

LIFE UNDER SIEGE

They're often misdiagnosed and misunderstood, with vastly differing symptoms, but all autoimmune diseases have one thing in common – a body under fire from its own immune system

WORDS JENNIE AGG

BEST BODY

The first thing Evelyn Forsyth-Barnett, 30, reaches for when she wakes up is her packet of propranolol – a beta blocker that she takes to slow her racing heart rate. It's the first of 15 tablets she has to take every single day. 'There's a strict schedule,' she says. As well as the beta blockers, there's 20mg of carbimazole four times a day to manage her overactive thyroid, two different antibiotics to help fight off bowel infections, and loperamide (to slow the function of the bowel) to be taken before meals and at bedtime. 'I wake up feeling awful,' she says. 'I have stomach pain and generally feel knackered.' Fatigue is constant; energy has to be carefully conserved. 'A 15-minute run leaves me feeling shaky two hours later.'

This can be the reality of life with an autoimmune disease, so called because it involves an individual's natural defence system attacking the body's own cells, believing healthy structures to be harmful foreign outsiders. Evelyn, who works for a gender equality not-for-profit, suffers from two: ulcerative colitis, where immune cells attack the lining of the bowel, leading to painful ulcers and diarrhoea, and Graves' disease, where the immune system produces antibodies against the thyroid, triggering an overproduction of the hormone thyroxine. A flare-up of the

latter is to blame for Evelyn's current pain and lack of energy – and much of the medication she has to take.

Evelyn's life is a far cry from what it was just a few years ago. She was diagnosed with ulcerative colitis as a teenager, requiring surgery to remove and then rebuild part of her bowel, and the condition was largely brought under control thanks to medication and a carefully managed lifestyle. 'I was living a relatively normal life,' she says. 'I had a fairly intense job, but the energy to do it. I was running between 30km and 40km a week and doing weights classes. I felt like I could manage everything I wanted to do.' But, just after her wedding in 2015, she noticed her hands starting to shake. 'Eventually, I couldn't get a spoon of sugar from the jar into my cup of tea,' she says. 'I also wasn't sleeping well, I was really anxious and I lost a lot of weight – about a stone and a half in three weeks.' Her experience reads like a list of symptoms of an overactive

thyroid, where excess thyroxine speeds up the body's metabolism, with Graves' disease the most common cause. The impact can be subtle for some – symptoms mild or keeping under the radar for months – or, as in Evelyn's case, they can present in a matter of days.

UNFRIENDLY FIRE

There are more than 80 known types of autoimmune disease and one in 16 people in the UK are affected, according to Lucy Walker, professor of immune regulation at University College London. This includes relatively common conditions, such as psoriasis, rheumatoid arthritis and coeliac disease, as well as



'There's a really strong gender bias – 78% of people affected are women'

very rare diseases, like neuromyelitis optica, sometimes called Devic's disease, in which immune cells attack the optic nerve and spinal cord. Symptoms of autoimmune conditions vary widely, depending on which system of the body is being targeted. Up to a third of people affected live with more than one autoimmune condition. 'It costs the NHS £13 billion a year,' says Professor Walker. 'There's also a really strong gender bias – 78% of people affected by autoimmune diseases are women.'

Autoimmune disease occurs when parts of the body come under friendly fire, which, it turns out, is anything but friendly. 'The immune system is incredibly clever at fighting infection and protecting the body; its cells – white blood cells known as T and B cells – have receptors whose job it is to recognise external threats and act to destroy that threat,' explains Professor Walker. 'The danger is that these cells mistakenly become activated by your own tissue and mount an immune response against it.'

Why do some people's immune systems turn on them? There's a strong genetic link, says Professor Walker, which sees conditions such as lupus and multiple sclerosis (MS) run in families. 'Environmental factors can also affect your propensity to develop an

autoimmune condition. This can cover everything from what you eat and how stressed you are to where you live and how much sunlight you get. In truth, it's likely to be a combination of influences,' adds Professor Walker.

As for why women are more likely to be affected? 'Genetics is definitely part of the answer,' she says. 'Women have two X chromosomes (while men have an X and a Y) and we know there are some key immune-related genes on the X chromosome.' Women, for example, naturally carry higher numbers of T cells. In addition, sex hormones, such as oestrogen and testosterone, are also known to affect the immune system; it's why some women find their autoimmune symptoms will often improve during pregnancy.

THE WAITING GAME

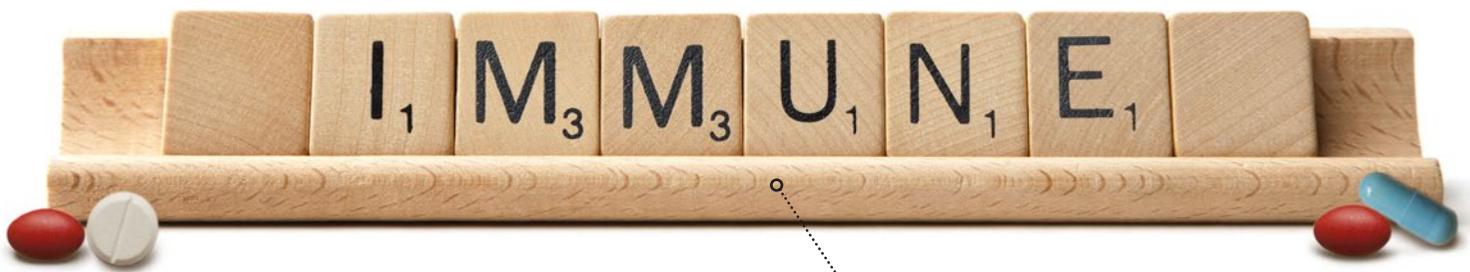
For most autoimmune sufferers, the journey to diagnosis is a long and frustrating one; it can take months or even years, and early misdiagnoses are not uncommon. For writer Stephanie Holland, 32, it took more than a decade from first showing symptoms to being recognised as suffering from coeliac disease, a condition where the body's T cells overreact to a component of gluten called gliadin, attacking the lining of the small intestine in the process, as well as developing antibodies against gluten so it's permanently considered a harmful invader.

