

Your First Few Months with the Kidney Care Clinic Patient Guide





Welcome to one of British Columbia's kidney care clinics. Our teams provide medical care, education, support, and practical information to patients living with decreased kidney function.

This guide will show you what to expect in the first few months at the clinic. It is divided into 5 steps. Your kidney care team will support you through each step.

What can I expect in my first few months with the kidney care clinic?



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|--------|---|
| Step 1 | Why have I been referred to a kidney care clinic? |
| Step 2 | What will I learn in my first few months with my kidney care team? |
| Step 3 | What can I do to keep my kidneys healthy? |
| Step 4 | What kidney disease symptoms might I experience? |
| Step 5 | What can I expect after my first few months with my kidney care team? |

Step 1: Why have I been referred to a kidney care clinic?

Step 1

Step 2

Step 3

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Step 5

People living with decreased kidney function are referred to a kidney care clinic to get help maintaining their kidney health. Unlike visits to your kidney doctor, the clinic gives you access to a team of health professionals. This includes a nurse, dietitian, social worker, clerk and, in some clinics, a pharmacist in addition to your kidney doctor. The team will provide information on several topics as you navigate your kidney journey, including lifestyle suggestions (diet, exercise) and medications. They will also prepare you for changes in your kidney function if necessary. The team will work closely with your kidney doctor during your time at the clinic.



What to expect

You will meet your kidney care team (either one-on-one or as a group). Our goal is to get to know you, as well as your experiences and concerns,

so that we can provide you with the best, most personalized care. You will learn basic information about kidney disease and ways to keep your kidneys as healthy as possible.



Things to think about and discuss (We recommend writing a list before the appointment)

- Your medical history
- Your medications (please bring the medications or a list of them)
- What you currently know about your kidney condition
- What's important to you (1 or 2 things)
- Your biggest concern(s)



What you can expect to learn

- How the kidneys work
- What it means to have chronic kidney disease (also called “CKD”)
- What might be causing your kidney disease (e.g., polycystic kidney disease, glomerulonephritis, high blood pressure, diabetes)
- What lab work you will need and how to get your results

Step 1

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What you can expect to learn (continued)

- The meanings of common kidney-related words, such as eGFR, KFRE, creatinine and ACR
- What we can work on together to keep your kidneys as healthy as possible:
 - Keeping your blood pressure in a healthy range
 - Maintaining a healthy weight
 - Controlling your blood sugar (if you have diabetes)
- How the nurse, dietitian, social worker, clerk, and pharmacist (if available) can support you
- How and when to contact your kidney care team

Resources

1. Welcome package

- [Welcome letter](#)
tinyurl.com/4jsbffhx
- [About BC's kidney care clinics](#)
tinyurl.com/6vxvy436
- [Chronic Kidney Disease](#)
tinyurl.com/yc6ze4a8
- [Kidney care and you](#) (please fill out and bring to your first visit)
tinyurl.com/mpfust3e



Scan and read resources 1

2. [Kidney Foundation of Canada Book #1](#)

- tinyurl.com/4wxapkf7*
- Chapter 1: How your kidneys work
- Chapter 2: Kidney disease



Scan and read resources 2

- Chapter 3, Section 2: Tips on managing your kidney health
- ### 3. Autosomal Dominant Polycystic Kidney Disease (ADPKD)
- [BC Renal](#)
tinyurl.com/23ueaksp
 - [PKD Foundation of Canada](#)
tinyurl.com/7dcmtjrp
- ### 4. Glomerulonephritis (GN)
- [Kidney Foundation of Canada](#)
tinyurl.com/yckfv385
 - [BC Renal](#)
tinyurl.com/35w9d8w7



Scan and read resources 3-4

Questions to ask your kidney care team:

- Why was I referred to a kidney care clinic?
- What does a “usual” visit to this clinic look like?
- How do I navigate having a kidney care team and a primary care provider (family physician or nurse practitioner)? Will they work together? If I have a concern or question between visits, who do I contact?
- What is the reason my kidneys are not working properly?
- What stage of kidney disease do I have, and what does it mean?
- What can I do to preserve as much kidney function as possible?
- I am doing everything my doctor/kidney care team has suggested. Why is my kidney function still going down?

