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# 'Every time I see him he's the worst he's ever been and the best he'll ever be': grief and sadness in children and young people who have a parent with dementia

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## ABSTRACT

Research suggests that the grief experienced by the family members of persons with dementia has a distinctive nature that differentiates it from sorrow attendant on most other ill health causes. Over a variable period of time, the way in which dementia manifests in cognitive and physical changes tends to be experienced as a series of serious losses, each of which can be a source of grief leading to significant stress and emotional, mental, psychosocial and physical ill health. Research to date has focused on spouses and adult children: here we seek to add to the literature by re-presenting the grief-related perceptions and experiences of children and young people who have a parent with a young onset dementia. We draw on findings from a narrative auto/biographical investigation to describe what dementia grief was like for study participants and to make suggestions for resources and support for those in this position.

## KEYWORDS

Grief; dementia; young onset dementia; children; young people

## Introduction: characterising dementia grief

Terminal illness is usually a sad affair for all it touches. In the case of dementia, when someone is there in body whilst being progressively and profoundly altered in terms of the characteristics that made them inimitably them, the sadness has a distinctive nature (Blandin & Pepin, 2015; Frank, 2008). Research suggests the grief of family members living with persons with dementia is a significant source of stress, depression, and physical, mental and emotional health issues, and a major factor affecting relationships, career/job and educational progress, and quality of life (Chan, Livingston, Jones, & Sampson, 2013; Holley & Mast, 2009; Large & Slinger, 2015; Sanders, Ott, Kelber, & Noonan, 2008; Shuter, Beattie, & Edwards, 2014; Sikes & Hall, 2016).

Blandin and Pepin (2015) apply the term 'dementia grief' to 'the unique role the disease process plays while implying pre-death status' (p. 3). Dementia grief can be seen as a 'tragic' (Holley & Mast, 2009, p. 388) variant of 'anticipatory grief' (Lindemann, 1944; Rando, 2000), exacerbated by the 'ambiguous' losses accompanying the trajectory of decline dementia

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involves (Boss, 1999, 2011). Large and Slinger (2015) suggest the notion of 'ambiguous loss' is useful for understanding the experiences of family members witnessing multiple, unpredictable and unexpected losses manifested through cumulative changes in personality and cognitive and physical capabilities. These changes happen at variable rates with swift declines followed by plateaus, while in other cases, they are slow and slight or sudden and dramatic (Sikes & Hall, 2016). Barring death from another cause, the person may seem to remain in body alone. As Blandin and Pepin (2015) put it, the known self recedes. This almost inevitably affects pre-existing relationships and can lead to 'social death' (Sweeting & Gilhooly, 1997) whereby the person with dementia is treated as being 'as good as dead' and is therefore, not interacted with at all or in any meaningful way. Consequently, dementia has been described as 'dual dying' (Jones & Martinson, 1992), with 'bereavement' experienced firstly as the disease evolves and 'takes away' the known person, giving rise to 'pre-death grief' (Holley & Mast, 2009, 2010; Lindauer & Harvath, 2014), and secondly, when physical death occurs.

Studies of dementia grief have focused on caregiving partners/spouses and adult children of those with Alzheimer's disease developed after the age of 65. The aim has been to understand dementia specific grief, which, Frank (2008) claims, is 'the major barrier faced by Alzheimer's caregivers', with a view to addressing its significant emotional, mental, psychosocial and physical consequences. Throughout the world, the greater part of dementia care is provided by family members (Wimo, Winblad, & Jönsson, 2007) and if, or when, they are no longer able to cope through their own incapacity, grave financial implications for governments are likely (Alzheimer's Disease International's, 2015).

## **Dementia grief and children and young people who have a parent with dementia**

The grief of children and young people who have a parent with a young onset variant of dementia (i.e. occurring before the age of 65) has largely been ignored despite current figures showing that incidence, and/or identification of these dementias is increasing ([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)).

This neglect reflects the general picture regarding the attention given to young onset dementias (YODs) by academics and practitioners alike. That such dementias are rare, constituting around 5% of cases in the UK (Alzheimers' Society, 2014), could be seen to justify a focus on common variants. Nonetheless, it is estimated that 42,325 people in the UK have YOD (<http://www.youngdementiauk.org/young-onset-dementia-facts-figures>), although, given general under-diagnosis of dementia and of YOD in particular, incidence is likely to be higher.<sup>1</sup> This is significant as the limited evidence indicates 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 when children are adult (Allen, Oyebode, & Allen, 2009; Barca, Thorsen, Engedal, Haugen, & Johannessen, 2014; Denny et al., 2012; Gelman & Rhames, 2016; Harris & Keady, 2009; Hutchinson, Roberts, Kurrle, & Daly, 2014; Johannessen, Engedal, & Thorsen, 2015; Luscombe, Brodaty, & Freeth, 1998; Millenaar et al., 2014; Roach, Keady, Bee, & Williams, 2013; Robertson, 1996; Rosenthal Gelman & Greer, 2011; Svanberg, Stott, & Spector, 2010, 2011).

