ABN’s quality standards to support models of good practice
February 2016

Contents

1) SCHEDULED CARE: NON-URGENT NEUROLOGICAL CONDITIONS 2
2) UNSCHEDULED CARE: NEUROLOGICAL EMERGENCIES AND ACUTE NEUROLOGY 3
3) PARKINSON'S DISEASE 4
4) TREATMENT OF DYSTONIA WITH BOTULINUM TOXIN 5
5) HUNTINGTON'S DISEASE 6
6) MOTOR NEURONE DISEASE 7
7) NEUROMUSCULAR DISORDERS 9
8) PERIPHERAL NEUROPATHY 10
9) MULTIPLE SCLEROSIS 11
1) Scheduled care: non-urgent neurological conditions

Revised February 2016 by the ABN Acute Neurology Advisory Group

Introduction
Patients are frequently referred to neurologists for advice on diagnosis and management of their symptoms. As a result, quality standards that are written on the basis of diagnosis are not applicable. For example, patients with numbness and tingling of the hand might have carpal tunnel syndrome, a cervical disc, multiple sclerosis, or a brain tumour. Thus many patients will be referred to general neurology out-patients for which generic standards are required. These standards refer to a pre-diagnosis care pathway.

Statement 1 New patients referred to the general neurology service will be seen in a timely fashion: in keeping with NICE guidance where appropriate (eg first seizure, 2 weeks) and within NHS waiting time standards for England, Scotland Wales or N Ireland (eg 13 weeks to meet 18 week standard in England)

Statement 2 General practitioners will have access to advice from a neurologist by letter, phone or email.

Statement 3 All neurology patients should have a plan of care indicating the diagnosis intended investigation pathway, treatment and where necessary the arrangement for follow up. In most cases, hospital policy dictates that all clinic letters are copied to the patient, which provides the relevant information. Patients should be entitled to receive written information within 5 days following their appointment.

Statement 4 Patients will have appropriate access to follow up appointments with the neurology team, to discuss results or monitor progress, at the time interval stated in their care plan. Patients with long term neurological conditions will have a named point of contact for re-accessing the service, in keeping with appropriate Quality Standard/NICE guidance) (eg Parkinson's disease, 2 weeks)

Statement 5 The service will be provided by appropriately trained and revalidated neurologists and members of the neurological care team, including specialist nurses, General Practitioners with a special interest (GPSI) and junior doctors, who will be appropriately trained and work within an appropriate framework of supervision and clinical governance.

Statement 6 Patients accessing the neurology service will have appropriate and timely access to neuro-imaging (MRI and CT), neurophysiology, neuropsychological testing, and ancillary investigations (serology and lumbar puncture), including in-patient assessment where indicated.

Statement 7 The service will have appropriate access to neurological rehabilitation including physiotherapy, occupational therapy, speech and language therapy, dietetics and neuro-psychology. Any patient discharged from hospital should have an appropriate handover to a ‘named, accountable GP’.

Statement 8 The service will have clear referral pathways to neurosurgery and orthopaedic spinal surgery.

Statement 9 The service will provide, where appropriate, information facilitating access for patients to enrol in clinical trials.

Statement 10 The service will maintain expertise through training, audit, and continued professional development.
2) Unscheduled care: neurological emergencies and acute neurology

Revised February 2016 by the ABN Acute Neurology Advisory Group

Introduction: These quality standards apply to patients with symptoms and signs consistent with an acute neurological problem (e.g. acute headache, confusion, seizure, progressive weakness). The problem in some patients will constitute a neurological emergency that may require inpatient care supervised by a neurologist. Patients with acute neurological problems will benefit from, and can be managed effectively and safely in a general medical setting if adequate neurology liaison services are available, coupled with rapid access outpatient neurology services. Patient presenting with features of a stroke will have access to a stroke pathway, but as many will turn out not to have had a stroke (stroke mimics), close cooperation between stroke and acute neurology services is important.

