Supportive Care for Kidney Disease

Information for Patients, Carers and their Families

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Acknowledgements

The contribution of the following clinicians is gratefully acknowledged.

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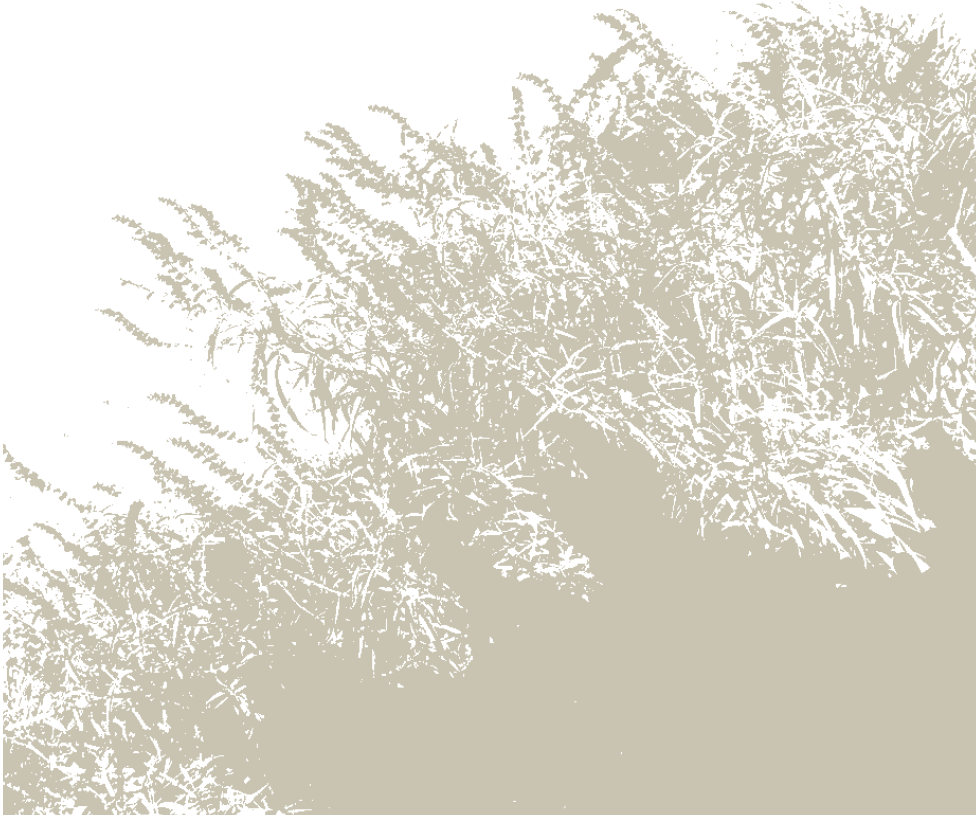

Section 1

Supportive Care of End Stage Kidney Disease

This booklet has been developed to provide you with information about **supportive care** so that you and those close to you are able to make an informed decision about your treatment and plan for the future.

A diagnosis of End Stage Kidney Disease means that you have to make some important decisions about your treatment. This includes the right to make decisions about your health and medical needs and to decide which treatment option is appropriate for you.

Your three treatment options for End Stage Kidney Disease are;

1 Dialysis: Haemodialysis or Peritoneal Dialysis
2 Kidney Transplantation

Dialysis and Kidney Transplantation will not cure your kidney disease but aim to prolong your life.

3 Supportive Care

Supportive care focuses on treatment for any symptoms that you may experience related to your kidney disease and any other medical, psychological or social issues that need to be addressed. It does not aim to cure kidney disease or prolong life. Choosing **supportive care** means you will eventually die from your kidney disease.

The decision to have supportive care is made in consultation with your Renal Specialist. **Supportive care** is an appropriate choice for some people as dialysis may not improve either their quality or length of life.

