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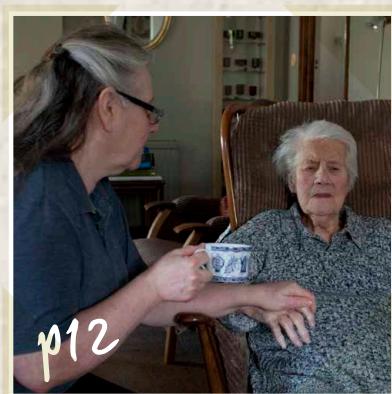
Income & finances



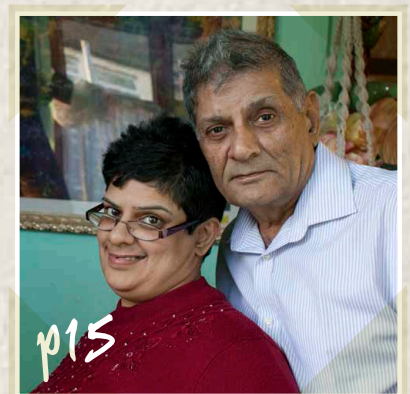
Health & care



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Recognition, information & advice



“

All I want is a life
where my husband
and I don't have to
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paying the bills.

”

Our evidence



This manifesto is built on the views and experiences of carers, including:

- > Over **5,000** carers who completed our *State of Caring Survey 2014* about the impact of caring on their lives and their priorities for the next Government.
- > National opinion polling conducted for *Carers Week* in 2014 which asked a representative sample of **2,000** members of the public what support they would want if they became carers.
- > Through Carers UK's year-long *Caring & Family Finances Inquiry (2013-14)*, which surveyed over **3,000** carers and conducted **15** detailed evidence sessions with over **200** carers across the UK.
- > Carers UK's annual *Carers Summits* attended by over **250** carers from across the country each year to discuss their experiences and their campaigning and policy priorities.

Policy across the UK

This manifesto sets out recommendations and analysis for the UK Parliamentary elections in 2015. As a result it makes recommendations for policy areas which are UK-wide, including social security and employment law. However in areas where policy has been devolved to Scotland, Wales and Northern Ireland, particularly health and social care, these recommendations relate to England only.





Introduction

Fifty years ago, a woman called Mary Webster embarked on a pioneering campaign to raise awareness of a hidden social issue. Mary spoke out about caring for her ageing parents – being forced to give up her career and only source of income, her health suffering and feeling ‘under house arrest’ – trapped by a lack of support. Her work to establish our charity thrust caring into the public eye. Despite significant progress in establishing carers’ rights, however, experiences of carers today show we still have far to go. Isolation, financial hardship, poor health and exclusion from paid work remain hallmarks of many carers’ lives.

Giving lie to the myth that we are an uncaring society, the number of families caring for loved ones continues to rise, with the sharpest rises amongst those providing the highest levels of care. The number of carers over-65 is increasing above any other age group, many spending retirements caring for parents in their 80s or 90s before then caring for partners.

But as families care more than ever, many of them are finding it harder and harder to get support as, year-on-year, the numbers able to access social care services in England fall; and families feel the effect of an

estimated £1 billion cuts to carers’ benefits by 2018. This is socially and economically unsustainable. Already, millions have given up work or reduced hours to care and caring is a major driver of middle-aged and older workers, particularly women, being forced to give up their careers entirely. If social care continues to recede, the toll will not just be on family finances. Business and the economy will pay escalating costs from loss of talent, skills and tax revenues. A lack of support now will also bring much greater long-term costs to our health and care services as rising numbers of carers reach breaking point and may no longer be able to provide care.

As a membership charity, we continually gather feedback on what carers need. This has remained consistent over the years – carers want support to enable them to live their own lives, stay healthy and, where possible, work alongside caring. As well as good quality support for the people they care for, carers need understanding and recognition of their vital contribution from health and care professionals and wider society.

This requires a coherent approach across Government so social care, social security, the NHS and employment policy all pull in the

same direction. Too often the opposite is the case, both in the everyday experience of families and on a national policy level.

The National Carers Strategies in 2008 and 2010 included some positive measures, but the co-ordinated, consistent and coherent cross-Government approach needed is still missing. At the last election, Carers UK called for a new ‘social contract’ between society and the nations’ carers – so carers could see what support they would be entitled to in return for their huge contribution.

