Past Caring

A carer-led narrative research project about carer bereavement

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Cover image: Figure 1 -'John'

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1. *Summary* ‘Past Caring’- A Carer-led Narrative Research Project about Carer Bereavement

Project Goals

This research project explored the phenomenon of carer bereavement. It was also about making opportunity and removing barriers to carers doing their own research. A group of bereaved carers undertook the project to collect the stories of people like themselves, people who have spent time caring for a person who has then died. The project was about what comes next, how carers feel and what they experience.

Method

The project was multi-method, collecting interviews and digital stories. 8 long, semi-structured interviews were conducted with a snowball sample of participants by 3 interviewers. These were digitally sound recorded. Training in interviewing techniques (for 2 peer interviewers) and qualitative analysis techniques (for 3 peer analysts) was provided as part of a capacity building aim. All participants were also invited to take part in a week long digital storytelling workshop as a second part of data collection. They each developed and scripted a short 250 word personal story into a multi-media digital film or digistory, using photographs, moving image and voice recording. Full training and support was provided. 5 people took part in the first course. Eight months later a second course was run for 3 further participants. 3 peer facilitators from the first workshop series were trained in digital storytelling techniques and themselves acted as tutors for the second course. Counselling support was offered at all project stages.

Analysis/ Outcomes

The interviews were co-analysed, and a project report was group edited, detailing in-depth accounts under seven emerging themes. The digital stories were produced onto DVD and www.youtube.com/folkusuk.

Findings

1. On **Caring Experience**, we found people keen to stress the difference between ‘usual’ and ‘unusual’ bereavements and the isolation experienced when they found themselves ‘out of sync’ with their peers. Parenting bereaved children was also key.

2. In **Positive Perceptions** of Caring, pride, love and respect were over-riding and people emphasized return altruism over a lifetime and personal reward to the carer. Positive aspects in bereavement focused on regaining some independence and being released from the engulfment of the caring situation.

3. **Dealing with Stress** was a third key on-going issue for bereaved carers and was the over-riding health related concern.

4. **Loss and Social Isolation** were also key and people described a graded series of bereavements or losses that do not simply coincide with the death of the cared for person. Understanding of an earlier period of ‘living bereavement’ -a time of suspension of much social and emotional support, when ‘moving on’ is not an option was stressed.

5. The importance of being given opportunity to recount a detailed **Death story** was a strong need expressed. The bereavement story is not rehearsed or valued in the same way and more attention to this might improve things for bereaved carers in coping and surviving.

6. The **Money Matters** theme showed the subtle ways money matters to the long term bereaved carers involved here who did not have specific financial hardship. They experienced difficulties in taking over financial custody for their loved ones, in money-related fears of community judgment, doubt of the altruistic caring motive and pressure from 'the whisperers' within communities.

7. In **Relations with Services**, carers spoke about how support offered did not match their needs for convoluted and complex reasons.

Participant reflections on project involvement showed the work was experienced as 'good but not easy', important for 'processing what's happened', made people feel 'less unvalued', 'restoring identity and confidence', providing 'something to share with others' and enabling people to 'use dormant skills and learn new ones'.

Dissemination

The project outcomes were used to share carers' stories with carers and other community groupsx and to lobby statutory and third sector services to better understand the needs of this group.

Recommendations

- Continuing work on preventing stress related breakdown, finding ways to acknowledge and thereby possibly help people expose feelings of residual guilt in particular.
- Increased support to carers in facing periods of transition and change linked to different kinds of bereavements at the end of the caring role and beyond.
- Provision of creative time limited peer mentoring and befriending co-support to help carers at key stages in the end of life, using skill-building learning as a focus to get people together.
- Offering increased opportunities to rehearse bereavement narratives to improve coping.
- Service re-focus away from just the short term, the time immediately after the death of the cared for person, to include a time further down the line in a bereaved carer's experience.

2. Background

2.1 Bereaved Carers

'Carers' provide unpaid care by looking after an ill, frail or disabled family member, friend or partner[1]. Bereaved carers are those who have had a 'cared for' person who has died. The term 'former carer' has been coined in the sociological literature, defined as 'someone who does not necessarily identify themselves as a former carer but has experienced an episode of caring in the past that ended with the death of their dependant. This caring was not carried out on a professional basis, and excluding benefits, was unpaid' (Larkin, 2009). The term 'bereaved carer' was used in this project as the preferred term of the authors. We included those experiencing 'living bereavement' within the term, those who's cared for person was lost to dementia or residence in a care home.

As Parkes (1972) pointed out 'Despite the awe which each of us must feel in the face of death, clinical observation forces one to conclude that it is easier to die than to survive' (p93). In the last decade, carer bereavement was 'barely recognised in public practice. Services are (if all goes well) mobilised for the dying. For the survivors who suffer more there is often nothing. There are ordinarily no carers for the carers in their bereavement as there were for the dying. They are on their own' (Young & Cullen, 1996, 147). The stories of carers who have been bereaved started to attract a little research attention in the last decade. Audrey Jenkinson published a 'The Beginning not the End', a book based on her own personal experience as a former carer and edited extracts from interviews with others in similar positions in 2004. This was a blend of personal stories collected by an actress whose parents had died, presented to uplift and woven into the author's personal twelve step recovery guide for past carers. In 2009, Mary Larkin published a paper drawing on her PhD research with former carers. She called for adoption of a more holistic approach to carers' needs, recognition of post caring support needed from professionals and she made recommendations about voluntary sector provision. She raised 'serial caring' and understanding of the phases of a post-caring trajectory as key issues to explore further.

Other work has given some attention to bereaved carers, but has not had this as its major focus. Young and Cullen (1996) held conversations with twelve East Londoners and their carers to see how they fared in the period leading up to their deaths. They included one short chapter on accounts from the surviving carers about what happened to them afterwards. This charts isolation, loss, deep grief and a devaluing of the bereaved carer experience. Lewis & Meredith (1988) and Brown & Stetz (1999) both interviewed former carers and explored the caring experience but the post caring experience was not a major focus of either study. McLaughlin & Ritchie (1994) studied former carers as part of a larger sample examining the effectiveness of social security benefits.

Some exciting narrative based projects had been carried out with carers in the UK at the time of writing (Kirklees, 2006; Patient Voices, 2012; Winslow, 2009). In a carer's digital storytelling project for Carers Gateway in Huddersfield, carers recorded a range of their stories (None were with those bereaved) (Kirklees, 2006). Those who have been running allied projects recognised there was a gap in current work. In the Sheffield Palliative Care Oral History Project (Winslow, 2009), Michelle Winslow said 'The interviews we currently do are not with bereaved people, though

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[1] The General Household Survey (GHS, 2000) shows that in the UK more than half of carers (52%) were caring for their parents or parents in law, 21% for a friend or neighbour, 21% for another relative, 18% for their spouse, 8% for a child (including adult children). Most carers look after elderly people, 70% of those cared for are 65 years or over (Carers UK, 2009). 62% of carers look after someone with a physical disability, 6% with a mental disability and 18% with both a physical and mental disability.

during the pilot study in 2003 we interviewed someone who lost her husband with Motor Neurone Disease. She talked a lot about living with the disease and afterwards asked if she could be a volunteer interviewer with the study… the experience was positive for her (Winslow, 2009). Health Talk Online collects interviews with a range of people talking about health. Each of their projects is a qualitative research study in itself, with analysis of the issues that people talk about, published on their website (Health Talk On-line, 2009). When we started this project, they had conducted some interviews with carers (for their projects on heart failure, dementia, Motor Neuron Disease and Parkinson's) and plan a future study on bereavement after caring to complement their studies on bereavement by suicide (launched 2009) and bereavement by sudden and traumatic death (launched in 2010). At the time of writing up our work, they had received funding from Marie Curie to interview 40 carers and bereaved carers to inform their 'Committed to Carers' initiative (MCUK, 2012).

The Patient Voices Project is another group who has done increasing amounts of work with carers, seeking to improve the quality of healthcare using digital patient stories (Hardy, 2004). They suggest patient stories have 'come to form a key part of patient-centered care and … to support the more deeply entrenched 'evidence-based medicine' in a balanced approach to healthcare' (Hardy, 2004, p2). They have recently collected some stories from people with early-stage dementia and one of their carers (Stenhouse et al, 2012). In considering the social context of bereaved carers within health and welfare, we also noted a growing interest area for narrative work at the end of life in the hospice movement and within palliative care (e.g. Brehaut, 2006; Lichter, Mooney & Boyd, 1993; National Council for Palliative Care, 2011).

2.2 Policy Context

The development of specific policy for carers was one of the striking developments of the past two decades (Twigg et al, 1990; Twigg & Atkin, 1994). Carers became the ascendant group within social care, 'on trend' for politicians and arousing increased academic interest. Luke Clements suggested that carers were six million people that were 'getting on with it', representing the classic neo-liberal dream, taking a huge strain and gradually articulating their situation as a minority group with rights (Clements, 2010). *Caring for Carers* (DH, 1999) was the first national carer's strategy, followed by new legislation affecting carers such as the *Carers and Disabled Children Act 2000* and the *Carers (Equal Opportunities) Act 2004*, *Work and Families Act 2006* and the *Pensions Act 2007*. A *New Deal for Carers was announced in 2007*, and carers were recognised by the DH in *Our Health, Our Care, Our Say* (2006), the Darzi review (Darzi, 2009) and the NHS Constitution (Department of Health, 2010d). Carer support was monitored by the Commission for Social Care Inspection (CSCI, 2007, 2008, 2009) CSCI recognised early that

'There are major tensions for councils in their policies to support carers. They are charged with improving efficiency and targeting resources effectively and are consequently restricting eligibility to services. But at the same time they are looking to support carers, recognising the risk that without support many carers own health and well-being may suffer and they, too, will need help in their own right. The danger, as ever, is that carers are only seen as a 'resource' and some carers continue to be socially excluded and barred from the opportunities others would expect' (CSCI, 2006). Many local authorities used their DH carers' grant to develop local carers' strategies and appoint 'carers' lead officers' (Fry *et al.*, 2009). In May 2010 the Conservative-Liberal government updated the National Carers' Strategy (2010) prioritising early identification of carers, carers educational and employment potential, 'personalised' support for carers and mental and physical well-being (HMG, 2010a:5). In November 2010, the 'Big Society' notion was put forward by the Tory party, while broader notions of civic or community involvement/engagement were more broadly accepted cross the political spectrum (HMG, 2010b).

Within all this, there was little mention of carer bereavement. The DH *End of Life Care Strategy* (2008) stated that surveys of bereaved relatives and carers were to be introduced, looking at the quality of services they received as their cared for person approached the end of life. It mentioned an intention to start research on how best to support carers as their relative reached the end of life, but said nothing directly about support for carers in bereavement (DH, 2008). A National Carers' Strategy Demonstrator Sites (DS) programme was developed from 2008, focusing on breaks for carers, health and well-being checks for carers and support for carers in different NHS settings. A national evaluation in 2011 mentioned bereaved carers only twice, reporting that bereaved and 'near end of life' carers were among the groups that no site demonstrated it had engaged effectively with (Yeandle & Wigfield, 2011). One NHS site had tried to engage bereaved carers, but with no evidence of success (Yeandle & Wigfield, 2011, p61). So at the time of writing, DH policy makers were at early stages of identifying bereaved carers at the local level, but activity through a variety of coalitions and national voluntary sector programmes was starting to have impact.

In 2009, the National Council for Palliative Care (NCPC) set up the Dying Matters Coalition to promote public awareness of dying, death and bereavement more generally (Dying Matters, 2012). They provided opportunities for people with personal experience of palliative and end of life care to participate in policy, good practice and media activities and their work contains lots of good examples of engaging with bereaved carer's stories and providing support networks. In relation to specific illnesses, resources and interest in issues that affect bereaved carers was also mounting. One example was the patient and carer engagement work of the Marie Curie Cancer Care (MCUK, 2012). Another was the on-going work of Age UK. Age UK Leeds and Age UK South Tyneside began a project in late 2012 focusing on the needs of older carers and providing support at end of life, including the time after their caring role has ended. This has been extended to some other areas of the country (Age UK, 2012).

2.3 Theoretical and Service Perspectives

Many reports exploring and evaluating the lives of carers and their service needs have a hugely political character, often being produced to legitimise a service or justify a policy or funding decision (Twigg et al, 1990). Most are very closely embedded in the politics of service development. The context of the Past Caring Project is different. While several of its participants have played important roles in carer service development (mainly from within activist and voluntary groups), the group came together through informal personal networks, and are diverse in their politics and experience.

As described above, carer bereavement is a current developmental area for service providers. The lack of existing knowledge about carer bereavement meant that the core project focus needed to be about establishing basic information about the phenomena of carer bereavement. Carers occupy an ambiguous social position within the social and medical care system anyway (Twigg & Atkin, 1994). We shall see in this study that bereaved carers become quickly hidden to all but the smallest of minorities on the margins of the social care world, unless they have on-going caring responsibilities for others.

Twigg acknowledged that carers pose moral responsibilities for welfare agencies as they cannot be assumed to pursue their own interests in a straightforward way –relationships and feelings of obligation have severe consequences for their lives. These continue when the cared for person dies. This Project helps us to look closely at 'the ties that bind ' bereaved carers. We look at the wider ways in which the 'restrictedness' of care-giving that limited and constrained the carers life when their cared for person was alive (including frustration, burden, claustrophobia) casts a forward shadow over their life during bereavement and beyond. We reveal private fears and thoughts that are scarcely ever articulated (and are hence especially easy for service providers to miss). In particular, we show the bereaved carers 'surrounding social choruses, the perceived critical voices shaping the way we give ourselves permission to live without the carer identity.

Carers are part of the 'taken-for granted' backdrop of health and social care provision where they occupy an 'uncertain and fragmented position' (Twigg et al 1990). Service providers and policy makers make assumptions about carer's availability, involvement and duties, structuring and resource-restricting their provision in the light of those assumptions. Some services have a specific carer-orientation. Others do not even formally acknowledge the carers existence. Very few mention bereaved carers in any way. Hence, what the Past Caring Study can offer in this area are rare detailed insights and oversights about the way the social and health care systems as a whole affect carers in their caring lives, in their bereavement and beyond. We stress the importance of the life-course perspective that this enables, as bereaved carers go on to articulate their own future health and welfare needs and those of other people, for whom some go on to care for.

We feel in particular that the project could be useful for medical services and in medical education, where the focus is very much on the patient, and the consequences of action for the carer are often dimly perceived anyway, vanishing from view at the time of bereavement. Presenting a more fluid, deconstructed account that ranges across the service system as a whole and addresses how services are provided as well as what is provided, might allow us to better reflect some of the complexities. Following Twigg's suggestions (Twigg & Atkin, 1990), we see services reflected in our participants accounts as 'contingent comings together of help, rather than as a coherent and unitary system' (p18). In this view, non-receipt or absence of a response are just as important in piecing together the stories.

In the Past Caring Project, we are treating the study of carer bereavement as a subject in itself – aiming to achieve a position of self-conscious articulation to force some key issues onto the policy agenda. We recognise that the task that follows is to re-integrate those accounts back into wider debates concerning social care and disability.

2.4 Service User-led Approach

We wanted to design a project where the participants were actively engaged in developing and planning the work, actively involved in the delivery of the work through their role as co-researchers and peer supporters and actively involved in analysing the findings, writing up the project and disseminating the results to achieve a policy and service impact. Essentially, the participants were acting as advocates for the needs and rights of those with previous onerous caring duties who have to weave themselves a new kind of life when their cared for person dies or has dementia or leaves them for residential care. Through this activity, we were interested in exploring the best ways for people to bring about change in their communities relating to the way bereaved carers are treated and understood. We were also experimenting with the most effective ways to involve people as participants and co-researchers and to share innovative practice in meeting bereaved carers needs for peer support and community involvement. We aimed to provide bereaved carers with opportunities for social engagement and for building or enhancing peer networks.

Whilst we recognised that bereaved carers are a diverse group and have different lifestyles, abilities and needs, we also knew that they have a wealth of skills and experiences that could potentially be harnessed and enhanced to enrich their communities. This project was built around bereaved carers coming together and inviting and enabling other bereaved carers to give their time, energy and skills within a user-led research project.

So this project aimed to undertake a robust piece of service user-led research. The definitions of service user research range from those which ask service users the questions, through to service users being 'equal partners' with professional researchers, to user led research (Ramon, 2003, Beresford and Wallcraft, 1997). In this project, User-led research meant that service users originated the idea, helped to get the funding, helped design and carry out the research, helped analyse the data and write it up and helped disseminate the findings. At times, the carers led on key areas, while others were researcher led, but we all commented on everything and co-authored most outputs. This is an idealised version of the model put forward in The Survivor's Guide to research (Faulkner and Nicholls, 2002). The project reflects many of the values and principles that underpin the user movement more generally: empowerment, collective action in order to effect strategic and political change, partnership and co-operation between service users. However, we recognise that as Maddock et al (2004) suggest, 'although efforts are being made to consider the possibilities of user/survivor led research and the shift required to offer space to such a discourse in research, there are those in many corners who continue to resist them... it is still an activity that sits on the fringes of user involvement'(p1). By undertaking this project, we share in a highly challenging but important goal to change the politics of research production (Beresford, 2008; Postle et al, 2008).

Models for involving people in all levels of research in this way can be seen in a growing body of emancipatory research (Barnes, 2003; Beresford, 2002; Hanley, 2006) where shared authorship is key (Frisch, 1990; Rouverall et al, 2000, 2003). We are helping to build on a growing body of partnership research in health and social care evident from the INVOLVE database (INVOLVE 2009 –INVOLVE is the national advisory group, funded by the Department of Health, that promotes public involvement in health and social care research). In designing this project, we were also mindful of local Peninsula College of Medicine and Dentistry (PCMD) guidelines and the project was approved by the PCMD Ethics Committee. Specific guidelines for the ethical conduct of research carried out by and with health service users were also used (Faulkner, 2004; Hanley, 2005).

Figure 2: Rosemary, Brian and Rachel at the first project development meeting

3. *Project Aims*

3.1 To explore carer bereavement, filling a gap in carer research

As mentioned above, carer's stories have been collected for some time by Health Talk On-line, Patient Voices and more local projects like the Gateshead Carers Project and the Sheffield Palliative Care Oral History Project. The directors of these projects acknowledged that there was an existing gap in relation to the stories of carers who have been bereaved when we started our work. Existing projects that had been carried out with bereaved carers have been very exciting, but small scale and limited to conventional anonymised designs (such as Mary Larkin's PhD research, 2009). This project aimed to contribute to further base-line information about the phenomenon of carer bereavement through research.

3.2 To give bereaved carers a voice

James Earl Jones once suggested that *'One of the hardest things in life is having words in your heart that you can't utter.'* This project aimed to take an interest in bereaved carer's stories and to collect, value and pass on these stories in order to give carers a voice they had not had to date. 'Patient stories have been recognised (Greenhalgh and Hurwitz, 1999 and others) as making a significant contribution to understanding the patient experience; they acknowledge the patient's own areas of expertise, i.e. his or her own life and unique experience of illness.' Hardy (2004, p76).

3.3 To directly improve bereaved carers lives

Telling stories in supported ways can have important cathartic effects. Potentially it allows participants to explore latent levels of personal meaning for themselves and to share these with others. We didn't want to just produce something coherent and attractive, but also stories that were difficult and controversial. Cheryl Mattingly showed that sharing stories gives participants new future stories (Mattingly, 1991). This project aimed to help people move beyond any disadvantage. Small et al (2009) suggested from their study of dying, death and bereavement with the carers of people with heart failure that input to carers after the death of their cared for person may reduce future demands on scarce services and so have an economic bonus. We were unable to measure this outcome here, but we did evaluate bereaved carers' experience of taking part.

3.4 To develop an innovative, multi-method design

By moving outside a reliance purely on written print media and peer reviewed academic publication, the project sought fresher, more inspirational ways of telling, sharing and presenting the stories of carers who have been bereaved through sound interviews and digital stories. This aim accorded with a drive to make sure research was both more accessible to and more accountable to those who take part and the public more widely.

3.5 To influence practitioners and change policy

Stories have been shown to offer powerful tools to influence policy agendas (Greenhalgh & Hurwitz, 1999). In her work on digital stories with the Patient Voices Programme, Pip Hardy made links to clinical governance and micro-systems, evaluating the role of patient digital stories as essential in improving the quality of healthcare and training. The 'Patient Voices' programme was suggested to 'both redress the balance of power between healthcare clinicians and managers and the people they serve, and it gave decision-makers a different kind of opportunity to understand the needs of patients – other than the dry results of surveys and statistics ' (Hardy, 2004, p76). Other storytelling interventions, like the one at the Royal Devon and Exeter Hospital (Health Foundation, 2008) which involved using a video about patient experience of venous thromboembolism (VTE) and brain damage to ensure doctor's own VTE prophylaxis performance was improved, have been used to spread improvement methods throughout the hospital. Stories from this project aimed similarly to inform a better, more ethically sensitive response by statutory and non-statutory services to the needs of bereaved carers. Through co-analysis of the interviews, we aimed to move beyond an informational educational role, providing clues to the wider symbolic workings of statutory services and other support networks for carers.

3.6 To change carer research agendas

Research agendas and topics are often set for carers and this project aimed to draw on carers own agency in changing the production of useful research. This project aimed to engage the power of carers to share and acknowledge bereaved carers stories that have not yet been publicly told and to create new spaces for their telling. Excellent carer involvement was sought, with carers initiating the project and taking control of the research design, implementation and dissemination. It was about making opportunity and removing barriers to carers doing their own research.

3.7 To offer carers high quality information technology training

Our aim was also to empower carers by offering participants training in different media and information technology techniques that would be useful for the project and an investment for their future. At the time of writing, there had been recent attention to engaging older people in improving their information technology skills and this project aimed to add to this agenda in a capacity building way.

3.8 To offer carers research support and skills exchange

A further aim was to offer on-going support in using research recording and analysis equipment and techniques, and sharing the existing research skills of those involved within the project group.

3.9 To offer carers emotional support

As a carer-led group, we were acutely aware of the need to offer to support carers who may be considered to be vulnerable to tell difficult and challenging stories with full back up support available from a trained counselor.

4. Research Questions

Box 1: Research Questions

1. The Phenomenon of Carer Bereavement

What are the personal situations of long term carers who have been bereaved? What have they been through? What are their specific needs? What is the impact of carer bereavement on day to day life?

How do people cope (financially, emotionally, socially, practically and spiritually)? When and to what extent can bereaved carers overcome any state of abeyance with employment or social life which was previously postponed for an indefinite period?

How do carer-oriented services affect carers in their bereavement? What support comes as a by-product of other help? Have any coherent models of support to bereaved carers emerged? In what ways can service providers be more sensitive to the needs and interests of bereaved carers?

2. Carer-led Research

How do bereaved carers shape their own accounts of their needs through the stories that they tell?

5. *Research Design*

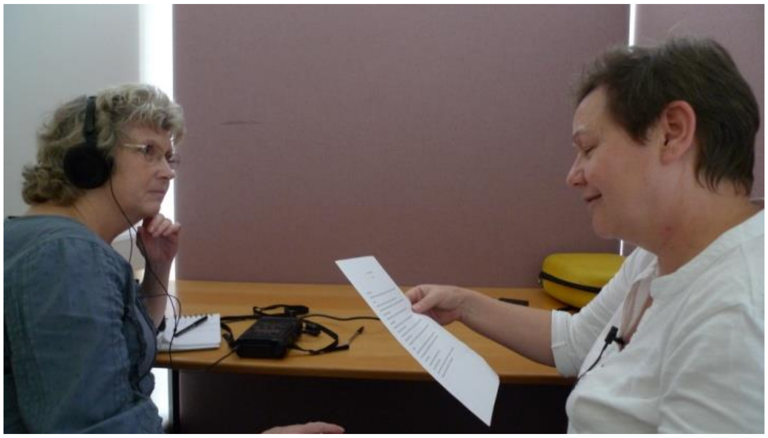

Figure 3: Victoria and Kath recording sound

5.1 Interviews

Semi-structured, one-to one, qualitative interviews were used (Collins, 1998; Kvale, 1987; Patton, 1987). Such interviews are considered useful to minimise potential threats experienced in relation to sensitive research topics (Lee, 1993). Participants were given the choice as to where they would prefer to do the interview, choosing between their own homes or an interviewing room in the Peninsula Medical School. The interviews lasted between 1-3 hours in length. Our goal was to make sure they were manageable and not too exhausting, while allowing for in-depth and penetrating accounts to be revealed. An open-questioning technique was used- drawing on a question guide to broadly structure accounts (see detailed description below).

