

# UN#91

[www.usersnews.com.au](http://www.usersnews.com.au)

## THE HEP C EDITION

**CELEBRATING ADVANCES IN  
HEP C TESTING AND  
TREATMENT**



**2018**





# REMEMBER

**Hep C treatment is available to everyone – no matter what**

**Testing is free – contact your GP, AMS, Sexual Health or OST Clinic**

**Treatment is low cost – available via Medicare**

**Cure rate is high – 95%**

**Side effects are low for most people**

**No luck with your local clinic?**

**Ring NUAA for advice on  
02-8354-7300 or 1-800-664-413**

# **USERS'S NEWS**

## **No. 91**

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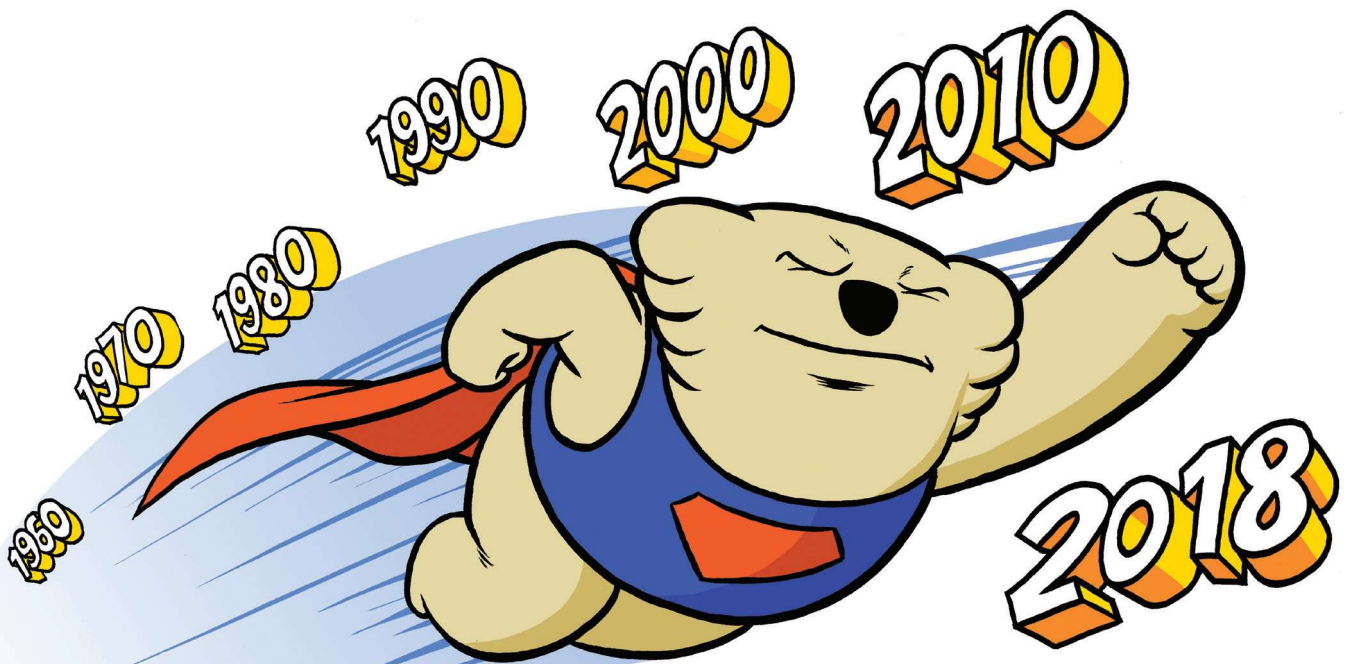
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## ARE YOU LIVING IN THE PAST?

SOME PEOPLE AREN'T GETTING TESTED OR TREATED FOR HEP C BECAUSE THEY ARE STILL RUNNING ON OLD INFORMATION.

THINGS STARTED GETTING BETTER A FEW YEARS AGO AND ARE CONTINUALLY IMPROVING.

HEP C TESTING AND TREATMENT IS NOW SUPER EASY, SUPER-SAFE, SUPER-MANAGEABLE AND SUPER-EFFECTIVE!

## WELCOME to TODAY..

...BECAUSE  
EVERYTHING  
HAS CHANGED  
IN HEP C  
TREATMENT!



# Stand Up and Be Treated Like Royalty



The World Health Organisation (WHO) agenda is to eliminate hepatitis C by 2030 worldwide.

It's easy to become cynical about these things: after all, how many targets have we heard? How about "We can end HIV by 2020"? Or "End global poverty by 2030"? And who could forget "A drug free world by 2008?"

With hep C though, I really feel as though we have both the motivation and the means, at least in Australia.

