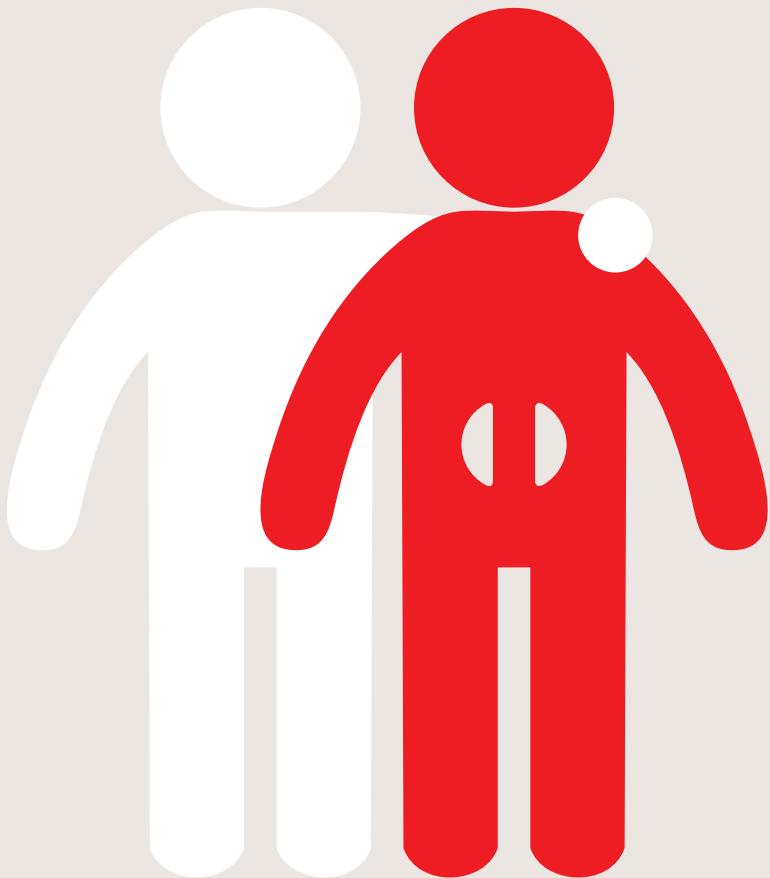


An Introduction to Symptom Management and Supportive Care



Prevent, Detect, Support.

Acknowledgements:

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NORTH SHORE
HOSPITAL**

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Management and Supportive Care
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Disclaimer

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. All care is taken to ensure that the information contained in this booklet is accurate at the time of publication.

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Foreword



This booklet has been designed to provide you with information about symptoms of kidney disease, and supportive care as a treatment option.

If you are reading this for the first time it may be that you have just received news that you need to consider treatment options for end stage kidney disease, or you may be supporting a loved one in this situation. Equally you may already be having dialysis and need some help to manage some of the symptoms of kidney disease.

Other booklets in this series cover dialysis (haemodialysis, home dialysis, peritoneal dialysis), and kidney transplantation. We encourage you to read all the booklets so you can make an informed decision.

Kidney Health Australia is here to assist you throughout your journey and our fully qualified team of nurses and allied health professionals are only a phone call away, should you wish to speak to someone confidentially.

Welcome to Australia's kidney community, and please keep in touch so that we can provide whatever assistance or guidance you may require.

Mikaela Stafrace
CEO
Kidney Health Australia

Introduction

Chronic kidney disease (also known as CKD) usually means that your kidneys slowly lose their normal ability to keep your body working well. This can happen over months or years. CKD is called a silent disease as there are often no warning signs. Sometimes people lose up to 90 per cent of their kidney function before getting any symptoms.

When your kidney disease has reached end stage, your kidney function is so poor that your body cannot get rid of extra water and waste products. If this is left untreated, it will eventually lead to your death.

Some people choose treatments that do some of the jobs that your kidneys are struggling to do. These treatments are **dialysis** or a **kidney transplant**. For other people, these treatments may not be the best option. This could be for a number of different reasons. In such cases, choosing **supportive care** is the best option.

