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# “It was then that I thought ‘whaat? This is not my Dad’”: The implications of the ‘still the same person’ narrative for children and young people who have a parent with dementia

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## Abstract

This research used auto/biographical interviews to explore the experiences of 19, 8 to 31 year olds who had a parent with dementia. Thematic analysis revealed challenges occasioned by the master narrative that people with dementia are ‘still’ the same person they were prior to the onset of their condition. While this notion is – rightly – at the heart of person-centered care in dementia services, the ‘still’ discourse conflicts with the experiences of young people. Their accounts suggest that the construction of their parent as the same person is not helpful and that, furthermore, expectations that they will behave and feel towards that parent as they did before are a source of distress in what is already a challenging situation. This paper highlights the need to equip young people with support that acknowledges that their parent may well be drastically different to the Mum or Dad they previously ‘knew’.

## Keywords

children, young people, young onset dementias, identities, stigma, family members

## Introduction

Those living with dementia are often described as being ‘still’ the same person they were before diagnosis. Indeed, the notion that, towards the close of a life ended by dementia, Alice, for example, is still Alice<sup>1</sup> appears to have achieved hegemonic status and become something of a master narrative, hard to question without occasioning negative criticism and

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denial. However, 16 of the 19 participants involved in our (UK) Alzheimer's Society-funded project, *The Perceptions and Experiences of Children and Young People Who Have a Parent with Dementia* said that they found this dominant narrative problematic. Their interpretation of their lived experience of having a parent with dementia did not support it. Furthermore, the fact they did not feel their parent was the 'same' person they were before their illness and that consequently they were not able to relate to and feel the same way towards them as they previously did was a cause of additional stress in what was already often an almost unbearable situation (Couser, 2009).

This paper explores the stories around the 'Still' narrative told by these participants and considers what they might mean for informing and supporting others in similar circumstances. The focus is unequivocally on the perceptions and experiences of the children and young people. While what they have to say may make for uncomfortable reading, to deny them expression of what living with a parent with dementia has meant for them is to silence an already marginalised and isolated group, especially given the evidence suggesting that parental dementia in families with children and young people causes greater social and psychological upset, damage, tension, hardship, and family break up than it does in families where children are grown up. Such familial difficulties are reported in studies by Allen, Oybode, and Allen (2009), Barca, Thorsen, Engedal, Haugen, and Johannessen (2014), Denny et al., 2012, Gelman and Greer (2011), Harris and Keady (2009), Hutchinson, Roberts, Kurrle, & Daly, 2014, Johannessen, Engedal, and Thorsen (2015), Lord (2010), Luscombe, Brodaty, and Freeth (1998), Millenaar et al. (2014), Roach, Keady, Bee, and Williams (2013), Robertson (1996), Svanberg, Stott, and Spector (2010, 2011).

In the UK context where the emphasis is (quite rightly) on living well with dementia, on positivity and enabling approaches, it can be difficult for researchers to investigate and report negative experiences (Fontaine & Oyebode, 2014; Griffin, Oyebode, & Allen, 2015; Nolan, Ryan, Enderby, & Reid, 2002). Failing to re-present perceptions and experiences as they are lived, however, does a serious disservice to the research endeavour and can prevent development and positive change. This is because it may mean that evidence relating to the fuller picture is not made available to the policy makers and service providers who are in a position to develop interventions (Fontaine & Oyebode, 2014, p. 1269). When the young people we spoke to told us how things were for them we felt ethically bound to respect and disseminate their accounts.

At this point, we want to note that we are aware that some consider it inappropriate to use the descriptor 'living with dementia' for anyone who does not personally have, or be moving towards, a diagnosis of dementia.<sup>2</sup> Our view, however, based on the stories we were told is that family members often feel the phrase does accurately capture the situation for themselves as much as for their relative, and that it does so without diminishing or appropriating the personal consequences of having dementia.

## **Identities, dementia and 'still the same person'**

There is an extensive literature dealing with issues around the ways in which 'illnesses', of various kinds, and/or being perceived to be 'differently abled', have consequences for personal and social identities. Sociologists Moji Anderson and Monika Asnani (2013), Arthur Frank (1995, 2013), Patti Lather and Christine Smithies (1997), and Andrew Sparkes and Brett Smith (2002), for instance, discuss, respectively, how having cancer or

experiencing spinal injury or living with HIV/AIDS or Sickle Cell Disease impacts, even hijacks, preferred identities, interrupts biographical trajectories (Bury, 1982) and affects pre-existing relationships. Illness also disrupts the identities of the 'patient's' family members and friends. They may end up becoming known, or being labeled, as 'carers' and/or as the partner, parent, child, or friend of a person with a particular illness (cf. Wiltshire, 1998). In addition, they may feel personally changed as a result of the trauma that they have experienced and/or continue to experience when a person whom they love or care for becomes ill. For instance, they may feel the need to adopt a harsher or distanced stance in order to protect themselves from further pain (cf. Miller, 2004). When the illness in question carries social stigma (Goffman, 1963), they can be stigmatised by association, with implications for their personal identity, sense of self, self esteem, and how others view and relate to them.

