

Job Description

Job Title: Motor Neurone Disease (MND) Care Co-ordinator

Department: Patient & Family Services

Responsible to: Myton Clinical Lead for MND

Primary Work Base: Coventry/Warwick/Rugby

(NB as we are a multi- site organisation some flexibility relating to place of work will be required. We reserve the right to change the work base of our employees to meet our business needs.)

Role Purpose:

Working across Coventry and Warwickshire managing the complex and evolving needs of people with MND and Kennedy's Disease. The post holder will bridge the gap between hospital, hospices and home to provide seamless and integrated support. To Coordinate the MND caseload (there is an existing Care Co-ordinator in North Warwickshire) and act as the key point of contact, ensuring seamless care pathways, improved patient experience and timely access to multidisciplinary support as and when appropriate. To work closely with healthcare professionals from all disciplines to co-ordinate a holistic approach to care across the disease trajectory from diagnosis to end of life.

Myton Core Values

Our Core Values underpin everything we do and all employees are expected to comply with our Values and reflect these in their day-to-day work



Main Duties & Responsibilities

Responsible for coordinating the assessment, treatment and support for people living with MND and their families within Coventry and Warwickshire from point of diagnosis. Working with individuals across the community and within acute settings, including hospitals, hospices and nursing homes.

This will involve ensuring continuity whilst achieving patient focussed goals in caring for the complex needs of MND patients and their carers. The post holder will liaise with and support the MND Coordinator for North Warwickshire (based at Mary Ann Evans Hospice) and chair the MND MDTs for Coventry and South Warwickshire. For Coventry, Rugby and South Warwickshire MDTs, the postholder will be the lead specialist, managing the caseload managing the caseload, directing referrals and acting as an advisory role. Working across service boundaries they will act as a single point of contact for patients, families, and healthcare providers, ensuring effective communication, support, and access to multidisciplinary resources that improve quality of life.

A key aspect of the role will require leadership and innovation in service development and delivery, to facilitate appropriate onward referrals and complex management. This will involve working in collaboration with other internal and external services and key stakeholders.

Required to plan and organise their own day to day work and make independent decisions to support patients with complex and often rapidly changing needs, seeking support where required.

The post holder does not have any direct budgetary responsibility but is required to negotiate and commission the purchase or loan of patient equipment and adaptations with statutory bodies, including equipment stores and social services.

Key areas of responsibility and accountability

- Co-ordinate care and provide a single point of access from diagnosis for patient, their families and health and social care professionals.
- Establish a relationship with patients and their families helping to enable them to make informed decisions about treatment/care and advance care planning.
- Provide information to patients and carers to enable them to make informed choices regarding care.
- To co-ordinate MND clinics and the Multidisciplinary teams which promotes a proactive, timely, and holistic approach to the care and management of people living with MND and their families.
- To improve education and awareness amongst health and social care professionals and care staff in the Hospices, hospital, community and relevant care homes of the impact of a diagnosis of MND on the patients, families and carers.
- Lead the coordination of the multi-disciplinary team (MDT) meetings pre and post the combined clinic and then to disseminate care plans to community allied health care professionals.

- Co-ordinate care between the specialist practitioners within the hospital, the Community Health and Social Care teams, hospices services and tertiary centres.
- To undertake appropriate coordination of onward referrals.
- Maintain close collaboration and communication with MND Association regional staff and with a view to promoting the MND Association and the services it provides for people affected by MND.
- To attend – as appropriate – local MND Association Support Group meetings
- To vary the style and level of communication with individuals in order to meet the differing levels of understanding. Including those with cognitive impairment and those with additional communication needs.
- Maintain and update electronic patient records (EPR) where appropriate
- To process patient referrals as the single point of access and liaise closely and align with already established MND Co-ordination in the North of the County.
- To receive and make referrals to the MND Association as appropriate
- To support the process of audit and service evaluation in collaboration with the MND Association.
- To support the family bereavement process including follow up support and notifying other agencies involved in the patients care about their death.

