

# CONCISE GUIDANCE TO GOOD PRACTICE

A series of evidence-based guidelines for clinical management

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NUMBER 10

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

NATIONAL GUIDELINES

March 2008



THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE



## Clinical Standards Department

The purpose of the Clinical Standards Department of the Royal College of Physicians is to improve patient care and healthcare provision by setting clinical standards and monitoring their use. We have expertise in the development of evidence-based guidelines and the organisation and reporting of multicentre comparative performance data. The department has three core strategic objectives: to **define** standards around the clinical work of physicians, to **measure** and evaluate the implementation of standards and its impact on patient care; and to effectively **implement** these standards.

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The guidelines are designed to allow clinicians to make rapid, informed decisions based wherever possible on synthesis of the best available evidence and expert consensus gathered from practising clinicians and service users. A key feature of the series is to provide both recommendations for best practice, and where possible practical tools with which to implement it.

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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.

## 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.<sup>1</sup>

The National Service Framework (NSF) for Long-term Conditions\* advocates lifelong care for people with LTNCs.<sup>2</sup> It highlights the need for integrated care and joined-up services. Within its 11 Quality Requirements (QRs), it makes recommendations for the provision of specialist neurology (QRs 2/3), rehabilitation (QRs 4–6) and palliative care (QR 9) services to support people throughout and to the end of their lives. In addition, QR 11 makes recommendations about the management of people with LTNCs when receiving care for other conditions, in any health or social care setting.

When someone with an LTNC is admitted to a general hospital setting for a procedure or because of acute illness, hospital staff have to manage both the 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 managing the condition, of maintaining close contact with the individual's regular team, and of calling for specialist help, if required. However, as many generalists have received little training in these areas of clinical practice, they are sometimes uncertain about the type of help that the different services can offer for people with LTNCs.

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\***National Service Framework for Long-term (Neurological) Conditions:** 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 challenge of lifelong care for people with LTNCs

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

- 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. Teams may also need specific training in postural management and physical handling, eg for someone with severe spasticity.

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. In addition, many neurology departments now have specialist nurses (for example in MS, MND or PD), who also provide long-term support for patients and their families.<sup>12,13</sup> 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 coordinated care for people with LTNC, rather than duplicating care provision and then competing for the scarce resources.<sup>2</sup>

## Aims and methodology

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. 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 Research and Evaluation (AGREE) system for guideline development.
- They build on work carried out by the neurological conditions policy group of the National Council for Palliative Care (NCPC). Further information, including good practice examples and details of a pathway to assist joint working, can be found in *Focus on Neurology* available at the NCPC website: [www.ncpc.org.uk](http://www.ncpc.org.uk)<sup>14</sup>

The Guidelines themselves are on page 9, and the methods of guideline development are shown in [Appendix 1](#).

## Brief summary of the evidence

For evaluation of the evidence, we used the typology and grading system developed for the NSF for Long-term Conditions.<sup>15</sup> The typology is designed to place value on the experience of users and professionals (Expert evidence E1 and E2 respectively) as well as research, and also to value high-quality research regardless of the design. Full details of this system are given in [Appendix 2](#).

There is strong evidence (Research grade A (RA)) from Cochrane and other systematic reviews that multidisciplinary rehabilitation can improve the experience of living with a long-term neurological condition, both at the level of functional activity and societal participation.<sup>16–18</sup>

There is strong indirect (Research grade B (RB)) evidence from the cancer literature that palliative care improves quality of life<sup>19</sup> and is cost effective.<sup>20</sup> Community-based palliative care teams can reduce time in hospital, allowing people to spend more time at home and increasing patient satisfaction in the terminal stages of their lives.<sup>21,22</sup>

There is also evidence (RB) that these principles translate into other non-cancer conditions.<sup>5,23,24</sup> Specifically within long-term neurological conditions, reviews by Voltz 1997,<sup>11</sup> O'Brien 1998,<sup>25</sup> Mitchell 2007,<sup>26</sup> and Travers<sup>27</sup> demonstrate that patients in the final stages of amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Huntington's disease and dementia experience very similar symptoms to those observed in cancer patients (ie pain, dyspnoea, death rattle, restlessness, delirium, drowsiness, nausea and vomiting, depression), and these experts suggest (E2) that the approach to controlling symptoms in progressive non-malignant conditions can be adopted from the strategy for managing cancer-related symptoms.

There is strong evidence (RA) for the effectiveness of pain relief – in particular in MND,<sup>7,12,28</sup> but also in MS and PD.<sup>29</sup> A number of authors (E2) have emphasised the need for well coordinated palliative and neurological care,<sup>8,30</sup> to reduce the call for active euthanasia and physician-assisted suicide, and to reduce the rate of suicides associated with many neurological diseases.<sup>11,26</sup>

However, the literature also highlights the longer-term and more variable course of conditions such as MS, and the variety of symptoms which may be less common in cancer patients – fatigue, spasticity, weakness, visual loss, sexual dysfunction, swallowing and speech problems, epileptic seizures, myoclonus.<sup>26,31</sup> There is a need for palliative care teams to learn additional skills – in particular postural handling and support, management of percutaneous endoscopic gastrostomy (PEG) feeding<sup>8,11</sup> and ventilation<sup>32,33</sup> (RA/E2), as well as skills in management of cognitive and behavioural problems<sup>27</sup> (Research grade C (RC)). Therefore the need has been stressed for coordination between palliative care and rehabilitation teams, which also have a track record in providing long-term care and psychosocial support.<sup>34–37</sup>

Despite the strength of this evidence, the research has demonstrated that a relatively small proportion of patients with palliative care needs not related to cancer can access the services,<sup>3</sup> and that many have unmet palliative care needs (RA).<sup>28,38</sup> Nevertheless, there are some pockets of good practice in the UK,

for example a network of MND care centres, and regional networks with user-centred multidisciplinary teams who have specialist knowledge of the needs of patients with neurological conditions.<sup>8,30</sup>

## The respective roles of neurology, rehabilitation and palliative care in LTNCs

As part of the preparation for these guidelines, a cross-sectional postal survey using parallel questionnaires was sent out to consultants in neurology, rehabilitation and palliative medicine by the National Council for Palliative Care through their specialist societies.<sup>37</sup> The full findings from this can be found in *Neurological conditions: from diagnosis to death* available at [www.ncpc.org.uk](http://www.ncpc.org.uk).<sup>39</sup> The aim of this study was to explore the interaction between the three specialties and the perceptions of the respective consultants regarding their relative roles in caring for people with LTNCs.

