

Sharing your MS

With Yourself, With Others and With the World



INTRODUCTION

"Kate, what you've learned is real. Write it down and send it out."

In December, the days get shorter, so I was running in the early afternoons. The ground had begun to freeze solid for the winter and the remaining surface water was crystallizing up into crunchy towers in the loose dirt of the running trails

that skirted my town. It was on one of these runs with a longtime friend that the idea for this "report" you are reading was born. Bluntly, my friend said, "Kate, what you've learned is real. Write it down and send it out."

"People will pass it around if they want to and maybe they'll get something from it they didn't expect. Just do it." That last line made us both laugh as we were actually running and we spent the rest of our time together discussing how we'd look in a Nike commercial...

Through living with MS personally and being the founder of the storytelling platform MyCounterpane, I have had powerful observations of patients and caregivers living with MS. These have come from reading and viewing thousands of entries on our platform over the last three years, and through talking to doctors, experts, writers and caregivers about the journey of adversity that challenges all of us with



KATE & HOLLY GO FOR A RUN

a chronic illness. Over and over, I have witnessed examples of how we can help each other to meaningfully recover from the diagnosis and go on to live prosperous and kick-ass lives.

My running friend and I had a conversation 10 years earlier when I was in a very different place. We had a longstanding date on our calendars to meet for an overdue catch-up and it turned out to be 6 days after my RRMS diagnosis. On January 3, 2007, I remember getting ready to go meet her for lunch on the Upper West Side of Manhattan where we both lived at the time and my tears kept getting in the way of me picking out something—anything—to wear. This was to be one of the first times I had gone out in public with my new badge of sickness. It didn't help that it new diagnosis made the act of putting one foot in front of the other seem harder than it was just 12 hours prior. Was I imagining it getting worse already, or was it? All I knew is that I was about to tell one of my oldest friends that I had MS and I had no idea what I was going to say: I was scared and felt so small and very, very alone.



I want to believe that sharing these patterns in ways that are actionable may get more people to an empowered place sooner.

Every reader here likely has his/her own story or knows of a similar one and we "snowflakes" understand that we are unique. Yet, amazingly, on MyCounterpane, we are beginning to identify patterns in our moments that are paving a way to perspective, purpose and possibility for our users and understanding at a higher level of what the journey of MS is really about.

When we work together as a community, we help each other integrate these emotional and behavioral patterns into our everyday lives to find a productive place sooner, for longer.

We are resilient in the face of illness and I am awed daily on how our users define and find strength, courage and generosity as they move forward through the story of them.

Step 1 to the healing process is **creating a way to communicate** to oneself, to others and to the world about our MS. With this in mind, we invite you to be part of this transformative journey by reading, applying, commenting and sharing the actionable patterns presented in the following pages. Let's do it!

KATE MILLIKEN Founder, My Counterpane



PART 1: Sharing with YOURSELF

○—You are not alone

If you are a person with a direct or indirect connection to MS, you have experienced voices in your head asking questions that you have no idea how to answer: "How will I cope? Will I end up in a wheelchair? Will I die?" These questions continue with chronic symptoms: "How can I keep doing this? Is this only going to get worse?" "Who can I talk to about how I feel?"

All of these questions are hard, but for so many people it's the last question that goes the deepest. "Who can I talk to about how I feel?" This question is layered for many of us because of the very personal way that each of us "feel" in our given situations. Sharing or exploring these feelings can seem scarier than the diagnosis itself, and as a result, we hide and we feel very lonely.

You are not alone. What we have seen is loneliness can be partially explained within the more heavily-researched topic of shame. Shame is a universal human emotion and it is the pivot point upon which connection relies. Researcher Brené Brown calls our relationship with shame as "the fear of disconnection".

You are not alone. Feeling weak and victimized, with no real way to talk about it can drive someone to disconnection and it prevents us from articulating our true feelings to ourselves. It makes it hard to explain to others. Being lost in this jumble of disconnecting emotions suddenly leaves us in a lonely place, both internally and externally. Thousands of people have spoken of this very same loneliness journey with MS.

You are not alone. The MS journey is still very much an unpredictable roller coaster that bounces us between loss-related responses (grieving what you can no longer do, losing your 'old self') and restoration-oriented responses (learning new skills, different perspective and norms of your 'new self'), but it's helpful to know that you are not alone.





