# RESILIENCE

ADDRESSING THE CHALLENGES OF MS

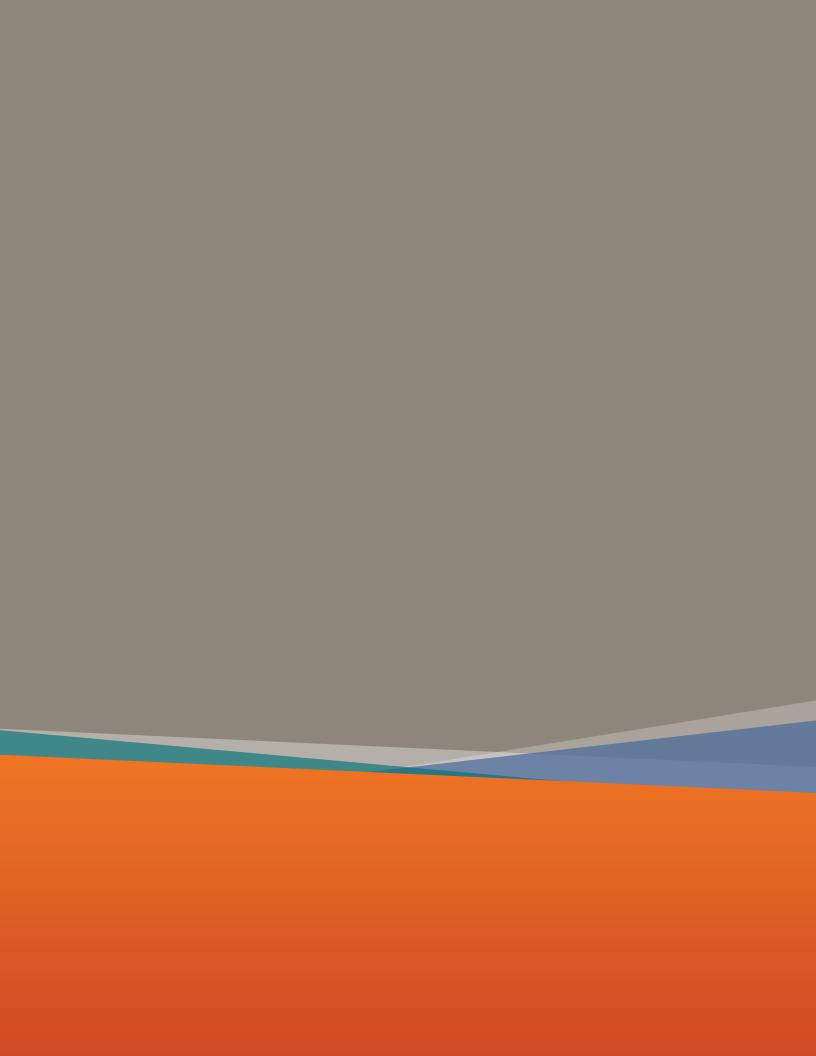


NORTH AMERICAN EDUCATION PROGRAM



National Multiple Sclerosis Society





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# Welcome to the North American Education Program, **Resilience: Addressing the Challenges of MS**, produced by the National MS Society in collaboration with the MS Society of Canada.

People with mu ltiple sclerosis may find that the physical, psychological and spiritual challenges of living with the disease can be overwhelming. Some may feel that the challenges of living with a chronic disease are very hard to face day after day. However, many people living with chronic diseases, including MS, have learned that practicing behaviors that promote resilience is the secret to not just coping with the disease, but thriving with it. Resilience helps create a mindset of growth and opportunities, of seeing obstacles as challenges rather than threats.

Some people have a natural tendency to be resilient. It's part of their makeup to be optimistic and to look for solutions to problems. But even if that's not the case for you, strategies to build resilience can be learned and practiced.

In the video portion of this program, you will hear discussions from clinicians and researchers at the forefront of resilience theory, as well as from individuals who have learned to become more resilient when facing MS as well as the ongoing challenges of everyday life.

This book provides an overview of the leading theories of resilience, as well as the positive changes that building resilience can create in one's life. It also outlines practical strategies for developing greater resilience. At the back of this book, you'll find resources for learning even more about this topic.

We hope you will find the program informative and engaging. For further information, call 1-800-344-4867 (U.S.) or 1-800-268-7582 (Canada) or visit **nationalMSsociety.org** or **mssociety.ca**.

Best regards,

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# **Contents**

Introduction	1
Personal Stories	2
Presenters	3
What Is Resilience?	4
Nature or nurture?	6
The biology of resilience	7
Environment and set point	8
Resilience is a verb	9
Why Is Resilience Important?	12
A deeper sense of self	13
Family	15
How to Build Resilience	17
Learning the ABCDs	21
Beyond the basics	22
Developing lifestyle skills	29
Practice makes progress	30
Be aware of bumps in the road	33
Moving forward	34
Resources	36
National MS Society Resources	37
Multiple Sclerosis Society of Canada Resources	37
Additional resources	38
Glossary	40
Notes	43



# INTRODUCTION

The unpredictability and changes in functioning that arise from living with MS and its symptoms can shatter a person's sense of safety and identity in the world. As with any stressful or traumatic event, each individual responds differently. Some people seem to have a natural ability to find solutions and bounce back—to demonstrate, in a word, resilience. Others struggle more to find their way.

In this book and in its companion video, we'll explore what resilience is, and why some people seem to come by it more naturally than others. We'll explain how people can develop greater resilience, and use it not just to manage their symptoms and other aspects of life with MS, but any stress they may experience.

When people become more resilient, they also experience positive changes in their moods, relationships and self-confidence, and are apt to see more opportunities in life. Instead of merely bouncing back, they bounce forward. It's our hope that the material contained in this program helps you to build your resilience so that you can bounce forward, and live your best life with MS.

# **PERSONAL STORIES**

#### **Dawnia Baynes**

# Diagnosed with MS in 2006

Dawnia, 36, lives in Los Angeles, where she enjoys attending church, movies, concerts and cultural events, and relaxing with her friends. She previously worked as a business operations generalist for the state of Georgia's Department of Natural Resources; now she is completing a degree in biblical studies.

# **Chuck Curry**

# Diagnosed with MS in 2003

Chuck, 50, lives on Bainbridge Island, near Seattle, and is passionate about scuba diving. Formerly an outdoor educator in Washington and Alaska, and professor of economics at Bellevue College, Chuck now volunteers as a diver in the cold-water exhibits at the Seattle Aquarium, and as a surveyor for a marine conservation organization.

#### Lauren Hansen

# Diagnosed with MS in 2005

Lauren, 35, lives in Lansing, Michigan, where she is a professional violinist and violin teacher. She also has a master's degree in public health and health education. In her free time, Lauren enjoys running as well as volunteering at a farm animal sanctuary.

# **Michael Ogg**

### Diagnosed with MS in 1997

Michael, 61, lives in Princeton Junction, New Jersey. Michael has progressive MS, and no longer has the use of his arms or legs, but operates a motorized wheelchair with a chin-operated proportional mini joystick. Michael has also overcome cancer. Previously an avid cyclist and a physicist, Michael now enjoys auditing classes at nearby Princeton University, and going into nearby New York City to see a show or visit a museum, or to roll down the pathways in Central Park. He is enthusiastic about using technology to expand his options.

# **Rachel and Brian Padgett**

Rachel, diagnosed with MS in 1993

Originally from England, Rachel, 44, now lives in Seattle with her husband, Brian. She had already been diagnosed with MS when they met, and she credits their strong, 15-year marriage as one of the primary factors in her resilience. Brian, 40, says that as a couple, they don't let MS define them. They work on controlling what they can, adapting to what they can't, and letting the rest go, he says. Rachel and Brian enjoy cooking, traveling and outdoor pursuits together. Rachel loves to swim for exercise and recreation.

# **PRESENTERS**

#### **George Bonanno, PhD**

George Bonanno, PhD, is a professor of clinical psychology at Teachers College at Columbia University. He received his PhD from Yale University in 1991. His research and scholarly interests since then have centered on the question of how people cope with loss, trauma and other forms of extreme adversity, with an emphasis on resilience and the roles of flexible coping and emotional regulation skills. Dr. Bonanno's recent work has focused on defining and documenting adult resilience in the face of loss or potentially traumatic events, and on identifying the range of variables that predict both resilient and unhealthy outcomes. Dr. Bonanno co-edited the scholarly book, "Emotion: Current Issues and Future **Directions**" (Guilford Press, 2001) and recently authored "The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life After Loss" (Basic Books, 2009). Dr. Bonanno has no pharmaceutical relationships to disclose.

### Dawn Ehde, PhD

Dawn Ehde is a professor in the Division of Clinical and Neuropsychology, Department of Rehabilitation Medicine, at the University of Washington School of Medicine in Seattle. Dr. Ehde is also an attending psychologist in the outpatient Rehabilitation Medicine Clinic at UW Medicine (Harborview Medical Center), providing neuropsychological and psychotherapy services to people with multiple sclerosis and other acquired disabilities. In controlled trials, she has evaluated the efficacy of various cognitive-behavioral, pharmacological and exercise interventions for pain and depression in people with MS and other disabilities. She is the principal investigator and training director of a postdoctoral fellowship program in MS rehabilitation research, funded by the National MS Society.