The survey showed general agreement about the core contributions offered by each specialty.

- Neurologists were seen by most as being the primary providers of assessment, diagnosis and management of the disease.
- Rehabilitation physicians were primary providers of therapy, equipment, social/psychological support and service coordination during the phase between diagnosis and death.
- Palliative physicians were primary providers of terminal care, and the management of death and bereavement.

The respective roles are described in more detail in Table 1 and illustrated in Fig 1. These are a guide only, as 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.

There were also some important areas of overlap which highlight the need for collaborative working



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

Neurology	Rehabilitation	Palliative care
<ul style="list-style-type: none"> <li>• Investigation and diagnosis</li> <li>• Information about condition and prognosis</li> <li>• Ongoing specialist advice</li> <li>• Treatments to modify the disease process, eg:               <ul style="list-style-type: none"> <li>– interferon, steroids etc</li> </ul> </li> <li>• Interventions for neurological sequelae, eg:               <ul style="list-style-type: none"> <li>– seizures</li> <li>– tremors, and other abnormal movements</li> <li>– dystonia</li> </ul> </li> <li>• Practical advice from specialist nurses, eg for:               <ul style="list-style-type: none"> <li>– incontinence, pain</li> <li>– sources of additional help and support</li> <li>– links with the voluntary sector etc</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing medical management including:               <ul style="list-style-type: none"> <li>– diagnosis/investigation based on longer-term observation</li> <li>– interventions for long-term symptoms, eg spasticity, nutrition, pain, depression, bladder and bowel programmes</li> </ul> </li> <li>• Practical holistic support and disability management               <ul style="list-style-type: none"> <li>– restoring independence where possible</li> <li>– supported care on long-term complex disability (neuropalliative rehabilitation)</li> </ul> </li> <li>• Coordinated multidisciplinary team interventions including physio, O/T, SLT, psychology, SW, orthotists</li> <li>• Aids and equipment:               <ul style="list-style-type: none"> <li>– eg wheelchairs, environmental control systems</li> </ul> </li> <li>• Planning and support:               <ul style="list-style-type: none"> <li>– integrated care planning – between health, social services, voluntary services etc</li> <li>– support for benefits, housing, adapted accommodation etc</li> <li>– vocational rehabilitation, education, leisure</li> <li>– driving/community mobility</li> </ul> </li> <li>• Communication and psychosocial support:               <ul style="list-style-type: none"> <li>– adjustment for long-term disability for patients and their families/carers</li> <li>– supported communication for cognitive/communication impairment</li> <li>– management of confusion/unwanted behaviours (including verbal and physical aggression) in conjunction with neuro-psychiatric services</li> </ul> </li> <li>• Medico-legal issues               <ul style="list-style-type: none"> <li>– assessment of mental capacity</li> <li>– Power of Attorney, Court of Protection etc</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Multi-professional management of distressing symptoms, usually in patients with limited life expectancy for rapidly progressive conditions. Particularly:               <ul style="list-style-type: none"> <li>– pain, nausea and vomiting, breathlessness</li> <li>– anxiety/depression, insomnia</li> <li>– management of confusion, agitation in conjunction with psychiatric and psychology services</li> </ul> </li> <li>• Support for end-of-life decisions and advance care planning, eg:               <ul style="list-style-type: none"> <li>– advance statements and decisions</li> <li>– choice over place of care</li> <li>– assessment of capacity in relation to these decisions</li> </ul> </li> <li>• Support of the dying person and their family, eg:               <ul style="list-style-type: none"> <li>– psychosocial</li> <li>– welfare</li> <li>– spiritual</li> </ul> </li> <li>• Bereavement counselling</li> <li>• Advisory/liaison service               <ul style="list-style-type: none"> <li>– links to local palliative care resources and teams</li> <li>– professional education in the provision of generic palliative care and support</li> <li>– provision and coordination of community support services</li> </ul> </li> </ul>

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

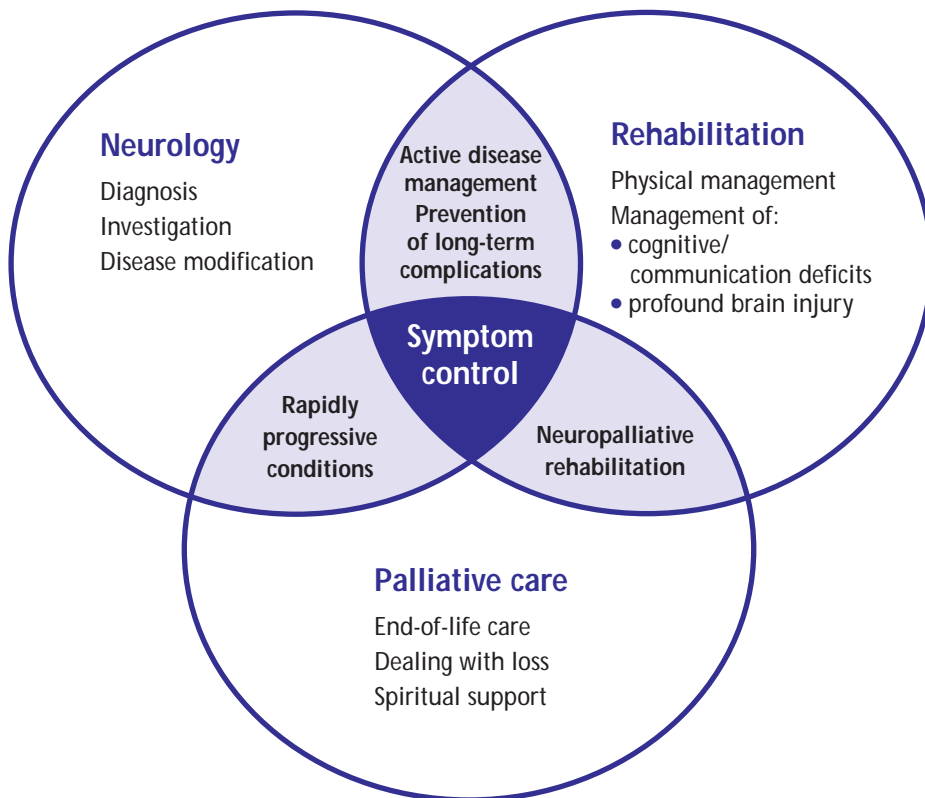


Fig. 1. The interaction between specialist neurology, rehabilitation and palliative care services in the management of patients with long-term neurological conditions.

practice, and for clinicians to respect the expertise of others in related areas. For example, in addition to diagnosis and prognostication, neurologists saw themselves as key providers of therapy, spasticity management etc, and rehabilitation physicians need to respect that. Conversely, neurologists need to recognise the diagnostic skills of rehabilitation physicians, who sometimes have the opportunity to observe patients at close quarters for longer periods to reach diagnoses that may have evaded earlier assessment.

