



MS family and friends 2019 survey findings

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Introduction

“Every case of MS is so different and it’s hard to know how quickly things will change or what might help.” – Clare, 69, from Buckinghamshire, who supports her son Trevor, 38, living with primary progressive MS.

Family and friends provide vital support to people with MS. From being alongside them in managing the emotional challenges of living with the condition, doing household chores which would otherwise exacerbate their MS symptoms, to intimate personal care tasks and help getting out of the house when they might otherwise be isolated. Their support helps many people with MS across the UK to live independent, healthy and meaningful lives.

Given how vital their role is, it is important that we better understand the impact providing such support is having on their lives and the support they most need themselves. We launched our first MS family and friends UK survey in 2019 to do just that.

There is certainly no one size fits all when it comes to family and friends supporting people with MS. However, many people (41% of respondents) are spending the equivalent of a full-time job or more each week supporting someone with MS - and are not feeling well supported financially, practically or emotionally. An overwhelming 90% of respondents reported negative impacts on their health and wellbeing, which is even more concerning considering that 40% of respondents are living with a long-term condition themselves. The fluctuating and progressive nature of MS adds a degree of complexity to their lives, as they may not know from one week to the next what support that person with MS will need. That can make juggling paid work and caring very difficult, which 3 in 5 working-age respondents are doing.

Family and friends supporting people with MS desperately need and deserve better support - from employers, the NHS, the welfare system, and social care. The adult social care system is under extreme pressure with budgets failing to keep pace with rising demand and complexity of need, and no plan for long-term sustainability. As a result, 1 in 3 people living with MS aren’t getting the support they need to complete essential daily activities.¹ In this context the number of unpaid family carers in the UK has grown to 8.8 million, as families step in to fill the gap.² One of our top priorities is calling on Governments to make care and support systems across the UK fairer, more effective and accessible, with long-term, sustainable funding.

There is a clear moral, as well as economic, incentive for action. 38% of respondents had left work early as a result of providing support and a further 11% said their work had been impacted due to tiredness and stress. Yet only 1 in 6 had been offered sufficient support to remain in employment. We asked what policy or system change would make the biggest difference to respondent’s lives – the most common response was appropriate care being available for the person they support. Working isn’t possible for many people

without a social care system that they can rely on to provide quality care to their loved ones.

UK residents now have a 65% chance of providing care in their adult lives – impacting their employment prospects, financial stability, and health and wellbeing.³ It is imperative that UK Governments act now to create the conditions in which we can look after our loved ones without severe and unfair consequences for our health, wellbeing or finances.

Finally, respondents gave us valuable insight into how the MS Society could better support them. Information and advice for them and the person they care for, came through as most important. We are committed to using this insight to improve the services and support we offer this year and into the future.

Thank you to Clare, Joy, Carole, Helen and their families for talking to us about their experiences. Their quotes appear throughout this report.

About MS

Over 130,000 people in the UK have MS. It's unpredictable, and different for everyone. It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel.

But it doesn't have to be this way. We're driving research into more – and better – treatments. For everyone.

Together, we are strong enough to stop MS.

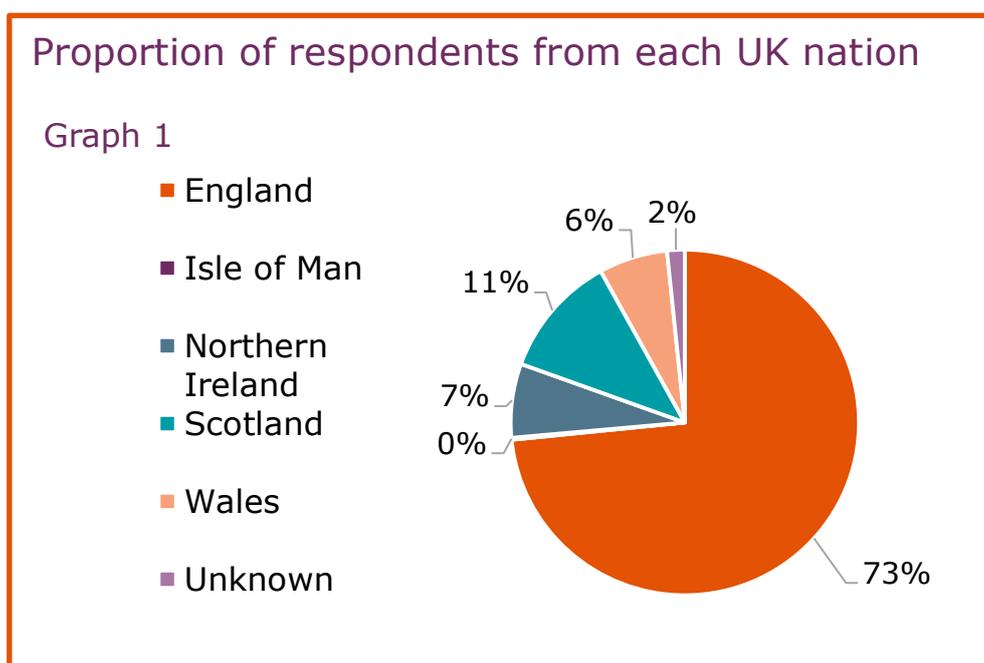
About the MS family and friends survey

We conducted a survey of 549 family members and friends of people living with MS between March and May 2019. We invited responses from anyone living in the UK that regularly supports a family member, partner, or friend with MS to carry out everyday activities (such as household chores, getting dressed, washed, getting out of the house and organising appointments). This is often referred to as unpaid caring, though not everyone would identify as a carer.

