Findings from the 2022 Family & Friends Survey

Survey findings for the UK

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Let's stop MS **together**

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1. Introduction

We, as the MS Society, have a commitment to understanding and highlighting the needs and experiences of the MS Community. This includes anyone affected by MS, including family members, partners, friends and loved ones of people with MS.

How we use the data

As part of this we undertake a number of data and intelligence gathering exercises; the Family and Friends (F&F) survey is an important part of that information gathering. This is the second F&F survey and this data was collected in 2022 and analysed in 2023.

The information we collect in these surveys has been valuable in many ways, for example, in campaigns and awareness-raising activities. This year, that includes data from this survey being included in a parliamentary debate on Carer’s Allowance. We also use the data to shape our goals and strategies.

Taking Action

Moving forward, we will continue to access and use this data to, for example:

- Highlight the needs of carers
- Make in-roads to rising levels of need across our community
- Consider our own services and how they meet the needs of our MS Community
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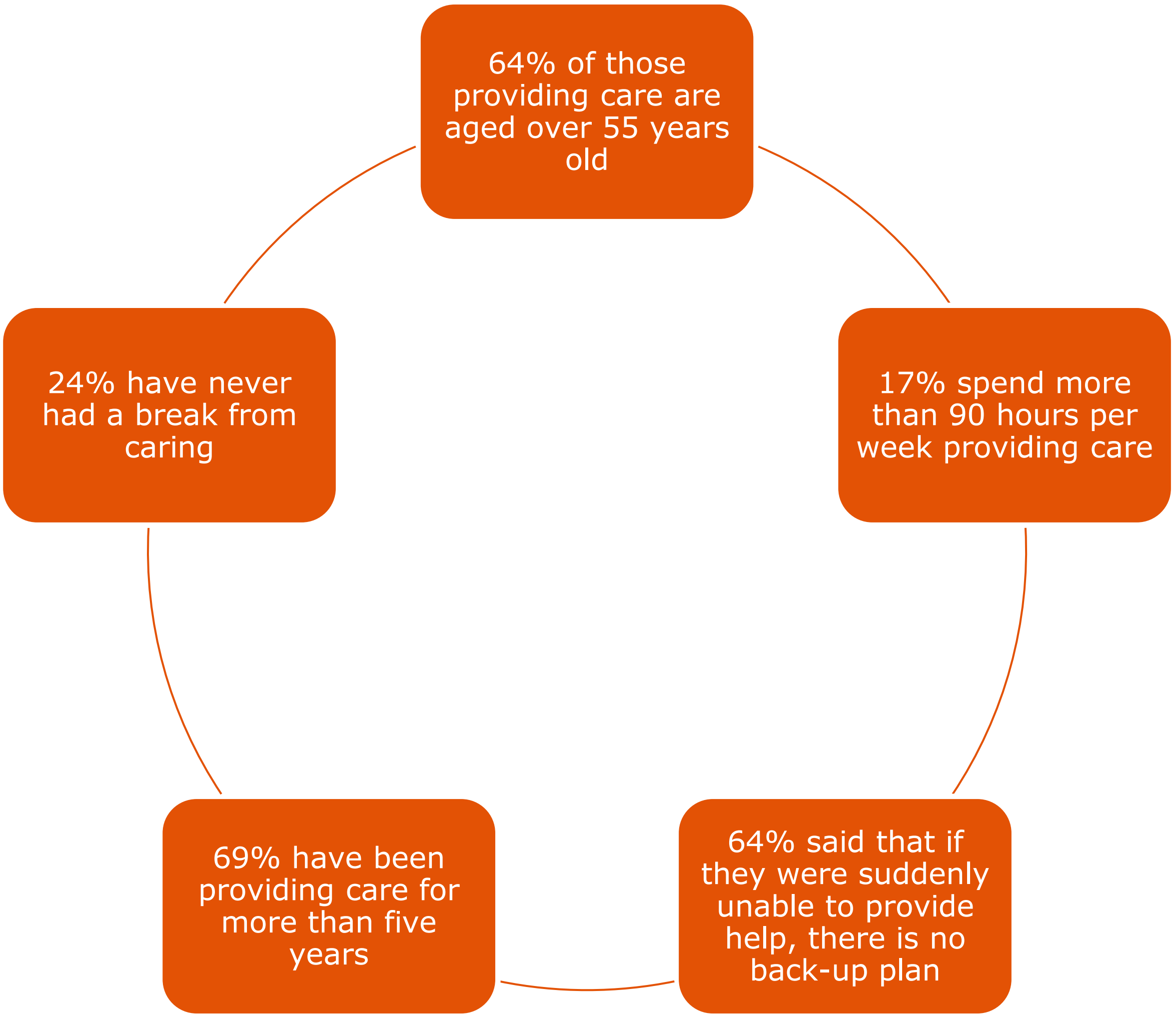
This Family and Friends survey is hugely important in our work for the MS community and we owe a debt of gratitude to everyone who took part in this piece of work. We look forward to continuing to work together to improve the lives of people with MS across the UK.

Key Findings

In the report that follows, are a number of datasets and statistics and below we highlight some key findings.

In this first image we capture just some of the data which shows a snapshot of the extent of caring being provided:



64% of those providing care are aged over 55 years old

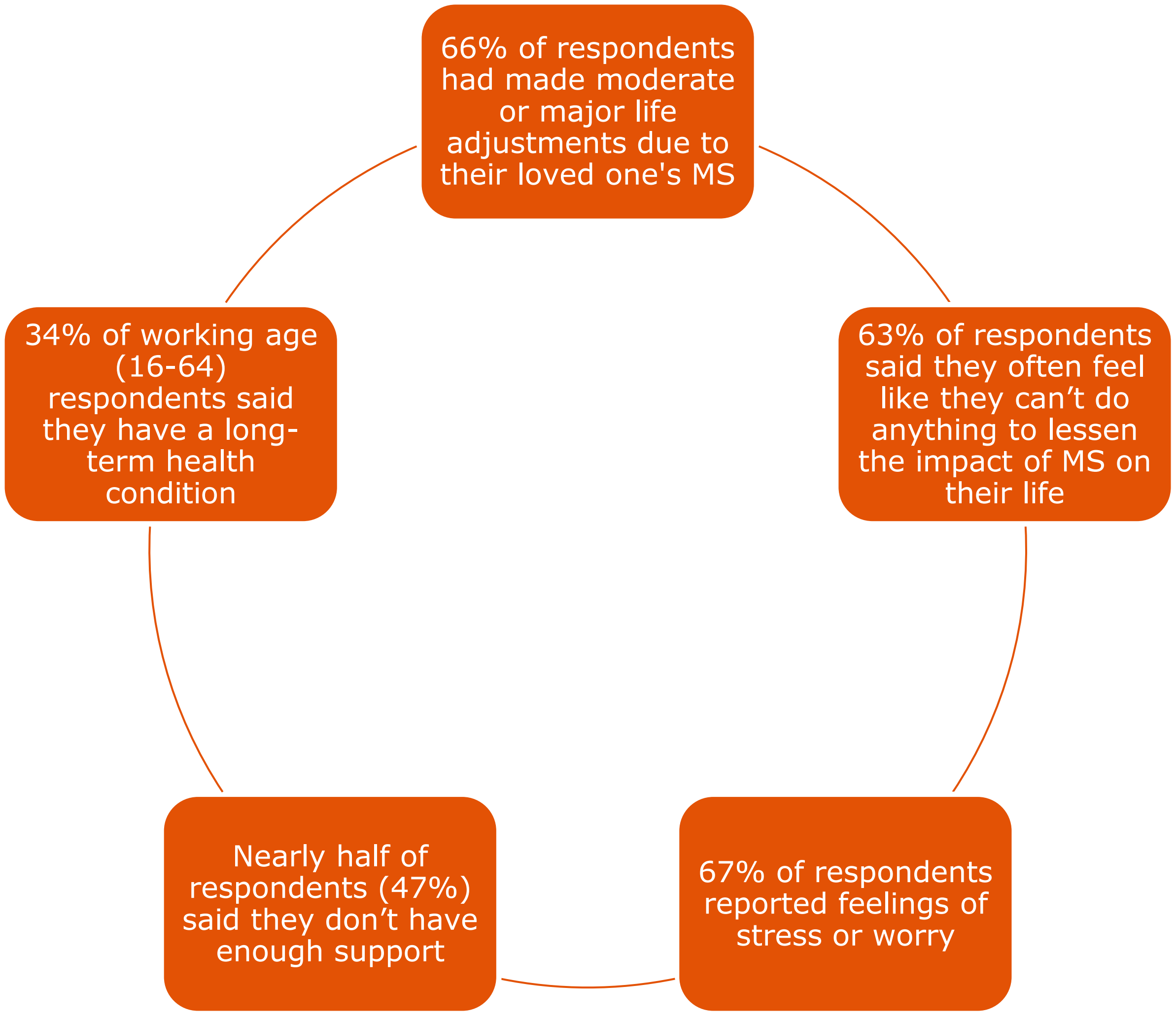
17% spend more than 90 hours per week providing care

