

MIND insights: How technology can help with challenges of daily living



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Background

Our vision is a world where motor neuron disease (MND) is both preventable and treatable. Through our expertise in early translational science, LifeArc is working to accelerate discoveries that enable earlier intervention, deliver more effective treatments and improve the quality of life for people living with MND.

We know from experience that research is most impactful when it is shaped by those it aims to benefit. To ensure this, we established the MND Insights Group, a group of people with lived experience of MND, to explore the challenges that matter most to those directly affected by the condition. Alongside facilitated discussions with this panel, we've also conducted surveys to capture wider perspectives from across the MND community.

The insights shared by those affected by MND are vital to guiding our research priorities and ensuring that technology and innovation address real needs. By aligning solutions with lived experiences, we aim to

transform how MND is detected, treated and managed. We are also committed to sharing these insights more widely to foster collaboration and drive progress across the field.

In September 2024, we held a workshop with the MND Insights Group and conducted a community-wide survey to explore the current and future role of technology in supporting daily life with MND. This report summarises the key findings, drawing out recurring themes that will help inform our funding priorities and shape the overall direction of our MND and Rare Dementias Translational Challenge.



About MND

MND is a progressive condition that affects the specialist nerve cells (motor neurons) in the brain and spinal cord that help tell muscles what to do. This causes the muscles to gradually weaken, stiffen and waste, affecting a person's ability to walk, talk, eat, drink and breathe. Some people also experience changes in their thinking and behaviour, but the disease affects everyone differently and can be difficult to predict.

It can affect adults at any age, but is more likely to affect people over 50. While the causes of MND are largely unknown, in rare cases, it is due to a genetic fault that can be passed down through families.



MND is life-shortening and there is no cure. However, treatments are available that can help manage symptoms and improve quality of life.

About LifeArc

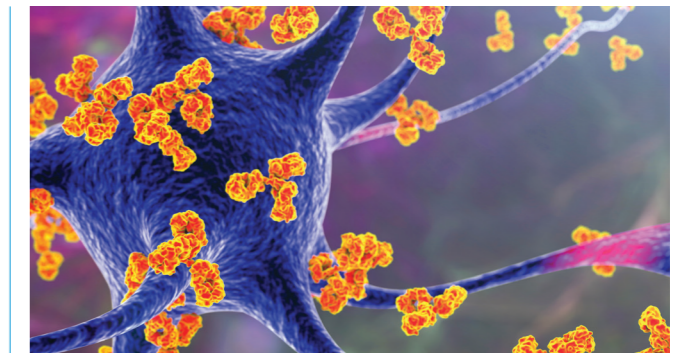
We are a self-funded medical research organisation with one clear purpose: transforming the lives of people with rare diseases and drug-resistant infections.

People affected by these conditions are at the heart of everything we do – they shape our priorities and guide our research. Our strength lies in conducting and funding pioneering research, and in accelerating the translation of scientific discoveries into practical medical and technological solutions.

We focus on transforming the lives of people living with rare diseases and globally resistant infections

through scientific breakthroughs, working with partners, and taking on the challenges others will not, to create new and better healthcare solutions.

We form partnerships and provide scientific expertise and funding to help break down the barriers preventing scientific breakthroughs from becoming life-transforming treatments and cures.



The main types of MND are:

Amyotrophic lateral sclerosis (ALS)

The most common form of MND, with weakness and wasting in the limbs, muscle stiffness and cramps.

Bulbar onset MND or progressive bulbar palsy (PBP)

Affects a smaller number of people than ALS, and mainly affects the muscles of the face, throat and tongue.

Progressive muscular atrophy (PMA)

Affects only a small proportion of people, with early signs often weakness or clumsiness of the hands.

Primary lateral sclerosis (PLS)

A rare form of MND, causing mainly weakness and stiffness that usually begins in the lower limbs.

ALS with frontotemporal dementia (ALS-FTD)

While ALS and frontotemporal dementia (FTD) often occur on their own, around 1 in 5 people with ALS will also develop FTD. They will experience mobility symptoms and cognitive symptoms simultaneously.

Foreword

At LifeArc, our commitment to improving the lives of people affected by motor neuron disease (MND) continues to be guided by a belief that those living with the condition should shape the innovations designed to support them. Their experiences, perspectives, and ideas are central to ensuring that research leads to solutions that truly meet their needs.

When we created the MND Insights Group 18 months ago, we hoped it would help guide our direction, and strengthen the connection between research and lived experience. What has emerged has exceeded every expectation. The openness, expertise and generosity of this group and their willingness to share personal experiences to help drive change have become an invaluable part of our journey. Their insights are shaping how we think, where we focus and what we prioritise in the future.

This second report builds on our earlier work exploring the everyday challenges of life with MND, turning the focus towards how technology – from assistive devices to digital tools – can help to preserve independence, dignity, and quality of life. Once again, the insights shared by people with lived experience of MND and their caregivers have provided clear and powerful guidance.

Their message is united and clear that technology has enormous potential, but only if it is designed in partnership with those who will use it. Devices and assistive technologies must be simple, adaptable and introduced in time to make a difference. They must reflect



Paul Wright
Head of MND and
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the rapid and unpredictable progression of MND, evolving as needs change, rather than arriving too late to be useful. The ideas shared through this report, from personalised digital care hubs to tools that preserve voice and identity, offer a powerful blueprint for future innovation.

What stands out most is the optimism and creativity of the MND community. Despite the significant challenges they face, participants spoke with hope about the role technology can play in restoring autonomy, supporting caregivers, and helping people to remain connected and independent for longer.

My thanks to every member of the MND Insights Group and to the wider community who contributed to this work. Your insights are shaping the future of MND research and technology, ensuring it remains focused on what matters most to you.

