Evidence for the Carers Strategy
Written Submission from Carers UK

About Carers UK and evidence base

- As the UK's only national membership charity for carers, Carers UK is both a supportive community and a movement for change. For the past 50 years we've been driven by carers raising their voices together to call for change and seek recognition and support. Whilst caring is part and parcel of life, without the right support the personal costs can be high as it can affect your job, your health and your finances.

- Carers UK is a membership organisation of carers, run by carers, for carers. We have 28,000 members and a reach of many more. We provide information and advice about caring alongside practical and emotional support for carers. Carers UK also campaigns to make life better for carers and influences policy makers, employers and service providers, to help them improve carers' lives.

- Carers UK’s advice and information services answer around 20,000 queries from carers and professionals every year. Our website is viewed by over 100,000 people every month, over 24,000 subscribe to our monthly email newsletters. Our social media networks reach in excess of 550,000 people. We’re in regular contact with around 1,500 local organisations, including many run by carers, who are in touch with around 950,000 carers. Carers UK works across the UK with offices in England, Wales, Scotland and Northern Ireland.

- Carers UK and major businesses have set up Employers for Carers offering help to employers to retain the 1 in 9 employees who are caring for a family member. Employers for Carers is a forum of employers – large and small – currently chaired by British Gas and supported by the specialist knowledge of Carers UK. Our Employers for Carers network covers well over 100,000 people juggling working and caring.

- This evidence base is drawn from a variety of sources:
A series of programmes of research directly from carers e.g. our State of Caring 2016 survey of 6,000 carers and past surveys which comprise approximately 10 years of continuous evidence from carers.

Our Advice and Information service which responds to over 20,000 queries from carers and professionals each year.

Our connections through our Forums and social media platforms where we connect with carers.

Our Carers Summit in 2015 where we asked for questions from carers in advance to feed into strategy developments.

Our Board of Trustees, the majority of Trustees must have caring experience.

Our work with employers.

Our work with other stakeholders, such as local authorities.

Wider international evidence gathered from our international conference on caring held in Sweden in September 2015 with representatives from 32 countries.

Carers UK welcomes the opportunity to respond to the Strategy. In addition to this response, Carers UK will be submitting:

- ‘Caring Homes’ – a more detailed paper on caring and housing
- A more detailed submission from Employers for Carers
- Evidence compiled through the Carers Week partnership – a research report and evidence from a roundtable discussion.

Carers UK’s vision for carers & the role of the Carers Strategy

Carers UK wants a society that respects, values and supports carers. Our vision is a world where caring is valued, where carers have a choice about caring and are able to care without putting their own lives on hold. Where carers do not have to face financial hardship as a result of caring for someone and have choices about whether or not to work alongside caring.

By 2017, we will have reached a tipping point in care where the demand from older people needing care will outstrip family members able to meet that need. This “care gap” is expected to increase rapidly over the next two decades\(^1\). With this date fast approaching, it is clear that we need to plan for the future.\(^1\)

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\(^1\) Linda Pickard (2013) *A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032* is published in *Ageing and Society*.\(^1\)
approaching, the new Carers’ Strategy has come at a crucial time. More unpaid care than ever is being provided by family and friends, at the same time that we are having children later and our working lives are being extended. Our public services need to adapt to this evolving world with a step-change in the support available for families.

The new cross Government Carers Strategy presents a vital opportunity to take a holistic view of the needs of carers. Carers UK welcomes the development of the Carers’ Strategy and its ambition to improve support for carers across all areas of their lives. Carers need a strategy matched by action that delivers concrete improvements.

All of us will be touched by caring in our lifetime, whether we take on a caring role or we need care ourselves. The Carers’ Strategy must deliver on strengthening support, value and respect for carers.

Carers UK has developed a series of outcomes that we want to see delivered through the Strategy:

**Recommended outcomes for the Carers Strategy:**

- Carers are supported so they are not forced into financial hardship
- Carers are able to juggle work and care, returning to work if they wish
- Carers understand their rights and entitlements and get access to the right information and advice at the right time, including when caring at a distance.
- Carers and the person they are caring for have access to the right care and support needed to live a full life. For carers, this needs to support them in their caring role.
- Carers’ health and well-being is supported whilst caring, and when caring comes to an end.
- Carers have the right laws underpinning their rights to maximise their entitlements.
- Carers are given the right training, education and support to be able to care safely and well, as well as having their skills and learning recognised and developed.
- Carers are recognised as expert partners in caring
- Carers are able to adjust and plan at all stages of caring, including caring at the end of life.
- Children and young people caring are protected from inappropriate caring roles, and have the support to learn, develop and thrive.
- Carers have a life outside caring.
- Carers are better supported and enabled to care through better housing.
- Carers know that their views matter
- Future generations of carers are more prepared for caring
Our response summarises what carers need for these outcomes to be achieved with recommendations for action.

**Key recommendations:**

- Carer’s Allowance needs to be raised significantly over the longer term and in the short term at least raised to the level of JSA – matching the pledges made in Scotland by all political parties to carers.
- The earnings threshold for Carer’s Allowance needs to rise year on year in line with the National Living Wage and a taper should be introduced.
- A new Government aim to make every workplace carer friendly.
- Introduction of a new right to paid care leave of between 5 to 10 days for carers in work.
- Increased funding for social care putting in place a sustainable funding settlement for social care and ring-fenced funding for carers’ breaks.
- A review of the implementation of the Care Act 2014 and the Children and Families Act 2014 in relation to carers’ assessments and support following assessments.
- A review of legal rights to support for those caring for disabled children under 18 with legal changes to bring rights into line with those caring for adults.
- A new duty on the NHS to put in place policies to identify carers and to promote their health and well-being – helping to build a carer friendly NHS.
- A new programme of work looking to support former carers – and support pre- and post-bereavement, including a review of benefits to give longer benefit run-ons and support with returning to work.
- New and earlier access to advice and information for carers and a new awareness campaign around planning for care in later life.
- A new programme targeted specifically at carers accrediting skills learned whilst caring.
- A new focus on technological solutions to make life easier for caring.

**Caring now and in the future**

The amount of unpaid care being provided is increasing

- Between 2001 and 2015 the UK’s population increased by 6.2%. The 16.5% rise in the number of people providing unpaid care thus outstrips the population

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² Census 2011
increase and represents a large growth in caring, with a higher proportion of people providing care. The increase in people providing substantial amounts of care (20-49 hours per week) was very large (up almost 43%) and rose sharply (by almost 33%) among those caring intensively (for 50 or more hours per week). The changes are dramatic and particularly affect the carers likely to be in greatest need of support. Between 2011 and 2015 the population increased by 3.4%; again the rise in people providing unpaid care (4.9%) has been greater than the population increase. The 6.9% increase in the numbers of people providing over 50 hours of care per week is especially remarkable. By far the largest increase is seen among people caring at this intensity, showing that carers are caring for even longer each week.

The value of unpaid care carers give each year in the UK is £132 billion.

Who is caring?

According to the Census 6.5 million people in the UK provide unpaid care. The majority of current carers are of working age and the peak age for caring is 50-64 – over 2 million people in this age bracket are carers. One in five people aged 50-64 are carers.

There are 1.2 million people in England aged 65 and over who are providing unpaid care to a disabled, seriously ill or older relative or friend. The number of carers aged 85 and over grew by 128% in just ten years.

Nearly 3 in 5 (59%) carers aged 85 and over are male.

Future carers

Carers UK estimates that by 2037 the carer population in the UK will reach 9 million.

By 2017, we will have reached a tipping point in care when the demand from older people needing care will outstrip family members able to meet that need and this “care gap” will increase rapidly over the next two decades.

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3 Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers – the rising value of carers’ support
4 Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers – the rising value of carers’ support
5 Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers – the rising value of carers’ support
6 Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers – the rising value of carers’ support
7 Census 2011
8 Carers UK & Age UK (2015) Caring into Later Life
9 Carers UK & Age UK (2015) Caring into Later Life
Demographic changes mean growth in caring roles will be experienced most acutely by older carers, male carers, and BAME communities, resulting in increased diversity of the caring population.

We will see the number of older carers rise to over 1.8 million by 2030.\textsuperscript{11}

International context

This is not an issue that we’re tackling alone, caring is an international issue. Our International Conference hosted representatives from 32 countries sharing a variety of approaches to ensure that an ageing population is sustainable.

Carers and the Equality Act 2010

Caring is full of diversity – in terms of conditions and disabilities that people have where carers are supporting them, to the populations they are drawn, income status, geographical location, etc. The Equality Act 2010 brought the landmark court judgment from the European Court of Human Rights recognising, for the first time, that carers could be discriminated against by association with a disabled person.

