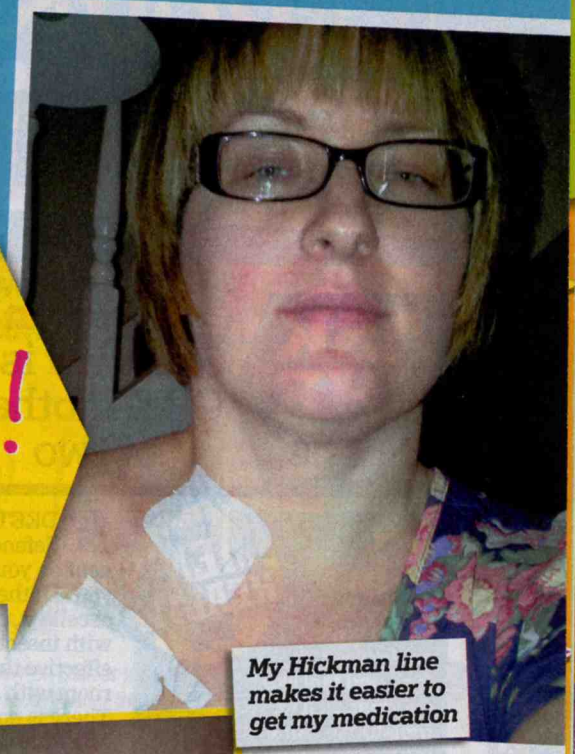
YOUR HEALTH

KATHRYN'S STORY

Swelling up!

Kathryn was desperate to beat the bloat...



Coming home from a busy day managing a call centre, I fell on to the sofa.

'I'll sort tea out,' offered my husband, Michael, 28, a marketing manager.

'Thanks,' I sighed, clutching my tummy. 'Although I'm not hungry.'

'Everything OK?' he asked.

'No,' I worried. 'My stomach's swelling up.'

'I'll start the car,' said Michael. 'We'll be at the hospital in 10 minutes.'

By now, Michael knew the drill, and I staggered out behind him...

You see, for the past 13 years I'd suffered with hereditary angioedema.

Known as HAE, it's a rare but serious problem with the immune system, which causes swelling, particularly of the face and airways, and abdominal cramping.

It had started when I was 15, when my stomach swelled to three times its normal size, and I developed diarrhoea.

The doctor thought it was irritable bowel syndrome, due to exam stress, but I passed out a year later and my throat swelled up so much I struggled to breathe. I was finally diagnosed at 18.

'Your body isn't producing enough of a blood protein known as the C1 Inhibitor, which fights disease, inflammation and helps the blood clot,' a doctor explained.

It was probably caused by a defective gene, which had mutated on its own.

I was put on steroids to force my liver to produce enough of the protein I needed, and went back to hospital every six months for liver scans, to check I hadn't developed tumours.

I tried to live as normal a life as possible, studying for my A levels and going out with friends. But the steroids made me tired, irritable and stressed. They also gave me achy joints, and my weight shot up from 8st to 9st.

My hands, feet and stomach still swelled painfully – making me bedridden – but at least it only happened once a month, compared to twice a week without the drugs.

Fortunately, when I met Michael Lowe at the University of Staffordshire while studying marketing, I told him about my condition and he was supportive and understanding.

Michael and me

And he was still my rock now, in February 2011, as he drove me to University Hospital of North Staffordshire.

'I wonder if coming off the steroids has prompted it,' he said.

The week before I'd stopped taking them, after telling my doctor we wanted to try for a baby.

I'd hoped my symptoms would be kept at bay, but I'd been unlucky.

My HAE was back with a vengeance.

After a three-hour wait in A&E, doctors gave me a shot of the C1 Inhibitor, before I was allowed home.

Over the next eight months I tried to carry on as best I could, but every five days my symptoms returned and I had to rush back to hospital for the shot.

Sadly, we didn't have any funding for me to administer the shot at home by myself.

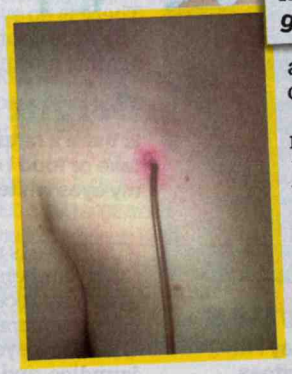
'Perhaps we should forget the baby,' said Michael. 'I hate seeing you this ill and having to keep going back to hospital.'

'No,' I replied. 'I want this.'

So, I was thrilled when, that October, I finally received funding for self-treatment of the C1 Inhibitor at home, after tireless campaigning.

But by December, my veins were so weak they'd virtually collapsed, making injecting impossible.

So, on 20 December 2011, I underwent a one-hour op under local anaesthetic to have a Hickman line fitted permanently in my neck so I could administer medication more easily.



My Hickman line makes it easier to get my medication

It means I can inject the C1 Inhibitor straight into the line.

It left me with a tiny hole in my chest, which was vulnerable to infection, so saunas, baths and swimming pools were no-gos, but it was worth it to stop my belly from swelling up.

Now, seven months on, the line isn't ideal, but at least I've beaten the bloat.

I'm still trying for a baby, so next time my belly swells I hope I'll be happy about it!

Kathryn Lowe, 31, Staffordshire

HEREDITARY ANGIOEDEMA > THE FACTS

WHAT? A rare and potentially life-threatening genetic condition occurring in about one in 10,000 to 50,000 people, it's caused by a defective gene, which normally controls a blood protein known as the C1 Inhibitor. It causes swelling in various body parts. Sufferers may also experience abdominal pain, nausea and vomiting.

WHY? HAE is hereditary – a child has a 50 per cent chance of inheriting it if one parent has it, but the gene can also spontaneously mutate, so you can develop the condition even if a parent didn't have it. Most attacks occur for no apparent reason, but anxiety, stress, minor trauma, surgery, colds and flu are triggers. Oral contraceptives, menstruation and hormone replacement therapy can also cause flare-ups.

TREATMENT: Often misdiagnosed, if you think you have HAE see your GP, who will refer you to a specialist. For information visit www.haeuk.org

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