

Life Changing

Getting around with MS



Contents

Introduction	1
Methods	2
Results	4
1. Which MS symptoms affect travel and transport?	4
2. What stops people with MS from travelling outside their home?	8
3. How much extra effort is involved in getting out with MS?	12
4. How do travel issues impact on the lives of people with MS?	14
5. What aids and services do people with MS need to get out and about?	17
6. What can we learn from places that are accessible for people with MS?	23
7. What changes are needed to enable more people with MS to get out and about?	25
Summary	25
Call to action	26
References	27

Introduction

As part of our role in raising awareness of the issues facing people affected by multiple sclerosis, the MS Trust run regular Listening Projects surveying the MS community. Intelligence collected from our helpline, conversations with health professionals and our previous Listening Projects indicated that travel and transport outside the home can be a challenge for people affected by MS.

Historically, MS has been associated primarily with mobility problems. Stereotypes of people with MS often focus on the accumulation of disability and a steady decline in mobility. 'Will I end up in a wheelchair?' is a frequently asked question for the newly diagnosed. This perception obscures the diverse range of MS symptoms and their varying expression over a lifetime. The true impact of MS is more complex and individually nuanced.

The ability to travel outside the home is a major factor in determining independent living, access to work and daily activities. Being less able to leave the house alone implies difficulty in retaining employment or relationships outside the household and a reliance on professional or family care. Transport and travel problems may also cause difficulties in the social prescribing of activity and a negative impact on mental health through isolation. Additional costs associated with travel and transport for people with MS may not be mitigated by the benefits and concessions available.

There is a fragmented approach to solving travel and transport problems for people with MS. Responsibility for symptom management, community transport, mobility-related benefits, access to mobility aids and adaptations, assessment and occupational health are spread around agencies from central government, local authorities, specialist and community health teams.

We are interested in understanding how people with MS navigate this and get the support they need. How effective is the support and where is the unmet need in this ecosystem? To what extent do family and carers fill the gaps?

We also want to explore what more needs to be done to remove the barriers to empowered and independent lives for people with MS.

This project explores the following questions:

1. Which MS symptoms affect travel and transport?
2. What stops people with MS from travelling outside their home?
3. How much extra effort is involved in getting out with MS?
4. How do travel issues impact on the lives of people with MS?
5. What aids and services do people with MS need to get out and about?
6. What can we learn from places that are accessible for people with MS?
7. What changes are needed to enable more people with MS to get out and about?

Methods

We conducted a series of structured interviews and focus groups in Autumn 2023. We involved people with all kinds of MS, members of our Inclusion and Involvement Panel, and specialist MS health professionals with an interest in movement and travel. Using insights derived from these conversations, we devised a draft survey that would allow respondents to express their views on the topics highlighted in our focus groups. We tested it with the initial focus group members and an additional panel of reviewers from the MS community. Once revised, the survey was circulated to people with MS in several ways.

- Through our MS Monthly email newsletter to **23,000** people affected by MS in the UK
- In a separate email dedicated to the Listening Project on Transport and Travel in MS
- Through social media posts including X, Facebook, Instagram and LinkedIn
- In person through our staff visiting MS therapy centres
- Through collaboration with MS community influencers.

A small budget was available to boost the visibility of our social media posts, and we were able to send reminders via email to our community to encourage response. Different distribution channels were tagged so we could see their specific response rate. The survey remained open for ten weeks between February-May 2024.

999 people with MS living in the UK responded to our survey.

As respondents were free to skip questions they did not wish to answer, the total sample size for each question varies.

Results come from all over the UK but are not evenly spread. **79%** of respondents indicate a home location in England with **24%** hailing from London and the South East. Our data under-represents the West of England, East Yorkshire and Lincolnshire. Compared to the relative populations of the home nations, our sample slightly over-represents Wales and Scotland and under-represents England and Northern Ireland.

	Our survey	Actual UK popn
Wales	6.47%	5%
Scotland	8.6%	8%
England	79%	84%
Northern Ireland	1.3%	3%

We did specifically reach out to two MS influencers in Northern Ireland to help us achieve that total, but results indicate that we could have done more to boost the visibility and response rate of this survey in some regions of the UK. Figures do not total **100%** because of responses from the Channel Islands and Isle of Man and from respondents who did not indicate the part of the UK they came from.

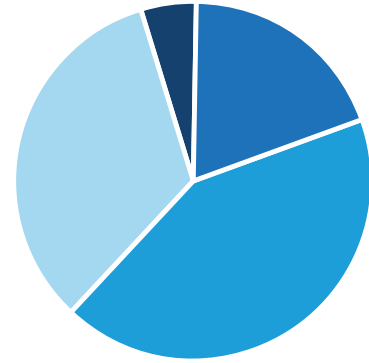
Our survey respondents represent a wide variety of personal experience with MS. 20% of respondents have had a diagnosis for 25 years or more, and 20% have had a diagnosis for 5 years or less.

How long have you had a diagnosis of MS?



- Under 2 years
- 2-5 years
- 5-10 years
- 10-15 years
- 15-20 years
- 20-25 years
- 25 years +

What kind of MS do you have?



- Primary progressive MS
- Relapsing remitting MS
- Secondary progressive MS
- Don't know/other

42% of respondents have clinically isolated syndrome or relapsing remitting multiple sclerosis, and **53%** have a progressive form of MS. Around **5%** either did not know or wish to share their specific diagnosis.

Respondents were not required to provide evidence of an MS diagnosis. Furthermore, demographic data such as relationship status, faith, household income, gender, sexuality and ethnicity are self-reported. Up to **18%** of respondents skipped some or all of these demographic questions. These are limitations to the data collected.

In brief, our respondents are **87% White British, 63% married, 54% Christian, 97% first language English, 90% heterosexual** and **77% female**. Although responses come from all age groups between **20** and **80** plus, **63%** of respondents who answered the age question fall between the ages of **50** and **69**.

This demographic profile aligns with those seen in similar surveys by other bodies⁽¹⁾ and with the general demographic profile of people with MS in the UK.

Results

1. Which MS symptoms impact travel and transport?

Physical symptoms

MS is a highly variable neurological condition with a range of symptoms that can be inconvenient, uncomfortable, unpredictable and distressing. People with MS experience an individual selection of symptoms to differing degrees and with the potential to fluctuate over time. This makes it difficult to express concisely what it is about MS that makes getting around outside the home difficult.

