

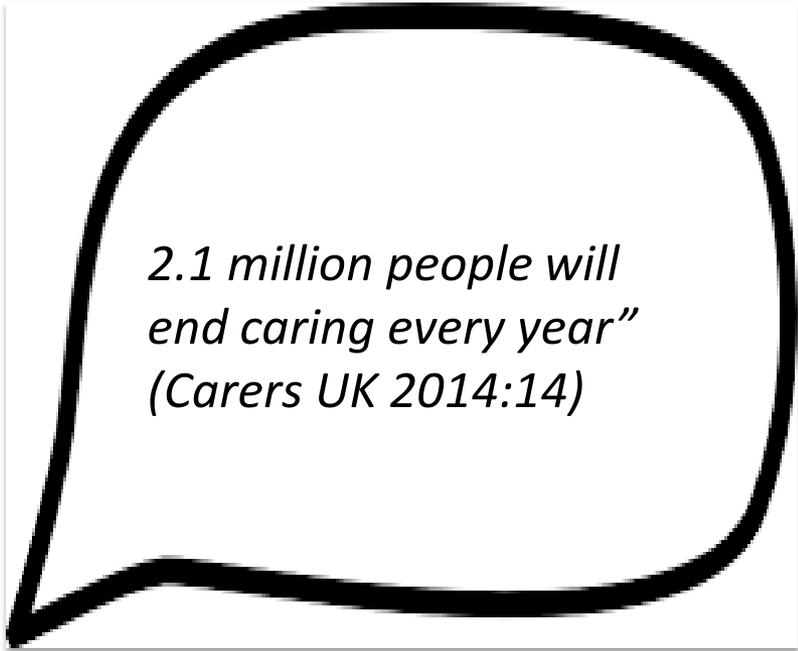


Making room for 'former carers'

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Introduction and outline

- 'what is known' about former carers and their experiences post-caring
- why we need to know more about former carers
- lessons about future proofing for the new demographics



*2.1 million people will
end caring every year”
(Carers UK 2014:14)*

Who is a former carer?

- 7 possible routes into becoming a former carer

When the cared-for person:

1. dies
2. is admitted to a hospital
3. is admitted to a hospice
4. is admitted to long term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)
5. recovers from their health problem (e.g. substance users)
6. goes into remission (e.g. for cancer patients)

OR as in the case of some young carers:

7. the carer moves on from the caring role (e.g. grows up and/leaves home)

- three approaches to defining former carers

The 'legacies of caring'

- financial
- employment and education
- social isolation
- health and wellbeing



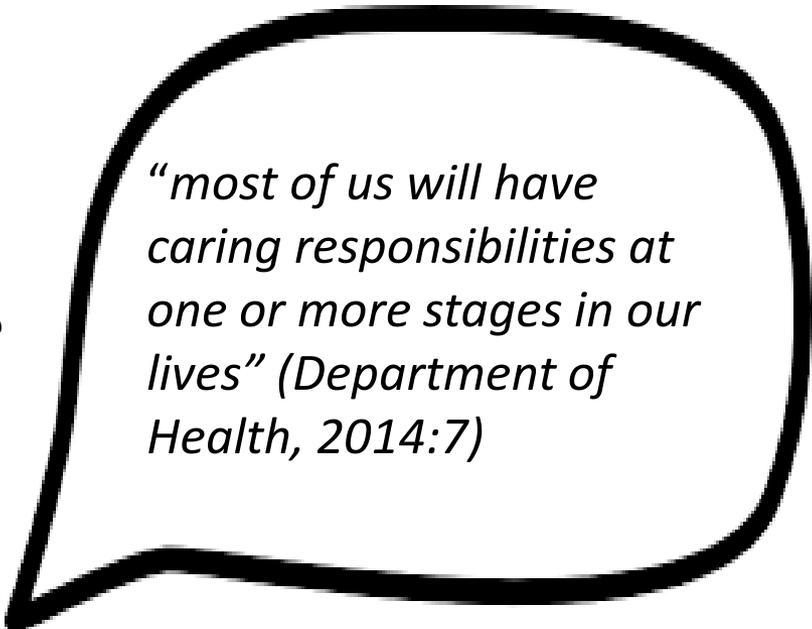
*“without help and support
...former carers can find
themselves facing debt, financial
hardship, stress and relationship
breakdown.”*

(Carers UK 2014a:3)

BUT- policy and practice acknowledgement of the importance of support for former carers is limited

Post-caring and more caring

- substantial evidence that the recurrence of family caring (often more than once)
- often former carers feel they have “little control over their resumption of the role of carer somebody who was closely related to them had needed care” (Larkin, 2009:1039)
- concepts such as “vocation carer” and “serial carer” have been used to reflect the sequential nature of caregiving roles across the life course.



“most of us will have caring responsibilities at one or more stages in our lives” (Department of Health, 2014:7)

Demographics and former carers

- a consequence of changing demographics is that the demand for family carers and demands on family carers are likely to increase
- the implications in relation to former carers are generally overlooked
 - there will be a growing number of former carers who will suffer from a range of complex financial, social, and emotional and health needs
 - changing demographics mean that many of those suffering the effects of having been carers will be needed to care again

Lessening post-caring 'legacies of caring'

- fundamental to social justice
- social rationale
- economic rationale

*“serious consequences for individuals, families, employers and the UK economy as a whole”
(Carers UK 2014:3)*

NHS England has made clear it will “include support for bereaved carers and relatives in its new ambitions for End of Life Care” (NHS England (2014:13)

Future proofing for the new demographics

'Make room' for former carers in:

- funded support services
- care and carer research
 - different types of former carers and implications of their caring experiences for their post caring lives
 - nature of former carers' status : its context, temporality, the fact that it is a relational experience and is embedded in a life course
 - effective ways of supporting former

Effecting future proofing....

- higher profile for former carers
- ringfenced budgeting for support services
- more funding opportunities for former carer research
- more longitudinal studies
- more studies that engage with carer generated perspectives to capture the distinctive needs of 'former carers'

REFERENCES

Carers UK 2014

Defining former carers

Three approaches:

- most studies simply use the term 'ex', 'past' or 'former' without developing a definition
- a small number of studies adopt an operational definition using the term 'ex', 'past' or 'former'
- Other studies define former carers by implication but do not employ any specific terms; the group of 'former carers' being studied is usually described and their "former" status acknowledged, but they are referred to simply as 'carers/caregivers'