This booklet talks about supportive care as a treatment option for end stage kidney disease. Other treatment options for end stage kidney disease, including dialysis and kidney transplantation, are explained in the resources below.



RESOURCES

📘 Kidney Health fact sheets (translated versions available)

📘 Kidney Health Australia booklets:
An Introduction to Kidney Disease Treatment Options

Kidney Health Australia book: Living with Kidney Failure

📘 www.kidney.org.au/your-kidneys/support

[www.kidney.org.au/your-kidneys/support/
kidney-disease/treatment/choosing-your-treatment](http://www.kidney.org.au/your-kidneys/support/kidney-disease/treatment/choosing-your-treatment)

📘 **My Aged Care**

The Australian Government's My Aged Care contact centre and website is a good starting point to access a range of aged care services. Information and further contact details are provided for all the topics listed above.

www.myagedcare.gov.au

1800 200 422

📘 **Palliative Care Australia**

The national peak body for palliative care. Provides information about advance care planning and palliative care services.

www.palliativecare.org.au

02 6232 0700

What is supportive care?

Supportive care (also called non-dialysis supportive care or conservative care) is care given to prevent or manage symptoms and consequences of end stage kidney disease, and does not involve dialysis. With supportive care, medications, diet and other support measures are used to manage your symptoms of end stage kidney disease to allow you to live as well as possible for as long as possible.

The symptoms and consequences of end stage kidney disease can be very broad, and may require physical, psychological, emotional, social and spiritual issues to be addressed.

The aim of supportive care is to assist you to manage your health so you can do things that are important to you, such as living as independently as possible and in comfort.

Choosing supportive care as your treatment for end stage kidney disease means that you accept that your loss of kidney function or any other health conditions you may have will eventually lead to your death. How long you will live is different for everyone. There are many things that will affect how long you are likely to live. Your health care team will be able to discuss this in more detail.

Sometimes people who have already started dialysis or have a transplant are still troubled by symptoms related to their kidney disease, other medical conditions or by the treatment itself. These people may benefit from the extra help that supportive care can offer in managing their symptoms. Ideally, everyone with end stage kidney disease should receive care to manage the burden of their symptoms and improve the quality of their life, regardless of whether they have other treatments such as dialysis or a transplant.

It is important to remember that choosing a treatment for end stage kidney disease is your decision to make. Your health care team will provide you with as much information as possible to help you make your decision.

Your treatment decisions can always be reviewed. If you initially choose supportive care but later change your mind, you can discuss the possibility of starting dialysis with your health care team.



