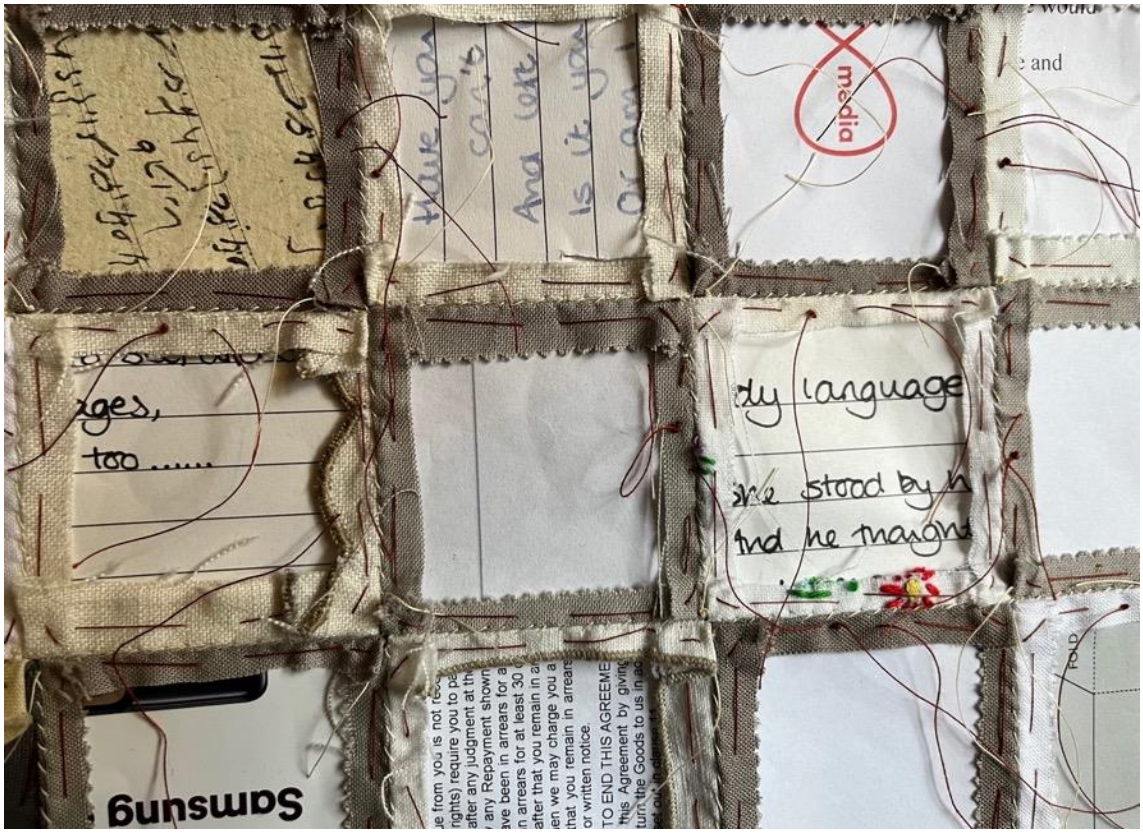

Figure 71: detail, Show Your Working, 3 of 3, side A

Figure 72: detail, Show Your Working, 3 of 3, side A

Show Your Working

‘When my students can’t write I tell them to think of themselves as builders: as designers. I tell them they can draw the story out on a whiteboard, or fold it out of paper.’ (Ashworth, 2019, p.170)

Show Your Working is a triptych of nonsense, formed from three impossible, uncomfortable things.

The pieces were made in tribute to the 1718 Coverlet, the oldest dated British patchwork coverlet. Paper templates used to shape blocks in the coverlet remain, and feature printed and handwritten texts which could only be read using a technique called transmitted light photography. (Briscoe, 2014, p13).

The triptych is symbolic of the journey through time. Each piece has a different colour palette to represent this and accumulates different kinds of paper. The fabric- only sections were influenced by the idea of asemic writing, with pixels making patterns and not-quite-letters that have no meaning.

