

CARERS AT BREAKING POINT

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Key UK findings

Key UK findings

6 in 10 carers have been pushed to **breaking point**

A quarter of those who had reached breaking point **required medical treatment as a result**

Almost half

46%

said they had **fallen ill** but just **had to continue caring**

1 in 9

said the person they cared for had to be **rushed into hospital, emergency care or that social services had to step in** to look after them while the carer recovered.

1 in 5 were **forced to give up their jobs** because they were in crisis

Introduction

Caring for an older or disabled loved one can take a serious toll on carers' mental and physical health, their personal relationships and family finances. Without the support they need, this can lead to carers' collapsing through exhaustion, suffering physical injury or becoming overwhelmed by stress and anxiety.

This research sets out the findings from Carers UK's State of Caring Survey 2014, examining the experiences of over 5,200 carers – asking if they have ever reached breaking point, the causes of crisis and what support would have prevented it.

Their experiences show that insufficient support from health and social care services is leaving carers isolated, burnt-out and unable to look after their own health.

The consequences of carers' health breaking down can be devastating. Carers UK has heard from carers who have collapsed and been admitted to hospital alongside the person they cared for, or who have been forced to refuse essential medical treatment for themselves because they cannot find replacement care to look after an older or disabled loved one. Others have been forced to quit their jobs when it all became too much, but have then had to resort to using up their savings or even selling their homes to cope financially.

On top of the personal impact of breakdown on carers and their families, there are serious risks for overstretched health and social care services and our wider economy. With a rapidly growing number of families taking on caring responsibilities and an even more rapid increase in the number of carers caring round-the-clock. But at the same time, social care and NHS services face unprecedented demographic pressures and the Government continues to make sharp cuts to social security.

This divergence between reducing support and families' growing need is unsustainable. This report shows that, unless urgent action is taken we will see even greater numbers of carers pushed to breaking point, at great cost to family life, public services and our economy.

Evidence

This report is based on responses from over 5,200 carers to Carers UK's 2014 State of Caring survey. The majority (84%) were caring, full-time, for more than 35 hours a week. The results reflect the responses of carers from across the UK (81% from England, 10% from Scotland, 7% from Wales and 2% from Northern Ireland).

“

I have suffered physical injury during caring. My mental health is suffering. I am an emotional wreck. I do not have any friends or social life: none, zero. I am trapped in this role and do not see any way out.

”

“

When you love someone you go on regardless. You have no choice, even when you know it is damaging your health and emotional wellbeing. Without help, I will soon get to the point where I cannot continue.

”



The causes of crisis

The causes of crisis can be complex and often carers' complicated lives include a range of stresses and pressures which come together to push carers over the edge.

Whilst there are often a variety of factors which contribute to carers reaching breaking point, there are some clear themes which emerge from carers' experiences. Most commonly mentioned by respondents were exhaustion, physical strain and a lack of support leaving carers' unable to look after their own health or even to seek vital medical treatment.

Physical health

Providing hands-on care can be extremely physically demanding – requiring lifting and turning of the person needing care, helping them move around the house, into and out of bed and support in the bath or shower. Carers often report that health and safety would prohibit care workers from providing this kind of care single-handed, and trying to do so without the support, equipment or training needed can result in strain and injury for carers.

This kind of manual care is also physically exhausting, and it is often combined with a chronic lack of sleep as carers need to get up in the night to help the person they care for use the toilet, to turn them in bed, respond to seizures or choking or administer medication. It is not just physical care that takes a toll; carers caring for someone with a mental health condition, learning disabilities or cognitive conditions like dementia also talk about the exhaustion which comes from being constantly vigilant, never having any 'down time' or responding to challenging or repetitive behaviour. A common theme for carers of people with dementia or those supporting someone with a learning disability was disrupted sleep as they needed to constantly wake up to get the older or disabled person to return to bed if they wander or grow distressed in the night.

Whilst injury, strain and a lack of sleep are common amongst all carers, they are much higher amongst carers who reported reached breaking point:

- Half had suffered a physical injury or seen deterioration in their physical health – twice the proportion of carers who said they had not been in crisis.
- 75% said they could not get a good night's sleep, compared to 50% of carers who had not reached breaking point.

“

The problem with providing 24/7 care is that you often suffer from sleep deprivation. My wife and I have to take it in turns during the night to cover the 24 hours for our daughter. There is the stress coming from lack of sleep, but also a lack of exercise and the loss of all social interaction – including between me and my wife.

