

Learning Objectives...

- Explore challenges, burdens and benefits of discussing end of life;
- Understand what happens as MND progresses and how patients might die;
- Consider ethical principles in managing end of life in MND;
- Increase understanding and awareness of processes in initiating conversations about end of life and apply to clinical practice.

Getting ready to vote at www.slido.com using **PIN 4008097**

Setting ground rules

What do we need to do to create a safe online classroom?

- Keeping confidentiality
- Respecting contribution of others
- Listening and sharing
- Sticking to the schedule
- During presentations, use the Chat function rather than 'raise hand'
- What to do if you need to step out of the training
- Other ground rules? (please add to the Chat function)

Learning....

Feel better prepared to answer patient

questions...building on existing knowledge... refresh and feel confident again...learn from others in the group

Opening up conversations about planning ahead

Ending conversations well

More knowledge on MND, specific insight into common trajectory at EoL, recognising dying

Discussion with patient around what to expect with progression, how not to scare them too much, promoting choices



The confidence, and knowing, to start an EoL conversations, and encourage questions

Increased confidence, and ways of using language (and to avoid) appropriately when having EoL discussions

How to approach families when they have difference in opinions about EoL or in denial

Gain confidence and understanding of how to have these conversations to support advance decision making and having difficult conversations

Understanding different ways to support MND patients and their families

How to introduce difficult topics, including withdrawal of ventilation and planning / enteral feeding

Burdens...

Emotional reaction/psychological distress to these discussions - patient, informal caregivers and professional

Not knowing if Patients or family members are ready for these discussions which can cause distress for all

Lack of resources to enable their wishes

Some patients and families do not want to know what will happen complex questions/family dynamics

Not my role in the MDT / no time

Destroying hope

Responsibility for action referrals



Worry about 'opening a can of worms'...leaving people feeling worse

sometimes feel like reactions are not quick enough due to service demands

Implications – professional, ethical, legal

But how do I start ?- unsure what conversations have already taken place

Lack of confidence or/and skills needed. No training received. Over the phone Questions I can't answer

Discussing things that may not apply to them and increasing anxiety unnecessarily

Breakdown in the relationship / rapport with patient and family / trust

Benefits...

Eliminates
guesswork

Empowers the person – patient,
relative and professional in decision
making / putting patient and family at
ease / getting affairs in order

Clarity for professionals,
patients, carers – things
are documented

Build trusting, therapeutic
relationship

Helps with ethical decisions - difficult to
withdraw treatments - better not to start if
person doesn't want an intervention

May help reduce fear
of dying process/fear
of unknown/put
affairs in order/avoid

A relief to talk...for all

Can debunk myths

unwanted

Anticipate problems, avoid/reduce
unnecessary hospital admissions



Good for practitioner
wellbeing

interventions

Opportunity for questions, can
often be a positive and
reassuring discussion

Professionals on the 'same page'

Helps with planning
ahead, promoting
choice, reduce
anxieties, better
end of life

Unpicks confusion when a patient lacks
capacity

Support patient
centred decision
making and
promotes choice

Getting right
equipment in
place/best use
of resources

Reassures person they have a voice, and that someone
is willing to listen...an evolving conversation...before
voice is lost

Find solutions, being prepared

Makes the most of time they have left