MS Society

Reduced to breaking point

The impact of the cost of living crisis on people with MS

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About MS

MS is a neurological condition that affects more than 130,000 people in the UK. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how people walk, move, see, think and feel.

About the MS Society

We're the MS Society. We're here by your side through the highs, lows and everything in between. Together we fund world-leading research. We provide information and services so that everyone can live well with MS. We make our voices heard and campaign for everyone's rights. And we support one another so no one has to feel alone. Together we're a community and together we'll stop MS.

Advice and support during the cost of living crisis

We know the cost of living is a real concern for many people with MS. We've got information on our website about claiming disability benefits and other financial support you could get. Our Helpline advisers are also here for you with free and confidential advice. Find out how to contact them.

Contents

Executive summary

Imagine having to choose between heating your home and travelling to medical appointments, or between buying decent food and seeing a physio to help you walk. With the cost of living getting much higher, these kind of impossible choices are becoming more common for many people with MS.

MS often leaves people unable to work, forcing them to rely on very small welfare payments as their only source of income. Government policy decisions mean that these costs are often much larger than the benefits designed to help with them.

Even before the current crisis, the support people with MS get to help them financially has got worse over time. This has been caused by inaction from the Government, and even sometimes because of policies that punish people with MS.

Policies like the benefit freeze caused inflation to overtake the incomes of disabled people many years ago.

In the first section of this report, we present the main findings of our new research. This looks at how the cost of living crisis, and struggling financially is affecting people with MS. The results paint a profoundly alarming picture. Among many concerning findings, we discovered that:

- Over a quarter of people with MS don't have enough money for food, with 1 in 20 telling us they've had to use a food bank in the past year.
- Almost two-in-five people with MS who claim means-tested benefits surveyed can't afford to keep their homes warm. And around a third of this group can't afford the medication or treatments they need.
- Almost a third of people with MS surveyed sometimes or often can't afford to eat balanced meals.
- Around 3 in 10 people with MS surveyed have had to reduce their spending by reducing or stopping therapies or treatments.

These results are clear. The social safety net in the UK is failing to give people a basic quality of life where they are unable to support themselves. When people cannot afford to manage their MS, their condition can get worse very quickly.

Throughout the report you can find short case study examples of people with MS affected by the issues we are discussing. Just a few of the faces behind the numbers. The stories of people, like Becky and Dave, show how different impacts are often connected. If you are unable to afford treatments, your MS can get worse which in turns makes it more difficult to work or live an independent life. This can make your financial situation even worse and have serious consequences for your mental health.

Throughout 2022, the cost of living crisis has continued to deepen. An initial package of support announced in May has provided some relief to people with MS. And we welcome the recent action taken by the Government to limit energy price increases.

However Government action so far has only limited some of the ways the situation has been getting worse. It has not addressed the fundamental crisis of inadequate social security for disabled people, including those with MS.

We believe further financial support is urgently needed to support people through the winter, ahead of more fundamental changes to the benefits system. (See the summary of recommendations below for details).

The second section of the report sets out the extra costs people with MS can face, giving the first ever estimates of how common different kinds of costs are. It shows that such costs have more of an impact on those living on lower incomes – a result of government decisions over previous years, as set out above.

The last part of the report examines the policy context that's created this situation and sets out recommendations for improvement. We consider four main policy problems:

- That financial support is simply too low.
- That specific benefit policies have created further problems.
- That financial support is too difficult to access.
- That wider state services like social care often shift costs onto people with MS.

Taken together our recommendations in each area chart a path towards a society where basic dignity and quality of life is assured for all. A very different picture to the one we have found in 2022.

Our key policy recommendations are set out in more detail below.

Summary of key recommendations

Provide another cost of living support package

The Government must provide another cost of living support package to make sure disabled people, including people with MS, can cope with the rising cost of living and get by over the winter.

This support should be based on four key principles:

1. It must be **enough** to help people cover all their costs. People have told us that they are already having to make impossible choices and are being pushed into debt. Without the right level of support, this is only going to get worse as we head into winter.

2. It must be provided **quickly** to people. People need to know that they are going to be able to pay their bills now and in the coming months.

3. It must be **targeted** and reach the people who need it most. This includes people with MS, who face extra costs due to their condition. And in particular, those living on low incomes.

4. It must be **flexible**. Over the coming months, the Government must regularly review whether the package is meeting its objectives. Where necessary, support must be increased again to enable people to manage rising costs. This would make sure people can be confident they will get the help they need as the crisis continues.

We are aware the external environment is changing rapidly and that the exact package that lives up to these principles may accordingly change with time. At the time of writing (28 September 2022), a cost of living package that meets these principles would be as set out below.

On top of the support already announced this year, at a minimum, the Government should provide:

- A £800 payment to anyone who receives means-tested benefits.[1]
- A £500 payment to anyone who receives Carer's Allowance.
- A £150 payment to anyone who receives non-means-tested extra-costs benefits.[2]
- A £300 payment to pensioners.

The first instalments of this support should be provided to people by 17 October 2022.

The Government should include those on non-means-tested benefits, such as Personal Independence Payment (PIP), in the Warm Home Discount Scheme.

And it must urgently reduce delays in the initial cost of living payments being provided to those living in Northern Ireland.

Change how benefit rates are set and increased

The Government must commission an independent review of the adequacy of all benefit rates:

- This should include an assessment of the adequacy of current disability benefit rates for enabling disabled people, including people with MS, to cover all their costs and meet their needs.
- The aim of the review should look at what level of income is needed for someone to have a 'socially acceptable' living standard - as defined by research on Minimum Income Standards - rather than one that just keeps them out of destitution.[3]

Following this review, the Government should increase benefit rates to a level which enables everyone to have a socially acceptable living standard, as identified in the assessment.

The Government must change the way it periodically increases benefits:

- All benefits should be increased every six months by at least the rate of inflation. This should be done using the 12-month inflation rate from the previous quarter.
- All benefits should be included in these twice-yearly increases, including legacy benefits and Carer's Allowance.

Pause debt deductions from benefits until benefits are increased

The Government must:

- Pause all deductions from benefits for debts to government sources, and only gradually bring them back in as the rate of inflation decreases or when benefits have been increased by at least the rate of inflation.
- Strongly encourage creditors to pause debt repayments from benefits for the same period, or where possible write them off.

Improve signposting and support to access benefits

The Government must:

- Make sure anyone applying for a benefit is given information on all support available to them. This should include information on benefits and wider support, such as housing and social care.
- Make sure anyone starting a claim for a disability benefit has the right to be assigned a single point of contact to help them navigate the claim process and beyond.

Reduce delays in the Personal Independence Payment (PIP) process

The Government must:

- Reduce delays in the PIP process to make sure disabled people get the financial support they need as soon as possible.
- Make sure everyone gets a decision within six weeks of first making a claim for PIP.

Reduce assessments and re-assessments

The Government must:

- Make sure claimants are only asked to go through assessments where there is a lack of evidence to do a paper-based review.
- Scrap unnecessary repeat assessments.
- Make sure people with progressive, lifelong conditions, like MS, are given ongoing indefinite benefit awards.

About this report

Devolved nations

This report makes a number of recommendations for how the Government should improve support for people with MS to help them financially. Unless otherwise specified, these recommendations are relevant to all nations of the UK, and to people with MS living across the UK.

Methodology

This report presents data from an MS Society online survey of 1,108 people affected by MS in the UK. The survey ran from 24 April – 16 May 2022 and was promoted by the MS Society via email, social media and local groups. The survey covered issues such as material deprivation and food insecurity, the additional costs people face because of MS and the impact of financial struggle on people with MS. Data from this survey was cleaned and analysed by the MS Society's evidence team.

People's experiences of additional costs and financial struggle were further explored through qualitative research. Potential participants were identified from the survey findings. The research was carried out by Walnut Unlimited, a research agency commissioned by the MS Society.

Over the course of a week in August 2022, 11 participants across the UK completed a daily diary, detailing the additional costs they have due to MS in different areas of their lives. This was followed by in-depth interviews where participants were able to share their experiences in more detail. Some of the stories people shared with us are included in this report.

This report also uses or references a number of previous surveys and other relevant research. All sources are referenced in the text and listed in the annex.

Quotes

All unattributed quotes included in the report are from people affected by MS who took part in the MS Society's online survey, or the research carried out by Walnut Unlimited. They are not by the people in the photos next to them. The other quotes are either attributed to specific people in the text, or are referenced in the text and listed in the annex.

1. Reduced to going without

More than 130,000 people live with MS in the UK, and for many, being diagnosed with MS can cause a loss of income. This could be because of having to make changes at work, or because of the extra cost of living with MS.

Some of this lost income could be replaced, for example through benefits. But most people with MS will see their expenses increase at a time when their income goes down.

They're struggling financially, especially those on the lowest incomes.

- **A third** (33%) of people with MS say they're either struggling or really struggling on their current income.
- This rises to **over half** (51%) for people with MS who are claiming means-tested benefits.

"Sometimes I'm just clinging on, my money is not brilliant, but I am frugal as much as I can be."

Financial struggle is nothing new for some people with MS but the current situation is making things much harder. Disability benefits have long failed to provide enough support to cover the extra costs of living with MS.

The rates of benefits aren't high enough and in recent years people have had their benefits frozen. Over the last two years, many people with MS have been left to get by on less than others.

For example, during the coronavirus pandemic those on legacy benefits (such as ESA, which is being replaced by Universal Credit) didn't receive the same temporary £20 weekly increase to their benefits as those on Universal Credit.

"I was going to say I'm just about managing, but I'm not. My friends are paying for some things. I'm going without things I need."

The Disability Benefits Consortium's (DBC) 'Millions Missing Out' report found that 78% of disabled people were in a worse financial situation than before the pandemic.

52% were spending significantly more on household bills and utilities and in July 2021, two thirds of disabled people said they were unable or were struggling to eat a balanced diet. 46% said they were falling behind on rent or mortgage payments.[4]

Over a year later, it's getting worse. With the spiralling cost of energy prices, and increasingly high rates of inflation, people with MS are worried about being able to afford essentials now and in the future.

And many are already near breaking point. The future looks bleak, and people with MS who responded to our survey have told us they fear what will happen to them as money gets even tighter.

Our 2022 survey on the cost of living (see Methodology section for more details) found when looking ahead to the next 12 months (see Figure 1 on following page):

- **1 in 4** (27%) people with MS are worried about being able to afford food.
- **1 in 4** (23%) people with MS are worried about affording medication, therapies or treatments.
- **Over half** (58%) of respondents are worried about being able to pay utility bills.

> "I can't even imagine how bad it's going to be...It feels pretty shit. It's going to be really dire, it really is."

> "My rent has gone up, and I'm struggling to make ends meet. I pay the rent, but it is a case of either paying the rent or eating...Once a month, I've got to find £150 out of every £180 to pay rent. That leaves me £30 a week for everything else. And you've obviously got bills and other things. It's crippling, it really is."

These responses represent people's feelings before the Government announced their cost of living package in May 2022.

However, with costs continuing to rise, the level of financial support is nowhere near enough to alleviate these fears. People with MS are still in dire straits and some are just trying to survive.

> "I was going to say I'm just about managing, but I'm not. I'm just really struggling – I am just surviving."

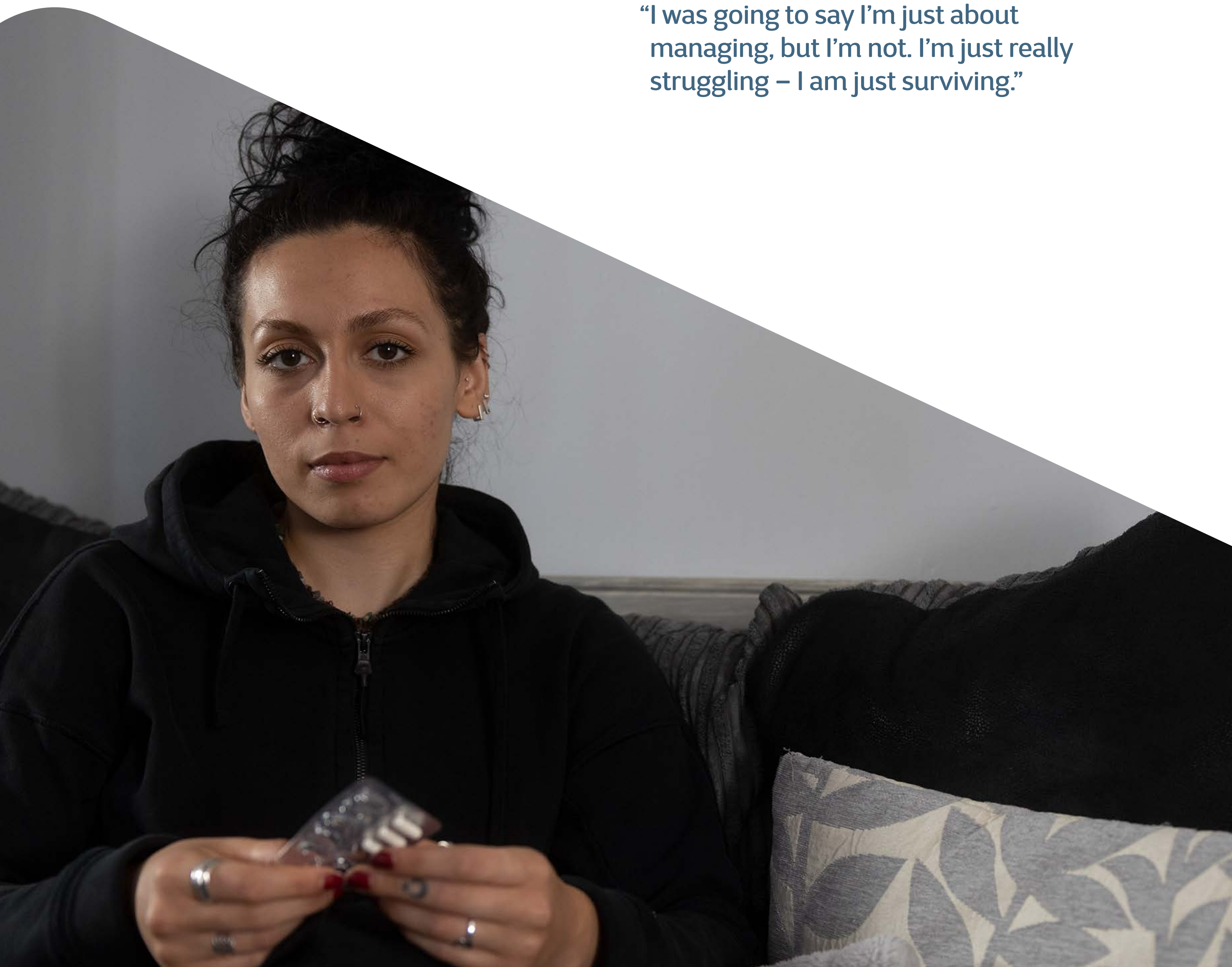
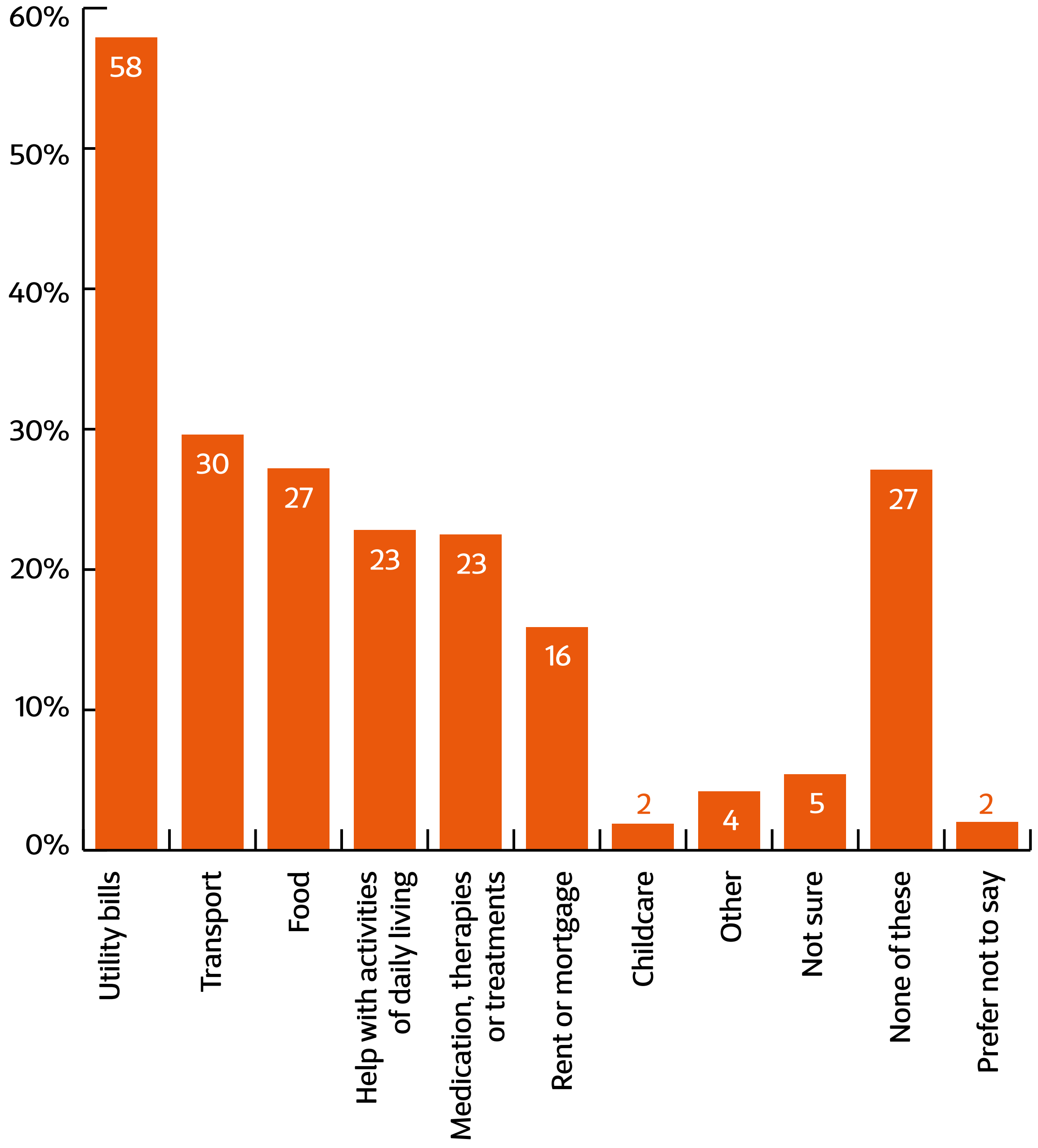


Figure 1
Percentage of people with MS who worry about paying for certain items over the next 12 months



Struggling to afford food

People must have access to sufficient and nutritious food to live well. One of the most distressing findings from our survey is the number of people with MS who are struggling to pay for food and going hungry.

