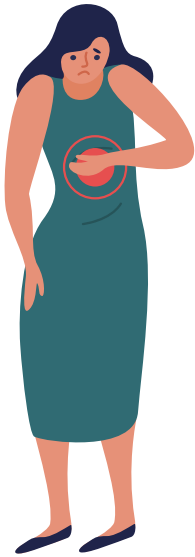


# Pain and Autosomal Dominant Polycystic Kidney Disease (ADPKD)



## What is pain?

Pain is the feeling of hurt or discomfort in the body. While it is a common symptom of autosomal dominant polycystic kidney disease (ADPKD), each person experiences pain differently and therefore your pain is unique to you. The experience of pain can be influenced by a person's cultural background, expectations, behaviors, and physical and emotional health.

This symptom can range from mild to intense and can be temporary or ongoing. Pain is the body's way of signaling that there is a health problem that needs attention. For this reason, it's helpful to monitor your pain and to know when to consult your care team.

## What kinds of pain are there?



**Acute pain** usually starts suddenly and is caused by something specific. It goes away when there is no longer an underlying cause for the pain.



**Chronic pain** is ongoing pain that's common in people with ADPKD. About 6 in 10 people who have been diagnosed with the condition experience chronic pain.

## What causes pain?

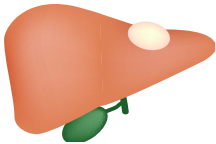
Understanding the cause of your pain will help your healthcare team treat it in the best way. Some things that might cause or worsen pain include:

- Some illnesses or diseases
- Medical procedures and tests
- Dialysis treatments (for example, pain from cramping or needling a fistula)
- Injury or joint/muscle conditions
- Stress, anxiety or depression
- The emotional, social, and spiritual impact of kidney disease
- Other problems, such as constipation and nausea<sup>1</sup>

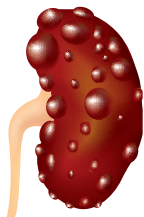
For information about symptom assessment and management in chronic kidney disease, visit: [BCRenal.ca](https://www.bcrenal.ca) ► [Health Info Managing My Care](#) ► [Symptom Assessment and Management](#)

## Common ADPKD-specific causes of pain

The more common causes of pain in ADPKD are from complications or problems related to the kidneys and cysts. These can be acute or chronic in nature with this disease. General descriptions of the pain and symptoms are provided below, however it is important to consider that these can be experienced differently from person to person.



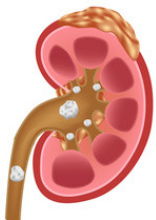
**An enlarged kidney or liver.** As the kidneys and/or liver grow in ADPKD, it may be painful if these organs press on neighbouring organs, or the outer lining of the kidneys and liver becomes stretched. You may experience the feeling of fullness which can impact your ability to eat a full meal or you may feel full after only a small amount of food. Acid reflux commonly known as “heartburn” is another symptom that may occur. It is important to connect with your renal dietitian to advise you on the best way to manage these symptoms and maintain your nutrition.



**Bursting and/or bleeding kidney or liver cysts.** The symptoms you experience will depend on where the cyst is located in your body, and can vary. For some people, this causes a severe, ‘stabbing’ pain in their abdomen, often in one area, and for some with kidney cyst rupture, blood may be visible in the urine. It’s possible to experience none, one or both of these symptoms. For example, about half of all patients with cyst bleeding do not have symptoms. Liver and kidney cysts can feel quite similar, can be equally as painful and can last up to a week or more. In the case of blood in the urine, contact your kidney team if the blood is not clearing/improving over the course of 24 hours, you are passing large amounts of blood or clots, feeling light-headed or dizzy.



**Pain due to changes in posture.** If the kidneys and liver become very large, this may affect your posture and cause other issues, such as chronic back pain.



**Kidney stones.** This is when hard deposits made of minerals and salts form in kidneys. This can cause severe pain that may begin and go away suddenly. Pain may be felt in the back, the side of the abdomen, and sometimes the groin. You may also have blood in your urine and feel sick and feverish. People with ADPKD often experience back pain that may be due to other causes, so it is important to differentiate between chronic back pain you may commonly feel due to ADPKD versus sudden, severe pain.



**Urinary tract infections.** Some people experience pain on one side of their abdomen or lower back when they have this type of infection. Other symptoms may include fever, chills and the need to urinate often. It’s common to experience pain or a burning sensation while urinating.