Some of the paper is handmade Nepalese cotton paper, made from rags, as close to fabric as it is to paper. Other include vintage ledger paper, credit agreements, junk mail and pages from my childhood books. In my box of things from the attic is a book of the first poems I ever wrote. Terrible teenage things that I wrote down neatly in fountain pen in a notebook that has travelled with me from house to house ever since.

I remember so clearly how I felt when I wrote them. I cried when I read them, to think of how miserable I was then. Including them was a struggle. Writing them made me feel better, but they were never meant for anyone else.

Some of the paper pieces are covered in pieces of linen that were donated by my friend Kirsten. They were tray liners and doilies for a dressing table, hand embroidered with cheerful flowers by her grandmother. They were well used and covered in stains.

With the paper left in, there is no seam available to attach to the other fabric. The pieces can’t be quilted, or lined, without covering the text. Each piece is double sided and appears to be inside out. In bright enough light the text on the back of the papers can be seen through the fabric. There is nothing to grab hold of, They are flimsy, bodiless things, that do not want to be hung.

Figure 73 - For Better, For Worse

Figure 74: detail, For Better, For Worse

Figure 75: detail, For Better, For Worse

Figure 76: wedding photograph of my grandparents

Figure 77: wedding photograph of my parents

For Better, For Worse

‘It often happens that we count our days, as if the act of measurement made us some kind of promise. But really this is like hoisting a harness onto an invisible horse.’ (Nelson, 2009, p37)

Wedding dress with appliqué motifs and hand embroidery.

Finishing the collection with a wedding dress is kind of a private joke with myself. I was drawn to the idea of finishing a collection with a wedding dress, as fashion designers often do. The biggest and most complicated sewing project my mum ever undertook was making her own wedding dress. A traditional, voluminous dress pushes the limits of what can be achieved on a domestic sewing machine.

My marriages (three now, I am nothing if not optimistic) have been the biggest flashpoints for transformation in my own sense of identity. In fairy tales, the heroines get married and live happily ever after, freed from domestic drudgery, and elevated to the status of queen. In my own life I have found the opposite to more often be true.

The text is taken from an Arts and Crafts tile panel, *Cinderella* (Morris, Marshall, Faulker & Co., 1863). It is on display in the Walker Gallery, Liverpool, a regular haunt of mine when I worked in an office just around the corner.

The wedding dress is not precious. I gave my own to a charity shop hoping that it would make somebody happier than it made me. The fabric I have used in the appliqué figures, however, is very special to me.

The bride wears silk taken from a dress that was handmade for my nana when she lived in Singapore. My mum kept it and sometimes let me dress up in it when I was little. The groom's suit is also made of memories of dressing up. The floral fabric is taken from an old dress belonging to my mother, a seventies affair with a tight bodice and flared skirt and sleeves. I once wore it in a play, when I was a teenager into amateur dramatics. Both dresses were always in the wardrobe at home, ready to be admired and reminisced about. It took me a long time to take the scissors to them.

The bride's veil is made from ribbon from decorations I made for my own wedding. When I started the PhD I hadn't even met my husband. That's the private joke part. Once again I am transformed. There is no motherhood this time, but I am now a stepmother, cast as a different character in the fairytale.

The visual style pays homage to Lorina Bulwer, and brings me full circle to the work which gave me the idea of writing using textiles in the first place.