The survey was only available online, and was advertised both online and offline to the MS Society community and people on the MS Register alongside our My MS My Needs survey.

About the respondents:

- ▶ 61% were a partner of the person with MS, while 13% were an adult child, 11% were a parent and 4% were a close friend.
- ▶ 7 in 10 respondents co-habited with the person living with MS.
- ▶ Nearly half had been supporting the person with MS for over 10 years.
- ▶ Three quarters (78%) identified as White, with very small numbers of Black (less than 1%), Asian (1%) and other Ethnic groups (2%).
- ▶ 55% of respondents were aged between 25 and 64 years, and of these 88% supported someone also aged 25-64 years old.
- ▶ 45% identified as female, 36% male, and 0.2% non-binary.



Clare, Trevor and
their son, Trevor



Key findings

Support provided

- ▶ 2 in 5 (41%) respondents provided 35 hours or more of unpaid care and support every week – the equivalent of a full-time job. 1 in 6 were providing over 90 hours a week - an intense amount of support.

Unmet need

- ▶ Half of respondents weren't getting the practical, emotional and financial help they needed despite the vital support they provide people with MS.
- ▶ Of those who did receive support, twice as many relied on family and friends (45%) as received any form of support from their local authority (22%).

Employment

- ▶ One in three (34%) respondents have either given up work completely or retired early as a result of supporting someone with MS.
- ▶ 3 in 5 working-age respondents were trying to juggle part- or full-time employment with their role supporting someone with MS. Only 1 in 6 respondents had been offered sufficient support to remain in employment.
- ▶ Providing care and support has impacted many respondents' ability to work – 18% have given up work completely, 20% retired early, 17% have changed their working hours, and 11% felt their work had been negatively affected through tiredness, lateness or stress.

Financial security

- ▶ A fifth of respondents were struggling or really struggling on their current income.
- ▶ Struggling financially has led to 80% feeling stressed or anxious, 74% unable to take part in hobbies or leisure activities, 59% seeing less of family and friends, and 57% unable to afford a break from their role supporting someone with MS.
- ▶ Only 16% of respondents received Carer's Allowance and 1 in 3 of those still experienced financial hardship despite receiving the benefit.

Health and wellbeing

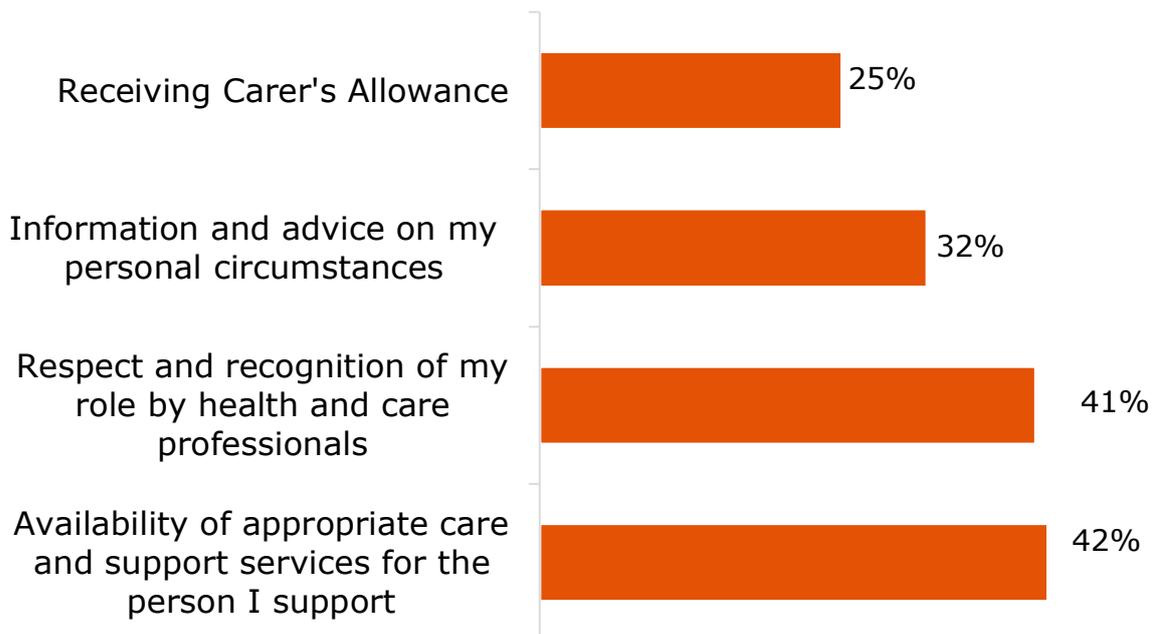
- ▶ 40% of respondents had a long-term health condition themselves.

