A narrative enquiry of experienced family carers of people with dementia volunteering in a carer supporter programme.

Keywords: peer support; volunteer; dementia; carer; narrative analysis.
Introduction

In the volunteering literature, many positive aspects of volunteering have been identified, including increased satisfaction (Butrica & Schaner, 2005; Low, Butt, Ellis-Paine, & Davis-Smith, 2007), self-esteem (Narushima, 2005; Primavera, 1999) confidence (Narushima, 2005; Thoits & Hewitt, 2001) enhancement of career prospects (Low et al., 2007; Primavera, 1999), social networking (Low et al., 2007; Morrow-Howell, Kinnevy, & Mann, 1999; Rook & Sorkin, 2003) and an elevated sense of community (Narushima, 2005). However, negative aspects of volunteering have also been noted, such as stress and burnout (Bakker, Van Der Zee, Lewig, & Dollard, 2007; Ross, Greenfield, & Bennett, 1999), poor training and support (Ross et al.,1999), a sense of obligation to stay (Low et al., 2007), and unrecognised efforts (Wilson, 2000). Research encompassing a variety of voluntary roles (such as administrative and practical as well as interpersonal), cite many positive benefits (e.g. Low et al., 2007). However, there seem to be more negative implications noted in interpersonal roles that involve potentially stressful work, for example with terminally ill (Bakker et al., 2007), and HIV/AIDS patients (Ross et al., 1999).

Peer support is a role that involves matching people in need of some form of support with volunteers who have had similar experiences (Hogan, Linden, & Najarian, 2002). In line with an ageing population and an increasing number of people with dementia (currently estimated at 800,000 in the UK; Lakey, Chandaria, Quince, Kane, & Saunders, 2012), their informal carers with unmet needs in social support are at a greater risk of role overload, role captivity and subjective stress (Gaugler et al., 2004). Many former carers continue to identify themselves in the carer role even after the person with dementia has died (Dobbins, 2007) and hold a sense of pride in the skills they have acquired, wanting these to be utilised (Yeandle, Bennett, Buckner, Fry, & Price, 2007). The increasing number of such ‘expert carers’ are in a unique position of understanding
to provide peer support to other carers of people with dementia (Nolan, 2001) and the development of peer support and learning networks has been stated as a key objective in the UK National Dementia Strategy (DoH, 2009). However, there may be periods of vulnerability for certain carers, wherein their motivation and appropriateness to volunteer should be carefully considered (Chan, Livingston, Jones, & Sampson, 2013).

A recent Cochrane review aimed to identify peer support programmes specifically for carers of a family member with a chronic mental or physical illness (Burnell et al., 2012). Only two studies evaluating one-on-one peer support programmes for carers of people with dementia were identified (Charlesworth et al., 2008; Pillemer & Suitor, 2002). Both studies revealed no significant changes in carer mental health and quality of life. However, Pillemer and Suitor (2002) reported positive qualitative feedback from the recipients of the programme, many of whom highlighted the importance of having a mentor who had had similar experiences to them. Limitations to the findings in both studies were noted, as the expected level of contact specified was not consistently achieved between all matches. Furthermore, Charlesworth et al. (2008) did not specifically recruit befrienders with experience of caring for a relative with dementia. However, the majority who volunteered did have such experience suggesting that this was a motivating factor in taking part. Whilst the aim of a befriending role is to provide “social support through the development of an affirming, emotion-focused relationship over time” (Mead, Lester, Chew-Graham, Gask, & Bower, 2010), it does not require the volunteer to have shared experiences.

In peer support, the current literature on how similar experiences between the volunteer and person supported need to be in order to facilitate a shared understanding is mixed. Carers of people with dementia have reported that only a fellow carer with dementia experience can
fully understand their feelings and frustrations, and this would make it much easier for them to form a peer relationship with a volunteer they had not met before (Sharpe, Koerber, Macera, & Euster, 1996). However, people supported by those with long-term health conditions different from their own still considered the peer supporters to have a shared understanding, which in turn increased their levels of self-efficacy (DoH, 2001). More generally, volunteers may arguably have life experience that can transfer to helping others, such as a broad knowledge of social issues, and personality traits such as patience and empathy (Narushima, 2005). In addition, there may be other attributes of equal or greater importance, such as shared demographic characteristics or interests.

