

Response to the draft neurological conditions 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 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. We welcome the draft neurological conditions delivery plan, and in particular the ambition it demonstrates for improving services. We do however have some concerns that the scale of the ambition is often not matched by specific commitments, and that there may prove to be insufficient resource or action to make the plan's aspirations a reality. This response expands on this concern in respect of the six delivery themes.
- iv. A recurring theme through this response will be the role of the voluntary sector, which we feel could be more thoroughly acknowledged in the plan in several respects. For instance, charities such as the MND Association are well placed to provide training and education in their specific disease areas. Still more importantly, neurological charities have been instrumental in driving improvements in services in Wales, as will be outlined below: we are a willing partner in this work, and will suggest several areas in which we could assist further; but we would not wish to be the sole driver of improvements in Wales, or for our contribution to be relied upon as a substitute for statutory services taking appropriate responsibility.
- v. As the plan acknowledges, the challenge posed by age-related neurodegenerative disease is going to grow over the coming years and decades. The plan states: "The neurodegenerative conditions, such as

Parkinson's disease, Alzheimer's disease and motor neurone disease largely affect older people. With an aging population their incidence is increasing but our ability to treat them is improving."

- vi. This statement is not correct and we urge that it be revised. We remain largely unable to slow the degenerative processes involved in these diseases and entirely unable to halt them, still less reverse them. While some drug therapies for controlling the symptoms of some diseases, such as Parkinson's, are now available, there is only one drug that slows the progression of any of them (riluzole, for MND). There have also been some improvements to non-pharmaceutical care interventions, such as non-invasive ventilation for people with MND. These advances in treating symptoms are almost certainly what the draft strategy refers to. But the true picture is of more people developing age-related neurodegenerative disease, with some of their symptoms better controlled than they might have been in the past but no means of slowing their progression. This challenge must be reflected fully in the plan.

1. Provision for people with MND in Wales

- i. We are pleased to see the plan acknowledge the importance of the Neuroscience Network in North Wales, although we recall that it was slow to emerge after the Neuroscience Review in 2009, with the full-time director appointed only in mid-2012. The Network has secured or initiated several important developments which must be safeguarded.
- ii. The Network has established an Academic, Education and Information sub-group, which is developing proposals for a neurological education framework to support health and social care professionals to improve their understanding of neurological conditions, from basic awareness through to specialised knowledge. The Network's work plan for 2014 includes work to map and enhance access to specialist nurses (both condition specific and neurology nurses), and to bring forward proposals for involving Neurological Commissioning Support in making a baseline assessment of service levels against which to measure future improvements (or to advocate that the Welsh Government develop its own tools for these purposes).
- iii. Three multi-disciplinary teams have been established to improve planning and co-ordination of services for people living with MND in North Wales. They are supported by a Disease Specific Advisory Group (DSAG), and it is hoped that this can be a model for further similar groups reporting to the Neuroscience Network. The DSAG's work in 2014 will include development days embracing all three MDTs and the Walton Centre, as well as its continued focus on coordinating services and ensuring equity of access. The Network and DSAG are a strong model that show how services can be improved without additional resource by adopting flexible and innovative approaches.

- iv. In South Wales, the MND Care Network has been operating for the last 18 months, expanding on the care centre already established by the MND Association in Cardiff. The network draws in two neurologists and one palliative care consultant as co-directors, plus there are three care co-ordinators, an occupational therapist and a member of Association staff. It must be emphasised that this is all delivered from within existing NHS and Association resources, and does not arise from any initiative or extra resources from the NHS. The network has worked to establish MDTs and establish MND clinics; its work is in line with the ambitions of the delivery plan: a commitment to resource both networks, in the north and in the south, fully, would represent welcome progress in adding more specific proposals to the delivery plan.
- v. We note also that the delivery plan refers to care pathways for MND, among other conditions, having been established. We infer this is a reference to the Maps of Medicine developed alongside the Neuroscience Review. If so, we have been somewhat disappointed by this initiative: as we understand it, Wales opted out of the Map of Medicine initiative and the maps were not adapted for local use or aligned with the Chronic Condition Framework as had originally been intended. We support the Welsh Neurological Alliance's longstanding call for national standards for neurological conditions in Wales.

