

## Living Well

### Long-Term Neurological Conditions (LTNC)

Revised: 17/02/2017

#### Introduction

A Long Term Neurological Condition (LTNC) results from injury, damage to, or disease of the nervous system - which includes the brain, spinal cord, and peripheral nerves. Nationally around 2 million people suffer with a LTNC (excluding migraine) – 350,000 of which need help with activities of daily living (*Neurological Alliance*).

LTNCs can present in many forms – from movement, sensation and psychological symptoms to communication and cognitive difficulties. It is therefore unsurprising that these patients require a range of agencies and services over time. According to [Department of Health](#) data, in 2012-13 a third of visits to GPs and a fifth of all acute hospital admissions are related to neurological conditions. On top of this, it is estimated that in the UK, some 850,000 people provide care for someone with an LTNC, an activity that itself is associated with high levels of stress, mental health and financial issues.

As a result, health spending on neurological services has increased faster than overall NHS spending. In 2012-13, £3.3 billion was spent on neurological services, representing 3.5% of the total NHS budget. Additionally, in 2013-14 local authorities spent £8.2 billion on social care services for adults with a physical disability (around one quarter of whom will have a LTNC).

#### What do we know?

Though there are many known forms of LTNC, there is no definitive list, and patient's experiences, disease course and needs vary significantly. Consequently it is difficult to understand the issue in terms of size, severity and trajectory. For brevity, LTNCs are broadly grouped into four categories:

- **Sudden-onset:** e.g. acquired brain or spinal cord injury
- **Intermittent and unpredictable:** e.g. epilepsy, headache or early multiple sclerosis (MS)
- **Progressive:** e.g. motor neurone disease (MND), Parkinson's disease (PD) or late stage MS
- **Stable:** e.g. post-polio syndrome or cerebral palsy in adults

This chapter will focus on the *five* LTNCs as shown in Table 1 below, but others not mentioned are equally significant. Importantly, service provision and commissioning considerations are often relevant across a range of LTNCs.

Notably not discussed here are dementia, migraine and stroke (please refer to relevant DNA chapters available elsewhere).

**Table 1: Long Term Neurological Conditions**

<b>LTNC</b>	<b>Description</b>
<b>Multiple Sclerosis (MS)</b>	<ul style="list-style-type: none"> <li>• A condition of the central nervous system whereby the coating around nerve fibres – think of the plastic insulation surrounding copper wire – is damaged</li> <li>• Around 100,000 people in the UK have MS, it is normally diagnosed between the ages of 20 and 40, and affects almost three times as many women as men</li> <li>• Relapses and remissions can lead to marked variation in the ability of the individual to undertake their normal activities and hence any care needed</li> </ul>
<b>Motor Neuron Disease (MND)</b>	<ul style="list-style-type: none"> <li>• A rare condition where motor neurons – responsible for movement – stop working</li> <li>• Around 5,000 adults in the UK have MND, it is normally diagnosed between 50 and 70, and men are affected twice as often as women</li> <li>• It leads to a progressive deterioration of muscle function, specifically seen as affecting the ability to walk, grip, speak, swallow and breath</li> </ul>
<b>Epilepsy</b>	<ul style="list-style-type: none"> <li>• The most prevalent LTNC, a condition of the brain causing repeated seizures</li> <li>• Around 500,000 adults in the UK have epilepsy, it is normally diagnosed between 18 and 65, and is more common in people with learning difficulties</li> <li>• Epilepsy is intermittent and unpredictable and here are over 40 sub-types</li> </ul>
<b>Parkinson's Disease (PD)</b>	<ul style="list-style-type: none"> <li>• A progressive condition in which the part of the brain that produces a chemical called dopamine becomes increasingly damaged</li> <li>• Around 127,000 adults in the UK have PD, it is normally diagnosed between 50 and 60, and it is slightly more common in men</li> <li>• Three main symptoms – abnormal slow movement, muscle stiffness, and an involuntary tremor – are confounded by tiredness, pain and depression</li> </ul>
<b>Acquired Brain Injury (ABI)</b>	<ul style="list-style-type: none"> <li>• An injury to the brain occurring after birth, with causes including falls, road accidents, tumours and stroke</li> <li>• Two age groups at higher risk are 0-4 year olds and 15 to 19 year olds</li> <li>• Wide variation in definition – can relate to traumatic injury, or can more broadly relate to any acquired brain injury including those arising through illness or disease.</li> </ul>

**What is the data telling us?**

Unfortunately, for reasons discussed later on, no single database on LTNC patient populations is currently available, not only in Berkshire, but nationally too. Indeed, epilepsy is the only neurological condition where there is local data available from the GP Quality and Outcomes Framework (QOF). As a result, two key sources of

information become local inferences based on national prevalence rates, and also Public Health England data based on coded secondary care activity. Below is an example of how this data can be applied to West Berkshire Local Authority – comprising Newbury and District CCG and North and West Reading CCG.

