# MND and wider MDT & how OT can impact at end of life.

## Session 3

Jenny Rolfe MSc Occupational Therapist

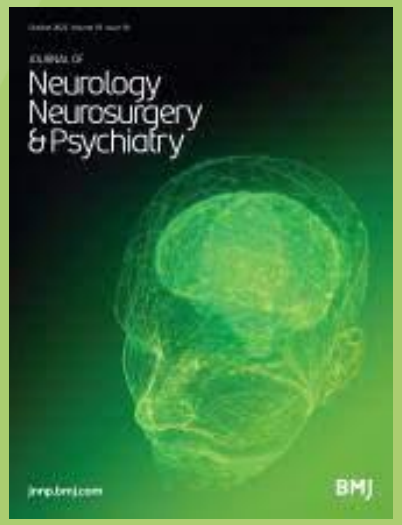
Accora

# Learning Objectives – emotional content….

- To be aware of the multidisciplinary team and the impact of good teamwork and communication on patient outcomes
- To be aware of the differences between multidisciplinary and interdisciplinary working and how this can impact OTs working with people living with MND
- Explore the role of OT in the end stages of life and planning for this for people living with MND

Accora

**Rooney J, Byrne S, Heverin M*, et al* A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *Journal of Neurology, Neurosurgery & Psychiatry* 2015;86:496-501.**




- Study of MND patients in RoI and NI 2005-2010:  719 cases

- Survival benefit for patients attending MDT clinic in RoI compared to
- patients from NI not attending MDT clinic

- MDT decision making, enriching options and outcomes for patients.

- NICE Guideline

Accora

## NICE NG42 - QUALITY STANDARDS

***Quality standards help you improve the quality of care you provide or commission.***

**Quality statement 4: Continuity of care**

*Adults with motor neurone disease (MND) receive personal care and support from a consistent team of workers who are familiar with their needs.*

Accora

# MULTI DISCIPLINARY AND INTERDISCIPLINARY TEAMS

A multidisciplinary team is **a group of health care workers who are members of different disciplines (professions e.g. Psychiatrists, Social Workers, etc.), each providing specific services to the patient**.

Interdisciplinary teams are an approach to healthcare that integrates multiple disciplines through collaboration. These teams can **help ensure that patients receive the best care and also improve how medical facilities function**.

While interdisciplinary teams are made up of various disciplines working collaboratively toward a common goal, multidisciplinary teams involve team members working independently to create plans specific to their discipline. **While these plans may be enacted simultaneously, it's done without regard to their interaction**

*GOOGLE ACCESSED 17/11/2022*

Accora

| OT | PT | SLT |
| --- | --- | --- |
| • Wheelchair<br>• Bathroom | • Stretches<br>• Transfers | • AAC<br>• Swallow |