Some other causes of pain that can occur with ADPKD but are not specifically from the kidneys or cysts include:

- **Aneurysm.** People with ADPKD are at higher risk of developing aneurysms. An aneurysm is a weak spot in the wall of your artery. It's possible to have an aneurysm but show no symptoms. In this case, the only way to know if you have an aneurysm is to have an MRI or CT scan. If the aneurysm's wall is thin enough, it can rupture, causing bleeding that can be dangerous. Bleeding from a brain aneurysm can cause sudden onset of a very severe headache. Contact 911 right away if you experience this symptom.
- **Diverticulitis.** Sometimes small pouches, called diverticula, can form in the intestines. These are usually harmless, but they can become infected, causing pain. Other symptoms can include: fever, nausea and a marked change in your bowel habits.
- **Gout.** This condition affects the joints, causing pain, swelling and redness. Gout is caused by a substance called uric acid forming crystals in the joints. Some medications, such as diuretics (water pills), can increase a person's risk of developing gout. Talk to your kidney team dietitian about diet changes you can make.

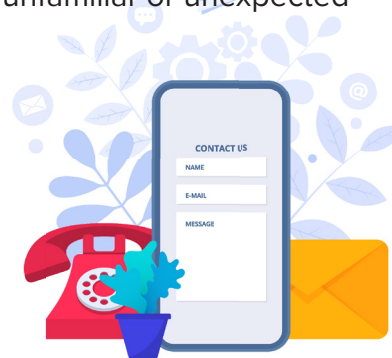
## When should I talk to my healthcare team?

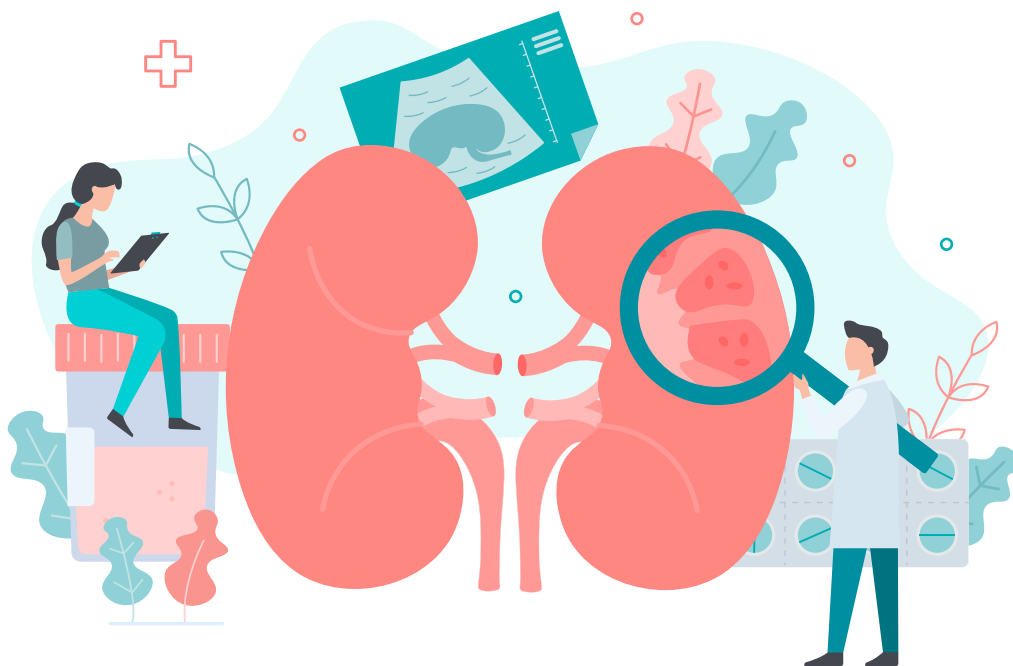
As you progress through your ADPKD journey, you will become more familiar with the various signs and symptoms associated with ADPKD. This will help you understand what's normal for you and what requires consultation with your care team.

In many cases, the cause of the pain can be identified and treated. However, sometimes the cause of the pain can't be identified, and some painful problems caused by ADPKD may not be fully resolved. Even if it may not be possible to eliminate the problem that is causing your pain, there are a number of pain management options that may help minimize pain or make it more manageable for you. Documenting your pain and using a pain scale (0 – no pain; and 10 – worst possible pain) can help you track and communicate what you are feeling to your healthcare team.

