

# Treatment, Life, Hep C & Me



# Foreword

*By Paulie Stewart*

*Singer with The Painters & Dockers, Dili All-Stars & The Transplants*

Now these here are brave people featured in this publication.

Admitting you have Hep C and then discussing it openly is a lot scarier than some might think, especially when until recently it was the subject of crude jokes on national late night live television. However, this one-time stigma is changing thanks to the great work of Hepatitis Australia, and to the efforts of people like the 12 featured in this book who discuss openly and honestly their relationship with hep C, and their journey with the subsequent treatment for its cure.

I was told that I had contracted hep C about a decade ago due to using intravenous drugs. As I always tell people 'It was only a handful of times.'

The number of times is actually irrelevant, the fact is I had the disease, and despite being warned, I stupidly did nothing about it, especially not curbing my excessive drinking at the time.

As a result of indulging in this (I can now see) stupid behavior, and going into 'hep C denial' I ended up real sick for nearly two years, and I was compelled to have a liver transplant at a Melbourne teaching hospital. Yuk!

My advice? Avoid going through this process at all costs. It is a nasty experience, and if there is a chance to avoid it, do so.

Of course there are other ways of contracting hep C, like being administered a bad blood transfusion, an unsterile tattoo or piercing, and sharing toothbrushes and razors. Obviously, sharing needles or razors is not a good idea; full stop.

If you are worried at all, my advice would be to get tested.

My second tip would be to act with caution if you indeed have contracted the illness.

My third tip is to seek medical treatment, seek advice and behave responsibly.

I wish a long life to my 12 fellow hep C survivors who reveal their engaging stories in this publication; 'Treatment, Life, Hep C and Me.'

People with hepatitis C wondering about treatment are sure to find this book both a resource and a comfort. For people without it, the stories offer an insightful and sympathetic look into the worlds of a dozen of the millions of folks globally who have hep C.

Rock On.



# Introduction

Hepatitis C can affect anyone, from any walk of life. In Australia, it is estimated that one percent of the population could be living with it. That's about two hundred and fifty thousand people.

If you've picked up this book, chances are you, or someone you love has been diagnosed with hepatitis C and may be thinking about treatment. Whether you are feeling shocked, angry, confused or afraid, this book is for you.

Hepatitis C is a big deal. It is a serious illness; one that invites a lot more shame and judgment than it or you deserve. For many of us, dealing with the symptoms of the illness is a walk in the park compared with working out how to manage the stigma, discrimination, hysteria and shame that hep C often invites.

In addition to a whole range of lifestyle issues you may need to think about, there's also the question of treatment. There are lots of resources out there to help you make decisions about diet, use of alternative therapies such as Chinese medicine and naturopathy (which can be very helpful as an adjunct to conventional treatment to help manage side-effects), use of alcohol and other drug use, or preventing the spread of hep C. This collection of stories however, is aimed at showing you how some people get through conventional treatment.

For many, the thought of enduring six, twelve or more months of interferon and ribavarin combination therapy (or one of the combination therapies with newer drugs) poses a big scary question mark. Along with a long list of possible side-effects, we have to consider how we will work, look after our families and maintain our lives and relationships while doing treatment.

For me, the lead up to treatment was like wincing before the pain actually came. Uncertainty, my fears of the unknown, hair-raising lists of side-effects, and the horror stories out there, combined to get me thinking treatment was going to be some hideous endurance test I would never get through. With time, I found out that my imagined treatment was a lot worse than the reality, and that has become more manageable over the years as the medicos understanding of the side-effects and the virus itself has improved. These days, for lots of us, it is doable. It sadly still doesn't come with a guarantee of cure, it can be deeply unpleasant, and there are times when you're hanging on by the skin of your teeth, yes. But these days pass. For some, serious side-effects can make the journey very hard going, But even those people looking back over the experience rarely say, 'I wish I hadn't bothered'. Even the significant number of people who don't clear on the first go often find some positive aspects of the treatment experience and its results to reflect on.

And that is what this collection of stories is about. It's a truth about human beings that we don't know just how resilient we are until we test ourselves. The twelve people I had the privilege to meet and chat with while writing these stories show resilience and courage in bucket loads. If they can get through treatment with their diverse circumstances, families, relationships and work lives, so can you.

I hope Fungi's story will inspire you, as it did me, with her tales of travelling home to an imploding Zimbabwe towards the end of her 12 months of combination treatment. BJ, similarly inspiring, illustrates that there's never going to be a perfect time to try treatment. So, you may need to just find a way to fit it in, even if your life involves 14-hour days working down a mine a long way from any family or friends to help you get by.

Lots of people find that having goals help them get through the bad days of treatment. Meera's summer dress hung in her wardrobe, ready to wear in the months ahead when treatment would be over. Walter, counting down the Sydney Morning Herald's TV guides from week 48 to 1 was one of the things that, along with walking his dog, kept him going week after week. Linda's meticulous pre-planning, including organising pre-treatment education for her sons, and writing in her treatment diary helped her keep a hold of treatment and its effects.

I hope you will find encouragement in Jala's story, doing treatment as she did, newly arrived in Australia as a refugee, isolated, missing her family, reliant on interpreters to communicate with her doctors. Nicky's story on the other hand shows how taking time out to go back home where there was support, away from her usual city life helped get her through. Paul's laid-back focus helped him avoid paying too much attention to the side-effects. Flo's story is a reminder that age should not be a barrier to considering treatment; her advice to nurture yourself comes from one who learned this through the treatment experience.

Emmy talks about what can happen when hep C is not diagnosed earlier, in her moving story about her mother, Jennifer. Shane demonstrates what can happen if it is diagnosed, and clear unequivocal medical or lifestyle messages are not given. Finally, there are some people out there who do treatment more than once, and remain positive about the experience. Jake's story is one of great courage; a veteran of three lots of treatment, but it's his message about standing up to stigma that I like best.

Finally, there isn't a prescription for any of this. At the end of the day, each of us will have to find our own way through. Along the way there's lots of practical advice and tips that can be shared by reading this book, or visiting one of the great websites such as [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com) and [www.hepcaustralasia.org](http://www.hepcaustralasia.org), contacting the hepatitis organisation in your state or territory by dialling the help line number 1300 437 222 (1300 hep ABC), or talking to the nurses on your treatment team if you're being treated through a public hospital. You're not alone.

Good luck.

Charlie Stansfield, 47, is a writer and counsellor who lives in Sydney. She contracted hep C in the 1980s after a dodgy tattoo and undertook 6 months of treatment in 2008. She cleared the virus in August 2009.

A silhouette of a person sitting on a white dog, likely a kelpie, against a vibrant, ornate background of paisley and floral patterns in shades of teal, purple, and red. The background has a glowing, ethereal quality.

**The benefits of having a pet while on treatment are enormous. If one single thing sustained me, it was my companion kelpie.**

**1**

# Undercover Treatment

There are lots of ways to conclude a driving holiday across America. Flying home quietly with swags of duty free, a Monica Lewinsky t-shirt and a good novel is one way. Being ordered to strip down to your underwear (designer label, thank god) and walk six times through a security gate that emits a blood curdling shriek each time you pass through, is another.

It was the late 1990s, the era of the Unabomber. He'd announced that LA airport would be blown up the day of my departure, so security was amped up. It was a mystery to me why, practically naked, I continued setting off the metal detectors. I pleaded with the militia that they could do whatever tests they liked just so long as I could get dressed. Finally they let me onto my flight.

Some months later, still thinking I had nothing more than a good travel story, I came across an article about hemochromatosis<sup>1</sup> and how in extreme cases it can even be picked up by security checks at airports. A few tests later – and a misdiagnosis or two – I tested positive.

For over a decade, my liver ached. I'd have sharp pains – what I called needles under the rib cage. I'd known I had hepatitis C since 1992 but hemochromatosis was another whammy.

In 1999 I was put on a blind trial – and drew the shortest of short straws – the maximum dose of raw Interferon three times a week. The side-effects were hideous. I sweated and shook so much I had to move into the spare room, and I believe the experience contributed to the eventual breakdown of my marriage. On top of everything else, the trial was cancelled after seven weeks. And I lost a heap of good hair in the process.

Although I'd come to terms with having hep C, a rusted liver and stage two cirrhosis, I made the decision to have treatment because I realised I didn't want any 'what ifs?' at the end of my life.

But I wasn't super-positive. Deep down, I didn't really trust treatment to work. I had a 'Plan A and Plan B' – 'If I do it and clear, I'll go on a world trip. If I do it and don't clear, then I'll go on a world trip!'

I also had the sense that I had gotten myself into this mess, so, I was going to have to try to get myself out. It wasn't that I wanted to punish the younger me but I did in some ways see doing treatment as my payback for years of fun and frivolous entertainment.

I started combination treatment in 2007, with the attitude that it wasn't going to get the better of me. I approached treatment the second time as a challenge, and all the negative stories of dropout rates and side-effects were not going to stop me. Fortunately, I was treated at my local hospital, which has outstanding primary care and support staff. I may even have fallen in love with several of the nurses.

I hardly told anyone I was on treatment. I discussed it confidentially with a colleague at my work, and she covered for me on the days that I sat in my office staring at a computer screen, or slept

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<sup>1</sup> Hemochromatosis is the abnormal and excessive absorption of iron from food in which the excess iron is retained and deposited in various joints and organs throughout the body, in particular, the liver.

under my desk George Costanza style. I structured my life so that I would have my shot on Friday nights, and I'd cocoon myself for the weekend when the sides were the worst. I worked full-time during the whole 48 weeks and did not take a single day off.

I had one friend that had done treatment, and she was my rock. I'd call her and talk about symptoms, side-effects and life. We laughed a lot and shared much humour, often at our own expense. Otherwise, I didn't disclose to anyone else apart from my ex-wife and a few people in my hep C support group. (Oddly, my ex who couldn't live with me unwell was there for every one of those 48 weeks!)

Of course, other friends knew something was wrong when I started dramatically dropping weight – I wanted to change my name to 'Gaunt'. A few friends came over in some form of 'intervention' and one tentatively approached me, rather sheepishly, to ask if everything was alright. They had huddled together and decided I had cancer and was hiding it. Their kindness was genuine and touching, but I kept up the lie and said there was something, but that I didn't want to talk about it.

I didn't want sympathy. I didn't want people gingerly stepping around me and asking, 'How are you?' all the time. Also, if I had disclosed, I'd then have to tell people later, whether it worked or not; and then the big stigma issue of *how, why, where and when did you get hep C?* It was easier to limit it to a few people. Funnily enough, this was a bit like my drug experimentation – something I went off and did secretly, something that only a very few people knew about. There's a certain perverse enjoyment in secretiveness.

Conversely, I've been quite open with the hemochromatosis – I would tell people about that without any hesitation, often when explaining why I didn't drink alcohol. However, I've been burned a few times with disclosing hep C. It doesn't seem to matter if your drug use and infection was half your lifetime ago and you no longer do the things you did then. Hemochromatosis doesn't invite the same kind of judgment as hep C.

There were a few things in particular that kept me going. One is my dog. Sick or not sick, every day, morning and night, I had to walk her. There would be days we'd be out and I'd be so slow and tired, I'd feel like some sad old man shuffling along with his dog. The benefits of having a pet while on treatment are enormous. If there was one single thing which sustained me, it was my companion kelpie.

Another important element is books and music. I deliberately fostered my interests into obsessions – such as reading everything by a particular author, or buying the collected works of the Grateful Dead. Their music would transport me from whatever negative mind state I might have been in; and their bass player, Phil Lesh, is also a big hep C advocate. I dropped in to his website fairly often during treatment. Lesh has created a wonderful space in which I found a community to share, read, laugh and participate in ([www.philzone.com/hep\\_c-board.html](http://www.philzone.com/hep_c-board.html)).

Following structured daily routines also soothed me, and made me more able to tackle the few really bad days. Routines gave me focus, made me feel like I was in control. I became good at finding milestones. 48 weeks sure can go slow on pegylated Interferon. I'd mark off time – 47 garbage collection days, 46 Herald TV guides, a football season, a birthday. Each day marked off my calendar was a victory. Blood tests and results are another important milestone. Each PCR or liver function test, each pick up from Pharmacy – they all became motivators and helped count down the clock.