Over the past few decades, researchers have made a connection from emotional to biological/cellular heath. Guy Winch, a licensed psychologist, author and speaker (TED Talk Why We All Need to Practice Emotional First Aid) states, "Loneliness makes our bodies feel like they are under attack ... It can cause an immediate and severe bodily reaction, create an increase in blood pressure and cholesterol, and/or activate our physical

"[Loneliness] can cause immediate and severe bodily reaction, create an increase in blood pressure and cholesterol, and/or activate our physcial and pyschological stress responses." —Guy Winch, TED talk

and psychological stress responses." Stress to the body, as you know, or will soon come to know, is an unwelcome trigger of MS.

Another study in a recent issue of the journal *Perspectives on Psychological Science* emphasized the difference between the subjective, self-reported feeling of loneliness and the objective state of being socially isolated and found them both potentially damaging. "If we just tell people to interact with more people, that might solve the social-isolation issue, but it might not solve the loneliness issue," The author, Brigham Young University researcher Julianne Holt-Lunstad, went on to say that, "I think we need to acknowledge that both of these components are important."

Today we are grateful for the research on these correlations, as their findings serve as valuable grounding points for beginning a journey that has the potential to transform you and your MS into something we at My-Counterpane call 'meaningful recovery'.

Welcome to the ride my friend.



—Access your vulnerability

Surely many other things happened in Houston in June of 2010, but there were 20 minutes of that month where a little known "storyteller" changed the lives of millions of people. Her talk on the TEDx stage that day has been seen by more than 28 million people last we checked and Brené Brown, with her PhD in social work, is now a world-renowned speaker on the topic of vulnerability. Why do we largely see vulnerability as weakness? How can we flip that notion on its head and see vulnerability as the ultimate state of connectedness; the opposite of loneliness?

If you are not surrounded yet by people who will let you be yourself in the face of this challenge, then know that you will find a community of people on MyCounterpane who will allow and inspire you to let go of who other people thought you should be.

"[The wholehearted] had connection as a result of authenticity... They were willing to let go of who they thought they should be in order to be who they were... you have to do that for connection."

Express your vulnerability——

Since the early 1980's Dr. James Pennebaker has been on a mission to examine how chronic illness and even strong feelings of loneliness adversely affect our immune systems. By releasing those buried secrets, the body is free to turn it's focus on longterm health preservation, rather than be in the short term survival mode that these conditions tend to induce. TEDx speaker and physician Lissa Rankin, M.D. also lays out scientific data in her book called Mind over Medicine that proves that "loneliness, pessimism, depression, fear and anxiety damage the body, while intimate relationships, gratitude, meditation, sex and authentic self expression help the body to heal itself."

So start writing! Start recording! Whether you simply pick up a scrap of paper, a journal, a notebook, your phone or you log on to MyCounterpane, you will literally be highjacking your old brain and leading it on a new path towards meaningful recovery.

In an ideal Pennebaker scenario, write or record for 20 minutes a day at the same time each day for 4 days. Write whatever comes to mind, with no attention to editing, deleting or intending to share any of this with the public. This effort should capture what you are feeling deep inside. Because your mind needs to work to visualize concepts before you can capture them in thoughts, it activates a part of the brain that is not responsible for the high stress activities that have been keeping your long-term healing functions on hold. Just this act of writing or recording is a step towards meaningful recovery. Do it now and do it often. This will prepare your mind to share your MS with others as discussed in the next section.



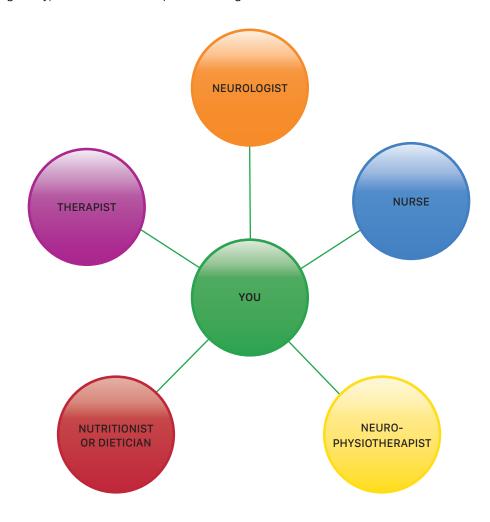
O—Build your health team

Reality TV star Jack Osbourne explains in his blog following his MS journey the troubles he had when first diagnosed with relapsing remitting multiple sclerosis (RRMS) and the questions that initially ran through his head. "When it comes to MS, people tend to have preconceived ideas and misconceptions. I sure did. When I was diagnosed, I was scared because I didn't know much about the disease. I thought, 'That's it, game over.' I assumed I'd end up in a wheelchair. I also thought MS was a disease for older people or women."