In 2015, as a growing number of carers provide higher levels of care with less support, Carers UK believes a new, public contract is needed between carers, public services, employers and wider society. Built on carers’ experiences, this manifesto recommends the measures needed to get there – calling for a fresh, strategic approach to supporting families with caring responsibilities and recognising the economic and social imperative for doing so.

- Heléna Herklots,
Chief Executive, Carers UK
- David Grayson CBE,
Chairman, Carers UK





Our evidence

- > One in three carers cannot afford to pay their utility bills, one in five cannot afford their rent or mortgage payments.
- > Over half of carers are using savings to pay everyday living costs. 1 in 10 carers have used up any savings they had and have nothing to fall back on.
- > 44% of carers have ended up in debt as a result of caring.
- > Over 4 in 10 carers are cutting back on food or heating.
- > Carer's Allowance is the lowest benefit of its kind, at just £61.35 a week it is worth less than £1.75 a hour for carers caring 35 hours a week.
- > Carers benefits are being cut by £1 billion from 2011 – 2018.

For many families, taking on caring responsibilities mean long-term financial hardship as a loss of income from paid work is exacerbated by higher household and travel costs.



Carers who had savings often use them quickly as they cope with a sudden loss of income and rising bills. Many are quickly forced into debt. The impact is lasting as years spent on low-level benefits or without any financial support mean carers cannot escape debt, build savings or contribute to a pension. If caring comes to an end before pension age, the barriers to returning to the labour market mean that carers may never be able return to work and face severe financial hardship into retirement.

Even for those able to work alongside caring, their work is likely to be affected by having to find lower paid work which is flexible around caring, cut their hours and forgo promotion and career opportunities. The costs of buying in replacement care whilst they are at work may mean work doesn't pay and outdated rules around carers' benefits act as a barrier to both work and training.

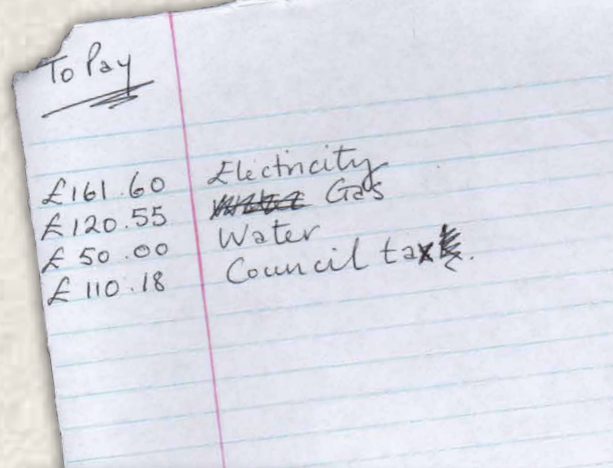
These pressures stand to worsen as carers and the people they care for face an unprecedented fall in incomes as a result of benefit cuts totalling over £1 billion to carers' incomes by 2018.

“We are always in debt”

When Julie's husband Peter suffered brain damage following a cardiac arrest their lives fell apart and meant the loss of both their jobs. Julie tried to combine work with caring but was forced to quit when she reached breaking point. The loss of over £40,000 in income from both of their jobs was devastating and by the time Peter qualified for disability benefits they were already deep into debt and faced bankruptcy.

Despite the fact they were already facing a daily battle to make ends meet, in 2013 they faced sudden cuts to the limited financial support they were receiving. Alongside losing support with Council Tax Bills following the scrapping of Council Tax Benefit, their Housing Benefit was cut as new rules meant their vital second bedroom was classed as spare despite being needed to store oxygen tanks and to give Julie respite when Peter's disturbed sleep keeps her awake.

