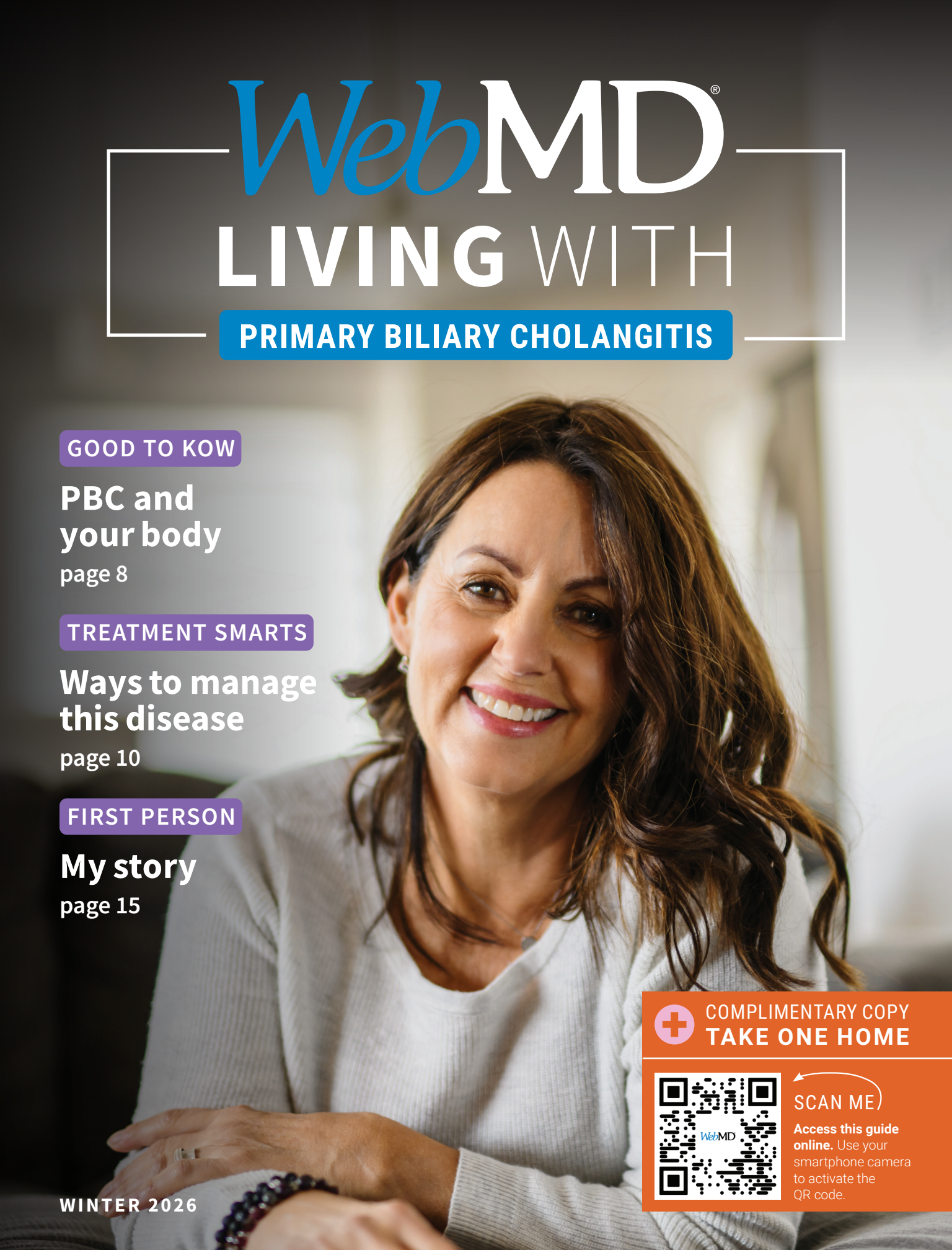
WebMD

LIVING WITH

PRIMARY BILIARY CHOLANGITIS



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WINTER 2026

Dear Reader,

WebMD's mission is to provide trusted, educational, and accurate health information. Our medical experts focus on topics that empower consumers to be active participants not only in their own healthcare, but also in the lifestyle and health decisions of their family and friends.

We create and distribute condition guides for doctors' offices to help you prepare for your visit, to have a productive dialogue with your physician, and as a take-home companion.

