

# A MOTHERS REFLECTION'S ON A DAUGHTERS JOURNEY WITH MULTIPLE SCLEROSIS



Cathy O'Brien

MY Daughter JOY has Multiple Sclerosis, as a single parent I have learned how important it is to have a support system to cope with the stress that accompanies chronic disease. While the patient is at the center of this chronic illness storm their caretaker's play an equally important role when it comes to their recovery. Below are a few observations on what I've learned as a both a mother and a caretaker.



Before Joys M.S. diagnosis she was a happy, funny, energetic and independent person and while she is still that person this disease has undeniability reshaped her reality. I have watched Multiple Sclerosis rob her of any illusions she ever had of being in control of her life. We all have to deal with that reality at some time in our life but when it comes in like a tornado I think it's different, cancelling plans because you lost the ability to walk is another thing altogether. All the biggest decisions we have to make like work, love, marriage are all up in the air, now the questions are reframed into can I work? Take care of my dog? What am I capable of doing and for how long? A few years ago, while Joy was still married, she told me that she was looking into living in an assisted living facility, clearly her marriage wasn't going well but beyond that she believed the world viewed her as a burden. When I questioned her further, she said that she had lost so many friends through her disease that she stopped sharing what was going on with anyone, even me. That made me sad to hear how alone she must have felt, this has to change now I thought. From that point on I set out to learn about both her journey and her disease in order to become a part of her tribe that not only loves her but supports her along this road. I believe in the transformative energy of love and its healing abilities.

## Health Care is in a Bad Place

This is why we all need family ,friends and advocates for reality checks along the way.

Yes that's not normal and don't pay that bill.



Date of Service	Procedure	Description	Procedure Rate
01/21/22	90844-01077	SCREEN	\$15.00
01/21/22		HEMOGLOBIN	\$15.00
01/21/22		PF FOLLOW UP WITH RISK ASSESS	\$30.00
01/21/22		CAPILLARY BLOOD DRAW	\$30.00
01/21/22		EMOTIONAL TECH ASSESS	\$40.00
01/21/22		PREV VISIT EST AGE 79-79	\$350.00

Shocked patient charged \$40 'for crying' during doctor's appointment

New York Post - 14h



## MY PERSPECTIVE OF JOYS JOURNEY WITH M.S.

As you can see from the bill above health care can be a cold and impersonal place, that's especially terrible if you are sick. When I stepped into Joys world of Multiple Sclerosis and watched how it affected her, I learned a few do and don'ts quickly. Mom rule # 1 **never** let on how much panic I feel when she talks about her symptoms, I'm better at that today but still feel it. Joys also an adult with a chronic disease not a child, she doesn't normally want my opinion so I don't offer it. If she does want to know what I think I try to find a few good questions to help her see the situation in a new way. I love questions they can open our mind to new perspectives. Another reality is watching people who offered to take her to a doctor's appointment or the hospital and bailed at the last minute, I'm guessing because they don't realize how important it is. I know their not bad people just wrapped up in their own lives but I always show up, always. To feel safe, you have to have people you can really depend on. As an Irish mother another coping tool I use is humor, I have seen situations change in an instant if you can learn to laugh. Joy is really funny and my humor borders on what they call gallows humor, laughing at weird things. My final observation on Joys process with M.S. is that I've started looking at as a new language. I don't ask her specific questions about her health but in scales or degrees. For example, on a scale of 1-10 how's your walking? It seems simpler to rate progress. My perspective about Chronic Disease has changed dramatically over time, I have listened to what modern medicine and Joy's doctors say but I don't fully believe them. Their verbiage is used to inform and mitigate liability, mine is to encourage hope and optimism. I have listened to the facts and believe about half of what they say but formed the rest of my opinions from my reality. I know people who have made full recoveries, found food that heals, vitamins that supports MS health and new protocols that show promising results every day. I think our attitude is at the heart of the healing process and try to support those aspects of JOYS recovery.

