End of life care in long term neurological conditions

a framework for implementation
3 Foreword
4 Introduction
5 Executive summary
7 Strategic context
9 End of life care tools
10 End of life care in neurological disease
15 Communication and advance care planning
19 Co-ordination and multidisciplinary approach to care
21 Management of physical symptoms
24 Holistic care - psychosocial and spiritual aspects
26 Care at the end of life
29 Carers
31 Workforce, education and training
32 Commissioning health and social care services
33 References
The care of people with long term neurological conditions is often complex and varied due to the symptoms they face and the rate of progression of the disease. This will vary from case to case but most people will deteriorate, dying as a result of their condition.

The National service framework for long term conditions, published in 2005, includes a quality requirement for end of life care (QR 9). This says “People in the later stages of long term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.”

At present there is often little discussion about end of life care (EoLC) for these individuals. Additionally, there is a lack of recognition that these people may experience cognitive changes and that therefore these discussions need to take place earlier.

Palliative care can improve quality of life throughout the disease progression. The holistic approach - with pain and symptom management - can be helpful. As the disease progresses multidisciplinary palliative care is effective towards the end of life.

This document aims to ensure all involved in this area of care are aware of end of life issues throughout the disease progression, and that they support people with neurological disease and their families as they face a declining physical and mental state. There is the need for close collaboration between many services - elderly care medicine, neurology, rehabilitation medicine, specialist palliative care, psychiatry, primary care, social care and voluntary organisations. This is a challenge for all involved if we are to improve the quality of life and EoLC for these people.

This document will start the dialogue. It will enable all involved to look carefully at the care they provide and how they can develop services that will enable individuals and their families to live with their neurological disease and receive co-ordinated, excellent EoLC.

Professor Sir Michael Richards,
National Clinical Director for End of Life Care

Dr Chris Clough,
Medical Advisor to the Department of Health Long Term Conditions Team

Dr David Oliver,
Clinical Lead for this document
This document has been produced by the National End of Life Care Programme (NEoLCP), in conjunction with the Neurological Alliance and the National Council for Palliative Care’s (NCPC) neurological group. The clinical lead for this project is Dr David Oliver, consultant in palliative medicine at the Wisdom Hospice, Rochester and honorary senior lecturer at the University of Kent.

The Department of Health and National End of Life Care Programme established a remote working group and held a one-day workshop of stakeholders in January 2010. This marked the start of work to develop an implementation framework for end of life care in advanced neurological conditions.

Those discussions inform the proposed structure and content of this guidance. The original stakeholder group consisted of:

- Dr David Oliver - Wisdom Hospice, Rochester and the University of Kent
- Beverly Hopcutt - Department of Health
- Isabel Quinn - NEoLCP
- Dr Chris Clough - Department of Health Long Term Conditions Team
- Dr Colin Campbell - St Catherine’s Hospice, Scarborough
- Dr Cynthia Benz - NCPC
- Rev Dr Barbara Chandler - Centre for Neurorehabilitation and Neuropsychiatry
- Debra Chand - Progressive Supranuclear Palsy Association
- Jane Appleton - Sue Ryder Care
- Dr Nigel Sykes - St Christopher’s Hospice, London
- Dr Eli Silber - King’s College Hospital, London
- Dr Mark Lee - NHS South of Tyne and Wear
- Simon Chapman - NCPC
- Lesley Robson - Newcastle PCT
- Sue Smith - MND Association

Following the initial consultation it was agreed that the NCPC neurological group would act as an expert reference point for this project. We are also grateful for the input of a range of end of life and neurological care organisations, as well as service user and carer groups.
From the initial diagnosis it is important that the changes in neurological disease progression are recognised - in all care settings - as triggers for the introduction and subsequent involvement of palliative care. This should be based on holistic assessment that includes multidisciplinary and multi-agency collaboration, good communication, regular review and the needs of carers.

There are many challenges involved in the EoLC of a person with neurological disease:

- Long duration of disease
- Sudden death (eg, motor neurone disease/multiple system atrophy)
- Lack of predictable course, or fluctuating course (eg, Parkinson’s disease)
- Complex multidisciplinary care (eg, multiple sclerosis)
- Specialist treatments (eg, deep brain stimulation in Parkinson’s disease)
- Neuro-psychiatric problems (eg, behavioural and cognitive changes)
- Rapidly advancing diseases may need palliative care early on
- Many people die with but not from their neurological condition
- Neurological conditions are widely variable, making planning of EoLC challenging.

Identifying when someone with an advanced neurological condition may be approaching the EoLC phase of their illness is important, because it enables the appropriate care to be planned.

Indicators that help identify this phase include:

- Swallowing problems
- Recurring infection
- Marked decline in physical status
- First episode of aspiration pneumonia
- Cognitive difficulties

- Weight loss
- Significant complex symptoms.

Communicating successfully with people who have neurological conditions is essential to ensure the individual is able to:

- Understand as much as they want to know about their disease
- Be aware of what may happen as their disease progresses
- Feel empowered to make informed choices over their future care
- Be part of a two way process - with the person feeling that their views and preferences have been heard and understood.

Advance care planning (ACP) is very important for people with neurological disease, who may face later cognitive change. There may be times when these discussions should be encouraged - for instance when there is discussion about potentially life prolonging treatment, such as ventilatory support.
Soon after the diagnosis a multidisciplinary team will be involved and co-ordination of care is essential. A single point of initial contact is helpful, using a key worker/key team model.

The control of symptoms for people with a long term neurological condition is a key part of holistic management. This starts at the point of diagnosis. It improves the quality of life for the person and family and can have a huge impact on how families manage after death.

Assessing people with a neurological disease can be time consuming, due to communication or cognitive changes. However, planning for - and giving - a person time to express themselves will help not only establish trust but also potentially reduce future misunderstandings or complications.

As someone faces the diagnosis and then the progression of a life-limiting condition many emotional and psychological issues may come to the fore, including fear of the disease, death and implications for the family.

Spiritual issues should be addressed - aiming for an understanding of what is important to the individual.

Recognition of the dying phase in neurological disease can be difficult. Its onset is signalled by symptoms that might include breathlessness, systemic sepsis, reduced level of consciousness without reversible cause, and pressure sores.

Services caring for people nearing the end of life at home will need to discuss the preferred place of death with the person and their family. Communication and understanding as part of planning will reduce the risk of emergency admission as an acute event.

Living as a carer for someone with a neurological condition is challenging and the process of caring and being cared for is not only demanding - physically, psychologically and emotionally - but also potentially stressful for all involved.

