

# Sandwich Caring



**Combining childcare with caring  
for older or disabled relatives**



# About us

**Carers UK** is a charity set up to help the millions of people who care for family or friends. At some point in our lives every one of us will look after an older relative, a sick friend or a disabled family member. Over six million people in the UK are caring now but whilst caring is part and parcel of life, without the right support the personal costs can be high. Carers UK supports carers, provides information and advice about caring, delivers training and consultancy services and campaigns to make life better for carers. For more details **visit [www.carersuk.org](http://www.carersuk.org)**

**Employers for Carers** (EfC) is an exciting, innovative and growing service for employers. Chaired by BT and supported by the specialist knowledge of Carers UK, its key purpose is to provide practical, 'hands-on', help to employers to support the one in seven carers in their workforce. Launched in January 2009 as an employers' membership forum, Employers for Carers now has over 60 member organisations, representing at least one million employees across the public and private sectors. Member services include a dedicated website with a range of practical resources, networking facilities, model policies and case studies, resources for employers and employees and access to expert training and consultancy. For further information please visit **[www.employersforcarers.org](http://www.employersforcarers.org)**



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# Foreword

Demographic change is bringing about a fundamental shift in how we all live, work and care, as we feel the effects of a wide range of demographic factors – rising life expectancy, shrinking family networks to support caring and childcare as families live further apart, parents having children later in life, huge progress in women's workforce participation, greater incidence of disability and learning disability and advances in medicine meaning that far more severely disabled children live into adulthood.



**Heléna Herklots**  
**Chief Executive, Carers UK**



For many families this is bringing a new mix of work, childcare and care for older and disabled loved ones – new challenges which previous generations have simply not faced. This report explores those challenges, as raising young children coincides with supporting older parents – something which as many as 2.4 million people are already coping with<sup>1</sup>.

Many respondents to this survey face even greater challenges as they combine support for older parents with care for children with disabilities, a disabled partner, or looking after a number of older relatives at once.

Yet public debate and policy prescriptions about these crucial aspects of family life are too often seen as separate, siloed issues – as ageing focusses on pensions and care for older people, whilst 'support for young families' is discussed through the prism of childcare and education.

The experiences captured in this research show that this approach is too often failing to meet families' changing needs – eldercare, support for disabled people, childcare and workplace support are simply not knitting together in the way families need.

The costs of a failure to support these families can be high, as the pressures of work alongside multiple caring responsibilities take a toll on their health, finances, relationships and careers. The families featured in this report counter the suggestion that, in times of austerity, families will simply have to do more in the future to absorb growing demand for care. That is a recipe for real damage to family life.

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<sup>1</sup> YouGov Poll April 2012 (2012) YouGov and Engage Mutual Survey - polling a GB representative sample of 1,008 people aged 45-60 who had elderly parents and 500 people aged over 65 who had adult children.

These costs and challenges must feed into current and emerging policy debates – showing in particular that quality and affordability of care for older and disabled loved ones is every bit as much of a challenge for families as childcare, and that caring across the life-course must be factored in to debates on economic participation and particularly women's workforce inclusion.

From families' experiences in this research we can already begin to see what good support looks like – as supportive workplaces, technology, flexible and affordable services and the support of friends, families and communities come together to help build strong families, improve health and wellbeing and keep people in work alongside family commitments.

So whether it is changes to welfare, funding of care and support or discussions around the cost of living and improving employment practices – it is time for services, workplaces and policy debates to catch up with this new reality of family life.



# Background – Caring and childcare

Caring for older and disabled relatives is an issue that affects almost every family in the UK, and at some point in our lives we will all care for a loved one or need care ourselves.

Caring without the right support can put serious pressure on carers' ability to work – with significant consequences for family finances and costs to the economy. In the UK, one in seven employees in any workplace is juggling paid work with care and a 2009 poll by Ipsos MORI found that around one million carers had given up work or reduced work to care, with an obvious impact on the benefits and pensions systems in addition to impacts on individual and family health and wellbeing<sup>2</sup>.

Demographic changes mean that more and more people are taking on caring responsibilities and projections show that by 2050, globally, three times more people of working age will be looking after two billion ageing family members<sup>3</sup>. Carers are a diverse group who have a variety of different needs that depend on a range of factors including the needs of the care recipient, gender, age, as well as employment and family circumstances.

Today more and more parents are combining looking after young children with caring for older or disabled loved ones. This is sometimes called 'sandwich caring' or 'dual caring' and those who fall under this category are usually referred to as 'the sandwich generation'. But this dual role can sometimes come at a cost and carers may suffer from ill health, face difficulties to access or stay in the labour market or experience financial hardship.

This report looks at a specific category of sandwich carers, namely those 'who combine looking after a dependent child under the age of 18 with caring for an adult'. However, the sandwich generation can also be considered to include those who support their adult children who are studying, working and trying to purchase increasingly expensive accommodation while at the same time supporting a spouse or their ageing, sick or disabled parents who require an increasing amount of care. It can also include grandparents who are looking after their grandchildren and at the same time supporting other family members. Carers UK will explore these caring relationships in future research.

Despite rising awareness of this 'sandwich generation' it is difficult to get a clear understanding of the extent of the caring roles of the sandwich generation. Carers UK and Employers for Carers conducted this research as an attempt to better understand the extra pressure these dual caring responsibilities have on modern families and their implications for policy, public services, employers and the labour market.

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<sup>2</sup> *One million give up work to care* (2009) Carers UK, DWP and Ipsos MORI

<sup>3</sup> *World population ageing* (2007) United Nations, Department of Economic and Social Affairs, Population Division

# Key findings

## Struggling to cope – emotionally and financially

*"It can be done – juggling dependent children and elderly parents. But at a cost – of friends, social life, personal life and quality time with the children and it takes all my strength and resources to take each day at a time."*

- Only 12% of sandwich carers felt they were juggling everything well, over four in 10 (42%) were struggling to cope or at breaking point.
- Three quarters (74%) said that caring for both children and older or disabled loved ones had a negative impact on their ability to earn.
- Over two thirds (69%) said they had seen a negative impact on their ability to afford household bills.

## A toll on family life

*"I feel truly sandwiched and guilty that I neglect children, mum, work AND husband most of the time."*

- Almost two thirds (63%) said that sandwich caring had taken a toll on their relationship with their spouse or partner. Seven in 10 (69%) had seen their friendships suffer.
- Over half of parents worried about the effect on their children of having to juggle childcare with caring for an older parent or disabled relative.
- Four in 10 feared they were letting down their ageing parents or disabled loved ones.

## Trying to juggle work and care

*"I feel as if my life has stopped. I was hoping that as children grew I would be able to have a career again, but feel chances are made less because these years I could have been retrained, are taken up with hospital appointments and caring for my parents. I'll be old before I know it and will have lost this part of my life."*

- Only half of sandwich carers surveyed were able to juggle work and care.
- A third were caring round the clock and the vast majority of these carers (85%) had been forced to give up work to care.

- Women were four times more likely than men to have given up work because of multiple caring responsibilities.
- A high proportion (79%) of carers who had seen their work affected attributed this to the stress of juggling everything together.
- One in five respondents (22%) who were managing to juggle work and care, said their jobs were negatively affected by caring as a result of tiredness, lateness and absence.
- Over three quarters of working carers (77%) said that their employer was aware of their caring responsibilities; but 23% had not mentioned their caring responsibilities at work.

*"I have cut my working hours to care and had to take a less qualified job to fit around my caring responsibilities. I cannot earn the sort of money I need for everyday life due to my care commitments and I am not able to progress in my career or take on promotion."*

## Finding support

- As many sandwich carers (almost one in five) said that the costs of care for older or disabled relatives had affected their ability to work, as those who mentioned the costs of childcare as a factor.
- More families found that struggling to access suitable eldercare affected their work (20%) than identified finding the right childcare (13%) as the issue.
- Over one in four (28%) said that additional support with the care of older or disabled relatives would make the biggest difference in helping them to manage, substantially more than those who picked more affordable or suitable childcare (6%).
- A fifth (20%) said that it was low-level domestic support that would make most the difference in helping them to manage.
- Whilst 77% of employers were aware of caring responsibilities and over half offered flexible working, only 16% had a specific policy for supporting staff caring for older and disabled loved ones.
- Although 40% found looking after children and older relatives equally easy to talk to their employers about, a third (30%) found it hard to talk about both responsibilities at work, and 25% said it was easier to talk about childcare than caring for a disabled adult.
- Less than a third were accessing assistive technology to help with caring responsibilities.

*"The pressure is huge. I can't concentrate at work and realise that my performance is dropping. I am short tempered or very negative. My partner and I have been arguing and sleeping in separate beds for the last month. I have suffered heart palpitations and digestive problems for the last six months which I assume are caused by stress. The house is a complete mess. I miss my own medical appointments. I have lost touch with friends. I feel trapped, like this is going to be my life for the next 10 years at least."*

# Emerging issues

## Sandwich caring: understanding a new social challenge

The experiences of sandwich carers set out in this report demonstrate that, without support, the pressure of combined caring responsibilities can take a serious toll on families' health, finances, careers and relationships.

This evidence further highlights the need both to improve access to and affordability of childcare, and deliver long-awaited reform of care for older and disabled people. But it also taps into wider significant political debates – around family breakdown and resilience, creating a more dynamic and enabling benefits system to support families into work, extending working lives and supporting women's workforce inclusion.

There are also clear implications for the commissioning of social care services. Support for those with caring responsibilities for older and disabled loved ones is often geared only towards those with round the clock caring responsibilities. Their needs must remain a priority, but this research also highlights the huge pressure on those providing under twenty hours of care a week for adult relatives when this is combined with work and childcare. In this situation, the cumulative impact of caring can push families into crisis – even though they may not be showing up as a priority group for policy makers.

Services and support should reflect this diversity amongst carers, recognise caring across the life-course and work to enable families to remain resilient when caring affects them – otherwise the personal, financial and economic costs are clear. Fragmented services which meet only some of families' needs and fail to match up with each other and with modern workplaces cannot provide the solution.

An understanding of all of these new care challenges must be embedded in policy debates across Government – to recognise the risks that they pose for families but also the opportunities for different policy areas to contribute to meeting them.

## Recognising the economic case for supporting families to juggle work and care

With the 6.4 million carers in the UK now expected to rise to nine million by 2037 the Government's Carers Strategy acknowledges that by 2017, we will reach the tipping point when the numbers of older people needing care will outstrip the numbers of working age family members<sup>4</sup>. This shift will also require more people to be able to work, and work longer, to meet care and pensions bills – including delivering support to enable carers and those who need care and support to lead longer working lives.

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<sup>4</sup> *Recognised, Valued and Supported: next steps for the Carers Strategy* (2010) HM Government, Department of Health, Gateway ref:15179.

However this is not just an issue for the future, it is very much an issue for the present. With as many as one in 6 carers giving up, or cutting back work, to care, this is already generating an unwelcome financial impact on businesses faced with losing skilled employees in whom they have already made a considerable investment.

Currently, 300,000 carers are forced to give up work to care each year, at a cost of £5.3 billion to the UK economy<sup>5</sup>. Add to that the costs of women unable to return to work after maternity leave, or who have to drop out of the labour market because of the affordability or availability of childcare, and we see a bleak picture for UK plc.

As well as retention of key staff, there is also the important issue of maintaining staff health and resilience. Caring is often a hidden issue in the workplace but the cost of not addressing it is considerable, not only for the employee but also for their employer. We know from analysis of the 2001 Census that working – and working age – carers pay a heavy penalty in terms of their own health if not adequately supported to work and care. Those with heavy caring responsibilities are two to three times more likely than workers without caring responsibilities to be in poor health<sup>6</sup>.

The effects of stress and ill health on productivity have been highlighted by Dame Carol Black<sup>7</sup>. However, supportive employers can play a key role in mitigating these impacts, and in thereby increasing staff resilience, productivity and performance in the workplace.

More employers are now starting to recognise the business case for supporting carers in the workplace. Employers for Carers is populated with progressive employers who have recognised the benefits of retaining key talent and helping staff to work healthily and productively. This is even more important in tight economic times when organisations need to work smarter and be resilient.

However, despite the excellent support offered by such employers, caring still remains a relatively hidden issue compared with childcare in many workplaces, though no less important in its impact on business and on working lives.

Employers who engaged in the childcare debate in the 1990s saw childcare as a fundamental condition for employment, as critical to them as transport or utilities. Forward-looking employers are now seeing care services in the same way, acknowledging that the tapestry of services that keep families resilient when they are juggling work with increasingly complex multiple responsibilities are essential for economic productivity.

A joint HM Government and Employers for Carers *Carers and Employment Task and Finish Group* was established in June 2012. Evidence from this research will feed into that work to explore these issues and help build the economic case for supporting families to juggle work and care.

**Caroline Waters OBE, Director, People and Policy, BT Group and Chair, Employers for Carers:**

*“Employers are seeing increasing numbers of key staff forced to give up work because they cannot get the support to juggle work with caring for ill or disabled loved ones. We need action now, to tackle this growing challenge to business productivity.*

*But also as the economy grows and as business grows, we will need to attract people to work. If we don't have the flexibility and services, then what we are saying is that up to 15% of the working population aren't able to join us.”*

## Opportunities for growth

Sandwich carers in this research identified an urgent need to improve affordability, quality and access to childcare, eldercare and care and support for disabled people, but also lower-level domestic support.

<sup>5</sup> Analysis by Age UK of the costs of giving up work to care on the economy. Published by Age UK and Carers UK on 26 September 2012 [www.carersuk.org/newsroom/item/2617-care-in-crisis-more-than-53-billion-wiped-from-the-economy](http://www.carersuk.org/newsroom/item/2617-care-in-crisis-more-than-53-billion-wiped-from-the-economy)

<sup>6</sup> *More than a Job: Working Carers: Evidence from the 2001 Census* (2006) Lisa Buckner and Sue Yeandle, University of Leeds

<sup>7</sup> *Working for a healthier tomorrow* (2008) Dame Carol Black's Review of the health of Britain's working age population

With inexorable growth in demand for care and support from an ageing population, services to meet this demand are surely *the* growth market. Yet the mechanisms do not yet exist to drive this growth. Local authority commissioning for services for older and disabled people is largely focussed on eligible need and those who fall below local authority means-tests, rather than wider need across the population. The recent social care White Paper made progress on moving local authorities towards market mapping and stimulation but, learning from the 2006 Childcare Act, duties to ensure sufficiency of supply of services for older and disabled people would help to deliver the economic emphasis on care needed to kickstart more rapid growth in the sector.

We are starting to see wider recognition of this potential, for example as Lord Heseltine's *No Stone Unturned in Pursuit of Growth* report identified the 'obvious potential for growth' of the social care sector. However the care market is still not yet recognised alongside other industries as a sector with potential for growth. It is essential that the cross-Government work of the Carers and Employment Task and Finish group<sup>8</sup> delivers concrete measures to stimulate the supply of services and raises awareness of this huge potential. European models for care market growth have already shown that responding to families' demand for a spectrum of services – from care to domestic services which are specifically geared towards meeting families' work and care needs can be a triple win: helping families to juggle work and care, enabling employers to retain key staff and acting as an engine for economic growth.<sup>9</sup>

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<sup>8</sup> New working group jointly chaired by the Department of Health and the Chair of Employers for Carers to look at how care and support provided across Government departments can help carers to juggle work and care. <http://www.dh.gov.uk/health/2012/06/new-working-group-to-help-families-juggle-work-and-caring-responsibilities/>

<sup>9</sup> *Growing the Care Market: Turning a demographic challenge into an economic opportunity* (2012) Carers UK, Future Care Series [www.carersuk.org/media/k2/attachments/Future\\_Care\\_Growing\\_the\\_care\\_market.pdf](http://www.carersuk.org/media/k2/attachments/Future_Care_Growing_the_care_market.pdf)

# Recommendations

With these issues in mind, we make the following recommendations for solutions to facilitate better support for 'sandwich' carers and their families.

