

A JOHNS HOPKINS PRESS HEALTH BOOK

Thriving with KIDNEY DISEASE

2nd Edition

A Practical Guide
to Taking Care
of Your Kidneys
and Yourself



WALTER A. HUNT

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Thriving with **KIDNEY DISEASE**

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Foreword by Ronald D. Perrone, MD



JOHNS HOPKINS UNIVERSITY PRESS

Baltimore

To my mother and sister, who did not survive kidney disease

Note to the Reader: This book is not meant to substitute for medical care of people with kidney disease, and treatment should not be based solely on its contents. Instead, treatment must be developed in a dialogue between the individual and his or her physician. Our book has been written to help with that dialogue.

The author and publisher have made reasonable efforts to determine that the selection and dosage of drugs discussed in this text conform to the practices of the general medical community. The medications described do not necessarily have specific approval by the US Food and Drug Administration for use in the diseases and dosages for which they are recommended. In view of ongoing research, changes in governmental regulations, and the constant flow of information relating to drug therapy and drug reactions, the reader is urged to check the package insert of each drug for any change in indications and dosage and for warnings and precautions. This is particularly important when the recommended agent is a new and/or infrequently used drug.

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Understanding Chronic Kidney Disease

ON AUGUST 11, 1997, a catheter was implanted in my abdomen so I could receive dialysis. My kidneys had failed. I could still urinate, but I couldn't eliminate all the waste products that I accumulated from food. It's natural to take urinating for granted—it's something we've done since the day we were born. As adults we think about going to the bathroom only when we can't get to one because we're trapped in a business meeting, say, or stuck in traffic. And we do not usually discuss urination in polite company. When we need to urinate, we just excuse ourselves or adopt a euphemism—we're going to the powder room or we're going to see a man about a horse.

When urinating is no longer a normal, almost trivial activity, our lives are altered. When urinating becomes a focus of our attention, our lives are radically changed. When my kidneys started to shut down, I found the prospect of kidney failure overwhelming. I had so many questions: *Why are my kidneys failing? Is there anything I can do to save my kidneys? How will I know when my kidneys have failed? What will it feel like when my kidneys fail? Is there a cure or treatment for kidney failure?*

The good news, as I found out, is that kidney failure is no longer a death sentence, as it once was. Those of us with kidney failure can still have productive lives. The bad news is that we may spend countless hours going to dialysis and doctors' offices and making

sure we take all our medications. There are some aspects of the disease that we can't control. One aspect of the disease that we *can* control is how well we understand it. Understanding kidney failure—what causes it, how it may affect our lives, and what options we have—can help us take an active role in treating our disease, lifting our spirits, achieving a better outcome, and improving our quality of life.

How Many People Have It?

Chronic kidney disease (CKD) (chronic kidney disease, chronic kidney failure, and renal insufficiency are used interchangeably with CKD) can develop from many causes and results in a progressive decline in kidney function to the point of requiring treatment, such as dialysis (chapter 6) or transplantation (chapter 7). CKD proceeds in five stages over many years (chapter 4) and in the final stage is known as *kidney failure*, formerly known as end-stage renal disease.¹ Fortunately, not all cases of CKD progress to kidney failure. However, screening of those at risk is an important step.

CKD and especially kidney failure have been increasing rapidly worldwide over the past two decades, affecting almost one billion people and killing nearly one million, based on 2013 data,² and touching the lives of men more than women. Here is some insight into what the world has experienced.

The number of people with CKD (called *prevalence*) is not uniform throughout the world, and deaths from kidney failure are often higher in countries without enough facilities or financial resources for dialysis and transplantation. In other cases, significant minority populations tend to have higher prevalence rates of CKD than the majority population. Examples of the latter case are the United States, Canada, and Australia, whose minority populations show prevalence rates two to ten times higher than the majority population.

In general, the United States, Canada, East Asia, and Western Europe have the greatest problems with kidney failure, whereas much of Latin America, Southern Asia, and Eastern Europe have the fewest problems.³ The major cause is diabetes. Kidney failure is seen more often in men than in women with only a few exceptions in minority populations. Although some regions of the world have an extremely higher problem with kidney failure than others do, the reasons for this are not yet understood, although it may have to do with diet (chapter 5). For more information about global prevalence and incidence of kidney failure, see the appendix.