Following the death of the person the family and carers - both within the family and professionals - may have many ambivalent feelings, such as sadness at the loss yet relief that the challenges of caring have eased. All involved need time to talk about these issues and some may require more formal counselling and bereavement support.

The *End of life care strategy* identifies the need for all health and social care staff to have the knowledge, skills and attitudes to deliver care at the end of life. All staff working in general and specialist services should have opportunities to develop their knowledge and skills, including an understanding of neurological conditions and the collaborative approach and joint working essential to delivering high quality EoLC.

Services providing care for people with advanced neurological conditions need to be co-ordinated, personalised, effective and integrated and treat individuals with dignity and respect. Effective commissioning of EoLC should start and end with those who have the neurological disease and the people closest to them.
The End of life care strategy was published in 2008. It was the first of its kind in the UK aimed at improving access to high quality care for all adults approaching the end of life irrespective of age, diagnosis, gender, ethnicity, religious belief, disability, sexual orientation or socio-economic status. The strategy also aims to encourage professionals working in all settings to improve their knowledge and confidence in caring for everyone with EoLC needs. EoLC was one of the eight clinical pathways developed by each of the strategic health authorities (SHAs) in England as part of Lord Darzi’s next stage review of the NHS.

About 10 million people in the UK have a long term neurological condition (LTNC), including those that are not life limiting (such as migraine) and they account for around 20 percent of acute hospital admissions. The most common condition is migraine with about 8 million sufferers. The estimated figures relating to progressive LTNCs, below, are not considered to be definitive, as the disease may not always be clearly defined on the death certificate.

This document aims to set out an EoLC framework for implementation that specifically meets the needs of those with neurological conditions and can apply to professionals in all care settings. GPs, for example, may only encounter one such patient in their entire career.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s disease</td>
<td>7,700</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>1,500</td>
</tr>
<tr>
<td>Motor neurone disease</td>
<td>1,500</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>240</td>
</tr>
</tbody>
</table>

For more details, see an updated version of the report Deaths from neurodegenerative diseases in England 2002-2008 (SWPHO, 2010), available at www.endoflifecare-intelligence.org.uk.
The End of life care strategy and the EoLC pathway

The twelve key areas addressed in the national End of life care strategy are outlined below. The following sections discuss these and other relevant issues in relation to EoLC for advanced neurological disease.

1. Raising the profile
2. Strategic commissioning
3. Identifying people approaching the end of life
4. Care planning
5. Co-ordination of care
6. Rapid access to care
7. Delivery of high quality services in all locations
8. Last days of life and care after death
9. Involving and supporting carers
10. Education/training and continuing professional development
11. Measurement and research
12. Funding.

The pathway looks at these aspects of care throughout the progression of a disease as shown below.
Recognised tools are already in place to facilitate the assessment and review of people with supportive and palliative care needs during the EoLC phase. These include palliative care and end of life care registers, which are part of the Quality Outcomes Framework (QOF) in primary care, and prognostic indicators in primary care as introduced by use of the Gold Standards Framework, preferred priorities for care (PPC), advance care planning (ACP) and tools such as the Liverpool Care Pathway for the Dying Patient (LCP).

The Gold Standards Framework (GSF) provides a valuable mechanism in primary and community care for effective person-centred planning during the last year of life. The framework encourages primary care teams to enhance their knowledge and understanding of palliative care and underlines the need for effective communications, co-ordination and continuity of care.

Advance care planning (ACP) will ensure the wider team knows what is important to the person, their beliefs, values and preferences for care.

Preferred priorities for care is a statement of an individual’s wishes and preferences for care, including where they would like to be cared for at the end of life. Some people living with a neurological condition may wish to document this very soon after their diagnosis - especially if they have a rapidly progressive condition or if they may lose their cognitive function as it progresses.

The Liverpool Care Pathway for the Dying Patient Continuous Quality Improvement Programme aims to translate the excellent model of hospice care into other health settings and to develop outcome measures using an integrated care pathway for the last hours or days of life. The LCP has been adapted for use in hospitals, hospices, homes or care homes.

An expert group was convened in 2009 to review the transferability of the generic LCP to support people with neurological conditions. Two key areas required further discussion: medication prescribing and specific information for relatives and carers. This work will now continue. The views of this expert group helped shape the current version of the LCP.

More information on EoLC tools can be found at www.endoflifecareforadults.nhs.uk/tools
With such a wide variety of symptoms and rates of disease progression it is important that changes in an individual’s condition are recognised in all care settings as triggers for the introduction of palliative care input. This decision should be based on holistic assessment.

**There are particular challenges in EoLC for people with neurological conditions:**
- The long duration of disease
- Potential for sudden death (eg, motor neurone disease, multiple system atrophy, epilepsy)
- Lack of predictable course, or fluctuating course (eg, Parkinson’s disease)
- Complex multidisciplinary care (eg, multiple sclerosis)
- Specialist treatments (eg, deep brain stimulation in Parkinson’s disease/disease modifying therapies in multiple sclerosis)
- Neuropsychiatric problems (eg, behavioural and cognitive changes)
- Rapidly advancing diseases may need palliative care early in the progression
- Many people die with but not from their neurological condition.

**Specific problems for EoLC of people with neurological conditions**

**Variability in progression**

Neurological conditions are widely variable, making planning challenging. For example, the progressive nature of motor neurone disease (MND) can mean it is possible to include palliative care input from the time of diagnosis.

With some conditions the rate of progression may vary from months (for many people with MND) to decades (for people with MS). Progressive neurological conditions, such as progressive supranuclear palsy (PSP) or multiple system atrophy (MSA), can be difficult to diagnose initially, so diagnosis may be relatively late or delayed.

Palliative care may therefore be required from diagnosis. It is essential to assess each person individually, regardless of any ‘label’ they may have been given.

Ensuring that care is co-ordinated and maintained with good communication among the various professionals involved requires a dynamic approach and is essential to maximise quality of life. The shared expertise of palliative care specialists working with others (eg, neurologists, elderly care physicians, rehabilitation consultants, psychiatrists, nurse specialists, physiotherapists, occupational therapists, dietitians, speech and language therapists, psychologists and social workers) will ensure that the person’s wishes are central to care plans and that each member of the team is clear about their roles and responsibilities. This will be reinforced by new ways of team working.