We've used the Household Food Security Survey Module (see annex) to get a better understanding of the experiences of people with MS and the levels of food insecurity within our community.

- **Almost a third** (33%) of people with MS said it was either often true or sometimes true that they couldn't afford to eat balanced meals.
- **Over 1 in 5** (22%) people with MS said it was either often true or sometimes true that the food they bought didn't last and they didn't have money to buy more.

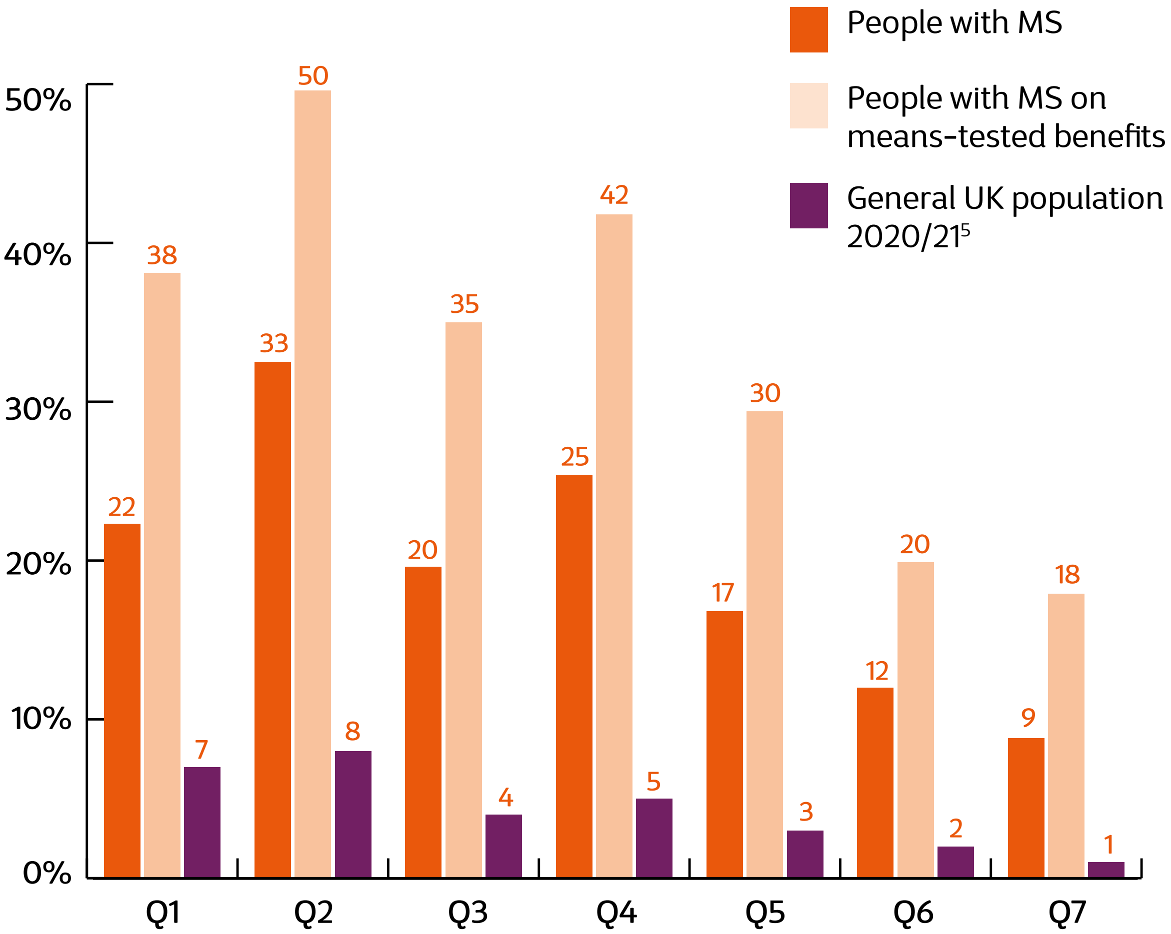
The numbers are stark for all respondents but people who are claiming means-tested benefits are even worse affected. Benefits which should be providing people with a level of support to enable them to live an independent and fulfilled life are too often failing to even keep people fed.

- **Half** (50%) of people with MS on means-tested benefits said it was either often true or sometimes true that they couldn't afford to eat balanced meals.
- **Over a third** (38%) of people with MS claiming means-tested benefits said it was either often true or sometimes true that the food they bought didn't last and they didn't have money to buy more.

> "I'm not eating quality food or a good balanced diet...I'm having to go without things I know are good for me."

Figure 2

Food insecurity - Percentage of people who said statements were “often true” or “sometimes true” for the previous 30 days



Q1	The food I bought didn’t last and I didn’t have money to buy more
Q2	I couldn’t afford to eat balanced meals
Q3	I (or others in my household) have had to skip or cut meals because there wasn’t enough money for food
Q4	I’ve eaten less than I felt I should because there wasn’t enough money for food
Q5	I’ve been hungry and not eaten because there wasn’t enough money for food
Q6	I lost weight because there wasn’t enough money for food
Q7	I didn’t eat for a whole day because there wasn’t enough money for food

Struggling to afford essentials

Material deprivation is defined as not being able to access essential items which provide a basic standard of living and level of social participation.

We adapted questions widely used in this measure to help us understand the level of material deprivation for people with MS (see annex).

They give us a clear indication of the essential items that people with MS are struggling to pay for.

- **1 in 5** (20%) people with MS say they don't have enough money to pay for the medication or treatment they need.
- **1 in 4** (25%) people with MS say they can't afford to keep their home warm.
- **Nearly half** (44%) of people with MS say they would like to spend money on themselves each week but can't afford to.

These findings are shocking enough but, as with food insecurity, the situation is graver for people with MS who are claiming means-tested benefits.

- **Nearly a third** (31%) of people with MS don't have enough money to pay for the medication or treatment they need.
- **2 in 5** (39%) people with MS are unable to afford to keep their home warm.
- **Nearly two-thirds** (62%) of people with MS don't have money to spend on themselves each week.

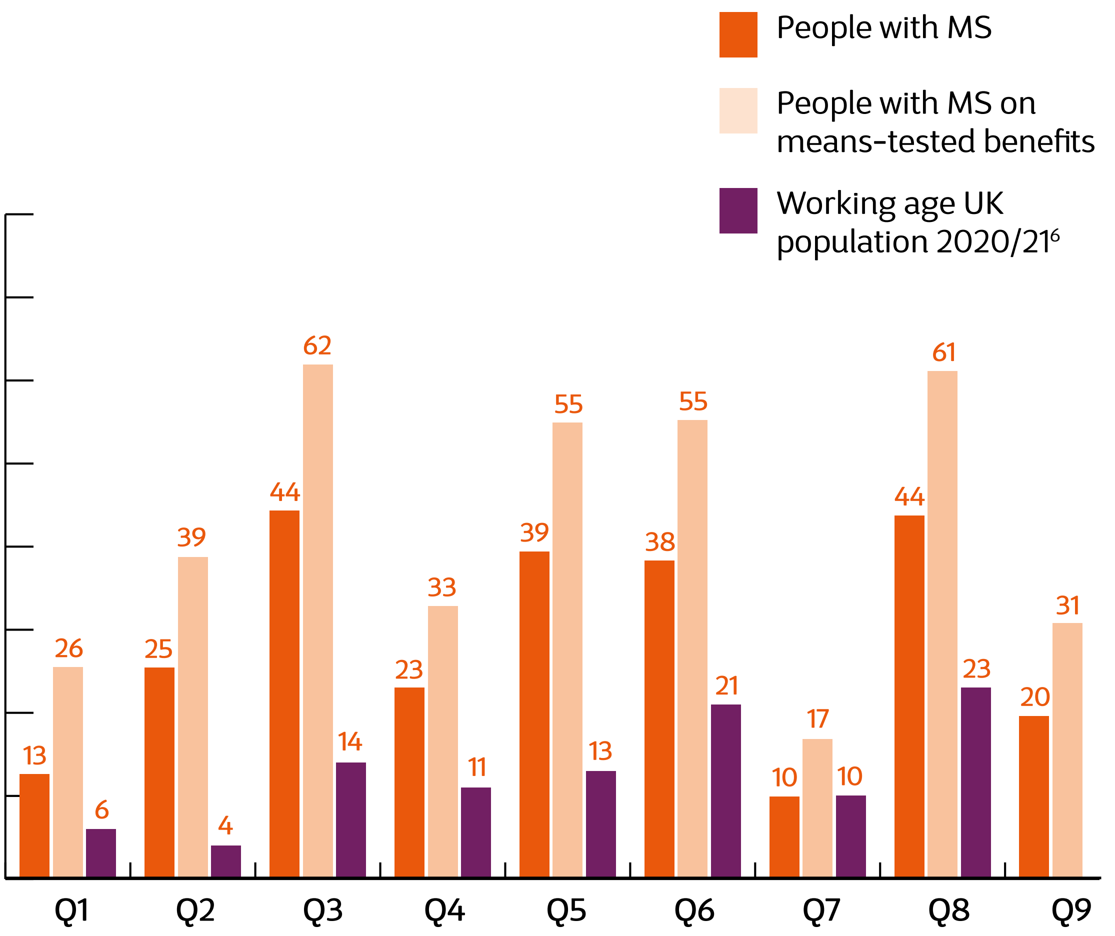
"I haven't had physio I need...they tell me what I need to do to keep well...to improve my drop foot and the pain in my spine."

"I use sanitary towels instead of proper incontinence pads because they can be much, much cheaper...it's embarrassing."

"We need to eat before we warm the house up."

Figure 3

Material deprivation - Percentage of people who would like but can't afford certain items or services



Q1	Keep up to date with bills
Q2	Keep house warm
Q3	Money to spend on self each week
Q4	Replace broken electrical goods
Q5	Replace worn out furniture
Q6	Make savings of £10 per month or more
Q7	Home contents insurance
Q8	Holiday away from home one week per year not with relatives
Q9	Money to pay for medication or treatment

Jilly

Jilly is 40, and lives with her Mum and Dad in Rotherham. She was diagnosed with relapsing remitting MS and finds her symptoms limiting meaning she is unable to work despite wanting to. Jilly's symptoms include constant fatigue, pain, and mobility issues.

Jilly describes her financial situation as a struggle, stressful and restrictive. Along with her parents, she writes everything down making sure they have enough to cover bills and looking at where they can cut back. One area they have made cut backs is Jilly's streaming subscriptions, which is something she has found very upsetting. "We can't afford them right now. But it's not very nice because it's one of my favourite pastimes and helps with my mental health."

Jilly claims ESA and PIP, which she says she uses to pay her bills rather than putting them towards the extra costs she faces because of her MS. To get to medical appointments, Jilly relies on taxis as she is unable to use public transport. The distance means they cost a lot of money, and she is worried about being able to afford them to get there. She has reduced the number of other trips she takes to make sure she has the money to go to appointments.

Jilly and her family are also cutting back on other necessities. They have been reducing the amount of time they spend in the shower, not putting the heating on unless they are really cold, and cutting back on toiletries. Jilly is aware that the things she needs for her MS can cost money the family don't have. She says her mum reassures her that if it's something she needs for her health, like over the counter medicines, or pads and dressings, they will find a way, but Jilly finds this distressing and says it's "horrible".

2. Reduced to making impossible choices

Struggling financially means many people with MS are having to make incredibly difficult decisions which nobody should have to face. It's a Hobson's choice – a decision where no outcome is preferable to the other.

With people already having nowhere left to make cuts or increase their income, choices are becoming more desperate.

People with MS have told us they've reduced their spending on essentials or in many cases are going without completely.

We asked what people are doing to try and increase their income. Most people who responded are both cutting spending and trying to increase income.

> "I pay for a podiatrist to help me with problems with my feet... I'd like to do it monthly...it's not a priority because I have to buy pads for my incontinence issues which is more important."

> "If we need to save money, I won't go to my hospital appointments unless it's really necessary. If I really had to I would, but I'd cancel because of cost unless it was an essential visit."

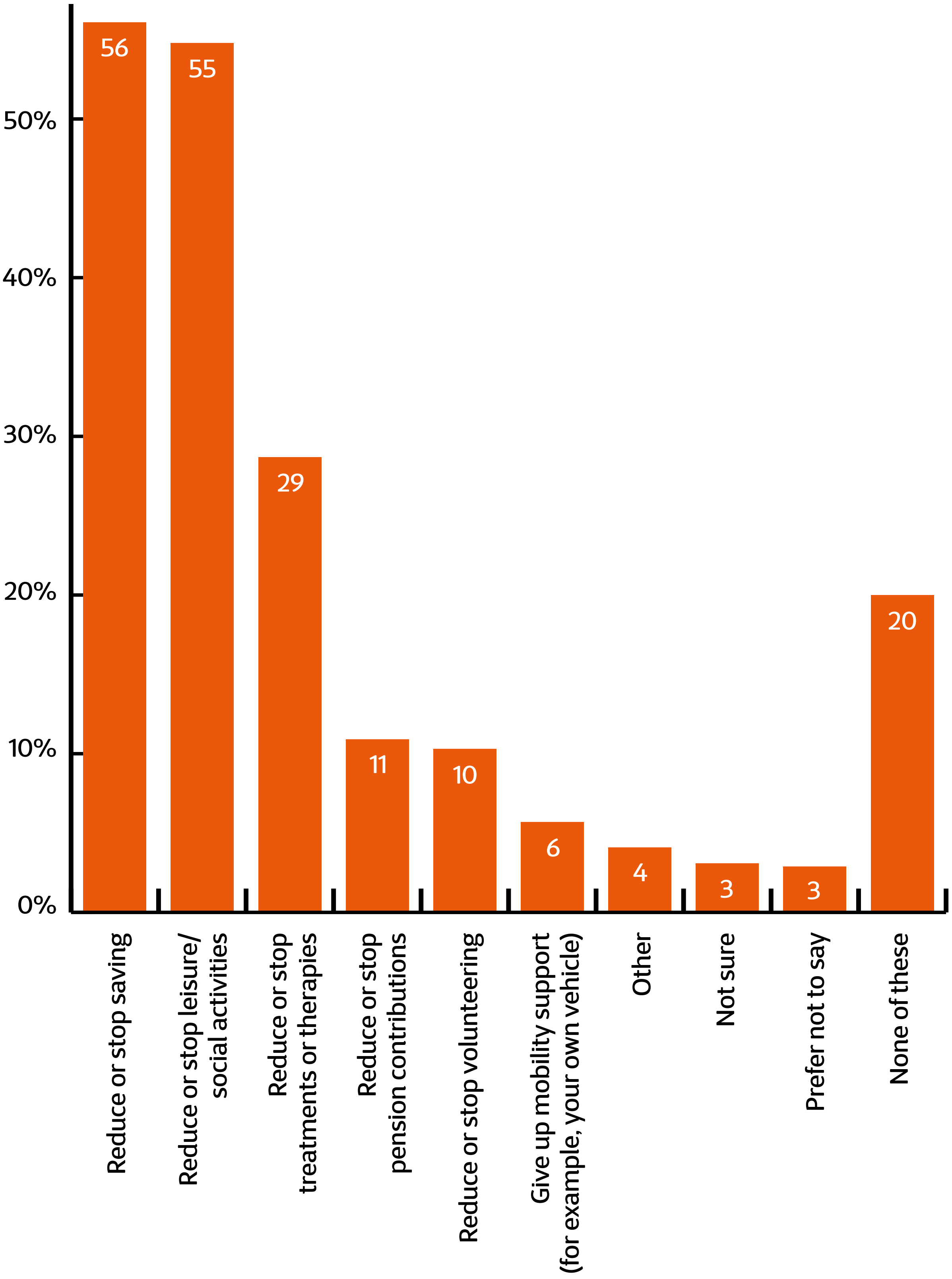
Cutting spending

What to go without today?

When we asked people with MS which essentials they were going without, the results were deeply concerning.

- **Around 3 in 10** (29%) say they've either reduced or stopped their spending on treatments or therapies.
- **Over half** (55%) say they've either reduced or stopped their spending on social or leisure activities.
- **Over half** (56%) say they've either reduced or stopped saving money.

Figure 4
Percentage of people with MS who had to reduce their spending in different ways



Going without food

As discussed in the first part of this chapter, many people with MS are struggling to afford food. So people are reducing their food intake to save money or because they simply can't afford the food in the first place.

We used questions from the same HMFSS survey (see annex) as we did for the previous questions around food insecurity.

"I've reduced my meals to one a day."

The results are heart-breaking. There are people in our community who are going hungry today. It's no surprise that those most affected are claiming means-tested benefits and are likely in the most need.

- **1 in 3** (35%) people with MS claiming means-tested benefits say it was often or sometimes true they'd had to skip or cut meals because there wasn't enough money for food.
- **Over 2 in 5** (42%) say it was often or sometimes true they'd eaten less than they felt they should because there wasn't enough money for food.
- **Almost 1 in 5** (18%) say it was often or sometimes true that they didn't eat for a whole day because there wasn't enough money for food.
- **1 in 5** (20%) say it was often or sometimes true that they had lost weight because there wasn't enough money for food.

"You've got to cut back on all sorts of things. Food in the end...and yeah, just hope that one day it gets better."

Food bank use is high among disabled people. The Trussell Trust report showed that 2 in 3 (66%) households referred to a food bank in early 2020 included one or more disabled person.

They say that "disability is exceedingly common among households referred to food banks in the Trussell Trust"[7].

We asked people in our survey if they'd used or needed to use a food bank in the last 12 months. 5% of people with MS said they had used a food bank and 8% said they hadn't, but needed to.

For people with MS claiming means-tested benefits this rose to 1 in 10 who had used one and 15% who hadn't, but needed to.

These figures show that people with MS are going hungry. They are skipping meals, sometimes for a whole day, and not just once a month, but regularly.

Where people are able to afford meals, they are often not balanced or healthy. And in the worst cases people with MS are losing weight because they cannot afford to eat.

This is a desperate situation. Aside from the horrible reality that people are going hungry, it also has wider, devastating consequences which we cover in the next section.

Increasing income

One way to try to make life easier is to increase your income through work. Some people with MS have either continued to work, taken on more work, or gone back to work. This is despite it sometimes having a negative impact on their health.

Nearly 1 in 10 (8%) people with MS said that because of their financial situation they've had to go back to work before they felt ready.