Through collaboration and shared purpose we continue to move towards a future where MND is not only treatable, but where life with the condition is supported by innovations that bring greater independence, comfort and hope.

Executive summary

This report shares insights from people living with MND, their caregivers, and the wider community, gathered through a workshop with the MND Insights Group and a community-wide survey. The goal was to understand the challenges of daily life with MND, identify unmet needs, and highlight areas where technology could offer meaningful support.

The findings reveal the profound impact of MND on mobility, communication, fine motor skills, breathing, continuity of care, and emotional wellbeing. Participants stressed that technologies must be adaptable, timely, and user-friendly to keep pace with the rapid and unpredictable progression of MND. Many current tools, while promising in principle, often arrive too late, require skills that individuals may no longer have, or fail to reflect the physical, emotional and cognitive realities of living with the condition.

While there was broad consensus that technology has significant potential to enhance independence, reduce caregiver burden and support quality of life, participants also described significant barriers. Current devices are often too bulky, complex, or reliant on physical strength and dexterity. In addition, delays and inconsistent provision can often lead to equipment arriving when it is no longer relevant. A lack of training and ongoing support also means many people are left unable to use potentially helpful tools effectively.

Despite these challenges, participants highlighted several opportunities for technological innovation. Specific ideas included digital hubs to share personalised care needs and improve continuity of care, carbon dioxide monitoring devices to help prevent episodes of fatigue, handwriting and voice banking to help preserve a person's sense of identity, passive exercise machines to alleviate immobility, symptom-tracking and progression-mapping tools to help anticipate future care needs, and apps that could record wishes and support legacy planning to help maintain autonomy.

A consistent message was the importance of adopting a patient-led approach. People living with MND and their caregivers want to decide which technologies to use, and when, based on their specific circumstances.

“ While there was broad consensus that technology has significant potential to enhance independence, reduce caregiver burden and support quality of life, participants also described significant barriers. Current devices are often too bulky, complex, or reliant on physical strength and dexterity.”



They also emphasised the value of tools that are lightweight, intuitive, adaptable, and supported with accessible and ongoing training.

In summary, technology has considerable potential to improve the quality of life for people affected by MND, but only if it is developed in partnership with those who will use it. Solutions must be timely, adaptable, and personalised, addressing not only the physical, but also the emotional and practical realities of MND. By listening to lived experience, we can ensure that future technologies are both innovative and life-enhancing.


Methodology


This report summarises the insights gathered from two sources: a workshop with our MND Insights Group and a community-wide survey.

1) Workshop with our MND Insights Group

We hosted a workshop attended by eight members of our MND Insights Group: four people living with MND and four bereaved caregivers.

The workshop focused on exploring the use of technologies to support daily life with MND. Participants were asked to share their thoughts on three key areas:

 The challenges of daily life with MND

 Experiences and perceptions of health technologies, particularly potential barriers to use

 Co-development of the community-wide survey

The session was held with the facilitation of two experienced co-chairs: Roger Leek, a bereaved caregiver with extensive involvement in MND advocacy and research, and Emma Willey, a registered nurse with significant expertise in MND care and mental health programme management.



Emma Willey



Roger Leek

2) Community-wide survey

We conducted an online survey to capture the perspectives of the wider MND community. It aimed to better understand the daily challenges faced by people affected by MND and the role that technologies might play in addressing them.

The three main goals were:

1

To understand the daily challenges experienced by people living with MND and their impact on quality of life.

2

To assess awareness of technologies and identify gaps in current solutions.

3

To explore people's attitudes, views, experiences and challenges regarding technology use.

The survey was structured into five separate streams, with the wording of questions adapted to accommodate the following groups of participants:

- people living with MND
- current caregivers responding on behalf of the person with MND
- current caregivers expressing their own views
- bereaved caregivers
- people at a high genetic risk of MND

The survey was open from 17 October 2024 to 10 December 2024, and was promoted via social media and through direct contacts of LifeArc, UK-based MND charities, and other health research organisations in the UK and worldwide. Data visualisation was used as the primary tool for data analysis, with artificial intelligence (AI) employed to support the qualitative analysis of free-text responses by identifying and categorising common themes.

Workshop insights

Through facilitated discussions, group members shared their perspectives on the current and future role of technologies in supporting daily life with MND.

1 Challenges experienced in daily life with MND

Conversations focused on the most pressing daily challenges for people living with MND and their caregivers, and the areas where technology might provide meaningful support.



Key challenges identified:

Maintaining continuity of care across home, hospital and hospice settings.

Loss of fine motor skills, limiting independence in daily activities.

Breathing difficulties and associated fatigue.

Communication barriers, particularly as symptoms worsen.

Unique challenges for people living with ALS-FTD, who may not recognise their symptoms as MND.

Social isolation resulting from reduced mobility and changes in their life circumstances.

Inadequate support, placing a significant emotional and mental health toll on caregivers.

Continuity of care

Maintaining continuity of care was described as a significant challenge. People living with MND and caregivers often have to repeatedly explain complex, individualised needs to unfamiliar staff, which can be exhausting and distressing. Frequent changes in home carers may mean critical aspects of care are missed, leading to unnecessary pain, discomfort or distress. In hospitals and hospices, rotating staff often lack the time or knowledge to understand a person's specific needs. This issue becomes especially important when communication difficulties are present, as familiar staff are better able to interpret an individual's adapted communication methods.

“Because MND takes so rapidly at times, it's important to have something that can really help people – help with their dexterity while they've still got it, help with their communication while they've still got it. I think that would have a huge effect on mental health to know ‘well we can't do that, but we can do this and this [device] is going to help us do this.’”

Bereaved caregiver

Fine movement

Difficulties with fine motor skills can limit independence in everyday activities, such as cooking, dressing and managing household tasks. While some assistive technologies exist, they are often costly, not tailored for people living with MND, or only useful for a short period. For example, voice-to-text software or voice-activated systems can be helpful, but some require hand dexterity and also may become redundant as a person's speech declines. Similarly, while some wearable devices can help support hand movement, they can often be impractical for people with limited dexterity.

