

MY MS

Second Act

DIGITAL
STORYTELLING
TOOLKIT



ABOUT THE PROGRAM

In partnership with Novartis and the Multiple Sclerosis Association of America (MSAA), *My MS Second Act* aims to educate the MS community about disease progression, including secondary progressive MS (SPMS).

We hope to inspire you to be vocal and vigilant about the next phase of your MS, and discover that by sharing your story you can face this “second act” with confidence, hope, and a resounding voice!

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THE POWER OF STORYTELLING

Each person living with MS has a unique story to tell.

From life before diagnosis to dealing with your changing symptoms and the uncertainty of progression, everyone's MS journey is different. Unfortunately, the unpredictability of MS can make it difficult to acknowledge health changes or talk about your journey with others. That's when storytelling can play a valuable role. According to storytelling experts,¹

- Processing experience through narrative can provide insight and action.
- Listening to stories can widen our perspective and help us realize what we have in common.
- A community is strengthened when its members share stories with one another.

HOW TO USE THIS TOOLKIT

The *My MS Second Act* toolkit is intended to provide more information on the progression of relapsing remitting MS to active SPMS, and empower you to talk about this "second act" of your journey. In this toolkit, you'll find:



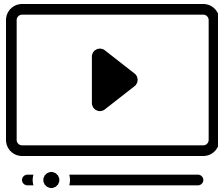
Tips and Tricks to Storytelling

This document combines useful prompts and suggestions to help you become an effective and engaging storyteller.



Testimonials

To give you inspiration, we've gathered the stories of three members of the MS community who have shared their experiences.



Video Storytelling Guide

Part of telling your story is recording it for others. We've included this guide to help coach you through the process of recording your story.



SPMS Fact Sheet

This fact sheet includes helpful information on SPMS and what it means to progress.

When you're comfortable telling your story, we encourage you to share it on the **TalkSPMS Facebook Page**—so others will be inspired to do the same. These storytelling tips can also help you feel better prepared when talking with your doctor and other health care providers (HCPs) during medical appointments.

TIPS AND TRICKS FOR STORYTELLING

STARTING FROM THE BEGINNING

So, you're ready to tell your story. Where to start? First things first, you have to create a plan.

Determine the purpose:

Think about the goal of telling your story.

Do you want to:

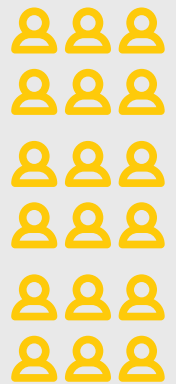
- Change an opinion?
- Have the audience relate to your experience?
- Spread awareness?
- Feel more prepared when talking with your doctor and health care team?



Determine the audience:

Once you decide who you're talking to, you can figure out how to deliver the story.

- Who are you speaking to?
- Are you sharing your story online or in writing?
- Are you creating a video or speaking in front of a crowd?

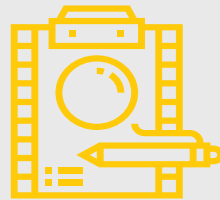


Determine the message:

Now is the time to think about what you want to share.

Keep it big picture. The time to narrow and refine comes later.

- What are the key moments?
- What do you want your audience to take away?
- What angle do you want to take?



MAPPING IT OUT

After brainstorming, it's time to craft your story. **Start by creating an outline and then fill in the blanks.** Telling a story can be difficult, so don't get discouraged or overwhelmed. It's your story, and you're in charge. Most importantly: have fun!

OUTLINE

Create an outline to help guide the flow of your story. Here are a few sample questions to get you started:

- How would you describe yourself before your diagnosis?
- How have you adjusted your day-to-day life since your diagnosis?
- Has your perspective changed over the years in regard to your MS?
- When did you start noticing symptoms?
- How did this change you?
- How did you approach progression? Were you aware of what was happening? Was it a shock or was it expected?
- How are you now? How have you had to adjust?
- What are some insights gained or takeaways from this experience? What is something you wish you knew earlier on in the process?
- Is there someone that helped you or changed your outlook?
- Do you have any words of wisdom for those early on in their journey with MS or those starting to progress?

