My MND, My Needs

Final report

REVEALING REALITY

mnda
motor neurone disease association

Project overview

Up to 5,000 adults in the UK are living with motor neurone disease (MND) at any one time. The MND Association focuses on improving access to care, research and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

To add further depth to the MND Association's understanding of the needs of people with MND, they commissioned Revealing Reality to conduct research specifically focusing on areas of unmet need.

Specific research objectives included exploring:

1 What **needs** people with MND have

2 Where people need more **support**

3 How the **MND Association** can help

Methodology

The research consisted of an ethnographic qualitative approach and a quantitative approach.

Before conducting the fieldwork, researchers created a long-list of ‘needs areas’ that people with MND may have based on a literature review.

Qualitative fieldwork, carried out between August 2023 and January 2024, involved 2-hour at-home interviews with 15 participants to understand how these needs areas manifested in real life. The sample included a range of ages, gender, locations, types of MND, dates of diagnosis, and socio-economic groups.

Following the qualitative stage, a survey was developed based on the key needs identified in the literature review and qualitative interviews. Researchers tested this survey with participants from the qualitative stage to improve its accessibility and relevance to people’s lives. This survey was completed by 925 people across England, Wales, and Northern Ireland.

Appendix

1. How to categorise needs – a review of wellbeing frameworks

MND, relationships and family

MND and emotions

My MND, My Needs

Living with MND?

We want to hear from you.

158 papers found

63 papers selected and reviewed

900+ responses

Literature review

Ethnographic fieldwork

Quantitative survey

The ‘needs areas’ identified in the literature review were developed into a draft ‘needs framework’

- Health & social care
- HCPs
- Feelings in life
- Relationships
- Palliative / EoLC
- Diagnosis
- MH & wellbeing
- Everyday life
- Physical
- General / misc.

→

Needs framework

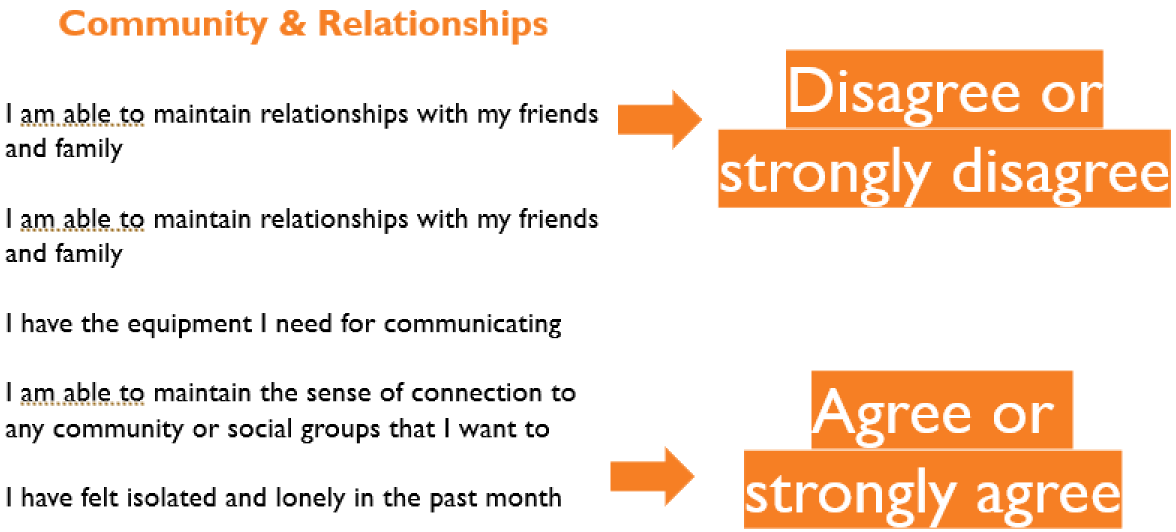
- Acceptance & peace
- Autonomy, independence & self-expression
- Support network & information
- Community & Relationships

Designing statements to explore needs

The qualitative interviews explored each area of need in more depth – including how it was being met, where there were more existing needs, what support they felt was working for them, and what more they wanted.

These were then developed into specific needs statements with questions that explored the proportion of respondents who 'disagreed' the statement reflected their life. If the statement was negatively framed (e.g. I have felt isolated and lonely in the past month) then respondents who 'agreed' with the statement were considered as having that need.

For each statement, survey participants were also asked whether they had support and if they wanted more.



Community & Relationships

I am able to maintain relationships with my friends and family

I am able to maintain relationships with my friends and family

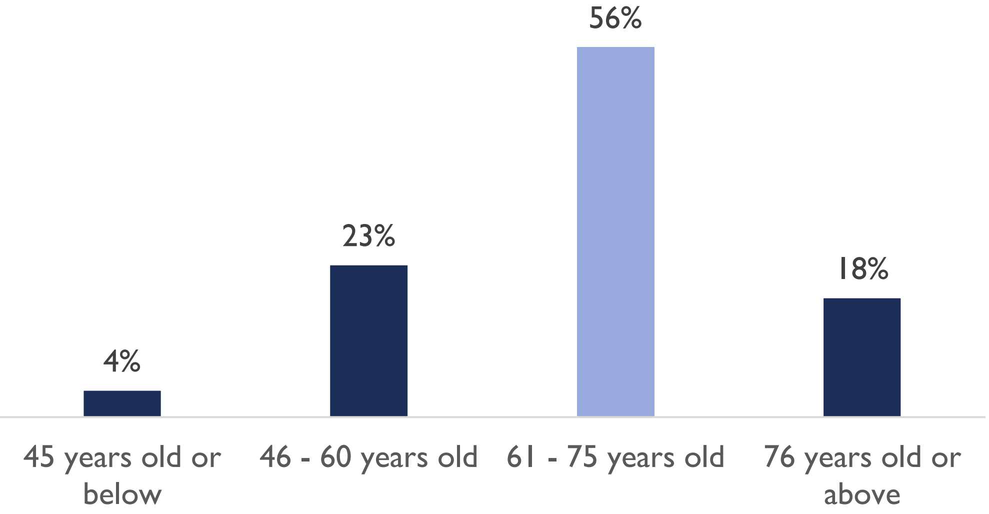
I have the equipment I need for communicating

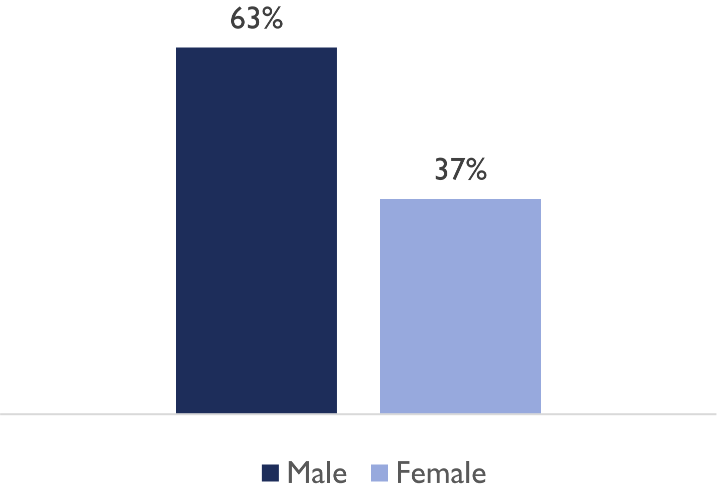
I am able to maintain the sense of connection to any community or social groups that I want to

I have felt isolated and lonely in the past month

The survey sample aligned with the demographic distribution of people living with MND

The survey sample was made up of an older age demographic. Likewise, more men than women completed the survey, which aligned with the known demographic distribution of people living with MND.



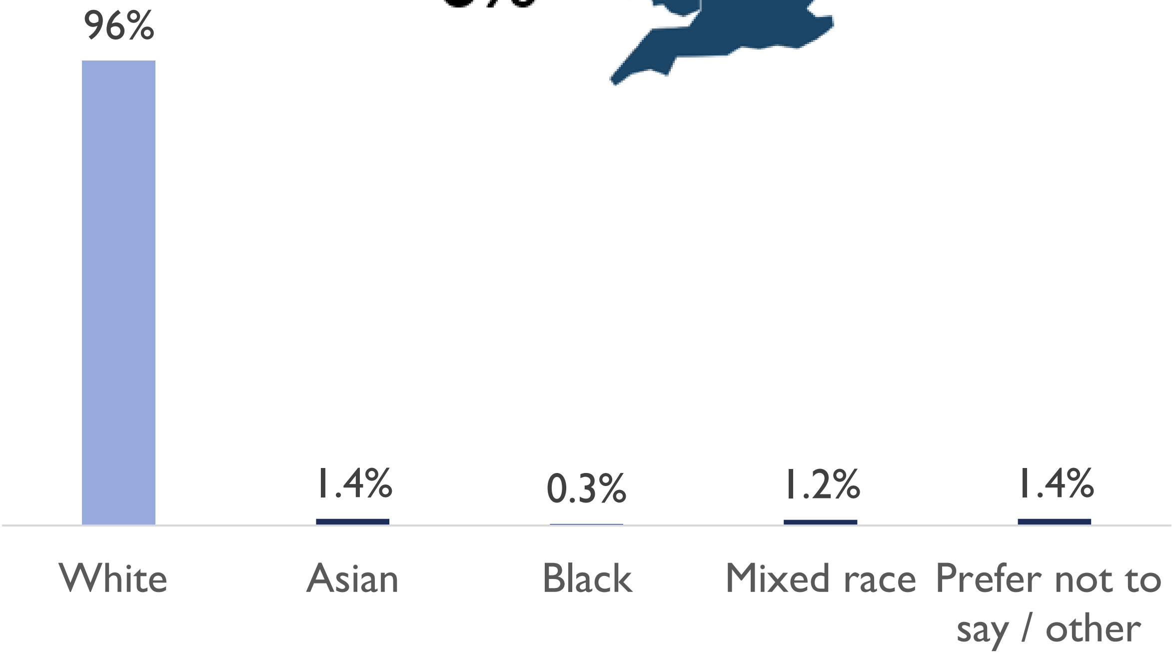


Q31: 'How old are you?' Base n=924
Q33: 'Which of the following best describes the gender you identify with?' – 'Female', 'Male', 'Non-binary', 'Transgender', 'Prefer to self-describe', 'Prefer not to say'. Base n=918. Please note that 4 respondents identified as non-binary (0%). Due to the small sample size of this group, their data has been excluded from the analysis.

Most of the sample were white and lived in England

The majority of the sample identified as white and lived in England, which was expected and reflective of the proportional population of each nation in the UK.

Determining the representativeness of the sample's ethnic diversity was challenging. The average age of ethnic minority populations in the UK is lower than that of white populations, meaning that the proportion of ethnic minority participants in the sample might appear lower compared to general population statistics. However, when accounting for the age distribution of people living with MND, the sample's ethnic diversity might be closer to representative levels.



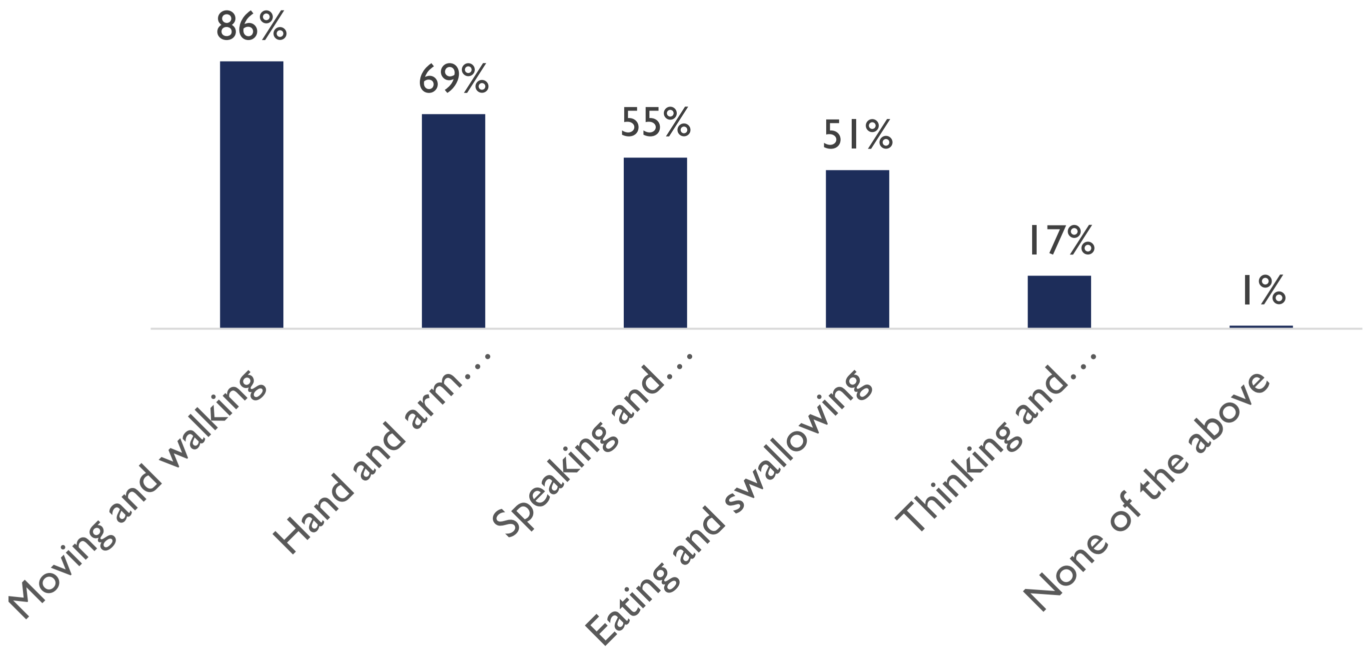
Q34: 'Which of the following best describes your ethnic group?' – 'White', 'Asian', 'Black', 'Mixed race', 'Prefer not to say / other'. Base n=925
Q35: 'Where do you live?' – 'England', 'Wales', 'Northen Ireland'. Base n=925 (total sample)

The survey collected data on how people were impacted by MND

To avoid asking potentially sensitive questions, researchers did not directly ask about MND symptoms, or specific interventions that participants had undergone.

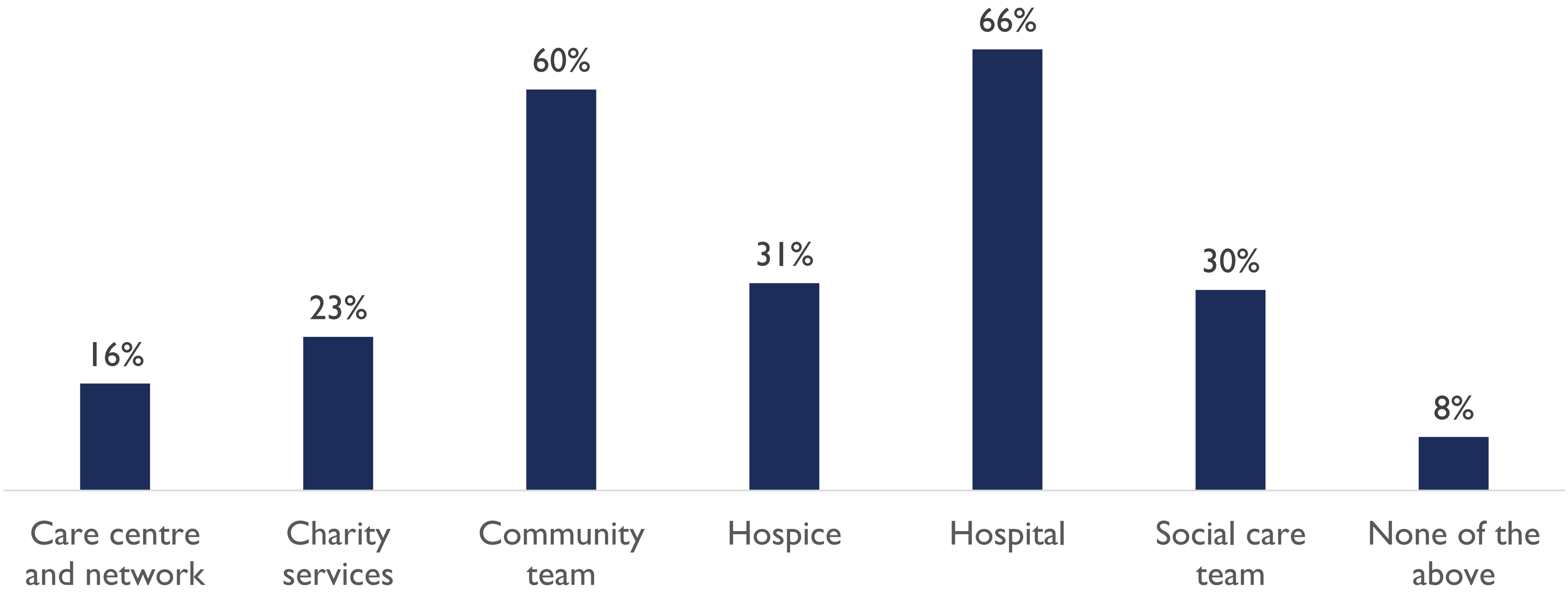
This means it is not possible to analyse the data based on the progression of an individuals MND. However, data on the areas of life, such as 'moving and walking', affected by MND can be used as a proxy measure.

This graph shows the proportion of the sample that said their MND had affected that area of life.



