



The State of Caring 2013



CARERS UK
the voice of carers

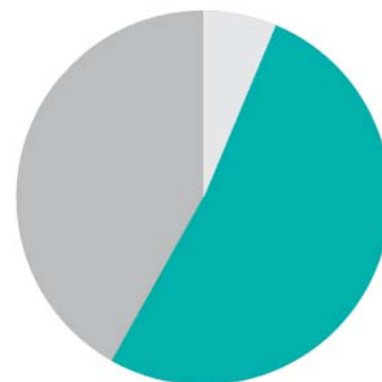
The State of Caring 2013

Over 3000 carers have filled in the State of Caring Survey, answering a wide range of questions about their experiences of caring. Of carers responding to this survey:

- **Almost a third** (31%) of those caring for 35 hours or more per week receive no practical support with caring.
- **Over half** (56%) of carers who gave up work to care spent or have spent over 5 years out of work as a result.
- **More than 4 in 10** (44%) of carers surveyed have been in debt as a result of caring.
- **84%** of carers surveyed said that caring has a negative impact on health, up from **74%** in 2011-12.
- **Almost half** (46%) of carers surveyed have raised concerns about poor quality care services.
- **Over half** (54%) of those caring for someone discharged from hospital in the last year had either not been consulted about their discharge or had only been consulted at the last minute.

In the next year do you expect your quality of life to:

- Get better 6%
- Get worse 52%
- Stay the same 42%



The State of Caring 2013 - Context

Caring is becoming part of life for more and more of us, as our ageing population and the fact that people are living longer with disability and ill-health, brings changes to family life. The 2011 Census showed that more people than ever are taking on caring responsibilities, with the number of those people providing round the clock care rising the fastest.

Our survey of carers looked at a wide range of issues affecting carers and their experiences to build a picture of the current state of caring, reflecting wider social, economic and political trends and circumstances over the last year and looking ahead to the impact of new policy and legislation.

As funding for social care has failed to keep pace with rising need, reduced local authority budgets have seen care and support services further stretched, and families stepping in to meet the growing demand for support. At the same time, carers are finding it harder to access services - a third (31%) of those we surveyed that care for 35 hours or more each week are receiving no practical support.

For families, this can lead to financial hardship, isolation and poor health, and YouGov polling commissioned by Carers UK has suggested that 2.3 million adults have given up work to care for an elderly parent, disabled or seriously ill loved ones¹. The difficulty of juggling work and care came out clearly in our survey: nearly two thirds (65%) of carers in work have used annual leave to care while nearly half (47%) have done overtime to make up for taking time off to care.

The last year has seen the start of major changes for carers. Carers and disabled people across the UK are starting to see the impact of the Welfare Reform Act 2012. Changes to financial support with housing and council tax in some areas mean many families experiencing reduced financial support from more than one of the changes. The economic downturn, a squeeze on wages and the increasing costs of essentials like food and fuel are all making it more difficult for carers to manage; more than four in ten (44%) of carers responding to our survey told us that they had been in debt as a result of caring.

The coming year will see other changes to the benefits system being introduced as the transfer of Disability Living Allowance to the Personal Independence Payment and Universal Credit are introduced.

¹ www.carersuk.org/newsroom/item/3033-research-reveals-over-2-million-quit-work-to-care

Devolved responsibility for health and social care means different developments across the UK; NHS England has just taken up its responsibilities and a new Health Secretary has brought new priorities for the health and social care system including a focus on dementia and improving the quality of services.

In the coming weeks, the Government will also publish legislation to put in place a new framework for delivering care and support services in England, giving new rights to carers to be assessed for support. The law will also establish a new system for funding care services, placing a cap on the amount individuals will have to contribute to the cost of their care.

In Scotland, new legislation is about to be introduced to bring the delivery of health and social care together. In Wales, Assembly Members are already considering legislation to make significant changes to the way that social services are delivered in Wales.

