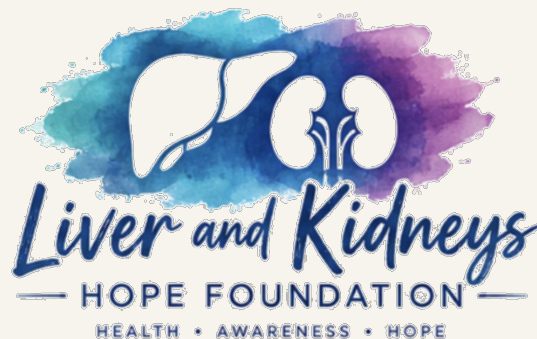




PATIENT & COMMUNITY EDUCATION SERIES

Understanding Primary Sclerosing Cholangitis

A plain-language, comprehensive guide to primary sclerosing cholangitis — a condition causing scarring of the bile ducts, its strong link to inflammatory bowel disease, and how it's monitored and managed.

Often shortened to PSC — covering diagnosis, cancer surveillance, and transplantation

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Primary sclerosing cholangitis is a condition this guide aims to explain honestly — including the areas where treatment options remain more limited than for some other liver conditions. It's also a condition with a genuinely wide range of individual courses, effective ways to manage its complications, and, when needed, a highly effective transplant option. This guide walks through the complete picture.

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A NOTE BEFORE YOU BEGIN

PSC has a genuinely wide range of individual courses — some people have very slowly progressive disease over decades, while others progress more quickly. This guide describes the full range honestly, including areas of real uncertainty, because we believe an accurate picture serves you better than false reassurance. It also aims to be clear about what is genuinely manageable, and where real hope exists.

SECTION 1 Your Liver: A Quiet, Hardworking Organ

Before discussing what can go wrong, it helps to appreciate just how much your liver does every day — usually without you noticing at all.

Your liver is the largest solid organ inside your body, weighing roughly 1.4 kg (about 3 pounds) in an adult. Scientists have identified more than **500 distinct functions** it performs — and one of them, central to this entire guide, is producing bile, a fluid that helps digest fat and carries waste products out of the body.

The liver's bile duct tree

Bile travels from liver cells through a branching network of ducts — starting as very small channels deep within the liver, merging into progressively larger ducts, and eventually forming one or two main ducts that carry bile out of the liver toward the intestine. This branching structure is often compared to a tree, with the main ducts as the trunk and the smaller ducts as branches.

Where PSC strikes

Unlike primary biliary cholangitis (PBC, covered in our companion guide), which affects only the smallest bile ducts, primary sclerosing cholangitis can affect ducts throughout this entire branching tree — including the larger ducts inside and outside the liver. This broader reach is one of the most important distinctions between these two conditions, covered fully in Section 4.

DID YOU KNOW?

Because PSC can affect larger, more visible ducts, it can often be directly seen on specialized imaging in a way that PBC's tiny duct changes cannot — a difference that shapes how each condition is diagnosed, covered in Section 9.

KEY POINT

PSC is fundamentally a disease of scarring within the bile duct tree, affecting ducts of various sizes — understanding this "tree-wide" reach is central to understanding this condition's diagnosis, complications, and treatment.

SECTION 2 What Is Primary Sclerosing Cholangitis?

Primary sclerosing cholangitis (PSC) is a chronic condition causing inflammation and progressive scarring of the bile ducts, both within and outside the liver, which can eventually narrow or block bile flow.

"Primary" indicates the condition begins in the bile ducts themselves, rather than resulting from another identifiable cause. "Sclerosing" refers to the progressive scarring (fibrosis) that develops within duct walls. "Cholangitis" means inflammation of the bile ducts. Together, the name describes ongoing inflammation and scarring specifically affecting the bile duct system.

A patchy, uneven process

Unlike some liver conditions that affect tissue relatively uniformly, PSC characteristically causes scarring in a patchy, uneven pattern along the bile duct tree — some segments become narrowed (strictured) while others may be relatively spared or even slightly widened between narrowed areas, creating a distinctive "beaded" appearance on imaging, covered in Section 9.

A genuinely variable condition

PSC's course varies enormously between individuals — some people have very mild, slowly progressive disease discovered incidentally and monitored for decades with few problems, while others experience more significant symptoms or complications earlier. This guide aims to give you the tools to understand where your own situation might sit within this range, in partnership with your care team.