Whilst there is an abundance of research on the positive and negative aspects of general volunteering, much less is known about the impact of volunteering on peer supporters. Buonocore and Sussman-Skalka (2002) evaluated the impact of providing peer support for people with age related vision loss. The vast majority of volunteers recommended that others take part in a similar programme, and were very satisfied with their experience. The benefits cited included teaching others valuable information, feeling useful, meeting new people, and learning new information. The programme had also prompted reflection of their own experiences of vision loss, facilitating self-learning as a positive outcome. However, there are questions about the generalisability of these findings to other health conditions and there may be particular considerations for carers of people with dementia.

Pillemer, Landreneau, and Suitor (1996) explored the motivations of experienced carers of people with dementia providing peer support for newer carers. A desire to help others and having had a similar experience were the most commonly cited reasons for volunteering. In providing support for newer carers, many of the volunteers reflected on how this had affected
their perception of their own caring experiences. Although the volunteers’ reflections on their own experiences was not the specific aim of the study, nor explored in detail, the authors suggested that programmes such as this provide the opportunity for experienced carers to connect not only with the newer carer, but also with their own experiences. Further research is needed to address this more directly.

The aim of the present study was to explore the impact of volunteering on experienced carers of people with dementia in a carer supporter programme. It was anticipated that the study would provide valuable insight into positive and negative aspects of the carer supporter role, as well as the influence of personal caring experiences on the overall experience of the programme.

Method

The present study was conducted as part of a larger UK-based study, ‘Support At Home: Interventions to Enhance Life in Dementia’ (SHIELD; Charlesworth et al., 2011). The SHIELD Carer Supporter Programme (CSP) aimed to develop, implement and evaluate an intervention in which more experienced family carers of a person with dementia (carer supporters) were trained to provide support for newer family carers of a person with dementia over a ten month period. The aim of the CSP was to improve a sense of self-efficacy and competence in the newer carer through encouragement and positive reinforcement of carer skills development and carer network building activities.

The CSP was hosted by voluntary sector organisations in four London Boroughs. Prior to being matched with a recipient carer, volunteers were provided with twelve hours of
compulsory training. This consisted of six two-hour modules, covering experiences of dementia and caring, the carer supporter role, listening and helping skills, working in other people’s homes, dementia awareness, and resources available to support carers. These were administered through a combination of teaching, group discussions, case vignettes, and personal reflection.

Carer supporters were matched with newer carers by the local volunteer coordinator based on socio-demographic background, caring experience, common interests, and availability. Their role required a minimum of weekly face-to-face or telephone contact with their match over a three month period, followed by fortnightly contact over the subsequent seven months. **The role of the carer supporter was to provide a ‘listening ear,’ moral support, encouragement to look after the carer’s own wellbeing, and signposting to local services and resources.**

**Participants**

Participants were carer supporters recruited from the CSP via the volunteer coordinators. They were considered eligible for participation in the study if they were over the age of 18 and had engaged in a minimum of five months of the programme. They were recruited from two out of the four hosting Boroughs. **Nine carer supporters were sent information regarding the study, eight of whom consented to take part. The one carer supporter that declined had left the programme after five months due to the pressure of other commitments on her time and felt she would not have sufficient feedback to provide.**

**Demographically, all eight carer supporters were White British, their ages ranged from 49-78, and five out of the eight were female.** Seven of the carer supporters were interviewed at home, and one requested to be seen at a local Trust site. Caring experiences of
the carer supporters and their matches are presented in Table 1. Carer supporter number five had been matched with two newer carers, and details of both are presented. Pseudonyms were used to ensure anonymity.

A Narrative Approach

The present study used a qualitative research design, utilising semi-structured interviews and a narrative methodology. Narrative research proposes that people organise their life experiences in the form of a narrative in order to make sense of it to themselves and others (Yardley & Murray, 2004), and much research to date has focused on making sense of the experience of illness (Murray, 2008). Narrative accounts strive for a sense of order to disruption in one’s life (Murray, 2008), which could arguably be, as Aneshensel and colleagues (1995) describe, the ‘unexpected career’ of dementia caring. The voluntary role can potentially provide a protective function to help address personal difficulties (Snyder & Clary, 2004), and the literature suggests that, for experienced dementia carers, a peer support role may offer them an opportunity to come to terms with their own, often difficult caring experiences (Pillemer et al., 1996). Therefore, a narrative methodology provides a space to explore this in terms of making sense and meaning from experiences.

