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# **Design and Production**



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### Correction:

Steve Zoric, husband of Sarah Zoric, was misidentified in "A chance to dance" (Fall 2016).

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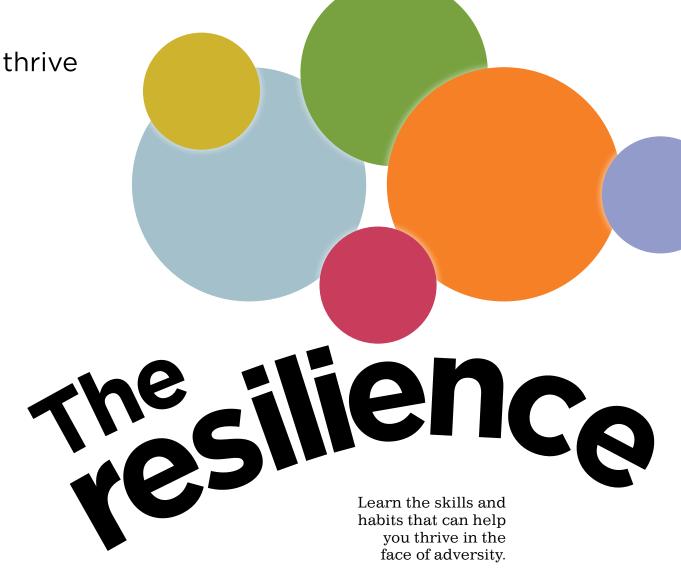
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by Vicky Uhland

ast May, Dawnia Baynes hosted a dinner party celebrating the 10th anniversary of her multiple sclerosis diagnosis.

Baynes and her friends didn't focus on her MS-related vertigo or the constant numbness and tingling in her feet and hands. Nor did they dwell on the balance issues that require her to use a cane or walker, or the numbness she experiences from her chest to her ankles. Instead, they spent the evening commemorating the resilience she's developed in the decade since her diagnosis.

"I actually believe I've gotten stronger," Baynes says. "My diagnosis made me realize I can't just sit back and let life happen to me; I need to make the effort to do things to help myself."

For Baynes, resilience means not giving up in the face of adversity. She thought she had already mastered that skill during a difficult childhood that included bouts of homelessness. But after she was diagnosed with MS at age 26, Baynes discovered she needed to augment her inherent resilience with even more coping tools.

Dawnia Baynes, who listens to music to unwind and feel at peace, has taken steps to increase her mental, emotional and physical resilience.



# thrive

"I was in denial for the first two years after my diagnosis. I wasn't consistently on medication, and I wouldn't have anything to do with MS programs or support groups," she says. "But then I realized if I just gave up, I'd always be thinking about what I coulda, woulda, shoulda done."

So Baynes took steps to increase her mental, emotional and physical resilience. She started seeing a physical therapist, and began participating in programs and support groups offered through the National MS Society in Los Angeles, where she lives.

"I decided I had to stop crying and realize that no matter what happens, it could always be worse," says Baynes, who credits her strong

faith as one of the key factors in her optimism. "I work to find the bright side in any situation—like how I may be on disability, but that means my student loans are forgiven."

Some people may be more naturally resilient than others. Baynes, for example, sees herself as a naturally optimistic person. But even if you tend to be more of an Eeyore than a Tigger, you can learn to be more resilient.

"There is enough research to suggest that, although a good portion of resilience is due to genetic, biological and environmental factors that you can't control, much of resilience is the result of skills you can learn and practice," says Alexandra Terrill, PhD, an assistant professor in the division of occupational therapy at the University of Utah.

Others living with MS agree with this assessment. "I think resilience is kind of like a muscle—something that develops with use," says Chuck Curry, a Bainbridge Island, Washington, resident who was diagnosed with MS in 2003. "We are all probably born with that muscle, and all sorts of things can happen during our lives that lead to its development or atrophy."

Strengthening your resilience muscle takes effort. But, as with any exercise, you can minimize that effort and



Dawnia Baynes engages in different activities, such as adult coloring and reading her Bible, to help her cope with stress.







Chuck Curry, here in Bainbridge Island, Washington, takes time for meditation as a way to bolster his resilience. Research has found that we can practice skills to improve our resilience over time.



