

Advance care planning and advance healthcare directives with a person with dementia



What is an advance care plan?

An advance care plan is written when a person with dementia and their doctor or nurse wish to record the outcome of the advance care planning discussion. Although an advance care plan often emphasises treatment decisions such as Cardio Pulmonary Resuscitation (CPR), antibiotics, and tube feeding; holistic care planning can also involve wider issues such as appointing an attorney under an enduring power of attorney, wills, environmental comforts, spiritual issues and anything else important to the person.

Plan for the probable, work for the possible, hope for the future.

(Ronan Smith, member of Irish dementia working group, Alzheimer Society of Ireland)

What is an advance healthcare directive?

An advance healthcare directive is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions, to give consent to or refuse treatment and communicate them to others. An advance healthcare directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. The Assisted Decision Making (Capacity) Act 2015 provides that a request for a specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required.

How does an advance healthcare directive differ from an advance care plan?

An advance healthcare directive may indicate refusal of treatment - this is legally binding. An advance care plan is not. (Please see guidance document for more information on both).

Key points about advance care planning with a person with dementia:



1. Advance care planning is a process of discussion and recording. It may take place over more than one conversation
2. People with dementia can participate in the advance care planning process and development of an advance healthcare directive
3. People can choose to or not to take part in the advance care planning process
4. Decisions recorded should be reviewed

Guidance on advance care planning with a person with dementia:



1. Always presume decision making capacity
 2. Help the person to maximise their decision making capacity
 3. Remember that the person with dementia can choose to not take part in the advance care planning process
 4. Be aware of how to assess a person's decision making capacity if required to do so
 5. Gain knowledge on what steps to take if decision making capacity is an issue
 6. Check existing advance care plans with the person regularly for validity and applicability
- (see over for how to engage in advance care planning with a person with dementia)

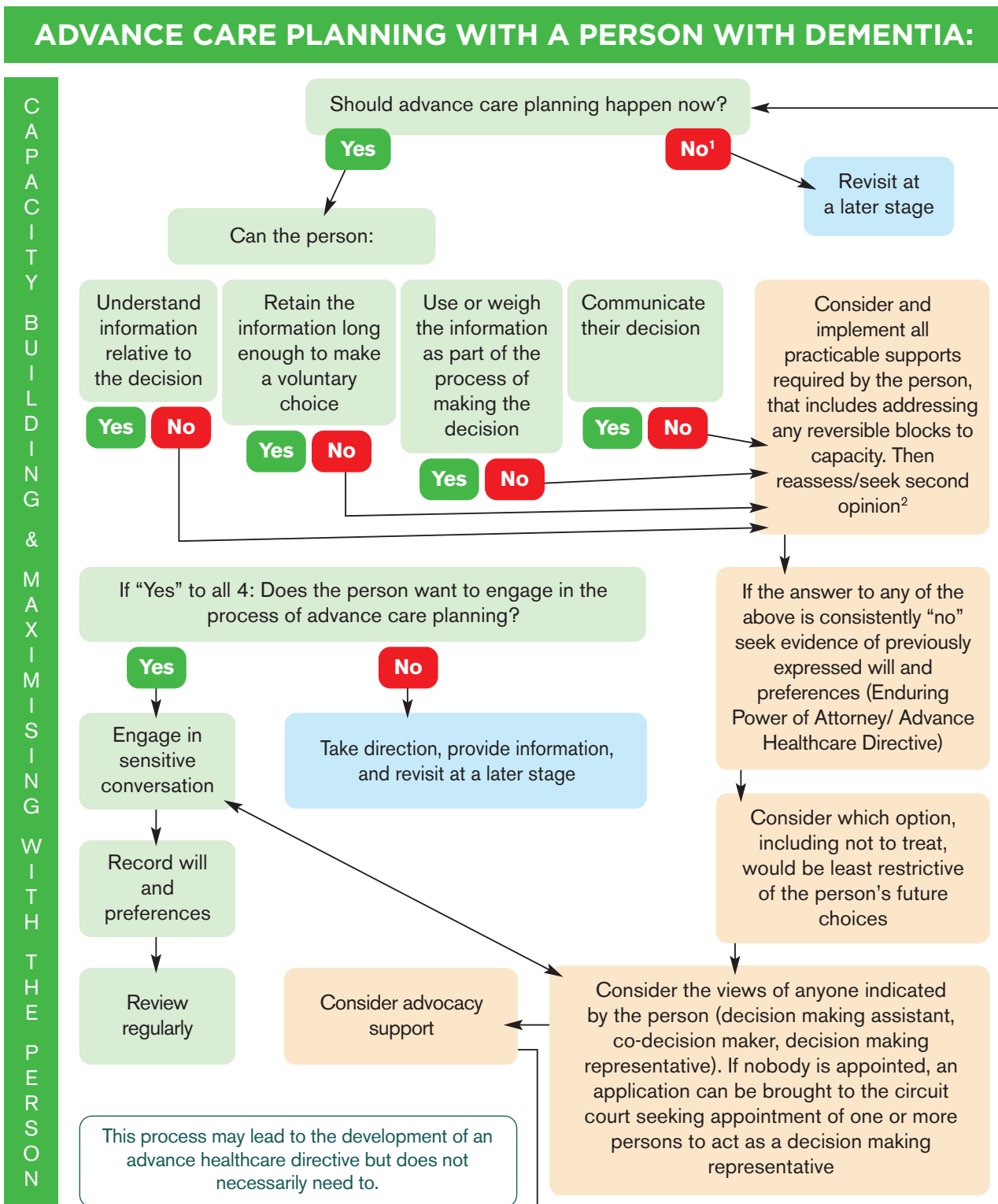
Guidance on advance healthcare directives with a person with dementia:

1. Become familiar with what an advance healthcare directive can include
2. Become familiar with what makes an advance healthcare directive legal
3. Check existing advance healthcare directives regularly for validity and applicability



FACT SHEET 2

The following advance care planning algorithm has been prepared in an attempt to illustrate engaging in the advance care planning process with a person with dementia. It is based on the Assisted Decision Making (Capacity) Act 2015 and the HSE National Consent Policy (2014) (Ireland). It is merely a guide. Each person should be cared for on an individual basis with due regard taken for applicable legislation in that jurisdiction.



1. It may be inappropriate to engage in advance care planning if there is a temporary issue with a person's decision making capacity, for example an acute delirium

2. The person/persons that may be called upon to provide a second opinion have not yet been outlined. It is the responsibility of the Director of Decision Support Service to provide guidance and information with regard to this