Forming narratives is central to how we perceive ourselves and our identity (Murray, 2008). Identity is largely challenged and questioned throughout the caring process, particularly so when carers have ended their role and attempt to socially reintegrate, forming a new identity of themselves (Aneshensel et al., 1995). Narrative research also places particular emphasis on the relational aspects of stories, and how narratives can provide insight not only into the
narrator themselves, but other people described in their lives, and the relationship between them (Andrews, Sclater, Squire, & Tamboukou, 2004). The emphasis on the narratives in this study was predominantly relational, that of the carer supporters’ experiences with the newer carer. However, it was also anticipated that other relationships would emerge and be explored, such as with the person with dementia they care for or used to care for, the person with dementia the newer carer is caring for, and other formal or informal forms of support.

Procedure

The interview schedule was developed with reference to the existing volunteering literature and research, considerations for narrative methodology, clinical and voluntary experience within the SHIELD team, and consultation with an independent group of former carers. The interview questions covered overall experiences as a volunteer, positive and negative aspects of volunteering, personal caring experiences, and any changes in outlook concerning their perception of themselves, personal experiences, and future goals. The semi-structured interviews with the eight carer supporters lasted between 21 minutes and 1 hour 22 minutes, and were audio-taped and transcribed verbatim (with pseudonyms used to ensure anonymity).

Non-verbal gestures and length of pauses in the narratives were presented in brackets, and emphasis on words/ phrases presented in italics.

Narrative Analysis

Each transcript was repeatedly listened to and read, both separately and simultaneously in order to ensure accuracy of the transcription and become familiarised with the data and general concepts emerging. Three levels of analysis were conducted. Firstly, a ‘micro’ level analysis focused on the structural components of the narratives; how the narratives were told, the ways in which form and language were used to communicate life chapters and key events,
and reflection on the significance of these being told at particular points in the narrative. Secondly, a content level analysis extracted predominant themes and subthemes expressed within and between the carer supporter narratives. Thirdly, a ‘macro’ level analysis addressed the wider socio-cultural and historical context, and dominant cultural narratives about issues such as ageing, dementia and caring (Emerson & Frosh, 2009). Quality checks for qualitative (Elliot, Fischer, & Rennie, 1999) and narrative research (Crossley, 2007) were adhered to throughout the analytical process to maximise the validity of the research and ensure methodological rigour.

**Results**

*Micro (Structural) Level*

Through exploring the impact of volunteering, most carer supporters naturally made links between the volunteering experience and their own caring experiences, without being prompted by questions. A positive aspect of the role, referred to by Helen as “selfish,” was a sense of comparative relief that they no longer had caring responsibilities. These evaluations provided a sense of contrast between a predominantly negative life chapter of caring for someone with dementia, and a positive volunteering experience. This suggested that involvement in peer support held the advantage of highlighting their new found sense of identity and control over their lives; the “selfish” as a gain to their sense of self.

Many carer supporters reflected on the positive impact of having had shared experiences with the newer carers, putting themselves in a unique position of truly understanding what it means to be a carer. One advantage to this was providing a sense of connection. For example,
Eleanor noted a lot of similarities between her previous position as a carer and Rose’s current position.

And she’s having to care for her big husband. I was having to care for my big husband [laughs].

This positioning of understanding held advantages and disadvantages in that whilst it facilitated a close relationship with the newer carer, (Helen: “...it was amazing how quickly my carer opened up to me”), it evoked queries of how to define the relationship, and to what extent they were a ‘professional’ or ‘friend.’ Helen ultimately defined the role by positioning it on a spectrum between professional and friend;

... [healthcare work] is very very, much more sort of um, clearly defined your role. Being a family member is clearly defined where your boundaries go because it’s to do with relationships. This was in the middle.

Related to this, carer supporters referred to the relationship following the end of the match period.

Anne: I’m still going to phone her and maybe meet up with her. Because that is it with a volunteer. You can’t just drop a person then go on to the next one.

