Carers at breaking point

Making the case for carers’ breaks in England
## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>03</td>
<td>Foreword from Helen Walker</td>
</tr>
<tr>
<td>04</td>
<td>Executive summary</td>
</tr>
<tr>
<td>06</td>
<td>Carers’ experiences of breaks</td>
</tr>
<tr>
<td>06</td>
<td>The impact of taking a break</td>
</tr>
<tr>
<td>08</td>
<td>A life alongside caring</td>
</tr>
<tr>
<td>10</td>
<td>Barriers to taking a break</td>
</tr>
<tr>
<td>12</td>
<td>Postcode lottery of access to and funding for carers’ breaks</td>
</tr>
<tr>
<td>12</td>
<td>The Better Care Fund</td>
</tr>
<tr>
<td>13</td>
<td>Spending on carers’ breaks</td>
</tr>
<tr>
<td>15</td>
<td>Carers’ access to breaks</td>
</tr>
<tr>
<td>16</td>
<td>Recommendations</td>
</tr>
<tr>
<td>18</td>
<td>About the research</td>
</tr>
</tbody>
</table>
Foreword from Helen Walker

On behalf of the millions of people providing care across England, Carers UK is campaigning for increased breaks. Carers have a right to have a life alongside their caring responsibilities and they need to be able to take time for themselves and to look after their own mental and physical health. Having a break is a fundamental part of human life and human rights. Can you imagine, as a worker, never having time off? It can feel like that as a carer if you don’t get the right support.

The 2011 Census found that there are 5.4 million carers in England, 1.3 million of whom are providing over 50 hours of care a week. However, recent polling by Carers UK suggests that the total number of adult carers in England may now be as high as 7.3 million, meaning 1 in 6 of the adult population could be providing unpaid care to a family member or friend.

Even though carers’ contribution to the economy can be valued at £132 billion a year, 3 in 4 carers don’t feel their caring role is understood and valued by their community1. Carers UK’s State of Caring 2019 report showed that 45% of carers expect their quality of life to get worse over the next year, compared to only 11% who expect it to get better. Access to high quality breaks is a vital part of improving carers’ quality of life, valuing the support they provide to family and friends and preventing deterioration of their own health in the longer term. Catching up on chores, doing the weekly shop, going to see the doctor, would you call that a break? Well that is how carers are spending their precious breaks time – not recharging their batteries – but just doing the basics.

The 2014 Care Act included for the first time a principle that local authorities in England have a duty to promote the well-being of carers from a physical, emotional and mental perspective. However, increasingly squeezed local authority budgets and unprecedented funding pressures on social care mean that many carers are left without support and are not able to feel the benefit of this landmark change in legislation five years later. This year, 1 in 8 carers reported that they, or those they support, received less care or support services during the previous year due to a reduction in the amount of support from social services, a trend that has continued over the last few years2.

Carers UK has welcomed recent funding increases to local authority social care budgets in the Chancellor’s Spending Review but it remains unclear what, if any, impact this will have on carers.

This research report builds on Carers UK’s State of Caring 2017 report which found that 4 out of 10 carers (40%) said they hadn’t had a day off for more than a year. The survey also found that carers who hadn’t taken a break from caring within the last year were more likely to report that their mental or physical health had suffered as a result of caring. When asked about what would make the most difference to improving their health and well-being, regular breaks from caring was the most popular choice.

Quality really matters for carers and the people they care for – worry, poor experience and an inability to find the right care because the provider market is collapsing all impact on carers’ ability to take a break.

This research also comes alongside work Carers UK did earlier in 2019 with the Social Care Institute for Excellence to provide guidance for commissioners and providers of breaks as well as new help and advice resources for carers looking to access breaks.

Having heard from carers about their differing experiences across the country, Carers UK undertook this research to further investigate what having a break means for carers. In addition we examined the funding situation through a Freedom of Information request to local authorities and clinical commissioning groups. This report includes these findings as well as case studies from carers.

I hope that the recommendations in this report are followed and many more carers are able to get the breaks they need in the future.