KEY POINT

PSC is a genuinely serious diagnosis that deserves honest information — but it is also a condition with highly effective ways to manage its specific complications, close surveillance protocols that catch problems early, and, when needed, a very effective transplant option.

DID YOU KNOW?

PSC was first clearly described in the medical literature in the mid-20th century, and understanding of its connection to inflammatory bowel disease (Section 5) has been one of the most important developments in recognizing and managing the condition since.

SECTION 3

How PSC Develops: Scarring of the Bile Duct Tree

Understanding the process behind PSC helps explain both its distinctive imaging appearance and why its complications develop the way they do.

Ongoing inflammation and scarring

In PSC, the walls of bile ducts become chronically inflamed, and over time, this inflammation triggers progressive scarring (fibrosis) within the duct walls themselves. As scar tissue accumulates, affected segments of duct become narrowed — a change called a stricture.

Bile buildup and its consequences

Narrowed or blocked ducts impair bile flow, causing bile to back up (cholestasis) in the liver tissue upstream of the narrowing — a process similar in concept to what happens in PBC, though PSC's pattern of larger, more localized strictures creates some distinctive complications not typically seen in PBC, covered in Section 12.

Why the exact trigger remains unclear

Despite decades of research, the precise mechanism that triggers this ongoing inflammatory and scarring process in PSC isn't fully understood. Current thinking suggests a combination of genetic susceptibility, immune system involvement, and factors related to the gut — particularly given the strong connection to inflammatory bowel disease covered in Section 5 — though the exact relationship between the gut and bile duct inflammation remains an active area of research.

KEY POINT

Because the underlying trigger and mechanism aren't yet fully understood, medical therapy hasn't been able to target the disease process as directly as treatments have for some other liver conditions — a point covered honestly in Section 15.

DID YOU KNOW?

The connection between gut health and bile duct inflammation in PSC is sometimes described using the concept of a "gut-liver axis," an area of active research that may eventually open new treatment approaches targeting this specific connection.

SECTION 4

PSC vs. PBC: Understanding the Differences

Because PSC and PBC share "biliary" in their names and both affect bile ducts, they're sometimes confused — but they are genuinely distinct conditions in several important ways.

	PSC	PBC
Ducts affected	Ducts of various sizes, including large ducts inside and outside the liver.	Only the smallest bile ducts within the liver.
Typical sex pattern	More common in men.	Overwhelmingly more common in women.
Key associated condition	Inflammatory bowel disease (especially ulcerative colitis), in the large majority of patients.	Other autoimmune conditions, less universally linked to one specific condition.
Diagnostic hallmark	Characteristic appearance on cholangiography (imaging of the bile ducts).	Positive antimitochondrial antibody (AMA) blood test.
Proven medical therapy	No medication has been clearly proven to slow disease progression.	UDCA is highly effective first-line treatment for most patients.
Cancer risk	Notably increased risk of cholangiocarcinoma (bile duct cancer) and, with concurrent IBD, colorectal cancer.	Increased liver cancer risk only once cirrhosis develops, similar to other causes of cirrhosis.

KEY POINT

While both conditions involve bile duct injury and share some overlapping symptoms like fatigue and itching, they are managed quite differently — which is exactly why an accurate, specific diagnosis (covered in Section 9) matters so much.

DID YOU KNOW?

Occasionally, a person can have overlapping features of both PSC and autoimmune hepatitis, similar to the PBC-AIH overlap discussed in our companion guides — a situation managed with an individualized approach by a specialist familiar with both conditions.

SECTION 5

The Inflammatory Bowel Disease Connection

One of the most distinctive, important features of PSC is its strong association with inflammatory bowel disease (IBD) — a connection so significant it shapes much of ongoing PSC care.

How strong the connection is

The large majority of people with PSC — commonly cited as somewhere around 70 to 80% in many studies — also have inflammatory bowel disease, most often ulcerative colitis, and less commonly Crohn's disease. This is one of the strongest disease associations in all of hepatology.

A distinctive, sometimes quiet relationship

The IBD associated with PSC can behave somewhat differently than IBD occurring on its own — it's sometimes milder in terms of bowel symptoms, can affect a more extensive portion of the colon, and, notably, can sometimes be present with few or no obvious bowel symptoms at all, meaning some people are diagnosed with IBD only after a colonoscopy prompted by their PSC diagnosis, not because of digestive symptoms.

