 **MND Suctioning Meeting Minutes**

**3rd April 2024 13:00**

**MS Teams**

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| **Present** |
| Cillian O’Briain (GMNISDN) | Emma Minshull (Stockport CNRS) |
| Vicki Worsley (Trafford CSNRT) | Jennifer Pearce (Bury PCT OT) |
| Hetal Sodha (HMR Respiratory Team) | David Derry (NW Ventilation Unit) |
| Melanie Worthington (MND Association) | Cathy O’Reilly (South Manchester CNRT) |
| Olivia Carlyon (North Manchester CSNRT) |  |

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| **Introductions and welcome** |
| The group introduced themselves and their roles.Cillian explained that there was a brief discussion at the GM MND Steering Group on the processes surrounding the provision of oral suctioning. In the meeting we identified a need to discuss further in a separate meeting. Topics mentioned in the steering group meeting included:* Some community teams using this as an intervention and others are referring to other services.
* Some teams access clinical training while most use knowledge and skills from previous roles.
* Variation in providers of equipment and consumables: Community teams, DNs, Equipment Stores and NW Ventilation Unit.
* Noted that this intervention is very rarely used for plw MND and reducing numbers using over recent years.
* Sometimes barrier to use is supporting patient/family set up and use the equipment.
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| **Discussion** |
| **Provision and maintenance of equipment and consumables*** North West Ventilation Unit are only commissioned for invasively ventilated patients.
* The group shared some examples of these processes from their localities:
	+ Bury (Palliative Care OT): can order equipment but not consumables. Noted DN’s will not input if not already seeing patient (not all patients will have DN input)
	+ HMR (Respiratory Team): Provide oral suctioning as an intervention however equipment and consumables are sourced from another team.
	+ Stockport (CNRS): DNs will provide equipment and consumables but not deliver family training.
* Patients and family/carer sometimes ask community team questions related to equipment provided by other teams.
* It is a challenge when an issue with equipment arises out of hours – no service to refer to for urgent maintenance needs.

**Patient & family/carer training*** Melanie noted that patients and family would benefit from a face-to-face training on how to use this equipment and then provide online resource for accessing afterwards.
* DNs can sometimes ask NW Vent Unit to deliver patient and family training. This is a challenge due to them not knowing what equipment has been issued.
* NW Ventilation Unit have a basic training video explaining suctioning equipment and use in practice (well suited to patients and family)- [How to use your equipment - Wythenshawe Hospital (mft.nhs.uk)](https://mft.nhs.uk/wythenshawe/services/north-west-ventilation-service/how-to-use-your-equipment/)

**Provision and maintenance of equipment/consumables & patient/family/carer training*** Overall varying processes across localities in GM.
* Provision of equipment and consumables can work well when provided by community teams as they often provide family training too. NW Ventilation Unit noted a recent example where this pathway worked well for a Tameside patient.
* DNs sometimes do not provide training despite providing the equipment.
* Ideally need a single point of access: A service that provides equipment, consumables, maintenance of these and patient/family training. Ideally would need to be GM ICB commissioned providing 24-hour service with technicians on call to respond to breakdowns.
* Melanie shared that Liverpool has a Medical Devices Lead that over sees the provision and maintenance of equipment and consumables. Also provides patient and family/carer training and an out of hours service when needed.

**Staff competencies and training*** Previous training, skillset and confidence levels vary across team members in relation to providing this as an intervention and supporting patient/family/carer training.
* Bury: It was noted that there is a training resource available on ESR however this is vague and may not meet the training needs of clinicians.
* NW Ventilation Unit have a basic training video explaining suctioning equipment and use in practice (may be more suited to patients and family rather than clinicians).
* It was noted that inpatient teams would have well established training and competencies for this and that it may be worth asking for information on these and sharing with community teams.

Action: Cillian to contact MND Care Centre physio and ask this question and share resources with community teams as able.**Impact on plw MND & family/carers**Question raised around the number of MND patients needing this intervention and risk to patient if there’s a delay in provision of intervention. * Not high numbers of MND patients requiring this and it is normally bulbar patients that need it.
* Oral suctioning as an intervention can have a significant impact on patients and family quality of life.
* While this intervention is not often used for plw MND, the group agreed that if the equipment was more readily available, it would be used more regularly.
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| **Next steps** |
| Melanie: To continue regional work looking into this and make contact with:* Other neurological charities to see if any other work is ongoing.
* MLCO & TLCO looking into this: Vicki to provide contacts to Melanie: melanie.worthington@mndassociation.org
* Ventilation Network Chair (SILVA) – Alison Armstrong: alison.armstrong1@nhs.net
* Tameside & Glossop Community team for example of an effective pathway (Cillian to provide contact)

All teams to share examples of challenges faced with local pathways surrounding the provision of suctioning interventions for plw MND with Melanie for use in a report to bring to the GM ICB.  |