Loneliness and isolation

Listening to experiences of loneliness and isolation in the lives of people affected by multiple sclerosis

MS-UK

Contents

Foreword

Multiple sclerosis (MS) is a disease of the central nervous system (your brain and spinal cord). Approximately 130,000 people in the UK live with MS and it causes different symptoms in different people at different times.

Symptoms can come and go; some are much more responsive to treatment and others can be more difficult to manage. Common symptoms include issues with balance (causing unsteadiness, clumsiness, and affecting limb movement and posture), bladder and bowel problems, fatigue and pain.

While MS-UK strives to ensure we are always here to offer support and information to people affected by MS in any areas of life, we believe that loneliness and isolation need a more targeted approach. This report outlines nine months of research by MS-UK. It is clear, from our research, that loneliness and isolation have a negative impact on the lives of people affected by MS.

The impact of feeling lonely on people's health is considerable and can result in an increased risk of depression, low self-esteem, reported sleep problems and increased stress response (1). Depressive disorders occur at high rates among patients with MS and this can have a major, negative impact on peoples' quality of life (2). Of the people we surveyed, 70 per cent said they were currently or had previously experienced loneliness and 72 per cent said they were currently or had previously experienced isolation (3).

There are compelling financial reasons for tackling loneliness and isolation in society as a whole. For example, lonely people are more likely to be readmitted to hospital or have a longer stay (4). There is also evidence that lonely people are more likely to visit a GP or A&E and more likely to enter local authority funded residential care (5).

But beyond this, as a charity we have a moral obligation to support people affected by MS in ways that truly make a difference. Exploring the issues of loneliness and isolation has not been an easy undertaking but it has been essential. We now know of the barriers to feeling connected and we have some ideas about what should happen next to make a difference for people in the future. Vitally, these ideas are from people affected by MS for people affected by MS.

Now is the time to take positive steps, so that people affected by MS in the future are less likely to experience loneliness and isolation. MS-UK cannot do this alone. We recognise that this report is a small non-representative sample and we hope that it will inform our conversations and inspire communities to come together with a common aim.

We have listened to the MS community. Now is the time to tackle these issues.

Amy Woolf
CEO, MS-UK

What we did

Why we began

In 2018, MS-UK spent a considerable amount of time engaging with our communities in order to create our strategic plan to support people affected by multiple sclerosis (MS) to live healthier and happier lives. Talking with people affected by MS, health professionals and other charities, the themes of loneliness and isolation kept re-appearing.

MS-UK's 2018 strategy consultation included focus groups, face to face interviews and an online survey.

Loneliness and isolation were featured throughout the survey responses in various comments, and over 40 people described these experiences, often linked to aspects of living with MS such as experiencing mobility issues and fatigue.

> **Not being able to be part of 'everyday life', not being able to get help with things when I need it, being so isolated and alone.**

> **Not having a meaningful / fulfilling social life.**

> **Difficulty in attending cinema, shows and other events due to poor mobility and weakness.**

> **Being alone and not independent.**

MS-UK is a community-led charity and as such we felt we had to dig deeper into these issues that were so obviously affecting the people we are here to support. In 2019, we began to research the issues of loneliness and isolation.

Our methodology

We wanted to gather the lived experience of people affected by MS who have faced loneliness or isolation, or both of these issues.

We approached our research in two ways:

- We undertook an extensive review of what's already happening around loneliness and isolation across the UK through desktop research
- We gathered qualitative insights from people affected by MS through an online survey, focus groups and one-to-one telephone interviews

What we asked

During our desktop research we reviewed a broad range of existing literature, projects and initiatives relating to the issues of loneliness and isolation. We looked at the UK broadly and more specifically at the experiences of people affected by long-term health conditions. In addition to this, we spoke with many professionals working in these areas and liaised with organisations across the country.

We ran an online survey to ask people affected by MS to define loneliness and isolation in their own words and share their experiences. From this survey, key themes were identified.

While over 200 people completed our online survey, we wanted to explore the complexities of the emerging key themes by conducting face-to-face focus groups and telephone interviews.

For the purposes of the focus groups and telephone interviews, we used the definition of loneliness as 'a feeling of being alone which has a negative impact on wellbeing' and the definition of isolation as 'a lack of social contact or support'.

Participants at this stage were mixed in their experiences of loneliness and isolation. One woman we interviewed on the telephone had not seen anyone except her husband in over a couple of months. One man we met at a focus group, whose wife lives with MS, spoke about the support he gets from bringing his wife to their local therapy centre and how this helps him feel connected too.

There were no 'right' or 'wrong' answers and we have tried to capture as many perspectives as possible in this report.

This research sets out our findings from all three stages of our research. After engaging with 258 people affected by MS and countless professionals, as well as consulting the existing research within this space, we hope this report presents a rich tapestry of experiences that adds further insight to the commentary around loneliness and isolation.

What we found

Desktop research

Diana Crowe, Head of Services at MS-UK, led our desktop research. By collating a range of literature and analysing it in depth, we were able to paint a picture of what has already happened across the UK with regards to tackling loneliness and isolation.

In 2011 the Campaign to End Loneliness was launched. Hosted by Independent Age and supported by National Lottery funding through the National Lottery Community Fund, as well as the Calouste Gulbenkian Foundation, the Tudor Trust and donations from the general public, the campaign aims to reach and support people at risk of loneliness.

This campaign marked the beginning of a concerted nationwide effort to address loneliness. By presenting evidence-based information to commissioners and facilitating learning, the campaign has built a research base and uses this to campaign publicly on a local and national scale.

The launch of the publication 'Promising approaches to reducing loneliness and isolation in later life' (6) saw a shift in how the UK responded to these issues. The Cabinet Office invested in tackling loneliness in 2015 and the late Jo Cox MP started the conversation about loneliness in 2017. The first ever Loneliness Awareness Week was launched in June of that year by the Marmalade Trust.

