

The world shrinks: Carer loneliness

Research report



by Carers UK as part of the Jo Cox Loneliness Commission

What do we mean by loneliness and isolation?

Social isolation is about how many social contacts a person has, while loneliness is a feeling of a lack of companionship. Loneliness is a feeling that can come and go, or it can be something a person feels all of the time¹.

Who are carers?

Across the UK today 6.5 million people are carers, supporting a loved one who is older, disabled or seriously ill². That's 1 in 8 adults who care, unpaid, for family and friends. Almost 1.3 million people in England and Wales aged 65 or older are carers and the 2011 Census estimated there were 178,000 people under 18 years old who have caring responsibilities³. Over 3 million people are juggling care with paid work⁴.

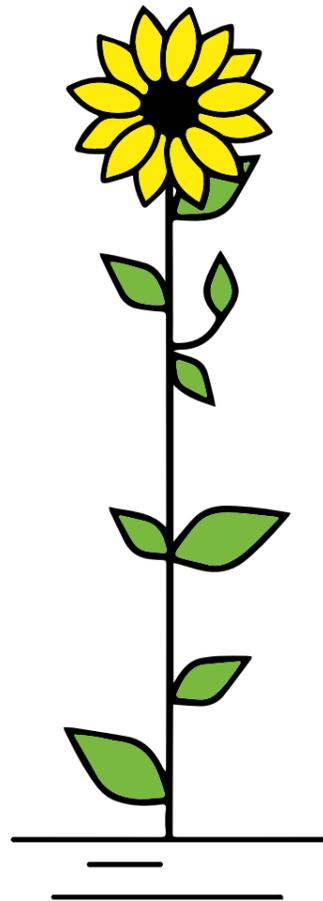
Summary and key findings

Caring is such an important part of life. It's simply part of being human. Carers are holding families together, enabling loved ones to get the most out of life, making an enormous contribution to society and with their support being valued at £132 billion a year⁵.

Carers say that providing care can be extremely rewarding, but it can also bring with it many challenges. The loneliness carers experience is caused by a range of circumstances, many of them out of their control. 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 pharmacy, 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.



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One by one... like leaves falling from an autumn branch... all gone...no one for years to hug, talk, walk, share with, anything at all really, lost.. that's it... there is nothing to offer...

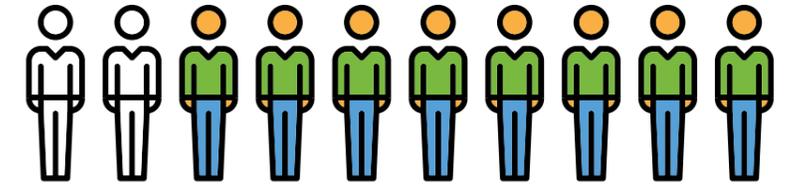
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About the research

Unless stated otherwise the following research findings and quotations are drawn from Carers UK's State of Caring 2017 Survey of 7,286 carers and former carers. Compared to the carer population as a whole, respondents to the survey are more likely to be caring for a high number of hours each week.

81%

8 out of 10 carers have felt lonely or socially isolated as a result of their caring role



This rises to nearly 86% of carers providing 50 hours or more a week

More than 9 in 10 (93%) of those caring for a disabled child have felt lonely or socially isolated due to their caring role.

Levels of loneliness and social isolation are also higher for those juggling care with bringing up children (86%).

Younger carers experience higher levels of loneliness or social isolation, 89% of carers under 24 years old said they had felt lonely or socially isolated as a result of their caring role.

The longer people have been caring for the more likely they are to feel lonely or socially isolated, 84% of those caring for 10 years have felt lonely or socially isolated.

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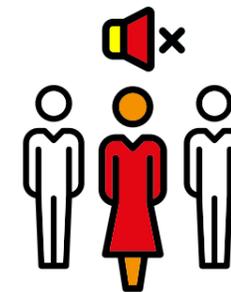
Others do not realise that I do not choose to turn down offers to go to events or social gatherings. Now, I am not included in things as a result of having had to turn down so many invitations in the past.

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What carers say makes them feel lonely or socially isolated

A third (32%)

said they had felt lonely or isolated because of **not being comfortable talking about caring with their friends**



48%

said **not having time to spend on social activities** has made them feel lonely or isolated



31% said

not being able to afford to participate in social activities made them feel lonely or socially isolated



Half (49%)

said **the difficulty of not being able to get out of the house much** has made them feel lonely or socially isolated



¹ The Campaign to End Loneliness has more information about loneliness and isolation, including different types of loneliness, at: campaigntoendloneliness.org/about-loneliness

² Census 2011

³ The estimated number of young carers varies from the Census 2011 figures of around 178,000 to a BBC study in 2010 which suggested there could be as many as 700,000 aged under 18.

