Approach to the care of the dying person: Last Days of Life

Palliative Care Study Day

24th September 2026

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Dignity | Respect | Compassion | Collaboration | Excellence | Kindness

St. Francis Hospice Dublin

Outline of Presentation

- What is a good death?
- Diagnosis of dying
- Symptom control
- Care of the family
- Resources

Background: Palliative care provision

National Adult Palliative Care Policy (2024)

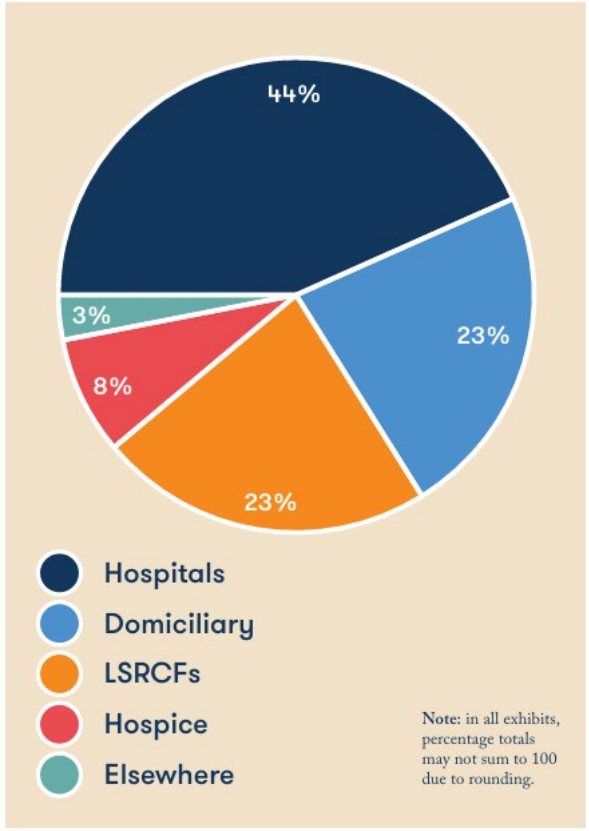
- Outlines an integrated approach palliative care in Ireland

- ‘Palliative care’ – umbrella term for services providing a palliative care approach (generalist) and/or specialist palliative care

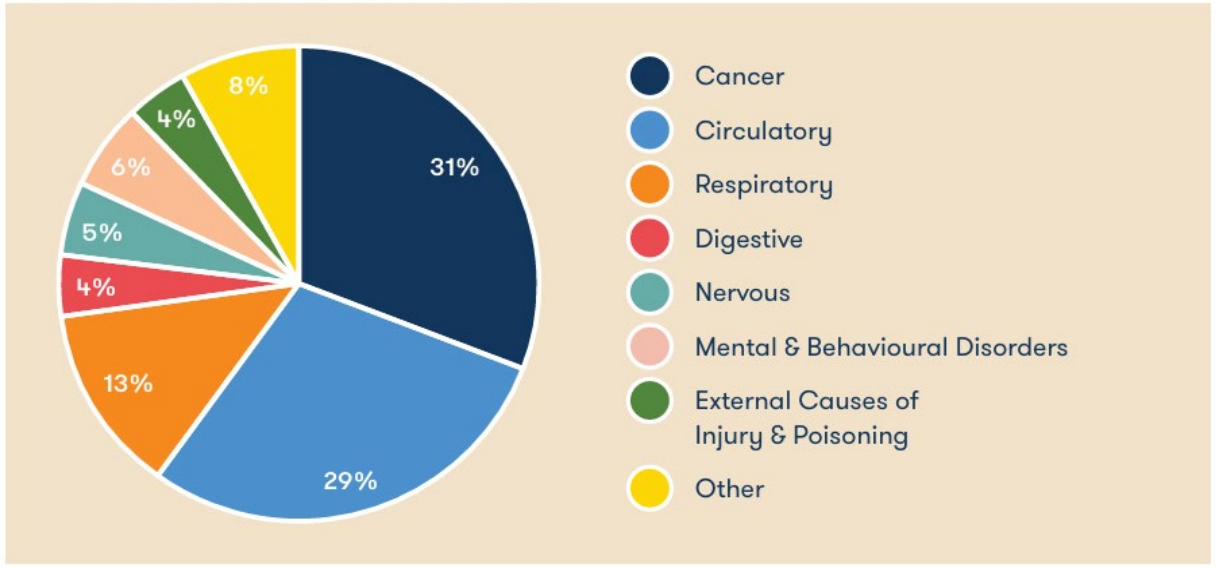
- Care at the right place, right time, right people
  - *‘Live as well as possible for as long as possible and then to have as ‘good’ a death as possible’*
  - *Empower communities to be ready to help people in their journey through illness, death, and bereavement*

Deaths: Where? Underlying Conditions?

