

# State of Caring

A snapshot of unpaid care in Scotland



2019

## State of Caring 2019

Each year, Carers Scotland carries out a survey of carers to understand the state of caring in Scotland.

Over **800** carers and former carers in Scotland shared their experience of what it's like to be a carer.

This report provides a snapshot of caring in 2019 by only including the responses from the **755** people who are currently providing care.

This is the **largest** State of Caring survey carried out by Carers Scotland to date.

## About the research

Carers Scotland carried out an online survey between March and May 2019. A total of 818 carers and former carers responded to the survey – we have only included responses from the 755 people who are currently providing care in this report.

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

Of respondents to the survey:

- 86% identify as female and 13% identify as male and 1% prefer to self-identify.
- 23% consider themselves to have a disability.
- 1% are aged 0–24, 4% are aged 25–34, 19% are aged 35–44, 32% are aged 45–54, 31% are aged 55–64, 9% are aged 65–74, and 3% are aged 75 and over.
- 4% identified as lesbian, gay or bisexual.
- 2.5% described their ethnicity as black or minority ethnic.

- 22% also have childcare responsibilities for a non-disabled child under 18.
- 44% are in paid work. Of those, 48% work full-time and 52% part-time.
- 33% have been caring for 15 years or more, 18% for between 10–14 years, 23% for 5–9 years, 24% for 1–4 years, and just 2% have been caring for less than one year.
- 48% care for 90 or more hours every week, while 17% care for 50–89 hours, 21% care for 20–49 hours, and 14% care for 1–19 hours a week.
- Most (74%) care for one person, 20% care for two people, 5% for three people, and 2% care for four or more people.

As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented in this Appendix, are based upon responses from fewer than 755 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

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## Context: The state of caring in 2019



Recent polling published by Carers Scotland has suggested there could now be as many 747,000 carers in Scotland<sup>1</sup>, compared to 492,000 adult carers recorded in the 2011 Census.

There have been a number of positive developments for carers in the last year. These include measures to support carers in the Carers (Scotland) Act 2016 an increase to carers' benefits through the Carers Allowance Supplement, greater awareness of caring as an issue, and an increased focus on personalisation across Scotland. But even with these developments, carers and the people they care for still face economic and societal pressures.

Many services in Scotland have reached crisis point, with unpaid carers facing the consequences of local cuts to budgets and squeezed public spending.

The results of this year's survey show clearly why system-wide reform is needed to ensure carers are properly supported and able to have a good quality of life alongside their caring responsibilities.

Carers' support is valued at £10.8 billion a year<sup>2</sup>, but this comes with high personal costs. Many carers are suffering from loneliness and social isolation, need support to help them stay in work, and are facing their own health problems as a result of their caring role. This is in addition to the financial cost of caring; with 37% of this year's respondents saying that they are struggling to make ends meet, and almost two thirds reporting that they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for.

A higher state pension age means that people are working for longer and are more likely to be working alongside caring. Increasing numbers of employers are recognising the importance of supporting carers in their workforce to continue working, so they can retain talented staff rather than incurring the costs of recruiting and retraining new employees. But with workplace support still very varied across the country, nearly half a million people have had to give up work over the past two years as a result of caring. This equates to around 600 people every day<sup>3</sup>.

<sup>1</sup> Carers UK (2019) Juggling work and unpaid care, polling [www.carersuk.org/images/News\\_and\\_campaigns/Juggling\\_work\\_and\\_unpaid\\_care\\_report\\_final\\_0119\\_WEB.pdf](http://www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_0119_WEB.pdf)

<sup>2</sup> Carers UK (2015) Valuing carers - based on 2015 carer projection

<sup>3</sup> Carers UK (2019) Juggling work and unpaid care, Yougov polling

Caring is still often thought of as being part and parcel of women's lives and within families women are still most likely to be providing care and most likely to be providing more hours of care. Women make up the majority (59%), of carers and 27% of women aged 45 to 54 are providing unpaid care to someone with a disability or illness, or who is older<sup>4</sup>. Providing support for carers, especially those looking to stay in, or return to, paid work, is essential if women are to be able to participate fully in the economy and live a life free from poverty in older age.

When asked how they expect their quality of life to change over the next year, 11% of carers said they expected it to get better, 44% expected it to get worse, and 45% expected it to stay the same. This shows that there is much to be done to increase support for carers and that many carers have serious concerns about the future. Two thirds of carers told us that they have focussed on the care needs of the person they care

for, rather than their own needs, and over half (51%) of those who have yet to retire are unable to save for their retirement. This brings to light the reality of the impact of caring on carers' ability to plan for their future retirement and their own care needs. Action must be taken to support them.

