

Building Carer Friendly Communities

Research report for Carers Week 2016



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Introduction

About carers and caring

Across the UK there are 6.5 million people caring unpaid for an ill, older or disabled family member or friend¹.

All of us will have our lives touched by caring at some point: 3 in 5 of us will be carers in our lifetime and many of us will also need care in our lifetime².

Each year, 2 million people become carers and around the same number cease their caring responsibilities. With an ageing population, and people living longer with long term illnesses, the number of carers is only going to increase; yet more of us will be called upon to care for an older, disabled or seriously ill family member or friend.

The reasons people might need help or support from someone can vary. It might be that someone's child was born with a disability or their partner had an accident that left them disabled or their best friend develops a serious illness or disease.

A person's problems may be physical or mental. They might need help because they are getting older. But what doesn't vary is that they need support, and for those looking after someone – for whatever reason – caring is part of life.

The ways in which carers help and the amount of time they spend caring varies too. Carers help with personal care like getting someone dressed, turning them in their sleep, helping them to the bathroom, helping them move about or administering their medication. Carers provide emotional support for those they care for, especially where the person might have mental health problems.

Carers also help with things like shopping, laundry, cleaning, cooking, filling in forms or managing money. A carer might help out for a few hours each week, popping in to check up on someone or to do their shopping. Another carer may be caring round the clock for their family member or close friend.

Although millions of people care for someone close to them, they often do not see this as caring but as just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a good neighbour. Looking after someone is “just something we do”. But caring can have a huge effect on an individual's life.

Whilst caring is rewarding and can bring, life-affirming experiences to people's lives, without the right support, it can also have a significant effect on a person's health, wellbeing, relationships, employment and finances. What all carers have in common is the need for support and understanding from their community.

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¹ Census 2011

² Carers UK (2001) *It could be you*

Building Carer Friendly Communities

This year we're focusing on building Carer Friendly Communities. Carers Week 2015 also explored this theme and following on from its success, Carers Week 2016 seeks to consolidate some of the positive work making communities more carer friendly that has already been achieved across the country.

For some carers, who have very significant or stressful caring responsibilities, to have to battle with a community that does not understand can push them to breaking point. It is vital that we build communities that make carers' lives easier, not harder; and as more and more of us will become carers, this is relevant to everyone in today's society.

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What are Carer Friendly Communities?

Carer Friendly Communities are places where carers feel supported to look after their family or friends, and are recognised as individuals with needs of their own.

They have some understanding of a carer's daily reality, recognising that they are often under a lot of pressure and tend to be hidden from view. For example, in a Carer Friendly Community, a GP service might offer carers appointment times to fit around their caring responsibilities; an employer might offer flexible working hours to carers or a university could offer students who are caring extensions with course work. Essentially, Carer Friendly Communities are places that reach out to support carers wherever they can by understanding caring, understanding disability and illness, and doing things differently. By working together, the charities and supporting organisations driving Carers Week are committed to building communities like these.

The funding for social care services, how health and care services work together and the reliability and quality of care services impact on how well carers are supported. Insufficient funding, coupled with uncoordinated, low quality health and social care provision result in poor experiences for carers, which will not change unless there is investment and structural change. However, by thinking about the needs of carers and working differently all parts of the community can make a difference to improving the lives of carers. This year Carers Week seeks to explore, celebrate and encourage this carer friendly activity.





Building Carer Friendly Communities

Caring and the community

Focussing on how communities can support carers to live well, the research looked at how easily carers were able to maintain or balance certain aspects of their life with their caring role. Carers were asked if they could maintain a healthy lifestyle, maintain relationships with family and friends, balance work, participate in education, get to essential shops or services, and find suitable transport to travel with the person they care for.



About Carers Week

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges carers face and recognise the contribution they make to families and communities throughout the UK.

Carers Week is brought to life by the individuals and organisations who come together to organise activities and events throughout the UK, drawing attention to just how important caring is.

This year Carers Week is made possible by Carers UK joining forces with Age UK, Carers Trust, Independent Age, Macmillan Cancer Support, Motor Neurone Disease Association and MS Society and is kindly supported by Sainsbury's, Nutricia and the Lockwood Charitable Foundation.



Key findings



Community

3 in 4 carers don't feel their caring role is understood and valued by their community



Health

Carers identified the main barriers to maintaining their health:

- My GP practice hasn't informed me about how to get practical support as a carer (55%).
- My GP practice doesn't offer an annual health check for carers (45%).
- I haven't received any training or information to help keep me well (42%).

Of carers who faced barriers to their health:



51%

have let a health problem go untreated



50%

said their mental health got worse



31%

only get help when it is an emergency



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Employment

Carers identified the main barrier to balancing work and care

- A third of carers (33%) say their employer doesn't have policies in place to support them.