For the interviews, we adopted what Bartunek & Loius (1996) describe as 'Insider/Outsider Team Research'. With roots in community psychology and action research, this model is informed by an ethical and political stance which seeks to empower research participants. By combining in a research team people with varying degrees of cognitive, conceptual and social distance from the group, 'a marginal perspective is created at the intersection of the contrasting perspectives represented by insider and outsider.' 'Insider' researchers are people whose biographies gave them a lived familiarity with the group being researched and that tacit knowledge informed their interviewing (Griffith, 1998). This 'insider' status was the entrée into the community of bereaved carers for the project and research evidence suggests that, for research in such sensitive areas, it offers greater possibilities for trust from participants (Darlington & Scott, 2002; 41). An 'insider' researcher will share cultural and personal understandings and may be better able to both empathise and to interrogate subtle nuances with an interviewee. An 'outsider' is someone with no intimate knowledge of the group being researched prior to her entry into the project team. Kvale suggests that the position of this interviewer should avoid and counteract risks described in the methodology literature as 'over-identification with participants… maintaining a critical perspective on the knowledge gained' (Kvale, 1996: 120) and particularly questioning 'assumed knowledge'.

The informed choice of participants, within a feminist praxis, was our key guide as to who interviewed who (Darlington & Scott, 2002). We were reflexive about the process and the interviewers worked closely together to examine insider /outsider factors affecting the resultant interviews.

5.2 Digital storytelling

Digital storytelling is a research technique that has become increasingly popular in recent years. It was introduced by the BBC to give television viewers and radio listeners a chance to make their own two minute broadcast and publication on the internet. People were invited to workshops where they were taught technical and story-telling skills, script-writing, industry standard image and video editing software. They made their own two minute films or sound broadcast. The experience of the BBC Telling Lives Project was that the process had a natural integrity. The media often come in to a community, take stories away and deliver them back to people in a voice they don’t recognise. ‘Through this workshop process there is no mediator or professional producer editing the completed story… participants deliver it to the producer in its finished form. There are no surprises for the storyteller when it is aired to the public’ (Stephenson, 2008, p3).

Digital Stories are short (under three minutes) ‘combining video, audio, still images and music that reveal patients’ stories in a unique way’ (Hardy,2004, p76). The method adopted in this study was developed by Barrie Stephenson and his colleagues has taken many years to germinate and comes supported by a significant body of exciting academic publication (Fyfe, 2007; Meadows, 2003) and a manual and set of ethical guidelines for producing digital stories. The digital storytelling workshops for Past Caring were designed by Barrie Stephenson and followed a set programme. They constituted a practical course where each individual created and produced their own digital story, using a collection of personal photographs and working in groups and individually. The format was as follows:

PREPARATION DAY to find out more about the project, meet others who have shared their stories and hear what it involves and what to prepare.

DAY 1, a story-circle to help people choose, script write and record the short story they choose to tell.

DAY 2 participants were invited to come in for a one hour slot to sound record their story.

DAYS 3 & 4 participants were invited to come to 2 day workshops to learn key software packages and use these to add images and film to their story. The final day ended with a film premiere.

Figure 4: The last day of a Digistory Workshop

The Patient Stories Project claims that digital stories have value in research and service development because they ‘can highlight gaps in the health and social care system, can reveal near-misses and form 'free learning opportunities', promote healing and reconciliation, can allow patients' and carers' (and professionals if appropriate) voices to be heard, can carry forward stories that might otherwise be lost, are created in a spirit of collaboration and partnership, *and* touch hearts, thereby reinforcing the notion of patients at the heart of care' (Hardy, 2004, p76).

6. *Participants and Sampling Method*

Previous qualitative studies of post caring used quite large samples and relatively short semi-structured interviews recorded at one sitting. Larkin interviewed 39 of an original sample of 44. Lewis & Meredith (1988) interviewed 41 former carers, McLaughlin & Ritchie (1994) 10 and Brown & Stetz (1999), 26 former carers. This developmental study aimed to work more intensively with a smaller number of adult participants. It was a project of partnership with carers, who had agency and control in the project. As such, we were not conventionally sampling the population, but working in partnership with a purposefully small number of people to look at information rich cases, in depth and detail. Snowball sampling is seen to be advantageous in this kind of sensitive context in that 'security' features are built into the method. 'Intermediaries who form the links of the referral chain are known to potential respondents and trusted by them. They are thus able to vouch for the researcher's *bona fides* (Lee, 1993).

The participants were initially, the 3 people in the project team who self identified and asked for Folk.us assistance to do the project (Rosemary Whitehurst, Brian Ruel and Victoria Jones). They had not previously worked together, but knew of each other through their Folk.us membership. They assembled a Project Advisory Group (described below) and together, recommended other people who might like to participate and some community groups to approach. Prospective invitations were discussed. An element of 'theoretical sampling' was embraced in this process (Coyne, 1997). There are 3 main ways in which carers are often categorised (Twigg et al, 1990), in terms of features of:

- themselves (male carer, elderly carer)
- their dependant (carers of elderly people, carers of disabled children) and
- their relationship (spouse, parent, non-kin carers such as neighbours).

Often research studies restrict themselves to one or other of these categories, but in the 'Past Caring' Project, we openly invited individuals as a way to stress important parallels and contrasts between these 'service-oriented' groupings. We could not hope to be representative, but aimed for a mix of people relating to these categories. We also aimed for some geographical spread across Devon[2]. We chose to emphasize what Twigg has termed 'the undifferentiated character of care-giving... the restrictedness, the assumption of responsibility'. At the same time, our interest was in the detail, in the particularity of experience, recognising carers are not a homogenous group. Unusually, we included in our project carers who are experiencing 'living bereavement', whose loved one has been lost to dementia or residence in a care home. Most caring that people do is for 2-3 years as a person ages and dies. However, for people with or who develop long term disabilities, caring can be very long term or life-long. Our focus in this project was on the latter – people bereaved after long term (and in some cases very long term) caring experience.

The age of our participants was limited to adults (age 54 to 85yrs) -child and youth bereaved carers bring particular requirements for ethical permissions and procedures that we were not able to cater for (but hope to in future). Our project did not allow for any systematic treatment of issues of class or race, in part due to our location in South Devon with its demographic of a predominantly white population. Our carer-led networking or snow-ball recruitment method and the sensitivity of the issues exposed by the project meant that we engaged more with people who were mobile and those who have had some contact already with other carers. We recognised that as predominantly 'middle class carers (we) were likely to have greater access to resources (Parker, 1990a) and this affected the caring experience and capacity for involvement in time-consuming research.

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[2] One participant, Kath worked in Devon but lived in Cornwall.

In all 11 people were invited to attend a project information afternoon and we spoke to 8 other individuals during the course of the project who had expressed interest. 8 participants decided to take part and were available for the negotiated workshop dates (Rosemary, Brian, Victoria, Gill, John, Liz, Sue and Kath). Sue chose not to record a digital story.

We recognised that bias was an almost inevitable feature of this sample as of most others 'because the social relations which underpin the sampling procedure tend towards reciprocity and transitivity… Networks tend to turn in upon themselves and to be homogeneous in their attributes, rather than providing linkages to others whose social characteristics are different' (Lee. 1993:68). However, Patton (2002, 563) suggests that in snowball sampling for small studies 'the issue is not one of dealing with a distorted or biased sample, but rather one of clearly delineating the purpose and limitations of the sample studied'.

Reflexivity was an essential part of this participative method. There was discussion and reflection within the project advisory group of transparent, sensitive and non-coercive recruitment, leaving an audit trail of decisions made, clearly reporting any refusals and monitoring impact on method and conclusions. People who chose not to take part were not required to give their reasons. However, those that volunteered information said timing (when the sessions ran) and the overall time commitment (especially for the digital story making) was too much. Some were balancing other caring roles (particularly for grandchildren and living partners). Some booked holidays and other activities at short notice and had to drop out. A few were suspicious of the project goals, concerned that the products would be amateurish and unconvincing.

Figure 5: Brian and Gill in pained concentration

7. *Project Team*

This project was run by a team of 5 people: 3 were bereaved carers, who also had a considerable range of research skills, experience and life experiences to share, initiated the project (Rosemary Whitehurst, Joanne Perry and Brian Ruel); 2 were senior researchers from Folk.us[3] (Wendy Rickard & Rachel Purtell) who facilitated and supported the team throughout the project. Joanne Perry moved to Canada near the beginning of the project. After the first six months, one of the participants, Victoria Jones, was invited to join the Project Team. Victoria became a key member. 2 freelancers (Barrie Stephenson and Julie Wyman) supported the team in digistories and counseling respectively (described below). A collaborative capacity building design was adopted. We will do our best here to clarify the resultant roles that emerged.

7.1 Interviews

3 interviewers worked on this project (Rosemary and Victoria and Wendy). They undertook about 3 interviews each. It is a rather crude description, but two functioned as 'insider' researchers (Rosemary and Victoria) and one as outsider (Wendy). Wendy had no existing personal or professional links to those being interviewed, other than in being part of forming a partnership for this project.

7.2 Digital Story Telling

Two digital storytelling workshops were run as part of this project. A digital storytelling trainer, Barrie Stephenson, lead the first digital storytelling workshop of the project. Amongst his 18 years of experience working at the BBC as radio producer and managing editor of two BBC local radio stations, he headed up the digital storytelling initiatives 'Telling Lives' and 'Capture Wales'. More recently, he conducted a digital story-telling project in partnership with a group of carers and social workers in Kirklees (Carers Gateway in Huddersfield, 2006). The project team studied the web-site and listened to the digital stories with interest as part of our background research. We contacted Kirklees Social Services, who strongly recommended Barrie[4].

One goal of the first digital storytelling workshop was to start to train the Project Team as digital storytelling trainers themselves (Rosemary, Brian, Victoria and Wendy). For the second digital storytelling workshop, the Project Team led the first two days of training (Story-circle, script-writing and photos). Barrie led the second two days of training, with input from the Project Team (digital images, film and movie-making).

7.3 Counselling

Many of the stories recorded were very personal and difficult to deal with before and after the telling. A trained counsellor was employed for the project duration to offer support sessions to any participant who felt they needed them. Julie Wyman, with significant experience of working with carers, was employed as part of the Project Team. She was available on demand throughout the

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[3] Folk.us works to promote service user, patient and carer involvement in research. Based at the Peninsula Medical School /University of Exeter, Folk.us was funded by the National Institute of Health Research (NIHR), Department of Health until March 2012.

[4] Barrie led the team at Radio York that won a Sony Gold Award for its community service to North Yorkshire during the floods of 2000 (Stephenson, 2009).

project period. 3 people took up counselling over a number of sessions. This open model was based on a model developed in other research initiatives[5]. None of the current literature on former carer research projects (Larkin, 2009; Jenkinson, 1994; Lewis and Meredith, 1988; *McLaughlin* & Ritchie, 1994; Ziebland & McPherson, 2006; Carers Gateway in Huddersfield, 2006; Winslow, Walsh & Noble, 2009; Hardy, 2005; Patent Voices, 2009) built in the offer of counselling in their research design so this was an innovative and experimental feature of the Past Caring Project.

Figure 6: Doing the final edits on digistories

7.4 Project Research Advisory Group

We also had a Research Advisory Group of 7 people, with an operational function to oversee the research team and to advise them on key areas of the project design, procedure and conduct. The Advisory Group was made up of the 5 members of the Project Team plus Pam De Clive Lowe (Research & Development Manager, Peninsula Primary Care Research Management & Governance Unit, Public Health Directorate, Devon Primary Care Trust, Commissioning Headquarters, County Hall and Part time Post Graduate Lecturer, Postgraduate Education Centre, RD&E Wonford Hospital) and Deirdre Ford (Lecturer in *Social Work*, School of Applied Psychosocial Sciences, University of Plymouth).

7.5 Guidelines and outside expertise

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[5] Most specifically, from 2003-7, the Living Stories Project (Experiences of People with Haemophilia and HIV and Experiences of the families of people with HIV and Haemophilia), ran as user-led initiatives with a research team of Robert James, Sian Edwards, Wendy Rickard and Krista Woodley (www.livingstories.org.uk). The projects were financed by the Heritage Lottery Fund and based at the University of Brighton. Melanie Ottewill was employed as a counsellor to support participants and interviewers on demand throughout both projects. The amount of support accessed on demand serves as our most immediate model for this project. At a reflective feedback event facilitated by Melanie Ottewill and Dr Rickard in Swindon in 2007, Living Stories Project participants described their use of the service and their feelings and experiences. It was rated as highly important and Krista Woodley wrote up the findings for a paper given at the International Oral History Conference (Woodley, 2008) The counselling role in the Past Caring Project drew on and further developed such experience.

There were potential problems in co-producing and co-editing the outcomes of this project as a team, overseen collectively by a project advisory group. A smooth process relied on consistently good personal relationships and agreed ways to work through any analytical tensions and disagreements, respecting people while also challenging each other creatively. We were mindful of work on shared authorship and experiences of others such as the Brighton Popular Memory Group in reflectively working through these issues. There were some other dangers and pitfalls in recording a personal story for public broadcast on a web-site (e.g. issues like defamation/libel; contempt of Court; taste and decency). BBC Guidelines were followed and referral onward to professionals in the field on specific issues. The key issue that arose about which we sought some outside expertise was in relation to use of music in personal digital stories and copyright.

8 Research Instruments

8.1 Question guide

A question guide for Past Caring was developed using knowledge and expertise of basic methods of interview guide development, but particularly those developed for long complex narrative interviews. The development of a guiding set of questions to inform an oral history interview is considered basic good practice by many practitioners (Yow, 1994; Perks & Thomson, 1993). We followed the advice that 'The detailed interview guide should be used as a memory jogger for what needs to be covered and how best to ask it, rather than as a rigid plan' (Thompson & Perks, 1993: 14). 'An interview guide is a plan for the interview… (it) will not be imposed on the narrator (Yow, 1994: 36). This preparation phase for interviewing was drawn from models written up in practical oral history texts (Thompson & Perks, 1993; Perks & Thomson, 1998; Yow, 1994).

In developing the interview guide, we also looked at those developed specifically with former carers. In particular, guidance was sought from Dr Mary Larkin, De Montford University, Leicester (Larkin, 2009). Through phone and email contact, Larkin kindly privately shared the research tools developed for her study of former carers and discussed their further development with some members of our Project Team. Jenkinson's book 'Past Caring: The Beginning not the end' (1994) served as another specific model, as did Lewis and Meredith's (1988) study of 'Daughters who care' and McLaughlin and Ritchie's (1994) 'Legacies of caring: The experiences and circumstances of ex-carers'. We studied their interviews and aimed to develop these and fill existing gaps in the work. We talked with Sue Ziebland at Health Talk On-line and studied the methodology and research instruments for the Health Talk On-line project (Ziebland & McPherson, 2006). We also looked at and listened to all Health Talk On line's existing holdings on carers and listened to full interviews. We listened to and spoke with the Kirklees Carers Project and the social workers who started that work (Carers Gateway in Huddersfield, 2006). Similarly, Michelle Winslow has shared with us some of her most relevant palliative care interviews (Davidson, 2003) and we have had private correspondence about these (Winslow, Walsh & Noble, 2009). The Patient Voices Project was another key model (Hardy, 2005; Patent Voices, 2009).

8.2 Project Information Sheet and Consent Forms

A project information sheet and consent form was written in accordance with the model set out by the Peninsula Medical School Ethics Committee recommended model. Participants were also asked to sign an additional consent form regarding permission to use photographs of them taken during the course of the project.

8.3 Equipment

For the interviews, we used A Marantz PMD 661 digital sound recorder with Lavaliere lapel microphones. For editing sound we used Soundforge. For the digital stories, we used mac laptops with iphoto and imovie. For photos, we used a Lumix LX 3. For analysis we used the Nvivo qualitative analysis package.

8.4 Payment

The participants in this research project were all offered payment to be paid research partners and were paid £50 for their involvement in the digital storytelling workshops. One participant chose not to accept the payment. Expenses for all were reimbursed using the existing agreement Folk.us had with PCMD finance - to pay the same rates as the University and PCMD for travel, and the actual cost of any trains, taxis or buses fares and mileage costs at 40 pence per mile and for time at the 'Visiting Academic' rate of the University[6]. The 3 participants /Project Team members were paid for all meetings, interviewing work, training and analysis.

9 Timeline

The project was completed over an 18 month period from November 2010 to March 2012, although project write up extended until August 2012 due to our time consuming group editing approach. Project planning started 2 years previous to this in 2008. It was important that this project was carried out when it was. Ken Plummer once suggested that 'Stories capture intimate life' (Plummer, 1995, p21). He stated that there are contextual conditions for stories to be received, at moments of public reception. From looking at existing published carers' stories and at government policy and other developments in carer services and support, 2011/12 was such a 'cusp' moment of public reception for bereaved carer's stories. At the same time, the project group came together at a time that was ripe for them to tell the stories of their recent experience. The participants sought opportunity to tell these stories with an urgency to capture the experiences and feelings.

10 Procedure

In initial project team meetings we shared ideas about project design and developed confidentiality and privacy policies for the group, forming a group project protocol to which we all committed and agreeing a method to reflect on the research process through similar project group meetings throughout and at the end of the project. The project was approved by the Peninsula College of Medicine and Dentistry Research Ethics Committee. In all, the project pre-planning phase took 2 years and we started the project in October 2010.

Through a series of one to one conversations with the Project Team and in an open information meeting for bereaved carers, the project design was explained to potential participants. People were invited to take part. 8 people came forward. Each participant was asked to sign a consent form at the outset, to be returned within 2 weeks of that first meeting.

5 people were invited to take part in a 4 day digital storytelling workshop in January 2011. This was held in a room at the Peninsula Medical School, RD&E Hospital. The digital stories were

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[6] For further information please refer to the precedents and policies set out in the following documents:
http://www.folkus.org.uk/files/expenses_costs_version_14th_September_2006.doc
http://www.gov.uk/.......PublicationsPolicyAndGuidance/DH_4138523.;
http://www.scie.org.uk/publications/reports/report08.pdf;
http://www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf

produced onto a CD and copies were returned to the participants. The stories were also put onto Youtube for internet access.

In the following 6 months, 2 members of the project team were trained in interview techniques and 8 people were interviewed (5 at the hospital and 3 in their own homes). The interviews lasted 1-3 hours and were mainly recorded in one session (one interview was recorded in 2 sessions). The interviews were digitally sound recorded. The interviews were summarized, transcribed and returned to the interviewees for checking and finalizing. All participants were provided with copies of their final summary, transcript and original recording on DVD or CD. 3 members of the project team received training in analysis techniques.

In September 2011, a second digital storytelling workshop was run for 3 participants, again over 4 days. This was again held in a room at the Peninsula Medical School, RD&E Hospital. The digital stories were again produced onto a CD, with copies returned to the participants and put onto Youtube with participant's permission[7].

From September to November 2011, 4 members of the project team worked together to analyse the interview data, working independently as well as in a group at 4 consecutive analysis meetings. We then wrote a final project report and designed and wrote content for a Project web-site. The edited data was presented in themes on the project website with an archive of the digital stories and full unedited interviews. With participants' agreement, the digital stories were placed on this web-site too. Each participant was involved with the editing of their themed information for web-site presentation.

A right to withdraw fully at any stage of the project, without giving a reason, was made clear and we accepted that people could change their minds about their contribution mid-project (though no-one did).

All raw data connected with the project was stored in a secure locked cabinet in the Folk.us office. Digital files were pass-word protected. Raw data will be kept for 5 years. Unlike other projects, participants chose to record their stories under their own names (Larkin (2009) used pseudonyms with fictionalised place names for example). It was a key finding of the project process that participants wanted to own their own stories. Research outputs that were put on the web and on You-Tube went into the public domain for an indefinite period, restricted by the participants' decisions at the end of the project. A de-briefing session including this discussion and decisions was conducted about the web-site and digital story sites.

Since participants all acted as paid co-researchers in the spirit of shared authorship, personal data remained with the lead researcher for the period required by University regulations and Finance Department, but negotiated with each person according to their personal circumstances.

11 Analysis Method

The project analysis was undertaken following qualitative thematic analysis models similar to that developed by Health Talk On-line (Pope, Ziebland & McPherson, 1999; Ziebland & McPherson, 2006) and the Health Experiences Research Group in Oxford. We adapted their style, but embraced a group editorial process working with 3 key participants who were given training. Such group processes have precedents in existing research literature produced by the Popular Memory Group and in what Bartunek & Loius (1996) describe as 'insider/outsider team research'.

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[7] One participant chose not to put her digistory on Youtube.

Like the Health Talk On-line analysis method, the interview recordings were fully transcribed and the transcript returned to the participant for review and correction. A computer assisted software package, Nvivo, was then used to help organise the interview transcripts for further analysis. Analysis began soon after the first interviews. Using grounded theory techniques and line by line coding, we drew up a list of low level categories for analysis of the first few interviews. As the analysis progressed, additional categories were added and modified as emergent tensions were explored (Tesch, 1990). We grouped and linked all of the sections of the interviews that covered a similar topic. When this initial coding and categorising was finished we looked at what everyone said about a particular topic, and gathered these together in a series of ‘reports’. These reports became the basis for the analysis development to structure the report findings. We then sent the draft analytical accounts back to the participants for comment and review. Participants made comments and sometimes decided that there were sections of the interview they would rather did not appear in the report or gave suggested edits, in which case they were removed from the public version. Health Talk On-line (2009) use a similar member-checking process.

During analysis the Project Team looked at the 'reports' and together made sure that important points, and every respondent’s perspective, were included in the topic summaries. At a series of 6 analysis meetings, there was discussion about meaning and interpretation of points made during the interviews and at later stages, these were also discussed with the Project Advisory Group. Baxter et al (2001) highlight that findings can be cross-checked with evidence from other studies to increase their robustness. In this project we compared our emergent findings with other former carer research findings where we could. Regarding publication, a write up of themes drawn from the analysis was published initially in this report and we then sought publication in a respected peer reviewed qualitative journal.

Figure 7: Kath and Liz selecting photos to accompany their digistories

12 Findings

In this section we present the findings from our analysis of the interviews that people contributed. The sections are ordered to present each distinct theme separately, with sub-themes or categories in each section, ending each with a brief overview. In presenting these findings, we acknowledge that the phenomenon of carer bereavement is messy, complicated, uncertain and soft. We seek an 'imaginative' or 'poetic' aspect in presenting the 'evidence', emphasising Arthur Bochner's (2000) six criteria presented in Box 2:

Box 2: Arthur Bochner's criteria for judging 'poetic social science'
(Green & Thorogood 2009, p281)

- Detail of the commonplace, of feelings as well as facts
- Narratives that are structurally complex and take account of time as it is experienced
- A sense of the authors, their subjectivity and emotional credibility
- Stories that tell believable journeys through the life course
- Ethical self consciousness: respect for others in the field, and for the moral dimensions of the story
- A story that moves the reader at an emotional as well as a rational level.

We start with a section titled 'The Participants' -a section with eight evocative descriptions of each of the people who took part in the project, to enable the reader to connect with them as individuals. These accounts are drawn directly from people's own words at interview, and each individual also edited their own section at draft stage, but direct quotes from interviews throughout the report are unedited. Analysis resulted in the identification of eight main themes, which we present broadly as Caring (sections 2 and 3), Loss (sections 4,5,6), and Practical issues (sections 7 and 8). The final section of the findings, reports on participants reflections about the Past Caring Project itself and seeks to evaluate the extent to which the project achieved its aims:

1. **The Participants**
2. **Caring Experience**
3. **Positive Perceptions of Caring**
4. **Stress**
5. **Loss and Social Isolation**
6. **Death Stories**
7. **Money Matters**
8. **Relations with Services**
9. **Reflections on Project Involvement**

12. 1 The Participants

In this section, we introduce the eight bereaved carers who took part in the project –Rosemary, Brian, Gill, Victoria, Kath, Susan, John and Liz –in no particular order. Where possible, we have used our own words from the interviews to give a glimpse of the past caring situations, the way we live now and the family we do or don't have around us, our own personal and occupational backgrounds and current activities. We remind readers again that we may be untypical and far too few to permit any generalisations, but we did not talk to each other for that purpose. We chose to speak as individuals who might be able to throw some light on the experience of bereavement after caring for a loved one over a long period. At the end of the section, we offer an overview of what the participants and their stories can and cannot tell us.