Elysa Lanz, who had several health setbacks in early life, has learned to focus on things she can do, as opposed to those she can't, during difficult times.

maximize your results by following proven procedures. Here's how medical experts, along with people living with MS, recommend you increase your resilience—and why they believe it's important to include resilience workouts in your daily activities.

# Is your personality resilient?

There are various definitions of resilience, but they all tend to focus on going beyond surviving and actually thriving during times of stress.

"Resilience is the ability to not only bounce back from adversity, such as a diagnosis of MS, but also the ability to maintain a good quality of life in the face of the frequent stressors that come with living with MS," says Dawn Ehde, PhD, a professor of rehabilitation medicine at the University of Washington.

But that doesn't mean you need to take a Pollyanna approach to your disease or your life. "Resilience is not the absence of ever feeling sad or lost or angry," Dr. Ehde says. Instead, it's the ability to not dwell on those feelings and to find a way to move forward.

For Elysa Lanz, a Covington, Washington, resident who has lived with MS for 27 years and now has the secondary progressive form of the disease, resilience means "thinking of something that happens to you not as a tragedy, but rather as a challenge. And then not giving in to that challenge, but finding a new way to circumvent it."

Lanz's resilience was honed during her childhood. "In fact, people always tell me I'm the poster child for resilience," she says. Lanz was born with a severe birth defect that required 11 major surgeries. As a result, she learned to reach out to her family and friends for mental, emotional and physical support. During long hospital stays, she developed hobbies to keep herself occupied so she wouldn't obsess about her health. And she discovered that giving to others, rather than just focusing on herself, was rewarding for everyone.

Some people are more naturally inclined toward such coping strategies; others develop them as life throws them curveballs. Research suggests that people who overcome a series of small adverse events as children grow into resilient adults.

Lanz found that her approach served her well throughout her MS journey and during her treatment for cancer in 2013. "I've found that when you get down—say you have an exacerbation and a new baseline level of functioning—[it helps to] focus on what you can do rather than what you can't do," she says. "And if it's something you can do for others, that's even better."

Lanz embodies many other qualities that contribute to resilience. In fact, researchers have developed several tools to measure an individual's resilience. One of them is the Resilience Factor Inventory, a 60-item questionnaire that is based on well-known resilience studies. This inventory assesses seven personality characteristics that contribute to resilience:

- Being able to control your emotions when you're under pressure.
- 2. Exercising control over your impulses and behaviors.
- 3. Accurately identifying the true cause of your adversity.
- 4. Believing you can solve problems and be successful.
- 5. Staying positive about the future while still being realistic.
- 6. Showing empathy toward others and developing relationships.
- 7. Thinking positively and embracing challenges and opportunities.

# l thrive

If this list seems daunting, Dr. Terrill says not to panic. "We're not all good at everything. Maybe being optimistic is difficult for you, but you have the ability to develop a really supportive social circle," she says. "I think we all have the opportunity to feel well and be happy."

Other researchers have defined an even larger list of "character strengths"—meaning there are more ways to develop resilience. For example, one list, at viacharacter.org, takes 24 different strengths and breaks them down into six broad categories. You may find that you're not big on teamwork, for example, but may have strong degrees of perseverance or kindness. Another source for inventories of your strengths and resilience is at talenttools.org.

If you have trouble identifying your particular strengths, whether through these inventories or other methods, a mental health professional can help you evaluate them objectively.

## Developing a resilience workout

Improving your physical, emotional and mental health can help you take the steps to becoming more resilient. What's more, the opposite is also true: Increasing your resilience can also make you feel better physically, emotionally and mentally.

Earlier this year, Dr. Terrill and her colleagues published a study in the Journal of Health **Psychology** in which they evaluated 1,862 people with MS, muscular dystrophy, post-polio syndrome or spinal cord injuries. The researchers used various tests to assess the participants' resilience; levels of depression, pain and

Dr. Terrill and her team found that the people who had higher resilience scores also had lower rates of depression and a higher quality of life—even if they had high levels of pain and fatigue.

fatigue; and overall quality of life.

Stress, too, affects resilience. "Our brain kicks into gear with stress hormones, like cortisol, to avoid real or perceived harm," says Ken Nowack, PhD, a licensed organizational psychologist with Envisia Learning in Santa Monica, California. This is known as the fight-or-flight response, and it's genetically preprogrammed in each of us. The more cortisol you produce when you're stressed, the more vulnerable you are to resilience zappers like depression and anxiety.