Our key recommendations centre around:

- 1) **Reforming** care services to address long-term underfunding of care and support services, ensure quality and affordability of services from childcare to eldercare, and shift to commissioning which reflects families' diverse needs not just crisis avoidance.
- 2) **Stimulating** a new generation of care and support services as part of national strategies for economic growth.
- 3) **Changing** workplaces by spreading good practice amongst employers – raising awareness of the business benefits of family-friendly workplaces which reflect both childcare and other caring responsibilities.'

## Reforming services: care and childcare

The Government has already published a draft Care and Support Bill on reforming the social care system, which includes a number of significant areas of progress in reforming the structure and legal basis for social care. However further action is needed to tackle affordability, sufficiency and access to both childcare and care and support for older or disabled people.

Carers UK urges the Government to:

- Tackle the crisis in funding care and support and put in place a sustainable settlement which can meet both unmet need and growing demand.
- Implement the recommendations of the Dilnot Commission, to protect families from catastrophic care costs and encourage planning for care and investment in preventative support.
- Take a fresh look at the affordability of care services, in both childcare and social care and the combination of both, to help families meet what are growing cost of living challenges.
- Work with local government, NHS services and private providers to explore new service models and explore how existing public services can be tailored to meeting the needs of carers with multiple caring responsibilities.
- Ensure local authority assessment processes recognise that those providing a few hours of care alongside childcare and work may be at severe risk of breakdown, as well as full-time carers.

- Lead a greater public debate on caring across the age spectrum, building on the work started by projects like Dementia Friendly Communities to take these principles forward to recognise caring.
- Urgently assess the impact of the Welfare Reform Act on family resilience and work incentives, and the knock-on impact on the NHS and social care systems. This includes £9 billion cuts to disability benefits, the inclusion of Carer's Allowance in the household benefit cap, reduced earnings disregards for certain groups of carers in Universal Credit and a reduction in support for some parents of disabled children under Universal Credit.
- Establish a Health and Care Technology Taskforce, with independent expert leadership, which will bring together UK Governments and key stakeholders – researchers, developers, providers, employers, and users – to lead on actions to unlock the potential of care technology for families and as an area of growth.<sup>10</sup>

## Stimulating a new generation of care services

Carers UK urges the Government to:

- Implement measures to stimulate the care market, including a duty on local authorities to ensure a sufficiency of supply of affordable care services for older and disabled people to enable families to juggle work and care.
- Build on measures announced in the Care and Support White Paper to deliver a universal information service based on the range of care and support services available in any locality, to support access to supply; and work to reorient information and advice around providing support for those people whose caring responsibilities might span both childcare and caring for an adult.
- Explore tax incentives, including care credits, tax allowances and tax exempt Care Vouchers, to promote affordability and greater private purchase capacity and stimulate demand.
- Ensure that the link between childcare, care and support services and families' ability to work is embedded in Joint Strategic Needs Assessments and new Market Position Statements (tools for local authorities to commission services and the local care market), so that services are seen as enablers for labour market participation.
- Embed childcare and care services for older and disabled people in central Government's growth strategy and in guidance for local growth mechanisms, particularly Local Enterprise Partnerships.

## Changing workplaces

Carers UK urges Government and employers to:

- Recognise that one in seven people in the workplace are likely to have caring responsibilities and that many of these employees may be juggling multiple caring roles.
- Include wider caring issues as well as childcare in 'family friendly' workplace policies and practices, for example, flexible working and leave.
- Work together, including on awareness campaigns, to improve recognition of the business benefits of being 'family-friendly' across the life course of care.
- Raise awareness to encourage carers to identify themselves and come forward for support, for example via staff communications, staff surveys and at relevant staff information events.
- Spread good practice on including caring issues in workplace support initiatives such as staff networks, employee assistance programmes, stress management programmes and online toolkits for employees.
- Support line managers to support carers in the workplace; include information about caring in relevant manager training programmes and supporting materials such as toolkits.
- Signpost employees to sources of external information on support on caring as well as childcare.

<sup>10</sup> For further details see *Care and Technology in the 21st Century* (2012) Carers UK



## Case study

*When Helen's mum, Jean, was diagnosed with leukaemia two years ago, there was no question that Helen would be there for her. Despite costs to family finances, their careers and family life, Helen and her husband, who also have two sons, have altered their working and home lives so they can juggle their work and time with their boys to enable Helen to be there for her mum.*

*Jean, who is 78, has lived alone since her husband died 13 years ago. She lives 10 minutes from her daughter and is determined to continue to live in her own home.*

*Helen said: "It's almost like two years ago our roles were flipped overnight. Mum used to look after my family, help me with childcare of the boys. Now I look after her.*

*I feel that Mum staying in her own home, with her family looking after her is the best thing for her, and I must make time to help her do that. My mum has lived in the same house since she was 18. I really don't want to put her in a care home and carry on with my life, I want her to be part of my life."*

*Helen visits her mum up to four times daily, stays over two nights a week, cooks, cleans, manages her finances and organises and accompanies her on her medical appointments. Jean is currently in remission but the leukaemia and subsequent treatment have left her frail and with limited mobility and short term memory. Helen has organised a care package which involves care workers helping Jean overnight and in the mornings when she cannot be there.*

*She feels guilty about the amount of time she is away from children. Her children are now 14 and nine and her oldest son is doing GCSEs so it is a big year for him. Helen says that it was hard when she first began staying with her mum, as her youngest got very upset. She says her husband also misses out a lot and they rarely if ever get any proper time together.*

*"Fortunately my mum accepts outside help and my partner and children have been unbelievable – but I do feel very guilty at times. I stay overnight with my mum twice a week when we have no care support and this can be difficult as the children need me as well."*

*Helen has been with her employer for twenty years and says she has had good support while she has been caring for her mum. When Jean first fell ill, Helen negotiated a year's leave. She has since returned to work but has had to halve her working hours. Her husband has also had to alter his working hours to try and keep their childcare costs to a minimum. The family have been left with no savings and despite budgeting carefully household finances are incredibly tight.*

*Helen says: "There are times when I think I can't cope. But I just feel it is the right thing to do."*

# Results

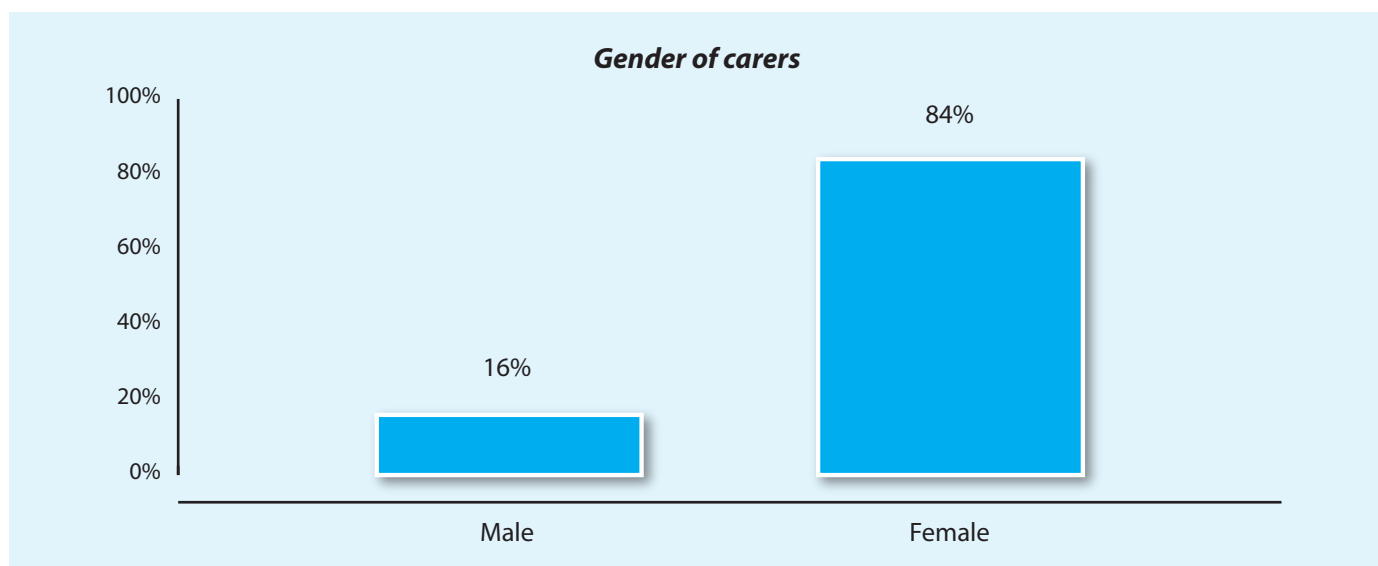
## 1. Study identity

This study was conducted in October 2012 and surveyed a total of 1,009 people who cared for at least one dependent child and an adult at the same time (sandwich carers or dual carers). For the purposes of this research dependent children were defined as *“any child under the age of 18 who is reliant on the respondent for the majority of their care, wellbeing and financial support.”* Children with a disability or long-term condition over the age of 18 are described as adults.

## 2. Demographic characteristics of sample

### 2.1. Gender of carers

More than three quarters of carers in our sample were females (84%). This contrasts with the general carer population where women account for 58% of carers, however, it supports figures from the General Household survey which indicate that women are more likely than men to be ‘sandwich carers’.<sup>11</sup>

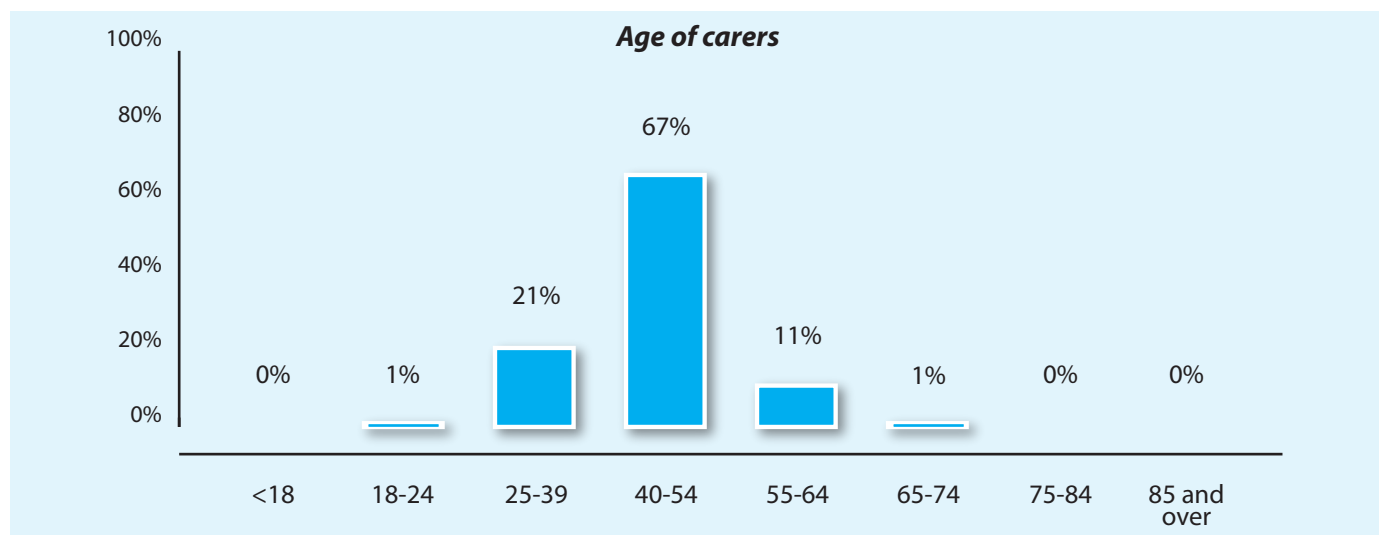


<sup>11</sup> *Simultaneous care for parents and care for children among midlife British women and men* (2003) Agree, E, Bissett, B and Rendall, M in *Population Trends* vol. 112 (Summer): pp.29-35

## 2.2. Age of carers

The vast majority of carers in our sample (98%) were of working age (18-65). This was an expected outcome as carers over the age of 65 are far less likely to have dependent children under the age of 18.

Most respondents were aged between 40-54 years (67%). Just over one in five (21%) were between 25-39 years followed by one in 10 (11%) aged between 55-64 years. General Household Survey data also shows that the peak age of caring is 50-59 years while the peak age for caring for those with 'dual caring responsibilities' falls between 40-49 years.<sup>12</sup> That fits well with our findings according to which the peak age of caring for sandwich carers is 40-54.

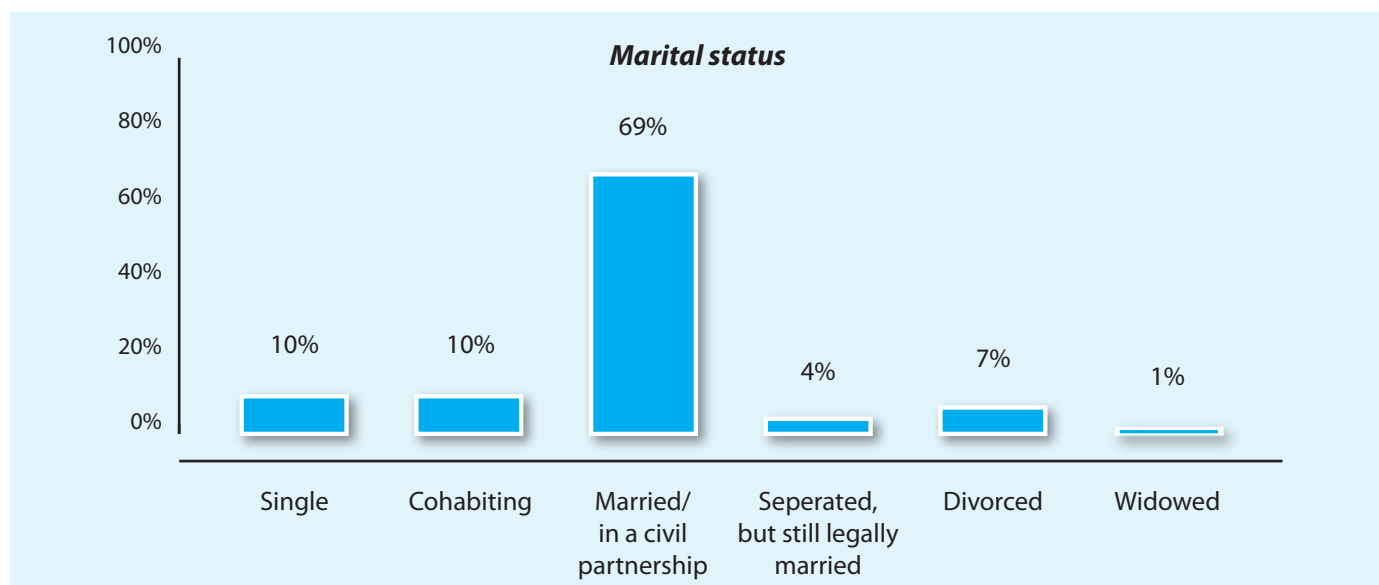


## 2.3. Ethnicity

The vast majority of respondents (90%) came from a white ethnic background, mainly British. This is in line with Carers UK analysis of Census data which indicates that 10% of carers are from Black, Asian and minority ethnic (BAME) communities.<sup>13</sup>

## 2.4. Relationships

Nearly 70% of respondents were married or in a civil partnership at the time of the survey.