As individual needs vary over time there may be a role for episodic involvement of palliative care services, especially at times of particular symptoms or psychosocial issues - such as the start of new interventions (like gastrostomy feeding or ventilatory support) or at the very end of life.
End of life care in neurological disease

Cognitive changes

Many people with neurological disease face cognitive change. The possibility of these changes occurring, and their impact, will affect how EoLC is planned. It may be necessary to discuss peoples’ wishes early, while they still have the capacity to do so. However, this can be hard for the person, their family and clinicians. Assistance may be needed to facilitate discussion and expression of views.

Complex treatments

Some people may require complex, often invasive, interventions and there may be complicated ethical issues to face. As the disease progresses withdrawal of treatments may be discussed.

Wider multidisciplinary teams face the challenges of empowering individuals and their families in making these difficult decisions and
in supporting each other throughout. There must be close collaboration and understanding between all the professionals involved so that the person’s expectations are managed appropriately.

Disease-specific problems

Multiple sclerosis (MS)

Most people with MS initially have relapsing and remitting progress, with attacks affecting different parts of the central nervous system and with complete or partial recovery between attacks. Whether the disease begins with a relapsing or progressive course, in most cases the disease progression will result in progressive disability. The disease may be highly variable, the majority of people will experience progression and for some, this can occur shortly after diagnosis.

Parkinson’s disease (PD)

This is a progressive condition and with modern dopamine replacement therapy it can be controlled for several years. However, most people will suffer a progressive decline before the end of life due to motor and non-motor fluctuations, neuropsychiatric problems and problems with muscle control.

This makes careful and timely care planning and provision essential. Palliative care should be involved at an early stage to assist with symptom management. Individuals should be encouraged to undertake ACP but they, their carers and clinicians need to be aware that people can deteriorate dramatically and appear close to death due to treatment problems, and/or intercurrent infections, only to recover swiftly with appropriate intervention and resume their previous way of life.

Parkinsonian syndromes - multiple system atrophy (MSA) and progressive supranuclear palsy (PSP) - may be difficult to distinguish initially from PD, but most are usually less responsive to medication and the progression of symptoms is generally more rapid. In MSA there is a combination of Parkinsonism with brain and nervous system dysfunction whereas in PSP there is limited eye movement, cognitive change and physical instability (leading to falls and fractures). The prognosis is usually two to four years from diagnosis - people develop considerable disability and require careful assessment and care.

Motor neurone disease (MND)

Whilst for many the course of MND is predictable and palliative care can be planned in a similar way to that of individuals with a cancer diagnosis, others can die suddenly from respiratory collapse. Around 10 percent have a slowly progressive form of MND that can last 10 to 20 years.

Other conditions

Muscular dystrophy, progressive nerve and brain disorders each pose their challenges. These include both inherited and degenerative conditions. Diseases of the central nervous system such as Huntington’s disease, prion diseases and cerebellar degenerations may have the additional complexity of cognitive loss. The nervous system can also be affected by a variety of cancerous conditions and the individual may have other diseases. Specialist management, a multidisciplinary team and close liaison with palliative care should all be considered.
End of life care in neurological disease

There may be disease specific issues at the end of life:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Specific issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>MS</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Spasms</td>
</tr>
<tr>
<td></td>
<td>Cognitive change</td>
</tr>
<tr>
<td></td>
<td>Difficulty swallowing with reduced hydration and nutrition</td>
</tr>
<tr>
<td></td>
<td>Skin fragility and increased risk of pressure sores</td>
</tr>
<tr>
<td></td>
<td>Mobility problems</td>
</tr>
<tr>
<td>PD</td>
<td>Rigidity</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
</tr>
<tr>
<td></td>
<td>Agitation/confusion from sepsis</td>
</tr>
<tr>
<td></td>
<td>Neuropsychiatric decline</td>
</tr>
<tr>
<td>MND</td>
<td>Respiratory failure or increased breathlessness</td>
</tr>
<tr>
<td></td>
<td>Reduced mobility</td>
</tr>
<tr>
<td></td>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td>MSA</td>
<td>Aspiration pneumonia</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Hallucinations/anxiety/psychosis/neuropsychiatric decline</td>
</tr>
<tr>
<td>PSP</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Cognitive and behavioural change</td>
</tr>
<tr>
<td></td>
<td>Visual impairment</td>
</tr>
<tr>
<td></td>
<td>Reduced mobility</td>
</tr>
</tbody>
</table>

Recognition of the end of life phase

Identifying when someone with an advanced neurological condition may be approaching the EoLC phase enables appropriate care planning. This can be very difficult when there is a long progressive decline over many years. However, indicators that could suggest a need for end of life care are often either not recognised or they are ignored.

There is a need for greater openness and discussion of dying and death and the Dying Matters coalition aims to address this more widely. The NCPC established the coalition to promote public awareness of dying, death and bereavement.

The following can suggest that the disease is progressing and end of life issues should be considered:

- Swallowing problems
- Recurring infection
- Marked decline in physical status
- First episode of aspiration pneumonia
- Cognitive difficulties
- Weight loss
- Significant complex symptoms

The pathway shown below identifies the need for regular assessment to identify the various triggers that may suggest there is a relevant deterioration in the person’s condition. Some symptoms may be reversible - for example, where there is an intercurrent infection, a period of depression or when medication can be changed or increased - and in all cases it is important to identify and treat any such problems.
End of life pathway for neurological disease

Some conditions may have specific triggers that may indicate end of life is approaching.
Clinicians need to consider what these may be in the following:
multiple sclerosis, Parkinson’s disease, motor neurone disease, multiple system atrophy, progressive supranuclear palsy, Huntington’s disease, neuromuscular weakness and inherited dystrophies.

Diagnosis of neurological condition

Future care discussion

Generic triggers/transition point
Marked decline in physical status
Swallowing difficulties
Significant weight loss
Recurring admissions
Frequent infection

End of life care discussions

Care in the last days of life

Care after death

Supportive care input
Palliative care input
Holistic assessment

Cognitive status
Ethical considerations
Proactive management plans
Place of care
Wishes and preferences
Advance decisions

Identification of key worker
Add to palliative care register
Discuss at MDT
DS1500 (use of ‘surprise’ question)
Detailed assessment of needs
Fax out-of-hours providers
Assess for continuing healthcare (use fast track tool if appropriate)
Mental Capacity Act/best interests

Diagnosis of dying - MDT discussion
Exclude reversible causes
Use a recognised last days of life pathway tool
Review existing medication
Convert meds to non-oral/proactive
Ethical decision-making
carer support

Bereavement care
Supporting information

End of life care in neurological disease
Effective communication is essential to ensure that the individual and their family can:

- Understand as much as they wish to know about the disease
- Be aware of what may happen as the disease progresses
- Feel empowered to make informed choices over future care.

