The process of dying

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End of life

- As every person’s lived experience is unique, so too is their dying.
- What is meant by a good death is something that is deeply individual.
  - A sense of life completion,
  - Being free from suffering,
  - Being treated with dignity and respect,
  - Being surrounded by family.

- Maintaining presence and relationships,
- Communicating and honouring wishes,
- Meeting spiritual needs.

Bekkema et al., 2015; Cithambarm et al., 2021.

Recognising dying

- ‘Part art, part science’ (Kennedy et al., 2014)
- Involve a competent professional
- Unexpected or expected deterioration?
- Seek expert opinion if disagreement
- Note: not all deaths may be anticipated

Gastrointestinal	Decreased interest in food or fluids Swallowing difficulties Weight loss
Neurological and musculoskeletal	Frailty and weakness Profound fatigue Delirium Reduced level of consciousness
Respiratory	Altered breathing pattern Noisy airway secretions Weak or absent cough
Circulatory	Altered pulse and cool peripheries Mottled or discoloured skin Cyanosis
Urinary	Decreased or absent urinary output
Psychosocial and spiritual	Withdrawal and reduced social interaction Personality and mood changes ranging from restlessness, anxiety, fear to peaceful awareness of impending death.

Responding to signs that a person may be dying

- Providing a decision is made that the person appears to be dying and in situations where the goals of care are focused on **comfort**, the next actions are to:
    - Talk to the person and/or family
    - Agree on an individual plan of care- place of care, food and drink, symptom control and holistic support
    - Ensure meds are available for symptom control and unnecessary medications are discontinued
    - Ensure all supports and resources are in place
    - Inform other relevant staff and HCPs
    - Prepare family, friends and any staff who may be involved

Communicating with the person with intellectual disability about serious illness and death

Experience of Death According to Intellectual and Socio-Emotional Age of the Person with Intellectual Disability, adapted from Meusen-van de Kerkhof et al. (2004)

Level of ID	Experience of the person	Support
Mild **IQ: 50/55 to 70**	Clear realisation of death	Engage in **open communication where desired**; engage with spiritual or religious supports where desired
	Logical thought coupled to specific events	**Offer closeness**: share experience and offer participation in rituals or behaviours associated with loss and grief
	Grieving process comparable to general population	Engage in reminiscence, life story work; **explore the feelings** that lie behind reactions
Moderate **IQ: 35/40 to 50/55**	Limited realisation of death Searching for logical explanations of illness and death; growing comprehension of the irreversibility of death Basic capability of putting oneself in another person's place; projection of own feelings onto other person; feelings of guilt and fear as reactions to other people's grief Grieving reactions may be delayed	**Offer the opportunity to express grief; give logical explanations to questions**, make connections visible where appropriate and desired; engage with spiritual or religious supports where desired **Offer closeness**: 'be there' for the other person; make use of stories and photographs to support reminiscence; maintain supportive environment

Level of ID	Experience of the person	Support
Severe **IQ: 20/25 to 35/40**	**Limited realisation of death**, death seen as temporary, magical thinking, realisation of death as irreversible starts to grow as deceased person is increasingly missed Beginning of linking up events such as sickness and death, understanding of death linked to **concrete experiences** Egocentric way of thinking Limited development of words, express emotions non-verbally Model behaviour of others has strong influence on experience of illness, loss and death	Keep daily life **organised and familiar** as far as is possible Offer closeness: 'be there' for the other person Make concept of death clear by answering questions (if asked) on a concrete level; **adjust imaginary images of death to prevent fear**; engage with spiritual or religious supports where desired Watch own (model) behaviour, make own emotions known, watch own language Use a variety of approaches to explore **emotions** e.g. play, music, art

