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LIVING WITH A SILENT KILLER

When Michelle Tolley discovered she would never recover from being infected with hepatitis C, she channelled her anger and grief into helping others. Rowan Mantell reports

Michelle Tolley lives half-a-year at a time. Each time a six-monthly liver scan comes back unchanged she relaxes and begins believing she can plan ahead for a while - until the relief fades as the next scan approaches.

"We were given a death sentence for committing no crime," she said.

Michelle was infected with hepatitis C when she was given a blood transfusion after the birth of her first child.

For 28 years the virus coursed through her body, wrecking her health, although it was not until 2015, that it was finally confirmed she had hepatitis C.

At first she collapsed in panic. But within months she was channelling her fear and anger into campaigning.

Today, despite having liver disease, kidney disease, diabetes, the bowel disease diverticulitis and debilitating fatigue, 57-year-old Michelle runs a national group for people affected by blood contamination, helps other infected blood and hepatitis organisations and charities and and supports people giving evidence to the Infected Blood Inquiry.

Even telling her story, spending a couple of hours sitting in a café going back over the years of illness, misdiagnosis, missed chances and finally having to fight for the best treatment, is exhausting for Michelle.

But despite the decades of chronic illness she is still a force of nature, radiating empathy and energy as she describes how hepatitis has affected almost her entire adult life and how she is desperate to find and help other people who might still not know they were infected.

As a child, growing up in East London, she wanted to be a singer or actor and perhaps that is what she taps into each time she has to tell her terrifying story.

She was 18 and working for the Met police civilian staff when she met Dean. They have been married for 38 years. Today Dean is her carer as well as her husband. "Dean has been my rock. I couldn't do all this without him," said Michelle.

Their first child, Daniel, now 35, was born in 1987, after which Michelle needed four units of blood. Lurking within was the virus hepatitis C.

Michelle and Dean went on to have three more children, Lauren, now 32, and twins Natalie and Dale, now 31. She had to have another transfusion after the birth of the twins but believes it was the first transfusion which wrecked her health because when she was pregnant with Lauren, tests revealed antibodies in her blood.

She remembers receiving two letters on the same day, one telling her she had pregnancy-induced diabetes, the other mentioning antibodies in her blood.

"I thought I had Aids," said Michelle. "Because that was what was always in the news at the time.

"Of course it wasn't, and I was just told it was common because I had someone else's blood in my system."

Four months after Lauren was born, Michelle was pregnant again - with twins. It was another difficult pregnancy and Michelle spent a lot of it in hospital with the babies born by emergency caesarean. "They thought they weren't going to survive. I was put to sleep for the operation thinking they would be dead," she said.

Instead the babies were rushed to special care and survived and thrived. But Michelle became more and more ill.

"We had a very busy few years." said Michelle, with some understatement. The family moved to Clacton, there were four children to raise and eventually Michelle was also working as a classroom assistant with children with special needs. She ran a Brownies group and children's cricket and rounders teams, became a school governor and PTA member - and was constantly exhausted.

"Not just tired, ridiculously, completely tired. But I just got on with it," said Michelle. "I would wake up and still be so tired."

Sometime in the mid-90s she saw a television report about blood transfusions not being screened for infections until 1991 and decided to visit her doctor and ask whether her symptoms might be related - but her fears were dismissed.

"He made me feel so small and stupid, and shooed me out, saying I was tired because of the children and would not have hepatitis C. He refused to test me."

Giving evidence to the infected blood public inquiry more than 20 years later, she said: "He made me feel like a silly little girl and as a young mum you look to the professionals, you trust them."

And so she struggled on. The children grew up and in 2010 Michelle and Dean moved to Norfolk.

"We'd always loved Norfolk," said Michelle. "We'd lived in town, and at the seaside and it was time for the countryside," They moved, first to North Elmham and now live in Sparham, near Reepham.

It should be a time to relax and enjoy playing with their eight grandchildren, but instead Michelle attends the funerals of friends, helps strangers struggling to access medical or financial help, and knows her own body is failing her.

Although expensive treatment (which she had to fight to access) has stripped the virus from her body, it has been left ravaged.

Her main mission now is to

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Michelle Tolley, who was infected with hepatitis after having a blood transfusion

Picture: DENISE BRADLEY

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make sure as many people as possible know about hepatitis C, and are helped as early as possible. She is tormented by the knowledge that if she had been tested when she first asked, the virus could have been stopped in its tracks before causing such devastation.

"Hepatitis C is known as the silent killer. It can live in your system, damaging you quietly, for more than 20 years," said Michelle.

She was finally diagnosed after visiting her doctor in Norfolk. "I had terribly itchy skin, hot flushes, fatigue.

