

An Introduction to

Comprehensive Conservative Care for Kidney Failure



Prevent, Detect, Support, Research.

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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.

Foreword

An Introduction to Comprehensive Conservative Care for Kidney Failure is designed specifically for people who are considering treatment options for kidney disease.

If you are reading this for the first time, it may be that you have just received the news that you need to consider treatment options for kidney failure. You may also have had kidney disease for sometime and be ready to learn more, or you may be supporting a loved one in this situation.

This booklet is designed to provide you with information about comprehensive conservative care - a treatment option for kidney failure that does not involve dialysis or kidney transplantation. Other booklets in this series cover dialysis (home dialysis, haemodialysis and peritoneal dialysis), kidney transplantation, and living kidney donation. We encourage you to read all the booklets so you can make an informed decision about your treatment.

Kidney Health Australia is here to support you throughout your journey. 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 may be able to provide you with whatever support and assistance you require.

To receive monthly updates on the latest in the kidney community and managing your kidney health visit **[kidney.org.au/subscribe](https://www.kidney.org.au/subscribe)**

The **Kidney Health Australia** team
1800 454 363
kidney.helpline@kidney.org.au
[kidney.org.au](https://www.kidney.org.au)

What are kidneys?

Most people are born with **two kidneys**, each growing to the size of your fist. Your kidneys are bean shaped and are positioned near the middle of your back, on either side of your backbone (spine). Your kidneys are part of the body's urinary system.

What do healthy kidneys do?

Kidneys are the unsung heroes of the body. The kidneys play a number of important roles in the body, such as:

- Extracting excess fluid to make urine (wee)
- Controlling blood pressure
- Filtering waste products from the blood
- Controlling body fluids
- Stimulating the production of red blood cells
- Controlling potassium, calcium and phosphorus levels
- Regulating vitamin D.

What happens when the kidneys don't work properly?

Sometimes kidney function can change quickly. For example, your kidneys may stop working properly because of a sudden loss of large amounts of blood (e.g. during surgery) or as a result of an accident, illness or infection.

A sudden change in kidney function is called **acute kidney injury**. This is often temporary but can occasionally lead to lasting kidney damage. More often, kidney function worsens over a number of years – it is a chronic, or ongoing, condition. **Chronic kidney disease** (also referred to as 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.

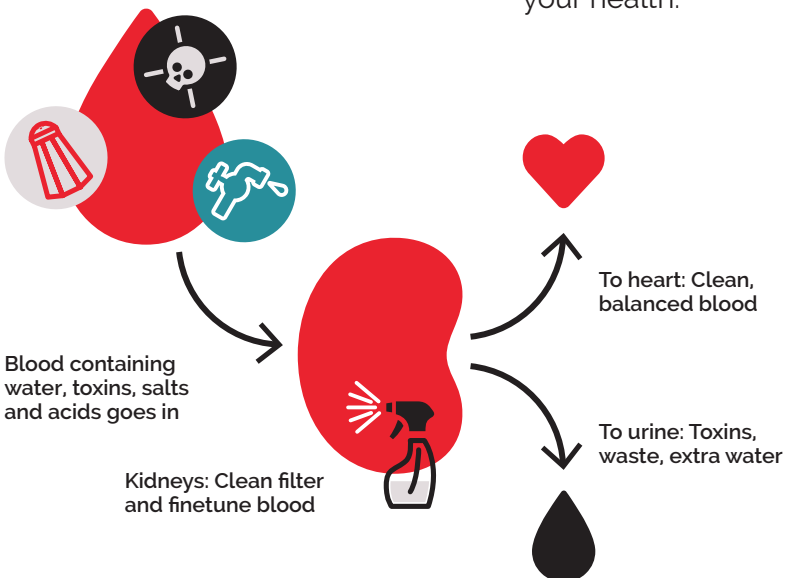
Symptoms you may experience

- Retention of fluid causing breathlessness and swelling
- Tiredness
- Headaches
- Poor memory and concentration
- Irritability
- Sleep disturbances
- Feeling washed out
- Itchiness
- Nausea and loss of appetite
- Weight loss
- Altered sexual function.