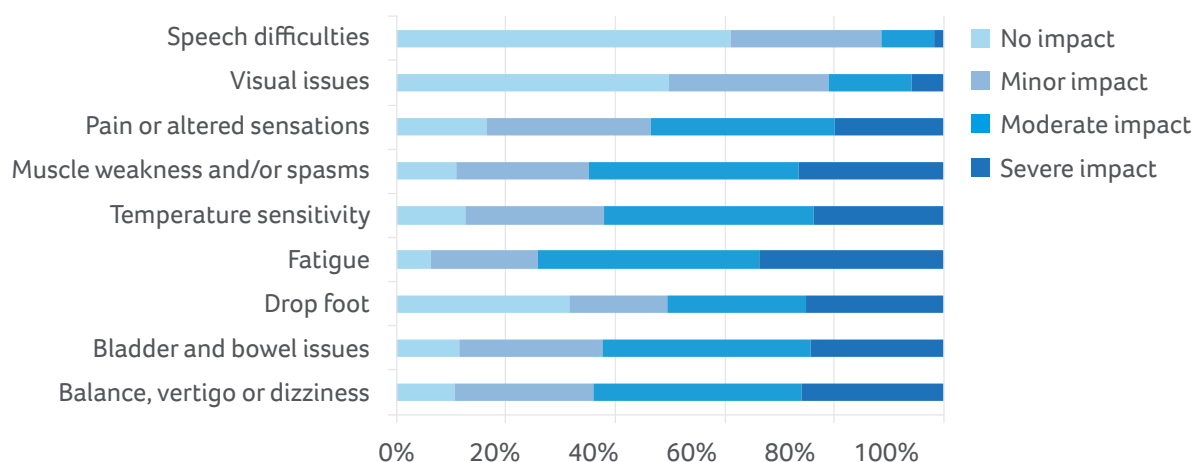
Mobility problems can be significant in MS, but can ultimately be caused by varied underlying symptoms, including muscle weakness, foot drop, spasticity or spasms, fatigue, pain, balance impairment or altered sensations such as numbness in the feet or legs. These symptoms can impair ease of movement, reduce strength and stamina, increase risk of falls or cause pain when moving. They may be mitigated by mobility aids such as rollators or wheelchairs, but these are associated with other issues like cost, bulk and manoeuvrability.

Other physical symptoms that can affect travel and transport include bladder and bowel problems, sensitivity to temperature extremes and issues with vision or speech and swallowing. These difficulties relate more to the different places and spaces the person with MS moves through and the facilities that are there. Places that are congested, poorly ventilated or noisy can be hard to negotiate in comfort. Publicly accessible toilets and places to rest are not always conveniently located.

"Because of my bladder, trips out of more than 20 minutes are impossible."

"Bowel issues have a major impact. I feel it is the worst thing I have to deal with."

How do the following physical MS symptoms impact your ability to get around outside?



Our survey results show high levels of moderate and severe impact for selected MS physical symptoms. Muscle weakness and spasms, fatigue, vertigo and dizziness, temperature sensitivity and bladder and bowel problems all present a moderate to severe impact on travel outside the home for over **60%** of respondents. Pain and altered sensations, and drop foot are also significant factors.

The most significant MS symptom impacting getting around with MS is fatigue, with **73%** of respondents rating it as moderate or severe. Fatigue is the most common MS symptom and is difficult to manage effectively.

It is important to recognise that it is not just symptoms traditionally associated with mobility that prevent people with MS from leaving their house.

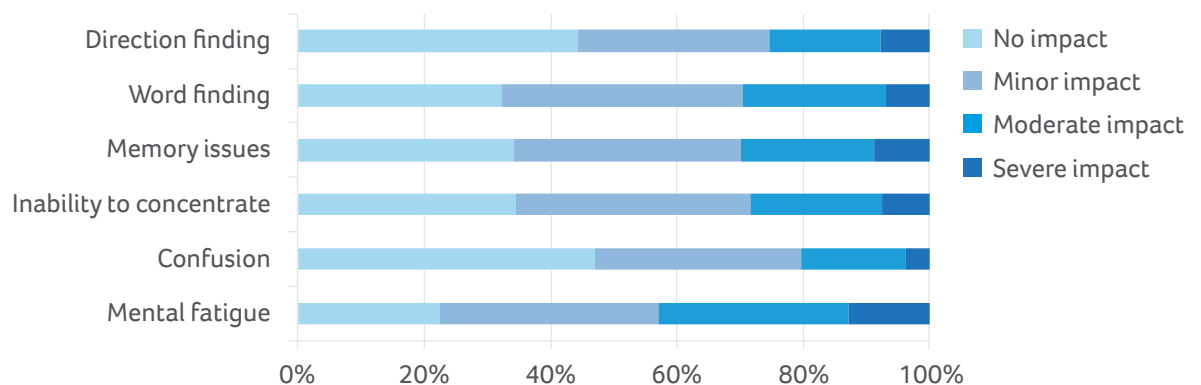
"Suffering with vertigo causes anxiety at travelling. I order everything online, so I don't have to think about travelling, the journey and possible effects of leaving the house."

Cognitive symptoms

MS can also affect thinking and memory skills, leading to cognitive symptoms like confusion, mental fatigue, problems with wayfinding or communication. Fewer respondents felt these symptoms affected them severely compared to physical symptoms. Nonetheless, there are **43%** of respondents who feel moderately or severely affected by mental fatigue and at least **20%** of respondents are moderately or severely affected by all other cognitive symptoms explored.

"I often get confused and have memory issues. It makes me very anxious to go out alone."

How do the following physical MS symptoms impact your ability to get around outside?



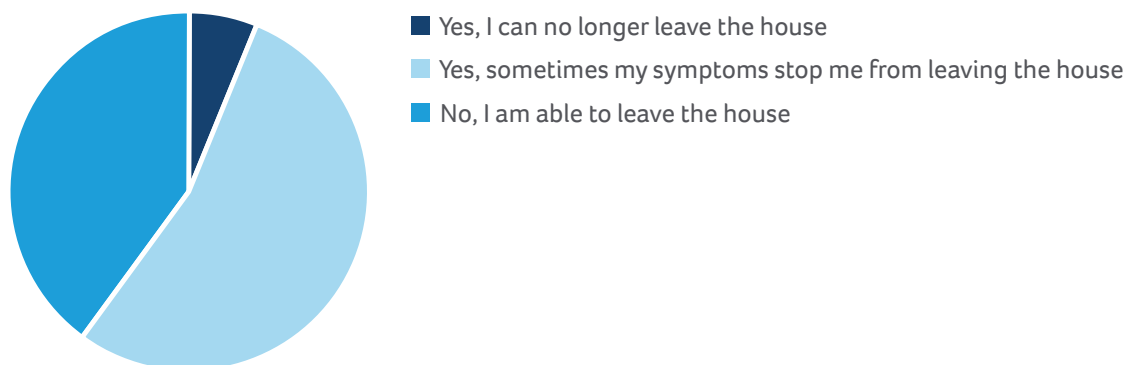
Both physical and cognitive symptoms can make people with MS feel less confident in their abilities to travel safely outside the home. The most significant issue across both physical and cognitive symptoms is fatigue. Fatigue sets up a barrier to both intention to travel and the ability to do so. Getting past the fatigue hurdle means that it takes more effort to plan and execute a journey for a person with MS fatigue. As a result, people with MS may stop trying to get out and about, becoming resigned to a less engaged and independent life.

"I find myself becoming more and more reluctant to leave home. It's hard work, I'm tired out by my pain, and the mental stress it creates in planning and executing a journey of any length is exhausting. If I get there, will I be able to get home? It's easier not to bother."

The impact can vary from day to day

Whilst around **6%** of respondents have MS symptoms that always restrict them to their homes, nearly **54%** of respondents feel that this is sometimes the case. This paints a picture of good days and bad days with MS. It is a reminder that a bad MS day can mean changing plans or stopping activities because it is no longer possible to leave the house due to a worsening of symptoms.