Consequently, loneliness affected the political agenda across the UK. HM Government, the Scottish Government and the Welsh Government all published strategies to tackle these issues in 2018 and in 2019, and Northern Ireland has begun working with the Campaign to End Loneliness as well. Resources began to be developed, such as loneliness measurement guidance and a framework setting out the full range of interventions needed from stakeholders across the community to support people at risk of loneliness.

As more research revealed the health and economic impact of loneliness and isolation, the issues became public wellbeing concerns. The Campaign to End Loneliness presented the facts - loneliness, living alone and poor social connections are as bad for your health as smoking 15 cigarettes a day. Lonely people are more likely to suffer from dementia, heart disease and depression and loneliness is likely to increase your risk of death by 29 per cent (7). Research commissioned by Eden Project initiative The Big Lunch found that disconnected communities could be costing the UK economy £32 billion every year (8).

Much more research has been published over the past decade, predominantly focusing on the experiences of aging populations. While it would be impossible to produce an exhaustive review of this literature published, some publications are noteworthy in relation to our work at MS-UK.

The charity Sense has looked extensively at the issues of loneliness and isolation in relation to living with a disability. In their report 'Someone cares if I'm not there –

Addressing loneliness in disabled people' (9) they found that while disabled people experience the same life transitions as everyone else, having a disability means that they are more likely to be chronically lonely than non-disabled people. Physical impairment can make maintaining existing relationships and making new social connections more difficult. Thirty per cent of people with mobility issues said that they are always or often lonely.

The report notes that loneliness and isolation are common experiences for people with neurological conditions as they often experience specific symptoms such as drooling, excess sweating, incontinence, tremor, swallowing issues, involuntary movements and changes to gait and facial expressions. This can lead to being mistakenly accused of being drunk and a loss in confidence. Loneliness is disproportionately high among disabled people, with over half of disabled people reporting feeling lonely, rising to three quarters for young disabled people.

In the report 'A right to friendship' (10), Sense found that six per cent of disabled people have no friends at all and more than half think that as a disabled person there are more barriers to making and keeping friends.

Additional research has highlighted other contributing factors. Unpaid carers are reportedly seven times more likely to be lonely compared with the general population (11). YouGov Plc research from May 2019 showed that people in cities (compared to the UK overall) that were surveyed had a higher incidence of feeling lonely; 25 per cent of adults have reported feeling lonely on weekends and that evenings were the most likely time to feel lonely.

During our desktop research we identified that much is already being done to tackle loneliness and isolation across the UK, with varying levels of success.

Some suggestions included creating opportunities for social interaction and one in six people with disabilities said that local support and social groups would make a difference. Two in five people with disabilities said that being able to get out more would enable them to see friends more often (10).

One of the many recommendations in the Loneliness Action Group report (12) says that the government should continue to work to develop a full-scale Loneliness Test and share how this has impacted public policy and in turn loneliness.

The Campaign to End Loneliness guidance for local authorities and commissioners focuses on harnessing the power of technology to help retain connections and independence and exploring ways to improve transport options that are affordable, accessible and safe (13).

In June 2019, the National Lottery Community Fund published their report 'Bringing people together: how community action can tackle loneliness and social isolation' (14), which provided insights and examples learned from over 8,000 projects in the community and voluntary sector that help to address loneliness.

Key findings from this report included:

- Helping to change a lonely person's mindset is the essential ingredient. Re-engaging with society needs the right mental space, not just practical opportunities to socialise

- Finding meaning is at the heart of tackling loneliness by supporting people to do what matters to them

- You can't prescribe friendship. People need to feel that they are valued as individuals, not seen as problems to be solved

- Providing support at vulnerable times, such as major life transitions which are triggers for loneliness and isolation

- It is hard to fix a problem that someone does not acknowledge – catch it early before it becomes entrenched

- Kindness matters

- Loneliness is normal, and even healthy. It only becomes a problem if people become isolated through circumstances beyond their control

- For many loneliness and isolation are interchangeable

The report explored prevention that works and found that investing in places and spaces is important and by collaborating, society can tackle loneliness and isolation in a way that identifies, nurtures and celebrates the connections we make with one another. By creating and maintaining services that are open, inclusive, welcoming and led by compassionate and kind people, means that simple solutions can be developed to tackle loneliness and isolation.

Additionally, a key finding in this report was that identifying trigger points is important and for MS-UK, we know that transitional periods of living life with multiple sclerosis (MS) are critical. We will continue supporting people affected by MS to manage periods of significant change such as diagnosis, relapse and disease progression through our current service provision and future initiatives.

Social prescribing is a development which may also be extremely effective in tackling loneliness and isolation (15). It is a means of enabling healthcare professionals to refer people to a person who can help them 'co-produce' their 'social prescription'- so that people with social, emotional or practical needs are empowered to find solutions which will improve their health and wellbeing, often using services provided by the voluntary and community sector (16). It is hoped that social prescribing will be available at all GP practices by 2023, with all professionals involved receiving training around identifying loneliness.

A full list of secondary resources which we consulted for our desktop research can be found in appendix A.

Qualitative research

The voices of people affected by MS inform all our work at MS-UK and during this research it was clear that these voices may be able to make a difference for people in the future who may experience loneliness and isolation.

In May 2019 we launched a survey for the MS community to gather people's experiences of loneliness and isolation in their own words. The survey ran for two months and was completed by 232 people.

The majority of survey respondents (210 people) stated that they lived with a diagnosis of MS.