This guide's topic is ***Primary Biliary Cholangitis*** with content including:

- Ways to manage this autoimmune disease
- Stress-busting strategies to help you improve your quality of life
- One woman's tips on how to empower yourself when living with PBC

This resource can be a powerful tool to help you be your own best health advocate.

We hope that you will find this condition guide to be informative and useful. Please share your thoughts in a short survey accessed through the QR code below.

Thank you.



Sincerely,

Laura J. Downey

Laura J. Downey
Editorial Director
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To the Office Manager: For any additional copies or needs, email Vanessa Cognard, publisher, WebMD Point of Care, at vcognard@webmd.net.

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Livdelzi®
seladelpar 10mg Capsules

For adults with primary biliary cholangitis (PBC)

Let LIVDELZI take on your PBC

while you take in the moment

#1 PRESCRIBED SECOND-LINE PBC TREATMENT

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Jennifer

Real LIVDELZI patient

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What is LIVDELZI?

LIVDELZI is a prescription medicine used to treat primary biliary cholangitis (PBC) in combination with ursodeoxycholic acid (UDCA) in adults who have not responded well to UDCA, or used alone in patients unable to tolerate UDCA.

LIVDELZI is not recommended for use in people who have advanced liver disease (decompensated cirrhosis). Symptoms of advanced liver disease may include confusion; having fluid in the stomach area (abdomen); black, tarry, or bloody stools; coughing up or vomiting blood; or having vomit that looks like "coffee grounds".

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LIVDELZI can cause serious side effects, including:

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Please see Important Safety Information continued on the next page and Important Facts about LIVDELZI on the last page of this ad.

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Livdelzi® seladelpar 10mg Capsules

FOR ADULTS WITH PRIMARY BILIARY CHOLANGITIS (PBC)

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- pain on the right side of your stomach (abdomen)
- black, tarry, or bloody stools
- coughing up or vomiting blood, or your vomit looks like "coffee grounds"
- mental changes such as confusion, being sleepier than usual or harder to wake up, slurred speech, mood swings, or changes in personality

The most common side effects of LIVDELZI include headache, stomach (abdominal) pain, nausea, abdominal swelling (distension), and dizziness.

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Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Certain other medicines may affect the way LIVDELZI works.

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Livdelzi®
seladelpar 10mg Capsules

(liv del′ zee)

IMPORTANT FACTS

This is only a brief summary of important information about LIVDELZI and does not replace talking to your healthcare provider about your condition and your treatment.

ABOUT LIVDELZI

LIVDELZI is a prescription medicine used to treat primary biliary cholangitis (PBC) in combination with ursodeoxycholic acid (UDCA) in adults who have not responded well to UDCA, or used alone in patients unable to tolerate UDCA.

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It is not known if LIVDELZI is safe and effective in children.

BEFORE TAKING LIVDELZI

Tell your healthcare provider about all of your medical conditions, including if you:

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- are breastfeeding or plan to breastfeed. It is not known if LIVDELZI passes into your breast milk. Talk with your healthcare provider about the best way to feed your baby if you take LIVDELZI.

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POSSIBLE SIDE EFFECTS OF LIVDELZI

LIVDELZI can cause serious side effects, including:

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- **Changes in liver tests.** Increased liver enzymes in the blood have happened when taking more LIVDELZI than prescribed. Your healthcare provider will do tests to check your liver before you start and during treatment with LIVDELZI.

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- yellowing of your skin or the whites of your eyes
- pain on the right side of your stomach (abdomen)
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Tell your healthcare provider if you have any side effect that bothers you or does not go away. These are not all the possible side effects of LIVDELZI.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

HOW TO TAKE LIVDELZI

Take LIVDELZI by mouth 1 time each day with or without food.

GET MORE INFORMATION

- This is only a brief summary of important information about LIVDELZI. Talk to your healthcare provider or pharmacist to learn more.
- Go to LIVDELZI.com, or call 1-800-GILEAD-5.

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PBC AND YOUR BODY

This autoimmune condition may start its course through your liver long before you see the signs. Learn what happens.

By Sonya Collins
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Primary biliary cholangitis (PBC) can work quietly for years, damaging the delicate network of bile ducts inside the liver long before you notice that anything is wrong.