Accora

How to get in and out

- Access
- Transfers

Position in chair

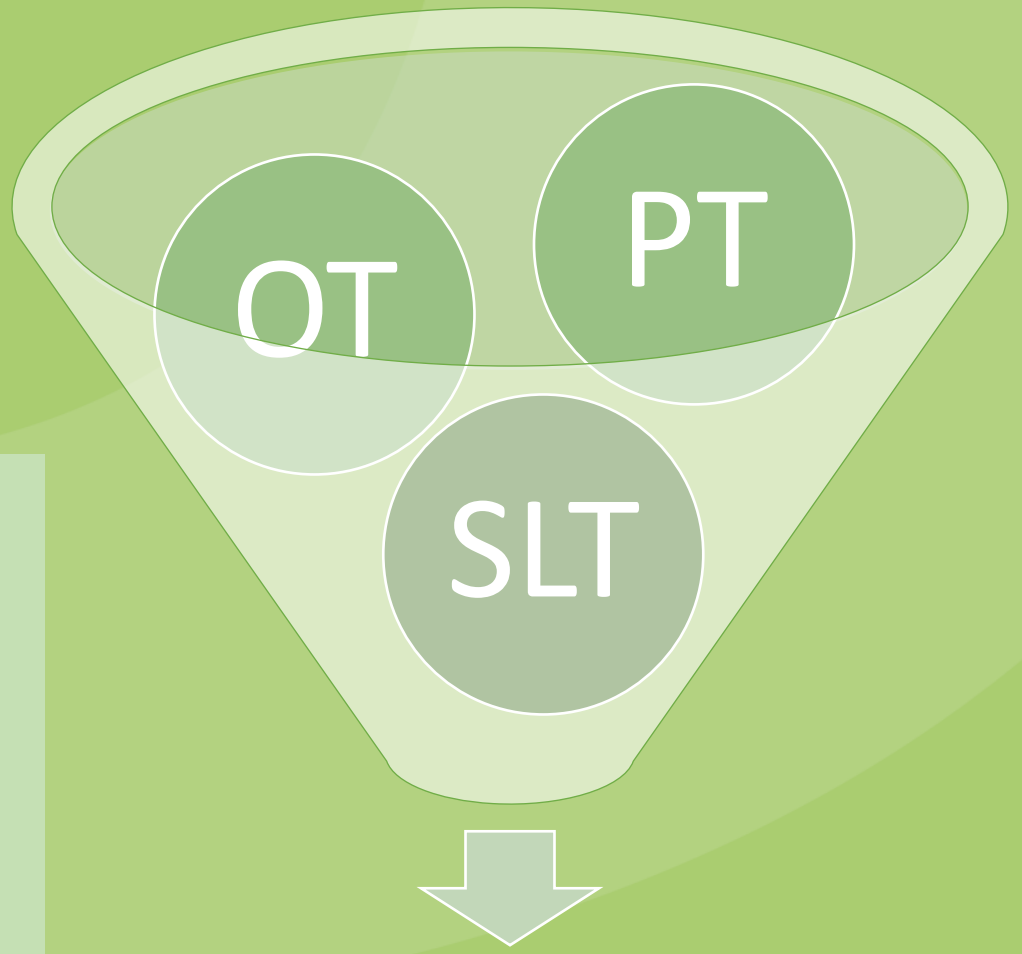
- Swallow
- Postural support

Mobility

- Assistive Technology
- Access

Accora

**Services need to consider….**




- Care Pathways
- System Pathways
- Seamless transitioning

**COMMUNICATION Systems**

- Fast Track Processes
- Review Processes
- Palliative care / Ongoing **care coordination**

Accora

# Neuro Palliative care

- Managed by neurology teams
- Managed by Palliative care teams

When do you refer for specialist palliative care?

- Diagnosis?
- End of life?

Who can provide this care?

Hospice / home / GP / nursing home / community / hospital

Accora

# Palliative Care

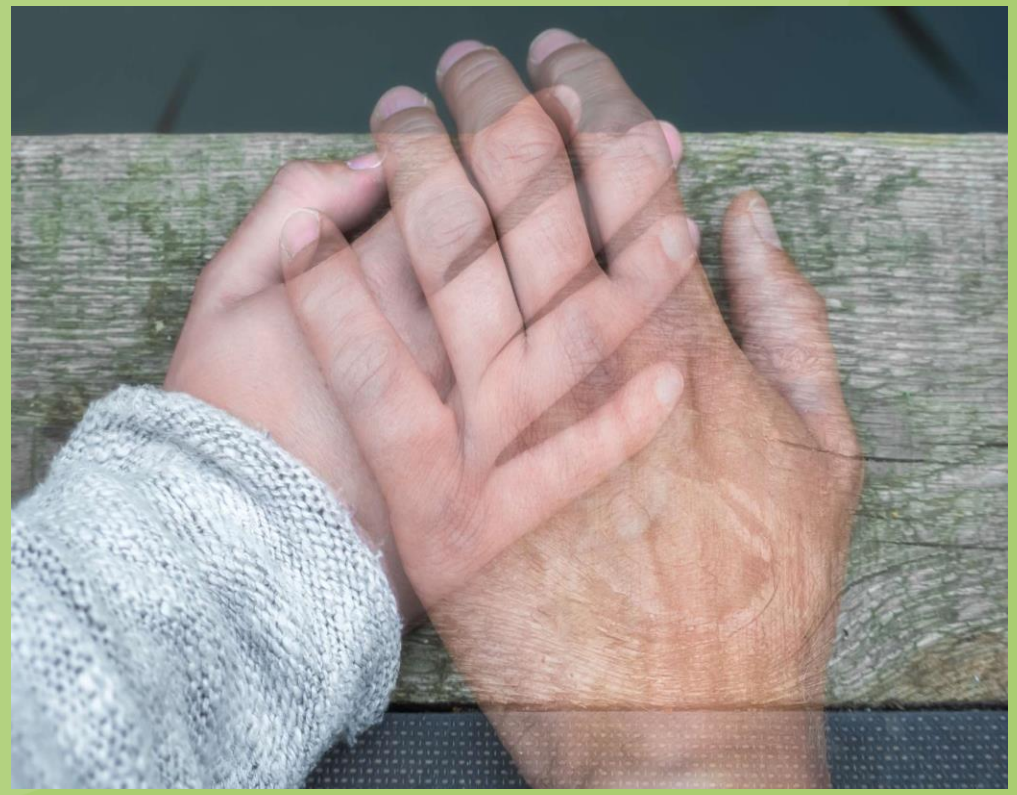
When? Who? What? Who?

