

Receiving a chronic disease diagnosis such as chronic kidney disease (CKD) can bring up many emotions. You might be relieved to finally have answers, but you may also feel overwhelmed, worried, sad, angry, or confused. Family members and caregivers may experience similar feelings as they support you through the process.

There is no right way to respond. Coping takes time, so be gentle and patient with yourself. These strategies can help you and your family manage the emotional and practical challenges that come with a chronic disease diagnosis.

Living with kidney disease

Kidney disease doesn't always follow a predictable path. It's more than a diagnosis—it can mean ongoing tests, regular procedures, and monitoring that continues for months or years. It's not unusual to feel nervous or uneasy before tests or procedures, even ones that may be described as routine or low-risk. You may feel that you have little control, predictability, or privacy.

Treatment of kidney disease can reshape everyday decisions in ways that go beyond the illness itself. Dialysis schedules, dietary adjustments, or fluid restrictions can complicate ordinary choices like eating out, travelling, or planning meals. Dietary and fluid restrictions can also bring up grief as food is often tied to culture, celebrations, body image, and connection with others.

If you've noticed yourself feeling more anxious or on edge, that doesn't mean something is wrong with you. It's a common response to living with a chronic condition, and it's worth mentioning to your care team who may be able to adjust how a procedure is explained or paced, offer extra support, or connect you with someone to talk to.

Common emotional responses

After a diagnosis, it is very common to experience:

- Shock or disbelief
- Anxiety about the future
- Sadness, grief or a sense of loss
- Anger or frustration
- Feeling overwhelmed by information or decisions
- Worry about family, work or finances
- Changes in sleep, appetite or concentration
- Feeling uncertain or "not yourself"

These reactions are a normal response to a significant life change. For many people, these feelings come and go and gradually become more manageable over time.



Supporting your mental health and wellness

Mental health is a critical part of your overall health, and it's completely okay to need support along the way.

You may notice:

- Ups and downs in mood that change over time
- Worry that comes and goes, especially around appointments
- Feeling emotional when thinking about the diagnosis
- Needing extra rest, support, or reassurance
- Gradually adjusting as you learn more and build routines

These experiences are common and often improve as you adjust.

Signs you may need extra support

It may be helpful to reach out for professional support if you notice:

- Feeling sad, anxious, or overwhelmed most of the time
- Loss of interest in things you usually enjoy
- Ongoing difficulty sleeping or eating
- Trouble concentrating or making decisions
- Feeling hopeless, helpless, or “stuck”
- Increased irritability or emotional distress
- Avoiding appointments or care due to distress
- Using substances or coping in ways that feel unhelpful

These signs do not mean something is “wrong” with you—they are signals that you may benefit from additional help.

Connecting with professional support

You do not need to wait until things feel severe to ask for help. Support may include:

- Social workers, psychologists, or psychiatrists
- Counsellors or therapists in the community
- Support programs through your hospital, clinic, or dedicated organization
- Peer support groups
- Spiritual care providers (if relevant to you)

Talking with a healthcare provider is a good first step. They can help connect you with the right supports.

Practical ways to cope

Finding ways to manage stress

Stress affects both the body and mind. Many people find it helpful to try different strategies to see what works best for them.

Here are some strategies that you might want to try:

- Talking with a family member, friend, or support person
- Exercising (as recommended by your care team)
- Deep breathing, meditation, or yoga
- Reading trusted health information about the diagnosis, treatment, and/or management
- Writing a story, journal entry, or letter
- Getting fresh air or spending time outdoors
- Listening to music or calming sounds
- Participating in art or creative activities
- Reading a book or magazine
- Attending a group or community activity
- Using a fidget toy, stress ball, or earplugs
- Where possible, continue activities that bring comfort or meaning
- Practising grounding techniques

Grounding techniques can help you regulate your nervous system. They can include:

The 5-4-3-2-1 method: Name 5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell, and 1 thing you can taste.

Box breathing: Visualize a square as you breathe, keeping each side perfectly equal in duration. Inhale deeply through your nose for 4 seconds, hold that breath entirely inside for 4 seconds, exhale slowly through your mouth for 4 seconds, then hold your lungs completely empty for 4 seconds. Repeat this full cycle 4 times to physically calm your nervous system.

The alphabet game: Choose a broad, familiar category (e.g., animal, countries, foods, etc.) and mentally work your way through the alphabet, naming one specific item for every single letter. For example, in the category “animals”: A is for alligator, B is for bear, C is for cat, etc. If you get completely stuck on a difficult letter, simply skip it and move to the next.