With respect to dementia, the work of Tom Kitwood (1997) focusing on personhood, has been influential in terms of how people with dementia are perceived and, as a result on how they are supported and cared for.<sup>3</sup> Drawing on Martin Buber's thinking about relationships in terms of dialogic, mutual encounters between 'I and Thou', (Buber, 1937/2004) Kitwood argued for a social, rather than a medical, model of dementia, writing that 'the key psychological task in dementia care is that of keeping the sufferer's (*sic*) personhood in being' (Kitwood & Bredin, 1992, p. 269). Kitwood's primary concern was with 'professional' carers working with older people living with Alzheimer's Disease. Within western society older people are, as a group, often homogenised, seen as 'past it' and are depersonalised and othered. Kitwood's challenge to this view is important and especially so when Alzheimer's, other forms of dementia, and mental health issues are also present. It is perhaps, particularly easy to lose sight of someone having their own unique personality and life history when they are old and confused and have lost their memory. We suggest that the 'still the same person' dementia narrative could partly have its roots in strategies, such as person-centered care, designed to counter such forgetfulness in professional carers who, unlike family members and friends, have no previous knowledge of those they are working with. In the context of older people with Alzheimer's Disease, it can be extremely valuable in furthering respectful relationships and care and in 'honouring', to use the poet John Killick's phrase, the person with dementia.

However, not all people with dementia are old and nor do they all have Alzheimer's Disease. Other forms of dementia such as frontotemporal dementia, vascular dementia, posterior cortical atrophy and dementia with Lewy bodies may primarily manifest, not in memory loss but in altered behaviours, including loss of empathy and lack of emotional awareness, which others may experience as personality change, particularly prior to any diagnosis. There are also language variants of dementia which affect ability to speak and/or communicate. Such changes can have significant implications for existing relationships (see Fontaine & Oyboode, 2014; Griffin, Oyboode, & Allen, 2015) and can make the 'still the same person' narrative much more difficult to espouse. Difficulties may be exacerbated when the person with dementia denies, or is unaware, that they have changed. Research which has looked at the extent to which people with a dementia diagnosis feel that their identity and sense of self has been affected has, unsurprisingly, tended to focus on those in the earlier stages of their condition. Findings from these studies are variable and seem to be related to the type of dementia experienced, with some acknowledging at least a degree of awareness (primarily in those with Alzheimer's Disease) and others reporting little or no cognizance of any changes even when relatives did feel there were significant differences (Caddell and

Claire, 2011; Griffen, Oyeboode, & Allen, 2015; Hedman, Hansebo, & Ternestedt, 2012). Our investigation provides some insights into how the children and young people we spoke with perceived and experienced these changes and at this point we will move on to provide some information about that study.

## **The perceptions and experiences of children and young people who have a parent with dementia study**

The study has its origins in the experiences of one of the authors' families.<sup>4</sup> At around the age of 55, when their children were 13 and 15, the author's spouse began exhibiting what, five years later, were confirmed as being dementia-related behaviours. At the time of writing, 10 years on, the spouse has a diagnosis of posterior cortical atrophy, lives in a care home, is extremely limited in ability to communicate and is increasingly physically incapacitated.

With its auto/biographical (Stanley, 1993) basis, the study is firmly rooted in C. Wright Mills' (1970) exhortation to employ the 'sociological imagination' in such a way that 'the personal uneasiness of individuals is focused upon explicit troubles and the indifference of publics is transformed into involvement with public issues' (1970, pp. 11–12). Mills, like Goodson (2013), Oakley (1979) and many others, recognises the opportunities available to those of us in positions where we can do research, to exploit the potential that auto/biographical approaches offer for connecting private and public in ways that could lead to transformative action at individual and wider social levels (Sikes, 1997, 2006, 2009, 2013; Sikes & Goodson, 2003; Sikes & Piper, 2010).