- ▶ 90% of respondents said their health and wellbeing had been negatively impacted because of their role supporting someone with MS.
- ▶ 1 in 4 respondents felt socially isolated.
- ▶ A third of respondents (29%) haven't had a break in two years or more and reported poorer health and wellbeing than those who had taken a break. The most common reason preventing respondents from taking a break was feeling guilty leaving the person they supported (46%).

Priorities for change

We asked respondents to pick the top four policy, systemic or societal changes that would make the biggest difference to them from a list. The top four options are detailed in graph 2 (respondents were asked to tick all that apply).

Graph 2



Policy recommendations

- ▶ We need a fair, effective and sustainably funded care system across the UK that addresses the needs of disabled adults, older people and their families and carers. We need a system free at the point of need and funded through our taxes, in which people don't have to wait to get worse before they get help, and can access quality care no matter where they live.
- ▶ The Government in England must urgently publish its promised plan for long-term reform of social care and deliver additional funding to stabilise the system in the short-term.
- ▶ Create a new right to paid care leave of at least 5-10 days across the UK.
- ▶ The UK Government must conduct a review of Carer's Allowance and its effectiveness at offsetting the financial penalties associated with unpaid caring across a person's life course. In the short-term, Carer's Allowance in all UK nations should be increased in line with Scotland. The earnings threshold must also be adjusted so that carers juggling employment and caring don't lose out when their working hours increase slightly.
- ▶ It shouldn't be assumed that a family member or friend is willing to provide care and support.⁴ NHS and local authorities assessing people with care and support needs should instead seek to involve family members and friends in decisions, with the permission of the individual being assessed.

Policy recommendations

- ▶ Create a duty on the NHS to identify people providing unpaid care and make sure they're signposted to sources of support. This must be accompanied by a training programme to make sure all NHS staff not only recognise and support unpaid carers, but also identify their needs.
- ▶ Government bodies responsible for health, social care and welfare across the UK should introduce campaigns to increase awareness, recognition and support for unpaid carers, among health and care professionals as well as the general public. Many people providing unpaid care and support don't recognise themselves as carers, which can be a barrier to identification and accessing support.
- ▶ UK governments should protect funding for carers' breaks. They should make sure it's spent on carers having vital breaks, by introducing better accountability around local spending. Making sure carers know about breaks they are entitled to and being flexible about how funding can be spent to take a break is just as important.
- ▶ All employers should have flexible working policies in place and offer paid care leave. They should tailor employee assistance programmes to unpaid carers and supporting their health and wellbeing in the workplace.

Findings

Wide-ranging support provided

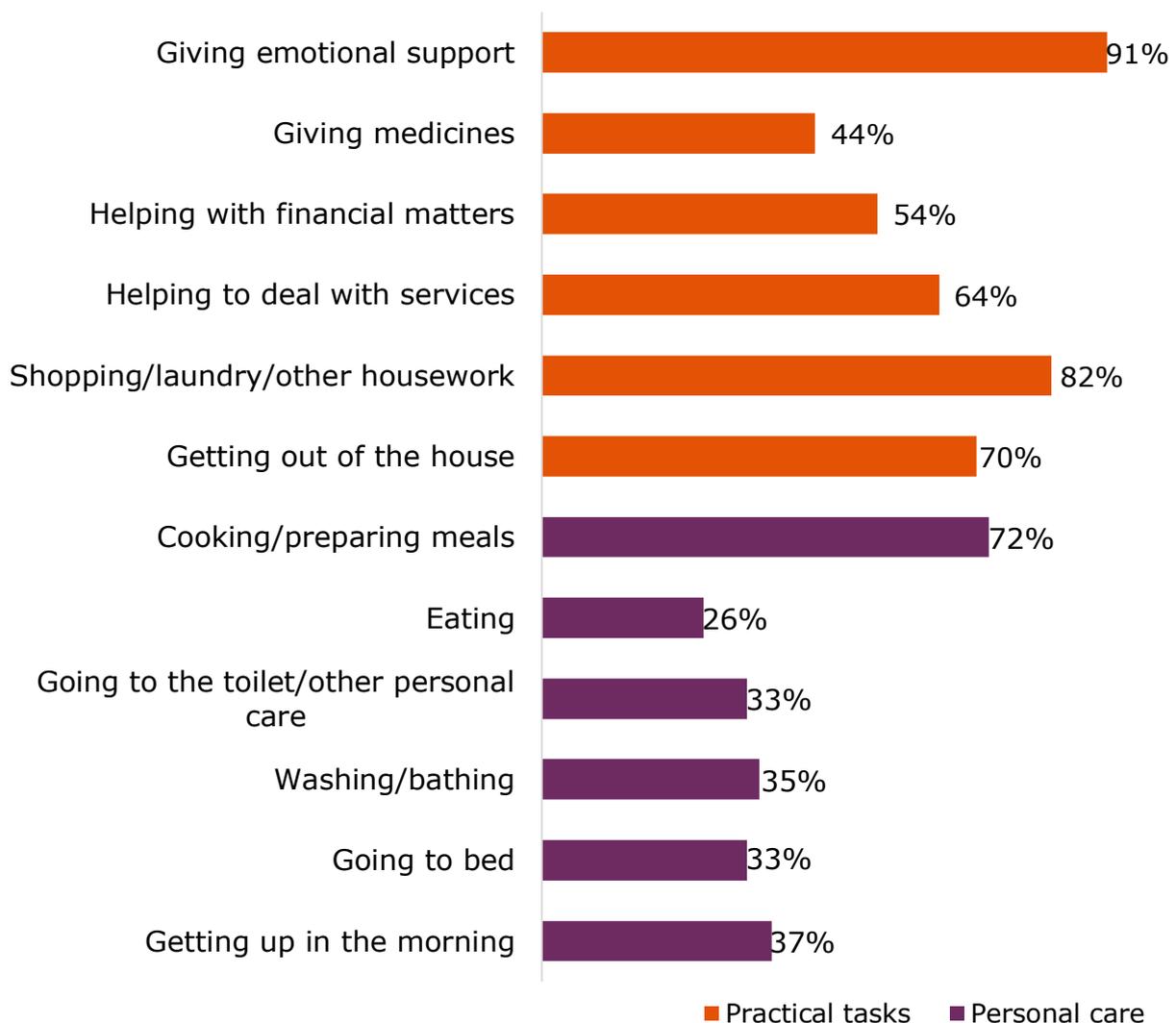
We asked family and friends what type of support they provide from a list of 13 tasks – ranging from assistance with washing and dressing, cooking and eating, going to the toilet, giving medications etc. It is clear that family and friends are providing a wide range of support, with a significant proportion undertaking personal care tasks (see graph 3 below).