Level of ID	Experience of the person	Support
Profound **IQ: Up to 20/25**	No realisation of death, loss mainly causes a disruption of **bonding, security and confidence**, understanding is based on sensual (body-centred) impressions and experiences Communication is non-verbal Reactions of mourning emerge only at a later time	Offer **closeness**: physical contact Keep daily life **organised and familiar** as far as is possible Important resources: posture, facial expression, intonation of voice, making use of one's favourite senses, respectful touching Allow people to concretely experience change but within the space of a secure environment; offer concrete experiences to help cope with loss and grief; engage with spiritual or religious supports where desired

Stancliffe, R.J., Wiese, M.Y., McCallion, P. & McCarron, M., *End of Life and People with Intellectual and Developmental Disability. Contemporary Issues, Challenges, Experiences and Practice*., 1, Switzerland, Palgrave Macmillan Cham, 2022, XXXIV - 519pp

Communication with family

Symptom assessment and management

- Self-report; symptom assessment tools; team working and proxy reporting
- Medication and non-medication strategies
- Anticipatory medications- pain, nausea, breathlessness, anxiety, confusion, chestiness
- Use of a continuous subcutaneous infusion/ syringe driver/ ‘pump’

Ethical dilemmas

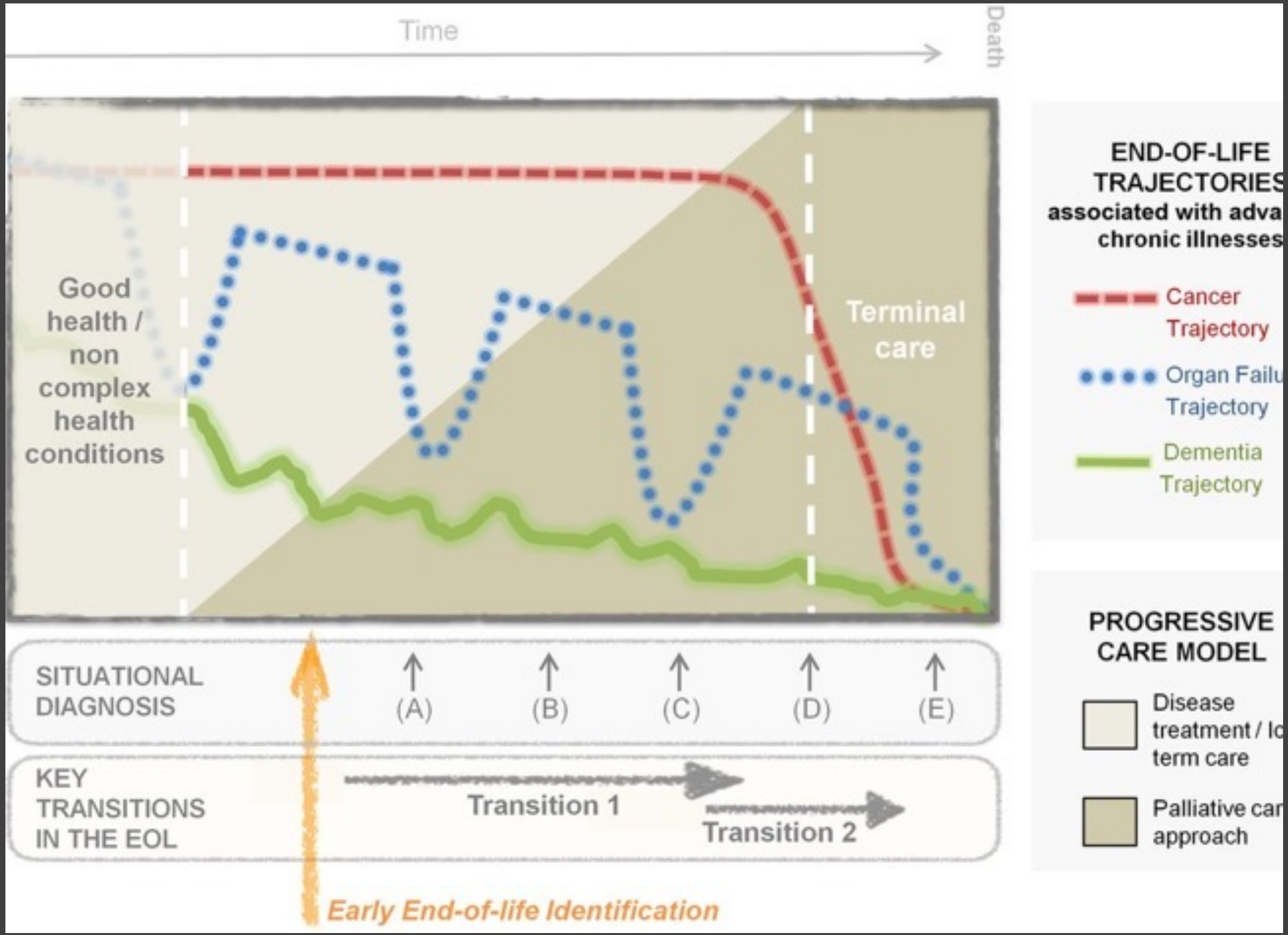
- Decisions occurring at the end-of-life may be clinically complex and emotionally distressing
- Legal uncertainties can complicate matters
- Food and fluids a common ethical dilemma
  - A person who is dying will not obtain the same benefits from artificial fluid/ hydration as a person who has a treatable condition; clear-cut evidence is lacking – communication and clarity of decision-making process are key with consideration of individual need
- Resuscitation and DNAR orders