The Scottish and UK Governments have committed to valuing, recognising and supporting carers, but if this is truly to become a reality then carers' voices, opinions and experiences must be heard, listened to and acted on. It is of paramount importance that even in the current challenging political context, governments focus on supporting carers and ensuring a sustainable future for our health and social care system.

This report contains a snapshot of what caring is like in 2019, capturing the impact that caring has on carers' lives and evidencing the policy recommendations that would improve this.



# Financial pressure

Many carers face very difficult financial situations due to their caring responsibilities, despite the valuable contribution they make to society. Carers often find their own income affected by caring (for example because of having to give up work or reduce their hours to care), and this can be compounded if their partner or another family member has also had to leave work due to their illness or disability.

When asked how they would describe their financial situation, over a third (37%) of carers say that they are struggling to make ends meet. This is a slight increase from 2018 when 36% said that they were in that situation, showing that even more carers are facing financial hardship.

Carers who care for more than 35 hours a week are more likely to say that they are struggling to make ends meet, with 40% saying this is the case. Half of carers who are receiving Carer's Allowance (53%) are also struggling to make ends meet.

More than a third

37%



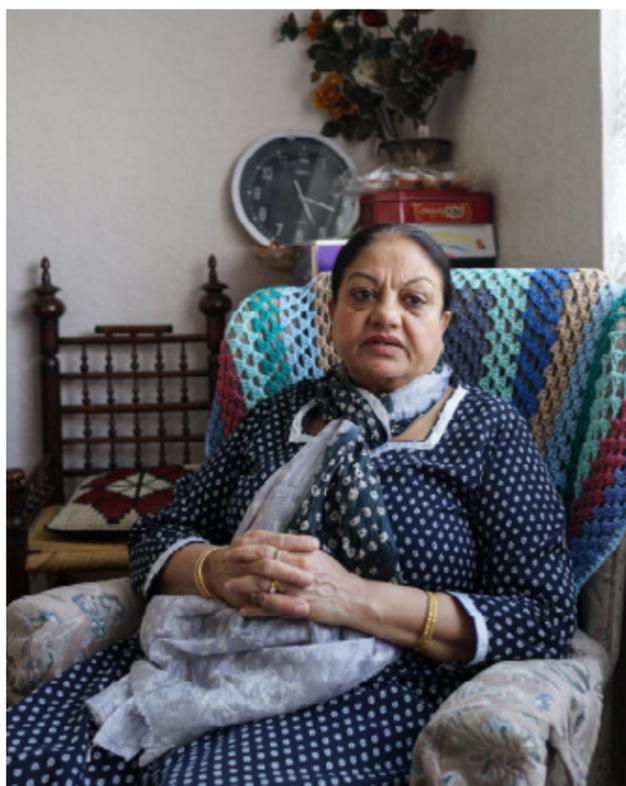
carers say that they are struggling to make ends meet

Over half

53%



of carers who are receiving Carer's Allowance are struggling to make ends meet



I was forced to give up my career and sacrifice a pension lump sum to care for my son. My husband reduced his hours of work. We struggle to maintain a modest home and have up holidays etc. years ago.



I went bankrupt as a result of taking on a full time caring role and not being able to work properly any more.



Every day is a juggling act. Constant worry and concern about finances.



I can afford bills because I am using my retirement savings.



Due to this situation, my savings are almost entirely gone. I had to spend huge amounts on private counselling just to cope and have no prospect of being able to return to work.



It was so serious that I went to foodbanks to be able to feed us plus I went bankrupt as a result of not being able to work full time any more. I am a nurse.



**I can't always afford to feed myself properly as I need to ensure Mum and kids are fed.**



Just under half of all carers (46%) say that they can afford their bills without struggling financially, but 21% are or have been in debt as a result of caring, 8% cannot afford utility bills and 4% cannot afford their rent/mortgage payments.

Carers who are struggling financially often have to make difficult decisions and cut back on spending. Of those carers who are struggling to make ends meet, 44% are relying on their savings and 36% are using credit cards. A third of carers who are struggling financially (33%) are using their bank account overdraft, 15% are falling into arrears with utility bills, and 9% are falling into arrears with their housing costs ie rent or mortgage payments.

Many carers find that cutting back on household spending is an essential part of balancing their budget. Whilst 81% have cut back on luxuries, 47% of carers have also had to cut back on essentials like food and heating.