"The doctor asked whether I was a heavy drinker, whether I'd taken drugs, had any tattoos, and it was no to everything until I had a light-bulb moment and remembered the transfusions," said Michelle.

At last she was tested.

"A few days later the doctor phoned me at home and said, 'I'm really sorry, you have hepatitis C," said Michelle. "It was like my whole world collapsed. I fell to the floor and sobbed. I thought I was going to die. When I closed my eyes all I could see was a coffin with my name on.

"Suddenly everything made sense. But I became very withdrawn. I couldn't speak to my kids, I didn't understand what had happened. I couldn't get my head around that I'd had it for 28 years.

"It took me two or three days to get to the surgery and then I had so much support from everyone. They have all been so good."

She was referred to hospital specialists but felt she had to push to get treatment as quickly as possible.

"There was a six month wait and I thought, 'No, I haven't done this to myself, you have done this to me.

"It made me feel dirty too. I'd get in the bath and scrub and scrub."

"Then I got very angry. That East End girl came out of me!

"I said to Dean, 'I have got to do something with this negativity or I'm going to do something I shouldn't and I have never done anything wrong in my life!"

And so she contacted BBC Radio Norfolk and the EDP, trying to find other people in a similar situation.

"I thought if I could reach out and find one person and help save one life, then in a way I could find a bit of peace," said Michelle.

"If this has happened to me, how many more people are there out there? People have lost homes, businesses, relationships...How many people have died and not known? I have been contacted by so many people and there are still thousands of people affected by Hep C from blood transfusions and not realising."

She now runs the national support group Contaminated Whole Blood UK and also helps other infected blood and hepatitis organisations and charities.

In the past few years she has appeared on the Panorama television investigation of the blood scandal, talked to MPs and government ministers, told her story to the on-going Infected Blood Inquiry into what has been called the worst treatment disaster in NHS history, and supported others to submit their evidence.

"When I was first asked about compensation I was upset. How can you put a price on life? They had taken my whole life away, because I was only 22 when I had that transfusion," said Michelle.

However she is now adamant the government must compensate all the victims infected and affected.

And as she discovered more her attitude to how people had become infected changed. As well as supporting people who were infected through transfusions and treatment for conditions such as haemophilia she has gone into prisons, with the Hepatitis C Trust, to talk about her experience of hepatitis C and the importance of getting tested and treated.

"In the beginning I thought these people had injured themselves and yet were being given treatment ahead of me. Now I know it's about what has made these people go down this route and have to resort to drugs. This is a person who may have hep C and I might be able to help them," said Michelle.

Last month victims were told to expect an interim payment of £100,000, although that has not yet been paid and, as Michelle points out, it sounds a lot of money but is nothing compared to what each family has lost.

Victims and bereaved partners currently get financial support payments but have not been compensated for loss of earnings, care costs, and other lifetime losses.

"If you divide the interim payment of £100,000 by 35 years, it does not work out as much," she said. A final settlement is expected to be worked after inquiry chairman Sir Brian Langstaff has delivered his findings.

An independent study commissioned by the government has said victims should eventually be compensated for physical and social injury, the stigma of the disease, the impact on family and work life, and the cost of care.

Victims range from babies, infected at just a few hours old to people who have been ill for decades

"Someone in the UK dies every four days because of the contaminated blood scandal," said Michelle.

"I don't know how I'm alive. I haven't got a future. I basically live for each day. I wake every morning and I thank God I have woken up and have another day."

If you are concerned about hepatitis C contact the Hepatitis C Trust hepctrust.org.uk Its confidential helpline on 0207 0896221 is open Monday to Friday 10.30am to 4.30pm.

STEVE'S STORY

– born without an essential clotting mechanism in his blood.

But it is not the haemophilia which has blighted his life, but the hepatitis C, contracted when he was just seven years old and given a contaminated product made from infected blood from the United States.

"The donors included prisoners with HIV and hepatitis. The British government was warned not to use it," said 51-year-old Steve, of Norwich.

"Haemophilia I can take, it's all the rubbish that goes with it. I was born with haemophilia, it's been in my family, we cope with it. What I'm very, very angry and bitter about is what I was given because of it."

Steve explained that he had previously been treated with a relatively safe drug called cryoprecipitate before being moved over to a product called Factor VIII.

"They had been testing it on chimpanzees, but children were cheaper," he said. Although he was tested for what was then called 'non-A, non-B hepatitis,' later named hepatitis C, he was only told he had the infection 11 years later.

Haemophilia is passed from mother to son through families and three of Steve's second cousins were affected too – and given contaminated blood products.

They all contracted Aids and are dead. Steve did not get Aids, but his family were hounded from their Essex home by people who thought he too was infected, graffitied the house and boycotted his dad's business.

