



# COLLABORATION COMMUNITY WORKSHOPS

Promise five: No one faces MND alone

## AT A GLANCE

### HOW MANY?

3 workshops in total.

### WHEN?

January, February and April.

### WHO ATTENDED?

Collaboration Community members.

The numbers varied from workshop to workshop.

### FACILITATORS

Domonique Dickens  
Participation and Engagement Officer

John Gillies-Wilkes  
Head of Inclusion and Wellbeing

## OBJECTIVES

To understand how we can reach people who don't currently use our services.

To identify areas of the NHS or social care that are not as accessible for people with and affected by MND.

## APPROACH

Each session covered one open question about accessibility and inclusion.

**LESSON LEARNED:** Initially, we had planned to work through three questions during the first workshop. However, with around 20 people attending it was difficult to hear from everyone and discuss all three questions. We decided as a group that instead of covering all three questions in one session, we would concentrate on the first question and come together again in four to six weeks to cover the next question and so on.

Attendees were invited to share their lived experiences, suggestions for improvement and ideas on the session question.

## RESOURCES AND FOOD FOR THOUGHT

### Resource

We used an online tool called Padlet to collect responses and feedback.

### Food for thought

At the end of each session we gave attendees a question to consider before the next session.

Attendees were invited to add their thoughts to a Padlet board, or share when we came together again.



# WORKSHOP ONE

How can we reach people who don't use our services to let them know what is available?

## KEY TALKING POINTS

A focus on the diagnosis process with attendees recounting their own diagnosis experiences. The general consensus is that diagnosis takes too long to receive and the sharing of information from health and social care professionals at this point can vary.

This led to an in-depth discussion about the information that is shared when someone is first diagnosed with MND. We touched on how relevant or useful the information was at the time and brain stormed how we can make this process more streamlined to ensure everyone gets the same information and signposting at the time of diagnosis.

We also discussed geographical restrictions to accessing services and the impact this has on the person living with MND and their families. Local support meetings can sometimes be quite a distance to travel to, meaning those who need or would like to attend aren't able to.

## TAKE - AWAYS

### Attendee take-aways

We explained the work currently underway to improve access to quality assured multidisciplinary care. We want this support to be available to all people with MND at the point of referral to a general neurologist and throughout their MND journey.

Some attendees were not aware of the NICE guidelines. They were signposted to the Association website to find out more.

We informed the group about the red flags tool and resource that is available on our website.

**FACT:** In the average GP's career, they will see 1 case of MND.

### Association take-aways

A lot of branches and groups offer both in-person support group meetings as well as virtual meetings, but this could be offered as a standard to ensure accessibility and inclusion to all. There was a suggestion to have local WhatsApp groups set-up as a way to keep in touch between meetings. We will look at how we can work with branches and groups to support them with digital tools such as WhatsApp, Zoom and other online platforms.

The diagnosis process is a high priority and most discussed topic within the MND community. As an Association we take this very seriously and are working collaboratively both internally and externally to help improve the diagnosis of MND.

## AT A GLANCE

### WHEN?

January.

### WHO ATTENDED?

21 members in total attended.

### FOOD FOR THOUGHT

We asked workshop attendees to consider the question: *What one thing can I do today to make the Association and my part in it more inclusive?*

Attendees were asked to share their ideas on a Padlet board. We re-visited this board at the start of workshop two.

## FEEDBACK

*"There's a lot on the website but people need to know about it - a letter of welcome, a letter of we're here for you."*

Emma MacLennan - workshop participant

As part of the recommendations from this workshop and the result of the Support Grant Evaluation, our webpages are something we will be updating to make the information about grants more clear and concise.

*"The MND forum is absolutely brilliant for ideas and suggestions - clothing even!"*

Denise Roper - workshop participant

We know the power of community and we are working to provide more opportunities for the MND community to come together to connect and support each other.

# WORKSHOP TWO

From your experience are there any particular health and social care inequalities faced by people with and affected by MND?

## AT A GLANCE

### WHEN?

February.

### WHO ATTENDED?

9 members in total attended.

### FOOD FOR THOUGHT

We asked workshop attendees to consider the question: *From your experience are there any particular health and social care inequalities faced by people with and affected by MND?*

Attendees were asked to share their ideas on a Padlet board. We re-visited this board at the start of workshop two.

## FEEDBACK

*"Receiving information about grants and fundraising at the same time gives a mixed message."*

Anonymous - workshop participant

This information has been shared internally across a variety of teams. We will work to review our messaging and ensure it is consistent throughout the communication.

*"Has there been much research into MND and the affects air pollution can have on a person who is living with the disease?"*

John Summerhayes - workshop participant

A review from March 2023 states "the growing literature on environmental factors in ALS (MND), particularly exposures to the surrounding environment, such as urbanization and air and water pollution, has yet to be fully appraised and presented in a systematic review."

## KEY TALKING POINTS

During the second workshop in this series, we discussed available financial support including Association support grants and loans. We also spoke about Government funded support such as Continuing Health Care (CHC) and Personal Independence Payment (PIP). Some attendees were not aware of at least one of these payments.

There is an element of information overload at the start of the journey. Attendees expressed there is a need to be taken through the relevant information at the right time.

There is a geographical inequality in the Association Visitor (AV) support available. Some people do not have an assigned AV due to unavailability in their area.

## TAKE-AWAYS

### Attendee take-aways

We explained to workshop attendees that Association support grants and loans are not means-tested.

We signposted people to more information on our website relating to CHC and PIP. We also advised there is an option to 'fast-track' new PIP applications to reduce wait times.