Do your MS symptoms stop you from leaving the house?



Examples given by respondents include hot weather bringing on fatigue and weakness, or a flaring of bowel symptoms meaning that the person opts to stay at home. Poorly managed or under-treated symptoms in MS could therefore be contributing to a sense of restriction to familiar surroundings.

"If you plan ahead you are still unable to predict how you will feel on the day."

The impact of MS symptoms is worse in lower income households

When we look at reported impact of MS symptoms split by household income, we see stark contrasts between lower and higher income households. People with MS in lower income households are more likely to report moderate or severe impact of their MS symptoms on their ability to travel outside the home. There are significant differences between the lowest and highest bands recorded for the following symptoms.

MS symptom	Prevalence of moderate/severe impact	
	Lower income households (<£19,999)	Higher income households (>£60,000)
Balance/vertigo/dizziness	71%	62%
Fatigue	85%	58%
Temperature sensitivity	74%	42%
Muscle weakness/spasticity	76%	46%
Pain/altered sensations	67%	37%
Mental fatigue	74%	62%
Confusion	29%	6%
Memory problems	44%	12%
Concentration problems	42%	11%

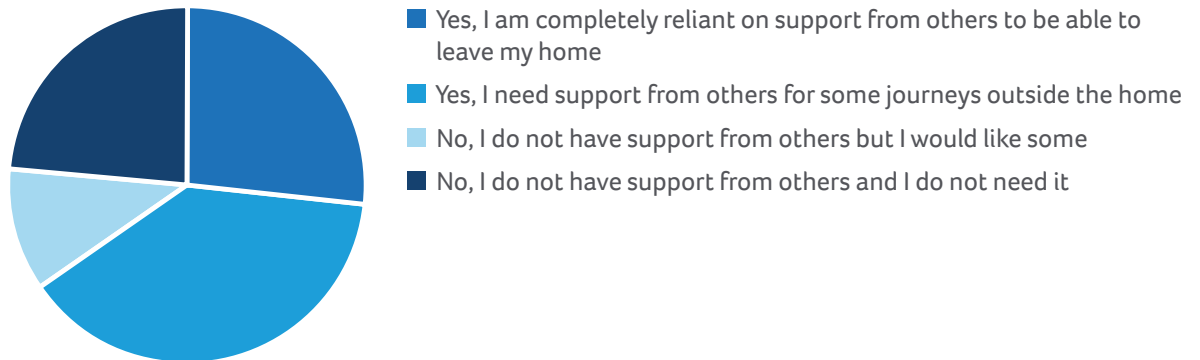
People with moderate or severe MS symptoms may be more likely to need to reduce or give up paid work, or have a family member need to stop work to care for them. This may explain the correlation between lower household incomes and increased difficulties reported.

2. What stops people with MS from travelling outside their home?

Having no-one to help

As discussed previously, the direct impact of MS symptoms can prevent people from leaving their home. Our focus groups indicated that having someone to help is another significant factor for being able to travel outside the home. We asked specifically about the extent to which people with MS rely on others for this purpose.

Do you currently rely on support from someone (paid or unpaid) to get out and about?



66% of respondents need support from other people in order to be able to leave their house, at least some of the time. A further **11%** would like support but do not have it. **27%** are completely reliant on others or they would be entirely housebound. This indicates that reduced independence and a reliance on others is prevalent among people with MS.

The friends, partners and family members involved in helping people with MS get out of the house may not see themselves as carers. However, this is undoubtedly an influence on their own choices and opportunities and can lead to tension within relationships.

"I only go out if my husband is available to give me a lift."

"I only go out on my own in extreme circumstances. I frequently get lost and when I go to busy or new places this causes my vertigo to flare up. That's before I even start to worry about my incontinence issues."

"I do not have anyone to travel with so do not go out much."

Analysis by household income band indicates that people with MS in lower income households are significantly more likely to report needing support from others to leave the home. This is the case for **34%** of respondents in the lowest income band, but only **14%** of respondents in the highest income band. This significant difference is likely to be driven by the greater impact of MS symptoms reported in this section of the community. Reliance on help from others, even for the shortest local journeys, may be underestimated by health and social care agencies.

Not knowing the route in advance

A further factor in determining ability to leave the house is familiarity with the journey and knowing where issues might arise. This relates to all kinds of journeys, whether on the pavement, in a car or on public transport.

Having reliable information about the accessibility and regularity of services is important in planning public transport journeys. Our respondents indicated that this was not always readily accessible.

"It's a significant barrier when you can't find info about accessibility in advance online – either it's not available, it's inaccurate or not up to date. If I know the lift at the train station is out of order it would help me plan an alternative route."

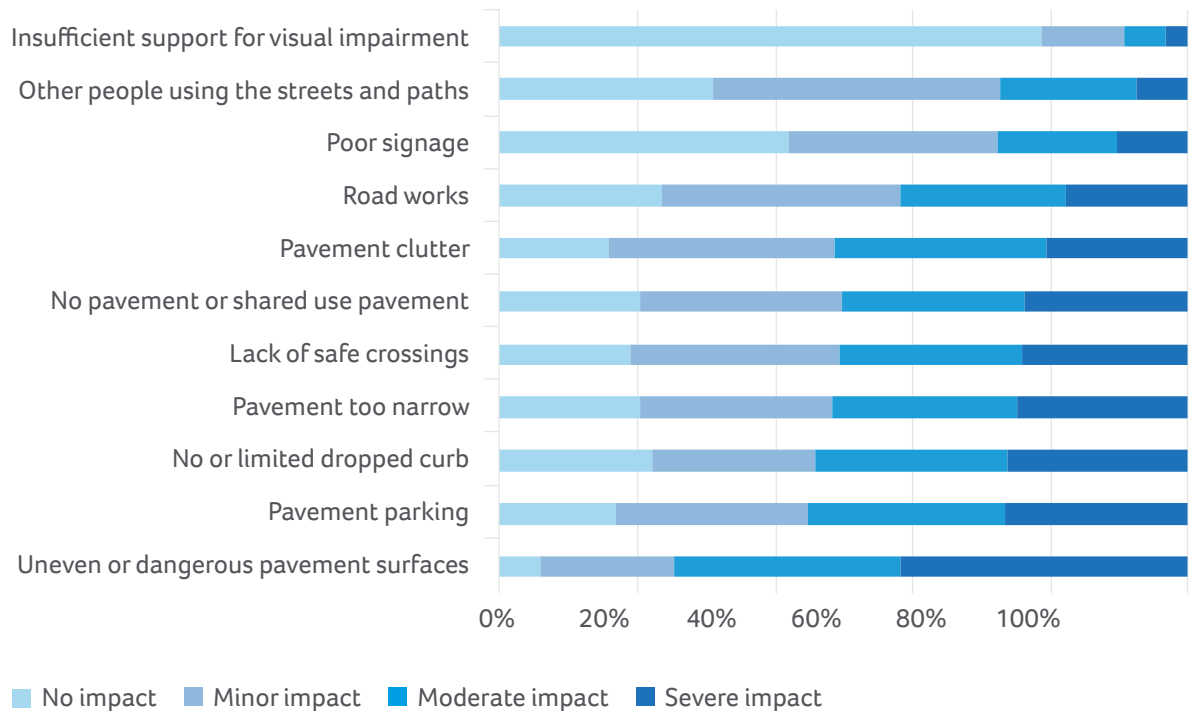
For private cars, people with MS may need to know where disabled or regular parking spaces are relative to their target destinations.