Dr. Ehde received her PhD in clinical psychology from the University of North Dakota in 1992, after completing her predoctoral residency at the University of Washington School of Medicine. She completed a clinical fellowship in rehabilitation psychology as well as a fellowship in rehabilitation research, funded by the National Institutes of Health. Dr. Ehde has no pharmaceutical relationships to disclose.



# What Is Resilience?

Stress happens. And chances are, at some point in your life, someone told you that adversity builds character. That may seem like cold comfort when you're in the midst of a difficult experience, but it turns out that the saying is true. Researchers have found that people who experience a moderate amount of hardship throughout their lives show greater well-being and resilience.

But what is resilience, exactly?

It's commonly described as the ability to bounce back from difficult circumstances—to find happiness and life satisfaction despite challenges with relationships, finances, health or any of the myriad stressors that we face in life. It's finding hope and meaning in life even while confronting obstacles. It's finding the motivation to take on new challenges and opportunities. It's thriving in the face of stress.

Naturally, people facing challenging circumstances have their own definitions of resilience. For example. Dawnia Baynes, who was diagnosed with MS in 2006, says, "It's [about] bouncing back up and finding ways to adjust your life ... pushing forward regardless of what's going on." But she doesn't stop there. She says an important component of resilience is self-advocacy. "Part of being resilient is speaking up for yourself when you need to, and asking people for things that you need, and fighting for them."

**Chuck Curry**, an avid outdoorsman diagnosed with MS in 2003, draws on his previous life experiences to conceptualize resilience. "I think resilience is like a muscle, and that you become more resilient by having the muscle exercised—by having challenges in your life," he says. "Resilience has characteristics of both strength and flexibility." he adds.

Lauren Hansen, who was diagnosed with MS in 2005, says, "I think resilience is that ability to really bounce back from situations, to take what's handed to you and to be able to make the best of it, and continue on with who you are as a person." As you'll read later, Lauren found that maintaining her identity in the throes of difficulty was essential to her resilience.

Michael Ogg, diagnosed in 1997 with primary progressive MS, says resilience means, "Whatever life throws at you, you just find a way to get through it." Though Michael is now quadriplegic, he adds, "And you just don't let it get you down—because there's always something more. However bad you might feel on a particular day, there's always something worth living for."

Rachel Padgett, diagnosed in 1993, has resolved to not let MS stand in the way of her overall happiness. "I never want this [disease] to stop me from doing anything," she says. "And I have learned, in making that promise to

myself, that there are lots of different ways to do things."

Rachel's husband, Brian Padgett, says that even for family and friends of people with MS, resilience is important. "MS is not predictable, so you have to deal with whatever the day gives you, and be able to adapt to those changing circumstances, whatever they are," he says. And when medical complications arise, "being the one who is there with boots on the ground, dealing with all fronts, that is hard. So that takes resilience."

Researchers describe resilience a little more clinically. The American Psychological Association says it's "the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress." Dawn Ehde, PhD, a rehabilitation psychologist at the University of Washington, says, "Resilience is the ability to maintain or regain well-being and progress toward valued goals in the face of adversity."

A recent study described it as the ability to focus on positive assets rather than deficits, and focus on thriving rather than merely surviving in the face of challenges.

To a person in the midst of adverse circumstances, such definitions may sound like a lot of pop psychology about looking at the bright side. To be clear, no one is suggesting that people

living with multiple sclerosis—or any other ongoing challenges—become dreamy-eved optimists. Says Dr. Ehde, "When someone faces a setback in their health, that can present pretty big challenges. When people are resilient, they still experience anger or frustration or grief or sadness. But that doesn't become who they are, and being resilient means they get through that."

So, resilience is not about acting happy all the time, or ignoring the very real difficulties in life. Resilience is not even about trying to eliminate negative thoughts or feelings. In fact, it's quite the opposite: A significant part of being resilient involves what researchers call "positive adaptation" or "realistic optimism"—remaining hopeful about the future while making plans that enable us to cope with our actual reality. It requires moving forward despite facing difficult events and emotions. It requires both courage and hope.

# Nature or nurture?

Some people may seem to be more naturally resilient than others almost as if they're born with a trait for resilience, and others just aren't as lucky. How is it that Nelson Mandela, for example, lived through 27 years of imprisonment and not only survived, but went on to become South Africa's first democratically elected president. while others who endure harsh circumstances feel resentful, bitter or depressed?

To a large degree, resilience is determined not by how many adverse events a person faces, but by how an individual perceives—and then responds to—such events. Those who see a stressful event as a challenge or a problem to be solved tend to be more resilient. Those who see it as a threat may respond instead by retreating or avoiding the problem, and may demonstrate less resilience.

**66** Hardship often prepares an ordinary person for an extraordinary destiny."

-C.S. Lewis

Michael Ogg says he's definitely in the first camp. "I think that adversity affects most people at some point in their lives. You can't get through life from zero up to 70, 80, 90 years old and never have bad things happen. ... but when I look at people, I see that they react in one of two ways: It can either break them or it can make them stronger. I think I've been fortunate that it's made me stronger. So whatever you throw at me, I think, 'OK, what you got next?'"

The truth is that some people are naturally more resilient. Researchers have found that people have a natural

"set point" for resilience that is determined partly by genetics, and partly by their early environmental circumstances. Together, those factors make up about half their capacity to adapt positively to significant challenges; but the other half of resilience actually comes from learning and using a set of cognitive, behavioral and interpersonal skills. Not only can these skills be learned, but they can also be practiced, so that when difficult times arise, you have tools that can help boost your resilience.

# The biology of resilience

To understand the concept of a genetic predisposition for resilience, it helps to remember that humans have a preprogrammed biochemical response to stress, commonly described as the "fight or flight" **response.** In prehistoric days, when a human encountered a saber-toothed tiger, he or she had two options: try to injure or kill the tiger, or run like mad. To facilitate a successful outcome with either of these options, the human body would respond by secreting a variety of hormones, neurotransmitters and other chemicals. Among these is **cortisol**, sometimes known as the "stress hormone." The release of cortisol and other biochemicals would temporarily "turn off" biological functions that weren't immediately needed, such as reproduction and immunity, and focus all of the person's energy and resources on survival. This was a highly useful and adaptive response to stress.

But in modern times, our sabertoothed tigers come in the form of chronic illness, job stress, relationship issues, financial difficulties and the like. As a result, many of us ramp up production of cortisol and other stressrelated biochemicals, not just once in a while during an especially traumatic event, but chronically, as we deal with ongoing difficulties. When these high levels of stress-related biochemicals are sustained in our bodies over time. we become more susceptible to anxiety, depression, obesity, heart disease and a host of other health problems.

66 It's not whether you get knocked down, it's whether you get up."

—Vince Lombardi

In addition, specific parts of the brain become activated during a stressful experience. These include the amygdala (commonly thought of as the seat of emotions), the hippocampus (responsible for emotions, memory and learning) and the ventromedial prefrontal cortex (involved with emotional control. decision making and the brain's reward system).

The degree to which an individual responds to stress with this cascade of brain and biochemical activation depends somewhat on his or her biology. Researchers have identified specific genes that dictate how intensely our bodies respond to stress, and this contributes to our set point for resilience. But genetics can't tell the whole story; environmental factors play a role, too.

# **Environment and set point**

It's believed that exposure to a series of manageable stressors early in life helps a child develop lifelong skills that contribute to resilience. Examples of such stressors include having to say goodbye to a parent when being dropped off at preschool; working through disagreements with peers; taking a challenging academic course; or sustaining minor injuries during play. In this context, children are likely to develop skills they can rely on throughout their lives to help them thrive under challenging circumstances.

Some of these skills include:

- Adaptability, or having mental and emotional flexibility to adjust to changing circumstances
- Good interpersonal communication, including empathy and ability to "read" nonverbal cues
- Good problem-solving abilities

- Ability to tolerate strong negative emotions
- Good impulse control, including the ability to enhance or suppress the expression of emotions, depending on circumstances
- Self-efficacy, or an individual's belief that he or she has the ability to exert influence over his or her life and succeed
- Curiosity, or the tendency to ask questions and attempt to understand things
- Humor, or the ability to laugh at oneself and with others
- Creativity, or using art, writing, music, theater, etc., to express oneself
- Realistic optimism, or the ability to stay positive and hopeful about the future, even while making plans for reality
- Initiative, or a tendency to seek out new challenges that stretch one's existing abilities, and to develop strengths and passions, without being restricted by perfectionism or embarrassment.

Having at least one close relationship with a supportive adult early in life also seems to help because it promotes a sense of safety.

Combined with genetics, these traits are considered "stable factors" that create a person's natural set point for resilience.

#### Resilience is a verb

Even when these traits aren't learned early, or don't come naturally, people need not be limited by their set point. Almost everyone can develop skills that lead to greater resilience. In fact, developing resilience is an active, ongoing process, and resilience levels fluctuate based on the balance between an individual's coping skills and the stressors he or she is experiencing at any point in time.

