

Understanding the experiences of unpaid carers of people living with MND



“

I never saw it as a responsibility, I only ever saw it as just being with him out of love and joy, and I would always tell him that. I didn't see myself as a carer, it's just easier to use that word sometimes with other people to make sense of what I was doing.

Former carer of someone with MND

”

Acknowledgments

Thank you to:

- The 245 unpaid carers who gave their time to complete our survey, focus groups or interviews.
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- The unpaid carers who guide and inform our work.
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About MND and the MND Association

Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop frontotemporal dementia. There are up to 5,000 people living with MND in the UK at any one time. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and groups, and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time, we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and die with dignity.

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Introduction

The onset of the coronavirus pandemic has put significant additional strains on unpaid carers of people living with MND, as well as exacerbating the issues they were already facing. In 2020, the Association reaffirmed its commitment to support unpaid carers of MND across its work and to strengthen the evidence base with new data and engagement with unpaid carers of people living with MND.

Following the onset of the Covid-19 pandemic, the models of support provided by volunteers needed to alter significantly in the light of lockdowns and social distancing. The MND Association's response, beginning in the summer of 2020, was a range of programmes of support delivered by MND Association staff and volunteers working in partnership. There were additional volunteers, including a significant number of Carer champions and Association visitors, who were involved in activities to support carers and the MND Association plan for ongoing support to carers through volunteers. Volunteer-led carers' support has included wellbeing and relaxation sessions, information sharing, and facilitated peer support. Through meaningful engagement with unpaid carers of people living with MND the aim of this research report is to strengthen the evidence base with new, current data on carers needs to help identify and prioritise future support with clear recommendations and calls to action.

About this research

Research scope

This research has included work with carers of people living with MND and MND Association volunteers. A collaborative approach was taken to understand and evidence the research conducted to date, and carry out timely research around the key issues unpaid carers experience. The research participants included: unpaid carers over the age of 18 years old (and did not include young carers under 18 years old) and current carers (not bereaved carers). Existing workstreams within the MND Association were already looking at the needs of young carers, and bereaved carers, therefore this work did not want to duplicate the work being conducted within those workstreams.

The aim of the research was to provide evidence of carers' experiences and needs, to inform responses to ongoing policy issues relating to unpaid carers (including the impact and ongoing effect of the coronavirus pandemic). The work concludes with implications and recommendations for future MND Association work across policy, volunteering and services. Using both previous research and the insights from this work,

it is envisaged that the evidence gathered will inform the next iteration of a government strategy for carers.

Methodology

To obtain the qualitative and quantitative data used in this report, we asked unpaid carers of people living with MND from across England, Wales and Northern Ireland to complete a survey or participate in a digital focus group (via the platform 'padlet'). MND Association volunteers, who support carers, were also invited to attend a virtual focus group (via MS Teams) or a one-to-one interview (via Zoom, MS Teams or telephone).

This resulted in 218 unpaid carers, aged over 18, completing the survey after invitation. An additional 29 carers were involved in either a digital focus group (26 carers) or a one-to-one interview (three carers). From the MND Association volunteers, seven attended the virtual focus group and four engaged with the one-to-one interviews. The survey was anonymous, and no identifying data is held about any of these unpaid carers. Unpaid carers self-identified before completing the survey; a short definition of an unpaid carer was provided in the introductory text of the survey. Survey completion, focus group and interview involvement was voluntary, and no-one received any reward or remuneration from the MND Association to be involved with the work. All participants were able to choose which questions they did and did not answer and to stop at any time. An email address was provided for any questions. All participants were signposted to support, for any participants for whom involvement brought up any difficult feelings. The opportunity to be involved with the work was promoted via the MND Association website and on the Association's social media channels. For the fieldwork, the survey (conducted using Smart Survey), focus groups (using Padlet and MS Teams) and interviews (using Zoom, MS Teams and telephone) were all conducted between November and December 2021. The survey had 50 questions of various types including radio buttons and free text. It was available in English. While the survey results have not been weighted by demographics and so are not necessarily nationally representative, it is nevertheless intended to provide a valuable snapshot of unpaid carers' experiences and views from across England, Wales and Northern Ireland. The topic guides for the focus groups and interviews can be found in Appendix 1.

Overview of respondents to the survey

A total of 218 carers and former carers responded to the survey – we have only included responses from the 184 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 week¹.

As not all respondents completed every question in the survey, a number of the figures given in this report are based upon responses from fewer than 184 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

Of respondents to the survey:

- 93% live in England, 3% live in Northern Ireland and 4% live in Wales.²
- 69% identify as female, 30% identify as male and 1% describe their gender identity in another way.³
- 35% consider themselves to have a long-term physical or mental health condition.⁴
- 2% are aged 18-25, 4% 26-35, 8% 36-45, 19% 46-55, 27% 55-65, 28% 66-75, 9% 76-85, 4% are 80 and over.⁵
- 92% described their ethnicity as White British, 3% White Irish, 3% described their ethnicity as Black or minority ethnic.⁶
- 15% also have childcare responsibilities for a child under 18.⁷
- 35% are in paid work. Of those, 22% work full-time and 14% part-time.⁸
- 5% have been caring for 10 years or more, 18% for between 5-10 years, 10% for 3-5 years, 40% for 1-3 years, 21% have been caring for less than one year, and just 5% have been caring for less than 6 months.⁹
- 43% care for 100 or more hours every week, while 9% care for 75-99 hours, 12% care for 50-74 hours, 15% care for 35-49 hours a week, 10% care for 20-34 hours a week, 5% care for 10-19 hours a week, and 6% care for 0-9 hours a week.¹⁰

There are a vast range of tasks provided by carers, with the majority of carers providing practical help (98.4%) with things like preparing meals, doing shopping, laundry, housework, gardening, decorating, household repairs, supporting trips to the doctor's or hospital. Providing emotional support was also a key feature (92.4%).

The help that carers provide ranges with practical tasks (98%)¹¹ being the highest need, to providing emotional support at the next prioritised need (92%).¹² The physical and mental exhaustion of caring means that many carers struggle to continue to provide support whilst managing high levels of fatigue and stress. This can result in carers feeling unable to manage their caring role.¹³

1 [CUK State of Caring 2021 report web.pdf\(carersuk.org\)](#)

2 Based on 178 responses

3 Based on 183 responses

4 Based on 183 responses

5 Based on 184 responses

6 Based on 184 responses

7 Based on 183 responses

8 Based on 179 responses

9 Based on 182 responses

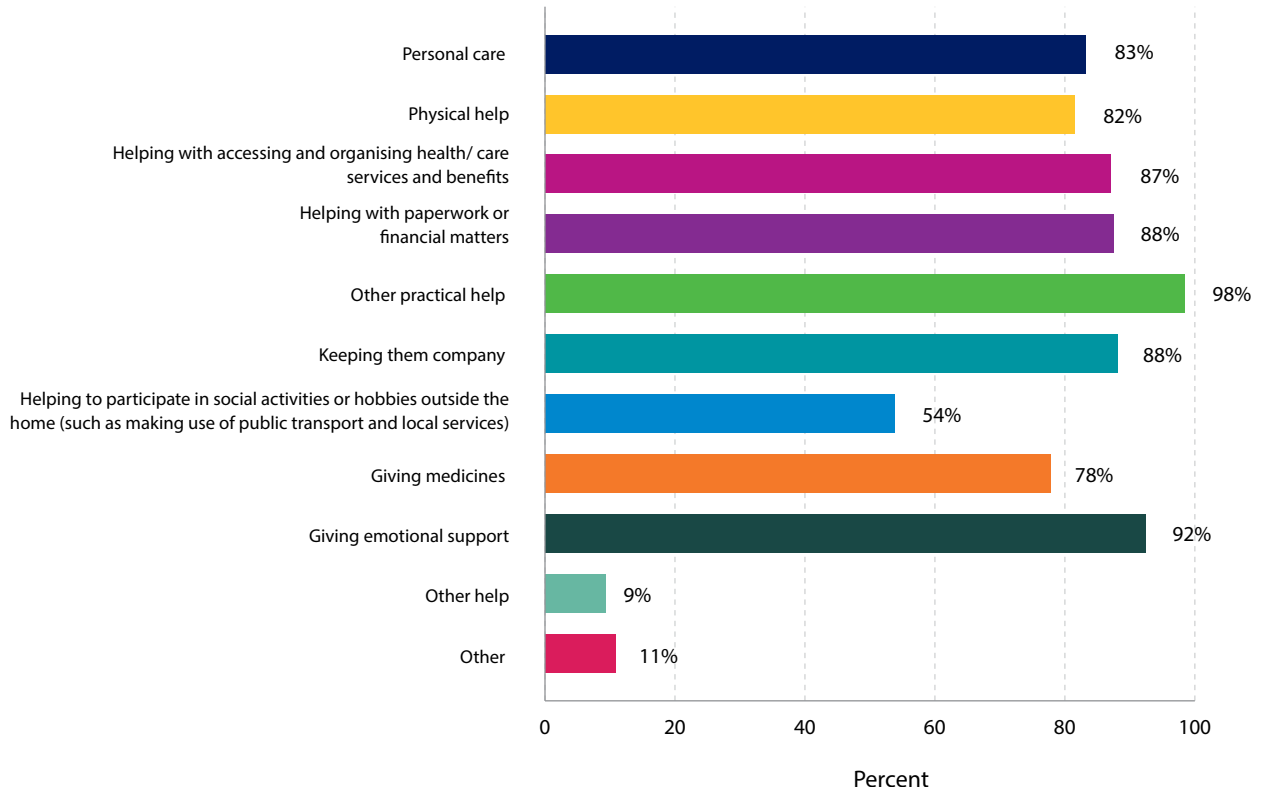
10 Based on 182 responses

11 Based on 181 responses

12 Based on 170 responses

13 Carers week 2020 Research Report

What kinds of things do you usually do for the person you care for?



What are the key issues faced by carers?

Physical and mental exhaustion

Many carers told us about the physical and mental exhaustion they experienced as a result of caring for someone with MND and the impact that this has on their own health and wellbeing. Respondents to our survey told us that they are exhausted both mentally (66%) and physically (64%) as a result of their caring role, and feel stressed from caring (75%).



