

Chronic Kidney Disease – Life After Diagnosis

I was diagnosed with chronic kidney disease in 1996. I had gone to see my internist because I had been suffering with severe headaches and nausea for a month. He gave me a physical. I peed in a cup and a nurse drew some blood. He sent me home with medication for the headaches.

Thirty minutes after I got home, I heard banging on my door. When I opened it, two nurses from the doctor's office were there. They told me I had to go to the emergency room immediately.

Based on my blood pressure, I could have a stroke any minute. My blood pressure was 210/102. Normal blood pressure is 120/80. I found out later that kidneys regulate blood pressure. High blood pressure is the second most common cause of kidney disease. However, in my case, my high blood pressure was caused by kidney disease.

My glomerular filtration rate was 3. Any number 60 and above is normal. A low filtration rate is the prime indicator of kidney disease. In fact, the nurses told me I had end-stage renal disease, ESRD, the fifth and last stage of chronic kidney disease.

I was on the verge of death from kidney failure if I didn't stroke out first.

Less than an hour later, I was a patient at Rex Hospital in Raleigh, North Carolina. The medical team told me both my kidneys had failed. I was stage 5, end stage renal disease, ESRD. My body was full of fluid and toxins that had to be removed immediately. They told me I was scheduled to have a catheter inserted into my upper chest that afternoon. Fistula surgery to create access for regular dialysis sessions would follow in a week.

I was scared. I was 26 and was about to have the first surgery of my life. I had never even heard of kidney failure.

My story is typical. As with most people with kidney disease, I walked into my doctor's office with a list of seemingly unrelated symptoms and walked out as a chronic kidney disease patient.

When most kidney patients look back, we realize there had been many early warning signs of our disease. We just didn't know they were warning signs.

In my case, the first signs showed up when I was a child. My pediatrician's tests had consistently found protein in my urine. My parents were concerned, but the doctor didn't advise them to follow up with a specialist. High protein levels and blood in urine were common on my mom's side of the family.

Besides, it's perfectly normal for humans to have low levels of protein in our urine from time to time. Occasional high levels are also pretty normal, especially for children after strenuous exercise or when they're sick.

But consistently high levels, known as proteinuria, can be a sign of kidney disease. I didn't find out until years after my diagnosis that proteinuria is a symptom of Alport syndrome, a genetic disorder that essentially guarantees kidney disease.

I hadn't exactly been a poster child for health. I've had migraines all my life and took lots of over-the-counter medicines to ease the pain. These were the same medicines that later turned out to cause kidney damage for many people – nonsteroidal anti-inflammatory drugs, NSAIDs:

- Aspirin
- Ibuprofen (trade names Advil and Motrin)
- Naproxen (tradenames Aleve and Naprosyn)

NOTE: Acetaminophen, also known as paracetamol, APAP, Tylenol and Panadol, are NOT NSAIDs. You still should not take too much of it.

I was also tired a lot and had frequent bouts of pain. No one seemed to know why.

In 1995, I tried to enlist in the Coast Guard, which had been a dream of mine for a long time. But the required urinalysis discovered blood in my urine, a condition called hematuria. It disqualified me from enlisting. I was crushed. I had always considered blood in my urine to be a minor inconvenience. I didn't know it might also be a sign of kidney disease – and the Coast Guard didn't tell me, either.

By the time I went to see my internist that day in 1996, I had a full boatload of kidney disease symptoms without knowing what they were. I was suffering from severe migraines and nausea, vomiting, high blood pressure and wicked fatigue. I worked and I slept. That was about it. Having a social life was impossible, which was probably one of the reasons I was in a failing relationship with my then girlfriend.

My life changed completely the day I was diagnosed.