As Chuck Curry explains, "Resilience, to me, isn't something that you do once. Resilience is something that you have to come back to every day. It's a constant practice. I don't have an expectation that my MS will ever be cured. So it's not something I'm going to overcome, but it's something I'll need to manage and adapt to for the rest of my life. And I think the ability to manage my disease and adapt to changing circumstances is the core of my resilience."

Rachel Padgett takes a similar view: "Resilience is a work in progress. And it changes all the time."

Dr. Ehde draws comparisons between resilience and a bank account in which you need to deposit resources in order to make withdrawals later.

One of the primary elements of improving resilience involves

changing one's perspective. The knowledge that thoughts influence emotions and behaviors underlies much of modern-day psychology. So, while there are many things in life that people can't control—illness, world events, traffic congestion people can change how they perceive and respond to such events.

A shift in perspective creates more than just positive thinking, however; it enables people to creatively identify new, effective solutions to problems.

That's why a person diagnosed with MS doesn't need to fear that her future is bleak, or that she has to rely on ill-suited coping strategies that were learned earlier in life. Rather, she can learn to enhance her resilience through **modifiable factors**—that is, by changing her thoughts, beliefs and actions as they pertain to her current circumstances.

This reframing also helps our bodies process stress differently; when we no longer perceive every setback as our own version of a saber-toothed tiger, our physiological responses get dialed back, too, creating opportunities for improved physical health.

People who cope with stress by creating solutions to their problems rather than avoiding or ignoring them may find themselves in the midst of what's been termed "post-traumatic growth," which is essentially the opposite of the

more familiar "post-traumatic stress disorder." These individuals experience greater self-confidence, personal strength, spirituality, compassion for others and stronger relationships. They sometimes describe the effect not as merely "bouncing back" but "bouncing forward."

66 It isn't what happens to us that causes us to suffer; it's what we say to ourselves about what happens."

—Pema Chodron

That's what happened to Lauren Hansen, a professional violinist and violin teacher whose MS symptoms included intense itching and numbness in the hand she uses to move the bow across the violin. Her neurologist recommended switching to a more aggressive disease-modifying treatment (DMT) to preserve her function in that hand. The recommended DMT, however, had a tradeoff: It was an immunosuppressive therapy, and as a teacher, Lauren had frequent interaction with small children—and their germs. Lauren realized she had a choice between going on a therapy that would potentially weaken her ability

to fight off infections, and losing her ability to play violin. She decided that for her, the new medication's benefits were greater than its risks and began taking it, without incident.

"Ultimately, I made the decision that allowed me to keep my identity as a musician and a teacher. And it's worked out wonderfully. My resilience came from choosing to continue something that held my identity." Today, Lauren continues to play successfully. "In the best moments of playing violin, you're connected with the music and the instrument, and it feels like you're flying," she says.

But perhaps even more importantly, she found a way to use the experience to move forward. At the same time that she was dealing with her MS symptoms, she was also going through a difficult divorce. "I found that the intense emotion I was going through and struggling with at the time, I was able to channel through my playing into the pieces. And it made my performances better."

Lauren notes that she also was able to discover new aspects of her identity— "to find out who I am now." She began to indulge her love of animals by volunteering at a farm animal sanctuary, and by doing so, formed deep friendships with new people and animals alike.

"With each of the decisions I've made, it really raised my self-esteem [to know that I will be] able to face what comes. "

George Bonanno, PhD, a professor of clinical psychology at Columbia University, is not surprised by this. When people say they are no longer the same person they were before MS, his response is: "It has changed you and, in a sense, robbed you of who you were. But you're still alive. You still are somebody, and the challenge is now to find out who you are now, and to make that bridge to the next part of your life."

Similarly, Chuck feels that he has evolved into a stronger, happier person as a result of his MS challenges. He had been working on a dissertation for his PhD, in hopes of securing a professorship at a four-year college, when he had his first MS attack. After some soul searching, Chuck realized it was more important for him to stay in the Seattle area, where his support network and personal life was centered, rather than pursue a career that would most likely mean moving around the country. It also motivated him to prioritize his health. Now living very happily on Bainbridge Island, Washington, where he is a volunteer scuba diver for the nearby Seattle Aquarium, and as a surveyor for a marine conservation organization. Chuck says, "I have no doubt that I wouldn't be living here, living the life I am now, if I hadn't gotten MS."



# Why Is Resilience Important?

Building resilience can improve the quality of life for almost anyone. Research shows that people with high levels of resilience have better longterm physical and psychological health. They have lower risks of heart disease and get infections less often. They are less likely to experience depression and anxiety.

What's more, resilient people tend to have healthier relationships with others, as well as greater self-esteem and self-confidence, and often find that new life opportunities arise as a result of these improvements.

In addition, Dr. Ehde says, "People who are resilient have the ability to grow from adversity. They can learn things about themselves, about what they value. They learn that they can get through tough things."

People with MS, perhaps even more than most, can benefit from building their resilience because of the ongoing, unpredictable changes they face in their health, abilities and self-image. For example, someone living with MS may have balance problems or muscle weakness one day and be able to walk unassisted the next. This kind of unpredictability can lead people with MS to believe they have little control over their lives—a feeling that can spiral into depression, poor

management of their disease or changes in their relationships.

Some people may even experience all of those setbacks, because when people feel helpless in one area of life, they often apply that sense of helplessness to other areas. With the multiple challenges that people living with MS face, this could have a snowballing, damaging effect on their lives.

But by learning new ways to look at their situation, they discover there is much they **can** control about their lives—and that sense of self-efficacy is one of the primary contributors to resilience.

# A deeper sense of self

"**Self-efficacy** is having the confidence in yourself that you can do what you need to do and manage what comes your way," says Dr. Ehde. "People with self-efficacy tend to be happier. They tend to be more resilient. They tend to manage better both life and MS." And, she says, "Being resilient can be particularly useful when there's a change in functioning or maybe some loss, such as realizing that one can no longer work. We also know it's very helpful in dealing with relapses. But certainly being resilient is useful no matter where you are in life or with your disease."

When people with MS give themselves permission to believe that they will be OK, and learn to adapt to their everchanging lives, they often find that things improve:

- They're able to maintain satisfying relationships, find meaning and hope in their lives and manage their disease with competence
- They often develop increased personal strength, spiritual change and greater appreciation of life
- In short, they experience posttraumatic growth.

Michael has navigated this change particularly well. In addition to living with progressive MS, he is also a cancer survivor. "There's nothing like very nearly dying to really make you appreciate being alive. And today I literally wake up each morning, so happy to be alive, and I think of all the wonderful things I can do that make life worth living, that make it so enjoyable. It might be nice weather and I'll go out for the day. Or it might be terrible weather and I'll stay inside and read or listen to music."

Chuck compares living with MS to his experience as an outdoor educator earlier in his life. In that role, he and his colleagues took students on 30-day wilderness expeditions, which included sea kayaking. "We had to deal with whatever came up," he says, noting

**66** Adversity has the effect of eliciting talents, which in prosperous circumstances would have lain dormant."

# —Horace

that often meant adjusting to changing weather conditions on the ocean.

"You've got to keep going and adapt to whatever's happening," he says, "even though the conditions aren't what you would have hoped for, and aren't necessarily easy."

Like Chuck, Michael relies on strengths learned in previous athletic endeavors for his sense of self-efficacy. Formerly an avid cycler, Michael pedaled through the Alps and other extreme locations. "If you're riding for 100 miles a day, which was absolutely normal for me, and halfway through you get heavy rain or it gets cold or the road's steeper than you thought, you don't have much of a choice. You gotta get through it," he says. "You gotta hang in there because

you know that when you get to the end of the ride there'll be a hot shower and a nice meal."

With MS, Michael says that sense of perseverance developed as each new problem arose. "Now, I'm completely quadriplegic. I can't move my arms or legs at all. For many people, that in itself would be pretty devastating." But the loss of movement happened gradually, so Michael adapted in stages, too, he says. First he got a cane, and eventually progressed to a wheelchair. Unlike many people with MS, he came to see the wheelchair not as a restriction, but as liberation, because it allows him to live his life fully, with activities that include auditing classes at Princeton University and taking weekly trips into New York City for cultural events using public transportation.

Lauren says that whenever a symptom arises, such as the difficulty she had with her hand, it helps her to think about what's actually happening, and what her options are for managing it: "Do I keep going with this course of action? Or do I have to find a different way around? And then choose this path or that path. It's really about looking at the situation as it is, and making decisions based on that course."

To do that, Lauren likes to keep a three-ring binder where she records detailed information about how she's

feeling, what strategies she's tried to feel better—whether a medication, a physical activity, or a complementary or alternative therapy such as massage or acupuncture—and then how the intervention actually made her feel. "It gives me a sense of control, at least, that I am taking charge of my life."

Lauren emphasizes, though, that sometimes, she truly doesn't have control. And in those situations, she says, "I have to allow myself to grieve." She adds that once she has grieved her losses, she finds it helpful "to get outside of my own head—to reach out and help others."

# **Family**

Resilience is important for family members of people with MS, too. The disease never impacts just one person. Spouses, children, parents and siblings all experience changes in their lives when a loved one has MS. Sometimes it means a shift in household or financial obligations; sometimes it changes a family's social life, or even where a family lives.

