

A Way forward

The Scarborough Approach

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&

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**MOTOR
NEURONE
DISEASE
ASSOCIATION**



Motor Neurone Disease (MND)

- **Terminal disease**
- **Rare illness**
- **Incidence: 2 per 100,000**
- **Prevalence: 5,000 people in the UK**

Our Vision

A World free of MND

Our Aims

- **To ensure that people affected by MND can secure the care and support they need**
- **To promote research into causes and treatments**

Our priorities following the NSF

- Multi-disciplinary teams
- Respiratory and Nutritional support
- Equipment provision
- Palliative Care
- Family and Carers

The role of the Regional Care Development Adviser

- **Influence**
- **Inform, support & advise**
- **Educate and train**
- **Work with Association Visitors/Branches**

The Regional Care Adviser as part of the role

- **Works closely with Palliative Care services, including hospices**
- **The Neurology Service at Saint Catherine's Hospice is an example of this type of collaborative working**

St Catherine's Hospice, Scarborough

Your community, your Hospice, our care



Saint Catherine's Hospice Neurology Service

Specialist palliative care for people with:

Multiple Sclerosis

Motor Neurone Disease

Other rare conditions

Neurology service embedded in all Saint
Catherine's services

Saint Catherine's Hospice Neurology Service

Current caseload

MS	102
MND	11
MSA	4
Other	11

Who are we?



What are our aims?

Care based upon principles of :

- maintaining quality of life
- informed decision making
- discussions regarding life prolonging treatments
- partnerships of care with the patient and their families
- collaboration with and support of other health & social care professionals

How do we do this ?

Neurology Nurse Input

- assessment
- information
- co-ordinating care & referral to other agencies
- monitoring role & ongoing support
- gateway to hospice services

How do we do this ?

- Day hospice - with specified goals
- Inpatient admission for symptom control, respite, with full MDT assessment
- Consultant review
- Palcall- out of hours advice line
- Lymphoedema clinic
- Complementary therapies

What else?

- Bi monthly multidisciplinary team meetings for MS patients and MND patients with RCA MNDA
- Patient & Carer Support groups for MS and MND
- Bereavement support service

The challenges

- Developing knowledge and expertise of hospice team
- Disease trajectory usually longer – demand on hospice services
- Collaborative working with Community and hospital teams

Final Message

- **This type of provision is achievable**
- **Close partnership working ensures the best possible support**
- **Service user choices are paramount**