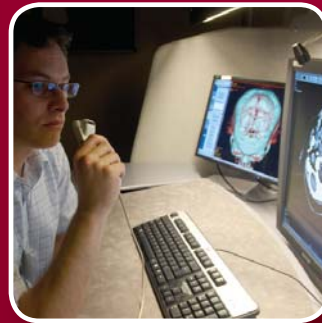


# Long Term Neurological Conditions

A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse



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**Six Steps** is a framework for integrated workforce planning developed by **NHS National Workforce Projects**. It is designed to provide an evidence based and effective model that can be adopted by any NHS or partner health and social care organisation. Using a model like Six Steps helps lead to sustainable workforce planning.

[www.healthcareworkforce.nhs.uk](http://www.healthcareworkforce.nhs.uk)



**National Workforce Projects**  
*part of Skills for Health*



The development of this guide has been project managed by **NHS National Workforce Projects**.

**NHS National Workforce Projects** is part of **Skills for Health**, working to support and develop a world class health workforce of the future with practical planning advice and solutions. Skills for Health is the Sector Skills Council (SCC) for the UK health sector, helping the whole sector develop solutions that deliver a skilled and flexible UK workforce in order to improve health and healthcare.

# Foreword

Improving the care of people with long term conditions is a key government priority. The national service framework for long term neurological conditions sets out a vision for neurological services, supplemented with advice and guidance for ensuring best practice.

This guide is unique in that it results from a partnership between three of the major charities for important neurological conditions, the Department of Health, the Royal College of Nursing and NHS National Workforce Projects. In this way the patient perspective has been heard from the outset and is truly represented, alongside that of professionals and government. It will be an invaluable handbook for service managers, staff and for commissioners aspiring to world class standards.

Patients with long term neurological conditions share some common characteristics despite the different trajectories of their illness. All of them face a future that can be uncertain and will, most likely, require quite major adjustments to their lives and that of their families. We also know that with prompt, expert care exacerbations can be minimised, symptoms better controlled, and people helped to live as full and enjoyable lives as possible, for as long as possible.

As we show in this guide, effective care does not necessarily mean more resources. Doing things differently, using good teamwork, specialist support and interventions, proper diagnosis and treatment planning can often increase available services.

I would like to offer particular thanks to the Multiple Sclerosis Society, the Parkinson's Disease Society and Epilepsy Action for their help in preparing this document, and also for their unstinting support, strategically, educationally and financially, to the long term neurological workforce, so that together, we can provide the highest quality service for our patients.



**Chris Beasley**  
Chief Nursing Officer for England

## Section One: Introduction: Who this guide is for

This guide is aimed at commissioners and providers of services for people with long term neurological conditions (LTnC) to help them offer the right service, delivered by an appropriate workforce, to meet the needs of this vulnerable group of patients. It outlines why services for neurological conditions are important, demonstrates the value of the multidisciplinary team (MDT) and clarifies the contribution of specialist nurses.

Reference is made to information required for commissioning, and patients' comments and examples of good practice can be found throughout the sections. There is information in the guide about where to get help as well as a summary of the NHS National Workforce Projects (NWP) six step methodology for integrated workforce planning. This guide does not replace the in-depth coverage available in other publications such as the National Service Framework (NSF)<sup>1</sup> or the clinical guidance produced by the National Institute for Health and Clinical Excellence (NICE), but forms a handy reference for those reviewing and redesigning their services.

The guide results from a collaboration between Epilepsy Action (EA), Parkinson's Disease Society, Multiple Sclerosis (MS) Society, the Department of Health (DH), the Royal College of Nursing (RCN) and NWP. Whilst it focuses on the conditions represented by its charitable partners, the content will be relevant to all those engaged in planning or delivering care for the full range of neurological disorders.

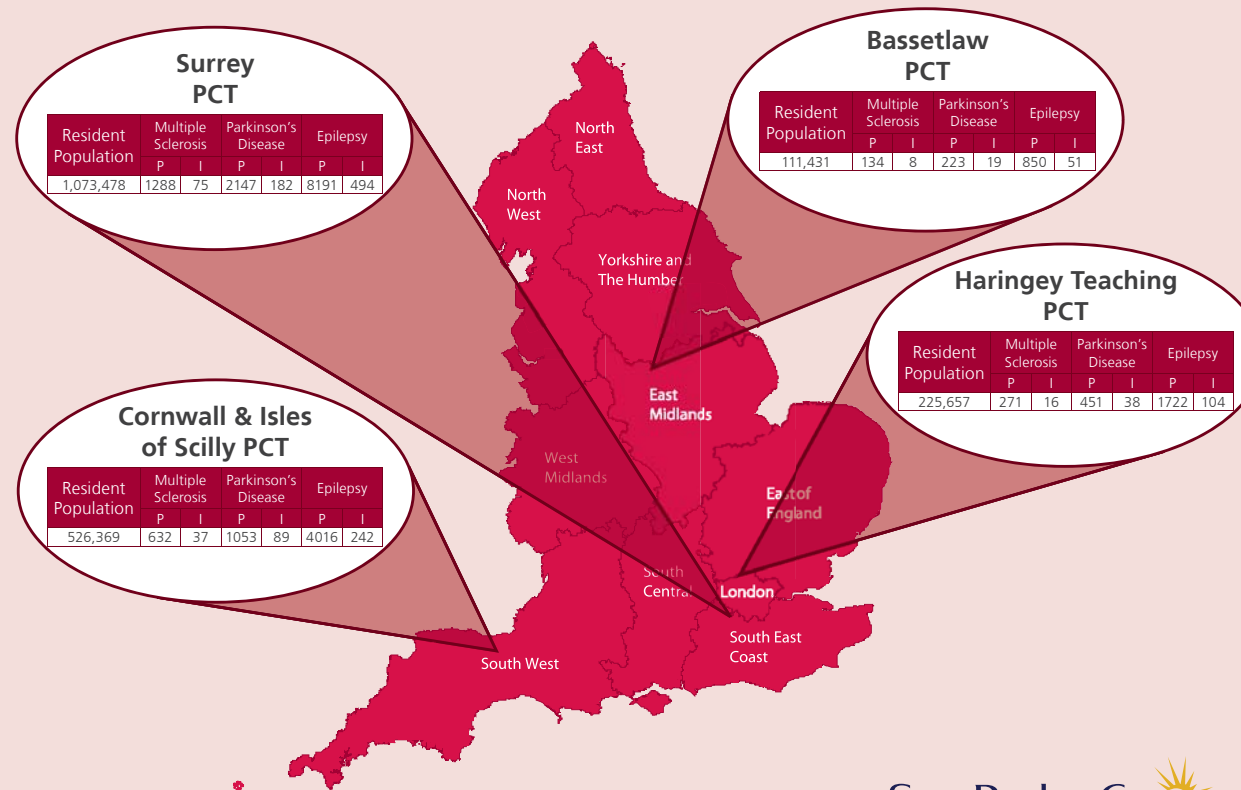


<sup>1</sup> The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005)

# Section Two: A picture of neurology

Approximately 10 million people across the United Kingdom (UK) have an LTnC, accounting for 20 percent of acute hospital admissions. An LTnC is the third most common reason for seeing a GP. It is estimated that 350,000 people in the UK need help with the activities of daily living because of a neurological condition, and 850,000 people care for someone with a neurological condition.<sup>2</sup>

## Incidence and prevalence of Long Term Neurological Conditions (LTnC)



**Incidence (I):** this is a measure of the number of newly diagnosed cases of a disease or condition per year.

**Prevalence (P):** this is a measure of the total number of cases of a disease or condition that exist in a population at any one time.

*Figures shown are estimates based on standard ratios.*

(Full data table is available in Appendix 1)

Data © Sue Ryder Care 2008



<sup>2</sup> The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005)

Although this guide focuses on MS, Parkinson's and epilepsy, it is hoped that the issues and solutions put forward in this document are equally applicable to a range of other LTnC including Huntington's disease, motor neurone disease, muscular dystrophy and brain injury. A list of these and other neurological conditions, including epidemiological data, is available in Appendix 2.

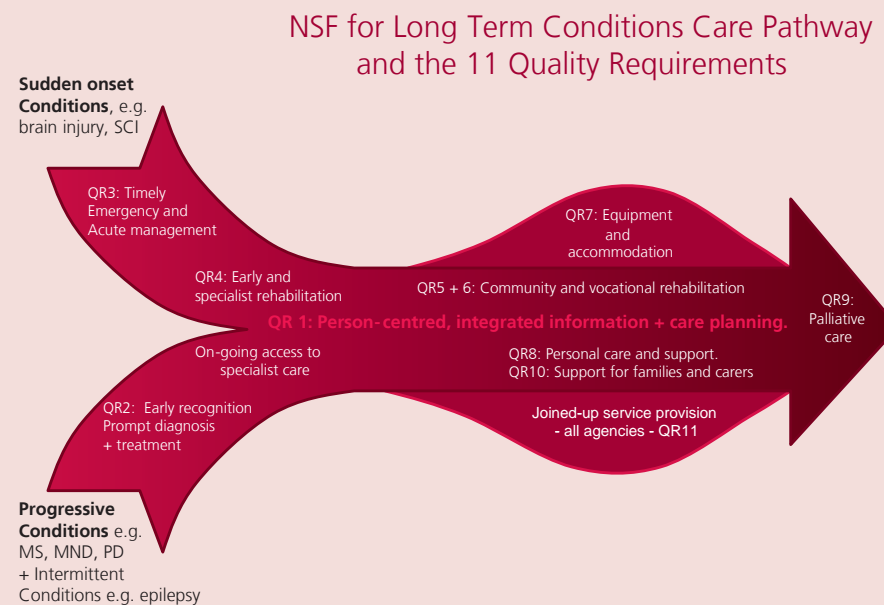
The care of patients with neurological conditions is very complex. The range of conditions covered by neurological specialties is broad and individuals are affected in many ways as the disease progresses. What they all have in common is that this group of conditions has an enormous impact on the lives of those affected, and on their families and carers. Some of the effects result from the physical manifestation of the illness, while others are psychological, as patients struggle to cope with limitations and changes in the way they live. There is no single pathway for the development of neurological services. Prevalence, patient needs and prevailing local circumstances must be taken into account as commissioners and managers seek to achieve high quality care within available resources.

