



In Sickness and in Health

A survey of 3,400 UK carers
about their health and well-being



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Introduction

There are an estimated 6.4 million people in the UK¹ currently caring for a child, friend, neighbour, partner or parent or a combination of these. Carers look after family and friends who are disabled, frail or ill. They work alongside professionals, volunteers, care homes, special schools and community groups often caring for people in their own home. The hours of care that they provide for ill, frail or disabled people often comes at a cost to their own health and well-being. The impact on a carers' health and well-being, finances and relationships cannot be underestimated.

In the run up to this year's Carers Week² a partnership of eight charities set out to explore through an online survey, the impact of caring on carers' health and well-being. In addition, the charities wanted to explore the extent to which carers were able to access services and if the cuts to social care were having an effect.

The following are the findings of the survey of nearly 3,400 carers and their experiences. It concludes with recommendations from the eight charity partners and a call to action for the four governments of the UK.

Key findings and recommendations

- **84 per cent** of carers that responded to the survey never expected to be a carer.
- Carers stated that caring had a negative impact on their physical health (**83 per cent**) and mental health (**87 per cent**).
- **39 per cent** have put off medical treatment because of caring.
- **37 per cent** of carers aged 18 to 64 years old had to cease working because of their caring responsibilities.

Carers also identified the factors they believe have impacted on their physical and mental health:

- **64 per cent** identified a lack of practical support as being a contributing factor and
- **50 per cent** stated that a lack of financial support had had an impact.

Cuts to public spending are also having an impact on carers and causing additional stress and anxiety:

- **26 per cent** of carers that responded to the survey reported that they had already experienced cuts to their services.
- **40 per cent** of carers also reported that the stress of waiting for financial and practical support had an impact.

The survey shows these changes to services are impacting negatively on carers' health, ability to work, afford services and so on. The Carers Week charities are calling for the following in order to take action on carers' health and well-being:

- Sustainable funding for social care;
- Ongoing support and breaks from caring;
- Timely and appropriate support for carers from their GP.

¹ Carers UK *Valuing Carers. Calculating the value of carers' support* (2011)

² Carers Week is an annual UK-wide awareness campaign. In 2012 it is a partnership of eight national charities – Age UK, Carers Trust, Carers UK, Independent Age, Macmillan Cancer Support, Marie Curie Cancer Care, MS Society and Parkinson's UK. It is also sponsored by Sainsbury's and Skills for Care/Skills for Health.

I. Caring impacts on health

The people who responded to this survey are a diverse range of individuals and families offering up hours of their time for days, weeks, months or years to care for a disabled, ill or frail relative, partner, friend or neighbour (see Methodology for breakdown, page 15). For some this role may have been expected; an inevitability they identified as their parents grew older. However, **84 per cent** of the respondents to this survey said they had never expected to become a carer: the shock of the news that your partner has terminal cancer or has been diagnosed with Parkinson's, that your parent has early onset dementia, that your child has autism or that your best friend has been involved in a road traffic accident is not something anyone can prepare for.

Nothing prepares anyone for, now let's see: giving up your working life, pressures on family ties, impact on your own life/time to myself! My health!... and yes, the time. However, I am positive and keep trying to be so.

Although I was prepared for the commitment I wasn't prepared for the long-term effect on my life. The lack of money, the health issues and the lack of understanding from family and friends.

As carers embark on this new role and relationship with the person (or people) they provide care for they are faced with a massive learning curve. They must understand the needs of the person they are caring for, the services they require, the medication they need and the support available. It is no surprise that carers take a while to think about themselves and what they need and often put the person they are caring for first. However, early identification of yourself as a carer is key so you can access the support, advice and information you need.

Caring for somebody can be very demanding on your time and energy. Dealing with medical professionals, arranging your finances and claiming benefits as well as worrying about the person you look after is stressful. The findings of the survey illustrate that for many people caring can impact negatively on an individual's physical and mental health:

83 per cent of carers stated that caring has had a negative impact on their physical health and **87 per cent** of carers stated that caring has had a negative impact on their mental health.

Sometimes I do feel depressed but you have to carry on because that is what you do.

[Caring] for my three sick children ... has affected my physical as well as emotional health. I have really bad backache, and suffer a great deal of emotional stress, even though I am a very positive person.

There is no doubt that my caring role has affected my physical and mental wellbeing. I have dealt with this by reducing my working hours to reduce stress, and hiring private care workers to supplement free care.

I have had many stressful jobs in my working life, but I have never experienced such stress as caring for somebody with dementia. No matter how rewarding some times are and how much you love the person you care for, there are moments when you wonder why you started and why you continue.