In Australia, hep C medication is on the Pharmaceutical Benefits Scheme (PBS) so it's cheap for people. It's simple and in many cases it's one tablet a day for 8 weeks. We have testing down to an artform – the age of less invasive testing has dawned with great new options for people with scarred veins. The treatment is safe, with few, minor side effects. And it works!

There is no reason to not be tested and treated and the results are amazing.

The Kirby Institute tells us that Australia is on track to eliminate hepatitis C by 2026. Yet there are around 200,000 people still to be treated.

If you are one of those 200,000 Australians can I ask that you read this issue of UN, that you talk to people who have had treatment, make an appointment with your GP or call NUAA to talk it through.

No matter what is holding you back, I ask that you tell someone about it and let your fears be put aside. Once you have been tested, and treated if necessary, you will feel better. Guaranteed. And you will have bought yourself more years lived in better health.

My husband was treated several months ago. He still has the 3 empty bottles of Harvoni (representing 3 months of treatment) on the

fridge, like a trophy. He will tell anyone who listens how amazing he feels to have the hep C virus out of his life after having it hang around for over 40 years. He no longer sweats like Katoomba Falls and he has more energy. He is less depressed and moody and more active and motivated.

Most of all, he knows he is not going to develop liver cancer. He wants to be around to see his grandchildren, but whether you have kids or not, being able to knock a health risk off the list is maybe the best reason of all. Being old and sick is a hard row to hoe. I know about that too – my first husband is on daily dialysis as a complication from hep C because the new treatments didn't come in time for him.

I am not sure what it will take to convince you but this is what I know, peer to peer. This is not a scam. This is not another crazy elimination scheme. People I love will die of liver damage if they do not get treated.

Together, we can get rid of hep C and make this a safer, healthier community. Because the more users who are cured, the less opportunity there is for hep C to be passed on.

It is also important that we continue to focus on prevention. Once you are cleared, you don't want it back. Accidents happen, so luckily you can be treated as many times as you need it. But let's work on using safely, loading up with sterile equipment, having extra for our friends, so we always can be sure of being safe.

Please think hard about it. I want you healthy and safe.

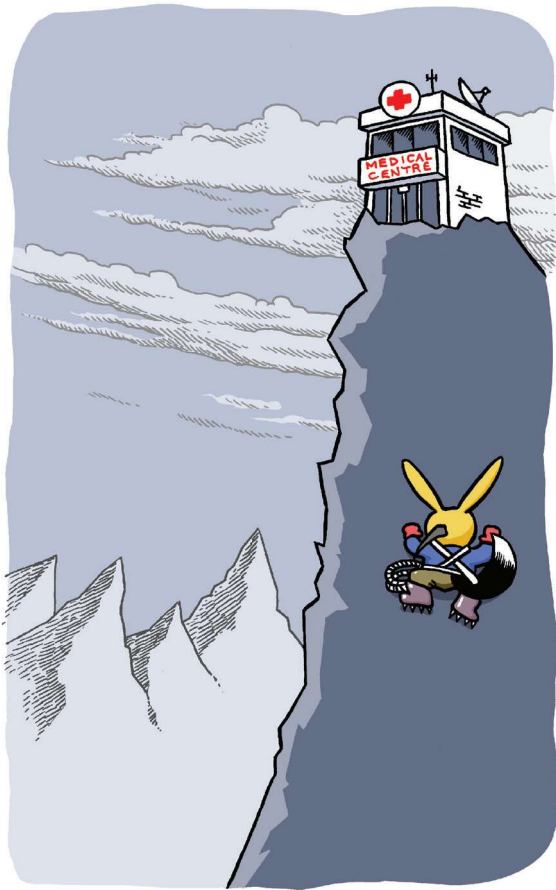
Love Leah xxxx



# IS IT HARD TO GET HEP C TREATED?

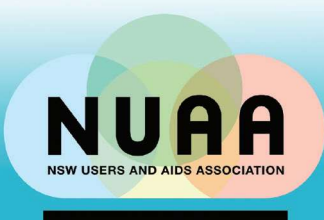
**BEFORE...**

**TODAY!**



IT USED TO BE, BUT DON'T  
LET OLD STORIES OR PHOBIAS STOP YOU.

HEP C TREATMENT IS NOW SIMPLE  
AND SAFE AND IT **WORKS!**



**IT'S COMPLETELY  
DIFFERENT TODAY!**

WANT TO KNOW MORE? CALL NUAА ON 02 8354 7300 OR TOLL-FREE 1800 644 413.

## Kyla's Letter

# She Must Have It Too

Dear User's News,

Almost 20 years ago I was diagnosed with hep C. My husband and I attended the sexual health clinic at a major Western Sydney hospital and were given the news together — we were both hep C positive. Back then not a lot of information was available, so I slowly had to learn what living with hep C meant for me.

