 **MND Steering Group Minutes**

**13th Jun 2024 10:00 – 12:00**

**Mayo Building, Salford Royal Hospital & MS Teams**

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| **Present** |
| Cillian OBriain (GMNISDN) | Christina Federico (MND Care Centre) |
| Tracey Thompson (MND Association) | Samantha Holden-Smith (MND Care Centre) |
| Ellie Monteith (Salford CSNRT) | Dr John Ealing (MND Care Centre) |
| Sophie Gordon (Central Manchester CSNRT) | Cheryl Adamson (Bolton PCT) |
| Nicola Boyle (North Manchester CSNRT) | Emma Minshull (Stockport CNRS) |
| Karen Lea (Wigan CSNRT) | Katie Hart (Bolton CNRT) |
| Selina Makin (Salford CSNRT) | Emma Minshull (Stockport CNRS) |
| Juliet Smith (HMR Respiratory Team) | Debbie Freeman (NWVU) |
| Sam Jones (South Manchester CNRT) | Lucy Haslam (MND Care Centre) |
| Liz Holloway (Trafford CSNRT) | Barbara Dandy (East Cheshire SLT Team) |
| **Apologies** |
| Melanie Worthington (MND Association) | Sarah Rickard (GMNISDN) |
| Andrea McEntee (MND Association) | Hayley Williams (MND Care Centre) |
| Dr Hisham Hamdalla (MND Care Centre) | Bernie Mason (Oldham CNRT) |
| Alicia Hattersley (Bolton PCT) | Chris Hyde (GMNISDN & Stockport CNRS) |
| Vicki Worsley (Trafford CSNRT) | Samuel Fisher (Bury SLT Team) |
| Cathy Armstrong (East Cheshire Community Therapy Team) | Jenny Pearce (Bury PCT OT) |

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| 1. **Introductions and review of previous meeting minutes**
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| The group had representation from the MND Association, GMNISDN, MND Care Centre, NWVU and GM community teams. Noted some new members joined the group – introductions done. The group reviewed actions from the previous meeting. Updates:* **Patient & Carer recruitment to the group.** The recent MND training day included a session on the lived experiences of MND. Anna and Martyn who shared their story said that they would be happy to join the steering group.

Action: SHS to reach out to Anna & Martyn and arrange for them to join our next meeting.Action: MND clinicians (MND Care Centre and Community Teams) to consider sharing information about the group, scope interest and invite patients/carers.* **Assessing and supporting cognitive decline** - Specialist OT at Preston Care Centre who has done some work on this, has since left their post.

Action: TT to link in with Preston Care Centre to see if can access information on the work done.* CO noted a recent national MND competency training event delivering webinars on ECAS – information and links to the webinar can be found on the network’s website [here](https://gmnisdn.org.uk/professionals/mnd-resources/).
* **Nutrition case studies (MND Association).** MW collecting case study examples for sharing with patients to support with difficult discussions relating to nutrition. MW is currently on leave.

Action: CF to link in with MW about this.* **MND Association - Care Centre Network Day** already past for this year – would be beneficial to bring to next year’s event.

Action: TT to explore getting this project on the agenda for next year’s event when developing agenda later in the year.* **MND Care Centre AHP Report** – CF noted that a meeting has been arranged to discuss the processes involved with sending these out to community teams. It was noted that it would be beneficial for community teams to look into their processes of sharing the AHP Report when it arrives so to ensure all appropriate clinicians receive it. Noted overall improvement in communication processes between the MND Care Centre and Community teams.
* MND Association are holding training on posture management and orthotics (MND) in Manchester in November 2024 – [see here for details.](https://mnd.eventsair.com/posture-management-and-effective-use-of-orthotics-for-people-living-with-mnd-19-november-24/ce24cvpw11/Site/Register)
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| 1. **Social Worker Role at the MND Care Centre**
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| Lucy Haslam (Social Worker – MND Care Centre) shared information about her role with supporting plw MND, their families and carers. Lucy meets with patients and their family/carers during their visit to the MND Care Centre MDT clinic. Discussions and information provided include:* Accessing adult social care support for both patient and carer including standard commissioned care, carers assessments.
* Lasting Power of Attorney
* Accessing benefits and where to find more detailed information – also provides contact details
* Blue badge
* Accessing MND Association support groups, volunteer support and grants available.
* Direct payments and more personalised care if appropriate
* Equipment and adaptation, falls pendants.
* Housing discussed – noted not enough adapted properties for the numbers that need it coming through creating a waitlist – priority is based on points. If housing is likely to be an issue, Lucy will advise to get on housing list asap.

