

Alone and caring

Isolation, loneliness and the impact of caring on relationships

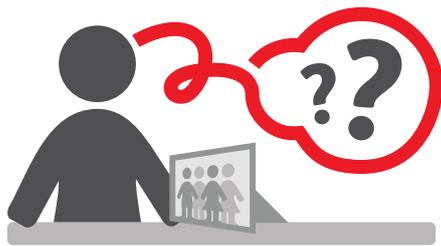


carers have felt **lonely or socially isolated** as a result of their caring responsibilities



8 in 10

carers have felt **lonely or socially isolated** as a result of their caring responsibilities

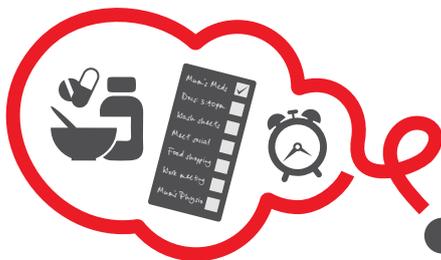


57%

of carers have **lost touch with friends and family** as a result of caring

49%

of carers say that they have experienced **difficulties in their relationship with their partner** because of their caring role



38%

of carers in full-time employment have felt **isolated from other people at work** because of their caring responsibilities



Summary

Key findings

- 8 in 10 (83%) carers have felt lonely or socially isolated as a result of their caring responsibilities¹
- 57% of carers have lost touch with friends and family as a result of caring and half (49%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role
- 38% of carers in full-time employment have felt isolated from other people at work because of their caring responsibilities
- Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.

What needs to happen?

More must be done to improve public understanding of caring and disability and raise awareness of the emotional and peer-to-peer support available for carers. It is also crucial that carers can access the practical and workplace support they need to be able to spend time with other family and friends and to have a life of their own outside of their caring role.

Isolation and loneliness

What do we mean by isolation and loneliness?

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 time.²

¹ Unless otherwise stated, all statistics in this research briefing are drawn from Carers UK's State of Caring Survey 2014 of over 5,000 UK carers

² The Campaign to End Loneliness has more information about loneliness and isolation, including different types of loneliness, at: campaigntoendloneliness.org/about-loneliness

Why might carers feel alone?

Isolation and loneliness is something that many people face as a result of their caring responsibilities for a disabled, older or seriously ill loved one; contrary to popular belief, loneliness is not all about being on your own.

Carers may feel isolated or lonely because, by putting the person they look after first, they no longer have the time to see other friends and family. They may feel unable to talk to colleagues about their caring responsibilities or have to leave work altogether. The extra costs of caring and fall in income many carers face may mean they cannot afford social activities anymore. Or it can just seem like no-one understands their situation. It can feel lonely even in a crowded room if carers have no-one they can talk openly to about their caring role.

Carers UK Chief Executive Heléna Herklots, in an essay for the Campaign to End Loneliness, explores how when you become a carer “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.”³

Carers can also face very particular challenges. They often feel responsible, sometimes solely responsible, for the person that they are looking after – something that it may be difficult for others to fully understand. Even if there are other carers that they can talk to, their experiences may be very different to their peers.

..... “It’s very hard being at work and being a carer for someone with mental illness...
..... even at a carers conference no one seems to have had [the same experiences as
..... me].”

Some aspects of caring can also be very difficult to share with others, even when talking to someone who understands. Personal care for example may feel like a private family matter, and difficult to talk about while respecting the dignity of the person being cared for.

³ Herklots, Heléna (2014) ‘Caring alone’, *Alone in the crowd: loneliness and diversity*, Campaign to End Loneliness and The Calouste Gulbenkian Foundation

money for replacement care or even a coffee with friends or the bus fare to attend a support group. In fact, three quarters (73%) of carers responding to Carers UK's 2013 survey said that they were cutting back on spending to see friends or family and 43% were reducing costs by using the phone less,⁶ making it much harder for these carers to stay socially connected.

“We can't afford to go out much together as our finances are tight so we have to sacrifice that to pay bills and for food and heating.”

Replacement care

This issue can be compounded by the fact that there are not always suitable replacement care services available, and if there are then they may not be affordable. Many families are not eligible for state-funded social care, and even when the state is responsible for meeting care costs, the costs of paying for services can still fall on families.