## Frameworks that support high quality neurological services

### National Service Framework (NSF) for LTnC

The NSF for LTnC, published in March 2005, is the government's strategy for the care of those affected. The NSF aims to transform the way health and social care services support people to live their lives. Key themes are independent living, care planned around the needs and choices of the individual, easier, timely access to services and joint working across all agencies and disciplines involved. At the centre of the NSF are 11 quality requirements<sup>3</sup>, designed to put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate at every stage from diagnosis to end of life. A full list of the 11 quality requirements is available in Appendix 3.

The NSF drives the philosophy of supporting people with LTnC to live as independently as possible. It is recognised that people with LTnC have improved health outcomes and a better quality of life if they can access prompt advice and support from relevant practitioners with dedicated neurological expertise.



<sup>3</sup> Turner-Stokes, L and Whitworth, D. *Clinical Medicine* 2005 5(3) 203-6.2005

To support the NSF, the Care Services Improvement Partnership (CSIP) has produced the *10 Quick Wins* poster and leaflet, which focus on high priority and high impact areas where services can be improved. One of the quick wins is to encourage organisations to appoint practitioners with specialist expertise in neurological conditions to enable early recognition, prompt diagnosis and treatment.

Full details of the NSF, the 10 Quick Wins and other supporting material can be found on the DH website at [www.dh.gov.uk](http://www.dh.gov.uk).

## NICE guidelines

NICE has produced clinical guidelines for the diagnosis, treatment and management of MS, epilepsy and Parkinson's. These evidence based guidelines outline the range of care that should be available. These include providing specialist services, a system for rapid diagnosis, a seamless and responsive service, thorough problem assessment and self referral after discharge. Full details of these recommendations are available at [www.nice.org.uk](http://www.nice.org.uk).

“People with long term neurological conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. This can cover: managing their medicines; treatment of specific symptoms; help to understand their condition and its current and future management. Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve wellbeing”

*The National Service Framework for Long Term Neurological Conditions (DH 2005)*

## An example of an MS nurse implementing the NICE guidelines

Southwark Primary Care Trust's (PCT) MS nurse covers Southwark, Lambeth and Lewisham PCTs. An evaluation, analysed by an independent audit department, demonstrated the nurse led service was consistent with key priorities recommended by NICE and achieved high levels of patient satisfaction.

One of the main outcomes was a holistic, first access specialist service for all people with MS throughout the disease trajectory. This includes a responsive service for relapses which has been shared across the PCT regions and adopted as best practice. More importantly, the nurse has coordinated a mitoxantrone and Natalisumab (also known as Tysabri) service and developed a care pathway to ensure governance of this intervention. This means that people with MS accessing this service receive timely, appropriate and safe treatment. An audit demonstrated that people with MS report feeling supported and involved with all decisions and that concordance with drug regimes was high. In addition, the audit demonstrated that all symptoms were considered as part of the service including hidden symptoms such as those detailed by NICE.<sup>1</sup>

<sup>1</sup> Shaw, Pauline (2006) *Improving the care of people with multiple sclerosis through implementing NICE guidance*. *British Journal of Neuroscience Nursing* 2 (8) pp.388-393

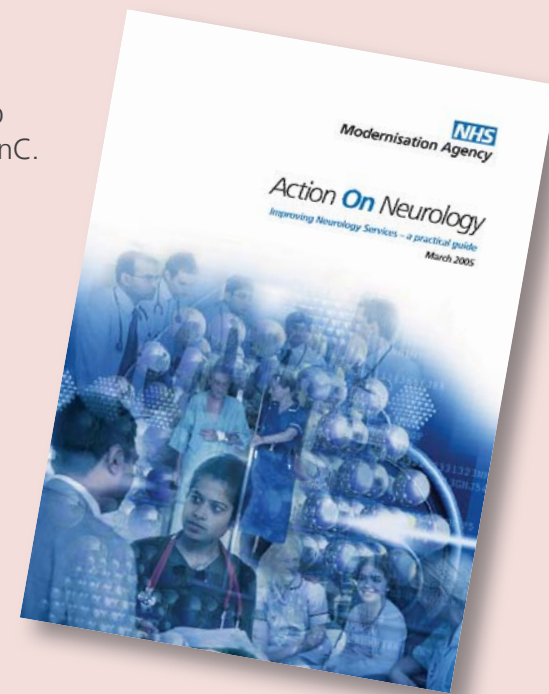
### Action On Neurology: Improving Neurology Services - A Practical Guide

The *Action On Neurology* guide was written for clinicians, managers and commissioners and providers to help improve services for people with neurological conditions and to support the implementation of the NSF for LTnC. It is based on the findings from the Action On Neurology programme, which was designed to find and test different ways of working that might both improve the quality and access to neurology services.

Further information can be found on [www.institute.nhs.uk](http://www.institute.nhs.uk).

### An overview of epilepsy, multiple sclerosis and Parkinson's

The details of three neurological conditions follow, outlining their prevalence and where any clusters of the condition may occur. This sort of mapping information is vital for commissioners and providers as it helps them look ahead at service requirements and ensure that there is an appropriately trained workforce to meet patient need.





## Epilepsy

Epilepsy is the most common, serious, neurological condition and is defined as a tendency to have recurrent seizures. A seizure is caused by a sudden burst of excess electrical activity in the brain. There are around 40 different types of seizure and a person may have more than one type. Epilepsy can affect anyone at any age and from any walk of life.

The age standardised prevalence rate of epilepsy in the UK is 7.5 per 1,000. This is equivalent to 1:131 people. However, epilepsy prevalence is 25 percent higher in the most socially deprived areas compared to the least socially deprived areas<sup>4</sup>. In adults, the social and economic disadvantages resulting from epilepsy can lead to a downward social mobility. This leads to a higher prevalence of epilepsy in deprived areas<sup>5</sup>. Also, more than one in five people with epilepsy have learning or intellectual disabilities.

Seventy percent of the population with epilepsy could be seizure free with optimal treatment. Currently this is achieved for only 52 percent, meaning 69,000 of those experiencing seizures in England could be seizure free. Every year approximately 990 people die of epilepsy related causes including sudden unexpected death in epilepsy (SUDEP). Of these, approximately 365 deaths are young adults and children. Of the total number of deaths, about 400 per year are potentially avoidable.

Polly is 20 years old. She was diagnosed with epilepsy when she was 12 years old. Having epilepsy has a huge impact on her life, as well as that of her friends and family. Polly says "It certainly feels at times that I am not a 20 year old woman, more a child needing constant care."

As Polly's epilepsy is uncontrolled she is not able to drive and has to rely on friends and family for transport. Having epilepsy has made a huge difference to her life and she finds living with epilepsy "frustrating for everyone involved." Polly has had to change medication several times and has to endure the "horrific side effects" of some anti-epileptic drugs. Polly would like more people to be aware of the wide impact epilepsy can have on the lives of those who have it, their family and friends.

Polly says, "People are slowly becoming aware of epilepsy, but there is still a long way to go. If more was taught about it in schools I think the stigma attached to having epilepsy would definitely be lessened. The medical profession are doing their best to help but, until society is made more aware, I don't think anything will really change."

<sup>4</sup> Joint Epilepsy Council, (2005) *Epilepsy prevalence, incidence and other statistics*

<sup>5</sup> Richard Reading, Robin Haynes, Richard Beach: *Deprivation and incidence of epilepsy in children. 2006 Seizure 15, 190-193.*

### Multiple sclerosis

MS is the most common disabling neurological condition in young adults, affecting around 85,000 people in the UK. It is most often diagnosed in people between 20 and 40, and affects three times more females than males. Diagnosis of this highly complex, variable condition can have significant psychological and psychosocial impacts. 85 percent of people diagnosed have relapsing remitting MS and, of these, half will develop the secondary progressive form within ten years of diagnosis. This form is characterised by worsening symptoms and fewer remissions. 10-15 percent of people are diagnosed with primary progressive MS in which symptoms develop and worsen. Although its cause is not known and a cure has yet to be identified, some treatments are available and specialist care can help people to manage symptoms. Approximately 2,500 new cases of MS are diagnosed each year, about 50 new cases per week in England and Wales<sup>6</sup> The prevalence of MS increases the further north one travels in the UK - from 1:800 in England to 1:500 in Scotland.

Julie is 32 and lives with her partner and two children. Julie was diagnosed with relapsing remitting MS three months after delivery of her second child. Julie has relapses which affect her sight and mobility and require high dose steroids quickly to reduce inflammation. When this happens she sometimes has to use a stick until her condition improves. Julie also copes with disease modifying treatment which means she needs to self inject several times a week. She copes with the drug side effects such as flu like symptoms and has found that being on this treatment has reduced the relapses she experiences.

Julie has adapted her lifestyle considerably to manage her MS related fatigue. Her urinary problems of frequency and urgency were distressing as they impacted on Julie's social life and intimate relationship with her partner. During an expert assessment these issues were identified, appropriate tests were carried out and treatment options/medication chosen. Julie's symptoms have now improved which has impacted positively on her confidence and relationships.

Julie worries about her children as she is not always able to do the things they enjoy. She fears for the future because she knows that her relapsing remitting type of MS may become secondary progressive MS at some stage. She thinks her children and partner are also worrying about her.

Julie knows she can phone her MS nurse whenever she requires help with a new problem or symptom she is unsure about. The MS nurse works in partnership with Julie providing listening, knowledge, appropriate support and educational resources. Julie now feels more positive, she has a greater ability and confidence to solve problems and to make informed decisions. She decides to talk to her partner and children to discuss, as a family, how they can support each other.

