mnda
motor neurone disease
association
cymdeithas
clefyd motor niwron

Response to the consultation on revising the framework for NHS Continuing Healthcare

Introduction

i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales. Half of people with the disease die within 14 months of diagnosis. There is no cure.

ii. The MND Association is the only national organisation supporting people affected by MND in Wales, England 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.

iii. While we welcome the intent behind the proposed changes, we have significant reservations over the planned approach to implementation. This response answers questions 4, 5 and 7 in the consultation paper.

Question 4. Are the proposed Assessment Process, Checklist/Screening Tool and Decision Support Tool, fit for purpose?
and
Question 5. Do you think it is helpful to move from the existing Welsh Decision Support Tool (DST) within the existing Framework, to the new proposed version, which will be based on the English DST?

i. We will address these two questions together, and make three key recommendations in response.

1. The use of DSTs tends to supplant clinical judgement and produce low quality, inaccurate assessments; consideration should be given to abandoning the DST approach in favour of holistic assessment by expert healthcare professionals
2. It should not be possible to withdraw an award from a person with progressive physical need, and accordingly some account of diagnosis must be taken
3. Assessment must be anticipatory.

ii. We will explore each of these recommendations in turn.

1. **The use of DSTs tends to supplant clinical judgement and produce low quality, inaccurate assessments; consideration should be given to abandoning the DST approach in favour of holistic assessment by expert healthcare professionals**

i. We advise that the English DST has proved highly problematic, and recommend strongly against its adoption in Wales. NHS England is currently developing a new operating model for CHC: as part of this process we will be pushing for the problems with CHC in England, chief among them the DST, to be remedied, and we fully expect many other patient groups to be making similar representations. We urge the Welsh Government not to import mistakes from England.

ii. Furthermore, we are unconvinced that the approach of using a crude support tool is beneficial for patients. As the consultation paper points out (paragraph 40), the DST is not intended to provide a strict determination; rather, "[t]he focus must be on a rounded and holistic assessment of the individual rather than DST scores." We know that in practice this does not happen, and assessment is conducted with often strict and unthinking adherence to the DST, and the suspension of professional judgement about the patient's actual needs. We would support a move away from the DST model to reliance on holistic professional assessment, which would produce higher quality and therefore more equitable decision-making.

iii. A specific feature of the DST in England is a tendency to result in well-managed needs being considered to be an absence of need, and for CHC to be refused, or even withdrawn, even though an accurate assessment of need would have resulted in an award. For instance, if a person's skin care or continence needs are well met, the person may be assessed as having no need – even though, in cases of reassessment, it may only be through the provision of CHC that the need is being managed. The draft framework explicitly states that well-managed need should not be considered an absence of need (para 6.5), but unfortunately so too does its English equivalent. We therefore see no reason to believe that the introduction of an England-style DST in Wales will not introduce similar errors into CHC assessments.

2. **It should not be possible to withdraw an award from a person with progressive physical need, and accordingly some account of diagnosis must be taken**

i. To a person with MND, who is quickly becoming physically disabled and who knows that they are terminally ill, the prospect of being re-assessed for any aspect of their care and support, and being told that it could be withdrawn, can be an enormous cause of anxiety and distress. We have seen cases of CHC being withdrawn from people with MND, even though the condition is progressive and it is a medical impossibility for their physical needs to have decreased.

ii. We strongly suggest that for selected serious diagnoses involving irreversible physical progression, CHC awards should be designated as lifetime awards. This should not preclude reviews to consider whether specific aspects of care need to be adjusted to meet changing need, but it should not be possible to revoke the award altogether.

iii. While it is right to consider the individual's needs in a holistic sense and not look only at their diagnosis, it is perverse not to take at least some account of a diagnosis as serious and as devastating as MND; failure to understand and take into account the implications of such a diagnosis immediately place the individual at risk of inadequate care provision.

iv. We acknowledge that there are some progressive conditions whose behavioural effects can mean that need does decrease later in an illness; specifically, some forms of dementia can entail difficult behaviour early in progression but more manageable behaviour, and therefore genuinely lower need, at a later stage. Physical symptoms do not abate in this way, however, and account should be taken of serious diagnoses involving progressive physical need.

v. It would still be acceptable and desirable for packages to be reviewed in order to ensure the care delivered is meeting need; but the prospect of the funding being withdrawn, with all the attendant anxiety this causes people, should not be on the table.

vi. We therefore strongly recommend that the fourth proposed principle in the framework be changed. It currently reads "Focus on need not diagnosis"; we suggest "understand diagnosis, focus on need" or a similar alternative to guide professionals to ensure they understand the implications of the patient's illness. We strongly recommend against any wording that appears to encourage health and social care professionals to disregard diagnosis when considering a person's needs. We regard the other principles as sound.

3. Assessment should be anticipatory

i. We believe that section 6.13, addressing deterioration, does not go far enough. MND is rapidly progressive and unpredictable: changes to a person's needs can occur rapidly and with little forewarning with regards to their timing. It can, however, be anticipated that such deterioration will occur. The framework must make explicit provision for anticipatory assessment, such that in cases where a person with a rapidly progressive condition may fall slightly short of meriting a CHC award on paper, an award is nonetheless made on the basis that it will soon be necessary, and slightly early provision is preferable to a long delay waiting for another assessment when the person's needs change again. This will require some account to be taken of diagnosis, and will not be possible if the health and social care professionals in the MDT are reliant on the tick-box approach of the DST.

Question 7. In your view does the proposed Framework link effectively with other health and social services policy and guidance? Are there any other linkages to good guidance or innovative practice we should be making?

i. It is a longstanding problem that the non-availability of direct payments for CHC can lead people with MND who have individually tailored social care support delivered through this route to resist moving to CHC for as long as possible; for although it would increase the amount of care available to them, it would undo the bespoke construction of their existing support arrangements. While the framework acknowledges this issue (paras 8.46-8.48), we urge the Welsh Government to go further in guaranteeing input from service users to their CHC packages, with a greater level of personalisation of care.

ii. More fundamentally, the proposed reforms will not address the underlying disjoin between health and social care, which often results in decisions being taken on the basis of financial considerations, with each side being motivated to shunt costs to the other whenever possible. This is a barrier to providing care that meets the needs of patients and service users, and it can be highly distressing to people with MND and their families to see that their future care is being determined by arguments about money. The Welsh Government should be more determined and aggressive in pursuing solutions to this problem such as pooled budgets and other payment models.

iii. We would also like to see more detail about how equipment provision and CHC will interact in Wales. A person with MND may need a substantial range of specialist equipment, including one or more wheelchairs, a riser-recliner chair, communication aids, environmental controls and other items. We are somewhat concerned that there is not more detail on equipment provision in this framework, particularly considering it was not included in the delivery plan for neurology either.

iv. Finally, we recommend that the Government ensures that a full range of data is gathered about CHC, beyond simple information about the number and amount of awards made. Data should also cover numbers of assessments, reassessments, withdrawals of awards and appeals against decisions. Diagnosis and primary health need should both also be recorded.

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