



A Plan of Care

A book to help people make health and personal care decisions for a person in NSW who has dementia

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The Advance Care Directive Association Inc.

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Foreword

Currently about 84,000 people in New South Wales have dementia. Over the next four decades it is projected that this number will quadruple to 341,000. In Australia it is estimated that there are about 245,000 people with dementia and by 2050 this figure will reach 1.3 million. These figures represent the visible part of the iceberg. Since for every person with dementia there are usually several family members also affected by the condition, most of us either live with dementia or know somebody living with dementia.

When people develop one of the dementias such as Alzheimer's disease they gradually lose the capacity to make decisions for themselves and a point is reached when somebody else must make these decisions. This can be very complicated and burdensome unless provisions have been made earlier.

Henry Brodaty
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Henry Brodaty is Professor of Ageing and Mental Health at the University of New South Wales. He cares for patients with dementia and has done extensive research in this area.

This publication outlines in plain language how to help people in New South Wales make health and personal care decisions for a person who has lost capacity. While much of it is applicable to people across Australia, laws vary between jurisdictions and readers outside NSW should check local laws and regulations.

The text is peppered with real life stories that sensitively illustrate the complexity of many of the decisions that need to be made. It brings the text to life and underscores the importance of planning ahead.

While the book is designed to help decision making for people with dementia it is applicable to everyone in the community. It is prudent for us all to consider arranging enduring power of attorney and enduring guardianship and thinking about whether we wish to make advance directives.

Contents

1	Introduction	1
2	What is ‘capacity’?	4
3	Who can give consent to medical treatment?	7
4	Enduring Guardian and Enduring Power of Attorney	11
5	Substitute decision making	14
6	What is a Plan of Care?	19
7	Completing a Plan of Care	23
8	A glossary of terms	30
9	Where to get more information	35

Plan of Care form – *back of book*

1

Introduction

Making decisions for people who have dementia

Every day, families, friends, and medical professionals are faced with difficult decisions about the care of people with dementia who have lost the ability to make their own decisions about their health and personal care.

This book, *A Plan of Care*, is for people faced with having to make decisions about medical treatment and personal care on behalf of someone who is no longer able to make their own health care decisions because they have dementia.

We have written this book specifically for the substitute decision makers of people with dementia who have lost the capacity to make their own decisions. In the next chapter we

describe in some detail what is meant by “capacity” and how we are able to recognise when a person has lost capacity.

Perhaps you are reading this book because you have been informed you will have to make decisions for someone else, or you are expecting that something like this will happen in your family soon. This book aims to inform you about what decisions you might have to make and gives you the information you need to make them.

Writing a Plan of Care

The book tries to make the process of decision making easier by explaining what is involved in making health and personal care decisions on behalf of another person; that is, in being a

substitute decision maker. A Plan of Care is a document which provides a plan for the patient's future medical and personal care when the person no longer has the capacity to plan their own care. Our book explains what a Plan of Care is in much more detail and what is involved in writing one. It also explains the technical terms you are likely to come across in the process.

People who have already written down their wishes for medical care and treatment before they became ill with dementia

Some people will have discussed what treatment they would want in the future. Some may even have previously written down their wishes in an Advance Care Directive, (sometimes called a Living Will). An Advance Care Directive states the types of medical treatment and personal care a person would have chosen if they had been able to express their wishes. If the person has written an Advance Care Directive or discussed their wishes, this should now be used to determine the treatment he or she will receive.

Other people will never have discussed with anyone the types of medical treatment and personal care they would want in the future. It may be unclear even to those closest to them what the person's choices would have been.

Making the best possible decisions on behalf of another person

When there is no Advance Care Directive this book is a practical guide to help you, as the substitute decision maker,

make the best possible decisions and plans for the health and personal care of the person. It is especially important to remember that you are making decisions that the person would have wanted, not the ones you would make for yourself. It is about trying to honour the person's wishes when they cannot communicate these for themselves.

There is no way you can be absolutely certain you have done exactly what they would have wanted, but you want to know that you tried to the best of your ability. Our hope is that with the information provided in this book, you and others involved in the care of the person will feel confident in the decisions made, no matter how difficult those decisions were at the time they were made.

If you are daunted by medical or legal language, remember that if you are the substitute decision maker, you can always ask the professionals involved to explain things in the plainest English possible. If English is not your first language, you can always ask for an interpreter.

Consent to treatment and the 'person responsible'

In this book, we refer to the person needing medical treatment as **the patient**. The patient will usually be your spouse or partner, a parent, a relative or a friend. We will be using the term 'patient' throughout this book to describe this person.

Except in the case of an emergency, a doctor needs consent from the patient before providing medical treatment. When the patient is unable to give consent because of their dementia, someone else needs to give consent on his or her behalf.

The person giving consent to the medical treatment, when the patient is unable to consent, is called the **'person responsible'** in New South Wales.

The 'person responsible' is a substitute decision maker who has the **specific** legal responsibility of consenting to a person's medical and dental treatment. In Chapter 3 we describe the role of the 'person responsible', we explain how to identify the 'person responsible' and describe what his or her obligations are.

If the patient has written an Advance Care Directive setting out clearly what treatment they would want (or would not want), it should be followed. The information in this book may still be helpful.

Finally, you should not use this book if the person is able to consent to treatment on his or her own behalf. In this case the person does not need a substitute decision maker because they are able to plan their own care and make their own decisions about their medical treatment.

2

What is 'capacity'?

This book has been written specifically about people who have dementia and lack the mental capacity to make decisions. As we said in the first chapter, the doctor needs the consent of the patient before providing medical treatment. The patient can only give this consent if he or she has the 'capacity' to do so. This chapter looks at what the term 'capacity' means.

Capacity

Adults (people 16 years and over) are presumed to be capable of making informed decisions if they understand the implications of their decisions. They are then said to 'have capacity' or to be 'capable' of making decisions.

Capacity is a legal term used throughout this book to refer to a person's ability to make informed decisions.

The decisions and choices a person makes may sometimes seem foolish to others. For example, a person may put a lot of money on a horse because a friend has given them a 'hot tip'. Even if other people do not agree with their decision to place a bet or the outcome of the decision was not what they had expected (for example, they lost all their money) the person placing the bet still had the capacity to make the decision and knew the risks involved.

In a medical situation a person with cancer may choose not to have chemotherapy even though the doctor has explained that this treatment

would most likely prolong his or her life. For various reasons the person may not wish to undergo this treatment, although other people would disagree with this decision. If the person has the capacity to make their own decisions, they have the right to make that decision.

Understanding the implications of the decisions that are made is what is important, not what other people think of the decisions.

Capacity to give consent to treatment

A person is generally considered to have capacity to consent to medical treatment if they can:

- Understand what their medical problem is.
- Understand the proposed treatment, as well as alternative treatments and the option of no treatment.
- Understand the risks associated with the treatment/s, such as side effects.
- Weigh up the risks and benefits of each option and make a choice based on this information.
- Communicate their decision regarding their treatment.

Whilst these points outline the principles of capacity, the patient can only understand their medical problem and treatment options if these have been explained clearly and in words that the patient can understand.

Lack of capacity should therefore not be confused with the inability to understand technical and complex issues.

A person's capacity to make an informed decision should also not be

confused with their ability to speak or understand English. A person who cannot understand English, but who has the capacity to make decisions in their own language, is still the person who should be consenting to their own treatment. They should be provided with a health care interpreter so they can discuss their situation with health care staff.

What does 'loss of capacity' mean?

A person's capacity is usually only questioned when they have a major illness or injury or their behaviour changes. Loss of capacity may happen suddenly or gradually. A sudden loss of capacity can occur when a person has a major stroke or is unconscious after a head injury from, for example, a car accident, or suffers from an episode of delirium. (See Glossary in Chapter 8). When there is a sudden loss of capacity some people will regain their lost capacity, others will not.