There are risks associated with caring and keeping healthy and well. The strain of lifting and moving people, the stress of providing around the clock care, finding time to exercise, get enough sleep, or get to the shops to buy and prepare a healthy and nutritious meal is not always possible.

The carers we surveyed were affected in the following ways: anxiety or stress (**91 per cent**), depression (**53 per cent**), injury such as back pain (**36 per cent**), high blood pressure (**22 per cent**) and the deterioration of an existing condition (**26 per cent**).

Constant tiredness, insomnia, aches and pains, loneliness, helplessness, etc.

I am now taking antidepressants my health is a lot worse, I am stressed at my work as finding the time and energy to do it is almost impossible.

I now feel at breaking point and if things continue as they are I don't know if I can continue to care for my wife. I am frightened I am going to have a heart attack as I am having difficulty in controlling my blood pressure with medication.

2. Neglecting their own health

Finding time to keep regular medical appointments, meet up with friends or simply relaxing can feel like an impossibility when you are caring for someone. Added to this nearly half of people caring juggle their role with working or volunteering either full- or part-time. Looking after yourself when caring for somebody who may need care 24 hours a day seven days a week is no easy task especially if you already have or develop your own disability, illness or health condition. The carers that responded to the survey reported having the following conditions:

57 per cent of carers reported having a mental health condition such as anxiety or depression, **53 per cent** of carers said they have a long-term condition or illness and **28 per cent** of carers stated that they had their own physical disability.

Fatigue is a major concern, as I suffer MS which includes severe fatigue. Caring makes the condition worse by overwork, caring and worrying about our financial position/getting the help we need.

I always put myself last. I often don't have time to seek medical support for my long term health condition. I know that this will have a long term effect on my health.

I am so worn out just dealing with my son and my dad's conditions that I always put off anything to do with me as I do not have the energy to fit it in. It is the only stuff I can take off my plate so to speak. My son and dad have to be dealt with but I can wait - and do.

Missing medical and dental appointments and regular checkups and screenings can have a damaging effect on anyone. With their caring commitments carers are a high risk group. The survey found that **two out of five** carers had put off medical treatment:

39 per cent of carers have put off medical treatment because of caring. As a result:

- It made the problem worse for **49 per cent** of carers.
- It extended the time for which carers are affected by the problem for **53 per cent** of carers.
- It caused an additional illness for **22 per cent** of carers.
- It stopped or made it harder for **26 per cent** of carers to undertake their caring responsibilities.

Respondents reported delayed diagnoses of cervical cancer, an untreated cough becoming acute bronchitis which affected lung function for eight months, putting off operations to their Achilles tendons and bowels (the latter resulted in the need to remove part of the bowel) as well as tooth loss and decay and many more conditions that may not have developed if carers had sought medical advice and treatment sooner.

I have put off going to see the doctor as I am worried I will need an operation. How am I going to cope then?

I should have an operation but it is so hard to bring everything together, when I managed it my blood pressure was too high to go ahead.

I had to postpone a hysterectomy by five months because the person I was caring for needed treatment for cancer - surgery, radiotherapy, chemotherapy etc.

The worry about having to leave the person you care for to have an operation, receive treatment or attend a regular check up also adds to carers' anxiety and stress. Carers reported in the survey that when they had taken action on their own health they found that there was not the support in place that they needed to make sure they could fully recover. Examples from carers included being discharged from hospital and the alternative care for the person ending at the same time so they did not have the time they needed to recuperate. This could have resulted in carers being readmitted to hospital at additional expense to the NHS.

Carers can be discharged from hospital too soon when there is not enough additional or necessary support at home for them to pick up, once again, their caring role immediately following their own hospital discharge from an illness. I was readmitted due to this.

Carers are storing up problems for the future as they are delaying check ups and medical treatments and not looking after their health. Changes in their behaviour due to taking on a caring role can result in poorer diets, lack of exercise and reduced hours of sleep (which can be a side effect of stress and depression). These can all add to the worsening of an existing medical condition or lead to a deterioration in carer's health.

52 per cent of carers are sleeping a bit or a lot less as a result of caring and **34 per cent** of carers are exercising a lot less as a result of caring.

Carers reported having insufficient time and resources to look after themselves.

Caring takes away any personal independent social life. As an ill carer I find it hard to fit in rest periods, I worry constantly about finances especially with the government clamping down and reducing spending in all areas. Worried there is never anyone to contact should either of us be unable to carry out care to enable us to enjoy some kind of normality. I've worried the whole time I have been a carer – 29 years – particularly about security, the rest we have to had to compromise or do without. Times are getting harder and I've got a progressive illness. What of the future? I dread to think.

The number of hours a person provides care can vary hugely. If people are trying to work while offering care for a significant number of hours a week this additional pressure can also have a negative impact on their health.