All deaths in Ireland by place of death, 2018 (%)

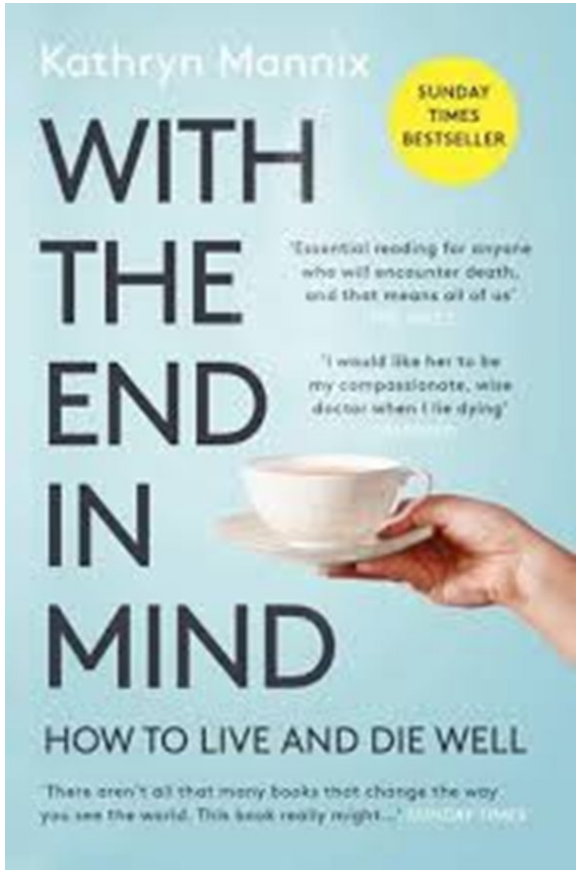


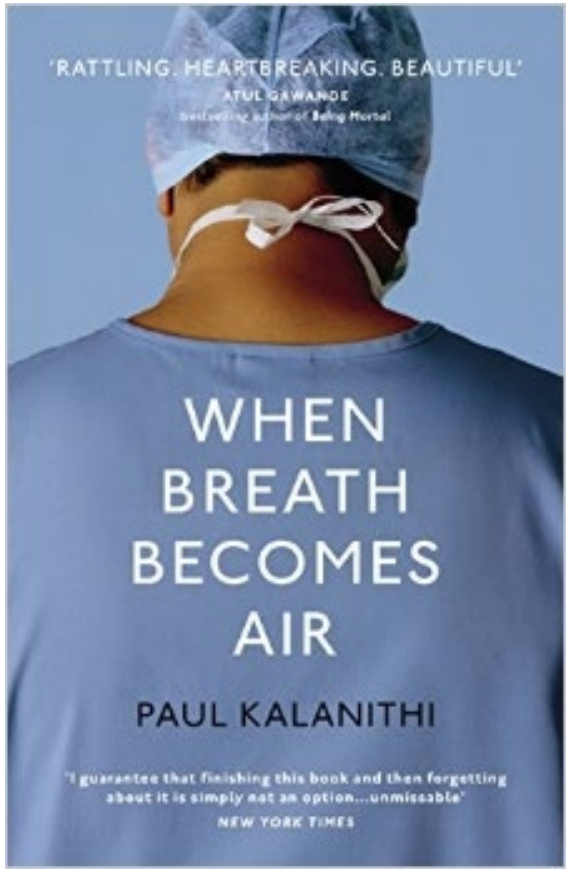
All deaths in Ireland by cause of death, 2018 (%)



Matthews S, Pierce M, O'Brien Green S, Hurley E, Johnston BM, Normand C, May P. Dying and death in Ireland: what do we routinely measure, how can we improve? Dublin: Irish Hospice Foundation; 2021.

