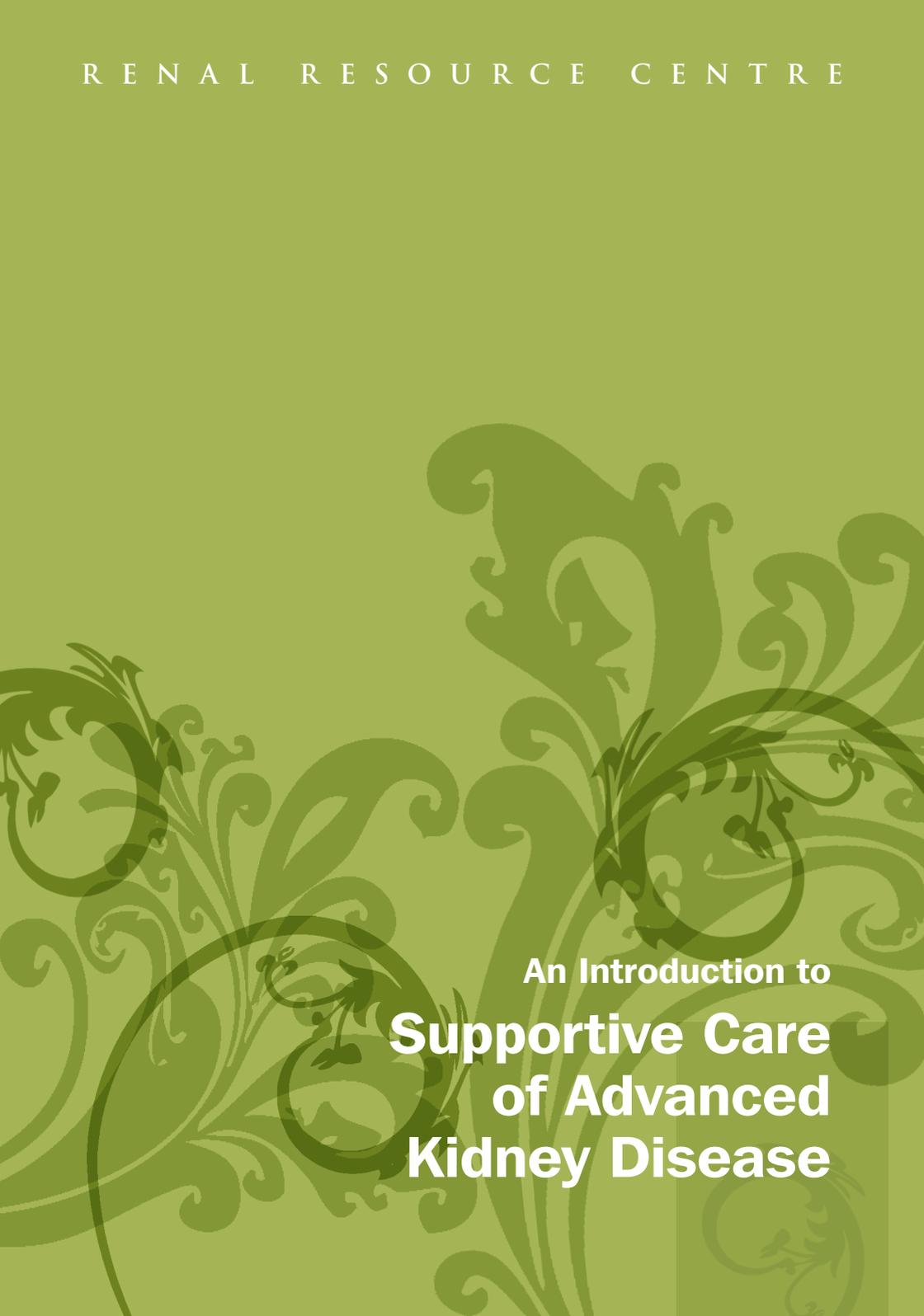


RENAL RESOURCE CENTRE

A decorative floral pattern in a lighter shade of green, featuring intricate scrollwork and leaf-like motifs, is overlaid on the background.

An Introduction to
**Supportive Care
of Advanced
Kidney Disease**

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of Advanced
Kidney Disease**



Foreword

Having been given a diagnosis of end stage kidney disease (kidney failure), you will be asked to contribute towards important decisions about your future medical care. These decisions will focus upon what treatment options will be appropriate and beneficial for you.