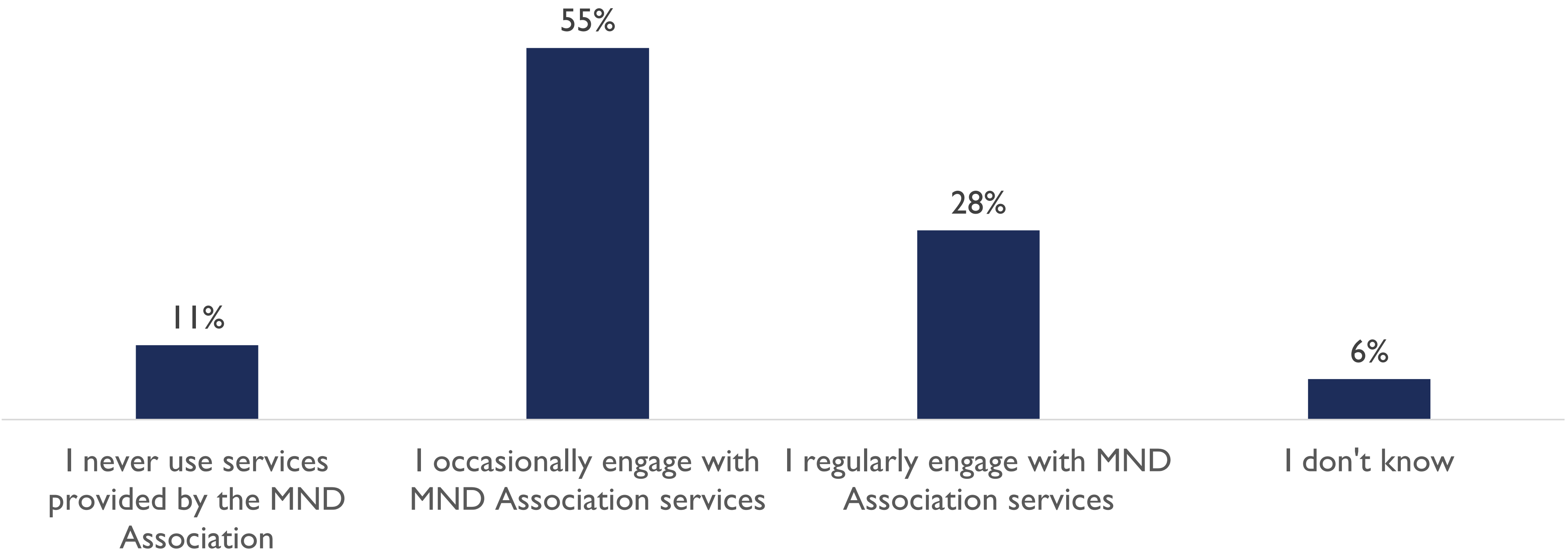
Q1: 'Which, if any, of the following ways does motor neurone disease impact your life? Please tick all that apply.' – 'Moving and walking'. 'Eating and swallowing', 'Speaking and communicating', 'Hand and arm movement', 'Thinking and concentrating', 'None of the above'. Base n=925 (total sample)

Participants received support from a range of sources



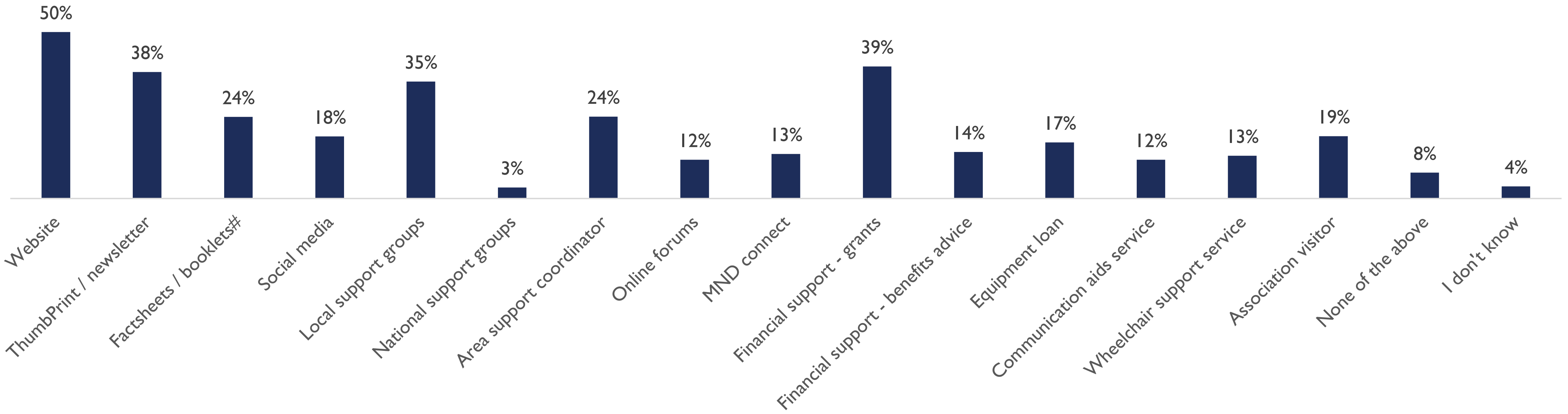
Q26: 'Which, if any, of the following services do you use? Please tick all that apply.' – 'Care centre and network', 'Charity services', 'Community team', 'Hospice', 'Hospital', 'Social care team', 'None of the above'. Base n=918

Most people had occasional engagement with the MND Association



Q36: 'How often do you engage with services provided by the MND Association?' – 'I never use services provided by the MND Association', 'I occasionally engage with the MND Association services', 'I regularly engage with MND Association services', 'I don't know'. Base n=916

Engagement with the MND Association encompassed a range of the Association's services



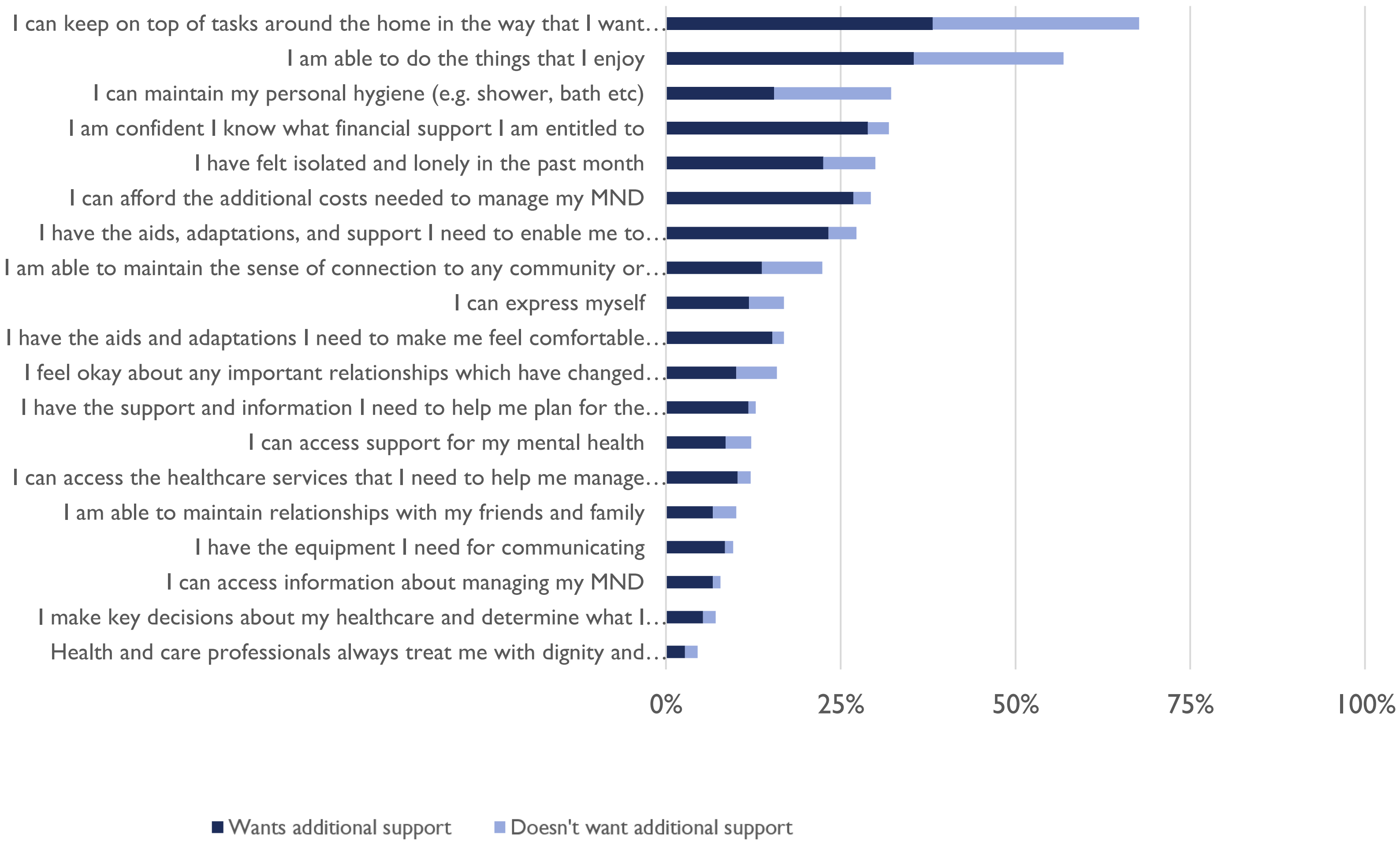
Q37: ‘Have you used any of these services provided by the MND Association in the last 12 months?’ – ‘Website’, ‘ThumbPrint / newsletter’, ‘Factsheets / booklet’, ‘Social media’, ‘Local support groups’, ‘National support groups’, ‘Area support coordinator’, Online forums’, ‘MND Connect’, ‘Financial support – grants’, ‘Financial support – benefits advice’, ‘Equipment loan’, ‘Communication aids service’, ‘Wheelchair support service’, ‘Association visitor’, ‘None of the above’, ‘I don’t know’. Base n=909

Understanding needs

These are the top five needs, with the top two significantly ahead. The proportion of those who wanted additional support is signified with the different shades of blue.

For certain unmet needs, nearly everyone desired support, such as financial support, aids and adaptations, equipment, and information.

In contrast, for needs like staying on top of tasks, engaging in enjoyable activities, and maintaining personal hygiene, many did not want further support.



Base n=925 (total sample)

Summary of initial scoping

➡ Most survey respondents, 50% engaged with the MND Association through their website.

➡ Only 3% of survey respondents engaged with the MND Association through national support groups.

➡ The most reported needs related to autonomy and independence, seeking financial support, and loneliness.

Q37: 'Have you used any of these services provided by the MND Association in the last 12 months?'. Base n=909

1

Autonomy, independence and self-expression was a widely unmet need

Understanding autonomy, independence and self-expression

The theme of autonomy, independence and self-expression came up frequently in the literature review, as well as the in the qualitative stage of the research. This finding was not surprising, given the progressive nature of motor neurone disease symptoms, and its impact on individuals' daily lives.

This was a broad needs area, particularly because it held different meanings for different people. To explore this area further and highlight specific unmet needs, six statements were developed for the quantitative stage of the research. These statements aimed to cover a range of topics from:

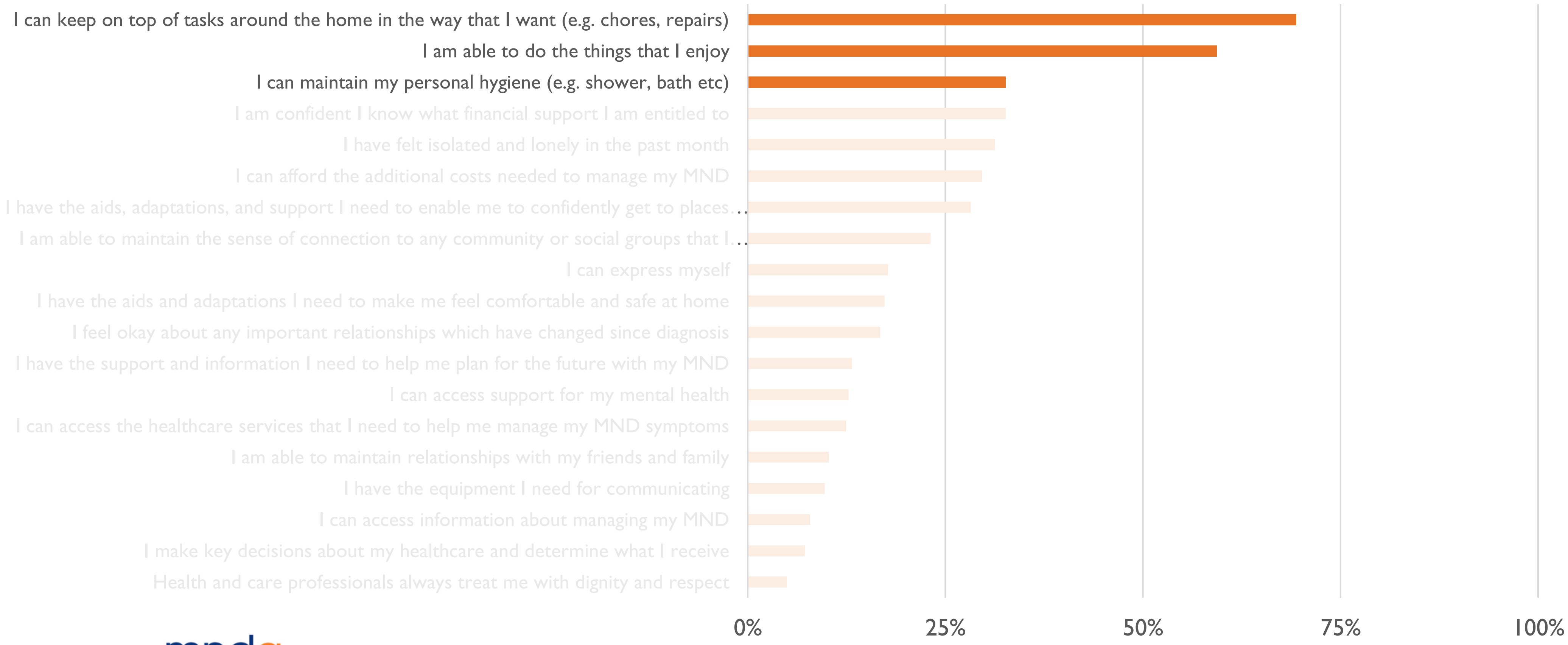
- Practical needs like having assistive technologies and at-home adaptations, which would allow people to travel outside of the home or keep on top of household tasks.
- More intangible and subjective needs relating to self-expression and being able to do the things that people enjoy.

Autonomy, independence and self-expression statements:

- I am able to do the things that I enjoy
- I can express myself
- I have the aids, adaptations, and support I need to enable me to confidently get to places I want to go outside my home
- I can keep on top of tasks around the home in the way that I want (e.g. chores, repairs)
- I have the aids and adaptations I need to make me feel comfortable and safe at home
- I can maintain my personal hygiene (e.g. shower, bath etc)

Q4: 'How much do you agree or disagree with these statements about autonomy, independence and self-expression?' – Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=925 (total sample)
Q12: 'How much do you agree or disagree with these statements about your life at home?' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=925 (total sample)

Needs around autonomy and independence were some of the most commonly identified needs

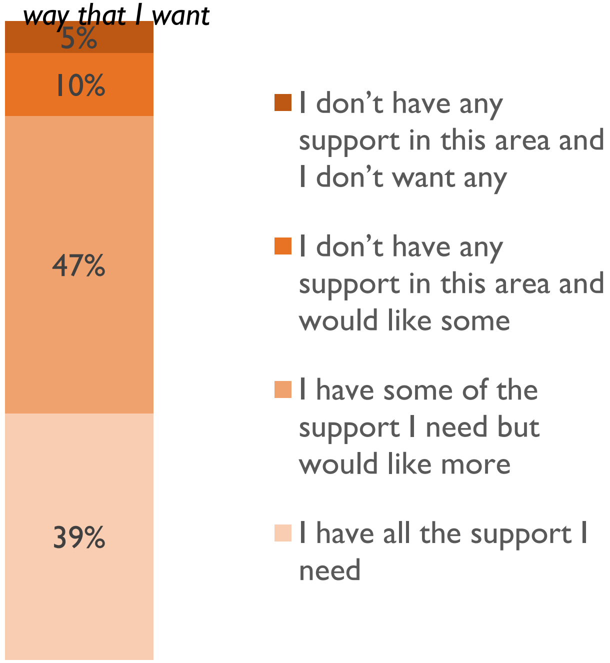


Base n=925 (total sample)

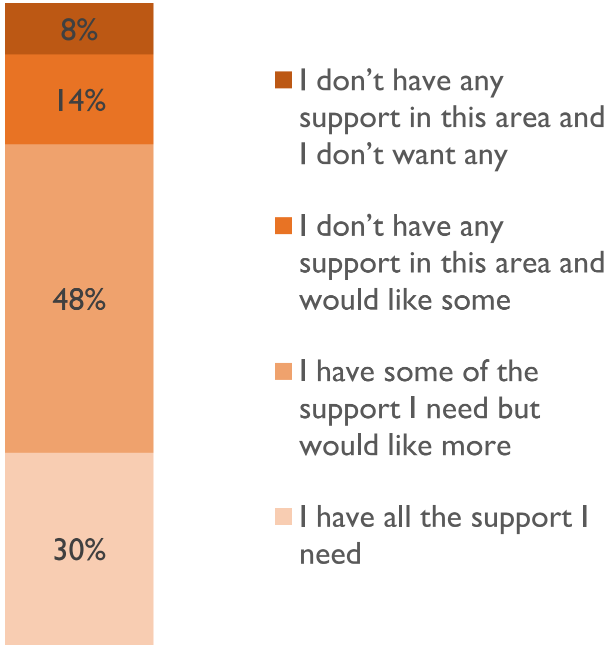
Almost half of people expressing these needs wanted more support.

