

PSC Support

Your donation will help us to:

- provide up to date and accurate information for anyone affected by PSC
- help PSCers connect with others sharing similar experiences
- provide support to patients and their families
- fund vital medical research
- organise meetings including questions and answers sessions, with hospital consultants with a special interest in PSC
- promote awareness and education about PSC to the medical community
- advocate for PSC patients for improved clinical care
- advocate for PSC patients regarding liver transplant policy and services
- promote organ donation

Help make our work possible: donate now
www.pscsupport.org.uk/donate

No one needs to face PSC alone

Organ donation

A liver transplant may be the only option for some patients with PSC. Sadly, there is a major shortage of organ donors in the UK and the number of people in need of an organ transplant is growing every year. This means that too often people are dying on the waiting list. In fact, three people die every day on the transplant list in the UK alone.

The wait for a liver transplant is terrifying for patients with PSC for many reasons, especially because of the unpredictable nature of PSC. The longer somebody is waiting for a transplant, the higher the risks become and the more likely it is that they will not get the transplant they desperately need.

Whatever your age, please sign up to the NHS Organ Donor Register today and talk about your organ donation wishes with your friends and family.

www.organdonation.nhs.uk

This publication has been reviewed by medical specialists and people affected by PSC. Special thanks to: Dr Roger W. Chapman and Dr Kate Lynch (née Williamson) for their input.

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References: www.pscsupport.org.uk/refs

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Helping people affected by
Primary Sclerosing Cholangitis



Let's Beat PSC

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.



What is the cause of 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 are the symptoms of PSC?

PSC is a complex condition that affects each individual differently.

The most common day-to-day symptoms are invisible, such as fatigue, itch and pain.

Some patients, but not all, progress to advanced liver disease. For those patients, liver transplantation is sometimes required.

People with PSC also face an increased risk of bile duct cancer, gallbladder cancer, liver cancer, and in some cases, bowel cancer.

Life with PSC can be uncertain and has been described as 'living with a ticking time bomb'.

Some patients, however, can have no symptoms and/or never have any complications.

Is there a treatment for PSC?

No. There is no effective treatment for people with PSC (other than a liver transplant), meaning that there is nothing that can slow down or halt progression of the disease.

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

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

Our vision is to see a world without PSC.

PSC Support is run by a small team of volunteers and is totally funded from charitable donations. This means that every penny you donate will be used carefully to support and make a real difference to PSC sufferers and their families.

PSC Support relies on fundraisers to continue our vital work.