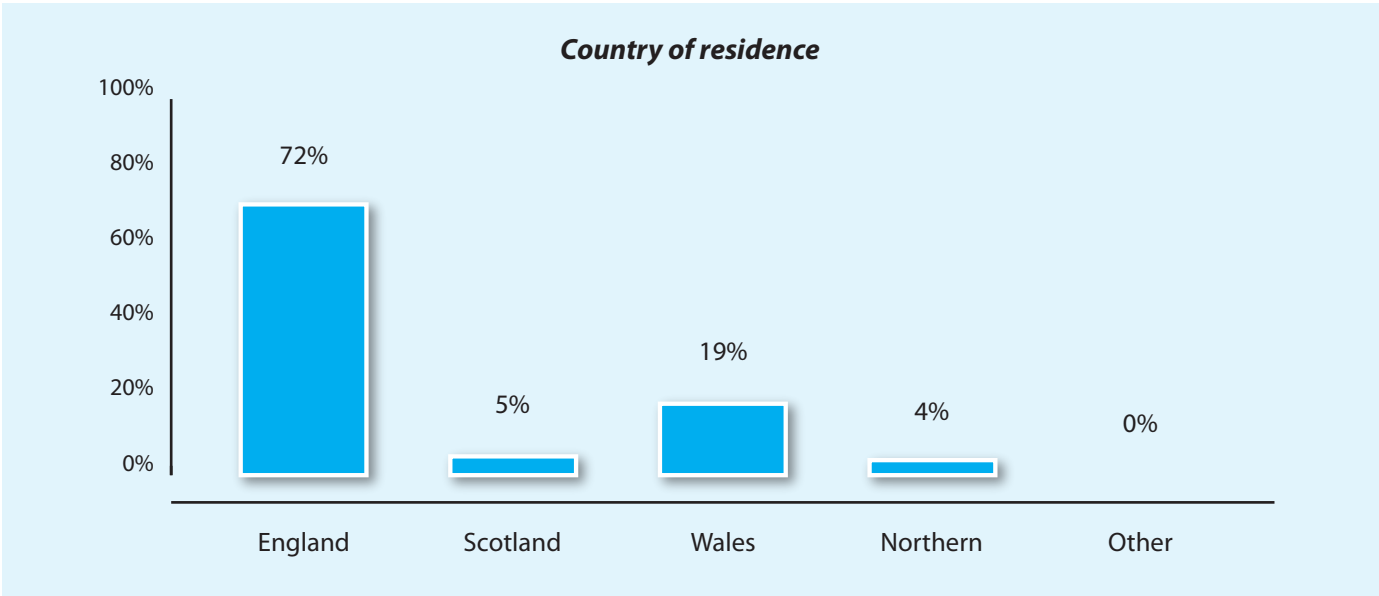


<sup>12</sup> *Simultaneous care for parents and care for children among midlife British women and men* (2003) Agree, E, Bissett, B and Rendall, M in *Population Trends* vol. 112 (Summer): pp.29-35

<sup>13</sup> *Half a Million voices: Improving support for BAME carers* (2011) Carers UK

2.5. Country of residence

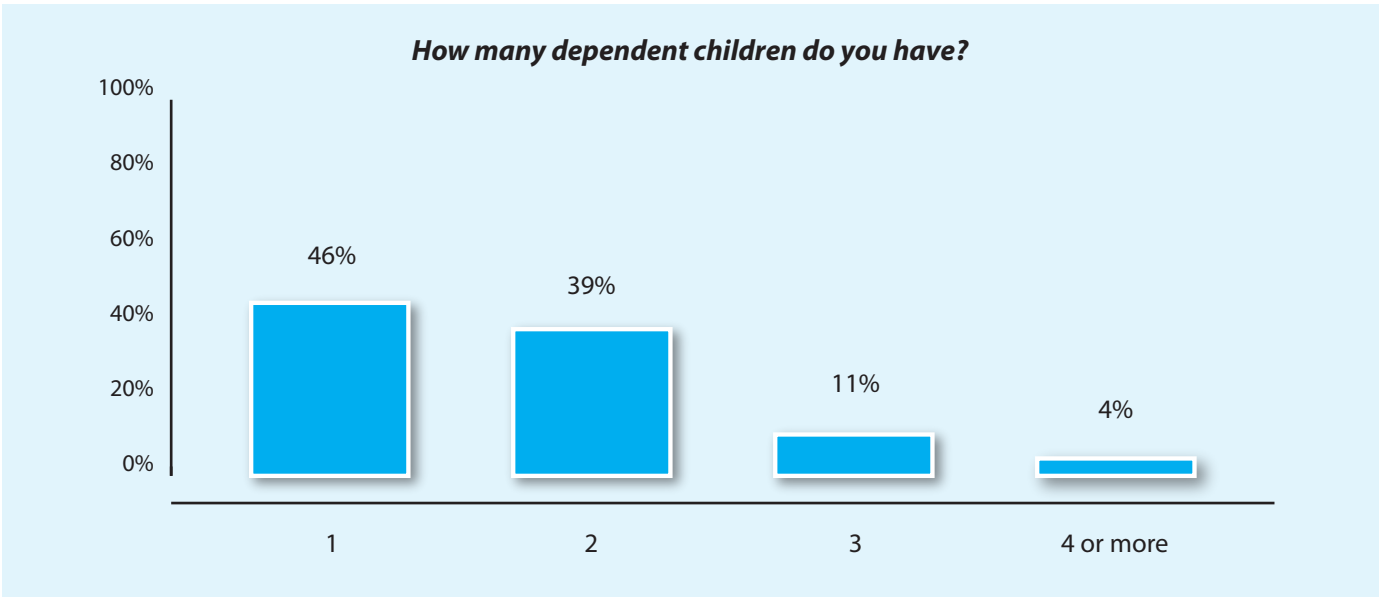
Almost three quarters of carers in our sample resided in England (72%), followed by one in five (19%) residing in Wales, 5% in Scotland and 4% in Northern Ireland.



3. Supporting dependent children

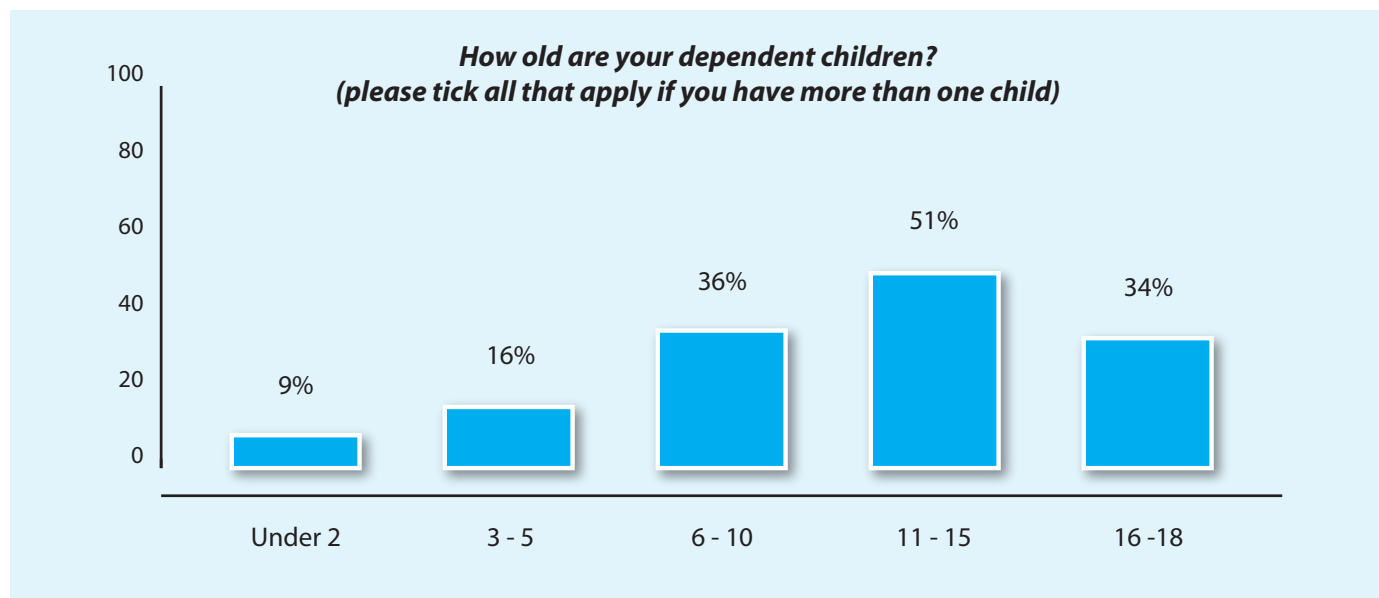
3.1. Number of dependent children

Just under half of carers (46%) had one child while another 39% had two children. Fewer respondents (15%) had more than two children at the time of the study.



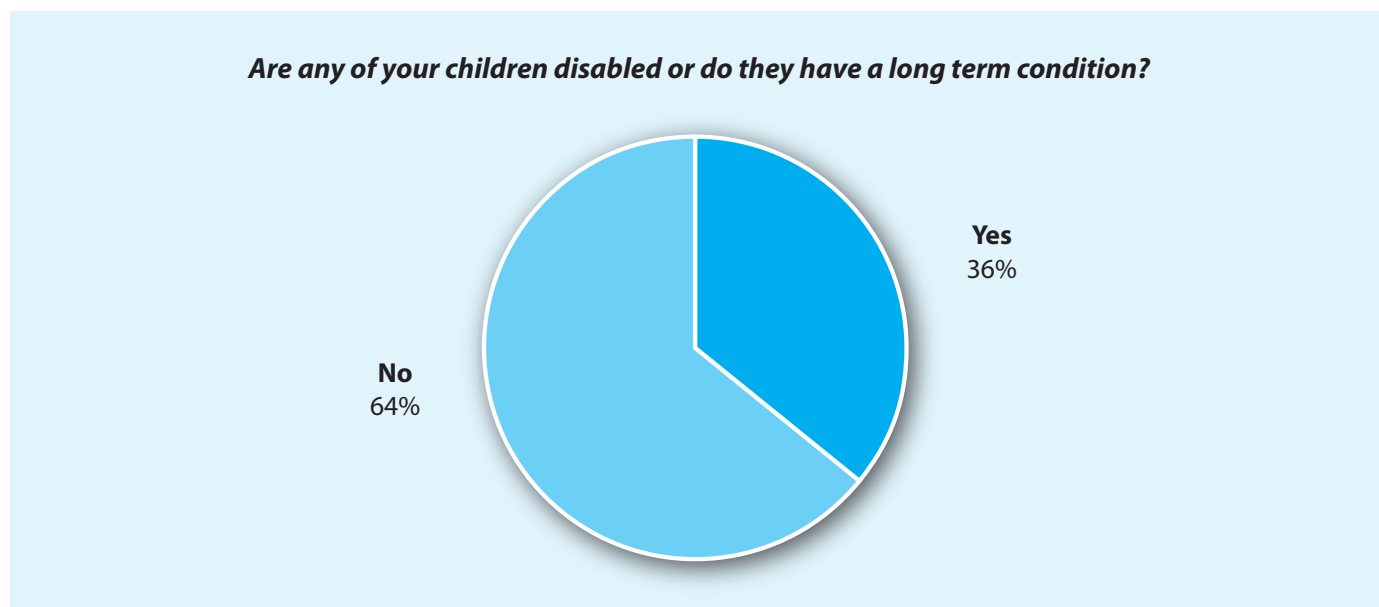
### 3.2. Age of dependent children

Just over half of carers had at least one child between the ages of 11 and 15 (51%). Carers were equally likely to have at least one child aged between six and 10 years (36%) and 16 to 18 years (34%). One in four carers (25%) had at least one child under 5 years. This reflects the likelihood that 'sandwich caring' years are more likely to fall on parents of older children, as their own parents are older. Parents of very young children are less likely to have parents with age-related conditions.



### 3.3. Health of dependent children

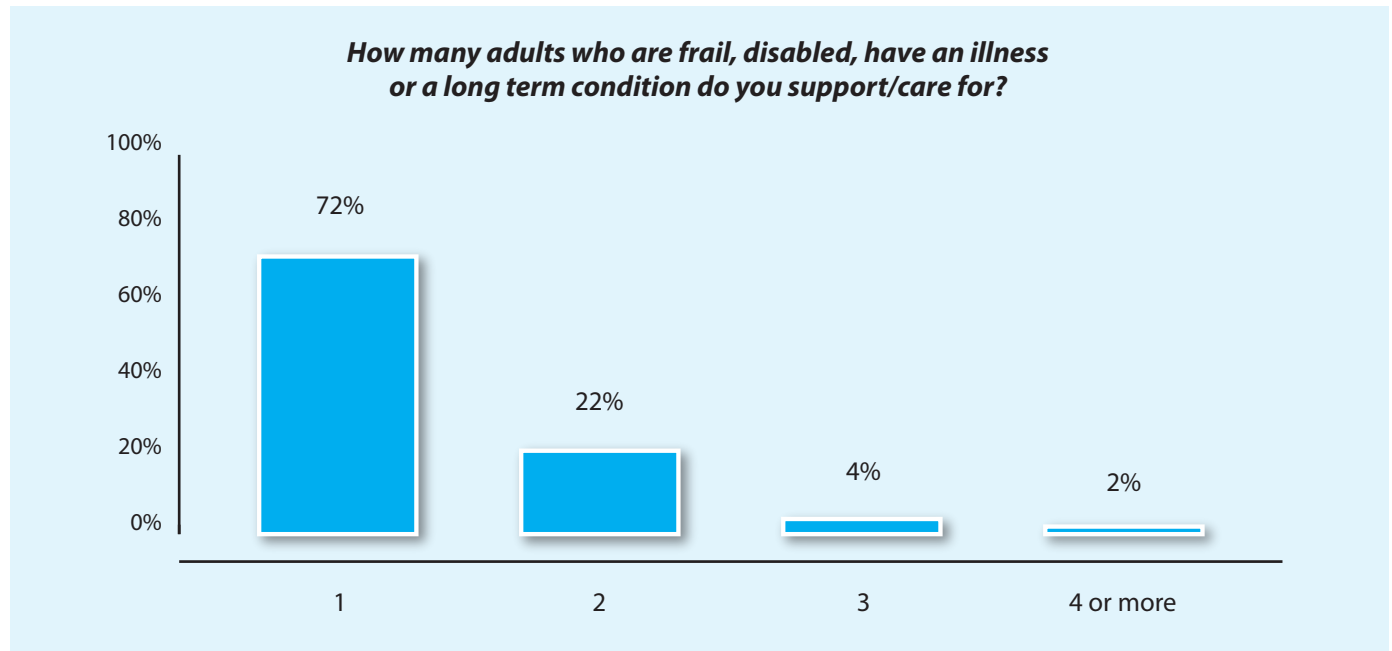
While nearly two thirds of carers said that their dependent children did not have any health issues, a significant 36% indicated that at least one of their dependent children had a disability or a long-term condition. This is higher than average because of the population from which this survey is drawn.



