



Laura Niles, Research Assistant, School of Nursing Center on Aging at The University of Texas Health Science Center, interviews Aletta de Wal on using creativity to recover from a health crisis.

Tell me about your background-education, former career, and illness.

I was only 19 when I graduated with a Bachelor of Arts in English and French Literature. I applied to 65 different companies. I finally got a job as a management trainee with a bank in Montreal, after they learned that I spoke French.

My bosses saw that I was really good at training others and I soon found myself running a teller training program, which took me back to Toronto. After this, I moved on into personnel, known today as human resources. I had a knack for thinking, "What's going on here? What are the symptoms and, what is the real problem?" - this led to my organization development work. The jobs I excelled in were all about helping people do their work better and enjoy it more. My curiosity, observation, listening and learning skills were paying off.

My career took a big turn when I became educational coordinator for *The Toronto Regional Council for the Institute of Canadian Bankers*. I learned so much about building relationships, work values, education, organization, public speaking, working with volunteers and managing a budget. I discovered that I could be the most successful by asking, "Who are these people?" "What makes them happy?"

I continued this kind of work in my next job at the Trust Companies Institute. Meanwhile I knew that education was my strength so I did a Masters in Adult Education part-time.

While I loved working with such a variety of companies, I wanted to deepen my skills inside one company. My networking led me to a challenging job where I was in charge of management and operations training and development for 30,000 employees worldwide with a \$600,000 budget. It brought all my education and experience together and I was able to do work that improved people's daily work lives.

I had a huge job, staff and heavy travel schedule. I was feeling the strain and fatigue. I actually collapsed in the bathroom one day, as I was about to board another plane. My whole body was doing weird things. I was shaking. I had aches all over my body. I went to several doctors and medical experts kept telling me that it was stress. They said, "It was all in my head." I knew in my bones that it had to be something more.

I took the summer off, and at the end of 3 months, I started to think, "Maybe it was the stress of my work after all." I had saved enough money to support myself for at least 18

months. I left my job and set up my own business. I had a great reputation from my previous jobs, so I had lots of work. It was exciting to be able to choose my clients and not have to deal with bureaucracy.

Almost 18 months later, I began to feel unwell again. I was working hard to build my business but this was more than simple fatigue. My prior experience with doctors left me unwilling to go back. But my health was getting worse. A friend with a rare blood disease referred me to the doctor who had broken through her mysterious symptoms. After 5 weeks of tests, they still didn't know what was going on. Then one day I woke up with a rash on my face one day in the shape of a butterfly. The doctor came in and said, "Well, the good news is we now know what you have. The bad news is that you're going to have it for the rest of your life, because it's chronic. It's lupus." Two weeks later I had my first stroke and another two weeks after that.

Lupus was only really getting properly diagnosed then, because a medical researcher had identified a list of 11 key factors. I learned that stress is one trigger. The simplest way to explain lupus is that there is no off switch in the immune system. After fighting off a cold in my body, the T-cells that fight the virus do not go back to rest as they do in healthy immune systems. They go on to attack weak areas of the body. In my case that was connective tissue – what holds your muscles to your bones and forms blood vessels.

What was the most challenging part of your recovery after your two strokes?

It was devastating to lose my ability to walk, talk and take care of myself. The strokes took away everything that allowed me to function independently in the world. Most of my identity came from using my head, and suddenly that was blank. What if that didn't come back – what would I do then? Aside from being independent, how would I make a living to support myself, since I lived alone?

I was in a lot of pain; so even moving was a problem. I especially appreciate walking now, something it's easy to take for granted. I tell everyone that I've had to learn to walk three times in my life. Once of course once was as a baby. The other time was when I was a teenager and broke my back.

I was really scared because the strokes were like stealth bandits. One minute you're fine and the next moment you're not. I didn't know when or if one of those would hit again. That to me was worse than the pain. I got pretty despondent. I felt helpless. I was pretty depressed that I had to depend on others for everything. I was wondering if I was ever going to be able to get out of bed again. I wasn't sure if I was going to make it.

At some point I realized that whether or not I was going to survive, being down about being ill wasn't helping. I thought, "I have to get through this." My determination kicked in. I made the decision that this could either take me over and I could die or I could fight it. I could still possibly die, but I would die fighting it. Once I made the decision, all sorts of support appeared.

People tend to move through the world fairly habitually, mostly because of ignorance - not malevolence. I learned some unpleasant things when it came to crowds. The first time I could use public transit, I was really happy. It gave me freedom of mobility again. Sometimes I had to go out in rush hour. I remember at times, holding on for dear life to the handrail on the stairs to the subway. Once someone pushing by clipped my arm. My cane

went flying out in one direction and I just hit the ground. No one stopped to help me. They didn't step on me, but no one stopped.

You realize the world really is not set up for people with disabilities – or for that matter for people who are older. I'd go into a public restroom and realize that the sinks and paper towel holders were way up high. I would get to a big door with my cane, and think, "How am I supposed to open this big heavy door, and pull it toward me while holding this cane?"