Why this connection matters practically

Because of this strong association, and because PSC-associated IBD carries its own increased colorectal cancer risk (Section 13), anyone newly diagnosed with PSC is generally recommended to have a colonoscopy, even without any bowel symptoms, to check for underlying IBD.

KEY POINT

If you've been diagnosed with PSC and haven't already had a colonoscopy, this is one of the most important, concrete next steps to discuss with your care team — identifying underlying IBD, even without symptoms, directly shapes your ongoing cancer surveillance plan.

DID YOU KNOW?

Interestingly, PSC can sometimes be diagnosed years before, or sometimes even after, a person's IBD is identified — and in some cases, PSC has been diagnosed in people who have already had their colon surgically removed for IBD, showing that the two conditions, while strongly linked, don't always follow a predictable order or fully depend on each other's activity.

SECTION 6 Causes & Risk Factors

The exact cause of PSC remains one of the more actively researched questions in hepatology, but several contributing factors have been identified.

Genetic susceptibility

Certain inherited genetic factors, including specific immune-related gene variants, are more common in people with PSC, suggesting a hereditary component — though, as with other autoimmune-associated conditions in this guide series, PSC is not directly inherited in a simple, predictable pattern.

Immune system involvement

PSC shares some features with autoimmune conditions, though it doesn't fit perfectly into that category either — for example, it doesn't reliably respond to the immune-suppressing treatments that work well for autoimmune hepatitis, suggesting its underlying mechanism may be somewhat different or more complex.

The gut connection

Given the strong IBD association covered in Section 5, researchers believe factors related to gut health — potentially including the gut microbiome, intestinal permeability, or immune signaling between the gut and liver — play a meaningful role, though the precise relationship remains under active investigation.

Who tends to be at higher risk

- **Men are affected somewhat more often than women** — a notable contrast to PBC's strong female predominance.
- **People with inflammatory bowel disease**, particularly ulcerative colitis.
- **Most commonly diagnosed in young to middle-aged adults**, often in their 30s to 40s, somewhat younger on average than typical PBC diagnosis.

KEY POINT

PSC is not caused by anything you did — it isn't linked to diet, alcohol, or lifestyle choices. Like other conditions in this guide series with an immune or inflammatory basis, it results from a complex interplay of genetic and other factors not yet fully understood.

SECTION 7 How Common Is It? Who Is Affected

PSC is considered a rare disease, generally less common than PBC, though — like several conditions in this guide series — increasingly recognized through more routine testing and imaging.

Estimates of how many people are affected vary by region, with somewhat higher rates reported in Northern European countries and North America compared to some other parts of the world — a geographic pattern that may relate to differences in IBD prevalence, given the strong connection between the two conditions.

Who tends to be affected

- **Men, somewhat more often than women** — roughly a 2:1 ratio in many studies.
- **People with inflammatory bowel disease**, particularly ulcerative colitis, who have a meaningfully increased likelihood of also having PSC compared to the general population.
- **Young to middle-aged adults**, though PSC can occur at any age, including in children.

DID YOU KNOW?

Because the connection between PSC and IBD is so well recognized, some gastroenterologists check liver blood tests periodically in their IBD patients specifically to screen for early signs of PSC, even without symptoms.

KEY POINT

If you have inflammatory bowel disease and haven't had your liver enzymes checked recently, this is a reasonable, low-burden step to discuss with your gastroenterologist, given how often the two conditions occur together.

SECTION 8 Signs & Symptoms

Like PBC, PSC often causes no symptoms in its earlier stages, with many people diagnosed through abnormal blood tests found incidentally, often during routine monitoring for IBD.

Common symptoms, when present

- **Fatigue**, similar to PBC and many other chronic liver conditions.
- **Itching (pruritus)**, which can be significant, similar to PBC — management approaches are covered in Section 17.
- **Discomfort in the upper right abdomen.**
- **Jaundice**, particularly if a significant stricture develops.

Symptoms suggesting a specific complication

- **Fever, chills, and worsening jaundice together** can indicate acute cholangitis (a bile duct infection), covered as a medical emergency in Section 12.
- **Significant, new abdominal pain or rapid weight loss** can occasionally signal a developing complication and warrants prompt evaluation.

SEEK EMERGENCY CARE FOR THESE SYMPTOMS

Fever, chills, and jaundice occurring together can indicate acute cholangitis, a serious bile duct infection requiring urgent medical treatment. This combination warrants **immediate emergency medical care** — do not wait to see if symptoms improve on their own.

