Two Stories about Generic Hepatitis C Drugs

October 3, 2015 By Greg Jefferys

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In the oldern days, when I was young fellow, one of the big issues in the medical realm was this idea that doctors thought that they were minor gods. Back in the 1950's and 60's one would never consider questioning a doctor's diagnosis or prescription of treatment. To do so was sacrilege.

To a large extent this has changed over they decades and most doctors are consultative and inclusive. They will consult with patients about treatment options and patients are encouraged to be well informed and make their own decisions about their health.

This type of doctor is now the norm. However as one moves up the doctor tree to the world of specialists this is less the case. Of course there are many wonderful, humble, inclusive, caring, open minded and consultative specialists but there are also many arrogant authoritarian specialists who are more interested in their career and research outcomes than the patient as a person who is desperate to be healed.

That has been my experience anyway.

Below are two stories I received yesterday from people who dared to ignore the "Wait, wait, wait." instructions of their specialists.

Hi Greg,

I hope all is well and you are now starting to feel the benefits of treatment.
I just wanted to fill you in on some info I have personally had to deal with concerning support during treatment.

After about a week or so into treatment I found I was out of breath walking to the car, sweating, chest pain.
My GP ordered some tests and found I was anaemic, so rang the Hep C clinic for advice, advice was refused!

I rang the X clinic and although the specialist was sympathetic, but he said he was under direction not to talk to or treat patients like me who had purchased their meds overseas.

My first reaction was to say that many people get their blood pressure meds overseas, and nobody refuses them care, as far as I know. If a heroin overdose comes in do they ask where you scored it before they treat you?

I'm contacting a reporter from the Herald who recently wrote a couple of articles about this sourcing of Sofosbuvir overseas, so I thought he might be interested in another dimension of the power of big pharma in Australia. I will ask if he would like to come along with me to the Emergency dept. at X

Hospital to document the care or otherwise in our public system. I would expect they will contact the specialist to get advice, as he has been prescribing Ribavirin (which as far as I know is the culprit), which I hope will put him on the spot. Who gave this direction to the clinics?

If asked do you mind if I explain that you were my first point of call in the procurement of my meds? You might have had enough of this B.S. by now and I can avoid if you like, no problems.

I want to thank you again for standing up and speaking out, not to mention making my life a little less stressful, by giving me some choices. Quite honestly though, had I felt up to the trip to India, I would have gone there and got better medical support than I can obtain in Australia, the country where I pay my taxes. I just want to try and get publicity and some answers, to expose this irrational (or corrupt) stance taken by public officials. As it might help the next lot of people sourcing overseas. Just one other thing, surely the Indian High Court has set a precedent, in that they didn't recognise Gileads patent, could it be tested in our courts and the Australian Govt. could save billions of dollars buying these medicines from India.

Take care mate. (do tell me if your over this, I would certainly understand)
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The account below is from another Liver Clinic in another state.
Dear Greg,

Hope your enjoying the warmer Spring weather. It's magnificent here today.

I'm getting back to you about the extra Ribavirin that I received. You might remember I was going to the Liver clinic to ask their advice and get my latest test results, which would give me a clearer picture of whether I needed to take the Ribavirin Sof and Dac for 24 weeks or the initial idea of me taking only the Sof/Dac for 12 weeks.

Over the past year my liver results have deteriorated and from one month to the next my ALTs were rising steadily.The specialists weren't sure if I had any fibrosis as some of my results were quite good/normal and the fibro scan I had about a year ago showed no scarring. but some were wonky.

I started the SOF/Dac treatment one week ago at the tail end of a really nasty flu that has debilitated half our little town. I woke one night thinking I should really just start taking the Ribavirin as well because I probably have scarring. Our brains can get very pessimistic in the middle of the night. I thought, my test results will probably be worse.....

Yesterday I went along to my appointment with the Liver Clinic not really knowing how they were going to react to me using the generic medications. I presumed they would have met quite a few patients like me already, but I wasn't sure what to expect. I decided to keep calm not get defensive, listen and hope they would be sympathetic.