**Advanced Care Planning**
Day to day management of symptoms
Messages for people / memory boxes
(www.thinkahead.ie)

**Advanced Statement**
How would like to be cared for and where would prefer to die

**Advanced Decision to Refuse Treatment**
Refusal of treatments which if not provide may bring about death (refusal of feeding, antibiotics etc)

**DNACPR**
Wishes for treatments would like to receive (not legally binding)



**REVIEW CHOICES**

Accora

# Getting your affairs in Order….

Lasting Power of Attorney
- About decisions around finances and health care decisions

Enduring power of Attorney
- About financial decisions

Wills

Organ and Tissue Donation

Funeral / memorial


Accora

# Symptom Management

- Respiratory support – NIV, Cough
- Saliva / Secretion Management
- Bowel care
- Nutrition
- Pain
- Communication
- Psychological Support
- Relationship support
- Carer Support / training

**Postural support** – static or wheelchair seating, Bed positioning shower chair / commode chair

Optimum position for *breathing* Seating & Bed positioning
(head of bed elevated – sliding down in the bed)

Optimum position for *saliva / secretion management*

Optimum position for *swallow*

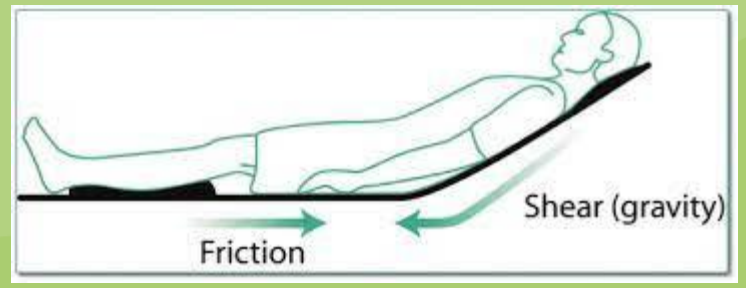
Optimum position for use of *eye gaze / communication*