Step 1

Step 2

Step 3

Step 4

Step 5

Step 2: What will I learn in my first few months with my kidney care team?

Step 1

Step 2

Step 3

Step 4

Step 5

We want to help you keep your kidneys as healthy as possible. In the first few months at the clinic, you will learn different ways to support your kidney function, and how we can best help you.



Step 2a

Step 2b

Step 2c

Step 2d

Step 2a: Eating well



What to expect

Your kidneys remove waste and extra fluid from your blood. When your kidneys can't do their job properly, your diet may need an adjustment. There is no 'standard' diet for chronic kidney disease. Everyone's nutritional needs are different. The dietitian at your kidney care clinic will help you make changes based on your personal nutrition assessment, kidney function

and bloodwork. All diet suggestions will take your culture, lifestyle, and preferences into consideration.



Things to think about and discuss

- What you eat during a typical day
- What vitamins, supplements, herbal, and traditional medicines you take
- Your favourite foods
- Other conditions that might affect what you eat (e.g., diabetes, high blood pressure, heart condition, kidney stones, gout)



What you can expect to learn

- Healthy eating for your kidneys
- Sodium: How much? What foods should you limit?
- Protein: How much? What types of protein?
- Ways to support your kidneys or other health conditions through your diet
- Meal planning
- Reading nutrition labels
- Kidney-friendly recipes and cooking tips
- How you and your dietitian can work together as partners

Resources

Useful for your first or second visit:

1. [Healthy eating for your kidneys](https://tinyurl.com/4av52m4k)
tinyurl.com/4av52m4k
2. [How to read nutrition labels](https://tinyurl.com/4jsrjjuu)
tinyurl.com/4jsrjjuu
3. [Kidney Foundation of Canada Book #1](https://tinyurl.com/4wxapkf7)
Chapter 5: Your diet for kidney health
tinyurl.com/4wxapkf7



Scan and read
resources 1-3

Useful after your first or second visit:

4. [Protein & Your Kidney Health](https://tinyurl.com/f7tjz3eh)
(English and Chinese)
tinyurl.com/f7tjz3eh
5. [The Mediterranean Diet and Kidney Disease](https://tinyurl.com/yukxu7pt)
tinyurl.com/yukxu7pt
6. [Eating Well](https://tinyurl.com/28au6rxu): Cooking classes, interactive Q&A with dietitians, Kidney Community Kitchen (Kidney Wellness Hub)
tinyurl.com/28au6rxu

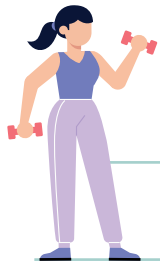


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resources 4-6



Questions to ask my kidney care team:

- What does it mean to eat a kidney-friendly diet? What is important for me to know?
- How can I keep a kidney-friendly diet interesting/appealing?
- Do I have to cut out protein or become a vegetarian?
- I have low energy and do not want to cook. How can I follow a kidney-friendly diet?
- Can I drink alcohol if I have kidney disease?
- I like to eat out. How can I maintain a kidney-friendly diet when I eat out?
- Are these diet changes permanent?



Step 2b: Staying active



What to expect

Staying active is very important to overall health and well-being. Physical activity strengthens the body, making it easier to complete daily tasks and to maintain your energy levels. It also works to lower blood pressure and cholesterol levels, and to improve sleep and mood. Every bit of physical activity helps. This can include cleaning the house, gardening, or going for a walk. Low-impact exercise (e.g., walking, tai chi, stationary bike) is a good place to start. Your abilities and endurance can improve gradually and over time.



Things to think about and discuss

- How to find time to exercise
- The best time of day or week to exercise
- Your favourite type(s) of exercise
- Setting realistic fitness goals



What you can expect to learn

- Ways to safely increase your physical activity level
- How often and how long to exercise
- Suggested types of activity:
 - Cardiovascular or endurance exercises (such as walking, biking, dancing)
 - Strengthening or resistance exercises (such as yoga, resistance band exercises, and using light weights)
 - Stretching or exercises for flexibility
- When to stop exercising (e.g. chest pain, dizziness, leg cramps)