I wasn't prepared for how physically hard it is manoeuvring another person bigger than me. It was only after I broke my leg and was provided with a Molift that I realised how I had been struggling.

I ache in places that I never have before, my shoulders, arms and back in particular.

Carer, Focus Group

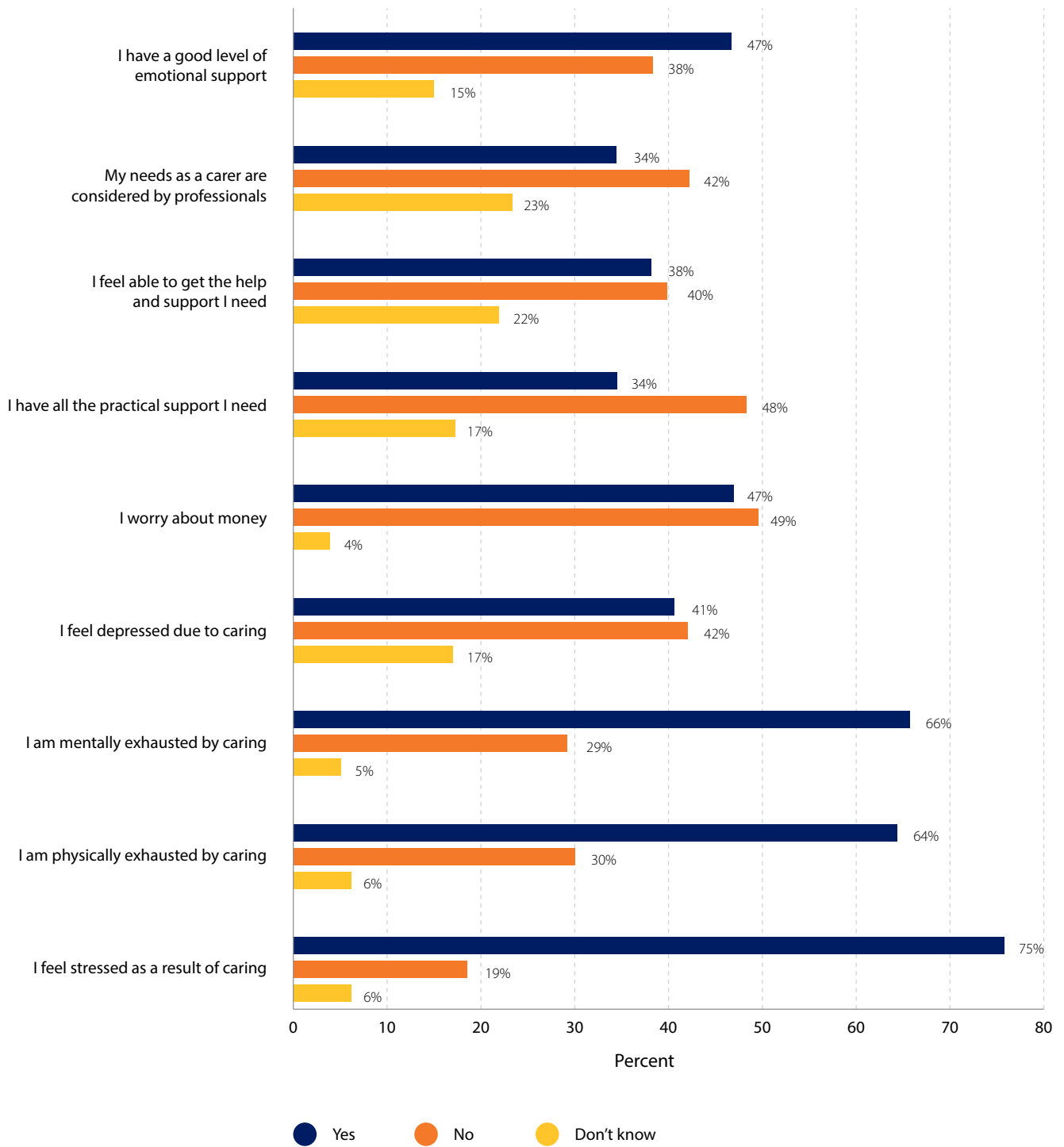


Being my wife's sole carer is exhausting both physically and emotionally. Every day is a gift and a struggle in equal measure, a flexible approach to her changing needs while being exhausted is often a challenge. Trying to stay focused yet worrying about her in addition to worrying what would happen if I became unwell and unable to care for her is terrifying.

Carer, Focus Group



Thinking about your life as a carer, how far do you agree with the following statements:



Many carers suffer from considerable stress, which has a negative impact on their mental and physical health. Worry and concern for the future are common experiences for carers. The exhaustion can be amplified for carers by the worry, fear for the future and isolation that many carers experience.



As I get older, I worry about the future for her where caring is concerned, but I also worry about the impact physically and mentally that it is going to have on me. I can't discuss this with her as she will just dig her heels in, and although I have Power of Attorney, I respect her wishes completely. I had a breakdown a couple of years ago, not due to my sister, but other personal issues, and this has left me in a very different mental situation where I find that I'm not coping as well as I used to. I'm tired of everything right now. Don't get me wrong, we also laugh a lot and try and see the lighter side to everything, but on the whole I'm so worried because I've been doing this a long time now and going forward I worry about how much longer I can carry on. I hate sounding a bit, me me me, because I'm sincerely not at all like that, I'm a generous, loving and giving person who will do anything for anyone, but I'm tired and emotionally drained, and it's greatly impacting my life.

Carer, Focus Group



A sense of despair was common across many carers' responses. Both isolation and loneliness are common experiences for carers. It was identified that support services need to improve the availability of support:



Had to give up work to care for husband with MND. Feel very isolated and worried about the future. Everyone we come into contact with, professionals and friends, ask what help we get but there is none out there. Hubby can now do little for himself. Washing, feeding, toileting is just a daily grind. He has now lost his speech so a conversation isn't even a possibility. He seems quite content fortunately and I don't want to worry family and friends are not really interested but I am barely coping mentally.

Carer, Focus Group



Having ways to connect with others and build social support can alleviate isolation and loneliness and make coping easier through a 'shared experience' of providing care. Providing carers with more support to be able to look after their own health and wellbeing is important. It is essential that carers are given the support to allow them to take time for self-care and to have opportunities to talk to others to share experiences and receive emotional support.



Just company, someone to talk to, sometimes the need to talk about anything other than the obvious. The need to be able to leave the house and have me time. To have a day at least to do something for me. It's been so long since I've been able to just go shopping, go for a walk, even just talk on the phone without being interrupted. I'm not sure what this is doing to my mental health.

Carer, Focus Group





The biggest thing for me would be to be able to talk to someone and share my frustrations. They say there is help and support out there, but when you ask, it's either non-existent or there is a waiting list months long, which has also now been impacted by Covid. Being able to talk to the right people is so important for me as I feel I'm locked up in a world of loneliness.

Carer, Focus Group



The ability to take breaks affects carers' capacity to complete essential tasks that others may take for granted, such as taking exercise, doing housework, or attending medical appointments. Carers reported not being able to take a break or had had fewer breaks than before the pandemic. This concurs with recent research, where 72% of carers reported not being able to take a break during the pandemic.¹⁶ In addition, 66% of carers who had received a break said they had not had enough breaks to protect their health and wellbeing or had had fewer breaks than before the pandemic.



I have been unable to organise respite care in a residential home as they have made a two-week minimum rule and my husband would have to stay in his room for the first week. Further, because the combination of Brexit and Covid has left care agencies short of staff our usual agency is unable to provide extra hours.

Carer, Focus Group

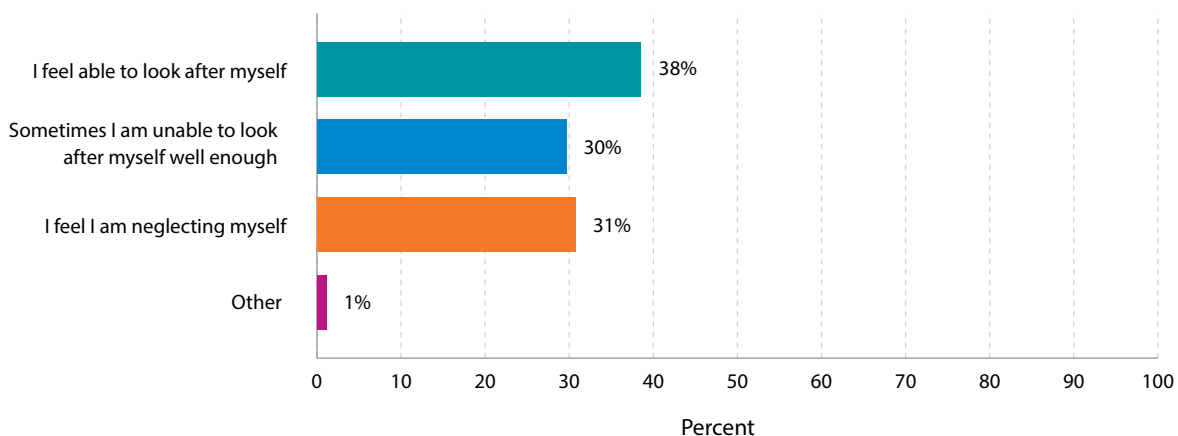


Access to breaks

Carers need support to enable them to have breaks and to rest properly. Only 38% of carers who responded to our survey felt they had the time to look after themselves,¹⁴ with 31% identifying that they are neglecting themselves.¹⁵

When carers were asked about how their health has been directly affected by their caring role, the majority reported that it had a negative effect. Feeling tired (85%) and disturbed sleep (76%) were top areas of concern.

Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?