Over three quarters of carers who are struggling financially (77%) have had to cut back on hobbies and leisure activities and 64% have cut back on seeing family and friends. 14% have even had to cut back on the support services which help with caring. 6% of carers who are struggling to make ends meet have said that they have used food banks and 3% have used pay day loans.

# Practical support with caring

Carers make a huge contribution to the lives of those they care for and to our wider society. Despite this, too many are going without the support they need and all too often they are going without any support at all. This year's survey found that one in five carers (20%) neither buy or receive support with caring. Whilst these figures in this section are largely similar to last year, there is still a large level of unmet need, with many carers struggling without any support at all.

Carers were asked what type of practical support they receive or buy. The most popular type of support was equipment in the home of the person they care for (like hoists, grab rails or easy-grip handles on taps) with 49% receiving or buying this.

Carers also reported receiving or buying the following types of support:

- help from family or friends 32%
- technology (eg alarms, sensors or remote monitoring to help with caring) 29%
- practical support from care workers coming in to help 28%
- a Motability vehicle 25%
- a break from caring 18%
- use of a day centre for older/disabled people 12%
- help with other household chores (eg shopping or cleaning) 10%
- help managing or co-ordinating care 5%



Shockingly, over two thirds of carers



said they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for

Of those struggling to make ends meet



regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for



of carers don't know what might happen to the practical support they receive in the future or worry that it might be reduced



In this year's survey we asked carers about spending their own money on support. Shockingly, over two thirds of carers (68%) regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for. This is even higher for carers who are over the age of 65 (70%), for those struggling to make ends meet (79%), and for people who care for more than 50 hours a week (73%).

When asked how they feel about the practical support they may receive in the future, less than 1 in 10 (9%) carers say that they are confident that the support they currently receive will continue in the future. Almost a third of carers (29%) worry that the support might be reduced and nearly two thirds (62%) don't know what might happen.

Carers were asked if they or the person they care for get a cash sum from their local authority or health and social care partnership to pay for care and support services directly eg a direct payment or personal budget. Seven in ten (70%) carers don't receive a cash sum for either themselves or the person they care for. However, for 3% of respondents they receive a cash sum for them as the carer, and for 4% the cared for person receives a cash payment. For 23% of respondents both the carer and cared for person receive a cash sum.

## Technology

Carers responding to the survey were asked if either they or the person/people they care for use any technology to support care and caring. 4 in 5 carers (78%) reported using one or more types of technology. This was slightly higher (79%) for distance carers who do not live in the same home as the person they care for.

Using a more inclusive definition of technology in this year's questions meant a considerable increase in the number of people using technology compared with 2018 when 49% of carers reported using it to support them to care.

Across the nations of the UK, carers in Scotland were most likely to use technology to support their caring.

Of those carers who use technology, the internet was the most popular type with 89% using it as a source of information and 35% using it as a form of communication or online support.

Remote health care such as online GP appointments, repeat prescriptions, online video consultations, or online mental health services was another popular way to use technology with 17% of carers saying they use this.

18% of carers who use technology said that they used remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, or GPS trackers, whilst

78% 

4 in 5 carers reported using one or more types of technology

11% use medication management tools such as medication dispensers or medication reminders.

6% of carers are using environmental monitoring such as heating and lighting control, door video systems, or smart appliances. 7% of those who use technology use vital signs monitoring such as blood pressure monitor, blood glucose monitor, and heart rate monitors.

3% of carers are using apps, including those which help with pain management, mood management and care co-ordination.

These figures show that there are still significant opportunities to increase the numbers of carers who use technology to help them in their caring role.



## Adult Carer Support Plans



21%

of carers in Scotland reported that they had an assessment or a review of their assessment in the last 12 months

In Scotland, the Carers (Scotland) Act 2016 gives all adults and young people caring for someone the right to an adult carer support plan from their local authority. These support plans look at the impact of carers' caring role on all aspects of their life and what support they and their families need as a result.

21% of carers in Scotland reported that they had an assessment, or a review of their assessment, in the last 12 months. In 2016, when we last asked this question in this way, 31% of carers had received an assessment. Carers who are providing palliative care and those looking after someone with a mental health condition were slightly more likely to have had an assessment with 31% of each group respectively saying this happened in the last year whereas only 19% of parent carers had an assessment or review in the last 12 months. 31% of carers for someone with dementia and 20% caring for someone with mental health problems had received an assessment or review in the last 12 months.

Out of all carers who received an assessment in the last year, 71% waited less than six months for this assessment but 29% waited longer than six months.