Few studies specifically consider grief in these families and fewer have canvassed the views of young people themselves. Notable exceptions include Allen et al. who interviewed 12, 13 to 24 year olds with fathers with YOD and drew on Doka's (1989) concept of disenfranchised grief to note that interviewees felt their grief was 'unnoticed because they *were* neither the patient nor the main caregiver' (2009, p. 475). These authors concluded that addressing dementia grief was a prominent psychological need (2009, p. 477). Their participants, like the 12, 11 to 17 year olds involved in Svanberg et al.'s (2010) investigation, were grieving the loss of 'normality' in their present and envisaged futures. Generally though, little is known about how children experience parental ill health per se. As Denny et al. comment:

research that addresses anticipatory grief in children tends to discuss factors that later affect child bereavement after the parent's death rather than investigating children's response to the terminal phase on its own. There is little available on the effects of a parent's illness on a child or teen during the actual period of the illness and what it is like to 'live with' the many stressors associated with an ill parent. (2012, p. 4)

Our study has sought to collect the 'what it is like to "live with"' data that is lacking.

## **The 'Perceptions and Experiences of Children and Young People Who Have a Parent With Dementia' study**

As is the case with many social science research projects (Letherby, Scott, & Williams, 2012; Merton, 1988; Oakley, 1979), the study was auto/biographically (Stanley, 1993) grounded in AUTHOR 1's personal experiences of YOD<sup>2</sup> and rooted in Mills (1970) exhortation to employ the 'sociological imagination' so 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). There is a twofold aim and purpose. Firstly to address what has been identified (Brown & Kleist, 1999; Green & Kleissen, 2013; Svanberg et al., 2011; van Vliet, de Vught, Bakker, Koopmas, & Verhey, 2009) as a significant gap in the research and literature around living with dementia by focusing on the perceptions and experiences of children and young people who have a parent with YOD. The paucity of research translates into an extremely limited range of services and informed resources targeted at supporting these children and young people. The development, production and dissemination of such services and resources is the other component of the project.

## **Methodological approach**

The study used an auto/biographical, specifically life historical and narrative approach. Narrative life history has been especially popular with researchers concerned with social justice issues seeking to give voice to hidden and 'silenced lives' (Goodson, Antikainen, Sikes, & Andrews, 2016; McLaughlin & Tierney, 1993; Plummer, 2001). The aim is not to generalise but to gain a sense of how individuals with different biographies go through similar social experiences (Sikes & Goodson, 2016): in this case being a young person whose parent has dementia. Participants are not asked specific questions but are 'simply' invited to tell their stories of parental dementia (Shuter et al., 2014, p. 381). The intention is to elicit detailed accounts which are considered in light of the particular social, cultural, historical and other contexts in which they are lived. The contextualised accounts are then analysed thematically

(Riessman, 2008). Narratives collected and interpreted in this way can capture something of the complexity of lives (Clandinin & Connelly, 2000) and show how individuals negotiate their identities, construct futures and make sense of and maybe challenge, social expectations regarding 'acceptable' feelings and behaviours, including those associated with grieving. Such an approach has not previously been used in this field.

Hutchinson, Roberts, Daly, Bulsara, and Kurrle (2015) have advocated adopting a social model of disability (Oliver, 2009) approach to dementia. They argue this perspective is more likely to empower children and young people who have a parent with dementia because it could better inform the development of more appropriate and inclusionary interdisciplinary services than can follow from the 'traditional' and exclusionary medical model. Findings from narrative life history clearly articulate with this model.

As we have noted, the project's origins lie in Pat's auto/biographical, rather than professional, experiences around YOD. Mel, however, had no previous personal connection with dementia. Both of us came fresh to the limited literature and sources dealing with the topic so our academic knowledge of the field developed more or less in tandem. All of the interviewing and transcribing was done by Mel whilst analysis was a joint enterprise. Inevitably Pat's interpretation of both the literature and the transcripts was coloured by her own family's experiences, whereas Mel's perceptions were somewhat more distanced. Mel did take the decision on occasions not to pass on transcripts immediately they were completed, being conscious of how Pat might receive them. For instance at the time when Pat was (painfully) placing her husband in residential care, the mother of one of the youngest participants was also doing the same and expressed similar feelings of guilt and grief. Mel waited a few weeks before sharing the details of that interview to allow Pat to come to it with less distress and possibly a clearer view. Our two positionings therefore, perhaps provided what could be considered a more rounded take on the data.

## Participants

The study was advertised on a project website, on the pages of two national dementia organisations, and on social media. With two exceptions who came via snowballing means, the 22 participants 'found' us when they were seeking information and support for themselves or, in 2 cases, for their children. This is, therefore, a self-selecting sample of mainly white, British, middle-class, participants. However, on the basis of extant research and anecdotes from health and social care professionals (in the UK and North America), we believe the grief experiences recounted are likely to be recognised by young people who have a parent with dementia. Narrative life history requires participants who are able to speak reflectively, fluently and at some length, which also rules some people out. We wanted a temporal dimension to the study to reflect the progressive nature of dementia and so the majority of participants were seen on at least 2 occasions over 18 months. Interviews, which were audio recorded and transcribed in full, lasted between 45 min and over 2 h with the average being an hour and a half. Sessions with under-10s involved play, drawing and family tree and 'my day' story telling activities (Edwards, Hadfield, Lucey, & Mauthner, 2005; James, 2005).