There is enormous power in talking about MS knowledgeably, and the first step is working

with a health team; those that will help make your life more manageable and can help shape your treatment.

By investing time and thoughtful conversations with any and all on your medical team, you get the facts, and an honest framework about your future. It's important to recognize that often the fear of the unknown is worse than the known and we all know through googling, our future looks bleak. It isn't! You are not MS, you have MS and framing what that means and communicating to others is the next step on the crucial path to healing.





EXERCISES: Sharing with YOURSELF

1. List the questions that you hear in your head		
2. Go to www.mycounterpane.com and search for someone JUST LIKE YOU		
3. If you are feeling shame or guilt, write about it here, privately. Writing about it is part of learning more about it so that you can manage it on your own terms—even if it never goes away.		
4. Go back to www.mycounterpane.com and moodify (publicly or privately).		
5. Track how many days you Moodify this week (and the next two weeks) using the boxes below. Fill them in with a check or a smiley face. :-)		
M T W Th F Sa Su		



PART 2: Sharing with OTHERS



Erika North, a well-known radio announcer in London, kept her MS secret even while talking about many personal stories on air.

ERIKA NORT

"I felt like damaged goods," she told the Daily Mail. "I was worried people would view me differently."

You can plan how you will share your news of your MS, but you can't plan how others react to it; we can hope to receive a reaction that is kind, nurturing and understanding, but you may get something different.

MS affects you if you've got it, but also impacts the people around you. Dr. Rosalind Kalb, VP of the National MS Society calls MS an "uninvited guest that shows up at your home, makes a mess and doesn't leave—and that means that the entire family is having to form some kind of a relationship with this uninvited guest."

The fact is, those who love you may not know how to react because most times, that diagnosis is as shocking to them as it is to you. The same voices enter their minds and they ask "Are you only going to get worse?" "Will you end up in a wheelchair?" "Will you die?"

"As you come to terms with your illness in your own head, another question begins to form, one that seems even more difficult with acceptance of your new normal: How do you tell others around you?"



○—Listen

Relaying your news does not have to be one fateful, sweaty palmed moment of proclamation—rather, it has the potential to turn into something relevant, a 2-way dialogue that transforms into a discussion that can take all parties involved to a more honest, empathetic, educated and empowered place. This starts with you not only sharing the news, but also asking questions such as:

- Do you know much about MS?
- What is your MS experience?
- What do YOU think MS is?

By steering the conversation into a question and answer-based discussion, both sides can share information, admit feelings and (most importantly) learn. The more you have this conversation the more you witness how exchanges take place and the more confidence you will build on knowing how your information will be received.

Sopranos star Jamie Lynn Siegler hid her MS for over 15 years and finally came out in 2016.

Through these discussions, keep your frustration in check when other people don't 'get it'. The moment of reveal becomes a catalyst to understanding who you are and resets the frame. This frame will serve as one of your primary tools in meaningful recovery.

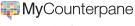
67%

of women in the workplace surveyed admitted they hid their MS from their employer

Sopranos star Jamie Lynn Siegler hid her MS for over 15 years and finally came out in 2016. "It's still a learning curve for me because I am so used to hiding it. I'm so used to not asking for help if I need it or anything like that [...] I sometimes have to remind myself 'oh, you don't need to be self-conscious anymore, everyone knows and it's okay to ask for someone's arm if you need something." I'm embracing it and I'm learning to ask for help, which is an important lesson, I think, for everyone."

Professionally speaking, the stakes often feel higher when sharing this news with colleagues and employees.

At the time Erika North (quoted earlier) was diagnosed, she was looking for her next opportunity and that pushed her farther in the closet. "I knew that if I was an employer, I would choose a healthy employee over an ill one. It is a competitive industry and I was too nervous and paranoid to admit any weakness." Even when women with MS have their jobs, they are prone to hide their illness. In 2015, the National MS Society and Working Mothers Magazine found that 67% of women surveyed in the workforce hid their MS.



