

## Until You Don't Anymore

Sorry? Say again? Oh, yes. The tour has started already. Actually, I saw the group head into the lecture room a little while ago. It's too late for you to join. First time to the Center for Living? Up for transplant, right? Well, the oxygen tank is a dead giveaway. They will want you here on time, you know. You'll have to work on that. Really? You don't say? I mean, I understand why you're late. You don't have to explain yourself to me. I can tell you though, they won't care. The transplant team expects you here five days a week, if at all possible. Me? Oh, I don't work for the gym. I've been helping my sister who just went through a double lung. Today's her last day of rehab, actually, but she's in the locker room now taking a shower, so I'm just waiting, probably for a while. Does she need help in there? Maybe, but now that she's post-transplant she's trying to do as much on her own as possible. She likes her privacy, as I'm sure you understand. And, there are emergency cords in all the shower and toilet stalls, so the front desk would be alerted and they'd tell me. Really? You took care of your mother all that time? I hear kidney cancer's a bitch. I'm sorry to hear that. Hey, don't shortchange yourself. It may have been years ago, but I don't care; once you see someone that way, I don't know, it just changes you. You know, if you want, I can give you the informal tour. I've still got some time before my sister's ready to go and, with some luck, we won't be back to this gym for a while. No, there's not a planned future procedure, but with lungs you never know how long they last. So let me give you a leg up. They don't tell you much anyway, the physical therapists, or the booklet about lung transplant. Trust me.

Okay, to start, all the doors have the same handicap square that you push to open. If you have a cane, feel free to use that, and often someone will be in front of you to push it first. It stays open plenty long enough for you to shuffle your walker through. Did you see Lee when you were walking in? Sitting on the bench under the awning? Good. He's nice and always there. His daughter just had a double lung too, and only had to be in the hospital 17 days. She came back a few days ago for post-op rehab. Her name? I have no idea. You'll find that here; names are nothing compared to your disease and outcome. You'll resist that at first, make an effort to put names

to faces, humanize their identity. You'll be proud of your effort. Then one day, you'll look around, and realize that whatever names you remember no longer have faces, and anyone you can label are by why they are here or how close they are to surgery. Anyway, Lee is her caregiver and sits outside for hours, pushing the handicap button for everyone. He always gets my name wrong, but he's sweet and tries, so I don't mind. You should say hello and smile and thank him when he pushes the button. It gives him something to do and you, human interaction. Where you came in just now, on the left, is the front desk where you flash your gym card. It should have been in your packet. It wasn't? You'll need to get a new card then, before you leave. This is technically an open gym for anyone who pays. I have a membership so I can come help my sister in an "unofficial" capacity, but I never workout here on my own. I mean, it's a little depressing. But that's why you'll see a scattering of people that don't fit in, running freely on a treadmill or leg pressing two hundred pounds. You will want to ignore them, gifted with health, just as they ignore your deteriorating bodies. We all do what we can to stave off the weight of mortality. Gyms are supposed to be invigorating, life affirming, and I guess, for you, it can be too. If you're lucky.

That is Brenda behind the desk. You don't have to talk to her, but saying hello, or nodding, is nice, but she never really notices. Occasionally she will comment on your shirt, or the color of your hair, or ask "How ya doing?" in a too-sweet voice if you look particularly shitty. Do not answer honestly. You will be disappointed by her lackluster response. If you want a locker, she is the one with the keys. This is the pile of towels, just to the right of the front desk. You always get a towel. It's a sanitation thing. You sit on this towel, wipe things off with this towel, wheeze and cough into the cleaner side of this towel. They also make you wear latex gloves whenever you touch anything that someone else might touch. You're allergic to latex? Oh, then, I bet the PTs have some you can wear. Or they may let you bring some gloves of your own. You'll have to ask. If you get a cold or are particularly paranoid, you will also need to wear a facemask, which will get sweaty and start to smell bad. Chewing gum helps with the smell. If you want, you can Purell your gloves instead of changing them to cut down on waste. It's been done before. These

doors on the left, and those down on the other side, go to the locker rooms. I've never been in the guy's, but the girl's is nice—warmer than the open gym, showers with really good water pressure, big lockers and long benches, and a scale to weigh yourself. You have to record that once a week. You will not spend much time in there though, at least not until you are done for the day. They do not want you hiding. Mostly, you will rest, and eat your snack, and try to catch your breath here, on any chair along this wall, with the windows that look into the small pool. Oh yeah? I love to swim too. If you ever gain enough cardiovascular endurance to swim again, however, you might want to wait until you go home. Some of the worst swimmers I have ever seen wrestle and slap their way up and down that pool. Swim at your own risk if you have to share a lane, because most who use the pool will knock you out and there is no lifeguard. Anyway, there's no assigned seating, but a few people get territorial about their chair and it's best to let them keep it.

