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Response to: the adult multidisciplinary respiratory neuromuscular clinic

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To the Editor:

We read with interest Shah, Murphy and Kaltsakas' article "The adult multidisciplinary respiratory neuromuscular clinic" [1]. The authors recognise the positive support which palliative care services can offer adult patients with neuromuscular disorders (NMD), but also that access to services can be restricted for several potential reasons. The authors suggest that indicators for the introduction of palliative care services in NMD would be helpful.

We have recently published a traffic light system which can be used to identify adult patients with NMD who would potentially benefit from advance care planning (ACP) [2]. Our traffic light system was modelled on "The spectrum of children's palliative care needs" [3], used commonly in paediatrics, and categorises patients as "red", "amber", "green" or "blue" based on cardiac, gastrointestinal, locomotor and respiratory status, recent hospital admissions and prognosis (figure 1). The system also includes

	Blue	Green	Events	Amber	Events	Red	Events
Respiratory		No support		Overnight NIV; significantly reduced lung function	Starting overnight NIV	Daytime NIV; unrecordable peak flow	Starting NIV during day
Cardiac		Normal cardiac function or mild cardiomyopathy		Moderate cardiomyopathy	ICD Insertion	Severe cardiomyopathy; arrhythmias	
Locomotor		Ambulant, or wheelchair user, able to transfer	Loss of ambulation	Wheelchair user; unable to transfer		Unable to self-feed dependent for all care	
GI		Oral feeding		Supplemental gastrostomy feeds	Gastrostomy Insertion	Dysphagia; risk of aspiration	
Acute hospital admissions		Occasional admission only		Increasing frequency		With life threatening event	ICU admission
Prognosis	Condition not expected to be life limiting	Condition expected to be life limiting Expected to have a period of stability, not expected to die within the next few years		You would not be surprised if this patient dies within the next few years? And/or significant palliative comorbidity		You would not be surprised if this patient dies in the next 12 months? And/or patient has significant palliative comorbidity	

Figure 1 *Traffic light system to identify adult NMD patients who would benefit from advance care planning. GI: gastrointestinal; NIV: noninvasive ventilation; ICD: implantable cardioverter defibrillator; ICU: intensive care unit. Reproduced from [2] with permission from the publisher.*

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A new "traffic light" system is recommended to identify adult NMD patients who would benefit from advance care planning and possible referral to palliative care services https://bit.ly/3mVDY0P

events that could lead to a change in category and can be used to indicate that both ACP and referral to palliative care services may be appropriate for an individual patient. Of note, with regard to respiratory function, commencing overnight noninvasive ventilation (NIV) or a significantly reduced lung function would lead to an "amber" categorisation, while commencing daytime NIV or an unrecordable peak flow would categorise a patient as "red". Our suggestion would be that all patients categorised as "red" should be offered the opportunity to discuss ACP and end of life care.

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Conflict of interest

None declared.

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