In other areas, I loosened up. I smoked a bit of pot most nights and that helped me relax, kept my appetite up and helped me sleep. And it made a lot of bad TV seem entertaining. I've always had

a very healthy diet, but on treatment I ate whatever I could, whenever I could. One night I had my first McDonalds in about 20 years. I thought a Big Mac was at least better than not eating anything; although in retrospect that may not be true. It was disgusting.

The hardest weeks were 30-42. It seemed such a long stretch and I was really over it by then. I didn't take any anti-depressants, but at times I wished for something that could quash my roller-coaster mood swings. I'd snap at just about anything. Things were broken, inanimate objects given names of body parts and functions. The dog would hide and the neighbours recoil as I literally attacked the washing line, wrestled with garden implements or cursed the god of liver disease.

My lowest point on treatment lasted about three days, and happened just over half-way through. It was New Year's Eve and I was too tired to go out to celebrate. I remember thinking bleakly, 'What has become of me? I'm mid 40s, single, it's f-ing NYE and I'm alone'. I couldn't see any light at all. I managed to get it together to call some friends I knew would be having a quiet one for very different reasons, they told me to come over, and we watched dud DVDs for the night.

Forty-eight weeks eventually passed, by the end I looked like an extra in a prisoner of war movie. I wouldn't say I had a post-treatment epiphany or anything like that. There was an element of depression afterwards. In almost every respect the last decade had been built on the premise that I was sick, that I had a disease and that this was my lot in life. Finishing treatment led me to confront a bunch of issues that I'd conveniently masked with hep C. We can allow our illness to define us just as others might define us by our illness.

I now walk down the street looking at people and think I really don't know what is going on in their lives. Behind the scenes they could be dealing with all sorts of terrible stuff. I'm far more tolerant and less quick to judge these days.

Having said that I did see someone recently wearing a t shirt that said *The liver is evil – it must be punished*. I wanted to punch that guy and say, 'Listen here you f-wit, how dare you make light of liver disease!'

At the support group, the outrageously entertaining cast of characters included some not yet on treatment. My advice to them was this: don't immerse yourself in the negative or dwell on the side-effects. Impotency, hair loss and impersonating Travis Bickell in *Taxi Driver* are all manageable, and mostly temporary. Get yourself a support system that includes those who have been through treatment, and others who can offer you support and companionship, not just sympathy and anxiety; and you need to have a laugh.

I've done a lot of things that some might say are courageous or risky. I've hitched and driven across America, travelled through the Middle-East and had a pretty full and interesting life, but nothing has given me a sense of accomplishment like completing 48 weeks of combination treatment. No-one could do it for me. It was up to me to work out how to find a way through. Completing treatment and clearing hep C are two of my proudest achievements.

Walter, 45, lives in the ACT. He has worked in the music industry, and in media and communications in the health sector. He completed 48 weeks of combination therapy and achieved a SVR in November 2008.

Walter continues to be treated for hemochromatosis. Next year he will be implementing "Plan A".

I told the psych I felt the need  
to face the treatment demon.  
He nodded.  
*“It’s your Mount Everest.”*



# *My Mount Everest*

I was watching television one spring night when the awareness that hepatitis C was eating away at my liver came to mind. I had lived with the chronic virus for twenty-two years. The first ten years I was asymptomatic, uneducated and in denial, but gradually fatigue and other symptoms – liver pain and brain fog – kicked in, impacting every area of my life. In time, I learnt more about hep C and the more I learnt the more anxious I became. I saw specialists in various cities over two decades, had two liver biopsies, and tried some alternative therapies and supplements to manage the symptoms.

I was told I was a genotype 2 by an excited specialist in 2002, and if you have to have hep C, geno two is the geno to have. After that, every medical professional I saw upon learning of my genotype, expressed astonishment that I had not yet undergone treatment, because geno two's have the best clearance rate of all the genotypes, and the shortest treatment duration. Whether I was met by encouragement or impatience, not one of them acknowledged the terrified human being sitting before them.

I had heard the horror stories, and was particularly prone to anxiety about health and drug side-effects, so geno two or not, when I turned forty I made a calculated guess about how much my fibrosis (liver scarring) might have progressed since my last biopsy. Though I figured I could well be getting close to cirrhosis, I decided I couldn't face treatment and that I'd rather take my chances with the virus. I led a healthy, liver-friendly lifestyle – no alcohol and a good diet – and felt it was possible I would, even with the significant degree of damage I had sustained, die of something unrelated.

And so, on that night late in 2005, I rehashed the story I had been telling myself for years: treatment might kill me, it might leave me with permanent disability or side-effects, it might not work, I am not brave enough, not strong enough, too sensitive to drugs, too psychologically fragile, too scared. But, just as I was about to come to the usual conclusion, another voice – loud, clear – entered my subconscious and commanded DO IT. I felt a seismic shift as fear gave way to conviction and I decided to obey that voice. I walked into the office of my specialist some weeks later and announced my decision. She smiled and said, 'Good'.

Back in 2004, I had tried treatment, lasting nine days before I stopped, felled by a bacterial infection in the first week (either due to bad luck or a plummeting white blood cell count), panic attacks and endless crying jags (having refused to go on anti-depressants prior to starting as recommended by the clinic). I limped out of the experience, more fearful and doubtful of my ability to withstand it than ever. It was another two years before I tried again, but this time I was resolved. I had spent decades resigned to living with this virus and had finally found some

courage. I had a vision of the life I wanted and it did not include hepatitis C and its burden of fatigue and worry. I was still afraid, and painfully aware of the dangers and possible consequences of treatment, but I was ready to do battle.

As start day approached, I mentally chanted a mantra: 'The drugs are powerful but I am more powerful'. I began the long process of visits to the hospital for screening and preparatory consultations with the nurses. I decided to take the anti-depressants this time, and to see the clinic psychiatrist. We talked about my previous experience, how my terror of both treatment and cirrhosis had dogged me for years. I told the psych I felt the need to face the treatment demon as much for the benefit to my mind as my body. He nodded. "It's your Mount Everest," he said.

Start day arrived. I would self-administer weekly shots of Interferon and take two doses of Ribavirin every day for six months. The drugs affect everybody differently so there was no way of knowing what side-effects would emerge, although some were more predictable than others. Having cleared the decks of my life, I opened the fridge and took out my first shot.

On the day of my first shot, the irony became evident. My hand held the syringe, hesitating and shaking. I did not want to inject myself with a substance that would make me feel bad. It felt like the karmic opposite of shooting heroin: the price of those ancient highs. A few hours later my body started aching, like flu, and I felt an odd indescribable sensation — of being no longer of and in the world in the usual way. It was as if I had entered a twilight zone, a world in which I no longer knew the perimeters and in which I no longer enjoyed the illusion of control.

The first few weeks of treatment were tolerable. I endured the intense 'flu-like symptoms' noted in the brochures after each shot and my energy dropped, but it was bearable with scaled back activity and expectations. Gradually I grew weakened by anaemia caused by Ribavirin, which destroys the production of red blood cells. Despite the anti-depressants, I was often angry and apprehensive.

By week four, I felt like a soldier sleeping with one eye open, as a litany of curious side-effects kicked in. At the same time I had to find a way to relax into the peculiar new normal, a way to make peace with the changes in my body. I had HCV-positive friends and was lucky enough to have one undergoing treatment at the same time but I often felt lonely and isolated. So I hunkered down at home with a host of new rituals, like eating small amounts of food often to reduce the nausea.

Around week seven, nasty gastro-intestinal side-effects hit (I was one of a lucky one-third who get them, according to the drug company) but were helped by massive doses of probiotics. The anaemia made my legs and arms weak. I sometimes had tantrums known as 'Riba rage'. I couldn't tolerate stress at all, and when the 'sides' piled up and overwhelmed me, I broke down muttering 'I can't do it. I can't do it.' The days and hours dragged at times, and I fantasised constantly about the end. I often wondered if I would make it that far. I clawed my way through the days longing for a break from the sides and minor complications, but the Interferon laughed and continued its handiwork.

I had been given the thrilling news that I had cleared the virus following a week four PCR – I was an ‘early responder’. Hepatitis C was undetectable in my bloodstream for the first time in over 20 years, so I was more determined than ever to see it through, but even so some days brought me to despair. One day when the Interferon was kicking my arse, I walked past a boutique and saw a summer dress. I realised that by the time it was warm enough to wear it, treatment would be over. I bought the dress and it hung in my closet for months, a symbol of hope and the future.

I reached the endpoint a wreck but with a strong sense that I’d do it all again for a chance to be free of hepatitis C, and a feeling that I gained something important besides, a new strength of character and confidence in myself. I had spent six months holed up and shut down, a machine whose only purpose was to withstand the drugs and deal with the curve balls they threw me. When I finally faced the prospect of coming back to my life and myself, I felt excited and emotional. I injected my final shot, sat down to dinner, and burst into tears of grief and relief.

Recovery from treatment might be quick and easy for those who breeze through it, but for people like me who come off the battlefield bleeding, it’s more like a lengthy rehabilitation. It was not just physical either. Treatment requires some of us to confront ourselves and our lives so deeply it can facilitate major internal and external change. The very act of choosing to undergo it signalled for me a new age, a decision to claim the life I want.

Six months post-treatment I felt like a new woman. The heavy burden of fatigue I’d lived with for years was gone and I was enjoying the kind of full and busy days I had watched others get through, with envy. I had every reason to be hopeful I’d remained negative and yet that moment of waiting for confirmation was nerve-wracking. ‘Hepatitis C undetected’ at the golden Sustained Viral Response stage sounded like the sweetest words in the English language and hearing them made it all worthwhile.

Meera Atkinson, 45, is a Sydney based writer.

This is an extract from her essay ‘My Mount Everest’ originally published in the Griffith Review edition 17 ‘Staying Alive’ ( Spring 2007).

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*I would like to offer some valuable advice -*  
**Nurture**  
*yourself.*



# Flo's Story

I was a blood donor for many years until one day in 1990, when I received a letter to attend the clinic for further testing. Unfortunately, those tests proved positive for hepatitis C. I remember reading the letter informing me I could no longer donate, thinking, 'What on earth is hep C?'

Little was known about the virus in those days. I was referred to a gastroenterologist who said that they were still working out what it meant for patients. I remember being told that within 20 years I would have deterioration in my health due to liver fibrosis.

I worked out I must have contracted hep C from a blood transfusion I had following surgery in 1978. I decided to change my lifestyle and started using complementary therapies, vitamins and other supplements, but otherwise pretty much ignored the fact that I had the virus.

People didn't tend to talk about these things because of the fear of judgment, and in the 1990s, one did not disclose being hep C positive, except to medical or other staff if requiring a procedure. On one occasion before some surgery, I was told I would be last on the list due to my hep C status.

At the time, I was a little put out, but then accepted this as being something that just happened if you had the virus, but I did start to think that it might be more serious than perhaps I had thought. A psychiatrist I worked with once asked me if I was angry about getting it through a transfusion. I never really felt angry about that. I was lucky in some ways not to have got HIV, and having hep C hadn't really impacted on my life that much.

I've worked full-time in mental health since 1966. In this work environment I have seen many people with mental illness go through hell at times. I have witnessed my clients suffer from judgmental attitudes and poor treatment. I have always been aware that I am very fortunate. It's not hard in this line of work to find someone who is worse off. I'm good at counting my blessings.

I would never disclose to my clients – that would not be professional. But years ago, I saw the mother of a teenager who'd just been diagnosed with hep C and the mother was extremely worried about this. By this time, I had lived a healthy active life for decades, with no signs of hep C symptoms; except for a slightly abnormal liver function. So, I was able to confidently reassure her that the diagnosis was not a death sentence and that her daughter would be fine if she pursued a healthy lifestyle<sup>2</sup> e.g. no alcohol or drugs. It's funny, another time a client got very paranoid that I was putting on gloves to give him an injection! I couldn't say, 'If only you knew I was doing this for your benefit'.

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<sup>2</sup> Whilst a healthy lifestyle can help people live well with hep C and reduce the likelihood of disease progression, it isn't a guarantee that it won't occur.

Even though I used complementary medicines, I've always been aware of the need to maintain contact with the liver clinic. Seven years ago I was involved in a five-year research project. This involved a full medical history, medications both prescribed and complementary, monthly blood tests, and a liver biopsy at commencement and completion. The result of the biopsy at commencement was fibrosis 1, but at the completion it was fibrosis 2-3, which was a complete surprise to my gastroenterologist and me. He strongly encouraged me then to consider treatment. I reluctantly agreed to an appointment with a clinical nurse consultant (CNC).

