

Living with kidney failure – information and tips for patients, family members, friends and carers

Finding out you have kidney failure, and living with it from then on can be overwhelming. Your energy will be directed to your treatment and physical well being. But looking after your emotional well-being is just as important as looking after your health. This information is to help you manage these changes.

Kidney failure does not just affect the patient but the entire family, your friends and those who care for you. Many of the changes and emotions affecting patients also apply to them and much of the following information and ideas apply to them as well.

Coping with kidney failure isn't just about managing the physical symptoms with treatment. You may feel that your life has been turned upside down. Having kidney failure means that you will experience important life changes, such as a change in your working life, personal and family life, finances and activities. These changes can cause a great deal of stress and a range of emotional reactions.

Recognising and understanding feelings that are experienced by others living with kidney failure can help you feel less isolated and get you the support you need.

Meeting and talking to other people with chronic kidney disease can be helpful, Check out <http://www.kidneys.co.nz/Patient-Support-Centres-Map/> for a kidney patient support group nearest to you.

People who are diagnosed with kidney failure are confronted with a range of emotions. Different people react in different ways. Some of the emotions you may experience are:

Stress

One of the main causes of stress is change. All human beings find change stressful, even change we are looking forward to, like moving house, can raise our stress levels.

As a person with kidney failure you will have to deal with more change than most people do. Not just the initial change of lifestyle that comes with the diagnosis, but ongoing changes as you deal with alterations in your diet, medication and forms of treatment.

These changes mean you have to take in a great deal of new information, make decisions and learn new practical skills. You also have to adjust to new ways of doing things, to doing less than you would like to, and to asking for help. This can be extremely stressful and it comes in addition to coping with the physical effects of kidney failure.

Shock

Being told you have kidney failure can come as quite a shock. Suddenly and for reasons you may not understand, you have a life threatening disease. You may feel numb and not believe what is happening. It may be hard to talk about how you feel, or you may find you can only take in small amounts of information; often having to be told the same thing over and over again.

Some people may find their feelings make talking about their illness with family and friends difficult. Others may feel the urge to talk about it as a way of helping to accept the news themselves.

Grief

You may feel sad or overwhelmed with grief over the loss of function, the changes it brings to your life and your loss of normality; a bit like a death of someone close to you. You may have a feeling of helplessness and have trouble dealing with everyday life.

Fear

This can be a specific worry related to something in particular, or a more general sense of “being on edge” or “not feeling safe”.

You may feel scared. Fear and anxiety are common emotions when you have been diagnosed with a chronic disease. You will wonder how this disease will affect you and your life, your family and your future.

Treatment for kidney disease can sometimes add to the anxiety. Whether you will undergo haemodialysis or peritoneal dialysis (PD) each requires surgery to create an access. Choices need to be made if you will go to a clinic for dialysis or treat yourself at home. You may worry about the disruption to your family life, especially if you opt for treatment at home. Will your loved ones adjust to seeing you attached to a machine? Will they dislike the constant reminder that you are not as healthy as you once were?

Loss of Control

When you are first diagnosed with kidney failure, you may fear that you'll lose your independence, or become a burden to those you love. Such feelings can be frightening and they may lead to some of the emotions discussed here. You may feel you could once predict your day, and now you are feeling uncertain about what each day will be like.

Anger

Feelings of anger are common among kidney failure patients. You may be angry that this has happened to you. You may be mad at yourself for getting sick. Some people are mad at the medical people for not taking better care of them or diagnosing the disease earlier. Many patients direct their anger at their family members or spouse. Anger and resentment can build to the point where it strains the relationship between you, your healthcare team and your family.

Feeling down

Feeling down is a normal part of chronic kidney disease.

You may feel sad and “need a good cry” sometimes. Even if you don’t feel depressed, sometimes you may have some typical symptoms of depression like irritability, loss of appetite, decreased interest in sex and difficulty sleeping. If, however, the sadness turns into a real sense of despair or hopelessness and last for more than two weeks, you should tell your doctor. This may be a sign of depression and you need to seek further help.

