motor neurone disease
association
cymdeithas
clefyd motor niwron

Response to the draft respiratory delivery plan for NHS Wales

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 of 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. We are very concerned at the absence of neurological conditions within the respiratory delivery plan as currently drafted. The plan takes a narrow view of respiratory health, clearly seeing it as essentially a matter of "lung disease". This represents a failure to acknowledge the full range of causes of respiratory problems, including neurological conditions such as MND, that causes us significant concern.

iv. We strongly recommend that neurological conditions are acknowledged within the plan and measures included to take account of the needs of people living with them. Many of these needs are already addressed, albeit indirectly, within the proposed plan; all that is needed in many cases is to recognise neurological conditions within the existing proposals. Alternatively respiratory care for people with neurological conditions could be addressed in a separate section of the plan but, while this would be acceptable, we would prefer to see neurology made integral to the plan's main provisions.

v. The Welsh Government is also currently consulting on a draft delivery plan for neurology: neither of these two plans currently addresses the respiratory needs of people with neurological conditions. We recommend that these needs should be recognised in the respiratory delivery plan if the Government does not wish to allow people with neurological conditions to fall – entirely needlessly – into gaps between services.

Respiratory support for people with MND in Wales

i. This section of the response gives a brief overview of respiratory support for people with MND in Wales, and is followed by responses to specific sections of the proposed delivery plan, with relevant sections reproduced in *italics*.

ii. In our paper 'Meeting the needs of people with MND in Wales: recommendations for the Welsh Government' (2012) we identified that access to respiratory support for people with MND varied between local health boards (LHBs). We believe this is still the case, although the Disease Specific Advisory Group of the North Wales Neurosciences Network is succeeding in driving improvements across the north – the delivery plan should recognise this work and ensure that it is incorporated into its proposals.

iii. We know that there is much work to do elsewhere however, with a lack of a clear respiratory pathway in Powys, and a need to formalise the pathways across Wales.

iv. Non-invasive ventilation (NIV) remains a relatively novel means of support for people with MND, having been recommended by a short clinical guideline from the National Institute for Health and Care Excellence (NICE) in 2010. Its use should be promoted in the delivery plan – points at which this could be done will be identified below.

6. WHAT DO WE WANT TO ACHIEVE?

At-risk groups who present with persistent respiratory symptoms receive appropriate diagnostic tests and are signposted to support and treatment as required

i. Presumably this description would cover people with neurological conditions – and if so, it should state as much explicitly.

ii. We are concerned, however, that this description is not adequate: the phrase "persistent respiratory symptoms" suggests that only people who have already developed symptoms are covered by it. People with neurological conditions that are known to produce respiratory symptoms, such as MND, should be having their respiratory function monitored on a regular basis, even while their respiratory function might still seem unimpaired. This is in line with the NICE guideline on NIV, which the delivery plan should not overlook.

6.3 Delivering fast, effective care

Conditions affecting respiratory health are numerous, varied and often complex, requiring a multidisciplinary approach to management offered by many different providers. We have identified five lung conditions where improvements in the delivery of effective care can result in high impact changes to the people of Wales's respiratory health. These are Asthma, Chronic Obstructive Pulmonary Disease (COPD) and Bronchiectasis,

Interstitial Lung Disease, Sleep-Disordered Breathing and Acute Respiratory Care.

Sleep Disordered Breathing

The obstructive sleep apnoea-hypopnoea syndrome (OSAHS) is common, affecting around 4-6% of middle-aged adults (2). If left untreated, OSAHS causes daytime sleepiness, impaired vigilance and cognitive functioning, reduced quality of life and is associated with an increased risk of road traffic accidents. The latter risk is particularly important for professional drivers of HGVs and public transport vehicles. Severe OSAHS in particular, is independently associated with causing or worsening many other chronic cardiovascular diseases such as stroke, hypertension and death. The established treatment for moderate-severe OSAHS, which is cost-effective, is overnight home ventilation. For less severe forms of OSAHS and other sleep-disordered breathing conditions other methods of addressing poor sleep hygiene are often successful.

The assessment and management of sleep-disordered breathing conditions requires an all-Wales network of adequately staffed and equipped sleep laboratories to undertake assessment, overnight sleep studies and the provision of the ventilators for those with moderate/severe OSAHS. There should also be hospitals identified as providing more specialised sleep investigations for those with complex sleep-disordered conditions (Lewis and Benjamin, 2010).

i. Sleep-disordered breathing is a symptom of MND, and is addressed by NIV. The above description gives a confusing message about whether or not NIV for people with MND is intended to be within scope of treatment provided as a result of the delivery plan. The description given of sleep-disordered breathing does not correspond with how it occurs in MND, but its effects are very similar to those described in relation to OSAHS.

ii. It should be clarified that NIV should be made available to people with MND in Wales whose needs would be met by it. In North Wales this has been achieved by making NIV available to people with MND through the existing sleep service, but it must be made clear that sleep services throughout Wales have responsibilities towards people with MND. Some sleep services currently deny that they have any responsibility for MND patients – this should not continue, and if the root cause of this reluctance is concern over staffing levels, appropriate staff should be put in place (funded if necessary by savings in emergency admissions – see below).