In the meantime, I acquired as much information as was available on treatment side-effects, research results for genotype 1 and the response rate. The more I learned, the less I wanted to do treatment. My GP described it like having the flu for a year. I have always had a busy life gardening, exercising, socialising and I just thought, 'Flu for a year! I really don't need that in my life'. Apart from anything else, I was well. The biopsy may have said the fibrosis had increased, but I still didn't have any serious symptoms. I had suffered arthritis and hypertension, but these run in the family and are not related to hep C.

However, about the same time my brother passed away after developing secondary liver cancer, and I had a sister-in-law who had hepatitis B and then went on to develop liver cancer also. Seeing how bad that was for them – well, there was just no way I wanted to go through that.

A close friend attended that first appointment with me to discuss treatment, as we knew that due to my negative attitude, I would not take in much of the information. It helped to have someone to discuss it with afterwards and to help with my decision making. After umming and ahing, for three to six months, I made the decision to start. I thought to myself, 'Well, I'm definitely going to have a holiday first!' So I went off to Vietnam for October and agreed to start in November.

The day I was due to start, I was half an hour late for my appointment with my CNC. When I got there she said she had thought I wasn't going to turn up. I just laughed. Once I commit to something, I stick to it. But I was still unsure about how it might affect me. I remember telling her that I planned to undertake some renovations to my house at the same time as I did treatment. She just looked at me and said, 'Have you got rocks in your head?'

Workwise, I sat down with the my director and my team leader, and told them I would like the first month of my treatment off, but beyond that, I really didn't know how treatment was going to affect me. They were supportive about this I think, because I have worked in the team for over ten years, they knew I wouldn't take sick leave unless I really needed it. They have always showed me respect, and I showed it to them by keeping them in the loop. I planned to work full time during the remaining 44 weeks.

Treatment commenced a month before my 66th birthday! The first few weeks were relatively symptom-free, except for occasional nausea, indigestion and increased arthritic pain. These I chose to ignore and continued on with my walking, exercising and gardening. If anything, I experienced a bit of a high when I first started.

Unfortunately then a disc in my back herniated, pinching two nerves, and I was unable to return to work for four months. My back could have gone at any time – there was no connection between this and treatment. However, it made things more difficult, especially as I had to rely on my daughter to come and cook for me. I grew up in a family of nine, and if you were sick

when you were a kid, well, you just learned to look after yourself until you got better. I found it hard to be dependent even on my daughter to look after me and during this time I felt guilty taking so much time off work. So I did get a bit down. But I continued with treatment and the guilt had a positive side, as it helped me build my determination to get better.

On return to full-time work, I found myself very tired at the end of a shift. I was breathless climbing stairs, walking and doing any form of exercise. I managed to continue, and surprisingly, each late night weekend shift I did was quiet with very few of the usual call-outs or emergencies. I had the sense that someone, somewhere, was looking after me!

If I felt upset by anything at work it never came out at the time, I'd be more likely to just be a little bit teary afterwards. I remember taking a call about a client who had a different form of medication-induced low white blood cell count. The alarmed caller said, 'This client is a code red. His neutrophils are only 1.8'. I just laughed. At the time, mine were 0.7.

Working was a distraction from the side-effects. However, I didn't listen to my body, then became sick with bronchitis and ended up with a chronic cough which didn't clear up until the end of treatment. Looking back, I can see it was madness to go back to aqua-fitness before I had fully recovered from the bronchitis, but there is a small group of us have been exercising together for 30 years. These friendships are important too! You've got to also have a life when you're doing treatment.

In hindsight, I was lucky not to have too bad a time from side-effects. I certainly didn't get a lot of the things they talk about in the hep C books. My hair got thinner, so I just kept it short. I lost a bit of weight. I think I coped better with treatment at 66 than I would have at 36 – when you are older you expect to feel a bit more tired.

I have been blessed to have a caring family, good friends, and an excellent treatment team. My CNC was very supportive; I got a lot from her. Even though my blood test results were looking doubtful at one stage, she kept telling me I was doing well, and was always positive. I have very good work colleagues, they continued to include me in social things even when I was off sick, they came and took me out when my back injury put me in a wheelchair. All of this helped me cope with treatment.

I would like to offer some valuable advice. Nurture yourself. Accept help from your family and friends ... graciously. Pay someone to do the housework and heavy gardening if necessary. Listen to your body. If you haven't started treatment yet, get yourself as fit and healthy as you can before you start, use complementary medicine. And don't be too stubborn!

Five months post-treatment, I am slowly returning to my former energy, socialising at night without wilting, spending a whole day window shopping. At three months testing, I was clear of the virus. I am confident I will be a 'sustained responder'. Don't ask me how I know that – I just do.

Flo Logan, 67, works full time in the mental health field.  
She completed 48 weeks of combination therapy in 2008.

**Postscript** : Six months after she completed treatment, Flo found out that she had relapsed. She may explore re-treatment.

This is how I approach all of life's challenges -  
**I give them everything I've got.**



# *Making a Difference*

When I was 18, I fell in love with a man who made me laugh all the time. We were good mates, a great match. We got married when I was 21 and later had two sons. After the honeymoon stage, when he had been drinking heavily, my husband started to beat me up.

I didn't know he was using heroin during our marriage; he used to sneak out of the house to have his hits. One day I caught him at a friend's house shooting up. He told me he'd stopped.

People often question why I stayed in an abusive relationship. It's not as simple as stay or go. At first I was in love with him, thought I could help him change. In those days in small town South Australia, no-one talked openly about domestic violence; it was a hidden subject. Women were looked down upon if they were battered by their husbands. I thought it was my fault, I thought I could handle it. One or two friends listened, and gave me a place to stay if I ever had to get out of the house.

A long time after the laughter stopped, I came to realise that I couldn't help him. I'd leave, he'd promise me that he had changed, and I'd go back for the sake of the kids. Of course, he hadn't changed and his violence continued. One summer in the late 80s, I left town at midnight with the kids and never went back.

Ten years later, I was diagnosed with hepatitis C.

I had never injected drugs, shared my toothbrush/razors or had any transfusions, transplants or tattoos. Hep C was the direct result of an exchange of blood between me and my ex. It's a legacy of his violence.

I did treatment in February 2004 for 24 weeks.

Almost immediately after the first shot, I was weak with flu-like symptoms and various aches and pains. A rash developed. I was lethargic and disorientated. I wasn't working at the time, so I tried to rest as much as possible, and this made it easier. I read a lot of books – actually, re-reading quite a few pages as I lost concentration and forgot what I was reading!

I had organised education and support for my sons before I started treatment, so they knew what to expect. We went through a counselling program. Having had a previous history of depression, I was also on antidepressants to help me manage the side-effects.

I remember one bad day I had to call my son at work, and ask him to come and help, because I was totally confused, walking round in circles at home, disorientated. I thought I was going mad and I just panicked. He came home, calmed me down, and I was able to get focused again and carry on. Anxiety passes eventually and after a while you learn to cope.

You have to do what it takes to get through this treatment. I found that taking it day by day, going with the flow, made it easier. Writing in a treatment journal helped keep things in perspective.

I became quite a hermit in those days, but hey, I did go out now and then to a family get-together or special function, although it was hard to try and be socially 'normal'. There was a group of friends and family that I couldn't tell I was hep C positive, let alone on treatment, which was hard. I didn't know some of them well enough at that stage, and I was worried they might assume things about me that weren't true.

I didn't have anyone around me with hep C then, nor did I know anyone who had done treatment. My doctors/specialists had never informed me that the Hep C Council existed or that they held support groups. Fortunately, I did have another great group of friends who understood what I was going through and they helped.

The virus was undetectable during treatment. When it got to the final month, that last injection, I can't tell you what a relief it was to finish. To know I'd done it.

Some months later, I went to the specialist for another reason, and out of the blue, he said, 'Oh yes and the virus is back'. My world came crashing down. I remember walking out of his office, crying, hiding my face from the people I passed in the hospital corridors. I reached the car park, got in my car and just sat there for a long time.

I wouldn't want to put anyone off though. Most people with genotype 3 do clear; it just happened that I didn't.

When the shock wore off, I became very angry that I had relapsed, and that I was back to living with the virus. I approached a lawyer, handed over all my documents and went for a victim of crime compensation claim. I wrote it all down – the whole story – just emptied my head of the memories. Three long years later, I won. That's all I needed, recognition that I had contracted hepatitis C from domestic violence. This is how I approach all of life's challenges, I give them everything I've got.

After that, I just got sick of 'hiding' my status, and now I just don't care anymore. I would rather tell a person what hep C is, and educate them, than not tell because I'm worried that they might think I've been a drug user. Anyway, if someone was a drug user, so what? No big deal, each to their own. Everyone has skeletons in their closets, no-one can point a finger and put another person down. None of us deserves this virus however we live.

In early 2006, my son, a self-taught website designer, would see me sitting at the computer for hours on end, reading, researching information and chatting to others from overseas. One day he said, 'Mum, come and look at this', and showed me his design for an Australian Hepatitis C Support (AHCS) forum. I was speechless. Later that year we launched the website.

A couple of months went by and I found the 'Hep C Australasia' site, run by the hepatitis organisations. So, I joined, and I now have good friendships with the members of that forum. I make sure information is shared between our two sites. It is important that I work with the hepatitis organisations; we're all in this together for the same reasons.

I'm now getting ready for re-treatment – well, women have babies, it hurts like hell, but they do it again don't they? I know what I'm in for. I'm not going into it uninformed and scared this time. I'm a strong person, always have been. I believe that I can deal with whatever life throws at me, and if I cannot get rid of the virus the second time, then I will just learn more on how best to live with it.

I found the courage to do treatment again, partly from the members of my forums who were undergoing treatment and clearing, and partly because I couldn't see a better option becoming available within the next couple of years. I am not getting any younger. I believe my odds of clearing get lesser as time goes by.

A valuable (medically trained) member of my forums has been researching insulin resistance for years, and she gave me studies that prove sustained viral response (SVR) is unlikely to happen if you are insulin resistant. I took this information to my specialist, got tested, and he agreed. I've had abnormal glucose levels for years and I was told I was 'pre-diabetic'. I'm sure this is why I relapsed the first time. So, with a higher dose of Ribavirin and my insulin resistance under control, hopefully I will get that SVR!

If you have an illness, you can't rely on others to get all the information to you, you have to find it yourself. I have good research skills, and if I can't find information, I will find someone who can. Listening and reading how other people cope is a must. By sharing, we learn and support each other. Through the forums, I want to provide an outlet for other people with hep C. I don't want anyone to be living with this disease alone.

I'm not thinking too deeply about re-treatment. I try to stay positive and just focus on the future. I've developed a lot of patience on my journey so far. If I fail to clear, at least I will have given my liver a break and possibly reversed some of the fibrosis, maybe even back to stage 1, who knows?

It seems to me that I was infected with the virus for a reason. It has led me to my purpose in life, which is to help other people. Even if I clear after re-treatment, I will still be running the forums, looking after the website, and doing my best to support all the others that come along.

Linda McInnes, 48, set up AHCS - Australian Hepatitis C Support ([www.hepcaustralia.com.au](http://www.hepcaustralia.com.au)) in July 2006.

In November 2009 she will begin 24-48 weeks of re-treatment using combination therapy.



The baobab tree has its roots in Africa.

It thrives despite adverse conditions,  
providing shelter, succour, resources  
and meaning to its people.

# Out of Africa

My journey begins in Africa 43 years ago when I was born. I was a real weakling growing up and the hospital was like my second home. Back then a nurse would fill up one injection to share between two, three or more people. I suffered whooping cough, constant nosebleeds and a ruptured appendix requiring surgery. I told myself at a very young age that I was going to be strong, that illness would never beat me. When I recovered, I became a competitive athlete. I did throws, sprints, jumps and long distance running.

I came from a large family where sharing was the order of the day. Uncles, aunts, cousins would forget their toothbrushes or razors and just grab anyone's from the cupboard. Time passed, I got married and had my babies in hospital. I nursed my mother as she battled cervical cancer. After her death, waiting in the shadows was the AIDS pandemic.

But you know every bad story has a good side. Before all these troubles started, I call it 'Before Mugabe's Madness', Zimbabwe was referred to as the 'Switzerland of Africa'. Harare was called the sunshine city, voted as the cleanest city in Africa. Zimbabweans are very peaceful people so there was a lot of migration there. Tourism was flourishing.