Carers UK’s work on BAME carers showed that Britain’s BAME population was relatively young and people in most BAME communities slightly less likely overall to be carers. However, the statistics also showed significant numbers on the cusp of moving into age groups where there is a higher level of disability and chronic illness – increasing the likelihood of a steep increase in the number of BAME carers. This is particularly true for certain communities and something which BAME carers felt that local authorities, public services and care services were not yet planning for.

Issues for other groups such as LGBT carers are not widely understood and would benefit from further work. Likewise, there are few user-led support groups focused these issues. Carers UK has published the first ever estimate of the number of LGBT carers at around 390,000 carers – a significant proportion of carers.\textsuperscript{12} One in twenty (5\%) of staff in the social care profession have witnessed poorer treatment or discrimination for a patient or service user because they were LGBT.\textsuperscript{13}

\textsuperscript{10} Linda Pickard (2013) A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032 is published in Ageing and Society.

\textsuperscript{11} Carers UK & Age UK (2015) Caring into Later Life

\textsuperscript{12} Carers UK, Facts about Carers, 2015

\textsuperscript{13} Stonewall (2015), Unhealthy Attitudes
Sex still has a role to play, with assumptions still being commonly made that it is a woman’s role to care. Women are less likely to be working full-time but caring and working part-time. Caring is therefore a significant factor in the gender pay gap and lower pensions in retirement for women.

- 72% of Carer’s Allowance claimants are women.  
- Female carers are more likely to be providing ‘round the clock’ care, with 60% of those caring for over 50 hours a week being female.
- About the same number of men and women care for a spouse or partner. But a much larger number of women than men provide care for someone outside of their household (1.9 million compared to 1.1 million).  

Men on the other hand often feel that services are set up around a system that doesn’t naturally see them as carers, creating a reluctance to seek support. Men are also more likely to be working full-time and caring.

For older carers, there are particular issues. There are 1.2 million carers aged 65 and over in England and 87,346 carers aged 85 and over. Whilst older carers might be more likely to receive an assessment and be offered rather than have to ask for one, the needs of older carers are significant and many have several health conditions of their own meaning that many older people are both providing and receiving care.

**Recommendations:**

- That Government and local government should work with the care sector to plan care services for diverse and changing communities, including ensuring that Public Sector Duty requirements under the Equality Act 2010 are being met.
- The Government and local government should create targeted information and advice for specific carer groups – particularly, BAME carers, carers who are themselves disabled and male working age carers.
- The Strategy should embrace the diversity of carers across many different caring situations, as well as carers from different backgrounds, communities and across the protected characteristics.

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14 Carers UK (2015) The importance of Carer’s Allowance Recognising and supporting family care
16 New Policy Institute (2016), Informal care and poverty in the UK
17 Carers UK & Age UK (2015) Caring into Later Life
Different stages of caring, advice and information

Strategy outcomes:

- Carers understand their rights and entitlements and get access to the right information and advice at the right time, including when caring at a distance.
- Carers are able to adjust and plan at all stages of caring, including caring at the end of life.
- Future generations of carers are more prepared for caring

Carers UK has identified several different stages of caring – moving from the new to the end of caring – where someone might die, become fully independent/move away or experience an improvement in their health.

At each stage of the caring journey different support and advice is needed. When asked what is most important to them, carers place an extremely high value on information and advice that is tailored and delivered at the right time.

“From the time the person you are caring for is diagnosed you need to be told what help you can get. Not left to find everything out for yourself”

Carers UK member

Most carers do not identify themselves as such but see themselves as mothers, sons, nieces, nephews, partners, husbands, close friends, etc. A whole new approach is needed to addressing the challenges faced at different stages of caring and planning for the future. The advent of smart phones, online information, curated content, open Application Programme Interfaces and digital planning and co-ordination tools open up a wealth of possibilities for public authorities, businesses and the voluntary sector to make use of in identifying carers, tailoring responses and delivering the support they need at different times.

Those critical times include when a carer is:

- New to caring – carers should be signposted to important information on diagnoses.
- At any important stage through the health service (identification processes are highlighted later in this response).
- At key stages in the caring journey such as changes in needs or a change in the support needed, help and advice around career transitions, etc.
- Finally, preparing for the end of caring, particularly around bereavement and when the caring role ends
“When he died, the shock was compounded by the fact that they took the car away as it was his car, the accommodation was because of him, so I had to move, and all the other financial and legal matters that I hadn’t planned for or knew about. Although people thought that I’d be better off because I was no longer caring, I just felt lost. I hadn’t got any friends left, no social life, no money. I got ill almost immediately and it was a completely nightmare. It’s taken years to recover.”

Respondent to State of Caring Survey 2016

Care Act 2014 duties on information and advice:
Local authorities have important new duties in the Care Act 2014 in particular the provision of advice and information including financial planning. An information and advice duty of a very basic nature has existed since around 1970, but as a target duty. The evidence that Carers UK has gathered from carers around the implementation of the Act is that too few were getting the right information as a result of a carer’s assessment. Our early work on the implementation of the Care Act 2014 showed that only 35% of those carers who had had an assessment in the last year were told how they were able to get all the information and advice they needed. The information and advice provided online by local authorities varies significantly from authority to authority – as does the information and advice provided by second tier authorities.

We would recommend that local authorities look at earlier intervention and easy access tools like Carers UK’s informal self-assessment tool – Upfront – a two minute questionnaire which leads to a tailored information prescription. A few local authorities are using the Upfront guide to Caring as a means of rolling out self-help and early intervention.

Whilst it’s vital to embrace the potential of digital technology to reach carers with information and advice, paper based and face to face advice is needed for many carers who are not able to access online information.

Recommendations:

- Government, namely the Department of Health working with other departments including the Department for Work and Pensions and Department for Business, Energy and Industrial Strategy should support a public awareness campaign to:
  - raise the profile and public understanding of caring
  - ensure carers are able to access information and support when they need it
  - encourage people to plan earlier for care in later in life

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- improve public awareness of the potential of health and care technologies to support them
- encourage employers to adopt carer friendly policies to support carers in and into work

- Government needs to work alongside the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) to look at the implementation of the information and advice duty in the Care Act 2014 to ensure that opportunities are being used to reach whole populations and give advice and information early in the caring journey.

- Government needs to review its own information provision to improve the coordination of different services for people looking for support with caring. For example:
  - A Carer’s Allowance application could trigger a link to support in the local authority
  - Gov.uk could be used to boost direct links to local authority sources of support.

**Building Carer Friendly Communities**

**Strategy outcomes:**
- Carers are able to juggle work and care, returning to work if they wish.
- Carers are recognised as expert partners in caring.
- Carers know that their views matter.
- Future generations of carers are more prepared for caring.
- Children and young people caring are protected from inappropriate caring roles, and have the support to learn, develop and thrive.
- Carers have a life outside caring.

In 2013, Carers UK developed the concept of Carer Friendly Communities which was later launched for Carers Week 2015 in partnership with other charities. The purpose of Building Carer Friendly Communities was to engage all parts of the community in supporting carers, taking a bottom up, community based approach that allowed individuals, businesses, employers, care services – essentially all parts of the community to make a contribution in some way. The campaign, for Carers Week, has taken a positive approach, building awareness of caring, whilst celebrating what is working in our communities and society for carers.
The Carers Week research shows that when carers are supported by their community, they face far fewer barriers to having a life outside of their caring role:

- Carers who are supported by their communities are three times more likely to always be able to maintain a healthy lifestyle (27% compared with 9%)
- Carers who are supported by their communities are three times more likely to always be able to maintain relationships with close friends and family (29% compared with 9%)
- Carers who are not supported by their communities are more than twice as likely to never be able to balance work with care (35% compared with 15%)
- Carers who are not supported by their communities are more than twice as likely to never be able to balance education with care (47% compared with 23%)

To date the campaign has engaged several thousand organisations. Over the last year at least 1400 activities were organised for Carers Week. The majority of events involved volunteers, and created and developed new partnerships with health bodies, public authorities, local employers, local community organisations and others.

Carers UK created and developed a Carers Checklist with support from other Carers Week charity supporters looking at what carers wanted and needed from carer friendly communities.

**Volunteering and social action**

The role of social action and carers continues to be vitally important and one which Carers UK is committed to continuing. Carers Week has a high level of engagement around social action as does the rights based awareness campaign run by Carers UK, Carers Rights Day. Whilst it cannot replace good quality public and other services, the evidence from our programmes is that the majority of people helped by our volunteers feel that it reduces loneliness and isolation, they feel more in control of their lives, they have improved ability to cope and they do not feel alone. Many are connected further to sources of advice and information which supports improvements in their lives.

**Recommendation:**

- That Government works with Carers UK to further develop the Carer Friendly Community concept into multi-year activity, engaging many sectors of the community to reach many more carers earlier in their caring journey and support cultural change and recognition that caring is a near universal experience.