KEY POINT

Because early PSC is so often silent, and because a specific symptom combination can signal a genuine emergency, it's worth knowing both patterns clearly — the quiet, common presentation and the urgent, less common one.

SECTION 9 How PSC Is Diagnosed: Cholangiography

Unlike PBC, which relies heavily on a specific antibody blood test, PSC is diagnosed primarily through direct imaging of the bile ducts — a technique called cholangiography.

MRCP: the standard first approach

Magnetic resonance cholangiopancreatography (MRCP) is a specialized, non-invasive MRI technique that produces detailed images of the bile duct tree. In PSC, MRCP characteristically shows multiple areas of narrowing (strictures) alternating with normal or slightly widened segments — creating a distinctive "beaded" or "beads on a string" appearance that is often sufficient to confidently diagnose PSC.

Blood tests

Liver blood tests in PSC often show a pattern similar to PBC — notably elevated alkaline phosphatase (ALP). Unlike PBC, there is no single antibody test that reliably confirms PSC; various antibodies are sometimes present but are not specific or reliable enough to serve as a primary diagnostic tool on their own.

ERCP: a more invasive alternative

Endoscopic retrograde cholangiopancreatography (ERCP), a more invasive procedure involving an endoscope passed into the bile duct system, can also visualize the duct tree and was historically the primary diagnostic tool. Today, it's generally reserved for situations requiring direct intervention (Section 16) rather than diagnosis alone, since MRCP achieves similar diagnostic detail non-invasively.

Liver biopsy

A biopsy is not required for most PSC diagnoses, given how characteristic the MRCP appearance usually is, but may be used when small-duct PSC is suspected (Section 10), since this variant doesn't show the classic large-duct changes on MRCP.

KEY POINT

If you're being evaluated for PSC, MRCP is generally the key diagnostic test — it's non-invasive and, for the large majority of patients, provides a confident diagnosis without needing a more invasive procedure.

SECTION 10 Small-Duct PSC & Other Variants

A distinct, generally more favorable variant of PSC exists — one that doesn't show the classic large-duct changes on imaging, and deserves its own understanding.

What small-duct PSC is

Some people have all the clinical and blood-test features suggestive of PSC, but normal-appearing large bile ducts on MRCP — because their disease affects only the smallest bile ducts, which aren't visible on standard cholangiography. This is called small-duct PSC, and is generally diagnosed through a combination of suggestive blood tests, normal MRCP, and a liver biopsy showing characteristic changes.

A generally more favorable course

Small-duct PSC is generally associated with a better long-term prognosis than large-duct PSC, including a notably lower risk of the cholangiocarcinoma covered in Section 13 — though some patients with small-duct PSC do eventually develop the large-duct changes typical of classic PSC over time.

PSC-AIH overlap

As mentioned in Section 4, some patients show overlapping features of PSC and autoimmune hepatitis, more commonly seen in younger patients, requiring an individualized treatment approach combining elements of both conditions' management.

KEY POINT

If you've been diagnosed with small-duct PSC specifically, this is generally more reassuring news than a classic large-duct diagnosis — it's worth understanding which variant applies to you and what that means for your specific monitoring plan.

DID YOU KNOW?

Small-duct PSC is thought to represent a meaningful minority of all PSC cases, and continues to be an area of active research regarding its long-term outcomes and optimal monitoring approach.

SECTION 11 Staging & Disease Course

PSC's disease course is notably variable between individuals — understanding the general patterns, while recognizing genuine uncertainty, helps set realistic expectations.

Fibrosis staging

Like other chronic liver conditions in this guide series, PSC can be staged based on fibrosis (F0–F4, covered in our companion fibrosis guide), assessed through elastography or, less commonly, biopsy.

A genuinely wide range of individual courses

Some people with PSC have very slowly progressive disease, remaining stable for many years or even decades with minimal symptoms. Others experience more significant strictures, complications, or faster progression to cirrhosis. Predicting which course any individual person will follow remains one of the more genuinely uncertain areas in PSC care, though ongoing monitoring helps track your own specific trajectory over time.

Prognostic scoring systems

Several scoring systems, incorporating blood tests and clinical factors, have been developed to help estimate individual risk and prognosis in PSC — your hepatologist can discuss whether and how these apply to your specific situation.

KEY POINT

Because PSC's course is so variable, regular, ongoing monitoring — rather than a single prediction made at diagnosis — is what actually guides your care over time. This uncertainty, while understandably difficult, is part of why consistent follow-up matters so much.