90%

of kidney function can be lost without experiencing any symptoms

Dialysis is usually started when you no longer feel well enough to live your usual life, have excess fluid or swelling, or your blood results show levels of waste that are becoming dangerous to your health.

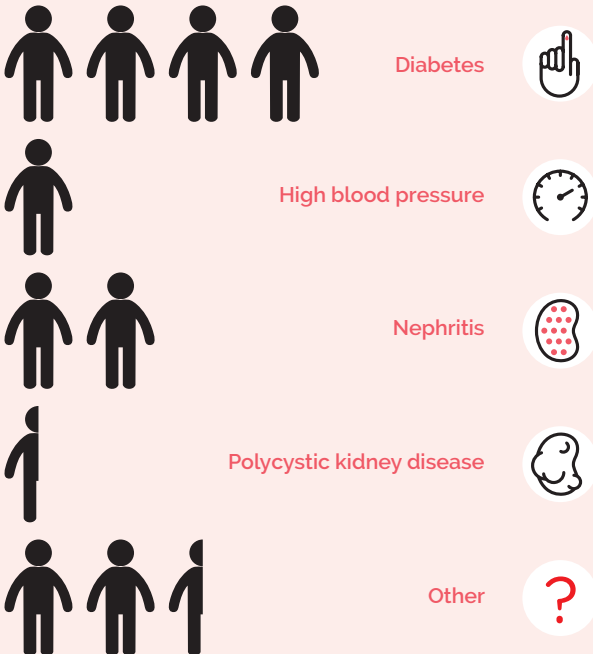


You are not alone

In Australia:

- Over 3,000 people start dialysis or receive a transplant every year
- There are currently over 25,000 people in Australia on dialysis or living with a transplant.

Out of every 10 people needing treatment for kidney disease the causes are:



What is comprehensive conservative care?

Comprehensive conservative care (sometimes called non-dialysis supportive care) is a treatment option for kidney failure that does not involve dialysis or kidney transplantation.

With comprehensive conservative care, symptom management through medication, diet and other support measures is carried out to allow you to live as well as possible for as long as possible.

The aim of comprehensive conservative 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.

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

Choosing comprehensive conservative care as your treatment for kidney failure means that you have chosen to accept that your kidney failure will eventually lead to your death. How long you will live with kidney failure is different for everyone, as there are many things that affect your lifespan. Your health care team will be able to discuss this in more detail.

How comprehensive conservative care works

Comprehensive conservative care as a treatment option for kidney failure 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.

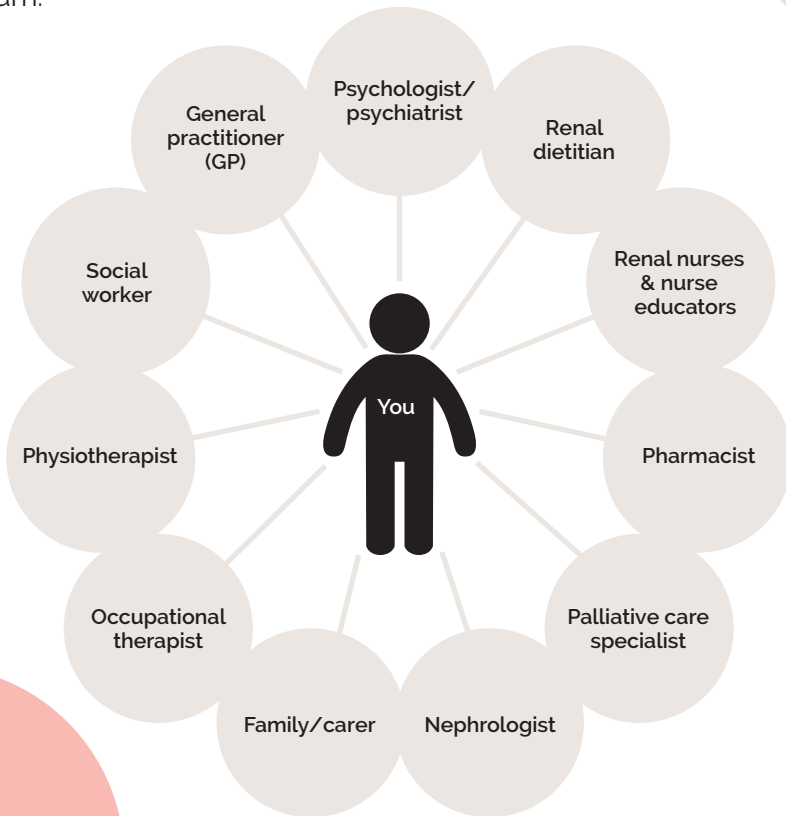
The members of your health care team will change depending on your needs and circumstances. People who may be a part of your health team are shown in the diagram below. See **What does that word mean** for more information about the health professionals shown here.