12.1.1 ROSEMARY

Rosemary cared for her Mother, Novello for ten years after her stroke. Novello died in 2005.

> And she was severely disabled, she lost all her speech, all intelligible speech, anyway. She had gobbledygook, which meant nothing... And she was right side impaired, but she was able to walk. And for the next seven or so years, she lived here. She did have a reasonable quality of life. And then I think she probably had some little strokes that we didn't know about and she'd gradually become a little frailer and then she had a very bad fall. And that made life very difficult thereafter in terms of caring for her, and they weren't able to provide the sort of care that I needed in order to look after her properly.
>
> And finally, she went into a hospital, because they couldn't find any care workers to come and help me round about that time, it was the start of the summer holidays, and so she went into Whipton Community Hospital to see if they could rehab her... but didn't succeed, and so, I remember, this multi-disciplinary team sat round a table with me and made it quite clear, really, that my mother could not come home, and that she would need to go into a residential home with nursing care. Which she did. She lived with me for seven and a half years and then she had another two and a bit years in a nursing home. It was in Exeter, so not far. And I used to be able to visit her, almost every day. More often than not anyway, I would say. I used to go after work, 'cause I finished work at four.

Rosemary lives alone in her house in Topsham, a small town suburb of Exeter, on the river estuary, where she has lived for 32 years. She has two daughters, both grown up with families of their own, and 4 grand children. Rosemary had a sister 6 years her senior, Margaret, who died of cancer when she was forty. Margaret had two children, Julie and Ian and Rosemary is close to her niece and nephew.

Rosemary originally trained as a secondary school teacher and later worked as an infant teacher. She went to teach in Hong Kong with the Service Children's Education Authority. On returning to the UK she went back to University to pursue further study in children's language development.

> When I was caring for my mother, I'd, I had a couple of jobs ... I used to work one day a week at South Devon College, working on returners' programmes, mostly women who wanted to get back into education or work. And so I was doing personal development with them. And also I was working for the Open University as an associate lecturer. (Rosemary)

Later, Rosemary was employed to research the link between the caring role and carers' health at the Westbank Centre, Exminster and then for about four years to develop carers link registers. After about ten years as a carer's development worker, Rosemary was made redundant. Rosemary is now a trustee of Carers UK, and Skills for Care and sits on a number of other important committees and boards.

12.1.2 BRIAN

Brian cared for his neighbour Herbie until he died three years ago in spring 2008. Herbie had no family support of his own and relied on Brian and his wife for a full range of practical and emotional support, including everything from medical and daily hygiene issues and washing to spontaneous visits in the middle of the night during crises or when accidents or bad dreams prevented sleep.

> I couldn't say I was a carer 'cos dear old Herbie did have a care package that Herbie stubbornly fought against -people coming in regularly on a planned programme to help him, he sort of viewed that as an intrusion to his privacy as he was very stubborn and proud man whereas he was very happy to let me do menial tasks that I was capable of like making cups of tea and I could help him put his socks on but I couldn't put my own on, it was a strange situation (laugh)...

> Over the time that I knew him, which was several years 'cos he didn't have a soul in the world, one distant cousin who I'd only seen twice in all the time that I'd been a friend of Herbies, and his eyesight was very very poor, he was totally blind in one eye and could hardly see anything in the other, needed a magnifying glass to read and fought against things all the time, getting ever stronger magnifying glasses to keep it going but sadly he had to give up reading and doing things, all the important documents that we all get and have to be signed and paid and everything else, he entrusted to me and my wife to do things on his behalf and every day I opened his letters to him, and read them out and told him what he had to do and what he hasn't got to do, and never ever officially signed up for power of attorney for him as he always viewed that as further intrusion, he was a man from a different time.

Brian lives with his wife Iris and two dogs in the rural town of Honiton, East Devon. He has two daughters, both recently married, with whom he is very close. They now live away from home. Brian's own health is precarious and has been for many years due to a horrendous football injury when he was 17 years old. Brian was signed for Tottenham Hotspurs at 13 years and was the youngest player ever to play for Millwall.

> I played in a football combination game, over in Craven Cottage, Fulham's ground... I twisted my ankle on a divot in the ground... I tried to get up but I fell down again, the studs in my boot were caught up behind my knee and blood was pulsing through the sock because my foot was turned right upside down. I'd broken the ankle completely and I had two sets of compound fractures and it was all flopping about... that was the start of all my problems... At least I can stand up even though I take strong medication, real strong medication, I've been on eighty milligrams of morphine now for over twenty years, every twelve hours. I'm MST slow release you know through day and night. As well as that I take Diazepam, Valium, Amitriptyline and there's a couple of other long named things, anti-depressant things I take, I take them every day, I kick off the day with them and at five O'clock some more and then 8 O'clock, yeah'.

Brian did his own research project on pain and long term use of pain killers through his GP practice (Ruel, 2007). He is interested in reading and the American Civil War in particular. He rarely goes out socially now.

12.1.3 GILL

Gill cared for husband John for 12 years, initially while working and then full time from 2000. Gill and John were together nearly all their lives. Gill met John at 14 years, they married in 1964 after an 8 year courtship and John died in 2009.

> He (John) was taken ill in 1997... He was in hospital eighteen days altogether. And he was diagnosed with chronic obstructive pulmonary disease... it's emphysema and chronic bronchitis. And my husband's lung capacity was reduced to about twenty percent, so breathing was really hard for him. His heart, surprisingly, remained strong.
>
> After he came out of hospital he was on all sorts of drugs, and oxygen. And he was supposed to be on oxygen fifteen hours a day... And then he took up, he'd been playing chess, and he'd carried on playing chess and even when he was in a wheelchair because he hadn't got the puff to walk... He, he went into hospital twice more when he had what they call exacerbations... And they sort of gave him different drugs and stronger drugs and he came out and carried on... He went into hospital the day before he died... And he's been dead two years today.

Gill had been a teacher, in education for forty years. After retraining as a School and Careers Counsellor, she came to Devon to do this full time. When the money for this post dried up, she did some teaching alongside the counselling, retiring in 2001. Gill counts her goddaughter Melanie, her husband and their two children as her family. She has no close relatives and lives on her own in Ottery St Mary, East Devon.

> I don't have any proper relatives anymore. I have an aunt whose husband was my father's brother, and she's obviously in her eighties, and I don't see anything of her and haven't for many years. I have some cousins who I have not had any contact with probably for forty-odd years.

Gill sits on a number of committees and has been part of a carer bereavement course run by Devon LINK. Gill has been a member of an early morning swimming group for some years and now finds she has opportunity to swim more regularly and is starting to build up a social life.

> I have been on three holidays in twelve months. And one of those holidays was to America... to stay with friends... If I go out, I tend to go out in the mornings. I still haven't been out much in the evenings, I don't like driving in the dark, but I have been out to the theatre with friends.

12.1.4 VICTORIA

Victoria and Nick had been together for more than twenty years when, in his early fifties, Nick began to lose his understanding of language. He was diagnosed with a rare early dementia at age 54. Now in her early sixties, Victoria has been unable to work for some years, having to leave a successful career as an education adviser to care for Nick. He remains at home seven years after diagnosis,

> I am living with a husband with a long term, in his case long term, deteriorating condition, which between the years 2001 and 2011, has taken him from being an extremely intelligent and extremely articulate man to a man who literally does not understand a word you say. That word literally is much over-used but it is true, he does not understand a word you say. That includes the names of his children or my name, it includes a simple thing like "I've run the bath", or, "Come and get some food". He does not understand those words at all, he can't read at all or write at all, so, in a very real sense, I have gone through, and am still going through, a very long process of losing the person that I'm married to... what Nick has is a very specific loss on one side of his brain, and it's the side that controls language and emotion.

Victoria and Nick live in Topsham –a small town on the Exe estuary- in a large Victorian terraced house which Nick restored and which is now something of a burden but forms Nick's only security in an otherwise unrecognisable world.

> I live in a house where as a family we've lived for twenty-five years this month. When we moved there we had a three year old, a six year old and a ten year old. And the three year old is now living about two hundred yards away and is about to get married, so I'm very happy that he is about to settle with his wife here in Topsham. My, the six year old is now thirty-one and she is at the moment living with us for a short time because other things have fallen through that she was doing, and the now thirty-five year old lives with her husband and small daughter in Oxfordshire.

Victoria enjoys books, swimming, cinema and theatre, acts and sings in a choir. She wants to travel more and has just returned from a walking holiday in Turkey where she hurt her ankle.

12.1.5 KATH

Kath was a carer for her son, Sam for nearly twenty years until he died in 2000 -eleven years ago.

> I was a single parent of a child who was born with cystic fibrosis. He was quite ill from birth… Initially, I had difficulty convincing the medical services that there was something wrong with him, and was told that I was a new mum and just panicking. But I kept on persisting and calling them out and eventually a locum doctor arrived who called an ambulance and his lungs were in a quite bad state by then, at which point I was castigated by the medical services at the hospital for not bringing him in sooner. Which…rankled somewhat.
>
> But that meant that he did then have continuing, quite serious lung problems throughout his, his, his childhood. When he was older, say from about fourteen, well, actually from about eight or nine, he started to have frequent intravenous antibiotics and from when he was about nine, I was doing that at home with support from the nursing staff at the hospital... By the time he was fourteen, his lungs were in a very bad state. He was having oxygen at home, frequent intravenous antibiotics and by the time he was fifteen, sixteen, he was, he was often on drips as well, which I, again, I often did them at home. And, frequently he had things like pulse oximeters and things like that set up at home for him, so that he could spend more time at home. When he was seventeen, he had a bilateral lung transplant, and was for some time much better. But unfortunately, he developed a form of chronic rejection which led to a sort of spiral and…eventually he died aged nineteen.

Kath described the range of onerous tasks that she grew to fulfill as a carer:

> Well I mentioned the intravenous drugs, I managed all his other drugs. He was on something like, at the height of it, fifty, sixty different treatments a day. So I would help him with his physiotherapy, I would count out all his medicines, I would give them all to him, I would feed him. He had a button that he got feed through, so I would be connecting that up for him. I would help him with his insulin. Eventually he was doing the injecting himself but initially I was having to do that... Cleaning all the equipment. He was on lots of nebulised drugs, including nebulised antibiotics that had to be vented out of the house so that he didn't have antibiotic residue causing you to grow your own superbugs. So that had to be cleaned and dried because a lot of the bacteria grew well in water, so you had to sort of, so you had this sort of corrugated tube that you had to hang out the window, then you had to wash it and dry it afterwards. Oof. All the normal mothering things, you know, the laundry and the washing up and the nagging and the [laughing], the stuff you have to do!
>
> While Sam was alive, He was home schooled for quite a lot of the time, partly because of the interruptions due to going in and out of hospital, but also, when he'd been very young, we'd lived in an area where there were quite serious problems in the local schools with some infections, including dysentery... He did go to school briefly, when he was about fifteen, but it was just too difficult for him to maintain, the interruptions that were happening with going off into hospital... After the transplant, he did go back to college, but again, you know, that was interrupted when things went a bit haywire.

Sam died at Little Bridge House, the children's hospice just outside Barnstaple. At the time of the project, Kath lived in Penzance where she has lived for about 25 years. When Sam was 16, Kath had a second son, Drew who was himself 16 years at the time of writing. Drew is still living with Kath. After Sam's transplant Kath did an access course and after his death completed undergraduate and a Masters degrees. Kath is currently doing a PhD in health research and is involved in community development:

> I'm quite involved in a number of community organisations and I enjoy very much meeting with my friends to work towards shared goals. As part of that, a local community group's

> running keep fit classes, which I've just started going along to, which I'm surprised that I enjoy so very much, but I do, they're very good. Trying to think what other things I do. I'm not very good at leisure. (Kath)

12.1.6 SUSAN

Susan cared for her second husband Tom who had Parkinsons and died in 2008, three years ago. Tom was first diagnosed with Parkinsons twenty years previously, while he was working in the RAF. He suffered progressive deterioration.

> He was studying for a PhD on the Royal Statistical Society with the Open University and... using up more and more drugs, so instead of taking tablets every two hours, he was taking them every half hour. And of course with all medication, there's some sort of side effect, and in the end he decided he couldn't go on like that....
>
> Well, Tom carried on with being able to play golf, but he found that more, well, more often than not, there were certain times when he was out on the golf course, he would suddenly freeze. He just could not move at all, and this is what Parkinson's can do... It had been suggested to him, and that was before the big bombings in London, 7/7, that maybe he would be suitable for the operation where they put the wires into the brain... it was delayed for a full year... So, when he did go in for the operation, he had deteriorated but the team were still happy to go ahead with the operation ... He went ahead with the operation, and everything went all right with that, but the only problem was that he was in theatre seven hours, rather than three and a half, which was really stressful for everyone. And I think through that stress, although the operation was a great success, Tom, after three months, went downhill very rapidly, and they then diagnosed cancer.
>
> And I, I do believe from experience of life anyway, that that stress kick started the cancer, and so within the year of him having the operation, he had died... But although Tom had such a short time of life after the operation, at least that time he was able to do things that he wanted to do, and enjoy his food, believe it or not.

Susan moved house when Tom died and has lived alone in the rural village of Witheridge, North Devon, for the last three years.

> I have three children [laughing]. My daughter, who's twenty-four, and I have two sons, one of whom is thirty-five and the other one's thirty-seven. And they of course are away from home.

Susan currently does voluntary work in the local community, helping out older people and she is an active member of the church. She helps at the local hunt kennels, caring for the beagles and also helps out with horses at a local stable.

12.1.7 JOHN

John was married to Peggy for 57 years until her death. Peggy developed Parkinsons and John cared for her from 1995 until 2008. The last two years were particularly challenging:

> Dementia started to set in about 2006, and at first I didn't take a great deal of notice. And then it got worse and it was very difficult. She would make conversations which were completely senseless... I lost my wife about two years before she died.

John's own health then deteriorated and he was very ill for two years.

> After my wife died in January, I was, I had to have a heart, pacemaker inserted and it worked very well. But I was taken ill with pneumonia in October, and was in hospital for a

> little while, a few days... I was in hospital and in the Masonic Care Home at Cadogan Court during the whole of that time (over a month).

John later befriended Judith, who has MS. He said 'Yeah, I'm still caring to some extent'.

John was brought up on a remote Welsh farm. His mother had a stroke three months before he was born and was paralysed down one side of her body. Hence, John was a carer for her for as long as he can remember.

> We were very poor and I was an only child, and the only income was my uncle's stipend for being a shepherd for about eleven to twelve hundred animals... I went to school when I was twelve for two years, that's all... And then, of course, the war came and I went to sea... I was discharged because I contracted tuberculosis and was two years in hospital. I then went to a business college in London for twelve months, and after that I went to work as an auditor at Grosvenor House in Park Lane in London where I met my wife. And since then we were in the hotel business right through our lives, from the time, from 1951 until 1988 when we retired and went to live in Cyprus. And we spent twelve years there, but unfortunately had to return because my wife developed Parkinson and we could no longer cope.

John has lived in a warden-controlled flat in Exeter since 2004, though in the past few years he has spent increasing amounts of time with his friend Judith who lives in a house on the edge of Exeter. John has 2 sons.

> One has got their own family and lives in Torquay now. The other one lives in Bath, and he's very, very busy, he comes down here…if possible every month because he has a summer house in Teignmouth, so we do see that much of him... I only have one grandchild and he's absolutely fabulous... Went to Oxford, and is working as a financial consultant in Dubai. And he's been there a year next month. He's twenty-two.

John is an active member of the Senior Council for Devon and has developed his own web-site about improving care for the elderly and disabled.

12.1.8 LIZ

Liz's husband Arthur died two and a half years ago in 2008. He had been a PE teacher, a Head of Department in Plymouth and then a teacher in Wiltshire. He had to leave work in 1985, when he was about 30 years, as his undiagnosed neurological condition worsened. He had difficulty walking and went into a wheelchair. Liz cared for him from this time, for thirty four years. He was later diagnosed with Guillain-Barre, a rare disorder affecting the peripheral nervous system with ascending paralysis beginning in the feet and hands. He died after progressive deterioration and many medical and care complications:

> So he was in plaster then for five months, so then I started having night care, you know, to put him to bed. And then of course, towards the end we had continuing health care because he then developed fits and he was peg fed and he had to have drugs and...

Liz said:

> I've had to resign myself to the fact that, well... it was aspiration pneumonia on the death certificate, and neurological degeneration. So, still don't know what exactly it was... he died at sixty-four.

Liz lives alone in Silverton, which is a village in Mid Devon, about nine miles out of Exeter. She moved there with her husband ten years ago. Liz helps look after her young grandchildren.

> I have two children, the youngest one has two daughters who are two and three, and my daughter, who's just forty-two has lost a baby last year and is pregnant this year at six months and we're all very, very happy about it. (Liz's eldest daughter gave birth to a baby girl during the course of the Past Caring Project in September 2011)

Liz managed to carry on working throughout her husband's illness and retired a year ago after a long career as an occupational therapist working with children. She is gradually becoming more busy in her life.

> I belong to a gospel choir, I work for the Blue Cross looking after dogs at the weekends. I've joined the local gym to try and get my weight down and fit [laughing]. And I've joined the walk and talk in the village, and I'm chair of mid-Devon Carers' UK, so there's quite a lot of stuff around carers.

12.1.9 Overview: The Participants

Of the 8 participants, 2 were men and 6 women. In age, they ranged from 54-85 years, with a fairly even spread across this age band[8]. The focus of the project was on one particular primary relationship in terms of the people they had cared for and the project covered a range of different relationships: Kath (son), Rosemary (Mother), Brian (Neighbour) and John, Liz, Susan, Gill and Victoria (wife and husbands respectively).

The focus was also on people who were long term carers. Liz was a carer for over 30 years, Kath for 20 years, Susan for 15 years, John for 13 years, Gill for 12 years, Rosemary for 10 Years, Victoria for over 7 years and Brian for 3 years. They had all been caring for a very long time. Liz cared for Arthur from the time he first started getting ill at the age of 29 years through to his death at 64 years. She did not call herself a carer for much of this time.

> Yes, I think probably till I was about fifty, when it probably became, well it became fashionable, didn't it, to say you were a carer, almost, because you could actually admit to it, whereas before you didn't. I didn't dare, because... ten years ago, I had it said to me by my manager, "I don't think it's worth you applying for this job with the PCT (Primary Care Trust) because if you can't get there, they will just go on without you, because you've had to do something at home"…

Victoria said:

> I have gone through, and am still going through, a very long process of losing the person that I'm married to... it's only by looking back that I think, hang on, six months ago, Nick could do that, a year ago Nick could do that, because it's a very creeping, creeping thing... Nick has just carried on on his little trajectory, which is very, very slowly going down and down and down.

Some people are clearly 'serial' carers. For example, John had cared for his disabled mother from a very young age, then later for his wife, Peggy and now for his friend Judith. Victoria had previously cared for her brother who died and Brian for his Mother and Father (we will discuss this further in a later section). In time since bereavement of the loved one referred to as the primary cared for person in this report, Kath's bereavement was the furthest in the past (11 years), Rosemary (6), Susan (4), John (3), Brian (3), Liz (2), Gill (2) and Victoria's husband was still alive and living with

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[8] Participants individual ages have been recorded for the project, but several people felt they did not want this information to be public unless there was a specific reason. We left it up to them about who did and didn't want their age identified in this report and gave each individual a chance to edit the personal profile presented here.

her with a rare form of dementia. We included Victoria in this project as someone who is experiencing living bereavement. Our participants strongly felt that this carer bereavement was very pertinent to her situation and those in similar positions. Victoria herself said:

> I would in no way compare myself to a widow, in terms of bereavement. On the other hand, I know that I've gone through all of the stages of bereavement and I also know that there is no sense whatsoever in which I have a partner. (Victoria)

In terms of involvement with carer's projects and other health and social care services activity, we had a very active group. Rosemary, Liz, Gill and Victoria all had some continuing involvement. Brian had previously been involved on a pain project with his local GP practice, Kath was doing a PhD in health and John was independently working with a friend on carer's disability issues and was also a member of Senior Council. Susan was active in her local church.

The particular stories in this report are all contextualised by fairly positive living situations. The section shows that all the bereaved carers here have some personal /family support (though some much more than others), that they were a mostly able-bodied and active and well in themselves at the time we were writing (except for Brian who was living with very significant continuous pain and had mobility difficulties) and all had secure homes and some financial security.

Geographically, the carers live in north, south and east Devon, with slightly more of them living in the city of Exeter. All lived in small towns and villages rather than in isolated locations, so the findings may be less relevant for people in isolated rural situations (see Duggleby et al 2011 for specific work on this with families bereaved after cancer in rural Canada).

Even this early section starts to problematise some key policy assumptions. Brian's account, for example, questions any policy assumption that neighbours do not have the same obligations as kin and will withdraw their caring support when the burden outweighs their own needs. Brian, Victoria and Liz's stories in particular highlight the issue about people not necessarily calling themselves 'carers' and therefore not clearly identifying their needs for services or becoming visible to the health and social care system. Kath's story most starkly reveals the challenges of services identifying carers as individuals in service terms, rather than as people within families who need support together. And John's experience highlights that the caring experience is often not one off and isolated –many people have 'serial' or continuing caring situations, some for the majority of their lives.

This section about the participants starts to reveal the personal situations of long term carers who have been bereaved. It shows the variety and depth of experience –signaling that no two experiences are alike. It powerfully shares just how LONG the caring time frame can be and hints at how profoundly the carers' life is affected. It also shows that these are not stories given lightly or described easily –they are not stories readily accessible to unknown service commissioners and providers. But, however painful, they are stories that bereaved carers want to tell and be heard.

12.2 Caring Experience

From talking with bereaved carers through this project, we became interested in the models that they had for the care they gave and how confident they were about the care they gave. The stories tell us about the extensive caring that some people do in their lives, caring for others as well as the deceased person described as the main cared for person in this project. They also tell us about others who come to full time, long term caring with very little experience to draw on. The stories remind us, in some cases very dramatically, that being a bereaved carer does not happen in isolation from peoples' other day to day life and death experiences. Serial carer bereavement is a particular acute reality. Parenting bereaved children, as well as caring for unwell and disabled people, presents its own challenges.

12.2.1 Good caring -' I felt when she died that I'd done the best I could'.

The bereaved carers in this project believed that they had done really 'good' caring for the person that they were talking about for the project. If they had not, we might predict that they would perhaps have been less keen to share their stories and we therefore recognise again, that the group of people speaking here has a commonality of positive caring experience that is not shared universally. However, understanding these stories is still valuable. They continued to care, sometimes in isolation from family support, for long periods and in difficult circumstance. It was important to all of them that they had done a good job and several thought that they had prolonged life by their good caring. Rosemary said:

> I felt when she died that I'd done the best I could. So I think, probably, unlike in many circumstances I've heard about, when she died, I didn't really feel the "if onlys" that I think I've heard many people talk about. Or wishing that they'd had a closer relationship or whatever. (Rosemary)

Gill used the term 'my good caring' many times during her interview.

> And just before he died, the specialist nurse at the hospital told us that normally people who get put on oxygen, they don't live beyond eighteen months, and John lasted from 1999 to 2009, 1997 to 2009. So he lasted twelve years. And the nurse said it was down to my good care. And my doctor, our doctor, said it was also down to my good care. And I'm very proud of that. I'm not boasting, but I'm trying to say how important a good carer is to a person... Various people have said to me, John lasted as long as he did because of my good caring... It's your lot in life, isn't it, you take what you're given and make the very best of it and I think I have made the best of my life, including the caring role, which I'm very proud of... Caring was new to me. But I think I did a good job. (Gill)

Liz described how Arthur had lived with his deteriorating illness for thirty years. Susan also described caring for a long time as Tom lived longer then medics expected. She said:

> When he was first diagnosed, they only, the specialist gave him five to seven years, and in fact he had another fifteen. So, you know, even if you're a specialist, you can't always be absolutely sure. (Susan)

Young & Cullen suggested that 'terminal patients seem to last longer if they are looked after by someone who is close to them and have other people round them as well. Loving care sustains and lengthens life, as one might expect... But a good death for the patient may work in exactly the opposite way for the bereaved. A good death can make for a bad bereavement... the carers have had to carry the burden for longer and have got so tired that they find it difficult to lift themselves out of it. (Young & Cullen, 152). This fits with Brian's description.

