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 5169855**

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….

Recognising dying in MND

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 Advance Care Planning

Ending conversations well

Better understanding managing specific issues that are commonly seen in deterioration and last days of life, including fear of death and sudden death

Ways of explaining why CPR unlikely to be successful in advanced MND

Introducing Hospice services

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

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

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

Gain confidence and understanding of how to support advance decision making, having difficult conversations, making eol plans /options for ACP, knowledge of ADRT’s

Working with wider MDT

Starting discussions about escalation of care – tracheostomy, NIV, withholding/withdrawing treatments and how end of life presents.

Navigating needs…..

Burdens…

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

Difficult conversations to have and to know when to start (?right time) and stop /difficult for family to take in

Not having the time…other things to do

Not my role in the MDT

Feels uncomfortable

Decisions that may not be what is clinically beneficial

Managing complex questions/ family dynamics

Lack of skill over the phone/device

People believe it will support them to die, rather than support them to live…

Worry about ‘opening a can of worms’…leaving people feeling worse

For some, if not done at right time or in correct manner, it can harm relationships

Implications – professional, ethical, legal

But how do I start?

Not having correct documentation and communication with wider

Lack of confidence and skills needed.

Patient comes out of consultations feeling depressed.

Person feels written off

Patient/family may not want the discussion/having to think about loosing a loved one…denial

Breakdown in the relationship if mentioned at the wrong time…or latching on to a specific practitioner

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

A relief to talk…for all

Can debunk myths

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

Anticipate problems, avoid/reduce unnecessary hospital admissions

Good for practitioner wellbeing

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

Professionals on the 'same page'

Helps with planning ahead (e.g. ReSPECT) for end of life /support collaborative working and ACP

Unpicks confusion when a patient lacks capacity

Support patient centred decision making and promotes choice

Getting right equipment in place

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

Patient autonomy

Makes the most of time they have left