Dementia affects judgement, insight and ability to look after self. This leads to reliance on carers. When dementia is diagnosed, there are important questions that must be answered, such as when to tell a patient about their condition and who should make certain decisions on their behalf.

This module looks at the important ethical and practical issues regarding capacity, conflicts of interest and empowerment in relation to the diagnosis of dementia.

Principles of medical ethics

- There are four main principles that underpin medical ethics. All decisions should:
  - respect freedom of choice (autonomy)
  - aim for the well-being of the recipient (beneficence)
  - not harm the recipient in any way (non-maleficence)
  - be fair (justice).

- There are ethical and practical issues involved when considering whether to reveal a diagnosis to a patient, including:
  
  **For:**
  - the patient's 'right to know'
  - the facilitation of future planning (power of attorney, making wills, choice in future care and living wills with advance medical directives)
  - taking that 'once-in-a-lifetime holiday'
  - it assists in persuading the patient to accept help and in managing social needs
  - driving safety can be addressed.

  **Against:**
  - fear of causing distress
  - fear of destroying or reducing hope or motivation
  - concern about depressive illness, suicide or catastrophic reaction.

- Information may ethically be withheld by the clinician if it may harm but cannot benefit the patient. This is called 'therapeutic privilege'.

Capacity

- According to the principles of capacity in the Mental Capacity Act 2005:
  - every adult has the right to make his/her own decisions and must be assumed to have the capacity to do so unless proven otherwise
  - adults should be encouraged and enabled to make their own decisions, or to participate as fully as possible in decision-making
  - capacity is decision-specific
  - capacity is time-specific
  - the inability to make a decision must be caused by an impairment of or disturbance in the functioning of the mind or brain (the diagnostic test).

- The Mental Capacity Act 2005 states that capacity requires the ability:
  - to comprehend information material to the decision
  - to retain the information (for as long as the decision is being made)
  - to weigh up the information in order to make a choice
  - to communicate the decision in some way.
• According to the Mental Capacity Act 2005, when a patient is deemed incapable of giving legal consent:
  • not just anyone can give consent on behalf of an incapable adult – they must be appointed in advance by the (still capable) adult, or by High Court in the event that no prior decisions have been made
  • valid prior refusal of treatment cannot currently be overridden, except in the context of the Mental Health Act 1983
  • High Court can rule where capacity is in doubt
  • medical decisions should always be in the person’s best interests and give weight to the decision being what they themselves would want.

Sharing information with carers

• According to the ‘rule of threes’, at diagnosis, carers should be told:
  • what dementia is
  • which medications are available
  • the behavioural and psychiatric symptoms of dementia.

• At an early follow-up appointment, the following information may be given:
  • what services are available to sufferers of dementia
  • the course of the illness
  • what to do in a crisis.

• At a later follow-up appointment, the carer can be given information on the following:
  • support groups
  • benefits available to sufferers of dementia
  • financial and legal issues.

• Following the first three stages of information-giving, information on psychological therapies and the effects of the illness on carers may be passed on.

Further reading


Department of Health (2001) National Service Framework for Older People. [PDF]

Gillon R (2003) Ethics needs principles – four can encompass the rest – and respect for autonomy should be “first among equals”. *Journal of Medical Ethics, 29*: 307–312. [PDF]