Of carers whose employers don't have policies in place to support them:



72%

have given up work or reduced their hours



57%

are more stressed about being able to care well



55%

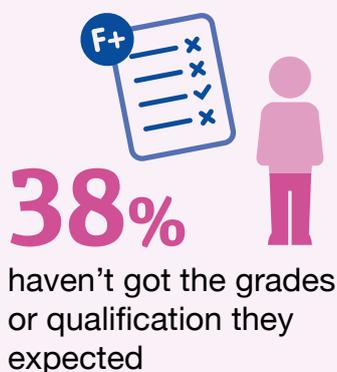
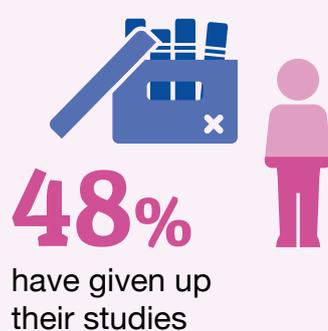
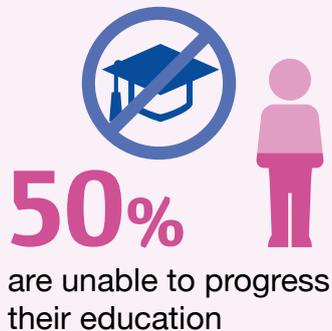
have struggled financially



Education carers identified the main barrier to balancing education and care.

- **Nearly half of carers (46%) say there are no policies in place to support them.**

Of carers whose places of education don't have policies in place to support them:

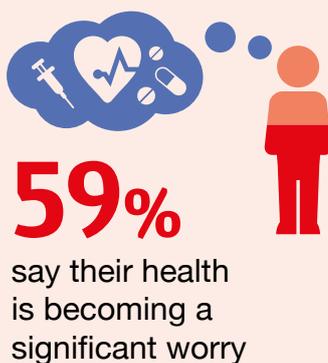
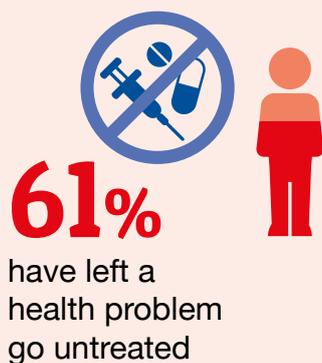


Older carers

Older carers unable to get to their appointments and check-ups were more likely to experience a negative impact on their health than other carers.

- **17% of older carers say that they are unable to get to health tests, specialist appointments or check-ups.**

Of those older carers who are unable to access appointments:



Nation view

Scotland

- 73% of carers in Scotland don't feel their caring role is understood and valued by their community.
- 23% of carers in Scotland whose communities valued and understood them reported that they were always able to maintain a healthy lifestyle compared to 4% of carers whose communities didn't.
- 24% of carers in Scotland whose communities valued and understood them said that they were always able to maintain relationships with close friends and families compared to just 6% of carers whose communities didn't.

Wales

- 72% of carers in Wales don't feel their caring role is understood and valued by their community.
- 26% of carers in Wales whose communities valued and understood them reported that they were always able to maintain a healthy lifestyle compared to 11% of carers whose communities didn't.
- 29% of carers in Wales whose communities valued and understood them said that they were always able to maintain relationships with close friends and families compared to just 8% of carers whose communities didn't.

Northern Ireland

- 76% of carers in Northern Ireland don't feel that their caring role is understood and valued by their community.
- 61% of carers in Northern Ireland whose communities valued and understood them reported that they were always or sometimes able to maintain a healthy lifestyle compared to 53% of carers whose communities didn't.
- 73% of carers in Northern Ireland whose communities valued and understood them said that they were always or sometimes able to maintain relationships with close friends and families compared to 57% of carers whose communities didn't.

Research by theme:

Community

The difference Carer Friendly Communities can make



Carers were asked whether, as a carer, they felt their role is understood and valued by their community.

In drawing out how carer friendly and understanding communities were of carers and caring, the research demonstrated the positive consequences that a supportive community has for carers.

Those carers who felt their community did understand and value them were overall much more likely to be always able to maintain or balance the other areas of their life. Those whose communities did not support them were more likely to never or rarely be able to balance or maintain other areas of their lives alongside caring.

In communities where carers felt valued and understood:

- 27% of carers reported that they were always able to maintain a healthy lifestyle compared to 9% of carers whose communities didn't.
- 29% of carers said that they were always able to maintain relationships with close friends and families compared to just 9% of carers whose communities didn't.
- Over half (53%) of carers stated that they were always able to get to essential shops or services compared to a third (32%) of carers whose communities didn't.

In communities where carers did not feel valued and understood:

- Almost half (47%) of carers reported that they were never able to balance education with care compared to 23% of carers whose communities did.

For carers where their communities understand and value them, it is easier to manage the other aspects of their lives. Carers find it easier to get to essential shops or services – this could be because those services and shops are carer friendly, for example, they have features, such as ramps; or that they are supported by the wider community to get to shops and services.

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Community

3 in 4 carers don't feel their caring role is understood and valued by their community



Carers' experiences:



We are very well known in our area and there is always someone who will help if needed. My husband goes out on his mobility scooter and people always look out for him. This makes a difference. It makes us feel safer because we are not surrounded by strangers. Friends invite me for coffee or days out. My husband can still safely visit his old haunts. This is the advantage of a caring community.



The local corner shop has delivered milk and bread if Mum has called them. The local council, following a letter from my Dad have improved access to the cemetery for wheelchairs so that my Mum and Dad can visit their daughter's grave.