Dialysis can prolong life but does not cure kidney failure. When examining each of the treatments available for kidney failure, it is important to consider whether dialysis will help you to achieve the quality of life that you consider acceptable.

For some patients, who have serious and complex illnesses or who are frail and elderly, dialysis treatment may be exceptionally burdensome with little benefit to either survival or quality of life. People who find themselves in this situation are often worried and unsure about what will happen and how long they will live if they choose not to have dialysis treatment.

This booklet explains what to expect from treatment and how to plan your future care should you not have dialysis. It will provide a basis for you and your family to discuss your individual circumstances and treatment preferences with your renal physician, general practitioner and other members of your health care team. These discussions will allow you to participate in your health care by making an informed choice about which direction is most suitable for you and to plan for the future.

Supportive care (treatment of kidney failure without dialysis) aims to preserve kidney function for as long as possible and to maximise your quality and enjoyment of life. The staff caring for you will assist you in your choice and will respect your wishes, well-being and dignity, whatever treatment you choose.



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An Introduction to Supportive Care of Advanced Kidney Disease

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Introduction

A diagnosis of irreversible kidney failure or end stage kidney disease will be followed by discussions with your renal physician and your family about which treatment option is most appropriate for you. This choice will take into account such factors as your physical and psychological health, your social situation, your lifestyle, your age and your quality of life.

These discussions may take place many months before symptoms appear or treatment is required. It is important that you understand how dialysis is performed before making any treatment decisions. Renal units conduct regular information sessions on treatment options to assist with this decision-making process. Booklets providing more detailed information on dialysis and transplantation are available from the Renal Resource Centre. *It is recommended that you read them to assist your decision making.*

The three treatment options for kidney failure are dialysis, followed by kidney transplantation (in selected patients) or supportive care without dialysis. Deciding whether or not to have dialysis and if so, what kind, is the first step in ensuring your future medical care is tailored to your special needs. It is very useful for you to be well informed about these treatment options, so that you can discuss them with your renal physician and with the other renal staff you will meet.

Often these discussions need to take into account particular medical issues, as well as social circumstances that favour one sort of dialysis over another. Sometimes it might be suggested that dialysis is not a good option at all. Your input into these discussions is essential and your wishes will be respected, as much as possible within the treatment options available.

It is common for people to want to delay these often difficult decisions but ultimately, earlier discussion of treatment directions will make this transition easier for you and your family. These discussions also assist the renal staff, who will help in your care.

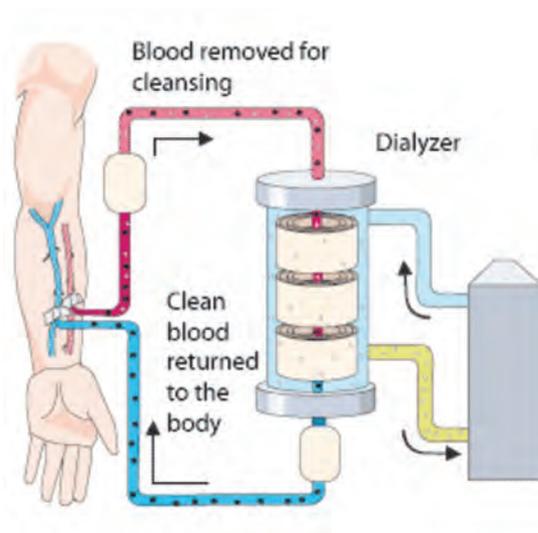
Treatment Options for Kidney Failure

1. Dialysis (Haemodialysis or Peritoneal Dialysis)

Dialysis treatment removes waste products and excess fluid from the blood using a semi-permeable membrane. It is a chronic treatment and does not cure kidney failure. There are two forms of dialysis: haemodialysis and peritoneal dialysis.