> "I'm continuing to work shifts full time, even though it takes all my energy and my quality of life on days is significantly reduced."

> "I only work so we can afford to live and eat. I can't physically do more than I already do...but I don't know where we'd be, I really don't, but we certainly wouldn't be affording bills."

> "Clients considering reducing their hours or stopping work due to their MS symptoms, are shocked when they hear how little financial support is available. Many say they simply cannot afford to reduce their hours or they will not be able to pay their mortgage and bills."
> MS Welfare Rights Adviser,
> Disability Law Service

Our survey also showed that for other people their financial situation was having the opposite effect. **1 in 10** people with MS said they've had to reduce or stop working altogether due to their financial situation. Reasons include being unable to afford care which for example, they may rely on to help them get ready for work. Social care support is a vital component in making work possible for many disabled adults of working age that are in work in the UK.

Transport costs also mean that people cannot afford to travel to work. For the people whose physical and mental health is worsening because they've had to reduce or stop their treatment, medication or therapies, work will become harder. In some cases, it will be impossible.

Many people with MS are unable to work because of their symptoms, for example fatigue or cognition problems. Increasing their income through work isn't an option.

Therefore, they rely on income-replacement benefits as their only source of income. They must depend on the safety net the government is meant to provide through the social security system.

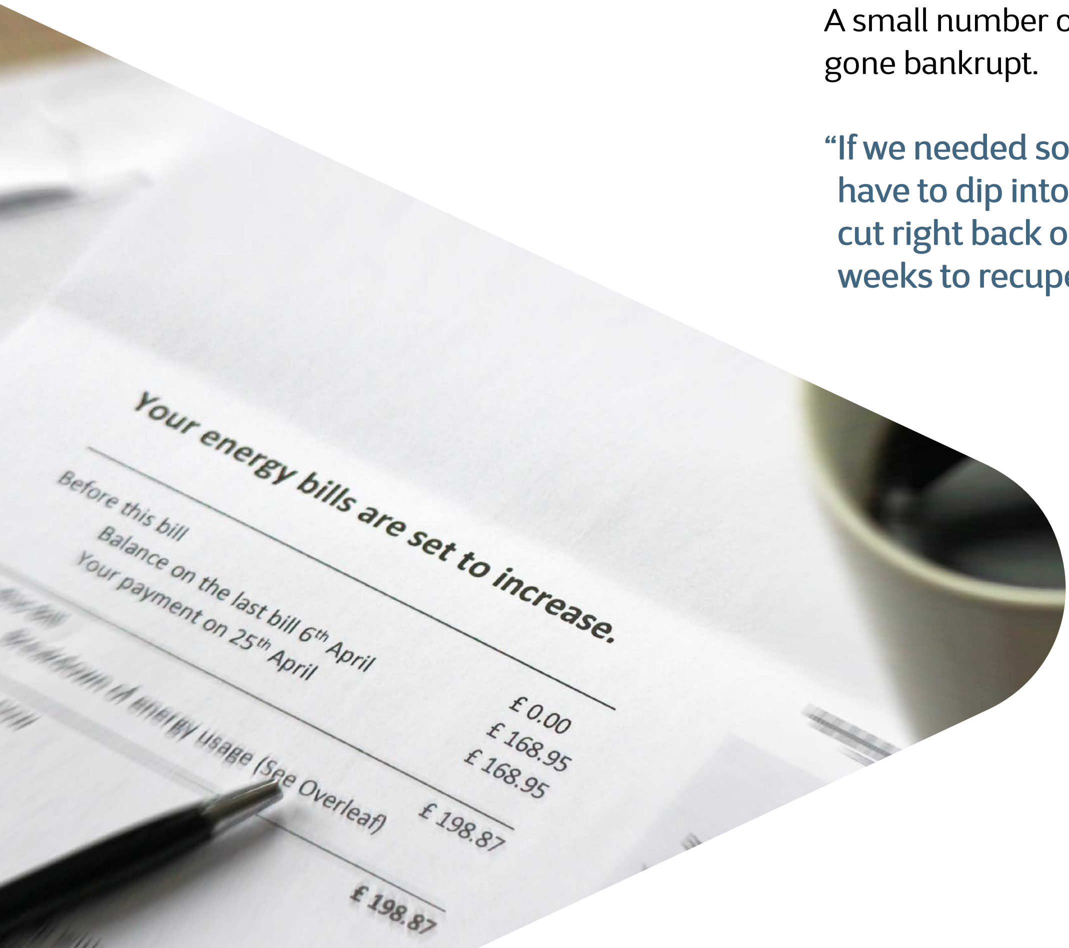
For those people who do work, often work is part-time and low-paid. For most people with MS increasing hours or finding another job isn't straightforward.

This means too many people with MS are turning to other ways to increase their income, many of which are unsustainable in the long-term and will have a negative impact on their lives.

Our survey shows that many people are struggling to get by. When faced with additional one-off costs they often don't have the extra money to pay for them. Many people are therefore relying on credit.

- **2 in 5** (40%) people with MS are currently having to borrow money in one way or another to make ends meet, including those who are working.
- This rises to **over half** (56%) for people claiming means-tested benefits.
- Types of borrowing include: borrowing or accepting money from friends and family (24%), taking out a bank or payday loan (9%), borrowing on a credit card (24%), or seeking financial help from other organisations such as charities (9%). Our survey shows that **1 in 5** (18%) people with MS are having to borrow money in multiple ways.

> "If something happens in the house, there's not the money to pay for it. I move my debts around to get by. I take credit cards, then I get a loan out to pay off the credit cards. With this winter I'm going to go into more debt."



> "If a big bill comes in, I don't know what we would do. If it was something unexpected, we would be in a bad way."

> "It's important I have them [vitamins and pads] ...I have to borrow money from family or friends...my brother is a blessing."

People with MS are looking to other methods of increasing their income. This includes selling things, including: their home (8%), jewellery, clothes, books etc. (20%) or cashing in things that they'd put in place for the future, for example, pensions, savings and insurance.

Over half (52%) of the people with MS who responded to the survey said they'd used their savings to get by.

People who've been putting things in place to protect them in their future are having to remove their safety net. People told us they've taken their pensions early to cover spiralling costs. A small number of people told us they'd gone bankrupt.

> "If we needed something we would have to dip into savings, or budget or cut right back on shopping for a few weeks to recuperate the cost."

Rachael

Rachael lives in East Yorkshire with her dog. She volunteers for the MS Society, as well as a number of other charities after leaving work in 2018.

Rachael says she is terrified of what's to come regarding her current finances. She is watching her money very closely and has a tight budget, but is already in arrears with her electric and gas. Even though she manages her money fortnightly and scrimps and saves, she can still run out and is then faced with difficult choices like whether to use her car in case there isn't enough petrol in an emergency.

Rachael's symptoms means she has difficulty with many day to day activities, including cleaning. She currently has a cleaner to help her, as she is unable to do anything at a lower level, but is now unable to afford it. Rachael is unable to hang her washing out, do the dishes, and uses an electric wheelchair. This means she uses more energy for things like a tumble dryer, dishwasher and charging her equipment. She says that the thought of the next six months is "utterly scary".

It's also impacting on other extra costs as a result of her MS. Rachael has problems with her bladder and was introduced to period pants which she says were amazing. However, she can't afford them and has had to look for an alternative.

Rachael says she cannot believe she's at the state where she is having to consider whether she can afford every little thing, and no longer knows where she can make cut backs.

3. Reaching breaking point – the impact of going without

We know people with MS are struggling financially. They are reducing spending on, and even going without some of the essentials which keep them healthy, independent, and living well.

Going without food, medication, treatment, and a social life has a devastating impact across all areas of people's lives. It's affecting their mental and physical health, relationships, and employment.

All this leads to a never-ending cycle of desperation and financial struggle which is getting worse.

We asked people what impact their current financial situation has had on their lives:

- **Over half** (56%) say it has had a negative impact on their emotional wellbeing.
- **Nearly half** (45%) say it has had a negative impact on their memory and thinking.
- **Over a third** (35%) say it has had a negative impact on their activities of daily living. For example, cooking, bathing, cleaning, and getting out of bed.

Financial struggle impacts on all aspects of life: where you live, how much autonomy you have over things like working hours, and how much security you have for the future. All of these factors and more, feed into and exacerbate the experience of struggling financially.

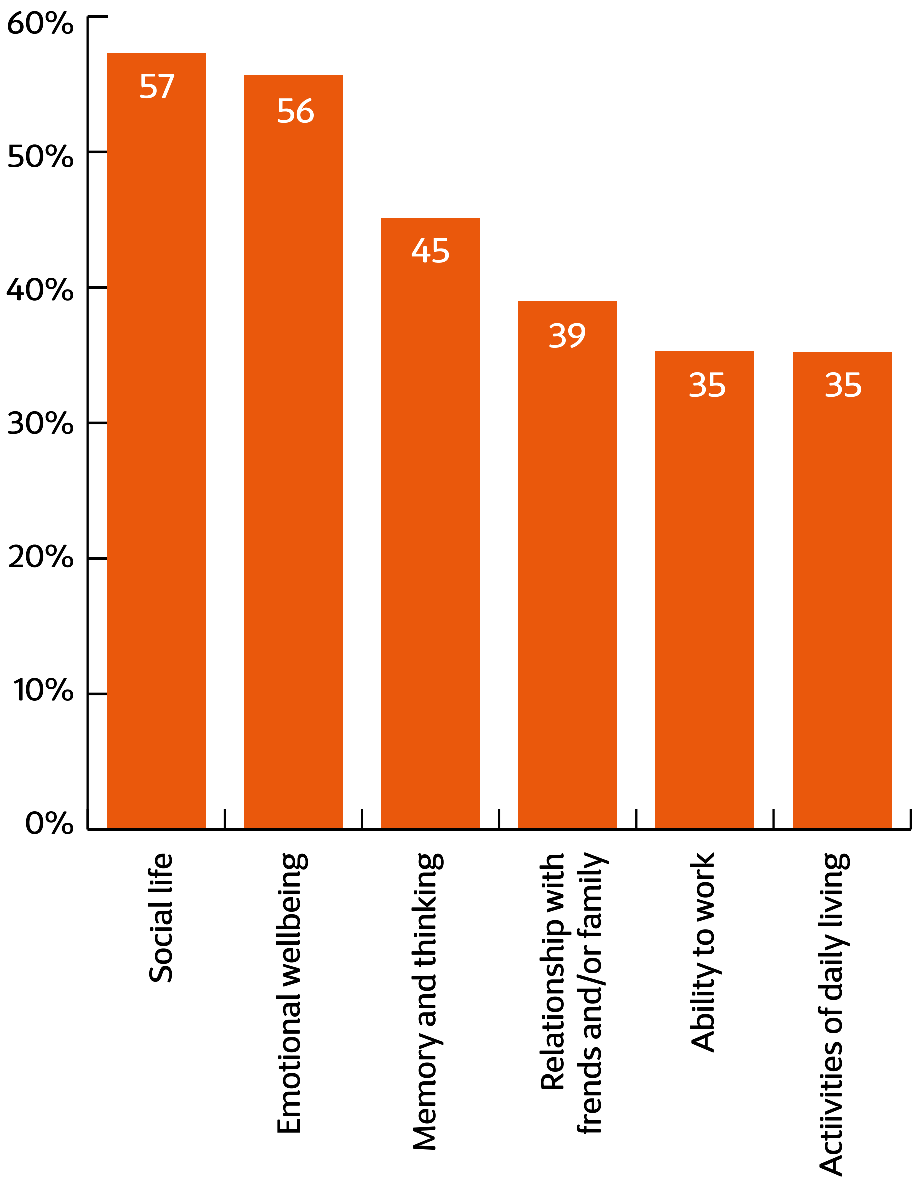
Separating the impact of financial struggle on specific areas of life is virtually impossible.

In many examples, you can't have one without the other. If you can't get to work because you can't afford to pay travel costs, you could then end up unemployed.

This could lead both to a worsening of your health and financial situation, which then has an even bigger impact on your health, and the cycle continues. Therefore, there's some overlap in the following sections.

Figure 5

Percentage of people with MS whose financial situation negatively impacted aspects of their life



The impact on people's health

Cutting back on food

Struggling financially can have a severe impact on disabled people's physical and mental health. Going without food or a healthy, balanced diet will have a direct impact on anybody's health. However, for people with MS, eating well can play an important role in helping them to manage their symptoms too. A healthy diet can help manage someone's fatigue, with bowel and bladder issues, and improve muscle strength. Some people with MS say that following a special diet gives them a feeling of control over their MS or makes them feel better, helping with their symptoms.

It isn't acceptable for anyone to have to go without food, or a healthy, balanced diet because of financial stuggle, no matter who they are.

Cutting back on energy usage

Rising energy bills are a major worry for people with MS. While not a medication, treatment or therapy, reducing spending or cutting down on energy use has a direct impact on people's health. Many rely on energy to regulate their body temperature to manage their MS symptoms. Many people find their symptoms get worse when they get hotter and some people find the cold more of a problem.

There are other reasons people with MS need to use the heating more than most. Our bodies generate heat from moving around, so it can be harder to stay warm if your mobility is affected. Other than turning up the heating, warm clothes can help, as might heat pads and hand warmers. Frequent hot meals and drinks can also help warm the body. All of which cost money.

> "I struggle to warm up, I get muscle spasms and my legs don't work...but we won't use the heating this winter."

Cutting back on treatments and therapies

One of the most concerning things that came out of our survey was the number of people who are reducing or stopping medication, treatment or therapies as a way to cut back on spending or to save money. This will have a direct negative impact on their MS where people could see a worsening of symptoms and more frequent relapses.

- **Almost 6 in 10** (58%) people who have reduced or stopped their spending on treatments and therapies say their financial situation has had a negative impact on their activities of daily living.
- **Over 6 in 10** (62%) people who have reduced or stopped their spending on treatments and therapies say their financial situation has had a negative impact on their memory and thinking.

> "You shouldn't have to choose between healthcare and welfare."

In August 2020 we asked people with MS how they were coping during the pandemic.[8] We asked if their symptoms had worsened during lockdown, and a third said they had. This could be for a number of reasons, but when asked, those who had seen a deterioration or worsening of their symptoms, **over half** (51%) said it was through the disruption to services they normally received. This shows how important it is to maintain consistency when it comes to someone's healthcare. It makes sense to consider someone's decision to stop or reduce treatment because they can't afford it as a disruption to their healthcare services in the same way.

During the pandemic, we also asked neurologists what impact reduced access to services could have on people's MS.

- **Over 7 in 10** (72%) said it will have a long-lasting impact on physical health for all or the majority of people with neurological conditions.
- **Over half** (56%) felt all or the majority of people with progressive neurological conditions would also experience long-lasting impacts on their mental health and wellbeing.[9] We explore impact on mental health and wellbeing in the next section.

Below are some examples of what people have told us they've reduced or stopped and the impact that could have on their health and MS symptoms.

Disease Modifying Treatments (DMTs)

Disease Modifying Treatments are a vital form of MS care as they can slow the progression of MS for some patients. DMTs require regular assessment and monitoring by MS professionals to make sure any side-effects are identified and managed. Prolonged delays between treatment doses, or abruptly stopping treatment can be harmful. It can lead to a deterioration in someone's health and people may end up needing emergency services or on neurology waiting lists in the near future.

> "It's an 80-mile round trip...we've agreed I'll go twice a year, but the nurse is meant to see my skin to monitor the side-effects."

> "A lot of appointments are monitoring my health from the DMTs, so not going will have quite an impact if there was anything wrong."

Rehabilitation services and support

These services and support enable many people with MS to live independent lives less restricted by fatigue, incontinence, pain, immobility, cognitive fog and other debilitating symptoms. They are key to helping people with MS to maintain mobility and manage their symptoms.

There's strong evidence showing continued, co-ordinated multidisciplinary rehabilitation in the community improves long-term outcomes and can help to reduce hospital readmissions.[10]

For those unable to access it we know their symptoms get worse, with some saying that their ability to walk deteriorates. People experience increased fatigue and pain, and struggle with low mood. In a 2020 survey, over half of people with MS felt that a reduction in, or changes to, specialist support had contributed to their symptoms getting worse. This varies from worsening balance, increased fatigue and muscle weakness, to pain and stiffness.

There are many points on the broad spectrum of rehabilitation, from recovery to maintenance. Whatever it's called, it's essential for people with conditions like MS.

Stopping or reducing this type of support or therapy and therefore making symptoms worse, because of struggle shouldn't be a choice someone has to make.

> "I'd love to have the ability to have more money to be able to receive some treatment which would make my condition much better than it is right now."

Physiotherapy

Physiotherapy helps many people with MS manage their symptoms. A physiotherapist can suggest particular exercises to treat and manage specific problems such as difficulties with mobility, balance, posture and fatigue. Bladder problems, pain and muscle spasms and stiffness can also be targeted by physiotherapy.

However, ongoing support in this area isn't widely available on the NHS, for example, rehabilitation in the community can be limited to six physiotherapy sessions within a 12-month period. This means that many people with MS find a way to pay for physiotherapy privately.

Stopping paying for physiotherapy has repeatedly come up in the survey as one of the things people are stopping or reducing to save money. This will only lead to worsening symptoms and poorer health for many.

> "Neurological rehabilitation is critical to maintaining function and quality of life in MS with a clear evidence base to support its use. Disability can be caused by the direct effect of MS, but disability can also occur indirectly because people at risk of health problems can be prevented. These problems include increasing stiffness of joints compounding mobility problems, poor levels of fitness aggravating fatigue, low mood driven by preventable job loss, and pressure sores caused by immobility. All these aspects of disability can be prevented by a good community neuro-rehabilitation team."
>
> Dr Diane Playford, Professor of Neurological Rehabilitation at the University of Warwick Medical School and a practicing Consultant in Rehabilitation Medicine at South Warwickshire NHS Foundation Trust

> "Physio, I have to think about, ok, do I spend on this when you want things like your fruit and veg."

Exercise

Excercise is important for people with MS, not just to maintain general standards of health and wellbeing, but it helps people manage the symptoms of MS. It can improve symptoms like fatigue, pain and balance, and mobility problems. Cancelling a gym membership, or being unable to afford a Pilates class, isn't a luxury someone is choosing to forgo. It's a symptom management tool that someone has no choice but to go without despite knowing the damage it could do to their health.

> "To keep my mobility up I try to go swimming weekly or go to the gym. My friend pays for me because my benefits don't cover them."

> "I have massages twice a month to help with my pain…they help me stretch out, lessen my spasticity and reduce the tightness in my limbs… I feel like I can breathe…my posture's good and I sleep better, but this is something I've had to cut back on."