64% said that if they were suddenly unable to provide help, there is no back-up plan

69% have been providing care for more than five years

24% have never had a break from caring

The next image captures just some of the data illustrating the impact on those carers and the risks to both carers and their loved ones.



66% of respondents had made moderate or major life adjustments due to their loved one's MS

63% of respondents said they often feel like they can’t do anything to lessen the impact of MS on their life

67% of respondents reported feelings of stress or worry

Nearly half of respondents (47%) said they don’t have enough support

34% of working age (16-64) respondents said they have a long-term health condition

2. More about the family and friends survey

Background

We first ran the Family and Friends survey in 2019 to understand the experiences and needs of loved ones of people with MS. The findings from the first survey were published in a policy report, which you can find **on our website.** This is the second time we have undertaken the Family and Friends survey and this is the report of the findings from that survey.

We developed this survey to be shared with family members and friends of people living with MS, inviting responses from anyone living in the UK that has a loved one with MS. Many of our respondents regularly support their family member, partner or friend with MS to carry out everyday activities. This is often referred to as unpaid caring, although not everyone involved in these supporting activities would identify as a carer.

Dissemination, response rates & analysis

The survey was open between 23rd May and 25th August 2022 and was promoted via MS Society social media channels. It was also promoted in My MS My Needs flyers, which were sent to people with MS by post.

The MS Society Evidence Team analyses the survey responses we receive. Part of this work includes ensuring that no individual can be identified in any use of the data. The analysis is done using specialist software, SPSS, which assists the team in organising, managing and reporting the findings. The findings are then used in this report and form the basis of a number of different uses.

542 people responded to our survey, which is similar to the response rate we achieved in 2019 (when we received 549 responses). You can find out more about the people who took part in this survey in the section “About our respondents” below. It is important to note that not all questions were relevant to all respondents, so the total number of responses to questions will not be consistent across the statistics we share below.

Using the findings in this report

The statistics used in this report have been rounded for ease of use. If you would like to use any of the figures, statistics or information within this report for your work, please contact the evidence team at evidence@mssociety.org.uk

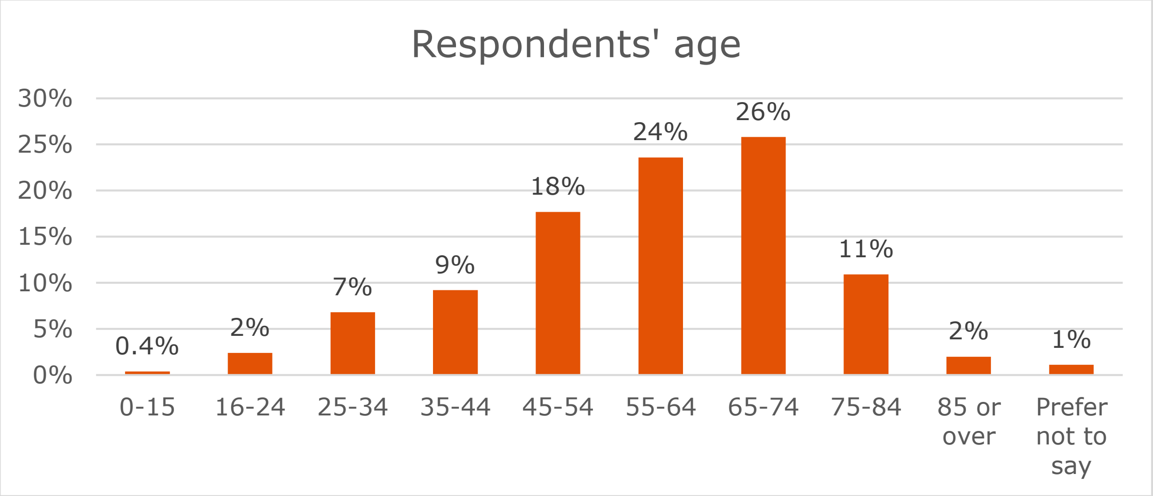
If you use any of the findings in this report, we ask that you cite it as follows: MS Society, (2023). *Family and Friends*. MS Society Report.

3. About our respondents

In order to understand the context of the findings, it's useful to understand a little more about the survey respondents. This can show us, for example, how well the sample represents our MS community or population.

Gender
60% of respondents were female, 38.4% were male, 0.4% were non-binary, and 1.3% preferred not to say.

Age
Nearly two thirds (63%) of respondents were over 55 years old.



N=542

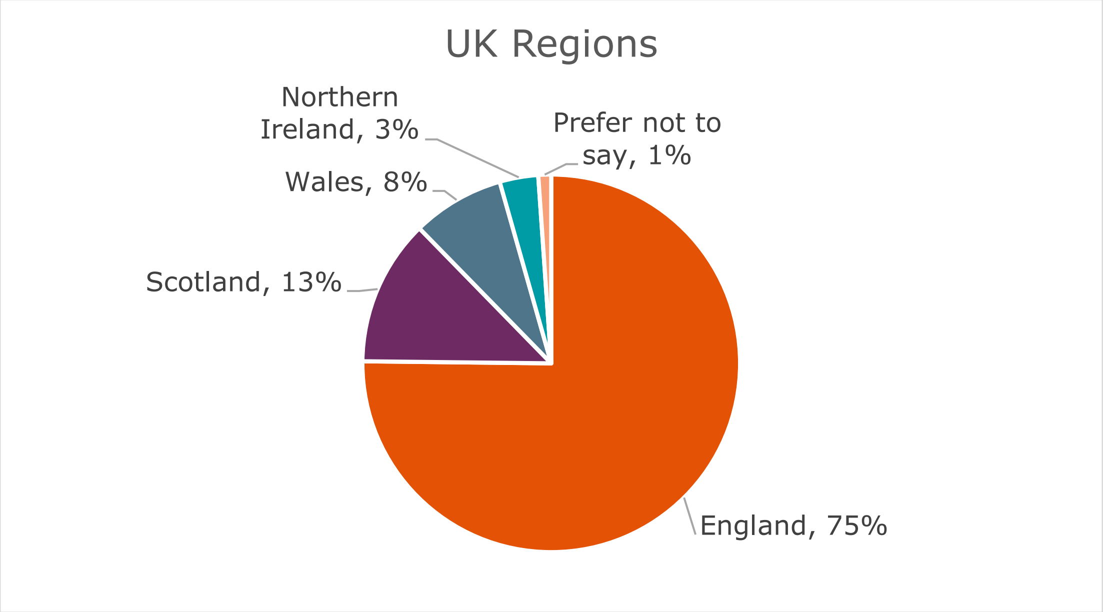
Ethnicity
93.4% of respondents identified as White, while 1.7% identified as Asian/Asian British, 0.4% as Black/African/Caribbean/Black British, 0.4% as Mixed/Multiple Ethnic Groups, 0.6% as Other Ethnic Group and 3.7% preferred not to say.