The purpose of the project is two fold. The primary aim is to begin to address a significant gap in the research and literature around living with dementia by focusing on, investigating and re-presenting the perceptions and experiences of children and young people who have a parent with a young onset dementia. There has been relatively little work dealing with this area and what there is has frequently taken the form of literature reviews pointing out the dearth of research (e.g. Brown and Kleist, 1999; Green and Kleissen, 2013; Roach, Keady, Bee, & Hope, 2008; Svanberg, Spector, & Stott, 2011; Tindall & Manthorpe, 1997; van Vliet, de Vught, Bakker, Koopmas, & Verhey, 2009). Exceptions include:

- Beach (1994) who described a pilot project to help children understand dementing illnesses;
- Barca, Thorsen, Engedal, Haugen, and Johannessen (2014), Davis, Clovis, Ingram, Priddy, and Tiklenberg (2000), Denny et al. (2012), Gelman and Greer (2011), Hall, Buckwalter, and Crowe (1990), Hutchinson, Roberts, Daly, Bulsara, and Kurrle (2015), Hutchinson, Roberts, Kurrle, and Daly (2014), Johannessen, Engedal, and Thorsen (2015), and Millenaar et al. (2014)) who reported on empirical studies, using questionnaires and/or structured or semi-structured interviews, which involved adolescents and young adults who had or had had parents with dementia;
- Harris and Keady (2009) who quoted people with young onset dementia reflecting on the effect the condition had on their children; and
- Luscombe, Brodaty, and Freeth (1998) whose study asked adult carers for their views of the impact of dementia on their children.

The lack of research in the field translates into a limited range of services and informed resources targeted at supporting young people who have a parent with young onset

dementia. Adding to, developing, producing and disseminating, such services and resources are the other component of the project. In the UK, charities and support groups (e.g. the Alzheimer's Society, Alzheimer's Research UK, Alzheimer's Scotland, the Familial Alzheimer's Disease Support Group, The Frontotemporal Dementia Support Group, Young Dementia UK, London Young Onset Dementia Support) have given some attention to children and young people living with parental dementia. These groups have produced factsheets and provide links to websites, relevant blogs and on-line videos. The Alzheimer's Society also has an on-line discussion forum, *Talking Point*, which carries a young onset thread, although this seems to be used more by people with dementia, their spouses and carers than by their younger (i.e. under 25) children. Informative and supportive resources can be extremely valuable because understanding what is going on when someone has dementia, sharing experiences and learning that one is not alone can be extremely important in the face of conditions which, *inter alia*, can: change personalities and consequently relationships; lead to altered financial and social living circumstances; involve watching a loved one become incapacitated; raise fears about one's own likelihood of developing dementia; expose one to the ignorance and consequent ridicule of others; result in guilt, grief and distress; affect educational progress and consequently, future life chances and outcomes.

## Methodological approach

The study takes an auto/biographical, specifically life historical and narrative approach to collect the in-depth personal stories of children and young people who have or have had a parent with dementia. Such approaches are complementary to research which seeks to address issues of social justice and give voice to hidden and 'silenced lives' (McLaughlin & Tierney, 1993; Plummer, 2001; Goodson & Sikes, 2001; Goodson, Sikes, Andrews & Atinkin, in press for publication 2016). On these grounds, they seem particularly suited to exploring and giving expression to the stories of young people who are in a minority, whose experiences violate 'normal' expectations of parent child relationships, and who are affected by a stigmatising (Goffman, 1963) and identity spoiling condition (Sabat, Johnson, Swarbrick, & Keady, 2011; Werner, Goldstein, & Buchbinder, 2010).

Life historians work in a collaborative fashion with the people whose stories of their experiences are the foci of their attention. These stories are then considered in the particular social, historical and other contexts in which they are lived thus helping to capture something of the complexity of lives and providing compelling and engaging evidence to show how individuals negotiate their identities, construct futures, make sense of social rules and roles, and adopt or reject 'culturally sanctioned plotlines' (Freeman, 2010). Analysis takes a thematic approach, with narratives being interrogated for themes in a manner that incorporates the story as a whole (Riessman, 2008).

The aim is not to generalise but rather to gain a sense of how people with different biographies go through similar social and cultural experiences: in this case, being a young person with a parent who has dementia. The approach does not involve asking pre-specified questions but rather participants are 'simply' invited to share their story of their parent's dementia. The intention is to elicit rich and detailed accounts that tell what the dementia has meant for them and to gain a sense of what was significant for each particular person rather than to obtain responses to questions based on researchers' assumptions that they know how it is and hence are in a position to ask the questions. Through dissemination and creating

support services and resources based in and on this data, others who learn how it was for research participants can identify – or not – and either way, learn about their own experiences and perceptions. Accounts of the lives of young people living with a parent with dementia could provide the social scripts or templates (cf. Goodson, 2013; Goodson & Sikes, 2001; *publication by author*) that are currently lacking within our culture and which could offer those finding themselves in this position pointers to how others have dealt with similar situations. Indeed the existence of scripts for older spouses and grown up children of elderly people with dementia could serve to intensify any sense that children and young people with a parent with young onset dementia have that they are marginalised and isolated (cf. Hutchinson, Roberts, Daly, Bulsara, & Kurrle, 2015) because they do not fit the normal profile of the child of a person with dementia (i.e. they are not a middle-aged or older person with a parent over 65).

