

## PSC Support

### Our vision is to see a world without PSC

PSC Support is the only UK charity solely focused on improving the lives of people affected by PSC and funding PSC research.

### Find information and support

Join our community at [www.pscsupport.org.uk](http://www.pscsupport.org.uk) and get regular information, resources, tips on living with PSC and news.

- Learn about living with PSC
- Find support
- Attend national meetings
- Connect with others affected by PSC
- Learn about research trials
- Join the UK-PSC study

**PSC Support Helpline:**  
**01235 25 35 45**



[www.pscsupport.org.uk](http://www.pscsupport.org.uk)

**No one needs to face PSC alone**

## Be part of the solution for PSC

PSC is referred to as 'the last black box in hepatology' because there is so much we don't yet understand about the condition, despite impressive progress in the last decade.

PSC patients urgently need a treatment that works.

PSC Support is part of UK-PSC, a research group of leading PSC researchers and specialists. We're encouraging everyone with PSC (including children) to take part and provide a blood sample. Your biological information is important and could help us to understand the causes of PSC, and ultimately, successfully treat PSC.

**For more information, visit**  
[www.pscsupport.org.uk/ukpsc](http://www.pscsupport.org.uk/ukpsc)

**UK-PSC**

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References: [www.pscsupport.org.uk/refs](http://www.pscsupport.org.uk/refs)

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Helping people affected by  
Primary Sclerosing Cholangitis



## Primary Sclerosing Cholangitis

Primary Sclerosing Cholangitis (PSC) is a rare, immune-mediated disease of the bile ducts in the liver that can affect anyone at any age.

## What is PSC?

PSC is a chronic immune-mediated disease characterised by scarring (strictures) in the bile ducts. This means the bile, which is normally able to flow through the bile ducts into the gut, can't drain properly and it builds up in the liver. This can then lead to infection and liver damage in some people.

## Who is affected?

Estimates suggest that PSC affects up to 10,000 people in the UK.

PSC can be diagnosed at any age but affects over twice as many males as females.

Many patients with PSC also have one or more autoimmune diseases, in particular, Inflammatory Bowel Disease (IBD).

People with PSC are usually non-smokers.

Alcohol is not a factor in the cause of PSC.



## Why do I have PSC?

PSC is complex and we don't fully understand what causes it. Current evidence suggests that people with a particular genetic makeup may be susceptible to some sort of environmental trigger, which causes their immune system to effectively 'attack' the bile ducts. We don't yet know what that trigger is.

## What will happen to me?

It is important to remember that PSC varies from patient to patient.

Many PSC patients go on to live normal lives. Others may be affected by symptoms such as fatigue, itch and abdominal pain, and some, but not all, progress to advanced liver disease. For those patients, liver transplantation is sometimes required.

**If you notice a sudden change in your condition, you should let your doctor know.**

## Bacterial Cholangitis

Occasionally PSC patients experience bile duct infections (bacterial cholangitis) which require urgent medical attention. Ask your specialist about the symptoms to look out for and read the bacterial cholangitis information on our website.

[www.pscsupport.org.uk/bacterial-cholangitis](http://www.pscsupport.org.uk/bacterial-cholangitis)

## What can my doctor do?

PSC is a complex condition that affects each individual differently. Ideally your care should be managed by a doctor with an interest in PSC.

While there is currently no curative treatment for PSC, your doctor can help manage your symptoms using current clinical practice guidelines for cholestatic liver diseases. Some patients with PSC take ursodeoxycholic acid ('urso' or 'UDCA') at low doses (15 to 20mg per kg body weight per day). It's not clear whether urso delays the progression of PSC, although it improves serum liver tests and may help improve the flow of bile.

People with PSC face an increased risk of some cancers. Your doctor should keep a close eye on you and monitor you regularly with scans and colonoscopies.

Your doctor can talk to you about opportunities to take part in research trials to access potential new drugs or therapies and/or better understand PSC. It doesn't matter what age you are, or how your disease is progressing, you can help researchers further our knowledge of PSC.