MS connection

■ I have a diagnosis of MS   ■ Other
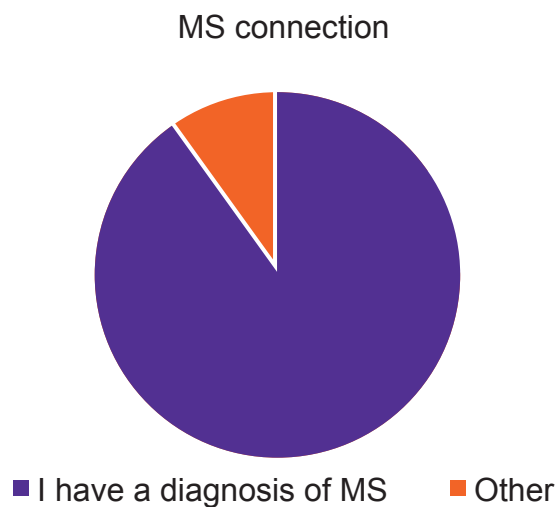
We also asked for their demographic information, such as age, gender and employment status. More than half of respondents stated their age was in the bracket 45 to 64 years old (65 per cent) and the majority identified as female (73 per cent). Employment status was mostly stated as 'medically retired / unable to work' or 'retired' (37 per cent).

Of those surveyed, 163 people said they were currently experiencing loneliness or had in the past.

Experience of loneliness

■ Experience of loneliness   ■ No experience of loneliness
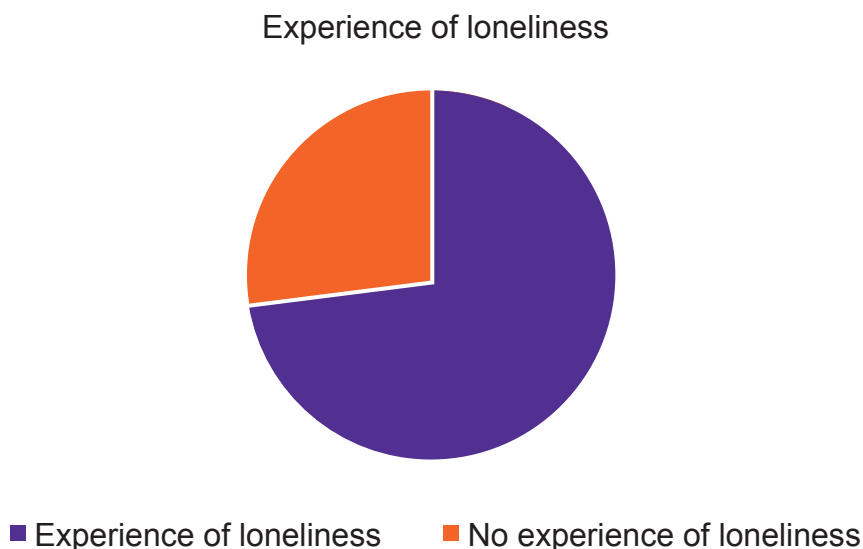
When we asked about isolation, 168 people said they were currently experiencing this or had in the past.

Experience of isolation

■ Experience of isolation   ■ No experience of isolation
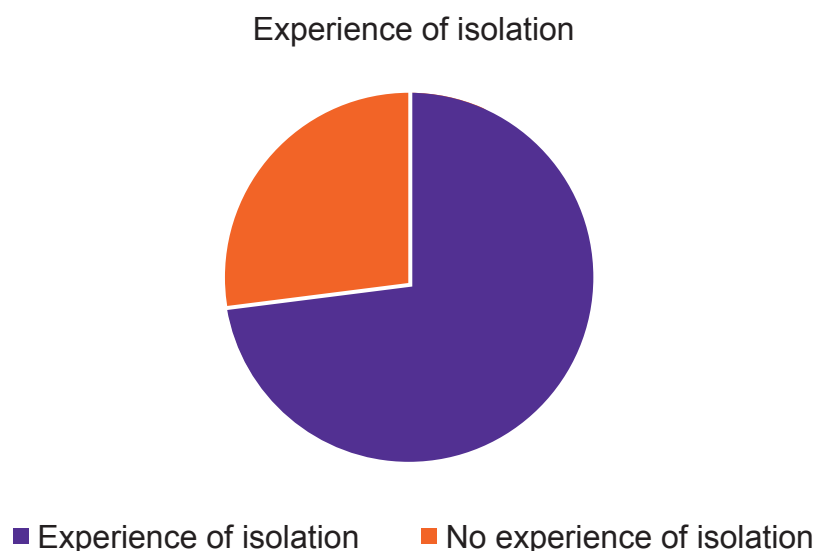
A full data breakdown of demographic information relating to survey respondents can be found in appendix B.

While some quantitative data was collected, it was the survey respondent's commentary that really emphasised the realities of the issues of loneliness and isolation.

We asked respondents to let us know what loneliness and isolation meant to them in their own words. Loneliness was described as 'feeling unable to reach out to others' and a 'loss of freedom'. Isolation was defined by respondents with a range of words such as 'shipwrecked' and 'stranded'.

In our focus groups, we explored the themes arising in the survey in more depth. We held five focus groups across the UK in September 2019. Groups took place in Manchester, Glasgow, Cornwall, Warminster and Essex.

We listened to 17 people at these focus groups, 10 women and 7 men. Each group lasted between 1 and 2 hours, depending on the number of attendees. We also carried out 9 telephone interviews, speaking to 8 women and 1 man.

We asked these 26 people to talk to us about reaching out for help if they experience loneliness and how MS-UK can support people to reach out. We asked how MS-UK could support people to feel more connected and more independent. Finally, we explored ideas and suggestions about what kind of things MS-UK could be raising awareness of with the general public specifically relating to living with MS.

In total, we consulted with 258 people affected by MS during our qualitative research.

Key themes

Key themes appeared in our online survey that were later explored and echoed in our focus groups and in telephone interviews.

These were that people struggled to reach out, stay connected, maintain independence and often faced a lack of knowledge about multiple sclerosis (MS) that added to their feelings of loneliness and / or isolation.

MS was described as a 'personal battle', making it more difficult for people to reach out for support. One survey respondent described being 'surrounded by people – yet alone' and this sentiment was echoed in the focus groups and interviews we conducted.

