

## SAMPLE PAGES

### **DIAGNOSIS**

*Long afterwards, she was to remember that moment when her life changed its direction.*

Evelyn Anthony

Each of us has our Diagnosis Story—the pivotal moment when we were told we definitely had MS. For some of us it took years of painful tests, running from doctor to doctor, desperately trying to figure out what was wrong; these days, improved technology and the emergence of better diagnostic tools makes it possible to get a definitive answer within weeks, sometimes even days after symptoms appear.

Whether it took forever or came as sudden, startling news, finding out we have MS has a profound impact. Our initial reaction may have been shock or disbelief; we may have felt scared, angry, hopeless, overwhelmed, even relieved to finally know what was wrong.

The realities of living with MS sink in gradually, over time. But the moment of diagnosis becomes a turning point in our history.

**AFFIRMATION: I REMEMBER**

## **INSTABILITY**

*Sit, walk, or run. But don't wobble.*

We all have our “wobbly” days, days when, no matter how hard we try to stay on firm ground, any one of many balance related MS symptoms causes us to lose our footing. One leg goes numb and we're suddenly in a heap on the floor. Vertigo makes the room spin around in a dizzying and disorienting roller coaster ride. We lean more heavily on our cane; we have to steady ourselves before attempting the

handicapped accessible ramp.

And then there are the emotional tremors, the fear and anxiety that challenge our capacity to remain calm. What can we hang on to when everything seems so shaky? How do we get a grip—literally and figuratively—when life seems anything but stable?

Wobbly doesn't mean weak; it takes tremendous resolve to maintain both physical and emotional composure. We may sit in a wheelchair. We may walk with a limp, but as long as we stay true to

our inner compass we have what it takes to stay the course.

**AFFIRMATION: I AM SECURE IN MY CORE.** Zen proverb

## **KINDNESS**

*My religion is very simple— my religion is kindness.*

His Holiness the Dalai Lama

Why is it that people are more inclined to offer kindness in times of sickness and crisis? A friend we've lost touch with lands in the hospital and we go out of our way to send flowers. Personal grudges and family tensions get tabled when someone we love is in trouble.

Witnessing pain makes us more acutely aware of our own vulnerability; we can't help but think: "there but for the grace of God go I." But we needn't reserve acts of kindness for emergencies. Being kind, not only to others, but also toward ourselves, is powerfully healing. By softening our heart, we let go of harsh judgments in favor of accepting ourselves—and others—as perfectly imperfect human beings, helping one-another in a spirit of compassion.

**AFFIRMATION: KINDNESS IS CONTAGIOUS.**

## **OPTIMISM**

*There is one thing that gives radiance to everything. It is the idea of something around the corner.*

C.K. Chesterton

We read, surf the net, and talk to our doctors to find out the latest developments in MS research. We cross our fingers and our toes as we slide (or is it glide?) through the silver tube, praying for an improved, or at least, stable MRI. A billion dollars are being spent on research by the best and the brightest doctors and scientists around the world.

I know, I know. We can send a man to the Moon, so why can't we grow myelin? Yet, look how far we've come with the emergence of disease modifying drugs. Handicapped access. The very fact that I can sit at my computer at 2:30 am in Minneapolis, knowing I can call a 24 hour MS help line or sign on to a website and share MS stories with someone in Slovenia is mind-blowing, to say the least.

We don't have all the answers, but we're making strides, quantum leaps, really, in the global effort to understand and cure —yes, cure— MS.

**AFFIRMATION: I AM OPTIMISTIC ABOUT THE FUTURE.**

## **HUMOR**

*My first neurologist had a very holistic approach to the illness. No more red meat, no more salt, no more alcohol. I said, ‘What about sex?’ He said, ‘I’m seeing someone.’*

Jonathan Katz

There’s a definite case to be made for the healing properties of humor. In fact, scientific research has offered up some pretty impressive data when it comes to showing how laughter can be the best medicine, or at the very least, a serious component in the treatment of cancer, chronic

illness, and certainly some of the pain and depression experienced by people with MS.

Releasing intense emotion, whether through laughter or tears, has a profound, cleansing effect that shifts our energy, boosts both our spirit and, quite possibly, our immune system. Laughter helps put things in perspective; when Katz, jokes: “I had a spinal tap, which didn’t hurt. I had an MRI, where they put you in tube [for] 45 minutes, and I actually enjoyed the privacy” we realize again, that we aren’t alone. Being able to laugh doesn’t trivialize the tough stuff; it just makes it a little easier to deal with.

**AFFIRMATION: I WILL SHARE THESE JOKES WITH SOMEONE ELSE WHO HAS MS SO THAT WE CAN LAUGH TOGETHER.**

## **PARENTING**

*My mother was about twelve when she stopped being able to lift the teapot.*

J.K Rowling

...and only 45 when she died, which motivated her daughter, J.K.Rowling, world- famous author of the *Harry Potter* series, to become an outspoken advocate for people with MS.