⁴ Census 2011

⁵ Valuing Carers: the rising value of carers' support, Professor Sue Yeandle (University of Sheffield) and Dr Lisa Buckner (University of Leeds), published by Carers UK, 2015

Loneliness in the workplace

32% of employees currently juggling work and care have felt lonely or isolated in the workplace because of their caring role



Anyone at work can face isolation or loneliness when they have no-one to talk to who understands their situation, even in a busy office.

While one in nine people will be combining paid work with unpaid care for an older, ill or disabled relative or friend, caring still remains a relatively hidden issue in many workplaces⁶. This may be for a number of reasons; often people may not recognise themselves as carers, do not know where to turn for help, or feel uncomfortable coming forward for support.



What carers say would make them feel less lonely

When asked what would make the difference to stopping them feeling lonely:

54%  regular breaks from their caring role would help

52%  more understanding from society would help

29%  said being in touch with other carers would help

1 in 5 (21%)  said being able to **take part in education or training opportunities** would help

A third (30%)  of those currently juggling work and care said **more understanding at work** would help

1 in 4 (23%)  said feeling more able to **talk to friends and family** would help

40%  said being able to **take part in leisure activities** would help

A third (31%)  said **support with paying for social activities** would help

Issues identified by this research

Replacement care and finances

Not being able to participate in social activities because of the pressure that caring can put on family finances and the difficulty of arranging appropriate and trusted replacement care can mean carers quickly become socially isolated and lose touch with friends and social networks.

Having regular breaks from caring was what most carers said would make a difference to their feelings of loneliness and isolation.

In previously published findings from Carers UK, high numbers of carers report not having a break for years. **A quarter of people (25%)** said they hadn't had a day off from caring for more than five years, while **4 out of 10 carers (40%)** said they hadn't had a day off for more than a year⁷.

Social attitudes to caring and disability

Even when carers are able to get out of the house they can face additional challenges. Many venues and public transport are not physically accessible to those with mobility problems which can make it difficult for carers to go out with a disabled family member. Many carers are also living with long-term health conditions or disability themselves. In addition, challenging behaviours, and even physical and sensory disability, are often misunderstood by the general public and can be met with hostility in a way that makes going out in public stressful for families.

The difficulty of talking to friends about caring is something that many carers report as leading to feelings of loneliness. Despite caring being something that most of us will do at some point in our lives, we need to be much more willing to talk openly about it.

Relationships

Caring can be a fulfilling and positive experience for many people which can bring carers closer to the person they look after and mean that they make new friends through their caring role. However caring often presents challenges for the relationship with the person you care for and for others. When one person takes on a caring role in addition to this, they can find that their relationship with the person they are caring for changes significantly as the dynamic shifts from husband and wife, parent and child, or brother and sister, into carer and cared-for.

Transitions

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

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People really don't understand how difficult it is to care for someone else especially when you can't even leave the house without the cared for person unless a support worker has been provided. Finances have been much tighter due to my caring role. People are scared of both epilepsy and learning disabilities.

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I tend to feel lonely when looking after my cared-for person with dementia because I feel he can no longer share my thoughts and interests and because that will continue to worsen as time goes on. I therefore try and keep busy and get out of the house whenever possible.

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Likewise, each day 6000 people come to the end of their caring role⁸.

Starting a caring role can be particularly bewildering and it's easy to feel overwhelmed by navigating a complex system of support, by the sense of responsibility and to feel alone. Equally, coming to the end of a caring role is also a very challenging time that may also be accompanied by bereavement. No longer providing care can mean the end of important support relationships as well as a loss of identity. Social contacts may have fallen away while caring and can be difficult or impossible to return to.

Carers and health

The majority of current carers who completed our State of Caring Survey have experienced a negative impact on their own health and wellbeing as a result of their caring role; 61% reported a worsening of their physical health while 70% reported experiencing mental ill health. For current carers who said they have felt lonely and socially isolated, the numbers reporting negative health impact is significantly higher with 67% saying their physical health had worsened and 77% reporting mental ill health as a result of their caring role. These reported health impacts are almost twice the rate of those carers who did not feel lonely, 35% of whom said their physical health had worsened as a result of caring and 42% said their mental health had worsened as a result of caring.

Addressing carer isolation

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 among carers. The cultural shift to break the isolation and loneliness of carers starts with small conversations.

Starting a conversation:

Everyone has a part to play in bringing about a cultural shift towards a society that recognises and understands caring, ageing and disability better. Caring is part and parcel of everyday life – more people openly talking about caring responsibilities would reflect this and allow everyone to understand caring better.

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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 begins⁹.

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I felt very isolated and joined a Carers Support Group. When it lost funding I decided to continue it voluntarily. This helped me tremendously and we are now a fully constituted group and meet every month. We ensure our members are aware of all the training on offer re caring, stress, health & fitness, advocacy etc. More importantly, we listen, care & share our feelings and have quite a few tears but always lots of laughter.

