

# **DIGNITY, RESPECT AND CHOICE: ADVANCE CARE PLANNING FOR END OF LIFE FOR PEOPLE WITH MENTAL ILLNESS**

AN INTRODUCTORY GUIDE



Health

**NSW MINISTRY OF HEALTH**

73 Miller Street

NORTH SYDNEY NSW 2060

Tel. (02) 9391 9000

Fax. (02) 9391 9101

TTY. (02) 9391 9900

**[www.health.nsw.gov.au](http://www.health.nsw.gov.au)**

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**Dignity, Respect and Choice: Advance Care Planning for End of Life for People with Mental Illness is a two-part resource, which consists of this introductory guide for people with mental illness and a comprehensive guide for health professionals. The comprehensive guide can be accessed at:**  
**<http://www.health.nsw.gov.au/patients/acp/Publications/comprehensive-guide.pdf>**

## **A message from the Chief Psychiatrist, Dr Murray Wright**

Advance Care Planning for future end of life care is important for everyone. It's about thinking, discussing, planning and documenting our health care needs for the future, particularly the physical health care we wish to receive as we approach end of life.

NSW Health's *Advance Planning for Quality Care at End of Life: Action Plan 2013-2018* (<http://www.health.nsw.gov.au/patients/acp/Pages/acp-plan-2013-2018.aspx>) sets out the steps to normalise Advance Care Planning and improve end of life care for everyone across the whole healthcare sector. The Plan is built on collaboration, openness, respect and empowerment – making it a central part of health care planning.

The Plan recognises that people with mental illness can take part in Advance Care Planning and should have their wishes respected.

It is important to acknowledge that mental health issues affect the whole community and to recognise the diversity of people with a lived experience of mental illness in many different forms. While there is no longer the same social stigma attached to having mental illness as there was in the past, unfortunately remnants of this stigma remain.

One of the more damaging aspects of stigma about mental illness is that it fosters false assumptions about people with a mental illness and these sometimes relate to Advance Care Planning and what it means for people with experience of mental illness.

A crucial step in challenging this stigma is addressing these false assumptions and encouraging and supporting people with mental illness to have access to Advance Care Planning.

This is one of the reasons why we developed this resource – it recognises the importance of dignity, respect and choice when it comes to people with mental illness and Advance Care Planning.

The resource will help support health professionals, particularly those whose patients have a lived experience of mental illness, with the complex and diverse issues which might arise around Advance Care Planning.

The resource is also supported by information for people with a lived experience of mental illness, their family and carers.

The resource is an important tool, alongside a wellness plan, to support personal recovery where possible and autonomy of the person with a lived experience of mental illness throughout life, including at approaching end of life.



**Dr Murray Wright, Chief Psychiatrist**

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## Key Messages about Advance Care Planning

**Key message 1:**

People with mental illness can take part in Advance Care Planning and should have their end of life wishes respected.

**Key message 2:**

It is best to start Advance Care Planning early, when a person is well.

**Key message 3:**

A key part of Advance Care Planning is deciding who can make decisions on a person's' behalf.

**Key message 4:**

Working together is critical to improve end of life care for people with mental illness.

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## Terms used in this Guide

Person with mental illness/ People with mental illness	Refers to individuals or people who have a lived experience of mental illness. This guide does not intend these terms to imply that such individuals or people are defined by their mental health conditions. This guide acknowledges that many people with mental illness have advocated for the human rights and citizenship of people who live with mental illness and prefer the term 'mental health consumer'.
Health professional	Any health professional providing health care services to an individual including allied health professionals, general practitioners, nurses, specialists and social workers.
Mental health professional	<p>Any health professional with experience and expertise in providing mental health services to people with mental illness. This includes allied health professionals, mental health nurses, psychiatrists, psychologists and social workers.</p> <p>While this Guide encourages mental health professionals to assist their clients with Advance Care Planning, it is important that these professionals are suitably qualified and have the skills and training to undertake this role.</p>
Capacity	<p>A person has the ability to make a particular decision when they are able to do all of the following:</p> <ul style="list-style-type: none"><li>■ Understand the facts involved</li><li>■ Understand the main choices</li><li>■ Weigh up the consequences of the choices</li><li>■ Understand how the consequences affect them</li><li>■ Communicate their decision.</li></ul> <p>For more information see <a href="http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capa_what_is.aspx">http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capa_what_is.aspx</a></p>

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PART ONE

## Who is this Guide for and what does it cover?

Anyone can use this Guide, but it focuses on people with mental illness.

