The Time Warp of Transplant

December 2, 2015 By Dan Palmer

I've just emerged from a Black Hole. I was sucked in, unbeknownst to me, and suddenly, it's months later.

OK, I'm kidding. It only feels like the past few months have been snatched from my grasp. Now I've begun to understand why, prior to my transplant on June 2, I was unable to find (or receive from already-transplanted friends) very much information on what was about to occur and what I could expect.

When I used to ask other patients for details about what lay ahead of me, they were all kind of vague about it. The usual reply to my queries went something like "you'll do just fine," or something similarly inane. So, I made a vow. I vowed to blog persistently, consistently, insistently, starting as soon as I got my transplant. I would personally fill that information void with my hard-won wisdom and experience (I say that sarcastically, in case you're wondering).

I come before you now, humbled. Confused as to what happened. Wondering where the time has gone. Ashamed to show my face, or my writings as the case may be, around here.

So, allow me to fill you in on the latest goings on.

Life is great. I mean, really great. Everything has changed, and I mean just about everything. I'm not even sure where to begin.

I don't want to depress any of you that may be fighting HepC and/or liver disease with all of the separate side issues that often go with them: fear, fatigue, brain fog, depression, unemployment, tiredness, nausea, sleep reversal, and don't forget fatigue and nausea. (Yes, I know I repeated some of those. I'm trying to stress that there is a lot of those.)

I also don't want to be insensitive to you who are in the midst of battle. Battling insurance issues, medical issues, depression and fatigue along with all of the other aforementioned maladies. You might even be battling with the people that you are depending upon to keep you alive. Rest assured, though, that I do know how it can be. Beyond that, I know how it was. It was that way for me just a few short months ago, and for six long years before that. Yes, I was on the waiting list for six years, through cardiac arrest, four comas, etc, etc, etc.

Instead, I want to inspire you to keep fighting, keep putting one foot in front of the other, keep the faith, the hope, the determination to make it, to get there, to finally celebrate victory over this insidious viral-caused disease. Because when you make it through all of that, it's a whole new world. It's all worth it.

Right now, I'm feeling so good about life in general that I'm actually looking forward to going through HepC treatment again.

Yes, that's right. My HepC is back. Some of you already know that, but I haven't actually blurted it out in a public space like this, so here it is: my HepC has returned. I found out just a couple of hours before I went into my transplant surgery, as I was lying in bed, needles and tubes protruding from me in three or four places already. Eventually, I would have a dozen or so needles and tubes in me during the anticipated surgery, but that's a story for another time. Suffice it to say that that's just one small bit of the information that most transplant patients don't tell you about and that I was only able to find out by experiencing it.

Now wait. I have to stop for a moment to make a side comment. There are so many stories and thoughts that run through my mind as I write, so many different directions I could go with this, so much I want to share with you, that I find it hard to keep this blog short. Eventually, I'll get all of these thoughts out on paper, but in case you think I'm just scattered and schizo, please just stay with me, I'll eventually explain everything. Probably not today, but send me a note if something piques your interest and I'll go down that rabbit hole next time.

Yet I digress. This is my HepC blog, not my transplant blog, so let me get back to the subject at hand … Hepatitis C. If you're reading this, you either know me already and you're just following along on the journey, or perhaps you or someone you know is affected by HepC, or maybe you're a bit of both. Whichever you are, here it is in a nutshell:

I've gone through treatment twice already. The first treatment was old school, interferon and ribavirin. It was a really hard treatment to go through. Injecting interferon once a week, eventually injecting procrit once a week in order to encourage my body to replace the red blood cells that the interferon was killing, and also eventually injecting neupogen once a week in order to encourage my body to replace the white blood cells that the interferon was killing. At the same time I was taking ribavirin every day, and all of this went on and on or so it seemed. In my case it lasted almost 8 months, accompanied by loss of appetite, nausea, sleeplessness, depression, and a host of other nasty side effects. It wasn't until I was done and my body slowly cleared all of the poison from my body that I realized just how hard it really had been.

Then, four months after completing that first treatment, my HepC returned. My viral load climbed quickly to a point that was three times higher than it had ever been previously. (I think HepC's motto may be "if it doesn't kill me it makes me strong.")

So, about a year ago, I started HepC treatment a second time. This time, because I have genotype 3a, it was Sovaldi and Ribavirin. For most patients, that's a three month treatment regimen. For me, it became 6 months. I again achieved undetectable status, then continued my treatment for another three months. This time, the treatment was quite tolerable, although the ribavirin finally began to get to me and make me nauseous during the last month or so.

I completed that treatment on April 17. On the day of my transplant, June 2, I found out it was back.

The good news is that regardless of it's return, I feel great. I know I said that earlier, but I can't tell you much different my life is. Granted, I've been very, very fortunate to avoid complications. My recovery continues smoothly and without a hitch. But my mind is clearer than I can ever remember it being. I can concentrate all day long. My fatigue has evaporated. My sleep reversal issues are gone. It's really unbelievable.

And THAT, is where the time has gone. I have felt so good and been so focused that time has been filled up with thoughts and deeds. I'm gently jogging and working out. I'm immersed in videography, learning and filming and editing. I'm walking with my dog. A lot. Melisa and I are getting out to see some shows, some street fairs, we've been sailing a couple of times, etc, etc. That's what has caused the time warp I referenced in the title.

So, now that I've trotted down that little path for a while, let me return to the subject at hand, HepC.

As of today, I have been cleared for my third round of treatment. I will be starting a regime of Sovaldi, daclatasvir, and ribavirin sometime near the end of December. At this point, I anticipate a 12-week regimen. This is currently the best option for genotype 3. Some patients don't tolerate ribavirin very well. I seem to do okay with it, though it begins to wear on me after a number of months, but this will be the shortest duration I've yet undergone, and I have the best chance so far to finally "slay the dragon." I don't anticipate any problems with the treatment or side effects.

As I wait for the treatment to begin, I remain amazed at the remarkable changes in my life in the last few months. Instead of merely dreaming of a future, I'm now planning for one. That's a huge difference.

So, in closing, I hope to encourage you. Keep your head up, stay focused, keep the faith. You can win your battle, as I will win mine. To be honest, I'm not overly anxious about my upcoming treatment. Yes, I want to get started. Yes, I want to finish it. Yes, I want to kick the dragon's butt. As my friend Mills Lane (he was really just an acquaintance, not really a friend, but he was a well-known boxing referee if you're into that sort of thing), used to say: "Let's get it on!!"

But at the same time, if I don't beat it this time, there are more new treatments in development right now. Eventually, I WILL win this battle.

In the meantime, "I'm so busy livin' I've got NO time for singin' the blues." (That song WILL be on my next CD.)

Stay strong. Stay tuned.

I wish you peace and love.

Dan