I can't overestimate the importance of help to reduce isolation. Having contacts from my community to discuss things with people who understand LGBT issues is vital – whether it's HIV or early onset dementia or mental health/anxiety. So very important to know that other people 'get it' and recognise that visibility is needed in mainstream support services for lesbian, gay, bisexual and trans people.



The local community isn't geared up to understand people with disabilities. There is no understanding. I feel that to be in the role of carer is to be discriminated against and despised.



As a carer attempting to get understanding, advice, support, help and emergency care from the 'community' such as GP, public transport, social services, dentist, pharmacies and hospitals can be very challenging, exhausting and beyond stressful.



Our son is very autistic and has severe learning disabilities as well as cystic fibrosis, he can be very challenging when out in public. A couple of close neighbours understand our role but others are positively hostile and will not even acknowledge us in the street. Very sad really.

Best practice



Macmillan East Kent Volunteer Service, in partnership with Crossroads Care East Kent

Macmillan East Kent Volunteer Service has established a thriving service with Crossroads Care East Kent and the three local Pilgrims Hospices, which recruit, train and supervise volunteers to meet the unmet practical and emotional needs of people living with cancer and help them cope. This directly and indirectly benefits carers, through offering practical help with things like transport to health care appointments including hospital visits, light household tasks like cooking, cleaning and gardening, and also emotional support through companionship and specialist listening ear support.

Hertfordshire Libraries

Hertfordshire County Council's library service works in partnership with Carers in Herts to give extra support for carers by running 'Coffee & Computers' and 'Tea & Tablets' sessions for carers to develop their IT skills and share information about library services. Hertfordshire County Council's Library Service also offers a Home Library Service for carers who might find it difficult to visit a library.

A carers' library card is also offered which gives carers an increased item allowance, an extension on the borrowing time for most items and an exemption from overdue and reservation charges. This offer was developed on the back of research that highlighted the difficulty that carers have in getting to the library regularly because of their caring commitments and the risk they run of building up high overdue charges.

Exeter's Royal Albert Memorial Museum and Gallery (RAMM)

Exeter's RAMM has been working since 2013 to make the museum more dementia-friendly and provide enjoyable, stimulating activities for people with dementia and their carers as part of their Living Each Season programme. The activities are based around a combination of object-handling, creative activities and gallery tours. They use the loose theme of the seasons, and the eclectic nature of the museum's collections – from Natural History and World Cultures to Fine Art and Archaeology – to spark conversations.

At the museum, visitors are free to define themselves, free from the role of carer or the person with an illness. Creative activities can be therapeutic for both people with dementia and carers, especially for those who have lost the time or patience to organise something they might once have enjoyed.

MND Association branches and groups

The MND Association has a network of branches and groups in England, Wales and NI which provide local support to people affected by MND.

The groups are run by volunteers and meet regularly in accessible places, each runs with the aim of bringing support to people in their area. The North Wiltshire group for example sends a card to new carers offering support and highlighting local services, and has established links with Care Support Wiltshire and the Swindon Carers Centre.

Health



It can be extremely difficult for carers to find the time to look after their own health, such as preparing healthy meals or exercising. Indeed, full time carers are twice as likely to be in bad health as non-carers.³ Carers also face financial obstacles as many are on extremely low incomes.

Low incomes are commonly linked to poor health outcomes.

Although not addressed specifically in the survey, it is clear from carers' responses that for many the lack of care and support services for the person they care for is the main barrier preventing them from looking after their own health and wellbeing. Lack of services prevents them from remaining in work, maintaining and developing relationships and pursuing opportunities for training and personal development.

A chronic lack of funding for the provision of care must be addressed with commitments from all governments across the UK to fill the funding gap in social care.

Yet, there are many simple ways in which health services and the wider community can support carers to maintain their health and be able to care well. In England, with the Care Act 2014 now in force, there are stronger requirements on the NHS to cooperate with local authorities to provide

support to carers and new funding initiatives such as the Better Care Fund are creating more incentives and opportunities for joint working.

There were two major findings from the survey – that a lack of support from health and social care services had a significant impact on carers and that carers whose communities valued and understood them faced fewer barriers to maintaining their health.

What was also very noticeable was that certain obstacles had much greater consequences for carers than others. For example, GPs not informing carers about how to get practical support or not offering an annual health check had more of an impact on carers than pharmacies not supporting them in their role or not finding the time to prepare healthy meals. Communities should focus on these areas, because these changes can have a positive effect on carers' health.

Barriers to maintaining good health

In this survey, carers identified three main barriers to maintaining their health:

- My GP practice hasn't informed me about how to get practical support as a carer (55%).
- My GP practice doesn't offer an annual health check for carers (45%).
- I haven't received any training or information to help keep me well (42%).

Other barriers to maintaining good health include:

- A quarter (26%) said they struggle to get to their own health tests, check-ups and specialist appointments
- Almost a quarter (21%) said their hospital does not recognise their caring role

The role that health and care services have in helping carers to maintain their own health is paramount. Carers need support from their GP, the hospital and care services to help them look after their own health. They also need the knowledge, training and skills to care safely and well. If carers are able to care safely and well then this also prevents or delays the need to use further support services.

