

Help, I Need Dialysis!

How to have a good future
with kidney disease



Dori Schatell, MS & Dr. John Agar



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The authors extend our profound gratitude to the people with kidney disease and the clinicians who took the time to review this book draft and provide their comments. Each of your contributions helped to create a better final product, and we appreciate your time and thoughtfulness more than we can say. We are also very grateful for a generous donation that made possible all of the original illustrations in this book and helped bring the concepts to life.





Disclaimer

Help, I Need Dialysis! is a guide for people who have chronic kidney disease or kidney failure. Use of this book does not replace the need to talk with your doctor and healthcare team about your care and your options. If medical advice or other expert help is needed, seek the advice of a competent professional.

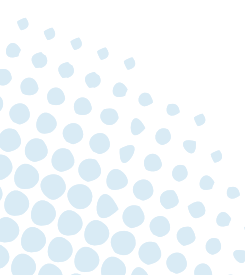
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Help, I Need Dialysis!

How to have a good future with kidney disease

A Book for People with Stage 3–5 CKD

Each year, more than 100,000 Americans start dialysis. Complete, accurate information about ALL dialysis options has been hard to find...until now.

*Anyone facing the life-changing decisions that come with kidney failure simply must read **Help! I Need Dialysis**. This information could add years and quality to their lives.*

About the authors. Two credible, renowned authors who are passionate about better treatments have collaborated on this book. Together they tell the full story.

Dori Schatell, MS — Executive Director of the non-profit Medical Education Institute. Ms. Schatell has 23 years of experience specializing in evidence-based and empowering patient education. She has written hundreds of educational pieces, conducted research and published peer-reviewed articles in nephrology, and launched several award-winning websites including Kidney School and Home Dialysis Central.

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About the Medical Education Institute, Inc.

The non-profit Medical Education Institute, which was founded in 1992, serves the mission of helping people with chronic disease learn to manage and improve their health. Our vision is to create a world where people with chronic kidney disease are knowledgeable, active partners in their medical care, using treatment options that allow them to live full, productive lives. Our programs include Kidney School (www.kidneyschool.org), Home Dialysis Central (www.homedialysis.org), and Life Options (www.lifeoptions.org). Our support comes from educational grants, government contracts, project fees, sponsorships from corporations, and individual donations.

Foreword

“Knowledge is an antidote to fear” Ralph Waldo Emerson

Being diagnosed with chronic kidney disease and needing dialysis is scary. You are undoubtedly afraid and probably feel totally overwhelmed. You have dozens of questions, but may not know where to find answers. Most of all, you wonder if life will ever be the same again.

Although life on dialysis may be different, it can still be very, very good. This book will help you fit dialysis into your lifestyle and live life on your own terms. It will arm you with the knowledge you need to understand the many different facets of dialysis care and to maintain your quality of life.

Knowledge is power—the power to make the best choices, to take control of your health, and to be an equal partner on your health team. After all, we are a society of “take charge” people. We love to be the one to “call the shots.” Yet we are often hesitant to transfer that assertive “can-do” attitude to the seemingly mysterious area of health care. The contents of this book will help you and your care partner do just that.

That’s not to minimize the adjustments. Anything new can be daunting. Think about learning to drive as a teenager. You might have been nervous about negotiating traffic and worried about fender benders, but by taking it “step by step” you became a confident, competent driver. Believe me; it’s not any different with dialysis!

Will there be bumps in the road? Absolutely. Will it always be easy? Of course not. However, consider this simple truism: most things in life are not without their unique challenges. I assure you that your life can be as good and as fulfilling as before, maybe even more so!

You may be thinking “who is she to tell us that a good life can coexist with dialysis”? I do speak from a certain amount of experience—besides being a nurse, my late husband was on home hemodialysis for 25 years. During the entire time, he worked 50-60 hours per week, played golf, and volunteered in our community. Together we traveled, renovated an old house and raised our son. You too can still have a busy, satisfying life.

The authors begin with the basics and gradually strip away the complexities of dialysis by presenting concepts in a straightforward, understandable way. The book is divided into easily readable chapters, each on a specific aspect of dialysis in a stand alone format for quick reference. Topics run the entire gamut from the role of the kidneys to the process of dialysis to questions about intimacy...and everything in between. Interspersed in the chapters are stories of real people on dialysis, those whose lives are immensely rewarding and personally satisfying.

Ms. Schatell and Dr. Agar bring literally decades of experience and expertise in the kidney community to the writing of this excellent book. Both authors are so in tune with those on dialysis that I have often accused them of being “patients in disguise.”

