

# Planning for future care and end of life for people living with MS

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No-one knows what the future holds but by planning ahead you can ensure that your affairs and the welfare of your family are taken care of in advance.

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## Why is it important to plan ahead?

Whilst the future is unpredictable, planning ahead enables individuals to maintain control over their arrangements for future care and end-of-life.

If you were very unwell and unable to communicate your preferences to others, who would you want to speak for you? What would you want them to say? How would you want to be cared for?

This fact sheet may help you with information about:

- Chronic Disease Management – GP Services
- Advance Care Planning
- Palliative Care
- End-of-life decision making

It might be helpful to read this information sheet in conjunction with our related fact sheet, *Financial and legal planning for people living with MS*.

## What is Chronic Disease Management – GP Services?

The Chronic Disease Management (formerly Enhanced Primary Care or EPC) — GP services on the Medicare Benefits Schedule (MBS), enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions, including patients with these conditions who require multidisciplinary, team-based care from a GP and at least two other health or care providers.

A chronic medical condition is one that has been (or is likely to be) present for six months or longer. There is no list of eligible conditions; however, the Chronic Disease Management (CDM) items are designed for patients who require a structured approach, including those requiring ongoing care from a multidisciplinary team.

Whether a patient is eligible for CDM services is a clinical judgement for the GP, taking into account the patient's medical condition and care needs.

## What is advance care planning?

Advance care planning promotes care that is consistent with a person's goals, values, beliefs and preferences. It prepares the person and others to plan for future health care, for a time when the person may no longer be able to communicate those decisions themselves.

Advance care planning is a routine part of a person's health care. When a person's values are discussed openly, their health care preferences can be respected at a time when they cannot voice their decisions. It's an ongoing process that needs cooperation between individuals, their families, care workers, and health professionals as well as community organisations and health care organisations.

Advance Care Planning Australia is a national program that provides information and resources to individuals, care workers and healthcare professionals to improve this cooperation.

Advance care planning helps to ensure that your loved ones and your doctors know what your health and personal preferences really are. That can give everyone some peace of mind.

Whatever our age may be, we all have values and preferences related to health and personal care. It's important to think about these values and preferences, discuss them and write them down in an Advance Care Directive, so that your preferences are understood and respected if you were in a situation where you were unable to communicate them yourself.

Advance care planning is particularly important for older or frail people, or those with a chronic illness, multiple diseases, an early cognitive impairment, or who are approaching their end of life.

Advance care planning involves:

- appointing a substitute decision-maker
- completing an Advance Care Directive

Remember that an Advance Care Directive only goes into effect if you are unable to make decisions for yourself. If that time ever comes, your Advance Care Directive will guide your loved ones and doctors so that they can make decisions that respect your values and preferences.

### **What is palliative care?**

Palliative care is person and family-centred care, provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the healthcare team is being delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care.

Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.

Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. Because palliative care is based on individual needs, the services offered will differ but may include:

- Relief of pain and other symptoms e.g. vomiting, shortness of breath
- Resources such as equipment needed to aid care at home
- Assistance for families to come together to talk about sensitive issues
- Links to other services such as home help and financial support
- Support for people to meet cultural obligations
- Support for emotional, social and spiritual concerns

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- Counselling and grief support
- Referrals to respite care services

Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support.

### What is voluntary assisted dying?

Voluntary assisted dying means administering a medication for the purpose of causing death in accordance with the steps and process set out in law.

Voluntary assisted dying must be voluntary and initiated by the person themselves, and it will usually be self-administered. Only those who are already dying from an incurable, advanced and progressive disease, illness or medical condition will be able to access voluntary assisted dying.

Voluntary assisted dying is only for those who face an inevitable, imminent death as a result of an incurable disease, illness or medical condition.

Voluntary assisted dying legislation has been enacted in two states in Australia: Victoria and Western Australia.

For more information, please visit:

In Victoria: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>

In Western Australia: <https://www2.health.wa.gov.au/voluntaryassisteddying>

### Useful contacts

#### ■ Contact details for your state MS organisations:

MS Limited (Victoria, NSW, ACT and Tasmania)	1800 042 138	<a href="mailto:msconnect@ms.org.au">msconnect@ms.org.au</a>	<a href="http://www.ms.org.au">www.ms.org.au</a>
MSWA (Western Australia)	1300 097 989	<a href="mailto:communications@mswa.org.au">communications@mswa.org.au</a>	<a href="http://www.mswa.org.au">www.mswa.org.au</a>
MS Society SA & NT (South Australia and Northern Territory)	1800 812 311	<a href="mailto:msassist@ms.asn.au">msassist@ms.asn.au</a>	<a href="http://www.ms.asn.au">www.ms.asn.au</a>
MS Queensland	1800 177 591	<a href="mailto:info@msqld.org.au">info@msqld.org.au</a>	<a href="http://www.msqld.org.au">www.msqld.org.au</a>

#### ■ Chronic Disease Management (formerly Enhanced Primary Care or EPC) — GP services

Chronic Disease Management (formerly Enhanced Primary Care or EPC) — GP services are services funded through the Medicare Benefits Schedule (MBS) to enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions.

For more information about these services, fact sheets, Q&As and other recourses, please visit the Australian Government's Department of Health website:

<https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement>

### ■ Advance Care Planning Australia

Advance Care Planning Australia (ACPA) is a national program funded by the Australian Government Department of Health, enabling Australians to make the best choices for their life and health care.

**Phone:** 1300 208 582

**Website:** <https://www.advancecareplanning.org.au/>

### ■ Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care.

Palliative Care Australia represents all those who work towards high quality palliative care for all Australians. Working closely with consumers, their Member Organisations (there are Palliative Care organisations in each state and territory) and the palliative care workforce, they aim to improve access to, and promote the need for, palliative care.

**Phone:** 02 6232 0700

**Website:** <https://palliativecare.org.au/>

## Information and assistance:

Some people may find issues relating to end-of-life care upsetting. If reading the material in this information sheet or on this site or thinking about end-of-life care has raised some issues regarding grief and bereavement or personal crisis, the helplines below provide telephone support and counselling 24 hours a day, 7 days a week. Some services may also provide online assistance (depending on the service).

**Australian Centre for Grief and Bereavement Phone: 1800 642 066**

**Lifeline Phone: 13 11 14**

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### Sources

This information sheet comprises material from: Advance Care Australia, Palliative Care Australia, and the Department of Health in each Australian state and territory.

**Disclaimer:** Information prepared by MS Australia. It is intended to provide useful and accurate information of a general nature and is not a substitute for medical advice.