

## No tears to shed

**Interview by Charlotte Dovey, Daily Mail with Bridget, BSSA Helpline**

Mornings for most people are straightforward - they open their eyes, get out of bed and get on with their day. For Bridget, it's a different story.

Her eyelids are stuck to her eyeballs and her tongue is stuck to the roof of her mouth. Her skin is tight and dry, her body is painful and she can barely get out of bed.

One would hope such symptoms would be instantly recognised. But for Bridget, 52, and the other 500,000 sufferers of Sjögren's Syndrome, an auto-immune disease, it can be years before diagnosis is made.

It is the UK's second most common autoimmune rheumatic disease. But, according to Dr Elizabeth Price, a rheumatologist at the Great Western Hospital, Swindon, and an expert on the syndrome, the average time for diagnosis is ten years.

Dr Price says: 'Many sufferers aren't taken seriously by their GPs, and those who are see consultants in a host of specialities, usually with no conclusions drawn, because the symptoms are so diverse.'

Auto-immune diseases such as Sjögren's occur when the body's tissues are attacked by its own immune system. Sjögren's causes disabling joint pain, muscle aches and fatigue. The body also attacks its own moisture-producing glands, leading to abnormal dryness of the eyes (sufferers struggle to produce tears), mouth, and vagina. In extreme cases it can lead to loss of teeth and blindness.

The slow-onset condition affects women more than men, typically diagnosed in their 40s and 50s. Frequently it's around the time of menopause which, because of crossover symptoms, adds to the confusion of diagnosis.



Bridget, an ex-nurse from Marlborough, Wiltshire, was 38 when her symptoms first appeared.

'I developed a sensitivity to airconditioning and car fans,' says Bridget. 'Initially I thought it was hay fever but as the months passed it worsened.'

Any trip in the car with her husband Toby, 57, a development manager of a corporate finance company, and three children Tom, 28, Will, 27, and Rosy, 23, left her whole face feeling tight and her sinuses dry and painful.

'Every day after driving to the nursing home where I was deputy matron, I'd grab a couple of painkillers, drink gallons of water and rest my face over a steaming cup of tea to get moisture back.' After 18 months, she saw her GP. He didn't have a clue what was wrong.

'My colleagues were sympathetic but after several years, I felt a bore mentioning my symptoms. I continued with painkillers and suffered in silence,' she says.

But when she was 45, with the menopause imminent, the symptoms worsened. Bridget changed jobs to work as an optician's assistant and spent her day in an air-conditioned shop. Along with the dryness in her sinuses, nose and mouth, she started getting pains in her shoulders and arms and, off and on, physical fatigue.

'I started to think I was a hypochondriac or it was down to the menopause,' she recalls.

But the discomfort didn't stop - in fact her condition moved up a gear. In 2001, the family moved house and she went for a check-up with her new GP.

'I broke down. I told her how I was unable to cope with the discomfort and my worry that I was going mad.'

Using private health cover Bridget had through her husband's work, the GP referred her to an Ear, Nose and Throat consultant at Ridgeway Hospital, Wiltshire.

'The consultant didn't know what was going on but suggested I had an operation on my nose to clear out my nasal passage and trim away excess mucus membrane.

'The excess can cause a vacuum in the sinuses which can make them painful. He also said he'd straighten out the septum (the muscle wall dividing the nostrils) which was deviated.'

Bridget went ahead with the 30-minute operation. But the symptoms remained. A secondary operation on her nose, carried out by a different consultant eight months later, failed to solve the problem.

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The symptoms were constant - her eyes felt as if someone was sticking hot poker in them. The fatigue was equally horrific. 'My husband was left to fend for the family - cook, do the washing, look after the kids - I didn't have an ounce of energy left. But thankfully both he and children were hugely understanding.'

In 2000 Bridget took voluntary redundancy. She wondered about Sjögren's Syndrome, which she heard about in the 1970s during nursing training. Until that point she had only associated it with the dry eyes, so hadn't connected it with the other symptoms.

'I went back to my GP, mentioned my suspicions and she referred me on to an ophthalmologist at the Great Western Hospital, Swindon. Listening to my history, he too felt it was Sjögren's.

'He examined my eyes, mouth and took blood. He also carried out a lip biopsy which involved taking slivers of salivary glands from my lower lip and tongue.'

If the glands contained lymphocytes (a type of white blood cell that fights infection) in a particular pattern, this would mean Bridget had tested positive for Sjögren's Syndrome. Two weeks later the results confirmed it. It had taken a decade to get to this point. For Bridget, the relief at knowing she wasn't a hypochondriac was immense.

She was referred to Sjögren's Syndrome expert Dr Price. 'I learnt that although there is a genetic link to auto-immune diseases, it's not specific to Sjögren's, so the real cause, unfortunately, isn't known. There was no cure.'

This wasn't what Bridget wanted to hear but the symptoms could be eased with medication.

For dryness she was prescribed Pilocarpine, an eye-drop normally given to those with glaucoma, but she takes it orally as tablets and it stimulates the production of tears and saliva.

Without it, she can produce a little moisture but is unable to cry properly.

Hydroxychloroquine, traditionally an anti-malaria pill, was prescribed to help her pains. Then there was Biotene to help replace the saliva, lubricating oestrogen gels for the vagina, and antacid drugs for her stomach.

'The list of paraphernalia I need to keep the condition in check is immense but my life improved almost instantly. I also found solace in the British Sjögren's Syndrome Association.'

WITH none of the antibacterial properties of saliva in her mouth, the condition leads to increased decay, and the lack of moisture in the eyes can cause ulceration to the cornea which can lead to blindness.

'I've developed blepharospasm (uncontrolled squinting and blinking) which is my eyes' way of trying to moisten my eyeballs, so every six months I go to Moorfields Eye Hospital, London, to have Botox injected around the eye area to paralyse the muscles. 'I've had minor surgery to close the drainage tubes at the corner of my eyes to keep moisture in.'

Every other week she now works on the Sjögren's Syndrome helpline. She has also set up local support group with a fellow sufferer.

'I do get annoyed that I had to put up with this condition for so long. But awareness amongst the medical world is improving.'

The BSSA would like to thank Charlotte Dovey and the Daily Mail for allowing us to print this article.