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

Remember

Comprehensive conservative care as a treatment option for kidney failure 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.

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



Why would I choose comprehensive conservative care as my treatment?

The decision to choose comprehensive conservative care (instead of dialysis or a transplant) is one that you will make together with your health care team, and family. 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 comprehensive conservative care may be best for you:

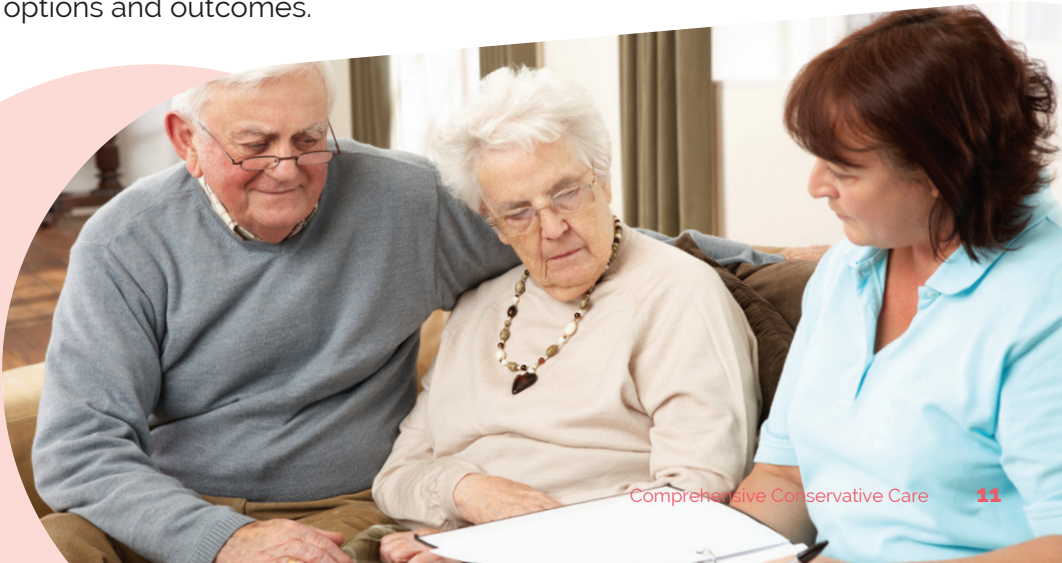
- Spiritual, cultural, or personal reasons. You may not want all of the extra tests, procedures and appointments that are needed for dialysis
- The potential burden caused by dialysis may outweigh the benefits to you
- Dialysis may be unlikely to improve your quality of life or the length (quantity) of your life. If you have other medical conditions then you may live just as long with comprehensive conservative 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 comprehensive conservative 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. If possible, it is a good idea to begin these conversations some time before a treatment decision is needed. Giving you and your family time to process and discuss all the options and outcomes.

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 kidney failure 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.