Dr. Terrill says devoting just 15 minutes a day to resilience skill-building—by using one of your existing strengths in a new and different way each time—can significantly boost your overall resilience and keep cortisol spikes at bay.

For example, if gratitude is your strength, perhaps you can write three things you're grateful for one day; and the next you can thank someone who did something kind for you. But on days when you feel fatigued or your schedule is overloaded, even 15 minutes may seem like an overwhelming chore. "And when you're stuck and all you see is the negative, to really be open to doing things that increase your resilience can be hard," she says.

That's where various types of therapy might help. A 2012 study found that people who participated in an eight-week course of occupational therapy (OT) focused on adapting to MS symptoms, like fatigue and cognitive difficulties, had significantly higher resilience levels than those who didn't participate. The study participants also engaged in physical therapy, psychological therapy and social work sessions focusing on overcoming housing and insurance difficulties. With new ways of adapting, participants did better.

Dr. Nowack says there are 12 lifestyle behaviors and habits you can learn that can substantially boost your resilience, no matter what your genetic programming. This type of skill-building—known as a biopsychosocial approach to resilience—was shown in a 2015 study to increase resilience in 196 adults with MS.

# Better by the dozen

"Twelve seems like a lot, but our research doesn't suggest you must do all 12 things to be perfectly resilient," Dr. Nowack says. For instance, if you have spasticity, you may have difficulty with sleeping or exercising, the first two practices on the list. "So look to see which of the other factors you have the capability to turn up instead," he says. The 12 lifestyle behaviors include:

- 1. Sleep. "Lack of sleep compromises emotional regulation," Dr. Nowack says, "so if sleep is an issue for you, talk to your doctor about ways you can improve it."
- **2. Exercise.** Any form of exercise helps the brain produce a peptide called BDNF, which has been shown



in some studies to help improve cognition. And the better you're able to think during times of adversity, the more resilience you can exhibit.

# 3. Social support.

The 2012 occupational therapy study found that people with MS who have more relationships and social networks also have greater resilience.

Michael Ogg, a Princeton Junction, New Jersey, resident who was diagnosed with primary progressive MS in 1997 and is now quadriplegic, says the support of his family and friends has helped him cope not only with MS, but also with the removal of a cancerous tumor in his gastrointestinal tract last year. "I think of myself as pretty resilient, but even resilient people can't be resilient all the time," Ogg says. "I don't reach out as much as I should, but I am very fortunate to have extremely supportive family and friends who watch out for me." (For more on building your social network, see "The friend zone" on page 50.)

4. Mindfulness meditation. A 2010 study showed that meditation improves quality of life and reduces fatigue and depression in people with MS.

Curry says meditation is easier than it appears. After his MS diagnosis, he took a course on mindfulness-based stress reduction from a Seattlearea hospital. "I knew I needed help managing the anxiety I had about my body not working the way it was supposed to," he says. Now, he meditates by simply paying attention to his breath or paddling in rhythm while kayaking. He occasionally throws in breathing exercises he learned during free-diving training. "There are days when I don't feel resilient at all," he says. "I know when I feel that way, I need to make time for my meditation."

Dr. Nowack says 10 to 15 minutes, several times a week, of simply sitting quietly and trying to be in the moment can build resilience.

Exercising, socializing and finding a purpose in life all help to bolster resilience. Left: Cherish Cazares, right, diagnosed in 2002, with daughter Kayla and son Diego, have a cookout. Right: Brian, diagnosed in 2012, enjoys cycling.

**5. Practicing gratitude.** Dr. Nowack says multiple studies show that as you get ready for bed, thinking of something that made your day special or meaningful can give you strong emotional benefits.

For days when you simply can't think of anything you're grateful for, Dr. Terrill suggests keeping photos as visual reminders of anything that makes you happy—whether they're specific events, a pretty nature scene or even your dog—or making a list of happy memories. Then look at a photo or item on your list and imagine the event as vividly as possible. "Savor it and even wallow in it," she says. "Use all five senses to make your memories even more effective—think of what you smell, how something tastes, what sounds you hear."

And don't forget to thank others. That takes your focus off of yourself, helps you appreciate what you have and strengthens social bonds, Dr. Terrill says.

