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How to cite:

Larkin, Mary (2015). Why carers are disadvantaged even when their responsibilities end. The Conversation, London.

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Version: Version of Record

Link(s) to article on publisher’s website:
http://theconversation.com/why-carers-are-disadvantaged-even-when-their-responsibilities-end-46973

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Why carers are disadvantaged even when their responsibilities end

October 19, 2015 6.12am BST

Recognition of carers and their vital role in society has never been greater. However, despite being the subject of a series of policy initiatives over the past 30 years – the Care Act 2014 being the latest – carers continue to be profoundly disadvantaged.

There is an extensive body of evidence about the multidimensional, adverse impacts on their health and well-being, quality of life, social networks, income and capacity to undertake education and remain in work.

For example, it is estimated that nearly three out of five carers are obliged to give up paid work to care, which represents an annual loss of more than £11,000 for each carer. Such evidence has consequently led to arguments that caring for carers remains one of the most challenging and complex issues of 21st century.

Life after caring

In contrast to the attention carers receive, the 2.1m carers who cease active caring each year are largely off the radar of services, policy and research. Studies that have been carried out suggest that post-caring life is characterised by a number of “legacies of caring”. One of these legacies is significant
financial hardship; costs arising from care-related expenses (additional laundry and heating, transport, paying for care) are known to deplete carers’ savings and increase their levels of debt. That carers are often unable to care and undertake paid work, is a further cause of income reduction post-caring.

Skills and networks lost during caring can also damage prospects of returning to jobs or embarking on new careers afterwards – in turn jeopardising opportunities to address financial losses. Time out of the workforce means being unable to make pension contributions which increases the risk of financial hardship after retirement. Former carers’ financial situations are also often worsened by the loss of carer-related benefits that cease once “active” caring ends.

Other legacies of caring include poor physical and psychological health; there is no evidence that caring-related health and well-being problems improve once caring is over. Former carers can experience significant distress once they no longer have caring responsibilities, especially in connection to depression – exacerbated by the fact that dwindling social networks while caring leave carers socially isolated. In some cases, new health problems start after caring ends – these relate particularly to sleep, exercise, eating, and alcohol consumption

There is growing evidence that the recurrence of family caring is not uncommon. Often former carers feel they have little control over resuming a caring role - somebody else who is closely related to them needs care with habit and family obligations playing an important role as drivers.

For instance, a middle-aged daughter who cares for an older frail parent, who later on in life cares for her elderly disabled husband. The concept “serial carer” has been used to describe this group, reflecting the sequential nature of care-giving roles across the life course.
Caring for our carers

Demographic change and improvements in the longevity of those with lifelong disabilities, coupled with reductions in public sector support, mean the number of those caring in the UK is estimated to rise from the current figure of 6.5m to 9.9m by 2045.

This 50% increase is accompanied by predictions of a shortfall between demand and supply – often referred to as the care gap. The intensity of care needs will also increase, the ongoing reductions in the use of institutional care and moves towards care in the home will mean that carers manage a greater, and often more complex, range of health conditions. Not only will the demand for family carers continue to rise, but so will the demands on carers.

Although these dilemmas are discussed in many different forums, their implications in relation to former carers are generally overlooked. There will be a growing number of former carers who, because of increasingly demanding experiences, will suffer a range of financial, social and emotional and health needs. Of equal consequence is the fact that, in order to meet the demand for carers, even more of those suffering the effects of having been carers will have to care again.

These connotations strongly indicate that the way forward in “caring for our carers” demands a broader approach; one which moves away from just targeting carers whilst they are caring and takes into consideration evidence about the life course. Underpinning future policy and practice developments with such an approach – and not relying solely on evidence about caring per se – will increase the likelihood of not only addressing the impacts of caring more effectively but also the reality of the way that caring impacts on people’s lives.

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