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The NHS, Health and Well-being

Strategy outcomes:
- Carers' health and well-being is supported whilst caring, and when caring comes to an end.
- Carers are given the right training, education and support to be able to care safely and well, as well as having their skills and learning recognised and developed.
- Carers are recognised as expert partners in caring.

Carers' health needs to be split into two:

a) Their own health and well-being
b) Their role as a carer in supporting others – needing the NHS and other health and allied services to recognise their role.

The latest Census suggests that those providing over 50 hours of care per week are twice as likely to be in bad health compared with non-carers\textsuperscript{21}. The GP Patient Survey 2015 showed that whilst 51\% of non-carers had a long-standing health condition, this rose to 63\% of all carers and 70\% of those caring for 50 hours or more. Carers’ own experiences suggest that long term back and mobility problems are caused by long term physical stress, moving and handling without the right equipment or training. Anxiety and depression rates are high, of Carers UK’s 2015 survey of carers providing significant care – 77\% recorded anxiety and 83\% had experienced depression since becoming a carer\textsuperscript{22}.

For those juggling work and care, carers are more likely to be suffering from ill-health and stress in the workplace. Many experience a drop in income, especially if they have to give up work to care, and this subsequently results in higher levels of stress and depression associated with money worries alongside caring\textsuperscript{23}.

The evidence from carers is also that they are not always able to care for their own health and well-being. As well as physical injury and mental ill-health as a result of caring, they are also less likely to be able to attend routine public health related appointments or follow-through with key health interventions. As part of Carers UK’s research for Carers Week carers identified the main barriers to looking after their own health:

\textsuperscript{21} Census 2011
\textsuperscript{22} Carers UK (2015), State of Caring Report 2015
\textsuperscript{23} Carers UK (2016), State of Caring Report 2016
45% said their GP practice had not offered them an annual health check

42% said not receiving any training or information on keeping well

26% said struggling to get to their own health tests, check-ups and specialist appointments

Previous evidence showed, at the extreme, heart operations being delayed, cancer follow-up treatment not taken, and screening appointments regularly missed.

In the last three years, the numbers of carers identified by GP practices has fallen, despite the promotion of good practice in some areas. Funding is not always consistent for promotion work and local improvements are not always sustained.

On the one hand, the NHS often expects family to support other members, but on the other hand can fail to equip them with the knowledge and expertise to do so, and does not consistently recognise or support them. Carers UK has long called for a duty on the NHS to identify carers and promote their health and well-being. As a target duty, not only would this change practice and activity, but it would also change culture – to one that values at the role of carers and treats them as expert partners in care.

Some good practice has been developed in hospitals using the model of carers passports as a basis. The development of a Commissioning for Quality and Innovation payment (CQUIN) in the NHS around John’s Campaign will help to drive practice around identification and support for carers of dementia patients. This could be broadened out into other areas where caring is particularly important.

The Government should work with NHS England to support a drive to develop more carer friendly hospitals and seek to have a carers passport system in every local hospital. The outcomes from successful schemes are documented in our policy and practice briefing which show improved staff/family/patient relationships, better hospital discharge, etc.

The issue of high charges for hospital car parking continues to be a problem for carers. Although the Hospital Car Parking Charges Bill was not successful, Carers UK welcomed a more explicit mention of carers in the guidance on car parking. Hospitals should be audited to look at the extent to which carers are being prioritised for free or discounted car parking. Carers UK continues to call for carers to be exempt from car parking charges.

“When my mother was taken into A&E with an infection, parking charges were the last thing on my mind. Over the next few days – and weeks – I was paying £6

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24 Carers Week (2016), Building Carer Friendly Communities, Research report for Carers Week 2016

25 Carers UK (2016) Carer Passport: identifying carers and improving support
a day to visit my mother in hospital. The cost of the 30 mile round trip and the parking took up most of my weekly Carer’s Allowance, which is my sole income. At stressful times, hospitals could do so much more to support carers; at the very least, they should provide free parking.”

Ann Brosnan, carer

For carers reliant on hospital and public transport, these services are essential in enabling carers to have time for themselves and combine working and caring if they wish to. Poor access to transport is a particular problem for carers in rural areas.

Role of technology

Technology has an important role to play in supporting carers’ health and well-being. Carers using Carers UK’s online forum state that their health and well-being is improved as a result of their interaction – a quarter of carers responding to our forum survey said their health was better as a result of using the forum and 42% said they feel less anxious. With more services available online – effectively giving 24 hour access to communications and services, carers are able to complete tasks at a time convenient to them, rather than when services are open.

Carers UK believes that electronic patient records, new services that speed up access and accuracy of services e.g. emailing pharmacists prescriptions, and professionals sharing information across health and social care and between primary and secondary care, should make life easier for carers. We also believe there is significant potential for health and care apps to support coordination of care, prevention and self-management. Cares UK has produced a care co-ordination app, Jointly, which is already supporting 4,500 carers manage their caring responsibilities, often alongside paid work or caring at a distance.

It is vital that the mandate for the NHS from DH ensures that carers are a core part of all technology developments. Carers UK will continue to work on the National Information Board’s key priorities and roadmap for change.

Recommendations:

- A new duty on the NHS to put in place policies to identify carers and to promote their health and well-being – helping to build a carer friendly NHS.
- NHS England should show consistent leadership on carers’ issues by ensuring that carers they are included in key NHS planning documents, including the NHS Mandate, the Outcomes Framework and implementation of the 5YFV, for example through Sustainability and Transformation plans.
- The Department of Health should look at developing a programme of work through pharmacies looking at how carers are identified and then supported with
advice and information including introducing a programme of annual health checks for carers to be carried out by GPs and pharmacists.

- Carers feel strongly that confidentiality is not always well understood, particularly in mental health. NHS England must carefully consider confidentiality implications for carers as part of the development of electronic patient records – with the aim of clear and consistent rules being applied.
- The Department of Health and NHS England should develop a core carers passport scheme that could be widely adopted across all NHS hospital settings, being adapted after time in GP practices to help build a more carer friendly NHS.
- The Department of Health and NHS England should monitor the impact of new guidance on free and discounted car parking and be ready to legislate to introduce mandatory free parking for carers.
- The Department of Health to work with NHS England to review the degree to which carers have access to mediation and counselling services, with a view to improving access to psychological therapy services where carers’ mental health and well-being is poor.
- The Department of Health should work with NHS England and local authorities to ensure that carers have access to health related training e.g. moving and handling, managing conditions, managing daily physio at home, managing medication, etc. if they are expected to perform these roles.
- Department of Health to work with NHS England to ensure the needs of carers are at the heart of the development and roll out of health and care technologies in the NHS with evaluation of the impact involving carers themselves.

### Supporting families: approaches, rights and entitlements

**Strategy outcome:**

- Carers have the right laws underpinning their rights to maximise their entitlements.

Carers’ rights are fundamentally important as they set the standards which society expects as a minimum response. Carers UK warmly welcomed the rights that carers secured through the Care Act 2014. We also welcomed the new rights of parent carers in the Children and Families Act 2014.

Carers UK has taken the first large scale early look at carers’ experiences of both pieces of legislation in our State of Caring 2016 research looking at the experiences of 3,000 carers in England. The whole family approach which underpins the legislation is
not yet in evidence in routine practice and would benefit from more work between the Department for Education and the Department of Health alongside the Local Government Association, Association of Directors of Adult Social Services and Association of Directors of Children’s Services.

Another issue is the difference between the rights of carers of disabled children and the rights of carers of adults only. The entitlement to support for carers of adults is clearer under the Care Act 2014 – where the carer has to have needs and the appearance of needs.

For parents of disabled children access to an assessment is taken to be where a child has a social care need as set out in the Children Act. However, in practice the threshold to meet this need is not always consistent and often high. This means that parents of disabled children are often, not offered or given assessments or seen as eligible for support. This is an area that needs to be worked through between the Department for Education and the Department of Health to ensure that carers of children have their own human rights respected and their well-being properly considered. This evidence has been provided through carers as well as practitioners acting on carers’ behalf. They have struggled to interpret the law as well as challenge practice.

There is an important need to address a gap in the rights base for carers of children without parental responsibility. The Children and Families Act only covers those with parental responsibility for a child and therefore excludes grandparents, aunts/uncles, older siblings etc. These carers retain a slightly different entitlement to an assessment under the Carers (Recognition and Services) Act 1995 but ideally an opportunity should be taken as early as practicable to tidy up this anomaly and make the rights of all those caring for a child consistent and in one piece of legislation.

When looking at the implementation of the Care Act 2014 in England with local authorities, Carers UK conducted a survey amongst practitioners in local authorities to look at opportunities around the new Act. They saw that there would be new opportunities given the refreshed duties on the NHS to co-operate with local government. However, they still felt very strongly that the imbalance of carers’ rights, entitlements and visibility between social care and health was a barrier to integration and joint working. This is where a duty on the NHS to identify carers and promote their health and well-being would create a more commonly shared rights base on which to better integrate services and support.

