

## *Help for those who want to stay in work, support for those who can't*

**A briefing note on welfare reform for MPs and Peers**

**The Neurological Alliance<sup>i</sup>, November 2008**

### **What people with a neurological condition need from welfare reform**

- **Neurological conditions affect 10 million people**

One in six people in the UK live with a neurological condition. Most of us have colleagues with a neurological condition.

- **Neurological conditions affect people of working age**

Neurological conditions do not only affect older people. A quarter of the 110,000 people who have a stroke in England every year are under 65 and the average age of diagnosis of MS is 35. For many people with a neurological condition, a main objective is getting back to work or staying in work – for financial reasons and to rebuild their confidence and regain their independence.

- **People with neurological conditions currently experience difficulty finding work, staying in employment as their condition progresses and receiving the support they need if they have to leave employment**

The forthcoming welfare reforms can really make a difference if they allow for flexible, personalised support.

### **Finding employment and staying employed**

Many people with a neurological condition struggle to gain employment:

- **50% of people with muscle disease of working age are not in employment<sup>ii</sup>**
- **14% of people with epilepsy are actively looking for work compared to an unemployment rate of 8.8 % for all disabled people<sup>iii</sup>**

A high proportion of those who want to stay in employment, leave because of factors associated with their condition:

- **up to 80% of people with MS will be unemployed within 10 years of their diagnosis<sup>iv</sup>**
- **a third of migraine sufferers face difficulties or discrimination at work because of their condition<sup>v</sup>**

Reduced earnings combine with the additional financial costs of living with a difficult condition. These impact the most on individuals and their families, but affect us all.

- **The average annual cost to the economy of the unemployment, early retirement and reduced working hours of one working age person with MS is £8480<sup>vi</sup>**
- **An estimated 25 million days are lost from work or school because of migraine each year<sup>vii</sup>**

Help for people with a neurological condition is more complex than for many other groups. Symptoms can fluctuate unpredictably and are often 'hidden' – things like continence problems or depression. Fatigue is often confused with laziness.<sup>viii</sup> Stigma remains an issue: people often play down their condition, afraid to be seen as unreliable or lose their job.

New welfare reforms should provide for flexible, personalised support, from people who really understand neurological conditions. Prospective and current employers and people with neurological conditions need this support.

### Leaving employment when necessary

Some neurological conditions like Motor Neurone Disease, Progressive Supranuclear Palsy or severe head injury are so devastating that people will not be in a position to stay in work. Those caring for someone with a severe neurological disease may also be unable to work.

When a rapidly progressive neurological condition is diagnosed, people should be supported to leave employment when they wish. They need to receive the benefits they are entitled to as quickly as possible so they can maximise their quality of life for the time they have left.

All carers of people with a neurological condition need support and consistency.

Reforms should not penalize those with severe neurological conditions, and their carers, who need to leave employment

**Contact Tahani Saridar** at the Neurological Alliance for more information.  
Telephone: 0207 5661540; Email: tahani.saridar@neural.org.uk

<sup>i</sup> The Neurological Alliance is the umbrella group of the third sector organisations supporting people with neurological conditions. Find out more at [www.neural.org.uk](http://www.neural.org.uk)

<sup>ii</sup> State of the Nation, a national patient survey of almost 1000 patients and families by the Muscular Dystrophy Campaign, September 2008

<sup>iii</sup> Office of National Statistics, Economic Activity of Working Age People with Disabilities. 2006

<sup>iv</sup> Sweetland, J; Riazi, A; Cano, S; Playford, D; *Vocational rehabilitation services for people with multiple sclerosis: what patients want from clinicians and employers*, Multiple Sclerosis, 2007; 13; 1183

<sup>v</sup> The Migraine Trust, 2004

<sup>vi</sup> McCrone, P; Heslin, M; Knapp, M; Bull, P; Thompson, A; *Multiple Sclerosis in the UK: Service Use, Costs, Quality of Life and Disability*, PharmacoEconomics, 2008, vol. 26, issue 10, pages 847-860

<sup>vii</sup> Steiner et al, Cephalalgia, 2003

<sup>viii</sup> Smith, M; Arnett, P; *Factors related to employment status changes in individuals with multiple sclerosis*, Multiple Sclerosis, Oct 2005; vol. 11: pp. 602 – 609