



Service User Focus Group meeting – 17th November 2025

Attendees

Service users: Geoff Stollard, Frank Sturzaker, Paul Jorden, Christina Gittins, Tristan Boedts, Kaye Shufflebotham, Diana Wright, Debbie Meadows

MD Support Centre: Zoe Ricardson (CEO / group facilitator), Lysa Ralph (guest facilitator / fundraising consultant)

Apologies

Mark Thompson, Suzanne Carter, Caren Hands, James Hennessy, Bhavesh Tailor

Welcome & introductions

Zoe welcomed everyone to the meeting and introduced herself and her role as focus group organiser and host. She gave apologies on behalf of service users who had been keen to attend but could not make Mondays.

Everyone introduced themselves. Of the eight attendees, two had been part of the prior Focus Group, and two had been members of the Project Board for the Transforming Access to Therapies project. One attendee regularly attends the MDUK Muscle meetings, and another Chairs a group for people with CMT.

Four were male and four were female. Attendees represented a broad range of ages and geography with people attending Daventry, Coventry and Birmingham. One member had Inclusion Body Myositis (IBM), two others had the related condition to MD of Charcot-Marie-Tooth (CMT), two had Limb-girdle muscular dystrophy (LGMD) and another had Spinal Muscular Atrophy (SMA).

Follow up actions from last meeting

Zoe presented the focus group terms of reference, which had been created in response to feedback at the last meeting. Zoe explained that these were representative of the Focus Group then and that this could be adapted further for this newly formed group. Zoe explained that meetings will be digitally due to geographical spread of attendees and meetings will be a minimum of once a quarter, with minutes circulated promptly and actions followed up and suggestions from the group discussed with the staff team and feedback reported back to the group at the next meeting.

Zoe stressed that she was keen to hear from members between meetings, and that she may email them on an ad-hoc basis for feedback on service development issues.

New service idea discussion

The new service ideas paper was shared on screen and introduced to members. Context was given that the logistics (insurance, risk, Health and safety, capacity, cost etc) are for Zoe and the team to resolve. The ideas presented were drawn from conversations with the MDSC team and Trustees in strategy discussions over the last couple of years, and at two staff awaydays this year as well as from feedback from service users.

Feedback from attendees included:

Acupuncture

Some attendees had personally experienced acupuncture and had had an excellent experience in terms of pain management so thought it was a great idea. One had had acupuncture from France the Osteopath as part of her appointment and said it was very beneficial

Clarity was given that an appointment for acupuncture would be separate to a physio or osteo appointments. Attendees suggested that it could be tagged onto an existing appointment (before or

after) given that many people travel long distances so it would be good to combine and extend the length of appointments accordingly.

Podiatry (leading to) Orthotics

Three attendees had personal experience of podiatry – one was able to access it at Reach for Health in Daventry and said it was brilliant. Attendees highlighted that whilst this was a good idea, it could overwhelm the charity financially. They said Podiatry was an expensive service which people would be happy to pay for, especially when it came to Orthotics which in some areas the NHS funds; essentially that they would not expect it for free.

Through discussion it emerged that there is a dire lack of NHS Orthotists – there is only one in Birmingham, and one in Oswestry. Also, as to funding, that it can be a postcode lottery as to whether – when you are recommended a certain type of Orthotic – the NHS will fund it. One member was turned down for NHS funding and had to pay privately. Some items of Orthotic (braces) can run into the thousands, and insoles can be £300+. Further, as the condition progresses, different types may be needed each year.

One attendee suggested it as a campaign issue; to get the NHS to recruit and train more Orthotists.

Talking therapies

Zoe gave context that this was 1:1 counselling, or CBT (cognitive behavioural therapy) whether face to face or online. Also that it had come about as therapist often find themselves giving emotional support and it would be good to have a professional to refer onto if people are struggling.

One attendee suggested considering the lifecycle of the various conditions to pinpoint at what stage it might be best to offer this service.

Attendees agreed it was a good idea and give it 'a resounding yes'. Several spoke about how MD was a lonely condition; especially with so many types and so few people around the country who will have the same condition. Family often don't understand it, difficult as we can legitimately blame our parents' – but difficult for family who do everything to help and do all the testing but find it difficult themselves.

In Warwickshire one attendee got referred for six 1:1 sessions with a NHS Clinical Psychologist and several of that team have knowledge of long-term conditions

'Alternative treatments' like Reflexology

One attendee with CMT reported that Reflexology had been highly effective for their mobility. As a result of having it on their feet they are now able to walk with sticks. They have found a mobile Reflexologist (ex district nurse) who comes to their house (£45 per hour) in Droitwich.

Another who is non ambulant had very good results in terms of improved bowel function. They get their sessions funded via the NHS and attend at Myton Hospice.

Another attendee mentioned facial massage which was offered during Covid from a therapist who understood MD which was very good for people who ground their teeth and clenched their jaw during sleep.

Context was given that Indian Head Massage is offered at Leicester (LOROS). One attendee reported that the Centre had previously offered Indian Head Massage in Coventry, however that the therapist was pushing expensive (£100) supplements / vitamins which she was selling through her own business so this was discontinued.

Attendees stressed that whatever the treatment was (which could all be accessed privately) the key thing was that the therapist understood MD, and was aware of which treatments had positive / negative benefits for different types of MD.

Other Related discussions:

One attendee spoke about the benefits of peer support – talking to others in the same situation and offering mutual support. Another suggested another service idea – peer support on specific issues like benefits: they had shared their experience of applying for benefit with another service user who was struggling to access the right information and that had really helped them.

One attendee suggested that for any of the ideas – staff produce a checklist setting out; potential benefits for service users, who it would most benefit, whether the benefits would be the same for all people with MD, pros / cons etc. Another suggested that it would be important to manage expectations as to where service users could access any of the new therapies and how long they would be available for – whether it was to be a pilot or permanent offer etc.

One attendee highlighted that whilst feedback about all the ideas was very positive, but that this was a small sample size.

[meeting closed with thanks to attendees]

Actions:

Members to share any further feedback on the new service ideas with Zoe.

Zoe to poll members on the best day / time for future sessions

Lysa to write up notes and Zoe to share with group.

Zoe to share Aquatic Therapies evaluation with group