> I suppose my depression started as everybody must get depressed with the loss of your parents, that was the kick off point and although your family closes around you I think it was the fact that I'd had such a wonderful upbringing that my parents were like my best

> friends so that intensified the traits towards depression that other people might get over far more easily. It’s easy to say when you know someone’s suffering that the ultimate passing is a release and it is, and you wouldn’t want anyone to suffer especially your own mother and father but when you actually lose them the book closes on the fantastically large part of your life time and then you think crikey. (Brian)

12.2.2 Serial carer bereavement –‘socially isolating... quite, quite grueling’

Some participants had significant prior experience of caring and carer bereavement, usually from looking after parents. Brian, in need of care himself, cared for his parents as they degenerated and died. His commentary also revealed how his own father neglected his health as he cared for his wife:

> My mother sadly lost her sight. She had macular degeneration and was aware of her sight gradually declining. First it was her peripheral vision she was left with and then she eventually went totally blind and I used to do everything I could for my mother. I saw her sometimes 2, 3 times a day as she lived very close to where I lived and when my father wasn’t around, I was. We made it a process of always having someone around and in a way my problems helped me to be around to keep an eye on my mum... We lost mum on December 5th 2000 so she lasted about 18 months after my dad.
>
> My father died in August 99. He had a horrendous battle, he had a ruptured aortic aneurysm… he was a very fit man all his life, strong cyclist, good footballer and very into sport and fitness in every way and for a long time we noticed he wasn’t well and because of my mother’s problems, he didn’t want to add to her worries and stress so he neglected going to see the doctor himself and it bordered on where we’d have mild arguments with my father, both me and my brother, and our wives, but alas we noticed his decline but he couldn’t see it himself until everything came home to roost one evening and there was a hell of a panic and that’s what happened and I got him to hospital. Everybody at hospital thought that he was drunk, he literally tried to get out of the car and fell over, and I parked right outside the R.D & E (Royal Devon & Exeter Hospital) here, memories are very vivid in my mind, I grabbed a wheelchair, put him just inside the door, lifted him up, I don’t know where I found the strength but I lifted him up, I felt my spine going pop, pop, pop, pop all the way up as I did but strange how people say you find strength in extreme times and that night it’s very true and I don’t know if I ever got over it but he survived for 67 days, survived the op, survived the subsequent amputation of his left leg just below the knee. Spirit wise and mentally, very buoyant, I spent every day with him to report back to my mum, morning and night, and he sadly couldn’t take no more and they had to fit a pacemaker to his heart to help boost him ‘cos his condition was flagging and he came through the operation of that OK, had multiple operations while in there, survived them all. Everybody knew him as Fred, you know it was not Mr Ruel, it was Fred, everybody knew Fred, and sadly while in recovery his heart just couldn’t take no more, they gave him open heart massage in recovery, and he came round twice but the third time he didn’t make it, very sad time you know for the family. (Brian)

For others, the level of family bereavement was much higher and more ‘unusual’. Victoria described a whole series of family bereavements.

> We suffered a series of bereavements…the worst of which for me personally was that my brother died in 2005. I cared for him and he died…

> My mother died in 2000, my daughter's partner, aged twenty-six, died in 2001. Nick's mother died in 2002. A very close friend of mine died in 2003. 2004, nobody died. But my brother had been diagnosed with bowel cancer at the beginning of 2003. He hadn't told us about the diagnosis until a few weeks after Nick's mother's funeral. That's what he was waiting for. So during 2003, he had nine months of very severe chemotherapy and he died in 2005.

Victoria's experience acutely highlighted how carer bereavement is embedded in a whole series of other challenging and unexpected life and death and caring situations within a family and within a community –it does not happen in isolation and it is not the only thing a person has to cope with. Victoria said:

> I think of 2004 as a really, really terrible year. Nick got his (dementia) diagnosis at the end of that year, but it was just an awful year. And one of the things I would say about Nick and me as a couple is that, of course, we've cared for people all our lives because we've had the three children and then it seemed as though, as the children gradually got more independent, these were all life events that we were going through together, including caring for my brother and then my brother dying at the beginning of 2005. So, people tend to think, you know, if you talk about dementia or Alzheimer's and possibly with other things, that's the one thing that's happening. Of course it wasn't in my life and in Nick's life, we went through this pretty appalling series of deaths. And the deaths of young people, of people younger than you, that's not what you expect.
>
> And …you know, the biggest deal in some people's lives is that their parents have died when they're in their fifties. And there are occasions when I feel like saying, "Lucky you, lucky you". Because my father died when I was young, my brother died when he was young. You know, those people who have been fortunate enough to reach their fifties and then, isn't it awful because their father and mother died? That's not to be unsympathetic, but I think if you suffer uncharacteristic bereavements, like early widowhood or losing a child, which I'm very glad I am not in that club, you know. Or losing your partner young, losing your parents when you're young, they're all socially isolating, because they're not experiences that your peer group is going through. And the experience that I am going through, still, and will continue to go through is not, not an experience that my peer group, on the whole, is going through. (Victoria)

Liz reinforced this idea. What Victoria described as 'a very strange feeling', being 'out of tune' (Victoria), Liz saw as being 'out of synch' (Liz). Liz said:

> Because their husband's are older and they're older. And, and they've got, they've got grown up grandchildren whereas I'm starting [laughing]. And you know, I'm in my sixties now starting what they are just coming to the end of with grandchildren. (Liz)

Rosemary also had to deal with some devastating deaths of those close to her as well as the later death of her mother Novello.

> I had a sister, Margaret, and she died of cancer when she was forty. Margaret was six years older than me... She first contracted cancer when I was living and working in Hong Kong, and I'd come home for a holiday, and during that period, she'd had treatment in fact, was doing quite well, and there was a belief that she would make a good recovery. And so I had gone back after my period of leave feeling fairly optimistic about the outcome, but in fact…after a period of time, the cancer came back and she became very ill and went to live with my parents... And I had started a new life in Hong Kong, which had been wonderful for me, and the girls. But I felt very guilty... And I felt that I should come home. And I remember my aunt writing to me…And…she said that she knew that I was probably thinking about coming home, but she would urge me not to…And the things that she said kind of

> gave me permission to stay… Anyway, I didn't come home…until she died. Obviously I came home for her funeral. (Rosemary)
>
> The father of my children died when they were two and a bit and about nine months... Unfortunately, my husband was a gambler, which made our lives very difficult indeed. And so we often found ourselves in financial dire straits. And finally my husband got himself in such a mess, financially, which was all tied up with the job that he had and the job that he had had a house in which we lived, that he in fact decided just to disappear, and so he left... I had to get out of the house. And…I went to live with my parents after that... And, about two years later, my husband was dead. Not a happy tale. (Rosemary)

Rosemary and Gill also raised an issue about the serial implications of close friends dying. Rosemary recalled her dear friend Margaret who had died aged ninety, the year before this study. Gill said:

> I lost my mum and dad, just before John died. I lost my, my girl best friend... then I lost John, who was my other best friend, and I had nobody to talk to. I had no *best* friend going back many years. (Gill)

Kath had a huge challenge when her sons Sam and Drew were very ill in hospital at the same time and she was caring for them both.

> …. also during that summer, Drew had developed something called Kawasaki's Syndrome, so they had both been in hospital at the same time. Both actually at death's door at one point, which was quite, quite grueling. But they got better during that summer. (Kath)

12.2.3 Parenting bereaved children –' sad to say, I got slightly annoyed with her (my daughter) in the end because she made it worse for me'

Another key theme that evolved in discussions about caring experience was about the caring/parenting that people were providing for their children as well as for the person who was ill or dying. In the literature, they have been described as 'secondary survivors', care-givers, family members and others who felt a bond with the dying person (Clark et al, 2011). Rosemary commented:

> My younger daughter always resented the fact that my mother took up so much of my time. When she came to visit…usually at the weekends, because she was working, this was before she had children, so many arrangements had to be put in place to enable us to get out, to be together, alone. And she admitted afterwards how resentful she felt about my mother, and how guilty that made her feel. Because my mother took up all the time that previously I would've given to her. (Rosemary)

Victoria described in her interview being told by a duty doctor some years ago that her children should support her. At the time, the children were in their twenties and lived far from home. In saying 'It's been very difficult for his children to, to accept and recognise what's going on, obviously...', Victoria hinted at how coping with her adult children's emotional response to their father's dementia was an added burden. However, she also pointed out that having them nearer now helped practically in caring for Nick's daily needs and emotionally, saying, 'I'm now in a more fortunate position in that both of my other children are living nearby, so I'm, I've been able to box and cox.' (Victoria)

As well as finding her daughter supportive and helpful at times, Liz sometimes found her daughter's response to her husband Arthur's illness frustrating.

> My daughter didn't cope very well when he (Arthur) was ill the first time. In fact, sad to say, I got slightly annoyed with her in the end because she made it worse for me, which sounds terribly selfish, doesn't it? Because she was coping so badly with it. I couldn't cope with her…hysterics and things. You know, I was having enough trouble keeping it together myself, and having to go in and do what I was expected to do at the hospital. And she was making all sorts of promises, 'cause she said, "Oh if he comes home, I'll help Mum look after him", and when he was admitted after this seven week stint the next time, the nurse said, "Did you daughter stay and help?" I said, "Of course she didn't!" I said, "She's got a job, she's got to earn her living". How naïve can you be? I thought, "I couldn't possibly ask her to do that, she's, you know, she's got to keep herself together, she can't do that". (Liz)

In this extract, Liz is describing the way she put limits on the levels of help she would request from her daughter, implying a recognition that she needed to lead her own life. This is described in the literature, where primary carers assume their own life is in a state of abeyance, with employment and social life postponed for an indefinite period and seek to protect their kin from also being in this situation (Twigg 1994). Liz also spoke of the support her daughter needed around her mis-carriage.

> My daughter, who's just forty-two has lost a baby last year and is pregnant this year at six months and we're all very, very happy about it, but she's been extremely brittle, you know, since she lost the last one, so it's been quite a difficult year for her, and probably all of us, because we felt as though we've been walking on eggshells around her. (Liz)

Here, Liz is describing the dual need to care for her daughter, signaling the way that family life goes on in other contexts and impacts on the caring resources of individuals who are already acting as primary carers. Liz also spoke honestly and openly of a difficulty that many people face in helping other family members cope with death. The nurse suggested:

> "Well we could ring your daughter up". I thought, you can't, I can't ring my daughter, she'll be on the motorway, she'll drive like a loony, and she'll come in here and she won't cope. And…I thought, I can't cope with this and that as well, which, I mean I probably made the wrong decision, I don't know. (Liz)

In this sense, the nurse appears to be almost blocking Liz as the carer from seeking help because she is implying that other family should be relied on to support carers on every occasion.

Kath spoke about coping with the emotions of her surviving son Drew after her son Sam's death.

> When Drew became very, very distressed again, I did contact a charity... And they provided a counsellor for him, quite separate to me, who was very, very supportive to him and helped him to make some sort of sense of that, which was very helpful. But I had to keep way back from that because at that time he was just, as I say, he went through this time of being very, very angry with me, and he needed really somewhere separate to deal with that, so that was very, very helpful that that was available then. (Kath)

Kath recognised that 'Drew's idea of normality was very strange from a very early age'.

> It's difficult to know what he was aware of, I mean, 'cause it was just normal to him, it'd always been that way…He was so used to spending time hanging around hospitals and going and staying in the hospice for a holiday and that sort of thing…It did mean that he had quite a lot going on in his life, really, a lot of movement, particularly when Sam had his transplant, I'm trying to think how old Drew was then. I suppose he must've been about fifteen months old, something like that. That involved a lot of disruption to our lives, you know, we were airlifted from the hospice in, well just outside Barnstaple. We were airlifted to Great Ormond Street and then we just spent months either staying in London or travelling backwards and forwards. (Kath)

> He was young and…it was several years later when he went through a most terrible angst…where he felt really guilty and stupid. He felt that he'd been stupid for not understanding what was happening at that time. And that was quite hard to help him through and saying, "Well no, you were very little, that's how, you understand things as you go along, you don't understand them all when you're small". But that, that was very hard for him to bear, that he hadn't really cottoned on to what was going on. (Kath)

Susan was stoic in describing the 'in the middle' challenge of living with what became a rather challenging relationship between her husband's teenage daughter and her husband Tom.

> Yes, it was. She and Tom got on really well to begin with, and then of course as she grew older and went through the teenage years, they couldn't appreciate each other's viewpoint, and that was really very difficult. And what had been quite a good relationship that Louise had had with Tom was more difficult, and of course, you know, I was in the middle, so you're trying to, but once again, it's all part of life, isn't it? (Susan)

Having devoted themselves to caring well over a long period, these mothers have managed to retain strong family relationships although they admit to stressful times. They want to be good mothers as single parents as well as being good carers. Brian and John expressed no difficulties in relations with adult children and spoke of them only as supportive. Perhaps this hints at a gender difference in caring –the male carers found family to strengthen resolve and were perhaps not so aware of the emotional needs of those family members themselves, had other women around them to take care of these needs or simply did not see it as appropriate to discuss these matters with an interviewer.

> Fortunate to have the wife I've got and the daughters and two son in laws, solid as a rock, solid as a rock, wonderful partner, I've been so lucky and both our brothers, first class, do anything for me they would, and I them, great lads. I'm very lucky in that way, I've not been very fortunate financially in life but in every other aspect, family, help, assistance, I'm rich. (Brian)

The literature suggests that secondary survivors experience isolation and powerlessness that is often unrecognised by formal service providers, so the primary care-giver often carries their emotions too (Clark et al, 2011). Recognising this potential burden is a first step to helping bereaved carers. Intervention strategies for helping families assert personal needs and develop greater closeness with the health care team and prepare for the processes associated with the end of life may be helpful during bereavement and is worthy of further exploration.

12.2.4 Overview: Caring Experience

Each individual story tells us something about the internal resources bereaved carers had to draw on, about trauma and death in families, about notions of usual and unusual deaths, of duty and responsibility and the extent to which being a carer is or is not embedded within the family and the wider community. Some people in this project highlighted the weight of serial carer bereavement. While there has been some attention in existing literature to notions of 'serial caring', such as Mary Larkin's analysis of different types of serial carer according to how many 'cycles of caring' they had been through for different individuals (Larkin, 2009, 1038), less attention has gone to understanding serial bereavement and its impact. The people in this project were keen to stress the difference between 'usual' and 'unusual' bereavements and the isolation experienced when they found themselves 'out of sync' with their peers. The other key theme raised in this section was about parenting bereaved children and the huge impact of this on the bereaved carer.

12.3 Positive Perceptions of Caring

This section focuses on positive meanings in the experience of caring long term for a loved one. It emphasises the role of love in the caring relationship and the reasons why, despite the considerable challenges, people choose to care long term for family and friends. It shows bereaved carers making sense of their experience as a coherent whole over life times, accentuating the benefit and satisfaction derived from caring which is so often missing from the troubled tales of caring. It shows how we perceived the benefits of the caring role from the hindsight of bereavement.

12.3.1 Caring as love –' you're doing what you're doing because *you care*. And it's done *with love'*.

We did not specifically ask any of the carers about love directly, but each of them spoke of it often in their interviews, and several returned to love as a key issue at the end of their interview, wishing to re-emphasis the importance of love for understanding why and how people care over long time periods. Susan quite simply said:

> I think that's a very good expression- you're doing what you're doing because *you care*. And it's done *with love*[9]. Otherwise you wouldn't be doing it, you'd be looking for other avenues. (Susan)

Brian said, 'I became immensely fond of him (Herbie)'. Gill spoke of her deep love for her husband John and her feeling that the love lived on after John's death and would continue to do so. Gill said:

> It (John) was also the person I loved... Well he's there all the time, isn't he?... I met him in 1956, and he was there all the time till 2009, and he's still there, he's still there. I think…I think to be honest, it will stay like that, I don't think it will change, I think he's always going to be there. (Gill)

The interviews were peppered with touching moments captured in the memories of the bereaved. Those that described fleeting moments of love, when loved ones had lost much of their ability to communicate were particularly striking. Near the end of her life, Peggy's ability to talk with John gradually slipped away. However, John recalls with great fondness the occasional moments when Peggy still expressed her love for him.

> But I always remember there was one very particular thing with Peggy which was when I went out to these meetings and came back, she would always get hold of my hand when I came in and kiss my hand and give me a big smile and say, "I'm glad you're back", you know. And that always boosted my morale enormously. (John)

Victoria had similar stories about her husband Nick who is living with dementia.

> At the moment, Nick always appreciates having his family there. I mean, last night as we were having a meal, my second daughter was there with us, and he ate his food and he always says, "It's lovely, it's lovely", and he means to see, to see us. I know it won't be long before he won't be able to say that. If he can still appreciate and love his family, which, you know, he is continuing to do for a long time, I know that'll go eventually, but that is, that's very good for the children and for me. (Victoria)

Rosemary said:

> Although there was clearly a downside... to having my mother living with me and my being her carer and being so responsible for her, nonetheless, there were good things as well. She was still good fun to be with, and she could make me laugh even though I hadn't got a clue

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[9] Susan's emphasis

> what she was talking about, but just the way she would babble on…I kind of got an inkling of what it was that she was talking about, and did make me laugh. (Rosemary)

A year or so before her husband died, Liz specifically challenged the medics to withdraw the treatment they were giving Arthur and replace his fluids only. From having been unable to speak and being terribly ill, Arthur got better.

> So they went in, took everything out, and he recovered, was back in the ward. And you know, he was there seven weeks, he was there a long time, and I think one of my proudest moments was when they came round with the tea trolley and asked everybody if they wanted tea and he, and he shouted out, "My wife would like one!" [Laughing] (Liz)

Kath affectionately recalled the humour in her caring experience and her son Sam's joyful character.

> He (Sam) had quite a wicked sense of humour. When he was in hospital in Cornwall, he got the numbers of all the hall phones around the hospital, all the extension numbers, and he would phone people up and tell them he was trapped in a cupboard [laughing]. They would answer the phone walking down the corridor and he'd be telling them he was trapped in a cupboard, that sort of thing. So he was quite, quite bad in that way. But, as I say, he was very charming with it, so he got away with quite a lot of that... He was very good looking, very charming. Very bright…Very stubborn [laughing]. He could be very, very stubborn. (Kath)

Kath's story reminds us of the place of familial love in the caring role and at the time of dying, situating the cared for person within the loving context of different family relationships. In this story, Kath describes her dying son Sam's relationship with his younger brother Drew.

> His (Sam's) relationship with his little brother was very touching, he was very, very fond of him and they would spend quite a lot of time together... Drew and he used to watch a programme called South Park, which…it was proper teenage boy stuff, but it was a sort of bonding thing between them... And so it was their thing that I wasn't really part of. And actually, when Sam died, that was on the television there and the rabbit was scrabbling around in its hutch in the bedroom. And…so it was very much their time as well... it was quite stunning that we could be able to manage it in that way. (Kath)

So love, pride and respect appeared to be strong threads linking our participants' stories. However we wonder if people who do not experience such love would have found it easy to share their stories. Gill reminded us of this in saying:

> I do know somebody who was very glad when her husband died, and I think that's very sad. Not because he was in pain or anything but he was, everybody said he was a horrible man and she did, and I can't imagine, I mean she's happy because she's bereaved. (Gill)

12.3.2 Caring as return altruism over a lifetime –'She was like a good fairy'.

Caring was also described as a deep way of cherishing the person the carer had known at earlier times in their life. By hearing in the interviews about Rosemary's stories of her relationship with her Mother over a life time, readers are reminded of the years and years of loving care that her Mother had shown for Rosemary, through everything from the inspirational trips to the theatre they took when Rosemary was a child, the help her Mother gave in helping to care for Rosemary's own children, through to the daily help with chores and household pursuits in later years.

> She was like a good fairy, really [laughing]. She was. She was just like a good fairy. I would come home and I would say, "Thank you, Mother", to myself. She was super. (Rosemary)

John took a step back in his reflections over his own 85 years of living and expressed his admiration for the people he had chosen to care for.

> There are three people I've met which I admire enormously in life, well more than that, but three people I've loved or loved to an extent, not love in that last one, it's not the correct word, which is my mother, which is an outstanding person, my wife was quite an outstanding person in the catering world as she was the first person, the first female to be trained at a catering college in Britain, and she graduated with very high degrees, and became deputy housekeeper in * House, which was a very big job, where we met. And, the other one is Judith, who is my friend now. The courage and determination she has, her father died quite suddenly through neglect by the health service, unfortunately. Her mother was a very traumatised person... She had one brother who was forty-one when they found him dead in his flat, and she has no other relations whatsoever. None. And, her brother had been dead in the flat for two weeks when they found him, so she's been through a very difficult time and she's still a very courageous woman. (John)

Victoria similarly spoke in her digital story of the beauty of her relationship with her husband Nick who was her soul-mate, her lover and her most precious companion. These stories together stress the value of taking a life-course perspective of carer bereavement, taking time to understand caring as an on-going relationship in a life time of experience.

12.3.3 Caring as reward – 'I thought well thanks for letting me into your life, you've helped me'

Several carers described caring as their own reward in later life. While recognising the harsh day to day caring tasks for his neighbour, Brian valued the trust Herbie showed in him and found this helped lift his own depression in later life.

> Things like doing the stoma bag in the middle of the night, I'm relieved that I no longer have to do that and there were unsavoury things that sadly people have to do..., that I did for Herbie ... at the same time they're handing over to you one hundred percent confidence in you and in a way it's nice to be thought of in that light, that you can make a connection with a total stranger and through circumstance, tragic circumstance, you can come through and gain that person's friendship and respect and at the same time help yourself through the fact that you've done something worthwhile, you know I really do believe that my rewards for Herbie is what's in here (Brian pats his heart), not what he wanted me to receive. It's in my mind... I thought well thanks for letting me into your life, you've helped me... he helped me through a patch for a few years where I was very down and I'll always be grateful for that. (Brian)

John said of his current caring role with his friend Judith at the time of the project:

> But even though, with all her problems, she cares more about other people and she is the one that brought me out of the darkness and back and made me realise that life was worth living again. And apparently, it's mutual, because suddenly she has found that she's enjoying life and that living on your own is not any good, that she is so grateful to have the company, so, I think we, we have mutually benefited each other. And that has given me a great deal of satisfaction, because I think if I do nothing else in my life, I've certainly done somebody a very big favour. (Judith)

Kath emphasised the importance of her own agency in choosing her caring role.

> I feel very strongly, is that I always maintained awareness in myself, of the fact that I chose that path and I chose to be Sam's carer. I think if I'd felt that it had, it was happening to me instead of I was doing it, it would've been much harder for me to cope with the difficult, painful, unpleasant and sometimes just plain nauseating things that I had to do in that role. And yet I think it was really, really important to me to actually think, this isn't something

> that’s happening to me, this is something that I am doing and I’m choosing to do. And maybe that, that helps me to take it forward. (Kath)

12.3.4 Positive things in bereavement –‘ I’d always kept bits of my life going’

In other sections, we talk at length about the challenges and difficulties of bereavement. For the positive perceptions theme we identified here, we also combed the interviews for positive things that people said, not about their caring but about their life in and after bereavement. Susan said:

> I think your memories, you know, are so vivid, the positive side of it (caring). And I think it’s always trying to look on the positive side, it’s always trying to have that cup half full, not half empty. (Susan)

Rosemary highlighted the value of having cared intensively for her mother, but consciously keeping her own life going at the same time:

> I’d always kept bits of my, my life going throughout the time when I was caring for her, so that I was able to sort of take things up again quite quickly, I think. And, I don’t know, I’d always managed to do a fair bit even when I was caring for her. (Rosemary)

Susan’s descriptions of finding herself after Tom died were stoical in nature, but she told of putting pressure on herself to ‘get on with life’ after her husband died and to learn to enjoy life again.

> Well I suppose, because, you know through life you have certain knocks, and then you think, “Well I’ve got to pick myself up and get on with it, life’s got to go on”, and knowing that, well I know that my husband wouldn’t wish me to sort of just sit there and wait... you have to pick up your life and move on, because you’ve got your responsibilities. (Susan)

Susan moved house, started helping at a local stables one day a week and another day with the puppies at the hunt kennels. She got more involved with the church and visited older people in her community as a companion. Gill made similar efforts to get on with her life. Gill joined an early morning swimming group and started travelling more, visiting friends abroad. Gill said of her current situation:

> I’m happy because I’m making an effort. You have to, as they say, life goes on. One of my favourite sayings is “onwards and upwards” and you know, I stick to that, I try to do that. There’s no point in moping, it doesn’t get you anywhere in this life, you’ve got to move on... I want to enjoy myself. I enjoyed myself when John was alive, so why I should stop now I don’t know. (Gill)

Several participants mentioned book clubs as important in their bereavement.