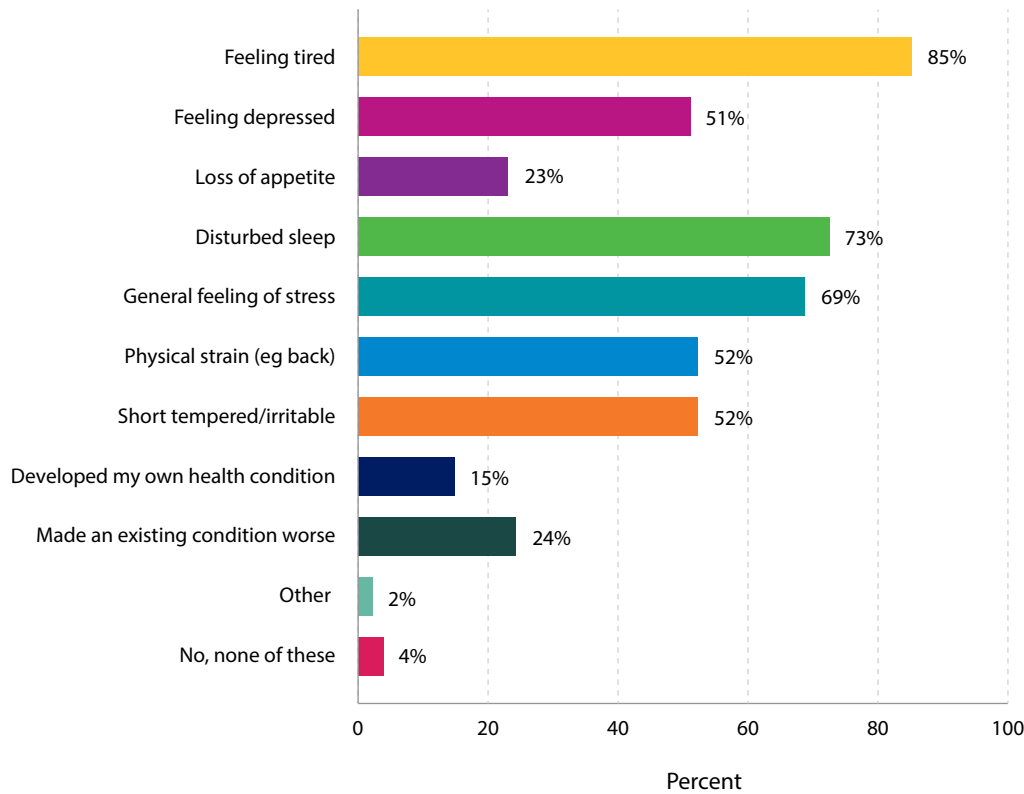


¹⁴ Based on 70 responses

¹⁵ Based on 56 responses

¹⁶ [carers-week-2021-research-report\(1\).pdf](#)

Has your health been directly affected by your caring role in any of the ways listed below?



Carers have experienced a lack of respite services for those they care for, such as a lack of day care provision, short break providers and replacement care provision. This is coupled with the impact of a paid skilled care workforce shortage which is due to a mixture of issues which includes low wages (and zero-hour contracts), Brexit-related workforce changes, and holiday leave. Having time away from caring is crucial for the health and wellbeing of carers and their ability to cope and sustain the level of care they provide.



On a practical level I think provision of sitting service so that they can absent themselves from the house is very important just to get away from the situation. Without a sitting service that's very difficult because they can't go with good grace, are watching the clock. Perhaps the person with MND can be left for two hours max or something, well by the time you get where you go when you have to turn round and come back. So, I think just to keep the batteries charged with the carer I think a sitting service is vital.

Volunteer, Focus Group

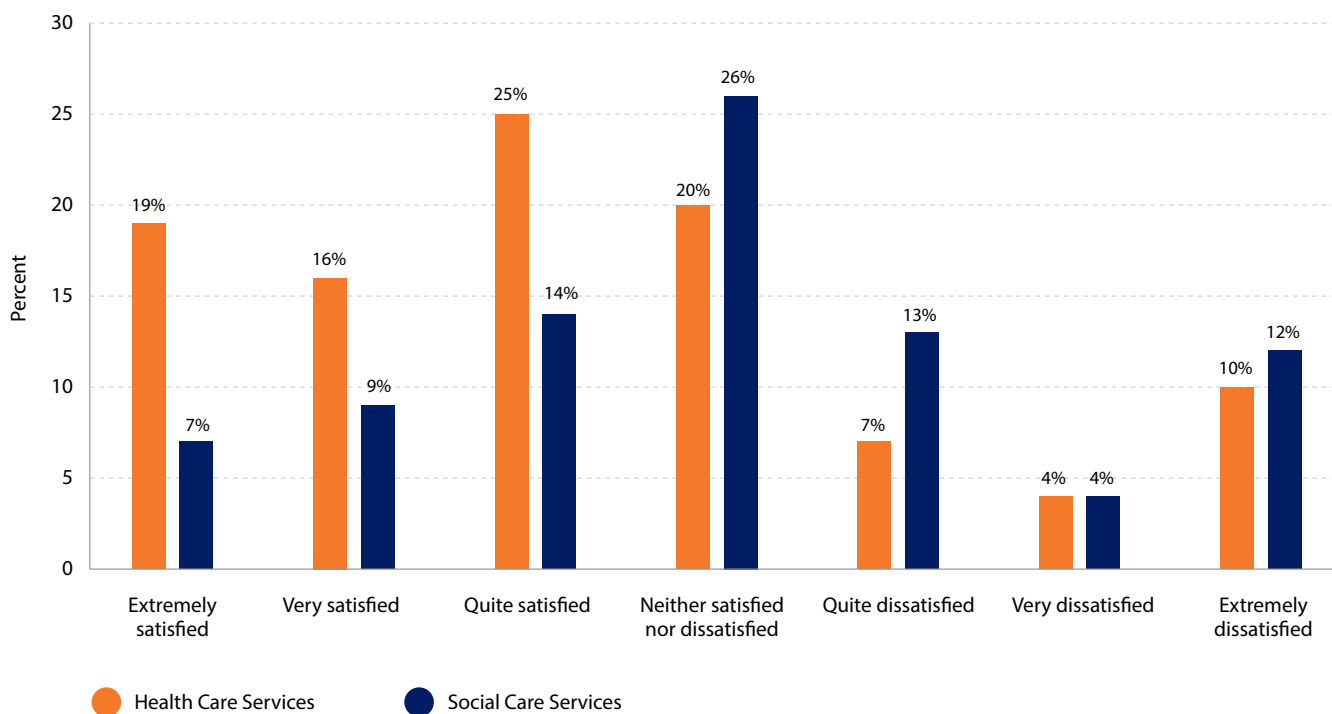


Carers also told us that in cases where a respite care service was available locally, it often did not provide access to care staff with the skills and experience required to support people with the complex care needs associated with MND. For example, people making use of equipment such as assisted ventilation or suction machines for saliva control require care staff who are trained in the use of such equipment.

The lack of access to skilled care workers who can provide the level of care needed for people living with complex MND, takes away the option of respite from some carers who are unable to leave the person they care for due to safety reasons. To enable carers to feel comfortable enough to leave the person they are caring for, carers often need to train staff themselves, over a period, to ensure they are suitably able to provide the care needed. Services that enable carers to take time off from caring can improve their quality of life and reduce the impact of their caring role, therefore training to ensure staff have the skills is essential.

Opportunities for carers to get some respite from caring were difficult to access before the Covid-19 pandemic. The pandemic placed additional stress upon carers, which increased the need for respite, at a time when access to respite was made more difficult. Carers felt more dissatisfied with social care services, than health services, during the Covid-19 pandemic. According to national carers research, 23% of carers reported that they received breaks through care services during the period, and 19% through day services, 9% from local age, disability or carers organisations and 8% from residential breaks.¹⁷ Carers, on average, lost 25 hours of support per month during the pandemic, and 65% relied on family and friends to take a break, compared with before.¹⁸

Thinking about your experiences during the Covid-19 pandemic, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from statutory health or social care services?



¹⁷ [carers-week-2021-research-report \(1\).pdf](#)

¹⁸ [carers-week-2021-research-report \(1\).pdf](#)

Recommendation and actions:

Improved access to respite for carers when they need it:

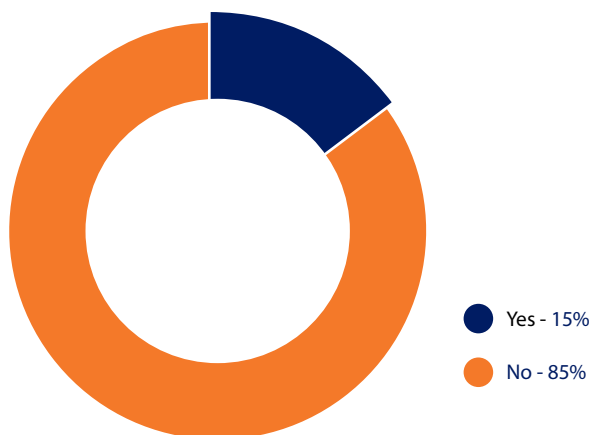
The UK government should deliver new, targeted investment to fund regular respite breaks for carers and support improved physical and mental health. The MND Association supports the calls made by Carers UK and the Carers Week Coalition for 1.5 billion of ringfenced funding to support carers' respite in England with commensurate funding for devolved nations.

Focus on carers health and wellbeing: Improved support is needed for carers to ensure they are able to manage their own health and wellbeing. A standard offer of carer wellbeing support should be made available, with built in flexibility, to ensure carers feel supported and have real choice about taking breaks to prioritise their health, whilst continuing their caring role and/or needing to manage other areas of their life. Professionals and care providers involved with supporting the needs of people living with MND need to ensure that they consider the care (and support) needs of carers alongside the individual, to ensure that both are included in care plans.

Caring in addition to parental responsibilities

A number of carers have parental caring responsibilities for children under 18 years old alongside caring for a person with MND. From the survey, 15%¹⁹ of respondents also have parental responsibility for children.

Do you have children aged 18 or under whom you have parental responsibility for?