3. Caring impacts on work

Caring can take a toll on all aspects of a person's life. As well as impacting on carers' health and well-being, it can also impact on their ability to continue working. Three million people juggle work and caring which comes with its own challenges and fears. Of the people who responded to our survey a higher (**64 per cent**) than average (21 per cent³) number were high end carers providing more than 50 hours of unpaid care a week. Needing and/or wanting to be available all of the time, appointments taking place throughout the working day and high levels of personal care being required by the person you care for results in many carers having to give up work or reduce their working hours.

³ Office of National Statistics *Census 2001* (HM Government, 2001)

37 per cent of carers aged 18 to 64 years old have had to cease working because of their caring responsibilities.

Having to give up my job was the worst of it all because now I cannot find my feet back due to the lack of jobs and my age group.

I cancelled my own hospital appointments in the past as I was unable to take additional time off work for myself. I just had to use my time off to take my mother for her hospital appointments. I had to give up my full-time job as I couldn't do everything.

Few would choose to give up work and it is unlikely that people considered in advance that this would be a choice they would have to make due to caring responsibilities.

56 per cent of carers were not prepared for the impact of caring on their ability to work.

I do not receive any services but would love to be able to work a few hours a week with support for my child. My husband works full-time on a low income and I have no ability to work as there is no one to care for my child when he is away from school due to illnesses, hospital appointments and school holidays. I feel like I have no future as anything other than a carer as he will be dependent for the rest of my life.

For those who continue to work **50 per cent** reported being stressed at work as a result of their caring responsibilities which in turn impacted on their health.

They take the carer for granted and fail to recognise that by withholding the luxury of support in work they add to our depression, isolation and sense of helplessness and instead of recognising our worth, classify us as dependant as the people we are looking after out of love... Work allows you time out from caring and from home, and gives you more income as well as more self respect and a chance of a future and an occupational pension to support you when your caring is finished. We carers are responsible adults who have made hard choices in which we put our own well-being second.

In the workplace, carers also worry about how their role and responsibilities outside of work will be viewed by their employers and colleagues. **One in ten** carers chose not to tell their employer. The reality is that carers should be able to work in an environment that supports them. This can be achieved through formal policies and procedures or informal arrangements and the support and understanding of sympathetic colleagues and managers.

44 per cent stated that caring responsibilities had affected their career progression. Only **one in four** carers stated that they had **not** let their caring responsibilities affect their work or career.

4. Making time for their health

The findings of the survey show that carers are not looking after themselves. However, carers did identify that they were aware that they needed to look after themselves, the problem is that they do not always feel they are able to do so. If people are caring they should let their GP (General Practitioner) know so that they can note it on their medical records. Knowing their patient is a carer, GPs should monitor and check if they are under pressure. They should also offer advice and support as well as diagnose and treat carers more effectively. However, for a number of carers just finding the time to make an appointment or finding someone to look after the person they are caring for in order to attend the appointment proved impossible tasks.

Appointments for my wife come first, I have missed physiotherapy and put off making appointments as don't have time or appointments clash.

NHS and social care professionals such as nurses, hospital staff, district nurses and so on have a role to play in ensuring carers are looking after their own health and well-being. GPs⁴ should know and keep a register of their patients who have a caring responsibility. However, just having a register is not enough, GPs should ensure that it is up-to-date and they use their contact with identified carers as an opportunity to signpost carers to additional support available, particularly carer's assessments from local authorities, but also support from other organisations such as charities and local voluntary groups. The carers that responded to our survey broadly stated that their GP knew they were a carer and many had been in contact with social services:

84 per cent of carers reported that they were known to their GP.

A carer's life can be very busy with much of their attention being on the person they are caring for. Often carers balance the pressures of working and family/social life alongside their caring role but they must not ignore their health needs. Making the time to have a health check is one way carers can look after themselves:

Only **23 per cent** of carers who responded to the survey reported having been offered a health check by their GP.

Of course carers have a role in taking responsibility for looking after their own health but this survey shows that support systems and alternative care are not available or accessible to enough people. It is vital that all those involved in the caring of ill, frail or disabled people look out for the carer's health and well-being too.

Looking after your own health is one of the most difficult aspects of caring which professionals don't seem to recognise or prepare for.

I am more aware of staying healthy because if I don't what will happen to us.

Caring has made me realise that I must look after myself to be able to continue to care for my son. Therefore I'm more focused on exercise and relaxation.

I am trying to take better care of myself. Using exercise to fix my back and lose some weight. Have stopped smoking and drinking partly for health and partly because I can no longer afford it.

5. Why caring can cause stress, anxiety and poor health

Overseeing and managing the practicalities of caring for somebody can be enormous. Finding your way through the benefits system, sourcing quality care provision local to the person you care for and wondering how all this is going to be paid for is very stressful. Added to this there is the problem that a third⁵ of working carers are caring from a distance.