DID YOU KNOW?

Because of this variability, some people live with a PSC diagnosis for decades with only mild, well-managed disease — a genuinely encouraging reality for many patients, even without a specific medical therapy that changes the underlying disease course.

SECTION 12

Complications: Dominant Strictures & Cholangitis

Two specific complications — dominant strictures and acute cholangitis — are distinctive to PSC's pattern of larger duct involvement and deserve dedicated understanding.

Dominant strictures

A "dominant stricture" is a single area of narrowing significant enough to meaningfully obstruct bile flow, distinct from the more diffuse, milder narrowing seen throughout the duct tree in PSC generally. These can cause worsening jaundice, itching, or set the stage for infection, and often benefit from direct endoscopic treatment, covered in Section 16.

Acute cholangitis

When bile flow is significantly obstructed, bacteria can multiply within the stagnant bile, causing a serious infection called acute cholangitis. This classically presents with fever, chills, and jaundice occurring together (sometimes called Charcot's triad), and represents a true medical emergency requiring urgent antibiotic treatment and, often, a procedure to relieve the obstruction and drain infected bile.

THIS IS A MEDICAL EMERGENCY

Fever, chills, and jaundice occurring together in someone with PSC requires **immediate emergency medical care**. Acute cholangitis can progress quickly and requires urgent antibiotics and, often, a procedure to drain the obstructed bile duct.

Why these complications are managed proactively

Because dominant strictures can be identified and treated before they cause a full infection, and because recognizing early warning signs allows for prompt treatment of cholangitis if it does occur, being familiar with these specific patterns is genuinely protective for anyone living with PSC.

KEY POINT

These two complications, while serious, are also well-understood and effectively treatable when caught promptly — familiarity with the warning signs is one of the most practically useful things you can take from this guide.

SECTION 13

Cancer Risk: Cholangiocarcinoma & Colorectal Cancer

PSC carries a meaningfully increased risk of two specific cancers — a serious aspect of this condition that deserves honest, direct discussion, alongside the effective surveillance strategies that exist to address it.

Cholangiocarcinoma (bile duct cancer)

People with PSC have a substantially increased lifetime risk of cholangiocarcinoma compared to the general population — a cancer covered in more depth in our companion liver cancer guide. This risk doesn't require cirrhosis to be present first, unlike the liver cancer risk seen with most other chronic liver conditions in this guide series, and can develop at any stage of PSC.

Why surveillance is challenging, but still valuable

Detecting early cholangiocarcinoma is genuinely more difficult than detecting early liver cancer in cirrhosis, partly because distinguishing early cancer from PSC's own characteristic strictures on imaging can be difficult. Despite this challenge, regular monitoring (imaging and specific blood markers, covered in Section 18) remains valuable, and any new dominant stricture or significant clinical change prompts closer evaluation specifically to look for this possibility.

Colorectal cancer

For the large majority of PSC patients who also have inflammatory bowel disease, colorectal cancer risk is further increased beyond the risk from IBD alone — meaning colonoscopy surveillance is generally recommended more frequently (often annually) for PSC-IBD patients than for people with IBD alone.

Gallbladder cancer

PSC also carries a modestly increased risk of gallbladder cancer, which is part of why gallbladder abnormalities found on imaging in PSC patients are evaluated somewhat more cautiously than they might be in the general population.

KEY POINT

This increased cancer risk is a genuinely serious aspect of PSC, and it's also precisely why structured, regular surveillance (Section 18) is such a central, valuable part of ongoing care — early detection meaningfully improves outcomes for each of these cancers.

TALK WITH YOUR CLINICIAN

It's worth asking directly: "What does my cholangiocarcinoma and colorectal cancer surveillance schedule look like, and am I currently up to date on it?"

SECTION 14

Treatment & Management: The Big Picture

PSC management rests on a few clear pillars — even without a medication that directly treats the underlying disease process, there is genuinely a great deal that can be done.

Pillar 1 — Managing complications as they arise

Treating dominant strictures endoscopically (Section 16) and promptly treating any episode of acute cholangitis are central, effective interventions.

Pillar 2 — Cancer surveillance

Given the risks covered in Section 13, structured surveillance for cholangiocarcinoma and colorectal cancer is a core, ongoing part of PSC care.

