

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

A COMPREHENSIVE GUIDE



| Health

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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 comprehensive guide for health professionals and an introductory guide for people with mental illness. The introductory guide can be accessed at <http://www.health.nsw.gov.au/patients/acp/Publications/introductory-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.

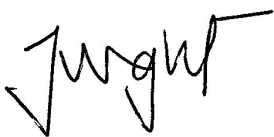
A crucial step in challenging this stigma is addressing these false assumptions and encouraging and supporting people with mental illness to have access to Advance Care Planning.

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

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">■ Understand the facts involved■ Understand the main choices■ Weigh up the consequences of the choices■ Understand how the consequences affect them■ Communicate their decision. <p>For more information see http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capa_whatIs.aspx</p>

PART ONE

Who is this Guide for and what does it cover?

This Comprehensive Guide is designed for health professionals whose patients or clients have a mental illness. It contains detailed information about complex issues that might arise around Advance Care Planning for people with mental illness. The Guide may also be of interest to people with mental illness and their carers and family.

The Guide:

- Explains what Advance Care Planning means
- Sets out key points to keep in mind about Advance Care Planning
- Examines false assumptions about mental illness and Advance Care Planning
- Explores how to deal with the effect of mental illness on capacity, both when planning for the future and when decisions need to be made
- Clarifies complex issues around substitute medical consent where there is potential overlap between different legislative regimes
- Explores specific issues for people receiving treatment and care under the *Mental Health Act 1987 (NSW)*
- Considers particular issues for Advance Care Planning in forensic mental health settings
- Uses hypothetical scenarios to illustrate how Advance Care Planning issues may arise in different clinical settings involving a person with a mental illness and suggests how to address these issues.

The Guide accompanies the *Introductory Guide*, which focuses on people with mental illness and may also be useful for their carers and families.

What is not covered?

The 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 professional(s) for more information about Consumer Wellness Plans.

■ **Euthanasia or assisted dying**

Advance Care Planning does not mean euthanasia. *Euthanasia* (also 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. It is not euthanasia when a medical practitioner declines to offer life-sustaining treatment or withdraws it and they are acting according to good medical practice when they do this, for example discontinuing treatments that are no longer effective or do not benefit the patient.

■ **Detailed information about all aspects of Advance Care Planning**

There are many other resources with extensive information about a wide range of Advance Care Planning topics (such as Advance Care Directives or legal issues), which are available to all health care professionals and the community. The Guide provides information about where to access these resources (see resources on page 40) but its main focus is on specific issues that may arise for health professionals and mental health professionals about Advance Care Planning and patients with a mental illness.

What is Advance Care Planning?

Advance Care Planning is an important process that helps a person to plan for future medical care. This process involves the person thinking about their values, beliefs and wishes about what medical care they would like to have if they cannot make their own decisions.

Ideally, 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 illnesses may experience a range of physical, emotional and cognitive issues that can impinge on their ability to communicate their wishes about end of life issues.

Advance Care Planning can include one, or a number of the following:

- **Conversations** between a person and their family, carer and/or health professional
- Developing an **Advance Care Plan** either by the person on their own or with help from another person. The Plan can also be made on the person's behalf by someone else such as their carer, family or involved health professional. The Plan should be prepared from the person's perspective to guide decisions about care. 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/>

- Making an **Advance Care Directive**. As part of the Advance Care Planning process, a person may decide to make an **Advance Care Directive**. The person must have decision-making capacity to make a valid Advance Care Directive. An Advance Care Directive records a person's specific wishes and preferences for future care such as treatment that they would like to have in the event of life-threatening illness or injury, and any treatments they would refuse. It is meant to be referred to and used in circumstances where the person does not have the capacity to decide for themselves and communicate their wishes.

An oral **Advance Care Directive** can be made but making a written Advance Care Directive is recommended as it provides more clarity about, and a record of, the person's preferences. A written Directive should be signed by the person who made it. There is no requirement for the Directive to be witnessed but this is a good idea.

A doctor should consider a person's **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 or assisted suicide.

- A doctor may complete a **Resuscitation Plan** as part of a person's medical plan of care when their death is expected in the near future. A Resuscitation Plan is a medically authorised order to use or withhold resuscitation measures, which also documents other aspects of treatment relevant at end of life. Doctors should consider instructions from an Advance Care Plan or Directive when completing the Resuscitation Plan. It is best practice to discuss the options within the Resuscitation Plan with the patient and/or Person Responsible, carer or family before completing the Resuscitation Plan.

PART FOUR

Key messages about Advance Care Planning for people with mental illness

When health professionals and mental health professionals are considering Advance Care Planning with patients who have a mental illness, it may be helpful to keep these key messages in mind:

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 in partnership with people with mental illness, their carers and families as well as with other health professionals and services is critical to improve end of life care for people with mental illness.

Advance Care Planning issues

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.

Much of Advance Care Planning is the same for people with mental illness as it is for other people. However, sometimes certain circumstances or aspects of managing mental illness might raise Advance Care Planning issues that are different for people with mental illness. It is important for health professionals and mental health professionals to be informed about these different issues so they can better assist their patients or clients to plan for quality end of life care. These issues are:

- False assumptions about mental illness and Advance Care Planning
- The impact of mental illness on capacity
- Complex legal requirements for substitute medical consent in some situations
- The particular needs of people being treated and cared for under the *Mental Health Act 2007 (NSW)*
- Specific issues for forensic mental health patients.

5.1 False Assumptions about Mental Illness and Advance Care Planning

It is important to challenge any ideas that Advance Care Planning for the end of life is not appropriate for people with mental illness. 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. 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 some may associate mental illness with people who receive treatment and care under the *Mental Health Act* in psychiatric facilities, this is a narrow view which fails to acknowledge that many people with mental illness live in the community and lead active normal lives.

One of the more damaging aspects of stigma about mental illness is that it fosters false assumptions about people with mental illness. Recognition that such false assumptions sometimes relate to Advance Care Planning and what it means for people with mental illness was one of the reasons for developing this Guide.

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

■ ***False assumption 1: Having a mental illness means a person is not capable of understanding Advance Care Planning and is too unwell to make her/his own decisions. It is better that someone else decides for them.***

Under NSW law, every person has the right to the presumption of capacity. Having a mental illness, on its own, does not mean a person is incapable of understanding and taking part in Advance Care Planning. Any concern about an individual's capacity to understand or participate in Advance Care Planning must be assessed on an individual basis. It cannot be assumed based on the person having a mental illness. This also applies to people with intellectual/cognitive disability and a mental illness.

Health professionals have an important role in helping their patients who have mental illness to understand Advance Care Planning and supporting them to take part. This may include tailoring their approach to Advance Care Planning to ensure it meets any needs the patient may have due to their mental illness or other disability. Sometimes, it might be necessary for the person with mental illness to have a substitute decision-maker. Where this occurs the person with mental illness should be included in discussions and decision-making as far as possible.

- ***False assumption 2: People with mental illness cannot cope with talking about serious physical health issues, such as the end of life, and will become so upset their mental health will suffer.***

Talking about the end of life can be difficult for anyone. All people should be given the same opportunity to have these conversations with the support of their carers, family and health professionals. Mental health professionals can use their expertise to help and support people with mental illness in these discussions by recognising and addressing any additional support needs arising from the mental illness.

- ***False assumption 3: People with mental illness will make poor choices when it comes to planning ahead for their future medical care. They need protection from making decisions that are not good for their health. They will use Advance Care Planning as a way to harm themselves, refuse beneficial treatment, even commit suicide, and health professionals cannot do anything about it.***

Advance Care Planning is not a way of facilitating a person's desire to end her or his own life or to harm herself/himself. It is about supporting all health consumers, including people with mental illness, to explore and make the best choices for themselves about their end of life medical treatment and care.

Health professionals should respect the choices made by people with mental illness about their medical care and are legally obliged to follow a valid Advance Care Directive refusing treatment. It is only when a health professional has concerns about their patient's choices or the validity of the Advance Care Directive, that they should consider exploring other options, such as the appointment of a substitute decision-maker or legal advice.

- ***False assumption 4: People with mental illness do not have any legal rights to make choices about their medical care once they are under the Mental Health Act.***

A person with mental illness who is treated under the *Mental Health Act 2007 (NSW)* should still be given the opportunity to take part in Advance Care Planning. Certain medical treatment decisions can be made for some types of patients without their agreement under the *Mental Health Act 2007 (NSW)*; however this does not apply to every patient for every kind of treatment.

STORY ONE: Kristy's story

Kristy is a 57 year old Aboriginal woman who is a voluntary patient in an acute mental health unit. She has recently experienced hallucinations, which have not been a symptom she has had during episodes of illness in the past. Kristy has co-morbid kidney disease. She is married to Mick and is close to her large family.

Read Kristy's story on page 31 for examples of how stigma and mistaken false assumptions about capacity can arise in practice and how to recognise and deal with these.

5.2 Dealing with the Effect of Mental Illness on Capacity

Health professionals may find that if their patient has a mental illness, then the issue of their capacity might arise at various stages of the Advance Care Planning and end of life process. For example, when making Advance Care Plans and talking about future care during the planning stage. Similarly, capacity questions may arise at the time treatment decisions need to be made at the end of life, such as when deciding whether to provide life-sustaining treatment.

- **Capacity issues at the time of planning for the future**

It is important not to assume that Advance Care Planning is inappropriate for people with mental illness simply because of potential capacity issues. The views and values of people with mental illness should always be sought and included in end of life planning, irrespective of their assessed capacity.

Health professionals and mental health professionals can support their patients with mental illness in the Advance Care Planning process by:

- Recognising that the capacity of a person with mental illness can vary and accommodating this by having Advance Care Planning discussions during periods of capacity
- Arranging capacity assessments if there are concerns about a person's capacity and following up with reassessments
- Being aware of the capacity required for the person to make the decision
- Involving people with mental illness in planning and decision-making even if they lack decision-making capacity
- Considering whether a substitute decision-maker is necessary and identifying or arranging this if needed.

Mental health professionals play a key role in understanding and managing the impact of mental illness on the capacity of people with mental illness to participate in Advance Care Planning. This includes modifying the approach to Advance Care Planning discussions to facilitate the person's participation to the maximum extent possible.

■ **Initiating/having Advance Care Planning discussions during periods of capacity**

Capacity is situation-specific. A person's capacity needs to be assessed for each situation or decision that is being considered.

People with mental illness may find it difficult to take part in Advance Care Planning because their mental illness might impair their capacity to think clearly and make decisions. However, their insight and capacity may also fluctuate and improve at different times and in different situations. During these periods, they are able to think rationally, communicate clearly and make reasoned choices.

The key to successful Advance Care Planning for people with mental illness is to take the opportunity to engage in Advance Care Planning during periods of capacity. This is particularly important if the person wishes to make a legally binding document or directive such as the appointment of an Enduring Guardian or an Advance Care Directive. These will only be valid if the person had capacity when they made them.

Mental health professionals, people with mental illness and their families, friends and carers can work together to identify the optimal times to discuss and plan end of life treatment and care. It may be necessary to have ongoing discussions and conversations at different times to accommodate the fluctuating nature of the person's capacity. Each time Advance Care Planning is discussed, it is important to review and confirm what was discussed or decided previously so health professionals and people with mental illness can proceed on a shared understanding of the current position.

