

Notes from Service User Focus Group meeting – 16th July 2025

Welcome

Attendees:

MDSC Staff: Ruth Hereford, Lysa Ralph, Nina Hanks

Attendees: Frank Sturzaker, Donna Scarrott

Apologies: Bhavesh Taylor, Mark Thompson

Nina welcomed everyone to the meeting.

Follow up actions from last meeting

Nina reminded everyone that we had discussed social activities in the extended space in the last meeting. A list of suggested social activities had been sent to the attendees who were asked to review it and come up with ideas on how to facilitate more social groups.

In light of the closure of unit 9, Nina mentioned that any new social activities would need to wait and be reconsidered until we have reconfigured our old space.

Nina enquired whether attendants had a chance to look at the list and how we could take things forward despite having a smaller space.

Attendees did not have a chance to look over the activities list yet.

ACTION:

- **Nina to feedback the ideas for social activities to the team to consider with the smaller space in mind**

Introduction

Lysa started by introducing herself. She explained that she has been involved with the charity's fundraising team for some time and is currently helping to shape the next 5-year strategic plan. Lysa is currently collating ideas from the team and service users that will all feed into prioritising plans for the next 12 months and further.

Given the huge growth of the charity over the last strategy period, the focus of the first year of the strategy will be on consolidation – focused on improving systems and processes to create a firm foundation for moving forward. This means a focus on improving what we are already doing, with no new projects progressed until after the summer of 2026.

Centre Update:

Ruth joined the meeting.

She started by updating the group on the ongoing recruitment for a new CEO. At the point of the meeting, the Centre was going through the stages of offering the role to a candidate and checking references. More information will be made public soon.

Discussion: Future of Focus Group

Ruth explained that she wants the Focus Group to become a bigger part in not only shaping our strategy but in being part of the process of change. We want to make sure you are not just feeding in ideas but can follow the cycle of how this get shared with the team, how it is actioned and what the results are.

Ruth asked for feedback from attendees of the group.

Frank feels that the meetings are a bit fractured given the time between meetings and not many actions taken. He would like to contribute and get involved more but feels that organising anything is a challenge due to our community being large and spread widely geographically and not fully engaged in the social or logistical side of the charity. Volunteering can be hard as everyone leads their own life.

Donna agreed that 3 months in between meetings is long. Both point out that actions taken by the team are not very visible or communicated well. Donna suggested that we make our action points, steps to be taken and achievements more visible to everyone by introducing a board in the Centre, as she successfully does this withing the NHS disability network.

Another suggestion by Donna were feedback forms, that could be quite useful information if service users were encouraged to fill them in.

Frank suggested that digital feedback forms could be used, just like the NHS uses in their GP services. It could be a simple text message prompting people to leave feedback or answer a few simple questions on the lines of: *Would you recommend this service to a friend or family. If yes or no, tell us why.*

All this feedback could then be turned into a visual for service users to see: You said, we did!

Lysa pointed out that from an external perspective the aim of the Focus group is a bit blurry with members being asked to follow up on actions as well as coming up with suggestions and suggested that we might want to be clearer on what the involvement of members of the Focus Group is.

The group agreed and proposed to create a new Terms of Reference document so that both existing member and new members know exactly what is expected.

ACTIONS:

- **Lysa to add the idea of ensuring that feedback is actioned and there is a cycle of updates – you said we did forms- into the consolidation plan for YE26**
- **Donna to share disability network's terms of reference**
- **Nina to share historic Focus group terms of reference**

- **Lysa to add the task of refreshing the Terms of Reference into the into the consolidation plan for YE26**

Ruth left the meeting,

Discussion: Wellness Hub

Lysa started the discussion by explaining that the Wellness hub runs every 6-8 weeks with the purpose of sharing information about topics relevant to living well with MD, sharing knowledge and learning about MD with external speakers coming in and sharing their expertise.

It is different to the Adapting to Change Group, which is a service user led peer-to-peer support group which is focused on themes related to adapting to change after a diagnosis, or after a change in the progression of the condition.

Our wellness Hubs are online events only, whilst the Adapting to Change group meets in person with online attendance as well - a hybrid event.

Frank raised his concern about hybrid events by pointing out that the quality of sound and visuals is often rather poor and individuals can get lost in the conversation.

ACTION:

- **Lysa to add a tasks to review the effectiveness of hybrid events to the consolidation plan for YE26**

Lysa continued to explain that we are trying to plan the Wellness Hubs 12 months in advance, so we have topics and speakers lined up. This should make communicating these events a little easier too.

The group discussed ideas that had been suggested already, and new ideas emerged:

- Menopause - how to live with the symptoms of MD and the Menopause and how medication might affect both
- Sleep management
- IBS
- Benefits of movement and Mindfulness and meditation – these were felt to be a duplication with what our therapy team offered in the online exercise programme
- Mental Health- as a follow on from session with the team at Oswestry.
- Relationship Management - discussing the condition with loved ones and friends, the impact of diagnosis on personal relationships, spouse turning into carers, sexual health in relationships after diagnosis. We discussed that this was a sensitive area – Nina suggested we could use break out rooms for men and women. A question was raised whether this was on the Adapting to change group agenda
- Genetics and MD

We discussed feedback on prior sessions had been that the speakers need to have knowledge of MD to make the session relevant to our community.

The idea was also raised of having a Wellness 'taster day' in person in Centre (maybe this could be combined with Open Day)

The question was raised if we should rename the Wellness Hub to something else, as wellness is very broad and could mean different things to people depending on background and age.

Ideas:

- **Learning Hub**
- **Knowledge Hub**

Donna suggested a community board to share hints and tips, initiatives etc on to raise awareness for schemes, help, discounts and more.

The group also discussed how to get in touch with the Centre when they see great initiatives in the day to day live or have an idea or suggestion for a hub session.

Lysa suggested a 'wellness hub' email address where people can send ideas to.

Action

- **Members to share contacts to any professionals you might know or have researched that may be able to speak to any of the topics listed above**
- **Lysa to add topic / name / sharing tips / break out room suggestions to the consolidation plan for YE26**
- **Nina to contact Adapting to Change Group to confirm if the theme of relationships is part of their agenda**

Lysa and Nina thanked everyone who attended and / or submitted their ideas for inclusion.

The meeting was closed.

Next proposed meeting date: Wednesday, 15th October 2025; 6pm-7.30pm online via Zoom
<https://zoom.us/j/5436792889?omn=94225800178>

Sign up here to confirm attendance: <https://bit.ly/MDSCfocusgroup>