Northern Ireland's carer assessment legislation is in place and changes from the Government's new Transforming Your Care strategy are starting to be felt. The Who Cares? Consultation into adult social care provision with a focus on 'home as the hub of social care' could mean carers face even greater strains as the changes roll out.

Carers are clear that without access to good quality services they have confidence in, their ability to go to work, pursue leisure activities, or simply spend time looking after their health, is severely reduced - almost half of carers have raised concerns about poor quality care services. The need for a fully integrated health and care system that recognises and involves carers is also clear from our survey and crunch points like discharge from hospital show that supporting carers and involving them in care decisions about those they care for is vital. Almost two thirds of those caring for someone discharged from hospital in the last year had either not been consulted about their discharge or had only been consulted at the last minute.

Government carers' strategies focus on ensuring carers are 'recognised, valued and supported'. The findings of our survey of carers' experiences present a series of challenges to do more to make this a reality.

This report highlights five challenges to improve carers' lives:

1. Ensure better access to support and information.
2. Deliver services and workplaces that support carers to juggle work and care.
3. Act urgently to prevent carers' financial hardship.
4. Ensure carers are able to achieve the best health outcomes possible.
5. Deliver high quality care and improve the interface between health and social care services.

1 Ensure better access to support and information

It takes time for people to identify themselves as carers and find out what practical support and information is available. This delay can mean carers missing out on financial, practical and emotional support. Carers tell us that by not getting the right information at the right time, they struggle to juggle work and care, while their independence and relationships with others suffer.

"Cuts to daytime respite and holiday clubs meant there was less on offer, less often, not enough places and the cost went up."

Carers are also seeing a squeeze on the services offered to them and those they care for as pressure mounts on local authority budgets. The failure of social care budgets to keep pace with rising demand means that families are increasingly stepping in to provide care with less practical support.



Two in five (42%) carers felt they had missed out on financial support as a result of not getting the right information and advice early enough.

Almost a third (31%) of those caring for 35 hours or more per week receive no practical support with caring.

43% of carers surveyed were not aware that technology is available to support their caring.

The challenge

Improve carers' access to support and information.

What Carers UK is doing

Extending our Adviceline hours to reach more carers and campaigning for more funding for care and support services. We are producing resources to support carers through the implementation of the welfare changes and ensure advice and information are delivered in community settings through Carers Week and Carers Rights Day.

How to meet the challenge

The Care and Support Bill in England and the Social Services and Well-being (Wales) Bill have the power to greatly improve the information and advice available locally, and for more carers to be assessed by their local authority for support. Northern Ireland's Carers and Direct Payments Act (2002) gives carers the legal right to an assessment of their needs and allows Health and Social Care Trusts to give services directly to carers. In Scotland carers are being offered support through self-directed support for the first time, allowing more personalised support. In Wales the Carers Strategies (Wales) Measure 2010 has placed a new legislative duty on the NHS in Wales to provide information to carers.

It is vital that local areas receive enough funding to make the opportunities under new legislation a reality, by increasing the amount of money in the social care system and setting national thresholds for support at a level which makes the duty to promote the wellbeing of carers and those in need of care and support a reality.

There is also an opportunity for local areas to use new and innovative ways to reach all carers, not only those receiving support, and they also have an important role in supporting the development and take-up of innovative health and care services including technology.

2 Help carers juggle work and care

3 million carers juggle work and care, around half of the UK's 6.5 million carers. As well as support from their employer, those juggling work and care need services which enable them to work alongside caring.

Nearly two thirds (65%) of carers in work have used annual leave to care while, nearly half (47%) have done overtime to make up for taking time off to care.

One in seven (15%) have taken a less qualified job or turned down promotion because of caring responsibilities.

A further **one in six (17%)** continue to work the same hours but find their job is negatively affected by stress, tiredness or lateness. **Over half (56%)** of carers who gave up work to care spent or have spent over five years out of work as a result.