■ **Advance Care Planning for those who lack capacity**

Where possible people with mental illness should be included in Advance Care Planning, even if they lack capacity to understand these discussions or to express their preferences for end of life care.

Although a person with mental illness may lack the capacity to make the decision at hand, they may still be able to be involved in discussions about the treatment/situation or have a view they wish to make known. The person has the right to supported decision-making (assistance in expressing her/his choices).

The United Nations has explained supported decision-making as:

With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision-maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual.¹

If a person with mental illness is unable to express their choices with assistance, Advance Care Planning can be done on their behalf by someone who knows and understands them well, such as a close friend or relative. It is important to acknowledge that in some cultures, large extended families are the norm, meaning many people may be involved in the Advance Care Planning.

If the person has an Enduring or Appointed Guardian with the authority to make decisions in this area, then the guardian can participate in this process on behalf of the person.

1 United Nations, *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities*, Chapter Six: From Provisions to Practice - Legal capacity and supported decision-making at <http://www.un.org/disabilities/default.asp?id=242>

A guardian, friends and/or relatives can help health professionals gather information about the person's values, views and preferences and incorporate these into an Advance Care Plan to guide treatment as the person's health deteriorates. It is particularly important to ascertain these for people with mental illness as they may have strongly held views and preferences about a range of issues and become highly anxious and distressed if these are not accommodated. For example, they may become highly agitated and upset in hospital settings if their daily routines are disrupted and may only feel safe and comfortable with certain kinds of people or in particular environments.

The treating mental health professional(s) may be a good source of information about the person if they have been involved in their treatment and care for a long time.

Finding out about the values, views and preferences of a person with mental illness, incorporating them in an Advance Care Plan and respecting them is key to ensuring that health professionals provide quality care to people with mental illness during periods of deteriorating health and at the end of their life.

What to expect from an Advance Care Planning discussion

It is the role of health professionals to encourage and guide Advance Care Planning discussions. Mental health professionals can play a valuable role in these discussions where the person involved has mental illness, particularly if they know the person well.

When preparing for these discussions, it is crucial to consider who else should participate. Like other health consumers, people with mental illness will have a range of views about who they would like to be involved. The health professional can assist by ascertaining and respecting these preferences when planning and having these discussions. Different people such as the person's carers, family and friends or other health professionals involved in their care may be part of those discussions at different times and for different purposes. They may all have different expectations about what the discussion will involve. In some cultures, talking about death or dying is taboo or may be perceived as 'giving up' on the person with a life-limiting illness. It is important to be aware of these differences and tailor the approach to the discussion accordingly. It may be necessary to seek advice from the Transcultural Mental Health Centre www.dhi.health.nsw.gov.au/tmhc/default.aspx or 1800 648 911 about how to best manage these discussions.

Talking about Advance Care Planning can mean:

- **For health professionals:** an opportunity to talk honestly and openly to their patients and their carers, families and friends about the person's health and the options for future care. It is a time for them to learn what the patient thinks and feels about approaching the end of their life and to clarify what they understand about this. Gathering information about the patient and their carers, families and friends and what is important to them at this time is a crucial part of these discussions.

The patient's needs for support and assistance to participate in Advance Care Planning, such as interpreters or translations of written information, should also be considered.

Health professionals can find these discussions challenging. The patient and their carers, family

and friends will often find it difficult and sometimes upsetting to talk about, and plan for end of life. Mental health professionals may find that health professionals and others will seek their advice about how to best help a person with mental illness with planning for end of life.

It is also a time to raise the issue of possible future loss of capacity and what options are available for substitute decision-making if that happens.

The PREPARED Model on page 15 has been developed to help health professionals prepare for and have Advance Care Planning and end of life conversations.

- **For the person:** It is a chance to express their thoughts and feelings about approaching the end of their life, what is important to them and why they are making certain choices. It is OK if they would like to listen rather than participate. It is a time to ask health professionals questions about medical treatment and care and available services. The discussion is also an opportunity to hear what their carers, families and friends think and feel about what is happening and what they want to do to help. While discussing medical treatment is important, it is equally important for people with mental illness to consider their mental health needs (at the current time and as they approach the end of their life) and how to best meet these. Exploring this issue with mental health professionals, carers, friends and family is a crucial part of the discussion. The person might also like to reflect on who they would like to make decisions for them in the future if they lose this capacity and what they would like that person to consider when making those decisions. They may ask for more information about this, such as how to appoint an **Enduring Guardian**.

It is important not to make assumptions that a person will have particular beliefs or preferences based on their cultural background. The conversations are a way of exploring the person's beliefs and values and how to best respect these as the person approaches the end of their life.

■ **For carers, family and friends:** While this discussion can be distressing and upsetting for carers, friends and family, it is an opportunity to have some clarity and structure around what will happen next for the person. It is a chance to hear what both the health professional and the person have to say about options for the future.

Importantly, carers, family and friends will have the opportunity to express what they think and feel and how they see their role as the person approaches the end of their life. It is a good time to talk about who would make decisions on the person's behalf if they lost capacity and what support the substitute decision-maker feels they made need. The knowledge and experience of carers, family and friends about the person's mental health needs will be invaluable in working out how to make sure these needs are met in the Advance Care Planning discussions and at the end of life.

The conversations are a time for carers to share their knowledge and understanding about what is important to the person and their family, such as religious or cultural beliefs or practices. Even if the person does not want their carers to be involved in some aspects of the Advance Care Planning process, it is important to keep trying to have open communication and revisit the issue of their involvement with the person, if appropriate.

The PREPARED MODEL of communication

The **PREPARED MODEL** of prognostic and end of life communication is one approach to having Advance Care Planning and end of life conversations. The model presented in Clayton, Hancock, Butow et al 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers' *Medical Journal of Australia* (2007) 186(12):S77 has been tailored to end of life issues below.

In addition to the steps shown on the following page, to establish a plan for limiting end of life treatment:

- Gauge the patient and families readiness to discuss and/or develop a plan
- Provide information about what's happening with the person's illness and likely prognosis, tailored to the information needs of the person (as per PREPARED above)
- Discuss with the patient their priorities and worries about the future
- Respond to emotion
- Ask if they would like you to make a recommendation about their medical care consistent with their current health and personal priorities
- Remind the patient and family of the supports and services available to them during the terminal phase.

Table 1 : The PREPARED MODEL of communication

P – Prepare for the discussion:

- Confirm pathological diagnosis and investigation results before initiating discussion
 - Try to ensure privacy and uninterrupted time for discussion
 - Negotiate who should be present during the discussion.
-

R – Relate to the person:

- Develop rapport
 - Show empathy, care and compassion during the entire consultation.
-

E – Elicit patient and caregiver preferences:

- Identify the reason for this consultation and elicit the patient’s expectations
 - Clarify the patient’s or caregiver’s understanding of their situation, and establish how much detail and what they want to know
 - Consider cultural and contextual factors influencing information preferences.
-

P – Provide information:

- Offer to discuss what to expect, in a sensitive manner, giving the patient the option not to discuss it
 - Pace information to the patient’s information preferences, understanding and circumstances
 - Use clear, jargon-free, understandable language
 - Explain the uncertainty, limitations and unreliability of prognostic and end-of-life information
 - Avoid being too exact with timeframes unless in the last few days
 - Tailor information to the individual needs of both patients and their families
 - Consider the caregiver’s distinct information needs, which may require a separate meeting with the caregiver (provided the patient, if competent, gives consent)
 - Try to ensure consistency of information and approach provided to different family members and the patient and from different clinical team members.
-

A – Acknowledge emotions and concerns:

- Explore and acknowledge the patient’s and caregiver’s fears and concerns and their emotional reaction to the discussion
 - Respond to the patient’s or caregiver’s distress regarding the discussion, where applicable.
-

R – Foster Realistic hope:

- Be honest without being blunt or giving more detailed information than desired by the patient
 - Do not give misleading or false information to try to positively influence a patient’s hope
 - Reassure that support, treatments and resources are available to control pain and other symptoms, but avoid premature reassurance
 - Explore and facilitate realistic goals and wishes, and ways of coping on a day-to-day basis, where appropriate.
-

E – Encourage questions and further discussions:

- Encourage questions and information clarification; be prepared to repeat explanations
 - Check understanding of what has been discussed and if the information provided meets the patient’s and caregiver’s needs
 - Leave the door open for topics to be discussed again in the future.
-

D – Document:

- Write a summary of what has been discussed in the medical record
 - Speak or write to other key health care providers involved in the patient’s care. As a minimum, this should include the patient’s general practitioner.
-

Capacity requirements

7.1 Capacity

Capacity is specific to the particular decision that needs to be made. In some circumstances, the law sets out what tests must be met for capacity to make certain decisions, for example to consent to medical treatment. The NSW Department of Justice has developed a **Capacity Toolkit** that sets out some of these different legal tests (http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capacity_tool.aspx).

The Toolkit suggests that a general guide to working out whether a person has capacity to make decisions is to consider if they are able to:

- Understand the facts involved in making the decision
- Understand the main choices
- Weigh up the consequences of the choices
- Understand how the consequences affect them
- Make their decision freely and voluntarily
- Communicate their decision.

A person does **not** lack capacity to make all decisions or even a particular decision because they:

- Have a mental illness
- Were unable to make a decision on a different occasion
- Changed their mind about what decision to make
- Are unable to make a decision in one part of their life
- Make a decision that other people believe is wrong, such as refusing to stop smoking although they have been diagnosed with lung cancer
- Have an intellectual / cognitive disability.

7.2 Capacity assessment

If a health professional has doubts or concerns about whether their patient has capacity to make a particular decision, then a capacity assessment may be needed. This applies equally to situations where the patient has a mental illness. A health professional may query whether that person has the capacity to understand Advance Care Planning discussions or make specific decisions, for example making an Advance Care Directive or appointing an Enduring Guardian.

There may be challenges in assessing the capacity of a person with mental illness to make treatment decisions about end of life care, including the decision to refuse life-sustaining treatment. Their mental illness may involve high levels of anxiety, a depressed or elevated mood or strongly held delusional beliefs about medical procedures and the dying process. The capacity assessment should be done by an experienced and skilled mental health professional, preferably someone who has treated the person for a long time and has a good knowledge and understanding of them and their mental illness.

As a person with mental illness's capacity can fluctuate over time and according to the decision at hand, capacity assessments should be repeated at different times when the symptoms of the person's mental illness are well-controlled.

The mental health professional conducting the assessment should use the specific capacity test applicable to the situation; depending on the 'task' the person is trying to do. It is critical to support a person with mental illness as much as possible during the assessment process so they can understand what is being asked and the information they are being given. This may include providing the person the opportunity to ask questions and allowing them sufficient time to digest and reflect on information about their physical illness and treatment options.

See the resources section on page 40 for more information on capacity and capacity assessments.

