

Transplant House of Cleveland Caregiver Tips

These tips might be most helpful to a caregiver/patient from out of state, and a caregiver who's working full-time.

Our journey took 16 years on a transplant list to finally get the transplant at Cleveland Clinic in Ohio. We had some time to think ahead about moving temporarily to Cleveland, so that gave us time to plan.

PRE-TRANSPLANT

AT HOME

Not knowing how long we'd be living out of state, to prepare, we asked a friend who was a **handyman** to come to our house and get familiar with things so that if our daughter living at home while going to college needed anything when we were gone, he'd have some idea of our circumstances. Thankfully, nothing ever happened.

AT WORK

At the time of my husband's liver transplant, I was working for a private university in Southern California. While being vetted at Cleveland Clinic, our social worker connected me with another wife caregiver, also out of state, with similar circumstances like mine—working full-time as a director—while waiting to get the call for her husband's organ. I took her advice, and had a conversation with my boss and my team about how one day I was going to "go dark." That they would only get a text from me saying that we got the call and are flying out to Cleveland. This prompted my department and my boss to prepare ahead of time. We were able to designate who was going to pick up which projects, and I was even able to bring in a freelance writer to pinch hit for me. When we received the call from our transplant coordinator that it was time to move to Cleveland, that's when I went dark. However, after moving there, my employer allowed me to work remotely—something that I know is extremely rare among caregivers because I met many while living there at Transplant House who had to quit their jobs, or lost their jobs to take care of their loved one. My employer didn't owe me the blessing of working remotely. They did, by law, owe me Family Medical Leave, but not the ability to earn a paycheck as I cared for my sickly husband as he waited for his transplant. The desk in our Transplant House apartment kitchen served as my "office" while our bedroom served as my "meeting room" to do phone calls with my boss. The best part of this was the different time zones. With Ohio being three hours ahead of California, I could answer emails before we'd leave for doctor's appointments in the morning, and my boss would have them in his inbox when he'd sit at his desk in California. And I could take the time with my husband during our hospital visits not having to rush back to my work.

TRANSPLANT

Do what your doctors tell you. Listen to them—patient and caregiver alike. They've gone before you, they know what they're talking about. Don't push the envelope to see what you or your patient can get away with. Respect your donor family and take care of your new organ. They made a very brave and courageous decision to allow their loved one to give life to complete strangers like you. Honor their choice.

We chose to not rent a **car** while living at Transplant House of Cleveland. With the amazing shuttle system that the Cleveland Clinic has—that can even take you to CVS for candy!—you really don't need a

car. When I needed to do a Costco or Walmart run, we had some amazing neighbors and friends at Transplant House who would either call me asking for my grocery list, or would give me a ride to the store while they also shopped.

Take **care of yourself**. Exercise by taking walks on the Cleveland Clinic campus, or around Transplant House. Walk to the art museum or shuttle to the museum and then walk indoors, get coffee at Presti's in Little Italy with another caregiver, walk to Case Western's campus. Do it because you can. Clear your mind and gain some sense of normalcy, even if it's just for a moment. You need to get away from your all-consuming role of being a caregiver and take care of yourself. It's ok!

Meet other caregivers at Transplant House. You just might make a new friend or two. Share stories, laugh together, fold laundry together—all to feel normal again for a moment. Go to the caregiver coffees. Go to the weekly dinners. Break bread together and be encouraged. Community is important. No one else will EVER know what you're going through. Not even your own family. But a caregiver will. Lean on them.

As you meet caregivers, it might turn out that your spouse and their spouse have more in common or just get along. Invite the couple over to your **apartment for dessert**. Host company in your apartment. Doesn't have to be a full spread. It could be cookies and ice cream from Walmart. Make a pot of coffee. No one's judging. Visit and feel normal again. It's a nice treat.

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Caregiver to husband Jerry who had a liver transplant at Cleveland Clinic April 8, 2018.