The project proposal specified a maximum sample of 20, 8 to 25 year olds (in line with World Health and UN definitions of youth). However, we spoke with 22, 6 to 31 year olds with most aged between 16 and 24. We included 4 over 25s who approached us saying they

**Table 1.** Participant details.

| Participant | Gender | Age | Parent | Diagnosis (if known)       | Estimated years of dementia | Family configuration          | Living arrangements   | Current activities |
|-------------|--------|-----|--------|----------------------------|-----------------------------|-------------------------------|-----------------------|--------------------|
| Sheena      | Female | 26  | Father | Dementia with Lewys Bodies | 8                           | Youngest of 3                 | Away                  | Employed           |
| Alex        | Male   | 24  | Father | Fronto                     | 4                           | Siblings                      | Away                  | Employed           |
| Anna        | Female | 30  |        | Temporal Dementia (FTD)    |                             |                               | Away                  | Employed           |
| Lily        | Female | 24  | Mother | Alzheimer's                | 2                           | Singleton; divorced parents   | Away                  | Employed           |
| Evie        | Female | 17  | Father | FTD                        | 5                           | Singleton                     | Father in a care home | Education          |
| Elizabeth   | Female | 28  | Mother | Alzheimer's                | 6                           | Youngest of 3                 | Away                  | Employed           |
| Madison     | Female | 23  | Mother | Posterior cortical atrophy | 5                           | Singleton; divorced parents   | Away                  | Undergraduate      |
| Gabrielle   | Female | 23  | Father | Vascular dementia          | 1                           | Parents divorced. Half sister | N/A                   | Employed           |
| Rachael     | Female | 24  | Father | Alzheimer's                | 2                           | Oldest of 2                   | Away                  | Employed           |
| Bethany     | Female | 21  | Mother | FTD                        | 6                           | Youngest of 2                 | N/A                   | Postgraduate       |
| Grace       | Female | 31  | Mother | Alzheimer's                | Died 1 year ago             | Singleton                     | N/A                   | Employment         |
| Colin       | Male   | 21  | Mother | Alzheimer's                | 10                          | Youngest with 4 half siblings | Away                  | Postgraduate       |
| Jade        | Female | 16  | Father | FTD                        | 3                           | Jade is adopted               | Home.                 | Education          |
| Amy         | Female | 24  |        |                            | 1                           |                               |                       | Employed           |
| Austin      | Male   | 8   | Father | FTD                        | 4                           | Youngest with 2 half siblings | Home                  | Education          |
| Ava         | Female | 22  | Mother | FTD                        | 2                           | Oldest of 2                   | Home                  | Postgraduate       |
| Holly       | Female | 21  | Father | FTD                        | 4                           | Oldest of 2                   | Away                  | Employed           |
| Rhian       | Female | 24  | Mother | Alzheimer's                | Died 5 months ago           | Youngest of 2                 | Home                  | Employed           |
| Harriet     | Female | 17  | Father | Vascular dementia          | 5                           | Singleton; divorced parents   | Away                  | Education          |
| Nathan      | Male   | 22  | Father | FTD                        | 1                           | Youngest of 2                 | Away                  | Education          |
| Alicia      | Female | 8   | Father | Alzheimer's                | 1                           | Siblings                      | Home                  | Education          |
| Bryony      | Female | 6   |        |                            |                             |                               |                       |                    |

wanted to contribute to making things better for others. We felt it would have been unethical to exclude them – and their retrospective accounts were clearly relevant. The younger participants (aged 6 and 7) were also included for ethical reasons: their mother contacted us saying she was eager for them to talk about their dad's dementia both for their own sakes and to contribute to understanding. Having spoken with them, the children were deemed to have capacity to consent to involvement. Table 1 provides biographical details of participants.

## Ethical considerations

We were asking participants to talk about seriously distressing experiences. As Richardson notes 'narrativizing, like all intentional behaviour ... is a site of moral responsibility' (1990, p. 131). When the narration is prompted by an auto/biographical study focusing on an emotional and sensitive topic (Renzetti & Lee, 1993), researchers carry a heavy burden for safeguarding their participants or, at least, minimising potential harm when eliciting accounts and also when re-presenting them in what becomes the research narrative (see Sikes, 2013, 2016).

Our approach, whereby people were invited to tell their own stories in a venue of their own choosing, provided some control over what was disclosed. We were mindful of potential 'power' issues around Mel's status as a researcher from a university, although she was – and looked – young enough to be the majority of the participants' 'big' sister. She made it clear that she was approaching the interview to gain insight into their lived experience, thus affording them a position of 'expert' authority. She was careful not to push, quickly asked if people wanted to continue if they began to show signs of distress, and carried contact details for support services. Pseudonyms were used. The project received clearance under our University's procedure.

## Dementia grief stories

Listening to the interviews and reading the transcripts, Richardson's caution around moral responsibility loomed large: there can seem to be something inherently unethical, othering and even violent (Redwood, 2008) about categorising sadness, even when the intention is to further understanding and inform support and therapeutic provision. And yet, with this caveat in mind, we present the stories in loose groupings that, in our view, illustrate some of the grieving experiences children and young people with a parent with dementia faced. This is not to say that others who are not in these specific circumstances will not have similar experiences, but the unique characteristics of dementia do bring specific challenges to the grieving process. We have used the thematic headings: Diagnosis; Ongoing Loss; Life on Hold; Missing Landmark Events; Envy; Coping or Not. These themes are not exclusive. It is also the case that some themes are more relevant to people of certain ages than others. By and large, the under 10s were not as aware of the implications of their parent's condition and their well parent had not, as yet, enlightened them about the terminal nature of dementia. Austin, for example, was four when his father, Kevin, was diagnosed and so by the time he spoke with AUTHOR 2 when he was eight, had lived half his life with YOD. He did, however, regret that his dad was unable to come and watch him play football as he had previously done and he understood that things were 'getting worse'. During the course of the project, Kevin moved to residential care and Austin missed him although life at home had got easier. We can only share a fraction of what we were told and whilst selection is usually the case in reporting social science, it seems particularly problematic here when participants were so generous in offering what were often such painful reflections. We have therefore, presented relatively long quotes with minimal commentary.