Complementary and alternative therapies

These therapies can benefit many people with MS. Massage is often used by people with MS to help with fatigue, spasticity, pain, and mental health. Similarly acupuncture, podiatry, and cannabis therapies are all known to help. Like a gym membership, these could be viewed as luxuries that would be easy to cut back on. For those using them to manage symptoms however, it will have a detrimental effect and see a deterioration in their MS for many.

The impact on people's mental wellbeing

According to a recent report by the Neurological Alliance, more than a third of adults with a neurological condition said it made their mental wellbeing much worse. For people with MS **a quarter** (25%) said their condition made their mental wellbeing much worse. **Over half** (56%) said it made it slightly worse.[11] People's mental health is likely to get worse as their physical health deteriorates due to making choices based on their financial circumstances.

We asked people what impact their financial situation was having on their emotional wellbeing.

- **Almost 8 in 10** (77%) people who have reduced or stopped spending on treatments and therapies said their emotional wellbeing had been negatively impacted by their financial situation.
- **Almost 8 in 10** people (78%) people who have reduced spending on mobility support said their emotional wellbeing had been negatively impacted by their financial situation.

Nearly everyone who said it was often or sometimes true that they were experiencing some form of food insecurity said their financial situation was having a negative impact on their emotional wellbeing. This is unsurprising.

“Emotionally, it’s probably one of the toughest things.”

Cutting back on mental health treatment or therapies

When people with MS access mental health support, they often say it has a positive impact – 70% of adults who received support said it made them feel better/more positive.[12]

However, over a third say their mental wellbeing needs aren’t being met.[13] This unmet need means some people with MS aren’t getting good mental health support, with some paying for counselling privately. People with MS are choosing to stop this therapy to make sure they’ve enough money for food or bills which in turn sees their mental health and wellbeing worsening.

“Last year I was paying for counselling. It’s access to a specialist like that which I’d love to have.”

Financial insecurity and mental health

Even before feeling the impact of having to make cuts or reductions, financial insecurity alone has a direct impact on people’s mental health. There is a wide range of evidence which explores the impact poverty has on people’s decision-making abilities, with many studies suggesting that poverty frames decisions differently and reduce people’s mental ‘bandwidth’.[14]

“I’m hanging on…it’s the mental side of being involved in financial difficulty, in the not knowing how to get out of it.”

The Joseph Rowntree Foundation use the term ‘scarcity mindset’ which is characterised by “an increased focus on immediate goals at the expense of peripheral tasks and long-term planning. This contributes to the perpetuating cycle of poverty…When resources are scarce money, food, time, people’s attention focus narrows, concentrating on the immediate task at hand.”[15]

People in this position spend much of their time and energy figuring out how to pay their bills which means they can be left with much less mental capacity to think about how to improve their overall condition in the long-run.

“Every day becomes a struggle with choices having to be made on every action that you take. Do I have enough money to put petrol in the car to get to work? How do I make £10 last three days to feed my family? Where do I get help and support for free and without any costs? How can I reduce my costs to make the income I have last longer? Do I eat or heat my home today? How can I afford to cook the food I’ve got from the food bank? The levels of stress that each person is under, greatly increases. They cannot concentrate at work, which can lead to fears about losing their job. They become socially isolated due to not having any spare funds to join in any social events or activities. People may be tempted to turn to crime. Parents go without food to feed their children. Life becomes so much of a struggle that some people may even consider suicide.”[16]

Dave

Dave has secondary progressive MS and was diagnosed in 2011. Some of Dave's symptoms include cognitive difficulty, weakness and drop foot, pain and spasticity. He says that medication for his spasticity has "been his friend" and that with pain relief too he's "managing".

Dave says he's meticulous when it comes to his finances, and planning and budgeting. Through his budgeting Dave has identified areas where he can save money or cut spending. This includes his physiotherapy, which he has stopped. Dave has noticed the difference not having a physio has had and says he feels like now he's in "stasis". He says physiotherapy is something he would love to have.

Dave says that he's not a social animal, but being able to go to the cinema is very important to him, so he has invested in a yearly cinema pass. This helps him get out of the house and he always makes sure to plan things on the same day, for example going to the supermarket, to save money. "I plan my journey to do multiple things... I'm getting the most bang for my buck."

Dave has noticed his condition is deteriorating, but will not reapply for PIP to see if he can get more. He's worried that if he does, he will end up with less, and lose his Motability car which he relies on.

Dave is worried about the future, and says it can be terrifying listening to the news. He has started to "batten down the hatches" and limits the number of times he goes out a week. He says the "goal posts have changed without me really noticing". The process of claiming PIP is particularly concerning for Dave, which he says is lacking in compassion, and is "complicated beyond belief...I don't feel like I get the support from the government, or the help, that will help me through these times."

Cutting back on connecting

Being independent, connecting with family and friends, going to support groups or counselling, and socialising are important factors for people's mental health and wellbeing. But it also impacts on many other areas of people's lives, which is why we have chosen to give it its own section.

One common remedy for mood and anxiety disorders is social support, but for someone struggling financially, maintaining social networks can be very difficult.

Social isolation, loneliness, and a lack of relationships with friends and family impact on many areas of people's lives.

Disabled people, including people with MS, are finding it increasingly difficult to establish and stay connected with each other and this is especially true of those on low incomes.

Some groups people with MS rely on to stay connected, such as community groups, have disappeared or been cut back due to a lack of resources available. This has had a negative impact on people's ability to maintain social networks.

In a recent MS Society report, almost **6 in 10** (58%) people with MS identify as having felt isolated. **6 in 10** (60%) identified as having felt lonely.[17] **8 in 10** (80%) of people with MS who had felt both said that being part of a local group reduced their feelings of isolation and loneliness which shows the importance of these groups and networks.

It's not just people's mental health that is affected, people's physical health is too.

People suffering from loneliness are more likely to have a higher incidence of falls, early entry into residential nursing care and use of accident and emergency services.[18]

We asked people with MS what impact their financial situation was having on their social lives and relationships.

- **7 in 10** (70%) of people who have reduced their overall spending said their social life has been negatively impacted by their financial situation.
- **Half** (49%) of people who have reduced their overall spending said their relationships with friends and family had been negatively impacted by their financial situation.

People with MS who are struggling have said they are having to borrow money from friends and family. **Around 1 in 4** (24%) people with MS told us they've borrowed or accepted money from friends and family.

This is causing pressure and distress, especially when family and friends are themselves in financially vulnerable positions.

If relationships with family and friends suffer so do people's care and support networks which many rely on to remain socially active, independent and healthy. We explore this in more detail below.

> "I'm not prioritising my social life; I have no savings...I feel like I'm a burden."

The impact on people's quality of life

Employment

Struggling financially has an impact on people's working lives. It's an integral part of the cycle of financial struggle. Being unemployed or underemployed when you are able to work can be due to financial struggle, but will also lead to more struggle. But being in work because you can't afford to leave, also impacts people's finances. Both situations can be damaging for the physical and mental health of people with MS.

People with MS who have left work because of their condition often say it was the right thing to do. But for those who have to remain in work because they can't afford to leave, it can lead to a worsening of symptoms and put pressure on other areas of their lives.

> "My employer told me that if I didn't come back to work after a relapse my pay would be docked by 50% which left me no choice but to return. I had to sit at my computer for hours on end, despite being in agony a lot of the time."

Cutting back on care

A high proportion of people with MS are forced to fund their own care and support while a smaller proportion receive government funded support. **1 in 3** people with MS aren't getting the support they need with essential everyday activities like washing, dressing and eating.[19] People are dependent on care from family because it's not being provided by the government. This lack of support continues the cycle of financial struggle. Without it, people are unable to carry out the most basic of tasks which enable them to live independently and have a good quality of life.

> "I was reassessed and told to contribute more to my care every week. They started billing me and the debt was building up. From that point on I just struggled alone."

> "Having the option to have paid support sometimes would help...rather than having to always call on family and friends."

Cutting back on support

To live independently, people with MS often need help around the home with daily activities such as cleaning, gardening or dog walking. For some people their symptoms make it incredibly difficult to carry out these tasks. Attempting them can lead to a worsening of symptoms, but we are hearing from people who are having to reduce or cut back on this kind of support because they are unable to afford it.

Without this support people feel like they lack independence, it leads to people's emotional wellbeing suffering and can lead to social isolation and loneliness.

> "I'm going to have to stop my cleaner. I really don't know what I'm going to do without her...I can't get down to places or do anything at a lower level."

> "If I lost my cleaner, it would have a massive, massive impact because we'd have a filthy house...I wouldn't want people to visit me."

Family and friends also provide vital care and support to people with MS, often stepping in to fill gaps in government funded support with significant impact on their own lives. This includes personal care, travel and helping out with daily activities.

People with MS sometimes pay family or friends to do this, either as part of a formal agreement, or informally as more of an offer of thanks.

This reliance on friends and family has its challenges. It can be damaging to relationships and leave people feeling isolated and lonely.

For some people with MS, it still doesn't provide the level of independence that would enable them to live well. It can leave people feeling like a burden and feeling guilty.

This feeling increases as people's finances are squeezed and they feel like they're asking people to do more for them for less.

> "One of my friends kindly comes round once a week to do some hoovering and ironing. My worry is there will come a point where my friend will no longer be able to help."

> "I appreciate [Dad] helping me to get about, but it shouldn't be like that...it's like I've got no independence. I know they'll do it, but I want to say 'no, I've got this."

Cutting back on aids and adaptations

It's important to disabled people, including people with MS, to be able to stay independent and be proud of their home. Having access to accessible housing, and adaptations and aids are vital in helping people to do this.

They can improve quality of life and people's feeling of choice and control, as well as better overall health outcomes. Unfortunately, people with MS are choosing to delay making changes to their home, or buy equipment. They are struggling to afford to use or maintain existing aids, and instead are going without or are reducing usage.

Adaptations and aids also allow people with MS to live safely. A home adaptation in someone's bathroom for example, can significantly reduce the risk of someone falling in the shower and ending up in A&E. Not having the right aids and adaptations could lead to a worsening of someone's symptoms. For example, not having a suitable bed could lead to muscle spasms, or not having suitable cooking equipment could lead to burns.

There is evidence that unmet need for adapted features is linked to lower incidence of social contact.[20] Barriers to accessible housing also play a significant role in disabled people struggling to access employment.

For example, disabled people who accessible housing needs aren't met are four times more likely to be unemployed and not seeing work than those whose needs are met, or those who are disabled but don't need accessible housing.[21] People have said that having adaptations in their house can mean symptoms can be easier to manage which means they are able to work, or it can speed up recovery following a relapse.

Many of the aids and adaptations people with MS use require electricity to work. This includes mobility scooters, stairlifts, and adjustable beds. We know people are going without some of these aids and adaptations because they are too expensive in the but even those who do have them are reducing their usage to help them save money on their energy bills.

As described above having these aids and adaptations in place make a huge difference to people's independence, but also helps them to manage their symptoms.

"I'd would love to have a downstairs bedroom, because at the moment I sleep on the sofa and I have done for quite a while now."

"I'm going to need a stairlift if I want to stay living independently. That's money I haven't got."

Cutting back on travel

Having access to a suitable method of transport, such as an adapted car, taxis or reliable public transport, makes a huge difference to someone's independence and quality of life. People with MS have a range of needs when it comes to transport, some may need adapted vehicles, others use public transport, and some use taxis or rely on friends and family to help them get around.

Having difficulty or being unable to travel because you can't afford the cost, or don't have support, affects every area of someone's life. This includes their ability to work, socialise, care for others, shop, and attend medical appointments.

It exacerbates the cycle of financial struggle, and has a significant impact on the overall quality of life for someone with MS.

"The price of fuel is terrifying. I haven't been able to go and see the kids as much as I'd have liked...I prefer not to dwell on it."

"There's a cost of petrol. It's just not worth it. It's not worth going out."

Sarah

Sarah was diagnosed with relapsing remitting MS in 2017. She lives with her partner, who works full-time. Sarah's symptoms include problems with her bladder, balance and drop foot, often stumbling and falling. Sarah suffers from "brain fog" and says her fatigue is "horrific" sometimes being unable to even wash her hair. Since her MS diagnosis, Sarah has also been diagnosed with depression, anxiety, and agoraphobia.

When Sarah was diagnosed she left her full-time job as she was unable to manage her workload as a result of her MS. She now works part-time but is frustrated that because of her symptoms she is limited to part-time, minimum wage jobs. She says the impact financially has been significant. If Sarah could afford to, she wouldn't work at all, as the impact of working has a "knock-on effect on my entire life". Sarah finds herself exhausted, and has collapsed following work.

Sarah says she is worried about the future. She is much more cautious and careful about what she spends, only buying necessities and cheaper alternatives. To save money, Sarah says they buy more tinned and frozen food so it lasts longer. She also uses sanitary towels instead of proper incontinence pads which she says would take a big chunk out of the weekly food budget.

Thinking of the future, Sarah is aware of the rising energy costs. She says that even though the cold makes her symptoms worse, she won't use any heating in the winter, and that food will be their first priority. She also says that if they need to save more money, she would not go to hospital appointments unless it was essential, despite needing to be monitored because of the treatment she receives.

4. The extra costs of MS

Like everyone, people with MS need to meet costs in different areas of their lives to live well. Everyone has to spend money on the essential costs of living, such as food, housing and heating. But people with MS are also likely to have extra costs as a result of their condition. These are the amounts of money people with MS need to spend on things to help them manage their condition. These costs are effectively unavoidable as people need to spend them to maintain the same standard of living as non-disabled people. For example, paying for a cleaner can be vital for someone who is unable to clean their own home due to symptoms such as mobility or fatigue.

Extra costs can often be substantial. This can be particularly problematic for people with MS on low incomes. They can sometimes find it impossible to find enough money to cover them. Some people are even forced to go without essentials in order to pay for extra costs, or vice versa. Recent inflation of more than 10% has caused many of these extra costs to increase for people with MS.[22] This is making it even harder for them to get by and live well.

However, it isn't the burden of all these costs that is in and of itself causing financial struggle for people with MS. Instead, it's the lack of financial support provided by the welfare system - support that ideally **should** enable people to cover their costs - that is leading to people with MS struggling to get by, particularly those on low incomes. This lack of support and how it's driving financial struggle is expanded on later in this report.

While people with MS are struggling with many of the same costs as everyone else, it's the extra costs they face which have a particularly significant impact on their finances. This section focuses specifically on the extra costs of MS and explores the financial burden they place on the MS community. Using evidence from our survey and from speaking to people with MS, we outline the types of extra costs people have, and give an estimate of how much they may amount to. We explain how they are being affected by inflation and rising prices, and how people with MS on low incomes are being particularly badly affected by these costs.

Types of extra costs

In our survey, we asked people with MS about the types of extra costs they face and to estimate how much they spend on them. We found that, overall, most people with MS experience extra costs due to their condition in a number of different areas, both on a monthly and one-off basis. The figures from the survey on extra costs are outlined in further detail below. Costs can vary a lot from person to person based on many factors including their MS symptoms, living situations and more. But our findings show that monthly costs are typically hundreds of pounds, and one-off costs are thousands. Since the extra cost data is based on estimates there are some limitations to the data which are explained further in the annex.

> "I've never really added it up before...in a way it's not a surprise...at the back of my mind I knew I was doing this and that."

Monthly extra healthcare costs

Almost 7 in 10 (69%) respondents have monthly extra healthcare costs. The average person with MS spends £63 on them.

These extra costs (Figure 6 on page 38) can include:

- Private treatment or drugs, which they may struggle to access on the NHS and need to use to manage their symptoms and stay well.
- Therapies, such as massages, osteopathy, and physio can play a key role for people managing physical symptoms such as pain, muscle spasms, and mobility.
- Over-the-counter medicines, which they may take to help with their MS symptoms.

> "I used to have oxygen therapy and physiotherapy but sadly can no longer afford them."

Healthcare hasn't been as badly affected by inflation compared to other areas, yet evidence still shows some healthcare prices have risen by up to 2.7% this year.[23] A lack of access to healthcare services on the NHS has also meant that some people are forced to go for private treatment, when they wouldn't otherwise do so. Rising prices in other areas may mean people have been forced to cut back spending on healthcare.

Monthly extra costs for help around the home

Over half (54%) of the respondents have monthly extra costs for help around the home. The average person with MS spends £104 a month on them.

These extra costs (Figure 7 on page 39) can include:

- Paying for a cleaner to clean their home, for example because they are unable to do this themselves due to issues with their mobility, pain or fatigue.
- Paying for a carer, for example if they need help to get ready in the morning due to their symptoms.
- Reimbursing family or friends who help them, for example if they ask a friend to do a repair in their home, as they find it difficult to do this themselves due to their symptoms.

> "It means that my floors are clean. Hoovering, any repetitive handheld task, I can lose power, and the pain can be worse. [Without a cleaner] we'd have a filthy house...we'd be in chaos."

> "I can't do much of anything anymore because I drop things and knock things over...it would be nice, someone to come in and clean for me."

It isn't clear to what extent inflation has affected the costs of cleaners and carers. However, barriers to accessing timely care through the social care system has led some to people paying for private care, when they wouldn't otherwise choose to.