With this brief global perspective of kidney disease, let us examine the data for the United States in more detail, since they are better characterized than the rest of the world and are more recent.³ The total numbers of people with kidney failure and of new cases are among the highest in the world, although the number of people with CKD has been stabilizing over the past few years. Still, 15 percent of the population has CKD. By the end of 2018, over 786,000 people in the United States were being treated for kidney failure. Uncontrolled diabetes was attributed to nearly half of the newly diagnosed people with CKD. Those with kidney failure required either dialysis or transplantation to live. During 2018, doctors diagnosed almost 132,000 new cases of kidney failure from all causes, although the number of these cases has leveled off relative to the rising population of the United States.

The primary causes of CKD are diabetes, high blood pressure (*hypertension*), glomerular diseases, and cystic diseases, such as polycystic kidney disease (PKD) (chapter 3). The number of people afflicted with these diseases who have progressed to kidney failure are shown in table 1.1. In figure 1.1, you can see the percentage of all people with kidney failure that can be attributed to each cause during the same period. The picture is changing, however, with more new cases being attributed to diabetes (figure 1.2).

Diabetes and hypertension account for 65 percent of the cases of kidney failure. The rest of the cases result from glomerular

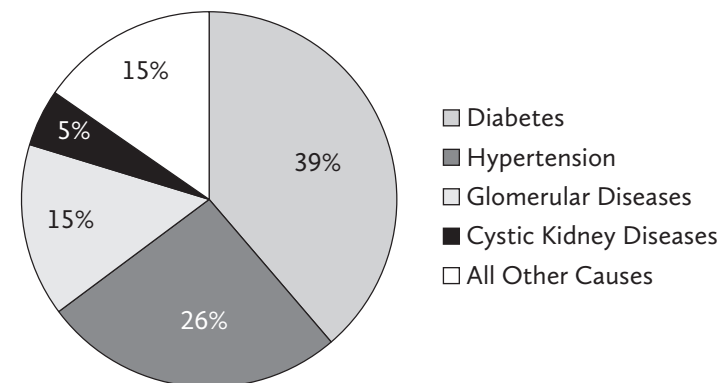
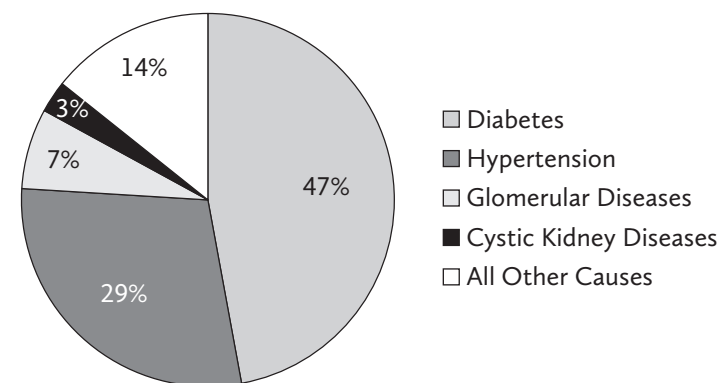
TABLE 1.1 Kidney Failure in the United States, 2018

Cause	Number of Cases
Diabetes	304,379
Hypertension	204,889
Glomerular diseases	117,235
Cystic diseases	38,657
All other causes	120,723
Total	785,883

diseases, cystic kidney diseases, and other causes not reflected in figure 1.1 (chapter 3). Alarming, the new cases attributed to diabetes and hypertension jumped to 76 percent during 2018 (figure 1.2). Diabetes, the most common cause of kidney failure, accounts for 47 percent of new cases. Because obesity can lead to diabetes and because an increasing number of people are obese or morbidly obese, more people are at risk of CKD and kidney failure. The new cases of kidney failure due to diabetes have accelerated to over sixty-two thousand cases in 2018. Most people are unaware that they even have CKD until later stages of the disease.

Demographically, men have a higher number of total and new cases of kidney failure than women do (figures 1.3 and 1.4),³ those 45–64 years old and above have a higher number of total and new cases of kidney failure than those under 45 (figures 1.5 and 1.6). Over the past decade, the total number of cases has climbed steadily with a greater increase among the elderly.