Loss of capacity may only occur in one area of decision making. For example some people retain the capacity to make decisions about their healthcare and treatment, but lose the capacity to understand financial matters or vice versa.

Other people gradually lose their capacity to make informed decisions about their medical treatment. For example, people with progressive dementia, such as Alzheimer's disease, lose their memory and forget recent events. They may eventually lose the ability to speak, become totally dependent and lose all capacity for decision making in relation to their healthcare needs.

When a person is gradually losing their capacity, it doesn't necessarily

mean they cannot make **any** informed decisions. They may lose the capacity to make complex decisions that involve weighing up many options, but are still able to make simple decisions. For example, a person may be able to consent to have a dressing put on a leg ulcer or to taking paracetamol for pain. They may not be capable of consenting to more complex treatment such as surgery for their leg ulcer. Lola and Sid's stories illustrate how a lack of capacity affects a person's ability to make decisions about their medical treatment. (See Glossary Chapter 8 for a definition of dementia).

Disputes about a person's 'capacity'

If there is a dispute about someone's capacity to consent to medical treatment, then only the Guardianship Tribunal or the Supreme Court can decide whether or not a person has the capacity to make such decisions. Doctors and other health professionals may be asked to provide an opinion on someone's capacity but only the Tribunal or Court can decide whether or not a person has the capacity to consent to the treatment.

Lola's story

Lola lives alone in her own home and has early dementia. She needs help with housework and showering, due to problems with her arthritis. She also has an ulcer on her leg. She has consented to the nurses changing the dressings on a regular basis. Lola is capable of consenting to this level of treatment. She may, however, not be able to comprehend the implications of surgery, such as a skin graft, if that is required later on. For this reason, if her doctor suggested this was necessary, her 'person responsible' (that is, her substitute decision maker) would need to give consent to a skin graft before Lola could have this treatment.

Sid's story

Sid is 73 years old and lives with his wife, Doreen. He was diagnosed three years ago with vascular dementia resulting from small strokes and is gradually losing the capacity to manage his finances and take care of himself. Although Sid prizes his independence, he has had to give up driving and can no longer go out alone. Doreen now takes care of all the bills and she increasingly has to remind Sid to do simple and routine daily tasks like dressing himself and eating meals. She currently goes with him to the GP and Doreen knows that she will have to do more and more for Sid as the disease progresses and his capacity for making decisions in other areas also diminishes.

3

Who can give consent to medical treatment?

A summary of what the law says about consent to treatment and who can consent

The law states that, except in an emergency, in order to treat a patient, health care professionals must first get consent to provide medical and dental treatment. This consent is usually given by the patient. If this is not possible, because the patient does not have the capacity to consent, then Part 5 of the Guardianship Act sets out who can give that consent. It can be the Guardianship Tribunal itself, an appointed guardian or the 'person responsible'. In most cases it will be the 'person responsible'. In New South Wales the 'person responsible' is the

legal term applied to the person who can give valid consent to treatment on behalf of another person (the patient) when they lack the capacity to give consent themselves.

Who is the 'Person Responsible'?

There are strict rules to be followed in identifying who the 'person responsible' is for each patient.

The 'person responsible' is not necessarily the patient's closest relative. To establish who is the patient's 'person responsible', you need to work your way down the list on the next page.

WHO IS THE 'PERSON RESPONSIBLE'?

GUARDIAN

with the function of consenting to medical, dental and health care treatments

If there is no guardian



A SPOUSE OR DE FACTO SPOUSE

with whom the patient has a close, continuing relationship
(de facto spouse includes same sex partners)

If there is no spouse or de facto spouse



AN UNPAID CARER

who is now providing support to the person or provided this support before
the person entered residential care

If there is no unpaid carer



A RELATIVE OR FRIEND

who has a close and continuing personal relationship with the person

The NSW *Guardianship Act 1987* Part 5 identifies a 'person responsible' as:

1. A guardian (including an enduring guardian) who has the function of consenting to medical, dental, and health care treatments;

A guardian is a legally appointed person with a range of duties and responsibilities (called functions), for the person for whom they are the guardian. An 'enduring guardian' is one type of guardian and in Chapter 4 we describe what an 'enduring guardian' is and does.

If there is no guardian, the 'person responsible' is

2. A spouse or de facto spouse with whom the patient has a close, continuing relationship (de facto spouse includes same sex partners);

If there is no spouse or de facto spouse, the 'person responsible' is

3. An unpaid carer who is now providing support to the person or provided this support before the person entered residential care;

Most unpaid carers are a family member but can be a close friend or neighbour. A carer may receive Centrelink benefits such as the Carer Allowance or the Carer Payment, but may not be employed professionally in a caring role with the patient. Residential aged care facility staff, visiting nurses or community service providers are all paid carers and cannot be the 'person responsible'.

If there is no unpaid carer, the ‘person responsible’ is

4. A relative or friend who has a close and continuing personal relationship with the person.

The ‘person responsible’ is not necessarily a relative but may be a close friend as Esther’s story shows.

Esther’s story

Esther is in her eighties and has one brother, Bernard, and no other relatives. Bernard doesn’t visit often and he and Esther are not close. Esther is frail, but has been able to stay in her own flat because her neighbour, Beverley, visits her three times a week and does her shopping and some house work. Esther considers that Beverley is a close friend. They have talked about what treatment Esther would want if she became ill and was unable to consent to treatment. Esther knows that Beverley is her ‘person responsible’ as she is a friend who has a close personal relationship with her. She is also her unpaid carer. This makes her Esther’s substitute decision maker. Although Bernard is Esther’s brother he has not provided support for her and is therefore not Esther’s ‘person responsible’.

What if the ‘person responsible’ doesn’t want the task of substitute decision maker?

The person identified as the ‘person responsible’ does not have to undertake the tasks of substitute decision maker. If they do not want to have this responsibility, they need to state in writing that they do not want to be the ‘person responsible’. Maria and Petros are an example of this situation.

Maria and Petros

Maria is the wife of Petros who has severe dementia. Her own health is poor, and she relies on her daughter Elena. Petros has fractured his hip and the doctor wants Maria to consent to the surgery as this will be the best way to relieve his pain. Maria does not want this responsibility and therefore declines, in writing, to be Petros’s ‘person responsible’. She gives this letter to her GP. Elena agrees to take on this role as the next person in the list of people who can be Petros’s ‘person responsible’. She talks to the doctor and the family. She agrees that an operation on his hip is the treatment Petros would have wanted and signs the consent.

What if the ‘person responsible’ is not capable of the task?

A medical practitioner or other qualified person can state in writing that, in their view, the person identified as the ‘person responsible’ lacks the capacity to fulfill this responsibility. Betty and Bruce are an example of what could happen in this situation.

Betty and Bruce

Betty and her husband Bruce live together. Betty has Alzheimer’s disease. Bruce suffers a serious heart attack and is taken to hospital. He requires coronary artery bypass surgery and the doctor thinks he is so unwell that he is incapable of providing his own consent. Betty is his ‘person responsible’ but the doctor realises that Betty lacks the capacity to perform this role due to her dementia. The doctor contacts their son who has provided support and care and is therefore the next ‘person responsible’ in the hierarchy. The doctor then notes this on Bruce’s medical record. The son gives consent to Bruce having heart surgery as he considers that this is the treatment Bruce would have wanted. Bruce recovers from the surgery and regains his capacity.

The examples above illustrate that when the ‘person responsible’ declines or is not capable of fulfilling that responsibility, the next person in the list or hierarchy needs to take on that role.

Can there be more than one ‘person responsible’?

There can be more than one ‘person responsible’. For example, two sisters may both be ‘persons responsible’. Mary’s story illustrates this.

