### FACT SHEET 2

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



### What is an advance care plan?

It is a healthcare document written usually by a doctor or nurse to record the outcome of the advance care planning discussion.

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?

It is an expression made by a person (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions and communicate them to others. An advance healthcare directive is legally binding when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply.

### 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 legally binding. (Please see guidance document for more information on both).

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



- Advance care planning is a process of discussion and recording. It may take place over more than one conversation
- 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 every three months.

## Why is advance care planning important for people with dementia?



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, housing issues, spiritual issues and anything else important.

Advance care planning allows people:

- Express wishes and preferences
- Help family members know will, preferences, beliefs & values
- Reduce anxiety
- Focus on living well

### How to assist a person with dementia to engage in advance care planning conversations:



- 1. Have conversations in a place and at a time when the person with dementia is best able to understand and retain information.
- 2. Ask the person with dementia if there is anything that would help them remember information or make it easier to make a decision, such as; bringing another person to the meeting, having audio or pictorial information, writing things down, using simple language, finding out how the person usually communicates, giving the person space and time, involving others as necessary. (See factsheet 1)

### 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). It is merely a guide. Each person should be cared for on an individual basis.

#### Advance Care Planning with a person with dementia: Should advance care planning happen now? Revisit at C a later stage Can the person: Understand Retain the Use or Weigh Communicate Consider and U information information long the information their decision implement all relative to enough to make as part of the practicable supports the decision a voluntary process of required by the person D choice making the that includes addressing Yes No Yes No decision any reversible blocks to Yes No capacity. Then reassess Yes No and/or seek a second opinion M If "Yes" to all 4: Does the person want to engage in the If the answer to any of the Χ process of advance care planning? above is still "no" seek evidence of previously M Yes expressed will and No preferences (Enduring power of attorney/ Advance Take direction from the person. Record Engage in healthcare directive) sensitive conversation in medical record. Provide conversation information, and revisit at a later stage Consider which option, W including not to treat, Record will would be least restrictive and of the person's future Н preferences choices Н Review Consider the views of anyone indicated by Consider advocacy regularly (Every the person (decision-making assistant, support 3 months) co-decision-maker, decision-making representative). If nobody is appointed, an application can be brought to the circuit court seeking appointment of one or more This process may lead to the development O persons to act as a decision making of an advance healthcare directive but representative if appropriate does not necessarily need to



This fact sheet is a visual aid to accompany IHF guidance document 2: Advance care planning and advance healthcare directives with a person with dementia. It is available to download on www.hospicefoundation.ie