## Diagnosis

Diagnosing dementia is typically a complicated process, often stretching over years (Chrisp, Thomas, Goddard, & Owens, 2011; Perry-Young, Owen, Kelly, & Owens, 2016; Speechly, Bridges-Webb, & Passmore, 2008). For rarer YODs it can take even longer (Crutch et al., 2013; Stewart, 2006; Van Vliet et al., 2011). By the time the disease is confirmed, families are likely to have gone through an extremely difficult period, involving confusion and uncertainty (Teel & Carson, 2003). Receiving a diagnosis – and an explanation for what are often disturbing changes in the personality and behaviours of the person with the condition – can bring some relief (Hall & Sikes, 2016). However, dementia is a terminal, stigmatising (Goffman, 1963; Werner, Goldstein, & Buchbinder, 2010) and sometimes inheritable disease for which there is currently no cure. This can be very painful and hard to understand and accept:

[Diagnosis] just made it more solid, you couldn't deny it anymore ... before it had always been my Mum MIGHT have dementia and then it was she DOES .... Then it was signed like a death warrant, that there's not gonna be a happy ending .... That was the one day I got out of control emotionally. (Colin)

When I got told he had dementia I was just so shocked and didn't know what to do .... There's no cure for that .... And I'm not ready for that. (Harriet)

I do not want to accept that this is happening. It just doesn't sit with me at all. I don't want to accept this is happening or the consequences of it ... why has this happened to me and my family? What's my Dad done to deserve this? (Nathan)

## Ongoing loss

Although it always involves decline, the dementia trajectory is unpredictable. The need to grieve what has been lost and then accommodate more negative change can seem relentless:

Every time I see him he's the worst he's ever been and the best he'll ever be. (Alex)

At the moment, I'm in more of like a settled phase of it but ... I get used to it and then she gets that bit worse and then ... I get really upset again. .... 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)

I felt like I was in this long queue waiting for my number to be told that he's died because you know it's coming .... you just don't know how long you've got to wait. .... They have one good day and three bad days and then the bad days outweigh the good days .... It's been three years of constant grieving. (Holly)

With something like cancer, there's a light at the end of the tunnel, there's a possibility of recovery. With this, there isn't .... You're in a waiting room basically .... every time you see her, it's a bit worse. (Colin)

It's like I explained to someone, you start grieving even though they're standing right in front of you. ... when eventually her body dies, I'm not entirely sure how upset I'll be .... I think I'll be most upset when she does stop walking, when she can't do anything for herself anymore. That's when for me at the moment I think I'll consider her life over sort of thing. It's hard to get people to understand. (Ava)



## Life on hold

For young people at a time of life requiring significant decisions around matters relating to education, career, relationships and starting a family, the uncertainty of their parent's condition can shape choices such as where, or if, to go to university and where to live. Some felt it led to them putting their lives on hold:

It affects my life choices as well because I'd probably be looking at having kids soon if it wasn't for this .... I think all kind of family plans are gonna be on hold ... you don't know how long each stage is gonna last .... My friends say that to me as well, they're like 'what kind of expectancy?' and ....I wish I could say 'yep, for the next year and a half, we're gonna be like this, Mum's gonna get gradually worse, but instead there's nothing, it could be like ten, fifteen years of this long drawn out horribleness. (Elizabeth)

I felt my life had been put on hold and I wasn't getting anywhere ... I didn't want to leave home. I wasn't comfortable leaving because I wasn't sure when I visited what stage Mum would be at and how much I would have missed. (Ava)

## Missing landmark events

Conversely while some things are placed on hold, life does go on and what Bethany described as 'landmark events' and Sheena as 'rites of passage', such as graduation, marriage, house purchase, do happen. A YOD diagnosis means parents may die prematurely before these events occur. It also means that their ability to understand may be compromised or impossible. Parents are expected to be there on these occasions and anticipating, let alone experiencing their absence, is a serious source of sadness and with the exception of the under-10s, all made some reference to it:

My future partner isn't ever gonna know her .... And she's never gonna know my kids if I have any and that's sad. (Colin)

My dad was a car mechanic. When I was younger, I used to sit on his lap at the steering wheel. The first time I was in a car when I was 17, he showed me how to do clutch control, it didn't go very well .... [Passing my driving test] ... was hard, one of those rites of passage, I couldn't tell him ... That's the first rite of passage thing .... I think there's going to be bigger days, wedding days and things like that and children, that are going to be harder. (Sheena)

Ideally I would like to get married quite soon because I want mum to be there and to **be** there. (Rhian)

Elizabeth picks up on Rhian's point when she explains that although her mum attended her wedding, being there didn't mean she was sharing the day. Indeed, her presence exacerbated the sense of loss:

I got married ... and that was absolutely lovely and people [said] 'at least your mum could come to the wedding' and it sounds ungrateful to say, but ... it was massively stressful having her at the wedding ... It was always hanging over me that something might go horrendously wrong ... she was there in body but she wasn't there as a mum, .... People don't see that ..., they just think you should be grateful that your Mum is still here and she's not dead and ... it's really not that simple. (Elizabeth)

Others also explained how being alive is not enough:

I got a first in my degree and I was really happy ... but Mum had no comprehension of what that was. She knew that I'd passed it but there was no awareness of what it meant so it was kinda hard to take, but she was there at my graduation which was good and we got her a nice outfit ... did her hair, it was a good day. But it was marred when you know that someone is there but they're not. (Ava)