I also had to deal with a lot of ignorance, in the pure sense of that word. Many people do not understand the effects of disabilities and confuse them with lower intelligence. As I was learning to talk again, I often had to ask people to repeat themselves. If they talked slowly I could understand them. Because I was having difficulty understanding them due to my strokes, they thought I was deaf so they would raise their voices. Finally one day during a conversation I got tired of being yelled at, so I held up my cane and said, "I'm not deaf, but if you think I am, you can speak into this microphone."

How did art assist in your recovery?

Over time, I wanted to do something other than work on my recovery. I discovered an art class for "absolute beginners." We started each class with a meditation and listened to music while we created something with art material that was sitting in front of us when we opened our eyes. The meditation was soothing and the materials were like treasures. Once I surprised myself with a picture of a fire-breathing dragon. When I took a good look at it I thought, "Wow, I really do have some anger over this whole illness thing." I kept my positive attitude but was able to include all of my feelings about this journey now. Art and music became a significant part of my healing and are now an essential part of my life.

It was interesting how things started to evolve. As I started to improve through months of physical and occupational therapy, I enrolled in a program called *Mastery of Learning*. One of the many great things I did there was a visualization of the place I wanted to live in. I drew it. I wrote about it. I saw myself walking around in it every night before I went to sleep.

I had this vision of a wonderful loft space and studio where artists could come have a kind of fellowship. This was my biggest art project ever. It really stimulated my recovery. Everything centered on making that place happen. I found a realtor who had a former textile factory that was the perfect place. I borrowed money and got work to pay the mortgage. Designing and building this loft became a metaphor for rebuilding my life.

Was stroke the main reason for your change in career paths?

Yes.

The loft was what got me to the point of combining business with art, and this becoming the core of my life. People saw what I had accomplished with this place. It had a dream studio and private space upstairs. Downstairs I taught workshops and coached people. I had an office space at the front, a gallery in the middle and kitchen in the back. I invited other artists to come in and sell their work. I called it *The Loft Gallery*.

I started exhibiting my own work. I first did this at a restaurant. Then I thought, "Why not do this at my loft?" I created art salons, where artists and collectors would just come and hang out. A lot of work sold in the process of people connecting with each other.

Tell me about your current career path.

Toronto was a fabulous art city, but it had become very polluted. I was doing very well in my business. When I began to get sick again, I knew I had to move. I was turning 50, and it was time to make some changes for the second half of my life. I sold my loft in August of 2001. My financial planner wanted me to invest my profit in the stock market. I wasn't interested in doing that at the time. I was tired. I just wanted to take time off and travel. We all know what happened on 9/11. Had I invested in the stock market, I would have lost everything. I was glad that I had followed my gut instincts. And I felt very lucky and grateful all over again.

I travelled for 6 months and decided I wanted to live in California. To stay here I had to get a job. I wanted to continue my work with art and artists. One day I went to an art fair and saw an artist who had illustrated a book that one of my storyteller friends had used in her workshops. I was intrigued by the "three degrees of separation" and by her obvious business sense. She had been a student of *Artist Career Training* online.

Synchronicity stepped in and I learned that the owner had an emergency in which a friend of his had a stroke. He was going to take over his friend's business. I define luck as preparation meeting opportunity, so I asked if he needed some help. That was in 2002 and I now have my dream job helping artists make a better living making art. It brings together all of my art interests and business skills in coaching and training artists to be entrepreneurs so they can be self-supporting.

Because of my world experience and my experience with disability, I treat artists as whole people, not as just clients who need help with their art business. I see their strengths and resources first, and then add the pieces that they need to complete what they want to do. I don't come in with a cookie cutter plan that is supposed to fit all people.

I choose who I work with. I don't work with every person that approaches me. If it's not a fit, than it's not going to be good for either of us. I've turned people away and sent them to other resources. To me, it's about the ethics of doing business. That means all the money I've earned, I've earned freely. The client values it and I'm worth it.

I come up with creative ideas that suit the time, money and energy the artist has. Despite my strokes – or because of the retraining I did after the strokes - I have a brain like a tennis ball machine. I can fire out idea after idea. If anything, I have to watch that I don't throw too many ideas out to people.

Does your stroke history interfere with your current life or job in any way?

Most of the time, it no longer interferes. In fact, it makes me take better care of my health than I might otherwise.

In some ways, it is an advantage, because I have many clients in their 50's, 60's and 70's who have disabilities or are caregivers for family members who are ill. Since I understand that experience firsthand, it helps me help them in way that incorporates these responsibilities.

What advice would you give to other stroke survivors?

I want them to know that it is true, that if you can think it, you can do it. You just have to believe in yourself and really believe in the goal. Take steps to make the goal real.

Visualize it. Think about it. Talk about it. Write about it. Make it a real multisensory party. The biggest obstacles to doing what you want to do are the ones in your own mind. The obstacles after that are in the minds of people who don't understand what you're trying to do. Part of your job is to educate people or to get away from the ones who aren't supporting you.

You can do everything. You take it one step at a time. Just keep in mind, that everything takes time, money and energy. If you don't have a lot of money, it's going to take you more time and energy. If you don't have a lot of energy, it's going to take you more and time and more money. If you don't have a lot of time, it's going to take you more time and energy – and probably some help of other people.



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Recovery Journal

http://www.geroeducation.org/CARes_eNews/RJ_Previous%20Index-07.htm

Center on Aging

<http://son.uth.tmc.edu/coa/default.htm>