Recommendations:
- A review of the implementation of the Care Act 2014 and the Children and Families Act 2014 in relation to carers’ assessments and support following assessments.
• A review of legal rights to support for those caring for disabled children under 18 with legal changes to bring rights into line with those caring for adults.
• Department for Education to work with local authorities to explore whether additional practice guidance is needed around parent carers’ rights implementation – particularly around who assesses, rights to receive support, etc.
• The Department of Education needs to boost parents’ awareness of their own rights by working with the voluntary sector and through Parents’ Forums.

### Supporting families: Income and Finances

#### Strategy outcome:
- Carers are supported so they are not forced into financial hardship

Carers UK’s 2013 Caring & Family Finances Inquiry looked at carers’ incomes and finances and produced extensive evidence as well as a series of recommendations looking at:

- Boosting carers incomes where they were solely receiving benefits – recognising the role that they play in society
- Putting in place preventative measures that ensure that carers do not have gaps in their pensions records.
- Maximising carers’ ability to work and earn as much as possible whilst also caring
- Recognising the additional costs of caring and disability
- Maximising carers’ ability to learn, whilst caring, to enable them to work

The evidence from carers on their finances is strong and consistent. The findings from our most recent State of Caring Survey completed by over 6000 carers found:\n
- 44% are struggling to make ends meet rising to nearly half (48%) of those caring for 35 hours or more per week.
- A quarter of carers (26%) report that they have been, or are currently, in debt as a result of their caring role and over a third (37%) of carers struggling to make ends meet are using up savings to get by, suggesting that their ability to manage is unlikely to be sustainable in the longer term.

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\[26\] Carers UK (2016), State of Caring Report 2016
Financial hardship is putting further pressure on carers’ ability to get practical and emotional support with their caring role as 13% of those struggling financially are cutting back on practical support with caring and nearly two thirds (64%) are cutting back on seeing friends and families, increasing the isolation that many carers experience.

Worry about finances has a knock on impact on carers’ own health too. Across all carers, whether they are currently struggling financially or not, the numbers who report a level of worry about finances that affects their own health is high at 43%. Three quarters (73%) of those struggling to make ends meet report that worry about their finances is affecting their health.

“Caring for someone and looking after our baby is a massive physical and emotional drain. Adding to this the stress of becoming increasingly in debt and the knowledge that continuing along this path will end in eviction and the inability to pay bills, eat and heat the property causes stress for me and directly impacts on my partner’s health and wellbeing.”

Respondent to State of Caring Survey 2016

“When my savings, which I dip into each month, have gone then the debt will accumulate.”

Respondent to State of Caring Survey 2016

Recent work by the New Policy Institute\textsuperscript{27} provides background evidence on carers’ underlying poverty rates in relation to Carer’s Allowance. This provides a helpful basis on which it should be examined:

1. 1.2 million carers are in poverty. The poverty rate among carers, at 22% overall, varies considerably by age, care intensity and relationship to the recipient.

2. The poverty rate is much higher among working-age adults caring for at least 20 hours per week (at 35%). Higher intensity carers living with the care recipient have a particularly high poverty rate as the household contain two people (the care giver and recipient) with a limited capacity to work. 1.4 million working-age adults provide at least 20 hours of care and have a poverty rate of 37%.

Carers feel very strongly about the need for Government to urgently address carers’ financial support. In Carers UK’s call for evidence for our 2015 survey, carers top priority for the new 2015 Government was to ensure that carers did not face financial hardship.

\textsuperscript{27} New Policy Institute (2016), Informal care and poverty in the UK
Level of Carer’s Allowance
Overwhelmingly, carers’ priority is to see the rate of Carer’s Allowance rise from the current low level. They feel the level of Carer’s Allowance is a reflection of what they do in society, and the fact that it is the lowest benefit of its kind doesn’t recognise their huge contribution.

We positively recognised the fact that the Government chose to protect carers’ benefits by allowing it to rise in line with the Consumer Price Index whilst other benefits remained frozen. However, the fact that many carers depend on means tested benefits that are frozen means that carers and their families are far from unaffected by this policy.

“Carer’s Allowance is derisory and doesn’t recognise the true cost of caring.”
Respondent to State of Caring Survey 2013

We recommend that the Government follows all major parties in Scotland who before the 2015 elections committed to increasing Carer’s Allowance to at least the level of Jobseeker’s Allowance at £73.10 a week.

In addition, Government should also look at a boost to the Carer Premium (or carer element in Universal Credit) to recognise the additional costs that caring brings.

Carers often say that having to claim ‘low income’ benefits along with other, very different, groups of claimants fails to recognise their unique circumstances and contribution:

“I am unable to work because I am caring. Carer’s Allowance is not enough to live on, so I have to claim Income Support. Having to receive poverty benefits in return for what I do makes me feel like my role is not valued. I have to run a car because the person I care for cannot use public transport, but then I cannot afford to heat the house, have a break or even a day out.”
Respondent to State of Caring Survey 2013

“It was recommended that we have care workers come in to get my husband up five mornings a week. However this would cost £17. It makes the 36p an hour of Carer’s Allowance I get seem insulting to say the least.”
Respondent to State of Caring Survey 2013

Furthermore, carers are often shocked to find that they do not receive Income Support on top of Carer’s Allowance. Instead, the amount of Income Support they receive is reduced by the amount of their Carer’s Allowance, because Income Support is means-tested and Carer’s Allowance is treated as income.
“It is awful. I get Carer’s Allowance but this is taken off my husband’s Income Support. I lie awake at night worrying how the bills will get paid and how much further into debt we will have to go.”

Respondent to State of Caring Survey 2013

Older carers
Carers over the age of 65 who continue to care also feel that it is a strong moral question that their care is not visibly valued by the benefits system. Although the system allows older carers to claim Carer’s Allowance, they are not paid the benefit if they receive the state pension due to the overlapping benefit rule. Although many will have an underlying entitlement that passports them onto other benefits or means they receive the Carer Addition to Pension Credit, older carers feel that they should be better recognised and often feel it is particularly unfair that payment of Carer’s Allowance ends just at the time when their caring role is becoming both more intense and more of a struggle due to their own health needs.

“It makes no sense. I paid into my State Pension all my life – I am entitled to it. I care for 35 hours a week – I am entitled to Carer’s Allowance. That should be that.”

Respondent to State of Caring Survey 2013

Restrictions on earning and learning
There are a number of regularly reported challenges with Carer’s Allowance that involve the earnings threshold, the 21 hour study rule, the 28 day linking rule and where two or more people are caring for a severely disabled person.

The earnings threshold, increased a year ago to £110 per week which was welcome, yet still poses a structural problem for those just at the level of the National Living Wage. Since the NLW was increased, carers are not able to work 16 hours and still receive the benefit. In the run up to April 2016, when people commonly received a pay increase, Carers UK received a spike in enquiries from carers who were at risk of losing their benefit. From their evidence it did not appear to be possible to reduce their working hours. This issue will arise every year that the National Living Wage rises, with more carers choosing to give up work because they cannot make ends meet and continue caring. It would make logical sense, as well as sending out a clear message around supporting carers in employment, to synchronise the earnings limit with the National Living Wage.

“If I work more than a certain amount of hours I am penalised by losing Carer’s Allowance. If I earn just one penny over the allowed amount, Carer’s Allowance
stops entirely. Why doesn't the system look after those of us who need our jobs not just for the money but for self-worth and pride in ourselves?"

Respondent to State of Caring Survey 2013

“I have only worked a few hours a week for the last twenty years to keep within the limits of Carer’s Allowance. I have done low paid menial work to fit in with the earnings limit and as the years passed, employers were willing to pay me less and less because they said I wasn’t working enough hours to have proper experience in the jobs I was doing. As my husband’s condition deteriorated it was harder to work and it was more and more difficult to find any job that would give me the right number of hours. I haven’t found the right work in two years. I doubt I will ever work again.”

Respondent to State of Caring Survey 2013

Carers UK would also like to see a tapering on the earnings threshold for Carer’s Allowance. The introduction of Universal Credit, with monthly assessment, real time information on earnings and a single taper rate, will further highlight the inflexible and punitive nature of the earnings rules for Carer’s Allowance – earn £1 over the earnings threshold and you lose the benefit completely.

Carers UK recognises that the administrative challenges of tapering for Carer’s Allowance are complex. However, with the introduction of real time information gathering for HMRC, it should be possible to build a system in the future which is responsive to fluctuating earnings as well as introducing a taper that is responsive to carers’ needs. Carer’s UK recommends that the Government look at this further.

