

**A Story of Hope and Inspiration
with Linda Olson**
Davis Phinney Foundation

Linda Olson: My life as an amputee and our lives, as Parkinson's patients have a lot of similar challenges, challenges we didn't ask for and challenges we share with our family and our friends and caregivers, things like walking, trouble with our hands, and sometimes just looking funny. Let me introduce myself the way I heard often 41 years ago, while I was an inpatient in the hospital. Linda Olson is a 29-year-old third year radiology resident who was involved in a train versus motor vehicle accident in Berchtesgaden, Germany. This resulted in traumatic amputation of both legs above the knee and a high above elbow amputation on the right side, along with fractures of the thoracic and lumbar spine.

Three and a half weeks after the accident, the patient was medevac'd back to the San Diego Naval regional medical center. Now, since I never lost consciousness, I could remember everything that happened that day when our van stopped on the track. I could see a monstrosity, huge train coming toward us. I remember trying to get out of the van and rolling onto the track. Then, looking into my husband Dave's eyes as he grabs me and for an instant, holds me in his arms. The breaking train screeches toward us and just when it can't get any louder, there is an earth-shaking crash as the locomotive smashes into the van, toppling it over onto the top of me and pitting me under it as I lay on the track.

Maybe I can stay alive if I hold my breath long enough. If I let it out, I'll never breathe again because the van is pressing down on me. I'm moving, sliding down the track, and then it stops. I have no feeling. In the stillness, I hear strange words. It doesn't matter what they are. If I can hear them, I'm still alive. The train backs up. I hear shouts as people grunt and strain to lift the van off of me. I'm told later that I was pushed the distance of two football fields down the track before the crumpled mass of me and the van came to a stop. It was really only 30 seconds from the beginning to the end. I look up and I can see the sun. Strangers peer down at me and they're easy to see because my glasses are still on my face.

I smile as they talk to me. Uh oh, something's not right. They're speaking gibberish. And then I remember I'm in Germany. They must be speaking German. They've just pulled the van off of me and I'm alive. Waking up in the Salzburg trauma hospital, I know where I am. I know what happened. What I don't know is how my husband Dave is doing. I haven't seen him since the accident. I had been told that he broke his ankle and was knocked out. But will he be okay? Will he be okay with a severely disabled wife

when he married a cute slim doctor whom he hiked with, biked with and traveled with? What if I can't do these things anymore? Why would he want to stick around?

The double doors swing open, and I hold my breath as Dave hobbles in with crutches, his left leg in a walking cast. I feel like I need to be strong for him. So, I smile as he reaches the side of my bed all the while silently rehearsing, the two sentences, I've carefully memorized. I've been thinking about things. I'll understand if you don't want to stick around. And then I wait. He lets go with the crutches and tears run down his cheeks as he squeezes my hand. I didn't marry your arms and your legs. If you can do it, I can do it. We'd been married less than two years when the accident happened. I remember saying the old-fashioned vows to have and to hold for better or for worse. We thought we knew what those words meant, but what if the minister had looked into the future and said to us, do you promise to stay together if a train hits you and Linda loses her legs and an arm and breaks her back until death do you part 50 or 60 years later?

It's really hard for me to understand why Dave would want to stay with me, until he sat me down one day and said, said, Olsie, that's the nickname he calls me, put yourself in my place. What would you do if I had been on the tracks instead of you? Hmm? I hadn't thought of it in those terms. And then he said, you need my muscles, but I need your spirit and positive energy. And so, we started our journey together. My first role was to make everyone feel good, convince them we'd be okay. My cheery, hi, how are you? Rang out every time someone came into the room. Transatlantic phone calls ended with, wow, you sound normal. And my answer was well, I'm the same person, just a lot smaller. Every morning, I knew I had a choice to make. I could keep my eyes closed and moan and groan, or I could sit up, look out the window at the fortress on the hill, have someone open the sliding glass door and think about what we could do today.

