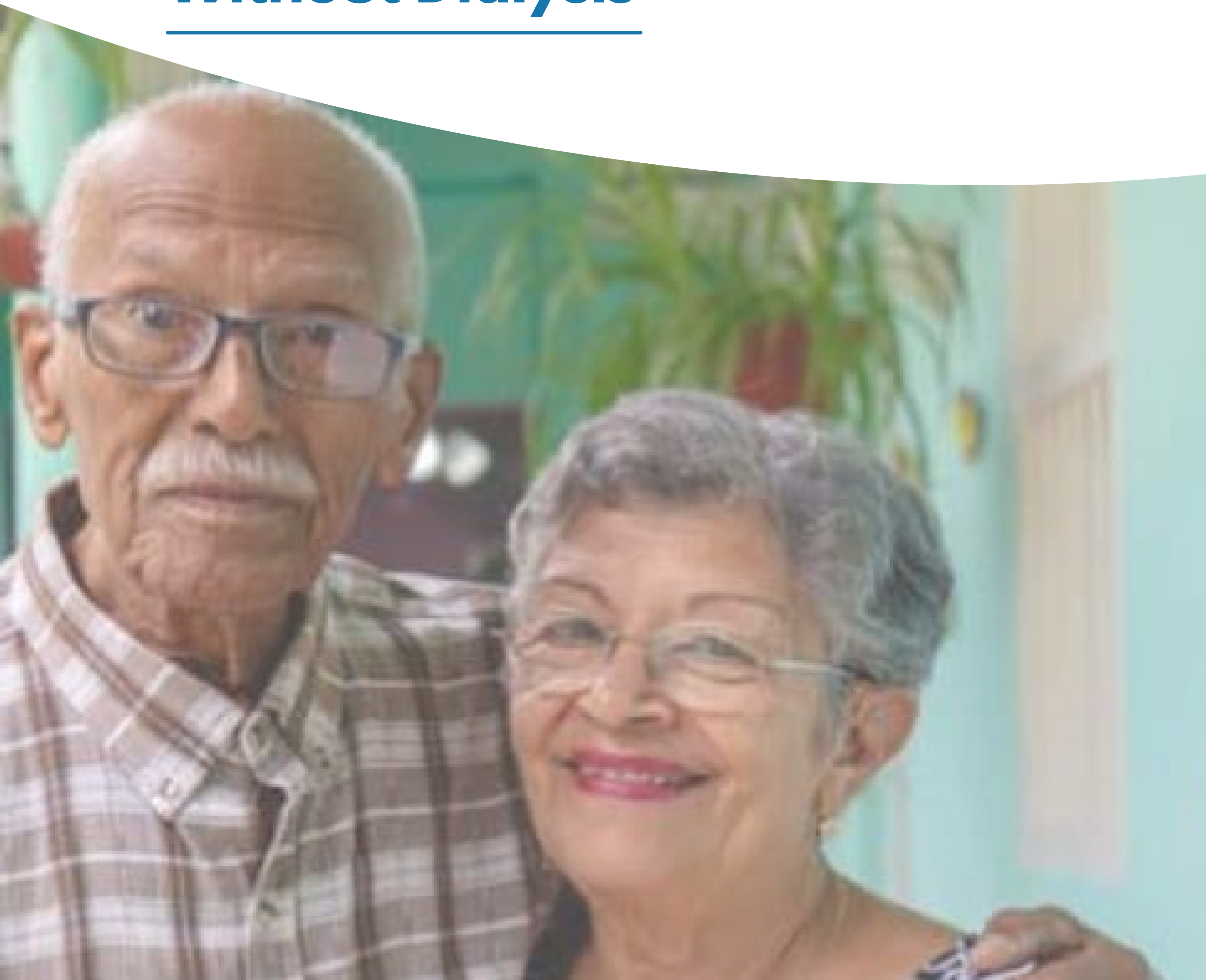


A Guide to Conservative Kidney Management

Treating Kidney Disease Without Dialysis



We are grateful to all who contributed content to and feedback about this Guide, including:

- Patients with kidney disease and their loved ones
- Doctors, nurses, social workers, health educators, and other health care providers

Quotes in this Guide are from patients with kidney disease who shared their views on conservative kidney management as part of a research study. We used stock photos and changed the names of patients and loved ones to protect their privacy.

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This Guide is for People with Kidney Disease Who:

- Want to learn about a treatment program that does not involve dialysis
- Need help deciding among treatments for kidney disease
- Cannot receive or do not want a kidney transplant

This Guide may also be helpful for caregivers and loved ones who support you and are involved in your care.

