



KELLY MANTOAN

BETTER

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OK

Finding Joy as a  
Special-Needs Parent



# Better Than OK

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Special-Needs Parent

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Our Sunday Visitor  
Huntington, Indiana

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# Introduction

While on our way home from vacation in the summer of 2016, my husband, Tony, and I found ourselves weaving through a strange neighborhood to find a church for Sunday Mass. The houses around us became more and more derelict, but Google Maps directed us onward.

“Is this neighborhood safe?”

“Where exactly are you taking us for Mass?”

“Will we make it before the Gospel reading?”

The litany of questions from the back seat was increasing in volume and length by the minute. I stared at the map on my phone and tried to navigate my husband through these last few turns without either of us losing our temper. Before long, the church stood in front of us, a traditional stone edifice amid a sea of crumbling homes and litter.

The neighborhood was quiet, with little traffic, so we parked our handicap van and trailer on the wrong side of the street and

Tony unloaded our sons' wheelchairs into the road. I scouted ahead for the handicap entrance, wondering if one even existed. Finally, I spotted it tucked around the side. We found a door that led to a small foyer with an old elevator. Our family of seven had to split into two trips to get to the chapel. I prayed we wouldn't make too much of a scene with our late arrival.

The door slid open and deposited us at the back of the nave where mothers chased toddlers, and ushers turned and smiled. We hadn't missed the Gospel, but there was nowhere to sit. So we stood in the back, my youngest sons parked in their wheelchairs, as out of the way as possible. We all quickly became uncomfortably aware of the fact that the air conditioning was not working.

I said a silent prayer thanking the Lord for getting us all to Mass in a mostly timely manner. I soon noticed a child lying on the rug near my feet, sucking on a pacifier, and I immediately recognized a long G-tube extension protruding from the leg hole of his onesie — which meant that he received at least some of his food through a special port in his stomach, just like my son Fulton. The boy's mother stood nearby and I smiled. We had something in common. My knee-jerk reaction as a mom to two children with a rare neuromuscular disorder, known as spinal muscular atrophy, meant that I couldn't help but consider a possible diagnosis: At the very least, his size and lack of crawling and walking probably indicated a gross motor delay.

I approached the mother at the end of Mass as she cradled him against her chest. "He's a cutie! How old is he?"

"This is Tim, and he's 18 months." She hesitated briefly before adding, "I'm Cindy. I read your blog. I don't know if you remember, but I emailed you recently about Tim once we realized he had the same diagnosis as my other son, Michael, who's sitting over there with his father."

Recognition dawned on me. I remembered her email. "Oh yes! I remember! How are your sons doing? How are *you* doing?"

Her answers were cut short by the people trying to file out of church and the pleas of Fulton and Teddy for permission to speed around the sanctuary, until she mentioned free doughnuts and coffee in the basement — just the incentive my family needed to stick around.

Having descended to the basement, my husband avoided making small talk by busying himself with the kids, who were trying to pilfer as many free doughnuts as possible. I quickly returned to my conversation with the young mother. Ever the extrovert, fueled on by a hot cup of coffee, I asked about the parish and the town. I talked about the family trip that had brought us to this part of the Midwest, and the grueling drive that still lay ahead. I tried to throw in some supportive words and advice, but I found it difficult to weave them into casual conversation. I don't recall saying anything particularly earth-shattering, though I understood and sympathized with the struggle this young woman and her family were facing.

When I noticed the big kids were looking for thirds, and Fulton and Teddy were starting to race faster and faster through the small, crowded church hall, Tony and I shared a glance and I knew it was time to go.

Once we arrived at home, and I got a good night's sleep under my belt, I jumped online and discovered a new email from Cindy nestled under our previous email exchange, which I'd saved to a special folder reserved for messages from blog readers, many of whom are struggling with a child's severe medical diagnosis. Cindy wrote, "My husband was so thankful to see your boys at Mass. Our four-year-old hasn't been doing very well and my husband has been having a hard time watching him decline. He commented that after seeing your boys in their chairs he feels more at peace and confident that Michael would be just fine in a wheelchair. Thank you for that!"

Her email gave me peace of mind because I had been wor-

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ried about saying just the right thing. Although I try to be the model mom of kids with special needs and be on *my* best Mass behavior, no matter how loud or rowdy the boys may be in their chairs, that wasn't what this woman, or her husband, needed that day. They needed to see that the worst fears we have for our children aren't always as bad as we imagine them to be. Two happy boys in wheelchairs gave them just a bit more hope than they had before.

You just never know how God will use your words, your actions, your example, or just your family's presence to change or comfort hearts and minds.

When I first started sharing my struggles and joys online, I didn't know God was going to do anything with my blog. I thought I was documenting my growing family's days before they slipped by and I'd forgotten all the stories and laughter. I didn't know I was growing in grace and gaining experience that would change my heart and prepare me to help others.

In both instances, God had a plan far beyond mine. He used my words, even the misspelled ones stuck together with poor grammar, to reach people around the world. When the emails started arriving in my inbox, I thought the first couple were a fluke. Surely these people had more reliable sources for information and support than me! I'm just a mommy blogger with a disastrous kitchen and piles of laundry, who still couldn't reliably order medical supplies on schedule. Nevertheless, emails kept coming, and I realized that many times I was the only sliver of hope these people could find in the darkness of their child's diagnosis.

The realization of how God was using my blog was both humbling and scary. Every time I started typing out a reply, I said a prayer to the Holy Spirit to help me to respond with just the right words.

Most of my exchanges with parents only extend to a few

brief emails before I file the conversation in my email folder. I rarely meet them or learn whether or not the struggle has lessened, whether something I wrote helped them or offended them.

I can only speak to my experiences and how being a mom to children with special needs has changed me in ways I never anticipated. I thought I would be unhappy, tired, and filled with worry forever. I thought my sons would also be sad and focused on all the things they couldn't do. I expected my older children to be upset that their younger brothers were disabled, and jealous of all the time I spent with them.

But I was wrong. And I want all the parents who reach out to me, and those who pick up this book, to know that your future, and your child's, is only a dark and scary place if you let it become one. You can move past the initial stages of grief that are common after a special-needs diagnosis and arrive at acceptance and renewed faith. I've come to see there's no such thing as a perfect child, except in that every child is perfect just as they've been created. I learned my love is not limited by a diagnosis, and neither is my sons'.

As you read my story, you'll probably see great similarities to your own, regardless of your child's diagnosis. And hopefully you'll see that, just as I came through the dark valley after my sons' diagnoses, you can too. I'm not special or a saint. Accepting your child's diagnosis and finding renewed hope, gratitude, fortitude, perseverance, humility, charity, understanding, and prudence — and, ultimately, joy — amid all the challenges is possible for anyone. My story is unique, but my outcome is not. I am a stronger, more humble, sacrificial, and faith-filled person than I was before I started this journey. These have not always been easy lessons to learn, and many remain works in progress, but I hope that by sharing them, those of you feeling overwhelmed in similar situations may find guidance and encouragement. Overcoming grief and growing in these graces does not happen



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overnight. But give God space to work in your heart, and in time you will see how he has helped you arrive at a better, more joyful place than you are now.

# 1

## Learning from Our Children's Example

### *The Grace of Acceptance*

When our fourth child was diagnosed with a rare neuromuscular disorder, my husband and I grieved the loss of the perfect life we'd envisioned for our family, and more specifically for our son. We had to learn to see our son as God saw him, and ultimately how our three other children viewed him as well.

That learning curve was not easy, but it was predictable. Most parents of children with special needs will likely go through identifiable stages following a special-needs diagnosis. My aim is to help you work through those stages, to overcome them through acceptance and childlike faith.

A special-needs diagnosis is not a literal death, but in hindsight I can see how I worked through, in true textbook fashion, all the stages of grief: shock, denial, anger, bargaining, and depression, with acceptance coming along at the end, when I was finally ready for it.

