

A palliative care led multidisciplinary MND service

Background and aims

For the past five years the multidisciplinary MND team at the Mid Yorkshire Hospitals NHS Trust has been led by a palliative care consultant, without regular input from Neurology. This was a pragmatic decision based on a lack of neurology consultants at the time, but the success of the change means this has been continued. This meets NG42 1.5.4 for a professional with expertise in palliative care being involved but would NOT meet the requirement for a Neurologist to be involved.

This work aims to demonstrate that this model of practice is effective in delivering care and increases access to advance care planning (ACP). The MND CNS post now sits within the palliative care service as well, to ensure care is as seamless as possible.

Description

Several methods have been used to review the service and demonstrate positive outcomes despite this deviation from the NICE guidelines:

- An audit in May 2018 which compared advance care planning rates to the baseline (2016) – this included all patients on the caseload and all patients who had died while under the palliative care led service.
- A repeat audit in December 2020 of current patients to ensure benefits were sustained.
- Ongoing Transforming MND Care audit including the patient experience tool
- A specific audit of saliva management to demonstrate effective symptom control in a specific area.
- A consultant specific patient survey
- Ongoing learning and engagement with local, regional and national services.

A Standard Operation policy has been written to ensure a clear pathway of referral from neurology, as well as back to them if this was required. This was reviewed in 2021 to re-establish links with Neurology when required.

Evaluation

The two audits have compared rates of advance care planning to before the service was led by palliative care:

	December 2016	May 2018	December 2020
Number of patients	25	36	33 (29)
% seen by palliative care	20% (5)	100%	100%
Consent to EPaCCs	16% (4)	89%	86%
Resuscitation discussed	16%	40%	51%
DNACPR form in place	16%	31%	41%
Preferred place of death documented	16%	33%	44%
Other advance care planning	-	-	52%
Any part of ACP completed	16%	89%	86%

On the review of all the patients who died within the first 18 months (15) 80% of patients had had a discussion about preferred place of death and 66% of patients achieved their preferred place of death.

"I and my husband do believe that Pinderfield's Hospital has made the right decision in that once MND has been diagnosed by a Neurologist, the condition is best treated and led by a Palliative Care Consultant who specialises in making living with the disease the best it can be and is also well placed to discuss end of life care."

A carer

The Transforming MND Care patient experience tool has not demonstrated any concerns about the service being led by palliative care. The consultant specific patient survey had one negative comment about my role as a palliative care consultant being unexpected and upsetting.

In an audit of saliva management 29 patients (over 2 years) were symptomatic and all received appropriate 1st line medication. Symptoms were re-assessed appropriately in all patient although it was recognised that an additional 6 patients (20%) may have benefited from a consideration of botox as a 2nd line treatment.

Being a *different* service has required engagement with local, regional and national support. However, it has also presented opportunities for learning, delivery of education (to specialists, non-specialists and volunteers) and engagement with a wide range of services.

SPECIFIC CHALLENGES:

- Initial transfer of patients from Neurology to Specialist Palliative Care
- Very few patients want to do advance care planning!
- More recently (due to covid and a CNS change) I am often the first person from the team patients meet post diagnosis, which requires sensitive handling.
- A perception from patients that this reduces their access to research.
- A huge amount of individual learning!

Conclusion

Although this service model is a deviation from the NICE guidance I believe it is a model which could be adopted by other services. Combining this role with being a community palliative care consultant means patients have continuity from diagnosis to death, even when they are no longer able to attend clinic appointments. This allows familiarity with patient's symptoms, advance care planning at their own pace and not feeling abandoned by a team when approaching the end of life. Flexibility to see patients in hospital, community and hospice has been beneficial to both patients and other healthcare professionals.

Recommendations and actions

That the lead clinician for a multidisciplinary MND service could be a palliative care consultant. This means patients can have earlier access to symptom management and advance care planning from a consultant who is known to them.

Locally we have reviewed our Standard Operating Policy to ensure clear links with Neurology, with the aim of establishing a quarterly joint MDT.