You already have oxygen, but they want you to use their tanks and their walkers while at the CFL. Why? I have no idea. Once you sign in, you go to the oxygen room, which is the next door after the guy's locker room, and someone will switch it out and give you the standard gym walker. You're paying for it, so don't argue that you like your home system better. They don't care. Maybe having everyone on standard equipment helps streamline how the PTs monitor oxygen and patient performance. Or maybe it's something with insurance coverage and the gym makes a little extra by charging for it. I don't know and they don't have to explain themselves. Here is the plastic folio that holds the paper folders for all the patients. Your last name? Ah, here. See? You're brand new, so your color is yellow, for "boot camp." Yeah, I understand your grimace. Your first twenty sessions is called boot camp for a reason. It's a crash-course-blood-and-tears-don't-matter-jump-into-preparing-your-body-to-be-cut-open-and-new-lungs-pushed-in exercise routine. It's all laid out here on the form that you put on a clipboard and carry around on your walker so you can check things off as you go. There should be a stubby pencil tied with twine on each board.

Yes, I agree it sounds unforgiving, but remember, this hospital has got lung transplant down to a science. That's what they keep telling us anyway. In boot camp,

they teach you the exercises and follow you everywhere until they're convinced you won't hurt yourself or someone else. Some people take longer than others to be trusted. Most patients here are new to physical activity, at least leading up to needing a lung transplant. Deteriorating lungs make pushing against the sedentary American norm very hard. Excuse me? Hey, don't get defensive. I'm not criticizing you particularly. I watched my sister do this, and I don't blame you. But they won't listen to excuses. It's probably hard to move around your house, right, which is why you're here, so three hours of activity will be hard. Maybe almost impossible. But remember, if you don't get the checkmark for the day's exercise, you don't get the lungs. Do what they say, even if it's only a sad excuse for the proper exercise. Never compare your movements to fellow group members. You will find horrible form everywhere. No one does them right. Tricep pull downs look like T-rex arm spasms. Assisted squats are hip twitches. Bicep curls look strained and sloppy with three pounds. But the PTs won't say anything unless you are doing it so badly you could injure someone, or doing nothing at all. Movement is what they want. As long as you're moving, even when your eyes are fighting to close and you need to crank the oxygen another unit because you've dropped below 90% blood saturation for the third time, they want you to move. Moving means you are not dead.

Okay, so you check in at 12:30, and before you do strength training there is a floor class in the middle of the gym at 1. Your packet says you need PT? Then that will happen first. Someone will beat on your chest so you can have help coughing up slug-sized mucus, theoretically making the day's work a little easier. Yeah, I doubt that too. It all sounds confusing, but you'll get used to it. You will be bored during floor class. You will barely understand the broken echo of one of the PTs over the microphone, but you will copy her movements in whatever approximation your joints allow. You will sit in a chair if you can't get off of the floor. You will be bolstered and propped up if you can get off the floor but cannot lay flat. You will be assisted into whatever position allows you to keep moving. You will have ankle weights and free weights. They will only be a pound or two, but they will feel heavy and your muscles will quake. You wouldn't be here if it were easy. You will hear "And up. And down. And up. And breathe. And-" so many times you will dream that

slow, metallic rattle in your sleep, with the background of coughing and wheezing and sputtering oxygen tanks. You are used to yourself being the sickest in a room, but now you are only one of dozens. This will not be a comfort. The sound of sputtering machines and people and the smell of antiseptic failing to cover sweat and bile will follow you home and you will need to watch television before bed to escape reality enough to fall sleep. That is, if you sleep anymore with the coughing and the labored gasping for air even with oxygen on your face. You will wake up the next morning and come again, day after day, until you don't anymore.

After floor class you will do the weights and nautilus equipment that I was talking about before. You will grow competitive and possessive over the stations. You will watch out the corner of your eye at people you recognize by face and judge their exercises, while you're waiting for the leg press or the row. Then you will do much better in your mind than your shaky, oxygen-starved body will allow. That, or you will have accepted your disease, identified with it, in competition the other way. Who can be the sickest and still not dead? Who can look the most pained? Who is the weakest in this room and therefore requires the most sympathy? But there is not enough of that to go around. No one has any left; sympathy. The boredom inevitably leaves you with memories of youth and health, even if you never were really "healthy." Even if you were a smoker, or a drinker, or a hundred pounds overweight, that has long since melted away with any strength and the ability of your lungs. The sicker you become, the healthier anything better starts to look. You used to be a runner? Well, it's worse for you then. You might have expected yourself to be more resilient, invincible. You are not used to being sick, weak, staring at mortality every day. Isn't 60 suppose to be the new 40? You've been gypped.