³ Census 2011

Consequences for carers' health

The survey looked at the consequences that barriers had for carers' health and wellbeing.

- 51% of carers reported that they have left a health problem go untreated.
- 50% of carers said their mental health has got worse.
- A third of carers (35%) reported that they have physically injured themselves through caring.
- 1 in 3 carers (31%) said that they only get help when it's an emergency.
- 3 in 4 carers (74%) feel their role as a carer is undervalued and unsupported.



Barriers that prevented carers from having increased support included not being told where to get practical support, not getting their health seen to or not monitoring their health – such as an annual health check, or getting to health tests, check-ups and specialist appointments. The negative impact of these barriers is significant for carers. Without practical support, carers are more likely to break down and suffer ill health. Similarly, if they cannot get to the doctor to ensure that they are in good health, it is likely that their health will deteriorate, hence the negative impacts seen in the research.

If carers do not have the information and advice or training to develop emotional resilience as well as physical resilience (moving and handling correctly) then they are less able to take care of themselves and will suffer negative health consequences as a result. The negative outcomes also increased when carers did not get the advice, information and training to keep well, eat well and exercise.

As a result of not receiving any training or information to help them keep well, carers reported more problems with their health and wellbeing:

- Over half of carers (55%) reported that they have left a health problem go untreated.
- 55% of carers said that their mental health has got worse.
- 4 in 10 (42%) carers reported that they have physically injured themselves through caring.
- Over a third (36%) said that their health is becoming a significant worry.
- 35% said that they only get help when it's an emergency.
- 14% of carers reported feeling that at times they have been unable to continue their caring role.

Where carers are not informed by their GP practice about how to get practical support as a carer:

- Over half (54%) of carers reported that they have left a health problem go untreated.
- Over half (53%) of carers said that their mental health has got worse.
- Over a third (34%) of carers said that their health is becoming a significant worry.
- 37% of carers reported that they have physically injured themselves through caring.
- A third (33%) of carers said that they only get help when it's an emergency.

When carers cite that they haven't been offered an annual health check as a key challenge to maintaining their health:

- Over half of carers (54%) reported that they have left a health problem go untreated.
- 51% of carers said that their mental health has got worse.
- Almost 4 in 10 (39%) reported that they have physically injured themselves through caring.
- Over a third (35%) said that their health is becoming a significant worry.
- 34% said that they only get help when it's an emergency.
- 13% of carers reported feeling that at times they have been unable to continue their caring role.

When comparing results, carers living in communities which value and understand them are more likely to be resilient to the impacts of the barriers they face than those who feel their communities do not value or understand them.

Where carers live in communities that value and support them:

- A third (33%) reported that they have left a health problem go untreated.
- A quarter (26%) reported that they have physically injured themselves through caring.
- 1 in 5 (21%) carers said that they only get help when it's an emergency.

This is, however, still a large enough proportion to cause concern. Comments by carers suggest that when they live in carer friendly communities they still experience problems supporting their health, e.g. the availability and affordability of care.

In communities where carers felt that they were valued and understood, the challenges to maintaining their health reduce. In communities not supporting carers in the same way, a much higher number of carers faced barriers. This is, in part, because carers who feel their community values and understands them are likely to have services in the community that are carer friendly so they will not face these challenges. However, it is also because, even if, for example, their GP does not offer them a health check, there are other supportive community services that mean this is not so much of a barrier to their health.

Role of rest of the community in supporting carers to look after their own health

The fourth most cited barrier to maintaining health was focussed around the wider community rather than health and care services in particular. 38% of carers reported that a key challenge was that there

were no discounts on local leisure and exercise amenities for carers. This increased to 42% for carers whose communities did not value and understand them.

Carers experiences



My GP has instructed me to inform the receptionist when I have to attend for an appointment that I am a carer so that if he is running late I will be moved up the list and not kept waiting as long. Also my surgery have telephone conferencing so that I don't even have to leave the house.



The GP and pharmacy have been excellent, the GP has done home visits on a regular basis and the pharmacy has delivered any medication.



I try to make sure that the GP appointments for both people I care for are made together as it is easier to take them both together.



My GP surgery told me I wasn't recognised as a carer because I don't get Carer's Allowance. I feel totally helpless.



I recently accompanied my sister to an appointment with a specialist hospital nurse who did all the right things about introducing herself to my sister, who has a learning disability, but who completely ignored me sat beside her!



I find my own health needs pushed further and further away until they break down completely and become an emergency.

Last time this happened I was in hospital for 10 days and the Occupational Therapist wouldn't let me leave until our care package was back in place properly. Needless to say it wasn't when I came out so had to bear the load myself.



Both people I care for have medical conditions that are not straightforward to manage. No one in the health services has an overview of either. Life gets very complex and I've found it difficult to maintain my own diet and exercise regime. And in a 10 minute GP appointment, there isn't time to explain everything.

Best practice



NHS Highland

NHS Highland joined forces with local carers support centre, Connecting Carers, and the health and wellbeing charity, High-Life Highland, to offer local carers access to High-Life Highland community and leisure facilities in the north of Scotland for just 50p a time.

This initiative addresses the serious effect that caring has on a family's finances as well as an individual's health and wellbeing by giving them much-needed respite and access to leisure facilities where they can go to exercise and socialise, without having to worry about the often high costs of gym memberships.