Figure 78: photograph of the author as a young maiden

Figure 79: photograph of the author as a nursing student, circa 1993

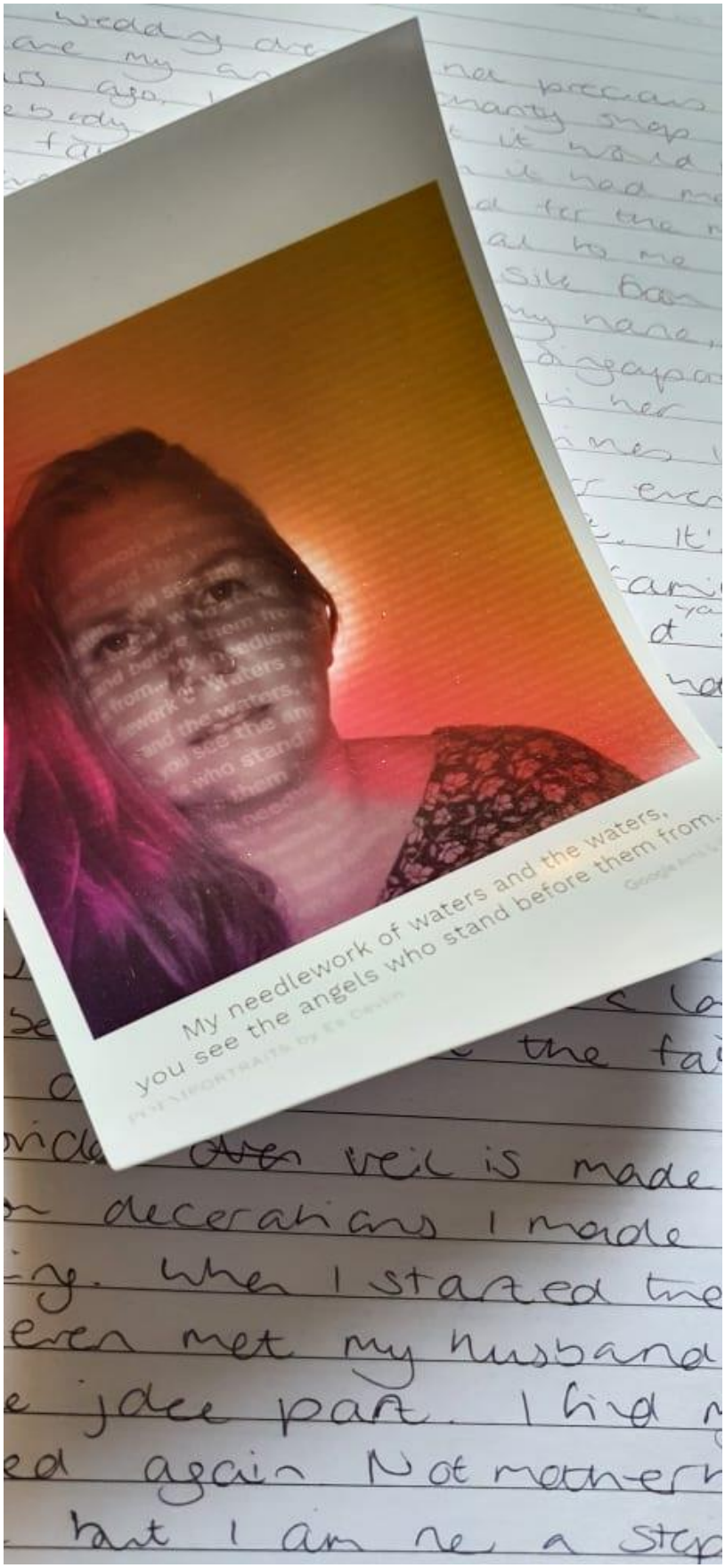

Figure 80 - PoemPortrait of the author

Conclusion

I was an experimental writer before I had ever heard of experimental writing. When I first began studying creative writing, with the Open University, I often managed to perplex my course mates with my writing. One fledgling poetry experiment was written with fridge magnets, using only one of each letter of the alphabet. Nobody could understand why. At that stage, I didn't understand why myself.

Perhaps it was inevitable that I would make my thesis in an experimental way, its patched together, fragmented form making visible my ideas about writing autobiography and constructing my own identity. In this way, I hope this thesis can contribute to the need for 'exploration and experimentation in how and what we produce as research outputs' (Atkinson and Hunt, 2020, p.3). Finding ways to make experimental praxis and academic research weave together has been difficult. It creates tensions, knots and contradictions that are often hard to resolve.