"Before you show symptoms, the body's own immune system is attacking the bile ducts," says David W. Victor III, MD, a hepatologist at Houston Methodist in Texas.

As those ducts become inflamed, bile—fluid the liver makes to help digest fats and carry away toxins—begins to back up, setting off a cascade of injuries that may eventually harden the liver.

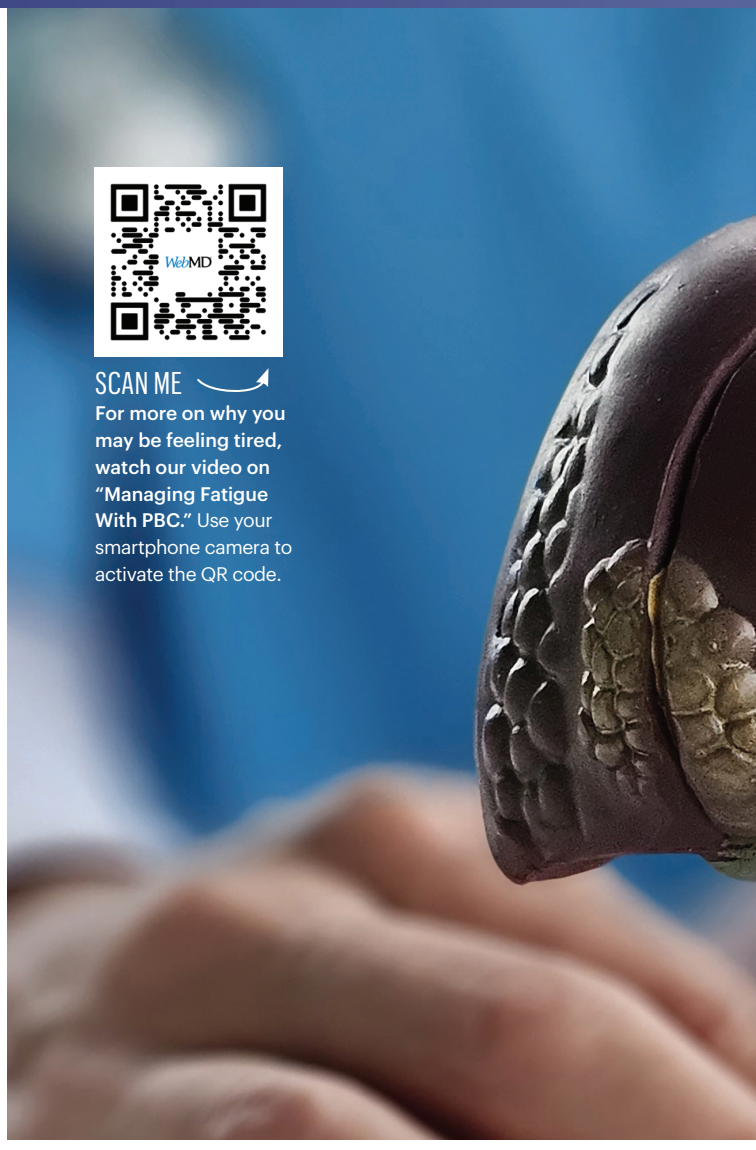
PBC AT A GLANCE

What: An autoimmune disease that damages liver bile ducts

Who: Mostly women, ages 30 to 60, but no one is immune

Symptoms: Fatigue, itching, dry eyes, dry mouth

Prognosis: Good, with treatment



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For more on why you may be feeling tired, watch our video on "Managing Fatigue With PBC." Use your smartphone camera to activate the QR code.

NADZEYA HAROSHKA/VIA GETTY IMAGES

THE IMMUNE SYSTEM ATTACKS

In a healthy liver, bile ducts serve as passageways for bile to travel from the liver to the digestive system. With PBC, the immune system mistakes these ducts for an outsider—a germ or other illness—to be fought off. It then creates antibodies that it hurls at these ducts, causing inflammation.

"The ducts get blocked and eventually destroyed, and bile gets trapped in the liver," says Nancy Yang, MD, a gastroenterologist and hepatologist at Duke Health in Durham, NC.

With an immune system that's always in overdrive, you feel worn out. That's one of PBC's key symptoms: profound fatigue.