From 1991 to 1999 our money had buying power, we had a lot of disposable income and were in the middle class. We were very happy. We had built a five-bedroom house. I miss that house! My heart will always be home. One day I will return and have my organic vegetables, chickens and fruit, and watch the sun set over the plains. All of the things I took for granted before the madness began and I was forced to leave.

Settling in to Wellington, New Zealand, in 2001, I had no choice but to work anywhere. I worked as a handyman, an industrial cleaner, laundry worker, dishwasher, and nurse's aid. I did any job to survive. Mostly these jobs involved very hard physical work. In two years, I changed jobs six times and moved house six times. Back home I had moved twice and kept one job for 10 years.

In Africa we have the baobab tree. It thrives despite the adverse conditions, and provides shelter, succor, resources and meaning to its people. The baobab is an African symbol of endurance, conservation, ingenuity, creativity and dialogue. Like the baobab, my experiences have made me strong.

In 2007 I was working as a health promoter in the area of HIV and AIDS. I did a lot of reading about infections and viruses, and one day I bumped into the hepatitis C virus. I insisted on getting the test after reading about how hospital conditions in Africa could put people at risk.

When I got the result, the nurse was very sorry to be delivering this message to me. I was not sorry to get that message from her. I understood from the beginning that there were two results out of every test. School exams it's a pass or a fail. Blood tests a negative or a positive.

So there I was, with my positive result calm as ever, laughing off my fears, comforting the nurse instead of the nurse comforting me.

I spent a few weeks running around like a headless chicken trying to get information and just getting confused. Mostly, I just didn't understand the medical terms or what having hep C meant.

It's painful to know that Wellington is the capital city, but there is nowhere where one can go and talk to someone else with hep C. Other places like Auckland and Christchurch have organisations that help; talking on the phone when I was in that situation was not adequate.

I went through a lot of emotions. The 'why me?' started. I was angry, for not knowing how I caught hep C, for not knowing how long I had the virus. I was fearful of the condition my liver might be in and angry for the 20 years I spent drinking like a fish, almost drinking myself to the grave. I began to fear death and wish I had done this and that in life.

I then moved to acceptance. Yes I had it, so what? This disease happens to affect human beings and I am a human being who happens to be infected. I had to accept, and after that, do something about it. Within that first month of my diagnosis, my journey took a different turn. I found help in the form of a computer. I googled and found the Hep C Australasia ([www.hepcaustralasia.org.au](http://www.hepcaustralasia.org.au)) support site.

I started to read information from the site. I met a lot of good people online, and got help. I started asking questions of my doctors. I demanded to see a specialist; more blood tests followed. Finding out that I was genotype 1b was another blow. There were no real answers for me, so armed with knowledge I got from the website, I demanded treatment.

I think because the treatment is very expensive, they don't seem to go around encouraging people to do it. Stigma could be another issue – 'Hey you got it from Africa your homeland, why make Kiwis pay for your medication?' But that is just my speculation, as after a short time treatment was granted.

I have been very open about my hep C status. I got the courage to be open from the work that I do. I knew I was in the same situation as anyone who has just got any diagnosis of blood-borne virus. My work is about de-stigmatising HIV and AIDS. I did not want to stigmatise hep C, or do any self-stigma. I'm proud that many people that know I am infected are now informed about hep C.

I started treatment in January 2008. The side-effects were not that bad, I managed them. I have fought many battles in my life, poverty, hunger, wars, and discrimination. I don't go down easily. I do a lot of comparing; if I was living in Zimbabwe I wouldn't even get treatment, so the side-effects were minimised by the gratitude I had for being given a chance.

From the treatment information I'd read, I was most worried about how I was going to manage my four-year-old son. I didn't want to be too weak to look after my baby. A tired mum is what he didn't need. At the start I slept a lot. I had to stop this habit when he came into the bedroom and said, 'Mummy why are you always sleeping?' I thought he was too young to notice, but they notice! After that I would stretch out on my lazyboy and for my son, mummy was in the lounge not just sleeping.

Most of the side-effects were headaches, insomnia and itching. I scratched so much at one point I thought I would end up looking like a hyena. When the itching stopped in one place on my body, it would move to another. I got tired of all the creams I got from my doctor that were not working and discovered my own concoction of camphor cream mixed with Vaseline. This helped.

I worked full-time for 10 months of treatment. My husband helped a lot more around the house, but emotionally it was a hard time. I felt lonely. I used the Hep C Australasia website leaving messages on the discussion boards, and phoned home to talk to my siblings regularly.

I think being an athlete in the past helped me with treatment. If I was a building, I would say I had a good foundation. Athletes train their body and mind so I was strong in both. Before I started, I thought if there is a 50% chance of clearing the virus with treatment, then I will be in the 50%. When

it started, my mindset was about competing. As with any athlete, it's all about beating an opponent and coming first. At the end I came first, the side-effects second. I won!

Some way into treatment, the Zimbabwe elections were on. I watched in horror at what started to unfold, and stayed in touch with my family regularly, fearing it would suddenly not be possible to do so.

We formed a 'Save Zimbabwe' group with very active members who would write press releases or meet government officials. I tried to lobby by writing emails to international bodies. They often don't bother to reply, but I wrote everywhere anyway. It was stress relief and was my way of dealing with the treatment insomnia. Going to bed at 3am after writing an email to United Nations, I felt good. During this time, nothing mattered more than change in my country. I concentrated on Zimbabwe and forgot about the side-effects and the treatment.

With two months left, I went back to Harare to visit family taking Interferon and Ribavirin with me. I wanted to see for myself how people were coping. The situation was terrible. I saw many people with severe malnutrition, sick children with no-one to care for them, hospitals with no staff and no medication, schools closed up, and people on the streets selling anything, anything they could. You had to carry wads of cash, millions of dollars that wouldn't even buy a loaf of bread. It was absolute chaos.

I wanted to help, so I collected clothes to distribute to people with HIV and AIDS. I also collected pants to give to women in prison. I attended one of the distribution ceremonies at a prison in Harare. Those images of suffering and starvation will be with me forever.

I wasn't sad all the time. I do have some happy memories of the trip back. We had family parties, relatives visiting, and I worked on my music (I play traditional instruments, marimba and mbira), but when I returned to Wellington, I wasn't normal. Who could be normal after that? I was depressed by what I saw in the prisons, homes and on the streets more than by the treatment side-effects.

I finished treatment mid-December 2008. Now I'm waiting for the result. Waiting for results and not knowing whether I cleared is painful.

In my work I deliver education. I think in terms of awareness; hep C is more dangerous than HIV and AIDS. People will continue to catch it because no-one knows it's out there. It's a slow, silent killer. Everyone knows the words HIV and AIDS but a lot of people don't know the words hepatitis C. Many of my relatives have it and some have died from it.

If you have got it, and you continue drinking, you are moving closer to your creator. You can walk into a bar anywhere in the world and find people drinking. If you ask them if they have been tested for hep C, I bet you out of 100, you will be lucky to find two people who know their status. I have heard a lot of people dying of liver disease, and I suspect it's undiagnosed hep C.

I'd say to anyone out there, go get tested! Find out your hep C status. Knowing could give you the chance to change your lifestyle, and might mean you can get treatment in time to save your liver.

Hep C affects people from anywhere in the world. It just so happened to affect me.

Fungisai Foto, 43, is a Shona woman who grew up in Zimbabwe, and now lives in Wellington, New Zealand. She has four children aged 22, 16, 11 & 5 and works full-time as an HIV and AIDS educator with the African community. Fungisai completed 48 weeks of combination therapy in 2008 and was clear of the virus at her six months post-treatment test.



**The stigma around hep C is closely connected to the stigma around drug use.**

**You rarely hear people talk about how they contracted it.**

**6**

# Giving it a Go

I remember back in the 1990s sitting in front of a journalist from a TV current affairs program doing an interview about hep C. He seemed okay at first, but when it became evident that I had contracted hep C from drug use, he changed, and suddenly it wasn't a pleasant place to be. He started to imply that people who use drugs bring things upon themselves, and he was questioning why anyone else should care what happens to them. In the end, I got so uncomfortable I asked the producer to stop and find someone else to interview.

In relation to how the public perceives people who use drugs, I don't think things have changed that much since then. There's been a gradual improvement in the level of acceptance of NSPs (Needle and Syringe exchange Programs), but whenever there are media reports that refer to drug users, it's always some sad story of neglect or despair; about someone not properly looking after their children, or being involved in some sort of crime. These are very powerful portraits of people who use drugs and they affect the way people think about drug use and people who have used or are using drugs. In the UK, there was a recent campaign that helped raise public awareness called 'Nice People use Drugs' I think this sort of thing can help, because it focuses discussion away from condemning drug users as inherently bad, and acknowledges that recreational drugs can be pleasurable, and for a lot of people they are not a drama.

The stigma around hep C is closely connected to the stigma around drug use. You rarely hear people talk about how they contracted it. Mostly you'll get people saying that how they got it isn't relevant, and then they'll deflect the conversation somewhere else. I don't have a problem with anyone knowing that I have hep C, but I do have an issue with having to tell people that I have used hard drugs. These days, if I was to go face-to-face with a journalist, I might be just as likely to tell them that I got hep C from my tattoos! Having hep C doesn't mean you have to waive your right to privacy about your past. In reality, I'd tell the reporter that it doesn't matter how I caught it.

I had hep C for 22 years before I did combination therapy in 2005 for 48 weeks. My decision to do treatment was really more about getting rid of the virus to avoid having the whole disclosure issue in dating people than having a cirrhotic liver or anything like that. I've had three biopsies, and so far have only sustained moderate damage. Most of the damage seems to have developed over the last five years, and I started to think that in another five years it could be worse again, so it felt like time to think about treatment again. Working in the hep C field, I'd seen the increased cure rates, and the treatment itself seemed to have improved somewhat; side-effects seemed to be less of a drama or maybe just better managed.

I think I approached treatment with the sense that I wouldn't pay too much attention to the 'sides'. I'm the sort of person to put my head down and grit things out – just basically get through it. I told myself things like, 'I'm doing this treatment, it'll take a year, and I'm not going to worry too much about what happens, I'm just going to do it!'

I was a model patient in lots of ways. The virus was undetectable within the first four weeks and I didn't get any flu-like symptoms post shot or any headaches or anything; the worst side-effect was constant itching. I remember one morning at 2am, I got out of bed and drove into work because

I knew that there was some aloe vera gel in the office first aid kit, and I knew I wouldn't sleep until the itching stopped. It didn't work! I treated the itching with a few different things before I discovered taking daily Pinetarsol baths, which helped.

I think for me, overall, the sides were quite subtle; they tended to creep up without me really noticing. I worked full time for the 48 weeks, and I must have got my needs for mental stimulation met, as I became quite reclusive and spent most weekends alone. I got into a routine: take the pills, go to work, take the pills, go to bed and every Friday, have the shot. In a bizarre way, that weekly shot became a bit like a little friend. Just about every Friday night for a year, there was just it and me. Each one done was a step closer to finishing.

I didn't anticipate that during treatment I would spend so much time alone cocooning, or that I wouldn't do the things I usually love to do, like spending time with my daughter or hitting the beach to check out the surf. Some weekends towards the end of treatment, I wouldn't leave the flat, sometimes not even leaving my bedroom!

Like a lot of people, I didn't really talk to the nurse at the clinic about what was going on. I just put a brave face on it and coped. I was worried that if I talked about the sides too much they might reduce my dose and I wanted to try with full dose and do the 48 weeks, give it the best go I could. On reflection, it might be that antidepressants could have helped. Maybe if I had taken them, I wouldn't have isolated so much.

There were a few challenging times; they seemed to happen when I was out in uncharted territory, away from the comfort of my living room. I remember I went on a surfing holiday with my brother, just the two of us, and parts of that were tough. There was an expectation that I would be sociable, which I wasn't. And we drove up the coast with only two CDs in the car, both of which were crap, so it was a case of sleeping a lot or pretending to sleep a lot.

I also did a three-week sail to Hobart as part of a crew living in cramped quarters on an old square-rigger tall ship, looking after 10 crew members in my watch. The sail was an exhilarating experience and there was a real sense of achievement when we were back home, but being on the boat, it felt like a very public space to be on hep C treatment. I had a funny emotional moment one day trying to find a quiet place to do my shot where I wouldn't be disturbed. It reminded me of the reaction I once had a couple of days after falling off a motorbike – sort of a delayed shock, 'losing control' thing. I got really choked up and literally couldn't talk. Apart from the ship's doctor and one of the officers, no one else knew I was on treatment. The loss of privacy was the difficult thing, not necessarily the treatment side-effects.