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All of us

A friend, family member or colleague that puts themselves in your shoes as a carer and tries to understand what you're going through.

A carer or former carer that reaches out to someone caring to make sure you know you're not alone.

Health and care professionals

The GP who asks how you are, not just about the person you are caring for.

The social worker who understands your situation and who helps you arrange the support that you need as a carer.

The hospital staff who welcome you and recognise your role as a carer.

The pharmacist who sees you picking up the prescription regularly and chats to you about your own health.

Role of employers

Employers that foster a workplace culture where caring responsibilities are supported with carer friendly policies that actively encourage you as a working carer to identify yourself and come forward for support.

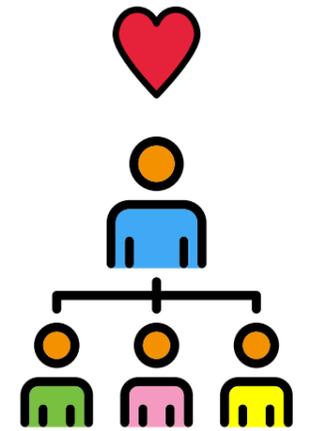
Employers and colleagues that support Carers Networks that enable carers to provide each other with peer to peer support.

The manager who you're able to share your circumstances with and who gives you the flexibility to manage working and caring

National and local government

National Government that recognises the huge contribution made by carers, putting in place significantly improved financial support that means you do not struggle to make ends meet as a carer or after caring ends.

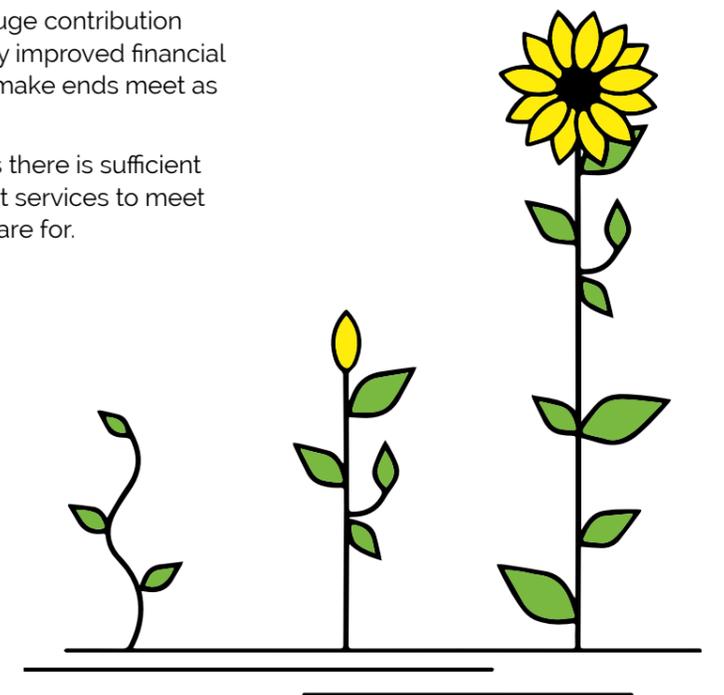
National and local government that ensures there is sufficient and sustainable funding of care and support services to meet your needs as a carer and the people you care for.



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I am a young carer of my dad and most of my friends have no idea what it's like to care. I am excluded because I can't leave him alone and they feel awkward coming to see me and don't seem to know what to say to support me.

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⁸ Carers UK (2015). Need to know: Transitions into and out of unpaid care

⁹ Quote from Carers UK's State of Caring Survey 2015



How Carers UK helps

The Carers UK Adviceline provides expert information and advice on financial and practical matters related to caring as well as a listening service for carers to talk through their situation with a trained volunteer who understands what they are going through (Mon/Tues only).

E advice@carersuk.org | **T** 0808 808 7777

carersuk.org/help-and-advice/talk-to-us

The Carers UK online forum is a place where carers can share what's on their mind, day and night, with other carers and former carers who can support them through the ups and downs of caring.

carersuk.org/forum

Carers can find out about local support available from organisations in their area at: carersuk.org/help-and-advice/get-support/local-support

Volunteering at Carers UK is a great way to connect with carers, building your skills and confidence while helping to make life better for carers and their loved ones.

carersuk.org/volunteer

Carers UK can help carers discover a world of products and equipment designed to help look after loved ones and make it easier to live your own life. carersuk.org/help-and-advice/technology-and-equipment

A yellow speech bubble with a black outline, containing text about carer loneliness.

Find out more about what Carers UK and others are doing to combat carer loneliness:

carersuk.org/loneliness



Find out more and make a pledge against loneliness:

jocoxloneliness.org