7.3 Documenting capacity assessments

Sometimes the false assumption is made that people with mental illness lack capacity to make decisions about their medical treatment, including planning for end of life or deciding to refuse medical treatment in the future. Health professionals who have limited information about a person with mental illness may be concerned about the validity of wishes expressed by them, such as in their Advance Care Plan or Advance Care Directive, because they have a history of mental illness.

Making sure that capacity assessments are recorded and are readily accessible (or attached) to the Advance Care Plan or Advance Care Directive is an important safeguard in ensuring the Plan/Directive is respected and followed. This may be of invaluable assistance for health professionals in the future who may be in the position of trying to establish whether a person with mental illness had capacity when the Advance Care Plan or Advance Care Directive was made.

7.4 Capacity to refuse treatment

NSW law recognises that all people, including people with mental illness, have the right to refuse medical treatment at the time it is proposed or in advance for future treatments if they have capacity to make the decision. This extends to all medical treatments, including ventilation, cardio-pulmonary resuscitation (CPR), dialysis, antibiotics and artificial feeding and hydration.

People with mental illness may choose to make an Advance Care Directive which refuses medical treatment in certain future situations.

An Advance Care Directive is only valid if it:

- Was made voluntarily by a capable adult.
- Is current, clear and unambiguous
- Extends to the circumstances at hand.

At law, where a person has a valid Advance Care Directive stating that they did not want specific treatment in the same circumstances that currently apply, health professionals have a legal and ethical obligation to respect and follow that Directive. This obligation applies even if the health professional strongly recommends treatment as the best option to improve the person's condition and preserve their life.

If a person with mental illness lacks capacity to refuse treatment and their Advance Care Directive is invalid, then substitute consent for treatment will be required for the proposed medical treatment to proceed. Even where a person lacks capacity to refuse treatment, both their current and previous views and objections to the treatment should be considered in the substitute decision-making process.

There are some limited exceptions to these rights to refuse treatment for people who fall within specific patient categories set out in the *Mental Health Act 2007*. However, those individuals should still have their views and preferences about treatment refusal respected and considered when decisions are made on their behalf. The Principles for Care and Treatment

in section 68 of the *Mental Health Act 2007* (http://www.austlii.edu.au/au/legis/nsw/consol_act/mha2007128/s68.html) recognise the importance of involving people with mental illness in treatment decisions and making sure their views are treated with dignity and respect.

For more information about refusal of treatment for under the *Mental Health Act*, see Complexities around substitute medical consent on page 21.

See the resources section on page 40 for more information on capacity and capacity assessments.

More information about refusing medical treatment and Advance Care Directives is available at:

- **End of Life, the Law and Clinical Practice** website <http://healthlaw.planningaheadtools.com.au/advance-care-plans-and-the-law/>
- **PD2005_406 Consent to Medical Treatment - Patient Information** http://www0.health.nsw.gov.au/policies/pd/2005/PD2005_406.html

7.5 Substitute decision-makers in Advance Care Planning

It is an essential part of Advance Care Planning for people with mental illness to consider who will make decisions on their behalf if they lack capacity in the future.

There are several options for this:

■ The Person Responsible

This is an automatic scheme which applies to all adults in NSW. If an adult lacks capacity to make decisions about medical treatment, then their Person Responsible has authority to make these decisions on their behalf. A Person Responsible does not have to be appointed. Health professionals can help a person with mental illness to work out who is their Person Responsible in Advance Care Planning discussions. A person with mental illness may decide that the Person Responsible identified in these discussions is the person they want to make substitute medical decisions for them and do not want to make any changes to that. The details of the Person Responsible should be included in Advance Care Plans. See Figure 1 on page 19 for how to identify an individual's Person Responsible.

■ Appointing an Enduring Guardian

An adult can appoint an Enduring Guardian to make personal and lifestyle decisions on their behalf if they lose capacity to make such decisions. If a person appoints an Enduring Guardian with authority to make medical treatment decisions then they will be their Person Responsible. Unlike a Person Responsible, an Enduring Guardian can have the authority to make substitute decisions about a range of personal/lifestyle areas, not just medical treatment decisions. Advance Care Planning discussions can be used to give a person with mental illness information and assistance about appointing an Enduring Guardian. Find out more about how to appoint an Enduring Guardian at <http://planningaheadtools.com.au/appoint-an-enduring-guardian/>.

■ Understanding the role of the Guardianship Division of NCAT to appoint guardians/consent to medical treatment

Some people with mental illness may have no-one in their lives who fits the Person Responsible criteria. They may choose not to appoint an Enduring Guardian or may lack the capacity required to do this. It is important to understand how the Guardianship Division of the New South Wales Civil and Administrative Tribunal (NCAT) plays a role in these situations and to explain this to people with mental illness when having Advance Care Planning discussions.

The Guardianship Division can appoint a guardian to make a range of personal and lifestyle decisions, such as where to live or what services to receive as well as having the authority to make medical treatment decisions. The Guardianship Division can also consent to medical treatments for adults who lack capacity to consent to these. More information is available from the *Guardianship Division of the NSW Civil and Administrative Tribunal* at <http://www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx>.

These options are set out in the *Guardianship Act 1987* and apply to all people with mental illness. However if a person with mental illness is also an involuntary patient or on a Community Treatment Order under the *Mental Health Act 2007*, then substitute consent arrangements for them are more complex.

For information about more complex substitute consent arrangements, see *Complexities around substitute medical consent* on page 21.

Remember

- A health professional who wants to provide medical treatment to a patient, needs to find out who is their Person Responsible so they can ask them for consent for the treatment.
- Under the *Guardianship Act*, the Person Responsible is the automatic substitute decision-maker when a person lacks capacity to make medical treatment decisions. The Act sets out the hierarchy for the Person Responsible.
- The person who is **highest** on the hierarchy is the Person Responsible and must consent to a proposed non-urgent treatment before it can be given, eg, an Enduring Guardian 'outranks' a person's spouse and must be asked for consent.
- Many people mistakenly think that a person's 'next of kin' can give substitute consent for their medical treatment and are not aware of the Person Responsible scheme.

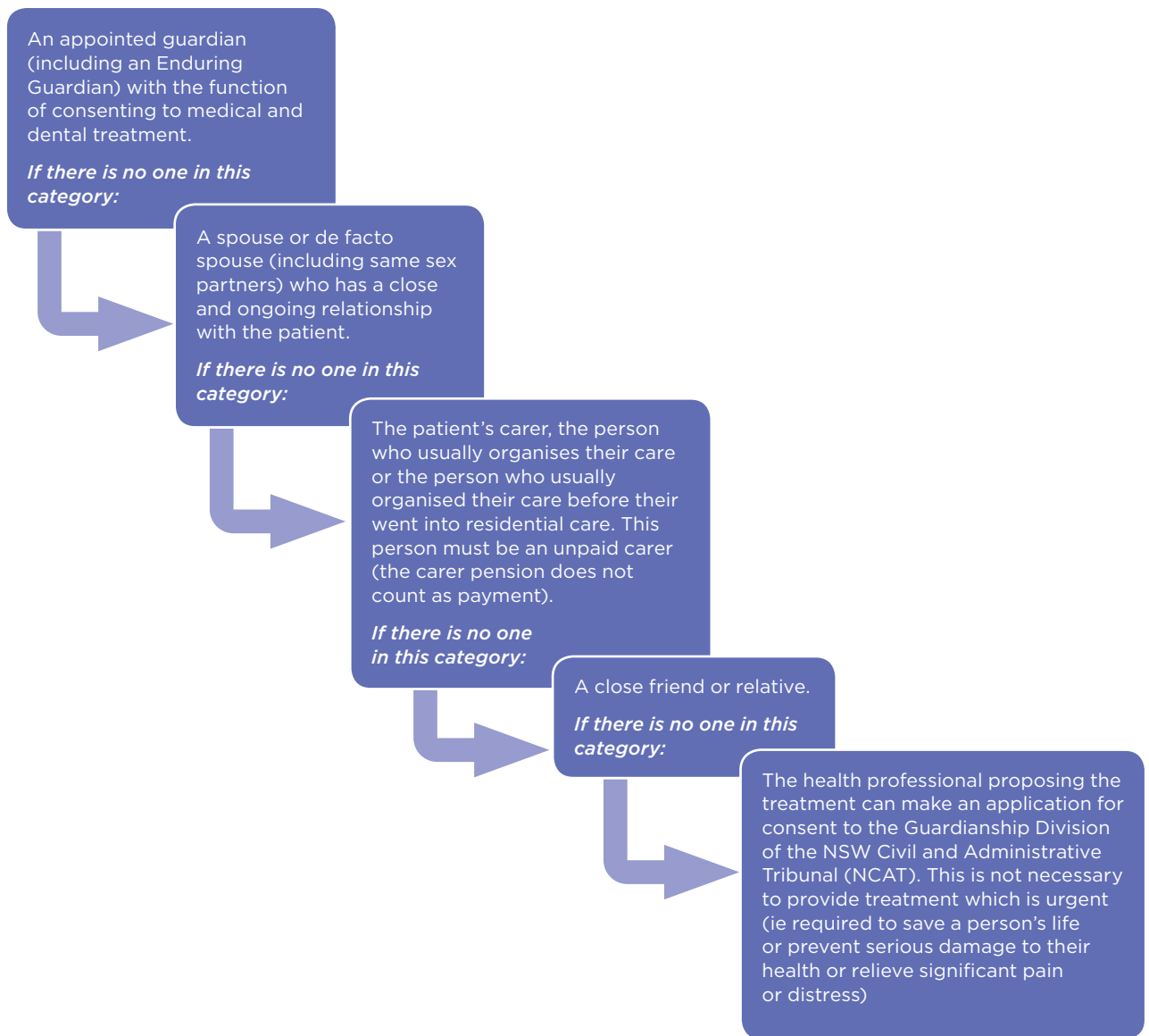
7.6 Capacity issues at the time end of life decisions need to be made

While it is critical that people with mental illness are able to express their views and preferences in the Advance Care Planning process, it is equally important these preferences are respected when the time comes for decisions to be made about end of life treatment and care. Capacity issues may arise at that time as there may be uncertainty either about a person with mental illness's current capacity to make decisions or their capacity in the past to plan and make decisions (such as refusing treatment) for end of life care in the future.

Ideally, the health professionals who are responsible for the mental and physical health care of a person with mental illness who has a life limiting condition, should have been closely involved in Advance Care Planning from the early stages of diagnosis of the physical condition. Similarly, the Advance Care Plan which results from this process should also be readily accessible to any health professionals who treat the person in the future.

However, in some cases, health professionals will need decisions to be made about end of life treatment or care for a person with mental illness but will have limited information about them. They may be uncertain about how to manage this situation and how to respond to the capacity issues which they may believe arise because the person has mental illness.

Figure 1: How to identify the Person Responsible



Health professionals should take the same approach for people with mental illness as they would for any health consumer. They may need to adapt this to take into account any specific needs of the person associated with their mental illness, such as being aware of fluctuations in capacity, however the focus on ascertaining and respecting their patient's treatment and care preferences should be the same.

