

Developing MND care in Northern Ireland

Challenges and opportunities

Background and aims

- Five Health Trusts
- Each health trust works independently of each other
- Approx 100 MND pts in NI
- Regional clinic held in Belfast. Additional clinic in Londonderry
- Two MND specialist nurses
- NIV specialist nurse for the region (covers all conditions)
- No dedicated respiratory physio cover until mid 2018



MND Respiratory Physiotherapy Pilot

- Ran from July 18 to Jan 20
- 4.5 hrs/week of respiratory physio cover
- Early respiratory surveillance and intervention
- Assessed 49 new patients (c/w 7 in previous year)
- Carried out 74 reviews (c/w 1 in previous year)
- 38 pts started on some form of cough augmentation (c/w 6 in previous year)
- 53 consultations with community staff (c/w 4 in previous year)

Challenges

- Lack of co-ordinated home ventilation service
- Reluctance from other trusts to pilot own respiratory physio service
- Lack of clear pathways/standardisation of ongoing care across the region
- Large distance for patients to travel to receive specialised care
- Limited opportunity for NI patients to access clinical research trials



Opportunities

- New regional contract for cough assist/suction equipment
- Awareness and communication improving
- Development of community specialist posts
- Hope to develop closer links with palliative care in the near future