## Ethical Considerations

The study involved asking people to talk about potentially distressing personal and familial experiences some of which could lead to them voicing socially unacceptable views: e.g. challenging the master narrative that a mum/dad is still the same person they were before they had dementia or saying that they don't like their parent now they have dementia. Laurel Richardson reminds us that 'narrativizing, like all intentional behaviour . . . is a site of moral responsibility' (1990, p. 131) and when the narration happens in the course of an auto/biographical study dealing with a sensitive topic which implicates family relationships, researchers bear a heavy burden for safeguarding and protecting their participants or at least, minimising potential harm.

Our approach, in which people are invited to tell their own stories, does offer some control over what they choose to disclose. However, we were prepared with contact details for support and therapeutic services were these deemed necessary. We have used pseudonyms for our participants in order to protect both them and their family members who have not given consent to be identified. The project received clearance from our University's Ethics Committee. This entailed submission of an application reviewed by three academics unconnected with the project. As we did not contact anyone via any NHS services we did not need NHS approval.

## The sample

The project proposal specified that we would talk to a maximum of 20 participants aged between 7 and 25 on at least two occasions. These numbers were based the following considerations:

- the aims of life history and the in-depth data it yields make large samples unnecessary and unmanageable for small research teams;
- interest in how having a parent with dementia impacts on educational careers from school through university;
- extant definitions of youth such as those from the UN (15–24), WHO (10–24).

In the event, we recruited 19, 8 to 31 year olds with the majority being between 16 and 24. We included 4 over 25s because they approached us, emphasising that they wanted to

contribute to making things better for others. We felt that it would have been unethical to exclude these people given their desire to speak out and because their retrospective accounts of their childhood and adolescent experiences were clearly pertinent.

The extent to which young people make use of the Internet to try to find information, advice and support around having a parent with dementia became clear when, four weeks after our project began we advertised it on the web, inviting potential participants to get in touch with us. Within an hour, we had been contacted by three people and by the end of the week, five others. Indeed, the majority of our participants came to us as a result of that initial posting. The others came via various snowballing links and social media.

Parents of participants were variously diagnosed with vascular dementia, frontotemporal dementia, dementia with Lewy bodies, posterior cortical atrophy and Alzheimer's Disease. Two parents had died. Some of the young people lived at home and a number of parents were in care homes. Just over half were in education – at school, sixth form, university at under and postgraduate levels – the others worked. Over the course of the project, given both the progressive nature of dementia and our iterative approach involving a number of meetings with each individual, situations changed. Table 1 provides information about participants.

Narrative life history work requires participants, who are able to talk for extended periods – conversations have lasted between 45 min and over 2 hours with an average of around an hour and a half – and they must be willing to recall and reflect on personal experiences. It also demands researchers who are skillful and sensitive listeners who can curb what are often 'natural' inclinations to ask particular questions which can lead to the imposition of their own stories and interpretations. Specific questions are additionally problematic in that they can lead to socially desirable responses. The vast majority of the, albeit limited work, that there has been with young people with a parent with dementia has involved structuring parameters and questions. Our study is, therefore, unusual in privileging and being centered on the experiences of participants themselves.

## Limitations

The study has limitations because the participants were self-selecting and the majority, although not all, are white, British and middle class. However, on the basis of the limited research evidence and also from anecdotal reporting by family members and professionals with experience of young onset dementias, we do believe that the perceptions and experiences participants told us about are likely to be widely shared by young people who have a parent with dementia.<sup>5</sup>

## Findings

### *Not the same person narratives*

In the stories participants told, references to how they believed dementia had changed their parent and how they felt about this were ubiquitous. Our view is that categorising narratives as 'types' or examples of particular perceptions and experiences risks violating the uniqueness of each individual account. However, because headings may help people to consider and compare what has happened to them in relation to others' experiences (which our participants were eager to facilitate) and because they may also alert professionals to what seem to us to be shared and significant areas we will use some