41%
of respondents provided unpaid care for 35 hours or more a week

Support provided

We asked respondents to select practical and personal care tasks they regularly supported with, from the following (they could select multiple)

Graph 3



41% of respondents provided support and assistance for 35 hours or more a week to someone living with MS. Of those people, 26% were also in full-time paid employment. Providing 35 hours is the equivalent of holding down a full-time job – the corresponding wage for a paid carer working 35-hour weeks would be £14,742 a year.⁵ 16% of respondents were providing 90 hours a week – this is an intense amount of support and likely to be having significant impact on the individual providing it.

Impact on employment

“I reduced my working hours when Patricia first became ill. My employer didn’t react too badly... I think they felt as if they had to make these adjustments for me legally, even though they didn’t really want to.” – Helen, 52, from County Antrim, supports her sister Patricia, 45, living with primary progressive MS.

The number of people trying to juggle work with providing unpaid caring is predicted to rise over the next decade due to increased demand for long-term care. An estimated 600 people in the UK give up work as a result of caring every single day.² It is estimated that between £3bn and £6bn are lost in income tax each year in England alone due to carers leaving employment.⁶ While some people are in a position to choose to retire early to care for a partner, parent and so on, others find themselves either struggling to balance work with caring or struggling financially having given up work.

51%

of respondents were
in paid employment

Overall, half of respondents were in paid employment: 1 in 3 of those full-time and 1 in 5 part-time. This is slightly higher than Carers UK (2019) found in their survey of carers in the UK, which had a much larger sample size and showed 1 in 7 unpaid carers in paid employment.²

We asked what impact supporting the person with MS had had on respondent’s ability to work (results illustrated in graph 4 below). While 32% of respondents had not had to change anything in relation to their work, significant proportions had either left work completely, retired early, reduced or altered their working hours, or turned down career opportunities. 2 in 5 felt that their work was negatively impacted due to tiredness, lateness or stress.