Helen Walker
Chief Executive, Carers UK

1 Carers Week (2016) Building Carer Friendly Communities
2 Carers UK (2019) State of caring 2019
The stories of carers like those featured in this report show that many people are at breaking point and need time off from their caring role to do activities which most other people take for granted. Imagine being on call all the time, on duty, never getting a night’s sleep, no time to yourself or proper time with family or close friends. This is the reality for many carers because of the shortage of good quality breaks, and a lack of funding for health and social care. This report also indicates that an unfair postcode lottery currently exists in England, with access to breaks and funding varying drastically across the nation.

Executive summary

The stories of carers like those featured in this report show that many people are at breaking point and need time off from their caring role to do activities which most other people take for granted. Imagine being on call all the time, on duty, never getting a night’s sleep, no time to yourself or proper time with family or close friends. This is the reality for many carers because of the shortage of good quality breaks, and a lack of funding for health and social care. This report also indicates that an unfair postcode lottery currently exists in England, with access to breaks and funding varying drastically across the nation.

Key findings

Experience of breaks

- Only 8% of carers felt that they had been able to take sufficient breaks
- 46% said they had not been able to take any breaks even though they would have liked to
- 50% of carers would use their break to catch up on sleep
- 33% of carers would use their break to attend their own medical appointments
- 38% of carers who haven’t been able to get a break said that they cannot afford replacement care
- 52% of carers would use their break to spend time with other family and friends
of local authorities reported spending a smaller percentage of their Better Care Fund budget on carers’ breaks in 2017/18 compared to 2016/17

£0-£6m

Some local authorities spend no money at all from their local Better Care Fund budget on carers’ breaks and others spend as much as £6 million.

78% of local authorities

69% of CCGs

Key recommendations

• The funding for carers’ breaks available to CCGs and local authorities through the Better Care Fund should be at least doubled from £130 million to £260 million in 2020/21, trebled in subsequent years as well as ring-fenced for this purpose.

• Local authorities must make breaks a key part of their preventative work and ensure that carers are able to access them.

• Carers’ breaks provision needs to be at the heart of the health and social care system in the short and longer term, including in continuing healthcare.

• Outcomes and resulting programmes from the Prevention Green Paper need to have carers’ breaks and support clearly included.

• Breaks should be part of a core strategy to prevent loneliness and social isolation.
Carers’ experiences of breaks

Just over 1,000 current and recent carers, the vast majority of whom were providing high numbers of hours of care every week, responded to a Carers UK survey asking them to share their experiences of accessing carers’ breaks.

We first asked carers if they had been able to take a break from their caring role in the last five years. Only 8% of carers felt that they had been able to take sufficient breaks and 39% said that although they had been able to take a break, they would have liked to have been able to take more.

Shockingly, 46% of respondents said they had not been able to take any breaks even though they would have liked to. 8% of respondents had not been able to take a break but didn’t want to.

The impact of taking a break

Carers who had been able to take a break were asked about the impact this had on them. Almost 7 in 10 carers (69%) said that the break had a positive impact with their health and well-being improving as a result. This echoes findings from Zarit et al (2014) about the measurable positive impact that use of an adult day service had on the stress levels of carers.

5% of respondents to the Carers UK survey said their health and well-being worsened as a result of taking a break and 27% said the break had no impact on their health and well-being. For those carers whose break worsened/didn’t have any impact on their health and well-being, this was most often because of poor quality replacement care, the break being too short or their unhappiness at returning to the caring role following the break.

Carers told us that over the last 5 years:

- 8% had been able to take sufficient breaks
- 39% had been able to take a break but would have liked to take more
- 46% had not been able to take any breaks even though they would have liked to
- 8% had not been able to take a break but didn’t want to

3 Zarit et al (2014) The Effects of Adult Day Services on Family Caregivers’ Daily Stress, Affect, and Health: Outcomes From the Daily Stress and Health (DaSH) Study - The Gerontologist Vol. 54, No. 4, 570–579
I was anxious all the time, worrying if my mum was being looked after OK by the private care workers.

Though I enjoy the break, I know I have to return to the same situation. It is only a very short temporary change in my life. I do look forward to it though.

It was absolutely imperative for my mental health that I was able to get away from my caring responsibilities and is absolutely essential that every carer has this.

Taking a break makes me feel like I am more my own person and I am worthy of some me-time, giving me time to process the difficulties in my life and work on managing my mental health and exercising.

Without these breaks, I would not have survived – physically, emotionally and practically. But even when I do take a break, it’s often just to catch up on chores and to keep my own life ticking over. I never really feel like I completely wind down and relax.