Years passed before I reached a place in my thoughts and in my heart where I could rejoice in my family and blog about the joys of family life, let alone extend those thoughts to give hope and encouragement to other parents in my position. The bottom line is that bad things happen to our children, but we don't need to stay trapped in sadness, anger, and despair. God wants more for us and for our children.

The Bible tells us that God doesn't call the qualified; he qualifies the called (see 1 Cor 1:27–29). Those of us called to parent special children with unique gifts and challenges can rise to meet these challenges in several ways, but I've found that by opening myself to God's grace, I've become the parent my boys needed much faster than through my earlier, unsuccessful efforts — which consisted primarily of complaining to God. I initially refused to accept the possibility that this life, as hard as it could be, might actually be wonderful. Rather than feeling that God's will had been forced upon my child and our family, I can now see how life's circumstances have strengthened me to be the woman God needs me to be to do his work.

We can do hard things. We can plod through them joylessly, or we can embrace whatever life has in store for us and allow it to grow our hearts and minds, and our relationship with God and those in our family and community. Being physically fit and healthy requires constant hard work. Being well-educated, or moving up the corporate ladder, requires hard work. Maintaining a clean home with happy kids requires hard work. Special-needs parenting is *hard*. Being an advocate, caregiver, and medical expert on top of everything else you do is extremely

hard. But you can do it. And you don't need to do it alone. You can move past grief in all its forms and open yourself up to God's grace and all the ways he will help you carry his yoke.

What follows is the longest chapter in the book because it covers all the stages you are likely to experience, or are going through right now. Some will last longer than others, and some will overlap. It's not uncommon to think you've moved past a stage only to find yourself feeling a certain way again. I have broken up the chapter by providing tips at the end of each section that will help you navigate through each stage. Your goal should not be to skip any of these stages or avoid the grieving process altogether, but to recognize each one, admit your feelings, allow yourself to feel that way, understand why your child's diagnosis has triggered this feeling, and move forward in the healing and acceptance process, rather than allowing yourself to sit and wallow in any one stage. Learning about grief, and all its manifestations, is an important first step in moving forward with joy.

### **Stage One: Shock**

For months we had convinced ourselves that Fulton's gross motor delays were nothing to worry about — nothing a little more tummy time and less spoiling by his adoring family couldn't fix. It wasn't until an informal evaluation by a friendly neighbor that we realized more was going on.

I sat laughing, wine glass in hand, trying to enjoy another laid-back homeschool moms social hosted by my good friend Julie. Fulton, my seven-month-old son, lay on the floor smiling, playing with the toys in his hands and enjoying his role as the center of attention. A new mom showed up late and introduced herself to me. I motioned to my son on the floor and she inquired about his age.

"He's seven months."

"Wow, he's really happy just laying around for a seven-

month-old!”

I forced a smile. “Yes, he’s showing some motor delays. That’s why I brought him. Julie’s neighbor is a physical therapist, and he agreed to meet with me tonight and give him a quick look over.”

I convinced myself it was nothing. Perhaps he just needed some physical therapy. I had three healthy children. There were no diseases on any branch of the family tree. Meeting with Julie’s friend was just to reassure Tony and me that it was no big deal. When Dan arrived, I carried Fulton into the living room where Dan looked him over seriously. I kept waiting for the reassuring words.

“He has a lot of head lag. See how floppy his head is? And if I lower him to the floor like this, you’ll notice he has no protective reflexes.”

“What does that mean?”

“He should try to put his arms up to protect his face, but he doesn’t.” I watched as he quickly lowered Fulton to the floor face down and Fulton looked distressed, but didn’t move his arms, or even lift his head away.

“We did notice his legs seem weak; he doesn’t crawl or try to stand.”

“He has muscle weakness all over, not just in his legs.” He showed me where Fulton displayed stiffness and limited range of motion in his shoulders from lack of use. Finally, Dan looked up from my son and met my gaze. “You need to take him to a neurologist immediately.”

I hesitated because I knew that would require a visit to the pediatrician for a referral. At Fulton’s six-month well visit, the nurse practitioner who examined him noted his delays, but blamed me for not interacting with him enough. I tried to juggle my three older children, ages five, four, and two, in the exam room with exaggerated patience as she chastised me for ignoring my baby. Clearly I was in over my head with my large brood and

could not provide enough of the tummy time, stimulation, and one-on-one interaction my baby needed. At the time, I simply brushed her off and made a mental note to never schedule an appointment with her again. Now I wondered if I would be able to convince a different doctor in the practice that Fulton really did need to see a specialist, based on this informal physical therapy evaluation.

I called to make a new appointment and told the scheduler our concerns. Within a few days, Fulton and I went by ourselves and saw a different doctor in the practice. Not only was this doctor alarmed at the delays, he immediately knew it wasn't a parenting issue. He pointed out in greater detail what he was concerned about, including the fact that Fulton had no reflexes. Repeated hammer hits to his knee were met with grumpy stares by my baby. I was stunned. How did no one pick up on this before? How could I have been so blind as to how far behind my son was in his physical development? I got my specialist appointment at the Children's Hospital of Philadelphia in no time. I tried to ignore the fact that everyone seemed so concerned and these appointments kept immediately opening up. Dr. Google was not helping either. Searches turned up scary things I'd heard of like muscular dystrophy and spina bifida, and scary things I'd never heard of and could hardly pronounce, like spinal muscular atrophy and mitochondrial diseases. I found myself hoping for spina bifida. It seemed the least threatening of the bunch. But I also held on to the belief that it would ultimately be nothing, or something that, with a little work, Fulton would outgrow.

Finally, my father-in-law drove Fulton and me downtown to the Children's Hospital of Philadelphia for our neuromuscular appointment. I tried to avoid looking at the other waiting patients, some with a physical disability. I worked to convince myself that we'd never need to return here like these families. Fulton and I were whisked back promptly to our appointment

and I described the symptoms to the intake nurse, then doctor. After only a quick examination, and much to my surprise, they wanted to admit him to the hospital for testing. At every turn, we kept waiting for the news that it wasn't a big deal, yet we kept moving in the opposite direction.

As I retold all the details of the first year of his life over and over during that first overnight stay, I wondered if I'd been overlooking too much. I started to question my ability as a mother. Shouldn't I have known sooner to bring him to a specialist? As each new medical professional entered the room, none would reassure me that it was nothing. All I wanted was for one doctor to tell me not to worry, or smile and say everything would turn out fine, but those words never came. Fulton's symptoms were confusing and tough to pin on one specific condition. Once they determined he wasn't in immediate danger, he was discharged with testing to continue on an outpatient basis. When the muscle ultrasound seemed to rule out muscular dystrophy, they told me they would test him for spinal muscular atrophy (SMA), just to rule it out, and call me with results in a week. The neuromuscular resident smiled and added that the doctor who specialized in SMA didn't think it was SMA because Fulton didn't exhibit certain symptoms. I was relieved we could check that off the list.

But a week later, when the results came in, we were given the shock of our lives when a medical fellow told me over the phone that the genetic test done to rule out SMA actually confirmed my son's diagnosis.

Two days later, my husband and I were back at the hospital with the doctor who originally didn't think our son presented the symptoms of SMA, now telling us Fulton had a disease that was like "Lou Gehrig's disease for children." I could barely follow the doctor's endless stream of medical jargon about genetics and proteins before he suggested joining a drug trial at Johns Hopkins Hospital in Baltimore, Maryland. My head was spin-

ning. Fulton laid on the table and happily allowed himself to be prodded for the millionth time since we had started trying to get answers four months prior. We were only a couple of weeks away from his first birthday, and instead of preparing for a big party, my husband and I prepared to accept a diagnosis that killed 60 percent of children diagnosed before their third birthday.