Sharing your MS

MS'er Debbie Adlard made a different choice, as she wanted to set the stage in case her



DEBRA ADLARD

illness progressed to a point where she could no longer handle it. "I did some homework on my legal rights, wondering if they could they fire me or what the implications would be. I booked an appointment to meet with my boss. I was petrified about what his response would be. The day came where I explained my story and answered

all his questions. My boss was so supportive! He promised to help me in any way that he could. I felt a sense of relief wash over my whole body and wrap my heart in a warmth that I hadn't felt for way too long. I will never be able to tell him how his response affected me; how it changed my entire being."

The fact is, the American Disability Act has laws in place to protect people with disabilities and, when discussing your

illness within your job it is important to know your rights. For example, on top of it being illegal to discriminate against your disability, you are legally within your right to ask for 'accommodations' in your job which includes requesting equipment and apparatuses necessary to your position to be reasonably adapted to better suit your disability. Helpful resources for more information on the subject can be found at Americans With Disabilities Act (ADA), the Family and Medical Leave Act (FMLA), and the Health Insurance Portability and Accountability Act (HIPAA).



—Think in Seasons

There are going to be good days and bad days— as sure as there are brutal winters, delightful springs, scorching summers and vibrant autumns.

The recognition of patterns, however loose, helps us to weather the seasons we don't like by looking forward to the seasons we prefer. It is precisely that act of healthy anticipation that triggers our bodies to both stay in the present without the anxiety that accompanies unknown futures. The biological difference between running away from something, versus running towards something is dramatic. When we are not running away from winter, for example, but rather we are running towards spring, our body fuels us differently. We are no longer laden with the survival driven 'flight' and stress hormones that limit the long-term healing resources.

By believing in and striving for the new season, our body begins to make preparations for a jouney that lasts beyond tomorrow. This opens our eyes wider, relaxes the muscles in our faces and makes us feel and even appear more attractive. The compound effects of better physical, emotional and mental health brings us to a place that is well beyond surviving and into a place of thriving and all-important resilience.

Thriving is often spoken about in terms of being proactively resilient in the face of other threats. Dawn Ehde, PhD, a professor of rehabilitation medicine at the University of Washington, in a recent article in *Momentum Magazine* says, "There are various definitions of resilience

but they tend to go beyond surviving and actually thriving during times of stress."... "Resilience is the ability to not only bounce back from adversity, such as a diagnoses of MS, but also the ability to maintain a good quality of life in the face of frequent stressors that come with living with MS." It's the bouncing back that enables us to thrive.

The biological difference between running away from something versus running towards something is dramatic.

The magic of the seasons is that everyone knows when they are coming and we are all on the same journey together. Not so with MS. We can't expect people to understand our patterns, but one way to reach a better understanding is to track the emotions of our journey over time. The moodifier tracker on www.mycounterpane.com does this for you every time you post and entry. By writing your own story from the moment of diagnosis, to today you can see a pattern in what you choose to remember. By tracking your emotions in real time going forward you can begin to observe how your "seasons" play out for real.

By writing, recording and tracking your moods frequently, you more confidently recognize the your own bounce-back



patterns. Your confidence with this cycle affects your posture, your mindset and your happines. This confidence is both healthy and contagious, and your connections to the people around you will become deeper and more authentic. This is what we have seen over and over on MyCounterpane, and this activity gives our users perspective.

With perspective you learn to live with your cycles without having to fight them all of the time. With perspective we have a better chance of having enough resilience to weather the dark times.

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

Understanding the patterns and limits of these cycles, whether they be physical muscles, resilience muscles, or willpower muscles, is a step in the direction of **meaningful recovery**.

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



EXERCISES: Sharing with OTHERS

In this section we shared the idea that MS has been called an "uninvited guest in your house." In that spirit, how do you explain MS to others?

Of the people with whom you shared your MS, list those people who took it well and who did not. After each name indicate how much they know about MS, or have come to know since you shared your diagnosis with them.

Name	
1 : KNOW VERY LITTLE	- 10 : VERY FAMILIAR
1: LEARNED VERY LITTLE	- 10 : LEARNED A LOT
1: KNOW VERY LITTLE	- 10 : VERY FAMILIAR
1: LEARNED VERY LITTLE	- 10 : LEARNED A LOT
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1: KNOW VERY LITTLE	- 10 : VERY FAMILIAR
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Can you identify three moments where How are they similar? How are they different?	you "bounced back" from a dark time? ?
1	
2	
3	
1-13 based on how frequently you feel each each feel for the feel of the feel	unterpane.com. Spend a moment to rank them emotion, #1 being your most frequent emotion. or names of the people with whom you prefer to me for each, think about the barrier that is keep-
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What have you learned from that relationship that you have used with other relationships?



