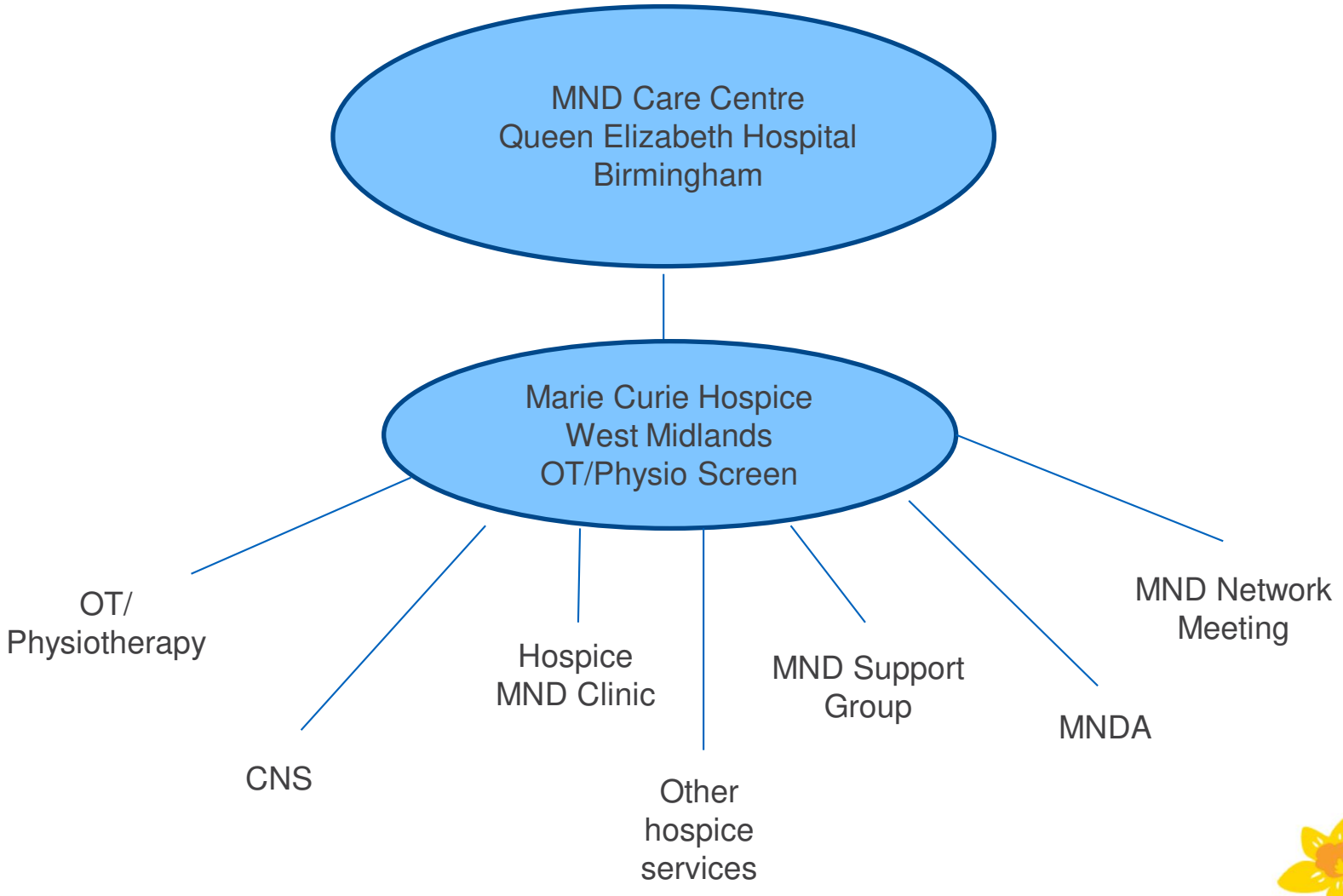
MARIE CURIE WEST MIDLANDS MOTOR NEURONE DISEASE PATHWAYS

Fiona Dawes, Occupational Therapist Marie Curie Hospice West Midlands

Monday 3 June 2019

Solihull MND Pathway



Motor Neurone Disease Care Centre
West Midlands

Based at Queen Elizabeth Hospital, Birmingham
Covers Birmingham, Black Country, Solihull, Worcestershire, South Warwickshire, Hereford and parts of Staffordshire and Shropshire

2 Consultant Neurologists, 2 MND Clinical Nurse Specialists, Physiotherapist, Occupational Therapist, SALT, Dietician, Orthotist and Palliative Care Consultant