We finally had answers, but they were much worse than anything we could have imagined. Children with SMA fall into four types — with type 1 the most common and most severe, usually diagnosed shortly after birth, up to type 4, which is rare and appears in adulthood. Fulton was considered a strong type 1 or weak type 2. He didn't require any respiratory support and could eat all his food orally. Although he couldn't move like a typical eleven-month-old, he could sit with assistance, roll from side to side, and thankfully SMA couldn't and wouldn't steal his joyful, carefree attitude. But children with SMA become weaker over time, gradually losing all voluntary muscle movement until they require complete support to breathe, communicate, move, and eat. Respiratory infections are dangerous for kids with SMA because all-over muscle weakness makes it difficult to clear their lungs and airways, making pneumonia a constant threat during the winter. A weak swallow can also lead to the accidental aspiration of fluid or food into the lungs and pneumonia. Scoliosis, or curvature of the spine, is common, and often treated with surgery. There is no way to predict how fast the disease will rob a child of his physical abilities.

Fulton would be completely dependent on other people to care for him his entire life. There were no cures, and only a few treatment options that showed inconsistent results. He would need continual physical and occupational therapy to keep what abilities he did have, and to prevent stiffness. Fulton would require a power wheelchair, and a van and home to accommodate it. His second-floor bedroom, in the home we'd purchased less



than a year prior, wouldn't do.

Overnight, our lives changed. It was as if we'd won the absolute worst lottery ever. We couldn't believe our son was the one in six thousand children diagnosed with SMA. The vastness of this prize was so large and overwhelming we couldn't comprehend all the ways in which it would change our lives. Neither of us knew anyone who was physically disabled, save for some distant or elderly relatives. We weren't close with anyone who was parenting a child with a major medical condition. My experience with special-needs children was limited to babysitting a child with Down syndrome when I was twelve.

I cried in those first few days after the diagnosis, even though I struggled to wrap my head around what we were facing. The diagnosis so completely surprised us and came out of left field that we were dazed and confused. If I happened to take my mind off the diagnosis for a while, when it entered my mind again, it was almost like a fresh slap to the face.

As I relayed the message to friends and family, I became familiar with the look of horror and pain that would quickly spread across their faces. Since we started trying to get to the bottom of Fulton's motor delays, I'd updated people through social media, and each time people responded with prayers and encouraging words. So when I had to share the worst possible news, everyone was shocked. My father was even outraged, suspecting that the hospital had messed up the genetic test and wondering out loud if we should get it retaken. Everyone, Tony and myself included, had worked hard to convince themselves that everything would be fine, so hard that, faced with the opposite, they were left speechless. Some, like my father, even still tried to convince me that it was a mistake, that doctors didn't know everything, and that Fulton might be just fine. It was hard to insist that he wouldn't be fine and the test was correct; Fulton had a devastating medical condition with no cure. I struggled to get the words

out of my mouth. I needed people to believe what I was saying and console me because I was still in shock and struggling to believe the words myself.

If your child's diagnosis blindsided you, know that a special-needs diagnosis is not on the radar for anyone. Whether it's diagnosed in utero or after birth, there is no anticipating its arrival. Three typical children did not protect me from becoming a special-needs parent. And even when I meditated on parenting and envisioned what I could handle, the most I could imagine was a child with a learning disability or maybe Down syndrome. Thinking about those first few days post-diagnosis will always stir up emotions, and the anniversary of that phone call is etched in my mind. I will never forget that difficult time and those first feelings of disbelief, no matter how many years pass.

### **What You Can Do: Handling the Shock**

Understand that this stage will move quickly, and overlap with the next stages. Don't bottle up any emotions that may rise to the surface as you grapple with the news. You may feel numb for a while, travel through the days in a haze, and not remember one hour from the next. Whatever emotions do rise to the surface in the early days, consider writing them down in a private journal, finding a close friend or mental health counselor you can speak to who knows to simply listen, or find a safe place to release your tears, screams, or any physical manifestations (I used to punch my bed, or ugly cry into my pillow).

Your shock is unique, but the news of your child's diagnosis will resonate much farther than just your immediate family. If you are still in shock, you do not need to break the news personally to every single person, and you can request privacy as you deal with the information. It is not your responsibility to help everyone else process their own shock. When someone suddenly dies, it's customary for an employer to give an employee sev-

eral days off; you, as a parent, are entitled to take time off too. Do not feel bad stepping aside from work or outside commitments for the first few days post-diagnosis. Designate a trusted friend or family member to let people know about your child's diagnosis, or post on social media for you. Limit your intake of information; gather what resources are given to you by doctors, specialists, case managers, etc., but you don't need to read and understand it all at this point. Set all that aside for later.

Imagine the shock felt by Mary as she met her son on the way to Calvary. Here was her only son, almost unrecognizable from the treatment he endured at the hands of his captors. And imagine the shock felt by the women who went to visit Jesus in the tomb, only to find the stone rolled away and the tomb empty. Those closest to Christ have suffered some of the greatest losses. We can turn to the first followers of Our Lord and ask for their prayers as we deal with this unbelievable diagnosis just given to our child. After the shock of the crucifixion and the empty tomb, the apostles enjoyed the Lord's resurrection and ascension, but this did not mean they were spared suffering. They went forth and did the work laid before them with all the graces we'll cover in this book.

Know that the shock you feel now will pass, and while it may seem hard to believe, you can be strengthened by God's grace for the path ahead. This is the beginning, and it is in many ways the hardest part, but it is a temporary season. Know that while things may get harder before they get better, the big picture is much brighter than what you can imagine right now.

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## KEY TAKEAWAYS

- The stage of shock will pass quickly.
- Designate a friend or family member to share the diagnosis with others, if telling people yourself is

too difficult.

- Take time off work, or step away from outside responsibilities, for at least a few days post-diagnosis.
- Save all the information given to you by doctors and specialists, but save it to read at a future time when you can give it the attention it deserves.

### **Prayer to Our Lady of Sorrows**

Our Mother of Sorrows, with strength from above you stood by the cross, sharing in the sufferings of Jesus, and with tender care you bore him in your arms, mourning and weeping.

We praise you for your faith, which accepted the life God planned for you. We praise you for your hope, which trusted that God would do great things in you. We praise you for your love in bearing with Jesus the sorrows of his passion.

Holy Mary, may we follow your example, and stand by all your children who need comfort and love.

Mother of God, stand by us in our trials and care for us in our many needs. Pray for us now and at the hour of our death. Amen.\*

### **Stage Two: Denial**

Once we had the diagnosis, I went back to the pediatrician for Fulton's one-year-old well visit. I scheduled the appointment with the same doctor who had sent us to the specialist. He had been sent the copy of the genetic test, and so in examining Fulton we both knew why he wasn't able to do what most one-year-olds could do. I filled him in on all the appointments in the works, and toward the end of the appointment he handed me a slip of paper.

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\*<https://www.catholic.org/prayers/prayer.php?p=2456>.

“This is a mom I know with a child who had SMA. He’s passed away, but she might still be a resource for you.”

Soon after at church, a friend approached me and said she knew someone whose daughter had SMA, but she hesitated to give me the name since this mother had left the Faith and she and her husband had divorced due to her daughter’s health and related caregiving. The daughter required a feeding tube, a ventilator, and couldn’t do anything independently. My friend wasn’t sure if I’d want to talk to this mom, but she could get me her info if I was interested.

When our parish priest talked to us, he expressed his sorrow and said he didn’t realize SMA was even a possibility for Fulton. The only time he’d heard of SMA was when another parishioner’s grandson died within a few months of his birth from the disease.

And so it continued for the first few months after Fulton’s diagnosis. Most people had never heard of SMA, but those who did often only knew of a child who had died, or was much more severely affected. I started to dread telling acquaintances because no one seemed to offer anything but sad stories.

In a couple of weeks, when we started receiving a magazine from a large SMA charity, I quickly threw it away to avoid looking at the large memorial section that documented dozens of kids each month who had died from the disease. Talking to other SMA families terrified me because I would be forced to confront all the worst parts of the disease. I felt like I already knew too much and couldn’t handle any more bad news they might have to share.