How do I make the choice?

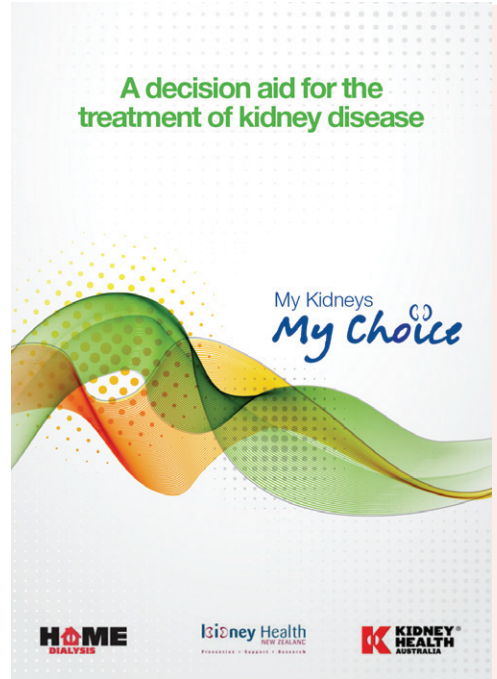
Your choice of treatment for kidney failure will depend on factors such as your age, health, lifestyle and what is important in your life.

My Kidneys, My Choice is a useful decision aid to help you to make your choice. It contains a check-list of issues that you should consider when making your choice.

The decision aid is available in the resources section of choosing your treatment page at

kidney.org.au/treatment

More detailed information about the different treatment options for kidney failure is available in the booklet **An Introduction to Kidney Disease Treatment Options**, and other resources shown below.



Resources

Kidney Health Australia booklets
An Introduction to Kidney Disease
Treatment Options.
kidney.org.au/resource-library

Kidney Health Australia book
Living with Kidney Failure.
[kidney.org.au/shop/books/
living-with-kidney-failure-
your-extensive-guide](http://kidney.org.au/shop/books/living-with-kidney-failure-your-extensive-guide)

Kidney Helpline

1800 454 363

kidney.helpline@kidney.org.au

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 comprehensive conservative care. Some symptoms may be more severe than others, and may affect different people in different ways.

Managing your symptoms will improve your quality of life. Treatments are available for most symptoms, so don't hesitate to talk to your health care team if there is anything concerning 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 kidney failure:

- **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, the build up of toxins (uraemia) and heart disease require different investigations and treatment.
- **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.
- **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 kidney failure 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.
- **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.
- **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:**

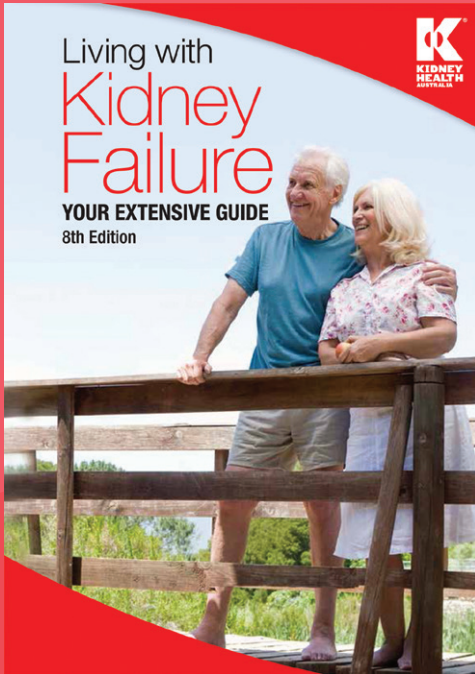
Kidney disease can result in changes to your memory, your concentration, and your ability to plan tasks in a step-by-step way. This can make it difficult for you to remember to do things that are necessary for you to manage your kidney disease, such as taking your medications as directed and following 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.

For more information on see the **Kidney Health Australia** fact sheet **Kidney Disease Treatment 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.

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.