Whilst the carer supporters had generally appraised their relationship with the newer carer as positive, an interesting observation was that predominant relationships featuring in the narratives were often not with the newer carer. Carer supporters often described relationships with other family members, friends, and professionals within extended voluntary roles and
other carer supporters. For example, from early on in the interview, Anne spoke frequently about providing support for a friend who was caring for her husband with dementia. She expressed a sense of connection through similar experiences as, “...she has been in exactly the same position...” They also frequently used visual prompts, imagery and gestures to recall the person they had cared for thereby creating a sense of their ‘presence’ in the interview, and the carer supporters’ current lives.

For example, Ben, being a current carer, spoke predominantly about his wife, Mary, but his narrative tended to focus temporally on a shared life and happy events prior to her diagnosis of dementia. These narratives were enriched through complementary use of other media such as photos, music and other visual prompts. This gave the sense of Mary being very ‘present’ in the interview.

This was further noted in other interviews through use of visual prompts and gestures. For example, Eleanor brought out a photo of her late husband, John, early on in the interview, perhaps as a way of providing a visual context and connection to her story for the researcher. Anne evoked a lively image of her mother when she was well;

“Mum was slight, nimble, could run up that garden and back [pointing to garden] with no problem.”

Overall, it was noted that the carer supporters regularly redirected the conversation towards relationships that seemed most salient to them and there was a strong interconnection between their personal caring experiences and their volunteering role, which facilitated the development of the relationship with the newer carer.
Three predominant themes emerged through the carer supporters’ narratives of the impact of the voluntary experience; connectedness, positive gains, and negative emotions.

A new found sense of connectedness to others included the sub-themes of reciprocity, gender connection and connection to a wider network. Generally, carer supporters felt they had been able to provide the help and support they had intended, and had in turn received something back from this relationship.

Bill: “She was um, she felt that no-body was helping her and she was on her own, and that my support was valuable, which was very comforting to me.”

All of the carer supporters had been matched with a newer carer of the same gender, with the exception of Bill. Of note, Bill expressed his preference for same gender matches.

“I did ask if I could um, really have males all the time... but um, you, you can’t always work out that way. I mean, I don’t mind seeing women but I seem to get on, I have more of a rapport with men somehow, I don’t know why.”

Bill described, and thereby seemed to view, his match more in a triadic sense; a relationship between himself, Elizabeth, and her husband Stan, rather than the dyadic match of carer supporter to newer carer. A sense of connection to a wider network, extending beyond the dyadic match relationship, facilitated a sense of belonging and identity. For example, Bill and
David’s sense of identity was expressed and reflected on in terms of an extended work network. Bill’s reason for taking part in the programme (following retirement), was a way of identifying himself as someone with purpose and worth, defined in this case through a work role. David’s narrative carried a central theme of identity by regularly reflecting on two contrasting life chapters and senses of self; the self as a former taxi driver working autonomously, and the self as a volunteer, working very much as part of a supportive team;

“It’s always been cut throat in the cab trade, you know, you going along with the cab someone cuts you up to get the fare before you do. But with, uh, with working as a team, I found it fascinating. Absolutely fascinating. Because people was, was willing to do my work for me…”

The connections formed through the programme were pertinent to Ben, appraised as, “...about the only good thing that’s come out of it [having a wife with dementia] for me really.” The extended networks and sense of identity and belonging facilitated a future script in terms of plans to nurture relationships made, and consider further matches with other carers. For example, Eleanor had planned to continue seeing her match and additionally set up a support group for people with dementia and their carers, with the help of the volunteer coordinator.

Positive gains tended to be expressed either in a practical sense, that of training and skill acquisition, or in terms of emotional gains.
David: ...well I think I just love to go there. And I love to come back. I’ve felt so positive when I’ve come back from meeting him.

Most of the carer supporters commented positively on the training programme, in terms of capturing their interest, enjoyment from learning, and application of this learning to support their matches.

Bill: ...the courses helped me out a great deal...and I did put into operation a lot of the things I’d learned on the courses, and they worked. So that was quite satisfying really.

Positive emotions such as confidence, pride, and self-esteem also extended to the general volunteering role, and within wider social and organisational networks.

Lisa: ...I’m very very proud to say what I do. Very proud to say what I do.

In addition to positive emotions, the narratives revealed how negative emotions could be evoked from the volunteering role by (as Sarah stated), “bringing it all back.” There were also reflections on the potential negative impact for other volunteers.