There is insufficient consideration given to the rights of carers to choose to work.



The assessment covered a lot of details but nothing happened afterwards and I feel I might as well not have had it.



All items were thoroughly considered and I get excellent support from Quarriers, but I am not able to seek sufficient support for my cared for or myself to actually make the right difference to juggling, breaks etc. My cared for is ineligible for social care as he is not in crisis. I am on the waiting list for social care as a carer.





At the moment all support I receive is 'attached' to my child. I have received 'short breaks' funding but this is only due to the expertise of carer's advisor (third sector) The appointed social worker for me (not my children's social worker) has not contacted me for over 10 months. I have asked repeatedly for plan but for some reason there is no commitment or willingness to do this.



After being assessed as critical we are still waiting for respite almost a year later.



The social worker omitted much relevant information which obviously toned down the assessment. Goal posts continually shifted to suit their agenda, very disheartening.



### Experiences of adult carer support plans

The majority of carers in Scotland who had been assessed/ reassessed in the last year felt that their needs were not given sufficient consideration. Of all the support aspects looked at in adult carer support plans, carers were most likely to say that their need to have a break (30%) was considered. Fewer carers said that other aspects of their needs had been thoroughly considered:

- carers' ability and willingness to provide care was only thoroughly considered and reflected in support in 35% of support plans;
- only 28% of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered;
- only 19% said that their need to juggle work and care or return to work was properly considered and only 20% said that wish to be say in or return to further education/learning was thoroughly considered;
- less than a third (29%) said the suitability of their home for their caring role was considered.

Only slightly more (32%) of parent carers who are looking after a disabled child under the age of 18 felt that their need to take a break was properly considered in their support plan or support provided, and only 20% felt their need to juggle work and care or return to work was properly considered.

The experiences that carers have shared suggest that implementation of the Carers (Scotland) Act is varied across Scotland and they are not yet realising the benefits that were intended by the legislation. Even for those carers who had a positive experience of the assessment itself, often there is not support available locally following on from it to relieve any of the issues they have raised.



I have had three carers assessments now and nothing has happened. Now have advocacy involved as the situation is getting critical with no respite and no help especially with transport as there are few buses and they are not accessible.



29%

of carers said that the suitability of their home for continuing their caring role was taken into consideration in their carer's assessment

Under a third of carers

30%

said their need to have regular breaks from caring was sufficiently considered in their carer's assessment

Only

28%

of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered



The assessment covered a lot of details but nothing happened afterwards and I feel I might as well not have had it.



# Costs, cuts and closures

When asked about changes in care and support services over the last year, 31% of carers reported that they had experienced a change in the amount of services that they receive. Of these carers who experienced a change, for 29% this was because the amount of care or support arranged by social services was reduced, whilst for 11% of respondents the care or support service was closed with no replacement offered. 4% of respondents reduced the amount of care or support received because the cost increased, and 4% reduced the amount of care or support received because the personal budget no longer covers it.

However, 29% of respondents who experienced a change in the amount of care or support arranged by social services saw an increase because the need for support increased, and for 3% of carers there was an increase even though the needs stayed the same.

Of all carers responding to the survey, 1 in 8 carers (12%) reported that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services. This is slightly lower than last year when 1 in 7 carers reported the same. However, we have asked this question every year and have seen constant reductions in support over time.

Numbers of carers reporting a reduction in support was higher for those who are struggling to make ends meet 14% reported less support due to a reduction in the amount of support from social work services.

29% of those experiencing a reduction in support are caring for over 90 hours a week and 32% have been caring for 15 years or more. It is deeply concerning that there has been a reduction in support for these people when there is strong evidence to suggest that these carers are more likely to suffer from poor health themselves.



We were discharged from social work as there was no further support. All four of my children are disabled and I've recently become a single parent. Both my physical and mental health have deteriorated significantly and when I have asked for support from the health visitor and social work I have been ignored.



1 in 8 carers



12% reported that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services



My daughter left school- she gets a budget which took a 9-month fight; my son gets no budget. I care for my mum she gets no help at all.



I now get help from a carer for 4 hours 4 days a week. This has hugely reduced the amount of stress I am under already and will eventually help me access mental health support too.



I care for my son 24/7 and we lost our PA. Been waiting 6 months on the social worker getting back to us. They are quite happy to run me into the ground. No trust or faith in them anymore.



The amount of respite we used to receive was halved, despite making the case to social work that we needed more.



We no longer have a life outside full time work and our family home resembles a care home our bills have trebled and quality of life decreased disappeared in fact.