Statement 1 - Adults referred to hospital as a neurological emergency should have access to care in an appropriate inpatient setting without delay (no more than 2 hours after presentation to hospital).1

Statement 2 - Adults admitted as a neurological emergency should be able to receive advice on their management from a neurology specialist at all times.

Statement 3 - Adults admitted as a neurological emergency should see a neurology specialist within 24 hours of admission to hospital.

Statement 4 - Adults referred to hospital with an acute neurological problem should have access to care in appropriate inpatient setting within 4 hours after presentation to hospital.2

Statement 5 - Adults admitted to Acute Medical Units with an acute neurological problem should have access to daily consultation or advice from neurology specialists, if necessary by telemedicine.

Statement 6 - Adults admitted to hospital with an acute neurological problem should have access to urgent inpatient imaging (CT and MRI) where indicated.

Statement 7 - Lumbar Puncture, when indicated, should be available 24/7 to all patients admitted with an acute neurological problem

Statement 8 - Rapid access pathways need to be established for adults referred from Emergency Departments and Acute Medical Units to neurology outpatient services on discharge. 3

Statement 9 - No patient should be discharged from a hospital setting without documentation of the neurological examination, including fundoscopy.

Statement 10 - Immediate transfer of care information should be sent electronically to a named GP for all patients, as well as printed information for the patient.

1Depending on the nature of the emergency this may be Critical care, High Dependency Unit or specialist neurology inpatient care. If a hospital lacks appropriate facilities to care for a neurological emergency, pathways need to be established for patients to be transferred to such a setting with staff trained in the care of adults with neurological emergencies

2Depending on the nature of the acute neurological problem and the setting, this may be an Acute Medical Unit or specialist neurology inpatient care.

3Where doubt exists over suitability for early discharge and for any referral to a rapid access neurology clinic this is best discussed with a neurology specialist.
3) Parkinson's disease

Revised February 2016 by the ABN Movement Disorders Advisory Group

**Statement 1:** People with suspected Parkinson's disease should be referred untreated to a specialist with expertise in the differential diagnosis and treatment of the condition and seen within 13 weeks of referral.

**Statement 2:** The diagnosis of Parkinson's disease should be reviewed at 6 to 12 month intervals and reconsidered if atypical clinical features develop.

**Statement 3:** $^{123}$I-FP-CIT SPECT should be available to specialists with expertise in its use and interpretation for appropriately selected patients.

**Statement 4:** People with Parkinson's disease should be reviewed regularly to monitor and treat the motor and non-motor features of the condition, including neuropsychiatric symptoms.

**Statement 5:** People with advanced Parkinson's disease, where oral and transdermal therapies are insufficient to control the condition, should be considered for apomorphine infusion, deep brain stimulation surgery or levodopa-carbidopa gel infusion.

**Statement 6:** People with Parkinson's disease should have regular access to a multidisciplinary team comprised of at least a Parkinson's Disease Nurse Specialist, physiotherapist, occupational therapist, dietician, speech and language therapist and mental health team with experience in managing the neuropsychiatry of Parkinson’s and related disorders.

**Statement 7:** People with Parkinson's disease and their carers should be given the opportunity, at an appropriate stage, to discuss end-of-life issues with appropriate healthcare professionals.

**Statement 8:** People with Parkinson’s have a right to their prescribed medication at the right time specified by their prescription.

**Statement 9:** End of life care includes health care professionals to be responsible to continue to administer medications in the patient's best interests.
4) Treatment of dystonia with botulinum toxin

Revised February 2016 by the ABN Movement Disorders Advisory Group

Statement 1 Patients with suspected dystonia should be referred to a specialist with expertise in the differential diagnosis and treatment of the condition.

Statement 2 Botulinum toxin injections are the main treatment approach for patients with primary focal dystonia such as blepharospasm, cervical dystonia, upper limb dystonia and laryngeal dystonia.