It's the battle for services that is the problem not the person.

I did not realise how much stress it puts on the carer and the effect it can have on your own health.

⁴ There is advice and information for GPs available here about how they can support patients with a caring role www.rcgp.org.uk/professional_development/continuing_professional_devt/carers.aspx

⁵ Employers for Carers Forum/Carers UK *Caring at a Distance: bridging the gap study* (Carers UK, 2011)

I should have sought help at the very beginning but did not know who to turn to when things got worse and was not guided in the right direction.

I don't get any help, I haven't had a holiday, a day off, a day out or a lie in for four years.

Having access to timely and appropriate advice and information is key to looking after yourself as a carer. The early months and years can be a critical time for carers as they struggle in their new role unaware of the support that is available to them or unsure how to request it or if they are eligible. Current Government policy is aimed at the identification of carers at an early stage and making them expert partners in care. Previous studies^{6 7 8} have identified that people looking after individuals do not define themselves as a carer – they simply call themselves a wife, a son, a friend and so on. This often presents a barrier to the carer seeking out formal support to undertake their role.

I often feel under stress as my own mental/physical health and financial situation deteriorates, due to the fact that I am not sure where to access all possible avenues of support and those that I have enquired about have turned out to be mostly 'blind alleys' as I don't fit into any neat little pre-existing categories properly. If I am ill (other than seriously) or unable to cope for any reason, there is seemingly no help available whether practically or financially so I am looking at a very bleak old age.

The survey asked carers to identify what had impacted on their physical and mental health. A lack of practical support was a reason for **64 per cent** of carers and **50 per cent** said they do not have enough financial support. Meanwhile **67 per cent** of carers who responded to the survey said they did not have enough emotional support.

40 per cent of carers also reported that the stress of waiting for financial and practical support had an impact on their health. In addition, **14 per cent** of carers said their workplace or businesses are not understanding of their situation which also impacts on their physical and mental health.

It is a constant battle to get services that meet my son's needs, there is constant anxiety over the amount and quality of care available. I am exhausted most of the time mentally and physically (my son gets up two or three times every night). I struggle to cope financially, I am unable to get out much even when my son is at day services as I have to be on call if there's a problem with transport or the service, or my son is unwell.

6. What would make a difference to carers' health?

Support services

When caring for somebody it is likely that at some point carers will need to source somebody to help with caring to enable them to have a break and recuperate. This can often be a difficult decision to make but it is important that help is found before the carer gets to breaking point.

Extra respite has given me more time to have some normal life, catch up on my sleep and recharge my batteries.

Increased respite has improved my own quality of life. I have been able to spend some time on my own interests and also have a break away! Woo hoo!

⁶ Marie Curie Cancer Care *Committed to Carers: Supporting Carers of people at the end of life* (Marie Curie Cancer Care, 2012)

⁷ Carers UK *In the Know. The importance of information for carers* (Carers UK, 2007)

⁸ Ipsos Mori for Macmillan Cancer Research *More than a Million* (2011)

Finding the right kind of replacement care is important both for the person being looked after and also for the peace of mind of the carer. Breaks can be found by asking a family member or friend to help, employing somebody, hiring a care worker from a care agency, arranging time in a care home or getting support from the local authority or trust such as a day centre and respite care. Most of these options come at a price though, and not enough carers are eligible for them despite the fact that having a break can make a real difference to their health. It can also be important for carers to be able to take a holiday together with the person they look after.

61 per cent of carers thought their health would be improved by more regular breaks from caring.

Access to regular breaks is vital to all carers but especially to many of the respondents to this survey as **43 per cent** were caring for more than 100 hours a week or continuing to work alongside a demanding caring role.

Depending on the needs and age of the person being cared for there could be a range of services available to these carers locally. Access to these services help share the responsibility of care, but arranging to access them and clarifying eligibility can be very stressful for carers. In particular, respondents to our survey reported the length of time (in some cases many months) it took the service provider/funder to make a decision on eligibility and access was very frustrating.

52 per cent of carers thought their health would be improved by more support from local services.

Day care has given me the chance to have five hours a week when I don't need to feel responsible for the person I care for.

Local services are provided or commissioned by local authorities and health trusts or health and social care trusts in Northern Ireland. In addition, private companies, educational establishments and voluntary and community organisations provide a wide range of services in the community. However, services are not always in a convenient location so people have to sometimes rely on additional services such as community transport to get them to it or carers need to do the driving.