A final cautionary word: Being on dialysis won’t automatically elevate you or your care partner to a state of instant perfection. You carry your former self into this new chapter of your life. You are the same person with the same hopes, dreams and goals as before and being able to pursue those goals is as important now as it ever was. This book will help you do that.


The authors say it best: this book’s goal is “to demystify kidneys and dialysis and to help you take charge of your health care.” They have succeeded admirably.

Denise Eilers, RN, BSN



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Become Your Own Expert

KEY POINT

You have options. You can match your treatment choice to your lifestyle. Learn all you can so you can choose a treatment that will help you feel your best and live your life the way you want to.

There are 305 million people in the U.S., and about one in 12 have some degree of chronic kidney disease (CKD).¹ More than half a million are being treated for kidney failure right now with dialysis and transplant. And each year, more than 100,000 people learn that their kidneys have failed. *You are not alone.*

You may not have known it was happening, but kidney failure from CKD is a long, slow process that takes months or years. Each kidney has about a million *nephrons* to filter the blood. You can lose most of your kidney function before you notice any symptoms. Some people say they feel fine and can't believe their kidneys don't work, even when blood tests show the damage.

Learning that you will need dialysis or a kidney transplant is a shock for you and the people who care about you. Maybe the news was a bolt from the blue, and you just found out. Or, maybe you're on dialysis now and want to know how your treatment works and how you can feel your best. Either way, we wrote this book for you. We're on your side. Here, you can learn what you need to know to make choices that can help you live a good life.

A *good* life? With *dialysis*? Is that even possible?



Yes. Kidney failure is the end of your kidneys—but it does *not* have to be the end of you, and your goals and dreams. If you make good choices, you may feel well and have enough energy to finish school, keep your job, do Ironman triathlons, go kayaking, climb a mountain, or ride a bike across the U.S. We are not making this up: people on dialysis have done *every one* of these things. Of course, not everyone on dialysis climbs mountains! Chances are, the folks who do so started before their kidneys failed. But if you have a passion—from baking to square dancing, or from working in your garden to raising prize puppies—dialysis alone should not stop you from doing it.

As Douglas Adams says in the *Hitchhiker's Guide to the Galaxy*, “Don't panic.” You have options. Many other health problems don't have effective treatments. Just 40 years ago, there were not enough dialysis machines to help all of those who had kidney failure. The treatment was experimental and costly. Most health plans would not pay for it. In some parts of the U.S., like Seattle, “Life or Death” committees of citizens and clergy would decide who would get the treatment and live—and who would not.² Today, some people live fully for decades with dialysis and/or kidney transplant(s), and you'll meet some of them in these pages. In the past, most were not so fortunate. It may not seem like it right now, but in a very real way, you are lucky.

A Normal Life

Your goal is to have as normal a life as you can despite your kidney failure, isn't it?

- You want to feel good from one day to the next.
- You want to keep your job if you have one, and your health plan.
- You want to spend time with your family and friends and be able to plan ahead.
- You want to keep doing your hobbies or volunteer work.
- You may be in a relationship—or want one—that includes a loving sex life, and want that to continue. Depending on your age, you may want to have a child.
- You want to eat good food, and not have to worry too much about what is or isn't in it to keep you healthy.
- You want a nice cool iced tea or lemonade on a hot day.
- You don't want to take (and pay for) a dozen or more pills each day.
- You don't want to be a burden on your loved ones.
- You don't want to have to think about kidney disease day in and day out.

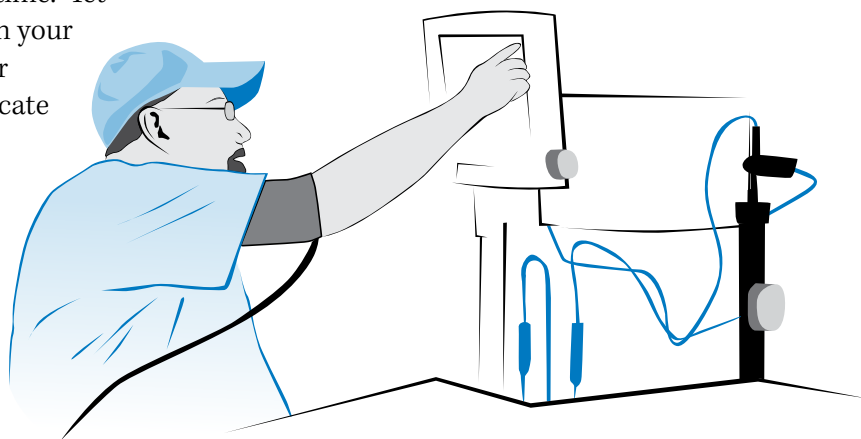
We can help. Our goal is to help you become your own expert so you can reach your goals.