**Table 2: Inferred incidence/prevalence of various LTNCs using national data and local populations**

Population/LTNC		MS	MND	Epilepsy	PD	ABI
UK	Incidence (Per 100,000)	4	2	80	17	175
	Prevalence (Per 100,000)	144	7	500	200	1,200
West Berkshire (155,732)	Incidence	6	3	125	26	273
	Prevalence	224	11	779	311	1869

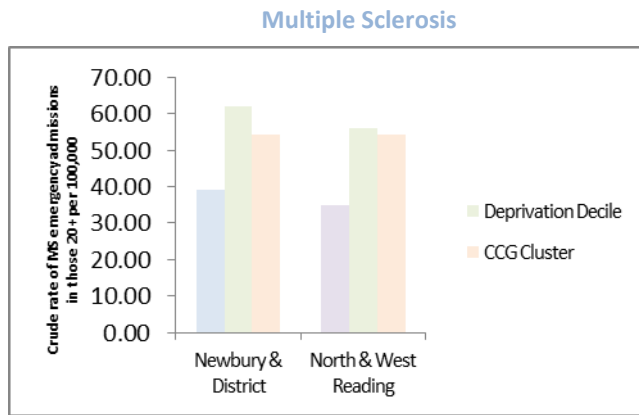
The data in Table 2 above applies national incidence/prevalence data to the defined CCG population of Newbury and District. National data was collected from the Neurological Alliance (*Neuro Numbers 2003*) and the North East Public Health Observatory Report (*NEPHO 2009*). A shortcoming of this approach is that different LTNCs have different epidemiological make-ups, and the taking total populations (rather than stratified ones) is rather crude. For example, rates of neurodegenerative LTNCs will be over-estimated in younger communities (and vice versa in older ones).

The following data comes from Public Health England’s Neurology Profiles, developed to support the work of the Neurology Intelligence Network (NIN) in providing health intelligence. Data are largely available for 2012/13 or 2013/14. Over the next few years, the intention is to co-ordinate further developments of these profiles to include a greater number of neurological conditions with relevant and detailed pathways, illustrating the actual and potential levels of demand for such services and the relative variation across England. Currently though we are unable to comment on trends of activity in any great detail (though as stated, LTNC spending is increasing). CCGs can be compared with other similar ones around the country, most usefully being grouped by deprivation decile and CCG cluster. In this example, Newbury and District falls into the ‘Least Deprived’ deprivation decile, and the ‘Less deprived areas with better health’ CCG cluster and North and West Reading falls into the ‘Second Least Deprived’ deprivation decile, and the ‘Less deprived areas with better health’ CCG cluster.

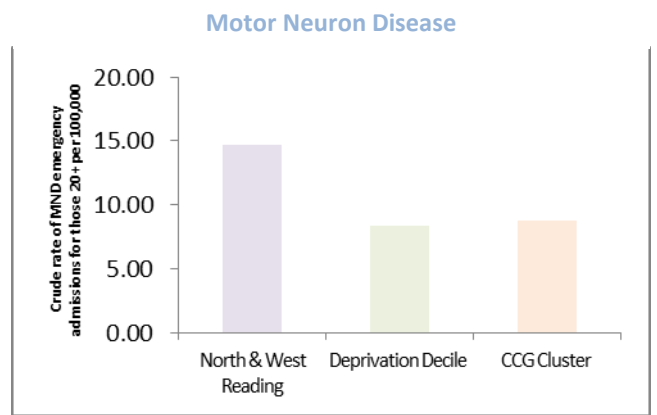
**Table 3: The DSR of admissions for various LTNCs - comparing CCG, Deprivation Decile and CCG cluster data**

Value	DSR of admissions (Mention) – Rate per 100,000					
	All Conditions	MS	MND	Epilepsy	PD	ABI
Newbury and District	2,167	39.2	-	294.8	120.9	38.1
Deprivation Decile	-	62.1	8.8	-	-	-
CCG Cluster	-	54.2	8.8	-	-	-
North and West Reading	2,145	34.8	14.7	222.9	144.6	42.2
Deprivation Decile	-	56.1	8.4	-	-	-
CCG Cluster	-	54.2	8.8	-	-	-
England	3,410	58.1	9.2	401.3	182.7	46.9