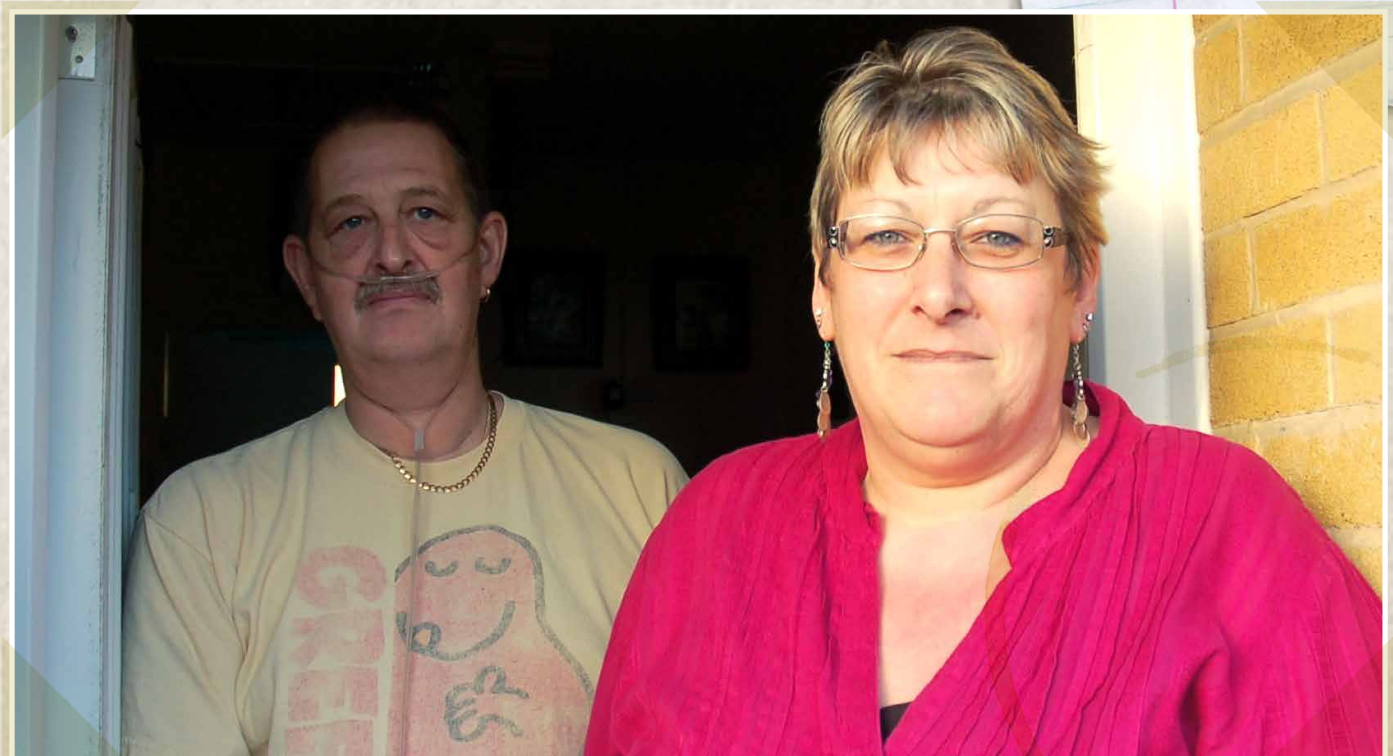
Julie says: “We have to pay the new rent and council tax payments but that means that other debts are building up. The water company are threatening court action and I have major arrears with our gas and electric. All I want is a life where my husband and I don't have to worry every day about paying the bills.”



“

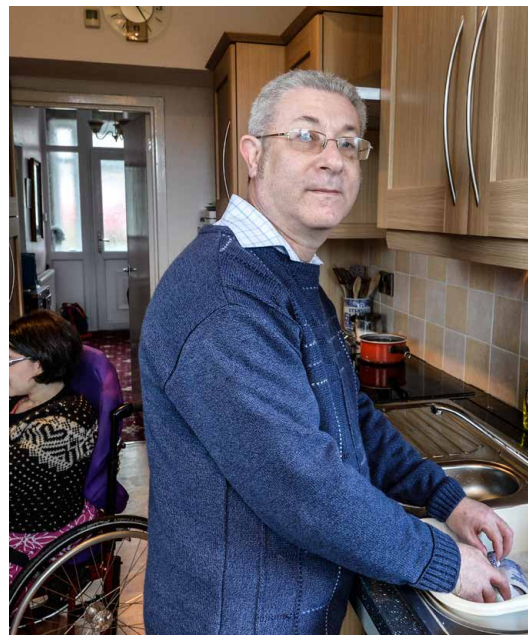
All I want is a life where my husband and I don't have to worry every day about paying the bills.