2. Delivery Theme 1: Raising awareness of neurological conditions

- i. For all delivery themes, we would like to see more specific commitments to action, and in many cases more detailed assurance measures.
- ii. For instance, in respect of the pledge to raise awareness and understanding of neurological conditions, we would like to see greater clarity about the audiences among whom understanding will be improved (for example, local authorities and their service providers should be included), and an acknowledgement of the need to bring expertise on conditions from patient organisations. We will be happy to work with NHS Wales and its partners to support this work.
- iii. We also fear that more assurance measures are needed than the single measure proposed. These might involve measuring training and awareness-raising activity delivered, for example.

3. Delivery Theme 2: Timely diagnosis of neurological conditions

- i. Diagnosis is of course a vital part of the MND pathway, and also one of the hardest to navigate: there is no diagnostic test for the disease, so it must be diagnosed by eliminating all other possible explanations for the patient's symptoms.
- ii. We recommend that expectations are clarified about the role of GPs in diagnosis, however. For rare and complex neurological conditions such as MND, we would not expect a GP to undertake the investigation or make the diagnosis: a neurologist should do the investigation, probably before referring to a colleague specialising in MND for final confirmation

(in North Wales, this would be undertaken at the Walton Centre in Liverpool, so continuing clarity about cross-border responsibilities is vital). The GP's role is to identify that a patient's symptoms are neurological – and if they can go so far as to flag a suspicion of MND while making the referral, so much the better.

- iii. A substantial danger at this stage is that the patient may be referred to other specialists – ear, nose and throat, for instance – to no avail, and be shunted back to their GP, perhaps more than once, before the correct referral is made. We have developed, with the Royal College of General Practitioners, a tool for use by GPs to enhance their recognition of neurological symptoms.¹ This is already being promoted by the DSAG and we would be pleased to work with NHS Wales to promote it further.
- iv. There are also some less common but sometimes problematic routes to diagnosis, which need to be addressed by effective co-ordination across the health and care system. One such is private diagnosis, where a person may be given the diagnosis by a clinician outside the NHS who then does not introduce them to the range of NHS and other services that they will need for their ongoing support. Diagnosis by a geriatrician can present similar problems. The DSAG is actively working to ensure that the system more effectively picks up people in these circumstances, and the issue should be recognised in the plan.
- v. Also addressed under this delivery theme is the issue of acute admissions to hospital. While we are doubtful that there are sufficient neurologists available to provide prompt neurology advice in every hospital as proposed, the North Wales Neuroscience Network has proposed having neurological nurse champions in all district general hospitals.
- vi. As with the previous delivery theme, we would like to see more assurance measures proposed here, for instance monitoring the creation of referral protocols and pathways and the timeliness of provision of outpatient services, including follow-up appointments after diagnosis.

4. Delivery Theme 3: Fast and effective care

- i. We welcome the strong emphasis on multi-disciplinary teams in the delivery plan. As noted above, three MDTs have been created in North Wales, supported by and accountable to the Neuroscience Network, and ultimately to the Local Health Board.
- ii. In Montgomeryshire a 'virtual' MDT has been created, which also picks up people living with MND in North Radnorshire. Powys is known to be an area where MDT coverage is lacking.

¹ Red Flags

[http://www.mndassociation.org/Resources/MNDA/Professionals/Documents/Red%20Flags%20Final%20\(3\).pdf](http://www.mndassociation.org/Resources/MNDA/Professionals/Documents/Red%20Flags%20Final%20(3).pdf)