Increasingly, care and support is provided through Direct Payments – cash payments given to people with care needs in place of local authority arranged community care services they have been assessed as needing. Direct Payments are intended to give users a greater choice about their care, but a quarter (24%) of those caring for someone with a Direct Payment who responded to Carers UK's survey were supplementing the payment as it did not cover the cost of care.⁷

Other carers have told Carers UK that although they have enough money to pay for care, there are no suitable services in their area for the person they are looking after (for example specialist dementia care, or care that meets the needs of a disabled child), or the person they look after refuses to accept care from someone outside the family.

Many others worry about the quality and reliability of care services. Nearly 3 in 10 (29%) carers who have experience of social care services have ended a service because of concerns about quality and nearly half (48%) said that poor quality care has a negative impact on their relationship with family and friends.⁸ Care quality has an even greater effect on certain groups of carers; for example BAME⁹ carers are more likely than other carers both to have had a negative experience of social care services, and to say that poor quality care has a negative impact on their life, including their relationships with family and friends.¹⁰

⁶ State of Caring Survey 2013, published in: Carers UK (2014) *Caring & Family Finances Inquiry: UK Report*

⁷ State of Caring Survey 2014, published in: Carers UK (2014) *The State of Caring 2014*

⁸ State of Caring Survey 2013, published in: Carers UK (2014) *Quality of Care and Carers*

⁹ Black, Asian and minority ethnic

¹⁰ State of Caring Survey 2013, published in: Carers UK (2014) *Quality of Care and Carers*

Problems such as these can mean that many carers are unable to take a break away from caring to socialise, catch up with other friends and family, pursue their interests or meet new people. 2 in 5 (41%) carers cite the lack of practical support with caring as a factor that makes it difficult to maintain relationships.

⋮ *“It is difficult to be flexible or spontaneous as needs of the person I care for must be met before making social arrangements.”*

⋮ *“The person I care for needs my presence every day. I can only go away if I get respite care, for example in a care home which costs £640 a week.”*

⋮ *“My life lacks spontaneity. It takes a lot of planning for me to take any time off. It's becoming much harder to find respite residential care which means I can't get the breaks I'm entitled to.”*

Public understanding of 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.¹¹

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. In a previous Carers UK survey, 1 in 7 (14%) carers even reported having been the victims of harassment or crime because of their disability or caring responsibility.¹²

⋮ *“People have often verbally abused my son and me because of his autistic behaviour.”*

Families who face these issues may find it easier to stay at home more and forgo some social activities, making social isolation more likely.

¹¹ Full-time carers are twice as likely to be in bad health as non-carers (Census 2011)

¹² State of Caring Survey 2011

Relationships

When asked what impact caring has had on their relationships, carers said:

- I have lost touch with friends/family (57%)
- I have experienced difficulties in my relationship with my partner because of my caring role (49%)
- I feel lucky that I have supportive friends or family (28%)
- Caring has brought me closer to family and friends (7%)
- Caring has brought me closer to the person I care for (29%)
- I have made new friends because of my caring role (21%)
- I have lost touch with people I used to work with (47%)
- It has put a strain on my relationship with colleagues at work (10%)

Caring can be a fulfilling and positive experience for many people, and the responses above show that it can bring carers closer to the person they look after, to other friends and family, and to new friends that they meet through their caring role. However, for the reasons outlined in this briefing many people also find that taking on a caring role can have a damaging effect on their relationships and social life.

Factors which affect how often carers can see friends and family – such as financial restrictions, lack of practical support to help with caring, and barriers to families going out in public – are exacerbated by just how busy many carers are. 1.4 million people provide 50 or more hours of unpaid care a week,¹³ and 3 million people are combining caring with work, so it is unsurprising that three quarters (73%) of carers who have found it hard to maintain relationships with friends, family or other social networks said a key reason is that they just don't have enough time to spend with other people they would like see. Over time, this damages relationships and leaves many carers increasingly socially isolated.