It goes back to this whole thing about wanting some control over what people know about my life. Doing treatment was something I didn't tell all of my friends about. Like anyone, I have friends from different parts of my life, they are all supportive but they have varying levels of closeness. For some, it was too much of a drama to talk about treatment, because that would mean talking about how I got hep C, dealing with their reactions, beliefs and views about drug use, and then possibly renegotiating a few relationships afterwards.

I do still have some fond memories of my year with Interferon. It coincided with a time of change. I had decided towards the end of the treatment to take steps to find a relationship. The decision to even try treatment was linked to an idea that if I got hep C out of the way, it might be easier to find someone. I'd been single, living alone, for many years, and had focused myself on other things. I'd wanted to keep things simple as I had my daughter and didn't want a stepmother/stepdaughter clash, and there was baggage from my younger years. I decided that since my daughter had grown up and was in high school, time was right for me to move on.

Spending all this time on the weekends alone at home, I started to chat to people online. I was using the time, I guess, to start meeting people via dating sites. I was a bit like a kid in a candy store, but after a while realised I wanted to meet someone who lived near my local area and who I could better relate to. Not long after treatment had finished, I met my now wife. It's odd to think I was living alone for all those years, and spending so much time alone on treatment, and when I did reach out, I met someone who had been living literally just around the corner all this time! It capped the year off wonderfully.

I got my end-of-treatment results over the phone. The specialist rang me at work and told me I had relapsed. I sat there and again, started to choke up a bit, got teary for about a minute and then continued working. I started to tell people gradually, made a few calls, told a few people at work. It was a shock, and a bit of a slap in the face, but after a few days I was over it. I thought, oh well at least I gave it a shot.

It's now been three years, and I'm probably going to do re-treatment with one of the new drugs, and have been accepted for a trial with MK 7009. It could be different this time around. Just because it wasn't bad the first time doesn't mean I'm off the hook. I do want to get rid of the virus, really only because the older you get the more you value good health. I'm not doing any special planning for re-treatment. My wife, Michelle, has been involved in the process, and I've made sure that I have a bit of leave if I need to take it. I will be more open about side-effects this time. I think the downside of toughing it out last time was that I isolated myself a lot, and I have learned since doing treatment that relationships are pretty good!

I would definitely encourage people to give it a go. Not to go in blindly, but at least to try, you don't have anything to lose. I wouldn't recommend people hide things from their treatment team, they are there to help! The potential rewards of treatment far outweigh sitting back and doing nothing, and the earlier you do it, the better your chances of clearing. People's perceptions of treatment are sometimes out of wack with the reality. I'd say definitely, give it a go.

Paul Harvey, 52, worked on high-rise construction sites for many years, before the birth of his daughter and vertigo forced a rethink, and he studied welfare work. Paul has worked for the NSW Hep C Council for 15 years, where he is responsible for The Hep C Review magazine, [www.hepc.org.au](http://www.hepc.org.au) and numerous information resources. He is also a moderator of the [www.hepcaustralasia.org.au](http://www.hepcaustralasia.org.au) online peer support forum. He is still an avid surfer.



Many years ago somebody gave me  
'A Fortunate Life' to read,  
and I think, just like Bert Facey,  
I've had a fortunate life.

# *A Fortunate Life*

I grew up in the western suburbs of Melbourne in the 1970s. It was rare for anyone to not use drugs. I got serious about them by the age of 17, about the same time that I got into my first long term relationship and not long before my first child was born. My partner and I both loved speed and the fast life. Despite a brief hiatus when the kids were born, I would hate to think of the amount of money we spent on it.

When we separated, she ran interstate with my kids and I didn't have much contact with them. Add a serious industrial accident to that, and I really fell apart. But when I got the feel of the steel and some speed in my veins, I felt bloody magnificent. So, for more years than I care to dwell on, I was a rogue idiot, shooting speed and staying up all night talking shit about how great my life was with the other losers.

There were a few things that made me stop. One was seeing my ex again, seeing what the drugs had done to her, and I guess, getting a reflection of myself. Another was seeing my kids after so long and realising that I had to be a better man for their sakes. Then there was my grandmother. She had taken me in and it would have broken her heart to know what I was doing to myself. I guess I had an epiphany of sorts, realised what an idiot I was and just stopped. I have never looked back.

The lifestyle of down and dirty behind me, I was having some repair work done on my body from my industrial accident, when there was a blood splash during surgery. As a result of this I was tested, and hep C came up a winner. My warm-hearted surgeon came in, saw me and said, 'You have tested positive for hepatitis, and you will have no feeling down one side of your arm because I accidentally cut a nerve during surgery, but you'll be okay'. Then he just walked away.

About a year later I saw a gastroenterologist. Interferon monotherapy treatment was discussed. He was a blunt sort of bloke and said that he didn't think I could take the treatment at the time, that my lifestyle wouldn't support it. I wasn't using any more, but I was drinking and partying, and had a lot of stress going on. He suggested I wait, so I did.

Over the years I looked into treatment two other times. Once I was advised that I wasn't eligible because my ALT readings weren't high enough, and another time I was told that I had to have a liver biopsy before having treatment. I read the literature on that, and when I got to the bit where it said, 'take out a small piece of the liver' I thought, nah, bugger that!

I lived in denial for a while. I still thought of treatment from time to time but always thought I hadn't the time to do it, and I didn't think my lifestyle would support it working away from home up to 35 days in a row, with no support.

But I was playing with my ten-year-old daughter one day and I just suddenly thought, 'I have to do my best to stay around for this little one'. My wife and I are 'older' parents, she is over 50 and I'm in my late 40s. So, when I was working 12-hour days and nights in mining, I decided that I had to find the time and the lifestyle for treatment.

The nurses at the clinic where I was treated were good, but they told me to take six months off work. Who can do that? So, thinking that I am indestructible, I dived into the treatment head first, with no sick leave and no chance of a break if things went belly up. I started the new financial year in 2008 sticking needles in myself again, only this time to try and repair the damage.

The mining life is a hard, unforgiving one and any visible handicap is seen as a weakness. All of the big sites are full of cliques depending on where you come from and what you do, and if you don't belong to one, as I don't, it is easy to be ostracised. So I did my treatment away from those I love, in a hole in the ground, with nobody around who knew what I was doing.

I was lucky that for most of the day, I had minimal interaction with others. There was just a 100 tonne bulldozer and me ripping up a pit while listening to the ABC talkback radio. Whether you are on days or nights, you are pretty much busy from 4am till 7pm so there's not much time off the job. However, I did have time to think about what was happening to me, and there was a lot. My teeth hummed, I got ear infections, toothaches I thought were going to send me insane, mouth abscesses, and flu for the first time in my life. I was wiped out. I found a new word: fatigue. I did not feel good. Towards the end of treatment, when I thought I couldn't take any more, a mate of mine whose wife had chronic fatigue, put me on to an amino acid called musashi creatine recovery stack. It only cost about \$30 for a month's supply and it made a huge difference. I was still sick, but I got through my days a lot better.

I was working in a small crew of blokes mainly in their early 20s, and despite them not knowing what was going on, I did find some support there. I don't know if it's because I was the 'old bloke' or not, but the young fellas got real worried about me and thought I was dying of cancer or something. When my weight dropped from 86 kilos to 68 rather quickly, I remember them getting together and one of them saying, 'Look mate, you need to see a doctor'. I told him, 'Mate, I'm seeing one, and something is wiping out my white blood cells', and he told me "well mate, see a better doctor, 'cause your one's no good".

As well as physical illness, I got the mental yips. I would get very emotional, I became my wife for a while, crying at songs or stories on the radio. I was lucky that nobody could see me because I could also get so angry that I was dangerous. There were times I felt abandoned because I was out working by myself, while my wife was enjoying the good life on the beach. I would break down regularly, but I also had the strength of mind and my beautiful wife to remind me that it was just the side-effects of the treatment drugs, and that I would eventually be all right. I love my family, wife, kids, brothers, sisters, parents, the whole lot, and I thought about them often, and about my part in their lives during the bad times, that got me through. That and knowing that I would be all right when the treatment stopped. I told myself it wasn't permanent. Anybody who has had adversity in their lives will find it easier to get through, cause you already know when things are down, that they can only get better.

My wife is the only non-medical person that knows I have hep C. I have never told any of my other family, and I don't think that I want any of them to know. It's complicated, but I don't want to let them down and I am a bit ashamed of the disease and how I got it. For my older kids, their mother was a drug user and I was a light they looked up to. I don't want to shatter that. And I don't want any of my kids to use drugs. I think that they look at me as a stronger person (still even with my many other weaknesses!) and it keeps them off drugs.

I think that a lot of the trouble with drugs is that people who use them don't know that they are dependent. The drugs are often a crutch for other things that are wrong; so you live in denial. When I was a junkie, I would never have called myself a junkie. When I realised I was one, I stopped. I realised I've just got an addictive personality and I need to be careful. After my accident I took serious painkillers regularly for years, till I realised I was eating them as a matter of routine. Then

I stopped them too. My body aches, I walk a bit funny in the colder times, but I've got used to it and I don't dwell on it. However, that doesn't stop me turning into a sook and grabbing aspirin when I have a toothache.

I have not been part of the drug culture for many years now and when not at work, I live a good life, but whenever I go back home I see the bad side of it. Not that I would have used them, but I think safe injecting houses are one of the best things that I have ever heard of. I have picked up syringes in school playgrounds as well as on beaches, and I will call other drug users on this. I'd say the chances are that you are carrying a disease like mine, don't leave things laying around for a child to get it too. You might say your drug use is a sickness, but you have to come to your own realisation to get off drugs or stay on them.

I don't think my disease has affected me that much in my life. Every now and again I feel my liver twinge a bit. I've been a bit yellow when I've misbehaved, but I'm rarely flat, sick, or weak. I've just got this thing that I don't want inside of me. The only time that it's a real issue is when I sometimes have gone back to Melbourne and got on the grog with my brothers. I don't drink much now, maybe a light one, when I pull my boots off at the end of the day.

After the treatment was over I was back feeling better than ever. Having been a rapid responder, I had very high hopes of a good result. I was at work at the start of five weeks away from my family again when I phoned the clinic for my results. Talk about floored. The virus was back. But hey, it only knocked me down the once, already I have an appointment with the doctors to talk about other options and any advances in treatment in the 12 months since I began it. I was sick and tired for six months, would I do it again if I knew how sick I was going to be? Yes. That's why I'm talking to the doctors again. If there's a chance for a cure, I would be silly not to go for it. So would you.

I have had more tragedies, more highs and lows in my life than most people, and I am lucky that through it all, I know myself pretty well. I came from the low end of town and I lived with that mindset for a long time. Now I work hard for a good pay that helps me look after my wife and daughter and they live a great life in a house on the beach.

Many years ago somebody gave me A.B. Facey's 'A Fortunate Life' to read, and I think, just like Bert Facey, I've had a fortunate life, and unlike a lot of my mates, I'm glad I'm still here to talk about it.

BJ, 46, works in mining and civil construction and is currently located in a remote area in the Northern Territory.

I KNEW I DIDN'T WANT TO JUST  
SIT AND MOPE . . . ART FORMED A BIG PART  
OF MY ROAD TO RECOVERY.



# Nicky's Vision

I found drugs at the same time as I found black history, which was part of studying for a welfare diploma. I didn't know that much about my culture, where I'd come from, or my identity before this. All of a sudden I could see how my own family had been through history. I lost my mother when I was 13 from a drug overdose and there is a lot of drug, alcohol and violence in the community. I could see there were reasons for this that I'd never realised. I started to reflect a lot. Unfortunately, at the same time I was studying, I was introduced to drugs as well. I began to question why I was studying welfare when I had so many problems to sort out from my background. I think in a lot of ways I used drugs to medicate myself.