If you are already trying pain management techniques and find that they are not working, tell your healthcare team and they may be able to suggest other options.

Contact a member of your care team If you experience any unfamiliar or unexpected pain.





## How are causes of pain diagnosed?

Your doctor will ask questions about your pain (e.g. when it came on, what makes it worse or better, and how severe it is) so it may help to keep a record of this information. If you are comfortable doing so, you could also take a sample of your urine in a clear container for closer inspection or take a photo of it in order to show your doctor at your next scheduled appointment.

Depending on the possible cause of your pain, your doctor may decide to order some tests. These tests can be as simple as a temperature check, a urine test or blood tests. If required, a sample of fluid may be taken from a kidney cyst for testing. In some cases, imaging may be required to further investigate the cause of your pain. These tests could include a CT scan or MRI, which help to check whether you have kidney stones or problematic cysts in your kidneys or liver.

Since people living with ADPKD often have CT scans to monitor cysts in the liver and kidneys, it may be helpful to ask your doctor to review the results of your scan(s) with you. You could also ask for a copy of the scan report for your own records.

In addition to a kidney specialist, you may see other specialists, such as a radiologist, hepatologist, urologist, physiotherapist, and/or pain specialist to help with diagnosing the cause of your pain.

Although your kidney specialist and kidney care team are familiar with ADPKD and associated symptoms, other providers such as your family doctor, emergency room doctors and other specialists may not be as familiar with ADPKD. It is important to be able to provide information about your condition to these healthcare professionals, so they can provide the best care for you. Be your own advocate!

## Self-Management

There are a number of different things that people do to manage their pain, and what works for one person may not work for another. You will need to find the combination of therapies and activities that are right for you. Some suggestions include:

### Physical relief



- Heating and/or ice packs (heat and ice may not be safe if you have numbness from nerve damage – check with your healthcare team)
- Finding comfortable positioning, some options include: cushions, pillows, and back braces. Wedged pillows may be especially helpful for sleeping more comfortably.

### Exercise



- Gentle exercise (e.g., yoga, stretching) can be helpful for some people
- If one part of your body is hurting, you can try exercises that use a different body part (e.g., arms, shoulders)
- If you feel less pain at certain times of the day, aim to exercise at that time
- Find an activity that's within your ability
- Try not to be hard on yourself if you are unable to exercise the way you'd like

If exercise is not possible for you or if you find that it is not helpful in relieving your pain, you should consider other treatment strategies. If you are uncertain about starting an exercise regimen, you can discuss this with your kidney care team.

## Other treatment strategies

- Physiotherapy
- Massage (make sure to inform your Registered Massage Therapist of your condition so they avoid pressure over the kidney area)
- Alternative homeopathic therapies (acupuncture, reflexology, etc.)
- Meditation, [muscle relaxation and breathing exercises](#)
- Distraction activities (e.g., watching TV or playing computer games)
- Healthy coping activities, (e.g., walking, reading, listening to music, or visiting with family and friends)

## Support

Be mindful about where you get your information and advice from. Consider talking about your pain to:

- Someone you trust and who is a good listener (for example, a friend or family member)
- Your care team
- A religious or spiritual person
- The Kidney Foundation of Canada or the PKD Foundation of Canada. Peer support is available through both organizations.

## Tracking Your Pain

Keeping a [record of your pain](#) can help you and your healthcare team to better understand and manage it.

Some details to track include:

- How intense is it?
- Where is it?
- How does it feel?
- How long did it last?
- What triggered it?
- How did you treat it?
- How did you feel after treating it?
- What worked well? What didn't work?

**Pain Diary**  
for Autosomal Dominant Polycystic Kidney Disease (ADPKD) **BCRenal**

Often, doctors ask patients to describe their pain using a scale from 1 to 10, where 0 is no pain and 10 is extreme pain. This scale also describes how pain is impacting your quality of life and/or ability to complete daily activities. You can use the infographic included in this pain diary to determine how to rate your pain.