DRAFT

Now that you've determined the direction of your narrative, it's time to create a draft. If you plan to share through a written post, write it out. If you plan on sharing by video, record yourself rehearsing.

The presentation doesn't have to be perfect, but practice is always helpful. What matters is that it comes from the heart.

REFINE

Now, set your draft aside. Come back later with a fresh outlook and fresh eyes. This will allow you to be critical and pick apart your work in a productive way.

Ask yourself:

- Are there gaps in my story? Where are they?
- Can I cut out anything?
- Is there something I'm missing or could elaborate on more?
- Am I addressing all of the points I want to address?
- Is my direction clear?

Make these adjustments and then set the draft aside again. Come back and make more changes.

Once you feel good about the story, it's time to finalize!

PUTTING THE PIECES TOGETHER

FINALIZE

Now that you are comfortable with your story, it's time to prepare the final version!

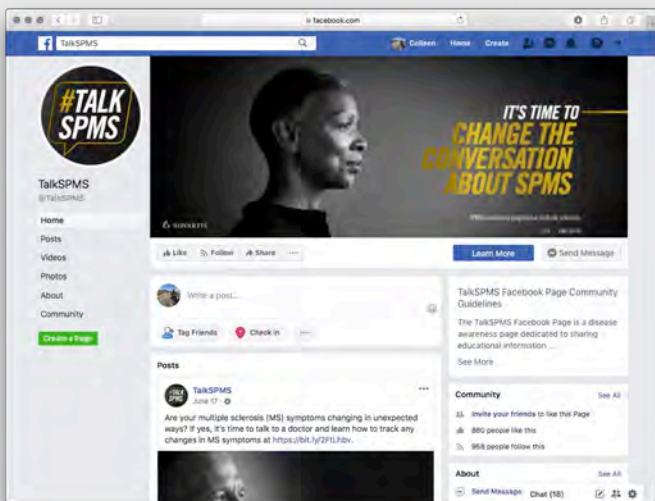
If you're recording:

- Sit in a well-lit, quiet area.
- If using a cell phone/tablet, hold the camera horizontally (landscape). If using a computer, make sure you're centered on the screen.
- Keep eye contact with the camera as much as possible and avoid looking around.
- Record as many takes as necessary until you've created a video you're proud of and that most accurately and authentically depicts your story.



SHARE

The final step: sharing your story. Show your family, friends, your doctor and other health care providers, and even share with the greater MS community at [Facebook.com/TalkSPMS](https://www.facebook.com/TalkSPMS).



We hope that by sharing your story, you feel more confident and hopeful as you face your “second act.”

For more information on SPMS visit [TalkSPMS.com](https://www.talkspms.com).

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HEAR FROM OUR STORYTELLERS

Before you tell your own story, get inspired by others who shared theirs. These three storytellers touch on life before MS, the journey to diagnosis and their experiences since progression. Whether you can relate or have experiences that are completely different, we hope you are **inspired by their strength and are encouraged to share your own story** with loved ones, your care team, and the entire MS community.



PATIENT: **Karen B.**

RRMS DIAGNOSIS: **Early 1997**

SPMS DIAGNOSIS: **Early 2013**

My story doesn't start at my formal diagnosis, but at my family's origin. In the last 25 years, all three of my sisters and I were diagnosed with MS. I've always been close with my sisters, but this adversity further solidified our bonds and fortified our built-in support network. In 1996, I experienced my first symptom—eye pain—which led to blindness in one of my eyes. In 1997, after a quick trip to an ophthalmologist and a trip to a neurologist, I was diagnosed with MS. Though it was difficult to cope with initially, my sisters' help and positive outlook kept me going.

As I started to progress, I began to experience numbness in the right side of my body and vision loss in one of my eyes. Eventually, I could no longer work. Although transitioning to an SPMS diagnosis was another big adjustment, I constantly remembered it could always be worse. It was difficult to hear the news when two of my sisters received their formal MS diagnoses in 2008 and 2019, but by helping each other, we keep moving forward and appreciate all of the good that life brings.

