WALKING 2.0

ONE WOMAN'S STORY ILLUSTRATES HOW HOPE, PERSEVERANCE AND EXOSKELETON TECHNOLOGY ARE REVOLUTIONIZING DISABILITY

By Amanda Boxtel

I was 24, and I felt invincible. I taught aerobics. I was a sprinter, a long jumper, the former athletics captain of my school and a ballet dancer. I loved to twirl in space, run on the beach and hike through the wilderness.

All of that changed in a split second. In a freak somersault while downhill skiing, I shattered four vertebrae, along with the illusions of my immortality. An electric current zapped through my legs, and then I lost all movement and sensation below my pelvis. I was paralyzed.

As I lay in a hospital bed, in the winter of 1992, a young doctor strode into my room and spoke words that resonated in every cell of my body: "Amanda, you'll never walk again." As if to soften the blow, he added, "But you can still have children." My unresponsive body lay still in the stark room. My mind was clouded with morphine. The shock left me totally numb.

Thoracic 10, 11 and 12 and the first lumbar vertebra—which the doctors referred to in shorthand as T10, 11 and 12 and L1—were crushed. Like jagged rocks crashing into a river, the shattered bone fragments had smashed into my spinal cord, denying oxygen to the cells and consequently causing them to die.

According to the Christopher & Dana Reeve Foundation, nearly one in 50 people, some six million in all, live with paralysis in the U.S., often as a result of stroke. I represent one of the 1.3 million people in the country who have a spinal cord injury. It is a cruel injury in so many ways beyond not being able to walk. It means grieving the loss of my sexuality and ability to void urine and empty my bowels on my own. It also involves dealing with secondary complications such as intense neuropathic pain.

It took time to turn my wounds into wisdom, to remove any self-imposed limitations and to live a richer and fuller life. It has taken 23 years of paralysis for me to understand that acceptance and hope must coexist. Adaptive technology has enabled me to ski, kayak and hand cycle. Yet my deepest yearning has always been to learn how to walk again.

Fortunately, we live in an era in which

DAN KITWOOD *Getty Images*

Amanda Boxtel takes a stand at the 2011 London International Technology Show. After 18 years in a wheelchair, Boxtel learned to walk in an exoskeleton. Today, with help from a physical therapist, she regularly uses an exoskeleton for rehabilitation.

technology is augmenting human potential like never before. Science is enabling people to dream big and help one another. For the first time in the history of assisted movement, there is a mobility option beyond standard wheelchairs and unpowered orthotics: the bionic exoskeleton suit. This technology has already transformed my own life, and it holds the promise of restoring dignity and self-reliance to a great many others. We are on the precipice of redefining the word "disabled."

Made for Mobility

When a person sustains a spinal cord injury, not being able to walk brings on a multitude of complications that can be life-threatening. The heart and lungs do not function as well, circulation is impaired, body temperature becomes dysregulated, and bowel and bladder function are significantly disrupted. The longer a person sits, the greater the risk for joint contractures, muscle atrophy, osteoporosis and pressure sores known as decubitus ulcers. Over time limited mobility can be socially isolating. Taken together, these issues lead to a shortened life span.

Can paralysis be reversed? Stem cell therapy certainly holds some promise. So does recent work that combines locomotor training with doses of electrical stimulation to the spine, demonstrating that spinal networks can learn with task-specific practice. The spinal cord, such research suggests, may be as smart and malleable as the brain. And yet the goal of using regenerative techniques to fully restore function remains distant.