It's hard being a parent living with MS. We don't want to appear vulnerable or helpless in our children's eyes. We hate having them see us suffer, we lose sleep over our ability to provide for them, we may even worry about them being embarrassed of us, wishing we were 'normal' like other parents they know.

On the bright side (yes, even this has a silver lining), our children's lives are enhanced by understanding that life isn't always easy. They become more self- reliant, and hopefully, more compassionate as they eventually come to appreciate all the love and care that goes into being

the very best parents anyone could hope for.

**AFFIRMATION: MY CHILDREN ARE RESILIENT AND ARE LEARNING VALUABLE LIFE LESSONS.**

## **SPIRIT**

*I have a strong heart; I have a strong soul.*

*I just have a little bit of trouble with my right leg,*

The late Senator, Paul Wellstone

In the short span between being diagnosed with MS and his tragic death in 2002, Senator Paul Wellstone inspired thousands of people with his calm, understated perspective, along with the passion and purpose he brought to every part of his life.

We benefit from his legacy. Whether championing the rights of people with disabilities or refusing to let MS derail his career, his indomitable spirit is a gentle reminder to focus on our strengths.

Acknowledging the ways in which we are fully functional, maybe even remarkable, keeps us going and enables us to transcend our limitations. Our bodies may not work perfectly, but they must be awfully strong to withstand the ravages of MS. Our hearts may ache, but they're beating like a metronome; our soul expands as we continue to strengthen our resolve.

**AFFIRMATION: I'M GETTING STRONGER EVERY DAY.**

## **CHOICE**

*It's choice—not chance—that determines your destiny.*

None of us would choose to have MS. But we can choose how to live with it. No matter how crooked the road, how high the bridge, how deep the holes, we always have choices. How do we choose to meet

our particular set of challenges? How do we handle the physical restrictions we're faced with? How do we greet each day without giving in to the fear that disease will win out, that tomorrow will bring more, maybe different sorts of obstacles, without allowing anger or fear or self-pity to rule?

We choose every belief, every act with utter confidence that, for better and for worse, this is what we have been given and this is what we will learn from, grow from, become stronger and better, not in spite of, but because of our MS. It's a lot to live with. But each day presents us with the opportunity to make powerful choices. Begin now:

**AFFIRMATION: I CHOOSE TO SEE MY MS AS A CHALLENGE, NOT A CURSE.**

## **SILVER LININGS**

*People who have not been in Narnia sometimes think that a thing cannot be good and terrible at the same time.*

C.S. Lewis

People with MS have an amazing capacity to see the cup as half full: Our legs are numb, but we're still ambulatory. We're in a wheelchair, but we still have our sight. Our sight is dimmed, but we've made all sorts of friends who admire our seeing eye dog.

Sometimes it's a reach. No one can constantly maintain a positive attitude. It takes enormous faith to believe there is goodness, perhaps even greatness within the not-so-great hand we've been dealt.

If today is one of those days when you're open to seeing the positives, consider the wonderful things that have come your way since being diagnosed with MS: The support you've received. The courage you've

displayed. The surprising moments when you've said to yourself: I would never be who I am today, were it not for the challenges of living with MS. If today is one of those not-so-great days, know that tomorrow is another day, another opportunity to see the silver linings.

**AFFIRMATION: I HAVE FAITH IN MY ABILITY TO SEE THE SILVER LININGS.**

## **TENACITY**

*I pulled out the old, red Encyclopedia Britannica from the 1970's, brushed off years of dust and looked under Multiple Sclerosis. It read: "A debilitating and degenerative disease resulting in paralysis."*

Kari Bertch

Imagine reading these chilling words at the tender age of 19: the abysmal prognosis would have been enough to make anyone throw in the towel. But not Kari Bertch— a lovely, resilient woman who, some twenty years later, is anticipating the birth of her first child.

I shudder at what may have happened if Kari, along with so many people who were given this stark and dismal description of MS before we knew what we know today, would have accepted a life-sentence as invalids on an inevitable downward spiral toward paralysis. Yet another example of the human spirit at its finest, refusing to give up, defying the odds, believing in ourselves instead of allowing the so-called "facts" to define who we are and what we're capable of accomplishing.

Today's definition may well become tomorrow's footnote as our understanding of MS continues to unfold.

**AFFIRMATION: MY STORY IS STILL BEING WRITTEN.**

**PATIENCE**

*Have patience with all things, but first of all with yourself.*

St. Francis of Sales

How to be patient while praying for a remission, knowing we have little, if any, control over the situation? How to be patient with symptoms that limit our ability to do the things that make us feel useful and give meaning to our lives?

Whether its meeting work deadlines, cleaning the house, playing with our children or making time for friends, living with MS forces us to constantly adjust our expectations of ourselves.