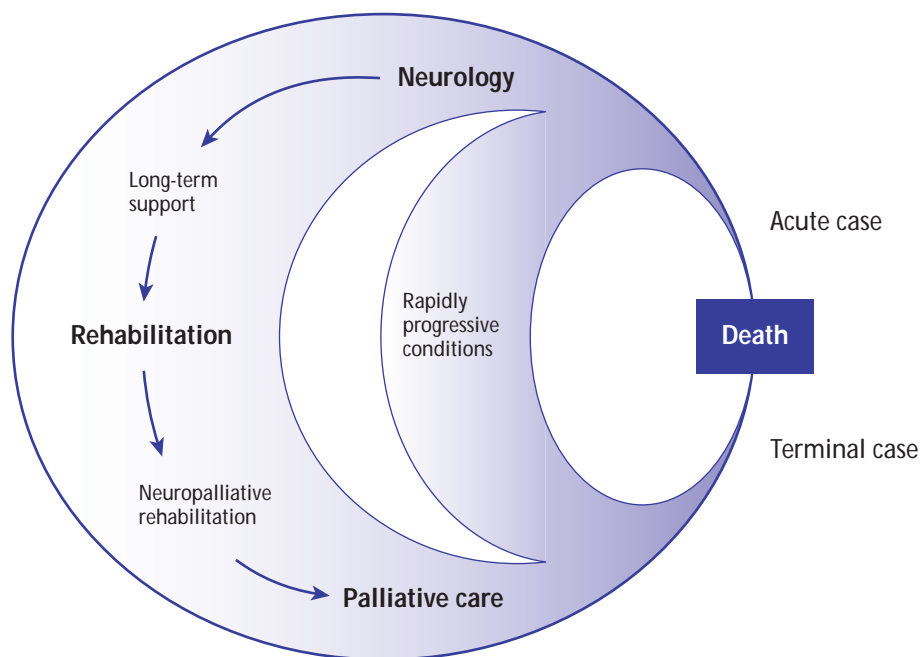
It is also important for neurologists and rehabilitation physicians to embrace the involvement of palliative physicians at earlier stages, and take advantage of their experience in managing symptoms such as nausea, vomiting and breathlessness which can occur in relative early phases of the disease. In return, rehabilitation physicians may have useful experience in managing people with profound cognitive and communication deficits, and it may be

helpful to share these skills with palliative physicians during the later stages of care in dealing with symptom management and end-of-life decisions.

A further interesting point to emerge was a difference in the frame of reference. Rehabilitation teams tend to be good at defining and working towards goals, but sometimes struggle where a patient's deteriorating health changes the goalposts rapidly and repeatedly. By contrast, palliative care teams, who are used to this progression, sometimes have difficulty with patients at stages where the disease is not advancing. Therefore rehabilitation teams may be slower to move to a 'symptom-management' mode, whilst palliative care teams may be slow to move to adaptive strategies – eg wheelchair training, seating programmes, use of orthoses, and environmental controls etc. Again this may be addressed by closer collaboration and cross-referral between the different services.

The survey highlighted a general shortfall in service





**Fig. 2. 'Life circles': proposed model for the relationship between neurology, rehabilitation and palliative care in caring for people with long-term neurological conditions.** In this model, the shading illustrates intensity of involvement of neurologists and palliative care physicians in acute and terminal care respectively. There is very close interaction between neurology and palliative care throughout the duration of rapidly progressive conditions, with a relatively smaller role for rehabilitation medicine physicians. However, rehabilitation plays a major role in providing long-term care and support, often over many years, in the more slowly progressive or stable conditions. As the patient's condition becomes more advanced, rehabilitation and palliative care approaches often overlap – we have called this 'neuropalliative rehabilitation'. (Reproduced from Ref 37.)

provision for both palliative care and rehabilitation services for people with LTNCs, particular in the community. There was also a marked lack of service coordination. Perhaps not surprisingly, each specialty reported greater ease of access to services within their own field, which further emphasises the need to work closely together.

Figure 2 illustrates a proposed model for service interaction. People with rapidly progressive neurological conditions require closely coordinated neurology and palliative care services throughout the relatively short span of their condition. However, for people with more slowly changing conditions, the major role for neurology is in the early stages of diagnosis and treatment, and for palliative care in the late stages. For many years in between, rehabilitation services provide the mainstay of support to coordinate services which help them to maximise

their independence and autonomy, with input from neurology as required. Towards the later stages, the roles of rehabilitation and palliative care become more closely intertwined in an approach which we have termed 'neuropalliative rehabilitation'.

**Table 2. Key skills in neurological palliative care and rehabilitation.**

**Every physician should have an understanding of the general principles of management, and should also be aware of when and where to refer if more specialist advice is needed in the areas shown below**

Exposure to people with long-term neurological conditions	<ul style="list-style-type: none"> <li>• Understanding disease progression and prognosis</li> </ul>
Symptom control	<ul style="list-style-type: none"> <li>• Ability to control key symptoms including:             <ul style="list-style-type: none"> <li>– pain in neurological conditions</li> <li>– breathlessness</li> <li>– nausea/vomiting</li> <li>– anxiety/depression</li> <li>– spasticity management</li> <li>– 24-hour postural support</li> <li>– bladder and bowels</li> <li>– seizure control</li> </ul> </li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Basic understanding of common communication problems including dysphasia, dysarthria, cognitive speech disorders and the different approaches to their management.</li> <li>• Ability to communicate with people who have cognitive/communication impairments             <ul style="list-style-type: none"> <li>– using assistive communication devices</li> </ul> </li> <li>• Communicating with patient and family             <ul style="list-style-type: none"> <li>– breaking bad news</li> <li>– addressing end-of-life decisions and advance care planning which will include choice over place of care.</li> </ul> </li> <li>• Managing expectations</li> </ul>
Legal issues	<ul style="list-style-type: none"> <li>• Ability to assess for mental capacity, and to assist people to make advance decisions and statements</li> <li>• Understanding of the Mental Capacity Act 2005 and ability to work alongside lasting power of attorney/court appointed deputy or independent mental capacity advocates*</li> </ul>