Life is much more worrying now and my stress levels and depression have returned. This coupled with a deterioration in my husband's health have made us wonder why we bother to carry on. Our love for each other is all that is keeping us together. The services we have been offered are terrible. Everything is taking so long that by the time we get it it will be too late. Budget restrictions have caused some of this. We need fast and effective services. We have been waiting six months for a few hand rails to be put up for my husband.

Carers also report having to wait a long time until there is space to be able to access services in the first instance. A recent report by Age UK⁹ found that out of two million older people in England with care-related needs, 800,000 receive no formal support from public or private sector agencies. Recent cuts to local authority funding, along with removal of ring-fencing for care funding are increasing the problem, leading many to highlight that the social care system is in crisis. An already large gap in funding for social care (in 2011 the Commission on Funding of Care and Support found that over the four years between 2005-06 and 2010-11, demand had outstripped expenditure by nine per cent¹⁰). With spending cuts underway the figure for unmet need is likely to pass one million between 2012 and 2014.

In the next section the cuts to local services are explored in more detail as carers are already reporting reductions in access to services and/or services being removed.

⁹ Age UK *Care in Crisis: causes and solutions* (2011)

¹⁰ Commission on Funding of Care and Support *Fairer Care Funding. Analysis and evidence supporting the recommendations of the commission on funding of care and support. Vol II* (2011)

Financial support

Accessing specialist equipment, medical kit, having alterations made on your home or moving to a care home can be expensive.

50 per cent of carers were not prepared for the financial impact of caring.

Carers who responded to the survey reported having to make decisions about what was a priority for their spending.

Due to trying to pay extra for care through other places other things are being cut out. We have had no holiday for three years, repairs to the house are not being done, food shopping is at the minimum it can be just so I can still work and pay the bills, mortgage etc.

When carers have reduced their hours or given up work they reported money being very tight, especially if their financial planning for their retirement had not ensured adequate monies for the level of care and support required.

52 per cent of carers thought their health would be improved by more financial support.

Carers also reported stress and frustration at the slow response from services in confirming whether funding or financial support could be made available. When the cared for person is at the end of their life, this can be even more stressful. Many carers also find they are not eligible for Carer's Allowance due to strict rules over who can claim it, and of those that receive it, the benefit is the lowest one of its kind at £58.45 a week (2012-13 rate). Marie Curie Cancer Care's research¹¹ found that many carers have to rely on savings, pensions and critical illness cover in order to survive.

Carers said that hearing that funding was being cut without sufficient warning also causes carers stress and anxiety.

More advice and information

Taking on a caring role can be a process that happens suddenly or their responsibilities can build over time or may fluctuate as the condition of the person that they care for changes. Carers' groups know that it can take a long time for carers to identify themselves as carers and as a result many are not fully informed about the practical and emotional support available to them. Frontline staff working in GP surgeries, care homes, NHS services and other environments therefore have a vital role in supporting and signposting carers to appropriate advice and information. We know that without access to timely advice and information people do not know what they are entitled to, cannot always make the best decisions about funding care and are not able to choose the best care option for them and the person they care for.¹² All of the above can cause carers stress and anxiety.

43 per cent of carers thought their health would be improved by more advice and information.

Practical support

Sharing the load or accessing specialist support to help care for somebody can make a difference. Most carers will benefit if the person they are looking after gets some more help and support. The best way

¹¹ Marie Curie Cancer Care (2012)

¹² Easterbrook, L *Getting Over the Threshold for Advice Issues Arising from the Care Quality Commission's unpublished review of English social services' response to people's 'first contact' for information, advice, help or support* (Independent Age, 2011)

for a carer to access this sort of help is through a carer's assessment. A carer's assessment is the responsibility of social services or the social work department of the local council/trust to carry out. However, research undertaken by Macmillan Cancer Support and Ipsos Mori in 2011¹³ discovered that over a million people looking after someone with cancer could be missing out on vital support because of not having a local authority carer's assessment. Similarly, research by King's College, London found that just over half (52 per cent) of carers of people with long-term conditions like MS and Parkinson's had been offered a carer's assessment.¹⁴

52 per cent of carers thought their health would be improved by more practical support (such as care workers and domestic help).

Identifying that you need additional practical support and being willing to allow others to help is, however, the first step. Making that decision does not always come lightly to carers as they worry if somebody new or not known to them will be able to care for the person as well as they do.

I am learning to trust others to share the caring role which I used to do alone, thus feeling a lifting of a burden of responsibility, and freedom to do my own thing occasionally.

Having extra support around your home or the home of the person you care for can make a difference. Maintaining gardens, doing odd jobs and DIY are sometimes the activities that get put second to caring responsibilities and play on carers' minds causing frustration if they have not had time to get these things done.