"I am nervous about driving to towns as I worry about the lack of disabled parking spaces. If there isn't space, I have to go home."

Physical barriers to travel

A further factor in determining ability to leave the house is familiarity with the journey. In our survey, people with MS recounted numerous issues with local transport, urban planning and poor maintenance of streets and pavements.

How do the following physical MS symptoms impact your ability to get around outside?



For walkers and wheelchair users, awareness of problem areas such as pavement parking, overgrown hedges or uneven paving make a difference to respondents' willingness to embark on a journey outside the house. The home and the destination may both be accessible, but if the path between them is not, then many of our respondents are stuck.

"Tree roots on paths, recycling bins blocking the way. I gave up using a mobility scooter because of the issues I encountered. Now rarely leave home because of this. Has had a huge impact on myself and my family."

The issue of pavement surfaces for people on foot or wheeling contributed to approximately **35%** of free-text comments on this question. People discussed how difficult it was to be constantly faced with impediments to walking, balance or wheeling safely. Cyclists and scooter users on the pavement as well as poorly positioned bins and street furniture were also highlighted as related issues. Insufficient dropped kerbs are mentioned in nearly **10%** of comments. They highlight how difficult it is when you can find one or if it is blocked by a parked car.

This strong sentiment is also reflected in survey data. Uneven or dangerous pavement surfaces was rated as having a **'severe impact'** for over **40%** of respondents and moderate for around **30%**.

Many respondents reported having had falls or needing to walk or wheel in the road to get around barriers. These concerns lead to worry about increased fatigue and risk of falls. People report staying at home if they have no-one to accompany them.

"Our local pavements are so bad that I often have to 'walk' on the roads – and they are so potholed that this isn't always feasible either."

"I live in an historic market town which has many changes of surface, cobbles, uneven paving, narrow pavements etc. Attractive but really difficult to get around using a rollator. I would not want everything changed to tarmac, but a bit more consultation with/consideration of people with limited mobility would be good."

"Uneven pavements that haven't been repaired have the biggest impact for me, with foot drop and concerns about tripping and falling. I have broken my foot twice in the past three years."

"I often struggle with the camber of pavements sloping into the adjacent road. Also, drop kerbs are often too high to mount in a wheelchair. I need to find alternative routes, mount the kerb backwards, which can often involve manoeuvring in the road, or risk accidents and damage to myself and my wheelchair."

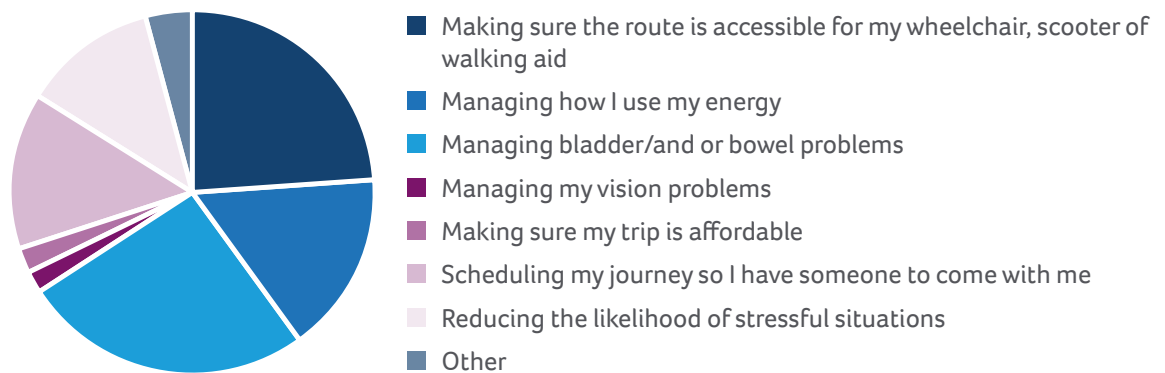
Again, the impact of poorly maintained environments falls unevenly on people at different household income levels. **48%** of respondents at the lowest income levels report a severe impact from damaged, blocked or uneven pavements compared to **20%** of respondents from the highest income band. This significant difference may reflect their larger symptom burden, as above, but may also indicate their household is in a neighbourhood with a higher level of deprivation and lower expenditure on maintaining the local environment.

3. How much extra effort is involved in getting out with MS?

Journey planning

Our preliminary focus groups signalled that journey planning is a significant additional burden for people with MS. We explored this in depth with five of our survey questions, tailored to cover topics raised in the focus groups. Our survey respondents supported this, speaking about the lack of spontaneity and the risks of embarrassment or stress if their needs were not met. Planning every journey in advance is time consuming but helps to reduce anxiety.

93% of people with MS feel they have to carefully plan some or all of their journeys. For **62%** of respondents this was often or always. In terms of time impact, spending around an hour on planning was most common (**40%**) but **32%** spent longer than this, up to five hours of research to plan one trip out of the home.



The reasons for planning ahead are varied. Respondents indicated that they often have several issues in mind. When asked to pick the single most important concern, accessibility, toileting and energy or fatigue management were the top three answers. For **42%** of respondents in the lowest income category, transport affordability required additional planning time, whereas only **11%** of people in the highest income band considered this. Some respondents talked about cognition issues caused by MS, and explained how the effort of planning reduces the risk of suffering confusion or anxiety.

"Trips are usually for medical appointments, so we need to calculate time needed to get my coat put on, load me into the car, the actual journey... and then, of course, finding a parking space."

"Knowing the lay-out takes away a lot of the worry (disabled parking, wheelchair access and disabled toilets are top of the list)."

"Making sure the route is accessible for my level of walking and standing ability (step free/small number of steps, seating if I need to sit, coffee shop if I need a break etc).."

Even with the best laid plans, over **70%** of survey respondents report that their planned journeys are still sometimes disrupted. Roadworks, building works or even the weather, can require a planned journey be dropped.

"It is usually the state of the infrastructure that causes most problems... lifts out of action, poor state of pavements, or lack of disabled parking."

"Because I'm standing waiting for buses the weather plays a part. If it is raining heavily, I would consider not making the journey at all."

For many respondents, the limited availability of supported transport is a significant reason for planning ahead. Supported transport services include dial-a-ride services, adapted taxis or buses. These services usually have limited operating hours and can be affected by other communities using them, such as schoolchildren.