Depression

Depression refers to feeling down or blue. People that are depressed often have trouble getting motivated to do things that bring enjoyment. Sometimes feeling depressed causes sleeping problems or may affect a person’s ability to think clearly. It is normal for a person to be upset and cry about the diagnosis of kidney disease. Expressing feelings good and bad, is a healthy way to cope. **But when the feelings of unhappiness are intense and persistent and they don’t go away even when things improve this could be depression.** You should seek help from a doctor or social worker. Those professionals are there to help with these kinds of problems.

Tiredness or Fatigue

Both physical and emotional fatigue can play a major role in reducing your quality of life. This can include the decreased ability to exercise and participate in social activities. Sometimes the many changes and stresses, especially if they go on for a long time, can lead to emotional exhaustion.

Just as you become physically exhausted after spending six hours climbing a steep mountain, you can become emotionally exhausted when you are constantly facing stressful situations. When you are physically exhausted you cannot move. With emotional exhaustion, you are not able to “move” in the direction that you need to go because your ability to provide and receive emotional support decreases..

Emotions such as worry, chronic frustration, and continuous mental strain all contribute to emotional exhaustion.

Fatigue can come on slowly and you might not feel it is a symptom worth telling your doctor about. Many patients are reluctant to tell their health professionals about their fatigue – even if it is severe - for fear of being considered unmotivated or weak.

Changes in body image

Your body image is something that can create issues. How we look to others is very important to most people. Everyone has different ways of experiencing and dealing with emotions around this.

There is Hope!

While you might not be able to change a diagnosis, you can change the way you deal with it.

You may want to talk about how you are feeling or you may find it hard to talk about how you are feeling.

Here are some ideas to help you manage these changes and feelings.

- Pay attention to how you're feeling and don't ignore it. Even if you think it could be nothing, report your symptoms. You need to be involved in your care and learn as much as you can about your disease and its treatment. As you learn more and talk to others with kidney disease it doesn't seem so scary.
- It is important you are able to talk about these changes and what they mean to you and your family.
- The cultural and spiritual beliefs of patients are very important and can affect the way you feel about your kidney failure. Most renal services have people you can talk to regarding these, or they can refer you to the appropriate service.
- Talk to your GP or someone from your renal care team.
- Talk to other people with kidney failure.
- Find out about your condition: knowledge is power. Learn as much as you can about your illness and the treatment you are having. Don't be afraid to ask questions. Staff like being asked and are happy to answer your questions. Keeping your concerns or worries to yourself will only increase your stress levels. Talking to someone you trust may be all you need to help.
- Keep open and honest communication with loved ones. It might be difficult talking about your feelings, however, most people feel a sense of relief to tell someone about their ups and downs. Family and friends are not mind readers. It is hard for them to know how to help you if you don't tell them.
- Seek out support. Talk to a social worker about your fears and concerns. They may be able to find different ways to help you with some of the issues you are having. Find out if there are support groups in your area. If you don't feel comfortable talking to people, keep a diary of your thoughts and feelings. Sometimes writing things down can help you cope with feelings and eventually it makes talking about feelings easier.
- Take good care of yourself. Talk to your dietitian about what you need as far as nutrition. Talk to your doctor about beginning an exercise program. Indulge yourself in things that bring you pleasure (healthy things). Listen to relaxing music, read your favourite magazines or go to the movies. It is OK to tell people you are unable to do something because you just don't feel up to it. You have to take care of you.
- Accept help when you need it. People offer because they want to help. It makes them feel they are needed, but let the person know what you need, so as not to become frustrated. It is really important to maintain your independence as much as you can.

Getting Support:

Your kidney team includes;

Nephrologist (Kidney Doctor) A doctor who specialises in kidney diseases and treatment and, together with you and the other team members, plans the best treatment for you.

Nephrology Registrar A senior trainee kidney doctor, heading towards becoming a nephrologist. Often works beside the nephrologist.