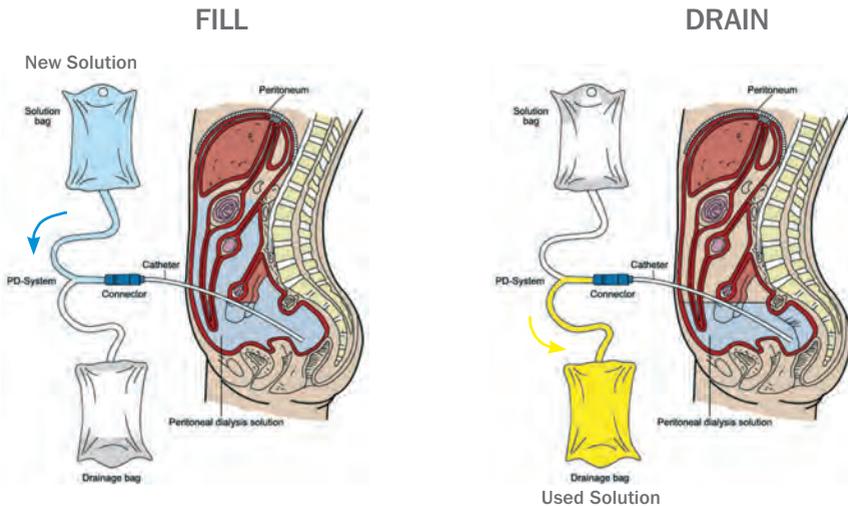
Haemodialysis is performed using a haemodialysis machine. Treatment accesses the circulation via two needles. Blood passes many times during a treatment through an artificial kidney. This is made up of thousands of hollow fibres, made of semi-permeable membrane. Treatment is typically performed for four to six hours at least three times per week. This treatment can be performed at home after specialised training of at least six to eight weeks' duration. At home, longer and more frequent dialysis is possible, usually through nocturnal (overnight) dialysis.

When home haemodialysis is unsuitable, due to medical or social reasons, haemodialysis can be undertaken in hospital dialysis units or community satellite dialysis units. Consideration needs to be given to how transport to and from the dialysis centre will be arranged and tolerated. Six journeys per week are required on an on-going basis.



Peritoneal dialysis is performed by running fluid through a tube into and then out of your abdominal cavity. The lining of the abdominal cavity (the peritoneum) acts as a semi-permeable membrane to separate the fluid you run in, from your blood stream. Impurities cross out of your blood, through the membrane and into the fluid, which is then drained out after about six hours “dwell time”. With peritoneal dialysis, there is no need to use needles to access the blood stream, as there is with haemodialysis.

This treatment is performed every day at home and is a chronic treatment. It does not cure kidney failure. It can be performed during the day as continuous ambulatory peritoneal dialysis (CAPD) or overnight as automated peritoneal dialysis (APD), using a cycler machine. Peritoneal dialysis training takes one to two weeks.



Peritoneal Dialysis works inside the body. Dialysis solution flows through a tube into the abdominal cavity where it collects waste products from the blood.

Periodically, the used dialysis solution is drained from the abdominal cavity, carrying away waste products and excess water from the blood.

2. Kidney Transplantation

Kidney transplantation is the process by which a kidney is removed from a living or deceased donor and transplanted into a matched recipient. Transplantation can sometimes occur before dialysis commences (pre-emptive) if a living donor is available. Powerful, anti-rejection medication must be taken for life to prevent the kidney being rejected by the recipient's immune system.

Transplantation is offered to patients who do not have other serious medical conditions, which could worsen due to transplant medication and who are well enough to be able to undergo the major surgery involved. Patients also need to have a life expectancy that is long enough to make undergoing the transplant worthwhile. Kidney transplantation may require more than one hospital admission and initially requires very frequent and regular follow-up care.

3. Supportive Care

Supportive care is sometimes referred to as medical management or conservative care of end stage kidney disease. It lets the disease run its natural course and focuses on treating symptoms. Dialysis treatment is not used. Treatment relies on dietary management and medications. As with dialysis and transplantation, your health care team will also treat the psychological, emotional and social issues that are associated with your kidney disease.

Supportive care aims to preserve kidney function for as long as possible but cannot stop the decline in kidney function. It does not replace kidney function. Dialysis and transplantation, whilst effective treatments, do not fully replace kidney function and do not cure the underlying disease or associated illness.

Choosing supportive care means that you accept that your loss of kidney function will progress and there is a high chance that this might lead to your death. On the other hand, in many cases, choosing dialysis would not lead to any longer survival.