This Guide Describes:

- What kidney disease is and its effects
- What conservative kidney management is and what to expect
- The pros and cons of dialysis and conservative kidney management
- What happens if you change your mind about your treatment choice
- What to think about as you decide about your treatment options
- What others say about conservative kidney management

This Guide is a first step to understanding conservative kidney management. Talk with your health care provider for more details about your kidney disease, what you can do about it, and your treatment options.

Kidney Disease and its Effects:

Kidneys help keep us alive and healthy. Their main job is to remove waste and extra water from the body. They also help the other organs to function well.

With kidney disease, your kidneys are weakened. Over time they work less well. As this happens, you may have one or more of these symptoms:

- Problems with balance and coordination
- Leg swelling
- Trouble breathing
- Nausea
- Low appetite
- Change in taste
- Loss of energy
- Weakness
- Itching
- Cramping
- Easy bruising and bleeding
- Feelings of confusion
- Shortened life span



Help me lead as close to a type of lifestyle that I would if I didn't have kidney disease. Support for me is having people around that care and do what they can for me.

~Sandra

Conservative Kidney Management and What to Expect

Conservative kidney management is a way to treat kidney disease without dialysis. The goal is to keep you feeling well and your kidneys working for as long as possible. This treatment choice is NOT "doing nothing."

You and your health care team work together to create a care plan that is right for you. Your kidney function and how you are feeling will affect the care you will receive.

If you feel well or have mild symptoms:

Your health care team may:

- Schedule regular check-ups and blood tests to monitor:
 - Your kidney function
 - Other organs affected by kidney disease
- Adjust your medicines or start new ones to:
 - Slow your kidney disease
 - Control your symptoms
- Talk with you about a kidney-healthy diet and lifestyle, such as:
 - What to eat and drink and what to limit
 - Safe activities to keep you fit
- Ask you to complete or update an *advance directive*, a legal document that states your care preferences and who you would want to make medical decisions on your behalf, in case you become sick and cannot speak for yourself
- Discuss dialysis and your preferences about *whether* and *when* you might want to receive it



I can't imagine that dialysis is going to improve anything about the way I live. I'm going to keep fighting for my life. My fight just doesn't include dialysis.

~Luis

If you start to have moderate to severe symptoms:

Your health care team may:

- Check in with you more often about your symptoms
- Adjust your medicines to control symptoms
- Check on your social, mental health, spiritual, and other health needs that affect your well-being and connect you with support services, such as:
 - Dietitians
 - Therapists
 - Social workers
 - Home health aides
 - Pharmacists
- Create plans to avoid health setbacks or lessen their impact, which may cover:
 - Warning signs and what they might mean
 - When and how to contact your health care team
- Confirm your choice about dialysis

If you are near the end of life:

Your health care team may:

- Adjust medicines to keep you from feeling sick
- Make sure you feel safe and comfortable in your home or other place you trust
- Ask you about *hospice care*, a medical service that provides care for patients at the final stages of serious illness
- Tell you about what to expect in the last months, weeks, and days of life
- Work with you and your loved ones through thoughts about future loss and feelings of grief

This is a full spectrum program. My team is broadly concerned with me as a whole person. It's a holistic approach.

~Lee



Pros and Cons of Dialysis and Conservative Kidney Management

It is **your choice** whether to receive dialysis or conservative kidney management. This will depend on your needs and what is important to you. It will also depend on the pros and cons of each treatment choice for you.

Dialysis

Pros: Dialysis gives most people extra months to years of life.

It can also improve certain symptoms, such as poor appetite and leg swelling.

Cons: Dialysis takes time and energy, and many people develop symptoms with dialysis, such as pain and feeling wiped out.

It also involves surgeries and spending time in the hospital.