Reaching out

The first step is often the hardest. Asking for help is not something that comes naturally to the people we consulted, and everyone mentioned to some degree how difficult it can be to reach out for help.

It takes a lot of courage to say, I need help...I know I tend to just say, I'm fine. – focus group attendee

Feeling unable to reach out to others. – survey respondent

The reasons for this difficulty were numerous. Living with a long-term health condition impacts personal relationships, from those with spouses, friends and family members through to colleagues.

I've always been the type who offers help, so no one would ever expect me, I don't think, to actually go and ask someone. – focus group attendee

> **Asking for help I find quite difficult and I've always got the feeling it changes the relationship.** – focus group attendee

Particularly in the online survey, respondents described a sense of abandonment and described the difficulties of maintaining personal relationships.

> **Being a viewer of the world and not part of it.** – survey respondent

> **Feeling unloved.** – survey respondent

> **No intimate or personal relationships.** – survey respondent

> **Having no one to share time and life with; to communicate and laugh with; wake up in the morning with, turn to, speak to, share worries with…** – survey respondent

Many people did not want to be a 'burden' to loved ones. Research participants described being known as 'the strong one' and following diagnosis they didn't feel like they had the permission to ask for support, as they hadn't before receiving a diagnosis.

"

I find it very difficult, full stop, to ask for help…you don't want to burden people with things you're going through. – telephone interviewee

"

Afraid of opening up in case perceived as a burden… – survey respondent

"

Don't you feel sometimes that you're putting your stress on to somebody else? – focus group attendee

"

Not wanting to burden people when I'm struggling. – survey respondent

Some participants felt there were expectations of them to be a certain way, especially if they experienced hidden symptoms.

"

I think most people see you the way you were before MS… it didn't change me very much for a lot of years…so some people forget. – focus group attendee

"

MS is complex and you feel isolated when you cannot find anyone who understands these complexities. – survey respondent

> **Frightened about what my body may or may not do.** – survey respondent

> **There's a few friends that have known me before MS hit who are still in contact…a small number…it tends to be people who have direct experience themselves…or through their own personal life.** – focus group attendee

In one focus group consisting of all women, the issues of personal hygiene and the expectation of having clean hair and wearing make-up when seeing people was discussed.

> **I'm shattered and I just got myself ready to go out.** – focus group attendee

> **I'm not able to get up and just do my make up and just have a shower, so if we're going out I have to plan.** – focus group attendee

Some felt that looking 'well' could have negative effects if people thought you were 'lying' previously.

> **I'm always getting 'you look great'…one of my friends always says 'You're lucky because you still look great'…but it takes a bit extra work to make yourself.** – focus group attendee

Several participants described having friends and family close by, however symptoms of MS often prevented them from reaching out. Also, it can be difficult to explain the symptoms that may cause barriers to engaging in social activities.

"

My cognition is affected so that makes me feel lonely as well, as I can't keep up with conversations with people, my mind drifts off. – focus group attendee

"

Symptoms preventing you from being active and going out, and not being able to have a conversation (cognition), eating alone (due to diet choices), mood, anxieties and body image. – survey respondent

"

I'm very lucky, I am very blessed, I have a wonderful husband…but I still find it difficult, even to ask him for help, at times, because he's so busy doing everything I can't do. – telephone interviewee

Participants recognised that people tried to encourage them to open up. One participant at a focus group spoke of how her MS nurse always asked, in a round-about way, if she was feeling lonely, but she could never manage to admit it.

Another focus group attendee spoke of how it became harder to ask for help as her condition progressed, because she'd always been used to 'knocking back' offers of assistance previously.

"

To have to admit to yourself is the difficult bit to begin with…but then go and approach somebody and say for the last five years I've been refusing X, Y and Z but maybe I do now need [help]. - focus group attendee

An overriding concern was the impact of MS on peoples' loved ones. Participants had worries that they would be experiencing loneliness and isolation too.

Their life starts to be limited as well as the person with MS and that's when the guilt kicks in – focus group attendee

Even though you have people around you a lot of the time you feel alone not able to tell other people how you feel. – survey respondent

I cry whenever I speak to the MS nurse and mention my husband…I cry…for all he does for me. – focus group attendee

Not being yourself – hiding your MS. – survey respondent

It does bring loneliness to both of you…not just one of you… both of you…because you end up not going to places as a couple. – focus group attendee

Pretending you are OK to protect others' feelings. – survey respondent

Knowing what is available in your area isn't always enough to make people reach out for support. Participants recognised that there was existing support available sometimes, but that a personal determination is needed to take the first step.

> **It's almost like stopping smoking – you've got to want to do it… stepping over the threshold for somewhere [like a therapy centre] is extremely hard and you've got to want to.** – focus group attendee

Ultimately, MS is a condition that affects everyone it touches, and in very different ways from person to person. Feelings of guilt, worry and responsibility add to people's experiences of loneliness and isolation. To support people to reach out more, it will be important to recognise these differences and feelings.

How to reach out

It is important for people affected by MS to invest time in feeling connected and to reach out. Whether physically leaving the house or keeping in touch with people electronically, people affected by MS will first have to acknowledge that it is worth the effort. That they are worth the effort.

> **There is life after diagnosis.** – focus group attendee

By supporting positive thinking, organisations can encourage people affected by MS to reach out on a regular basis, and especially if they are feeling lonely or isolated.

> **Be braver than I am.** – telephone interviewee

Suggestions for doing this included setting achievable daily targets and having a list of useful telephone numbers to hand should things become overwhelming.

Feeling connected

Many people described feeling disconnected from the 'old' life which they had before a diagnosis of MS.

The phone calls you might have got for the first few years… they drop away. – focus group attendee

Disconnected from a social and normal environment. – survey respondent

Grieving the life lost. – survey respondent

Loss of old me and old life. – survey respondent

I've found that my 'before' friends…they try…they can be very frustrated…but that's just because I look fine, I look ok, but that's not what's happening. – focus group attendee

Loss of identity. – survey respondent

There was a genuine feeling of being 'disconnected', especially around letting people down over an extended period of time and how this may cause problems in the future.