<sup>6</sup> Target Multiple Sclerosis 2007 Association of the British Pharmaceutical Industry

## Parkinson's

Parkinson's is a progressive neurodegenerative condition, caused by the loss of dopamine producing nerve cells in the part of the brain that controls movement. There is no cure for Parkinson's. Symptoms and progression vary significantly from person to person. Although predominantly a movement disorder, other impairments frequently develop including depression, dementia, sleep disturbances, bowel and bladder problems. Treating Parkinson's is complex, and involves combining drug and other therapies in an individual care plan, including professionals from a wide MDT.

It is estimated that there are 120,000 people with Parkinson's across the UK, which equates to 1:500 of the population. The prevalence increases with age and one in 20 will be under the age of 40 when they are diagnosed - representing a significant number of younger people with Parkinson's.

Karen, now aged 44, was diagnosed with Parkinson's in her 30s. It took her four years to be diagnosed after doctors mistook her slowness, stiffness and muscle spasms to be signs of MS. Karen first noticed that something was wrong when she had difficulty using a keyboard. She had been a data processor for over 10 years when she started hitting the wrong keys. She later developed a spasm in her big toe and noticed that her handwriting was getting a lot smaller to the point where it was impossible to read.

Although Karen has made changes to her lifestyle, her symptoms vary on a day to day basis. Some days she can barely walk or get through doors and will experience freezing, other days she can be "up on the dance floor so it makes you live for the day and do what you want, within reason".

Karen is now on a mixture of medication, taking tablets every two to three hours. This includes antidepressants, which have helped her to cope with the psychological impact of the condition. Her relationship with the Parkinson's disease nurse specialist (PDNS) enables her to get on with her life, knowing expert advice is available when medications don't always work as they should.

Neurological specialties can involve a complex case mix and consideration needs to be given to the management of the patient at different stages of their condition. For example, the support available to patients at the initial diagnosis may not be sufficient during an acute phase. Patients also need support to help them take an active role in the management of their condition. Consideration needs to be given to the structures that are required to deliver the current and future services. This will involve an understanding of the whole patient pathway across primary, secondary and social care. The pathways will need to identify the number and complexity of cases and the staff skills and competences required to deliver services. There is already useful guidance available for this, publications such as *Raising the Profile of Long Term Conditions*<sup>7</sup> give good examples of current best practice and integrated care and organisations such as Skills for Health are taking a lead on developing competence descriptions to help organisations develop competency based planning.

<sup>7</sup> *Raising the profile of long term conditions (DH 2008)*

## Section Three: The characteristics of an effective workforce

In planning the future workforce to meet patient need, there is no ‘one size fits all’ approach, especially in a specialty as broad and complex as neurology. This guidance and the NWP *Six Step Guide to Integrated Workforce Planning* outlined in Section Four aim to help organisations develop their own workforce plans to meet the needs of the local population. By using these and other available planning tools, organisations can review the current support available to patients and develop a flexible, affordable neurological workforce that is able to cope with all stages of the patient journey and respond to future advances in treatment.

Providing better long term conditions care is a key DH objective, with improvement in long term conditions care being a major theme in Lord Darzi’s next stage review.

The *NHS Operating Framework*<sup>8</sup> states that “PCTs are expected to improve care for people with long term conditions and to ensure more choices for these patients”. It lists a range of areas that a more personalised service should provide, including care closer to home. PCTs, as commissioners and providers of services, “are expected to ensure that the workforce, financial and service plans are linked together while mitigating risks to service delivery caused by lack of capacity and capability in the workforce”.

People with LTnC account for a considerable portion of staff time and financial resources in a typical PCT. At present, many patients still experience care that is fragmented, punctuated by acute exacerbations of their condition, and involve them in frequent trips to hospital. The NSF is clear that “People with these conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. This can cover: managing their medicines; treatment of specific symptoms; help to understand their condition and its current and future management. Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve wellbeing”<sup>9</sup>.

It is estimated that the impact of neurological conditions on health and care services is significant and includes the following:

- 10 percent of visits to A&E Departments are for neurological issues
- 17 percent of GP consultations are for neurological symptoms
- 19 percent of hospital admissions are for a neurological issues
- 25 percent of people between the ages of 16 and 64 with a chronic disability have a neurological condition
- 33 percent of disabled people living in residential care have neurological conditions.

<sup>8</sup> The NHS operating framework 2008/9 (DH 2008)

<sup>9</sup> The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005)

It is clear that with effective coordination, better team work and a greater focus on preventative strategies that enable people to stay as well as possible, not only can cost effectiveness be improved, but patients and their carers can experience better clinical outcomes, improved quality of life and higher levels of satisfaction.

Services need to be personalised, empowering, effective, integrated and lead to an improved quality and, where possible, length of life. Services must treat individuals with dignity and respect.

Commissioners and providers of services in partnership with their local authority need to commission services which cover the full range of areas of the long term conditions pathway:

- Early detection and diagnosis
- Management and integrated care
- Self care
- Specialist care
- Therapy and rehabilitation
- Palliative care.

Neurological charities are taking forward two key initiatives to strengthen commissioning and service monitoring by putting users at the heart of the process. The Quality Neurology Project involves the Multiple Sclerosis Society, Motor Neurone Disease Association, Parkinson's Disease Society and Ataxia UK in the development and roll out of an audit tool based on NSF requirements and user generated measures of success. The Commissioning Support Service offers the support and expertise of patient organisations comprising the MS Society, Parkinson's Disease Society and Motor Neurone Disease Association to inform the commissioning process, with a particular focus on developing user engagement.

For further information about the Commissioning Support Service and the Quality Neurology Project please contact the MS Society's service development team on **020 8438 0700**



### Investing in effective services and teams

Service transformation and use of the right systems, levers and incentives are important, but the NHS and social care workforce is crucial to delivery of better care and support. People with LTnC, particularly those with a more complex range of needs, often require care or support from a range of different professionals and agencies. Bringing these together into an MDT is essential as it underpins a coordinated, seamless approach to delivery of care and support, avoiding fragmentation, confusion and duplication of effort.

The workforce can contribute to delivery of better outcomes for people with LTnC by having:

- The right skills, knowledge and competences
- Good networks in place
- Effective partnerships and strong MDT working
- Integrated working across agencies
- Good approaches to case management
- Effective care planning arrangements
- Strategies to promote self care, choice and independence.

### MDTs are best placed to meet patient's complex needs

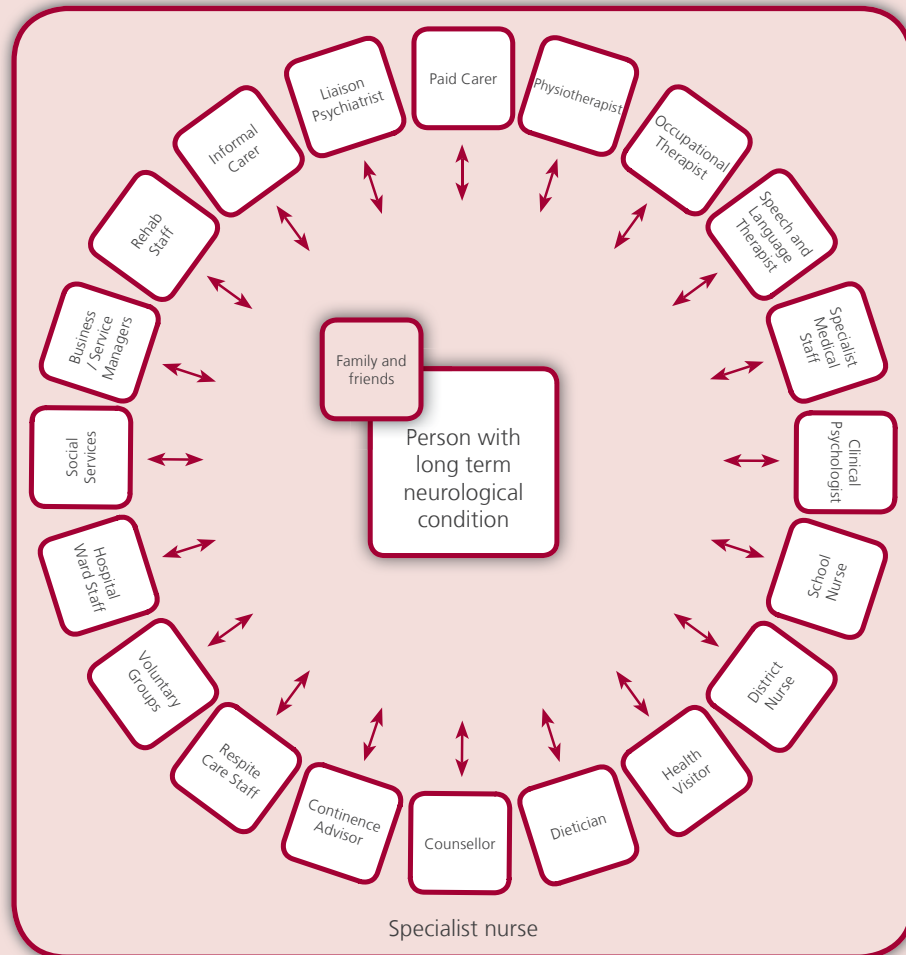
“It is important to recognise that my role as an epilepsy specialist nurse is part of a larger MDT. Our team includes a local consultant neurologist, a consultant psychiatrist (for learning disability and epilepsy), and a GP with an interest in epilepsy. The MDT has a vital role in promoting good communication, and ensuring that the services we offer are patient/client centred and consistent.”

*Epilepsy specialist nurse*

The needs of people with LTnC are complex. Whilst there are numerous LTnC, a feature they have in common is that the number of professionals and agencies involved is high, and services provided are generally specialised and interdependent. Individuals' needs are often complex and fluctuate along the disease pathway, but without exception they need tailored and responsive services, whether their condition is newly diagnosed, or something they have lived with for a number of years.

Services should be designed around care pathways and the requirements of people with LTnC, rather than fitting available professionals into care delivery - this requires mapping pathways based on available evidence and information; thus being able to provide appropriate staff with the right skills to deliver the right care.

