Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care

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ABSTRACT – Long-term neurological conditions (LTNCs) comprise a diverse set of conditions resulting from injury or disease of the nervous system that will affect an individual for life. Some 10 million people in the UK are living with a neurological condition which has a significant impact on their lives, and they make up 19% of hospital admissions. These guidelines build on the Quality Requirements in the National Service Framework for Long-term (Neurological) Conditions to explore the interaction between specialist neurology, rehabilitation and palliative care services, and how they may best work together to provide long-term support for people with LTNCs and the family members who care for them. The guidelines also provide some practical advice for other clinicians when caring for someone with an LTNC, and outline indications for specialist referral. This article provides a brief summary. Full details of the methods and literature evaluation, as well as tools for implementation, are available in the full guideline.

Background

Long-term neurological conditions (LTNCs) form a diverse set of conditions resulting from injury or disease of the nervous system that will affect an individual for the rest of their lives. They include:

- sudden onset conditions (eg acquired brain injury of any cause (including stroke), spinal cord injury)
- intermittent conditions (eg epilepsy)
- progressive conditions (eg multiple sclerosis (MS), motor neurone disease (MND), Parkinson's disease (PD) and other neurodegenerative disorders)
- stable conditions with/without age-related degeneration (eg polio or cerebral palsy).

Taken together, LTNCs are more common than most clinicians realise. Some 10 million people in the UK are living with a neurological condition which has a significant impact on their lives, and they make up 19% of hospital admissions.[1]

The Department of Health's National Service Framework (NSF) for Long-term Conditions was published in March 2005. Although much of the guidance applied to anyone living with a long-term condition, the main focus of the document was on neurological conditions. To avoid confusion with other policy documents contained within the Long-term Conditions Strategy (which includes the frameworks for renal services and for diabetes) the NSF has subsequently been re-badged as the NSF for Long-term (Neurological) Conditions. The NSF advocates lifelong care for people with LTNCs.[2] It highlights the need for integrated care and service provision including specialist neurology, rehabilitation and palliative care services, but also stresses the importance of other clinicians being aware of the particular needs of this group of patients when they present for treatment of other conditions.

When someone with an LTNC is admitted to a general hospital setting for a procedure or intercurrent illness, hospital staff are required to manage both the acute illness and the LTNC. Many patients are maintained on finely tuned management routines, eg 24-hour spasticity management programmes, treatment for PD symptoms, or bladder/bowel regimens which, if disturbed, may lead to increased morbidity and distress, and can take weeks to re-establish. In addition, patients require an accessible environment and access to their usual equipment, eg wheelchair, communication aid. The NSF emphasises the importance of recognising the expertise of a person and their family in the management of the condition, of maintaining close contact with the individual's regular team, and of calling for specialist help, if required. As many generalists have received little training in these areas of clinical practice, however, they are sometimes uncertain about the type of help that the different services can offer for people with LTNCs.