> **If you keep saying no, you'll stopped getting asked, I think that's a fear.** – focus group attendee

> **Lack of social / meaningful interactions and not being able to take part in activities.** – survey respondents

Transitional periods, such as leaving work or a change in mobility, impacted on how connected people felt to their immediate circles and wider society.

> **At my age, my friends still work, they've still got their careers, I had to give mine up…** – focus group attendee

> **Medically retired – lost a whole contact point – life as I knew it has ended.** – survey respondent

> **I didn't work for five years after being diagnosed…when I applied for a job here people said 'it's overrated, just stay at home'…but no, I can work and I need to work.** – focus group attendee

When you hear people say 'oh I've got to go to work today' and you think, I'd love to get back to work. – telephone interviewee

You lose a lot of friends…not through anybody's fault, but you might say I don't know if I can do…I will not be good company...they are just wanting your company, no matter what… – focus group attendee

Several people we spoke to at the focus groups agreed that it was important to take the first step personally.

It's a stupid statement, but you've got to get out…I know it's dead easy to say it, but you've got to…if you stay in watching daytime television, you'll end up suicidal. – focus group attendee

You have to invest a little bit of time in yourself. – focus group attendee

Modern technology was seen as an opportunity to feel more connected to others and to learn more about MS. However, it was also seen as a negative influence in that it stopped people physically going out into their local community and engaging face to face.

Things have changed now because you have all the information on MS is there at the touch of a button…you don't need to leave the house, you don't need to speak to anybody. – focus group attendee

Online forums had negative and positive aspects, from making people feel supported to finding people online could 'argue' a lot or give out unsolicited advice.

> **I actually feel really close to the people in this [Facebook] group but I've never met them, I've never spoken to them…we kind of support each other.** – focus group attendee

> **In some ways I'm afraid to read the blogs…you don't want to hear the really awful, frightening stuff…but in other ways it would be really reassuring and helpful for me to know that other people are going through what I'm going through and what they do to help themselves.** – telephone interviewee

> **I don't do Facebook…I'd rather meet people and talk to people.** – focus group attendee

Both members of our focus groups and telephone interviewees mentioned the positive impact of physically leaving the house and noted that pets were useful at encouraging this.

> **Everybody needs other people…physical contact.** – telephone interviewee

> **I've a dog and she forces me to go out.** – focus group attendee

"

I live in a small village and I've got a dog…the best thing for people who are lonely is to get a dog, you get out with a dog and most people are quite friendly with dogs and they stop and talk to you. – telephone interviewee

Peer support was seen as vital and many participants felt that those who had experience of living with MS just 'got it' when referring to symptoms or experiences. A lack of peer support exacerbated experiences of loneliness and isolation.

'To have the friendship group of others who have MS is very helpful in the sense that you're not having to start off with an explanation…you can just say I'm having a really tough day and they all acknowledge that.' – focus group attendee

"

Not knowing anyone with MS to talk to. – survey respondent

"

Part of the reason of coming [to a therapy centre] is you talk to people…you find out about things. – focus group attendee

Listening to people about feeling connected and how MS-UK can support this, it was clear that participants felt there is no definitive solution but there may be several opportunities to foster connections. By empowering people to say 'yes to life' and sharing information about what networks already exist, making connections could be easier in the future.

How to feel connected

Our emotions are so unique and feeling connected is different for everyone, so it's important that there is no 'one size fits all' approach to supporting people. A range of ideas were suggested during our research, including the following:

- Face to face peer support
- Social media groups and forums
- A buddy scheme
- Newly diagnosed groups
- Age-specific groups

It is clear from our initial research into the areas of loneliness and isolation that much is already being done in many of these areas. There are buddy schemes operating across the UK, led by a range of organisations, and many of the MS therapy centres we visited operated befriending schemes and outreach support to people in their local areas to those affected by MS.

Social media, and specifically Facebook groups, have grown enormously in recent years and now offer people a way to connect even if they are unable to leave the house. Peer support, whether in person at MS Society groups or via online forums such as Shift.MS, is recognised as valuable and is widespread across many parts of the country.

I think there should be community groups – telephone interviewee

If people affected by MS know more about what is available in their locality and online, reaching out and connecting may be a lot easier.

Feeling independent

Independence may be thought of as the state of wanting or being able to do things for yourself and make your own decisions, without help or influence from other people.

When we asked our research participants about the importance of independence, practical considerations and emotional aspects were stated as having an impact.

I feel sometimes, from my own experience, trying to be independent is like a double-edged thing, because you almost fool yourself into thinking…that you can cope…then it all gets too much then it all crumbles. – telephone interviewee

> **Loss of independence and spontaneity.** – survey respondent

Venue accessibility and knowing where you can actually go were mentioned several times.

> **It's amazing…they'll get one thing right and then they'll get another thing wrong…they'll have a wide door so you can get a wheelchair in [to a toilet] and then it'll have a small room so you can't turn your wheelchair around.** – focus group attendee

> **Inaccessible venues with a lack of appropriate facilities close by.** – survey respondent

> **I don't go out very often in the evening, I get invited places and I think, 'toilets'.** – focus group attendee

> **My friends are really supportive, but they won't see the fact that it's hills…so I won't go there.** – focus group attendee

Transport is an issue for many people. Some participants in rural areas described buses only arriving every two hours, while others described no longer being able to drive and having to rely on loved ones or taxis for transport.