"Any autoimmune process can be energy draining," Yang says. The fact that this process is an offensive on the liver makes it worse. "The liver is an energy source," Yang explains. The more damage this organ incurs, the more lethargic you feel.



BILE BUILDS UP

As bile builds up in your liver and your bloodstream, PBC's hallmark itching begins. "Chemicals in the bile enter the bloodstream, get into the skin, and make the nerves more sensitive," Yang says. This, she explains, leads to the itching.

Because bile helps the body process fat, cholesterol, and nutrients, when its flow is impaired, cholesterol starts to rise, and certain vitamins and nutrients aren't absorbed. "We start to see thin bones and vitamin D deficiency," Victor says.

ONGOING LIVER DAMAGE

As the immune system continues its assault on the liver, the liver lays down tough scar tissue to protect itself, a process called fibrosis. Without treatment, as thick scar tissue overtakes soft healthy tissue, the liver stiffens over time, a condition called cirrhosis.

WHAT DOES BILE DO?

When bile acid can't flow through the liver, it can't do these important jobs.

+ Break down fats in the food you eat
+ Help your body absorb nutrients for energy and ongoing health
+ Flush waste products out of the body

"Patients who develop cirrhosis from PBC have a risk of liver and bile duct cancers," Victor says. "We recommend screening for these once they reach cirrhosis, but we hope to meet them before that happens."

Once the liver has reached cirrhosis, it can no longer perform its essential tasks that are necessary to keep the body running. At this point, transplant may be the only option.

Fortunately, Yang says, "The progress of PBC is on the slower side and we can slow it further with various medications."

YOUR OPTIONS

Ways to manage this chronic autoimmune disease

By Rachel Reiff Ellis
Reviewed by Brunilda Nazario, MD,
WebMD Chief Physician Editor, Medical Affairs

Treatment for PBC won't cure the disease, but it can ease symptoms and help protect your liver. The sooner you start treatment, the better your chances of preventing serious complications.

MEDICINES THAT SLOW LIVER DAMAGE

The first treatment most doctors prescribe for PBC is a bile acid medication you take as a capsule or tablet that helps bile move through your liver and slows damage to your liver.

"We assess you after six to 12 months and compare your liver fibrosis at that point to your baseline and see how things have changed," says Sooki Hon, MD, PhD, a gastroenterologist and transplant hepatology specialist at Atlanta Gastroenterology. "About 40% of people on the first line of bile acid medication don't respond well enough, and an additional 2% to 3% have side effects they can't tolerate. At that point, we move to second-line therapies."

Second-line options are in a drug class called peroxisome proliferator-activated receptor (PPAR) agonists. You also take these as a pill, and your doctor may either add them to the bile salt medication or have you take them alone. These medications can reduce inflammation in your liver and improve liver test results.



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MEDICATIONS FOR MANAGING SYMPTOMS

PBC can cause itching, fatigue, high cholesterol, and weakened bones. Your doctor may recommend medications, dietary supplements, or lifestyle changes to help manage these problems. For example, antihistamines may help itching, statins may help control cholesterol levels, and treatments for osteoporosis can help protect your bone health.

If PBC causes severe liver damage and leads to liver failure, you may need a liver transplant.

"A transplant does not cure the autoimmune process that caused PBC, but it can replace a damaged liver and significantly improve quality of life and survival for people with advanced disease," says Hon.

LIVING WELL WITH PBC

Here's what helps when itching and fatigue persist

By Sonya Collins **Reviewed by** Neha Pathak, MD, WebMD Chief Physician Editor

Getting a diagnosis of primary biliary cholangitis (PBC) can feel overwhelming. Medications can slow the disease and help protect your liver. But even when they work, some symptoms may persist.

"Most of the time patients have profound fatigue and itching," says Pratima Sharma, MBBS, a transplant hepatologist and gastroenterologist at Michigan Medicine in Ann Arbor. "Itching may abate with treatment. But fatigue sometimes remains despite being on therapy."

Understanding why these symptoms happen—and how doctors manage them—can help you feel more prepared to handle them.

SCRATCHING THAT ITCH

The itching that comes along with PBC is different from the kind caused by dry skin or allergies. When bile isn't flowing properly through the liver, substances that build up in the body can trigger itching.

Newer targeted medications for PBC may help. For people who don't get relief from these medications, or for people not on these particular treatments, doctors will take other steps to get the itching under control.

