

# Your Journey: Coping With and Adjusting To Dialysis



For more information scan this QR code or go to [myhealth.alberta.ca/coping-and-adjusting-to-dialysis-pathway](https://myhealth.alberta.ca/coping-and-adjusting-to-dialysis-pathway)

**Living with dialysis is not easy and many people need extra support. Emotional wellbeing (how you think, feel, and act) is an important part of living well with dialysis. This pathway will help you to know what to expect as you work with your healthcare providers, and cope with and adjust to dialysis.**

Remember, you are the most important part of your healthcare team. If you have any questions along the way, please ask your healthcare team. (Click on the page numbers in blue below if you want more information about the step in your journey.)

## Understanding your wellbeing ([page 4](#))

- Consider your health and wellbeing which includes physical, emotional, spiritual, financial, and social elements.
- Write down how you feel, your symptoms, and any questions or concerns.



## Talking with your dialysis healthcare provider ([page 5](#))

- Consider some ways to start a conversation about your emotional wellbeing.
  - Ask: "Can I talk to you about how I'm feeling with my dialysis?"
- Share your symptoms and concerns with your healthcare provider.
- Use words that you feel comfortable with.
- If you feel comfortable, consider bringing a family member or friend to support you.



## Answer some questions ([page 7](#))

- Answering some questions can help you understand how you are coping with dialysis.
- These questions may include how you have been feeling in the last 24 hours, 2 weeks, or in your lifetime.



## Review your answers ([page 8](#))

- Talk with your dialysis healthcare provider about your answers.
- Clarify and discuss anything you would like more information on.



## Review your resources & management options ([page 9](#))

- Your healthcare provider may help you better understand your emotional wellbeing and give you important strategies to live well with dialysis.
- There are many options, such as exercise, meditation, psychological counselling, medication options, and more. Decide with your healthcare provider what may work best for you.



## Talk with your healthcare provider about a referral ([page 11](#))

- You may need or want a referral based on your specific needs.
- Ask who you are being sent to and what they do.
- Ask how long it will take to be seen and what you should do if you don't hear back.



## Manage and watch your emotional wellbeing ([page 12](#))

- As time changes, so does how you feel, think, and act.
- Check in with yourself and your healthcare provider regularly and be aware of any symptoms that suggest you might need a different level of support.



## Keep taking care of yourself ([page 13](#))

- Keep taking care of your overall health.
- Look for other healthy lifestyle resources and supports.



Whole-person health ([page 2](#))

### Important Tips:

#### Need a family doctor?

[ahs.ca/findadoctor](https://ahs.ca/findadoctor)

#### Need a translator or interpreter?

Let your healthcare provider know

#### Need health advice?

Call Health Link at 811

#### Need to find programs and resources in your community?

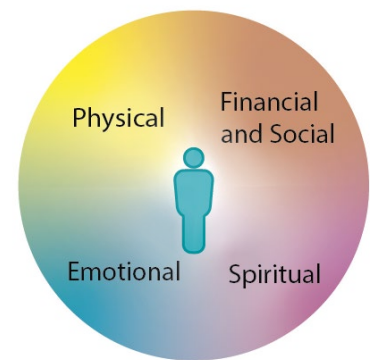
Call 211 or visit [ab.211.ca](https://ab.211.ca)

## Whole-person health

The whole-person health approach will help you and your healthcare team better manage your emotional wellbeing. It is drawn from the teachings of the medicine wheel.

Whole-person health means thinking about all parts of your health and wellness: physical, financial and social, spiritual, and emotional. All of these parts are connected and influence each other. It's important to be aware of your personal needs in each part and to share that information with your healthcare team.

- **Physical:** your specific health conditions and how well your body works
- **Financial and Social:** your ability to meet your housing, transportation, food, and health needs; feeling supported to manage your daily life; and having meaningful relationships
- **Spiritual:** your beliefs, sense of connection, and purpose
- **Emotional:** how you think, feel, and cope with life events



Whole-person health

Whole-person health also reminds us that we are all connected and work together: you, your support systems, and your healthcare providers. Your dialysis healthcare providers could include your family doctor, kidney doctor, nurse practitioner, dialysis nurse, pharmacist, social worker, dietitian, exercise therapist, spiritual health care provider, psychologist, or a team that comes together with you to plan and organize your care.



### Helpful tools and resources

Unsure of what each healthcare provider can help you with?

Visit [ahs.ca/info/Page8480.aspx](https://ahs.ca/info/Page8480.aspx) where you can find out more about what each healthcare provider does.

