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 Some patients
Patients or family and families
members are do not want to
ready for these know what
discussions which will happen
can cause distress

complex

questions/

family

dynamics

Not my role in

the MDT / no

time

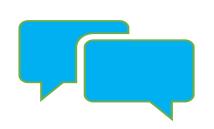
for all

Lack of resources to enable their

wishes

Destroying hope

Responsibility for action referrals



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

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

Build trusting, therapeutic relationship

A relief to talk...for all Can debunk myths

Anticipate problems, avoid/reduce unnecessary hospital admissions

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

Support patient centred decision making and promotes choice

Getting right equipment in place/best use of resources

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

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



Good for practitioner wellbeing

Professionals on the 'same page'

Unpicks confusion when a patient lacks capacity

Clarity for professionals, patients, carers – things are documented

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

interventions

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

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