> I didn’t manage much reading when John was alive because, you know, when I wasn’t doing anything else I was sitting with him and we were talking, that’s another way of caring. So, you know, I’ve got a pile of books to read. I share books with people. The book club I belong to looks as if it’s folded, which is a shame. But nevertheless, I think some of the members will still pass books to each other [laughing], so it’s still ongoing, but we don’t meet to discuss the books. (Gill)

One of the participants had found a new close friend since his bereavement. After being ‘very lonely’ John said:

> I also have a very close friend who has MS (Multiple Sclerosis). I’m probably extremely lucky, I met this lady...and we became very close friends, and I spend most of my time down there... I decided, after my wife died, that…that sitting in a chair watching television is the quickest way to go out of the door feet first, as I’ve heard so much about people who’ve done this and I’ve said, “No way am I going to do this”. (John)

John, Rosemary, Gill, Victoria and Liz had all joined carer related organisations and committees. John said:

> I survived that time simply because I was on so many committees. I was out about four days a week... I kept myself occupied. I would not have survived if I hadn't been on these different committees. (John)

Consciously changing routines was an important positive step in many people's lives during bereavement. When you are caring for someone long term, the routines that you establish can become very set. For example, John said:

> We used to watch television a lot, particularly dramas and things like that and current events. And it got to the stage that she could no longer watch television, it irritated her. Then we started using the music box to give her some music, she enjoyed that for a while, but then she said the noise annoyed her and we really got to the stage that we…there was very little we could do, hardly anything we could do together. (John)

Several people reported deliberately changing routines. Gill spoke of a trip to America to visit friends early in her bereavement.

> And I think going to America helped as well, because it helped me break habits. I was still doing the same things that I used to do when John was there. I was watching the same television programmes, I was doing the same things in the afternoon that we'd always done together, and it was silly. And this helped me break that habit. (Gill)

Others spoke of cultural and creative ways of keeping memories alive in bereavement. Many people had special photographs, pieces of music or places that they still visited that celebrated the life of their loved one. Rosemary's memories of her mother, Novello, were regularly triggered by a particular holiday photograph she kept.

> I have a lovely picture of her in my bedroom. It's a picture I particularly liked and I thought encapsulated my mother when she was fit and well. It was taken when we were in Turkey, as many of the best photographs always were, and we'd been in a particularly pretty valley in an area called Cappadocia and... We wanted to stay there for the night and the places to stay were all at the top of the hill, and we had to climb upwards to get to the hotels, having gone down in the valley to look at some old churches, and I remember the strenuous nature of it all, climbing up this hill. And we finally reached the top and my mother had made it, and she was over eighty by this time, and she was sitting on a rock, and I took a photograph of her, and [laughing] she looked, she looked so good. So that's my photograph of her, and…she's just there, when I go to bed and when I wake up…So that keeps her memory alive, really, on a daily basis. (Rosemary)

Music was also key as an activity in recovery. Rosemary and Victoria both reported taking part in amateur dramatics societies and Victoria and Liz sang in choirs. Brian played old records and Gill enjoyed listening to the jazz music she and John had once shared. As mentioned elsewhere, Susan, Liz and Brian also enjoyed being with animals in bereavement and found this joyful and helpful.

12.3.5 Overview: Positive Perceptions of Caring and Bereavement

Positive perceptions of caring and of processing memories in bereavement came over as a strong theme in our stories. Pride, love and respect were over-riding and the beauty in the nuances of stories about particular touching moments in a caring life, were a privilege to witness. Hearing these stories may be an important connective moment for other bereaved carers. Sharing them with service providers may also give emphasis to sides of caring and aspects of individual lives that they hear much less about, confining their knowledge to the organisational or the clinical.

Much of the research work that has been done with carers has tended to focus on the plight of carers, on ways that they are mistreated and ignored for example, but a few recent studies have started to explore how people make sense of both their positive and negative caring experience. For example, a study of 22 bereaved informal cancer carers in New South Wales, Australia by Wong & Ussher (2009) suggested that people experience positive aspects of providing palliative care. These included a sense of reward for doing something good, meeting the expressed needs of the patient, continuing with normal life as much as possible, improving the conditions of the relationship and meeting cultural expectations of the right thing to do. The positive aspects of caring most frequently mentioned in the stories collected here had some elements of these factors, but emphasised love, return altruism over a life time and personal reward to the carer.

Positive aspects mentioned about life in bereavement focused to an extent on the joys of regaining some independence and being released from the engulfment of the caring situation. Book clubs, swimming, music, voluntary and committee work, travelling and animals all featured.

Figure 8: Barrie assisting in the digistory editing process.

12.4 Stress

We did not ask the bereaved carers any specific questions about health, but as part of the telling of their stories, each wove in tales of the stresses of bereavement, some linking back to earlier times of stress in their lives, and more often than might be expected, times of complete breakdown. They also spoke about the impacts of residual guilt on their lives during and after bereavement, and a little about the drive to stay healthy in bereavement.

12.4.1 Stress-related problems – 'When you adapt to that sort of level of stress, it's, it's very difficult to let go'.

While most of the bereaved carers managed to stay healthy while they were caring, many experienced minor problems exacerbated by extreme tiredness and reported broken sleep. John and Susan recall being left weakened and, for John, chronically ill himself.

> When she (Peggy) wanted something I woke up, looked after her and then, I'm very lucky, I immediately went back to sleep until she called me again... whether it was a complete deep sleep or not, I don't know, because I did get run down quite a bit... My health stayed pretty good while I was caring………, I managed. I think I didn't take much notice of it, anyway. But after she died, of course, I was completely shattered. (John)
>
> It's not immediately after that person has died, it's maybe two or three months on and you then begin to realise how tired you are, because of all that caring. And it's the mental strain as well as the physical. And I think it's, it's being able to recognise it and sometimes, someone to give you permission to say, "I'm tired because", 'cause sometimes we hold it in and try and appear to be, you know, fine, but actually all you want to do is go and crawl into a hole. (Susan)

All the participants told of some ongoing stress related health issues during their bereavement and beyond. While she was caring, Rosemary had two bouts of psycho therapy to cope with the stress. In bereavement, Rosemary and Liz mentioned blood pressure problems.

> Trying to keep as fit as possible and as healthy as possible looms larger, as one gets older... And I do have a couple of problems, health-wise. Well, probably more than a couple, actually. But two pressing ones, and one is that my blood pressure, I have difficulty keeping it at a reasonable level. And also, I do suffer from migraines and they seem to be happening more frequently just recently, which is a worry. I've had them all my adult life, but it is a worry. (Rosemary)
>
> I've got blood pressure, well I did have. I probably haven't now, and I can't get my blood pressure machine to work. (Liz)

Others recognised that there were stress related problems there, but told of how they had stoically carried on. Kath said 'There were a number of issues that related to stress, really, you know. But, you just get on with it, don't you?' (Kath). Kath found:

> It's all right, I mean I'm growing older and I'm creakier and I, you know, there are still some sort of stress related issues…When you adapt to that sort of level of stress, it's, it's very difficult to let go. I don't know, maybe one day I'll be able to lie on a beach, but I, I can't imagine it... I think that's partly why I am such a workaholic is that I, I lived at that sort of level of, of stress and uncertainty for so long that relaxation is a bit alien. (Kath)

Victoria recognised a level of stress that could be reawakened by certain triggers.

> Anything that reminds me of work still causes me a great deal of stress. So for example, I was on the committee of the local drama group and the aspect of it which I found unbearable were the aspects that are like work... the petty politics that go on. (Victoria)

And as a carer in a situation of 'living bereavement', Victoria also pointed out: 'There's a lot of feeling that the worst is yet to come'. (Victoria)

12.4.2 Breakdowns 'I think it was a sort of awesome responsibility'

It was striking that five of the bereaved carers in our very small group (over half the group) mentioned having had complete breakdowns linked to caring. Victoria and Gill described breakdowns tied in with their caring roles that in each case precipitated giving up work.

> 2005, my brother died... I took Nick for a week's holiday to the Scilly Isles in the very end of August, 2006. And for whatever reason, I did not settle back down into work. And, in the very beginning of November, I had a gum infection, which the dentist said was down to stress, and I never got back to work. But when asked to pin point why that happened, or what had specifically happened to trigger that, I don't know. I knew that I wouldn't go back to work, and I had to go through the very traumatic process of not, not so much with the GP, but then with the people that you have to see in order to prove that you're so unfit you can't go back to work. (Victoria)
>
> The teaching got me down and I had a breakdown. And I took early retirement by a few months. And, as I said earlier, that coincided with John's deterioration, so I suppose in some ways it was, it was lucky. And I've not counselled or taught since. So, I stopped working the end of 2000, and finally retired in 2001. (Gill)

Rosemary had had a breakdown earlier in her life in response to a difficult marriage, a young family and her husband's death.

> I did have a nervous breakdown... and I think it was a sort of awesome responsibility really of two children, small children… And so, I think the stress of all of this finally took its toll, and I did find myself having panic attacks and a certain amount of agoraphobia… so I was quite ill for, I suppose, the best part of a year or eighteen months. (Rosemary)

Rosemary did not have a breakdown when her mother died and appeared to have built up real resilience from this earlier experience of breakdown. Two of our group had a breakdown in bereavement. John was devastated after his wife Peggy's death and became very ill. He was hospitalised initially and then put in a nursing home. He remembers very little about this time.

> I was taken ill with pneumonia in October, and was in hospital for a few days. And then I came home, but I went to stay with my friend Judith and I was taken ill, and from about the eighteenth of November 2010 to, 2009 rather, to the beginning of January 2010, I have no memory whatsoever of where I was and what happened to me. I lost six weeks of my life, completely. And I believe, personally, that I had a minor stroke, but, this was not what was diagnosed at the time. According to them I was suffering from stress, which I could be to an extent right, but it certainly wasn't the total…thing that happened to me... I was in hospital and in the Masonic Care Home at Cadogan Court during the whole of that time.
>
> Well I was heartbroken during most of that period, and I also wasn't caring for myself, food-wise, as I should have been. By the time I came out of the nursing home at the beginning of January, I had lost three and a half stone. Obviously you can see I've put it on since then. But, I'd had a very bad time and a very, very lonely time. A lot of it was spent looking at four walls… (John)

And Brian reported major problems following the death of his parents in 1999 and 2000.

> I (was) so depressed and reclusive, you know and my aches seemed to feel worse magnified by depression. I did go through a period of quite acute depression and yet it manifested itself in me being very quiet. I didn't want to talk or engage in conversation unless really pushed and I got round it by burying myself in books. (Brian)

These problems came on top of Brian's ongoing severe health problems which, as mentioned earlier, resulted from football injuries early in his life: 'I've got multiple medical problems… I've been on eighty milligrams of morphine now for over twenty years, every twelve hours'. (Brian)

12.4.3 Residual Guilt –'Did I do enough?'

One aspect of this project was that people spoke with real braveness, honesty and clarity about how they felt. Although it is clear to anyone hearing the stories in full that the guilt described in these stories was never justified, several people expressed a 'residual guilt' that stayed with them, particularly around difficult treatment decisions they had to make near to death. At several points during her interview, Liz highlighted a high level of residual guilt that she was still carrying from the time of her husband Arthur's death.

> I think you also probably have to recognise that you're likely to still be left with some guilt, "Did I do enough? Should I have done this, should I have done that, did I handle that properly". And I think that's going to go on, for me, for years, really, because I have these moments when I think, "Why didn't I do that? What about that?" And, you know, there's nothing I can do about it now. Have to live with it, I suppose, and put it in the right place and say, "Well, if you look at how things were going, and how he was deteriorating and how he was feeling himself, it was inevitable". (Liz)

Kath also struggled with her decision to withdraw non-opiate treatments from her son Sam when he became so unwell he had no treatment options left other than a respirator.

> It was fairly grim. And…making that decision, there is always, there's always that doubt. What if, I don't know, some miracle had happened and…One of the things that, that was quite difficult for Drew when he was older and we went through that, you know, working out what happened, and he wanted me to talk through it and explain to him exactly the sequence of events, so I did. And he was very angry, "You killed my brother!" He was really, really angry. But…I suppose I felt like that as well on some level, so I could understand what he meant. It was very hard. It still is, it's very hard to have made that decision. But, that doesn't make it less right to have made it. (Kath)

John spoke eloquently in his digital story and interview of how his later worry about his agreement to follow the Liverpool Care Pathway for Peggy led to himself becoming very ill for two years.

> I was shattered at what happened and how it happened, because I felt, to an extent, that I was guilty of ending her life, because I'd agreed to this. And until many months later, I still blamed myself until I got…an explanation from the Marie Curie organisation as to what the Liverpool Pathway is, and they were kind enough to send me some leaflets [cough] and information, and I realised that what we had done was probably the kindest thing that we could do in the circumstances, so I didn't feel guilty any more. (John)

These were huge issues for the participants to open up about and we hope we have presented their words with utmost sensitivity. The stories of guilt have been found in other studies of widowhood and bereavement. For example in Bennett & Vidal-Hall's collected death narratives, Mrs A spoke frankly of her feelings of guilt associated with turning off her husband's life support machine and said '....you know we all put on this wonderful brave face, err, that's hiding the big hole inside that's umm, forever there' (Bennett & Vidal-Hall, 2000, 424). It is notable that the three people mentioned here had not sought or received any counseling around these issues. A challenge for services might be to find subtle and creative ways to acknowledge these bleaker private accounts and give people space to find ways to talk about death in a way that they have maybe not been able to do before. This could contribute to both a public recognition and a private transformation of anguish into acknowledgement.

12.4.4 Fitness and mortality –'I'm very well aware that tomorrow... I could even be dead'

Rosemary expressed how carer bereavement made her 'super aware of your own mortality' .

> I'm very well aware that tomorrow I could have a stroke, a heart attack, or I could even be dead. And when you reach my age that is always something that you do think about. (Rosemary)

This can become an anxiety in itself for the bereaved. In response, a number of the female bereaved carers spoke about conscious efforts to keep fit. Liz, Victoria, Rosemary and Gill all mentioned swimming regularly.

> As part of that, a local community group's running keep fit classes, which I've just started going along to, which I'm surprised that I enjoy so very much, but I do, they're very good. (Kath)
>
> I spend quite a lot of the time, also, when you've got dogs, you spend a lot of time exercising them, keeping them fit. And yourself, which is important. (Susan)
>
> Remaining physically fit, obviously, for me. And remaining healthy and able to see my, my one grandchild and, with any luck, any more that may come along. (Victoria)

12.4.5 Overview: Stress

This section revealed that dealing with stress related issues was a key on-going issue for bereaved carers and was the over-riding health related concern. This is not too surprising given the long term and demanding nature of their previous caring roles and is supported by other carer studies. For example, the Princess Royal Trust for Carers found in a recent survey of 639 carers that 65% of older carers have long term health problems or a disability themselves and seven out of ten (68.8%) said that being a carer had an adverse effect on their mental health.

The findings suggest that services could usefully find ways to pre-empt some of these bereaved carer stresses and prevent breakdown in order to alleviate individual suffering and to instill real economic benefit for service provision. Preventing stress-related problems might well be cheaper than responding to the catastrophic impact of breakdown within families and communities. It is noted that during the course of this study, GP Practices and pharmacies across Devon started to offer ccarers health and wellbeing checks. During their appointment they are asked a number of health questions, which inform specialist nurses and pharmacists of their general health. Carers may also be offered vascular checks if they're between 40-75 years of age. They are also informed of a Carers helpline (Devon Carers, 2012)

Finding ways to acknowledge and thereby possibly help people expose and put to rest any feelings of residual guilt was another urgent and subtle need. The stories show as well that responses to bereaved carers needs, should necessarily include attention to new possibilities for fitness programmes, although several of the carers here showed themselves to be aware of these issues and capable of seeking out fitness support in their own communities.

12.5 Loss and Social Isolation

In this section, we looked at the social issues raised by the participants prior to, at the time of their bereavement and beyond. We problematised issues about when bereavement starts, finding that carers often described feeling bereaved – of a loved one, of freedom and of expectations, well before a person died. We looked at 'living bereavement' and 'pre-bereavement'. We went on to explore the types of isolation described, looking at the impact of carer bereavement on day to day social and emotional life and ideas about returning to 'normality'.

12.5.1 'Living' bereavement – 'a sort of double loss... A loss of the mother, ... and a loss of my life'

Carer bereavement is generally assumed to begin when someone dies and our existing health and social care service structures have tended to be set up to respond to this. However, the stories collected in this project supported a much more fluid and gradual understanding of when bereavement starts for some people. Participants were particularly keen to give emphasis to a notion of 'living bereavement' following disablement of their loved one. Rosemary described her foreknowledge of loss of her own independence as a result.

> I think it probably started when she (Mother) had her stroke and I realised how disabled she was going to be. And that she would need to come and live with me, there was never any question of her going back to her own home. And somewhat selfishly I guess, I thought about the implications of that for me, what that would mean in terms of being able to live my life as freely and independently as I had always been able to live it before, really. I'd always been very fortunate, in that…I had always been able to live independently, apart from my dad buying this house. I'd managed to support myself, I didn't have to rely on anybody else, and, I think I'd had plans for when I retired that I would do a lot of travelling and maybe buy a property abroad and all that sort of stuff, really. And I realised that my mother coming to live with me would, would really impact on the way I was going to be able to live my life. (Rosemary)

This bereavement began long before her mother's death. Rosemary described it as a double bereavement, 'a sort of double loss, really. A loss of the mother, who'd been very close to me and a good friend, and a loss of my life, as I'd hoped it would pan out' (Rosemary). Victoria's 'living bereavement' had been going on for many years.

> There's obviously nobody, my partner isn't there to cheer me up, and at the same time, of course, you can't do this, this thing of moving on, because I'm not going anywhere. I'm not moving on to anywhere... I guess I lost myself in the process of looking after Nick and I feel that what was important to my identity in very, very many ways was lost, because, if you're caring for someone who, whose personality changes, and that person is the person that you're most close to and reflects yourself back to you, you actually just completely lose all your bearings and I feel that's a process that I went through. (Victoria)

As described earlier, Victoria still lived with her husband Nick, who has a rare form of dementia. She sees herself as being bereaved of Nick already and yet she will still face a final bereavement at some time in the future if Nick dies. Victoria spoke eloquently about the earlier togetherness of caring as opposed to both her and Nick now being alone.

> One of the strange things that happened during Nick's illnesses that [sighs], for a long time I think he felt he was in it alone, and I had to persuade him that it was something that was happening to both of us, and therefore we were in it together in order to support him. But of course, I've gradually had to step back because I am in it alone. And that means that he's in it alone as well. I can't follow him down the path he's going down, can I? He's, he's gone too far down it. (Victoria)

In total, three of the participants had experienced some form of 'living bereavement', when the person they had cared for was alive, but no longer there in the same way. John, the oldest participant, got closest to his retirement dream with his wife Peggy. After a life time of working in the catering and hotel industry, they retired.

> Before she (Peggy) was ill, we had planned this retirement in Cyprus for many years, and we had got a beautiful flat, it was built to the way we wanted it, where we wanted it. And we were delighted, you know, we were very happy, we'd made some wonderful friends, and everything. (John)

As Peggy became more disabled by Parkinson's, the couple moved back to the UK and life became very different. In describing the occasional moments of frustration, John revealed here how much he lost, as he decided Peggy had lost the will to live.

> And the great, heartbreaking thing was trying to get her to take her pills, and trying to get her to take her food. Again, I will put this on record. Anybody that tells me, as a carer, a family carer, when they're doing this that they don't lose their cool occasionally, I'm sorry I can't believe it, because you do. It is heartbreaking because you know, if they don't take these pills, they're going to deteriorate. If they don't take food, they're going to get so weak and develop an illness which will kill them. And I even had doctors coming to try and help me, particularly a lady doctor who was a very kind person. And even then we still couldn't. And when you get to that stage, it is heartbreaking because you know very well that the person that's decided, in their quiet little mind, that life is no longer worth living. (John)

Dealing with the double loss of the cared for person and the loss of your own life together as well as taking on the role of caring for them is a huge burden that is increasingly being recognised. A glance at the blog page on the Alzheimer's Society web-site reveals a plethora of stories of people coping with a living bereavement. For others to better understand and respond to people in this situation is vital.

12.5.2 Pre-bereavement isolation – 'creeping isolation'

The bereaved carers, particularly those caring for their partners, described a feeling of increasing isolation from their friends, neighbours and community that grew during the last years of their cared for person's life. John and Liz both mentioned the isolation caused by the limitations of wheelchairs and others lack of understanding of their situations.

> We were very isolated before she died, because, again, I was living in a flat in a complex which has a hundred and twenty-two flats, but my wife was in a wheelchair and people would say, "Good Morning!", "Good Afternoon!", but they would never come near you because... they're afraid that somebody might ask them to do something for them. I didn't want anybody to do anything, I was very disappointed in the way people behaved... And I was very, very hurt that nobody turned up for her funeral either. (John)
>
> Our social life shrank. Considerably. You know, we couldn't go out to dinner with people any more 'cause we couldn't get in their houses. And one or two people that we knew… husbands, said, "Oh you ought to go out and do a bit more", I used to say, "Well, yes, but it's not easy to get in anywhere, as you've found, we can't get in your house very easily, we need three people to help us, and I work full time and I'm afraid that I know that I limit what my husband does because I haven't got the energy after working all week and doing the chore-y things to actually always want to go out". (Liz)

Liz described the creeping isolation of her and Arthur's life while he was alive.

> I wouldn't like anybody to think we were completely without a social life and friends, but I was aware that they were dropping off, and it was the postcard, the phone call, it wasn't the

> interaction that we'd had before. And, I could understand it... I'm afraid my philosophy was if you get too hung up about it and bitter about it, nobody wants to talk to you anyway and you never know what problems other people have got. And he lost, I suppose we did do, both of us did, really, as things progress, you also start to lose people. And I, you know, we've got some friends now and, even at the funeral I said, you know, "Why didn't you come and see Arthur?" They said, "Well, we couldn't understand what he said". (Liz)

Victoria also spoke of becoming isolated as a couple:

> You are very socially isolated because what happens is that I was living with a person who I know was regarded as difficult, arrogant, anti-social in various ways, for some time. I knew that this person was ill, but not in a way which we could explain to people. So, gradually, we became, as a couple, quite isolated. (Victoria)

This 'creeping' gradual isolation is again difficult to pin-point in terms of its start and finish, and it was clear from these stories, that the carers were not well placed to respond to their own growing sense of isolation because of the restrictedness of their caring tasks on top of their daily chores, their limited time and their virtual rejection from their existing social worlds.

12.5.3 Early bereavement memory loss – 'I suddenly couldn't remember the names of things'

Nearly everyone described a period of memory loss immediately after the death of their loved one. This has been a common finding across much work on bereavement, described by Larkin, for example, as the 'post caring void'. Kath noticed that she lost some of her intimate and detailed knowledge immediately after Sam died:

> After Sam died, there were big gaps, things that I'd known really, really well and been doing for years, I suddenly couldn't remember the names of things, so that, when I came to write my undergraduate thesis, I had to go and look up the names of drugs that I'd been using four times a day for nineteen and a half years [laughing], and it was like suddenly walls came down. I suppose they were sort of protective barriers where things were painful, and I just, it took me a long time to be able to sort of access some of those and some things still I can't. I just can't remember. (Kath)

Susan described a similar experience of details being 'washed away'.

> You know being a carer and time moving on, when you look back, there's certain things you know you did but you can't actually remember doing them for that person, because it's like water under the bridge, it's gone. And you can only, the not so nice memories tend to get washed away, I think, and the better memories stay. (Susan)

John said:

> I lost my wife about two years before she died, and…yes, when she did die, it was still a complete shock, I was at her bedside and, unless you've been through it, nobody will understand it, I don't think…It is, it's shattering, and I don't remember anything about the week that followed that. I stayed with my son and I have no idea what happened. (John)

Liz spoke about Arthur's funeral in this context:

> I think when I look back, I mean it's like the vicar saying to me afterwards, you know, after the service, you know, "Did I do the service okay and was it meaningful for you?" Actually, I don't remember much about it. No, I mean I can remember choosing the music, I can remember the coffin coming in, I can remember my daughter getting upset and…you know, I can remember us all sort of collapsing in each other's arms afterwards, and then people

> coming back to the house, which was very nice and people hadn't seen them. But you know, in between's a complete blur. Complete blur. Perhaps you, perhaps your mind makes you switch off, I don't know. I don't know.