**Table 1.** Participants' Details.

Participant	Gender	Age	Parent	Type (if known)	Estimated duration of dementia <sup>a</sup>	Family configuration	Living arrangements	Current activities
Sheena	Female	26	Dad	Dementia with Lewy bodies	Eight years	Youngest of three	Away	Employment
Alex	Male	24	Dad	Fronto-temporal	Four years	Siblings	Away	Employment
Anna	Female	30	Mum	Not specified	Two years	Only child of divorced parents	Away	Employment
Lily	Female	24	Mum	Not specified	Two years	Only child of divorced parents	Away	Employment
Evie	Female	17	Dad	Fronto-temporal	Five years	Only child	Home	Father in a care home
Elizabeth	Female	28	Mum	Not specified	Six years	Youngest of three	Away	Employment
Madison	Female	23	Mum	Posterior cortical atrophy	Five years	Only child of divorced parents	Away	University
Gabrielle	Female	23	Dad	Vascular. Died eight years ago (cancer-related).	One year	Parents divorced. Half sister from her father's side.	N/A	Employment
Rachael	Female	24	Dad	Not specified	Two years	Oldest of two	Away	Employment
Bethany	Female	21	Mum	Fronto-temporal	Six years. Died one year ago	Youngest of two	N/A	Postgraduate study
Grace	Female	31	Mum	Not specified	10 years (when aged 11–21). Mum died when Grace was 21	Only child	N/A	Employment
Colin	Male	21	Mum	Not specified	Three years	Youngest of five. Two siblings are his mother's from a previous marriage; two from his fathers'	Away	Postgraduate study
Jade	Female	16	Dad	Fronto-temporal	One year	Siblings. Jade is adopted.	Home	Education
Amy	Female	24	Dad	Fronto-temporal	Four years	Amy has a young daughter	Home	Employment
Austin	Male	8	Dad	Fronto-temporal	Four years		Home	School

(continued)

Table 1. Continued.

Participant	Gender	Age	Parent	Type (if known)	Estimated duration of dementia <sup>a</sup>	Family configuration	Living arrangements	Current activities
Ava	Female	22	Mum	Fronto-temporal	Two years	Two siblings from his mother's previous marriage		
Holly	Female	21	Dad	Fronto-temporal	Four years. Deceased less than six months.	Oldest of two	Home	Postgraduate study
Rhian	Female	24	Mum	Not specified	Five years	Oldest of two	Away	Employment
Harriet	Female	17	Dad	Vascular	One year	Youngest of two	Home	School
						Only child of divorced parents	Away	

<sup>a</sup>This is based on respondent's recollections. They largely relate to the formal diagnosis, though some include the lead up. Where parents are deceased, this number refers to what they consider to have been the timeframe.

FE, Further Education; N/A, Not Applicable.

broad ones for presentational purposes. Unfortunately we only have space to share a fraction of the 'Still' stories we were told.

### *'They had to Hollywood it'*

The study commenced in the autumn of 2014 and in the spring of 2015 the widely publicised film, 'Still Alice', based on Lisa Genova's (2007) book of the same name premiered in the UK. The film won many prizes (see <http://www.imdb.com/title/tt3316960/awards>), including 'best actress' Oscar, Golden Globe and BAFTA awards for Julianne Moore who played the eponymous heroine, Alice, a brilliant linguistics professor who develops young onset Familial Alzheimer's Disease. Not surprisingly a number of people mentioned this film:

On my birthday, I went to the cinema with my Dad and for some reason, I was upset, I'd never heard of it, there was a book/cinema launch at the cinema we were at and I read the blurb of it. Are you kidding me? It's my birthday. And this event is on! So I was like, I'll read the book before I can criticise it. So I read the book and it really bothered me. It presented *dementia* in quite a comforting manner and they didn't show the mum getting that ill. It made me angry. I haven't seen the film. My friends say it is very cinematished, Hollywood, it doesn't show the reality... I felt that if the author wanted to raise awareness, she kind of sold out a bit... *This still thing is a theme* and some of my friends are like 'she's still your mum, she still loves you'. She doesn't know how to love me! Don't give me that. I know they are trying to comfort me but it's not comforting. The *Still Alice* thing bothered me because it's not from personal experience. It should be from people who know about it so it's more realistic. (Madison, 23)

I hope people watch it who aren't affected by *dementia* because if you have no clue then it gives you a good grounding in it but the warning would be yeah, it's not about the spouse or children, it is purely from Alice's perspective and it's helpful but yeah. Julianne Moore, I like her, she was really good in it, there's not enough of the stressful. It was very Hollywood and it has to be to get to any mainstream market, like if you had a film of what my Mum is like, it would just be like 'fucking hell' and boring and repetitive. So they had to Hollywood it. (Elizabeth, 28)

From the perspective of the participants, *Still Alice* paints an unrealistic picture that could affect how others understand what they are experiencing and makes it even more difficult for them to be open about how it is for them. Madison finds no comfort in the notion that her mum is 'still' her mum because as far as she is concerned, her mother is no longer capable of loving her. Similarly for Elizabeth, whose mother now swears a great deal and whose life is currently ordered around repetitive ritual, there is little positive in a portrayal that apparently ignores how things are for family members and minimises the difficulties.

