



A palliative care led multidisciplinary MND service

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MYHT Multidisciplinary MND clinic

- Evolution of the clinic
 - December 2016 – Clinical leadership change
 - December 2017 – Strategic leadership change
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- Patient expectations
 - MDT expectations
 - My expectations



Assessment of quality/outcomes

- Audit of palliative care role
 - Baseline (2016) – repeat (2018) – repeat (2020)
- Transforming MND Care audit including patient experience tool
- Assessment of symptom control - audit of saliva management
- A consultant specific patient survey
- Ongoing learning and engagement with local, regional and national services.

NICE Guidelines [NG42] Feb 2016

- The core multidisciplinary team should consist of healthcare professionals and other professionals with expertise in MND, and should include the following:
 - Neurologist.
 - Specialist nurse.
 - Dietitian.
 - Physiotherapist.
 - Occupational therapist.
 - Respiratory physiologist or a healthcare professional who can assess respiratory function.
 - Speech and language therapist.
 - A healthcare professional with expertise in palliative care (MND palliative care expertise may be provided by the neurologist or nurse in the multidisciplinary team, or by a specialist palliative care professional). **[new 2016]**

Audit

	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%

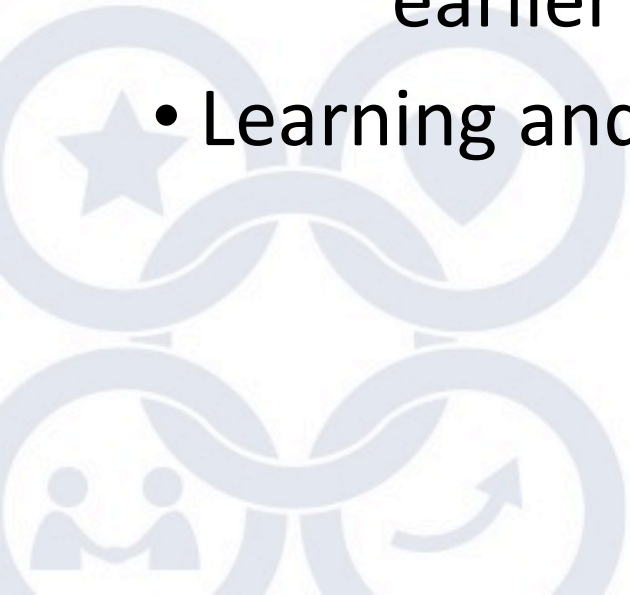
Surveys

“Dr Lowe visited me at home in relation to my new MND diagnosis. In introducing herself she referred to her consultancy in palliative care – not something I was expecting and most upsetting.”

“ 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.”

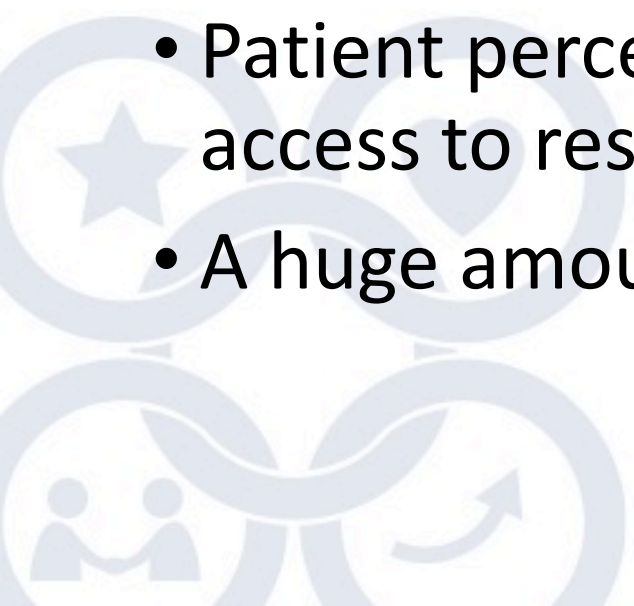
Other assessments

- Saliva management
 - 29 patients (2 years)
 - 1st line = all appropriate
 - 2nd line = 20% may have benefited from earlier botox
- Learning and engagement



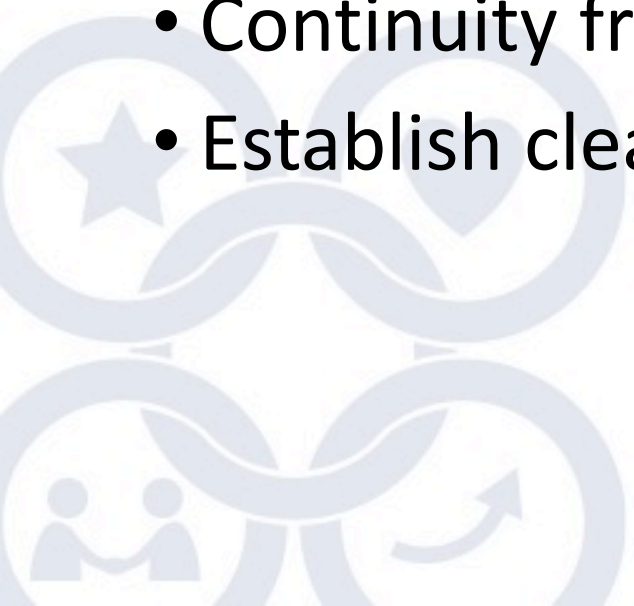
Specific challenges

- Initial transfer of patients
- Patients openness to advance care planning and my expectations.
- Initial meeting with palliative care
- Patient perceptions – role of examination, access to research, role of palliative care
- A huge amount of individual learning!



Conclusions/discussion

- A multidisciplinary MND service can be palliative care led
- Early/timely access to symptom management and advance care planning
- Continuity from diagnosis to death
- Establish clear links with Neurology



Questions/discussion