It may be useful for carers, families and friends, mental health professionals, mental health peer workers and other health professionals.

This Guide is about how people can make plans for the health care they want to receive for a physical illness as they approach end of life. It is about encouraging people to think ahead and make plans while they are well. This helps make sure their wishes are considered when they reach the end of their life, especially if they do not have the capacity to make decisions about their care.

This Guide is an introduction to Advance Care Planning for people with mental illness. It covers:

- **What Advance Care Planning** is and **where to get more information**
- **What to expect** from an Advance Care Planning conversation
- **Key messages** about Advance Care Planning for people with mental illness.

## What is not covered?

This guide is NOT about:

### ■ **Planning for future mental health care**

**A Consumer Wellness Plan** is for care of mental illness. It includes managing symptoms, preventing relapse and planning for a crisis. This Guide is not about Consumer Wellness Plans, however it is important that if a person has a Consumer Wellness Plan and an Advance Care Plan for end of life, the two are co-ordinated. This will help make sure the person has comprehensive care for their physical and mental health needs as end of life approaches. See the person's treating mental health professionals for more information about Consumer Wellness Plans.

### ■ **Euthanasia or assisted dying**

Advance Care Planning does not mean euthanasia. *Euthanasia* (sometimes called *assisted suicide* or *assisted dying*) means acting at a person's request with the intention to cause their death so as to stop their suffering. Euthanasia is illegal in NSW.

### ■ **Detailed information about advance care planning**

This is an introductory Guide only. More detailed information is in the resource *Dignity, Respect and Choice - Advance Care Planning for end of life for people with mental illness: A Comprehensive Guide*, which was written for health professionals. It contains in-depth information and stories about Advance Care Planning and end of life decision making for people with mental illness.

## What is Advance Care Planning?

**Advance Care Planning** is an important process that helps a person to plan for future end of life care. This process involves the person thinking about their values, beliefs and wishes about the health care they would like to have if they could not make their own decisions.

### **It is best if Advance Care Planning happens earlier in life, when a person is still well.**

Advance Care Planning is important for everyone in the community. It is especially important for people with mental illness because people with mental illness have higher rates of physical illness and reduced life expectancy compared with the general population. Some people with some mental illness may experience a range of physical, emotional and psychological issues that can affect their ability to communicate their wishes about end of life issues.

Advance Care Planning can include one or more of:

- **Conversations** between a person and their family, carer and/or health professional.
- Development of an **Advance Care Plan** by the person, on their own or with help from another person. An Advance Care Plan is the documented outcome of advanced care planning. Like an Advance Care Directive, an Advance Care Plan also records preferences about health and treatment goals. It may be made by, with or for the individual. For more information about developing an Advance Care Plan visit the website at: <http://planningaheadtools.com.au/advance-care-planning/>
- Appointing an **Enduring Guardian**. An Enduring Guardian can legally make decisions on a person's behalf about medical and dental care, if the person loses the capacity to make the decision. Deciding who should make decisions for a person if they do not have capacity is an important part of Advance Care Planning. For more information about an Enduring Guardian see <http://planningaheadtools.com.au/appoint-an-enduring-guardian/>
- Make an **Advance Care Directive**. An Advance Care Directive records a person's specific wishes and preferences for future care. This includes

treatments they would accept or refuse if they had a life-threatening illness or injury. An Advance Care Directive is to be used where the person does not have capacity to decide for themselves or to communicate their wishes.

It is recommended that an **Advance Care Directive** be written down and signed by the person and a witness. Although this is not necessary to make the Advance Care Directive legal, it is a good idea.

A doctor should consider an **Advance Care Directive** valid and legally binding if:

- The person had decision making capacity when they made it
- The person was not influenced or pressured by anyone else to make it
- It has clear and specific details about treatment that they would accept or refuse
- It is current (the person has not since changed their mind since they made it)
- It extends to the situation at hand.

An **Advance Care Directive** cannot contain instructions for illegal activities, such as euthanasia, assisted suicide or assisted dying.

- A doctor may write a **Resuscitation Plan** as part of the person's medical plan of care when their death is expected in the near future. A person's Advance Care Plan or Advance Care Directive must inform decisions recorded in the Resuscitation Plan.

**Capacity to make a decision** is an important issue in Advance Care Planning. If it is not clear whether a person has the capacity to do something, a capacity assessment may be needed. This would involve a review of the person's capacity by their treating doctor or by a mental health professional.