Statement 3 Adults, who require Botulinum toxin injections, have access to specialised Botulinum toxin services within 2 months of diagnosis.

Statement 4 The Botulinum toxin service will be located within reasonable travelling distance from the patient’s home address.

Statement 5 The patients who benefit from Botulinum Toxin injections, are treated at intervals, adjusted to the duration of the therapeutic benefit of the treatment (usually 2 to 4 months, sometimes longer).

Statement 6 Patients treated with Botulinum toxin can contact member of the medical team in case of side effects, discussed at the time of consultation.

Statement 7 Patients who do not benefit from Botulinum toxin (non responders) are identified early and referred to a specialist centre with EMG and/or ultrasound facilities to review diagnosis, treatment and injection procedure.

Statement 8 Each treatment centre records at the time of each injection, interval time, duration of benefit, response, side effects from last injection and brand of Botulinum toxin injected, dosage and sites of injection.

Statement 9 Each treatment centre should audit outcome and safety.
**5) Huntington's disease**

Revised February 2016 by the ABN Movement Disorders Advisory Group

**Statement 1** People with suspected or proven Huntington’s disease should be referred to a specialist with expertise in the differential diagnosis and treatment of the condition and seen within 6 weeks of referral.

**Statement 2** All relevant investigations, in particular direct genetic testing, should be available to specialists with expertise in their use and interpretation.

**Statement 3** Clear local or regional referral guidelines and care pathways should be in place to ensure that people with Huntington’s disease will be reviewed in a multidisciplinary setting with input from neurologists, psychiatrists, clinical geneticists and other relevant specialties.

**Statement 4** Management of Huntington’s disease should focus on the priorities of the patient and their family with the aim of preventing avoidable complications and retaining function and autonomy. Their management should include both pharmacological therapy and non-pharmacological treatment options (e.g. physiotherapy, occupational therapy, speech and language therapy).

**Statement 5** Huntington’s disease specialists should work closely together with Huntington’s Disease Association (HDA)-regional care advisors to improve continuity of care.

**Statement 6** People with Huntington’s disease and their carers should be given the opportunity, at an appropriate stage, to discuss advance care planning/end-of-life issues with appropriate healthcare professionals.
6) Motor neurone disease

Revised February 2016 by the ABN Neuromuscular Disorders Advisory Group

**Statement 1** Patients with symptoms suggestive of motor neuron disease (also called amyotrophic lateral sclerosis) should be assessed as soon as possible by an experienced neurologist. Early diagnosis should be pursued, and investigations, including neurophysiology, performed with a high priority.

**Statement 2** The patient should be informed of the diagnosis in a sensitive manner by a consultant with a good knowledge of the patient and the disease, in an appropriate private setting, with a relative or friend present if the patient wishes one to be. A follow up appointment should be arranged to review the patient within 4 weeks.

**Statement 3** Following diagnosis, the patient and relatives/carers should receive regular support from a multidisciplinary care team, with a single point of contact for all information, and review appointments every 3 months in typical cases, but tailored to individual needs.

**Statement 4** Medication with riluzole should be initiated as early as possible.

**Statement 5** Where available, patients should be managed according to accepted care pathways (e.g. NICE guidance on Motor Neuron Disease, non-invasive ventilation, treatment with riluzole).

**Statement 6** Control of symptoms such as sialorrhea, thick mucus, emotional lability, cramps, spasticity and pain should be attempted. Percutaneous endoscopic gastrostomy feeding improves nutrition and quality of life, and gastrostomy tubes should be placed before respiratory insufficiency develops. Non-invasive positive-pressure ventilation also improves survival and quality of life. Maintaining the patient’s ability to communicate is essential.

**Statement 7** During the entire course of the disease, every effort should be made to maintain patient autonomy. Advance directives for palliative end-of-life care should be discussed early with the patient and carers, respecting the patient’s social and cultural background.