"There is nobody around…I think that is quite isolating…you can't even just pop out to the shop." – telephone interview

"Lack of transport. – survey respondent

"I can't travel long distance now, I can't drive it.
– focus group attendee

"Trapped at home. – survey respondent

"I feel isolated because I can no longer drive and mobility is poor.
– survey respondent

"Even if I could manage to get over [to the bus stop] I wouldn't be able to get on the bus...it does pose a lot of problems.
– telephone interviewee

"Physically housebound due to physical or mental health issues.
– survey respondent

Issues getting out and about physically definitely have an impact on independence, but they are not the only considerations that need to be taken in to account. Hidden symptoms also play a part in planning outings and meeting up with friends.

"**Pain and fatigue are my issues…and its them that stop me getting out, not the fact that I've got a crutch.** – focus group attendee

"**Invisible symptoms – people don't get it.** – survey respondent

"**There's loads of symptoms you can't see which are going on inside people.** – focus group attendee

Asking for support to maintain independence can be hard for people and some participants were concerned about asking for help or feared rejection.

"**I don't like relying on anybody at all…it's extremely hard, but I think sometimes you do have to accept support.** – focus group attendee

"**Friends and family not having time for you when you can't get to events.** – survey respondent

> **People don't want to keep hearing that you're lonely or that you're not well, people just don't want to hear that all the time.**
> – telephone interviewee

> **I don't think people want to reach out for help because they want to give the impression they can cope with MS.**
> – focus group attendee

Signposting is a common tool used within service provision, where professionals direct individuals to other services that support their identified needs and this was seen as a key area of development in promoting independence for people affected by MS. Mental health was mentioned several times as an area that requires further exploration.

> **There is nothing in my area if you are having a really bad day, mentally.** – telephone interviewee

> **Depression keeps people away.** – survey respondent

Some participants felt it would be useful for MS charities across the country to signpost to each other and share what each does.

> **These different charities, sharing information more.**
> – focus group attendee

Practical information about a range of topics would be useful for maintaining independence. Topics mentioned included holidays, travelling, parking, accessibility 'hacks' such as radar keys and venues that let carers in for free, as well as more detailed information about benefits such as Personal Independence Payments (PIP) and car schemes.

How to feel independent

Independence is important on so many levels and changes to circumstances can have a big impact on just how independent someone feels.

" **With MS, with all the physical side…just getting [out] is an uphill struggle.** – telephone interviewee

During our research ideas for supporting people to remain independent focused primarily on practical resources. These included:

- Knowledge of accessible venues, what's on and holidays
- Information about transport (whether accessible public transport, information about funding for taxis or information from the DVLA about driving and car adaptations)
- Top tips for what is already out there, such as parking information, radar keys, free carer entry to venues and respite care facilities

Participants felt it would be good to have an online 'map' of what's local to you that could be searched via entering a postcode. This could include information about what health and social care services are nearby and a list of health professionals too.

Another idea was to provide all GPs with a short list of local support organisations around loneliness and isolation that would be given to anyone visiting their GP about living with MS.

Raising awareness of multiple sclerosis

Raising awareness about MS is a suggestion that repeatedly came up during our research. In our strategic planning research in 2018, 78 per cent of our survey respondents stated that a lack of understanding about MS was by far the biggest issue they faced.

MS-UK has a commitment to increasing people's understanding of MS if they live with this condition and providing people with all they need to make informed choices and decisions. This was seen as important by our research participants.

> **Disability in general is a whole new world when you have one.**
> – focus group attendee

Increasing understanding of MS for those who do not have the condition was also seen as an essential undertaking for the future. A focus on hidden symptoms was voiced as a priority by several participants.

> **There's so many aspects of MS…whereas if you break your leg, you've got something to show.** – focus group attendee

> **I think that people need to know much more about the invisible stuff.** – focus group attendee

> **I think the problem is if you took the crutches away and looked around the group here, you'd say 'oh you all look healthy' because we're seated.** – focus group attendee

> **Although a lot of people with MS may look pretty normal from the outside…appreciate all the invisible stuff that's going on.**
> – telephone interviewee

Several specific symptoms were mentioned when we brought up the theme of raising awareness of MS at our focus groups and in our telephone interviews. These included bladder issues, spasticity and fatigue.

> **Getting the message out that fatigue is not tiredness.**
> – focus group attendee

Many participants felt that the general public have little or no knowledge of MS as a whole.

> **Once you say you've got multiple sclerosis they look at you with this blank expression.** – telephone interviewee

> **Lack of understanding and empathy.** – survey respondent

Suggestions were given about how organisations (including MS-UK) could raise awareness of MS, from hosting events that 'simulate' symptoms to encouraging more soaps on television to include MS storylines.

> **The biggest impact you can have is for people to experience it themselves.** – focus group attendee

Many participants agreed that a high-profile celebrity or well-known personality talking about living with MS publicly would have an impact on the general publics' awareness of MS. In our focus groups in particular, several people spoke about getting more media coverage for MS on a national level and one idea included creating a documentary about the realities of living with MS.

There were several key groups that could be targeted, including schools, employers and GPs which may help to raise awareness of MS.

How to raise awareness of multiple sclerosis

A lack of understanding about the realities of living with MS were mentioned by many participants during our qualitative research stage.

I don't think there is a good awareness of a lot of illnesses.
– telephone interviewee

Several people commented that before they received a diagnosis of MS, they did not fully understand it or appreciate what living with a disability may entail.

There were several ideas on how this could be tackled:

- Raise awareness with employers
- Focus on hidden symptoms, especially fatigue, and try to demonstrate what it's like to live with hidden symptoms in a practical way
- Support newly diagnosed people to stay positive
- Education about MS in schools
- Support GPs to better understand MS
- Share information about all the charities available and what each one does, so people know what's out there and don't get confused
- Raise awareness of disability in general, possibly working with other charities, to promote empathy and tolerance
- Use simple ideas to raise awareness, such as the spoon theory or the idea of a battery running low with regards to fatigue

MS-UK already has a strategic commitment to raising awareness of MS, however these ideas will help us to focus our activities and reach more people in the coming years.

