

Hepatitis

New Zealand's silent epidemic

The story of one New Zealander with an illness that affects 40,000.

By VALERIE SCHULER.

"Pretty devastated" is how Paul felt when he found out his hepatitis C virus had advanced to the most critical stage and he may need a liver transplant.

Paul (not his real name), a 30-year-old Auckland web designer, contracted hepatitis C as a 17-year-old through intravenous drug use.

"I only shared needles on one, maybe two, occasions, but that was enough," says the father of two.

"It was stupid, I wasn't aware how high the risks were and didn't know anything about hepatitis C at the time."

Paul is not alone; the Hepatitis C Resource Centre estimates that 40,000 New Zealanders are currently infected with the potentially deadly virus.

Around 25 people are added to the list each week.

To raise awareness of the "silent epidemic", the World Health Organisation is running the fourth annual World Hepatitis Awareness Day on October 1.

Hepatitis C is a blood-borne virus that causes inflammation of the liver. The disease progresses over many years and can lead to cirrhosis (scarring of the liver) and liver cancer.

Leading liver transplant physician and hepatologist Dr Ed Gane says only about a quarter of those with the disease know they have it, meaning the rest go untreated and are at risk of infecting others and developing serious liver disease.

If current trends continue, by 2020 the number of cases will have trebled, potentially costing the government up to \$400 million a year, says Robyn Brown from the Hepatitis C Support Group.

Ed Hornell, chief executive of the Hepatitis Foundation of New Zealand, says the major reason many people do not get tested is they do not experience symptoms for many years.

Paul says he cannot recall having symptoms before he was

diagnosed.

At 22 he decided to get tested after finding out some of his old friends had the virus.

Some of the most common symptoms of hepatitis C are headaches, mild fever, fatigue, muscle aches, loss of appetite and depression.

In Paul's case, fatigue, moodiness and lack of concentration became major problems at about 25.

"Your whole body just feels wiped out and totally exhausted.

I don't think anyone who hasn't experienced this sort of thing would understand.

I was at uni at the time and really struggled," he says.

For many years the standard treatment for hepatitis C was a combination of injected interferon, a manufactured form of naturally occurring virus-fighting proteins, and the oral antiviral ribavirin. A new form of interferon, peginterferon, was introduced in 2004.

This treatment is administered over 24 to 48 weeks. It is government-funded, but only for those who have genotypes one and four of several hepatitis C strains, or those starting to show signs of cirrhosis, says Brown.

"Those who have genotypes one and two are more likely to react to this treatment," she says. Over 13 years, Paul's virus has progressed to level four. He is now showing early signs of cirrhosis. The peginterferon treatment he began in March is funded for six months. Should he require further treatment, he will

have to cover the cost of approximately \$800 a week himself.

"I was shocked when I found out it had got this bad. Ironically, it means I now qualify for treatment," he says.

In Paul's case the side effects of the treatment, which has a success rate of around 50 per cent, have been severe. He has lost more than 15kg and suffers from constant aches and pains, moodiness, insomnia and loss of concentration.

He has also lost all sense of taste.

"That's the worst to be honest. It's the weirdest thing and I've really mourned the loss of taste."

A proud parent, his moodiness and short temper have also affected Paul's family life.

"I have to be so careful not to snap at my boys," he says.

The treatment means Paul has to take three tablets each morning and night and get a weekly injection. If the treatment is unsuccessful, Paul will have to go on the waiting list for a liver transplant.

No other disease results in more liver transplants and hepatitis C is the country's second leading cause of liver failure.

Each year about 60 people nationwide need transplants, but there are only around 30 liver donors, says Gane.

There are also many risks involved with liver transplants. There is a high chance the body will reject the new organ. In some cases the virus can return even if the transplant is successful.

For Paul, the risks are unthinkable. "I'm hopeful the treatment will work and don't want to think about a transplant. We'll cross that bridge if we get to it," he says.

Hepatitis C is most commonly spread among drug users who share infected needles. Some people contract the disease from

unsterilised tattooing and body piercing equipment, but this is less common.

It is extremely rare for the virus to be spread through sexual contact, says Brown.

Paul's partner of 12 years does not have the disease and says getting infected has not been a major concern for her.

"But of course we have to be careful and take precautions. We can't share tooth brushes or razors," she says.

Paul's children, aged four and six, do not have the virus.

Until the 1990s some haemophiliacs and surgical patients contracted hepatitis C through infected blood transfusions. But this has become increasingly rare since routine blood screening was introduced in the developed world in 1991.

Living with the stigma associated with hepatitis C has been another major struggle, says Paul.

He recalls a visit to the dentist when the nurse took a few steps backwards and looked at him like he was "something dangerous and dirty".

"I have often been made to feel second class, like a junkie," says Paul, who is self-employed, holds a masters degree and has been drug-free for more than ten years.

Hepatitis is not just a problem in New Zealand; approximately 600 million people worldwide are infected with either hepatitis B

or C. The aim of the annual World Health Organisation's awareness day is to educate the public and encourage those

at risk to get tested.

The Hepatitis Foundation encourages anyone who suspects they have come into contact with the disease to talk to their doctor and arrange a blood test.

Some sexual health clinics, such as the one at Auckland Hospital, offer free testing.

For Paul, getting tested was the first step to getting the treatment that could save his life.

Even though Paul says he does not condone drug use, his message to anyone at risk of contracting the virus is this: "Honestly, don't ever share a needle — just that once and it will haunt you for the rest of your life."



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