In situations involving end of life decisions, health professionals should ask these three core questions:

1. Can the person decide for herself/himself what they would like to happen? See *Capacity requirements* on page 16.

2. If the person does not have capacity, is there any evidence of prior views or planning? See *Documenting capacity assessments* on page 16.
3. If the person does not have capacity to make the decision and there is no evidence of prior planning, who should decide? See *Substitute decision-makers in Advance Care Planning* on page 17.

Asking and answering these questions will assist health professionals to respond appropriately in situations where a person with mental illness is facing end of life issues.

STORY TWO: David's story

David is a 65 year old man with obsessive compulsive disorder and chronic kidney disease who has had type 1 diabetes since childhood. David arrives at an emergency department requesting treatment for the kidney disease. He has discussed Advance Care Planning with his GP and has an Enduring Guardian to make decisions for him. His capacity to make a decision about treatment varies according to his mental and physical wellbeing.

Read David's story on page 33 for examples of how his mental illness can affect his capacity to make decisions and how to deal with this.

Complexities around substitute medical consent

In most situations, person with mental illness have the right to make their own decisions about their medical treatment, provided they have capacity. Complexities can arise about who can provide substitute consent for people with mental illness because there are two different legislative schemes which can apply, depending on the person's circumstances.

8.1 The *Guardianship Act 1987*

If a person with mental illness lacks capacity to make the medical treatment decision then the *Guardianship Act 1987* (http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/) usually applies. It provides a way for substitute decisions to be made for adults in NSW who lack capacity to do this due to a disability, including mental illness. It establishes the Person Responsible scheme for medical consents and enables guardians to be appointed to make medical and/or other decisions, such as decisions about accommodation and services.

Under the *Guardianship Act*, substitute decisions about medical treatment can be made by:

- A Person Responsible
- The Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT).

A Person Responsible includes a guardian or Enduring Guardian who has been given the authority (or 'function') to make medical treatment decisions.

It is a health professional's role to correctly identify a person's Person Responsible and seek consent from them if the health professional wishes to give non-urgent treatment to an adult who lacks capacity. Find out how to identify the Person Responsible in Figure 1 on page 19.

8.2 The *Mental Health Act 2007*

The *Mental Health Act 2007* (http://www.austlii.edu.au/au/legis/nsw/consol_act/mha2007128/) deals primarily with people who have mental illness or mental disorder. Every person who is admitted, detained or treated in a mental health facility has a patient status; voluntary patient or involuntary patient. This status determines how decisions should be made about their mental and physical health treatments and who has the legal authority to make them.

The *Mental Health Act* provides for substitute decisions to be made about certain specified medical treatments by:

- The Secretary of NSW Health
- Senior Officers within NSW Health who have been designated this role by the Secretary of NSW Health
- The Mental Health Review Tribunal.

A person who is under a Community Treatment Order or a patient under the *Mental Health Act* also has an automatic primary carer. A person can also nominate someone to be their primary carer.

A primary carer is not a substitute decision-maker for medical consent but they do have rights to be given information about the person, such as the medication being given to them, and to be notified of certain proposed treatments, for example surgery for the person.

More information about primary carers can be found at http://www.austlii.edu.au/au/legis/nsw/consol_act/mha2007128/s71.html.

IMPORTANT NOTE: *Mental Health Act* changes

Amendments to the *Mental Health Act 2007* have removed the term *primary carer*. These changes have not come into effect yet but when they do, there will be two types of carers for patients under the *Mental Health Act*:

1. A designated carer

The term primary carer will be replaced with **designated carer**. The role of that person will remain essentially the same as the primary carer. A person will now be able to nominate more than one person as their designated carer.

2. A principal care provider

This is a new carer status under the *Mental Health Act*. It means *the individual who is primarily responsible for providing support or care to the person (other than wholly or substantially on a commercial basis)*. While the designated carer and the **principal care provider** can be the same person, this may not always be the case. For example, a person may have the Public Guardian as their **designated carer** but their mother is their **principal care provider** because she primarily provides the person with support or care and is not paid or employed to do this.

The **designated carer** and the **principal care provider** will not have a role in consenting to medical treatment. However, under the changes, both the **designated carer** and the **principal care provider** will have rights to be given information about a patient, including information about their medication.

The **designated carer** must be notified of certain proposed treatments such as surgery but there is no requirement to notify the **principal care provider**. Whether or not the designated carer of a patient who does not have capacity supports surgery impacts on whether the Secretary of NSW Health or MHRT will be the substitute decision-maker.

There will also be a new obligation to consider information provided by the designated carer and the principal care provider when determining whether a person is a mentally ill or a mentally disordered person or whether to discharge them from a mental health facility.

8.3 Overlap between the *Mental Health Act* and the *Guardianship Act*

In some circumstances, the *Guardianship Act* may also apply to decision-making for medical treatment for a person under the *Mental Health Act*. Because the *Mental Health Act* and the *Guardianship Act* are different, it can sometimes be challenging to work out which one applies to a particular situation involving a person with mental illness. The law says that if there is an inconsistency between the provisions of the *Mental Health Act* and the medical consent provisions of the *Guardianship Act*, then the *Mental Health Act* provisions prevail (see s 34(2) of the *Guardianship Act* at http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/s34.html).

The question of which Act applies and who is the appropriate substitute decision-maker for a person with mental illness depends on:

1. The person's status under the *Mental Health Act*. For example are they a voluntary or involuntary patient?
2. If they do have a status under the *Mental Health Act*, then what type of treatment is being proposed (medication, surgery etc)?
3. Is there an inconsistency between the *Mental Health Act* and the *Guardianship Act* provisions?

In the majority of situations, the *Guardianship Act* applies for most treatments for most people. However, if a person is an involuntary patient, then the *Mental Health Act* applies instead for certain treatments such as surgery.

Table 2 on page 23 shows whether substitute medical consent should be sought under the provisions of the *Mental Health Act* or the *Guardianship Act*.

Table 2: Substitute Medical Consent for *Mental Health Act*

Mental Health Act status	Treatments	Which Act applies? Who can decide?
<ul style="list-style-type: none"> ■ Voluntary patient ■ Assessable person (involuntarily admitted but before the Mental Health Inquiry) ■ Mentally disordered person 	Mental health treatments	<p>For voluntary patients: mental health treatments require consent. If the voluntary patient lacks capacity to consent, the <i>Guardianship Act</i> applies.</p> <p>For assessable and mentally disordered patients: s84 of the <i>Mental Health Act</i> applies. Decisions on mental health treatment can be made by an authorised medical officer.</p>
	Electro convulsive therapy (ECT)	<p>The <i>Mental Health Act</i> applies and provides decisions can only be made by:</p> <ul style="list-style-type: none"> ■ The Mental Health Review Tribunal
	Sterilisation	<p>The <i>Guardianship Act</i> applies and provides this is a special medical treatment which can only be consented to by:</p> <ul style="list-style-type: none"> ■ The Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT)
	Termination of pregnancy	<p>The <i>Guardianship Act</i> applies and provides this is a special medical treatment which can only be consented to by:</p> <ul style="list-style-type: none"> ■ The Guardianship Division of NCAT
	Any other treatment, surgical or non-surgical	<p>The <i>Guardianship Act</i> applies and provides decisions can be made by:</p> <ul style="list-style-type: none"> ■ A Person Responsible ■ The Guardianship Division of NCAT
<ul style="list-style-type: none"> ■ Involuntary patient - involuntarily detained after the Mental Health Inquiry (MHRT order has been made) 	Mental health treatments	<p>s84 of the <i>Mental Health Act</i> applies. Decisions on mental health treatment can be made by an authorised medical officer.</p>
	Electro convulsive therapy (ECT)	<p>The <i>Mental Health Act</i> applies and provides decisions only can be made by:</p> <ul style="list-style-type: none"> ■ The Mental Health Review Tribunal
	Sterilisation	<p>The <i>Mental Health Act</i> applies and provides that this is a special medical treatment which can only be consented to by:</p> <ul style="list-style-type: none"> ■ The Mental Health Review Tribunal
	Termination of pregnancy	<p>The <i>Mental Health Act</i> applies. This is a surgical treatment under the Act so, depending on the circumstances, can be consented to by:</p> <ul style="list-style-type: none"> ■ The Secretary of NSW Health ■ Senior Officers within NSW Health who have been designated this role by the Secretary of NSW Health ■ The Mental Health Review Tribunal
	Surgical treatment	<p>The <i>Mental Health Act</i> applies and provides that, depending on the circumstances, this is can be consented to by:</p> <ul style="list-style-type: none"> ■ The Secretary of NSW Health ■ Senior Officers within NSW Health who have been designated this role by the Secretary of NSW Health ■ The Mental Health Review Tribunal
	Any other non-surgical treatment	<p>The <i>Guardianship Act</i> applies and provides decisions can be made by:</p> <ul style="list-style-type: none"> ■ A Person Responsible ■ The Guardianship Division of NCAT

8.4 Rights under the Mental Health Act to refuse medical treatment

People who have a patient status under the *Mental Health Act* (whether in a mental health facility, a forensic facility or on a Community Treatment Order) still have the right to express their views and preferences about refusing medical treatment, even if the treatment is necessary to keep them alive. Whether a health professional has a legal obligation to respect and follow those views and preferences depends on the person's patient status under the *Mental Health Act*.

■ Voluntary patients, mentally disordered persons and assessable persons

If a person with mental illness has the status under the *Mental Health Act* of a voluntary patient, a mentally disordered person or an assessable person, they:

- CAN refuse any medical treatment² if they have the capacity to make that decision
- CAN make an Advance Care Directive for the future if they have capacity to make the Advance Care Directive
- SHOULD have a current, valid Advance Care Directive respected and followed if they had capacity when it was made.

This includes refusing treatment which is needed to keep the person alive.

■ Involuntary, correctional and forensic mental health patients

That a patient should have a current, valid Advance Care Directive respected and followed if they had capacity when it was made also applies to involuntary, correctional and forensic mental health patient, **except** where the medical treatment³ involves surgery or special medical treatment (ie treatments which will make a person permanently infertile such as sterilisation).

If an involuntary, correctional or forensic patient has a valid Advance Care Directive which refuses specific surgery, then this surgery could still be approved by the Secretary of NSW Health or the Mental Health Review Tribunal, despite the Advance Care Directive. However, the Secretary or the Mental Health Review Tribunal may need to have close regard to the Advance Care Directive

when deciding whether to consent to the surgical operation in these circumstances.

If a surgical operation is proposed for an involuntary patient, a forensic patient or a correctional patient then the Secretary of NSW Health or the Mental Health Review Tribunal can consent to it if the:

- Patient lacks capacity to consent to the operation OR
- Patient has capacity to consent to the operation but refuses to give that consent OR
- Patient has capacity to consent to the operation neither gives nor refuses to give that consent AND
- Secretary of NSW Health or the Mental Health Review Tribunal is satisfied that it is desirable having regard to the interest of the patient.

The *Mental Health Act* provisions can override the refusal of consent of an involuntary, forensic or correctional patient whether that refusal was given by an Advance Care Directive or at the time of surgery. However, the fact that the person has refused to consent to the surgery in the Advance Care Directive would be a factor which the Secretary or the Mental Health Review Tribunal may need to consider in making a decision.