Triangle of Care England and Scotland

The Triangle of Care programme developed by Carers Trust brings together mental health service providers and carers organisations to implement the standards of the Triangle of Care in their services. Carers organisations work in partnership with mental health services to improve the identification, provision of information and the referral of support of carers in mental health services.

Since the launch of the guide in 2010 and the formal launch of a membership scheme (England) to measure and monitor progress in 2013, 28 Trusts have joined the scheme and are working towards long term culture change.

Research by theme:

Employment



The research looked at the barriers that carers face in balancing work with caring. Only carers who had experience of being in work whilst caring completed these questions.

Barriers to balancing work and care

Carers identified three main barriers to balancing work and care:

- I don't feel comfortable talking about caring at work (38%).
- My employer doesn't understand my caring role (35%).

- My employer doesn't have policies in place to support carers (33%).

Carers also noted that finding good quality and reliable replacement care to fit around their working hours was another obstacle to balancing their caring role with work.

Consequences for carers' employment

Without support in the workplace, or outside it, to juggle work with care, carers can find it extremely difficult or impossible to continue with both roles. Both employers and the wider economy are losing out on the skills and experience that carers can offer when they have to give up work because the strain is too much.

Where carers faced barriers to employment:

- Two-thirds (66%) of carers surveyed felt they had no option but to give up work or reduce their hours.
- 28% of carers reported not pursuing or turning down a promotion in order to be able to care.
- 47% of carers reported that they have struggled financially.
- 4 in 10 (41%) carers said their work suffered.
- 58% of carers reported being more stressed about their ability to care well for their family member or friend.
- In cases where carers really struggle to balance caring and employment, there will be times when they are unable to continue caring: 13% of carers said this was the case for them.
- 64% of carers reported feeling that their role as a carer is undervalued and unsupported.

When comparing this to those carers who felt that their community valued and understood their caring role, the effects were considerably less. For example, whilst 59% of carers felt that barriers to balancing work with care meant they were more stressed about being able to care for their family member or friend well, 50% of carers in a supportive community felt this way. Equally, when comparing those carers whose communities do not value and understand them, the effects were more negative as a whole.

Where employers don't have policies in place to support carers:

- 7 in 10 carers (72%) have given up work/reduced hours to care.



- 44% said their work had suffered.
- Nearly a third (29%) said they were unable to pursue or had to turn down a promotion.
- Over half of carers (58%) are more stressed about being able to care for their family member or friend well.

44%



said their work had suffered

29%



said they were unable to pursue or had to turn down a promotion

Impact of lack of understanding at work

The level of understanding in the workplace has a critical impact on outcomes for carers. Where carers did not feel comfortable talking about caring at work, where their employer did not understand their caring role or where they felt worried about telling their employer they are a carer, the negative effects were more significant:

- 6 in 10 carers (62%) were more stressed about being able to care for their family member or friend well.
- Two-thirds of carers (64%) have given up work or reduced hours to care.
- 1 in 3 carers (29%) have been unable to pursue or had to turn down a promotion.
- One half of carers (48%) say their work has suffered.
- One half of carers (50%) have struggled financially.
- 15% of carers say that at times the pressure has meant they have not been able to continue their caring role.

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Carers' experiences



My boss and immediate supervisors have been great and they make time to have a chat about my situation. However, I do feel some of my colleagues don't seem to understand my caring role and I have had some "jokey" comments about being a part-timer and having so many "days off".



My employer is very supportive. I can work flexibly and work from home when I need to. I have also had paid time off when my husband was in hospital and unpaid time off to move my mother-in-law into sheltered accommodation.

Research by theme: Employment



My employer has been very supportive, allowing me to go off without notice during emergencies and also allowing me to change my hours to support my caring role.



I am conscious that I will be discriminated against if people were aware of the demands I had at home.



I was unable to continue in same job as my working hours and getting my child to a special school were incompatible.



I once asked for provision to be put in place to assist with care and was told it wasn't possible. My boss is careful to sound supportive until I ask for tangible support at which point it isn't there.

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Best practice



Employers for Carers

Employers for Carers is Carers UK's forum to help businesses support carers in their workforce. The Forum has over 100 members, including FTSE 100 businesses, financial services and Government departments, and 11 Leadership Group members, including Sainsbury's, Nutricia and British Gas. Employers for Carers offers bespoke workplace training, resources and opportunities for business leaders to meet and discuss what more can be done to create carer friendly workplaces.

Carer Positive

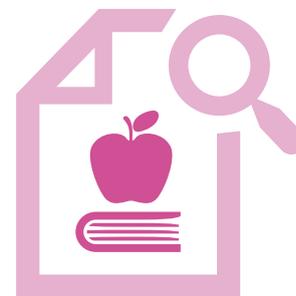
Carer Positive is a scheme to recognise employers in the workplace which is operated by Carers Scotland on behalf of the Scottish Government. Already over 180,000 employees in Scotland are now working in awarded organisations. More and more employers are applying to be recognised as Carer Positive.

