

The Peninsula MND Network

(Devon, Cornwall & Isles of Scilly)

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NHS - Peninsula MND Network Coordinator

Plan:

To briefly outline the aims and processes of the MND Peninsula Network, specifically how we link with DeNDRoN

MND / ALS

- Terminal neurodegenerative disease
- UK incidence 1 in 50,000 – approx 7000 across UK at any one time.

(Talbot & Marsden 2008)

- Approx 100 - 120 across peninsula
(55 people were newly diagnosed (2008-2009)
- Approx 350 – 364 across South West
(Approx 104 people newly diagnosed a year)

Key points

- Rare
- A person has to face a life limiting illness plus increasing disability
- This often necessitates the involvement of many different disciplines

Background

July 2005: Board Paper

'To recommend a novel approach to achieve the establishment of a Care Centre in the South West of England covering Devon and Cornwall.'

Develop a network as opposed to a centre based model

Generalisations of each model

Care Centre

- Lead Neurologist(s)
- Specialist MDT Clinics (hospital based)
- Hospital teams liaise with community teams
- PwMND travel to team

Network

- Strategic Lead Neurologists
- Locality MDT meetings (community based)
- Network team outreach to local teams
- Team travel to PwMND

Peninsula Network Core Team

Bill Nevin: MND Regional Care Development Adviser

Tim Harrower: Co-Director – Consultant Neurologist

Jonathan Stewart: Co-Director – Consultant Neurologist

Stuart Weatherby: Co-Director – Consultant Neurologist

Louise Jarrett: NHS Network Co-ordinator

Peninsula Network Partners



Aims of the Peninsula Network

1: Improve the support and coordination of services for people living with MND

2: Promote effective integrated working between health, social, research, charity and volunteer sectors

The network does not...

Replace a person's existing care team but works in partnership with them to promote and develop effective service delivery

Route of referral to Peninsula Network

- Neurologist confirms diagnosis
 - Refers to network via LJ – email / telephone / clinic letter
- LJ within 2 weeks of referral will:
 - **Contact person and establish information / support needs**
 - **Establish if can share details with MNDA / Research Group**
- BN / MNDA receives referrals as before
- MDT members can also refer

Peninsula Network Partner Interface



Established partnership working with research colleagues

- Consent from PwMND to share information with research and charity sectors
- Joint meetings
 - Clinical Staff / Researchers / MNDA

Thank you

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