Discussing the diagnosis

Conveying the initial diagnosis of a potentially serious neurological disease can be difficult and requires great sensitivity from the clinician. It has a significant influence on future care, including EoLC.

There are basic principles that need to be considered:

- Invite the person to bring someone with them when they are getting test results
- Ensure a private room is available, free from distractions and interruptions
- Convey the diagnosis sensitively and at a pace that is manageable for the individual
- Allow time for crucial information to sink in
- Avoid medical jargon
- Keep checking that the individual understands what has been said. For example, ask open questions to gauge their level of understanding
- Offer literature about their condition to read later
- Provide a follow-up contact number
- Arrange a review appointment in the near future for further discussion
- Provide information about sources of condition-specific and general support
- Provide a quiet room or other similar facility, where they may rest before they leave
- Start difficult discussions at or soon after diagnosis by exploring people's attitudes and views before decisions have to be made and any possible cognitive change has developed
- Ensure the individual has the opportunity to come to terms - if they are able to - with the reality of having an incurable and progressive neurological disease.

Communication throughout the illness: a two-way process

As the disease progresses, there may be issues to face such as loss of speech, intellect or mood change. The person should feel that their views and preferences have been heard and understood.

Some people will need to express their feelings and these need to be acknowledged. Someone hearing significant news may experience a range of emotions from dismay to anger, accompanied by difficulty in understanding what this means for them. Individuals and families will value the clinician and supporting multidisciplinary team who can listen with empathy to what may seem like powerful negative emotions.

People will generally cope better if provided with information at a rate they can handle mentally and emotionally. The discussion of these difficult issues will be a process over a period of time. Some may need to hear the same information several times. It is important to check their level of understanding - do not assume comprehension.

Helping individuals and their families understand what is happening now, and how they can best deal with what may happen in the future, is the cornerstone of good neurological care.
Principles of communication include:
- Listening to the person and their family's concerns
- Information enables people to make truly informed choices about their future care
- There is a judicious balance between overwhelming people with choice on the one hand, and being paternalistic on the other
- People need information at the outset and at stopping-off points throughout the disease trajectory. They should ideally be well informed of what symptoms to expect as the disease progresses
- When a neurological disease reaches the more advanced stages, difficult choices may need to be made. Ideally, everyone would wish that their lifetime preferences, and their current wishes, are respected when these decisions are made; these include who will care for the person and where that care will be available
- Awareness of the possible cognitive and speech changes that may develop - these may affect the person's ability to make or express decisions.

Discussing life-prolonging treatments

These are commonly used in advanced neurological diseases without knowledge of the person's wishes. These include:
- Treatment of serious infections with antibiotics
- Clinically assisted nutrition and hydration
- Artificial ventilation
- Cardiopulmonary resuscitation

People's preferences should always be considered. These may differ from those of their family and carers. This needs to be acknowledged and skilfully managed.

For some with an advanced neurological disease, their life has become one of suffering - and possibly unacceptable loss of control and dependence on others. They may choose to decline any treatment that could prolong life.

In such cases the focus of care should move to managing symptoms and keeping the person comfortable.

Others may actively seek any intervention that keeps them alive. They will nevertheless feel better able to cope with any associated side effects if they can discuss them in advance - considering the potential benefits, burdens and risks of the intervention.

It requires sensitivity to discuss these delicate matters but it is always helpful to discern who does, and who does not, wish to receive life-prolonging treatment.

These difficult discussions are at the heart of compassionate care, respecting the person's autonomy and helping them to make choices in keeping with their own circumstances, attitudes and beliefs. These discussions should start at diagnosis. This is the opportunity to find out the person's attitudes, before decisions have to be made and cognitive changes have developed. Regular review of care needs is essential.
Suggested prompts for talking about life-prolonging treatments:

“Has it been helpful in the past to know a bit more about your condition?”

“Do you like to know what is happening with your condition?”

“Would it be helpful to talk about how this condition may progress from here?”

“How have you been coping with things since you found it harder to swallow?”

“What you would like to see happen from here?”

Advance care planning and mental capacity

People living with a neurological condition can plan for the future. For example, they can talk with their family and friends - and the care team - about what their wishes are in relation to future treatment should they lose the capacity to make decisions themselves. The need for information and the desire to be involved in decision-making will vary from case to case.

Clinicians can provide opportunities to have open and honest conversations - including end of life care discussions - at all stages of the illness. There may be times when care professionals need to actively encourage discussion, for instance when potentially life-prolonging treatment such as ventilatory support is being considered.

These discussions will also ensure that the individual can make a truly informed choice, knowing that decisions about future care can be made clear at this earlier stage.

ACP should be used while a person has the capacity to plan ahead and anticipate needs. Other ways to ensure the individual’s wishes are known include:

- Advance statement - a written expression of the person’s wishes and preferences
- Advance decision to refuse treatment (ADRT) - a refusal of specific treatment in specific circumstances, which is legally binding
- Lasting power of attorney - appointing someone else to make decisions on behalf of the person if and when they lose capacity as the condition progresses. These may be around healthcare or personal/financial matters.
- Care professionals may need to emphasise the potential loss of involvement in future decisions if there is communication deterioration, encouraging people to plan ahead.

Mental Capacity Act 2005

The Mental Capacity Act provides a comprehensive framework for decision-making for the care and treatment of people who lack capacity to make decisions for themselves. This has particular relevance for anyone who wishes to make provision for their future care and welfare. It also has particular relevance for individuals who may lose their cognitive function as a result of their illness or other decline.

The Mental Capacity Act is underpinned by five key principles:

- An assumption of capacity
- All practical steps must be taken to support people to make their own decisions
- People have the right to make unwise or eccentric decisions
- Any decision made on behalf of a person who lacks capacity must be in their best interests
- Rights and freedoms must be restricted as little as possible.
Capacity is a legal definition but means that the person has the mental ability to make each decision. Each assessment of capacity will vary according to the type of decision. The more complex or difficult the decision, the greater the level of capacity required. The act requires any such decision or action made on behalf of an individual to be made in that person’s best interests - strict criteria are in place for this.

No one should be treated as unable to make a decision unless all practical steps to help them do so have been taken. Fluctuating capacity may mean putting off a decision if it does not need to be made immediately, or ensuring that a person has sufficient time to decide. It may mean choosing the best time of day, for example, excluding times when medication might cause drowsiness.