Carer’s story
Neeraj, 50, from Southampton

“It all started seven years ago, back in 2012. I was working in the USA as a Dental Hygienist and after my wife and I married I decided to come to the UK to help her care for her family, who were in dire need of help and support. I decided to sacrifice my profession and opted for a whole new life being a support worker and unpaid carer.

“Between us my wife and I care round the clock for both her parents, age 83 and 78, and her brother, 50. My mother in-law developed arthritis, has limited mobility and is unable to do much at home. My father in-law is doing better and has some independence, but can’t do anything round the house. In the past my brother in law relied on alcohol and sometimes became violent, but with our constant support he is doing much better. Every day we work hard to keep the family together and ensure everyone is happy. I have even learned Gujarati so I can speak with my wife’s parents!

“But juggling care for my family and my job as a support worker, I haven’t had been able to take a proper break at all in the last seven years. Not having any friends or family nearby means we’re unable to take time off. I can’t invite anyone to the house and there is no time to go out. My wife and her family haven’t even met my family yet as we can’t get away. I find the clients I work with are often my main source of social interaction.

“I will cancel my own medical appointments when another family member needs something that day. My wife and I would love to have children and are trying to progress IVF treatment, but that means travelling to Bristol for a few days and we just can’t afford to leave the family for that long. If we were able to take a break we would be able to pursue the IVF treatment more fully. I would love the opportunity to see and experience new places with my wife where we don’t have to worry about what would happen to my in-laws and my brother in-law while we’re away.”
A life alongside caring

Carers who hadn’t been able to take a break but would have liked to were asked what they would do with this time. Taking part in hobbies and leisure activities such as going to the cinema or reading was the most popular choice with 63% of respondents choosing this option. The full list of things carers said they would do with their time included:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking part in hobbies and leisure activities</td>
<td>63%</td>
</tr>
<tr>
<td>Spending time with other family and friends</td>
<td>52%</td>
</tr>
<tr>
<td>Catching up on sleep</td>
<td>50%</td>
</tr>
<tr>
<td>Pampering themselves (eg getting a haircut or massage)</td>
<td>38%</td>
</tr>
<tr>
<td>Completing practical tasks (eg housework)</td>
<td>37%</td>
</tr>
<tr>
<td>Attending their own medical appointments</td>
<td>33%</td>
</tr>
<tr>
<td>Studying or attending training</td>
<td>22%</td>
</tr>
</tbody>
</table>

63% of carers would use their break to take part in hobbies and leisure activities

52% of carers would use their break to spend time with other family and friends

50% of carers would use their break to catch up on sleep

38% of carers would use their break to exercise
However, when asked about the same categories of activity, carers who had taken a break in the last few years answered differently about how they had actually spent their free time.

This shows that carers’ access to breaks affects their ability to complete essential tasks that others may take for granted. 68% of respondents said that they used their break to spend time with other family and friends, showing how important breaks are to ensuring carers are not lonely or socially isolated. The full list of ways in which carers had actually spent their time included:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spending time with other family and friends</td>
<td>68%</td>
</tr>
<tr>
<td>Completing practical tasks (eg housework)</td>
<td>47%</td>
</tr>
<tr>
<td>Taking part in hobbies and leisure activities</td>
<td>47%</td>
</tr>
<tr>
<td>Catching up on sleep</td>
<td>45%</td>
</tr>
<tr>
<td>Attending their own medical appointments</td>
<td>44%</td>
</tr>
<tr>
<td>Pampering themselves (eg getting a haircut or massage)</td>
<td>37%</td>
</tr>
<tr>
<td>Exercising</td>
<td>30%</td>
</tr>
<tr>
<td>Studying or attending training</td>
<td>9%</td>
</tr>
</tbody>
</table>

Many of these tasks are fundamental to carers’ ability to live their lives as well as maintain their health and well-being. Attending a medical appointment is hardly a break, yet this is how carers are spending their precious time off.

It’s very hard being a carer. I feel I’ve lost myself at times. I love my daughter but I have no life.

I make appointments for essential medical needs but cannot find sitters or dare not leave my husband even for a short time and so have to cancel.

