Timely Advance Care Planning in Motor Neurone Disease

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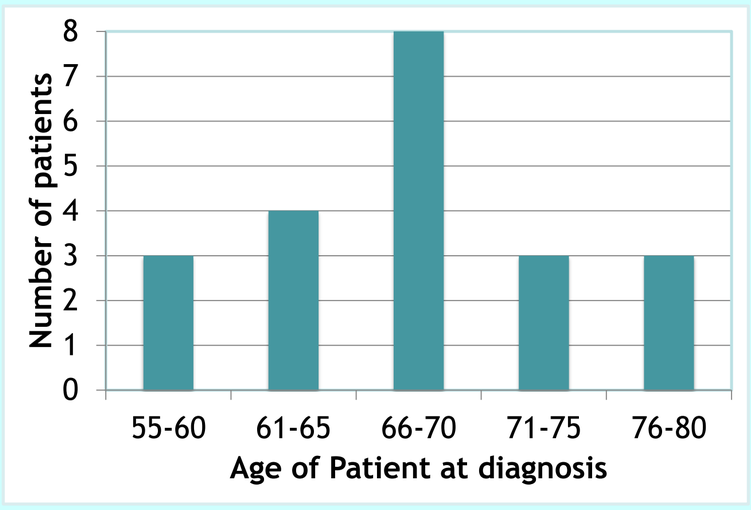
Introduction

- 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

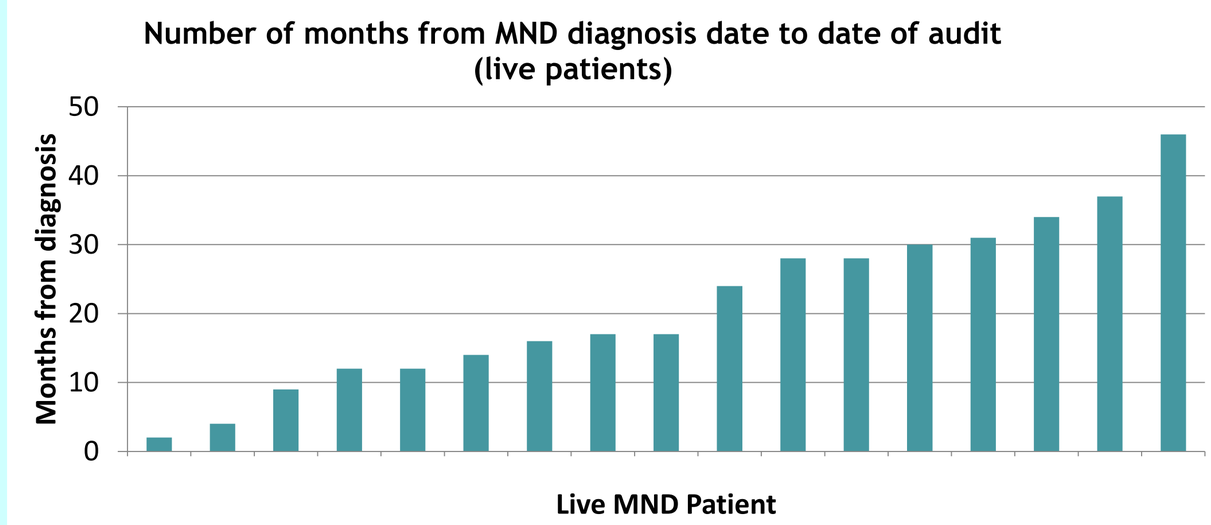
- Retrospective case notes audit, a snapshot picture of the prevalence of advance care planning (ACP) with MND patients across Shropshire and Powis.
- 21 patients with MND who have been looked after by the hospice team during the year of 2018 were randomly selected. This includes patients who had died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

Demographics



	Female	Male	Total
Number of Patients	11	10	21

Figure 1: Age of patients at MND diagnosis
Table 2: Gender of patients
Figure 3: A graph to show the time since diagnosis of MND (number of months).



What percentage of patients have discussed the following ACP topics?

