



Primary sclerosing cholangitis (PSC)

A long-term condition of the bile ducts, often linked with IBD

PE-GIC-22

PSC causes slow inflammation and scarring of the bile ducts. It often occurs together with inflammatory bowel disease. There is not yet a medicine proven to slow it, so regular monitoring, early treatment of complications and, for some people, liver transplantation are the pillars of care.

What is it?

Bile is made in the liver and flows through small tubes (bile ducts) to the gut, where it helps digest fat. In primary sclerosing cholangitis, the bile ducts inside and outside the liver become inflamed and scarred. Over time they develop narrowed areas (strictures), bile flow slows, and the liver can be damaged. Progression is usually slow and varies a great deal between people.

The cause is not fully understood. It is thought to involve the immune system, genetic tendency and signals from the gut. It is not caused by alcohol or diet, and it is not contagious.

The link with IBD

- Most people with PSC also have inflammatory bowel disease, most often ulcerative colitis, and less often Crohn's disease of the colon
- The colitis in PSC is often mild in symptoms, may involve the whole colon, and can be present without being noticed
- Anyone diagnosed with PSC should have a colonoscopy with biopsies, even without bowel symptoms. If no colitis is found, the colonoscopy is usually repeated about every 5 years, or sooner if bowel symptoms appear
- If you have both PSC and colitis, a colonoscopy every year from the time of PSC diagnosis is recommended, because the risk of bowel cancer is higher than with colitis alone. This continues after a liver transplant

Symptoms

- Many people have no symptoms at first; PSC is often found because of abnormal liver blood tests
- Tiredness
- Itching, which can be troublesome
- Pain in the upper right abdomen
- Later: yellow eyes or skin (jaundice), dark urine, pale stools, weight loss
- Episodes of cholangitis (bile duct infection): fever, shivering, abdominal pain and jaundice

Tests and monitoring

- Liver blood tests every few months
- MRI of the bile ducts (MRCP) is the main test for diagnosis. Imaging is then repeated once a year, preferably by MRI (sometimes by ultrasound), to watch the bile ducts and look for early signs of bile duct or gallbladder cancer; your team may advise more often if something changes
- An ultrasound of the gallbladder, usually yearly. Gallbladder polyps in PSC are more likely to be harmful, so polyps of 8 mm or more, and smaller ones that are growing, are usually removed by surgery, taking your liver condition into account. Smaller polyps that are not growing are checked by ultrasound about every 6 months
- Liver stiffness scans (FibroScan) to follow scarring
- Bone density scans and vitamin A, D, E and K levels, because poor bile flow reduces their absorption
- If cirrhosis develops, liver cancer surveillance every six months

Treatment

No medicine has yet been shown to slow PSC or prevent the need for transplantation. Ursodeoxycholic acid (UDCA) at moderate doses may improve liver blood tests and is used by some specialists, but high doses are not recommended because they were linked with harm in a clinical trial. Several new medicines are being studied. If you have been prescribed UDCA, do not stop it or change the dose without speaking to your team.

- Itching: specific medicines can help; tell your team rather than putting up with it
- Cholangitis: treated promptly with antibiotics

- A new or worsening narrowing of a bile duct: ERCP may be used to stretch it and take brush samples to check for cancer
- Vitamin and bone health: supplements and bone treatment when needed
- Keep your IBD well controlled, and attend your yearly colonoscopy

Liver transplant

For people with advanced liver disease, repeated cholangitis or severe itching that does not respond to treatment, a liver transplant can be life-saving and has good long-term results. PSC can come back in the new liver in some people, so follow-up continues after transplantation.

Get urgent medical care if you have

- Fever or shivering, especially with abdominal pain or yellow eyes: possible cholangitis
- New or deepening jaundice
- Dark urine with pale stools
- Vomiting blood or black stools
- Confusion or unusual sleepiness
- Rapid abdominal swelling

Common questions

Is there a special diet for PSC?

No diet slows PSC. A balanced diet with enough protein and calcium is recommended, with vitamin supplements if your levels are low. A separate sheet gives practical eating advice.

Will I need a transplant?

Not everyone does. PSC progresses at very different rates, and many people live for many years before needing one, if at all. Regular monitoring helps your team plan at the right time.

Why do I need a colonoscopy every year if my bowel feels fine?

Colitis in PSC is often quiet, but the cancer risk is still higher. Yearly checks find early changes when they are easiest to treat.

Is my family at risk?

Parents, brothers, sisters and children have a higher risk than average, but the actual chance remains low (under about 1 in 100). Routine screening of family members is not recommended.

This leaflet is general information and does not replace advice from your own doctor. Version 1.0, October 2026. Next review October 2028.

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