When I’m caring, it’s impossible to leave the house to take exercise and there isn’t enough room for something like an exercise bike. It is a stressful, demanding and sometimes downright scary job but it’s important to appear calm and cheerful at all times – even though I sometimes want to scream in frustration or just sob. Often I’m totally wiped out from only a few hours sleep a night.

I am able to do things like go for a walk, read a book and complete craft tasks but there are times when I could do with a longer rest. Being able to afford the right kind of supported holiday, where the person I care for could come too, would be ideal.

I feel worn out and don’t know how much longer I can go on without respite care.

33% of carers say they *would* use their break to attend their own medical appointments

But of those who had actually taken a break in the past few years, nearly half had used their break to attend their own medical appointments.
**Barriers to taking a break**

Carers who hadn’t been able to take a break were asked for further details about why they hadn’t been able to in order to look more at the barriers they face. 40% said that the person they care for is unwilling to accept replacement care. The survey did not ask for further details on this point but this echoes other research from Carers UK about worries carers have about the quality and suitability of replacement care.

Cost was a big issue with 38% of carers saying that they cannot afford replacement care whereas 34% said that they cannot afford to do any activities during the free time.

The full list of reasons included:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person I care for is unwilling to accept replacement care</td>
<td>40%</td>
</tr>
<tr>
<td>Not being able to afford replacement care</td>
<td>38%</td>
</tr>
<tr>
<td>Not being able to afford any activities to do during the free time</td>
<td>34%</td>
</tr>
<tr>
<td>Not knowing how to find out information about taking a break</td>
<td>28%</td>
</tr>
<tr>
<td>Not wanting strangers looking after the person/people they care for</td>
<td>25%</td>
</tr>
<tr>
<td>Replacement care having a negative effect on the well-being of the person they care for</td>
<td>25%</td>
</tr>
<tr>
<td>Lack of availability of replacement care for the complex needs of the person they care for</td>
<td>22%</td>
</tr>
<tr>
<td>Thinking that the quality of replacement that is available is not good enough</td>
<td>19%</td>
</tr>
<tr>
<td>Not being able to take a break from multiple caring roles at the same time</td>
<td>18%</td>
</tr>
<tr>
<td>Being rejected for funding for a break from the council</td>
<td>11%</td>
</tr>
</tbody>
</table>

38% of carers say that they cannot afford replacement care

The area in which I live is extremely deprived, so all services are stretched to breaking point and the standard of care available is appalling. I cannot risk my mother's health and well-being by handing her over to any of the providers that we could afford to employ.

Care homes don't cater for someone with special dietary needs in certain parts of the UK or able to communicate with ethnic minority people.

I have never been offered or had anything mentioned to me about breaks available.

When it’s your husband you are caring for saying you need a break is difficult for them to hear.

The severity of cut backs in our area means the standard of care available does not provide staff that are qualified to deal with complex needs.

Because we live in a rural area we frequently get told care breaks are not available locally. Respite was offered in a care setting more than 100 miles from home with us having to provide transport there and back to make a difference.
Carer’s story
Paul, 62, from Walsall

“I started caring for my Dad, now 95, about 15 years ago. He has extra needs as a result of getting older and struggles to move around his home nowadays. He has an arthritic shoulder and pain in his knees, as well as a long standing heart condition.

“I only live a few minutes away from my Dad and travel to his house early in the morning each day and stay with him for 10 hours, every day of the week. I gave up my job as a shipping exports manager about seven years ago to provide the care he needs.

“I help him with most aspects of life including personal care, cooking and cleaning, and moving around the home – supporting Dad’s independence and quality of life is really important to me. He also has care workers to support him.

“The local care services for Dad have been quite hit and miss so when I leave Dad’s house I never go too far where I can help it.

“It’s not clear from social services how much support they can provide to enable me to take a break. Sometimes they can offer half an hour here and there which is helpful, but it would be great to have more time to unwind.

“The nature of my caring role means I am no longer able to get out and see my friends, and I’ve had to stop playing tennis which was one of my greatest joys.

“My caring responsibilities for Dad are such that I also only get four to five hours’ sleep every night which takes its toll. Just some time to catch up on sleep would be nice.

