

Surviving unscathed: Sim

I was diagnosed with HCV just over three years ago as part of a routine check at a sexual health clinic. The result came as a complete shock. I can still hear those words the doctor spoke as he became the central character in one of those thankfully rare life changing moments: “there seems to be a problem with one of your results.”

A few months’ experimentation with drugs in my early 20s had probably exposed me to the virus. I had thought I’d been fairly careful and as this was over 20 years ago, I had thought I’d got away without any serious consequences of that brief, but now apparently significant, episode in my life. Even now, I’m still not convinced that this is the way that I contracted the virus. There is no way of telling how long since initial infection though, and I have learnt not to dwell too much on the source of the infection.

As for ‘what to do next’, there was never any real doubt about undergoing treatment. As soon as I was diagnosed, the questions I asked were about treatment. I was initially told I would have to wait about six months for the chance to start treatment, which at the time seemed an eternity. However, this turned out to be an underestimation by the clinic staff and it eventually took two years. The long wait was primarily due to my refusal to undergo a liver biopsy, something I considered to be an unnecessary and potentially dangerous medical procedure.

I found out a few weeks after diagnosis that I was genotype 1a. A fairly devastating discovery as I was fully aware that genotype is the primary indicator of treatment success, and this wasn’t good. Additionally it meant nearly a year’s worth of treatment.

Soon after, I got a viral load result; this was in the millions and not a good result, this being the second strongest indicator of treatment success. Add to this gender (wrong one), length of time of infection (too long) and age (too old). Things weren’t looking too good.

However, I realised that all these factors were things that I couldn’t change and that I should only concentrate on things that I could change and aim to push those statistics up again. The

stats for someone in my position I calculated at about 40%. By careful preparation, I thought I could push this to 50% and, given the success rate at the clinic where I was being treated, maybe push this higher, possibly up to 60%.

Things weren’t all that bad; there was some good news. The liver function tests were nearly all in the normal range, the exception being the GGT (an enzyme that is produced in the bile ducts) which was just above normal. An ultrasound scan showed no abnormalities, so the chances of having a cirrhotic liver were probably very low. I have always had a fairly good diet and never been a heavy drinker so I was confident that there was minimal liver damage, which would increase the chances of treatment success.

The factors that I could do something about – in increasing my chances of success – would be in the preparation for the year ahead. My aim was to be in the best mental and physical condition that I could achieve, and then to maintain that to keep the chances of success as high as possible. In other words, I was determined that, if my physiology would allow it, this treatment was going to work.

I decided to try and enjoy the year as much as I could, to treat it as a year off, almost like a long holiday. I was lucky in that I could claim state benefits so that I would not have to work and could take time to look after myself and indulge myself in activities that I enjoyed.

Having a positive attitude to treatment is, I believe, vital to getting through treatment and increasing success rate. One of the things that I liked about my treatment clinic was that they shared this view.

Since being diagnosed I had access to a social worker who, while not always agreeing with me, did give me good advice and challenged me to think about what I was doing and therefore helped me achieve and maintain a positive outlook on things.

I also had access to a psychologist throughout the treatment to help with strategies to overcome negativity, low moods and other problems.

There were other factors that helped in maintaining a positive attitude: firstly I was lucky that I did not have any major depression



non's treatment story

problems or other mental health problems that a lot of people have to cope with on treatment.

Also I had told a couple of friends about what I was going through and they were very supportive. Generally I didn't tell friends and family simply because they didn't need to know and their ignorance of what I was going through helped me to maintain a sense of normality; I found that this stopped me focusing too deeply on the treatment experience.

The clinic staff were very supportive – not only the treatment nurses and consultants, but the admin staff and 'blood' nurses were also very helpful. I used to actually enjoy visiting the clinic; it was as if I had acquired an extended family. This was particularly beneficial to me, as I was in the clinic at least once a week, partly due to my neutrophils count dropping to levels that were causing concern.