”

Of those who had reached breaking point

50%

had suffered a **physical injury** or seen a **deterioration in their health**

“

Mum was up all night, every night, slamming doors, shouting and throwing objects around. I just couldn't carry on without sleep.

”

“

My doctor described it as 'burnout' – the next step after chronic fatigue.

”

The most common health conditions cited by carers echo findings from existing research on the impact of caring on carers' health, particularly for carers caring around the clock. The UK Census showed that carers caring for 50 or more hours a week are more than twice as likely to be in bad health than non-carers.¹ The GP Patient Survey in 2013 highlighted the impact of caring on carer health – whilst 51% of non-carers had a long-standing health condition this rose to 60% of all carers and 70% of carers caring for 50 or more hours a week. The survey showed significantly higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression amongst carers.

Without time to recover or seek treatment, these problems can escalate, resulting in a health crisis and the carer either being hospitalised or emergency care services having to step in for the older or disabled person as the carer recovers.

Mental health

Alongside the physical strain and exhaustion of caring, carers report high levels of stress, anxiety, worry and depression. These indicators were far higher amongst those who had been pushed to breaking point:

- 9 in 10 (90%) said they were stressed compared to just over half of those who were not in crisis.
- Almost 8 in 10 (79%) reported anxiety compared to under half of carers who said they were coping.

Caring can result in a range of complex and often conflicting emotions – alongside feelings of love and duty, carers report feeling trapped, desperate and angry at their situation but then guilty about these feelings. With degenerative conditions like Motor Neurone Disease or Parkinson's, carers may also feel they are already grieving for the person and the relationship they feel they have lost. Many worry constantly about the future, particularly parents of disabled children or of partners who know their caring responsibilities will be life-long. Several respondents mentioned suicidal feelings.

These feelings and mental exhaustion can build to crisis point, with respondents saying they had 'nervous breakdowns' which required medical treatment, hospitalisation or emergency care for the older or disabled person to allow the carer to recover.

Nearly two thirds

63%

had suffered from depression as a result of caring.

¹ Census analysis (2013) Carers UK

“

The lifting has left me with constant back pain and arthritis and I eventually had to stop as I had to have a hernia operation.

”

“

I had a heart attack from the stress and worry of it all.

”

“

I feel constantly angry, bitter and resentful. We had a bad relationship already but with dementia, Dad is not a nice person and his behaviour is destroying me. I've had episodes where I've sat and howled.

”

“

One day I couldn't take any more, I was just crying uncontrollably and couldn't function – my family stepped in to look after mum so I could just rest and pull myself together.

”



- Carers who say they have reached breaking point are twice as likely to say they are socially isolated by being unable to leave the house.

Carers also often find that their personal support networks are eroded by caring as they lose contact with friends and family – unable to take time to socialise, pursue their own interests or seek support from others. A lack of understanding of the pressures of caring also has a big impact on carers. When friends or family members do not understand why carers are unable to join social occasions, and embarrassment about the condition of the person needing care can stop them from visiting.

Inadequate support: access to care services, breaks and medical treatment

- One in five carers received no practical support with caring.
- Almost half (46%) of those who have reached breaking point said that they had fallen ill but had been unable to take any time off from caring.

The impact of caring on carers' mental and physical health is often exacerbated by carers going without the practical support they need – being unable to find time to rest, attend medical check-ups or access treatment. Many also report having to 'fight' for support, becoming exhausted by bureaucracy and feeling that no-one is taking responsibility for their case or that health and care professionals do not recognise the pressure they are under.

Two in five carers say that they have been forced to put off treatment because of their caring responsibilities² – unable to find suitable and affordable replacement care or get flexibility from the NHS to access health services around their caring responsibilities. In addition, carers talked about covering up their own health problems as they did not want the people they care for to see the impact that caring has on them.

Health and care services across the UK face huge demographic pressures. In England, rising eligibility thresholds, driven by chronic underfunding of social care services, also mean that, increasingly, only those with the highest needs and little or no savings qualify for support.

Carers feel that the bar to qualifying for support is often set so high that they will have to be at breaking point to qualify for help. They say that if they look like they can carry on coping they will get nothing.

This is borne out by the experiences of those who have reached crisis point and only then have local authority social care services stepped in.

“

I cannot afford to go out but even if I get out of the house I cannot relax as I constantly worry, and then get a call that my husband needs me to have to leave early. You can't enjoy social activities when you are tired and stress and unable to 'switch off from caring'. You keep missing social events and eventually people just stop asking. I resent it.