“It's all very well knowing that I can use voice activation now, but will I have my voice in 2 years? It's the progressive, changing nature that makes it so challenging.”

Person living with MND

Breathing difficulties

Breathing difficulties and the resulting fatigue afterwards can significantly impact quality of life. Episodes of high carbon dioxide due to impaired breathing, particularly at night, can lead to exhaustion the next day. Detecting and managing these episodes soon enough to take preventative action is challenging.

Communication

Both people living with MND and caregivers highlighted the ability to communicate effectively as a major challenge. Eye-gaze systems and text-to-speech tools can help, but are often limited by age, accessibility, and decline in physical abilities, which makes them harder to use over time. These barriers often exacerbate feelings of frustration and isolation.



ALS-FTD

People with ALS-FTD may not understand or recognise that certain symptoms, such as fasciculations, cramping and bowel difficulties, are related to having MND. Caregivers spoke of the emotional strain of repeatedly explaining the condition to their loved one, as well as the difficulties this creates in having conversations with healthcare professionals, further complicating the delivery of appropriate care and support.

Social isolation

People living with MND can feel very socially isolated due to changes in their life circumstances and their condition. For example, reduced mobility and increased care needs often make it difficult to visit family members or maintain friendships, leading to a sense of disconnection and loss of social contact.

“You are eroded away as a person – you are treated more and more as a difficulty, a burden, a patient, a client, so little remains of your humanity and it's eroded away constantly.”

Person living with MND

Caregiver mental health

Caregivers described the heavy emotional and psychological burden of their role. Some felt they couldn't express their own struggles, as they needed to remain strong and present, especially if they were the sole caregiver. A lack of dedicated mental health support was identified as a significant gap.

2 Ideas for new technologies in MND

We explored potential technologies that could improve daily life for people living with MND and their caregivers. Many of their suggestions reflected the need for tools that adapt to disease progression, reduce caregiver burden, and preserve a sense of identity and independence.



Summary of key ideas:

A digital hub to record and share personalised care needs with care or medical professionals, supporting continuity of care.

Handwriting banking to help preserve a person's sense of identity.

Wearable devices to ease hand spasticity, preserve identity and reduce pain.

Passive exercise machines to stimulate movement and help reduce swelling from immobility.

Continuous carbon dioxide monitoring devices to detect respiratory issues early and help prevent fatigue.

An interactive app or roadmap predicting MND progression to help guide timely adoption of technologies.

Digital tools for people with ALS-FTD, including symptom explanations and behavioural tracking to improve communication and support caregivers.

Apps for recording future wishes to provide autonomy and reduce the burden on family members.

Technologies that maintain normality, independence, and support relationships, enhancing quality of life.

Adaptable, user-friendly devices designed to support changing abilities and one-sided disability.

Continuity of care

A person living with MND proposed a digital 'hub' where care needs could be recorded and updated by the individual or their caregiver, then securely shared with care or medical professionals. To be effective, it would need to be adaptive to the progression of MND and include accessibility options like voice-noting, and include language translation tools to support effective two-way communication with carers or staff with limited English.

Hand spasticity

Hand spasticity can make it difficult to hold a pen and write, and spasms can be very painful and difficult to 'unlock' without assistance. One person suggested 'handwriting banking' to help preserve a person's sense of identity by enabling typed or dictated messages to appear in their own handwriting. A wearable device to independently relieve hand spasms was also proposed, providing both pain relief and increased autonomy.

Managing immobility

A participant suggested passive exercise machines to simulate movement, which could help alleviate fluid build-up in the legs, or other immobile areas of the body.

Monitoring breathing

Continuous carbon dioxide sensors could help alert individuals or caregivers before dangerous episodes occur, enabling timely intervention – reducing associated fatigue and improving wellbeing.

Understanding progression

Caregivers expressed the need for digital tools that can track symptoms and predict progression. One proposed an app to log changes over time, supporting conversations with healthcare professionals and enabling better planning of care.

ALS-FTD specific needs

For people with ALS-FTD, an app providing simple explanations of MND symptoms during moments of confusion could help improve understanding. Symptom and behaviour trackers could also help caregivers to communicate more effectively with healthcare professionals.

Communicating wishes

An app for recording future wishes would allow people living with MND to maintain a sense of control over their future and end-of-life decisions. Such a tool would help ensure their preferences are respected, as well as reducing the practical and administrative burdens on families during the difficult time after their loved one has passed away.

Improving quality of life

Technologies that support independence were seen as vital. One person described their stairlift as 'the most valuable' piece of technology in their home, allowing them to move freely and reducing reliance on their spouse, helping to preserve a sense of balance in their relationship.

Adaptation and resilience

A caregiver highlighted the value of technologies that people can adapt as their abilities change. For example, when their family member lost dexterity in one hand, they attached household objects to that hand. They suggested that wearable devices for one-sided use could be especially helpful in cases where disability progresses asymmetrically.

“ You need to make them accessible, and possible to be used for as long as you can.”

Person living with MND



3 Barriers to technology use in MND

Discussions highlighted a range of barriers that prevent people living with MND and their caregivers from making the most of available technologies. These reflected both the practical realities of living with a fast-changing condition and the systemic challenges in accessing and supporting appropriate tools.



Summary of key barriers:

Accessibility: Age, dementia, and language barriers make digital tools difficult to use without simple, intuitive, or translated interfaces.

Progression of MND: The fast-changing nature of the disease limits the usefulness of many devices, which may arrive too late or quickly become ineffective.

MND-specific design: Devices must be lightweight, comfortable, and operable with minimal strength or dexterity.