If you choose **supportive care** you will continue to receive ongoing treatment of your kidney disease from your renal team, along with specialised support and symptom management from the palliative care team if and when necessary.

Once you make a decision on a treatment course, you are always free to review that decision. For instance, if you choose **supportive care** you can later choose to start dialysis. Similarly, if you choose to start dialysis you can later withdraw.

Choosing Supportive Care

Psychiatry and Social Work services are used commonly in supporting End Stage Kidney Disease patients. Making decisions about your treatment options can be a time when you feel confused, hopeless, sad, and angry and need support clarifying your thoughts and feelings. Experiencing these feelings and emotions is completely normal and expected. A psychiatrist may be asked to assess and ensure that you are making an informed decision.

SECTION 2

KIDNEY DISEASE SYMPTOM MANAGEMENT AND PALLIATIVE CARE

As your kidney function decreases you will eventually develop symptoms related to the loss of your kidney function. Everyone experiences different symptoms at different times. It is difficult to predict how long you will live with Kidney Disease after electing supportive care, as every situation is different. Speaking regularly and honestly with your Renal Specialist and General Practitioner is important so that your symptoms can be monitored and managed as soon as they appear.

Your renal team may involve the palliative care team when specialised help with symptom management is required. Palliative care is provided for someone at the advanced stage of a medical condition, in your case, End Stage Kidney Disease. Palliative care is specialised care, support and symptom management provided by a team of doctors, nurses and allied health professionals. It involves providing support for patients, carers and families and aims to assist you to live as well as possible towards the end of your life. It can be provided at home, in a hospice or in an aged care facility.

Below is a list of symptoms that different people experience with worsening renal function. By no means will you experience every symptom. It is important to remember that your Renal Specialist can manage and improve many of these symptoms.

- **Lack of Energy or Tiredness**

Your kidneys make a hormone called Erythropoietin (Epo) which controls the making of blood cells. As your kidney function declines the amount of Epo decreases and you may develop Anaemia (low red blood cells). This causes tiredness and fatigue. Your Renal Specialist can prescribe Epo injections to treat the Anaemia which will improve your energy levels.

- **Change in Taste, Loss of Appetite**

A change in taste and a loss of appetite can occur early in kidney disease and may be due to a number of causes. Your Renal Specialist can refer you to the Renal Dietician. They may be able to assist you in overcoming your loss of appetite by encouraging you to have smaller more frequent meals, or to avoid eating certain foods.

- **Nausea and Vomiting**

Nausea and vomiting may occur as your kidney function declines. This can be due to a number of reasons and your Renal Specialist can use different medications to treat this symptom.

- **Itchiness**

Itchiness is a common symptom. This can be due to increasing dryness of the skin or the effect of toxins on the nerves that can cause you to feel itchy. Your Renal Specialist can prescribe skin creams and medications which can minimise this symptom.

- **Restless Legs**

Restless legs is the feeling of your legs wanting to move or twitch when you are at rest. This is an involuntary movement that can be particularly problematic at night when you are lying in bed. Your Renal Specialist can prescribe medications which can minimise this symptom.

- **Fluid Overload**

Fluid overload is a build up of fluid/water in your ankles. This is known as Oedema or “puffy ankles”. Severe fluid build up can go to your lungs and you may start feeling short of breath. This may be noticeable when trying to walk up flights of stairs or short distances. This can be monitored by checking your weight regularly and looking for swelling in your ankles. Your Renal Specialist can use various medications to control the fluid build up.

- **Sleep Changes**

Sleep patterns can change once your kidney function decreases. You may find that you want to sleep more during the day and less at night. Talk to your Renal Specialist if you are having concerns about your sleep patterns.

- **Drowsiness**

As your kidney function declines you may experience drowsiness which can lead to feeling forgetful and having difficulty concentrating. This is due to toxins accumulating in your brain. As your kidney function deteriorates further, you may become more confused and be unable to make decisions about your care. It is important to remember that this is a slow process and usually develops over weeks and months.

