

My dry eyes and gut symptoms were signs of a little-known disease that mainly strikes women - here's the test you should ask for to avoid years of suffering – Written by Jo Waters



When Louise Mountford was blue-lighted to hospital in an ambulance with agonising pain just below her right ribs, she was convinced something in her stomach was about to burst.

‘I normally had a high pain threshold, but I was crying out with pain even though I was given morphine,’ says Louise, 66, who runs a farm in Shropshire with her husband David, 75.

Scans and tests found no obvious problem, however. Instead doctors concluded it was ‘probably constipation’ and gave her an enema and intravenous paracetamol. But it wasn’t an isolated incident.

Louise had been struggling with a range of unexplained gut symptoms, including diarrhoea, bloating and difficulties swallowing dry food for more than a year.

‘I could go three days without a bowel movement and then have explosive diarrhoea,’ she says.

‘I also had painful bloating, which made me feel heavy and weepy. I thought it was strange to suddenly start having these symptoms in my late-50s.’

Yet neither a gastroscopy (where a camera is passed down the throat to inspect the gullet and stomach) nor a colonoscopy (where a similar device is passed via the anus to inspect the bowel) revealed anything wrong.

She also began to suffer with other new – apparently unrelated – symptoms: dry eyes, dry mouth, vaginal dryness, jaw pain and dental problems.

After four years of mystifying symptoms, Louise Mountford was diagnosed with Sjögren’s disease, a little-known but relatively common condition where the immune system attacks any tissues that produce moisture in the body

‘I also had no tears and couldn’t cry,’ says Louise. ‘I couldn’t eat crackers or any meat unless it was covered in a sauce as my mouth was so dry I couldn’t swallow.’ The day she was rushed to hospital she’d been doubled up on the floor, rocking back and forth on her bedroom floor.

She recalls: ‘The pain had been building up all day from 3pm when I was in a meeting. By 10pm I’d taken the maximum dose of paracetamol, and yet the pain was relentless. I’d never known anything like it.’

Yet all standard hospital tests that day came back negative, again.

By now frustrated and feeling desperate, she consulted a private gastroenterologist, who ordered a gut transit test – which involved swallowing a pill containing a tiny camera that travelled through her gut, recording images. But again nothing was found.

However, the specialist also ordered blood tests to check for antibodies associated with autoimmune diseases – and this proved to be a breakthrough after four years of mystifying symptoms.

Louise was found to have antibodies called anti-Ro/SSA and anti-La – both are associated with Sjögren’s disease, a little-known but relatively common condition where the immune system attacks any tissues that produce moisture in the body.

It explained the odd mix of symptoms that had plagued Louise for four years – she saw a rheumatologist privately a month later who confirmed the diagnosis.

As Professor Simon Bowman, a consultant rheumatologist at University Hospitals Birmingham NHS Trust, told the Daily Mail, Sjögren’s affects secretory glands all over the body, which include secretory glands from the mouth to the anus, in the nasal passages, breathing tubes, lungs, vagina and bowel.



Louise's symptoms included dry eyes, dry mouth, vaginal dryness, jaw pain and dental problems. 'I had no tears and couldn't cry,' she says

Many of the gut symptoms are related to dryness and research by Limoges University Hospital in France, published in *Advances in Rheumatology* in 2021, found 95 per cent of the Sjögren's patients studied had gut symptoms, such as abdominal pain and constipation.

Sjögren's used to be considered rare. However, Dr Kelsey Jordan, a consultant rheumatologist at the University Hospitals Sussex NHS Foundation Trust, says it's now believed to affect around 1 per cent of the population. But this could be an underestimate – some estimates put the true figure at half a million sufferers.

Typically it's women aged 40 to 60 who are affected. However, 10 per cent of cases are men and younger people can also develop it.

The exact cause is unclear, but certain genes are implicated.

But lack of awareness of the condition, coupled with the varied nature of the symptoms, means it can often be overlooked by healthcare professionals, says Dr Jordan.

As a result, patients with milder symptoms may never be referred for specialist assessment or else get referred 'many years after their symptoms first start, meaning they could miss out on treatment for years'.