Increased understanding and support from GPs and healthcare staff including regular health checks

Although GPs should keep a register of carers they do not always do so. If carers are sharing their caring role with working or volunteering then health professionals need to consider the practicalities of attending meetings and appointments and remember to check or be more flexible. Carers who responded to our survey also reported that GPs and healthcare staff did not think about their availability and other commitments when booking appointments.

36 per cent of carers thought their health would be improved by increased understanding and support from GPs and healthcare staff including regular health checks.

As explored earlier, regular health checks could make a real difference to carers' health by identifying health issues before they become a problem and affect the ability to care or are made worse by caring.

31 per cent of carers would like to have more regular health checks.

More practical aids in the house

Having adaptations made to a home such as the installation of a stair lift, wet room and telecare services can make a difference to carers' health. Lifting and moving the person you care for can result in injury:

36 per cent of carers reported having an injury such as back pain as a result of their caring role.

¹³ Macmillan Cancer Support and Ipsos Mori *More than a Million: Understanding the UK's carers of people with cancer* (2011)

¹⁴ Kings College, London LTNC Research Initiative *How do carers of people with long-term neurological conditions experience the provision of replacement care* (May 2011)

16 per cent of carers thought their health would be improved by more practical aids in the house.

In the workplace

When asked to highlight what measures could be implemented at work to improve their experiences and be more supported carers suggested the following:

More flexible working hours (**49 per cent**), knowing their rights in the workplace (**45 per cent**), access to emotional support (**44 per cent**), having a 'carers champion' (**40 per cent**), and being signposted to relevant information (**40 per cent**).

In addition some other suggestions from carers included informal networks for carers to support each other, improved information in staff handbooks signposting to local support and places to access advice and information and carers' leave.

7. Impact of cuts on carers

The preceding section paints a worrying picture of the impact of caring on health because of a lack of support, information, advice and understanding. With significant change and cuts to services locally as local authorities in England attempt to grapple with a 28 per cent cut in revenue over four years (following the Spending Review in 2010), against a population with growing need right across the UK, carers will be bearing the brunt of these cuts. Carers who responded to the survey told us that they were concerned the cuts would impact on their independence, health, ability to pay for services and essentials as well as their ability to continue working. The impact of the cuts, with more set to come, represents a worrying future for the UK's 6.4 million carers and the people they look after.

Some local authorities and trusts are managing the cuts to services by innovating in some ways. Unfortunately, others appear to have no option but to tighten eligibility criteria, ration services, raise charges and introduce waiting lists/waiting times. Carers affected in this way told us that:

30 per cent of carers are worried about how they will cope with cuts to public services.

As the cuts to services have already started to take an effect, carers reported if they had been affected.

26 per cent of carers that responded to the survey reported cuts to their services.

Respondents to our survey reported costs of services doubling and in some cases funding no longer being available for local groups, care homes and services. There are also changes to the eligibility criteria for support and services which could limit availability.

There is real concern that further cuts will have a drastic impact on carers health and well-being as carers end up picking up the slack in the system, taking on the burden and as a result end up buckling under the strain.

Cuts mean less or no help or when available the costs increase. You have to fight for the basic right of a night's sleep.

Just over **three-quarters** of carers who responded to the survey reported receiving some services. The cuts have already started to bite, but the picture varies across the UK as local councils and health trusts

look at how best and fairly they can allocate their budgets. In the survey we asked carers to tell us how they thought the changes to the services they received would impact on them and the person they cared for and supported.

Independence

Finding time for yourself and maintaining a social life is valued by carers. Through the availability of respite services, care workers, day centres and transport services to get people to them having a break from the people you care for has a positive effect.

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

57 per cent of carers that responded to the survey thought that changes to services would have a negative impact on their life because of an impact on their independence.

I rarely have conversations with anyone about anything other than my husband's health issues. I miss just having fun conversations.

I have gone from having an active social life to having none. Friends are not understanding when I have to cancel meeting at the last moment [because] mum is ill. When I do go out I have the constant worry something may have happened and the guilt of leaving mum in the house alone. I find I'm very isolated and if I'd known before I became a carer what I know now I would not have taken on the responsibility.

I didn't realise the impact it would have on my health, personal relationships and social life, at times I don't feel I have a life other than caring. I cannot do anything on the spur of the moment. Everything needs a lot of planning due to my caring role.

Feel I am tied to the house, feel my health takes a back burner so wish I could go to work. Had great jobs in the past and miss the company.

Health

As detailed above there is a direct link to carers' health and well-being and the expectations of their caring role. As funding reduces, services tighten or change their eligibility criteria and centres and charities close this is going to have a knock-on effect on carers' health.

58 per cent of carers that responded to the survey thought that changes to services would have a negative impact on their life because of an impact on their health.