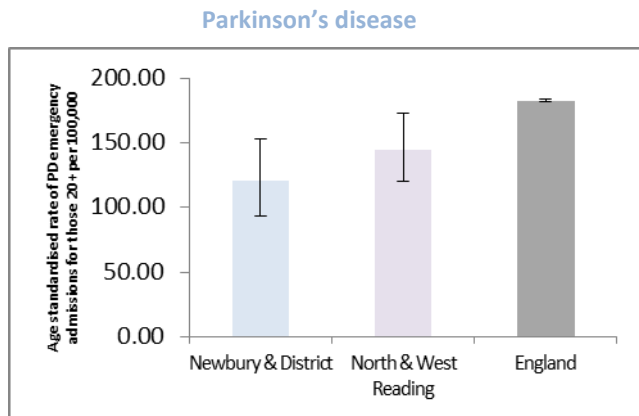
**Figure 1: Rate of emergency admissions to hospital for different medical conditions**



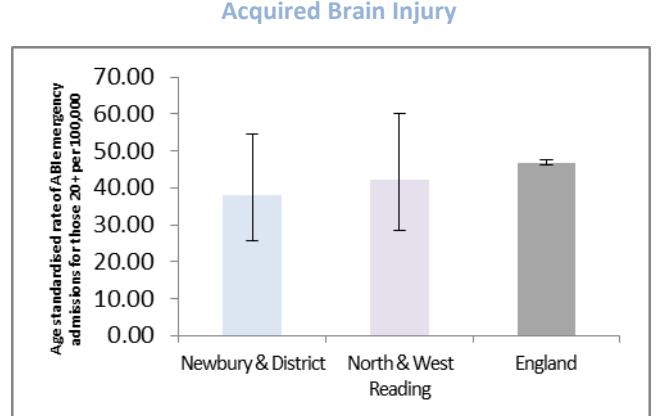
The crude rate of emergency admissions to hospital with a mention of Multiple Sclerosis and Inflammatory Disorders in the diagnosis code, per 100,000; 20+ population – comparing CCG value, Deprivation decile value and CCG cluster



The crude rate of emergency admissions to hospital with a mention of Motor Neurone Disease and Spinal Muscular Atrophy in the diagnosis code, per 100,000 20+ population – comparing CCG value, Deprivation decile value and CCG cluster value



Age standardised rate of emergency admissions to hospital with a mention of Parkinsonism and other Extrapyramidal Disorders/Tic Disorder in the diagnosis code, for those aged 20+ - comparing CCG value, and national data



Age standardised rate of emergency admissions to hospital with a mention of Traumatic Brain and Spine Injury in the diagnosis code, for those aged 20+ - comparing CCG value, and national data

**Multiple Sclerosis:** Around 31 people from Newbury and District CCG, and around 26 people from North and West Reading CCG with a diagnosis of MS are admitted to hospital each year. Both these counts are significantly lower than the national rate.

This tells us that either the prevalence of MS (or the rate in which it is recorded) is lower, or that MS is better managed in local primary care preventing the need for hospital admission.

**Motor Neuron Disease:** Around 11 people from North and West Reading CCG with a diagnosis of MND are admitted to hospital each year. This is statistically similar to the national rate.

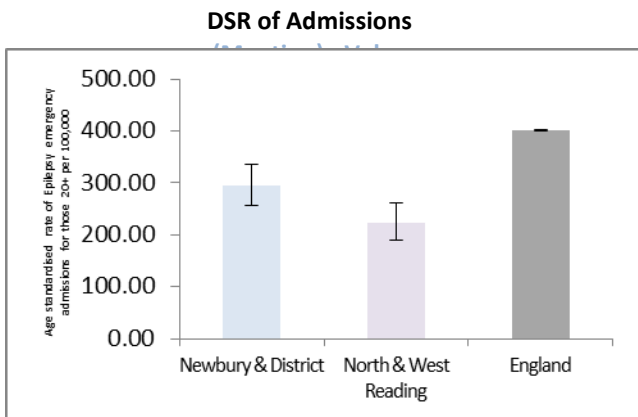
**Parkinson's Disease:** Around 86 people with a diagnosis of PD are admitted to hospital each year from Newbury and District CCG, and 96 from North and West Reading. This is significantly lower than the national rate.