The sole press: Sit up straight with your back supported by your chair. Place both feet perfectly flat on the floor. Press down firmly through the soles of your feet, feeling the solid resistance of the ground. Focus 100% of your attention on that pressure for 10 seconds. Release the tension slowly, then repeat the press 3 more times.



Lean on your support system

You do not need to manage this alone. Support can come from:

- Family and friends
- Care partners or caregivers
- Peer support groups
- Community or faith-based supports
- Your healthcare team
- Mental health professionals

Prepare for appointments

Medical appointments can feel overwhelming. Consider bringing:

- A support person
- A notebook or phone for notes
- A list of questions or concerns
- A list of medications
- Comfort items such as fidgets toys, earplugs, or a small blanket (if appropriate and permissible)

Questions or concerns to raise may include:

- Symptoms or changes you've noticed
- Concerns about treatment or daily life
- Things that are helping or making your experience harder

Take things one step at a time

A chronic disease diagnosis can feel overwhelming. Everyone processes information differently. You may want to find as much information as you can right away, or you might prefer to take your time. Both are equally valid. If you're feeling stressed, it may help to:

- Focus on one appointment or decision at a time
- Break information into smaller steps
- Set realistic, small goals
- Be patient and allow yourself time to adjust

When looking for information, make sure you're consulting trusted sources, avoid information overload, and always ask your healthcare team for guidance.

For family members and care partners

A diagnosis affects a patient's whole support network. It can help to:

- Listen without needing to fix things
- Ask how you can best support the person
- Take care of your own well-being
- Seek support for yourself when needed
- Learn about the condition together when possible

Caring for someone with a chronic illness can bring up its own mix of emotions. Know that feelings like guilt, fear, resentment, or grief are a normal part of caregiving, not a sign you're doing something wrong.

Resources

Ontario Structured Psychotherapy (OSP)

Free, evidence-based psychotherapy for adults 18+ experiencing mental health challenges. You can access this service without a doctor's referral. Find your regional network at <https://ontariohealth.ca/>

Self-Management Ontario (Chronic Disease Self-Management Program)

A free six-week workshop for adults living with any chronic condition. It's led by trained volunteer facilitators, many of whom live with chronic conditions themselves, and teaches practical skills for managing symptoms and daily life, not just information.

There is also a fully online version for people who prefer to participate remotely. No referral is needed. For more information or to register, visit selfmanagementontario.ca

The Kidney Connect Peer Support Program | The Kidney Foundation of Canada

Connects people affected by kidney disease with others who've been there. Free and confidential.

Includes support for those diagnosed, their families, and living donor candidates. Volunteers are trained peers who understand what it's like to live with kidney disease, though they don't provide medical advice.

To get connected, visit kidney.ca/en/support/peer-support or call 1-866-390-7337.



Kidney Info | The Kidney Foundation of Canada

Explore trusted resources on chronic kidney disease, kidney failure, dialysis, transplantation, and conservative kidney management. Whether you're living with kidney disease or supporting someone who is, Kidney Info offers evidence-based information, support resources, and tools to help you navigate every step of your kidney health journey. Find more at kidneyinfo.ca.

Kidney Community Kitchen | The Kidney Foundation of Canada

A free tool aimed at making food and cooking easier for people navigating kidney-related dietary restrictions. Visit kidneycommunitykitchen.ca.

Short-Term Financial Assistance | The Kidney Foundation of Canada

A last resort, short-term emergency financial assistance program to cover expenses associated with kidney disease and treatment. This assistance is provided only when all other sources of funding have been exhausted. To learn more, visit kidney.ca and enter "short-term financial assistance" in the search bar to learn more.

Kidney Wellness Hub | The Kidney Foundation of Canada

Discover practical, evidence-based resources to support your physical, mental, and social well-being while living with kidney disease. The Kidney Wellness Hub offers expert-led classes, wellness tools, educational content, and community connections to help you live well at every stage of your kidney journey. Learn more at kidneywellnesshub.ca.

RBC Patient and Family Learning Space | Centre for Addiction and Mental Health (CAMH)

An interactive hub for patients, families and the community to access reliable information about mental health, wellness, substance use and recovery. Free workshops, webinars and clinics each month to support coping and wellbeing (i.e. mindfulness circles, art classes and journaling workshops). Learn more at <https://www.camh.ca/pfls>.

Always follow the advice and recommendations of your healthcare team regarding your individual health needs.

Developed in collaboration with