Overall, those who said they 'disagree' or 'strongly disagree' with these statements were open to getting more support.

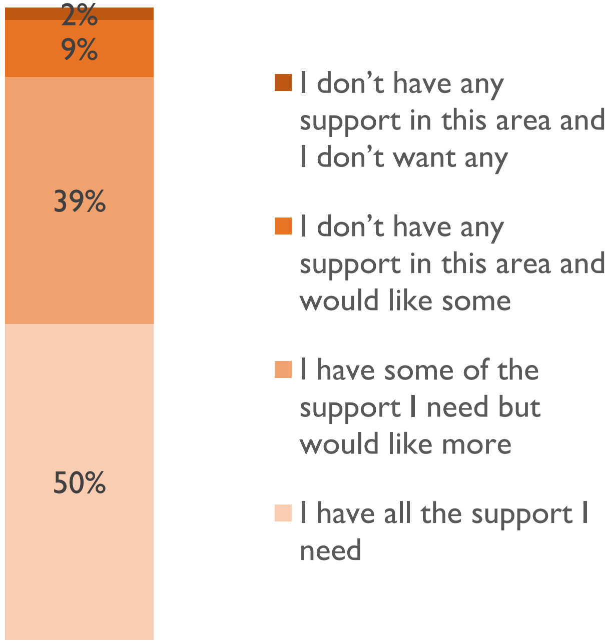
Keeping on top of tasks around the home in the way that I want



Doing the things that I enjoy



Maintaining my personal hygiene



How much support do you receive to help with the things below… Q13a: 'Keeping on tasks around the home in the way that I want'. Base n=626. Q5a: 'Doing the things that I enjoy'. Base n=526. Q13c: 'Maintaining my personal hygiene'. Base n=298

Liz felt she was trapped within her home.

Liz felt that her MND significantly impacted her autonomy. She said she had to think about making difficult life decisions based on what was best for her health and safety. These decisions were sometimes at odds with what she wanted for her family

> *"You know, that's the best-case scenario, that I break up my family but I'm living somewhere safe where I can get out the house…there isn't anywhere where I can be with my family and live my remaining time with my family and be able to get out the house. This is the wellest I'm going to be, this is the most able I'm going to be and I'm stuck in the house 90% of the time."*
>
> **Liz, 51**
> London
> Diagnosed in November 2022

Liz needed specialist carers to help her leave the house.

Her ability to live her life and do what she enjoys was shaped and limited by her flat. She spent most of her time in bed and relied on a series of carers, her family, and some serious organising to be able to leave her flat. Despite this level of organisation, if just one part of her network of carers falls through, or the equipment fails, it is impossible leaving her house.

She faced similar frustrations within her flat too. The tight corners and narrow corridors of her flat, and the set-up of her kitchen, made it difficult to manoeuvre freely. This meant she could not freely move around her home or use her power chair independently.

She left the house once a week.

This left Liz incredibly reliant on others, meaning she spent much of her time waiting for her family or carers to visit. She knew that independence was something she was majorly lacking in her life, but did not know how to best address this need.

She said one option for her could be moving to a wheelchair-accessible home with additional adaptations and on-site support, - this would give her much more freedom and control over her remaining time. However, for her, there was a serious tension between having appropriate accommodation and being able to live with or even be near her family. As Liz described, the best-case scenario for her was to move into extra-care housing, which would meet her needs and be safe, but that would mean leaving her son and partner behind.

> *"In any case, because I own my own flat, I'm not eligible for any support with accessible housing and I'm likely to continue to be trapped in my unsuitable and unsafe flat."*
>
> **Liz, 51**
> London
> Diagnosed in November 2022

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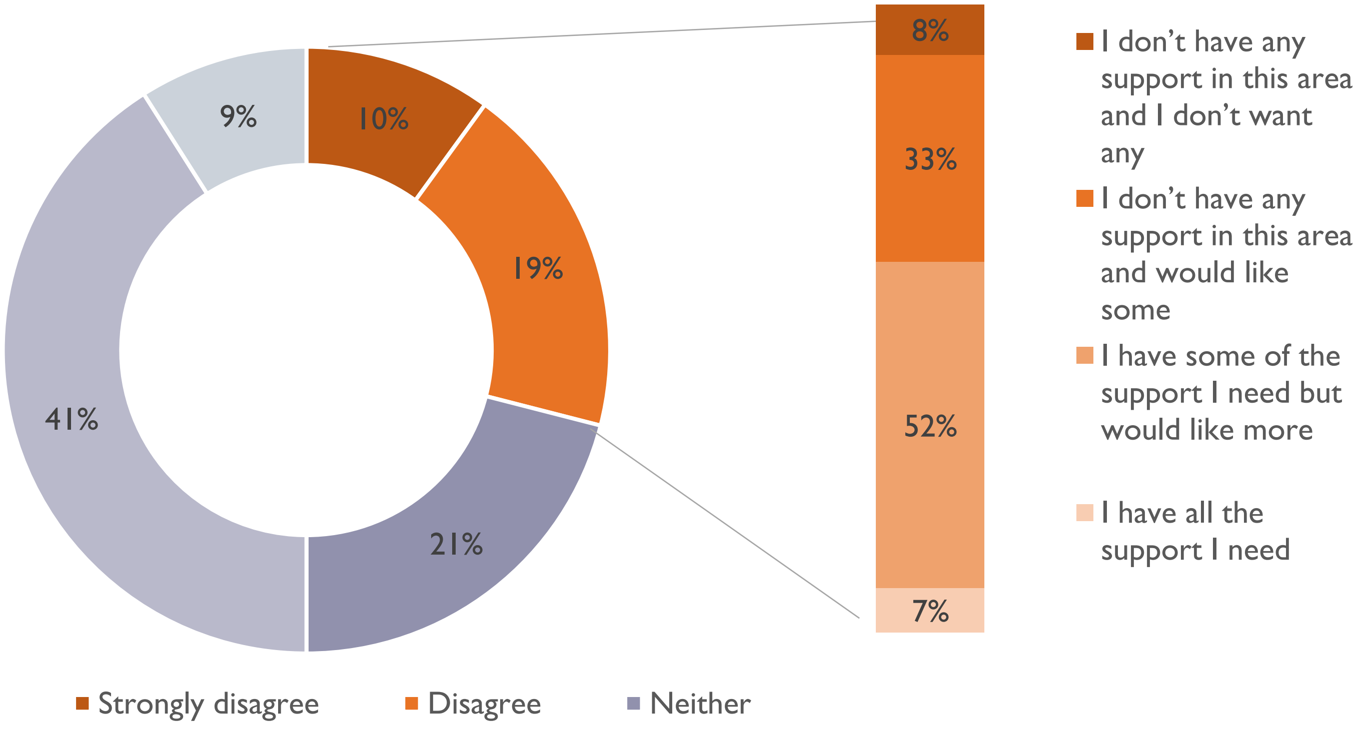
28% of people said they did not have the adaptations they needed to leave the home

The research aimed to further explore this idea of having independence at home and being able to travel outside of the home in the survey.

Almost 1 in 3 (29%) of the sample disagreed or strongly disagreed that they currently had the adaptations they needed to be able leave the home.

Of this 29%, 85% wanted more support for this are. This includes:

- 52% who are already receiving some support but say they would benefit from more.
- 33% who are receiving no support for this area but would like some.



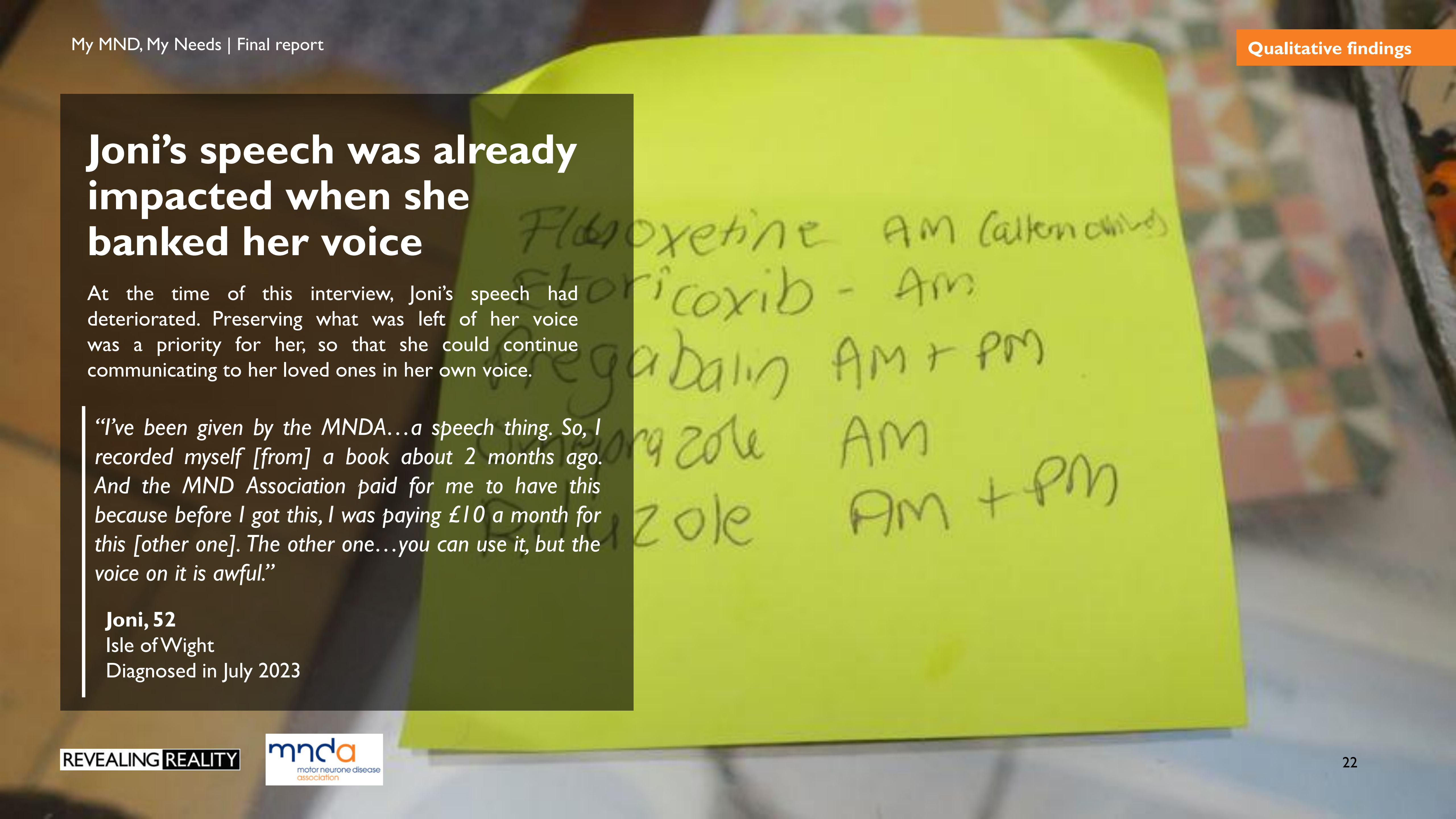
Q4c: 'I have the aids, adaptations, and support I need to enable me to confidently get to places I want to go outside my home' – 'Strongly Disagree', 'Disagree', Neither agree nor disagree', 'Agree', 'Strongly Agree'. Base n=890.

Q5c: 'Having the aids, adaptations, and support I need enables me to confidently get to places I want to go outside my home' – 'I have all the support I need', 'I have some support I need but would like more', 'I don't have any support in this area and would like some', 'I don't have any support in this area and I don't want any'. Base n=261

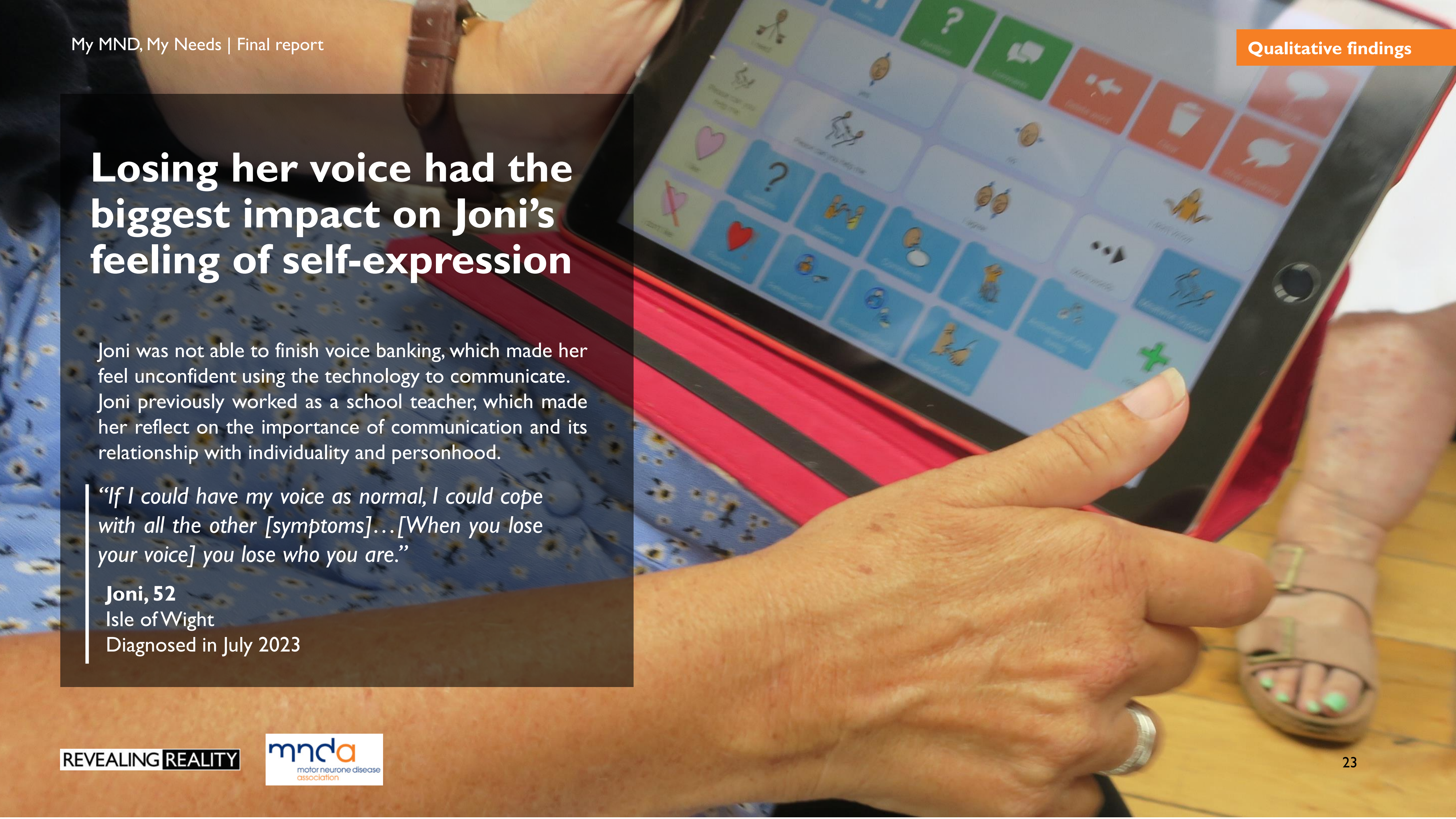
Joni’s speech was already impacted when she banked her voice

At the time of this interview, Joni’s speech had deteriorated. Preserving what was left of her voice was a priority for her, so that she could continue communicating to her loved ones in her own voice.