The participants were perhaps reflecting on a natural response to 'forget' traumatic memories, to develop memory holes about some of the harsher details and practical realities of death and the blur of the immediate post death experience in the bereavement trajectory.

12.5.4 Bereavement isolation –'I can't be jumping jack flash and join clubs and things'.

Following the death of their loved one, everyone on the project said they experienced a sense of deep isolation and loss. Liz spoke of the closed, tokenistic offers of support she got following bereavement: 'Quite a lot of people sent me cards, even in the village, and said, "Oh you must come round for coffee", but they never invited me' (Liz). She also highlighted the emptiness of her personal space:

> No, I suppose there were times when I would've liked people to come round and give me a hug. I think it's a physical presence of somebody else that you miss such a lot. And although my husband couldn't do anything and what have you, but you know, I always, I now come home to an empty house... I go home and there's nobody there... That is a really hard thing to come back to. (Liz)

Brian described an uneasiness with returning to 'normal life', when caring for Herbie had occupied so much of his time.

> It was a void because he (Herbie) was a part of my daily routine and that was taken away and I had to fill part of my daily routine back to the books, back to playing old record albums, which again as my wife stressed to me was living in the past, but I can't do things in the future, I can't be jumping jack flash and join clubs and things. I can only do things which associate me with the past, it's strange, catch twenty two, you know it's nice when you're going out and socialising. The family on Iris' side particularly, because mine are all gone now except for me and my brother, but Iris' two brothers constantly come down and stay with us and they view it as a weekend to get away, to come down to Devon is lovely for them, and it pleases me that they take Iris out but I don't go with them because they hike and walk and go to all the strange places that some of them I've never heard of, they know more about Devon than me, we're the ones who live here. (Brian)

Kath mentioned the energetic pace at which she lived post- bereavement suggesting that 'normal' changed permanently during bereavement.

> Oh gosh, yes, yes. I mean I think that's partly why I am such a workaholic is that I lived at that sort of level of stress and uncertainty for so long that relaxation is a bit alien. (Kath)

Kath had very little to say about having a social life herself, even eleven years after her son's death. She appeared to have almost blended her bereavement isolation into her life without Sam in an on-going way. It had changed her permanently and there was not a sense of returning to a sense of normality that she had previously known. John became ill after Peggy died. His heart break at Peggy's death left him very alone, apart from some activity joining committees.

> Well I was heartbroken during most of that period... I also wasn't caring for myself, food-wise, as I should have been. By the time I came out of the nursing home at the beginning of January, I had lost three and a half stone... I'd had a very bad time and a very, very lonely time. A lot of it was spent looking at four walls…I did try and carry on with all my committees, all different work I did, and that helped me enormously

Seven years after her mother's death, Rosemary was reflective about her feelings of isolation. She described it as a need to be needed.

> But then I think I could go for a walk or I could open my computer and see how many emails I've got [laughing]. Or who wants me to do what. Perhaps it's a need to be needed, perhaps that's what it's all about. Perhaps now my mother no longer needs me, my children no longer need me, and even my grandsons…probably don't need me. Although one of them does, a little bit. Perhaps that's it, perhaps I have this great desire to be needed. (Rosemary)

Liz spoke of the strain of trying to make new friends, but recognised the value of the effort.

> So I've tried all I can to cultivate some new friends, and you know, joining the choir, made myself go, and the gym, you know, I know people at the gym now and I'm at home so I have a chance to get to know more people in the village, which I didn't know before. So I made a mental note in my head, "You have got to make the effort, people aren't necessarily going to come to you". (Liz)

Gill's measure of having 'moved on' socially was when she could honestly say she was too busy to take up an offered social engagement sometimes. Gill said:

> 'Don't say no if somebody asks you if you'd like to meet up for coffee, or do you want to go to the theatre'. That advice was given to me by another bereaved person, actually. I'm now in a position where I can actually say I think, I don't think I can make that. So that has to be good. (Gill)

So these were descriptions of isolation in bereavement that had eventually lifted for each individual, but their loss had created a new 'normal' in social terms. None saw themselves as having returned to some kind of normality that they had previously known.

12.5.5 Overview: Loss and Social Isolation

In undertaking this study, we recognised that in our focus on carer bereavement, we were imposing an artificial construct for analysis. By looking at different levels of loss and isolation, this section evidenced the need to understand people's experience in terms of a graded series of bereavements or losses that do not simply coincide with the death of the cared for person. While we found some evidence for Larkin's notion of a post-caring trajectory that includes a 'post-caring void', a period of 'closing down the caring time' and then 'constructing life post caring', our study suggested that to develop this idea of a trajectory, it was useful to include understanding of an earlier period of 'living bereavement' -a time of suspension of much social and emotional support, when 'moving on' is not an option. This evidence also suggested that support to carers is needed in facing periods of transition and change linked to different kinds of bereavements at the end of the caring role and beyond, perhaps allowing them to better anticipate and plan for periods of transition. The provision of time limited peer mentoring and befriending co-support to help carers at key stages in the end of life and end of care path, which can extend for many years, is something that a project like Past Caring perhaps provided a model for. Other existing initiatives that provide this kind of support are seen through the 'Dying Matters' initiative and the locally based work of Age UK.

12.6 Death Stories

Although our interviews strove to focus on the bereavement experience, stories about this were much shorter conversational turns relative to the elaborate stories about death that we collected in trying to get people to briefly contextualise their bereavement stories. This was true even when the death had been many years earlier. We therefore felt it relevant to single out these stories that people chose to give around death and to examine their clear meaning and important function for people who are bereaved in mediating the past.

12.6.1 Long death story, short bereavement story- 'If I stop, I'm never going to start again… so I must just do something'.

The lead up to Kath's sons' death was incredibly traumatic due to mistaken mis-management of his antibiotic drug treatments in hospital and in her interview she tells this difficult story in a lot of detail. At the end, Kath said:

> I…pulled out all sorts of hell and had pharmacists and doctors running around and got the dose reduced, because the thing is they, they hadn't checked that, they'd carried on doing it overnight, so he'd still been pumped full of the damn stuff. So I took him home, I mean I just arranged immediately for him to come home. But he was very, very poorly and I knew that actually, it was going to be really difficult for me to manage that... When Sam died, I mean, we were all together. Because we stayed a Little Bridge House at that point, I removed Sam from the hospital after the incident with the prescribing and took him up to Little Bridge House, so Drew was there with us and the rabbit came as well, you know, so we were all there... And he died… just after half past nine that evening while watching, well he wasn't watching but, in Drew's mind he was watching South Park with him. (Kath)

Kath's narrative is one of rescuing her son from mis-treatment and restoring dignity and safety to his last moments. The trauma of Sam's death resolves at least in being there to honour his final moments together as a family. Her narrative about what happened after that was markedly shorter, abrupt and lacking the same kind of detail:

> So he died on the Friday, the cremation was on the Wednesday. We went back to Penzance on the next Friday and I started college that day and Drew went to nursery. And it was whoomph, whoomph, whoomph. And it was really just; "If I stop, I'm never going to start again. If I go home and go to bed, I'm not going to get up, so I must just do something". So that's, that's how I got through that. (Kath)

For Susan, trauma came shortly after her husband Tom's death, but she maintains a positive narrative about this and said relatively little about the impact of immediate loss of Tom's body and what happened to her next.

> So she (the District Nurse) came in, and had a look and she said, "Oh yes". So upped his pain depressant, really. And she went away and he had died within half an hour... his elder sister was staying with us, and…and one of the daughters... it was all very peaceful. And it, it's what he wanted, you know, which is, it was great to be able to do that at home... Now the thing is here that Tom had bequeathed his brain to the hospital in London, and with anything like that, they have to have it removed very, very quickly, 'cause it's one of the first things that deteriorates. And we had got it all organised with the undertakers beforehand and they were there within half an hour of the doctor signing the death certificate, 'cause everything was rushed forward. And I suppose that was Tom's final thank you, really, for the care that he had had from the medics. (Susan)

These shorter bereavement stories gave a strong indication of the biographical disruption that occurs in the life of the carer and the apparent 'blunting' of their own personal narrative at the time of death and in the immediate post bereavement period.

12.6.2 Predictable or unpredictable time of death -“These are probably your mother’s last days”, I mean nobody actually said that.

All the participants provided very detailed narratives of their feelings and experiences close to the death of their loved one. While acknowledging the obvious loss and grief in these tales, people were keen to recount, share and appreciate the positive experiences that were blended into this time of immense grief. Those who were able to predict and plan for the death of their loved one quite expectedly had the most positive experiences. For example, Brian said:

> I was there when he (Herbie) slipped away, he was gripping my hand and I felt him go, I was talking to him and I was brushing his hair like I did with father and I felt him just drift away comfortably. My initial thoughts were ‘Herb you don’t have to suffer anymore’. (Brian)

Susan said of her husband Tom’s actual death:

> I was really quite happy for Tom, ‘cause I knew he was happy, ‘cause he’d gone to the ultimate goal, and he was no longer in discomfort. I think that’s the main thing. And I knew those last few days he was really frustrated because he knew that that was the end. (Susan)

Rosemary described how she had a long lead up to her Mother Novello’s death, but nevertheless experienced it as unexpected.

> I was quite devastated when my mother died, I had been preparing for it for a long time. Really her stroke, when she had her stroke, there was a death there, for me, because the mother I knew was no longer, was no longer there... And then the next sort of bereavement, I guess, was when she went into residential care, and I was, I felt…that she’d been kind of taken over, really, by other people…So…so I’d lost her then... her health spiraled downwards, and so that was like a second stage, I suppose, of bereavement. And then the final bereavement, obviously, came with her death. Which, although I’d had plenty of time to get used to, nonetheless, was a, was a profound loss.

Poor communication with residential staff marred Rosemary’s experience a little. She said of Novello,

> And in fact she was poorly for about three days and was starting to breathe very, very loudly and rattly. And although nobody actually said to me, “She’s dying”, I think I probably knew that she was. And they rang me at about six o’clock in the morning one morning to say that she’d died during the night.
>
> ... The staff in that home... were great at nursing, the sort of professional aspects of nursing, (but) they were not good at communication. Their English wasn’t wonderful. And so somebody being able to sort of sit with me and say to me, you know, “These are probably your mother’s last days”, I mean nobody actually said that. I think they avoided saying it. I don’t know. (Rosemary)

Liz spoke painfully about how difficult she found it to stay with Arthur right at the end of his life.

> So at about five thirty…I was finding it, if I’m honest, finding it extremely difficult to sit there and watch this breathing. And he, his colour was changing and he was looking as though he was sweating but he was getting cold and clammy and I…And I thought well I can’t, they said, “Well we could ring your daughter up”. I thought, you can’t, I can’t ring my daughter, she’ll be on the motorway, she’ll drive like a loony, and she’ll come in here and

> she won't cope. And…I thought, I can't cope with this and that as well, which, I mean I probably made the wrong decision, I don't know. (Liz)

12.6.3 Place of death – 'he was shunted into a side room and put on a syringe driver and left'

Research has shown that value is commonly placed on death at home (discussed in depth by Wong & Ussher, 2009) and in recent years, the focus on caring for vulnerable people has shifted from the institution to the home. However, for people with very long term caring needs, death at home is not necessarily possible or desirable. Amongst those we spoke to, only Susan's husband Tom died at home. Gill's husband John was at home until the day before his death.

> He (John) went into hospital the day before he died... he'd been diagnosed the previous week with pancreatic and possibly liver cancer. And I don't think the hospice care nurse realised how close he was to death, or the doctor. And she suggested that he went into the local hospital... to give me a bit of a break. And he went in on the Monday and died on the Tuesday. So, yes, he was not at home. But John wasn't one of those people that would've said, "Oh, I must die at home!" like lots of people... So, right up till the last day, the last twenty-four hours, he was at home. Being looked after by me. (Gill)

Though not at home, some people specifically sought to avoid their loved one dying in hospital. Rosemary's mother Novello was at her residential nursing home when she died. Rosemary had made a specific request in her mother's last weeks that if her health deteriorated, she was not to be taken into hospital but was to stay in her residential home. Rosemary said:

> And when she did die, although I could've wished that she didn't have to have gone into residential care, and that I could've looked after her until the end, nonetheless, I felt when she died that I'd done the best I could. (Rosemary)

As mentioned earlier, Kath removed her son Sam from hospital and took him to a hospice at the time of his death, where he had a peaceful, family-oriented death that Kath was proud of.

Brian's friend Herbie did die in hospital and Brian was with him. He experienced this in a positive light. Liz's husband Arthur and John's wife Peggy, however, both died in hospital in difficult circumstances. John told the following story.

> Well, leading up to the death, she wasn't well for the week before and I'd called the doctors and I'd called the ambulance, but they had this idea that, she was short of breath and had a certain amount of coughing, and it was decided that she didn't need to go to hospital yet. And then she fell down and I had to call them in, they said, "We must take her in". They took her in on the Tuesday, and I was called in on the Wednesday morning and was approached by a doctor and a consultant and was told that they were proposing to put my wife on the Liverpool Care Pathway, which meant absolutely nothing to me. And they explained that what it amounted to was that they would no longer try and feed her or give her any medication and that they would be injecting her regularly with morphine so as to stop any pain until she died, which they expected to happen within seventy-two hours. As it happened, it did happen at five o'clock the next morning. I was shattered. (John)

John talked powerfully in his digital story that accompanies the interviews, of how the residual guilt from this experience left him ill and distraught for two years following Peggy's death. Liz also had an incredibly difficult time with her husband Arthur's death in hospital.

> The decision had been made to put him (Arthur) on to the palliative care pathway, and he was shunted into a side room and put on a syringe driver and left (pending decisions at the Consultant's morning round). So I, regrettably, decided that I had to go home... And I came back, and this clock, it was about ten past six, I think. They rang and said, "Your husband's

> passed away”. When I look at it logically, which one must I suppose, if they couldn’t feed him, life wasn’t sustainable, was it? Because every time they put him on the feed, he was vomiting. So…you know, he wasn’t, I suppose we’d come to the end of the line. (Liz)

By definition, hospital deaths are going to be more likely where health needs are more complicated and obscure and where complex clinical intervention and decisions are needed. However, communication around death in hospital does come over as problematic in these stories collected here. John’s tale of not understanding the Liverpool Pathway and not having it properly explained to him at the time of Peggy’s death, is heart-rending. As can clearly be heard in Liz’s story, she remained full of unanswered questions after Arthur’s death, questions she was still asking herself at the time of the telling –clearly using the telling as a way of resolving conflicts and doubts in their minds. This self questioning was not a feature of people who had experienced less prolonged, less chaotic service responses, and it may be coincidence, but people who had not experienced death of their loved ones in hospital.

12.6.4 Overview: Death Stories

Although our interviews strove to focus on the bereavement experience, narratives about this were much shorter conversational turns relative to the elaborate death narratives we collected. Being given opportunity to recount a detailed story of death appeared to be a strong need expressed in our interviews. This has been found in other work such as Bennett and Vidal-Hall (2000)’s Leicestershire study of widowhood. They suggested that the narrative shape and fluency may be the result of telling the death story on many occasions to other people and that the need to do this is a way of valuing the person who has died. This leads to the obvious conclusion that the bereavement story is not rehearsed or valued in the same way and more attention to this might improve things for bereaved carers in coping and surviving.

Wong & Ussher (2009) found that being present at the time of death was described as being rewarding as it fostered the inclusion of others, provided an opportunity to say goodbye, provided closure and was a spiritual experience. We found less detailed observations of this, because few of our participants had this opportunity. Some, like Liz, who did have the opportunity, simply found it too painful. Rather, people reported the predictability of the death itself being a key issue in the quality of experience for the carer and the place of death also had relevance, in the main linked to communication challenges with service providers, particularly those in hospital.

We conclude that remembering the events appears to be a goal in itself for bereaved carers, as a demonstration of respect for their loved ones. Finding opportunities to rehearse these narratives may be vital for the bereaved carer in coping and surviving, yet current support services do not recognise this explicitly. Current support services tend to focus on the short term, the time immediately after the death of the cared for person, yet this is a time when most bereaved carers report quite considerable memory losses. So one finding of this study might be that work with and around death narratives would be very valuable and this needs to happen not in the immediate aftermath of a death, but further down the line in a bereaved carer’s experience.

12.7 Money Matters

In this world nothing can be said to be certain, but death and taxes
(Benjamin Franklin,1789[10])

Money matters surfaced in almost every interview, often with a sense that a tale had been ongoing for years and took a great deal of mental and emotional energy, not to say dogged determination. For our group, these were not tales of financial hardship, but money matters still emerged as a dominant theme in our interviews. The stories we heard were about financial matters after a person has died, but also about the financial aspects of being a carer and managing other people's finances before they have died, matters that live on in the psyche of the bereaved for a long time and inform how they deal with finances in bereavement. Putting these weighty, dry money stories somewhere by recounting them in the interviews appeared to visibly lift burdens for some bereaved carers.

12.7.1 Money issues while a cared for person is alive –'I won't fit the criteria'

The bereaved carers spoke at length about the relevance of money matters for carers when their loved ones are alive, as a focus for networking, initiating conversations with each other and sharing knowledge and skills. Like many others, Victoria explicitly recalled how it was money that first took her into her own acknowledgement of being a carer. Victoria gave up work in 2006 to care for Nick, who had been unable to work since 2004. She had not been aware that she could claim any benefits, because she didn't see herself as a carer until her friend mentioned her own husband's situation (recovering from a stroke, aided by Disability Living Allowance).

> And, she said, "Of course, when he was in hospital they advised me to get this and I've had this", and at that point I thought, "That's interesting, 'cause he's an awful lot better than Nick's been for about [laughing] three or four years!" Even with the stroke, he was a lot better [laughing]... And so, I got the forms and filled in the forms for this Disability Living Allowance with most of me believing, and I think this is so sad because.. this has come back to me from so many other people in caring situations, believing that I'm not a carer …and I have a really nice life and…I won't in any way fit the criteria for this, there's no way…that I would qualify for this. Oh and they eventually wrote back saying, "You've got the medium rate Disability Living Allowance and it's backdated to when you sent this form in". (Victoria)

As Carers UK advocate, 'Recognising yourself as a carer is the very first step to getting the support you need' (Carers UK, 2012). The bereaved carers in this project suggested a significant financial thread from this first moment of carer identity right through to bereavement for a lost relative or friend.

While recognising its immense value, the bereaved carers also spoke about anxieties of receiving local authority financial support as a carer. Again we draw here on Victoria's words, as she was the only one still receiving carer related benefits at the time of the project. Victoria said, 'When I first had the funding I worried myself sick. I used to wake up night and day worrying about it, and it's stupid isn't it?... it makes you always frightened' (Victoria). Victoria and others experienced insecurity as social services and health staff created an atmosphere where everything might be questioned and had to be justified in an overall picture of cuts.

Like many of us, carers take time to get around to sorting out finances for their loved one, even when they have been caring for years knowing the death could come to their cared for person in the imminent future. Rosemary was 'caught out' initially, by not organising her mother's finances

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[10] Benjamin Franklin (1706-90) in a letter to Jean-Baptiste Leroy, 1789, which was re-printed in *The Works of Benjamin Franklin*, 1817.

before Novello became 'mentally incapable'. She describes how complex her mother's financial situation became while she was alive.

> Well, my mother lost what was regarded, as the law was then, mental capacity, before we had ever got round to sorting out what might happen in just such an eventuality. I had always.., my daughters had urged me to sit down with my mother and sort things out, while she was still well, and I promised them that I would do it when we went to Turkey that year. And of course we didn't go to Turkey that year, that was the year she had her stroke, when I was supposed to do it. So in other words, I'd left it too late.
>
> ...So that meant, in order to manage my mother's affairs, I had to go to what was then called the Court of Protection, and become …a receiver for my mother's financial affairs… She didn't have a bank account [laughing], she always dealt with cash, but she did have building society accounts. … I had to set up a bank account for her, a receivership bank account, so that everything that was spent on her behalf went through this bank account. And every year, I had to submit accounts to the court of protection, to show money in, money out, exactly what was spent, final balance. It was really like having to file company accounts [laughing]. It was really quite arduous! And until I got a computer, it was incredibly arduous, because I had to do it all manually, and in my head [laughing]... But it was something I always used to dread, every year. (Rosemary)

Together, the stories show that we should take seriously the worry that carers expend over money while their loved one is alive and think of practical ways to alleviate or counter some of this worry in an 'upstream' response, rather than focusing instead on 'downstream' solutions, treating any resultant stress related issues (see stress section)[11].

12.7.2 Managing money in early bereavement–'It was incredibly arduous'

Nearly all the bereaved carers reported finding that sorting out financial matters in the early stage of their bereavement was extremely difficult and between them our participants had a range of different difficult experiences with it. For some, they were simply not well enough themselves to cope with financial issues of any kind. The early period of bereavement left John in a particular financial predicament, with emergency support from formal services put in place for him when he himself became ill, but with the expectation that he paid the bill. He felt that he was taken advantage of as the hospital transferred him to a private nursing home for which he had to pay. He had no memory of that time so believed he could not have given meaningful consent:

> I was in hospital and (then) in the *(named)* Care Home[12] during the whole of that time. And I, I don't think I should say too much about it, as I have got a legal disagreement with the Hospital about the way I was treated. The simple reason is, they put me into *(named)* Care Home, I think it was somewhere about, oh, beginning of December, and I came out on the fourth of January, and I had to pay nearly three and a half thousand pounds out of my own money for it. I didn't even know that I was being put in there, and they say that I gave

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[11] In public health, upstream approaches seek the causes of disease and disability and address problems through prevention rather than treatment. The upstream metaphor goes like this: People are drowning in a river. Rescue workers are pulling them out but soon realize that no matter how hard they work, there are always more people floating downstream. Public health advocates decide to take a walk upstream, to see why people are falling into the river in the first place. During the 20th century the average life span in western countries increased. Some suggest less than 20% of the increased life span can be attributed to medical care, while public health efforts deserve the credit for the remaining 80%. Nearly all these gains are due to programs and policies that address social and environmental factors that influence our health. (Bournhonesque & Mosbaek, 2002)

[12] The names of the particular hospital and care home have been anonymised here.

> them permission. Well if I did, I don't remember anything about it. And they didn't consult my family about it, so we have an ongoing tribunal... I was very badly cared for. (John)

Others who were previously dependent on the deceased for financial administration, found the transition to independence took some time. Gill had left managing the finances to her husband John and described how overwhelmed she initially felt after he died.

> John had always been the money man in the family and although he taught me to do lots of things, you are still left with it. And I had an income tax form come, with my new tax code. And I looked at the old stuff with John's writing all over where he'd checked them, which he always did, and I didn't know how to check it. So I just had to guess they were right. But in the next fortnight, I had seven different tax codes, so I don't know whether they were right or not. (Gill)

Young & Cullen suggested that carers like Gill may have become so intertwined with the deceased as the deceased has become more dependent on them, that at first... it is difficult to move towards any form of independence' (Young & Cullen, 1998, 152). Susan came to realise she was in some financial hardship after her husband Tom died. She had to move from their shared home.

> And then, once it was all over, I knew I couldn't afford to stay on there. And what I hadn't realised, Tom and I when we were first together, it was sharing everything, knowing about the bills coming in and going out, monies and everything else. But as Tom got more and more ill, he would hang on to certain things he felt he could actually do, because he thought he was "normal", and I put that in inverted commas. But he wasn't able to, and it wasn't till after he'd died I began to realise how much he'd been hiding away because of his dignity. And I think that's another thing one has to understand and respect. But sometimes it can create an awful lot of problems afterwards. (Susan)

For Susan, money matters highlighted her husband's rather controlling behaviour and this opens up legal and ethical dilemmas about respect for the dying and how bereaved carers can stand legally.

