

RESILIENCE

A Lifestyle Magazine for People With Disabilities Who Want to Live More Fully

The Dream-Doer

Overcoming
Negative
Thoughts

Getting
Back
to Work



Yes, You Can Dance!

The Imperfect Caregiver

Research News

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RESILIENCE

www.RESILIENCEmag.com

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Message From the Publisher and Editor

Welcome to *RESILIENCE*, the new lifestyle publication that is intended to inspire, motivate, entertain, inform and share stories about people with disabilities and those involved in our lives.

Over my decades of working on several publications for people with disabilities, I have realized that we often also have great abilities. And when we need to, we also acquire new abilities to help us survive and thrive in a world that wasn't built for us.

Time and time again, I have witnessed those who have something considered a disability do or learn to do something that is beyond normal ability. A person who has no arms, for example, who can paint beautiful artworks with their mouth, who can fix cars, or who can drive a car or even pilot a plane. A person who uses a wheelchair but travels throughout multiple states without assistance. A person without arms and legs who can climb mountains. And, yes, although every person with a disability doesn't have to climb a mountain to prove ourselves, it's pretty cool when we do.



Then there's a good friend of mine and ally of this publication, Dr. Donna Walton. Although she lost a leg to cancer when she was just 18 years old, she has gone on to achieve many of her dreams in the midst of struggle. In this issue and in the future, you'll learn more about this amazing woman and the organization she founded, Divas With Disabilities (www.divaswithdisabilities.org). Stay tuned to be encouraged to adapt. In fact, she didn't simply adapt, she went on to fully reinvent herself. That's another level of adaptation, and you may decide to go that route yourself. It's up to you.

The list could go on and on of people who have difficulties in one area of our lives but go on to excel in another area. We can fill years of magazines with such stories and still not tell them all. But we're gonna try!

This magazine will tell you about many such people, with hopes of letting you and the world know that we are not only disabled but *abled*.

It will also help inform you about things that can help make our success in life more possible and help us go beyond what we ever imagined.

How does a person with a disability support himself or herself? Social Security may not be enough for some. How does a person with a disability get around on a college campus? It's not always easy—going up and down steps outside or navigating a wheelchair for long distances on a snowy day. Does the world make it easier or more difficult? If more difficult, what can we do to change that? Are laws helping or hurting? There are so many issues that constantly have to be faced and dealt with.

One person with a disability can help others with a disability learn how to deal with such issues. Those who've been around know the ropes and have insider knowledge. This ain't their first rodeo.

In this magazine, people with disabilities will help each other. Adapting is the minimum goal, and they are the guides. And, if you want to go beyond that minimum, some of them can also help you reinvent yourself so that you can fly higher than you imagine.



Illustration made using Midjourney

I hope you enjoy this issue and the ones to come. Please share it with others and help us grow. **Because Information Changes Lives.**

- Rick Bowers

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Your Dreams Are Our Business

THE DREAM-DOER

How One Woman Overcame Adversity to Achieve Multiple Dreams

By Rick Bowers

Talk about
a dreamer.

A doer.

A builder.

And a star.

Donna R. Walton
certainly
fits all of those
descriptions
—and many more.



Yet, for many years, her dreams were set aside for a variety of reasons—most of which originated with the dreaded C-word: cancer.

The Beginning of the Loss

The loss of Donna's left leg—and nearly her life—to bone cancer when she was just 18 led to a struggle for many years to deal with a multitude of issues. These included low self-esteem, a negative body image, being made fun of, being rejected by men, self-doubt, and low expectations, pity and negative thinking from others and from herself.

For people Donna's age at the time of her limb loss, physical appearance is often of utmost importance, and it was no different for Donna, maybe even more so since she had long dreamed of being in the spotlight as a dancer, singer and actress before her amputation.

“In the hospital, I couldn't get certain negative thoughts and words out of my mind, no matter how hard I tried,” she says. “Handicapped. Disabled. Crippled. Flawed. One-Legged Donna. I thought this was how others would see me now that I'd lost my leg, but it was, in fact, also how I saw myself. And I did not have much empirical evidence to refute my beliefs.”

Getting such thoughts out of her head and coming to terms with her so-called disability and new life situation would prove a difficult process.

A Life-Changing Moment

At some point, Donna came to a pivotal moment in her struggle, however. During an argument with a rival for a man's attention, the rival told Donna that she was less than a woman because she had only one leg. Donna was immediately devastated. However, the remark also made her ask herself and her rival an important question: “What's a leg got to do with it?”



Then, as she thought more and more about it, the question ultimately became a statement and a personal motto: “What's a leg got to do with it!”

That question and the resulting statement changed her life. “Once I got my focus off that leg, it was as if I had once been blind and then gained 20/20 vision,” Donna noted in her memoir, *Shattered Dreams, Broken Pieces*. “I could now see my many other positive qualities, skills and talents.”

Struggles With Triple Jeopardy

In addition to her own feelings, however, she also had to deal with how others saw her.

When she didn't get accepted into a broadcasting program at Syracuse University or a TV broadcasting internship she applied for, she had to wonder why. She realized that she was facing obstacles on three fronts—as a black person, as a woman, and as a person with a disability. It's a condition sometimes referred to as triple jeopardy—and she had it.

“Being black, female and disabled was certainly not a recipe for success in 1984,” she says. “Each of these three things alone could hinder a person’s efforts toward success, but all three combined, it seemed, would make it nearly impossible.”

Realizing that she had triple jeopardy and that it could make achieving success more difficult, she made an important decision. “I knew that, for the rest of my life, I would have to strive to become impervious to and rise above the limitations imposed on me by others. ... I was not going to take no for an answer. It was not in my nature.”

These experiences made her realize that she needed to become so qualified that no one could turn her down in the future. She would have to somehow make herself that valuable.

Reinventing Herself and Excelling

To succeed with all the obstacles she faced over the years, she realized that she wouldn't just need to make minor changes to her life but would instead have to reinvent herself—to become a new person. She would need to throw out everything that wasn't working and then use the parts that were working, mix them with new parts, and put herself back together.

She began striving to improve her situation, even in the midst of physical and emotional difficulties that tried to keep her down.

“Unfortunately, many of us believe ... that once something is broken, putting it back together is impossible,” she says. “When our lives are shattered by some kind of trauma, we believe that there is no hope to rebuild them, and we simply give up. Some of us become incapacitated and depressed. Others become suicidal. The reality, however, is that broken lives can be renewed, remade, rebuilt, recycled, reinvented, rebranded. And, in many cases, our new lives can be even better than our old ones—if we know how to deal with the trauma. It's true. Millions of people have proven it. They have done so even when the obstacles blocking their way were like giants and seemed way too large to overcome.”

Discovering Her Purpose

In 1996, Donna got a major boost when she discovered her life's mission and began to work tirelessly to fulfill her new dreams and then some of her older ones.

She wanted more education to become a teacher and to enhance her credibility for building a nonprofit organization to help others.



Teaching Days

“In the end, I made the decision to pursue my doctorate,” she says. “My mother had always encouraged me and my sister to get as much education as we could, and by now I was coming to grips with the reality that I would not be living out my dreams in Hollywood. People were also beginning to ask me to share my experiences with others, and I did not want to do so based on my life experiences alone. I wanted to provide greater value to those I spoke to, and I thought that my talks and presentations would have more credibility if I had higher academic credentials.”

When she received her EdD in rehabilitation counseling in 2005, she says she realized that her preamputation dreams had not been lost, only changed.

“It took me nearly 10 years and a lot of hard work to achieve this great accomplishment, and I am proud to have not given up,” she says. “Of course, there were times when I felt like it, but my determination carried me through.”

With her doctorate in hand, she felt that even though she was black, female and disabled, she had what she needed to successfully navigate the often-challenging job-seeking terrain.

“I was now a much more valuable candidate for potential employers, and I had far less competition for positions because usually only a few candidates possessed the required qualifications,” she explains. “As planned, my doctorate also gives me more credibility when I speak to others and interact with them on behalf of my organizations. ‘Dr. Walton’ has proved to be a much more impactful title than ‘Ms. Walton.’”



With her doctorate, she was able to have a long professional career before retiring from her position with the United States Department of Defense in August 2020.

At around the same time she received her doctorate, in 2005, she changed the name of a fledgling company she had started from Dream Reach Win to LEGGTalk, Inc. In this business, she uses her professional training, work experience and life experience to offer “Lessons of Empowerment for Achieving Goals and Greatness.”

The company’s services currently include public speaking, life coaching/counseling, workshops, and disability awareness and training. With her new life as a greater testament that individuals can achieve abundance with a positive spirit and attitude and the determination to soar, she educates and motivates others to change their thinking, attitudes and behavior.

“Through these services, I teach people to use their inner power to become champions—people who strive to win, no matter what their circumstances,” she says.

With a desire to help others even more, she also started an international movement called The Divas With Disabilities Project (DWD) in December 2012.

She originally launched it as Facebook group page because she wanted to create a space where black and brown women could share their lived experiences. She chose the word diva because she wanted to show that if a woman wants to be a diva and lives with a disability, she can because diva and disability can co-exist in a single person. Because the word divas conjures up a certain meaning, a new meaning was assigned to the word - Dynamic, Illuminating, Victorious, Achieving Sisters.

"With Divas, I wanted to reach out especially to black and brown girls and women because of my own experiences as an African American woman," she says. "I'd started the page simply as a way to connect and network with others and maybe make a few new friends. I had no idea or expectation that it would grow into anything else. But when I opened the page that day, I found a lot of activity and realized that perhaps the page was filling a need. ... Many visitors to the page said that they found refuge and inspiration in realizing they were not alone."

Over time, she began to think of the project as something much greater than she'd originally envisioned. She started posting to the page more often and then decided to expand and build a website for it as well. Today, it continues to evolve into a major movement for black and brown girls and women with all types of disabilities.

"For purposes of the divas with disabilities movement, a diva is defined as an empowered woman, and the project promotes and empowers women of color who have disabilities, chronic medical conditions, and congenital anomalies," she explains. "Our goal now is to thrust more women of color with disabilities into the spotlight through media exposure—to shape the perspective of 'what disability looks like.' ... As we move forward on exciting new initiatives, our mission is to serve as a platform for women to learn, share, and grow and to empower them to live fulfilling lives."

DWD[™]
The Divas With
Disabilities Project

RESHAPING WHAT VISIBLE
DISABILITY LOOKS LIKE



Now the dream for the project has grown further. Perhaps, she says, there'll be a podcast, a television show, a mentorship program, an awards ceremony, a conference, and a related foundation. "Our work has just begun."

The Return of Earlier Dreams

Even though Donna was achieving many dreams around this time, her dream of being a performer—of being in the spotlight—was still there.

"My dream of being an entertainer—of singing, dancing and acting—was not merely the passing fantasy of a teenager," she says. "It was something deeply rooted in my being. I had loved singing and dancing as far back as I could remember. ... In junior high school, I was a cheerleader and a member of the drill team. When we performed our routines during our schoolwide events, I felt as if everyone was watching me! Then, when I got a starring role in the school play *Purlie*, my dream was sealed. I knew from the moment I stepped onto that auditorium stage at Carter G. Woodson Junior High School that I was bound for stardom. The applause, the stage lights, and the ovations were intoxicating."

It was, therefore, especially gratifying in April 2014 when she received an e-mail from the groundbreaking Raw Beauty NYC photography exhibit (www.rawbeautyproject.com), which showcased photographs of 20 women with various disabilities who represented beauty, sensuality and empowerment. The project invited Donna to be a model for the exhibit.