Barriers

From our research, one thing seems to be clear. There is an abundance of initiatives already in place across the country to tackle loneliness and isolation. Problems accessing these initiatives seem to stem from people's ability to reach out for help when they need it and from not knowing what is available.

The barriers to accessing existing support are:

- A lack of confidence (of people affected by MS)

- A lack of adequate signposting (by health and social care professionals)

For those who do have confidence to reach out or who do know where to go, additional barriers are:

- A lack of accessibility

- A lack of specific interventions catering for bespoke groups (i.e. people newly diagnosed)

- A lack of awareness of MS (of the general public)

Next steps

So, what are the next steps?

How do we learn from these findings and what exists already to take meaningful action that has an impact on the lives of people affected by multiple sclerosis (MS)?

We cannot presume to know all the answers, but here are our recommendations for next steps based on suggestions from people affected by MS and our research in its entirety.

How MS-UK will continue this work

MS-UK is committed to responding to the issues of loneliness and isolation in 2020 and beyond. People affected by MS are at the heart of our work and to this end we will be taking positive action to reach this community in a way that supports them to live healthier and happier lives.

We have reflected on what we have learned and identified areas of work that we will now take forward.

Peer support

Peer support has clearly been identified as a highly valued and needed service for those affected by MS. Online groups can provide the opportunity to connect with others across the world in order to share experiences and provide support. Befriending services whether face to face or by telephone can provide new supportive and reliable relationships to individuals. Local MS groups can provide friendship and access to support and information.

We acknowledge the existing work already being undertaken by MS charities both face-to-face and online and these should continue to support people affected by MS to feel connected through these different channels.

We are committed to developing and providing the following:

1 **An online forum**

We will develop with the MS community a new online forum for people affected by MS to ensure it meets their needs, provides choice and is based upon our values which guide all of our work. MS-UK's values include being community-led, independent, professional, unbiased, non-judgemental and supportive. It is by embedding these values within our forum that will set this forum apart form others. The forum will enable members to offer each other peer support, something so highly valued by people affected by MS. By creating a new online community, we hope to bring people together digitally to share their experiences and provide a safe space where anyone affected by MS can feel accepted and understood. It will facilitate connections among people and encourage them to share their knowledge and insights to help others.

2 **Local groups and activities**

Our research showed that may people affected by MS benefit from local groups in their communities. We will continue to provide a social group locally and will work to ensure more people are aware of what other MS organisations are doing in their locality to bring people together.

3 **Raise awareness of loneliness and isolation in MS with social prescription services**

Social prescribing is one of the government's responses to tackling loneliness. We will partner with a number of social prescription organisations to develop the right type of support that can be rolled out nationally. This may include developing a training toolkit or information pack, dependent on what our consultation demonstrates would be most successful.

Mental health

MS-UK has led the way in addressing the importance of people's mental health when living with MS and we plan to expand in this area.

1 **Counselling**

In 2017, we launched the first ever telephone counselling service in the UK for people affected by MS. Since then, we have provided thousands of counselling sessions and we will continue to offer people with MS access to our counselling service across the country. We will further develop this vital service by expanding to include provision by video link and widening our audiences to include family members and carers.

2 **Mindfulness**

Mindfulness was recommended by the National Institute for Health and Care Excellence (NICE) for those affected by MS in 2014 and several research participants recommended mindfulness.

For several years we have reported the benefits of Mindfulness by sharing the lived experience of people affected by MS as well as offering Mindfulness courses locally. We will offer this service to even more people in the future by scaling up this initiative on a national level.

3 **Signposting to other places for mental health support**
Mental health support should be available to people affected by MS. Solutions include offering a range of therapies, and several were mentioned during our research including humour therapy, reminiscence therapy and cognitive behavioural therapy (CBT). We will ensure that we continue to signpost to organisations that can provide these services across the UK.

Raising awareness

This is already a strategic priority for MS-UK, however we will plan to take this further over the coming years which will include promoting this report, influencing and building relationships with organisations and creating partnerships. This will enable us to share our knowledge, influence change and facilitate us to widen and deepen our impact, ultimately allowing us to support more people who are affected by MS.

1 **Campaigns**
We will publicly launch a campaign during Loneliness Awareness Week 2020 to highlight the work we have carried out and to share our learning far using a multi-channelled approach to reach a variety of audiences.

Campaigns around the hidden symptoms of MS and encouraging self-help will be a priority.

Supporting people to have the confidence to reach out and rebuild friendships following diagnosis was particularly important to those who took part in our qualitative research.

Promoting kindness makes friendships possible and our research indicates that raising awareness of the value of being kind and having connections is vital.

We can also challenge the stigma surrounding these issues and continue to maintain a positive approach to how we use language in our campaigns.

2 **How to identify and support people living with loneliness and isolation**
We can further develop our own staff to recognise the signs of someone experiencing loneliness or isolation in the coming year. Once we have established a best practice model, we will work with health and social care professionals, employers and other key target groups to provide them with the training and resources they need to better support people who experience loneliness or isolation.

How communities and organisations can support this work

While MS-UK is committed to tackling the issues raised in this report for people affected by MS, we cannot do this alone.

We are privileged to work with a wide range of charitable organisations that support people affected by MS. We believe MS charities across the UK can come together and find ways of combining our workforces and resources to proactively use the learning from this report to help tackle the issues of loneliness and isolation.

Accessibility is something which is already on the public agenda, yet it is important for the whole of society to recognise just how essential access is to everybody. Physical access to transport and buildings is still a problem for people living with a range of long-term conditions. In addition to this, the design and availability of adequate toilet facilities has not reached the level it should be across the UK yet. For those planning our communities and public spaces, accessibility needs to be a priority. Embracing accessibility does not stop with physical spaces though. Accessible communications should be fundamentally incorporated into all organisations, from corporate companies to governing bodies. For all people, of all abilities, to truly be able to engage with society and take positive action to tackle experiences of loneliness and isolation, access is not only important, it is vital.