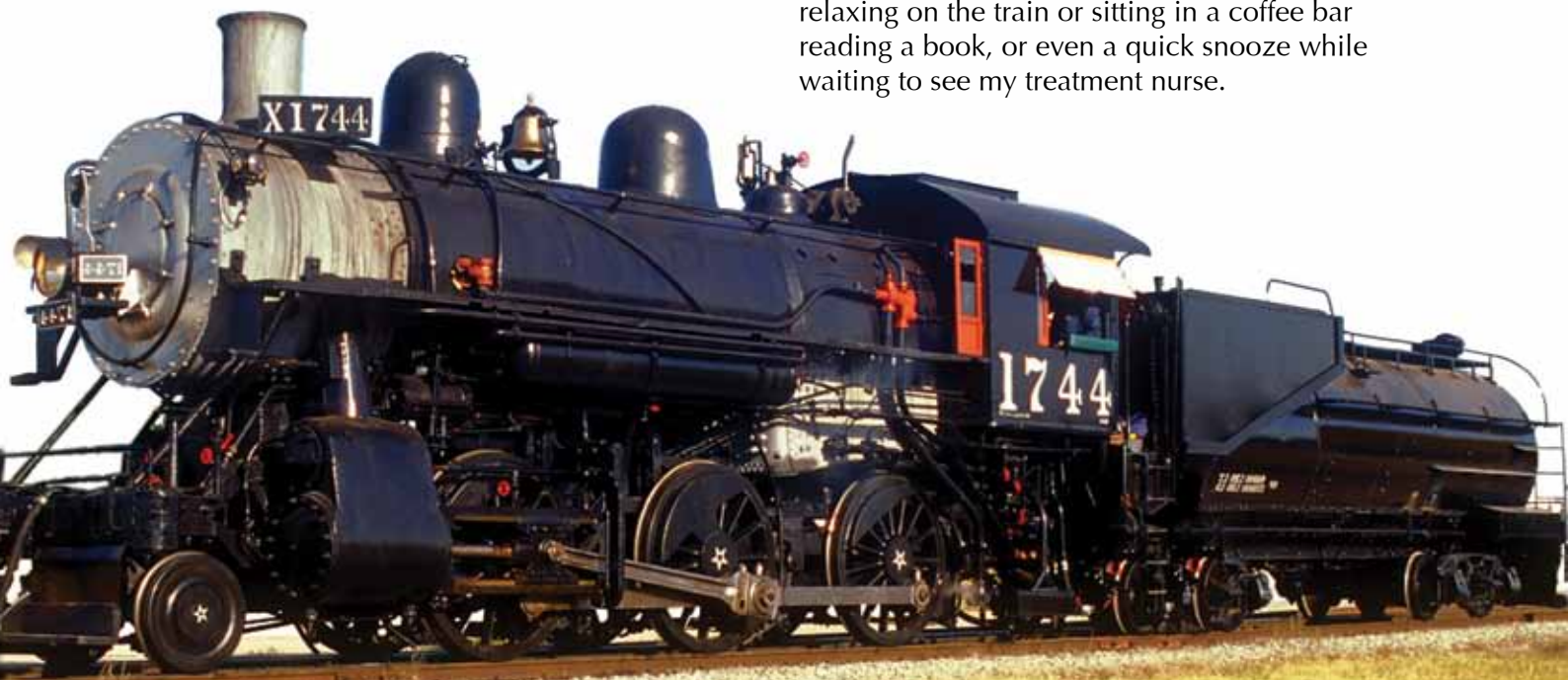
To stay as fit as I could, I increased my involvement with a local walking club. It was not only the exercise that was important but the achievement of being able to walk regularly eight to 12 miles every week, despite being on treatment gave me a psychological boost. The walking group has a very active, social aspect to it which I took an increasingly active part in.

Meeting new people and doing new things turned out to be a central theme of my treatment experience.

Another source of exercise was involvement with railway heritage. Before treatment began I was training to be a fireman on a local heritage steam railway. Unfortunately this was one of the few things I had to give up. I did go regularly to help with the cleaning and maintenance of steam locomotives and still got out on the footplate on various occasions. I was not strong enough to be able to finish the training and qualify as a fireman; this is just about the only regret I have about treatment.

For most of the treatment year I was regularly visiting a sauna and steam room at my local sports centre, partly as this was very relaxing but also as I thought it might stimulate the lymphatic system to expel the virus that can be found there. I have spoken to other people who have found saunas too much when on treatment, but I had no problem with them and found them extremely beneficial.

I was not completely free from side effects; I was very tired at times but rarely had to spend time in bed resting. I ensured that I had plenty of rest by learning to get this where I could, for example relaxing on the train or sitting in a coffee bar reading a book, or even a quick snooze while waiting to see my treatment nurse.



I was lucky in not suffering any serious side effects following the Interferon injections, although I did tend to take them before going to bed, just in case. I did become very breathless due to anaemia and this was probably the worst part of the treatment. I had to be careful when out walking that there weren't any serious hills to climb, as I could have problems ascending.

I did occasionally suffer from 'riba rage', but kept it under control and managed to direct it to people who deserved it! Other side effects were itchiness and rashes, which were annoying but not serious, and I also tended to be easily confused and had problems concentrating. Again, not serious but annoying. I did, however, go back to college to complete a certificate in counselling. This was very therapeutic, as I confided in the other students on the course what I was going through and it was helpful to check in every week and have the chance to discuss issues outside of the clinic.

The only serious side effect problem was that my neutrophils dropped to a level where I had to take an additional drug to boost these. This meant another injection each week, which seemed to make the breathlessness slightly worse but luckily nothing more serious.

After 48 weeks, I was relieved that it was all over. I had survived relatively unscathed, but there was a slight feeling of sadness in that I would not be in regular contact with the people at the clinic who cared for me. Their professionalism and dedication has been inspirational and I owe them a huge debt of gratitude. I feel that the time on treatment has taught me things about myself and overall it has actually been a positive experience that will help me in the future.

I don't yet know if this has worked; I will have a test in a few weeks' time to determine the outcome. I really hope it's good news and I can put this episode behind me. However, if the news isn't good then I have no major anxieties about trying new treatment options in the future, as I have shown that I should be able to tolerate them and hopefully turn them into positive experiences. But I hope it has worked and I can direct my energies to other enterprises!

Simon, NSW

Have you finished treatment for hep C?

If you completed hep C treatment at least six months ago, we would like to talk to you about your experience of life after treatment.

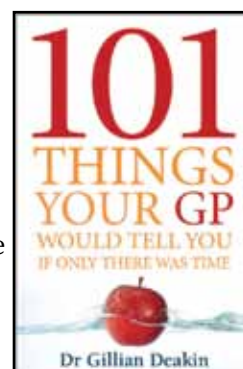
- Interviews last for about an hour.
- Please contact Max on 9385 6436 or nchr@unsw.edu.au to arrange an interview.

This is a research project of the National Centre in HIV Social Research, The University of New South Wales.

101 things your GP should tell you

Dr Gillian Deakin,
Random House Australia
(rrp \$34.95)

Dr Gillian's thought provoking book is a very useful guide for people who want to communicate effectively with medical professionals. There are practical tips on how to choose the right professional and how to help your doctor help you. It also discusses how to deal with hospitals, specialists, and making tough decisions.



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