REMEMBER

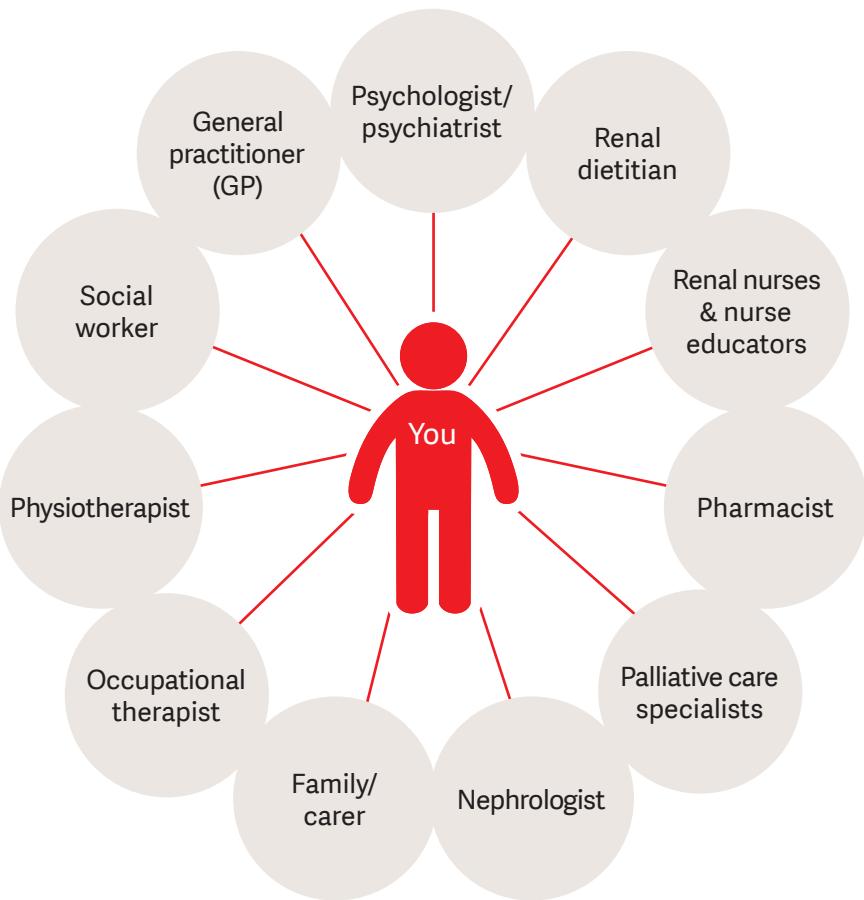
Supportive care as a treatment option for end stage kidney disease does not mean no treatment. Diet, medications and other types of support are used to help you to live as independently and in as much comfort as possible.

How supportive care works

Supportive care as a treatment option for end stage kidney disease involves a team of health professionals. Your health care team will focus on issues such as:

- Symptom control
- Self-management support (helping you to be involved with managing your health)
- Providing education for you, your carers, and your family
- Psychological support
- Support to do everyday activities
- Referrals to support services and programs
- End of life planning
- Bereavement care

The members of your health care team will change depending on your needs and circumstances. People who may be a part of your health team are shown in the diagram below. See 'What does that word mean' for more information about the health professionals shown here. It is important to remember that it is your decision to make and your health care team will help to provide you with as much information as possible to make the decision.



Why would I choose supportive care as my treatment?

The decision to choose supportive care (instead of dialysis or a transplant) is one that you will make together with your health care team, family and loved ones. Your health care team will help you to understand your treatment options, and how these treatments may impact on your quality and quantity of life.

Some reasons why supportive care may be best for you:

- Spiritual, cultural, or personal reasons. You may not want all of the extra tests, procedures and appointments that are needed for dialysis.
- The potential burden caused by dialysis may outweigh the benefits to you.
- Dialysis may be very unlikely to improve your quality of life or the length (quantity) of your life. If you are frail and elderly and have other medical conditions then you may live just as long with supportive care as you would with dialysis treatment.

Everyone's situation is different, so it is important to think about the best option for you.

Making decisions about whether to choose supportive care as your treatment option may seem hard, especially if you are feeling unwell. It can also have a significant emotional effect on you and your family. It is okay to ask to have some time to think about the information provided to you by your health care team and in this booklet.

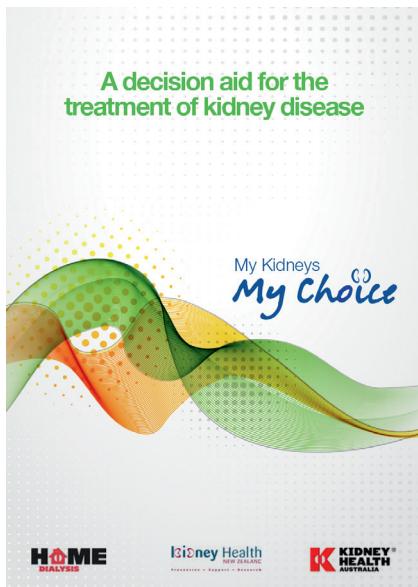


Making an informed choice

Your choice of treatment for end stage kidney disease depends on factors such as your age, health, lifestyle and what is important in your life.