> *“I’ve been given by the MNDA…a speech thing. So, I recorded myself [from] a book about 2 months ago. And the MND Association paid for me to have this because before I got this, I was paying £10 a month for this [other one]. The other one…you can use it, but the voice on it is awful.”*
>
> **Joni, 52**
> Isle of Wight
> Diagnosed in July 2023



Fluoxetine AM (altern days)
Etoricoxib - Am
Pregabalin AM + PM
Omeprazole AM
Riluzole AM + PM



Losing her voice had the biggest impact on Joni's feeling of self-expression

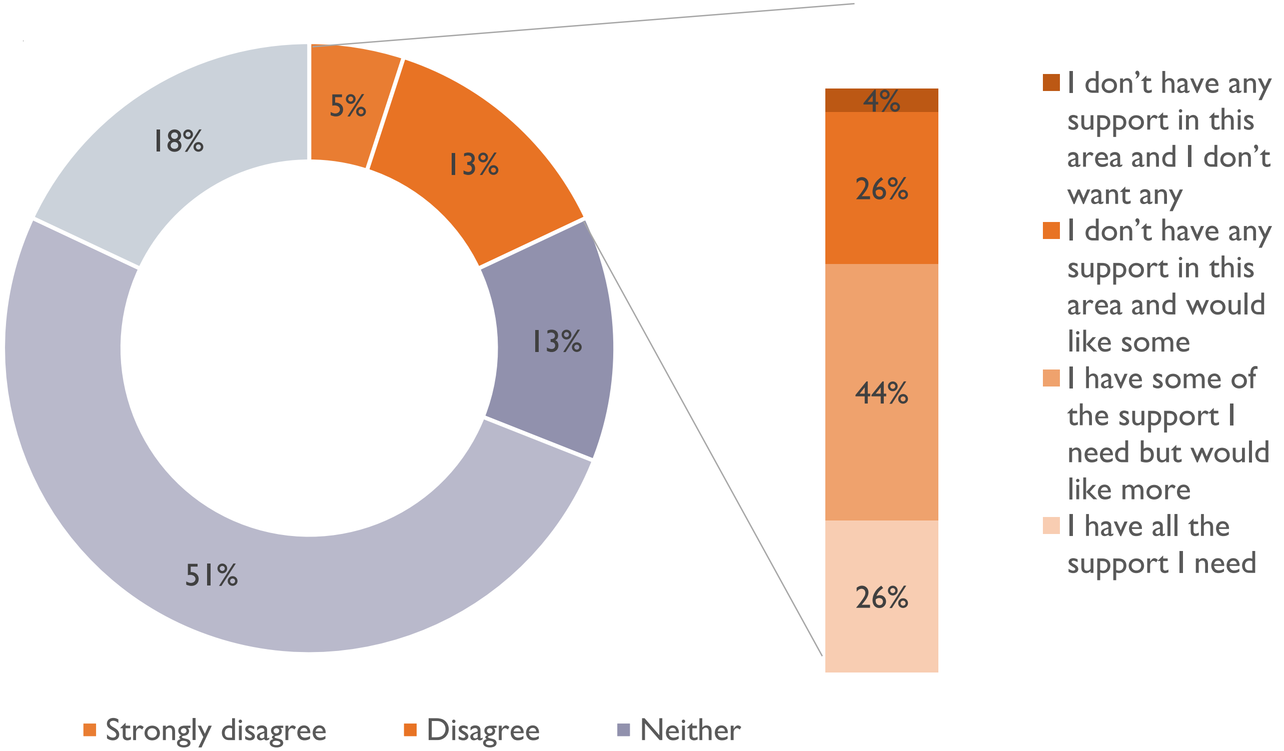
Joni was not able to finish voice banking, which made her feel unconfident using the technology to communicate. Joni previously worked as a school teacher, which made her reflect on the importance of communication and its relationship with individuality and personhood.

> *"If I could have my voice as normal, I could cope with all the other [symptoms]…[When you lose your voice] you lose who you are."*
>
> **Joni, 52**
> Isle of Wight
> Diagnosed in July 2023

Almost one fifth felt they were not able to express themselves

This sense of not being able to communicate was felt by a wider group of survey respondents. 1 in 5 said they 'disagree' or 'strongly disagree' with the statement 'I can express myself.'

Of this group, 70% wanted more support, regardless of if they already had some support.



Q4: 'I can express myself' – 'Strongly disagree', 'Disagree', 'Neither disagree nor agree', 'Agree', 'Strongly agree' . Base n=925 (total sample)
Q5: 'Expressing myself' – 'I have all the support I need', 'I have some support I need but would like more', 'I don't have any support in this area and would like some', 'I don't have any support in this area and I don't want any'. Base n=925 (total sample)

2

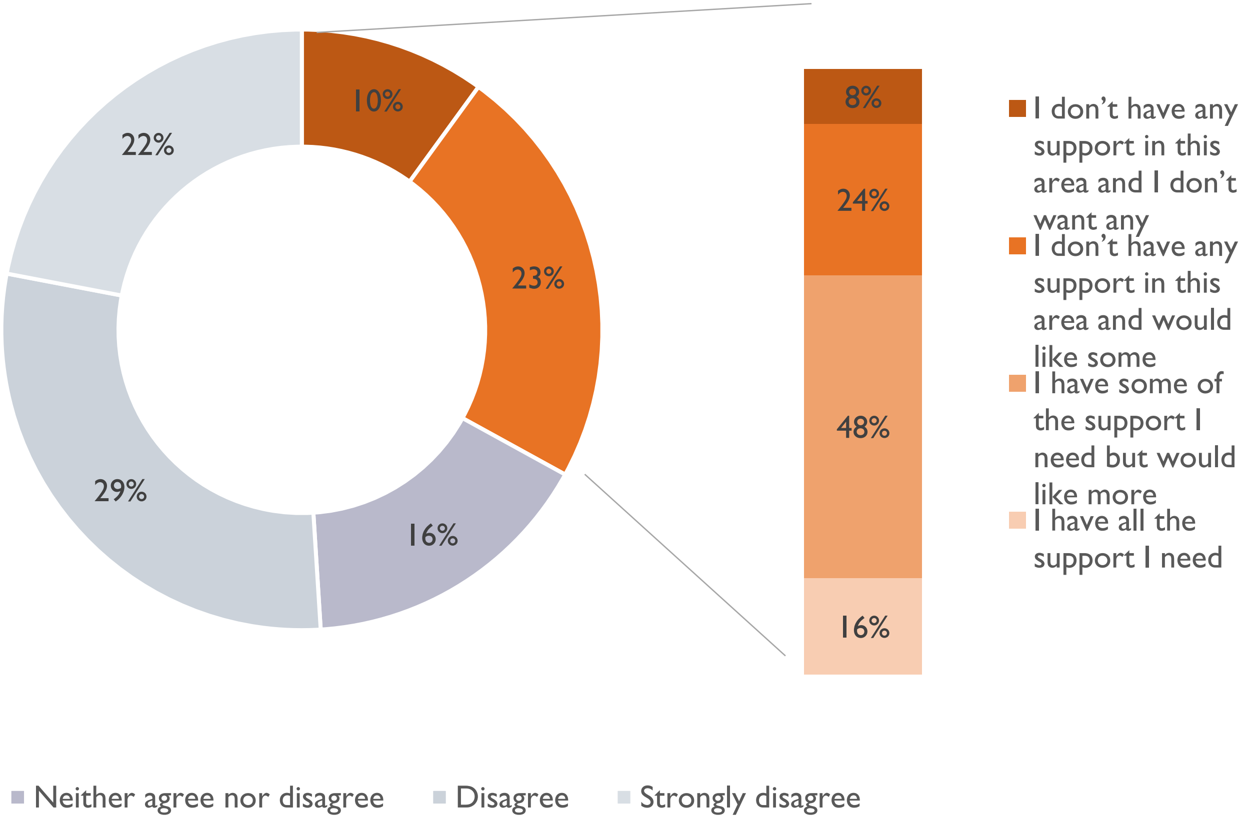
Many people were feeling socially isolated, and wanted more support.

One in three reported feeling lonely or isolated in the past month

This was one of the most highly identified unmet needs in the survey, with 1 in 3 saying they ‘strongly agree’ or ‘agree’ with the statement ‘I have felt isolated and lonely in the past month.’

Within the overall ranking of unmet needs, loneliness and feelings of isolation also ranked 5th, falling just above ‘I can afford the additional costs needed to manage my MND.’

Of this group, 72% said they would like more support in this area, regardless of if they already have some support in place.



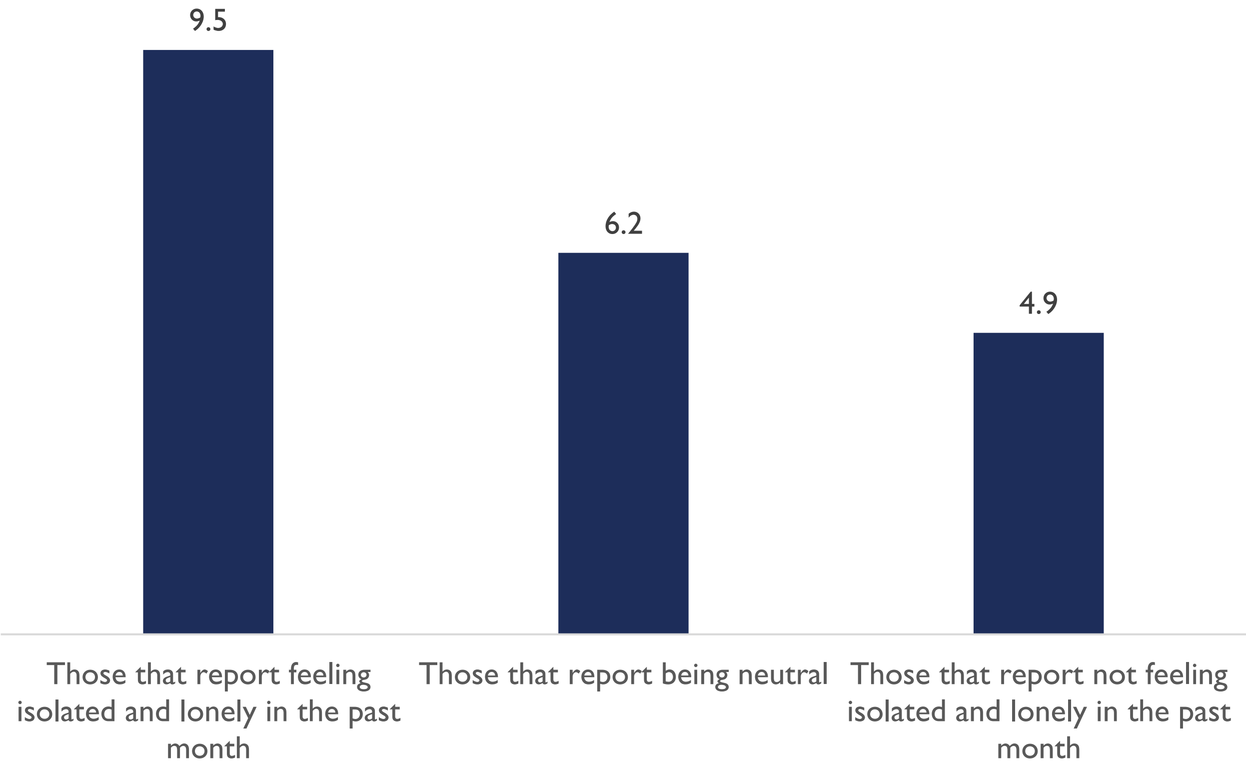
Q2: ‘I have felt isolated and lonely in the past month’ – ‘Strongly agree’, ‘Agree’, ‘Neither agree nor disagree’, ‘Disagree’, ‘Strongly disagree’. Base n=883

Q3: ‘Feeling isolated and lonely in the past month.’ – ‘I have all the support I need’, ‘I have some support I need but would like more’, ‘I don’t have any support in this area and would like some’, ‘I don’t have any support in this area and I don’t want any’. Base n=277

Those who felt isolated had a higher average number of unmet needs overall

People who reported feeling lonely were also more likely to report a high number of other unmet needs compared to those who did not experience loneliness in the past month.

The graph on the right shows the average number of unmet needs identified by respondents, categorised by their reported feelings of isolation and loneliness in the past month. The group that experienced loneliness had the highest average number of unmet needs, with nearly twice as many unmet needs on average compared with those who did not.



Q2e: 'I have felt isolated and lonely in the past month' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'.
Base n=883

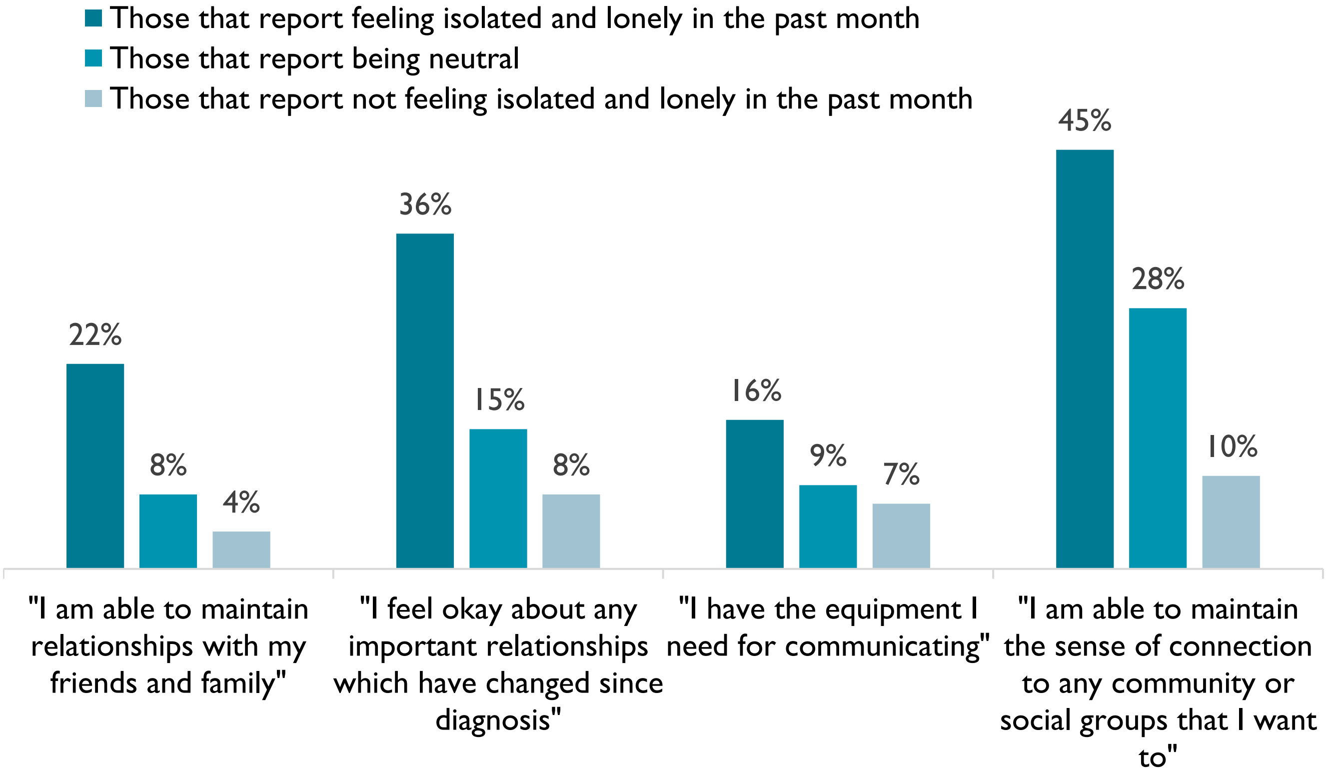
People who reported feeling lonely were more likely to have other unmet needs around relationships and community

People who reported feeling lonely were also more likely to express other unmet needs within the category of community and relationships. Specifically, they were more likely to report that they:

- Could not maintain relationships with friends and family.
- Did not feel comfortable with important relationships that had changed since the diagnosis
- Did not have the necessary equipment to communicate effectively.
- Did not feel capable of maintaining a sense of connection to their community or social groups.

These issues tended to cluster for people, suggesting a link between practical challenges with relationships (e.g. having the right equipment for communication) and emotional aspects (e.g. feeling content with relationships).

Those that disagree with the following statements:



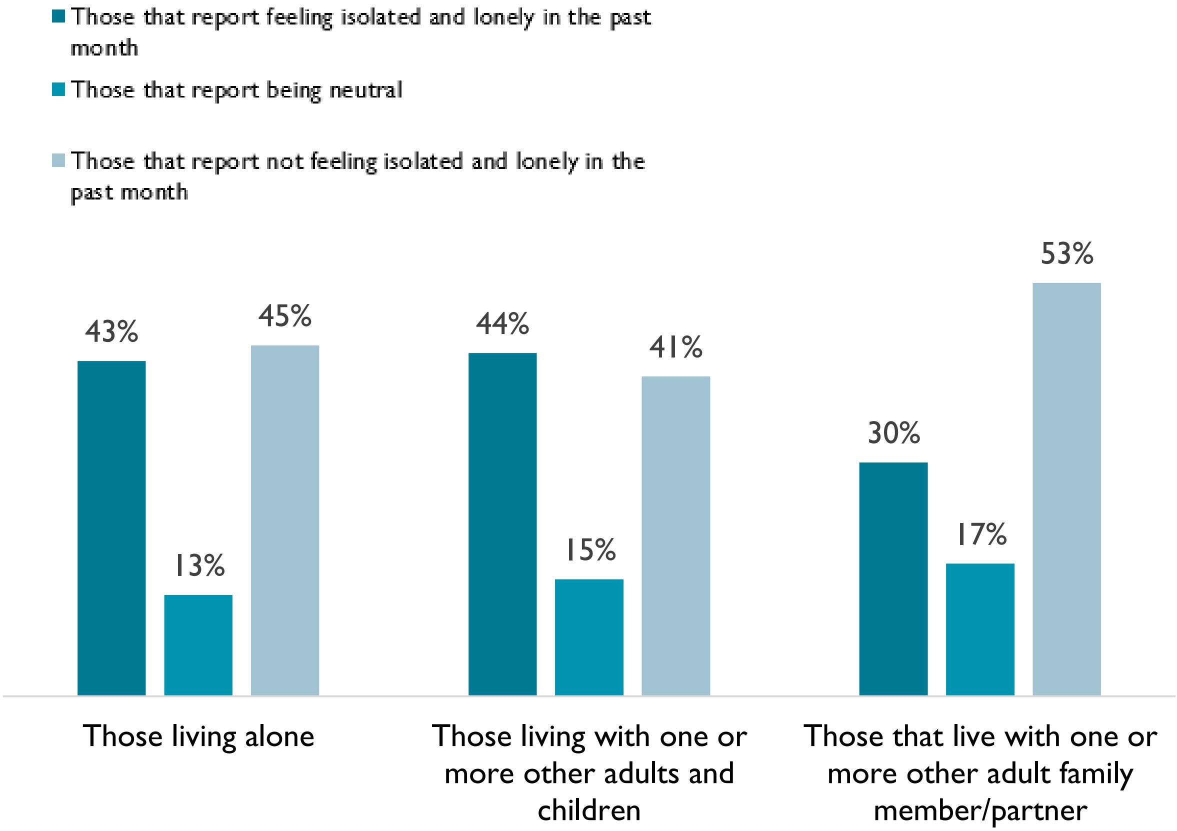
Q2: 'How much do you agree with these statements about community and relationships?' "Base n=849-875

Living alone was not an indicator of loneliness

Living alone was not the main predictor for loneliness. On the other hand, a higher proportion of people who lived with other adults and children reported feeling lonely in the past month.