The same SMA charity held a conference every year, and newly diagnosed families could attend for free. As I looked at the upcoming announcements and photos on the magazine cover, I balked. How could I explain to Fulton’s siblings that the children pictured within — on ventilators and pushed in strollers laden

with medical tubing and supplies — could someday be their brother? How could I bear to look at pictures of children, teenagers, and adults whose bodies were curved from scoliosis and dependent on machinery to move, breathe, and eat, and know that was the future in store for my child? I couldn't. I couldn't deny that something was wrong with my son, but I could deny that it would change our family now, or down the road. Those children were not my son, even though the genetic results said otherwise. He would never look like that, and I would never be one of those parents pictured with a smile on their face, at a conference full of other parents, happy to spread awareness and talk SMA nonstop.

When Fulton was accepted into a drug trial at Johns Hopkins in Baltimore, I met my first representative from the Muscular Dystrophy Association. Since SMA is a neuromuscular disease, the MDA provides services to SMA families. Despite the rep's friendly smile and persistence, I refused any assistance with meeting other SMA or MDA families.

But other doctors, nurses, therapists, and social workers couldn't let it go. At every appointment at Johns Hopkins or Children's Hospital I was asked if I'd connected with other special-needs or SMA parents. Did I want to be introduced to someone whose child, usually, had died of SMA? NO, THANK YOU.

I took the scraps of paper with phone numbers and names, all so carefully written down, and shoved them in a bin of papers and ignored them. I didn't call any of the contacts people gave me. I didn't read any of the literature sent to me by SMA organizations or handed to me by doctors. I refused to call myself an SMA mom or mother of a child with special needs. I didn't know what the future held, so I avoided thinking about it at all costs. Instead, I tried to maintain the same rhythm and routine we'd always had in our home, even as Fulton required more care, more equipment, and more appointments. We had created a wonder-

ful family, and I hoped that by closing my eyes and ignoring other SMA families I could pretend that nothing out of the ordinary lay down the road.

I was quite sure I didn't need a special group of people to talk to. Those people would certainly force me to face how awful this disease was and then require me to discuss it in detail. I preferred to remain in my bubble, viewing SMA only through the lens of my family, and special-needs parenting as only one tiny sliver of all the other parenting I was already doing.

As long as I avoided talking to other parents, I didn't need to face the reality of SMA. I could believe that everything would remain the same in our family and that nothing would arise that I couldn't handle. As if my six years of parenting had prepared me for whatever medical calamity Fulton would present. I could believe I would be strong enough, my marriage would be strong enough, and everything would be fine. We would handle SMA the Mantoan way, which we would just make up as we went along.

As a type A person, a planner, and a list writer, I wanted complete control over my life. When problems arose I wanted to quickly figure out a solution, make a plan, and move forward. Facing spinal muscular atrophy destroyed my sense of control; the disease meandered and created damage at its own unpredictable pace. With no cure and no reliable treatments at the time, the progression of the disease was completely out of my hands. I had no way to know what the future would look like for Fulton. This wild, uncontrollable uncertainty reminded me that I was not in control, God was; but that didn't mean I would get custom-engraved stone tablets telling me what to expect or how to prepare. I quickly went into denial to try to forget how little control I had over the situation.

But of course, SMA was here to stay whether I wanted to look it in the face or not. By denying the severity of SMA, I thought I was in control of the situation, but I wasn't, because I

was still faced with a disabled child whose needs were unlike my other children's in significant ways.

### **What You Can Do: Taming Denial**

Even when presented with a clear-cut test result with 99.99 percent accuracy, we can turn a blind eye to the symptoms and struggles our child is facing, or will face in the near future. Repeating the refrain, "Not our child, not our family," over and over in our head distances us from the truth in front of our faces.

Our Lord appeared in the Upper Room with his apostles, but Thomas wasn't there, so he didn't believe his friends. Thomas denied the Resurrection and claimed he could not believe until he put his hand in Jesus' side and his fingers in the nail holes. What reason had he to doubt? Didn't he trust the other apostles? Didn't he believe Jesus would do as he had promised?

What reason have you to deny your child's diagnosis, besides your desire to preserve your life as it is and maintain a predictable future path for your family? Christ's resurrection upended Thomas's life and the whole world. As much as Thomas wanted to preserve his life as he knew it, Jesus' invitation to put his hand in the Lord's side forced Thomas to admit that things could not be as they were before. As painful as loss of control and uncertainty is, denial only prolongs a false sense of control and temporarily disguises our fear.

Avoiding doctors, appointments, and other parents whose children have the same condition doesn't mean your child is no longer disabled. It simply means you are in denial. Refusing a "label" or making excuses for your child's behavior or lack of abilities is not protecting them. It's holding them back from the help they need, and it's holding you back from acceptance. Connecting with people and becoming educated is not throwing your hands up in defeat and resigning yourself to worst-case scenarios. It is being led down the path to wisdom. Denial seeks



to remain ignorant, and in the process cuts itself off from hope, because it can't imagine joy outside a preconceived narrative of what family life should look like.

Saint Peter denied Our Lord three times, just as Jesus predicted, because he was afraid of what would happen if he admitted to being a follower of Christ. Once the cock crowed, he immediately regretted his behavior, recognized that his actions were motivated by fear, and knew he had acted contrary to his love of Our Lord.

Fear also sits at the root of your denial — fear of the unknown and a fear of being out of control of a situation. Recognize that by allowing yourself to be motivated by fear, you too may actually be withholding the love and care your child needs. It's OK to admit you're scared. It's OK to say you don't know what to do next. It's OK to view an uncertain future with hesitancy. These are all normal feelings, but like Thomas and Peter, we must recognize our fear and seek to move forward, even when we don't know what the future holds.

You can wallow in denial for a long time. Unlike shock, it will not pass on its own, but requires the courage to accept that which is scary and unknown. Face your future head-on, as hard as that may be, so you are best equipped to care for your child and your whole family. Denial may also reappear down the road. Don't be surprised if a change in condition brings about renewed feelings of denial. "He doesn't need that now! He's been stable and doing fine." "What do you mean the medicine is no longer working? We haven't noticed a change." Recognize those feelings for what they are: moments of grief amid an otherwise joyful life.

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## KEY TAKEAWAYS

- Denial is rooted in fear. Admit that you are scared of your child's diagnosis and the resulting uncertainty.

- Avoiding doctors, treatments, therapy appointments, and other special-needs parents makes it harder for you and your child to get the help and support you both need.
- Don't deny that you can have a happy family life, even with your child's diagnosis.
- Start talking with other special-needs parents to see how they manage their children's diagnoses. Speak honestly with them about your specific fears and concerns.
- When presented with a change in your child's condition, resist the urge to retreat into fear and denial rather than confront the new challenge head-on.

### **Prayer to Saint George**

You may not be literally fighting a dragon, but your child's diagnosis probably seems just as big and scary. We can't run and hide as much as we'd like. Remember Saint George and ask for his intercession as you work up the courage to fight this monster.

Faithful servant of God and invincible martyr, St. George; favored by God with the gift of faith, and inflamed with an ardent love of Christ, thou didst fight valiantly against the dragon of pride, falsehood, and deceit. Neither pain nor torture, sword nor death could part thee from the love of Christ. I fervently implore thee for the sake of this love to help me by thy intercession to overcome the temptations that surround me, and to bear bravely the trials that oppress me, so that I may patiently carry the cross which is placed upon me; and let neither distress nor difficulties separate me from the love of Our Lord Jesus Christ. Amen.\*

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<https://www.ewtn.com/catholicism/library/novena-in-honor-of-st-george-11864>.

### **Stage Three: Anger**

Upon learning of my son's diagnosis, so many women's first response was to try to comfort me by sharing their own child's health struggles. They attempted to empathize by relating tales of peanut allergies, sprained ankles, and learning disabilities. Rather than helping, I often left these conversations angry and biting my tongue. I began to loathe every conversation with well-meaning people who approached me with the words, "I understand ..."