If a person with mental illness who is a patient under the *Mental Health Act* does not have capacity to decide about medical treatment, then their views about that treatment should still be taken into consideration by the person or tribunal making medical treatment decisions on their behalf.

■ Further resources

For *Guardianship Act* consent regimes including information about Person Responsible, Enduring Guardian and guardians appointed by the Guardianship Division of the NSW Civil and Administrative Tribunal, see <http://www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx>. or

For *Mental Health Act* consent regimes including information about the Mental Health Review Tribunal and the role of the primary carer, see the <http://www.mhrt.nsw.gov.au/the-tribunal/>.

2 Where the patient is mentally disordered or an assessable person s84 of the *Mental Health Act* may be relevant for mental health treatments.

3 s84 of the *Mental Health Act* may be relevant for mental health treatments

STORY THREE: Juanita's story

Juanita is a 78 year old woman with severe vascular dementia complicated by behavioural and psychological symptoms of dementia who has been transferred to an older people's mental health inpatient unit from the general hospital.

Read Juanita's story on page 35 for an illustration of how complex medical consent issues may arise for a person with mental illness and how to approach these.

Specific issues under the *Mental Health Act 2007* (NSW)

People with mental illness may find that, at some periods of their lives, they are admitted to a declared mental health facility to be treated under the *Mental Health Act 2007* (NSW). Mental health legislation which provides for the admission, detention and treatment of people with mental illness has changed over time from a focus on in-patient treatment to more flexible approaches where treatment which can be provided in the community, for example through the use of community treatment orders. There is great diversity amongst those who have a status under the *Mental Health Act* and many will only spend a brief time in an in-patient facility. However there are also those who are admitted, discharged and re-admitted several times during their life and others whose experience of mental illness means they will spend the majority of their lifetime residing in those facilities for treatment and care. Advance Care Planning needs to be tailored to meet the needs of this group of people with mental illness so they can participate as much as possible in planning for their end of life care.

9.1 Factors to consider

Some people with mental illness have lived in long term residential mental health facilities for significant periods of their adult life. They are usually involuntary patients but some are also voluntary patients. They may have lived with severe and persistent mental illness for many years and experience few, if any, periods of lucidity or insight into their illness. This does not necessarily mean that these people lack the capacity to make decisions about their end of life care. It is important that health professionals attempt to encourage and support these people with mental illness to engage in Advance Care Planning for the end of life and ensure Advance Care Planning discussions are comfortable and positive for these people.

There are several key issues affecting people with mental illness in these facilities, which need to be considered in Advance Care Planning. People with mental illness in these settings may have:

- Experienced significant stigma, discrimination and prejudice
- A history of traumatic past experiences, including abuse and neglect before they came to live in a mental health facility and, sometimes, during that time
- Led itinerant lifestyles and been homeless
- Lost confidence that they can have any control over their medical treatment. They may have found that others always made medical treatment decisions for them and their views and decisions were not sought or if they were expressed were not respected or considered important
- Decided that any unusual or unconventional views they expressed about their physical health or medical treatment were regarded as being part of their mental illness and therefore not deserving of any attention
- Become socially isolated from life outside the facility and have no family or friends in the community. They may regard the facility as their home and have a closer and more long-standing relationship with their professional care staff than is usual with other health consumers, especially if they have been a long term resident. They may regard other residents in the facility as being their family and their closest friends
- Fears and anxieties about other health professionals and other health settings, especially hospitals
- Observed how end of life issues were handled for other people within the facility and have ongoing fears and misunderstanding about that
- Other characteristics which present challenges to communication and understanding about end of life issues such as intellectual disability and specific communication and/or behavioural difficulties.

Mental health and health professionals who know people with mental illness well, can assist them to plan ahead for the end of their lives so their values, beliefs and preferences are respected at that time. This may require a flexible and innovative approach to dealing with their perceptions of death, treatment, home and family.

9.2 False assumptions about Advance Care Planning for people with mental illness in declared facilities

Health professionals may find that false assumptions continue to be made about Advance Care Planning and end of life for people with mental illness who are in declared mental health facilities. These false assumptions include:

- **False assumption 1: People with mental illness who are at the end of their life should be transferred to a general hospital or hospice and remain there until they die. They should not be treated palliatively or die in a mental health facility.**

Advance Care Planning is about a range of end of life preferences. Persons with mental illness may prefer to be treated in a place which is comfortable and familiar to them rather than a hospital or hospice. While there may be difficulties in accommodating their wishes about this due to whether the facility can provide the required clinical care to the patient, it is important to work towards enabling this to happen.

- **False assumption 2: Resuscitation must be given to involuntary patients who are dying but live in a declared facility. The facility has an obligation to resuscitate these patients, irrespective of whether this is clinically appropriate. Therefore they should be transferred to a general hospital as they enter the dying phase of their illness, because a Resuscitation Plan can be made there which provides that resuscitation does not need to be provided.**

Advance Care Planning for people with mental illness in declared facilities can include appropriate planning in advance for resuscitation in the facility. Resuscitation Plans are one tool which can be used in the Advance Care Planning process and these can be made for people with mental illness who live in declared facilities as appropriate. These can provide that resuscitation is not appropriate in the circumstances specified in the Plan. There is no reason why Resuscitation Plans cannot be made in the same way they would be made for other health consumers in similar situations. Health professionals are able to act on these Plans for people with mental illness so they are not inappropriately resuscitated in mental health facilities or transferred to acute facilities for resuscitation where this is not clinically appropriate.

- **False assumption 3: If a person with mental illness dies within a declared mental health facility then there will have to be an inquest and health professionals are at risk of adverse findings because the person died whilst in their care.**

If a person with mental illness dies within a declared mental health facility then this death is reportable under the *Coroners Act 2009* (http://www3.austlii.edu.au/au/legis/nsw/consol_act/ca2009120/). However, the Coroner may not proceed with an inquest solely on this basis. Concerns about a possible coronial inquest are understandable but are not an acceptable reason to disregard a person with mental illness's preference to die in the facility which they regard as their home. Efforts should be made to accommodate and respect the person's expressed wishes to ensure the person's end of life experience is as comfortable as possible. Health professionals can prepare for any possible coronial enquiry by keeping clear and accurate records of all Advance Care Planning discussions and documenting this process for any person with mental illness who has expressed a preference to be treated palliatively within the facility.

STORY FOUR: Anton's story

Anton is a 62 year old man with schizophrenia who is a long-time resident of a declared facility. Anton has been diagnosed with advanced colorectal cancer. He has an elderly mother.

Anton's story on page 37 raises issues which may need to be considered in end of life care for a person who has lived in a declared mental health facility for most of their life and suggests how to deal with these.

Specific issues in forensic health settings

A forensic patient is a person who the NSW Supreme Court or District Court has:

- Found unfit to be tried for an offence and ordered to be detained in a correctional centre, mental health facility or other place
- Found not guilty by reason of mental illness or nominated a limiting term and ordered to be detained in a prison, hospital or other place
- Found not guilty by reason of mental illness and detained or released into the community subject to conditions.

Prisoners may also have a mental illness and receive treatment and care for this in the jail environment or in a prison hospital. These are known as correctional patients.

Sometimes forensic patients live in the community on leave arrangements. Prisoners with mental illness may also live in the community because they are on parole.

Advance Care Planning is an important issue for people with mental illness in forensic or correctional settings because this is increasingly becoming an ageing population.

10.1 Factors to consider

There are specific issues and challenges involved with Advance Care Planning for forensic patients and many of these also apply to prisoners with a mental illness:

- Forensic patients come from a diversity of backgrounds and have a variety of mental and physical health conditions. This means forensic patients will have different needs. These needs may arise from:
 - Cultural background: Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds are over-represented in prisons
 - Age: The average age of people in prison is rising which means there is a greater need for engagement in end of life issues as some will see out their lives in prison
 - Intellectual disability
 - Drug and alcohol use.

- Engaging in end of life discussions with forensic patients in the correctional system has its own sensitivities as patients face the probability that the end of their life and their death will take place within a correctional setting rather than in the community
- Whilst mental health treatment for forensic patients is provided in forensic health settings, their physical health needs are usually provided within the general health setting in hospitals. Forensic settings often have limited capacity to provide end of life management and care. This shared responsibility can create challenges for the continuity of care and handover of care plans, including Advance Care Plans. Stigma and fear about treating forensic patients in mainstream services still exists and a collaborative approach is needed to allay these concerns
- Forensic health services are provided in conjunction with the correctional system. The correctional system has its own distinct culture, legislative system, policies and procedures which can have an impact on continuity of care and end of life decision-making, for example prisoners and forensic patients may be transferred to different correctional facilities raising issues for continuity of care and information exchange
- Forensic patients who live in the community and receive services there have different needs from those who live within a correctional setting
- Forensic patients often have a complex family and social history with fractured or estranged family relationships and social isolation. Their closest relationships may be with others in the forensic system, including health professionals. Long term institutionalisation often means they have no home in the community and regard the institutional setting as their home
- The substitute decision schemes for forensic patients is not well understood as there can often be interplay between different mental health, guardianship and correctional legislation and responsibilities.

10.2 False assumptions about Advance Care Planning for forensic patients

Health professionals who work with forensic patients may find there are still false assumptions in the community about forensic patients, prisoners with mental illness and end of life care.

■ **False assumption 1: Forensic patients who have serious physical health issues should not be transferred to a general hospital because they might try to harm themselves or other patients and hospital staff**

There is still misunderstanding and fear in the community about people with mental illness and this extends to people with mental illness who live in a forensic setting and require treatment in a hospital with other health consumers. These people with mental illness have the right to be treated with dignity and respect when they are in a general hospital or present at an Emergency Department. Information and guidance for health professionals on how to best provide services to people with mental illness in a hospital setting can be found in the *Mental Health for Emergency Departments: A Reference Guide 2009*:

<http://www.health.nsw.gov.au/mhdao/publications/Publications/pub-emergency.pdf>.

■ **False assumption 2: Resuscitation must be given to forensic patients who are dying but live in a correctional or forensic facility. The facility has an obligation to resuscitate these patients, irrespective of whether this is clinically appropriate. They should be transferred to a general hospital as they enter the dying phase of their illness because a Resuscitation Plan can be made there which provides that resuscitation does not need to be provided.**

Advance Care Planning for forensic patients in correctional or forensic facilities should include appropriate planning in advance about resuscitation in the facility. Resuscitation Plans are one tool which can be used in the Advance Care Planning process and these should be considered for forensic patients. There is no reason why Resuscitation Plans cannot be made in the same way they would be made for other health consumers in similar situations. Health professionals are able to act on these Plans for forensic patients, so they are not inappropriately resuscitated in forensic or correctional facilities or transferred to acute facilities for resuscitation where this is not clinically appropriate or does not accord with their wishes.

■ **False assumption 3: If a forensic patient dies within a declared mental health facility then there will have to be an inquest and health professionals are at risk of adverse findings because the person died whilst in their care**

If a forensic patient dies within a declared mental health facility then their death is reportable under the *Coroners Act*. However, the Coroner may not proceed with an inquest solely on this basis. Concerns about a possible coronial inquest are understandable but are not an acceptable reason to disregard a person with mental illness's preference to die in the facility which they regard as their home. Efforts should be made to accommodate and respect these expressed wishes to ensure the person's end of life experience is as comfortable as possible. Health professionals can prepare for any possible coronial inquiry by keeping clear and accurate records of all Advance Care Planning discussions and documenting this process for any person with mental illness who has expressed a preference to be treated palliatively within the facility.

