



Inspiri

Unexpected

It's hard not to think about gifts this time of year. Even if you don't celebrate one of the traditional gift-giving holidays, our consumer society still barrages us with reminders of the practice in general. Not that it's a bad practice, of course. In fact, at *IG Living*, we think it deserves its own special section. But we're not focusing on material goods here. Because for many of us, the gifts we receive aren't always shiny new objects (not that there's anything wrong with that kind, either). In that vein, some gifts don't always come in packages that are easy to recognize. Oftentimes, it's through another lens altogether (such as hindsight or a new perspective) that we recognize the value of what we've been given.

For this issue, *IG Living* would like to share with you four stories from members of our community. If you're anything like us, these heartfelt gems will rival anything else you may receive this year.

ng Spirals

Gifts Received Along the Way



The Gift of Perspective

By Deena Marie

I'm running. I look up and see a big, beautiful blue sky randomly spotted with white puffy clouds. I'm moving so fast that every so often I can feel the weight of my body lift from the ground. I feel invincible. As the wind whips around me, I feel a smile slowly spreading across my face. I wake up and I gasp.

As I attempt to wipe away the deep sleep from my face, I realize that my face is wet; I've been crying. Frustrated with myself, I reach for a tissue. I swing my heavy legs to the side of my bed and fill my lungs with a slow measured breath. A breath that I will exhale as soon as I know my feet are firmly planted on the floor and that my legs will hold my weight. I carefully stand and release the breath in relief. My biggest triumph of the day and yet it's taken for granted by so many.

There are 400,000 Americans currently suffering from multiple sclerosis (MS). Statistics state that there are 200 people newly diagnosed every week and 2.5 million people

affected worldwide. These numbers are astounding to me. The unfortunate reality, though, is that there is no cure.

Scientists are making great strides and developments at a rapid rate. There is now medication to help slow disease progression, which is a development that gives us all hope. Ironically enough, "hope" is the motto of the National MS Society. If you donate and receive a bracelet, you'll see the word "hope" in big bold capital letters proudly stamped into it.

Recently, I visited an MS chat room. I was very skeptical about entering. I assumed that everyone in there would be complaining and depressed and I didn't want to further damage my already fragile emotional state. Boy, was I wrong. I was the one who ended up complaining. I complained about the fatigue, the pain, the emotional toll it has taken on my family, the numbness, and the red spots left on my body from my injectable medication. The support I received was phenomenal. It came from people all over the world.

When you're diagnosed, you learn what MS has done to your body already. You learn what else MS can ➤

potentially do to you. You learn how MS has affected the people you know who are already diagnosed. You learn what all the “book-raised” experts tell you. What you’re not prepared for is how much MS impacts every aspect of your own life. It affects not only your body and what you are physically capable of, it affects your state of mind, your career, your family, your friends, everything. The only people you can learn that from and get real advice on how to cope are the ones who are living with it right alongside of you. These people are more than just numbers, they aren’t just statistics. They’re real.

These individuals have shown me that there is no need to feel alone. There are others out there suffering. There are others out there afraid of taking their injectable medication. There are others who get red spots on their skin. The fact is: There are other people. I’ve connected with a community who truly understands me and exactly what I’m going through.

While in the chat room, as I’m complaining, I received a response that completely stopped me in my tracks. One woman’s reply to the mention of the residual red spots on my skin was “to think of them as little red spots of courage and hope—a reminder to not give up.” I was so taken aback that while sitting in front of my computer, I started to cry. Sobbing like a child and feverishly wiping at my face so that I could see well enough to type, I thanked this woman. I thanked her for giving me the determination to keep fighting.

What this woman had really given me was a gift. She gave me the gift of perspective. The cliché that “it could always be worse” is true. Every time I get a shot or see a bruise or a red spot on my body instead of crying or complaining, I smile. I smile because I realize I’m not alone. I smile because I realize that I’m not giving up. I smile because I still have the ability to dream.

My online support group has led me to some really amazing people and for that I am truly grateful. They don’t know it but I pray for each one of them every single night.