12.7.3 Managing money in later bereavement -'we compare notes'

Although money management in early bereavement was described clearly as very challenging, especially when a former carer was still in the fog of deep mourning and dealing with new responsibilities, and new realisations as in Susan's case, the findings from our study suggested that some carers can develop new financial skills in a very able way and the practical focus of sorting out money matters associated with their loved one becomes a useful (though perhaps not chosen) focus for energy. Two years after his death, Gill's experience and ability to deal with money increased enormously.

> I became obsessed with money. I suppose this was because John had always done it, and he just used to leave me to do all the practical stuff because he couldn't... And I've got a friend who's also bereaved and we compare notes about building society accounts and so on, and sort of help each other.

However, without John's guidance, Gill showed an ambivalent attitude to spending money on herself. At one point in her interview, she said, ' I keep wanting to spend money, but I can't find anything much to spend it on, except I have been on three holidays in twelve months.' Then later, 'No, the only counselling that I've had was as part of this project 'cause it was available counselling. If you just go to a counsellor, it costs a great deal of money' (Gill). Other carers struggled to think of their own needs much at all and did not mention money once. Kath merely said, 'I'm not very good at leisure' (Kath).

While Novello was living in a nursing home, Rosemary realised she could be eligible for National Health Service (NHS) funding for her care. A large sum of money was at stake.

> Towards the end of her life I realised that she was probably eligible for NHS Continuing Care funding, which would've meant that all her fees for the nursing home could've been paid by the National Health... And I then set about applying for continuing care funding, and I was turned down, and I went to appeal, and I was turned down again. And then it went to the Ombudsman, who reckoned that the Health Authority had not carried out the process properly. And so I had to appeal again. We were still turned down [laughing]. And then it went to a final appeal, and it was awarded. And by this time, my mother had died... So I think the whole process took about three, three or four years. But finally, the money, it was allowed, and the money was re-paid. It was about fifty thousand pounds. [Loud sigh] (Rosemary)

Rosemary described how she later dealt with her mother's house and money.

> And the other thing, actually, was about her, her fees, another little known arrangement, which they don't advertise over much, is that you don't actually have to sell your house when somebody goes into a nursing home to pay the fees, if you have no other form of income. My mother did have a very small income but it nowhere near enough to pay the fees. You can ask for a charge to be put on the property, and you can delay paying the fees until the person dies and the property is sold. And no interest is charged up to six months after they die. So I did read about this, and I did put, I did ask for a delayed payment arrangement and a charge was put on my mother's house, to pay her fees. Which were round about, by the time she died, about thirty thousand pounds.
>
> And so I gathered together the money that I'd managed to save, for my mother, she was a lot wealthier when she died than when she came to live with me, 'cause I managed to save her money and invest it in reasonably high interest savings accounts and things like that. And by borrowing some money from my daughter and by cashing in some of my own savings, I managed to pay the thirty thousand pounds, so we didn't have to sell her house. And I've just sold it now, five years later... So there you are, it's all quite complicated, looking after somebody's finances, it really is. So that battle over, I decided my battling days on behalf of my mother were over. And I sold it. (Rosemary)

The degree of tenacity required to juggle finances in life and bereavement were highlighted here. For bereaved carers, opportunities to share decision making and experiences about financial matters are appreciated. The stories also suggest that this is one area where former carers develop appreciable skills and abilities that could perhaps be pooled towards community development aims in other areas in the later stages of bereavement.

12.7.4 Spiritual or emotional guidance with finances –'Never alone'

Several years after her husband's death, Gill still believed John was helping her and would have been 'proud' of how she managed her money.

> I think John would be incredibly proud of what I've done. …..Instead of having John as my financial advisor, I had to find a financial advisor and John helped me there, even though he wasn't there, because he rated the *(named)* Building Society and he had looked at their financial services and thought they looked good. And they were recommended by the Daily Telegraph, which John thought was a good newspaper, so I went to the *(named)* Building Society. And even now I still talk to John and I get the answers because I know what he would say.'

What this story suggests, is that even with the physical and conceptual ability to cope with financial

matters after years of not having to do so, some carers find it helpful to believe in higher powers supporting them. Others found this higher power or emotional help to sort out financial matters, in religion. When asked about money during bereavement, Susan responded as follows:
So you had lots of financial issues to sort out?

> Yes. Yes. But there we are, you know, and I'll be quite honest, I just pray to the Lord, ask for guidance and yeah, it's come. (Susan)

Hence, even when the practicalities of sorting out money become easier, some bereaved carers do seek and appreciate long term spiritual or emotional support with the financial aspects of life.

12.7.5 Inheritance issues –'I'm not over here for money'

Brian's story about his neighbour Herbie highlighted the vulnerability of an elderly and frail man, and also of the complex position a neighbour carer such as Brian is put in. As a 'non-kin' carer, Brian was in a very sensitive position regarding Herbie's money.

> He wanted me to go with him to go to his solicitors to sign up to be the sole heir to his estate which was considerable, he was a man of great wealth, I didn't know at the time. He owned several properties; a farm and had just under nine hundred thousand pounds in the bank... and I came to know this through having to do and manage his affairs, his policies, and renewals, and the statements that came through to him that had to be dealt with... And he said when are we going over to the solicitors, I said 'don't start talking to me about that, I don't want to know, you talk about that and I'm going to go and I won't come over anymore' and he used to start to cry and I'd say 'I'm not here to make you cry, we've got to finish this crossword, come on let's get back to what we're doing' so that was how things went on day after day. I used to tell Iris and she used to say 'ah, god almighty'. (Brian)
> So he died a very wealthy man and with a power of attorney that passed away several years before him and at the time Herbie died, the estate, Herbie's estate went to people that he never knew, that was set up by this other party for their benefit, and they've reaped their benefit since, they've developed on Herbie's land, made houses, made a lot of money and I look back and I think 'god, you know, these people I just couldn't be like that'. (Brian)

Brian was constantly aware of trying to keep Herbie's money separate from their caring /friendship. He was also always worried about what the other neighbours might think of his motives for caring for Herbie so attentively.

> And I said 'Herb, I'm not over here for money, I don't want anything' but he said 'you must take something, you and Iris, you do so much for me' and he used to send a hundred pound over at Christmas. What we used to do, used to put in an envelope with his card, one hundred pound for Herbie, so that hundred pounds came back and forth across the road every year and I said 'I tell you what Herb, I'll take twenty pound and then I can take Iris out for a meal' he said that will please me so I took twenty pound... And to this day people down the lane think that Herbie showed his gratitude to me and my wife in a financial way but I can honestly say if I don't get out of this room alive, I never befriended Herbie for financial gain, and never took anything from him at all. (Brian)

Stories like Brian's remind us that taking care of people within the community, through altruistic intentions, is not supported by the formal service system (for example in terms of benefits etc) or by the public. Neighbour carers are particularly prone to other people's suspicions of their motives and their own complex worries about what other people might be thinking.

12.7.6: Overview: Money Matters

As described at the outset, these are not the tales of financial hardship that have become a focus for a body of good work within Carers UK (2011). Instead, for everyone apart from Susan, these are stories that show in what subtle ways money matters to long term bereaved carers who do not have specific financial hardship, but who nevertheless experience difficulties associated with money matters.

The role of money and benefit claims in recognising yourself as a carer initially was mentioned. Perhaps this indicates a site where more long term carers could potentially be picked up by services, particularly by those GPs that claim that they do not know who the carers are within their constituency. Would there be any possibilities for developing systems where benefit claims could act as a trigger for referral to Carer Services? Supporting long term carers in taking over financial custody for their loved ones would also reduce stress and dread in people's lives. At the time of writing, financial support and advice was to be offered to Devon's carers as part of the delivery of its Carers Strategy, funded by new monies given to the Primary Care Trust. Finding innovative solutions to develop and deliver this will be an interesting challenge that perhaps bereaved carers themselves could become involved in through working with their peers, given the skills that they themselves can develop through their own experience.

The interaction between money and bereaved carers' fears for what other people in the community think of them comes out strongly in these stories. These fears of community judgment, doubt of the altruistic caring motive and pressure from 'the whisperers' within communities bear heavily on the carer prior to and post bereavement.

Figure 9: Rosemary, Victoria and Liz talking about money issues

12. 8 Bereaved Carers Relations with Services

As described in our introductory section, it is current policy for carers to be supported in their caring role by formal services. Less has been said or put in place to date for formally supporting bereaved carers. This chapter reveals, experiences to date have been very patchy. This section considered how people coped with and without formal support and their thoughts on support available, especially through groups. It looked at what services were used by the bereaved and pieced these together with some reasons given for non-receipt or sometimes non-use of bereavement support services on offer. We also try here to highlight some of the complexities of carers and bereaved carers relations with services by presenting a few crass remarks from service providers that lived long in the thoughts of the people speaking. The final section homes in on people's particular communication difficulties with and distance from their loved ones' medical services.

12.8.1 Support services for carers and bereaved carers –'emotionally too complicated'

Services for bereaved carers have not been common, but through the interviews, we were interested to explore any experiences people had had of formal support in bereavement. Only one person had chosen to take up any *specific carer bereavement support*. Gill had used a pioneering short series of six bereaved carers support sessions run by East Devon Carers. She found the sessions beneficial and was full of praise for the organiser. Two other people mentioned disappointment at the lack of specific support groups for bereaved carers, but they had not chosen to use these sessions. Kath mentioned that support had been available through the Hospice that her son had used, but geography and travelling time was one factor that made using this support difficult:

> I literally, I didn't know how to dress myself, because I couldn't think who I was and…a bit of continuity of contact beyond the bereavement, I think might've helped me to re-construct a bit sooner, I don't know. It (might have) made me feel less unvalued, perhaps... That did make me appreciate the continuing support that (The Hospice) provided, but you know, they were quite distant. They were in Barnstaple and I was in Penzance, and having some kind of local provision would've been useful. (Kath)

There is clearly also an issue of timing, in that it was too long after bereavement for some people to need this kind of support. Or perhaps it was timidity or other engagements. People were curiously reticent on this. But if it was an issue of timing, the question thrown up is –What is the time-span of people needing basic support in their bereavement? Our findings were curiously equivocal and we'll come back to this point later in the section in discussing carer group support options.

Some general *bereavement support* groups did exist in Devon at the time of this study and former carers could go to these. Only one person in our study chose to attend. John went to the Council for Bereaved People, run by Cruse, on a weekly basis:

> ... which was extremely helpful. And the people there were very helpful because they'd all suffered the same sort of thing one way or another, and I still see some of them because I go out for lunch every Monday and they go to the same place. (John)

Cruse got a number of mentions by others interviewed, showing people were aware of the *bereavement support* they offer, but no one else had wanted to attend. Gill said she had stayed away as she had not felt anything in common with others in the group. She also felt it only attracted people (like herself) without family support:

> Most ex-carers I know who are bereaved have family, and they've got family support. Most areas have got the bereavement support groups, it just happened to be not for me. But I

> think the people I know have not gone to bereavement groups, they've got their family to support them. (Gill)

Three people in our group spoke of using *carer support* groups. Victoria attended a group at the Alzheimer's Society and described in detail how she came to feel about seeking this support.

> I rang the Alzheimer's Society and they rang back, of course, as I now realise they would. And they were going to start coffee mornings, and I went along to the first one. And I think at that point I was still in that phase of, again I suppose this relates to bereavement, this wasn't really happening to me, and it wasn't really happening to Nick. 'Cause really, there's a life which we had which was happening in parallel, you know, that life that you were going to have where things were actually fine and one morning I was going to wake up and all of this was literally a bad dream and I was going to wake up and Nick was perfectly okay. So actually accepting that, it's all part of the acceptance, you know, accepting that I needed help, because that's really horrible. When you're an independent couple in your fifties who've always done everything on your own, or together…You're accepting you need help, you're accepting that this isn't going to go away. And that's really hard... And I went along and the person running the coffee morning is the same age as me and has been looking after her husband for many years now. And the other person was younger than me and was looking after her husband who is the same age as Nick. And that was the first time I felt, yeah, this is me, this is what is happening to me, this is the sort of person I am now, this is where I can get support from. So that was all my coming out as a carer, really. Which I still think's quite a difficult term. (Victoria)

Gill and Rosemary, engaged with *carer support* and planning services and continued going after they were bereaved. Both were part of a carer's locality engagement forum and various carers' services development groups. They recognised the difficult decisions that carers groups had to make about how long former carers should continue within carer support services. Rosemary was a trustee of Carers UK, the national campaigning organisation for carers and the local branch of this. She asked:

> At what point after their bereavement should they be taken off the Carers Link Register? I know there was a belief that the sorts of services that were available for people who were on the Link Register should cease. And then there were arguments about how many years [laughing] after the services should cease, or if you were applying for something like the chair of one the locality forums, how many years since you had bereaved was a valid period, or how recent your caring experience had to be before you could remain as, as one of the chairs or vice-chairs.

What was the magic number?

> Carers' UK...is an organisation to which I still belong, although my mum died now five years ago. I'm on my second… period as a trustee... There has to be a certain ratio of current carers, or very recently bereaved carers, to non-carers, on the board. Which is right and proper... But from, from the point of view of an ex-carer, the feeling is not so good, in that, while you're caring, the amount of time that you've got left over for other things is, is very limited. But of course once you become an ex-carer, a former carer, for many people this means that they have quite a lot of, of time, and many carers feel that they'd like to give something back. And the opportunities for doing that become less and less the longer the time period is between the cared for person dying. So there's a lot of experience and expertise and willingness to help that goes begging, 'cause it's not wanted. (Rosemary)

Continuing involvement in *carers groups* and services becomes increasingly contentious as your time since bereavement lengthens and participants became self-conscious, imposing guilt on themselves not to 'take up a place that might debar a new carer' (Rosemary). Gill had clear ideas of how long carer group involvement should continue:

> I haven't been a carer now for two years and I have to move on. And I have been moving on... I now know, lots of bereaved people. And my support group, we had five deaths of cared for in a twelve month period, including John. And I tried to encourage them to carry on coming for the support, and I've carried on going, but I am stopping in June, I'm not going any more to the support group. You do have to move on, you can't stay feeling bereaved forever. You've got to move on. And I'm the only one who is still going, the others have stopped.

Victoria was very scathing about using the term 'moving on'. In her situation of 'living bereavement', Victoria was very conscious of not having a 'moving on' option. Victoria said:

> You can't do this, this thing of moving on, because I'm not going anywhere. I'm not moving on to anywhere, and you know, I've had friends who've been widowed in their early fifties... gone through the process of grieving and moved on. That includes, I have friends who have had their husbands diagnosed with the same condition or with other types of dementia who've, you know, their husbands have got, have had the diagnosis, have become worse, have gone into a home, have died... I have lost my partner, my best friend... So, yes, and again in terms of the, whatever the stages of bereavement are, which is a bit of a strange, strange concept. But I know I've gone through them all.

Others did not use *carer support groups* before or after bereavement. Liz did not feel able to seek carer support services while caring due to lack of time and energy:

> I think the Carers' organisations and other organisations are there if you want them, and if you've got the time and space to do it, but I always felt that, living day to day was hard enough without getting involved with anything else. I hadn't got space, capacity, to do it. (Liz)

Susan did not feel she had real opportunity to join a carers' support group when Tom was alive, so to attend one after death may have felt like something of a betrayal. Susan said:

> I think what I would've appreciated was maybe going with Tom *(husband),* if only he had wanted to, to a group where a lot of things could be discussed and to me, and sometimes I think if you're suffering from something and you find other people who've had the same problems, it helps you, and then maybe they've found a way to overcome them. And then the carer knows how to help. But at the same time, you've got to respect the person who is ill and suffering, and really go along with that, because if you went behind their back and did something, that would actually create more problems. And it's just not worth it, 'cause their life is, you know, they're looking at a death sentence, really. (Susan)

This perhaps highlighted the degree to which someone cared for can be quite controlling of the needs of the carer for support. Susan's option was to seek support from a place of which her husband approved, through the church. Susan said 'I think we both have strong faith, and I know that that certainly helped Tom come to terms with it'. When asked what things had been most helpful to her in her bereavement, Susan said her faith was most important: 'Well I'll be quite honest, I think the Lord, because of my faith again' (Susan). Liz said the church and her Christian faith were important to her, but Liz was less emotive about its power to help her. When asked if her religion had been a consolation to her, Liz said 'Yes, possibly. Do you know what I mean?...it's a bit divisive, really... But no, I didn't feel deserted'. (Liz)

Kath and her other son had some support, as a carer and as a family, from the Hospice they had used during Sam's life. For Kath, the reasons for not keeping up with *bereavement support* offered after her son Sam's death, were more personal. Kath said:

> We went to a bereavement weekend at Y *(our Hospic*e) about a year or so after Sam died. And I, I found it very difficult. It was…like…not a lot left to have in common with people and

> that was, particularly as I mean, some of the people that I'd been quite close to who had also been bereaved…their relationships had broken up, partly I think around the, the stress and the strain of the bereavement…So there was a feeling like…that you'd need to sort of be taking sides to, to remain friendly with one or the other, but there wasn't really an option of being friends with both and that was, that was quite difficult. And I just found it just emotionally too complicated. So I, I just stepped out of it. (Kath)

12.8.2 Crass Remarks from service providers: 'the problem is you have the wrong needs'

People in the interviews reported lots of positive things about individual staff who provided services to them and the person that they cared for. However, one sub-theme that emerged from the interviews around the topic of services, was 'crass remarks' by service providers that had lodged themselves indelibly in carer's minds for years to come and had in some cases seriously affected their perception of health and social care services. Here are a few we'd like to share:

> There were some very good people involved. The system was far from optimal. I was actually told during one assessment that, "The problem is, we recognise your needs, the problem is you have the wrong needs and there is nothing we can do to help". Which I thought was absolutely splendid, that it was all my fault for having the wrong needs. (Kath)
>
> And another time, when I had, it was actually the housing association with an occupational therapist who came to assess our need for adaptations to the house and I was actually told by the representative of the housing association that it would take quite a long time to get these adaptations done, they recognised that Sam needed things done but that it would take time to happen. Because it wasn't worth their while hurrying these things, because people quite often ended up going into hospital or dying. (Kath)
>
> And at that point it suddenly tripped into my brain that we ought to go and ask to see a neurologist because, in the preceding few months, he (Arthur)'d been going to our GPs, there were about eight in the practice, and he'd seen all of them, and virtually all they'd told him was, "You're not getting enough sex". One of them actually said that to him. So he said, my reaction to him was, "Well are you getting enough?", at which point he shut up. (Liz)
>
> And then one of the district nurses said to me afterwards, she stopped me somewhere and she said, "Oh wasn't it a good death then?"... I thought, your choice of words aren't very good, I'm not going to prolong this conversation. I know that, you know, there's all these documents about good death and all the rest of it, but it was not appropriate at the time. (Liz)
>
> … 'cause the one thing I would say that's negative about the personnel who come to visit is, what I don't think they should do, and they do with me and it might be partly 'cause I'm an ex-professional person or whatever, but they pass on to you the stresses that are in their job. So they'll say, "Oh you know, you have to justify this because social services will do that, or the medical people", you know, "Oh you'll have to do this, this and this, because the panel might think this", and… actually, none of this is my concern… the stresses of your job. I mean… one advisor who came… was really, really helpful, but she spent about ten minutes advising me and she spent half an hour telling me about her mum who had dementia. Now, that's not her job and I'm not there to listen to that. I can see why, but it's not appropriate, is it? [Sighs] …I don't need to know. And I think what happens is, they kind of, 'cause with all the cuts and everything, people feel bad about passing on the effects of that to others. (Victoria)

These comments do not come from one service sector but emerged from individual service providers in a range of services, perhaps in unthinking moments. Putting the crass remarks all together amused us, but also saddened us, as their impact for the people on the receiving end has been hurtful and harmful and we hope people reading them will recognise some of the insensitivities implied. The challenge is for service providers across the board to constantly alert staff to the power and resonance of a seemingly throw away crass remark and the limited understanding that it implies. Evidence presented under 'crass remarks' showed how indelibly some off the cuff remarks to carers by medical professionals in particular can 'cut deep' in people's psyche's and stay with them long into their bereavement.

12.8.3 Carers communication with medical services – 'I had to do all the difficult discussions... the awkward person'

The bereaved carers in this project nearly all felt separate and sometimes isolated, from decisions about their loved one's medical care. Liz was frustrated by her husband's seeming secrecy about his health decline and the pain of feeling cut out of the information loop with medical services:

> And it wasn't, I think, until…well I went up to Wiltshire to work in '85, and he took a really serious downward slide. I had the feeling that things weren't right, but he didn't tell what the consultant said or what he said to them when he went and had his visits at the hospital. But I sort of noticed things weren't right, he wasn't very steady on his feet and his grip wasn't very good and what have you... But in the meantime, he was still going for appointments [with the neurologist], which he didn't really tell me what, what was said. (Liz)

Victoria felt very emotional and ambivalent about her husband's commitment to psychological testing:

> From 2001, Nick's particular dementia has been researched by a clinical psychologist who was at the University of X (*name removed*) and subsequently moved, and there were points where I hated that because he would come back from sessions with this psychologist and he would come back so exhausted that I would rage and get really angry and say "he shouldn't be doing this to you", because it was a question of testing Nick until he couldn't take any more. And he always said, "I want to do this to help other people", so I think that's really quite important. It's quite important for me to keep that going. (Victoria)

Susan's husband's commitment to neurological research for people with Parkinson's was something she grew to admire, but the way she spoke of it showed that she felt very outside of and separate from Tom's decisions about medical treatment and a little doubtful about its contribution to perhaps hastening Tom's death. Susan said:

> And he'd been going up to London quite regularly to go up to the Neurological Hospital in (*name removed)* and they were very interested in his progressive deterioration. I'd been up with him once or twice. Wonderful team up there, very compassionate. But of course, as Tom said, he was able to live as long as he did from what they had learnt from other patients, and he wanted to be part of their research so that they could learn more from the progress of Parkinson's, but Parkinson's hits people in different ways... It had been suggested to him... that maybe he would be suitable for the operation where they put the wires into the brain... It was delayed for a full year, and of course they're very thorough in doing a good medical beforehand to make sure that there aren't any underlying problems... So, when he did go in for the operation, he had deteriorated but the team were still happy to go ahead... They usually have the cut off about seventy, and Tom was coming up for sixty-seven.

> He went ahead with the operation, and everything went all right with that, but the only problem was that he was in theatre seven hours, rather than three and a half, which was really stressful for everyone. And I think through that stress, although the operation was a great success, Tom, after three months, went downhill very rapidly, and they then diagnosed cancer. And I, I do believe from experience of life anyway, that that stress kick started the cancer, and so within the year of him having the operation, he had died. And I know that the team were terribly upset, they were thrilled that the operation went so well and you know, he was able to do all sorts of things that he hadn't been able to do for a while. (Susan)

John gave his account of difficulties in communicating with medical professionals when he was asked to give permission for Peggy to be put on the Liverpool Care Pathway. John made this story the focus of the digital story that he chose to make for the project. John felt that worry and guilt associated with this scenario led to him being extremely ill for the next two years of his life, until a Macmillan nurse was able to explain it all properly to him.

Kath was also keen to stress that, as carers, your communication with medical services in particular, can be challenging as you are forced into particular roles. Kath said:

> He (Sam) very much wanted to present himself well to the medical professionals, so that meant I had to do all the difficult discussions and the difficult stuff, which was quite problematic, it did tend to mean that I was presented as the awkward person. So he would be telling me how he wasn't going to do this and he wasn't going to do that, and there's no way he'd co-operate with such and such, and then he'd be all sweetness and light to the professionals and it would be me that would have to be difficult. But I think that was just part of the bargain, really. (Kath)

In our introduction, we referred to Twigg's (1994) idea that in medical services and medical education, where the focus is very much on the patient, the consequences of action for the carer are often dimly perceived anyway, vanishing from view at the time of bereavement. The carers needs appear superseded in the medical planning process with the disabled person, dispensing with any carer involvement and yet relying utterly on them to provide support after treatment and surgery. The accounts presented here support the strength of this notion and point to some clear work needed in educating medics about the needs of carers and bereaved carers.

12.8.4 Overview: Bereaved Carers Relations with Services

This section revealed tensions between informal carers and services. In some instances, the stories revealed carers treated more as what Luke Clements has called 'pit-ponies', supported solely to ensure the disabled person's care is sustainable and dispensed with quickly when that role is no longer required. Yet, the accounts also hint of an awareness amongst the bereaved carers that a former carer should be entitled to support in their own right. And an awareness too that some after care support was available, but many did not find that this available support quite matched their needs. Yet the ways in which it did not match their needs was convoluted and complex and no clear recommendations jump out. Perhaps the most obvious finding was that the process and involvement in a practical, shared learning project like 'Past Caring' of itself, gave people new energy and satisfaction in expressing their stories, which in itself helped and supported them, even though they were each at disparate places on their bereavement journey. The camaraderie and mentoring opportunities built in to the project were also key. The evidence connected with these points are presented in our final results section to follow here.