I always preached about the importance of a college education to my daughters, so shortly after my diagnosis I decided to take my own advice

and go back to school to earn my college degree. As a homework assignment in a political science course, we were asked to send a letter to our state representative. I decided to write about including an MS donation option on tax forms. Weeks later, I testified my case in front of the state tax committee, earning me a prestigious MS award for my activism.

"As I recall these moments, I realize I've come a long way and I should feel proud of all that I've been through, and all that I've accomplished..."

Later that year, I attended the beautiful banquet with my two daughters. Hearing how proud they were as I walked off the stage with my award was truly empowering and is a memory I will cherish forever. As I recall these moments, I realize I've come a long way and I should feel proud of all that I've been through, and all that I've accomplished.

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PATIENT: **Faith A.**

RRMS DIAGNOSIS: **Early 1999**

SPMS DIAGNOSIS: **Mid-2017**

My journey starts in the summer of 1969 at the famous music festival, Woodstock. This moment changed my idea of community forever. From that moment on, the ideals of sharing and providing for those in need were forever ingrained in me. Thirty years later, I was diagnosed with MS and inducted into an entirely new community. Although the MS community is quite different from the one of my past, my outlook remains the same.

After being diagnosed with MS, my employer of over 15 years requested a proof of my diagnosis. When this happened, I felt alone, betrayed and heartbroken. My coworkers were my community and support system and I no longer felt accepted by them. At this point, I turned to the MS community for education and support, participating in local meetings, walks, and lectures. I will never forget completing my first 5K MS walk with my daughter by my side, walker in hands, and in absolute dead last. Not one person left or packed up their things; they all stayed to cheer me on and greet me at the finish line. I realized that I found my people and I was now part of a new and caring community.

As I started to lose my mobility and require assistance to walk, I knew progression was upon me. In 2017, I received a formal SPMS diagnosis. But with the help of my community, I've been able to remain positive and take these new challenges in stride. And I try to do the same for my peers by educating them and staying hopeful, even when life can get hard.

"With the help of my community, I've been able to remain positive and take these new challenges in stride."





PATIENT: **Mike O.**

RRMS DIAGNOSIS: **September 2012**

SPMS DIAGNOSIS: **Spring 2015**

One day at work in 2007, I was meeting with a colleague and started to feel like my mind was in a bubble and I couldn't form any words. This episode was the first time I had an inkling that something might be wrong. A few months later, I couldn't drive to work without nodding off. While these cognitive episodes and extreme fatigue did not seem normal, countless doctors credited my age and stress level for these symptoms. I focused on my health and cut back at work, but my symptoms persisted, leading to an emergency room visit three days into a new job.

To the outside world, I looked fine. Once, an ER doctor even told me, "the ER is for sick people." I felt enraged. The ER was the last place I wanted to be, but I knew something was wrong. Eventually, I was diagnosed with Lyme disease. I felt relieved to finally receive a diagnosis. But pretty soon, my symptoms started to get worse and I became more and more frustrated.

Things started to change five years later. In 2012, I was at a lunch meeting when my attorney and now friend noticed something was off—he saw an eerie resemblance to something his wife experienced years ago. I started to share my medical journey. There were striking similarities between his wife's experience and my own, even down to the misdiagnosis of Lyme disease. Soon after, I was referred to an MS specialist and a few months later I finally received my official MS diagnosis. I was relieved to receive a diagnosis but, after years of misdiagnoses, I was weary. Family and friends touched by MS came out of nowhere to share their stories with me and try to connect. Despite these nice gestures, I was overwhelmed. All I could think was, "This isn't my MS."

"To be honest, I had mixed emotions. I was relieved to receive a diagnosis but, after years of misdiagnoses, I was weary."

At this point in my journey, I was already progressing. In the spring of 2015, I was officially diagnosed with SPMS and around the same time, I attended my first support group meeting. I met a diverse group of people living with MS—some in wheelchairs, some using walkers, some who experience "cog fog"—and I felt that I could not only relate to them, but actually laugh for the first time in what felt like forever.