Brian Padgett, whose wife, Rachel, had MS long before the two met, knows that well. "Some days, Rachel can do everything and other days she can't do as much ... and I take on the bulk of that. It's not fun, but I do it because I have to and because we are in it together."

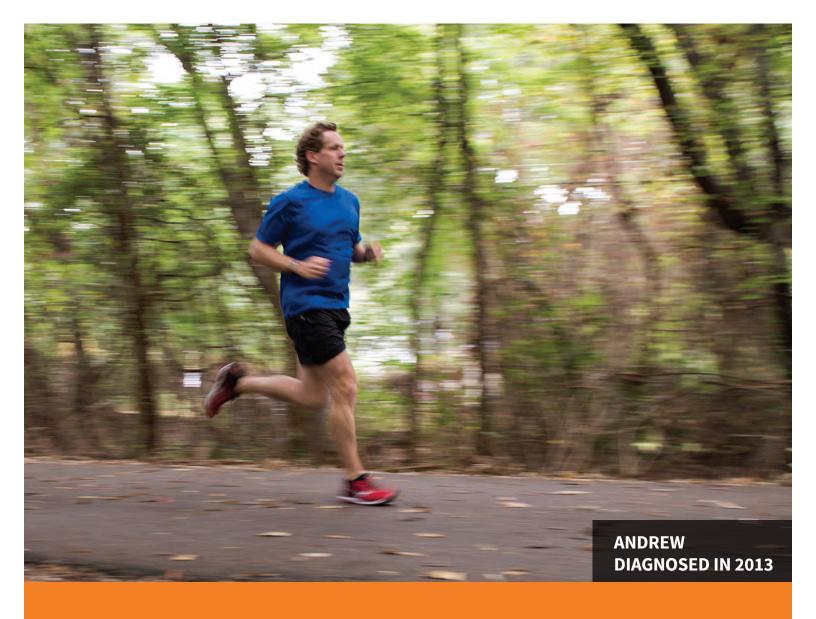
He's also learned that prioritizing Rachel's health makes both of them feel better in the long run. "If we are at a party and having a great time ... and Rachel says we need to go, my answer is always, 'Yeah, let's go.' If I give her a hard time or pout about it, she is not going to share [her needs] with me next time; she is the kind of person who is just going to power through," increasing the likelihood that her symptoms will worsen, and make things more difficult for both of them.

Rachel says she and Brian have learned that the hard way: "You have to respect that there's no pushing through. There's doing what you have to do to get to the next day. That was really hard for Brian at first." But as Brian and Rachel have both nurtured their resilience skills, life together has become easier. Says Rachel, "We have, together, made a really good way to manage and be resilient to the disease. ... I feel so grateful that I have this very healthy, wholesome kind of relationship ... and a partner who can respect what's going on and help me."

Families, like individuals, can react to the realities of MS with either a crisis-centered or growth-centered approach. In many families where a parent has MS, children seem to thrive, particularly when the parent demonstrates his or her ability to overcome obstacles. It sets an example for the children, who then learn to develop their own strategies for having a happy, meaningful life while living with MS.

The irony is, it's only when people are faced with challenges that they know how resilient they can be.

"I don't think I really felt all that resilient while I was going through these periods of crisis," Lauren admits. "At the beginning, I thought, 'There's no way I can get through this. It's too hard. It's too much.' I wanted to curl up into a hole. But looking back, I realize, 'Hey, I actually made it through that.' And I feel a sense of accomplishment and strength. And then I think, 'If I can make it through that, what else can I face?' And each challenge that you make it through builds that resilience muscle, so to speak. And a lot of it is trial and error. You throw everything you've got at the situation and you see what sticks and what helps, what gets you through it. And you start learning skills about yourself, and things that you can tap as resources for getting through things."



# How to Build Resilience

Researchers have outlined three stages that people typically work through on the road to developing greater resilience. These include:

- **1. Understanding.** People in this stage invest their time and energy in learning as much as they can about the situation they are facing. People newly diagnosed with MS might begin learning about the symptoms of the disease, the leading theories on what causes it, and how their disease may change over time. They may begin to seek out others living with the disease, and expanding their understanding of the range of ways MS can affect people.
- **2. Managing.** People in this stage begin to learn new coping strategies and lifestyle behaviors. Not only do they discover how to best take care of themselves physically, socially and financially, but they also start to try different methods for managing the stress and unpredictability that can occur with a disease like MS. As a result, people in this stage may begin to feel more confident and empowered.
- **3. Growth.** People in this stage may start to experience shifts in their priorities. They have a more developed understanding of what is important to them in life and what is not. They may begin to pursue their passions

and take steps to strengthen their relationships. They may begin to feel a sense of gratitude for the positive things in their lives.

Chuck believes it's important for people to take their time in "understanding," the first stage. "I think not knowing what MS is, uncertainty about what can happen with MS, can lead to much more anxiety than having good information and knowledge about the disease and about the resources that are available," he says.

Dr. Bonanno agrees, noting, "First we have to understand what's happened to us, and what we need to do. What's being demanded of us? What is the situation calling for?"

When people have moved into the "managing" stage, they have assimilated a lot of new information acquired in the first stage, and now have the opportunity to learn skills that contribute to greater resilience. The most significant one is how they perceive and respond to a potentially traumatic event.

For example, a person involved in a minor car accident might feel his stress levels rise as he begins to think about phone calls with the insurance company and getting any damage repaired. He may even begin to feel helpless to avoid future accidents. Or,

he could frame it differently and feel gratitude that no one was injured, and think about how he might practice defensive driving in the future.

As an article in The New Yorker magazine by psychologist Maria Konnikova put it, "Frame adversity as a challenge, and you become more flexible and able to deal with it, move on, learn from it and grow. Focus on it, frame it as a threat, and a potentially traumatic event becomes an enduring problem."

Consider Dawnia Baynes, who was diagnosed in 2006 with relapsingremitting MS, years after her father was diagnosed with progressive MS. Because she already knew quite a bit about the disease, she was focused on finding ways to live well in spite of it. "I refused to lay down and die, or wait for my MS to progress. I realized I can still do things— I just have to make adjustments."

Dawnia recalls wanting to attend her favorite musician's show. "All his concerts are standing room only, and I can't stand that long." So she called the venue ahead of time, and arranged for seating for herself and her friends. "It's like, what do I need to do so I can enjoy life?"

Dawnia has a "bucket list" of other activities she wants to experience and bowling was on it. "I didn't think I could bowl anymore," she says, but realized she could if she just used a lighter ball than in the past. In

addition, she has arranged for a shuttle to take her from her church's parking lot to the door; while working on her biblical studies degree, she has learned to record lectures when she's not able to take notes; and has asked her physician for a physical therapy referral so she can maximize her functioning. Meanwhile, she also asked for a walker so she has assistance when she's not at her best. "I'll go to movies and concerts ... and conferences and festivals." Dawnia says this approach of careful planning and strategizing has helped her feel empowered and successful in life, the hallmark of flourishing stage two progress.

For Rachel, one of her strategies in the second stage was to start telling people about her MS. When she was first diagnosed, and for several years afterward, she kept her MS secret from all but those closest to her. But once she began using a cane and missing occasional appointments, she decided to start disclosing her disease. "I couldn't tell white lies anymore about why I was leaving parties early or needed 10 hours of sleep or kept falling over and breaking things," she says. "Being open about my disease has made me feel a lot more empowered as an individual because I'm taking control of my situation. I feel less guilty. I feel happier. I think it has enhanced every single relationship that I have, with anybody from a casual acquaintance to a co-worker to my husband and my family," she adds. "It has probably been one of the most spectacular things I've ever done in my life."

Nevertheless, Rachel says, "I think for anybody, regardless of whether you have a chronic illness or not, accepting who you are and what your limitations are is really hard. I certainly always found it really hard, even when it's not about my disease. But I have to be really honest with myself about where I am emotionally and physically, and I have to make smart decisions based on that."

For Rachel, that includes taking an antidepressant to manage the mood changes that MS can cause. "I think it's really important to be honest about the things I need to live the life I want to live, and to be able to ask for help when I need it, even if it's emotional help." Rachel notes that "integrating the knowledge of my disease into my life has made me realize that I've worked hard with this disease to do the things that I have done, and I am resilient."

Not only is Rachel now managing her physical and emotional symptoms, but finding ways to thrive in spite of them, a signpost of stage three resilience. A lifelong swimmer, Rachel decided to participate in a 2.4-mile swim across Lake Washington last year. On the day of the swim, she says, "It was a horrible, rainy, cold, windy day in August," and the water was cold and choppy.

"They've been doing that swim for 14 years, and they said it was the worst conditions they'd ever seen. The lake was a dark, gray expanse. It looked like an incredibly long way to the other side. And I felt like, once I got in and started going, there's no turning back. At some point, I'm not going to be able to touch bottom anymore. And it's just getting to the other side." Despite her dread, she did get to the other side. "When the bank that we were swimming toward came into sight and I could put my feet back on the ground, I was overcome with exhilaration, excitement, satisfaction—that I'd actually done this thing that I'd set out to do."

of human experience would lose something of rewarding joy if there were no limitations to overcome. The hilltop hour would not be half so wonderful if there were no dark valleys to traverse."

