Time to get Listed for a Liver Transplant

July 29, 2015 By Karen Hoyt

Karen Hoyt is a blogger who has a story about hepatitis C, cirrhosis, end-stage liver disease, liver cancer, and liver transplantation. This excerpt first appeared on Karen's I Help C blog, July 2, 2015

I am absolutely positively sure that every person who hears the word transplant in regard to their own body takes some time to freak out. Moi included. My doctors and team gave me a lot of information but it was a little blurry. I had instruction and tons of paperwork for sure. But I was also running around getting chemo and tumor blasting procedures. I had bone scans, MRIs, a bajillion vials of blood drawn. Looking back from the vantage point of 10 weeks post transplant, I thought it would be helpful for you to see a bit about the time to get listed for a liver transplant.

Every person will vary according to their diagnosis so this will be a pretty general discussion. If you have been listed for a liver transplant because of liver failure, your experience will be very different than mine. For example, you will probably be as yellow as a daffodil (jaundiced), look pregnant (ascites), and be in and out of the hospital prior to transplant. You may or may not even be aware of what is going on around you due to brain fog (hepatic encephalopathy). In either case, your transplant team, family, and friends will be doing a lot of the thinking for you.

My experience is from the viewpoint of liver cancer. My journey started the day they found the tumor on ultrasound. It was on Friday and they sent me right down to get a CAT scan. I heard back on Monday that was indeed a tumor and they had scheduled an MRI. From there all of the information went to the tumor board.

After the tumor board pronounced that they were going to treat the tumor with TACE, (read about that here) the testing began for transplant listing. My pre-transplant coordinator was Barbara. no pic :(She has worked there for almost 20 years. Beautiful, smart, logical and to the point, it was her job to make sure that myself and many others were listed with UNOS and kept up to date in the system. Her assistant, Angela, stayed busy giving me instructions. There were checklists, emails, and phone calls. I was a hot mess. I would forget where to go and she would email me a back up copy of my schedule. She also handed out great, and I mean really really great hugs every time I saw her. I'm crying now remembering how tightly she held my hand and heart through the process. I love you Angela.

I had to get a mammogram, dental check up, pap smear, and primary care statement. You men will get to skip a couple of those tests. The team has a goal in mind with all of this; the bloodwork and tests were performed to be sure that cancer had not spread to any other part of my body. If it spread, I would not make the transplant list due to Milan Criteria. Those tests are repeated every three months to stay on the UNOS list.

Meanwhile, a transplant evaluation schedule was made at the hospital. I was to take family members with me to Oklahoma City for 4 days. My daughter and granddaughters were my posse. We got a family suite at a hotel within walking distance of Integris. It had free breakfast, a pool and a little kitchen. We did our best to make a party of it. They had practically moved in with me any since the diagnosis and

wouldn’t let me out of their sight. Plus I knew that my brave girl armor was always strongest when I was around my kiddos. With my husband or sisters, the chance of a meltdown was greater.
The transplant team looked at 3 different areas of my life. Physical, Psycho-social, and Financial. It’s like a 3 legged stool. If one leg is weak, the other two can’t hold up...
To learn about a typical liver transplantation listing process, read the rest of Karen’s blog "T[ime to get Listed for a Liver Transplant](#)"

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