

Health and Wellbeing in the post-caregiving period

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Care and caring: future proofing the new demographics
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Life-changing Learning
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Health and wellbeing post-caregiving

Former carers or bereaved carers

- Individuals for whom caregiving has come to an end
- May due to death, care home admission, or recovery
- 2 million people each year become former carers (Carers UK 2014)
- Increasing large section of the population
- Unmet needs, but valuable resource

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Temporal models of caregiving

- Letting Go (Willoughby and Keeting 1991)
- Exit Stage (Lingreen 1993)
- Role Disengagement. (Aneshensel et al, 1995)
- A New Beginning (Nolan et al 1996)
- Resuming Life – Healing and Renewal (Pfeiffer 1999)
- Taking the Next Step (Brown and Stetz)
- New Horizons (Cavaye 2006)
- Post-Caregiving Transition (Ume and Evans 2011)

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Former Carers Study

- Small prospective study
- Part 1: online web-based survey – www.formercarers.co.uk
- Part 2: in-depth qualitative interviews (ongoing)
- Co-produced with former carers
- 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 a child

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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

- 48% - still suffered from stress
- 42% - depression and low mood
- 16% - anxiety
- 7% - unresolved anger about their experiences of being a carer
- loss of confidence
- loss of focus in their life
- low self esteem

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Psychological wellbeing

- *“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

- 32% - still felt tired or exhausted, trouble sleeping
- 16% - had musco-skeletal problems
- 13% - had weight problems
- 10% - had problems with skin conditions
- 9% - reported digestive tract problems

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Physical wellbeing

- *“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 between these responses and duration of caregiving
- No direct association with age, co-residency or intensity of caregiving either.

“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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New Horizons

- 79% had gained new knowledge and skills
- 56% continue to use this new knowledge and skills
- 59% derived satisfaction from caregiving.
- 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
- 20% doing voluntary work for the first time

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Conclusions

- Former carers report poor psychological and physical health and wellbeing
- For the majority, poor health and wellbeing is a lasting legacy of caregiving
- 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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