**Statement 8** Patients should have access to research programmes, including involvement in clinical trials and other studies to determine the cause and management of this condition, for which there is no effective cure, and the cause remains largely unknown.

**Statement 9** There should be access to training and education for professionals involved in supporting and treating patients with motor neuron disease.

**Statement 10** The appropriate diagnosis and management of motor neuron disease includes a recognition of the overlap with frontotemporal dementia and access to specialist input to assess cognitive function.

**References**

NICE guidance: The use of non-invasive ventilation in the management of motor neurone disease. July 2010
NICE pathways: Motor neurone disease overview


ABN guidance: Guidelines for the management of motor neurone disease. 1999


Motor Neurone Disease: A Problem-Solving Approach (MND Association, 2012)
"Red Flags" tool for diagnostic referral (MND Association, 2014)
7) Neuromuscular disorders

Revised February 2016 by the ABN Neuromuscular Disorders Advisory Group

**Statement 1** Each Region should provide a fully integrated multidisciplinary service for patients of all ages with neuromuscular disorders

**Statement 2** Management of individual patients may be at a specialist centre, or through a shared-care protocol at a district hospital

**Statement 3** Except for the rare curable neuromuscular disorders, specialist care should generally continue life-long

**Statement 4** A regional Centre should provide advanced diagnostic facilities (e.g. specialist neurophysiology, muscle pathology) and collaboration with National reference services (e.g. NCG services)

**Statement 5** Prompt assessment (First appointment) should be available at the specialist centre for new referrals from primary or secondary care

**Statement 6** Where available, patients should be managed according to accepted care pathways (e.g. Duchenne dystrophy)

**Statement 7** All patients should have ready access to a neuromuscular care advisor/specialist nurse. They should provide signposting to appropriate services including voluntary agencies and community groups.

**Statement 8** Patients should be made aware of national and international disease-specific registries that enhance development of treatment guidelines and standards of care, as well as enabling access to research studies for interested patients and families.

**Statement 9** Multidisciplinary care should include appropriately trained and experienced specialists in respiratory care (physicians and physiotherapists), non-invasive ventilation, cardiology, genetics, orthopaedics (spinal and tendon surgery), gastroenterology (PEG/RIG), physiotherapy, occupational therapy, speech therapy, dietetics, and orthotics

**Statement 10** Specialist multidisciplinary transition clinics should be available for adolescents moving from paediatric to adult care

**Statement 11** When appropriate, patients should have a personalised emergency care plan, for example with respect to managing respiratory and cardiac issues

**Section 12** There should be access to training and education for professionals involved in supporting and treating patients with neuromuscular disorders

**Section 13** Psychological support services should be available to help individuals at all stages of their journey, from initial diagnosis to end of life care, where appropriate

References:
Duchenne Standards of Care – (NICE accredited) - from Lancet Neurology 2009/10
NHS Commissioning Board, Service Specification No. 8 – Specialised Neurosciences. 2012/13
8) Peripheral neuropathy

Revised February 2016 by the ABN Neuromuscular Disorders Advisory Group

**Statement 1:** Patients with symptoms suggestive of a peripheral neuropathy should be assessed within 13 weeks by an experienced neurologist. Early diagnosis should be pursued, and investigations, including neurophysiology, performed within 18 weeks of referral.

**Statement 2:** Complex patients should be referred to a specialist peripheral nerve clinic, which should have access to advanced diagnostic facilities including neuropathology in collaboration with National reference services (e.g. NCG services)

**Statement 3:** Each Region should provide a fully integrated multidisciplinary service for patients of all ages with neuromuscular disorders. Patients should have access to a neuromuscular care advisor/specialist nurse. They should provide signposting to appropriate services including voluntary agencies and community groups

**Statement 4:** Multidisciplinary care should include appropriately trained and experienced specialists in immunology, pain management, respiratory care, non-invasive ventilation, cardiology, genetics, orthopaedics (spinal and tendon surgery), physiotherapy, occupational therapy, speech therapy, dietetics, and orthotics

**Statement 5:** There should be access to training and education for professional involved in supporting and treating patients with neuromuscular disorders

**Statement 6:** Psychological support services should be available to help individuals at all stages of their journey, from initial diagnosis to end of life care, where appropriate.