Often, I was put in the position of comforting and reassuring them that everything would be alright with their child rather than finding greater peace with my own situation. Tony and I started to feel resentment toward our friends and family who, in our eyes, were blessed with normal children and yet seemed hung up on trivial concerns that would in no way shorten their child's life or cause him or her pain or suffering down the road.

People offered us advice, or even product samples, of natural remedies. Others emailed or shared articles or newspaper cutouts with promising research for diseases that had nothing to do with SMA. I found myself explaining that vaccinations didn't cause SMA; it was a missing gene and not something I had control over.

It was also not uncommon for people to become emotional and break down and start crying as I told them about Fulton's diagnosis and robotically ticked off statistics about the disease. I tried to present a very strong front so I could help my friends and family members with their own emotions. Because they were struggling, I felt I couldn't open up to them about my own feelings, especially when, many times, I felt angry with them.

*How dare you cry about my son's diagnosis in front of me! I'm the one who needs a shoulder to cry on!*

*How dare you try to give me false hope and say he might still walk! Tell me it will be OK if he never walks!*

*How dare you compare your child's minor illness to my son's condition!  
Don't trivialize the severity of what we're facing!*

No matter what someone said, I would feel angry. People didn't know how to relate to our situation, and I didn't know how to express my feelings of frustration at their lack of understanding, so I confided in others less and withdrew into myself. It seemed easier to bottle it up, feign strength and courage, and then lie awake at night worrying and crying.

Some people suggested we were special, spiritually blessed if you will, to be chosen to raise a child with special needs. Maybe they saw it as a compliment. I didn't see SMA as a blessing, but rather a curse upon my child and my family. I would never tell anyone they were lucky to get cancer, or lose a loved one suddenly to a heart attack, or that God thought they were special and that's why they suffered from infertility. I couldn't be grateful for this disease, and it seemed flippant to try to twist the situation in order to make myself feel good about it.

It sounded to me like they were telling me to thank God, when it was God himself whom I was most angry with. I blamed him for this awful disease and for every struggle, past, present or future, that would befall my son. If I was so "special," what did that make them? I'd rather not be special in the eyes of God if this was how he was going to treat me. And if I had a nickel for every time someone told me, "God doesn't give you more than you can handle!" with an ear-to-ear grin, I could have paid cash for Fulton's wheelchair. I was 110 percent sure I'd been given more than I could handle, and I didn't want my cares and concerns dismissed so flippantly with a clichéd saying.

I wish I would have been more honest with people at the time and told them how I was feeling. Because I'd refused to meet other SMA parents, I didn't have anyone to vent to who would understand and validate my feelings. I couldn't get the support I needed from my friends and family, so I struggled

with my anger, and it interfered in my life in unexpected ways. It was a vicious cycle: Concerned people would ask how I was, I'd reluctantly share my concerns, they'd accidentally say something to anger me, I'd vow not to talk to people and bottle up my anger. But in becoming withdrawn, those who knew me would become more concerned and want to know how I was doing so they would ask ... and so on. I'm an extrovert, I love talking and socializing — and now it seemed I had lost most of the pleasure associated with these activities.

I didn't want to go out to social events or family gatherings because Fulton's diagnosis would often take center stage and lead to conversations that angered me.

Spiritually, emotionally, mentally, and even physically, I was being eaten up by anger. I could feel my pulse quicken, my face grow red, and my blood pressure rise during conversations between other people, and in my limited interactions with God. So I stopped praying and learned to bottle up all my anger. Unfortunately, it still came out. Usually more frequently when driving, when my kids were acting up, or when I was especially frustrated with some new aspect of Fulton's care. Almost anything could cause me to snap. I wasn't a fun person to be around anymore.

I moved quickly from shock to denial and then lingered in anger, and it coexisted with the next stage of bargaining, probably because I was prone to anger in everyday life already. Because I couldn't avoid being around people, I couldn't avoid the conversations that would inevitably upset me. It was the feeling of being the only person I knew who was carrying this load, a kind of special-needs isolation that finally moved me from anger into depression (with a brief stop at bargaining). If I was unhappy with the situation and had no one to help me process it, what was the point?

### **What You Can Do: Alleviating Anger**

It will be easy for you to recognize when you've reached the stage of anger. What will seem different from your experience of anger in the past is the particular things that trigger your anger now. Try to find out what is triggering your anger. Recognize that your response has less to do with what is triggering you, and more to do with your own complex emotions about your child's diagnosis.

Avoid situations that will make you unreasonably angry until you are able to respond appropriately. If you cannot avoid the triggering situations or people, be honest and tell them when their words or actions upset you, and that you cannot talk about or do the suggested things while you are still processing your child's diagnosis. Admit your struggles and ask for prayers for this specific intention.

Even when I was angry with God, I still found peace in the quiet of adoration. The stillness of the chapel could always calm my angry mind, even when I didn't know what to say to God in his presence. Go to confession more and confess your anger as much as possible, especially if you are bottling up your anger and directing it toward other people. Make time for quiet — whether outdoors, in a church, through prayer, mindfulness or meditation; allow yourself some space for peace.

Don't lash out at doctors, nurses, therapists, or anyone who works with your child. They aren't the cause of your child's diagnosis. There may be times when you need to advocate forcefully for your child, but in the first few months post-diagnosis, extend some grace to the medical professionals who are trying to help you, and seek a second opinion from another experienced special-needs parent or specialist if you have concerns. Take a friend with you to appointments to calmly advocate on your family's behalf if you don't feel you can keep a cool head for the near future.

Apologize to friends and family if anger shows up and directs itself at an innocent person. Don't beat yourself up if you find yourself flying off the handle more than usual. Anger is a normal step in the grieving process. It may seem like you have no time for yourself, but consider finding a physical outlet to release your anger: Running, walking, etc., may give you somewhere to direct your anger and frustration in a way that doesn't harm others.

It is easy to get stuck in the stage of anger. We feel justified in being angry with God, the world, the doctors — everyone, because our child has been given a devastating medical diagnosis. It's not fair. We want justice for our innocent child. We want to do something and change the outcome, but we can't, so we respond with anger. And the thing is, most of the world will agree with us — "it's not fair, it's terrible what happened to your child" — and they will justify your anger, even your anger at God. But we can't feed our anger and allow it to grow and fester, or bear a grudge toward God. Anger can put up a wall between us and not only God, but our loved ones as well.

You're right, your child's diagnosis isn't fair. But remind yourself that you are a better parent and caregiver when your actions are motivated by love, not anger.

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## KEY TAKEAWAYS

- Try to recognize what triggers you to become unreasonably angry.
- Be honest with people about situations and conversations that make you angry, and why you need to avoid these things for the time being.
- Spend time alone, in silence, to help calm your nerves.
- Ask for forgiveness when you lash out, and seek out

confession more frequently.

- Take a knowledgeable friend or family member with you to medical appointments to advocate on your family's behalf if you are struggling to keep a cool head in such situations.
- Find a physical outlet to vent your anger: sports, exercise, etc.

### **A Prayer for Release from Anger**

Saint Jerome was known for having a bit of a temper. We can find solace in knowing that even the holiest of saints struggled with an emotion that may be overcoming us right now. This short prayer written by Saint Jerome can help us when we are lashing out at others from our woundedness.

