



2007

Response to the NSF for Long Term Conditions

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Introduction

The National Service Framework for Long Term Conditions was published in March 2005. This NSF defines 11 quality requirements intended to transform the way health and social care services support people with long term neurological conditions to live as independently as possible. It is explicitly stated that the NSF focuses on people with long term neurological conditions. The long term conditions NSF is a 'long term' ten year programme for change.

In his introduction, John Reid (currently Home Office Minister, erstwhile Secretary of State for Health), states that it is about improving the quality of lives of patients with multiple sclerosis or Parkinson's Disease by:

Giving people choice through services planned and delivered around their individual needs.

Supporting people to live independently and play their full part in society.

Co-ordinating partnership working between health and social services and other local agencies.

At the heart of the NSF are 11 'quality requirements'. These quality requirements can be broadly grouped into:

QR1: a person centred service

QR2 and QR3: prompt diagnosis, appropriate referral and treatment

QR4 – QR6: rehabilitation, adjustment and social integration

QR7 – QR11: life long care and support for people with long term neurological conditions, families and carers.

No specific targets were defined by the NSF and no ring fenced financial resources allocated, although Dr Ladyman, in announcing the NSF, stated that the money had already been allocated to PCT's. A long term condition care group workforce team was established to take a national view on the health and social care workforce pressures of the NSF. A number of early actions were suggested for implementing the NSF, including setting up local strategy groups, assessing and auditing local services, skills and training needs and re-designing services.

Various organisations, e.g. Motor Neuron Disease Association, have produced leaflets describing how the NSF can be applied to their neurological condition and the Neurological Alliance with the Brain and Spine Foundation have been actively lobbying to ensure that the NSF is implemented, particularly by influencing commissioning.

The ABN, of course, has been determined to improve services for patients for many years^{1,2}. The organisation has long been aware of poor access for patients with neurological emergencies to specialist neurological advice, the long waiting times for a routine out-patient appointment and the lack of co-ordinated satisfactory long term care for patients with chronic neurological conditions. These factors are largely due to the continuing small number of adult Neurologists in the UK, particularly in comparison to North America and the rest of Europe.

The NSF for Long Term Conditions does, however, hopefully provide us with an opportunity to try to remedy these deficiencies in services over the next ten years. This should be done as a joint project between Commissioners and local Neurologists, identifying gaps in the service and working out a gradual programme for improvement. A survey of the current care pathways and services for the management of some common neurological conditions was carried out by the ABN Services & Standards Sub-Committee representatives of the various regions of the UK with the following results:

<i>Written and agreed care pathway</i>	33%
<i>GPwSI</i>	12%
<i>Specialist Nurse</i>	65%
<i>Referral guidelines</i>	44%
<i>Review protocols</i>	32%
<i>Good access to rehabilitation</i>	52%

These results represent the current baseline and indicate the large amount of work required to develop neurology services over the next ten years.

This document sets out the ABN guidance and standards for the management of acute neurological emergencies, out-patient diagnosis and long term care. General standards for the management of neurological long term conditions are specified with some examples from particular common long term conditions to illustrate these. Monitoring performance standards are included so that the process can be audited to assess implementation and guide further development.

The document has full support of the neurological charities, Neurological Alliance and Brain and Spine Foundation. Commissioners in adult neurology are encouraged to involve members of the appropriate charities in the development of care pathways. We hope that you will find the advice contained in this document useful and wish you the best of luck in its implementation.

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General principles and standards

1 *Referral and Diagnosis**

- A referral must be made to a specialist with appropriate neurological training who will usually be a consultant neurologist.
- This referral appointment should be within an appropriate time frame. In particular circumstances, this may need to be urgent, eg suspected motor neuron disease, myasthenia gravis, MS relapse etc.
- Accurate diagnosis is essential for appropriate treatment and long term management, highlighting the importance of the neurologist in this process.

2 *Investigations*

- These would normally consist of some of the following:
 - MRI scanning*
 - CT scanning*
 - EEG and EMG and Nerve Conduction Studies*
 - Video telemetry*
 - CSF examination*
- These should be available locally (DGH) where possible.
- These should be carried out to appropriate standards, including reporting.
- Access for discussion of the results of these investigations in multi-disciplinary meetings is essential.