First, the doctor may check your thyroid. About 1 in 4 people with PBC also have hypothyroidism. "Patients with hypothyroidism have very dry skin, which can make itching worse," Sharma says.

Next, they might try you on medications called bile acid binders. There are also medications for other conditions, such as certain antibiotics, antihistamines, antidepressants, and a drug used for substance use disorder, that can have the collateral benefit of relieving PBC-related itching.

DIY strategies may help, too, like moisturizing lotions and avoiding very hot showers.

STAYING AHEAD OF FATIGUE

Fatigue is often the most frustrating symptom of PBC—and the hardest to treat. It's not completely understood why PBC can cause debilitating fatigue, but fatigue is a common symptom of many autoimmune conditions. Unfortunately, medications that help with fatigue from other causes don't seem to help people with PBC.

If you have severe fatigue, "It's important to make sure we're not missing something else that may be causing it," says Allyce N. Caines, MD, a gastroenterologist who treats patients with liver disease at Henry Ford Health in Detroit. Your doctor might check for anemia, thyroid disease, sleep apnea, and depression.

"Once those are all controlled or excluded, we help them with coping strategies," Caines says.

These might include:

- Regular exercise
- Mindfulness and yoga
- Planning activities and breaks around your energy levels

These strategies won't eliminate fatigue, but they can make it easier to live well with it.

FIND STRENGTH IN SUPPORT

You don't have to power through these symptoms alone. Work closely with your doctor, speak up about symptoms, and connect with support groups if you find them helpful.

"Your symptoms are valid, so voice them to your doctor," Caines says. "Don't just suffer. Your doctor wants to work with you."

With the right care—and the right support—you can continue to lead a full, active life.

WHEN TO TELL YOUR DOCTOR

Talk to the doc if you have ...

- **Itching** that keeps you awake
- **Fatigue** that interferes with daily life
- **New symptoms** such as severe dryness of the eyes or mouth
- **Symptoms of thyroid problems** (cold intolerance, hair loss, weight changes)

TAME YOUR STRESS

When you have PBC, mind-body practices can boost your mood and improve quality of life

By Kendall K. Morgan **Reviewed by** Neha Pathak, MD, WebMD Chief Physician Editor

While treatment is available for your primary biliary cholangitis (PBC), you may still experience chronic fatigue and mental health challenges, including chronic stress. You may have normal or near-normal liver tests and still feel unwell, says Puneeta Tandon, MD, a liver specialist at the University of Alberta in Canada.

"Many people with PBC live with fatigue, itch, poor sleep, brain fog, anxiety, low mood, and the uncertainty of having a chronic disease," Tandon says. "Fatigue in PBC is real, complex, and often invisible, affecting up to 80% of individuals. Stress management is not a replacement for medical treatment, but it can give people practical tools to cope with symptoms, uncertainty, and the day-to-day emotional load of living with PBC."

WORSENING PBC SYMPTOMS

Stress has a way of making everything else worse.

"While stress does not directly cause PBC, it can severely worsen existing symptoms such as fatigue and itching," says Nancy Reau, MD, a liver specialist at Rush University Medical Center in Chicago. "Stress triggers inflammatory responses in the body, which exacerbate symptoms driven by inflammation."

STRESS-BUSTING STRATEGIES

To ease stress, Reau suggests identifying your stress triggers and planning to reduce them as much as you can. Practice good self-care, including exercise, good nutrition, and getting enough sleep. A strong social support network can help, too, along with other more private practices such as journaling, she says. Give yourself time to find what works.

"Stress management is an easy buzzword but requires a lot of introspection on what your triggers are and what the potential solutions are," Reau says. "This isn't going to be the same for everyone."

MIND-BODY PRACTICES

A clinical trial led by Tandon and her colleagues found that a 12-week online mind-body program could improve mental wellness and quality of life in people with PBC. While the program itself isn't readily available, Tandon says it included many elements you could safely try at home. Those include gentle movement, mindfulness, meditation, and simple breathing practices.

"People might try slow belly breathing or a calming sigh where the out-breath is longer than the in-breath,"



SCAN ME

For more healthy habits, flip through our slideshow titled "Lifestyle Changes to Help With Your PBC." Use your smartphone camera to activate the QR code.

Tandon says. "Even five minutes of breathing or gentle movement done consistently can help symptoms."