¹⁹ Responses based on 27 out of 183

²⁰ Based on 47 responses

Carers told us that MND and caring can have a significant impact on children and young people whose needs often have to come secondary to the person living with MND. During the Covid-19 pandemic, the responsibilities of MND carers increased considerably. A number of carers reported spending more time on providing care for the person with MND alongside caring for children and juggling parental responsibilities. The feeling of being torn between responsibilities added additional pressure:



I am torn between priorities constantly with 3 children and needing to look after my husband. I am not able to leave him alone safely and so the children are impacted in what we do with them all of the time. I have no time for myself at all.

Carer, Survey



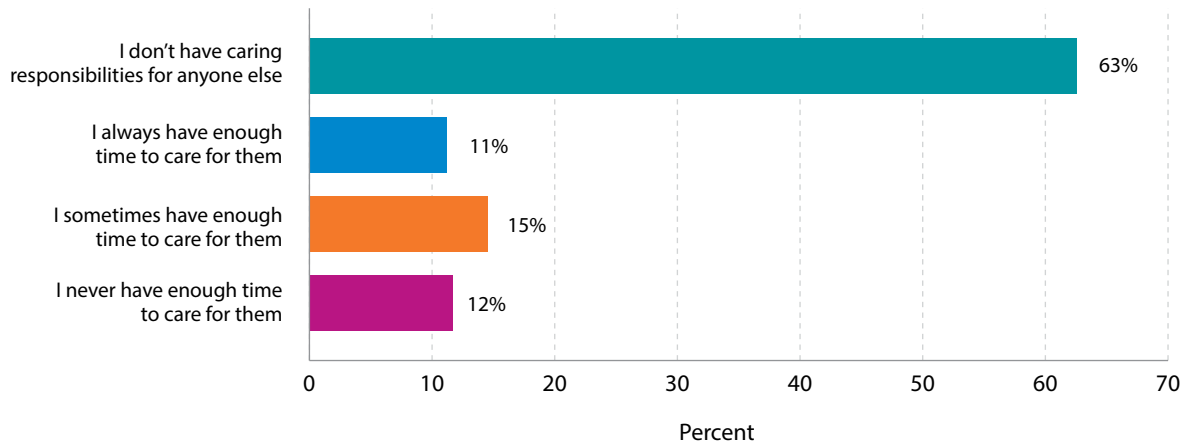
It is a constant juggling act, trying to look after my six-year-old whilst caring for my husband and working full-time. I don't feel like I do any of my roles very well as I am constantly rushing from one thing to the next.

Carer, Survey



From the carers who answered the question, over 26% of them felt that they didn't have enough time to care for their children.²⁰

Thinking about the other people you have caring responsibility for, which of the following best describes your current situation?



Figures displayed in charts are rounded to the nearest whole number and consequently may not total exactly 100%



I am torn between carrying on a normal life and doing things with the children or being at home to care for their dad. Also, trying to keep working so I can support them financially now and in the future.

Carer, Survey



Support for carers with parental responsibilities is paramount, as they report feeling conflicted between providing care and support to the person with MND and meeting the needs of their children. Many children forgo activities that enhance their quality of life because of this.



I have less time to spend with them for leisure activities. I worry more about them and the emotional effect our situation may be causing them.

Carer, Survey Participant



They don't get as much time from me as all my spare time is taken up with caring for Mum. I have a 16-year-old at college and a six-year-old. They have to fit around me and what I need to do rather than the other way around.

Carer, Survey



Guilt at my child not having a 'normal' life and everything having to evolve around her father's needs.

Carer, Survey





I have less time for my children. My workplace now frowns upon me taking time off work to go to parent review days at school as I take time off for my husband's appointments. I have less patience for my children and expect them to be more independent. I no longer have time to take them to activities such as swimming lessons after school. Homework time and listening to them read is getting harder as most time is spent cooking and cleaning and getting ready for the next day.

Carer, Survey



This feeling of conflict adds additional pressure and stress to carers who are often just about managing.



I am not spending as much time with my children as I have to fit them in around my caring responsibilities. I feel more pressured in my caring role due to my parental responsibilities.

Carer, Survey



Services need to be sufficiently flexible to respond to families in these situations and address the needs of parents appropriately. Support needs to be accessible and appropriate for carers with parental responsibilities. Consideration of what is appropriate is crucial to avoid further barriers (for example, picnics and coffee mornings may not be the most accessible options for carers struggling with their responsibilities).

Recommendation and action:

Support to balance parental and caring responsibilities:

Health and social care systems must recognise that many carers balance caring and parental responsibilities and take these additional pressures into account when planning care and support services. As a priority, carers with parental responsibilities should be offered flexible respite and support services that meet their needs. UK and devolved governments must work to improve availability, quality and access to statutory care services to alleviate the pressure on family carers.

Zoe – young carers juggling parenthood, work and providing care!

My husband was in his early 30s when he was diagnosed with MND, just after our son had turned one. He was a fit and healthy young man – we thought a sports injury was affecting his legs, so his diagnosis came like a bolt out of the blue. It's now been over five and a half years since his diagnosis. I have done varying amounts of my husband's care over that period as it is an ever-evolving situation.

In the early days following my husband's diagnosis, it was really overwhelming as I had to organise a move to more suitable accommodation whilst also getting to grips with my husband's MND and being a carer. I was working four days per week and desperately trying to hold down my job. I had a young toddler to look after, whilst also trying to manage a house move and help my husband get dressed and showered. At one point I actually bought our two-year-old son a wetsuit and we would be in the bathroom showering my husband together - can you imagine it?! The whole bathroom was soaked! After that, I'd take my son to nursery then arrive at work late and exhausted. In the evenings, once my duties as a carer and parent were completed for the day, I then had to stay up into the small hours night after night, dealing with the paperwork for our house move. I got to the point where I was falling asleep anywhere and everywhere – on the toilet, washing up, mid-sentence in a meeting with someone senior at work - I was like a walking zombie!

We did start to get professional carers in, but it is not the silver bullet that all your friends and family seem to assume it will be. It is hard enough finding professional carers with the right skills for my husband's complex needs, but we have the added challenge that it's not easy having carers in the house when you've got a really young child. Sometimes the way that they interact with our child can be upsetting or uncomfortable.

The pandemic dealt a hammer blow to my situation as a carer, making everything ten times harder. One day in February 2020 my husband went to work, where he had a carer with him all day, and I went to my own office. The next, we realised the severity of the pandemic and have never been back to our offices since. We went into complete isolation to shield my husband and, overnight, I became a full-time unpaid carer. We took our son out of school to protect his father and spent the next five months in total isolation, without once stepping beyond our garden gate.

Since then we have been through phases of greater and lesser isolation, and isolated again at the start of this year.

By the outset of the pandemic my husband was already completely paralysed, unable to speak and barely able to eat. I cannot even begin to explain how challenging it was trying to take care of my husband's needs without professional carers during the first part of the pandemic, whilst also looking after and home-schooling a young child trapped within our house for months on end. I barely slept for months on end as my husband reached the point of needing help every hour, every night just at the height of the second wave of Covid, when we were terrified to let help in. Unsurprisingly my own health has finally collapsed.

I also worry about the impact of this period on our young son's well-being. There were many days when my husband would cough, choke and yelp and scream in distress all day, needing constant help with repositioning his head and clearing his saliva secretions, while our young son looked on in confusion. There were even days when I couldn't give our son his meals on time because my husband choked and choked for hours on secretions. There were nights when I would be trying to settle our son for sleep with my husband in noisy distress in the background, in our small home.

People often forget that those who have had to shield during the pandemic can have young children. There is this constant assumption that the person you care for is your parent, not your husband. Support services for both my husband and myself as a carer all seem to be set up based on this assumption. People constantly tell me to "look after myself", but when you are trying to juggle being an unpaid carer for your husband, a mother to your young child and working life or home-schooling on top of that, this has proved to be impossible.

Carers' experiences of care and support

Providing care and support for someone with MND can be physically and emotionally exhausting and a lonely experience. From the survey over half (52%) of carers of people with MND provided over 75 hours of care per week. The support and care that carers receive can make a difference to whether they feel able to cope and continue in their caring role.

Only 29% of carers feel that they have enough support in their caring role,²¹ while a large majority feel ignored and unsupported by social care and statutory services. Many carers told us of how difficult they found it to access appropriately skilled care locally for the person they care for, leaving them with little or no support in their caring role.



I mostly feel lost and ignored!

Carer, Survey

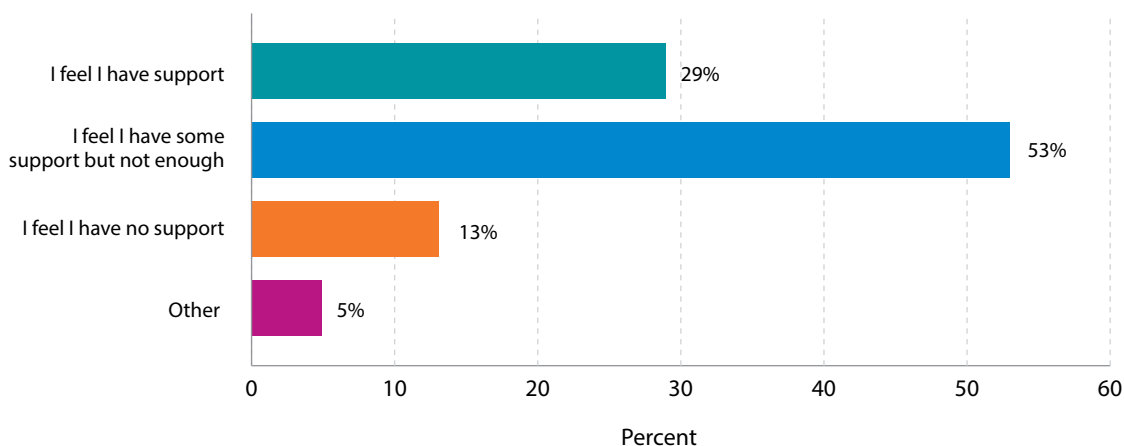


There are no services available. Any respite is non-existent. I had a carers assessment in which I apparently scored highest in every area and was then told I could have £150 to spend on myself. What use is that?

Carer, Survey



Thinking about support in your caring role, which of the following statements best describes your current situation?



