

## Planning ahead

### What you should know

- Planning ahead can help you feel less worried about the future with MND, and organise your future health, lifestyle and financial needs
- Advance care planning is a way of thinking about, discussing and writing down your wishes for care and medical 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 when you cannot
- Managing your personal needs, finances and making a Will are important – a Will is the best way of leaving clear instructions about what will happen to your estate in the event of your death

### Why plan ahead?

Planning ahead involves thinking or talking about end of life with family and friends, and this can be hard, which is completely natural. You may feel very concerned about what lies ahead and how decisions about your health care, lifestyle and finances will be made. Talking about your future wishes for end of life care is important, however, and helps with planning ahead<sup>1</sup>. Planning ahead can help you feel more in control of what's going on and bring some peace of mind to you and your loved ones<sup>2</sup>. It's more likely that you will receive the care you want and have the best quality of life possible.

### Getting started

The main things you need to start thinking and talking with loved ones about for planning ahead are:

- advance care planning – medical care and treatment
- appointing a substitute decision-maker – health care, lifestyle or finances
- managing finances and making a Will
- donating organs or tissue, funeral planning and your digital legacy
- having regular discussions about your wishes and needs because these may change over time.

### Legislation varies across Australia

Depending on where you live in Australia, there are different legal documents for planning ahead. The documents vary but they all address how your wishes are met, including those for Advance Care Planning and Power of Attorney<sup>3</sup>. It's important to be aware of differing legislation across Australia, and your state MND Association can help you find the information that best suits your needs (see over page).

### Advance care planning – medical care and treatment

Advance care planning involves thinking about and 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<sup>4</sup>.

#### 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.

Advance care information can then be used to *guide* a substitute decision-maker, family member or health professional when you are unable to communicate, or no longer have the ability to make decisions for yourself. For example, you may wish to specify what happens if your main carer is unable to support you for any reason.

In all states and territories, you can record your information in a formal document. Depending on where you live, the document may be referred to as an 'Advance Care Directive', 'Living Will', 'Health Direction' or 'Advance Health Directive'. You are able to record your values, life goals and preferred outcomes, or wishes about care and treatments. You can also use the document to appoint a substitute decision-maker.

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

A substitute decision-maker can make decisions about specific areas of your life, based on your instructions<sup>5</sup>. Decisions can range from those for medical treatments and the managing of bank accounts, to the use of social media accounts, funeral arrangements and guardianship of children. You need to complete certain advanced care documents to make a substitute decision-maker be recognised in law.

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. It is recommended that the substitute decision-maker is involved in any advance care planning you undertake and is someone who will make decisions based on what you would want. To find out more contact your state MND Association, visit [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au) or talk to a solicitor.

## Managing finances and making a Will

Managing your financial planning early will help you to better deal with your affairs and the costs of end of life care, including making a Will. For example, Medicare covers palliative care costs but there may be additional health care costs that may or may not be covered by your private health insurance or other government funded schemes<sup>6</sup>. Carers and others supporting you may also be eligible for support through payments, discounts or subsidies to purchase necessary aids, equipment or services. You may also benefit from speaking with a qualified advisor for managing superannuation, insurance, daily or regular payments and other financial matters<sup>7</sup>.

A Will is a legal document that lets you leave clear instructions about what will happen to your money, property and belongings (known as your estate), in the event of your death<sup>8</sup>. If you have children, you can also provide instructions in a Will for appointing their guardian, and their education and wellbeing. A simple Will is not usually expensive and could save your family costs in legal fees. Contacting different solicitors and getting a few quotes for legal work may help you reduce costs. A Will also makes managing your affairs much easier for your friends and family, particularly if your beneficiaries are not legally related to you. Your State MND Association can advise on best ways of going about making a Will, or see more information below.

## Personal needs – relationships, your digital legacy and donating organs

Roles in relationships change when dealing with MND. If you have a partner, it can help to speak with them about everyday activities they may need to deal with, such as cooking, managing appliances, dates for family birthdays or gardening and similar household chores.

Your digital legacy refers to any online records you leave in your name<sup>9</sup>. You may wish to think about what happens to any:

- digital records that have emotional value rather than financial worth, such as photographs
- social media accounts you run and their passwords (content may be comforting for loved ones).

If you would like to donate body tissue or organs for MND research it is always best to make any arrangements well in advance, and involve your family and health care team. Speak with your neurologist or state MND Association about donating body tissue.

## More information

- your state MND Association or an MND clinic or service
- your general practitioner
- your palliative care service
- Advance Care Planning: [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)
- Wills and power of attorney, Commonwealth of Australia

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.mndaustralia.org.au](http://www.mndaustralia.org.au)

## References

1. Murray, et al, 2016, 'Advance Care Planning in Motor Neuron Disease: A Qualitative Study of Caregiver Perspectives', *Palliative Medicine* 30(5): 471–78.
2. Ray et al, 2014, 'Dying with Motor Neurone Disease, What Can We Learn from Family Caregivers?', *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy* 17 (4): 466–76.
3. Advance Care Directives and the Law, Advance Care Planning Australia, accessed April 2020: <https://www.advancecareplanning.org.au/individuals/advance-care-directives-and-the-law/>
4. Waller et al, 2017, 'Improving Hospital-Based End of Life Care Processes and Outcomes: A Systematic Review of Research Output, Quality and Effectiveness', *BMC Palliative Care* 16 (1): 34.
5. How to do advanced care planning, Advanced Care Planning Australia, accessed April 2020: <https://www.advancecareplanning.org.au/individuals/how-to-make-an-advance-care-directive/>
6. What does palliative care cost? Department of Health, accessed April 2020: <https://www.health.gov.au/health-topics/palliative-care/about-palliative-care/what-does-palliative-care-cost>
7. Financial considerations for end of life, Better Health Victoria, accessed April 2020: <https://www.betterhealth.vic.gov.au/health/servicesandsupport/financial-considerations-for-end-of-life>
8. Wills and power of attorney, Commonwealth of Australia, accessed April 2020: <https://www.australia.gov.au/information-and-services/family-and-community/wills-and-powers-of-attorney/wills>
9. Coop and Marlow, 2019, 'Do We Prepare Patients for Their Digital Legacy? A Survey of Palliative Care Professionals', *Palliative Medicine* 33 (1): 114–15.