

From Me and My Friends, to You and Yours Sphincter of Oddi Dysfunction (SOD)

Each slide has a blue and yellow striped background. Text is in a yellow box, outlined by a darker blue line. Titles are in dark blue and the rest of the text is in dark grey

Slide 1 - What is Sphincter of Oddi Dysfunction?

Digestion, through which the body transforms the food we eat into the energy we need, is a complex process. The liver, the pancreas, and the sphincter of Oddi all play important roles.

The liver provides a chemical called bile to the digestive process, and the pancreas provides pancreatic juice. These chemicals flow into the small intestine to help with digestion. The flow of these chemicals is controlled by a muscle called the sphincter of Oddi.

A sphincter is a muscle (usually round) that can open and close. When it's working properly, the sphincter of Oddi opens to allow bile and pancreatic juice to flow through, and then closes again. However, in a condition called sphincter of Oddi dysfunction, the sphincter muscle does not open when it should. This prevents the bile and pancreatic juice from flowing through, and causes a backup of digestive juices. The backup can cause severe pain in the abdomen.

(At the bottom of this page, there is a diagram of the sphincter of Oddi inside the pancreas, zoomed in)

Slide 2 - What is Sphincter of Oddi dysfunction?

There are two basic types of sphincter of Oddi dysfunction:

- Biliary dysfunction (the digestive juices are backing up in the bile ducts from the liver);
- Pancreatitis (the backup is occurring in the pancreas, and the pancreas is becoming inflamed).

There are also three categories of sphincter of Oddi dysfunction:

- In categories I and II, doctors can find clear evidence of the dysfunction, such as abnormal blood test results or, with an ultrasound, a dilated (widened) bile duct.
- In category III dysfunction, there are no clear-cut lab findings or abnormalities, and the only evidence of the dysfunction is the abdominal pain.

Type III dysfunction is much more difficult to diagnose. Recent studies suggest that these symptoms may not be due to sphincter of Oddi spasm, and that they do not respond to treatment with endoscopic retrograde cholangiopancreatography (ERCP) and sphincterotomy.

Slide 3 - How does Sphincter of Oddi Dysfunction affect my body?

Pre-diagnosis I got very malnourished and dehydrated as my Sphincter of Oddi Dysfunction (SOD) was flaring badly, I couldn't keep much food or drink down at all. Now I have started treatments, I have more symptom-free days, and my symptoms are much less severe. I get reflux, vomiting, nausea, upper right quadrant pain and upper centre pain, "attacks" of pain that

manifest like a heart attack. This condition has damaged my whole GI tract, causing bile acid malabsorption, severe IBS and chronic bile and acid reflux.

Slide 4 - How does Sphincter of Oddi Dysfunction affect me mentally?

This condition has caused a lot of low moods, due to the fact that I have severe anxiety leaving the house in case my SOD flares, or I have a bad SOD attack in public. To manage this, I have made my friends and family aware of my condition and they know when I need to leave ASAP.

How does Sphincter of Oddi Dysfunction affect my life?

A lot of my spare time is taken up by hospital visits, tests, treatments, etc, which has severely impacted my social life. I have to carry medical supplies everywhere and I cannot do anything on a whim, it has to be thoroughly planned. I have to take extended periods of time off work due to flare ups, or treatments.

Slide 6 - What can friends do to support you?

1. Research about my condition due to its rare and complex nature
2. Talk to me about my continuous, how it impacts me, and how I persevere
3. Acknowledge that I may not be able to attend everything, but still know that I want to be there

Slide 7 - Find out more

Guts UK:

<https://gutscharity.org.uk/advice-and-information/conditions/biliary-sphincter-disorders-former-sphincter-of-oddi-dysfunction/>

The Cleveland Clinic:

<https://my.clevelandclinic.org/health/diseases/14516-sphincter-of-oddi-dysfunction>

The Sphincter of Oddi Dysfunction Survival Guide by Brooke Lee Keefer

About the author

Hi! I'm Ella (she/her) and 18 years old from Derbyshire, in the UK. I suffer from multiple chronic illnesses, to which you can follow my journey on Instagram (@chronicallyellaaa). However, I am still living my best life and I love painting, travelling and reading!

(Photo of Ella on this page - she is a white girl wearing blue dungarees with a white t-shirt, she has long strawberry blonde hair and blue eyes)