21 Based on 53 responses

Carers need more flexible support from social care and statutory services to enable them to manage and cope, especially during times of crisis:



What I could do with now is a responsive and reliable social care support system. Social care took 12 weeks to be put in place, we were assessed as requiring four x 30 minute visits each day but I said that I would do the morning and evening, getting up and putting to bed, which leaves a mid-morning and mid-afternoon call. The initial thinking was so that I could go back to work (working from home) and my husband would get a drink or toilet break during each half day. When I broke my leg in August I asked to reinstate all four visits but was denied these. What I need is a social care system which is as responsive as Health services and could have dealt with a short-term issue like me breaking my leg. I also would like continuity of care with regular carers rather than different carers every week. This would mean that we could build up a relationship with them and begin to trust them. If we could trust them we would welcome their help with the intimate aspects of caring like showering and dressing. My husband is a private man and doesn't want the indignity of being naked in front of numerous strangers. I agree with him, but this places more pressure on me which means that I can't return to work.

Carer, Focus Group



Social care is lacking, I haven't seen a social worker and they are not responsive at all. Everything is too much effort for them. I really feel sorry for people who are on their own.

Carer, Focus Group



The availability of statutory care and support for people living with MND is critical, so that carers are supported in their role, don't feel ignored and can sustain the level of support that they provide. Access to appropriately skilled, high-quality care is crucial for people living with MND, a complex and progressive condition which brings about significant physical changes. This is threatened by chronic workforce shortages in both the NHS and social care systems, with an estimated 99,460 vacant posts in the NHS and 105,000 in social care as of September 2021. Despite these shortfalls, the Government's awaited health and care workforce plan, promised in Spring 2022, has not yet materialised. The Government must publish its plans to address workforce shortages and act decisively to deliver the appropriate funding needed to properly resource health and social care services.

Recommendation: The Government must urgently bring forward its promised workforce plan to address the serious workforce shortages that undermine access to appropriately skilled health and care support. The plan must deliver concrete steps to support the recruitment and retention of skilled social care staff, underpinned by sustained and significant investment over the short and long term, to ensure that those living with complex care needs can access essential care and support and alleviate the pressure on unpaid carers.

Co-ordinating care and support

People living with MND often have complex care needs which require care and support from a range of different agencies, organisations and a variety of health and social care professionals. Co-ordinating this effectively requires the carer to know how to navigate the care and support services 'system', which is time consuming and frustrating for carers:



We are at the end of our tether through tiredness, frustration, fear for the future, where to go to get the practical aids needed. Finding the way round the loops of NHS, social services and Government is difficult enough if one is internet savvy and reasonably intelligent, but not everyone is blessed with this and such folk must need more hands on help.

Carer, Focus Group



Many carers reported fulfilling the role of co-ordinating care and advocating support for the person they care for, whilst navigating relationships with healthcare professionals:



One aspect that I find difficult to cope with is the number of people involved in support and how to remember who is responsible in each team and their contact details.

Carer, Focus Group



It is clear to me that a diagnosis of MND affects patients very differently, this makes caring quite difficult as one person's symptoms and the care needed to support them is quite different from others. When reading posts on the MND forum this becomes very obvious. From a personal experience I find this true of some of the medical professionals who seem to have expectations of the progression of the disease and when I explain that these things aren't occurring don't really know how respond. An example; I am continually asked about my wife's speech and her eating/swallowing issues, there are none, she is articulate but quietly spoken and eats normally.

Carer, Focus Group



Carers highlighted the need for professionals to work in an integrated, co-ordinated way (crucial for follow-up and continuity of care) and emphasised the lack of it in the reality of their experiences:



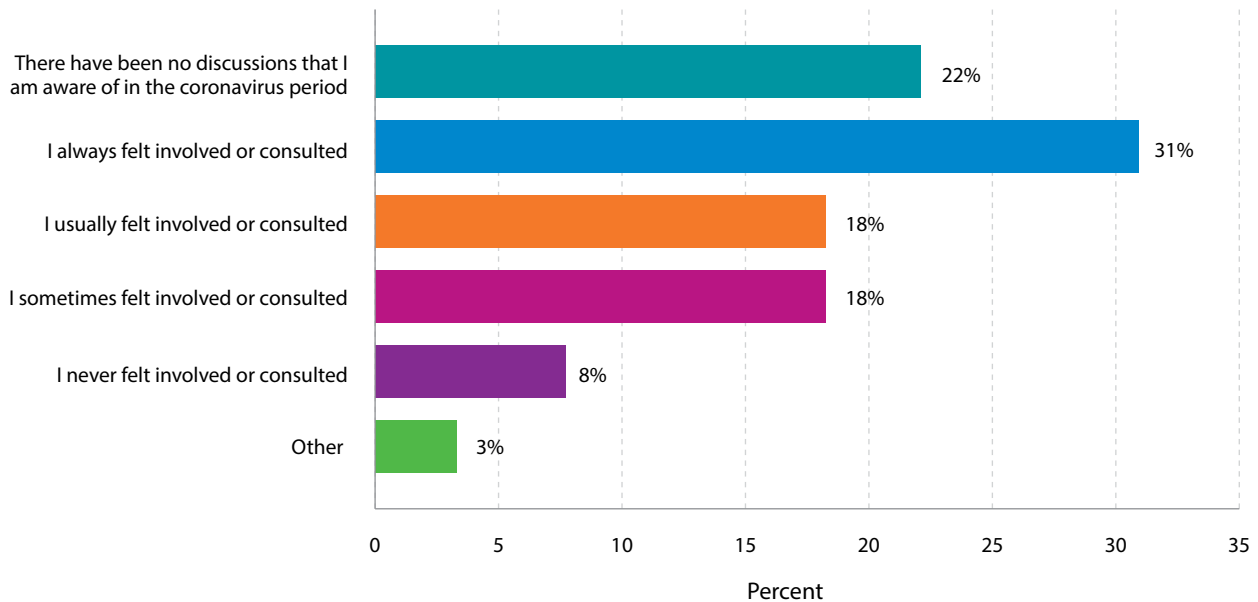
I think the help is available but it isn't always co-ordinated. No-one is in overall control of what is needed and when. For example, an electric armchair was ordered for my husband because he can't use his arms to lever himself into the standing position, by the time it came, he can barely operate the buttons on the remote because he lost so much finger strength in the meantime. It arrived, but there has been no follow up for weeks to see if it is helping him.

Carer, Focus Group



There is a need for more specialist practitioners with the right skills and training to respond efficiently and effectively, to ensure that care is integrated and co-ordinated to support the needs of the individual. Flexibility needs to be built into the system to ensure that care can be provided as and when needed, rather than it having to be prescribed at a time to suit the care agency or professional. Many carers did have positive experiences of services provided by their local hospice or the NHS MND multidisciplinary team, with support at specific stages as the disease progressed. However, only 31% of carers felt fully involved or consulted as much as they wanted in discussions about the support or services provided to the person they care for.²²

Have you ever been involved or consulted as much as you wanted to be in discussions about the support or services provided to the person you care for?



Forward planning and delivery of good care for people with MND (involving carers in the planning and decisions) is imperative. Being consulted and involved in support decisions makes carers feel listened to and helps them to continue to provide comfort and care to the person they are caring for whilst managing the progression of the condition. Making plans for adjustments in the future, with a multidisciplinary care approach, is crucial. This includes difficult discussions around decisions for future care, including end of life decisions. Planning ahead with MND can be emotionally challenging for carers. Conversations with the multidisciplinary care team can be difficult, but they are important as they ensure that the right plans are put into place to address future progression of the disease.

Recommendations and actions:

Co-ordination and information sharing: Carers should not have to be relied upon to navigate services and advocate support for the person they care for. Commissioners and providers in the health and care system must ensure that professionals work in an integrated, co-ordinated way to ensure effective continuity of care. The introduction of the Health and Care Act, bringing the implementation of shared care records across local health and care systems, has the potential to support better co-ordination of care. Local health and care systems should prioritise improved information sharing and co-ordination across health and care services and settings, so that carers only have to give their details once when moving

between care and health settings, and the information can be safely seen by everyone providing care.

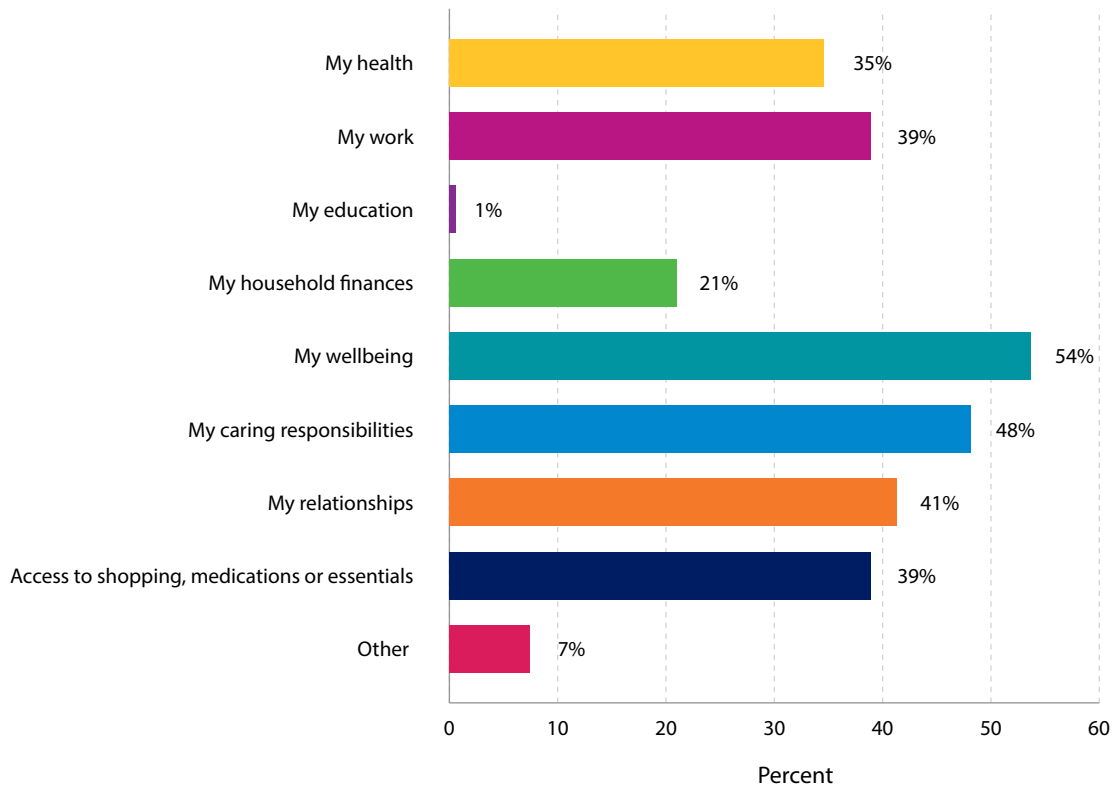
Investment in co-ordinated multidisciplinary care:

Continuity and flexibility of care is crucial to meet the complex needs of people living with MND and to support carers to sustain the level of care that they provide. Change is needed at a strategic level to provide the appropriate funding to properly resource health and social care services. The social care workforce and wider social care agenda of reform needs to be responsive to the needs of carers, and recognise the enormous contribution they make to the health and wellbeing of those they care for.