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The guidelines

Recommendation	Grade
A General service coordination	
Neurology, rehabilitation and palliative care services should develop closely coordinated working links to support people with long-term neurological conditions (LTNC) from diagnosis to death, including:	E1/2
• proper flow of communication and information for patients and their families	
• a designated point of contact for each stage in the pathway	
• a needs assessment identifying the patient's individual problems.	
B Neurology services	
1 A person who is suspected of having an LTNC should be referred promptly to a specialist neurological service for investigation and diagnosis	RA
2 A person who is confirmed to have an LTNC should have:	RA
• ongoing access to specialist neurological services for disease-modifying treatment, if appropriate	
• ongoing support and advice with regard to management of their condition and its sequelae	RB
• support from specialist neurological nurses for practical advice on living with their condition.	
C Rehabilitation services	
1 A person with an LTNC should be referred to a specialist neurological rehabilitation service if:	
• they develop significant disability or symptoms such as incontinence/spasticity management/nutrition/pain/depression which fall within the remit of the rehabilitation physician and may require an interdisciplinary approach *and/or*	RA
• their circumstances change in a way that affects their independence or participation in their current environment.	
2 A person with significant ongoing disability due to an LTNC should have timely and ongoing access to specialist neurological rehabilitation and support services which include:	
• initial needs assessment and provision of support according to the list in Table 1	E1/2
• ongoing integrated care planning – including an annual multi-agency needs assessment including health, social services, and voluntary sector input	
• coordinated service provision in accordance with changing need, including equipment, environmental adaptation, rehabilitation for vocation/leisure, psychosocial support.	
D Palliative care services	
1 A person with an LTNC should be referred to specialist palliative care services if they have:	RB
• a limited lifespan – usually 6–12 months, *and/or*	
• distressing symptoms – especially pain, nausea and vomiting, breathlessness, which fall within the remit of the palliative physician, *and/or*	
• a need or desire for end-of-life planning, with or without competence issues.	
2 A person who is dying from an LTNC should have timely and on-going access to specialist palliative care services which include:	RB
• symptom control	
• planning and support to the end of their life	
• aftercare and bereavement support for their families.	

The challenge of lifelong care for people with LTNCs

The place for palliative care in non-cancer patients is increasingly recognised,[3–6] especially in rapidly fatal neurological conditions such as MND,[7–8] and many guidelines now recommend early referral to palliative care services.[9–10] However, there are some significant differences in the palliative care needs of people with LTNC, compared with cancer.[4,11,12]

- In general, neurological conditions have a longer and more variable time course – it is often hard to determine exactly when a patient is entering the terminal stages of life.
- Symptoms are diverse, and many patients have complex disabilities which include cognitive, behavioural and communication problems as well as physical deficits. Palliative care teams used to caring for people who can talk to them may find it challenging to manage someone with profound dysphasia or cognitive dysfunction.

Table 1. Key roles of neurology, rehabilitation and palliative care services in supporting people with long-term neurological conditions.

Neurology	Rehabilitation	Palliative care
• Investigation and diagnosis • Information about condition and prognosis • Ongoing specialist advice • Treatments to modify the disease process, eg: – interferon, steroids etc • Interventions for neurological sequelae, eg: – seizures – tremors, and other abnormal movements – dystonia • Practical advice from specialist nurses, eg for: – incontinence, pain – sources of additional help and support – links with the voluntary sector etc	• Ongoing medical management including: – diagnosis/investigation based on longer-term observation – interventions for long-term symptoms, eg spasticity, nutrition, pain, depression, bladder and bowel programmes • Practical holistic support and disability management – restoring independence where possible – supported care on long-term complex disability (neuropalliative rehabilitation) • Coordinated multidisciplinary team interventions including physio, O/T, SLT, psychology, SW, orthotists • Aids and equipment: – eg wheelchairs, environmental control systems • Planning and support: – integrated care planning – between health, social services, voluntary services etc – support for benefits, housing, adapted accommodation etc – vocational rehabilitation, education leisure. – driving/community mobility • Communication and psychosocial support: – adjustment for long-term disability for patients and their families/carers – supported communication for cognitive/communication impairment – management of confusion/unwanted behaviours (including verbal and physical aggression) in conjunction with neuro-psychiatric services • Medico-legal issues – assessment of mental capacity, – Power of Attorney, Court of Protection etc	• Multi-professional management of distressing symptoms, usually in patients with limited life expectancy or rapidly progressive conditions. Particularly: – pain, nausea and vomiting, breathlessness – anxiety/depression, insomnia – management of confusion, agitation in conjunction with psychiatric and psychology services • Support for end-of-life decisions and advance care planning, eg: – advance statements and decisions – choice over place of care – assessment of capacity in relation to these decisions • Support of the dying person and their family, eg: – psychosocial – welfare – spiritual • Bereavement counselling • Advisory/liaison service – links to local palliative care resources and teams – Professional education in the provision of generic palliative care and support – Provision and coordination of community support services

O/T = occupational therapy; SLT = speech and language therapy; SW = social worker.