"There is not a day that goes by without me thinking of our finances. Whilst I have cut back and am lucky not to be in debt it has been extremely difficult. I cannot take the commitment of promotion to increase my earnings because of my caring responsibilities."

Why carers gave up work

A recent Carers UK/YouGov poll showed that the equivalent of 2.3 million people have given up work at some point to care for an older or disabled loved one.

State of Caring Survey: Of those who gave up work, retired early or reduced hours to care:

25% of those did so because the cost of replacement care is too high

23% said services were not flexible enough

20% said services were not reliable enough

The challenge

Deliver services and workplaces that support carers to juggle work and care.

What Carers UK is doing

We have worked with Government and employers to set up a taskforce to look at solutions for those combining work and care. We are also providing expert resources and advice to help those juggling work and care.

How to meet the challenge

The Carers and Employment Task and Finish Group established jointly by HM Government, Carers UK and Employers for Carers presents an important opportunity for the Government, employers and others to understand, present and spread best practice in supporting carers to remain in work.

As well as working with employers Government has a key role to play in ensuring that a choice of high quality, affordable local care is available for those carers who wish to or need to combine a job with caring.

There should be a specific duty on local councils to assess and report on the sufficiency of supply in their area. In England, this could be included in the Care and Support Bill.

3 Prevent carers' financial hardship

Just as many families see reduced capacity to earn, they simultaneously face substantial additional costs as a result of ill-health and disability. This combined pressure can take a serious toll on family finances.

"I have had to put an extension on the house to accommodate two wheelchairs and as a result have plunged myself into debt."

Four in ten (44%) of carers surveyed have been in debt as a result of caring.

Nearly one in four (58%) carers spend at least 10% of their income on energy bills. Up from 54% in 2011/12.²

36% of carers are struggling to afford utility bills like electricity, gas, water or telephone bills. Up from 34% in 2011/12.

52% of carers say that financial concerns are affecting their health. Up from 47% in 2011/12.

"Charges have gone up so I am restricted now to how many hours of care for a break that we can afford."



What are carers cutting back on in 2013?

41% of those struggling are cutting back on essentials like food and heating
14% have cut back on care support services
45% have cut back on food

44% have cut back on heating
74% have cut back on seeing friends and family
44% have cut back on phone use

The challenge

Act urgently to prevent carers' financial hardship.

What Carers UK is doing

Carers UK has launched its Caring & Family Finances Inquiry to provide a definitive examination of the financial impact of caring and assess the impact of the Government's changes to the benefits system. We are producing plain English resources to help carers through the changes and help them challenge decisions.

How to meet the challenge

The Government urgently needs to review the financial support available to carers including considering the cumulative impact of a range of benefits changes on the families of older and disabled people and those in ill-health.

4 Improve carers' health and wellbeing

As well as being rewarding, caring can have a huge impact on the physical, emotional and mental health of carers. Carers are significantly more likely to be in poor health than people without caring responsibilities.

Without proper training and equipment, carers are at risk of physical injury from lifting and moving someone. Anxiety, lack of sleep, social isolation and depression often lead to mental ill health or stress-related illness.

Too often carers put their own health needs last, forced to put off medical appointments and treatment. Where carer health is not addressed, unnecessary, distressing and expensive emergency admissions can result.



84% of carers surveyed said that caring has a negative impact on health. Up from 74% in 2011/12.

Nine in ten (92%) carers said that their mental health has been affected by caring with only 1% saying that caring has improved their mental health.

67% of carers said their GP is aware of caring responsibilities but gives them no extra help.

"I have received some support and advice but only when I have asked for it. I feel that GPs should do more to help carers. Very often carers don't even have time to make appointments, therefore it would be helpful to many carers if GPs took the initiative more often."

The challenge

Ensure carers are able to achieve the best health outcomes possible.

What Carers UK is doing

Carers UK is working with the Department of Health, Royal College of GPs and Carers Trust to improve GP support for carers. Carers UK has recruited a network of carer volunteers to work with GPs to improve services for carers and provide emotional support to carers. We work with expert partners to develop resources on carer health and nutrition.

