



Treatment for hepatitis C saves lives

By Sue Paton

The Hepatitis Foundation estimates there are around 50,000 New Zealanders with hepatitis C (hep C) and only half these people know they have the virus. Twenty percent of those infected develop cirrhosis and 3 percent develop hepatoma or liver cancer. Therefore, hep C is potentially fatal in a significant proportion of those infected. This makes the diagnosis and treatment of hep C a priority for the addiction treatment sector.

Many of our clients are injecting drug users (IDUs) or have a history of intravenous (IV) drug use. People born 1945-1965 are a particularly high-risk group (even if not IDUs), as is anyone with a history of injecting drug use, whether regular or recreational. Other risk factors include a history of imprisonment, tattoos, transfusions prior to 1991, haemophilia and immigration from higher risk countries such as East Asia.

Injecting carries its own particular stigma and, as such, there is an increased likelihood of non-disclosure of historic IV use. There have also been barriers for current and past IV users accessing treatment for hep C – some, perhaps, related to discrimination or stigma. Anecdotally, many people with hep C, both here and globally, report experiencing stigma and discrimination. This leads to shame and further compounds the effects of the virus itself.

Stigma includes: misconceptions about how it is contracted; discrimination in the workplace; family members buying paper plates or not swimming with someone who is infected; and social isolation (cited in Tony Farrell 2016).

The stigma relating to having hep C can cause low self-esteem, diminished mental health and reduced access to medical care through fear of disclosing the disease. Conversely, stigma may contribute to a discriminatory hesitancy on the part of some medical providers and dentists to treat people infected with it.

However, with the advent of new, exciting medications it has been very pleasing to see the rates of treatment uptake in primary care where the majority of infections can be cured. These new treatments are very effective and most who need them can take them.

On 12 June 2017 PHARMAC announced that the funding criteria for cirrhotic hep C treatment drug Harvoni would be widened starting immediately. This is wonderful news and will save

lives and unnecessary suffering. While inequitable access for those with genotype 3 hep C remains, it appears there is now more willingness to break down barriers to treatment.

About a year earlier, on 1 July 2016, PHARMAC had announced the approval of three antiviral drugs for treating hep C (Harvoni, Viekira Pak and Viekira Pak-RBV). These drugs were the new direct acting anti-viral medications (DAAVs) but the variations of these approved were only suitable for treating people with genotype 1a or 1b, or those with decompensated cirrhosis.

There are six major hep C genotypes and 43 percent of New Zealanders with the disease have a genotype other than 1a or 1b meaning a lot of people did not have access to funded treatment unless they had severe liver disease (Pharmac June 2016).

Both changes PHARMAC has made are a significant step forward. However, the threshold for meeting the criteria, while lower than it was 12 months ago, is still high. In effect, it means around 100 people will now receive treatment each year – an increase from 40.

Before 1 July 2016 some people were treated with DAAVs accessed via trials, but the majority were treated with interferon which is injected and tends to have severe and unpleasant side effects including nausea, diarrhoea, itchy skin rashes, insomnia and severe depression. This led to poor compliance and many felt their effects made treatment worse than the disease itself. To top it all off, their success rate was only around 40 percent. No wonder some people with hep C chose not to 'take the cure' when these were the only options.

Viekira Pak and HARVONI, by contrast, are taken in simple pill form once or twice daily, don't have debilitating side effects and have a 96-99 percent cure rate after just 12-16 weeks. This is great because if we have full access to treatment for all genotypes we will be able to cure this virus and eradicate it in New Zealand. The majority of liver transplants are hep C related, so the reduction in suffering and health costs will be considerable.

Our liver cancer rates are also rising dramatically (with a median survival rate of less than three months once a person is diagnosed). Those infected are often not aware of when they became hep C positive. This means many of the 50,000 or with hep C became infected in their late teens or early 20s but didn't come to be diagnosed until much later in life. Meanwhile the damage has been quietly done, especially in males over 40 and those who consume alcohol and eat fatty food.

Most people in New Zealand who are infected became so through IV drug use. There is now a lot of collaboration with needle exchanges and opioid substitution treatment to engage users into testing, fibro-scanning and treatment. Liver biopsies are a thing of the past as a GP or specialist only needs a liver function test, a genotype and a fibro-scan to have enough information to decide on suitable treatment.

We are entering a "treatment is prevention" paradigm, and that is why antiviral drugs like Harvoni are such a breakthrough. The challenge will be engaging past and present IDUs as many are not currently in treatment. Needle exchanges are gearing up to provide peer support, fibro-scans and non-judgemental privacy-assured access to treatment.

It is great PHARMAC has extended funding – but have they gone far enough?

Out of PHARMAC's hands is the exorbitant price set by Gilead – \$1000 a pill for crying out loud! The actual estimated production cost is \$1 per pill, and it is difficult to understand how profit drivers can completely override making access to lifesaving treatment a reality. PHARMAC has shown a real commitment in these two decisions to extend the reach of this effective treatment and are waiting for better prices of newer DAAVs so that the health dollar is spread further.

In November 2016, Naomi Wickens wrote an article for the dapaanz bulletin that raised these issues and promoted the Fix HepC Buyers Club as an alternative for those who don't qualify for funding through PHARMAC.

New Zealand has done well in the fight against HIV/AIDS to the point that few people here die of it any more. We've achieved that through better screening and medication and, importantly, through education and reducing stigma. Meanwhile, the rates of people dying of hep C have climbed exponentially. This is due to greater numbers of people in a highly stigmatised area that we haven't dedicated a proportional amount of research, advocacy and investment to.

Let's hope the PHARMAC announcement is a sign that the times are a-changing and that fear in whatever form will no longer be a barrier to those wanting help with either their disease or their addiction.

For those who don't qualify under PHARMAC's criteria, the Fix HepC Buyers Club provides a viable alternative to more affordable and safe generic drugs sourced in India and Bangladesh. The New Zealand Hepatitis Foundation endorses these.

If you do not qualify for the currently funded medications the <http://fixhepc.com/> website will lead you through a step-by-step process on how you can talk to your GP. There is also information on the website for GPs who, through the Fix HepC Buyers Club, will be able to help you access generics in a safe and legal manner.

To make it simple, GPs can follow leading expert Professor Ed Gane's¹ step by step guidelines at www.hepatitisfoundation.org.nz/wp-content/uploads/2016/10/edarticlepdf.pdf

While there are challenges ahead, the main message is that hep C is curable, the majority of hep C patients can be treated now, and we look forward to the day when all patients have access to treatment and the virus is successfully eradicated.

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