Care Coordination

- Undertake complex holistic needs assessments and complete management plans across the disease trajectory from diagnosis to end of life.
- To co-ordinate with key workers within the community to prevent delays in supportive treatment and to avoid hospital admissions.
- To support, within the relevant care setting, those newly diagnosed with MND.
- To work collaboratively with regional partners such as Birmingham MND Care Centre, University Hospital of Coventry and Warwickshire, Mary Ann Evans Hospice, The Shakespeare Hospice, to ensure timely, high quality, equitable care for all people with MND in the Coventry and Warwickshire ICB footprint.
- To support early identification and review of inpatients and co-ordinate with community teams to reduce length of stay.
- Use highly specialised knowledge to work with people with MND, and their families in outpatient clinics, in-patient settings, their own homes and other settings to manage symptoms and provide support.
- Demonstrate the use of advanced communication skills where appropriate to support patients and families through life changing events.
- Initiate and make referrals to Consultants, Physiotherapists, Nutritional, Respiratory and other Specialist services where required.
- Have an understanding and awareness of the range of MDT professionals care input that will promote quality of life for people with MND, for example orthotics, OT equipment, warning signs of dysphagia, voice banking, weight loss and nutrition.

Management

- Co-ordinate specialist care following the diagnosis of MND.
- Provide an advisory service across the whole of Coventry and Warwickshire as and when required acting as a point of reference and specialist advice for patients, families and health and social care professionals
- Be responsible for planning and development of services within the local area: identifying gaps in service, areas of good practice and ways to address service improvement.
- Be responsible for the development and running of MND MDT clinics.
- Facilitate a seamless service in partnership and collaboration with all multi and interdisciplinary agencies and persons involved.

Professional Development

- Maintain professional registration at all times.
- Maintain excellent standards of documentation and be able to provide information regarding the present needs of people with MND.
- Maintain evidenced continued professional development.
- Attend annual MND Association Care Centre and Network Day, Regional Special interest groups and become an active member of the Association's Community of Practice.

Leadership

- Act as a positive role model and provide clinical leadership.
- Demonstrate the highest professional standards and support the development of clinical expertise.
- Lead the development of practice within post holder's specific area of professional practice.
- Establish and lead Multidisciplinary teams in order to provide a systematic and holistic approach to care and management of people with MND.
- Provide effective local leadership and support of staff, planning and directing activities to provide optimal standards of care.
- Support MDT staff to feel confident and competent in delivering care to people with MND.
- Explore and develop local pathways to recognise unmet need.
- Advise, initiate, facilitate and implement changes in clinical practice to meet policy or service development for specialist area, which may impact on other disciplines.

Communication

- Demonstrate excellent communication and organisational skills in balancing the demands of this unpredictable and complex condition.
- Assess complex issues and facilitate decision-making relating to patient care, safety, treatment options and outcomes, and supervise others in doing this.
- Acknowledge and accommodate barriers to communication and understanding including speech, hearing, language and emotion.

- Use skills (visual and auditory) to interpret the spoken word and understand patient dialogue, i.e. being empathic, patient and able to concentrate on the spoken word when patients struggle to form words and sentences.
- Use advanced verbal and non-verbal communication skills to impart sensitive, complex and potentially distressing information to patients and carers regarding disease progression.
- Communicate highly complex, sensitive information with people with MND and carers on MND to ensure their active involvement in the medical care planning, treatment delivery and informed consent process.
- Assist people with MND, families and carers to develop understanding of MND promoting self-management.
- Communicate in ways that empower patients to make informed choices about their health and care.
- Provide specialist advice to a range of health care professionals within the scope of specialist practice.
- Liaise with other members of the multidisciplinary team to achieve optimum levels of care in relation to specialised area of practice.
- Access external networks with peers to share good practice.
- Present highly complex and sensitive information within a variety of both formal and informal settings.
- Build and maintain links with local professionals and voluntary services and develop expert knowledge of other local resources that can provide help and support with e.g. benefits and bereavement services.
- Develop and maintain an up-to-date database of local resources that can meet the needs of people with MND and their families.

