



Section 4: Frequently Asked Questions About CKD

When people are told they have chronic kidney disease (CKD), the first questions they often have are “How long will I live?” and “How well will I live?” This section answers these and other questions about CKD, while also presenting thoughts from patients.

1) What is chronic kidney disease (CKD)?

“About 2 years ago, I was constantly going to the bathroom all the time, you know, the lower part of my back is always hurting and I was wondering why...and so they diagnosed that kidney problem.”

–Dialysis patient

ANSWER:

Chronic kidney disease is permanent kidney damage due to injury or disease. CKD ranges from mild, to severe. If CKD reaches the point of kidney failure, dialysis or a kidney transplant is needed to support life. Since CKD may worsen over time, early diagnosis and treatment can help slow down the damage, depending on the cause of the problem. (See Section 5: Chronic Kidney Disease – What You Can Do) If your doctor says you have a kidney problem, find out the medical name (and spelling) for your diagnosis, if you can. Knowing the name can help you look for more information.

2) How long can I live with chronic kidney disease?

“As of June, 2001, I marked my 30th year on hemodialysis.”

–Dialysis patient for 30 years

ANSWER:

Many people think that if their kidneys fail, they will die immediately. This used to be true 40 years ago when there were not enough dialysis machines to go around and medical knowledge about kidney disease was limited. It is no longer true today. How long you can live with CKD depends on your age, other health problems, and how involved you become in your care. Some people with early CKD never have kidney failure. Others reach kidney failure and live for decades with dialysis or kidney transplants. There are major advances in today’s healthcare—we have better drugs, know more about how to slow down kidney failure, and have technically advanced dialysis machines. But the most important factor is still the individual who has the disease. Research shows that patients who become partners in their care live longer. So, ask questions, and explore with your doctor and care team the best way for you to help manage your disease.



Section 4: Frequently Asked Questions About CKD *cont.*

3) How good will my life be with CKD?

“Think Positive! Always think on the positive end. It could be worse, but it’s not. You know, think of the person who is worse off than you are. Nowadays they’ve got a lot of things that can help you, but it’s your attitude, it’s more your attitude than anything else—how you think about it.” –Dialysis patient

ANSWER:

How good your life can be with CKD depends on you! In the early stages, CKD may have symptoms that are so subtle you don’t even notice them. In later stages, fatigue, itching, loss of appetite, and other symptoms can reduce your quality of life—if you don’t act. How? All of these symptoms can be treated. Learn what to watch for and tell your doctor, so you can get the help you need. You can also keep a good quality of life by following your treatment plan. For example, taking your medications in the right doses at the right times may help slow down your kidney disease. Your quality of life with CKD depends on your attitude, and how you accept the changes and take control of your health and your life.

4) Can I still have a good life if I need dialysis?

“I had to come to terms with the fact that this was the way things were going to be for the rest of my life. Once I did, I stopped feeling sorry for myself—and decided that I would do everything I could to make the best of my situation.”

–Dialysis patient for 32 years

“Start working toward your dream whatever it may be. Ask yourself what you want your life to be, and then make it happen. It’s up to you. It’s in your hand to make it better.”

–Dialysis patient for 30 years

ANSWER:

Yes, you can live long and live well with dialysis. Many people—even those with family members on dialysis—don’t know that there are several types of dialysis. You can choose a type of treatment that lets you keep doing all or most of the things you value. Some people with CKD put off dialysis as long as they can, because they are afraid. But people who start treatment before they are terribly ill and malnourished do much better. And people who are very sick before they start dialysis are often surprised to find that they feel much better a few weeks or months after starting dialysis. The unknown that you imagine is often much scarier than the reality. Learning as much as you can, and talking to patients who are doing well, will help you see that you can have a good life on dialysis.

**Section 4: Frequently Asked Questions About CKD *cont.*****5) I'm tired all the time. Is there a treatment for fatigue?**

"I've had a job since I've been 13, and at times in my life I've had two or three jobs at one time. And now I just like, I can't hardly get up and go sometimes, you know? It's just hard for me to get up and go. I had one unemployment check in my whole life. So I've always worked. And now I'm not working." –CKD patient

ANSWER:

Even healthy people complain of being tired. But people with CKD can be so exhausted that they fall asleep during the day—even after 8 to 10 hours of sleep at night. One reason for fatigue can be anemia, a shortage of oxygen-carrying red blood cells. People with CKD often have anemia because damaged kidneys make less of a hormone called erythropoietin (epoetin, or EPO). EPO signals the bone marrow to produce new red blood cells. Without a constant supply of new red blood cells, the body has less oxygen—so you are more tired, feel cold, can't concentrate, and are less able to fight disease. Untreated anemia can damage your heart, and heart disease is the leading cause of death for people with CKD. If your fatigue is due to anemia, your doctor may prescribe injections of a synthetic form of EPO.

