MND Nurse Specialist/Care co-ordination service

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Background

The Walton Centre is a tertiary/specialist hospital caring for pw Neurological and Neurosurgical needs across Merseyside/Cheshire, North Wales and Isle of Man.

Specialist MND Care Centre in 2000's under the Medical direction of Professor Young

MND Newly Diagnosed clinic every other week

MND follow up clinic weekly

1 nurse specialist:240 pts (approx.)

Dr Sathasivam took over the MND Care Centre as medical director in 2020

MND Newly Diagnosed MDT clinic every week

MND follow up clinic twice weekly

Twice weekly autonomous nurse specialist led clinic

Twice weekly Nurse Advice Line

1 nurse specialist:240 pts (approx.)

Nurse Specialist Role VS Care Co-ordinator/Key worker

Single point contact
Autonomous nurse led clinics
Nurse Advice Line
Symptom control
Care co-ordination
MDT communication
Referrals
Audit/Service Development
Supporting research
Assessments, i.e. FVC/weight/BMI
Education

Built momentum c.2015
1.2wte care co-ordinators in N. Wales
0.6wte key worker in Wirral
Single point of contact
Signposting
CHC support
Home visits/telephone contact
Facilitate MND MDT meetings

MNDA grant application

- Grant application submitted Dec 2022
- Recruited April 2023
- 3.5years funding for 1.0 wte
- Clinical responsibility/autonomy
- Annual report of services to the MNDA

Future Development Objectives:

1. Provide coordinated care for people with MND via a specialist MND multidisciplinary team approach (as per NICE guideline 1.5.1)

2. To establish or formalise MND care pathways throughout Cheshire & Merseyside

3. To improve communication between the MND care centre and local community

4. To improve patient's access to palliative care and end of life services (as per NICE guideline 1.7)

5. To encourage and enable patients to participate in the MND Register

6. To increase access to research for harder to reach patients

7. Develop links/partnerships with the MNDA and the voluntary sector

What we've achieved in year 1:

- Completed competencies
- Attended & developed community MND MDT's
- Participated MNDA care co-ordinators meeting(s) England/Scotland
- Improving patient experience
- Developing Welsh care pathway (in progess)
- MND Register
- NICE audit, Mortality audit, Service evaluation

MND Nurse Clinic Service Evaluation

- Electronic questionnaire
- 60% return rate
- 97% had a telephone appt
- 97% happy with timing of appt
- 58% want a telephone appt next

Recommendations:
- Repeat annually
- Review questions
- Evaluate service specifics

Psychology;
- 64% where asked about their mood
- 52% relatives/carers asked about their mood

67% pf patients are interested in research

Respiratory;
- 94% asked about respiratory symptoms
- Respiratory assessment discussed
  - Yes 52%
  - No 18%
  - N/A 30%
- 42% using NIV
- 24% using a cough assist

Nutrition;
- 79% asked about nutritional needs
- 18% enteral feeding tube was discussed/referred
- 24% had a PEG/RIG

Palliative;
- 30% referred to a hospice/specialist palliative care team
- 52% asked about future care planning
- 39% discussed advanced care planning

Year 2 goals

- Increase autonomous nurse led clinics/NAL capacity
- Assess patient satisfaction of services
- Engage with community AHP’s
- Continue attending MND specific MDT’s
- Scoping of Palliative care services
- Develop local care pathways

Any questions?