2 Consultant outpatient clinic a week
1 MDT clinic every month

Role of the MND Clinical Nurse Specialist

Visit patients at home

Phone/email support line

Support following diagnosis

Referral in community teams

Ongoing patient support

Development of pathways

Attend MDTs and support health professionals in MDTs with patient care

Teaching

Referral to Marie Curie Hospice, Solihull

Referral received from MND CNS at MND Care Centre

Screened by Hospice Occupational Therapist (Fiona Dawes)

Referral directed to the appropriate service at the Hospice

This initially includes:
- OT/ Physio home visit
- CNS referral
- Hospice MND Clinic

Patient is also connected into the MND MDT Network meeting

Occupational Therapy and Physiotherapy Assessment

Takes place in patient's home

Explanation of hospice pathway

Hospice services available - OT/ physio specific assessments

Discussion about MND support group

Informed about MND MDT network group

Contact details for further support

Outcomes may include:

Ordering equipment
Referral to wheelchair services
Referrals to other in MDT – e.g. SALT; dietician; social services; MNDA
Referral to other hospice services

Hospice MND Clinic

From 1st February 2016:

MND nurse-led clinic

OT, physio and community SALT attend

Motor Neurone Disease Association representative present

Held in Marie Curie Hospice, Solihull

Approximately 4 patients and their carers invited every month

OT and physio see patient in one room

MND CNS and SALT see patients in another room

Frequency of attendance dependent on patient need

Transport not provided

Home visit offered if attendance to clinic not possible

Hospice MND Clinic

Background:

Came from a need to improve patients' access to MND MDT support, particularly for those who cannot travel to the Queen Elizabeth Hospital

Access for patients to holistic assessments and support, at local level

Improved MND MDT working

To compliment existing services

Pilot project for 12 months initially

Support Given

Individual health professional assessment

IPOS (Integrated Patient Outcome Scale) completed by OT/ physio

If appropriate, Edinburgh Cognitive Assessment Scale completed

Time for patient to discuss any further questions or concerns

If needed, can be seen urgently by a doctor or nurse

Motor Neurone Disease Association representative can make contact and clinic evaluation form

Any follow-up visit referrals are made

Letter to GP and MND Care Centre

If appropriate, equipment demonstration

Introduction to day hospice team

Patient palliative care CNS can attend if needed

Aims

Provide coordinated care for people with MND & their families, using a clinic-based, specialist MND multidisciplinary team approach (NICE 2016)

Local to people and timely

Introduce people to the hospice and its services early in their journey

Ensure all MND patients have the opportunity to discuss advanced care planning and symptom control

Provide a holistic assessment

Cost neutral

Patient Feedback

"Whole thing has been totally excellent"

"It's local, covers all areas, would be better with a dietician, good parking"

"There is only one conclusion, everything is excellent"

"Nice and relaxed environment. I felt able to ask questions that I hadn't asked before"

"More convenient, it has better parking, access is good, quieter than UHB (regional clinic), it has better access to services"

"I feel better informed about services at the hospice"

MND Support Group

Started in 2013

OT-led (Fiona Dawes)

Regional Care Development Advisor from the MNDA supports (Alison Noakes)

MNDA Volunteers support

Patients and carers meet once a month

Talks from different speakers

Sign-posting of patients to services

Discussion of support available

Links with the MNDA

Meeting with other patients for peer support

MND MDT Network Meeting

Set up in 2003

OT Led (Fiona Dawes)

Every 2 months in hospice

Attended by any Health and Social Care Professional with interest in MND or MND patients

Update on MND research; services etc.

Improvement of services

Discussion of MND patient case loads

Discussion of new referrals

Sharing of information

The aim is to improve communication between MND services to the benefit of the patient

Marie Curie/ Macmillan Palliative Clinical Nurse Specialist

Home visits

Palliative Care Support

Advance Care Planning Support

Symptom management - pain and saliva management

Psychological support for patient and family

Linking with GPs

End-of-life support

Monitoring respite / care support

Liaising with appropriate members of the MDT

Input varies depending on patient stage of disease, and patient need

Other Hospice Services

Day Hospice
Marie Curie Helper Service
Marie Curie Nursing service
Mens Shed
Daffodil Coffee Morning
Complementary Therapy
Respite Care (dependent on funding)
Exercise Groups
Inpatient care – medical support
Access to: Social Worker
Chaplaincy
Pre and post bereavement
Child support
Psychology (dependent on funding)

The Future

More attendance to the MND MDT Network

Constant review of service and improvements based on patient feedback, and changing NHS services

Support for other areas to adopt a similar pathway

Increasing education of health care professionals on MND

Promote hospice services to local GPs

Continue joint working with the MND Care Centre and the MNDA

Any questions?