“I appreciate being able to take half an hour here and there when Dad’s care workers are with him but it would be brilliant to take a few days to take part in sports or enjoy time with my girlfriend.”
The Better Care Fund

The Better Care Fund (BCF) is a programme across both the NHS and local government, first introduced in 2013, which seeks to join-up health and care services to improve people’s experiences of health and social care and support them to live independently for as long as possible with a good quality of life.

The BCF operates as a pooled budget between local authorities and CCGs and can be managed by one or both of these organisations, which was why both types of organisation were asked to respond to the FOI request. Ever since its incarnation, the BCF has included £130 million national funding for carers’ breaks which comes through the CCG minimum allocation of the pooled budget. This method of national funding for carers breaks was originally introduced in the 2008 Carers Strategy.

The Better Care Fund planning requirements for 2017–19 stated the following:

“The CCG minimum allocation to the BCF also includes, as in 2016–17, £130m of funds previously earmarked for NHS replacement care so that carers can have a break. Local plans should set out the level of resource that will be dedicated to carer-specific support, including carers’ breaks, and identify how the chosen methods for supporting carers will help to meet key outcomes.”

Importantly, these planning requirements require BCF plans to set out the level of resource for carers’ support, but not to specifically set out the level of resource for carers breaks so this is not always included within plans making it difficult to hold budget holders accountable.

The FOI request did not seek to provide a full analysis of local spending on carers’ breaks, instead it looks at

Carers UK conducted a Freedom of Information (FOI) request with local authorities and clinical commissioning groups (CCGs) across England, the results of which indicate that there is a postcode lottery of support for carers with an unfair and unequal provision of breaks services across the nation.

Postcode lottery of access to and funding for carers’ breaks
the effectiveness of the Better Care Fund as the national Government’s funding stream for carers’ breaks. As such, this research does not provide detail on individual areas, instead focusing on the national picture and the differences within this.

**Spending on carers’ breaks**

Out of 98 local authorities and 18 CCGs who responded to the FOI request and were appropriate to include in the report4 there was huge variety in the amount that different areas spent on carers’ breaks in the year 2017–18, both in terms of absolute figures and as a percentage of their overall Better Care Fund budget.

A quarter of local authorities and a sixth of CCGs were unable to say how much they were spending on breaks from the Better Care Fund indicating that there is a real issue with transparency and accountability of how this funding stream is being spent. A small minority (3 local authorities and 3 CCGs) reported not spending any of their BCF income on carers’ breaks despite the requirement to do so.

---

4 See ‘About this research’ section for inclusion criteria

---

**Carer’s story**

Anonymous

“I care for my daughter – now 30 – who has Down’s Syndrome, is profoundly deaf and with vision impairment. My daughter’s communication processing skills are delayed and her mobility poor, which makes it tricky for her to move around. I adopted my daughter when she was six months old and I have cared for her ever since. It’s been incredibly difficult working with some health and social care professionals over the years. Most of the time I feel they don’t understand my daughter’s needs or recognise my role as her carer. Getting a break from my caring role has been extremely difficult, apart from the odd time extended family who live far away from us have been able to help.

“There is no suitable respite care available in my area. My daughter receives a direct payment package but I’m unable to spend it because there isn’t the quality or level of care available that will meet her needs. The services in our area seem more focused on elderly and dementia care, which just isn’t right for her.

Learning and Development support is still the undervalued Cinderella care service.

“Not being able to take any time out from caring means I struggle to get to my own medical appointments. There are some appointments I would rather attend without my daughter as I don’t feel it’s always appropriate for her to come along. But I cannot do this. Recently I discovered my overall general health had deteriorated. The hospital consultant said I needed to have a CT scan, to help understand the extent of the issue, but I knew if the medical team used the contrast dye it may affect my ability to care for my daughter. So I just didn’t have the CT scan with the dye. How could I receive the subsequent treatment if I needed to anyway?

“There is no flexibility in life and there is no chance of being spontaneous, or last minute as everything has to be planned to the last little detail in advance. This can feel at times, not always, like being caged. It would be lovely to be me, just me, and put me first. For one small moment of time, for my life to be catered to my needs, because I matter too.”
As an absolute amount the highest spending local authority spent over £6 million and the highest spending CCG spent just over £1 million from their BCF funding on carers’ breaks compared to the lowest spending who spent nothing. When carer population size in each local authority is accounted for, there is still a huge difference with the highest spending £97.25 per carer and the lowest spending nothing. From their BCF budget, local authorities spent an average of £19.47 per carer on carers’ breaks.