..... *"I have no time for social interaction. I'm lucky that I do have my wife for company but it's not enough."*

Some carers find that it is not just getting out and about that is the problem – it is having someone to talk to who understands what they are going through. Nearly 2 in 5 (38%) carers say that they don't have anyone to talk to about caring while three quarters (75%) feel that people don't understand the impact that caring has. 7 in 10 (70%) feel that the stresses of caring make it hard to maintain relationships.

¹³ Census 2011

Talking about caring may be especially hard for some carers. For example, BAME¹⁴ carers were more likely to say that not being comfortable talking to their friends about caring has made them feel lonely and socially isolated.¹⁵ This could be because for some carers from BAME backgrounds there is a cultural barrier to discussing caring and disability openly or a stigma around particular conditions.¹⁶

Male carers may also face particular challenges, with research suggesting that many (particularly young and employed) male carers are reluctant to describe themselves as carers or seek support with their caring role, and 7 in 10 (72%) said that they miss out on spending time socially with other friends and family members.¹⁷

Relate has found that living with disability and poor health can itself change the nature of a relationship and put it under some strain.¹⁸ 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. In a Carers Week survey of over 2,100 carers, 7 out of 10 (71%) said that they had been unprepared for the change in relationship with the person they look after.¹⁹ Although this is not a relationship lost, it can be very difficult, if not impossible, for carers to talk about the stresses of caring with the person they are looking after.

A breakdown in relationships, particularly with a partner or close relatives and friends, can leave carers feeling alone with no-one to talk to about the challenges that they are facing. With 2 in 5 (42%) carers saying that they have had a breakdown in a relationship with a family member,²⁰ it is unsurprising that so many carers report experiences of social isolation and loneliness.

..... *“I have sometimes felt so left behind as friends' children develop and this makes it hard to maintain friendships sometimes.”*

..... *“I have felt angry and disappointed that my friends and family have not been there for me, so this has affected my relationships with them.”*

..... *“I just wish I had something else to talk about – I just feel as if all that people get out of me is about caring and I keep thinking that it must be so boring.”*

¹⁴ Black, Asian and minority ethnic

¹⁵ 43% of BAME carers said this, compared to 36% of all carers

¹⁶ Carers UK (2011) *Half a million voices: Improving support for BAME carers*

¹⁷ Carers Trust and Men's Health Forum (2014) *Husband, Partner, Dad, Son, Carer?*

¹⁸ Harries, E. and de Las Casas, L. (2013) *Who will love me, when I'm 64? The importance of relationships in later life*, Relate and New Philanthropy Council, p.29

¹⁹ Carers Week (2013) *Prepared to Care?*

²⁰ Carers Week (2013) *Prepared to Care?*

“Some family relationships have been permanently damaged: my relationship with the person I care for is extremely delicate, my relationship with my ex-husband is almost non-existent. [...] Some personal friendships can be very supportive, some not so. All friendships are affected by the restrictions in my life.”

Loneliness at work

Even for those who work in a busy office or other workplace, caring can still be a lonely experience. Carers may feel that no-one at work understands their situation, be stressed that they can't always give their work their full attention, or worry about how their loved one is coping while they are away from home.

3 in 10 (29%) carers in full-time employment say that caring has put a strain on relationships with their colleagues at work and 38% have felt isolated from other people at work because of their caring role.

This feeling of disconnection from colleagues can be exacerbated by a lack of time to connect with others socially outside of work. Carers often tell Carers UK that they have to use up all of their annual leave as well as their spare time to provide care to a loved one, leaving them with little time to spend with other family and friends.²¹ 4 in 5 (85%) carers in full-time employment said that they have found it hard to maintain relationships because they don't have enough time to spend with other people they would like to see (compared with 73% of all carers who responded to the survey).

There is good practice emerging from employers who are taking steps to better support their working carers, in recognition that this has business benefits as they improve staff retention and productivity and reduce absence and stress in their workforce. New extended rights to flexible working²² are also a step forward in helping carers to manage caring and work alongside maintaining social relationships. More can also be done by government to improve carers' rights at work, and by employers to foster a workplace culture where employees are supported to have a healthy work-life balance.

“When I first cared for my father (before I had direct payments) I felt very lonely and isolated as I didn't have time to do anything else but work and care.”