“Dirty fuckin junkies, now got their own disease!”

“They should round them all up and shoot them. Just don't let their blood get on you. Hahaha.”

“Yeah, I don't wanna be drinking out a cup they've used.”

“We have a right to know who these people are.”

This from my co-workers. They didn't know I was positive.

Looking back, I find it hard to believe that people had these opinions. Nowadays, I'd definitely call out anyone who spoke like that. I just didn't have the tools or experience to do so at that time.

After a few years, I just got used to living with hep C. We had to teach our daughter not to share toothbrushes or razors. We made sure to try to eat well. We were kind to ourselves. But we never considered getting the interferon treatment. The side effects were just too much.

Fast forward 18 years to this new, enlightened age of hep C, with new treatment and less stigma. I wanted to get tested again, but really hesitated due to the condition of my veins. A new doctor that had been highly recommended to me offered to do the blood work himself. He seemed so confident that I let him go ahead. He got a vein first try (yes, I go back to him for everything now!)

The very next day, He rang me to ask where and when I had been diagnosed. Turned out, I had never had hep C. But I had lived as though I had it and experienced the trauma of stigma and discrimination. Even the misdiagnosis, I believe, was the result of discrimination — “if one of them is positive, the other one will be too”.

I had also had the benefits that come with eating well and being kind to yourself, and a drive to educate myself about the health issues surrounding injecting drug use. User's News played a large part in that education.

If I learnt anything from this, it is to treat others as though you have the virus — i.e. never share equipment as you don't want to infect others.

And treat yourself as though you don't have the virus — i.e. never share equipment, you don't want to infect yourself.

Thank you, UN, for all the great info over the years.

Kyla



Dear Kyla,

Thanks for your letter on this important topic. Thank you also for your sweet words about User's News (and you're very welcome!).

You are one of many people I have heard from who have been misdiagnosed as having hep C or have found they have cleared it since their initial diagnosis. Thanks for reminding us how important it is to get tested for hep C on a regular basis if you're at risk — at least yearly.

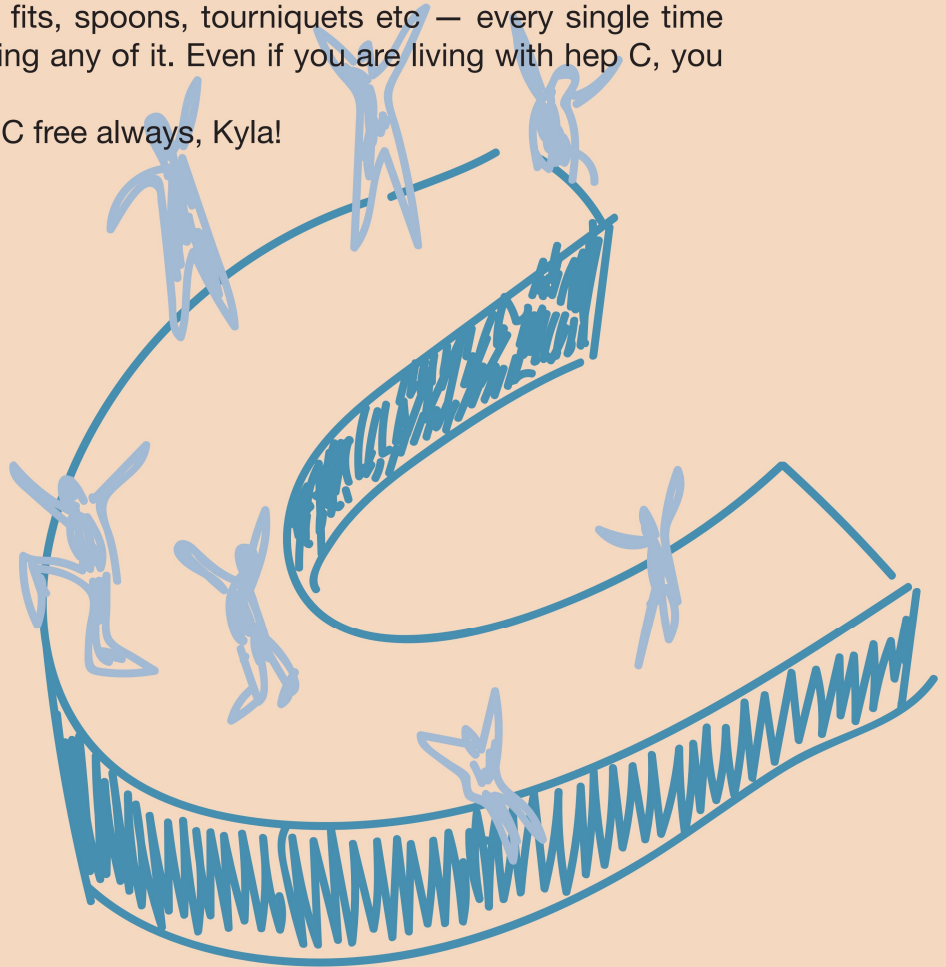
It is totally possible to have a test mix-up as you experienced, but more likely to clear hep C without treatment, like in Serena's story in this edition. In fact, it is estimated that around a quarter of people who test positive for hep C actually clear it spontaneously. Just because you have been told you have hep C once doesn't mean this will never change.