- **Pain**

Pain from kidney failure itself is unusual. However, many patients can develop pain caused by other illnesses. Talk to your Renal Specialist who can prescribe medication to control this symptom. The Palliative Care team can be involved with your renal team when specialised help with pain management is required.

- **Emotional Responses**

You and your family may experience a range of feelings in response to having a chronic illness. These feelings may include: anxiety, depression, anger, guilt, shock and fear about what the future may bring. These are all normal and expected reactions and you may find it helpful to speak with a member of your renal team about how you are feeling.

SECTION 3

PLANNING FOR YOUR FUTURE

As you may be in good health now it can be difficult to think about or discuss end of life issues. However, there is no way of knowing when your symptoms will get worse and when they do it can be difficult to think clearly, plan for your future and make your wishes known.

Planning for your future may include -

- Being aware of who your legal 'person responsible' is
- Advance Care Planning
- Writing an Advance Care Directive
- Appointing an enduring guardian
- Appointing an enduring financial power of attorney
- Preparing a will

Your Person Responsible

The medical team have a legal responsibility to obtain consent from you for any proposed treatment. Usually you would be able to give consent but if you are not capable of consenting, the medical team will seek consent from your 'Person Responsible' (traditionally known as your 'Next of Kin').

In order of priority your 'Person Responsible' is -

1. An appointed enduring guardian (whom you legally appoint).
2. Your most recent spouse, including de facto spouse with whom you have a close and continuing relationship with. This includes people in same sex relationships.
3. An unpaid carer providing support and assistance.
4. A relative or friend whom you have a close relationship with.

Advance Care Planning

Advance care planning is a process of careful consideration about your values towards your life and health. It is you planning and communicating how you would like to be medically treated towards the end of your life so that your wishes can be respected if you become unable to communicate or make them known in the future. This involves discussing your wishes regarding your future healthcare with others, which may include family, friends, your 'person responsible', and your health care professionals.

You may feel that talking to those close to you is enough to make your wishes known or you may decide to also put your wishes or instructions in writing, this is called an 'Advance Care Directive'.

Advance Care Directives

An advance care directive is also called a 'living will'. An advance care directive is useful because it allows you to have control over your future health care and treatment. It also enables those close to you to confidently communicate your wishes.

You can either make your own advance care directive or use a form that is available. You can write down your wishes around end of life care and provide both general and specific instructions regarding your health care and treatment. Examples of what can be included in an advance care directive are: specific kinds of care, treatment and feeding.

The directive should be clear and written specifically to guide medical care. In order to do this you may find it helpful to write the directive with a medical practitioner or health professional. You can change the directive at any time and it may be useful to look over the directive

from time to time especially if your condition changes.

It is important to distribute your Advance Care Directive to those close to you, your 'person responsible' and your health care team, so that it is available when a decision about your health care needs to be made.

Where Can I get more information about Advance Care Directives?

- **Advance Care Directive Association** - 0423 157 003 or http://www.advancecaredirectives.org.au

- **Respecting Patient Choices** www.respectingpatientchoices.org.au

- www.racgp.org.au/guidlines/advancecareplans

Enduring Guardianship

An enduring guardian is someone whom you legally appoint to make personal or lifestyle decisions on your behalf and must act in your best interests. You are able to choose which decisions you want your enduring guardian to make, which can include deciding what health care you receive. Your enduring guardian will only take over if you become unable to make your own personal or lifestyle decisions as a result of your health condition.

Where can I get more information?

- **Guardianship Tribunal (Guardianship)** - 1800 463 928

Where can I get legal assistance?

- **Lawaccess NSW**

Provides free legal information and referrals to other services and organizations which may be able to help - 1300 888 529 or http://www.lawaccess.nsw.gov.au

- **Community Legal Centres** - 1300 888 529

- **Law Society Community Assistance Service** - 1800 357 300 or (02) 9373 7300

Enduring Power of Attorney and Will Making

An Enduring Power of Attorney is someone you can legally appoint to have legal authority to look after your financial affairs on your behalf if you become unable to do so in the future as a result of your health condition.