Mary’s story

Mary is a widow, who, despite her loss of capacity to make her own decisions, lived alone before she went into a nursing home. Her two daughters, Sandra and Narelle, shared the care giving responsibilities when Mary lived in her own home. They would take her to appointments and arrange services for her. They were both her ‘person/s responsible’ as they were both providing care.

When Mary went into the nursing home, the staff said they would like just one person to be their main contact. The daughters decided that as Narelle didn’t work full time she should be the person for the nursing home to contact. The sisters agreed between themselves that they would both discuss major decisions for their mother.

4

Enduring Guardian and Enduring Power of Attorney

What is an 'Enduring Guardian'?

Under the NSW Guardianship Act 1987 people can choose to appoint an enduring guardian, or more than one if they wish.

To appoint an enduring guardian a person needs to visit a solicitor or the Registrar of the Local Court whilst they still have capacity and appoint the person (or persons) they wish to be their enduring guardian (or guardians) to this position.

An enduring guardian is a person to whom the patient has given the authority to decide certain matters such as:

- Where the patient lives
- What health care services the patient receives

- What kind of personal services the patient receives.
- Whether to give or withhold consent to medical and dental treatment on the patient's behalf.

We return to Sid and Doreen's story to show what happens when a person does not have an enduring guardian.

Sid and Doreen

Earlier in the book we met Sid who is gradually developing dementia. When Sid had capacity he did not appoint an enduring guardian. In the absence of an enduring guardian Doreen is Sid's 'person responsible' because she is his wife (spouse).

What is an Enduring Power of Attorney?

Many people confuse the term ‘Enduring Guardian’, which was described earlier, with ‘Enduring Power of Attorney’.

An enduring power of attorney is a legal document which details the appointment of a person (or persons) to make decisions about property or financial affairs if the person has lost the mental capacity to do so for themselves. The person who makes an enduring power of attorney is known as ‘the principal’. The person who is appointed to make decisions is known as ‘the attorney’. An enduring power of attorney does not include healthcare or lifestyle decisions. Similarly, an enduring guardianship appointment cannot include decisions about property or finances.

Only people who have capacity can appoint an Enduring Power of Attorney and/or an Enduring Guardian.

Sophie’s story

Sophie is a widow, who lives with her daughter and now lacks capacity to make medical and financial decisions. When she still had capacity she had appointed her son as her Enduring Power of Attorney and her daughter as her Enduring Guardian. There is some confusion in the family as the brother thinks he should make all the decisions.

When Sophie needs surgery, the doctor explains to the son that his sister is the Enduring Guardian and, as such, the ‘person responsible’. It is therefore the sister

who needs to give medical consent. Her brother only has responsibility over financial matters.

If Sophie had not appointed her daughter as her Enduring Guardian she would still be the ‘person responsible’ as she is her unpaid carer (providing the majority of her care).

What if there is family conflict or dispute?

When a family member develops dementia it is often a time of great anxiety and emotional distress for those involved in decision making about the patient. This can give rise to conflict between family members. There may be disagreement not only about what type of care or treatment is best for the patient but also about who should be making care decisions.

This is illustrated by Sophie’s story above but also, in a different way, by Mary’s story.

Mary’s story continued

Whilst in the nursing home Mary became unwell and the staff wanted her transferred to the hospital to establish what was happening to her. Although Sandra agreed with the staff of the nursing home, Narelle did not agree to Mary being sent to the hospital. She wanted Mary to be treated in the nursing home, as she believed that was what her mother would have wanted. As Narelle had been identified as the nursing home

contact the nursing home did as she asked. Mary was managed in the nursing home and had treatment for the urinary tract infection that had made her so unwell.

The nursing home was aware of the ongoing conflict between Narelle and Sandra. The staff suggested to the sisters that they try and sort this out. When this was not successful, a meeting was arranged involving the sisters and the nursing home staff to discuss the ongoing management of Mary's care. However this still did not resolve the issue and the nursing home staff decided that they needed to apply to the Guardianship Tribunal to sort out who would be Mary's guardian. The Guardianship Tribunal held a hearing to consider everyone's point of view before determining who should be appointed as Mary's guardian. The staff had previously advised Narelle and Sandra that they themselves could apply to the Guardianship Tribunal, but Narelle and Sandra had not taken up that option.

5

Substitute decision making

What is involved in substitute decision-making?

Making health care decisions for someone else should always be based on **the patient's** needs and wishes. However, sometimes it can be hard to tell the difference between our own wishes and what the patient would have wanted.

When making decisions for the patient as their 'person responsible' the principles set out in the NSW *Guardianship Act 1987* must be followed.

These principles include:

- The welfare and interests of the patient should be given the highest consideration.

- The views of the patient should be taken into consideration.
- It is important to preserve family relationships and the cultural and linguistic environment of the patient.
- The patient should be protected from abuse, neglect and exploitation.

(For more information see *Understanding Guardianship*, Office of the Public Guardian:
www.lawlink.nsw.gov.au/opg)

Sometimes the 'person responsible' will make decisions about medical treatment with which other people with a concern for the patient may disagree. Where conflicts cannot be resolved, the Guardianship Tribunal will be able to give advice about what to do. Health professionals can also contact the Guardianship Tribunal on

behalf of the patient. They can apply for a guardian to be appointed if there is family conflict that is preventing decisions from being made, or if they believe the ‘person responsible’ is not acting in the best interests of the patient. (See Chapter 9 for contact details for the Guardianship Tribunal.)

What does the ‘person responsible’ need to know before consenting to treatment on behalf of the patient?

The ‘person responsible’ has a right to know and a responsibility to understand:

- What treatment is proposed for the patient.
- What the risks and alternatives are.
- That they can say ‘yes’ or ‘no’ to the proposed treatment on behalf of the patient.

The medical practitioner has a responsibility to give this information to the ‘person responsible’ and to obtain their consent before treating the patient. The only treatment to which a ‘person responsible’ cannot consent is described by the Guardianship Act as ‘special treatment’ (see glossary, Chapter 8, for definition). The ‘person responsible’ may also decide to seek a second opinion from another health professional if they have any uncertainties.

Substitute decision making – in practice

Making decisions about the care and treatment of someone who can’t make their own decisions because of dementia can be very difficult. It can

also place extra stress on individuals and families. In this process conflict can occur or existing tensions can be made worse. Deciding what the patient’s wishes and needs would have been, had they been able to speak for themselves, is essential in these situations. Concentrating on the patient can sometimes help families resolve differences and communicate with each other.

Substitute decision making is about the patient’s wishes and choices, not your own. You should decide on treatment by thinking about what the patient would want to happen, and not what you would want to happen to you if you were in the same position as the patient.

What if the patient’s wishes are known?

Maybe the patient told you what they would want to happen in a certain situation. You may still need to reflect on how clear they were about their wishes and how those wishes apply to the situation that they are now facing. Perhaps the situation they are in now is different from what you had discussed with them in the past. Think about how this situation is different and whether this might change what the patient would have wanted.

Edna's story

Edna and Dave were both in their 60s. They have been living together for nearly forty years and had two adult children. Dave suffered a stroke, leaving him partially paralysed. At this time Edna and Dave each decided to complete Advance Care Directives stating their wishes for care and treatment should a time come when they could no longer speak for themselves. They told their children what they had decided. Dave had another stroke two years later from which he died.

Ten years later, Edna was in her late 70s and had advanced dementia. She lived in a nursing home. Her original Advance Care Directive had been lost, and she no longer had the capacity to write a new one. However, her son and daughter were aware of her previous choices for care and treatment. They and the staff of the nursing home all wanted to document the choices she had made, so that everyone involved in her treatment would follow her wishes. The staff suggested they write a Plan of Care setting out Edna's known wishes.

Edna was given the care she would have wanted and when she eventually died in the nursing home, her children and staff members were with her. They were all relieved that her wishes had been carried out.

What if the patient's wishes are unknown?