Supportive Care of End Stage Kidney Disease

Choosing Supportive Care

The decision to choose supportive care is made in consultation with your renal physician. It is an appropriate choice for some people when dialysis is very unlikely to improve their quality or length of life and may even significantly reduce their overall enjoyment of life. Studies have shown that prolonged supportive care of frail elderly patients with end stage kidney disease can achieve similar clinical results and quality of life as comparable patients receiving haemodialysis. In other words, if you are frail and elderly and have a complicated medical history, you may live just as long being supportively managed as you would with dialysis treatment. This may also apply to people of any age who have other complex illnesses in addition to kidney disease.

Occasionally, family members may have unrealistic expectations of what dialysis can achieve and may not easily accept your decision not to have dialysis or your physician's recommendations for supportive management of your kidney failure. They may believe that they should defend your right to access dialysis, no matter what its effect on your quality of life and overall well-being. In other cases, family members and medical staff may recommend dialysis, when you are committed to a more conservative approach. Sometimes, reaching agreement can be difficult.

Family conferences with medical and other staff are useful in helping family members to understand all factors involved and to weigh up the pros and cons of dialysis treatment versus supportive care. *In the event of disagreement, your comfort, dignity, wishes and values should be paramount and respected and supported by all parties concerned.*

If you choose supportive care, your renal physician will continue to provide ongoing treatment of your kidney disease. He/she may refer you to a palliative care physician and team for specialised symptom management. Both teams will work together to achieve the best outcomes for you and your family.

Treatment decisions can always be reviewed. If you initially choose supportive care but later change your mind, a decision to start dialysis may be discussed with your physician. Likewise, if you start dialysis but decide that it is not as you expected, you can withdraw from dialysis treatment.

Making an Informed Choice

Do not rush into making a decision about your treatment options. Gain as much information as you can through reading and education sessions organised at your hospital. Be guided by your renal physician, general practitioner and other members of your health care team, who know your medical and social history. You may also wish to discuss your options with your spiritual adviser.

It is expected that you and your family will require assistance when making decisions about which treatment will best suit you. This is a time when you may feel fearful, depressed, angry and confused and even hopeless. When weighing up the advantages and disadvantages of each treatment, realistic discussion about what each treatment can offer is very important. This way you can be sure you are fully informed and have thoroughly explored *all* possibilities.

Staff can help you to clarify all the medical information, and talk with you about your thoughts and feelings. Your emotional reactions and those of your family can be very intense. Your family may have concerns that need to be addressed and resolved. The renal social worker can provide counselling to you and family members about these issues. This will help in your decision making. It will also explore the practicalities of each treatment choice and the services that may assist you, whichever path you take.

It is important that you do not make a decision to decline dialysis when you are severely depressed or not fully aware of the consequences of such a decision. In some circumstances, it may be useful for you to speak to a psychiatrist about the effect feelings of depression or anxiety might have on your ability to make the best choice for your circumstances.

Kidney Disease Symptom Management

Advanced Chronic Kidney Disease

When kidney function is severely impaired and reaches 15% of normal function or less, most people will experience some symptoms of kidney failure. However, these range from being relatively minor to quite severe.

Symptoms that some people experience include itch, nausea, loss of appetite, tiredness, pins and needles in the hands or feet, bruising, fluid retention with ankle swelling and shortness of breath. Dialysis generally improves some of these symptoms but others usually require additional drug treatment.

If you elect not to have dialysis and choose conservative care of your kidney disease, most of these symptoms will be successfully managed with medications and diet. However, your health will decline as your kidney function deteriorates. It is difficult to predict how long you will live, as every situation is different. Your renal physician may be able to give a general estimate, based on such things as your general health and the rate of decline of your kidney function.

Symptom Management

When kidney function is severely reduced, some of the following symptoms can be experienced at different times and with varying severity. Palliative care specialists and your renal physician are experts in managing and reducing these symptoms so that you can remain comfortable. It is important to remember that people on dialysis commonly experience some of these symptoms too.

- **Lack of Energy or Tiredness**

The kidneys make erythropoietin (EPO), a hormone which helps the bone marrow to make red blood cells. As kidney function declines, the amount of EPO produced by the kidneys decreases and the number of red blood cells is reduced. Anaemia is the medical term used for this.