**Additional skills for physicians specialising in neurological palliative care and rehabilitation**

Specialist interventions	<ul style="list-style-type: none"> <li>• Local and intrathecal interventions for spasticity (eg injection of botulinum toxin/phenol and use of baclofen pumps)</li> <li>• Specialist procedures for pain control</li> <li>• Management of confusion/unwanted behaviours – management under sections of the Mental Health Act 1983</li> <li>• Ventilation</li> </ul>
Specialist equipment	<ul style="list-style-type: none"> <li>• Wheelchair seating systems</li> <li>• Environmental control systems</li> <li>• Specialist communication aids</li> </ul>
Counselling and psychological support	<ul style="list-style-type: none"> <li>• Dealing with loss and fear of loss</li> <li>• Spiritual support</li> <li>• Bereavement – past and future</li> </ul>
Welfare advice	<ul style="list-style-type: none"> <li>• Understanding the social care system and benefits</li> <li>• Vocational support</li> </ul>
Additional sources of help and support	<ul style="list-style-type: none"> <li>• Understanding the interaction between health, social services and voluntary support agencies</li> <li>• Negotiating skills in obtaining services</li> </ul>

\* Terms such as 'living will' or 'advance directives' are often used to describe documents in which people write down their wishes and choices about their future care. However, these terms do not have any legal standing. Under the Mental Capacity Act 2005 (MCA) it is now possible for people to make legally binding advance decisions to refuse treatment as well as non-binding advance statements about their wishes and priorities for care, to take effect should they lose the capacity to make decisions for themselves. For clarity, it is important to use this language wherever possible. Any statements about future care and treatment must be considered in the light of the MCA. For further guidance on the MCA, see [www.ncpc.org.uk/publications](http://www.ncpc.org.uk/publications)

# THE GUIDELINES

<i>Recommendation</i>	<i>Grade of evidence*</i>
<b>A General service coordination</b>	
Neurology, rehabilitation and palliative care services should develop closely coordinated working links to support people with long-term neurological conditions (LTNCs) from diagnosis to death, including:	<b>E1/2</b>
<ul style="list-style-type: none"> <li>• proper flow of communication and information for patients and their families</li> <li>• a designated point of contact for each stage in the pathway</li> <li>• a needs assessment identifying the patient's individual problems.</li> </ul>	
<b>B Neurology services</b>	
1 A person who is suspected of having an LTNC should be referred promptly to a specialist neurological service for investigation and diagnosis.	<b>RA</b>
2 A person who is confirmed to have an LTNC should have:	
<ul style="list-style-type: none"> <li>• ongoing access to specialist neurological services for disease-modifying treatment, if appropriate</li> <li>• ongoing support and advice with regard to management of their condition and its sequelae</li> <li>• support from specialist neurological nurses for practical advice on living with their condition.</li> </ul>	<b>RA</b> <b>RB</b>
<b>C Rehabilitation services</b>	
1 A person with an LTNC should be referred to a specialist neurological rehabilitation service if:	<b>RA</b>
<ul style="list-style-type: none"> <li>• 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, <i>and/or</i></li> <li>• their circumstances change in a way that affects their independence or participation in their current environment.</li> </ul>	
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:	<b>E1/2</b>
<ul style="list-style-type: none"> <li>• initial needs assessment and provision of support according to the list in Table 1</li> <li>• ongoing integrated care planning – including an annual multi-agency needs assessment including health, social services, and voluntary sector input</li> <li>• coordinated service provision in accordance with changing need, including equipment, environmental adaptation, rehabilitation for vocation/leisure, psychosocial support.</li> </ul>	
<b>D Palliative care services</b>	
1 A person with an LTNC should be referred to specialist palliative care services if they have:	<b>RB</b>
<ul style="list-style-type: none"> <li>• a limited lifespan – usually 6–12 months, <i>and/or</i></li> <li>• distressing symptoms – especially pain, nausea and vomiting, breathlessness, which fall within the remit of the palliative physician, <i>and/or</i></li> <li>• a need or desire for end-of-life planning, with or without competence issues.</li> </ul>	
2 A person who is dying from an LTNC should have timely and ongoing access to specialist palliative care services which include:	<b>RB</b>
<ul style="list-style-type: none"> <li>• symptom control</li> <li>• planning and support to the end of their life</li> <li>• aftercare and bereavement support for their families.</li> </ul>	

\* For explanation of grades of evidence, see [Appendix 2](#).

## Implications for implementation

The literature review and survey undertaken to underpin these guidelines 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 improve the use of current services, by improving communication and networking between specialist and local services, and enhancing coordination between the specialties.<sup>30</sup>

### Training

A key step in implementing these guidelines is improved training. Key skills that every physician should have are listed in Table 2, as well as a set of higher level skills that will be required by physicians specialising in this area. These required skills and competencies can be achieved through enhanced recognition of the importance of rehabilitation and palliative care in the training curriculum, setting key skills and competencies to be achieved alongside other basic medical and surgical skills. Extra training and exposure may be achieved through placements, and via joint training days for trainees in the specialties of neurology, rehabilitation and palliative care designed to pool knowledge and share skills.

### Tools for implementation

A set of tools to support the above training and also implementation of the guidelines is offered in [Appendix 3](#). They include a checklist to guide clinicians when a patient with an LTNC is admitted to a general hospital, as well as a series of pathways to guide management of bowels and bladder (Figs A1, A2), and specific symptoms: pain (Fig A3), nausea and vomiting (Fig A4), and breathlessness (Fig A5).

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For key to bold type below, see [Appendix 2, page 13](#).