Involvement in care planning and decision-making:

Carers must be given the opportunity to be fully involved in discussions with multidisciplinary care and support teams when decisions are made regarding the support and services provided to the people they care for.

Which areas of your life have been affected by the Coronavirus (Covid-19) pandemic?



Impact of Covid-19 on care and support

It is clear from the findings of our engagement that carers' lives have been affected by the pandemic. Survey responses illustrate that 53%²³ of carers' wellbeing and 35%²⁴ of carers' health needs have been affected. Without the opportunity to have a break and attend GP appointments, carers' health and wellbeing is being put at great risk.

The Coronavirus pandemic has impacted heavily on the provision of care and support (both for the carer and the person with MND) which has created problems and delays. This has impacted on many carers' abilities to cope. Many have been impacted by a delayed diagnosis of MND:

“The main impact the pandemic had was that my wife's MND was not diagnosed for over eight months due to all the GP referrals being continually cancelled or not available. This led to my wife's immediate hospitalisation for seven days after MND diagnosis due to her extremely low blood gas level! After MND was diagnosed we had difficulty accessing the GP services but following a telephone consultation I suggested that the surgery added a priority notice to my wife's file, which they did and since then the GP and the staff have been extremely responsive to our needs.

Carer, Survey Participant

²³ Based on 87 responses

²⁴ Based on 56 responses



My wife's diagnosis was delayed by the lockdown measures, in particular, I was unable to visit the GP Surgery and explain how her voice was worsening (because of her once perfect BBC voice, to a stranger she still sounded fine). Being unable to socialise and the stress of the lockdown may have triggered the MND as my wife was also diagnosed with PTSD five years ago. We are both still shielding and she only finds small groups of four or less workable with her voice.

Carer, Survey Participant



My husband started with MND symptoms Jan 2020. He was misdiagnosed as having migraine by a telephone consult with neurologist in September 2020. He then had EMS studies. We paid to see a consultant in April 2021 to get results of studies when MND was diagnosed. He was seen November 2021 for his first NHS consultant appointment. Without the pandemic we feel the diagnosis would have come a year earlier and he would not have been misdiagnosed by telephone.

Carer, Survey



The Covid-19 pandemic has been very challenging for everyone. As you can imagine with being in lockdown it was very difficult to get appointments. Everywhere he was sent he was supposed to attend on his own. By this stage he was in a wheelchair because of his breathing he couldn't walk very far. During lockdown my husband had to attend several hospital appointments: chest x-ray; CT scan; ENT; and the chest specialist. He was admitted to hospital for four days and sent home. They said: "there's nothing wrong with him" and that he was having a reaction from his steroids being reduced as he had been on a very high dose. Eventually in September 2020 the neurologists agreed to having my husband in hospital for IVIg (Intravenous immunoglobulin) treatment for the CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) he was diagnosed with. As we were in lockdown we weren't allowed to visit to see how he was or what was going on. They started the course of IVIG treatment and he suffered respiratory failure being sent home after ten days on a ventilator. We were then sent to the respiratory clinic hospital in Leicester to see if they know what was wrong with him but they couldn't find any problems relating to his lungs or his heart to cause his breathing issues. So he was taken back in hospital again in January 2021 for IVIG treatment and we went to see his neurologist in February 2021 to have the nerve conduction test done again. It was at this stage when they sent us to Oxford for a second opinion that we were told that my husband had got MND. It has been very challenging dealing with everything that's been going on.

Carer, Survey Participant



The social distancing measures that were introduced to manage the pandemic resulted in many support services being paused. Some carers and people living with MND were also concerned about having support services enter their homes if services were continuing or re-instated due to potential infection risk. The measures also impacted on, and reduced, the amount of help available from family and friends, which cut carers off from their usual networks of support. The withdrawal and lack of support services put additional pressure onto the carer:



The main impact has been the withdrawal of any support be that formal or informal. Professionals have been reluctant to visit and when they do are swathed in PPE. Family want to protect us and it is difficult to balance between risk of the virus and the welcome support of family and friends.

Carer, Focus Group



Lockdown and the worry of the virus has certainly impacted on us. The desire to go out but the worry of what could happen if we do. The inability of being able to relax and enjoy freedom again. The new fear of another virus and the worry of trying to arrange home visits for boosters and the GP surgery seemingly unable to help not just with the vaccinations but anything else.

Carer, Focus Group



The knock-on effect of Covid-19 restrictions has been an increase in loneliness and isolation which has been compounded by feelings of fear and worry:



The pandemic has made a difficult, lonely and frightening time, even more difficult, lonely and frightening.

Carer, Focus Group



No support, left feeling abandoned and very stressed.

Carer, Focus Group



Many carers (65%) had to shield during the coronavirus period to protect the person they were caring for.²⁵ National carers research showed that 21% of carers chose not to take any breaks because they were worried about catching Covid-19.²⁶ Carers reduced services and domiciliary care workers coming into the house due to the fear and risk of infection.²⁷ At the same time, the number of people providing care to a friend or family member increased, with an estimated 4.5 million people becoming carers during the pandemic.²⁸

²⁵ Based on 177 carers

²⁶ [carers-week-2021-research-report\(1\).pdf](#)

²⁷ [carers-week-2021-research-report\(1\).pdf](#)

²⁸ <https://www.local.gov.uk/parliament/briefings-and-responses/support-unpaid-carers-and-carers-week-2021-house-commons-22-july>

During the Coronavirus period, since March 2020, have you had to shield to protect the person you care for?



When carers were asked what areas of their life have been affected by the Coronavirus pandemic, the social limitation and its impact on their health and wellbeing was evident:



I have felt totally isolated. Everyone tells me I am not alone anymore, that there are people ready to help but I have not had help at all.

Carer, Survey



Covid has been a real downer for us. In the early days in lockdown it made everyday life very difficult - as it did for everyone - but with her diagnosis that really compounded the uncertainty and fear around MND. Lack of face-to-face contact with family and friends had a profound effect although we did manage to maintain a degree of cheerfulness. [...] Basically Covid doubled (or more) the harsh effects of the MND diagnosis.

Carer, Survey



It is likely that the impact of Covid-19 will be felt by carers of people living with MND for some time as they deal with the consequences of delayed diagnosis and a lack of support. Without the support of unpaid carers the response to the Covid-19 pandemic could have been very different, with health and care services becoming quickly overwhelmed. Many people were turned into full time unpaid carers overnight due to the pandemic, having to pause or give up work to provide care. Many carers have been unable to return to work, even as restrictions have started to lift, as services and support aren't available to enable this. Carers have felt unable to accept support, even if it could be provided, due to the additional risk of infection. Carers have been pushed to breaking point and have struggled to cope with the levels of care they have provided, without access to breaks and their usual support.



Increased feeling of isolation and more defensive towards outside world during shielding. Lack of physical support has not helped. Loss of social interaction has also had a psychological impact.

Carer, Survey Participant





The stress and challenges of Covid-19 have had a negative impact on unpaid carers and people living with MND, lasting long beyond the restrictions easing. Governments need to ensure continued access to support for carers (and those who are cared for) with clear communication. Carers' experiences, and lessons learnt, need to be incorporated into Covid-related policy as restrictions ease. It is essential that governments engage with carers and the people they care for to understand how they have been impacted by the pandemic, and what support they require going forward.

The Carers Week Coalition has called for a Respite and Recovery Plan for carers, recognising the enormous burden placed on them during the Covid-19 pandemic. This would help to ensure that governments understand the myriad of impacts that the pandemic has had upon carers, including its impacts on physical and mental health and wellbeing, the effects of reduced contact with sources of help and support, and its impacts on household finances. The MND Association fully supports this proposal, which should be taken forward as soon as possible.

Recommendation and action:

We support the call for the UK and devolved governments to bring forward a Respite and Recovery Plan for carers to understand and address the additional impacts on carers arising from the Covid-19 pandemic. In addition, the UK Covid-19 public inquiry must ensure that it considers the pandemic's impact on carers within its scope, and brings forward recommendations to ensure they are fully supported going forward.

Carers Assessments

The Care Act 2014 in England gives anyone aged 18 years and over - who is looking after another adult who is disabled, ill or elderly - the right to a carer's assessment.²⁹ In Northern Ireland, the Carers and Direct Payments Act (Northern Ireland) 2002 gives carers the right to an assessment. In Wales, the right to a carers assessment is provided through the Social Services & Well-being (Wales) Act 2014. In Scotland, it is provided through the The Carers (Scotland) Act 2016.

