The Final Pathway

The pathways below were devised following this thorough process and are now available on the NCPC website. The first pathway reflects the pathway to diagnosis (Figure 9), the second, the Neurological Care Pathway, has been designed to support professionals in meeting the palliative needs of people with LTNC (Figure 10a and 10b). A form for comments continues to be provided

with the pathway to ensure ongoing feedback. Following the process a list of key bullet points was added for those less receptive to visual flow diagrams. The full details of the pathway consultation and piloting process are being presented at the International Symposium on Motor Neurone Disease in November 2007 and publication is in progress.

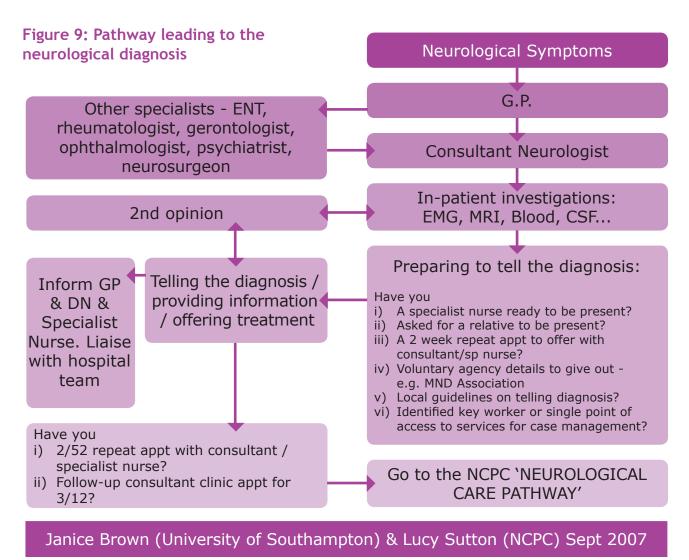


Figure 10a: Neurological care pathway At point of telling the diagnosis Would you be surprised if No patient was not Would you alive in 6-12 be surprised Inform GP & DN & months? if patient Specialist nurse in could not Discuss Advance Care hospital: liaise with communicate Plan / Decisions & hospital team Yes in 6 months? consider Gold Standards Framework Identify key worker or Consider Referral single point of contact for to Neuro-Palliative Consider Referral to Specialist Palliative Care case management Rehab Indicators for referrals / decisions Consider: Cognitive difficulties Communication Breathlessness Swallowing Mobility issues Social issues 18 Week issues, difficulties with eating & drinking, Delivery poor nutritional Medical Financial, **Employment** Quality Of Input from **Impaired** Life Input from co-ordinated (by KW) multi-professional team, Family issues: co-ordinated ability to SALT, OT, dietician, physio, neuropsychiatry, mental health Input from rehabilitation make services, voluntary agencies, genetic counselling, community social team: therapists, continence, pain team decisions? team, physio, care OT, wheelchair manager, services, grants team, motability, **Patient** Consider PEG No benefits Yes Consider active environmental Choice adviser, Vol feeding tube management: antibiotic & controllers, agencies assisted ventilation spasticity clinic Life expectancy Psychologist, predicted < religious Preferred Patient wants active management 6-12 months Yes leaders, Place Of counselling Care teams Advance care No, not sure Symptom / Refer to plan / Decision appropriate comfort acute service management Comfort Advance care plan / decisions **Consider Advice from and Linking** Consider referral to Neurofor future with Specialist Palliative Care Palliative Rehabilitation (see definition) management Continuing Care Janice Brown (University of Southampton) & Lucy Sutton (NCPC) Sept 2007 Assessment

Focus on Neurology

Figure 10b: Neurological care pathway

REMEMBER:

Palliative care (symptom control) is an integral part of the management of many neurological conditions. This may be especially important in people with advanced disease or significant disability.

Early referral may be needed to a variety of specialisms, including palliative care, depending on symptoms and speed of progression, to ensure a relationship is established prior to any crises occurring. There is a local specialist palliative care service based in either the hospital or community who may be able to help.

Patients with complex needs require care co-ordination - it is therefore important to identify a key worker early on. The local specialist palliative care team may also be able to contribute.

Patients may not need ongoing input from the specialist palliative care team.

CONSIDER SPECIALIST PALLIATIVE CARE REFERRAL WHEN:

- There are intractable symptoms causing suffering, especially pain but also nausea or breathlessness.
- Difficulties with care co-ordination / management of complex needs.
- Lifespan is likely to be limited.
- Issues of communication and competence.
- There is a need for care planning, advance decisions.

THE CONTACT FOR YOUR NEAREST SPECIALIST PALLIATIVE CARE SERVICES ARE AVAILABLE AT www.hospiceinformation.info

NEUROPALLIATIVE REHABILITATION - involves an holistic approach to the care of neurological patients with significant disability, complex needs and a potentially shortened life-span. It is patient-centred and involves diagnosis of clinical problems at all stages, rehabilitation to maintain function, care coordination and appropriate palliation to relieve symptoms.