Resources

Kidney Health Australia fact sheets **Kidney Disease Treatment Options** and **Depression and Chronic Kidney Disease** as well as sheets on common complications such as **Anaemia**.

kidney.org.au/resources

Kidney Health Australia book **Living with Kidney Failure**.
kidney.org.au/shop/books/living-with-kidney-failure-your-extensive-guide

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 kidney failure. 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.

For more information see:

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

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.

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.

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.

palliativecare.org.au
02 6232 0700

What support 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 kidney failure or end-stage 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 kidney failure, 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.

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.

palliativecare.org.au

02 6232 0700

Carers Australia

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

carersaustralia.com.au

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 is overwhelming you, 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

Kidney Health Australia fact sheets **Depression and Chronic Kidney Disease**.

kidney.org.au/resources

Kidney Health Australia book **SANE Guide to Good Mental Health for People affected by Kidney Disease**.

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 24 hour crisis support and suicide prevention services.

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.

Automated Peritoneal Dialysis (APD)

A type of PD where a special fluid is put into the peritoneal cavity through a soft plastic tube, then drained out of your body continuously for a few hours by a machine, usually at night. See also CAPD.

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.

Comprehensive Conservative Care

A treatment for kidney failure that does not involve dialysis or kidney transplantation. With comprehensive conservative care, medications, diet and other support measures are used to manage your symptoms and side effects of kidney failure to allow you to live as well as possible for as long as possible.

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.

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 failure

The stage of kidney disease when your kidneys have stopped working and treatment, such as dialysis or a kidney transplant, is needed to sustain life. Previously referred to as end-stage kidney (renal) disease (ESKD), or stage 5 CKD.

Kidney transplant

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

N

Nephrologist

A doctor who specialises in treating conditions of the kidney.

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 (drugs).

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

A patient-centred initiative that complements kidney failure treatments. Supportive care aims to help you live as well as possible with kidney failure no matter what treatment you are having. It is focused on reducing pain and suffering and improving your quality of life.

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.

Where can I get more information?

This booklet contains information about comprehensive conservative care as a treatment option for kidney failure. Other booklets in this series cover dialysis (haemodialysis, home dialysis, peritoneal dialysis), kidney transplantation and live kidney donation. We encourage you to read all the booklets so you can make an informed decision about your treatment.

Resources

Visit kidney.org.au

If you want to read more, **Kidney Health Australia's** publication **Living with Kidney Failure** (8th edition) provides comprehensive information about all aspects of living with kidney disease.

Connect with

Kidney Health Australia:

- Community Newsletter
kidney.org.au/subscribe
- Social groups - Kidney club
- Facebook, Instagram, Twitter.



Kidney Helpline

1800 454 363

kidney.helpline@kidney.org.au

Free health information service for anyone requiring assistance with managing their kidney health, understanding their kidney disease diagnosis or information on **Kidney Health Australia** support programs.

As the peak body for kidney health in Australia, we strive to create a healthier community through increased awareness and early detection of kidney disease. We connect kidney patients to vital resources and services to help them manage their condition and improve their quality of life. We also support and foster advocacy and research to drive improvements in the diagnosis, management and eventual cure of kidney disease.

Our support services

- Educational resources on kidney health and kidney disease, covering diagnosis, treatment options and management
- Fact sheets, books and educational videos and apps about kidney disease
- A large range of self-management resources including recipe books and nutrition resources
- Renal unit locations guide
- Holiday dialysis bus
- Transplant housing
- Support groups
- Kidney Health Week – national kidney awareness week
- Community events and challenges
- Regular newsletters.

Primary care education and resources

- Free accredited face-to-face and online education for health professionals
- Accredited Quality Improvement activities
- Monthly webinars
- CKD management handbook and CKD-Go! app
- Educational videos
- Nephrology referral guidelines and downloadable referral letter templates
- eGFR calculator and resources
- Scientific reports and publications.



Connect with us:

Freecall 1800 454 363

www.kidney.org.au