It is quite common for people to be faced with making a decision on behalf of a patient when they don't really know with any certainty what that person's wishes would have been. If you find yourself in that situation, think about other things that might help you understand what the patient might have chosen in this situation.

Roy's story

Roy had a serious head injury and had been in a coma for several months. His partner, Phil, had to make a decision about his treatment. He reflected on many conversations, including one in which Roy had made the comment that he would never want to be kept alive if he could not recognise his friends and family again. Phil had a meeting with the treating doctors who explained Roy's medical situation and that he was unlikely to recover. Phil took the doctors' advice that the respirator should be turned off. He felt certain from his knowledge of Roy that he would not want to be kept alive on a respirator if he would never be able to recognize his family and friends. Roy did not breathe for himself and subsequently died. As hard as it was to lose his partner, Phil felt he had made the decision Roy would have wanted him to make.

It might be useful to think about conversations you have had with the patient that could help you understand the choices they would have made. Perhaps they said what they wanted to happen if they were ever in this situation, or a similar one. You can ask yourself what you think the patient would be saying if they could speak for themselves.

We know from talking to people that the kinds of things they say are:

- I want to die in my own home.
- I don't want to be found dead alone .
- Don't ever put me into a home.
- I never want to be a burden on my children.
- Don't ever attach me to a machine to keep me alive.
- If I lose my marbles I don't want to be kept alive.
- If I can't recognise my children I wouldn't want to live.
- What will be, will be.
- When my time comes I'll be ready for it.
- I'll struggle on till my time is up.
- I'll go out fighting.
- It's not my decision, or anyone else's. God decides when it's time.

These kinds of things all give you a clue as to the way the person for whom you have to make a decision views their life and death. They might help you decide the kind of treatment a person would have chosen but can't now tell you about, if they have a serious or terminal illness.

It should be recognised that it may not always be possible to carry out a person's wishes to the letter, particularly in relation to a move to residential care or the circumstances of a person's death.

If you have known the patient for a long time, you may recall events in their life that help you with these decisions, for example, the death of a parent or very close friend. What did your father say and how did he react when his mother (your grandmother) died? Did your father say "thank goodness my Mum didn't suffer?" Or did he say "I'm pleased Mum went out fighting and you need to fight to the end"? These comments may put you in touch with your father's personal values and what he would want for himself.

Many families interpret "fighting for life" as a struggle to stay alive, no matter what. But if the patient can't tell us, we need to be sure that we are not misjudging their struggle, which could be a "fight to let go".

You might remember your mother making important and difficult decisions when for example, she had to decide about whether or not to undergo surgery. She may have said "So long as it gives me a chance, I will take the risk" or she could have said "I would not have a knife stuck in me for anything." These examples are intended to illustrate the range of attitudes and values people use to make decisions.

When making a decision about care and treatment for someone else it is also very important to think about the outcome you are trying to achieve for the patient. If the goal is to restore someone to full health, the decisions you make on their behalf may be very different from those you will make if the goal is to alleviate pain and distress. Finding out as much information as possible from the health professionals who are caring for the patient is crucial in deciding the aims and outcomes of any treatment.

You may discover that the expected outcomes of the proposed treatment are different from those you thought likely. For example, you might have thought the patient would regain physical independence but find that they will need continued help with physical tasks.

Richard and Maggie's Story

Maggie moved into a nursing home following a stroke and was visited daily by her husband, Richard. She had a middle-aged daughter who lived in England who had her own health problems. Maggie was unable to hold a conversation, but repeated the same word over and over. She could however sing all the words of hymns in the weekly church service, which she enjoyed.

Richard was diagnosed with progressive incurable cancer. He was worried about what might happen if Maggie needed further medical care in the future and he was no longer able to consent on her behalf. Richard therefore decided to write a Plan of Care. He considered that Maggie's strong religious beliefs and her enjoyment of life were such that she would want to strive for life at all cost. The Plan of Care documented that she should be transferred to hospital if her condition ever worsened.

After Richard died, Maggie became ill and she was transferred to hospital. She had a partial bowel obstruction and a decision needed to be made about surgery. The staff at the hospital applied to the Guardianship Tribunal for consent. The Tribunal was made aware of the Plan of Care and used this to help make the decision. She underwent the surgery and this relieved her pain.

6

What is a Plan of Care?

A Plan of Care is a document which

- provides a plan for the patient's future care
- is part of an ongoing care planning process
- does not replace the need for consent by the 'person responsible' to specific medical and dental treatment.

In writing a plan of care you will need to:

- identify the 'person responsible' (the legally authorised substitute decision-maker)
- identify the treating doctor (this will usually be the patient's GP)
- establish that the patient is unable to make healthcare decisions for themselves – that is, that the patient has lost this capacity
- record any wishes regarding the patient's health and personal care that they may have expressed when they had capacity
- describe the patient's current level of functioning and assess whether this would be acceptable or unacceptable to the patient (see Chapter 7)
- state whether cardiopulmonary resuscitation (CPR) should be attempted
- state which levels of care you as the 'person responsible' would agree to, should the patient's condition deteriorate
- choose what type of feeding may be provided in the future.

The Value of a Plan of Care

Having confirmed with the doctor that the patient has lost capacity, it could be the time to make a Plan of Care.

Completing a Plan of Care will ensure medical, nursing and other health professionals know what type of care the 'person responsible' would want for the patient if their condition worsens. It may be used for patients who are in hospital, in nursing homes and hostels, as well as for those who are living in their own homes. Completing a Plan of Care helps all parties to work together with a common understanding.

However, it is still necessary for the treating doctor to discuss individual treatment decisions as they arise and to obtain consent to the proposed treatment. A Plan of Care is not a substitute form of consent. It is a guide to what, to the best of your knowledge, the patient would have wanted, had they been able to speak for themselves. **It should be reviewed every 12 months or when there is a major change of the patient's medical condition.**

The Plan of Care should be completed following consultation with the treating doctor and others involved in providing care. This is best done when the patient's condition is stable.

The Plan of Care is not a legal document. It is intended to assist the 'person responsible', doctors and other health professionals in the process of providing treatment and care.

An outline of a Plan of Care is provided at the back of the book. The next chapter discusses the various options that you will need to document in the Plan of Care.

How to decide on a Plan of Care?

By working through this book and reading different people's stories, you will be in a better position to complete a Plan of Care. It will also help you to discuss your understanding of the patient's wishes with health professionals caring for the patient.

Who can you talk to in order to help with substitute decision making and writing a Plan of Care?

1. DOCTORS

It is helpful to speak to the patient's doctor to find out the patient's medical conditions. Discuss the aims of care and treatment so that you can better understand what level of care may be best suited to the needs of the patient. The patient may have more than one doctor treating them. For many, the local doctor (General Practitioner or GP) will be able to provide you with different kinds of information to help you make decisions about the patient's treatment. The GP may also be able to pass on information from other doctors treating the patient. Some patients will be treated by a medical specialist or hospital doctor and, if so, this is the person to contact.

To do this you will need to ring or visit the doctor who is currently caring for the patient and enquire about making a time to discuss this in person. If the patient is in hospital, enquire if the GP has been contacted by the hospital staff and is aware of the patient's condition.

For patients in a large hospital, the medical specialist is often assisted by

a doctor known as a registrar or by a resident doctor or intern. Ask the ward staff for each of the doctors' names and contact details. It may be helpful to have a notebook in which to keep all these details when the patient is in hospital.

2. A FAMILY CONFERENCE – SOMETIMES CALLED A CASE CONFERENCE.

A family conference brings together the people who are involved in the care and treatment of the patient. This may be organised by the health professionals or you may ask for a family or case conference. This is an opportunity for you as the 'person responsible' to gather as much information as possible about all treatment options and expected outcomes.

A family or case conference can help you to understand what everyone involved thinks about the patient's situation. It can also help to get agreement on the aims of future care and management strategies.