The *Capacity Toolkit* available at [http://www.diversityservices.justice.nsw.gov.au/divserv/ds\\_capacity\\_tool.html](http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html) has more information about what capacity is and how to assess it. A person who is unhappy about the decision made about their capacity can contact the Guardian Division on 1300 006 228 and 'press 2' or through their website: [www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx](http://www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx)

## What to expect from an Advance Care Planning conversation

Advance Care Planning conversations involve health professionals talking with a person who has been diagnosed with a health condition that may shorten their life. These conversations give the person the opportunity to talk about what they would like to happen as they approach the end of their life and what they think and feel about it. These conversations might seem hard to begin with but it is important to start them.

People with mental illness may find these conversations hard in some ways because of the way their mental illness affects them. Mental health professionals can play a crucial role working with the person to support them in these conversations. Advance Care Planning conversations may also involve the person's family, carer and friends but only if the person wants them to be part of the discussion.

Health professionals and mental health professionals can work together to:

- Help the person deal with their thoughts and feelings about the end of life.
- Make sure the conversations are held in a way that best meets the person's individual needs. For example, planning the conversations for times when the person feels "well" and can participate in the discussion.
- Make sure the person's spiritual, social, cultural needs are recognised and addressed. For example, arranging for an interpreter if the person or their family or carers need one and providing written information in the person's preferred language.

Every Advance Care Planning conversation is unique to the person who is facing the end of their life. However, in most conversations, the person, and their family and carers (if the person wants them involved) can expect to:

- **Get information** from health and mental health professionals

These conversations are a good opportunity for health professionals to give clear, honest and realistic information about the person's illness and what to expect as they approach the end of their life. The person can use this time to ask about future treatment and care options and available support services. Mental health professionals can

also talk with the person about how their experience of mental illness might affect what they need from their end of life care. They can work with the person and the health professionals to come up with the best approach.

- **Express** their thoughts, feelings and ideas and needs

The most important part of these conversations is learning about what matters to the person approaching the end of their life. The person should be encouraged and supported to talk openly about their feelings and discuss any worries. Most people find this helpful, although no one should be made to do this if they do not want to. They can let others know what they need to help them get through this phase of their life by sharing their values and personal beliefs about death and dying, so these can be respected in future care. This is especially important if the person has religious beliefs or cultural values that the health professionals might not know or understand. Where the person wants their family and/or carers involved, these conversations are useful for families and carers to talk about how they feel and what they want to do to help the person.

- **Work** towards making an Advance Care Plan

These conversations are a way of bringing everyone together with the common goal of making an Advance Care Plan that suits the person and ensures they have quality care at the end of their life. Conversations can deal with many different parts of end of life care. For example, thinking about who should make a decision on the person's behalf if they lose capacity to make their own decisions.

Making an Advance Care Plan takes care, patience and time. Often, the Plan keeps evolving to reflect changes in the person's circumstances and their views and feelings about end of life. Sometimes, the person will not want to write a Plan after the discussions. This is fine; many people find it helpful to simply have the conversations. The person may make an Advance Care Plan or Advance Care Directive but later change their mind and decide not to have one at all. This is also fine.

## Stigma – the wrong ideas about mental illness and Advance Care Planning

Unfortunately, some people have experienced stigma and discrimination simply because of their lived experience with mental illness. This stigma might lead to people having false assumptions and the ‘wrong idea’ about whether people with mental illness can be involved in Advance Care Planning. For example, they might:

- Wrongly assume a person with mental illness does not have the capacity to understand Advance Care Planning.

Everyone is entitled to the presumption that they have capacity. This also applies to people with mental illness. If there is concern about a person’s capacity to make a decision, then their capacity to make that decision should be assessed by a health professional.

- Wrongly assume a person with mental illness is too unwell to make their own decisions so it is better that someone else decides for them.

A person with a lived experience of mental illness has the right to make their own choices.

A substitute decision maker should only be involved if the person clearly lacks capacity.

Even then, the person should be supported to participate in decision making and their views considered.

- Wrongly assume the person might find it too upsetting to think or talk about the end of their life.

Many people might find it hard to talk about end of life. Respecting people with mental illness means respecting their right to honest, clear information about their health and offering them help and support if they need it.

