A collaborative approach to improving Motor Neurone Disease care in Greater Manchester

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mnda motor neurone disease association

NHS Greater Manchester Neurorehabilitation & Integrated Stroke Delivery Network

What is MND?

- Fatal, rapidly progressing disease affecting the brain and spinal cord
- Attacks the nerves that control movement so muscles no longer work
- Leaves people locked in a failing body, unable to move, talk and eventually breathe
- Over 80% will have communication difficulties, including for some, a complete loss of voice
- Around 35% experience cognitive change. A further 15% show signs of FTD resulting in more pronounced behavioural change.
- Kills a third of people within a year and more than half within two years of diagnosis.
- Affects people from all communities

GM MND Collaboration

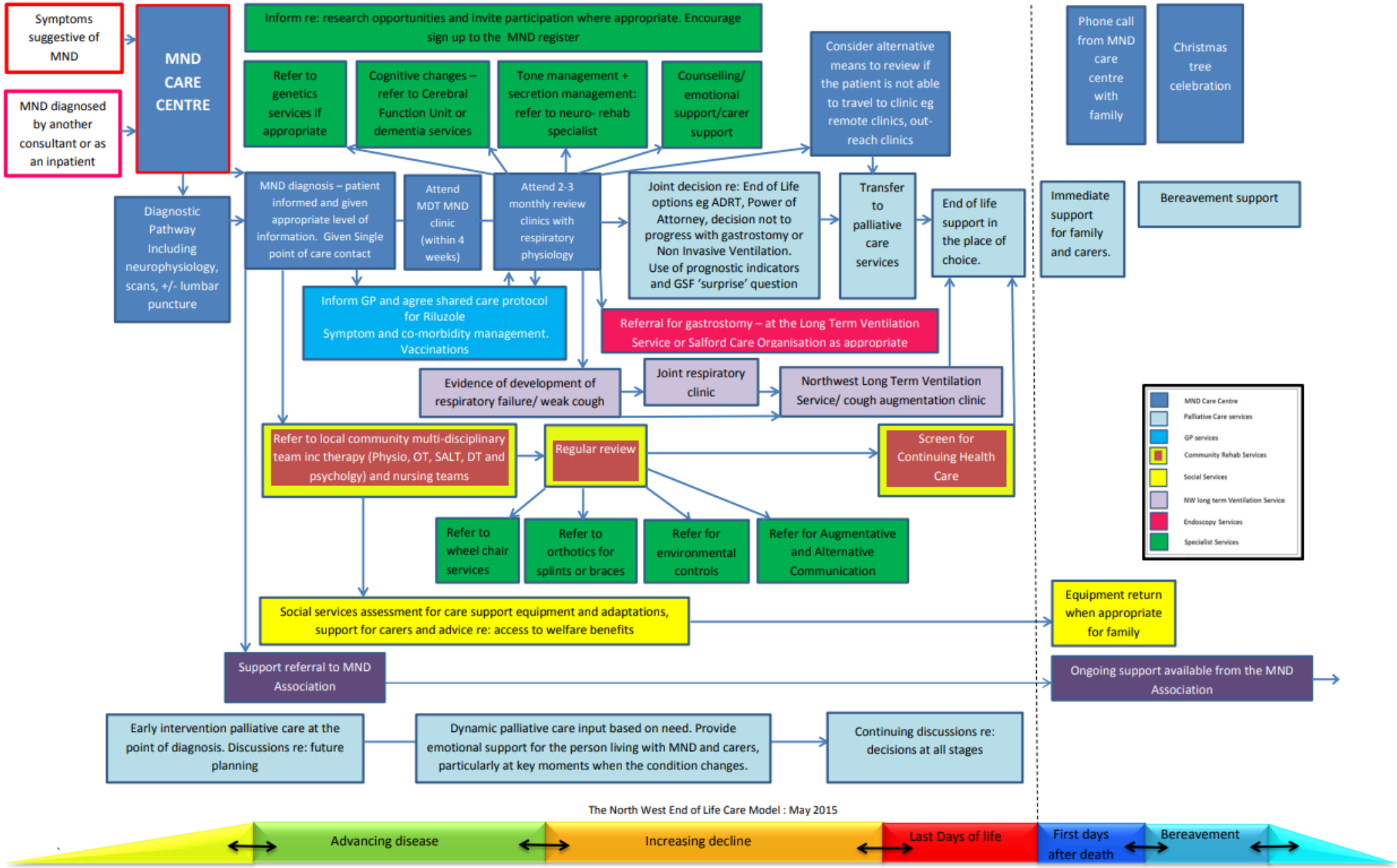
- Approx. 250 people living with (plw) MND in GM
- Inequity of access to health and social care across GM
- NICE guidelines and recommendations for MND (2016)
- Collaboration developed between MND Association, MND Care Centre and GMNISDN
- MND Association funded x2 posts
  - 0.2 WTE – MND Care Centre: Nutrition Project
  - 0.5 WTE – GMNISDN: MND Care Pathway Project
  - Fixed term (2022 – 2024)

