

Introduction

The Neurological Conditions Group was set up by The National Council for Palliative Care (NCPC) to improve and extend the provision of palliative care services for people with neurological conditions from diagnosis through to the end of life.

Since its inception in March 2005, the group has produced a range of publications and presentations on the topic. In an attempt to make these resources as widely available as possible, we have brought them together in one place. We hope that they will be useful to professionals working with people with neurological conditions throughout health, social care and beyond, and to others with an interest in the promotion of palliative and end of life care.

Membership

The group is chaired by Vicki Morrey, NCPC trustee and Director of Nursing at Trinity Hospice, and is supported by NCPC's Policy & Parliamentary Affairs team.

Members of the group consist of a range of professionals with experience of neurology, rehabilitation and palliative care, and people with personal experience of this area.

We work with partner charities such as the [Motor Neurone Disease Association](#) (MND), [MS Society](#), [Parkinson's UK](#), [Sue Ryder](#), [the Neurological Alliance](#) and [Neurological Commissioning Support](#). Identifying models of good practice and disseminating learning is a core part of the group's role.

As of May 2011, the membership was:

- **Vicki Morrey** (Chair), Director of Nursing at Trinity Hospice and NCPC Trustee
- **Cynthia Benz**, Volunteer and person with experience of MS
- **Lynne Brown**, Programme Lead for Nursing, MS Society
- **Amanda Cheesley**, Long Term Conditions Advisor, Royal College Nurses (RCN)
- **Sue Dewar**, Clinical lead for End of Life Care, West Sussex PCT
- **Robert Hall**, Regional Operations Manager, Sue Ryder
- **Sally Hughes**, Head of Service Development, MS Society
- **John Kell**, Policy Manager, MND



- [Vicky Knowles](#), Head of Special Projects and Policy, Sue Ryder Care
- [Mark Lee](#), Consultant in Palliative Medicine at St Benedict's Hospice
- [Anjali Mullick](#), Consultant in Palliative Medicine, St Joseph's Hospice
- [Eli Silber](#), Consultant Neurologist, Kings College Neuroscience Centre
- [Sue Smith](#), Regional Care Advisor, MND Association
- [Nigel Sykes](#), Medical Director & Consultant in Palliative Medicine, St Christopher's Hospice
- [Sue Thomas](#), Head of Neurological Commissioning Support
- [Lynne Turner-Stokes](#), Director Regional Rehab Unit, Northwick Park Hospital
- [Anjuli Veall](#), Social Policy and Campaigns Manager, Parkinson's UK
- [Arlene Wilkie](#), Chief Executive, Neurological Alliance

We would like to extend our thanks to previous members of the group who have contributed to the group's work and achievements over the years.

Resources

The group has produced or contributed to the following resources on neurology and palliative care, arranged chronically from newest to oldest:

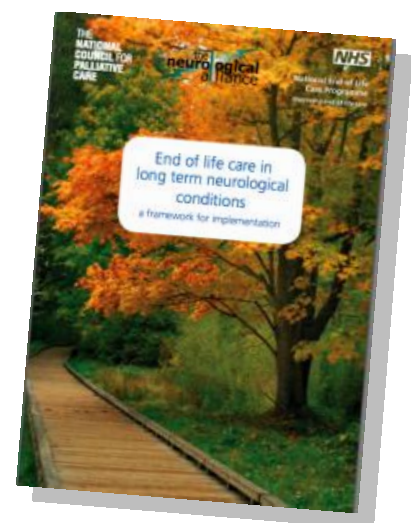
Improving end of life care in neurological disease: a framework for implementation

National End of Life Care Programme (NEoLCP) in association with NCPC and the Neurological Alliance. November 2010.