I was expecting my reading would be worse especially as I'd had a really bad flu.
The clinician that called me into the partitioned room and seemed friendly enough. I sat and waited for her to get my results up on the screen and we both looked over them.

Surprisingly all of my readings were near normal. My ALT was only 43 which it has never been since I was diagnosed 20 years ago - the last reading was 465. I suddenly felt a wave of positivity and

confidence flow through my being. The clinician said she couldn't explain why my levels had changed. She then began to ask me if I would consider treatment, that I would only need to take a 6 month course of Interferon and Ribavirin. This was my cue to deliver the news that I was one week into the new treatment using the generic drugs.

Then her tone really changed and she berated me for being completely irresponsible and how could I expect that they would want to monitor me if I was going to do something so dangerous. I held my own and took some long even breaths. She then asked where these drugs came from. "India and China," I said Her face went red!

"India! I wouldn't buy a thing from India." she exclaimed.

I thought, "Ok so you're racist." But I kept breathing and waited for her to calm. After a while of her saying how I've been ripped off and what a scam etc etc.. she stopped. "I'll have to get my senior", she left the room. Sitting there alone in the plastic cubical I knew that I was doing the right thing, I was mainly excited and perplexed to see that my liver function tests were so good. There seemed to be some magic that sits in-between the reality and what was happening.

In about 20 minutes the angry one and her senior came back into the room. I would have loved to have written down their names or even remembered them but my heart, ...my heart was racing. I felt like a naughty school girl waiting in the principal's office.

The Senior specialist was a charming and modern woman and she bounced into the room introducing herself. She had an expression of wonderment across her smiling face. She looked perplexed and excited. She asked me to explain. She kept saying, " Wow! I've never heard of this! This changes so much, This is like a movie, unbelievable..."

Then when she settled down she said

"Oh no, don't get pregnant what ever you do."
I explained I was way post menopause but she was ranting at this stage about the dangers of me being pregnant. I decided to take this as a compliment. Back to the questions...
Then she asked about how many people were doing this, if it is just in Australia? Just me?
I answered, "No, all over the world".

Oh my! I could feel her underling seething on the other chair next to me.

The cat's out of the bag now what? Will they monitor me? What if this treatment doesn't work and I need to come back for their help. I need to keep on their side. I said a million thank you's and a few I'm sorries and I hope you can understand my position type things. I wanted to get conformation about whether I should be taking the Ribavirin but the senior said "I don't know, we're never treated anyone with these new drugs, not sure." She shook my hand and apologised for laughing so much but said she was in a bit of shock.

The boss said they would be happy to monitor me and she was really curious. I figure her curiosity and compassion is why she's the Senior. I'm due back for tests in 3 weeks, that will be 4 weeks into the Sof/Dac treatment and we may see some further improvement. I suggested she watch the 7.30 report and read both The AGE and SMH articles look up information on the net and speak to her colleagues, as

I’m sure they must know about this.

Wow! this was not what I’d expected. I was left with the grumpy one. I asked, as I usually do, for a print out of my results, they often forget to send them through to my GP and I’m also collecting my own files.

“I doubt there is a printer here, I don’t think so” says the grumpy one.

I kept thanking her for her time and smiling, eventually she obliged but printed out the wrong results for me. I didn’t ask her again. I suddenly needed fresh air and to be away from her awful negativity and get back to my home. It’s not unusual for the lower senior ranks to have power issue problems, I noted.

So, the spare Ribarvirin? I punched out 3 cards worth into my plastic daily dosage pack. So what’s left I could pass on but it’s short of the 12 weeks. What do you think?

I’d like to report also that I’m feeling fine, excited actually. I had a few hours of wakefulness last night but I felt like a kid at Xmas.
Was that a dream?
I’m going to have to wait to get a print out of the results when I go back in 3 weeks to re confirm this Hopefully the grumpy one won’t be on duty that day.

Warmest regards,
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