

Understanding PBC

A guide for friends and families of people living with primary biliary cholangitis (PBC)

“Life throws things at us all the time. We have a choice whether or not to let them bother us, and I choose to stay positive.”

Wayne and his wife, Elaine, partners in taking on Wayne's PBC diagnosis since 1992



Your loved one has been diagnosed with PBC

Facing a diagnosis of primary biliary cholangitis (PBC) can be scary and overwhelming for both you and your loved one. Learning more about PBC, including ways to support the person you care about, can be helpful.

What is PBC?

PBC is a progressive and chronic autoimmune disease that affects the bile ducts in the liver. The **exact cause** of PBC is **unknown**.

- **Progressive** and **chronic** mean that PBC can get worse and will not go away over time
- **Autoimmune** means that the disease causes the body to attack itself, causing inflammation and damage

In a healthy liver, bile ducts carry bile to your small intestine to help with digestion. With PBC, damaged bile ducts cause bile to get trapped in the liver. This buildup is called **cholestasis**, and it can lead to harmful scarring in the liver known as **fibrosis**. Worsening fibrosis can lead to **cirrhosis**, which severely interferes with liver function.

- The cirrhosis caused by PBC is **not related to alcohol**; even people who don't drink alcohol can get cirrhosis from PBC

PBC by the numbers

- Up to 55% of people living with PBC also have another autoimmune disease. If your loved one has more than one autoimmune condition, he or she is not alone
- Approximately 90% of people who have PBC are women
- Most people affected by PBC are between 35 and approximately 80 years of age



It's important to know...

- **PBC is not contagious**, and it's not your loved one's fault
- **Scientists think PBC can be inherited**, so if one person in a family has it, other members of the family are likely to have it as well

Managing PBC and liver health

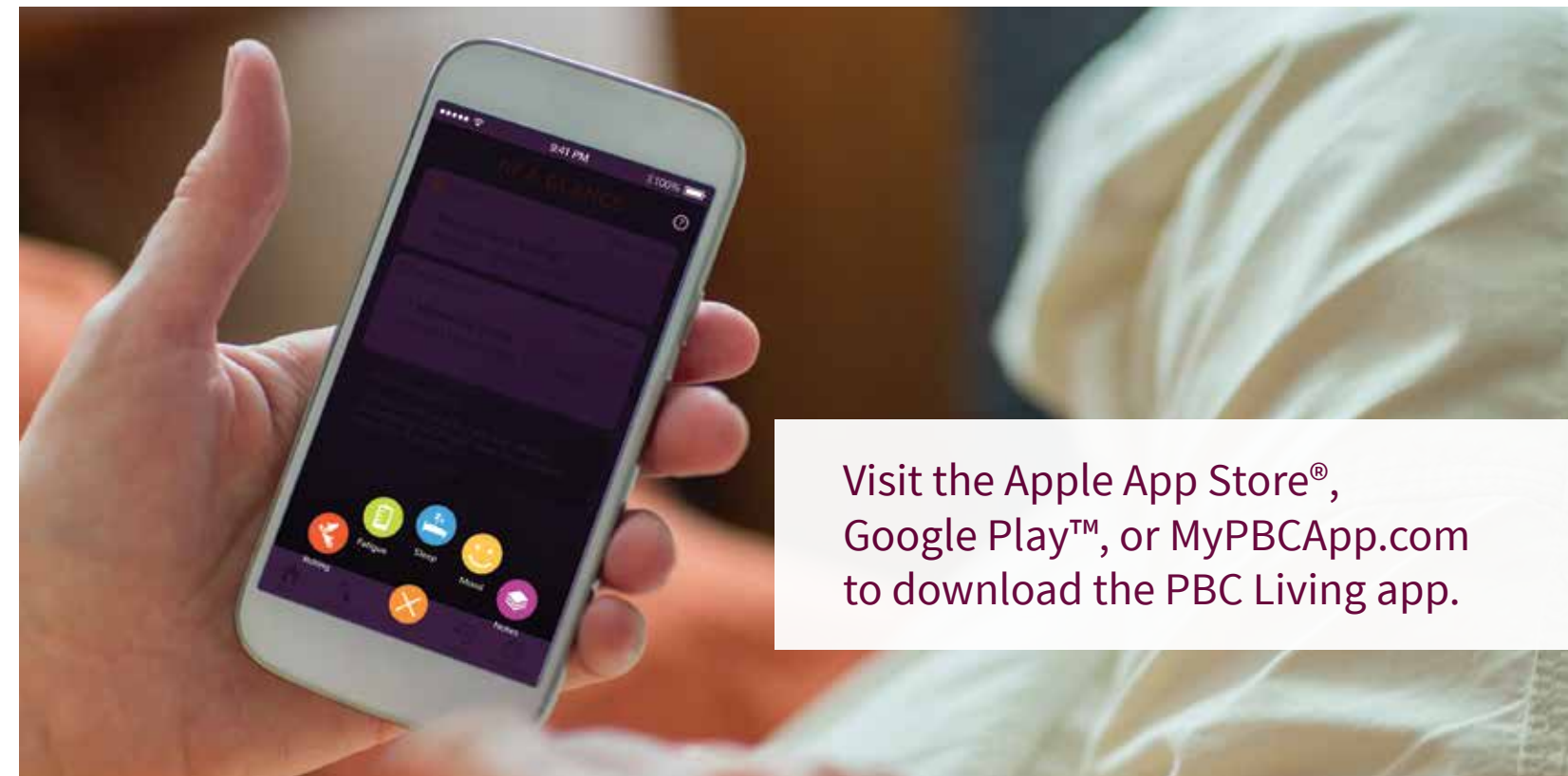
A simple blood test can measure 2 key markers that are important for managing PBC and liver health.