### The complex web of care



“Every time another element of my Parkinson’s came out, I had to go back to the GP to get a referral. When I then saw the new service, such as continence or speech and language, I had to explain about my Parkinson’s again. Nobody seemed to be looking after the whole of my disease.”

In commissioning neurological services care must be taken to ensure that the provision meets the patients/users needs. These services should be of a high quality and affordable by the health and social care economy. The main issue in LTnC is that the services need to cover a wide range of specialties, with care provision in a wide variety of locations and take into account the complexity of care provision across health and social care.

All commissioners and providers of these services need to ensure that there is appropriate capacity and capability to deliver effective services for people with LTnC.

This diagram (left) shows the complex web of care that can surround those with LTnC demonstrating the need for sustained orchestration and coordination of services to meet patients’ needs.

Any neurological service will need to demonstrate an effective skill mix to ensure that the right skills are in the right place at the right time. Specialist care provided by neurologists and other practitioners is crucial. The role of the specialist nurse has been well documented and examples of best practice are included within this guide. As well as the key role of specialist nurse, any provision of services needs to look at the mix of skills required in the broader clinical team and explore other roles such as support workers and administrative staff in order to release the clinical time of the more specialised staff.

Adapted from  
The key elements for developing MS specialist nurse services in the UK (UKMSSNA, RCN and MS Trust, 2001)

### Bringing care closer to home

The clinical epilepsy team in Bradford PCT has evolved over time and provides an excellent service. The service is based around an MDT working to provide care closer to patients in their homes. It is now overseen by two hospital based consultant neurologists and comprises of four GPs with a special interest in epilepsy, two part time epilepsy specialist nurses and a psychotherapist who is currently piloting demand for this particular area of the service. The service coordinator and secretary provide a contact point for patients. The team holds clinics around the city on a weekly basis so that all patients can be reviewed at a convenient location near to their homes. In addition, the nurses are available to give telephone advice and undertake home visits at alternative times. The doctors also provide an advice service for all GPs in the city. The team is in the process of producing patient care plans for every person with epilepsy in the PCT. The epilepsy service in Bradford is well within the 18 week target and meets all the requirements of the NICE guidelines on epilepsy.

### Developing a one-stop approach

The service at Edgware Community Hospital integrates health and social care to support patients from diagnosis to the end of life. The Parkinson's clinic offers a one-stop shop enabling coordinated patient care and reducing the need for patients to deal with multiple appointments from various health care professionals including specialist nurse, specialist doctor, physiotherapist, occupational therapist, speech and language therapist, and dietician at different sites. This patient centred service fulfils the recommendations set out in the NICE guidelines for Parkinson's. Through the integration of health and social care services and the provision of seamless care, patients have experienced significant improvement in their quality of life. For many patients, the multidisciplinary holistic approach has helped to increase independence, reduce hospital admissions and delay the need for institutional care.

### A patient centred team approach

A community MS clinic in Hammersmith and Fulham has been set up where people see a consultant neurologist, the MS nurse specialist, a community physiotherapist and occupational therapist, a social worker and the chairman of the local branch of the MS Society - in one visit - to develop a patient centred plan.

The concept of the clinic is based on multi-partnership working. Close links have been established between local social services and the community rehabilitation therapists and the health team. The local branch of the MS Society is very supportive and through this clinic, it has funded a counsellor for people with MS and their direct carers.

“I see my role as supporting the patient with all aspects of their epilepsy. That can be reviewing seizures, adjusting or changing medication and providing information, but it also means giving support and time to help an individual and their family plan their lives, in which epilepsy plays a part. It means putting the person first and reducing the impact of the condition.”

*Epilepsy specialist nurse*

“For the first time since diagnosis I felt included and listened to.”



The clinic provides a psychological boost to a group of people who had felt invisible and alienated. It gives them access to specialist medical, nursing, therapy and social care and provides greater choice through increased knowledge of what is available. Patients have an active involvement in the decision making process and the clinic meets many of the quality requirements of the NSF for LTnC and the NICE MS clinical guidelines. Patient feedback about the service is very positive and is in addition to tangible benefits such as a 45 percent decrease in A&E attendances, a 22 percent decrease in non-elective admissions and a 67 percent increase for planned day case admissions.

## The role of specialist nurses in the MDT

The role of the specialist nurse and the part they can play in the MDT, is worth describing more fully in view of the importance people with LTnC consistently place on specialist nursing support. Whilst many current services have been developed around specialist nurses, or by them, nationally there is no consistency or shared understanding. Some work as key members of the team, whilst others are more isolated and can lack the support needed to get the very best out of their contribution. What they do have in common is the ability to act as a catalyst for change, the potential to lead service development, and to be the constant figure in the patient's journey through the system, initiating preventative interventions, supporting self care, and frequently taking on the role of case manager, especially for those with complex needs and high levels of morbidity.

Though presently there is no national standard for defining what constitutes specialist and higher levels of nursing practice, there does appear to be an emerging view within the profession, that nurses who fill this function should broadly conform to the description below.

These nurses are regulated professionals who work in a tightly defined area of practice and who have developed degrees of expertise in their field. This expertise is likely to be evidenced by study in that subject at levels beyond that required for primary registration.

They are competent to:

- Manage episodes of care
- Manage the treatment of specific long term conditions
- Contribute to the development of care pathways
- Handle highly technical aspects of care
- Offer advice and guidance to other professionals on specialist interventions
- Provide formal teaching sessions
- Prescribe medicines independently.

“I know if I have a problem with my medication I can ring the Parkinson's disease nurse specialist (PDNS) for help. Her availability saved me having to go back to hospital to see my consultant.”

Those having additional advanced level skills will:

- Exercise higher levels of judgment
- Apply higher levels of knowledge
- Undertake more complex procedures, which can carry significantly higher levels of risk
- Be self directed and manage risk
- Hold high levels of communication skills - for example having 'difficult' conversations with range of patients, carers, relatives and colleagues
- Complete tranches of care - such as:
  - Comprehensive history taking and physical examination
  - Identifying potential diagnosis, referring for investigations and making final diagnosis
  - Admitting and discharging patients
- Coordinate and manage complex packages of care, assessing and monitoring input of others
- Teach, set standards and protocols for others to follow.

These definitions should be regarded as a guide only, as *Modernising Nursing Careers* (DH 2007) is likely to regularise the definition of specialist and higher level of practice. Depending on the outcome of work associated with the white paper, *Trust, Assurance & Safety*, specialist nurses may become subject to higher levels of regulation by the Nursing and Midwifery Council.

“MS nurses are a vital component of the MS service. They act as a patient advocate and provide continuity of care from initial diagnosis through the early relapsing and remitting and secondary progressive stages to the terminal stages of disease. They are actively involved in patient education, symptomatic treatment, management of relapses and the identification of patients who may be candidates for disease modifying drugs. They work closely with neurologists and liaise with GPs, rehabilitation, palliative care and other local services. They provide telephone helpline services, nurse led clinics based at hospitals or in the community, ward consultation services and home visits. No other healthcare professional can provide such a range and depth of patient centred services. MS nurses are essential to ensure the standards outlined in the NICE MS guidelines and NSF for LTnC are met. Indeed it is impossible to conceive how an MS service could function without MS nurses.”

*Consultant neurologist, Manchester*

“I tried to ignore what was happening at first and wouldn't listen to anyone. However, I have been able to talk about all my worries that had been building up inside of me with the specialist nurse, who has told me ways of how I can manage and overcome them.”

## How service redesign promotes development of a competent workforce

The recommended route to deliver a systematic approach is to utilise multiprofessional teams and integrated patient pathways to ensure closer integration between health and social care. Different interventions should then be used for patients with different degrees of need. The NHS and Social Care Long Term Conditions Model sets out a delivery system that matches care with need. It draws on the ‘pyramid of care’ developed by US healthcare provider Kaiser Permanente which identifies the population of patients with long term conditions into three distinct groups based on their degree of need.<sup>10</sup>

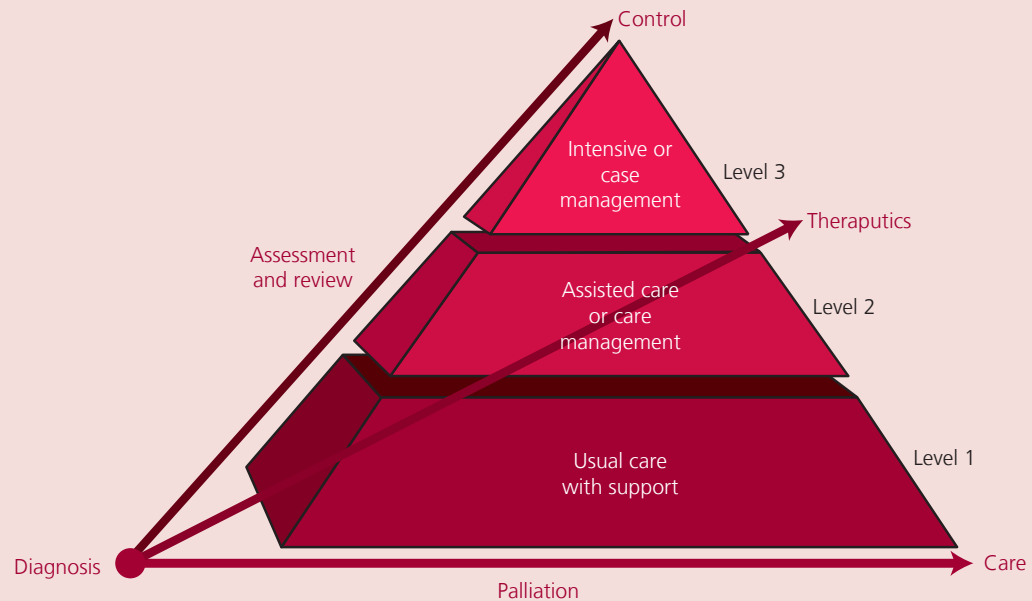
**Level 3: Case management** - requires the identification of the very high intensity users of unplanned secondary care. A case management approach, to anticipate, coordinate and join up health and social care is required.