”



What carers want

- > To be able to maintain financial resilience which enables them to have a life alongside caring and which means carers aren't left in debt, with little or no savings and facing financial hardship into retirement.
- > For carers' benefits to recognise their huge contribution to society rather than highlight how poorly valued they are.
- > A social security system which supports rather than prevents carers working or studying alongside caring.
- > For all financial support to rise with the cost of living and for the additional costs of caring in household bills and transport costs to be recognised through additional support.



Recommendations

- > **Alleviating carers' financial hardship must be reinstated as a core priority of the National Carers Strategy.**
- > A cumulative impact assessment of the impact of the Welfare Reform Act 2012 on carers and their families.
- > A 'carer income guarantee' to ensure carers' benefits do not fall further behind the cost of living. Disability and older people's benefits must also rise with inflation.
- > Urgent measures to improve the level and structure of Carer's Allowance, including applying an earnings taper, the removal of barriers to study and training and improving how older carers are supported.
- > Action to reduce carers' living costs, including:
 - Improved access to reduced energy tariffs for carers and their families.
 - Local schemes in place across the country to ensure carers have access to discounted travel on public transport.
 - A 'carer friendly hospitals' scheme including discounted or free hospital car parking for carers.
- > An immediate pause and review of the introduction of Personal Independence Payment to assess the impact on disabled people and carers and address serious delays in assessments and decision making. Immediate measures should also be introduced to mitigate the impact of wider benefit cuts on carers, including:
 - Exempting carers from the household benefits cap and the 'spare room' changes to Housing Benefit for the social housing sector (also known as the 'bedroom tax' or 'spare room subsidy').
 - Identifying carers and disabled people as priority groups for local support with Council Tax bills/Rates Relief.
 - The carers' and disability elements should be able to be claimed simultaneously in Universal Credit.
 - Implementing a run-on of Carer's Allowance for families where a disabled person loses entitlement to disability benefits following a reassessment.



Our evidence

- > Full-time carers are more than twice as likely to be in bad health as non-carers
- > 80% of carers say caring has had a negative impact on their health
- > Half of carers say they have experienced depression after taking on a caring role
- > 61% of carers say they are at breaking point
- > 1 in 5 carers receive no practical support
- > Despite an ongoing rise in the number of carers in the UK and sharp rises in the numbers caring full-time, the number receiving carers' assessments and carers services is falling
- > 175,000 children under the age of 18 are providing care.

Demographic change means that not only are there more carers, but there have been sharp rises in the proportion caring for over 20 hours a week and a 25% rise in the number caring for 50 hours or more.

But growing demand for care from an ageing population is being met with less, rather than more, support from social care services. Carers report cuts to vital care packages, rising care charges and direct payments failing to keep pace with the costs of care services.

Families are being forced to fill the growing gap between demand for care and the support available, often doing serious damage to their mental and physical health and pushing them into social isolation. There are also wider economic costs to reducing access to care services. Over half of carers who have given up work to care blamed problems with accessing suitable care services. Unlike childcare, good quality, reliable and affordable social care is not seen as a condition of employment to enable carers to combine work and family responsibilities.

Children are also being pushed into providing inappropriate care as a result of a lack of care and support for their disabled parents or other disabled family members. There are an estimated 175,000 child carers in the UK, whose education, health social inclusion and life chances are at risk.

The GP Patient Survey shows that carers are significantly more likely to have long-term health conditions – presenting a significant, but unrecognised public health challenge. Carers are more likely to have arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression (footnote needed). Carers attribute this health risk to a lack of support, with 64% citing a lack of practical support and 50% a lack of financial support, as major reasons for their poor health. This leaves many carers unable to find time for medical check-ups or treatment, with two in five carers saying that they were forced to put off treatment, or even discharge themselves early from hospital – unable to trust or find suitable and affordable replacement care.

Carers also report feeling doubly excluded from health and social care services. 1 in 5 carers say they feel their role and skills are ignored by health and care professionals, but many also feel their own health needs are not understood. Although the vast majority of full-time carers say they have a GP who knew of their caring responsibilities, of these carers, almost three quarters said that their GP didn't do anything differently to accommodate them.

Case study

"My own health suffered terribly"

Julie cares full-time for her 14-year-old son Lewis who has drug resistant epilepsy, cerebral palsy and an autism spectrum disorder.

Lewis has considerable care needs. His physical and learning disabilities mean he needs help throughout his daily life. He has a low immune system, leaving his health fragile and he often suffers illness. As he grows into adulthood, Lewis will continue to depend on his mum.

