

## 7. ADULTS

### 7.9 Long Term Neurological Conditions

Neurological conditions result from damage to the brain, spinal column or nerves, caused by illness or injury. Many of the precise causes of neurological conditions are not yet known. Neurological conditions affect young and old, rich and poor, men and women and people from all cultures and ethnicities.

Some neurological conditions are life-long and people can experience onset at any time in their lives. Others, such as cerebral palsy, are present from birth. Some conditions, such as Duchenne Muscular Dystrophy, commonly appear in early childhood, some, such as Alzheimer's disease and Parkinson's disease affect mainly older people.

There are also conditions which have a sudden onset due to injury or illness, such as a head injury or stroke, or cancers of the brain and spine. Some neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, affect people mainly in adulthood and will cause deterioration over time, affecting a person's quality of life and their ability to live independently.

#### *7.9.1 The impact of long term neurological conditions*

People with long term neurological conditions face lifelong challenges and risks to their health, development and life opportunities (particularly in employment and living independently).

Most neurological conditions severely affect people's quality of life and many cause life-long disability. There are significant care requirements for many people with debilitating neurological conditions and many carers have to give up their own employment, in addition to the person with the condition being unable to continue to be economically active. This can have severe negative impacts on a family's economic situation.

Furthermore, neurological conditions are very poorly understood by the general public. Levels of awareness are low even about relatively common conditions, such as epilepsy.

#### *7.9.2 Numbers and prevalence*

Within Buckinghamshire it is estimated that around 13% of people have a neurological condition, approximately 67,600 people.

Within this cohort, 16,900 are under 18 years of age, 40,560 are of working age (19-64 years of age), and 10,140 are of retirement age (greater than 65 years of age)

Stroke, Alzheimer’s disease, Parkinson’s disease, Epilepsy, ABI and ME make up the vast majority of neurological disability in Buckinghamshire (Combined >90%).

A further consideration of the factors influencing prevalence and number of people with profound and complex long term long term neurological conditions in Buckinghamshire are the presence of both the National Society of Epilepsy in Chalfont St Peter and the National Spinal Injury Unit in Stoke Mandeville hospital.

### 7.9.3 Trends

Using national prevalence information it is possible to estimate the number of people with a long term neurological conditions in Buckinghamshire, as shown in the following table:

**Table 1 Estimated number of people in Buckinghamshire with a long term neurological condition**

Common Neurological Conditions	National Prevalence Rate per 100,000	Estimated Numbers for Buckinghamshire based on national prevalence 2015	Estimated Numbers for Buckinghamshire based on national prevalence 2030
Parkinson’s Disease	200	1,040	1,110
Multiple Sclerosis	100-120	520-624	555 - 666
Motor Neurone Disease	7	36	39
Huntington’s Disease	13.5	70	78
Muscular Dystrophy	50	260	278
Cerebral Palsy	186	967	1,033
Spina Bifida and congenital hydrocephalus	24	125	133
Spinal Cord Injury	50	260	278
Traumatic Brain Injury leading to long term problems	1200	6,240	6,662
Stroke	500	2,600	2,776
Epilepsy	430-1000	2,236-5,200	2,387 - 5,552

It is expected that the prevalence figures for LTNCs will rise sharply following 2030 to coincide with a dramatic shift in the aging population of Buckinghamshire. This rise is expected to occur to a greater degree within the Aylesbury Vale CCG area where population growth is set to rise rapidly due to expansion of settlements in and around the Aylesbury area. Other influencing factors include improved survival rates, improved general health care and infection control, increased longevity and improved diagnostic techniques.

#### *7.9.4 Inequalities*

A review of death certification by the National End of Life Care Intelligence Network reported that the place in which a person dies varies largely on type of neurological condition he or she has:

- About half of people with a neurological condition die in hospital. This compares with national average of 58% of people without neurological conditions dying in hospital.
- 25% of Motor neurone disease / Multiple sclerosis deaths occurred at home, compared with 9% of people with PD who die at home
- One third of Parkinson's disease / Huntington's disease deaths occur in a nursing home

This report was written in response to The [National Service Framework for Long-Term Conditions](#) (DH, 2005), outcome 9 concerning palliative care, and stated that:

“People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care”

It is clear from the evidence that steps must be taken to ensure that as far as possible, people are given choice and control over where they chose to spend the end of their lives.

#### *7.9.5 Demand*

Neurological conditions are the most common cause of serious disability and have a major, but often unrecognised, impact on health and social services.

Each year 600,000 people (1% of the UK population) are newly diagnosed with a neurological condition. This equates to around 5,200 people within Buckinghamshire, of which over 4,500 will of working age and above.

10% of visits to Accident and Emergency Departments are for a neurological problem

17% of GP consultations are for neurological symptoms

19% of hospital admissions are for a neurological problem requiring treatment from a neurologist or neurosurgeon

Approximately one third of disabled people living in residential care have a neurological condition. Further to this cohort, there are an estimated 4,420 people in Buckinghamshire with a carers responsibility for somebody that has a neurological condition.

#### *7.9.6 Horizon scanning*

Early summer 2016, will see the implementation of a new health and social care strategy on behalf of the CCGs and Buckinghamshire County Council that will refocus the provision of services offered to disabled people in Buckinghamshire including those with long term neurological conditions. This will provide an opportunity for improved coordination between health and social care and the network of neurological conditions providers. Continued operation of both inpatient and outpatient services in Buckinghamshire alongside condition specific support will be essential in maintaining the high quality of neurological services in Buckinghamshire.

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