Flashing back - episode 1

June 21, 2015 By Dan Palmer

Hi friends -

When I first got sick, I fell into a black hole. After my first 3-week hospital stay in August of 2009, I was released and told not to return, that I had four months to live and there was nothing that I could do for myself, nothing they could do for me, and if there was anything I had always wanted to do, that I should do it now and put my affairs in order.

As they wheeled me out of the hospital, complete with an oxygen tank (my esophageal varices had burst and I had gone “code blue”, which means I experienced cardiac arrest and flatlined), Melisa was reading the discharge papers. She asked the nurse “what is ESLD?” The nurse said, “that stands for End-Stage Liver Disease, that’s what Dan has.” After three weeks of fighting for my life, it was the first time we heard what was actually going on with me. No one had given this diagnosis before, and hearing the words “end-stage” was immediately frightening.

Previously, I had been fighting my health issues with natural homeopathic remedies, all to no avail. I tried it all: colloidal silver, n-acetyl cysteine, milk thistle, dandelion root (even searching it out fresh from a local organic farmer), I had been injected with large doses of Lasix (a diuretic, also used in race horses, where the term ’piss like a race horse’ originated) and I had been through oxygenation therapy for my blood, special infrared light and far-out radio frequency treatments, and many other unsuccessful, even “quack” (with no scientific evidence that they work) treatments.

Those treatments gave way to paracentesis, where they insert a needle into the abdomen, the needle attached to a flex tube which is attached to a vacuum bottle, and withdraw fluids from your belly. At first, this was done in the doctor’s office (with no ultrasound available, which poses it’s own risks), and later at an outpatient facility. At that facility, they withdrew 16 liters of fluid on a Friday afternoon. That turned out to be way too much, and I barely survived the weekend. When I called the facility, they said they don’t do follow-up care, they only do the procedure. Of course, my naturopath D.O. doctor was gone for the weekend, probably buying a new car with the money I had already paid him, or at least out playing golf, so we were left alone and fighting blindly for my life. I experienced severe shock and barely made it until Monday.

Getting ready for an ultrasound
of my liver

Ultrasound Underway

Anyway, five or six days after being discharged from the hospital, Melisa was able to secure an appointment, due to her constant vigilance in calling, checking on, and begging for cancellations, at California Pacific Medical Center (CPMC) in San Francisco, for the next day.

We borrowed my brother's SUV, put a mattress in the back, where I crawled in with my oxygen bottle and got as comfortable as I could for the normally 4 1/2 hour ride to CPMC. 6 1/2 hours later we arrived, found a hotel, checked in, and were at the hospital the next morning. I was expecting to discuss how I might be considered for a liver transplant.

Within a short time of meeting the doctor, he recommended they start some testing right away, especially since we had come so far to get there, that it would take a couple of days, and then I could go home.

As it turned out, I spent another three weeks in the hospital, and with the exception of a few gigs and some visits with family, I have not returned to the place that I called home for over 30 years. I left behind my family, my friends, my business associates, everything.

At the end of that three weeks, Melisa and I were convinced that we needed to stay close to SF, and avoid the complication of needing to cross Donner Pass, notorious for huge winter blizzards and storms, in the event of a call for transplant. So after spending a couple of days back at the hotel, we went for a drive through the Stockton River Delta area, exploring options for residency. We stopped at a hotel that night, where I entered an encephalopathic coma while I was standing upright. When I next woke up, I was alone in an unknown place, intubated (meaning I couldn't speak because of the tube in my throat), and tied down in the bed so that I wouldn't pull IV's and tubes out while unconscious, and it was three days later.

Melisa had stepped out of the room for a few minutes, leaving me alone and terrified for a few interminable minutes.

At the end of another three week residency at CPMC, I was again released. We had decided to settle in Sacramento, which is halfway between Northern Nevada and San Francisco, at the base of the Western slope of the Sierras, and that's where we settled for the next two years.

Somewhere along the way, Melisa started a blog at Caring Bridge. Though the first few entries seem to have been lost or deleted somewhere along the way, I am going to begin to copy/paste some of those selected writings here so you can learn more of my journey, probably on a weekly basis. If these entries pique your interest, you can go to that site and read most of my back story. Melisa made a lot of the initial entries until I was able to take over.

So, here we go, starting Dec. 8, 2009 and ending with my first entry on December 15.

Remember, the best way to keep up with my journey is to "follow" this blog. I'll have another new entry soon, probably early next week. I'm just trying to decide what to write about, as I have so much to choose from, lol ..

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Dec. 8, 2009

Thank you to friends that are entering notes in the Guestbook-it's exciting to see the hello's. Dan's family and I just returned from an educational day in San Francisco with the liver transplant staff. We attended a 1.5 hour high MELD score class-please google MELD score to find out what that means-it is a score that is very important to us weekly. We attended a 1.5 hour support group meeting-each of us introduced ourselves and said what we felt like saying and we met several amazing people who have already had their transplants and a gentleman whose sister and brother-in-law who have just moved next door to him to be his support people. We had a 45 minute Q&A with one of our favorite people on the liver transplant staff who continually helps me & Dan in every way she can and then we had our hour doctor's visit with Dr. Davern who has written an article that explains our current monitoring of Dan http://knol.google.com/k/hepatic-encephalopathy#

I hope that Brother Dan will get his transplant soon. He is stable today with a touch of encephalopathy; per our doctor. Today was a very important and powerful day for the family. Please be sure to check in for updates. Kindly, Melisa

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Dec 9, 2009 9:53pm

Melisa here-our calendar is continually changing. Dan's tooth broke on Monday and now we have some major dental work to do. This is actually how it all began in May, a broken tooth, antibiotics & zap-Dan's body blew up to 246 pounds in a matter of a couple of days. We will head to San Francisco tomorrow to work with the dental complex that is connected to the liver transplant center. We will put Stella (our dog) in the local boarding facility for an overnight or two stay. Does anyone have friends in Sacramento that takes care of animals? Dan will not be driving until after his transplant because of his encephalopathy. We will need to do a fundraiser in 2010 for basic travel, hotel, gas, living expenses. We look forward to reading the Guestbook entries-thanks for checking in with us.