### *My parent is a different person*

Kesstan Blandin and Renee Pepin (2017) talk of 'receding of the known self' when describing the significant and serial changes observed in people with dementia. Blandin and Pepin are particularly concerned with the ambiguities around the way in which someone with dementia is there in body but at the same time is profoundly altered in terms of the characteristics that made them uniquely them. They suggest that family members and caregivers living with dementia go through a unique grief process involving what they call pre-death grief and post-death complicated grief and that as a result they 'experience a magnitude of stress in dementia caregiving preceding physical death considered equal to or greater than the stress

in bereavement after physical death' (2015, pp. 1–2). This stress can result in physical and mental health conditions. Experiencing one's parent as a different person is extremely difficult and painful, especially as the grieving process cannot be as 'quick' or 'clean' as it may be when there is an actual death:

I felt a bit of a disconnect with who that person was in the hospital and I went to visit him because I cared about him and he was my Dad but there was definitely, that that's not who I know. It was almost being there for the sake of it, sounds horrible, it's definitely not who I know... It was really difficult knowing what to do when he was there, I'd talk to him and make jokes like you do when you feel awkward and it was almost like talking to a stranger really yeah. I don't really think about the disease every day. When I think back to who my Dad was, I think of a really bubbly energetic healthy person. That wasn't him then. (Harriet, 24)

She's kind of almost it's like there's two Mums and in your head, you never quite let go of... but you're constantly grieving for the old Mum because she's sort of there but not... it sounds awful, but people who have a parent who dies when they are in their teens or twenties, it's like quick, and it's awful but then you're allowed to grieve... whereas people don't see that with this, they just think actually you should be grateful that your Mum is still here and she's not dead and it's like well, it's really not that simple but I think admitting that to anyone is really hard because people don't expect you to think that, I don't think. (Elizabeth, 28)

### *My parent doesn't know me*

In Western society, we tend to look to our parents for unconditional love and acceptance, which is, furthermore, seen as essential for successful identity construction and transition into independent adulthood. Such love and acceptance is dependent on recognition and implicit knowledge of a shared history. A parent's failure to recognise their child or to remember important and defining details about them contradicts deeply held understandings of family and relationship. Those of the participants whose parents still recognised them as their child all spoke of their fears of when this would no longer be the case: those who had experienced lack of recognition could recall in detail the first time this happened. It is hard to believe your parent is still your parent when they don't know your name or your relationship to them.

Sometimes I'll see her, she'll be really bad and I'll be alright with it and other times I will crumble. When I went home in early November, she knew who my Dad was and not me and I was like fuming with him! Like you're divorced! Why do you know him and not me? And that really hurt. (Gabrielle, 23)

I came out to my parents as gay, in 2010, but my Mum has now started forgetting which is difficult and she keeps asking me if I'm going to get a girlfriend and when I'm gonna marry, things like that. So then I remind her and she says things like, 'oh yes, I remember now'. But she's become much less, she used to be really accepting of it but now she's become quite narrowminded. It's no longer in her world, she can't fathom it anymore. She says 'don't you want a family?' Things like that. Whereas previously she would have understood that it doesn't mean the end of that idea. (Colin, 21)

### *My parent isn't very nice*

Parents and children do not always get on and may not like each other even though the social expectation is that they should. When relationships were good, prior to dementia,

it can be particularly upsetting – and guilt inducing – to come to dislike one’s parent as a result of their changed behaviours.

So really, the worst thing about the whole position is that it makes someone who was a lovely character really easy to dislike and you have to really fight not to hate your own parent. And sometimes you fail in that. (Colin, 21)

Elizabeth is particularly frank about how her mother is now, whilst at the same time acknowledging ‘it’s not her fault’.

I don’t like Mum at all. I said to my friends, a while ago, my Mum, by all social concepts, my Mum is an utter bitch. If she was a normal person and you met her, by any normal human standards, she is a total, selfish, it’s not her fault, but yeah, my Mum is a bitch, she doesn’t know my name 99% of the time, she doesn’t remember what I do, she’s rude, always talking about herself, really negative bringing the conversation down, talks over, over and over, talks over you and doesn’t let you talk to anyone else - how is that a nice person? (Elizabeth, 28)

### *My parent is aggressive*

People living with dementia can become violent. Evie was under 16 when her father’s completely uncharacteristic behaviour towards her prompted the social services to intervene and place him in care in order to protect her – occasioning serious guilt and regret on her part.