**Level 2: Disease specific care management** - involves providing people who have a complex single need or multiple conditions with responsive, specialist services using MDTs and disease-specific protocols and pathways.

**Level 1: Supported self care** - collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively.

**Population management:**  
More than care & case management

Targeting population(s) → Redesigning processes → Measurement of outcomes & feedback



<sup>10</sup> Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration (DH 2005)

This diagram reminds commissioners and providers to think, not just about individuals that are already known within their service but to give consideration to the whole population within the health economy with an LTnC and the services that will be required from diagnosis through to palliative care.

If timely intervention from an appropriately skilled workforce is given this can enable individuals to be directed back towards self care. Crisis management and unscheduled care can be prevented.

### Service redesign in Cornwall and Isles of Scilly PCT

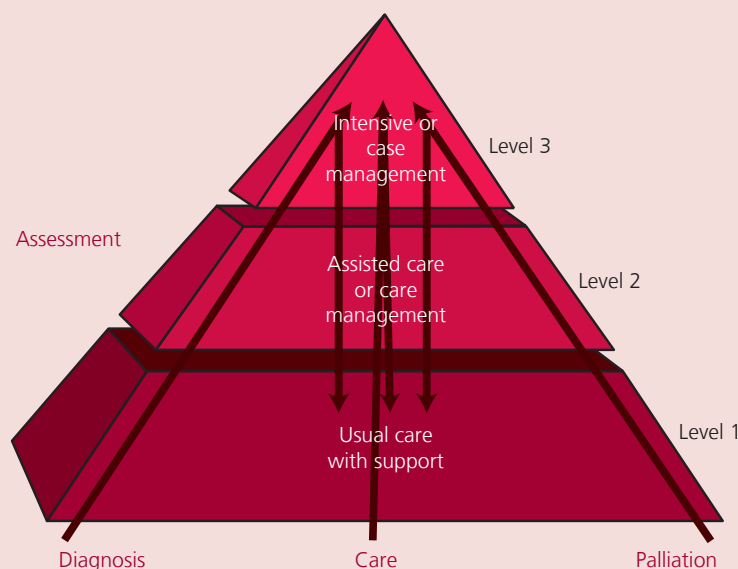
Cornwall and Isles of Scilly PCT has redesigned its Parkinson's services because of the geography and demography of the county. There are around 1,500 people in Cornwall with Parkinson's and patients had to travel great distances to the specialist clinics in the Redruth area which was a problem, especially as the area has a large influx of holiday makers in the summer.

There was a need to develop services closer to home in differing areas of the county so that patients did not have to travel so far. Community based clinics have been formed and the workforce was upskilled through development of a managed clinical network of multiprofessionals including physiotherapists, occupational therapists, speech and language therapists, nurses, community matrons and social care staff. Patients are now seen more locally by the appropriate team member who has the ability to triage patients who may not necessarily need specialist hospital care.

Parkinson's specific expert patients' programmes have also been developed and the Trust is forging links with the voluntary sector which runs drop in self help groups for patients.

### How do nurse specialists help?

Facilitating access to *and from* specialist care -  
More than care & case management



## Service redesign in Sheffield PCT

Sheffield PCT has redesigned Parkinson's services locally which has ensured equity of care for people with Parkinson's across the health economy. Service redesign was led by a Parkinson's stakeholder group chaired by a local geriatrician at the Northern General Hospital Sheffield. The stakeholder group developed new networks between the PCT, service commissioners and providers, neurologists, elderly care physicians and the MDT and enables greater understanding of each professional's potential contribution to clinical management.

Prior to the redesign, only patients seeing neurologists had access to a PDNS leading to an inequity of care for older people with Parkinson's who are the most likely to have problems. Redesign of an elderly rehabilitation day hospital clinic and wider involvement of the multiprofessional team has enabled patients to benefit. The stakeholder group has been able to bring together all staff involved in the care of the condition in the city and follow a step by step process of service redesign to effect change. The result has been the development of integrated services and a competent multidisciplinary workforce.

A PDNS was appointed with funding from Parkinson's Disease Society and referral guidelines have been developed for GPs to streamline care and ensure 18 week targets are met. Regular audits have been undertaken to identify gaps in service and enable these gaps to be addressed. GP referrals are now more appropriate to secondary care.

The doctor who led the group developed the competence to manage patients with Parkinson's by attending a masterclass training programme<sup>11</sup> and several of her consultant geriatrician colleagues and a GP with special interest in Parkinson's have also undertaken training to ensure all patients have access to specialist support regardless of where they live. This team has benefited from strong coherent leadership, a major contributing factor to it winning the Hospital Doctor of the Year Awards 2006 Parkinson's disease category.

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11 *British Geriatrics Society (Special interest movement disorders section) [www.bgs.org.uk/PDF%20Downloads/MasterStrokes\\_Oct07.pdf](http://www.bgs.org.uk/PDF%20Downloads/MasterStrokes_Oct07.pdf)*

## Section Four: How to redesign neurological services

### Six Step Guide to Integrated Workforce Planning

At its simplest, effective workforce planning ensures you will have a workforce of the right size, with the right skills, organised in the right way, within the budget that you can afford, delivering services to provide the best possible patient care. NWP has developed the *Six Step Guide to Integrated Workforce Planning* to assist organisations in developing integrated financial, service and workforce plans. The guide follows a series of simple steps from visioning the future workforce, modelling supply and demand options through to developing a practical action plan that can be implemented within the organisation.

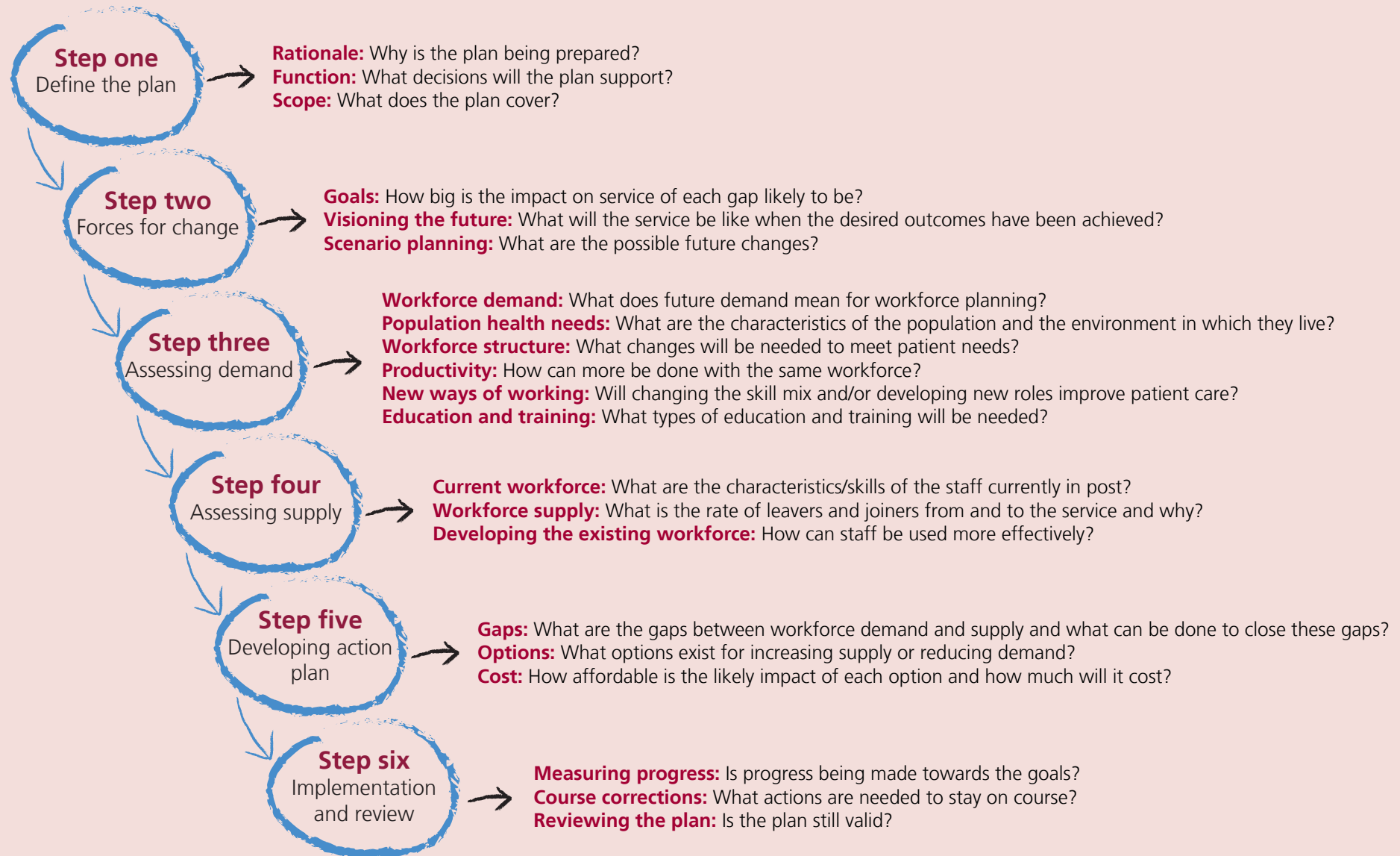
Workforce plans are prepared at many levels. At a local level, there are the plans – staffing rotas - prepared once a month by a ward manager to ensure that their ward has all its shifts covered by staff with the correct skills and competences to ensure that patient services are delivered safely and effectively.

At the most complex level, there are SHA level workforce plans which might be an aggregation of all the plans submitted by the PCTs and by provider organisations which is used to support strategic and financial planning and education commissioning.

You may need to plan your future workforce needs in the context of plans to reconfigure services. On the other hand, you may want to rethink the delivery of services in the context of an anticipated shortage of staff with particular skills.