Anaemia can cause tiredness, lethargy, possible breathlessness and a reduced ability to exercise. EPO is available as an injection and regular doses will improve your energy levels and reduce other anaemia-related symptoms. Your renal physician will also treat other causes of anaemia, such as dietary deficiencies of iron, folate (folic acid), and vitamin B¹². Most people who use erythropoietin are also given iron (intravenously or orally) to prevent iron deficiency.

• **Metallic Taste, “Uraemic” Breath and Loss of Appetite**

A build-up of wastes in the blood (uraemia) can make food taste different and cause a “uraemic” breath. Many people notice that they stop liking to eat meat or lose weight because they just do not feel like eating.

• **Nausea and Vomiting**

Nausea and vomiting can occur as kidney function declines. The renal dietitian will be able to help you obtain the nutrients and calories you need. Smaller and more frequent meals and the avoidance of certain foods may be recommended. Medications can also be prescribed to help reduce these symptoms.

• **Itchy Skin**

Itchy skin is a common symptom for people with kidney disease. Chemical imbalances and changes to nerves and dry skin all contribute to this symptom. The prescription of medications to help improve chemical balance and reduce nerve impulses, as well as skin creams to treat dry skin can help.

• **Sleep Disorders and Restless Legs**

Many people on dialysis or with end stage kidney disease not on dialysis, have trouble sleeping at night because of aching, uncomfortable, jittery, or “restless” legs. A strong impulse to kick or thrash the legs is common. Moderate exercise during the day may help but exercising a few hours before bedtime can make restless legs worse. Sleep patterns may change also. Sleeping more during the day and less at night is not unusual. Some people find relief through massages or warm baths. Medications to minimise restless legs and improve sleep can be prescribed.

• **Shortness of Breath**

Trouble catching your breath can be related to the kidneys in two ways. Firstly, extra fluid in the body can build up in the lungs. Secondly, anaemia (a shortage of oxygen-carrying red blood cells) can leave your body oxygen-starved and short of breath. Medication to reduce fluid retention and to treat anaemia can be prescribed.

• **Feeling Cold**

Anaemia can cause a feeling of coldness all the time, even in a warm room. Treating anaemia with EPO will help to control this symptom.

- **Swelling**

Failing kidneys do not adequately remove fluid. Extra fluid can build up in your body causing swelling in the legs, ankles, feet, face, and/or hands. Medications and dietary fluid restriction can help to control this.

- **Drowsiness**

When uraemic toxins (waste products) accumulate in your brain, memory and concentration can sometimes be affected. As kidney failure advances over weeks and months, confusion may become noticeable and making decisions can become difficult. Drowsiness is common and becomes more frequent as kidney function declines.

- **Pain**

Death from kidney failure is usually painless and peaceful. It involves slipping into a coma (deep sleep) from which you will not wake up. Some people may experience pain from other medical conditions. Many very effective treatments are available for controlling pain in these circumstances.

- **Emotional Responses**

Chronic illness is associated with a range of feelings. You and your family may experience a variety of responses at different times throughout the course of your kidney disease. These can include shock, denial, anger, depression, anxiety, guilt and fear, especially about what the future may hold for you and those you love. These are perfectly normal reactions. Talking about your thoughts and feelings with your social worker or physician and learning about what to realistically expect, can make dealing with them easier. Very often, what we expect is far worse than the reality.



Nursing and Community Services

Maintaining Independence at Home

As your health declines, independence at home may become more difficult. To ensure your comfort and ability to manage as independently as possible, community home care and nursing services are available to support you and your family.

These services include nursing, personal care, cleaning, grocery shopping and carer respite. Each State and Territory provides these services. In addition to home nursing services, specialist community-based palliative care teams can help to ensure your symptoms are well managed and your family is practically and emotionally supported.

Commonwealth Government Community Services

These have been established to support care at home and include:

- **Commonwealth Respite and Carelink Centres**

These are located around Australia to help people find suitable care and support to continue living independently in their own homes. Centre staff can provide information about community, aged care, disability and other support services. They can also help to arrange respite care when carers need a break, including in-home, emergency and other flexible respite options.

www.commcarelink.health.gov.au

Freecall: 1800 052 222 (business hours)

Emergency respite support outside standard business hours

Freecall: 1800 059 059

Department of Veterans' Affairs Veterans' Home Care

The Veterans' Home Care (VHC) programme provides low level, home care services to eligible veterans and war widows and widowers. The programme provides assistance with cleaning, personal care, grocery shopping and respite care. To receive this service, you must receive a pension from the Department of Veterans' Affairs.

www.dva.gov.au

Freecall: 1300 550 450

End of Life Nursing and Palliative Care

If long-term care at home eventually becomes unmanageable for your partner or family, even with the help of community services, then consideration of alternative arrangements, such as nursing home placement, is usually advised. In some but not all metropolitan and rural areas, community based palliative care teams can provide guidance and support to staff in nursing homes.

