



Medical treatment decision making and advance care planning for people living with dementia

OPA encourages future planning, including advance care planning for all adults

The Office of the Public Advocate (OPA) encourages all adults to engage in future planning generally, including advance care planning.

Future planning is about planning for the management of your affairs in the event of accident, illness or death. (For example, by making a power of attorney or a will, or organising insurance.)

Advance care planning is about planning for medical treatment in the future should you lose decision-making capacity.

Diagnosis of dementia is a trigger point for considering advance care planning

The particular trigger points for discussion about advance care planning are at:

- times of diagnosis with significant illness or disease (including dementia)
- admission to residential aged care or
- reaching a particular age (there is a Medicare item for detailed assessment of people aged 75 and over).

However, it is important for all adults to consider advance care planning at different relevant life stages.

It can be quite confronting for a person to be introduced to advance care

planning close in time to diagnosis or associated with end of life decision making.

Hopefully, advance care planning will become a more mainstream idea in the general community and people will have engaged in advance care planning at earlier or less traumatic life stages. They will therefore be ready to continue to engage with advance care planning upon a dementia diagnosis.

Advance care planning options

Advance care planning may consist of electing one of the options set out in the *Medical Treatment Planning and Decisions Act 2016*.

These are the:

- appointment of a medical treatment decision maker
- appointment of a support person
- completion of an advance care directive.

The person needs decision-making capacity to execute any of these documents.

However, advance care planning can also consist of informal methods. For example, discussing preferences and values with family members and health practitioners, and writing down these preferences and values.

So long as a person is able to do so, they should be encouraged and supported to express their preferences and values.

Advance care planning is an expression of autonomy and is about human rights

Advance care planning is sourced in a person's autonomy to make their own decisions about their own medical treatment. It is sourced in the human right not to have medical treatment without full free and informed consent.

A person has a right to engage in advance care planning and, equally, they have the right to choose not to do so.

No person should be coerced by well-meaning family members and/or health systems to engage in any particular form of advance care planning. Advance care planning is not a systems issue, it is a human rights issue.

Advance care planning is a creative process

Advance care planning is a creative process and should reflect an individual's unique needs, circumstances, relationships, views, preferences and values.

Advance care planning is a process. Good documentation is an outcome of good planning and discussion. A person may choose to document their preferences and values, whether in an advance care directive or otherwise, but ideally this would be the outcome of discussion.

Providing someone with a form to complete will not necessarily result in advance care planning which will effectively promote decision making consistent with the person's preferences and values.

Can a person with dementia make a medical treatment decision?

If the person has decision-making capacity to make the medical treatment decision, then it is their decision to make. If the person does not have decision-making capacity to make the medical treatment decision but

previously made a relevant instructional directive in an advance care directive, then that will be the decision. If not, then the decision will be made by their medical treatment decision maker.

A person has decision-making capacity to make a decision if it is possible for the person to make a decision with practicable and appropriate support.

This may mean:

- allowing more time for appointments
- providing information in simple English or in a different community language
- permitting the person to have a support person present
- choosing the time of the day when the person is most cognitively alert
- creating a calm non-conflictual space.

Can a person with dementia engage in advance care planning?

Any person with decision-making capacity can engage in advance care planning. This includes people living with dementia.

If a person with dementia chooses to appoint a medical treatment decision maker or support person, or complete an advance care directive, then two witnesses will need to be satisfied that the person has decision-making capacity to do so. (For an advance care directive, one witness must be a registered medical practitioner. For either of the appointments, one witness must be a registered medical practitioner or authorised to witness affidavits.)

A person with dementia should be encouraged to consider likely future health conditions and treatments relevant to their condition, and be given adequate information so that if they wish to make an instructional directive they are properly informed.

If the person with dementia does not have decision-making capacity to

appoint a medical treatment decision maker or support person, or complete an advance care directive, it does not mean that they cannot express their preferences and values. They should be encouraged and supported to do so now, and at regular future points in time.

A person with dementia may wish to consider common illnesses and treatments:

- antibiotics for pneumonia
- medication for managing mood and anxiety
- medication for managing behavioural and psychological symptoms of dementia (BPSD)
- falls, resulting in fractured neck of femur, and other injuries
- diagnostic tests (for example, a person may prefer not to have diagnostic tests if their preference is not to have curative treatment for the likely disease that the diagnostic tests are likely to disclose)
- transfer to hospital for medical treatment which can only be delivered in a hospital
- resuscitation for cardiac/respiratory arrest.

Other future planning considerations for a person living with dementia

All adults, including a person living with dementia should also be encouraged to consider other future planning, such as:

- appointment of an enduring power of attorney for financial and/or personal matters
- preferences for future accommodation
- wills and testamentary issues.

What role is there for the medical treatment decision maker of a person living with dementia?

A health practitioner will ask a medical treatment decision maker to make a

decision only if the person:

- does not have decision-making capacity to make the decision him or herself, and
- did not, when they had decision-making capacity to do so, make an advance care directive with an instructional directive in which they have made a relevant medical treatment decision (to consent to, or refuse the medical treatment decision).

Note: a health practitioner can provide medical treatment without consent in an emergency (unless there is a relevant instructional directive, refusing the treatment).

What role is there for family members of a person living with dementia?

Family members can support the person living with dementia to engage in advance care planning.

If the person lacks decision-making capacity to complete an advance care directive, a family member may wish to complete the form '*What I understand to be the person's preferences and values*'. See the OPA publication *A medical treatment decision maker's guide* for more information.

One of the principles in the Medical Treatment Planning and Decisions Act is "a partnership between a person and the person's family and carers and health practitioners is important to achieve the best possible outcomes."

Visit the OPA website for more information and fact sheets on:

- Advance care planning and substitute medical treatment decision making
- Advance care planning and residential aged care.

www.publicadvocate.vic.gov.au

The material in this fact sheet is intended as a general guide only and readers may require legal advice for specific circumstances.