**Acquired Brain Injury:** Around 30 people with a diagnosis of ABI are admitted to hospital each year from both CCGs, statistically similar to the national rate.

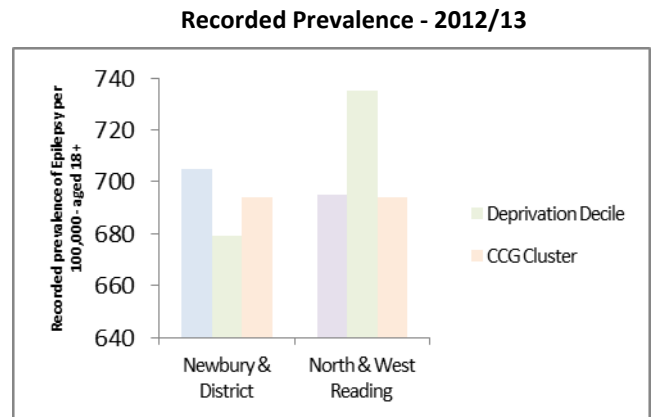
Epilepsy: Table 4 shows prevalence, morbidity and mortality data for people aged 18 years and over receiving drug treatment for epilepsy recorded on practice register - taken from *PHE - Neurology Profiles*

Value	Epilepsy		
	Recorded Prevalence (Crude Rate per 100,000)	Seizure Free (12 Months)	Mortality
Newbury and District	705	69.1%	1.55
Deprivation Decile	679	69.2%	N/A
CCG Cluster	694	66.0%	N/A
North and West Reading	695	70.5%	1.55
Deprivation Decile	735	66.7%	N/A
CCG Cluster	694	66.0%	N/A
England	780	61.6%	1.64

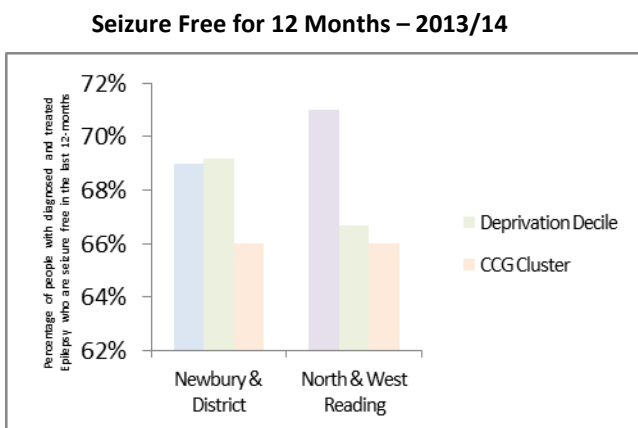
Figure 2: Data related to epilepsy



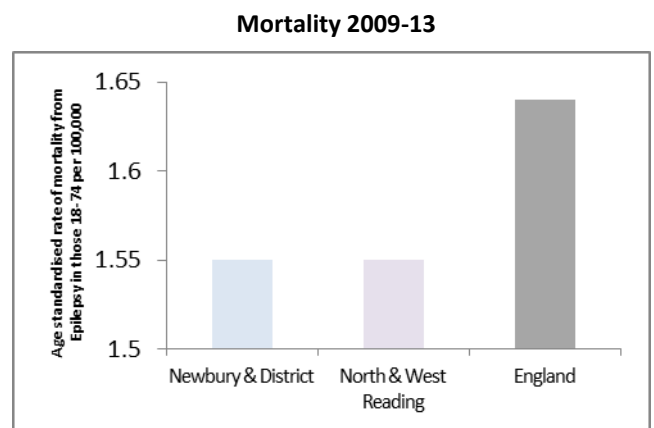
Age standardised rate of emergency admissions to hospital with a mention of Epilepsy in the diagnosis code, for those aged 20+ – comparing CCG value and national data



The number of people aged 18 years and over receiving drug treatment for epilepsy recorded on practice register (18+) – comparing CCG value, Deprivation value and CCG value



Proportion of individuals aged 18 years and over receiving drug treatment for epilepsy recorded on practice register who have been seizure free in the last 12-months – comparing CCG value, Deprivation value and CCG value



Age-standardised rate of mortality from epilepsy in persons 18-74 years old per 100,000 population – comparing CCG value and national data

In 2012/13, 632 people from Newbury and District CCG, and 590 registered with North and West Reading CCG were recorded as having a diagnosis of epilepsy.

