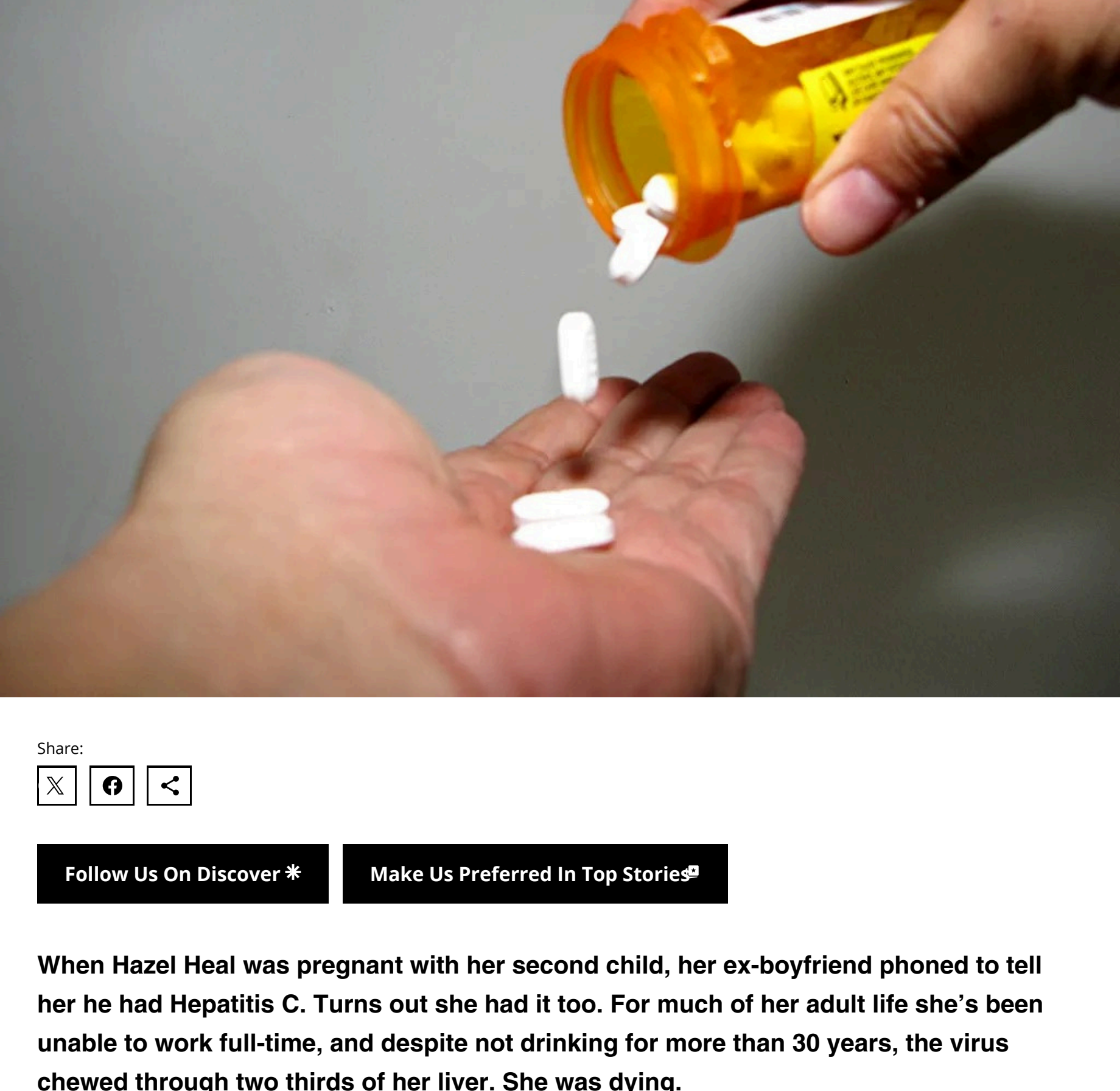


Health

An Affordable Cure For Hep C: the New Zealand Medical Profession’s Little Secret

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April 11, 2017, 12:41am



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When Hazel Heal was pregnant with her second child, her ex-boyfriend phoned to tell her he had Hepatitis C. Turns out she had it too. For much of her adult life she’s been unable to work full-time, and despite not drinking for more than 30 years, the virus chewed through two thirds of her liver. She was dying.

The drugs that could cure her cost only US\$100 to manufacture, but they aren’t publicly funded in New Zealand. With a \$200,000 bill for treatment, her only other options were selling her house to fund the drugs, or facing the long waiting list for a liver transplant.

About 50,000 New Zealanders have Hep C. Fifty-seven percent of them have strain 1, treatment for which is funded by PHARMAC—the government agency that decides which pharmaceuticals are publicly funded. But if, like Hazel, you’re one of the 22,000 people who have strains 2-6, the situation is bleak. The drug Sofosbuvir—usually taken in combination with other drugs like Daclatasvir in Hazel’s case—has a 90 percent cure rate, but it’s hugely expensive because it’s heavily patented. Many sufferers simply can’t afford it.

The truth is there is a safe and affordable way to get treatment in New Zealand, via a buyers club. Medical authorities told VICE they are okay with it. Doctors are allowed to do it under New Zealand law. And yet Hazel’s doctors in Dunedin wouldn’t help. Medical professionals are keeping it a secret from their patients because it’s seen as “not official”.

Hazel says Hep C patients already suffer from stigma around what has become known as ‘the druggies’ disease. Failing to advise people of life-saving treatment is “the most scandalous and needlessly cruel form of corruption of our generation,” she says.

Hazel’s liver was shutting down when she heard about a proven supply chain, or buyers club set up by Australian doctor James Freeman. Thanks to a legal loophole, patients can import three months of a generic form of medication from the country where the drugs are manufactured. The process is hard to navigate but for less than NZ\$2000, Hazel’s completely rid herself of a 30-year struggle.