Your healthcare provider needs to understand who you are and what matters to you. This helps to build trust. But it can be hard to know what to share or what to say. Start by asking yourself:

**“What are the things in my life that are important to me?”**

**“What are the things in my life that may be affecting my health, including my emotional wellbeing?”**



Bringing forward what matters to you is important. Here are some examples of things you may want to talk about with your healthcare provider:

#### **Physical**

“It’s hard to take care of myself because I am always so tired from dialysis.”

“I have muscle cramping, dry and itchy skin, and I am always worried about my restricted diet and fluid intake.”

“My symptoms are making it hard for me to do my job.”

#### **Financial and Social**

“I’m worried I won’t be able to get to all of my dialysis appointments.”

“Dialysis appointments make it hard for me to travel and visit my relatives who don’t live close to me.”

“I need my daughter with me as a translator.”

“I’m not sure how I will pay for my rent/groceries/vehicle payments this month.”

#### **Emotional**

“I’m lonely and have no one to talk to.”

“I have a lot of stress and anxiety, and I’m not sure how to manage it.”

“Ever since my friend died, I’ve been struggling with my feelings.”

#### **Spiritual**

“It’s important that I follow traditional healing practices.”

“How can I include my culture’s foods and family recipes in my nutrition plan?”

“It’s important that my religious practice of fasting is respected and brought into my care.”

## Understanding your emotional wellbeing

Many words, feelings or sentiments may be used to describe how a person is feeling about their dialysis journey. While some healthcare providers may use words like “mental health”, “depression”, or “anxiety”, some people may not feel comfortable using this language. Instead, you may prefer to use words like: “I feel like I am not coping with or adjusting to dialysis very well. I am feeling down/worried/anxious/on edge/\_\_\_\_\_”.



Throughout this pathway, some words like mental health, depression, and anxiety may be used. However, your overall emotional wellbeing is much more complex. It is important to use language **you** are comfortable with when talking to your healthcare providers.

Mental health conditions, such as anxiety and depression, are **common** and affect people from all backgrounds:

Nearly 1 in 3 of Albertans receiving dialysis treatment experience symptoms that may look like depression.

About 1 in 5 of Albertans receiving dialysis treatment experience symptoms that may look like anxiety.

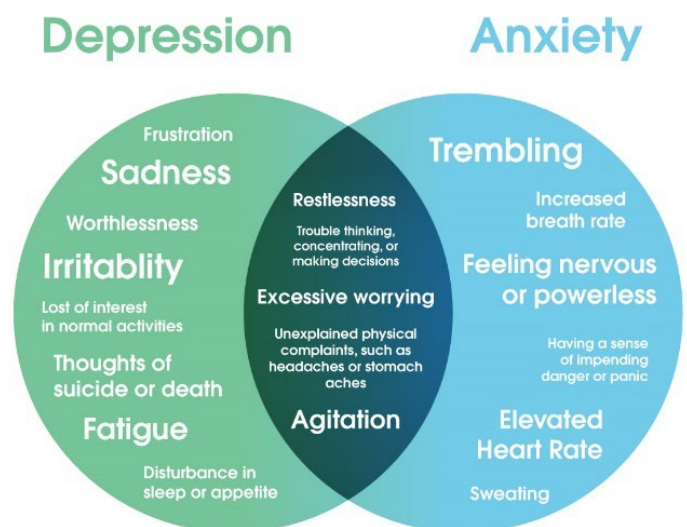
About 1 in 6 of Albertans receiving dialysis treatment experience symptoms that may look like depression and anxiety.

Feelings like anxiety and depression have been linked to certain chemicals in the brain. These chemicals can be ‘out of balance’ (higher or lower than expected) and change how we feel, think and act. Mental health conditions are complex but experts believe they can be related to:

- family history
- genetic makeup (DNA, genes)
- stressful life events
- major life changes

**Depression** is a mental health condition that causes you to feel sad, lose interest in activities that you used to enjoy, withdraw from others, and have little energy. Find a full list of signs and symptoms of depression by visiting [myhealth.alberta.ca](https://myhealth.alberta.ca) and searching for "Depression" in the search bar.

**Anxiety** is a mental health condition that causes you to feel overly worried, nervous or on edge, and causes physical or emotional symptoms that interfere with your life. Find a full list of signs and symptoms of anxiety by visiting [myhealth.alberta.ca](https://myhealth.alberta.ca) and searching for "Anxiety" in the search bar.



