



PRINCIPLES OF END OF LIFE CARE

Basics

- 1% of the practice population will die each year; 80% of care home residents are in their last year of life.
- Not just relevant for cancer – consider those dying of long-term conditions, dementia, frailty.
- 'Would you be surprised if this patient died in the next year' – if answer is no, add to palliative care register.
- Look out for key decisions in letters e.g. not to start dialysis.

Identifying end of life

- [GSF](#) and [SPICt](#) tools can be useful.
- General – unplanned admissions, ↓ performance status (e.g. bed/chair bound), ↑ need for carers, weight loss, symptoms despite optimal management, family needs more support.
- Dementia – can't walk/dress/eat, incontinence, no speech, recurrent infections.
- CVD – SOB/CP at rest or on minimal exertion.
- COPD – MRC grade 4/5, FEV1 <30% predicted, needs long-term O2, previous ventilation, R heart failure, >6/52 oral steroids in last 6/12.
- CKD – stage 4/5, complicates other health issues, not fit for dialysis.
- Liver – diuretic resistant ascites, encephalopathy, bacterial peritonitis, recurrent variceal bleeds.
- Neurological – progressive deterioration, can't control symptoms, dysphagia → recurrent aspiration, ↑ difficulty in speech.

ORGANISATION OF END OF LIFE CARE

Regular palliative care meetings

- Multi-disciplinary (GP, community, palliative care team).
- Prioritise who is discussed at each meeting (RAG rating).
- Consider psychosocial and bereavement needs.
- Continuity of care crucial.
- Details on how to run meeting in resources section of toolkit.

Prioritisation

- RAG rating:
 - Red – last days of life
 - Amber – last weeks of life, ↑ decline.
 - Green – last months of life, advancing disease.
 - Blue – incurable but could live for years (e.g. dementia).

Improving care

- Discuss all deaths – in retrospect, should some of those not on register have been there?
- Review those who died in hospital if it wasn't preferred place of death – was admission preventable?
- Encourage culture of trust/learning.

LAST DAYS OF LIFE

How to identify

- Not easy!
- ↑ fatigue, agitation
- ↓ appetite/weight, conscious level, speech, mobility.
- Noisy/altered breathing.
- Dehydration – mouth and lip care may be more important than actual fluid intake.
- See resources section and local guidance for detailed information on symptom management.
- Consider getting [Daffodil Standard](#) accreditation.

Communication

- Consider [capacity](#)/lasting power of attorney and previously expressed wishes about how much they want to know and who should be involved in care decisions.
- Be honest, including about uncertainty and why some wishes may not be achievable.
- Discuss spiritual needs and plans for after death if this is wanted.

Don't forget.....

- Use local systems so out of hours/ambulance has info.
- 'Just in case' meds in house if appropriate and access to professional to set up syringe driver out of hours.
- Stop unnecessary meds and avoid IM injections.
- Consider if pain is due to a reversible cause e.g. urine retention or constipation.
- DNACPR form in house.
- Carer support, during and after the final days of life, and signpost to practical/financial help (e.g. via social prescriber).