

Motor neuron disease specialist palliative care: impact of COVID-19 pandemic

The multidisciplinary care of people with motor neuron disease (MND), also known as amyotrophic lateral sclerosis (ALS), is now widely established and recommended in several guidelines.^{1,2} However, the COVID-19 pandemic has affected most services, as hospitals across the world have struggled to cope with increased admissions, including intensive care, for people infected by COVID-19. The effect of the pandemic on the care of people with MND has been assessed as part of a wider survey of care.

An online survey was undertaken to ascertain the involvement of specialist palliative care services with people with MND in the UK from September to December 2020, including a question exploring the effects of COVID-19 on services. The details of the survey were distributed by the Association for Palliative Medicine, which represents doctors working in palliative care in the UK and Ireland. Consent was assumed if the respondent started the survey.

Eighty-six specialists responded—representing about 40% of the specialist palliative care units in the UK. Ninety-seven per cent of respondents were involved in the care of people with MND. The majority of services (79%) saw patients when there were specific needs or at any time in the disease progression. Only a small number were involved in care solely at the end of life.

Services had been greatly disrupted due to the pandemic. Sixty-two (72%) of the respondents added a free text comment about the effects of the COVID-19 pandemic. Twenty-three (37%) of those making a comment talked of the use of virtual support for patients, as visiting or attendance at outpatient clinics was restricted.

Six services were providing virtual clinics and four were part of wider virtual multidisciplinary teams.

Thirteen services had only virtual contact with patients, 8 had reduced visiting to patients at home, 16 services had closed the day facility, which had supported patients and families at home, and 2 felt that there were fewer admissions to the inpatient unit, due to reluctance of patients or the demand for admission of other patient groups. Patients had expressed reluctance to visit any hospital or medical unit and were reluctant to have visits at home.

Patients receiving non-invasive ventilation (NIV) were particularly affected. Admission to the specialist palliative care unit had stopped in 13 services. This was due to lack of specialist personal protective equipment, in particular respirator masks, to cope with the issues of aerosol spread, as this equipment had been restricted to acute hospitals. Visits at home were also restricted because of this issue. One patient underwent withdrawal of NIV at home, as admission was not possible, although it was reported that this had been undertaken without any adverse events and had been preferred by the patient and family.

The general support of people with MND was reduced. Specialist palliative care visits and contacts were restricted, and the support groups, often provided by the MND Association, had stopped, although some had transferred to an online system. These had been successful, and had been able to include very disabled patients, who had not previously been able to join face-to-face meetings but were able to be involved online.

The results of this survey show that there have been major changes due to the COVID-19 pandemic in the care provided for people with MND, in common with many other specialties, with a move to telemedicine. For the very disabled patients, or those in more isolated areas, telemedicine may increase the

accessibility to ongoing supervision and care, and reduce the burden of journeys to appointments for both the patients and caregiver.³ It has also been suggested that monitoring of research, including drug trials, may be possible using telemedicine and thus increase accessibility to more disabled and isolated patients.⁴ Similar increased accessibility was seen for patient support groups, when they used online systems.

The loss of socialisation for people with ALS/MND can be profound. This study has shown that services may be restricted and the regular attendance at day facilities, where there would be socialisation, as well as activities, respite for family carers and the possibility of multidisciplinary team involvement, would be a real loss. The restrictions to outpatient clinics and visits at home would also be further loss for patients and families, who may feel a loss of emotional or social support.

Patients receiving NIV were particularly at risk of not receiving the same care as before the pandemic. NIV may cause aerosol dispersion, and could infect other people, without extra personal protective equipment including ventilator masks. The lack of such equipment for specialist palliative care services has resulted in patients being admitted to hospital, often with very little opportunity for any visiting by families. The same issue may have delayed the starting of NIV for some patients, as reported by respondents in this study. It has been suggested that modifications to ventilators could reduce these risks, but it is unclear if this has been undertaken in the UK.⁵ The support of these patients, who already face coping with NIV and its implications, is essential.

Thus, the pandemic may lead to many changes for people with ALS/MND, with possible negative sequelae, and the multidisciplinary team may need to spend time in enabling patients and families to re-establish their lives,

with increased support, when the restrictions of the pandemic lessen. However, the use of telemedicine has shown that contact can be maintained and is seen positively, and this may be very helpful in supporting very disabled and isolated patients and families. The role of telemedicine and monitoring may also allow more patients to be involved in research projects. Although these developments may continue, there will also be the need to re-establish face-to-face contact with the wider caring team, to provide the most effective and accepted support to patients and their families.

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