Ability to work

Respondents to the survey shared fears that cuts to after school and respite services as well as access to professional support, would impact on their ability to carry on working. Carers also have to balance the amount of household income with the thresholds for eligibility to services and benefits. Many chose to cease working as it no longer became feasible to try and balance the two. As a result carers lose some of their independence, their finances are affected and some reported feeling worthless.

47 per cent of carers that responded to the survey thought that changes to services would have a negative impact on their life because of an impact on their ability to work.

Ability to afford services

Carers and the people they care for already pay for services if they are not eligible for social services or their income is above a threshold. This can range from domestic assistance to care workers. Some services will be arranged through the local authority or trust and others through private companies. The services of local voluntary groups or charities are also accessed widely and subject to cuts and reduction or removal of funding. If the service is no longer provided carers and the people they care for still require the support and assistance it was offering. In addition, changes to benefits including the introduction of Personal Independence Payments (PIP) and changes to Employment and Support Allowance (ESA) will lead to substantial numbers of people losing benefits which may mean that the person being cared for can no longer purchase the service. This can mean carers finding alternative ways to pay for the service, dipping into savings, getting into debt or they have to go without the service.

50 per cent of carers that responded to the survey thought that changes to services would have a negative impact on their life because of an impact on their ability to afford the services they needed.

Ability to pay for essentials

In more detailed responses to the survey carers shared how they were making tough decisions about what they could afford to pay for. For example, opting for lower cost food in order to keep the heating on as the person they cared for felt the cold more as a result of their condition. Some carers explained how they were in poverty as a result of taking on a caring role.

42 per cent of carers that responded to the survey thought that changes to services would have a negative impact on their life because of an impact on their ability to afford essentials (like food or heating on top of the cost of care).

I have had to cut out meat, buy cheaper brands, groceries and cleaning products. Have had to make clothes last longer and have fewer outings. Have to be very careful about electricity and gas usage. If there are any more cuts I may lose my house.

Ability to have a break

A break for a carer can mean as little as half an hour to sit down and have some 'me time' to a night out with their partner without having to worry if the person they care for is going to come to any harm. Above we looked at the importance of respite and short breaks for carers but having time out with friends, managing a holiday (with the person you care for) or having time to go out to the shops, have a swim or go for a walk are all really important for carers.

59 per cent of carers that responded to the survey thought that changes to services would have a negative impact on their life because of an impact on their ability to have a break.

8. The future

It is a scandal that the UK's carers are being let down in this way. Society has a responsibility to look after its carers. The invaluable contribution they make in time and skills caring for people needs to be recognised. Currently carers' support saves the governments across the UK £119 billion a year¹⁵. It is critical that we invest in carers. With 700,000 in poor health¹⁶, there are clear potential risks to long-term health problems. The results show already the highly negative impacts of caring on carers' health and well-being, their ability to work and afford services and essentials and their independence.

It is widely recognised in the UK that there is a crisis in care and although social care reform is planned the social care system has been underfunded for too many years¹⁷. The Carers Week partners are all very clear that investing now in appropriate support for carers and the people they look after means savings longer term. This could be additional funding or ongoing funding to ensure carers can access the support services, advice and information¹⁸ they need so they can look after themselves better and continue their caring role safely for longer. This can also mean people being supported to remain living at home including until end of life, looked after by their carer and health and social care professionals saving on costly residential costs¹⁹.

In the current economic climate there are concerns that an already struggling system is going to be further hit. Cuts to services will only make matters worse. For some carers, the ultimate impact will be giving up caring because their health has deteriorated so much that they can no longer do it. This comes at a significant cost as the person they care for may need to be admitted to residential care. For others they are storing up serious problems for their future. So, who will be there to provide the care in their place if carers are no longer able to carry on?

¹⁵ Carers UK *Valuing Carers* (2011)

¹⁶ Carers UK *In Poor Health. The impact of caring on health* (2004)

¹⁷ Glasby et al *The Case for Social Care Reform, the wider economic and social benefits*. Health Services Management Centre and Institute of Applied Social Studies (2010)

¹⁸ Princess Royal Trust for Carers and Crossroads Care *Supporting carers: The case for change* (2011)

¹⁹ Marie Curie Cancer Care *We Know About End of Life Care* (2012)

Conclusions and recommendations

The responses of the nearly 3,400 carers to the survey show that the UK's army of carers are risking their own health and well-being looking after ill, frail and disabled family members and friends. Their health problems are a result of a system stymied by bureaucracy and over complication, and a lifestyle with limited time between caring and working to take a break, have a social life and keep up with routine medical appointments. Added to this knowledge about and access to services, for carers and the people they look after, varies so take up is patchy. Provision and eligibility differs from one area to another.