Updated guidelines from the British Society of Rheumatology published in the journal *Rheumatology* earlier this year [2025] recommend a number of specific tests for Sjögren's.

As well as tests for dry eyes, salivary flow and the Schirmer test, used to measure tear production, these include the anti-Ro antibody blood test, which detects antibodies produced by our immune system to clear bacteria and viruses: in some people antibodies bind to proteins in our own body causing damage to healthy tissue – several of these autoantibodies are seen in Sjögren's.

Professor Bowman notes that some people can test negative for antibodies but still have all the symptoms – in which case, doctors can use their clinical judgement to make a diagnosis.

Delayed diagnosis can cause long-term complications. Over time, left untreated, Sjögren's can damage the kidneys, blood vessels, liver, pancreas, nerves and lungs. Sjögren's patients also have a four to seven-fold increased risk of developing non-Hodgkin lymphoma, a type of blood cancer.

Professor Bowman says: 'There is evidence that a high level of Sjögren's disease activity is linked to a greater risk of developing lymphoma and greater mortality rates – so arguably if there is earlier diagnosis and intervention this risk might be reduced.

'In addition, some patients have high levels of fatigue, dryness and other symptoms and so an earlier diagnosis may improve their quality of life.'

In recent years there has been greater awareness of Sjögren's and in the US at least, the average time it takes to be diagnosed has improved from six years to around three years, according to the Sjögren's Foundation of America.

'Nevertheless, it is not as well-known as other rheumatic diseases, such as rheumatoid arthritis or lupus,' says Professor Bowman.

Katherine George, 35, a social media director, was diagnosed with Sjögren's in 2022 aged 33 – after experiencing digestive and dry eye symptoms since the age of 19.

'It sounds silly but I've never been able to eat a dry biscuit, I've always had to dunk it in tea to be able to swallow it,' she says. 'My mouth and throat has always felt so dry and I would sometimes feel like I was choking just trying to get food down.'

Katherine was finally diagnosed after an optician noticed her dry eyes and ordered an antibody test.

‘Six weeks later I found out I had Sjögren’s – I ticked nearly every box when a rheumatologist showed me a long list of symptoms which included digestive problems, dry eyes, dry mouth, vaginal dryness, a persistent cough, mouth ulcers and fatigue,’ says Katherine, who lives in Falmouth, Cornwall, with husband Ross, 35, a heating engineer.

‘Looking back, I’m amazed no doctor ever connected all the different symptoms.’ When it comes to treatment the new British Society of Rheumatology guidelines recommend preservative-free eyedrops (preservatives can irritate the eyes), using artificial saliva drops for dry mouth and the drug pilocarpine, which stimulates secretion glands, for treating dryness throughout the body.

The drug hydroxychloroquine can also be prescribed in more severe cases where previous treatments haven’t worked, as well as newer disease-modifying drugs such as methotrexate, which help by suppressing the immune system.

Recent research suggests there may be other, improved treatments around the corner.

Clinical trial results announced in August for the drug ivalumab, a monoclonal antibody drug (which targets immune cells called B cells) showed it significantly improved symptoms in Sjögren’s patients. The manufacturer, Novartis, is set to submit the drug for fast-track approval in the US; with a UK approval expected shortly after.

Louise was prescribed hydroxychloroquine, but suffered side-effects including severe headaches and nausea and was taken off it. She now uses eye drops, saliva substitutes and vaginal pessaries for dryness.

‘I’ve seen a dietitian and got advice about a healthy diet and now eat lots of greens and drink three litres of water a day to prevent constipation,’ she says.

‘Taking medication for all my Sjögren’s symptoms is time-consuming and like a military operation. I have to spend 20 minutes steaming my eyes and put eyedrops in seven times a day.’

‘It’s important people know Sjögren’s isn’t just a dry eye or dry mouth disease, greater awareness of the other symptoms could speed up diagnosis.’

‘There isn’t currently a drug available that will treat the underlying cause of Sjögren’s just treatments for individual symptoms – but I’m hopeful because of new research that there will be one soon.’