Another recurring issue that Carers UK receives enquiries from carers is in relation to Carer’s Allowance is around the 21 hour study rule. This is one of our most common queries for younger people who contact our adviceline, but it also affects adult returners who want to gain new skills or qualifications whose courses are considered “full time”. Because they are caring, they have no other way of supplementing their income as well as studying, unlike other students, and Carer’s Allowance is a valuable and reliable benefit. Further, unlike for the disabled people they care for, student support provides no additional support for carers. Carers UK would recommend abolition of the 21 hour study rule, and in particular for vocational related courses.

“My daughter spends a few hours a day at a day centre. Why wouldn’t the Government want me to use that time to learn new skills or train to try to get a job which I could do along with caring?”

Respondent to State of Caring Survey 2013

Run–on of benefits
Other issues raised with Carers UK include, in a few key cases, where the 28 day linking rule causes loss of benefits. This is most likely to be caused by longer hospital stays or more frequent respite care. Given the level of services rationing across health and social care, these are often the most severely disabled people in need of support. Carers UK has warmly welcomed the new measures which allow families of disabled children to keep entitlement to DLA whilst they are in hospital for a prolonged period (and correspondingly keep entitlement to Carer’s Allowance). In one case our adviceline received a call from a woman caring for her severely disabled adult son with very complex needs and challenging behaviour – her choice was to choose a break or choose her benefit. We do not have figures which look at how many carers are affected by the 28 day linking rule.

**Structural problems with Carer’s Allowance**
The final areas include problems for carers providing full-time care but who are prevented from getting Carer’s Allowance. This includes:

- Those who are caring for a very severely disabled individual needing at least two people to care for them, but only one can claim Carer’s Allowance.
- Those who are caring for two disabled people for a total of at least 35 hours, but for neither one a total of 35 hours a week on their own.

Carers UK recommends that the Government looks at both issues. Carers UK would welcome information which looks at carers’ experiences of the introduction of Universal Credit and will work with the DWP to look at how this develops further.

**‘Bedroom tax’**
The benefits system also needs to better recognise the role of carers. Whilst disability is often protected, caring is not and this is a problem for certain categories of carers. We have welcomed the Government’s work on the benefit cap which will now exclude carers with entitlement to Carer’s Allowance. We also hope that the Government will consider additional measures to exempt carers who are subject to the housing benefit size criteria (commonly known as the bedroom tax). More detail is provided in our submission on caring and housing.

**Extra costs of caring**
Families also incur a number of costs in caring and commonly they cite those costs as additional heating bills, different food bills, additional petrol from extra journeys made, specific products and the costs of adaptations, costs of prescriptions and additional medication, extra costs of travel, etc. Measures that allow free travel e.g. free bus passes for carers, free parking, and free entry to attractions make a big difference to the lives of all families and help to build a more carer friendly community. Since caring often comes with additional costs, this leaves less disposable income for carers.
Carers UK would like to see these additional cost areas examined to reduce the financial impact of disability/ill-health on the family.

“I travel 240 miles weekly now to visit and support two elderly people – my mum and mother-in-law. The extra petrol, tyres, insurance and the wear and tear to my car all costs me and I get nothing for it.”

Respondent to State of Caring Survey 2013

“We receive free pads for day use but none for night – so we have to pay for these.”

Respondent to State of Caring Survey 2013

According to the Department of Work and Pensions nearly 200,000 people with caring responsibilities could receive a boost to their pension – worth hundreds of pounds a year – by claiming Carer’s Credit. But currently only an estimated 5% of those eligible are signed up to receive these additional National Insurance contributions. Carers UK welcomed the measures that Government put in place to plug gaps in carers’ pensions records namely Carers Credit and we will continue to work on this to improve take-up.

Recommendations:

- Carer’s Allowance needs to be raised significantly over the longer term and in the short term at least raised to the level of JSA – matching the pledges made in Scotland by all political parties to carers.
- The earnings threshold for Carer’s Allowance needs to rise year on year in line with the National Living Wage and a taper should be introduced.
- A new programme of work looking to support former carers – and support pre-and post-bereavement, including a review of benefits to give longer benefit run-ons and support with returning to work.
- Review the possibility of a taper on Carer’s Allowance for the future.
- Lift barriers to study and training, by removing the 21 hour study rule – as a minimum for vocational related courses.
- The Department for Work and Pensions should consider introducing a ‘carers income guarantee’ ensuring that carers’ benefits are uprated at a ‘triple lock’ guarantee. Since the argument is that those receiving a pension are less likely to be in work. Carers receiving Carer’s Allowance similarly are less likely to be in work.
- Department of Work and Pensions should work with other Government departments such as the Department of Transport, Department for Business,

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Energy and Industry Strategy and Department of Health to review the costs associated with caring across other responsibilities of Government departments to see whether the costs of caring can be reduced such as reduced energy tariffs, discounted public transport, free hospital car parking, free NHS prescriptions.

- The Government should implement the Local Government Association’s proposal that there should be a council tax reduction of £100 a year for carers. anyone providing at least an hour of unpaid care per week.\(^\text{29}\)

- The Department of Transport should look at the feasibility of introducing a series of schemes/pilots for a ‘carer transport card’ scheme to provide discounted or free public transport for carers visiting the people they care for in hospital, and covering all care-related travel. This could be measured in terms of outcomes against health and well-being, of the carer, of the person being cared for, etc.

- The Local Welfare Assistance programmes are essential for supporting those carers in most financial hardship with difficult larger payments to make. It is important that long term certainty is provided for this funding.

- Review support, advice and information for families in debt to provide tailored support for carers facing long-term debt as a result of caring.

- The Department of Work and Pensions should continue to promote the Carer’s Credit to ensure carers don’t miss out.

- A review of support for former carers should look at support following bereavement including:
  - Eligibility for funeral payments should be reviewed to better recognise those caring for people at the end of life. The amount of the funeral payment should be regularly reviewed so that it keeps pace with the actual costs of a funeral.
  - The Government should increase the run on of Carer’s Allowance after the death of the person being cared for from 8 weeks to three months.

### Children and Young Adult Carers

**Strategy outcome:**

- Children and young people caring are protected from inappropriate caring roles, and have the support to learn, develop and thrive.

There are an estimated 175,000 young people are currently caring in the UK. Many children and young people struggle through the education system without being

\(^{29}\) [www.local.gov.uk/media-releases/-/journal_content/56/10180/7425493/NEWS](http://www.local.gov.uk/media-releases/-/journal_content/56/10180/7425493/NEWS)
recognised as a young carer; their needs and those of the person for whom they are caring are often only identified during a crisis. There are many reasons why a young person may be reluctant to be identified as a carer such as concerns about their family being split up. A duty on education providers would drive practice and awareness in schools, colleges and universities of the need to support young carers.

Carers UK has warmly welcomed new legislation in the Care Act and Children and Families Act giving children and young people caring much clearer rights to assessments and support with a clear message in the legislation that services must be put in place to avoid children from taking on inappropriate caring roles.

A particular focus is needed in supporting young carers at transition ensuring that they do not fall through the cracks between children’s and adult social services.

Recommendations:

- The Government should put in place a duty on education providers to identify and support carers
- Department of Education and Department of Health should work with local government to review waiting times and quality of Young Carer’s Assessments, including the quality of outcomes.
- Targeted careers advice should be available to young adult carers which addresses the skills developed through their caring responsibilities and supports them to consider all available options.

Supporting families: housing

Strategy outcome

- Carers are better supported and enabled to care through better housing.

Carers UK has developed a detailed paper on carers and housing which will be submitted separately to the call for evidence. In it, we specifically look at the issues raised in relation to caring and housing looking across the benefits system, social housing sector, the role of aids and adaptations and technology in supporting carers, supported housing, tenancies, private rented sector, privately owned sector as well as future planning and building rules. This is the first comprehensive paper on caring and housing, with input from industry, housing and community experts.

The approach Carers UK has taken is that housing is an integral part of ageing and disability and correspondingly has an impact on carers too – their ability to care well, safely and be free from hardship, homelessness and poverty. Future housing should, and must, incorporate carers’ needs if caring is to remain sustainable alongside a
shrinking working age population relative to people living in the community with care needs.

“The person’s home is a private rent, we had to move him last year because the landlord wanted the property back, it would be good for him to access social housing so that he could settle and avoid the stress of moving and uncertainty.”

Respondent to State of Caring Survey 2016

“No one has mentioned the possibility of adaptations or offered advice or help on how to go about getting them.”

Respondent to State of Caring Survey 2016

The international evidence also makes it clear that housing is an integral part of the future management of care. Perspectives and presentations from Danish carers organisations and those in Holland also make this a priority. German society prioritises prevention as does Sweden.