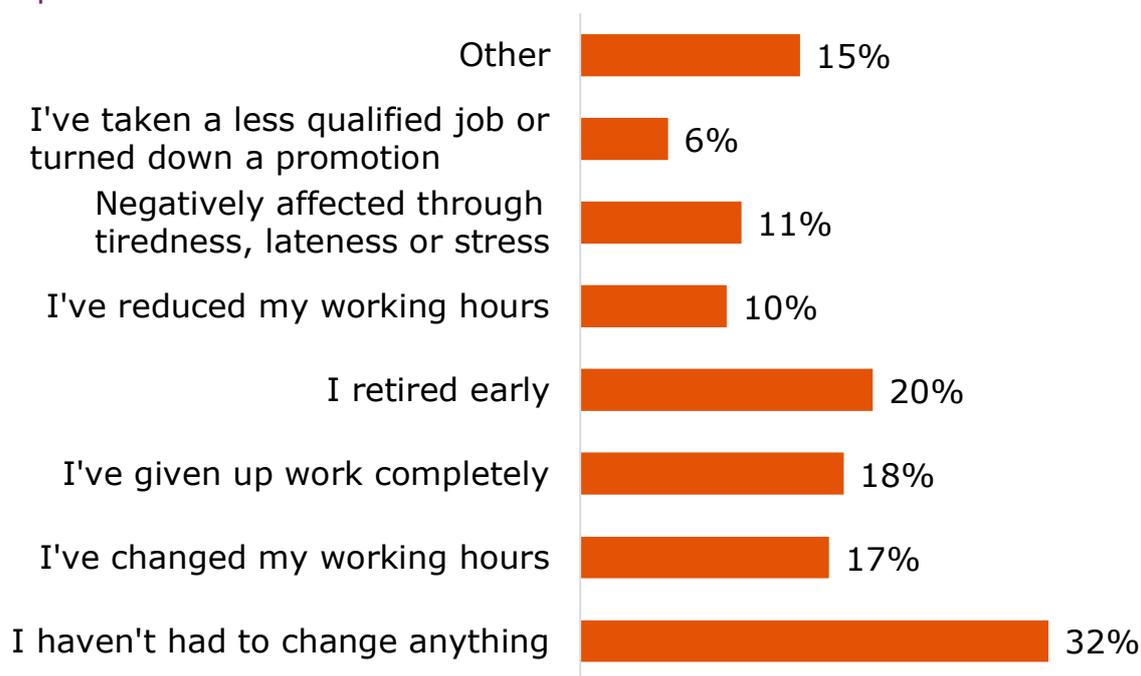
However, only 1 in 6 respondents were offered sufficient support to help them remain in employment, whether from their employer, the NHS or any other source. This points to there being missed opportunities to support those caring for someone with MS to remain in work. Employers should have flexible working policies and health and wellbeing programmes tailored to carers, while UK Governments should introduce a statutory right to paid care leave and

create a social care system in which no one is forced to leave work to ensure their loved one gets the care they need.

Impact on employment

We asked respondents if their ability to work had been impacted in any of the following ways, because of their supportive role (they could select multiple options).

Graph 4



Financial security

Having a condition like MS can be expensive, whether it is specialist equipment needed, home adaptations, paying for accessible transport or care services. People with neurological conditions like MS face, on average, extra costs of £10,000 per year if they were to maintain the same standard of living as a non-disabled person.⁷ Yet, nearly half of people living in poverty in the UK live in a family where someone has a disability – 6.8 million people.⁸ Most respondents to our survey lived with the person they support (68%). Carers UK (2019) found 68% of unpaid carers used their own income and savings to pay for care or support services, equipment or products for the person they care for.⁹

Overall, only 2 in 10 respondents told us they were struggling or really struggling on their current income. However, one third of respondents said they have an annual household income of less than £24,999 – this is

somewhat below the median income of the general UK population (£29,400).¹⁰ Among this group, 4 in 10 reported they were struggling or really struggling on their current income. 6 in 10 also reported they weren't getting the support they needed compared to those in higher income brackets.

Of those who were struggling or really struggling on their current income, 80% had felt stressed or anxious about their financial situation, 74% couldn't afford hobbies or leisure activities, 59% had seen less of friends and family, and 57% couldn't afford to take a break from supporting the person with MS.

57%

of respondents struggling on their income were unable to afford to take a break

Overall, while most respondents weren't struggling on their income, it is concerning that the most financially vulnerable appear to have poorer mental health and are less able to afford a break from caring.

Carer's Allowance

"I get Carer's Allowance, and Craig gets the full allowance of PIP (both Care and Mobility) which doesn't always cover living costs. We don't do anything other than exist on things we need like food, heating, and water." – Carole, 59, from Wales supports her husband Craig, 60, living with secondary progressive MS.

Carer's Allowance is the main State benefit for unpaid carers, £66.15 a week in the UK, with a supplementary £226.20 twice a year in Scotland.¹¹

The Department for Work and Pensions released figures showing 1.3 million people were receiving Carer's Allowance across England, Wales and Scotland and nearly 50,000 people claiming in Northern Ireland.^{12 13}

16%

of respondents received Carer's Allowance

16% of respondents to our survey received Carer's Allowance. Only a third of those who spend 35 hours or more a week (one of the eligibility criteria for claiming) supporting someone with MS received it. We can't tell from this survey how many MS family and friends are entitled to Carer's Allowance. However, wider evidence suggests as many as 4 in 10 people who are entitled to the benefit aren't claiming it.¹⁴

One barrier is the earnings threshold - you can only claim if you earn less than £123 a week in employment. Carer's Allowance isn't intended to replace an income to live on and because eligibility relies on caring for 35 hours per week, some people are unable to undertake part-time work to boost their income and struggle financially as a result. This is an active disincentive to work, directly counter to the Government's stated policy ambitions for the welfare system overall.

1 in 3 respondents that received Carer's Allowance still said they were struggling or really struggling on their current income. While this is based on a small sample size, it is reinforced by Carers UK's larger State of Caring survey (2019) which found 53% of carers receiving Carer's Allowance were struggling to make ends meet.⁹

We believe Carer's Allowance needs an urgent review to determine how we best protect unpaid carers from financial hardship across their lifetime. In the short-term, it is only fair to remove the present inequity in the level of Carer's Allowance and increase it across the UK in line with Scotland. It is also important the earnings threshold is adjusted so that carers juggling employment and caring don't lose out when their working hours increase slightly.

