



Transplant House Guests: Kati and Kathy

A young woman with cystic fibrosis breathes easily now, thanks to a double-lung transplant

Until recently, Kati only knew a life with cystic fibrosis (CF)- a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time. That life required Kati to perform 12 breathing treatments each day to keep her airways open and to thin the persistent mucus in her lungs. Despite the limitations of her disease, Kati grew to do many things she had hoped to do, including attend college, play sports, and hold a job. She knew that one day she might need to consider a lung transplant, as there is no cure for CF.

It was rather suddenly, at age 33, that Kati's disease turned worse. "I thought Lizzy would be the one," Kati explained, naming her older sister, who also has CF. "I had envisioned how I would support her through her transplant."

Kati's medical decline became significant in 2015. She had just traveled for work and for pleasure to four different states, and was working out at the gym five days each week. Therefore, it was a shock when in February, her doctors at home in Chicago began talking about transplant. Kati visited Cleveland Clinic in September 2015 to begin the evaluation process for a lung transplant. Shortly after she returned home from that trip, her health deteriorated rapidly, she was hospitalized at Northwestern, and almost immediately, was sent back to Cleveland on a medical flight. Her parents, Kathy and Pete, who live in Oklahoma, flew in to Cleveland, too.

"When you are born with a disease, you think you understand it," Kati explains. "But this was sudden. We are the type of family that talks things out together. There was no time for that. We ended up in such a state of not knowing. We made decisions quickly. We needed to catch up mentally and emotionally and couldn't."

While Kati was hospitalized at Cleveland Clinic, her parents stayed in an on-campus hotel for the first few nights. Soon, Pete had to prepare to fly back home to work and hated the thought of leaving Kathy with no car, staying at a lonely hotel. "We had a scenario in mind for all of this- we thought we'd have more time to plan," said Kathy.

Thankfully, someone told Pete and Kathy about Transplant House. Pete was visibly relieved to see the space and learn that the 15-apartment row house building that constitutes Transplant House is more than convenient and affordable. It would surround his wife and eventually his daughter with staff, volunteers, and other families who would watch out for them. It would allow them to take a free shuttle to the hospital, and find all they needed in the neighborhood, without a car. Kathy checked into the House and began to think of her 550 sq. ft., full-furnished and equipped apartment as "home."

Kati waited 4 ½ weeks for her transplant- hospitalized the entire time. Kathy shuttled back and forth daily, visiting Kati at the hospital during the day and rejuvenating at Transplant House in the evening. At the hospital, Kathy did all she could to understand Kati's condition, get to know the medical team, and help Kati stay mentally and physically strong during the indeterminate wait for the lungs that would save her life.

At the House, Kathy could do things that she would do at home- cook, bake, do laundry, watch TV, sleep well, and take walks. She could also join the weekly "family meal" - provided by volunteers in the community space, and get to know the other guests, and give and receive support.

"Two days after Mom's birthday, the organ donation came," Kati explains with eyes glistening. Kati's transplant went smoothly and her recovery progressed just as doctors had hoped. Just two weeks

after transplant, Kati was at Transplant House with her mom, shuttling to the hospital for the needed biopsies and blood tests several times weekly, and “practicing” being at home before she would be allowed to return to Chicago.

“Transplant House offers a good mix of space- our own space that allows us time to be alone, and shared space that allows us to talk to other people who understand this unique situation we are in,” explains Kati. “You have to absorb what you heard at hospital. Whatever stage of the transplant process you are in, there are emotions that go with that stage. At Transplant House you can find support for that. It gives a sense of home that a hotel just doesn’t give.”

“What am I going to do with my time now?” asks Kati, giggling. “CF is so time consuming! There were 12 breathing treatments a day and now I’m down to one per week. I used to be up at 5:00 a.m. for a 45 min aerosol, then I’d have a workout. At 6:00 a.m., I’d be back home, do treatments, get enough to eat, rest, do aerosol treatments again....there were not enough hours in day.”

Kati adds: “I am now [less than two months post-transplant] back to exercise- walking to the store, and doing things I had put on hold or had given up. I am excited to have those things back. I haven’t come off that high yet.” She says that she is most happy to be able to laugh. “When coughing makes you sick, you suppress your laughter. I had done that all my life. But at Thanksgiving this year [after transplant], my stomach muscles hurt from sitting with family and sharing stories and laughing!”

Kathy recalled her daughter taking her first deep breath, with her new lungs. “We were walking back to the House from Starbuck’s, up an incline that would have been too much of a challenge for her own damaged lungs. Kati stopped and breathed deeply- beaming over this gift and personal victory.”

Kati further describes the importance of the House: “Coming back here [to the apartment] it’s all on you- no nurses. You have to deal with your new routine. There are 20 meds and eating mindfully. Having a kitchen is great and so is the location. We can walk around safely. It feels like in a neighborhood and you feel the energy of the college here. I can’t imagine not having this place.”

“If I were going through it again, I would evaluate a transplant program based upon housing. We know how important it is. A hotel is not sufficient,” says Kati. Kathy, nods in agreement.

We said a fond and excited farewell to Kati and Kathy in February, 2016- three months after their scary arrival in Cleveland. Just two weeks after Kathy returned to her home and to Kati’s dad in Oklahoma, daughter Lizzy was called for a lung transplant in St. Louis, so Kathy was quickly on a flight in a new direction, to be support through the life-saving procedure again. Both young women are doing very well, and have since run a 5K race together!

Kati has a degree in Public Relations with a hospitality focus, so we hold her praise of Transplant House in high regard. She had been working for W Hotels before her transplant, and it became difficult to give hotel tours while pulling an oxygen tank. She stepped down from that position, but was able to work from home in a different capacity. Her employer allowed her a leave of absence during her transplant and recovery, and Kati is now back at work- promoted to Director of Sales. We recognize W Hotels for its compassionate, reasonable and responsible treatment of Kati.

*An ornament painted
By Kati, honoring the
Angel who donated
Her lungs*