3 *Review appointment to communicate the diagnosis*

- This is of critical importance and should provide sufficient time to explain the diagnosis and agree an appropriate future management plan. This should include:
 - Follow up arrangements*
 - Key worker with appropriate resources (telephone and secretarial support)*
 - Information regarding appropriate support agencies and the condition (leaflet)*
 - Contact details for follow up*
 - Information to enable reaccess to the service*
 - Specification of a named consultant responsible for the patient*

*See ABN Document Standards of Care³ for people with neurological symptoms prior to diagnosis and treatment

4 Long Term Management

- There should be an integrated care pathway for each long term neurological condition to provide care linking general practice, social services, voluntary organisations, specialist services and supporting clinical specialists.
- The network should have a lead clinician and provide a flexible multi disciplinary team which should include nurse specialists, health psychologists and others who can address the complex medical, social, psychological and gender specific needs of patients with long term neurological conditions.
- A key worker should be able to coordinate other agencies such as education, employment and benefit.
- Referral by a general neurologist should be made to a sub-specialist neurologist where appropriate.
- Review intervals for the patient should be specified.

References

- 1 *Acute Neurological Emergencies in Adults. ABN (2002)*
- 2 *UK Neurology – the next 10 years – putting the patient first. ABN (2003)*
- 3 *Standards of Care for people with neurological disorders. ABN Services & Standards Subcommittee (2004)*

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Disease specific guidance

Epilepsy Integrated Care Pathway

- People with suspected epilepsy should have rapid access to a specialist in epilepsy, usually a consultant neurologist, for diagnosis, investigation, appropriate treatment and follow up in accordance with NICE guidelines.
- There should be links with local obstetric services to provide care for pregnant women with epilepsy.
- There should be an adolescent clinic to transfer care from paediatrics to adult neurology.
- There should be close links with cardiology services for the investigation of black-out/funny turns where the diagnosis of epilepsy is in doubt.
- The needs of those with psychogenic non-epileptic attacks should be recognised and appropriate links with mental health services should be provided in every clinical network for the management of these patients, including access to Psychiatrist and Psychologist
- Services for those patients with epilepsy and learning disabilities should be structured to provide investigation and management, taking into account the specific needs of these patients.
- There should be access to specialist epilepsy centres for the management of refractory epilepsy
- Training in epilepsy should be given to medical and nursing staff

Monitoring/performance indicators:

- Number of patients with suspected first seizure seen by epilepsy specialist within 14 days
- Waiting time to MRI/EEG in under 4 weeks
- Provision of videotelemetry in each managed clinical network
- Provision of epilepsy nurse specialists in each network
- Provision of psychologist/psychiatrist for management of non-epileptic attack disorder in each network
- Progress on implementation of standards in NICE guidelines

Implementation:

- Identification and appointment of the workforce required to make up the regional managed clinical network (these should include: a lead clinician, Neurophysiologist, Radiologist, Psychiatrist, GP with special interest in epilepsy, Health Psychologist, Epilepsy Nurse Specialist, Pharmacist, patient representative and technical staff for EEG).

Parkinson's Disease Integrated Care Pathway

- A patient suspected of Parkinson's disease should be referred to a consultant with specialist training in PD.
- Each specialist network should have agreed shared care protocols between secondary and primary care for drugs used in the treatment of PD.
- Each network should have appropriately trained nurse specialists who can manage some of the routine follow up case load of people with PD and thereby improve access to specialist services.
- Each network should have nominated leads in relevant multi disciplinary services, notably physiotherapy, occupational therapy, speech and language therapy and dietetics.
- There should be agreed protocols for referral of patients for surgery for PD.
- Each specialist service should have agreed arrangements for the transfer of care to HCE of elderly patients in whom the PD is no longer the dominant pathology.

Monitoring / Performance Indicators:

- Commissioners should identify those responsible for the management of specialist services for people with PD including those responsible for newer surgical treatments. It will also be important, where appropriate, to identify PD leads involved in the UK Dementia and Neurodegenerative Disease (DND) Local Research Networks.
- Shared care protocols agreed.
- Number of PD Nurse Specialists per 100,000 population.
- Time to first consultant clinic appointment.
- New to follow up ratio in hospital led clinics
- Patient satisfaction

Implementation:

- Commissioners to identify existing services and gaps in service provision particularly in terms of Allied Health Professionals (AHPs) and PD Nurse Specialists.
- Numbers of follow up patients attending neurology and HCE clinics to be identified to establish how many patients might have their follow up frequency reduced in consultant clinics, thereby improving access of new referrals to, and the ongoing management of complex cases in, consultant clinics.
- Shared care protocols for PD drugs to be agreed between primary and secondary care at regional i.e. SHA level.
- Development of agreed funding arrangements for new drugs and surgical procedures.
- Recruitment and training of GPwSI, AHP's and Nurse Specialist