Sexual orientation
86.9% of respondents identified as Straight, with 2% identifying as Gay or Lesbian, 1.8% as Bisexual, 0.6% preferred to use their own term (2 asexual, 1 queer), and 8.7% preferred not to say.

Long-term health conditions
42% of respondents said they have a long-term health condition, while 51% said they didn't. 7% preferred not to say.

When looking at only those respondents who are working age (16-64 years old) and providing care, 34% said they have a long-term health condition.

UK region
The majority (75%) of our respondents lived in England, while 24% live in either Scotland (13%), Wales (8%) or Northern Ireland (3%).



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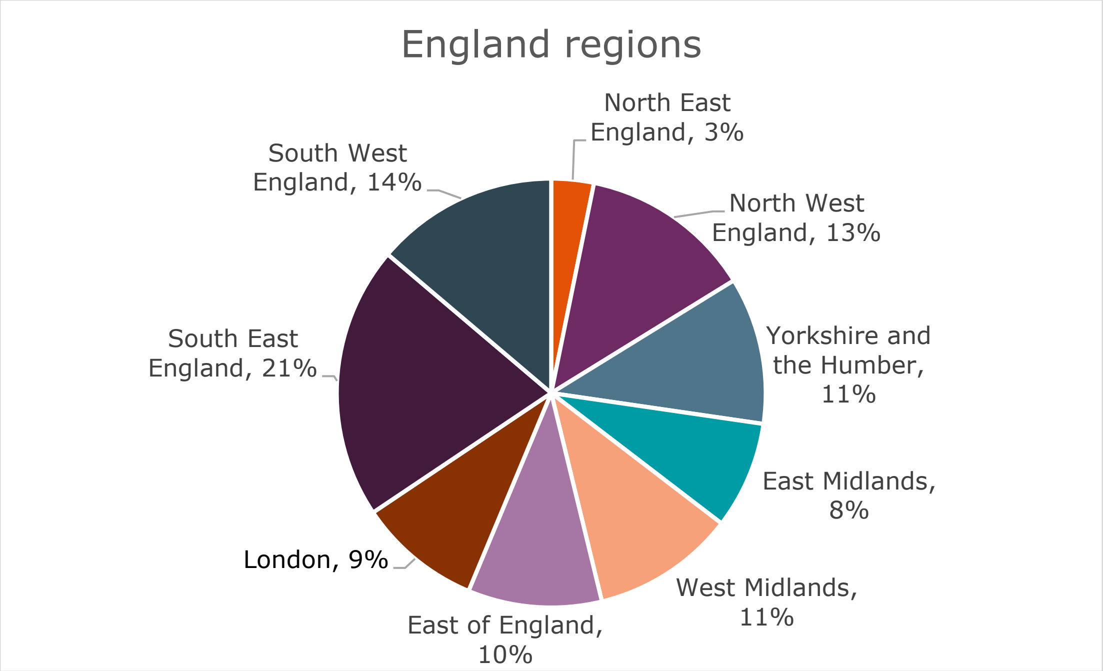
For the 75% living in England, they were spread across the country as shown in the chart below, with the highest proportion (1 in 5) living in South East England.



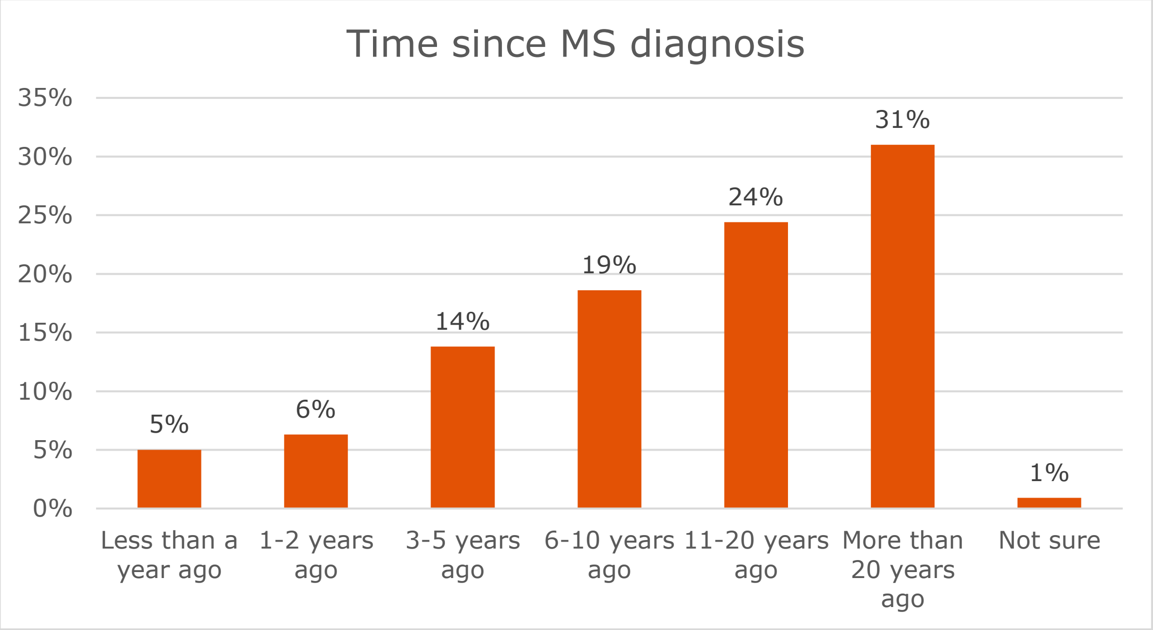
N=413

About our respondents' loved ones with MS

Relationship to person with MS

49% of respondents were a partner of the person with MS, while 23% were the parent of an adult child with MS, 9% were a child of a person with MS, 7% were a sibling and 6% were a close friend.

Time since diagnosis



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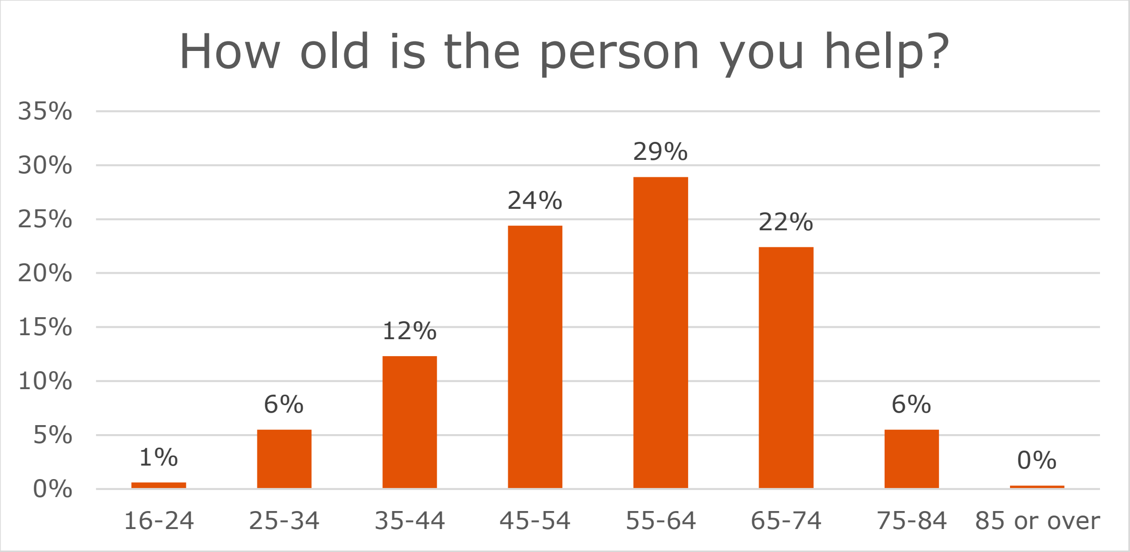
4. What help and support do family and friends provide to people with MS?

About the person with MS

To better understand the context around what help family and friends provide, it's important to understand more about the people with MS they are helping, and how MS affects them.

Age
57% of people with MS that the respondents help were over 55 years old.