Topics to discuss at a family or case conference may include:

- Cardio-Pulmonary Resuscitation (CPR)
- Various options for levels of care of the patient
- Types of feeding
- In what circumstances the patient will be treated at home, in a residential aged care facility or will be transferred to a hospital.

This information may help you weigh up the risks and benefits of various treatments. You might also want to talk about things that are specific to the patient's illness, their social circumstances and their wishes. A

family or case conference provides you with an opportunity to do this.

3. AGED CARE ASSESSMENT TEAMS (ACATS)

In some circumstances a patient will need to be assessed by an Aged Care Assessment Team. You, as the 'person responsible', will need to be present at this assessment.

An Aged Care Assessment Team consists of health professionals appointed to assess the type and amount of care a patient needs. Their decision is used to decide a patient's eligibility for various aged care services. These include residential care in an aged care facility (a hostel or a nursing home) and, if appropriate, services provided to support the patient at home so that he or she can remain at home. (You can obtain the phone number of your local ACAT by phoning the Commonwealth Respite and Carelink Centre: 1800 052 222 or look at the website: www.commcarelink.health.gov.au)

4. AGED CARE SERVICES

Aged care services are provided by a variety of organisations. They include services to people in their own homes (for example home nursing, Meals on Wheels) as well as residential aged care (previously known as hostels and nursing homes). They may be provided by non-government, private for profit or government organisations. Staff from these services may also be able to assist you with information to help you make decisions about the patient's medical and personal care. (For information about your local services phone Carelink: 1800 052 222 or look at the website www.commcarelink.health.gov.au)

Cath's Story

Cath was in her 80s. She had advanced dementia and lived in a nursing home. She was widowed and had four children, all of whom phoned Cath often. Two of her children, Geoff and Sue, lived nearby and were also able to visit frequently.

After a year in the nursing home, Cath became bedridden and could no longer speak. She then stopped eating. Geoff and Sue were very upset and were confused about what their mother would have wanted in this situation. They decided to write a Plan of Care following discussions with the GP and nursing staff and based on what care they thought she would have chosen. They decided after speaking with their brother and sister that reversible medical conditions such as infections should be treated by the GP at the nursing home.

Some weeks later Cath developed aspiration pneumonia (where food goes into the lung) and Geoff and Sue reviewed the Plan of Care with the GP and nursing home staff. The GP explained that aspiration pneumonia is common in people with end stage dementia. She also explained that antibiotics could only be given to Cath intravenously (in her vein) as she could not swallow. The GP also told them that using a needle to feed the antibiotics into Cath's vein would be painful. This was because Cath's limbs were stiff and tight, and she was bedridden. Her arm would need to be extended and strapped in order to give her antibiotics in this way. She also said that because Cath was very frail, she

was unlikely to recover from the pneumonia even with antibiotics.

Geoff and Sue were upset and worried about their mother being in distress. They decided that the pain of giving the antibiotics was greater than Cath's possible distress from finding it hard to breathe. They decided to ask the GP to provide Cath with treatment that would keep her as comfortable and pain free as possible. They made a decision not to use antibiotics into the vein.

Not long afterwards, Cath died peacefully. All four children were glad that their mother had not been given the antibiotics but were, nevertheless, worried that they had not made the right decision. They discussed this at a family gathering after Cath's funeral and came to the conclusion that although they could never be completely sure, they had certainly made the best possible decision based on what they believed their mother would have wanted for herself, and on the medical information provided by the GP.

7

Completing a Plan of Care

In writing a plan of care, there are three main areas to consider, although you may add others as you see fit. The three areas are:

1. Cardio-pulmonary Resuscitation (CPR)
2. Level of care
3. Types of feeding

However, before considering these you will need to assess the patient's level of functioning as this will affect the decisions you make regarding the patient's care.

What does level of functioning mean?

A person's level of functioning is about what they are able to do and understand. An illness, such as a mild cold, causes almost no change in the level of functioning of an otherwise healthy person. On the other hand, some illnesses can have a big impact on a person's level of functioning. A person with severe arthritis may have difficulty walking, climbing stairs, doing their shopping, getting on a bus and visiting friends but may have good mental functioning. At the far end of the spectrum people living with advanced dementia may not be able to talk, wash, dress or feed themselves

and have little understanding of their situation or be able to make decisions.

In the space below write a note about what you believe the patient would have described as an unacceptable level of functioning for them.

‘Acceptable’ and ‘unacceptable’ levels of functioning

One of the most important parts of completing a Plan of Care is stating what you believe would be an ‘unacceptable’ level of functioning in the view of the patient. What is the bare minimum of functioning you think they would find acceptable?

Levels of functioning you may want to think about are:

- not being able to recognise loved ones, and/or
- not being able to communicate, and/or
- not being able to wash themselves and/or
- not being able to dress themselves and/or
- not having control of bladder and/or bowels and/or
- not gaining pleasure from simple activities.

Determining when you think an unacceptable level of functioning has been reached is an important step in writing a Plan of Care. If you consider that the patient has reached a level of functioning that would be unacceptable to him or her then this will influence the types of care you will be choosing for them.

Is the patient at this point now?

Yes No

Other comments

CARDIO-PULMONARY RESUSCITATION (CPR)

Let's first consider the use of cardio-pulmonary resuscitation (CPR) when someone has reached an unacceptable level of functioning.

'Cardiac' and 'cardio' are medical terms for the heart. When a person's heart stops beating, they are said to have had a 'cardiac arrest'. 'Pulmonary' means 'of the lungs'. When a cardiac arrest occurs, methods to start a person breathing and their heart beating again are called 'cardio-pulmonary resuscitation', or CPR for short.

You may know of CPR as emergency mouth-to-mouth resuscitation and pushing on the chest with the hands to keep the blood moving through the body. In hospital, when a patient has a cardiac arrest, an electric shock from a defibrillator can be used to re-start the heart and ventilators can keep the person breathing.

In healthy people, CPR is often successful. This is why basic hands-on CPR is a standard part of any first-aid course. Started quickly, it can save a life in an emergency, after which the person has a good chance of successful recovery. However, when a person has a long-term irreversible illness, CPR does not have such a good success rate. Commonly, the patient does not return to their original functioning. It can also result in bruising and fractured ribs. In many cases CPR will automatically be commenced, unless there is documentation stating that this is not to be provided.

In the Plan of Care, you can state that CPR should or should not be commenced (see also *NSW Guidelines for end of life care and decision making* and *NSW Guidelines for CPR - Decisions Relating to No Cardiopulmonary*

Resuscitation Orders (<http://www.health.nsw.gov.au/policies>)

Note here what you think the patient would have wanted in terms of CPR.

LEVELS OF CARE

The patient may not suffer a cardiac or respiratory arrest and therefore they will not require CPR. However, their condition may deteriorate further, if they develop an additional illness. The illness may be easily managed or require other more active measures. You will need to consider these treatment options in terms of how beneficial they will be to the patient or what side effects they may have. You also need to think about whether the benefits outweigh the side effects. You will be able to obtain this information by discussing it with the health professionals who are caring for the patient.

The four levels of care for life-threatening illness are:

- 'palliative level of care'
- 'limited level of care'
- 'active level of care'
- 'intensive level of care' .

1. 'Palliative level of care'

The aim of 'palliative level of care' is to provide physical, social, psychological and spiritual support to

someone who is dying, and to keep them comfortable. Prolonging life is not the aim of this care.

Any investigations or treatments will only be to provide pain relief and to ease discomfort.

‘Palliative level of care’ may occasionally include surgery, tests and medications (including antibiotics) but only when the purpose of such treatments is to improve the patient’s comfort.

This is the level of care generally offered to people who are dying and may be provided at home, in a hospital, in a hospice or a residential aged care facility.