Dr James Freeman and Hazel Heal. Photo credit Ruby Harris.

Half of the Hep C medication that’s manufactured is labelled as generic and half of it is branded. Generic forms are made under licence to the patent holder and have been proven through clinical trial to be identical to its branded counterpart. Because of this patent, however, it’s too expensive to be publicly funded in New Zealand.

“The world is being held to ransom over pharmaceutical pricing.”

“The world is being held to ransom over pharmaceutical pricing,” Dr Freeman told VICE. “And like the brigands of a bygone era, pharmaceutical companies are demanding ‘your money or your life’”.

PHARMAC operations director Sarah Fitt told VICE they would love to extend their funding to accommodate genotypes 2-6 but it’s not a reality.

“At current prices it would cost over a NZ\$1 billion—more than the entire budget PHARMAC has to fund medicines in New Zealand.

Through Dr Freeman, Hazel got the “miracle drug” and in just three days she noticed the results. Having completed the 12-week programme her liver is now almost fully recovered.

“It was indescribable. It’s radically impacted my quality of life. I’ve been living a half-life for 30 years and a heavy grey carpet has lifted from my shoulders. Of course I feel like a kid again,” she says.

Yet, in Hazel’s hometown of Dunedin, she says no doctor advised her of the alternative avenue, or prescribe the medication because although the Medicines Act 1981 allows an exemption around importation, the drug isn’t registered for distribution in New Zealand.

“It’s very disturbing when you realise that this information has been consciously withheld”

“I get it that there’s limited funding, but when there’s a safe avenue for people it’s very disturbing when you realise that this information has been consciously withheld. People feel betrayed,” says Hazel.

The situation has highlighted a significant divide between doctors and the Ministry of Health; with the ministry and health boards recommending against the treatment due to its unregulated status, and the Royal College of General Practitioners supporting the option.

Southern DHB chief medical officer Dr Nigel Millar told VICE the district health board endeavours to ensure patients are aware of all treatment options that are available. But they support the position taken by Dunedin specialists who don’t wish to take responsibility for prescribing drugs purchased abroad, which cannot be assured as safe and effective.

“Southern DHB gastroenterology service assesses, treats, and supports many patients affected by advanced liver diseases, including hepatitis C, without prejudice and we’ll continue to support efforts to widen access to direct acting antivirals through recognised New Zealand regulatory channels,” Millar says.

The same goes for the Waikato DHB. Director of Pharmacy John Barnard told VICE he “trusts the current process serves the New Zealand population as best possible”.

“There is no assurance that the medicine that is obtained is what it says it is.”

Waikato DHB is contractually bound to support PHARMAC activities, and any medical practitioner needs to follow DHB procurement processes.

“There are many risks with direct importation of medicines and going outside the NZ Medsafe registration process. There is no assurance that the medicine that is obtained is what it says it is,” Barnard says.

The buyers club has been endorsed by New Zealand Gastroenterologist Specialists Association, the New Zealand Hepatitis Foundation and medical director of The Royal New Zealand College of General Practitioners Dr Richard Medicott told VICE he supports the new treatment options available.

Yet Ministry of Health Integrated Service Design Group Manager Clare Perry told VICE the Ministry won’t endorse the buyers’ club or any other unapproved medicines.

“As unapproved medicines have not been assessed by Medsafe, the medicines regulator, the quality of the product cannot be assured and therefore cannot be endorsed by the Ministry.”

Confusingly, the Ministry has a policy to support health practitioners who choose to import and use unapproved medicines if they deem it appropriate.

Green Party co-leader Metiria Turei says the government must ensure that medical professionals tell patients about the availability of these buyers’ clubs.

“The Ministry of Health need to clarify this stance to District Health Boards and it’s of vital importance that DHBs comply. Lives matter.

“We know that a lot of Hep C sufferers don’t go to hospital for treatment because of the stigma—that they’re embarrassed. The first step is to promote the fact that access is available. Then it’s about reducing the stigma so people have good access to decent healthcare.”

“The stigma pervades society utterly, everywhere. If I say Hep C, you think, ‘oh what’s that again? Something dodgy’.

Hazel says the issue goes unnoticed because it involves a group of people that are silent and stigmatised.

“The stigma pervades society utterly, everywhere. If I say Hep C, you think, ‘oh what’s that again? Something dodgy’. The next question is, ‘how did they get it’ and the answer people want to hear is through drug use, so they can reassure themselves the disease has nothing to do with them.”

Hazel has encountered prejudice even within a medical setting, she says. “That’s where I’ve encountered the most outright ignorance. There’s a mentality that those with Hep C deserve to suffer... because they brought it on themselves. Because it’s for a population that’s silent and discredited, it makes sense that this issue has gone by the wayside,” she says.

But Dr Freeman says while many people with the disease may have used IV drugs at some point in their lives, because it couldn’t be tested for until 1991, and it was present in blood supply, a lot of people got it from blood transfusions, poor tattoo sterility, poor dental sterility, and poor immunisation sterility.

“In what must be one of the greatest tragedies of modern times, these life-saving medications are not being deployed on a mass scale.”

Now, it comes down to legality and morality of using generics to bypass patents and excessive prices, he says.

“It is easy to understand why patients will seek out treatment, the question for us, as the medical fraternity, is how we respond.

“Hepatitis C, Hepatitis B, HIV, Tuberculosis and Malaria are the five major causes of infectious disease death worldwide. In a breakthrough that rivals the invention of penicillin, drugs that cure Hepatitis C, with minimal side effects and high success rates, have reached the market, but, in what must be one of the greatest tragedies of modern times, these life-saving medications are not being deployed on a mass scale.”

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