The MS Society

The MS Society's carers policy recognises that carers are more likely to work longer for an employer who values them and understands their caring needs and responsibilities. MS Society staff with family caring responsibilities are entitled to paid carers leave of up to five days, to allow them to deal with short-term, planned or unexpected care needs. Flexible working is encouraged, with carers able to work their hours differently around their caring responsibilities.

Even if people don't take the extra leave offered, the knowledge that they could takes pressure off them. The MS Society is a member of Employers for Carers and is also developing a Carers Network to provide further avenues of support and information for staff with caring commitments.

Education



The survey looked at the challenges that carers face with regard to education. This applies to young carers who are at school, college or university but it also applies to many other carers who are pursuing education or training later in life.

It must be noted that most of the responses to this section are from adults furthering their education or training, not from younger carers. It might be that because of their caring role they have decided to continue with their education, or retrain for a different role. Or it could be that they wish to pick up new skills that they might use after their caring role comes to end, or that a carer simply wishes to learn and feel they have a life of their own alongside their caring role.

Barriers to participating in education or training

Students of all ages face barriers to balancing education with care. Whether it is the practicalities of finding the time to study and there being no flexibility with deadlines or class times, or the lack of understanding encountered and strain of hiding their caring role, it is important that the obstacles to balancing education with care are removed. As the survey findings show, the inability to balance care with education, can have a devastating effect on a carer's future prospects. With those carers who are returning to education, perhaps to reskill, it is important that they are also supported to study. Survey respondents indicated barriers to balancing care with education:

- Almost half (46%) of carers said there were no policies – such as bursaries, deferring exams or courses in place to support carers.
- 4 in 10 (39%) carers reported a lack of flexibility in timetabling or with deadlines.
- 4 in 10 (39%) cited that their teachers or lecturers not informing them about the support available to them.
- Almost a third (29%) of carers said that an obstacle was feeling unable to talking about their caring role to other students.
- A quarter (25%) reported that their teachers or lecturers did not understand their caring role.

Consequences for carers' education

As a result of this, carers reported a range of consequences to their health, wellbeing and educational opportunities.

- Two thirds (66%) of carers have reported stress, anxiety or depression as a result.
- Almost two thirds (63%) of carers reported feeling alone in their caring role.
- For 4 in 10 carers (40%), this has meant they were unable to progress their education.
- 40% of carers reported actually giving up their studies.
- Over a third (35%) of carers said that they are now worried about their future employment prospects.
- Nearly a third (32%) of carers reported not getting the grades or qualifications they expected.

Research by theme: Education

Where carers say there are no policies in place to support them:

- Half of carers (50%) have been unable to progress their education.
- Half of carers (48%) had to give up their education.
- One-third of carers (38%) haven't been able to get the grades or qualifications they expected.
- 7 in 10 carers (71%) have experienced stress, anxiety and depression.

Impact of a lack of understanding

As with juggling work with care, it is the barriers that are linked to the incomprehension of caring that have the greatest effect on carers.

Where carers feel unable to talk about their caring role to other students and where their teachers or lecturers do not understand their caring, there are much more negative outcomes for carers. 71% of carers have experience stress, anxiety or depression as well as feeling alone in their caring role as a result. 46% haven't been able to progress their education with 44% giving up their studies altogether. 38% haven't been able to get the grades or qualification they expected and 37% are worried about their future employment prospects.

50%



have been unable to progress their education

71%



have experienced stress, anxiety and depression

48%



have given up their studies

38%



haven't got the qualification or grades they expected

Carers experiences



I have recently started an access course. I have had to give up good voluntary and paid work to do this in the hope that it will pay off. It is a struggle to manage but has been a welcome break from caring, stimulating and I am applying for university next year.



There are no barriers as I'm a part time distance learner with the Open University. They are a fantastic learning provider and are very understanding and supportive of my role as a carer. However I struggle to find time to study and meet deadlines, and often fail to reach grades I know I am capable of.



There have been courses which I should have liked to attend but the hours or location have been impossible to work around.



My school know about my situation but avoid talking about it. They won't tell my teachers about my circumstances - they make me keep everything private. I don't want to keep everything private; I am not ashamed. They have offered no emotional support. They wait for me to approach them and they never start a conversation with me first. They are trying to help me but they are going about it in the wrong way. I don't blame them, it is not their fault, they just don't understand.

Best practice



Sheffield Hallam University

Sheffield Hallam is a Carer Friendly University, supporting students with caring responsibilities from before they start through to graduation and beyond.

Students are encouraged to let the University know about any caring responsibilities when they enrol. A named contact in the Student Transition and Progression team can then provide support with settling in, information about relevant services, and one-to-one advice about University life and local carers' groups.

The Carers Café based at the Student Union also provides an information place for student carers from Sheffield Hallam and the University of Sheffield to meet, share experiences and find out more about support available to them.

Stockport School

Stockport School has achieved a Gold Young Carers in Schools Award from Carers Trust and The Children's Society in recognition of the school's actions to identify and support students with caring responsibilities.

Through assemblies and tutor time, staff training, the school's website and other communications with parents and families, the school has raised awareness about young carers and the support the school provides significantly, and ensured all school staff are able to spot the signs that a pupil may be a hidden young carer. The monitoring of young carer outcomes are embedded within existing school systems and a named school lead meets regularly with young carers to discuss academic progress and identify possible interventions. The school works closely with the local young carers service and other agencies to ensure the needs of the young carer and their family are met.

