

'I cry BLOOD'

YOUR
real-life
stories



Bleeding from my eye

Sharon's baffling episodes led to a shock discovery **Sharon Gregg, 55**

Tip your head back!' my Year 3 teacher said, alarmed as blood gushed from my nose.

I shrugged, wondering what the fuss was about.

My dad, Jim, and younger brother, Clarke, also had frequent nosebleeds.

A strenuous PE session or knock in the playground set me off.

In my teens I saw my GP, but they just put it down to my hormones, and it didn't stop me from being active.

In 1999, aged 29, I even met and fell in love with Edwin, also 29, in a mugendo class – a mix of karate kicks and boxing.

Edwin was a butcher, so he wasn't squeamish when dates with me ended in a bloody mess!

In June 2000 we got married, and walking down the aisle I was worried about bleeding all over my white dress. But I managed to get through the ceremony in one

piece... Let's just say several guests had tissues at the ready!

As Dad grew older his bleeds got worse and he was frequently hospitalised.

Shockingly, in 2006, my brother Clarke was tragically found dead at home. He was just 34. An inquest into his death at the time was inconclusive.

In 2011, Dad died, aged 71, after a five-year battle with lymphoma.

Six months later, working as a mobile hairdresser, I was driving to see a client when blood suddenly started pouring from my mouth. Terrified, I called the woman and asked her to phone emergency services, so an ambulance was waiting for me at her house.

It was my first major haemorrhage, and in hospital a specialist asked

me if I'd ever heard of a blood disorder called hereditary haemorrhagic telangiectasia (HHT).

'Your symptoms fit every criteria,' he said.

But I was discharged without a formal diagnosis.

Back home, Edwin googled the condition.

'Sharon, this looks really serious!' he said.

HHT is an inherited genetic disorder that affects the blood vessels and causes bleeding and haemorrhages – just like our family nosebleeds.

But worse – it can cause bleeding from other parts of the body, including the internal organs, and there's no cure. Not only are patients at risk of iron deficiency and exhaustion, but major bleeds can be life-threatening, and there's also an increased risk of having strokes.



In hospital after a serious nosebleed

Thinking how we'd lost Clarke so suddenly without explanation, it all started to make sense. And our grandfather Jim – my dad's dad – also suffered from nosebleeds.

Meanwhile, my condition seemed to be getting worse and, if I plugged my nose with wads of tissue, the blood would start gushing from my eyes, ears or throat instead.

I was literally crying blood.

In 2014, after collapsing and being found to have blood clots in my legs and lungs, I was finally diagnosed with HHT after genetic testing.

Meanwhile, I was bleeding heavily vaginally outside my monthly cycle, and scans revealed a dangerous clump of blood vessels in my

uterus. So in 2015 I had a full hysterectomy, pushing me into medical menopause.

HHT can become more severe as you age, and for me hormone changes seemed to put everything on fast-forward.

Soon blood was pouring from my nose, mouth, eyes and ears, multiple times a day. Stomach and bowel bleeds meant I filled the toilet bowl with blood, and I even started bleeding from the tiny veins beneath my fingernails.

I often woke at night with my pillow soaked red.

I tried to keep working, but it became too difficult, so I was forced to give up my mobile hairdressing business in 2023.

Meanwhile, I slowly stopped going out. It was too difficult to manage a big bleed in public – not to mention the reactions of other people.

'Don't come to me if you're bleeding, I'll faint!' one neighbour joked – not realising how alone those comments made me feel.

Edwin and I stopped eating in restaurants or staying in hotels – how could we check-in to a nice place knowing the white bedding and towels were likely going to get wrecked?

We arranged for our house to have a surgical waste bin, so the garbagemen didn't ring the police when they found blood-soaked cloths and bandages in our rubbish.

Now I reckon I lose around four to nine cups of blood a day, and I've had so many blood and iron transfusions that I've lost count. There aren't any other treatments – it's just careful management.

I even have two mobile phones on different providers so I can always get a signal to call for help.

Some days I'm so exhausted that I struggle to climb the stairs.

But I refuse to feel depressed, and on good days I love to go out for walks with my camera. I love photography, and even if I can just make it to the bottom of my garden to snap the birds around our feeder, I'm happy.

We've also bought a motorhome so we can go away on short holidays and manage my bleeds in privacy.

It's estimated



My life has been saved by strangers donating blood

that HHT affects around one in every 5000 people, but many don't suffer as seriously as I do.

As 90 per cent of people are undiagnosed, there must be so many people walking around thinking their nosebleeds are just 'normal' – when they actually have HHT.

I'm very thankful to everyone who donates

blood. If you're not a donor, please consider signing up. My life has been saved many times by the kindness of strangers.

As for getting blood stains out of clothes and bedding? It's a good job I'm an ex-hairdresser. Peroxide works a treat! ●

As told to Jade Beecroft

I was driving when blood poured from my mouth

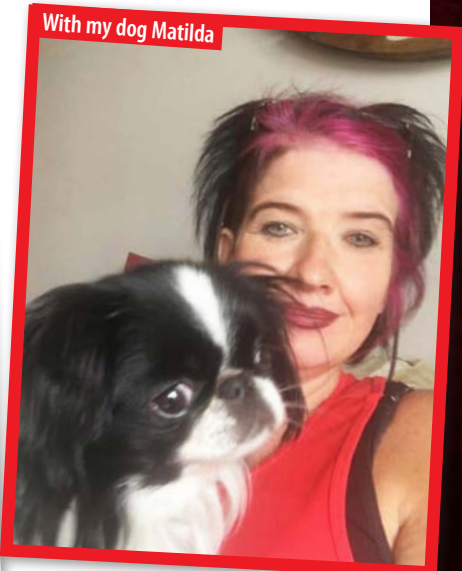
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My brother Clarke and me



My dad Jim and me on my wedding day



With my dog Matilda