—Helen Keller

Then there's Lauren, who also seems to have successfully navigated all three stages. Though it took more than a decade for her symptoms to be recognized as MS, she was instrumental in her own care. Her detailed symptom tracking helped her physicians make the initial diagnosis. Then, she learned as much as she could about her symptoms and her MS in her determination to live the life she wanted. "I had goals, and I was going to complete them no matter what," she says.

"When I had the trouble with my hand, I had to really look at it. I could try to ignore it; I could try to push through it. I could choose to stay on the medication I was on," she says, but ultimately her decision came down to: "What's going on with my body? What resources do I have? What's important to me?" The answers will differ for everyone, but for Lauren, her identity as a violinist was a priority, and that informed her decision. She also realized she needed more social support after her diagnosis and her divorce, and she took steps to create that with her volunteer work at the farm.

# **Learning the ABCDs**

The art of changing one's perception about adversity relies on developing **insight**—a person's ability to recognize her own beliefs about the cause(s) of her adversity, and to

understand how that may affect her emotions and behavior.

Once you have this self-awareness, you have a greater capacity to see things as they are, rather than through a filter. You can put them in perspective, without being influenced by fear or other emotions. This enables you to avoid a downward spiral of catastrophic thinking, or other unhelpful mindsets, such as tunnel vision (focusing on just one aspect, rather than the whole picture, of a situation) or personalizing (attributing an adverse event to your own personality or actions).

Psychologists outline the process for this shift in perspective as **ABCD**:

- **Adversity:** The events in our lives that we can't change
- **Belief:** Our interpretation of the event, including why we think it happened, and whether we think it's temporary or permanent
- Consequence: How we think, act and feel as a result of the event
- **Disputation:** When we acknowledge our belief as a belief, not a fact, and then challenge it by looking for other possible explanations. We can develop a "counterfact"—a new way of framing the event so we feel fortunate rather than helpless. To do this, it may be helpful to pretend we're arguing with a friend about it.

Chuck provides a great example of how he developed counterfacts when he was an outdoor educator. "It really taught me to look at a given situation and all the ways it could've been worse. We'd get through some challenging situation, and then the other instructors and I would talk about, 'Aren't you glad this didn't happen,' or, 'Can you imagine if that guy's boat had flipped over when that other thing was happening?"

He applied the same strategy when he was diagnosed with MS. "My initial reaction was, 'Wow, I'm really glad it wasn't bone cancer.' Michael in fact did develop cancer after living with MS for many years, and still reframed it. The day after getting the cancer diagnosis, he says, "I realized, 'Well, I know how to get through MS. So maybe cancer's no different." And now he lives with a gratitude for being alive, and treats MS as a "condition" rather than a disease. "I've got every opportunity and I'm able to do everything that life throws at me."

See page 23 for some examples of how different people might interpret and reframe (dispute)—the same event,

# Beyond the basics

People facing adversity can also learn ways to calm and focus themselves to temporarily change where they place their attention and to quiet their emotions. This gives them an

opportunity to think things through, so they respond to their situation with insight, not impulsivity. Mindfulnessbased stress reduction (MBSR) is one type of nonreligious meditation that has been shown to help in such circumstances. MBSR teaches people to experience their emotions without judgments or anxiety. Research suggests that after about two months of practice, positive changes in the brain associated with improved resilience can be observed.

Chuck took a class in MBSR. "I don't have a sitting meditation practice," he confesses, "but that course taught me that meditation could be done anywhere and during any activity." He's found it useful in diving and in life. "When you are diving, you want to do everything you can to slow down and slow your heart rate because that extends the amount of time you can stay down on a given tank of air. So there's a meditative quality to it," he says. Likewise, diving reinforces his meditation practice. "The breath that I've developed through diving is something I use when I'm out of the water. Every day, I do a series of stretches that involve rhythmic breathing—holding the breath, and then letting the breath go. ... It helps to relax me. And if I'm in a situation where there's stress, or my emotions are ramping up, I can go back to my breath and it really helps center me and keep me calm.

# **EXAMPLES OF REFRAMING THE SAME EVENT**

	PERSON #1	PERSON #2	PERSON #3
A.	New MS symptom appears	New MS symptom appears	New MS symptom appears
В.	Person thinks, "My MS is getting worse. I'm probably transitioning to progressive MS. I'll be blind and unable to walk before long." (catastrophic thinking)	Person thinks, "My MS is getting worse. It's probably because of something I did wrong. I've really messed up." (personalizing)	Person thinks, "This might be an exacerbation. I'll watch this symptom for a couple days, and if it doesn't subside, I'll call my doctor."
C.	Person feels anxiety, panic, despair, depression; may begin to decline social and physical events.	Person feels guilt, shame, depression. May feel that he or she is not worthy of self-care, and begins to neglect diet, exercise, medication, etc., causing physical and emotional health to deteriorate further.	Person feels concern, but is confident that physician will help manage any new symptom and/or exacerbation.
D.	Person thinks, "Wait a minute. Things don't spiral out of control so quickly. I bet if I call my doctor, we can get this under control and limit further deterioration."	Person thinks, "Wait a minute. MS affects everyone differently, and part of the disease involves relapses. It's not my fault. I'll call my doctor and see if we can get this new symptom under control so I can start feeling well again."	Person thinks, "I sure feel good that I paid attention to my body and noticed this symptom before it got much worse."

In addition to these skills, researchers have identified numerous lifestyle factors or habits that people can cultivate to support resilience.
These include:



**Maintaining strong social connections** with families and friends, and with others who have MS.

Research shows that social support reduces depression and helps people manage stress, leading to better physical and psychological health. "Sometimes supportive relationships can provide somebody to talk to," Dr. Ehde says. "But often, it's important just to spend time and engage in fun, pleasurable or meaningful activities with people who you enjoy being around."

Maintaining supportive relationships can be challenging for anyone, though, and when one person in a relationship has MS, additional stressors are introduced. Sometimes relationships change, friendships fall away or it just feels as though people no longer seem to "get" you. As a result, it's common to feel lonely or even depressed when living with MS—which is all the more reason to nurture supportive relationships.

When you connect authentically with people, they can help you get through the rough times as well as celebrate the good times. If you don't already have a strong social support

network, build one. People do this through different avenues—some join a church, synagogue or mosque; others take classes or join social groups like **meetup.com**. Still others find support through self-help groups or online chat rooms. Or, there's the route that Lauren took, volunteering with an organization that supported her passion. There's no question that any form of social support helps people manage stress and leads to better overall quality of life. "Those connections," says Chuck, "are very important for helping all of us stay resilient."



Maximizing physical wellness with healthy eating habits, exercise, sleep and MS therapies.

Both exercise and sleep can promote improved mood and memory, which will help an individual's outlook and problem-solving skills. MS therapies can reduce the risk of relapses and all the stress they can entail. "Resilient individuals tend to be better at taking care of their physical and emotional health," Dr. Ehde notes. Both Chuck and Rachel rely on their physical activities to provide them with stress relief and strong bodies. "I love to challenge myself on my health and well-being by swimming as much as I can. I love to get in the pool. I can't lose my balance and I can't fall," Rachel says. "I feel safe. I feel strong."



Setting realistic goals and moving toward them. This helps people feel fulfilled, competent and in control

when they're successful. Conversely, it's important to know when to say when. If goals are unrealistic, people may begin to feel overwhelmed. Research has found that people who quit unattainable goals actually have better mental and physical health (and lower cortisol levels) than those who keep pushing against all odds. "Anytime we have repeated small successes, we are going to build our confidence and our self-efficacy," Dr. Ehde says. It's important to recognize, however, that there are going to be days with MS when things are easier, and days when they're more difficult, she adds. "If you're not meeting the goal for the day, it helps to have the flexibility or adaptability to shift the goal to something else, knowing you can always come back to that original goal on another day. ... If you can get to that place where you see that variability as part of living with MS, something you can manage, you will do better."

That's exactly how Rachel sees it. "I think one of the most challenging things about living with MS on a dayto-day basis are the setbacks. There are so many setbacks, especially when you're like me, and you get your mind set on something that you want to do. I try to use the setbacks as a way to build resilience or feel empowered.

I just started swimming again after a few falls, and every day I count how many lengths I swim. On the first day, it was 10 lengths and now it's a few more than 10, but every day that I'm doing well I have to count as a victory." Rachel says that her progress does not occur in a straight line, however. "It's like, what can I do today that I can count as a victory? Maybe one day it is swimming Lake Washington, but five days ago, it was getting up and taking a shower."



**Practicing gratitude** for the positive things in their lives. Many people, including Lauren, find it

helpful to keep a gratitude journal, listing one or more good things each day that they feel thankful for. "Some days, my 'thankfuls' are, 'I am in a house; I have a roof over my head.' Other days, they're just really great, amazing things that I get to put down. It really helps to bring into focus that there is always something positive there," Lauren says. This doesn't mean pretending everything is wonderful; it just means noticing and appreciating things when they are.