The graph on the right shows the percentage of people who reported feelings of isolation and loneliness across different living situations. Those living with one or more other adults and children reported the lowest levels of loneliness (30%), while those living with one or more other adults and children reported the highest levels of loneliness (44%).

One hypothesis for this was that those living with other adults and children might have experienced the most disruption to daily life and relationships following an MND diagnosis.



Q31: 'Who do you live with?' – 'I live alone', 'I live with one or more adult family members / partner', 'I live with one or more other adults (not family nor partner)', 'I live with one or more other adults and children under 18', 'I am the only adult in the household but live with children under 18'. Base n=925 (total sample)

Luke lived alone but had a strong support network around him

Luke had a strong network of friends on whom he sometimes relied for informal care. He had developed these friendships through various social clubs he participated in, such as karaoke and football. Despite his limited mobility, slurred speech, and fatigue at the time of the interview, Luke reflected positively on his fulfilling social relationships.

> *"My friend and his wife, we met at school, they come up once a week. She hoovers my floor, she takes my washing away and does my washing. They're lovely."*
>
> **Luke, 52**
> Newcastle Upon Tyne
> Diagnosed in 2017

3

Many said they would like additional financial support, but some did not know how to seek it

Simon had funded advanced adaptations to his home

Simon and his wife had bought a large house with plans to start a family. Following his diagnosis, they changed these plans, in favour of making their home more comfortable for Simon. Despite the challenges posed by his diagnosis, Simon considered himself fortunate to have enough funds from his pension to make the appropriate adaptations to their home, such as installing a lift, to accommodate his changing needs.

> *"We thought we were going to have children and things and we got a house…so we thought let's just turn it into a care home then…[Simon:] It cost a small fortune."*
>
> **Simon, 44**
> Bedfordshire
> Diagnosed in July 2020

Joni's partner was carrying out most of the adaptations himself

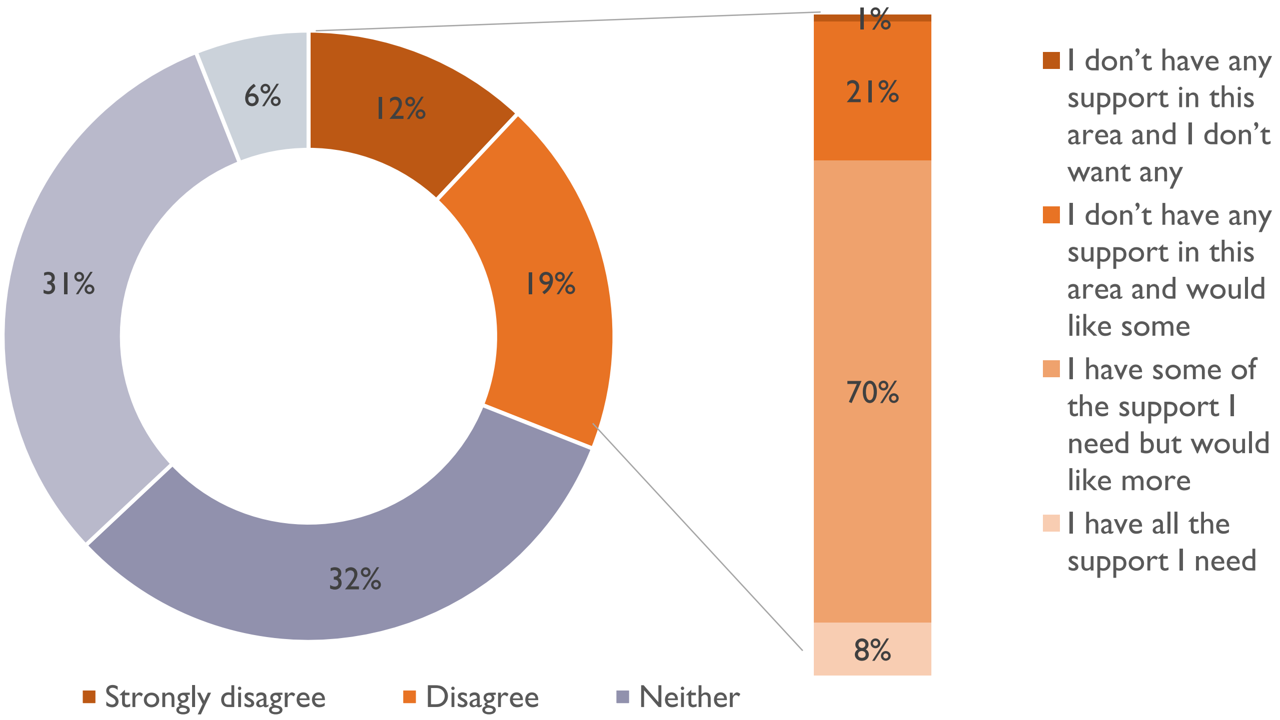
Joni's experience was quite different to Simon's. Joni and her partner found that the main costs associated with MND were related to adapting their home to ensure the family could continue living there. However, due to limited funds, they had to take a more hands-on approach, which included turning to the internet to research and plan modifications to their home.

> *"I understand that eventually I could be bed bound, which is hopefully not for a long time. [My partner] is helping me with figuring out how to get me from the lounge to the hallway…he's talking about raising the ground outside the house, so I don't have steps as well."*
>
> **Joni, 52**
> Isle of Wight
> Diagnosed in July 2023

29% of people said they couldn't afford the additional costs needed to manage their MND

Almost 1 in 3 survey respondents said the additional costs associated with MND were too much for them to manage.

Of this group, 92% said they wanted more support to manage these costs, regardless of whether they already had some degree of support in place. Only 8% said they already had all the support they needed.



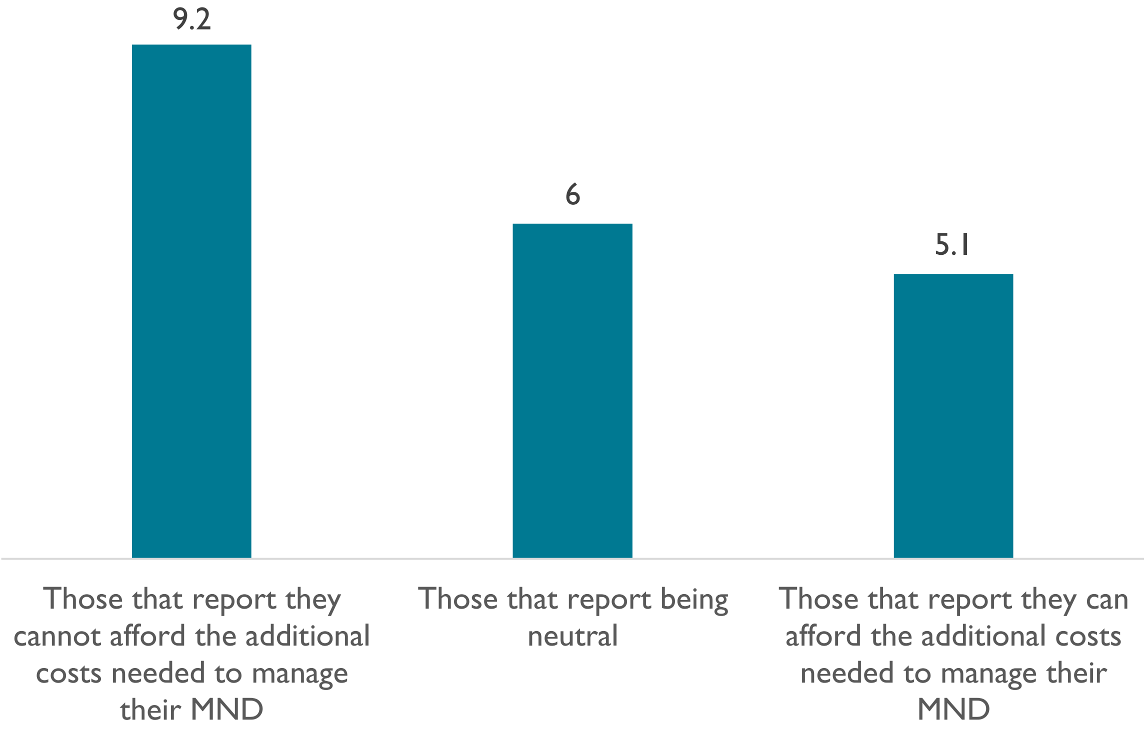
Q8: 'I can afford the additional costs needed to manage my MND' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=888

Q9: 'Affording the additional costs needed to manage my MND.' – 'I have all the support I need', 'I have some support I need but would like more', 'I don't have any support in this area and would like some', 'I don't have any support in this area and I don't want any'. Base n=271

This group had higher number of unmet needs in general

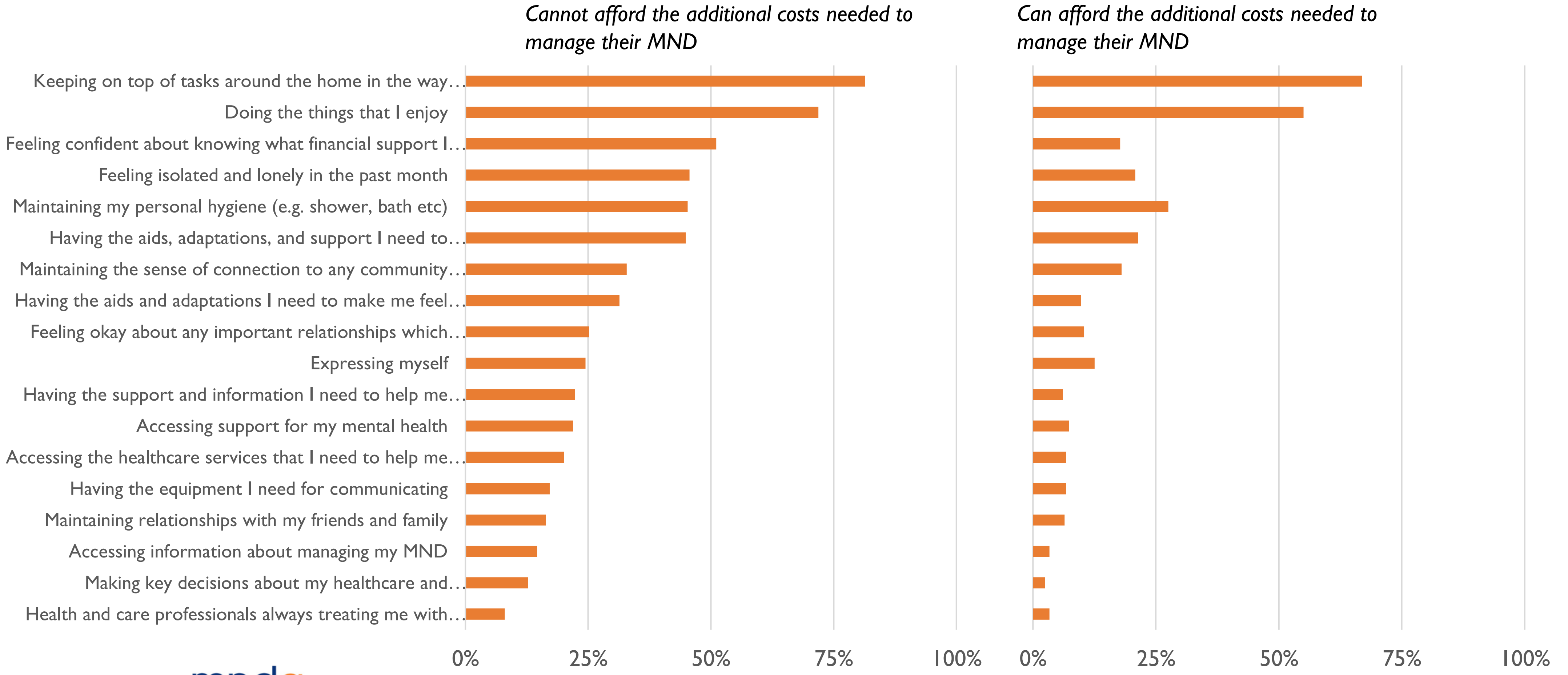
Those who reported struggling with the costs of MND appeared to be experiencing more challenges, and a greater number of unmet needs overall.

For those struggling with finances, the average number of unmet needs was nine, compared to just five for those who felt they could afford all the additional costs associated with MND.



Q8: ‘I can afford the additional costs needed to manage my MND’ – ‘Strongly agree’, ‘Agree’, ‘Neither agree nor disagree’, ‘Disagree’, ‘Strongly disagree’. Base n=888

People struggling with additional costs had higher levels of need across almost all other areas

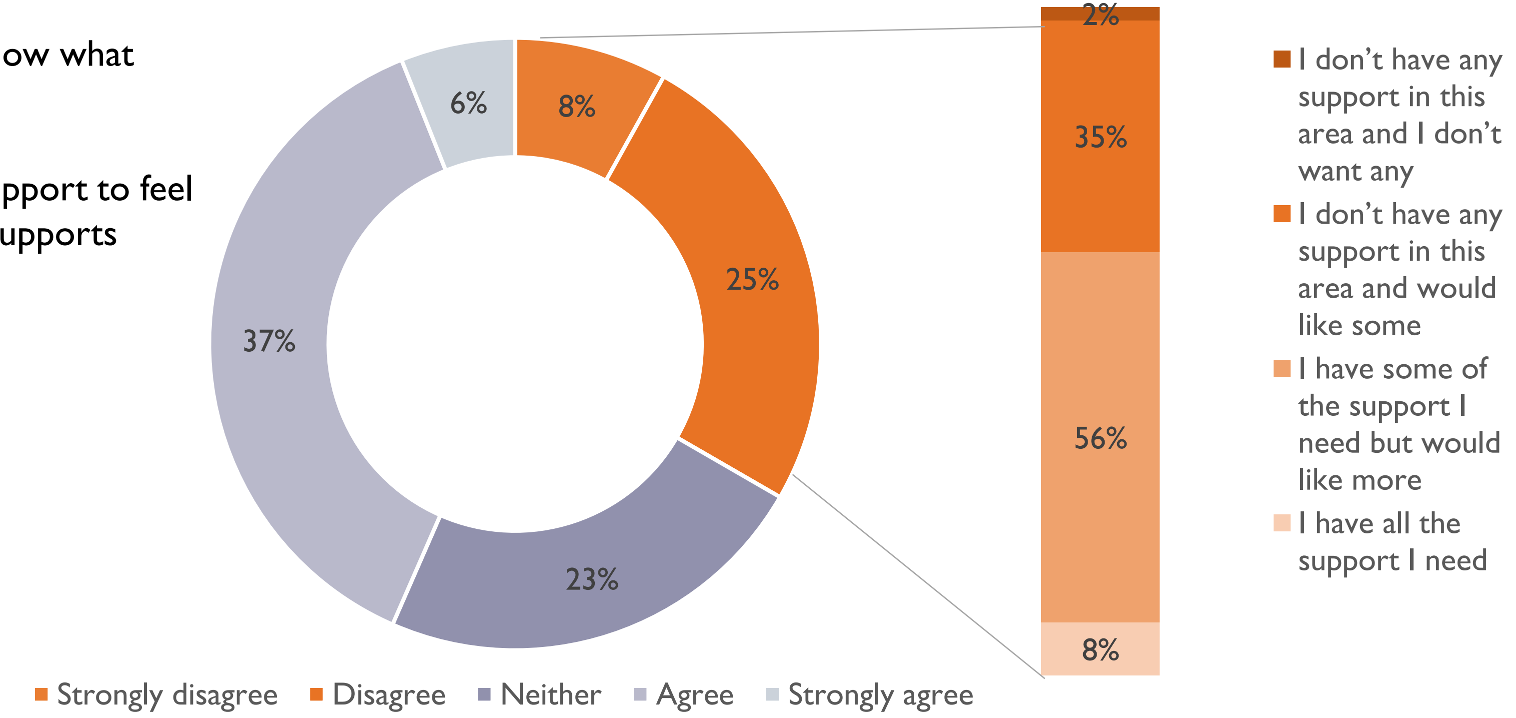


Q8: 'I can afford the additional costs needed to manage my MND' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=888

33% of people did not feel confident that they knew what financial support they were entitled to

1 in 3 survey respondents said they did not know what financial support they were entitled to.

Of this group, 91% of people wanted more support to feel more confident navigating the resources and supports available.



Q8: 'I am confident I know what financial support I am entitled to' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. ©REVEALING REALITY
Base n=904
Q9: 'Feeling confident about knowing what financial support I am entitled to' – 'I have all the support I need', 'I have some support I need but would like more', 'I don't have any support in this area and would like some', 'I don't have any support in this area and I don't want any'. Base n=295

Megan felt there were other people who might need grants more.

