

Coping with Kidney Disease

*A 12-Step Treatment Program
to Help You Avoid Dialysis*

Mackenzie Walser, M.D.

with

Betsy Thorpe

and contributions by

Nga Hong Brereton, M.S., R.D., I.B.C.L.C.



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To my wife, Betsy

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Introduction

Kidney disease is a huge, underrecognized and undertreated problem in the United States. In *Coping with Kidney Disease*, I hope to raise awareness about this disease among patients and their families and caregivers, and strongly advocate the benefits of predialysis care. The cornerstone of this treatment is a very-low-protein diet, which, as I have shown through my work with patients at Johns Hopkins University, can effectively delay or indefinitely postpone the need for dialysis in those with kidney failure. This diet, and many other effective treatments, will be explained and illustrated with patient histories throughout the book, such as this one:

Horace Lysenko, a 54-year-old self-employed art consultant, was referred to me four years ago with the following history: One year before, he had developed severe kidney failure caused by obstruction from an enlarged prostate. The prostate gland, which surrounds the urethra, frequently becomes enlarged in older men, obstructing the flow of urine from the bladder. Following surgical relief of the obstruction, his kidney function was only partially restored: Two-thirds of his kidneys had been destroyed by the increased back pressure from his bladder. His kidney function was measured at one-quarter of normal. He was placed on a very-low-protein diet, supplemented by essential amino acids—the treatment outlined in this book. In the ensuing five years, his kidney function has actually improved somewhat. Despite severe damage to his kidneys, he remains free of symptoms and may never go on dialysis.

The Scope of the Problem

Like Horace, millions of Americans have reduced kidney function (that is, kidney failure), and don't know it. At least 6 million people have an elevated blood level of creatinine, a likely sign of kidney failure. Among older people with diabetes or hypertension (which includes the majority of older people), 1 in 8 has kidney disease. Among noninstitutionalized adults in the U.S., 1 in 10 has either an abnormal amount of protein in their urine or reduced kidney function, or both. Americans of all ages have kidney failure, especially older people, blacks, and Native Americans.

The Lack of Effective Care

Kidney failure is often undertreated by doctors. Patients frequently are told to come back for care only when they are in such discomfort that they are ready for dialysis. Numerous articles have been published in medical journals reporting various means to slow the downhill course of kidney disease; even so, most patients never receive these treatments. Untreated kidney failure usually progresses to end-stage renal disease, at which point dialysis or transplantation becomes essential for survival. Every year some 60,000 people start dialysis in the U.S. But many people on dialysis don't feel well. In fact, dialysis is so grueling that, according to the official government report of the U.S. Renal Data System for 1999, "1 in 5 patients withdraws from dialysis before death." In other words, in effect they commit suicide. It should be noted, however, that death by withdrawal from dialysis is usually a "good death," meaning that suffering is minimized. But clearly it is best to avoid dialysis as long as possible.

The Solution

First, kidney failure has to be identified, and then, measures to treat it must be undertaken. The United States is shockingly deficient in both areas.

Symptoms of kidney failure don't appear until most of kidney func-

tion has already been lost. However, people at risk for kidney disease can check their own urine using simple tests, and get their physicians to check their blood for problems early on. If more at-risk people found out earlier that they had kidney disease, they could markedly improve their future health by taking effective steps immediately.

This book lets people know about the available and effective treatments (many of which can be done in their own home) that can slow the progression of kidney disease. By these means, people can delay dialysis or transplantation for as long as possible or even totally avoid either procedure.

The treatment I describe alleviates symptoms markedly. Appropriate care for kidney failure includes a very-low-protein diet, with supplements, as well as blood pressure control and specific therapies to regulate the metabolism of sodium, potassium calcium, phosphorus, and acid, and to correct anemia, high blood cholesterol, and high blood uric acid (which causes gout). Certain drugs are helpful and others are contraindicated. Transplantation, which has become more successful but is limited by the number of donors, may become more widely available; this book discusses how.

Note: This book does not discuss children with chronic kidney disease. As children are treated at Johns Hopkins exclusively by pediatricians, I have no experience caring for them.

Ella Johnson, a 49-year-old schoolteacher came to Johns Hopkins in 1994 for treatment. She suffered from polycystic kidney disease, an inherited kidney disease that consists of cysts in the kidneys. Her mother had also had polycystic kidney disease and had been treated here for several years. Ella also had high blood pressure and recurrent urinary tract infections. Her left kidney could easily be felt during a physical exam, and was therefore considerably enlarged. She was placed on a low-protein diet supplemented by essential amino acids. She also started fish oil capsules and gets regular exercise. During seven years of follow-up, her kidney failure has progressed very slowly. The rate of loss of her kidney filtration capacity, also known as glomerular filtration rate, is only 1.8 ml per minute per year, compared with an average rate of about 7 ml per minute per year in patients with polycystic kidney disease. At this rate, she will be well into her 70s before she needs dialysis or a transplant.