

National Clinical Programme for Neurology

Model of care

The aims of the Neurological Programme are;
To improve access to services
To improve the quality of Neurological care

Once diagnosed information about MS, what it is, it's course, symptom management, and psychosocial implications should be provided.

The programme will aim to **EMPOWER** people living with neurological conditions.

MS is one of four conditions with a specific diagnosis and treatment pathway. This pathway is an outline of anticipated multidisciplinary care, set in an appropriate timeframe.

Treating Symptoms

Commence Disease Modifying Therapy

Relapse Management

Review Appointments

MS PATHWAY

Welcome to the community

Access to MS Nursing Services

Info Advice on Treat and Self-care

From diagnosis **NO** more than 6 weeks

At the moment only 50% are within this timeframe.

BUT

To achieve this we must first distinguish between **URGENT & ROUTINE**

TO NEURO Consultation

Clear lines of communication will be developed between community and hospital based staff to ensure continuity of patient care

Model of Care - National Clinical Programme for Neurology

What does it mean for people with MS?

The model of care of The National Clinical Programme for Neurology, which was launched on 27th September 2016, is a blueprint for the future set up of neurological services for Ireland. The model of care was developed with input from a wide range of key stakeholders including clinicians, patient organisations and people with neurological conditions and their families.

Below is a summary of the content of the Model of Care document, with particular reference to how it relates to the diagnosis, treatment and management of multiple sclerosis.

Recommendations

The main recommendations in the Model of care are:

- 1. Optimising service delivery and Multidisciplinary care** – e.g. addressing gaps in services, ensuring access to multidisciplinary therapies (e.g. physiotherapy, occupational therapy etc)
- 2. Staffing & resourcing within neurology** - Ensuring safe standards of staffing in line with international best practice
- 3. Service configuration and managed clinical networks**
- 4. Links to other health specialities** - e.g. providing support for GPs in managing MS; clear lines of communication between the hospital and the community; collaborating with other healthcare professionals with different specialities as necessary
- 5. Medicines management & access to diagnostics** – equal and fair access to diagnostic services including MRI scans; centralised funding for high cost medications to ensure fair and equitable access (for example, MS medications that are delivered via hospital-only infusions)
- 6. Education & Training** - Supporting the development of advanced practice for healthcare professionals
- 7. Research & Programme Metrics** – development of high quality research; national register of patients with neurological conditions
- 8. Cross programme collaboration** - Recognition of the opportunity to learn from colleagues

Implementation

An implementation framework will be developed for the Model of Care of the Neurology Programme. The implementation of the model of care will be on a phased basis and will be subject

to appropriate resourcing of services. The implementation framework will include the following areas:

1. Review of priority areas for resourcing

Based on the findings from the national survey of neurology centres, priority areas for increasing resources will be identified and business cases and submissions prepared to increase resources in these areas, as part of a process of bringing Ireland's neurology services in line with international recommended standards.

2. Review of access to diagnostics

Engagement with key stakeholders to develop recommendations to address access issues and waiting times for diagnostic services.

3. Equitable access to high cost MS medications

A national reimbursement scheme for MS medications that are currently delivered in hospitals (Lemtrada and Tysabri) is under development. Upon implementation, the current inequities in access to these treatments, which currently depend on the budgets of individual hospitals, will be minimised.

4. Collaborative projects

Various collaborations are identified, including working with the Social Care Division and Rehabilitation Medicine Programme regarding the implementation of the National Strategy & Policy for Neurorehabilitation Services in Ireland (2011-2015). This will include development of regional neurorehabilitation facilities and community based neurorehabilitation teams.

Multiple Sclerosis Pathway

MS is one of four conditions with a specific diagnosis and treatment pathway identified in the model of care (the others being Parkinson's Disease, Headache and Motor Neurone Disease).

Referral management

A person with suspected MS should be referred to a neurologist and seen within a specified timeframe. The model of care references the UK NICE guidelines for the recommended timeframe, which is six weeks from referral to neurology consultation and then six weeks to diagnosis of MS. Currently in Ireland, an audit of one MS centre suggests just over 50% of people with suspected MS are receiving a diagnosis within these timeframes. Where delays occur, these are mainly due to delayed access to MRI and deficiencies in administrative support.