Serena-Lynn Brown, MD, PhD

Depression & Anxiety Symptoms. (2021). [Graphic] Image adapted by the Psychiatric Associates of Southern Connecticut. Original source from Anxiety.org.

What is a symptom? A symptom is something that a person feels or experiences that may lead them or their healthcare provider to further explore their current health.



## Talking with your dialysis healthcare provider

Who is a “dialysis healthcare provider”?

- Depending on where you receive dialysis (at home, in-centre, in-hospital), how you receive dialysis (hemodialysis, peritoneal dialysis, nocturnal dialysis), and your overall health, a dialysis healthcare provider may be somebody different from person to person.
- A dialysis healthcare provider includes anyone who helps you with your dialysis journey. For example: a kidney doctor, nurse practitioner, dialysis nurse, pharmacist, social worker, dietitian, exercise therapist, spiritual health care provider, psychologist, family doctor and many others.

Talking about how you are coping with and adjusting to dialysis is important. You **or** your dialysis healthcare provider may start this conversation.

After reflecting on your emotional wellbeing, here are tips to help you start a conversation about your wellbeing with your dialysis healthcare provider:

- If you feel comfortable, ask someone you trust (such as a family member or friend) to go with you to your appointment. They can help you ask questions, write down instructions, and remember explanations.
- Remember or write down what symptom(s) you’re feeling, when it started, how often it happens, and what makes it better or worse.
- Write down a list of your questions and concerns. When you’re done, read your list and mark the most important things.
- Make a list of the prescription and non-prescription (over-the-counter) medicines you use, including any vitamins, herbs, and supplements.



**To start a conversation about your emotional wellbeing, consider asking:**

“Can I talk to you about how I am feeling with my dialysis?”

**Your healthcare provider may start the conversation by asking:**

“Can I ask you about how you are adjusting to or coping with dialysis?”



You are an important member of your healthcare team.

1. Every person is unique: Every person should be seen as different and unique, with their own story.
2. Being heard: At each appointment with your dialysis healthcare provider, you should be given the time and space to talk about your feelings and how your health journey is going.
3. Shared responsibility: Your health journey decisions should be shared between you and your dialysis healthcare provider. Working with your healthcare provider is important, and is a joint partnership.

Sometimes, your dialysis healthcare provider may use words that you have not heard before, or that may be confusing. It is important to clarify anything that may be unclear.

**Consider asking:**

“This is new to me. Could you please explain it slowly, using language that is easier to understand?”

“It sounded like you said that I should... Did I understand that correctly?”





## Answer some questions

After starting the conversation with your dialysis healthcare provider, they might ask you some questions. These questions can help your healthcare team better understand your emotional wellbeing, help diagnose certain conditions, and determine what specific supports may be needed.

You can expect questions similar to the one below:

**Please circle the number that best describes how you feel NOW:**

Best Wellbeing      0   1   2   3   4   5   6   7   8   9   10      Worst Possible Wellbeing  
(Wellbeing = how you feel overall)

How to prepare for these questions: Reflect on how your dialysis journey has impacted your life, the things that are important to you, and your emotional wellbeing.

Your dialysis healthcare provider may invite you to answer questions in the Edmonton Renal Symptom Assessment: <https://cansw.org/wp-content/uploads/2020/02/Edmonton-Symptom-Assesment-System-Renal.pdf>. These questions were developed for dialysis patients and can be completed by you or with the help of your family member, friend, caregiver, or healthcare provider.

Based on your answers, your dialysis healthcare provider may follow up with further questions. They may invite you to complete more questions by saying:

- “I would like to learn a little more about your symptoms that look like anxiety. Please answer the questions on this screening tool and we will discuss them together.” Generalized Anxiety Disorder Screening Tool: [myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=abn2339](https://myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=abn2339)
- “I would like to learn a little more about your symptoms that look like depression. Please answer the questions in this questionnaire and we will discuss them together.” Patient Health Questionnaire: [albertahealthservices.ca/frm-19825.pdf](https://albertahealthservices.ca/frm-19825.pdf)







## Review your answers

It is important to know what your answers are and what they mean for you personally. Take time to discuss your answers with your dialysis healthcare provider. Medical terms can be hard to understand. Ask your healthcare provider for explanations and examples to make sure you fully understand.

**Seeing your answers may be helpful, but they do not replace a conversation with your healthcare provider.** Feel free to talk about how you are feeling in your own words.

Your healthcare provider may tell you that your answers showed a “minimal, mild, moderately severe or severe symptom” of a specific health condition.