When Lewis was born, Julie gave up her career to care. Coping with Lewis's disabilities and health needs has not been easy. In recent years Julie has also provided increasing support for her parents as they grow older.

At the age of 6 Lewis needed major brain surgery. The operation was needed to try and manage his epilepsy, but could only be done in London, by a specialist team at Great Ormond Street Hospital. For the following five years Julie, a single parent from Renfrewshire, Scotland, travelled regularly to London for follow-up medical treatment.

The stress that comes with Lewis's disabilities and the physical and emotional demands of caring have taken a toll on Julie's own health and she suffers with both a chronic pain and immune disorder, which were undiagnosed and untreated for many years.

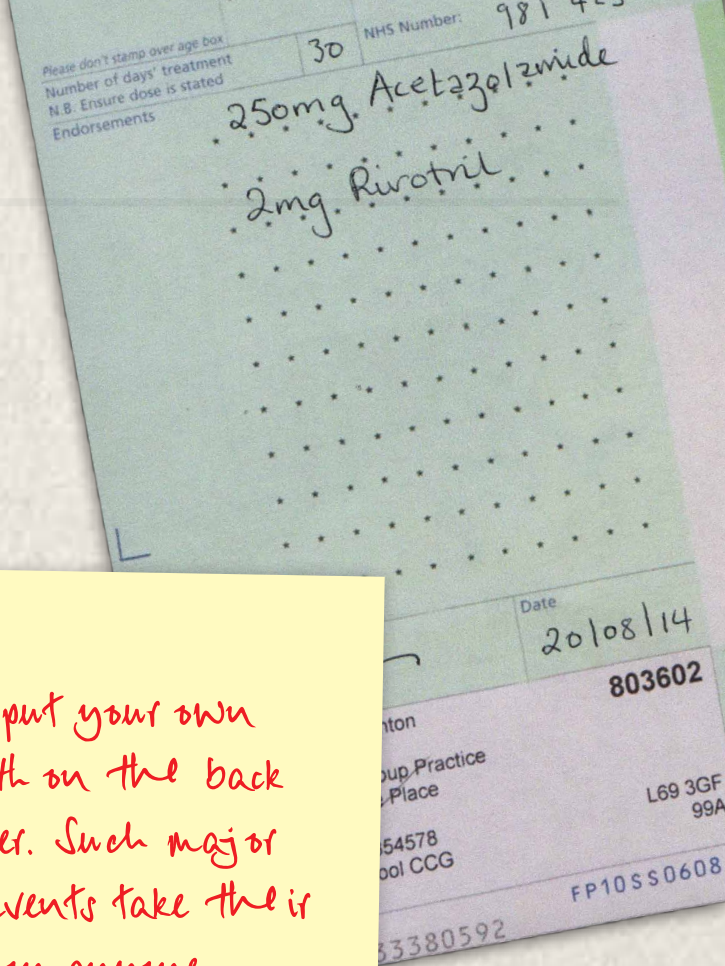
"For me, it was a terribly traumatic time. But there just wasn't time for me to think about my health."

"Caring has changed my life to the effect it is 24/7 care for my son. The trials and tribulations have been numerous. Sleep deprived, poor diet, no social life. My own health has now deteriorated. It has been a most humbling, rewarding experience to date, but can be an isolating and lonely experience for the carer."

“

You put your own health on the back burner. Such major life events take their toll on anyone.

”



What carers want

- > Good quality, reliable and affordable care services which enable them to have a life alongside, caring.
- > Health and care services which recognise carers as expert partners in care.
- > Health services which recognise that carers' have their own health needs and provide flexible support which proactively seeks to reduce carer ill-health.
- > Reform of funding for social care and the NHS based on principles of shared risk.