Carers are not asking for much. The concerns for carers go beyond just those issues that affect their health and well-being short- and long-term. It would be immensely reassuring for people to know that their employers would show understanding, support and flexibility to enable them to continue working while caring. A sympathetic, understanding and supportive relationship with social care and health professionals, access to support and breaks when they require it (and that meets their needs) would make a real difference. As well as the advice and information they need to make the right decisions about how they manage their caring role including the planning of care through the lifecycle to end of life care and beyond. Having a listening ear and effective peer support as well as access to professionals who can support carers with their responsibilities and the emotional impact of caring would also make a real difference.

Carers Week's eight national charities are calling for the following to take action on carers' health:

- 1. Sustainable funding of social care:** social care is chronically underfunded. Carers and their families are being pushed to breaking point by a lack of support, seeing their services cut or unable to use poor quality or unreliable services. It is also vital that we have a skilled and trained workforce to support people. We need the government of the four nations and local government to work together to deliver sustainable funding for social care to meet unmet need and growing demand.
- 2. Ongoing support and breaks from caring:** carers already struggling to care are concerned that funding for carers services, and particularly short breaks, is not always spent on carers or may be cut. With evidence of a growing number of carers, and that carers are caring for longer hours it is essential that funding is maintained, or increased.
- 3. Support from their GP:** GPs are often the first people who families speak to when they are dealing with ill health and disability. GPs have a key role to play in identifying and registering carers, monitoring their health and signposting them to advice, information and support, including ensuring they know they are entitled to a carer's assessment.

Methodology

To assess the impact of caring on carers' health and well-being Carers Week surveyed **3,387 carers** between February and April 2012. The majority of respondents completed the survey online, with **66** respondents completing paper versions.

2,422 of the respondents were from England, **206** from Northern Ireland, **322** from Scotland and **423** from Wales.

- **60 per cent** were aged between 45 and 64, **18 per cent** were over 65, **52 per cent** were aged 25 and 54, and **two per cent** were aged under 24.
- **80 per cent** of respondents were women and **20 per cent** were men.
- **66 per cent** of respondents had been caring for more than five years.
- Respondents were weighted towards heavy-end carers, with **64 per cent** caring for 50 hours a week or more. **22 per cent** were caring for more than one person.
- **31 per cent** were caring for a parent or parent in law, **43 per cent** for a spouse or partner, **35 per cent** for their son or daughter, three per cent for a sibling and three per cent for a friend.
- **92 per cent** of respondents were White British and **three per cent** from Black, Asian and other minority ethnic (BAME) communities.

Appendix

The following is a breakdown by responses from England, Scotland, Wales and Northern Ireland of the key findings of the survey.

Did you expect to become a carer?	UK	England	Northern Ireland	Scotland	Wales
Yes, I did expect to become a carer.	16% (501)	15% (352)	19% (37)	17% (52)	15% (60)
No, I did not expect to become a carer.	84% (2,699)	85% (1,947)	81% (158)	83% (250)	85% (344)

Has caring impacted on your health?	UK	England	Northern Ireland	Scotland	Wales
Positive impact on physical health	17% (432)	17% (318)	19% (26)	13% (21)	18% (57)
Negative impact on physical health	83% (2,521)	83% (1,513)	81% (112)	87% (203)	82% (261)

	UK	England	Northern Ireland	Scotland	Wales
Positive impact on mental health (including stress and depression)	13% (360)	13% (256)	12% (17)	13% (31)	17% (56)
Negative impact on mental health (including stress and depression)	87% (2,321)	87% (1,693)	88% (131)	87% (217)	83% (280)

Have you had to put off medical treatment for yourself, because you are caring?	UK	England	Northern Ireland	Scotland	Wales
Yes	39% (1,223)	39% (884)	31% (55)	40% (117)	43% (167)
No	61% (1,881)	61% (1,364)	69% (122)	60% (170)	57% (225)

Are you in paid employment?	UK	England	Northern Ireland	Scotland	Wales
No I have had to stop working because of my caring responsibilities.	37% (1,188)	39% (894)	19% (38)	37% (110)	37% (146)

If caring has impacted on your physical or mental health, why is that?	UK	England	Northern Ireland	Scotland	Wales
Lack of practical support	63% (1,659)	63% (1,185)	75% (105)	62% (155)	62% (214)
Not enough financial support	50% (1,296)	49% (924)	48% (68)	51% (127)	52% (177)

In the last year my/our service have....	UK	England	Northern Ireland	Scotland	Wales
Been cut back	26% (557)	28% (426)	18% (22)	25% (49)	22% (60)

If caring has impacted on your physical or mental health, why is that?	UK	England	Northern Ireland	Scotland	Wales
The stress of waiting for financial and practical support to happen.	40% (1,051)	41% (764)	34% (48)	41% (102)	40% (137)

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