motor neurone disease
association
cymdeithas
clefyd motor niwron

Consultation response: Social Services and Well-being (Wales) Act 2014 Amendments to Regulations in relation to Part 4 of the Act (direct payments and choice of accommodation) and Part 5 of the Act (charging and financial assessment)

Introduction

i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

iii. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

iv. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales.

v. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

Response

This response relates to questions 1, 3 and 4of the consultation. The Association has no comments to make on question 2.

Question 1. Are there any consequences of the decision to increase the capital limit that you would wish to make Welsh Government aware of?

The MND Association welcomes the Welsh Government's proposal to uplift the capital limit used for charging for residential care from £24,000 to £50,000. It is positive that people requiring residential care will be able to retain a larger amount of their capital without having to use it to pay for care. However, this proposal must be taken alongside the proposal to increase maximum weekly care charges (discussed in our response to Question 3). The welcome increase in the level of capital that users of residential care can retain is offset by the proposal to increase the maximum charge. As a result the proposals represent a missed opportunity to move towards a sustainable funding settlement that reduces the financial burden on individuals and families by pooling the social care risk more widely through greater use of tax funding.

The Association is also concerned about the lack of detail provided on the timeline for the ‘phased approach’ to implementing the higher capital limit following the first increase to £30,000 in April 2017. No detail on the timeline beyond this date is given, apart from the vague assertion that “further increases will be introduced in later years”. The suggestion that the delay will be used to monitor the impact of increasing the capital allowance appears to allow for the possibility that the increase to a £50,000 cap could be postponed or cancelled, depending on the results of the monitoring process. Rather than allow this uncertainty to affect people in receipt of care and their families, the Welsh Government should set out a clear timeline for raising the capital limit. Any monitoring and evaluation periods should be set out within this timeline and should include a clear end point, after which full implementation can begin.

Finally, the Welsh Government should give close consideration to how it will communicate any changes to the charging regimen to the individuals and families concerned. The MND Association’s 2016 Improving Care Survey found that of 548 people living with MND, only 38% agreed with the statement that “the cost of my social care, including how much I have to contribute, has been explained to me in a way that I understand”.[i] It is essential that any measures that would increase the financial burden of care on individuals be clearly communicated to all recipients of care.

Question 3. Do you agree that this increase strikes the right balance between helping to raise additional income for local authorities (to help meet increasing cost pressures in providing care and ensuring the quality of the care provided) and being fair and affordable for people in receipt of non-residential care?

The Association believes that the proposed increase to the maximum weekly charge to social care is the wrong way to address the funding pressures currently affecting the social care system. The higher charge of £70 per week will increase the financial impact experienced by individuals with social care needs, and the Association notes with concern the further proposal expectation that the charge will reach £100 per week by the end of this Welsh Government’s term in 2021-22. This would therefore represent a 66% increase over five years from the current maximum charge of £60 per week.

The Association recognises the financial pressure that the social care system is currently under. However, the burden of relieving this pressure should not fall primarily on the people living with disabilities and long-term health conditions who rely on social care services. The Welsh Government should instead consider solutions that would pool the burden of social care risk more evenly across the population, including a greater role for tax funding.

Question 4. What impacts do you think the proposals in this consultation will have on groups with protected characteristics? Please describe them.

The increased maximum weekly charge for social care will primarily impact on the individuals in receipt of social care services and their families. Many of these individuals meet the definition of disability as defined by the Equality Act 2010, which defines a disabled person as someone with “a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on [his or her] ability to do normal daily activities.” Consequently the Welsh Government should consider alternative funding solutions that share the burden of social care funding more equally across society, rather than increasing the burden on the people most directly affected by the impact of disability and long-term ill-health. This should include consideration of a greater role for tax funding to support the delivery of a financially sustainable social care system.

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[i] https://www.mndassociation.org/wp-content/uploads/improving-mnd-care-survey-published-on-website-120716.pdf