Madison interpreted other people's lack of understanding of dementia in terms of their failure to grant her the privileges usually accorded to the recently bereaved:

People are given leeway once someone has died but I've been dealing with my mum dying for a long time and losing her, continually losing her, and I don't feel I necessarily get the same breathing space like if someone had lost someone. Job hunting, no one would be expected to find a job just after their parent has died and I'm dealing with the fact that my mum will at some point soon deteriorate ... but I still have to go on and live my life so I get a bit grumpy about that ... no one would be expected to work at their best when someone has just died and I'm expected to be an adult and do bills and get a job .... If it had been that my Mum had died two weeks before my exams, no one would be thinking 'you need to be getting a job now' but because she's not physically dead, I'm still expected to go around living my life like a proper adult. (Madison)

Shifting the focus but still considering landmark events, it is in the normal order of things for adult children to organise their parents' funerals. For Madison at 23, however, this imminent responsibility was daunting.

I for a long time have worried about my Mum's funeral .... I think about that a lot especially once I found out she was at the end stage. What will that be like? What am I going to say? What music am I gonna pick, what hymns?. How do I invite people? But I don't think too much past that. Obviously I worry about the situation, how she dies, when. How I find out. Any time the nursing home call me, I'm in fear. ... I remember asking her about what her favourite hymns are ... and I've known she never wanted to be cremated so we had talked about it but not in depth. I kind of wished I'd sat down with my mum and been like 'tell me exactly what you want'. But I was a lot younger when Mum got ill .... And I was thinking that no one has put anything in place for getting her last [Catholic] rites because Mum was so religious and that is important to her and I realised that no-one, especially my Jewish father, no-one had considered that. (Madison)

## Envy

Envy was frequently mentioned. Not only were participants envious of those whose parents were well and able to take a 'normal' part in their children's lives, but some expressed envy of parents who had diseases for which there was a cure, or which did not affect cognitive function.

My friend's mum recently died of MS, and it'd been gradual and deteriorating but she was still her Mum right to the end. So she would go and visit her and get advice from her, talk about it and discuss boyfriends, and discuss this, that and the other and what she was wearing whereas like I haven't had a normal conversation with my mum for six or seven years ..... I still get Mum-jealousy .... when people are like 'oh I went home and Mum always cooks for me everyday, treated me to stuff, shopping'. (Elizabeth)

I get a bit bitter when I see girls with their mums or middle aged women with elderly women and I'm like, that's not really fair .... If my friends moan about something their mum has done, I'm like, you don't know how lucky you are and that really bothers me .... I get really bad mum envy. (Madison)

## Coping or not

The need to keep 'getting used to a new normal' did not get easier and coping could be difficult. Evie had a counsellor but although she had found some strategies that helped, there wasn't anything that could be done to actually change the circumstances causing her anxiety:

I get stressed over things that I never used to get stressed over, like sometimes school work ... and putting it down to Dad's illness, it might be wrong but it seems like it's all stemmed from that because it's been a massive change .... I've got a counsellor ... but .... because I know where my anxiety stems from, there's not a lot that she can say to change the situation at all really. (Evie)

Colin had coping strategies including what he called 'detachment' but which could be interpreted as being anything but that. His explanation of his state of mind as a result of his mum's illness is contradictory and complex:

Recently I've said to my Dad when I've really not been coping 'I'm beyond caring, I just wanna turn my back and walk away' .... Which is obviously an awful thing to say but, there's a bit of logic to it because I don't really see what the advantage is in putting myself through it all the time when I could quite easily detach myself completely, and in a way, I already have part detached that allows me to get on with my life. .... I had a period recently where I was having real bad sleep difficulty and I went to the GP and he said that I had anxiety which I don't want to be diagnosed with .... I think it's too broad. Who isn't anxious in their final year of university? I'm not gonna deny that it's put an extra pressure on me but I don't see it really having any effect on the way that I'm living my life. Because when I do think about it, it's contained and I get it over with. It's a bit worse at night: if I'm left to my own thoughts, I'll encourage it. I'll play a song I know will upset me, try and push it out, but it's forced. I suppose also I've become a bit more hedonistic, a bit more wild with nights out, things like that. I was never a saint but I am going for it harder than I used to. I feel like that's probably because subconsciously or consciously, I'm wanting to forget something but the irony is, the opposite happens and actually by the end of the night, it's all I can think about. But I keep doing it. (Colin)

For Anna, coping with her father's dementia was complicated by her mum's response:

It just makes me sad and makes me think I'm not coping with it all [wiping tears] ... I just find it so hard seeing Mum so sad. And then I feel guilty because I've told her sometimes, there was one night the other week, I saw her three times in one week, and she was such a mess all three times .... then on the third time, we were out for a meal with family friends and she just started crying and ... I was like 'I'm not getting upset in this nice restaurant, it's meant to be a really nice occasion'. And I went to the toilets and she came and I was like 'Mum I can't do this, I'm not talking about this here. I feel like we spend our whole lives talking about it, I'm out'. I went back and I said to her friends you probably think I'm harsh but I just can't deal with it sometimes. (Anna)

In the event of physical death, a number of participants mentioned experiencing – or anticipating – relief but, as with any bereavement, grief can hit in the future. Grace suggested grieving can be lifelong:

[I was 22 when mum died after 11 years illness] Dad was the only person I'd talk about it to, I didn't want to bother anybody with it and there was a day I just started crying .... I ended up off work with depression, it was a year after mum died, it .... I just couldn't cope, I couldn't speak to anyone .... I went to the doctors and they said depression. I had tablets for a bit but I took myself off them, they made me feel worse ... I had six months just to try and sort myself out. I still get days where I'm sad .... You never get over it. .... Because I didn't just lose her when I was 22, I lost her before that ....., you go through your life dealing with it, not always dealing with it but just trying to cope with it. (Grace)