**Nurturing** positive emotions, including hope, optimism and humor—and savoring them when they

occur. Encourage this by engaging in activities that result in positive emotion, whether that's a hobby,

getting together with a friend, or going to religious services. Dr. Ehde says that humor can help people see the silver lining in things. Dr. Bonanno says that his research even shows that laughter helps people cope with difficult circumstances. "It's a very adaptive thing. I always tell people to laugh when you can. Go to a funny movie, tell a joke. Do something to make yourself laugh. Give yourself permission to find humor." He adds that not only is it healthy, it also helps people bond with others—and that can enhance their social support.

Dawnia admits she has always been someone who looks for the bright side of every situation, to the point that her friends tease her about it. "I choose to stay positive and just have fun. Why be serious when you don't have to be?"

Likewise, develop a plan to stop doing things that result in negative emotions. Finally, notice when good things arise, even from adversity.



Allowing oneself to feel negative emotions, such as anger, frustration, grief or sadness, without getting

stuck in them. Many people learn to think of negative emotions as being like the weather—something that will eventually pass. "It is important to know **when** to allow yourself to feel strong emotions, and when to curtail them and know that it's not the right moment," Dr. Ehde says. "When someone is having

a strong emotion, there are a number of things they can do. And one of them is to simply be aware of the emotion, and recognize that it doesn't define who you are or how you're going to feel in the next moment. It's just a feeling, and it doesn't define you as a person." Other times, she says, such feelings may signal that it's important to take a break, or do something enjoyable, or talk with a friend. "We all have strong emotions. They're a byproduct of being human," she says.

Lauren says that expressing her negative emotions—whether through her violin, journaling or other means has helped her process them. "I had to allow myself to grieve. And then after that process, really look at life the way it is at that point. And then find another way around, use my resources."

"I've spent more than my fair share of time worrying about what's going to happen next, and what does MS hold for me tomorrow or next week," says Rachel. "I think it just comes with the territory, and I really try not to live in those places. I try to let those feelings just fall over me, kind of like a waterfall—and just let them disappear. I try to remind myself that's not who I am." Her husband, Brian, echoes that, "There have been times where it gets you down, and there is crying and railing against the world for the unfair hand that you have been dealt. But it doesn't have to be the only thing you focus on."

Chuck says that his diving experience has come in handy in that regard. "Underwater, when things go wrong, the last thing you want to do is panic. Divers say, 'Panic kills.' As long as you're breathing, everything's OK. You can always deal with the problem as long as you're breathing. And I think the same thing is true above water. If I can bring my attention back to my breath, that helps me calm down physically, mentally and emotionally."



Using mindfulness and relaxation approaches to minimize intrusive thoughts and emotions.

This can include the use of breathing techniques, imagery, progressive muscle relaxation and mindfulness meditation. such as MBSR. Professionals as well as websites and mobile apps can guide you through it. (See the **Resources** section for suggestions.) "It takes my mind off things that I'm worried or anxious about. Worrying seems pointless, but it's hard to not let my mind go there, so mindfulness-based practices help me be aware of those thoughts and then choose to let go of them," says Chuck. "It isn't about pushing those thoughts down. It's about hearing them, and then saying, 'OK, I'm anxious about my MRI next week. I'm going to set that thought aside now and come back to my breathing, and focus on that."



**Practicing forgiveness** toward people who've hurt you, or even toward circumstances, life or

God (or any higher power you that acknowledge)—so you can release resentment and bitterness. Holding onto these emotions is associated with higher cortisol and blood pressure levels, which are linked to negative health outcomes.



Planning for the future by accounting for actual needs and limitations; this can also mean simplifying

life and not overcommitting to activities and people that aren't priorities. When Dawnia arranges for seating at a concert or a shuttle bus to church, she's doing this. She knows her limitations and plans for them, rather than allowing them to restrict her options. "It's just being one step ahead of where I'm trying to go," she explains.

Or, as Brian describes it, "If it rains, I have to deal with it. Either I am going to get wet or not." It all depends on how he prepares for it. "Same is true with MS," he says. "We don't know what's going to happen. Rachel may be in remission for the rest of her life that would be awesome. But when we remodeled our bathroom, we made sure it was ADA\* compliant."

\*ADA: Americans with Disabilities Act

Michael is the very picture of planning for reality. Because he had no idea how disabled he would eventually become, when he purchased his house, he considered numerous factors: It had to be all on one level, with a rollin shower, and near a train station. He incorporated technology into his wheelchair, including a device that allows him to tilt and recline it. as well as move the chair forward or backward. It even communicates with his iPad, which in turn allows him to control the lighting, heating, door locks and other functions of his home. "I've been over the Brooklyn Bridge a few times in my wheelchair. I've been up and down the shores of the Hudson River. I go to Philadelphia now and again. I've even been to Washington, D.C., in this wheelchair."



Finding a sense of meaning and purpose in life, whether through volunteer work, social

activities, relationships or other avenues. Some research has even suggested that this results in lower levels of inflammatory gene expression.

Michael says one of the things he's most proud of is how he's raised his daughters while living with MS. "One of the wonderful, positive things about being severely disabled is that my daughters have grown up understanding how fortunate they

have been, and how much they want to contribute to helping other people."



**Helping others**, which can make you feel good, and build your social network. Dawnia says MS has taught

her to communicate more with others. Even when she has to go to the hospital, she says, "I get to talk to people and encourage them. I just try to share my knowledge of anything I've learned. Why have knowledge and not share it with other people?"

In addition to her work on the farm, Lauren also volunteers with the National MS Society. "I started a selfhelp group. I did some public speaking for the Society on what it's like to live with MS. And I loved it so much that I went into public health for my master's degree because I thought, 'I want to do this for my career.' I love talking about MS, getting the word out, because it had been so invisible for me and I wanted people to know there are so many people living with MS, and we need an understanding for it." She adds that it helped "to get outside of my own head—to reach out and help others."



Turning to one's faith or spirituality. Faith communities can be supportive in difficult times,

and may help you address questions like, "Why me?" Spirituality doesn't have to mean religion (though it can), but can

also refer to a sense of belonging to something larger than oneself.

Dawnia says she relies on her faith to get her through her occasional dark days. "That's how I keep my peace, by reading the Bible. I truly believe it's my faith that keeps me going. I have a few Scriptures that, when I'm struggling, remind me that it's going to be OK. I begin my day with praying and reading because I have to have the right attitude to start the day."

Chuck says he is not a religious person, but still finds a sense of spirituality in the wilderness. "Being in the outdoors is where I go to church. It's where I feel like I get to connect with some power greater than me. I call it 'cosmic oneness."



Learning to tell your story in a different way, to yourself and to others. Honor the challenges, but

also what they've taught you, and what strengths you've developed as a result. When you can see both sides of your adversity, your story is richer and more meaningful, and you begin to understand that without darkness, we can't appreciate light.

# **Developing skills**

Even if you don't currently possess or practice all of these skills and habits, most of them can be learned. This

was shown to great effect in 2009, when the U.S. Army collaborated with psychologists at the University of Pennsylvania to develop a resilience training program for soldiers, who clearly face ongoing, extreme stress. To accomplish this, the program focused its training on developing optimism, problem solving, selfefficacy, flexibility, impulse control, close relationships, spirituality, a sense of meaning and more.

The program relied heavily on using the ABCD model of building resilience. Soldiers who participated in the program were taught to evaluate the accuracy of their beliefs and separate the true nature of an adverse event from what they tell themselves about it in the midst of the challenge. They learned to identify "icebergs"—deeply held beliefs, such as, "Asking for help is a sign of weakness"—and then learn to examine whether the belief is accurate and useful, whether it's still meaningful to them, or perhaps overly rigid and creating emotion that is out of proportion to the event.

The soldiers also learned how to manage their energy in the midst of adversity. Other skills they were taught included problem solving, minimizing catastrophic thinking and cultivating gratitude.

After the soldiers learned these core skills, they moved on to identifying

their own character strengths, such as perseverance, curiosity or hope—and then learned to use them. (A total of 24 strengths have been identified in six broad categories: wisdom, courage, humanity, justice, temperance and transcendence. See page 31.) Finally, soldiers learned to strengthen their relationships, partly by relying on their unique strengths.

In 2011, researchers found that soldiers who underwent the training had significantly improved resilience 15 months later—as noted by higher scores in optimism, adaptability and other traits that contribute to resilience, as well as fewer diagnoses of mental health disorders and substance abuse—and sustained those improvements.

Identifying and leveraging one's strengths can be helpful for everyone, not just soldiers. To do this, begin by asking yourself questions such as:

- How have I gotten through difficult times before?
- What and who helped?
- What skills did I use?
- What have I learned about myself by going through these experiences?
- What has made me feel more hopeful about the future?

In addition to answering questions such as those above, you may find it helpful to take a strengths inventory.

See the **Resources** section at the end of this book for websites.

# Practice makes ... progress

The goal of identifying your strengths is to become comfortable using them day in and day out—so that when you're faced with trying circumstances, you can rely on your strengths to see you through. Once you've identified your strengths, practice using them often in new ways.

Martin Seligman, one of the pioneers of resilience training, published a study along with his University of Pennsylvania colleagues that showed that people who identified and used one of their signature strengths in a new and different way each day for a week reported significant increases in happiness and fewer symptoms of depression for six months. Additional studies building on Seligman's work have found that this practice seems to create a "virtuous cycle," in which those who practice their signature strengths are better able to maintain social support and make progress toward their goals, which then gives them further confidence.