Loneliness and isolation have such far-reaching ramifications on our future health and social care services, society must take responsibility for ensuring we limit the impact of these issues on individuals and signposting appropriately can support this positive action. It is the responsibility of charitable organisations to know what is available locally or nationally and to signpost accordingly so they can fully support their beneficiaries.

By supporting the provision of mental health support or researching the benefits of mental health interventions for those affected by MS, charities can campaign for greater access and funding for this across the UK and support even more people to have good mental health.

Knowing where to turn for help and providing support to navigate existing services and interventions designed for people affected by loneliness and isolation, or those at risk of these issues, is crucial. With limited time and resources, it is understandable that public bodies and patient-facing staff struggle to effectively signpost people on to further support. However, healthcare professionals, including MS nurses, can effectively signpost to a wide range of resources by having meaningful conversations with those they support. Through training and education, statutory and third sector staff will be better equipped to recognise when someone may be at risk of experiencing loneliness or isolation and offer support accordingly. Working with the principles of social prescribing in mind, particularly around times of transition for those who may be at risk of loneliness or isolation, signposting can become more beneficial for all. During 'trigger points' in life, professionals can act as direct conduits to further support in the wider community.

Additional recommendations

Our next steps are based on the primary concerns of people who took part in this research. However, many more suggestions were shared with MS-UK in 2019 and a list of additional recommendations can be found at appendix C.

We encourage everyone providing services to those affected by MS to see if you can take forward any of these recommendations individually or collaboratively.

Acknowledgements

We are extremely grateful to everyone affected by MS who participated in our research. The suggestions and ideas that were discussed across the UK are extremely valuable to us and enabled us to take positive action to bring some of these concepts to life.

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This report was written by Diana Crowe, Head of Services and Laura May, Communications Manager, MS-UK.

About MS-UK

MS-UK is a national charity formed in 1993. We are here for people affected by multiple sclerosis (MS) – that's around 130,000 people in the UK and 2.3 million worldwide.

MS-UK is here for anyone affected by multiple sclerosis, to empower them to live healthier and happier lives by improving the understanding of MS and providing support where it is needed most.

Our values
All staff at MS-UK sign up to our values and actively use them in their day to day roles.

These are the values that guide our work...

Community-led
The voices of people affected by MS inform all our work.

Independent
We do not accept funding from sources that may, or can be perceived to, jeopardise our ability to act in the best interests of people affected by MS.

Professional

We are knowledgeable and provide high quality services.

Unbiased

We will always be balanced in the information we share.

Non-judgemental

We respect an individual's right to make choices for themselves.

Supportive

We treat everyone fairly, with respect, care and compassion.

Our services

The MS-UK Helpline offers unbiased, professional support for anyone affected by MS. Our trained helpline and information officers discuss treatments, symptoms, lifestyle choices that are beneficial and more. They also produce our Choices booklets on a wide range of topics such as MS symptoms through to living with MS day to day.

New Pathways, our global, community-led and bimonthly magazine is filled with recent MS news exploring the latest trials, drug and therapy research and developments, as well as providing product reviews and special offers. It features expert opinions and real insights from people affected by MS about how they live happier and healthier lives.

MS-UK Counselling is an online counselling service for anyone with a diagnosis to talk to a qualified counsellor with knowledge of MS, about the impact of their diagnosis and ongoing experience of living with MS.

Josephs Court is our wellness centre which serves people in our area, nestled in the heart of Essex. There is a range of specialised equipment designed to improve mobility, strength, balance, function, reduce spasms and can help manage MS symptoms. We also offer a variety of complementary therapies which are chosen by clients, for our clients and our thriving Social Group connects the local MS community.

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Appendix A

Secondary resources

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Appendix B

MS-UK loneliness and isolation survey
Demographic data

MS Connection	Total	Has experienced loneliness	Has experienced isolation
I have a diagnosis of MS	210	162	144
I am a carer for someone who has MS	7	6	7
A relative of mine has MS	1	1	1
A friend of mine has MS	1	0	0
Professional working in the field	10	8	6
Other	3	1	2
Age			
25-44	27	23	23
45-64	151	121	103
65-74	47	30	25
75+	6	4	5
Prefer not to say	1	1	1
Gender			
Male	60	39	38
Female	170	138	129
Trans	1	1	0
Unknown	1	0	0
Employment			
Employed full time	33	30	23
Employed part time	16	11	11
Medically retired/unable to work	86	72	71
Not employed, looking for work	6	6	5
Not employed, not looking for work	20	16	16
Retired	63	41	34
Other	7	3	5
Unknown	1	1	0

Appendix C

Additional recommendations

Additional recommendations for tackling loneliness and isolation that were presented to MS-UK.

- Appropriate social care should be provided to all who need it
- Better care in the home, including support with cleaning and cooking

- Financial support to access services people wish to

- Establishing an emergency crisis line

- Liaison between health professionals such as neurologists, MS nurses and occupational therapies and physiotherapists around equipment, mobility and rehabilitation

- Provision of aids and adaptations or transport to enable people to be part of society and physically leave the house

- Funding and support for more MS nurses and community nurses

- Training to support professionals to screen people at risk and give staff the knowledge they need about social prescribing to be able to effectively support these people

- Establish support groups targeted at specific groups with shared interests

- Campaigns could raise awareness of schools, employers and GPs

- More accessible public toilets

- Promote volunteering opportunities

- Value people as individuals, not as problems to be solved

- Supporting carers

- Offering ideas to be people who may be at risk or experiencing loneliness or isolation. Some ideas included write a journal, take part in hobbies, share meals out and volunteer

- Simulation of hidden symptoms to others can experience the reality

MS-UK

Unsworth House
Hythe Quay
Colchester
Essex CO2 8JF

Call: 01206 226500

Email: info@ms-uk.org

Visit us at: www.ms-uk.org