Reading


Kathryn Mannix
SUNDAY TIMES BESTSELLER
WITH THE END IN MIND
HOW TO LIVE AND DIE WELL


'RATTLING. HEARTBREAKING. BEAUTIFUL'
ATUL GAWANDE
WHEN BREATH BECOMES AIR
PAUL KALANITHI
'I guarantee that finishing this book and then forgetting about it is simply not an option...unmissable'
NEW YORK TIMES

‘Good Death’

- No definite, shared understanding of what the characteristics of a good death are
- The concept of a good death is highly individual, changeable over time and based on perspective and experience
- What is a good death to one individual may not be to another

Institute of Medicine: Definition of a Good Death

- Free from avoidable distress and suffering for patients, families and caregivers
- In general in accordance with the patients' and families wishes
- And reasonably consistent with clinical, cultural and ethical standards

End-of-Life Care Committee of the Institute of Medicine of the National Academies (IOM): *Field MJ, Cassel CK (eds) Institute of Medicine. Approaching death: Improving care at the End of Life. Washington, DC: National Academies Press; 1997.*

Observations of Patients, Families and Providers

Methods

Focus group discussion & interviews with:

- Physicians
- Nurses
- Social workers
- Chaplains
- Hospice volunteers
- Patients
- Recently bereaved family members

Results

- Pain and symptom management
- Clear decision making/communication
- Preparation for death
- Completion – resolving unfinished issues
- Contributing to others – memories, legacy
- Affirmation of the whole person – recognition of the person

Steinhauser, K.E. and E.C. Clipp (2000), ‘ In search of a Good Death: Observations of Patients, Families and Providers,’ Annals of Internal Medicine 132 (10):825-832

Good Death: Team Approach

- Team effort
- Nurses, doctor, chaplain, social worker, carers...
- Individualised care
- Death ≠ failure
- Family as the unit of care

- Often requires ongoing assessment, support and symptom control
- Communication

‘Diagnosing’ dying

- When are we dying?
  - End of life ≠ dying

- **End of life:** Period when a person is living with an advanced or progressive condition and death is anticipated - the last months, weeks, or days of life

- **Dying:** process of actively approaching death - likely to occur within hours or day

- Wrong more often than right

Diagnosing dying – Prognostication

Estimation of clinicians[1]

- Over-optimistic 63%
- Over-pessimistic 17%
- Correct 20%

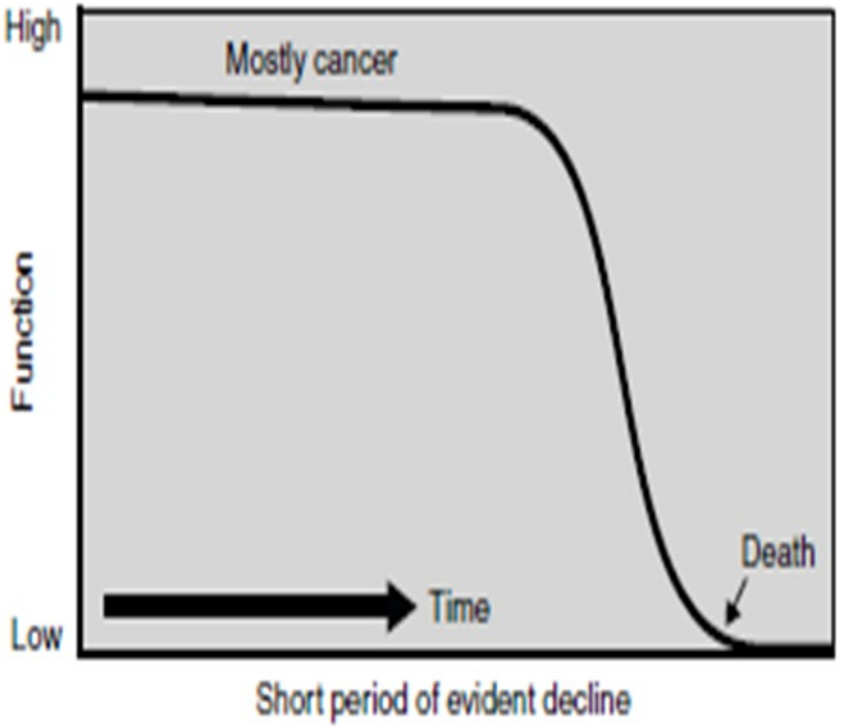
Reasons for uncertainty

- Inexperience[2]
- Attached to patient[2]
- Reluctant to see “our” treatments “fail”
- Attempting to be too exact (specific time vs. time range)
- Sudden unexpected events – unpredictable
- Individuals are different – variability

1. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ. 2000 Feb 19;320(7233):469-72. doi: 10.1136/bmj.320.7233.469.
2. Smith JL. Why do physicians overestimate life expectancy of a person who is terminally ill?: Commentary. West J Med. 2000 May;172(5):313-4. doi: 10.1136/ewjm.172.5.313.