"It was like coming back to my original dreams in a way," she says. "When I first lost my leg, I believed that my dream of being in the spotlight was over. And really, at that time it was true. Fortunately, many people and organizations are now working to change that. Raw Beauty NYC, mobileWOMEN.org, Models of Diversity (www.modelsofdiversity.org), The Bold Beauty Project (www.boldbeautyproject.com), and my own organization, The Divas With Disabilities Project (www.divaswithdisabilities.org), are helping society realize that there is no single standard of beauty."



Photographer - Paul Morse

The following year, more huge things happened. She was also a model for The Bold Beauty Project, and *O, The Oprah Magazine* published an article about the Raw Beauty NYC Project. These wins for people with disabilities provided opportunities, Donna says, “to show others that life does not have to end because you lose a piece of you, you have a disability, or you look different from others. It also gave me another chance to see myself as not only beautiful but as the celebrity I always dreamed of becoming.”

Then, in 2021, she got her first professional acting role in *The Retreat*, a series produced by [Nuanse Entertainment](#). Since then, she’s also modeled for ads, done numerous local and national commercials, and will guest star in an upcoming TV series, *The Other Black Girl*, set to air on Hulu in September 2023.

Having overcome everything that disability has thrown at her and not allowed it to end her dreams, she is now working to grow LEGGTalk and DWD to the next level.

Her goal is to get more funding for DWD and take it from a mostly volunteer-run organization to a professional organization with paid staff and consultants to increase its reach and help more women with disabilities around the world connect, help each other, and benefit from those who have gone before. This nearly lifelong dream is going forth, and Donna is making a difference as she has long hoped.

To fully achieve this goal, however, she’ll need to acquire more donors and sponsors and win larger grants. That’s on the list.

“I believe in my heart that DWD can help, and I feel that if I don’t take it as far as I can, many women with disabilities will fall through the cracks of a world that wasn’t made for them,” she says. “I want to make sure that they have all the tools they need to navigate that world and overcome all the obstacles it puts in their way.”

What Fuels the Passion?

Now that Donna is retired, she could simply rest on her laurels and take it easy for the rest of her life, but the dreams won’t let go, even though she knows there’s more work to be done.

“One way I’ve been able to keep my passion alive all of these years is simply by understanding that succeeding—fulfilling our dreams—takes work and time,” she explains. “I know what to expect, so I can deal with the process and be patient. When I realized that I wanted to make my new life about helping others reinvent their lives and fulfill their dreams, I soon realized that it wasn’t just going to happen overnight. I was going to have to strive to make it happen.”

Her life—and continuing dream—is about helping others overcome the hardships she’s had to deal with.

“If you ever see the smiles on women’s faces when they learn what they can accomplish—regardless of so-called disabilities that they might have—you can understand why I do what I do and struggle to achieve more. It is a wonderful feeling that can’t be duplicated.”

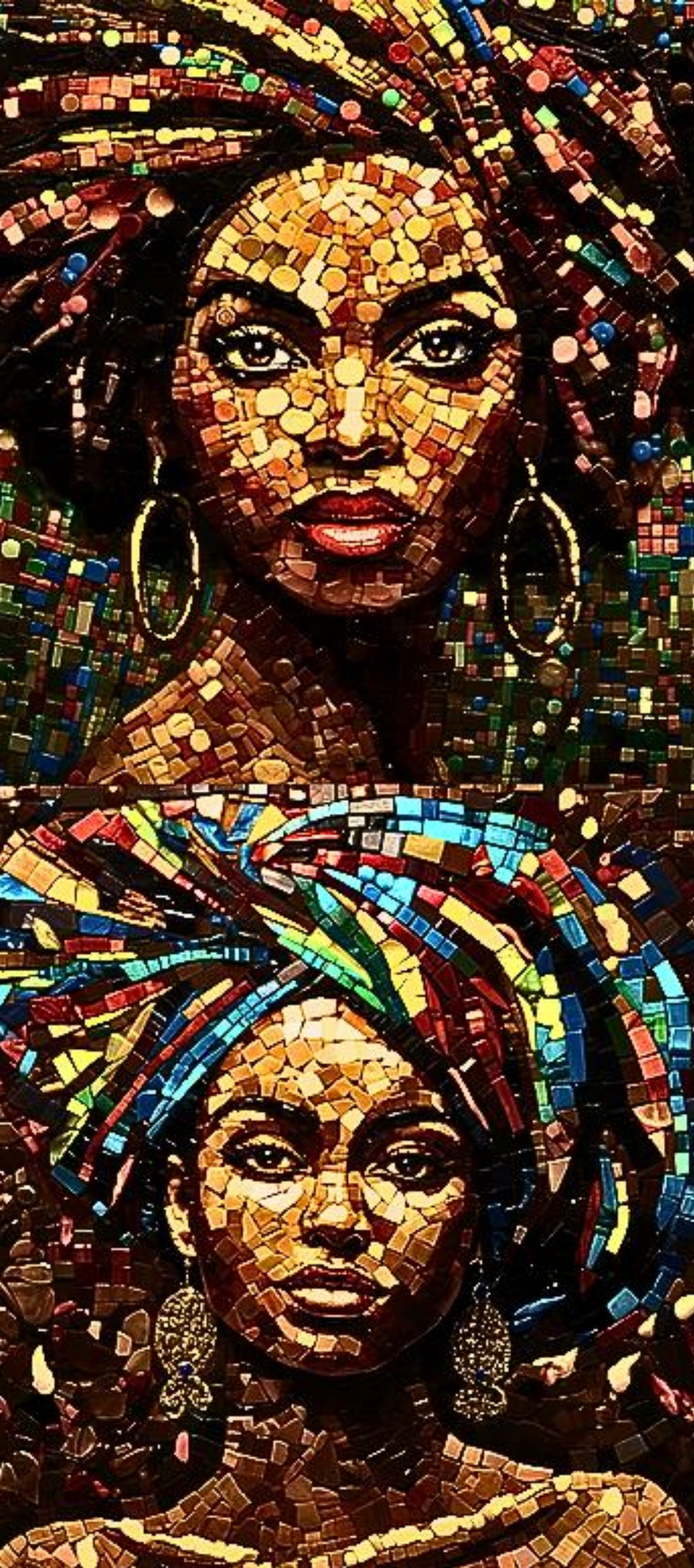
“If what you want isn’t behind Door Number 1, Door Number 2, or Door Number 3, don’t settle for less. Knock a hole in the wall, and make a new door.”

—Donna R. Walton



Photo by
Tim Coburn
Photography

www.DivasWithDisabilities.org



As a person with a disability, can you relate to this poem from the beginning of Donna Walton's memoir?

Broken Pieces

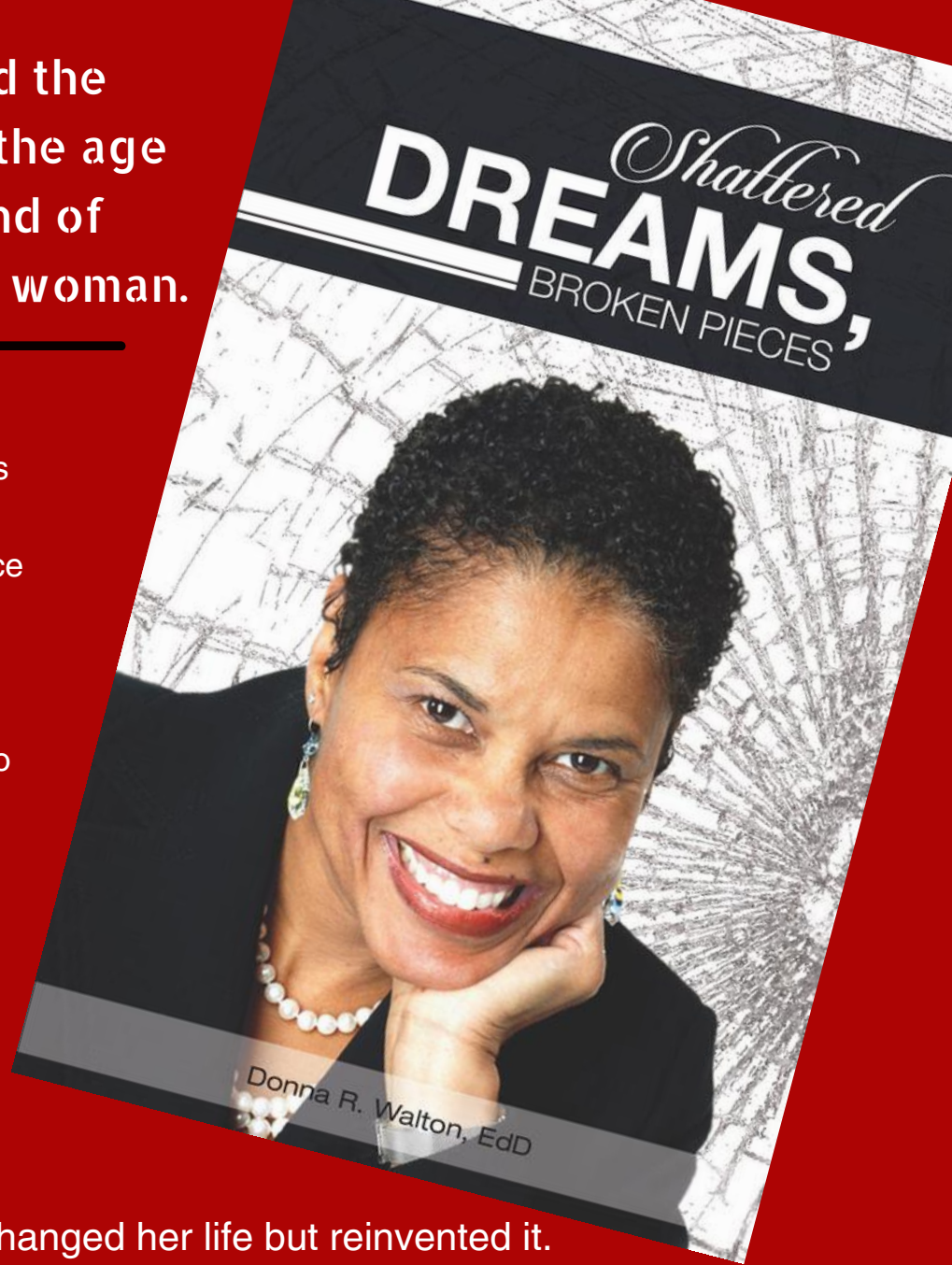
Regret not
the broken pieces,
for nothing
built by humans
is possible
without first
breaking something that already exists
and somehow altering it.

Even a new life,
a new and beautiful mosaic
made of broken pieces
of living human clay,
starts with the broken pieces of
some previous life.

Therefore,
when our lives
are shattered,
sometimes beyond recognition,
we must ask
ourselves
if we should
bemoan our fate
or rather
joyously
pick up the pieces
we want to keep,
paint them in bright and beautiful colors,
and rejoice
at the possibility
of a new
me.

Overcoming cancer and the amputation of a leg at the age of 18 takes a special kind of heart. A special kind of woman.

Shattered Dreams, Broken Pieces is the encouraging story of the decades Donna Walton spent rebuilding her world and discovering new confidence and a fresh sense of purpose after facing these tragedies. Through disasters, setbacks, trials and tribulations, the author proves that no crisis is too large to recover from. In this memoir, she reveals the path she took to healing and offers readers valuable insights for overcoming the obstacles in their own lives.