I asked for a care worker to come in for my husband's afternoon medication as it was too late some evenings when I got home from work. This extra visit has made it easier to get a better routine in place and lets me get my husband to bed earlier too.



# Support for emergencies and contingency planning

Many carers worry about what will happen in case of an emergency where they are unable to care or the person they care for needs urgent treatment. The Carers (Scotland) Act 2016 requires that all carers should be offered an emergency plan as part of their Adult Carers Support Plan (or for young carers, in their young carer statement).

## Planning for contingency and emergencies

The survey asked carers about emergencies and found that only 1 in 5 (21%) said that plans for an emergency had been thoroughly considered in their Adult Carer Support Plan. Often carers first conversation about this will be with a health professional, for example, their GP. However, only 1 in 6 carers (16%) have had such a conversation with a health professional (eg a GP or a nurse) about what to do if they are no longer able to provide care or if the condition of the person they care for deteriorates.

Carers experiences of emergency planning and talking to health and social care staff are varied with some saying that there is excellent support available while others have struggled to have the issue taken seriously or don't know where to start with this conversation.

Only one in five carers



said that plans for an emergency had been thoroughly considered in their adult carer support plan

Only one in six carers



said that they have had a conversation with a NHS professional about what to do if the condition of the person they care deteriorates or if they are no longer able to provide care for them



I have been told emergency planning is only for carers over 55 years old. Despite having my own health needs and having caring responsibilities for my husband and daughter.



Have set up an anticipatory plan which is regularly reviewed



I didn't think about it. But I did collapse emotionally and he needed to go into emergency care.



Totally pointless, no one wants to discuss "what if" until "what if" happens and then it's too late. I've also had a discussion with GP regarding my own long term health problem which is made worse at times by my caring role and I was helpfully told to "join a club", "take a holiday", "give yourself 2 hours a day me time" and "make your mum do more things for herself"!!



## Emergency hospital admissions

Just over a third of carers (34%) said that the person they care for had been admitted to hospital in an emergency (ie an unplanned admission) at some point in the last 12 months. Half of carers (50%) felt that their emergency admission could have been prevented with more care or support in some form. This means that one in five of all carers responding to the survey (17%) had an emergency admission in the last year which they thought could have been prevented.

Of carers who'd had an emergency admission for the person they care for, 21% felt that the admission could have been prevented if they'd had more care and support for the person they care for or more support for them as the carer (eg breaks from caring) would have prevented the admission.

A quarter (24%) felt that higher quality care for the person they care for would have prevented the admission, whereas 13% felt adaptations in the home of the person they care for would have made a difference. 11% felt that the emergency admission could have been prevented if they had access to a district nurse.

Almost 1 in 10 carers (9%) felt that following a previous discharge from hospital, not enough time was taken to put in place adequate care and other arrangements that could have prevented the subsequent emergency admission. 7% of carers thoughts that telecare or telehealth services (eg monitoring equipment, alarms and sensors which remotely check the health of an older, sick or disabled person and that they haven't wandered, had a fall or accident) could have prevented the emergency admission, and a further 8% thought replacement care when the carer needed medical treatment would have prevented it. 2% of carers thought it could have been prevented if they'd had access to a hospice.



No one has talked about what happens when we can't care. It has all been how well we are doing and basically we can keep on doing it for an unknown number of years.



1 in 6 of all carers



had an emergency hospital admission in the last year which they thought could have been prevented



of carers felt that an emergency hospital admission could have been prevented if they'd had more care and support for the person they care for



It is assumed by all medical professionals that I will take full responsibility to alert them if my Mother's conditions get worse.



My doctor assumes I will care for my mum even though I look after my daughter 24 hours a day and cannot manage more.



# Planning for the future



For many carers, whether their caring responsibilities start suddenly following a diagnosis, or they develop over time as an older relative needs more support, they can find their future plans affected – in particular their future retirement plans.

## Planning for retirement

We asked carers **who are not retired** about how they intend to pay for their retirement. The most common source of income for retirement was a state pension with 75% of carers expecting to use this.

Other sources of money which carers are planning to use for retirement include:

- workplace pension 44%
- personal savings 16%
- a main home you could downsize from 14%

Almost a quarter of carers

24%



don't know how they are going to pay for retirement

54%



of carers said that they are not able to save for their retirement

However almost a quarter of carers (24%) don't know how they are going to pay for retirement. Carers who are over 50, and therefore closer to retirement age, are less likely to say they don't know how they are going to pay for their retirement with 16% of over 50s saying this compared to 24% of under 50s.