After the accident, I knew I had to move my body, or it would essentially begin to die. We are made for mobility. I willed myself through my darkest moments by affirming: *All you have to do is pick up your feet.... Destiny waits for no woman. You are ready. It's up to you and you only.*

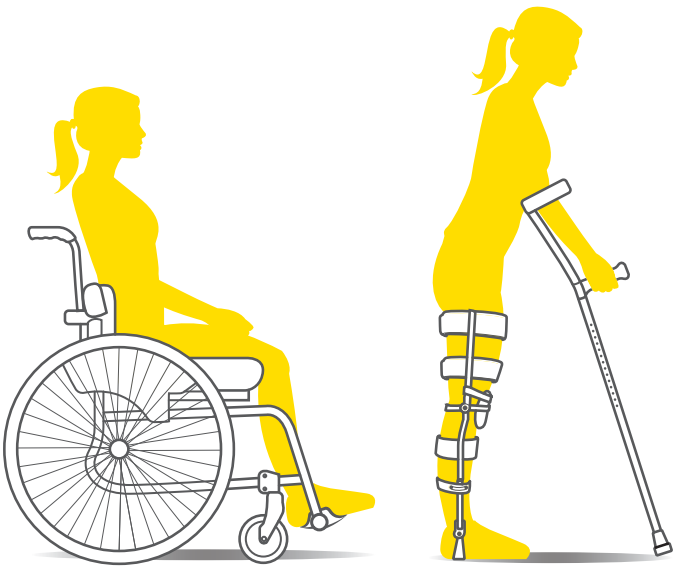
I have learned firsthand how important it is for the neuromuscular system to stay active. In the years after my accident, I maintained range of motion and flexibility in my limbs through intensive therapies such as yoga, Pilates and physical therapy. I trained four to five days a week, combining all kinds of muscular, cardiovascular and balance exercises. I used an antigravity treadmill (which elevated the body so I could engage in cardiovascular exercise without bearing weight on my legs), wore long leg braces while using a walker for balance and vibrated on a side-alternating therapeutic platform to mimic the left-right alternation of walking. A well-rounded exercise regimen helped me maintain fitness and functional independence.

FAST FACTS
MOVEMENT REVOLUTION

1. An estimated six million people in the U.S. suffer from some form of paralysis.
2. Bionic exoskeletons offer a new kind of therapeutic intervention, enabling people to enjoy the physical, emotional and psychosocial benefits of moving upright at a natural gait.
3. Cost and accessibility remain the greatest challenges in connecting people who could benefit from using exoskeleton technology.

I also made myself a guinea pig to test cutting-edge treatments. Sixteen years postinjury, I became a "radical stem cell tourist." I was the first person in the U.S. to undergo controversial human embryonic stem cell treatments in India. The procedure still has not undergone rigorous scientific review, so I cannot recommend its use—but I am nonetheless grateful that it allowed me to regain trace muscle power and sensation. These benefits improved my quality of life, even if they did not enable me to walk.

Through all these experiences, it became clear to me that in any given therapy, at least one of three components of walking was missing. First was the challenge of bearing my full weight on my legs. Second, no treatment enabled me to walk naturally: with joints and bones lined up correctly and a reciprocal gait, which entails moving one arm, then the opposite leg, and being able to bend my knees and strike my heels on the ground with each step. Finally, I could not experience the visual and muscular feedback (called proprioception) that accompanies moving over a certain distance.



These limitations did not discourage my efforts. Instead they served as further motivation. I knew that if I ever hoped to walk again, I would need to prepare my body for the challenge. And in my waking dreams, I began to imagine moving in perfect alignment, encased in an outer shell—a robotic suit that I could strap on, stand up and walk in.

On My Feet

On a Friday afternoon in the summer of 2010, I received a telephone call from Eythor Bender, then CEO of Berkeley Bionics (since rebranded as Ekso Bionics). Bender had heard of me through word of mouth. By that point, I was already giv-

CLINT FORD

ing talks about my story, publicly pursuing new treatments and working with a nonprofit organization that helped people with paralysis enjoy outdoor recreation. Bender had a proposition: he wanted to see if I would test-pilot an exoskeleton prototype for a *National Geographic* television series. I could not possibly refuse.