Multiple Sclerosis Integrated Care Pathway

- The diagnosis should always be made by a consultant neurologist.
- There must be a lead clinician and service to provide consideration of and prescription of DMT's, incorporating follow up of DMT therapy.
- There should be rapid access for assessment of potential relapse. There should be a relapse management programme.
- There should be a facility for self-referral for those not under regular review.
- Access may also be needed for :-
 - Continence service*
 - Sexual dysfunction service*
 - Orthotics*
 - Fatigue management programme*
 - Specialist spasticity management*

Monitoring/Performance indicators:

- Commissioning network should identify lead clinicians and supporting specialist services.
- A comprehensive and up to date local directory should identify services
- Times to first appointment, investigation and follow up have been set out in NICE guidelines
- PwMS should be able to re-enter the service at will at any time through a single point of contact – the care coordinator who may be an MS nurse.
- Development of patient held record and integrated care pathways are a central requirement of the NSF.

Implementation:

- Commissioners to identify MS provider networks and undertake GAP analysis.
- Identify which roles should be key workers i.e. nurses, PAMs or social workers.
- Determines suitable caseload for individual key workers.
- Write and implement clinical protocols for key workers.
- Develop patient held record with MS Society.

Motor Neuron Disease Integrated Care Pathway

- The diagnosis should always be confirmed and communicated by a consultant neurologist.
- Care should be coordinated using a multi disciplinary approach respecting that care should encompass the whole person and those that matter to them.
- Intervention should be available promptly for securing symptom control and improving quality of life, especially equipment and adaptation to the patient's home.

Monitoring / Performance Indicators:

- Agreed care pathway with all elements of care.
- Numbers of confirmed cases offered treatment with riluzole and nutritional support.
- Availability of NIV where appropriate.
- Evidence of involvement of palliative care services in managing patients with MND
- Use of MNDA audit and standards of care guidance
- Audit of time from referral to diagnosis.
- Audit of time from symptom onset to diagnosis.
- Audit of time from prescription and intervention to its provision whether this be drugs, aids or social support.

Implementation:

- Confirmation of the predicted caseload in each SHA.
- Identification of lead clinician in each provider network.
- Development of trained MDT including Nurse specialist and PAMs.
- Development of Integrated Care Pathway for MND.
- Costing of elements and predicted number of interventions in ICP
- Engagement with palliative care services to develop a strategy for MND palliative care.

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Management of Acute Neurological Conditions

- Every patient with an acute neurological condition requiring admission to hospital should have access to an opinion from a neurologist within twenty-four hours.
- This could be achieved by Trusts providing a consultant neurologist led ward round on a daily basis. This has been proven to substantially reduce length of stay, use of investigations and enable earlier correct diagnosis.
- This could often take place in the medical assessment unit following the emergency physician's ward round with referral of those patients requiring an urgent neurological opinion.
- Out of hours advice should be provided by the regional neurological centre, whereby patients requiring urgent assessment would need to be transferred and others could either be discharged with an urgent out patient appointment, or kept in hospital until the next available neurology consultant-led ward round.
- Trusts should obtain DGH based neurologists or visiting neurologists to provide five day cover. Approximately one PA per day would be required for this, with appropriate support staff (neurology specialist registrar or trained associate specialist). DGHs should make formal arrangements with their regional neuroscience centre for out of hours cover.
- The trust would need to develop:
 - Neurology team
 - Neurology ward
 - Neurology trained nursing staff
 - Lead radiologist with interest in neuroradiology
 - Local facilities for EEG, EMG and NCS

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Standards

- What proportion of patients with acute neurological emergency see a Neurologist within 24 hours of admission?
- In what proportion of these is the diagnosis changed?
- In what proportion are the investigations changed?
- Has the DGH got a Neurology team? Yes/No
- Has the DGH got a Neurology ward? Yes/No
- Has the DGH got Neurology nursing staff? Yes/No
- Has the DGH got a Lead Radiologist with an interest in Neuroradiology? Yes/No
- Has the DGH got local facilities for EEG, EMG and NCS? Yes/No
- Does the A & E have written proforma for the management of blackouts and headache? Yes/No