Decision aids are tools that have been developed to help you become involved in decision making. *My Kidneys, My Choice* is a useful decision aid that has been developed for people of all ages choosing treatment for end stage kidney disease. *OPTIONS* is another decision aid that has been developed for people older than 70 years of age.

These decision aids provide information about end stage kidney disease treatments and help you to work out what is important to you.



My Kidneys, My Choice is available from the *Treatment for kidney disease > Choosing your treatment* page at kidney.org.au, or contact Kidney Health Australia for your free copy. *OPTIONS* is also available by contacting Kidney Health Australia.

Talk to your health care team if you would like help to use one of these decision aids.

More detailed information about choosing a treatment for end stage kidney disease is available in the booklet '*An Introduction to Kidney Disease Treatment Options*', and other resources shown below.



RESOURCES

- ❶ Kidney Health Australia booklets:
An Introduction to Kidney Disease Treatment Options
Kidney Health Australia book: Living with Kidney Failure
- ❷ [www.kidney.org.au/your-kidneys/support/
kidney-disease/treatment/choosing-your-treatment](http://www.kidney.org.au/your-kidneys/support/kidney-disease/treatment/choosing-your-treatment)
- ❸ Kidney Health Information Service (KHIS) **1800 454 363**

Managing your symptoms

Kidney disease symptoms can affect many areas of your health and well-being. These symptoms may be caused either by the kidney disease itself, or by its treatment (for example side-effects of dialysis or medications). These symptoms may be experienced by people on dialysis as well as those choosing supportive care. Some symptoms may be more severe than others, and may affect different people in different ways.

Managing your symptoms well will improve your quality of life. Treatments are available for most symptoms, so don't hesitate to talk to your health care team if you have a symptom that is bothering you. You may be asked to regularly complete a symptom assessment and quality of life survey so that your health care team can monitor the frequency and severity of your symptoms.



The following are some of the more common symptoms that may be felt by people with end stage kidney disease.

- Lack of energy

People whose kidneys are not working can feel tired for a number of reasons and these may vary from person to person. Some reasons, such as low red blood cell count or **anaemia**, can be treated with medication. Other reasons such as poor sleep, depression, uraemia and heart disease require different investigations and treatment.

- Change of taste, bad breath, or dry mouth

As your kidney function declines, wastes will build up in your blood. This is called **uraemia**. Uraemia can lead to a metal-like taste in your mouth and bad breath. It may also lead to a loss of appetite as foods can change in taste. Dry mouth is another common symptom of reduced kidney function. This can be relieved by the use of saline spray, ice, or chewing gum if appropriate.

- Feeling sick in your stomach (nausea and vomiting)

Nausea and vomiting can occur as kidney function decreases. This may lead to a loss of appetite, and weight loss. A **renal dietitian** or **renal nurse** will be able to provide advice on what to eat to obtain the nutrients your body needs. Eating smaller amounts more often, or avoiding certain foods may be helpful. Medications can also be prescribed to help reduce these symptoms.

- Itchy skin

Itchy skin (also called **pruritus**) is a common symptom for people with kidney disease. Chemical imbalances and changes to nerves and dry skin all contribute to this symptom. Medications and skin creams may provide relief.

- Restless legs

Many people with end stage kidney disease experience aching, uncomfortable, jittery, or “restless” legs. A strong impulse to kick or thrash the legs is common. This may make it difficult for you to sleep at night.

You may start sleeping more during the day and less at night. Some people find massages or warm baths can provide relief. Medications to minimise restless legs and improve sleep can also be prescribed.

- Sleeping problems

There are many reasons why you may have trouble getting to sleep, or difficulty sleeping through the night. Some possible reasons may be pain, worrying thoughts or low mood, restless legs, difficulty breathing or snoring. If you are having problems with sleep please discuss this with your health care team as there are many tips and treatments that may be helpful.

- Shortness of breath

Trouble catching your breath can be due to anaemia, or from extra fluid building up in your lungs. Medications can be prescribed to try to reduce fluid retention and to treat anaemia.

