

A Little Breathing Space

There's usually no good news after a diagnosis of ALS, but Cindi Dunckel, 44, has found a little respite thanks to Pilates.

by Cindi Dunckel,
as told to Beth Johnson



I miss moving. It's been two years since I was first diagnosed with ALS, and so much has changed. I'm no longer able to move my legs and am now 100 percent wheelchair-bound. My arms are also growing weaker. I can still brush my teeth and scratch my face, but flipping a light switch, or reaching a water faucet, is difficult. Eating has become a chore. My family dresses me, and my daughter bathes me.

This huge change has been especially difficult because I always was such an active, sporty person. As one of six kids growing up in Bellevue, NE, I was always on the move. I played soccer and was on my high school's volleyball and track teams, and even the dance and pom-pom squad, the Belvidettes!

After graduating from high school in 1990, I worked and went to the local community college—and at a school party, I met my future husband, Keith. We hit it off right away. He was an athlete, like me, and we had a lot of fun together. He played baseball at a nearby college and soon thereafter, was recruited as a pitcher in the Midwest League, for the San Diego Padres AA team.

A FULL LIFE

We got married in 1995, while living in Des Moines, IA, and after that, we moved a lot, following Keith's career in the tire industry, going from California to Tennessee to Oklahoma and finally to Topeka, KS. I'd been told that I wouldn't be able to have kids because I had endometriosis. But within a year of getting married, I had my first son, Brooks, 19! Our daughter Savannah is 17, and our youngest, Satchal Paige (named after the great baseball player) is 12. Going from thinking I might never have kids to having three was such a blessing.

I'd been a stay-at-home mom, but when we moved to Topeka in 2008, Keith went to work for Goodyear Tire Company, and I began working as the manager of a floral shop. For the next five years, I had a full-time job I enjoyed, and we raised our three terrific, active children. Even with such a busy life, I stayed in really great shape. I weight-trained, and I worked out with my husband.

TROUBLING SIGNS

Looking back, though, I now realize I'd been experiencing some intermittent muscle twitching and cramping as far back as 2012. I dismissed it as dehydration from exercising. The next year, in 2013, I started feeling a bit of weakness in my left leg; I figured I just needed to work out more! So I started running harder and lifting more weights. As an athlete, I knew about soreness, but this soreness didn't go away—and I wasn't getting stronger.

But I really started to get alarmed in February 2014, when I developed foot drop (difficulty lifting the front part of my foot). I had

to lift my left leg higher when I walked so that my foot didn't drag on the ground. My first thought was that it was because I had been on my feet for 10 hours a day for two weeks during the Valentine's Day rush at the floral shop. I quit my job shortly after that, in order to be around for my eldest son's last year of high school; I was hopeful that less time on my feet would help. I also went to a chiropractor recommended by a trainer at the gym. He suggested laser therapy to get the nerve functioning again. But after five laser sessions, there was no improvement.

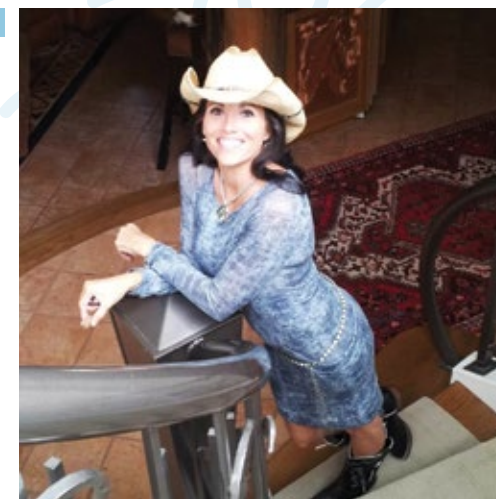
WHAT'S GOING ON?

Once I realized that the foot drop wasn't going away, I knew I needed to find a top doctor as soon as possible. After visiting several specialists, I was referred to a neurologist at the University of Kansas Medical Center. At the first appointment, she did an EMG (electromyography) test on my legs. She stuck a needle into my leg, which measured the electrical activity of the muscles and the nerve cells that control them.