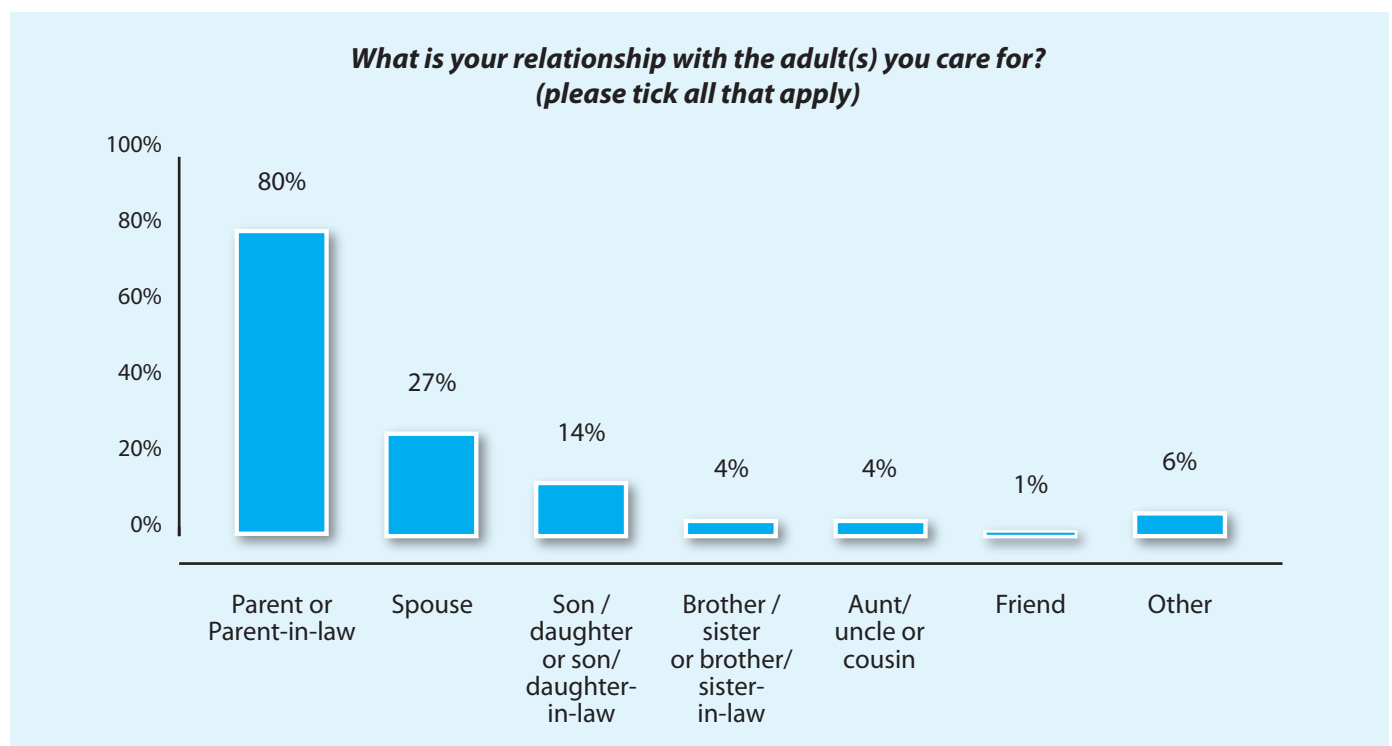
## 4. Supporting adults

### 4.1. Number of adults, age and relationship

The majority of carers in our sample (72%) were supporting one adult who was frail, disabled or had a long-term condition. Over one in five carers (22%) cared for two adults and another 6% – the vast majority of which were women – supported more than two adults.



Four out of five carers (80%) supported a parent or a parent-in-law, over one in five (27%) a spouse and over one in 10 (14%) an adult son/daughter or son/daughter-in-law. These results encompass those caring for more than one person, answers were not exclusive.

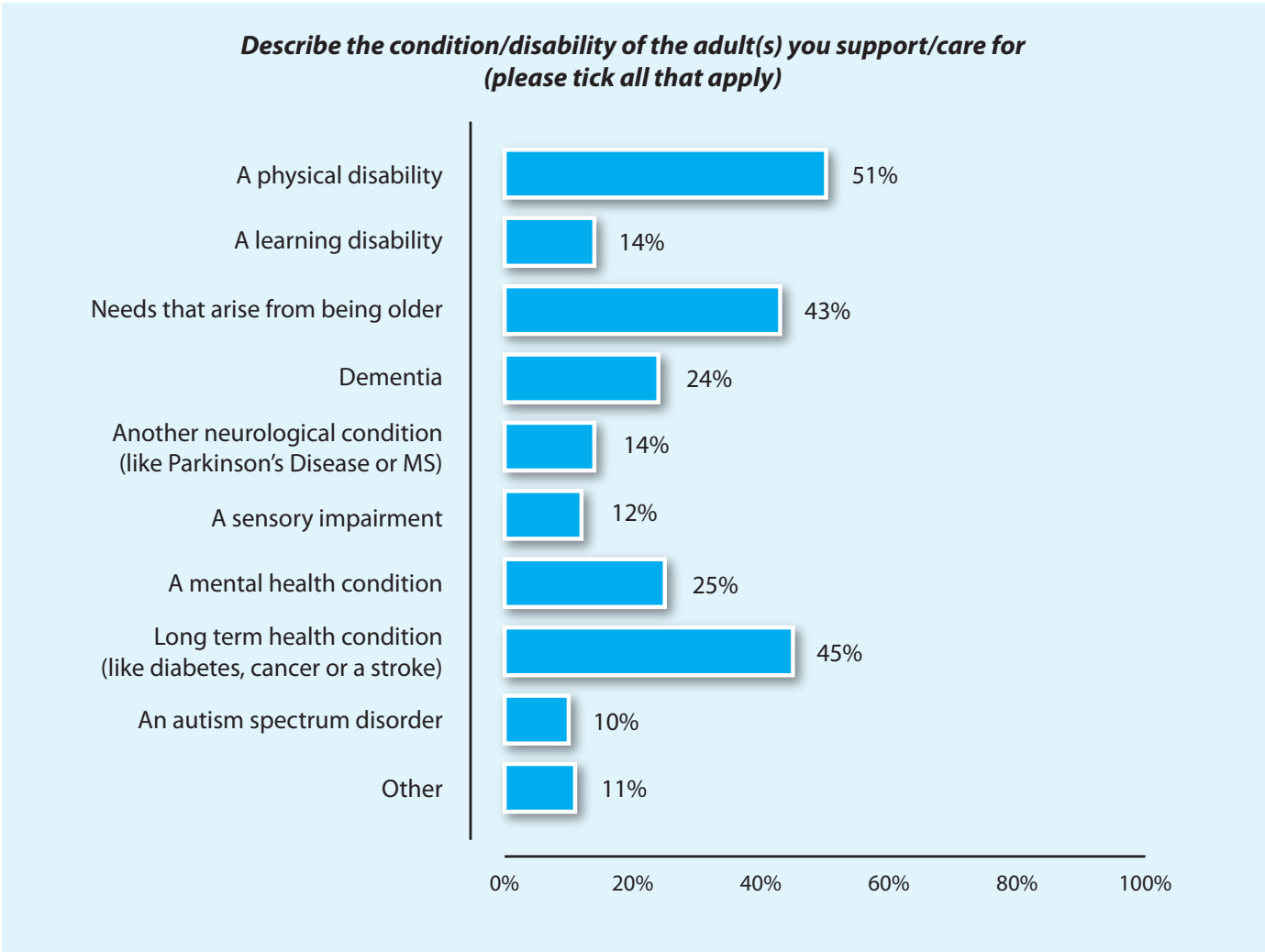


From those supporting only one adult, that person was more likely to be a parent or parent-in-law (44%) mainly aged over 75 years. Just over one in four in the same group cared for a spouse (27%) mostly aged between 40 and 54 years, and less than one in ten (8%) supported an adult son/daughter or son/daughter in-law (mainly aged 18 to 24). The majority of this latter group were women.

Men were generally more likely to care for one adult – 83% of men compared to 69% of women. Within the group of those supporting only one adult, men were more likely to care for a spouse – 53% of men compared to 22% of women – and women were almost twice as likely to support a parent or a parent-in-law.

**4.2. Health condition of dependent adults**

We asked carers to describe the condition or disability of the adult person they supported. Just over half indicated that they cared for at least one adult with a physical disability, while almost equally high was the likelihood of supporting someone with a long-term condition (45%) or with needs that arise from being older (43%). One in four carers (25%) cared for someone with a mental health condition. Nearly 40% of respondents cared for someone with a neurological condition. More than two thirds of those cared for someone with dementia. Fewer carers indicated other conditions such as a learning disability (14%) or a sensory impairment (11%).

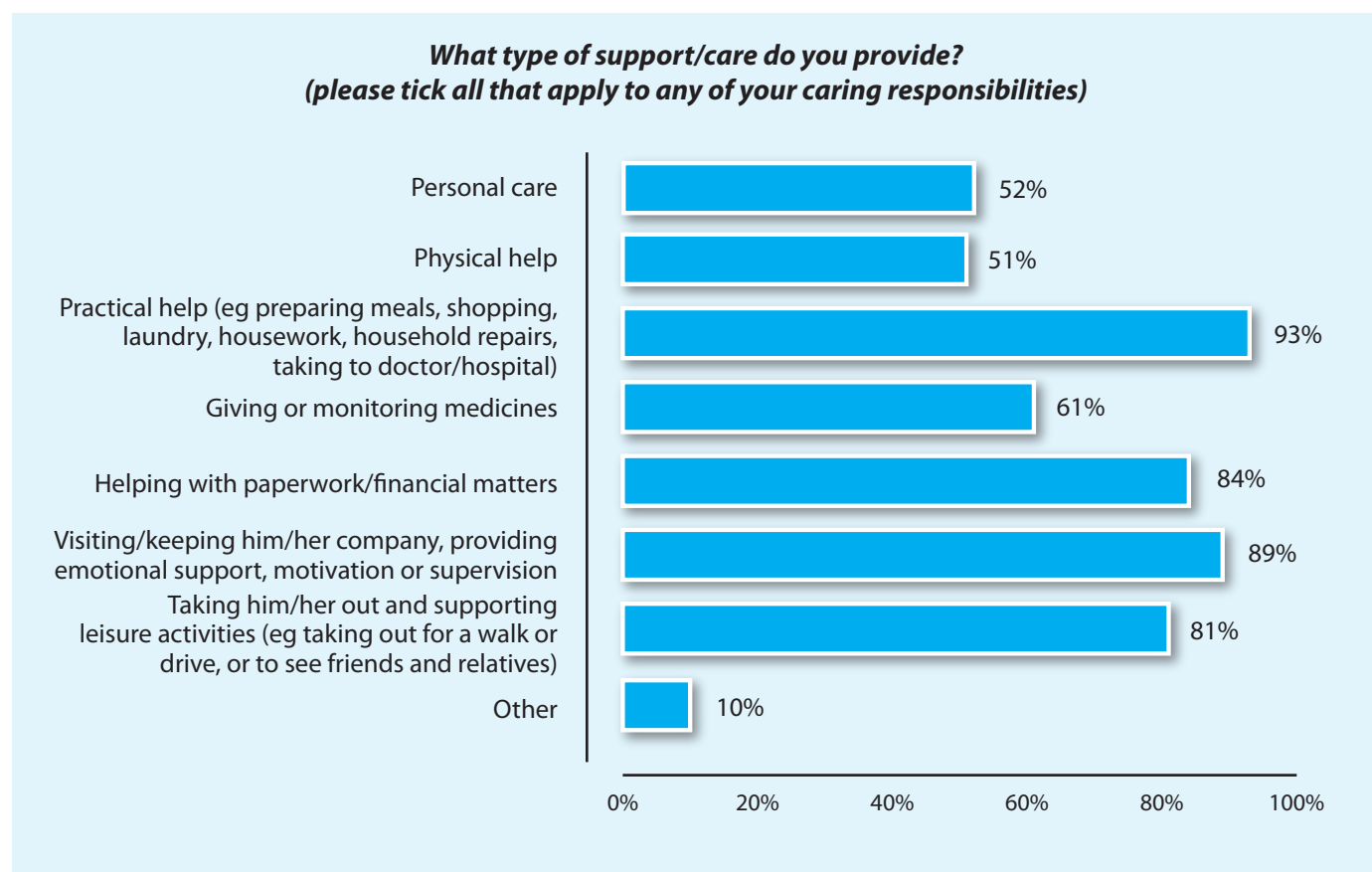


### 4.3. Type of support provided by carers

We encouraged carers to think what type of support they provided to their dependent child(ren) as well as the adult(s) they cared for.

Most carers (92%) mentioned practical help (preparing meals, shopping, housework, etc). Carers were most likely to provide support such as visiting, providing emotional support, motivation or supervision (89%), helping with paperwork or financial matters (84%) or supporting in leisure activities (81%).

Many carers offered support in terms of monitoring or giving medicines (60%), while just over half of carers provided support with personal care (dressing, bathing, washing, etc) and physical help (walking, getting into bed, etc).



### 4.4. Distance

We asked carers to tell us where the adult(s) they support lived. Nearly half (47%) indicated that they lived at the same house with at least one adult they cared for. This sample appears higher than the general population, where the General Household Survey recorded 31% of carers living in the same household as the person they cared for.<sup>14</sup>

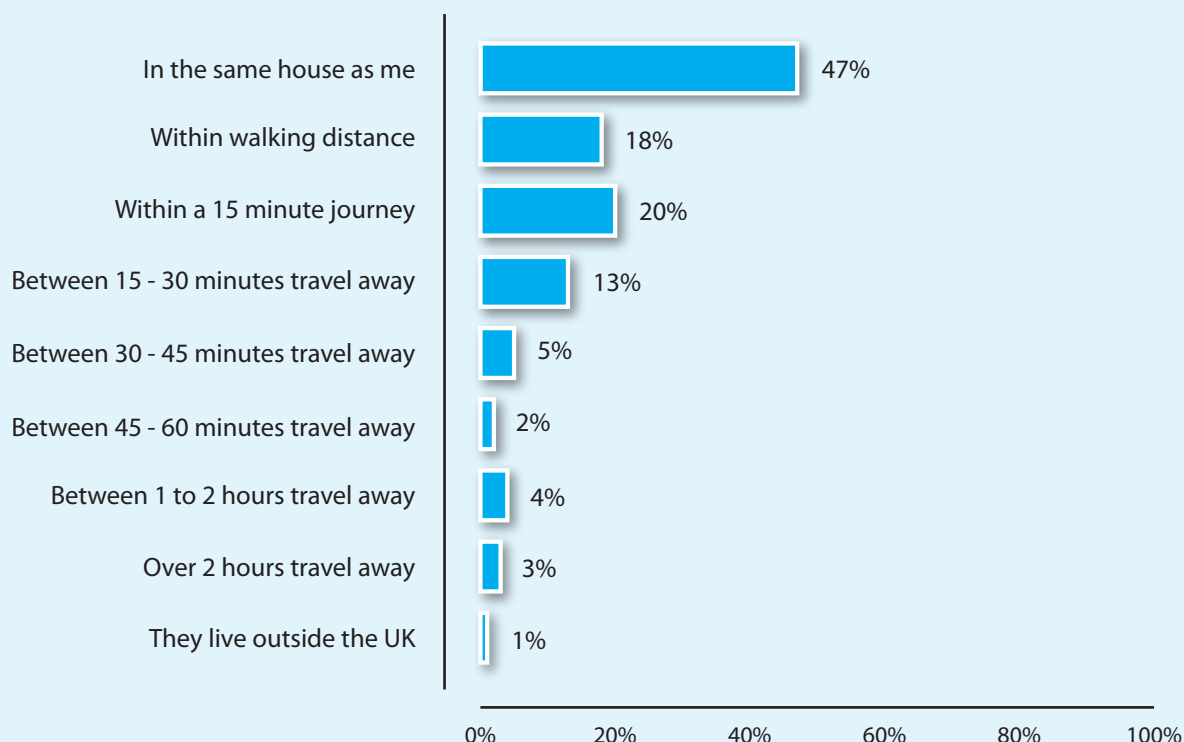
Almost two out of five carers (38%) lived within short proximity with the person they supported (ranging from walking distance to a maximum of a 15 minute journey). One in seven was caring at a distance – anything from 30 minutes away to considerable distances.