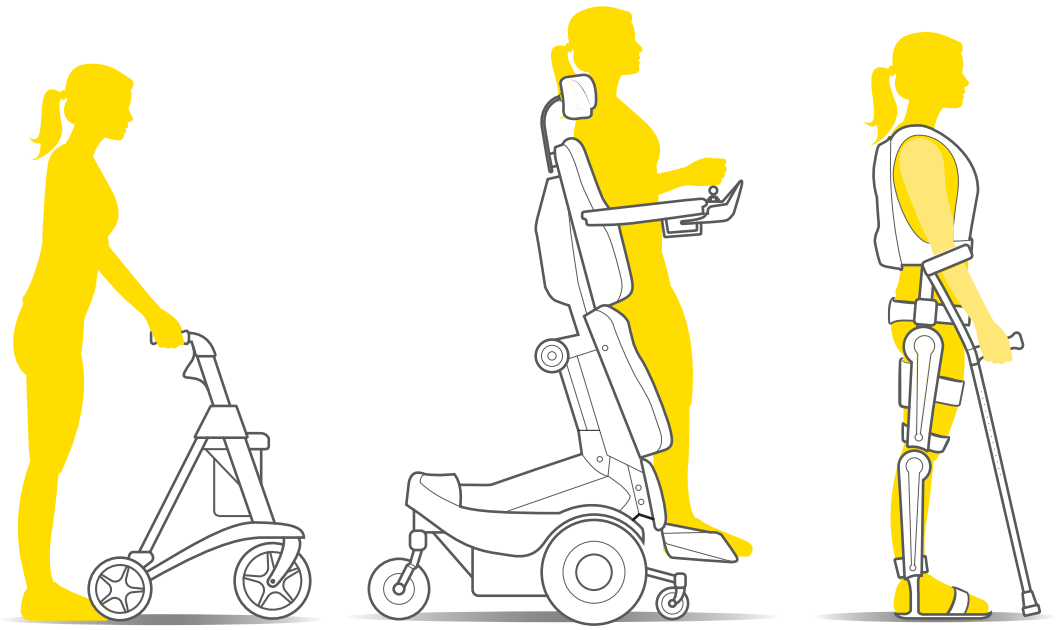
Eight days later I flew to the company's location in Berkeley, Calif., where the film crew had allotted me just four days to demonstrate that I could walk in the exoskeleton. The prototype was primitive by today's standards, but the basic idea, which remains at the core of exoskeleton design, was based on the human body. The metal frame served as a skeleton, motors gave me power much like my muscles, and sensors sent signals to a central computer, located on a backpack, just as nerves communicate with the brain. Together these pieces made up a wearable robot that could be manipulated by remote control.

To use the device, engineers strapped me into the exoskeletal frame that encompassed my legs and feet. They connected me to a pulley-and-tether system rigged to the ceiling for extra safety as the robot powered me upright and onto my feet in a natural sit-to-stand motion. The engineers controlled all the robot's motions with a remote. My job was to maintain my center of gravity and shift my weight as appropriate to keep my balance. I tipped and stumbled while the engineers watched and guided me. Had it not been for my rigorous training, I might not have managed to stay upright, but I was walking independently (with a spotter) by day four.

Those moments were profound. I had to unlearn the double-handed pushing habits that had become ingrained during 18 years of using long-legged braces with a walker and propelling a hand cycle and a wheelchair. I had to relearn the natural motions of walking, such as moving limbs cross-laterally (right arm, then left leg, and so on). I stared straight ahead into space, nervous and tentative, concentrating on my positioning. The experience was exhausting, exhilarating and incredibly emotional. Imagine wanting something intensely for nearly two decades and suddenly receiving it in one powerful, upright moment.

My first steps in an exoskeleton would be followed by many more. I became an ambassador for Ekso Bionics and continued practicing with newer models as the technology improved. In 2012 the company's Ekso suit became commercially available for rehabilitation centers for an average cost of $110,000 plus service and warranty fees. A year later, after a massive community fund-raising effort, I acquired my own personal suit. I named it "Tucker" in memory of my beloved late golden retriever so that we could still, in a sense, go for walks together.

