

Maintaining Quality of life for people with MND in a Rural Community

Introduction

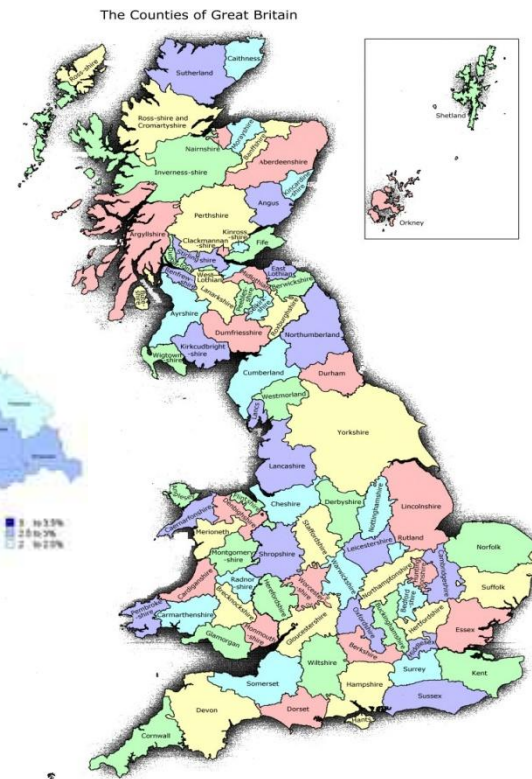
- Multidisciplinary Working
- Partnerships
- Focus on Mobility Needs



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North Wales

- North Wales is the northern most region of Wales, a country that is part of the UK
- The population of North Wales is approx 700,000 people



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Idyllic Environment – Amgylchedd Prydferth