**6. Post-traumatic growth.** When something bad happens, "ask yourself, What can I learn from this challenge and how can I change my behavior?" Dr. Nowack says. This is known as reframing a situation, and



Dr. Terrill admits it takes a lot of practice to actually change your thinking patterns.

Cognitive-behavioral therapy can be very effective for this, Dr. Terrill says. She also recommends two books: Feeling Good: The New Mood Therapy by David Burns (Harper, 2008) and **Mind Over** Mood, Second Edition: Change How You Feel by Changing the Way You Think by Dennis Greenberger and Christine Padesky (The Guilford Press, 2015).

**7. Creating a mind shift.** Resilient people don't look at misfortunes from an all-or-nothing perspective, Dr. Nowack says. He suggests taking a pair of Post-it notes and writing "catastrophe" on one and "annoyance" on the other. The next time something bad happens to you, choose a note. Chances are you'll find yourself grabbing the "annoyance" note more often than the "catastrophe" one.

Jagub Gurule, a 24-year-old Grand Junction, Colorado, resident who was diagnosed with MS when he was 19, goes so far as to change what the initials "MS" mean to him. "I call it 'Man Stud,'" he says. "I see it as a challenge rather than something to cry about. MS is a part of me, not who I am, so I will just keep man-studdin' on."

**8. Practicing optimism.** Dr. Nowack says some researchers believe that people have an optimism set point that's determined genetically and accounts for about 50 percent of their happiness. And studies of people who have won the lottery show that only about 10 percent of happiness is situational. That means you can create as much as 40 percent of your own happiness by simply focusing more on the positive than the negative.

For instance, Lanz says if she's on a walk and all she can think about is how much her feet hurt and how tired she is, "I tell myself to stop and look for something beautiful. And that instantly changes my mind-set."

### 9. Having a purpose or meaning in life.

"Engaging in an activity that makes you feel like you're contributing to the world can change your thinking," says Dr. Ehde. "It doesn't have to be something big just something that is meaningful to you."

When he was diagnosed with MS, Gurule was a twotime collegiate National Runner-Up in wrestling, with dreams of competing in the Olympics. Tremors, double vision and heat sensitivity not only forced him to give up wrestling, but also to stop attending college full time.

"I realized I was going to have to rewrite my book," Gurule says. Graduating college became his purpose. "It took me six years, but now I have a construction technology degree and certificates in business administration and construction management," he says. "Instead of thinking of how I couldn't wrestle anymore,

# I think resilience is kind of like a muscle something that develops with use."

—Chuck Curry

I kept moving forward by thinking of all the things I can still do."

**10. Knowing when to let go.** We live in a culture in which "toughing out" a situation is thought to lead to success, says Shawn Achor, author of **The Happiness** Advantage: The Seven Principles of Positive **Psychology That Fuel Success and Performance** at Work (Crown Business, 2010). But Achor and Dr. Nowack point out that research actually shows the opposite—quitting a project or pursuit of a goal in the face of unattainable odds can increase your resilience and even boost your longevity.

11. Practicing forgiveness. Dr. Nowack says one study found that people who are unwilling to forgive have higher levels of cortisol and thus more depression or anxiety. It may be necessary to actually forgive your MS or your symptoms or exacerbations in order to improve your resilience and quality of life. If you're having trouble doing this, a therapist can help.

# 12. Identifying and deploying signature **strengths.** Dr. Nowack says research shows that people who spend time doing things they like and are good at have a clinically significant decrease in depression.

"Developing and pursuing goals allows you to act rather than react," says Dr. Terrill. This is particularly important with a disease like MS, in which the symptoms are variable and can leave you feeling like you have little control.

And finally, give yourself a break. "So often I see people with MS feel like they have to focus on their duties first, and pleasure becomes secondary," Dr. Ehde says. "They think they don't have the energy for pleasure."

Rather than making resilience-building exercises another daily duty, focus on the ones you really enjoy. Watching a movie with your friends or children builds resilience. So does knitting or collecting model cars. And taking time to simply watch the clouds or listen to your breathing can also boost your resilience.

"It's within the vast majority of humans to become more resilient—to develop the hope that leads to feeling more happy or content," Dr. Ehde says. ■

> Vicky Uhland is a freelance writer and editor in Lafayette, Colorado.



To learn more about resilience, download the Society's book and video about the topic at nationalMSsociety.org/resilience.

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