This document aims to set out an end of life care framework for implementation that specifically meets the needs of those with neurological conditions. It covers:

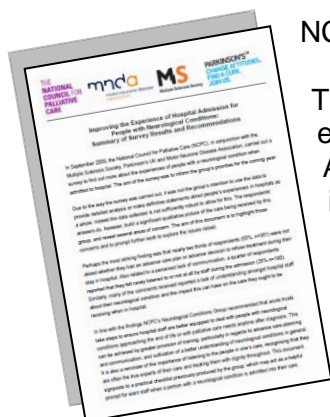
- * Strategic context
- * End of life care tools
- * End of life care in neurological disease
- * Communication and advance care planning
- * Co-ordination and multidisciplinary approach to care
- * Management of physical symptoms
- * Holistic care – psychosocial and spiritual aspects
- * Care at the end of life
- * Carers
- * Workforce, education and training
- * Commissioning health and social care services

Click the image or [here](#) to download the publication



Improving the Experience of Hospital Admission for People with Neurological Conditions: Summary of Survey Results and Recommendations

NCPC, July 2010



The Neurological Conditions Group carried out a survey of the experiences of people with neurological conditions admitted to hospital. Although the study involved a small sample size, the data received indicated that nearly two thirds of respondents were not asked whether they had an advance care plan or ADRT during their stay in hospital. Other concerns relating to a perceived lack of communication, dignity and understanding of the condition the person had, were reported.

Free to download [here](#)

Exploring the Interface: A Survey of Neurology Nurses' Involvement with Specialist Palliative Care Services and Identification of their Training Needs

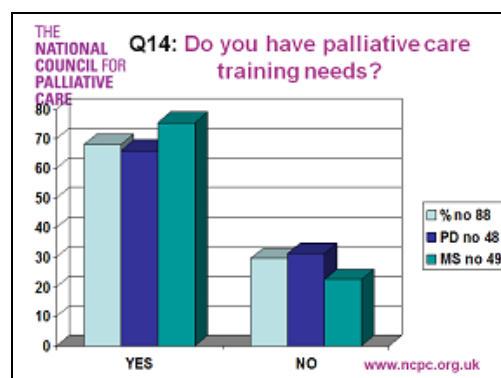
NCPC and Royal College of Nursing, June 2008

This document provides results of the survey of neurology nurses that was carried out jointly between NCPC and the Royal College of Nursing Neuroscience Forum. The overriding message from this survey and NCPC's previous work is the need for the different people caring for those with neurological conditions towards the end of life to come together and work in collaboration, sharing skills and expertise.

To purchase [here](#) (free to NCPC subscribers)



Related: A presentation at NCPC's 2008 conference *Piecing it Together* gives a snapshot of the findings. View it [here](#).



Three academic papers were also produced on this topic:

From diagnosis to death: Exploring the interface between neurology, rehabilitation and palliative care in the management of people with long-term neurological conditions. Turner-Stokes L, Sykes N, Silber E, Khatri A, Sutton L, Young E. *Clinical Medicine*, 2007; 7: 129-136.

Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care. Turner-Stokes L, Sykes N, Silber E. *Clinical Medicine*, 2008; 8: 186-191.

Concise Guidance to Good Practice: Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care

NCPC, British Society of Rehabilitation Medicine and Royal College of Physicians. March 2008.

These guidelines build on the Quality Requirements in the National Service Framework (NSF) for Long-term Neurological Conditions (LTNCs) 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 recommend a collaborative model for interaction between the different specialties involved in the care of people with LTNCs.



Free to download [here](#)

Focus on Neurology – Addressing Palliative Care for People with Neurological Conditions

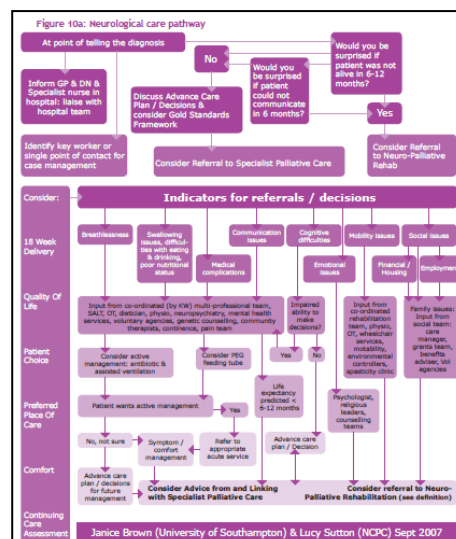
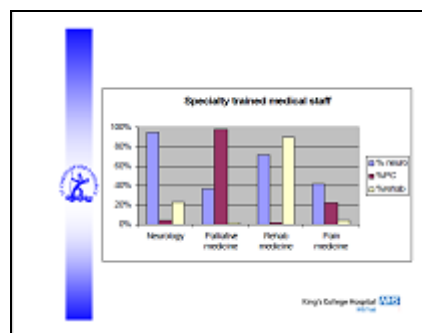
NCPC, October 2007

This publication brings together the learning of the group between 2005 and 2007. It presents the first ever national survey of palliative care, neurology and rehabilitation services. It relates the journey from developing a pathway for meeting the palliative care needs of people with neurological conditions, to designing the final pathway, which is explained in detail. The document also contains illustrative case studies and best practice examples.