Unmet need for support

"We don't know what's available, we don't know what's out there to ask for and make life easier." – Joy, 50, from Birmingham supports his wife Sharan, 42, living with relapsing remitting MS.

Joy, above, reflects the experience of many family members and friends caring for people with MS who regularly tell us how difficult to navigate they find the benefits, social care and health systems. It is striking that 46% of total respondents to our survey hadn't received sufficient information about support/services that could meet their needs.

A carer's assessment should be a gateway to appropriate information and support. It's meant to assess the impact of caring on a person's physical, mental and emotional health and wellbeing, and whether they are willing to take on a caring role. Then, support and signposting determined and offered, whether it's entitlement to paid care at home for the person with MS, financial advice, peer support groups, or funding for a Carer's Break.

In England, Scotland and Wales anyone who provides unpaid care is entitled to have their needs assessed by their local authority or Health Board, through a carer's assessment or joint assessment with the person they care for. This differs in Northern Ireland where only those providing regular and substantial care are entitled to this assessment.¹⁵

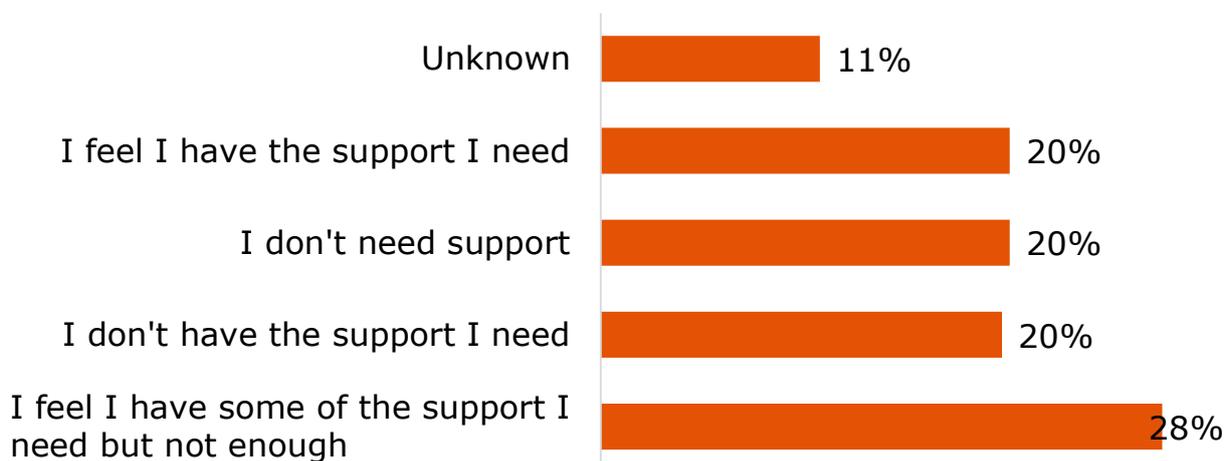
However, we found that less than a quarter of respondents had had a carer's assessment or joint assessment with the person they support in the past twelve months. This fits with a trend among carers as a whole, at least in England, for which official data on adult social care activity shows that 22% (96,380) fewer carers were assessed or received support from their local authority in 2018-19 compared to 2014-15.¹⁶ Of respondents that had had an assessment, only 1 in 3 felt their ability and willingness to provide support had been properly considered. And 1 in 5 didn't know what a carer's assessment was.

Given how few have had a carer’s assessment, it is perhaps unsurprising that when asked what type of support respondents receive from a list of sources, the most commonly selected was none of the above (51%). This was followed by help from family or friends (21%), while only 10% said they received support from their local council (either in the form of a direct payment, funding for a break, or other). Nearly half of all respondents expressed some level of unmet need for support in their caring role (see graph 5 below).

Support needs

We asked respondents to tell us which statement best describes how they feel about their support needs as a whole (practical, financial, emotional, etc.).

Graph 5



In terms of statutory support received by the person with MS, only a small number of respondents said the person they care for received support from the Local Council/Health Trust or NHS (15%). Of those, 6 in 10 still didn’t feel they have the support they need.

Overall, these findings suggest local authorities and Health Boards are missing opportunities to identify and support carers. Part of this is likely that carers don’t always identify as such and ask for support, hence the need for Government bodies to introduce campaigns to increase awareness. We also need to see an approach to assessments that doesn’t assume family and friends will step in to fill the gaps in statutory support. However, we need a sustainably funded care system across the UK if the support on offer is to improve.

Health and wellbeing

“Every day I’m so tired. I don’t sleep. I’m getting up at stupid hours. I haven’t got time to go to the GP.” – Joy, 50, from Birmingham supports his wife Sharan, 42, living with relapsing remitting MS.

An overwhelming 90% of respondents told us that their health and wellbeing had been impacted in the past 12 months. Tiredness was most common (65%), followed by general feeling of stress or worry (64%) and disturbed or loss of sleep (54%).^a

In the past 12 months, over a quarter of respondents had sought medical advice or attention due to their role supporting someone living with MS – 18 had visited A&E and 123 had seen their GP. 2 in 5 were also trying to manage their own long-term condition alongside their caring role.