Three years later, I am still fighting and I am still dreaming of running. I’m dreaming of running down my neighborhood street, chasing my future children around my backyard; I’m dreaming of running the way I used to as a child. I may not be able to trust my legs now but I’ve promised myself that, as soon as I can, I’m not only going to walk, I’m going to run.



The Gift of Communication

Patricia Haynes, GSW

All the plant books tell us to talk to our plants, they like it and will grow for us, right? Well, my husband says I could talk ivy to death. Not only can I talk to plants, but I can talk to rocks, trees, kids, dogs, and other people just fine, thank you. But communicate? Now, that hasn’t always been so easy. Especially during the last few years—after a car accident marked the onset of multiple other symptoms that left me trudging from doctor to doctor trying to figure out what was wrong. I assure you, that was not a fun time. Not knowing how to effectively communicate with family members and doctors only exacerbated what was already a difficult situation.

Up until the accident, my life was full. I ran 24-7, and was pretty much on call for everyone (work, four boys, and my then-boyfriend, now-husband). After the accident I started to notice exhaustion, back pain, a lack of concentration and anxiety. Not just any old anxiety but a social anxiety, a fear of being around and speaking to people (even plants) I didn’t know.

I remember telling colleagues that it was all temporary and that I’d be back to “normal” in a day. Within a month of the accident, however, I was a walking zombie. Too tired to drive and too sore to sit, I also did not have the mental faculties to perform my job well. But I simply did not want to admit that I was ill, so I quit the demanding job, thinking I’ll just take an easier one. My doctor gave me several medications to cope. I started a bookkeeping job. I stayed three weeks.

Even then, I still couldn’t admit what was happening. I wasn’t ready to let go of the person I had been: a strong, capable, quick-to-learn woman who could raise kids, go to school, work two and three jobs and still cook, bake and sew. But I knew I needed to find out what was wrong with me. So I saw a new doctor. Determining that I had ruptured a disk in my back, he suggested I rest to see if it would heal. I followed the doctor’s advice and rested. My back got stiffer and stiffer.

My husband started taking off work to take me to the doctor, who continued to tell me that sleep was the best healer. I slept, my husband wondered, and my kids started to talk about mom getting fat and sloppy. Because I couldn’t acknowledge what was happening, and because I didn’t know what was wrong, I couldn’t communicate

with them. All I would say was “I don’t feel good, I’m going to sleep now.”

Finally, the doctor said that I needed an MRI. I soon learned that the disk had continued to bulge and was pressing the sciatic nerve down the left leg. After a year of being in bed, finally someone had told us part of the problem: I needed back surgery.

The surgery was not successful. Bone and metal shards still floating around in my back were rubbing the sciatic nerve and causing excruciating pain. After a second surgery, I became extremely ill. I couldn’t keep food down, and I had pneumonia twice. Unable to maintain any body heat, I couldn’t stay awake more than 20 minutes at a time, and I had mystery rashes and hives constantly. I began looking for other doctors.

This was an extremely difficult time for my husband and sons. My husband had never been ill, and my boys’ worst illness had been when the middle kids, twins, had their tonsils out in 10th grade. My behavior and problems were simply unacceptable to them. No one wanted to know what was wrong, except me. The extent of our communication made it clear that everyone in my family thought that mom was acting like her mother, “the hypochondriac.” Their general MO was to ignore me until I came to my senses.

Six doctors later, the truth came out. I had primary immune deficiency disease (PIDD), autoimmune illnesses and osteoarthritis. Though now I had answers, I still was not ready to deal with the implications of my illnesses. Because of this, neither was my family. For months, we were not able to communicate effectively. It was especially difficult for my husband. Baffled and hurt, he had many questions. He wondered how I had become so ill all of a sudden, and why any of it was happening in the first place.

During this time, I had to get used to my diagnoses. Angry, sad and distraught, I tried to bargain with God that I would stop doing anything that would cause problems (like sin). Then, one day, I saw things differently: Yeah, I have these things, now what am I going to do about them? At this point, I knew I had to become proactive about my care.