Speed was my drug of choice, and when I was on it, I felt confident, like I could handle anything. When I wasn't, I felt hopeless and confused. Hep C was a positive thing in some ways, a wake-up call to change my life. When I was diagnosed, I could see straight away that hep C was a direct consequence of what I was doing, how I was living. I'd never thought about my health, never thought about how important it was to my living. I was just into drugs and drinking. Looking back, I had three options opening up for me: homelessness, prison or death. My life was in chaos. I freaked out when I got the diagnosis over the phone, because I thought it was a death sentence, and that I would never be able to have children. There wasn't much information available about hep C then. This made me get into drugs a lot heavier, but eventually your body kicks in, takes over, and says, 'Nah, you're really sick!'

So eventually I stopped using. It was tough. I had the physical symptoms of withdrawing from the drug. It was weird, for a while whenever anyone mentioned speed it was like my body would go into a sort of jolt, like it was remembering the effects of speed. I also had to withdraw from most of my friends and spend a lot of time alone. I did feel very lonely at times, but I knew that I didn't want to go back, and I knew that the people I did drugs with weren't 'real mates'. I remember one day my uncle (Mum's brother) arrived at my door, without saying much he put me in the car and drove me eight hours back to family land near Gladstone. He'd heard on the grapevine that I wasn't good. He got a couple of his friends to take me out fishing every day to keep my mind off things, and he gave me fish to eat, day in, day out for a month. I think he thought it would be healing, and it was.

I'd already started some counselling through an Indigenous health service and this helped because before I even knew I had hep C, I had begun to slowly question my drug use and how I could reduce it. I used rehab and went to Narcotics Anonymous (NA). When I came out of rehab, I felt drawn to go to church one day. I'd gone to a Catholic school as a kid. I remember going up the steep hill to the church, noticing a syringe lying on the ground, and I remember I carried on walking putting it behind me.

I ended up dropping out of the welfare course. Someone saw me doodling one day on a piece of paper; I used to sit around and doodle a lot, and they said, 'Why don't you study art?' There was a course at the Koori Institute of Education, (part of Deakin University) in Melbourne. There was a lot of support there, and the study was organised in blocks so you could still live at home and they flew us in to do the courses. So I did that, and after a few years, I graduated with a BA (Fine Art). Even though I was still using for part of this course, it's true that art formed a big part of my road to recovery.

At first I found it hard to be open about my hep C. I didn't talk to anyone about it, but I went to a support group, and it was good to hear other people talk about their difficulties living with hep C; about the symptoms, about not being able to get through a day without a nap, that sort of thing. I had a friend who was working in the community and she was giving a talk on hep C one day and persuaded me to come along to be her 'person-with-hep C'. So I went from not telling anyone, to telling the whole community at once. It wasn't so much of a problem, people at the talk were all engaging in the sort of risky behaviours I had done, so they were supportive. I like to use my experience to help others, so opening up and telling people was doing just that. I think people at risk of getting hep C should know about it before it happens to them. I'm always telling people, 'Careful don't do that! Remember hep C, it could happen to you, it happened to me.'

I did treatment in 2001 after being clean for two years. When I gave up drugs I started setting myself goals. One of the prerequisites for treatment at that time was that you had to be clean for two years.<sup>3</sup> So staying clean was linked to being able to do treatment. I had to try treatment because the hepatitis was really affecting me; I felt sick if I ate anything fatty, and I was struggling to get through a day at Uni; I was just so tired and couldn't concentrate. I think I was the first Indigenous woman to do six months' treatment and clear. I never knew it was such a big deal at the time, but now I do. I still wake up some days and think, 'What if I hadn't cleared?'

Treatment was hard going at times, I told myself if I could give up amphetamines, I could handle anything treatment might throw up. I planned it a bit. My partner and I talked about what might happen, so she knew what to expect. I told her that I didn't understand what the specialist was saying, so she came to the appointments with me, and afterwards, she would remember and tell me what he had said. I took anti-depressants because I knew I had vulnerability there. I went back home to Bribie Island (Queensland) where my family are from. I realised that I would need to be around them. I knew if I had a bit of support, I would be right, and I was.

I spent my time on Bribie fishing, painting, doing the markets. It was a really productive time for me in terms of my art. I did more on treatment than I ever have since. I knew I didn't want to just sit and mope so I kept painting. I was just producing and producing. I managed to win the Robyn Ochins art award, and got nominated as one of the top 100 Indigenous artists during that time.

My family was wonderful. My dad put in a bit of money so I could design and sell t-shirts. My partner also looked after me. I would sleep after my injection and wake up to a clean house with the smell of dinner cooking. She just took a lot of stress out of it all. I looked after my niece who was doing her last year of high school. She knew Aunty was doing treatment and that she had to be good. Even though I took the anti-depressants, I was still emotional and quick to react. I got so bad at one point that I thought I might pull out of treatment. My youngest sister had been in a car accident, and was in the Intensive Care Unit. We thought we were going to lose her. This made me very emotional and I felt like I couldn't cope, but I did. When I'd go off the deep end a bit over things, my partner would just grab me and hold me until I calmed down. Going through treatment strengthened our relationship in lots of ways.

I'd been clean, and post-treatment for a good while when I went off on my own to Hervey Bay (Queensland) for a bit of time out. I was still in a process of change at that time. I felt I wanted to do something to symbolise all the changes I'd been through and what I wanted for the future. I went to a tattooist and was really drawn to a design of a manta ray. I wasn't quite sure why, but it seemed to symbolise the ocean around me there and then, but also the ocean that surrounded the land where I grew up. Obviously, I knew there were risks in tattooing, so I checked that the artist used a fresh needle and checked that he was aware of safe infection control and when I was happy with that, I went ahead with my tattoo. After all this, I returned to the city and seemed to settle down a

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<sup>3</sup> This is no longer a prerequisite for access to treatment.

lot more. About a year later my uncle saw the tat and said, 'That's your totem!' Totems are important for Indigenous people, it's part of your identity, part of who you are.

These days I work as a Project Officer for the Hepatitis Council of Queensland. I never thought I could do this job, but everyone at the Council always did. They knew. I run art workshops in local Indigenous communities. People come along to the workshops; art is the hook that gets them in. That's when I talk to people about hep C. Indigenous people are visual people, so you need pictures. I show pictures of scarring and the virus, and pictures of tattoos and such. I do have concerns about freaking people out about it, so I use myself as an example of how you can get through and have the treatment. You have to build up trust working with the community and it takes some time for the messages to get out. Doing the artwork helps people feel more relaxed, which makes it easier to deliver the message. During a workshop, people might come up quietly and ask me, 'Have I been at risk, should I get tested?' They feel safe enough to ask me. These people wouldn't go to a mainstream medical centre, and probably wouldn't know they had been at risk. There's a big shame factor with Indigenous people and hepatitis. It prevents them from getting tested or openly talking about it or doing treatment. In my work I try to teach people gently, that it's important to put that shame aside for your health.

I never knew that I would have such a passion for this work. Empowering people to take care of their health makes me feel good. If I can get just one person in the workshop to consider testing if they have been at risk, then I think it's been successful.

Nicky Newley (Nigooli), 42, is a Wuthathi woman and gifted painter. Her family heritage on her Grandmother's side is from Shelburn Bay Cape York Peninsula and from her Grandfather's side from Darnley Island in the Torres Straight Islands. Nicky lives in Brisbane with her partner. She is believed to be one of the first Indigenous women to undergo treatment and clear the virus.

A man with a beard and short dark hair is smiling and looking towards the camera. He is wearing a grey t-shirt with a red logo that says 'CHOPPERS' and light blue jeans. He has a watch on his left wrist. The background is a collage of green leaves and a large, semi-transparent yin-yang symbol. The overall tone is positive and natural.

**I tend to believe that  
what you give out, you get back in life.**

9

# Strength of Reason

I was a drug pig. There's no nice way to put it. I'd hit up anything and everything. I'd sharpen my fits on the concrete pavement. I remember collapsing after shooting up in the toilets of the Rex Hotel in Sydney. I started using when I was 14. I'd ended up in Mulawa (women's jail) and nearly died a couple of times. One day my mother persuaded me to see a social worker. I think I went along just to shut her up. Anyway, I don't know what the social worker said or how she reached me but obviously she said the right thing at the right time, and that was it. I went to detox aged 20, and eventually gave up the drugs. I now know that I just have a very addictive personality - relationships, food, and drugs. Can't get enough of them. I don't know why this is.

I grew up with an understanding that I was different. I was Giovanna Carmella Dorothea Bernadette Lewis (Joanne Carmen Lewis), Maltese-Welsh. As the eldest daughter there were a lot of expectations such as me growing up, getting married and having kids, something I knew wouldn't ever happen. I have a great family, don't get me wrong, but there was still this expectation that was hard to ignore. I didn't look like a 'Dago', but my sister did, and she was picked on all the time; she is a lot younger than me so I had to protect her. In a way, having this helped me bond with the Koori kids, and I was always hanging out and playing around The Block in Redfern, Sydney. I was sexually and physically abused when I was young and, as a lesbian, I was bashed by a guy on King Street, Newtown, Sydney.

As far as getting hep C goes, I do have a few risk factors. I've got tattoos, piercing, and there's years of drug use in the 70s. I also had a blood transfusion in 1988. So it could be one or all of these.

I've done treatment three times. In 1997-1998 I did twelve months of interferon monotherapy. I remember it was hard, but I coped. I drank alcohol through this treatment and I am convinced now that this is why I relapsed. I can't remember if anyone told me not to. I guess I used it to mask the side effects.

In 2000, I did three months of combination treatment through a Brisbane hospital and failed to respond at all. After the three months, I was taken off the treatment and left with no follow up, nothing. I basically fell into a dark hole. I broke down, and very heavily contemplated suicide. I was so disappointed and felt very alone with it all, and I think that the treatment contributed to a depression that was just made worse when I was taken off treatment.

In 2003-2004, I did another twelve months of combination therapy. I don't know that I thought that much about doing it. I'm a gung-ho person; I just leap into things without thinking or worrying too much about them. Even though I did know the odds weren't that good, I had a great specialist who was able to get me onto a trial. I'd planned to work full-time. I tend to believe that what you give out, you get back in life. So, I was feeling positive about treatment, and lucky to be given another chance.

This time it was tough going. All this bullshit about 'mild flu symptoms', well that might be the case for some, but it wasn't the case for me; more like malaria! I was working full-time for a non-government organisation that knew I was doing treatment and had promised to support me through it. I became moody and irritable. It was hard working with some difficult people. There was one

person where I worked that got everyone's back up, treatment or no treatment. So one day, I told her in no uncertain terms what I (and everyone else) thought of her. I got the sack. Talk about betrayed. I had worked for this organisation for seven plus years and in the community sector for 20 odd years, and they knew I was on treatment and had promised to support me. To make it worse, I only said what everyone else was thinking anyway. They didn't cut me any slack at all, and I still get angry when I think about that.

However, during this time I did a lot of work as a member of the management committee for the Hep C Council in Queensland, which, for various reasons, was close to being dismantled. I knew if it didn't continue we might not get the funding back. So I spent this treatment time working for free to get the Hep C Council back on track. The work was a good distraction from the side-effects of treatment.

My specialist during this time was brilliant. He got the post-treatment results at the same time that he shared them with me. He said he'd kept a bottle of red in his office to celebrate. He was so sure that I was going to clear as I had well over a two-log drop three months into the treatment. I told him 'I don't drink' and he said, 'The wine's not for you, it's for me'. When he saw I'd relapsed, he was really disappointed as well.

Working on the hep C helpline after that was a bit difficult. Telling people that I had relapsed, and talking to people who had cleared was hard at times. Now when I hear someone has cleared, I'll be rooting for them! I have to be honest in my work, so if people ask, I tell them I relapsed, if they then sound put off by that, I'll say, 'Don't ask me what didn't happen; ask me what did happen'. Then I'll tell them. I got through 12 months of treatment. I had a major reduction in my ALTs, my viral load dropped substantially, and this of course helps to stop the virus bombarding the liver; that's what I focus on. I know lots of people with genotype 1b that have cleared on treatment, so I would also say that. There are good things that can come out of treatment, even if you don't clear. It is certainly worth a try.

Back when I was 24, I began to think about transitioning from female to male. I had a girlfriend at the time that I loved, but her mother just could not cope with the fact that she was lesbian and this upset her a lot. I found myself seriously wondering, well, maybe if I was a bloke they would accept it all more. Even when I was a little girl, I remember knowing I was a girl, but not feeling quite right about it, not really wanting to be a girl. Growing up, I was quite butch and liked hanging out talking to guys. I was physically really strong, and worked as a labourer for a gay Italian bricklayer, and I'd often work with my shirt off and no bra on. I'd forget that women don't do things like that. These things sit in the back of your mind I guess. When my 92-year-old Nana died, I decided to do something about it. We had a very close connection, and I just knew I couldn't do anything while she was still alive. So she passed, and I thought it was time. I was 46. I sent out emails to everyone I knew asking them to call me Jake and explaining what I was about to do. I still have the replies. They were so supportive they make me want to cry.