Find out how Walton not only changed her life but reinvented it. Like Walton, you'll learn that you don't have to remain in a life you no longer like or want. If you are willing to change your thinking and put in the work, you can reinvent your life too.

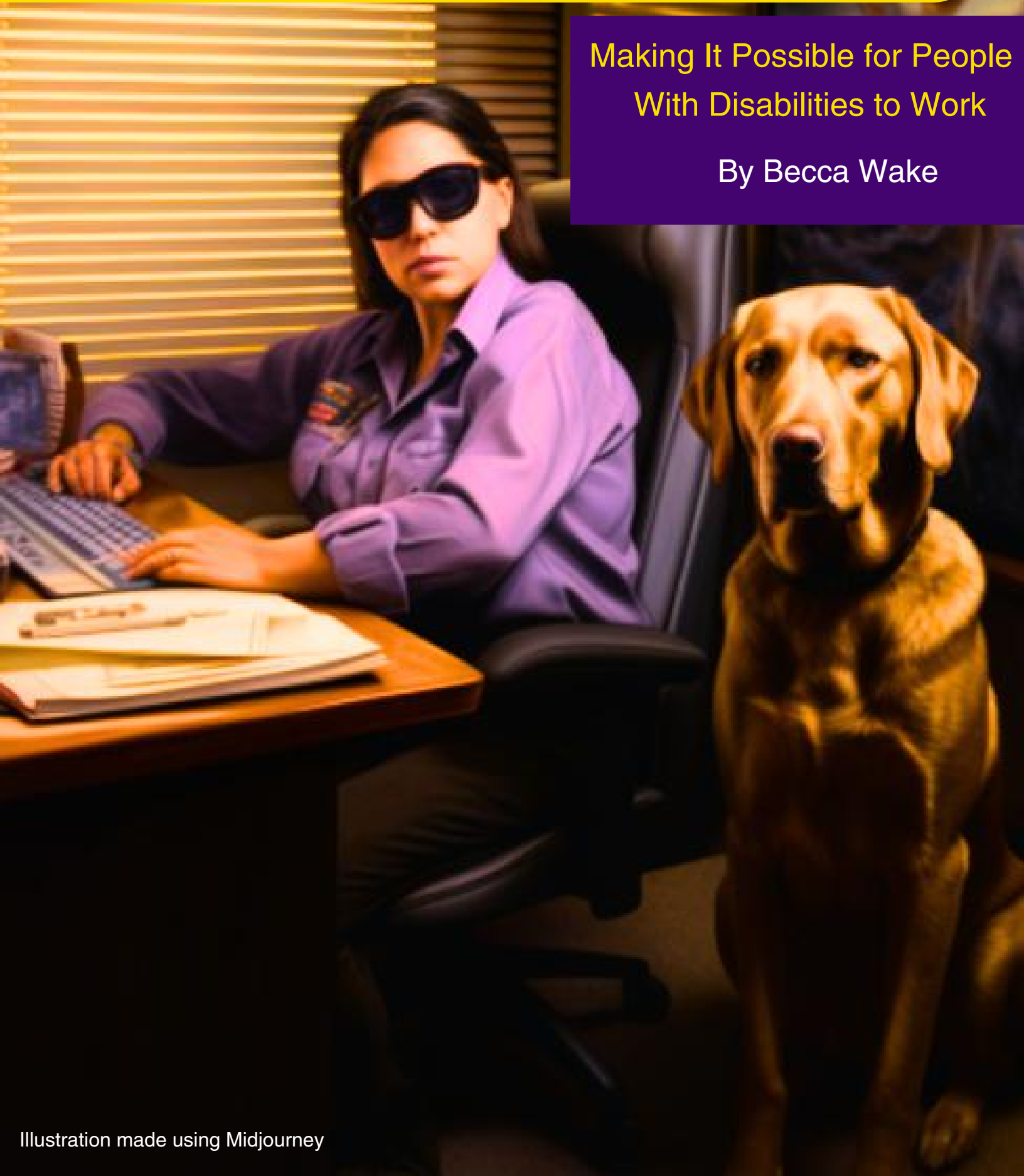
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***To order multiple copies, contact Donna Walton at donna@donnawalton.com for a special discount.

Reasonable Job Accommodations

Making It Possible for People
With Disabilities to Work

By Becca Wake



If you think you can't work and have a career because of your disability, you might want to think again. In fact, people with disabilities can work in almost any field today—many with the assistance of mind-boggling technology and many with simple and inexpensive low-tech or no-tech solutions. Whatever your disability, you should know that if you want to work or need to work, there is a great possibility that you'll be able to.

What Makes This Possible?

Many people today believe that equal access to opportunities is important, and societies have therefore striven to overcome the obstacles that hinder people with disabilities from keeping their employment or finding a job or career.

In the United States, the Americans with Disabilities Act also made providing reasonable accommodations to achieve this goal the law. According to the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), "Under Title I of the Americans with Disabilities Act (ADA), a reasonable accommodation is a modification or adjustment to a job, the work environment, or the way things are usually done during the hiring process. These modifications enable an individual with a disability to have an equal opportunity not only to get a job, but successfully perform their job tasks to the same extent as people without disabilities. The ADA requires reasonable accommodations as they relate to three aspects of employment: 1) ensuring equal opportunity in the application process; 2) enabling a qualified individual with a disability to perform the essential functions of a job; and 3) making it possible for an employee with a disability to enjoy equal benefits and privileges of employment."

This law requires certain employees to provide these accommodations to people with disabilities, unless doing so would cause the employer undue hardship. Such reasonable job accommodations may include flexible schedules and hours, remote working allowances, modified workstations, ramps, job restructuring and assistive technology.

If employers who are required to provide such accommodations fail to do so or retaliate against employees who request them, they may be sued for discrimination. It is important, therefore that employees know their rights and employers know their responsibilities.

The Job Accommodation Network (JAN)

For those employees who may need accommodations and those employees who are required to provide them, many helpful resources are available.

JAN, for example, is a valuable resource for both. It is a free consulting service that provides information on their rights under the ADA and other legislation and on various types of job accommodations. With consultants who are knowledgeable about the specifics of many disabilities, it can provide employees and employers individualized consultation. It can also help employers identify accommodations for their employees and avoid discriminating against them, even unintentionally.



Importantly, potential employers should know that most accommodations are inexpensive (\$500 or less) or free. They could be as simple as providing extra breaks, allowing an employee to bring their service animal to work, or providing a reserved parking spot near their work area.

By cooperating to find solutions, employees and their employers can each benefit—one by following the law and being a good employer and the other by maintaining more of their independence and being able to maintain a job and an income.

Together, by knowing their rights and responsibilities, they can ensure that workers are treated fairly and that those with disabilities are not unduly harmed.

Resources

The Job Accommodation Network (JAN)

www.jan.wvu.edu

Employer Assistance & Resource Network

www.askearn.org

RESNA

www.resna.org



Illustration made using Midjourney

EEOC Sues Nonprofit for Disability Discrimination



Nonprofit Denied Employee With Breast Cancer Reasonable Accommodations and Forced Her to Resign, Federal Agency Charges

The United Labor Agency (ULA), a Cleveland-based nonprofit that focuses on workforce development, violated the Americans with Disabilities Act (ADA) by discriminating against an employee based on her disability, breast cancer, the U.S. Equal Employment Opportunity Commission (EEOC) alleged in a suit filed in February 2023. The ULA denied the employee a reasonable accommodation of temporary remote work and subjected her to intolerable work conditions that resulted in her discharge, the EEOC charged.

According to the EEOC's lawsuit, after ULA required its employees to return to in-person work following a long period of COVID-related telework, it denied the employee's ADA accommodation request to remain on telework for several months while she was undergoing radiation treatments and was immunosuppressed. After being required to return to the office, the employee was repeatedly left off staff emails notifying personnel of COVID-19 exposures, despite her requests to be notified. The employee, who had been with ULA for nearly a decade, was finally forced to resign because of the risk to her health, the EEOC alleged.

The ADA prohibits discrimination based on disability. It requires an employer to provide reasonable accommodations if doing so would not pose an undue hardship. The EEOC filed suit (*EEOC v. United Labor Agency 23-cv-00283*) in U.S. District Court for the Northern District of Ohio after first attempting to reach a voluntary pre-litigation settlement through its conciliation process. In the lawsuit, the EEOC seeks back pay,

compensatory and punitive damages for the employee, and equitable relief to prevent future discrimination.

"It is an employer's responsibility to know its obligations under the ADA," said EEOC Philadelphia Regional Attorney Debra M. Lawrence. "This includes complying with the temporary medical restrictions of employees who are receiving ongoing treatments for serious medical conditions, unless it can demonstrate that doing so would pose an undue hardship."

Jamie Williamson, the district director of the EEOC's Philadelphia District Office, added, "So many employees face the challenge of working while receiving lifesaving cancer treatments. When these employees request reasonable accommodations, the employer must be well-informed and engage with the employee about the request in a substantive and meaningful way before making a decision."

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Breaking the Shackles of

Irrational Thinking



Nobody cares!

I'm ugly!

I'm a loser!

I'm worthless!



Nobody loves me!

By Donna R. Walton, EdD



“Our thoughts are either a fierce army of enemies marching to destroy us or compassionate paramedics coming to our rescue.”

— Donna R. Walton

For many years after I lost my leg to bone cancer when I was just 18, I struggled with negative thoughts that fought to become lodged in my mind for the long term. Because negativity is so too easy to slip into, I’m sure this is common for many people, whether they have a disability or not, especially when things aren’t going quite the way they planned.

Sound familiar?

In the late 1990s, I developed an interest in cognitive behavioral therapy, which seemed to be somewhat of a solution to negative thinking and its impact on our lives.

To learn more about this area of psychology, I read several scholarly books and self-help books by Albert Ellis, Dr. Wayne W. Dyer, and Deepak Chopra. This search helped me better understand why I became depressed when my self-esteem was under attack, why I needed to work so hard to build and maintain positive self-esteem, and how to improve my life by controlling my thoughts.

Around this time, I was also awakened by a professor's research, which found a positive relationship between self-concept and adjustment to disability, regardless of age, disability or other characteristics of the samples. These things ultimately led me to pursue becoming a certified cognitive behavioral therapist through the American College of Certified Forensic Counselors (ACCFC), which is the Certification Commission of the National Association of Forensic Counselors.

While I benefited from writing down my feelings in a journal and reading scholarly and self-help books, I also got the opportunity to benefit from professional therapy in 1999 as a requirement for my doctoral degree. This requirement was based on the idea that good counselors get therapy too—that the only way to help others is to help yourself first. Still, since I had gotten my life together to some extent over the previous years, I balked a little at the idea of participating in therapy at that time.

My First Experience as a “Patient”

As I sat in my car outside the therapist's office before my first session, I wondered why I was there—other than to fulfill my degree requirements.

I was nervous.

In retrospect, it's kind of funny. Even though I was studying to be a cognitive behavioral therapist, I still had the stereotypical concerns about therapy. Did seeking therapy mean that a person couldn't cope with life, had mental problems, was weak?

Finally, I got up the courage and went inside the building, telling myself that if professional therapy was fine for movie, music and sports stars, it was also fine for me.

When I finally went inside the therapist's office, she smiled and held out her hand to greet me.

“Please have a seat,” she said in a very calming voice, as she directed me toward a comfortable sofa. The session began just as I expected with the anticipated first question: “What brings you here?”