Depending on your answers and your conversation with your dialysis healthcare provider, they may give you a list of resources, or refer you to another dialysis healthcare provider.

If you or your healthcare provider are extremely concerned about your emotional wellbeing and personal safety, they will make an urgent referral to another healthcare provider or emergency department.

You may be encouraged to fill out and review your Personal Safety Plan Form: [albertahealthservices.ca/frm-18600.pdf](https://albertahealthservices.ca/frm-18600.pdf)

### **Health is a complicated thing.**

When discussing your results, it is important to consider all parts of your life, including other health problems, as they may affect each other.

You might ask:

**“What does this mean for me?”**

**“These results aren’t what I expected... Can you explain what this means?”**

**“Is there a current concern? If so, what is it?”**



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## Review your resources & management options

Changing daily habits and starting new activities such as being active, eating well, meditation, breathing techniques, journaling, and more, can have major impacts on your mood.

**For a full list of resources for patients receiving dialysis, including phone numbers, online websites, services, and phone apps, please visit:**



Scan me!

[Environmental Scan:  
Resources for coping with  
and adjusting to dialysis](#)



There are 119 resources on this website, with brief descriptions, to help you cope and adjust to dialysis. Topics include:

1. Information on Mental Health
2. Resources for your Self-Care
3. In-person & Live Online Services
4. Regional and Crisis Resources

On this website, you can find resources like the ones listed below:

<b>Kidney Wellness Hub</b>	Free online wellness resource hub for kidney patients. Includes resources on staying active, eating well, emotional wellbeing, and socially connecting.	<a href="https://kidneywellnesshub.ca">https://kidneywellnesshub.ca</a>
<b>Mindfulness Exercises</b>	Free courses, audio, worksheets, and videos about mindfulness and how it can help.	<a href="https://mindfulness Exercises.com/free-mindfulness-exercises">https://mindfulness Exercises.com/free-mindfulness-exercises</a>
<b>Mindshift CBT App</b>	Free tips, coping cards, thought journal, audio recordings, and interactive cognitive behavioral therapy (CBT)-based tools. Learn how to relax, be mindful, and cope with anxiety using strategies based on cognitive behavioural therapy.	<a href="http://www.anxietycanada.com/resource/s/mindshift-cbt">www.anxietycanada.com/resource/s/mindshift-cbt</a>  Available on App Store and Google Play
<b>Feeling Good App</b>	Relaxation, cognitive behavioural therapy and resilience-building techniques to help improve positive feelings, self-esteem and self-confidence.	<a href="http://www.feelinggood.app/onboarding/national-wellbeing-hub">www.feelinggood.app/onboarding/national-wellbeing-hub</a> Available on App Store and Google Play.
<b>Kidney Community Kitchen</b>	Find recipes and information on how to manage a renal diet. The Kidney Community Kitchen website has recipes, a meal planner, videos, a dietitian blog and questions & answers.	<a href="http://www.kidneycommunitykitchen.ca">www.kidneycommunitykitchen.ca</a>



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Medicines can also have a positive impact on daily mood and any feelings you may be experiencing. Your dialysis healthcare provider may suggest starting (or changing) a medicine. This is a good time to explore medicine options and how they may fit into your dialysis journey.

#### **How do medicines for anxiety or depression work?**

- Every person and medicine is different. Based on an open discussion with your healthcare provider, they may suggest a medicine based on your health history, allergies, symptoms you are experiencing, and other medicines you may be taking.
  - For most people, it may take 2 to 8 weeks to see any difference in mood after starting a new medicine; it can take 8 to 12 weeks or more to see the full effects.

Starting, stopping, or changing a dose of these medicines needs to be watched carefully. Do not make any changes before discussing this with your healthcare provider.

Asking the following questions can help you make an informed decision about your different treatment options and resources and help decide which one(s) will work best for you:

**“What are the advantages and disadvantages of each option?”**

**“Can I use any of these treatment options together?”**

**“How will this make me feel? Will it have side effects?”**

**“What results can I expect?”**





## Talk with your healthcare provider about a referral

After your conversation with your dialysis healthcare provider, they may refer you to another healthcare provider. This may include a family doctor, kidney doctor, nurse practitioner, dialysis nurse, pharmacist, social worker, dietitian, exercise therapist, spiritual health care provider, psychologist, or a team that comes together with you to plan and organize your care.

Social workers and psychologists are often specially trained to discuss challenges you may be experiencing when adjusting to or coping with dialysis.

They may meet with you to discuss your health concerns, order more tests, or discuss resources or management options with you.

