

The Past Caring Project: a carer-led narrative research project about carer bereavement

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By Wendy Rickard and Victoria Jones

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. There are about six million carers in the UK who are simply 'getting on with it' and taking a huge strain, some for many years of their lives. In the Past Caring Project, carers got together to develop research around carer bereavement from the people who quietly experience it. The Past Caring Project collected stories of people who have spent a long time (three to 30 years) caring for a person before they died or for a person lost to dementia. The project was about what comes next, how we feel and what we experience.

This developmental research project took a group of nine bereaved carers through two sets of intensive four-day courses where we each made a digistory (digital story) or short film. Victoria said: "I called my digital story 'Every Picture Tells a Story', and based it on the first photo where I could see my husband was 'gone' from me into dementia. It was taken for our silver wedding anniversary, before we had a diagnosis, and where others see a happy family portrait, I see only the blankness in his eyes." Our digistories are on YouTube for

everyone to see: www.youtube.com/folkusuk

As part of the research design, we also each did an extended interview about our experience of caring and of losing the cared for person. Two from our group had interviewing skills from their past work experience and received some additional specific training on interviewing before undertaking interviews themselves in partnership with the researcher. Three from the group received training in qualitative analysis techniques and Grounded Theory (a systematic generation of theory through the analysis of data). We spent a year working together to gather these interviews, and analyse and examine what we found. Intensive support was provided and there was also counselling support for everyone who wanted it throughout the project period.

The project design was participatory and emancipatory – the project (which was endorsed by The Princess Royal Trust for Carers) was originated and managed by carers, with carer involvement at every stage. One of our participants 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 losses.”

The draft research findings are grouped around six key emergent themes: stress, death stories, positive perceptions of caring, experience to care, social world and money matters. We are just completing the write up of a full research report. We feel we have a powerful and adaptable carer-led research model that we can use to support and enable a larger group of bereaved carers. As a start, we were generously awarded funding by Devon Virtual Carers to run a social evening and film show for carers at Exeter’s newly refurbished Royal Albert Memorial Museum & Art Gallery on 1 June 2012. We want to share with other carers what one small

group of Devon carers did when dealing with change linked to the end of a caring role. We are also interested in creating a platform to explore the best ways for carers to bring about change in their communities through their own research.

The current group of Past Caring carers and ex-carers has been trained to teach most aspects of the digital storytelling course and to undertake interviewing and analysis. Support from our technical experts will gradually taper off, hopefully leaving the project more affordable, flexible, self-directed and sustainable at the local level. During the next year, we plan to experiment with offering flexible short courses utilising iPad technology and split into accessible chunks of time (one to two day sessions).

Do get in touch if you are interested in our work or would like to share your own experiences of developing service-user led research opportunities.

Contact: **Victoria Jones** (Carer Researcher) or **Wendy Rickard** (Folk.us Research Fellow)

Email: victoriashrubbery@btinternet.com or W.Rickard@exeter.ac.uk

Tel: **0139 240 3049** or **07805 420465**