

End of Life Care Anticipating
Needs
In patients with Dementia

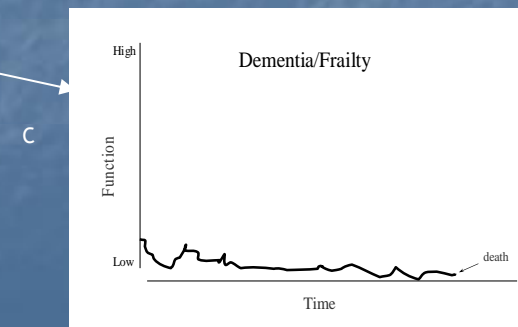
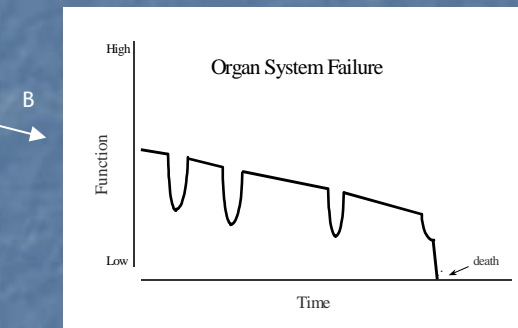
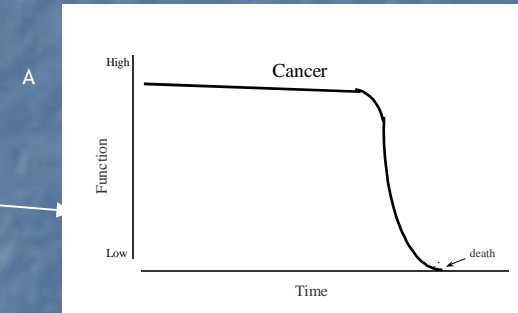
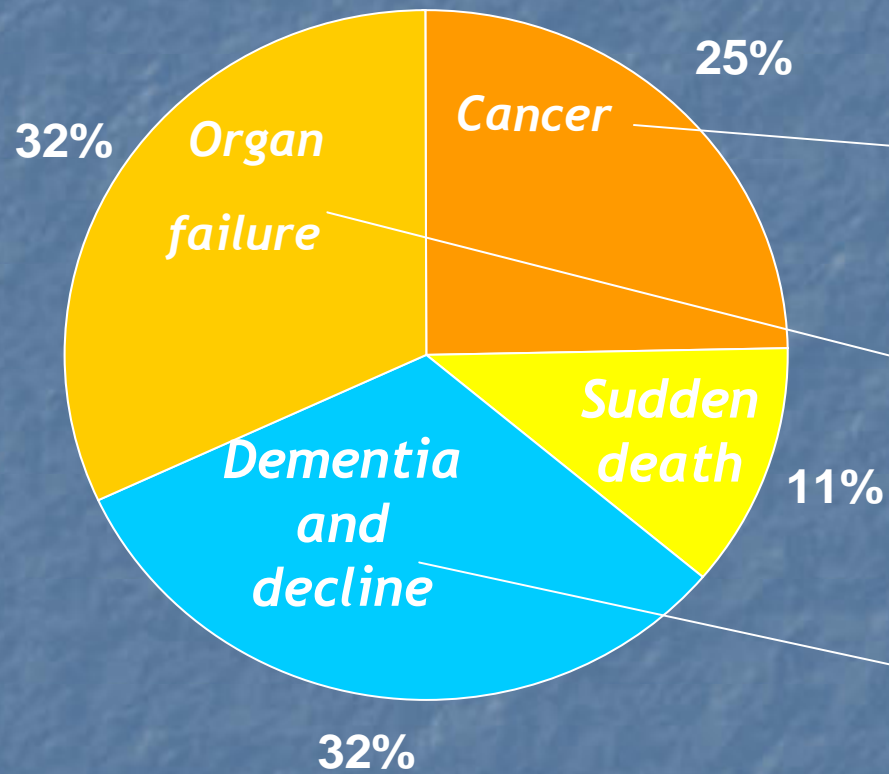
Nottingham NHS CitiHealth
End of Life Care Team

What are the elements of good EOLC?

- Physical – managing symptoms such as pain, sickness, tiredness or loss of appetite; good ‘tender loving care’ such as preventing pressure sores
- Psychological – giving emotional support to the resident and those who care about them, giving time to listen to them and understand their concerns
- Spiritual – a need to explore thoughts about the meaning of life, or concerns about what happens after death.
- Social – giving support and advice on practical matters such as getting their affairs in order
- Advance care planning – ensuring appropriate plans are in place. Wishes and preferences and possible future care options are discussed and documented

Why is it difficult in dementia ?