PART 3: Sharing with THE WORLD

"He saw a good way to look at his situation and committed to faking that perspective, hoping that his genuine self might eventually catch up... He refused, for example, to let himself believe that his life was extra difficult now, only uniquely difficult as all lives are..."

Those are the words of B.J. Miller profiled in a *New York Times* story January 8th, 2017. His story begins one early morning in 1990 when, as a sophomore at Princeton, he was electrocuted during a night of drinking. The incident led to the amputation of the bottom half of three of his four limbs. While he does not have MS, the perspective with which he lives his life (stated above), is one example of re-contextualizing suffering in a way that is applicable to how we might share our MS with the world.

At some point in each MS journey, many of us experience a spiritual-like evolution that informs how we see ourselves in the world and how we then invite the world to see us. For some this process of growth is intentional and calculated. For others, this new and

unexpected path to purpose shows up unannounced! Like MS there is no one way this happens, but many have found it helpful to look at few versions of these 'path to purpose' stories in search of a version that fits best with their own experience when the time is right. We took the liberty of naming them, too—Boomerangs, Light Switches and Windmills.

"Boomerangs" are people who take their diagnosis of MS and turn it back on MS. They return the force of MS to MS itself as they work to find a range of solutions for the community of MS'ers and their caregivers.

"Light Switches" are people who use their MS diagnosis as a wake up call to live the life they have always wanted to live. Whether they make simple or larger changes in their life, the fact that MS gave them a newfound sense of courage to change at all, becomes a blessing in disguise.

"Windmills" are people who absorb their condition in a way that moves them to live their life with contagious integrity and awe inspiring conviction. We call them Windmills for the magical way they help other people to convert their adversity to power.

In each story you will see that MS does not need to be a burden that pulls you back, or even holds you still, but rather often times it can be seen as a source of strength and inspiration. As B.J. Miller said in the quote above, each of our lives is uniquely difficult regardless of any inward or outward manifestation of illness.

We are not MS. We are people who have MS.

–Boomerang

On the day of Kate Milliken's diagnosis she flipped the camera back on herself. The fear, the tears, the questions that she had were all captured. She got hit and now she's hitting back for others. People like Kate share their MS with the world by committing their new lives with MS to one that focuses on changing the world for other people with MS. They take their MS diagnosis and flip the power of it back on MS itself. It's powerful. At times it seems heroic. To many of the people in our Boomerang stories, they simply couldn't imagine it any other way. In addition to our own Kate Milliken of MyCounterpane, there are dozens, if not hundreds of others who have turned their life focus toward helping those of us with MS to live their lives to the fullest.

Here are a few of them.



Randy Patrick, host, #Chat MS (Twitter) Randy realized talking with others helped him accept his diagnosis, so he decided to user Twitter to bring MS'ers together through a weekly Tweetchat called #ChatMS.By doing it, RANDY PATRICK he is destroying the misconceptions about MS that are out here, those

advocate for many years.

However it wasn't until she

and Heather Leffell decided

to co-host MS & Me. a radio

show which draws online listeners from over 10 different countries, that she truly

found her purpose.

Erika Lyons Richardson During her 38 years of living with MS, Erika was an MS Awareness

falsities that get in the way of healing.



ERIKA LYONS RICHARDSON

Carolyn Lloyd Palmer and Mary Pettigrew

Carolyn and Mary met in Texas where they both reside. In the face of their diagnoses, both decided to get educated about MS and find others. This morphed into MS Pals, one of the largest MS Facebook groups online with over 15,000



members. Daily, they provide information, support, a listen and a hug for others.

Gina Litwin 18 years ago, Gina came out of a wheelchair, which her doctors had told her



would never be possible. Gina focuses her efforts within MSPals, and is developing ways to introduce their members offline, through local meetings.

Heather Love Leffel In 2012, Heather saw a video made by a fellow MS'er and decided to make a video herself. That video got a powerful response which made her want to do more.