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Dec 12, 2009 6:33pm

Our "miracle tour" is continuing and is just that. The head guy at the dental school in San Francisco (also attached to the transplant center) went above and beyond his call of duty yesterday by getting us in to an emergency dental surgery for Brother Dan. Dan is comfortably moving forward with ice packs on his jaws and eating lightly having to take pain medication because of the extractions. We are back home in Sacramento and happy to have a place to recover. We will head back to San Francisco this Thursday to meet another surgeon to talk about the liver transplant that we are striving for. Thank you all for being our support people. We CAN NOT do this without you. Love, Melisa/Brother Dan & Stella

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Dec 14, 2009 3:30pm

Melisa here. Thank you so much for sending your love on the Guestbook Page-Dan looks at it daily. He is recovering from last Friday's dental surgery. We are putting all the food in a blender for him to eat and Brother Dan is resting a lot with ice packs on his jaws. Dan is a trooper and everyday he is trying to get stronger. We will be meeting with a surgeon from the transplant team in San Francisco on Thursday to learn more about how to get Dan further up the liver transplant list. Because Dan is doing "good", meaning walking/talking/eating, he is on a pretty long waiting list. Keep us in your prayer's.

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Dec 15, 2009 11:16am

Okay, it’s my turn to say something. First, thanks to all of you for your ongoing love and support. The notes you leave really do make a difference, especially on the harder days.

Everything I’m going through is a double-edged sword, both good news and bad. For instance, I’m feeling better, and my MELD score is down to 14. So the good news is, I’m feeling better. The bad news is, that means I’m further from getting the transplant I need.

**NEW NOTE: I’m not sure that Dr. Davern’s article that Melisa refers to in an earlier journal entry is still available, so click here for a MELD score defintion and here for a definition of Hepatic Encephalopathy. I was at 29 on the MELD, had a TIPS in my liver from Aug. of ’09 until transplant, and survived 4 HE comas, all of which are referred to in those two links. Now, back to the original post …

I was able to get out to a pickin’ circle last week and played for a couple of hours with some local boys. Melisa dropped me off and got back in time to hear me sing “Diggin’ Up Bones”. Later, with a tear in her eye, she told me how beautiful it was. I had to laugh until she told me it’s the first song she’s heard me play and sing all the way through in seven months. I guess it is a beautiful thing.

A couple of nights later, I made it to a coffee shop a few blocks from our apartment for an all-original open mic night. I did three songs, and only dropped a couple of phrases in one of them. (Can you say ’encephalopathy’?)

Anyway, all told, things are looking up. Although it’s morbid, I’ll be staying in Sacramento for the holidays in order to be close to the transplant center, as the holidays are a time when lots of people die in travel accidents. In fact, in the SF support group, it’s said that “motorcycle riders are our best friends”. Even though I am one, the risk of death is higher, and guys like me get a new liver when guys like me are done using theirs.

Once I receive a transplant, it will probably be a year before I’m able to return to international travel, due to rejection issues and other possible complications. In the meantime, my songwriting is taking on new purpose, and I hope to be up to recording a new CD (or even two) this spring. That will of course require financing that I don’t currently have, and as my condition pretty much precludes me from working, you’ll be hearing more about my financial needs as things progress.

Thanks for the love and support you all give me. My medical fund bank account is still available at any Bank of America branch, just ask for the “Brother Dan Medical Fund” account, and you should be able to deposit directly into it.

Write to me, and I’ll respond when I can.

Love to all . . .

Brother Dan

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Well, that’s probably enough for now … thanks for following along, and reliving some of my past with me, and I’ll be back with current updates and observations in my next post.
By the way, the bank account referred to above is no longer in existence, but if you’re interested in
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supporting me, I’d be honored if you’d buy a couple of my all-original CD’s. I have two of them available, “Nothing Better Than This” and “Fishnet Stockings,” and they sell for $15 each or two for $25. If you order them both, I’ll also send a copy of a 3-song EP of songs written specifically for Liver Patients. That cd includes “Lactulose Is My Friend,” “Since I Stopped Drinking Beer,” and “Thoughts of My Friends.” The song I wrote for caregivers, titled “Don’t Walk Away”, along with “Since I Stopped Drinking Beer” and “Thoughts of my Friends” and many others, is already on the Fishnet Stockings CD.
Alternatively, you can listen to and download the lactulose song at my ReverbNation page for free if you simply want to have a laugh and learn about lactulose, its effects, and the love/hate relationship I’ve had with it for the past 5 1/2 years. https://www.reverbnation.com/brodan/songs Just drop me a note here or at Facebook and I’ll get right back to you with details and to get your address if you want to contribute. I accept PayPal payments, so it’s an easy process.
I love you, and wish you peace.
Dan

This post first appeared on Dan’s Perspective blog, June 20, 2015 and is reprinted with permission.