N=308

How MS affects the person with MS
Nearly two thirds (65%) of respondents say that the person with MS they support had made major adjustments to how they go about their life due to MS, and 24% said the person had made moderate adjustments.

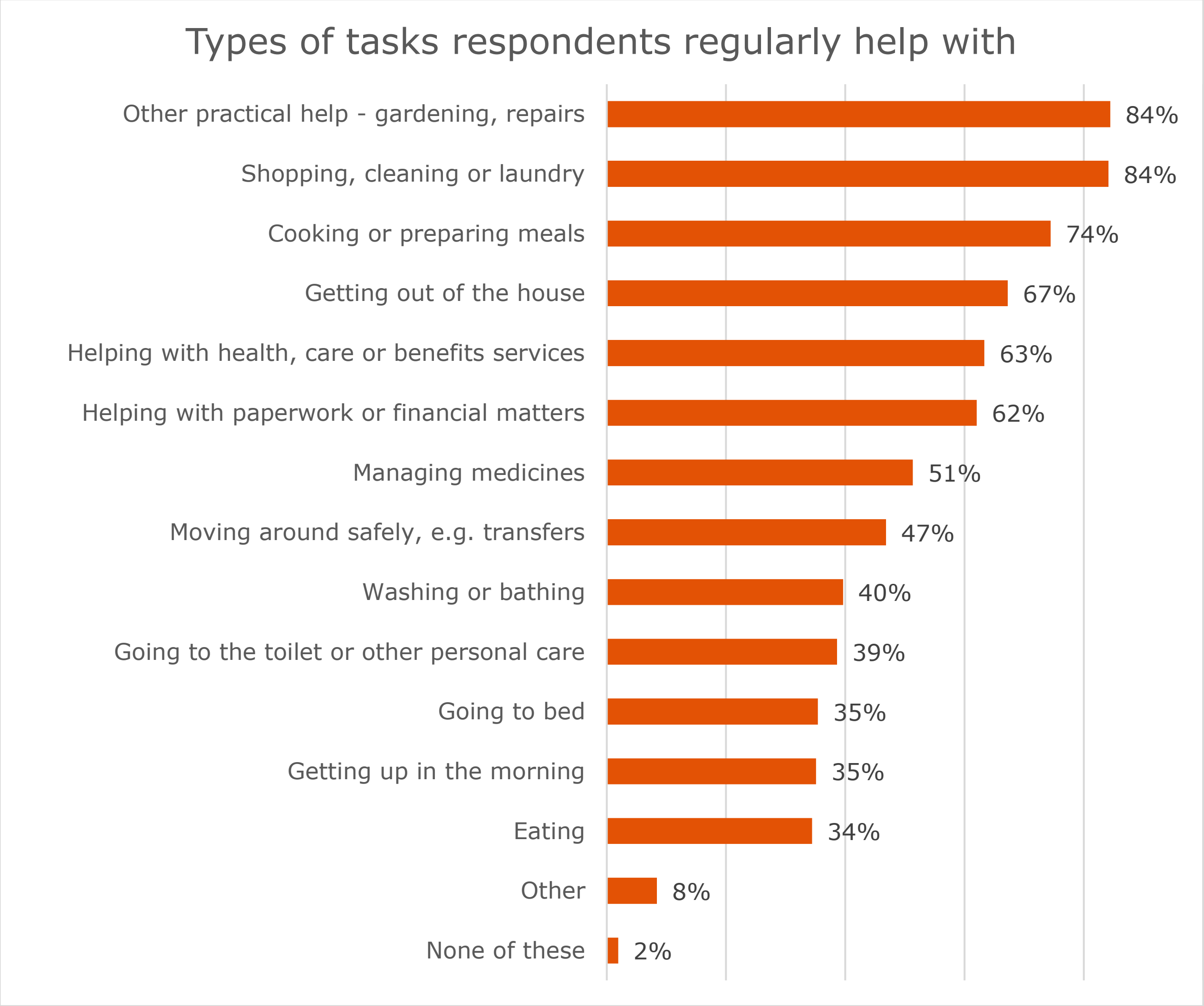
Help provided by family and friends

Help with everyday activities
Over half (57%) of respondents said that they provide help with everyday activities, such as getting washed or dressed, household chores, etc. 78% of those who said they help with everyday activities also live with the person they help.

Of those respondents who help with everyday activities, 66% say they don't have adequate support (this compares to 47% of all survey respondents).

The most common activities family and friends help with are household tasks such as shopping, cleaning or doing laundry (84%) and cooking or preparing meals (74%) as well as practical tasks like gardening or repairs around the home (84%).

Activities more related to personal care are less common, however a large proportion help with these as well. Around 2 in 5 help with washing or bathing (40%) and going to the toilet and other personal care (39%). Around 1 in 3 also help with going to bed (35%) or getting up in the morning (35%), and with eating (34%).



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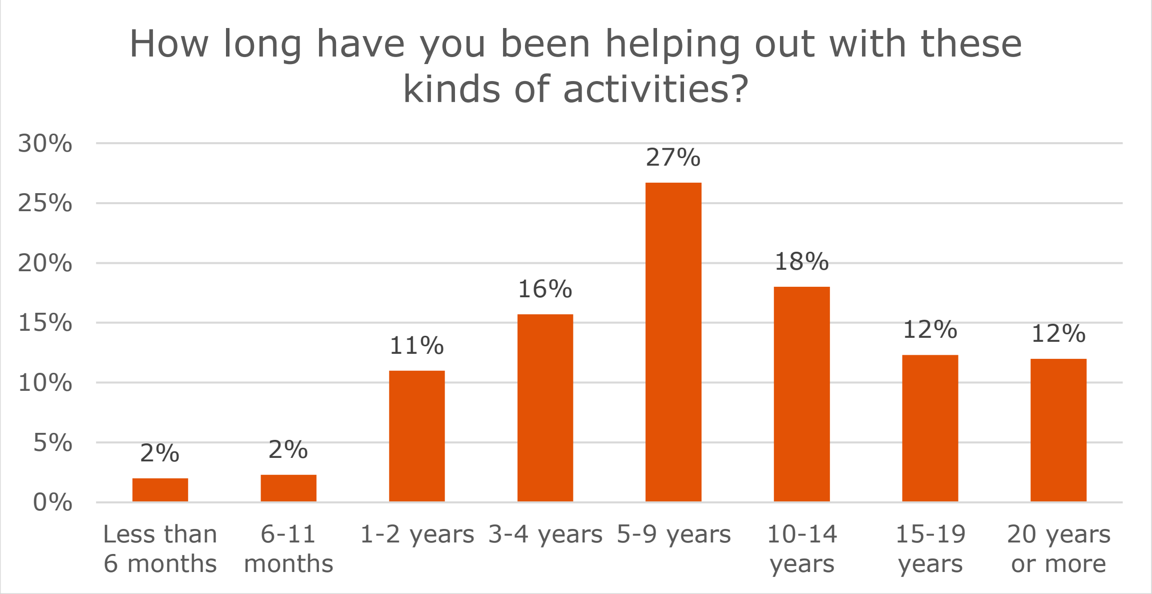
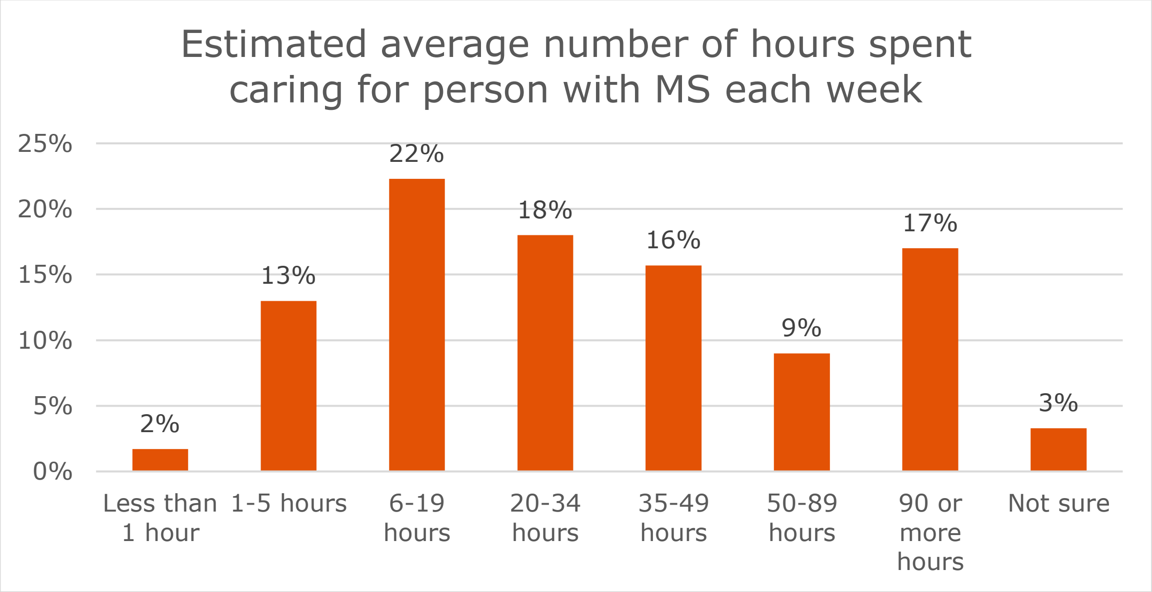