- iii. Coverage of MDTs across South Wales is largely good, although in some areas, for instance in Hywel Dda Health Board, work is still underway to establish these more firmly and develop their effectiveness.
- iv. Again, it appears that the voluntary sector is making the running in improving these services: firm commitments to mapping, developing and maintaining robust MDT coverage across Wales would be most welcome.
- v. We would also like to see additional assurance measures, for instance patient surveys and focus groups to provide evidence of the quality of care. Gaining input to these in relation to lower prevalence conditions may be a challenge, and we would be pleased to assist in respect of MND.
- vi. In the context of this delivery theme, we additionally recommend that reference is made to several ongoing initiatives with which the plan should be coordinated. One such is the Carers Strategy for Wales: while we are largely supportive of this strategy, we do feel that its goals need to be embedded in, and aligned with, this delivery plan.
- vii. Secondly, the delivery plan for end of life care should be heavily referenced within this plan, and their objectives explicitly aligned. End of life and palliative care are crucial elements of care for people with MND, and while the end of life plan is referred to periodically here, the specifics of the two plans are not drawn together to produce a coordinated approach. Palliative care is also mentioned only very occasionally within this plan: it is not synonymous with end of life care, and should be addressed in its own right. Within existing structures, palliative care consultants provide leadership to the DSAG and the three MDTs in North Wales, and hospices are well embedded within their work, so there is a strong starting position in many areas; the importance of this aspect of care should, nonetheless, be built into the plan.
- viii. Thirdly, engagement and involvement of people living with neurological conditions should be included within the plan. In North Wales, the Network is developing plans for a Neurological Patient Forum, to be run in collaboration with LHBs and the Welsh Neurological Alliance, so again there is a strong starting-point; but this should be enshrined within the plan.

5. Delivery Theme 4: Living with a neurological condition

- i. The devastating nature of MND usually means that people live with it for only a short number of years, sometimes only months after a diagnosis is confirmed. It is one of the conditions that are exceptions from the generalisation made here about neurological conditions being something that most people live with for “many years”. We feel this is not sufficiently reflected in the delivery plan, most notably in this section. We strongly recommend that fast-track processes, for referral, treatment, equipment

and other services be instituted for rapidly progressive conditions such as MND (or where they are suspected).

- ii. Indeed, the use of the phrase “long term conditions” is perennially awkward in respect of MND: it is a long term condition in the sense that the person who has it will have it for the rest of their life; but in most cases, the disease will curtail their life significantly. We advise that the delivery plan sticks to the term “neurological condition” throughout.
- iii. We would also like to see more firm commitments to support carers and other family members during the course of a person’s illness, and during bereavement, either in this section or elsewhere in the delivery plan.
- iv. In terms of assurance measures, measurement should be undertaken not only of whether patients feel satisfied with their care, but of whether they are achieving the outcomes identified in their care plans. We would also like to see a measure of numbers of people referred to appropriate third sector and/or patient groups.

6. Delivery Theme 5: Improving Information

- i. More assurance measures are needed than the single one currently proposed. These might include assessment of mechanisms for obtaining patients’ views and the extent to which they are capable of influencing service delivery.

7. Delivery Theme 6: Targeting research

- i. We welcome the ambitions under this delivery theme pertaining to access to clinical trials, and the positive reference to Neurodem, whose focus on neurology has grown recently, in addition to its work on dementia. We would like to see much more ambition in respect of neurological research in Wales, however, as despite some areas of strength much more could be done.
- ii. Analysis by the Association of Medical Research Charities of spending on medical research in the UK by the voluntary sector shows that Wales attracts considerably less funding from this source than one would expect based on its population share.² Given that charitable funding represents one third of all non-private investment in medical research, this suggests Wales has more to do to attract and develop medical research.
- iii. As in many areas already discussed, there is existing good practice to build on. Neurodem is a partner of the Welsh Neurological Alliance and member of the Neuroscience Network in North Wales, and through this is undertaking work such as the planning of a research conference in North Wales later in 2014, and strengthening links with the Walton Centre in respect of neurology research. Biomedical research is cross-

² Briefing on charity funded research in the UK
http://www.amrc.org.uk/sites/default/files/doc_lib/2013-AMRC-briefing-on-charity-funded-research-UK-regional-1.pdf

border, and indeed global, in character: Neurodem must continue to promote research in Wales, and to forge links with networks and institutions beyond Wales; the two approaches will reinforce each other.

- iv. We therefore support the Welsh Neurological Alliance's call for a comprehensive neurology research strategy for Wales, to drive this work forward.

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