Writing in this way has been easier than taking a conventional approach, but it has not been easy. Autobiographical vignettes were simpler to disrupt than a flowing discussion about other people's research projects. The presentation of my written work in patches of text mirrors my textile practice, purposely disrupting existing texts and bringing them into conversation with new material. The experience of reading this can be dislocating, as the conventional flow of text from one theme to another is broken. Reading in this patchwork form is like wandering from one idea to the next, sometimes with diversions along the way. It invokes the feeling of navigating a conversation that is not always logical and coherent. This marks a departure from the linearity of conventional thesis writing, to instead explore more experimental approaches to creating research.

I have used my textile autobiography as a different way of writing, using a fragmented, experimental approach at odds with more conventional understandings of life-stories as a resurrection of the past. Machado's (2019) metaphor of the memoir as a malleable clay ball, formed from braids, does not leave room for gaps or holes to exist and implies the ability to assemble a

coherent whole. There is no room for ‘not-knowing’ (Flint, 2004, p.152). The textile autobiography is pieced together in two ways, in the making of each individual piece, and in the coming together of the various pieces to make a linked sequence which does not claim to represent a whole. The textiles themselves are storied. Quilts have their own language, in the style of their blocks, their layout and the choice of fabric colour. Reading them is an active process which requires the viewer to decode this language. Vintage pieces invite questions about their previous owner, hinting at personal histories which are distinct from my own.

Throughout the writing of this thesis, in sewing and on the page, I have had to confront the question of what I want to be known about my personal history. The spectre of a future audience has at times inhibited me when writing the critical thesis, but has had a lesser impact on my sewn autobiography. By combining mundane phrases or scraps (such as pieces of junk mail) with materials or texts of great personal significance, a flattening of emphasis occurs as all the materials are presented equally. Their significance becomes ambiguous and no particular attention is drawn to more difficult elements.

I am more present in my textiles than I imagined I would be. As with Dutton’s *Dementia Darnings* (2017), when viewing my textiles, I find it impossible to not view them as embodied records of the hours spent making them, or as an expression of myself as a writer and maker. Each pieced together fabric, each embroidered stitch, all these things made with my own hands.

Anne Basting’s approach avoids difficult memories, bypassing reminiscence and memoir altogether. Basting believes the personhood of the participants is allowed to shine through in their imagination-based contributions instead. There is opportunity for a person to talk about themselves but no pressure to do so. I wonder though, how present the person is in the finished story and whether they are more visible in those projects which further develop the stories into plays or performances and include the storytellers as performers. In my textile practice I avoid using imagination-based writing in favour of found texts and existing stories, which position me in relation to the society and culture around me. This is a decentring of the self, a move towards a more relational understanding of

autobiography (Eakin, 2019). The combination of found texts and more personal personal elements enables me to present different versions of myself in which I am both present and absent, known and unknown. The use of familiar stories, poems or songs as a basis for writing can also provide a point of connection for people living with dementia. The presence of fragments of familiarity in a finished piece remind me of the way my nana communicated, singing the same song between snippets of conversation.

arthur+martha's Stitching the Wars (2017) project allowed hundreds of participants to share their experiences of living through the wars, in small groups. Experimental writing techniques were used to transform memories into poems which were then embroidered onto the quilts. The quilts form a chorus of collective memories. This approach is an excellent example of using textiles to the stories of people who are living with dementia. However, I believe that patchwork quilts offer an ideal opportunity for the individual voice to be recognised within a greater whole, as in Chevalier and Fine Cell Work's *The Sleep Quilt* (2014), which joined individual blocks created by a single maker, into a whole quilt. Just as Killick's (2004) one-to-one approach honours the individual, an approach which preserved each individual contribution, whilst placing them in (literal) connection with other contributions would promote a greater sense of selfhood in the finished piece.

