



When a person living with advanced dementia deteriorates, they are usually unable to communicate their own wishes and preferences, nor participate in decision-making processes.

This can make decisions about end-of-life care difficult.

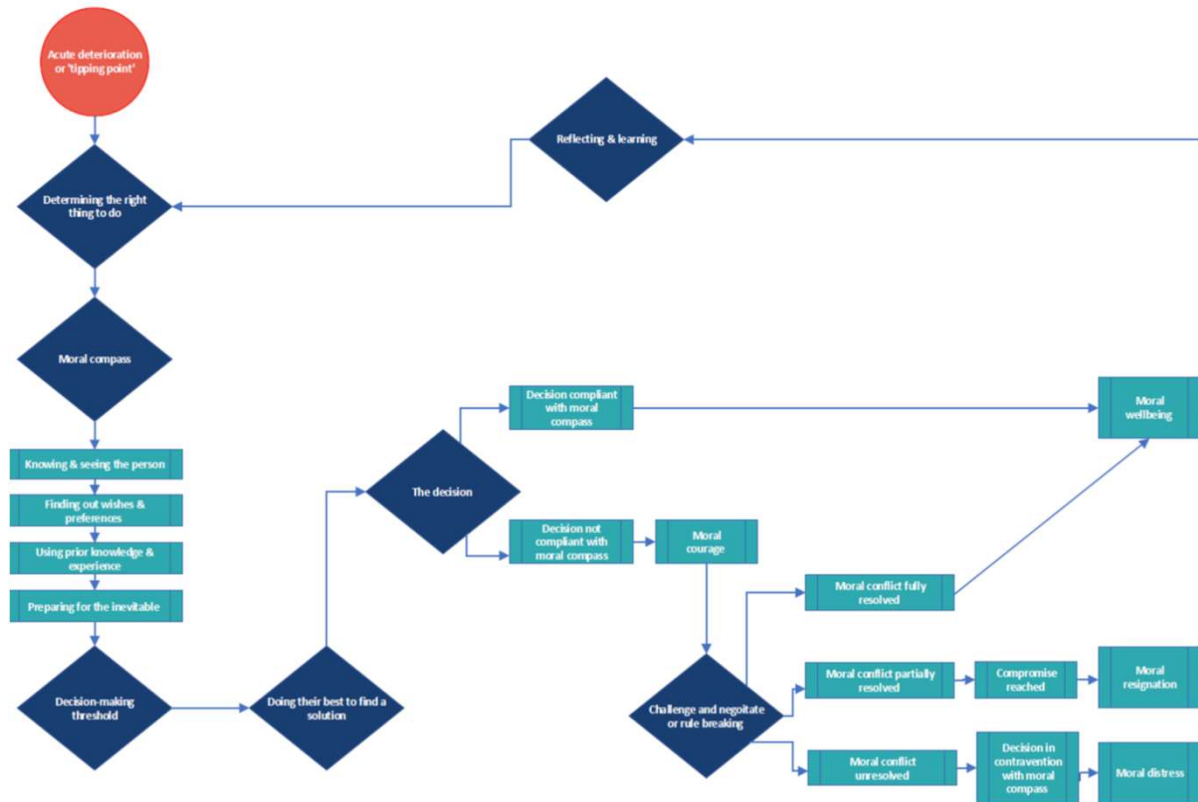
Nursing home staff increasingly take a holistic, person and relationship-centred approach to end-of-life care. The skills and emotional investment required to deliver this are neither recognised nor valued.

The biopsychosocial perspective of death is often at odds with a more medicalised view of death.

An evidence-based discussion tool has been developed to support end-of-life shared decision-making, to enable a good death for residents and reduce incidences of moral distress for care staff.

**Overview:**

- The concept of deterioration informing decision-making at end-of-life is more complex than algorithms and vital signs.
- It is about valuing different perspectives, including knowledge about the person, their family, and their wishes to make an informed decision that is morally right and in the best interests of that individual.
- Different perspectives about end-of-life care exist; what might be medically or procedurally the right thing to do, may not be the morally right thing for that person, or vice versa, leaving staff feeling morally conflicted.
- Care home staff have an invaluable perspective of the right thing to do for each resident because of their role and contemporary relationship with the person. They should feel comfortable to advocate on their behalf, however, this can prove difficult due to hierarchies and decision-making thresholds.



**Benefits of the tool:**

- This tool offers a non-clinical framework to aid reflection acknowledging the impact that decision-making has upon staff, and encourages the translation of experience into learning to improve future outcomes and experiences.
- It is important that not only perceived bad deaths are reflected upon, it is incredibly valuable to encourage staff to reflect upon the occasions when they have been able to positively influence outcomes and enable a good death for their resident.
- Using this tool to support MDT discussions could improve mutual understanding of the often different perspectives and priorities of health and social care staff.
- This tool empowers staff to speak up and demonstrate moral courage, challenging decisions that they believe are not “morally right” for the person when delivering person and relationship centered dementia care.

This discussion tool enables individual and team reflexive learning, recognising the impact delivering increased levels of end-of-life care has on staff and their ability to influence opportunities to facilitate a good death.

Understanding the impact that providing person and relationship-centred care has on nursing home staff when delivering end-of-life care can inform the development of positive support and coping mechanisms.

Demonstrating moral courage can reduce incidences of moral distress by improving opportunities to deliver a good death, which can in turn reduce burnout and staff turn-over.