Pillar 3 — Managing symptoms

Addressing itching and fatigue (Section 17), which can significantly affect quality of life, similar to PBC.

Pillar 4 — Monitoring for disease progression

Regular assessment of fibrosis stage and liver function, watching for the point at which transplant evaluation (Section 21) becomes appropriate.

A WORD OF CAUTION

Specific treatment decisions depend on your individual disease pattern and complications. **This guide cannot recommend specific treatments for you.** These decisions belong with your treating hepatologist.

KEY POINT

Even without a medication that changes the underlying course of PSC, effective management of its specific complications, combined with vigilant surveillance and, when needed, transplantation, offers a genuinely comprehensive approach to care.

SECTION 15

Why There's No Proven Medical Therapy Yet

This is one of the more difficult, honest facts about PSC worth addressing directly: unlike PBC, no medication has yet been clearly proven to slow the underlying progression of this disease.

What's been tried

Ursodeoxycholic acid (UDCA), so effective in PBC, has been studied extensively in PSC. While it can improve liver blood tests, larger studies have not shown a clear benefit in slowing disease progression or improving survival, and high-dose UDCA has, in some studies, shown potential concerns — meaning UDCA is not routinely recommended as a disease-modifying treatment for PSC the way it is for PBC.

Other approaches under investigation

Various other medications, including some being studied for other liver conditions in this guide series, are under active investigation for PSC specifically, reflecting a genuinely active area of ongoing clinical research — though none have yet achieved the clear, proven benefit that would make them a standard, recommended treatment.

Why this matters for how PSC is approached

Because no proven disease-modifying medical therapy exists, PSC management focuses heavily on the other pillars covered in Section 14 — managing complications, surveillance, and, when the disease progresses sufficiently, transplantation, which remains a highly effective treatment for advanced PSC.

KEY POINT

This is a genuine, current limitation in PSC care, and it's worth understanding honestly rather than being told otherwise. It does not mean nothing can be done — it means the "something" currently looks different than medication for many patients, and it means ongoing research genuinely matters for this community.

DID YOU KNOW?

Because of this gap, clinical trials are a particularly active and relevant area for PSC specifically — it's reasonable to ask your hepatologist whether any current trials might be appropriate for you.

SECTION 16

Endoscopic Treatment: Managing Strictures

While no medication treats PSC's underlying process, a specific, effective procedure exists for managing dominant strictures directly — one of the most tangible, valuable interventions available.

ERCP with dilation

Endoscopic retrograde cholangiopancreatography (ERCP) can be used therapeutically, not just diagnostically, to directly treat a dominant stricture — typically by dilating (stretching open) the narrowed segment, and sometimes placing a temporary stent to help keep it open.

Why this matters

Treating a dominant stricture can relieve jaundice and itching, and, importantly, reduce the risk of acute cholangitis by improving bile flow through the previously obstructed segment.

Brushings for cancer surveillance

During ERCP for a dominant stricture, cells are often brushed from the area and examined under a microscope — a way of directly checking for cholangiocarcinoma at the same time the stricture itself is being treated, combining treatment and surveillance in a single procedure.

KEY POINT

If you're told you have a dominant stricture, this is a specific, well-understood situation with an effective, targeted procedure available — not an escalation without a clear plan.

TALK WITH YOUR CLINICIAN

If a dominant stricture is identified, it's reasonable to ask: "What did the brushings show, and when should we expect to know the results?"

SECTION 17 Managing Itching, Fatigue & Nutrition

As with PBC, itching and fatigue can significantly affect quality of life in PSC — and, as with PBC, they deserve dedicated, proactive management rather than simple tolerance.

Managing itching (pruritus)

PSC-related itching, like PBC's, generally doesn't respond well to standard antihistamines, since it's driven by a different mechanism. Similar treatment approaches to those covered in our companion PBC guide are used, and this symptom is worth raising persistently with your care team if it affects your quality of life or sleep.

Managing fatigue

Fatigue in PSC, similar to PBC, doesn't always track closely with liver blood test results, and its exact cause isn't fully understood — pacing activity and discussing the impact on daily life openly with your care team are reasonable, practical approaches.

Nutrition and fat-soluble vitamins

Impaired bile flow can reduce absorption of dietary fat and fat-soluble vitamins (A, D, E, and K), similar to PBC — periodic monitoring and, if needed, supplementation guided by blood testing is a reasonable part of ongoing care, alongside attention to bone health given the same cholestasis-related osteoporosis risk covered in our companion PBC guide.