Something that would get us one day farther away from the accident. And one day closer to the new normal. It was going to take a long time to work through. I was just now beginning to accept my condition, my new reality. There was no time for why or what if or blame. I knew it would take all the energy I had to move on. Dave took charge by setting up a schedule, which consisted of breakfast, reading, bathing, visiting family, and lots of daily time outside when we were able to get outside. On our first trip to the garden, we'd noticed something highly unusual. They were selling beer in the hospital lobby. All of a sudden, we had a plan. When everyone arrived the next afternoon, we loaded up our books and blankets, rolled our wheelchairs down to the lobby, bought a few bottles of beer and paraded out into the garden.

Looking at this now, I can't tell if Dave is making me drink the beer, or if he thinks I've already had too much. From then on, we held court every afternoon outdoors with the warm September air and smelling of cut grass and flowers. We tried to outdo each other with jokes and funny stories, becoming more rye-balled as the afternoon shadows grew

longer. My goal was to make everyone laugh, to see the future as positive and to avoid tears and negativity. After everyone left at night, we forced ourselves to talk until nine o'clock in the evening. At first, it was mainly Dave. He picked things out of our life that we enjoyed; music, work, travel, reading, and eating out. And if you take a look at that bike down there, that's a picture of the bike I used to ride. And as I was thinking about speaking at the Davis Phinney Foundation, today, I realized I thought this was a very, very special racing bike.

And I used to ride it from where I lived in Redlands and Loma Linda up into the mountains above Redlands up to Big Bear and stuff like that. And I loved that bike. I thought it was just a fabulous thing, but anyway, I couldn't do that anymore. So, we crossed those things off our list. I couldn't play the pipe organ anymore. And we moved on. So, Dave chose things that we could do and what needed to be done. And we decided it was useless to talk about what we couldn't do. Dave has always been a black and white sort of person. His immediate response to a problem is to create a solution. Notice that I didn't say think about, or look for, I said, create. He also tried to make sure it was reasonable. Thinking and planning were two things we could do in our hospital room.

So, within the first week we started making lists. A notebook miraculously appeared, and Dave started writing down goals for us to achieve and what he thought was a reasonable time for achieving each one. He told me later, it was the only way he could think of to regain some control over what seemed like a totally out of control situation. I tried to put the components of my life on paper and then flesh out what I thought I needed to concentrate on. And as you would guess, as most of you are, I was right-handed. So, this was the first attempt for me to start writing with my left hand. So, you're going to see what looks like scribbles to me at this point, I do write a lot better now and it's 40 years later. I was already thinking about my team and how I'd relate to them.

Our marriage was uppermost in my mind, knowing that I'd have to lean on Dave, but wanting to maintain our very different personalities was a really big issue for me. We knew we'd need our friends and didn't want to push them away. At the top of my rehab list, were the basic activities of daily living, my hope to drive a car again, and to use prostheses, while way off in the future, were my plans to go back to work. One morning, I decided to reach out to my colleagues at work. This was about two weeks after the, the accident, I think. My new left-handed efforts at writing gave me my first opportunity to attempt reconnecting with my career. The first three words run up and then downhill "Deer.. rad.. gang, I couldn't have found a prettier town to have been incarcerated in." I choke up a little as I start. I try to make it funny, a little bit about being incarcerated and to sound positive, a prettier town. My childish handwriting continues. "They have let me look at my x-rays before and after. They'll make an excellent teaching file." This is really weird. I can't spell. It's shocking to write a sentence and discover that several words

have letters or whole syllables missing. I forced myself to spell the words out loud and then squeeze the missing ones in haphazardly. I haven't given a thought how to spell these simple words since I was in second grade. From the beginning of my hospitalization, I wear two hats. Clearly, I'm a severely injured patient, but the doctor in me keeps peeking out from under the sheets and bandages. My eyes close as I'm transferred onto the x-ray table for a thoracic spine series. Funny, I never knew what this felt like before. As I stare at the ceiling, I think of all of the times I walked past an x-ray room and saw a patient lying on the table.