- This suggests that approximately **705** and **695** people per 100,000 (respectively) have epilepsy, which is significantly lower than the recorded national rate of **780** people per 100,000. This does not necessarily mean that the prevalence is truly lower as people's diagnosis may not be recorded on the GP system.
- However, significantly fewer people from both CCGs are admitted to hospital with a (a mention of a) diagnosis of epilepsy which may support a lower prevalence or could indicate that epilepsy is better managed in primary care.
- Further evidence for the good management of epilepsy in primary care in both CCGs is provided by a significantly higher rate of people with diagnosed epilepsy being seizure free for a 12 month period than the national rate.

The rate of mortality from and underlying cause of epilepsy was however significantly higher than the national rate in both CCGs.

The numbers of people with LTNCs will grow sharply in the next two decades due to improved survival rates, improved general health care, increased longevity and improved diagnostic techniques (*Neurological Alliance*). This means effective implementation of care frameworks like the NSF will be more vital than ever. Just over ten years on however, determining what the NSF has achieved is very difficult, again not just locally to West Berkshire, but nationally too. Though clearly the numbers are encouraging for Newbury & District, and quantitatively would suggest above average LTNC care, epilepsy aside, we have no true indicators of the quality of this care or its adherence to the NSF. We thus have no clear pointers of where there are deficiencies in care or where improvements could be made. This is due to a number of factors:

- The Department of Health put in place no specific arrangements for monitoring how commissioners implemented the Framework
- There was no national baseline assessment of the cost, access to, and quality of, neurological services, when the Framework was introduced, and no national monitoring of its impact.
- The Department of Health has no way to measure the effect of the additional spending on services or patient outcomes

Data limitations aside, in their 2011 report, the National Audit Office (NAO), concluded that implementation of the NSF has generally been poor. They state that nationally, though people with LTNCs have had better access to health services, key indicators of quality have worsened. A summary of their key points is below:

- **Positively:** Waiting times for inpatient and outpatient neurology has decreased since 2007
  - Between 2004-05 and 2007-08, emergency bed days for people with LTNCs reduced by 12 per cent
  - The number of beneficial, elective, neurological operations being performed has also increased



- **However:** The number of adults with a physical disability receiving social services has fallen since 2005-06
  - The rate of emergency admissions to hospital involving patients with LTNCs has increased significantly
  - There is large variation in emergency admission rates between Primary Care Trusts
  - Emergency readmissions following an overnight stay increased

This would be in general agreement with other studies. [NEPHO](#) rated performance against the QRs for all Primary Care Trusts in its region as below 'the good-doing well' standard, and a report by Neurological Commissioning Support of 11 sites across England found that not one had fully met a single quality requirement.

**What are the key inequalities?** On a local level, this is again a very difficult question to answer. It is clear that certain CCGs will find providing good LTNC more challenging than others not just because of their care infrastructure, but due to the make-up of their community. Though neurological conditions affect all ages, there is increased prevalence of neurological conditions in older people as some conditions particularly affect older people and others are lifelong. Some conditions are more likely to affect a specific gender (e.g. MS is more likely to affect females) and others have proven or suspected patterns of genetic inheritance. Though this means each CCG will face unique challenges, the [NAO](#) identified a number of the more significant problems that exist in LTNC care on a national level.

- Significant variation in the quality and speed of the diagnosis process
- Poor quality information and advice given to patients and carers
- Fragments and poorly coordinated ongoing care
  - No personal care plan or single person coordinating care
  - A continual cycle of referral–discharge–referral; and poor coordination between health and social services
- Significant variation in the amount of services available to people with LTNCs
  - No universal level of expert services (including physiotherapy, occupational therapy, and speech and language therapy) or specialist nursing
- People with LTNCs receiving care from health professionals without neurological training when admitted to hospital as emergencies
- Little coordination between health and social services

### Recommendations for consideration

The following are therefore suggested as key recommendations to improve care for people with LTNC:

- Explore the possibility of setting up a primary/secondary care disease register. This would aid in:
  - Establishing the true prevalence of LTNCs

## West Berkshire Council Joint Strategic Needs Assessment

- Provide greater detail on LTNC patient service use
- Identify gaps in local service provision
- Help direct future spending
- Build the capacity of GPs to improve the care of people with LTNCs, including an information resource, and ideally, an identified local GP lead
- Ensure as much is done as possible to promote the migration of care from hospitals to the community.
  - Specialist nurses can help to improve patient care and the coordination of health and social services resulting in reduced hospital admissions
- Consider the opportunity for greater integration between health and social care, drawing on the highly-valued support and experience of voluntary organisations, charities and advocacy groups

### Other services and partner organisations

#### [West Berkshire Neurological Alliance](#)

An association of people and voluntary organisations with an interest in people with a neurological condition (including MS, Parkinson's Epilepsy, Stroke), based in and around Berkshire West. It links to the National Neurological Alliance.