The reverse is also true. Just because you have cleared hep C doesn't mean you won't ever get it again. The only way to avoid hep C is to use all new equipment — fits, spoons, tourniquets etc — every single time you inject, never sharing any of it. Even if you are living with hep C, you need to be safe.

I hope you stay hep C free always, Kyla!

Best wishes,

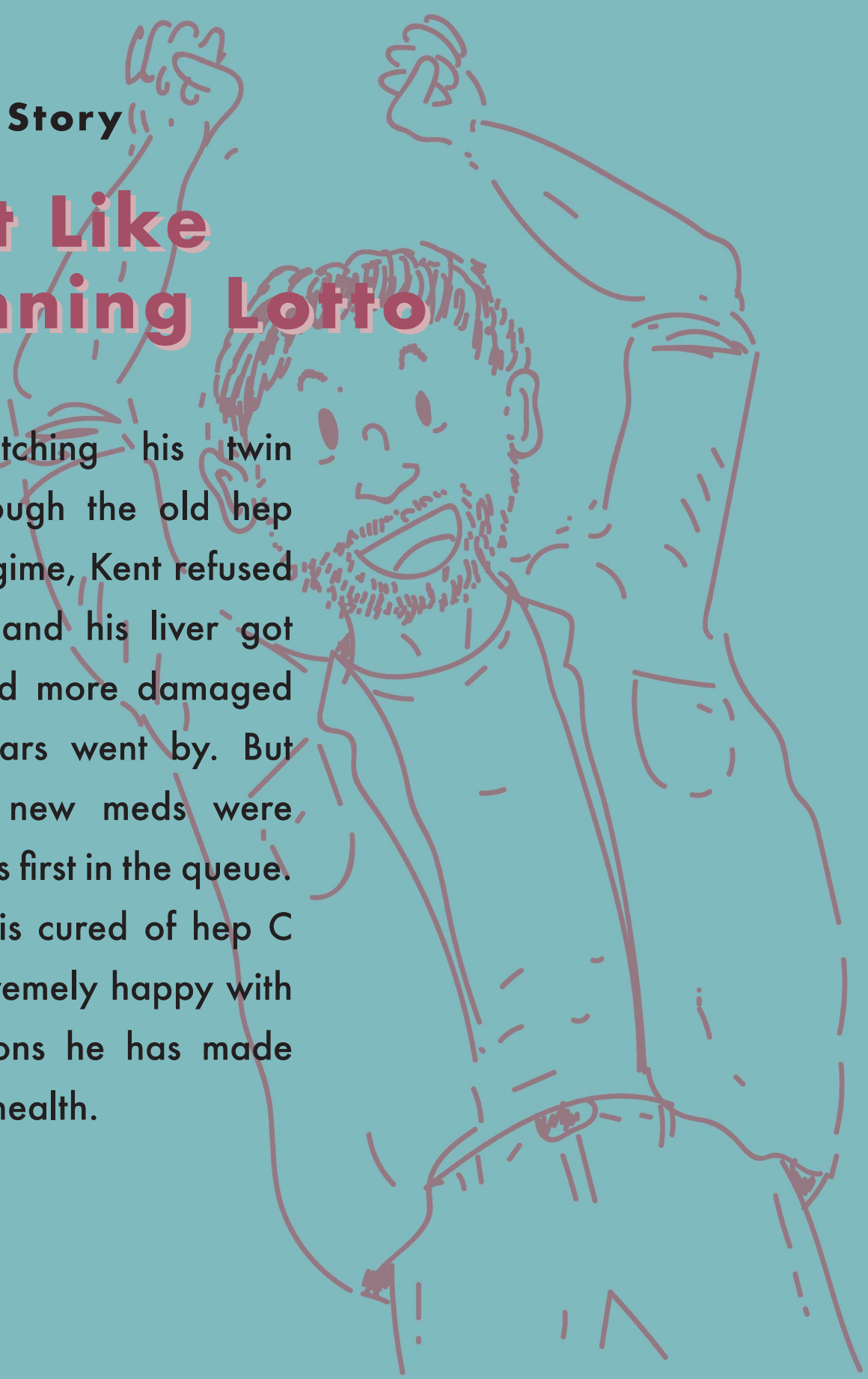
Leah xxx



## Kent's Story

# Just Like Winning Lotto

After watching his twin suffer through the old hep C drug regime, Kent refused treatment and his liver got harder and more damaged as the years went by. But once the new meds were out, he was first in the queue. Today he is cured of hep C and is extremely happy with the decisions he has made about his health.