Carers who are not retired and are struggling to make ends meet are less likely to have made financial plans for the future – 33% don't know how they are going to pay for retirement.

There were some notable differences between how male and female carers are planning to pay for their retirement. For male carers of all ages, 49% have a workplace pension and 76% plan to use their state pension to pay for their retirement, but the numbers are lower for women – 44% and 72%.

More men were also expecting to rely on personal savings (27% compared to 15% for women) and women are over three times more likely to be relying on what their spouse or partner has arranged (14% of women compared to 4% of men).

Carers who are not yet retired were also asked about their future plans and 54% said that they are not able to save for their retirement. This rises to 59% of carers who are regularly using their own income or savings to pay for care or support services, equipment or products for the person they care for. 76% of those who describe their financial situation as struggling to make ends meet are not able to save for retirement. Three quarters of those who are receiving Carer's Allowance (74%) are not able to save for retirement.

Some carers are saving or have saved less for their retirement with 17% saying they did this because their working hours were reduced. 17% said that they have saved less or were saving less because their short-term financial needs are too great to afford to save for the long term.

Only 1 in 7 carers (14%) responding to the survey said that their ability to plan or save for retirement had not been affected by caring. This is even lower for carers who have been caring for over 15 years or more (8%) and carers who care for over 50 hours a week (6%). Of carers who are already retired, just over a third (34%) said that their ability to plan or save for retirement had not been affected by caring, suggesting that their caring roles started after they retired.



### Planning for carers' future care needs

Almost two thirds of carers (66%) say that they have focussed on the care needs of the person they care for, and not on their own needs.

A third of carers (32%) say that they worry about their care needs in the future but cannot do anything about it. For carers who have been caring for over 15 years this is even higher with 39% reporting that they worry about this but cannot do anything about it.

Only 2% of all carers feel that they have prepared for any care needs they may have in the future for themselves.

Almost two thirds of carers

**66%** QQQ

say that they have focussed on the care needs of the person they care for, and not on their own needs



I really haven't thought about it, my focus is on my parents.



We know we will have to move home again, which isn't ideal. Our current home costs way too much to run and maintain for the 2 of us. When mum in law is no longer living with us we will need to release equity to ensure our next home meets my physical needs.



I am already using my life savings and they won't last much longer so I don't know how I will survive.



Because I stopped work early it had a negative effect on my private pension and of course my earnings.



It's often too upsetting to think about the future. In terms of finances, we are always on the back foot. Years of reduced working hours means we have done little to modernise or maintain our house and depleted any savings long ago.



## Health and well-being



Caring can have a significant impact on health, with carers often finding that both their mental and physical health are affected. When asked about how their health is in general, carers described their physical and mental health as follows:

All carers	Very good	Good	Fair	Bad	Very bad
Physical health	6%	26%	43%	21%	4%
Mental health	5%	21%	42%	24%	7%

Given the immense personal cost that comes from providing round the clock care it is unsurprising that carers who care for more than 50 hours a week reported poorer health with 27% reporting bad or very bad physical health and 34% reporting bad or very bad mental health.

Carers who have been caring for over 10 years were more likely to report poorer health with 29% describing their physical health as bad or very bad. Just over a third (34%), similar to carers caring for 50 hours or more a week, described their mental health as bad or very bad.

The Census in 2011 found that carers were a third more likely to be in poor health than non carers, with carers caring 50 hours or more each week twice as likely to be in poor health.

The most recently health and care experience survey in Scotland, 35% of carers disagreed or disagreed strongly with the statement that caring had NOT affected their health and wellbeing, up 1% from 2015/16.<sup>5</sup>

<sup>5</sup> 2018 GP Patient Survey



Loneliness is such an integral part of caring. I no longer have a husband. I care for him. We cannot share what we used to, we rarely do things together because of my husband's health. I've been to some dark and hard places over the last few years as his health has become poor...lots of long, lonely nights. Caring for your spouse brings a lot of emotional trauma that people do not appreciate or understand.



Lots of people no longer keep in touch. As if you are tarred with a brush being a carer.



When asked about physical exercise, 90% of carers responding to the survey said that they are not able to do as much physical exercise as they'd like to do.

However, a third (33%) said they wanted to take part in physical exercise with top reasons being for fun and to feel good, to relax and unwind, and to be part of something.

The need for the NHS to routinely identify and support carers was the top priority for carers in every nation except Scotland where legislation and measures are already in place to ensure carers are identified.