See the Mental Capacity Act 2005 code of practice\textsuperscript{11} for additional information.
From early on in the disease process of many neurological conditions a multidisciplinary team will be involved, making co-ordination of care vital.

In its guidance on the diagnosis and treatment of PD, the Royal College of Physicians says: “The care of people with PD is best undertaken in a multidisciplinary way throughout each stage of the disease.”

There must be an established, reliable means of communication between professionals, co-ordinating their involvement and their communication with the individual and all those involved in their care. As the disease progresses, more professionals are likely to become involved. The burden of trying to co-ordinate and communicate with all these people can be overwhelming for the individual and their family.

**Multidisciplinary involvement at different stages of neurological disease**

**At the time of diagnosis the professionals involved may be the GP, specialist neurologist and specialist nurse. However, an increasing number of professionals may become involved including:**
- Social workers
- Social services managers
- Community nurses
- Physiotherapists
- Occupational therapists - from health and social services
- Speech and language therapists
- Rehabilitation physicians
- Dietitians
- Orthotic technicians/wheelchair services
- Neuro-psychologists
- Specialist palliative care/hospices

**The benefits and drawbacks of multidisciplinary care**

The aim is to ensure all aspects of the individual’s care are met by the combined approach no matter what the setting.

Poor communication between professionals can mean conflicting advice is given,
particularly if some team members are not kept up to date with changes in the person’s condition. Individuals and their carers may have to repeat their concerns many times. There may be anxiety and confusion over which professional to contact if a particular problem arises. This can lead to unnecessary emergency hospital admissions.\footnote{14}

It can be difficult for the individual and their close family to maintain the privacy and dignity of their own home, as many professionals - as well as family and friends - may visit.

The evidence supports a multi-professional approach to neurological conditions as summarised in guidelines around the interface between neurology, rehabilitation and palliative care.

These say “Neurology, rehabilitation and palliative care services should develop closely co-ordinated working links to support people with long term neurological conditions from diagnosis to death, including:
\begin{itemize}
  \item Proper flow of communication and information for people and their families
  \item A designated point of contact for each stage in the pathway
  \item A needs assessment identifying the patient’s individual problems.” \footnote{13}
\end{itemize}

In order to achieve the best quality of care it is important that professionals recognise the limits of their own experience and know when to contact other specialists for support.

Recognition that EoLC is part of the individual’s journey should enable a more integrated approach. Indicators of the end of life phase of a condition\footnote{14} and triggers (page 13) for involving palliative care services should allow discussion with the individual and - with their agreement - discussions with their family regarding their ongoing care.
Effective symptom control is a key part of the holistic management of the individual and their family. It not only improves quality of life but it can also have a huge impact on how families manage after death.

Many families today are living with the legacy of relatives whose deaths involved unnecessary suffering.

Symptoms may be physical, psychological, spiritual or related to social circumstances. None of these occurs in isolation. For example, uncontrolled physical pain can adversely affect the psychological state and cause people to ask questions about the meaning or purpose of their situation. This can place a huge strain on families or carers who may not know which of the many professionals involved they should turn to for help.

Successful pain management involves addressing all this - it may not be possible to deal with the wider social or psychological issues without addressing the physical symptoms.

The principles of the management of physical symptoms

The principles of symptom management will be similar for all neurological diseases, although the specific treatments and interventions may depend on the specific needs of the individual. These principles are absolutely vital in achieving optimal symptom control, as they are embedded in an understanding of the person as a whole. The management of symptoms relies on comprehensive assessment. (See NEoLCP guidance on holistic common assessment for more information).

Assessment can be time consuming, due to communication or cognitive changes. However, enabling individuals to express themselves will establish trust and can reduce future misunderstandings or complications.

The management of physical symptoms when there are communication difficulties

Communication issues can relate to motor speech problems (common with MND), language problems (common with MSA) or cognitive problems (common with Huntington’s disease, MS or advanced PD). They can vary dramatically in severity.

People with cognitive problems often receive suboptimal pain control. It is therefore incumbent on health care professionals, especially speech and language therapists, to optimise communication and encourage the use of ACP while using the knowledge of the relatives or carers to interpret signs. They should also consider the use of appropriate behavioural/distress tools, such as DisDAT, which involves carers in assessing the presence of symptoms when communication may be limited.
Management of physical symptoms

Common physical symptoms in LTNC

**MND**
- Weakness
- Immobility
- Constipation
- Speech difficulties
- Pain
- Insomnia
- Drooling
- Breathlessness
- Weight loss/anorexia

**PD**
- Slow movement
- Pain
- Tremor
- Drooling
- Anxiety
- Drowsiness
- Stiffness
- Immobility
- Dry mouth
- Memory problems

**PSP**
- Vertical gaze palsy
- Slow movement
- Falls
- Postural instability
- Speech problems
- Swallowing problems
- Postural problems
- Apathy
- Double vision
- Photophobia

Non drug interventions: physiotherapy; positional/postural changes; pressure-relieving devices; mobility aids; aids to help daily living; Transcutaneous Electrical Nerve Stimulation (TENS); heat; massage and acupuncture.

Drugs: The World Health Organisation (WHO) analgesic ladder should be used as a framework for prescribing analgesic pain relief. This involves using simple analgesics, such as paracetamol, then weaker opioids and moving to stronger opioids, such as morphine when required.

Other medication may be needed, such as anti-spasticity drugs or medication for neuropathic pain in MS. These approaches are often used together. Care is needed to avoid problematic drug interactions or contraindications.

Many people may have skin pressure pain from immobility. Opioids can be helpful in reducing this discomfort.

In using medication those involved will also need to consider the route of administration. For a person with swallowing problems, transdermal patches or subcutaneous infusions, (particularly at the end of life) may be considered.

Pain

It is important not to assume that the pain is related to the primary diagnosis. In any neurological disease it may be due to the underlying condition itself (eg, cramps in Parkinson’s disease) or an unrelated condition (eg, co-existing angina or constipation). Furthermore, non-drug treatments may be more effective than drugs at controlling pain. This may be especially important if there are swallowing difficulties.
Management of physical symptoms

The person-centred approach is essential in the management of symptoms, including attention to detail, involvement of and communication with the wider multidisciplinary team, and regular review of the management plan.