6) How can I keep my kidneys working as long as possible?

"...It's not written in stone that you're going to have to have dialysis. But, they let you know it's possible. I want the facts, I want the facts. And I want, you know, some options. Don't tell me that this is the only way out." –CKD patient

ANSWER:

There are a number of treatments, including medications and lifestyle changes, that may help keep your kidneys working longer. People can even get transplants before having dialysis, especially if they have a willing living donor. You need to ask your physician exactly what would help *you*. For more information on possible treatments, see *Section 5: Chronic Kidney Disease – What You Can Do*

**Section 4: Frequently Asked Questions About CKD *cont.*****7) Should I keep working?**

“At the job I’ve got now the boss has told me... ‘You work what you can work. When you don’t feel like working, you go home. There’s nothing going to be held against you, you just do it as you can handle it.’ And that makes me feel pretty good.” –CKD patient

ANSWER:

Disability payments may sound like a pretty good deal, but most people find that disability pays much less than working—but your bills don’t go away. Plus, once you get on disability, people worry about finding a job and risking losing their disability. So if you have CKD and you are working, try to keep your job if you can, or find a new one that fits better with your current situation. Work can make you feel like you’re still *you*, even with kidney disease, and that you are still helping to support your family. Work may also be an important part of your social life. If your work offers health insurance, it may be easier for you to get good medical care and pay for medications. If you find that you feel too tired to work, see your doctor! Fatigue can be caused by anemia, which can be treated. Ask your employer if you need an accommodation—more breaks, a different shift time, or energy saving devices to keep your job. You can find helpful information about employment support programs, laws, and resources to help people with disabilities on the Social Security website (<http://www.ssa.gov/work/index2.html>).

**Section 4: Frequently Asked Questions About CKD *cont.*****8) What questions should I ask my doctor?**

“When your doctor is prescribing medication to you, ask him about what you are taking. You know, because a lot of times they just give you stuff, and you take this and go to the drugstore and pick this medication up, and the pharmacist will tell you, ‘Well, did they tell you about the side effects, or did they tell you...?’ And on the little pamphlets, it has all that on there, but your doctor never tells you any of this. So ask them about all that.” –CKD patient

ANSWER:

No two people are alike, so asking questions is the best way to find out about *your* health. On the Life Options website (<http://www.lifeoptions.org>), you can download a *Patient Interest Checklist* that will help you figure out questions. You’ll also find a few basic ideas below, and you can add your own. If you write your questions and show the list to your doctor, you may be more likely to get them answered. Write down the answers, too—or have a family member come along to help you remember the answers.

- 1) What percent of kidney function do I have now?
- 2) What is the cause of my kidney problem?
- 3) What are my lab test results right now?
- 4) What can I do to keep my kidneys working as long as possible?
- 5) What treatment is available for my symptoms? (List symptoms)
- 6) What are the next steps for my treatment?
- 7) Will I eventually need dialysis or a transplant, if so, how long might it be until I do?

**Section 4: Frequently Asked Questions About CKD *cont.*****9) Where can I find more information about chronic kidney disease?**

“I went to the library first. That was my first stop. I went, I just looked in the, you know, they have a computer thing and I just looked up under the kidney disease first, and then I just went and found that list and I just pulled out books I thought would be interesting.”

–CKD patient

ANSWER:

Asking questions and getting them answered—by a healthcare professional or in a book or other reliable source—is a key part of doing well with any chronic disease. Ask your healthcare team to teach you about your condition and to give you any information they have. Never feel shy about coming to a clinic visit with a list of questions—and write down the answers. At the Life Options website (<http://www.lifeoptions.org>), we have a long list of kidney links and many booklets and fact sheets about kidney disease that you can read and/or download. The library is another option. The National Kidney Foundation (NKF), American Association of Kidney Patients (AAKP), and the United Network for Organ Sharing (UNOS) are sources of information and support. Depending on the cause of your kidney problems, there may be another organization to help you—type your diagnosis into a search engine on the Internet to learn more.