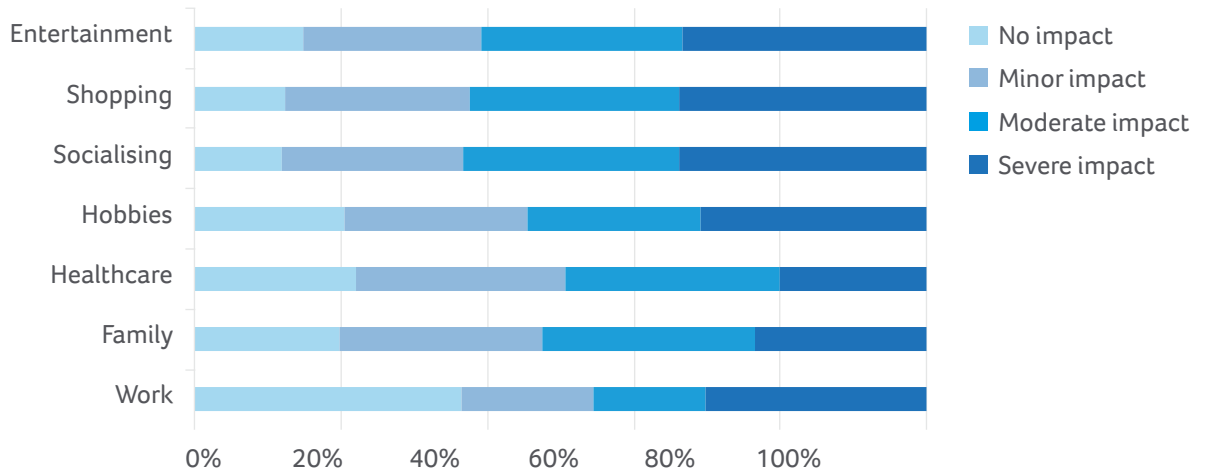
"As I am a full-time wheelchair user, in order to go out independently I need to use the dial-a-ride service in London. Unfortunately, I need to book a week in advance to ensure I get a booking for my weekly session at the MS therapy centre. This means I cannot book any other journeys in advance. This means that I can only plan for one regular journey a week."

"Where I live, adapted taxis that can take me in my wheelchair will not pick up at home and therefore cannot be pre-arranged. This makes it difficult to book tickets for future events as I'm unsure if we can get a taxi for that day."

Some respondents flagged difficulty with finding the information needed to plan effectively. For example, finding accessibility information on venue websites. The result is that people with MS may be less able to be spontaneous in their travel outside the home.

4. How do travel issues impact on the lives of people with MS?

Our respondents told us that travel issues affect all aspects of life, to varied degrees. We asked questions about work, family life, entertainment, socialising, healthcare and shopping. For all categories except work and healthcare, a moderate or severe impact was reported by over **52%** of respondents, rising to **63%** for socialising.



"I am not able to socialise as I cannot get out unless someone takes me, so I have lost many friends which has impacted my mental health and social life. I just sit in the house all time."

"Visiting family is nearly impossible due to the problems with the rail network and getting assistance. I'd like to visit friends and family more often, but I live on my own."

"I am lucky that my friend drives and is willing to take me shopping, but when she is away, I am stuck."

Our previous research showed that people with MS often give up valued hobbies and pastimes following their diagnosis, for reasons that include access to the right locations, including sports or outdoor pursuits.

"In my previous life I was a landscape archaeologist, I enjoyed exploring the outdoors. As pretty much all disabled access concentrates on the built environment, I am very much restricted in where I can go, unless I save up to buy a very expensive all-terrain wheelchair"

Working life

The pattern of responses for the impact of MS-related travel problems on working life is somewhat different to that of other categories. Respondents either reported no impact or severe impact, with fewer intermediate responses. Some respondents reported using the Access to Work scheme for transport to work or shared the arrangements made for them to have access to easy parking or other workplace support.

Nonetheless, there is clearly a more binary expression of impact of MS on working life than on other aspects of living. At some point, a person with MS is likely to make the decision to stop working or retire. If their MS has been a factor in that decision then they may report a severe impact of MS on their working life.

"I'm able to travel to work for now because I have a plan in place that has been repeated each day."

Healthcare

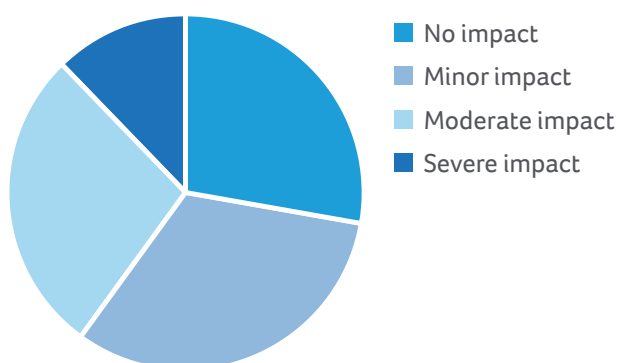
It is notable that healthcare is the category least likely to be described as severely impacted by travel problems caused by MS. For some people with MS, travelling to healthcare appointments are the major reason for journeys outside the home. Where supportive transport services are available, they are used predominantly for this purpose, leaving little capacity for other travel purposes such as socialising or entertainment. Even if they make no other journeys outside the home, a person with MS may consider a healthcare appointment is a priority.

"I only go out for hospital appointments now."

Mental health

Exploring the impact of MS-related travel problems on people's lives, we asked several questions around mental health and wellbeing, after our focus groups shared insight that the barriers to travel could affect feelings of low self-worth and hopelessness. Over **70%** of respondents reported some impact of transport problems on their mental health, with **12%** reporting this as a major issue. Among respondents in the lowest income households, this rises to **20%** reporting that transportation issues caused by MS impact their mental health.

What impact do transportation issues have on your mental health?



"It's exhausting and the pain and fatigue is unbearable. I feel worthless and stupid when I cannot access the "normal" facilities and activities that others can."

"I often feel a burden to my family especially my husband."

"Every time you face a barrier it brings home that you have MS. Again and again, it makes everything feel like an uphill battle. When travelling with friends or colleagues they have no concept of living with MS and don't understand my needs (like how little I can walk) which has impacted my relationships and mental health."

Risk of isolation

77% of respondents felt isolated at least sometimes, with **32%** often or always feeling isolated because of transport issues. Over **50%** of respondents said that they would go out more if their transport needs were better met.

"I spend too much time at home alone. I sometimes feel trapped and lonely. Travel issues contributed to me having to stop work. It's hard to visit friends or go out."

"I would love to be able to access the community more and currently feel very isolated due to the restrictions caused by my mobility and lack of transport access."

For this issue again, the impact is more significant on people with MS living in lower income households. Compared with people living in the highest income households, people in the lowest income bracket are nearly five times more likely to always feel isolated (**19%** compared with **4%**).