It's easy to say, "alter your expectations", but lowering the bar doesn't exactly enhance our self-image or motivate us to keep going. On the other hand, forcing ourselves to take on too much is a sure recipe for frustration and exhaustion. My personal compromise is to push myself when I'm feeling relatively well so that I'm ahead of the game if and when I'm flattened again. Then I gently remind myself:

**AFFIRMATION: I'M DOING THE BEST I CAN**

## **OPPORTUNITY**

*Life is full of obstacle illusions.*

Upon learning he has MS, a confirmed workaholic commits to spending more time with his family. A depressed, overweight woman with a sedentary secretarial job gets serious about her health. A 30- year-old mother of three fulfills her lifelong passion of becoming a painter.

Recognizing opportunities in the midst of crisis requires identifying the ways in which seeming obstacles are, indeed, openings for

transformation. One person living with MS might have the proverbial “ah hah!” experience that inspires a profound commitment to make positive strides toward personal growth; others might make smaller, but equally significant changes, like starting to exercise or improving their diet.

Living with MS can be a unique opportunity to learn and grow. Opportunities abound. But only when we are ready to identify and act on them.

**AFFIRMATION: WHAT AM I LEARNING? RESLIENCY**

## **TRANSCENDENCE**

*There is often in people to whom “the worst” has happened an almost transcendent freedom, for they have faced “the worst” and survived it.*

Carol Pearson

We see it all the time. The eerily angelic photograph of a child with leukemia in People Magazine. An inspirational speaker whose words ring with truth in describing a near brush with death. My 84 year-old father’s calm, reassuring presence, walking around with only one artery open, knowing any moment may be his last.

Likewise, many of us living with MS feel a certain sense of peacefulness and freedom as a result of continuing to survive—and thrive—despite enormous pain and adversity. New symptoms are less upsetting once we realize how capable we are of coping with them. Living with the unknown doesn’t seem quite so ominous as we learn to stay focused in the present and confident that we have what it takes to carry on. We may or may not have seen the worst—but we know who we are and we know what we’re made of, which makes all the difference in the world.

**AFFIRMATION: EVERYTHING WILL BE ALL RIGHT.**

## **WORKPLACE**

*I was beginning to appreciate how truly difficult I was making life for the people I worked with, the majority of whom didn't know about my health issues. My behavior must have seemed flaky at best....*

Michael J. Fox

In his memoir, *Lucky Man*, actor Michael J. Fox, describes the craziness he felt before going public with the news of his Parkinson's.

While most of us don't share his celebrity status, we still face the dilemma of deciding if, when, and how to disclose that we have MS. Regardless of a company's official policies, we may fear the more subtle discrimination that can accompany the stigma of having a serious, chronic disease, such as our co-workers looking at us differently. Being passed over for a promotion. Losing our job, and worse yet, our health insurance.

Being forthcoming about living with MS can be risky business or an incredible relief. Worst-case scenario, we may feel more vulnerable in the workplace; best-case scenario, we may be pleasantly surprised by the outpouring of support from our colleagues.

**AFFIRMATION: I NEEDN'T LET MS GET IN THE WAY OF MY CAREER.**

## **CALCULATED RISKS**

*Please know that I am aware of the hazards. I want to do it because I must do it.*

Amelia Earhart

In his book, *Blindsided: Lifting a Life Above Illness: A reluctant memoir*, journalist and MS patient, Richard Cohen, describes his insistence on taking subways instead of cabs and stairs instead of elevators. His wife, television personality, Meredith Vieira, says: “I hate it. I think he sometimes puts his life in danger and it worries me.”

I’d worry, too. There’s a fine line between empowering ourselves and endangering ourselves. Some risks are worth taking because they enhance our sense of mastery and independence. Others may be dangerous, self-destructive or just plain stupid! We may need to test ourselves, but we mustn’t fall into the trap of ignoring common sense to prove anything to anyone. We take responsibility for our actions, measuring the risks and taking our loved ones’ feelings into consideration. What counts is knowing that we’ve done all we can, putting it all out there without pushing ourselves to the point of diminishing returns.

**AFFIRMATION: I WILL THINK TWICE BEFORE TAKING RISKS.**

## **THE STUPID THINGS PEOPLE SAY**

*I know exactly how you feel.*

Lots of well-meaning, but terribly annoying people

What is it about these words that make us feel like screaming: “No. You don’t know how I feel. In fact, you don’t even have a clue!” Try, for example, explaining MS- related fatigue to someone who needs a good night’s rest. Or describing the constant sensation of pins and needles, feeling like you’re burning up when your temperature is normal, restless leg syndrome, vertigo, incontinence, and any number

of other physical challenges (and indignities) of living with MS, not to mention the significant economic and emotional toll it can take.