Illness trajectories



Source: Lynn and Adamson (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*

Causes of death in patients with dementia

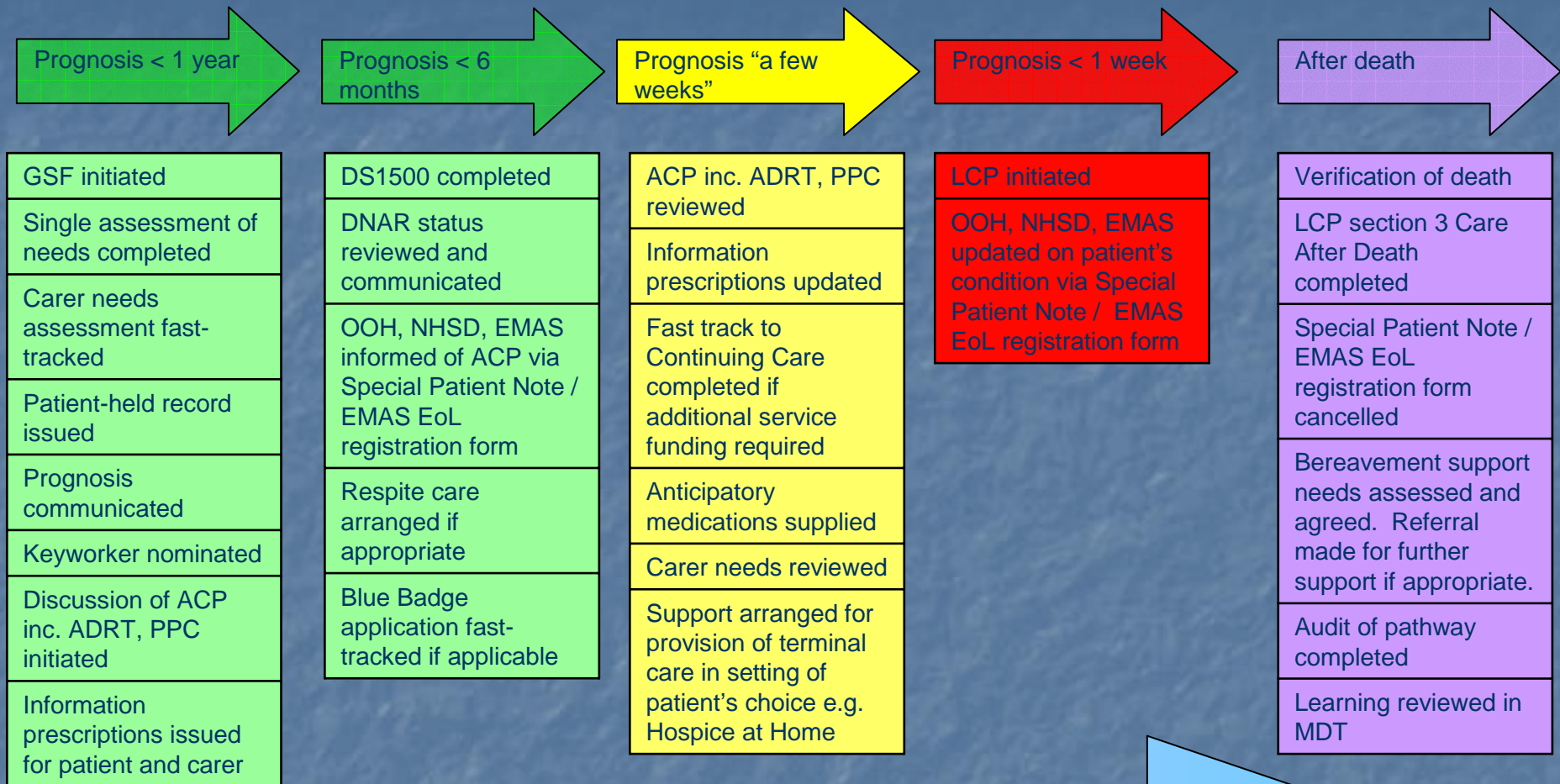
- Immobility and its complications: orthostatic pneumonia, DVT and PE, and pressure sores.
- Falls and trauma – including hip fractures
- Swallowing difficulties and appetite loss, leading to compromised nutrition and aspiration pneumonia
- Proneness to infection – due to age, poor nutrition and communal living (e.g. influenza, other pneumonias and diarrhoeal diseases)
- Other fatal diseases (heart disease ,cancer)

Diagnosing Dying

Triggers for supportive /Palliative Care

- Use the Surprise Question
- Clinical Indicators
- Choice Need

Nottinghamshire End of Life Care Pathway



The following will be provided at the appropriate time according to individual patient and carer needs:

Specialist care (condition-specific and/or palliative)	Self-help and support services
Specialist psychological support	Equipment
Respite care	
Spiritual support	

24 hour access to advice and co-ordination of care underpin the pathway

Triggers

- Swallowing problems
- Recurring infection
- Marked decline in physical status or weight loss
- First episode of aspiration pneumonia
- Worsening cognitive difficulties
- Recurring hospital admissions.

Prognosis < 1 year

- Gold Standards Framework (GSF)
 - Systematic evidence based approach to optimising the care for patients nearing the end of life in the community
 - To improve the organisation and quality of palliative care for all diagnoses with regular multi disciplinary review meetings
- Discussions re Advance Care Planning (ACP)
 - Entirely voluntary process
 - Puts patient in control, enabling choice
 - Preference regarding delivery of care
 - Preferred Priorities of Care (PPC) - usually place of care
 - Advance Decision to Refuse Treatment (ADRT)
 - Do Not Attempt Resuscitation (DNAR)

Prognosis < 6 Months

- DS1500
 - Highest rate of attendance allowance (non means tested)
 - Accessed where patient has prognosis of 6 months or less
- DNAR status reviewed
 - Clinical decision
 - GP or Consultant led
- Any clinical advance decision inform
 - NEMS - Special Patient Note
 - EMAS - End of Life Care Decision

Last few weeks / days

- Encourage participation by the patient's family and friends, to review decision making and practical care, according to their views and wishes.
- Reassess needs. Look for non-verbal clues of distress (agitation, grimacing, groaning), examine possible sites of pain (pressure points)
- Treat distressing symptoms, and stop all unnecessary medication.
- Ensure anticipatory medications are in place
- Dry mouth is caused by mouth breathing, drugs, and/or poor fluid intake. Use local measures to relieve dry mouth. These must be done regularly and assiduously. Relatives can usefully help in doing this.
- Continue skin care and containment of incontinence – use a sheath or pads if necessary
- Support family and friends
- bereavement care

And finally

People with dementia deserve a good death



Together we can make it happen