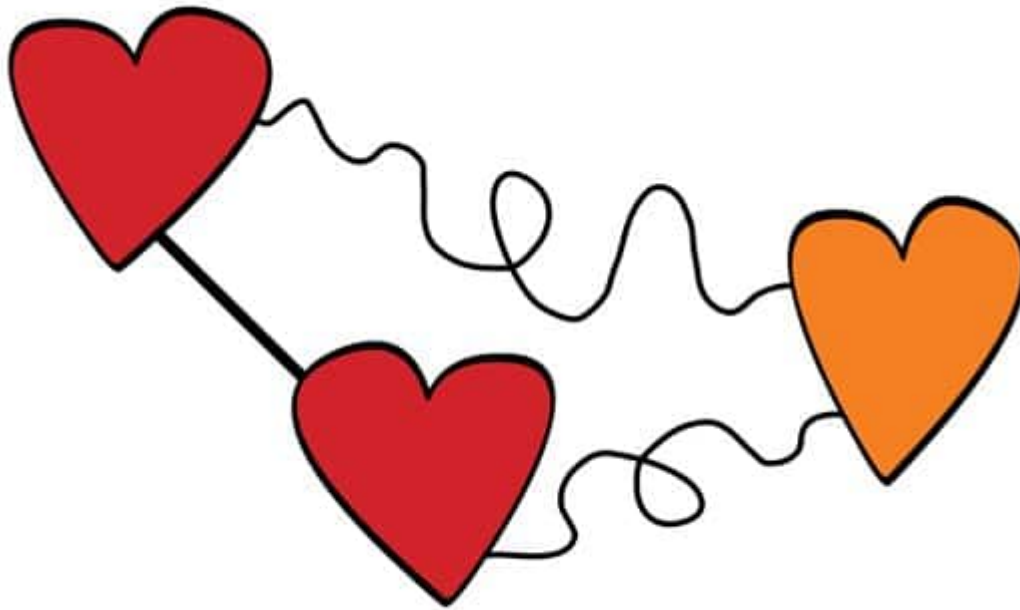


A Love Triangle: Him, Her and MS



Building a successful relationship is hard work. Throw MS into the equation, and it can be even more challenging.

We talked to Kate and Frank, married for over 10 years, to discuss how MS affects their relationship and family life.

How has MS changed you as a person?

Kate: As a carepartner, MS has made me more aware that every day is unique, and one bad day does not mean that another will follow. I can say this now, a few years into our new life as an MS family. But when we had a baby and a toddler while learning how to maneuver through a diagnosis, I felt like one bad day would last forever. I try a little harder now to not dwell on one bad day, or even one bad morning. It's also made me "try" to take better care of myself and recognize when I need a break. We've often prioritized Frank's rest, and that meant that I would shoulder most of the responsibilities of our family and home. It's taken a few years for all of us to realize that no one person can do everything and that I can only help others if I help myself sometimes first.

Frank: MS has changed me in almost every way a person can change. It has given me a new approach to life and made me recognize and value the "good times" more than I ever have because there have been plenty of more challenging times. It has also changed me physically since I've been exercising more than I ever have.

How has MS changed your marriage?

Kate: We just celebrated our ten-year wedding anniversary last summer. I don't think I fully appreciated this milestone until it came. After Frank and I began writing blogs for the National MS Society, we started to hear from people whose marriages were impacted, both positively and negatively, by MS. It was comforting, sobering and heartbreaking to hear people share stories of marriages tested by MS, but like most things in our life, I didn't dwell on the idea that MS can and does make marriage harder for some people, and that we are sometimes counted in that number. For us, MS means that we have to spend weekends apart because I'm taking the boys on a trip so Frank can rest, and that's not always easy when our time together is already limited because of our schedules. While MS has certainly made our marriage more difficult in some ways, it's made us stronger in our commitment to each other. By continually facing obstacles together for so many years, we know we can handle almost anything. We truly live our vows and make sure that we communicate as best we can, especially to tell the other when we're feeling run down by the reality of fighting MS daily.



Frank: I consider us to be lucky in that I don't think it has fundamentally changed our marriage despite the fact that it easily could have broken it down. We had a great foundation of a loving and caring relationship for over a decade prior to my diagnosis which has helped carry us through difficult times.

What are your tips for managing MS as a family?