Skimpily covered by a thin hospital gown, waiting for a radiologist to come in and do a procedure. This table feels like a rock slab. It's really hard. And it's really cold. I vow that when I returned to my residency, I'll never ever let a patient lie unattended on one of these. Maybe I'll even make all my fellow residents undress and lie flat on their backs and see what it feels like. I can tell that my radiology persona is coming back to life. At night, when it's dark in the hospital when it's quiet, I imagine myself back in the reading room at the White Memorial Medical Center in Los Angeles, where I was doing my residency. The x-ray films are all hung and ready for me to read. With only one hand, will I be able to pick up the Dictaphone and speak into it and scribble the findings of the patients on the jackets at the same time, while pushing on a foot pedal to roll the alternator to the next set of films. Can I do it fast enough to keep up with my colleagues? Over and over, I imagine the whole sequence in my mind, and each time I find a way to speed it up. It seems more doable every time I practice it in my mind. I opened my eyes and I smiled to myself. I'm really lucky to be a radiology resident and not in some other specialty that would require me to stand all day or have two hands.

Our last night in the Salzburg hospital came in late September. Five surgeons filed in and stood at the foot of our bed to bid us any emotional farewell. Three and a half weeks ago these vastly experienced, gray hair trauma surgeons had saved my life. The one who was fluent in English spoke for them. We have something we'd like to say. We've been watching you for the last three weeks. And if you were Austrian, you might not have opened your eyes yet. You have shown us what we believe is the American spirit. Dave and I were silent, not wanting to break the spell. We knew it was time to leave the house and our castle on the hill and to go home and prove these men right. With Dave's love, I knew we could do it. We were medevac'd back to the Balbo and Naval regional medical center, where Dave went back to his residency as a radiation oncologist in the Navy.

There were very few triple amputees in the United States. And the doctors who consulted on my case told me that I probably wouldn't be able to walk. And then I met Lieutenant Donna Pavlick, a hard driving 29-year-old woman, just like me, who pushed me, pulled me, cajoled and provoked me. My goal was to get her to laugh every day. Hers was to get me to concentrate. Our contagious enthusiasm was contagious. Other

patients and therapists watched and helped. A stranger looking in would have seen people laughing. Sitting or lying on the floor, butt walking, doing one hand pull-ups or lopsided one hand pushups, all of them vying to see who could have the best time. Sweat rolled down my face as I stood in my new legs, legs that looked something like they'd come from a plumbing store. Clutching the parallel bar with my left hand, I lifted one leg and put it back down.

“Hey, hon, remember it takes a baby a year learned to walk, give it time,” Dave said. Up and down the halls, we walked, then, out onto the hospital grounds, tethered to Donna by a rope and a belt around my waist. People see me. Some of them say hi, but most look away. In my mind I say, “Hey, I’m just like you. In fact, this could be you.” Four months after I first tried on my fake legs, I walked a mile. I was thrilled, over the moon with happiness. Four months before, life as I knew it had seemed to be over, but was it? Are we defined by our legs? And what do you do once you get new legs? Are you the same person? Dave and I worked hard to recreate our lives. And then one day we discovered we had really recreated. We were going to have a baby.

All of a sudden, this wasn't just about me anymore. This would be changing diapers, cooking, feeding, and playing with just one hand. We were going to be a family and do all those things families do. So, we had to be as normal as possible. Two months later, Dave and I are back in Los Angeles, turning into the parking lot of the White Memorial Medical Center, ready for me to go back to work. I've had 12 months to get ready. My new fiberglass and aluminum legs behave most of the time. And I think I'm ready to be on my own. I've successfully mastered the activities everyone thought necessary to live on my own again, go to the bathroom by myself, sit down and stand up from a chair, put my legs on by myself, bathe or shower, get up off the floor by fall, go up and downstairs and walk long distances comfortably with a cane.