Access and availability: Provision varies across regions and depends heavily on healthcare professionals' knowledge of MND.

Lack of personalisation: A one-size-fits-all approach is ineffective; individuals need patient-led choices at the right time for them.

Training and support: Without tailored training or simplified versions, even potentially helpful technologies can go unused.

Reliability: Failures in vital devices, such as communication tools, can be deeply disruptive, underscoring the need for reliable products and accessible repairs.

Perceptions and attitudes: Assumptions about rapid progression and limited life expectancy can limit proactive adaptations from healthcare providers and workplaces.

Accessibility considerations

Participants noted that technologies rarely account for the wide variation in age, comorbidities, and language needs across the MND community. Because the condition is both rare and highly variable, many existing tools are not designed with this group in mind.

Rapid progression and timeliness

The unpredictable speed of progression can mean that technologies are only useful for a short period. Receiving a device too late – or when it's no longer fit for purpose – was described as more frustrating than not receiving one at all. Adaptable tools that evolve with the users' changing needs are essential.

MND-specific design needs

Devices must accommodate declining strength, dexterity, and fragile skin. Heavy or bulky devices are unsuitable, and wearables must be easy to put on and remove independently. Technologies such as voice-activated tools may also lose relevance as speech deteriorates, underscoring the need for adaptable design.

Waiting times and access

Long delays in receiving equipment, such as power wheelchairs, leave many without timely support. One person described how they were advised to apply for a power wheelchair a year in advance, which they found distressing as it forced them to confront future needs prematurely. By the time the equipment arrives, it may no longer be suitable, highlighting the disconnect between service timelines and the fast-changing nature of MND. Access also varies depending on geography and the expertise of healthcare professionals, particularly occupational therapists.

Personalisation and trialling equipment

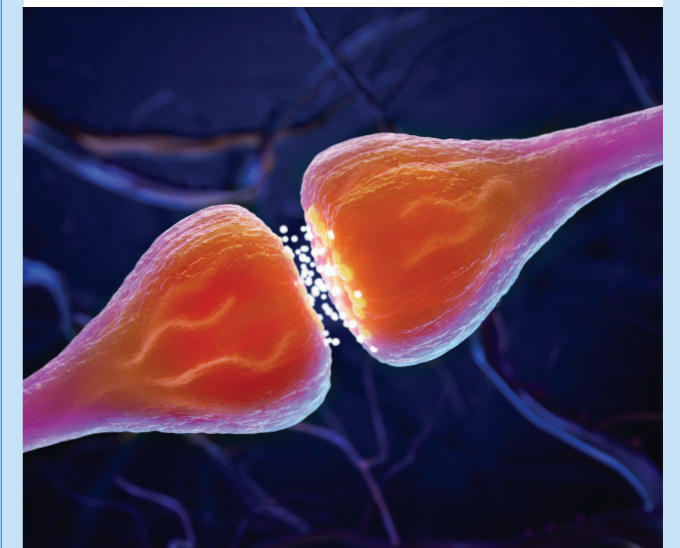
A lack of personalised approaches to technology access was seen as a major barrier. Without the chance to test devices, people risk buying costly tools that prove unusable or helpful only briefly. A "library of things" model was suggested to enable trialling before committing.

Training and support

Digital technologies often require extensive training to be used effectively. Without built-in guidance or an accompanying training programme, many apps are not accessible or fit for purpose. Participants emphasised the need for simplified versions, ongoing training, and infrastructure that supports both users and caregivers.

“ Whilst all these technologies are being developed and that's amazing, the infrastructure around it needs to be as powerful as the technology. The people that are giving it to the carer or the person living with MND need to be fully trained and proficient in helping, answering questions and understanding the frustrations people feel in using it.”

Bereaved caregiver



Reliability and failures

Technology failures can be devastating for people with MND, particularly when they impact vital functions such as communication. Devices must be robust, with specialist repair and accessible assistance hubs readily available.

Attitudes and assumptions

Finally, negative perceptions of MND – including assumptions of rapid decline and limited life expectancy – were reported as barriers to adaptation in both healthcare and workplace settings. Participants stressed that proactive and flexible support should not be withheld based on prognosis.

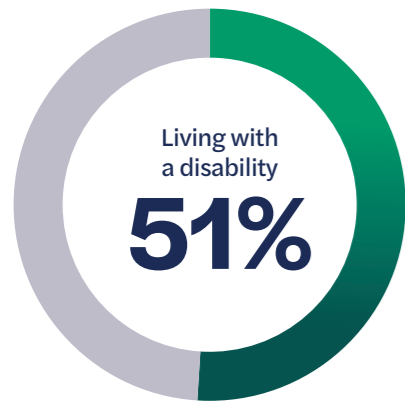
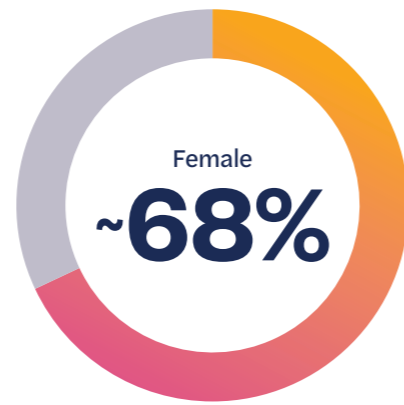
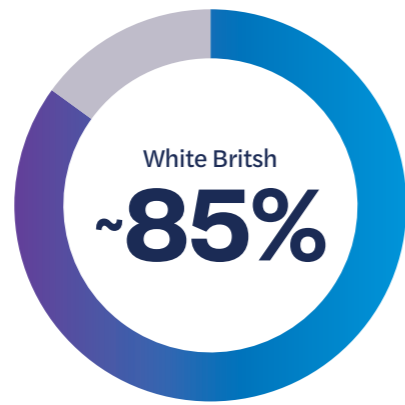
Insights from the community survey

Our community survey provided perspectives from the wider MND community on daily life challenges and attitudes towards technology.