Palliative care is provided at the end of life by specialist physicians, nurses and other health care professionals to ensure symptoms are well managed and your physical, emotional and spiritual needs are met. Where such services exist, this expert care and advice can be provided at home, hospital or in specialist palliative care units.

Admission to a specialist palliative care unit or hospice is only ever considered or advised when symptoms are very complex and difficult to manage and/or life expectancy is less than one month.

If presentation to a hospital emergency department is necessary for any reason, the most suitable on-going care arrangements will be made in consultation with you and your family. These may include admission to hospital, transfer to another health care facility or discharge home with appropriate nursing and community services.

• Palliative Care Australia

Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care for all at the end of life. It provides resources and information about local community palliative care.

www.palliativecare.org.au

Telephone: **02 6232 4433**

Your general practitioner, renal physician and social worker can advise you about the most suitable services and care as your circumstances change.

Planning for the Future

For many people, thinking about end-of-life issues can be difficult, especially when their health is still good and the possibility of developing a serious illness is remote. However, being diagnosed with kidney disease that will eventually lead to kidney failure, is very serious and confronting. The need to plan for the future becomes more urgent.

It is not at all unusual for people diagnosed with serious chronic illness to have frequent thoughts about their mortality. Most people worry that they will die as a result of having kidney disease, whether they choose dialysis, transplantation or supportive management. Discussing and planning for end-of-life issues can be especially difficult, as it requires taking some action. However, once these issues have been discussed and plans have been made, a sense of relief often follows. This is because much of the uncertainty that was causing the anxiety has been removed.

It is wise to plan for future care when you are still able to think clearly and rationally and are able to make your wishes known.

Planning for the future may include:

- Identifying a “Person Responsible” for consent to treatment
- Advance Care Planning
- Writing an Advance Care Directive
- Appointing an Enduring Guardian
- Appointing an Enduring Financial Power of Attorney
- Preparing a Will

“Person Responsible”

The medical team has a legal responsibility to obtain your consent for any proposed medical treatment. If you are unable to give consent, the medical team will seek consent from your “person responsible”.

A “person responsible” is not necessarily your “next of kin”.

A “person responsible” is either:

- a guardian (including an enduring guardian) who has the function to consent to medical, dental and health care treatments or if there is no guardian:

- the most recent spouse or de facto spouse with whom the person has a close, continuing relationship. ‘De facto spouse’ includes same sex partners or, 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 or if there is no carer:
- a relative or friend who has a close personal relationship with the person.

If a person identified as being a “person responsible” declines in writing to exercise the function of “person responsible” or a medical practitioner or other qualified person certifies in writing that the person identified as “person responsible” is not capable of carrying out those functions, then the person next in the hierarchy is the “person responsible”.

Advance Care Planning

Advance care planning involves careful consideration of your values about your life and health and medical treatment. It allows you to plan and communicate how you would like to be medically treated at some future time, if you were incapable of making those decisions for yourself. It can be as simple as discussing your wishes about your future health care with your health care providers, family, friends and other important people in your life.

An advance care plan offers you an opportunity to say now what life-prolonging medical treatment you would and would not want in the future. If, in the future, you are unable to express your wishes about treatment, your doctor and family will know what you would have wanted or how you would have liked the choices to be made.

You may make your wishes known through these discussions or you may wish to formalise them by giving your instructions in writing. This is called an “advance care directive”.

Advance Care Directive

An advance care directive is sometimes referred to as a “living will”. It is a way of recording your health and personal care instructions for family members, doctors and health care providers at a particular point in time.

It allows you to record now the type of care and treatment you would want if in the future, you are unable to communicate or if you lose the ability to make decisions for yourself. It also enables those close to you to communicate your wishes, with confidence.



An advance care directive is only used if you are unable to communicate or if you have lost the ability to make decisions for yourself.