My suit is more sophisticated than the prototype I tested in 2010. Tucker is equipped with smart crutches, for example, which enable me to initiate walking and standing modes and let me trigger my first step. Another assistive feature enables me to engage the trace muscles in my legs to contribute maximum effort to my step while the robot's artificial intelligence powers me through to finish the step in a normal gait. Although I own Tucker, all of my walking is done in a rehabilitative context, with a



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THE AUTHOR

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Boxtel visits the Maroon Bells scenic area in Colorado with her dog, Benson.

physical therapist spotting, to ensure that I am safe and everything is working properly. (The Ekso is for clinical use only and not designed for daily living. The U.S. Food and Drug Administration is currently revisiting this technology's safety and efficacy in light of new regulatory classifications.)

To date, I have walked more than 130,000 steps with Tucker. The health benefits have been numerous. Walking causes my digestive system to become more efficient, with increased bladder and bowel regularity. I have better circulation in my legs: they are warm to the touch and pink rather than cold and splotched with purple. Swelling is reduced in my legs and ankles. My legs actually tingle through to my tippy-toes when I stand up and walk. My heart pumps more blood through my body. I have relearned proper gait patterns and the best way to align my joints and bones.

I have also regained an awareness of where my body is in space, finding my center of gravity with weight shifts as though the exoskeleton has become a part of my own body map. My sleep has improved with high-dosage walking. I have increased mental acuity, as if a veil has been lifted from my head. My neuropathic pain dissipates almost completely, and I enjoy a better quality of life. I firmly believe that exoskeleton technology can reduce the risk of secondary complications and become a preventive health care measure.

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I am not alone in that belief. Researchers at leading rehabilitation hospitals around the globe, including the U.S. Department of Veterans Affairs and the Kessler Foundation, a New Jersey–based nonprofit, are investigating how exoskeletons could modulate the secondary consequences of being unable to walk. Gail Forrest, an expert in human movement at Kessler, found preliminary evidence in 2012 that in 13 patients with spinal cord injury, using the Ekso suit could improve heart, lung and circulatory health.

When I don the exoskeleton, stand up and walk, I feel the tallness of my body—something I never imagined was possible in my lifetime. Each time I stand, a moment of euphoria sweeps through my body as I feel my five-foot, seven-inch frame. I look across a room and at the tops of things. My greatest joy is standing at eye level and feeling a heart-to-heart hug. In my 23 years of paralysis, my mother has grieved my loss and hoped to see me walk again. Every step I make is for her. And I feel like I am walking for every brother, sister, friend, neighbor or colleague who shares that same dream for a loved one.

Beyond Disability

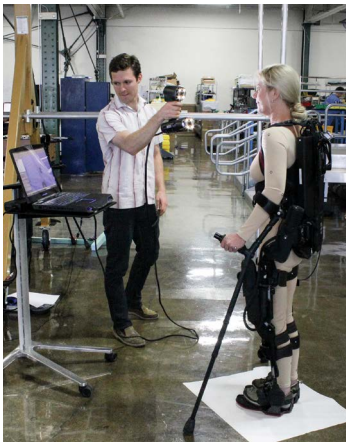
Exoskeletons carry important symbolic significance beyond their practical uses. For 1,500 years, the wheelchair has been the only mobility option for millions of people. And although it may enable someone like me to live a full life, it is also the universal symbol for disability, which can be disempowering. For some users, the wheelchair becomes their entire identity. Today, for the first time, we are encountering an alternative with radically different connotations. Exoskeletons are science fiction's great equalizers: helping Ellen Ripley defeat the extraterrestrial queen in *Aliens* and transforming Tony Stark into Iron Man. They represent human enhancement and imagination.

In the past decade we have begun to see exoskeletons take their place in society for industrial and military uses as well as for physical rehabilitation. In 2008, with support from the

CHARLES ENGELBERT

U.S. Department of Defense, Berkeley Bionics developed an exoskeleton called HULC (for human universal load carrier) that allows soldiers to squat, march and leap over rough terrain while carrying 200 pounds of gear. Multiple manufacturers are looking to exploit a more general market by taking exoskeletons into industrial applications, such as helping warehouse workers lift very large boxes or firefighters climb multistory buildings.