You will think about death, and the ventilator post surgery, and the imaginary donor who's lungs will "save your life." And yet you will be unable to ignore the facts. That the mortality rate of lung transplants isn't bad to start, but then plummets after the five year mark to 50%. No matter how many people say "You never know," and, "There was that one woman who had the same set of lungs for 17 years," you will think about dying, about rejection, and drowning in your own blood bubbling from your chest as your body attacks the foreign organ you just

worked a year to get. You will get used to people referring to lungs as sets and pairs, like the organ transplant system is a catalogue and your "numbers" are your size. You will slip into using these words yourself, even when you're appalled at first. That's how these things work. You will think about all the meds you will be on if you survive surgery. You will think about God, even if you don't believe in that, which is unlikely. You will find a lot of God here. Unless you are a strong non-believer, sickness and encroaching death can make the most apathetic spiritualist come to arms. You will need a reason, you will need meaning, you will need more than oblivion as an alternative.

Then you will need a snack. Many people bring energy bars and yogurt cups. You may bring whatever you want and can keep down. You will want to remain sitting after snack. You will be exhausted. Your eyes will begin to close and you will want to take a nap, but a PT will come over and check your oxygen level and pulse and ask how you are feeling. They do not want an honest answer. Nothing short of passing out will get you out of the work, and even then you don't get the checkmark for the day. And you need lots of checkmarks to earn your new lungs. And do not think throwing up is the golden get-out-of-work card it once was in your younger, healthier times. I have seen enough vomit cleaned off of the track to know that they don't care. If you are conscious and can move at all, they want you to move. If you can help it, save the vomit for someone who will think it still means something.

You will have to dangle the potential for a better life in front of you as the carrot that forces you to stand up from your snack. Then you will push your oxygen tank over to a NuStep or a recumbent bicycle, fall or fold into the machine, and look like you are moving for twenty minutes. You will be bored again, but you will be exhausted and remember how dangerous thinking is, so you will turn your mind off and ride in the no-thought bliss of apathy. You will count down the minutes and be proud when you reach zero on the little screen, then disappointed when you realize both that you have to get off of the machine and that you are not finished. Now you have to walk the track for 30. Walking is hard. Your lungs hate walking. You took it for granted until recently, though you know, even if you could time travel, you would not believe your own warning from the future, your own caution to respect

what you have. None of us really learn any other way than by personal experience. You will shuffle with your walker around the track among others in your similar situation and yet in their own worlds. You do not really share anything with them. You will go around and around the gym, seeing and not seeing people work for their own lives too. You will be faster than some and slower than others. You will hear passing conversations of a few who have enough breath for that. You will hear people's earphones. You will sometimes chuckle and sometimes be annoyed as the Singer Guy passes by you once again. Part of you thinks, "Yeah, if you want to sing, why care about the dozens of people around you. Be who you are," and the other part thinks, "If he can sing so damned loudly, why the hell does he need oxygen? He could show a little respect for the rest of us." Much of your time here will be a confusing mess of emotions.

You will notice there are a few young people—thin, small, and with oxygen tanks too. You will think they are quite young, like ten maybe, and you will think "poor sick kid" even though you are a "poor sick adult." Even to you, sick kids are still sadder. You have two daughters? Then it will be that much harder as you superimpose your own children's faces onto theirs. You will be surprised to find out they are 16, 22, 27. You will not believe it. Even when the youngest in the gym has pink stripes in her dark hair and a lip ring under her oxygen nosepiece, you will think "poor little girl." Even when she is doing all she can to grow up, despite her disease eating away her muscle mass making her even skinnier, you will try to talk to the "sick little girl" and be told, a little too loudly, "I can't hear you. No hearing aids," as she points to her purple head phones with black skulls on the ear pieces that you can tell are blaring but she only hears a little of the bottom beat. You will feel uncomfortable because you have nothing to say anyway, you just feel bad that a kid is as sick as you. No one ever knows how to handle hearing loss, so you will not feel guilty about your inability to communicate. She's the one who's deaf, you will think. You will then notice a young woman walk up to the sick kid and smile, and start signing unknown things with her unwrinkled, swift moving hands that are well fed and pink with oxygen-rich blood pulsing through to the tips. You will look down

at your own hands, and notice the blueness under your fingernails. You will pause, and try to remember the last time they were rosy and warm.