Despite the winding journey to my MS diagnosis, I am forever grateful to my friend who listened, cared, and redirected me; for my wife who always believed in me; and for those I've met along the way and have supported me. It is because of their kindness that I believe sharing your story with friends, family, coworkers, and even just acquaintances, can change your life. There is a power in storytelling and you never know how your audience can help you or, in turn, how you can help them.

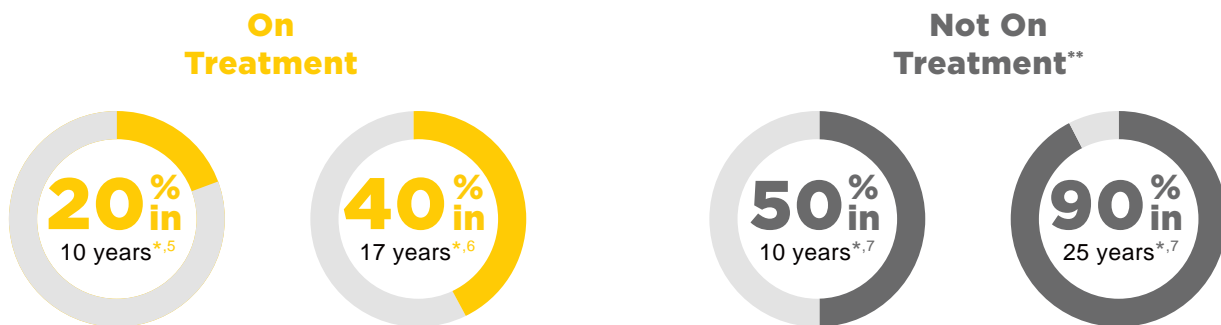
UNDERSTANDING SECONDARY PROGRESSIVE MULTIPLE SCLEROSIS

FROM RRMS TO SPMS

Multiple sclerosis (MS) is a chronic disorder of the central nervous system that disrupts the normal functioning of the brain, spinal cord, and optic nerve through inflammation and tissue loss.² MS affects approximately 2.3 million people worldwide³ and is often characterized in three forms: relapsing remitting MS (RRMS), secondary progressive MS (SPMS), and primary progressive MS (PPMS).⁴

The majority of people with RRMS who are not on treatment will eventually transition to SPMS.³ SPMS is a form of MS that leads to progressive, irreversible disability.⁴ There are two stages of SPMS: active, when a patient experiences new inflammation, including relapses, and nonactive, when a patient eventually experiences continued progression of disability independent of relapses.⁴

Following the initial RRMS course, there is a gradual increase in the percentage of patients transitioning to SPMS following the initial RRMS course:



*Approximate percentages.

**Data set from a geographically based 1984 study.

SYMPTOMS OF SPMS

Every patient who transitions from RRMS to SPMS will have a unique experience, whether active or not active, with progression or without. Following an initial period of RRMS, symptoms gradually worsen over time, with or without evidence of disease activity (relapses and focal lesions), which can be difficult to notice.⁴

CHANGES CAN INCLUDE BUT ARE NOT LIMITED TO:

- Symptoms that are worsening, new, or lingering between relapses⁸
- A need for enhanced walking aids and wheelchairs⁹
- Physical activities such as walking the dog or visiting family become harder⁸
- Bladder dysfunction⁹
- Decreasing number of active lesions on MRI scans¹⁰



As a result of these physical and other functional impairments, this stage of the disease can substantially impact the lives of patients and those around them.³ Because MS progresses over time, taking a “wait and see” approach can make it harder to manage down the road. It is important for patients to learn how to identify and get in front of progression. Caregivers can play an integral role in the daily management of SPMS and treatment, as appropriate, and recognizing these changes in symptoms.

UNMET NEED IN SPMS

Many patients and physicians do not talk about SPMS symptoms because the lack of information and diagnostic criteria makes it difficult for both patients to identify signs and symptoms of progressive MS and for physicians to diagnose. Patients with MS experiencing new or worsening symptoms should talk to their doctors about the changes they are noticing.

FOR MORE INFORMATION ON SPMS, VISIT TALKSPMS.COM

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