Most common symptoms and treatments

**Drooling** - a symptom of impaired ability to swallow. Careful assessment should determine if there is an underlying reversible cause, management of which might be enough. Refer early to speech and language therapy for assessment and management. If these non-drug methods are not successful then a variety of medications, including antimuscarinic medication, Botox injections and radiotherapy, can be used.

**Breathlessness** - a very common symptom in MND, primarily caused by respiratory muscle weakness. While physiotherapy assessment may be helpful, non-invasive ventilation (NIV) can also improve symptoms and often the length of survival. The NICE guidance provides clear advice on the monitoring of respiratory function and the use of NIV for MND 19.

While positional changes and physiotherapy assessment may be helpful, NIV may be considered after careful discussion with all involved, but with disease progression its use may increase and withdrawal may be considered. Opioids are also useful in relieving the distress of breathlessness.

The MND Association has developed Just in Case resources, to enable discussion about the end of life and provision of medication. The programme leaflet can be useful in wider discussions and an accompanying box can be used to store medication, making the right drugs readily available in case of urgent need - including out-of-hours.

The person-centred approach is essential in the management of symptoms, including attention to detail, involvement of and communication with the wider multidisciplinary team, and regular review of the management plan.

Most common symptoms and treatments

**Drooling** - a symptom of impaired ability to swallow. Careful assessment should determine if there is an underlying reversible cause, management of which might be enough. Refer early to speech and language therapy for assessment and management. If these non-drug methods are not successful then a variety of medications, including antimuscarinic medication, Botox injections and radiotherapy, can be used.

**Breathlessness** - a very common symptom in MND, primarily caused by respiratory muscle weakness. While physiotherapy assessment may be helpful, non-invasive ventilation (NIV) can also improve symptoms and often the length of survival. The NICE guidance provides clear advice on the monitoring of respiratory function and the use of NIV for MND 19.

While positional changes and physiotherapy assessment may be helpful, NIV may be considered after careful discussion with all involved, but with disease progression its use may increase and withdrawal may be considered. Opioids are also useful in relieving the distress of breathlessness.

The MND Association has developed Just in Case resources, to enable discussion about the end of life and provision of medication. The programme leaflet can be useful in wider discussions and an accompanying box can be used to store medication, making the right drugs readily available in case of urgent need - including out-of-hours.
As it can take several years for a person’s neurological condition to reach advanced disease stage, there may be many changes for the individual to adjust to including:

- A decline in independence with progressive limb weakness or loss of control over limb movement
- Increasing difficulty with, for example, working memory, problem-solving ability and information processing speed
- The feelings that individuals display are not necessarily what they feel
- Relatives will face these changes in their own individual way
- Human beings have physical, psychological and spiritual needs. Changes can include difficulty in engaging in a regular faith group activity, difficulty meditating, concentrating on reading or anxiety around the ‘big questions’ of life and death.

To provide high quality EoLC, all these aspects of change must be addressed.

Psychosocial care

As someone faces the diagnosis and then the progression of a life-limiting condition there will be many emotional and psychological issues that come to the fore, including:

- Fear of the disorder. It may be unknown to the person and their family, or there may be a family history of the disease, with memories of these experiences. Either will be a frightening prospect
- Fear of the future, including fears around deterioration, dependency and dying
- Fears for the family, including concerns about how their partner will cope with the death or being alone in bereavement
- Losses of independence and ability to undertake day-to-day activities as a parent, spouse, sexual partner or participant in sport or other leisure activity
- Fears of losing abilities, mobility, personal care, feeding, toileting, sexual function
- Practical issues of finances, housing, making a will and ensuring care for dependents
- Cognitive changes: as the person loses cognitive ability they may initially be aware of this and fear the progression and loss of awareness and brain function
- Concerns as to the possibility of children being affected by the disease. This may be a specific concern for some - with Huntington’s disease there is a risk because it is genetic - and for others when the genetic basis of the disease may be less clear or not even an issue at all
- Multiple losses for both the person and their family involving many of the items listed above. This, and the changing family roles involved, may be profound.

Advice and support may be necessary, from counselling and social work support in coping with fears and losses through to financial planning and social services provision.
Spiritual aspects

Spirituality is difficult to define. It is often at times of trauma or distress that people will reflect on profound issues of life and death and it is not at all uncommon to question why life is being cut short, to seek some meaning and to look for signs of hope. A definition of spirituality is emerging which encompasses concepts - depending on the individual's cultural and religious experience and belief - such as the inner essence of being, relationships with a higher power, true humanity and anything which gives meaning to life.

NHS Education for Scotland suggests ways of supporting staff in this area. It says “Spiritual care is that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. [It] begins with encouraging human contact in a compassionate relationship, and moves in whatever direction need requires.”

This emphasises that offering spiritual care is not about learning a new technique or taking on a new role, it is “more about how things are done and how people share and communicate” 20. To this end all health and social care staff should be able to offer spiritual care that reaches out to the individual in their time of need. Specialist help is available within hospital and hospice settings through chaplaincy teams. For individuals who are part of specific faith groups there will be help available through that community, which health and social care professionals can access.

A significant part of spiritual care involves listening to individual narratives. An understanding of what was important to the individual before cognitive decline may help here. This might involve being a parent, enjoying music or poetry or being outdoors. Aids to prayer that can be held, such as a rosary, can help when words are not possible. The same applies to physical contact other than just within care tasks - such as holding a hand or a gentle massage that allows real human contact.

Where appropriate the individual and family should be asked in advance about care of the body after death, including religious practices.

Families and friends may also need support at this time. Staff asking after their wellbeing indicates concern beyond the level of simply doing a job. Close relatives may wish to talk about how the individual used to be. As a care team it is easy to forget that this very disabled individual once may have run marathons or travelled the world. Listening to the narrative brings the humanity into caring and this is the essence of spiritual care.

Bereavement

Following death the family and carers - both within the family and professional teams - may have many ambivalent feelings. They might be sad at the loss and relieved that the challenges of being a carer have gone. All involved need time to talk about these issues and a proportion may require more formal counselling and bereavement support. It is important that family and carers are provided with information about practical arrangements they will need to make.
Triggers to recognise the end of life

The recognition of dying with neurological disease can be difficult. With PD or MS, deterioration can extend over many years and death results primarily through respiratory or other infection. Marked debility - including cognitive dysfunction - may be present for a prolonged period and does not necessarily herald death.