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# Appendix 1. Guideline development process

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## Scope and purpose

Overall objective of the guidelines	To improve the quality of care offered to people in the later stages of a long-term neurological condition (LTNC) through better collaboration between neurology, rehabilitation and palliative care teams.
The patient group covered	Adults with long-term neurological conditions including: <ul style="list-style-type: none"><li>• sudden onset conditions (eg acquired brain injury of any cause (including stroke), spinal cord injury)</li><li>• intermittent conditions (eg epilepsy)</li><li>• progressive conditions (eg multiple sclerosis, motor neurone disease, Parkinson's disease and other neurodegenerative disorders)</li><li>• stable conditions (eg polio or cerebral palsy).</li></ul>
Target audience	Doctors and health professionals involved in the long-term support, rehabilitation and palliative care of people in the later stages of LTNC. Providers and purchaser of neurology, rehabilitation and palliative care services.
Clinical areas covered	<ul style="list-style-type: none"><li>• How should specialist neurology, rehabilitation and palliative care teams integrate in the management of this group of patients?</li><li>• How should non-specialist clinicians care for people with LTNCs when admitted to hospital for other conditions, and when should they call for specialist help?</li><li>• What training should be provided within each field to ensure that future generations have the necessary understanding and competencies to provide best quality of care?</li></ul>

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## Stakeholder involvement

The Guideline Development Group (GDG)	A multidisciplinary working party convened through the National Council for Palliative Care including: <ul style="list-style-type: none"><li>• physicians, nurses and other allied health and social services professionals practising in neurology, rehabilitation and palliative care</li><li>• representatives of patients and user groups including Sue Ryder Care, and the Motor Neurone Disease Association.</li></ul>
Funding	The British Society of Rehabilitation Medicine (BSRM), the Royal College of Physicians and the National Council for Palliative Care all contributed funding or resources towards the guideline development.
Conflicts of interest	All GDG members were asked to declare any personal or financial conflicts of interest, but none were identified.

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## Rigour of development

Evidence gathering	Evidence for these guidelines was based on systematic reviews of the literature undertaken in preparation for the National Service Framework (NSF) for Long-Term Conditions <sup>15</sup> in 2005 and updated in 2006/7. Reviews covered the major databases (Medline, Embase, Cochrane etc). A survey of UK physicians in the three fields was undertaken <sup>37</sup> to ascertain current working patterns and perspectives, and two open conferences have been held with a wide selection of stakeholders, both professional and users, to explore the proposed pathways for more integrated care. Full details of this process can be found in <i>Focus on Neurology</i> available at <a href="http://www.ncpc.org.uk">www.ncpc.org.uk</a> .
Review process	The evidence was evaluated by members of the GDG.
Links between evidence and recommendations	The system used to grade the evidence and guidance recommendations is that published for the NSF <sup>15</sup> (see <a href="#">Appendix 2</a> ).
Piloting and peer review	Not yet piloted.

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## Implementation

Tools for application	Tools for implementation are included in <a href="#">Appendix 3</a> .
Plans for update	The guideline will be reviewed in 3 years (2011).

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## Appendix 2. Methods used to evaluate the evidence

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The typology and grading system developed for the National Service Framework for Long-term (Neurological) Conditions were used to evaluate the evidence.<sup>15</sup> The typology is designed to place value on the experience of users and professionals as well as research, and also to value high-quality research regardless of the design.

Each piece of evidence is reviewed and given an 'E' and/or an 'R' rating:

**E = Expert evidence.** This is evidence expressed through consultation or consensus processes rather than formal research designs. It could be professional opinion, or that of users and/or carers or other stakeholders.

**R = Research evidence.** This is evidence gathered through formal research processes. Each piece of research-based evidence is awarded a rating based on three categorisations:

- **research design** – category of research design
- **research quality** – rated high, medium or low
- **applicability of research** – whether the study population is within the context of long-term neurological conditions ('direct') or in other populations ('indirect').

**Research design** is classified according to the following categories:

### Primary research-based evidence

P1 Primary research using quantitative approaches

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P2 Primary research using qualitative approaches

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P3 Primary research using mixed methods (qualitative and quantitative)

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### Secondary research-based evidence

S1 Meta-analysis of existing data analysis

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S2 Secondary analysis of existing data

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### Review-based evidence

R1 Systematic reviews of existing research

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R2 Descriptive or summary reviews of existing research

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**Research quality** is assessed using five questions with a possible score on each question of 0, 1 or 2, giving a maximum score of 10:

<i>Each quality item is scored as follows: Yes = 2; In part = 1; No = 0</i>		Score
1	Are the research question/aims and design clearly stated?	
2	Is the research design appropriate for the aims and objectives of the research?	
3	Are the methods clearly described?	
4	Is the data adequate to support the authors' interpretations/ conclusions?	
5	Are the results generalisable?	
<b>Total</b>		<b>/10</b>

- High-quality research studies are those that score at least 7/10.
- Medium-quality studies score 4–6/10.
- Poor-quality studies score 3/10 or less.

**Applicability of research** is classified as shown below:

**Direct**      Studies that focus on people with long-term neurological conditions

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**Indirect**    Extrapolated evidence from populations with other conditions

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### Examples

- A well-conducted qualitative study, scoring 8/10 and demonstrating the benefits of a given intervention in people with multiple sclerosis would be classified as: **P2 High Direct**.
- A post-hoc analysis scoring 5/10 on quality assessment, demonstrating the benefits of palliative care in cancer would be classified as: **R2 Medium Indirect**.

*Some sources, such as a pre-existing set of guidelines/standards, reviews or book chapters, may include both research evidence and expert opinion and so might be graded as: **R1 High Direct/E2**.*

## Grade of research evidence

Each individual recommendation or statement is then given an overall evidence rating of **A**, **B** or **C** based on the quality of all the research evidence supporting it and how much of it was directly relevant. The overall grade of evidence is rated as shown below.

<i>Grade of evidence</i>	<i>Criteria</i>
Research Grade A ( <b>RA</b> )	* More than one study of high-quality score (7/10) and * At least one of these has direct applicability
Research Grade B ( <b>RB</b> )	* One high-quality study <i>or</i> * More than one medium-quality study (4–6/10) <i>and</i> * At least one of these has direct applicability
	<i>Or</i>
	* More than one study of high-quality score (7/10) of indirect applicability
Research Grade C ( <b>RC</b> )	* One medium-quality study (4–6/10) <i>or</i> * Lower-quality (2–3/10) studies <i>or</i> * Indirect studies only

## Appendix 3. Tools for implementation

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### A. Checklist to use on admission of patients with a long-term neurological condition

#### 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.

**Table A1. Checklist for the management of patients with an LTNC when admitted to a general hospital ward.**

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#### 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 are made on their behalf, so always consider and respect their advice and wishes.**

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#### Prior to admission consider the following:

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

#### 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 it.
  - Check the patient's 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. Neuro-physiotherapy 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?