When being referred to another healthcare provider, you might ask:



**“What are the next steps to contact this healthcare provider?”**

**“Can you give me an idea of when I will hear from this healthcare provider?”**

**“How can this healthcare provider help me?”**

**“Is there anything I need to do or prepare for before I meet with this healthcare provider?”**

If you have not heard from the healthcare provider you have been referred to within the timeframe you are expecting, feel free to reach out to your dialysis healthcare provider.



### Helpful tools and resources

To learn about how to prepare for your healthcare provider appointment, visit [ahs.ca/quire](https://ahs.ca/quire).





## Manage and watch your emotional wellbeing

As you continue on your dialysis journey, remember that if something doesn't work the way you thought it would, think about other options and connect with your healthcare provider to find a treatment that will work for you.

Remember to watch for changes in your mood and how you are feeling. It is normal for day-to-day mood to change, and some days may be better or worse than others. Your friends, family members, and healthcare providers are great resources to listen to you and help you with your dialysis journey. Joining a support group can also broaden your support network by connecting you with others who are living with dialysis.

Your healthcare provider should be regularly checking in on how you are coping with and adjusting to dialysis, and after any major changes in your life.

If you would like to bring the discussion up again during your next appointment, consider asking:

**"Last time we met, we talked about how I was coping with dialysis. Can we talk about how the last \_\_\_ weeks/months have been for me?"**

Watching your emotional wellbeing is important. Call your healthcare provider, Health Link (811), or the Alberta Wide Mental Health Help Line Telephone (1-877-303-2642) if you have any concerns. You might feel like you don't want to bother your healthcare team, but no detail is too small to share. If it matters to you, it will matter to your healthcare team.



Do you need a safe space to talk to someone now? Call 9-8-8.

A trained responder can help you 24 hours a day, 7 days a week at the [Suicide Crisis Helpline](#).

Follow up is needed sooner if you have:

- Severe changes in mood
- Concerns about your emotional wellbeing and safety
- Thoughts of harming yourself or others

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You can clarify with your healthcare team what to expect regarding follow-up communication. Connect with your healthcare team whenever you:

- Have questions
- Notice your symptoms getting worse
- Have problems with your medications
- Haven't received test results or heard back about an appointment in the timeframe you were expecting



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## Helpful tools and resources

**811:** If you can't reach your healthcare provider and need health advice or information, call Health Link anytime, day or night, by dialing 811. Health Link provides a number of clinical services including tele-triage and health advice, navigation services and online content support for all Albertans.

**Alberta Wide Mental Health Help Line Telephone:** This help line is available anytime, day or night, at 1-877-303-2642 (toll free). This confidential service provides support, information and referrals to Albertans experiencing mental health concerns. You can talk to: nurses, psychiatric nurses, social workers, occupational therapists, and psychologists.



## Keep taking care of yourself

There are many important parts of living well with dialysis. Sleeping well, eating nutritious foods, exercising, and socializing with family and friends all help to improve mood.

Remember to look after yourself as a whole person: physical, emotional, spiritual, financial, and social. All of these parts are connected and influence each other. It is important to be aware of your personal needs in each part. Examples may include looking after spiritual needs, attending group exercise classes, reviewing dietary considerations, or ongoing or recurrent blood work.



## Helpful tools and resources

### Find resources and services in your community:

211 helps Albertans find the right resource or service for whatever issue they need help with, at the right time. 211 is available anytime, day or night, by phone, text, and online chat. It is confidential and available in over 170 languages over the phone. To contact 211:

- Call 211
- Text INFO to 211
- Visit [ab.211.ca](http://ab.211.ca)

Workshops, classes, and services from the **Alberta Healthy Living Program** can help you to improve your health and quality of life with a chronic condition: [ahs.ca/ahlp](http://ahs.ca/ahlp)

**Chronic Disease Management support:** [ahs.ca/cdm](http://ahs.ca/cdm)

**Health Information & Tools:** [myhealth.alberta.ca/Pages/HealthInfoToolsDefault.aspx](http://myhealth.alberta.ca/Pages/HealthInfoToolsDefault.aspx)



## Resources

There is a lot of information out there, and it can be confusing to know what information is accurate and true. Here are some great resources that may be helpful for you.