12. 9 Participants' Reflections on the Past Caring Project

Every now and again you have to climb one of the tallest trees and look at where you've been, and are you still headed in the direction where you want to go? And I think that's, for me, what, what this is all about.' (Kath)

This section aims to draw together participants reflections from comments made and recorded at the end of their /our interviews, and from six month feedback questionnaires and letters received. Together, we aim to reflect on the degree to which the project achieved its aims, as set out in the introductory section of this report.

12.9.1 'Good... not easy'

Overall, each participant said they valued the 'Past Caring' Project experience, with general comments like 'but personally it's been good for me' (Brian); 'yeah, I think it's been good' (Gill); 'it was of great benefit' (John); 'it was a good thing for me personally... I've found that a really, really good experience, because it's a really creative and involving experience (Victoria). 'Overall I am extremely glad that I took part and am grateful to you all for making it happen' (Kath).

For everyone, it was an emotional experience and because of the sadness of bereavement, not necessarily easy. Liz said: 'that's been fine (telling the story), no I'm all right now, my blood pressure's gone down, I'm fine'. Susan said it was 'quite uncomfortable... but very good... it's been very positive, all right, and… [crying] I find talking about Tom's death still difficult' (Susan). Brian mentioned the way it had taken him back to emotions he had experienced earlier in their bereavement. Brian said 'it re-ignites feelings and emotions that I thought I'd got over'. Others said:

> It's felt okay. It's brought back lots of sad memories. I've cried a lot. But it's all right. Yeah. It's okay. Just makes me feel sad... I think my emotions are really quite near the surface. I do cry easily. But then I do laugh easily, too. No good at hiding my emotions, no good at all. But it's felt all right. I mean, I haven't minded. (Rosemary)
>
> A number of emotional issues that had been well buttoned down were surfaced by this process. This had both negative and positive effects: increasing stress and anxiety but enabling reflection and positive action. (Kath)

12.9.2 'Processing what's happened'

Reflecting on her experience of the project, Kath said 'It's been fine'. Using terms like 'its been fine' and 'I haven't minded' express some reservation about voicing difficult and often traumatic experiences. There are resonances here with work that has been done with Holocaust survivors and in other traumatic and taboo-laden situations (Rickard, 1998, Rouverall et al, 2000) -there are aspects of revealing difficult stories that are uncomfortable and uneasy. Both Kath and others, however, went on to emphasize the value of putting the stories somewhere, of taking stock and re-orienting themselves for the future, almost in properly acknowledging and re-evaluating what they had been (and were still going) through. Kath said:

> I think it's really useful for me to make time to remember the journey. It's painful, but as I said off-tape, it's actually painful whether I talk about it or not, and actually bringing it to the surface and looking at it now and again I think is something that's quite useful to do....
> …I went to a lecture by a sociologist called Erik Olin Wright and he talked about us trying to create a better world and it being like a journey, and he said that every now and again you have to climb one of the tallest trees and look at where you've been, and are you still headed in the direction where you want to go? And I think that's, for me, what, what this is all about. (Kath)

Rosemary said ‘I think it’s quite cathartic, actually, talking through these things’. Victoria similarly commented:

> I just think making the digi-story was a good thing for me personally…. because for me it’s processing what’s happened, and it’s also, in that you learn more things about it as you process it. (Victoria)

Participants were able to explore the wider context of bereavement in their lives as a whole through the project. Liz was very worried about telling her story at the outset and on reflection felt the telling helped her to recognise a ‘residual guilt’ that needed putting ‘in the right place’.

> And I, I’d hope that people would think that they should be able to challenge and should be able to ask questions and not be intimidated, and stick it out. But I think you also probably have to recognise that you’re likely to still be left with some guilt, “Did I do enough? Should I have done this, should I have done that, did I handle that properly?”. And I think that’s going to go on, for me, for years, really, because I have these moments when I think, “Why didn’t I do that? What about that?” And, you know, there’s nothing I can do about it now. Have to live with it, I suppose, and put it in the right place. (Liz)

Liz used the project to re-orient her memories towards her husband:

> Having listened to the digi-story, I realised that I had not shared enough about how I admired my husbands’ ability to cope quietly and largely positively with his failing health and shrinking life. Perhaps I needed to get the very negative and emotionally hard things about his treatment in hospital out of the way to be able to move on. This I think I may have achieved as a result of sharing it with people who have been there as well.(Liz)

Gill said:

> The interview gave me a chance to reflect on my relationship with my parents. I did not grieve for them but it was obvious that I needed to reflect on my life after their demise. (Gill)

Participants noted subtle differences in how they felt depending on how many times and to whom they had told their bereavement story before. Only one person said he had had the opportunity to go through it all already:

> Yes, it’s felt fine because I’ve been thinking a great deal about my past and what I’ve suffered and what I haven’t and the great things and the wonderful things that have happened in my life... I’ve talked about it before and I’ve talked about it a great deal with J (friend). (John)

Another key issue was about how the project affected people depending on the time since their bereavement. For some, bereavement was relatively recent and still rather raw, but even those who had been bereaved many years previously, like Kath who’s son, Sam, had died 11 years ago, there was value in re-focusing on the bereavement experience through the Project. When asked who she would most like to hear her story, Kath said: ‘Me! (Laughing) It is about reminding me of the journey’ (Kath). This perhaps highlights the long shadow that bereavement casts –that bereavement does not finish one day, but is something that changes life for the bereaved carer long into the future and is usefully revisited at times. This suggests that in line with other research on life review and reminiscence, telling bereavement stories is personal and intense and a particularly powerful, active way to rehearse and ‘retrospectively mediate’ or come to terms with the past (Bennett & Vidal-Hall, 2000). Kath went on to say:

> I can’t really begin to describe the impact of being involved in this project. Looking for photographs led me to open drawers and albums that I had not looked into for years. Some of this was very confronting and distressing. However it has led me to move forward in a number of areas, sorting and clearing and re-connecting with people I had lost touch with. (Kath)

For Victoria, whose experience of living bereavement was ongoing at the time the project was being written up, the rawness of the bereavement was a huge issue. Victoria later said:

> It took a long time for the project to get funding and when the introductory day came, I went home thinking maybe I didn't want to be involved – I felt a long way from Nick's diagnosis in 2004 and I wasn't sure I wanted to face that raw grief again. I am so glad that I continued with the project. (Victoria)

12.9.3 'It made me feel less unvalued'

Victoria stressed the challenge of being the source of focus, an often unfamiliar experience for carers:

> I did feel the digi-story was far more about me, whereas other things have been, the focus has been on Nick, and I've found that quite uncomfortable, because I'm out of the habit of thinking about me much. But also very good for that reason. (Victoria)

Kath similarly reflected on the need to feel valued as a bereaved carer:

> I think some sort of continuity of service with social services and the hospital service, the way that those relationships were just severed was quite, it was as if I hadn't been involved in all of those things for all those years. They'd been providing a service to Sam and, and I was a bit irrelevant to that. And it was like having my identity disappear... I literally, I didn't know how to dress myself, because I couldn't think who I was and…a bit of continuity of contact beyond the bereavement, I think might've helped me to re-construct a bit sooner, I don't know. It (might have) made me feel less unvalued, perhaps. (Kath)

Victoria, however, felt she needed something more, beyond her voice recorded for the project to really put across her story and Victoria's on-going involvement in the further development of the project will hopefully enable her to explore this:

> Well good, but I'm always surprised that I feel, I've said a lot, in terms of words, but I feel I haven't said very much in terms of conveying it all, do you know what I mean? (Victoria)

12.9.4 'It has restored the identity and confidence I lost'

Participants noted how their confidence had fluctuated during the course of the project. Recruiting participants to take part was complex. We know that some people were put off taking part because they did not want to 'come out' as a carer –they resisted acknowledging that identity and to take part, people were essentially forced to. Several of the people who initially liked the idea of the project said that they had felt slightly uncomfortable before coming to the first session. Gill said: 'I must admit that I went in with fear and trepidation, The very confident person who is actually in fear and trepidation of all the technical stuff.' Brian said 'I greatly enjoyed (it) and I'm glad I was included 'cos initially I was going to opt out to allow someone else to do it, but I'm glad that I did it'. John said:

> It did help my confidence... I shall certainly make use of what I learned in making it (the digistory). (John)

For Brian in particular, the issue of confidence has raised itself throughout the project. Brian mentioned becoming self-conscious.

> I know we got our DVD with everybody's story, naturally I've looked at them all and I thought mine's the worst through lack of photos and everything else, and with my London dialect it doesn't lend itself to easy listening you know, whereas ladies such a yourself who

> speak well, narrates properly it comes over much better, whereas I'm sort of a Millwall dialect, it doesn't come over great does it? (Brian)

The project group worked hard to reassure Brian. It was very positive to have Brian involved as a peer-trainer /co-interviewer, though the task was challenging at the outset.

> I'm a bit daunted going forward imparting what we did to the next interns because I am aware what we did was completed and done but I don't feel that I'm sufficiently skilled and have retained all the knowledge to impart that to someone else. (Brian)

The second digital storytelling workshop went very well and Brian's confidence and belief in what we could do increased. He later said:

> We did well. It worked really well... I enjoyed doing it as a team, all expressing their problems and getting over obstacles individually that we each felt difficult at the time, part of a team venture. (Brian)

Victoria, who also became a co-trainer said:

> It has restored the identity and confidence I lost when I left work through stress, and enabled me to use skills I thought were lost to me, as well as learning new ones. (Victoria)

Bennett & Vidal-Hall (2000, p423) suggest that narrative work around death allows people to define their past identity, as wife, nurse, organizer, carer, worker and their present identity as 'chief mourner'. Victoria is perhaps hinting that adding new skills aided her in piecing together a future identity too.

12.9.5 'To share that with people'

Participants were asked who they would most like to hear their stories. For many, it was about having something to share with family and friends, now and in the future.

> Oh just people who know my mother. People who know me, people who know my mother. So my daughters, my niece, my nephew, grandchildren. And people who knew my mother before her stroke. Some of whom have already seen it, yeah. (Rosemary)

> As far as the digistories were concerned, there was a very positive effect for myself and my family in watching the story afterwards. (John)

For Gill, Rosemary and Kath, other friends and family's reactions to directly hearing the voice were notable.

> The feedback that I've been getting from people who've seen the video on You Tube has been great, and the friends in California said it was really nice to hear my voice coming over as well. (Gill)

> My niece said it made her cry [laughing]. Funnily enough, my younger daughter just commented on my voice…I don't think it did touch her emotionally, which is quite interesting. (Rosemary)

> Although he had given his permission for me to use his images, I was concerned that my son, Drew, would be unhappy with his inclusion in the digistory. In fact he was fine about it and it has probably helped us to communicate more effectively about the issues it discusses. (Kath)

The stories seemed to help people get their version of events validated by others. Victoria commented on sharing the stories with the wider community of carers through dissemination of the stories.

> …But also to share that with people and for them to say, "Yes", you know, "I recognise that, that's, that's taught me something", then that's really good. ...if that can be useful to other people who are in similar situations, then that, for me, is quite important...So, who I would like to see it would be people who've felt... "I haven't had that opportunity and now I know I'm not on my own". (Victoria)

Victoria immediately started to share her digi-story with others independently of the project just after she made it.

> So what I will do is to put, put it into the next newsletter of the, the group that I'm part of which is the Pick's Disease Support Group, which is for fronto-temple dementias, which Nick, I was going to drop a note to the editor of their newsletter to put it there so that people could see it, 'cause I think that would, that would help them. I hope so, anyway. (Victoria)

John's comments resonated here.

> I think I would like very much for carers to have an access to it, and I would very much like disabled people to have an access to it... I think the more people who hear the sort of things I've been saying, the more understanding there will be in the community about carers and disabled people, (John)

Others stressed a personal satisfaction in having something to share with service providers as well.

> I think I would like my GP, Dr D (*name removed)*, to hear it. I did tell him, I wrote him a note about the, the DVD video on You Tube. And I think perhaps the, the nurse, respiratory nurse, a specialist nurse at the hospital, I think she's retired now, I suppose I could contact her through the hospital, that might be nice, because, you know, she knew us for a long time and, and was unusual to have somebody for that long, because normally people died. (Gill)

12.9.6 'It enabled me to use dormant skills and to learn new ones'

We were interested to note that participants valued the capacity building aspects of the project for their own learning.

> The interview was of great benefit as I learnt a great deal about interviewing and being interviewed... As far as the digistories were concerned... I shall certainly make use of what I learned in making it. (John)

At the age of 85 years, John remarkably went on to make another digistory independently with his friend after the project and introduced the model to a service provider group he was working with in the hospital, who in turn went on to make their own digistory. At the outset, Gill said 'I am technologically challenged'. She then said 'However, it quickly became obvious that Barrie, with Wendy as back up, would see me (and anyone else who needed it) through'. Gill said:

> I was still on a high for a long time after the finish of this part of the project (digistories) because I had achieved a DVD. I am still telling people about my being able to do this. (Gill)

Victoria said:

> It recognised my carer experience as valuable. It restored identity and confidence I'd lost, enabling me to use dormant skills, and to learn new ones. It felt safe for me to acknowledge my grief in the group. We were all there because of our loss. (Victoria)

This point about sharing bereavement experiences within the group was key. Liz said: 'I enjoyed participating in the project and learnt a lot about other peoples' experiences and coping skills'. Liz felt the project came to her at an important moment in her post bereavement re-engagement with the world:

> I think bereavement is overlooked by professionals, unless you need a pill. But it has a profound effect for a long time, whether it is unexpected due to an accident or sudden death or longer term as with dementia or a deteriorating condition. Long term carers particularly have issues that persist sometimes for the rest of their lives unless something is done to re-engage them meaningfully in life. (Liz)

Other researchers have written about the value of an opportunity to 'tell it like it is', of a need to 'make sense of it all' and by 'offering experiences up', bereaved people implicitly invite others to help create meaning and to negotiate an acceptable version of events (Bennett & Vidal-Hall, 2000, 424). Meaningful involvement was also Brian's phrase.

> (I am) Not a worker, a happily involved person that's been saved from being a recluse, that's how I would describe myself from being involved with wonderful people who stopped me withdrawing virtually completely which I would do, I know I would do. (Brian)

And for Rosemary, life without involvement would be depressing.

> My brain is still active and not doing anything of this sort does fill me a bit with gloom. (Rosemary)

Kath reflected on the value to her of using her caring skills in the wider context of her current PhD study.

> I've always been involved in volunteering things but the sort of things that I do now have changed quite dramatically and largely due to my experience as a carer. Campaigning for what my perceptions of what, what I and my family needed in the way of support made me realise that I did have more of a brain than I'd perhaps given myself credit for in the past. And I learnt research skills in order to give evidence to my arguments when I wanted services to change. (Kath)

12.9.7 The way the Project was run

There were lots of positive comments about the way the project was conducted.

> The whole thing was extremely well organised and dealt with enormous understanding of people's personal feelings... I can't see how the experience could have been improved. (John)
>
> The experience was a good one for me, so no I don't think that it could have been improved for me. (Gill)

For some, the personal, open-ended style of interviewing was highlighted as important:

> If I may say so, it's very easy to talk to you, it really is *(I'm glad)* it is, it's so easy it's like talking to a long time friend, this is what I mentioned earlier, I don't know how people will open up and how long for but you know obviously everyone seems to know, but personally it's been good for me, I hope I haven't bored you to death. (Brian)

For Gill, being able to choose <u>when</u> the interview happened was important. Gill used the interview as a celebration of the anniversary of her husband's death:

> And I chose this day especially. Because I thought, if I stopped at home I will mope, but I didn't want to mope. 'Cause we had forty-five wonderful years, yes downs, but lots and lots and lots and lots of ups. And I'm very proud to have looked after him. (Gill)

Participants were also given a choice about <u>where</u> they would like to be interviewed and valued that flexibility. Liz chose to come to the hospital venue as a way of tackling a phobia she had developed during her husband's illness and death:

> I get…I don't suppose I'd call it anxious, but I get uncomfortable about coming to this hospital, ……. But I do find that I still get het up about coming into this site. Can't stop it. Silly, isn't it? But it, I suppose I've had so many bad experiences in here that if I ever have to have anything done myself, I don't know what I shall do because I'd be absolutely terrified of getting MRSA or C-dif. Absolutely terrified. So, yes, it's a bit like my phobia about the dentist I think [laughing], having a phobia about the hospital, you know. (Liz)

For Kath, who also chose to be interviewed at the hospital, issues about the interview location were unusually difficult. With no notice, we were told there was an important inspection that particular day and our interview room had been taken over, leaving only the small office to be interviewed in. Kath quite fairly noted:

> There was a lot of confusion about practical arrangements. This did increase stress... The circumstances and surroundings for the interview were not ideal, particularly given the nature of the subject. (Kath)

The free counselling support offered as part of the project was taken up by just under half the participants and received very positive feedback. Participants primarily used it as a way of dealing with unexpected issues that had come up for them during the project.

> And the counselling that followed was good, and the fact that there was a counsellor available only goes to show you it was a proper research project... I was very surprised at what surfaced for me from what others in the group said. After the event I gave it a lot of thought and was very glad that a counsellor was available to us. (Gill)

> I was surprised at the unexpected benefits of this (the counselling)– once I'd talked myself out about Nick and the effects of his illness on our whole family, I found myself talking about how I'd had to leave work through stress. I had not previously realised how much this too had affected my confidence and the loss of identity it had entailed. (Victoria)

Some of those who chose not to use the counselling offered gave their reasons. John simply felt he had already received a lot of bereavement counselling prior to taking part in the project. For Kath, the counselling offered seemed inaccessible, but she did not speak to the project team about this at the time so we were unable to tackle the geographical issues.

> Before the workshop I had not met the counsellor, having experienced poor and damaging counselling processes in the past I was reluctant to accept help from someone I did not know. During the four days of the workshop I was very busy and focused on producing the digistory, I felt that counselling at that time might interfere with that process. Because I live a more than three hour journey from where the project was based, I did not feel able to access this service later when I got home and issues arose. (Kath)

Kath took part in the second set of digital story workshops, where we invited the counsellor to the first day session so people could meet her and get to know her. It is interesting to note that this was not enough for Kath, who intimated she would have valued counselling support at a later date than the project was able to offer. But Kath also added 'Thank you for what was a very difficult but interesting, useful and rewarding project'.

12.9.8 Overview –Reflecting on the Past Caring Project Aims

Recent research has highlighted that practical, ethical, methodological and emotional challenges are experienced by those conducting research around death and bereavement (Kendall et al, 2007). This reflective summary was important in helping us as a project team to assess to what extent we had met our project aims (set out in an early section of this report) and how we faced some of the challenges. We conclude that we succeeded in giving bereaved carers an unmediated voice. Having that voice was not easy for them and the reflections reveal strongly that no-one came lightly to this project. The hardest challenge for the project was to recruit the participants –to make people feel valued enough and comfortable enough to commit to taking part and for them to find time in their lives to make space to do this. The fact that all those who did take part then stayed with the project and are supporting it strongly still was evidenced in full attendance at a final project meeting called to discuss what we all wanted to do with the findings.

For those who did take part, the project did allow participants to explore latent levels of personal meaning for themselves and to share these with others. Catharsis, sense of purpose, self awareness and empowerment were prominent notions. As mentioned earlier, we didn't want to just produce something coherent and attractive, but also stories that were difficult and controversial. We hope that the weight of telling is captured in the participants words presented here. It seems to support evidence from oral history work around recounting traumatic experiences, that telling stories of trauma helps people looking for natural ways to heal and that the 'freedom of expression and self determination' of storytelling 'can at least restore validity and dignity to individual memory' (Perks, 1993, p 43). Hunt & Robbins have suggested that in the last century, at least in Western Society, it has 'become the role of psychologists to tell the story of trauma, often on behalf of the victim. While treatment for trauma has supplied a means of reducing the symptoms for such victims, it has had negative effects, medicalising and pathologising them' (Hunt & Robbins, 1998, p 58). Our small number of stories collected here may reinforce an idea that storytelling is one valuable alternative. (It is noted however, that terms such as victim, trauma, and symptoms did not occur at all in the words of our participants).

There was also humour in our stories. It was a device used by the speakers to tell of incredibly difficult aspects of caring, to share challenging and traumatic stories, and perhaps as a gentle and unobtrusive way of inviting the interviewer into the closet of shared knowing. In co-analysis of the material, carers and researchers did empower each other to support a more confident collaboration and experimentation within the project and by reassessing their own bereavement in a life context through the project, we found strong suggestions that participants did start to develop 'new future stories' in accordance with Mattingly's (1991) theories. We were surprised and delighted by the extent to which the participants 'owned' the material produced and started to do things with it independent of the project team as well as part of it.

We suggest that the project design of using sound interviews and digital stories worked and was very enthusiastically received, though no-one participating had familiarity with the methods at the outset. We feel excellent carer involvement was achieved, with carers initiating the project and taking control of the research design, implementation and dissemination. In this sense, we did make opportunity and remove barriers to carers doing their own research. Some participants found the time commitment of the analysis, write up and dissemination activities very onerous (because it is!) and it was interesting how the input from different team members meant they were able to commit more or less at different times (not reported here). It was central that we had research support from a paid member of Folk.us who was always there to keep driving the project (and the write up particularly) forward to completion.

As was pointed out in the introduction, there has been recent attention to engaging older people in improving their information technology skills and this project aimed to add to this agenda in a capacity building way. The participant's words suggest this worked to a degree –carers increased their confidence, learned new skills and reinforced existing ones. The sharing of research skills was also successful, culminating in full project completion and research write up. The emotional support offered to carers to tell difficult and challenging stories with trained counsellor back-up was appreciated by those who took up the opportunity. For some, we may need to rethink how to make this counselling offer more flexible and fund it over a longer time period. However, funding to do this will always be a key challenge. We will find out during the course of dissemination whether the visual and aural nature of the research outputs will make the research more accessible to the public and whether we can influence service providers and commissioners with this work.

Figure 10: Carers, their friends and family gathered at a Social Event organised by Folk.us and the Past Caring Project Team at Exeter's Royal Albert Memorial Museum in June 2012

13 Dissemination

We disseminated the powerful stories and research findings from the 'Past Caring' Project in a number of ways.

1. The project report, project summary and all articles connected with the work were made accessible on the internet through the www.folkus.org.uk website. The Project digital stories were posted on Youtube for full public access www.youtube.com/folkusuk
2. We wrote short articles about the project for the INVOLVE Newsletter, the Pik's Disease Newsletter, and a special issue of the Institute of Palliative Care Newsletter (Jones and Rickard, 2012). At the time of writing, peer reviewed journal articles were being prepared. We also disseminated our findings to Carers projects across Devon and to Torridge CCTVS Carer Bereavement Mentoring Project in particular. The project was endorsed by The

Princess Royal Trust for Carers, which is a UK-wide network of nearly 150 Carers' Centres, reaching over 350,000 carers. The Trust helped disseminate project outcomes.

3. Devon Carers awarded Short Breaks Funding (2011-12) to the research team for a Carers Social Evening at Exeter's newly refurbished, award winning, Royal Albert Memorial Museum (RAMM). This event included a premiere viewing of the digital films on the big screen, with presentations by the originators of each. It also included a community empowerment /buddying goal to further engage carers in future research work about their needs and experiences.

Figure 11: Carers, their friends and family gathered at the RAMM Social Event

4. We presented at the Folk.us 'Turning the Tide' Conference on 6th April 2010 and at a 'Lived Experience in Research' seminar, University of Bristol on 16 March 2012 and at the November 2012 INVOLVE Conference.
5. We sought to continue this project, offering more bereaved carers a chance to take part over a wider geographical area. We would like to develop the technical aspects of the project (by using IPads) to make it more flexible in terms of the time commitment required of participants, developing a model we can use with groups, individuals and pairs and potentially work with people in their own homes. We would also like to explore developing the model in different partnership contexts, particularly in hospices and perhaps in other geographical areas of the UK (to build on the community making goal of the project). This project will continue under the governance and control of the bereaved carers on the team.

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