## Discussion

We found that, like the spouses and adult children of older people with dementia, as well as being straightforwardly sad because their parent had an untimely terminal illness, younger relatives experienced anticipatory and pre-death grief associated with, *inter alia*, the changes in relationships and expected futures the disease involves. It did not seem to us, however,

that Boss (1999) notion of ‘ambiguous loss’ was particularly helpful since, whilst participants talked about sadness because their parent was there in body but not in personality, there was nothing ambiguous about their sense of loss. The parent they had had was gone: they were no longer still there in any meaningful parental way (Sikes & Hall, 2016).

A narrative, life historical approach helped illustrate what grief can mean for young people starting out and making life-shaping decisions about education, career and family, with some altering plans and others choosing to put aspects of their lives on hold until their parent’s death. It also provided pointers to the legacy they were likely to carry forward in terms of guilt, sadness and regret and a sense of missing out on what have come to be, in western society, family-related norms. None of those we spoke with had a parent definitively diagnosed with a genetic form of dementia and so, although there was some mention of the possibility of inheriting the condition, no one expressed grief related to the curtailment of their own life. Had the ‘sample’ been different, so might the accounts have been.

Public awareness – or more accurately, ignorance – of the characteristics and pathology of YOD could be seen to aggravate and even intensify grief. Well meaning comments like ‘at least your mum/dad is not dead’, fail to recognise that being alive is not enough. This sort of reaction can be seen as symptomatic of a culture that sometimes appears to prize existence above life and its quality (Gawande, 2014). Reflecting on these issues, participants voiced ambivalent – usually guilty – feelings about whether it might be better for their parent and for the family if they were to die. Elizabeth had talked about this with her counsellor and he responded in a way she found helpful:

I said I felt really bad, I kind of am saying I want my Mum to die and he was saying ‘no you’re not. What you’re saying is that you want the situation to end and if it could be the other way and her not have Alzheimer’s, you would choose that. You’re not wanting to kill her . . . . You want the suffering of you and her and everyone else to end.’ (Elizabeth)

The issues surrounding ‘euthanasia’ are complex and problematic especially with regard to dementia and this is not the place to broach them.<sup>3</sup> However, all of our participants over 16 mentioned considering questions around the present or future quality of their parent’s life. Those who had been bereaved spoke of ‘relief’ for them and ‘release’ for their parent when death finally came. Any terminal illness can provoke such reflection but the protracted and singular nature of the pathway towards death involved in dementia engaged these young people in a particularly painful type of grieving experience that could affect their psychological and emotional health well into the future.

The research focusing directly on the views of young people who have a parent with dementia all indicates a serious sense of isolation and lack of understanding rooted in the ignorance of peers, the general public and professionals (social and health care workers, teachers, etc) alike. The findings of a (NCB, 2016) National Children’s Bureau study confirmed this state of affairs and identified a significant lack of age appropriate support services. In the UK, at least, support is very much dependent on location, and those in proximity to dedicated YOD services and organisations are usually better served. Even where there is provision, accessing specialist grief/bereavement counselling that could help in addressing issues can require individuals to find out what’s available and to have the sort of awareness of the potential value that not all who could benefit will possess. In addition grief counselling is often not available on the NHS and is costly. In the case of school age children, it may be even more difficult to gain appropriate help since their issues may fail to be recognised and even if they are, the evidence suggests a widespread view that only psychiatrists and

psychologists – who are in limited supply – have the skills to deal with bereaved children (Beswick & Bean, 1996), let alone those suffering pre-death related grief.

In arguing that a social model of disability can help to empower young people who have a parent living with dementia, Hutchinson et al. (2015) call for the ‘dementia sector’ to embrace technology to establish ‘greater connectivity’ with young people who have a parent with dementia. Beginning with the recruitment of participants, our study demonstrated the extent to which young people make use of the internet and social media to obtain information and advice and to make contact with others who have had similar experiences and who understand what it is like. Sharing in and of itself cannot ease the pain of grieving, but it can offer the reassurance that comes from knowing that you are not alone either in terms of what you are going through or with regard to the difficult feelings some people have towards their parent with dementia. It can also provide examples of the sorts of social scripts (Goodson, 2013) currently lacking for these young people which could act as maps to help them navigate their grieving journey. On the basis of what participants told us they would have found useful at different points of their parents’ illnesses, we are making use of internet technology, of social media and blogs to provide links to information about YODs and existing support groups etc. We are also re-presenting the stories told by project participants because it was these, we were told, that were most helpful in offering reassurance and affirmation that yes, having a parent with a YOD can be awful and can cause particularly debilitating and prolonged grief that needs attention if people are to have a chance to move forward into ‘successful’ and ‘adjusted’ lives. These stories also have much to teach those responsible for dementia services and policies in recognition that the impact and consequences of dementia are far reaching and profound.

## Notes

1. The Health Economics Research Trust in 2010 reported a figure of 64,000 but this may have been based on inaccurate estimates (<https://www.futurelearn.com/courses/faces-of-dementia/1/steps/76481>).
2. Around the age of 55 when their children were 15 and 13 Author 1’s husband began exhibiting what, 5 years later, were diagnosed as behaviours related to posterior cortical atrophy. At the time of writing the children are 24 and 26. Their father lives in a care home unable to communicate and reaching the end of his life.
3. See the contributions to a special edition of *Feminism & Psychology* (2010, 25, 1) for views on suicide, assisted death and dementia.