I soon found that talking about my confusion, self-esteem issues, fear, unsatisfying relationships, and other problems really made me feel better.

Although I only attended sessions for a little under a year, they were healing and brought me to a much better acceptance of my disability and how it affected my life. The therapy especially helped me understand how my disability and I would have to co-exist and get along if I was going to be the diva—the empowered woman—I wanted to be.

It was the best medicine for my soul and spirit that I could have given myself, and I'm glad now that I gave it a chance.



A Deeper Understanding of Negative Thinking

One of the things my personal reading, my doctoral education, and my therapy sessions taught me was how much our thoughts impact us. I now know that one of the reasons it took me a long time to reinvent myself after my cancer diagnosis and amputation was that I, like many (probably even most) people, was guided by irrational thinking.

Such irrational thinking can include things like too much negative thinking and pessimism, too little positive thinking and optimism, catastrophizing (or always expecting the worst to happen), and overgeneralizing things (for example, thinking that everything is screwed up because a few things are going wrong or that no one will ever love us because a few people have rejected us).

I learned that to be resilient and succeed, I needed to overcome these irrational thought habits. When we spend too much of our thinking on the negatives and pessimism and too little on the positives and optimism, it can drain our energy and enthusiasm. It can make us feel like not even trying because “What’s the point?”

Catastrophizing is even more extreme. If we expect that the worst is going to happen, we become fearful of the future. For me, I had always feared that the cancer would return and take my life, and perhaps that had held me back from pursuing the life I really wanted. Why try so hard if I was going to die from cancer soon anyway. Right?

Overgeneralizing is when we take something and consider it all-inclusive and without exceptions. Our irrational overgeneralizing can usually be recognized by our use of words like *always, never, everyone, no one, everybody, nobody, all, none, everything, nothing*, and so on.

“Nothing good ever happens to me!”

“Nobody cares about me!”

“Everybody thinks I’m ugly (or stupid or worthless or untalented, etc.)!”

“I’ll never succeed!”

“I’ll always be a failure!”

Unfortunately, as humans, we tend to see things as either black or white when, in reality, things tend to be gray. When our day has not gone well, we say, “This is the *worst* day of my life. It *absolutely* sucks,” forgetting that we are still alive, may have had three delicious meals, were able to take a nap, and may have received hugs from our children when we got home.

We allowed the many good things we experienced in the day to be overshadowed by the three bad hours we experienced.

When we think or speak in absolutes, we are usually overgeneralizing, and we are usually wrong. There are almost always exceptions. Therefore, whenever we find ourselves using such all-inclusive language, we should reevaluate what we are saying and what we are believing. It could improve our feelings dramatically.



My Personal Experience

While my own thoughts had not been totally irrational over the years, they had been up and down, positive and negative. As a result, even with my naturally positive and upbeat personality and high self-esteem, I had experienced both “good” and “bad” periods in my life.

In relationships, I had come to believe that nobody would ever fully love me the way I wanted to be loved because I was “handicapped, disabled, crippled, flawed, less than a woman.”

In thinking about my future, even many years after the cancer had been out of my life, I was catastrophizing and thinking that it would return and take my life, and this had perhaps held me back from pursuing a full life of hope and dreams and fulfilling my true purpose. And without the purpose that a person needs to truly live, I was not fulfilling my destiny, not being who and what I was meant to be.

Once I started breaking the shackles of irrationality that were binding me, however, my life began to improve dramatically.

By the time I'd entered my doctoral program in rehabilitation counseling and had begun participating in therapy, I had already changed a lot of my thinking and had begun fixing myself. However, the understanding I gained from my training and therapy helped me develop and heal even further. I now had a better understanding of the problems I had dealt with and, in some cases, had actually caused myself.

I also realized that even if a person is normally rational and positive, it only takes a small dose of irrationality and negativity to ruin it. It's like the old saying about one bad apple spoiling the bunch. Irrationality and negativity must, therefore, be beaten down as soon as they rear their ugly heads. We must immediately defeat them through rational thoughts, positive self-talk, and affirmations. The battle of thoughts is truly a battle for who and what we are.

Making Positive, Rational Thinking a Habit

Of course, all of this is not as easy as it sounds. It doesn't just work automatically when we read that we must change and monitor our thoughts. Often these negative, highly destructive thoughts are deeply rooted habits and have become a part of what each of us sees as “my story.” It is therefore important to realize that solving the problem might take time. Positive, rational thinking must also become a habit.

I was tired of having low self-esteem and a poor self-image, but to rebuild them, I had to realize that I was not going to get them back from a new prosthesis, the miraculous regrowth of my lost limb, or from another external source. It wasn't going to come from convincing everyone to stop being cruel. It would rather have to come from within myself—from taking the focus off my missing limb and putting it on the many things I had left. It would come from recognizing that I am much more than the sum of my physical parts and am also defined by my feelings, thoughts, beliefs, ideas, relationships, talents, abilities and many other things. I would have to continually affirm my positive qualities and characteristics and silence or ignore the negative voices from inside and outside myself.

As I built up my self-esteem and self-image, I also knew that I would have to maintain them as other people reminded me of my missing limb, past failures, and current problems and as my own inner judge, or critic, tried to bring me down from within.

My doctoral studies and therapy instilled more deeply in me the understanding that I needed to focus not on the external things that I could not control or change—my missing limb, other people’s feelings toward me, and other people’s prejudices—and instead focus more on the things I could control and change—especially my own thoughts and perceptions.

While I had already understood this at some level, the reiteration of this concept and a more research-based understanding of it helped me implement it more fully.

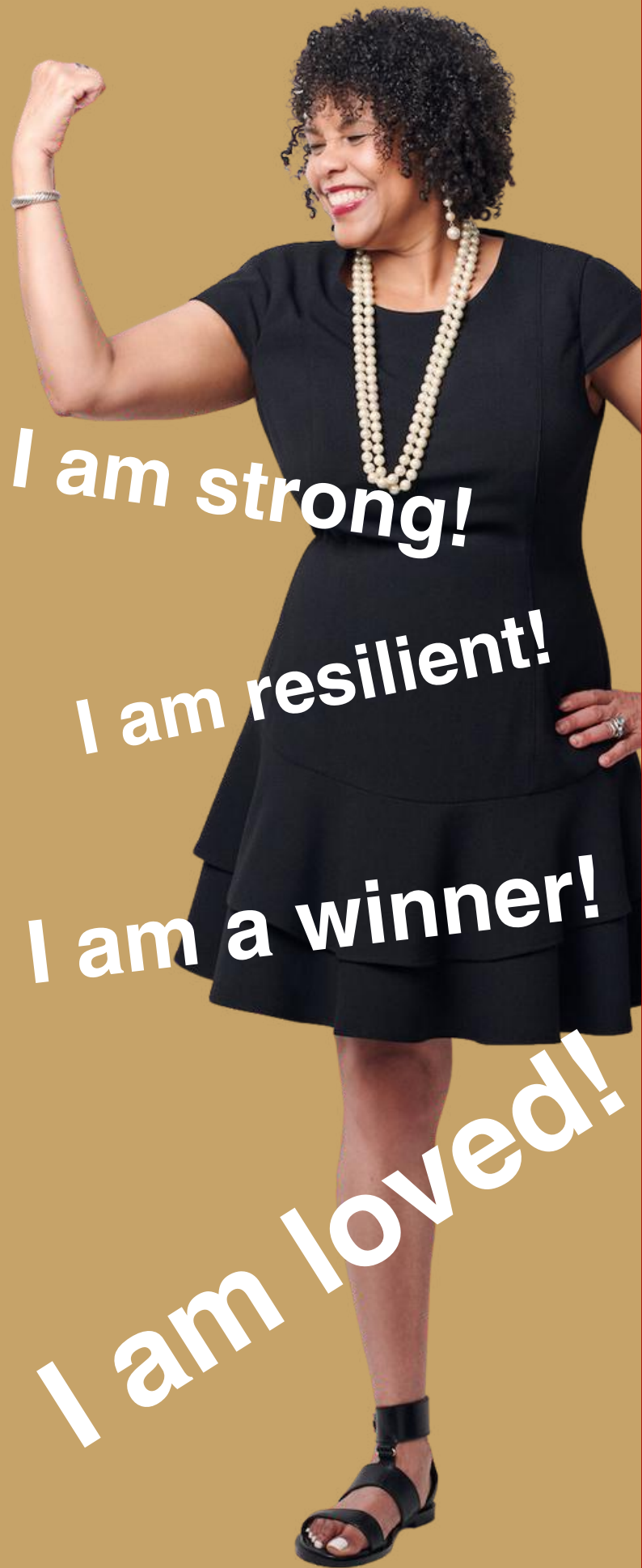
Try it in your own life. You might be pleasantly surprised at the results.

“You have power over your mind—not outside events. Realize this, and you will find strength. The happiness of your life depends upon the quality of your thoughts.”

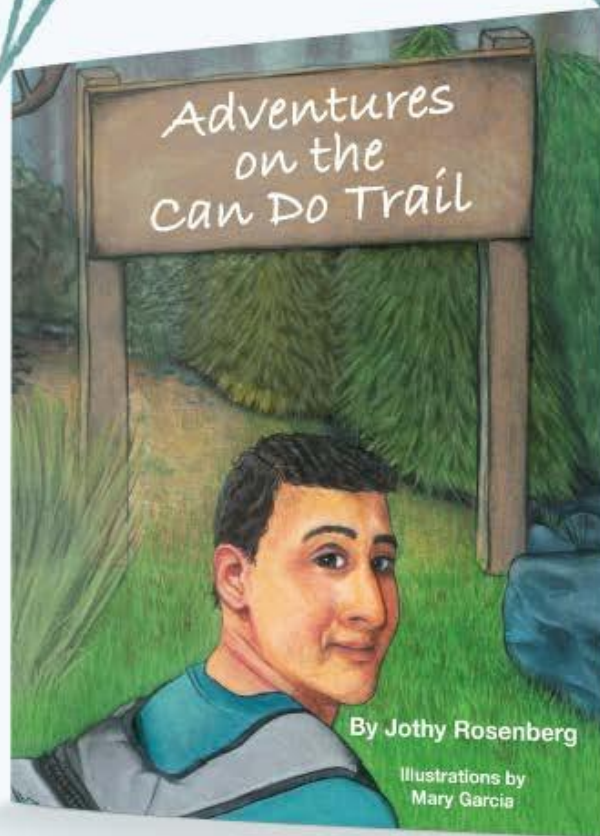
— Marcus Aurelius

This article was adapted with permission from “The Power of Our Thoughts,” a chapter in Dr. Walton’s memoir, *Shattered Dreams, Broken Pieces*.

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Donna Walton. Photo by Tim Coburn Photography.



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DANCING DREAMS

**Yes, You Can Dance
in a Wheelchair!**

By Rick Bowers



Illustration made using Midjourney

As he rode across the dance floor in his electric wheelchair, the man picked up one young woman after another, carrying each on his lap and smiling with glee. He and the young ladies were clearly having a blast. As I watched this scene at a disability conference decades ago, it was clear that almost anyone (myself excluded) can dance—disability or not.

Admittedly, the man was no Michael Jackson or Fred Astaire. But even though he wasn't the best dancer I'd ever seen, he was certainly enjoying himself immensely, even in a wheelchair. And, ultimately, isn't that what really matters?

Since that time, several such wheelchair dancers have gone professional, performing before huge audiences and making a name for themselves.