ASK FOR HELP

Tandon recommends speaking with your liver care team or primary care provider, especially when stress, anxiety, depression, sleep problems, or fatigue are interfering with your daily life. Consider reaching out to patient organizations offering education, connection, and the reminder that you're not alone in this, she advises. Remember that trust in yourself and your experience is essential to getting the help you need.

"I want people with PBC to know that their symptoms are real, even when their bloodwork looks OK," Tandon says. "With exciting developments in both pharmacologic and non-pharmacologic options for PBC, people shouldn't hesitate to bring symptoms up with their physician. There are strategies that can help, and they don't need to tackle this alone."

YOUR STRESS MANAGEMENT TEAM

Along with your liver care team, your stress management team may include other experts and tools such as:

+ Psychologists
+ Counselors
+ Social workers
+ Physiotherapists
+ Occupational therapists
+ Online self-management programs

KATHRIN ZIEGLER/VIA GETTY IMAGES

BE YOUR BEST ADVOCATE

Get informed and share your story so others will understand

By Kendall K. Morgan
Reviewed by Brunilda Nazario, MD,
WebMD Chief Physician Editor, Medical Affairs

Advocating for yourself is an important way to get your healthcare needs met. It means giving voice to your needs, wishes, questions, and concerns, enabling you to serve as an active member of your care team. While self-advocacy is always key, it can be especially critical when you have a condition such as primary biliary cholangitis (PBC). You'll need to advocate for yourself not only with your liver care team but with all your care providers.

"Anyone who has a rare disease like PBC needs to learn to advocate for themselves because every healthcare provider they encounter will not know about PBC or be updated on the latest treatments available," says Carol Roberts, president of the Rochester, New York-based PBCers Organization, an online and in-person support group for people with PBC. "It is important that they all be aware of your diagnosis so when you are being treated for any other health issues your liver disease is considered, and nothing is done contrary to your liver. As an educated patient, you should speak up and ask questions, be a part of your own care plan."

GET INFORMED

Roberts says the first step to becoming your own best advocate is educating yourself on your disease. She advises learning all you can about symptoms and changes you should watch out for. Consider joining a support group to learn from others who've been there. Read up or watch webinars that explain PBC and its treatment in detail.

"Being well informed allows you to understand and discuss your treatment plan with your treating physician," Roberts says.

MANAGING YOUR SYMPTOMS

Monika Sarkar, MD, a liver specialist at UCSF Health in San Francisco, notes the importance of pushing for treatment options that can help not only with your liver but also with the "extrahepatic manifestations of PBC." About 3 in 4 people with PBC will have autoimmune-related problems and symptoms outside the liver. Symptoms of PBC include fatigue, itchy skin, dry eyes, joint pain, and more.

"Sometimes people may be given lifestyle recommendations like lowering the temperature of the shower or using creams, not lotions, without providers offering more aggressive treatment to deal with itching," Sarkar says. "It can be debilitating."

She says it's important to ask about all your treatment options and how they can help with itching or any other troubling symptoms you have, to ensure you'll have the best quality of life possible despite your PBC diagnosis.

SHARE YOUR STORY

Your role as a self-advocate need not be limited to healthcare settings, according to Roberts.

"Many patients have said they don't feel people understand how their PBC affects them," Roberts says. "Advocating for yourself includes making sure you're sharing your story so others can learn about PBC. Throughout your journey, you will need other's help and understanding."

ASK AWAY

When you have PBC, it's important to ask questions. Here are a few to get you started:

- How much liver damage do I have?
- What treatment do you recommend, and will it slow the damage?
- What else can I do to protect my liver?
- Can PBC treatment help my symptoms, including the itch?

MY PBC STORY

Liver disease taught me how to stand up for myself

By Victoria Dennis
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Although I didn't realize it at the time, my primary biliary cholangitis (PBC) symptoms started when I was 14. Routine blood tests showed slightly elevated liver enzymes, but doctors weren't concerned because the numbers were only mildly abnormal, and I felt completely healthy.

This continued to happen several more times throughout my young adulthood while I was going to college, changing doctors, and living a normal life. But I didn't have any of the classic signs of liver disease. I wasn't jaundiced or sick—but I was tired.

