Palliative + End of Life Care for pwMND

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Palliative Care

Palliative care ... improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

WHO

Palliative care (2)

Palliative care:

- provides relief from ... distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach ...
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life

WHO

Things to consider

Physical: symptoms

reversible factors

Psychological: information needs

Social: activities of daily living

pleasure finances

relatives / informal carers

Spiritual: religion

other sources of comfort + meaning

- Future and advance care planning
- Practicalities of End of Life Care
 withholding and withdrawing treatment
 confirmation of death

Things to consider 2

A palliative approach: life limiting illness

any prognosis

End of Life Care: prognosis weeks – months

Terminal Care: prognosis days – hours

'last days of life'

Is this patient 'sick enough to die'?

Physical symptoms in MND

- Pain
- Continence, constipation, CoBH
- Poor appetite, weight loss
- Choking, aspiration, LRTI, drooling
- Headache, daytime somnolence
- Lethargy, fatigue, weakness
- Breathlessness
- Sensory disturbance
- Other

Physical symptoms

- Similar approach for all symptoms
 - listen to the patient
 - examine / investigate why is this happening?
 - where possible treat underling cause
 - remember non-pharmacological measures
 - as well as symptom control meds.

At the end of life: last days - hours

Address the 'Five Priorities of Care':

- 1. Recognise (and communicate) the possibility of imminent death -
 - Diagnose dying: deterioration, no reversible factors.
- 2. Sensitive communication with the dying person, and those important to them
- 3. Ensure that the dying person, and where appropriate, those important to the, are involved in decision making -
 - Plan for ceilings of intervention: CPR status, tissue donation.
 - Where does the dying person want to be?
- 4. Explore the needs of the 'family' and address these where possible

At the end of life 2

Address the 'Five Priorities of Care':

- 5. Develop an individualised, holistic plan of care
- Nutrition + hydration,
- Respiratory support
- Psychological, spiritual + social support,
- Symptom control incl. PRN SC meds:

anxiolytic, antiemetic, antisecretory, analgesic,

Monitor comfort, (not BP, temp, bloods, sats. ...).



https://book.pallcare.info/



Any Questions?