Figure 6
Percentage of people with MS facing monthly extra spend on **healthcare** costs

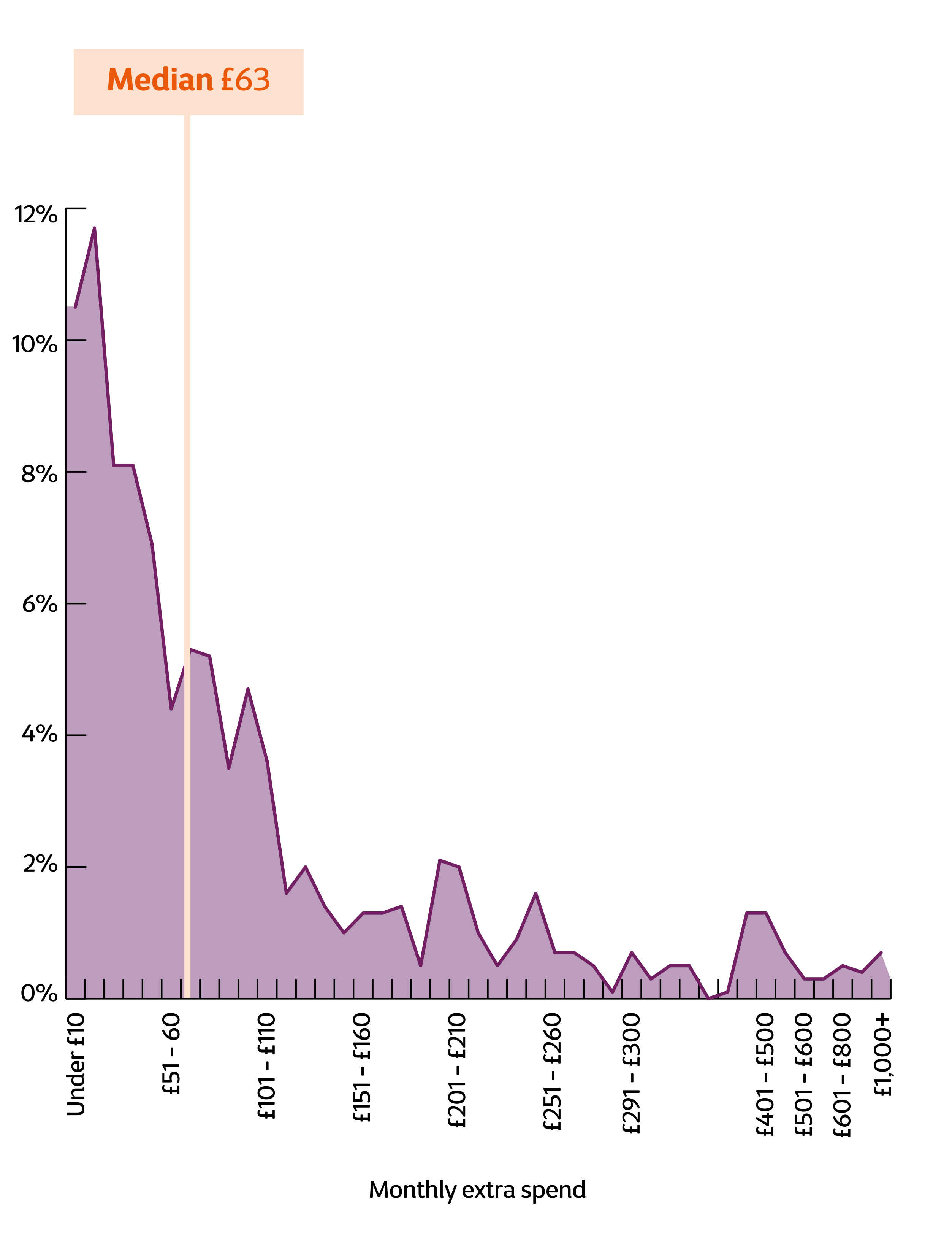
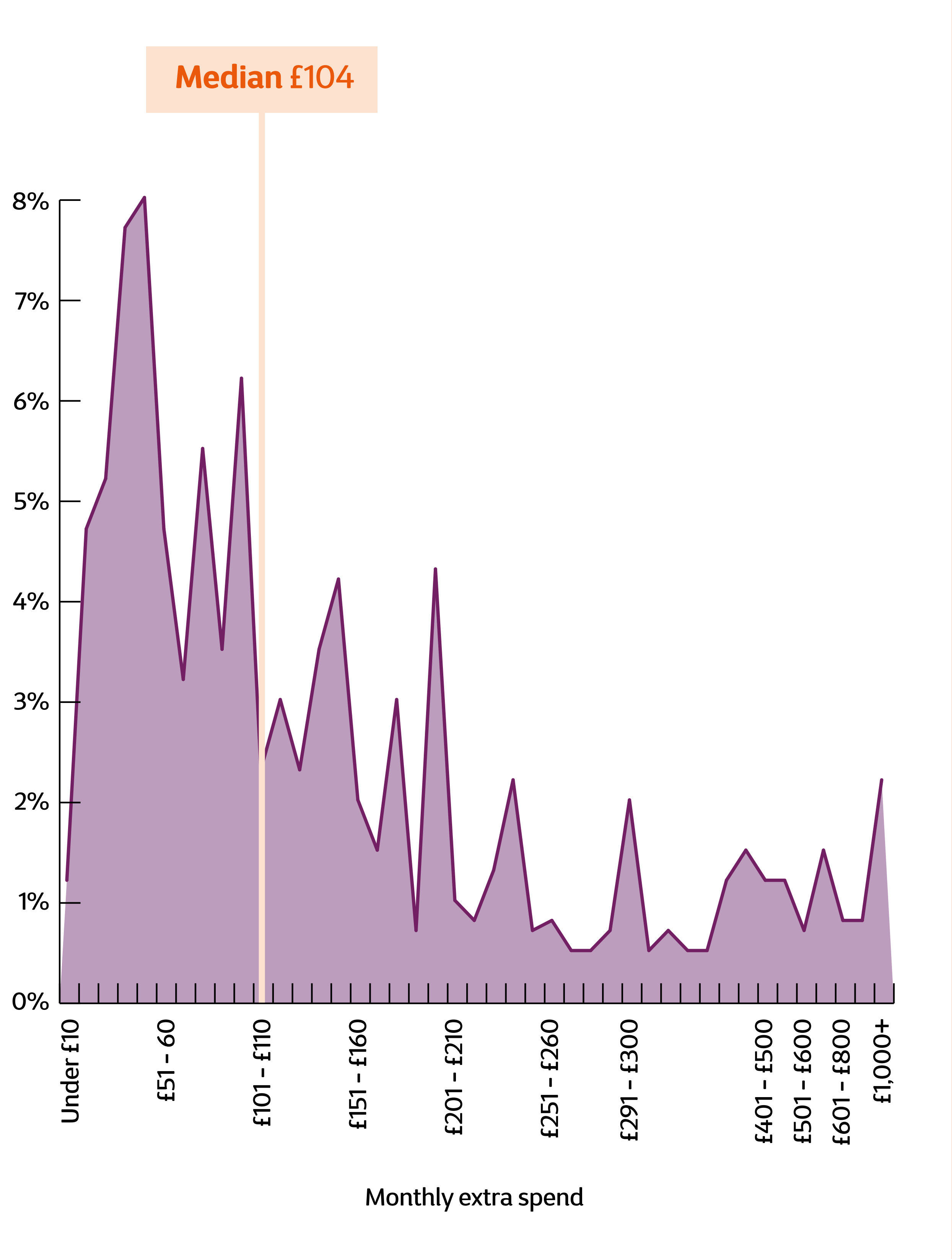


Figure 7
Percentage of people with MS facing extra spend on **help around the home**



Monthly extra transport and travel costs

Almost 6 in every 10 (59%) respondents have monthly extra transport and travel costs due to their MS. The average person with MS spends £60 on them. These extra costs can include:

- Paying for their own vehicle, such as leasing an adapted Motability vehicle so they're able to maintain independence and get around.
- Using taxis, such as to attend essential medical appointments, or get to work, because they are unable to drive or use public transport because of the symptoms of their MS.

> "My hospital is around 25 miles away therefore the petrol costs are significant."

These costs have been affected by inflation, for example, new cars have risen in price by 7% and taxi fares have increased by up to 9% in some areas.[24]

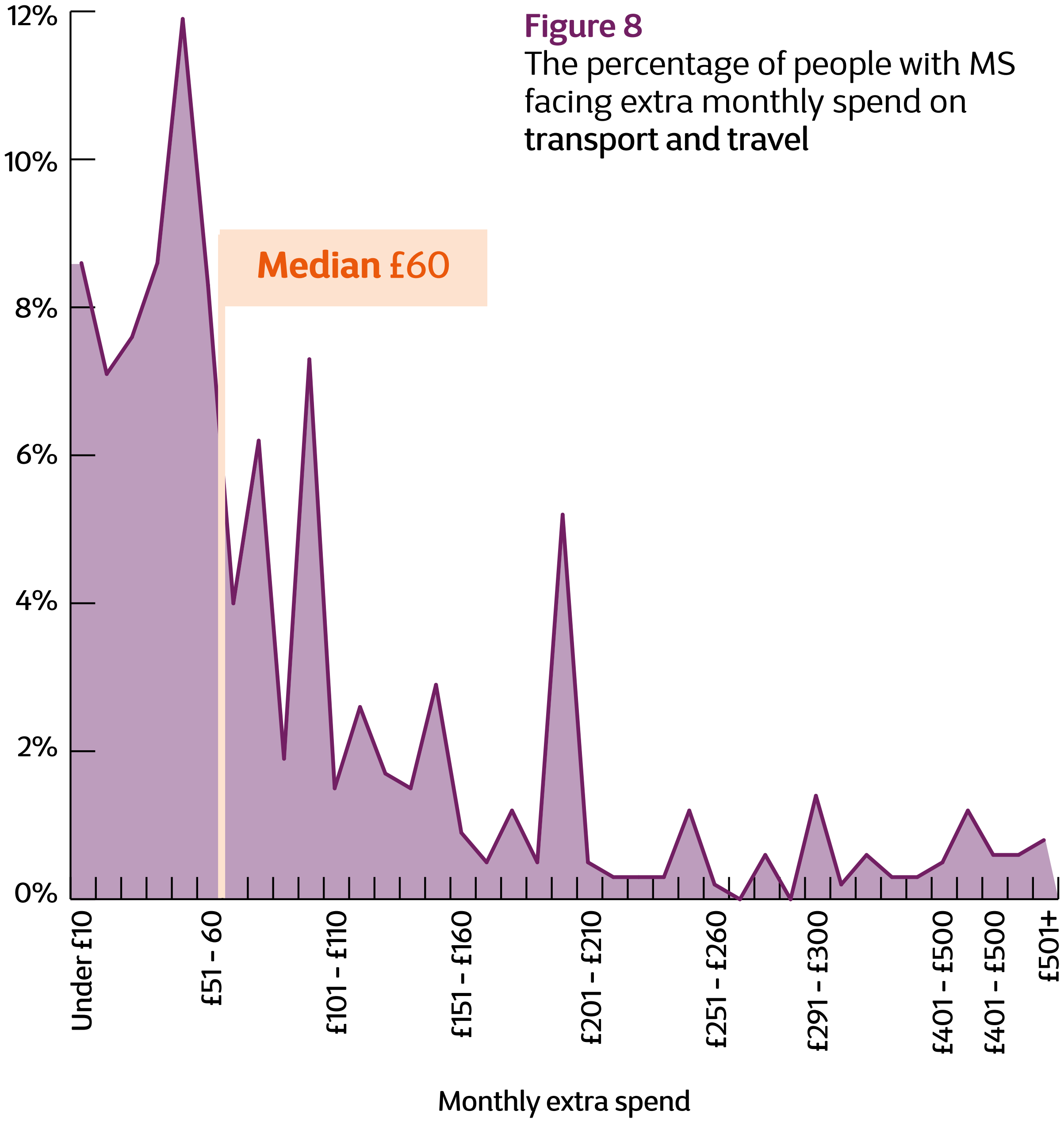


Figure 8
The percentage of people with MS facing extra monthly spend on **transport and travel**

Monthly extra day-to-day living costs

Over two-thirds (73%) of respondents say they have monthly extra day-to-day living costs. The average person spends £110 on them. These extra costs can include:

- Utilities, such as using the heating to help them maintain circulation or putting on fans in the summer to stay cool.
- Food expenses, for example because they have a special diet to help them with their symptoms or they have to shop online due to issues with their mobility.
- Rent/mortgage payments, for example if they have to pay more for housing which is suitable for their mobility needs.

> "I have things I use electricity for – a tumble dryer because I can't hang washing out, a dishwasher and electric wheelchairs, a stairlift – which all need charging all the time."

> "I've got plans in place which means I will just heat one room rather than heating the whole house."

These costs have seen particularly high increases during the cost of living crisis. For example, the energy price cap increased by 54% in April. More people now work from home than before the coronavirus pandemic, including many people with MS. While this way of working can benefit some people with MS, it has also sometimes led to higher energy costs due to them being at home more.[25] Many food items have increased in price by well over 10%.[26]

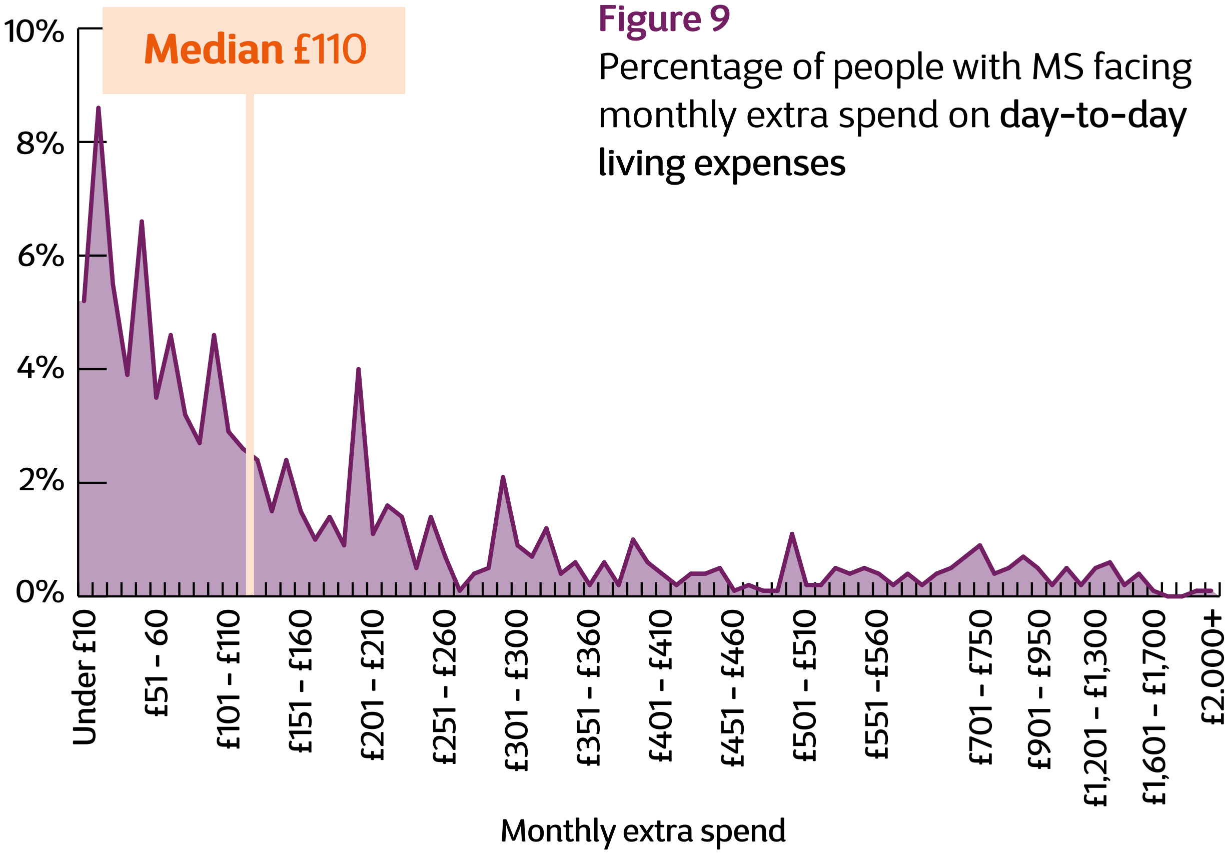


Figure 9
Percentage of people with MS facing monthly extra spend on **day-to-day living expenses**

One-off extra costs

Over two-thirds (67%) of respondents have faced one-off extra costs as a result of their MS. The average person with MS has spent a total of £2,035 on them. These extra costs can include:

- Paying for an adaptation in their home, for example to help them do activities and get around safely if they have issues with their mobility, such as a stairlift or special equipment for use in the kitchen.
- Paying for a mobility assistance vehicle, for example, buying a mobility scooter to use to get around they have issues with their mobility.
- Paying for adaptations to their vehicle, for example, an aid to help them get in and out of the car more easily if they have issues with their movement.

> “Various kitchen gadgets so I don’t cut my hands off. My sister calls it ‘indestructible oven gloves’ because I can burn myself quite easily and depending where the hot things land, I don’t always feel it.”

These costs have been affected by inflation: as outlined above, new cars have increased in price by 7%. Equipment people with MS may need to manage their symptoms has also gone up in value. For example, the price of heaters and air conditioners has risen by 17.2%.[27]

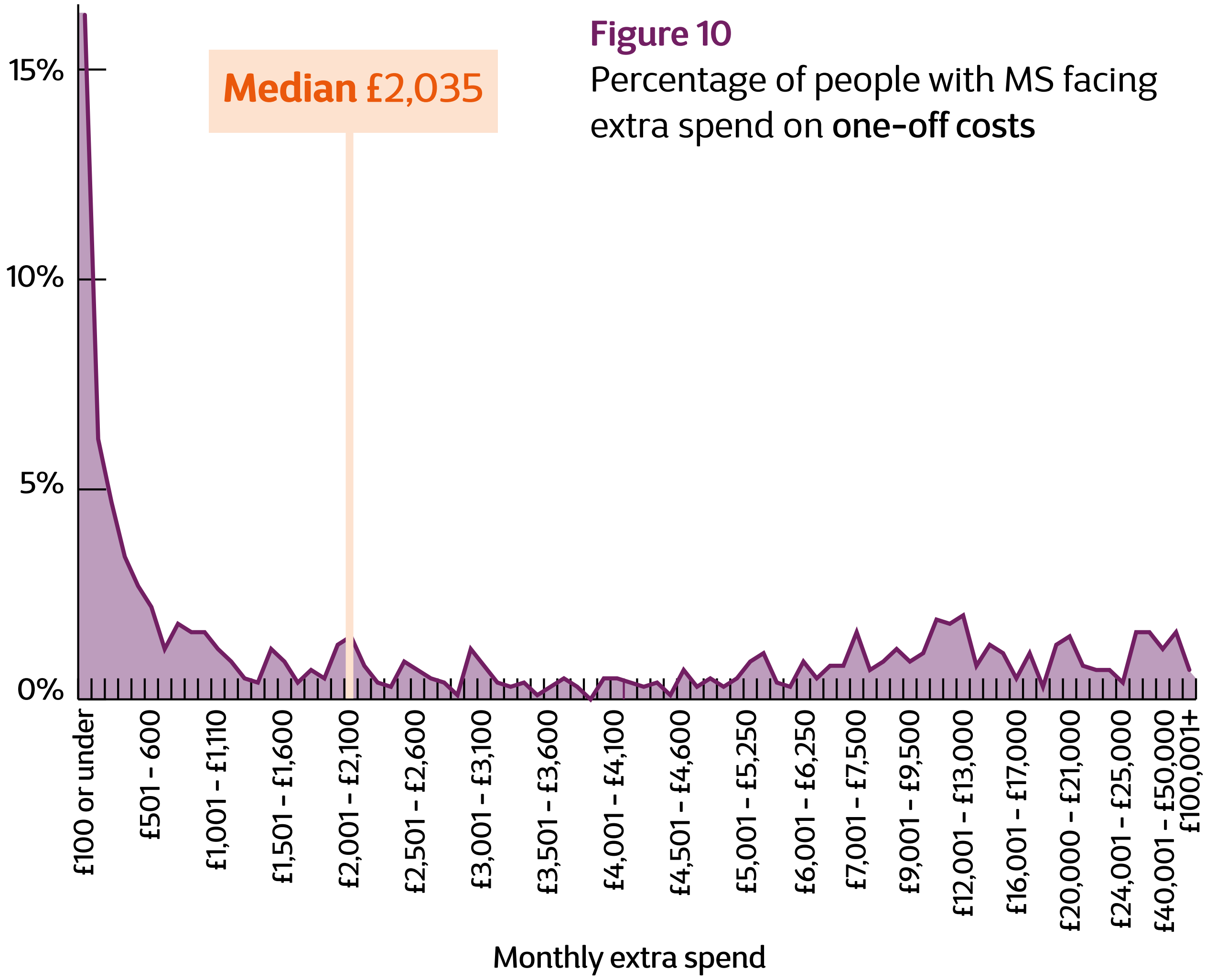


Figure 10
Percentage of people with MS facing extra spend on **one-off costs**

Annie

Annie is 71 and lives in Bolton with her dogs Bruno and Milly. She reluctantly gave up work because of her MS, and until recently volunteered at a local food bank. Now, Annie leads a virtual reading group and a mindfulness group.