Some further points discussed during the meeting:* Lucy will see all GM patients coming through the MND Care Centre but can only commission services for Salford. However, can link in with Social Workers for other areas if needed
* Lucy will review patient notes prior to meeting them - if there are children in the household, she will provide MNDA leaflets with supporting information for this during their meeting.
* Lucy will send them an email with a summary of their discussion afterwards and provide them with her contact details so that if any further questions come up, they can contact her.
* Noted that community teams can signpost patients to Lucy if needed. Contact details below.

Lucy Haslam (MND Care Centre Social Worker)lucy.haslam@nca.nhs.uk 01612064820 |
| 1. **Suctioning update**
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| * Working party group set up – had meeting on 3rd April 2024 (minutes from meeting below)
* Noted it would be beneficial to have a centralised service
* Similar challenges across the country – not just GM
* HMR Resp Team order the equipment from Millbrook equipment stores. Team then go out and deliver family training. Get consumables from district nurses.
* Action: JS to share these processes with Melanie Worthington (email below)
* Action: Teams to share examples/case studies of challenges and best practice with Melanie: melanie.worthington@mndassociation.org
* Plan to meet again later in the year when examples/case studies collated.

Minutes from the meeting have had an amendment after some feedback:* North West Ventilation Unit are only commissioned for invasively ventilated patients.

Please find updated minutes here: |
| 1. **MND Project Update**
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| **GM MND Contact Directory**CO shared the GM MND Contact Directory and plans to ensure it is kept up to date. Can be found on our website here: [MND Resources - GMNISDN](https://gmnisdn.org.uk/professionals/mnd-resources/)**MND Community Review Checklist Template**CO thanked the community teams that sent their review checklist templates. CO has collated these into a sample MND Community Review Checklist template. It is in word format so that teams can add/amend it for their own teams/areas.Action: Teams to offer feedback and/or suggest changes **by Friday 12th July** to CO: Cillian.obriain@nca.nhs.ukAction: CO to upload to the network website when ready.**MND Toolkit on network website**Already many resources available to professionals through the MND Association website. GM specific resources now available through the network’s website: [Motor Neurone Disease Toolkit - GMNISDN](https://gmnisdn.org.uk/professionals/motor-neurone-disease-toolkit/)Action:MND clinicians to send CO any further resources for adding.**Training programme*** Practical training day was a success in April.
* Venue booked for 10th December for next one. In process of confirming speakers/facilitators. Will open to registration when confirmed.
* Action: MND clinicians in MND Care Centre and Community to let CO know if they wish to present/facilitate a session.

**Nutrition**CF shared updates on the MND Nutrition project.  |
| 1. **Project legacy**
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| **MND Steering Group*** CO shared the progress of the MND Steering Group during the project’s timeline. Extended stakeholder engagement has brought many benefits and supported steering the direction of the project.
* Plan is to continue with the 6 monthly Steering Group and work towards further extending stakeholder engagement e.g. patient/carer, social care, district nurses

**MND Training Day*** Discussed future options for MND training programme from 2025. Noted that it would be beneficial to have working parties discussing specific topics related to MND working alongside the biannual MND Steering Group.
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| 1. **MND Association Grant Application**
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| In process of submitting a grant application to MND Association for a project exploring emotional support provision to plw MND, their families and carers. Aiming to submit for July panel with a view to commencing the project early 2025. |
| 1. **Any other business**
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| TT noted that some similar project work is ongoing in West Yorkshire. Noted it would be beneficial for GM and West Yorkshire to meet and share information.Action: TT to link CO in with project leads at West YorkshireMND Global Awareness Day (21st June) – MND Association support group in Bolton celebrated this with an event. Information was shared out for anyone that wished to join. SHS shared information about an MNDA event in Warrington where they are hosting a cinema night – 17th July. She has sent information out to community teams. If interested, please contact Sam on samantha.holden@nca.nhs.uk JE shared information about [Interlukin-2](https://www.mndassociation.org/research/clinical-trials/treatment-trials/interleukin-2) which is a drug that can slow down progression of MND in people with particular biomarkers. Currently waiting for research to be published and for the application to the MHRA to have the drug licenced. Unknown when this will get rolled out – likely at least a year away. Delivery will require a subcutaneous injection once daily for five days a month for appropriate patients. Question raised around the funding and practicalities of rolling this out in GM. Noted it would be beneficial to link in with local District Nurses and look at this collaboratively. Potentially some established pathways for delivering sub cut injections for MS patients available to look at.Action: Teams to send CO contact details of District Nurses for inviting to the Steering Group. |
| **Next meeting:** 19th November 10:00-12:00 |