For the emotional shock of the diagnoses, as well as the constant pain, I began therapy. I also started attending

support groups, which have been informative and wonderful, as well as Internet chat groups, which are full of information one cannot get anywhere else. The people who work for this magazine have been some of the most important in my life. They not only directed me to doctors who stopped my own hysteria, but they gave me a new lease on life. Finding the right doctors to direct my care and to talk with me honestly and straight has been the biggest battle of all. Having professionals who helped lay the groundwork for me to become an active and vital part of my treatment was key.

Finally, I learned how to be good to myself. I took it easy.

I stopped punishing myself because I didn’t know how to tell myself or my family what I felt or needed. But most important, I finally learned how to do just that—to acknowledge to myself, and then communicate to my family, what I feel or need. With new tools in place, I reached out to my boys and asked for a few minutes to explain my illnesses. I also sent each one of them a letter with the illnesses listed and lightly defined. Because I continued to work on communicating with them, and gave them facts without excess emotion, they were able to really hear what was going on. Further,

they became able to help me when I asked (learning to ask, of course, was a new skill for me, too). My kids are proud that they can help out when things get rough or when my husband is out of town. My husband and I have learned to talk to one another about my conditions. A well-functioning unit, we now are able to coordinate and communicate.

I thought I was too well-educated, strong and capable to need anyone else to help me cope with my illnesses, but I wasn’t. By accepting this and reaching out to others, I have learned an enormous amount. And this has made all the difference in the quality of my life—which I now enjoy to the fullest. Not that I have been magically cured. I’m still ill, and I still experience pain. But I am happy and well-adjusted. Professionally and personally, the gift of communication has allowed me to bring my life back into balance. Best of all, I now regularly enjoy my two favorite activities. First on that list is playing with the grandkids. Second is making others laugh. Plants too, even if they don’t always get my jokes. ➤

“Professionally and personally, the gift of communication has allowed me to bring my life back into balance.”



The Gift of Independence

By Kris McFalls

As parents, we tend to give to our kids even at the expense of taking care of ourselves. Sometimes we forget about what we need to give ourselves. That can be especially true when it comes to having kids with common variable immune deficiency (CVID). I should know—I've got two of them.

Raising two kids with CVID has been both a challenge and a real blessing in my life. Although I wouldn't wish the disease on anyone, especially my own children, the special people and experiences it has brought into our lives are irreplaceable.

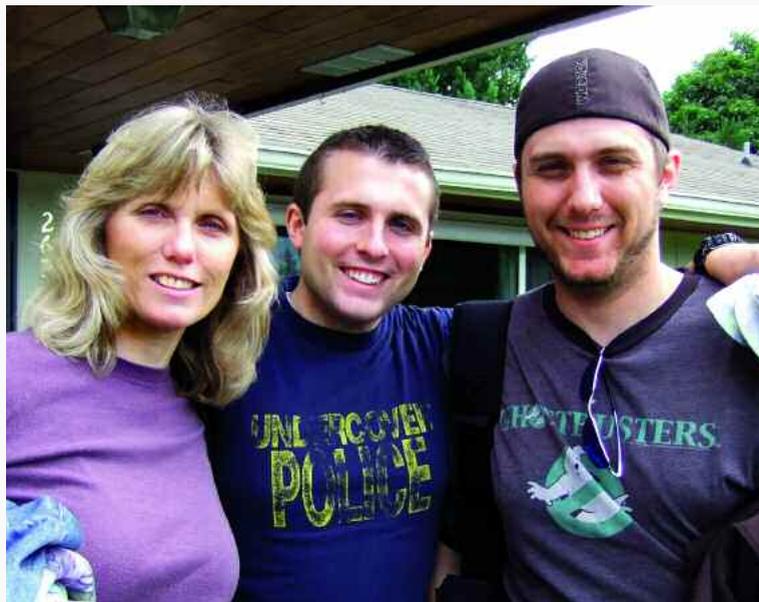
I never mourned the loss of my children's good health, to be quite frank, because they never really had it. The day of their diagnosis was more of a relief and less of a burden. I didn't at all understand what the doctor was telling me about this disease. I only heard that there was a treatment. My biggest worry at that point was the big camping trip I had planned and making sure this treatment didn't mess it up. Up until the diagnosis doctors kept telling me, he just seems sick all the time because you are a new mom. Or don't worry they will grow out of it. Well, they are 21 and 23 now and still show no signs of growing out of it. Instead, they have learned to live their lives to the fullest and not let their disease get in the way. Reaching that point, however, was a process filled with lumps, bumps and fears.