Recommendations

- > **An urgent new, sustainable settlement for social care and the NHS, which sets out the funding mechanisms which will deliver the funding needed to tackle the existing gap between need and supply and to keep pace with growing demand.**
- > Sufficient funding to implement positive new duties included in the Care Act (in England).
- > A duty on NHS services to identify and support carers.
- > A duty on educational bodies to identify young and student carers.
- > Ring-fenced funding for carers breaks and transparency on how this funding is spent in each local area.
- > Good quality, reliable and affordable care services to be recognised as a condition for employment and embedded in local employment and economic growth strategies.
- > The Care Quality Commission must ensure that quality measurement and inspections include the impact of care quality on carers, not just care-recipients.
- > A right to an annual carer health check.
- > Co-ordinated action, using new duties in the Children Act and the Care Act, to prevent child carers from taking on inappropriate caring responsibilities.
- > A new 'carer-friendly NHS' programme to ensure carers are respected and involved in decision making, including:
 - 'Carer-friendly hospitals' – to involve carers in hospital admissions and discharge and decision making, to recognise carers role as expert partners in care and to provide carers with additional support including discounted or free parking and hospital-based access to information, advice and support.
 - 'Care-friendly' primary care services – for example via carers champions in GP surgeries to ensure signposting to advice, information and support through primary care.
- > Equal rights to carers services for parent carers of disabled children to carry through new rights to an assessment of their needs.
- > Inclusion of carers in the NHS Outcomes Framework and a renewed NHS Commitment to Carers in 2015.
- > Evaluation of the impact of personalisation on carers particularly focussing on support with administration and management of direct payments, analysis of the comparative levels of support following transition to direct payments and the sufficiency of direct payment funding compared to the rising cost of care services.
- > Support with caring responsibilities to be made a priority in Government and employer 'healthy workplaces' programmes.



Our evidence

- > Over 3 million people combine caring with paid work.
- > 1 in 3 carers have seen a drop of £20,000 or more a year in their household income as a result of caring.
- > 2.3 million people have given up their jobs to care at some point in their lives and 3 million have reduced working hours.
- > Over half of carers cited problems with accessing suitable care services as the reason they gave up work.
- > The cost to the UK economy of carers giving up work to care is over £5 billion a year, UK businesses lose a further £3.5 billion

Whilst the nature of some carers' caring responsibilities is so intense that work alongside caring would be impossible, many carers want to combine work and caring but cannot access the support to do so.

A lack of rights to paid leave for caring responsibilities, insufficient flexibility at work and a lack of good quality care services at home mean that many carers forced to give up their jobs. 1 in 9 of the workforce do juggle work and caring but many have reduced their working hours, forgone promotion or taken on lower-skilled and paid work which can be flexible around caring.

The costs of this failure to support working carers are high. In addition to the long-term personal costs to families, the UK economy is paying the price too. Evidence from business forum Employers for Carers, international and academic research shows that billions of pounds are wiped off the UK economy in lost tax revenues, additional social security costs, lost productivity and higher recruitment and absence costs.

An ageing workforce means that a growing proportion of the working population will fall into the age brackets most affected by caring. Caring responsibilities are a significant contributor to poor workforce inclusion amongst middle-aged workers, particularly women – 1 in 4 of whom have caring responsibilities during their fifties and early sixties. Often becoming a carer at this age results in permanent exit from the labour

market. As the retirement age rises and the number of older carers grows faster than any other group, without greater support, caring responsibilities will act as a major barrier to older workers remaining in the workforce.

Despite this evidence, the UK is only just beginning to make a link between sufficiency of quality care services and the carers workforce inclusion. But, unlike childcare services, there is no support through the tax system to make care services for older or disabled people more affordable in order to support carers to combine work and caring.

Carers UK analysis shows the UK falling far behind in workplace rights as countries from Japan to Poland have put in place rights to 'care leave' to allow employees to take short periods off work to manage caring.

Caring for older or disabled relatives must now be seen in the same light as parental responsibilities – where support at work and care services at home are seen as part of our core economic infrastructure.

