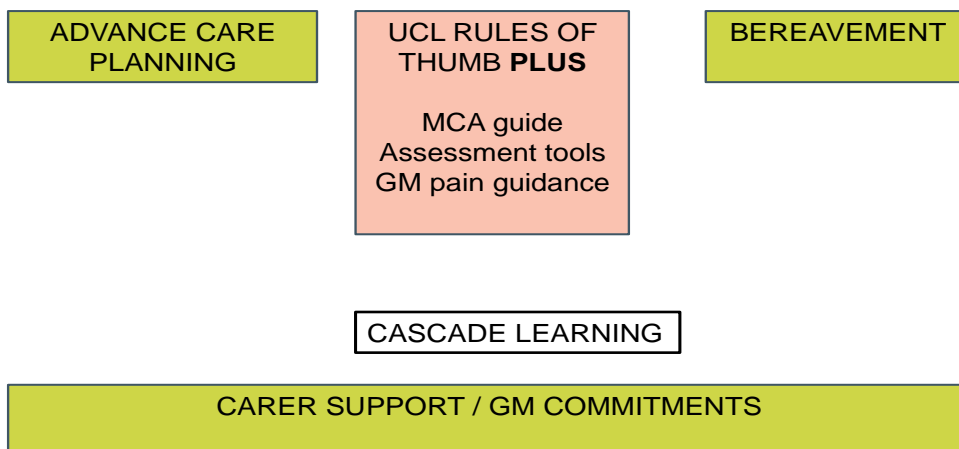


Greater Manchester syllabus for training on End of Life Care of those with dementia



Learning Outcomes of Training:

1. To understand that dementia is a neurodegenerative condition that will shorten life and may impede decision making in the future. There are common non-cognitive symptoms that follow a similar course and although that can be unpredictable, it is possible to recognise the dying phase earlier.
2. To have confidence in taking a palliative approach to people's personalised care and in initiating future planning conversations whilst they are living well. This would include introducing the concept of ceilings of care and using local Advanced Care Planning documents or digital formats.
3. To have confidence in the legal frameworks that surround the decision making processes when someone is dying with dementia i.e. Best Interests.
4. To be able to recognise the dying phase of dementia and use the toolkit to aid decision making around common dilemmas

UCL Rules of Thumb for End of Life Care for People with dementia:

- a. Eating and Swallowing Difficulties – good mouthcare, hydration?
 - b. Agitation and Restlessness / indications where someone with dementia cannot verbally communicate why they are distressed e.g. they are in pain (don't attribute "challenging behaviour" to dementia – investigate environmental and physical causes).
 - c. Reviewing treatment and interventions at the end of life
 - d. Providing routine care at the end of life
5. To understand the importance of the family and/or carer in getting personalised care right e.g. take into consideration age, culture, religion. Among other things this should include their prior knowledge of the person with dementia, the importance of their input to future planning and their ability to recognise early signs of deterioration.

6. To recognise the impact on carers of meeting the needs of the person with dementia and the complex early and late grief that may be experienced.

Dementia Specific Resources for people with dementia and carers:

- DEEP/Pennine Care “Let’s Talk About Death Shall We” [leaflet](#)
- Dementia UK/Admiral Nurses “Understanding Dying” [leaflet](#)
- Alzheimer’s Society End of Life Care [Guidance](#)
- Alzheimer’s Society “[This is Me](#)” document for professionals to understand who the person with dementia is to enable person centred care.

Dementia Specific Resources for professionals supporting people dying with dementia:

- UCL Rules of Thumb [document](#) for End of Life Care for People with dementia
- North West Coast Strategic Clinical Networks Palliative Care [Guidelines](#) in Dementia 2nd Edition
- [NHS England My Future Wishes](#) – Advance Care Planning for people with dementia in all care settings
- [Abbey Pain Scale](#) to assess pain in non-verbal patients with dementia
- [Document](#) that includes a film sharing the perspectives of people living with dementia and their carers

Additional General Resources:

- Greater Manchester Commitments to End of Life Care?
- Greater Manchester palliative care pain and symptom control [guidelines](#) for adults
- <https://compassionindying.org.uk/> have created a [guide](#) to help with future planning
- Greater Manchester Delirium Toolkit
- [RESTORE2](#) A physical deterioration and escalation tool for care homes.

Locality Specific Resources

- Contact for palliative care/hospice
- Contact for dementia specialist nurse
- Contact for Later Life CMHT
- Contact Independent Mental Capacity Advocate (IMCA) services
- Contact for local bereavement services