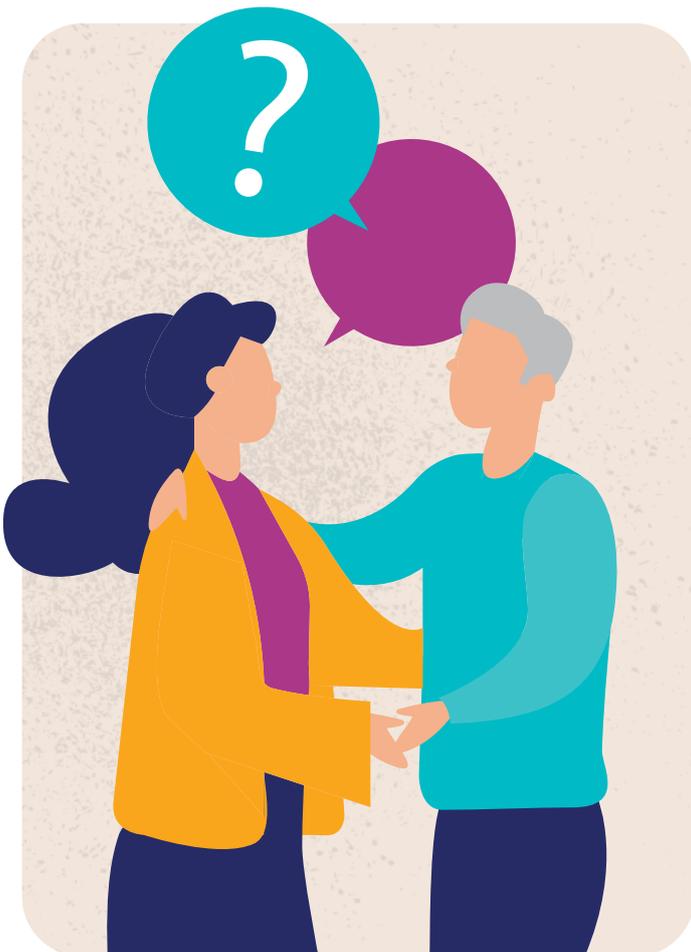


The important conversations – Making decisions for the person you are caring for (when they are no longer able to do it for themselves)



When you realise that the person you are caring for is likely to die from their illness at some point in the future, it is important to consider having some difficult and important conversations. It may feel easier to avoid these conversations. However, talking about what care they would want at the end of life can help you both.

Conversations can also have legal implications that are important to understand for the person and for you as the carer. It is never too early to sort out the legal arrangements you will need to make sure a person's wishes can be respected. Remember that the laws relating to these decisions can vary depending on which state you live in.

Thinking about the following can help guide your conversation.

What would they want to happen to them medically if they can't communicate for themselves?

Advance care planning is a discussion which explores the person's preferences for their end of life if they become unable to communicate and make decisions for themselves.

An Advance Care Directive is a legal documented instruction of the person's preferences for their end of life if they become unable to communicate and make decisions for themselves.

As part of the above processes, you may want to discuss whether they would choose treatments to prolong life or choose treatments that focus on their comfort only. Some examples of treatments which prolong life include CPR or resuscitation, tube feeding, artificial ventilation, or kidney dialysis.

You and the person you are caring for may wish to speak about treatment options with other family members, a general practitioner or main treating specialist.

Some good conversation starters include:

- If your condition got worse, what kind of medical treatment would you want or would you not want?
- What is important to your quality of life? What do you value most in your life? What does a good day look like for you? What's unacceptable to you?
- If there was an emergency, what sort of medical treatment would you want and not want?
- Where would you like to be when you are at the end of life?





Who would they like to make medical decisions on their behalf if they can't speak for themselves?

Most people will also appoint a Substitute Decision-Maker, depending on your state or territory this might be known as an enduring guardian, attorney, or medical treatment decision maker. A Substitute Decision-Maker is the person nominated to make decisions on their behalf if they cannot communicate for themselves – that is they have lost capacity to do so. As the primary carer, you may be nominated as the Substitute Decision Maker.

The ways to be legally appointed as a Substitute Decision-Maker include:

1. Being nominated in an Advance Care Directive (for some states and territories only)
2. Being nominated in the relevant legal form (this needs to be specific to the state/territory)
3. If neither of the above is in place, the law identifies who will be nominated based on a default list (e.g. spouse or partner, parent or adult child)

If you are nominated as the Substitute Decision Maker, you can lawfully make decisions on a person's behalf about:

- Medical and dental treatment
- Living arrangements
- Support services

It is going to be easier to make decisions for the person you are caring for, if you understand what is important to them and what their preferences for treatment are.

Things to consider before accepting the role of Substitute Decision-Maker?

At times it can be challenging to make decisions for someone else. You may find that you are uncertain about making some decisions, particularly if their preferences are unclear. You may have questions about a treatment and may need to talk to different health professionals before making a decision.

You should be making the decision the person would make if they could do so, even if other people do not agree with that decision.

Consider whether you feel comfortable with the person's end-of-life preferences and values. If you do not feel like you can carry out their wishes (due to your own values or beliefs) it is best to tell the person and get them to appoint someone else.



You are allowed to withdraw or resign from the role at any time. However, if you feel like you will not be able to make decisions on behalf of the person and can't be readily available, tell them and support them to appoint someone else.

You may want to consider support from a close friend, counsellor, or community or religious leader during this time.

Other Important Conversations

Other important conversations you may like to consider are:

1. What would they like to happen to their assets and possessions? Consider having their wishes formalised in a Last Will and Testament.
2. Who would they like to manage their finances if they are not able to do (this is called a Power of Attorney)?
3. Are there any family or friends they would like to reconnect or reconcile with?
4. Anything they would like to do or experience?
5. What do they want to happen with their pets?
6. Do they have any specific wishes for their funeral?

For more information

Advance Care Planning Australia has all the information and forms that you need to do an Advance Care Directive or be a Substitute Decision Maker, including links to State based information (www.advancecareplanning.org.au or call 1300 208 582).