

## Planning ahead

### What you should know

- Planning ahead can provide you with the opportunity to think about, discuss and set in place arrangements for health, lifestyle and financial decision-making
- Talk with your family, friends and health professionals about your future preferences
- Start these discussions and make decisions while you are able to clearly communicate your wishes
- Advance care planning is a way of thinking about, discussing and writing down your wishes for care and treatment should the time come when you are unable to express your preferences
- Legally appointed substitute decision-makers are given the power to make decisions on your behalf in instances if you are unable to do so
- Making a valid Will is the best way to document how you want the things you own to be distributed after you die

### Why plan ahead?

If you are living with motor neurone disease (MND) you may feel particularly concerned about what lies ahead and how decisions about your health care, lifestyle and finances will be made.

Although it can be difficult, talking with family and friends about your future wishes is an important step in planning ahead. Planning ahead can provide you with the opportunity to think about, discuss and set in place arrangements for health, lifestyle and financial decision-making. Once you have started having these discussions you and your family may feel more at ease about the future.

### Legislation varies across Australia

Depending on where you live in Australia, there are different legal documents that you can complete which will help ensure that your future health and financial wishes and goals are known and respected. For further information contact your state MND Association (see over page).

### Getting started

This fact sheet outlines arrangements you might consider setting in place. These include:

- advance care planning – medical care and treatment
- appointing a substitute decision-maker – health care, lifestyle or finances
- making a Will – finances
- donating tissue

#### Important Note

Documents about your future wishes are best kept in an accessible place. This way when the need arises, no time will be wasted trying to locate these documents. One suggestion is to have a note on the fridge which explains where the documents are kept.

However, even once your arrangements are in place, have regular discussions about your wishes because these may change over time.

## Advance care planning – medical care and treatment

Advance care planning is a way of thinking about, discussing and making decisions about your wishes for care and treatment should the time come when you are unable to express your preferences.

Advance care planning involves discussing with your family, friends and health professionals:

- what your likely future health care needs will be
- what care and treatment options are likely to be available
- what care and treatment options you would choose.

This information can then be used to *guide* a substitute decision-maker, family member or health professional on decision-making in instances if you are unable to express yourself.

In some states a document is written up, often referred to as an 'advance care plan/directive', 'living Will' or 'statement of choices'. This document is used to *instruct* a substitute decision-maker, family member or health professional on decision-making in instances if you are unable to express yourself. This document is only used in situations when you are unable to communicate or no longer have the ability to make decisions for yourself.

It is important to realise that if other people do not know what your preferences would be, or if you do not have a document to *instruct* a substitute decision-maker, decisions could be made on your behalf that may not reflect your preferences, values, beliefs or wishes.

For links to advance care planning resources in your state or territory visit [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au) or contact your state MND Association.

## Appointing a substitute decision-maker – health care, lifestyle or finances

You can appoint one or more substitute decision-maker to make decisions in areas of your life specified by you, ranging from health care and lifestyle through to finance. However, you need to set in place specific documents to appoint a substitute decision-maker who is recognised in law as having the power to make decisions on your behalf in the areas of your life you specify.

Once the documentation is in place, the substitute decision-making power is usually only initiated when you are unable to make or communicate decisions for yourself. For this reason, it is strongly recommended that the substitute decision maker is involved in any advance care planning you undertake.

To find out more contact your state MND Association, visit [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au) or talk to a solicitor.

## Making a Will – finances

A Will is a legal document that sets out how you want the things you own to be distributed after you die. Making a clear, legally valid and up-to-date Will is the best way to ensure that the things you own are distributed according to your wishes. A Will also makes managing your affairs much easier for your friends and family. This is particularly true if your beneficiaries are not legally related to you.

Although you can write your own Will, you may consider seeking advice from a solicitor to ensure that the Will is valid.

## Donating tissue

If you would like to donate body tissue for MND research it is always best to make any arrangements well in advance, and ensure your family and health care team are aware of your wishes. If you are interested in finding out more about tissue donation, speak with your neurologist or state MND Association.

## More information

- your state MND Association
- your general practitioner
- your palliative care service
- MND clinic or service
- Advance Care Planning: [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

To find out about motor neurone disease and other fact sheets in this series contact the MND Association in your state or territory ph. 1800 777 175 or visit [www.mndaust.asn.au](http://www.mndaust.asn.au)