Further resources

More information about forensic patients is available from the:

- Justice Health website:
<http://www.justicehealth.nsw.gov.au/>
- Justice Health Policy 1.174: *End of Life Care, Not for Cardio-Pulmonary Resuscitation Orders and Advance Care Directives - Adult Centres Only*, December 2013
- Mental Health Review Tribunal website:
<http://www.mhrt.nsw.gov.au/the-tribunal/>

STORY FIVE: John's story

John is a 59 year old long-term forensic patient, who has been diagnosed with advanced oesophageal cancer. John has no family.

John's story on page 39 considers the approach to take when decisions are needed about end of life care for a forensic patient.

Stories

This section contains five hypothetical stories about people with mental illness in different end of life situations. The stories illustrate how the key issues of stigma, capacity and complex medical consent requirements can arise in practice and how specific issues about end of life care apply for those who are treated under the *Mental Health Act* or live in forensic health settings.

The information is intended as a guide for health professionals about the questions which should be asked and what approach to take. Health professionals should always seek advice if they are unsure of what action to take in a real-life situation.

Story One: Kristy is a 57 year old Aboriginal woman who suffers from a mental illness. She is a voluntary patient in an acute mental health unit and recently experienced hallucinations. These are not a symptom she has had during episodes of illness in the past. Kristy has co-morbid kidney disease. She is married to Mick and is close to her large family.

Story Two: David is a 65 year old man with bipolar disorder and chronic kidney disease who has had type 1 diabetes since childhood. David arrives at an emergency department with acute renal failure but refuses dialysis. He has discussed Advance Care Planning with his GP and has an Enduring Guardian to make decisions for him. His capacity to make a decision about treatment varies according to his mental and physical wellbeing.

Story Three: Juanita is a 78 year old woman with severe vascular dementia complicated by behavioural and psychological symptoms of dementia who has been transferred to an older people's mental health inpatient unit from the general hospital.

Story Four: Anton is a 62 year old man with schizophrenia who is a long-time resident of a declared facility. Anton has been diagnosed with advanced colorectal cancer. He has an elderly mother.

Five: John is a 59 year old long-term forensic patient, who has been diagnosed with advanced oesophageal cancer. He has no family.

STORY ONE: Stigma about mental illness and advance care planning – Kristy

Kristy is a 57 year old Aboriginal woman who suffers from a mental illness. She is a voluntary patient in an acute mental health unit. Whilst visiting relatives in the city recently Kristy experienced hallucinations. These are not a symptom she has had during episodes of illness in the past. The city is far from her home. Kristy has kidney disease and was receiving dialysis prior to coming to the city. While in the acute mental health unit she has been receiving dialysis daily through the renal unit at the hospital.

One day Kristy mentions to the psychiatric nurse looking after her that she thinks she does not want any further dialysis; however she wants to discuss this with her family before making a decision. A large group of people arrive at the unit the next day. It includes Kristy's husband Mick, daughter Sophie, cousins and other people from her community, along with an Elder. It is a large group and the staff arrange for them to talk in the staff meeting room. When they start to talk about possible decisions to be made about end of life care, Kristy becomes very upset and starts to cry. She says she does not want to talk about it at the meeting. She also seems confused about what the meeting is about. The staff decide that Kristy should not remain for the rest of the meeting because they feel it is obviously too distressing for her and in their view she won't be able to understand what they are talking about.

Kristy is taken back to her room and the meeting continues in her absence. The renal specialist is contacted. She advises that while the treatment is not urgent, the portable renal machine will be sent down to the unit.

When the machine arrives in the unit, the nurse who has come to set up the dialysis expresses concern that Kristy appears confused and unsure about the treatment. The renal specialist visits Kristy and talks to her on her own. She explains to Kristy the treatment options, the alternatives and the likely consequences if she does not have the treatment. Kristy's treating psychiatrist is present during this visit. The treating psychiatrist assesses Kristy's capacity to make a decision about having dialysis now. She determines that Kristy does not have capacity as she does not understand the nature of the treatment or why she needs to have it.

A staff member approaches Kristy's husband Mick for consent to provide dialysis, however, Mick says he does not want to make the decision. The Elder comes forward and says that Kristy had indicated she wanted to return home, which meant no further dialysis, but had not stated a decision. The staff member is unsure what to do.

Questions

1. Can Kristy decide for herself what treatment she should receive?

No. She has been assessed as lacking capacity to consent to the dialysis at this time. However her views about having the dialysis should still be taken into consideration.

2. Is there any evidence of prior planning?

Kristy had mentioned that she was thinking about declining further dialysis, however, she had not expressed a clear preference for or against treatment.

3. If not, who should decide now?

Culture has a big impact on how people interact with the health care system, who they want to receive information about their care and who they want to make decisions about the care they will receive. Sometimes what a person sees as culturally appropriate does not align with the law in NSW with regards to consent to treatment and substitute decision-making.

In this scenario, consent for the dialysis is legally required from the Person Responsible as Kristy has been assessed as not having capacity to make decisions at this time. Although Kristy had started to consider her preferences for treatment, she does not appear to have reached a decision.

Although Mick would like the Elder to speak for Kristy, under the *Guardianship Act*, Mick is Kristy's Person Responsible because he is highest on the Person Responsible hierarchy. Mick can refuse to be Kristy's Person Responsible. This refusal needs to be in writing and would mean Mick is not the Person Responsible for all future medical treatment decisions, not just this decision. If Mick ceased to be the Person Responsible, either Kristy's daughter or another close relative or friend would be the Person Responsible. The appropriate Person Responsible would need to be determined based on the relationship between Kristy and each person. The Elder may be the appropriate Person Responsible, depending on their relationship. Talking with the Elder and other family members about Kristy's treatment and the law regarding the Person

Responsible may be important in building consensus around treatment. Kristy's views and preferences about the dialysis must be taken into account by her Person Responsible before a decision is made.

4. What impact does stigma about mental illness and Kristy's Aboriginality affect have on Advance Care Planning for Kristy?

Because Kristy has a mental illness, staff may have assumed that her reaction at the meeting means she lacks capacity to engage in the Advance Care Planning and is not able to cope with talking about her future care preferences. Assumptions about her ability to understand the different options about end of life care may mean that she is excluded from discussions and her views and values are not respected. A lack of understanding about Aboriginal culture can lead to false assumptions being made about her capacity and her reluctance to discuss end of life issues with others.

5. What steps could be taken to overcome this stigma in practice?

It is important to communicate openly with Kristy and her family about her values, preferences and views about what she would like to happen next. Being flexible in allowing time and an appropriate place to have discussions with Kristy and her family are vital. Kristy's capacity may fluctuate and it is crucial to time these discussions for times when she is at her best. Even if Kristy is assessed as lacking capacity to make decisions, she will still have values, beliefs and preferences which should be considered.

The staff may find it helpful to engage an Aboriginal Liaison Officer, if there is one in the hospital. Regardless, the discussion with Kristy and her family should be approached with respect, openness, an acknowledgement that the health professional comes with their own culture and without any presumption about culture. For example, it should not be assumed that Kristy would want to die in country (her ancestral home) or be reluctant to talk about issues related to death. A good approach is to ask Kristy and the family what would be appropriate in the circumstances. The health professionals working with Kristy and her family should provide relevant information about Advance Care Planning, but leave the decision about whether to engage in planning to Kristy and her family.

For many Aboriginal people, the events of the past have an impact on the way they view public institutions and professionals, including hospitals and health professionals. They may see hospitals and other mainstream services as institutions to be approached with apprehension because they are run according to *white* rules with little understanding of Aboriginal culture. This, combined with sensitivities around discussing death, may affect Kristy and her family's engagement with health professionals in regards to Advance Care Planning.

STORY TWO: Dealing with the effect of mental illness on capacity – David

David is 65 years old. He has bipolar disorder, which is usually well controlled but he has periods when he has a relapse and the symptoms of his illness return. He has been treated by the local community mental health team but is not on a community treatment order. David has significant type 1 diabetes and has chronic kidney disease. He has had the same GP since his diagnosis of kidney disease and visits her regularly. The GP is very involved in managing care for his mental health, diabetes and kidney disease in collaboration with the community mental health team and David's renal specialist.

David's GP has tried on many occasions to talk to him about Advance Care Planning for the end of his life and his preferences for treatment and care. David did not want to talk about this for many years but six months ago he started a relationship with Lee who moved in with him and became his partner. With Lee's encouragement and support, David and Lee have now had many conversations with David's GP about what David would like to happen for his care as his kidney disease worsens and he approaches the end of his life.

David has been very clear in these discussions that if he loses the capacity to make a decision about treatment, he does not want to have life-prolonging treatment. He says he has many friends on dialysis. He sees it being "needles, no improvement, no quality of life, too hard to get transport there and back – what's the point?" He says he doesn't want to have that and put himself or Lee through the same experience.

Given his medical history, David decides he wants to appoint Lee as his Enduring Guardian as he trusts him to make decisions which are in keeping with his preferences and values about end of life care. David worked with Lee, his treating psychiatrist, his renal specialist and his GP to choose a good time to make the enduring guardianship appointment; when his mental illness was well controlled and he had capacity. He gave a copy of the appointment to his GP and asked her and his treating psychiatrist for a report confirming he had capacity to make the appointment. He asked them to keep a copy of this with his Enduring Guardianship appointment. Lee also kept copies of these documents.

Lee and David break up and David goes on holiday in regional NSW without telling any of his friends or family where he is going. He is very upset and stops taking his medication for his bipolar disorder. He becomes very mentally unwell as his mental illness relapses. He also becomes physically unwell with an infection which leads to fever and dehydration. He goes into Acute Renal Failure and is taken to the nearest major emergency department. The treating doctor determines David's kidneys are not functioning and he requires dialysis. David refuses the dialysis saying that it is not necessary because he is able to 'cure' his kidney disease himself through the power of his own mind. When the treating doctor explains he will die without dialysis, David denies this will happen as he is 'invincible'. David tries to leave the emergency department because he thinks he is going to be forced to have dialysis and no-one is listening to him.

Questions

1. What could the treating doctor do about his/ her concerns that David's confusion could be affecting his capacity to make the decision about dialysis?

David's capacity to decide about dialysis should be assessed, remembering that the assessment is specific to making a decision about dialysis at this time. Further information about conducting a capacity assessment is available in the *Capacity Toolkit* (http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html). It is also important for David's capacity to be reassessed as his capacity may improve once his illness is brought under control.

2. Can David decide for himself what he would like to happen?

This does not appear likely at the current time. David is assessed as lacking capacity to decide whether to have the dialysis or not. Although he lacks capacity, his views and wishes should still be taken into account. He should be treated with respect as discussions about the dialysis progress and be reassured that his views are being listened to.