There are a few things I miss about being a woman. Kids for example. Young children love me; I'm like a magnet for them. In the past I might be out somewhere and I'd see a kid and I would immediately engage them or pick them up. The other week I was in a café and a kid spotted me and made a beeline, I smiled, and went to give her a cuddle, and then saw the look of horror on her father's face. And I stopped. You forget men don't do that sort of thing. The other thing I'm missing is the lesbian community. It's a strong good thing to be part of and I'm not anymore. The transgender community isn't as strong. There are times when I don't really feel complete; gender surgery can only go so far. But I do feel that the outside matches the inside more these days.

I wouldn't say I was religious, I'd say I was spiritual. I'd say people who are religious are scared of going to Hell, and people who are spiritual are people who have been to Hell! I grew up in a

Catholic family, and there are still things about it that I like, such as the ritual of prayer and the number of people who practice, even though there are a lot of hypocrites. Ages ago, I got a tattoo of a dragon on my shoulder. I think the dragon symbolises a lot. First there's the Welsh connection. But the dragon itself is a symbol of strength and courage in being different. The dragon is a mythical beast; its shell is very different to what is inside.

I often tell people who feel ashamed of their past or their hep C status or current lifestyle a motto I've learned to live by. It is, 'people who mind don't matter, and people who matter don't mind'.

After three attempts at treatment, I believe now that I didn't clear for a reason. I truly believe there is a reason for everything, you just gotta find your reason.

Jake Lewis, 49, works full-time as an Educator for the Hepatitis Council of Queensland. He lives in outer Brisbane with his partner and her 21-year-old daughter, three dogs, two cats, a bird, a horse and a couple of chickens.

I try to have faith.  
I tell myself  
everything that happens  
is God's wish.



# Jalal's Journey

I grew up in a rural province in northern Burma. My mother die when I was young, and I didn't meet my father until I was in my 30s. I was raised as orphan by different aunties and uncles. I got married and had three children before my husband die suddenly.

I had to look after my family, so I work selling things. One time I cross the border into India to sell some goods. I got caught. Once I cross the border, and I was afraid to go back to Burma, as I knew I would be punished. I went to New Dehli where I find out the United Nations (UN) provide 1400 rupees (\$AUD35) per month for refugees. Although this was something, it was not enough to live on. There are no refugee camps in Dehli, so I share a 2 x 4 metre room with six other people. We sleep, eat and live in the same place. Every day we roll up the mats we sleep on, and wash and cook in the same room. I live there four years. I do odd jobs during this time, look after children, work for the YWCA, or help out in the Kachin community. You can't get a visa to stay in India, because India already has too many people. The UN help me make visa application for Australia.

I came to Australia in 2006. I was here a short time when Evelyn (interpreter and support person) took me to Refugee Health Centre because I had skin problem; a rash on my body. The doctor say, 'How about we do blood test to just check for hepatitis C and HIV?' I agree. The result came back and I was positive in both. I was very upset and very depressed. Before this test, I never knew that I had diseases. I didn't know anything about hep C. In Burma and India, all you know about HIV is that it means you will die. So that is where my mind went straight away. I thought I would soon die in Brisbane and never see my children again.

I don't know how I got HIV or hep C. I never use injecting drugs. But growing up in Burma, whenever I was feeling sick or weak I would see village doctor. Sometimes he would put drip in my arm. When you are sick in my country, you see the village doctor and always you have an injection: sometimes vitamins, sometimes iron. The village doctor would use syringe that isn't sterilised that he use on other people. In India and in Burma I also saw dentist who did treatment with needles. Nobody talk about getting hep C or HIV in this way. Maybe there are lots of people infected.

I did hep C treatment because it was what my doctor suggest. Treatment took ten months I think. At first I was frightened of using needle on myself. It was very difficult. I watch a dvd that explain how to do it, and this help. For first four weeks, a nurse came and gave me injection. Then I got confident and started to do it myself. The side-effects of the medicine started straight away. I had vivid dreams; I couldn't eat or drink much, so I lost weight and was sometimes dizzy. One day I faint. I felt afraid all the time, and had hallucinations. I lost some of my hair. I felt very lonely, and thought of my children, and that I would never see them again. I saw psychiatrist a few times, and had some counselling. I made lots of phone calls to Evelyn.

I keep going because I believed what the doctor and the nurses told me, it was the right thing to do. I trust them. I knew I was having expensive medicines that I would never get at home, or in India. When the side-effects were bad, I keep thinking one day I will be clear of this disease, and I talked to the nurse and doctor, and everything they said I should do, I did do. I follow their advice. I only forget to take the medicine once in the whole time.

I saw dietician and saw psychiatrist again. I try to have faith. I tell myself everything that happens is God's wish. I read the Bible a lot. It is very hard in Burma to get a visa to leave and come to Australia, and impossible if you have no money. I got the visa and got the treatment for free, and I had no money. I tell myself, I got to Australia for a reason - God's will. I encourage myself that treatment is good thing to do. I have hope. I thank God for getting me to Australia. It is a beautiful country.

I was afraid to tell people about treatment. I didn't tell family in Burma as I don't want to worry them. I tell them I have liver problem that is all. In the end I tell a few friends, so I have someone with me after the injection. Now they just act normal, but they were shocked at first. I don't know if anyone has had test since they hear my story, because everyone has different views and beliefs about these things. Some people won't have test if they think the medicines or treatment is going to cost them a lot of money, but if they know that treatment is free, then they would be more likely to have test.

I get depressed now when I am hoping for something and it doesn't happen. Sometimes, I feel useless because I can't get job and I want to have job so I can earn money and be independent. Sometimes I think I have got job and it falls through. This make me sad. I need job so I can sponsor my children to come here and join me. They are living with my father-in-law and he is too old and not in good health. It is too expensive for him to look after them. Inflation and cost of living in Burma is so high. My father-in-law cannot keep looking after my children. They are over in Burma with no money, and I am here in Brisbane with no money to help them. When I think of all this, I get very down and when this happen, I read my Bible. After a while, I calm down, and can be normal again. Reading my Bible gives me courage. I think if God wants things to happen, then he will help me make them happen.

My hep C treatment is now finished and it was a good result. The disease has gone. I am very happy about this. I would not offer advice to someone who hasn't been in my situation, but if someone has come here from Burma as a refugee, I would advise as soon as possible to check your health. If they tested positive to hep C or HIV, I would say don't be afraid. I would tell them the treatment is free. I would say that health is the most important thing. If you are healthy you can do anything, when you are sick you suffer and you can't do anything. I would say, look at me. I might look like I am small and soft, but I am very strong. If I was still living in Burma I would probably soon die. Now I know I can survive.

### *Evelyn:*

We never see hep C in my community. I think it has been there all the time, just nobody talks about it. I was there as the interpreter at her medical appointment. It was terribly hard telling Jalal that she had been diagnosed HIV positive and hep C positive. I don't know how best to say it. I don't know much about hep C and I was shocked about the HIV. Since then, I have been with her for the whole journey. She is first person with hep C I have supported. Jalal doesn't have anyone else. She is my client, but I'm sometimes like her mother!

When I was supporting Jalal with treatment, there were other services involved. They are all non-government services. They help her with food, transport, companionship and counselling. Without these services, it would have been more difficult, and she would have been alone.

When she was on treatment, I was very worried about her. She got so depressed and she was weak. She phone me all the time, and she was so forgetful. I feel guilty as one day I raise my voice

to her when she had forgotten an appointment. I regret this. She was so lonely. I persuaded her to let me tell some of her friends about her treatment, so that after her injection each week, someone could stay with her.

Jalal did treatment at a hospital in Brisbane. She would like to thank her doctor and the hep C nurse. They really treat patients with such kindness. I've never seen such doctors and nurses in my life.

I will be running information workshops in my community in the near future. I hope to get Jalal to tell her story, so that others can benefit from her experience.

Jalal, 42, is from the Kachin state in northern Burma. She has three daughters and one son who still reside in Burma. She has lived in Australia since 2007, and currently lives in Brisbane.

Mrs Evelyn Thwe Thwe Win Pe provided the essential interpreting and translating work that enabled the sharing of Jalal's story.

*I started to think  
this isn't right, she deserves better than this.  
I knew there must be something more  
that could be done to help her.*



# Remembering Jennifer

Every six months for thirty-odd years, Mum would travel from Port Stephens to Sydney to see the doctor that prescribed her methadone. More often than not she would travel on her own. But I do have vivid memories of when I accompanied her. I recall it being such a mission!

Growing up, Mum openly talked about the appointments she had with the doctor whom she referred to on a first name basis. I had the impression they had formed a friendship. I suppose this was only natural, the doctor had known Mum for thirty years, longer than Mum had known me. It very much seemed like a social visit, I recall Mum speaking about the doctor's daughter and her love for horse riding. I got the impression Mum and the doctor conversed a lot about their families over the years. Mum needed the doctor for her methadone, but it seemed more than this, Mum trusted this lady and viewed her as a friend, a confidante.

Mum and I had a special relationship, more like best friends. I sometimes wondered if people found it odd that we'd go everywhere together. On the rare occasion I would be out on my own, I was always asked, 'Where's Jenny?' Mum loved a chat with my friends and they loved her youthful essence. She was young at heart, she called it 'ageless'. She loved her Papillon dogs, and carried hers around in a handbag long before Paris Hilton ever did. She'd get so indignant if her dog was mistaken for a Chihuahua.

After losing her mother when she was eleven, Mum and her younger sister were raised by their father. Her upbringing was tough, both for the girls, and for 'Pop Wright'. In hindsight, I believe Mum had insecurities and a lot of pain bottled up. I recall her saying she felt that she never was really liked. She would mask all this with her chatty nature. She loved having a 'mag' (chat) - it was often a struggle to get a word in. She relaxed by losing herself in the two or three novels she got through each week, or by pouring herself a glass of wine every day when 'The Bold and Beautiful' came on TV.

Mum would often speak about her past. She was never ashamed of it. It was common knowledge in our family that she had used drugs in her youth. I don't know a great deal about Mum's drug use, other than it was part of the scene that she had got involved in during the 1970s. I recall her making reference to the people from that era, acknowledging that most of them either ended up in prison or they overdosed.

When we were growing up, we were all too aware that Mum had to make visits to the pharmacy three times a week. This meant we were limited on what family holidays could be planned. We never really went out of state, due to this. Of the four of us children, not one has ever even tried drugs. I believe this is due to the fact that Mum was so open. She also instilled morals, trust and self-respect into us.

In about 2004, Mum fell very ill and was admitted into hospital. She was diagnosed with diabetes and for the first time, she was tested for hep C. She was advised not to drink, but other than that, wasn't given any education in relation to testing positive for hep C. On the other hand, I recall her attending workshops and receiving lots of information about managing the diabetes. She had type one and had to administer injections daily and strictly monitor her insulin levels. I remember the

doctors being quite shocked with the type one diagnosis. As a family, we were given no information. We weren't informed about the Hepatitis NSW, and as far as I know, Mum never saw a gastroenterologist. All in all, the hep C was minimised, and as a result of this, none of us thought it was a very big deal.

It was Australia Day 2007, when our lives would be altered forever. We were at the Country Club celebrating, when I noticed Mum had lost weight and was a terrible colour (basically yellow). She was admitted into hospital the following day. The same doctor that had made the diagnoses two years earlier saw her. He pretty well said, 'You haven't helped yourself, so we can't help you. Go home to die!' and she was discharged. I recall Mum calling me in hysterics to pick her up, after she received this news.

From January to May, Mum was housebound. She developed severe ascites and was more or less bedridden. The hep C was taking its course. We were left to believe that we weren't entitled to any medical assistance, and we watched, helpless, as Mum withered away in front of us. After a few months I thought this isn't right, there must be something someone can do to help her.

I took Mum to two doctors until I got one who took us seriously. He couldn't believe his eyes. He was astonished that Mum had been bedridden since January without receiving any medical care. He called the hospital immediately and Mum was admitted that day.