90%

of respondents reported negative impacts on health and wellbeing

This should be of great concern to the NHS and local authorities, given the increased pressures that would result in a carer finding themselves too unwell to be able to continue caring. Unpaid carers in general are more likely to have poor mental and physical health outcomes and lower quality of life scores than the general population.¹⁷

1 in 4

respondents felt socially isolated

They are also 7 times more likely to experience loneliness compared to the general population.¹⁸ Our survey found 1 in 5 respondents were experiencing loneliness and 1 in 4 felt socially isolated. Level of unmet need was connected with loneliness – nearly 9 in 10 of those respondents who reported that they were lonely also had high unmet need for support (including financial, practical and emotional support).

This can be due to the heavy emotional demands of caring, loss of employment and limited disposable income to spend on social activities, or drifting away from family and friends because of extra responsibilities.¹⁸

“That’s another thing I worry about - the stress of going out, because I don’t like to leave him. If I do go out, it’s only to the corner shop because if he needs anything, he’s stuck. . . I only ever go out if I really need to.” – Carole, 59, from Wales supports her husband Craig, 60, living with secondary progressive MS.

^a Participants were asked to select all that apply from a list of 14 options.

The lack of a break from caring responsibilities is compounding the negative impact on health and wellbeing. A third of participants hadn't had a break in more than two years. This group reported more negative health and wellbeing symptoms associated with their extra responsibilities – including tiredness, anxiety, stress or worry, or poor sleep.

There are many reasons why carers haven't taken breaks. While a third of respondents didn't want to take a break, the majority of people surveyed felt that there were barriers preventing them.

Barriers included: feeling guilty leaving the person they support (46%), lack of appropriate replacement care for the supported person (25%), concerns regarding the quality of replacement care (20%), and the stress of organising it (18%).^b

Carers may not always prioritise their own health and wellbeing or feeling guilty doing so, as our above findings indicate. Proactive efforts are, therefore, required to reach out to carers and prevent their health deteriorating. Hence, there should be a duty on the NHS to identify, assess, and signpost those who are providing unpaid care, and awareness should be raised locally about support that is available across services, as well as funding for carers' breaks protected.

“I can't really remember the last time I had a break – a couple of years ago? I used to go on holiday by myself a lot, but I can't do that now. There needs to be two of us in case my son falls, so I can't travel.” – Clare, 69, from Buckinghamshire supports her son Trevor, 38, living with primary progressive MS.

^b Participants were asked to select all that apply from a list of 11 options.