5. What aids and services do people with MS need to get out and about?

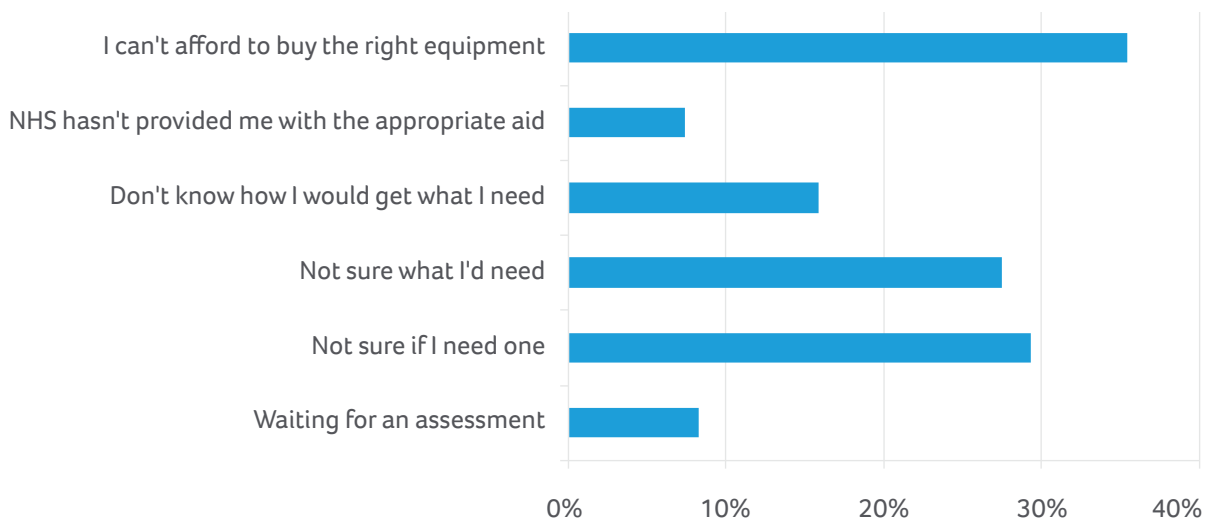
Mobility aids

Nearly **40%** of our survey respondents never walk unaided. Nearly **80%** of respondents have a mobility aid of some kind, with **65%** using it regularly. For most people this is a walking stick or walking poles. Mobility aids such as sticks, wheelchairs, rollators and powered scooters are popular and valued for getting around outside the house.

"I use walking poles when out to help with balance and proprioception."

There are indications in the survey that the provision of mobility aids does not match the desire for them. **40%** of respondents would like an additional mobility aid, with the most common items on the wish list being powered scooters or wheelchairs. Cost is a strong barrier to getting the equipment needed, according to **35%** of respondents (**51%** of lower income households, and **15%** of higher income households). Many other respondents expressed confusion on how to find out what aid they need, **8%** are currently waiting for a mobility aid assessment.

What are the barriers stopping you getting a mobility aid?



Some survey comments talk about readiness to accept a walking aid. For some people this is a key moment in coming to terms with their condition. Focus groups talked about the visibility of walking aids, which can be positive or negative for different people and situations. Careful counselling could encourage the uptake of mobility aids resulting in more independent travel for people with MS. However, some homes are unable to accommodate bulky mobility aids.

"I use a stick outside but am reluctant to use other aids at the moment, even if it means not doing certain activities."

"I don't have a scooter or use my wheelchair because my rented council flat is not accessible. I wouldn't be able to get them in/out of the property and have nowhere to keep them outside."

"Having the right mobility aid (wheelchair) and having help with an appropriate car to get it in and out would increase my quality of life."

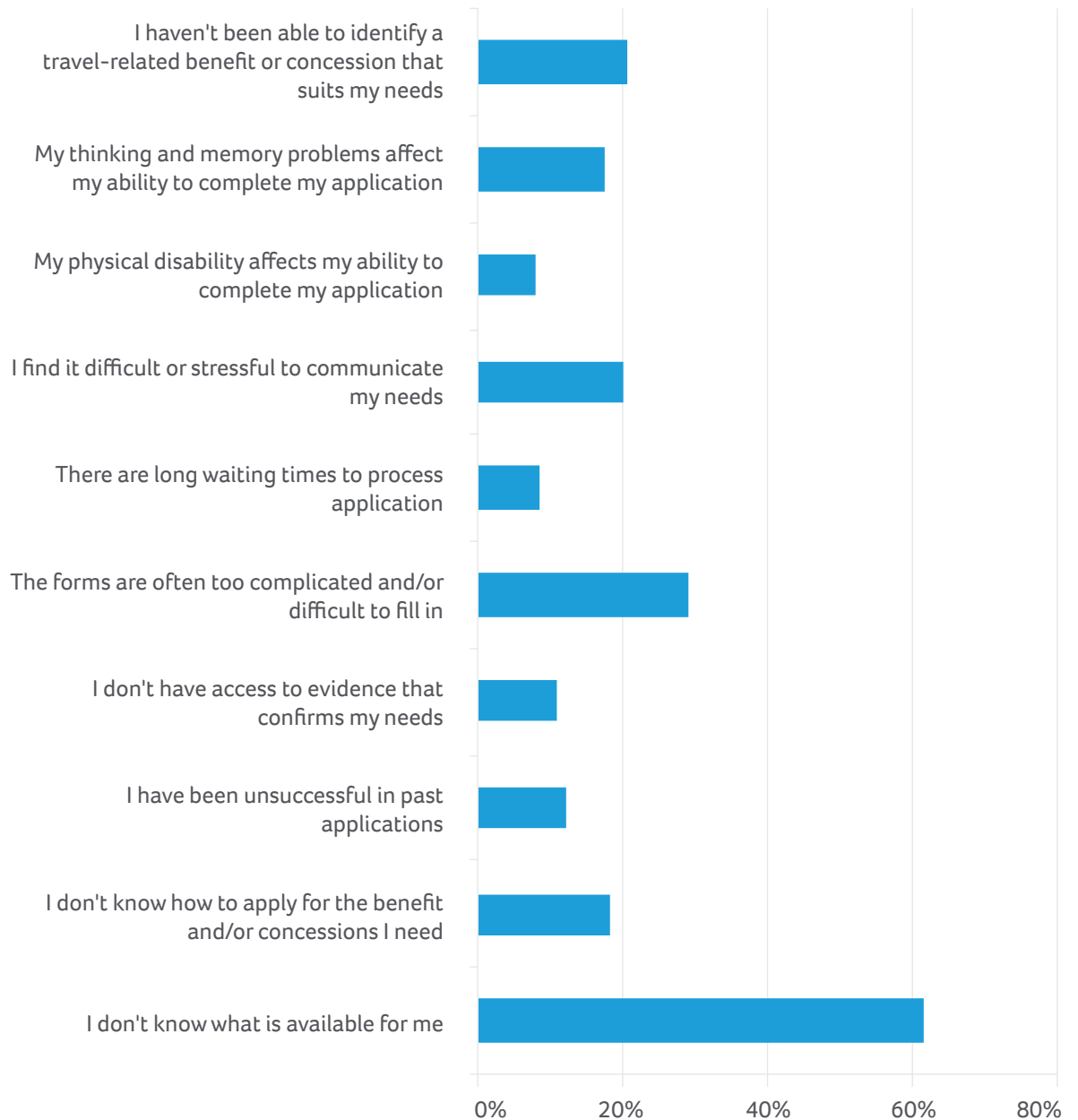
Financial benefits and concessions

607 respondents said they had a blue badge giving access to disabled parking, by far the most common transport concession. The next most common concession was the Personal Independence Payment (PIP) enhanced award with **331** respondents plus another **46** having the equivalent enhanced Scottish Adult Disability Payment.

Around **15%** of comments on this discussed the difficulty of applying for benefits, particularly the Personal Independence Payment (PIP). Further responses highlighted the value of MS health professionals and charity staff in helping respondents to fill in benefit applications. However, **38%** of respondents said that they had no help to apply.

Many respondents shared their anxiety over applying for the benefits that could help them remain independent, or loopholes that meant they were unable to claim. Many people referred to the difficulty of the application process and forms, and expressed concern that they would not be able to apply without help.