Leading Service development:

- Work with partners and commissioners to review and streamline pathways for accessing appropriate care and interventions e.g. gastrostomy insertion, ensuring equity for patients across the region.
- Working with partners, develop and implement pathways to ensure that all people with MND have timely access to genetic testing and access to disease modifying medication such as Tofersen if appropriate.
- Deliver Training and education for patients/family and carers, and health care professionals (internally/externally) for complex case management, neuro-respiratory conditions and interventions.
- Service evaluation - Collates and records quantitative and qualitative data to provide evidence of productivity, outcomes and quality, through audit and research
- Work in liaison with the MND Association regarding grant, priorities, auditing.
- Work in partnership with the MND Association on initiatives to develop and improve services to support people with MND, their families and carers.
- Develops new skills in response to emerging knowledge and techniques.
- Instigates and manages change within a complex environment and advising other clinicians, social care professionals, and voluntary agencies on the development of services for people with MND.
- Develop, implement and evaluate policies relevant to own area of work and within the parameters of the MND Association objectives.

- Establish working links with the MND Association to ensure access for patients and families to the local support offered through volunteers, branches and support groups.

Education and Training

- To proactively lead and develop knowledge and skills in others through formal and informal education
- To act as a senior clinical role model to other clinical staff in supporting the development of others, sharing advanced level knowledge and skills
- To lead the planning and delivery of high-quality education and training events including but not limited to topics like End-of-Life Care (EOLC), respiratory care for both internal and external provision
- To provide training and supervision for other staff members on the use of specialised equipment and develop supporting documentation for this.
- Lead on submitting articles for publication to share improvement work

Key Contacts

- University Hospital of Coventry and Warwickshire neurology department
- Birmingham MND Care Centre – Care Coordinator and Specialist Nurse.
- Patients and family members living with MND or Kennedy's Disease.
- Coventry and Warwickshire Hospices Clinical Leads Therapy & Family support services
- Therapy teams
- Clinical admin Team
- MND MDT (Speech and Language Therapy, Dieticians, OT, Physio, Palliative Care, Social Care etc)
- Sleep Service
- Consultants e.g. Respiratory, Neurology, Palliative Care, General practitioners
- Motor Neurone Disease Association & other relevant charities
- Respiratory nurse specialist
- Neurology outpatients
- Community services (e.g. wheelchair services, oxygen services, etc)
- All appropriate key Stakeholders / Partners
- Suppliers / agencies and other bodies, commercial and non-commercial, relevant to the role and purpose of the post.
- General public

GENERAL RESPONSIBILITIES & OBLIGATIONS OF ALL EMPLOYEES

Policies and Procedures

The post holder is required to have a good understanding of and to comply with all relevant Myton policies, procedures and guidelines. Any contravention of Myton policies or procedures may result in disciplinary action.

Volunteers

Myton recognises the valuable contribution that volunteers make and we expect all employees to be able to support and work effectively with our volunteers.

Confidentiality and Data protection

It is a requirement of employment with Myton that all staff must comply with the obligation of confidentiality relating to personal information that could identify individuals. The Data Protection Act 1974/1998 safeguards the handling of information held in both electronic and manual filing systems and it is the duty of all staff employed by Myton to uphold the principles of the Act, adhere to Myton policies and to maintain strict confidentiality at all times.

Infection Control

All employees of Myton must be aware of infection prevention and control policies and are expected to follow them at all times. Any breach of infection control policies which places patients, visitors or colleagues at risk may result in disciplinary action.

Equality & Diversity

The post-holder must at all times carry out his/her responsibilities in line with Myton's Equality & Diversity Policy.

Health & Safety

Employees must be aware of the responsibilities placed upon them under the Health and Safety at Work Act 1974, to ensure the agreed safety procedures are carried out to maintain a safe working environment for patients, visitors & colleagues. The post holder is required to conform with Myton's policies on Health & Safety and Fire Prevention, & to attend related training as required.

Safeguarding Vulnerable Adults and Children

It's the duty of all staff working for Myton to safeguard children and vulnerable adults and undertake safeguarding training at an appropriate level.

Code of Conduct

Employees are required to represent Myton in a positive light and embody the corporate identity in appearance, demeanour, values and ethics.

Review of Job Description

This job description is an outline of the key duties and responsibilities of the role and is not intended as an exhaustive list. The job description may change over time to reflect the changing needs of the service. The post holder may be required to undertake other duties that could reasonably be considered commensurate with the post. This job description is subject to periodic review and may be changed/updated following consultation with the postholder(s).

Employee/Managers Signature

I agree that this Job Description is a true reflection of the main duties and responsibilities of my role:

Employee Name: _____

Signature: _____ **Date:** _____

Managers Name: _____

Signature: _____

Date: _____

Last reviewed June 2026