2. ‘Limited level of care’

‘Limited level of care’ includes everything in the ‘palliative level of care’ and may also include limited measures to prolong life, such as antibiotics, investigations, transfusions and oxygen.

This level of care does not include elective surgery, except for comfort or pain relief. (Elective surgery is surgery that is planned rather than emergency). At this level of care, the patient would not be put on a life support machine (ventilator). If their kidneys were failing they would not go on a kidney machine (dialysis).

If they could speak for themselves, people whose level of functioning has become unacceptable and who have a life-threatening illness might choose a ‘limited level of care’. This would mean that they would only go to hospital if they could not receive the necessary care at home or in their residential aged care facility. Some hospitals and health services are able to provide additional services like ‘hospital in the home’ or ‘post acute care services’

to decrease the length of time spent in hospital. A limited level of care provided at home or in the residential facility may be appropriate for someone with advanced dementia who will often become more confused and distressed if they are transferred to hospital.

3. ‘Active level of care’

The aim of ‘active level of care’ is to prolong life and improve outcomes. An ‘active level of care’ includes everything in the ‘limited level of care’ as well as transfer to hospital and all possible treatment including elective surgery (for example, a knee replacement) if required. However a breathing machine (ventilator) would be used only for the purpose of surgery, or recovery from surgery.

4. ‘Intensive level of care’

This level uses every available piece of technology to maintain life. ‘Technology’ in this instance includes all the options outlined in the other levels as well as life support (machines to assist with breathing), dialysis & transplants.

In serious medical emergencies, patients usually go straight to the Intensive Care Unit.

‘Intensive level of care’ is the obvious level of care when the person has a good chance of recovering fully. It may not be offered by doctors if they consider that level of treatment is futile or not likely to be of benefit, given the patient’s circumstances.

Note here what you think the patient would have wanted in terms of level of care:

TYPES OF FEEDING

In the case of life-threatening illness or major loss of functioning, the ability to feed oneself is often reduced. When this happens alternate methods of supplying life-sustaining food have to be considered.

There are four types of feeding: oral, supplementary, intravenous and tube feeding. Some people may also choose to have 'fluids only' or 'no food'.

1. Oral feeding

This is where the patient is fed with foods, both fluids and solid food which may be thickened or pureed as required.

2. Supplementary feeding (includes oral feeding)

Supplementary feeding means that in addition to oral feeding, the patient receives extra supplements such as vitamins or high energy drinks. For these patients, supplementary feeding helps them get adequate nutrition. This level of care does not include intravenous feeding; that is, through a needle in the vein.

3. Intravenous feeding (may include oral and supplementary feeding)

In this level of feeding, food and fluids may be given to the patient through a tube put into the veins. Intravenous feeding can include a drip into the arm or hand (peripheral) or a longer term device put into a larger vein (central). Peripheral intravenous fluids can only be provided for a short time because the veins tend to get damaged.

4. Tube feeding

When a patient's stomach and intestines can absorb food, but the patient cannot swallow, a 'nasogastric' tube can be passed through the nose and into the stomach. Food and liquids can then pass through the tube directly into the digestive system. The success of this type of feeding can vary. Some people have no problems with it, while others find the tube uncomfortable and even painful. Some patients, in their distress, pull out the tubes. Sooner or later, nasogastric tubes have to be removed from all patients because they get blocked, dislodged or cause irritation.

A 'gastrostomy' tube can be inserted directly into the stomach. Minor surgery is required to cut a path for the tube through the skin into the stomach. When a person needs tube feeding for a long time, a gastrostomy tube is a better option than a nasogastric tube, because it is generally better tolerated. Sometimes tubes can become blocked or dislodged, requiring the tube to be replaced. This in some instances may require a general anaesthetic.

Note here what you think the patient would have wanted in terms of type of feeding:

OTHER ISSUES THAT MAY BE IMPORTANT FOR THE PATIENT

This may include spiritual needs, personal care, food preferences, music and other issues.

Note here any other issues:

WHERE CARE WILL BE PROVIDED

As the substitute decision maker you will need to consider where the patient would have preferred to receive care. Some patients would prefer to receive care in their present environment even when they become more unwell. Others would prefer in these circumstances to be moved to a hospital setting. Some treatments are only available in hospital; in other cases there may be a choice.

Note here where you think the patient would have preferred to be treated:

Writing a Plan of Care

A Plan of Care takes a considerable amount of time, thought and effort on the part of the 'person responsible' and the health professionals. However, people report that they have found the process helpful and worthwhile. Joanie's story illustrates when it might be helpful for you, as substitute decision maker, to write a plan of care.

Joanie's story

Joanie was widowed and lived in a residential aged care facility. Her daughter and one adult granddaughter visited daily. Between them they were present to feed her at lunch and dinner time. Joanie was very deaf, wheelchair bound due to arthritis and had a diagnosed dementia. The staff cared for Joanie in a way which indicated that they thought she was

able to articulate her wishes. Her family members thought this was not the case. They felt clearly that she had lost the capacity to hear and understand what was being said and additionally was unable to express her wishes.

Her daughter and granddaughter felt it was important to write a Plan of Care so that they, the GP and staff were clear about the types of care they believed Joanie would have wanted and that everyone shared that understanding.

They discussed and documented options regarding cardio-pulmonary resuscitation and levels of care but they were quite surprised that feeding was included as an item. Following an explanation, they decided to leave the feeding section blank. However, they spoke to the staff two weeks later, having considered the issue as a family and having reflected on what they felt Joanie would have wanted. They decided on oral and supplementary feeding, but not tube or intravenous feeding. They felt this was what she would have wanted. They added this to the Plan of Care.

Joanie's condition deteriorated unexpectedly while her daughter was undergoing major surgery. Joanie's granddaughter and the nursing and medical staff felt confident in the care being given to Joanie, having had these discussions and documenting the Plan of Care.

You as the 'person responsible' have taken a great deal of time and care to consider and now write this Plan of Care. We suggest that you keep a copy for yourself and give a copy to everyone who will play a part in the care of the patient. A copy of the Plan of Care should always accompany the patient should they need to be moved to any other place like a hospital or any other care facility.

You always have the right to change the plan but also to be informed of changes to the patient's health and to be asked to give or withhold consent to specific treatments that may be proposed in the future.

8

A glossary of terms

‘Active level of care’ means being treated in hospital and having all possible treatment, including investigations and surgical operations. The patient will not be put on a ventilator unless they are having surgery or recovering from surgery.

Advance care directive (ACD) is a document in which a person gives instructions about their future healthcare. It comes into effect only when the person is no longer capable of making their own decisions.

Advance care planning is a process enabling a person to express wishes about their future health care in consultation with their health care providers, family members and other important people in their lives. An advance care directive can be part of this process.

Aged care home: see Residential aged care.

Brain death means there was a period when no blood supply or oxygen went to a person’s brain. The brain cells die and cannot grow or be replaced. The brain has stopped functioning and will never function again. Other organs such as the heart, kidneys and lungs may still be functioning and the patient may be on a ventilator. By law, brain death means that someone has really died. There are a number of tests, including brain function and reflexes, that specialist doctors can make to be absolutely certain of this. Brain death is an irreversible condition.

Capacity (competence) and **incapacity (incompetence)** are not absolute concepts. A capable adult can include someone with a mild intellectual disability or in the early

stages of dementia. In general, the more complex the legal document or decision, the greater the capacity to reason would need to be, although some assistance may be given.

Coma is where someone is unconscious but they will still react to certain things. Tests, such as shining a light into the eye, produce a reaction that shows the brain is still functioning and receiving a blood supply. A coma is very different from brain death, because it is possible the patient will regain consciousness. Medically and legally, a person in a coma is considered to be alive. Coma is a potentially reversible condition. Outcomes may range from full recovery through to a permanent vegetative state.