There's Auti Angel, for example.

Paralyzed from the waist down as a result of a car accident in 1992, Angel later returned to a dance career she'd begun years earlier when she was 18.

After starting the hip-hop wheelchair dance group Colours 'n' Motion, she was later featured in the 2012 reality TV series *Push Girls* and the film *Musical Chairs*.

Although Angel passed away in 2022 at age 52, dance groups such as Infinite Flow, Para Dance UK, No Limits, The Rollettes, Rolling With Me, and AXIS Dance Company carry on the torch by including dancers with disabilities.

Wheelchair dancing provides a showcase of the dancers' talent, skill, strength and creativity. Originating in Sweden in 1968, it now includes exhibitions, shows and dance competitions around the world. Participants may include those who use wheelchairs and those who don't, and the dances may be done individually, with a partner, or in a larger group. It's available to almost anyone.



ABOVE: *Alana Wallace of Dance>Detour moves with the music.*

Just Do It!

Sunshine King is a great example. Many probably thought that King, now 43, would no longer be able to dance after she was shot four times on Nov. 6, 2004, in a domestic violence incident, which left her with a T4/T5 spinal cord injury and needing a wheelchair for mobility.

Sunshine, however, refused to give up and didn't give anyone the opportunity to say she couldn't dance anymore. She just started doing it.

“Due to my upbringing, we don't seek out validation from others,” she says.

Sunshine not only returned to dancing again, she also became a dance instructor for people with and without disabilities and a choreographer.



Sunshine King. Photo courtesy of Sunshine King.

“As a professional dance instructor, I just kept my dream alive and started my organization called Sunshine Project H.E.L.P. (Healing. Educating. Loving. People.) in 2005. We have Sunshine Models On Wheels and WheelPower Dance and Fitness. We have performed at expos, trade shows, and other festivals over the years. And, man, it feels great! The audience energy changes, and, yes, they are participating too!”

When she’s out dancing on her own, she says she’s always the only person in a wheelchair unless she brings her group along.

“It’s a fun way to educate and be seen in the dance community more,” she says. “I love all that I do; therefore, I must share it with others.”

Not a Fluke

And if you think King’s being able to dance after her injuries is just a fluke and that she’s one of a kind, Ammie Morgan should put that theory to rest.

Like King, Morgan, now 32, became a paraplegic after being shot in a domestic violence incident about 13 years ago and is also dancing again.

“Dancing was very important to me,” she says, noting that she had been dancing since she was 5. “[Would I be able to dance again] was one of the questions that I asked my doctor when I woke up. ... I always knew within my heart that I was gonna be able to dance again,” she says. “I just had to figure out a way.”

She says that the first time she danced around able-bodied people, everyone was shocked.

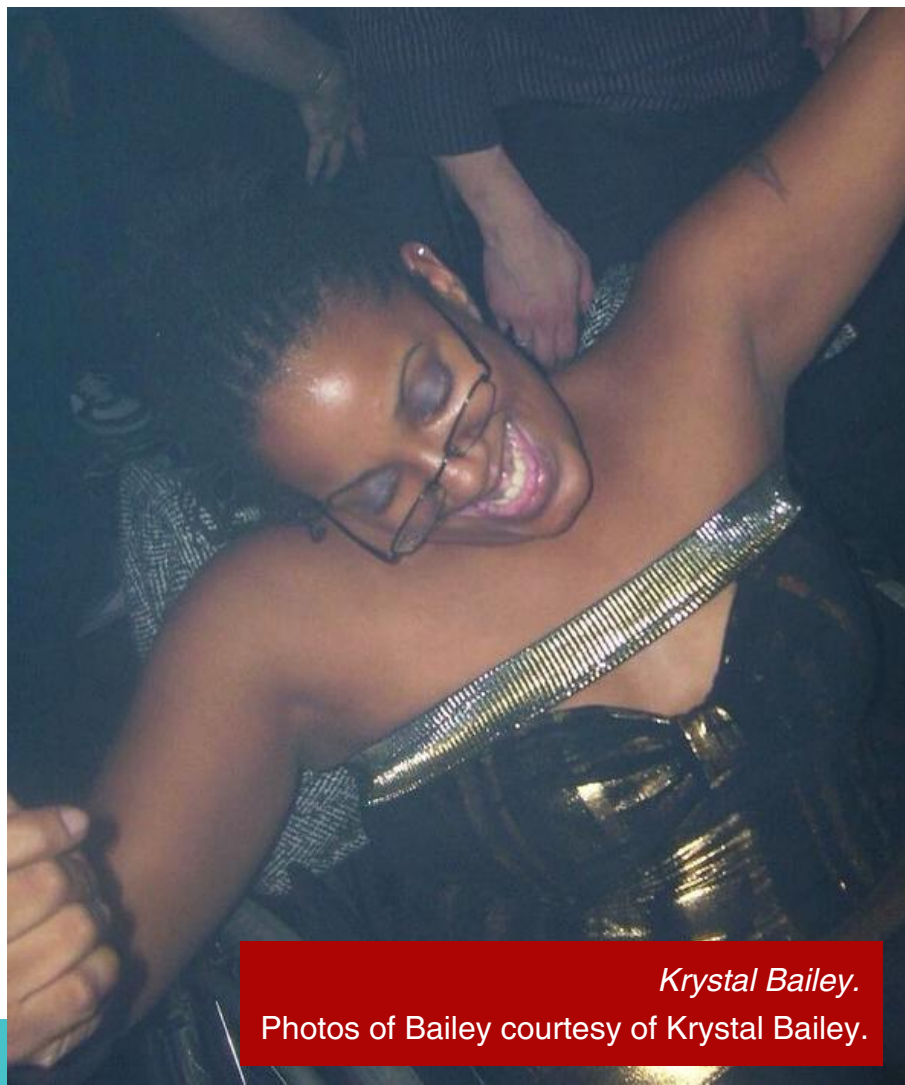
“They were so scared that I was going to fall out of my chair. Now everybody knows that I’m the life of the party.”

Wheelchair dancing offers the young woman many benefits.

It makes me feel free,” she says. “It’s a form of expressing myself.”

Another wheelchair dancer echoes Morgan.

“It feels free and stressless,” says Krystal Bailey, who also dances for fun with both wheelchair and able-bodied dancers and says that dancing gives her release.



Krystal Bailey.

Photos of Bailey courtesy of Krystal Bailey.

Now 41, Bailey has used a wheelchair since she was about 4 years old as a result of being born with spina bifida. She has been dancing since she was a kid.

“During family gatherings, music and dancing were always included,” she says. “I had a cousin who taught me that with adaptations I could do almost every dance.”

Later, as an adult, she also participated in adaptive dancing classes.

“Because of my energy,” she says, “it’s always a good time.”

Unlike King, Morgan and Bailey, Alana Yvonne Wallace, now 71, didn’t dance in a wheelchair until she was in her 40s. After she had polio as a child, she started walking with crutches and leg braces through age 40 and has only used a wheelchair for about 31 years. Still, she ultimately began dancing professionally internationally for more than 25 years.

“In my 40s, entertainer icon Ben Vereen introduced me to the Cleveland Ballet Dancing Wheels (a mixed-abilities dance company),” she says. “I was wowed! After taking classes in the art form, I formed Chicago’s first professional physically integrated dance company —Dance>Detour.”

Over the years since, she has danced with dancers with and without disabilities.



Krystal Bailey



*Alana Wallace
and Dance>Detour*

She says she loves the freedom of expressing herself through movement. “It feels like an ice dancer gliding freely across a smooth surface.”

Watching such dancers perform is awe-inspiring and can be quite eye-opening for spectators.

Sometimes people are amazed at the abilities of a wheelchair dancer,” Wallace says. “I enjoy the challenge of demonstrating what dance IS and WHO can be included.”



Alana Wallace and Dance>Detour.
All photos of Wallace and Dance>Detour courtesy of Alana Wallace.

Whether you're interested in hip-hop, jazz, samba, ballroom dancing or some other dance form, you should be able to find some kind of dance that you can enjoy either as a spectator or, better yet, as a participant—regardless of your disability. Moreover, with a quick Internet search, you should be able to find free or low-cost adaptive dance classes in your area or online.

Don't miss out. Isn't it time to have a little fun?

Visit the Following Links for More Information

Dance>Detour video

<https://tinyurl.com/dancedetour1>

Sunshine King Facebook

www.facebook.com/sunshine.king.7

Instagram: @sunshineking01

Wheelchair Dancers Organization

www.wheelchairdancers.org

Dance Mobility www.dancemobility.org

Infinite Flow Dance www.infiniteflowdance.org

“These Wheelchair Dancers Are Stunningly Talented” <https://tinyurl.com/wheeldance>

“Wheelchair Dance Company Builds Reputation as 'Dancing With the Stars' on Wheels” <https://tinyurl.com/dancewheels>

American DanceWheels Foundation

www.americandancewheels.org/index.htm

The American DanceWheels Effect

<https://tinyurl.com/wheelseffect>

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CAF's Annual Grant Distribution Helps Nearly 4,000 Individuals

Athletes with disabilities receive grants for adaptive sports equipment, training and competition expenses

In 2023, the Challenged Athletes Foundation (CAF) announced its largest grant distribution, providing life-changing access to sports and physical activity through 3,996 grants valued at more than \$7 million. CAF is a world leader in the adaptive sports movement and has supported thousands of athletes with physical challenges, empowering their lives through sport.

Since 1994, CAF has committed to positively impacting athletes at all experience levels through its global grant program, which provides financial resources for items rarely covered by medical insurance, such as running prostheses, adaptive sports equipment, and expenses related to competition travel, training and coaching. This year, CAF's grant distribution reached athletes ranging in age from 2 to 88, those living in 50 states and 39 countries, and spanning 101 different sports and activities, including wheelchair basketball, surfing, adaptive fitness training, cycling, wheelchair rugby, Alpine and Nordic skiing, sled hockey and outdoor recreation.

“We believe sport has the power to change lives and that’s why we are committed to helping overcome the barriers to access by providing support for equipment, travel and competition expenses to athletes of all abilities across 101 sports,” said Kristine Entwistle, CAF chief executive director. “Each year, we are creating a continuum of support and expanding our efforts to engage new athletes and build community on a global scale.”

For more information on CAF grants and to apply, visit www.challengedathletes.org.



Illustration made using Midjourney

2023 Grant Distribution Facts and Figures

- 101 sports
- 50 states + Puerto Rico
- 39 countries
- Youngest grant recipient - Age 2
- Oldest grant recipient - Age 88
- 28% of grant recipients under the age of 18
- 36% are first-time grant recipients
- 35% are female
- 64% are male

Income Stats

- 33% of recipients have household earnings under \$20K/year
- 26% of recipients' households earn income between \$20K-\$50K/year

Breakdown by Disability

- 20% Limb Loss/Limb Difference
- 12% Spina Bifida
- 10% Cerebral Palsy
- 8% Spinal Cord Injury
- 7% Paraplegia
- 4% Visual Impairment
- 2% Retinitis Pigmentosa
- 2% Quadriplegia

DWDTM
The Divas With
Disabilities Project

Join our community and movement for black
and brown girls and women with visible disabilities.

Showing up *unapologetically*
to reshape what visible
disability looks like



[DivasWithDisabilities.org](https://www.DivasWithDisabilities.org)

Illustration made using Midjourney

NAMI Celebrates National Minority Mental Health Awareness Month

In July 2023, the National Alliance on Mental Illness (NAMI) honors the legacy of Bebe Moore Campbell, a trailblazer who tore down barriers to mental healthcare in underserved communities. Her work crossed boundaries of race, ethnicity and identity, helping to destigmatize people who seek mental healthcare.

