

## Caring alone

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*“It was getting tougher and tougher. I collapsed under the strain of trying to be a carer and to carry on working and I was advised by the medical professions that I needed to have a rethink. I didn’t feel isolated while I was able to go out to work and do caring. Once I tried to be a carer here full-time, I felt totally isolated because your whole network’s gone. People come round for a while but not for long. So you really need to rebuild that network but you don’t know where to look, because you think everyone else is coping and you think it can only be me that isn’t coping.”*

There are 6.5 million people in the UK caring unpaid for an older or disabled family member or friend, and the numbers are increasing. The 2011 Census showed that there are nearly 1.3 million carers over the age of 65, a 35% increase since the Census in 2001, representing the fastest growing group of carers. It’s important to note also that the people who make up that 6.5 million are changing all the time. Every year 2 million people become carers, and a similar number find that their caring role has come to an end. The gender balance is closer than you might suppose, as 42% of carers are men.

All of us, at some point in our lives, will either be carers, or need the help of carers. So if caring or being cared for is a near universal experience, how is it that being a carer can be so isolating and lonely? This is the experience of many carers I’ve spoken to in my work at Carers UK and is a theme in the body of research around caring. There have been significant improvements over the last 50 years in the recognition of carers starting with the work of the Reverend Mary Webster, who founded the carers’ movement. But the fundamental challenges of being a carer haven’t changed significantly. So whilst the word ‘carer’ is increasingly recognised today, people’s experiences of being a carer are not so different from those Mary had in the 1950s and 60s.

The loneliness carers experience is caused by a range of circumstances, many of which are imposed on them. You may be so busy that you have no time or energy left to see friends and other family, or they may drift away as your life becomes so different from theirs. You may find the emotional demands of caring for a loved one and focussing on their well-being means that you neglect your own. The costs associated with caring, particularly if you have had to give up work to care,

can mean that you are struggling financially and cannot afford to do some of the social activities you did before. You can find that your relationships become increasingly transactional rather than affirming and sustaining. For many carers, the world simply shrinks. Your role can become one of providing and co-ordinating care, taking your loved one to medical appointments, going to the chemist, liaising with care workers. You can feel invisible, as you fade into the background and the needs of the person you are caring for take centre stage. It can be lonely bearing so much of the responsibility of caring for a loved one.

The Reverend Mary Webster was 31 when she gave up her work as a church minister to care for her elderly parents. It was 1954 and there was no concept of a 'carer', no recognition of the role, and no support. Mary was a single woman and as the demands of caring grew, her isolation also grew. Mary described her situation as like being under 'house arrest' – a phrase that resonates strongly today. Thinking that there might be other women in the same situation as her, caring for elderly parents and being cut off as a result, she reached out through the newspapers to tell her story and was inundated by letters from others in the same situation. Mary brought what had hitherto been a private issue, into the public domain. It is thanks to this pioneering work that the carers' movement was born and the charity that became Carers UK was established in 1965.

Each day 6,000 people become carers and the transition to caring, and particularly to full-time caring, can plunge you into isolation.

*"Nothing prepared me for the loss of identity...when I had to stop working – overnight I stopped being superwoman and became a nonentity, a scrounger living on benefits. I feel that I am invisible now – as soon as you mention that you are a carer, whether talking to a professional or a stranger at a bus stop, their eyes glaze over. Once you are a carer it is as if you cease to exist, or only live as a shadow. It is hard."*<sup>1</sup>

*"My experience came as a complete shock with a cancer diagnosis so there was no time to prepare. There was an overwhelming sense of shock and loneliness."*

At the same time, when people's caring roles come to an end this can also bring feelings of loneliness.

*"After my caring role ended I felt out on a limb... Even when you know it's going to happen it is a change in lifestyle and is very frightening; just as frightening as when caring begins. You feel lost and alone and have no idea what to do with your time. After caring long term carers especially should be given time to grieve and get their head back in some sort of order."*

These individual experiences are reflected in the research that Carers UK has undertaken over many years. In our 2013 *State of Caring*<sup>2</sup> survey – completed by

over 3,000 carers – 92% said that their mental health has been affected by caring. Research carried out for Carers Week 2013 showed that 6 out of 10 carers had found it difficult to maintain friendships, 42% had had a breakdown in a relationship with a family member, and 71% of carers were not prepared for the change in relationship with the person they cared for.

*“I had no idea...[of] the degree that [caring] would impact on my life, particularly my ability to leave the house, have a social life of my own, follow my own interests, have holidays, and be able to look after my health. In becoming a carer, I’ve lost my own identity to a great extent, strange though that might sound.”<sup>3</sup>*

What can be done? We need nothing less than a societal shift in recognition and understanding of caring. Although caring is such a normal part of life, it is not seen as a shared experience. Contrast it with parenthood, where there is a societal understanding of a shared experience and an ease of talking about it with friends, at work, with family. We need to find ways to ‘normalise’ caring, so that it is acknowledged as the universal experience it is, and so that carers too are recognised, valued and supported.

As a society we need to reach out to carers so they know that they are not alone. We also need to ensure they can get both practical and emotional support. Crucially we need to do this in a way that doesn’t always rely on people identifying themselves as carers. It can take years before someone self-identifies as a carer, and this can mean essential support doesn’t reach them. But we can all play a role in tackling loneliness amongst carers. The cultural shift to break the isolation and loneliness of carers starts with small conversations:

- The GP who asks how you are, not just about the person you are caring for
- The employer who you’re able to share your circumstances with and who gives you the flexibility to manage working and caring
- The social worker who understands your situation and who helps you arrange the support that you need as a carer
- The pharmacist who sees you picking up the prescription regularly and chats to you about your own health
- The carer who recognises that you are a carer too, and understands and helps you feel less alone
- The public figure who talks about their own experiences of being a carer and acts as a catalyst for other conversations
- The friends who stay with you, and the new friends that you make

These conversations won't solve everything, and have to be accompanied by practical and financial help and support. But they really can help to break the loneliness that many carers experience. Some of these conversations happen already, but they need to happen more consistently, for example with health and care professionals who are so important to ensuring that carers get practical help and support. For this to be achieved, understanding and awareness of carers needs to be built into training, education and ongoing practice. For instance, we know that the role of the GP is crucial, which is why, funded by the Department of Health, we are working with the Royal College of GPs and Carers Trust to raise awareness and support for carers amongst GPs. The work that NHS England is carrying out under its NHS Commitment for Carers also has the potential to improve the recognition and support that carers receive from the NHS.

Alongside the cultural shift that is needed, there must also be better practical support for carers. Reliable, high quality health and social care for the person they are caring for is vital, as is the opportunity to take a break from caring. Also essential is the right financial support for carers – whether caring full-time or trying to balance caring with working. And when the caring role ends, carers need time, understanding and support to adjust to the life change, and to rebuild a life after caring.

How we care for each other is one of the biggest challenges we face as a society, and one of the most important things any of us do in our lives. We shouldn't have to do it alone.

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**Heléna Herklots**

Chief Executive  
Carers UK

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- 1 Carers Week (2013) *Prepared to Care?*
  - 2 Carers UK (2013) *State of Caring 2013*
  - 3 Carers Week (2012) *In Sickness and in Health*