## 8 TIPS OF WHAT PATIENTS NEED

#1 PRACTICAL HELP like doctor's appointments, hospital trips, picking up food, medicine or money.

#2 DEPENDABILITY I want her to trust that there's always someone you can depend on,  
Always

#4 EMOTIONAL SUPPORT is always focusing on the positive no matter what the subject. I try to focus on things that can make her future better, healing foods, strengthening exercises, art projects (food for the soul) finding the good even when that means digging, Staying away from anything that's stressful.

#5 HOPE & MOTIVATION Helping focus on a better future not worse. Miracles are always possible and brake throughs happen every day.

#6 BELIEVE I Listen to whatever she tells me about her health even if I don't understand it, chronic illness is often invisible

#7 DON'T TRY TO FIX Just support her in own knowledge that whatever she decides will be right

#8 REMEMBERING TO LAUGH sometimes it's hard to see anything funny when living with an Auto-Immune disease but its always worth the effort

JUST  
breathe

## SELF CARE FOR CAREGIVERS

Taking care of your own needs isn't just important it's a necessity as BURN OUT happens too easily on this journey. Sometimes I stop in my day and remind myself to just breathe, a deep breathe can release stress and I like easy solutions. Another key ingredient is putting myself first, if I don't, I can easily burn out, I've learned that the hard way. I found lots of things that work for me in my process, it's important if you're a caregiver to take the time to find what works for you.

## MY PERSONAL COPING SKILLS LOOKS LIKE

- **EXERCISE** walking, hiking and yoga keeps me from going down my rabbit hole
- **SPENDING TIME WITH FRIENDS** however you like to get together with friends the time spent always helps.
- **WORKING** because I love my work it helps me stay grounded
- **SPIRITUAL TIME** whatever that looks like for you is what's important, I love meditation and support groups.
- **LAUGHTER** is therapeutic for me. Disease is a serious subject and can be intense for long periods of time, watching funny movies or my favorite comedians can help me shift out of crisis mode. I need laughter like some people need air, it immediately shifts my mood.
- **SELECTIVE AMNESIA** I read an article about a person who had a concussion where they temporarily lost their memory. They were sent home to recuperate and loved being with their family even though they had no memory of them After their memory returned, they wished that in regards to their family that it hadn't. Like all of us we have history with those around us, sometimes wonderful, sometimes not so much and in this case, they discussed how nice it was to be able to be present with people without any negative awareness, just love t. I choose to live in the state of **SELECTIVE MEMORY**.
- **ALANON** When you fall off of an emotional wagon this is a great tool. I need to preface this by saying I am in another 12- step group but attend Alanon as a caregiver because I feel it's the same situation. Being with people that you want to Love who don't always behave in a loving way can present its own set of challenges. The twelve step beliefs are being written about in context of many different life circumstances now because people found that they work. Alanon helped me not to take the behavior of my daughter personally if she was behaving in a less than loving way.

**JOYTHRUMS**

### MS PATIENTS AND FAMILY MEMBERS

#### WHAT I NEED AS A MULTIPLE SCLEROSIS PATIENT

GIVE ME SPACE WHEN I PREFER TO BE ALONE,  
I'LL COME AND TALK TO YOU WHEN I'M READY

BE PATIENT WITH ME ESPECIALLY WHEN I'M  
IRRITABLE, I PROMISE IT WONT LAST LONG

AGREE ON THE PARAMETERS OF A TIME OUT  
WHEN WE BOTH NEED A MINUTE

PLEASE DONT SAY YOU UNDERSTAND  
ABOUT THINGS YOU CANNOT UNDERSTAND

DONT PITY ME

KNOW THAT I LOVE AND CARE ABOUT YOU  
EVEN IF I ACT LIKE A JERK

I WANT TO SHARE MY FEELINGS BUT AM  
AFRAID OF OVERWHELMING AND LOSING THE  
PEOPLE I LOVE

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