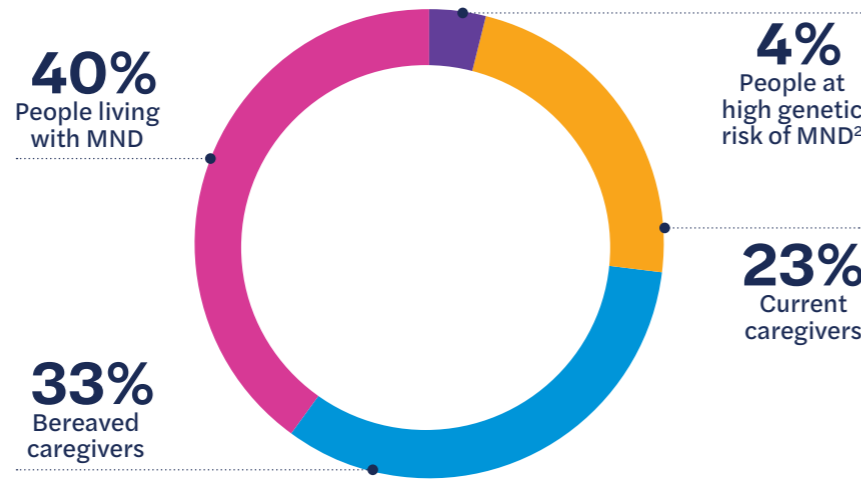
A total of 114 complete responses and 91 incomplete¹ responses were received, with all participants who answered at least one question included in the analysis.

Participant demographics

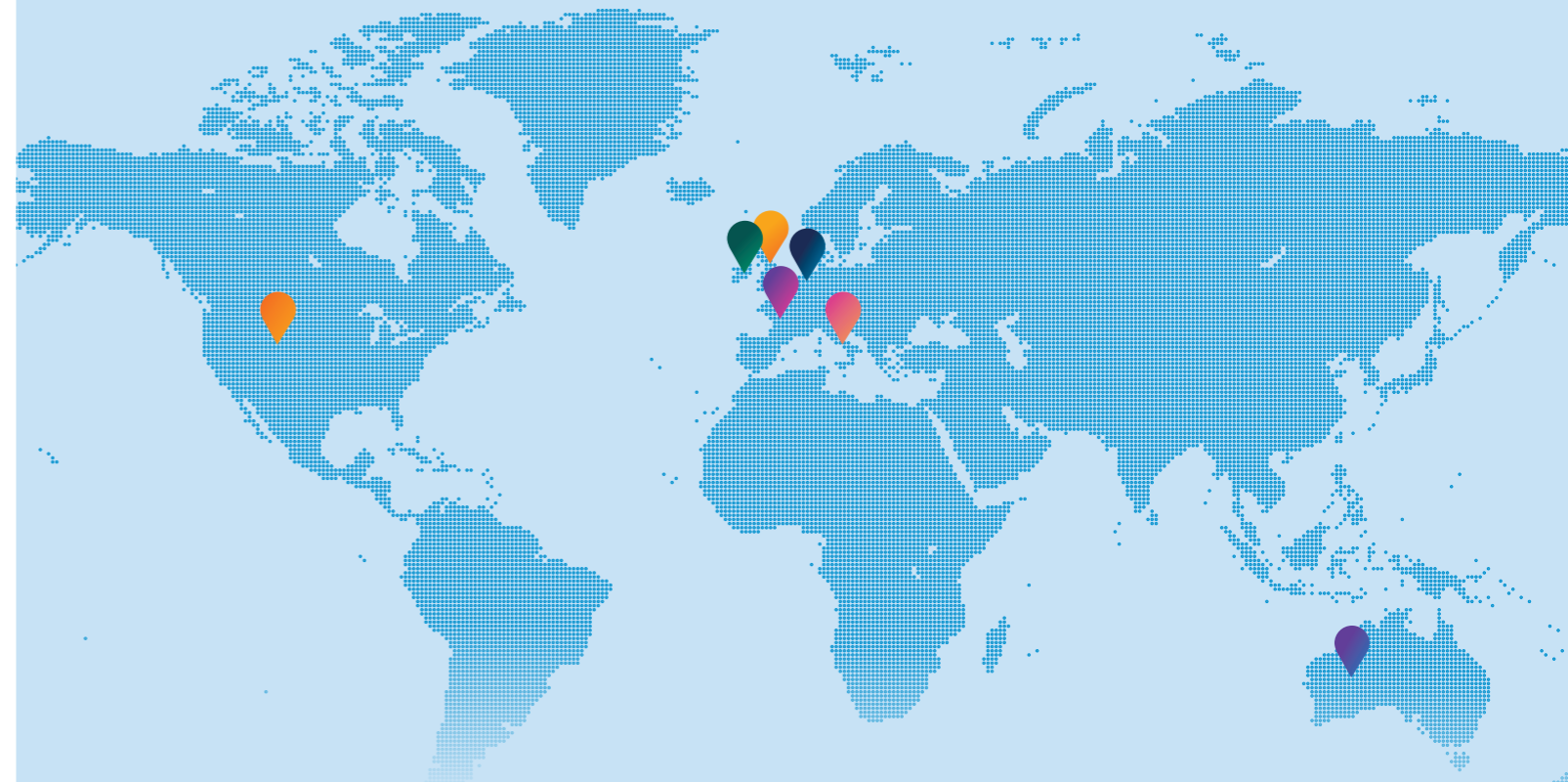
Most respondents were aged between **40-69**



Respondents included people affected by different subtypes of MND, including ALS, PLS, PMA, PBP and ALS-FTD, with time since diagnosis ranging from **less than six months to five years or more.**



¹Responses were marked 'incomplete' if the participant had only partially completed the survey and not pressed 'submit' at the end.
²Questions for this group were focused on their awareness and comfort with technology, its perceived usefulness and barriers.