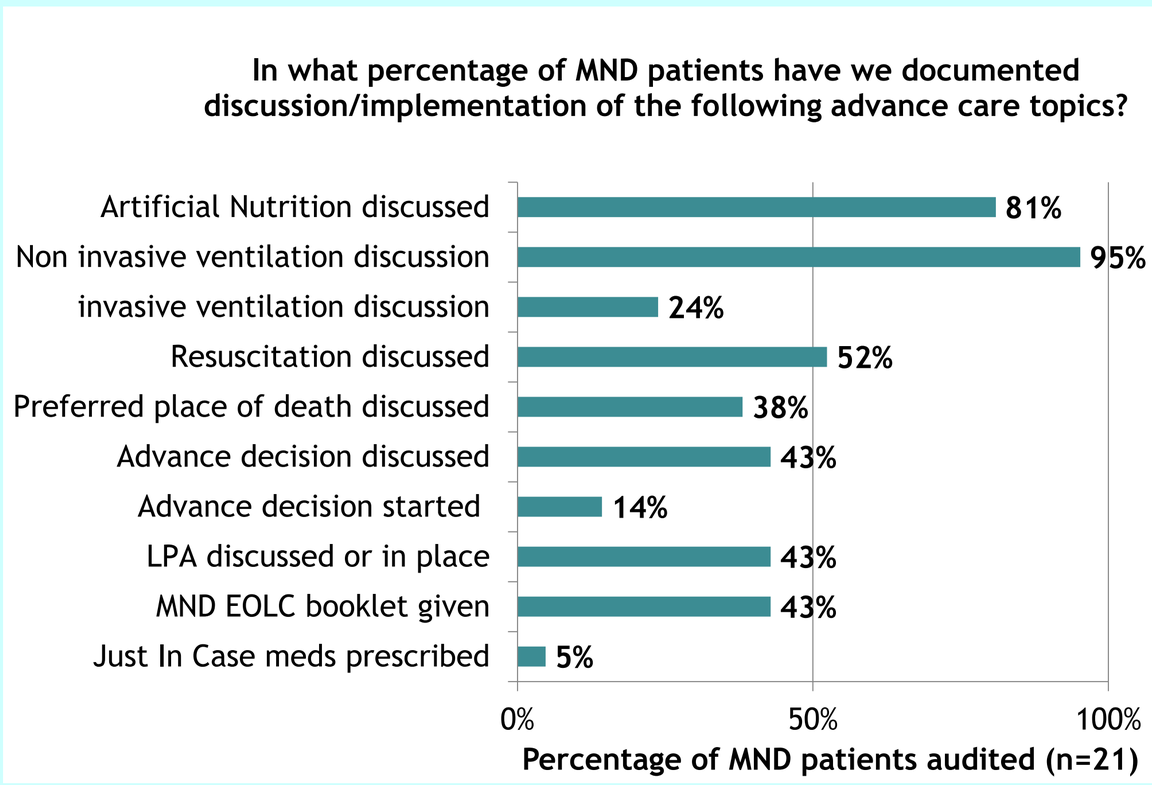
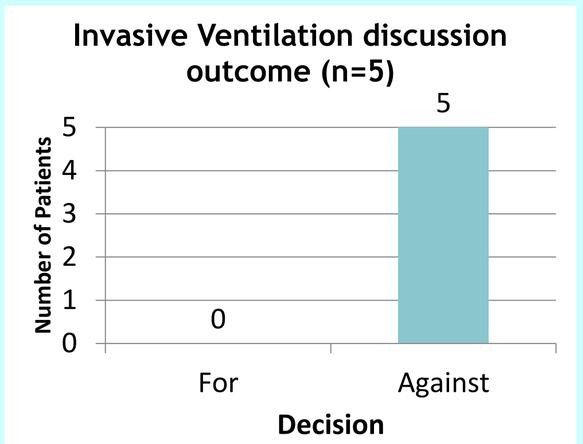
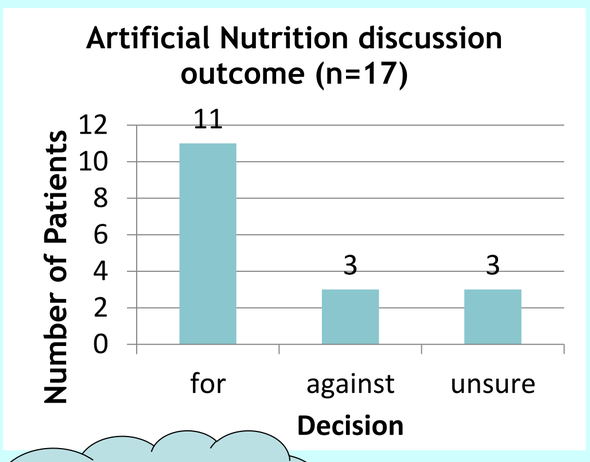
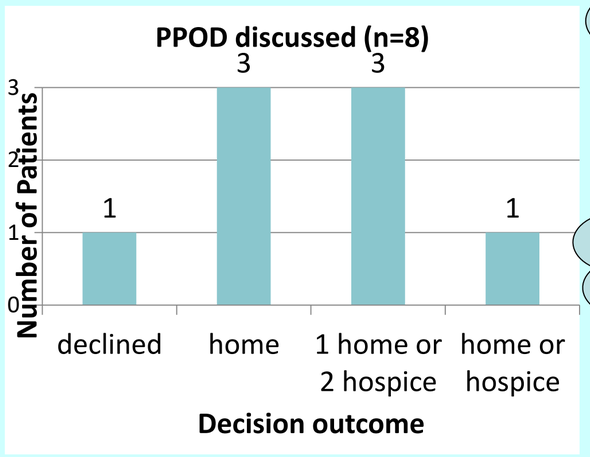


Figure 4: The majority of patients audited had documented discussion of NIV (95%) and artificial nutrition (81%) at time of audit, 52% had discussed resuscitation. However invasive ventilation was only discussed in 24%, LPA in 43%, Preferred place of death (PPOD) in 38%, and advance decisions to refuse treatment in 43%. 14% of patients had commenced an advance decision to refuse treatment document

What was the decision made?