The reason basically he went to the care home was because he grabbed my arm and he twisted it and he did it with such, he’d done it before and I knew it wasn’t really him, but it didn’t hurt me, but the way he did it. He wasn’t letting go and I knew that something had changed . . . And like with the frontotemporal dementia, his personality is the first thing that changes, his personality, that was obvious, the way he was with me, he went from - me and him were so close that if me and Mum were to have a petty argument he’d probably go with me to my side - and then he went to being so horrible that I thought ‘whaaaaat?’, this is not my dad. (Evie, 17)

### *My parent is suspicious*

Paranoia and suspicion are common symptoms of dementia. Being accused of stealing or failing to look after a parent, especially when it happens constantly, and didn’t before, is damaging.

I think the paranoia was directed towards me which was kind of the worse thing, so he’d say, ‘you’ve stolen my remote’, it was stupid, he was obsessed with his TV remote. I’d be like ‘no Dad I haven’t, I haven’t touched it’, ‘yes you have’ . . . And I was like, no I haven’t, honestly, he’d just blame me for things, ridiculous things like ‘well you’ve taken my car keys’, ‘why would I take your car keys?’ ‘well you have’. And then I’d find them down the back of the sofa which was the worse thing and I’d go ‘found ‘em’, he’d go ‘see, told you’. (Evie, 17)

I was looking after him for the weekend because mum was working away and he went round the neighbours telling them I was stealing from him and ripping him off and not feeding him. That was so upsetting. They didn’t believe him because they knew but he went out in the street and he was doing that. (Rachel, 24)

### *My parent can't talk to me*

Semantic variants of dementia obviously affect speech and communication and it is not unusual for other forms of dementia to involve similar difficulties too, particularly as they progress. According to Blandin and Pepin, these difficulties are central to the unique form of dementia grief they suggest is experienced by those whose loved ones have dementia. They write:

Dementia grief is distinguished from anticipatory grief (*experienced in many terminal illnesses*) by disruptions in communications and impairments in awareness that occur even early in the disease. With most terminal medical conditions, there is an opportunity for conflict resolution and sharing feelings between the dying person and their family members up until death... However, the opportunity for similar resolution is limited for dementia caregivers due to language deficits and a lack of insight in care recipients resulting from disruptions in reasoning that can manifest in the early stages of dementia' (2015, p. 3)

Limited or no communication where previously there was interaction can make it very hard to conceive of a person as still being the same. What Madison had to say about her mum's loss of speech seems particularly poignant and also provides a clear illustration of losing the opportunity to resolve conflict and share feelings because the person who could have done that is no longer 'there' to do it with.

We think she stopped talking around June or July this year. It's one of those things, it almost creeps up on you, there's never a big warning sign, like this is the last time they're gonna speak and we just suddenly noticed that she wasn't answering our questions anymore. She'd sort of stopped speaking in sentences and then she'd just... say no, or Tesco and that was it for a while. And then we noticed that it stopped completely... Now to think I won't hear her say anything or it's unlikely that we will, that's quite difficult. It's communication, when you can't speak to someone or they can't speak back to you, it takes it away... I know I feel an awful lot of guilt because... when the symptoms were starting to show, one of the things she used to do... there was one day she called me four times in an hour and every single time, she'd say 'I've just put the washing machine on' and I was in the middle of doing an essay, I had three days to do it and I was like 'Mum you need to stop calling me, you've already told me this three times today' and I got really angry at her. I called Dad and told him to call her and get her to stop calling me and I suppose if we'd known, I would have been more patient but we didn't know and I feel guilty about the way I'd spoken to her and the way I dismissed her and because of that, she stopped calling altogether and it was only when I called and I sort of feel I missed an opportunity to hear her voice and if I could do it all again, I'd sort of stand there and appreciate that that was her voice and it was part of her and I'm not gonna hear that again and through my actions, I stopped her calling me. (Madison, 23)

### **Discussion**

To be a child or young person who has a parent with dementia is to be in an unenviable position. Of course, losing the care and love of a parent prematurely for any reason (be it as the result of death, illness, incapacitation or desertion) can be difficult, as can the loss of a mum or dad regardless of their child's age: we know a 75 year old, for instance, devastated by the death of his 103 year old mother. Young onset dementia, however, seems to be particularly cruel in that the child frequently has to observe their parent being on an

apparently unrelenting downwards trajectory of negative change in terms of alteration in personality and loss of cognitive, emotional and physical abilities. As two of our participants summed it up: 'every time I see him he is the worst he's ever been and the best he'll ever be' (Alex, 24), and 'you get used to a new normal every few weeks it seems, or even a shorter time. There's a new normal and it's so unpredictable (Madison, 23).

Dementia can seem to leave a body, or rather a carapace, that lacks the characteristics that made a parent the parent that they once were. The existence of this body that cannot share in supporting a child through the 'normal' experiences that accompany growing up, let alone be involved in what Bethany aged 21 called 'the landmark events' such as graduation, marriage, birth of grandchildren, house purchase and so on, emphasises what isn't there and what is different.