Optimum position for *comfort / pain relief*

Accora

## Manual Handling

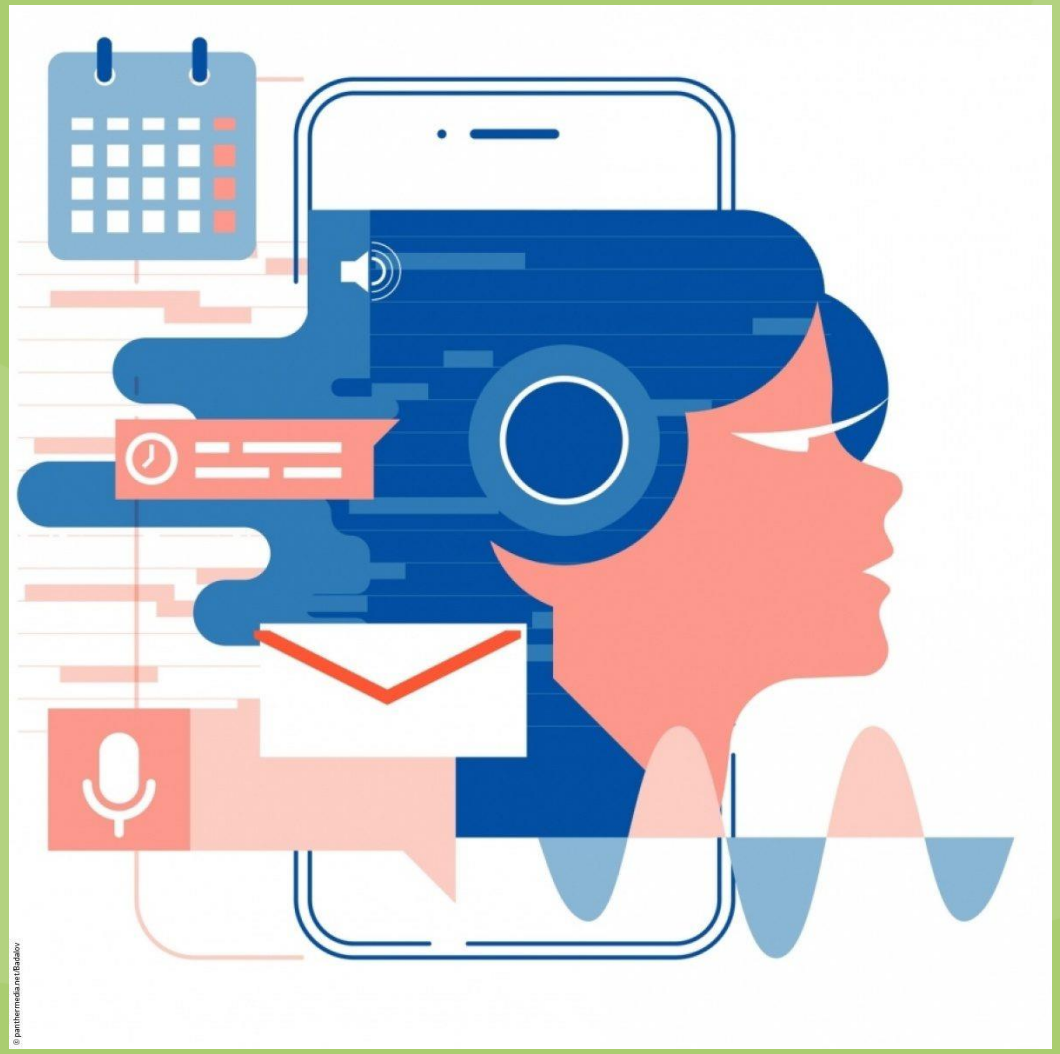
Toileting / bowel care
Carer support
Transfers
Pressure care




## Positioning

Positioning in chair
Positioning in bed
Positioning in shower chair

Accora



# Assistive technology

Ensuring access

Ensuring compatibility

Ensuring use

Accora

## Difficult Discussions – how to die….

### *“Its not for me to do… I'm just the OT”*

- Be aware of plans - even if OT role is minimal or absent.
- Be aware of views of person and their families

You may be able to facilitate the journey – comfort, ease, quality of life.