My youngest son, Keegan, required a great deal more care beyond his CVID. He had neurological impairment requiring years of speech and physical therapy. It seemed every day there was some kind of appointment for him. Konner, having only CVID, seemed so normal in my world. The challenge became making their lives feel as normal as possible, thus incorporating the disease into our lives rather than letting our lives be ruled by the disease.

Early on my kids taught me they needed control over what was happening to them and who was treating them. Keegan in Irish means "little fiery one." Aptly named, Keegan had no problems telling doctors and nurses exactly how he felt. My saving grace in the beginning was Keegan's severe speech problems; not many doctors could understand him. That was until Konner started translating. My kids taught me I needed to give them as much control as possible. That meant things like they could choose where they wanted their IV or what was on the

TV when they got their IV, but whether or not to have the IV was not a choice. To teach my kids to think of themselves as healthy, I learned never to refer to them as sick unless they had an active infection.

Thanks to Keegan's assertiveness, I even learned how to infuse both boys myself. Keegan got frustrated with the turnover of nurses and one day crossed both of his arms and told his nurse, "Nope, Mommy do it!" After overcoming the initial fear of poking my own kids, we learned to appreciate the autonomy that self-infusing brought to our lives. Our schedule no longer revolved around a nurse's schedule or business hours. We were truly fitting the IV into our lives rather than letting the IV rule our lives.



Kris McFalls with sons Keegan (left) and Konner

As the kids grew, I started to understand they were not always going to be with me and therefore they needed to learn how to care for themselves at a much younger age than most kids. In their teens, they started running the show with their doctor appointments. They kept their own lists of their medications and symptoms. The doctor would talk directly to them discussing medications and treatment plans. The doctor was their doctor, not mine, and it was their appointment, not mine. That line needed to be very clear for all involved.

When it came to chores, my kids were given no leniency. I expected them to clean their rooms just like any other parent. And just like any other teen, they ignored me.

Nonetheless my expectations for them were always high, and (aside from their rooms) they never failed to meet them. In high school both boys started making their own appointments. Thinking he had indeed grown out of his disease, Konner even made the decision to stop treatment for a while. With his doctor's approval (and under a watchful eye), Konner trialed off IVIG. After a year Konner came to appreciate the wonders of his liquid gold and never again entertained the thoughts of life without treatment.

College brought new challenges. I learned this disease was indeed my kids' disease, and they had to take it with them when they left home. Again it was Keegan who changed our path and showed us all a new direction. With memories of nurses sticking him with needles still unfaded, he announced three weeks before leaving he wanted to switch to subcutaneous infusions (SCIG). Six months later Konner made the same decision. I had adjusted to Keegan's decision but was not quite ready to adjust to Konner changing too. For me, that day meant I spent time with at least one of my sons, which I relished. I was actually enjoying IV day. I was shocked by my own feelings of loneliness and lack of control. Konner taking full control of his infusions was almost more difficult for me than the day my kids were diagnosed. All this time I had worked hard to prepare my kids to take control of their disease and live their lives to the fullest. I prepared them to be independent and to be able to care for themselves, but I had not taken the time to prepare myself. I was not ready for the life I now had. After giving my kids the gift of independence, I realized I hadn't given the same thing to myself.

After some time, though, I was able to give myself the same gift. I've learned what makes me happy, such as time with friends, church activities and multiple hobbies. By filling my life with these things, I'm able to keep smiling, move forward and appreciate the blessings life has to offer.



The Gift of Appreciation

By Jordan Scott and Amanda M. Traxler

As a shortstop, Jordan Scott, 17, likes to think ahead.