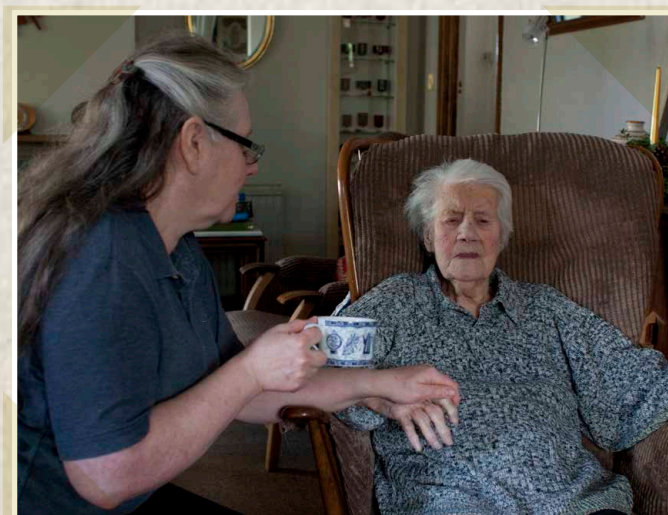
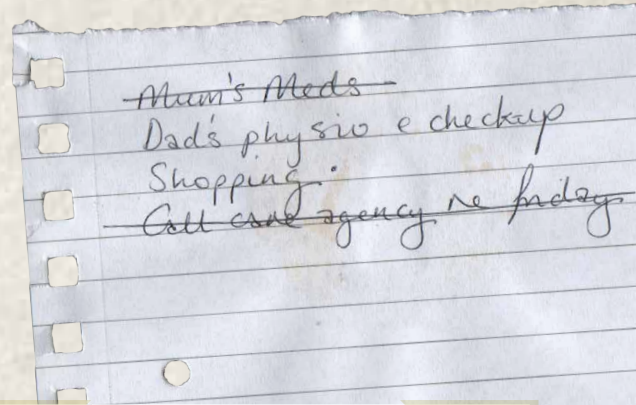
"Soul-destroying, shattering and isolating"

Gill has been caring for nine years for both her parents who are in their 90s. Her mother Mabel has dementia and osteoporosis and her father has very fragile health and mobility problems.

Caring has cost Gill her career and her financial security. She initially tried to combine full-time work with caring for them but reached crisis point when her mother contracted the potentially fatal hospital infection C-difficile. The stress, worry and exhaustion of nursing her mother through the illness left her with no option but to give up work to care full-time.

Providing around-the-clock care for her mother is she says "soul-destroying, shattering and isolating." Her father's health needs have also increased and she has found herself on a number of occasions trying to manage care for one parent at home and spells of hospital admission for the other.

Before giving up work to care, Gill had been careful to save for her future throughout her career, which included many years as a transport manager in the shipping industry and most recently as a senior administrator in the voluntary sector. Now, with Carer's Allowance at just £61.35 a week as her only source of income, Gill fears for her own financial future.



“

I lost my career and
I am losing all my
savings and we may
lose the home my
parents and I bought.

”

What carers want

- > To have access to good quality, reliable and affordable replacement care services so they can have confidence in the care being provided whilst they are at work.
- > Flexible, understanding employers who recognise the value of supporting carers to combine work and caring.
- > Rights at work which recognise and value caring as much as other family responsibilities and allow carers time off to care.
- > Support to return to work when caring comes to an end.
- > A benefits system which supports carers to work or study alongside caring, rather than makes it harder.



Recommendations

- > **A right to between 5-10 days of paid care leave from paid work and a debate on longer term leave from work to enable carers to care for seriously or terminally ill or significantly disabled loved ones.**
- > Stimulation of the care market with an explicit focus on guaranteeing sufficiency of supply of services to support carers to work. Existing measures in the Care Act should be subject to a detailed review to assess progress on developing the care market.
- > A review of how tax breaks could support families to buy care or other services to help carers remain in work alongside caring.
- > 'Day one' rights to request flexible working – rather than having to wait 26 weeks into a job.
- > A commitment to deliver new cross-Government 'Support to Work' programme (including between the UK and nation governments) to help carers combine work and caring and return to work. This should include funding to enable carers to engage in training and study courses, through supporting the costs of replacement care and course fees.
- > Development of good practice, led by the Government as an employer and using the expertise of Employers for Carers, including:
 - The development of 'carer passports' in the workplace, so that carers can 'carry' flexible working arrangements into different posts in the same organisation and that agreed flexibility can be easily demonstrated to different line managers, supervisors or colleagues.
 - Awareness campaigns and staff training to change workplace culture to ensure support for carers is embedded throughout workplaces.
- > Government should use procurement policies to encourage carer-friendly workplace practice amongst suppliers.
- > Implementation of an earnings taper to Carer's Allowance, and, in the short term, an annual uprating of the earnings limit to keep pace with the minimum wage,
- > Travel costs should be added to the list of deductible costs from weekly earnings for the purposes of Carer's Allowance.



Our evidence

- > An estimated £1 billion in carers' benefits go unclaimed each year.
- > 42% of carers have missed out on financial support as a result of not getting the right information and advice.
- > Half of carers say they feel society does not recognise or think about them at all.
- > 17% of carers report being treated negatively because they received benefits and a shocking 14% had been victims of crime like damage to property or verbal abuse.
- > 75% of carers said it was hard to maintain relationships and social networks because people do not understand the impact that caring has.