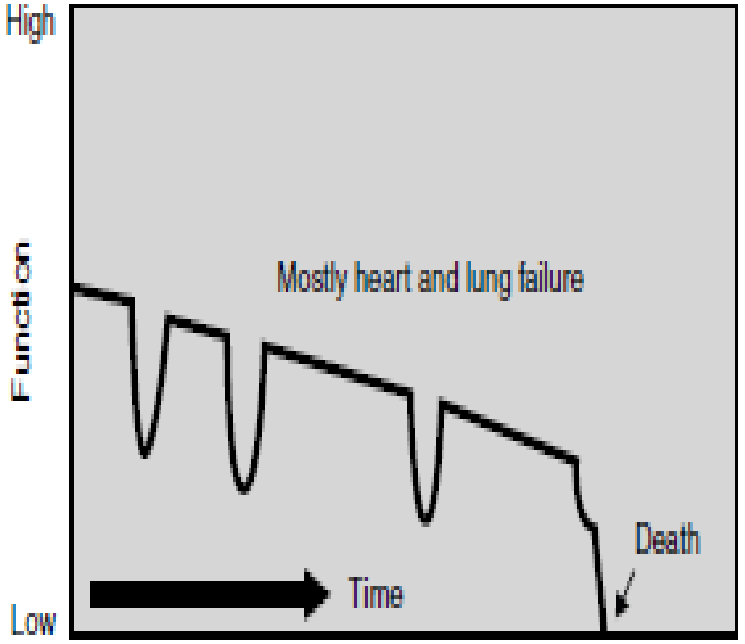
Typical Trajectories

Cancer



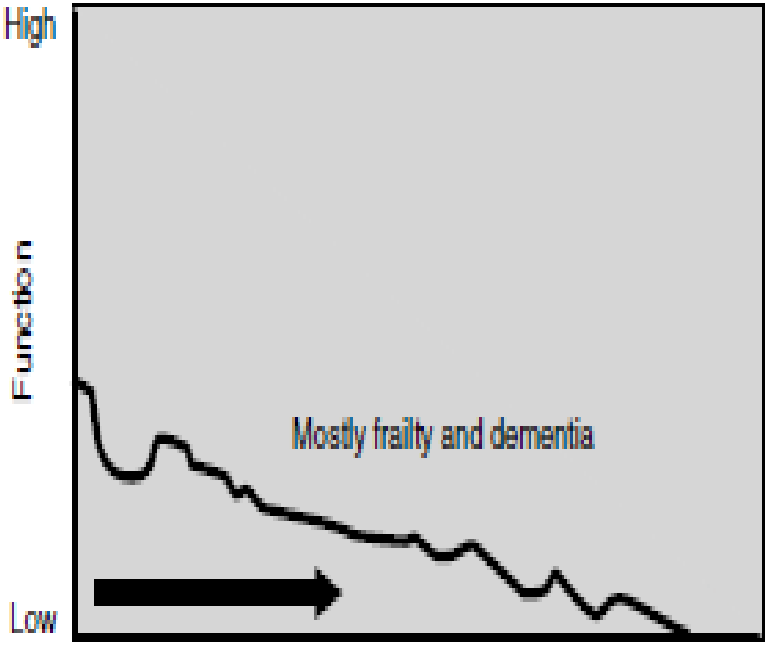
Short period of evident decline

Organ Failure



Long-term limitations with intermittent serious episodes

Frailty / Dementia



Prolonged dwindling

‘Diagnosing’ dying: Signs

- Rate of deterioration key clue – observation/assessment of trajectory
- Day to day deterioration with no reversibility

- Reduced interaction
- Reduced activity
- Sleeping more
- Reduced level of consciousness

- Vital signs not reliable

Is this person dying? - Caution

- Consider potentially reversible causes:
  - Infection
  - Opioid toxicity (delirium, myoclonus, vivid dreams or hallucinations)
  - Hypoglycaemia
  - Hypercalcaemia
  - Seizure disorder
  - Benzodiazepine toxicity
  - Uraemia, due to reversible cause – e.g. obstructive uropathy

- Clarification of treatment escalation plan
  - Comfort focus vs. treating reversibility

Goals for Last Days of Life

Patient comfort

- Physical
- Emotional
- Spiritual

Dignity

Support family

- Information
- Involvement

Respect patient & family wishes

Care planning

- Prioritise symptom control and comfort.
- Stop investigations and interventions that no longer benefit the patient.
- Avoid unnecessary intervention:
  - Blood tests/phlebotomy
  - Routine vital-sign monitoring
- Review medications and discontinue those that are no longer essential or do not contribute to comfort.
- Reduce the burden of oral medication when swallowing becomes difficult.