*Table A1 continued overleaf*

**Table A1. Checklist for the management of patients with an LTNC when admitted to a general hospital ward (cont'd).**

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- Nutrition: is this adequate? Is the patient able to feed themselves?
  - Respiratory capacity:
    - check and monitor vital capacity if compromised.
  - 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.
- 

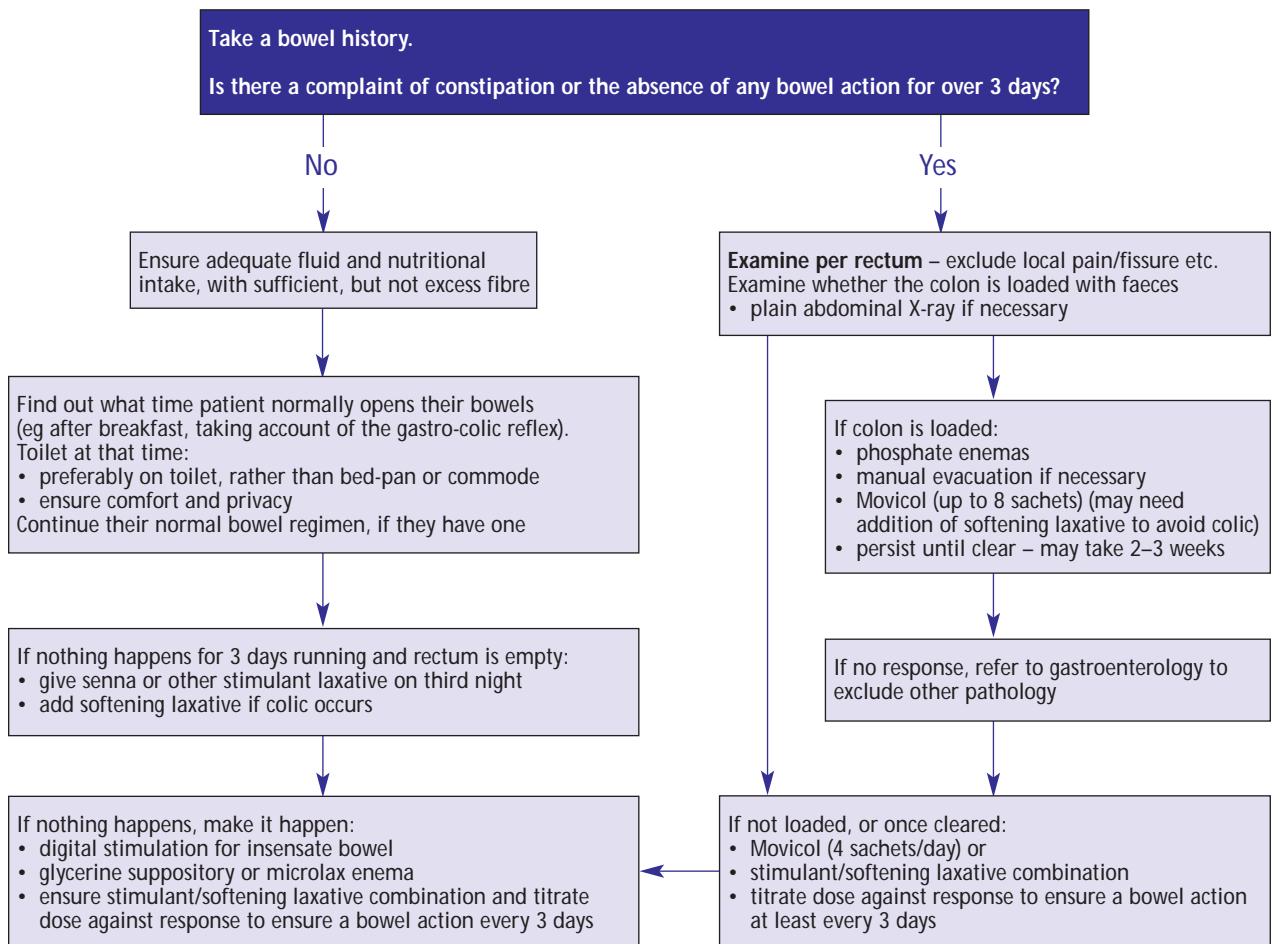
**If considering a procedure, consider once again:**

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

**Prior to discharge:**

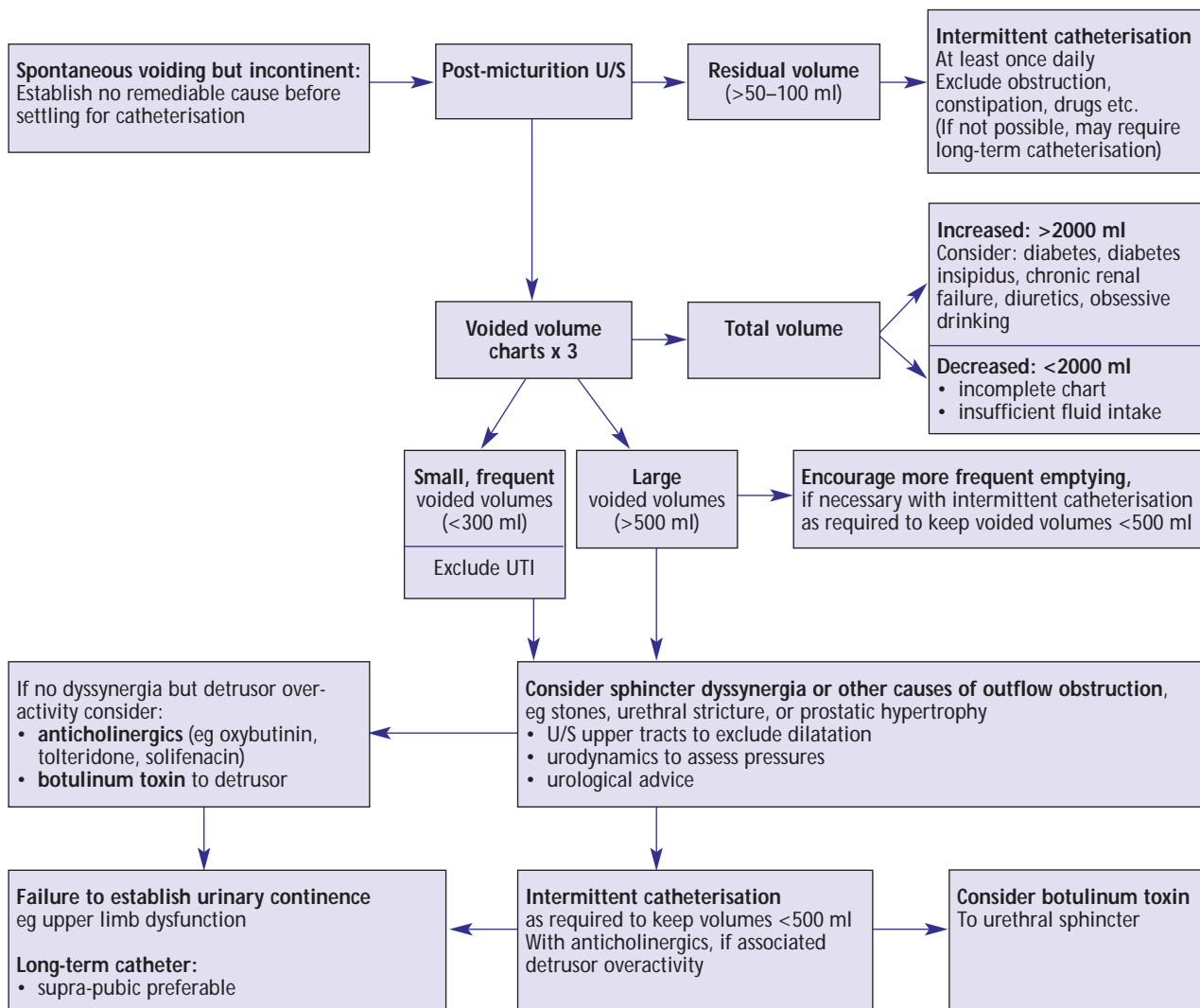
- Consider whether the arrangements at home are appropriate – did they trigger the admission?
- Assess how the patient's discharge will affect the family and their ability to cope.
- Review and re-start the care package – revise if necessary.
- Inform the team that usually cares for the patient in hospital, in the community, or at home.
- Arrange follow-up if necessary – try to coordinate this if the patient has difficulty accessing hospital.