The average percentage of their BCF funding which a local authority spent on carers’ breaks was 1.55% however one local authority spent as much as 8.44% of their BCF budget on this. For the CCGs the average percentage of their BCF budget spent on breaks was 1.06%, but again there was huge variety with one CCG spending 3.03% of their budget on this. If the current funding is to be used for this desired effect, the spending requirement needs to be ring-fenced to protect it and to ensure consistency despite the different areas of the country carers happen to live in.

32% of local authorities said that this was their only spending on breaks which further underlines how valuable this funding source is for local authorities and how important it is that it is maintained. However, 61% of local authority respondents stated that they spend money outside of the BCF budget on breaks and 7% didn’t give an answer to this question.

Respondents were also asked to comment on how their spending through the Better Care Fund changed from 2016–17 to 2017–18. 78% of local authorities and 69% of CCGs reported spending a smaller percentage of their Better Care Fund budget on carers’ breaks in 2017/18 compared to 2016/17. Whilst this decrease in spending could be due to the fact that almost all areas saw their Better Care Fund budget increase following the introduction of the Improved Better Care Fund (IBCF) in that year, these results still indicate that this further funding is not being directed towards carers’ breaks.

---

5 Figures taken from the 2011 census – these do not necessarily represent the number of carers the local authority supports due

6 An additional funding stream included in the Better Care Fund from 2017/18 onwards to many carers not being identified or not using council services.
Carers’ access to breaks

The FOI request also asked local authorities to report on how they ensure carers are informed about breaks available to them. The results further underline the postcode lottery that exists with a wide variety in how carers are able to access breaks across England and how they can find out what is available in their area.

When asked about how they advertise breaks to carers, almost all local authorities said that this information is provided online on their website. Most respondents also reported a combination of advertising through a commissioned carers service and through social care staff where the cared for person was known to the council. Some local authorities further advertise through other publication channels such as information packs in GP surgeries, signposting from voluntary sector partners and in one area there is an app that carers can download.

However, in some areas, the only way to access or find out about breaks is through the formal carer’s assessment process. This is particularly worrying given that only 27% of carers reported having an assessment in the last 12 months in the State of Caring 2019 report. One local authority reported that their short breaks service had recently closed meaning that the only option for carers was a direct payment after an assessment.

Given this huge variety, it is unsurprising that carers report difficulty in finding out what is available locally and in many instances simply do not know what is available or how to access it. Deciphering the health and social care system is complicated enough for people with care needs and their families without the added complication of an inability to find out what is available locally.

Carer’s story

Geoff, 71, and Jean, 67, from St Helens

“My wife Jean and I have been married for more than 40 years. In 1999 Jean was diagnosed with multiple sclerosis and as her condition has progressed she has had more difficulty with her balance and walking. Jean now uses a wheelchair and is tetraplegic, meaning she isn’t able to use her arms or legs.

“The nature of Jean’s condition means she needs round the clock care – much of which I provide with the help of care workers, who visit every weekday morning for three hours to help get her up, showered and dressed, then for an hour in the evening to get her into bed. We also have support from care workers during the day.

“Jean’s care was initially funded through direct payments and the Independent Living Fund, then five years ago we received a Continuing Healthcare Assessment which has helped us both enormously. It was carried out thoroughly and looked clearly at Jean’s needs but also mine, and I felt able to contribute to the plan. The care package provides Jean with the right support, giving her independence and enabling her to maintain relationships with her friends. It also allows me to look after my own health and well-being, giving me breaks to keep mentally and physically fit and also stay connected within my community. The support means I can keep up my interests alongside caring for Jean.

“The overnight care she receives three days a week, from 10pm to 7am, really helps me. Care workers are there to listen out for Jean in case she needs help which she often does and several times during the night. This support means I can get a good night’s sleep and rest in the knowledge that Jean is safe and being well looked after.

“Our care package enables us both to lead fulfilling lives and gives me the opportunity to have my own life alongside caring.”
Recommendations

Urgent change is needed to ensure that carers are able to get the breaks they need and deserve.

Funding for carers breaks needs to be increased, ring-fenced and made more transparent to ensure that many more carers are able to take a break

• The funding through the Better Care Fund available to CCGs and Local Authorities should be at least doubled from £130 million to £260 million in 2020/21 and trebled in subsequent years.