N=300



N=300

2 in 5 (42%) of respondents said they spend 35 or more per week caring, which means that many spend the equivalent of a full time job or more caring for a loved one with MS. 17% of respondents said they spend 90 hours or more a week caring.

Need for additional care

Some people with MS need help with everyday activities from someone else besides their family or friends. This was the case for 220 respondents. Out of all respondents who said their loved one with MS needed help from someone besides themselves, 28% didn't have this need met.

Out of the 72% who have this need met, 49% get additional help from other family members or friends, 48% get additional help from a paid care worker and 3% get additional help from a volunteer or charity.

5. How does their loved one’s MS affect family and friends?

Adjustments due to MS

MS is unpredictable and difficult to deal with, and can have huge impacts on how people go about their lives. This is also true for loved ones of people with MS.

- 66% of respondents said that they had made moderate or major adjustments to how they go about their lives because of their loved one’s MS. Of those:
    - 24% had made moderate adjustments
    - 41% had made major adjustments

Our data also suggests that the length of time since the MS diagnosis is associated with higher levels of adjustments made by family and friends. This could be due to a number of reasons and may be an area for future research.

- 57% of those whose loved one had been diagnosed more than 20 years ago said they had made major adjustments, vs. 30% of those whose loved one had been diagnosed 3-5 years ago, or 17% for those whose loved one had been diagnosed less than 2 years ago.

Impact of MS on family and friends

Managing the impact of MS

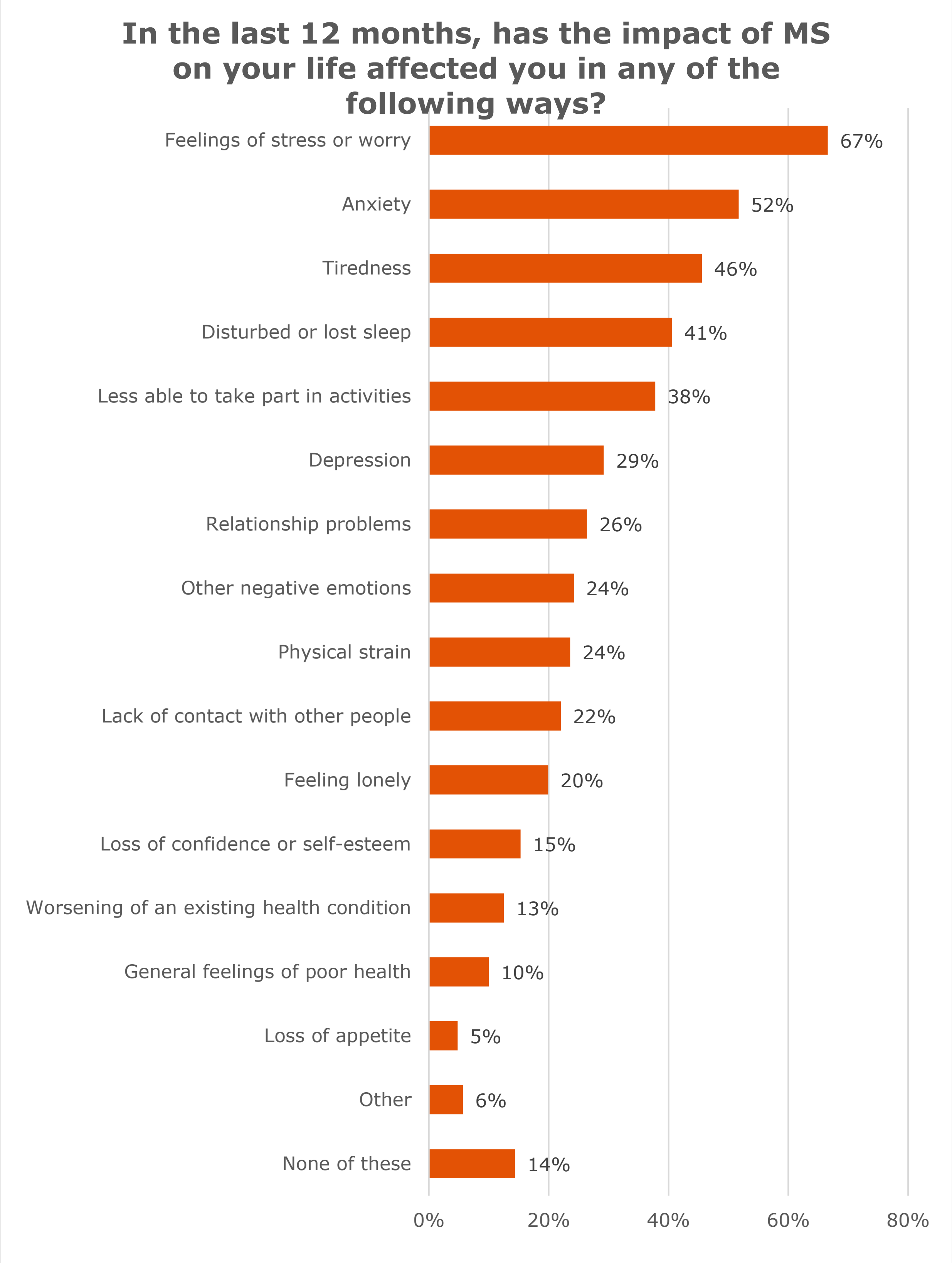
63% of respondents said they often feel like they can’t do anything to lessen the impact of MS on their life.

33% of respondents said they don’t know how to get help to manage the impact of MS on their life.

- For those respondents who said that they had made major adjustments to their lives due to their loved one’s MS (n=220), 45% said that they don’t know how to get help to manage the impact of MS on their life.

How does the impact of MS affect family and friends?

Two thirds (67%) of respondents said that they experienced feelings of stress or worry because of the impact MS had on their lives. Other common experiences included anxiety (52%), tiredness (46%) and disturbed or lost sleep (41%). 38% also said they had been less able to take part in activities due to the impact of MS on their lives.


In the last 12 months, has the impact of MS on your life affected you in any of the following ways?
Feelings of stress or worry
67%
Anxiety
52%
Tiredness
46%
Disturbed or lost sleep
41%
Less able to take part in activities
38%
Depression
29%
Relationship problems
26%
Other negative emotions
24%
Physical strain
24%
Lack of contact with other people
22%
Feeling lonely
20%
Loss of confidence or self-esteem
15%
Worsening of an existing health condition
13%
General feelings of poor health
10%
Loss of appetite
5%
Other
6%
None of these
14%
0%
20%
40%
60%
80%

N=542

6. What support do family and friends access and/or need?

Help from healthcare professionals

In the last 12 months the responding family/friend, as a result of the impacts of MS, had needed to:

- 17% had to gone to their GP
- 7% had requested or were receiving counselling
- 5% had requested or were receiving other psychological support

And

- 24% said they should have asked for help, but didn't

Carer's assessment

- 29% of respondents said that they had had a carer's assessment
- 19% of respondents said that they hadn't had a carer's assessment, but need one

Support needs

Nearly half of respondents (47%) said they don't have enough support.

