

PRIMARY SCLEROSING CHOLANGITIS (PSC)

What is PSC?

Primary Sclerosing Cholangitis (PSC) is a rare and chronic disease in which the ducts that carry bile from the liver develop inflammation.

Causes

No exact cause of PSC has been identified. PSC is an autoimmune disease, meaning that the body's own immune system attacks healthy cells. Studies show that mutations in some genes of the immune system are more commonly found in people with PSC. Environmental factors likely play a role, too.

Complications

PSC can cause severe inflammation and scar formation (fibrosis) in the bile ducts, which prevents bile from leaving the liver as it should. When this happens, liver damage can occur because of the toxic effects of the retained bile.

Some people with PSC develop complications, while others do not. Complications can include jaundice (yellowing of skin and whites of eyes), bile duct inflammation (cholangitis), thinning of bones (osteoporosis), cirrhosis (advanced scarring of the liver), and more.

Symptoms

PSC often does not present symptoms. People who do experience symptoms may have severe itching, jaundice, fatigue, and sudden fevers, chills, or abdominal pain. Those who develop advanced (decompensated) cirrhosis may experience weight loss, malnutrition, fluid buildup in the belly area, and internal bleeding.

Diagnosing PSC

PSC is diagnosed based on the finding of scars in the bile ducts, including ducts within or outside the liver. This is done through lab and imaging tests such as MRI.

Managing PSC

There is not yet a cure for PSC, but patients may take ursodiol (ursodeoxycholic acid) to reduce bile duct inflammation in PSC. Ursodiol has not been shown to cure PSC or keep the disease from worsening. People with PSC should be monitored for infections of the bile duct, bone loss, and vitamin deficiencies. In addition, people with PSC are recommended to be checked for colitis (inflammation in the colon). If colitis is found, yearly colonoscopies are recommended to check for colon cancer. Yearly imaging tests of the bile ducts may be helpful in detecting bile duct cancer if it begins to develop. People who develop advanced cirrhosis may be evaluated for liver transplant.

Research about PSC continues. Patients can speak to their doctors about clinical trials for treatments and explore if participation in a clinical trial is right for them.

To learn more about PSC, scan the QR code below. For a complete list of all of our free resources, please visit: liverfoundation.org/resource-center.

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For questions about liver wellness and disease, or for emotional support to patients at the point of crisis and information on local resources including physician referrals, please contact our Helpline at 1-800-465-4837.