Your Job in Your Kidney Disease

This book will demystify kidneys and dialysis and help you take charge of your health care. That may sound a bit strange, since we're used to thinking doctors are in charge. And, if you have a sudden, curable “acute” health problem, like a broken arm, that makes sense. You are in pain; the doctor can fix you. You get a cast put on, rest and take pain pills, and in a few weeks you're better.

Chronic, long-term health problems like kidney disease are not the same as an acute illness. You have to deal with your illness all day long, day in and day out. But you may only see your doctor once a month for a few minutes. Even if you are on dialysis now, three times a week, your treatment is only supervised for about 14 hours a week—out of 168. That's just 8% of your time. Yet in the 92% of the time that you're out in the world on your own, *you* decide what to eat and drink, manage your symptoms, take prescribed drugs (or not), and advocate for yourself. All of that is part of what we call *self-management*.

We don't call you a “patient” in this book. Do you have an illness? Yes. But whether you want it or not, chronic disease gives you a new job: to keep a positive attitude, learn all you can, and take an active role in your care—not a *patient* one. Your job is to self-manage. In other words, you need to become your own expert. So, in our book, you're a person who self-manages a chronic disease, not a patient.



How do we know that becoming your own expert is important? We talked to people who lived on hemodialysis for 15 years or more. We do research with people who have kidney disease. We've talked to *thousands* of people over the years who have kidney disease and asked what helps them most, in person, on the phone, and through email. You can see our other efforts to educate people about kidney disease and kidney failure on our websites:

www.homedialysis.org | www.kidneyschool.org
www.lifeoptions.org | www.nocturnaldialysis.org

You Have Choices

Most people who face dialysis don't know that their choice of treatment will affect *every* aspect of their lives. In 2009, 91.7% of people on dialysis in the U.S., did hemodialysis (HD) in a clinic three times a week, for 3–4 hours at a time.³ We call this “standard in-center HD.” Most of those 91.7% never even knew they had other options. In fact, the only large study of options awareness in the U.S. found that just 1 in 4 knew of any treatment other than standard HD.⁴

In 2008, Medicare changed the rules for dialysis clinics. Now clinics are *required* to tell you about ALL of the treatment options for kidney failure *and* where to get them. This book may help them do that.

When you finish this book, you will know how your treatment choice can affect:

- What you can eat and drink
- How many drugs you need to take
- How much energy you will have
- How well you will sleep
- Your sex life and whether you can carry or father children
- Whether you will be able to keep your job (and health plan)
- How often you will be in the hospital
- How long you may live

We'll tell you all about it. We've used hundreds of references from medical journals so you have proof that can help you talk with your doctor about what you want to do. And, we share stories from real people who have faced the same choices you face now, so you can see how things are working out for them.

Something else that many people with kidney failure don't know is that ***you can change treatments.*** (NOTE: Some people call treatment options “modalities.”) If one treatment fit everyone all the time, there wouldn't be a need for all of the other options. Based on what you want *your* life to look like, one treatment may be a better fit for you now. Another may work out better for you down the road. Or, you may try a treatment that sounds like a perfect fit, but doesn't work out that way. That's okay, you can switch. In a long life with kidney failure, it's likely that you'll use more than one type of treatment. That's not a failure, it's a life plan!

Try Treatments on for Size

A long-time kidney disease educator has some good advice about choosing a treatment. She suggests that you think through your day and how it might work with each type of treatment you are thinking about:⁵

- **Wake up** – What time would you want to get up? To start or stop treatment for the day? Do you mind seeing dialysis equipment or supplies in your home, or would this be a deal-breaker for you? Do you want to be able to choose when to wake up, or is it okay if a clinic tells you to arrive at 5:00 a.m.?
- **Eat breakfast** – What sort of diet and fluid limits are you willing to live with each day? Standard in-center HD has the most limits, peritoneal dialysis (PD) and short daily HD have fewer, nocturnal HD has the least.
- **Take medications** – How many pills will you want to take in a day? Standard in-center HD has the most pills (about half of people who use it need to take 19 pills a day). Nocturnal HD has the least.
- **Go to work** – Do you have a job? How will your treatment times fit your work life, and how much control will you have? How much will your income drop if you quit your job and take disability? Social Security Disability takes 6 months to start, and pays only about 35% of the average worker’s earned income.
- **Get your treatments** – If you live far from a clinic or don’t have a car, in-center HD can be costly and inconvenient. Home treatments mean that after training you visit the clinic just once or twice a month for clinic appointments. PD or short daily HD treatments can be done throughout the day—is that a plus or a minus for you?
- **Deal with childcare** – Do you have young or school-aged children? Who will care for them if you get your treatments in a clinic? What will happen during school vacations or summer breaks?
- **Eat dinner** – How much will family meals be affected by your diet limits? Will your treatment give you the energy to cook? If not, who will prepare meals?
- **Spend time with family and friends** – Headaches, muscle cramps, and fatigue can keep you from making plans and having fun with your loved ones. What’s important to you?
- **Go to bed** – How well are you sleeping on your treatment choice? Could you sleep with a machine in the room? Could you sleep in a clinic for nocturnal treatments? How will your body image and sex life be affected by your treatment choice?