Conservative kidney management

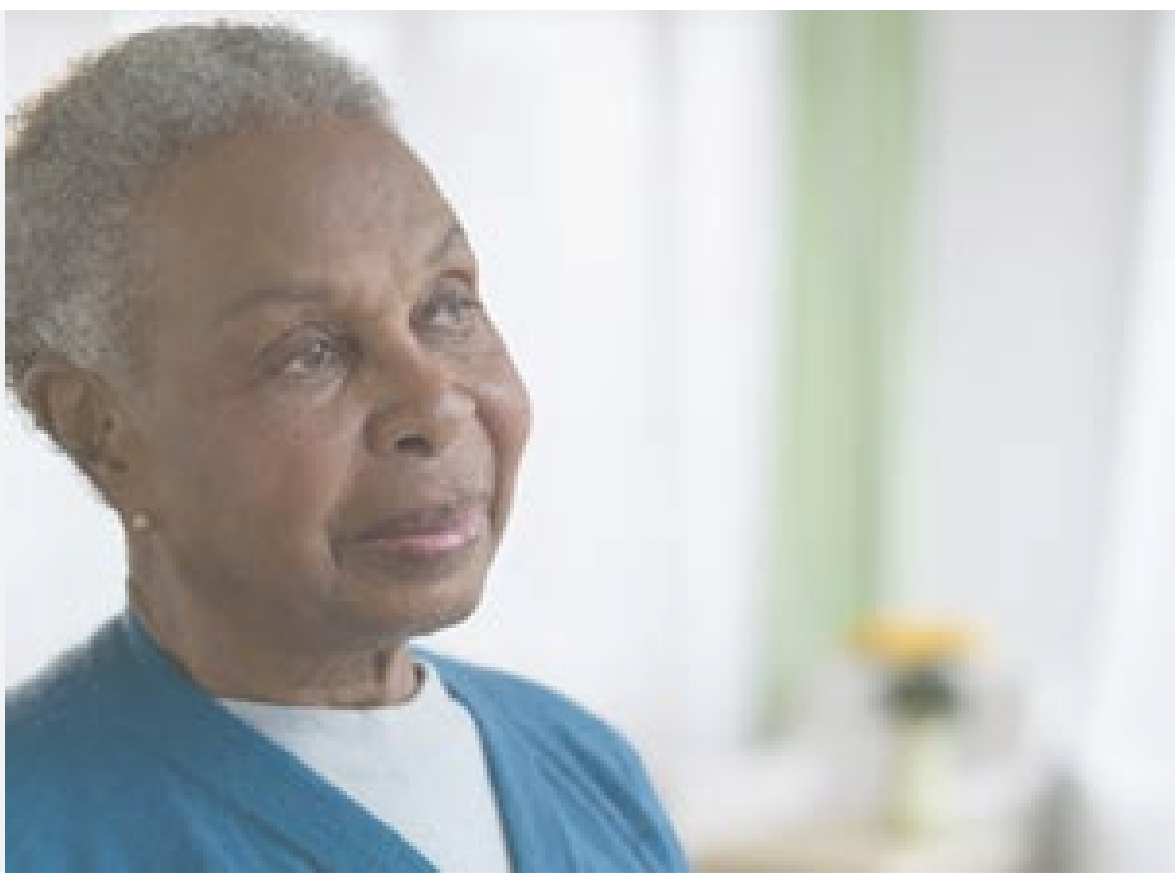
Pros: Conservative kidney management is about helping you live as well and for as long as the kidney disease allows.

People who choose conservative kidney management spend more time at home and less time in the hospital. It does not involve surgeries or machines.

Cons: Some symptoms, such as shortness of breath and low energy, can still be hard to control even with conservative kidney management.

Age, level of kidney function, other medical problems, and overall health affect how long and well a person might live with kidney disease.

For some people, dialysis does not add to how long they live or to their quality of life beyond what can be done with conservative kidney management. Most times, this is the case for older people who are sick and have other serious health problems.



It's hard to read this stuff. It's difficult in the sense that it's about one's own mortality. I wouldn't say it's a great difficulty, but it's tough issues. I told my doctor, "I'm a tough bird."

~Yolanda

Changing My Mind about Conservative Kidney Management

You always have options. Some people choose conservative kidney management and never start dialysis. Others start with conservative kidney management, and if it does not meet their needs, then they switch to dialysis. There are also people who return to conservative kidney management after they decided dialysis was not right for them.

Talk with your health care team about your preferences and the pros and cons of conservative kidney management and dialysis **for you**.

Questions for You and Your Health Care Team

Each person will have different questions. Write down your thoughts and questions. Bring your notes with you when you talk with your health care team. If you can, bring someone with you for this talk.

Common questions:

- What can I do to slow the loss of my kidney function?
- What kinds of medicines can I take for my symptoms?
- What would my day-to-day life look like with conservative kidney management?
- If I try dialysis and then decide it's not for me, what happens if I change to conservative kidney management?
- What might happen that would require me to need extra help at home?
- Can you predict how much longer I have to live?

Other questions

There were questions and stuff in here that my family and I looked over, and that's when we decided that the kidney doctor should be involved in this, too. She went through all my questions. She wanted to make sure about what I really wanted and said it was my choice.