- 19% of respondents said they don't have the support they need, and 28% of respondents said they have some support, but not enough.

When looking at respondents who are working (n=115), these numbers are even more concerning

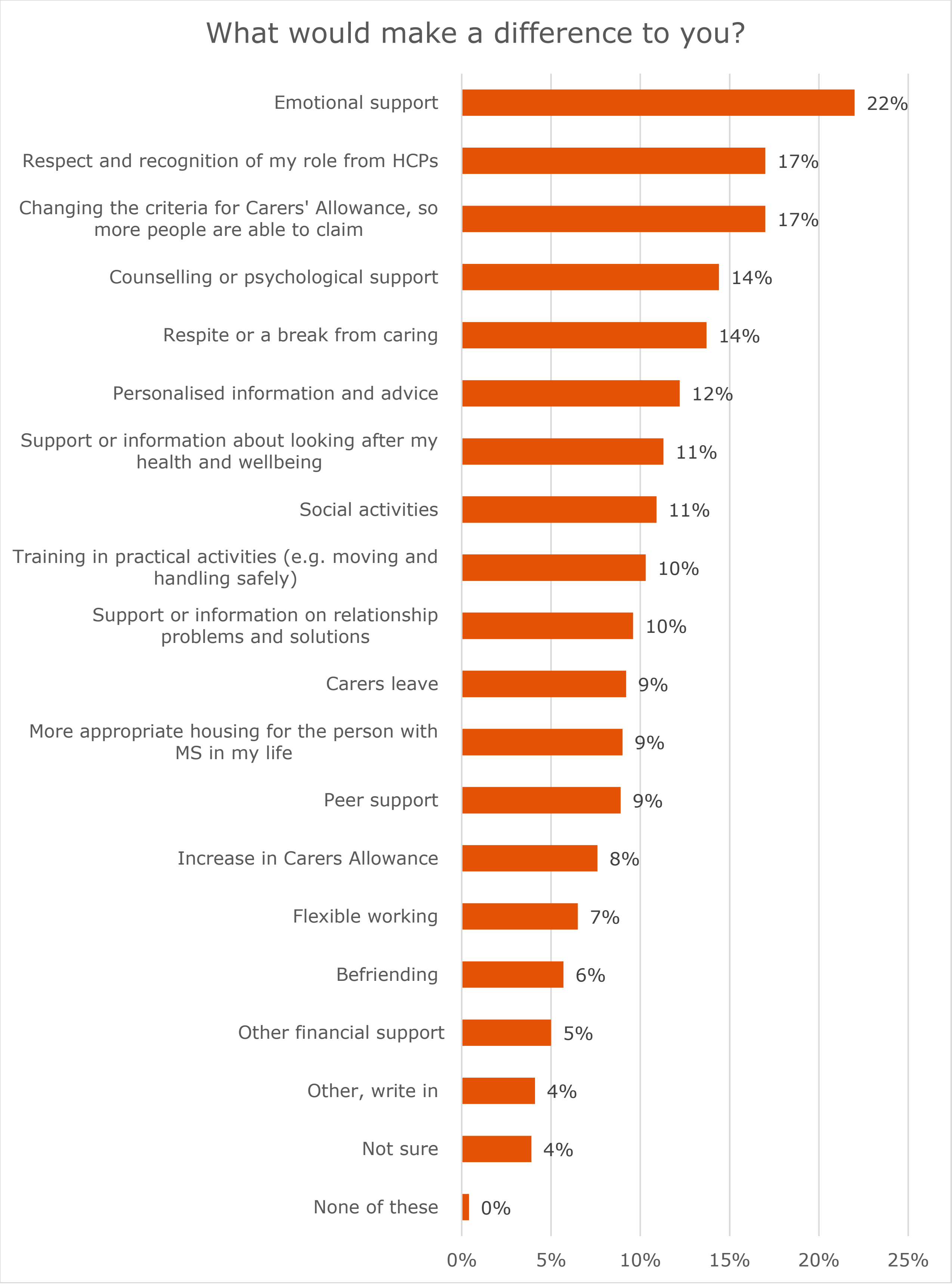
- 76% of respondents who are working said they don't have adequate support, of those:
    - 30% said they don't have the support they need
    - 45% said they have some support, but not enough

Plan for managing without

Nearly 2 in 3 (64%) said that if they were suddenly unable to provide help, there is no plan for managing without them. This illustrates the potential vulnerability of the person receiving the support.

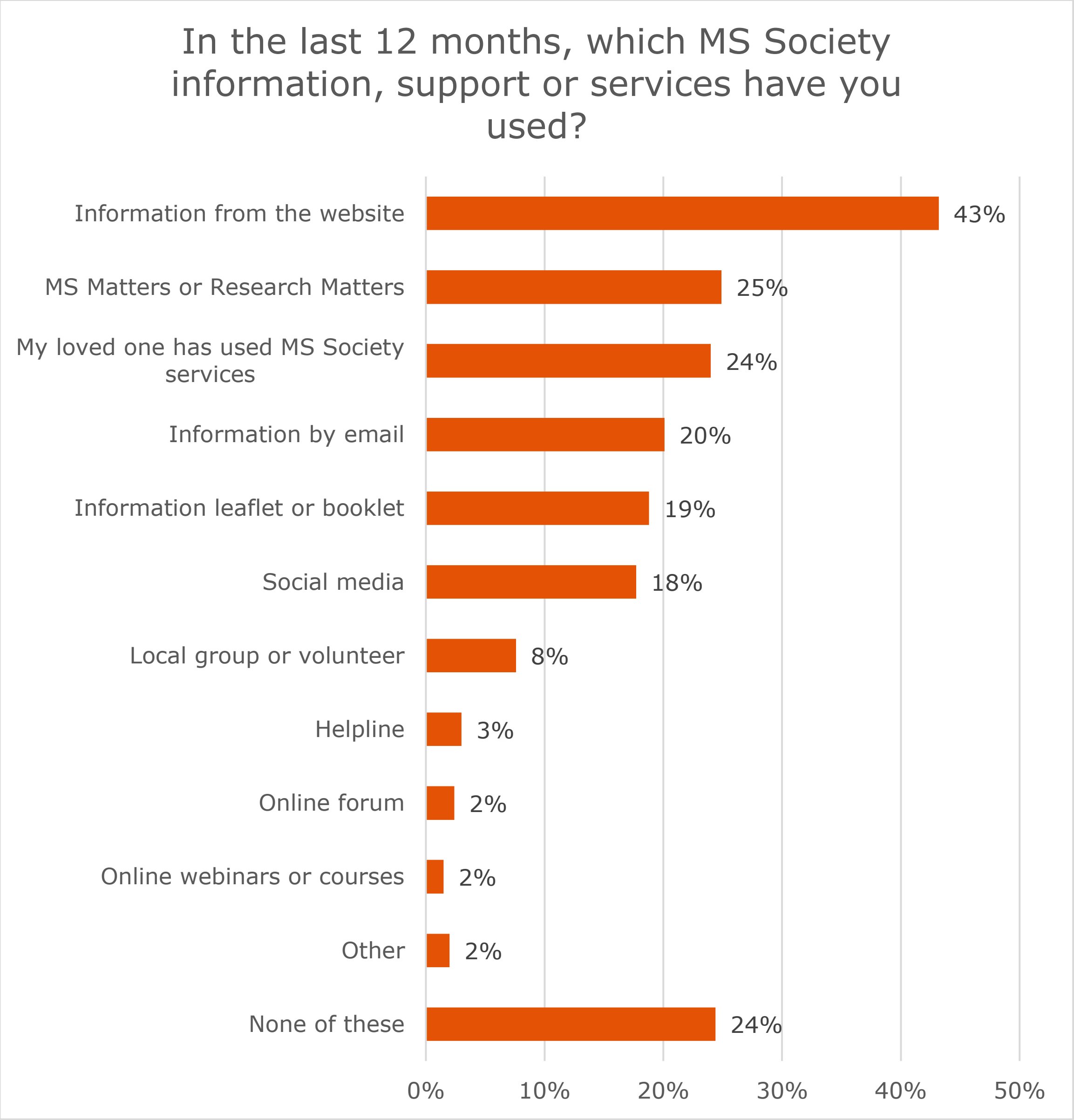
1 in 5 (19%) said that there is a plan, but don't believe that this covers all the help they provide.