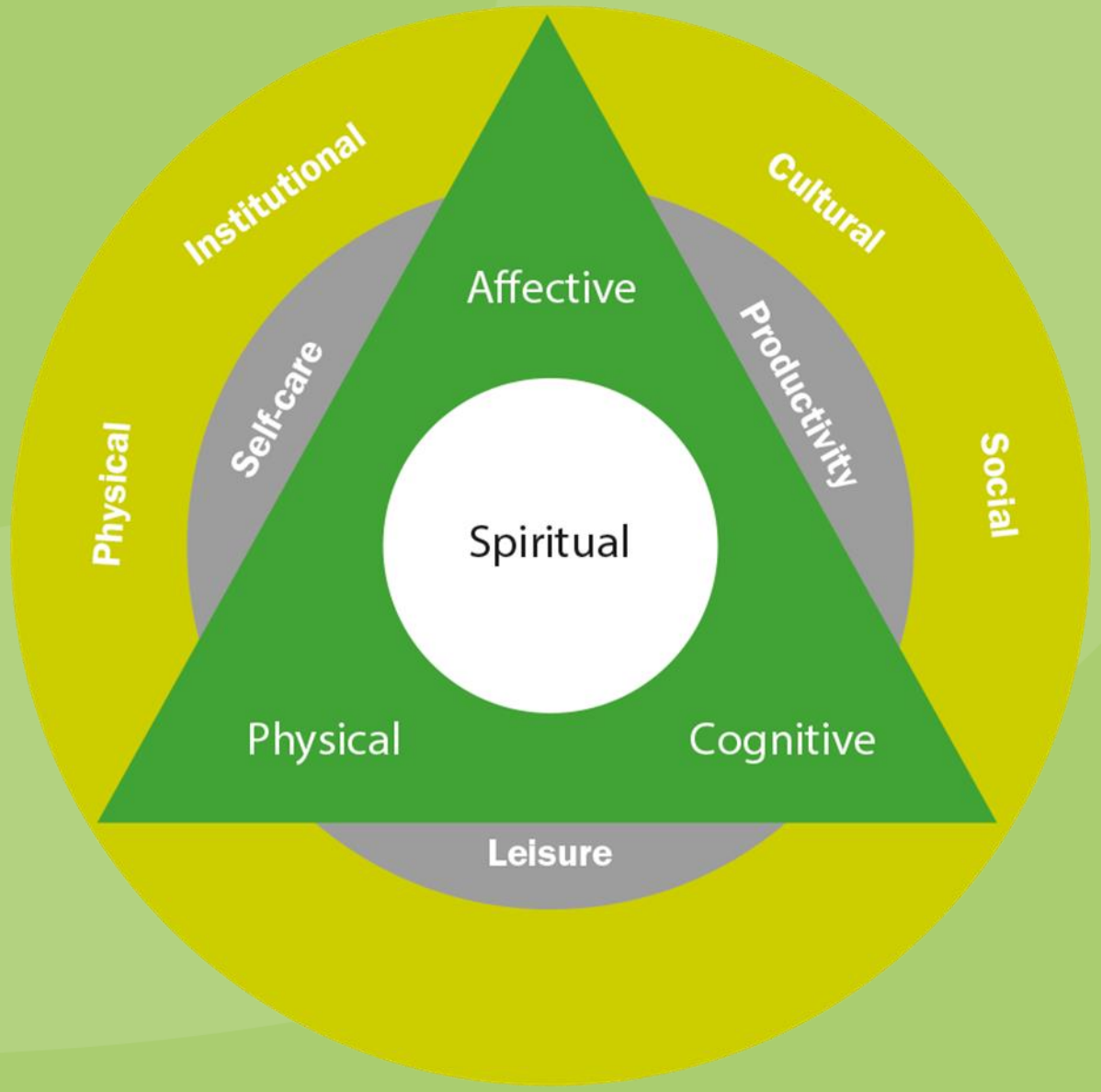
### *“my patient told me they are going to commit suicide – what should I do?”*

- Be aware of team members and who you can discuss with and who can take things forward.
- Listen to person
- Don’t hit panic button!

Accora

Accora

Accora


Institutional
Cultural
Physical
Social
Self-care
Productivity
Leisure
Affective
Spiritual
Physical
Cognitive
Person
Occupation
Environment

Accora

## Spirituality / religion / leaving a legacy

- Someone's spirituality can help them form their wishes and how they want to be remembered.
- Understanding the person's spirituality and views and beliefs helps you understand their wishes.
- Working with the person and their family on how they want to leave their legacy – memory boxes, letters, cards, books, etc.

*Equipment collection and support for families post death*

**Resources:**
https://hospicefoundation.ie/i-need-help/i-want-to-think-ahead/
https://imnda.ie/
https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/palliative-and-end-of-life-care/

Accora


Accora

# Self Care
# Wellness and Compassion

- Compassion fatigue
- Burn out
- Transference

Make sure you have good supportive systems and networks within work / supervision

- Mindfulness
- Taking time out
- Recognising the emotional load

Accora

**IMNDA**

https://imnda.ie/

**MNDA**

https://www.mndassociation.org/

**MNDA CoP**

https://www.mndassociation.org/professionals/community-of-practice/

Accora

# Thank you for listening

# Questions?

Accora

**Accora**
Charter House, Barrington Road,
Orwell, Cambridge SG8 5QP

**T:** +44 01223 206100

**E:** info@accora.care

**W:** www.accora.care

Accora