Timely Advance Care Planning in Motor Neurone Disease

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Introduction

- The MND Association suggest patients with MND should be encouraged to talk through options for their care and preferences for end of life promptly, before the need is urgent, or communication becomes too difficult. This can be detailed in an advance care plan or advance decision to refuse treatment document.
- We aimed to establish how often and how promptly we have been addressing advance care topics with our MND patients.

Method

- Retrospective case notes audit, a snapshot picture of the prevalence of advance care planning (ACP) with MND patients across Shropshire and Powis.
- 21 patients with MND who have been looked after by the hospice team during the year of 2018 were randomly selected. This includes patients who had died during this year.
- Their notes were read to identify if and when ACP took place.

Demographics

- Number of patients (n=21)
- Number of patients from MND diagnosis date to date of audit (live patients)

What was the decision made?

- Invasive Ventilation discussion outcome (n=5)
- Artificial Nutrition discussion outcome (n=17)

How quickly after diagnosis did advance planning discussions take place?

- Number of months from MND diagnosis date to date of audit (live patients)

What percentage of patients have discussed the following ACP topics?

- In what percentage of MND patients have we documented discussion/implementation of the following advance care topics?

Conclusions

- This study shows that we are discussing ACP with all our MND patients, but that some ACP topics are more frequently discussed, such as NIV and artificial nutrition, whereas some topics, such as invasive ventilation, are discussed less often.
- This may be as conversations about NIV and artificial nutrition more naturally occur earlier in the course of MND, and therefore the prevalence of these discussions is higher.
- Anecdotally, we believe that patients with bulbar onset MND may have advance discussions earlier, further research is planned to compare ACP in bulbar and limb onset MND.
- This review of current practice has highlighted which ACP topics are potentially being missed (e.g. invasive ventilation) and will prompt us to review our practice with ACP discussions.
- A summary notes sheet (right) is going to be used in hospice notes to help to prompt these discussions and document their outcome.