The model of care recommends the need to develop a standardised referral pathway from GP to Neurologist and standardisation of information sharing between GPs, Neurologists and administrative staff. These should include referral guidelines which distinguish between urgent and

routine referrals. IT systems should also be improved to support referrals and tracking of information.

Confirm diagnosis of MS

A Consultant Neurologist should make the diagnosis of MS on the basis of established up-to-date criteria, such as the 2010 McDonald Criteria. Following diagnosis, the person with MS and their family members should be offered verbal and written information regarding the following:

- About MS, its course, symptom management and psychosocial implications
- Adjustments and modifications that may be necessary to lifestyle, setting priorities and promoting self-care
- Information about counselling, support groups, entitlements and other sources of information, advice and support
- Self-care, improvement of coping skills and facilitation of communication about needs and concerns

Consultation with service users

When developing the pathway, the neurology programme, supported by MS Ireland, carried out a number of focus groups with people with MS and their families/carers.

When asked about their requirements for healthcare services, the attendees at the focus groups highlighted the following:

- The need for primary care support
- The need for access to community services, particularly rehabilitation and support groups
- The need for vocational support
- Support in relation to health promotion and keeping healthy
- Access to therapies as needed

When asked about current challenges they faced, the following were identified as recurrent themes:

- Lack of knowledge of MS among general healthcare staff at both hospital and community level
- Poor links between hospital and community
- Repeated avoidable admissions through ED
- Long waiting times for neurology appointments and when at neurology clinics
- Limited access to respite care
- Limited access to health and social care professionals at both hospital and community level
- Delays in receiving entitlements which causes stress and anxiety
- Restrictions in access to medical cards
- Limited access to equipment
- Lack of home help and PA services

Access to MS Nursing services

Currently the average caseload for an MS Nurse in Ireland is 844 people per one full-time nurse. This is more than twice the caseload level recommended by UK best practice guidelines. These deficits must be addressed so that the MS Nurse can be available to provide the following supports:

- Information and support at diagnosis – information about MS, the likely disease course, advice on self-management
- Education on treatment options – the potential benefits, risks and common side-effects associated with the various disease modifying therapies
- Telephone support – advice relating to medication management, symptom management and support in challenging times
- Relapse management

Commence Disease Modifying Therapy (DMT)

Initiation of therapy is advised as soon as possible following a diagnosis of MS and determination of a relapsing course. People with MS should have the opportunity to actively participate in decision - making and should be fully informed of all treatment options open to them. Once established in a course of treatment, people with MS should attend a specialist clinic regularly for monitoring and review. Access to therapy should be equitable and in no way impacted by the person's demographics (e.g. which hospital they attend).

The Neurology Programme also supports the development of a national treatment registry for all MS patients in Ireland. The aim of such a registry would be to encourage regular reviews of MS patients where their clinical progress is assessed. Based on this clinical evaluation, recommendations would be given with respect to changes in their prescriptions. These changes could be changing medication type, increasing or decreasing dosage and discontinuation of treatments which are not proving effective.

Treating symptoms

There are different options that can be taken to manage MS symptoms, both pharmacological and non-pharmacological. Treatment options should be made with the person with MS, with their personal choice reflected in the decisions made. Pharmacological treatments should be initiated by the treating Neurologist. Adherence and the success of these treatments can be managed via the MS Nurse. The MS Nurse and multi-disciplinary team should also play a role in advising about non-pharmacological treatment options for symptom management.