You will look back up and notice the chalky-faced sick kid smile, miraculously, and open up just enough for a beam of life to escape tired eyes and you will not want to look at them anymore. You will feel bad for hating them, especially the emaciated one, for smiling. You will fight your resentment for the healthy one who dares to flaunt pink cheeks and force yourself a grimace, hoping it passes for a weak smile, and you will wheeze out to the woman, "Tell her I hope she feels better," even though you know they are empty words. No one ever just feels better here. You will turn your walker around and out of the corner of your eye you'll see hands and arms moving, but you will have no idea if your empty words are shared or not. You will know it doesn't matter either way. It will be your life or not that you leave this place with. You may learn some names, some diseases, some war stories from the hospital, but there are no friends here. No one has anything to give. You may once again, but walking around this track takes all you've got for now. You will be lucky to have anything at all for your family tonight, for the caregiver that has traveled with you. You have no room for friends. You will soon notice old faces disappearing, new ones arriving. You will learn that it is a never-ending cycle of patients, and the PTs are the only ones who stay. And you will never know, most of the time, if someone left because their transplant recovery was a success, or because they died.

Here. I got you a tissue. That was a big coughing fit. Do I need to get a PT? No? You got breath back? I'm sorry. I know I'm laying it on pretty thick. Guess it's been hard on me too, the past year. But I think it's important to know what it's really like to show up day after day, just so you're prepared. Anyway, we're almost done. Once you complete boot camp, what they call "graduation," that would be your day. But, unfortunately, boot camp also includes twenty lectures you are required to attend. After fighting fatigue for nearly three hours, after months and maybe years of inactivity, you have to squeeze into a small, windowless room to hear "lectures" and try not to fall asleep. You will need to change out your walker again for a smaller oxygen tank holder because there's no room for all the bodies and their full



equipment. Some tanks hiss, some have generators, and the proximity of everyone fills the room full of wheezing, coughing, gasping. Only patients are allowed and attendance is taken. Caregivers have their own lectures earlier in the day. Both patient and caregiver lectures will largely be useless. If they trusted you to read the papers they gave out, they would not need these regurgitation sessions. They will draw outlines of lungs on a dry erase board in black and squiggle lines in red where surgeons will cut. They will show you anatomical posters and give third-grade definitions of the most common lung diseases. They will use a skeleton model laid on its back on a chair to show you how they will lift your rib cage away from your body, and you will see the plastic cartilage stretch and you will feel the chill down your own spine, as the PT points with a pencil the different places they might make the incision to pull out and push in lungs. You will learn that, while lungs have to match your body to a degree, they can cut, trim, and mold the donor organ to your chest cavity. You will learn about blood vessels, and bacteria, and what rejection looks like, and all the meds you will be on for the rest of your life and how important proper shoes are for walking and how the donor system works with organ matching and about the ventilator and walking the next day after surgery and when, at the end, you are given a chance to ask questions, no one ever does. Maybe because half are nodding off after all afternoon fighting inertia, maybe because you know too much as it is, maybe because the only way you keep going is to not think about it too hard—to put your body in the hands of strangers who've spent many years of their life becoming an expert in taking diseased lungs out and putting healthier ones in.

Remember, this program runs like a machine. You cannot think hard about the medical system, about how much trust you are putting into this hospital, into pills, into policies. You cannot think about how much this is costing you, your family, even with medical insurance, because there are many different types of payment. You sit there, catching your breath, trying to stay awake as the representative from some non-profit is talking about why they are raising money for lung transplant specific research. You cannot digest the fact that out of all organs, lungs are one of the least successful over time. You take the info sheets passed around, you look at the models, you hear words, you wait until 4:15 when it is all over and you can go

home, or the hotel, or apartment that you have rented for the duration of the transplant process. You bargain with existence, you barter for days, you think, "It will all get better, it has to." You will try not to think about all that as you wait for someone to help you into your car. You will try to rest up and be back tomorrow to do it all over again.

So there you have it. What I've learned, in a nutshell. Even describing this place is exhausting. Yeah, I know, and I'm not even a patient. True, caretakers give a lot, but it's different. Oh, hey, look who's finally come out of the locker room – behind you, that's my sister. There, she's seen me now. Shit, she looks tired. I need to get our stuff and load up. Tomorrow we drive home, our real home. Feels like a long time. Oh, one last thing: you should be clear about what you are working for, what makes all this worth it. Yes, "family," I know. That's always a big one. But still, you're doing the work, you should know why. Well then, nice to meet you, and best of luck. You're going to need it.