

Notes from Steering/Focus Group meeting – March 2024

Welcome

Attendees:

MDSC Staff: Sarah Ann Moore, Nina Hanks

Attendees: Mark Thompson, Nick Randle, Bhavesh Tailor, Emily Bonner, Neil Corfield, Frank Sturzaker

Sarah welcomed everyone to the meeting and invited introductions. For the benefit of any new attendees, she described the history of the Steering/Focus Group and its key role in enabling the mission and culture of the Charity to continue to be led by service users.

Sarah welcomed everyone to the meeting. She explained some of the key things that have been going on in the Centre since the last meeting, including collating the results of the annual service user survey (for discussion at the next Steering/ Focus Group meeting) and, now that the Charity is in the final year of its Transforming Access to Therapies 5 year Strategy, updating the strategy and planning for the future. The Charity is keen to get the Steering/ Focus Group actively involved in this process in future meetings.

Sarah introduced the topics and agenda for the meeting, being:

- Collaborations
- Community Engagement and Fundraising
- Any other topics or ideas that the group would like to share/ discuss!

Discussion: Collaborations

Sarah introduced the subject, explaining that the Charity has been through an intense period of change and growth and so a theme for the team in 2024 is consolidating and embedding that change. The Charity wants to facilitate and grow a wider network of support for service users but, being a small charity, cannot do everything itself, so wants to actively partner/ collaborate with other organisations that can provide support (such as MIND, SMA UK and MDUK). The group were asked for their opinions on this approach and for any ideas of specific organisations or other holistic therapies that were worth approaching/ considering.

- Frank asked to clarify what the Charity wants to get out of the collaborations – is it about information exchange, joint activities or signposting?

Sarah answered that it depends on the organisation – any or all the above.

Crucially, the Charity does not want to reinvent the wheel or duplicate an activity that another organisation is doing well - if we know there is an organisation out there already offering a good service, perhaps we just signpost them on our website and in our communications, at other times we might want to actively work together on a service or project.

- Nick mentioned that any help and support from organisations that can help with negotiating the benefits system would be important, for example the PIP process. He suggested Citizens Advice. Frank agreed and suggested Age UK to be a helpful resource for people over 65.

Sarah mentioned Pathfinders Neuromuscular Alliance, a charity run by people with MD / other Neuromuscular conditions that offers PIP and advocacy support. She has a meeting planned with them this month and is excited to hear more about what they do.

- Emily recommended Remap, an organisation funding tailored disability equipment adaptations that are not readily available on the market elsewhere.
Links : Age UK - <https://www.ageuk.org.uk/> ; Pathfinders Neuromuscular Alliance - <https://www.pathfindersalliance.org.uk/>, Remap - <https://remap.org.uk/>
- Bhavesh asked if MD Support Centre knows/ is working with anyone who offers practical psychological support, including through a redundancy/consultation process in the workplace.

Sarah suggested MIND's Recovery Wellbeing Academy who she met with recently, can offer courses to help individuals navigate psychological and other challenges (including a training session on PIP) and that MIND can also offer 1 to 1 counselling support <https://www.recoveryandwellbeing.co.uk/>

- Mark mentioned that some sort of grief support would be helpful. This could be group support through MIND, or the new mobility transition group that MD SC's Chair Ruth has recently initiated.

Sarah confirmed that the Transition Group has had a first meeting and will be formally communicated/ launched shortly, likely at the upcoming Open Day in June.

DATE FOR DIARY: 29th June – MD Support Centre Open Day

Discussion: Community Engagement and Fundraising

Sarah moves on to the next topic on the agenda around how to engage more people in fundraising and community engagement activity. One of the key messages for the Charity for the year is: "We are a small charity. We need your support." How can we inspire and engage our community in fundraising activities? What could we do more of to support? What are we currently not doing?

- Nick shared that he is keen to organise a pub quiz as he has connections to a local pub. He acknowledged that he has inspiration but sometimes lacks the motivation to take ideas forward. Bhavesh mentioned that he would like to see more quiz and social nights and would love to get involved with organising a quiz night.

ACTION – connect Bhavesh and Nick

- Sarah asked what the uptake for the MDSC social group's Saturday social (cocktails/ mocktails) night currently is. Emily confirmed that numbers became very low, and it is not really happening anymore.

- Frank suggested exploring the option of a big online quiz night that everyone can join regardless of location (or other online social events). Sarah questioned whether we had been too hasty to move away from such online events post COVID and that this might be a great idea if there is an appetite for returning to Zoom quizzes. Frank mentioned that he would love to organise it but has not got the technical knowledge to arrange via Zoom (setting up of individual “rooms” for teams etc.). Bavesh offered his support to help investigate Zoom as a platform for a large quiz event.

ACTION – connect Bhavesh and Frank

- Neil came up with the idea of a treasure hunt around Coventry as it is something that can be done in teams to socialise and gets people out into the fresh air exercising. He said he would be happy to organise this but has no knowledge of Coventry. Emily suggested that there are companies out there who organise such treasure hunts or adventure challenges.
- Nick explored the idea of a casino night. He mentioned that he is aware of some companies who come into the event space and run the night, but that they are not cheap. Sarah agreed that casino nights can be great fundraisers with enough participation but are expensive. All agreed that the take up might be too low at this moment in time, but that it could be a great idea for the future.
- The group explored together other activities such as a “stroll and roll”, the Charity previously organised one at Bosworth Water Park (and there is a big charity one annually at Cannon Hill Park). The group also discussed other accessible walks and days out such as a social BBQ in summer (depending on the weather) like the one that the Charity held for staff last summer.
- Another idea discussed was hosting accessible disco, the challenges of which being finding a location that worked for as many service users as possible and the accessibility (including regarding toileting) of any venue.

Any other business

- Bhavesh asked about whether the Charity had any update on provision of Hydrotherapy.

Sarah confirmed that the Charity continues to actively search for hydro pools that it can rent to reestablish a hydro service. No solution has been found at present. In the meantime, the Charity will be offering aquatic exercise classes again this summer at the Xcel centre in Coventry for qualifying service users from 23 July to 27 August. Therapists will be talking to service users about this over the coming weeks.

Next steps and Close

Sarah thanked all attendees for their time, participation, and ideas.

All attendees consented for their comments to be shared in meeting notes to be posted on the Charity’s website.

Sarah then closed the meeting.