Then in my mid-20s, I became more tired than ever and was falling asleep at my desk at work. Clearly something wasn't right, but liver disease was the last thing on my mind.

A LIFE-CHANGING DIAGNOSIS

The turning point came during the height of COVID-19. I kept brushing off my symptoms, but they became impossible to ignore. I woke up every morning with severe nausea. My bowel movements were pale and grayish. And I itched constantly.

It felt like the itch was in my bones and blood. Nothing helped. My whole body was covered in scratches, and sunlight made it worse. Then I noticed my eyes turning yellow. One night, after feeling especially sick and exhausted, I went to the emergency room. Doctors admitted me immediately. My liver enzymes were extremely elevated, and I was clearly jaundiced.

After two weeks of testing, doctors diagnosed me with both PBC and autoimmune hepatitis. The next few years were difficult. I developed vasculitis and ascites, signs that my liver disease was progressing. I felt frustrated because I was told to wait until I was sicker before pursuing a transplant, even though I was constantly in and out of the hospital and felt terrible all the time.

BECOMING MY OWN ADVOCATE

Eventually, I switched hospitals, sought out a living donor program, and within six months received a liver transplant. Today, I no longer have PBC or autoimmune hepatitis. I still take antirejection medications and have regular blood tests, but my liver is stable.

If you're newly diagnosed, know that your voice matters. Speak up when things don't feel right or you have questions. And connect with the liver disease community. You'll be able to imagine a better future for yourself and feel less alone.

VICTORIA'S TIPS



How to empower yourself with PBC.

+ **Ask questions** until you understand your diagnosis.
+ **Get a second opinion** if you want one.
+ **Research** all treatment options.
+ **Connect with others** living with liver disease.



JETCITYIMAGE/VIA GETTY IMAGES; INSET PHOTO COURTESY OF VICTORIA DENNIS

STATS & FACTS

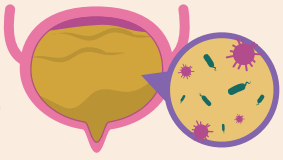
Reviewed by Neha Pathak, MD,
WebMD Chief Physician Editor

ABOUT 15%



Estimated amount of people with PBC who also have autoimmune thyroid disease.

35%



Amount of people with PBC who have bacteria in their urine but do not show any symptoms of a urinary tract infection.



30%

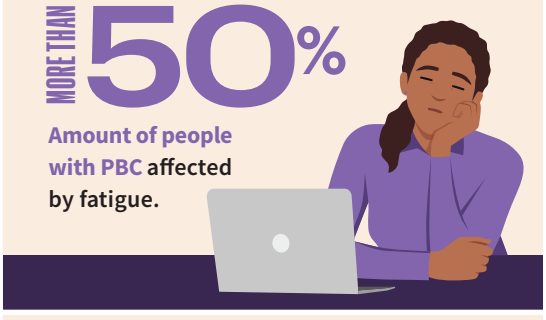
Amount of people with PBC who reported experiencing itching severe enough to significantly affect their well-being, based on a survey.

ABOUT 1 in 4



Number of people who have had PBC for 10 years who may develop liver failure as the disease progresses.

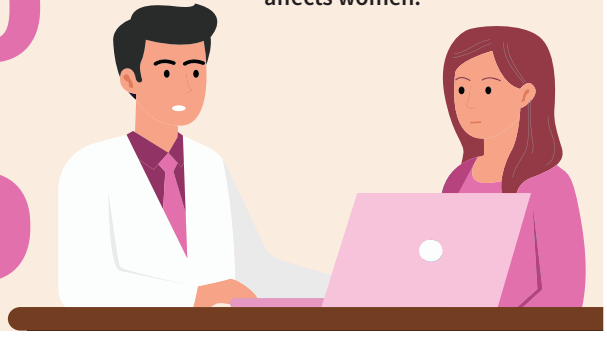
MORE THAN 50%



Amount of people with PBC affected by fatigue.

40 to 70

Age range in which PBC most commonly affects women.



5.5 to 12

Range of years people with symptomatic PBC are expected to live if they do not receive treatment after symptoms begin to develop.

SOURCES: American Liver Foundation, Medscape, *Digestive Diseases and Sciences,* Autoimmune Association, *The Lancet*

This content was created using several editorial tools, including AI, as part of the process. Human editors reviewed this content before publication.

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