Megan and her family were making as much of the home adaptations themselves as they could. Megan worried that others might need the money more, so was reluctant to accept more support. While this concern wasn't explicitly shared by others, her experience highlighted the uncertainties some faced navigating financial support.

> *"It will all need to be on one level to be accessible…for a wheelchair and electric wheelchair and things. We were in the process of speaking to the council about that, they did say they thought the work would cost around £80,000 – we don't have that. Now we're waiting for the council to come back to us, to say 'is that realistic?' How much support, financially, do they provide?"*
>
> **Megan, 38**
> Salford
> Diagnosed in May 2023

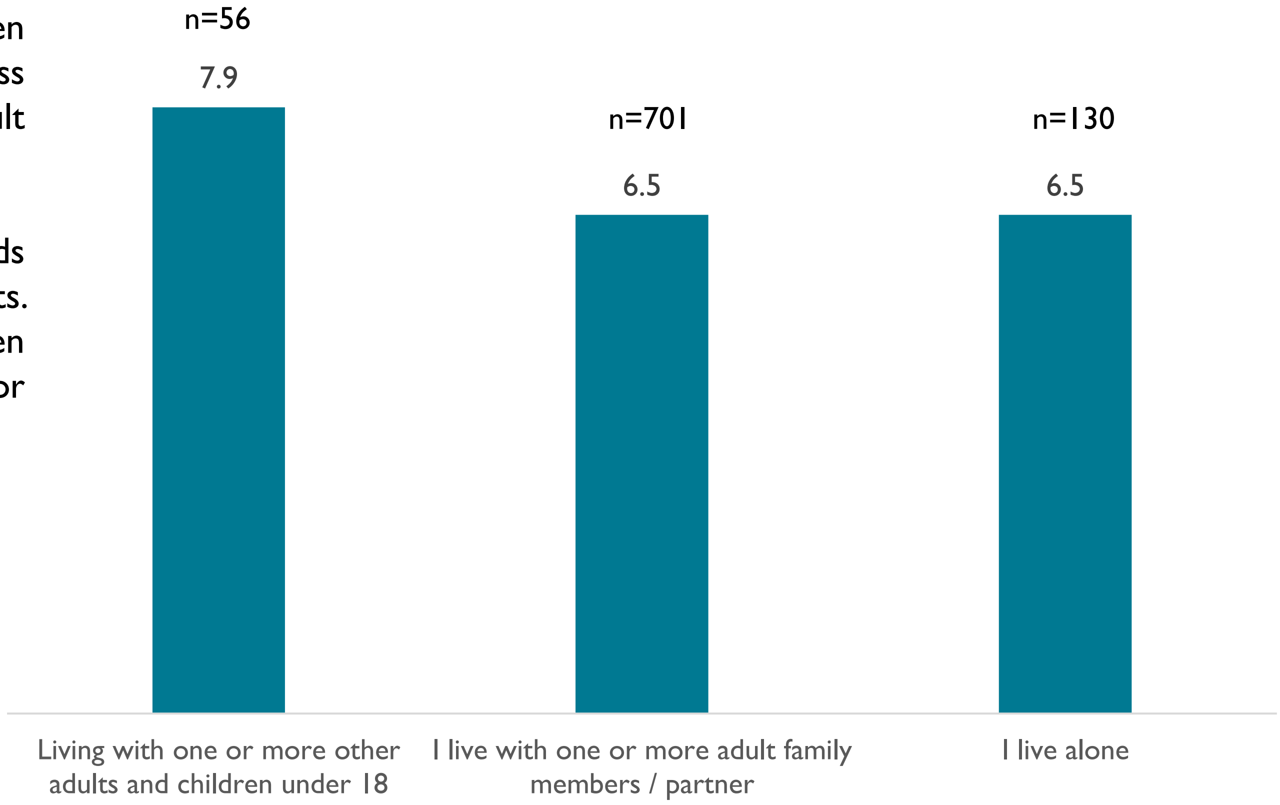
4

Younger people with children seemed to be struggling more

People living with adults and children had a higher average number of unmet needs

Those living with one or more other adults and children generally reported a greater number of unmet needs across all categories compared to those who live with another adult or partner, and those who live alone.

The graph on the right shows the average number of needs reported by individuals with different living arrangements. Those living with one or more other adults and children under 18 had, on average 7.9 needs, compared to 6.5 for those who live alone.



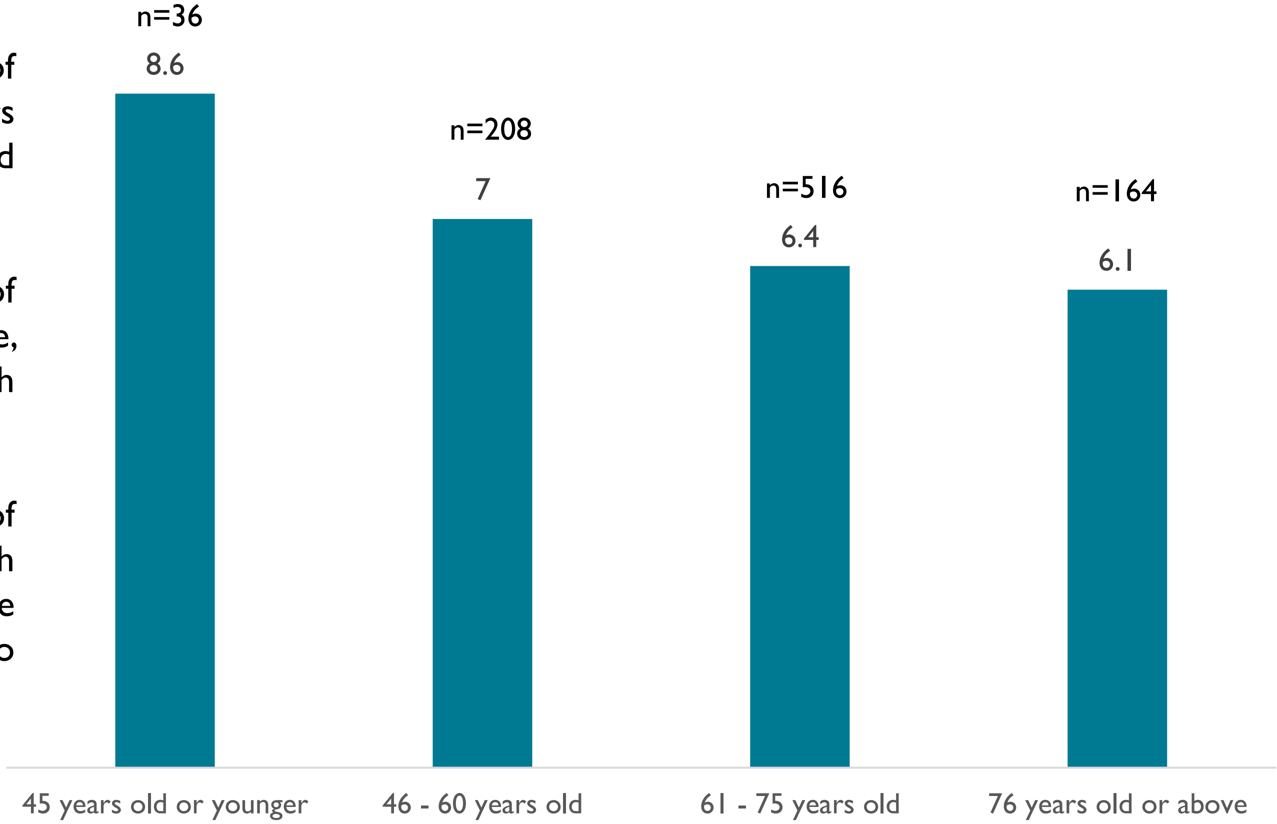
Q31: 'Who do you live with' – 'I live alone', 'I live with one or more adult family members / partner', 'I live with one or more other adults (not family nor partner)', 'I live with one or more other adults and children under 18', 'I am the only adult in the household but live with children under 18'. Base n=56-701

The same trend was seen for younger people, who had a higher average number of unmet needs

Likewise, younger people had a higher average number of unmet needs than older people. While people under 60 years old had an average of 7.3 unmet needs, those aged 76 and older had an average of 6.1 needs.

This pattern was even more stark for those under the age of 45. However, this group represented only 4% of the sample, due to the older age demographic of people living with MND.

As mentioned, this trend may be a result of the higher risk of disruption to daily life for young people and those living with families. Further, some older people may be receiving care from younger family members, or from care professionals, so may have some of these needs addressed.



Q31: 'How old are you?' Base n=924, n=36-516

Liz worried about her son becoming a young carer – but needed his support

While Liz struggled with the prospect of potentially not living with her family in the future, if she moved to more suitable accommodation, she also worried about relying too much on her son for informal care. Although she needed his support, she was reluctant to place this responsibility on him.

> *"I don't want him to be a young carer. I want him to concentrate on being a kid and doing the things he loves and doing his GCSEs…inevitably this has made him grow up too quickly. I try and shield him from doing my personal care, but he has had to empty my commode on occasion."*
>
> **Liz, 51**
> London
> Diagnosed in November 2022

Joni had lost contact with her daughter after her diagnosis

Joni had a daughter in her early twenties. On the day of the interview, it was Joni's daughter's birthday, but she wasn't spending the day with her mother. Joni found that her daughter struggled to spend time with her, because her mother's situation was too emotionally challenging.

Like Liz, Joni was concerned with protecting her daughter from some of the difficulties associated with living with MND.

> *"[Joni's daughter] said she went to London with her boyfriend but couldn't enjoy herself because in the back of her mind, [she thought] 'I'm losing my mum.'"*
>
> **Joni, 52**
> Isle of Wight
> Diagnosed in July 2023

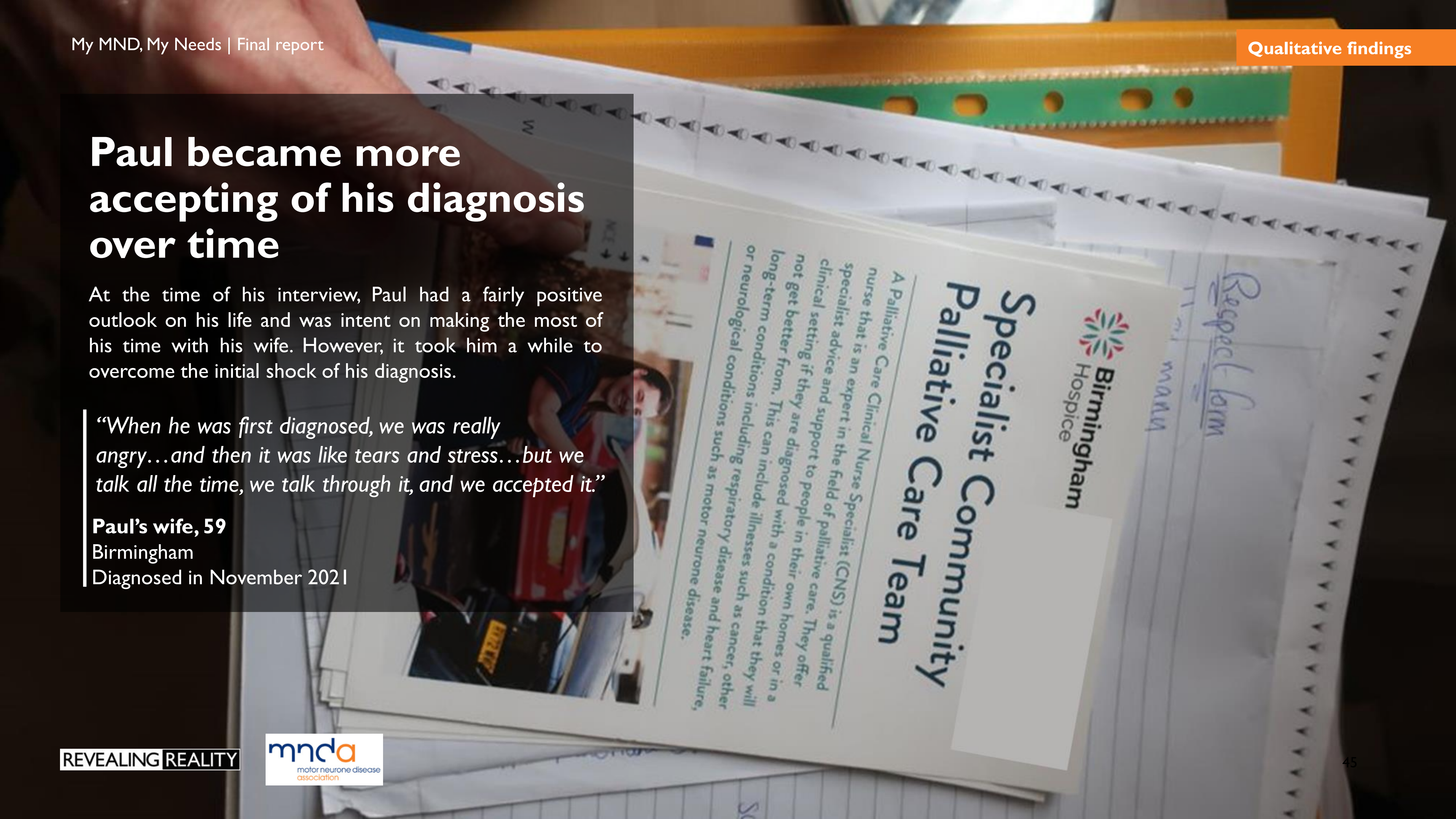
5

Those who had been able to accept and find peace with their diagnosis seemed more able to find joy day-to-day

Paul became more accepting of his diagnosis over time

At the time of his interview, Paul had a fairly positive outlook on his life and was intent on making the most of his time with his wife. However, it took him a while to overcome the initial shock of his diagnosis.

> *"When he was first diagnosed, we was really angry…and then it was like tears and stress…but we talk all the time, we talk through it, and we accepted it."*
>
> **Paul's wife, 59**
> Birmingham
> Diagnosed in November 2021



Birmingham Hospice

Specialist Community Palliative Care Team

A Palliative Care Clinical Nurse Specialist (CNS) is a qualified nurse that is an expert in the field of palliative care. They offer specialist advice and support to people in their own homes or in a clinical setting if they are diagnosed with a condition that they will not get better from. This can include illnesses such as cancer, other long-term conditions including respiratory disease and heart failure, or neurological conditions such as motor neurone disease.

Understanding acceptance and peace

The theme of acceptance and peace came out in the literature review as a frequently unmet need. In the qualitative stage of the research, it was observed that individuals who seemed to have reached a level of acceptance and peace with their diagnosis and the trajectory of their condition appeared to be coping better and finding more joy in their daily lives. This finding was particularly striking when considering the advanced symptoms some of these individuals were experiencing.

To explore this need further, while keeping in mind that how acceptance and peace looked different for everyone, various statements were developed for the survey. These statements related to:

- Individuals' current ability to live their lives as they would like and do the things they like best.
- Making plans for the future and having conversations about end-of-life.

Recognising the sensitive nature of questions related to death, dying, and end-of-life care, and the fact that not everyone would be willing or ready to discuss them, survey respondents were given the option to choose whether they wanted to answer these questions.

Acceptance and peace statements:

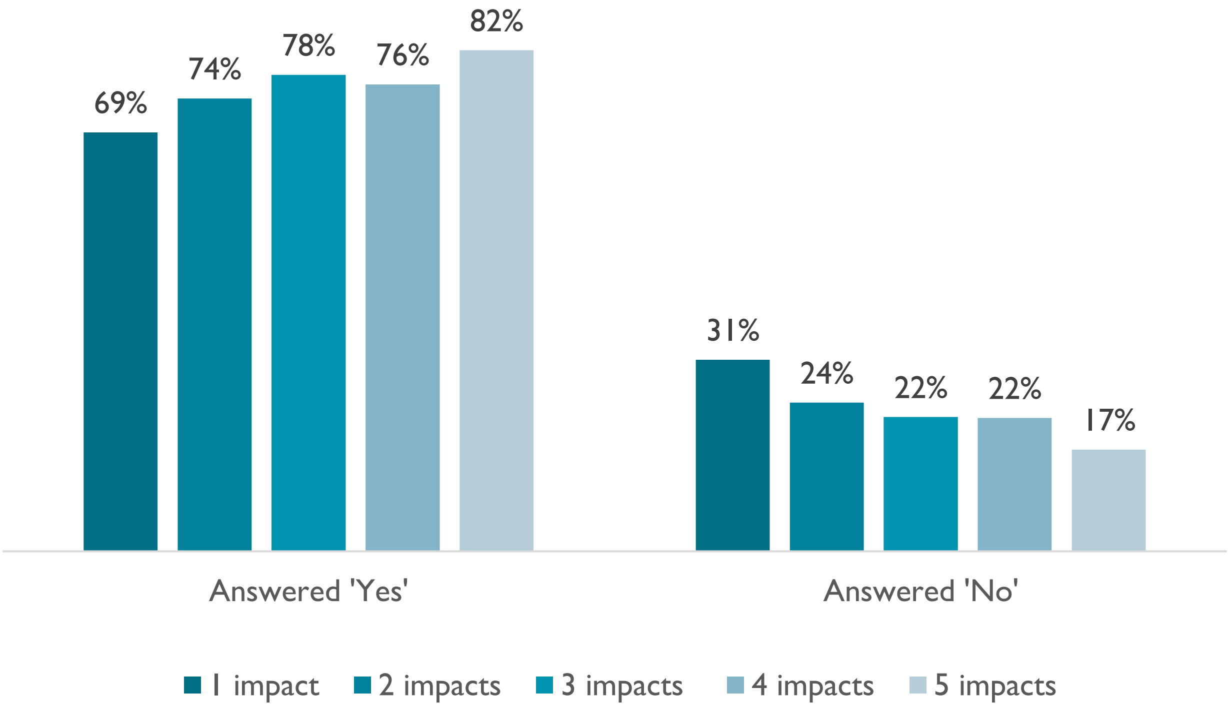
- I find it difficult to adapt to limitations imposed by my MND
- I cannot do what I like best because of my MND
- I have a plan that I am happy with for my future with MND
- If I need to talk about death and dying, I have someone to talk to

Q21: 'As with previous statements, please share with us the extent to which you agree or disagree with the following statements.' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=693 (people who answered questions about dying, end of life care, and their future with MND)

People who were happy to answer these questions tended to say MND had more impacts on their life

The willingness to answer questions about death, dying, and end-of-life care could be an indication of how far along individuals were in their experience with MND. 82% of people whose MND was affecting five areas of their life (e.g. walking or eating) were open to discussing death and dying, in contrast to 69% of those whose MND was affecting just one area.