## B. Key areas of symptom management



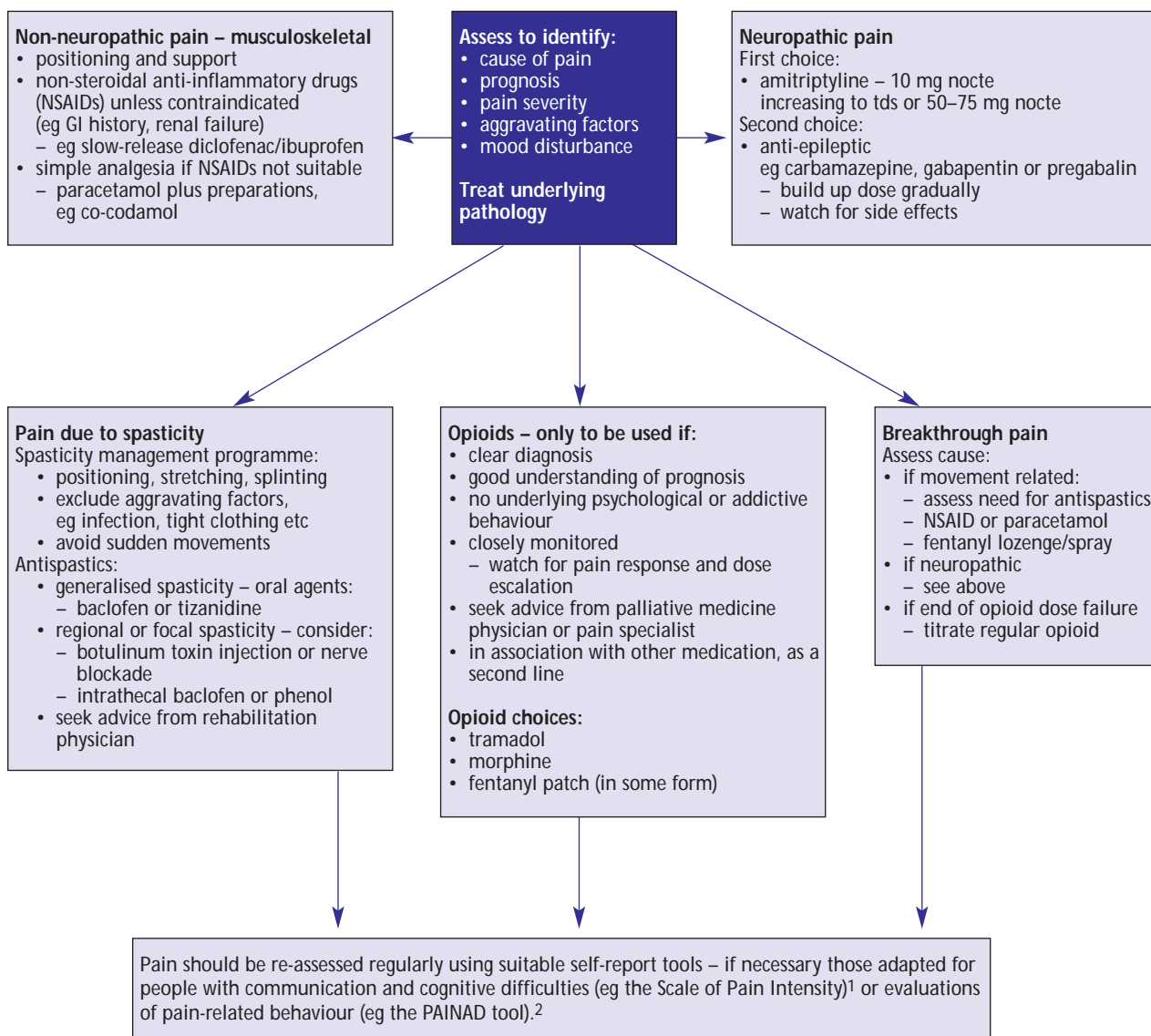
**Fig. A1. Bowel management in patients with long-term neurological conditions.**

Movicol = polyethylene glycol 3350.



**Fig. A2. Managing urinary incontinence in patients with long-term neurological conditions.**  
U/S = ultrasound; UTI = urinary tract infection.