CPR (Cardio Pulmonary Resuscitation) can be used if the heart stops beating. It could involve mouth to mouth resuscitation and heart massage. It could also involve drugs being injected into veins, electric shocks to the heart and a breathing tube being put into the throat.

Dementia is the term used to describe a condition where a variety of different functions of the brain such as memory, thinking, decision making, recognition, language, planning and social skills deteriorate over time. The most common type of dementia is Alzheimer's disease, but there are many other types with different causes.

Many people worry about becoming forgetful. However, the loss of memory with dementia is different from normal forgetfulness. Unlike normal forgetfulness, dementia is accompanied by a decline in mental ability and having dementia makes it more difficult for people to function in everyday life.

Although some young people have dementia, this is rare, and most people

who have dementia are over the age of 65. About one in twenty people over this age have dementia and this rises to about one in five among people over 80.

Nearly everyone who has dementia will get worse over time. The progression of dementia can be described in four phases. Some of the conditions in each stage are as follows:

Mild – The person may be developing some problems with their memory and or personality. They may have difficulty travelling to new locations or become lost. They may misplace or lose things, or have less ability to carry out activities involved in banking, shopping or bill payment.

Moderate – The person may require assistance with more complex tasks such as bathing as they may have difficulty adjusting the water temperature, turning on taps etc. Toileting may be difficult as the person may be unable to wipe themselves properly or dispose of toilet tissue appropriately. The person may experience difficulties in finding words or suffer from agitation or insomnia.

Severe – In this stage the person may become incontinent of urine or faeces on more than one occasion. Their ability to maintain a conversation may become more limited. They may become resistant to care. Eating may become more difficult and there may be a reduced ability to recognize food, cut up their meals, use utensils and coordinate chewing. At this stage people may need assistance to walk as their walking becomes unsteady. This may lead to falls.

Terminal – The person's speech ability is limited to the use of only a few words, or they may repeat one word over and over. The person may develop swallowing difficulties. They may not be

able to sit up without assistance. Some people may be unable to smile or hold up their head independently. Recurrent episodes of infections are likely to occur.

Delirium is an illness characterized by a sudden deterioration of brain function. It is a serious medical problem which comes on rapidly. It is often brought on by an underlying medical illness or medications. It results in a reduced ability to focus, sustain or shift attention. Hallucinations or delusions may also develop. Delirium is associated with a gradual deterioration of physical and brain function. It is important for families and carers to note any sudden change in brain and other functioning as this may be due to delirium and seek medical care. Delirium can occur as a complication of dementia. There is a high death rate from delirium.

Enduring guardian is someone you appoint in accordance with the provisions of the NSW *Guardianship Act 1987*, to make personal, health or lifestyle decisions on your behalf, when you are not capable of doing this for yourself. You can appoint one or more guardians and they can be appointed to act either jointly or separately.

Enduring power of attorney is a legal document signed by a person appointing someone else as their agent with authority to carry out those instructions relating to their business, property or financial affairs that the person has asked them to carry out. Unlike a power of attorney, it remains in force even if the person becomes unable to make their own decisions.

Euthanasia is the active and deliberate intervention by a second party to end life, at the expressed wish of the first party. It is quite different from discontinuing or not starting a

treatment at a patient's explicit request, given verbally or through an advance directive. Active euthanasia is illegal in all states and territories of Australia.

Feeding (Intravenous) means that, if necessary, the patient would be given fluids and/or nutritional supplements through a vein.

Feeding (Oral Feeding) means the patient would be given food and fluids by mouth and, if necessary, helped to eat, for example with a spoon. The patient would not be given food through a tube, nor would fluids be injected into the veins.

Feeding (Supplementary) means that in addition to oral feeding the patient may be given additional vitamins and high energy drinks.

Feeding (Tube) means that, if necessary, the patient would be fed through a tube. This could be a tube into the stomach through the nose (a nasogastric tube) or it could be a tube which goes through the skin into the stomach (a gastrostomy tube).

(The) **Guardianship Tribunal** is a legal tribunal. It appoints guardians and financial managers for people aged 16 years and over who are incapable of managing their personal affairs, and have no appropriate or safe informal mechanisms in place. The Tribunal may also act as a substitute decision maker in relation to medical and dental treatment proposed by others for adults 16 years and above who cannot give a valid consent to their own medical or dental treatment.

Hostel: see Residential aged care.

'Intensive level of care' means everything possible will be done to maintain your life. If necessary, you will go into an Intensive Care Unit and all

possible means of life support will be used, including appropriate surgery and transplants.

'Limited level of care' includes everything in 'palliative level of care', but you may also be given antibiotics, have tests and investigations, and be treated in hospital. You would not have elective surgery except for comfort or pain relief. You would not go into an Intensive Care Unit or be put on life support systems (such as a breathing machine).

Living will is another term for an advance care directive.

No CPR means that if your heart stops beating no attempt will be made to resuscitate you or restart the heart.

(The) **NSW Trustee and Guardian** is an independent statutory official, separate from the Guardianship Tribunal, who can be appointed to protect and administer the financial affairs of people who are unable to manage for themselves. The NSW Trustee and Guardian may be appointed by the Supreme Court, the Guardianship Tribunal, a magistrate or the Mental Health Review Tribunal. The Public Trustee NSW and the Office of the Protective Commissioner merged on 1 July 2009 to form NSW Trustee and Guardian (NSWTG).

Nursing home: see Residential aged care.

'Palliative level of care' aims to keep you free from pain and discomfort as much as is possible. Any treatments or investigations will be only be for pain relief and to ease your discomfort.

Person responsible is a substitute decision maker for medical and dental treatment for a person aged 16 years old or over who is unable, for some

reason, to give valid consent for their own medical or dental treatment.

Physician-assisted suicide is when a physician (doctor) supplies a patient with the information and/or means to take their own life. Physician-assisted suicide is illegal in all states and territories of Australia and is not discussed in this book.

Power of attorney is a legal document signed by a person appointing someone else as their agent with authority to carry out those transactions to do with their business, property and financial affairs that the person has asked them to carry out. It ceases to have effect when the person loses the capacity to make decisions for themselves. (See also 'enduring power of attorney' and Department of Ageing, Disability and Home Care, *Planning Ahead Kit*, page 34).

(The) **Public Guardian** is an independent statutory official, separate from the Guardianship Tribunal, who can be appointed as a guardian for a person with a disability, in circumstances where it is appropriate to appoint some other person as guardian. The Public Guardian can be appointed by the Guardianship Tribunal.

Residential aged care includes hostels (sometimes called low care aged care facilities, homes or services) and nursing homes (sometimes called high care aged care facilities, homes or services). They provide specialised care for dependent frail older people, including those with advanced dementia.

Special Medical Treatments

There are two types and include:

1. Sterilisation, termination of pregnancy, prolonged use of addictive

drugs (unless for cancer or terminal care), aversive treatments (which provide a negative stimulus), and

2. New treatments that have not yet gained the support of a substantial number of practitioners who specialise in this area. This includes

- Psychotropic (for behaviour modification) medications when the treatment is outside the usually accepted use in terms of dosage and combination, given the person's condition, and
- Androgen (hormone) reducing medications to control behaviour.

Substitute decision maker is a person who makes health and personal care decisions for someone who has lost the capacity to make their own decisions.

A **Will** is a legal document that a person capable of making a decision signs to express how they wish their property and other assets to be disposed of after they die.

9

Where to get more information

Alzheimer's Australia NSW

www.alzheimers.org.au

PO Box 6042
North Ryde NSW 1670

Tel: (02) 9805 0100

24-hour Dementia Helpline:
Freecall 1800 100 500

Alzheimer's Australia provides information about legal issues related to dementia, including the booklet *Legal Planning and Dementia*. It includes useful information on planning for future medical and financial decisions and is available by phoning the Dementia Helpline. It is also available on their website along with a summary of legal resources for each state – go to *Publications & Resources*.