These assessments cover topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with others. They are the responsibility of local authorities in England, Wales and Scotland, and of Health and

Social Care Trusts in Northern Ireland. The experiences of carers in Wales, Scotland and Northern Ireland are available in each of the nation results of State of Caring 2021.³⁰

Only 25% of carers of people with MND had either received a carer's assessment or were in the process of having one.³¹ 40% were unaware of their right to one.³² It was also felt that there is a lack of understanding of MND amongst assessors and the full impact of providing care on the carer. Recent research conducted by the Carers Trust highlighted concern about carers' needs assessments, as local authorities have been very stretched in the pandemic. The report indicates that a high number (around 70%) of carers have not had assessments/ support plans or re-assessments/reviews of their needs.³³ The report found that although being assessed as needing support,

29 [Care Act 2014 \(legislation.gov.uk\)](https://legislation.gov.uk)

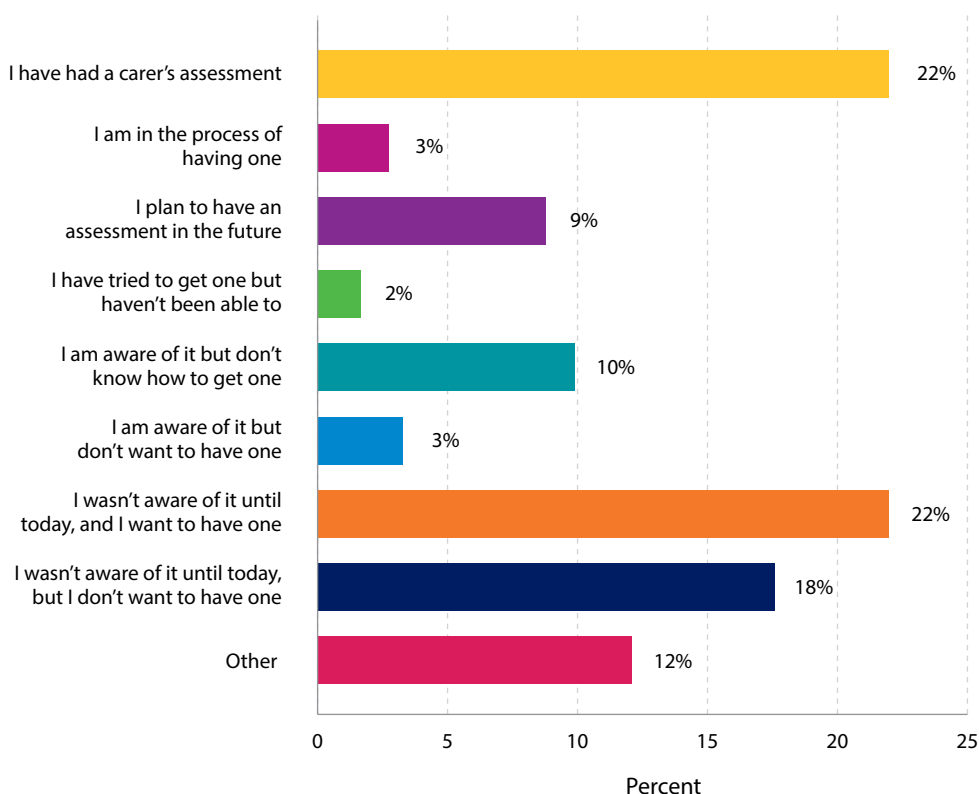
30 [cukstateofcaring2021reportdigital\(2\).pdf](https://www.carers.org/state-of-caring-2021-report-digital-2.pdf)

31 Based on 45 responses

32 Based on 78 responses

33 [pushed-to-the-edge.pdf \(carers.org\)](https://www.carers.org/pushed-to-the-edge.pdf)

A carer's assessment is an assessment of your needs as a carer. It is provided by your council (or in Northern Ireland by your health and social care trust). All carers are entitled to a carer's assessment. Which of these statements best describes your current situation?



approximately 77% of carers were not receiving a personal budget to pay for support to meet their assessed eligible needs.

The carers who had received an assessment had a range of experiences, with many left feeling disappointed and it being a pointless exercise with no support offered:



Poor support from social services. Although the carers assessment was done it was very soon obvious any help would have to be paid for. As always, to be ill you need to be poor or very rich. Pace of reaction is also painfully slow and no continuity.

Carer, Focus Group



Useless just about sums it up.

Carer, Survey



The support that was offered has not yet been fully arranged nor funded and I find I am fighting a constant running battle with the council to get support that we are entitled to. Further, the support that we are entitled to has not been clearly articulated by the council.

Carer, Survey



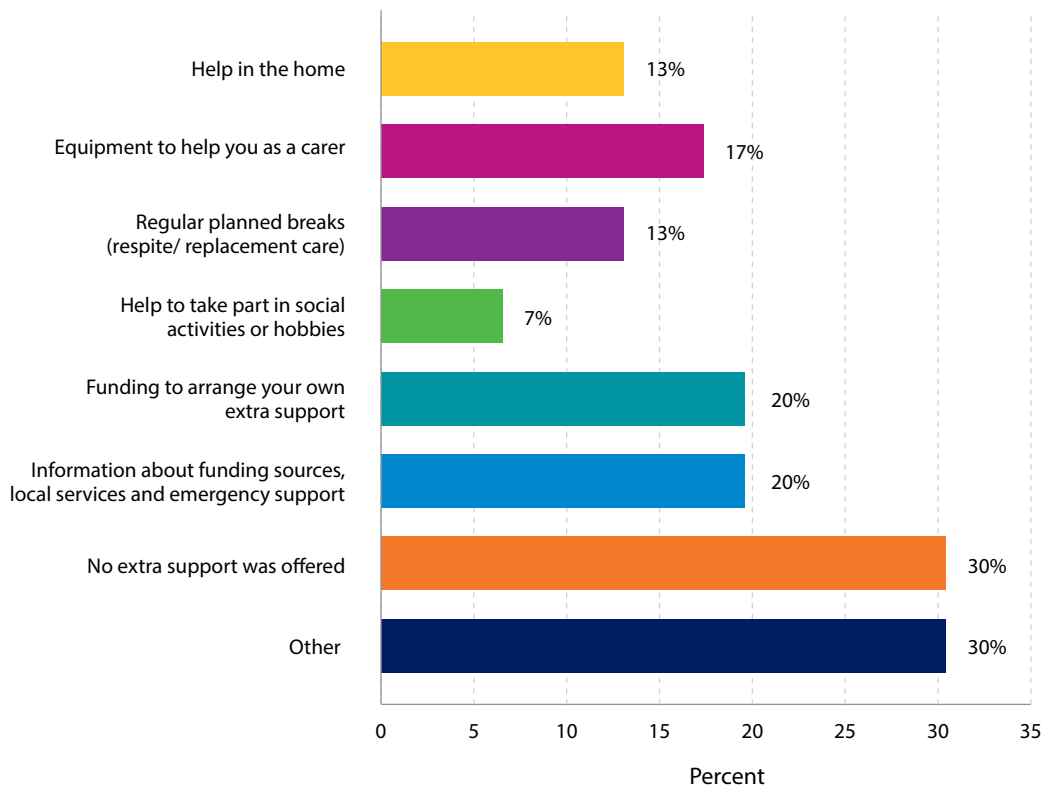
I asked for a carers assessment and I just got the feeling that because we were self-funding it was just down to us to look after ourselves. They gave us a list of care providers, out of the six that could provide to our area, not one of the agents could actually provide anybody. So, we had to go and look round for somebody who wasn't on the council's list. The carers assessment I was not very happy with, I got a spa voucher to get a manicure or something and of course it's a bit ironic they give you some money to spend on a spa treatment but you can't get there because they won't provide anyone to come, again it goes back to it you get everything except practical help.

Carer, Survey



From those carers in the survey who had received a carers assessment, 30% reported that they had not received any extra support as a result of the assessment.³⁴

Thinking about the carers assessment that you had, what extra support were you offered as a result?



The purpose of a carers assessment is to identify the needs of carers and provide the appropriate support to ensure they are able to provide care and feel supported within their role. The assessment should be an opportunity to discuss how caring affects their: mental and physical health; relationships with others; education and work life; and opportunity for social interactions and leisure. Carers identified frustration with the assessors for not only misunderstanding the complexities of caring for someone with MND, but also for missing the bigger picture of need (through offering inappropriate outputs for respite). This was illustrated through offering vouchers for the carer to spend, without adequate respite cover to enable the carer to use them.



£120 a year token payment, pointless exercise.

Carer, Survey



There is a need for better integration and communication across health and social care to ensure that carers assessments take place. Upon diagnosis of MND, multidisciplinary teams should identify if a carers assessment is required and refer to the local authority to highlight the need for a carer's assessment. Carers should not be expected to have to identify and trigger an assessment themselves.

Recommendations and actions:

Review of carers assessments: The Government should conduct an urgent review of carers assessments, with a particular focus on improving awareness, availability and access. It is not acceptable that high numbers of carers have not received a carers assessment, leaving them without access to vital support. The review should work with local authorities to identify and address the barriers that continue to prevent a high proportion of carers from accessing the support they need and are entitled to.

Prioritise identification and assessment of carers: Local authorities, and Health and Social Care Trusts in Northern Ireland, should prioritise ensuring that carers in their local area

are aware of their rights to receive a carers assessment, and all carers receive an assessment to address their support needs. They should work with the NHS to improve early identification of carers and ensure they are made aware of their right to have a carers assessment. They should consider putting in place a formal fast-track process for the delivery of carers assessments for those who are caring for people with severe, progressive conditions such as MND.

Juggling work and caring

Having to balance caring responsibilities with work, looking after children and other domestic duties can take its toll on the quality of carers' lives. Many carers are juggling their caring responsibilities alongside working (either part-time or

In addition to your caring role, please tell us which of the following also applies to you?



● Doing voluntary work	4%
● Employed full-time	18%
● Employed part-time (working 30 hours or less)	10%
● In education or training	1%
● Not in paid work	14%
● Retired	36%
● Self-employed full-time	4%
● Self-employed part-time	4%
● Other	9%

full-time) and with the restrictions imposed by the Covid-19 pandemic many carers found themselves working from home, whilst continuing to provide care. Working carers represent a significant proportion of the working population and at the height of the pandemic, Carers UK estimate that over a quarter (26%) of all workers were juggling work and care.³⁵ From the carers in the MND carers survey, 36% of them identified themselves as managing work (full- or part-time) in addition to providing care.³⁶

Carers who chose the 'other' option included carers on sick leave, a sabbatical or had chosen to work fewer hours due to their caring role(s).