Common symptoms at End of Life

Symptom	Prevalence
Pain	52%
Agitation / restless	42%
Excess resp. secretions	56%
Dyspnoea	22%
Urinary dysfunction	53%

A Review of Clinical Signs and Symptoms of Imminent End-of-Life in Individuals With Advanced Illness. Ijaopo EO et al. A Review of Clinical Signs and symptoms of Imminent End-of-Life in Individuals With Advanced Illness. Gerontol Geriatr Med. 2023 Jun 26;9:23337214231183243. doi: 10.1177/23337214231183243.

Pain in the Dying Person

Assessing Pain

- As consciousness decreases, the patient may be unable to verbally report pain

- Pain should therefore be assessed using non-verbal signs, including:
  - Grimacing or frowning
  - Groaning or other vocalisations
  - Tense posture/body language

Pain in the Dying Person

Non-pharmacological

- Repositioning
- Treat reversible cause (e.g. constipation, catheterise)

Analgesia in the Last Days

- Choice based on patient's clinical condition and ability to take medication
- WHO Analgesic latter
- Strong opioids are particularly useful because they can be administered subcutaneously and incorporated into a subcutaneous infusion
- PRN analgesia may be sufficient.
- If repeated breakthrough doses are required, a CSI can provide medication continuously and avoid repeated injections.

Opioids – important considerations

- Opioid use must take account of:
  - Previous opioid exposure
  - Current symptoms
  - Comorbidities
  - Organ function
  - Response to medication

- Transdermal opioids – usually for stable pain
- An existing opioid patch may be left in place near the end of life, with additional analgesia provided as required

Dyspnoea

- Reverse what is reversible (if appropriate)
- Non-pharmacological/General supportive measures:
  - Explanation
  - Position
  - Address associated fear, anxiety – Breathing exercises
  - Fan/cool airflow, relaxation techniques
  - O2 if symptomatic benefit, least invasive

Pharmacological

- Opioids – not what you think!
  - Limited evidence in breathlessness with longer prognosis, better evidence when dying
- Benzodiazepine
  - E.g. midazolam subcutaneously, as required +/- regular

Agitation/Restlessness

Reversible causes

- Pain
- Urinary Retention
- Constipation
- Pyrexia
- Anxiety and fear
- Cerebral irritability
- Medication side effects

Management

- Management of the above issues
- Explanation, reassurance
- Family, music
- Medications e.g. midazolam s/c PRN or regular via CSI

Nausea & Vomiting

- Uncommon as new symptom

- Consider Underlying cause
  - Constipation
  - Biochemical – uraemia, hypercalcaemia
  - Bowel obstruction

- Common anti-emetics
  - Haloperidol
  - Cyclizine
  - Levomepromazine

Respiratory Tract Secretions

- “Death Rattle”
- Fluid pooling in hypopharynx

Management

- Communication and reassurance
- Not drowning / choking
- Repositioning

- Medications to reduce volume / production
  - Hyoscine butylbromide (Buscopan) – subcutaneous
  - Glycopyrronium bromide - subcutaneous

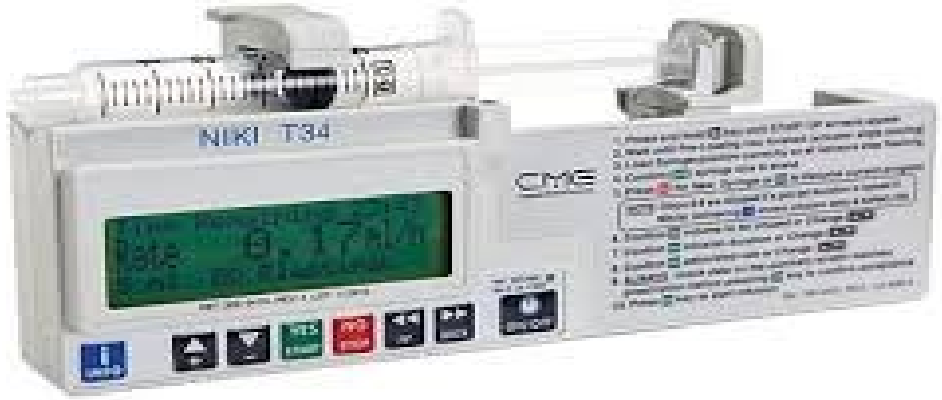
When the Oral Route Is No Longer Possible

- Difficulty swallowing is common in the last days of life.
- Medication may therefore need to be administered subcutaneously.
- Subcutaneous administration is often more practical than intravenous administration in this setting.
- If medication is needed regularly, a continuous subcutaneous infusion (CSI) can be used.
- PRN/“as required” medication should also be available for breakthrough symptoms.