**References**
- NHS Commissioning Board, Service Specification No. 8 – Specialised Neurosciences. 2012/13
9) Multiple Sclerosis

Prepared April 2014 by the ABN Multiple Sclerosis and Neuroinflammation section.

Statement 1: MS patients must have access to a specialist neurological service providing an effective care pathway. It is the responsibility of the Commissioners to ensure that there is an accessible and comprehensive service for patients with MS across England based on local population needs.

Statement 2: Patients are entitled to a timely and ready access to a diagnostic service, seeing a neurologist within 2-4 weeks from the time of onset of suggestive symptoms who can offer a diagnosis of MS based on contemporary practice. MRI and other investigations (e.g., lumbar puncture, evoked potentials) should be undertaken, if required, within 2-4 weeks of seeing the neurologist. The results should be explained to patients and therapeutic options discussed within a further 2-4 weeks, preferably by a neurologist with specialist interest in MS.

Statement 3: There should be an agreed pathway for consultant-to-consultant referral to specialised services in a regional neurosciences centre or to tertiary clinics for selected MS patients attending the local service. This may apply when there is a lack of diagnostic clarity for further clinical assessment, additional investigations and consideration of invasive procedures (e.g., diagnostic biopsy in rare cases); for specialised management of acute MS relapses (e.g., plasma exchange), for aggressive relapsing disease; for specialised treatments (e.g. botulinum toxin), for refractory chronic symptoms, or for access to specialist input (e.g. neurorehabilitation, neuropsychiatry).

Statement 4: Patients receiving a diagnosis of MS should be provided with contact details of a local MS nurse specialist: unless declined by patient, the MS Nurse should establish contact within 5-10 working days of the diagnosis. Where appropriate, life-style issues should be discussed, and advice on employment and equality, access to physical rehabilitation, genetics, family and career planning, and access to counselling and/or psychological support offered.

Statement 5: Patients with acutely relapsing episodes should be seen in a rapid access "relapse" clinic for appropriate assessment, investigations and advice. They should be supported by the multi-disciplinary team and seen within 2-5 working days of reporting a suspected relapse.

Statement 6: Patients with relapsing MS are to be offered disease modifying therapy according to current ABN Treatment Guidelines – or an appropriate treatment switch, if disease activity continues on treatment.

Statement 7: Patients with persistent problems require appropriate symptomatic management to improve quality of life and self-care abilities. For example, patients with urinary symptoms should have access to a continence nurse specialist or uroneurology service. Prevention of recurrent urinary tract infections should be considered a priority to reduce hospital visits or acute admissions.

Statement 8: Patients with MS should have access to a review by an MS specialist service and multi-disciplinary team at least once a year; and the opportunity to self-refer to the clinic earlier if necessary.

Statement 9: Patients with chronic MS who may be at risk of osteoporosis (post-menopausal women, patients with mobility impairment, frequent use of steroids and long term use of anti-epileptic drugs like phenytoin or carbamazepine) should be
considered for bone densitometry to prospectively identify and treat osteoporosis in order to reduce fracture-related hospital admissions.

**Statement 10:** Patients with chronic disability from MS require needs assessment of long-term care support addressing key components of individual patients in terms of current health status and HRQoL. The care plan should identify community nursing, rehabilitative, psychological and social resources for continuation of support. There should be named care provider and home support teams for MS patients that must set out clear targets to meet patient’s and family’s educational, emotional, physical and cognitive needs.

**Statement 11:** Participation in clinical research should become an expected standard of MS services as it offers the opportunity of linking with local academic clinical networks and national clinical trial units. MS patients should be made aware of research projects where they may volunteer and participate.