I got hep C when I was very young, at 14. I remember it clear as day. There were a handful of us youngsters living in a unit in Glebe, just doing our best to survive. By this stage I'd been doing things my own way for about 6 years, having left home aged 8 or 9, leaving behind a father who was violent and cold — a hard man.

I was walking down Glebe Point Road when suddenly I felt totally exhausted. I could barely put one foot in front of the other. I got to a phone and rang someone to ask them what I should do because I had no idea how to deal with it. They told me to get to a doctor, so I did.

I was so weak I passed out in the doctor's rooms. I was jaundiced — my skin was yellow. The doctor took blood and asked me if I was an IV user. I said I was. I had started injecting heroin around 12 after a year or so snorting it when an older user told us kids we were wasting it by not using a needle. The doctor said he thought I had some type of hepatitis.

The test came back “non-A, non-B hepatitis” — which is now called hepatitis C.

The doctor told me to drink plenty of water and rest. I followed his advice and the yellow skin settled down eventually. I felt not so dead tired, but I never went back to the energy levels I had before. Still, I adapted and life went on.

I was told that I got hep C from using drugs IV, that it was passed on blood to blood. I kept using but I had to learn pretty quickly how to use responsibly to make sure I didn't pass hep C onto anyone else. I told everyone — don't use my fits, the risk is too great. I told people about cleaning fits with bleach. I never let people share my equipment and I never shared anyone else's.

I now knew to keep an eye on my liver. I made sure I had regular blood tests and scans. My ALT levels got progressively larger as the years went on, so I knew I had significant liver damage. [Alanine transaminase, known as ALT, is an elevated liver enzyme shown on blood tests to indicate liver damage: Ed]

My twin brother had also got hep C. He was a personal trainer and very healthy. He had never had any symptoms from his hep C. When he was tested and came up positive, his doctor insisted he go on treatment straight away. We're talking the old treatment, that is 12 months of interferon injections plus ribavirin tablets.

I watched very closely to see what he went through. The treatment literally aged him about 10 or 15 years. He looked different after the 12 months of treatment. His hair went grey, his skin went hard, he got wrinkles, he had a whole body change. Yes, he cleared it, but it really knocked him around. He was a different person.



I feel like he was used as a guinea pig, that it wasn't necessary that he go on treatment at that time. His liver was fine, he was fit and energetic, he felt great. They shouldn't have put him through that process.

He really regretted going on treatment at that point. I mean, the cure was worse than the problem. After seeing all that I thought: "No way I'm getting on that." I just carried on, with my liver becoming more and more damaged.

When I heard new treatments were coming, I got interested again. I connected with NUAA and kept my ear to the ground. I put my hand up for trials on new medications, putting my name down everywhere — even in different states. I went to St Vincent's to liver specialist Professor Greg Dore's clinic. I literally harassed him to get on a trial.

Then the call came: "You are on a trial, the last person allowed! When can you get here?" I said: "I'll be there first thing in the morning" and I was. But when I arrived, the nurse apologised. "Sorry, there was a change of quota. They don't need any more sclerotic livers on the trial. You aren't eligible."

I was gutted. I can't tell you how shattered I was. I was actually off the trial because my liver was too damaged. I really took it to heart and got the shits with the whole thing. I stopped thinking about it for about 12 months.

When, finally, there was talk in the media that the new treatments were going to be available on the public Pharmaceutical Benefits Scheme (PBS) to make them affordable for all Australians, I decided I'd do it. If passed, this would mean that instead of costing around \$100,000 for the medications, my chance at a cure would be funded by the federal government and cost me under \$20. And talk was, the new meds were nearly 100% successful. I kept an ear out and I got myself back to Dore.

On March 1, 2017, the meds were approved for funding on the PBS. And that was the date on my script.

I knocked down the door. I felt like I'd won Lotto when I got my first month's medications. I got the script filled as soon as I left the Liver Clinic. I remember leaving the chemist, so excited.

I did worry about side effects of the new medications. After all, knowing things had changed and trusting they'd changed were two different things. But I decided to take people at their word. And it really was ok. I did feel a bit tired out in the first couple of weeks, but it was just my body getting used to the medications. That went away as my body adjusted.