Companies in at least five countries now manufacture and sell medical exoskeletons. All must be used with a physical therapist, with the exception of the ReWalk system from ReWalk Robotics. Last year the FDA approved the $70,000 device for at-home use with a friend or family member serving as a spotter. What I have learned from my own research and experience testing a variety of exoskeletons is that all of them provide similar psychological and basic physical therapeutic benefits. The challenges to more widespread use are weight, cost, accessibility, minimizing fall risk, improving functionality and individual customization. Most of today's suits weigh between 22 and 50 pounds and cost more than $70,000.



In 2013 Boxtel participated in a research and development project led by engineers at 3D Systems. In the photograph at the right, the team scans Boxtel to design 3-D-printed components for a form-fitting and highly personalized exoskeleton.

COURTESY OF 3D SYSTEMS

Future exoskeleton technology will not only produce lighter and cheaper models, it could fuse robotics, 3-D printing, smart materials, nanotechnology, neural interfaces and design to morph flawlessly into the human body. That would bring us closer to the true definition of the singularity—that is, the merging of human with machine [see "Melding Mind and Machine," on page 52]. But we must keep individuality and humanity at the forefront; the goal is to humanize machines, not mechanize humans.

I have had a glimpse of this future. In 2013 design engineers at 3D Systems invited me to participate in a research and development project to create the first hybrid partially 3-D-printed exoskeleton. The design team scanned my body to tailor the suit exactly to it and tapped my ideas for the device's appearance. The 3-D-printed parts—designed to resemble my muscles—were lightweight, ventilated, flexible and strong. The resulting suit was easily doffed and donned, and it provided support without pinching any pressure points. I felt, for the first time, as if the outer casing of the suit was one with me. Because I helped to create it, it matched my personality.

With 3-D-printing, we can showcase the human body and stunning design, along with functionality. I was a co-creator of the design process, bringing the human experience into the equation. I can envision suits that are sleek, sexy, streamlined and feminine or rugged and practical for the no-makeup, adventuresome athlete that I am. As exoskeleton manufacturers engineer more functional suits for daily living, we can look forward to creating designs that enable individuality and self-expression—the ultimate personal fashion statement.

Making Strides

My experiences have convinced me that walking should be seen as a human right. By supporting research and development, we can usher in the next generation of exoskeletons and increase their access and affordability around the world. Two years ago I founded the Bridging Bionics Foundation, which educates the public about bionic advances and raises money for further study and helps communities gain access to bionic equipment. Although there are potentially millions of Americans with limited mobility who could benefit from an exoskeleton, manufacturers currently estimate that fewer than 1,000 devices have been sold in the U.S. The challenges are many, but chief among them are access and price. Not only are the devices costly, but training and annual maintenance fees can also be prohibitively expensive. Most of these costs are not covered by insurance.

This year I donated Tucker to my community so that others could share in this tremendous gift. (I will still visit and use my exoskeleton at the rehabilitation center.) In addition, I led a fund-raising effort to raise tens of thousands of dollars for training other individuals who are paralyzed and meet the inclusion criteria to walk in this device.

For individuals who are paralyzed or have some form of lower-extremity muscle weakness, the exoskeleton has come to represent a fusion of biology and technology, the most complicated neuroprosthesis ever imagined. It is a fantastic example of the power of combining science, engineering and the human spirit. I foresee a day when people will no longer hear the words: "You'll never walk again." Instead they will hear: "Yes, you can. It'll just be different. Let's show you how." M

FURTHER READING

- **Walking 2.0: Humanizing Machines with Functionality, Design, & Beauty.** Talk by Amanda Boxtel. TedCity2.0 Michelin Salon, Chengdu, China, November 2014. **www.youtube.com/watch?v=HAWT5CeoH9g**
- **A Survey of Stakeholder Perspectives on Exoskeleton Technology.** Jamie Wolff et al. in *Journal of NeuroEngineering and Rehabilitation,* Vol. 11, Article No. 169. Published online December 19, 2014.
- Bridging Bionics Foundation: **www.bridgingbionics.org**

From Our Archives

- **Mending the Spinal Cord.** Ulrich Kraft; October/November 2005.