KEY POINT

These quality-of-life symptoms deserve just as much attention as the more visible complications covered elsewhere in this guide — don't hesitate to bring them up repeatedly if initial approaches aren't providing enough relief.

TALK WITH A PROFESSIONAL

A registered dietitian experienced in liver disease can help address nutritional needs specific to your situation, alongside your hepatologist's guidance on vitamin monitoring.

SECTION 18

Monitoring, Cancer Surveillance & Your Care Team

Given PSC's variable course and specific cancer risks, structured, regular monitoring is one of the most important, protective aspects of living with this condition.

What ongoing monitoring involves

- **Regular liver blood tests**, tracking overall liver function and any acute changes.
- **Periodic imaging (MRCP or ultrasound)**, watching for new dominant strictures or other changes.
- **Cholangiocarcinoma surveillance**, often combining imaging with a blood marker (CA 19-9), at intervals your hepatologist will determine.
- **Annual colonoscopy**, for those with concurrent inflammatory bowel disease, given the increased colorectal cancer risk.
- **Bone density scans**, similar to PBC, given cholestasis-related osteoporosis risk.
- **For those with cirrhosis**, the additional liver-cancer surveillance covered in our companion cirrhosis and liver cancer guides.

Who might be on your team

Hepatologist

Gastroenterologist (for IBD)

Interventional endoscopist

Primary care provider

Registered dietitian

Colorectal surgeon (if relevant)

KEY POINT — YOU ARE THE CONSTANT

Given how many surveillance streams are involved — liver, bile duct, colon — keeping your own simple record of when each test was last done, and when the next is due, genuinely helps ensure nothing is missed across your care team.

MAKE THE MOST OF APPOINTMENTS

Worth asking regularly: "Am I current on all my surveillance — liver imaging, colonoscopy, and bone density?" — one question that covers the full picture.

SECTION 19 Living with PSC

Living with PSC means navigating both genuine uncertainty and genuinely effective management — this section addresses both honestly.

Navigating uncertainty about the future course

Because PSC's individual course is so variable, and because no medication currently changes that course, many patients describe uncertainty about the future as one of the more emotionally challenging aspects of this diagnosis. This is a completely understandable response, and it's worth discussing openly with your care team, who can help you understand what your own specific monitoring results suggest about your situation over time.

Coordinating two conditions, if you have concurrent IBD

For the large majority of PSC patients who also have IBD, coordinating care between hepatology and gastroenterology, and keeping both conditions' surveillance on track, becomes a routine, manageable part of life for most people, even if it initially feels like a lot to juggle.

Emotional aspects

The combination of a variable disease course, absent disease-modifying medication, and real cancer risk can bring up significant anxiety. These feelings are entirely understandable, and connecting with others who understand this specific, less common condition — including its uncertainties — can genuinely help.

IF YOU ARE STRUGGLING

If you are experiencing persistent low mood, hopelessness, or thoughts of harming yourself, please reach out to a healthcare professional or a crisis line. The **988 Suicide & Crisis Lifeline** (call or text 988 in the United States) is free, confidential, and available 24/7. Support is available, and you don't have to manage this alone.

COMMUNITY MATTERS

Dedicated PSC patient organizations, alongside groups like The Liver and Kidneys Hope Foundation, can connect you with others who understand this specific condition — including the particular emotional weight of its uncertainties.

SECTION 20

Special Situations

PSC management looks somewhat different across certain groups and circumstances.

Children (pediatric PSC)

PSC can occur in children, sometimes with overlapping autoimmune hepatitis features more commonly than in adults, requiring pediatric hepatology expertise for diagnosis and management.

Pregnancy

Many people with PSC have healthy pregnancies; specific considerations depend on disease severity and any IBD activity, warranting coordination between hepatology, obstetrics, and gastroenterology before conception where possible.

Concurrent IBD management

Interestingly, treating IBD doesn't clearly change the course of PSC, and vice versa — the two conditions, while strongly associated, are generally managed somewhat independently, each according to its own specific treatment and surveillance needs.

PSC without identified IBD

A minority of PSC patients never show signs of IBD despite thorough evaluation — their PSC is managed with the same principles, though their colorectal cancer surveillance needs may differ from those with confirmed concurrent IBD.

TALK WITH YOUR CLINICIAN

If any of these situations apply to you or a loved one, mention it directly — it may change monitoring or coordination between your specialists.