For example, Dawnia has relied on her signature strengths of optimism and problem solving. "There were times when I did not want to participate in things because I felt like I would be a burden," she says. But after her

### **VIA CLASSIFICATION OF CHARACTER STRENGTHS**

WISDOM	<ul> <li>Creativity: originality; adaptive; ingenuity</li> <li>Curiosity: interest; novelty-seeking; exploration; openness to experience</li> <li>Judgment: critical thinking; thinking things through; open minded</li> <li>Love of learning: mastering new skills and topics; systematically adding to knowledge</li> <li>Perspective: wisdom; providing wise counsel; taking the big-picture view</li> </ul>	
COURAGE	<ul> <li>Bravery: valor; not shrinking from fear; speaking up for what is right</li> <li>Perseverance: persistence; industriousness; finishing what one starts</li> <li>Honesty: authenticity; integrity</li> <li>Zest: vitality; enthusiasm; vigor; energy; feeling alive and activated</li> </ul>	
HUMANITY	<ul> <li>Love: both loving and being loved; valuing close relations with others</li> <li>Kindness: generosity; nurturance; care; compassion; altruistiism; "niceness"</li> <li>Social intelligence: emotional intelligence; aware of the motives and feelings of other people and oneself; knowing what makes other people tick</li> </ul>	
JUSTICE	<ul> <li>Teamwork: citizenship; social responsibility; loyalty</li> <li>Fairness: being just; not letting personal feelings bias decisions about others</li> <li>Leadership: organizing group activities; encouraging a group to get things done</li> </ul>	
TEMPERANCE	<ul> <li>Forgiveness: mercy; accepting the shortcomings of others; giving people a second chance</li> <li>Humility: modesty; letting one's accomplishments speak for themselves</li> <li>Prudence: careful; cautious; not taking undue risks</li> <li>Self regulation: self control; disciplined; managing impulses and emotions</li> </ul>	
TRANSCENDENCE	<ul> <li>Appreciation of beauty and excellence: awe; wonder; elevation</li> <li>Gratitude: thankful for the good things; expressing thanks; feeling blessed</li> <li>Hope: optimism; future-mindedness; future orientation</li> <li>Humor: playfulness; bringing smiles to other people; lighthearted</li> <li>Spirituality: religiousness; faith; purpose; meaning</li> </ul>	

friends reassured her that was not the case, she lit up with her usual positive attitude and found ways to stay engaged in the activities she loves, and to ask for help when she needs it. That, in turn, reinforced her relationships and gave her the confidence to do the next thing, and the next thing.

## **66** The greatest glory in living lies not in never falling, but in rising every time we fall."

### —Nelson Mandela

Lauren used creativity and leadership, two of her strengths, to rebuild her social network. When she was feeling lonely, she looked into self-help groups for people with MS in her area. Finding none that targeted young adults, she took the required training to launch her own National MS Society-affiliated self-help group and became a group leader. "That group helped me so much to navigate a lot of the things I was facing with MS," she says. "And it also allowed me to not sit at home and grieve this diagnosis but to get out there and connect with other people."

Building these practices into habits will take effort, of course. In fact, it will take what researchers call

"deliberate practice"—focused, intentional attempts to improve. There's a bit of folk wisdom often heard that says it takes 21 days to cement a habit. Research shows that's not entirely true. In one study, it actually took anywhere from 18 to 254 days, depending on the complexity of the behavior being learned as well as the individual's personality. But the average length of time it takes for new behaviors to become habitual is 66 days, the researchers found.

And how you practice a habit is just as important as how long you practice it. To succeed, deliberate practice must start with a "trigger" to initiate action. The trigger should be an existing behavior or routine, and the simpler the trigger the better. For example, if vou want to meditate before bed, tie it to your habit of brushing your teeth before bed. Eventually, every time you brush your teeth at night, you'll remember to meditate afterward. It's also important to celebrate the new behavior, no matter how small, immediately after completing it. The celebration doesn't have to be elaborate; it can be as simple as a fist pump, or saying "Awesome job!" to oneself. It's important to incorporate these strategies, and not rely on motivation alone, as motivation frequently waxes and wanes.

In addition, it's helpful to practice strategies for resilience on smaller

challenges—for example, finding ways to incorporate physical activity into the day, or preparing a healthy meal in spite of problems with fatigue, balance or other MS symptoms—so that when you need these skills for bigger challenges, you've already become comfortable and successful with them, and don't react with a crisis mindset.

In Chuck's case, his resilience comes from a combination of strength plus flexibility, he says. "When I do my physical therapy exercise, when I do my stretches, I know those things help me feel better and stay healthy. And if I build a habit of doing them, then it doesn't take as much willpower to do them when I'm tired or feeling down. And as circumstances change, I'm able to adapt to those changes.

### Be aware of bumps in the road

Naturally, there are obstacles to resilience as well, which seem to be most prominent during early and middle adulthood, when people are acutely focused on careers and families, and managing MS symptoms feels particularly difficult. These obstacles include physical fatigue, depression, social isolation, whether initiated by the person with MS—or his or her spouse or family member or by a process of losing friends who don't seem to understand the disease

and its impacts. People who feel burned out or anxious about their constantly changing symptoms, or who feel a stigma associated with having a chronic illness, also have a harder time developing resilience. Perfectionism, too, can get in the way. It's a difficult lesson for many, but sometimes "good enough" has to be enough.

Ongoing stress can also be an obstacle to resilience. "Acute stress is adaptive because it spurs us to action," Dr. Bonanno says. "But chronic stress is not good. Chronic stress wears us out and depletes our resources." For this reason, it's helpful to work on developing your resources—social, emotional, financial, physical and spiritual—to the greatest extent possible when you're feeling well.

Not everyone is going to be naturally resilient, Dr. Bonanno says. "Some people just can't get over what's happened to them, and they struggle. ... and that's when we turn to professional help. And that's OK. That's life too."

Various organizations have created tools for assessing your current level of resilience, and the factors that contribute to it. If you take a strengths survey, either on your own or while working with a professional, it can provide considerable insight into your individual patterns of stress response.

### **Moving forward**

Resilience is a useful quality to have, not just in times of great adversity, but also when handling life's daily stressors. The skills that contribute to resilience can be useful when dealing with difficult relationships, broken appliances, work deadlines, the kids' chaotic schedules, or anything else that gets your cortisol rising. And the more you practice these skills on an everyday basis, the easier they'll be to implement when times get really tough.

In the past, it was believed that almost everybody would naturally "bounce back" after difficult circumstances, and often were left alone to process it. Now we know how important social support is in helping a person return, not just to where he or she was before the difficult event, but to an even better place.

Existing psychotherapy techniques can be helpful in this regard. Cognitivebehavioral therapy teaches people to change their patterns of thinking and behavior, which in turn affects their emotions. Similarly, acceptance and commitment therapy helps people develop mindfulness and acceptance of their circumstances, and leads to greater psychological flexibility one of the cornerstones of resilience. Self-help groups can enable people to feel connected to and supported by others who are experiencing

similar challenges—and can provide opportunities to help others.

People often think about acceptance as a passive state, a type of resignation to one's circumstances, Dr. Ehde says. "But really, acceptance is about recognizing where you are—having a realistic appraisal of your weaknesses and strengths, what some challenges might be, and using that to move forward in your life."

"There are many different ways to be resilient." Dr. Ehde adds. "There are many pathways. So, for one person, being resilient might include a lot of physical activity or supportive relationships. And for another, it might have more to do with communion with nature, or setting goals to gradually increase something important to them. So there's really no one way."

However people come by their resilience, building it pays off. "After almost 25 years of living with MS, I am at the point now where I embrace the disease to a certain extent, and know it's a huge part of me," says Rachel. "That means managing it and finding ways to do what I want to do and have the life I want while living with the disease and respecting the limitations it puts on me. By challenging myself in different ways, it helps me to be stronger while living with the disease. Swimming is a huge challenge that I set for myself because the rewards are so big. Having strong relationships with my friends and getting the support where I can are also really important factors, and they help me keep bouncing back and focusing on all the good things that I have in my life, in spite of living with a chronic illness."

In the end, the important thing is finding ways to transform adversity into opportunities—and become even stronger.

**66** A diamond is just a piece of charcoal that handled stress exceptionally well."

—Unknown



# Resources

### NATIONAL MS SOCIETY **RESOURCES**

The National MS Society has an extensive library of resources about MS, including publications about treatment options, symptom management and living well with MS.

The Society's MS Navigators® also offer assistance in answering questions about living with MS. These highly skilled professionals can help you connect to resources in your community, access optimal healthcare, meet workplace challenges, understand health insurance, plan for the future and much more. Whether you are a person living with MS, a family member or someone who cares about a person with MS, you can call an MS Navigator at 1-800-344-4867 during business hours Monday through Friday. You can also email us at contactusNMSS@nmss. org or find us on Facebook at facebook. com/NavigatorMS.

The Society also offers self-help groups throughout the country. These groups bring together people who share common life experiences for support, education and encouragement. To find a self-help group in your area, call an MS Navigator at 1-800-344-4867.