While most participants lived in different geographical locations across the UK, 12 respondents were international (7 from the USA and 1 each from Australia, France, Ireland, Italy and the Netherlands).

Summary of key learnings:

The biggest daily challenges reported were MND-related symptoms, emotional and mental wellbeing, mobility and fine motor skills.

Most participants believed technology could improve quality of life and help address everyday challenges, particularly with mobility and communication.

Emotional wellbeing was recognised as important, but seen as less amenable to technological solutions.

Awareness of existing technologies for mobility, communication, and breathing support was relatively high, but many felt these tools needed improvement.

Barriers to technology use included difficulties with hand function, reliance on others, difficulties with setup or installation, and tools being overly complex or not user-friendly.

Comfort with technology varied considerably. People with MND were generally more comfortable with smartphone apps and computer-based tools, but found Eyegaze and voice commands more difficult.

Q1: What are the biggest challenges in your daily life with MND?

Participants were asked to identify the biggest daily challenges they, or the person they care(d) for, experienced in everyday life. They were presented with a multiple-choice list, grouped into six categories, and could select as many options as they felt were relevant. The table below lists all of the response options:

Category	Daily challenge response options
Communication	Not being able to talk, slurred or faint speech, difficulties with gesturing and expression, unable to use communication aids.
Problems with fine movements	Problems with writing, problems with typing, problems with dressing (opening and closing zips and buttons), problems with eating (holding cutlery, cutting food).
Mobility	Problems with walking, problems climbing stairs, problems with turning in bed, tripping and falls, using a wheelchair for most of the day, being in a chair or bed for most of the day.
Continuity of care	Communicating care needs to external carers (e.g. after a change in care personnel), effective communication with healthcare professionals (e.g. during consultations with specialists), transportation to appointments, getting the support needed at the right time.
Emotional and mental wellbeing	Changes in emotional responses or fast changes in mood (emotional lability), changes in thinking and behaviour (cognitive changes), problems with memory or dementia, irritability, anxiety, depression, changes in concentration, confusion, social isolation.
MND-related symptoms	Poor sleep quality, breathing difficulties, problems with swallowing or salivation, fatigue (extreme tiredness), pain, problems with muscle control, bowel and bladder problems.

For people living with MND and current caregivers, the biggest challenges were:

MND-related symptoms: including fatigue, problems with muscle control, poor sleep quality, problems with swallowing and salivation, and breathing difficulties.

Emotional and mental wellbeing: anxiety and social isolation were the most important challenges, followed by emotional lability and depression.

Mobility: including turning in bed, walking, and climbing stairs.

For bereaved caregivers, the biggest challenges were:

Mobility (problems with walking, climbing stairs, tripping and falls), problems with fine movements (challenges with eating and dressing), and MND-related symptoms (problems with muscle control, fatigue, and poor sleep quality), especially early in the disease. At later stages of the disease, other MND-related symptoms (breathing difficulties and problems with swallowing and salivation) were considered the biggest challenges, followed by communication (problems with talking, gesturing and expression, and use of communication aids) and other challenges with fine movements (problems with typing, writing and eating).

Q2: Which challenges most affect quality of life?

Participants were asked to identify the daily challenge that most affected their quality of life in a free text answer. Their responses were diverse and varied, highlighting the wide range of deeply personal experiences with MND, but several common themes emerged:

Mobility challenges significantly affect independence and the ability of people living with MND to carry out everyday tasks, with bereaved caregivers highlighting the emotional toll of this increased dependence.

Speech and communication difficulties create frustration and isolation for people living with MND.

Physical discomfort and pain are a major issue, particularly for current and bereaved caregivers, but less commonly mentioned by people living with MND. These symptoms are often inadequately addressed by healthcare providers.

Emotional and psychological impact is a shared experience, with both people living with MND and their caregivers reporting mental health struggles such as sadness, anxiety and depression.

Social isolation can result from communication and mobility difficulties that make it challenging for people to engage in social interactions or leave the home.

Loss of former lifestyle and enjoyed activities, such as hobbies, outdoor activities, outings and social gatherings, contributes to feelings of frustration and depression for people living with MND.

Dependence on caregivers for daily tasks and personal care is mentally and emotionally challenging for both people living with MND and caregivers, who report frustration and feelings of helplessness.

Inadequate support and care, such as delays in diagnosis, lack of understanding among healthcare professionals, and inconsistency in care, were a common concern, particularly among bereaved caregivers.

Financial and practical difficulties related to the cost of care create significant strain, with caregivers highlighting the broader impact on wellbeing and quality of life.

Q3: Would technologies help to improve quality of life?

More than 60% of respondents across all groups believed technology could significantly improve quality of life by helping with most daily challenges. While the specific priorities varied slightly between groups, the greatest potential was seen in mobility, fine movements, continuity of care, symptom management and communication. In contrast, respondents considered emotional and mental wellbeing as an area where technology was less likely to help. While some saw possible benefits in reducing social isolation or managing anxiety, many felt technology had limited potential to support emotional and psychological needs.

Q4: Are you aware of existing technologies to help with daily challenges?

Participants were generally aware of technologies for mobility, communication and breathing, but 40 to 60% felt they needed improvement. In contrast, there was low awareness of tools supporting other MND-related symptoms such as fatigue, problems with muscle control, poor sleep quality, bladder and bowel problems, and pain.

Q5: How can technologies help with daily challenges?

Across all groups, communication and mobility emerged as the daily challenges where participants most wanted technological support. Current caregivers and people living with MND also emphasised breathing difficulties as a major area of need. Problems with swallowing and salivation, and pain management, were also frequently mentioned by both current and bereaved caregivers.

