

Supporting your family through PBC



Advice and tips for talking to children of different ages about primary biliary cholangitis (PBC).

GETTING STARTED

Being diagnosed with primary biliary cholangitis (PBC), a liver disease that affects the bile ducts, can be a challenging experience, both for you and your family.

It's natural to have questions and concerns about what this means for your health, your treatment options, and your future. For parents, one of the biggest challenges can be explaining the diagnosis to your children.

This brochure is designed to help you navigate this conversation. Whether your children are younger or older, it's important to talk to them about what's happening and help them understand what PBC is, what symptoms you may experience, and what treatment options are available.

The following pages will provide tips and advice for talking to children of different ages about PBC, as well as information on how to manage your symptoms and access support resources. Our goal is to help you and your family be informed, empowered, and prepared.



0-5 YEARS

Keep the language simple and use visual aids, such as pictures or drawings, to explain what is happening.

Here are some helpful tips:

- For this age group, it's important to **focus on reassurance** and explaining that it is **not the child's fault**
- Emphasize that the parent may need to **rest more or take medication** to feel better
- Use simple language to **describe the symptoms that the child may see**, such as feeling tired or needing to take a break.

You can also use simple language to explain the role of the liver in the body, such as:

“Everyone has a liver in their body, and it helps us stay healthy. The liver helps clean our blood and gives us energy to do things like run and play. But sometimes, the liver can feel tired or sick, and it needs some extra help. That's why I am taking medicine and seeing a doctor, to help my liver feel better.”

6-12 YEARS

It's important to keep the conversation open and honest, and to provide age-appropriate information that your child can understand.

Explain that PBC is a chronic disease that affects the liver.

- **Use visual aids**, such as diagrams of the liver, to help explain what is happening in the body (see page 8)
- **Describe the symptoms** that you may experience, such as fatigue, itching, and abdominal pain
 - Explain that you may need to take medication or have treatments to manage the symptoms
- **Encourage them to ask questions** and express their feelings about the situation
- **Offer reassurance** and let them know that you're doing everything you can to manage your condition and stay healthy



6-12 YEARS

Finding the appropriate language can be challenging.

Here is an example of something you can say:



*I have a condition called **primary biliary cholangitis (PBC)**. That means my body's immune system, which is like an army that helps your body fight off germs, is attacking my liver by mistake. The liver is an organ that helps our body process the food we eat and gets rid of harmful waste.*

PBC is not something I caught like a cold or the flu. It's just something that happens to some people, and I'm getting the help I need from doctors to manage it.

*One of the symptoms of PBC is **itchiness**. Sometimes I feel really itchy, and it can be uncomfortable, but I'm taking medicine and using lotions to help manage it. Another symptom is **fatigue**, which means I can feel really tired and might need to rest more than usual.*

***PBC is not contagious, which means you can't catch it from touching me or me breathing on you.** And while it can be scary to hear about, there are many treatments available to help me manage my symptoms and stay healthy.*

If you have any questions or want to talk about how you feel, please remember that I'm always here to listen.



13-18 YEARS

Provide more detailed information about what PBC is and how it affects the liver.

- **Discuss the symptoms** that you may experience and how they may impact your daily life
- **Talk about the different types** of treatments that are available to manage the symptoms and slow the progression of the disease
- **Emphasize the importance** of maintaining a healthy lifestyle to manage the disease and reduce the risk of complications
- **Provide information** about support resources, such as patient organizations and counseling services
- **Discuss** the potential **long-term effects** of the disease, such as **liver damage** and the potential need for **transplantation**



13-18 YEARS

It's important to be honest and open about your condition while also maintaining a positive outlook and focusing on the things that are within your control.

Here is an example of something you can say:



*I have a condition called primary biliary cholangitis (PBC), which is a type of autoimmune disease that affects my liver. **It's not something I did or something you did, it's just something that can happen to anyone.***

*One of the symptoms of PBC is called '**pruritus**', which means I can feel really itchy all over my body. It can be uncomfortable and distracting, but I'm taking medication and using other strategies to manage it.*

*Another symptom is **fatigue**, which means I can feel really tired and might need to rest more than usual.*

Living with PBC can be challenging, but I'm doing everything I can to manage my symptoms and stay healthy. If you ever have any questions or concerns about my health or PBC in general, I'm here to talk and provide you with information.

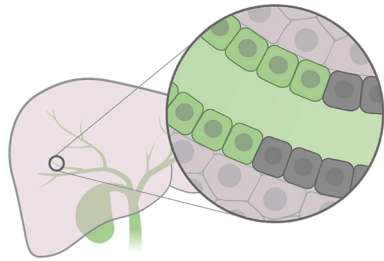
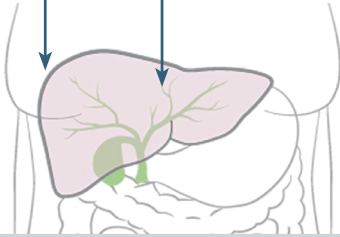
*While having a medical condition like PBC can be tough, it's important to stay positive and focus on the things we can control. **I'm lucky to have a supportive family like you, and I'm confident that we can get through this together.***



UNDERSTANDING THE PROGRESSION OF PBC

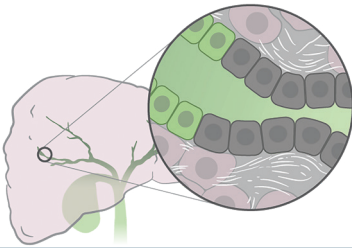
Liver: Produces a substance called bile (a yellow-green fluid) that eliminates toxic substances from the body and also aids in digestion

Bile ducts: Small tubes that carry bile from the liver to the small intestine to help with digestion

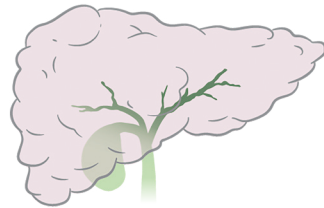


Autoimmune response: In PBC, the body's own immune system mistakes your bile duct cells as foreign objects and attacks them.

Cholestasis: Damage to the bile ducts causes bile to be trapped in the liver. Bile acid buildup is toxic and leads to further damage to the liver, which is indicated by high levels of alkaline phosphatase (ALP), a liver enzyme.



Fibrosis: Over time, the accumulation of bile acids leads to more damage causing scarring of the liver.



Cirrhosis: Occurs when there is widespread scarring of the liver.

What does PBC mean?

Primary: Occurs without an obvious cause

Biliary: Related to, or affecting the bile ducts in the liver

Cholangitis: Inflammation of the bile ducts

GETTING A HELPING HAND

With proper management, most people living with PBC are able to live full and active lives.

If you or someone you know is living with PBC, don't hesitate to reach out to the Canadian PBC Society for support and guidance.

For more information and to hear stories from other people living with PBC, visit/click the websites listed below:

The Canadian PBC Society

Website: pbc-society.ca

Youtube: youtube.com/@canadianpbcociety6295

Facebook: facebook.com/CanadianPBCSociety

Phone number: 1-866-441-3643



This document was developed in collaboration with the Canadian PBC Society.

Reference:

Bharadwaj P, Sandesara N, and Sandra E. Talking with Children About a Parent's Serious Illness. *Am Fam Physician* 2013;88:571-572.