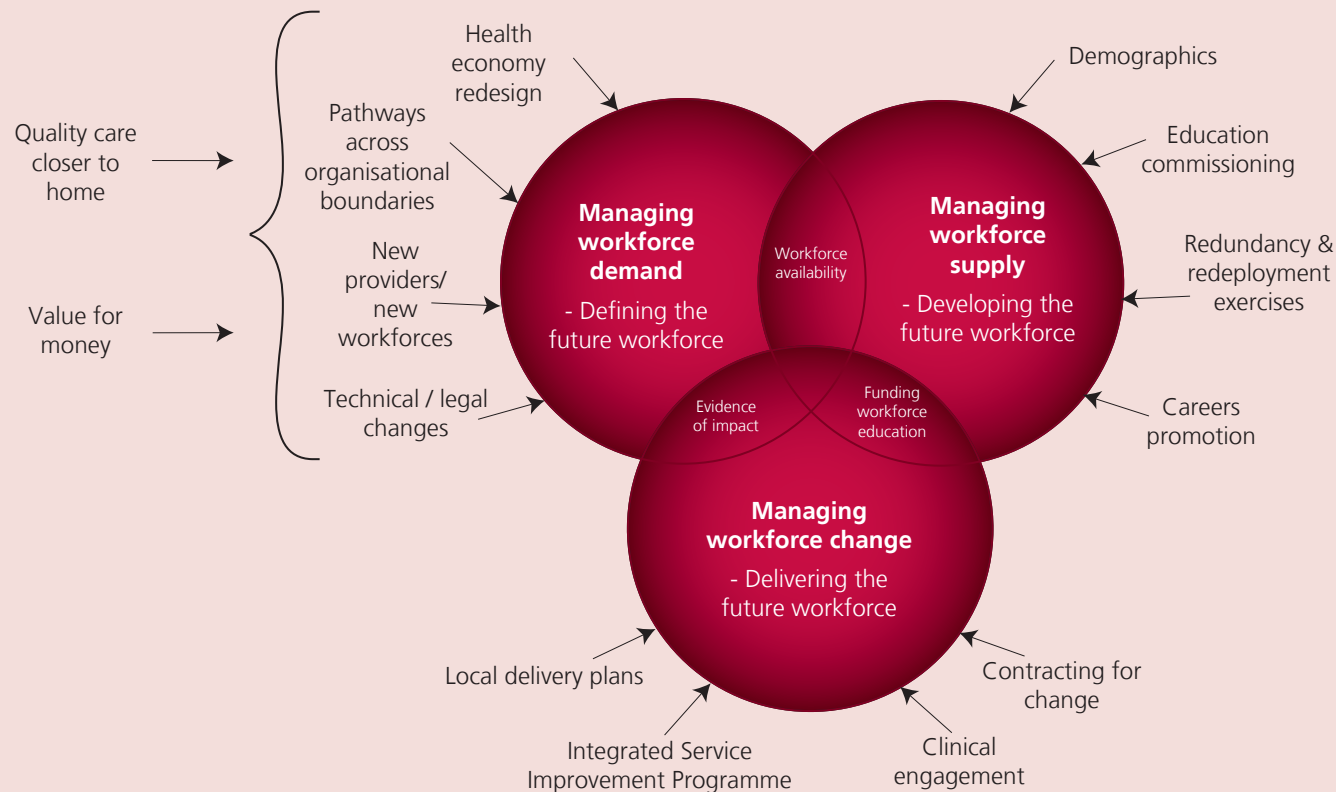
The main aim of the six step guide is to set out in a practical framework those elements that should be in any workforce plan.

The diagram on the following page outlines the individual steps and the different elements involved in the development of the plan. In addition there is an e-learning CD-ROM version of the six steps guide inside the back cover.



## Commissioning issues

From the commissioning perspective, there is a need to consider best practice guidelines, challenge the productivity and efficiency across the whole health economy and meet the changing patient demand for services. Commissioning of future services needs to take account of the demand for certain skills - with the advances in technology and new ways of working it cannot be assumed that the same skill mix will be needed in the future. Commissioners and providers also need to ensure through effective education commissioning that the skills required will be in place. Workforce supply and demand issues need to be underpinned by effective management of workforce change with clear planning and effective engagement of key stakeholders across healthcare.



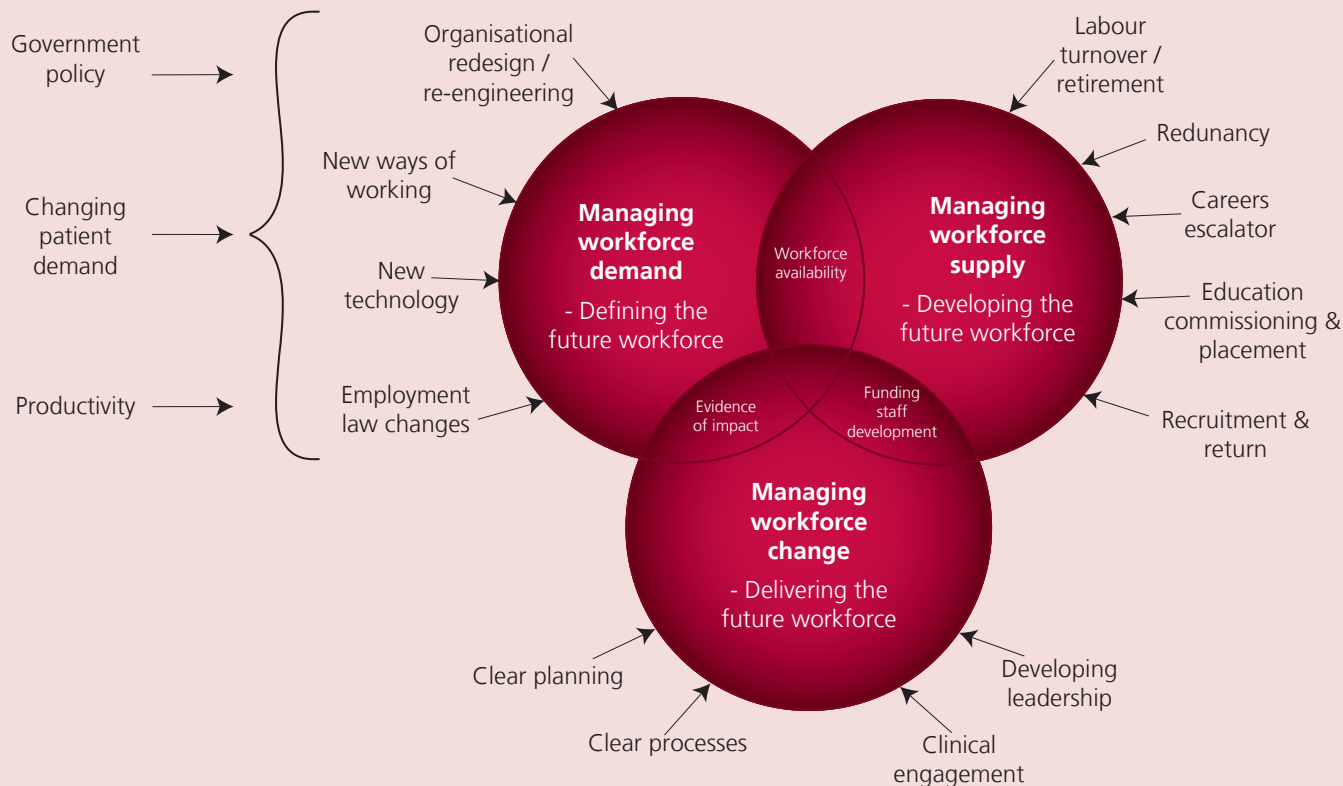


## Provider issues

From the provider perspective, the drivers will be to deliver high quality care, close to home and within budget. Increasingly this is being achieved by redesigning how care is delivered, by whom and in what location.

Planning for future service provision needs to take account of the workforce issues alongside those of service and financial planning. Providers will need to develop their future staffing needs, taking account of new ways of working, technological advances and how care is to be delivered closer to home. In addition, they will have to ensure the supply of future staff by looking at retaining existing staff and developing innovative solutions to developing the right skill mix in teams. In designing services providers should, of course, pay attention to the needs of all service users, taking into account particular needs that may be related to their ethnicity, disability, gender, age, religion, beliefs or sexual orientation.

Above all, organisations will have to become skilled in developing flexibility within the workforce to be able to cope with the fast pace of change in the future. In many areas clinical engagement in the development of future plans will be key to delivering effective patient care in the future.



### Competences for workforce design

The delivery of safe, high quality, cost effective services for people with LTnC depends significantly on having health and social care staff with the right skills in the right place at the right time, in the right numbers. The role of the commissioner in determining the mix of those skills is, however, one of facilitation rather than direct planning. It is the provider who is responsible for the employment, deployment and design of the workforce to deliver a service to the described specification.

### Skills for Health

Skills for Health has a database of hundreds of nationally agreed competences which can be used as the building blocks from which you can design a flexible, transferable, healthcare workforce. There are competences available specifically for workforce planning, neurological conditions, case management of LTnC, rehabilitation and therapy.

To enable you to find and use the competences that are relevant to your service there are a number of application tools that are available free of charge to the sector.

[www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)

### Skills for Care

Working in consultation with carers, employers and service users, Skills for Care aims to modernise adult social care in England, by ensuring qualifications and standards continually adapt to meet the changing needs of people who use care services.

[www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)

## Section Five: Increasing clinical impact and maximising cost savings

The following case studies outline the economic costs of caring for patients with LTnC. While these figures are average figures across the UK, there will be significant scope in all health economies to look at efficient models of care that meet the current and future patient need.

### The economic impact of Parkinson's care

The cost of Parkinson's is extremely high in both economic terms and in terms of the impact on patient's lives. Economic costs escalate with disease severity and patients use more healthcare resources. To ensure best values in outcomes and resource utilisation, clinicians should focus on treatments that maintain independence while minimising the impact of disease progression.

In 1998 the direct costs of care in the UK were evaluated in a sample of people with Parkinson's. Although drug costs and inflation mean that these figures are now an underestimate of the current costs, the figures reveal important information about how money is spent on people with Parkinson's.