- Feeling cold

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

- **Swelling**

As your kidney function declines, your kidneys do not remove enough excess fluid from your body. This extra fluid can build up causing swelling in your legs, ankles, feet, face, and/or hands. Medications and restricting the amount of liquid and salt in your diet can help to control this.

- **Constipation**

Reduced kidney function can lead to bowel problems such as **constipation**. This can cause stomach pain, bloating and nausea. A renal dietitian or renal nurse may be able to suggest how to safely increase the fibre in your diet. Gentle exercise such as walking can also help. Medications can also provide relief.

- **Pain**

Body pain is common for people with kidney disease. This pain may be in your muscles, bones or joints such as arthritis, nerve pain such as pain in the feet, calves and hands that may occur with diabetes, or headaches.

Medications can successfully relieve your pain. However, it is important that you discuss pain management with your health care team as some medications are not appropriate for people with kidney disease. The use of physiotherapy to include gentle exercises into your daily life can also help with pain management, especially for muscle and bone pain. You may be referred to a specialist pain clinic if your pain is difficult to manage.

- Mood and well-being

Mood disorders are commonly experienced by people at all stages of kidney disease. Depression, anxiety, anger and stress can be a reaction to your diagnosis and management of kidney disease, or even a side-effect of your medications.

There are many different therapies and medications that can help if you are feeling any of these emotions. Talk to your health care team who can refer you to a specialist. Your health care team can also investigate physical causes or possible medication side-effects.

- Changes in memory, attention and concentration

Kidney disease can result in changes to your memory, your concentration, and your ability to plan tasks in a step-by-step way. This can make it difficult for you to remember to do things that are necessary for you to manage your kidney disease, such as taking your medications as directed and following the advice of your health care team. If you, or your family or carers notice changes in your memory, attention or concentration, talk to your health care team about tips that may help.

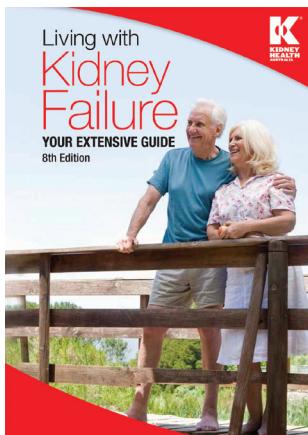


CALL TO ACTION

Talk to your health care team if your symptoms are making you uncomfortable. Treatments are often available, but you may need to try a few different options before you find one that works for you.

For more information on symptoms and treatment options see the Kidney Health Australia fact sheet 'Common Kidney Disease Symptoms and Management Options'.

Additional information about how to live well with kidney disease, including tips on how to manage your medications, and how to keep doing things that you enjoy is available in the book 'Living with Kidney Failure' and other resources shown below.



RESOURCES

- 🕒 Kidney Health Australia fact sheets:
Common Kidney Disease Symptoms
and Management Options
Depression and Chronic Kidney Disease
- 📖 Kidney Health Australia book: Living with Kidney Failure
- 📞 Kidney Health Information Service (KHIS) **1800 454 363**

Planning for your future

Advance Care Planning

Advance care planning is important for everyone. It is especially important for people with a life-limiting condition like end stage kidney disease. An advance care plan lets people know your wishes with regards to your medical care for a time when you are unable to communicate or participate in decision making. It can make sure that your wishes, values and preferences about your future care are taken into consideration.

It is important to plan ahead as you must organise your advance care planning while you are still fully able to understand the decisions that you are making.

Advance care planning can include:

- Making a plan for your future medical care and life based on your values and preferences. For example, you may think about what are acceptable and unacceptable outcomes of treatment? Are there any treatments you would not want?
- Selecting someone you trust to make medical treatment decisions for you if you are unable to communicate or participate in decision making. You also need to discuss your future medical treatment plans with this person.
- Developing an end-of-life plan together with your health care team.

