

# Developing MND Care in Northern Ireland – challenges and opportunities

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Belfast Health and Social Care Trust

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respect & dignity



openness & trust



leading edge



learning & development



accountability



# Background to MND Care in NI

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



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# Geographical Spread of MND Patients in NI



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# MND Respiratory Physiotherapy Pilot

- Ran from July 18 to Jan 20.
- 4.5 hrs/week
- Attend 2 regional MND clinics a month
- Run 2 review clinics a month
  
- Early respiratory surveillance and intervention
- Timely access to therapy as disease progresses
- Upskill/support community teams
  
- Regional position



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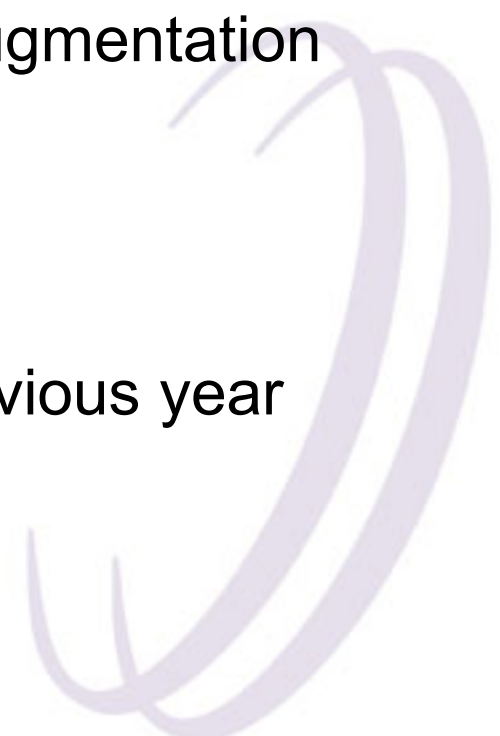
# MND Respiratory Physiotherapy Pilot

- Assessed 49 new patients (c/w 7 in previous year)
- Carried out 74 reviews (c/w 1 in previous year)
- 38 have started on some form of cough augmentation (c/w 6 in previous year)
- 53 consultations with community staff (email/telephone/face to face) c/w 4 in previous year



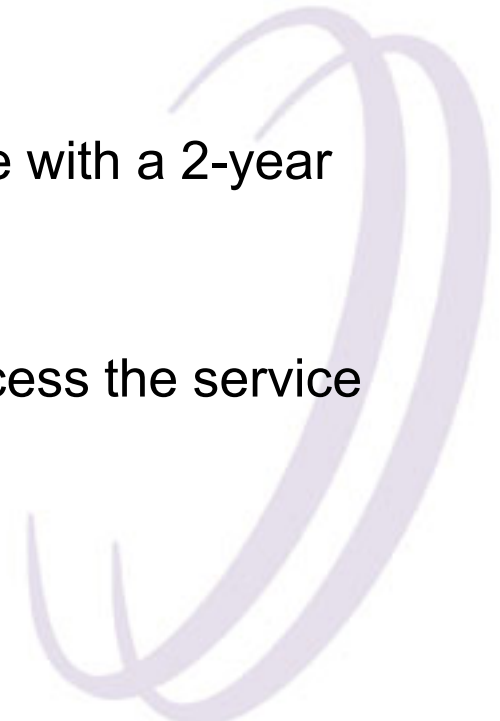
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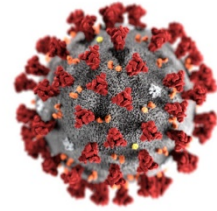


# MND Respiratory Physiotherapy Pilot

- KPI 37I (% of people with MND who require cough augmentation can access it within 2 weeks) 89% (c/w 16% in previous year)
- 84% of patients found the service very beneficial
- 100% of patients knew who/how to contact if any concerns or deterioration
- Gained support within local trust to take over service with a 2-year phasing out of the MNDA grant
- Caveat that other neuromuscular conditions can access the service



# Impact of Covid



- Clinics suspended
- No identified area to do AGP's
- Service changed to home visits/virtual appointments
- Return to urgent care only
  
- 28 new patients (7 in first 9 months)
- 23 reviews (6 in first 9 months)
- 29 pts started on some form of cough augmentation (8 in first 9 months)



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# Impact of Covid continued

- Change of staff in team
- Regional clinics re-established but with lower capacity
- Loss of elective inpatient NIV ward



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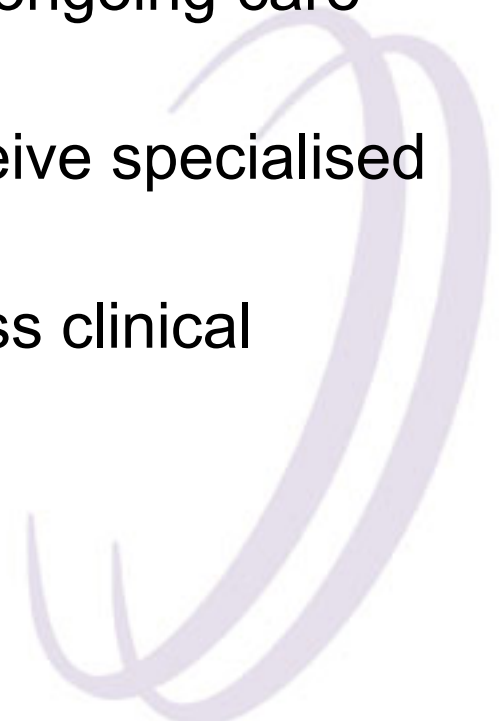
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# Challenges

- Lack of co-ordinated multi disciplinary home ventilation service
- Reluctance from other trusts to pilot own respiratory physio service due to lack of recurrent funding
- 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
  - Switch from Nippy Clearway to Eove cough assist machine
  - Much more streamlined process – can order machine for patients from any trust
  - Each trust being billed for their own patients
  - Positive feedback
- Awareness and communication improving
- Development of community specialist posts
- Hope to develop closer links with palliative care



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