She came back with a possible diagnosis of Charcot-Marie-Tooth disease (CMT), a non-fatal neurodegenerative disease that takes away your ability to use your arms and legs. I was speechless. There had to be another, better diagnosis.

I was sent to a more specialized neurologist, and over the next three weeks, I had three more EMGs and an MRI. In August 2014, my husband and parents joined me for the appointment to hear the results. The doctor ushered us into a room and said, "I'm really sorry to say this, but you have ALS." It was a shocked room, to say the least. Then the doctor described the lousy prognosis of amyotrophic lateral sclerosis, aka Lou Gehrig Disease, a progressive neurodegenerative disease: There is no cure, and it's fatal within two to four years of diagnosis. I was devastated, and in the same instant, my heart broke for my parents, my husband and, most of all, my children.

But I knew that dwelling on the prognosis would do me no good. I quickly decided I



OPPOSITE PAGE:

DUNCKEL IS ALL SMILES DURING A LAT PULL-DOWN IN HER WHEELCHAIR, WHICH SHE USES AS A PIECE OF APPARATUS DURING HER SESSIONS.

ABOVE, TOP TO

BOTTOM: DUNCKEL, PRE-DIAGNOSIS, IN 2013; AND IN 2014, SHORTLY AFTER LEARNING SHE HAD ALS.



With every Pilates session, I felt relief in my muscles, and more connected to my body, which was wonderful.



ABOVE, LEFT TO RIGHT: DESIMA DAWDY ASSISTING DUNCKEL IN A MODIFIED CHEST EXPANSION ON THE BALANCED BODY CLINICAL REFORMER AND THE CUSTOM PED-O-PUL; STACY ZEIGLER CUES DUNCKEL AS SHE DOES ASSISTED LEG SPRING SERIES/SCISSORS ON THE CADILLAC, WITH THREE BALANCED BODY UPHOLSTERED WEDGES CONFIGURED IN A V, BEDNASIUM STYLE.

OPPOSITE PAGE: DUNCKEL'S LOVING AND SUPPORTIVE FAMILY.

wasn't going to let ALS take me down one second sooner than it had to. I wanted as much time with my family as was left to me.

TURNING TO PILATES

I turned to my girlfriend Stacy Zeigler, who's an instructor at Pilates Performance & Rehab in Topeka. From everything I had learned about Pilates from Stacy, I felt it gave me a good shot at fighting against and delaying my decline for as long as possible. She introduced me to Pilates Performance & Rehab's owner and director, Desima Dawdy, who took me on as a client even though she'd never worked with an ALS patient before. She researched the disease, and consulted with an orthopedic surgeon in Topeka, Dr. Phillip Baker, in order to understand what was happening in my body.

So that September, I started seeing Desima twice a week. She gave me one free session a week, and the studio held fund-raisers to pay for the rest.

IMPROVISING WITH PROPS

At that point, my upper body was still strong, while my lower body was weakening. I was using a cane, but I could get myself up on the table with a little help from Stacy, who assisted in my sessions.

Desima wanted to concentrate on movements that would help me function at home. Most of the focus was on the legs and lower body, where I was losing strength the quickest. Using the Balanced Body Clinical Reformer with custom Ped-O-Pull, I did a lot of stretching and used an assortment of props to, well, prop me up because of my lower-body weakness. That meant custom bolsters under the knees, head support and padded foot supports.

We used the foot plate on the Reformer a lot to try to counteract the foot drop. Footwork helped the pins and needles feeling that I was getting in my feet. Initially, Desima had to hold my foot, but for a while,

I was able to progress to keeping my foot on the Reformer. The fact that early on I made progress amazed everyone—and it was thanks to Pilates.

Because of my weak leg ligaments and foot drop, we also did a lot of stability work. For instance, since my knees were beginning to turn inward—a common symptom of ALS—Desima slipped a Magic Circle around my outer thighs and I worked on pressing out. To make it easier for me to use the toilet, we'd do Horseback on the Ladder Barrel.