Conversely, the terminal phase can be short or sudden in conditions where the predominant mechanism of death is respiratory failure, as in MND, PSP or MSA. In a series of 124 people with MND cared for until death, 40 percent deteriorated suddenly and died within 12 hours; a further 18 percent had died within 24 hours of a change in condition first being noticed. In MSA there is estimated to be a one-in-five chance of sudden death.

This has implications for the preparations the caring team must make in order to respond quickly to symptom changes and, particularly, the advice they must give families in order to prepare them for what may appear to be a catastrophically sudden death.

Where respiratory failure is the prime cause of death, life may be extended by interventions such as the use of assisted ventilation and gastrostomy feeding - and EoLC is altered completely. Non-invasive ventilation can extend life significantly but eventually respiratory failure occurs despite it. When this happens medication will be needed for breathlessness in the same way as when NIV has not been used, and the ventilator withdrawn. Early discussion of the management options and completion of an ADRT may help in these decisions.

Fears about dying

The most common fears about dying from neurological disease concern uncontrollable pain, breathlessness or choking. In fact, pain and breathlessness seldom become uncontrollable, and choking - although a common and distressing sensation in those with swallowing difficulties - is very rarely a cause of death. The person and their family should receive accurate information and continual reassurance from all professionals involved in their care. There should also be an active approach to symptom control throughout the illness.

ACP discussions that address specific individual preferences should have taken place before the final phase of the illness.

Managing the symptoms of dying

The LCP or equivalent should be used in the last phase of life as it, and other similar pathways, provide a framework for the care of dying people and those close to them.
Clinically assisted nutrition and hydration

Ceasing to eat and then no longer drinking is a normal part of the dying process, whatever the disease. It can, however, cause much distress to those close to the person, who may interpret these changes as the cause rather than the result of their deterioration. This distinction needs to be sensitively discussed, as the symptom-relieving role of clinically assisted nutrition and hydration at this stage is unclear and may even exacerbate some symptoms.

Many people have already had insertion of a gastrostomy tube because of the development of dysphagia, but it is usually appropriate to reduce the volume of feed or even stop it when dying is recognised because of the body’s diminishing ability to handle fluid or nutrition. This requires careful communication with family and carers.

Delirium

Some degree of confusion has been reported in at least 80 percent of dying people and can give rise to restlessness or agitation. An appropriate response is to use a benzodiazepine for its anxiolytic and muscle relaxant properties. This may take the form of diazepam suppositories administered rectally or as liquid via a gastrostomy. It should be given as required or in regular doses two or three times a day where appropriate. Alternatively, midazolam can be administered subcutaneously and can be combined with opioid and anticholinergic agents in a syringe driver.

Pain

If pain has not been a problem earlier in the illness it is unlikely to be so as death approaches. A dying person may not be able to report pain directly but if they appear restless or uncomfortable and a reversible cause such as a full bladder has been ruled out it is appropriate to try an analgesic.

Respiratory secretions

Any severely ill person with reduced ability to cough can accumulate secretions in the upper airways, resulting in noisy breathing which can distress the individual and/or their carers. If respiratory failure follows unsuccessful treatment of a chest infection there is likely also to be pus present. The first step in management is to explain to the family why the breathing is noisy, what is being done and what its limitations are, and to reassure them that by this stage the dying person is unlikely to be as aware of the sound.

If an anticholinergic agent is already being given by gastrostomy it can be continued and the dose increased. Atropine, glycopyrronium bromide, hyoscine butylbromide or hydrobromide are also effective in combination with an opioid and midazolam.

Family support

Any EoLC service caring for people at home needs to discuss the preferred place of death. This reduces the chance of an unplanned hospital admission in response to the distress of a family member who has not been involved in discussions about their relative’s EoLC. Accessible, reliable support for carers, including at weekends and out-of-hours, is vital.
Support for professionals

Professionals caring for those with neurological conditions may have known the individual over many years and grown close to them. Most only infrequently experience the death of someone they are caring for and may be unfamiliar with both the recognition and diagnosis of dying and the management of the symptoms of dying itself.

It is therefore important that professionals can access specialist palliative care advice and practical support. The absence of such support might not only mean suffering for the person and their family, but staff themselves may be left damaged in a way that will make them less able to provide EoLC to people with neurological disease in the future.

After a death it can be useful for staff to meet as a multi-professional group to reflect and discuss their care of the individual. This reflection time provides the opportunity to identify ways to improve care in the future, and to recognise and celebrate what has gone well.

It should be a managerial responsibility to identify staff members who have particular problems resulting from the experience of care. Without imparting a sense of inadequacy, such staff members should be provided with the opportunity to talk through important issues confidentially - either at work or with an independent counsellor.
Caring for someone with a long term neurological condition can be overwhelming. In 2005 there were estimated to be over 850,000 people providing such care. The National service framework for long term conditions stresses that carers should have access to “appropriate support and services that recognise their needs both in their role as a carer and in their own right.” 1 The carer role may be carried out by younger relatives or by people who also have their own support needs to attend to.

The course of many neurological conditions is unpredictable and may be progressive. Symptoms are often unfamiliar and complex. Care needs change over time and they intensify if the condition relapses or progresses rapidly. Strains can develop within the caring relationship - especially when there are issues and difficulties in communication, mood cognition and empathy for either the person or the carer.

Many voluntary agencies offer support services, such as home visiting, befriending and respite care, and can offer help with practical aspects like form filling and signposting to useful local services.

People newly diagnosed with a neurological condition and their carers need:
- Appropriate information about the condition
- Helpful support
- Contact details for their specialist nurse or key worker
- Early follow-up appointments to share concerns and ask further questions
- Contact details and/or referral to a support organisation for the relevant neurological condition.

Both people with neurological disease and their carers should have an initial needs assessment.

Carers should be registered as such on the practice register and given priority appointments and support as necessary.

A link should be made with a team contact who can help manage the case and liaise with the multidisciplinary team.

Links to and regular contact with professionals are essential to review needs, provide opportunities to talk over concerns, offer guidance and discuss advance care planning.

Challenges relating to carers:
- They may feel they have already ‘lost’ the person and experience episodes of grieving
- People whose condition leaves them increasingly dependent - and their carers - often feel left without a voice and need ‘champions’ from within the multidisciplinary team
- Recognising any signs of stress and discussing the best support options
Everyday contact with the outside world can be limited, compounding isolation that may arise if other relatives and friends feel overwhelmed and withdraw.

Many carers underestimate how much the stresses of caring erode their physical, mental, emotional and spiritual well-being. They delay asking for help until in crisis.

Priority access to support such as seeing their GP or respite care is often needed.