Continuous Subcutaneous Infusion (Syringe Driver)

Indications

- Patient too weak to swallow oral drugs
- Intractable vomiting
- Severe dysphagia (any cause)
- Poor GI absorption



- Convenient, constant, no iv line needed

- 4-5 hours before therapeutic effect achieved

Sudden Events/Emergencies

Sample causes

1. Haemorrhage (rare)
2. Seizure
3. Stridor

- Rare
- Traumatic
- May be pre-empted/predicted
- Inform family of risk and what to do
- Emergency medications at hand e.g. midazolam

Care of Family/Carers

"Because of the support he received, my husband died well. Because he died well, I live well" (Forum on End of Life Care, Dublin Castle, 2013)

- Communication / information
  - Explanation of what to expect
  - Answer questions
- Honesty
- Acknowledge:
  - Previous experiences
  - Grieving – anticipatory
  - Guilt
- Children
- Honesty

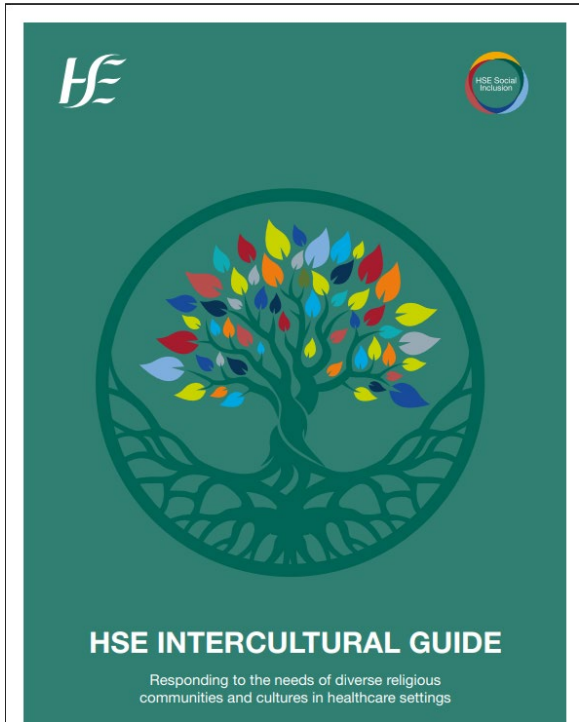
Moment of death

- Private, family time
- Allow as much time as needed, with privacy
- Respect wishes regarding prayers, rituals
- Staff: Slow, calm

Pronouncement of Death

- No palpable carotid pulse
- No heart sounds on auscultation
- No observed respiratory effort
- No breath sounds on auscultation
- Pupils dilated and not reactive to light