Helen: a lot of it’s focused around what the [newer] carer needs or what the patient needs. But I think, um, assessment of the person who wants to volunteer, you’d need to look very carefully, to see if you, you’re actually going to bring harm to them emotionally by exposing them to this scenario again.”
Macro (Socio-Cultural) Level

Carer supporters often reflected on their volunteering experiences compared with their own caring experiences in order to appraise how people with dementia and their carers are currently supported in society. These beliefs were mixed. Anne reflected on the “marvellous” services available for her match Sue now compared with when she was a carer:

The help is tremendous now. There’s so much more into it isn’t there now... from years ago.

Sarah had felt let down by the system and described in detail a key event when formal carers had been stealing from her mother.

What sort of people, they’re supposed to be a carer, you know. Those people that were going in to help [2] you know... that you could steal from somebody like that. It’s awful [2].

Sarah tried to make sense of a situation that clearly made no sense, after all, “they’re supposed to be a carer,” and she concluded with a generally pessimistic view of society’s care system; “I think people take advantage of people in that position.” This suggests that she continued to hold such a view.

Lisa also spoke very passionately throughout the interview about the continued lack of recognition for the elderly in society, and people with disabilities in general.
I think this is where this country lets its elderly down. It really does. I think this country’s very geared towards babies, young children. But it’s not geared towards the elderly, or people with long term illnesses and that sort of thing.

There was also a sense of concern for how future aspirations and their role in the voluntary sector may be affected in uncertain times of service cuts.

David: Obviously with the cuts in the government, and the local councils, uh, it sounds as though we’re on borrowed time.

More positively, some carer supporters had found themselves becoming actively engaged with up-to-date research and media coverage of dementia.

Sarah: All I, all I like to do is find out as much as I can now. Whenever I see a television programme or I see something in the newspapers I’m there and I always want to, you know, know what’s going on with research and what’s going on.

Discussion

This is the first study to explore the experiences of the volunteers in a carer supporter programme in the context of previous caring experiences. Carer supporters tended to reflect on their own personal experiences, and on the positive impact of having shared experiences with the newer carers. The majority of carer supporters described a predominantly positive relationship with their newer carer, and their initial positioning of themselves as a person to provide help was generally validated through the process of the volunteering experience. Emotional and practical gains from participating in the programme were frequently
expressed, as well as a greater sense of connection with others, extending to a wider social and organisational network. However, carer supporters also reflected on the negative emotions that could be evoked and the issue of the timing of the role.

Having shared experiences facilitated a positive relationship between the carer supporter and their newer carer. Objectively, the sample were considered to be relatively heterogeneous in terms of how similar these experiences were between matches; for example, in the relationship to the person cared for, type of caring support, and living circumstances. However, it seemed that an appraisal of shared experiences was more subjective. If peer support involves matching people with “similar difficulties” (Hogan et al., 2002), this evokes the question of how similar caring experiences need to be between the volunteer and person they support in order to develop a good relationship. In this study, gender seemed to be an important socio-demographic factor in developing a sense of connection between the carer supporter and newer carer. This was particularly so for males who are recognised to be in the minority when considering informal caring roles and the provision of peer support (Charlesworth et al., 2008; ONS, 2002). Further research could explore what makes a successful match, including how both objective and subjective shared experiences influence this.

The carer supporters struggled to define the relationship with the newer carer and positioned themselves at different points along a continuum between ‘friend’ and ‘professional.’ This evokes an interesting issue relating to Nolan’s concept of the ‘expert carer’ position between the informal support of relatives and friends, and professionals (Nolan et al., 2001). This is further complicated by the carer supporters’ reflections on how this relationship positioning might potentially shift after the official ending of the match. Despite four of the carer
supporters having officially ended the ten month match period, all were still in contact with the newer carers. However, it was too soon to predict how the relationship may evolve over time.

Positive emotions expressed were of value, confidence, pride, and enhanced self-esteem. Such gains have been commonly cited in the general volunteering literature (Narushima, 2005; Primavera, 1999; Thoits and Hewitt, 2001). The more practical positive gains were often attributed to skill acquisition and the training offered by the programme. This highlights that the context of volunteering may be equally or more important than the dyadic peer support relationship; the structure of the programme, training, and relationship with the volunteer coordinators. Furthermore, a sense of pride may have stemmed from a combination of the skills acquired through personal caring experiences (Yeandle et al., 2007), and the training programme itself.