Half of the carers supporting one adult were living at the same house with this adult (49%). Within this group 52% were caring for a spouse, 30% for a parent or parent-in-law and 12% for an adult son/daughter or son/daughter-in-law.

<sup>14</sup> Carers 2000 (2002) Office of National Statistics



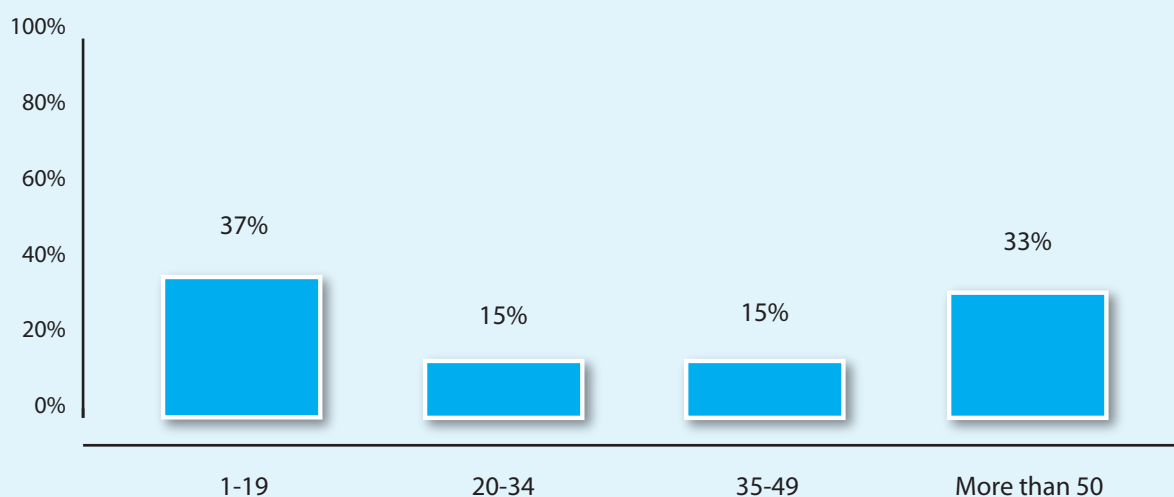
**Excluding your dependent children, where does the adult you are supporting/caring for live?  
(please tick all that apply if you are supporting/caring for more than one person)**



#### 4.5. Hours of caring

We asked carers to indicate how many hours of caring they provided per week – excluding any care they did for their dependent children. Nearly two fifths (37%) of carers provided one to 19 hours of care per week and respondents were equally likely (15%) to provide 20 to 34 and 35 to 49 hours of care per week. A significant number of over 30% provided more than 50 hours of care per week. Women were four times more likely to provide more than 20 hours of care per week than men as well as four times more likely to care for more than 50 hours per week.

**Apart from the time spent looking after your children, how many hours of care do you provide a week to a disabled/older adult(s)?**



## 5. Employment

### 5.1. In or out of paid work

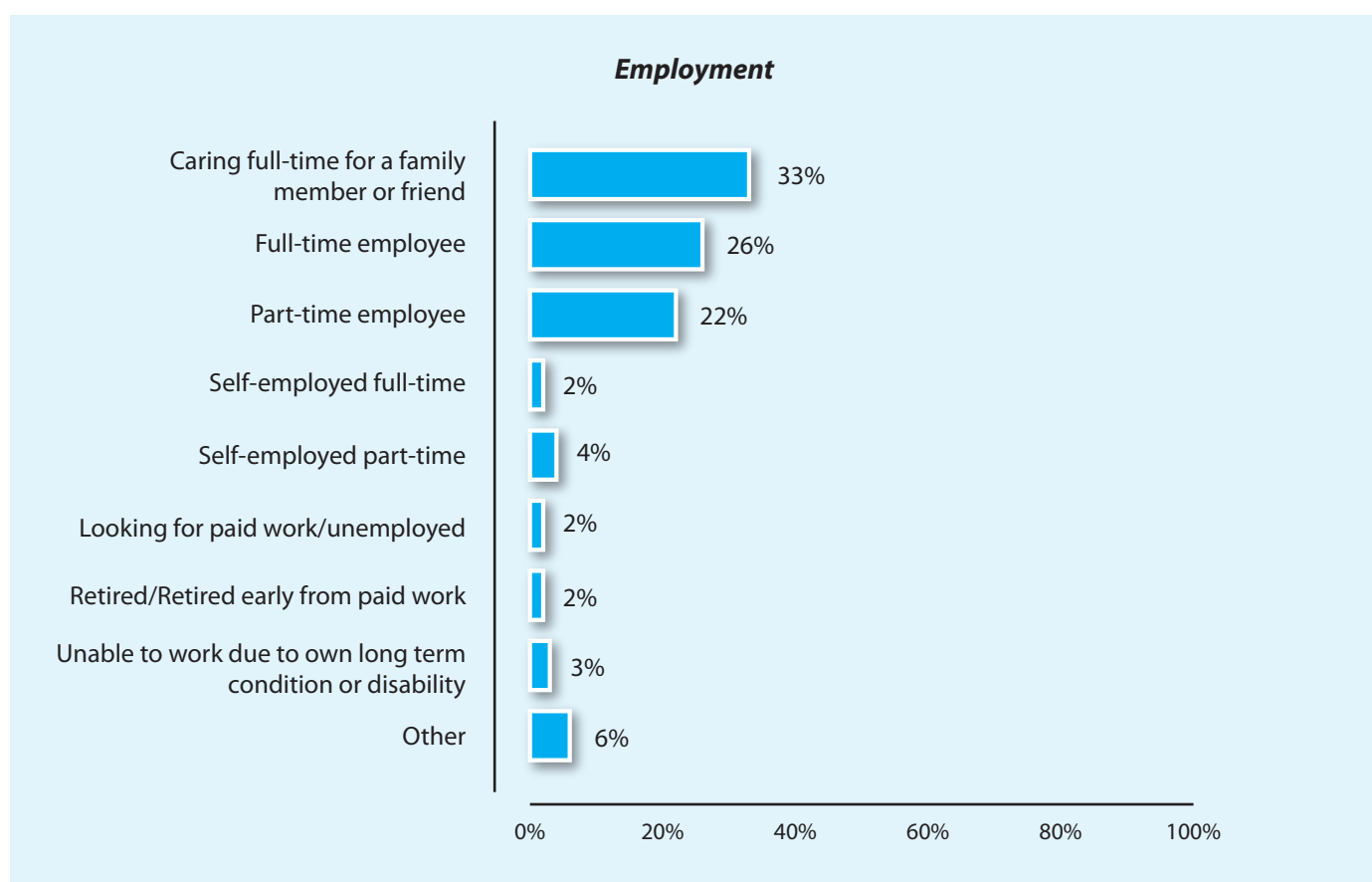
One third of carers (32%) were not in paid employment and caring full time for a family member or a friend. Within this group four out of five carers (81%) were women.

Over half of carers (54%) were employed at the time of the survey. This is a substantially smaller proportion than the wider population of carers (people caring for older or disabled loved ones) where around two thirds of working age carers are able to juggle work and care<sup>15</sup>.

Respondents in work were mainly working either as a full-time (26%) or part-time employees (22%). Women employees were equally likely to be working full and part time, however, within male employees, 83% were working full time.

Fewer people (6%) were self-employed, just over two thirds of who were working part-time (70%). However, self-employed women were more likely to be working part time, with 73% of self-employed women working part time compared to 50% of self-employed men.

2% of carers were looking for paid employment; another 2% were retired, while just over 3% could not work due to having a long-term condition themselves.



Just over three quarters of working carers (77%) said that their employer or line manager were aware of their caring responsibilities; however, a significant 23% of carers had not mentioned their caring responsibilities to their employer or line manager. There were no notable gender variations.

<sup>15</sup> *Facts about Carers* (2012) Carers UK

### ***Does your employer/line manager know about your caring/support responsibilities?***



## **5.2. Employer support**

Looking into the types of support provided by employers to working carers, the most prevalent was flexible working arrangements with just over 50% of working carers indicating that their employer offered at least this type of support.

Nearly one in four (24%) of carers indicated that their employer offered flexible leave arrangements, while 16% of respondents said that there was a specific policy for carers in place at their work. Other types of support included an employee network for carers (10%), childcare vouchers (10%), emergency childcare support (10%), emergency care support (10%), signposting to information (9%), awareness raising events (10%) or other practical support such as Employee Assistance Programmes (15%).

*"In the past I have used their carer's leave which is very good in emergencies. I manage to sort everything mostly in my own time but when I do need to leave work my employer recognises that it isn't often so they accommodate me."*

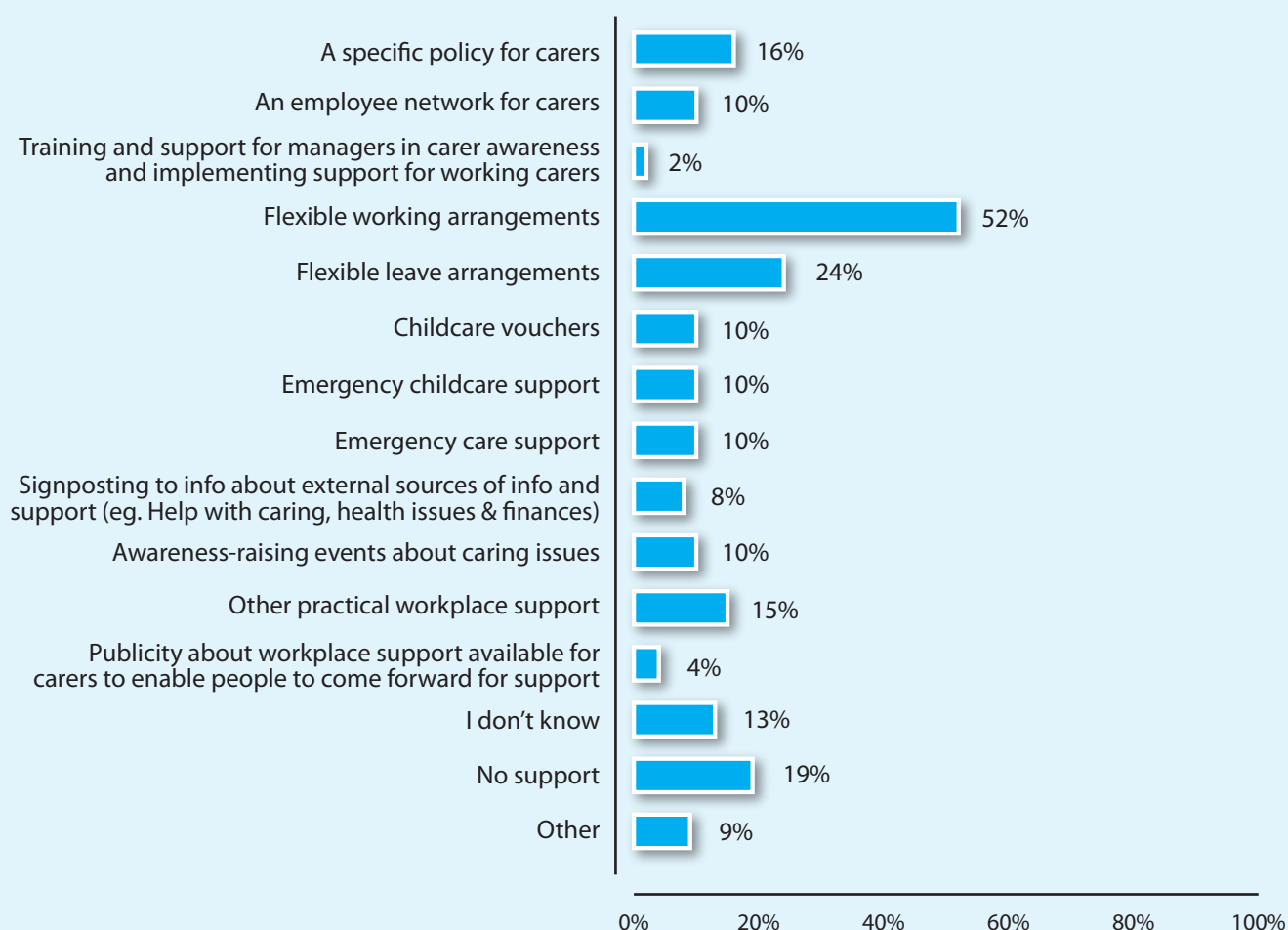
Interestingly, only 2% of carers indicated that there was any carer awareness training and support for managers, a finding consistent with *Caring at a Distance*, a research report published in 2011 by Carers UK, Employers for Carers and Nomura.

Just over one in 10 working carers (13%) was not aware about support available in the workplace and nearly one in five carers (19%) stated there was no specific support in place at their work. These results also correlate closely with our earlier research on distance caring.

*"I am lucky that I can work flexible hours and as a senior manager I can juggle my work so that it is not affected by my caring responsibilities by working at home in the evenings if necessary."*

One in seven of the UK workforce has caring responsibilities – a significant proportion of the workforce and, given the peak age for caring, these are often individuals also at the peak of their skills, experience and value to employers. These results show some of the progress made in establishing the importance of supporting carers for older and disabled relatives in some workplaces – with the important development of specific carers policies or emergency care support. However carers responding to this survey demonstrate that this kind of support remains only available or accessible in a minority of workplaces.

**What support does your employer provide to help you manage your caring responsibilities?  
(please tick all that apply)**



### Talking about caring in the workplace

We asked working carers how talking about childcare responsibilities in the workplace compared to talking about adult care responsibilities. One in four carers (25%) found it easier to talk about childcare responsibilities and an encouraging 40% said that it was equally easy to talk about adult care as it was for childcare. Nearly one in three carers, however, found it equally hard to talk about any care related issue at work. There were no significant gender variations in this finding.