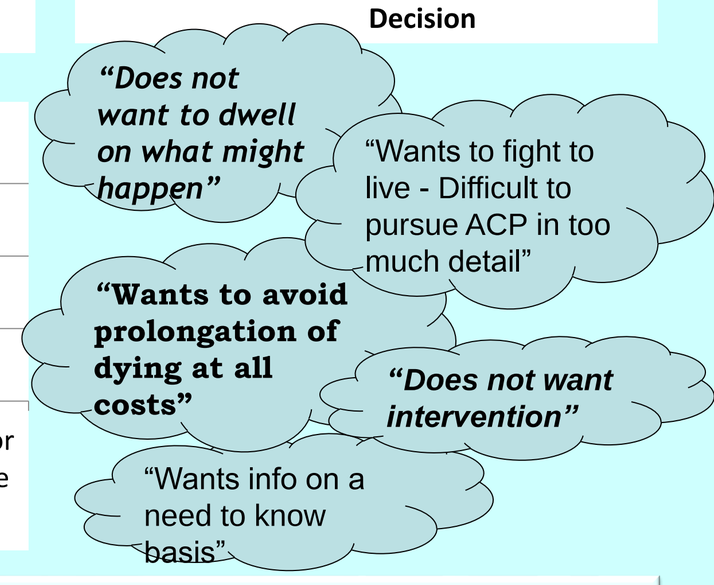


Figure 5: 100% of 5 patients decided against invasive ventilation
Figure 6: 65% of 17 patients decided for artificial nutrition, 18% decided against, the remaining were still unsure.
Figure 7: 50% of 8 patients wanted to either be at home of in a hospice for the end of their life, 38% wanted to be at home, 1 patient did not want to make a decision. Of the 4 patients who had died, 2 had died at their PPOD, 1 lacked capacity to state PPOD and 1 had declined to make a PPOD decision.
Figure 8: Responses and opinions of patients with advance care discussions.

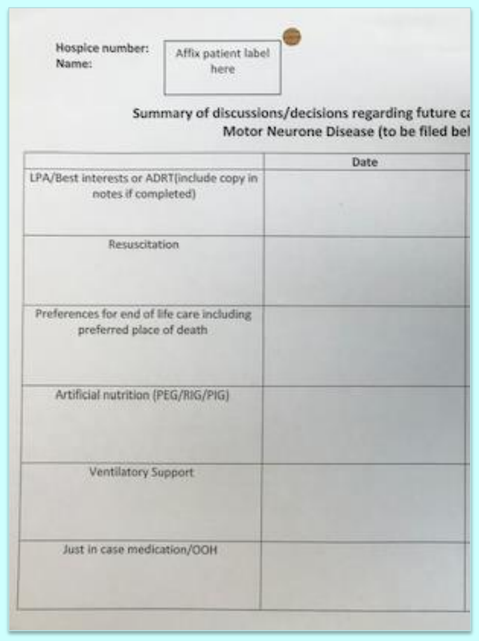
How quickly after diagnosis did advance planning discussions take place?

	LPA discussed	ADRT written	ADRT discussed	DNAR discussed	PPOD recorded	artificial nutrition discussed	NIV discussed	invasive ventilation discussed	Just In Case Meds prescribed	EOLC book given
n=	9	3	9	11	7	17	19	5	1	9
Minimum (months)	1	6	0	0	5	0	0	3	9	2
1st quartile (months)	3.0	6.0	5.0	7.0	6.5	3.0	1.0	5.0	9.0	7.0
Average (months)	8.6	9.7	8.2	10.8	10.5	7.5	8.9	8.2	9.0	12.2
3rd quartile (months)	12.0	11.5	10.0	16.5	15.0	8.5	11.0	10.0	9.0	16.0
Maximum (months)	18	17	16	20	19	20	32	17	9	23

Figure 9: On average EOLC topics were discussed 8-12 months after MND diagnosis (range of 0 – 32 months). Artificial nutrition, ADRT, LPA and ventilation were discussed earlier than DNAR, Preferred place of death and the EOLC MND booklet. All patients (21) had discussed at least one ACP topic.

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.


Hospice number:
Name:
Affix patient label here
Summary of discussions/decisions regarding future c
Motor Neurone Disease (to be filed be

	Date
LPA/Best interests or ADRT(include copy in notes if completed)	
Resuscitation	
Preferences for end of life care including preferred place of death	
Artificial nutrition (PEG/RIG/PIG)	
Ventilatory Support	
Just in case medication/OOH	