”

“

I can do nothing for me whilst doing my caring role. Others do not understand what I do. I have had much criticism from family members who think I am a state scrounger.

”

1 in 5

received **no practical support** with caring

“

I carry on – I can't let my mum see me upset or that I'm ill. She's going through enough with her disability.

”

“

I know that I will have been forced to give up my job and be caring 24/7 by the time we qualify for support – I've been told as much by social services.

”

² In Sickness and In Health (2012) Carers Week

Even where families do qualify for social care support, they frequently describe services which are inadequate, unreliable or poor quality. Carers UK's recent research into the impact of care quality on carers showed that, of respondents in receipt of social care, 48% had raised concerns about the quality of care and 29% had ended a service because of concerns about quality.³

The most common complaints are around 'flying visits' from domiciliary care services where care workers did not have the time to complete basic care tasks, the lateness or unreliability of these services, poorly trained care workers and a lack of suitable services for people with complex needs.

Some poor quality of care can also mean that services designed to take the pressure off carers can be counter-productive. Even if they have been able to take time off from caring, inadequate or poorly delivered replacement can result in the older or disabled person being so distressed that neither they, nor the carer, would consider it again in the future.

The situation is also worsening. Social care budgets in England have seen cuts of £3.5 billion in the last four years⁴ and carers who were struggling already are seeing the limited support they receive reduce.

There was a clear correlation between carers who had reached breaking point and those who had seen services cut or a hike in care charges.

- 45% of carers who had reached breaking point had seen their services cut or charges for care services rise.

Financial pressure

Financial hardship was also seen to be a significant contributor to carer breakdown. A loss of income from paid work combined with higher living costs associated with disability had left many carers unsure how they would cope financially in the future or facing the imminent collapse in their family finances.

- 1 in 7 (13%) of carers cannot afford their basic utility bills.
- A third of carers (30%) are in debt.

“

I broke down and only now do social services listen to me and assess us.

”

“

You feel you can't carry on but you just cry, dust yourself off and dig deeper. No one cares, no practical and appropriate care is available and councils only deal with crises they have created themselves due to the lack of appropriate support.

”

“

No care home will take him with complex nursing needs. This means I can't get healthcare for myself that I need.

”

“

I was told his care required two people but that we only got one, so in order for them to do anything I had to be there with her.

”

“

I feel **put through the wringer** by social services. They don't make contact between annual assessments unless I nag them. There is **no one to call in a crisis** and when I do call they often don't get back to me. I feel that me, my husband and my mum are **penalised for managing the bulk of personal care** between ourselves.

”



³ Quality of care and carers (2014) Carers UK

⁴ ADASS Budget Report (2014) Association of Directors of Adult Social Care

- 4 in 10 (39%) were cutting back on essentials like food and heating to make ends meet.

Reduced spending on essentials puts carers' health at risk – with examples of carers feeling constantly cold, turning the heating off when the person they care for is not at home, or reducing their own food intake to ensure they can afford sufficient, or specialist, food for the older or disabled person they look after.

But carers also talk about debilitating money worries taking a toll on their health.

- 45% of all carers report their financial circumstances were affecting their health – rising to 54% amongst those who had reached crisis point.

They also worry deeply about their financial future, particularly if they have given up work to care. Carers UK's State of Caring 2014 report showed that nearly half of carers (44%) who had left work to care said they would not be able to save for a pension and over half (58%) reported that they would not be able to save up to provide for their own care needs.⁵

For those who do not qualify for social care services, the costs of care are high. Families can struggle to afford the care services they need when they are already coping with the financial impact of lost earnings and higher household bills. For some, this means difficult trade-offs between much-needed care services and household bills; for others the cost of replacement care means that taking a break is simply unaffordable.

At the same time as many families are seeing care services cut, Carers UK has also calculated that, by 2018, the Government will have cut carers' benefits by over £1 billion – as Housing Benefit and Council Tax support are cut, thousands face losing Carer's Allowance as a result of disability benefit cuts and carers on means-tested benefits see real-terms cuts in their benefits resulting from below-inflation rises in the benefit levels.⁶

Respondents to our survey were already feeling the effects of these reductions in support, and talked about how cuts, changes and reassessments for disability and carers benefits were a growing source of stress, sometimes desperation, which some felt was tipping them 'over the edge.' Those who faced the biggest reductions, typically to Housing Benefit and support with Council Tax, reported being pushed into unsustainable debt or falling behind on rent or bill payments – unsure how long this could go on.