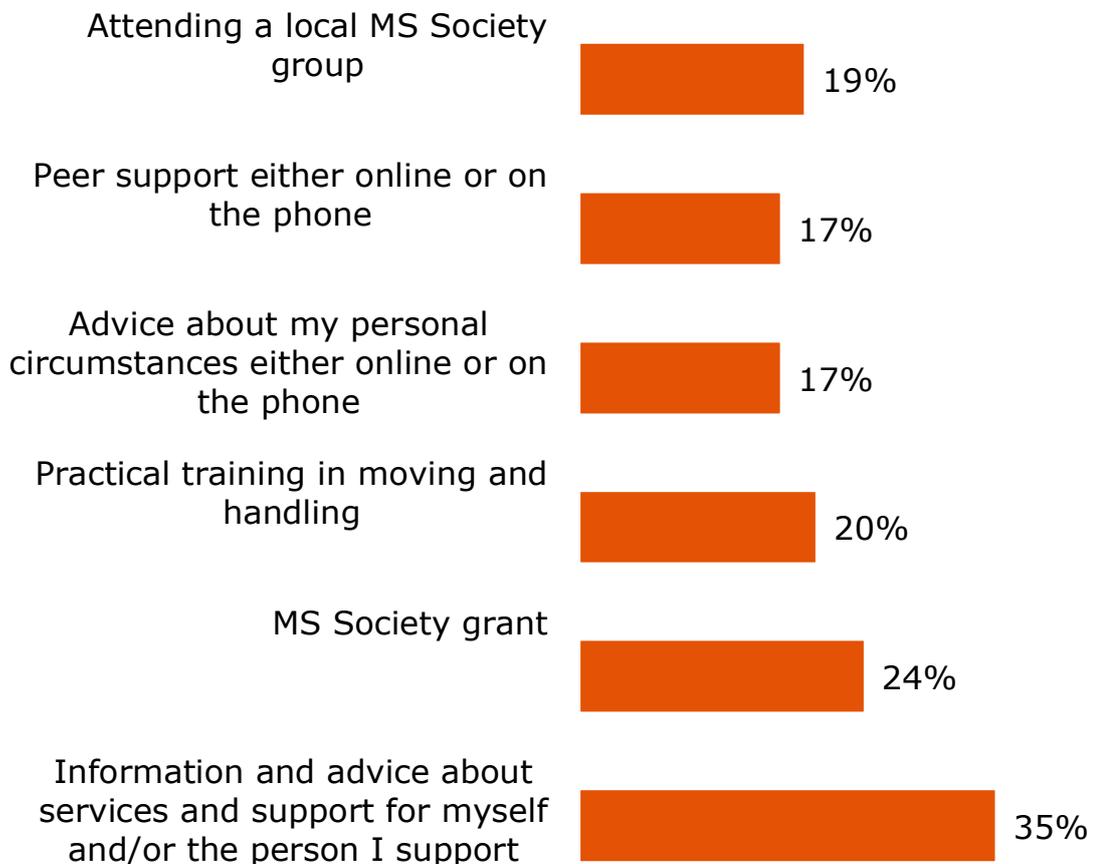
MS Society services and support

We asked what types of services respondents would be most likely to access from the MS Society (detailed in graph 6 below). 35% said they would be likely or very likely to access MS Society information and advice about services and support for themselves and/or the person they support. Information, both in printed form and online, were the most commonly accessed form of MS Society support in the past 12 months.

However, almost the same proportion of respondents that had accessed our information (32%) said they didn't access any MS Society services/support at all (36%). There was also significant interest in types of support we don't currently provide, including peer support by phone or online (17% said they would be very likely to access this). Such insight will help us to improve our support offer to family members and friends supporting people living with MS.

We asked respondents to select the types of support they would be very likely to access from the MS Society from the below list the (they could select multiple options).

Graph 6



Summary

“The most challenging aspect of caring is not knowing how to plan ahead. Especially the long-term. We’re really, really worried what will happen when we die or become incapacitated. He’s also scared about what could happen. He can’t possibly live on his own. I presume carers will come in if he needs help?” – Clare, 69, from Buckinghamshire supports her son Trevor, 38, living with primary progressive MS.

The findings of this survey illustrate the urgent need for better support for family, friends and unpaid carers. This is at both local level and UK-wide Government, across the NHS, amongst employers, and charities such as ourselves.

Identifying carers is a crucial starting point. The NHS should have a duty to identify carers and Governments should introduce campaigns aimed at encouraging carers to self-identify, and raising awareness of the support available.

We also need a social care system that works alongside carers and supports them far better than it is equipped to do at present. We are calling on the Government to create a fairer, more effective and sustainably funded care system across the UK.

People providing valuable unpaid care simply should not be left financially vulnerable as a result. Governments need to review Carer’s Allowance to make it fit for the future, and take the short-term measures recommended to better support carers now.

Being able to take a break from caring should be a right, not a struggle. Governments should introduce a statutory right to paid leave of at least 5-10 days, across the UK, and funding for carer’s breaks must be protected.

Employers have an important role to play, helping people to remain in or return to work, and stay well in work, by offering flexible working, paid care leave and employee assistance programmes which are tailored to unpaid carers.

There is no one size fits all approach to supporting MS family and friends, but the changes above would make a tangible difference to their lives. We won’t stop advocating for change and the support people like Clare, Joy, Carole, Helen and their families need and deserve.

“As a carer, sometimes I am absolutely shattered by the end of the day, but when I go to bed leaving Craig clean, comfy, and content, I know that that day, I’ve done the best for Craig that I can. That’s all that matters to me.” - Carole, 59, from Wales, supports her husband Craig, 60, living with secondary progressive MS.

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- ¹MS Society, My MS My Needs 3, 2019 (unpublished).
- ²Carers UK, Juggling work and unpaid care, 2019.
- ³Carers UK, Will I care? The likelihood of being a carer in adult life, 2019.
- ⁴The Care Act, 2014.
- ⁵Calculation based on median pay for care workers in the independent sector in England of £8.10 per hour, as of March 2019 (from Skills for Care, Pay in the adult social care sector, 2019).
- ⁶New Economic Foundation, NHS England: Socioeconomic costs and benefits of unpaid carers, 2019.
- ⁷Extra Costs Commission, Driving down the extra costs disabled people face, 2016.
- ⁸Social Metrics Commission, Measuring Poverty 2019: A report of the Social Metrics Commission, 2019.
- ⁹Carers UK, State of Caring, 2019.
- ¹⁰Office for National Statistics, Average household income, UK: Financial year ending 2019 (provisional), 2019.
- ¹¹Carers UK, What is Carer's Allowance?, 2019.
- ¹²Department for Work and Pensions, DWP benefits statistical summary, August 2019, 2020.
- ¹³Department of Communities, Benefits statistics summary publication (national statistics) – August 2019, 2019.
- ¹⁴Citizens Advice, The role of Carer's Allowance in supporting unpaid care, 2015.
- ¹⁵Carers UK, Carer's assessment, 2019.
- ¹⁶NHS Digital, Adult social care activity and finance report, England for 2018-19, 2019.
- ¹⁷Brimblecombe, N., Fernandez, J-L., Knapp, M., Rehill, A. and Wittenberg, R., 2018. Review of the international evidence on support for unpaid carers. Journal of Long-term Care, September, pp. 25-40.
- ¹⁸Carers Week, Getting carers connected: research summary Carers Week, 2019.