NHS
Greater Manchester Neurorehabilitation & Integrated Stroke Delivery Network

mnda
motor neurone disease association

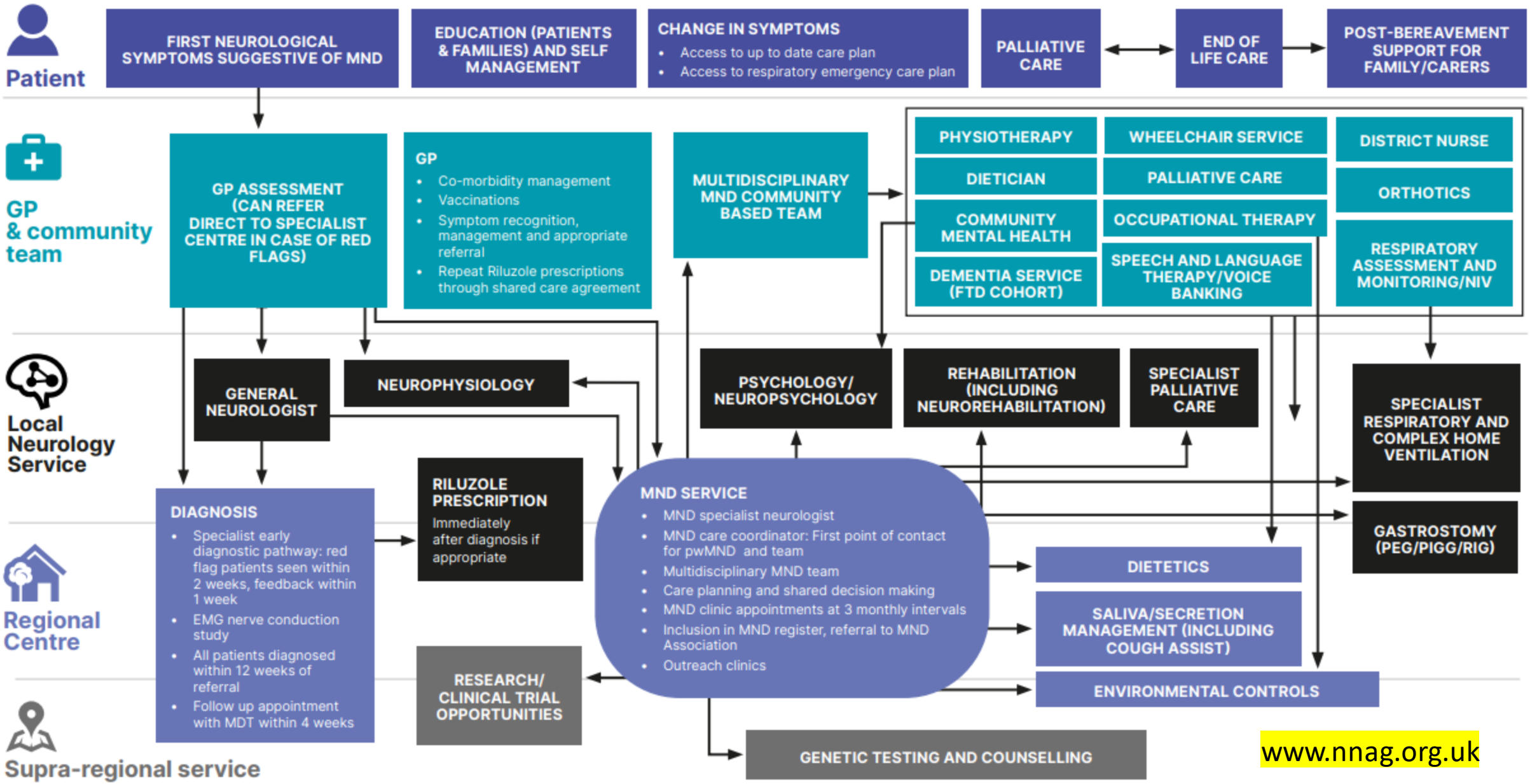
NHS
Northern Care Alliance
NHS Foundation Trust