There are no right or wrong answers to any of these questions—only what will or won’t work for *you*. Your needs may change over time, too. People who have lived with kidney failure for decades often find that over the years they may try *all* of the dialysis types, plus one or more transplants. We will freely admit our bias up front, though: if you use dialysis, *more is better* for both your short- and long-term health.

Every treatment for kidney disease has pros and cons. You are the only one who can decide what will best fit your needs and your lifestyle at any given time. We hope you'll choose a form of dialysis that is more like having healthy kidneys and will help you to feel your best and do what's most important to you. If you choose standard in-center HD, we'll tell you how to get the most benefit from it.

Once you make a choice, you need a *nephrologist* (kidney doctor) who will support you and prescribe it. Your treatment choice affects your lifestyle and even how long you may live. Making a treatment choice for yourself is key to how well you may do. One large study put 2,418 people new to dialysis into three groups, based on how they chose a treatment.⁶

- Group 1 (636 people) made their own choice
- Group 2 (922 people) worked with their care team to decide
- Group 3 (860 people) said their care team chose for them

Five years later, those who made their *own* choice (Group 1) *were significantly more likely to live longer and to get a transplant*. This was true even after adjusting for age, sex, race, other illness, blood test levels, level of kidney function, education, work, and marital status.

You are the one who must live with the treatment from day to day. It makes sense that you'll feel better if the choice is yours. This may mean that you have to persuade your doctor—or change doctors.

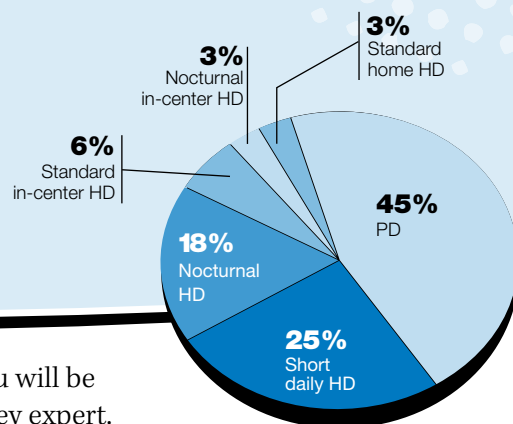
By the way, you don't have to read this book cover to cover. Jump around! Look for what you need right now. If you find that a section has too much detail for you now, skip past it. You can always choose to go back later and delve deeper if you want to.

What Treatment Would Kidney Doctors Choose for Themselves?

In 2010, the Medical Education Institute did a national survey of U.S. nephrologists to find out what they thought about dialysis.⁷ One question we asked was, “*If you had kidney failure and had to wait 5 years for a transplant, which type of dialysis would you choose?*” See the pie chart for what the 629 respondents said.

So, all told, 94% of nephrologists would choose an option *other than* standard in-center HD—yet nearly all Americans with kidney failure get this option. Why? Good question. We suspect there may be a few reasons:

- They're doctors – they figure they can learn the treatment, but you can't (prove them wrong!).
- They don't trust that people who go home for dialysis will really do their treatments.
- It's easier for doctors to have folks dialyze in clinics, where they can see lots of people all at once.



Read on! By the time you finish this book, you will be well on your way to becoming your own kidney expert.

Help, I Need Dialysis!

How to have a good future with kidney disease

Has your doctor told you that your kidneys are failing? Are you afraid of how dialysis might change your life? Then, this book is for you! There are several ways to do dialysis, and you can do some of them in the comfort and privacy of your own home. ***Learn how you can have the best possible life with dialysis.***

Some people live for decades with kidney failure—but this doesn't happen by accident. Find out what you need to do to live long and well if your kidneys fail. This book will help you to choose a treatment that will fit your lifestyle and goals for the future.

For each option, we'll tell you:

- How much time it takes out of your week (awake or asleep)
- How you may feel during and after a treatment
- What limits you may have on what you can eat and drink
- How many medications you may need to take (and pay for)
- How it may affect your work, travel, and exercise
- How it may impact your body image, sexuality, and fertility
- How well you might sleep
- How long people tend to live

Learn about the latest and best treatments, diets, and medications. It's all here.

Become your own expert—and you may add years to your life!



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