The total mean annual cost of care per patient for all patients was £5,993 in 1998. Social care costs accounted for 34 percent of total costs and tended to rise with increasing age. NHS costs accounted for 38 percent of total costs. Total annual direct costs were £4,189 for each patient living at home; £15,355 for patients whose care was divided between home and residential or nursing home care; and £19,338 for patients in full time care<sup>1</sup>.

In 2005/6, analysis of hospital episode statistics showed that 34,839 people with Parkinson's were admitted into hospital in England, many on more than one occasion. Based on Parkinson's prevalence of 1 in 500, it is estimated that there were 101,380 people with Parkinson's living in England in 2005/6, therefore more than one third of the people with Parkinson's in England are admitted into hospital each year. The data also showed an average length of stay of five days longer than a comparable elderly population.<sup>2</sup>

<sup>1</sup> Findley .LJ. *The economic impact of Parkinson's disease*. [www.elsevier.com/locate/parkreldis](http://www.elsevier.com/locate/parkreldis)

<sup>2</sup> *Analysis of Hospital Episode Statistics (HES) data for Parkinson's admissions in England, 2005/06*

### Costs of misdiagnosis of epilepsy

Misdiagnosis rates in the UK where a diagnosis of epilepsy is incorrectly made are between 20 - 31 percent. Using an assumed rate of 23 percent, this equates to 105,000 people with a diagnosis of epilepsy and receiving anti-epileptic drugs who do not have the condition. This high misdiagnosis rate has a major impact on people's lives, including the physical implications of the side effects of taking anti-epileptic medication. One of the main reasons for the high level of misdiagnosis is the lack of training and the limited access for people with epilepsy to epilepsy specialists<sup>1</sup>.

In 2004, the medical cost associated with misdiagnosis in England was £23 million and the non-medical cost was £111 million<sup>2</sup>. Developing the epilepsy service and having the correct workforce in place should help to improve the rates of accurate diagnosis thus reducing the amount of costs associated with misdiagnosis.

A randomised controlled trial<sup>3</sup> found that patients who consulted an epilepsy nurse specialist as well as their neurologist were significantly less likely to seek additional consultations with their GP or clinic doctors. This led to an annual saving of £184 per patient, as GP and clinician time was freed up by patients being able to access the epilepsy specialist nurse for advice and support.

<sup>1</sup> All Party Parliamentary Group on Epilepsy, *Wasted Money Wasted Lives: the human and economic cost of epilepsy in England, June 2007*

<sup>2</sup> *Epilepsy prevalence, incidence and other statistics. The Joint Epilepsy Council August 2005. [www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)*

<sup>3</sup> Warren E, *An evaluation of a nurse specialist / case manager intervention in the management of Epilepsy (RF13, 1998)*

## Cost savings with service redesign

### Developing new services

The MS team at the National Hospital for Neurology and Neurosurgery, University College London Hospital Foundation Trust has developed a successful multidisciplinary specialist relapse service for people with MS. Over five years, the service has evolved from an inpatient to an outpatient service progressing to a trial of a home delivery. Service redesign has reduced variations in practice between clinical teams and led to a reduction in average waiting times to treatment from 6.2 weeks to 6.1 days. The trial demonstrated an average cost saving of £1,797 per patient treated with steroids for a relapse at home instead of within a day care hospital setting.<sup>12</sup>

<sup>12</sup> Porter, B., Matheson, F and Chataway, J (2007) 'Key steps to delivery of a person centred relapse service' *The National Hospital for Neurology and Neurosurgery and the Multiple Sclerosis Trust*

## Outcomes

- Due to the education and information provided by the MS nurse, people with MS felt confident in knowing when to contact the team and self refer for an assessment of their needs and signposting to the most appropriate service
- By encouraging people with MS to self report new symptoms, the MS nurse was able to provide a timely service. The telephone service allowed people with MS to self refer for provision of 1) a timely assessment, 2) outpatient cannulation, 3) delivery of intravenous steroids (if appropriate). The service allowed MS nurses to expertly assess and triage appropriate patients to the clinic or direct them to other areas of treatment and support locally
- The telephone screening service was such a success that it led to the development of a weekly outpatient relapse clinic that could be accessed by self referral. MS nurses joined up with other key specialists from the MDT such as physiotherapists, continence advisors and occupational therapists to provide this additional service.
- By working with the MDT and producing an expert consensus group to agree local guidelines, the MS nurse was able to help streamline clinical practice between teams dealing with the management of urinary tract infections and the number of infusions offered per year. As a result, waiting times were reduced from 6.2 weeks to 6.1 days<sup>13</sup> and high levels of patient satisfaction was reported. The support and infrastructure of the MDT and Trust wide interest was crucial in service development
- The trial demonstrated that home delivery of intravenous (IV) steroids during acute relapses was superior to the outpatient experience, safer to administer and cheaper. (Porter et al, 2007: 40) The coordination of care was better, treatment was more convenient and timely and the calmness of the environment at home (as opposed to hospital) was reassuring and comforting for the patient
- It is estimated that PCTs will have more than 10 patients requiring relapse treatment per annum. If an MS nurse is available to treat each one of these at home instead of in hospital, then this produces a cost saving of £17, 970 to the PCT. (Porter 2007: 40)

“The support of an MS nurse is invaluable. There is someone you can call, and get help straight away. I would have had so many doctor appointments if I wasn't able to call my nurse.”

<sup>13</sup> Matheson, F. and Porter, B (2006) *The evolution of a relapse clinic for multiple sclerosis: challenges and recommendations*. *British Journal of Neuroscience Nursing*, vol 2 (4), pp. 180 – 186

### Reduction in A&E attendances

In February 2005 an adult epilepsy specialist nurse came to post, working for Surrey PCT. Prior to this, there was no epilepsy specialist nurse in post.

Data from the Royal Surrey County Hospital shows a reduction in attendances for people with epilepsy at A&E from an average of 29 a month in 2005 to 15 a month in 2007. This results in an average of 14 less a month and 168 a year. Under Payment by Results this would attract the tariff of £102 giving a saving of £17,136 a year. The epilepsy specialist nurse achieved these outcomes by:

- Managing medication
- Adjusting medication
- Educating people with epilepsy - self management
- Educating carers and family in the use of rescue medication
- Interception through telephone clinics
- Educating ambulance technicians.

### Treatment of acute episodes

Any individual with MS who experiences an acute episode (including optic neuritis) sufficient to cause distressing symptoms or an increased limitation on activities, should be offered a course of high dose corticosteroids. Intravenous methylprednisolone or high dose oral methylprednisolone should be given as soon as possible after the relapse.<sup>14</sup>

In 2006, the North Northamptonshire PCT based MS service began delivering oral steroids to people in their own homes, removing the need for them to go into hospital for IV steroid treatment. During the period 2006/7, 34 episodes of oral steroids were administered to people in their own homes, resulting in a cost saving of £65,773. Due to the work of the MS specialist nurse the need for secondary care neurology appointments has decreased by 52 percent, freeing up capacity and producing further cost savings of £16,402.

The MS nursing service works with GPs and the general hospital on admission avoidance and is working with the long term conditions team developing anticipatory care plans for people with MS who are frequent users of acute services.

The MS service also provides education, support and advice to professionals, providing a bi-annual, newly designed, 'Getting to Grips' course which gives information and support to all those diagnosed two years or less on relapse management, infections, symptom flare-ups and who to contact.

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<sup>14</sup> NICE (2003) *Multiple Sclerosis: management of multiple sclerosis in primary and secondary care. Clinical guideline number 8. November 2003. Developed by the National Collaborating Centre for Chronic Conditions. NICE: London*

## Reduction in admissions and length of stay

For two years before the PDNS came into post, Harlow PCT had established robust data on hospital admissions for primary and secondary diagnosis of Parkinson's. When the nurse came into post, she was able to identify trigger factors for hospital admissions. Working with the MDT, the specialist nurse ensured early therapy interventions and established herself with patients as the first port of call in a crisis. She was also able to use daily admissions reports and patients at risk of readmission (PARR) reports to allocate her resources to where they were most needed. In changing the way patients accessed the service, she was able to reverse the upward trend in admissions and length of stay for patients with Parkinson's. These changes delivered an £80,000 saving to the PCT and its patient group felt supported and informed.



## Section Six: Sources of support and useful links

As this guide outlines, local health and social care services have a key role to play in supporting service delivery. The voluntary sector also provides a wide range of services to people with LTnC, their families and carers.

EA, the MS Society and Parkinson's Disease Society are the three largest neurological charities in the UK representing over 660,000 people with neurological conditions. Over the course of nine years, these charities have together invested over £16m both in pump priming nursing posts and in providing education and training for specialist nurses. Each has their own nurse funds which have been established to support professionals. As membership organisations, access to a specialist nurse is one of the key priorities for people living with MS, epilepsy and Parkinson's, second only to research in to the conditions. The third sector has expertise in specific conditions and can provide support to the MDT and local health trusts. In addition to the charities below, many other charities provide support for people with LTnC.

### Epilepsy Action (EA)

EA is the UK's largest member-led charity for people with epilepsy. EA provides a range of services, including a free telephone helpline, providing information to anyone interested in epilepsy, and branches throughout the UK which are run by volunteers.

EA runs the Sapphire Nurse Scheme which aims to help appoint epilepsy specialist nurses into NHS trusts. A sapphire nurse, or sapphire epilepsy specialist nurse to use the full title, is a nurse who has a wealth of knowledge and experience in caring for people with epilepsy. Generally, there are three types of sapphire nurse: those who specialise in caring for adults with epilepsy, those who specialise in caring for children (paediatric) with epilepsy and those who specialise in learning disabilities. Sapphire nurse posts have been funded initially by a grant from EA or, in the case of most paediatric posts, by a grant from the Roald Dahl Foundation.

EA can provide a range of tools, resources, support and expertise to support commissioners and service managers with the redesign of neurology services, as well as bringing the user perspective to the commissioning process. Further information is available from their website [www.epilepsy.org.uk](http://www.epilepsy.org.uk).