My doctor told me I had to be on the meds for 6 months because I had a sclerotic liver. My ALTs were in the 30s. That meant that my liver was so damaged with scar tissue that my liver was literally hard.

After a month on the meds, I had my first blood test. I had already got rid of hep C! I still had to complete the treatment, but I was rapt.

You know, I wasn't really sure how much hep C knocked me about till I was cured. You can't know what is hep C and what is life, or getting older, or a lifetime of drug use. But once I got rid of it I knew — hep C had really held me back.

I used to get waves of tiredness that would stop me in my tracks. I got rid of that. It was not normal tiredness, it was hep C tiredness, a totally different thing. I could fall asleep in my chair any time of the day.

***You can't know what is hep C and what is life, or getting older, or a lifetime of drug use. But once I got rid of it I knew — hep C had really held me back.***

I used to have to have a sleep at lunchtime every day. I don't do that anymore.

I also used to get pains in my liver — it was really tender because it was so hardened. That stopped.

Now I am cured I have finally found out how much hep C was affecting my life — and it was massive.

My advice to anyone who isn't on hep C treatment is this: You cannot get on treatment quickly enough. Don't delay. Don't wait. Don't let old stories or phobias stop you. It's all completely different today. The drugs are much better and they work.

If you have any doubts at all, get connected with NUAA and get your questions answered and your fears sorted out. I recommend NUAA because it is at users' level. You won't be judged. The people at NUAA understand. They know, because where ever you have been, so have they.

Don't overcomplicate it, just do it. Your life will change for the better.

# Just A Little Prick

A stylized, light blue line drawing of a hand being pricked with a lancet. The hand is shown from the side, with the index finger extended. A small red dot on the fingertip indicates the point of the prick. A lancet is shown above the hand, with its tip touching the skin. The drawing is simple and clean, with no shading.

## WHAT IS FINGER PRICK TESTING?

Goodbye and good riddance to the days of having a nurse draw up vials of blood with a syringe (usually from the crook of the arm and often in your best, sometimes only, vein) to test for hep C.

You no longer have to worry about whether you have good enough veins to be tested for hep C, a huge barrier for some older people who use drugs. More and more services are realising that the easiest way to get vein-challenged people tested is to forget veins and vials in favour of collecting drops of blood from a fingertip.

Finger prick testing is fast, convenient and easy to use – and you are in control.

It involves sticking the end of your finger with a needle or lancet (a device that makes a tiny insertion or cut, quickly and fairly painlessly). It is the same procedure people with diabetes use daily to check their blood sugar.

Then, the blood drops from the finger and you collect it on a special [blotting] card which is dried and tested (in the case of Dried Blood Spot) or it is drawn up by capillary action by a thin glass tube for transfer to the cartridge used for the point-of-care testing machine.

Fingerprick blood work is used in two ways: Dried Blood Spot testing and Point of Care testing.”

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*Not sure if you have hep C? The first step is to see if the virus has ever entered your blood stream. Get a Dried Blood Spot Rapid Diagnosis home test sent to you to see. To order one, go to <https://www.hivtest.health.nsw.gov.au/> or call 1800 451 624. Smear some blood from your fingertip on the card provided and send it back then wait for the results! Simple, private and free.*

# 1. DRIED BLOOD SPOT TESTING

Dried blood spot testing for hepatitis C is available through a NSW Health research study. The study tests for HIV and hepatitis C and the test is available via a website (<https://www.hivtest.health.nsw.gov.au>) or it can be picked up at Sexual Health Clinics, ACON offices and the NUAA NSP (more information below)

## WHAT DOES IT TEST FOR?

The DBS test tells you if you are hepatitis C positive (if you have a current infection - HCV RNA) and HIV (positivity, CD4 count)

## HOW DOES IT WORK?

- You prick your finger, drop the blood onto a card provided in the testing kit, wait four hours for the blood to dry and send it off. If there is a health care professional assisting the testing process, they can take care of sending the test.
- Your card is sent to the lab for analysis. You will receive a text message when your results are available which will give you a number to ring the Sexual Health Information Line. Alternatively, if you've done the test through a local service, they will receive and follow up on the results. If you test negative then you will receive a text letting you know.
- The test is 99% accurate

## WHERE TO GET IT?

- Good news for rural and remote communities and everywhere! If you are over 16, you can register online and be sent the test card, a reply-paid envelope and instructions. You then do a self-test and send it back for free. Go to <https://www.hivtest.health.nsw.gov.au/> and click on Get Started. You can (and should) order tests for hep C and HIV here.
- The website has directions in Chinese, Bahasa Indonesian, Thai, Vietnamese, Arabic, Portuguese, French and Spanish.
- You can call 1800 451 624 if you aren't connected to the net and want a test kit sent to you, or if you have trouble with the test.