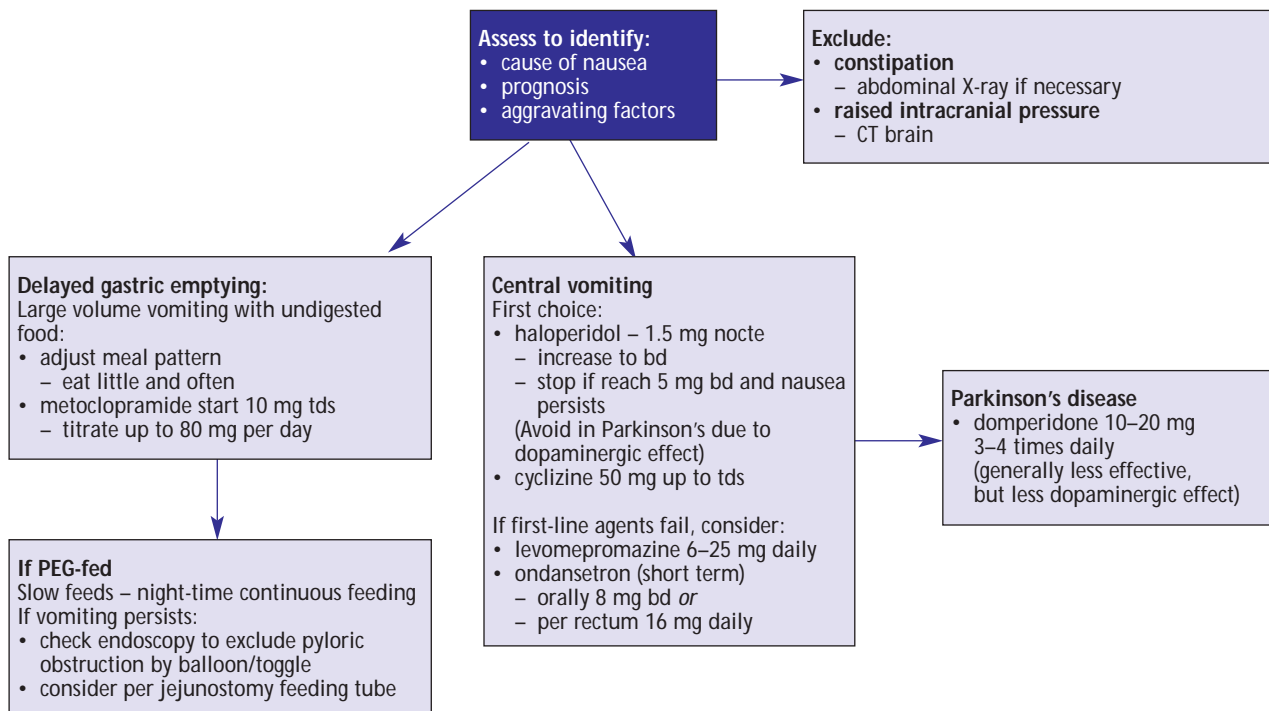




**Fig. A3. Managing pain in patients with long-term neurological conditions.**

<sup>1</sup>Jackson D, Horn S, Kersten P, Turner-Stokes L. Development of a pictorial scale of pain intensity for patients with communication impairments: initial validation in a general population. *Clin Med* 2006;6(6):580–5.

<sup>2</sup>Ward V, Hurley AD, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *J Am Med Dir Assoc* 2003;4:9–15.



**Fig. A4. Managing nausea and vomiting in patients with long-term neurological conditions.**

CT = computed tomography; PEG = percutaneous endoscopic gastronomy.

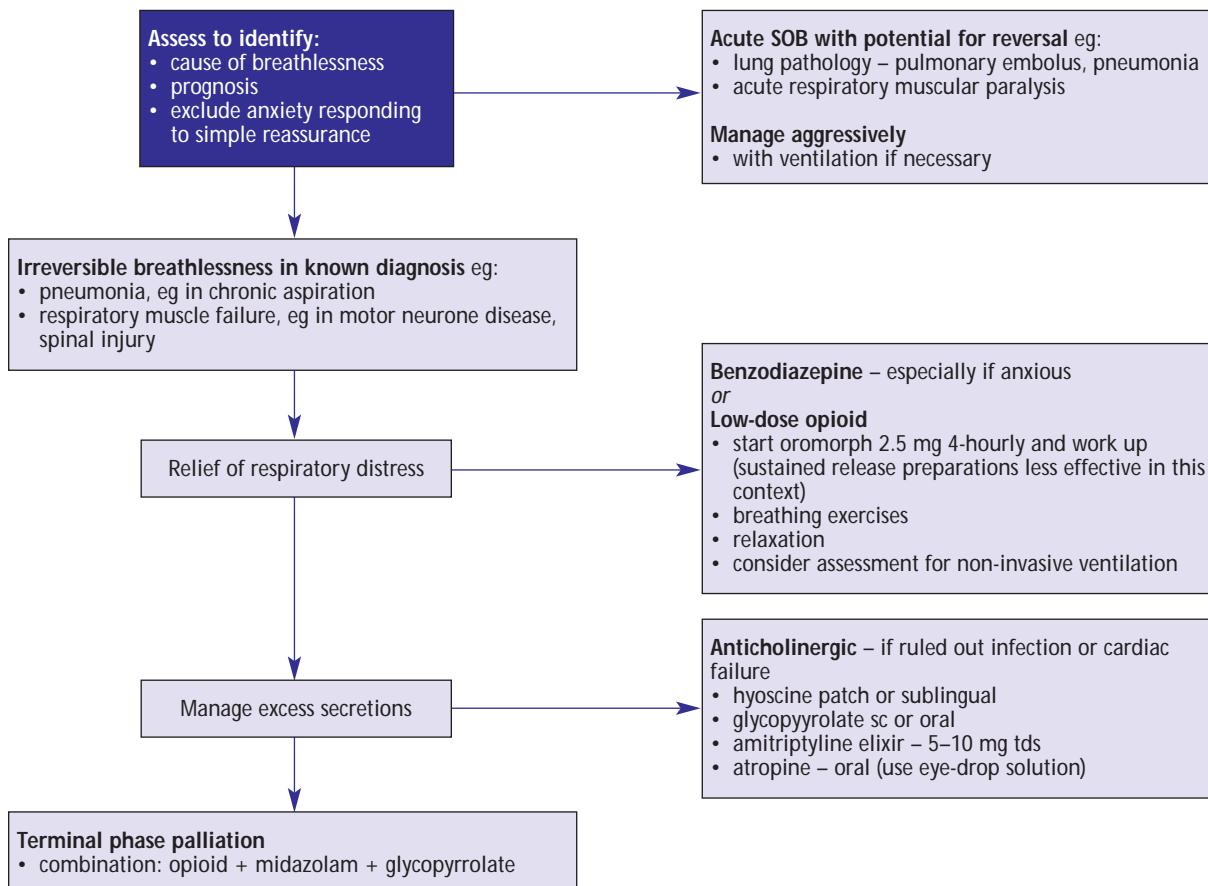


Fig. A5. Managing shortness of breath (SOB) in patients with long-term neurological conditions.