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The standard of care in amyotrophic lateral sclerosis: a centralised multidisciplinary clinic encounter sets a new benchmark for a uniquely challenging neurodegenerative disorder

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Once a patient has been diagnosed with the neurodegenerative disorder amyotrophic lateral sclerosis (ALS),[1] management varies considerably around the world. Some patients are managed by a variety of healthcare professionals, for example, a primary care physician, a neurologist, general or palliative care physician, who may each act in relative isolation. Alternatively, it may involve more recently developed multidisciplinary models of care, led by someone with specialised knowledge of the uniquely complex, often rapidly-evolving needs of this patient group, and of those that care for them.

The Motor Neurone Disease Association of England, Wales and Northern Ireland, established in 1979, pioneered a Care Centre model of ALS led by a coordinator, typically with a nursing background. It seems logical that the concentration of patients with ALS in highly specialised clinics would go hand in hand with the accumulation of resources and clinical expertise, and that a combination of symptomatic and disease-modifying therapy would be optimal. However, even within the established evidence that a multidisciplinary approach is useful,[2 3] there is no consensus about what constitutes best practice in relation to the composition of the clinical team, or which therapies benefit patients most (in quality of life, as well as survival terms).

Nonetheless, with the advent of multidisciplinary care introduced over the past two decades, the survival of those diagnosed with ALS may have been improving. Making use of a unique geo-political divide, the timely manuscript by Rooney and colleagues[4] refines the standard of care. Specifically, the authors convincingly demonstrate that a centralised multidisciplinary clinic led by an ALS neurologist, delivered independent survival benefit over a specialist nurse-led, community-devolved multidisciplinary team (MDT) model of care.

Appointments in the Dublin model were 2–3 h, and involved a highly specialised ALS neurologist, in addition to the differences in multidisciplinary care delivery. It does not seem unreasonable to assume that patients with ALS will place high value on being seen by someone who is an expert in their condition. Explaining why the disease has occurred, including an increasingly nuanced discussion around hereditary factors; what the patient and carers can expect and over what time frame in a clinically heterogeneous condition; plus issues around consent and advance directives, all mean that appointments need to be significantly longer than routine hospital clinic schedules. This is in addition to the time needed for MDT interventions. This study did not capture any potentially independent value of a more specialised neurologist, or more generous consultation time. Importantly the authors did control for prognostic factors such as age, Riluzole, site of onset, non-invasive ventilation and gastrostomy. There will of course always be potential confounds that have not been captured, for example, unexpected variation in the socioeconomic status of the populations, and cognitive function (a more recently recognised prognostic factor).

Prior to specialised care, late-stage patients with ALS ran the risk of emergency admission to the intensive care unit with pneumonia. Aside from prioritising patient autonomy, preventing hospital admissions by pre-empting the complications of ALS is also a central tenet of the 'business case' for a specialised multidisciplinary clinic, and is a quantifiable parameter that hospital financiers may respond to. The authors considered the travelling distance to the clinic as a potential confound, which would be an important consideration in applying this model to a larger country for example, USA. Undoubtedly the physical effort to attend hospital clinics may be prohibitive in the later stages of ALS, though the increasing ease of tablet-based telemedicine may offer a partial solution (recently introduced in the Oxford ALS Centre, UK).

In conclusion, this study adds to benchmarks in care published by USA[5] and European[6] specialists. We believe that all those with ALS should have the opportunity to regularly attend a dedicated clinic that offers access to a MDT that can address mobility, respiratory, nutritional, communication and psychological needs in a timely manner. As well as any survival benefit, the exponential growth in ALS research over recent years[7] has ridden a wave of improved phenotyping of patients that was only possible through such specialist encounters. When the therapeutic strategies in ALS inevitably arrive, such clinics will also be essential for their rapid application.

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REFERENCES

1 Kiernan MC, Vucic S, Cheah BC, *et al*. Amyotrophic lateral sclerosis. *Lancet* 2011;377:942–55.

2 Traynor BJ, Alexander M, Corr B, *et al*. Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study, 1996–2000. *J Neurol Neurosurg Psychiatry* 2003;74:1258–61.
3 Chio A, Bottacchi E, Buffa C, *et al*. Positive effects of tertiary centres for amyotrophic lateral sclerosis on outcome and use of hospital facilities. *J Neurol Neurosurg Psychiatry* 2006;77: 948–50
4 Rooney J, Byrne S, Hardiman S *et al*. A multidisciplinary clinic approach improves survival in ALS: A comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry* doi:10.1136/jnnp-2014-309601 (In press).
5 Miller RG, Rosenberg JA, Gelinas DF, *et al*. Practice parameter: the care of the patient with amyotrophic lateral sclerosis (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology: ALS Practice Parameters Task Force. *Neurology* 1999;52:1311–23.
6 Andersen PM, Abrahams S, Borasio GD, *et al*. EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)—revised report of an EFNS task force. *Eur J Neurol* 2012;19:360–75.
7 Turner MR, Hardiman O, Benatar M, *et al*. Controversies and priorities in amyotrophic lateral sclerosis. *Lancet Neurol* 2013;12:310–22.

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