Renal Social Worker Often described as the “glue” for the family the social workers role can vary, but they are there to help you to understand the information and processes involved in applying for financial support, as well as assisting you with housing and travel. Renal social workers will work together with you and other team members to assess your needs and social/family situation to find a way for you to best manage your kidney disease.

Each DHB should have clear guideline as to what support their renal social workers provide.

It is important when you start attending clinic appointments for your kidney problem that you ask the nurse or receptionist for the contact details of a social worker.

Pre dialysis educators Each renal unit has at least one pre dialysis nurse who is a valuable resource and may be able to assist with your concerns; they will also be able to refer you to the appropriate people as necessary

Renal Nurses They work closely with you during your treatment; they also work with the rest of the renal care team to ensure you are getting the best treatment. They provide education and support for you and your family.

Renal dietician This person works with doctors and other members of the kidney team to establish a diet plan that suits you and your lifestyle as part of the treatment you are having.

Where else can I get support?

Your family may be your main source of support. For others it may be close friends. If you live alone it might be community groups and other organisations. Your renal team can recommend specialised help if needed such as psychiatrists, psychologists or hospital chaplains.

Your local kidney patient support groups can be very helpful, especially if you want to talk to someone else unrelated or not connected to your health care team about your concerns. Often these groups are run by people who have been on dialysis and/or had a transplant, or supported someone who has. To find out more about these groups and to contact them go to

<http://www.kidneys.co.nz/Patient-Support-Centres-Map/>

Message boards on the internet are another way of getting in touch with people in a similar situation at any time of the day or night. You can read about other people's experiences and you can share yours if you want to. Some sites to look at include <http://bigdandme.wordpress.com/>
<http://www.globaldialysis.com/forum.html?lang=en>

For family members, friends and carers

Caring for or living with someone with kidney failure can turn your life upside down. This can steadily get worse without you noticing how it's taking over your life. It can have its ups as well as its downs.

Helping someone you care about to manage kidney disease can be overwhelming for anyone. Your life will have changed in ways you had never planned and it is easy to become totally absorbed in the new demands placed on you, or to become depressed yourself about how this change has affected your life.

You may feel it's up to you to fix things when the person you are supporting is unhappy, angry or upset about their illness or its treatment. In fact, they usually prefer it if you don't try to provide answers but just listen and understand so they don't feel so alone.

There is HOPE!

While you may not be able to change what is happening in your life, you can find ways to deal with how you might be feeling. Some things that may help

- To keep things in perspective it is essential that you take time out for yourself. Organise your needs into the daily schedule of medical appointments, shopping trips etc.
- Make time for friends who share interests with you and have nothing to do with kidney disease. Go to a movie or out for a meal.
- Use relaxation techniques, meditation or exercise built into your day to mentally take a break from it all. You will feel better for it and it might just make dealing with the impact kidney disease has on you a little easier.
- Talk to others caring for or living with someone with kidney failure
- Take care of yourself.

Other Handy Hints

Recommended reading – **Managing chronic illness, reclaim health and well-being** by
Veronica Latham

- Write down things you might want to ask the doctor or nurse as you think of them and take the list with you at your next appointment, so you remember to ask all the questions you might have. Sometimes it might help to write down what is said at your visit or perhaps to bring a support person with you.
- It is important to remember to fit your treatment (dialysis) around your life, not your life around your dialysis. Although this is a treatment you have to have it is important not to let it control your life.
- English may be a second language for some patients. It is important to ask for help when you don't understand what your healthcare team is saying. There are translation services available. Ask the social worker about this service.

Feeling overwhelmed

With all of the changes and challenges that kidney failure brings, it is easy to feel overwhelmed. However, thousands of people have already met the challenge of kidney failure and its treatment and returned to a normal lifestyle; even if it is different to what it was before. The important thing is to learn to face the challenges one by one. If you deal with each situation as your strength and motivation allow, your victories will accumulate. Don't try to accept and adjust to everything at once.

Most importantly, you need to remember that you aren't alone. Help and support are available to you. Remember, that help is available, but you have to ask for it.