UPS AND DOWNS

But over time, there would be movements that I'd been able to do the week before and then all the sudden couldn't. ALS was progressing a lot faster than I'd expected. I'd get tired quickly. I could still drive, but getting groceries would exhaust me for the rest of the day. I'd gone from being a super-active mom, to being more and more dependent on my family.

At my Pilates sessions, I'd often only be able to do about four reps of each movement, and after a half hour, I'd have to stop. But with every Pilates session, I felt relief in my muscles, and more connected to my body, which was wonderful.

As I moved to using a walker, and then an electric wheelchair about eight months after my diagnosis, my arms were remaining strong. I was able to transfer myself onto the Trap Table with some help. And once I was in the adjustable electric wheelchair, we started using it as a piece of Pilates equipment. We'd do modified seated pull-downs off the back of the Trap, or they would help me get my feet up on the Trap, and I'd open and close my legs like a butterfly.

LEARNING TO BREATHE

But I think the biggest thing that I got out of Pilates was the breathing techniques. We especially concentrated on strengthening my

diaphragm and pelvic floor when breathing because with ALS, the end comes when the diaphragm stops working and you suffocate. The fact that my breathing and voice are still fine—unusual for someone with ALS—I attribute to Pilates. (In fact, I wish I'd learned this when I was younger and an athlete, because it would have really helped me!) I also use Pilates breathing techniques to calm me down when I have anxiety attacks about my condition.

PILATES AT HOME

Last May, I realized that it had become just too hard to get myself to the studio. I became exhausted just trying to get my pants on, and my arms were starting to get tired easily, making driving more difficult. I didn't want to use up all of my limited energy getting ready for a 30-minute session, and then come home and have to sleep for five hours to recover.

Instead, I got a massage table at home; my family and friends help me with Pilates-related leg exercises, trying to keep my muscles from stiffening. Insurance doesn't cover anything that is used to prevent injury, so I'm so blessed to have all the help that I have. My friends organized fund-raisers such as golf tournaments and garage sales that enabled me to get two lifts/slings at home. That way, no one has to ruin his or her back lifting me into bed or onto the toilet.

WHERE I AM NOW

At this point, some days are better than others. I'm only in pain when I lie in a position for long periods. My husband usually moves me twice at night to avoid bedsores. I use pillows to prop up my feet and keep them in a flexed position. Pilates has definitely helped prevent me from getting stiff and needing pain medication.

A NEW "APPARATUS"

I also use my wheelchair a lot to help keep myself moving by using the full recline and tilt modes, so that I'm never just sitting still. Thanks to advice from Desima, the wheelchair company made some modifications on my chair that helps my body to be in better, more relaxed positions, such as adjusting the lumbar area to keep me from overarching my back, and raising the footplate for more comfort.

RETURNING TO THE STUDIO

Something wonderful happened in September of this year, though. For the first time in months, I went back to Desima's studio to take photos for this article—and the experience was wonderfully surprising. My daughter Savannah drove me there, and helped me get onto the equipment. We did a little arm work while I was seated in the wheelchair, off the back end of the Trap Table. I did a modified

Spine-Stretch Forward. I had not been able to do a pelvic tilt all summer, and yet I was able to do it with Desima's help. I don't know who was more surprised, Desima or me! In that moment in the studio, I didn't think about what my body can't do.

I've decided that, for now, I'm going to keep going to the studio for sessions with Desima. All of the effort to get there is worth it for the relief that Pilates brings me.

KEEPING MY BREATH

The strongest part of me now is my breathing. They test it on a regular basis and, at this point, I'm testing very well. I'm so competitive that I work hard to show them what I can do! I'm also participating in clinical trials to help ALS research. There's no cure for ALS, but there's hope—most especially for research to be funded so a cure can be found.

I'm determined to keep my breathing muscles working the way they always have, for as long as I can. I believe that Pilates has made that possible for me. It means that I've had more time to be with my amazing children and my wonderful husband, and the rest of my loved ones. And for me, there's no better gift I could ask for. **PS**

If you'd like to contribute to Dunckel's fight against ALS, go to www.fundrazr.com and search for Team Cindi Dunckel.

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PHOTOS BY EMMA WHEATLEY