Her audience grew, and now, her story and thoughts garner thousands of views. Heather has realized she wants to help people with MS and their loved ones understand what symptoms are and what MS'ers go through in terms anyone can understand



HEATHER LOVE LEFFEL

—Light Switches

For Light Switches, sharing MS with the world does not have to mean dedicating life and work to giving back to the MS community, but rather the MS simply gives permission or incentive to transform life into something surprising and more beautiful than it was. MS'er Courtney Carver says it best, "Everything about my life has changed since my diagnosis, what I thought would be a really negative thing in my life turned out to be an enormous blessing. I became a vegetarian and gave up dairy, paid off all my debt except my mortgage, became a selfprofessed "yoga junkie," quit my job to build a business I love, and gave away a lot of material items that I no longer needed. I am happier and healthier than I was before my diagnosis, and I live more fully and embrace uncertainty and change because I can clearly see that there is often something better on the other side."

For Light Switches, MS teaches them to become a more authentic version of themselves.

David Brooks, while not a Light Switch himself, writes in his book entitled *Road to Character* about our propensity to pursue either that which builds your resumé or that which ends up in your eulogy. So many of us today are hell bent on the resumé side that it takes a significant event to realize that there may be more to life- a rock bottom of sorts. With MS, many of us feel like we've hit rock bottom.

If you identify with a Light Switch, actively listen for your path and let it play out. It will connect you more deeply to those around you whether they know of your MS or not.

Windmills -

The windmill stands strong in the wind and creates power for others. While stable on its base, its humble way of yielding to the wind gives it its power.

The NY Times story mentioned earlier profiled B.J.Miller's story and his work at Zen

Hospice Guest House. In his journey of adversity he is transforming the process of dying for other people, in part because he was able to see a part of himself die early in life. His perspective did not come without the ups and downs of which we spoke earlier, but his empowered state



BJ MILLER

of being is born out of his reflection on these cycles. Why is suffering a disruption to normalcy rather than accepted as a part of everyone's normal? He lives with his journey and not outside of it, just as a windmill works with the wind and not against it. It is through this lens that he continues to see and treat patients as he continues to imagine new possibilities for palliative care.



EXERCISES: Sharing with THE WORLD

There is no one way to define success.

1. For the next 7 days, first thing in the morning, write down and work though your own personal definition of success. Over the week it may change, or evolve... or devolve! That's ok. Capture your thoughts in the morning for 7 days. Here are some thought starters.

- "Success is about having something worth sharing" ANONYMOUS
- "A man is rich in proportion to the number of things he can afford to let alone." THOREAU
- "Success is not having to worry about money" ANONYMOUS

Day 1	
Day 2	
Day 3	
Day 4	
Day 5	
Day 6	
Day 7	



EXERCISES: Sharing with THE WORLD continued

2. How has your MS changed the way you define success to yourself? For others? For the
world?
${\tt 3.Doyouseeyourstoryinanyofthenamedunexpectedpathwaystopurposeoutlinedabove?}$
If so, which one? If not, how would you describe your unexpected path to purpose? We'd love
to hear for version 2.0 of this report. Send your suggestions to <u>SAYHELLO@MYCOUNTERPANE.COM</u>
4. Log on to www.mycounterpane.com and moodify this milestone: "Just finished 'Sharing
your MS' "



Conclusion

You may be someone living with MS who feels isolated with thoughts of a challenging future and we see you!

They say there are 400,000 people living with MS in the United States, but that formal counting study was done years ago; the number now is closer to 800,000 (2.5mm in the world), with an estimate of 200 new cases a week . In the past decade, there's been enormous progress in the field of MS conventionally and holistically- with treatments and awareness; all of it has potential to aid in fighting your fears with hope. People are there to help and support you in your ups and downs and we have thousands of examples on MyCounterpane of what that looks like. We should not be too proud to ask for help, too scared to talk about it, or reluctant to encourage questions. There is nothing to be ashamed of, but rather be proud of what you have accomplished. By communicating who you are, what you know and how you feel, you are not only helping yourself but helping others too. We look forward to continuing to help people not only feel better, but be better- together.



The information provided in this Report is for informational purposes only and is not professional medical advice, diagnosis, treatment, nor is it intended to be a substitute therefor. Always seek the advice of a physician or other qualified health provider properly licensed to practice medicine or general health care in your jurisdiction concerning any questions you may have regarding any information obtained from this Report and any medical condition you believe may be relevant to you or to someone else. Never disregard professional medical advice or delay in seeking it because of something you have read in this Report.

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