And yet the dominant messages about dementia in Western society are that the person with dementia is still the same person they were before they developed the condition. Apart from anything else, such a message seems to discount the ways in which those who are not ill may change in terms of for instance, interests, concerns and sympathies throughout a 'normal' life course. It also assumes that each of us have one essential and unchanging self, which remains the same in all circumstances and across all relationships. This is not usually, if ever, the case. Human persons are beings in relation (cf. Buber, 1947/2014; Freeman, 2014) and this is so for people with dementia as much as for anyone else. To lock people and their family and friends who are living with dementia into how things were pre-diagnosis is both limiting and unrealistic.

For the young people we spoke with who had intimate experience of living with a parent with dementia, denying the 'still the same' narrative also served as a protective safety mechanism. This is because they wanted to believe that their pre-diagnosis mum or dad, their mum or dad who was 'in their right mind' (Colin, 21) would not, for instance, hurt them, was interested in them, cared about them, remembered their birthday, was not going to embarrass them in public by wetting or soiling themselves, and actually recognised and knew who they were. Of course it is crucial to preserve person-centered approaches when working with people with dementia: however, and at the same time, it is important to acknowledge the needs of families who are experiencing anything but 'still'. This presents a dilemma. Hearing the difficult stories is perhaps a step in the 'right' direction which could lead to a more holistic, family centered approach to addressing the situation and perhaps, finding situationally 'good enough' 'solutions'.

A common complaint made by the young people we spoke with was that in the public perception dementia is equated with Alzheimer's in older people and that their experience of a parent with a young onset variant was very different. Some mentioned having told friends that their parent had dementia and the response being that they knew just what it was like because their grandparent had had Alzheimer's. Older people with Alzheimer's can be aggressive, uncommunicative, rude, and so on, but the different forms of dementia can manifest in quite different ways that make a blanket consideration and understanding inappropriate and erroneous. Also, the 'usual' differences in relationship between grandparents and children and parents and children in terms of expectations, care, roles and so on, mean that it is not often possible to make a straightforward comparison. For instance, and as we noted earlier, the fact that it is 'normal' for parent child relationships to go through a challenging period during adolescence can mean that for those whose parent develops dementia at this time, resolution and restoration of amicability may not be possible, causing further and potentially lasting distress (cf. Blandin and Pepin 2017, p. 3).

On the basis of the stories we were told it does appear that for family members living with dementia, the ‘still the same’ master narrative can lead to guilt and to mental and emotional ill health. These findings support and add detail to the research, referenced earlier, that suggests that parental dementia in families with children and young people causes greater social and psychological upset, damage, tension, hardship and family break up than it does in families where children are grown up. We believe that all of our participants loved their parent with dementia as their parent – even if they did not always like what they did. For them to say they did not consider them to ‘still be the same person’ is not to say they did not care but rather to reflect the experiences that they had had. In the resources to be prepared, we will be saying that it is ok to dissent, on the basis of informed experience, from the notion of ‘still the same’. There is an urgent need for wider understanding of the issues and for an acknowledgement that for many children and young people who have a parent with young onset dementia, living well with the condition is not easy and in some cases, may not be possible. Help, in the form of counseling and/or other forms of therapy could well be required and it is important that it is built in to support systems provided for families living with young onset dementia. Current figures ([https://s3.amazonaws.com/14078\\_Alzheimers\\_Interactive\\_Infographic/pdf/as\\_downloadable\\_infographics.pdf](https://s3.amazonaws.com/14078_Alzheimers_Interactive_Infographic/pdf/as_downloadable_infographics.pdf)) suggest that there are 42,325 people with young onset dementia in the UK, many of whom will have families. Failure to attend to their possible needs could lead to considerable problems in the future and could also result in lives being spoiled.

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### **Notes**

1. This is a reference to Lisa Genova’s (2007) book and the 2014 film of the same name.
2. See for example various postings in the blog written by Kate Swaffer – at <http://kateswaffer.com>
3. We are aware that Kitwood’s work has been variously interpreted (Baldwin and Capstick, 2007) and critiqued (e.g. Adams, 1996; Flicker, 1997) but these perspectives do not undermine the significance and reach of his ideas on dementia care.
4. Malthouse (2011) and Tindall and Manthorpe (1997) similarly studied aspects of dementia as a result of personal, familial experience.
5. We have attended various events (e.g. conferences and support groups in the UK and in North America) bringing together those with personal and professional experiences of young onset



dementia and all have offered very similar accounts. See also the film made by Young Onset UK in 2015 accessible at <https://youtu.be/rrYohqK1maQ> which further supports our view.

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