Racially, whites have more total cases of kidney failure than do African Americans, Hispanics, and other racial and ethnic groups (figures 1.7 and 1.8). However, these data do not account for the relative size of the population of each group. When this is done, the greatest burden of kidney failure is among Native Hawaiians and Pacific Islanders, being over six times greater than among whites.⁴

FIGURE 1.1. Number of Cases of Kidney Failure in the United States by Disease, 2018**FIGURE 1.2.** New Cases of Kidney Failure in the United States by Disease, 2018

Of the other racial groups, African Americans have the next highest rates, with the rest of the groups having lower rates but all having rates higher than those for whites. Despite this bleak assessment, there is some good news. Native Americans have shown a considerable improvement in the number of total cases over the past

Coping Skills for Patients and Caregivers

When the reality of CKD set in, I was frightened and didn't know what to do. Over the decade during which my kidneys were progressively failing and at the end of which I received a successful transplant, I learned how to manage my disease. Sometimes it wasn't easy. General information about CKD and treatment options was available, but information about *how* to decide which options to pursue and *how* to adapt to them were not. From my experience, I will share some considerations I had with my disease that I hope will help you with your own experience. First, here are some general coping skills I learned that helped me. They may help you, too.

Move Quickly through Denial and Face Your Disease Directly

I experienced all the emotional reactions to loss, described earlier, to varying degrees, but finally realized that I was ultimately responsible for my health. I had to accept that I was sick. Although the thought was unpleasant and I wanted to hide from it, I was better off confronting my disease. No one would be more motivated than I would be to get well and live as well as I could. In a sense, I felt empowered by accepting my disease. This can be true for you too, although the time needed to reach acceptance may vary.

Be Your Own Advocate

In addition to educating myself about my disease to reduce fear, I found it important to use my knowledge to help my doctors give me the best care possible. Doctors cannot read minds. They often rely on feedback from their patients about how you feel and about reactions to treatments that they prescribe. If you do not tell your doctors about your reactions to their treatments, they will have a more difficult job in treating you. Furthermore, doctors should understand how these treatments affect your life. After all, *you*

must live with them. Do not be afraid to ask questions or challenge a treatment option if you think you cannot handle it. If you are too sick to be your own advocate, find someone who can do that for you. It can be a family member or friend. My friends helped me when my condition was very serious.

Doctors do their best to be aware of the latest treatments available for you. However, some new approach may come along that you might want to pursue. Discuss it with your doctor to determine if it might be beneficial for you.

Embrace Your Inner Strength

We each have different personalities and temperaments. On one extreme, some people feel weak and powerless, sensing that they have little control over their lives. Mostly, they depend on others for support and feel that they cannot live without the help of others. At the other extreme, some people feel in total control and independent. They can take on the world and do things with help from relatively few people. Most of us fall between these two extremes.

When adversity strikes, even the strongest of us can question ourselves and doubt our ability to conquer our situation. The weakest can feel even more helpless and hopeless. I was in the middle. I went through many self-doubts when I knew my kidneys would fail. However, I discovered in time that I had a reserve of inner strength that I had not appreciated. To survive psychologically, I had to find that inner strength. I am not sure how I found it, but I think it came from a strong desire to survive. Once I knew I had this inner strength and realized I needed to improve my situation and conquer my disease largely alone, I embraced my strength. You, too, can do it. I have no secret formula, but you will find it, if you allow yourself to look for your inner strength and use it to help you through the difficult times. Some people turn to religion to find the strength, whereas others discover it in their ability to solve their own problems. No matter how you do it, I have learned that finding and embracing your inner strength is worth the journey.

Glossary

Acidosis. Buildup of acid in the blood.

Adrenal glands. Small organs sitting atop the kidneys that secrete aldosterone, promoting fluid and salt retention.

Albuminuria. Protein in the urine. Protein in the urine is a symptom of kidney disease.

Aldosterone. *See* adrenal glands.

Alport's syndrome. An inherited glomerular disease that not only affects the kidney but also vision and hearing.

Anemia. Low red blood cell count.

Aneurysm. Ballooning of a major blood vessel that can rupture, causing massive bleeding.

Angiotensin system. Regulates blood pressure when salt concentration is low; renin stimulates the conversion of angiotensin I to angiotensin II, which constricts blood vessels to raise blood pressure.

Antibody. A protein created by the immune system to attack and destroy foreign entities like microorganisms and organs transplanted from other people.

Antigen. "Name tag" on cells that identifies the cells as belonging to a specific individual.

Atherosclerosis. Buildup of plaque in blood vessels that can contribute to hypertension.

Autosomal dominant polycystic kidney disease (ADPKD). Dominant form of PKD; a child has a 50 percent chance of inheriting the disease from an affected parent.

Autosomal recessive polycystic kidney disease (ARPKD). Recessive form of PKD; a child has a 25 percent chance of inheriting the disease if both parents are carriers of the mutated gene, but the parents do not have ARPKD themselves.

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