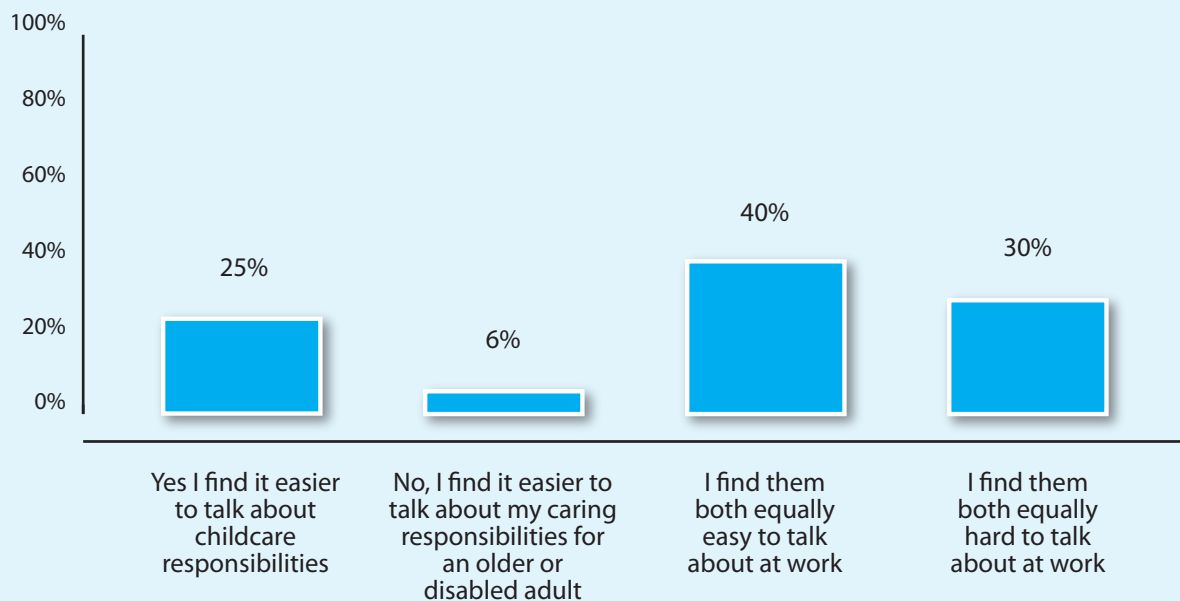
Whilst real progress has been made in normalising childcare in the workplace, with parents of young children now feeling more able to talk about and request flexibility around childcare, carers often report this is not the same for caring responsibilities for older or disabled relatives. Whilst asking to leave early for a school parents' evening would not seem out of the ordinary, carers often find it harder to ask for time off for hospital appointments for older parents or to collect a disabled relative from a day-care centre.

*"This support is 'provided' but not encouraged."*

*"Good support is available, but I don't always want to admit needing the support – as I'm trying to manage and balance everything."*

*"I work for BT and I have the support of a 'wellbeing manager' – this is amazing as it includes regular, dedicated calls to talk about how I am coping and help with organising a period of special leave."*

**At work do you find it easier to talk about your childcare responsibilities or your caring responsibilities for an older or disable adult?**



## 6. Impact of caring

### Case study

*Caring for both parents with dementia, as well as looking after a young family and working full-time has almost brought Jessica to breaking point. When Jessica's father was diagnosed with Alzheimer's Disease eight years ago things were not too bad and her mum could largely manage his care. Then two years ago Jessica's mum was also diagnosed with Alzheimer's and her deterioration was very fast. Almost overnight, Jessica needed to be there round the clock for her parents. Jessica's two children are just 9 and 7.*

*"My parents are incredibly demanding of me although they don't realise it. I cook, clean and manage finances for both households as well as provide emotional support for my parents, which is probably the biggest strain. My children often come second to my parents' needs which is wrong, but I have to rely on my husband to support the children. I get my own emotional support from friends as my husband finds it difficult to say/do the right thing when I am struggling to cope and in his defence, he is the one I scream at when I need to let off steam – which is becoming a regular event these days."*

*"My work does offer me a break from dementia otherwise it would be all I thought and spoke about but I am conscious that I under-perform but not surprising when I've managed to get through a day of the trials and tribulations of Alzheimer's, managed to get the children's homework done and them in bed and then had a night of constant phone calls."*

### 6.1. Impact of caring on ability to work

Combined caring responsibilities for adults and dependent children seemed to have significant impact on people's ability to work with only a minority of all respondents (5%) reporting no impact at all.

## Giving up work to care

What was striking was that all those carers who had previously indicated that they were not currently working and were instead caring full-time (one third of all carers in our sample), the vast majority had given-up work in order to care (85%). Women were four times more likely than men to have given up work to care.

A further small group of carers (2%) had retired early in order to care, however this is reflective of the relative youth of respondents compared to the wider carer population.

*"I think there is little likelihood of me working again because of the competing needs of my son, husband and parents. In fact the job centre advisor even commented to me 'I doubt you'll work again'. Deeply depressing."*

## Stress, tiredness and absence

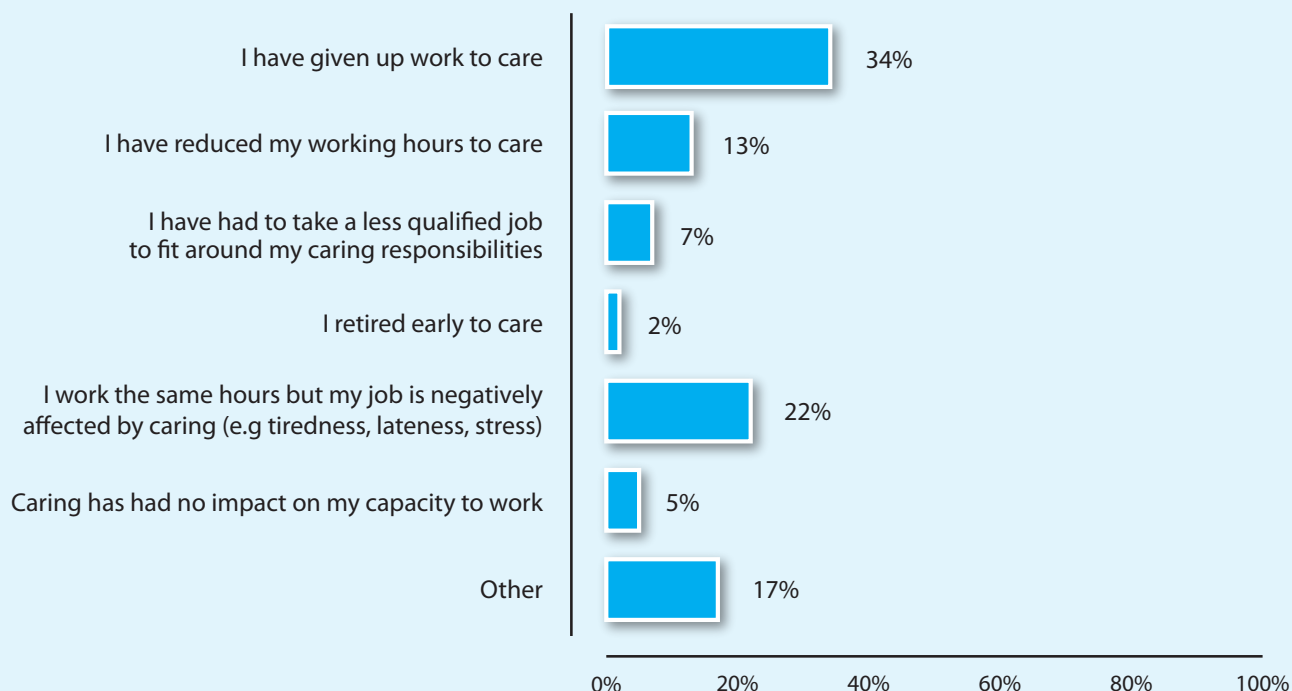
There was also a clear cost to carers who were managing to juggle work and care. Alongside those who had to leave work in order to care (34% of all respondents), carers who remained at work pointed out that in order to juggle they had reduced their hours (13%) or had to take a less qualified job (7%). One in five respondents (22%) continued working as they did before but their job had been negatively affected by caring (including stress, tiredness, lateness and absence).

*"My previously lucrative skills and earning power have been eroded over the last decade as now I am basically out of the marketplace with out-dated skills."*

Excluding those who gave up work to care, working women were more likely to report impact on ability to work than working men, with 85% of those reporting any impact being women.

Many respondents' caring and employment situation was more complex, entering and exiting caring and employment at intervals so many carers opted for the other choice in this question.

### How has your work been affected by caring for an older/disabled adult as well as dependent children?



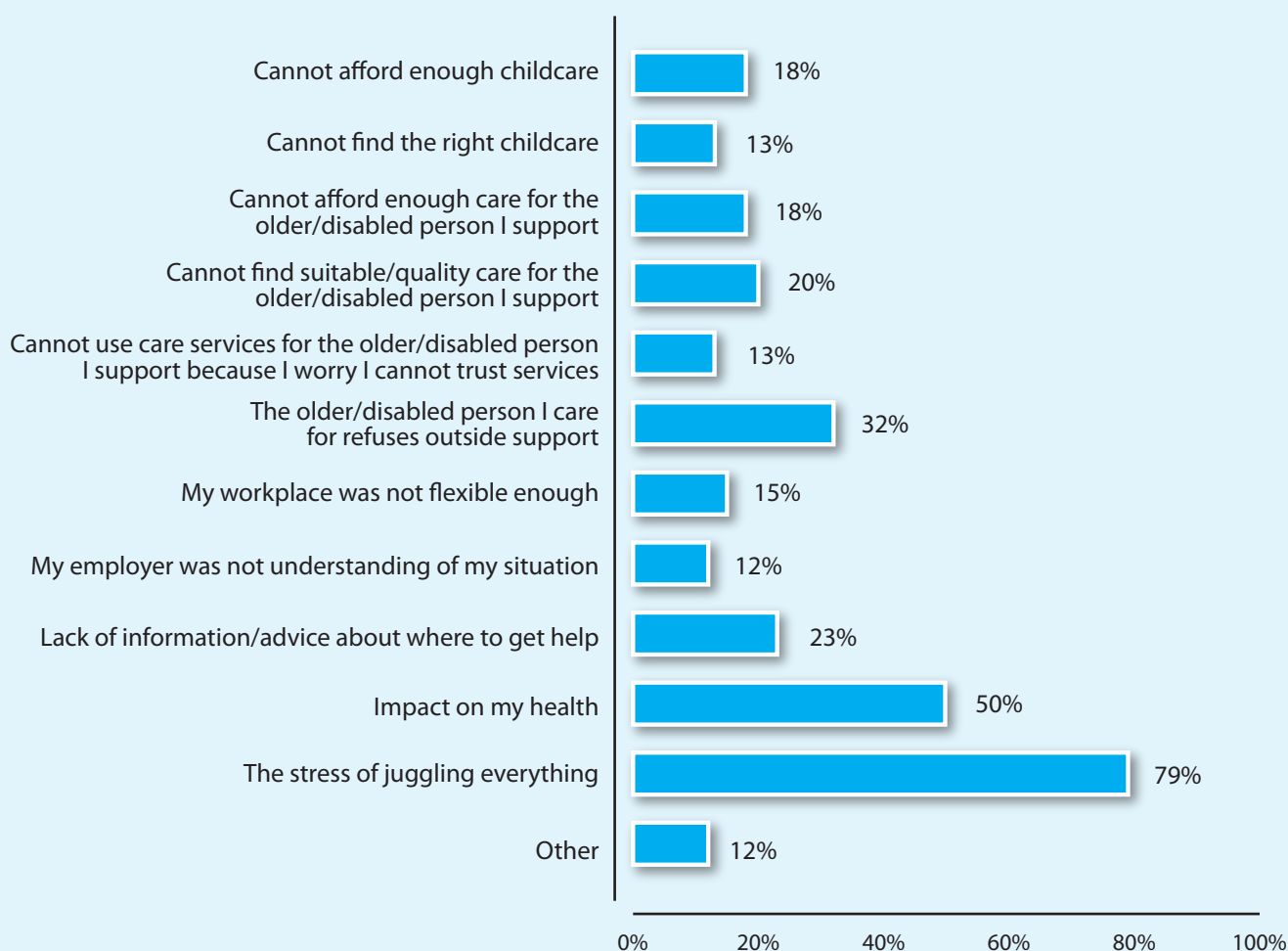
## Why work was affected

We asked those carers whose caring responsibilities for an older/disabled adult alongside childcare had affected their ability to work to explain what factors had caused this. For an overwhelming 80% of carers the stress of juggling everything together was the main factor, while half of respondents reported impact on their own health. For nearly a third of carers (32%) an added challenge was the resistance of the person they cared for to receive external support.

Further factors included inability to afford childcare (18%) or to find the right childcare (13%), inability to afford enough adult care (18%) or to find suitable adult care (20%), or inability to trust adult care services (13%). This is significant – with the same proportion of families finding affordability of care for older or disabled loved ones a challenge as did the cost of childcare. In addition, a greater proportion found accessing suitable adult care a challenge than did childcare.

Nearly one in four carers (23%) indicated that they did not have enough information/advice about where to get help.

### ***If caring for an older/disabled person alongside childcare has affected your work, what factors have caused this? (please tick all that apply)***



Interestingly, when looking into employed carers (excluding those self-employed) it was evident that many carers felt either that their workplace was not flexible enough (14%), or that their employer was not understanding of their caring situation (12%).

### Case study

*Mother of two, Nadine has cared for her 86-year-old mum, Margaret for over 10 years. Prior to his death six years ago, Nadine also helped care for her Dad. Nadine's mum is increasingly frail and vulnerable - she has heart disease, poor vision and hearing, suffers arthritis and has poor mobility. Nadine worries desperately about her Mum being at home alone, particularly since she was recently burgled after unknowingly letting rogue tradesmen into the house. But Margaret is determined to retain her independence and will not accept help other than from her two daughters.*

*Nadine works full-time and has two children, aged 17 and 10. She lives a 20 minute drive from her mum and visits her mum daily after work and at the weekend. During the day she and her sister have a rota to keep in touch with Mum by telephone. Nadine's sister lives further away and visits twice weekly. Nadine takes her Mum meals, organises her medicines, buys her shopping and helps with household chores and finances. She organises and accompanies her on all medical appointments.*

*"There is just not enough time to do everything really well. There is an old saying about a duck gliding on the surface, but paddling like mad underneath which I feel I am," Nadine says. 'I feel guilty because I just have to cut visits short sometimes and I feel guilty when she calls and I have to cut her short because I know she is just lonely."*

*Nadine works for PricewaterhouseCoopers, a member of Employers for Carers.*

*"Work has been really supportive and obliging. We have an in-house online forum which means you can talk in confidence with people who understand. We also have access to counselling and there is an appreciation of family issues. There is an understanding about the need for time off. I'm not saying we get reams of time and it does have to be negotiated. But there is an understanding and there have been times when I have had to leave work at the drop of a hat and I've just had to fill in my time sheet and I've not come back to someone calling for me to make the time up."*

*Through Pricewaterhouse Coopers in-house carers programme Nadine was also put in touch with Carers UK where she has been able to access further support, advice and practical help.*

## 6.2. Impact of caring on financial situation

We asked respondents how their financial situation has been affected by caring for an older/disabled person as well as for a dependent child(ren). Overall, people's ability to earn seemed to have been affected the most, followed by their ability to afford household bills.