In 2008, the U.S. House of Representatives designated July as “Bebe Moore Campbell National Minority Mental Health Awareness Month” in recognition of Campbell’s endless drive to create positive change in communities of color. NAMI is celebrating and building on her impact all month with special programs and resources.

A Legacy of Humanity

Campbell recognized that mental health affects us all and that everyone should have the right to be heard and healed without shame or judgment. She worked to create safe spaces for people in communities of color to connect with others who share similar experiences and cultural backgrounds. These safe spaces provided a gateway to vital mental health resources and support networks.

“By emphasizing our shared humanity, we hope to shift attitudes toward empathy and compassion, regardless of race, culture or identity,” said NAMI CEO Daniel H. Gillison Jr. “We want everyone, especially the most vulnerable, to know that reaching out for help is a sign of strength, not weakness.

“This July and beyond, we’re not only honoring Bebe Moore Campbell’s legacy, but we’re also working to empower, uplift and elevate historically underrepresented communities in their mental health journeys, while eradicating stigma.”



Illustration made using Midjourney

Culturally Relevant Mental Health

Resources: A Beacon of Hope

NAMI is building on Campbell’s work with culturally relevant mental health resources and providing support and education programs tailored to different cultures, languages and identities.

NAMI Sharing Hope and NAMI Compartiendo Esperanza are presentations created for black/African ancestry and Latino communities to safely explore conversations on mental health. Both are designed to promote mental health awareness, explore signs and symptoms of mental health conditions, and highlight how and where to find help.

A new page <https://tinyurl.com/InvolvedWithNAMI> on NAMI's website features ways to join the conversation, including resources and shareable content that celebrate #ShadesOfMentalHealth.

Amplifying Voices With Strength Over Silence Docuseries

Strength Over Silence: Stories of Courage, Culture and Community at

<https://tinyurl.com/StrengthOverSilence> is a NAMI docuseries that highlights mental health perspectives of people across different backgrounds and communities. Through candid and courageous stories of lived experience, these mental health champions share their resilience and recovery, emphasizing the importance of culture and identity in the mental health movement.

Through these initiatives, NAMI is working to increase community-based engagement, offer mental health information, share resources and insights from people with lived experience, and increase access to culturally appropriate support.

If you or someone you love needs help, contact the NAMI HelpLine <https://www.nami.org/help>, Monday–Friday from 10 a.m.–10 p.m. Eastern Time. Call 1-800-950-6264, text “HelpLine” to 62640, visit and chat online at [nami.org/help](https://www.nami.org/help), or email helpline@nami.org.

The NAMI HelpLine is a free, nationwide resource staffed by trained peer-support specialists to answer questions, listen and offer support. They can provide practical next steps and help identify the best local resource options for your individual concerns.

This article was adapted from information provided by NAMI.



Illustrations made using Midjourney





AgrAbility

Helping Agricultural Workers With
Disabilities Work in Their Field

By Zach Kiser

On Sept. 18, 2018, things went tragically wrong for Laurie Hayn, who had been farming since 1983. As she was working on her farm, she was swept into a combine—a large machine that harvests crops—and ended up losing her left arm and leg as a result of the accident.

Although she was fortunate to survive such a horrific event, we can imagine a devastated Laurie in the hospital wondering what her life would look like now. Would she be able to do the things she'd always done—the things that mattered to her, other than just being alive? Hiking, traveling, baking, cooking, taking care of her family, working on her farm?

While she was in the hospital, however, a program called AgrAbility contacted her quickly, offered assistance, and encouraged her to contact Vocational Rehabilitation. It took her a while, but about a year later, she reached out to Vocational Rehabilitation and began receiving assistance from AgrAbility.



Laurie Hayn lost her left arm and leg in a combine entanglement in 2018, and the AgrAbility program helped her continue farming after her accident. (Photo credit: MJ Multimedia.) Her inspirational story can be viewed at <https://tinyurl.com/lauriehayn>.

Someone from AgrAbility then visited her farm to assess what she needed to continue farming. Fortunately, because her limb loss was on the left side, she was still able to drive her tractor as it was, but she needed assistance getting into it. AgrAbility, with assistance from another organization, fixed her up with an automatic lift, and she was able to return to work.

This change made a big difference in Laurie's life, and today she tells others about the value of AgrAbility.

While Laurie's story is encouraging for anyone who wants to return to working in agriculture, she is just one of thousands of agriculture workers with disabilities that AgrAbility has helped regain their lives since it was begun by the United States Department of Agriculture (USDA) in 1991.



Illustration made using Midjourney

The program helps farmers, ranchers and other agricultural workers with disabilities by offering them the support and resources they need to continue their work in agriculture and enhance their quality of life.

Along with the national AgrAbility Project, there are state-based programs around the country. AgrAbility also works locally with other organizations to offer more services and resources.

The Realities of Agricultural Work

Agricultural work is hard work, and it often requires long hours outdoors in the elements in extreme temperatures; repetitive tasks; bending and lifting heavy objects; and working around dangerous pesticides,

animals and machinery. This means that it's also risky work. Whether from a tractor accident, getting caught in a combine, falling off a horse, exposure to pesticides, illnesses, or some other cause of injury, many of these workers end up with a life-changing disability that affects their ability to work. They may end up having back injuries, neck pain, spinal cord injuries, respiratory problems, arthritis, amputations, brain injuries, visual impairments, or some other issues.

Some may even believe that they can't work after they acquire a disability.

That's until they learn about the AgrAbility Project.

Evan Criswell, an Indiana farmer who has received AgrAbility services, demonstrates a truck-mounted lift. (Purdue Agricultural Communications photo)



Among the many services AgrAbility provides is help with assistive technology. This could include devices, systems or equipment such as ergonomic equipment, modified tractors, and specialized tools to help agriculture workers perform tasks that they were not able to do without it. While AgrAbility does not itself provide grants or other funding, it provides many resources that may be able to help at www.agrability.org/funding-assistance. The project also offers training and education,

such as seminars and workshops to teach workers about technology, new farming techniques, and various types of equipment that can help them. Moreover, it may help workers acquire funding and work on their business planning and marketing.

The program has had great success since its establishment, and it continues to help agriculture workers such as Laurie continue to work in their chosen field.

For more information, visit www.agrability.org.





Farmers' Mental Health in Danger

What's Driving the High Suicide Rate Among Farmers?

Adapted from an original article by Sharita Forrest,
University of Illinois Urbana-Champaign News Bureau

Illustration made using Midjourney



Professor Josie Rudolphi is conducting a five-year study on the mental health needs of people who live and work on farms. Photo by Fred Zwicky.

Josie Rudolphi is a professor of agricultural and biological engineering at the University of Illinois Urbana-Champaign whose research examined suicide among farmers and ranchers, as well as the mental health of their children. She is the co-director of the North Central Farm and Ranch Stress Assistance Center, a 12-state, 15-partner collaborative based in Illinois Extension that offers stress management and mental health interventions. Rudolphi spoke with News Bureau research editor Sharita Forrest about the mental health needs of people in the farming industry.

Recent data from the U.S. Centers for Disease Control and Prevention indicated that farmers are twice as likely as people in other occupations to die by suicide. What are the unique stressors affecting the mental health of farmers?

While most farmers in the Midwest had a good harvest this year and commodity prices are strong, they are faced with incredibly high input costs. Unpredictable commodity prices have so much impact on the viability of a farm. There's a lot to celebrate, but the future is so uncertain.

And they can't control the weather. While Illinois had good weather this growing season, that wasn't the case nationwide. There were drought conditions in other parts of the country, and that's a huge concern for some of our partners who are providing stress assistance for those farmers.

Migrant workers experience different types of stress than do producers—such as issues with immigration status, acculturation, language and discrimination. We need to focus a lot more attention on the mental health of farm workers, too.

There's a dearth of healthcare providers in many rural areas. In addition to that, what are the barriers to providing mental healthcare to farmers and farm workers?

Most parts of Illinois are designated mental healthcare shortage areas—meaning we just don't have the providers and services to meet the need.

In terms of barriers, we talk about the four A's—accessibility; availability, and we see that as a huge barrier; affordability; and acceptability or stigmatization.

Most farmers are independent producers who operate on very thin margins. Mental healthcare is often considered a luxury or an unnecessary expense.

Geographical distribution of the populations is another challenge—farmers are scattered across the counties and states. They're not in one centralized workplace like a healthcare facility or university campus that would make mental health education and outreach easier. And their schedules are incredibly varied.

We still see stigmatization around mental health in these communities, but I think that's starting to change. Stigma seems to be more pervasive among certain demographics. For example, it appears as though it's more challenging for older generations to talk about mental health issues.

And in small communities, people are very conscious of other people knowing what their vehicles look like and not wanting people to recognize their car or truck parked outside a mental health clinic.



Illustration made using Midjourney

Your study on suicide found that few of the male farmers who died had discussed how they were feeling with family members or friends, while the female farmers were more likely to have done so prior to their deaths. Does the culture of farming—which is still largely a male-dominated occupation that values self-sufficiency and endurance—affect producers' willingness to seek help?

There's a ton of identity tied up in agriculture, like there is for people in many other occupations.

Agricultural producers are highly independent, and society rewards resiliency and stoicism; however, these labels may be damaging and discourage them from seeking help or reaching out. Our results underscore broader observations among the general population that men are more likely to internalize their experience, meaning they are less likely to talk about what they are going through and how they are feeling.

In the farmer suicide study, we found that older men and women who farmed were more likely to die by suicide if they had health problems, while younger men were more likely to have had relationship problems. Women farmers who lived in medium-sized towns had higher suicide rates compared with those in rural areas. That was interesting because we typically think of urban and micropolitan areas as having more resources such as access to mental healthcare.

How prevalent are anxiety and depression among family members, such as minor children?

A farm is not just a place of business; it's also a residence. We recognize that there are 2 million youths living and growing up on farms. We must acknowledge that children are experiencing—or at least being exposed to—some of the realities of the farm.

In a five-year study we have underway on farm youths, during our first year, we surveyed 122 farm families, including at least one adult and one adolescent from each family. We administered several instruments that assessed sources of stress and symptoms of depression and anxiety.

We found that almost 60 percent of the parents experienced at least mild symptoms of anxiety or depression—and the ratio was the same among their children. The severity of depression in the parents and their children was comparable, as well.

It really underscores the need to consider the whole family when we think about mental health initiatives.



Illustrations made using Midjourney

Warning Signs of Suicide

- Talking about wanting to die
- Looking for a way to kill oneself
- Talking about feeling hopeless or having no purpose
- Talking about feeling trapped or unbearable pain
- Talking about being a burden to others
- Increasing the use of alcohol or drugs
- Acting anxious, agitated or recklessly
- Sleeping too little or too much
- Withdrawing or feeling isolated
- Showing rage or talking about seeking revenge
- Displaying extreme mood swings

What to Do

- Do not leave the person alone.
- Remove any firearms, alcohol, drugs or sharp objects that could be used in a suicide attempt
- Contact the 988 Suicide & Crisis Lifeline by dialing 988
- Take the person to an emergency room, or seek help from a medical or mental health professional

Provided by [ReportingonSuicide.org](https://www.reportingonsuicide.org)

Resources

988 Suicide & Crisis Lifeline

The 988 Suicide & Crisis Lifeline is a free hotline for people in crisis or for those who want to help them. Call 988, or visit [988lifeline.org](https://www.988lifeline.org) for more information or for crisis chat services.

