

## Living with Chronic Kidney Disease (CKD) – information and tips for patients, family members, friends and carers.

Living with a new diagnosis of chronic kidney disease (CKD) can be overwhelming at first. Your energy will be directed towards planning what your future might look like, thinking about your treatment options, and managing your physical wellbeing to optimise your health. But looking after your emotional wellbeing is just as important as looking after your physical health.

A diagnosis of CKD does not just affect the person, but their entire family/whānau, their friends, and those who care for them. Some people feel that their life has been turned upside down. As a result of getting a diagnosis of CKD, the person may have to manage changes to their working life, family life, finances and activities, particularly if they feel tired, or are having to juggle dialysis commitments.

These changes can cause a great deal of stress, and a range of emotional reactions that is similar to grieving. Some people may feel shock, anger or sadness. Some people may have trouble adjusting to an altered sense of identity when being diagnosed with a chronic illness. Others report a loss of control or independence in their life. Some people find it hard to talk about how they are feeling. These feelings can be overwhelming, and relationships, work and home life can suffer without the right support.

Fortunately, most people learn to live with CKD, but they may need to adjust some aspects of their lives in order to manage their wellbeing, their energy, and to reach a place of acceptance of this new diagnosis.

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### CKD and emotional wellbeing

Acceptance of living with CKD may not always come easily or without support from others. While you may not be able to change a diagnosis, you can change the way you deal with it.

Here are some ideas that may help you manage these changes and feelings:

- Maintain open and honest communication with loved ones. Keeping your concerns or worries to yourself will only increase your stress levels, and it's hard for those who care about you to know how to help if you don't tell them how you are feeling, or what it is that you need. Talking with someone you trust may be all you need to feel better. Most people feel a sense of relief when they share how they're feeling with someone.
- Accept help when you need it. People offer support because they want to. It makes them feel useful. Let the person know what it is you need, so they know how they might be able to help. It can be frustrating getting offers of help that are not wanted or needed, and it is important to be able to maintain your independence.



- You are encouraged to talk with your GP. As well as being able to refer for counselling support and prescribe medications, they can help with symptom management. For example, if you are having trouble sleeping, have a loss of appetite, or have low mood or energy, your doctor will listen, and will work with you to help manage these symptoms, which may make you feel better. Even if you think it could be nothing, report your symptoms. It's important that you talk about these changes and what they mean to you and your family.
- Knowledge is power. Learn as much as you can about your condition and the treatment options. Don't be afraid to ask questions. Your GP or your renal team will be happy to answer your questions.
- Set goals that are important to you and that are realistic. This will support your mental health as well as give you a sense of achievement. Those goals might involve planning for weekly walks or outings, or socialisation with family or friends, which will support your emotional wellbeing.
- Try to stay active. Physical activity benefits your emotional wellbeing, as well as keeping you fit and well. Talk with your GP about beginning an exercise programme. Many GP practices employ Health Improvement Practitioners (HIPs) and green prescriptions are available.
- Take good care of yourself. Indulge yourself in healthy activities that bring you joy, whether it is listening to music, reading, or enjoying movies.
- Talk with the renal dietician about what modifications, if any, you might need to make to your diet.
- It's OK to tell people you aren't up to socialising if you're not feeling up to it. You need to manage your energy levels and take care of you, but don't isolate yourself. Find times that will work for socialising, eg weekends, or during the day if you are too tired to do things in the evening. Adaptation is the key to managing the impact of living with a chronic medical condition.
- Talk with other people with CKD, join a community support group, or social media group. Other people are on the same journey as you and understand what it is like to have CKD. Talking with others who are living with CKD can help a person to feel less isolated, and it may not seem so scary.
- People's cultural and spiritual beliefs are very important and can affect the way a person feels about their kidney disease. If you have already been referred to hospital renal services, you can request cultural and spiritual support as needed.
- If you have been referred to hospital renal services, you can ask for support. Most renal services have renal social workers, and some have psychology support available. A social worker can assist with such issues as travel to dialysis, housing, care supports, employment or financial supports. If you are struggling with your mental health, let your renal specialist know. You may be able to talk with a renal psychologist.