O Lord, show Your mercy to me and gladden my heart. I am like the man on the way to Jericho who was overtaken by robbers, wounded and left for dead. O Good Samaritan, come to my aid. I am like the sheep that went astray. O Good Shepherd, seek me out and bring me home in accord with Your will. Let me dwell in Your house all the days of my life and praise You for ever and ever with those who are there. Amen.\*

### **Stage Four: Bargaining**

I'd been to New York City a few times, but somehow never managed to make it inside St. Patrick's Cathedral. We learned shortly after naming our son Fulton that his namesake, Archbishop Fulton J. Sheen, lay (at that time) under the altar in a crypt at St. Patrick's. We had a few Fulton Sheen books and recordings in our home, plus a second-class relic on a holy card. After the diagno-

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<sup>\*</sup><https://www.learnreligions.com/prayer-of-saint-jerome-542709>.



sis, we ratcheted up our devotion to this Servant of God, hoping his intercession would prove miraculous. A couple of months post-diagnosis, Tony decided we needed to take things to the next level. Sure, we'd been good Catholics, but clearly God wanted more from us; why else hadn't our son already been healed by our prayers?

Tony started focusing all his energy on planning a pilgrimage to New York City to touch Fulton to the tomb of Archbishop Fulton J. Sheen. Tony couldn't imagine raising a child with special needs. If he thought about the future at all, it had to involve a cure, miraculous or medical. Since the medical community couldn't give us any hope at the time, we had our hearts set on divine intervention. Tony tried to make a deal with God: "We'll do this big pilgrimage with all our kids, and lots of people from the parish, and then Fulton will get cured. OK, Lord?"

I kept my Protestant family in the dark about the trip until the last minute because I was afraid they'd think such a trip was wishful thinking, and I didn't want discouragement. I wanted to pull out all the Catholic stops when it came to my son, and I didn't want anyone dismissing the traditions and practices I was clinging to for dear life. I'd tried making deals with God in the past and fallen through on my promises, so I was perhaps more guarded than Tony. I wanted so desperately to be worthy of a miracle, and I guess I felt like I wasn't.

We rented a coach bus and packed it with people from our parish. Other families drove themselves up in vans. I tried to create a video that explained SMA to those on the bus. I knew people had questions, and outside of close friends, not everyone who came along understood what we were facing. I didn't want to give a speech, but when the bus's DVD player didn't work, I answered questions from a few people, controlling my own emotions as one woman finally understood the severity of Fulton's diagnosis and started to cry.

Our parish priest made arrangements to get me, Tony, and Fulton down into the crypt under the altar, which was usually off-limits to tourists. Our large group full of young families walked through the imposing St. Patrick's Cathedral, decked out in scaffolding from ongoing renovations. I snapped pictures of the side altars, while our older children explored the sanctuary.

I wondered what a miracle would look like if we got it. I tried to picture Fulton rising up and walking like the lame man healed by Peter and John. Would we all leap and sing for joy? I tried to tell God we would sing his praises and be the best Catholics ever if we could just get this one little thing.

When our group gathered behind the high altar and we went into the crypt, we saw a nun praying there. Our priest interrupted her rosary to ask her to pray for our family and our son. We put Fulton up against the wall with Sheen's stone. I snapped a picture of Tony smiling; Fulton was not quite sure what all this business was about.

We left the crypt and moved to the Eucharistic chapel and prayed with our tour group. As we left the cathedral, we stopped in the gift shop, and then walked around Rockefeller Center. There was no ray of light, no appearance of angels; by all accounts it was a normal, sunny, fall afternoon in New York.

We toured another church, loaded the bus, and went home. There was the palatable feeling of at least we had done something, but we were not granted our miracle. Afterward, Tony never spoke about the subject, except to always dismiss the possibility. He wouldn't allow his hopes to ever get that high again.

I wondered how God decides who gets miracles and who doesn't. I knew enough about the Faith to know he could bring good from Fulton's illness, but I'd hoped he would use a miraculous cure to make his point instead. Why not our family? What else could we do? What hadn't we done right? Weren't we open to life? Hadn't we been good Catholics? Why couldn't we get a

miracle or, at the very least, find peace with our state in life?

Maybe there was just one more prayer or novena we needed to say, or perhaps another shrine we needed to visit. We wanted GPS-precise directions to a miracle, but that's not how God works.

If we couldn't negotiate with God, maybe we could defy science. Perhaps with more physical and occupational therapy, healthier food, and the latest therapy equipment we could realize fantastic, never-before-seen gains in a child with SMA! If we put in more time and effort we should be guaranteed something amazing; it was only fair. How could we give and give and give, and seemingly get nothing in return?

Without a miracle, it was easy to move from bargaining into depression. I developed a despairing resignation to the fact that God wasn't listening to our prayers, and we were obviously on our own to figure out life with a child who has special needs.

### **What You Can Do: Ending the Bargaining**

Bargaining with God is an argument we can't win. We can't approach our heavenly Father as if we're in hostage negotiations. We *can* counteract bargaining with trust. Rather than making one-sided promises and agreements with only our interests in mind, it helps to remember the wonderful things that have come from trustful surrender to God's plan. When we trust in the value of a product, we don't try to haggle or bicker over the price. We recognize its worth. We are willing to pay a fair price.

Your child has worth and value you don't recognize yet, but God does. He does not see your child as imperfect or flawed, and he wants you to see your child as he does. He hears your prayers and pleas, and rather than giving you what you're asking for right now, he's asking for your trust. You don't need to go on pilgrimages, wear sackcloth, fast for weeks on end, or upend your life with new spiritual practices and mortifications. God

will certainly take all your good works and use them for your benefit, but that doesn't necessarily mean the miraculous cure of your child.

Untangle your feelings of your own shortcomings and failures as a Catholic, or human being, from your child's diagnosis. Realize your child's future health is not determined by how good of a person you are. "Then he said to them, 'My soul is very sorrowful, even to death; remain here, and watch with me.' And going a little farther he fell on his face and prayed, 'My Father, if it be possible, let this chalice pass from me; nevertheless, not as I will, but as thou wilt'" (Mt 26:38–39). It is OK to ask God to let this chalice pass. But if it does not, we must be willing, like Christ, to ascend our own Calvary, trusting in a greater glory to come. You may be willing to pay any price to regain a "normal" child, while within your grasp is loving and enjoying the child you have.

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## **KEY TAKEAWAYS**

- God sees the value in your child just as he or she is right now.
- Your child, and family, can be happy without a cure, divine or medical.
- Your child does not have a disability because of some parental spiritual shortcoming. Therefore, your child's health is not dependent on your spiritual practices.

## **Prayer for Trust in Jesus**

Rather than continuing to bargain with God, step back and pray for trust. Even as the big picture eludes you, try to trust that God knows the good that can come from this situation.

O Christ Jesus, when all is darkness and we feel our weakness and helplessness, give us the sense of Your presence, Your love, and Your strength. Help us to have perfect trust in Your protecting love and strengthening power, so that nothing may frighten or worry us, for, living close to You, we shall see Your hand, Your purpose, Your will through all things. Amen.\*

### **Stage Five: Depression**

In the early fall of 2009, Tony and I were finally getting an evening out sans kids at a parish event. Everyone around me was laughing, drinking beer, and swaying along to the loud polka music. The smell of bratwurst and sauerkraut hung in the air, and children in lederhosen ran haphazardly through the church hall. Our table of friends talked loudly and clinked steins. It was our parish's first Oktoberfest, and by all accounts it was a smashing success. I nibbled at my food and sipped my Riesling. I drifted in and out of conversations, distracted by my own thoughts rather than the blaring accordion. My husband and I had bought tickets as soon as they went on sale, expecting to be cheered up and to enjoy a bit of adult fun together for the first time in months. We had started attending a local Oktoberfest in our hometown back when we were in college. As our family grew, we traveled hours to attend the festival and tried to instill in our kids a love of bratwurst, lederhosen, polkas, and anything Bavarian. After tucking our kids into bed at their grandparents', we would go back out, meet friends, and sing loudly while dancing around the floor. We were thrilled when plans for a similar festival closer to home began to take shape in early 2009, but so much had changed for us since then that I wasn't surprised to find I wasn't enjoying myself.

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\*<https://www.xavier.edu/jesuitresource/online-resources/prayer-index/ignatian-prayers>.