What would make a difference to family and friends?



N=542

MS Society information, support and services



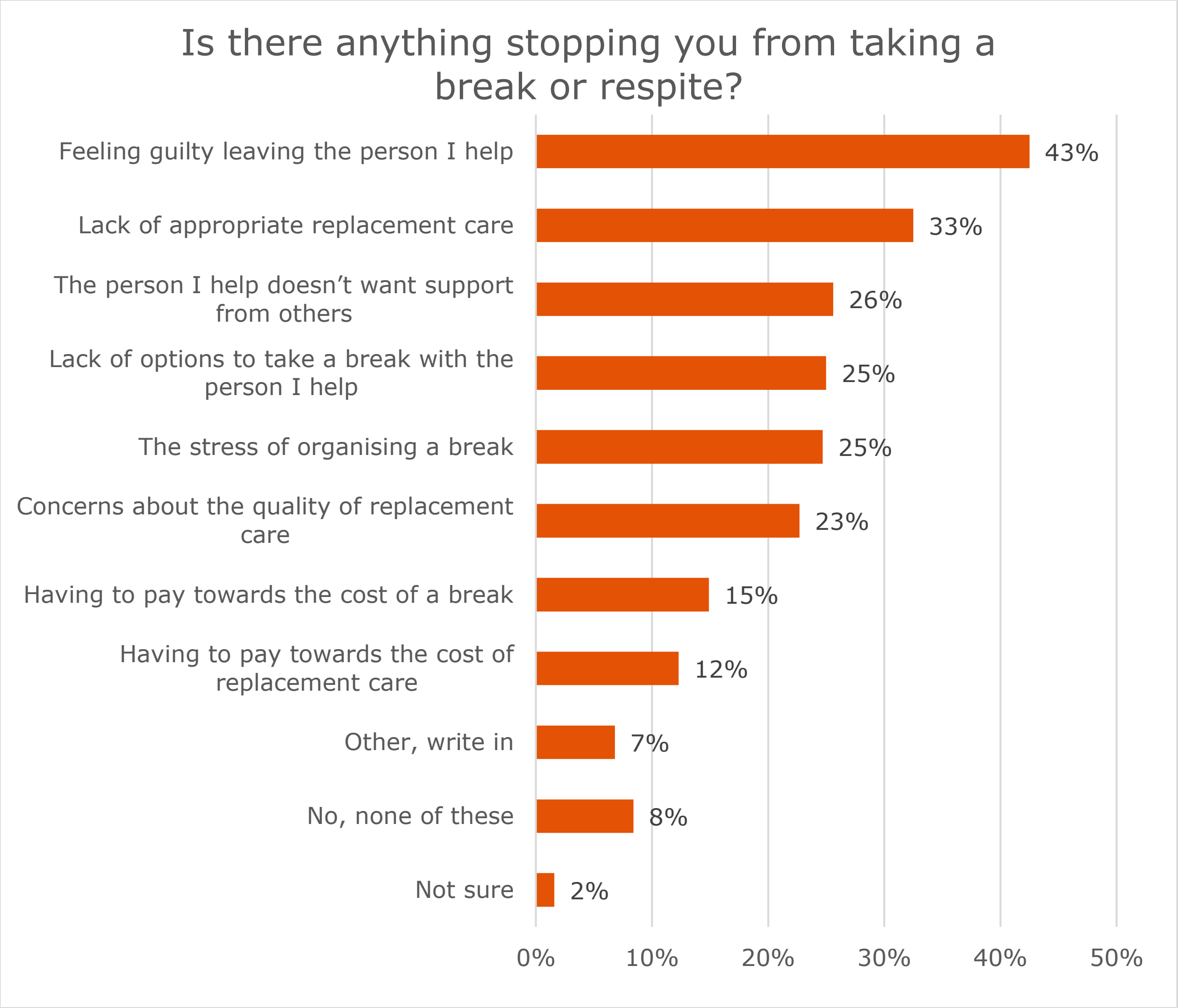
N=542

Break from caring

We know that carers often find it difficult to take a break from caring. The data collected here shows:

- 17% had their last break was more than two years ago
- 24% said they had never had a break from caring

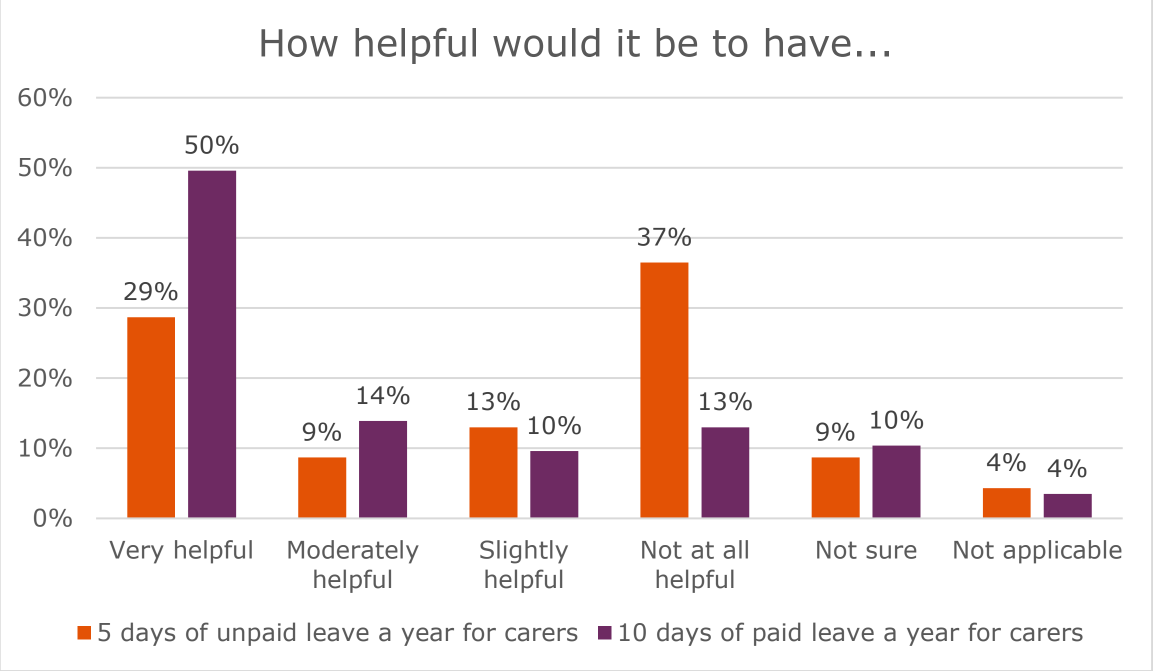
Things that stop carers from taking a break or respite



N=234

Unpaid/paid carers leave
We asked working respondents how helpful they would find 1) 5 days of unpaid leave a year and 2) 10 days of paid leave a year for carers. Although 38% said that 5 days of unpaid leave would be very or moderately helpful, 37% said it would not at all be helpful.

When asked about 10 days of paid leave for carers, 64% said it would be very or moderately helpful, with only 14% saying it would not be helpful at all. The following table breaks down the data further.