List of resources in Alberta to help cope with and adjust to dialysis:

[www.healthyqol.com/files/Quality-of-Life-Resources-Environmental-Scan-Kidney-AB.pdf](http://www.healthyqol.com/files/Quality-of-Life-Resources-Environmental-Scan-Kidney-AB.pdf)

### Get help now:

- Emergency: Call 911
- Health Link: Call 811

### Mental health, addiction, and crisis support and resources:

- Addiction Helpline: 1-866-332-2322
- Mental Health Helpline: 1-877-303-2642
- Crisis Text Line: Text CONNECT to 741741
- Crisis Services Canada: 988, or visit [talksuicide.ca](http://talksuicide.ca)
- My Health Alberta- Information and Tools- Anxiety
- My Health Alberta- Information and Tools- Depression
- Personal Safety Plan Form (AHS): [www.albertahealthservices.ca/frm-18600.pdf](http://www.albertahealthservices.ca/frm-18600.pdf)
- Psychiatric Associates of Southern Connecticut, PC - Am I Depressed or Am I Anxious?  
*This site offers information about the similarities between anxiety and depression*

### Helpful tip

If you can't print this resource at home, ask a family member, friend, or your healthcare provider to print it for you. You can also use a computer and printer at your local library.

### Community and social supports:

- Alberta 211: call 211, or visit [ab.211.ca](http://ab.211.ca)
- Family Violence Info Line: 310-1818, or visit [alberta.ca/family-violence-find-supports.aspx](http://alberta.ca/family-violence-find-supports.aspx)
- Income Support: 1-866-644-5135, or visit [alberta.ca/income-support.aspx](http://alberta.ca/income-support.aspx)

### Alberta Health Services programs:

- Home Care: [ahs.ca/homecare](http://ahs.ca/homecare)
- Find a Dietitian: [ahs.ca/nutrition](http://ahs.ca/nutrition)
- Spiritual Care Services: [ahs.ca/spiritualcare](http://ahs.ca/spiritualcare)

### Primary care (family doctors):

- Find a doctor: [ahs.ca/findadoctor](http://ahs.ca/findadoctor)
- Virtual care guide: [ahs.ca/virtualhealth](http://ahs.ca/virtualhealth)

### Patient concerns and feedback:

- Office of Alberta Health Advocates: [alberta.ca/office-of-alberta-health-advocates.aspx](http://alberta.ca/office-of-alberta-health-advocates.aspx)
- Alberta Health Services Patient Relations: 1-855-550-2555, or visit [ahs.ca/patientfeedback](http://ahs.ca/patientfeedback)

## Important phone numbers

Name or clinic name:

Phone number:

Name or clinic name:

Phone number:

Name or clinic name:

Phone number:

## Notes

Use this space to take notes.



## Background

### About this Pathway

With the guidance of the Provincial Pathways Unit, this patient pathway was co-developed in partnership with:

- University of Alberta Faculty of Nursing: Alexandra Birchall, Dr. Kara Schick-Makaroff, Dr. Charlotte Berendonk
- A Community Advisory Committee: Monika Bolin, Jeff Costley, Sandy Johnstone, Kevin Kemp, Loretta Lee, Justin LeRoux, May Tourangeau, Sabiha Zaman, and 1 other member.
- A Steering Committee

It is current as of April 2025.

A Community Advisory Committee, including nine Albertans with lived dialysis experience, voiced the need for a patient-facing version of a clinician-facing pathway on “Mental Health Care for Albertans on Dialysis”. This patient-facing pathway is a lay version of the clinician version; they are mirror images of each other. Topics covered in this pathway reflect those discussed in the clinician version. We recognize that people living with kidney disease who are not on dialysis or are pre- or post-transplant, are not represented. Similarly, specific populations such as First Nations and Métis people are not represented.

### Authors & Conflict of Interest Declaration

This pathway was reviewed and revised by: a Steering Committee comprised of nine allied health professionals in dialysis care, administrators and researchers in kidney care, and one primary care provider.

### Pathway Review Process

Patient pathways undergo scheduled review every three years, or earlier if there is a clinically significant change in knowledge or practice. The next scheduled review is April 2028. However, we welcome feedback at any time. Please email comments to [albertapathways@primaryhealthcare.ca](mailto:albertapathways@primaryhealthcare.ca).

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### Disclaimer

This pathway represents evidence-based best practice but does not override the individual responsibility of healthcare professionals to make decisions appropriate to their patients using their own clinical judgment given their patients’ specific clinical conditions, in consultation with patients/alternate decision makers. The pathway is not a substitute for clinical judgment or advice of a qualified healthcare professional. It is expected that all users will seek advice of other appropriately qualified healthcare providers with any issues transcending specific knowledge, scope of regulated practice or professional competence.



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