Depending on where you live in Australia there may be different names for the documents that you need to complete for advance care planning. What is important is that you:

- Discuss your wishes with your family, carers, and health care team
- Document (write down) your decisions using the format that is required in your state or territory



CALL TO ACTION

Discuss your advance care planning with your family, carers, and health care team sooner rather than later.

Wills and Financial Planning

Planning for your future also lets people know your wishes with regards to your personal affairs when you may no longer be able to communicate or participate in decision making.

This may include:

- Selecting someone you trust to manage your assets and financial affairs for you (for example, operating bank accounts and paying bills).
- Preparing or updating a will that outlines your wishes regarding the distribution of your assets after your death, and can allow you to express your preferences regarding your funeral.

For more information see:

*[www.australia.gov.au/information-and-services/
family-and-community/wills-and-powers-of-attorney](http://www.australia.gov.au/information-and-services/family-and-community/wills-and-powers-of-attorney)*



RESOURCES

Advance Care Planning Australia

A national program that provides information and services to help with completing an advance care plan. Includes information on what forms you need in each state and territory.

www.advancecareplanning.org.au

1300 208 582

Palliative Care Australia

The national peak body for palliative care. Provides information about advance care planning and palliative care services.

www.palliativecare.org.au

02 6232 0700

What if I am struggling to cope?

It is normal to feel anger, despair, fear and other emotions during the journey of kidney disease diagnosis and treatment. These feelings usually improve with time. If the impact of kidney disease treatments and the changes to your lifestyle are overwhelming you, then it is important that you talk to someone.

The nurses, social worker or doctor at your renal unit are the best place to start. Social workers are employed in renal units to provide professional counselling to patients and their family members. They are very familiar with the issues you are experiencing. There is no need to feel embarrassed or ashamed or to suffer in silence.

You can also see your GP who can arrange a referral to a psychologist or social worker in your community. These services can be accessed through Medicare.



If you find yourself feeling low, please ask for help.



RESOURCES

- ④ Kidney Health Australia fact sheets:
Depression and Chronic Kidney Disease
- ④ Kidney Health Australia book:
SANE Guide to Good Mental Health for People
affected by Kidney Disease
- ④ *beyondblue* (**beyondblue.org.au** or call **1300 22 4636**)
provides a confidential telephone information and
advice helpline
- Lifeline* (**lifeline.org.au** or call **13 11 14**) provides a
24 hour crisis support and suicide prevention services

What help is available?

Help staying at home

As your health declines, it may become more difficult for you to stay independent in your own home. 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 and carers. These services include nursing, personal care, cleaning, grocery shopping and carer respite. The Veterans' Home Care (VHC) program provides low level home care services to eligible veterans and war widows and widowers.

Ask your GP for a referral to your local aged care assessment service, or contact your local council for more information.

Help in aged care homes

If living at home eventually becomes unmanageable for your family and carers, then you may need to consider alternative arrangements, such as an aged care home. Staff in the aged care home can help to develop a care plan that best supports your physical, emotional and spiritual needs.

Palliative Care

Palliative care is care that helps people live their life as fully and in as much comfort as possible, when living with a life-limiting or terminal illness. Palliative care is for people of any age who have been told that they have a serious illness that cannot be cured. Palliative care assists people with illnesses such as cancer, motor neurone disease and end-stage kidney or lung disease to manage symptoms and improve their quality of life.

Palliative care may mean special health professionals visit your home, nursing home, or other location to provide the support that you and your family and carers need. This will vary depending on your individual situation. Whether

you are able to stay at home or need to make alternative arrangements, your health care team will continue to make sure your physical, emotional and spiritual needs are met.

Caring for the carers

There are many organisations that can help and support carers look after a loved one with end stage kidney disease, or any other chronic condition. This support can cover a range of issues, such as assistance with meals, social groups for emotional support, or financial aid (such as Centrelink benefits). See the resources below for more information or talk to your GP.