It had been hard, sweaty, grueling and hard work that was oftentimes discouraging, but it was done. It's hard to believe, but it's real. I'm going to be independent living on my own again and loving it. Tiffany was born on March 12, 1981. Three years later, our son Brian was born. Our lives look pretty normal now just about like everybody else. We'd get up early every morning. Dave would help me put my legs on. I'd get in my car, which was adapted for me to drive, take the kids to school and go onto work at UCSD where I walked with my cane and worked nine to 10 hours before going home to fix dinner and get everybody ready for bed. While Brian and Tiffany thought everyone's mom had a wheelchair, an elevator, and walked with a cane, their friends thought it was kind of weird. When told I'd lost my arm, their friends often wanted to help me find it. After all, that's what you do when you lose something.

Having kids forced us to innovate, to get out and go. First, it was the beach in San Diego, at least twice a week with dinner in the sand, Frisbee games and beach toys.

Growing up, I'd love the outdoors. I'd hiked Mount Whitney and half dome, both of them twice and I've been to the bottom of the Grand Canyon, but because I thought I'd feel bad about all the things I couldn't do; we'd not been back out into the great outdoors since the accident. Brian was five and Tiffany was eight when my college roommate Carla called one day and said, "Hey, Linda, when are you going to get your butt back outdoors and go camping? Are you going to raise city slippers or real kids?" So just like that, we had a new team, our camping team, a rambunctious Montana family with two kids.

Yellowstone became the first chapter of our travel saga. For five days we canoed the remote South end of Yellowstone Lake, which was accessible only by non-motorized boats. Boy, did we ever get back into the wilderness. Canoeing and kayaking became the conveyances of choice. 10-day long trips, usually over a hundred miles of lakes and rivers, places where we rarely saw anyone else. We camped in the dirt where I was queen in my kitchen without walls. I butt walked down the shore to the Lake and pumped water through the filters. It might've looked funny, but it was fun, and I felt like I was contributing. At the end of the first trip, we realized the need to carry me. And so, Dave concocted the first of many pack frames. My vanity got in the way, so the first editions saw me with my legs on; a totally stupid way of doing things.

It didn't take long to realize that fake legs were useless out in the wilderness and we could go much farther without them. Plus, it was entertaining to watch people's faces as they saw us coming toward them with the two headed hiker on the trail. So, legs became a thing of the past and they stayed at home or in the car. Over the next 20 years in addition to wheelchairs, I was pulled on dog sleds, snow sleds, rafted, that's a seven-day trip down the Grand Canyon and the Colorado river, which I would highly, highly recommend everybody here listening today, it's a fabulous trip. Sometimes I was even wheelbarrows in places. This one was down in South America where it was hard to get around. We were on an Island out in the middle of the Food river. And this turned out to be the easiest way to move me from place to place in the camp. Not everything worked. To the left is my mermaid swimming plan that didn't really work. My prosthetist had made a set of legs for me with fins on them, thinking that we could put them on when I was someplace on a lake or river and that that would propel me around. And it didn't work, as did the miniaturized skier. This is up here at Squaw Valley, which is close to where I am right now. I'm in Davis today. It didn't work either, but it was worth the try.

Everyone who knows us would say that our lives were normal. And so, after 30 years of interpreting over half a million imaging studies at the University of California in San Diego, I agreed with Dave that it was time for us to retire. Time for us to enjoy our granddaughter, to travel and enjoy life. It was time to figure out new things and new ways like paddling and kayak. Now I'd been in a kayak for years, but I'd never really been a very effective paddler. One afternoon we were down at mission Bay and I was

putting on a new life jacket. And for some reason before I zipped it up, I just took the paddle and I stuck it between my chest and the life jacket and snug it up really tight and realized that this was just like having two arms. Cause once it's that tight and it's so closely applied to your body, all you have to do is lean each way and you can paddle. So, I could paddle, and Dave could fish a little bit. He would normally sit behind me in this tandem kayak. And it was kind of an exciting adventure. So, the message being to myself was that even if you've been doing things for a long time, there's often something else that you can do that will make it better or easier to do.