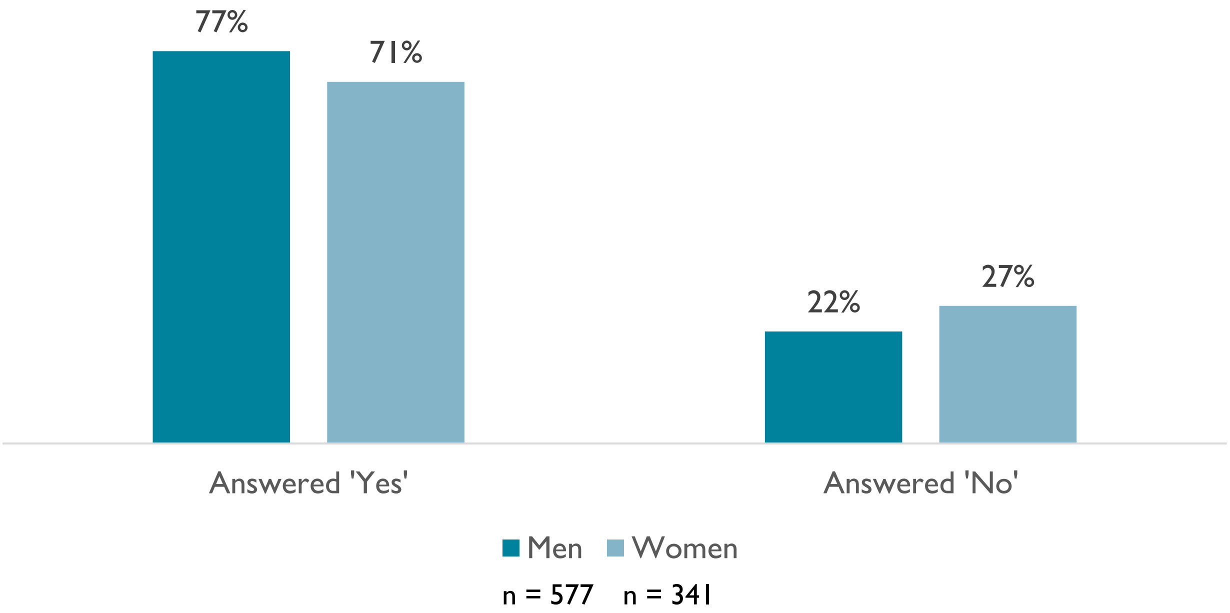
One reason for this trend might be because it is more likely for individuals to be receiving support from HCPs and hospice teams when MND is having a more significant impact on daily life.



Q20: ‘Would you like to answer questions about this topic?’, Q1: ‘Which, if any, of the following ways does motor neurone disease impact your life? Please tick all that apply.’ Base n=925

Men were slightly more likely to answer questions about death and dying

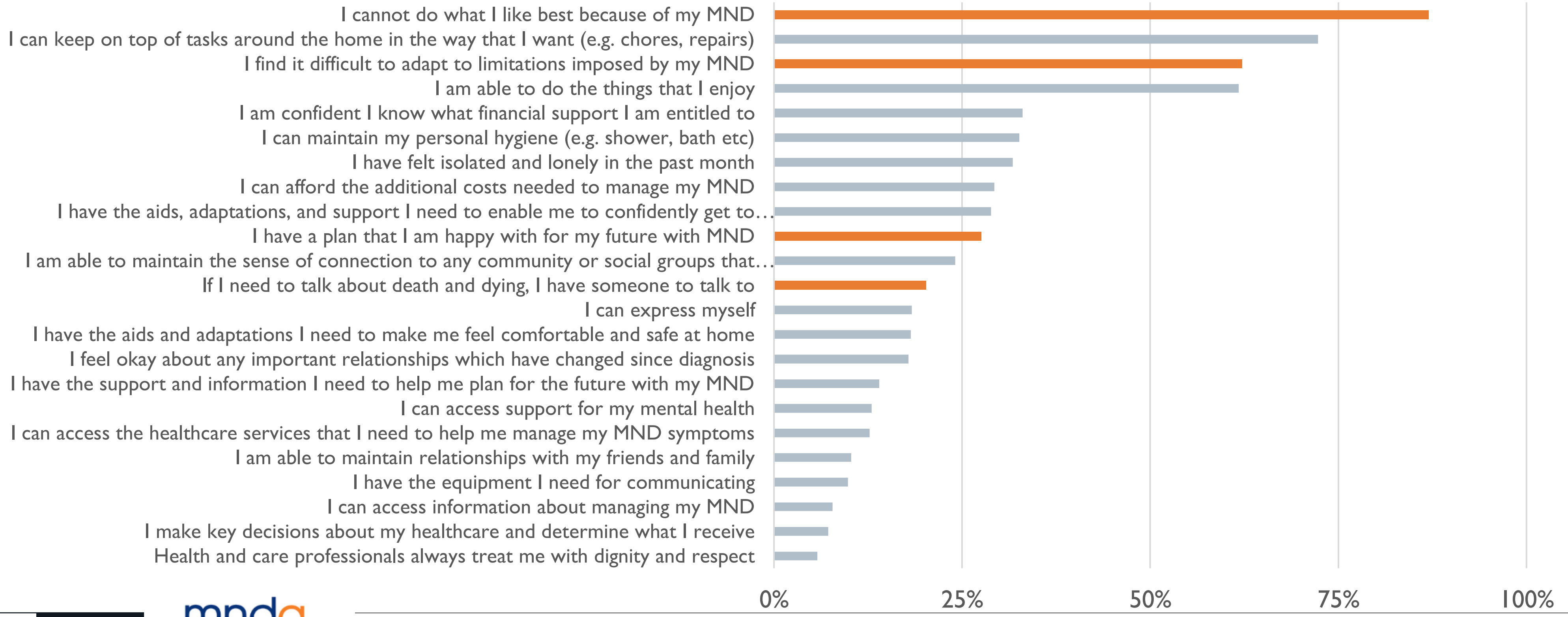
While 77% of male survey respondents responded ‘yes’ to answering questions about death and dying, only 71% of women expressed the same openness. This suggests that men may be slightly more likely to talk about death and dying compared to women.



Q20: ‘Would you like to answer questions about this topic?’, Q33: ‘Which of the following best describes the gender you identify with?’ Base n=918

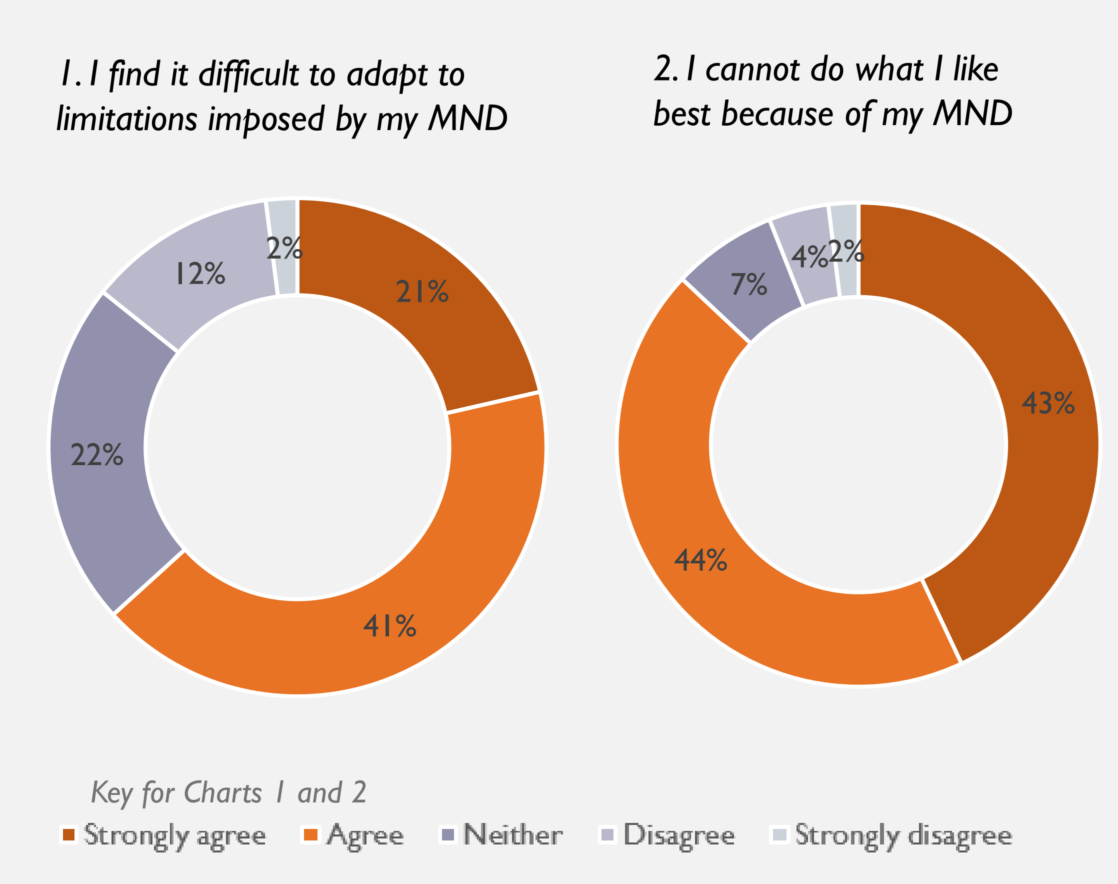
Where people answered these questions, many identified unmet needs

Statements about acceptance, peace, and feelings about future plans with MND tended to be highlighted as unmet needs by a significant proportion of respondents. Two of these statements moved up into the top three most reported unmet needs, for those who answered questions about death, dying, and end of life care.



Base n=693 (people who answered questions about dying, end of life care, and their future with MND)

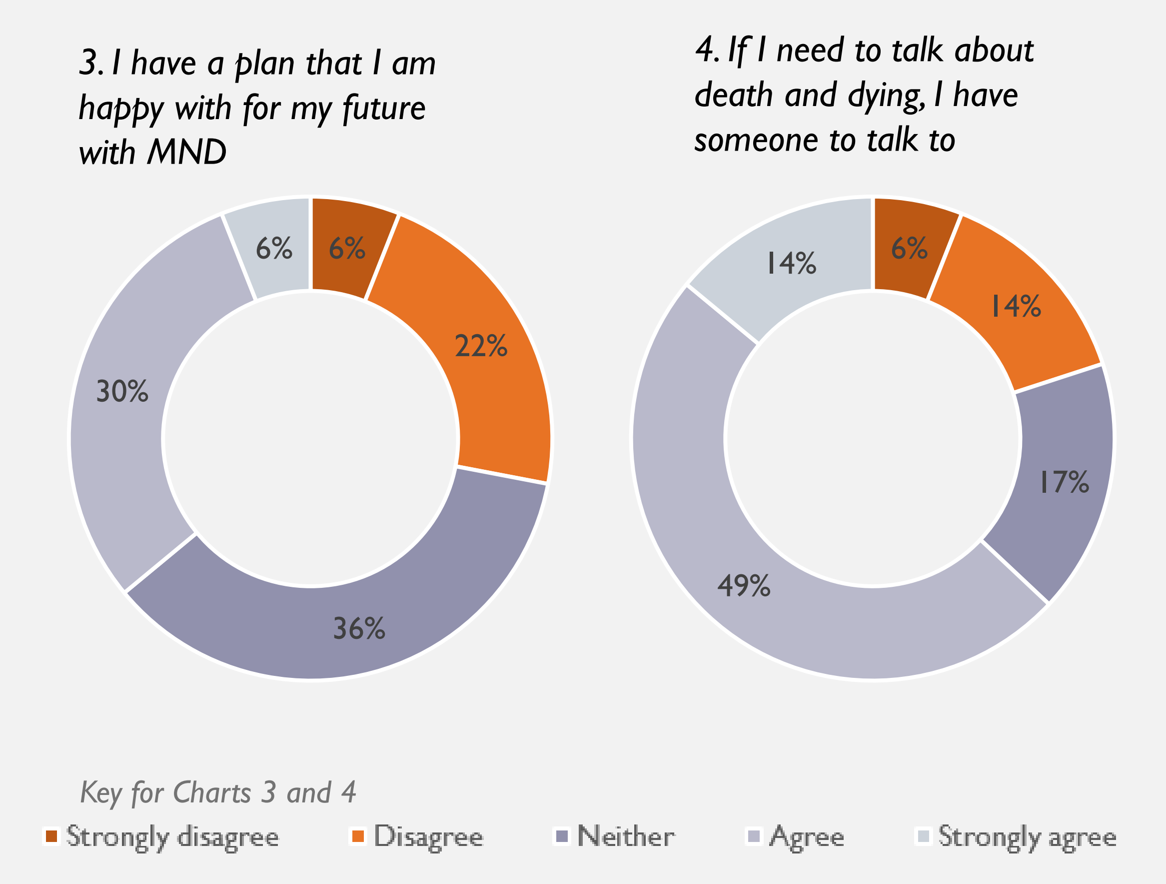
People who were happy to answer these questions tended to say MND had more impacts on their life



1. I find it difficult to adapt to limitations imposed by my MND

2. I cannot do what I like best because of my MND

Key for Charts 1 and 2



3. I have a plan that I am happy with for my future with MND

4. If I need to talk about death and dying, I have someone to talk to

Key for Charts 3 and 4

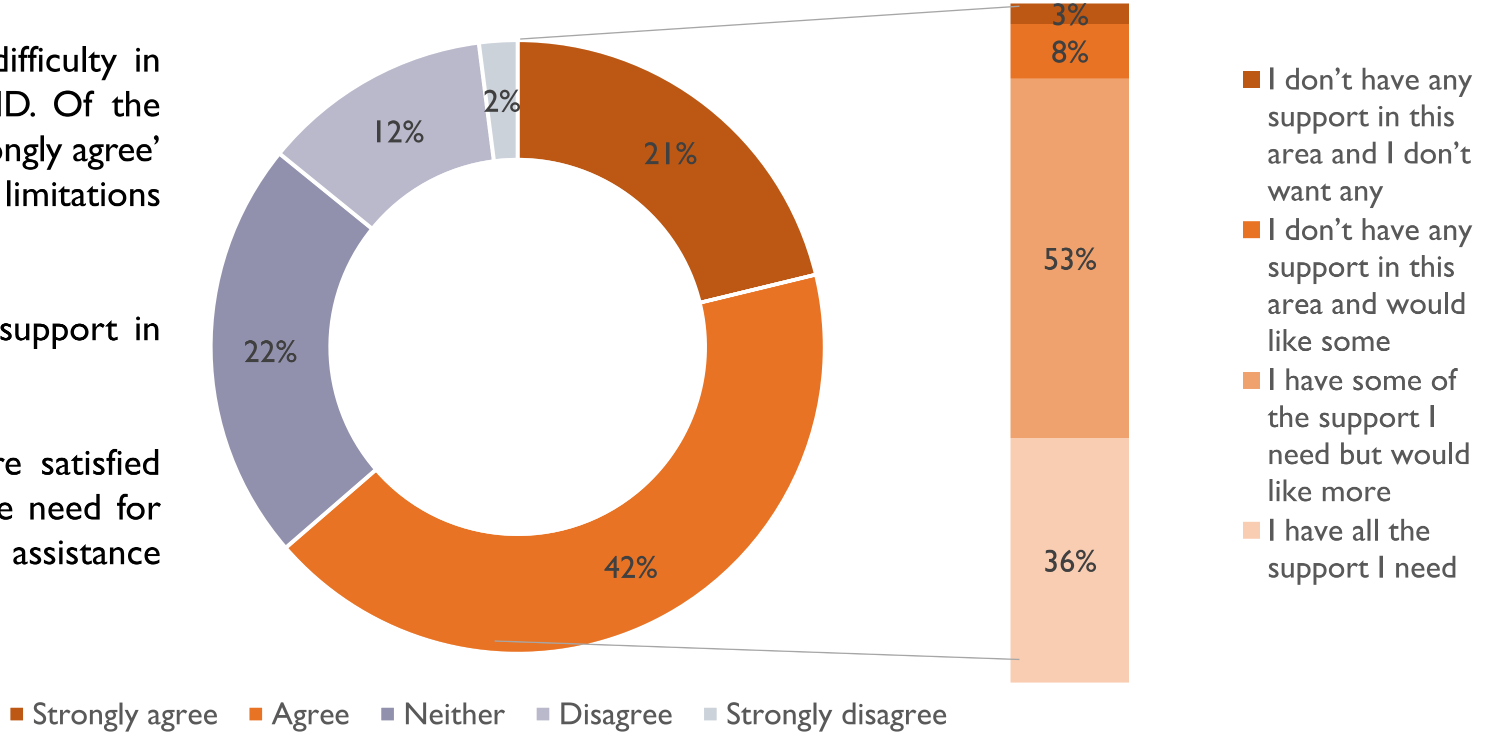
Q21a: 'I find it difficult to adapt to limitations imposed by my MND', Base n=682. Q21b: 'I cannot do what I like best because of my MND', Base n=680, Q21c: 'I have a plan that I am happy with for my future with MND', Base n=678, Q21d: 'If I need to talk about death and dying, I have someone to talk to', Base n= 683

More than 6 in 10 found it difficult to adapt to limitations from their MND

The majority of survey respondents reported difficulty in adapting to the challenges posed by their MND. Of the survey respondents, 63% said they 'agree' or 'strongly agree' with the statement 'I find it difficult to adapt to limitations imposed by my MND.'

