10 July 2013

Multiple Sclerosis Society

SELF-DIRECTED SUPPORT: CONSULTATION ON DRAFT STATUTORY GUIDANCE ON CARE AND SUPPORT

About Multiple Sclerosis (MS)

Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults. Scotland is reported to have the highest incidence of MS in the world, with over 10,500 people living with MS in Scotland today.

For most people, MS is characterised by relapses followed by periods of remission, while for others it follows a progressive pattern. Even those with relapsing-remitting MS typically experience increasing disability and morbidity. Overall, MS symptoms include loss of mobility, pain, fatigue, visual impairment, numbness, loss of balance, depression and cognitive problems and it can lead to severe and permanent disability.

About the MS Society

The MS Society is the leading UK charity for people living with MS, with approximately 4,000 members in Scotland. We are fighting to improve treatment and care to help people with MS take control of their lives.

We are working with partners around the world to fund research that we believe will beat MS for good. While we work towards a cure, we continue to fight the corner for people affected by MS – demanding the highest quality care and support, wherever they live.

Consultation response

The MS Society welcomes the opportunity to respond to this consultation. Many people with MS rely on formal and unpaid care and support to help retain their independence. While for some people the experience is a positive one, our evidence suggests that there is a postcode lottery between areas in Scotland with respect to the quality of care provided and the information and support given to people about their options for self-directing their own support.

We are pleased to see the proposed legislative changes and statutory guidance to improve choices for how an individual wishes to manage their care.

The MS Society is a member of the ALLIANCE and supports the comments and suggestions contained in the ALLIANCE's response to this consultation.

In addition we wish to stress the following points:

1. Individuals need to be given open and unbiased information about the different options and their implications, and they need to be given sufficient time to consider which option to select. The guidance should specify that individuals are given a

written record of the discussion and offered time to reflect on this after the assessment meeting in order to make an informed choice.

2. One of the main concerns raised to the MS Society is around being able to manage direct payments, with some people concerned about the legal and administrative implications of becoming an employer. In order to enable individuals to make an informed choice and be supported in that choice, the guidance should state that as part of those discussions the individual is given information on where to get further support in setting up and managing a direct payment.

3. MS is a fluctuating condition with periods of more active disease and changing disability. We believe that the guidance needs to take greater account of people with fluctuating conditions to ensure that the assessment process is able to reflect the individual’s changing condition and needs.

Contact details

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