

Making Change Happen: The Motor Neurone Disease Palliative and Supportive Care Pathway Project

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**Leicestershire &
Rutland**

Location

- Leicestershire and Rutland.
- Population 910,000.
- City 280,000 over 28 square miles.
- County 609,578 over 965 square miles.
- Rutland 34,5000 over 150 square miles.
- 50 people with MND.

Health and Social care in the UK

- NHS free at the point of delivery.
- Private health care.
- GPs
- Nursing needs or Social care needs.
- Ambulance service.
- Voluntary sector.

Background

- Local pockets of excellence but a fragmented approach to care.
- Communication not always brilliant.
- Unmet need.
- Key individuals – MND CNS, Palliative care, Local MND association.
- Mapping day.

Mapping day

- People with MND
- Carers
- Local Neurologists
- Primary Care
- Social Services
- Specialist Services – SALT, Dietician
- Voluntary Sector
- Palliative Care
- MND CNS
- SHA

Needs highlighted

- Improved communication between the MDT.
- Patient choice, support, information needs.
- Timely anticipation of evolving need – equipment and adaptations.
- Social Services referrals and interventions.
- Timely interventions in accordance with identified need and patient's wishes.
- Avoidance of unwanted emergency admissions to hospital.
- MND CNS support.
- Advanced care planning – end of life care.

MND supportive and palliative care pathway project

- Steering group
- Grant 'Care beyond cancer' Help the Hospices and St James's Place.
- Project worker 1 year 20 hrs per week.
- Task and finish groups.

Timely interventions

Enteral feeding

- HENS
- Dietician
- Nutrition Specialist Nurse
- MND CNS
- Palliative Care Consultant
- MND project worker

Developments

- Alternative methods researched and investigated.
- Check lists devised.
- Referral and supportive pathway established.

Ventilation

- MND CNS
- ITU Nurse Consultant
- Respiratory Consultant
- Respiratory Technician
- MND project worker

Patient choice, Information and Support

- Leicestershire MND Association.
- Carers support group.
- Sister Neurology ward.
- Consultant Neurologists.
- MND CNS.
- MND project worker.

Developments

- Improvements around telling the diagnosis.
- Support group.
- Local information and contacts.
- Information pathway and responsibilities.
- Involving patients and carers in service development.

Avoiding unwanted emergency admissions to hospital

- Person with MND and their carer.
- MND association – local and national.
- EMAS Clinical director.
- EMAS PALS.
- EMAS Emergency care practitioner (ECP).
- Consultant in Palliative Medicine.
- Consultant Geriatrician.
- MND project worker

Developments

- Notification DNR .
- ECP treatment at home.
- Which hospital.
- Drugs
- Support group.
- ECP training.
- Advance Care Planning.

Communication

- Whole MDT involved.
- MDT meetings
- Social services representatives attend
- Communication sheet
- Pre respite admission sheet
- Partnership working
- Paperwork and documentation
- Whole pathway

Multi disciplinary Clinic

- Pilot established September at LOROS
- Fortnightly.
- MND CNS, Palliative Care Consultant, MND association, SLT, OT.
- Combine clinic and MDT discussion.
- Evaluation and Review.

Vision

- MND Multidisciplinary clinic and follow up service.
- In consultation with patients, carers and the MDT involved.
- MND supportive and palliative services commissioned as a whole.
- Social services and health working in partnership with voluntary sector.
- MND CNS as Key worker..
- Model for other Long term neurological conditions.

Future

- Further work around specialist equipment.
- Further partnership development with Social Services.
- Educational DVD.