²¹ Carers UK (2014) *The Case for Care Leave*

²² In England, Scotland and Wales the right to request flexible working has been extended from some carers and parents to cover all employees with 26 weeks service or more. This extension is intended to apply in Northern Ireland from April 2015. For more information about the right to request flexible working see: carersuk.org/help-and-advice/work-and-career/your-right-to-flexible-working

“There is lack of understanding of caring – even amongst colleagues I am ashamed to tell them as they will not understand the time I need and the strain I feel when the person I care for has psychosis for instance, as I have to be in touch all day. They think I am the one with a problem as I’m always on the phone.”

“I used to feel lonely at work but I asked my employer if we could set up a staff carers forum. They agreed and it has been marvellous.”

Impact on carers’ health

Social isolation, and the factors that lead to it, can have a big impact on carers’ health and wellbeing. Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house, and are also more likely to have experienced depression as a result of caring (63% of carers who have reached breaking point said this, compared to 50% of all carers responding to the survey).²³ Research brought together by the Campaign to End Loneliness shows that lonely people are more prone to depression.²⁴

Loneliness and social isolation can also have a serious impact on physical health: a lack of social connections is as damaging to our health as smoking 15 cigarettes a day and has a bigger impact than well-known risk factors such as obesity.²⁵

What can make a difference?

Anyone can face isolation or loneliness when they have no-one to talk to who understands their situation, even in a busy office or surrounded by family and friends. However there is help and support available, including emotional support from people who do understand, and Carers UK will campaign throughout its fiftieth anniversary year and beyond to raise awareness of caring and make sure no-one has to care alone.²⁶

²³ State of Caring Survey 2014, published in: Carers UK (2014) *Carers at breaking point* and Carers UK (2014) *State of Caring 2014*

²⁴ Cacioppo et al. (2006) and Green et al. (1992), collated by the Campaign to End Loneliness. For more information about loneliness and health see: campaigntoendloneliness.org/threat-to-health

²⁵ Holt-Lunstad (2010), collated by the Campaign to End Loneliness

²⁶ For more information about Carers UK’s 50th Anniversary please see: carersuk.org/alone

Everyone is different, and carers all have different needs for support, so there must be a range of options available. Peer support from people who understand can help many carers feel less alone, for example through a carer support group or social activities organised by a local carers organisation. Others may not feel comfortable opening up in that setting, and may prefer online support through social media or the Carers UK forum.

It is crucial that there is also practical support in place so that carers have the time to be able to work if they want to, to spend time with friends and family, and to have a life of their own outside of their caring role. This may include equipment or technology such as telecare and telehealth, or social care support such as help from care workers in the home or periods of residential respite care. This social care support must be accessible and affordable, as well as good quality and reliable if it is to give carers the peace of mind they need to undertake other activities with the confidence that their loved one is in good hands.

There are also further steps that we can all take, as a society, to ensure that no-one has to care alone.

Recommendations

What we can all do:

- Everyone has a role 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
- Individuals can put themselves in the shoes of a family member or friend who is caring and try to understand what that person may be going through and the different ways in which they may be able to help.

There are also roles for central, national and local government, health and social care bodies, employers and local voluntary and charity organisations – across all sectors of society, everyone has a part to play.

Carers UK recommends:

1. A stronger rights base in the workplace that government should improve and support with policy and legislation, including a statutory right to 5-10 days of paid care leave and an urgent debate on longer-term leave from work to care²⁷
2. Employers should foster a workplace culture where caring roles are supported with carer-friendly policies²⁸
3. A radical improvement in the financial support available to carers and their families to prevent poverty and hardship
4. Sufficient and sustainable funding of care and support services to meet the needs of carers and the people they care for
5. A clear duty on duty on NHS bodies to identify carers and promote their health and well-being (England only)²⁹
6. Support for national and local advice services that provide carers with essential emotional and practical support
7. Flexibility for local government to foster support networks through housing, planning and welfare policy and to ensure carers are able to remain close to those networks
8. Understanding of the strain that caring can place on relationships and strategies in place to address this. This should include access to counselling services and support for carers.

²⁷ For more information about care leave please see: Carers UK (2014) *The Case for Care Leave* and Carers UK (2014) *Care leave: impact on business*

²⁸ These could include care leave, promotion of workplace rights including to request flexible working, support for a carer network, and encouraging line managers to have open and supportive conversations about employees' caring responsibilities.