Acute respiratory illness

People can develop one of many acute respiratory illnesses with or without pre-existing lung disease. Such illnesses are common and include community-acquired pneumonia, acute exacerbations of COPD, asthma attacks and a number of less common conditions, which together represent a major demand in primary care in the first instance. The ensuing hospital admissions from what is a large and challenging respiratory population at risk,

represent significant pressures and demands on resources. There is the potential to develop a variety of admission-avoidance initiatives aimed at treating people successfully in the community and at home. Moreover, there are various early assessment and discharge schemes that can be utilised to reduce delays in effective treatment and subsequently the length of hospital stay, thus optimising the use of hospital beds and reducing the considerable costs of such conditions.

i. This passage illustrates the importance or recognising neurological conditions such as MND throughout the strategy: timely and anticipatory assessment of people with MND for respiratory problems, and the timely provision of treatment and support, can save significant costs arising from unplanned admissions as well as offering a much better experience of care.

ii. Provision of NIV can cost in the order of £5-6,000 plus training and staff time, whereas a stay of several months in intensive care following a respiratory crisis would cost hundreds of thousands of pounds. Some people with MND have been denied NIV and subsequently died in intensive care after such an episode – this delivery plan should make clear that such poor decision-making must not happen in Wales in future, and that the respiratory needs of people with MND must be adequately monitored and met.

OUTCOMES:
• Reduction in number of emergency admissions to hospital, readmissions to hospital and average length of stay
• Increased access for patients to community-based teams able to manage individuals closer to home across relevant disease groups

i. We support these proposed outcomes: the provision of community-based teams will assist the management of people with MND, who must be included in the list of relevant disease groups. Co-ordination should occur between these teams and the North Wales Neurology Network and South Wales MND Care Network.

Local Health Boards will:
Ensure that pathways for the investigation of sleep-disordered breathing are established to assess and treat patients with OSAH within established RTT
• Undertake a population needs assessment and review current levels of service for sleep-disordered breathing against the recommendations of the Strategy Document for Sleep Disordered Breathing Services in Wales 2010
• Develop initiatives with community leads to promote the management of acute respiratory conditions in the patient's home and intermediate care, where appropriate

i. These proposed actions are pertinent to MND, but we would like to see more specifics in terms of either deliverables from this work, or patient outcomes.

ii. Baseline measurement exercises should be undertaken to quantify the current state of services before this work is taken forward, and measurement undertaken subsequently to assess their success.

iii. Particular attention should be paid to current levels of provision of NIV, cough assist and physiotherapists. While we believe access to NIV has improved, subject to our points above regarding some sleep services, we believe that inequity persists in the provision of cough assist devices and physiotherapists. This should be assessed and, if necessary, remedied.

iv. We also recommend adding that LHBs should:
- Develop enhanced discharge and follow-up schemes to facilitate, when appropriate, quicker discharge from hospital and community support to reduce risk of re-admissions
- Develop pathways to address acute conditions across an enhanced primary-secondary care interface and to manage them where appropriate in the community setting.

v. Additionally, co-ordination of respiratory services with palliative and end of life care should not be overlooked. While MND care is palliative from diagnosis due to the lack of curative treatments, the most common cause of death is respiratory failure. Respiratory symptoms in MND are therefore often acute at the end of life: close co-ordination is necessary between respiratory and both palliative and end of life care services.

Local Health Boards will:
Ensure that all people with respiratory conditions have a personalised self-management care plan in place, which is regularly reviewed, within three months of diagnosis

i. In line with our previous comment, we welcome the proposal for personalised self-management care plans, regularly reviewed. But it must be made clear that this cannot be done in a respiratory silo: for complex, demanding conditions such as MND, care planning must involve a wide range of services including neurology, palliative and end of life care, respite care, physiotherapy, occupational therapy, dietetics, speech and language therapy and many more.

ii. In particular, this section of the delivery plan should signpost clearly to the neurology and end of life delivery plans, as should they to this one.

Ensure that all respiratory patients have the necessary key measurements taken annually to identify early decline in disease and facilitate appropriate interventions

i. While it is welcome to see the concept of anticipatory assessment introduced to the delivery plan, albeit late and somewhat tentatively (planning should begin before the start of deterioration is detected in cases where the deterioration of a function can be reasonably predicted,

not when it starts to manifest), annual assessment of respiratory function, or any other, is far too seldom for MND. The NICE guideline on NIV recommends monitoring respiratory function every three months.

7. WORKING TOGETHER

*The **third sector** has an important role to play, both in providing services and acting as the voice of individuals.*

i. This is far too narrow a conception of the role of the third sector in relation to healthcare. Third sector organisations also play a vital role in providing education and training to health and social care professionals, and in guiding and assisting the development and provision of services. The lack of recognition in this delivery plan of respiratory needs arising from neurological conditions is evidence of the importance of this role; the work of the North Wales Neurology Network and South Wales MND Care Network show it in action.

For further information contact:

John Kell
Policy Manager
MND Association
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG

Tel: 020 72508450

john.kell@mndassociation.org

December 2013