This book's companion video is available by calling 1-800-344-4867, and online at nationalMSsociety.org/videos.

The following articles and brochures, available by calling 1-800-344-4867

or found online, may prove especially helpful in learning more about resilience.

### **Everyday Matters** —

### nationalMSsociety.org/ **everydaymatters**

A program developed by the National MS Society and supported by Sanofi Genzyme, to illustrate how people facing the everyday challenges that MS can bring find the path to their best life.

### **Wellness Discussion Guide** for People with MS and their **Healthcare Providers** —

### nationalMSsociety.org/ wellnessguide

This guide is designed to ensure that people with MS and their healthcare providers have the information and materials they need to engage in effective conversations and decisionmaking about wellness and lifestyle interventions.

### **MULTIPLE SCLEROSIS SOCIETY OF CANADA RESOURCES**

The Multiple Sclerosis Society of Canada offers information and support that individuals can easily access through various self-serve and assisted-serve channels including the website or by connecting with a trained MS Navigator. Navigators are knowledgeable about research and treatment options for people with MS and are able to discuss these and other important topics. The queries they help with range from general

information to complex situations, and those they assist include people affected by multiple sclerosis, internal staff and volunteers, community groups, students, researchers, and healthcare professionals. Connect with an MS Navigator today by calling 1-844-859-6789, emailing msnavigators@mssociety.ca, or visiting mssociety.ca.

### **ADDITIONAL RESOURCES**

The following publications, organizations and websites may be able to help you find more information about building resilience.

"The Happiness Advantage" by Shawn Achor (Crown Business, 2010).

"Before Happiness" by Shawn Achor (Crown Business, 2013).

### STRENGTHS INVENTORIES

A strengths inventory may be useful in identifying your own resources that can contribute to your resilience.

### VIA classification of character strengths — viacharacter.org

Learn about the 24 character strengths that have been identified, and take a survey to determine your own top strengths so you can rely on them to become more resilient. Registration is required to take the survey.

### **Authentic Happiness** —

authentichappiness.sas.upenn.edu

An initiative of the widely researched and cited Penn State resilience program, this site offers information about resilience and happiness, as well as strengths inventories and other quizzes. The site requires registration before accessing the quizzes.

### **University of Washington MS-Self Management Program Strengths Inventory**

This brief worksheet (reproduced on page 39) helps individuals think about personality traits, beliefs, skills and other strengths they can rely on during times of difficulty.

### MINDFULNESS-BASED STRESS **REDUCTION (MBSR)**

### Center for Mindfulness —

umassmed.edu/cfm/stress-reduction/

The original MBSR program, developed by Jon Kabat-Zinn, PhD, consists of eight weeks of training (either in-person or online). Other centers nationwide also provide MBSR training.

### **UCLA Mindful Awareness Research** Center — marc.ucla.edu/

Offers free mindfulness meditation exercises online.

### Mindfulness mobile apps

Apps—both free and paid—enable you to practice mindfulness using your phone or tablet. Visit the Apple or Google Play app stores for more information.

### UNIVERSITY OF WASHINGTON MS SELF-MANAGEMENT PROGRAM **STRENGTHS INVENTORY**

Below is a worksheet that is used at the University of Washington. We've filled it in with some examples, but take time to fill it in with the responses that are true and useful in your own life.

Useful personality traits	Example: I ask lots of questions. That could help me find new ways of understanding something.
Skills I possess	Example: I'm a good communicator. When I need help with something, I'm able to ask for it.
Beliefs that give me strength	Example: I believe I am part of something larger than myself.
People in my life I can count on	Example: My brother is always willing to help me when I'm in a jam.
Resources I can access	Example: I can call the National MS Society for help with finding a therapist.

<sup>© 2016</sup> University of Washington. Worksheet is provided for personal use.



# Glossary

### **ABCD**

A model for changing one's thinking about adverse events, where A stands for adversity, B stands for beliefs, C stands for consequences and D stands for disputation.

### **Acceptance and** commitment therapy

A type of psychotherapy that helps people develop mindfulness and acceptance of their circumstances, and leads to greater psychological flexibility.

### **Amygdala**

An almond-shaped structure deep in the brain that is often considered the seat of emotions. Becomes activated during a stressful experience.

### Calm and focus

A strategy in which people learn to change the focus of their attention and quiet their emotions so they can make clear decisions.

### **Catastrophic thinking**

A thinking pattern that focuses on the worst possible outcomes in a given situation.

### Cognitive-behavioral therapy

Sometimes called CBT, this type of psychotherapy helps people change thinking patterns that are no longer helpful, which in turn helps them modify their emotions and behaviors.

### Cortisol

Sometimes known as "the stress hormone," cortisol helps the body engage in fight-or-flight scenarios. Too much of it can have negative effects on health.

### Fight or flight

The body's biochemical response to stress, which prepares it to attack or run from a physical threat, but which also occurs during other types of stress. When it occurs chronically, it can have negative effects on health.

### **Hippocampus**

A structure in the brain associated with learning, memory and emotions. Becomes activated during a stressful experience.

### **Icebergs**

Deeply held beliefs that may no longer be accurate, useful or relevant.

### **Insight**

A person's ability to recognize his or her own beliefs about the cause(s) of their adversity, and to understand how that may affect their emotions and behavior.

### Mindfulness-based stress reduction

Sometimes abbreviated as MBSR, this technique teaches mindful, nonjudgmental awareness to increase resilience.

### Modifiable factors

Lifestyle choices and habits that contribute to a person's resilience.

### **Personalizing**

A thinking pattern in which people believe they are the cause of their own misfortune.

### **Post-traumatic growth**

Positive growth in spirituality, compassion, personal strength, selfconfidence, relationships and more that occur after successfully working through difficult circumstances.

### **Self-efficacy**

The belief that one has the ability to exert influence over his or her life and succeed.

### Stable factors

The genetic and environmental contributors to a person's resilience.

### **Tunnel vision**

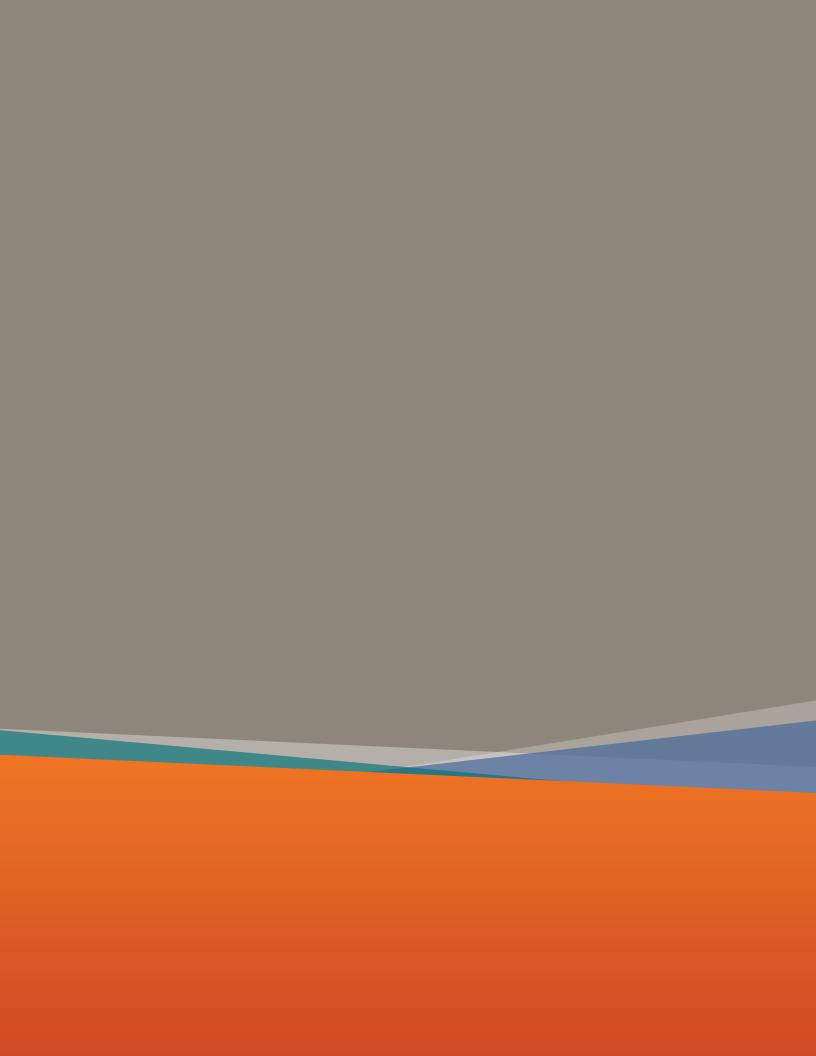
A thinking pattern that focuses on just one aspect of a situation while ignoring the rest.

### Ventromedial prefrontal cortex

A structure in the front of the brain involved with emotional control. decision making and the brain's reward system. Becomes activated during a stressful experience.

NOTES	

# **NOTES**





### National Multiple Sclerosis Society

Our mission is to help people affected by MS live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.

national**MS**society.org 1-800-344-4867

### **PUBLISHED IN PARTNERSHIP WITH:**



Our mission is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

mssociety.ca 1-800-268-7582