Marchant's dance movement psychotherapy offers a novel creative approach with few barriers to participation. Her lists of observations remind me of list poems and could be the basis for creative project themselves. Her experience highlights not only the difficulties of working with people with advanced dementia but also the possibilities. Marchant's work demonstrates that it is still possible for people to engage with music even after they have lost the ability to be participate in songwriting activities. This ethos of participation will inform my future practice in therapeutic settings. I believe that the tactile nature of the sewing process means that people can engage with fabric and other textile materials, even if they can no longer co-create using them.

McNicol's (2020) process involves collaborating with people with dementia to write and draw a comic, supported by dementia advocates as well as a supporting

artist. This offers a model for future projects which champions the input, and wellbeing, of participants. The resulting comic is accessible for people who are living with dementia and has had wide distribution to caring agencies. The comic differs from other creative approaches since it acts as an educational resource, offering practical solutions to people who have been newly diagnosed with dementia. In doing so, this project prioritises accessibility and educational value over aesthetics or entertainment. Comic books have great potential for telling more broken stories, like *Aliceheimer's: Alzheimer's through the looking glass* (Walrath, 2016) and *Tangles*: *A story about Alzheimer's, my mother and me* (Leavitt, 2010), and I would be very interested to replicate McNicol's model of working, to co-create a comic with sewn and collaged elements which explores and the changing nature of identity in the lives of people living with dementia.

In light of my intention to implement my approach in therapeutic settings, it is necessary to reflect upon whether the process of writing and making has been a healing one for me. I know that it has changed me. My understanding of myself and of the way in which I represent my own identity is greater than when I set out. Things are now known to myself and others which weren't known before. Blind spots and secrets remain but I have experienced an increase in self-awareness and perhaps, despite my cynicism towards approaches favouring catharsis, some relief at getting things 'off my chest'.

However, the work has also been isolating, with many hours spent solo, engaged in the slow business of sewing. One advantage of this slowness is a mindfulness in the making, at times when embroidering, I have stopped perceiving letters as letters at all, seeing only a series of linked shapes which need to be stitched. The slowness of the work offers scope for long term, ongoing projects like Stitching the Wars, but the prospect of funding smaller scale, quicker projects may be more palatable to commissioners. I have been thinking of faster ways of working which would fit into a workshop format, of making quilt blocks out of texts instead of fabric, of framed fabrics with texts written across the glass and of letters which are stamped instead of sewn.

I want to return to Flint's (2004, p.152) suggestion that 'not knowing' forms the basis of therapy. This sense of not knowing has followed me throughout the creation of my textile pieces, as well as this critical thesis. To bring this thread to a close, I reflect on how this feeling has manifested in different ways, as not only a basis for therapy, but a key facet of the practice I have developed here.

There is a not knowing built into the whole process of completing a PhD. In order to produce an original contribution to knowledge it is necessary to bring to light something which is not already known.

There is not knowing in dementia. This is a not knowing in which that which was once known is now lost. There is potential for some of these lost things to be held by others who can remember the stories, or in pieces of art or performances which preserve their heritage.

There is a not knowing in my creative practice. When I sew, the piece evolves throughout its making. I cannot work by making a plan for a finished piece and then executing it. The finished form must be adapted to the limitations of the materials I use. The embroidered writing happens within a restriction of the room available to write in. Sometimes I am not sure if the various parts will fit together at the seams at all.

There is a not knowing for the viewer of the finished textile pieces. They must decide how to interpret the fragmented texts and the language of the textiles themselves. My own identity exists in small glimpses, interspersed with other materials, making it hard for viewers to know me.

There is a not knowing in autobiography. There will always be things which we don't know about ourselves. The things we don't know are always missing from our stories. So much else is missing too, especially mundane things like what we had for breakfast, our daily commute, doing the washing up, or having a cup of tea. The relentless ongoingness of everyday existence cannot be documented. All our stories are broken.

There is the not knowing which Flint suggests offers the possibility of healing. A space in which people can come together and work to create something which makes them feel better.

In this thesis I have attempted to create such a space for myself and for the reader. I hope the reader will embrace the ambiguities within this body of work as spaces of creative possibility, where new connections can be made. In doing so, we can meet within this sense of the unknown and find value in holding space for things that are not known.

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