I am burnt out from being the primary carer during the pandemic. I was furloughed due to caring responsibilities during the pandemic but have not been able to go back as I'm too exhausted.

Carer, Survey



Self-employed but choosing to work fewer hours due to caring responsibilities.

Carer, Survey



Until 18 months ago my caring support was compatible with Jane's needs but it suddenly became obvious that my part-time retirement jobs were incompatible.

Carer, Survey

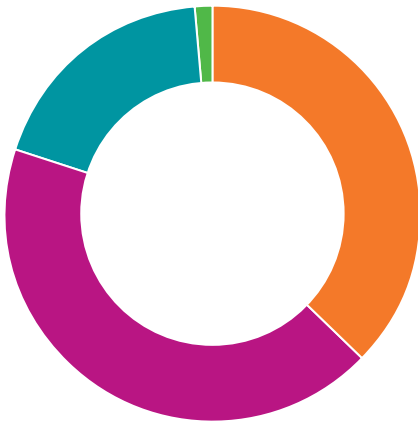
³⁵ Carers week 2020 Research Report

³⁶ Based on 67 responses



When carers were asked to describe their work and caring responsibilities, 17% highlighted that they are not in work because their caring role prevented it.³⁷ Previous research published by the Carers Trust highlights how employers should be doing more by: offering flexible working so that more unpaid carers can combine work and care; and paid carers leave to

Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation?



- I am in paid work - 35%
- I am not in paid work as I am retired - 40%
- I am not in paid work because of caring responsibilities - 17%
- I am not in paid work for other reasons - 1%

support particular times of need.³⁸

As illustrated by carers in the survey, the caring role can have a profound impact on people's ability to work. As carers do not often receive the sufficient financial support needed to manage, this has an impact on their finances. Offering greater flexibility and choice to carers is important to enable them to remain in and return to work as and when the time is right for them. In 2017, the government in England proposed, as part of addressing the social care need, to enable carers to take up to 52 weeks off (unpaid) to enable them to return to work.³⁹ More opportunities to enable carers to return to work, when it is appropriate, need to be made available to ensure that carers are not penalised for fulfilling their caring role.

Recommendation and action:

Improve employer support for carers: The Government should legislate to guarantee a right to carers leave in the workplace. A standard offer of a minimum five days of paid carers leave should be available, with built-in flexibility to ensure carers feel supported in the workplace and have real choice and options to work whilst continuing their caring role.

³⁷ Based on 31 responses

³⁸ [Carers survey - A few hours to call my own.pdf](#)

³⁹ [The Independent \(2017\)](#)

Financial impact of caring

Recent research has demonstrated the extent to which **many unpaid carers are being put into financial hardship because of their caring role.**⁴⁰ A lack of adequate financial support for carers from successive governments is a key driving force contributing to this. Nearly 50% of unpaid carers who responded to the survey felt that caring had caused them financial difficulty. People living with MND, and their families, particularly face a significant financial burden due to extra costs that arise through living with the condition.⁴¹

Many carers report that they are facing emotional and practical challenges. These challenges are compounded by a lack of support which impacts on their wellbeing, relationships, and prevents them being able to provide the care they want to. The financial hardship that some carers experience can exacerbate the challenges they face.

becomes more difficult to manage as the condition progresses, and the care, support and equipment needs increase.⁴² The financial impact of caring is also now being exacerbated by the recent increases to the costs of living, driven by increasing energy and food costs.⁴³ The financial impact of caring has never been so high.

When carers were asked whether they were easily able to access the welfare benefits available to carers, 27% didn't know what benefits they are entitled to,⁴⁴ and 38% said that they weren't easy to access.⁴⁵

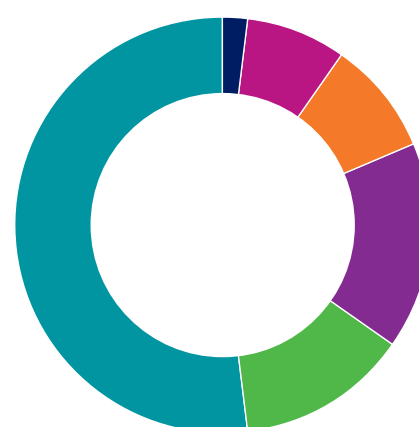
Has caring caused you any financial difficulties?



- No, not at all - 50%
- Yes, to some extent - 38%
- Yes, a lot - 11%

A report on the financial impact of MND found that it particularly impacted those of working age and with children living at home, who appeared to be particularly vulnerable to negative financial consequences. The financial effect of MND

I am easily able to access the welfare benefits available for carers



- Yes, I strongly agree - 2%
- Yes, I agree - 8%
- Neither - 9%
- No, I disagree - 16%
- No, I strongly disagree - 13%
- I don't receive benefits - 52%

⁴⁰ [Carers Trust social care survey findings, 2022](#)

⁴¹ [DEM15449_Financial_impact_report_090617_WEB.indd\(mndassociation.org\)](#)

⁴² [DEM15449_Financial_impact_report_090617_WEB.indd\(mndassociation.org\)](#)

⁴³ [Carers UK research briefing - Under Pressure - Caring and the cost of living crisis.pdf\(carersuk.org\)](#)

⁴⁴ Based on 49 responses

⁴⁵ Based on 61 responses

Carers are keen for the MND Association to continue to push the government for changes to benefits to support carers:



The range of support from the MND Association, in my opinion, is excellent and the only area that I believe could be further improved is to continue pushing for Carer's Allowance for retired people, because are we going to stop our caring, I don't think so!

Carer, Focus Group

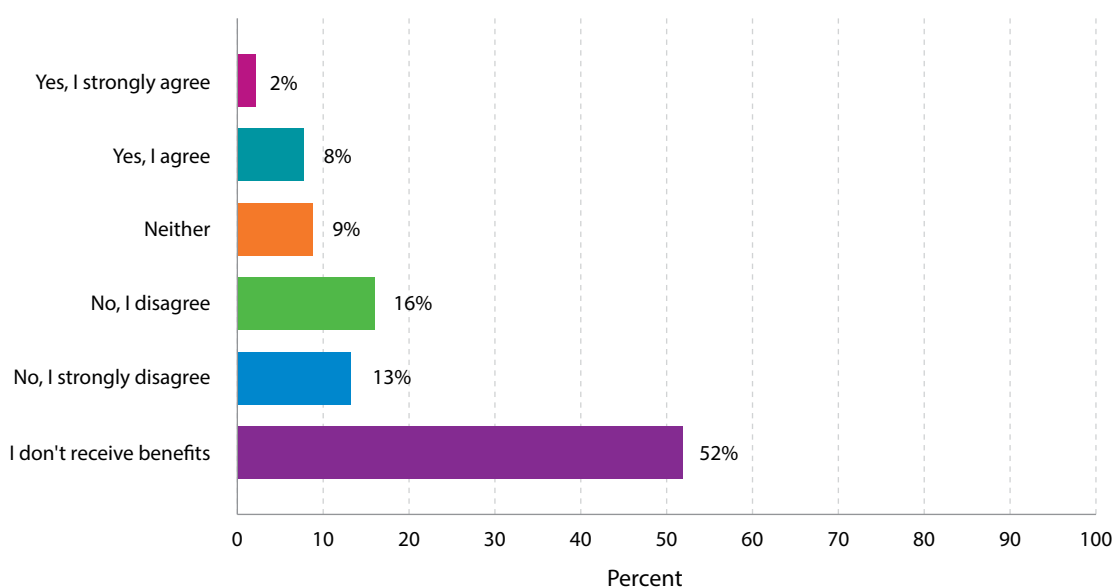


When carers were asked about their receipt of benefits 52% of them stated that they didn't receive any benefits at all.⁴⁶ Providing awareness of entitlement to benefits is important in improving uptake to alleviate some of the financial difficulties. Carers who receive the state pension highlighted the barrier that the pension creates in preventing them from claiming Carer's Allowance.

In 2019, there were 1.3 million people claiming Carer's Allowance in the UK.⁴⁷ Due to the strict eligibility criteria, many more carers are unable to claim it and are experiencing financial difficulty. Carers save the **UK economy £132 billion per year, an average of £19,336 per carer** (in care costs).⁴⁸ Based on the carers surveyed in this report, 43% of MND carers are providing over 100 hours of care; if this care was charged at £9.50 per hour (in line with national minimum wage), it would cost the government £950 per week. The financial contribution by the Government does not reflect either the support needed, or account for the invaluable contribution and saving carers make to the system. A number of carers also told us that they found the term "allowance" infantilising and insulting, particularly given that the value of Carer's Allowance payments are dwarfed by the value of the care they provide.

Significant reform to Carer's Allowance is needed, both in terms of eligibility and benefit rate, to ensure carers are not in financial hardship but are supported to continue to provide valuable care especially as the UK's current cost of living is in crisis (with energy bills rising to over 50% and food prices increasing). After a challenging two years caring through Covid-19 this is adding to carers stress and strain. Without additional support from UK Government, many carers will be unable to cope. Carer's Allowance, Universal Credit and other benefits need to rise in line with current inflation predictions.

The welfare benefits I receive meet my needs as a carer



⁴⁶ Based on 94 responses

⁴⁷ [DWP benefits statistics: February 2022 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/statistics/dwp-benefits-statistics-february-2022)

⁴⁸ [Facts and figures - Carers UK](https://www.carersuk.org/facts-figures)

Recommendation and action:

UK governments should ensure carers are protected from financial hardship and poverty. Carers shouldn't be financially worse off because of caring. UK governments should immediately uplift the rate of Carer's Allowance by £20 per week, and ensure that it continues to rise in line with inflation. A full review of the financial support available to carers should be undertaken in light of the impact of the Covid pandemic and the cost-of-living crisis. The financial support available to carers should better reflect the enormous value they provide to society as a whole.



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