

With the ongoing impact of hepatitis C symptoms – fatigue, brain fog, lack of energy and motivation – and his increasing arthritis and joint problems with haemophilia, Gavin took early retirement from his job in the public service but continued his volunteer roles with HFWA and HFA.

In 2009 he tried the pegylated interferon and ribavirin treatment again, but his treatment was stopped after 6 weeks when tests showed it wasn't working.

TREATMENT AND CURE

In 2016 the new direct acting antiviral (DAA) treatments for hepatitis C became available in Australia. They were described as 'revolutionary' – and in Gavin's opinion, lived up to their promise.

'I had one of the new treatments, Harvoni, and it was a doddle. One tablet a day for 12 weeks and minimal side-effects. And I was cured – it was fantastic. It was the best thing I ever did. Now I feel fine and my liver test results are good too.'

Checking liver test results to make sure his liver had recovered was an important step. This testing took place as a standard requirement when Gavin joined a

clinical trial for a new haemophilia treatment, but he encouraged others to ask about testing if they didn't know what their liver test results were after being cured.

'Don't wait' was the message he had for others considering treatment for hepatitis C.

'Don't even think about it. Go for it – get it done. These new treatments have such positive results and there is hardly any impact on your life to undergo the course of treatment. There are several different treatments, so your doctor will be able to find one that suits your individual health and lifestyle.'

'If you are worried about having hep C treatment, ask your haemophilia team or your hepatitis clinic to put you in touch with someone who has had the new therapies so they can have a chat with you about what it's like. These days you don't need to think about the implications for your work or home life because it's so easy to take and there are hardly any side-effects. And when you are cured it puts you in good stead to deal with the rest of your life with haemophilia.'

Women can have hep C too

Mary Jane's story

Mary Jane is an Australian community member with von Willebrand disease (VWD). She spoke to HFA about her experiences with hepatitis C and being cured. Our thanks to Mary Jane for sharing her story.*

Women with bleeding disorders don't usually think of themselves as being at risk for hepatitis C. Mary Jane's story is a reminder that anyone who had blood products before 1993 might have been exposed to HCV, the virus that causes hepatitis C.

Mary Jane has von Willebrand disease (VWD) type 3, which is a severe form. Over the years she has experienced a range of bleeding problems, including

bruising, heavy periods, joint bleeds and gum bleeding. Growing up, she had the treatment product cryoprecipitate to control her bleeding. Cryoprecipitate is a clotting factor product manufactured from human plasma – the pale yellow fluid part of blood. Over the years she also had other gynaecological problems such as ovarian cysts and had a hysterectomy in the late 1980s, treated with whole blood products to manage bleeding.

In the past, human blood products – whole blood, cryoprecipitate and clotting factor concentrates - were a risk for bloodborne viruses such as HIV and hepatitis C. By 1985 Australia had introduced testing of blood donations and viral inactivation manufacturing



processes to prevent transmission of HIV through blood products. A test for hepatitis C virus became available in 1990, followed quickly by testing of blood donations. By 1993 there were similar safety measures to remove or inactivate HCV during the manufacture of blood products. They were important steps for blood product safety but too late for people like Mary Jane.

Mary Jane discovered she had hepatitis C after abnormal liver function tests just over 20 years ago.

'I didn't really know much about hep C. We heard more about HIV at that time, because we knew that people with haemophilia in our community were affected by it.'

'I had probably had hepatitis C for about 20 years, but I wasn't aware that I had symptoms. I had some fatigue, but I thought that was just getting older and being tired from work. I didn't classify it as there is definitely something wrong with me.'

Discovering she had hepatitis C impacted not only on Mary Jane but also made her worry about the people close to her.

'I was pretty horrified to find out I might have had hep C for 20 years or more and not known the risk of transmitting it. I was concerned about my husband. He needed to have a hep C test as well – which was negative. I was much more conscious of what I was doing – for example, if I cut myself, I was careful to make sure my blood didn't go on anyone else, like the kids.'

Her first round of hepatitis C treatment involved injections of interferon and ribavirin tablets and was not successful. In 2016 she had treatment again, this time with the new Direct Acting Antiviral (DAA) therapy.

'It wasn't too traumatic - very easy to take, just tablets, and I didn't have any side-effects.'

Mary Jane took the treatment for 6 months and her test results confirmed that she had been cured. Follow-up tests also showed that her liver was functioning normally.

'I feel fine now. My joints still give me trouble, of course!'

Her message for other women in her situation?

'Just go and get tested. It's not difficult in any way. If it turns out you have hep C, treatment is very straightforward and simple and the specialists at the hepatitis clinic keep an eye on you all the time. If you have any questions, you can ring them or go to see them anytime. It's all very easy.'

*name changed for privacy reasons