~Yaneth



Who is on your health care team?

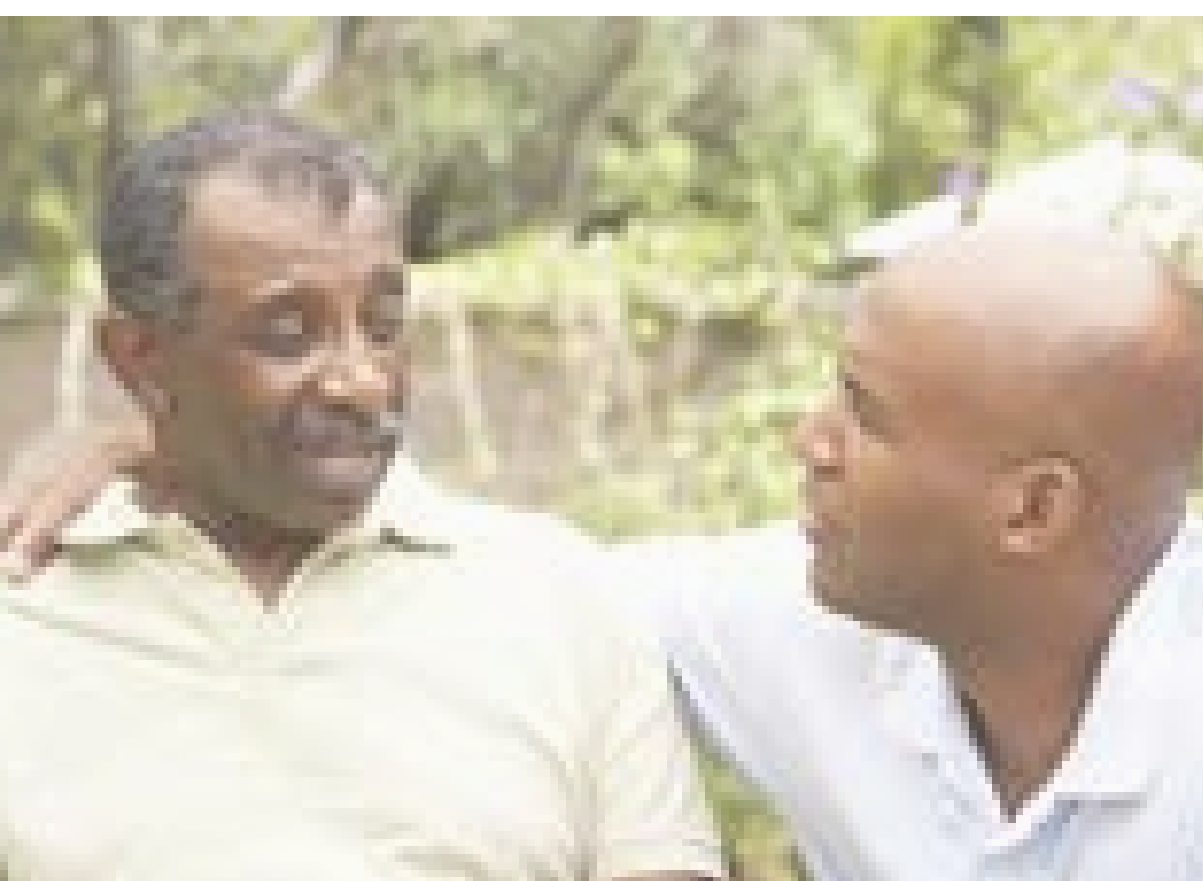
Choosing a health care team you trust makes it easier to talk about treatment options and get the help you need.

Who and what else matters in helping you make care choices?

You are not alone in making these choices. Apart from your health care team, you might lean on family and friends for help in making care choices. Or you might rely on your faith or spirituality for help.

What matters most to you about your health and your daily life?

Knowing about your goals and priorities will help your health care team outline the pros and cons of the treatment options for you.



If my kids thought I needed to be doing something other than what we are doing, they'd be on my back. They are supportive of my conservative kidney management. It makes me feel comfortable with my decision and that it's right for my situation.

~Charles

To Learn More

Talk with your health care team about what you need to know to decide what treatment option is right for you. The resources listed below may also be helpful.

Conservative kidney management

ckmcare.com

Talking with your health care team

prepareforyourcare.org

Kidney-healthy lifestyle and diet

kidney.org.uk - exercise and activities

kitchen.kidneyfund.org - recipes and healthy eating tips

Next Steps