You can compose the directive yourself or you can use a special form. You can record your wishes about end-of-life care and treatment and provide both general and specific instructions. For example, details about specific kinds of care and treatment.

The directive should be clear and up to date and written specifically to guide medical care. You may find it helpful to write the directive with the help of a medical practitioner or other health professional, such as a social worker. You can change the directive at any time and it is a good idea to review it regularly.

Distribute it to those who may possibly be asked to make decisions for you: your spouse, family, “person responsible” and your health care team.

For state specific forms and information:

Royal Australian College of General Practitioners

<http://www.racgp.org.au/guidelines/advancecareplans>

Austin Health Victoria Respecting Patient Choices

<http://www.respectingpatientchoices.org.au/>

Advance Care Directive Association Inc

<http://www.advancecaredirectives.org.au/>

Enduring Power of Attorney

An enduring power of attorney is a legal document through which you (known as the principal) can appoint a person (known as the attorney) to make decisions about your property or financial affairs. This means that they can operate your bank accounts, pay your bills and sell or buy property or shares on your behalf.

An enduring power of attorney is different to a “general” power of attorney, which ceases to have effect after you lose the mental capacity to make financial decisions. An enduring power of attorney will continue to have effect even after you lose mental capacity.

An enduring power of attorney cannot be used to make medical or lifestyle decisions for you. If you want to appoint someone to make medical or lifestyle decisions on your behalf, you will need to appoint an enduring guardian.

Enduring Guardianship

Enduring guardianship allows a legally appointed, substitute decision maker of your choice to make lifestyle and health care decisions, should you lose the capacity to make your own decisions at some time in the future.

If you wish to appoint an enduring guardian, you must sign a form of appointment. You can appoint one or more enduring guardians with the same functions on the same form. If you want to appoint two or more enduring guardians with different functions, you will need to fill out separate forms for each enduring guardian appointed.

You can choose which decisions you want your enduring guardian to make about your future health care. The enduring guardian will only take over if you are unable to make your own decisions because of an accident, disability or illness.

Will Preparation

A Will is a legal document which states your wishes regarding the distribution of your assets after your death. Your will should be clear, legally valid and up to date. You can change your Will as often as you like. The best way to change your Will is to make a new Will.

If you die without a Will, the law decides who gets your assets. This is called “dying intestate”.

Assets will usually pass to your surviving spouse/partner and children and then to next-of-kin. These rules apply to everyone and do not take into account an individual’s wishes or situation.

If there is no valid Will, an application must be made to the Supreme Court for “letters of administration”, rather than a grant of probate. A grant of probate is a court order giving the executor permission to carry out what the Will says.

For matters relating to Wills and Estates, Powers of Attorney, Enduring Powers of Attorney and Enduring Guardianship, it is a good idea to talk to your lawyer and/or financial adviser.

A Final Note

Reviewing Your Life

Reading this booklet may have stirred many thoughts and emotions about your life, your family and your spiritual beliefs. Speaking with your physician, other health care staff or spiritual adviser may help to clarify your thoughts and feelings and reduce anxiety.

An issue as complex as the choice to have or decline dialysis, can take time to examine and reach a decision. For this reason, you may revisit it several times. If you cannot reach a decision, don't worry. Speak further with your physician and other members of your health care team. Your social worker can provide counselling to you and your family to help clarify your thoughts and wishes and to resolve any differences of opinion within your family.

Use the blank space on the last page to write down any questions you now have after reading the booklet. You can use these to guide your discussions with your doctor, your family and others whose opinions and advice you value.

Information on end-of-life choices for patients and families:

www.caresearch.com.au

www.respectingpatientchoices.org.au

www.racgp.org.au/guidelines/advancecareplans

www.advancecaredirectives.org.au

www.palliative.org.au

www.kidneyeol.org

www.kidney.org.au

Any information provided does not constitute medical advice and is intended for information only. Consult a healthcare professional for specific treatment recommendations.

The Renal Resource Centre provides information and educational materials on kidney disease, dialysis and transplantation for patients and health professionals.

The primary objective of the Centre is to ensure that patients have easy access to such information, are well informed and can actively participate in their own health care. The Renal Resource Centre is committed to providing education and service to the renal community.

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Northern Sydney
Local Health District



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