What might stop you from applying for a benefit or concession?



"I am too frightened to apply for PIP because of the bad press, and I work full time and can't have an assessment over the phone. I struggle every day to keep going with a stiff upper lip because no-one really cares."

"It is unclear in my county council area whether I can have both a Blue Badge and a bus pass. I use buses to get to hospital as parking at the hospital is very difficult."

"I rely on voice recognition software. Some of the applications involve photographs. This can be quite challenging to assemble the information using my voice."

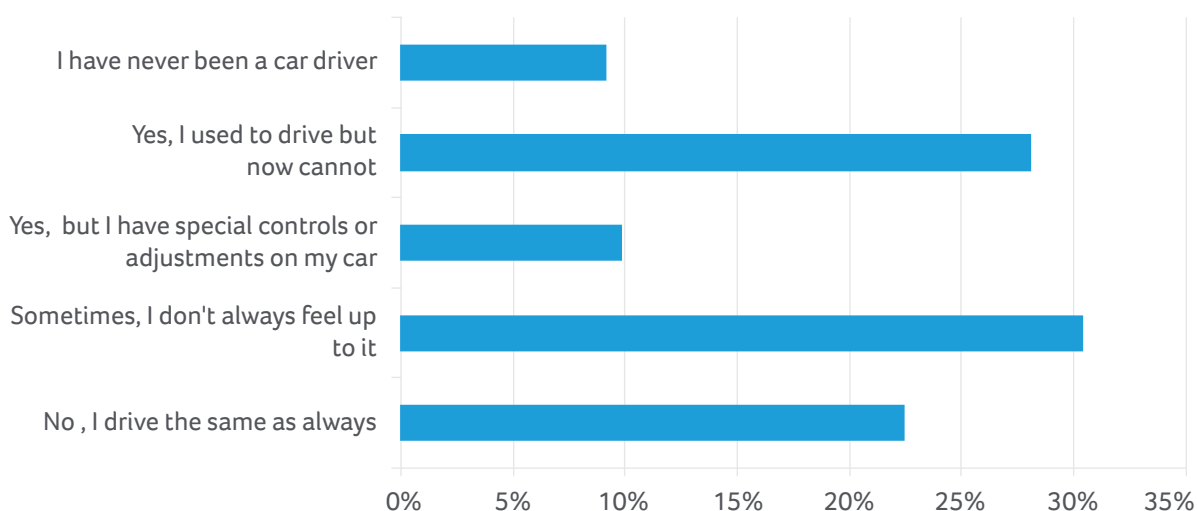
"Most benefits seem to relate to walking. Although I can walk short distances, I cannot carry shopping while walking and am easily thrown off balance by poor surfaces and crowds of people."

"Extremely upsetting. One has to think of what one cannot do. When we try so hard to cope and do our best. Repeated applications when there is no cure or relevant treatment are exhausting and cruel."

Adapted cars

Nearly **8%** of free text comments on driving referred to having switched to automatic vehicles and how this was helpful. Respondents noted the freedom of private car travel and how car ownership allows them to have more control over their journeys. Having access to a car also reduces the number of awkward or fatiguing transfers that are sometimes required when using public transport. Car access is significantly higher in higher income households (**53%**) than lower income households (**33%**).

Do your MS symptoms affect your ability to drive?



However, MS clearly has a significant impact on ability to drive. We found that **28%** of respondents no longer drive at all, **10%** have special controls or adjustments, and **30%** sometimes don't drive, depending on how they feel.

"Because I was over 65 when I was diagnosed with MS, I am not eligible for PIP and therefore also not eligible for the Motability scheme. I find this profoundly unfair."

Better parking

Our survey uncovered three main issues relating to car parking for people with MS. Respondents said that there were too few destinations with adequate disabled parking close by, that disabled parking spaces were often used by people without a disability, and that there isn't always enough space to transfer out of car into a wheelchair even in a disabled space.

"I rely on the few disabled parking spaces being available, if they are not, I often have few other choices. Without the space I cannot unload my wheelchair, and I often have to take my wife with me in case I get stuck."

However, it is not just the number of spaces that matters, the number and position of disabled parking spaces are also important, and these spaces need to be large enough to transfer to mobility aids with ease.

Respondents also want disabled parking spaces to be monitored for misuse by people who are not disabled, and for policies on disabled parking to be standardised across the country.

"Sometimes parking spaces are too narrow, especially at the hospital where the limited number of blue badge parking spaces are always full. Trying to get out of the car and set up, balanced and ready to go on two walking poles can be a challenge."

"A clear national policy on blue badge parking on yellow lines would be great. Local policies make it more difficult to visit new places."

"Many car parks have too few blue badge parking spaces and charge a fee if you are parked in a non-blue badge space which seems very unfair."

607 respondents said that they have a Blue Badge, and free text comments on parking included many respondents expressing their gratitude for their Blue Badge. However, a number of people expressed their difficulties getting a Blue Badge. As these are administered by county councils, there is variance in how they are awarded.

There were also comments about feeling judged by people for having a Blue Badge, especially if the respondent had invisible disabilities. Conversely, some comments referred to suspicions that other people are misusing the scheme.

Reliable public transport

The results in this section were dominated by issues relating to reliability of public transport services. Respondents wanted reliable timetables and vehicles as well as staff trained in disability rights.

Lifts and facilities at stations were sometimes out of order, and that proved to be insurmountable for some users. Our respondents also struggled with poor access to wheelchair spaces, some of which were difficult to use or blocked by other passengers.

For public transport to be really usable by people with MS, respondents wanted to see sheltered and comfortable places to wait and vehicles that can take multiple wheelchairs as well as people with buggies or prams.

"It is all very well having a bus pass but you need bus services that meet your needs to use it!"

"My dad and I both have MS and my mum cares for us both. We use wheelchairs and cannot go out on a bus together as the bus will only take one wheelchair at a time."

Few respondents were aware of accessible transport schemes in their area, including dial-a-ride or hospital transport. **52%** are unaware of community transport options locally and **92%** say that they never use community transport. The key issue here appears to be lack of information and there is scope to improve uptake of these services if potential beneficiaries can be made aware of them.

6. What can we learn from places that are accessible for people with MS?

Familiar places

We asked our respondents to describe the features of places that were accessible or inaccessible to them. Around **5%** of respondents described a place close by that they liked to go because they could travel there more easily and because they can rely on it remaining accessible. These included locations for work and leisure. Our respondents explained that they have devised a good route for travelling there and because they know it well are less concerned about problems arising.

"I only go to places where the bus stop is directly outside and places I've been to before, hence know the route"

Good facilities

Our respondents said that places such as shopping centres, supermarkets or leisure centres which have large car parks are easier to visit. This ties in with larger themes around parking issues above. Some mentioned town centre or shopping mall schemes offering mobility equipment to borrow. Others raised examples of urban environments that they found accessible including transport in London, especially the Elizabeth Line, and city centres like Manchester and Edinburgh.

"I like to drive to a local park. There is always on street parking nearby, plenty of benches to stop and rest whilst walking and some public toilets."