The Greater Manchester Motor Neurone Disease Care Model



Produced by Jane Leicester Manchester MND Care Centre Jan 2020

Executive summary: Motor Neurone Disease Optimal Pathway



Information, education, advice, supported self- management, shared decision making, access to research opportunities at all levels

www.nnag.org.uk

MND Motor neurone disease **MDT** multidisciplinary team **PEG** percutaneous endoscopic gastrostomy **PIGG** Per-Oral Image Guided Gastrostomy **RIG** Radiologically Inserted Gastrostomy

Identifying pathway development opportunities

- Information gathering
  - Semi-structured interviews with GM community teams
  - Shadowed MND Care Centre Clinic and MDT Clinic
  - Report on the information gathered completed
- Expanded MND Steering Group attendance to include more stakeholders
- Map the GM MND pathway against the National Optimal MND Pathway (2023)

Access to community services

Locality	Community team access for plw MND
Bolton	• Bolton Palliative Care Team • Bolton CNRT
Bury	Bury Palliative Care OT
Eastern Cheshire	East Cheshire Community Rehabilitation Team
Manchester	• Central Manchester CNRT • North Manchester CNRT • South Manchester CNRT
Oldham	Oldham CNRT
Rochdale	Heywood, Middleton & Rochdale Respiratory Team
Salford	Salford CNRT
Stockport	Stockport CNRT
Tameside	Tameside & Glossop Community Rehabilitation Team
Trafford	Trafford CNRT
Wigan	Wigan Wrightington & Leigh CNRT

- All areas have access to: OT, PT, SLT, Dietitian and Nurse
- Workforce structures vary in teams with some having to outreach for input
- 12/13 localities have access to a specialist Community Neurorehabilitation Team (CNRT)
- Variation leads to inequitable access to services and delivery of care e.g. access to neuropsychology and specialist neurologically trained therapists and nursing staff

Access to Neuropsychological Care

Psychological support

- Neuropsychology
- Counselling
- Wellbeing hubs
- Mental Health networks
- Hospice
- MND Association
- Work based initiatives ‘wellbeing’
- Genetics