A good first step would be to join the employers' forum Employers for Carers which provides practical advice and support for employers seeking to develop carer-friendly policy and practice and retain skilled workers. To find out more visit: employersforcarers.org

In Scotland, employers can take part in the Carer Positive award scheme for employers who support carers, learning from other employers and building policies to support their employees with caring responsibilities. To find out more visit: carerpositive.org

²⁹ In Wales the Carers Strategies (Wales) Measure 2010 already places this duty on health and local authorities to identify and signpost carers. The Carers and Direct Payments Act (NI 2002) requires Health and Social Care Trusts to make sure carers know about their statutory right to a carer's assessment and gives Trusts the power to supply services directly to carers in their caring role. In Scotland and Northern Ireland, as part of the GP contract, GPs must identify carers and keep a carers register, and the NHS has duties to identify and provide information to carers. These measures must be retained and built on.

Support from Carers UK

- The **Carers UK Adviceline** provides expert information and advice on financial and practical matters related to caring five days a week (lines open Mon-Fri, 10am-4pm) 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

Carers in Northern Ireland can call 028 9043 9843 to find out about local Carers Support Groups.

- **Jointly** is a mobile and online app designed to make caring a little easier, less stressful and a lot more organised by making communication and coordination between those who share the care as easy as a text message.

carersuk.org/help-and-advice/our-products-for-carers

About Carers UK's 50th Anniversary year

Carers UK was established 50 years ago in 1965 by the Reverend Mary Webster, who gave up her career in order to care for both her parents. She felt incredibly alone and isolated in this role, memorably describing a feeling of being 'under house arrest'. Mary started the organisation that is now Carers UK to campaign for better rights for carers, improve access to information and advice and to put carers in touch with one another. 50 years later and, although caring is better understood than it once was, the impact of caring still comes as a shock to many people and carers can often still feel very alone.

In Carers UK's 50th Anniversary year we want to ensure that no one has to care alone. We will mark the year by improving public understanding of caring, raising awareness of the support on offer and working to break carers' isolation, including by:

- **Giving help and advice.** Through our Adviceline, we give expert information and advice, and a listening ear when someone just needs to talk. We would like to grow our capacity so we can help many more carers.
- **Sharing experience.** From the beginning, the carers movement has been about carers helping carers – both by providing support and raising awareness. During our 50th Anniversary year, we are growing our online forum and inviting carers to log on to give and receive support.
- **Reaching out.** In our 50th Anniversary year, Carers UK is launching a new national volunteering programme, inviting people to 'Be one of the 500'.
- **Campaigning for change.** In order to ensure that no one has to care alone, there needs to be real change in the way that carers are valued and supported. The carers movement has achieved a lot over the past 50 years, but a lot more needs to be done to make it possible for carers to look after loved ones without putting our own lives on hold.

For more information about Carers UK's 50th Anniversary year, please visit: carersuk.org/alone

Contact

Shona Cleland, Policy, Research and Public Affairs Officer
T: 020 7378 4930 E: shona.cleland@carersuk.org

Keep up to date with our campaigns and research:

Web: carersuk.org **Facebook:** facebook.com/CarersUK **Twitter:** twitter.com/CarersUK

Carers UK is a charity led by carers, for carers – our mission is to make life better for carers.

- **We give expert advice**, information and support
- **We connect carers** so no one has to care alone
- **We campaign** together for lasting change
- **We innovate** to find new ways to reach and support carers

Carers UK

20 Great Dover Street, London, SE1 4LX

T: 0207 378 4999

E: info@carersuk.org

Carers Wales

River House, Ynys Bridge Court, Cardiff,
CF15 9SS

T: 029 2081 1370

E: info@carerswales.org

Carers Scotland

The Cottage, 21 Pearce Street, Glasgow,
G51 3UT

T: 0141 445 3070

E: info@carerscotland.org

Carers Northern Ireland

58 Howard Street, Belfast, BT1 6JP

T: 02890 439 843

E: info@carersni.org

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London, SE1 4LX.

© Carers UK January 2015