Communication and care of health and social care professionals

Handover
Support
Disenfranchised grief

Preparation of peers with intellectual disability

Managing the uncertainty inherent in the dying process



J Amblàs-Novellas et al. BMJ Open 2016;6:e012340

Conclusions

- People with an intellectual disability who are coming to the end of their lives need high quality care and treatment to support them to live as well as possible until they die, and to die with dignity.
- Staff should be prepared and supported to care.
- Many people who are dying will experience some degree of physical, psychological, emotional, social or spiritual distress.
- Prompt recognition and response to distress should be the norm and in situations where problems are complex, collaboration with specialist palliative care teams can help to address any challenges that may arise.
- Although the person with an intellectual disability who is dying is the primary focus of care, it is important to remember that family members, peers with intellectual disability, and formal carers also are experiencing grief and loss, and their needs should also be considered and addressed.

Resources

- Tuffrey-Wijne, I. (2013). How to break bad news to people with intellectual disabilities: A guide for carers and professionals. London: Jessica Kingsley. Guidelines for practitioners, families and carers to ease the process of explaining bad news. http://www.breakingbadnews.org
- DisDAT tool: A resource for understanding distress in people with communication difficulties: Regnard, C., Mathews, D., Gibson, L., & Clarke, C. (2003). Difficulties in identifying distress and its causes in people with severe communication problems. International journal of palliative nursing, 9(4), 173-176. https://doi.org/10.12968/ijpn.2003.9.4.11501 https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/
- Glancing back, planning forward, A guide for planning end-of-life care with people with Intellectual disability. Trinity Centre for Ageing and Intellectual Disability has developed an accessible planning tool for people with an intellectual disability to help them, their families and their carers plan ahead so that their wishes can be respected at the end of their life. https://www.tcd.ie/tcaid/accessibleinformation/index.php
- Talking End of Life…with People with Intellectual Disability [TEL]. Australian website with 12 modules on end of life and people with intellectual and developmental disability. Designed for disability support workers but also helpful for families, health professionals, and educators. https://www.caresearch.com.au/TEL/
- Decision-making about the best place of palliative care for people with intellectual disabilities A guide for care staff and healthcare professionals providing palliative care for people with intellectual disabilities (Bekkema, Tuffrey-Wijne, et al., 2015, ISBN 978-94-6122-333-3, https://www.nivel.nl/ sites/default/files/bestanden/Handreiking-decisionmaking-palliative-care-disabilities.pdf)

Thank you