The neurological care pathway can be viewed [here](#) or by clicking on the image opposite. The purpose of the pathway is to:

- be a template for ideal care - promoting the key worker concept,
- be used by professionals,
- keep the patient/family at the centre of care decisions
- recognise the need for local variation
- support the proactive interface between pivotal services eg neurology, palliative care, geriatric care, rehabilitation, voluntary agencies, social care

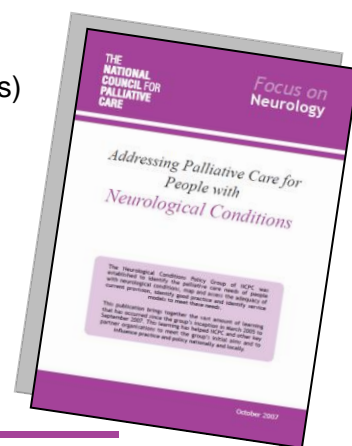
Related: The group present an insight into the first national survey to review the current links between palliative care, neurology and rehabilitation [here](#).



The full publication is available to purchase [here](#) (free to NCPN subscribers)

You may also be interested in reading the following article written by then Director of Policy Development, Lucy Sutton who previously oversaw the group:

[Addressing palliative and end-of-life care needs in neurology](#) Sutton, L.
British Journal of Neuroscience Nursing May 2008 Vol 4 No 5



Series of articles in the British Journal of Neuroscience Nursing

[Spiritual support and its role in end-of-life care](#) by Simon Chapman. April/May 2011 Vol 7 No 2

[End-of-life care for people with dementia should be discussed early](#) by Simon Chapman. Feb/Mar 2011 Vol 7 No 1

[Recognizing when a change in care is needed](#) by Simon Chapman. December 2010/January 2011 Vol 6 No 8

[Promoting respect and dignity at the end of life](#) by Simon Chapman. October/November 2010 Vol 6 No 7

[Long-term neurological conditions: End of life](#) by Emily Sam. August/September 2010 Vol 6 No 6

[Raising awareness that dying matters](#) by Mayur Lakhani. June/July 2010 Vol 6 No 5

[Addressing palliative and end-of-life care needs in neurology](#) by Lucy Sutton. May 2008 Vol 4 No 5

Copies of the articles can be obtained by emailing policy@ncpc.org.uk or by logging on to the BJNN website: www.bjnn.co.uk

Related: the [Dying Matters](#) coalition to raise awareness of dying, death and bereavement
www.dyingmatters.org



'Let's talk about it'

Conferences

September 2009

NCPN held a joint conference with Royal College of Nursing Neuroscience Forum to discuss next steps in implementing the End of Life Care Strategy.

- **Eli Silber** gave an [overview of how neurologist work and why palliative care is relevant](#)
- **Simon Chapman** spoke about [the first annual report of the strategy and why progress is needed](#)

June 2009

The Multiple Sclerosis Society Professional Network for Palliative Care held in partnership with NCPC a conference looking at the issues facing people with neurological conditions one year on from the publication of the Strategy. The presentations can be found [here](#), including:

- [An overview of the palliative care issues in MS from Lucy Sutton previous Director of Policy at NCPC](#)
- [Legal and ethical issues with Simon Chapman](#)
- [The National End of Life Care Strategy with Isabel Quinn \(then National Programme Manager\)](#)
- [Overview of Palliative Care with Edwin Pugh, Consultant in Palliative Medicine](#)

June 2008

NCPC hosts *Piecing it Together: Partnership Working to Meet the Palliative and End of Life Care Needs of People with Neurological Conditions* at Royal College of Nursing.