"RHS Wisley is easy to get to by car, lots of blue badge parking, wheelchair friendly, and has all terrain electric scooters if you choose to book one."

Trained staff

Having people around that understand disability needs and who can support access makes a big difference to our respondents. Staff at train and bus stations, leisure and retail destinations, and volunteers at support groups were all highlighted in comments.

"A support group is held at my local hospice, it's on the ground floor, and I can park in a disabled bay literally right next to the door. There's just a short walk to the room, doors are held for me, a volunteer asks what I'd like to drink and brings it over, I feel really looked after."

"Eurostar – you can book everything online like anyone else and you get full assistance on arrival until getting on the train. I travel with my wife but could do Eurostar on my own if I really needed to and I cannot say that about anywhere else."

"My local supermarket usually has plenty of disabled bays and considerate staff."

Accessible by public transport

Public transport can be accessible and valuable to people with MS. Some examples of good practice were described by respondents.

"Using the ring-and-ride bus service I can manage to get to Solihull town centre, theatres, concert halls where friends can meet me to push me around in my wheelchair."

"I use Chorleywood station as there are quite a few disabled parking spaces. Kings Cross station has lifts in and out and there are facilities in the St Pancras hotel which I use (even though I realise it is a bit cheeky)."

7. What could change to enable more people with MS to get out and about?

Summary

It's clear from our survey that people with MS face significant challenges in travel and transport outside the home. This is not unexpected. Our research looks specifically at the experiences of people with MS but confirms the findings of other recent studies looking at other aspects of disability and transport.

Our respondents have identified that their key needs as car travellers are for good parking, accessible toilets, plus accessible information about their journey and destination so they can plan. Where this is missing, people with MS face significant barriers to travel in private cars ⁽²⁾, often opting to not make journeys where there may be a risk of difficulties.

The people with MS that we surveyed also confirmed that public transport often fails to meet their needs. Less than half our respondents use trains, buses or trams. It has previously been shown that disabled people may struggle on public transport, are often unaware of their rights to travel and complain, and frequently feel poorly supported ⁽³⁾. Our respondents talked about poor accessibility, low reliability and inadequate staff training leading them to rule out public transport as a realistic option.

Local accessible transport solutions such as dial-a-ride services may be hugely enabling ⁽⁴⁾, but too few of our respondents were aware of services near them. These schemes are limited to local areas and there is not equitable coverage across the UK. They may be subject to funding fluctuations as local authority budgets come under pressure. Services may also be limited, requiring users to prioritise some journeys, such as those for healthcare, over journeys for leisure or social opportunities.

Other studies have demonstrated that barriers to travel outside the home lead to isolation and loneliness ⁽⁵⁾. Our research confirms the profound impact on mental health from restricted travel and reduced independence. People with MS living in lower income households tend to experience more severe symptoms, report more barriers to travel and transport, and experience a greater impact on their mental health.

This indicates the vital importance of appropriate benefits and concessions for people with disabilities arising from MS in preventing a whole range of negative impacts. Applying for benefits and concessions can be confusing, frustrating and difficult, particularly for people with MS dealing with fatigue or cognitive symptoms.

Some concessions are administered locally, and under variable eligibility criteria, so that a Blue Badge in one place may not be available to people with the same needs or offer the same benefits elsewhere. National benefits such as Personal Independence Payment (PIP) or Adult Disability Payment (ADP) may need tenacity and patience to be obtained by people with MS. Many of our respondents relied on help from health professionals, carers and family to apply, but still found the process exhausting and dehumanising.

Our survey includes evidence that people with MS may give up or fail to get benefits like PIP and ADP at the level to which they could be entitled due to an unwillingness to apply or appeal. People with MS speak about their fear about the assessment process and their concern that the assessors have insufficient knowledge of MS. They explain how difficult it is to communicate the impacts of a complex, fluctuating condition like MS effectively.

Our survey shows that people with an enhanced mobility PIP or ADP award still experience profound barriers to travel and transport, indicating that the benefit is not addressing all the unmet need. The people who do not have an enhanced mobility PIP or ADP award are also struggling with transport and travel and may be put off from applying for more support. People with MS need flexible support packages that they can tailor to their personal needs ⁽⁶⁾.

Our respondents are clear that benefits, while welcome, do not restore a level playing field to people with MS related disability. There is a long way to go to ensure that people with MS are not disadvantaged by their MS symptoms and disability, and by the additional costs and barriers they face in travel outside the home.

Calls to action

There are many opportunities to improve infrastructure and support so that people with MS and other disabling conditions can remain independent travellers outside their homes.

We need to raise awareness of the impact of MS on travel and transport outside the home, especially the impact of poorly managed symptoms of all kinds. We have seen that it is not just mobility that causes problems for people outside the home. Invisible symptoms that affect energy levels, stamina, toileting, and the ability to navigate public spaces can also be debilitating. It is critically important to ensure that health professionals can identify people at risk of losing their independence due to MS and refer them to appropriate pathways for support to avoid isolation.

We must also acknowledge the significant role played by family and informal care in supporting the transport and travel needs of people with MS. This places an additional burden on family caring relationships and is a point of vulnerability for people with MS if they don't have this support or if their carer becomes infirm or ill themselves.

We must also recognise the impact of poorly maintained paths and poorly designed urban environments on people with disabilities, including invisible disabilities. We have seen examples where inclusive thinking about navigating historic places and shopping, health and leisure facilities has improved accessibility. Conversely, our respondents have also shared examples where a lack of thought has led to problems for people with MS at transport hubs, town centres, roadworks and building works.

Here are three ways that we can make a difference for the MS community.

1. The MS Trust will create a tool kit for MS health professionals to help them recognise and support people with MS struggling with travel and transport issues.

This will help health professionals and people with MS make decisions about travel together.

We want to help health professionals recognise the symptoms and social determinants that put people with MS at risk of isolation due to travel and transport issues.

- 2. The MS Trust will work with people with MS to provide practical, high-quality information and signposting about accessing support – such as PIP – through our online resources and our MS helpline. We will empower people with MS to apply for the support they are eligible for.**

This will simplify and demystify the process of accessing PIP, benefits, mobility aids, and other concessions.

We want to encourage people with MS to build their knowledge and confidence to take up local support schemes, apply for benefits and empower people with MS to remain active travellers for as long as possible.

- 3. The MS Trust will raise awareness of the causes and impacts of travel issues in the MS community, sharing personal stories of people with MS, and working with carers and advocacy groups.**

This will highlight the impact of poorly maintained pathways, a lack of public facilities, and poor urban planning / public transportation on families affected by MS.

We want to draw attention to the significant role played by family and informal carers, as well as the isolation that occurs when people with MS do not have access to such care systems.

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6. Thank you for shaping our response to the PIP consultation. 2024 [Thank you for shaping our response to the PIP consultation | MS Trust](#)

**If you have been affected
by the issues in this report,
there is help available.**



For any questions about MS,
contact our helpline on
0800 032 38 39 or **ask@mstrust.org.uk**



Browse our transport webpages here:
mstrust.org.uk/home-and-travel



Find other sources of information and
support here:
mstrust.org.uk/information-support



Our podcast series looks at all issues
relating to MS, including several episodes
about travel and transport:
mstrust.org.uk/podcast