“

We just want to enjoy what time we have left together and not have to fight for every little crumb the government throws our way. But now we've lost £1,000 a year in benefits because of the 'bedroom tax' and losing Council Tax Benefit. My husband cannot go without the right amount of food for his condition and he cannot be cold so I have had no choice but to cut down myself to one meal a day.

”

“

There is nothing else we can cut back on. The boiler is broken so we are freezing cold. I buy reduced or unhealthy cheap food from the shops.

”

4 in 10

are **cutting back on essentials** like food and heating to make ends meet.

“

Money is a constant worry and fear. I give myself a pat on the back at the end of each month and just think 'good, I've somehow managed it again'.

”

“

We paid for respite care for a few days so that I could get away, but it was very short and extremely expensive. This means that I can only have time away when I am in extremis.

”

⁵ State of Caring Survey 2014 (2014) Carers UK

⁶ Caring & Family Finances Inquiry UK Report (2014) Carers UK

The consequences of crisis

The short and long-term impact of carer collapse can be devastating. Carers can end up in hospital – often panicking about what is happening with the person they look after, or sometimes in a double admission alongside their ill or disabled loved one.

- A quarter of those who reached breaking point required medical treatment as a result.

Unless emergency plans have been put in place, family members, social care services and the NHS are often left scrambling to put in place emergency care arrangements.

- For 1 in 9 carers who reached breaking point, the person they cared for had to be rushed into hospital and emergency care or social services had to step in to look after the older or disabled person whilst the carer recovered.

Not only does this often cause disruption and distress for the person needing care and huge worry for the carers, but it is extremely costly for emergency services.

Crisis can also result in carers having to make snap decisions which affect the rest of their lives. Carers' experiences included:

- Older or disabled relatives being forced to permanently move into residential care because the carers' health was too fragile to continue caring – despite neither they nor the carer wanting this.
- Carers frequently report being forced to quit their jobs, retire early or resign from university or training courses.
- Some talked about making short-term financial decisions which they knew put at risk their financial security in the future. These included selling their homes, using up savings, taking on debt or taking early lump sums from their pensions because they reached financial breaking point.

Many carers tell Carers UK that 'breakdown is not an option' – they end up in crisis, in hospital for a few days or seeking help from their GP but they are just offered temporary solutions, or no help at all, and have no choice but to continue what are unsustainable caring responsibilities.

“

Prior to leaving my job I had reduced my hours to give more time to caring but I was still very stressed, especially with lack of sleep. Before that I had been signed off with stress twice, once for six months, and eventually it just all became too much.

”

1 in 4

carers who reached breaking point **required medical treatment.**

“

I have reached breaking point repeatedly, the first time I gave up work. The next time I had to demand that social care was increased to give me time off. But then my son was put on medication and later had to go into residential care.

”

Almost half
48% of those who had reached breaking point said they had fallen ill as a result of breaking down, but **just had to continue caring.**

Preventing breakdown

The right support can make a huge difference, and carers often speak about moments of crisis having finally led to NHS or social care services realising the pressure they are under and stepping in to provide more help.

Carers often also talk about family members stepping in to help them when they need it most.

Changing family structures now mean that local support networks of extended family are increasingly rare, so this support is often only a temporary, 'sticking plaster' measure, with family members having taken time off work or travelled long distances to give the carer some time off.

Carers also describe not being able to rely on this kind of help, as relatives and friends have their own families, jobs and caring responsibilities. Relatives' ability to 'drop everything' in a crisis is very limited and carers depending on loved ones can be pushed into crisis by that help falling through.

Furthermore, many carers say they simply have no-one nearby who can help at all.

The longer-term solutions seem to lie in frontline health and social care professionals spotting the warning signs early, and guiding carers to advice, information and support which might prevent crisis.

But advice and information must also result in access to high quality, affordable care services. Carers talk about how their lives can be transformed by good care services – which give them the confidence to take time for themselves, go to work or just to rest without the constant worry of what is happening to the person they care for.

A significant proportion of carers spoke about the difference support from their GPs made – referring them to social care services or counselling, talking through treatment for depression and anxiety and, importantly, recognising them as a patient, not just as a carer.

In addition, support does not just come in the form of health or care services. Carers UK's estimates indicate that £1 billion in Carer's Allowance goes unclaimed each year⁷ – income which could help families worry less about their bills or afford additional care services. A supportive employer who gives time off in emergencies or flexibility around appointments and care arrangement can also reduce the pressure on carers juggling work and care and prevent them falling out of the labour market altogether.