*"I made the decision to give up working because it became impossible to cope with an emotionally demanding job and my son's needs, my husband's deteriorating physical and mental health and the increasing needs of elderly parents including hospitalisation due to serious illness. However not working means I constantly worry about money and how I will be able to pay bills."*

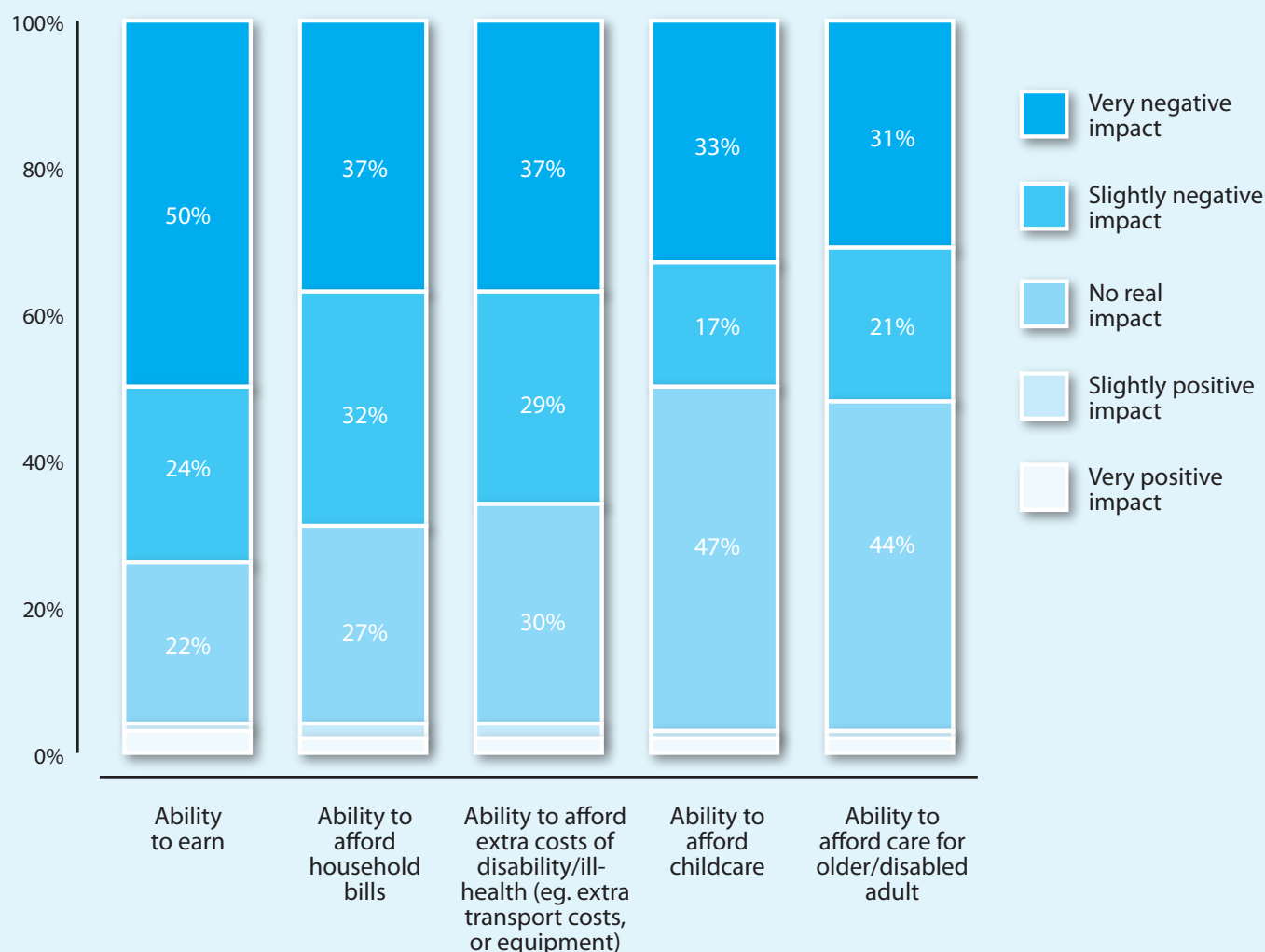
Nearly three out of four carers (74%) reported a negative impact on their ability to earn (two thirds of which indicated a very negative impact).

More than two thirds of carers (69%) had seen either a very negative or a slightly negative impact in their ability to afford household bills and a similar (66%) of respondents experienced a negative impact on their ability to afford extra costs of disability/ill-health such as extra transport costs or costs related to equipment.

Half of carers reported that sandwich caring had a negative impact on their ability to afford childcare costs, and again a slightly higher proportion felt that their ability to afford adult care had been negatively affected.



**To what extent has your financial situation been affected by caring for an older/disabled adult as well as dependent children?**



### 6.3. Impact of caring on personal relationships

Sadly, for many people, combined caring responsibilities had negatively affected their personal relationships. Relationships with a partner/spouse or with friends were more likely to be negatively affected by caring – with nearly two thirds of carers (63%) reporting a negative impact to their relationship with their partner/spouse, while 69% of respondents felt the same was true about their relationships with friends.

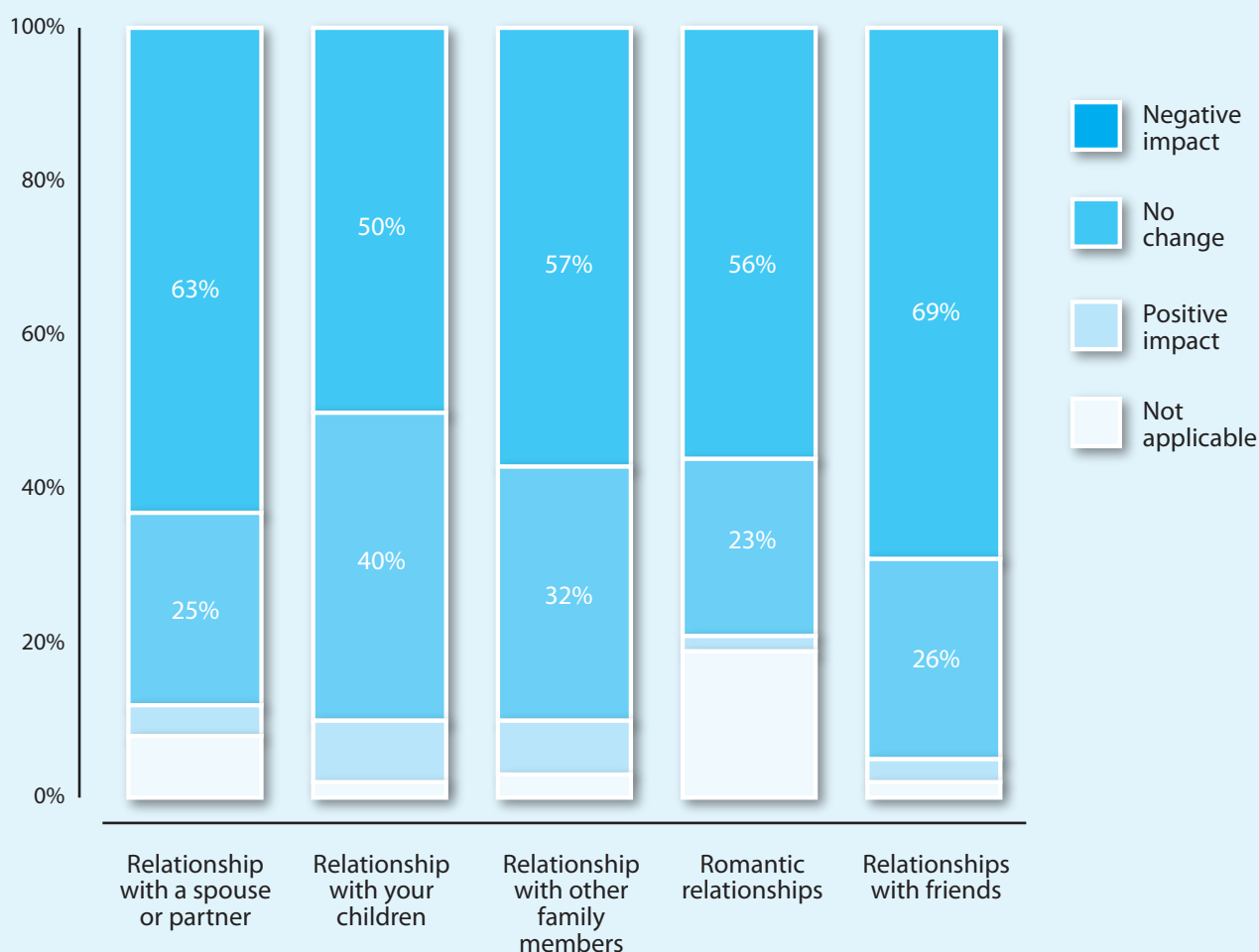
Romantic relationships and relationship with other family members were almost equally likely to be negatively affected (56% and 57% respectively).

Relationships with children were marginally less likely to be affected; however, half of carers reported negative impact.

*"Huge impact on relationship with my husband, marriage breakdown .... Complete drain and negativity on the family as a whole."*

*"I feel guilty when I am not with my mum who has Alzheimer's and guilty when I am not with my children. I worry about the effect my caring role will have upon my children – will they be better people because of my caring role or will they resent the effect it has had upon their lives. I don't know."*

**How have your personal relationships been impacted by caring for an older/disabled adult as well as dependent children?**



#### 6.4. Impact of caring on ability to cope

Only just over one in ten respondents felt they were able to juggle everything well and half of them (51%) felt that things were difficult but they were coping. A significant 35% of respondents were struggling to cope, while nearly one in five was at breaking point (17%).

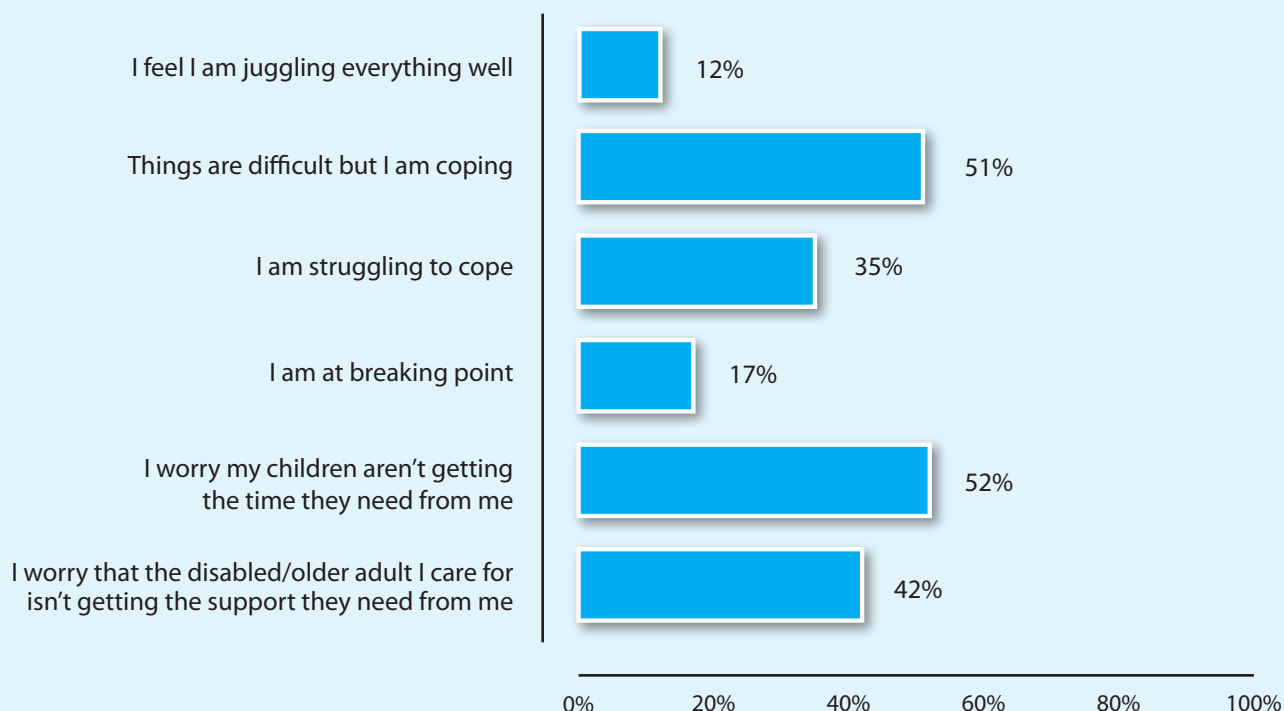
Overall just over two in five carers (42%) were either struggling to cope or at breaking point or both. Women were four times more likely than men to be struggling to cope or be at breaking point.

Just over half of carers (52%) worried that their children did not get the time they needed and two in five carers (42%) expressed fear that they did not adequately support the older/disabled adult(s) they cared for.

*"There is no let up... Sometimes it feels impossible, but I keep going because they need me."*

*"Totally devastating. I have no life, I never wanted to be the only child of older parents but I am left caring for my 85 year old mother and I resent it. I am only 45 but my life is over. I have 2 young daughters and a husband but my life revolves around caring for my 85 year old mother and I hate it. I have no life."*

**How would you describe how you are managing at the moment?  
(please tick all that apply)**



## 7. Support for carers

*"I feel pulled in all directions and no sector of society is geared to support me."*

### 7.1. Accessing support

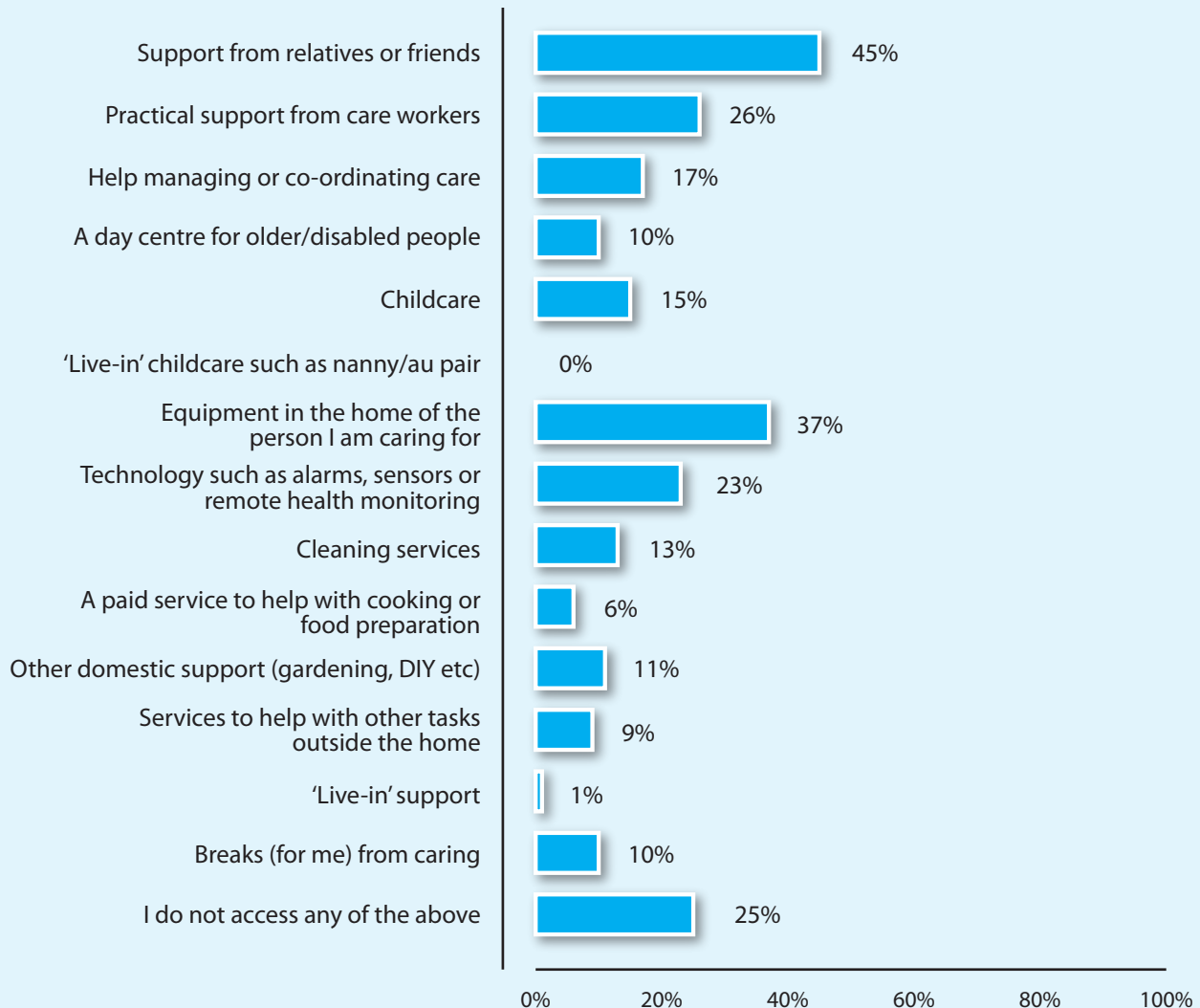
In terms of accessing support, a shocking one in four carers (25%) did not receive any support with sandwich caring (either paid support or unpaid support from family and friends).