Waiting times

Equity

PLWMND – families / children

Understanding of MND

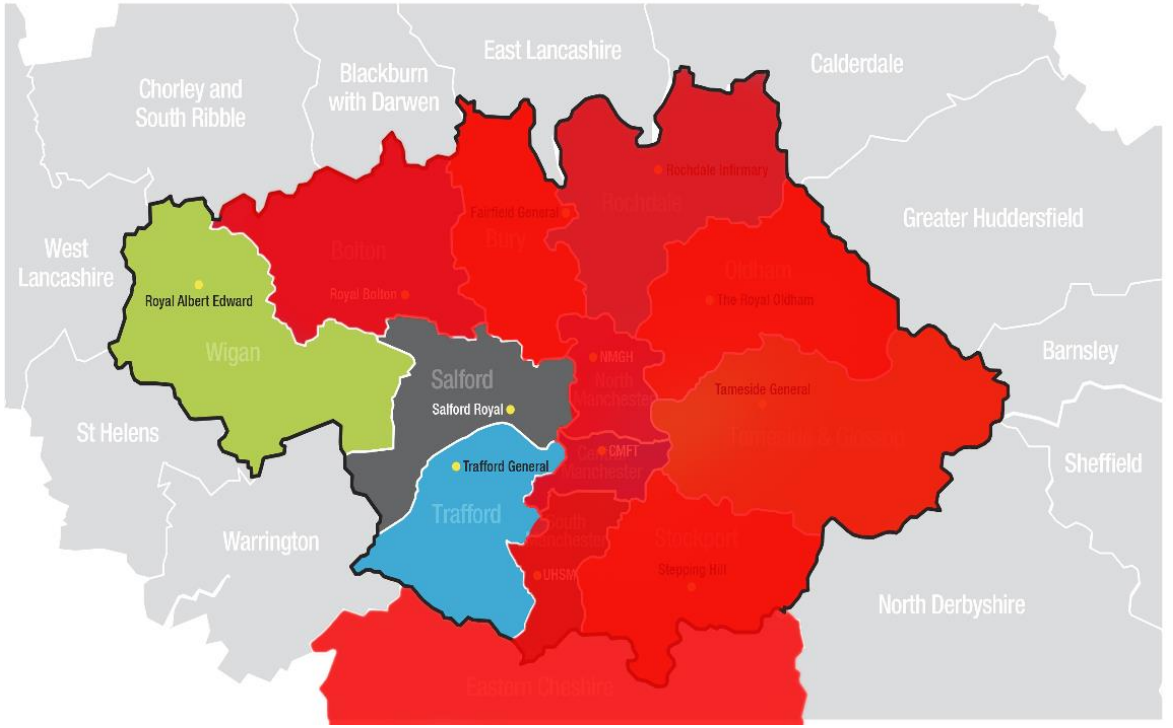
What is required v What is available

Timely Access

Patient voice helping shape future

Access to Specialist Neuro Dietetic care in the community

- Access in just 3 CNRT services across GM
- No access in 10 areas – requires outreach to main adult community service



- Varying triage models leading to inequity in waitlist and review times
  - Specialist Neuro Dietetic service within CNRT: **Avg. wait 1.5 wks** **Avg. review time 4 wks**
  - Dietetic service with Adult Community Team: **Avg. wait 5.4 wks** **Avg. review time 10.7 wks**
- Recent survey: Higher levels of confidence in managing nutrition and supporting with tube feeding discussions for MND among Specialist Neuro Dietitians compared with Dietitians in Adult Community Team

Patient impact

- John: Diagnosed in Dec 2022
- 56 yrs old – Lives in an area **with** a CNRT Dietitian.
- CNRT referral sent at point of diagnosis – no nutritional intake concerns in initial assessment
- Referred to **Specialist Neuro Dietitian** within CNRT and seen 1 week after referral
- Reviewed in **Jan 2023** highlighting 4kg weigh loss – initiated feeding tube discussions
- Following x3 visits to discuss/support feeding tube – tube inserted **Apr 2023**
- Shortly after feeding tube insertion oral intake started to decline and became more reliant on feeding tube
- John currently has **1-2 visits monthly for review**

- Liz: Diagnosed in 2020
- 68 yrs old, lives in an area with separate dietetic dept.
- **Mar 2022**: new difficulties with nutrition, not known to **community dietetic service**
- GP referred – 8 week wait for input
- Liz experienced 8kg weight loss
- Limited MND dietetic support and expertise available – required support from Dietitian in the MND Care Centre
- Dec 2022: decision made for feeding tube
- **Apr 2023:** Feeding tube inserted with further 4kg weight loss while waiting for insertion
- Liz is currently **reviewed every 2-3 months** by local Dietitian

4 months

Time taken from initial nutrition concerns to feeding tube insertion

13 months

Images: Generated through an online AI image generator: canva.com

What has been achieved so far?

- **Identified gaps and inequity in service provision highlighting areas requiring focus**

- **Created opportunities for clinicians to network, build connections and share resources**
  - Regular locality MDT meetings.
  - GM MND Contact Directory
  - GM MND Toolkit
  - GM MND Steering Group

- **Upskill clinicians** - MND Training Programme

- **Raise the profile of MND and pathway development**
  - Board meeting, GM ICB CEG, GMNISDN Conference, Rehab Subgroup, GMNISDN Dietetic stakeholder meetings, MNDA – community of practice & other care centres, British Dietetic Association Neurosciences group.
  - Social media

- **Measurement**
  - Training Evaluation – Clinician's skill, knowledge and confidence
  - Patient Related Outcomes – Transforming MND Care Experience Survey
  - Project Report

What have we learnt?

- Benefits of Collaboration across teams, organisations and localities.
- Improvements can be cost neutral
- Exemplar for GM pathway development

Ongoing Developments

- Embed learnings and changes into business as usual
- Emotional wellbeing pathway for all those living with MND.
- Genetic testing
- Gastrostomy pathway development in partnership with NWVU.

Possible investment.

- Inclusion of dietetics within CNRTs
- Greater access to psychological intervention.
- Gaps identified – possible need for future funding

Thank you

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