

# NHS RIGHTCARE PROGRESSIVE NEUROLOGICAL CONDITIONS TOOLKIT

NHS England, MS Trust, Parkinson's UK et al

## Why is a toolkit needed?

People with progressive neurological conditions are experiencing delays in diagnosis and treatment, uncoordinated services, limited availability of neurospecialist rehab and a lack of psycho social support. This toolkit aims to address these issues with advice and guidance on how to tackle the key challenges when treating people with progressive neurological conditions.



**Multiple sclerosis • Motor neurone disease • Parkinson's disease • Multiple system atrophy • Progressive supranuclear palsy • Corticobasal degeneration**

**Around £10m could be saved on emergency admissions for MS, Parkinson's and motor neurone disease combined and 2,500 fewer emergency admissions could be avoided if CCGs achieved the rate of their best 5 peers.**

## The National Challenges for multiple sclerosis

- Increasing specialist nurse and neurologist capacity and getting the best value from MS services.
- Ensuring that high quality care is joined up and coordinated across the whole pathway for all MS patients.
- Improving care and coordination for advanced MS patients.
- Reducing the burden of the DMD pathway on MS services.

## Four priorities were identified for the multiple sclerosis care pathway

### 1. Formalised MDTs across specialised teams

*Increasing formal multidisciplinary working would help to get the best out of specialist resources by ensuring that the right members of the multidisciplinary team are involved at the optimal time for patient care.*

#### Actions to take

- Ensure there is an appropriate level of administration support available to support specialists.
- Ensure that nurse specialists have dedicated administration support available to them.
- Formalise shared care MDT arrangements across a range of disciplines.
- Formalise MDT networks across different healthcare settings.
- Have a network of care coordinators equivalent role to support patient journeys through the system
- Ensure that all patients are provided with a named care coordinator.

### 2. Better use of data technology

*Improving access to data and technology will improve patient care. Information will be real time and will not require repetition from the patient, which takes up valuable clinic time. Shared protocols on information sharing across MS teams and providers is essential, so that the DMD coordinator has access to a system for tracking everyone on the caseload.*

- Use of digital tools will support people with MS to self manage
- Digital care planning employed where appropriate
- Improved data analysis around MRI planning and avoidable hospital admissions

#### Actions to take

- Develop shared protocols on information sharing between settings.
- Locally implement the use of MS specific database systems, such as iMed and DAWN.
- If technology does not allow the use of systems such as iMed and DAWN develop an excel database incorporating monitoring review dates.
- Assess the individual's ability to use digital tools and apps to self manage.
- Signpost patients to available tools and apps.
- Where appropriate provide patients with access to an electronic written care plan.
- If information systems allow, ensure this care plan is accessible to all those health and care professionals involved in a patient's care in accordance with patient consent.
- Ensure patients are offered opportunities across the care pathway to co-produce a care plan with a healthcare professional and to review that plan when circumstances/their condition changes.
- Routinely analyse diagnostic imaging datasets to understand how long people are waiting for MRIs and to implement effective services.

### 3. Improved DMD administration

*DMDs vary in terms of their benefit/risk profiles. All carry risks and need to be prescribed and monitored by an MS specialist teams. As a result MS teams have become increasingly overwhelmed by the workload associated with DMD provision. Improved administration for DMDs will free up valuable clinical specialists time.*

- Increased use of pharmacists for monitoring DMDs
- Use of virtual clinics and telemedicine, to communicate blood test results with patients
- Workforce training and development for MS nurse specialists to request repeat prescribing and MRIs.
- Ability to schedule blood tests without MS nurse or neurology appointments first

#### Actions to take

- Ensure formal MDT arrangements are in place between pharmacists and specialist prescribers
- Workforce training for MS nurse specialists to request repeat prescribing and MRIs
- Develop protocols for nurse specialists to be able to order MRIs
- Increased use of virtual clinics and increased use of telemedicine to get blood test results
- Implement virtual clinics for routine appointments or to receive test results
- Ability to schedule blood tests without MS nurse or neurology appointments first

### 4. Comprehensive access to holistic support (particularly for advanced MS patients)

*A holistic flexible MS service with strong referral routes into community support and specialist therapies will significantly improve care and outcomes for people with MS leading to improved quality of life.*

- Access and referral to local, community based, and other specialist services including; fatigue management, emotional support, peer support, neuro rehab, vocational rehab, palliative care, neuropsychology services.
- Patients with progressive MS should be offered an annual review with an appropriate member of the MS MDT.
- Named professional lead for advanced MS in every MS team.

#### Actions to take

- Have a local directory of services and support available, to enable ease of signposting or referral for people with MS. This should include national organisations and helplines.
- Commission a range of holistic community and specialist support services to meet the needs of the local population with MS and develop quick and easy referral pathways into such services.
- Offer patients with progressive MS an annual review with an appropriate member of the MS MDT.
- Ensure that all patients are reviewed at least annually to identify any changing needs.
- Named professional lead for advanced MS in every MS team.
- Have a network of professional leads that can be assigned to each MS patient.

**To view the full toolkit visit: [www.england.nhs.uk/rightcare/products/pathways/progressive-neurological-conditions-toolkit](http://www.england.nhs.uk/rightcare/products/pathways/progressive-neurological-conditions-toolkit)**