**TIP:** You can get an "i am non-verbal" card from the [Hidden Disabilities website](#).

### Association take-aways

Several people expressed a preference for oral discussion and information sharing. Whilst some said they would prefer to receive information in writing. We are actively considering how we can provide a combination of both written and oral information.

We are also reviewing how we display our information. Taking feedback into consideration, we are discussing the potential to present information in a layered approach - as opposed to all in one place. That way, people can interact with snippets of information as and when they need to.

There is a general need for practical and financial advice alongside medical and clinical advice.

50%+ of attendees did not know about CHC support. We will take this point away and work internally to ensure messaging around available financial support is clear.

# WORKSHOP THREE

What in your experience are the main barriers to participation in Association activities?

## KEY TALKING POINTS

The third workshop in this series invited attendees to share what they thought are the main barriers to participation in Association activities. Throughout this session we discussed travel difficulties and how this can restrict attendance to events such as support group meetings, fundraising activities and Association events.

We also heard from participants who highlighted the need for a more hybrid approach to available support. Some suggestions shared included integrating a 'chat' function to the MND Connect support line and ensuring people have sufficient time to communicate using the channel or method of their choice.

When discussing

## TAKE-AWAYS

### Attendee take-aways

Many of the attendees were not sure if their local branch or group had the option to attend a support meeting online. We encouraged people to find out if this was an option available to them.

Most Association events that take place online are recorded. This is because we understand not everyone is able to attend a call, webinar or workshop at the time it is scheduled, but still wish to hear updates and contribute towards the discussion. We recommend individuals speak with whoever is running these online events to see if a recording is available.

### Association take-aways

In most cases, participants shared the view that an element of scene-setting would be beneficial when branches or groups invite a newly diagnosed person with MND to a support group meeting. There is some hesitancy to attend the first support meeting as people are not necessarily informed what to expect. Suggestions were made to send an explanatory email/letter when inviting someone to attend their first support group meeting. This letter could include information on things such as the format of the meeting, who will be there and any topics of conversation that will be covered.

All workshop attendees agreed there is a need to provide support via a web-chat function. Currently, MND Connect is only available on the phone. A web-chat or instant messaging function would be most welcome - particularly for individuals who have lost, or are losing, their voice. Links can be shared, chats could be saved locally. Both of these functions would allow the person to revisit the guidance and information in their own time.

## AT A GLANCE

### WHEN?

April.

### WHO ATTENDED?

9 members in total attended.

### FOOD FOR THOUGHT

We asked workshop attendees to consider the question: *What in your experience are the main barriers to participation in Association activities?*

Attendees were asked to share their ideas on a Padlet board. We re-visited this board at the start of workshop two.

## FEEDBACK

*"Since the pandemic I think people have gotten more comfortable using technology."*

Robert Oates - workshop participant

Advancements in technology as well as increased exposure to using online tools has helped people gain confidence online. We have seen this echoed in the formats of branch and group support meetings - a lot of branches and groups offer both in person and online support.

*"It would be great if MND Connect had a chat function."*

John Nelson - workshop participant

As an Association, we are working to support different methods of communication. A web-chat/instant messaging function is something we have been reviewing internally and we hope to establish in the future.



# SUMMARY

Summarizing the Promise Five workshop series

## THANK YOU!

Thank you to all for attending this workshop series.

This series was the first of its kind as part of the Collaboration Community and was a great opportunity to come together to share and learn.

We appreciate you taking the time to attend the workshops and are grateful for your input and willingness to share your experiences and suggestions for improvement.

## FEEDBACK

*"I like listening, thinking about what I've heard and then responding by email. It suits me best and is less stressful. I am keen to participate and help in any way I can."*

Sue Vale - workshop participant when discussing the best approach for her input to the sessions.

*"These workshops have been invaluable, the two way conversations have increased my awareness of how things work on the ground and really helped inform my thinking"*

John Gillies-Wilkes - Head of Inclusion and Wellbeing at the MND Association

## WHAT WE LEARNED

We have taken away some key items from each session, and will be discussing actions and next steps with the appropriate teams. As items progress and updates become available, we will be sure to let you know.

We learned about restrictions people experience when invited to attend a local event or Association event, including suggestions for improvement. We heard from attendees about the sometimes mixed messaging they receive from us. The support received from MND nurses, neurological nurses, and Care Centres had a significant impact on people living with and affected by MND. MND Connect, the MND Association's forum and MND groups on social media were also cited to be immensely helpful resources when navigating the MND journey.

## WHAT WENT WELL

During the workshop series, we used an online tool, Padlet, to help capture thoughts in the form of 'posts' between workshops. These posts are visible to everyone that visits the Padlet board and can be multi-media. For example, you can add an image, PDF, link and more to the post to capture the readers attention and add personality to the post.

We asked workshop attendees to add to a Padlet board asking individuals to 'Introduce yourself'. The group were then able to interact with each post by commenting or liking the content (similar to most social media platforms). This allowed participants to connect with one another away from the sessions themselves and find common interests, allowing them to build rapport.

## WHAT COULD BE DONE BETTER

The workshops were mainly free-form, meaning there was no set agenda for each session. We simply came together and chatted about the session topic. In future sessions, I would be inclined to set more of an agenda or structure the sessions in a way that encourages people to share, but also provides attendees with guidance on how the session will go.

Time was also a potential issue and sometimes the session closure felt a little rushed. I would look to increase the amount of time for each session by 30 minutes - totally 1.5 hours.