Kate: We've only just started to find our successes as managing MS as a family, so my first tip is to be patient. There were plenty of times early in Frank's diagnosis that I thought that there would be no way that our family would live a normal life. As time passed, I learned to embrace the notion that there is no "normal" by which we had to measure our life and that we create systems that work best for us. Second, MS can and will impact everyone differently, but **EVERYONE** is impacted. While Frank is the one experiencing the most change and dealing with symptoms, treatments and flare ups, our whole family has been impacted and changed. Our two young boys were just babies (4 years old and 1 year old) when Frank was diagnosed, so they don't know much about life before MS. But now that they are growing, they see when Frank is tired, at the doctor, participating in an MS fundraising event, and they can react to all of these in any number of ways (as kids do). I try to keep in mind that they, like most adults, are

sometimes confused by what having MS means, and I try to support them if I can tell that they are struggling.

Frank: Be selfish and squad up! While family is always important, the immediate family unit becomes that much more important after a diagnosis. In our case, the two of us, our two boys and our dog are by far the most important thing. Take care of each other, learn how to say no to things and focus on that family unit. At the end of the day, that's who lives through the daily struggle so that is who you need to focus on.

What's been the biggest challenge MS has created?

Kate: For me, the biggest challenge has been trying to keep Frank's MS from impacting our boys too much. As parents, we always want to protect and support our kids and that's even harder when one parent has an energy draining illness like MS. MS is unpredictable, and kids thrive on routines and predictability, so we've had some hard times because of that. Our boys don't understand why Frank can one day play a full nine inning backyard baseball game and the next day be in bed all morning. We've tried to talk to them as much as is appropriate about the reality of having a chronically ill parent, and it sometimes resonates and sometimes doesn't.



Frank: Not knowing how I'm going to feel when I open my eyes every morning. Sometimes it's accompanied with a headache and it's always accompanied with numbness in my left leg. I have also experience more issues with depression than I have ever experienced before. Dealing with all of this while working full time, being a dad to two young children and trying to be the best spouse that I can is often times overwhelming.

Kate, what do you wish other people knew about being a carepartner?

Kate: Something I wish I knew when we first started dealing with the diagnosis was that it is, in fact, going to sometimes be hard to be a carepartner, and that its okay to feel overwhelmed, scared, frustrated and lonely. When Frank was first diagnosed, all of our energy was put towards his recovery and treatment plan, and a lot of the responsibility for supporting him, our family and our home fell to me. From being the person to help

his administer his steroids at home, to being responsible for our two boys when Frank wasn't feeling up to being around, I sometimes felt like I was supposed to do it all and be it all. Over time, and through communication with each other and people in our network, I've tried to avoid burnout as much as possible.

Frank, what advice would you give to carepartners about how to support their spouses?

Frank: Try to be as understanding as possible. MS changes everything about you and part of the struggle is finding out who you are after your diagnosis. An understanding carepartner goes a long way in helping work through that time. While we are sick, don't treat us as if we can't do anything. Not being able to do things for my family is difficult but when I see my wife doing too much because she thinks I need the rest makes me feel even worse.

Know that we're doing the best we can. Unfortunately, there are many days when our "best" is downright bad.

What advice would you give to other couples dealing with an MS diagnosis?

Kate: When Frank was first diagnosed, I remember making an effort to educate myself on the basics of the disease as much as possible. Just knowing the terms helped me feel more armed to understand the impact that was coming. For example, knowing that sometimes MS causes cognitive difficulties helped when I noticed Frank struggle with some thoughts or words during a flare up. Just knowing what to expect helped me as a carepartner and I, in turn, was able to tell him what I learned.

Even more important than learning about the disease is being an advocate for your partner and their role in dealing with the disease. Over time, Frank and I have landed on the same page of the script - we tell others what **we** need, not just what Frank needs. So, if that means that we can't go to a night out with friends or family because I'm feeling particularly drained from caretaking, he'll help convey that message so that people know that it's not just about his health, but about mine as well. Likewise, if he's having a hard time, I'll be the one to help others understand how they can help not only him, but our whole family. I know that MS impacts families and couples differently, but this team approach has helped us not only keep communicating our needs with each other, but with the people in our lives who really don't know what it's like for us each day.

Frank: Be there for each other as much as you can. As the "sick one" it's still very important for me to be there for my wife and make sure she gets breaks and time for herself. She gives me so much time that it's important that she get taken care of as well.

Editor's note: read more about Frank's story [here](#); read more about Kate's story [here](#).