Resources

1. [Staying Active \(Wellness Hub\)](https://www.wellnesshub.ca/active)
tinyurl.com/bdzre3bj
2. [Being Active](#) (HealthLink BC, call 8-1-1 and ask to speak with Physical Activity Services)
tinyurl.com/uvtr873k
3. Exercises to do at home (BC Renal):
 - [General exercises](#)
tinyurl.com/mpt82d3b
 - [Strengthening exercises](#)
tinyurl.com/ycxtpfww
4. [KidneyFit Video Series](#) (Manitoba Renal Program)
tinyurl.com/yshz4n87



Scan and read
resources 1-4



Questions to ask my kidney care team:

- What types of activities would be best for me?
- Is it okay to do vigorous physical activity (e.g. running)?
- How can I incorporate physical activity in my day-to-day life?
- I like to travel. How can I keep up my exercise routine when I'm away?
- Where can I find community resources/activities (e.g. group walks, yoga classes)?



Step 2a

Step 2b

Step 2c

Step 2d

Step 2c: Taking medications



What to expect

Medications can help slow the progression of kidney disease and also prevent heart problems. Your kidney doctor will discuss the ones that might be best for you. Many patients require several medications to keep them as healthy as possible.

Your kidney doctor, pharmacist or nurse will help you manage your medications. They may suggest changes to help you get the most out of them.



Things to think about and discuss

- What medications you take
 - Prescription medications
 - Non-prescription (over-the-counter) medications, including vitamins, supplements, herbal and traditional medicines
- Side effects from your medications
- Medications that you are allergic to or have made you feel ill in the past
- Potential barriers to taking your medications (such as cost or forgetfulness)

- Current health problems (e.g., constipation, nausea, indigestion, pain, itchy skin) and which medications you have tried to help with these problems
- Vaccinations
- If you smoke or vape (and your willingness to quit or cut down)
- Your preferred pharmacy



What you can expect to learn

- Managing your medications when you are sick
- Which non-prescription (over-the-counter) medications are safest, and which you should avoid
- How to keep an up-to-date list of your medications
- Best times of day to take your medications
- Letting your kidney care team know if your medications change
- Important vaccinations and how to get them
- Letting your community pharmacy know you have kidney disease
- Funding for kidney medications
- How to register for BC PharmaCare (if not already registered).
- If you smoke or vape, ways to help you quit

Step 1

Step 2

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Step 4

Step 5

Resources

1. [Medication Changes When You Are Sick](#)
tinyurl.com/456smmfp
2. [Non-Prescription Medications and Your Kidneys](#)
tinyurl.com/ycyzjrbh
3. [QuitNow BC](#) (stop smoking or vaping)
tinyurl.com/mr2b3suj
4. [Vaccinations](#)
tinyurl.com/2b9u4r6j
5. [Kidney Foundation of Canada Book #1](#),
Chapter 4: Managing your medications for kidney health
tinyurl.com/4wxapkf7

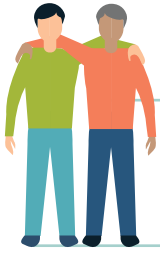


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Questions to ask my kidney care team:

- If another doctor (e.g., family doctor, heart doctor, diabetes doctor) changes any of my medications, how do I let my kidney care team know?
- What are all my medications for? Can any of them be stopped or the dosage reduced?
- Are any of the medications that I am taking (including vitamins, supplements, herbal or traditional medicines) bad for my kidneys?



Step 2a

Step 2b

Step 2c

Step 2d

Step 2d: Identifying and building a support system



What to expect

Chronic kidney disease can affect you physically, emotionally, socially, and spiritually. After your diagnosis, you may experience a range of emotions: surprise, fear, or even relief. Reactions to the diagnosis differ for each person, and your feelings may change over time. Learning to live with a condition that will affect you for the rest of your life is challenging. This section focuses on how to build your support system and maintain overall wellbeing.



Things to think about and discuss

- Tell us about yourself:
 - How are you coping?
 - How have you coped with stress in the past? Who do you call on for help/support?
 - What brings you joy? What do you do for fun?
 - What is important to you?
- What do you already know about your kidney disease?
- Right now, what concerns you the most about your kidney disease?

- What would you like to focus on while at the kidney care clinic?