Stephanie's symptoms, such as extreme fatigue, full-body aches, 'brain fog' and insomnia were initially put down to chronic fatigue syndrome (CFS/ME) and anaemia, diagnosed while she was at university in 2009. Then she started losing weight. 'I'd had diarrhoea, crippling stomach pain and vomiting – eventually, I just didn't want to eat.' This led to a referral to an eating disorder unit. It was only after the unit staff asked her to keep a food diary that Stephanie herself made the connection between her symptoms and gluten. 'Within two months of cutting it from my diet, I wasn't vomiting any more. I had more energy. I went back to the doctor, who said, "Keep doing what you're doing," and suggested I had a gluten intolerance – but no one ever mentioned coeliac disease.'

Stephanie's own diet management kept her symptoms under control but, two years ago, she and her partner started trying for

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Put in a good word

a family – and the final piece of the puzzle slotted into place. ‘I had three consecutive miscarriages. I threw myself into researching causes and read that coeliac disease can sometimes affect fertility,’ she says. ‘I pushed for a test for my own sanity.’

Blood tests, genetic testing, a gut biopsy, colonoscopy and endoscopy followed, and all confirmed the diagnosis. Doctors explained how important it was for Stephanie to avoid even the tiniest amounts of gluten, as coeliac disease can cause long-term damage to the gut lining. These days, she’s extremely vigilant. ‘We bought a new toaster and chopping boards to avoid cross-contamination and I rarely eat out or with family and friends now,’ she says. Happily, after going strictly gluten-free, Stephanie went on to have a healthy pregnancy and her daughter was born earlier this year. ‘It was an eye-opener of a diagnosis,’ she says.

stressed about them.’ At home, though, her illness does affect her relationship with her husband, Evelyn says. ‘If you’re anxious and have no energy, it does affect how you are with your partner and how you communicate with them.’

LIVE IN HOPE

Each autoimmune disease has traditionally been treated in isolation because they all affect different parts of the body, but Professor Walker hopes that, in the future, research will focus on treatments that work across the spectrum of autoimmune conditions. ‘Although their symptoms may look different, the fundamental trigger – the immune system becoming intolerant of your own body – is the same,’ she says. There may be mileage in new treatments

For many, the journey to diagnosis is arduous – it can take years

British Psychological Society chartered psychologist Dr Charlotte Hilton says that because autoimmune disease symptoms may mean people have to retreat from normal social activities, they can become increasingly isolated. Then there’s the stress of living with a condition that may not be well understood by the outside world. ‘As with many illnesses where you can’t always see the symptoms, people with autoimmune conditions may struggle to be seen as legitimately unwell – and that can cause a lot of distress,’ says Dr Hilton. ‘That can feed into a cycle of stress, which can lead to the worsening of symptoms.’

This rings true for Evelyn, who’s felt in the past that she had no choice but to leave jobs because of symptom flare-ups. Fortunately, her current employer is ‘very supportive’. She can work flexible hours and from home if she needs to. ‘I don’t have to take annual leave for hospital appointments and blood tests, which helps me not to feel

evolving from medicines originally developed to treat cancer. ‘There are drugs designed to activate the immune system to attack cancerous cells,’ says Professor Walker. ‘So we need to see if we can do the opposite; use the same pathway to *suppress* the immune system.’

In the meantime, Evelyn is waiting for her daily medication to rebalance her thyroid levels enough in order for her to have a type of radiotherapy that destroys cells in the thyroid, stopping the overproduction of hormones. She hopes that, following treatment, she’ll be able to get back to the exercise she loved. She also hopes that, one day, conditions like hers will be better understood. ‘I don’t think people get it,’ she says. ‘One thing I wish people would appreciate is that when I don’t go to things, or say I’m not well enough to come, I’m not being dramatic or cancelling because I can’t be bothered – I’m really not well.’ **WH**

UNDER ATTACK

Here’s a snapshot of the most common autoimmune conditions to affect UK women

TYPE 1 DIABETES

Unlike type 2 diabetes, type 1 isn’t ‘caused’ by weight or diet, but by immune cells attacking insulin-producing cells in the pancreas. It affects 400,000 people in the UK. Symptoms include feeling very thirsty and tired, losing weight without trying and recurring thrush.

MULTIPLE SCLEROSIS (MS)

More than 130,000 people in the UK have MS, which affects the nervous system (the brain and spinal cord). Symptoms include vision problems, pins and needles, pain, muscle spasms and fatigue, as the immune system attacks the coating that protects nerve fibres.

COELIAC DISEASE

Thought to affect around one in 100 people, coeliac disease occurs when the immune system attacks the digestive tract in response to the consumption of gluten. Symptoms include bloating, diarrhoea, nausea, weight loss and mouth ulcers. Undiagnosed, it can be a factor in infertility and recurrent miscarriages.

RHEUMATOID ARTHRITIS

Rheumatoid arthritis happens when the immune system mistakenly attacks the lining of the joints, causing inflammation, pain, swelling, stiffness and redness. It affects 700,000 people in the UK and is more common in women.