

Ethical decision making in end-of-life care and the person with dementia



Core ethical principles to underpin decision making



- Justifying an action by appealing to ethical principles means having to defend that choice of action over others in a manner which goes beyond our own perspective, bias, values and interests. By choosing an action based on principles, we remove our own partial viewpoint from the decision and appeal to a more general sense of what is the right thing to do.
- There is rarely one overarching ethical principle or value that can be used to solve an ethical problem. Critical judgment is required based on the individual's rights and interests, the situation, the risks and the context in which the decision is made.
- There is rarely a single right solution for what should be done, and in fact reasonable disagreement can be expected and even encouraged.
- An approach to decision-making where solutions emerge in the course of dialogue, disagreement and negotiation often works best.



Five Core Ethical Principles Underpin Ethical Decision Making in Dementia Palliative Care.



Core ethical decision making principles



Autonomy

- ✔ Focus on the experiences of the person and on what matters most to them
- ✔ Be attuned to the way in which they make sense or meaning out of the world
- ✔ Help the person to express themselves
- ✔ Meet the person where they are in themselves and in their environment of care
- ✔ Enable and foster relationships that are important to the person
- ✔ Recognise and meet the needs of carers

Avoiding Harm and Doing Good

- ✔ When making decisions for individuals who lack capacity to make any decisions about their medical treatment or care, in the absence of any advance plan or directive, caregivers should act to promote the person's overall well-being, e.g. attention should be paid to pain and symptom management and to the avoidance of unnecessary suffering as well as the creation of opportunities for positive experiences and joy.
- ✔ Promoting a person's well-being goes beyond weighing the burdens and benefits of proposed actions: it also involves taking the person's past and current wishes and preferences into account.

Personhood and Value of Life

- ✔ The life of a person with dementia should be valued just as much as that of a person without dementia, with a particular focus on the person's capabilities, rather than on presumed deficits.

Justice

- ✔ Requires that access to treatment and care should not be restricted on the basis of age, disability, psychological or intellectual impairment.
- ✔ Requires that attention be paid to the way in which group differences (e.g. gender, ethnicity) can place individuals and families at a disadvantage, and to the need to develop strategies/practices to ameliorate inequities.

Solidarity

- ✔ Our interdependence as human beings means that any of us may be touched by dementia and all of us will certainly be touched by end-of-life issues. The quality of care provided should reflect the standard of care we would expect for ourselves and the people we love.

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Ethical decision making tool



Articulate the ethical problem(s) and identify relevant facts

- ✓ Be ethically sensitive and communicate clearly



Identify stakeholders' interests, needs and values

- ✓ Be respectful and inclusive

Weigh up the merits and demerits of available courses of action

- ✓ Be informed and fair

Select the action best supported by ethical principles

- ✓ Be impartial and transparent

Review

- ✓ Check: Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

See Guidance Document No 6 for more Information and Case Studies

Persons with dementia have the same rights as all persons

e.g. the right to life, autonomy, dignity, bodily integrity, freedom from inhuman and degrading treatment as well as the right to information, to consent and to confidentiality



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Guidance

Guidance Area 1

Promoting Autonomy and the Capacity of the Individual to Consent to or Refuse Treatment and Care

The autonomy of the person with dementia may be promoted and enhanced by engaging in a process of Advance Care Planning (ACP) while the person still has the capacity to make decisions about future treatment. Even if an Advance Care Plan or an Advance Healthcare Directive is in place, an autonomy-centred approach requires that healthcare professionals pay attention to what the experience of their condition means to the person who is now living with dementia and their carers. It requires that healthcare professionals and carers actively support the person with dementia so that they are encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.

Guidance Area 2

Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment in cases where individuals have refused it or in situations where it offers no overall benefit. Omitting to administer a particular treatment such as CPR for a particular person is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. When discussing judgments of futility, it should be made clear that it is not people's lives that are judged futile – judgments relate to the expectation that the treatment will not provide any benefit for this particular person at this stage of their dementia and/or related illnesses.

Guidance Area 3

Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

As a person with dementia approaches the end of their life, the body's increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty in swallowing. However, food has an emotional, symbolic and social importance which should not be underestimated. Offering feeding assistance to someone who is sick is a 'powerful instinctive act' and the human contact provided by the act of assisting someone to eat and drink may be of therapeutic benefit. Deciding whether or not the administration or continuation of Clinically Assisted Nutrition and Hydration (CANH) is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the person with dementia. The evidence indicates that CANH does not offer clinical benefit in the long term and especially at the end of life. Any deliberations about CANH should include the person's illness trajectory, the potential impact of the intervention on the person's condition, the expected clinical outcomes, the impact of a potential inpatient admission on the person, and the preferences/values of the person.