- Consider role of coroner



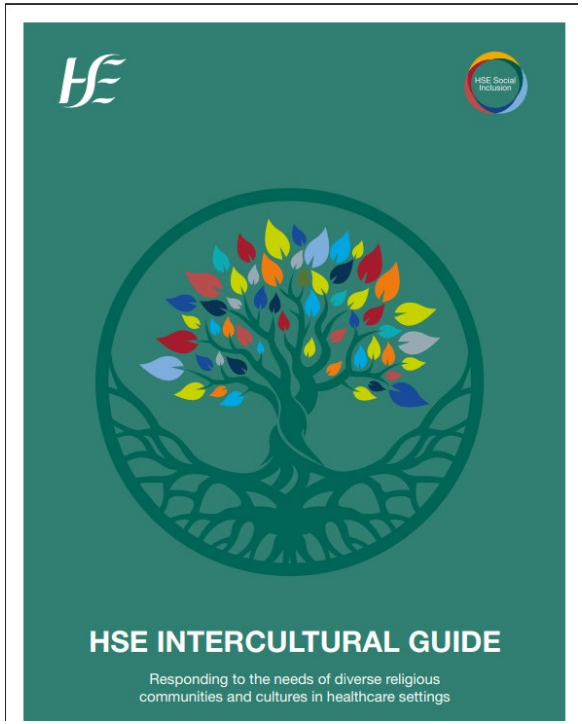
Care after Death

Practicalities

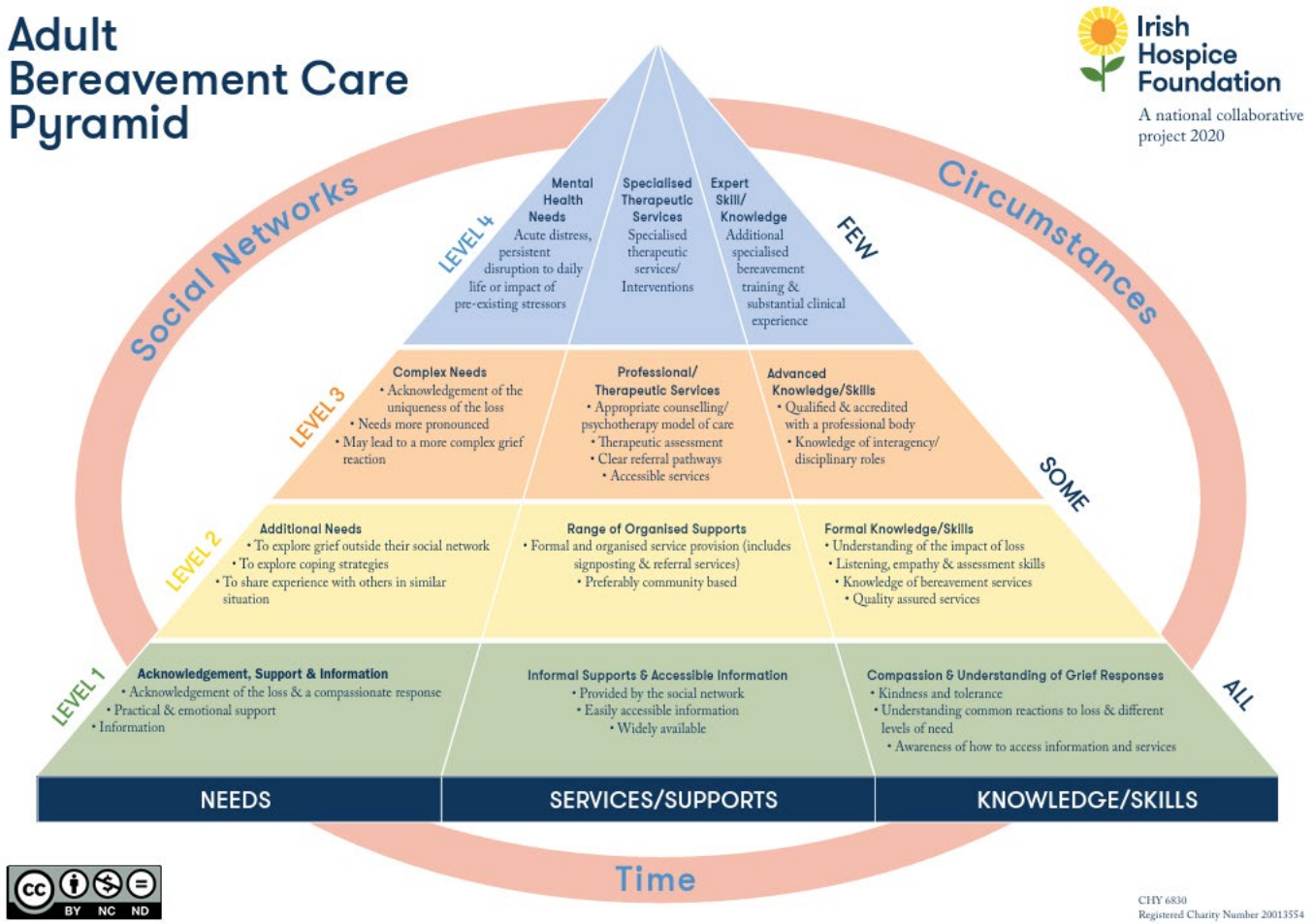
- Certifying the death +/- coroner
- Contacting undertakers /death notice
- Rituals – HSE Intercultural guide