The programme seemed to facilitate a wider connection to extended voluntary roles and a support network for carer supporters, which was appraised as a positive consequence of taking part. This can be seen as a positive form of social reintegration after the dementia ‘caregiving career’ has ended (Aneshensel et al.,1995). This extension of voluntary and social roles also provided the carer supporters with a future script, with plans to continue these roles and relationships, and pursue new ones. This is in line with Narushima’s (2005) finding that volunteers often continue to pursue further roles once involved.

Carer supporters’ reflections on previous caring experiences were mixed. Whilst some expressed a comparative feeling of relief and positivity at no longer being in a personal caring role, the voluntary role had also evoked negative emotions. At times, such narratives
were incoherent and ‘broken,’ and expressed in a sad reminiscent tone. It is unclear to what extent these negative emotions are a ‘normal’ part of a grieving process, or if they have longer-term implications. Carers of people with dementia have been identified as more susceptible to complicated grief with a higher need for bereavement services compared to carers of people with other long-term illnesses, given the neurodegenerative nature of the illness (Chan et al., 2013). There is also a need to consider transitional periods wherein they may potentially be more vulnerable and stressed, such as care home placement or post bereavement. For example, there may be a higher risk of low mood in the few years post caring (Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). However, there is great variability on how transitional points affect carers (Seltzer and Li, 2000). Further research is needed to explore the longer-term impact of the voluntary role and how it may help or hinder the process of grief.

At a wider societal level, Narushima (2005) highlighted positive aspects of volunteering, which were also expressed in the present study; an elevated sense of community, and realisation of the needs of society. Mixed feelings were expressed about how society supports people with dementia and their carers, both in the past when they were carers, and the present. This drive to contribute to society was often a motivating factor for further voluntary work, and this was noted by the way in which some carer supporters had begun compiling information, and keeping up to date with research and media coverage. This demonstrates how former carers are active agents in shaping the future of dementia care services.

It is recognised that, as a limitation of the present study, ideally purposive sampling would have been used to ensure recruitment of a sample representative of carers of people with dementia in terms of demographic background and relationship. However, open sampling
was used due to the limited size of the sample population available at the early stage of the Carer Supporter Programme (CSP). In spite of this approach, the study included a diverse sample in terms of gender, relationship to the person they care or cared for, and status in the CSP (on-going or post match period). The high recruitment rate was also notable. Of nine carer supporters approached, eight agreed to take part. Carer supporters exhibited enthusiasm in sharing their experiences, with several preparing notes in advance and expressing an interest in receiving feedback from the study. However, it is worth noting that the carer supporter who did not wish to take part in the study had left the programme before the match had ended, and did not feel that she would be able to provide sufficient feedback. Although she had stated her reason for leaving the programme as due to other commitments, it is also possible that her experience may not have been entirely positive. It is therefore possible that the sample was biased in favour of those who had continued with their matches and had a predominantly positive experience.

In conclusion, this study has provided insight into the experiences of volunteering in a peer support programme, in the context of personal experiences of caring for someone with dementia. A narrative methodology allowed an in-depth exploration in terms of how their experiences were expressed, what predominant themes emerged, and the influence of the wider socio-cultural context. Many positive gains were noted, and the programme facilitated new roles and relationships for the carer supporters. However, the timing of the role should be carefully considered in the context of potentially stressful transitional points throughout the caring role. Carer supporters can provide a valuable role in line with recent health and social care policy changes, providing an ‘expert carer’ position between the informal support of relatives and friends, and professionals (Nolan et al., 2001). These findings have clear service, clinical and social relevance by highlighting the value and potential benefits of
experienced carers of a person with dementia acquiring new roles and identities within an enriched social and organisational network.
References


Table 1

*Caring Experiences of the Carer Supporter/ Newer Carer Matches*

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<thead>
<tr>
<th>Carer Supporter</th>
<th>Newer Carer</th>
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<td><strong>Pseudonym</strong></td>
<td><strong>Caring for/ Cared for</strong></td>
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<td>Grandfather</td>
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<td>‘Anne’</td>
<td>Mother</td>
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