York College and York Carers Service

Collaborative working between York College and York Carers Service has improved the identification of students who are eligible for a student's bursary because of their caring role. They collaborate by conducting initial assessments, running drop-ins, liaising with the welfare team and providing additional opportunities for carers. This has improved uptake and student outcomes including a lower drop-out rate and increased attendance.

Research by theme:

Older carers

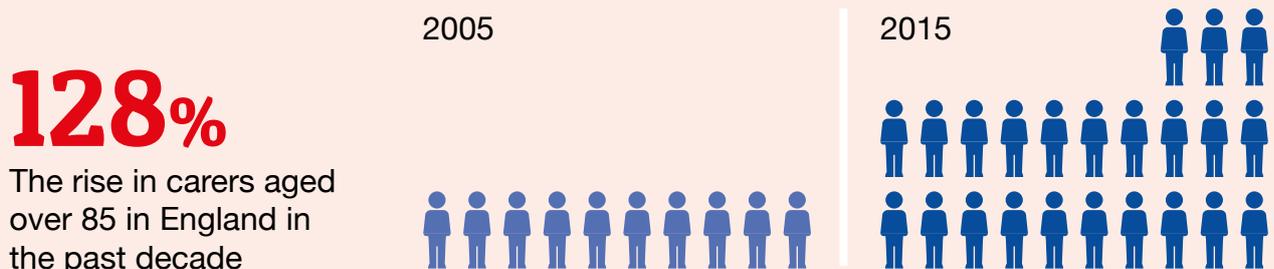


There are almost 1.3million people over the age of 65 providing unpaid care to a family member or friend in England and Wales and this number is rapidly growing.

There has been a 25% rise in carers over 65 in England over the past decade and a 128% rise in carers aged over 85.

Over half of carers aged over 85 provide 50 hours or more of care a week.

Older carers are more likely to co-care than other groups and have health issues of their own that require care and support. Ageing and declining health also impacts on older carers' ability to maintain their health.



Barriers and impact on older carers' wellbeing

The main barriers that older carers find prevent them from maintaining a healthy lifestyle mirror those of the wider carer population:

- Almost a half (49%) of older carers said that their GP practice hasn't informed them about how to get practical support as a carer.
- 44% of older carers reported that their GP practice hadn't offered them an annual health check.
- A third (33%) say that they haven't received any training or information to help them keep well.
- Only 38% of older carers said that they live in a community that supports and understands them.

For older carers, it is especially important that they get to health tests, check-ups and specialist appointments as when they are unable to it has

very negative consequences for their health. Any impact could have worse consequences for older carers because it will come on top of issues that affect those later on in life such as increased number of long term health conditions, reduced social networks and increased isolation and loneliness. As more services or access to services move solely online, some older carers will also be at a disadvantage.

- 6 in 10 older carers have let a health problem go untreated, compared to 34% of older carers who don't have this as a specific obstacle.
- 46% of older carers have physically injured themselves as a result.
- 59% reported that their health is becoming a significant worry (this is much higher than the carer population of the survey as a whole).

Carers experiences



My mother's dispensing pharmacy is the most emotionally supportive of all the agencies. Both my mother's and my GP surgery are very, very busy.



My pharmacist is excellent and provides help and support.



The most important problem is getting enough exercise. I sometimes get out for a short walk when the care workers are here but they often need my presence to interpret his needs.



I am close to 80 years of age and lack information or assistance from my GP practice. Other than completing a discharge survey my hospital has little interest in my caring role.

Best practice



Age UK Dacorum Carers Support

Age UK Dacorum offers its Carers Support to people living in the Borough of Dacorum in Hertfordshire who give unpaid care to a relative, neighbour or friend, where one of them is over 50. Their aim is to help carers take control of their life and situation so they can make decisions that are right for them. They are there to help in a non-judgemental and empowering way, if and when carers need them.

The service offers accurate information and guidance on a range of issues from sitting services and respite care, to adult needs assessments and help securing financial entitlements. They also provide volunteer home visits for carers who are housebound or isolated, information about leisure and social activities, fortnightly carer support groups, and provide regular emotional support phone calls.

Recommendations

With a new Carers Strategy in development in England and new governments forming across Scotland, Wales and Northern Ireland, this report comes at an important time.

These recommendations should be implemented as new policies are designed and as the Carers Strategy is drawn up. The evidence from carers shows the difference that having the right support across the community can have.

Across the UK, there is a need for adequate funding of social care support which must be addressed by newly elected governments and assemblies in Scotland, Wales and Northern Ireland and by the UK Government as a matter of priority.

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Importance of raising awareness and increasing understanding about carers

Carers who felt that their community understood and valued them were less likely to face obstacles in maintaining a healthy lifestyle, maintaining relationships, balancing work or education with care. Even where they did face these challenges, they were much more resilient to the consequences.

This shows the importance of carer friendly communities in supporting carers to keep well and sustain their caring role whilst having a life of their own.

It is time for all aspects of the community to take positive steps towards being truly carer friendly.

As a first step, we would encourage community services and business to commit to taking carer friendly action as part of Carers Week 2016.

