Dealing with a diagnosis of kidney disease

Patient Information

Working together for better patient information
There is plenty of information on the medical aspects of being diagnosed with chronic kidney disease (CKD). However there is very little regarding the emotional impact that such a diagnosis is likely to have on you and your loved ones.

This leaflet aims to support you on the journey you are about to take and provides advice on where to go to for further support.
Most people are creatures of habit. We have our preferred way of living our life, with free choice over how we pass our time. Finding out that you have CKD can have a big impact and you may feel that your choice and freedom will now be limited. On the other hand, you may be relieved that you now have a diagnosis, so that you know what has been making you unwell and can discuss treatment options with your doctor.

Understanding your feelings is the first step to taking care of yourself and identifying what support you need. There is no set timeframe for this and you should give yourself as long as you need to process everything.
Coming to terms with a diagnosis of CKD is like going on a roller coaster - there are ups and downs, and some days you may feel like you are going backwards. Everyone’s journey is different but the diagram below shows some of the emotions you might feel.

You may never reach a state of full acceptance and will likely bounce between different emotions. This is natural and it is important to take as much time as you need in each stage.
Coming to terms with a diagnosis of CKD can have physical side effects, on top of those that you already experience because of your condition.

**These may include:**
- Difficulty sleeping
- Loss of appetite
- Lack of energy
- Low mood
- Anxiety

It is important to talk to your doctor if you are affected by any of these issues. It is normal to feel stressed after receiving a potentially life-changing diagnosis. How you cope with that stress will have a big impact on all areas of your life.
The shock of receiving a diagnosis can stop us from taking in all of the information that is given to us. It is important to take time to reflect on what you have been told. Don’t be afraid to ask your doctor or nurse to repeat or clarify something if you don’t understand.

There may be practical things to consider such as work, travel and financial considerations. Talk to your doctor or nurse about any concerns that you may have. They can give advice or point you in the direction of experts for issues such as applying for benefits.

There are links to further sources of information at the end of this leaflet.

Your family and friends will also be feeling a lot of the same emotions as you but may be afraid to discuss them for fear of upsetting you. Talking to them can help reduce worries on both sides. You may like to involve a family member or friend by inviting them to some of your doctors’ appointments so they can ask their own questions. This will save you from having to explain things to them.

It is important to look after yourself. Do things that you enjoy, such as going for a walk or taking part in a hobby. Finding things that relax you such as reading or listening to music may also help.
Knowledge is power. Understanding your diagnosis can help reduce worries and allow you to make an informed decision about your treatment. Being diagnosed with CKD is likely to have a big impact on your life but it is important to remember that it is still your life and that CKD is just one aspect of this.

The main thing to remember is that you are not alone and there is support available if you need it.
Where can I find out more information?

- Your renal unit may have a dedicated psychologist or counsellor that you can speak to. Ask your kidney doctor or GP for a referral to specialist support if you feel this will help.
- Patient View - [www.patientview.org](http://www.patientview.org) – online access to your health records. Ask your renal unit for details about how to join.
- Kidney Care UK - [www.kidneycareuk.org](http://www.kidneycareuk.org) - the leading kidney patient support charity providing advice, support and financial assistance to thousands every year. A free counselling service is available through the charity. See the website for details.