Key recommendations:

- A national cross-Government housing strategy needs to be developed with the needs of an ageing population at its heart.
- The Government should exempt carers who need an extra bedroom to help them carry out their caring responsibilities from the ‘bedroom tax’.
- Local authorities need to support and encourage the creation of a nationwide database of suitable properties. This would help local authorities to make better use of their existing stock and adapted properties.
- Carers and their families need greater choice and flexibility of housing. Local authorities must ensure that a range of housing products are developed and built in their area, including sufficient provision of specialist homes. Care and support planning and housing planning needs to be done locally in an integrated way.
- Planning obligations should be better utilised, to help ensure that more accessible and suitable homes are built which are flexible across the life course and enable family caring.
- The vast majority of new homes being built must be adaptable – this will mean that our housing stock is flexible across the life course and will make savings overall.
- In monitoring the implementation of the Care Act 2014, the Government should include an assessment of whether housing needs are being considered as part of carer’s assessments and needs assessments.
- Carers need to be supported with housing costs and a fairer system across all tenures should be developed.
• Independent, impartial information and advice about housing and related finances must be promoted and provided by local authorities.
• Guidance on Discretionary Housing Payments should emphasise the needs of carers for continued support following the death of the person for whom they care.

Full recommendations on housing can be found in our submission Caring Homes.

Using technology to support families better

Strategy outcomes:
- Carers understand their rights and entitlements and get access to the right information and advice at the right time, including when caring at a distance.
- Carers and the person they are caring for have access to the right care and support needed to live a full life. For carers, this needs to support them in their caring role.
- Carers’ health and well-being is supported whilst caring, and when caring comes to an end.
- Carers are given the right training, education and support to be able to care safely and well, as well as having their skills and learning recognised and developed.
- Carers are able to adjust and plan at all stages of caring, including at caring at the end of life.

We already know that assistive technology can give both carers and the people they care for greater independence and reassurance. Carers UK research in 2013 showed that almost three quarters (72%) of carers using technology said that it had given them greater peace of mind. Over 10% said that using health and care technologies had either helped them to get a job or stay in work alongside caring. Despite this, we are only now starting to realise the opportunities for practical and online technology to help families to co-ordinate a better work-life-care balance, access peer-to-peer support and save time.

If we are to realise the potential that health and care technologies have to help promote good health and deliver good care, then it is vital to understand public awareness of and attitudes towards health and care technologies.

Our polling conducted in 2013 found that whilst use of technology is widespread in many areas, there is a lack of awareness about how technology can be used to support health and care\textsuperscript{31}. However, our polling also revealed a significant appetite to make better use of health and care technologies.

When people are informed about what health and care technologies are, the vast majority would consider using the services. Only 1 in 8 say they wouldn’t use this kind of support. This enthusiasm extended well beyond telecare when respondents were given a menu of options on how technology could help\textsuperscript{32}.

**Information and advice**

Carers UK has developed a very quick self-assessment tool called *Upfront* for carers which takes a few minutes to complete, but which delivers a tailored plan of advice, tips and support, directly in line with their needs.

**Health and wellbeing**

There is a vitally important area of work for the NHS to do on maximising the potential of technology to support carers to maintain their own health – both in preventing the development of health conditions, and in accessing timely treatment and support. This has been covered in the NHS, Health and Wellbeing section of this submission.

**Building community and resilience**

Many carers see a significant impact on their ability to maintain supportive social relationships as a result of their caring role. This can be about ability to get out of the house, finances or just finding people with similar experiences who understand. Our work with carers for our *Alone and Caring* Report\textsuperscript{33} found:

- 8 in 10 (83\%) carers have felt lonely or socially isolated as a result of their caring responsibilities
- 57\% of carers have lost touch with friends and family as a result of caring and half (49\%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role
- 38\% of carers in full-time employment have felt isolated from other people at work because of their caring responsibilities
- Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.

There are many ways in which technology based solutions can address carer isolation and build resilience. Online forums such as the one provided by Carers UK offer a

\textsuperscript{31} Carers UK(2013), Potential for Change
\textsuperscript{32} Carers UK(2013), Potential for Change
\textsuperscript{33} Carers UK (2015) Alone and Caring
supportive community where carers can share their experience, offer their own expertise and knowledge, and offload their stresses. Users of our forum said:

“Thank you all so much for your kind words and help. I feel for you all having to go through the same feeling I am going through. Thank goodness for this forum where you can talk to people who understand completely. You have helped and you have taken the time to make me feel better. You are all heroes. Take care of yourselves. and so glad I found this forum. Xx”

Carers UK member and forum user

“It is a relief just to be able to say all this on the forum, because of course I do not normally, not even to my close friends.”

Carers UK member and forum user

Online e-learning resources can also provide the information and tips for wellbeing that can be delivered flexibly and at low cost to build resilience.

Technology and employment
With an estimated 2.3 million people having given up work to care, and a further 3 million having cut their hours, businesses are bearing the costs of a failure to support families to combine caring and work, employers should be looking to see how technology can help them to be better employers for the 3 million people who juggle work and caring.

There are two aspects to how employers can help here – firstly, by enabling staff with caring responsibilities to manage their work responsibilities more easily and secondly by supporting them in their caring role. On the first point, new models of remote working and online support networks with other carers in the workplace are both examples of ways in which technology can support carers in the workplace. On the second point, employers can also help by promoting health and care technologies that can support their staff with caring such as: smartphone apps which tells a staff member that a care worker has arrived on time, co-ordination tools for them to organise care between them and their families, or alarms and monitors at home which give carers peace of mind at work.

Recommendations:
- A new focus on technological solutions to make life easier for caring
- Government to work with sector skills and education bodies including Health Education England to consider how to build greater awareness of technology into training for health and care professionals.
Government to work with local authority groups and NHS England to produce guidance to use with carers and those they care for when discussing technology solutions as part of health management and care and support packages.

Department of Health to work with local government to embed the use of technology – including digital information and health and care technologies - in Care Act implementation of duties on information and advice, prevention and wellbeing.

Encourage employers to promote health and care technologies that can support their staff to balance work and caring responsibilities.

Government should support a vibrant, accessible health and care technologies market focused on consumers, which delivers attractive, affordable products and services which reflect how families live and work.

Government should raise facilitate the development and roll out of new products and technologies by investing in a stronger evidence base and removing barriers to market entry for new and innovative suppliers.

Government to support a certification quality mark scheme for use of data in the technology sector.

**Services and systems that support carers better**

**Strategy outcomes:**

- Carers are able to juggle work and care, returning to work if they wish.
- Carers understand their rights and entitlements and get access to the right information and advice at the right time, including when caring at a distance.
- Carers and the person they are caring for have access to the right care and support needed to live a full life. For carers, this needs to support them in their caring role.
- Carers’ health and well-being is supported whilst caring, and when caring comes to an end.
- Carers are given the right training, education and support to be able to care safely and well, as well as having their skills and learning recognised and developed.
- Carers are recognised as expert partners in caring.
- Carers are able to adjust and plan at all stages of caring, including at caring at the end of life.
- Children and young people caring are protected from inappropriate caring roles, and have the support to learn develop and thrive.
- Carers have a life outside caring.
Without practical support with caring from health and care services, carers cannot get the time they need to look after their own health and maintain relationships with others. Replacement care for the person they support is essential in enabling carers to juggle work, study or have hobbies and interests alongside caring, or to manage care with other family responsibilities such as childcare.

Integration of health and care support
One carer, Mark, talks about the complex web of caring for his wife with MS, whilst working and having small children. The fragmentation of services, the need to repeat information comes up as a consistent concern across carers from all backgrounds in all situations.

The health system has already been discussed and measures must be in place. The care system is equally a system that is fragmented, difficult to understand and the quality of services is highly variable – a fact corroborated by inspections through the Care Quality Commission.

Funding and availability of care and support
One of the biggest and most consistent challenges coming through from carers’ evidence is the degree to which there is unmet need amongst carers. For the last few years, Carers UK has benchmarked whether carers services have increased, stayed the same, or decreased despite needs remaining the same. The trajectory over the past few years has been downward, with the last year showing a decrease in carers receiving services that are needed.

Official statistics also show a downward trend to date in the numbers of carers’ assessments being undertaken, a downward trend in the number of carers receiving support as a result of assessments\(^{34}\) and a downward trend in the number of older people in particular receiving a service\(^{35}\) – arguably with families picking up the shortfall or the older or disabled person going without any support at all. Even taking into account the precept on local authorities a shortfall of between £2.8 and £3.5 billion in social care is predicted by 2020\(^{36}\).

\(^{34}\) National Audit Office (2014), Adult social care in England: overview, The number of informal carers receiving any of these local authority carer services, following an assessment, fell from 387,000 in 2009-10 to 354,000 in 2012-13, representing approximately one in fifteen carers.