3. Is there any evidence of prior planning?

Yes, David has appointed Lee as his Enduring Guardian and told Lee what is important to him when decisions are being made for him in the future. As David is not currently competent to consent to the dialysis, Lee is his Person Responsible because he is his Enduring Guardian and has the legal authority to make decision about dialysis and other medical treatment for David.

It is crucial for the treating doctor to find out from David about his previous medical and mental health care so he can contact health professionals who know him well. David's GP has long-standing and in depth knowledge about David and his views about dialysis. She will also be able to provide a copy of the Enduring Guarding appointment and inform the treating doctor of David's prior views about refusing dialysis in similar circumstances. If there are any concerns about whether David had capacity to make the appointment, the GP could provide a copy of the reports stating he had capacity. The GP may also have Lee's contact details so the treating doctor can contact him to request consent.

4. Is Lee still David's Person Responsible, even though they have broken up?

Yes, Lee will remain the Person Responsible unless he resigned as David's Enduring Guardian or the appointment was revoked. For more information see the Planning Ahead Tools website at <http://planningaheadtools.com.au/appoint-an-enduring-guardian/>.

5. If David is competent to make the decision about dialysis, would there be time to involve other people in the decision about whether to follow and respect the wishes David expressed when he came into the emergency department?

This would depend on the urgency of the dialysis. If the doctor deemed the treatment was urgent, he/she could start the dialysis and then seek legal advice about whether to follow David's wishes to refuse the treatment.

If the treatment was not urgent, the doctor should continue to try to contact Lee, the Enduring Guardian and involve the GP in discussions. If there is a conflict between the views of David and Lee about medical treatment, the doctor could seek advice from the senior clinician, legal counsel or senior administration of the facility or Local Health District/Specialty Network.

STORY THREE: Complexities around substitute medical consent - Juanita

Juanita is a 78 year widow who was born in Chile and moved to Australia in the 1970s when she was in her thirties. Her husband died in Chile before she moved to Australia and she raised their only child, Isabel in Sydney. Juanita lives in a nursing home and has severe vascular dementia complicated by behavioural and psychological symptoms of dementia (BPSD) (e.g. hitting other residents and staff). She was transferred from the general hospital where she was admitted for delirium secondary to recurrent pneumonia as a voluntary patient to an older people's acute mental health unit, due to concerns about persisting distressing hallucinations. Although these have now settled and she is awaiting discharge back to the nursing home, her observations such as her blood pressure fluctuate and staff are uncertain about what action they should take should she deteriorate. They are not sure who they should ask for consent if she requires further medical treatment or who should make decisions about her end of life care. Her Mini Mental State (MMSE) score is still 8/30 and she has severe communication deficits. She has co-morbid ischaemic heart disease, diabetes, hypertension, atrial fibrillation and a past history of stroke. She has no Advance Care Directive in place nor has Advance Care Planning been initiated.

Isabel cared for Juanita for many years when she was living in her own home, before she moved to the nursing home. Juanita's older brother, Pablo lives in Melbourne and is a respected leader in the Chilean community.

Questions

1. Can Juanita decide for herself what she would like to happen?

Juanita's dementia would trigger a capacity assessment. The assessment shows she is unable to make a decision about what treatment she would like if she deteriorates.

2. Is there any evidence of prior planning here?

No. Juanita does not have an Advance Care Directive and Advance Care Planning has not been initiated.

3. Who should decide now?

Juanita is a voluntary patient under the *Mental Health Act* so the Person Responsible under the *Guardianship Act* can give consent. Her daughter Isabel is her Person Responsible because she was Juanita's former carer before she moved to long-term residential care. Her role includes participating in Advance Care Planning and consenting to minor or major treatment to which her mother does not object.

4. Are there any cross-cultural issues which staff should consider?

It is important not to make assumptions that Juanita holds any particular views about death and dying due to her Chilean background. However, it would be prudent to talk about this with Isabel to find out what is important to Juanita from a cultural perspective. Although Juanita's older brother is not her Person Responsible, it would be worth exploring whether there is a cultural expectation

that he, as the senior male in the family, should be involved in decision-making and end of life planning.

Communication with Juanita may be difficult due to her cognitive and physical disabilities however it is crucial to pursue this and to consider whether communicating with her in her native language would assist. It is essential not to use Isabel or any family member to interpret for Juanita but to use an accredited and independent health interpreter.

Juanita's distressing hallucinations may reflect difficult experiences in Chile and it is important to find out more about this and, if appropriate, involve specialists with trauma expertise.

Staff could contact the Transcultural Mental Health Centre Information and *Clinical Consultation and Assessment Service* for guidance and information about multicultural services and resources: <http://www.dhi.health.nsw.gov.au/Transcultural-Mental-Health-Centre/About-Us/Contact/Contact/default.aspx>

5. Whose responsibility is it to initiate Advance Care Planning?

Although Advance Care Planning can be initiated by health professionals, patients or their families or carers, health professionals may be in a better position to understand the trajectory of the person's illness and therefore the best time to initiate Advance Care Planning discussions. Helpful strategies for initiating the conversation may be found in the Clinical Practice Guidelines on

Communicating Prognosis and End of Life Issues with Adults (see resources on page 41). Although Juanita may not be able to engage in Advance Care Planning discussions, her daughter Isabel can take part on her behalf. Isabel can explain to the health professionals what is important to Juanita in her treatment and care so this can be considered and respected in planning for her end of life.

6. When should Advance Care Planning be initiated with a person with dementia?

Ideally Advance Care Planning is done while a person can make their own decisions. For people with early dementia, this may be close to diagnosis, depending on the person's capacity to be involved in the discussions. Changes in illness trajectory or prognosis may trigger further discussions. More information is available at <http://www.fightdementia.org.au/services/advance-care-planning-resources.aspx>.

7. How can Juanita's values, views and beliefs be taken into account in the Advance Care Planning process if she doesn't have capacity?

Although Juanita may not be able to engage in Advance Care Planning discussions, her daughter Isabel can take part on her behalf. Isabel can explain to the health professionals what is important to Juanita; her lifelong values, beliefs and views so these can be considered and respected in planning for her end of life treatment and care. Any needs or preferences Juanita may have which stem from her cultural background should also be discussed.

8. What could a health professional do if they were concerned Isabel was making treatment decisions that were not in Juanita's best interests?

The health professional can apply to Guardianship Division of the NSW Civil and Administrative Tribunal for the appointment of a guardian with health care and medical and dental consent functions. They should ask for an interpreter for the hearing if this would assist Juanita to communicate with the Tribunal.

9. If Juanita was an involuntary patient and lacked the capacity to make a treatment decision, who could make decisions on her behalf?

As an involuntary patient, Juanita should still have the opportunity to be involved in Advance Care Planning discussions. Her daughter Isabel can do this on her behalf and if consent is needed for particular treatments, then Isabel may be able to make those decisions, depending on the type of treatment involved. Juanita's views, values and preferences should still be respected as much as possible even if she is an involuntary patient.

Under the *Mental Health Act*, Isabel is Juanita's primary carer (see page 22) and has the right to be notified about treatments proposed for Juanita and to be given information about her care.

If the treatment proposed was emergency surgery, an authorised medical officer or the Secretary of NSW Health may consent to the surgical operation. The authorised medical officer must notify Isabel, as the primary carer, and the Mental Health Review Tribunal as soon as practicable after becoming aware of the emergency surgical operation.

If the surgery was not emergency surgery and Isabel, as Juanita's primary carer, agreed to the surgery, then the authorised medical officer must apply to the Secretary of NSW Health for consent to carry out the surgery. If Isabel did not agree with the surgery, the authorised medical officer must apply to the Mental Health Review Tribunal, which can make a ruling regarding whether the surgery can be carried out.

If the treatment proposed for Juanita was not surgical treatment, then the *Guardianship Act* would apply and Isabel could make the decision as Juanita's Person Responsible.

STORY FOUR: Specific issues for the *Mental Health Act* – Anton

Anton is a 62 year old man who has experienced severe and persistent schizophrenia. He has lived in a declared mental health facility for more than 30 years and is currently a voluntary patient. He decided to try living in the community with support from the mental health service, but did not cope well with this and requested to return. He has had no contact with his family since he was admitted to the mental health facility.

Recently Anton was diagnosed with very advanced colorectal cancer. The treating team believe it is likely he will die within the next three months. Anton is currently psychologically unwell and denies he has cancer or that he is likely to die from the cancer. The staff think Anton is in pain but find it hard to understand how much pain and are not aware of Anton's wishes regarding treatment and accommodation. It is not clear if staff in the facility will be able to look after Anton while he is dying from cancer.

The medical team who diagnosed Anton advise his treating psychiatrist that they would like to offer Anton palliative radiotherapy under sedation. It is unclear if Anton has capacity to decide about this treatment, any future treatment or his accommodation. Some of the staff are concerned about caring for someone who is dying as they do not feel they are trained or resourced to provide such care. One staff member expresses concern about the involvement of the coroner in a death in a psychiatric unit.

Anton has an 86 year old mother. She has dementia and limited capacity to make decisions about Anton's care. Anton has no other family.

Questions

1. Can Anton decide for himself what he would like to happen?

This depends on whether Anton has the capacity to make the decision. In this scenario, Anton's current mental illness would warrant an assessment of his capacity.

His treating psychiatrist assesses his capacity to decide about the palliative radiotherapy and his accommodation and determines that Anton is not competent to make either decision because he lacks capacity to understand his illness, treatment and prognosis.

If there were reason to revisit these decisions, Anton's capacity would need to be reassessed, based on the specific decision at hand.

2. Is there any evidence of prior planning?

No.

3. If not, who should decide now?

As Anton is a voluntary patient and the treatment he is being offered is non-surgical, the *Guardianship Act* would apply. Under the Act, his mother is his Person Responsible because she is his only close relative; however her dementia should trigger a capacity assessment. The assessment should be specific to making a decision about palliative radiotherapy. The assessment should not include the issue of accommodation as a Person Responsible

does not have authority in relation to lifestyle decisions, such as where a person lives. An application could be made to the Guardianship Division for the appointment of a guardian to make such decisions.

The doctor assessing Anton's mother determines that she is not competent to decide whether Anton should receive palliative radiotherapy under sedation as she does not understand the nature or risks of the treatment. The doctor needs to certify in writing that Anton's mother is not capable of carrying out the functions of a Person Responsible. Anton does not have another close relative or friend. He therefore has no Person Responsible.

As the treating team would like to deliver the palliative radiotherapy under sedation, it is treated as a major treatment under the *Guardianship Act*. Therefore consent for treatment must be sought from the Guardianship Division of NSW Civil and Administrative Tribunal. Further information about how to apply is available at http://www.ncat.nsw.gov.au/ncat/guardianship/application_process.html.

4. Should Anton be told he has colorectal cancer and his prognosis?

All people have a right to be informed about their condition, prognosis and their treatment options, including their burden versus benefit, to an extent which is acceptable to them. The medical team who diagnosed Anton's cancer may be unsure about

whether to tell Anton that he has cancer and his prognosis, given he is currently experiencing acute symptoms of his mental illness but it cannot be assumed just because he is unwell that he lacks capacity to understand. In this scenario, when the subject was broached with him, he was unable to understand his illness or prognosis. The team should seek advice from Anton's treating psychiatrist about how to best provide information to Anton and maximise his involvement in decision-making .