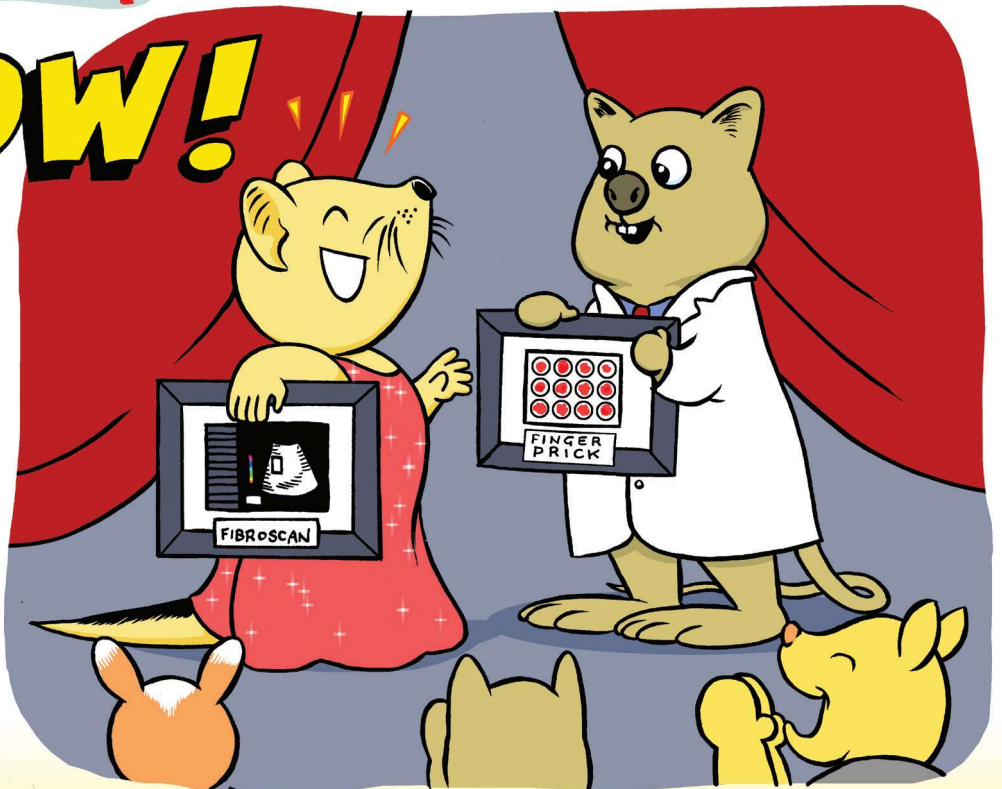
**I'M STUCK BECAUSE I JUST  
CAN'T HACK THE TESTS!**

**THEN...**



**...NOW!**

**TESTING  
PROCEDURES  
ARE  
CHANGING  
RAPIDLY  
TO MAKE IT  
EASIER AND  
LESS  
INVASIVE.**



**IT'S COMPLETELY  
DIFFERENT TODAY!**



**WANT TO KNOW MORE? CALL NUAAA ON 02 8354 7300 OR TOLL-FREE 1800 644 413.**



## 2. POINT OF CARE (POC) TESTING

### WHAT DOES IT TELL US?

Point of care testing gives you a full picture of your hep C status: Are you living with hep C right now? And if so, what is your genotype? And how healthy is your liver?

### HOW DOES IT WORK?

- You prick your finger, let it flow into a blood collection device and hand it to the health worker. Your job is then over.
- The sample is placed into a cartridge and loaded for the machine to run – which takes about an hour.
- There is no need for a second appointment to get the test results. The results come out and the health worker explains it all to you along with your options for treatment if necessary
- In most cases, you will no longer even need a fibroscan to check the health or hardness (elasticity) of your liver — although this is still a good idea and it can also check for Fatty Liver. Most people will leave with their medication and be able to start treating their hep C straight away, no mucking about.

### WHERE TO GET IT?

- Point of care testing is only available through research studies at the moment. It's a bit of a case of "watch this space", but it won't be long.
- NUAA will be participating in the TEMPO study starting soon which uses rapid testing and provides on-the-spot treatment as will ACON. There are plans to expand this study across NSW.
- POC testing is also being trialled in a couple of jails and more to follow.
- We'll keep you up to date at NUAA or call your local hospital's Liver Clinic to ask how you can get POC testing.

# DOES HEP C TREATMENT WORK?

## THEN...



THE OLD  
TREATMENTS  
DIDN'T WORK FOR  
MANY PEOPLE.