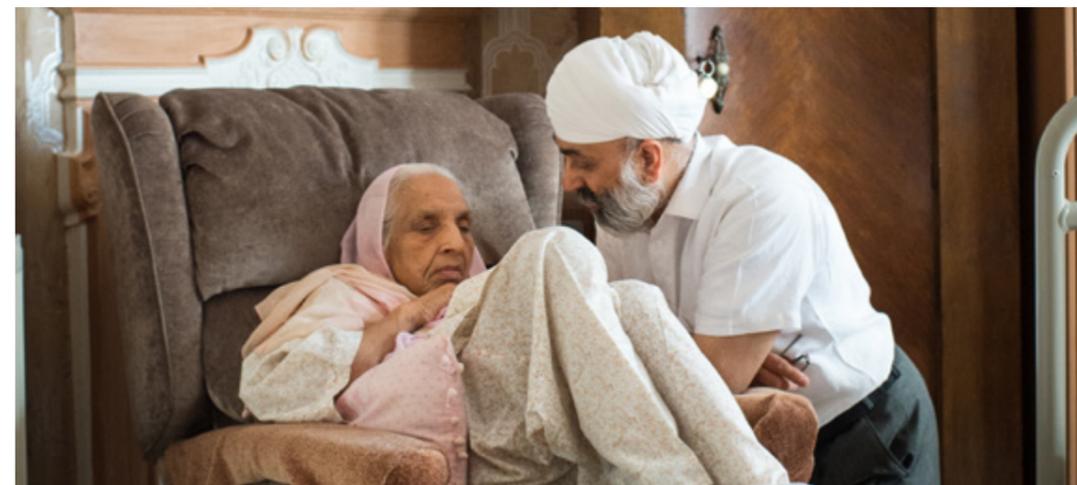
### Loneliness and well-being

This year, the Carers Week research report highlighted the impact of caring on people's loneliness and wellbeing.

Carers are seven times more likely to say they are always or often lonely compared with the general population.<sup>6</sup> Only 5% of the population say they are always or often lonely compared with over a third (38%) of unpaid carers. Overall, 9 in 10 (93%) of all carers reported having ever felt lonely or isolated as a result of their caring role.

The research report also revealed that carers in the UK are nearly twice as anxious as the general population. Carers placed their levels of anxiety at an average of 5.4 out of 10 compared with a population average of 2.8.

Carers in Scotland UK reported levels of happiness over a third (37%) lower than the general population. Carers placed their level of happiness at 4.7 out of 10 compared with a population average of 7.5.



<sup>6</sup> Carers Week (2019) Getting carers connected



“It is lonely and isolating to be the only care-giver. I have become depressed/ anxious myself which has had a hugely negative effect on my self-esteem/self-worth and I avoid social interaction so that has exacerbated the loneliness.”



“If anyone had paid any attention when I asked my mental health wouldn't be broken now.”

“I am really stressed as not able to get respite I need.”

“I can no longer cope with my mum's Dementia as she has deteriorated and I have up working my own health and mental health has been affected.”

“The amount of time I have to myself is decreasing and I don't get any silent time, and I get panic attacks with the constant questions, demands and general chatter.”

# Juggling work and care



Image - © Olivia Hemingway

Recent research by Carers UK found that the number of those juggling work and care across the UK could be far higher than previously thought – around 4.87 million (compared with 3 million in the Census 2011). This is one in seven of all workers<sup>7</sup>. There are an estimated 270,000 people who juggle work and care in Scotland.

Almost half of carers (44%) responding to the survey reported being in paid work. These working carers can be broken down as follows:

- 45% are full-time employees
- 41% are part-time employees
- 3% are self-employed full-time
- 10% are self-employed part-time<sup>8</sup>

Carers often find that it can be a struggle to balance their responsibilities in work with their caring responsibilities. 38% of all carers reported that they had given up work to care and 21% had reduced their working hours. 1 in 6 carers (17%) said that they work the same hours but their job is negatively affected by caring, for example because of tiredness, lateness, and stress. 14% of carers said that they have had to take a

less qualified job or have turned down a promotion to fit around their caring responsibilities.

Just over 1 in 10 carers (10%) said that they had retired early to care. Only 3% of respondents of all ages said that caring has had no impact on their capacity to work.

Less than one in five (19%) of carers who aren't yet retired and had an assessment in the last year felt that their need to combine paid work and caring was sufficiently considered in their carer's assessment.