Annie has been diagnosed with primary progressive MS. She suffers from numbness in her hands and legs, and has problems with her balance and vertigo. Annie also has quite severe bladder issues, which make her day-to-day life difficult. Fatigue is a big issue for Annie. “I can do one thing a day, I can get up, have a shower, get dressed, feed and walk the dogs. But on days where I need to do something else, like meet a friend or have a mindfulness group, I have to make sure I’m not doing anything else.”

Living alone, and with no family close by, Annie relies on others to help her with day-to-day activities. At the moment, she is able to pay someone to do this, but she says thinking about the future is “scary”. She has begun to look at ways to save money, including cutting down on energy bills by only heating one room, and keeping the temperature low. Annie was told by health care professionals that it is unsafe for her to walk up and down the stairs, especially at night so she now sleeps on the sofa. Annie has space to create a downstairs bedroom and “would love to” but the cost is too much.

Annie said taking part in this research has made her think about the extra costs she has because of her MS, in a way she hasn’t before. Many of the changes Annie made to accommodate her MS were made so long ago, that they are now a part of her life, “it’s just what I do, the research has made me realise how having MS controls and limits the choices I can make.”

People with MS on low incomes are worst affected by extra costs

It's people with MS on lower incomes who are particularly badly impacted by extra costs. Not only do they spend a disproportionately high amount of their income on them, but they also face the 'poverty premium'. This is where they are forced to spend more on the goods and services they need to live well compared to people on higher incomes. It is estimated the poverty premium costs the average low income household £490 a year.[28]

Examples of where people with MS on low incomes may pay more for the goods and services they need include:

- Living week-to-week so having to pay for their gas and electricity by prepayment meter, which costs more than paying by monthly direct debit.
- Having to pay for an adaptation to their home by monthly installments which works out more in the long run than paying for it up-front.
- Paying more for vehicle insurance as they live in a deprived area.

To make matters worse for people on low incomes, many of the areas where they are likely to pay more are where price increases have been the highest in recent months. For example, gas and electricity. In effect, people with MS on low incomes see their incomes squeezed on several fronts. By facing extra costs due to their disability, by struggling with rising prices during the cost of living crisis and by being subject to the poverty premium.

"Our grocery shop has gone up by about £30, So what would have normally cost us £100 is now costing us like £130."

"Cost of living is going up and at the same time my health and ability to work is going down – at some point there is going to be a point where people feel despair, but what can you do?"

5. Financial support is too low

Disability benefits are the main type of financial support people with MS get from the government. People with MS, in and out of work, claim them. Those who are unable to work and living on low incomes are particularly reliant on this support. Benefit rates should be enough to allow people to cover all their costs and to live well. But from speaking to people with MS, we know they are failing to do this. People have told us that inadequate benefit rates are one of the main reasons they are struggling financially.

> "I don't use them [benefits] for my MS, I use them to pay bills."

Disability benefits

The main disability benefits people with MS can claim can broadly be categorised into two groups: 'income-replacement' benefits and 'extra-costs' benefits.

There are different payment rates within each benefit, which are paid to people depending on their level of need. This is assessed by the government. In principle, those with a higher level of need should get a higher level of support.

Income-replacement benefits

- These benefits are intended to support disabled people with their essential living costs when they are unable to work due to their condition, or can only work limited hours.
- Given that as many as 80% of people with MS have to give up work within 15 years of their diagnosis many have no choice but to rely on these benefits to get by.[29] And many who are only able to work reduced hours due to their condition also need to claim these benefits to top up their limited employment income.
- These benefits are 'means-tested', which means people's incomes and capital are taken into account when calculating the level of benefit they are entitled to.
- People with MS who claim these types of benefits most commonly get Universal Credit or 'old-style' Employment and Support Allowance (ESA).
- Most people with MS who claim Universal Credit and ESA are placed in the 'Limited Capability for Work-Related Activity' group and 'Support Group' respectively. People in these groups have been assessed as being unfit to work and aren't expected to look for work or do any work-related activity.
- Old-style ESA is considered to be a 'legacy benefit' as it's gradually being replaced by Universal Credit.

Extra-costs benefits

- These benefits are intended to enable disabled people to cover the extra costs of their MS and to support them to live independently.
- They can be claimed by people in and out of work.
- They are 'non-means-tested', which means people's incomes and capital are disregarded when assessing eligibility.
- People with MS who claim these types of benefits most commonly get Personal Independence Payment (PIP) or Disability Living Allowance (DLA).
- People who get the highest rates of the mobility component of PIP and DLA can also lease an adapted vehicle from the Motability scheme. A share of their benefit is deducted to pay for this.[30]
- Over the last nine years, DLA claimants have been getting moved over to PIP, and people are no longer able to make new claims for DLA. In Scotland, PIP is being replaced by Adult Disability Payment (ADP) from August 2022 onwards.

How disability benefit rates are set

The Government says that disability benefits help disabled people to cover their costs and get by. But the rates of these benefits have never been set using an assessment of whether they meet these objectives. When disability benefits were first brought in in the 1940s, rates were set at a level which the government of the day saw as a 'compromise' between what it believed it could afford and what was deemed to be necessary for 'subsistence'.

Since then, benefit rates have been periodically increased over the years, primarily in relation to the value of earnings and prices. Most working-age benefits are increased annually in April, by reference to year-to-September inflation figures from the previous year.[31]

Increases haven't happened every year, as over the past decade, there have been some years where working-age benefit rates were frozen - most recently between 2016 and 2020 - or saw below-inflation increases.

This means benefit rates have fallen substantially in 'real-terms' over the years.[32] 'Real-terms' refers to a value that has been adjusted to take into account the effects of inflation. A real-terms cut to benefits happened most recently this year, when benefits were increased by 3.1% in April. This was a real-terms cut as the rate of inflation reached 9% in April.

The State Pension has typically been increased more generously by the government compared to working-age benefits. It's currently 'triple-locked', which means it has to rise annually at least in line with the highest of inflation, earnings or 2.5%.[33] But the State Pension also saw a real-terms cut this year when it was increased in April, for the same reason as working-age benefits.

Benefit rates are too low

No government has carried out or published an assessment of the adequacy of disability benefit rates since the 1960s, and successive governments have shown little interest in undertaking such an assessment.[34]

Recent policies have contributed to even further cuts to benefits for disabled people. The temporary £20 weekly uplift to Universal Credit applied during the coronavirus pandemic has now been removed.

Those claiming legacy benefits, such as old-style ESA didn't even receive this increase in the first place. This meant they missed out on about £1,500 of support through the pandemic despite being in very similar circumstances.[35]

The Government says current disability benefit rates do enable disabled people to get by. But by hearing from people with MS, we know that this is far from the truth. **Over half** (51.2%) of people with MS claiming means-tested benefits told us they are struggling or really struggling on their income.

The evidence from people with MS who claim benefits – set out across this report - paints a very concerning picture. People with MS are struggling to afford the basic essentials they need to live, such as food, heating and their medication, and the extra costs of their MS. One of the main reasons for this is because the financial support they get from benefits is so poor.

It's important to note that many people with MS who claim benefits are unable to work due to their MS, or can only work reduced hours. They've no choice but to claim these benefits to help them get by, and are unable to increase their incomes by working.

"I didn't choose to not be able to work, I've paid into the system. It just feels very cruel for people like myself."

As shown earlier in this report, many people with MS who rely on disability benefits have told us they are going hungry as they cannot afford to eat. And some have been forced to visit food banks to get support.

"The benefits I'm on, they don't go up with everything else. I went to Tesco last week and everything has gone up a £1. I was going to say I'm just about managing, but I'm not."

Many people with MS who claim disability benefits also told us they are unable to afford other essential goods and services they need to have a reasonable standard of living, such as medication and heating.

"My wife and I are supporting each other as much as we can; thanks in no small part because of the ongoing and excessive rises in electricity and gas; not to mention petrol. The way things are going we will not be able to heat our home over winter."

Becky

Becky has primary progressive MS, and lives with her husband, who is also her full-time carer. Becky's symptoms include difficulty with her memory, balance, and fatigue. Over time her mobility has got increasingly worse, and Becky has found ways to help her manage such as making sure furniture is placed in a certain way around the house.

It's important to Becky to stay active. She tries to go out with her friends once or twice a month and her and her husband like to visit a nearby lake and have a picnic, but this is something they have been doing less of because of the cost of petrol. Becky says they have to consider how much petrol is left in the car in case of emergencies. "If one of us needs to go to the hospital quickly then we can just go."

Becky describes her financial situation as "not very good". They rely on benefits such as PIP, ESA and Carer's Allowance as their main source of income and take things day by day. Becky has seen her food costs increase, but doesn't have the option to shop around like others. Her MS means that she is unable to walk around looking for cheaper alternatives, and there is only one shop that delivers to her.

Becky worries about having to pay for big ticket items like a washing machine or cooker and replacing things like a broken settee. At the moment they are able to save a little, but it goes very quickly on household things they need.

Regarding the future, Becky is worried about prices going up when her money isn't. She knows she is going to have to cut back on essentials, like clothing, food, and trips out. "I have to laugh, otherwise it's just crying and being depressed. I cope by making jokes and my husband does too."

[Talking about cleaner] "Prices will go up when the term starts again in September, it's only a pound an hour, but's that a bottle of milk. I cannot believe that I'm in that state now where I literally have to wonder whether I can afford a pint of milk."

People with MS who get disability benefits have had to reduce spending and increase their incomes. For many, this is in ways which are unsustainable on a long-term basis, and which could negatively their quality of life and health. People feel they've been forced into this situation to simply have any chance of being able to get by.

It's clear disability benefit rates are completely inadequate for enabling people with MS to live well. This isn't an issue that has emerged since the cost of living crisis began. For several years, far too many people with MS have told us disability benefits don't give them the level of financial support they need.

"Lots of things have increased in price especially energy costs; fuel and food. We budget for spend on a monthly basis; but even with budgeting find ourselves overdrawn far more often than we did previously. We even had notification today of an increase on our monthly electricity payments. We can no longer afford things we didn't think twice about before."

Inflation and rising prices over the last few months will be making the situation even worse, plunging even more people with MS into financial difficulty. It's now more imperative than ever before that the Government takes action to increase financial support for disabled people, including those with MS. Without the Government improving support, people with MS will continue to go without and this will continue to have a terrible impact on their health, quality of life and ability to live independently.

The government's own evidence, which was obtained and published by the Work and Pensions Select Committee this year, matches what we have heard from people with MS.[36] Some participants in the government's research who claim disability benefits reported not being able to meet the costs of their essentials, such as food and utility bills. Participants with very limited financial resources said an increase in benefit payments would improve their overall wellbeing.

The Government needs to urgently bring in financial support to make sure people with MS can cope with spiraling prices over the coming months. It needs to carry out longer-term reforms aimed at completely changing the way benefit rates are set and increased, to make sure that people with MS actually get a level of support that meets their needs.

"How are you going to help me as a disabled person on benefits? There are 4.5 million people on benefits that you're not even taking the slightest bit of notice of. They really need to start looking at who they prioritise."

"They haven't demonstrated in any shape or form any compassion for people with a disability…I don't think the Government care about people like me…For the Government to save money they should be taxing Amazon etc., not punishing the poor. It doesn't seem fair."

In May 2022, the Government announced a package of measures aimed at supporting people to cope with the rising cost of living.

Support is being rolled out from summer 2022 onwards and is primarily targeted at those on the lowest incomes. Those receiving income-replacement benefits, such as Universal Credit and old-style ESA, are getting a £650 payment.

Those on extra-costs benefits, such as PIP and DLA, are receiving £150. All households are being given £400 off their energy bills. Pensioners are being awarded a £300 payment.[37]

This means people with MS on the lowest incomes are to receive £1,200 in total, assuming they claim an income-replacement benefit and an extra-cost benefit.

And they can get the additional £150 as a council tax rebate if they live in one of the lowest four council tax band areas.[38]

> “My house is cold. How on earth are we going to pay for the heating? I don’t have anything extra. What is £150 going to do?”

Since the package was brought in, inflation has risen even further and many prices have shot up, which now means the level of support provided is no longer sufficient. Even after the September announcement of the ‘Energy Price Guarantee’ and the previously-announced energy bill rebate of £400, energy bills for low-income households are likely to be about £600 higher than last year. The cost of food and other essentials has gone up by £1000 during the same period.[39] This means the highest level of support someone with MS could receive is still around £800 less than the increases they can expect.

This is before we take into account any rises to the extra costs of having MS set out in ‘The extra costs of MS’ section of this report. Some people with MS have also told us they are using the support provided to pay off existing debts, rather than to keep up with rising prices.

There were other shortfalls in the support provided in the May 2022 package. Unpaid carers (people who provide informal care for friends and family) who get Carer’s Allowance – including those caring for people with MS - cannot get any of the one-off payments to benefits claimants.

This is despite this benefit having the lowest rate of its kind and the significant pressure informal carers have been under during the coronavirus pandemic and beyond.

Those claiming non-means-tested benefits, such as PIP, are no longer eligible for the Warm Home Discount Scheme. This means, in effect, the £150 one-off payment in the package for people claiming this benefit acts more as a replacement for being in the Warm Home Discount Scheme, rather than as a net financial positive for these claimants.

Urgent recommendation

Provide another cost of living support package

The Government must urgently provide another cost of living support package to make sure disabled people, including people with MS, can cope with the rising cost of living and get by over the winter.

This support should be based on four key principles:

1. It must be **enough** to help people cover all their costs. People have told us that they are already having to make impossible choices and are being pushed into debt. Without the right level of support, this is only going to get worse as we head into winter.

2. It must be provided **quickly** to people. People need to know that they are going to be able to pay their bills now and in the coming months.

3. It must be **targeted** and reach the people who need it most. This includes people with MS, who face extra costs due to their condition. And in particular, those living on low incomes.

4. It must be **flexible**. Over the coming months, the Government must regularly review whether the package is meeting its objectives. Where necessary, support must be increased again to enable people to manage rising costs. This would make sure people can be confident they will get the help they need as the crisis continues.

We are aware the external environment is changing rapidly and that the exact package that lives up to these principles may accordingly change with time. At the time of writing (28 September 2022), a cost of living package that meets these principles would be as set out below.

On top of the support already announced this year, at a minimum, the Government should provide:

- A £800 payment to anyone who receives means-tested benefits.[40]
- A £500 payment to anyone who receives Carer's Allowance.
- A £150 payment to anyone who receives non-means-tested extra-costs benefits.[41]
- A £300 payment to pensioners.

The first instalments of this support should be provided to people by 17 October 2022.

The Government should include those on non-means-tested benefits, such as PIP, in the Warm Home Discount Scheme. And it must urgently reduce delays in the initial cost of living payments being provided to those living in Northern Ireland.

This package would provide vital and direct financial support to people who are particularly badly impacted by the rising cost of living. This includes those living with MS who face extra costs due to their condition – and in particular people with MS who rely on benefits to support themselves.

The lack of support for people claiming Carer's Allowance in the original package would be redressed. And those claiming non-means-tested benefits would also get vital support through the Warm Home Discount scheme again.

During the coronavirus pandemic energy and food companies worked with charities and others to provide support for those most in need. They should consider how they may be able to support disabled customers, including people with MS, during this period of rising prices. Although this should not be seen as a substitute for the recommendations we set out above for the Government.

> "The way things are going we will not be able to heat our home over winter...We really do feel if not at the bottom of the pile; somewhere quite near to it; with little hope of improvement in the near future."

Rebbecca

Rebbecca was diagnosed with relapsing remitting MS in 2018. Her symptoms are wide-ranging and include brain fog, fatigue, low memory and problems with her balance. She currently works part-time in a secondary school.

When it comes to her finances Rebbecca says she is managing as best she can. But this is only because she consistently budgets and cuts back on certain things to make sure she has enough money including things she uses to manage her MS and her wellbeing. For example, physiotherapy, massage and yoga. Unfortunately, Rebbecca has chosen to stop these so she can afford to pay her electricity, gas and food bills. This is despite knowing they were helping her symptoms and mental health.

Rebbecca wishes she was able to support herself more independently – such as support with cleaning which she finds very difficult, or getting from A to B in a taxi – and not have to rely on her family’s generosity. She says even though her Dad drives her around, and doesn’t mind doing this, she would like to have the choice to say she can do it herself.

Rebbecca tries hard not to stress too much or worry because she’s conscious there are people worse off than her, but also because she doesn’t want to make her MS worse. This was one of the reasons why, until recently, she chose not to apply for PIP. She has now applied, because of the impact her MS has on a daily basis and the rise in the cost of living. She hopes that if she gets PIP it will help her pay for things which will help her manage her MS and mental health too.

Recommendation:

Change how benefit rates are set and increased

Another cost of living support package - as set out above - will provide a vital lifeline for many disabled people, including people with MS. But it's a short-term measure for the long-term problem of inadequate disability benefit rates. Benefits should be supporting people with MS to live fulfilled and independent lives, and this should be the case regardless of whether someone can work or not. But our evidence has shown that benefits fail to provide many people with MS with even the most basic standard of living.