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## References

- Allen, J., Oyebode, J., & Allen, J. (2009). Having a father with young onset dementia: The impact on well-being of young people. *Dementia*, 8, 455–480.
- Alzheimer's Disease International. (2015). *The global impact of dementia: An analysis of prevalence, incidence, costs and trends*. London: Author.
- Alzheimer's Society. (2014). *Dementia UK: Update*. London: Author.
- Barca, M., Thorsen, K., Engedal, K., Haugen, P., & Johannessen, A. (2014). Nobody asked me how I felt: Experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics*, 26, 1935–1944.
- Beswick, G., & Bean, D. (1996). Group work for bereaved children: A team approach. *Nursing Standard*, 10, 35–37.
- Blandin, K., & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia*, online first, 1–12. doi:10.1177/1471301215581081
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boss, P. (2011). *Loving someone who has dementia: How to find hope while coping with stress and grief*. New York, NY: Jossey-Bass.
- Brown, T., & Kleist, D. (1999). Alzheimer's Disease and the family: Current research. *The Family Journal*, 7, 54–57.
- Chan, D., Livingston, G., Jones, L., & Sampson, E. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry*, 28, 1–17.
- Chrisp, T. A., Thomas, B. D., Goddard, W. A., & Owens, A. (2011). Dementia timeline: Journeys, delays and decisions on the pathway to an early diagnosis. *Dementia*, 10, 555–570.
- Clandinin, J., & Connelly, M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey Bass.
- Crutch, S., Schott, J., Rabinovici, G., Boeve, B., Cappa, S., Dickerson, B., ... Fox, N. (2013). Shining a light on posterior cortical atrophy. *Alzheimer's and Dementia*, 9, 463–465.
- Denny, S., Morhardt, D., Gaul, J., Lester, P., Andersen, G., Higgins, P., & Nee, L. (2012). Caring for children of parents with frontotemporal degeneration: A report of the AFTD task force on families with children. *American Journal of Alzheimer's Disease and Other Dementias*, 27, 568–578.
- Doka, K. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lanham, MA: Lexington.
- Edwards, R., Hadfield, L., Lucey, H., & Mauthner, M. (2005). *Who is a sister and a brother? ESRC Families and Social Capital Research Group Working paper 13*. London South Bank University. Retrieved from [http://www.lsbu.ac.uk/\\_\\_data/assets/pdf\\_file/0018/9342/biological-social-ties-families-research-working-paper.pdf](http://www.lsbu.ac.uk/__data/assets/pdf_file/0018/9342/biological-social-ties-families-research-working-paper.pdf)
- Feminism & Psychology (2015). *Feminism, suicide and assisted death: reflections on Sandra Bem's death*. 25,1.
- Frank, J. (2008). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 516–527. doi: 10.1177/1533317507307787
- Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*. London: Profile Books.
- Gelman, C., & Rhames, K. (2016). In their own words: The experiences and needs of children in younger-onset Alzheimer's disease and other dementias families. *Dementia*, online first, 1–22. doi:10.1177/1471301216647097
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey, NJ: Prentice-Hall.

- Goodson, I. (2013). *Developing narrative theory: Life histories and personal representation*. London: Routledge.
- Goodson, I., Antikainen, A., Sikes, P., & Andrews, M. (Eds.). (2016). *The Routledge handbook of narrative and life history*. London: Routledge.
- Green, T., & Kleissen, T. (2013). Early onset dementia: A narrative view of the literature. *Indian Journal of Gerontology*, 27(1), 1–28.
- Hall, M., & Sikes, P. (2016). From 'What the hell is going on?' to the 'Mushy middle ground' to 'getting used to a new normal': Young people's biographical narratives around navigating parental dementia. *Illness, Crisis and Loss*, online first, 1–21. doi:10.1177/1054137316651384
- Harris, P., & Keady, J. (2009). Selfhood in younger onset dementia: Transitions and testimonies. *Aging and Mental Health*, 13, 437–444.
- Holley, C., & Mast, B. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, 49, 388–396.
- Holley, C., & Mast, B. (2010). Predictors of anticipatory grief in dementia caregivers. *Clinical Gerontologist*, 33, 223–236.
- Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M. (2014). The emotional well being of young people having a parent with younger onset dementia. *Dementia*, 15, 609–628. doi:10.1177/1471301214532111
- Hutchinson, K., Roberts, C., Daly, M., Bulsara, C., & Kurrle, S. (2015). Empowerment of young people who have a parent living with dementia: A social model. *International Psychogeriatrics*, 28, 657–668. doi:10.1017/S1041610215001714
- James, A. (2005). Life times: Children's perspectives on age, agency and memory across the life course. In J. Qvortrup (Ed.), *Studies in modern childhood: Society, agency and culture* (pp. 248–266). London: Palgrave.
- Johannessen, A., Engedal, K., & Thorsen, K. (2015). Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors. *Journal of Multidisciplinary Healthcare*, 8, 245–254.
- Jones, P., & Martinson, I. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *IMAGE: Journal of Nursing Scholarship*, 24, 172–176.
- Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia*, 14, 164–183.
- Letherby, G., Scott, J., & Williams, M. (2012). *Objectivity and subjectivity in social research*. London: Sage.
- Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, 70, 2196–2207.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141–148.
- Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: Diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*, 13, 323–330.
- McLaughlin, D., & Tierney, W. (1993). *Naming silenced lives: Personal narratives and the process of educational change*. London: Routledge.
- Merton, R. (1988). Some thoughts on the concept of auto/biographical sociology. In M. Riley (Ed.), *Sociological lives* (pp. 17–21). Thousand Oaks, CA: Sage.
- Millenaar, J., van Vliet, D., Bakker, C., Vernooij-Dassen, M., Koopmans, F., Verhey, R., & Vught, M. (2014). The experiences and needs of children living with a parent with young onset dementia: Results from the NeedYD study. *International Psychogeriatrics*, 26, 2001–2010.
- Mills, C. W. (1970). *The sociological imagination*. Harmondsworth: Penguin (First published in 1959 by Oxford University Press).
- NCB. (2016). *Young people caring for adults with dementia in England: Report on NCBs survey findings and internet research*. London: Author.
- Oakley, A. (1979). *From here to maternity: Becoming a mother*. Harmondsworth: Penguin.
- Oliver, M. (2009). *Understanding disability: From theory to practice* (2nd ed.). London: Palgrave Macmillan.
- Perry-Young, L., Owen, G., Kelly, S., & Owens, C. (2016). How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography. *Dementia*, online first, 1–27. doi:10.1177/1471301215626889
- Plummer, K. (2001). *Documents of life 2: An invitation to a critical humanism*. London: Sage.

