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The Importance of Not Delaying Treatment

December 19, 2016 By Greg Jefferys

One of the most fantastic things about doing this work that I, assisting people access affordable Hep C treatment, is when someone writes to me and tells me they are cured and their liver is healing itself. Unfortunately this does not happen for everyone. Below is a story sent to me a while back from Pete, an Australian guy who was in that first wave of people accessing generics. He had G3 and was a non-responder to treatment with Sof+Riba but refused to give up and tried again with Sof+Dac.
Please read his story, it is a story of courage and resilience and an amazing refusal to be defeated.

Pete’s Story: Fighting Back
It’s difficult to say when I contracted Hep C, most likely in the late 1970’s when I briefly experimented with IV opiates (when I say brief I mean three times, and I didn’t even like their effects, but hey it only takes one infected shot).
Or it could have been when I was traveling through Indonesia in the early 1970’s where I contracted a couple infections that required injections of antibiotics. One of those was given by friends who were I.V. drug users. Another injection of antibiotics was by Catholic nuns in a Leper Hospice. And then there was that tattoo as the last possibility.

Hepatitis C was unknown back in the 1970’s and 80’s, and it wasn’t until an acute onset with nausea, extreme fatigue and jaundice in 1996 that I was diagnosed with non A or B hepatitis. The doctor that diagnosed me really wasn’t up to speed, as Hep C was actually discovered in 1989; he couldn’t wait to get rid of me and offered no help or advice.
So I battled the transition from acute to chronic for a couple of years, until the amount of sick leave I had to take led to early retirement.
During that time I did suffer from some stupid discrimination from people who knew I had Hep C. Stuff like a group who wouldn’t use the plates and cutlery from the cafeteria that I ate in. Seriously dumb arseholes. But that said, the vast majority of my workmates and management were very supportive.

I did consult with specialists in the public system who offered nothing but invasive tests, so with the support of my new GP (who I have now been with for over twenty years now) I monitored and managed the monster, which turned out to be Genotype 3… the hardest dragon to slay.

Then in 2007 a routine ultrasound scan revealed cirrhosis, so it was back to another specialist who convinced me to undergo the interferon + ribavirin combo therapy. Needless to say it failed and gave me terrible side effects including pancytopenia which left me zero red blood cells and platelets. Interferon therapy caused me so much damage with no benefits.

(Pancytopenia is a deficiency of all types of blood cells, including white blood cells, red blood cells, and platelets. It occurs when your body cannot produce enough blood cells because the bone marrow stem cells that form blood cells do not function normally.)

With not more treatment options but with the support of my GP I did the best I could to manage my disease with many complimentary therapies and dietary and herbal supplements.

Then along came a T.V. current affairs show that my Mum saw and alerted me to. There was an interview with a gentleman named Greg Jefferys, who was assisting people from all over the world to legally obtain the latest, (normally) outrageously expensive but very effective hep c drugs, from licensed generic manufacturers overseas at an affordable cost.
The T.V. show explained that Greg was a Hep C sufferer himself and had undertaken a trip to India to access the new treatment, which was successful in clearing the virus from him. To his great credit he teamed up with other good souls and put in enormous effort to make the treatments available to others in need without the need to travel abroad.
After little research I found out how to contact Greg and he organised my meds without fuss or hesitation, or any great effort on my part. He provides remarkable support for Hep C sufferers around the world, and gets a huge thank you from us all.

My wonderful GP who had supported my unorthodox treatment suggested I was well overdue for an ultrasound, but I don’t always take her advice, and this was one of those occasions. So without the ultrasound I went on the ribavirin and Sofosbuvir twelve week treatment, but nothing happened, there was no change in my bloods, just some unpleasant side effects from the ribavirin.
By this time Daclatasvir had appeared, which combined with Sofosbuvir was considered the answer for G3. Once again Greg steered me in the right direction. Unfortunately adding the Sofosbuvir + Daclatasvir gave the same result, nothing!
By this time my doctor and I both knew something was very wrong so I finally had that ultrasound she had suggested I pre-treatment. The results were bad, and a follow up CT scan confirmed multiple hepatocellular carcinomas, end stage cirrhosis, portal hypertension, and several other bad things.

An appointment with the liver specialist in preparation for palliative care caused a glimmer of hope, as he thought my general health ticked all the boxes to make me eligible for consideration for a transplant. Unfortunately the team at Princess Alexandra Hospital in Brisbane felt my cancer was too advanced for a good outcome. Once again we were shattered, but to his credit my liver specialist sent me off to the oncologist, confident that there were procedures that could buy me some time, even though there was no chance of a cure.

My oncologist sent me off to the interventional radiologist for a TACE (transarterial chemoembolization) procedure, whereby chemotherapy drugs and tiny particles the size of a grain of sand are delivered directly to the tumor via a catheter through the hepatic artery. This method reduces side effects and allows for stronger doses, the tiny particles block the blood supply that feeds the tumour and also keeps the chemo in contact with the tumour for the maximum time. After a couple of weeks recovery life is pretty well back to normal, maybe even a bit better than before. A follow up CT scan after a couple of months will reveal the effectiveness of the treatment.

After all this waffle my message to anyone afflicted with this nasty super virus we call Hep C is short and simple, get treatment ASAP. Find a good GP get a referral to a specialist. Get every relevant test and scan, and find out about the state of your liver. Then get treatment, the earlier the better.

If this sounds too straightforward, it may well be. Finding caring competent medical practitioners is not always easy, even some so called support sites can be compromised. So it’s up to yourself to become educated and informed, knowledge is power. Your wellbeing is ultimately your responsibility. All this from someone who has made too many mistakes too many times, some of us are slow learners, or maybe just lazy.
I’m a classic example of what happens when you wait too long for treatment, in my case in spite of Greg’s assistance with obtaining the meds before they became readily available the damage was already done. The journey through life is a short one, but when you get a death sentence there is a sense of devastation. Don’t get me wrong it’s a miracle I’ve survived almost four decades of Hep C and despite some monumental mistakes, life has been remarkably good to me.

Living is still good, with new experiences and stuff to learn and you never know how strong you are until being strong is your only choice.

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Postscript; I just received the scan results of my two months post TACE treatment, the three out of four tumours that my interventional radiologist blasted have gone, while this is not a cure, it does buy me more time, and I feel better than I have in a long time. Thank you Dr Letitia De Villiers for your skill, judgment and caring.