"I can't keep sitting here pretending to have fun," I finally said to him, already feeling a lump in my throat. "I need to go sit alone in the chapel for a bit."

Tony's face sank as he realized this rare date night was not the respite we had hoped it would be. "OK," he said. "Let me know when you want to leave."

I quickly walked from the church hall to the chapel. The lights were off and only the sanctuary lamp burned overhead. I sank down in a pew directly facing the statue of Our Lady, illuminated by a single spotlight. I exhaled deeply and began to cry. Soon my cries became deep, body-wracking sobs. I held my head in my hands and gasped for breath.

I had cried so much before this night, I was amazed I still had so much sadness and hopelessness left inside of me. I was glad everyone was too distracted by the music and alcohol to hear my sobs fill the empty chapel.

Despite almost four months having passed since Fulton's diagnosis, I was still devastated and still unable to be happy and find joy in my family, my friends, or even an Oktoberfest.

I spent my days tending to the needs of my young family of four kids, ages six and under. I tried to homeschool, keep on top of the laundry, and feed my children, while simultaneously making and attending numerous new doctor visits, arranging and assisting at in-home therapy sessions, and filling out paperwork for prospective drug trials. I was busy, and I tried to stay busy so as to not have time to stop and think.

Since our failed attempt at a miracle, every conversation between my husband and I was heavy, dark, and reflected our hopelessness. Instead of sitting together sipping coffee in the morning and discussing current events or our favorite reads, we simply sat and stared into our mugs ruminating, always next to each other but miles away in thought. We couldn't and wouldn't talk about a future that seemed scary.

As I moved away from anger and bargaining, even conversations with friends took on a more pessimistic slant. A couple of weeks before the Oktoberfest, as a friend prepared to leave my house after a playdate between our children, my eyes filled with tears and I suddenly blurted out, "I just realized, he'll never be an altar boy!"

She tried to console me. "Maybe he will. Maybe they could modify —"

I cut her off. "He won't be an altar boy. He'll never be a priest." The enormity of those thoughts caught in my throat and I pulled myself together long enough to see her out the door, knowing her sons would all be on the altar helping Father within a few years. Now everything people said made me sad, and all I saw were the dire predictions and missed opportunities.

Perhaps my older son would never become a priest, or a professional football player, or a fighter pilot, but there was still a chance. Because these occupations were definitely out of reach for Fulton, I mourned the loss of these possibilities, as far-fetched as they were for any child. I tried to use dark humor to stop myself from upsetting other people or revealing how much I was hurting.

As I sat in the church for the rest of the Oktoberfest crying myself out to the point of exhaustion, I poured all that bottled-up pain at Mary's feet. No one could understand the pain in my heart except a woman who had watched her innocent son be scourged and hung on a cross to die. That was the only fate worse than spinal muscular atrophy that I could imagine happening to my child. I took comfort in knowing that at least one person understood my pain completely, but I wondered how I was supposed to recover from this grief when I was not perfect like Mary. Rationally, I understood my Catholic Faith and that God was with me during this struggle. I hadn't been abandoned and he hadn't given my son this diagnosis as a punishment or test.

But for the first time, I felt my deep faith could not transcend my deep pain. I had been talking the talk, but now I couldn't walk the walk. I couldn't even get up off the ground. I stopped praying unless it was in anger, or in sobs, or to question. I went through the motions of my faith — attending Mass, going to confession, instructing our children in our daily prayers — as if I was moving on autopilot. My mind was always elsewhere. Consequently, I felt like a bad Catholic. Here I was, where the rubber met the road, and I wasn't patient with the Lord like Job, or picking up my cross and joyfully skipping down the path to heaven.

Why couldn't I find peace? Why did I not find comfort and solace in the one thing, the most important thing, the truth of which motivated us to even have these four kids? Through all the previous stages of grief, I tried to maintain the outward appearance of a faithful Catholic, but my actions were superficial and could barely mask the despair that was eating away my faith.

After an hour in the chapel, when I finally stopped crying, I returned to the Oktoberfest celebration. I went to Tony and quietly told him it was time to leave. I knew that I was mentally, physically, and spiritually at rock bottom.

Reflecting on it now, I can still remember exactly how it felt; my chest tightens instinctively and my eyes begin to burn. My life overwhelmed me. I couldn't imagine carrying that load of grief around with me every day for the rest of my life. It was too much.

My oldest son, Byron, had a birthday party around the same time and a few moms helped me organize an afternoon of games and food for our pack of rowdy boys. One of the moms snapped pictures throughout the party and emailed them to me. As I viewed them later that night, a smiling picture of Byron and me filled the browser. There was a big cake between us, and you could tell he was eager to get to the cutting and consuming part of the party. I stared at my smiling face and remember thinking



how amazing it was I could look so happy and glowing on the outside (it was a very flattering picture) and feel so horrible on the inside. I almost couldn't look at or enjoy that photo because my expression seemed like such a lie. I wasn't really having a fun afternoon as much as I wanted to for my oldest son's sake. The smile I wore in that photo and all the rest was fake. I saw how I was faking so much on a regular basis just to keep the status quo at home. It was all a charade.

I had a friend tell me that one day I would be happy again, but that seemed impossible. How could I ever be happy when Fulton had this awful disease? I didn't want to die, I wanted to raise my family. But living this way, devoid of joy forever, horrified me. The immensity of the darkness hanging over me was smothering.

When that party and a long-awaited Oktoberfest failed to raise my spirits, I knew I needed help. I recognized that I was depressed and even despairing, and that without a change, my children and marriage would be negatively affected.

### **What You Can Do: Managing Depression**

The depression that comes after the diagnosis of a child will last as long as we let it. If you cannot pull yourself out of depression, you will need to seek professional help to get your life back on track.

This is the last stage of grief. Like anger and denial, it may blend into other stages, but it represents the last major hurdle to taking control of your grief and achieving acceptance. As you recognize signs of depression, be forgiving of yourself. Remind yourself that the emotions you're experiencing (sadness, emptiness, etc.) are a normal part of grief and depression. You are not a failure as a Catholic, as a parent, or as a human being. God has walked with you through this grieving process every step of the way and he wants to take away the pain you're feeling. "For I, the LORD your God, / hold your right hand; / it is I who say to you,

“Fear not, / I will help you” (Is 41:13).

Now is when we need to choose not to allow our fallen human nature to dictate that we stay stuck in patterns of denial, anger, or depression. Some of us will only be able to do that with professional help, and that is OK. You are allowed to accept help in all forms to overcome the big emotions your child's diagnosis stirred up. Get help, and take care of yourself through the process. Don't let basic self-care fall to the wayside. Not sleeping, eating, or practicing basic hygiene is a sign you need professional help. Your journey through depression will not match anyone else's, probably not even your spouse's. Allow each other to process your feelings, and move through these stages in your own unique ways. Be as encouraging to one another as you can, but understand you may need outside support from friends, family, or professionals if you're both struggling. If your spouse chooses to stay stuck in depression, or any other stage of grief, for the sake of your own health and the well-being of your family, you must choose to take care of yourself and not allow his or her feelings to negatively impact your parenting and caregiving. Also encourage, pray for, love, and support your spouse, but know that until they are ready to move forward on the journey to acceptance, they will remain stuck where they are. Consider marital counseling if the clash of emotions is disrupting family life.

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## KEY TAKEAWAYS

- Depression will last as long we let it.
- Sadness and depression are a normal part of the grieving process, and they represent the last stage before acceptance.
- You may need professional help to overcome depression, and that is OK.
- Your spouse may experience depression differently

from you. Encourage each other as you are able, but recognize the need for help outside one another.

- You cannot force someone to not be depressed.
- Focus on helping yourself, so you can continue to support a struggling spouse, while also being the best parent and caregiver to your other children.