How to meet the challenge

Health professionals must do more to improve carer health, taking steps to ensure that carers are identified and offered health checks and appointments that fit around their caring responsibilities.

In setting out priority outcomes at all levels of the NHS and Social Care, the Department of Health, and national governments in Wales and Scotland and Northern Ireland must create accountability mechanisms for improving carer health.

Investing in support for families in the community can help to avoid more costly intervention like emergency hospital admission.

5 Improve care quality and the interface of the NHS and social care

Quality of care is a major factor in whether families are able to work and pursue their own life alongside caring. Unreliable and poor care can put huge pressure on families, preventing them from having time away from caring or peace of mind when away from the person they care for.

Health and care professionals need to recognise the expertise in families and involve them in decisions about the care being provided.

Hospital is a key transition moment as carers begin to take on caring responsibilities. It is a time where the right support and advice can make a huge difference to the ability of carers to cope. It is also a time where co-ordination between the NHS and social care services is needed and carers are too often caught in the middle.

“Good care empowers and enables both the carer and the cared-for. Poor care leads to ill-health and stress for both carer and cared-for person.”

“Care workers cancel at the last minute or don’t turn up. The poor standard of care means I’m not happy to leave the home. Care workers often aren’t interested in their work and are sometimes on their phones.”

Almost half (46%) of carers surveyed have raised concerns about poor quality care services.

Over half (52%) of carers surveyed have recommended a service or given positive comments about a service.

Over a third (38%) say poor care has affected their ability to work.

Half (50%) of carers surveyed felt that health and care professionals involve and consult them about the treatment of the person they care for.

Of those who cared for someone who had been admitted to hospital as an emergency in the last three years, **more than one in five (22%)** felt that this emergency admission to hospital could have been prevented if they had received replacement care to look after their own health or been given more respite and support.

Four in ten (42%) of those caring for someone discharged from hospital in the last year felt that the person they cared for was not ready to come out or that they did not have the right support to be at home.

Over half (54%) of those caring for someone discharged from hospital in the last year had either not been consulted about their discharge or had only been consulted at the last minute.

77% of those caring for someone discharged from hospital in the last year were not given any other options when the person they cared for was discharged.



“The impact of a rapid discharge back home with me, even when I said I couldn’t manage, has been one of the most highly stressful things that I’ve had to deal with.”

“Poorly organised, virtually no links between NHS social worker and social services social worker, couldn’t get hold of NHS staff that we wanted to see, far too much communication with patient (who didn’t understand or remember it) and none with me.”

“She was discharged too early, without proper medication which resulted in her being re-admitted to hospital within three days.”

The challenge

Deliver high quality care and improve the interface between health and social care.

What Carers UK is doing

New resources to support carers through discharge from hospital, local hospital-based project work to support discharge, and campaigning for Government to recognise the wider costs for families of poor care.

How to meet the challenge

The problems of high turnover, inadequate training and low pay for care workers were highlighted by carers as obstacles to good social care and need to be addressed by Government, regulatory bodies, commissioning bodies and care providers. The Government’s aspiration to eliminate ‘commissioning by the minute’ is vital, but cannot be achieved without relieving the pressure on social care budgets.

Carers need to be involved and listened to at all stages. Hospital discharge is a key point where health and care professionals have a duty to ensure that carers are willing and have sufficient support and information to take on caring responsibilities. Coordination between health and social care, and between departments within the NHS needs to improve so carers are not caught in the middle of disputes or left without vital equipment. In Scotland, there are opportunities through new legislation to involve carers in the design and development of integrated services in their areas.

Carers UK
www.carersuk.org info@carersuk.org

Tel 020 7378 4999 Adviceline 0808 808 7777

Carers Wales
info@carerswales.org 02920 811 370

Carers Scotland
info@carerscotland.org 0141 445 3070

Carers Northern Ireland
info@carersni.org 02890 439 843

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