No wonder we feel enraged at the sheer presumption that anyone, regardless of his or her best intentions, can truly understand what its like to live with MS. That said, there’s no excuse for rude retorts. However clumsy, people are just trying to help. Embrace the intention. Let go of the rest.

**AFFIRMATION: IT’S NOT WORTH GETTING UPSET OVER.**

## **SUPPORT**

*There was only one thing we had in common: none of us wanted to be there.*

Xenia Rose

It's a good start! Whether it's signing up for an early diagnosis support group, attending an MS patient program, or participating in a walkathon, none of us would have eagerly signed up for membership in this particular club.

Yet doing so can be a real lifesaver. Some of us seize the opportunity to attend a support group, grateful for the empathy and information that only comes from having “been there” — a quality even the most devoted friends can't necessarily offer. On the other hand, we may be put off by the idea of spilling our guts to utter strangers, much less being burdened by their grief.

Getting involved in a support group, whether you're ready now or considering it down the line—is a personal choice with some very tangible perks: It's a great way to meet people who relate to what we're going through. It's a terrific resource for learning coping strategies direct from the front line. And, it's a way of getting perspective. As we get to know others in various stages of living with MS, we are more able to assess our own growth and healing.

**AFFIRMATION: SUPPORT IS GOOD, IN WHATEVER FORM IT COMES**

## **COGNITIVE PROBLEMS**

*You may forget your keys, misplace your wallet, drop a glass or misspell your own name—several times in a row.*

Harold Bloomfield

“I kept joking that I had early Alzheimer’s, but deep down I was really scared I was losing it,” says Jill, a recently diagnosed schoolteacher. “Fortunately, I had read about cognitive problems associated with MS; still, it was frightening to feel as if I was losing my mind.”

Memory loss, mental distraction and disorientation are cognitive issues faced by a fair share of individuals living with MS, so here are some anxiety-reducing memory aids: 1. Always keep your keys, wallet, and other valuables in the same place. 2. Make lists (phone number lists, grocery lists, to do lists) instead of relying on memory. 3. Tell someone where you put the lists in case you forget.

Most importantly, don’t panic! Focus on one thing at a time—it’s the best way to keep your head on straight enough to handle everything you’re dealing with right now.

**AFFIRMATION: THE AUTHOR HAS BEEN WRITING ALL NIGHT AND IS IN A MS MENTAL MELTDOWN, SO GO AHEAD AND MAKE UP ONE YOURSELF.**

## **COURAGE**

*The word courage derives from coeur, the French word for “heart.”*

John Welwood

I like this definition; it implies a softening of our heart rather than a hardening of will in order to survive.

It's common for people to think that courage is a matter of squaring our shoulders and pushing through our pain. In fact, vulnerability is the prerequisite to courage. Bravery in the face of adversity is measured by our willingness to transcend bravado for the far more difficult task of allowing our sadness to surface, our fears

to be exposed (and that means, you, too, all you MS alpha males out there!).

Even as we go on with our daily lives, we pray for the courage to let our hearts lead the way, to feel the full measure of what living with MS means in our lives.

**AFFIRMATION: I AM BRAVE ENOUGH TO LET MY HEART CRACK OPEN.**

## **HOPE**

*Hope is the feeling that the feeling you have isn't permanent.*

If I were to choose just one quote to put on my wall, it would likely be this one.

It suggests that hope is what ultimately gets us through even the most dreadful experiences, including serious MS relapses and/or new and escalating symptoms. It affirms that our feelings of hopelessness—and who doesn't feel hopeless once in a while?—are a normal response to living with MS. And, it reminds us that our despondency is temporary—a positive promise to hold on to when we fear that pain is our

permanent destiny.

Time and time again I've heard people with MS say: "The one thing that's kept me going is believing that I won't always feel this way." Feelings ebb and flow, changing subtly all the time. Tomorrow will be better than today-and the next day and the next. I will hold on to hope and remember that:

**AFFIRMATION: CHANGE IS THE ONLY THING WE CAN TRULY COUNT ON.**

## **VISION**

*Just because a man loses the use of his eyes doesn't mean he lacks vision.*

Stevie Wonder

Optic neuritis is a fairly common MS symptom, in many cases the first clue that something is wrong. On the positive side, the dramatic onset of vision problems tends to be relatively short lived and/or reversible. Even so, lots of people with MS experience marked deterioration in vision, yet another example of a loss that requires a choice between falling into despair and finding a way to “see” things in a different light.

Without sugarcoating, it helps to remember the distinction between sight and vision. Sight is external, vision comes from within. Sight is limited; vision knows no bounds. Having never experienced blindness, I can't imagine how difficult it must be. But I know this much: We can be blind and still have vision, the core of all creativity, the inner eye that fashions our view of the world and guides us forward in our path.

**AFFIRMATION: I HAVE INFINITE VISION.**