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28th March 2013

Dear Sir/Madam

Thank you for your letter requesting our views on the petition received from Helen Jones. Alzheimer's Society strongly supports the recommendations within Helen Jones' petition. People with dementia have experienced particular difficulties trying to obtain NHS Continuing Care funding (NHS CC). The artificial distinction made between care provided by the NHS (free of charge) and social care arranged by social services (means tested) is at the heart of the problem. We would like to submit the following comments:

1. "Bring to an end the discrimination against dementia sufferers in Wales who apply for NHS Continuing Care Funding, by allowing for the cognition category of need (known as the domain) to go up to the level Severe in the Welsh version of Decision Support Tool. This would bring it in line with the English version."

The purpose of an NHS Continuing Care assessment is to determine whether a person has a 'primary health need' and therefore whether the NHS is legally obliged to fund care to meet that need. The decision support tool supports this assessment and should ensure consistent decision making.

A person has a primary health need if the nursing or health services they require are "more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for a person's means, under a duty to provide; or "Of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide."

A 2010 WAG circular on CHC urges the following to be key factors in determining whether care is beyond the power of a local authority to provide: **nature** (physical / mental / psychological), **intensity** (extent and severity), **complexity** and **unpredictability** of the condition.¹

The Decision Support Tool portrays need are based on 12 care domains which are each subdivided into statements of need which represent: no needs, low, moderate, high severe or priority levels of need. Not all of the care domains include all these levels.

A multidisciplinary team carrying out the assessment should consider which description of need for each domain best represents the individual. Once the DST is completed, the MDT

should consider the overall level of need and the interaction between needs in different care domains, bearing in mind the four factors described above. It is the totality of a person's day to day care needs that determine whether they have a primary health need.

In the Welsh DST the highest rating in the cognition domain is 'high'. It does not include a severe level. This domain is problematic for two reasons.

Firstly, Alzheimer's Society believes that the descriptive terms used within the 'high' band do not capture the severity of need or level of risk experienced by a person with very severe dementia. For example a person who scores 'high' is judged to have "awareness of only a limited range of needs and basic risks." While everyone experiences dementia differently, a person who is very severely cognitively impaired may have no awareness at all of need and basic risks. They may be completely incapacitated. This is not captured within the descriptive terms within the 'high' band. Because the Welsh DST is not able to capture the full range of the need of someone with dementia we believe it cannot effectively inform NHS CC assessments.

Secondly, having only a 'high' band within the cognition domain suggests that cognitive impairment does not contribute significantly to a person's overall health need. This tips the balance within the Welsh DST towards the physical aspects of healthcare. A very high level of impairment of the mental processes of the brain, including thinking, judgement, etc., clearly presents a severe and complex need in itself. In addition, the interaction of severe cognitive impairment with other health needs (as commonly experienced by the elderly) will often result in a very challenging set of needs. However, with only 'high' level of needs available within the domain for the assessor to consider makes it more difficult for someone with a primary health need due to dementia to obtain NHS CC funding than it would for someone with a health need arising from a physical condition.

In contrast the English Decision Support Tool contains a 'severe' band within the cognition domain. The descriptive terms better capture the extent of cognitive impairment in an individual with severe dementia:

"The individual is unable to assess basic risks even with supervision, prompting or assistance, and is dependent on others to anticipate their basic needs and to protect them from harm, neglect or health deterioration."

The English DST therefore is much better able to capture the needs of a person with dementia and provides a better balance between mental and physical health needs. It is much better placed to assist a fair and effective assessment. We fear that in Wales people with very severe dementia are denied the funding that is their right and local authorities are providing care that is beyond their power to provide because the tool is not able to assess their level of need.

Alzheimer's Society urges the Welsh Assembly Government to end the discrimination faced by people with dementia in Wales by including a 'severe' band within the cognition domain.

2. Direct Local Health Boards to implement the National Framework for N.H.S continuing Care Funding correctly in terms of patient eligibility and without regard to budgetary constraints.

The Alzheimer's Society NHS Continuing Care Volunteer Support Group offers direct support to people who wish to appeal when someone with dementia has been turned down for NHS Continuing Care funding. The volunteers have personal experience of appealing an NHS Continuing Healthcare cases for their own family members and are passionate about helping others that are in similar situations to them.

Through their work the Volunteer Support Group collect evidence of problems with the implementation of NHS Continuing Care policy within Wales. It is their experience that it is becoming increasingly difficult to obtain NHS Continuing Care funding and thresholds for eligibility are being gradually raised without statutory authority, i.e. the benchmark standard provided by the Coughlan case is being ignored. There are also frequent problems with the implementation of the Framework, for example a failure to provide family members with advice in relation to the process as required by the Framework and as a consequence they are unable to make a meaningful contribution to the assessment process. The Welsh Ombudsman has noted cases where no reasons were provided to families, and no minutes were available to document the reasoning behind the decisions of LHB panels.

We recognise the current financial situation, but it is important that individuals are awarded the funding and support that is their right. The appeal process is incredibly complex and stressful, and can be very emotionally challenging, usually for people who also have the substantial burden of caring for someone in the later states of dementia. NHS Continuing Care assessments that follow the Framework correctly would help to avoid this stress and also the need to direct resources towards appeals.

Please do not hesitate to contact me if you would like any further information. I look forward to learning the outcome of the Committee's discussions.

Yours sincerely

Samantha Sharp
Senior Policy Officer