Crisis Text Line

Text SAVE to 741741

This a free and confidential texting service for emotional crisis support.

Visit the website of the **North Central Farm and Ranch Stress Assistance Center** at www.farmstress.org.



Illustration made using Midjourney

Disability-Related Dates & Events

Visit the following links to learn more about upcoming dates and events.

AUGUST

Camp No Limits - Maryland

<https://tinyurl.com/CNLMaryland>
August 24-27

Spinal Muscular Atrophy Awareness Month

<https://tinyurl.com/SpinalMonth>

SEPTEMBER

Camp No Limits - Arizona

<https://tinyurl.com/CNLArizona>
September 22-24

September 4 - World Cerebral Palsy Day

<https://worldcpday.org>

Suicide Prevention Awareness Month

<https://tinyurl.com/yemyc87j>

Pain Awareness Month

<https://tinyurl.com/PainMonth>

Peripheral Artery Disease (PAD) Awareness Month

<https://tinyurl.com/PADMonth>

Spinal Cord Injury Awareness Month

<https://tinyurl.com/4td2h327>

OCTOBER

Invisible Disabilities Week – October 15-21

<https://tinyurl.com/InvisibleWeek>



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Attention Deficit Hyperactivity Disorder Awareness Month

www.adhdawarenessmonth.org

Down Syndrome Awareness Month

<https://tinyurl.com/DSAware>

National Disability Employment Awareness Month

<https://tinyurl.com/EmploymentAware>

Spina Bifida Awareness Month

<https://tinyurl.com/SpinaAware>

Confessions of an Imperfect Caregiver

By Rick Bowers



Being a caregiver for my aging and disabled parents was perhaps the most challenging and enlightening experiences of my life. And, as I've discovered from other caregivers' stories, my journey was not uncommon.

The physical demands, time commitment, financial burdens, and emotional complexities involved in caregiving make it crucial for all parties to remember that love is the foundation of your relationship and the reason you stand together in this situation.

Before I became a caregiver myself, I had learned a lot about caregiving from working in a hospital, from working in various group homes for people with disabilities, and from my stints as an editor of disability-related publications. However, even all of that knowledge did not prepare me for what it was really like. I learned a lot more firsthand when I became the sole in-person caregiver for my mother and then my father for

several years.

I'd always thought that when my parents got older and started having health problems, I would move them in with my family and take care of them in any way they needed.

The hope and intentions were good. Unfortunately, it didn't work out that way.

Still, when they started having health problems, I didn't want them to go to a nursing home, and they didn't want to go to one. Therefore, I tried my best to do everything I could to help them in their own home.

Fortunately, I had already started working from home as a writer and editor, which gave me the freedom and flexibility to help my father care for my mother when she started having major health problems, including diabetes and its complications, high blood pressure, chronic obstructive pulmonary disease (COPD), Parkinson's disease, and back and hip problems. Yes, she had almost everything.

At the time, my father was also having health problems but was still able to help with my mother for a while.

Initially, I drove to their house every day, sometimes twice, despite the over-30-minute trip each way. I'd take them food, help around the house, and help move my mother as needed after she became bedridden 24/7, 365 days a year.

I wanted to help more, but it was difficult since I was quite busy and also had back problems and other health issues myself, including diabetes and obsessive-compulsive disorder (OCD).

From time to time, my mother and I would lose patience with each other and end up in heated arguments. I'm talking about the woman who had always been there for me and my wife and children and had a great relationship with us. Still, the stress and strain of caregiving led us to sometimes lash out at each other, which I, of course, deeply regret to this day.

I still took care of her, and there were many happy times as well.

Eventually, her health deteriorated to the point where I had to move into their spare bedroom and live with them. It was tough because I still had to work, plus I had to be available to help her with her increased care requirements. Her situation required me to give her medication around the clock; adjust her position in the bed from time to time; take care of household chores; pick up or make breakfast, lunch and dinner for her and my father; and take care of all of her bathroom needs since she couldn't get up.

In addition, for a while, she required a breathing machine that had an alarm that would constantly go off throughout the night and require me to get up and try to fix the problem that was causing the alarm. The machine was very sensitive, and the slightest problem would set off the alarm. Moreover, I also needed to take care of all of their paperwork and bills and sign up for their insurance, etc.



Illustration made using Midjourney

Taking her to the doctor was extremely difficult, and we had to pay a transport service to help us. On one occasion, while we were preparing for an appointment, she fell while we were trying to get her out of bed. After we struggled a long time to try to get her back in bed ourselves, we had to call the rescue squad to come and lift her back into the bed.

My father also started having more health problems and would have to go to the hospital and a rehab facility from time to time. As a result, he became less able to help with my mother. At that point, I was juggling work, responsibilities at my own house in a nearby city, and caring for them all alone in their house.

Ultimately, my mother's condition worsened, and we organized hospice care for her at home. It was horrible as she screamed night and day in agony. I was having to give her morphine and many other medications around the clock, every hour or two hours or so, and was often too exhausted to move but had to anyway. At that point, my daughter started coming over to help me out.

Now that I reflect on it, I know that my nerves were shot, and I hope that I can blame them for some of our blowups. Even though I realize that, I still have feelings of guilt.

My mother's pain became so unbearable that her medicine was not enough to relieve it to a sufficient degree. Her condition worsened so much that we finally had to arrange for her insurance to pay for her to go to a healthcare facility for a few days to provide her better care and to give me a physical and emotional break. Insurance would cover this respite care for a few days, and then she was to be returned home.

Transporting her to the facility required an ambulance, and we and the ambulance team struggled to move her from her bed into a wheelchair and then onto a stretcher and into the ambulance. She stayed at the facility for a few days until her insurance wouldn't pay anymore, and they were getting ready to bring her home even though she was in no condition to return. They finally allowed us to pay for extra days so that she could stay.

She passed away at the facility a few days later.

And I was sad but also relieved. Her quality of life had vanished, leaving her with only extreme pain and suffering. It was time.

My purpose for sharing my experience is so that anyone who needs caregiving can understand the caregiver's dilemma and know that even when caregivers have the best intentions, they can fall short. It doesn't mean they don't want to help or that they don't want to do better. Sometimes, it's just more than they can handle. Just remember, if they're there, even when they fall short at times, get frustrated, or complain about something, they still love you and they will regret those things and feel guilty about them. I also want caregivers to understand that their loved one's anger with them might be related to the medications they're taking, the pain they are suffering, their embarrassment at needing assistance, their guilt about causing you difficulties, their fear of the future, and a host of other reasons. The psychological factors involved in such a relationship are complex.

When I sometimes think about the problems my mother and I had, I also realize that she and I both had diabetes, which is known to heighten feelings of anger.

What I know now is that my mother didn't truly want to be angry with me, and I didn't truly want to be angry with her.

The situation was more difficult than both of us expected, and we both failed at times to overcome it. If you are a caregiver or the one who is being taken care of, I hope you will see that this situation is common and will forgive yourself and your loved one for any moments that seem like "failure."

Always hold on to the happy times and the cherished moments you once shared. And remember to smile.

No one should misunderstand this article and think that my purpose is to complain about the difficulties of caregiving. In fact, I consider my caregiving experience with my parents as one of the highlights of my life. I am so thankful that I had the opportunity to be able to assist them during this difficult period. I simply want caregivers and those they care for to know that it's common for each of them to fall short of perfection during such a stressful time and to forgive each other and themselves.

*** Special thanks to my wife, children and sister, who were all part of the care team that made it possible for me to stay with my parents full time. I don't know how we could have done it without everyone playing their part.

Celebrating the 24th Anniversary of the *Olmstead* Decision - a Huge Win for People With Disabilities

On June 22, the U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), celebrated the 24th anniversary of the U.S. Supreme Court's seminal decision in *Olmstead v. L.C.*, with a new national initiative to help drive compliance with the integration mandate and protect the rights of people with disabilities. *Olmstead* recognized that Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act protect the right of people with disabilities to receive services in the most integrated setting appropriate to their needs. OCR enforces these statutes, as well as Section 1557 of the Affordable Care Act, to ensure that the promise of *Olmstead* is realized for those with disabilities nationwide.

“Twenty-four years ago, the Supreme Court affirmed that people with disabilities have a right to live and receive services where they live. The landmark ruling has enabled millions of Americans to have greater independence, autonomy, and opportunities to participate fully in their communities,” said HHS Secretary Xavier Becerra. “Progress has been made, but there is still much work to be done. This new initiative from OCR creates additional opportunities for people with disabilities to live, work and participate in their communities.”



Illustration made using Midjourney

“The *Olmstead* decision’s holding that unjustified institutionalization of people with disabilities is illegal discrimination has changed the lives of hundreds of thousands of people with disabilities who want to live in their own homes and communities,” said OCR Director Melanie Fontes Rainer. “Today, OCR is proudly launching a revitalized *Olmstead* enforcement initiative that will further ensure the rights of people living with disabilities [to] live with purpose and dignity. This initiative is at the core of OCR’s work and supports the Biden-Harris Administration’s pledge to break down silos and integrate our programs and services to further our commitment to community living for all.”

“Olmstead affirms the right to community living for people with disabilities, but to exercise it, people must have the services and supports they need,” said Alison Barkoff, acting administrator for the Administration for Community Living. “That’s why ACL is working to expand and strengthen the workforce of direct care professionals and improve support to family caregivers, who together provide most of the assistance people need to be truly included in their communities. We also are working to increase availability of the services provided through the disability and aging networks, particularly for those in greatest need, and of affordable, accessible housing. We are proud to work with OCR to end the discrimination that often leads to institutionalization.”

“Olmstead stands for a fundamental principle—that disabled people have the same right to be full and equal members of their communities as everyone else,” said Samuel Bagenstos, HHS general counsel. “Starting in the days after the Supreme Court decided the case, HHS has been at the forefront of enforcing *Olmstead’s* requirements. I am proud to support OCR’s expansion of its *Olmstead* enforcement.”

For more information about community living and the Olmstead decision, please visit <https://tinyurl.com/OCROlmstead>.

If you believe that you or someone else has been discriminated against because of your disability, race, color, national origin, sex, age or religion in programs or activities funded by HHS, you may file a complaint with the HHS Office for Civil Rights.

This article was adapted from information provided by HHS.

"I Want to Do More So I Can Be Ready"

Since he was in the fifth grade, Spc. Matthew Peite knew he wanted to be in the military. He had big dreams to get out of his small town and see the world.

"I'm from a small town in Idaho you've probably never heard of—Mullan, Idaho," he says. He's returning there after a short career in the Army due to an injury.

"In November 2021, I was preparing to deploy to Kuwait," says the 21-year-old fire support specialist. "We were training down in Texas and New Mexico. One day, we had a six-mile ruck march with 80-pound packs. On mile four, my foot snapped. I didn't realize at the time it was that bad, so I finished my six-mile ruck march."

After the march, Peite went to clean up and took his left foot out of his boot. He then says that grapefruit-size swelling began. "My toes were purple, my foot swelled up immediately, and I was like, that doesn't look healthy."

Thinking the swelling would go down after icing, he waited a day and ended up at an emergency room in Texas where they had him go through a battery of tests. Three weeks after the injury, tests were inconclusive due to the severe swelling. He received a boot, crutches and orders to the Joint Base Lewis-McChord Soldier Recovery Unit (SRU).