Frequently anxiety is expressed about loss of income, how to provide for dependents, and where to get information and guidance.

People with neurological disease and carers should be helped to access relevant benefits - such as Attendance Allowance/Disability Living Allowance.

Continuing health care funding should be considered.

Early referral to a specialist palliative care / hospice team and social care services may be necessary for specialist symptom control and holistic care.

Supporting carers towards death

Everyone ponders at some point how and when the end may come. Many people have never seen anyone die. People with neurological disease and carers are often very frightened of the dying process and may be more fearful of the process of dying than of death itself.

If they ask what to expect near the end of life, appropriate information on further support is essential as well as opportunities to share their concerns and fears. Some individuals and their carers will have been told that their condition is not one people die from and therefore may be unprepared, especially for severe progression and rapid death.

Sometimes families need help to recognise the signs that death is approaching. Carers could be the first to recognise and interpret subtle changes in reduced energy, engagement and mood as the neurological condition worsens.

Care routines for people with long term neurological conditions may be increasingly interrupted by serious and recurrent crises, normally triggered by infection (typically urinary, lung or chest) which may require hospital admission.

Carers must be kept informed about significant changes in care management, for example, in oral feeding and hydration.

Cultural and religious differences around the end of life deserve respect. Contact with an appropriate supportive network may well help the family. If there are still unmet social, psychological, physical or spiritual needs, swift referral to palliative care and/or chaplaincy services may be required. This can help prevent severe psychiatric illness and even suicide amongst carers.

Support for carers should continue into bereavement.
The *End of life care strategy* identifies the need for all health and social care staff to have the knowledge, skills and attitudes to deliver care at the end of life. It says:

“A cultural shift in attitude and behaviour related to end of life care must be achieved within the health and social care workforce.”

All organisations involved in EoLC should consider staff training needs across the whole of the EoLC pathway, particularly in relation to the four key areas in the diagram below.

All staff should have access to opportunities to develop their knowledge and skills, including an understanding of neurological conditions as well as the collaborative approach and joint working essential to achieve this.

A range of workforce initiatives has been developed to support EoLC delivery, including e-learning modules. Some of these focus on advanced neurological conditions. For more information please visit [www.endolifecareforadults.nhs.uk/education-and-training](http://www.endolifecareforadults.nhs.uk/education-and-training) and [www.e-elca.org.uk](http://www.e-elca.org.uk).

**Education opportunities include:**
- Attendance at study days
- Other formal teaching
- Interdisciplinary education between teams
- ‘Informal’ initiatives with information being cascaded through teams.

The NICE clinical guidance on supportive and palliative care for adults with cancer says “Good face-to-face communication between health and social care professionals, patients and carers is fundamental to the provision of high quality care.”

---

**End of life care workforce development competences**

- Communication
- Assessment/care planning
- Symptom management
- Advance care planning

---

**Overarching values and knowledge**
Services providing care for people with advanced neurological conditions should be co-ordinated, personalised, effective and integrated - and treat individuals with dignity and respect. EoLC commissioning should start and end with patients and those closest to them.

**Personalised care planning, including ACP, should be defined in commissioning plans. These should reflect:**
- Preferences and choices that are culturally sensitive
- Receipt of co-ordinated care and support, including information
- Rapid access to specialist advice, clinical assessment, high-quality care
- Support in preferred place of care
- Services that treat people as individuals, and with dignity and respect
- Services that acknowledge the individual and their carers as part of the care team
- Equity of access
- Services of consistent high quality.

From a broad commissioning perspective, this requires local strategic plans underpinned by robust financial and operational plans that set out how these aims will be achieved and the investment and timescales required. As EoLC services will, of necessity, span a range of needs (not solely health-related) and involve a range of potential service providers, strategic planning and service co-ordination need to be undertaken jointly with partner local authorities. This planning and co-ordination should be informed by sound joint strategic needs assessment (JSNA) processes.

**Effective commissioning for EoLC should include the following key characteristics. It should:**
- Be based on need
- Be flexible to cover the complexity of the illness
- Be based on partnership
- Promote and assure equality of access
- Build from pathway-based specifications
- Embed choice.

Long term conditions tariff development has included work on costing a year of care, an approach which is better suited to long term conditions which require ongoing care rather than one-off interventions. The MND Association has developed and trialled a Year of Care pathway for an individual with advanced disease that is transferable to other LTNCs.

Lead commissioners for LTNCs may wish to develop local applications of this approach. It can also be used to inform the development of local pathways for individual budgets and personal health budgets as part of the personalisation agenda.

Commissioners may also need to consider the needs of young adults with neurological conditions. Although figures may be low, many children are now surviving into adulthood with a range of conditions and adult services may not be configured to meet their needs.

Successful EoLC commissioning depends on good partnership working across care sectors - with an understanding that this requires resources and support.

However, these neurological conditions are relatively or extremely rare, with each organisation dealing with small numbers of people approaching the end of life each year.


8. An integrated framework of early intervention palliative care in motor neurone disease as a model to progressive neurodegenerative diseases, P Bede et al, Poster at European ALS Congress, May 2009, Turin, Italy


10. Concise guidance to good clinical practice number 12: advance care planning, Royal College of Physicians, 2009 [http://www.rcplondon.ac.uk/pubs/contents/9c95f6eac57e-4db8-bd98-fc12ba31c8fe.pdf](http://www.rcplondon.ac.uk/pubs/contents/9c95f6eac57e-4db8-bd98-fc12ba31c8fe.pdf)


12. Parkinson’s disease: national clinical guideline for diagnosis and management in primary and secondary care, Royal College of Physicians, 2006 [http://bookshop.rcplondon.ac.uk/contents/pub34-550d0f9e-e15f-46dd-9ec7-a669859f10fa.pdf](http://bookshop.rcplondon.ac.uk/contents/pub34-550d0f9e-e15f-46dd-9ec7-a669859f10fa.pdf)

13. Concise guidance to good practice number 10: long term neurological conditions, Royal College of Physicians/National Council for Palliative Care/British Society of Rehabilitation Medicine, 2008 [http://www.rcplondon.ac.uk/pubs/contents/55a60dba-3ba6-429c-8d2d-b1f178513b2b.pdf](http://www.rcplondon.ac.uk/pubs/contents/55a60dba-3ba6-429c-8d2d-b1f178513b2b.pdf)
14. Gold standards framework, the three triggers http://www.goldstandardsframework.nhs.uk/TheGSFToolkit/Identify/TheThreeTriggers


