Planning future healthcare for people with dementia nearing end of life

Modernisation Initiative

end of life care

What

We set out overleaf an easy to read flowchart designed for health and social care professionals. It provides an approach to planning for future decisions that may need to be made in relation to the care of a person with dementia whose capacity to make decisions about his or her own care can no longer be assumed. It can be held in a team resource file and used for training.

Who

Any health and social care professional who is caring for a person with dementia, who is looking to plan ahead for possible future care needs that may occur when there is a change in circumstances. Such discussions should include a health professional as a part of the multidisciplinary team.

When

You are caring for a person with dementia where that person's capacity to make decisions can no longer be assumed and it is prudent for planning to be put in place to deal with possible future care needs. Examples of care needs might include swallowing difficulties resulting in weight loss. Whilst you can't make binding decisions now about how to deal with crises in the future, you can plan ahead by making sure that you have considered how a decision will be made and recorded the things that should be thought about and who might need to be contacted.

Why

The Mental Capacity Act 2005 requires clinicians to start from an assumption that the person has capacity, but as a person's dementia progresses, this assumption needs to be tested. Once it can no longer be assumed that a person has capacity to make decisions about his or her own healthcare, and a decision need to be made, the Act provides a framework for assessing capacity, and where this is lacking, for determining how a decision should be made. Every health and social care professional needs to be aware of this framework.

The Act requires the judgement about whether a person lacks capacity, and if so what to do about it, to be made at the time the medical decision has to be made. However, often at the point a crisis occurs it may be difficult to consult everybody who should be consulted. It is best practice therefore, to plan ahead.

This planning should be made in the context of the framework established by the Act and the flowchart provides a much simplified reminder of what those principles are. Any conclusions reached as part of this planning process will need to be kept under review and there will still be the need to ensure compliance with the Mental Capacity Act when the time comes for a specific decision to be made and implemented.

This guidance is a supplement to: *Concise Guidance to Good Practice Number 12 Advance Care Planning National Guidelines*, Royal College of Physicians 2009.

http://bookshop.rcplondon.ac.uk/

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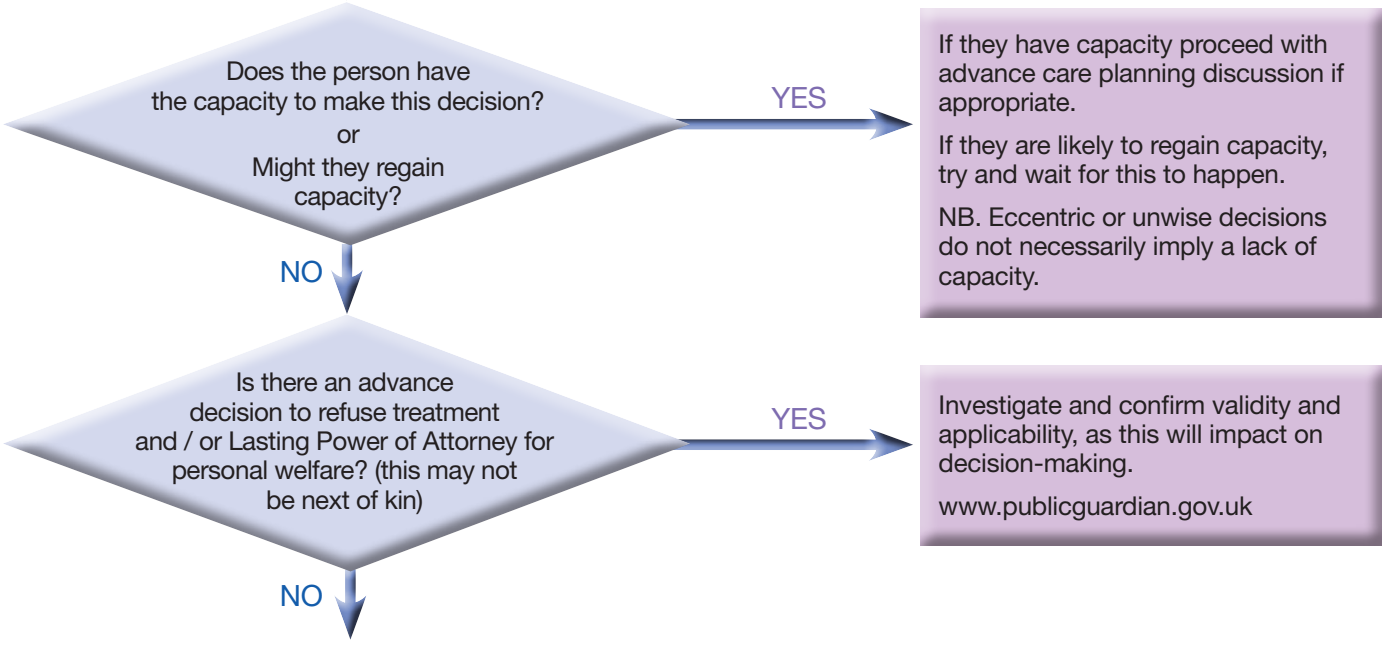
Assume the person has mental capacity

If the person has an impairment of, or a disturbance in their mind or brain function which means they can't make a specific decision when they need to, then test their capacity as follows:

1. Can they understand the information? This must be clear and accessible – you need to make every effort to make it understandable.
2. Can they retain the information? This only needs to be long enough for them to weigh up and use the information.
3. Can they weigh up and use that information? They must demonstrate that they can consider the benefits and risks of the proposed treatment and the alternatives.
4. Can they communicate their decision? Carers must try every method possible to enable this.

If the person can do all of the above they have capacity to make the specific decision at this particular time.

Document the result of each step of this assessment – ideally by quoting the person.



Appoint a lead professional (e.g. health or social care professional) to:

- Set up a best interest meeting to plan for the future
- Consider whether this person would require the input from an Independent Mental Health Capacity Advocate (IMCA) in the future if there is no one appropriate to consult
- Encourage the person to participate in the meeting
- Find out and consider the person's views (past and present wishes, preferences, beliefs and values) expressed verbally, or recorded in an advance decision to refuse treatment or advance care plan
- Identify all the circumstances relevant to the decision (clinical, social, psychological, spiritual)
- Consult others (within the limits of confidentiality) including family, friends, carers, those with Lasting Power of Attorney, Independent Mental Capacity Advocate or Court Appointed Deputy to determine what views they believe the person with dementia would express if they had capacity
- Weigh up all the factors in order to work out the person's best interests in the future.

Record the recommendations.

The recommendations should be reviewed as necessary and do not remove the need for the actual decision to be made under the mental capacity act at the time when the decision is necessary.

If there are unresolved conflicts, consider involving:

- The local clinical ethics committee
- The Court of Protection, possibly through a Court Appointed Deputy.

Adapted from p10 of 'Advance Care Planning' National Guidelines, No. 12.' published by the Royal College of Physicians of London, 2009
Website: www.gsttcharity.org.uk/projects/eolc.html