What you can expect to learn

Ways that we can support you:

- Deepening your understanding of kidney disease's effects on mental, social and emotional well-being
- Helping you identify your support network
- Provide education about the health care system and how to make the most of your appointments
- Connecting you with resources in your community (such as home and community care)

Ways to build your support network:

- Spend time with people you trust
- Be open about your kidney condition and your feelings
- Don't be afraid to ask for help (emotional, practical, or otherwise). This will keep you as independent as possible for as long as possible
- Connect with others who have kidney disease:
 - Sign up for the Kidney Wellness Hub (it's free!)

Step 1

Step 2

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What you can expect to learn (continued)

- Participate in activities on the Kidney Wellness Hub (e.g., cooking classes, art classes)
- Connect with others via the Kidney Wellness Hub (one-on-one conversations or groups)
- Continue with activities you enjoy or try new ones. Joining a local organization (such as a community centre) that runs an activity of interest is a great way to meet like-minded people!
- You can ask to talk to a social worker in person or by phone. They are trained to help you with emotional or practical needs. They can provide support as you navigate your kidney journey

Resources

1. [About BC's kidney care clinics](https://tinyurl.com/6vxvy436)
tinyurl.com/6vxvy436
2. [Kidney Wellness Hub poster](https://tinyurl.com/bdh3nudn)
tinyurl.com/bdh3nudn
3. [Join the Kidney Wellness Hub](https://tinyurl.com/5y3dv9c5)
tinyurl.com/5y3dv9c5
4. [Kidney Wellness Hub website](https://tinyurl.com/363wxxk2)
tinyurl.com/363wxxk2



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resources 1-4

Questions to ask my kidney care team:

- I can't get my head around having a chronic disease. Is there someone I can talk to?
- I've lost a lot of my energy. What are some ways I can manage fatigue? If I need help, how can I access it?
- Since finding out I have kidney disease, I feel very anxious and sad. Is this normal?
- I have lost interest in sex. Why is that? Can I get help?
- I want to be prepared if something unexpected happens to my health. How can I plan ahead?

Step 3: What can I do to keep my kidneys healthy?

Step 1

Step 2

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Step 4

Step 5

You can live a healthy and fulfilling life, even with a chronic disease. With guidance and support from your kidney team, you have power over your health and quality of life.



Step 3a

Step 3b



Step 3a: Taking an active role in your care and treatment decisions



What to expect

Your kidney care team will encourage you to take an active role in your care and treatment decisions. They will talk to you about lifestyle changes and treatment options. They will help you set goals and support you

to meet these goals. Together, you can decide what works best for you.

While it's not possible to reverse kidney disease, you can take steps to slow its progression. Take the time to learn about your condition and focus on finding a healthy balance for your kidneys. Eating and sleeping well, staying physically active (wherever possible), managing stress, and staying connected with others all play an important role. Making these changes can be hard, especially when you might have no symptoms, but research shows that patients who take an active part in their care and treatment decisions have better overall outcomes. Your kidney care team will be there to support you as you navigate your involvement and set personal goals.



Things to think about and discuss

- Any questions you might have about your kidney condition and day-to-day care
- What things you would like to work on and what's most important to you right now
- How to track important information (e.g. contacts, appointments, medications, your moods and physical activity levels)

Step 1

Step 2

Step 3

Step 4

Step 5



What you can expect to learn

- How to get involved in your kidney care and treatment decisions
- Ways to get the most out of your health care appointments:
 - Writing down questions, taking notes, bringing a family member or friend along
- How to set small goals for yourself and make a plan to meet those goal(s)
- Identifying barriers to meeting your goal(s) and overcoming these barriers

Resources

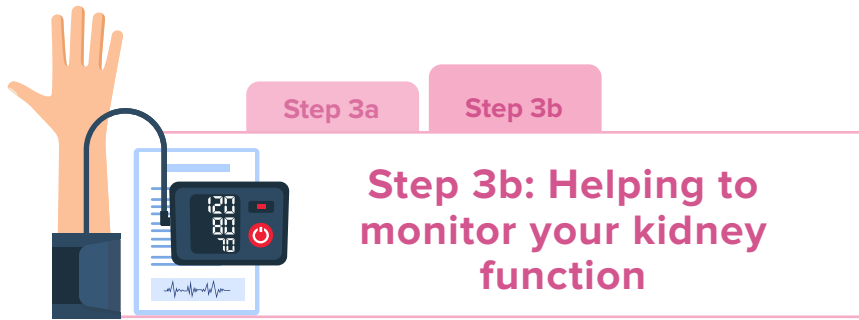
1. [BC Renal Self-Management](#) (Tools and Resources)
tinyurl.com/yemcfhja
2. [Kidney Foundation of Canada Book #1](#), Chapter 6: Developing a personal care plan of action
tinyurl.com/4wxapkf7
3. [Kidney Wellness Companion Journal](#)
(free when you join the Kidney Wellness Hub)
tinyurl.com/5y3dv9c5