Among people at high genetic risk of MND, continuity of care and fine movements were identified as other key challenges where technology could play a valuable role.

Q6: How comfortable are you with using technologies?

People living with MND were generally comfortable with typing, smartphone apps and computer-based programmes, but many were less comfortable with using voice commands or dictation. Eyegaze technology did not apply to many participants, indicating either that many had not used it or had not been introduced to it as an option. Among those who had used this technology, about half reported they were either unable to use it or were not comfortable using it.

Current and bereaved caregivers described varied experiences regarding their loved ones' comfort with technology. Some noted comfort with smartphone apps and virtual consultations, while others described significant difficulties with typing, touchscreens and voice-based tools. People at high genetic risk reported general comfort with all technologies (although Eyegaze was not assessed for this group).

Q7: What are the challenges with using digital health technologies?

The most common challenges were difficulty using hands, needing help from someone else to use the technology, problems with setup or installation, and technologies not being user-friendly.

Free-text responses detailed a variety of barriers.

Physical difficulties related to MND: Loss of hand function, muscle strength, spasms, and fatigue significantly limit the ability to use most devices, especially those requiring hand dexterity.

Slow input to communication devices: Input into augmentative and alternative communication (AAC) devices is often slow, making real-time conversation difficult.

Technical setup and usability issues: Many devices are hard to set up and adjust. Eyegaze was highlighted as particularly challenging to use for people who wear glasses, due to difficulties in eye tracking by the software.

Lack of training or support: Insufficient instruction on how to use assistive technologies hinders effective usage.

Access and integration barriers: Access to some technologies is tied to employment and becomes unavailable once a person stops working, as they are often not integrated with personal devices.

Emotional resistance: to learning new technologies before it was necessary, making it challenging to adopt these tools when needed.

Unsuitable or late equipment provision: Equipment was often not available in time or was unsuitable for their living spaces and specific needs.

Caregiver overload: Managing technology adds to caregivers' already significant responsibilities and can be overwhelming.

Generational and technological discomfort: Many caregivers mentioned the age of the person they cared for and that they are not from a generation comfortable or familiar with digital technology.

Need for simple solutions and support: There was a strong call for simpler technological solutions with clearer instructions and hands-on support.

Combined analysis

Insights from the workshop and the community-wide survey reveal consistent themes about the realities of daily life with MND and the role technology could play in offering support.



Rapid and unpredictable progression of MND

Participants stressed that devices must be introduced in time, but also remain adaptable as needs evolve. Many reported that existing tools – such as mobility or communication aids – often arrived too late or were only effective for a brief period, leading to frustration, wasted resources and missed opportunities to improve quality of life.

Continuity of care

Both people with MND and caregivers described the exhaustion of repeatedly explaining highly individual needs to unfamiliar staff across home, hospitals and hospice settings. A proposed solution was the development of a digital 'hub' to securely record and share personalised care information, ensuring consistency across services and reducing the burden on people living with MND and caregivers.

Accessibility and usability

Reduced dexterity, muscle weakness and fatigue can make it difficult to type, use touchscreens, or operate devices independently. Systems such as Eyegaze or voice commands were seen as promising, but often challenging to use in practice – due to physical limitations, complexity, or inadequate training. Participants consistently called for lightweight, simpler, intuitive technologies, supported by clear training and ongoing technical assistance.

Communication

While aids such as text-to-speech and eyegaze can be useful, their effectiveness depends heavily on timing and adaptability. For people with ALS-FTD, additional challenges arise from cognitive symptoms, which can make it difficult to recognise or understand symptoms and complicate communication with healthcare professionals.

Emotional and mental wellbeing

This featured prominently, especially among caregivers, who reported high levels of stress and isolation but little tailored support. While technology was not generally seen as a solution to these challenges, participants acknowledged that certain tools – such as apps to preserve voice or handwriting, record future wishes, or facilitate social connection – could offer meaningful support.

A more personalised approach

Many felt that current systems are rigid, offering generic solutions that do not reflect individual needs or preferences. Suggestions such as 'library of things' for trialling assistive devices were seen as ways to help people find the right tools more efficiently.

Case study

Co-creating CognoMND™ with people with lived experience

CognoMND™ is an innovative AI-based tool currently in development. It aims to detect cognitive and behavioural changes in people living with MND earlier and make access to support easier.



Understanding the need

Cognitive and behavioural changes affect up to half of people living with motor neuron disease (MND), influencing thinking, decision-making, emotions and communication. These changes can appear before or alongside physical symptoms, and can have a profound impact on daily life for both individuals and their families.

Yet, despite their importance, these issues are often overlooked. Few people with MND are offered a cognitive assessment, and access to appropriate mental health or behavioural support is limited. Earlier detection could help people and their caregivers better understand what is happening, plan for the future, and access timely advice and support.

What is CognoMND™?

CognoMND™ is an online assessment tool designed to identify early changes in cognition (thinking abilities) and behavioural change in people living with MND. It is an adaptation of CognoSpeak, a digital toolkit designed to detect early cognitive decline in conditions such as dementia. It has been proposed that CognoSpeak could be adapted to help better support people with MND who currently lack opportunities for cognitive assessments and mental health support.

CognoMND™ aims to detect subtle changes in areas commonly affected by MND, including attention, language, and social reasoning. The tool is designed to be used independently at home, guided by a computer-generated digital doctor that asks questions and records responses.

These are then automatically analysed to identify signs of change as well as any indications of depression and anxiety that might otherwise go unnoticed.

Unlike traditional assessments, CognoMND™ is fully automated and can be completed at home without clinician involvement. It has the potential to support earlier interventions, improve care, and reduce the burden on families and clinical services.

How are people with lived experience shaping this tool?