A lack of recognition of who carers are and the impact of caring results not just in carers missing out on advice and support, but also prejudice, discrimination and social exclusion for families with caring responsibilities.

Caring comes in many forms – from providing round-the-clock support to a disabled child, to combining work, childcare and caring at a distance for an older parent at the other end of the motorway. It can happen overnight or grow gradually. As a result, not everyone identifies themselves as a carer or knows where to turn for support and too often health and social care services fail to identify carers and guide them to support. This leaves many missing out on benefits, hands-on help and advice, sometimes for years, exacerbating the financial and health penalties carers face.

A lack of time and understanding from friends, colleagues and family, as well as society can also lead to carers becoming isolated as a result of their caring responsibilities. 57% of carers report that they have lost touch with friends – almost half attributed this to a lack of practical support to enable them to socialise.

Carers also tell us that they do not just feel ignored – they face prejudice and discrimination too. In workplaces carers can feel worried about asking for flexibility or revealing they have caring responsibilities. In their neighbourhood carers talk about being told they are 'scroungers' because their family receives benefits. They are tired of hearing in the media that

people receiving benefits are not contributing to society and ought to be at work, or that uncaring families in the UK are failing to look after older or disabled loved ones.

This ignorance and disregard has been reinforced by the repeated failure of the Government to conduct timely and full impact assessment assessing the impact of policy on carers.



“When we became carers we were completely isolated and cut off.”

Prabhudas, and his wife Minaxi care for their daughters Bhavini and Meeli who both have severe learning disabilities. Caring for their daughters for over 35 years has brought a combination of isolation, constant struggles to access services and huge challenges in trying to combine work and caring for both of them.

Prabhudas retired two years ago after a career of juggling work and care including years of nightshifts on an assembly line. Minaxi continues to work as an assistant at the special needs school the girls went to when they were young.

The girls both go to a day centre during the week, but local services for adults with learning difficulties are getting harder to find. No support is available for Bhavani and Meeli at the weekend or after the day centre closes.

Prabhudas and Minaxi are finding their daughter's behaviour has become more challenging as they get

older, at the same time as their own health as carers is suffering. For the last year Minaxi has been sleeping in the same room as their younger daughter because she wakes so frequently at night.

The couple have been married 38 years – but find it hard enough getting out as a family and rarely get any time as a couple.

The family's battles to access services have driven Prabhudas to devote the little free time he has volunteering as a Carers UK local ambassador, trying to improve local support so other carers face less of a struggle to get help.

“Carers face real challenges. So many don't know what support is or where they should look for it. We need to help carers get the information they need and it is important they have somewhere they can go and to have something which enables carers to talk about their problems.”

“

Carers face real challenges. So many don't know what support is or where they should look for it.

”



What carers want

- > For their role to be recognised and respected as a crucial part of society.
- > For Government and the media to proactively combat myths about families receiving disability and carers benefits.
- > For advice, information and support to be easily accessible wherever carers are, rather than them having to seek it out. Health and social care professionals, workplaces and community settings should work to identify carers and guide them to support.
- > For caring to be given the same political and economic prominence as alongside becoming a parent – so that ‘supporting families’ financially, through services and in workplaces is not just about childcare but about caring across the lifecourse.



Recommendations

- > **A commitment to ‘carer-proof’ future social security, NHS, social care and employment legislation and policy to ensure it does not negatively affect families’ ability to care.**
- > A new strategy to connect different ‘contact points’ across public services to improve carer’s access to information and advice. Wherever carers come into contact with public services frontline the opportunity should be taken to advice, information and support. For example, benefits applications should be an opportunity to signpost carers to information on their rights in the social care system, GP appointments should guide carers to information on social security entitlements and local support groups.
- > Government and local authorities to work together to develop good practice on how new duties in the Care Act can promote tailored advice and information for carers.
- > A campaign to spread good practice on supporting carers in the workplace.
- > The introduction of longitudinal research, similar to the English Longitudinal Study of Ageing, to improve understanding of the impact of caring responsibilities on health, workforce inclusion, household family and structure, retirement and social inclusion.
- > Government and the media to proactively combat inaccurate and damaging stereotypes about carers, disabled people and families in receipt of benefits.



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