- **Alkaline phosphatase** (ALP), sometimes called "alk phos," is an enzyme found in the body. An abnormally high ALP level can be a sign of liver damage
- **Bilirubin** is yellow bile pigment that is processed by the liver and secreted as bile
 - Bilirubin is especially elevated in more advanced PBC

Medical guidelines recommend that healthcare teams track ALP every 3 to 6 months in people who are living with PBC.

Ways to help your loved one:

- Help set up phone or calendar reminders for blood tests
- Encourage your loved one to schedule the next appointment after each blood test
- Download and explore the PBC Living® app together to track blood test results
- Partner with your loved one to actively manage his or her PBC by helping to prepare questions and important conversation topics for the healthcare team before each appointment



Visit the Apple App Store®, Google Play™, or MyPBCApp.com to download the PBC Living app.

What are the symptoms of PBC?

Most people who have PBC do not have symptoms at the time they are diagnosed. However, everyone responds to PBC differently. Your loved one may experience symptoms that others do not. Symptoms of PBC also may not be obvious, so your loved one may “look fine” on the outside but not feel well or feel up to doing regular activities.

Common symptoms of PBC, and ways to offer support



Itching, clinically known as pruritus

- Can happen anywhere on the body
- May be brushed off as seasonal if palms and feet itch
- Becomes worse at night for some people

Ways to help your loved one

- Encourage your loved one to talk to his or her healthcare team about the itching so possible treatment options can be explored
- Urge your loved one to talk to his or her healthcare provider about the medical guidelines for treating pruritus, including prescription medicines and lifestyle management options



Severe fatigue (tiredness)

- Up to 85% of people with PBC suffer from fatigue
- Fatigue caused by PBC can happen any time of day or night
- Some people describe their PBC-related fatigue as preventing them from functioning or causing them to suddenly fall asleep

Ways to help your loved one

- Run errands, cook meals, clean, care for pets, or pick up prescriptions
- Offer to drive him or her to office visits or procedures
- Provide emotional support by listening and trying to understand his or her situation without being dismissive

Other symptoms of PBC include **dry eyes and mouth** and **trouble remembering and concentrating**.

“Aim to make good choices and live the healthiest, happiest life you can.”

Kathy, diagnosed with PBC in 2007

Debbie, diagnosed with PBC in 2011



It's important to know...



- The extent of itching and fatigue is not related to how far your loved one's disease has progressed
- Experiencing these symptoms does not mean his or her treatment isn't working
- Continuing to take medication as prescribed is important, so encourage your loved one to stay on track and discuss questions or issues with his or her healthcare team

What types of healthcare providers treat PBC?

People with PBC often have a team of healthcare providers and liver specialists to help manage their disease. **Gastroenterologists** and **hepatologists** are 2 types of specialists that treat PBC.

There are **benefits to including liver specialists** on the team because they:

- Have the education, training, and resources to diagnose and manage PBC
- Are likely to be familiar with treatment options and management techniques
- Are more likely than primary care providers to have managed or seen other cases of PBC

What about treatment for PBC?

Detecting PBC as early as possible may lead to better management of the disease.

There are treatments available for PBC, so it's important for your loved one to work with his or her healthcare team to find the right approach. It is also important to address PBC with medication, because it is chronic and will not go away.

The goal of a PBC treatment plan is to help slow damage to the bile ducts and lower ALP levels. Encourage your loved one to **check in regularly** with his or her healthcare team to keep track of his or her progress.

Since PBC is chronic, it's also important for your loved one's healthcare team to work with him or her to create **long-term treatment goals**.



Ways to help:

Looking for a specialist who can treat PBC? Asking current trusted healthcare providers for referrals is a great place to start.

You can also look to organizations such as the **PBCers Organization**, a resource for PBC education and support. **Visit [PBCers.org/find-a-doctor](https://www.pbcers.org/find-a-doctor)** to learn more.

Visit **[LivingwithPBC.com/pbc-specialists](https://www.livingwithpbc.com/pbc-specialists)** to download and print a **discussion guide** that can be used to start a conversation about PBC and make the most of your loved one's time with his or her healthcare team.

Finding support

LivingwithPBC.com

Resources and support for those diagnosed with PBC as well as their friends and families. Find and register for educational PBC events in your area that people living with PBC and loved ones can attend together.

PBC Living® app

An on-the-go tool to help track and monitor every aspect of one's journey with PBC. Available through the Apple App Store and Google Play.

Living with PBC Facebook community

Join us on Facebook for stories, information, and sharing with the active PBC community.

PBCers.org^a

The mission of the PBCers Organization is to unite people diagnosed with PBC. The organization helps people with PBC and their caregivers, friends, and families cope with PBC and improve the quality of their lives through education and support.

^aIntercept Pharmaceuticals does not endorse this organization. The information/links provided by Intercept are meant for informational purposes only and are not meant to replace a physician's medical advice.



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