\(^{35}\) ADASS 2016 Budget Survey

\(^{36}\) Nuffield Trust, The Health Foundation and the Kings Fund (2015), The Spending Review: what does it mean for health and social care?
With £5.5 billion having been taken out of social care budgets in the last 6 years\textsuperscript{37}, the recent ADASS budget survey suggests that efficiencies have been exhausted and cuts were now taking place to services, at the expense of prevention. Asked about the impact of social care spending reductions, 85 per cent of directors say that the NHS is under increased pressure, 85 per cent say that more providers face quality challenges, and 84 per cent say that providers are facing financial difficulty\textsuperscript{38}.

Today 25 per cent fewer older people are receiving social care support than five years ago\textsuperscript{39}. It is no surprise, therefore, that the figures showing the number of carers providing care have increased according to the Census and other reports as well as the number and proportion of people providing over 50 hours of care per week, now 1.3 million people in England\textsuperscript{40}. This rapid increase has a number of effects:

- The overall health and well-being of the population – because of the impact of caring, will decrease overall, whilst increasing health costs longer term.
- The ability of the workforce to juggle work and care is decreased, with the likelihood of early exit from the labour market or reduced working hours and income
- Although caring can be a rewarding experience that many would do again if they needed to, caring responsibilities that have a large impact can put pressure on family relationships with partners and children in particular, loss of social networks and isolation\textsuperscript{41}.

The fact that so many people wish to care for relatives and close friends is a measure of a cohesive society, but not when it risks people’s financial and personal health and well-being.

"The social worker who assessed my wife said all direct payments in the borough were being reduced. We discussed the needs and were advised we would be informed of any change. Without warning or notification the budget was cut by 30% immediately."

Respondent to State of Caring Survey 2016

The role of care services, that are publicly funded are critical in this mix. Government needs to look, urgently, at improving the sustainability of publicly funded care services

\textsuperscript{37} King’s Fund (2016), \url{www.kingsfund.org.uk/blog/2016/07/taking-control-our-social-care-system}
\textsuperscript{38} ADASS Budget Survey 2016
\textsuperscript{39} Kings Fund and Nuffield Trust (2016), \url{www.kingsfund.org.uk/blog/2016/07/taking-control-our-social-care-system}
\textsuperscript{40} Census 2011
\textsuperscript{41} Carers UK (2015), Alone and Caring
and the diversity of the care market. Instead of looking at the cost of care services as a pull on the public purse, Carers UK has looked at this in economic terms.

The loss to the exchequer is around £1.3 billion of carers leaving the labour market\(^{42}\). The lost overall to the economy is in the region of £5.3 billion\(^{43}\). Other countries such as Belgium, France and Denmark have looked at using care services to boost the employment market for those providing services, as well as helping families to stay in work. Carers UK believes there should be a fresh new look at care services and their role in the economy. With a fragile residential and home care market, it is vital that these services are sustained in the longer term and that they provide the services that families depend on. The evidence from our work is that a weak, disappearing, unaffordable or poor quality care market locally results in carers giving up work to care and poorer health and well-being. 46% of carers responding to our research who have left work to care cited problems with care services as a contributing factor\(^{44}\).

“Care workers now come more frequently but are provided by a private company rather than council. The quality of care provided has gone down since this happened with little continuity due to so many different care workers coming in and virtually no communication from care provider’s head office regarding times of attendance, care worker names etc. This means I am basically on call 24/7 in case they don’t turn up or do what they are supposed to do.”

*Respondent to State of Caring Survey 2016*

**Care Act 2014**

The rights base that the Care Act 2014 affords is a good one that has been warmly welcomed by Carers UK. The problem of underfunding care has had an impact on the delivery of the Act, but there are also several practice areas that could be improved in relation to the Act. The evidence set out in our State of Caring 2016 report suggests that some reasonable time limits should be introduced for those who request an assessment. Information and advice provision could be boosted and those caring at the end of life need fast-tracking in particular. Health and well-being needs to be routinely considered and this is where closer working, integrated services and a stronger rights base for carers in the NHS would benefit. The growth of social prescriptions in the NHS is a welcome benefit - demonstrating positive outcomes in Surrey and Hertfordshire for example.

\(^{42}\) Linda Pickard (2013) *A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032* is published in Ageing and Society.

\(^{43}\) Age UK (2012) *Estimation of the Financial Impact of Leaving Work due to Caring Responsibilities*

\(^{44}\) Carers UK (2014) *Quality of Care and Carers*
The method by which carers receive an assessment also needs consideration. The degree to which information about assessments or self-assessments online vary enormously between councils, the methods adopted vary, the degree to which they outsource carer’s assessments or keep them in-house, leads to a picture of variability, fragmentation, confused outcomes for carers and lack of clarity of direction. There are also differences across service types e.g. across mental health and adult social care – suggesting a disparity in approach.

**Carers’ breaks**
Since the ground-breaking decision in 1999 to deliver carers’ breaks funding to local authorities, Government has continued to identify funding for carers breaks which is welcome. Whilst it has not been ring-fenced or specifically purposed around services or support which enables carers to take a break, it has been used creatively over the years to provide everything from basic homecare services, to standard and well-loved sitting services, direct payments to pay for diverse services and support, breaks prescriptions through GPs. The vast majority of these services have been provided free of charge, streamlining administration, removing barriers and stigma and local monitoring demonstrates high levels of outcomes and satisfaction. Carers UK strongly recommends that Government continues to fund breaks services for carers, and encourages them to be made free at the point of delivery.

“Less respite per year means having less quality time with my husband. Day care has been reduced so having to care for more hours, feeling tired and stressed.”

Respondent to State of Caring Survey 2016

**Recommendations:**
- Increased funding for social care putting in place a sustainable funding settlement for social care and ring-fenced funding for carers’ breaks.
- A review of the implementation of the Care Act 2014 and the Children and Families Act 2014 in relation to carers’ assessments and support following assessments.
- Monitoring of the success of the Care Act 2014 in relation to carers through a variety of sources e.g. HSCIC data, RAP and SALT returns.
- The Adult Social Care Outcomes Framework needs to clearly include carers’ rights under the Care Act, in particular carers’ experiences of post-discharge care
- Tracking the Care Act, particularly in relation to parent carers, carers of people with mental illness and those at the end of life.
- A review of waiting times and quality of carer’s assessments, including the quality of outcomes.
- Support to manage direct payments and personal budgets.
- Carers need clear information and support to plan for emergencies and crisis care needs to be part of the person’s care and support plans.
- Review care services through the lens of an economic benefit for disabled people and carers – as a generator of growth.
- A review of emergency admissions and degree to which they are caused by carer breakdown/carers concern that was avoidable.
- A review of discharge arrangements, ideally placing a carers lead in every discharge team.
- A step-change in public and professional awareness of health and care technologies so that the use and purchase of technology to support caring becomes a normal part of life and of professional practice.

**Carers and work**

**Strategy outcome:**
- Carers are able to juggle work and care, returning to work if they wish.

Carers UK’s 50 years of working to establish support for carers started in those early years by our founder who had to give up a job that she loved in order to care for both her parents. Employment and choice is a core part of what we do and it is becoming increasingly evident that this is not just a national issue, but a global one too.

A key part of our strategy is to enable carers to continue working, if they wish to, and to support the mechanisms around that. Our 100+ strong and growing Employers for Carers Forum, which is employer led, continues to make progress looking at key issues affecting carers in the workplace. 1 in 9 people in the workforce are juggling care with paid work, yet many face a lack of understanding from colleagues and managers. Working carers are looking for a mixture of support; ranging from understanding and flexibility at work to reliable, affordable care services that give them peace of mind that the person they support is being well cared for. Without this and the information and support to coordinate care, working carers are ending up stressed and anxious without access to the time they need for themselves as well as feeling isolated from their colleagues.

The facts are clear: 3 million people juggle work and care out of a potential working age carer population of around 4.3 million. Around 2 million have given up work to care,

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45 Census 2011
46 Census 2011
and more have reduced their working hours, particularly women\(^{47}\). As the pension age increases, the likelihood of caring during working life, is increasing. Employers, through our forum and through others like CIPD, are reporting increasing numbers of employers seeing stress, ill-health and difficulty in juggling work and care amongst their employees and rate this as one of the fastest growing issues in their workforce. Despite the challenges of combining care with employment, 400,000 people are doing a full working week alongside long hours of care (20 hours or more)\(^{48}\).

“I had to reduce my hours at work as there were no care facilities for my son.”

Respondent to State of Caring Survey 2016

“My career choices were limited because of my caring role. I gave up jobs I loved because they couldn’t fit round my caring role.”

Respondent to State of Caring Survey 2016

**Costs of losing carers from the workforce**

The work that Carers UK has done with employers shows that the loss to the company of an employee is roughly equivalent to a year’s salary, if not more. Centrica (which chairs the Employers for Carers forum) estimates potential costs savings of £2.5 million through increased staff retention and £4.5 million through reduced unplanned absenteeism\(^{49}\). Whilst there is good evidence that Employers for Carers members are moving towards ever better practice, and flexible working as an issue across all employers is improving, the evidence from carers shows that the issue still remains largely hidden in the workplace. For example, implementation of rights could be improved, and businesses are not aware that they need to maximise the potential from their employees, because they are not aware of the impact of caring.