• This funding should be ring-fenced – this would ensure it does not get lost within local budgets and it is used for the intended purpose.

• Councils and CCGs should have to report their planned spending on carers’ breaks within their Better Care Fund plans to strengthen the spending requirement.

Local authorities must make breaks a key part of their preventative work and ensure that carers are able to access them

• Local authority health and well-being boards should enquire what support is being offered to carers in their area and if the Better Care Fund income is being used as intended.

• Local authorities must ensure that carers are made aware of how to access breaks in their area through advertising campaigns. This should include targeted support for those who struggle to get breaks, for example parent carers and those who self-fund caring services.

• Local authorities must give specific consideration to carers’ need for breaks and short term replacement care in the development of the local care services market.

• Commissioners and providers of carers’ breaks should make use of the best practice guidance produced by the Social Care Institute for Excellence to inform their planning.

• Commissioners of breaks need to look at the equalities aspects of their breaks provision to ensure that marginalised groups, including those with complex disabilities, are not excluded from breaks.
Carers' breaks provision needs to be at the heart of the health and social care system in the short and longer term

• National government must ensure that the upcoming social care funding solution includes an acknowledgement of carers' need for breaks to look after their own health and well-being alongside a substantial increase in funding through taxation so that care and support is free at the point of use.

• Carers' health and well-being, as well as the health and well-being of the people they look after, needs to be given consideration in the roll out of the NHS Long Term Plan.

• NHS England should require sustainability and transformation partnerships (STPs) and integrated care systems (ICSs) to ensure that carers' health and well-being is factored into plans for improving population health.

• Public Health England to see caring as a determinant of health and act accordingly to target support.

• It is regrettable that carers are currently omitted from the Green Paper on Prevention and any outcomes and resulting programmes relating to prevention need to have carers' breaks and support clearly included.

• High quality replacement care services must be available at the point of need across the country.

• Breaks should be part of a core strategy to prevent loneliness and social isolation.
About the research

About the Carers UK Breaks Survey

A total of 1,041 respondents in England responded to this survey between 18th December 2018 and 7th January 2019. Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

- Of respondents to the survey:
  - 80% identify as female and 19% identify as male
  - 25% consider themselves to have a disability
  - Less than 1% are aged 18–24,
    - 4% are aged 25–34,
    - 13% are aged 35–44,
    - 30% are aged 45–54,
    - 37% are aged 55–64,
    - 11% are aged 65–74 and
    - 3% are aged 75 and over.
    No carers aged under 18 took part
  - 4% are lesbian, gay or bisexual
  - 19% also have childcare responsibilities for a non-disabled child under 18
  - 34% are in paid work (41% full-time and 59% part-time)
  - 30% have been caring 15 years or more, 17% for between 10–14 years, 25% for 1–4 years and just 3% have been caring for less than one year
  - 50% care for 90 or more hours every week, while 19% care for 50–89 hours, 22% for 20–49 hours and 9% care for 1–19 hours a week
  - Most (72%) care for one person, 20% care for two people, 6% for three people and 2% care for four or more people.

As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented in this Appendix, are based upon responses from fewer than 1,041 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

About the Freedom of Information Request

The request was sent to local authorities (LA) and clinical commissioning groups (CCG) in December 2018 and responses were received between December 2018 and February 2019. Responses had to satisfy 2 criteria to be included in order to be considered:

The LA/CCG had to say that they were the host body of some or all of the local arrangements regarding the Better Care Fund were considered.

The LA/CCG had to provide the information in a reasonably easy to access format – eg if the researcher couldn’t find the information in the web links given by the LA/CCG this would have been disregarded.

Together these two criteria meant 106 CCG responses and 24 LA responses were not analysed.
Carers UK’s
Give us a Break campaign

This report is part of a wider campaign to increase access to breaks for carers across the UK.

Every week millions of carers are providing unpaid care for their family and friends, often without support and without a break to look after their own needs. Urgent change is needed to ensure that carers are able to get the breaks they need and deserve.

To find out more about our campaigning work, please visit carersuk.org/campaigns
Across the UK today 6.5 million people are carers – supporting a loved one who is older, disabled or seriously ill.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person's health, finances and relationships.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.