Relapse

The following treatment pathway for MS relapses is recommended:

1. Referral is triaged; those requiring urgent care are referred for an urgent appointment with a neurology centre

2. The Nurse Specialist is usually the first point of contact and they will facilitate the patient if an urgent appointment is required. It is recommended that assessment/review slots should be left available in clinics on a weekly basis to accommodate urgent referrals
3. A face to face relapse assessment is carried out where the relapse is confirmed. Relapse is defined as:
 - New or worsening of symptoms attributable to MS lasting greater than 24 hours in the absence of temperature and a period of 30 days should be observed between each event to differentiate separate attacks
 - Symptoms should be persistent
4. The management of relapse may be treated with a short course of Intravenous Methylprednisolone (IVMP) which can hasten recovery from the attack, as per each Neurology centre protocol. Oral treatments may also be used if the Neurologist deems it appropriate to do so. Short and long-term side effects should be fully explained to the person with MS
5. Admission may be necessary if the relapse is considered severe

Review appointments

Regular review appointments should be scheduled taking into account the needs of the person with MS and the course the disease is taking. While specific recommendations are not given in relation to timeframes between reviews, an annual review would be considered appropriate. Symptoms and impacts on lifestyle should be discussed at each review, as applicable.

Rehabilitation Services:

Role of Physiotherapist

Physiotherapists are essential in the management of MS. Considerable research evidence supports the benefits of both inpatient and community physiotherapy for people with MS. NICE guidelines recommend regular access to physiotherapy for people with MS especially at time of relapse or when any sudden increase in disability or dependence. They recommend a specialised neurological physiotherapy assessment and management to help with problems with mobility, spasticity and weakness.

Guidelines recommend a combination of strength and endurance training and specific exercises to improve activities of daily living. It is recommended that people with MS are able to access the advice of a chartered physiotherapist before engaging in any exercise programme. The physiotherapist may also have a role in tailoring interventions to people with MS with greater limitations in activities, and in facilitating behaviour change.

Role of Occupational Therapist

Occupational therapists set goals with each person with MS to address their functional independence, including:

- Cognitive rehabilitation therapy
- Insight and awareness training

- Functional re-training
- Upper limb assessment
- Postural management
- Fatigue and pain management
- Education and emotional support

Role of the Speech and Language Therapist

Any person with MS should be referred to an SLT if there are concerns relating to speech, language, voice or swallowing problems. People with swallowing problems or newly diagnosed or deteriorating communication problems should be assessed by an SLT as soon as possible.

People with MS should have regular reviews with SLTs to monitor changing communication ability, eating, drinking and swallowing ability as the condition progresses.

Role of the Dietician

As MS progresses, a wide range of complications can develop, some of which can compromise nutritional status. Support provided by a dietician may include:

- Assessment and treatment of people deemed at risk of malnutrition
- Ensuring nutritional adequacy of modified consistency diets
- Advice regarding the importance of nutritionally balanced diets and risks involved with restrictive exclusion diets
- Involvement in the decision making process for people being considered for gastrostomy insertion

Dietetic services need to be made available for all community settings including non-HSE funded nursing homes and for domiciliary visits as needed.

Role of the Orthoptist

People with MS who have eye symptoms such as blurred vision require orthoptic services to manage their symptoms and for appropriate referrals, assessments and screenings. Close links need to be established between orthoptics and neurology, to ensure all people with MS have access to this pathway.

Role of Neuropsychologist

The unpredictable course of MS may lead to diverse cognitive difficulties, which can often be best understood and ameliorated once understood fully through detailed neuropsychological assessment. Informed by this assessment, neuropsychologists can support individuals, their families and clinicians to understand and manage these difficulties appropriately. In cases where people may have very significant cognitive difficulties, neuropsychological assessments can be invaluable in informing behaviour management plans, in establishing long term care choices and needs or in assessing capacity to make treatment or other decisions.

Referral to other services

As MS is a long term condition, the vast proportion of care and treatment is provided in a non-hospital setting. The neurology programme recognises that the effective management of MS is reliant on a range of other services and supports within the healthcare system including:

- An effective response in primary care for diagnosis and ongoing management
- Access to multidisciplinary neurorehabilitation services within both the hospital and the community
- Access to respite care and long term care supports
- Access to palliative care services
- Access to a range of disability and healthcare supports such as equipment, medical cards, personal assistants and home care packages
- Continuation of services and supports once people with MS reach the age of 65, with a smooth transition to older people's services

Role of MS Ireland

MS Ireland is recognised by the neurology programme as playing an important role in supporting, educating and advising people with MS and their families from their diagnosis throughout their journey with MS.

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