Recent work carried out by Carers UK with Age UK which examines the challenges and barriers facing carers aged 50+ as they attempt to juggle their caring responsibilities with work found that caring impacts people’s ability to remain in work in later life, even when they are caring for as few as five hours per week\(^{50}\).

The future of the ageing population has a big impact on this whole agenda. Countries with faster ageing populations than the UK have reached this situation earlier, by implementing stronger rights to care leave – in Japan, Germany, etc. A review of global

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\(^{48}\) New Policy Institute (2016), Informal care and poverty in the UK

\(^{49}\) Centrica Best for Carers and Eldercare, Top Employers for Working Families Special Awards 2015

\(^{50}\) Age UK & Carers UK (2016), Walking the tightrope - The challenges of combining work and care in later life
rights shows the UK lagging behind the US, and other countries in the workplace rights base in the area of care leave\textsuperscript{51}. Countries introducing the right, and Japan is probably the clearest in this sense, have seen a clear link between the right sustaining work and care at the same time and have looked at it through a strong economic lens.

For the UK and England’s services where there are acute skills shortages, such as the NHS and care services, the loss of any skilled employee is problematic and highly costly to the efficient operation of the service. Despite its global search to resource its skills shortages; the NHS still has gaps in key areas. With an higher than average likelihood of being a carer, the NHS workforce in particular, has a great deal to gain in retaining employees.

As well as the cost to employers, there is also a personal cost to carers of giving up work to care. Of those who gave up work, retired early or reduced working hours, 69% said the stress of juggling work and care was a contributing factor, 31% said it was because there are no suitable care services and 21% said care services are too expensive. 16% said that the leave available from work was insufficient to be able to manage caring alongside work and 18% were unable to negotiate suitable working hours\textsuperscript{52}.

Carers who have given up or reduced hours to care were asked to name the top three things they felt would have helped them stay in work. More support from care workers coming to the home of the person they care for was the top choice of most carers (28%) and 54% of carers put it in their top three. 45% of carers put support with household chores such as help with shopping as a top three priority and one third (34%) put support managing or coordinating care in their top three\textsuperscript{53}. This underlines that it isn’t only those providing personal care that are seeing an impact on their ability to stay in work but also those arranging and organising care for loved ones.

Health services that are not joined up or co-ordinated cause carers to give up work because of multiple and badly timed appointments. Many carers do not know the range or value of assistive technologies which can also be hard to access through public services in terms of the range and outcomes. There needs to be a shift of perspective in which good quality, well-coordinated services support carers to remain in work – and are seen as a pre-condition for work. The direction in the rest of Europe is to increasingly looking at services in this way\textsuperscript{54}.

\textsuperscript{51} Carers UK (2013), The Case for Care Leave: Families, work and the ageing population
\textsuperscript{52} Carers UK (2016), State of Caring 2016 Report
\textsuperscript{53} Carers UK (2016), State of Caring 2016 Report
\textsuperscript{54} European Federation for Services to Individuals (2014) Personal and Household Services. How to fully exploit their benefits for our societies?
Back to work support

Having given up work, many carers wish to return. This may be after a short period of time, or may be after many years. Skills audits with carers show that they feel disempowered, disconnected, outdated and a long way from the labour market. Work that Carers UK did as part of an European Social Fund funded piece of work – Action for Carers and Employment – showed that pre-vocational training for carers was vital. A skills based programme for carers could range from pre-vocational training, to skills accreditation whilst caring, to amendments in the benefits system to allow vocational training whilst caring. Carers UK has experience and expertise in developing this type of training for carers, but built with carers and co-produced with them, achieving good positive outcomes across health and well-being in addition.

A system of “returnships” could be developed with employers that fit older workers, disability returners and carers alike – with NI holidays for employers who develop this approach. Encouraging, and incentivising, employers to provide workplace apprenticeship programmes for older workers and carers, as well as for younger people, would also help. Training and resources should also be made available to job centres to skill up staff to identify and support carers (and former carers) to return to training or employment or to keep in touch with the labour market.

Carers are also slightly more likely to be self-employed – often a status of choice because it fits around caring responsibilities, the hours can be more flexible for some and it is possible to have “micro jobs” that introduce greater flexibility.

Two areas in particular are looking at boosting carers’ knowledge of how to become self-employed and set up your own business. Successful businesses set up through these programmes include positive activities in care homes and independent living, dog walking, relaxation therapies for carers delivered by carers, coaching, advocacy, craft based workshops, care assistants, etc.

A programme focussed more on developing self-employment skills including the advice and support given through DWP and the learning and skills programme suggested for carers could enhance opportunities further. Some of the rules in Universal Credit may need to be examined to make sure that they move with, rather than against, this direction. As well as offering employment to many carers, self-employment also offers the possibility of niche, diverse and tailored services, support and products for others.

Recommendations:
Every workplace to be carer friendly
- Government to support the adoption of an employer recognition scheme such as the Carer Positive scheme run by Carers Scotland. The scheme could be trialled as a
pilot initially with a view to becoming a self-funded self-sustaining model in the future.

- Employers could consider adopting the concept of a carers passport in the workplace, which is already in place in some large employers so that carers can carry arrangements internally into different posts.
- Information and support to be available to carers throughout the ‘employment journey’ through Public Health England’s health at work programme including those seeking to enter/return to/remain in employment (and moving in and out of self-employment).
- Government departments who have not already done so should show leadership by joining Employers for Carers and championing Employers for Carers to other public sector organisations.

Flexible working
- Carers need a right to request flexible working from day one of their employment.
- Employers should be encouraged to advertise positions as flexible.
- Stronger guidance is needed from Government that employers should look positively at requests for flexible working from carers (as recommended by the House of Lords Select Committee on the Equality Act 55). Guidance should also seek to improve employer knowledge of flexible working options needs to be promoted and maximised: i.e. flexi-time, job sharing, home working, condensed hours and how technology can facilitate flexible working.

Rights to paid care leave:
- Government should introduce a new right to paid care leave of between 5 to 10 days for carers in work.
- Employers should consider introducing paid care leave in the workplace so that carers are not forced to take annual leave for caring emergencies. NHS England and Government departments should show leadership by adopting a care leave policy.

Supporting carers into and back to work including self-employment
- The Government should include carers as a major plank of its Health and Work agenda.
- Training and resources to be made available to Job Centres to skill up staff to identify and support carers and former carers to return to training or work including becoming self-employed, or to keep in touch with the labour market.

55 Select Committee on the Equality Act 2010 and Disability (2016), The Equality Act 2010: the impact on disabled people
• Government and employers to promote apprenticeships for older workers
• Government to introduce a National Insurance holiday for employers who employ a carer or former carer.
• Government to explore opportunities for self-employment/micro employment including rolling out learning from Carers in Employment pilots.
• Government should invest in a new programme targeted specifically at carers accrediting skills learned whilst caring.
• Employers to implement carer friendly recruitment policies and practices which include young adult carers.

Addressing external barriers faced by employers and cares
• Government to recognise the need for a sustainable funding settlement for social care and the need for a diversity of care and support services to be available for working carers including the case for social care as a ‘condition for work’.
• Government should work with local government to support the implementation of the Care Act duty on shaping the care market with reference to sufficiency of supply for carers and disabled people in work or seeking to return to work by:
  o Including support for working carers in planning guidance around health and work for Sustainability and Transformation Plans
  o Including the need to reflect requirements of working cares in Joint Strategic Needs Assessment guidance.

Conclusion and implementing the Strategy

The recommendations outlined in this report demonstrate both the scale of the challenge, and the opportunity, facing Government.

Our ageing population and the breakthroughs we’ve seen in the treatment of complex health conditions, combined with unprecedented pressures on public finances, mean that demand for care is ever increasing. For families to be able to provide this care, it is clear that a step change is needed in the support they receive, from Government, local government, employers and wider society as whole.

Caring will touch all of us at some point in our lives and is part of being human yet there is huge diversity in the lives and caring roles of the UK’s growing population of carers. In order for this strategy to improve the lives of all carers, it is essential that the implementation of the strategy is monitored and an assessment is made of how well it succeeds in meeting these diverse needs.

Government, by providing clear leadership on carers’ issues, can help create this momentum for change. The development of a new Carers Strategy is a significant and
welcome signal of intent, yet the Government also has a much wider leadership role in promoting the cultural shift needed to better understand and support carers. This means not only adhering to the recommendations of a Carers Strategy, but going much further, ensuring carers are mainstreamed and considered in all aspects of Government policy and their role is openly valued and championed.

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