RESOURCES



My Aged Care

The Australian Government's My Aged Care contact centre and website is a good starting point to access a range of aged care services. Information and further contact details are provided for all the topics listed above.

www.myagedcare.gov.au

1800 200 422



Palliative Care Australia

The national peak body for palliative care. Provides information about advance care planning and palliative care services.

www.palliativecare.org.au

02 6232 0700



Carers Australia

The national peak body representing and providing information, support and advice for carers.

www.carersaustralia.com.au

Where can I get more information?

This booklet contains information about symptom management and supportive care as a treatment option for end stage kidney disease. Other booklets in this series cover dialysis (haemodialysis, home dialysis, peritoneal dialysis), and kidney transplantation.

We encourage you to read all the booklets so you can make an informed decision about your treatment. Visit the Resource Library at www.kidney.org.au to order or download your copies.



RESOURCES

- 📘 Living with Kidney Failure booklet 8th edition,
Kidney Health Australia
- Community newsletter
- 🌐 www.kidney.org.au
- 📱 Connect with us on Facebook, Instagram and Twitter
- 👥 Social groups – Kidney Club
- 📞 Kidney Health Information Service **1800 454 363**
- TelEconnect **1800 454 363**

What does that word mean?

A

Anaemia

When there are only a small number of red blood cells in your blood or your blood cells are not working properly. Red blood cells carry oxygen, so if you have anaemia you can feel weak, tired and short of breath.

C

Chronic kidney disease (CKD)

A term used widely to describe kidney damage or reduced kidney function (irrespective of the cause) that persists for more than three months. Sometimes CKD leads to kidney failure, which requires dialysis or a kidney transplant to keep you alive.

Constipation

Bowel movements that are infrequent or hard to pass

D

Dialysis

A treatment for kidney failure, which removes wastes and extra fluid from your blood by filtering through a special membrane. There are two types of dialysis, haemodialysis and peritoneal dialysis.

E

End stage kidney disease

The stage of kidney disease when your kidneys have stopped working and treatment, such as dialysis or a transplant, is needed to sustain life. Also referred to as End Stage Kidney (Renal) Failure (ESKF), kidney failure or stage 5 CKD.

G

General practitioner (GP)

A doctor who treats acute and chronic illnesses and provides preventive care and health education to patients.

H

Health care team

The team of people involved in your care. This may include health professionals, family members, loved ones, and yourself.

K

Kidney transplant

A treatment for end stage kidney disease where a kidney is removed from the body of one person (the donor) and put it into the body of the person with end stage kidney disease (the recipient).

N

Nephrologist

A medical doctor who specialises in kidney function.

O

Occupational therapist

A health professional trained to help you find solutions to problems you may meet when carrying out your daily activities. This may include physical or emotional difficulties with work, daily tasks and leisure activities.

P

Palliative care specialists

Doctor and nurse specialists who support you with symptom management and end of life care.

Pharmacist

A health professional who is qualified to prepare and dispense medications.

Physiotherapist

A health professional with specific training in treating conditions and injuries with physical methods such as massage and exercise.

Psychologist/psychiatrist

Health professionals who are trained in treating mental health and behavioural problems. A psychiatrist is a medically trained doctor. A psychologist is a university-qualified health professional.

R

Renal Dietitian

A Dietitian experienced in kidney disease who can help develop an eating plan needed as part of the management of kidney disease.

Renal Nurse

Nurses who are trained in kidney disease treatments.

S

Social worker

Health professionals who are available to support and advise you and your family about daily stresses, lifestyle readjustments and practical issues associated with kidney disease.

Supportive care

Care given to prevent or manage symptoms and side effects of end stage kidney disease. With supportive care, medications, diet and other support measures are used to manage your symptoms of end stage kidney disease to allow you to live as well as possible for as long as possible. Also called non-dialysis supportive care or conservative care.

U

Urea

Waste product from the breakdown of protein.

Uraemia

A raised level of urea in your blood and other wastes that are normally removed by your kidneys.

Connect with us

www.kidney.org.au

Freecall 1800 454 363

