

**GREATER MANCHESTER SYLLABUS FOR  
TRAINING ON END OF LIFE CARE OF THOSE  
WITH DEMENTIA**

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

ADVANCE CARE  
PLANNING

UCL RULES OF THUMB PLUS  
BEST INTERESTS / MENTAL  
CAPACITY ACT  
ASSESSMENT TOOLS  
GREATER MANCHESTER PAIN  
GUIDANCE

BEREAVEMENT

CASCADE LEARNING

CARER SUPPORT / GREATER MANCHESTER COMMITMENTS

### 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 with dementia'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 advance 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 UCL (University College London) rules of thumb toolkit to aid decision making around common dilemmas

### UCL rules of thumb for end of life care for people with dementia:

- Eating and swallowing difficulties – including good mouth care
- Agitation and restlessness - indications where someone with dementia cannot verbally communicate why they are distressed e.g. they are in pain (important not to attribute “challenging behaviour” to dementia and to look for cause of distress)
- Reviewing treatment and interventions
- Routine care

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 their 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 Guide](#) for end of life care for people with dementia
- North West Coast Strategic Clinical Networks palliative care [guidelines](#) in Dementia 2<sup>nd</sup> Edition
- [NHS England My Future Wishes](#) – advance care planning for people with dementia in all care settings
- [Recording](#) of Yorkshire and Humber Strategic Clinical Network virtual “Advance Care Planning” and “Best Interests Conversations” training delivered to care homes and domiciliary care staff
- [Abbey Pain Scale](#) to assess pain in non-verbal patients with dementia
- [Document](#) created in partnership with Tide and DEEP that shares the perspectives of people living with dementia and their carers on end of life care and post bereavement support – includes film.

#### **Additional General Resources:**

- Greater Manchester [commitments to end of life care](#)
- Greater Manchester palliative care pain and symptom control [guidelines](#) for adults
- [Compassion in dying](#) have created a [guide](#) to help with future planning
- [RESTORE2](#) - A physical deterioration and escalation tool for care homes.
- Social Care Institute for Excellence - using the Mental Capacity Act film (17mins49)
- Social Care Institute for Excellence - Mental Capacity Act making 'best interests' decisions moving home film (6mins10)

#### **Locality specific contacts (to be provided)**

- Contact for palliative care/hospice
- Contact for dementia specialist nurse
- Contact for later life Community Mental Health Team
- Contact for Independent Mental Capacity Advocate services
- Contact for local bereavement services

# GET IN TOUCH

[gmhscp.dementiaunited@nhs.net](mailto:gmhscp.dementiaunited@nhs.net)  
[dementia-united.org.uk/](http://dementia-united.org.uk/)

 [@GM\\_HSC](https://twitter.com/GM_HSC)

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