

Caring for older carers: Recognition, celebration, and support



'Bear one another's burdens and so fulfil the law of Christ' Galatians 6:2

I didn't know YOU cared!

Since 2001 the National Census has asked people to report the amount of time they give to looking after, helping or supporting family members, friends or neighbours because of 'long term physical or mental ill-health or disability or problems related to old age'. The results have revealed the extent of informal unpaid care that takes place in the UK, and that a disproportionate amount of this care is provided by people over 65. Around 15% of over-65s give a significant amount of care, and older carers are likely to be giving more hours of care per week than their younger counterparts. In fact, as age increases the amount of care provided rises; across the UK there are about 8,000 people aged over 90 who provide more than 50 hours of unpaid care per week¹.

This may surprise us, because when we think about care in relation to older people, we tend to think of care given *to* older people, not care given *by* older people.

Of course many older carers are caring for other older people. The most common scenario is an older person caring for an even older parent, or an older person caring for a spouse who may be somewhat older. However, older people may also care for adult children with special needs, such as mental or physical disability or severe mental health problems. Older people may also be involved in the care of grandchildren, even being the primary carers in the context of family breakdown. (Grandparents – many of whom are in the younger 45-65 age group - are the main providers of child care for about one third of families where the mother is working or studying².)

Many of these older carers are retired, but many continue in some sort of paid employment alongside their caregiving commitments. Equal numbers of men and women take on these roles; women predominate in the 65-75 age group, but the majority of very old carers are men³.

¹ Based on figures from Office for National Statistics Census 2001, General Register Office for Scotland Census 2001, Northern Ireland Statistics and Research Agency Census 2001.

² Stanham, J. (2011). *Grandparents providing child care*. Institute of Education, University of London; Loughborough University; Personal Social Services Research Unit, University of Kent.

³ Based on figures from Office for National Statistics Census 2001, General Register Office for Scotland Census 2001, Northern Ireland Statistics and Research Agency Census 2001.

This massive group of people is largely invisible. Indeed, a recent Age-UK campaign for greater recognition of older people who give care was entitled 'Invisible but Invaluable'⁴. The invaluable bit is important: these people save the nation millions of pounds through their unpaid service, and by the worrying fact that older carers tend not to take up all the monetary benefits to which they are entitled⁵. They are also a source of enormous 'social capital'⁶, sustaining an ethos of care in local communities.

What do we mean by 'caring'?

'Caring' covers a wide range of activities. It may involve hands-on physical care, offering practical help with the tasks of life, or being a source of emotional support. It may mean that you are identified as *the* one who cares about that person, steps in when things go wrong, or takes overall responsibility – feeling that the buck stops with you.

Patterns of caring relationships are very diverse. They may be continuous or sporadic – responding to need. They may be routine, or focused around crisis. They involve making oneself available physically or emotionally - often both. So, caring is highly demanding.

Issues for older carers

- Finances: Older carers are living off pensions. Claiming the benefits to which carers are entitled involves understanding a complex and changing system, and much of the relevant information is available on the internet. Older people may not have computer skills or access to the internet.
- Identity: Older carers often do not identify with the word 'carer'⁷. They see what they are doing as a natural part of their relationship. (This is one reason for the low take up of benefits.)
- Vocation: Older carers often take great pride in caring for a loved one, enabling him/her to remain in familiar and comfortable surroundings, and in their turn to receive love and companionship.
- Health: About 50% of older carers are themselves coping with a limiting long term illness⁸. Caregiving itself can cause stress, depression, and exhaustion⁹, and carers often do not have time to take part in health-giving activities¹⁰.

⁴ <http://www.ageuk.org.uk/get-involved/campaign/older-carers/>

⁵ Take up is only about 10% (based on figures from the Department of Work and Pensions 2005 and the Northern Ireland Statistics and Research Agency 2003).

⁶ 'social capital' refers to features of social organisations such as networks, norms, and social trust that facilitate co-ordination and co-operation for mutual benefit. Putnam, R. (1995), *Bowling Alone: America's declining social capital*. *Journal of Democracy*, 6, 65-78. Jochum, V, (2002), *Social Capital and the Voluntary Sector in Britain*. London: NCVO.

⁷ Age UK survey, 2010.

⁸ Based on figures from Office for National Statistics Census 2001, General Register Office for Scotland Census 2001, Northern Ireland Statistics and Research Agency Census 2001.

⁹ Maher J, Green H (2002). *Carers 2000*. London: The Stationery Office.

¹⁰ O'Connell, B., Bailey, S., & Walker, A. (2003). Promoting the health and wellbeing of older carers: A proactive strategy. *Australian Health Review*, 26, 78-86.

- Social isolation: Carers can have difficulty taking a break from the caring role because of unavailability of respite services, or guilt and worry at leaving their loved one. For older carers and those in rural settings transport can be a particular problem.
- Lack of recognition: Sometimes carers may collude with this in order to protect their loved-one from stigma, for instance covering up for someone who is in the early stages of dementia.
- Mourning: There can be silent grief for someone they used to know who is no longer fully present to them, or not present at all; or grieving for someone for whom they perhaps had different hopes
- Abuse¹¹: It is all too easy for relationships of care to develop into emotionally or even physically abusive patterns. Carers can be abused and they can also abuse.
- Fear: Older carers fear that their own health may deteriorate so that they will not continue to be able to care for their loved ones¹²; they fear what will happen to their loved ones after their death; and a difficulty in 'letting go' (especially adult children with special needs)¹³.
- Expertise: Carers hold a good deal of expert knowledge about those in their care, but this is not always given due recognition and weight by professionals.
- Spirituality: The opportunity for carers to exercise a ministry outside of their caring role is likely to be restricted. Carers have spiritual needs of their own, including the need to attend public worship or informal fellowship groups, which often go unmet. Particular spiritual issues that arise in the context of caring include:
 - Being honest
 - Dealing with feelings of guilt
 - Giving and receiving forgiveness in the relationship
 - Finding a space to be oneself
 - Exploring caring as vocation or worship
 - Learning to receive from others
 - Learning to let go

¹¹ If you have any concerns about the safeguarding of a vulnerable adult, please see <http://www.oxford.anglican.org/pcc-and-dcc-support/safeguarding/>

¹² O'Connell, B., Bailey, S., & Walker, A. (2003). Promoting the health and wellbeing of older carers: A proactive strategy. *Australian Health Review*, 26, 78-86.

¹³ Bowey, L. & McClaughlin, A. (2007). Older carers of adults with a learning disability confront the future: Issues and preferences in planning. *British Journal of Social Work*, 37, 39-54.