“

I have reduced hours and taken time off from work and will have to do so again in order to continue caring. I am torn between caring, working and being there for my own family. I don't want to care anymore but I have no choice. I will jeopardise my job, health and personal life in the process – I don't know what will happen to me in the future.

”

“

I have been close to breaking point, but I talked to friends and now have a key worker to help organise things and fight for more support when needed which has been very positive for us.

”

“

I was lucky that friends and family rallied round and supported me greatly – when I contacted the local mental health unit to explain the situation they were zero help – offering nothing more to my husband or to me as his carer.

”

“

Trying to work full time (which is necessary!) and look after my father caused me to almost get to breaking point. This is when I was advised to contact social services about direct payments. I have since found out that I could have received direct payments for the past three years due to my father's condition, but nobody advised our family of this.

”



“

We have no other close family to call on. It can make you feel very alone. The two close friends I have could only offer sympathy and no practical help, but they have now also started to care for their own parents.

”

“

My sister, who lives two hundred miles away used to give me emotional support over the telephone. She would take annual leave and look after my mother so that I could take an annual break to recover a bit.

”

£1 billion

in Carer's Allowance goes **unclaimed**
each year

“

During the day we now have support when I'm at work which means I don't get stressed about him falling. Good care workers are a godsend and I can now spend quality time in the evening with him and care for him.

”

“

With a supportive GP, counselling and other outside help, I have been able to carry on, better equipped. I was going through a period of feeling very upset. The time with a counsellor and a short course of sleeping tablets helped me try to re-establish a better sleeping pattern.

”

“

My employer gave me time off to get my life in order and to put in place care for my husband that enabled me to get back to work. That made the difference and stopped me giving up my job entirely.

”

⁷ Caring & Family Finances Inquiry UK Report (2014) Carers UK

Recommendations

Carers UK is publishing a full manifesto for the 2015 election, including the following key measures to address carer breakdown.

1.

An urgent new, sustainable funding for health and social care

We need bold decisions to set out the funding mechanisms which will end cuts to social care, deliver the funding needed to tackle the existing gap between need and supply, improve quality and to keep pace with growing demand in the future.

3.

A duty on NHS and educational bodies to identify and support carers

Too often carers are only identified and supported when they are in crisis. A duty on health and education bodies, like GP surgeries, hospitals, schools and colleges, would ensure earlier identification, advice and support.

5.

Financial hardship must be a core priority of a new national carers strategy

A pledge to end carers' financial hardship was dropped from the Coalition's 2010 refresh of the UK National Carers Strategy. A new strategy is urgently needed, including urgent measures to prevent carers' family finances from reaching breaking point.

7.

Improved access to information and advice

Navigating the complex health, social care and benefits system is stressful and time consuming. Up to date, high quality and carer-specific information and advice about national and local sources of support and advice must be available to guide carers to support.

2.

Quality, flexible and affordable care

Care services should work around the needs of families and not the other way round. Services which allow carers to care alongside work, access leisure and educational opportunities and have a life outside caring. National and local incentives must stimulate the growth in new kinds of care and household services. All those providing health and care services must get the training, terms and conditions which give them the time and skills they need to deliver good care.

4.

Stop cutting carers' benefits

£1 billion in cuts to carers' benefits are pushing families into crisis. Alongside publishing a cumulative impact assessment of the impact of the Welfare Reform Act 2012, Government must ensure all carers' benefits rise with inflation and reverse decisions to cut support with housing costs and Council Tax. The introduction of Personal Independence Payment must be immediately paused and reviewed to assess the impact on disabled people and carers.

6.

A right to care leave

Many carers combining work and caring use up all their annual or sick leave to attend hospital appointments or deal with caring crises. To help prevent working carers being forced to give up their jobs in moments of crisis, we need a statutory right to between five to ten days of paid care leave from paid work and a debate on longer term leave from work to enable carers to care for seriously or terminally ill or disabled loved ones.

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Carers UK Adviceline

For expert information and
advice about caring.



T 0808 808 7777

(open Monday to
Friday, 10am-4pm)



E advice@carersuk.org

Carers UK makes life better for carers.

Caring will affect us all at some point in our lives.

With your help, we can be there for the 6,000 people who start looking after someone each day.

We're the UK's only national membership charity for carers. We're both a support network and a movement for change.

- 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.