The Government needs to completely change the way it sets and increases disability benefit rates. This should be done to make sure that disabled people, including those with MS, aren't only able to keep up with the cost of living, but actually get the level of financial support they need to live well. The Government should commission an independent review of the adequacy of all benefit rates:

- This should include an assessment of the adequacy of current disability benefit rates for enabling disabled people, including people with MS, to cover all their costs and meet their needs.
- The aim of the review should look at what level of income is needed for someone to have a 'socially acceptable' living standard - as defined by research on Minimum Income Standards - rather than one that just keeps them out of destitution.[42]

Following this review, the Government should increase benefit rates to a level which enables everyone to have a socially acceptable living standard, as identified in the assessment. For people with MS, this would be an income which allows them to cover all the costs, and to be able to live a fulfilled and independent life. This should be regardless of whether they can work or not.

While these measures would improve the incomes of people with MS, the Government would also need to change the way it periodically increases benefits to better support people on an ongoing basis. This would be important for protecting the incomes of people who claim benefits against the effects of inflation. The Government should change the way it periodically increases benefits:

- All benefits should be increased every six months by at least the rate of inflation. This should be done using the 12-month inflation rate from the previous quarter.
- All benefits should be included in these twice-yearly increases, including legacy benefits and Carer's Allowance.

These policies would allow for benefit rates to better keep pace with inflation, and provide a greater level of ongoing protection to the incomes of people with MS who claim disability benefits.

> "Increasing benefit rates would vastly improve the lives of people with MS and help ensure everyone with MS is able to afford to pay for food, bills and their housing costs, as well as all the extra costs needed due to their MS."
> MS Welfare Benefits Adviser,
> Disability Law Service

6. Benefit policies reduce incomes

There are other benefits policies which negatively impact the finances of people with MS. People with MS who claim benefits may have money automatically taken from their benefit to pay off debts. This can trap them in an ongoing cycle of debt and financial struggle. The benefit cap also unfairly reduces the amount of benefit some people receive.

Debt deductions from benefits trap people with MS in a cycle of debt

The government can automatically deduct money from people's benefit payments to pay off debts to government sources, such as for Universal Credit advance payments and council tax arrears. They can also be for debts to private creditors. Compared to other forms of debt collection, most deductions are automatically made at a fixed rate and affordability assessments aren't conducted before they are made.

While it's not clear how many people with MS face these deductions, evidence shows that 1.8 millions households in receipt of Universal Credit have been subject to them.[43] It's therefore likely that many people with MS are having money taken from their benefits in this way. To some extent, the Government has recognised benefit deductions can cause difficulties, by reducing the maximum amount that can now be deducted from 40% to 25%. This is a positive move, but it still means the government can automatically deduct a significant amount of money from someone's benefit without conducting an affordability check beforehand. During the current cost of living crisis, the Government has encouraged private creditors to pause or write off debt repayments for people struggling financially. But, according to the Work and Pensions Select Committee, the government isn't 'following its own advice' as it's still deducting money from people's benefits even while inflation is high.[44]

Urgent recommendation

Pause debt deductions from benefits until benefits are increased

During the current period of high inflation and rising prices, it's vital the Government reduces the financial pressure created by debt deductions.

It must:

- Pause all deductions from benefits for debts to government sources, and only gradually bring them back in as the rate of inflation decreases or when benefits have been increased by at least the rate of inflation.
- Strongly encourage creditors to pause debt repayments from benefits for the same period, or where possible write them off.

Recommendation:

Restructure debt deductions policy so people aren't trapped in a cycle of debt

In the longer-term, the Government must make wider changes to how debt deductions from benefits work to make sure they are always manageable for people. It must:

- Make sure affordability assessments are always carried out before any deduction is applied.
- Make sure government staff proactively check in with claimants around whether deductions are causing financial difficulties, and offer to lower or pause them if they are.
- Replace the current approach of Universal Credit advances with non-repayable grants.

The benefits cap adds to the financial struggles of people with MS

The benefit cap is an overall limit on how much each household of working age can receive in benefit payments in any given year. The cap affects some benefits but not others. It affects Universal Credit and ESA, but not PIP and Carer's Allowance. People over the State Pension are also not affected. The maximum amount a household can receive is £23,000 inside London, and £20,000 outside London.[45]

For people with MS who are subject to the cap, it can affect them worse than non-disabled people. This is because people with MS typically need a higher income to have a good standard of living due to their extra costs.

The Government has tried to justify the cap by saying there are ways for people to avoid it, for example, taking up work, moving to cheaper accommodation or taking in a lodger.[46]

However, these options aren't possible for many people with MS. And it's unfair to put the onus onto people claiming benefits to avoid the cap by forcing them to make life choices they might not otherwise have to make.

Recommendation:

Scrap the benefits cap for disabled people

The Government must reduce the financial pressure people with MS experience due to the benefit cap. It must:

- Remove the benefit cap for everyone who receives a disability-related benefit.
- Make sure this includes removing the cap for those in the work-related activity group of ESA or equivalent in Universal Credit.

Ju

Ju is a mother and grandmother, diagnosed with relapsing remitting MS in her late 20s. Now 48, Ju is possibly transitioning to secondary progressive MS after noticing her symptoms changing.

She has the start of drop foot and has been referred to a physio, and has been getting spasms and claw hand too. Ju also suffers from neuropathic pain, "cog fog", fatigue, and bladder issues at night.

Ju is worried about the future, especially winter and keeping her home warm. She relies on coal and wood to heat her home and water, which she normally saves up for to use over the winter.

This year, due to having to pay a large down payment on her Motability car, she has been unable to do that. "It's wiped out our savings for winter. It's just gone". Ju is considering steps she can take to save money, such as swapping baths, which help her relax, for showers.

Ju is on her third DMT. Living in a rural area makes it expensive to attend regular appointments to monitor her side effects. They have come to an agreement to limit appointments to twice a year. Ju has also cut back on other therapies which help her to manage her MS, including massages which lessen her spasticity, and reduces the tightness in her limbs.

Overall, Ju says that her mental health is suffering, she has no savings, she's not prioritising her social life, and looking to the future knows that it is "going to be very difficult".

7. Financial support is too difficult to access

Many people with MS tell us they are struggling financially because they've found it difficult to access benefits they are entitled to in the first place. Some people with MS are missing out on support because they aren't aware it exists, or they struggle to find out what they might be able to get.

Problems with the assessment process for disability benefits are leading to lots of people being awarded a lower level of support than what they should be getting. Far too many people with MS are even put off applying for benefits because they are worried about navigating the assessment process.

Signposting and support to access benefits doesn't work for people with MS

Signposting and advice provided by the government isn't clear enough to help people with MS understand what support they can get and how to apply. They've told us it's hard to find clear information about all the benefits they may be eligible for. There is a sense that information about benefits is scattered around in different places. Some feel that the government isn't open enough about the help they provide to disabled people.

Urgent recommendation

Improve signposting and support to access benefits

The Government needs to improve the signposting and support it gives to disabled people, including people with MS, to help them more easily access benefits and wider support. It must:

- Make sure anyone applying for a benefit is given information on all support available to them. This should include information on benefits and wider support, such as housing and social care.
- Make sure anyone starting a claim for a disability benefit has the right to be assigned a single point of contact to help them navigate the claim process and beyond.

> "They should be open... 'this is what you're entitled to, what is your living situation', and that support should be there for you, because when you come from a full-time job and you're just thrown into this world, it's like they keep it hidden from you."

> "I put off claiming PIP...I'm concerned about putting myself through such a stressful process and worsening my symptoms...but I've applied for it now because having the extra money will help."

People with MS have also told us they were left to their own devices to navigate the whole benefit claims process, as they didn't get any support from government staff. These issues lead to people with MS struggling to access the benefits they need, and cause them to experience struggle through lack of support.

The latest government figures show that many people who are likely to be entitled to disability benefits are not getting them. For example, 307,000 people who are unfit to work and claiming Universal Credit are not getting PIP or DLA.[47]

A lack of support from the government to access benefits means some people have to rely on charities to help them get what they're entitled to. For example, since 2019, the MS Society's MS benefits advice service estimates it has helped its clients gain over £2,366,000 new benefits claimed and successful appeals.

How people are assessed for disability benefits

To access disability benefits, people with MS need to submit an application to the Department for Work and Pensions (DWP) and then go through an assessment process. People have to do this for any disability benefit they wish to claim. The Work Capability Assessment (WCA) is carried out to assess eligibility for Universal Credit and ESA.[48] The PIP assessment is done to assess eligibility for PIP.[49] Assessments are carried out by private companies on behalf of the government.

After people have submitted their claim for a disability benefit, they usually go through a face-to-face, phone or video assessment with a healthcare professional, who asks the claimant how their condition affects their day-to-day life and mobility. The assessment process also looks at evidence from the claimant. This is usually from medical professionals who know them, or family members. Sometimes, someone can be assessed using their evidence alone, and they aren't asked to go through an assessment. This is called a 'paper-based' review.[50]

Following the assessment, a report is submitted to the government, and it makes the final decision on what level of support is to be awarded to the claimant. If someone isn't happy with their award they can appeal the decision. They do this by submitting a 'Mandatory Reconsideration', and then if they are still unhappy with the decision after this, they can appeal through an independent tribunal process. Some people get a revised award after going through these processes.[51] The process will be different for some people with MS living in Scotland from August 2022 onwards. This is set out in more detail at the end of this section.

The assessments process doesn't work for people with MS

Many people with MS have told us issues with the assessments for disability benefits are causing them to miss out on the level of financial support they should be getting. People may be forced to go through a long and stressful appeals process to finally get the support they are entitled to, but not everyone has the energy for this. Some people are put off claiming in the first place, as they are worried about the whole process. Others already claiming delay telling the DWP that their symptoms have got worse, because they are so worried about losing the support they already have.

The Government must make several changes to the assessment process to make sure all people with MS get the financial support they are entitled to easily, the first time round. It needs to carry out both short-term, urgent improvements to the process, as well as longer-term reforms.

Urgent recommendation

Reduce delays, assessments and re-assessments

The latest PIP statistics, released in April 2022, show new claimants are waiting on average 20 weeks between registering a claim for PIP and receiving a decision. These delays mean disabled people, including some people with MS, who are claiming PIP for the first time are waiting many months until they actually get their award. This leaves them without vital financial support during this period.[52]

The Government must:

- Reduce delays in the PIP process to make sure disabled people get the financial support they need as soon as possible.
- Make sure everyone gets a decision within six weeks of first making a claim for PIP.

Far too many people with MS are still asked to go through face-to-face, phone and video assessments when they have enough evidence for a paper-based review to be carried out. These assessments are completely unnecessary and create stress for people going through them. And they sometimes lead to them missing out on the support they need because they weren't assessed accurately.[53]

The Government must:

- Make sure claimants are only asked to go through assessments where there is a lack of evidence to do a paper-based review.
- Assessors should always exhaust all possible avenues to gather reliable evidence from the claimant, people who know them and their medical professionals to make sure they only have to go through an assessment as a last resort.

> “I get PIP, full for mobility and standard for daily living...my condition is deteriorating but I wouldn’t want to reapply because it can also go in the other direction. I’ll wait till my renewal is due in 2024.”

People with MS are also often asked to go through unnecessary repeat assessments. The government’s stated objective of repeat assessments is to make sure people are receiving the right level of financial support over time. This could be because they may be entitled to more support as their condition gets worse. But assessments may also be done to see if people should get less support if their condition improves over time.[54] For people with MS, repeat assessments to see if their condition has improved are unnecessary. There is no cure for MS and it’s a progressive, lifelong condition. Someone’s MS won’t improve significantly, and their need for support won’t diminish over time. Repeat assessments being carried out poorly can also lead to people losing the level of award they previously had.[55]

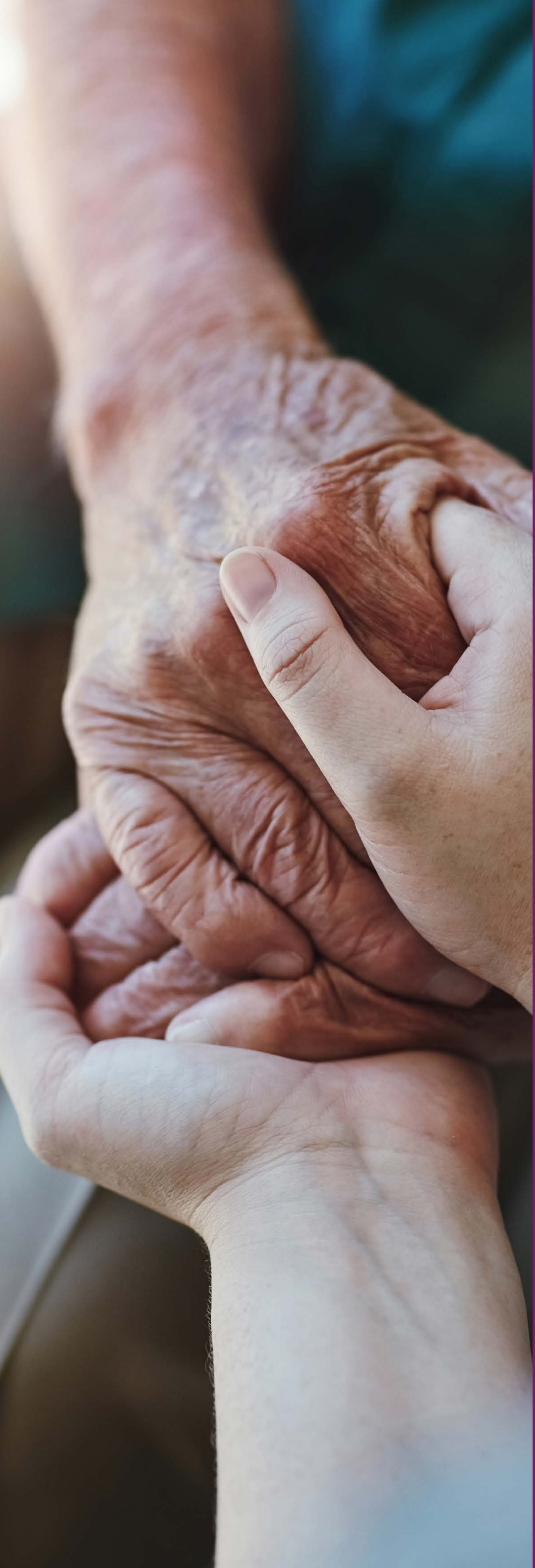
> “There are people you meet along the journey who don’t make it and you’re told that the stress and aggravation of going through the PIP process and then being refused, they’re bad and then broken...It’s barbaric.”

It’s important for the government to identify whether the needs of people with MS increase over time, and increase support accordingly. But this doesn’t need to be done through compulsory repeat assessments.

The Government must:

- Scrap unnecessary repeat assessments.
- Make sure people with progressive, lifelong conditions are given ongoing indefinite awards.
- Make sure people not on the highest award rates are contacted every three years in a way that suits them to check if their need for support has increased. If they say it has, they should be able to choose to be re-assessed to get higher support.

> “Believe the reports of GPs, Consultants, carers, family etc. who know the person and their problems. Assessment from a stranger with an agenda and quotas to meet is absolutely the wrong way to do it. I have felt humiliated, mistreated, judged, looked down upon, misunderstood and terrified by the assessment process. Doctors and carers know their patients/clients and have all the information about them to hand, it would be far more straightforward and less costly to use this information and certainly far less stressful for the claimant.”



Michael

Michael lives in Worcestershire and was diagnosed with primary progressive MS in 2016, but had been having symptoms for many years prior to this. He experiences a wide range of symptoms, including fatigue, drop on one side, bladder issues and balance problems. Describing his current financial situation in three words, Michael says “stretching the budget” and that sometimes he’s finding that there’s not enough money in the month. He is worried about the future, and is trying to save money where he can, including cutting down the amount of energy he uses.

Michael finds other therapies and treatments can help him manage his MS, but these have had to be cut as he tries to save money. For example he uses a podiatrist, but has decided that this is something he can’t afford to do regularly. A higher priority for him is to be able to afford incontinence pads, and even then he’s had to find a cheaper product.

Friendships are important to Michael. He is often invited out with friends, but won’t go if he can’t afford it, not wanting to rely on other people to pay, even when they offer. He is worried and says he’s aware if you keep saying no, you will stop getting invited. Michael finds this frustrating saying that it’s a balance between maintaining those friendships and being sensible about what he can afford to do.

Michael tries to take the approach that things could always be worse, and that sometimes “you have to try to get on with things and manage within the limits you’ve got”.

Recommendation:

Improve how assessors carry out assessments

Assessments sometimes lead to people being awarded the wrong level of financial support because they aren't carried out properly. Some people with MS have said their assessor didn't assess whether they could do an activity safely, reliably, repeatedly and in a timely manner – as guidance state they should - and assessed them by making an 'informal observation'. For example, this could be when an assessor assumes an individual can walk 20-metres because they watched them walk across the car park to the assessment centre. But this failed to consider the hidden symptoms walking may be causing such as pain and fatigue, and whether the person could walk the distance again.[56]

> "Not all our disabilities are obvious and people cope in different ways. For example: through MS I lost the sight in my left eye, I suffer severe fatigue and frequent bouts of brain fog and falling. To the observer I appear to manage fine - but I don't, it takes me days to recover from a simple trip out. I know I am not the only one."

Assessors play more of a deciding role in assessments than a person's healthcare professional and those who know them best. People with MS have told us this is one of the main reasons why assessments don't work for them. Without a good understanding of MS, assessors are often unable to ask the right questions to help them understand how someone's MS affects them.[57]

> "People who have very limited awareness of your condition are asked to score you subjectively on what they think you can and cannot do based on a report from an outside medical 'professional' who has never seen that claimant before."

Many people with MS have said they found the assessment process itself upsetting and unempathetic. This can make the assessment process stressful for people with MS, and can aggravate their physical and mental health. It has also led to others who have heard of these experiences through word-of-mouth not applying in the first place for fear of going through the same thing.[58]

The Government must:

- Make sure informal observations should no longer play a role in the WCA and PIP assessments.
- Make sure people with MS are only assessed by assessors who have some professional experience of neurological conditions.
- Make sure all staff working for and on behalf of the government treat all disabled people with empathy, dignity and respect at all times. This standard should be enforced across all government services.

> "They need to develop some empathy and look at individuals, not just some amorphous, nameless, faceless mass. But one by one, individually, they need to make some connection with the real lives that real people actually live. People with disabilities, chronic illnesses."