Address: St Joseph's Church Hall Newbury, 105 London Road, Newbury, RG14 1JP

Telephone: 01635 202605

#### [West Berkshire Therapy Centre](#)

Specialised therapy gym for people with disabilities in west Berkshire and surrounding areas. Exercise is proven to help many conditions such as stroke, multiple sclerosis, parkinsons and arthritis. With specialist power assisted equipment, West Berkshire therapy centre allows for exercise in a safe, relaxed, accessible environment supervised by a qualified physiotherapist. Open Monday to Friday, 10am to 3pm, Saturday 10am to 4pm. Evening opening on Wednesday, 6pm to 8pm.

Address: The Frank Hutchings Hall, Bradley-Moore Square, Harts Hill Road, Thatcham, RG18 4QH

Telephone: 01635 864561

Email: [info@westberkshiretherapycentre.org.uk](mailto:info@westberkshiretherapycentre.org.uk)

### National and local strategies

The Department of Health's 2005 [National Service Framework \(NSF\) for Long-term \(Neurological\) Conditions](#) identified a range of problems faced by people with neurological conditions. It proposed a framework that stressed for best outcomes;



LTNC patients had to receive not only timely and accurate diagnoses, but early, person-centred, and life-long ongoing care. To achieve this, the NSF pointed to the need for integrated care and service provision including specialist *neurology*, *rehabilitation* and *palliative care* services. It proposed eleven quality requirements (QRs) and includes thorough explanations of how each should be delivered;

1. Person-centred - the 'core' requirement of all services
2. Early diagnosis and treatment
3. Those in hospital are treated in a timely manner by people with appropriate skills and facilities
4. Early and specialist rehabilitation
5. Community based rehabilitation and support
6. Vocational rehabilitation
7. Improving access to assistive technologies
8. Increasing access to palliative care
9. Providing personal care and support
10. Supporting families and carers
11. Meeting neurological needs when receiving treatment for other reasons in other health/social care settings

The framework allowed local commissioners to determine the speed of implementation according to local priorities, but the QRs were to be fully implemented by 2015. Building on this work, the [Guideline Development Group](#) (convened by the *National Council for Palliative Care* and the *British Society of Rehabilitation Medicine* in association with the *Clinical Standards Department of the Royal College of Physicians*) proposed further guidance for LTNC service provision, from diagnosis to death.

By design, the [NSF](#) did not have traditional government handles to support its implementation – including national monitoring, targets and ring-fenced funding. It reflected changes in the way that the NHS was managed, significantly devolving decision making in order to allow for the flexibility LTNC patients need.

What the [Guideline Development Group](#) added was a reminder that LTNC care must not only be adaptable, but also holistic. This means remembering that LTNC patients will have other health needs too. Just as is the case with other – perhaps better defined – long-term illness groups (e.g. diabetes), the LTNC diagnosis must not be forgotten. Acutely, this means that when they are being treated for other overlaid illness and problems, the LTNC is also still cared for. In the long-term, LTNC patients should have access to chronic disease services including, but not limited to, special nurse input and vaccination programmes.

#### **Further Guidance:**

- [National Institute of Clinical Evidence \(NICE\) Guidance – Multiple sclerosis: Management \(2014\)](#)
- [NICE Guidance – Motor neurone disease \(2016\)](#)
- [NICE Guidance – Epilepsy: Diagnosis and Management \(2012\)](#)
- [NICE Guidance – Parkinson's disease in over 20s: diagnosis and management \(2006\)](#)
- [British Society of Rehabilitation Medicine \(BSRM\) – LTNC \(2009\)](#)  
[BSRM – Neuro-rehabilitation services \(2015\)](#)

**Other chapters you might be interested in**

Mental Health in Adults  
Mental Health in Old Age  
Cardiovascular Disease

If you have any questions about this chapter, please contact Public Health and Wellbeing Team on [publichealthandwellbeing@westberks.gov.uk](mailto:publichealthandwellbeing@westberks.gov.uk) or 01635 503437