*Spc. Peite learning how to wakesurf.
Photo courtesy of Spc. Matthew Peite.*

“When I got to JBLM, the orthopedic surgeon had more X-rays of my foot, and this time it was obvious. He said you broke your entire foot in half.”

Peite had crutches until June 2022 and then a scooter until August 2022. He also had an epiphany about having a 20-year career in the Army vanish.

“When I first showed up here, I was broken bad. I was beating myself up because I couldn’t walk. I worried about my future in the Army, and my life was upside down. The folks at the SRU encouraged me to try things to help get a grip on my situation. It was more than helpful. I now had the mental will to want to do better. I want to do more so I can be ready.”

Adaptive reconditioning and learning about the educational opportunities provided in the SRU would prove to be a great path to Peite’s new normal.

“I am so thankful for all the treatment and care I’ve gotten here at JBLM because I don’t think I would be as far along in my progress or have such high hopes for what my future holds if it wasn’t for this place,” he says. “I’m walking now, so that’s a plus. I have complex regional pain syndrome. It’s a condition that affects the nerves, so all the nerves in my foot and ankle fire continuously 24 hours a day—nothing but pain signals.”

The condition compounds the issue with Peite’s healing foot. He is in the process of becoming medically retired, and his thoughts are focused on life after the Army.

“I’m not sure how long I will be able to work again,” he says. “My condition will progress, and, eventually, I won’t be able to walk.”

Fortunately, while he was in the SRU, Peite took advantage of classes to help in his future search for work.

“In the Career Skills program, they introduced me to a variety of classes, and I graduated from a roofing class that will help me tremendously,” he says.

He wants to work in the building industry when he returns home to Idaho for as long as he can. “I have experience in that, and I eventually want to open my own remodeling business.”

Peite acknowledges the confidence building that happens when you apply yourself and take advantage of opportunities at the SRU. “I’m learning wakesurfing. I met former Team Army athlete Anthony Farve, who is an amputee who surfs. He’s an inspiration to watch,” explains Peite, who says he’s grateful for everyone in the SRU who tested his limits and pushed him further into recovery.

Even though his Army career was cut short, he hopes to be a positive example for others who may one day need the SRU.

“Do everything you can here,” he advises. “The SRU provides so much opportunity and so many benefits. ... Do as much as you can here that you are mentally and physically able to do. You will benefit from it far more than you realize.”

This article was adapted from a story provided by the U.S. Department of Defense. The appearance of DoD visual information does not imply or constitute DoD endorsement.

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Research-Based Information Related to Living With a Disability

"We sometimes base our decisions and actions on our past experiences or on intuition or advice from others. Those strategies often, but not always, are effective and turn out well for us. However, in many, if not most, cases, we will be better served by basing our decisions on scientific research and data. This section shares research that could help us make better and more successful decisions. It's at least worth considering."

- Rick Bowers, *RESILIENCE* Editor

Closed-Loop Insulin Delivery Systems May Improve Blood Sugar Control in Children With Type 1 Diabetes

Closed-loop insulin delivery systems improve glucose control in children with type 1 diabetes without causing adverse effects, according to a study presented in June at ENDO 2023, the Endocrine Society's annual meeting in Chicago, Illinois.

A closed-loop system consists of devices that use a continuous glucose monitor and insulin pump to automatically regulate blood sugar levels for people with diabetes. The system operates “closed-loop” because it continuously monitors and adjusts (starting and stopping) insulin delivery based on the person's blood sugar levels, without the need for manual intervention.

The first closed-loop system was approved for pediatric use in the United States in 2020. Since then, many randomized clinical trials have been performed on closed-loop systems. However, according to study researcher Amanda Godoi from Cardiff University in the United Kingdom, until now no review of studies evaluating the effect of prolonged use of closed-loop systems on glucose levels in children and adolescents with type 1 diabetes has been performed.

“Treatment of type 1 diabetes in children is a clinical challenge,” Godoi said. “We found using closed-loop systems led to improved glucose control, which represents an important treatment opportunity to reduce complications and morbidity in children with type 1 diabetes.”

The researchers reviewed nine studies of randomized controlled trials lasting at least 12 weeks comparing closed-loop systems to usual care in a total of 892 children with type 1 diabetes. Usual care is the delivery of insulin through multiple daily insulin injections or sensor-augmented pumps, which are commonly used in treating diabetes.



Illustration made using Midjourney

These are not automated and thus require the patient to monitor blood sugar levels and adjust the insulin delivery accordingly.

The children and teens using a closed-loop system had a small important 0.35 percent reduction in HbA1c levels—a blood test that measures average blood sugar levels over the past three months. They also had an average 9.96 percent increase in time in an optimal glucose range, without increasing the risk of adverse effects such as hypoglycemia (too-low blood sugar) and diabetic ketoacidosis (a serious complication of diabetes that develops when the body cannot produce enough insulin).

“Our results show that closed-loop technology seems to be safe and superior to usual care in controlling glucose levels,” Godoi said.

This article was adapted from information provided by the Endocrine Society.

Surgery May Reverse Diabetes Complications

For more than 100 million Americans who are obese, bariatric surgery may reverse complications related to diabetes, including regenerating damaged nerves, a Michigan Medicine study shows.

A research team led by the University of Michigan Health Department of Neurology followed more than 120 patients who underwent bariatric surgery for obesity over two years after the procedure. They found that all metabolic risk factors for developing diabetes, such as high glucose and lipid levels, improved outside of blood pressure and total cholesterol, according to results published in *Diabetologia*.

Investigators also found that patients two years removed from bariatric surgery showed improvements in peripheral neuropathy, a condition marked by damage to the nerves that go from the spinal cord all the way to the hands and feet.

“Our findings suggest that bariatric surgery likely enables the regeneration of the peripheral nerves and, therefore, may be an effective treatment for millions of individuals with obesity who are at risk of developing diabetes and peripheral neuropathy,” said senior author Brian C. Callaghan, MD, MS, a neurologist at University of Michigan Health and a professor of neurology at U-M Medical School.

Obesity is the second leading risk factor for peripheral neuropathy after diabetes, which affects more than 30 million Americans.

Researchers assessed two primary measures for peripheral neuropathy in patients with obesity by taking skin biopsies that show the nerve fiber density in the thigh and the leg. Two years after bariatric



Illustration made using Midjourney surgery, nerve fiber density improved in the thigh and remained stable in the leg.

Compared to previous studies of medical weight loss, when providers guide a patient’s weight loss goals, bariatric surgery led to better metabolic improvements and even greater improvements in peripheral neuropathy.

“Given the natural history of peripheral neuropathy decline in patients with obesity, even stability in nerve fiber density may be considered a successful result,” said first author Evan Reynolds, PhD, lead statistician for the NeuroNetwork for Emerging Therapies at Michigan Medicine. “Therefore, our findings of stability of nerve fiber density in the leg and improvement in nerve fiber density at the thigh indicate that bariatric surgery may be a successful therapy to improve or reverse peripheral neuropathy for patients with long-term metabolic impairment.”

Treatment for peripheral neuropathy currently focuses on pain, including oral medications such as gabapentin and sodium channel blockers; topical analgesics; and non-medical treatments such as exercise and cognitive behavioral therapy.

This article was adapted from information provided by Michigan Medicine - University of Michigan.

Black Patients With Arterial Plaque Buildup in the Legs More Likely to Have a Stroke, Heart Attack or Amputation Than White Patients

A new study from Keck Medicine of USC has uncovered significant racial disparities in the diagnosis, treatment and outcomes of peripheral artery disease (PAD) among black and white patients in the United States.

PAD, which affects approximately eight to 12 million Americans and is associated with nearly half of the 150,000 yearly amputations in the U.S., is a potentially life-threatening condition in which the arteries that carry blood from the heart to the legs narrow or become blocked by the buildup of fatty plaque. This can lead to a heart attack, stroke or amputation of the affected limb.

“We discovered that black patients are nearly 50 percent less likely to receive vascular interventions to potentially restore the blood flow than white patients, and consequently are at a disproportionately higher risk of a stroke, heart attack or amputation,” said David Armstrong, DPM, PhD, a podiatric surgeon specializing in limb preservation with Keck Medicine and an author of the study. “Additionally, black patients tend to have more advanced PAD and are sicker at the time of diagnosis, indicating they may not be getting as timely medical attention as their white counterparts.”

PAD often starts out with no or mild symptoms, such as a leg cramp or muscle pain, and therefore often goes underdiagnosed.

Once detected, generally through a blood test, PAD is typically treated with medication to reduce the plaque in the arteries and through suggested lifestyle changes, such as increased exercise and a healthy diet. If these measures don't work, physicians usually recommend a procedure known as revascularization.



Illustration made using Midjourney

Revascularization either improves the blood flow to the arteries by using a balloon or stent to open them or reroutes the blood to a healthier artery, which can reduce the risk of a cardiac incident or amputation.

The study discovered that black patients are more likely to only receive medication and lifestyle change recommendations, while white patients also receive revascularization. “Our findings suggest black patients are missing out on potentially limb- and life-saving treatments,” said Armstrong. “And because black patients tend to be sicker at the time of diagnosis than white patients, they may actually be in more need of a revascularization than other patients.”

While the study did not analyze why disparities in the detection, treatment and outcomes of PAD between black and white patients exist, one factor may be that black patients are already at a higher risk of developing PAD, said Armstrong. He also hypothesizes that the inequalities may be due to broader systematic issues in healthcare such as unconscious bias or barriers to healthcare access for certain populations.

“We hope this study will encourage physicians to take these differences into account when diagnosing and treating PAD to ensure that vascular interventions are being equally provided to all patients,” he said. “We also urge health professionals to offer more routine screenings for PAD in black patients.”

Additionally, Armstrong advises patients to proactively seek medical advice and testing if they have any symptoms related to PAD—leg cramping, pain, numbness, weakness or discoloration—and advocate to be considered for all treatment options after diagnosis.

This article was adapted from information provided by Keck Medicine of USC.



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Your Dreams Are Our Business

News & Stories You Might Have Missed

The following links are to press releases and media reports that might not have been widely publicized but that include information relevant to people with disabilities.

NOTE: Clicking on the links will take you away from this publication to another website.

HHS Announces Actions to Protect Consumers and Lower Health Care Costs

<https://tinyurl.com/CMSConsumerProtect>
(July 7)

Late Breaking Weight Loss Innovations: New Drug Therapies Shown to Offer Positive Outcomes for Obesity and Type 2 Diabetes Management

<https://tinyurl.com/35c65nyc> (June 25)

Behavioral Health Interventions Positively Impact Adults and Youth Experiencing Diabetes Distress

<https://tinyurl.com/distressdiabetes>
(June 24)

AAPD Welcomes Protection of the Voting Rights Act In Supreme Court Ruling

<https://tinyurl.com/AAPDruling>
(June 13)

AAPD Celebrates Supreme Court Ruling That Protects Rights of Medicaid Recipients

<https://tinyurl.com/AAPDTalevski> (June 13)

Social Security Administration Expands Outreach and Access for Supplemental Security Income

<https://tinyurl.com/accessSSincome> (May 25)



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Biden-Harris Administration Takes Action to Help Schools Deliver Critical Health Care Services to Millions of Students <https://tinyurl.com/criticalservice>
(May 18)

CMS Announces Medicare Will Cover Seat Elevation Equipment for Eligible Power Wheelchair Users
<https://tinyurl.com/seateligible> (May 17)