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Surviving the transition from active to post-caregiving: the experiences of former carers

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Surviving the transition from active to post-caregiving: the experiences of former carers

Dr Joyce Cavaye

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Healthy lives: technologies, policies and experiences
ESHMS 16th biennial congress, University of Geneva
27-29 June 2016

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Life-changing Learning
.....

Surviving the transition

Former Carers Study

- Exploratory study
- Co-produced with former carers
- Part 1: online web-based survey – www.formercarers.co.uk
- Part 2: in-depth qualitative interviews (ongoing)
- Self-selected sample
- Selection criteria – end of caregiving more than 6 months ago but less than 5 years
- Ethics approval from OU HREC committee

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Participants

- 90% female and 10% male
- Ages ranged from 37 – 72 years
- 68% caring for a parent
- 19% caring for a partner
- 8% had looked after a sibling
- 3% had looked after a grandparent
- 2% had looked after adult children

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Duration of and time spent providing care

Amount of hours per week	%
Under 20	17
20 – 50	31
Over 50	52

Duration in years	%
Less than 1	09
1 - 3	23
3 - 5	08
5 – 10	31
10 – 15	20
15 - 20	03
20 +	06

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Psychological wellbeing post-caregiving

- *“Still stressed”*
- *“There was hardly a day went by when I was a carer that I didn’t think ‘when this is over I’ll be free to do whatever I want’. When it was finally over I felt I had lost all direction had no energy or enthusiasm to look for another.”*
- *“There is a sense of emptiness in my life and anger at some of the ways my father was treated during the last couple of years of his life”*
- *“My life changed after the death of my sister. It took me at least 2 yrs to come to terms with her loss. I became very depressed”*
- *“I collapsed mentally and two and a half years later I am still trying to recover. I suffer from anxiety and mental fatigue but I am starting to get better lately. It has been a very confusing time for me because as a family we have all been quite robust in our mental faculties, and I looked after 52 employees. Now I find it difficult to deal with 4”*

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Physical wellbeing post-caregiving

- *“I still get tired very easily and have interrupted sleep patterns”*
- *“I spent so much time looking after someone else, I had no time to care for myself. I have gained 4 stone in weight and have developed stress related psoriasis”*
- *“the physical impact on me are back and shoulder pain”*
- *“I got shingles while I was looking after both my parents, which still has repercussions on my health. I got rosacea and other problems that they said stemmed from my anxiety and the way it affected my digestion”*
- *“After I finished caring I was ill with a number of different problems such as ulcers, reflux disease, bladder problems and more. In the first year and half I had over 15 courses of antibiotics”*

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Resilient carers?

- 20% said that being a carer had **not** affected their physical health
- 19% said that being a carer had **not** affected their mental health
- No direct association with duration, age, co-residency or intensity of caregiving

“No, I have a good sense of humour and am fairly calm in nature”

“No, nothing permanent but I’m sure there were times when I felt down”

“Not really. I was a bereaved carer and felt appropriately low in mood. Also when one person you care for dies, you may have to go straight back to caring for another and this gives no time to grieve”

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Employment Status

While a carer:

- 30% continued working
- 18 % reduced their working hours
- 23% gave up their job
- 10% were not in paid employment
- 71% said the being a carer affect their ability to work a lot

After the end of caregiving:

- 37% were in paid employment
- 31% employed full-time in the same job as prior to caregiving
- 14% employed full-time but in a different job
- 14% employed part-time but in a different job
- 8% employed part-time in the same job
- 33% voluntary or unpaid work
- 20% doing voluntary work for the first time

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Levels of Support

- 60% had no support
- 34% had a little or some support
- 6% had a lot of support

Support provided by:

- 67% Family and friends
- 19% Formal service providers
- 14% Bereavement counsellor
- 10% Work colleagues
- 10% No one

“No one ever asked me how I was or offered help”

“If all those people we got to know well over the years hadn’t dropped away so suddenly, it may have helped”

“I think follow up from the hospice team would have helped”

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Adaptation to non-caregiving life

- 14% easy to adapt
- 40% fairly difficult to adapt
- 23% very difficult to adapt

“Grief mixed with guilt – could we have done more or better? If all these people we got to know well over the years hadn’t dropped away so suddenly it may have helped”

“It took me a long time to come to terms with the loss. It was hard resuming distant / broken relationships. I needed to re-learn how to relax and enjoy myself. I felt guilty about having time to do things for me”

“My job as a carer was finished and I thought “ what do I do now?” I was so in the routine of caring for him that I suddenly had all this time to fill and I found that difficult”

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New Horizons

- 59% derived satisfaction from caregiving
- 94% had learned something from being a carer
- 79% had gained new knowledge and skills
- 65% continue to use this new knowledge and skills
- 59% would not want to be a carer again
- 41% would be happy to be a carer again

“Happily, I am working with people who have dementia. I feel the experience I gained through caring for mum had a direct bearing on me getting this job”

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Conclusions

- Former carers find it difficult to negotiate the transition into the post-caring period.
- They struggle with the psychological and emotional aspects of transition.
- Adaptation is shaped by age and the level of support that is received
- An isolating experience underpinned by a legacy of poor health and wellbeing.
- For some, health and wellbeing does improve in the post-caregiving stage
- There is life after caregiving with many returning to their jobs
- Others take up new jobs and voluntary work
- Policy and service providers need to address the needs of former carers



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