- NCPC gave an overview of [why a palliative approach is needed in neurology](#)
- **Mark Lee** talks about [ways of identifying when a person with a neurological condition requires palliative care](#) and the [importance of addressing pain](#)
- **Nigel Sykes** [provides case studies highlighting this need](#)

February 2007 and September 2006

NCPC holds two successful conferences on palliative care and neurological conditions at the end of 2006 and beginning of 2007 to scope the need, current provision and challenges faced. From the start a strong relationship between those working in palliative care, neurology and rehabilitation was felt to be of critical importance.

- **Nigel Sykes and Eli Silber** on the [results of the first national survey to review the current links between palliative care, neurology and rehabilitation](#)
- **David Oliver** gave [an overview of palliative care and the work his service had done locally](#)

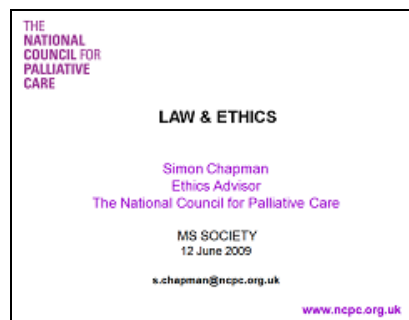
Other resources

Advance Care Planning and Mental Capacity Act

Planning ahead and understanding one's rights for the event that one's loses capacity to make decisions is particularly important for people with neurological conditions.

NCPC has worked closely with many partners including the National End of

Related: NCPC's presentation at the 2009 Professional Network Palliative Care Conference gives an overview of the Mental Capacity Act and other legislation relevant to people with neurological conditions. View it [here](#).



Life Care Programme to provide information and guidance about Advance Care Planning and the Mental Capacity Act 2005. Publications include:

- [Planning for Your Future Care](#) (free download)
- [Good Decision Making – the Mental Capacity Act and End of Life Care](#)
- [The Mental Capacity Act in Practice: Guidance for End of Life Care](#)

Both available to purchase [here](#) (free to NCPC subscribers)

- [The differences between general care planning and decisions made in advance](#) (free download)

Data

- NCPC's Minimum Data Sets (MDS) now collects data about the number of people accessing specialist palliative care services in England, Wales and Northern Ireland. Contact mds@ncpc.org.uk for more information
- National End of Life Care Intelligence Network (NEoLCIN) has collected data about neurological conditions, for example *Deaths from Neurodegenerative Diseases in England, 2002 to 2008 (Nov 2008)* Download for free [here](#).

National End of Life Care Strategy (2008)

The first comprehensive strategy for palliative and end of life care in England was published in 2008. Its vision was to build services in health, social care and beyond which can ensure that all people, including those with neurological conditions, could have a good death.

You can read the strategy [here](#).

The National Service Framework (NSF)

In 2005, the Government published the [National Service Framework \(NSF\) for Long Term Neurological Conditions](#) which focussed on improving the management of long term neurological conditions. The document outlined 11 Quality Requirements so that quality standards for people affected by a neurological condition could be improved over the 10 year implementation phase.

Quality requirement 9 concerned palliative care, and stated that

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

Progress on the NSF

[Halfway through – are we halfway there?](#) A report by Neurological Commissioning Support

In the absence of the Department of Health's own mid-point review, Neurological Commissioning Support (a joint initiative led by the MND Association, MS Society and Parkinson's UK) undertook their own review of the NSF.

The resulting report found that '5 years after this NSF was published, not a single audited site could meet a single Quality Requirement'. None of the 11 sites assessed met the overall Quality Requirement for palliative care and only 18% of services could claim a 'part met' for the requirement.

You can download the report [here](#)



Feedback

We welcome your comments on these resources.

Please contact policy@ncpc.org.uk or 0207 697 1520

About NCPC

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430.

www.ncpc.org.uk

About Dying Matters

Dying Matters is a national coalition led by NCPC which aims to support changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make 'living and dying well' the norm.

The Dying Matters Coalition, which currently has over 14,000 members, is working to address this by encouraging people to talk about their wishes towards the end of their lives, including how they would like to be cared for, where they want to die and their funeral plans, with friends, family and loved ones.



To find out more about the range of resources available or to join visit www.dyingmatters.org