Care of the team

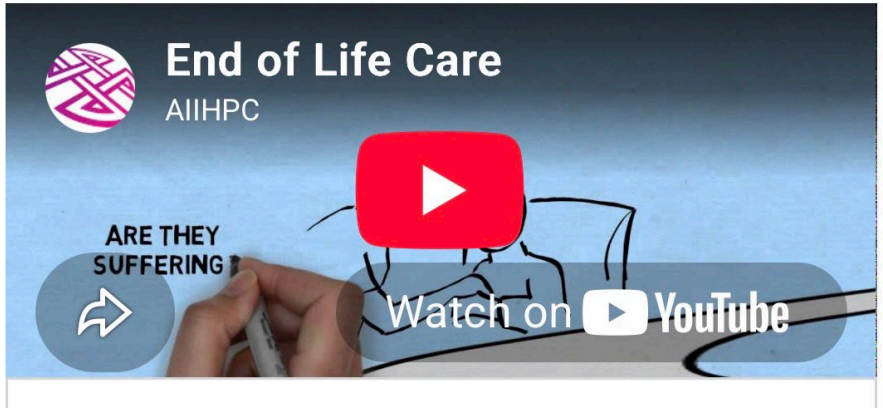
- Colleagues
- Yourself
- Debriefing/reflections



Bereavement support



Resources: Explaining Death

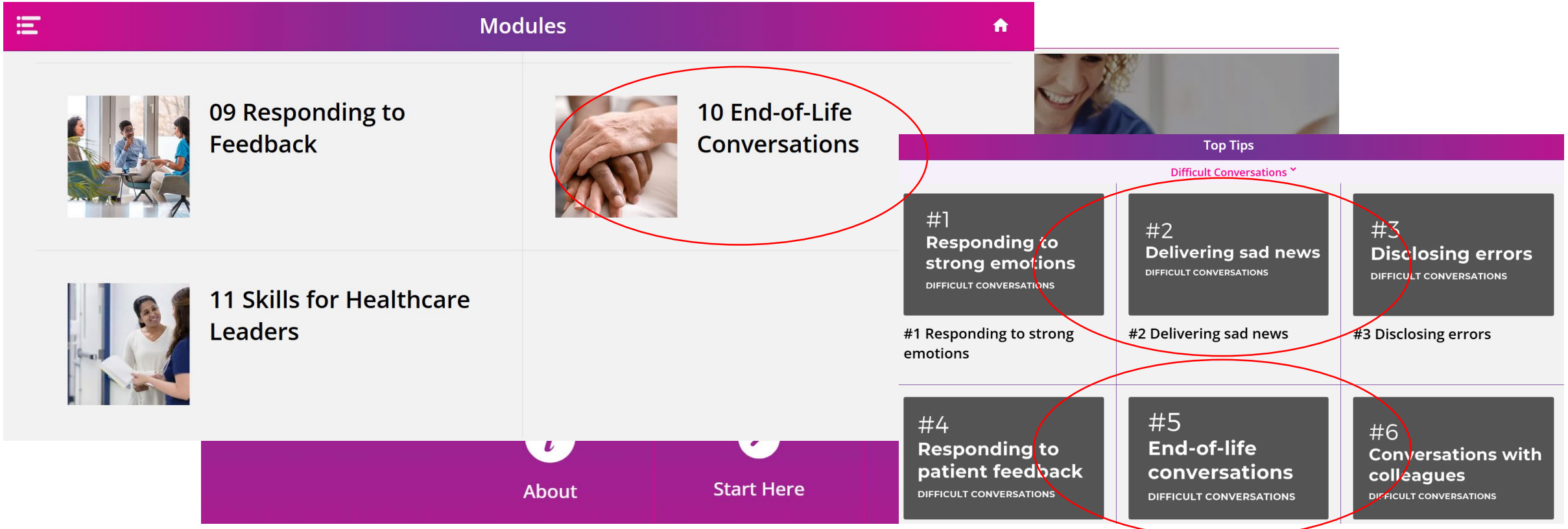


- Video for patients/families

- Dr Kathryn Mannix
- https://www.hospiceuk.org/latest-from-hospice-uk/what-happens-when-someone-dying

Resources: National Healthcare Communication Programme

- Initiative to support clinicians to improve communication
- Modules & top tips



1. *WHO: Effective communication in health care: implementing a national training programme in Ireland*
2. *National Healthcare Communication Programme* https://www.nhcprogramme.ie/about-nhcp

Resources: Training/Workshops

Hospice Friendly Hospitals

- End-of-Life Care Education and Training
- Workshops for staff working in hospitals

CARU

- Continuous learning programme
- support and empower nursing home staff in the delivery of person-centred palliative, end-of-life

Conclusions

- Comprehensive approach: Physical, psychological, social/family
- Team input
- Focus on person's and family wishes, beliefs
- Communication with person/family is key: Explanation of situation, what to expect
- Anticipate issues that may arise: Plan, prepare, pre-empt
- Your role in care of dying person: Responsibility and a privilege
- Resources for HCPs/families: Irish Hospice Foundation, Palliative Care Hub

Thank You

Questions?