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resources 1-3

Questions to ask my kidney care team:

- What changes can I make that will give me the greatest improvement in my kidney health (and overall health)?
- I need help setting goals and making a plan. Is there someone who can support me?
- I don't think I can afford some of the things on my plan (e.g., a gym membership). Is there someone who can guide me through this?
- I struggle with feeling motivated. What can I do to better stick to my plan?



? What to expect

You can play an important role in monitoring your kidney health. As a patient, two day-to-day responsibilities are:

1. Regularly checking your at-home blood pressure, and
2. Keeping track of your lab results after getting blood taken

If you have diabetes, working with your diabetes team and primary care provider to keep your blood sugar within target is also important.

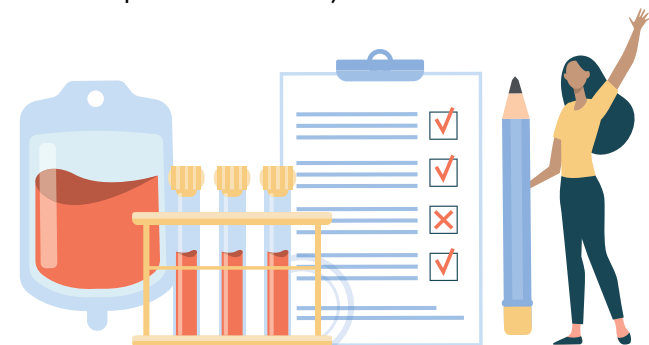
✓ Things to think about and discuss

- How to access and use an at-home blood pressure monitor
- Whether your blood pressure is where it needs to be (i.e., within your target range)

- Whether your blood sugar and A1C levels are where they need to be (if you have diabetes)
- How to access lab results on your computer or cell phone
- Your preferred lab location

📖 What you can expect to learn

- How to get a blood pressure monitor
- How to take your blood pressure, and what the results mean
- How often you will need to get lab work
- How to find your lab results, and what the results mean
- If you have diabetes, the importance of good blood sugar monitoring and management
- How to track metrics related to your health (e.g., health journal, Kidney Wellness Hub Companion Journal)



Resources

Home BP monitoring

1. [Getting a BP Device](https://tinyurl.com/mppfmexd)
tinyurl.com/mppfmexd
2. [Measuring Your BP at Home](https://tinyurl.com/msksfd68)
tinyurl.com/msksfd68
3. [Home BP Monitoring Log](https://tinyurl.com/ykwbxjf3)
tinyurl.com/ykwbxjf3



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Kidney lab work

4. [Get to Know Your Lab Work](https://tinyurl.com/3t484ten)
tinyurl.com/3t484ten

Kidney disease and diabetes

5. [Diabetes Canada: Just the basics](https://tinyurl.com/457ex2kj)
tinyurl.com/457ex2kj

Tracking your health

6. [Kidney Foundation of Canada Book #1](https://tinyurl.com/4wxapkf7),
Chapter 6: My personal log
tinyurl.com/4wxapkf7
7. [Kidney Wellness Hub Companion Journal](https://tinyurl.com/5y3dv9c5)
tinyurl.com/5y3dv9c5

Questions to ask my kidney care team:

- What is my target blood pressure?
- How do I know when my blood pressure is too high? What should I do?
- Why do I need to get lab work done so often?
- Does it matter if I go to a hospital or private lab? Is there a difference?
- I have diabetes. What's my target for blood sugar, and what do I do if it's out of range?

Step 4: What kidney disease symptoms might I experience?

Step 1

Step 2

Step 3

Step 4

Step 5



Chronic kidney disease involves a gradual loss of kidney function. In the early stages, you might have few or no symptoms. You might not realize you have kidney disease until

the condition has advanced. As the disease progresses, you may begin to experience a variety of symptoms. Your primary care provider or kidney care team can help you manage these symptoms.