Even at school, he said, other children and teachers refused to be in the same classroom.

The family moved to Norfolk when Steve was 13 but he did not discover he had hepatitis C until it was mentioned, in passing, at a medical appointment when he was in his 20s. "They said not to worry, I'd be fine!" he said.

But Steve was not fine. The virus had been taking its terrible toll for years.

"I have been ill for 45 years. I have never known what it was like to feel well. I was always tired and had no oomph," said Steve. He started work in catering and bars, and loved his job, but lost that too because of his ill health.

Eventually, after an arduous and unpleasant course of medication and injections, (the treatment is now less punishing) he is free of the virus but the damage has been done.

The hepatitis C has left him with cirrhosis of the liver, extreme fatigue and bones so damaged they break if he stumbles. He can only work part-time. Every six months he has a scan. "Then you know you have got another six months," said Steve. Two months ago he was devastated when a lump was found on his liver – although it turned out to be benign.

His illness has affected his family too – he has a partner and five children from two relationships.

"It's all I talk about. It's consumed their lives as well," said Steve. "It's ruined my life. I do want compensation and why shouldn't I? It's not my fault.

"I want the infected and affected to be compensated. I have been fighting since 1995. I have spent my life fighting. I didn't want to do that.

"I want to enjoy the rest of my life. I don't know how long I have left."

> *"It was like my whole world had collapsed. I fell to the floor and sobbed"*

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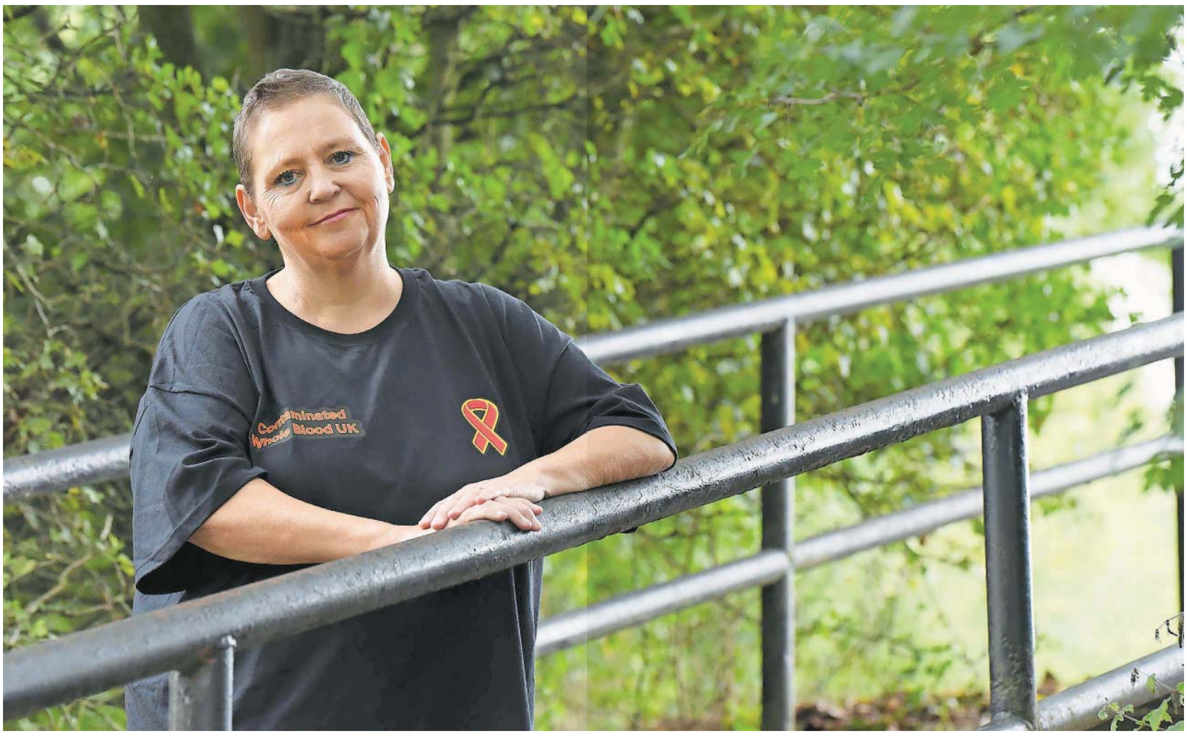

MAIN:
Michelle Tolley of Sparham

LEFT:
The Infected Blood Inquiry is being held in London

Pictures: DENISE BRADLEY/PA/ARCHANT

TOP RIGHT: Michelle Tolley began fighting for the voices of infected blood victims to be heard after she was diagnosed with hepatitis in 2015