Advance Care Directive Association

www.advancecaredirectives.org.au

Publisher of *My Health, My Future, My Choice: An Advance Care Directive for New South Wales*

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NSW 2038

Phone 0423 157 003

This phone number is only for requests for order forms. The Association cannot give personal advice about making advance care directives.

Australian Government Department of Health and Ageing

Dementia Resource Guide.

www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm

Guardianship Tribunal

www.gt.nsw.gov.au

Level 3, 2a Rowntree Street
(Locked Bag 9)
Balmain NSW 2041

Tel: (02) 9556 7600 (metropolitan area)

Freecall 1800 463 928 (outside
metropolitan area)

TTY: (02) 9556 7634

Provides information about how to appoint an enduring guardian or an enduring power of attorney. Contact the Tribunal or visit their website – go to ‘Plan for your Future’. There are also helpful publications about consent to medical/dental treatment – go to ‘Publications’.

Land and Property Information Division

(NSW Department of Lands)

www.lands.nsw.gov.au

1 Prince Albert Road
Queens Square
Sydney NSW 2000

Tel: (02) 9228 6666

Provides information about how to register a power of attorney and the fees involved. The form to appoint an enduring power of attorney is available from their website.

Law Society of NSW

www.lawsociety.com.au

170 Phillip Street
Sydney NSW 2000

Tel: (02) 9926 0333 (main switchboard)

The Solicitor Referral Service of the Law Society of NSW can provide the names of private solicitors and legal services in your area. The service is provided by phone and on the website.

Tel: (02) 9926 0367 (metropolitan area)

Freecall 1800 422 713 (outside the
metropolitan area)

The Solicitor Referral Service also operates a recorded information line, providing legal information, including Powers of Attorney and Making a will.

Tel: 1300 888 529

NSW Health

www.health.nsw.gov.au

For further information on Advance Care Directives or planning for care at the end of life, contact:

NSW Health Department
Health Services Performance
Improvement Branch
73 Miller Street
North Sydney NSW 2060

Tel: (02) 9391 9000

HSPIB@doh.health.nsw.gov.au

NSW Trustee and Guardian (NSWTG)

www.tag.nsw.gov.au

Central Office:
19 O'Connell Street
Sydney NSW 2000

GPO Box 7
Sydney NSW 2001

Tel: (02) 9252 0533

Fax: (02) 9231 4527

For other suburban and country offices
see website or phone books.

Office of the Public Guardian

www.lawlink.nsw.gov.au/opg

160 Marsden Street
Parramatta NSW 2124

Tel: (02) 8688 2650

Freecall 1800 451 510

TTY: 1800 882 889

Seniors Information Service

Tel: 13 12 44

This service provides confidential information about a wide range of issues affecting older people. Callers can be referred to appropriate services if needed.

Plan of Care

This document has been developed to provide guidance for the future care of the patient with dementia as described in the book "A Plan of Care". It should be reviewed every 12 months or when there is a major change of medical condition.

This plan of care has been developed in regard to the future care provisions for:

_____ (the patient) ____/____/____
Given name/s Family name Date of birth

I am the 'person responsible' for healthcare decisions and for consenting to treatment (as identified by the NSW Guardianship Act (1987)) for this patient:

Name _____

Phone: Day _____ Evening _____ Mobile _____

If there is more than one 'person responsible' then please add details below:

Name _____

Phone: Day _____ Evening _____ Mobile _____

Name _____

Phone: Day _____ Evening _____ Mobile _____

I, Doctor (print name) _____ confirm that this person is incapable of consenting to medical treatment because

- He/ she cannot understand the nature and effect of the treatment and/or
- He/ she cannot indicate whether or not he/ she consents to treatment (tick box/es)

Signature _____ Date _____ Phone _____

Other people involved in developing this Plan of Care were:

Name _____

Position/Role _____ Phone _____

Name _____

Position/Role _____ Phone _____

Name _____

Position/Role _____ Phone _____

I / we:

1. want the patient to be kept comfortable and as free from pain as possible
2. understand that any treatment to which I/ we consent must be in the best interests of the patient
3. understand that this treatment must reflect the patient's previously expressed wishes as far as these are known

The patient's previously expressed wishes and values are (if any known) _____

Name of person/s who has supplied this information

4. understand that I/ we cannot consent to special medical treatment (see glossary chapter 8 of "A Plan of Care") nor can I/ we override the patient's objections to a treatment
5. understand that the treatment options documented may not necessarily be offered if the treating doctor considers those treatments to be futile.

The patient's current medical condition (situation) is

CPR	Answer Yes or No	Comments/ Special considerations
<p>CPR:Cardio-Pulmonary Resuscitation</p> <p>Used when the heart stops beating. May include mouth to mouth resuscitation & heart massage, drugs and IV lines for fluid via a needle in the veins, electric shocks to the heart, breathing tube in the throat.</p>		

Levels of Treatment	Answer Yes or No	Comments/ Special considerations
<p>Palliative:</p> <p>Aims are to keep the patient free from pain and discomfort. Any investigations or treatments will be to provide pain relief & ease discomfort.</p>		
<p>Limited:</p> <p>= Palliative + antibiotics and investigations. May include treatment in hospital, if necessary. Does not include elective surgery except for comfort or pain relief. No life support machines or intensive care.</p>		
<p>Active or Surgical:</p> <p>= Limited + transfer to hospital & all possible treatment including operations. Breathing machine (ventilator) used only for the purpose of surgery, or recovery from surgery.</p>		
<p>Intensive:</p> <p>Everything possible will be done to maintain life. If necessary, intensive care unit and all possible means of life support will be used including surgery, transplants, dialysis and ventilator support.</p>		

Levels of Feeding	Answer Yes or No	Comments/ Special considerations
Oral or Basic: Food & fluids by mouth, helped to eat and drink. No food via a tube or intravenous line (drip) into veins.		
Supplementary: Oral + additives for the patient's requirements. May include additional vitamins and high energy drinks.		
Intravenous (IV): Supplemental + fluids & nutritional supplements given through a vein.		
Tube: IV + a tube into the stomach through the nose (nasogastric tube) or a tube which goes through the skin into the stomach (gastrostomy tube).		

I / we would prefer that _____
Name of patient

should where possible have their care provided at _____

Other issues which are important for care of this patient are: *(This may include personal care, food preferences, music, spiritual needs and other issues)*

Names and signatures of those involved in Plan of Care

Name _____

Signature _____ Date _____

Name _____

Signature _____ Date _____

Name _____

Signature _____ Date _____

A Plan of Care

Feedback form

We welcome your feedback on the 'A Plan of Care' book so that we can improve future versions of the book and the form.

1. Overall, how easy or difficult was it to understand the information in 'A Plan of Care'?

- Very easy Quite easy A bit difficult Very difficult

2. Were there any words, sentences or parts of the book that you found particularly difficult to understand?

- Yes No

If **Yes**, please write these below (including the page number(s)):

3. Did the book help you to make decisions on behalf of the patient?

- Very much Quite a lot Only a little Not at all

If **Only a little** or **Not at all**, what other information or guidance would have helped?

Continued overleaf

4. Did you fill in the form (or try to fill in the form) at the end of the book?

- Yes No

If **Yes**, did the book help you to fill in the form?

- Very much Quite a lot Only a little Not at all

5. Did you discuss the book with:

- Family and friends The patient's GP Another health professional
(nurse/social worker etc)

If so, did the book help you in these discussions?

- Yes No

6. How would you describe yourself?

- Carer/substitute decision maker of a person with dementia
- Health or Welfare professional
- Other (please specify)

7. Do you have any other feedback or suggestions about how we could improve this book?

(Continue on a separate sheet if needed)

**Thank you for taking the time to complete this survey.
Please post the completed form to**

ACD Association
18/113 Johnston Street
Annandale NSW 2038