- Rando, T. (2000). *Clinical dimensions of anticipatory mourning*. Chicago, IL: Research Press.
- Redwood, S. (2008). Research less violent? On the ethics of performative social science. *Forum: Qualitative Social Research*, 9, 2, Article 60. Retrieved March 21, 2016, from <http://www.qualitative-research.net/index.php/fqs/article/view/407/882>
- Renzetti, C., & Lee, R. (1993). *Researching sensitive topics*. London: Sage.
- Richardson, L. (1990). Narrative and sociology. *Journal of Contemporary Ethnography*, 19, 116–135.
- Riessman, C. (2008). *Narrative methods for the social sciences*. London: Sage.
- Roach, P., Keady, J., Bee, P., & Williams, S. (2013). 'We can't keep going on like this': Identifying story lines in young onset dementia. *Aging and Society*, 34, 1397–1426. doi:10.1017/S0144686X13000202
- Robertson, S. (1996). *Younger people with dementia: The impact on their children*. Stirling: University of Stirling, Dementia Service Development Centre.
- Rosenthal Gelman, C., & Greer, C. (2011). Young children in early-onset Alzheimer's Disease families: Research gaps and emerging service needs. *American Journal of Alzheimer's Disease and Other Dementias*, 26, 29–35.
- Sanders, S., Ott, C., Kelber, S., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's Disease and related dementia. *Death Studies*, 32, 495–523.
- Shuter, P., Beattie, E., & Edwards, H. (2014). An exploratory study of grief and health-related quality of life for caregivers of people with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 29, 379–385.
- Sikes, P. (2013). The ethics of writing life histories and narratives in educational research. In P. Sikes (Ed.), *Autoethnography* (pp. 57–70). London: Sage.
- Sikes, P. (2016). 'But Who Is Mrs Galinsky, Mother?': From Nana Sikes' stories to studying lives and careers. In I. Goodson, M. Andrews, A. Antikainen, & P. Sikes (Eds.), *The Routledge handbook of narrative and life history* (pp. 405–417). London: Routledge.
- Sikes, P., & Goodson, I. (2016). What have you got when you've got a life story? In I. Goodson, A. Antikainen, P. Sikes, & M. Andrews (Eds.), *The Routledge handbook of narrative and life history* (pp. 60–71). London: Routledge.
- Sikes, P., & Hall, M. (2016). "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. *Dementia*, online first, 1–19. doi:10.1177/1471301216637204
- Speechly, C., Bridges-Webb, C., & Passmore, E. (2008). The pathway to dementia diagnosis. *Medical Journal Australia*, 189, 487–489.
- Stanley, L. (1993). On auto/biography in sociology. *Sociology*, 27, 41–52.
- Stewart, J. (2006). The frontal/subcortical dementias: Common dementing illnesses associated with prominent and disturbing behavioural changes. *Geriatrics*, 61, 23–27.
- Svanberg, E., Stott, J., & Spector, A. (2010). 'Just Helping': Children living with a parent with young onset dementia. *Aging and Mental Health*, 14, 740–751.
- Svanberg, E., Stott, J., & Spector, A. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics*, 23, 356–371.
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health and Illness*, 19, 93–117.
- Teel, C., & Carson, P. (2003). Family experiences in the journey through dementia diagnosis and care. *Journal of Family Nursing*, 9, 38–58.
- Van Vliet, D., de Vugt, M., Bakker, C., Koopmans, R., Pijnenburg, Y., & Vernooij-Dassen, M. (2011). Caregivers' perspectives on the pre-diagnostic period in early onset dementia: A long and winding road. *International Psychogeriatrics*, 23, 1393–1404.
- van Vliet, D., de Vught, M., Bakker, C., Koopmas, R., & Verhey, F. (2009). Impact of early onset dementia on carers: A review. *International Journal of Geriatric Psychiatry*, 25, 1091–1100. doi:10.1002/gps.2439
- Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer's Disease patients. *Qualitative Health Research*, 20, 159–169.
- Wimo, A., Winblad, B., & Jönsson, L. (2007). An estimate of the total worldwide societal costs of dementia in 2005. *Alzheimer's & Dementia*, 3, 81–91.