How helpful would it be to have...
60%
50%
40%
30%
20%
10%
0%
29%
50%
9%
14%
13%
10%
37%
13%
9%
10%
4%
4%
Very helpful
Moderately helpful
Slightly helpful
Not at all helpful
Not sure
Not applicable
5 days of unpaid leave a year for carers
10 days of paid leave a year for carers

N=115

7. Family and friends’ financial security & employment

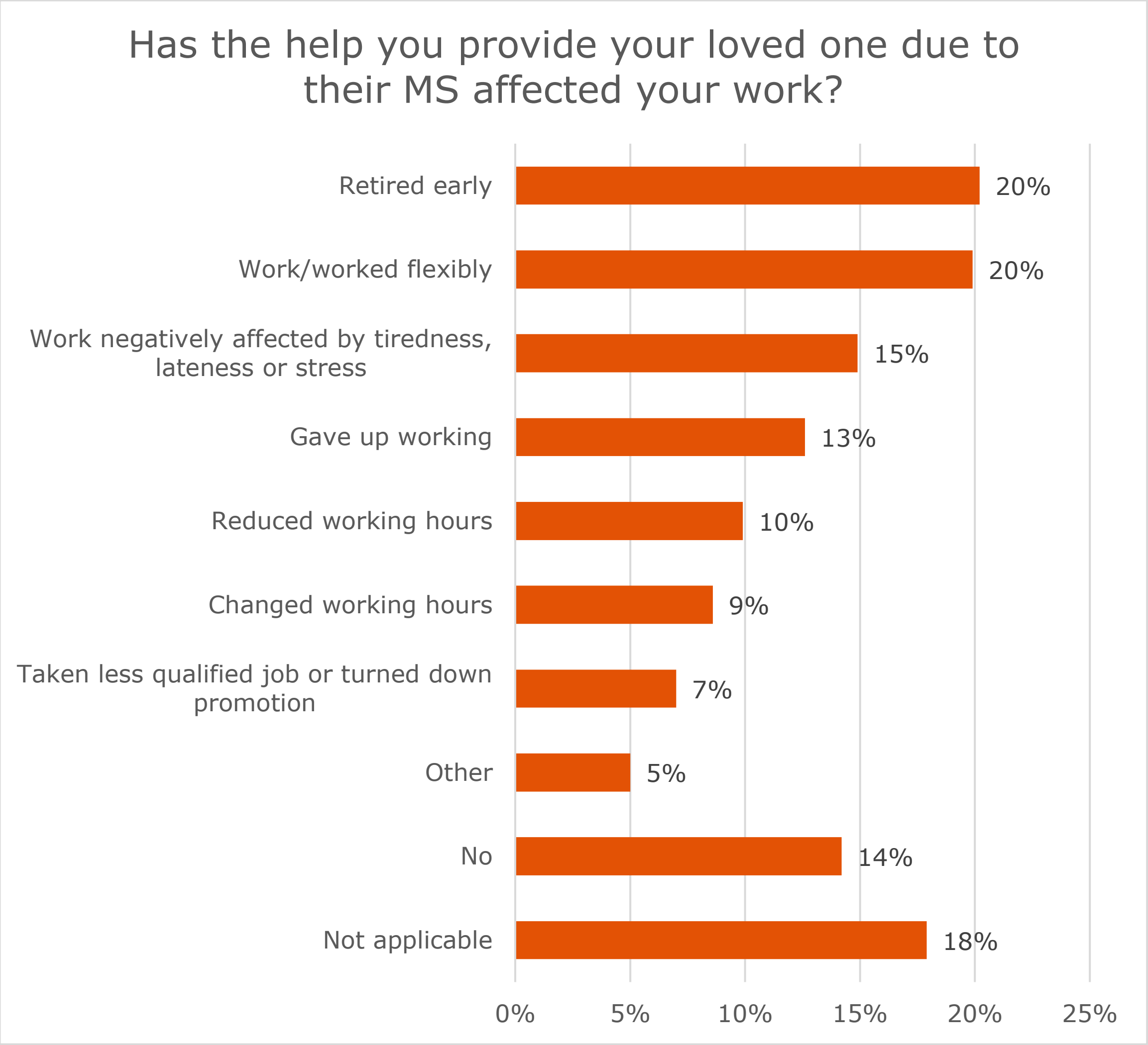
Employment

- 38% of respondents were working either full or part-time
- 47% of respondents were retired
- 8% of respondents were not working and not looking for work

Impact of MS on work

In total, 34% of respondents who provide care said that they had made changes to work due to their loved one’s MS. The graph below gives more detail on the different changes people have made or how the help they provide to their loved one has affected their work.

When looking at only working age respondents aged 16-64 (n=115), 42% said that they had made changes to work due to their loved one’s MS.

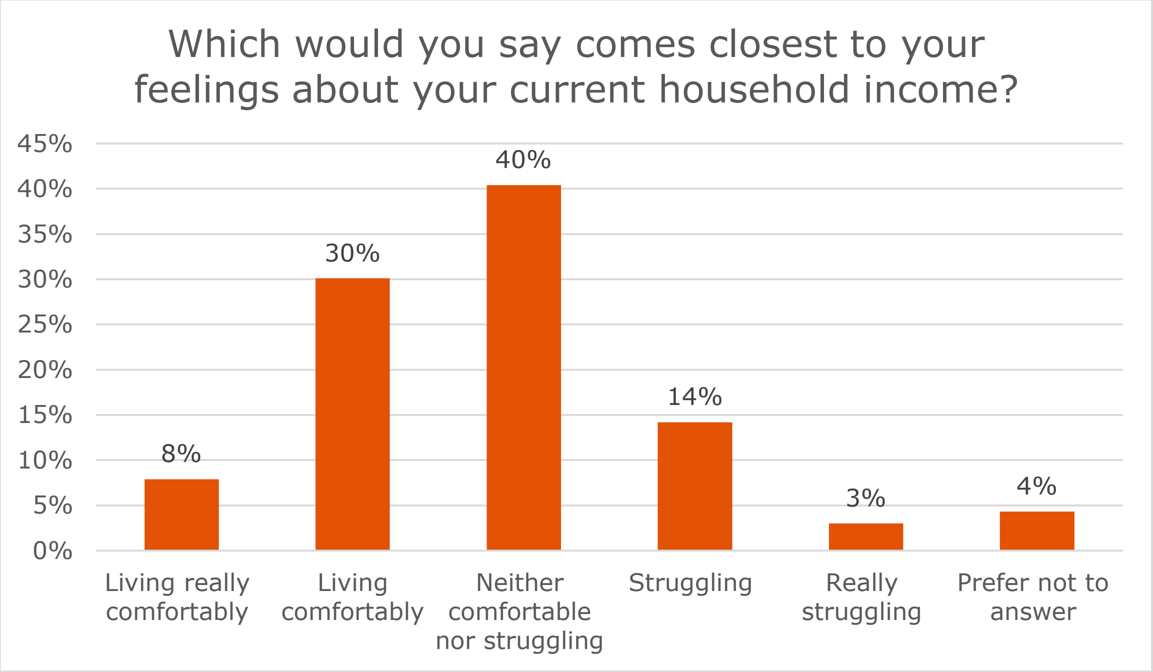


N=302

Advice or support to stay in work

14% said they need advice or support to stay in work, but haven’t been offered it.

Financial security



N=302

Carer’s allowance

Carer’s Allowance is the main benefit for carers. People can claim it if they provide at least 35 hours of care and earn no more than £132 a week. This criteria can stop the majority of carers working full-time from getting it. The amount people receive comes to around £3,300 a year. As can be seen from the data shared, unpaid carers offer important support for people with MS with things like household chores or personal, intimate care.

- 17% of our respondents who provide care said they receive Carer’s Allowance.
- 24% said they don’t receive it, but would like to.

8. Closing observations

We hope that this data will be useful to you in your work. We feel it highlights both the extent of caring activities being provided and some of the effects that has on individual’s lived experiences.

If you have any comments or questions about this work, please do contact the MS Society Evidence Team: evidence@mssociety.org.uk

We’re the MS Society.
Our community is here for you
through the highs, lows and
everything in between.
We understand what life’s like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk

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