Then it happened. It's Christmas day and we are expecting 30 people for dinner. Our grown children are happily cooking, but I'm freaking out. Out of nowhere I start yelling at them. "Hurry up, we aren't going to make it in time. What's wrong with you guys?" I'm hyperventilating and shaking. What is wrong? Linda the cool as a cucumber person has just lost it, which has never happened. It didn't even happen after we had the accident. Five weeks later, I hear the words. I think you have Parkinson's disease. Our smart medical friends, all say, "You can't have that, you don't have the typical signs." Wanting more certainty, I seek a second opinion, but they can't make the diagnosis either. It's then that radiologist inside me says, go ahead, get the nuclear medicine scan so you'll know if it's true or not. As I watched the images appear on the monitor, I see the abnormality, an absence of radionuclides uptake.

Oh no, it's another amputation. But this time it's part of my brain that's missing. Dave and I start thinking about the little things that have snuck into my life over the past few years, difficulty writing, occasional slurred speech and restlessness in my arm and a leg and that anxiety. So, it seems like we're back to square one. We've been hit and knocked down. What are we going to do? Well, 41 years ago, I was sweating and working out all day in physical therapy to get strong enough so I could walk. Exercise is even more important for me now instead of just strengthening my muscles, I now see it as a medicine, which I need, as importantly as I need my Sinemet. I've learned that when I start feeling anxious or internal tremors, my first thing to do is stretch, do seated jumping jacks or phantom boxing jabs at my unseen Parkinson's enemy. But as you can imagine with just an arm, it's difficult for me to exercise enough to get sweaty and raise my heart rate. Since I'm unable to run, I use a stationary bike. There's many days I'd just like to tell my legs to get going and ride on without me. It hasn't worked yet, but I'm going to keep trying when challenged, I can occasionally show off by doing one arm push. But for everyday nitty-gritty exercise, I'm limited by my missing extremities. So, one of my new missions in life has become finding alternative ways to exercise, to find new teams to work with. Just like we did when we started camping with our kids. Luckily in Southern California, as most other parts of the country, we have a lot of opportunities. I happened to work with Caroline Jordan Fitness and have encouraged her to create lots of seated or chair cardio workouts. Her enthusiasm helps me get through each video.

And recently I've joined the Rogue Power PT virtual workouts, another program located in Southern California. I can't do all of the moves, but I can improvise enough to make it work. And I always feel better when I'm done. I'm pretty sure that your home-town Parkinson's associations have a list of local physical therapy programs that will fit your needs. If not, you can now join virtual gyms anywhere in the world; one of the unexpected COVID blessings. These programs work big muscle groups like the biceps, triceps and those snazzy six pack abs. But those of us with Parkinson's disease need to pay attention to some less publicized muscles. Two of them being the vocal cords and diaphragms. Our vocal cords are tiny, a 10th of a centimeter to two-tenths of a centimeter, but they are a huge part of our lives. It's easy to take them for granted. I know it's hard for me to remember to do my voice exercises, as much as anything, because I'm worried about people listening to me or hearing me when I'm not at home.

We are lucky to have a whole potpourri of exercises. You should be able to find one or more that you can enjoy and participate in routinely.

So, what do we do after the words we hear, "I think you have Parkinson's disease." Well, I'd suggest going back to the three things that helped me after I became a triple amputee. First, we have to accept the fact that we have this crummy disease. Then we need to learn how to adapt to the changes in our bodies, in our brains. And finally, we need to innovate as we go along, figure out how to keep doing things in a different way, so that we can get out and go and keep ongoing. Thank you.

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