## MS Society

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. It provides respite care, a freephone MS helpline, grants for home adaptations and mobility aids, education and training, and a wide range of information. The MS Society also funds over 40 vital MS research projects in the UK.

The MS Society is committed to working at both a national and local level to ensure that access to high quality health and social care services is a reality for everyone affected by MS. It has a strong history of working with commissioners and providers and health and social care professionals and can provide expertise in a range of specialisms (including nursing, physiotherapy, independent living and audit and evaluation) as well as local information and the service user perspective. The MS Society can also provide funding for MS specialist practitioners including nurses and other allied healthcare professionals. Once in post, MS specialist practitioners are supported with a comprehensive range of educational opportunities to enhance their continued professional development including educational bursaries and membership to the MS Professional Network to promote and share best practice.

The MS Society also has a local branch structure that caters for people of all ages and interests. Through its local branch network the Society provides a range of services in partnership with professionals to complement statutory provision.

For more information visit: [www.mssociety.org.uk](http://www.mssociety.org.uk).

## Parkinson's Disease Society

The Parkinson's Disease Society is the main UK charity representing people with Parkinson's. The Parkinson's Disease Society has helped many local health organisations scope their Parkinson's services, and can support local teams find a model of specialised Parkinson's services that works for them and works for the needs of people with Parkinson's in their area. They can also offer financial support for up to two years to employ key Parkinson's practitioners such as a PDNS, as part of the PCT's ongoing commitment to improve and maintain Parkinson's services.

The Parkinson's Disease Society can facilitate access to Parkinson's services users so commissioners and service managers can hear directly the views and experiences of people who are dependent on local services for the effective management of their condition. In each PCT area the Parkinson's Disease Society employs staff locally who can offer one-to-one advice and support on accessing health and social care services. Linked to a Parkinson's multidisciplinary care team, these staff can support people with Parkinson's in managing their condition and becoming expert patients.

The Parkinson's Disease Society has a well developed professional education programme including regional training teams, educational bursaries, conferences, publications and a comprehensive website. The Parkinson's Disease Society also has a national programme of continued professional development and mentorship for every PDNS.

For more information on the Parkinson's Disease Society and support available go to [www.parkinsons.org.uk](http://www.parkinsons.org.uk).

### Useful Links

Department of Health  
[www.dh.gov.uk](http://www.dh.gov.uk)

Royal College of Nursing  
[www.rcn.org.uk](http://www.rcn.org.uk)

Multiple Sclerosis Society  
[www.mssociety.org.uk](http://www.mssociety.org.uk)

Parkinson's Disease Society  
[www.parkinsons.org.uk](http://www.parkinsons.org.uk)

Epilepsy Action  
[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

NHS National Workforce Projects  
[www.healthcareworkforce.nhs.uk](http://www.healthcareworkforce.nhs.uk)

Skills for Health  
[www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)

Skills for Care  
[www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)

The Neurological Alliance  
[www.neural.org.uk](http://www.neural.org.uk)

Brain & Spine Foundation  
[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

Joint Epilepsy Council  
[www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)

Epilepsy Nurses Association  
[www.esna-online.org.uk](http://www.esna-online.org.uk)

Care Services Improvement Partnership  
[www.csip.org.uk](http://www.csip.org.uk)

The UK MS Specialist Nursing Association  
[www.ukmssna.org.uk](http://www.ukmssna.org.uk)



# Appendix 1

## Estimated Incidence and Prevalence of Multiple Sclerosis, Parkinson's Disease and Epilepsy in 4 PCTs

The incidence and prevalence are calculated by applying national estimated rates (see Table 2) to the local PCT population.

**Table 1: Incidence & Prevalence by PCT**

PCT	Resident population	Multiple Sclerosis		Parkinson's Disease		Epilepsy	
		Prevalence	Incidence	Prevalence	Incidence	Prevalence	Incidence
Bassetlaw PCT	111,431	134	8	223	19	850	51
Cornwall & Isles of Scilly PCT	526,369	632	37	1,053	89	4,016	242
Haringey Teaching PCT	225,657	271	16	451	38	1,722	104
Surrey PCT	1,073,478	1,288	75	2,147	182	8,191	494

**Table 2: National estimated rates**

Condition	No. per 100,000	
	Prevalence	Incidence
Multiple Sclerosis	120	7
Parkinson's Disease	200	17
Epilepsy	763	46

**Sue Ryder Care** 

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### References:

- 1 PCT resident population - National Statistics 2006 mid-year estimates (provisional). All ages. Released November 2007.
- 2 Multiple Sclerosis rates - Department of Health (2005) The National Service Framework for Long-term Conditions. Annex 4, p.107 (prevalence = 100-120; incidence = 3-7. Highest value has been used in calculation. Some literature suggests prevalence as high as 143 per 100,000)
- 3 Parkinson's Disease rates - Department of Health (2005) The National Service Framework for Long-term Conditions. Annex 4, p.107
- 4 Epilepsy rates - Joint Epilepsy Council (2005) Epilepsy prevalence, incidence and other statistics. (Prevalence is estimated as 1 in 131).

## Appendix 2

### Incidence and prevalence of some neurological conditions in the UK<sup>19</sup>

Condition	Incidence per PCT population <i>(New cases per year)</i>			Prevalence per PCT Population <i>(Cases per 100,000 of population)</i>		
	100,000	200,000	300,000	100,000	200,000	300,000
<b>Cerebral Palsy</b>	N/k			186	372	558
<b>Charcot-Marie-Tooth Disease</b>	N/k			40	80	120
<b>Dystonia<sup>20</sup></b>	N/k			65	130	195
<b>Early onset dementia<sup>21</sup></b>	N/k			67	134	201
<b>Epilepsy<sup>22 23</sup></b>	24-58	48-116	72-174	430-1000	860-2000	1290-3000
<b>Essential tremor</b>	N/k			850	1700	2550
<b>Huntington's disease</b>	N/k			13.5	27	40.5
<b>Migraine<sup>24</sup> (England)</b>	400	800	1200	15,000	30,000	45,000
<b>Motor neurone disease</b>	2	4	6	7	14	21
<b>Multiple sclerosis<sup>25</sup></b>	3-7	6-14	9-21	100-120	200-240	300-360

19 Unless indicated otherwise this table is based on figures in Neuro numbers: a brief review of the numbers of people in the UK with a neurological condition. See paper for details on other conditions such as ataxia, brain tumour, Guillain Barre syndrome and narcolepsy. Where additional and comparable information has become available it is added in italics with a footnote.

20 Unless indicated otherwise this table is based on figures in Neuro numbers: a brief review of the numbers of people in the UK with a neurological condition. See paper for details on other conditions such as ataxia, brain tumour, Guillain Barre syndrome and narcolepsy. Where additional and comparable information has become available it is added in italics with a footnote.

21 Primary idiopathic - ie not associated with another condition.

22 For Alzheimer's Disease in over 65s the incidence is 25,000, prevalence 1,000 and approximate total numbers 700,000. Alzheimer's Disease and other dementias are covered in the NSF for Older People

23 Figures for England and Wales from NICE Guidelines

24 Figures from Dr Richard Harvey, Dementia Research Group, Imperial College School of Medicine

25 Steiner TJ et al, Epidemiology of migraine in England. Cephalgia 1999: 19:305-6.

Condition	Incidence per PCT population (New cases per year)			Prevalence per PCT Population (Cases per 100,000 of population)		
	100,000	200,000	300,000	100,000	200,000	300,000
Muscular dystrophy	N/k			50	100	150
Parkinson's disease	17	34	51	200	400	600
Post polio syndrome	N/k			250	500	750
Spinal cord injury <sup>26</sup>	2 <sup>27</sup>	4	6	50	100	150
Spina Bifida and congenital Hydrocephalus	N/k			24	48	72
Young onset stroke <sup>28</sup>	55 <sup>29</sup>	110	165	N/k		
Traumatic brain injury leading to long term problems <sup>30</sup>	175	350	525	1200	2400	3600
	Leading to hospital admission			With long term problems		

26 Figures from NICE Guidelines for England and Wales

27 Kurtzke JF. Epidemiology of Spinal Cord Injury. *Neurologia Neurocirurgia Psiquiatria* 1978; 18: 157-91

28 The Spinal Injury Association gives 666 new patient admissions to Spinal Injury Centres in the UK and Ireland in 2000. (equiv to about 2/100,000).

29 For Stroke in all ages the incidence is 204, prevalence 800, and approximate total numbers 300,000. Stroke is covered in the NSF for Older People

30 Admissions to hospitals in England 2002-03

## Appendix 3

### Neurological Long Term Conditions Quality Requirements

#### **Quality Requirement 1: A persons centred service**

People with long term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

#### **Quality Requirement 2: Early recognition, prompt diagnosis and treatment**

People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

#### **Quality Requirement 3: Emergency and acute management**

People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

#### **Quality Requirement 4: Early and specialist rehabilitation**

People with long term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

#### **Quality Requirement 5: Community rehabilitation and support**

People with long term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

#### **Quality Requirement 6: Vocational rehabilitation**

People with long term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

#### **Quality Requirement 7: Providing equipment and accommodation**

People with long term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

#### **Quality Requirement 8: Providing personal care and support**

Health and social care services work together to provide care and support to enable people with long term neurological conditions to achieve maximum choice about living independently at home.

#### **Quality Requirement 9: Palliative care**

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.

#### **Quality Requirement 10: Supporting family and carers**

Carers of people with long term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as a carer and in their own right.

#### **Quality Requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings**

People with long term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

# Six Step Guide to Integrated Workforce Planning e-learning CD

Six Steps is an interactive e-learning programme that gives you a guide to effective integrated workforce planning.

At its simplest, workforce planning ensures you will have a workforce of the right size, with the right skills and diversity, organised in the right way.

Six Steps aims to help those doing workforce planning gain an understanding of how to work through the maze of information to prepare a workforce plan which can be implemented and which will deliver the required changes. Simply load the CD into your PC and work your way through the programme at your own pace.





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Product code: NWP-0809-001