Of this group, 61% said they would like more support in this area.

28% also reported not having a plan they were satisfied with for their future with MND, emphasising the need for additional support in implementing appropriate assistance and adaptations.



Q21: 'I find it difficult to adapt to limitations imposed by my MND.' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=682. Q22: 'Adapting to limitations imposed by my MND' – 'I have all the support I need', 'I have some support I need but would like more', 'I don't have any support in this area and would like some', 'I don't have any support in this area and I don't want any'. Base n=693 (people who answered questions about dying, end of life care, and their future with MND)

Initially, Paul resisted making adaptations for his MND

This meant that when his mobility started to deteriorate, and he was less able to do the things he usually did, Paul did not have the right support systems in place.

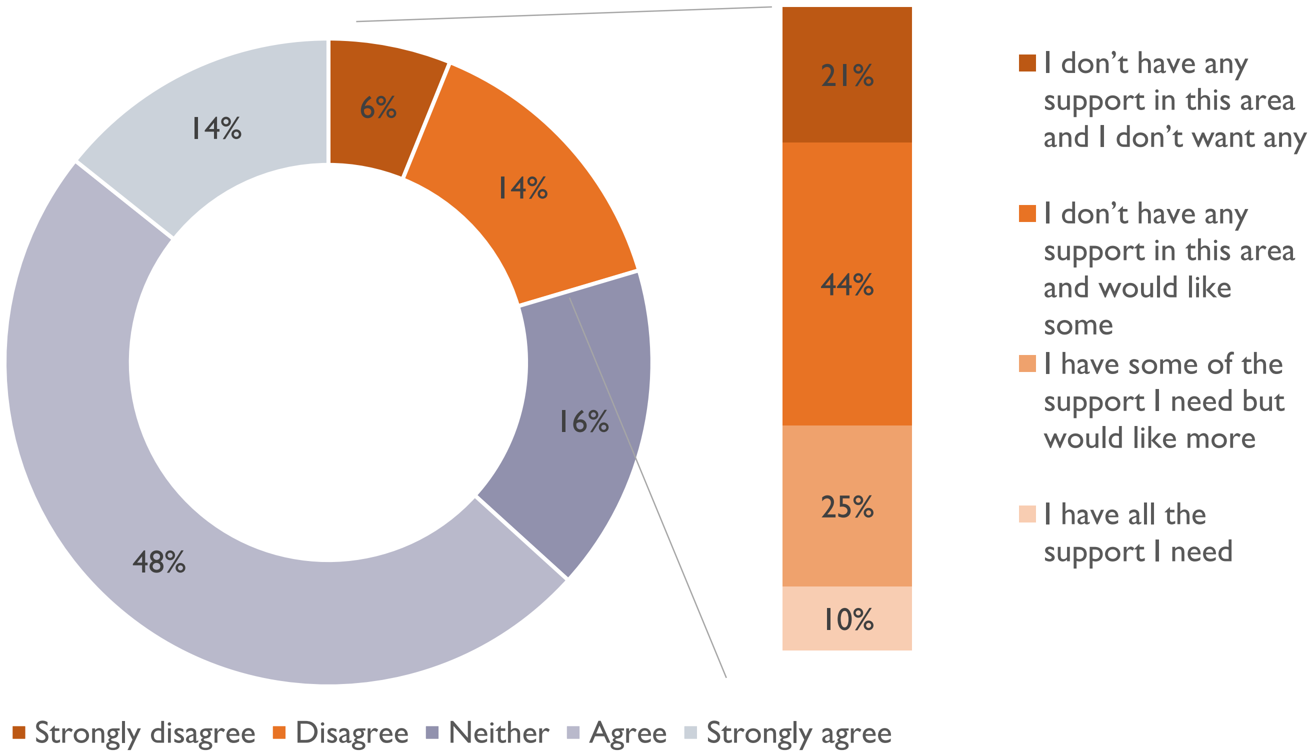
> *“What it is with MND...you tend to carry on like nothing’s going on and you can do the things you use to do…and you don’t think about the precautions, about being safe, about being aware of your surroundings. And that’s what happened. The postman rang the doorbell, I tried to get in the chair. And as I stood up, both legs collapsed underneath me. And that hurt…I stayed on the floor for an hour because I didn’t want to ring anyone…it’s my own fault. I didn’t want to unduly stress [my wife].””*
>
> **Paul, 59**
> Birmingham
> Diagnosed in November 2021

1 in 5 didn't feel they had anyone to talk to about death and dying

20% of the sample didn't feel they had the right place or person to go to talk about the end of their life. Age seemed to influence the perception of acceptance, peace, and future planning as unmet needs. A higher proportion of younger respondents (29% of those under 60) disagreed with having accepted their diagnosis compared to older groups (18% of those aged 61–75 and 15% of those aged 76 and above). Financial constraints also affect acceptance. Among those who couldn't afford the additional costs of MND, 29% disagreed with having accepted their diagnosis, compared to 16% of those who could afford the expenses.

Of the 20% who reported not having someone to talk to about death and dying, 69% said they would like more support.

While not specifically related to this statement, 14% raised that they could not access support for their mental health. This suggests there is a small minority of people who are struggling to access the right people to talk to about wellbeing.

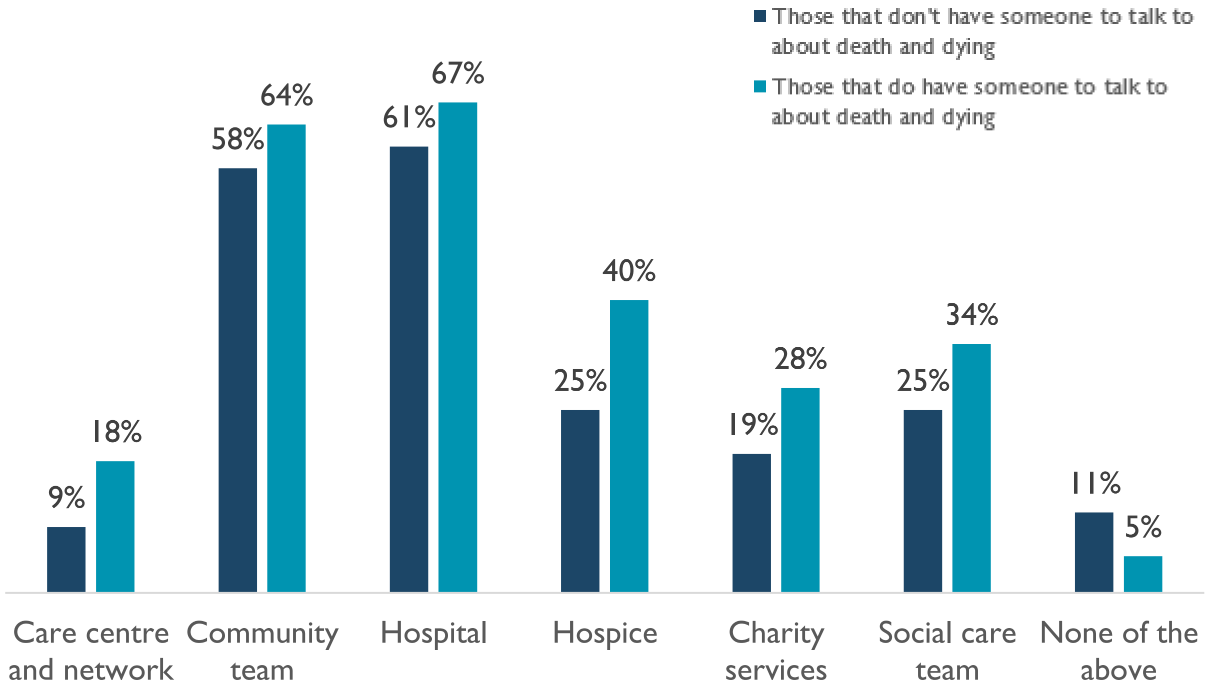


Q21: 'If I need to talk about death and dying, I have someone to talk to' – 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree', 'Strongly disagree'. Base n=693 (people who answered questions about dying, end of life care, and their future with MND). Q22: 'If I need to talk about death and dying, I have someone to talk to' – 'I have all the support I need', 'I have some support I need but would like more', 'I don't have any support in this area and would like some', 'I don't have any support in this area and I don't want any'. Base n=139.

Those who didn’t feel they had anyone to talk to about death seemed less likely to be have contact with services

Those who reported not having someone to talk to about death and dying appeared to be less connected to support services compared to those who did have someone to discuss these topics with.

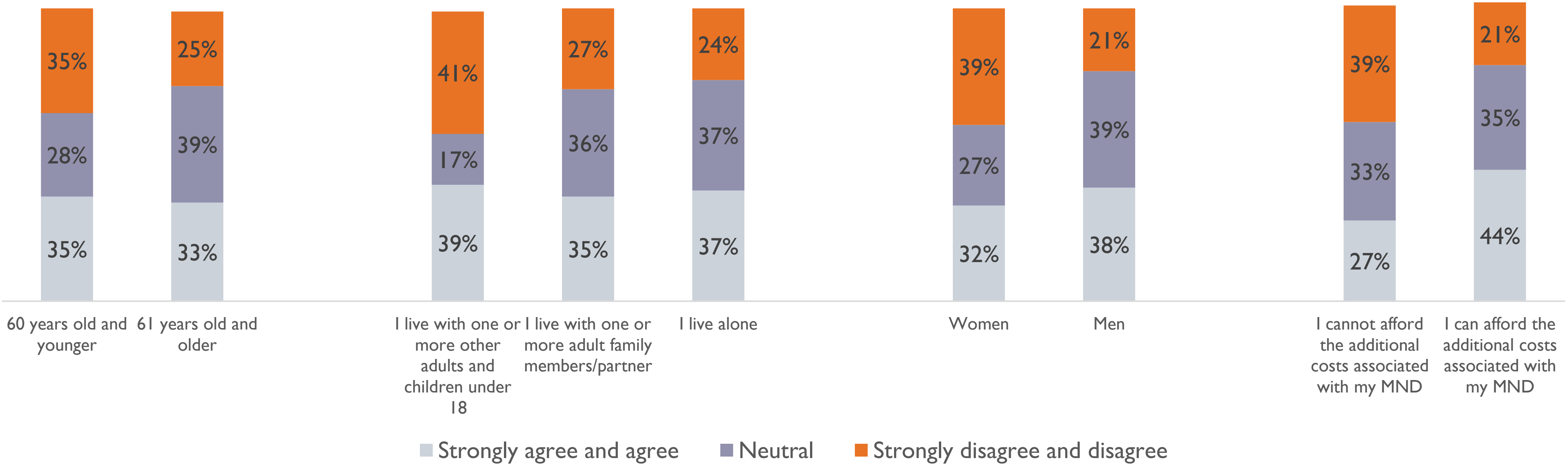
67% of those who had someone to talk to about death and dying were in contact with a hospice team, compared to only 40% of those who did not have someone to talk to. Similarly, 61% of those with someone to talk to were connected to a hospital team, while only 25% of those without someone to talk to reported the same.



Base n=693 (people who answered questions about dying, end of life care, and their future with MND)

Young people, those living with adults and children, women, and those struggling with finances were also less likely to have contact with these services

Younger respondents also seemed to be less likely to accept their diagnosis, with 29% of those under 60 saying they had not accepted their diagnosis, compared to 18% of 61-75 year-olds, and 15% of those aged over 76. Similarly, those who reported being unable to afford the additional costs of living with MND were less likely to accept their diagnosis.



Base n=693 (people who answered questions about dying, end of life care, and their future with MND)

Megan felt she was on her way to acceptance

By the time of this interview, Megan's symptoms included weakness on the left side of her body, a dropped left foot, weakening of her right hand, and a weakening voice. Although she and her husband had started making adaptations to their home, as outlined earlier, Megan said she still struggled with accepting her condition. Coming to terms with leaving her career and leaving behind her three teenage daughters made acceptance particularly difficult for her.

Megan's story illustrates that acceptance was a gradual process for some, and that it required time and support.

> *"Like with everything, it takes time to kind of go through that grieving process, to get to acceptance. So I'm nearly there."*
>
> **Megan, 38**
> Salford
> Diagnosed in May 2023

Simon had a positive outlook despite his advanced symptoms

Simon was an example of someone with very advanced symptoms, and who maintained positivity about his future. As with Paul, Simon's MND diagnosis was devastating for him and his wife. Now fully immobile, and only able to communicate with an eye-sensor computer, Simon has been able to process and accept his new life with a sense of humour.

> *"I have said that I might be wrong and this could all be over tomorrow or any number of reasons. I feel good about the future. The way I look at it is simple. The longer I hang around, the better chance there is of an effective treatment being found. And I might as well have some fun while I am waiting."*
>
> **Simon, 44**
> Bedfordshire
> Diagnosed in 2020

REVEALING REALITY

mnda motor neurone disease association

Summary for the MND Association

Summary of key findings

1 Needs around autonomy, independence, and self-expression were highlighted by many

2 There is demand for more financial support with a third not feeling confident about what they are entitled to

3 Isolation and loneliness was more felt by those living with other adults and children

4 Younger people and those living with children have more unmet needs

5 Making peace with a MND diagnosis enabled some to find more day-to-day joy

Thank you for reading

REVEALING REALITY

mnda
motor neurone disease association

Technical appendix

Literature review

The first phase of this research was a literature review, to ensure the primary research was building on what is currently known about the needs of people with Motor Neurone Disease (MND). This laid the groundwork for the qualitative research approach, ensuring an accurate understanding of the current landscape and highlighting any potential evidence gaps.

158 articles were identified through key search terms agreed with the MND Association, from a variety of academic articles, charity reports, and patient information websites. These included 'MND and' with a list of areas of someone's life, including mobility and movement, personal care, relationships and family, and experiences with health and social care.

63 papers were included based on their relevance and avoiding duplication and repetition.

Some of the key evidence gaps highlights included:

- The needs around relationships beyond carers
- The experiences of people with MND who had smaller or minimal support networks
- Understanding significant milestones outside of wheelchair use
- The every day needs around personal care, eating and drinking

Technical appendix
Qualitative interviews

This qualitative research explored the experiences of people living with Motor Neurone Disease (MND) in various life areas, including their relationships, home life, mobility, interactions with healthcare services, and finances.

The research materials and interview structure was shaped by the needs framework developed in the literature review. This framework ensured a thorough exploration of the broadest range of needs experienced by people living with MND, and was both utilised and expanded upon based on insights from the respondents.

Revealing Reality interviewed 15 individuals diagnosed with MND, encompassing diverse ages, geographical locations (including Northern Ireland), types of MND, dates of diagnosis, socio-economic backgrounds, genders, and the use of adaptations. These were recruited through the MND Association's network, other charity and support organisations, and social media groups. It's worth noting, the sample was designed to ensure representation of a wide range of experiences with MND and so is not representative of the population of UK adults with MND.

To amplify the voices of those less frequently heard by the MND Association, the research materials were designed as an adaptable toolkit to accommodate the varying needs of participants. The interviews began with respondents reflecting on different life areas, followed by questions about potential improvements, goals, concerns, and queries. Additional probes and tools were employed to explore specific areas highlighted as having unmet needs.

Health & social care

Diagnosis

HCPs

MH & wellbeing

Feelings in life

Everyday life

Relationships

Physical

Palliative / EoLC

General / misc.

Technical appendix
Quantitative survey

The research culminated in a quantitative survey involving 925 participants with Motor Neurone Disease (MND), designed to provide a sense of scale to the ‘needs’ highlighted in the literature review and the qualitative interviews. The survey was also designed to provide an understanding of the scale of ‘unmet need’ or demand for further support.

The initial needs framework was developed to further reflect the experiences of those with MND, using insight from the qualitative interviews. For example, needs previously categorised under ‘Everyday life’ were reclassified under ‘Autonomy, independence, and self-expression’. To assess the fulfillment of these needs, statements such as "I have the equipment I need for communication" and "I have felt isolated and lonely" were used to explore the different aspects of needs in each category.

The survey was rigorously tested for clarity and accessibility with people with MND, incorporating feedback from those using screen readers or eye movement technology. It was then disseminated through various channels, including the MND Association's contacts database, social media, support groups, and relevant charities.

Analysis focused on responses to positively framed need statements (e.g., "I am able to maintain relationships with my friends and family") and negatively framed statements (e.g., "I have felt isolated and lonely in the past month"). Analysis then examined the level of support participants had or desired, allowing ‘unmet’ needs to be identified.