Recommendation:

Improve the assessment criteria

Assessments also often don't work for people with MS because the assessment criteria itself fails to properly take into account the fluctuating nature of MS and hidden symptoms. In particular, the 20-metre rule for assessing mobility in PIP is an arbitrary measure which fails to reliably indicate what the mobility needs of people with MS are. The 20-metre rule was introduced when PIP replaced DLA, and means that people who can reliably walk even the smallest distance over 20-metres can no longer receive the highest rate of mobility support.[59] The 20-metre rule has had a negative impact on many people with MS. By losing the highest rate of mobility support, many people with MS have ended up receiving a lower level of financial support. They've also lost access to an adapted vehicle from the Motability scheme. This has led to people becoming more isolated from family and friends, and made it harder for those who can work to be able to do so. And for those who don't own a car already, losing out on financial support has meant they can struggle to afford taxis when they cannot use public transport.[60]

The Government must:

- Work with disabled people, disability charities and health professionals to review and change the WCA and PIP assessment criteria to make sure they more effectively consider the fluctuating nature of MS and its hidden symptoms.
- Scrap the 20-metre rule for assessing mobility for PIP. A review and design exercise should come up with an appropriate alternative, and in the meantime, the 50-metre threshold should be reinstated.

Scotland - Adult Disability Payment (ADP)

In Scotland, PIP is gradually being phased out and replaced by ADP from August 2022 onwards. For most claimants, entitlement conditions for ADP are effectively the same as PIP. The two components are paid at the same rates, and the assessment criteria, including the 20-metre, is the same. The benefit is also not means-tested or affected by work.[61] Only time will tell whether ADP will work well for people with MS living in Scotland. However, on paper, some of the differences between ADP and PIP are positive, and it's possible these will lead to people with MS getting the financial support they need more easily. The Scottish Government says that assessments will only be used as a last resort for ADP, and where at all possible, decisions will be made on the basis of evidence alone. Assessments are carried out by Social Security Scotland, a government body, rather than by private companies.[62] The Scottish Government has also committed to review the 'moving around' component of ADP, including the 20-metre rule, in the coming year.[63] Claimants on the highest components of ADP whose needs are highly unlikely to change may be eligible for an 'indefinite award'. In effect, this means that some people may not need to go through reassessments or reviews and can rely on their new benefit for the long-term.[64]

Vince

Vince is 50 years old, and lives alone in Lancashire. He was diagnosed with MS 10 years ago and his symptoms include issues with his balance and memory. Vince is medically retired, so his main source of income comes from his pension and PIP. Vince says he has down days sometimes, but that he tries to look on the bright side.

Once an avid runner, it's important to Vince to remain active, so he tries to walk as much as he can, using a walking stick to help him. Vince still plays an active role in his local running club where he has friends, but unfortunately has found he's been going less because of the extras that come with attending. "I was going to go along [to the Great North Run] with friends, in memory of another friend, but it's the added expense of bus, tram, train, somewhere to stay. I can't do that."

Vince uses the bus to get around, and has a disability bus pass. He says no longer having a car has saved him some money but without the bus pass that wouldn't be the case. At the moment he's using the savings he's made to pay for a cleaner and a gardener, things he's unable to do himself. Vince says not having this support could lead to worsening symptoms putting pressure on the local health and care system.

Vince says he's ok at the moment, but that it's a fine line. He's reduced the amount of money he's saving, but is also tapping into them more regularly. He says he can see them slipping away. He is also making savings when it comes to his food shop, saying it's cheaper to eat rubbish than it is to eat sensibly.

Vince says emotionally, he's hanging on, and that for him, the mental side of being in financial difficulty is what he finds hard.

8. Lack of access to wider services and support

Struggling financially can make it hard for people with MS to access many of the things they need to be able to lead a fulfilled and independent life, such as care and transport. But barriers to accessing these can also **contribute** to financial struggle. For example, for those who can work, not having the right care or access to suitable transport can make it difficult to get ready in the morning and get to their job. And this could reduce their ability to stay in employment.

The Government must improve services and support for many of the things that support people with MS to live well, in order to help them financially. This includes social care, healthcare, employment, housing and transport.

Social care

The social care system across UK should be meeting the needs of people with MS. But our evidence shows this isn't happening. For example, 1 in 3 people with MS in England don't get support with essential day-to-day activities.[65] A lack of access to timely, affordable and appropriate care is contributing to financial struggle in the MS community. Without the right care and support, people's MS can get worse, which can cause costs to further rise. If someone has increased extra costs due to their condition, they must make their income go further to meet their needs.

Some people with MS may have to pay for private care as they cannot access free, affordable or suitable care through the social care system, adding further pressure to their finances. Lack of care can also make it hard for those who can work to find and stay in employment. Some people need help getting ready in the morning, and without this support, being able to work is made much harder.

The UK Government and devolved nations are currently considering plans for improving social care. In each of the nations of the UK, the Government must:

- Increase social care funding to make sure all disabled people, including those with MS, can get the care they need, while protecting them from high costs.
- Improve pay and conditions across the social care sector, which are a major contributing factor in workforce shortages.
- Provide more training to support the care workforce to provide individualised, appropriate and person-centred care.

Many family and friends also provide care for people with MS (often called 'informal' or 'unpaid' carers) and they are missing out on support. This form of care can be vital to people with MS, but often those providing it don't have the practical, emotional or financial support they need. Many informal carers rely on Carer's Allowance, a benefit paid to those caring for someone for more than 35 hours a week. However, it's paid at a very low rate, and there is a lack of support, with carers being given little respite or opportunities to take a break.

The Government needs to provide better support for informal carers. To do this, it must:

- Include people claiming Carer's Allowance in eligibility for the new cost of living support package we proposed earlier in this report.
- Increase the rate of Carer's Allowance every six months by at least the rate of inflation from the previous quarter.
- Implement the Carers Leave Bill, giving carers a right to 5-10 days unpaid leave, and look to introduce 10 days' paid leave in the near future.[66]

Healthcare

Having timely access to appropriate healthcare support and services is vital for helping people with MS to effectively manage their condition. In particular, people with MS can benefit from rehabilitation services to help them maintain physical and emotional health and wellbeing. This could include physiotherapy, speech and language therapy or seeing a continence specialist.

Despite the importance of this support to people with MS, far too many people have been unable to access it. Our evidence from August 2020 showed that 7 in 10 people with MS hadn't been able to speak to a rehabilitation professional when they needed to.[67] People with MS also experience barriers to accessing emotional and mental health support. Only 36% of people with MS who wanted to access mental wellbeing support reporting they had been referred onwards by a health professional.[68]

People with relapsing MS, and some forms of progressive MS can be prescribed Disease Modifying Therapies (DMTs). DMTs are a vital form of MS care as they can slow the progression of MS disease in eligible patients. There are now over a dozen licensed DMTs available on the NHS. These can decrease the number and severity of relapses and slow the speed of progression in eligible people with MS.[69]

However, many people with MS who could benefit from DMTs aren't able to access them. Our evidence shows that being able to speak to an MS specialist and get the right information is key to accessing these treatments. In our 2019 survey, we found of the people who hadn't seen an MS nurse or neurologist in the past 12 months, just over 17% were on a DMT, compared to 65% who had seen a specialist.[70]

Access to symptom management treatments for people with MS is also poor. Symptom management treatments can help with problems such as spasticity and walking, supporting people in managing the day-to-day effects of their MS. Licensed SMTs for MS include Sativex, Fampyra and Botox. NHS prescribing data shows that just 18% of those eligible are able to access Sativex on the NHS in England.[71] Access to Fampyra is even poorer, with NICE having rejected the treatment for use on the NHS in England on the basis of lack of cost effectiveness. People with MS are therefore being driven to private prescriptions, with many spending as much as £500 a month to access these treatments in order to manage their symptoms.[72] For many this is simply too much. People have told us they face choices between heating and paying for the prescriptions they need to manage their symptoms.

If someone is unable to access the rehabilitation or treatments they need, their condition is more likely to progress. This potentially reduces their ability to work and increases their extra costs. This could lead to their incomes getting squeezed further. They may be forced to pay for rehabilitation or treatments privately, which puts them under even more financial pressure.

The Government should reduce the barriers to healthcare experienced by people with MS, which can contribute to financial struggle. It must:

- Make sure all people with MS have timely access to appropriate health services, including a full multi-disciplinary team.
- Make sure all MS teams have enough administrative staff to carry out non-clinical duties.
- Make sure there are enough Allied Health Professionals and other staff with appropriate specialism to deliver rehabilitation and mental health support.
- Make sure conversations about treatment options, including DMTs, begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
- Make sure all licensed treatments for MS are made available on the NHS across the UK.

You can read our Neurology Now report for more information on the barriers people with MS face to accessing healthcare.

Employment

Most people with MS start experiencing symptoms during the peak of their working lives, and 80% retire within 15 years of their diagnosis. Many say leaving work was the right thing to do, usually because their MS symptoms had made working too hard. However, others were forced to exit their job earlier than they wanted to. Having to leave work earlier than they wanted can lead to people struggling with their mental health, their MS symptoms may get worse, and they can experience a big drop in income.[73]

Often people have had to leave work because they couldn't get the support they needed from their employer or the government to stay in work. Support that can help people with MS at work can include 'reasonable adjustments'. These are changes that an employer must make to remove or reduce a disadvantage related to an employee's disability. This could include an employer allowing an employee to work flexibly so they can manage their condition better at work.[74]

While most people with MS are unable to work due to their condition, employment can be an important part of the lives of some in the MS community. And it can help them to increase their incomes. But without the right support from the government and employers, too many people with MS will struggle in the workplace, and be forced out of employment.[75]

The Government needs to improve support to help people with MS stay in work for as long as is right for them. It must:

- Strengthen the Equality Act duty for employers to make reasonable adjustments. This should include making employers give a written response to employees' requests for reasonable adjustments within two weeks, and give a timeframe for when the adjustments will be put in place.
- Improve statutory sick pay (SSP) by allowing people to claim SSP from the first day they are ill, and bringing the SSP rate in line with the National Living Wage.
- Improve the application and renewal process for Access to Work, and reduce delays. Access to Work is a government scheme which provides practical and financial support to disabled people to help them move into and stay in work.[76]

You can read our report Employment without barriers for more information on how people with MS face barriers to employment.

Housing

Not having access to accessible housing can contribute to increased financial struggle for disabled people, including those with MS. For example, it can lead to people struggling to manage their symptoms, their condition getting worse and their extra costs increasing. Without the right housing, they may need to rely more on care, which can often be costly.[77]

Barriers to accessible housing can also lead to people with MS struggling to access employment. For example, disabled people whose accessible housing needs aren't met are four times more likely to be unemployed or not seeking work than those whose needs are met.[78]

Across the UK, there is a severe shortage of accessible homes for disabled people, including people with MS. Disabled people are more likely to live in social housing, yet this sector is under particular pressure, with long waiting lists. In the private rented sector, far too many landlords aren't willing to put in place adaptations or other support.[79]

The Government should reduce the barriers to housing experienced by people with MS, which contribute to financial struggle. It must:

- Build far more accessible, adaptable and affordable homes for disabled people.
- Improve the installation of home adaptations, including through expansion of the Disabled Facilities Grants scheme.

- Make sure people with MS are more effectively matched to suitable homes in the social housing sector.

Transport

Lack of access to suitable transport can contribute to financial struggle for people with MS. For example, if someone is unable to access accessible public transport or an adapted vehicle, then they may have to rely more on taxis. This then increases their extra costs.

People with MS who get the higher rate mobility component of PIP can swap some of their benefits for access to an adapted vehicle through the Motability scheme. These vehicles can allow people with MS to live independently, and for those who can work, they can be vital for enabling them to get to their workplace.

But many people with MS who could benefit from access to the Motability scheme are denied it due to being put onto the lower mobility rate in PIP. This is despite them needing an adapted vehicle to carry out many of their day-to-day activities.

Inadequate PIP assessment criteria - as outlined in earlier sections - in particular the 20-metre rule for assessing mobility, are one of the main reasons too many people don't get the higher level of mobility support and miss out on the scheme.

Disabled people, including those with MS, also face barriers to accessing accessible public transport. This affects those living everywhere, although is particularly acute in less urban areas.[80]

The Government must reduce the barriers to transport experienced by people with MS, which contribute to financial struggle.

It must:

- Scrap the 20-metre rule for assessing mobility in PIP assessments. The Scottish Government should also remove the equivalent rule in ADP.
- Make the Motability scheme available to disabled people who are on standard mobility PIP or low mobility DLA and to disabled people not claiming PIP. The scheme should also be made available to those on the equivalent rate of ADP in Scotland.
- Work with Local Authorities and transport companies to improve provision of accessible public transport for disabled people.

Becky S

Becky lives in Manchester and was a primary school teacher until she was diagnosed with relapsing remitting MS. Fatigue is a big issue for Becky. Her other symptoms include drop foot, difficulty with her vision and pins and needles in her hands. She has bladder and bowl problems, and pays herself for Botox which can help. Her current financial circumstances means she is cutting back on treatments and therapies which help her manage her MS. Becky isn't able to afford the supplements that are recommended, she can't afford to have physio despite it helping with her drop foot and pain in her spine. She's also stopped having counselling, and says its access to specialists that she would love to have.

Becky claims ESA and PIP, and is able to use the Motability scheme which she says allows her to have a car, which is her "freedom". Becky says without her car she would be stuck on her street with no way to get about.

Being able to afford to heat her home this winter is a major concern for Becky, and she says the support the government has said it will provide won't go far enough. To help her pay bills, she uses her credit card, but then has to take a loan out to pay off the credit cards, ending up in a cycle of debt. She knows this is not sustainable as bills increase and is worried about falling deeper into debt so she can heat her home.

Becky initially felt she was managing. But she came to realise that really relying on the generosity of friends, borrowing from one credit card to pay off another and worrying about paying for heating is not managing. Becky says she is actually just surviving and that she feels forgotten and ignored by the Government.

Conclusion

No one can look at the extremely concerning financial situation of people with MS and say the UK social safety net is working. Huge numbers of people in the MS community are going without essentials like keeping their homes warm, buying medicine and treatments, or eating balanced meals. We have found consistently that those relying on benefits as their main source of income are struggling the most, meaning government support is simply not adequate.

The recommendations set out in this report point the way to a different future – for the people whose stories we tell throughout and for many others. With the right level of support Dave and Rebecca could afford the vital physio they have had to give up. Rachael and Becky could eat a normal diet without worrying about cost, Michael could afford to see his friends regularly, and Becky S could avoid a cycle of debt trying to heat her home.

These are all basic parts of quality of life many of us take for granted – if as a society we cannot ensure these for everyone, we must recognise that something has gone very wrong.

Immediate action is required. The Government must implement the urgent recommendations set out throughout this report – especially another cost of living support package. But it must also begin fundamentally rethinking the benefit system – both in terms of the level of support provided and the ways that people access it.

A future is possible where all people with MS - and all disabled people – can live well, but only with a radically different approach starting now.

Annex

Food security measure

Food security means that people have reliable access to sufficient and nutritious food. To measure food security, we used the Household Food Security Survey (HFSS) Module in our survey with people affected by MS.[81] Although the measure was originally developed for the USA, it's now commonly used in population level surveys around the world, including the Family Resources Survey.[82] This is an annual survey about the incomes and living circumstances of households and families in the UK. Using the measure allowed us to compare levels of food security between people with MS and the general UK population.

The full 18-item version includes questions specifically for children's food security and also includes some questions that assess how frequently some food security issues occur. For example, whether people are skipping meals only occasionally, or whether it's a weekly occurrence. In our survey we used an abridged version as shown below:

Have any of the following statements been true for you or your household in the last 30 days?

Select: often true, sometimes true, never true, prefer not to say.

- I've worried we would run out of food before I had money to buy more
- The food I bought didn't last and I didn't have money to buy more
- I couldn't afford to eat balanced meals
- I (or others in my household) have had to skip or cut meals because there wasn't enough money for food
- I've eaten less than I felt I should because there wasn't enough money for food
- I've been hungry and not eaten because there wasn't enough money for food
- I lost weight because there wasn't enough money for food
- I didn't eat for a whole day because there wasn't enough money for food

Note: Due to an error with the survey there is no data available for the first statement: 'I've worried we would run out of food before I had money to buy more'.

Material deprivation measure

Material deprivation describes an inability to afford or access essential items that provide a basic standard of living and level of social participation. It's a measure that provides a complementary perspective on poverty or financial hardship beyond income measures.

In our survey we used material deprivation questions also used in the Family Resources Survey (FRS), to allow for comparisons.[83] The FRS includes specific measures for children and pensioners, but we used the items aimed at working age adults. Although this limits the possible comparisons, since part of our sample is retired, we felt this set of questions was the most relevant for people with MS.

Given the specific needs of people with MS in this context, we also included another item – 'Have enough money to pay for any medication or treatment you need'. The full set of items used in our survey is below:

Do you (and your household)

Select: We/I have this, We/I would like to have this but can't afford it at the moment, We/I don't want or need this at the moment, Not applicable.

- Have enough money to keep your home in a decent state of decoration
- Have a holiday away from home at least one week a year, not staying with relatives at their home
- Have household contents insurance
- Make regular savings of £10 a month or more
- Replace any worn out furniture
- Replace or repair major electrical goods (like fridge or washing machine) when broken
- Money to spend on yourself each week
- Keep your house or flat warm
- Keep up to date with any bills and regular debt payments
- Have enough money to pay for any medication or treatment you need

Note: Due to an error with the survey there is no data available for the first item on the list: 'Have enough money to keep your home in a decent state of decoration'.

Extra costs due to MS

We asked respondents to our survey to estimate their extra costs across different areas such as healthcare, help around the house or travel and transport.

For some of these areas, a small number of respondents may have overestimated the costs and shared the overall cost, rather than only the extra spend that is due to MS. The data was carefully cleaned and all responses where it was clear from text comments that respondents gave the full cost rather than the extra costs were excluded. But we can't be certain that we identified and removed all overestimations. Costs such as healthcare and caring costs are likely to be the most accurate, since they are closely linked to the person's MS.

It's also possible that the figures from the survey underestimate the true extra costs of living with MS. This is because it only asked people to estimate their extra costs based on costs they've actually accrued in the past, which is heavily influenced by their financial situation. It didn't consider what people would have spent their money on due to their condition, and by how much, had they had the money to do so.

Although it's important to be aware of the previous caveat, much care was taken to maximise the quality and robustness of our data and to minimise the impact of any errors or variance in the data. Alongside cleaning the data carefully, all averages given in this report are median averages. The median is the middle value which separates the higher half from the lower half of the data sample. This reduces the impact of outliers in the data and is more representative of the average person.

Therefore, the figures provide a useful indication of the types of extra costs people with MS face and how much they typically spend.

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Notes

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.

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