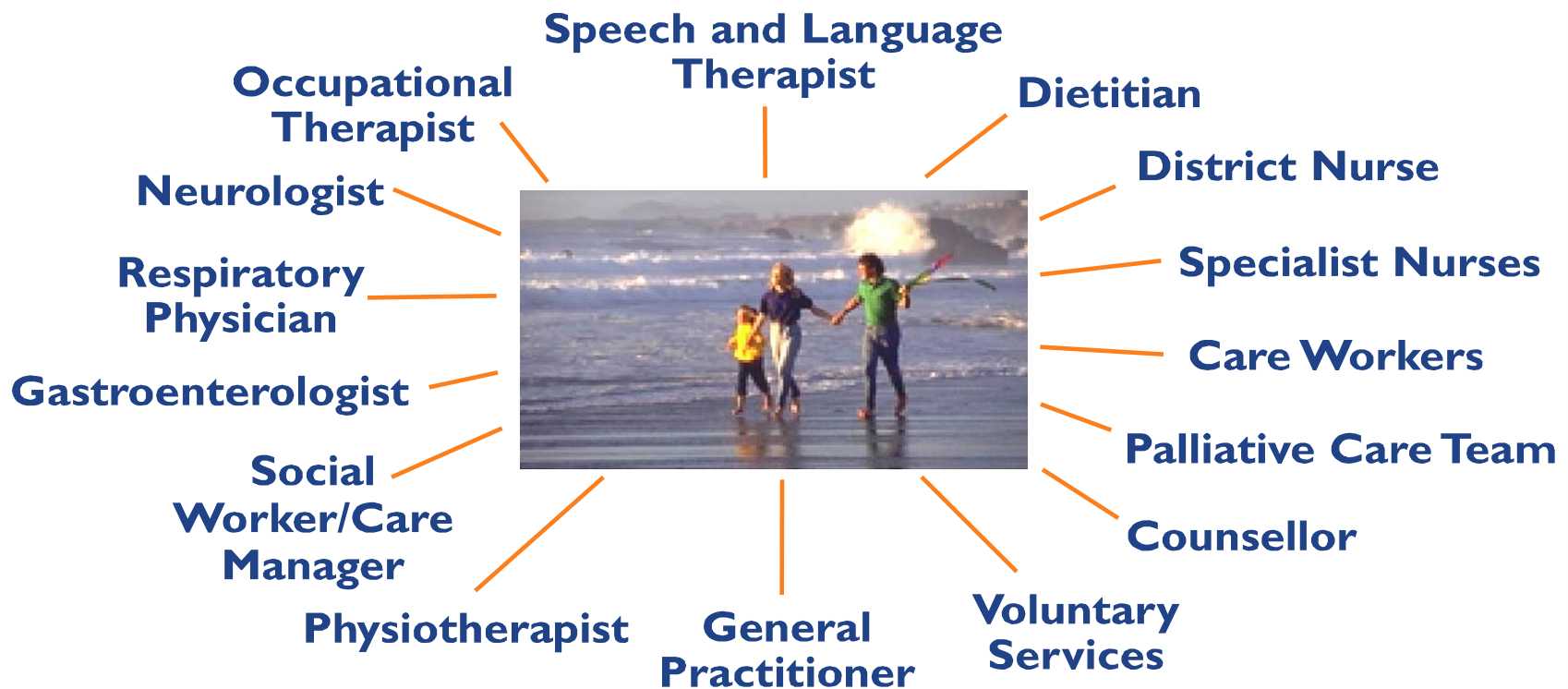


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Not such an idyllic environment when you have been diagnosed with MND!

- No specialist neurology centre.
- Small towns and villages with few local health services.
- Community health services based in larger towns.
- Poor knowledge of MND within local generic teams.
- Poor transport links. Mainly single carriageway roads.
- Poor public transport by bus or train.
- Dependent on transport to access medical, social or community services.

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Multidisciplinary (MDT) working as a catalyst for change

- An informal MDT set up in central area of North Wales
- Professional networks developed over time
- Service gaps identified
- Posture and Mobility Service, managed by the Artificial Limb and Appliances Service (ALAS), acknowledged service deficiencies and allocated an OT to attend MDT meetings
- Working with colleagues in the MDT identified the issues and proposals for service improvement

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Posture and Mobility Services

Historically – inconsistent NHS Posture and Mobility Services due to;

- Delays in assessment and provision of wheelchairs.
- Powered wheelchairs provided were often unsuitable and became less suitable as mobility needs deteriorated.
- Poor understanding of MND amongst OT's.
- Poor monitoring of needs as mobility deteriorated.
- Services assessed and provided for differently depending on where people lived.
- Lack of coordinated service planning, assessment and provision.

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Proposals

- ALAS allocate an OT with specific responsibilities for MND Cases
- Establish early referral system through MDT working
- Establish fast track assessment system
- Partnership working between the MND Association and ALAS to plan service improvement

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Outcomes

- ALAS aware of all people with MND with mobility needs in North Wales
- People with MND and/or referring professional provided with information on mobility options early
- Timely assessments
- Appropriate and sensitive provision of mobility equipment
- Changing mobility needs monitored directly through ALAS or in agreed arrangement with locality OT
- No current waiting lists for assessment or provision of manual or powered wheelchairs in North Wales
- Development of a range of mobility solutions through statutory, voluntary sector, and private sector solutions

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Advantages

- Enables the person with MND to access equipment to meet current mobility needs and to get on with living.
- Timely and sensitive provision of equipment.
- Allows person with MND to adjust to idea of using a powered chair.
- Provides timely information for future practical preparations for an NHS powered chair to be used eg adaptations to home environment, including ramped access.
- Early information enables informed choices regarding vehicle consideration for transport of powered chair

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Learning

- MDT working is essential in ensuring mobility needs of people with MND are met and monitored throughout the disease progression
- Mobility solutions can be met through partnerships across professional disciplines, across agencies, and across geographical boundaries
- People with MND are empowered to make mobility choices throughout the disease progression with sensitive and timely provision of information
- Services which have professionals with specific MND responsibility improves local expertise, knowledge and experience of the needs of people with MND

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Recommendations to the field

- In rural communities anticipatory service planning needs to be based around early referral ahead of need
- This enables professionals to work at the pace of the person with MND by planning ahead
- MDT Working ensures that deterioration in mobility is monitored and promotes early referral to other disciplines in a timely manner
- Holistic solutions require partnerships to be created across several boundaries

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Benefits of Multidisciplinary working for people living with MND

- Support from diagnosis
- Coordinated care planning
- Seamless referrals between Health and social care
- Access to appropriate information
- Earlier access to palliative care services
- Support for carers

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Benefits of Multidisciplinary working for Professionals

- Local professional support networks
- Local knowledge, skills and expertise
- Anticipatory care planning - 'Plan B'
- Anticipatory care planning - Efficiency
- Access to a wider range of services
- Identifying service gaps

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Multidisciplinary team working improves services for people living with MND and improves the skills knowledge and expertise of professionals.