Just under half of respondents (45%) indicated that they received support from relatives and friends. Less than one in five carers (15%) accessed childcare and a similar number received help in managing/co-ordinating care (17%). One in four carers received practical support from care workers (26%) and one in 10 carers (10%) accessed day centres for adults.

Just over one third of carers mentioned equipment in the home of the person they supported (37%) and nearly one in four used technology such as alarms, sensors or remote health monitoring in the home of the person they cared for (23%).

Other types of support carers accessed included low level services such as cleaning services (13%), paid service for food preparation/cooking (6%), other domestic support – such as gardening or DIY/ (11%) and services to help with other tasks / such as picking-up/delivering medication or shopping – (9%).

**Do you access any of the following support?  
(please tick all that apply)**



## 7.2. Support that would make a difference

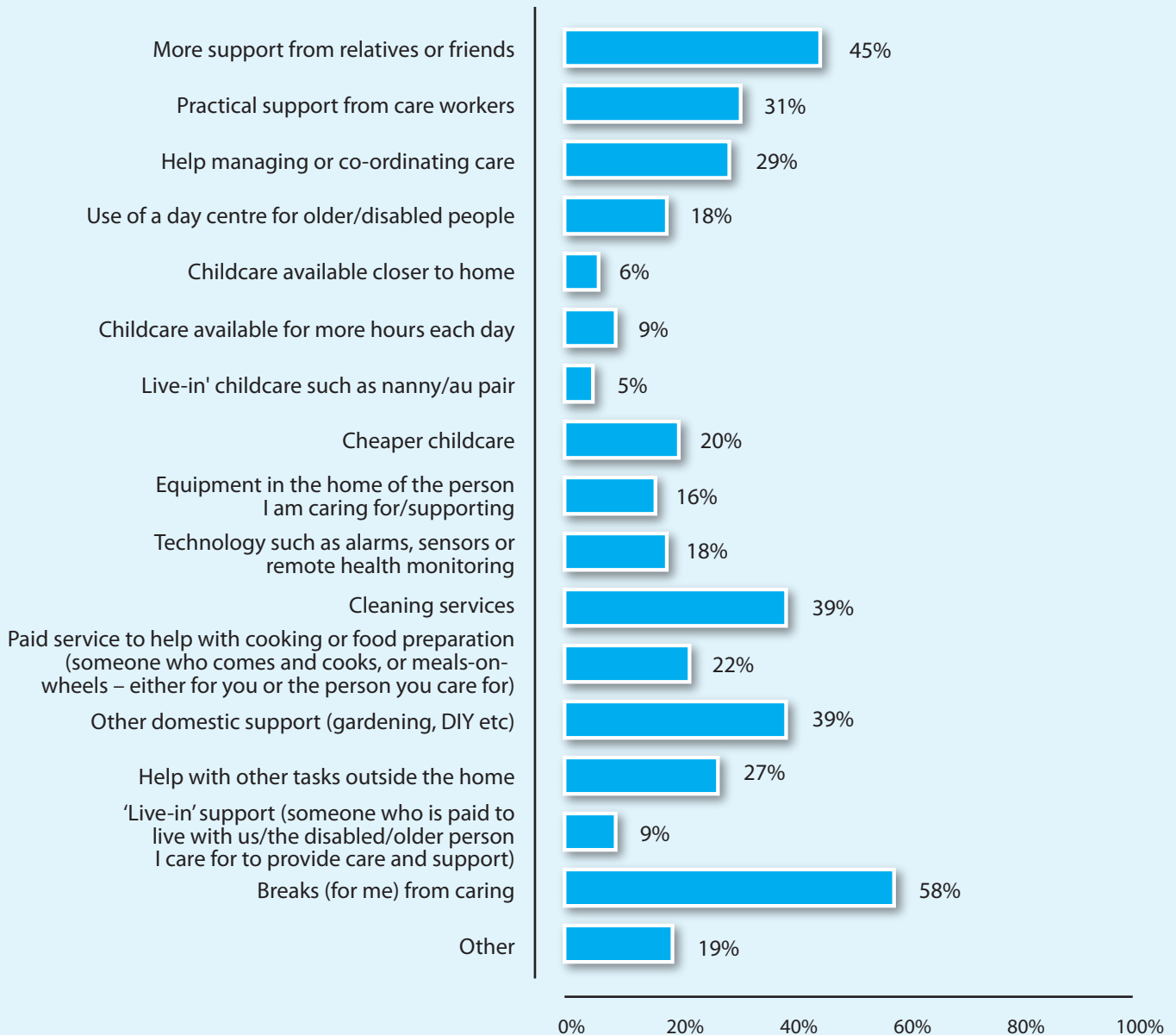
The majority of respondents (58%) said that they most needed more practical help to take breaks from looking after children or adult relatives. Carers also needed more help from family and friends (45%), on going practical support from care workers (31%) and help in managing/co-ordinating care (29%).

One in five respondents needed access to cheaper childcare and nearly one in ten carers wanted to gain access to available equipment and/or technology (16% and 18% respectively).

It is interesting to note that low level services such as cleaning, cooking or gardening, were significantly high in carers' list of support that would make a difference (39%, 22% and 39% respectively).

When comparing support for adult care to childcare, carers were twice as likely to indicate that support with adult care would make a difference (27%) rather than support with childcare (14%). Although this finding is indicative of families needing more support with adult care, we should note that the majority of respondents in our sample had children over the age of six and quite many of them over the age of 11 and would, therefore, have lower needs for formal childcare provision if they are not disabled.

**Do you access any of the following support?  
(please tick all that apply)**

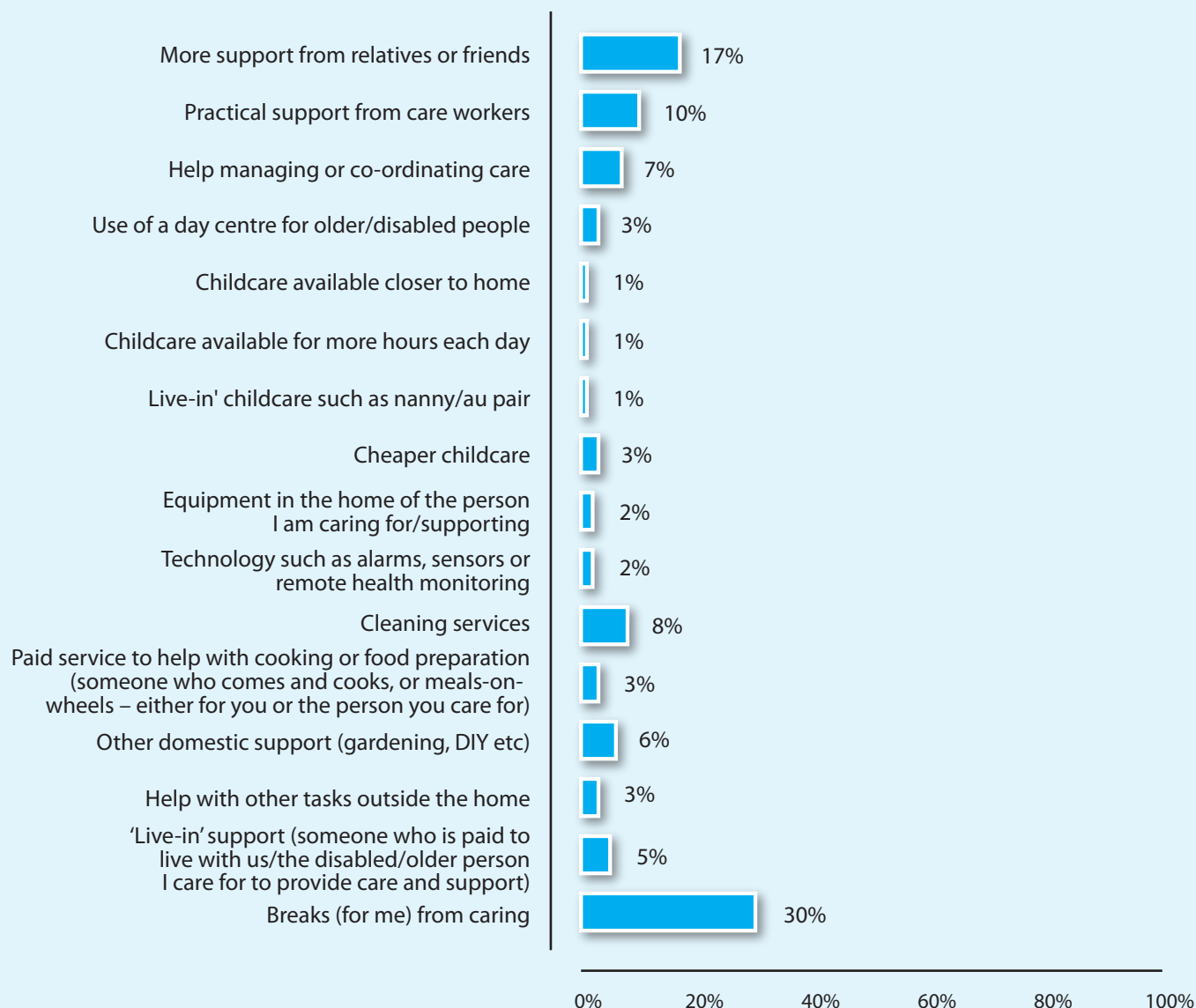


### What would make the most difference?

One in three (30%) said that they most needed more practical help to take time off from looking after children or adult relatives. A total of 28% said that some kind of care or support related to their older or disabled relative would make the most difference (practical support from care workers, live-in care, a day centre, help co-ordinating or managing care, services to provide food or meals). This was significantly more than the 6% who picked options relating to additional childcare as their top choice.

Interestingly, low-level services seemed to be of value to carers scoring higher in some cases than available/affordable childcare. One in six carers in our sample (17%) indicated that such support would make the most difference. Almost one in five (17%) needed more support from relatives and friends.

***Of the above which would make the MOST difference in helping you to better manage caring for an older disabled adult alongside your children?***



## 8. Assistive Technology

### Awareness

Looking into awareness of assistive technology (such as alarms, sensors linked to response centres, telehealth monitoring, etc) whilst 58% were aware of such support, two in five carers were not.

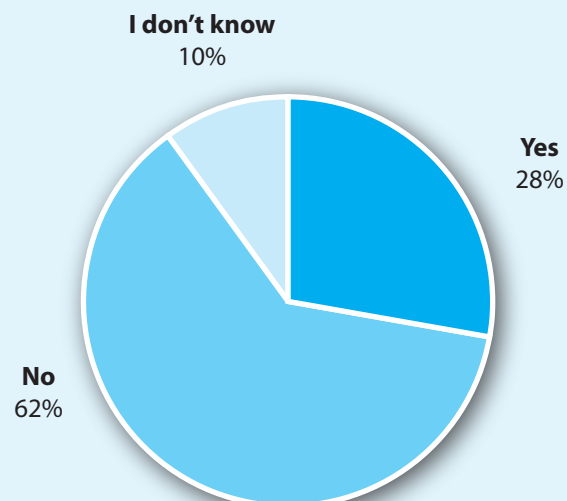
***Are you aware of supportive/assistive technology which can help with caring (such as alarms and sensors linked to a 24/7 response centre, medication reminders, telehealth monitoring, online support or care management applications) that help to better manage support/care?***



### Access to technology

However, the majority of carers aware of assistive technology solutions had not accessed such solutions for themselves or the people they supported (62%) and another 10% were unsure whether the person they supported had used any technology. Three in 10 carers had accessed assistive technology solutions.

***Have you, or the people you support/care for, used any supportive/assistive technology?***



We are grateful to Employers for Carers members and the Daycare Trust for support in promoting this survey.

All quotes and case studies used in this report are genuine and were provided by survey respondents – names and some details may have been changed to protect their privacy.

# Further research

Visit **[www.carersuk.org/professionals](http://www.carersuk.org/professionals)** for additional Carers UK and Employers for Carers research, including:

## ***Caring at a Distance (2011) Carers UK, Employers for Carers and Nomura***

This report examines the impacts on employers and employees of managing the increasing challenge of caring at a distance. It is based on a research survey of around 1000 employees who have caring responsibilities at a distance, along with 50 major employers.

## ***Future Care: Care and Technology in the 21st Century (2012) Carers UK***

The first of Carers UK's *Future Care* series, this report explores the current landscape of care and technology and calls for a technological transformation in the way we support families caring for ill, frail and disabled loved ones.

The report argues that the way families already use technology to work, plan their lives, shop and socialize should also be reflected in how we care and calls on the Government to set up a new independent, expert taskforce to drive innovation and partnership on care technology.

## ***Carers and Telecare (2012) Carers UK and Tunstall Healthcare Ltd.***

By looking at carers' experiences, this report explores in more detail the evidence and opportunities afforded by telecare and telehealth technologies to support carers and their families and the barriers to greater take-up.

## ***Future Care: Growing the Care Market (2012) Carers UK***

In the second *Future Care* report, Carers UK looks at reform of social care through an economic lens – exploring the economic costs to families and business of a lack of support forcing carers to give up work to care, but also the economic opportunities of stimulating growth in the care market. Looking to international evidence, and exploring the barriers and stimulants to growth, the report calls for a new National Care Strategy in partnership with the business community.

## ***Facts about Carers (2012) Carers UK***

A comprehensive digest of all the key facts and figures about carers – drawn from key Carers UK and external research looking at who carers are, with statistics on employment, health, age, tasks, finances and poverty, and rights. It is our most popular and widely used briefing.









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