5. Should the approach be different if Anton and his mother were Russian and regularly attended services at a local Russian Orthodox Church?

Different religions have varying beliefs and practices about death and dying. It should not be assumed that Anton would want to follow the practices of the Russian Orthodox Church surrounding death and dying simply because he attended services with his mother. However this is a factor which should be explored. Although Anton's mother may lack capacity to make decisions for him, it may be that the priest of the Church can assist with explaining Anton's religious and cultural values and preferences about death. Anton may wish to have a priest hear his final confession and administer communion when he reaches the end of his life. If this is the case, then Anton should be told he has colorectal cancer so he can be included in making arrangements for this to happen and ensuring his cultural and religious needs are met at this time.

6. How might the situation be different if Anton had a valid Advance Care Directive that stated that should he become ill with an incurable physical condition he does not want any treatment, including life-sustaining treatment and wishes to remain in the facility, which he considers his home, and be cared for by the staff with whom he is familiar?

The health professionals caring for Anton would not be able to administer the palliative radiation therapy as Anton has declined the treatment in advance. His wishes regarding where he should live are not legally binding, just as an expressed statement to die at home cared for by family cannot be enforced. However, his wishes regarding accommodation should be respected and taken into account in planning his place of dying.

7. What issues should the treating team consider in deciding whether or not Anton should remain in the facility until his death?

Some of the issues the treating team may consider are:

- What resources, including staff skills, would be required to care for Anton
- Infection risks that are outside the normal risks of a psychiatric unit
- The potential impact of caring for a dying patient on the staff and other patients on the ward
- Whether Anton can be visited by the palliative care service so he can receive appropriate pain management
- Anton's status under the *Mental Health Act*
- The terms of any order by the Mental Health Review Tribunal
- What services may be available to support Anton and the staff, such as Anton receiving visits by a palliative care nurse to administer pain relief under the supervision of a palliative care specialist.

8. Could the treating clinician complete a Resuscitation Plan withholding resuscitation?

Yes. Anton's cancer is sufficiently advanced and his prognosis poor enough to warrant withholding CPR. One of the doctors looking after Anton could complete a Resuscitation Plan stating that Anton is not for resuscitation.

9. If Anton died in the declared facility, which is his home, would his death be reportable under the Coroners Act?

Yes. If a person dies whilst they are a patient of a declared facility then their death is reported to the NSW Coroner. However, this does not necessarily mean that the Coroner will proceed with an inquest.

10. How would this situation be different if Anton was an involuntary patient?

As the treatment is non-surgical, there would be no difference. Consent for treatment must be sought from the Guardianship Division of NSW Civil and Administrative Tribunal.

STORY 5: Specific issues in forensic settings – John

John is a 59 year old man with chronic schizophrenia. He has been residing in a high security forensic hospital for the past five years, having spent the previous seven years in custody. He was found not guilty by reason of mental illness (NGMI) for the murder of his mother 12 years ago. John has been treated for his schizophrenia with clozapine for many years. He has responded well to medication with a marked reduction in the positive symptoms of psychosis. He now experiences no overt delusional beliefs or auditory hallucinations but continues to display some unusual thinking on certain topics, mild thought disorder and a blunted affect. He has displayed no aggression or interpersonal violence since his admission to the forensic hospital. However his insight into the nature of his psychiatric illness is limited and his reluctance to accept his diagnosis has impeded his transition to a less secure hospital placement.

John has advanced oesophageal cancer. Medical opinion, as expressed by the oncology team, is that John should be treated palliatively (provided with pain relief and symptom management) as curative chemotherapy options have a low chance of enhancing survival and may contribute significantly to his side-effect burden. The treating psychiatry team agree with this. John's family members (two sisters) are estranged from John and do not want to be involved in any discussion about his treatment. They think his cancer diagnosis is 'God's justice'. The treating psychiatry team have conducted a capacity assessment which found that John's ability to weigh up the risks and benefits of further chemotherapy treatment is significantly impaired and he lacks the capacity to make decisions about his medical treatment. John tells the psychiatry team that he believes that he has special reserves which will allow him to fight the cancer better than 'ordinary people'. He is suspicious of the diagnosis and has expressed concern that the palliative care option is really just a way of someone in authority "trying to kill him off". On the basis of these beliefs, John is requesting full medical intervention, insisting that he should be receiving ongoing curative chemotherapy and that he should be resuscitated if he loses consciousness due to a cerebral episode. He says he does not want to leave the forensic hospital to have palliative care in the nearby general hospital because he is afraid of the medical staff there and does not feel safe there. He wants to remain in the forensic hospital and be treated there. If he does die, he wants to die amongst his friends at the hospital.

Questions

1. Can John decide for himself about his treatment?

No. John has been assessed as not having the capacity to make this decision.

2. Is there any evidence of prior planning?

No.

3. If not, who should decide now?

Chemotherapy is a non-surgical treatment, therefore the *Guardianship Act* applies. Under the Act, one of John's sisters would be his Person Responsible; however, she could not consent to the palliative treatment, as John is objecting to it. Therefore an application should be made to the Guardianship Division of NSW Civil and Administrative Tribunal for the appointment of a guardian with a medical consent and health care function and for authority for the Appointed Guardian to override John's objections to treatment. A Guardian with a health care function has authority to make decisions that involve the withdrawal of life-sustaining treatment, provided such decisions are made consistent with the best interests of the protected person.

4. If active treatment is futile, can the treating health professional refuse to provide it?

Health professionals are not obliged to provide treatments that are futile, that is, treatment that is unreasonable, offering negligible prospect of benefit to the patient. However, the senior treating clinician remains responsible for the process whereby a consensus about end of life decisions might be sought with the patient or his/her Person Responsible, clarifying prognosis and defining an appropriate course of action and treatment plan.

This term is used in clinical practice but remains ambiguous and value-laden. A treatment is usually said to be futile in the context of disagreements about whether it should be continued, or ceased. For instance, the real disagreement between the treating clinician and family is usually not about whether the treatment is futile, but rather about what goal is appropriate or, put differently, what outcome is worth aiming for.

The NSW Health *Guidelines for end-of-life care and decision-making* (http://www0.health.nsw.gov.au/policies/gl/2005/GL2005_057.html) sets out a fair and transparent process by which treatment decisions can be made in such scenarios that reduce dissent to levels that permit a practical outcome.

Advance Care Planning resources

Website	Information
Advance Care Planning	
<p><i>Advance Care Planning – Making your wishes known</i> http://www.health.nsw.gov.au/patients/acp/pages/default.aspx</p>	NSW Health website with links to NSW Health policies, guidelines and resources.
<p><i>End of Life Decisions, the Law and Clinical Practice</i> http://healthlaw.planningaheadtools.com.au/decision-making-at-end-of-life/</p>	This resource addresses a range of legal issues that may arise in Advance Care Planning including capacity, Advance Care Directives, substitute medical consent and refusal of medical treatment. The resource has been endorsed by the NSW Ministry of Health, the Australian Medical Association (NSW), Australian Salaried Medical Officers Federation (NSW) and NSW Nurses and Midwives Association.
<p><i>Get it in Black and White: Planning Ahead Tools</i> http://www.planningaheadtools.com.au/advance-care-planning</p>	Information about Advance Care Planning, Enduring Guardianship, Power of Attorney and Wills. The website includes forms and translated resources.
Capacity and capacity assessment	
<p>Capacity Toolkit – Information for government and community workers, professionals, families and carers in New South Wales http://www.diversityservices.justice.nsw.gov.au/divserv/ds_capacity_tool.html</p>	Toolkit produced by the NSW Department of Justice. It contains information on capacity and capacity assessment.
<p>Capacity Australia http://capacityaustralia.org.au/</p>	This website promotes public and professional awareness of decision-making capacity issues. It includes references to academic resources and information about developments in this area.
<p>O'Neill N., Peisah C. (2011) <i>Capacity and the law</i>. SydUPLawbk1 (Sydney University Press) http://www.austlii.edu.au/au/journals/SydUPLawBk/2011/1.html</p>	Online book on capacity
<p><i>PD2005_406 Consent to Medical Treatment – Patient Information</i> http://www0.health.nsw.gov.au/policies/pd/2005/PD2005_406.html</p>	NSW Health policy directive
How to involve people with decision-making disabilities in decision-making (including supported decision-making)	
<p><i>Decisional capacity: toward an inclusionary approach</i> Peisah C., Oluwatoyin A., Sorinmade L.M., Cees M.P.M, Hertogh, <i>IntPsychogeriatr</i>. 2013 October; 25(10): 1571-1579 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3750821/</p>	Full text article on supported decision-making involving the Assess, Simplify, Know the person, Maximise the ability to understand, Enable (ASK ME) Model.
<p>Capacity Australia http://capacityaustralia.org.au/</p>	Information on decision-making capacity

Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities, Chapter Six: From Provisions to Practice – Legal capacity and supported decision-making

United Nations resource

<http://www.un.org/disabilities/default.asp?id=242>

Health professionals – how to initiate and conduct Advance Care Planning discussions

There are many guides for health professionals on how to initiate and conduct Advance Care Planning discussions with health consumers. These guides are equally applicable to discussions about end of life decisions with health consumers with a mental illness

Communicating Prognosis and End of Life Issues

MJA Clinical Practice Guidelines

<https://www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults>

Table 1: PREPARED MODEL on page 15

The PREPARED model of communication recommended by the above Guidelines and modified to focus on end-of-life issues

Vital Talk

A blog with information and resources on communication between health professionals and patients.

<http://vitaltalk.blogspot.com.au/>

Health professionals – understanding cross-cultural issues in advance care planning

'Planning ahead' among community-dwelling older people from culturally and linguistically diverse background: a cross-sectional survey'

This article explores preparedness of end of life care planning among community-dwelling older persons of culturally and linguistically diverse background.

Jeong S., Seok O., Pich J., Saul P. and Ho A., *Journal of Clinical Nursing*, 24, 244–255 at:

<http://onlinelibrary.wiley.com/doi/10.1111/jocn.12649/pdf>

NSW Health Conflict Resolution in End of Life Settings Project (CRELS) Report

This Report discusses how to approach and understand cross-cultural issues in end of life settings, particularly in the context of conflict resolution.

http://www0.health.nsw.gov.au/pubs/2010/pdf/conflict_resolution.pdf

Health consumers, carers, family and friends – what to expect in Advance Care Planning discussions

Get it in Black and White: Planning Ahead Tools

The NSW Government website has information about Advance Care Planning for individuals, families and carers.

<http://www.planningaheadtools.com.au>

My Wishes Advance Care Planning Program

This South Western Sydney Local Health District resource includes information for the community, health professionals (including GPs) and residential aged care on Advancing Care Planning.

<http://www.swslhd.nsw.gov.au/myWishes/>

Advance Care Planning Workbook

This Central Coast Local Health District resource contains a written form and guide for completion.

http://www.cclhd.health.nsw.gov.au/patientsandvisitors/CarerSupport/cpa/Documents/ACP_Workbook.pdf