## Key messages about Advance Care Planning for people with mental illness

### **Key message 1: People with mental illness can take part in Advance Care Planning and should have their end of life wishes respected**

Just like everyone else, the wishes of people with mental illness about their end of life treatment and care should be respected. Advance Care Planning encourages people with a lived experience of mental illness to talk about what is important for their end of life treatment and care with their family, carers, friends and health professionals. When the time comes to make end of life decisions, health professionals should respect the person's values, ideas and views that they learnt about during the Advance Care Planning process. Doctors should provide care in accordance with a person's considered and documented wishes. In many cases they have a legal obligation to do this.

As long as they have decision making capacity, people with mental illness can refuse burdensome treatment at the end of their life. They can also have someone of their choosing make decisions on their behalf. If they do not have capacity to make a decision at the time the decision needs to be made, their wishes can still be considered and respected. They can include their wishes in an Advance Care Directive and choose an Enduring Guardian and let them know their wishes.

People with mental illness have the same rights as all health consumers such as:

- The right to the presumption of capacity. This means everyone, including people with mental illness, are assumed to have the capacity to make decisions about their lives unless established otherwise
- The right to receive the same standard of physical health care as those who do not have a mental illness, including palliative care and adequate pain relief at the end of life
- The right to be treated with humanity and respect for their dignity at all times, including at the end of life.

### **Key message 2: It is best to start Advance Care Planning early, when a person is well**

Mental illness may involve a changing ability to make important decisions. Planning early when well can help people with mental illness to:

- Choose who they would like to make decisions for them and let those people know about their wishes
- Access support to make decisions, if this is needed
- Prevent problems later. For example, health professionals trying to figure out a person's wishes at the last minute
- Decide in advance whether to agree to, or refuse, medical treatment, even if it is needed to keep them alive.

### **Key message 3: A key part of Advance Care Planning is deciding who can make decisions on a person's behalf**

An essential part of successful Advance Care Planning for all health consumers is identifying the person who can make decisions on their behalf if they lose capacity in the future. This person is called the substitute decision maker. Having a substitute decision maker is particularly important for people with mental illness whose capacity may vary at different times.

Advance Care Planning discussions provide the opportunity to talk about who is the person's substitute decision maker for medical decisions. It is also the time to talk about whether the person would like to appoint an Enduring Guardian to make medical and other decisions for them if they lose capacity and to give them information about what this means and how to do it.

### **Key message 4: Working together is critical to improve end of life care for people with mental illness**

Good end of life decisions and care require effective partnerships between a person with mental illness and their family, carer and health care professionals, including mental health professionals and specialists, such as the palliative care team. If a person is being cared for in a health facility, it is important to make sure there is effective transfer of key documents and information (such as clinical care plans) if the person moves from one facility to another.

## More information

Resource	Description	Author
<p><i>Advance Care Planning-Making your wishes known</i> website at:  <a href="http://www.health.nsw.gov.au/patients/acp/Pages/default.aspx">http://www.health.nsw.gov.au/patients/acp/Pages/default.aspx</a></p>	NSW Health publications about Advance Care Planning and links to other useful websites	NSW Ministry of Health
<p><i>Planning Ahead Tools</i> website at:  <a href="http://planningaheadtools.com.au/">http://planningaheadtools.com.au/</a></p>	Information about wills, Power of Attorney, Enduring Guardianship and Advance Care Planning including forms and example Advance Care Directives	NSW Trustee and Guardian
<p>The Way Ahead Directory at:  <a href="http://www.wayahead.org.au">www.wayahead.org.au</a></p>	The website contains up to date information on over 4,200 mental health and welfare related services across NSW.	Mental Health Association NSW
<p>ARAFMI NSW for families, carers and friends of people living with a mental illness:  <a href="http://www.arafmi.org/">http://www.arafmi.org/</a></p>	This website provides support, education and advocacy to help families and carers fulfil their caring role.	ARAFMI NSW – Mental Health Carers
<p>BEING  <a href="http://www.being.org.au/">http://www.being.org.au/</a></p>	Support for people with a lived experience of mental illness	BEING (formerly NSW CAG)
<p><i>Capacity Toolkit</i> available at:  <a href="http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html">http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html</a></p>	The Toolkit has information about what capacity means and how to assess capacity to make decisions in different situations.	NSW Department of Justice
<p><i>End of Life Decisions, the Law and Clinical Practice</i> website at:  <a href="http://healthlaw.planningaheadtools.com.au/decision-making-at-end-of-life/">http://healthlaw.planningaheadtools.com.au/decision-making-at-end-of-life/</a></p>	Guide for health professionals on a range of legal issues which may arise in Advance Care Planning.	NSW Ministry of Health