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.

Where can I get more information?

- **NSW Trustee & Guardian (Powers of Attorney & Will making)** - 1300 364 103

SECTION 4

COMMUNITY SERVICES

If you and your family need more help at home as time goes on the following are some services that may be of assistance when choosing supportive care. It is important to note community services can be limited and all will have a small cost involved. Your health care team or Social Worker can give you further information.

- **Home Care Service**

Long term assistance for patients, carers and families. They can provide assistance with cleaning, personal care, grocery shopping and carer respite - 1800 350 792

- **Department of Veterans Affairs Home Care**

Long term assistance provided to veterans, war widows or widowers. They can provide assistance with cleaning, personal care, grocery shopping and carer respite. To receive this service, you have to receive a pension from the Department of Veterans Affairs - 1300 550 450

- **Commonwealth Carer Respite Centre**

Short term emergency assistance for carers. They can provide assistance with cleaning, personal care, grocery shopping and carer respite - 1800 059 059

- **Commonwealth Carer Resource Centre**

Information, referrals to other services or carer support kits. They provide emotional support and counselling programs - 1800 242 636

- **Private Nursing**

Professional nursing services at home for a fee. A list of contact details can also be provided by your Social Worker or the Yellow Pages.

Further information, resources or other community Palliative Care Contacts:

- **Palliative Care Australia** - (02) 6232 4433 or www.palliativecare.org

- **Community Palliative Care** - 1300 722 276.

A service for anyone who has a terminal illness. It can be provided in the person's own home, a hospital, a hospice or even a nursing home.

- **Hospice**

A hospital where specially trained doctors, nurses and other health professionals care for people who are dying. Further details can be provided by your health care team.

- **Bereavement Service**

Face to face bereavement counselling for families and significant others when a family member has died. It's a free service and self-referrals are preferred - (02) 9767 5656

SSWAHS (Eastern Zone) Renal Unit

Contact Details

Sydney South West Area Health Service, (Eastern Zone) SSWAHS Renal Unit

- (Eastern Zone) SSWAHS Satellite Dialysis and Training Centre (02) 9515 3500
- Chronic Kidney Disease Co-ordinator (02) 9515 3428

Concord Repatriation General Hospital

- Switchboard (02) 9767 5000
- Renal Ward 4N (02) 9767 6420
- Haemodialysis Unit (02) 9767 7012
- Renal Specialists 4W (02) 9767 6447
- Social Work Department (02) 9767 6680
- Renal Case Manager (02) 9767 5711

Royal Prince Alfred Hospital

- Switchboard (02) 9515 6111
- Renal Ward 6E1 (02) 9515 7704
- Haemodialysis Unit 6ED (02) 9515 7638
- Renal Specialists (02) 9515 6600
- Social Work Department (02) 9515 9902
- Renal Case Manager (02) 9515 7635

SUMMARY

Being diagnosed with End Stage Kidney Disease can be a difficult and confusing time in your life when you are faced with many questions and decisions that need to be made. It takes time, education and support to make a decision about the treatment option which is best for you and which will offer you the best quality of life.

It is not unusual for patients with End Stage Kidney Disease and other complex medical problems to decide not to start dialysis. In some cases starting dialysis may not improve quality or length of life and may be seen as a burden. It can therefore be reasonable to consider supportive care as a treatment option.

We hope that this booklet has provided you with helpful information about supportive care as a treatment option for End Stage Kidney Disease. Our aim is for you and your family to feel empowered to make informed decisions about treatment options and plan for your future.

We encourage you to discuss your concerns and wishes with your Renal Specialist and your Renal team. Remember, once you make a decision on a treatment course, you are always free to review that decision. Whatever decision you arrive at, your wishes will be respected and supported. This is because choosing a treatment option is about deciding what is right for you.

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November 2009

AVS 61246