Many physicians think of rehabilitation as a short-term intervention following a single incident illness or injury. However, long-term disability management is also a core element of many rehabilitation services, which often work in the community to support people to the end of their lives.[9,13] In addition, specialist nurses (for example in MS, MND or PD) can be a further source of long term support.[14,15] Given the current financial pressures on the NHS, an understanding of the interface between neurology, rehabilitation and palliative care is critical to ensure that services work together to provide joined-up care for people with LTNC, rather than duplicating care provision and competing for scarce resources.[2]

Guideline development

These guidelines build on the NSF Quality Requirements to explore further the interaction between specialist neurology, rehabilitation and palliative care services, and how they may best work together to provide long-term support for people with LTNCs and the family members who care for them (see the guidelines). They also provide practical advice for other clinicians who may find themselves caring for someone with an LTNC, as well as outlining indications for specialist referral.

- They were drawn up in accordance with the Appraisal of Guidelines for Research and Evaluation system for guideline development.
- For evaluation of the evidence, the same typology and grading system developed for the NSF for Long Term Conditions.[16] The typology is designed to place value on the experience of users and professionals (Expert evidence E1 and E2 respectively) as well as research-based evidence, and also to value high-quality research regardless of the design.
- Full details of the methods and literature evaluation, as well as tools for implementation, are available on the Royal College of Physicians' website, www.rcplondon.ac.uk.

A cross-sectional survey of specialists in neurology, rehabilitation and palliative medicine was undertaken in preparation for the guidelines and has provided some closer definition of their respective roles in caring for those with LTNC.[17] These are shown in Table 1 and illustrated in Fig 1. These should be used as a guide – the roles described will vary between different specialists and different clinical services. However, non-specialist clinicians may find this a useful resource when considering referral for specialist help with a given problem.

Implications for implementation

The literature review and survey both highlighted gaps and deficiencies in the services at every level. Rehabilitation and palliative care have long been 'Cinderella specialties' within the NHS and to a certain extent the need for investment is inevitable. However, much could be done to develop the use of current services, by improving communication and networking between specialist and local services, and enhancing coordination between the specialties.[18]

Training and tools for implementation

A key step in implementing these guidelines is improved training. The required skills and competencies can be achieved through enhanced recognition of the importance of rehabilita-

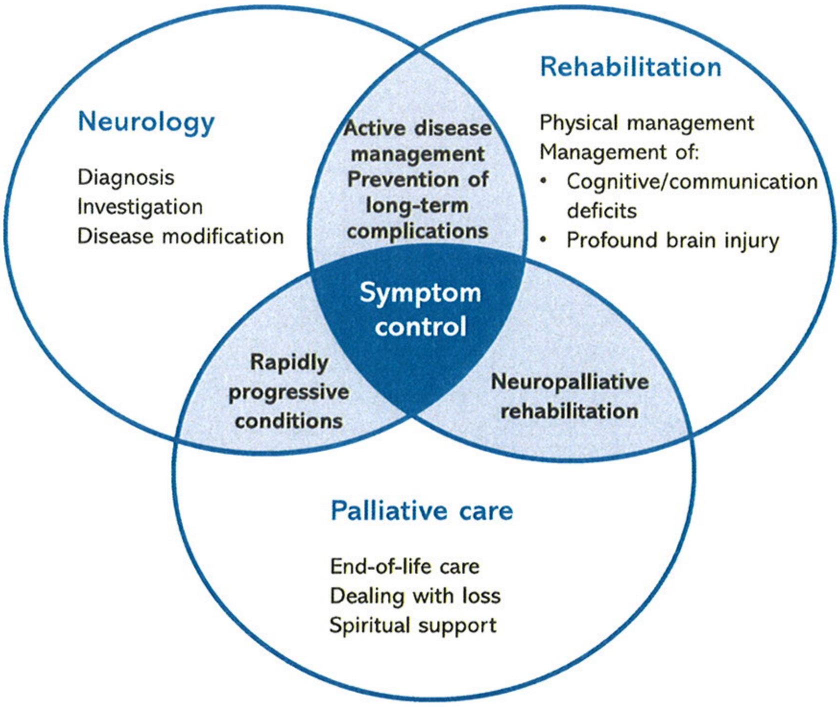

Fig. 1. The interaction between neurology, rehabilitation and palliative care services in management of patients with long-term neurological conditions.