The CognoMND™ team is committed to co-designing this new tool in partnership with people affected by MND and their caregivers. This partnership has included:

- **Qualitative interviews** exploring attitudes to cognitive testing in MND.
- **A Lived Experience Advisory Steering Group** providing ongoing guidance to keep development grounded in patient perspectives.
- **Patient and public involvement and engagement (PPIE) workshops** bringing together people affected by MND and caregivers to shape design and usability.

These sessions have provided detailed feedback on everything from the look and feel of the interface to the wording of prompts and the design of individual tasks. The team is using this input to refine how the tool operates, ensuring it is more accessible, more intuitive, and better aligned with the realities of life with MND.

“The feedback from the MND Insights Group is vital. It allows us to shape CognoMND™ around the needs and challenges experienced by people living with MND, to ensure the tool is not only innovative but also acceptable, fit for purpose and supportive for people living with MND and their families.”

Lise Sproson, NIHR HRC in Long-Term Conditions (Devices for Dignity)

MND Insights Group workshop

In July 2025, the MND Insights Group met with Lise Sproson, the patient and public involvement and engagement (PPIE) lead for the National Institute for Health and Care Research (NIHR) HealthTech Research Centre (HRC) in Long-Term Conditions (Devices for Dignity) to discuss the tool’s development and share personal experiences of cognitive and behavioural change.

Changes to thinking and behaviour

Participants described a wide range of challenges, including memory problems and reduced concentration. In some cases, particularly where frontotemporal dementia (FTD) is present, these symptoms appeared before physical signs of MND. Despite this, most people reported never being offered a cognitive assessment. Support for mental health or cognitive changes was very limited, leaving many people living with MND under extreme mental strain and feeling neglected.

Using CognoMND™

Feedback on CognoMND™ was constructive and thoughtful. Participants welcomed the idea of early detection, and the potential value in tracking disease progression, supporting mental health and monitoring the impact of future treatments. The group also highlighted concerns about self-assessment without clinician support, lack of follow-up care, accessibility for those with speech loss or using Eyegaze technology, and the need for clear explanations of how results are interpreted. Caregivers emphasised that they often notice subtle changes first and should be included in the process.

The team will consider and utilise the feedback from the Insights workshop to inform further development of the CognoMND™ tool.

Lessons learned

Engaging with the MND Insights Group has been crucial for the development and future implementation of

CognoMND™. The team was made aware of the critical needs of individuals and families managing MND and important suggestions were made to significantly improve the development of the CognoMND™ platform to ensure that it is usable, beneficial and suitable for all to use. We hope that this feedback and report will help others develop future innovations for families living with MND.

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Find out more:

For further information on the project, please visit the project website: www.cognospeak.com/cognoMND

If you have questions or may like to consider taking part in the study, please contact the Project Manager for the project, Dr Clare Bartlett (c.bartlett1@nhs.net).

Key recommendations for technology development in MND

The following recommendations outline the key considerations for developing new technologies that can deliver meaningful support for people living with MND and their caregivers.

1

Prioritise usability and independence

Technologies should be simple, lightweight, and intuitive, requiring minimal setup and training. Designs must accommodate limited dexterity, muscle weakness, and fragile skin, avoiding bulky or uncomfortable devices. Wherever possible, tools should be operable without caregiver input, enabling individuals to maintain independence and reducing pressure on caregivers.

2

Design for adaptability and personalisation

Given the rapid and unpredictable progression of MND, devices must have the ability to evolve with the user. Communication aids, for example, should offer seamless transitions from supporting speech early on to alternative modes as speech declines. Technologies should include customisable settings, allowing individuals to decide when and how to adopt new tools in line with their changing needs, preferences and readiness.

3

Improve access and support

Access to equipment should be faster and more consistent, with reduced waiting times and systems that match the pace of disease progression. Models such as lending libraries or “try before you buy” can help individuals trial devices before committing to them. Clear, accessible training and ongoing technical support are vital, tailored to different levels of digital confidence. Inclusive features, such as translation tools, should also be incorporated to support carers and staff who speak English as a second language.

4

Strengthen continuity of care

Technologies should integrate seamlessly into care pathways, enabling secure sharing of personalised information across settings. By reducing duplication, improving communication, and supporting care teams to quickly understand individual needs, well-designed tools could enhance both quality of care and patient experience.

5

Challenge limiting attitudes

Finally, technology development must be accompanied by cultural change. Assumptions about rapid decline or short life expectancy often limit access to appropriate support. Raising awareness among healthcare providers and employers of the variability of MND, and the potential of well-designed technologies, is critical to ensuring people receive timely, proactive, and dignified care.

Conclusion

This report highlights the vital role technology can play in supporting people with MND and their caregivers. Feedback from the MND Insights Group and a community-wide survey revealed that while current tools can provide support, they are often introduced too late, too complex to use, or poorly aligned with the realities of living with MND.



Participants emphasised the need for technologies that are simple, adaptable, and responsive to the rapid and unpredictable progression of MND. Tools must remain useful across different stages of the disease, support independence, and be accessible for those with limited dexterity, fragile skin, or impaired speech. People called for better training and ongoing support, timely access to equipment, and more personalised approaches that allow them to test and adopt tools at their own pace.



Communication and mobility were seen as key priorities where technology could offer meaningful support, alongside technologies that help preserve identity, autonomy, and dignity, and reducing social isolation. Caregivers also highlighted the need for more integrated solutions – such as digital care hubs and symptom trackers – that would help ease their burden and improve continuity of care.



Above all, these findings underline that meaningful innovation will only be achieved by embedding lived experience into every stage of development. By listening to the voices of people living with MND and their caregivers, and fostering collaboration between researchers, developers, and healthcare providers, new technologies can become truly transformative – helping to improve dignity, autonomy, and quality of life for those affected by this debilitating condition.



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- MND Scotland
- My Name's Doddie Foundation

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