What to expect

Symptoms of kidney disease differ from person to person. Potential symptoms include: nausea, poor appetite, weight loss, fatigue, dry and itchy skin, muscle cramps, swelling of feet and ankles, and shortness of breath. You may also experience physical pain.

Some symptoms might be related to your kidney disease, and some are not. If you start experiencing a new symptom, talk with your primary care provider or kidney care team.

Living with kidney disease can be challenging, and it can take a toll on your mental health. People with kidney disease often face higher levels of anxiety and depression. If you're struggling with these feelings, now you're not alone. Talk to your primary care provider or kidney care team; they can help you navigate both your emotional and physical wellbeing.



Things to think about and discuss

- What symptoms you're experiencing (if any), and if there's a pattern
- Ways you've tried to improve your symptoms, and if you've had any success
- How your symptoms impact your daily life (i.e. difficulties they may cause)



What you can expect to learn

- Common symptoms of kidney disease
- What you can do to reduce these symptoms

Step 1

Step 2

Step 3

Step 4

Step 5

Resources to support my learning

1. [Common Symptom Guides](https://www.tinyurl.com/mffvj9ny) (BC Renal)
tinyurl.com/mffvj9ny
2. [Symptoms](https://www.tinyurl.com/4nyev9ks) (My Kidneys My Health)
tinyurl.com/4nyev9ks
3. [Mental Wellbeing](https://www.tinyurl.com/ynj3puj5) (Kidney Wellness Hub)
tinyurl.com/ynj3puj5
4. [Mental Health](https://www.tinyurl.com/y5jcvxj9) (BC Renal)
tinyurl.com/y5jcvxj9



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Questions to ask my kidney care team:

- Why don't I experience any symptoms? What should I watch out for?
- What causes the symptoms I am experiencing? What can I do to relieve them?
- I am doing everything my doctor/ kidney care team has suggested. Why do I still get new symptoms?

Step 1

Step 2

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Step 4

Step 5

Step 5: What can I expect after my first few months with my kidney care team?

Step 1 Step 2 Step 3 Step 4 **Step 5**

Though some patients may only visit the KCC for a few months, most will visit for much longer (several months or years). Whether you're with us for a few months or a few years, we want to help you live the best life possible.



What to expect

You will continue regular visits to the kidney care clinic, usually every 3 - 12 months

- The frequency will depend on your kidney function and the level of support you require/prefer

- Some visits may only require seeing one member of the team, while others may involve more. This will depend on your current needs
- Visits may be in-person and virtual (by phone or video)
- You may receive phone calls from our team between visits. You are also welcome to call anytime if you have questions or concerns

You will also continue with regular lab work as suggested by your kidney care team. Depending on your needs, this may be more or less frequently than the first few months

It is important for you to keep your list of medications up-to-date. This includes prescription and non-prescription (over the counter) medications

Things to think about and discuss

- What is important to you in the long term

Things to think about and discuss (continued)

- How your new routines and lifestyle changes are working for you
- Who can help and support you making decisions about your treatment



What you can expect to learn:

As you spend time with your kidney care team, you will better understand your condition, what to do to treat it, and how to stay involved in your care. You will hopefully feel comfortable with your new routine (i.e., regular lab work, appointments, medications) and with making lifestyle changes (e.g., eating a kidney-friendly diet and getting regular physical activity).

Ongoing visits to the clinic will focus on (1) slowing the progression of your kidney disease (lifestyle changes, medications); and (2) helping you to live the best life possible.

It is common for kidney function to decline over time. This can happen even if you are doing all the right things. Some patients may experience a decline in kidney function, but their kidneys can still manage. Others may get to the point where their

kidneys no longer work (kidney failure). If needed, your care team will talk with you about treatment options for kidney failure.

Resources

1. [Kidney Foundation of Canada Book #1](#), Chapter 7: If your kidneys fail
tinyurl.com/4wxapkf7



Scan and read resources 1

Questions to ask my kidney care team:

- How long will I keep coming to the kidney care clinic?
- I want to learn more about treatment options for kidney failure. Where can I find this information?

Step 1

Step 2

Step 3

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Step 5



Phone: 604-875-7340

Email: bcrenal@bcrenal.ca

Web: BCRenal.ca

