RESILIENCE

ADDRESSING THE CHALLENGES OF MS

DISCUSSION GUIDE AND FAQ

NORTH AMERICAN EDUCATION PROGRAM
Introduction

Welcome to the North American Education Program: Resilience: Addressing the Challenges of MS, brought to you by the National MS Society in partnership with the MS Society of Canada.

People with multiple sclerosis may find that the physical, emotional, cognitive, 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. But many people living with chronic diseases, including MS, have learned that practicing behaviors which 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.
The 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.

We are pleased to have the following doctors and researchers contribute to the program:

**George A. Bonanno, PhD**
Teachers College at Columbia University

**Dawn Ehde, PhD**
University of Washington Department of Rehabilitation Medicine

We’d also like to thank the following individuals for so graciously giving their time and sharing their stories with us: Dawnia Baynes, Chuck Curry, Lauren Hansen, Michael Ogg and Rachel and Brian Padgett.

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**Resources**

The National MS Society has an extensive library of resources about MS, including information about treatment options, symptom management, and facing the day-to-day challenges of living with this disease. For more information, contact an MS Navigator at 1-800-344-4867 or [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org), visit [nationalMSsociety.org](http://nationalMSsociety.org) and refer to the sections **Symptoms and Diagnosis** and **Living Well with MS**, or visit [MSconnection.org](http://MSconnection.org).

**Program Survey**

The National MS Society strives to provide information, resources and programs that are relevant and important to people living with MS. Your feedback, and that of your group, is vital. We want to know what is important in your lives and what you consider to be critical programming. Please complete a short online survey at
surveymonkey.com/resilience, or fill out a hard copy survey provided by your local chapter. Mail completed hard copy surveys to:

National MS Society  
Services Department  
900 S. Broadway, Suite 200  
Denver, CO 80209

Presentation Format

If you’re considering bringing in a speaker, talk to your Society staff liaison about finding or coordinating a licensed mental health counselor, social worker, wellness coach or life coach.

The 21-minute video shares personal stories of people living with MS and their accounts of resilience. Researchers explore what is known about resilience and how it can be developed.

Please provide each participant with the companion book, which goes into more detail than the video, allowing you to delve deeper into the topics. If any participant would like to watch the video again, they can request a DVD by calling 1-800-344-4867 or watch online at nationalMSsociety.org/videos.

Discussion questions are provided to help facilitate conversation with your group after watching the video. For help with any questions that may arise, please utilize the list of frequently asked questions (FAQs) in this guide. These questions are not all-inclusive. Please refer unanswered questions (or questions that are outside the scope of the presentation) to an MS Navigator at 1-800-344-4867 or contactusnmss@nmss.org, or to one’s healthcare team.

Group Discussion Questions

What is resilience?

TALKING POINTS:

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 whatever life throws at you. Resilience is the ability to maintain or regain well-being and progress toward valued goals in the face of adversity.

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.

**Do you consider yourself resilient? Why?**

**TALKING POINTS:**
Allow people to share why they think they are resilient.

**Looking back, do you think you were always resilient or this something you had to develop?**

**TALKING POINTS:**
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.

**What was the defining moment for you, where you had to draw upon your resilience or develop it?**

**TALKING POINTS:**
As in the video, people may have moments where they had to tap into that extra strength to overcome and move forward. Lauren’s divorce was one of those moments. For Rachel, it was deciding to swim Lake Washington. Chuck felt his
family’s crisis is where his resilience was really tested. For Michael, the progression of his disability has forced him to draw upon the resilience he gained while cycling. After two years of denial, Dawnia took control of her MS.

What do you think contributes to your resilience?

TALKING POINTS:

• 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

How do your supportive relationships contribute to your resilience?

TALKING POINTS:

Research shows that social support reduces depression and helps people manage stress, leading to better physical and psychological health. Supportive relationships can provide somebody to talk to. It’s important just to spend time and engage in fun, pleasurable or meaningful activities with people who you enjoy being around.
Self-help groups are one facet of your personal relationships and can be influential in building resilience in yourself and others. Mutual understanding and support can help you realize resilience in yourself you may not have been aware of. When you meet with your group members, make a point to be aware of and gently recognize the resilience you see in others. This will encourage and empower others.

How has your resilience impacted your MS?

TALKING POINTS:

Building resilience can improve the quality of life for almost anyone. Research shows that people with high levels of resilience have better long-term 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.

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. 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.

Resilience is also 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.

What do you consider obstacles to your resilience?

TALKING POINTS:

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, and social isolation (whether initiated by the person with MS, 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.
Of the resilience stories told in the video, who resonated with you the most?

What did you learn about resilience that you can apply?

TALKING POINTS:

Identifying your strengths helps you 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.

The three steps to building resilience are:

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 the 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.
Frequently Asked Questions
Related to Building Resilience

What is adaptability and how does it impact resilience?

Having mental and emotional flexibility to adjust to changing circumstances. 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 a place where you see that variability as part of living with MS, something you can manage, you will do better. Being adaptable will help you to still have “wins” despite your goals changing.

Why is the ability to change one’s perspective important?

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—they can change how they perceive and respond to them.

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

How does one go about changing their perspective or perception?

Psychologists outline the process for this 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.
What is post-traumatic growth and what role does it play in building resilience?

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.” They experience greater self-confidence, personal strength, spirituality, compassion for others and stronger relationships. They sometimes describe it not as merely “bouncing back” but “bouncing forward.”

What is self-efficacy and how does it contribute to resilience?

Self-efficacy is having the confidence in yourself that you can do what you need to do and manage what comes your way.

Why is physical wellness an important component of building resilience?

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.

How does setting realistic goals help build resilience?

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.

How can practicing gratitude contribute to resilience?

Practicing gratitude for the positive things in their lives is helpful. Many people keep a gratitude journal, listing one or more good things each day that they feel thankful for. It really helps to bring into focus that there is always something positive in life.
Why is managing your emotions important in building resilience?

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. Nurturing positive emotions, including hope, optimism and humor—and savoring them when they occur—contributes to building resilience.

Why is faith and spirituality a component of resilience for many?

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.

What is mindfulness?

Mindfulness is a state of active, open attention on the present. When you're mindful, you observe your thoughts and feelings from a distance, without judging them good or bad. Instead of letting your life pass you by, mindfulness means living in the moment and awakening to experience. Mindfulness can help shift our perspective and change our mindset. 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.

Conclusion

We sincerely hope that you and your group enjoy and find benefit from this year's program and discussion. Many people living with chronic diseases, including MS, have learned that practicing behaviors which promote resilience is the secret to not just coping with the disease, but thriving with it. It is our hope that you will continue to thrive, embrace your own resilience and the resilience of others, and apply the strategies learned in this program to create a mindset of growth and opportunities. Thank you for your active involvement in moving us closer to a world free of MS.