tion and palliative care alongside other basic medical and surgical skills in the training curriculum. Extra training and exposure for trainees within the three specialties may be achieved through placements and joint training days to pool knowledge and enhance the opportunity to share skills and experiences.

A checklist to guide clinicians when a patient with an LTNC is admitted to a general hospital is shown in Table 2. A further set of tools to guide management of specific symptoms including incontinence of bladder and bowels, pain, breathlessness, and nausea and vomiting is offered in the full guidelines.[19]

Table 2. Checklist for the management of patients with a long-term neurological condition (LTNC) when admitted to a general hospital ward.

Background:

Patients with LTNCs may be admitted to hospital for a variety of reasons including:

- exacerbation or progression of disease
- complication of disease (eg infection/pressure sores)
- an unrelated problem.

These admissions are often poorly managed in general wards where the teams do not always have the experience and resources to manage people with complex neurological problems.

REMEMBER:

Patients with LTNCs and their families or carers are often expert at managing the disease and medications.
They live with the consequences of the management decisions that we make. Consider and respect their advice and wishes.

Prior to admission consider:

- Is the admission necessary?
  - Is it appropriate given the level of disability/prognosis?
  - Can this be managed as a day case/in the community?
- Plan the admission/coordinate with the team caring for them.

On admission:

- Inform the neurological/rehabilitation/palliative care team caring for the patient.
  - Obtain old notes.
- Check medication and continue unless contraindicated (especially anti-epileptics and anti-Parkinsonian medication).
- Check that the patient has been admitted with their equipment (hearing aids, communication aids, adapted wheelchair) and that staff are capable of using this.
- Check their competence to make decisions regarding their care. Is there an advance directive (AD)?

Review in hospital:

- Posture and spasticity management, especially with pain, infection, fractures. Neurophysiotherapy review is often helpful.
- Pressure sores and management strategy to prevent these.
- Anticoagulation prophylaxis to prevent deep vein thrombosis.
- Bladder: is the patient continent? In retention?
- Bowels: is the patient incontinent/constipated?
  - especially with altered diet/opiates.
- Swallow: is this safe? Is the patient aspirating?
- Nutrition: is this adequate? Is the patient able to feed themselves?
- Respiratory capacity:
  - check and monitor vital capacity if compromised.

Review in hospital: – *continued*

- Cognition:
  - beware of an acute deterioration with illness, medication.
- Depression:
  - triggered by hospitalisation/change in condition/pain.
- Pain: is important. In addition to the acute problem, pain may be due to a combination of:
  - neuropathic pain (which may respond to anti-epileptics and tricyclics)
  - spasticity
  - musculoskeletal pain – pay careful attention to positioning.

If considering a procedure, consider once again:

- Is this appropriate given their underlying neurological condition and prognosis?
- Does the patient have capacity to consent – is there an AD?
- Respiratory function – is there need for anaesthetic advice?

Prior to discharge:

- Consider whether the home set-up is appropriate – was this the trigger for admission?
- Assess how the patient's discharge affects the family and their ability to cope.
- Review and restart the care package – revise if necessary.
- Inform the team that usually cares for the patient in hospital, in the community, or at home.
- Arrange follow-up if necessary – try to coordinate this if patient has difficulty accessing hospital.

Note: See full guideline on the Royal College of Physicians' website for tools for implementation including practical advice on the management of common symptoms such as incontinence, pain, breathlessness, nausea and vomiting.

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