SECTION 21

Liver Transplantation, Prevention & Myths vs. Facts

For those who progress to advanced disease, liver transplantation offers a highly effective option — and while PSC itself can't be prevented, its complications are substantially manageable through the surveillance and treatment approaches covered throughout this guide.

Liver transplantation

PSC is one of the recognized indications for liver transplantation, covered in depth in our companion guides, generally considered once cirrhosis decompensates, or sometimes for recurrent, difficult-to-manage cholangitis even without full decompensation. Transplant outcomes for PSC are generally favorable. PSC can, in a minority of cases, recur in the transplanted liver over time, requiring ongoing monitoring afterward.

Prevention (of complications)

- **Consistent surveillance** for cholangiocarcinoma, colorectal cancer, and bone health, as covered in Section 18.
- **Prompt treatment of dominant strictures** to reduce cholangitis risk.
- **Rapid recognition and treatment** of any fever-chills-jaundice combination.
- **Staying current on colonoscopy** if IBD is present.

Myths vs. facts

Myth	Fact
"PSC and PBC are basically the same condition."	They differ meaningfully in which ducts are affected, typical sex pattern, diagnostic approach, treatment options, and cancer risk.
"Since UDCA doesn't work for PSC, nothing can be done."	Managing complications, endoscopic treatment of strictures, structured surveillance, and transplantation all offer genuine, effective paths forward.
"If I don't have bowel symptoms, I can't have IBD alongside my PSC."	PSC-associated IBD can be present with few or no bowel symptoms, which is why colonoscopy is recommended regardless of symptoms.
"A dominant stricture always means cancer."	Dominant strictures are usually benign narrowing from PSC itself, though they're evaluated carefully (including brushings) specifically to rule out cancer.
"There's no point in surveillance since cholangiocarcinoma is hard to detect early."	While detection is genuinely more challenging than for some other cancers, regular surveillance still offers a meaningful chance of earlier detection and better outcomes.

KEY POINT

If you remember one thing from this page: PSC is a genuinely serious condition without a proven disease-modifying medication yet — and it is also a condition with effective complication management, valuable surveillance strategies, and a highly effective transplant option when needed.

CLOSING

Questions, Glossary, Resources & Disclaimer

Questions you might ask your doctor

- Do I have large-duct or small-duct PSC?
- Have I been screened for inflammatory bowel disease?
- What does my cholangiocarcinoma and colorectal cancer surveillance schedule look like?
- Do I have any dominant strictures, and would endoscopic treatment help?
- What symptoms should prompt me to seek emergency care right away?
- At what point would we start discussing transplant evaluation?

Glossary

Term	Plain-language meaning
Cholangiocarcinoma	Bile duct cancer; a specifically increased risk in PSC.
Dominant stricture	A single, significant narrowing of a bile duct that may benefit from endoscopic treatment.
ERCP	Endoscopic retrograde cholangiopancreatography; a procedure to view and treat the bile ducts directly.
MRCP	A non-invasive MRI technique that images the bile duct tree; the standard PSC diagnostic test.
Small-duct PSC	A variant affecting only the smallest bile ducts, generally with a more favorable course.
Sclerosing	Progressive scarring, as it affects the bile duct walls in PSC.

About The Liver and Kidneys Hope Foundation

The Liver and Kidneys Hope Foundation (TLHF) is a Nevada-based 501(c)(3) nonprofit dedicated to liver-health education, community support, and outreach. Through educational materials like this guide, community programming, our chapter network, volunteer efforts, and fundraising initiatives, we work to raise awareness of liver conditions and support the people affected by them, including those living with primary sclerosing cholangitis. The Foundation is not a medical provider and does not deliver clinical care.

A NOTE ON SOURCES AND CURRENCY

This guide reflects widely accepted, general medical understanding of PSC intended for patient education. It does not cite individual studies, and research into potential medical therapies is actively ongoing. For the most current, individualized information, your healthcare team is the best resource.



Full disclaimer

PLEASE READ

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Do not use this guide to diagnose or treat a health problem or disease, and do not disregard or delay seeking professional medical advice because of something you have read here. Fever, chills, and jaundice occurring together can indicate a serious infection requiring immediate emergency medical care. If you think you may have a medical emergency for any reason, contact your local emergency services immediately.

The Foundation makes no warranties about the completeness, accuracy, or currency of this information and accepts no liability for actions taken based on it. Always consult your own healthcare professional.

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