At the hospital, Mum received treatment, education and, more importantly, hope that things could be better. I cannot thank 'Dr Geoff' and his medical team enough for the care and support they gave us. The staff couldn't believe our story and the lack of information we'd been given back in 2004 when the hep C was first diagnosed. We changed Mum's diet to very low sodium, and she had given up smoking and drinking by then, and she had no further deterioration of her liver.

I don't know how much detail to go into. Despite having better care, at 52 years old, Mum was dying. Watching your Mum die as a result of end stage liver disease, well, I wouldn't want to wish that on anyone. Not when you're pregnant and caring for a loved one with an illness that doesn't qualify for palliative care or community support. This was my situation and I sometimes wonder how we got through it.

Mum was always the sort of woman who took a lot of care with her looks. She wore nice clothes, denim skirts and t-shirts. She loved dusty pink and would wear a lot of that colour. She'd get her hair streaked and she always had her hot rollers in. I remember she used to say, 'It hurts to be beautiful'. Mum would put her make up on just to go out to the mailbox.

When she got sick my husband and I had to stand on either side of her if she needed to walk anywhere. She was terribly malnourished, weak, and incontinent sometimes, and her arms were stick thin and covered in tiny red veins. Because of the ascites, her stomach, legs and feet swelled up; so she could only wear rubber thongs. Nevertheless, she loved havaiana thongs and had a pair in every colour.

When she was discharged home, Mum felt very responsible and hated that we had to care for her. She felt a burden. The hardest part was when she developed encephalopathy as a result of all the toxins in her brain. She was confused, disorientated and sometimes, wouldn't know who I was. There was a period where I was fighting every week, just to get her back into hospital. The problem with the build up of toxins was that by the time she was sick enough for hospital, she'd lost all her powers of reasoning, and she would just refuse to go in.

I would often call an ambulance who would want to take us to the first hospital, as that was the closest to where we lived. I never wanted her to go there again. The doctor there as well as not giving us any information, had written 'Uses methadone' on Mum's file. She didn't 'use'

methadone. It was a medical treatment she chose to take. I sensed that he had judged Mum harshly. So, I would have to fight for her to be admitted to another hospital where they seemed to care.

In hospital, Mum was quite often used as an example for medical students. When they came around she knew not to have her full makeup on so they could see how she really looked. They would come around to her bed and the Specialist would talk to her, and they'd all observe and ask her questions. Mum had said when she agreed to this, 'Well I can't donate my organs, so I may as well help in another way'. By then I think she could see a greater purpose. I remember one young doctor came up to Mum afterwards and said, 'I want to apologise to you, for the way the medical system has treated you'.

When she was dying, I was able to have a scan and so Mum knew I would be having a girl and that I would be calling her Jennifer. Mum said, 'I want a jacaranda tree in the back yard so I can sit in its branches, and look over Little-Jennifer playing'. So after her death on 21 November 2007, we had a tree planting ceremony, so now, there's another thing that makes me think of Mum, the jacaranda that blooms close to the time of the year when she passed.

On the first anniversary of her death I knew I had to do something. I thought I can fight the negligence I saw in the medical system in relation to Mum, or I could fight the ignorance of hep C in the community.

I began to distribute information about hep C. I dropped leaflets and Hepatitis NSW bookmarks in newsagents, chemists, beauty parlors, medical centres, optometrists (well, I thought they might have to pick something up to read to test their glasses, so why not these leaflets?). I left lots of information in pubs where I knew the bikies went. All the places I dropped information, I never got one negative response.

I wrote to the doctor who had prescribed Mum's methadone for all those years and asked her if she could send me some information from Mum's files. I think I wanted the information from Mum's files partly due to my grief, trying to keep Mum alive through stories of her life. I thought after 30 years, this doctor would have a pretty big file, possibly with information I didn't have, maybe with some stories I might one day want to share with my daughter. I never got a reply from the doctor. I wrote again, saying why I wanted some more information, and asking again for copies of Mum's files. I still haven't got a reply.

I don't know why Mum wasn't offered a hep C test earlier. It was obvious that she'd been at risk. When we did find out about the hep C we never knew there was a treatment for it. I think if people are worried about treatment taking six or 12 months, I'd say to them that it's such a short time out of your life when you think of what could be the alternative.

I talk openly about Mum and her battles with hep C. I think the only way to reduce stigma is to talk about it, so that doctors, psychiatrists and anyone else out there gets to know that early diagnosis is absolutely vital, and, so they get to appreciate that behind every 'methadone case' there's a person, with a life full of highs and lows, good and bad choices, but most importantly, a family that loves them.

Emmy Le Cornu, 26, works as a primary school teacher and mum to Little-Jennifer. She plans to continue her work raising awareness of hepatitis C, in memory of her mother, Jennifer.



*I've always been a happy-go-lucky type.*

*Things are at their best  
when they're at their worst.*

# Rocking On

In my early 30s I had a major relationship breakdown and one day found myself standing on the street in my overalls with the door slammed shut and the locks changed. I kinda thought, 'Right then, what shall I do now?' I had a good paying job, somewhere to stay, so, I started partying. For about four to five years I got heavily into drugs. I thought I was moving forward but really, I was just digging myself a big hole. I was working 10 hours a day at hard physical work and every cent I was getting, I was spending on a bunch of bad stuff. At one stage I was having a hit just to get up and go in the morning. I realised a few years ago that I probably had depression, and that was just the way I buried it.

By the end of that decade, I had come off the drugs and managed to dump the methadone. Not many people give up methadone. Heroin detox takes about four days, but for methadone you can just times that by ten. I went to a friend's house and locked myself in his garage for two weeks. He looked after me a bit, cooked meals and stuff. Every now and then he would get me to come outside and mow the lawns or empty a truck or something like that. I knew that the withdrawal couldn't kill me, so I just kept going. I wanted to be rid of it.

I was first diagnosed with hep C at a Melbourne hospital, back in 1996. The specialist discussed interferon monotherapy with me, but then said, 'Don't worry about it, there'll be a cure in five years.' So I just carried on playing in bands, drinking, not taking anything too seriously. But six years later I started going downhill really fast. I had encephalopathy. I was confused and didn't know who or where I was at one point. Two close friends told my partner, Michele, that I was dying. I remember talking to the specialist, then going outside into the hospital gardens with Michele, holding her as she went limp in my arms and saying over again, 'Listen, I am not dying!'

I'd been sick with fevers and cramping in my face, my body, everywhere. During this time I had been discharged with 'fever of an unknown origin' from two major hospitals before the doctors at another hospital realised that it was related to my liver and the hep C, that it wasn't going to work just trying to manage it and that I was in big trouble. They said my only option was a liver transplant, 'If they'll have you'.

The specialist knew another specialist at a hospital where there was a renowned transplant team, and he wrote an old-fashioned referral letter for me, and they accepted me for a transplant work up. I think without him I wouldn't have survived. By then I had given up smoking and drinking and was looking after myself. The work-up takes about three months. Before they decide you can have a transplant, they assess you carefully. I saw specialists in this, that and the other department, and saw the psychologist there but I reckoned he had more problems than me. The guy was hiding behind a beard and a dead-fish handshake. He didn't stay in the job that long. They did regular tummy taps; where they drain ten litres of fluid from your stomach, it's when the whole liver has just shut down basically. I went into hospital at 135 kilos and when I left I weighed 84 with no muscle tone in my legs or arms and this great big face. It wasn't a good look. I spent so much time in hospital in those days I started to see it like a second home, a place to go where you get looked after.

Anyway, after all the assessments, you then have to wait for a suitable liver to come up. I think the waiting was tougher on my family than on me. I had the feeling that things would take care of themselves. It was midnight when the specialist came into my room, tapped me on the head with his mobile phone, and said, 'You're going in, Mate.'

I had the transplant on 31 July 2004. I was discharged home in 13 days. I had my birthday and wrote 30 songs. I wrote a song and a poem for the family of the donor. It was passed on to them. I do think about the donor from time to time. He was a young guy who died in a car accident. I don't dwell on it though, or have any guilt. I'm just lucky to get another chance. I've always been a happy-go-lucky type. Things are at their best when they're at their worst. I try to keep people's spirits up and not be too sombre. With all these times in hospital, I've been placed in wards where people are dying, and I've always tried to have a smile and a laugh. There's nothing anyone gains by being depressed. I'm not saying clinical depression isn't a terrible thing or that people don't suffer with it. I just try to keep myself up.

One day when I was at the Liver Clinic, I noticed this guy with black fingernails. I thought I recognised him. Then when they called his name out, he turned out to be Paul Stewart from the (Melbourne punk band) Painters and Dockers. He ended up writing an article about organ donation, and another muso, drummer Bob Carey read it and said it made his mind up about deciding re organ donation. The three of us got together with my sister who is a singer and a few other ring-ins, and formed an 'on again off again' band, the Transplants. We played old Painters and Dockers numbers and some of mine at the World Hepatitis Day concert and at an event to raise awareness for organ donation. The whole idea is to use the music to raise awareness so that others might get the opportunity to live longer and healthier lives. It gives me a feeling of giving back as I have been given so much.

When you have your liver transplant and then get discharged home, there's a euphoria that happens. Mine hasn't gone away yet. I still think it's just amazing. There were some complications after I had a biopsy and I ended up in hospital again having chest surgery after they had accidentally clipped my diaphragm. But before the transplant, I'd thought I was gone, and I've had two plus years of good health now. I have a great life. I've worked for community television for ten years, I write songs, perform, I've got into editing. I've started learning new things and doing things since I got my health back. It's been a long road but I got there in the end.

I haven't really felt the stigma of having hep C. Most of my friends are artists or musicians from a certain era, and a lot of that crowd have hep C. I know lots of people who have died from liver failure or liver cancer and usually it's a result of hep C. Outside that community of course, there's a lot of stigma about drug use and hepatitis. I'm not shy about talking about it, and I'm not shy about showing my scars.

It's not possible for me to have treatment for hep C. I've got one of the more tenacious genotypes-1a. They've told me that my body wouldn't take the interferon. Since the transplant in 2004, the virus has attacked the new liver, which is now partly cirrhotic. I know a lot of people who have hep C are scared of treatment. I'd say don't be. Treatment is much better now than it was when I was looking into it. I wouldn't hesitate to try it if I could. From what I know a small number of people do get horrible side-effects, and a small number don't get any. I never get any side-effects of drugs. I've been on immunosuppressant drugs that aren't even on the PBS (Pharmaceutical Benefits Scheme) and all I've had is a bit of dry skin.

I'd say that the majority of people that do treatment for hep C just muddle through. If I had the knowledge I have now, back then when I was diagnosed, I'd have done treatment, for sure.

*Extract:*

“When the final days come, you don’t really reflect on what your life has been, but you do fully live in the now. People weeping (oh stop that!) There’s no time for that. There’s only just enough time to give everyone a wink to let them all know that it’s alright.

Just as the light starts to dim, I get a tap, and a man says, “Hey! I’ve got a present for you. If you come with me, downstairs now, I’ll give it to you”.

Well we got downstairs very quickly, but then I went to sleep, waiting so long to see my present. When I awoke I said, “where’s my present?” and he replied “I already gave it to you”.

I didn’t believe him, but sure enough, a beautiful young man from the country had to go. So he sent me his life, so that mine might go on.

Like a broken toy soldier, I was repaired, good as new. They took out my bad bit and put in the good bit and I went on like nothing had happened.

Man, sometimes I just can’t believe how lucky I am.”

<http://www.youtube.com/watch?v=i3SRrNSey0g>

Shane Laffy, 54, is a veteran of the music industry, performing with bands such as 20 Flight Rock, Man Friday, and most recently with the Transplants. He spent the past decade working in community television in Victoria where he lives with his partner, Michele.

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The opinions expressed in this book are entirely those of the storytellers, not those of Hepatitis Australia. As most of the people interviewed are ordinary people, in their stories they may not have expressed contemporary understanding of drug use, drug treatment, or of treating hepatitis C. Suffice to say that nothing said in these stories is intended as specific advice, and anyone reading these stories should seek their own medical advice about treatment.

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Hepatitis Australia was incorporated in 1997 as the peak community organisation to promote national action on matters of importance to people affected by hepatitis C. Our mission is to provide leadership and advocacy on viral hepatitis and support partnerships for action to ensure the needs of Australians affected by, or at risk of viral hepatitis are met. Our members are the eight state and territory hepatitis organisations.

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