Carers Week has a role to play too in promoting awareness of carers, thereby increasing understanding and helping to build carer friendly communities.

Health



The research showed the importance of support from health services as well as the vital role that advice and information plays in keeping carers well.

The NHS must take more steps to become carer friendly and support carers. Health services must ensure that carers have access to flexible services, are directed to the right support and are involved in decisions about the care for their family member or friend.

Simple actions health services could take:

- Offer flexible appointment times, priority time slots for carers or home visits for carers as routine.
- Offer health checks.
- Hospitals to introduce Carer Passports for carers of patients to help identify and improve support for carers.

- Note on patient records both whether the patient has a carer, and if so who that carer is, but also if they are a carer themselves. If they are, ask them how they are managing their caring role and whether they need support with it.
- GP practices and hospitals should consider including a question on any admission procedure identifying carers and requirements for replacement care which would enable carers to access much need appointments or treatment.
- Hospitals should introduce Carer Passports for carers of patients to help identify them and to let them know about carer friendly policies. These might include free car parking or allowing some carers to spend time with the person they care for outside visiting hours.
- Link with key local organisations to help signpost families to support.
- Ensure carers can access free replacement care in order to be able to attend health appointments.

Employment



Employers who create a carer friendly workplace where carers are able to be open about their caring role without a feeling of incomprehension from managers or colleagues are much more likely to be able to retain their employees when they take on a caring role. With even more workers taking on caring role in the future as our population ages, it is important that employers take action now.

Employers could take the following carer friendly actions:

- Introduce and promote flexible working policies.
- Introduce paid care leave so that carers are not forced to take annual leave for caring emergencies or to support the person they care for, for example at health appointments.
- Set up or encourage staff to set up a carers' staff network.
- Ensure that there is regular communication to employees informing them of their rights, including their right to request flexible working and take emergency time off to care for dependents when they need it.

Recommendations

Education



The research showed that barriers to education can affect a carer's future employment prospects and finances. With almost half of carers reporting that there were no policies in place to support them, it is important that educational establishments take action to ensure they have these in place.

With lack of understanding providing a significant barrier to carers being able to balance education with care, schools, colleges and universities have an important role to play in starting those conversations, breaking down misconceptions about current or future caring and educating young people about caring.

Other practical actions educational bodies can take:

- Colleges and universities should offer flexibility with timetabling or internal deadlines.
- Colleges and universities should offer remote access (such as Skyping into a class) or distance learning where possible.
- Schools should include caring as a subject within the school curriculum. Talking about caring as a normal part of life is important for improving understanding – whether it is having grandparents who support each other, a brother or sister with a disability who needs care, or being a carer yourself.
- Schools should adopt a whole school approach to identifying and supporting young carers as set out in the Young Carers in Schools programme.
- Schools should ensure young carers benefit from targeted support funded through the Pupil Premium.
- Colleges and universities should proactively identify and support young adult carers, including providing financial support through bursaries for all ages.
- Education providers should have systems in place to signpost to support, including sources of support for the person who is being cared for, in order to prevent or reduce the carer's caring role.

Older carers



Older carers reported worse consequences for their health if they were unable to get to their appointments and check-ups. It is therefore important that older carers are supported to get to hospitals, GP practices and clinics for any tests they have scheduled or when they have a health concern.

- GP practices and hospitals should ensure that older carers are offered flexible appointments and home visits where possible.
- Older carers should be offered information and advice on planning for the future and managing their caring responsibilities along with their own health needs.



Appendix

The research for this report was carried out as part of Carers UK annual State of Caring survey.

A total of 6,149 carers and former carers responded to Carers UK's annual State of Caring Survey between March and April 2016.

Only responses for the 5,682 current carers who completed the survey are included in this report as it is designed to provide a snapshot of caring in 2016. However, Carers UK will be using the responses of former carers in other pieces of work throughout the year.

Compared to the carer population as a whole, respondents to this survey were more likely to be female, disabled themselves and caring for a high number of hours every week.

Of respondents to the State of Caring Survey 2016 who are currently caring:

- 78% live in England, 9% live in Scotland, 8% live in Wales and 5% live in Northern Ireland
- 78% are female and 22% are male
- 26% consider themselves to have a disability
- Only 1% are aged 0-24, 3% are aged 25-34, 13% are aged 35-44, 28% are aged 45-54, 34% are aged 55-64, 16% are aged 65-74 and 5% are aged 75 and over
- 19% also have childcare responsibilities for a non-disabled child under 18
- 31% are in work (13% full-time and 18% part-time)
- 35% have been caring 15 years or more, 16% for between 10-14 years, 23% for 5-9 years, 23% for 1-4 years and just 3% have been caring for less than one year
- 52% care for 90 or more hours every week, while 16% care for 50-89 hours, 22% for 20-49 hours and 10% care for 1-19 hours a week
- Most (75%) care for one person, 19% care for two people, 5% for three people and 1% care for four or more people.



Carers Week is an annual awareness campaign to celebrate and recognise the vital contribution made by the UK's 6.5 million carers.

Find out more and get involved at carersweek.org

 info@carersweek.org  [/carersweek](https://www.facebook.com/carersweek)  [@carersweek](https://twitter.com/carersweek)

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