Carers Scotland is working with forward thinking employers to improve carers support in the workplace through the Carer Positive employer recognition award. Carer Positive is a Scottish Government funded initiative, operated by Carers Scotland and developed with the support of a strong partnership between private, public and voluntary sector organisations in Scotland. It supports and recognises employers to build a supportive and inclusive workplace for staff who are, or will become, carers and to make the most of the talents that carers can bring to the workplace. For more information visit [carerpositive.org](http://carerpositive.org)

<sup>7</sup> Carers UK (2019) Juggling work and unpaid care

<sup>8</sup> Due to rounding, these do not add up to 100



I had to give up my career in law when my son started school as his needs could not be met and my employer would not support me as a carer.



I have to take unpaid leave frequently for all her hospital appointments and therapy appointment.



My caring responsibilities affect my health, sleep, etc. which has impacted on my work. I am fortunate my colleagues are extremely supportive and work can be fairly flexible at times.



I still work the same hours but have adjusted working week pattern to facilitate caring responsibilities.



My employer has now become a carer friendly organisation and I have a carers passport in place. I am fortunate and will not be looking to change job or seek promotions while I am caring. I would not be able to take on any more responsibilities and I would struggle to find another employer as supportive and accommodating as my current.



As well as the demands of the person I care for impacting on my ability to work, negative attitudes of colleagues when I needed time off work for medical care for my son etc affected me enormously.



I was unable to work full time as a newly qualified nurse. I have only managed to work 36 hours in 4 weeks (3 shifts). My pension, salary and obviously promotion have gone out of the window and I have been left broke and bankrupt as a result. I am completely overlooked for any promotion and barely find an employer to keep me as a full time carer. If they weren't so desperate for nurses, even though I am reliable and never ever go off sick myself, I do not think I would be in paid employment at all.



# Recommendations

Concrete actions need to be taken across all levels of Government in order to put in place the support that carers need both urgently in the shorter term and over the longer term, to ensure the sustainability of the health and social care system.

## Ensure that carers and their families do not suffer financial hardship as a result of caring

- Whilst welcoming the increase in Carer's Allowance (just £66.15 on 2019/20 rates) through the Carers Allowance Supplement (£226.20 paid every 6 months), measures should be taken to provide an increase that is equivalent to Carers Allowance Supplement in carer premia to ensure that those on the lowest incomes also benefit from this increase. In the longer term, financial support for carers must be increased significantly.
- The earnings threshold for Carer's Allowance needs to rise year on year in line with the National Living Wage, pegged at least to the equivalent of 16 hours a week so carers don't have to choose between Carer's Allowance and staying in work.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that they do not suffer financial hardship later in life.



## Deliver health and social care services that recognise, value and support carers

- A new duty is needed on the NHS and health and social care partnerships to put in place measures to specifically promote the health and wellbeing of carers, including their own employees who are juggling work and care. Ensure that all staff are trained to know about carers and how to support carers.
- Increase identification and support through primary care.
- Ensure carers are better prepared for caring and can get support early to look after their own health and wellbeing with easily available advice and information as well as learning and training for carers to help them plan, prepare and provide care.
- Ensure integrated services lead to improved support for carers.



## Put in place enough funding so that older people and people with disabilities are able to access the quality and affordable care they need and that they are able to have a good quality of life alongside their caring roles

- An urgent and significant increase in funding for care services is needed now or the role of families and friends caring will become increasingly unsustainable as carers are pushed to breaking point by a lack of support.
- Consideration of new funding models for social care and the priorities for future NHS spending must have carers' contribution, both financial and practical, at their heart and deliver a sustainably funded health and care system that is fairer for families.



## Give carers a break: Provide funding and choice of quality services to enable carers to take the breaks they need

- Increase and ring-fence funding for carers' breaks. Funding should also be transparent so carers know what they are entitled to, and ensure greater consistency in what is available. A choice of appropriate and good quality care must be available or carers cannot get the breaks they need for their own health and wellbeing.



## Ensure carers are able to juggle work and care, if they wish to, with support to return to work alongside or after caring

- Create a new right to paid time off work to care of at least 5–10 days.
- Put in place tailored support for carers looking to return to work, including recognising the skills carers have developed through their caring role.
- Work with employers to include carers in health and well being support at work.
- Recognise that good quality and affordable care services are an essential part of enabling carers to remain in or return to work alongside caring.





Across Scotland today more than 680,000 people are carers - supporting a loved one who is older, disabled or seriously ill.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person's health, finances and relationships.

Carers Scotland is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community. Carers Scotland is part of Carers UK.

We're here to make life better for carers.

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