Pain Intensity	0	1-2	3-5	6-7	8-9	10	
	No pain	Mild Pain	Moderate Pain	Severe Pain	Very Severe Pain	Worst Pain Possible	
Impact on Quality of Life (QoL)	Normal	Normal	Normal	Normal	Normal	Normal	
Quality of Life (QoL)	Work/volunteer; normal activities each day Social life outside of work Take an active part in family life	Work/volunteer; be active 8 hours daily Outside social activities Have energy to make plans for social activity Take part in family life	Work/volunteer; at least 6 hours daily Active at least 5 hours a day Do simple activities on the weekend	Work/volunteer; limited hours Take part in limited social activities on weekends	Work/volunteer; minimal hours Struggle to fulfill daily home responsibilities Chores around house Minimal activities outside of home 2 days a week	Not able to work/volunteer Get dressed in morning Minimal activities at home Contact with friends via phone, email	Get out of bed but don't get dressed Stay at home all day Stay in bed at least half the day Have no contact with outside world

[Link to references](#)  
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Often, doctors ask patients to rate their pain on a scale between 1 and 10, where 1 is very mild pain and 10 is very intense. By rating your pain over time, your care team will have a better understanding of your pain and how well pain management is working.

## Medical Management



Along with self-management and other treatment strategies, there are some medical options available for managing pain. Pain specialists are challenging to access, so that is why it's important to work with your kidney care team to determine the best approach to medical management for you.

## Psychological approaches

- Cognitive behavioural therapy (CBT)
- Mindfulness and/or meditation
- Self-help guides written by pain management specialists



## Medications



It's important to discuss any new pain medication including over the counter medications and natural supplements with your care team, and to take medications as prescribed. Some medications involve side effects, which affect people differently. If you are experiencing side effects that are impacting your quality of life, you can talk to your care team about exploring different options.

Talk to your healthcare team if what you are taking is not working well, if you are concerned about the amount you are taking, or if you are worried about addiction or dependency.

Some medications that are used to treat pain include but are not limited to:

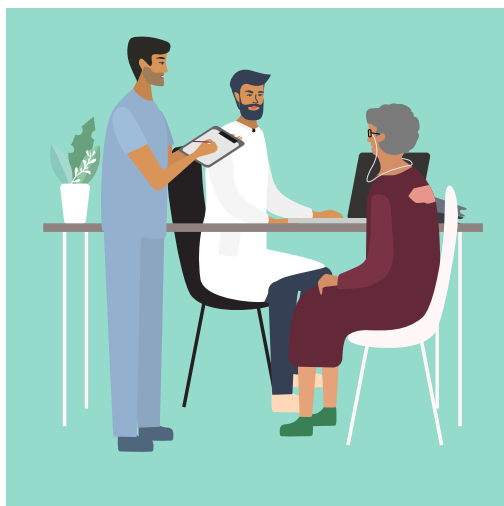
- NSAIDS (consult with your kidney specialist, as these medications must be limited for those with reduced kidney function)
- Acetaminophen
- Opioids
- Over-the-counter rubs like diclofenac (for example, Voltaren Emulgel)

Cannabis is an alternative option that some people with chronic pain have found helpful. If you are considering this, discuss this with your doctor or healthcare team.



## Procedures

If pain is severely impacting your quality of life, surgery may be considered to address the cause of pain. Another procedure that may be recommended and has been found to be effective is to drain the liver or kidney cysts through interventional radiology to relieve the pain and pressure felt.



Both surgery and interventional radiology are invasive procedures and there is no guarantee that they will offer sufficient or long-lasting pain relief. Therefore these options are generally only considered when other measures are no longer effective. These types of procedures are not for all people with ADPKD and need to be discussed with your care team.

## Pain & Mental Health

Living with chronic pain is associated with an increased risk for some mental health conditions like depression and stress, and these conditions can worsen pain. If you are experiencing these feelings, please let your

care team know and consult them about treatment options. You can also visit our mental health page for more information. [BCRenal.ca](#) ► [Health Info](#) ► [Managing My Care](#) ► [Mental Health](#)

## Other Pain Resources

- Online apps are available to help you track pain and other symptoms that are common with chronic health conditions.
- Self-management resources are available for those in chronic pain.
- PainBC is an organization that offers extensive resources for pain management.

## References

1. Ontario Renal Network (2019). How to Manage Pain. Retrieved from <https://www.ontariorenalnetwork.ca/sites/renalnetwork/files/assets/HowToManagePain.pdf>
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This resource was developed in collaboration with the Kidney Foundation, BC and Yukon Branch, and the PKD Foundation of Canada.



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