

# A review of a joint palliative care service for adults with neuromuscular disease – are referral criteria fit for purpose?

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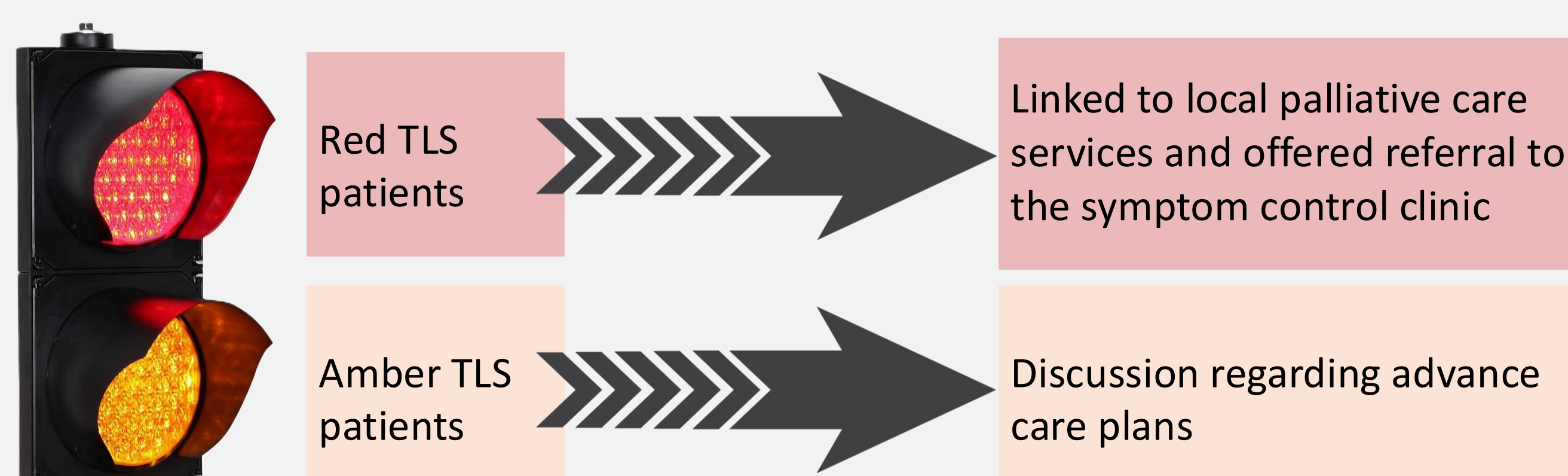
## Introduction

The joint services of Robert Jones Agnes Hunt Hospital and Severn Hospice have worked on developing palliative care services for adults with neuromuscular disease

- This collaboration has produced two national guidelines for adults with Duchenne Muscular Dystrophy (DMD, 1) and Myotonic Dystrophy (2)
- Referrals into the service have used a 'traffic light system' to determine which patients need palliative care support (3)

## Method

Since 2017, the traffic light system (TLS) has been applied to patients' clinical states related to various systems (e.g. cardiovascular system) on the local neuromuscular database.



The proportion of 'amber' and 'red' patients in 2023 with TLS allocation were quantified.

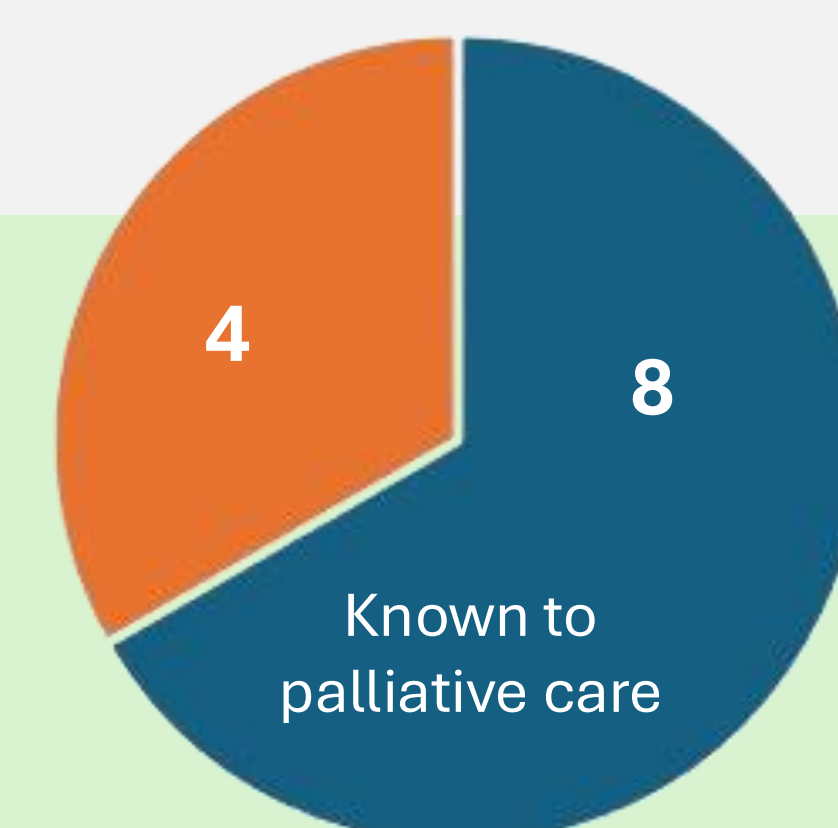
The deaths of adults under the care of the service were reviewed over the same calendar year.

## Results

In 2023:

- 25 of the 47 'amber' neuromuscular patients had advance care plans completed
- 11 patients were assigned as 'red' on the TLS
- 12 adult deaths in total, of whom:
  - 8 were known to palliative care
  - 2 refused referral
  - 2 were 'unexpected' deaths
- Of the 12 deaths:
  - 7 died in hospital
  - 5 died at home (3 were expected and died with local palliative care support)

Figure 1 – a pie chart illustrating the proportion of patients who died in 2023 that were known to palliative care services



## Conclusion

- Small numbers within this group, but data suggests that the traffic light system is effective in identifying patients who need palliative care involvement
- Multi-centric reviews of the system need to be conducted

## References:

- (1) Quinlivan R, Willis T, Willis D et al Adult North star Network A Consensus Guideline for Standard of Ca for adults with Duchenne Muscular Dystrophy Journal Of Neuromuscular Disorders Sept 2021.
- (2) Willis D, Willis T, Bassie C, Turner C Myotonic Dystrophy type 1 Palliative care Guidelines British medical Journal Supportive and Palliative Care Jan 2024
- (3) Willis T, Macfarlane M, Vithlani R, Willis D Neuromuscular Disease and Advance Care Plans: the traffic light system British Medical Journal of Supportive and Palliative care June 2020