motor neurone disease
association
cymdeithas
clefyd motor niwron

Response to the consultation on the Public Health Outcomes Framework for Wales

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.

vi. In this submission, we are responding only to question six in the consultation paper. We have no comments in response to questions one to five.

Question 6: Do you think that these proposed outcomes are the right ones? If not, what changes do you suggest?

i. In respect of the basis of the framework, we support the focus on prevention and integration. We would welcome further clarity, however, on the intended definition of 'prevention'. Neurodegenerative diseases such as MND cannot be prevented in the same manner as, some cancers or cases of diabetes. However, effective care for people living with MND, and

support for their carers, can be highly effective in preventing unnecessary complications and adverse symptoms, such as falls, pressure sores or intolerable strain on a carer. Physiotherapy and other interventions can also be effective in maximising the remaining function a person with MND still has as the disease progresses, lessening and slowing (but not avoiding) its inevitable impact. We would encourage an approach to 'prevention' that unambiguously encompasses this aspect of the term. This may be covered by the area noted for future consideration of 'a health service that prevents ill health' – if so, this should be stated more clearly.

ii. Because of the nature of MND, relatively few of the obvious 'public health' indicators are relevant. Within the proposed list of indicators, however, the inclusion of 'people feeling lonely' and 'hip fractures among older people' are very welcome, as they address both the socially isolating effects of MND and the risk of falls that accompanies it.

iii. In respect of 'premature deaths from key non communicable diseases' we would welcome clarity on how this will be defined. It could readily be framed so as to include MND: although it is a fatal disease, poor care for MND can lead to unnecessarily early death by, for instance, failing to prevent respiratory crisis or infection, insufficient nutritional intake once swallowing becomes impaired, mistaken administration of oxygen in a hospital setting (which can 'switch off' the reflex to breathe) and even driving people to seek suicide or assisted suicide if care is so poor that people are left feeling they have no other option. We recommend that 'premature deaths' be framed in such a way, rather than via a narrow focus solely on, for instance, deaths from treatable cancers.

iv. In respect of the employment rate for those with a long term health condition (indicator 13), we strongly recommend that this is defined in such a way as to recognise that some illnesses and disabilities make it wholly inappropriate for people to seek further employment. Many people of working age who are diagnosed with MND attach great importance to remaining in work for as long as they can, as leaving the workforce represents a significant and highly unwelcome milestone in their illness. However, there will come a point when the disabling effects of MND make it impossible for someone to work; beyond this point, any expectation that a person with MND should seek work is wholly unacceptable.

v. Finally, we would encourage a broadening, now or in future iterations of the framework, or indicator 17, in respect of housing. Accessible housing, or housing that can be adapted to be accessible, is vital for maximising the quality of life of people with MND, and we recommend that Wales's housing stock be monitored with this in mind.

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