"In baseball you have to think about what you're going to do if the ball comes to you," Jordan said.

As the only child of three in his immediate family who does not have immune deficiencies—sister Julia, 20, and brother, Jonathan, 13, both have common variable immune



From top left: Jordan, Julia and Jonathan Scott with parents Jeanette and Kevin

deficiency (CVID)—such adaptability comes in handy.

"You sometimes have to be thinking about if this happens, what would I do," Jordan said.

Case in point? Unexpected hospital visits. Especially to see Julia, whose condition became apparent when she was just an infant. Often sick, Julia purportedly took her first steps in a hospital bed. Jordan's brother, who was diagnosed three years ago, still has regular doctor visits, of course, but has not been as sick comparatively.

"If they're in the hospital sick, you just can't walk in and say to them 'Oh, how's it going?'" Jordan says. "Because you know it's not going good if they're in the hospital."

Following the cue of his parents and grandparents, Jordan says he usually tried to "come to the room and maybe bring her something ... [but mostly] just hang out because nobody wants to be in the hospital, obviously, but if you have people who love you there supporting you, then at least that helps."

Not the usual middle child, Jordan knows his perspective is different from his friends'. ➤

"I've never really talked to anyone who has the same situation because normally people don't have siblings with medical problems that are serious," Jordan says. "My friends all know that my brother and sister have something, but you can't really put yourself in the situation."

As a well child, Jordan knows he's experienced situations that many won't deal with until a much later age.

"There's things I've gone through already that most people don't go through until they're a lot older, you know, as far as like loved ones being in the hospital and being extremely ill," Jordan said.

As a young boy, however, normal for Jordan meant going to the hospital—which was usually exactly where he wanted to be when his sister was sick.



From left: Jonathan, Jordan and Julia

"My sister's medical condition was a lot more serious when I was younger. It hasn't been as serious now as we've grown up," Jordan says. "She's actually gotten a little better and doesn't have to do as much. Back then ... if my sister had to go to the hospital, then I would want to go to the hospital ... because she was one of my best friends growing up, so there wasn't anything I wanted other than to be with her when she was going through stuff like that."

As he grew older, Jordan understood that not everyone spent so much time at the hospital. This is when he began to understand the gravity of the situation. With this, though,

also came the gift of appreciation.

"I definitely have come to see what's important," Jordan says. "Just seeing what my sister went through and stuff, I appreciate things, like getting to hang out with her, more than others would. Some of the things that people worry about I'm not exactly too worried about because I know there's more important things."

Not that Jordan's siblings don't know what a more-typical "normal" is like.

"Growing up, my parents tried ... to have them live a normal life, even if they have an immune deficiency."

Jordan's parents tried to make things as normal as possible for him too, which sometimes meant understanding and accommodating Jordan if ever he didn't feel up to going to the hospital.

"If there was any time that I didn't want to go to the hospital ... I would definitely tell my mom I didn't want to be here. She understood that, so she would work things out and have me go with family for a weekend so I didn't have to do it."

Along these lines, Jordan's perspective means he has some wisdom that will likely resonate in *all* families.

"Just be open with others, because if everyone is hiding their emotions and what they want to say, then everyone is going to be unhappy."

And if you think that's not bad for a 17-year-old shortstop, then just keep reading. What follows are Jordan's own words about what his brother and sister have taught him.

When I'm having a hard time, it sometimes makes me sad to know that Julia and Jonathan face the same things, but they have even more to go through with illness. I've never told them, but if I could take the pain and illness from them and let them live a normal healthy life, I would. Most of the time, I don't know what to say to them because it is so hard to imagine having to go through what they do. I love Jonathan and Julia more than anybody in the world, and seeing them hurt from an illness they have no control over hurts so much because I couldn't imagine my life without them. Knowing that they have something that can harm them and take them from me is the worst feeling ever. I know that they have both made me a better person, even though they don't know they have taught me more than anyone ever could. In so many ways, they have made me stronger than other kids. Everything I do is for them so that they can be happy and proud of me, their healthy brother. I love them. ■