## ...NOW!

NOW,  
NEARLY  
EVERYONE  
GETS  
CURED!



## IT'S COMPLETELY DIFFERENT TODAY!



WANT TO KNOW MORE? CALL NUAA ON 02 8354 7300 OR TOLL-FREE 1800 644 413.

## Charlotte's Story

# Things Can Change

**Charlotte suffered from stigma and discrimination for years because of her hep C. But when she got tested to get treatment rolling, she got a big surprise.**

I found out I had hep C in 2001. I had asked for a test because I was in pain with an inflamed liver. I was absolutely sure it was from hep C because I had shared needles with my partner who was living with hep C at the time. It seemed unlikely I would have gotten away with doing that, and I was right.

Over the years, I was tested from time to time and heard “Do you know you have hep C?” several times.

I was on the end of a lot of stigma and discrimination because of my hep C. It was across all my medical files. Any time I went to hospital or had a medical appointment it would come up, even when it wasn't relevant. One dentist even refused to treat me because of it. I still don't know how he found out because I didn't tell him, but I live in a small town where gossip is rife.

It seems to me that hep C is seen as a marker of a drug user, although no-one has ever asked me if I was using before jumping to conclusions I was “drug-seeking”. I believe the reason I was refused pain killers for serious pain in the past was simply because I had hep C, because I don't have any history of doctor shopping or using prescription drugs.

It was the stigma and discrimination more than any physical symptoms or health concerns that made me want to clear my hep C. But even though I really wanted to get rid of it, I was scared of the treatment. It seemed

like the cure was worse than the complaint. I was particularly scared of the liver biopsy. Plus, I had seen people on treatment sick and struggling to the point of suicide. I just didn't feel well enough to be that sick, if you get my meaning.

When I heard about the new tests and treatments, I decided to jump on board. I was on buprenorphine and hadn't used a needle for a while, so I felt it was a good time to deal with my hep C. Plus I had heard that you no longer needed a biopsy and that the new medications didn't have the same side effects.

I went to get another blood test so my doctor had all the information he needed to prescribe the right medication. I was really shocked to find I had cleared it somewhere along the line. I found out this is called a “spontaneous clearance” and it happens for about a quarter of those who get hep C. I was absolutely over the moon to be one of them.

My doctor didn't know when I might have cleared it. I wonder if some of the blood tests I did only picked up the antibodies — that first test that tells you that you have been in contact with the virus, rather than the sophisticated PCR test that give you info about your genotype. And because the doctors weren't up on hep C, they jumped to the conclusion that I was still living with the virus.

I was happy to be hep C free, but I was a bit cross when I thought of all the discrimination I had suffered as a result of my hep C diagnosis. I might have been clear for a long time. My advice? It's absolutely worth getting tested, even if you are borderline about getting treated. You never know, you might find that like me you have cleared it spontaneously and can stop living like someone with hep C. I'm now fighting to get my hep C diagnosis taken off my medical records.

My next challenge is the diagnosis my doctor delivered just a couple of weeks ago: Chronic Obstructive Pulmonary Disease (COPD) from smoking cannabis. I'm working on a new health plan for coping with that right now.



# Lean On Me

**Our hep C Buddy support worker, Rodd, helped Logan to better health – and not just for his hep C.**

## Logan

Nearly 32 years ago, in the mid-1980s, I was literally thrown out of a doctor's surgery and my file was thrown after me. The nurse on reception screamed at me: "You have AIDS, get out of here now." That's how I found out I was living with HIV.

I didn't tell anyone — not friends or family. The stigma and fear were too great. I moved to Melbourne so the people I loved didn't have to see me deteriorate. I didn't deal with the fact I was living with HIV and expected each month to be my last.

Then I met Dr Sandy Beveridge, who was working in HIV/AIDS patient care. He turned my attitude towards my health around completely. With his encouragement and support, I ended up on every trial going. I was an enthusiastic guinea pig for a long time.

Eventually I got to the point where I didn't want to take any more pills. I had a low viral load anyway and it just didn't seem worth it. I didn't take any meds for 5 years.

Along the line I moved back to Sydney. Although I wasn't taking any meds, I kept up regular tests. I'd been attending a HIV specialist service but I got sick of my doctor always being late for appointments. When I complained I was told I was unemployed and had plenty of time. I didn't want to go to a service that treated me like a second-class citizen, so I stopped going.

I had real difficulties finding somewhere to go after that. A good friend of mine, Rodd, was working for NUAA with the Hep C Buddy Program. He suggested I get my HIV tests done at NUAA but also wanted me to test for hep C. I had been immunised against hep A and B as part of Workplace Health and Safety for a job, and even though I'd had hep C tests in the past, I had always come up negative. But I wanted to help him in his new job, so I agreed.