### **Prayer to Saint Dymphna**

Grief has put us through the wringer, and now we feel at our lowest, physically, mentally, and spiritually. However, God has not abandoned us, and as hard as it may be for us to pray at times, we can still turn to him and ask for the intercession of his saints, to help us overcome this last hurdle of depression.

O God, we humbly beseech You through Your servant, St. Dymphna, who sealed with her blood the love she bore You, to grant relief to those who suffer from mental afflictions and nervous disorders, especially for help in overcoming the depression I feel related to my child's diagnosis.

Saint Dymphna, helper of the mentally afflicted, pray for us.

Saint Dymphna, comforter of the despondent, pray for us.

Saint Dymphna, renowned for many miracles, please hear my plea. Amen.

Glory be to the Father, and to the Son, and to the Holy Spirit, as it was in the beginning, is now, and ever shall be, world without end. Amen.\*

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*\*Hope & Healing: St. Dymphna Novena* from Diocese of Orange Office of Pastoral Care for Families of All Stages. <https://www.rcbo.org/resource/mental-health-2/>.

### **Stage Six: Acceptance**

A few days later, I stood staring at the religious bookshelf at my local library, anxious for some guidance, when I came across *Arise from Darkness* by Father Benedict Groeschel. The title accurately stated exactly what I was looking for — a way to rise out of my despair. Later that day, as Fulton lay on the floor on a tumbling mat, allowing an early intervention therapist to move his legs, I sat in a rocking chair by the woodstove, misty eyed. Father Groeschel's words finally started to crack through the depression and sadness I'd allowed to consume my soul:

When we are knocked down and defeated by life ... that is when we can pick up the Cross and wave it at grief, sadness and death. To boast in the Cross, it seems to me, is an almost fierce gesture when we confront all that would defeat us and say: "Look at the Cross, all of you, and know that I shall not be overcome, because the Lord of Life is with me, and in me, and he will go with me even through the valley of the shadow of death."

I didn't immediately lay down the book after a couple of days of nonstop reading and feel 100 percent better, but Father Groeschel's words helped me find the humility to accept our situation without a miracle or divine explanation from God. I acknowledged that I couldn't control the situation, and I couldn't demand a cure or answers, but I could choose to be OK and love my son anyway.

The idea that I could "confront all that would defeat" me, and refuse to be overcome, helped me to see how I was allowing Fulton's diagnosis and the ensuing stages of grief to beat me down and have power over me. I realized I wanted to fight back; I wanted control of my life again. I couldn't change the fact that Fulton had SMA, but I wasn't completely powerless or a helpless

victim. We can pick up our crosses and wave them at grief, and I was finally ready to do that.

Parents facing a devastating medical diagnosis or traumatic event need to acknowledge the stages of grief and admit it's not a failure of their faith to feel a certain way. We expect a certain type of life for our child, and from a young age we imagine them hitting certain milestones. To trade those dreams for an uncertain, and scary, future is a form of death. But as Christians, we acknowledge that no death is final. From the crucifixion, we received the Resurrection and everlasting life. From whatever cross God puts in front of our children and families, he can bring something good in this life and the next. Acceptance means having faith that God will bring good from your child's diagnosis.

Acceptance means you see the value in your child outside his ability to walk, talk, hold down a job, raise a family, or even survive outside the womb for more than a few hours. Acceptance means knowing God wanted your child to be here, and for you to be her parent. Acceptance means you understand your child has a purpose and mission in his life. Acceptance means knowing that while your child may never learn on grade level, gain fame, or hold a prestigious job, she can never be denied the kingdom of heaven.

However, acceptance isn't easy. Many special-needs parents stay trapped in the anger, bargaining, or depressive states of grief. Some parents only accept their child's diagnosis as a burden on themselves and their family. The disease is something only to be hated or healed; it can never be the cause of anything good. They can only see their child in terms of her limitations, her suffering, and her missed opportunities. They are blind to all the love and potential their children do have, even if they are medically fragile, nonverbal, or here only a short time this side of heaven.

When we view our child's disability through our own fears, anger, grief, and frustration, it's easy to see our children as vic-

tims and to feel hopeless. We see everything they can't do or won't live to see, and we miss all the happiness that's actually present. But our children are not burdens or hardships to be endured. They are gifts from a loving God to be loved and enjoyed so long as we are blessed to have them with us. That is the truth acceptance brings.

Because I went through all the normal stages of grief, I felt I wasn't a good Catholic, or good parent. I thought I should have been able to just accept circumstances and be patient with the Lord like Job. But in hindsight, I could clearly see how I moved through shock, denial, anger, bargaining, and finally depression. I recognized that holding on to any stage would no longer serve any useful purpose in my life. In fact, it could only serve to negatively affect my relationship with my children and husband. I learned that it was me, not God, who was dragging out the stages of grief. Grief is an ongoing struggle in many ways, but choosing acceptance yields benefits far greater than allowing yourself to sink further into sadness or anger. Choosing to stay angry or depressed may seem like the path of least resistance, and many people may not question if you do exactly that. But there is so much to gain and nothing to lose by embracing acceptance.

When I finally allowed myself to accept Fulton's diagnosis, I wasn't saying everything was fine. I was a completely different person. Our family would never be the same, or like any other family I knew. I would still have days when I got angry or depressed, but I could now have good days without feeling guilty for being happy. I could see everything my son was doing, rather than what he wasn't.

In many ways, acceptance for me became the practice of mirroring the way my older three children behaved. They simply saw nothing wrong with their brother, and happily worked harder to include him in their play. They didn't get sad when he couldn't do things. They loved him exactly as he was. Sometimes

they got frustrated because I spent so much time with Fulton, or it seemed to them he was getting all sorts of fancy new stuff (actually medical equipment) when it wasn't even his birthday or Christmas. But attention-seeking and jealousy over gifts were parenting problems I tackled before SMA. Fulton's diagnosis didn't negatively impact my children, and I realized it didn't need to harm me either.

Christ tells us to have faith like little children, but why? As an adult whose life was upended by a medical diagnosis, I see how hard it is to maintain that trust and hope in God's divine providence. I would rather sit alone with my dusty prayerbook and read than have to joyfully accept my cross without question. It is harder for me to assume the best outcome, to keep hope that miracles (medical or divine) do happen. It is harder for me with all my "valuable life experience" to blindly accept that God always knows what's best. And yet, *that is my children*. That is most children. Untainted by cynicism, unburdened by despair, my children want to see the silver lining and can find it in the most troubling of circumstances. They refuse to give up hope, and will hold on to it long after I believe all is lost and that I have been forsaken.

I learned to look to my children for the example of how I should be. While my example is supposed to lay the groundwork for their future spiritual well-being, their example led me out of grief in all its stages and back to a simpler faith. They believe without question, without reserve, without hesitation. Reaching acceptance meant I was starting to break down my resistance to God's grace; the barriers of anger, despair, and pride that I allowed myself to construct. My children became my motivation to do better and my blueprint to follow.

My faith suffered after Fulton's diagnosis, not because God had done something wrong, but because I was not willing to commit myself to his plan for my life once I realized it did not

look the way I wanted it to be. Acceptance helped me start to rebuild and renew my faith because I was willing to trust God again and not just plod through life, but love my life because everything in it was a gift from him. We are all called to be joyfully obedient to God's will in our lives, even when it's scary, heart-breaking, uncomfortable, and looks completely different from what we pictured our life to be. It means realizing that God calls us to do hard things that will require us to sacrifice and die a little to ourselves daily.

I had to work through the stages of grief because Fulton's life would not look as I imagined, and I needed to come to terms with that loss. But with acceptance, I came to realize that the life we did have in front of us, as new and uncertain as it seemed, could still be a life of joy. Life will be OK. Our family's life will be OK. Even if it's sometimes hard and messy, it will be OK, and more often than not, better than OK. It will be better than the safe, confined life to which we often try to constrain ourselves. Fear of the uncertain often limits us from experiencing greater love than we can imagine. There is joy and freedom in trusting God and allowing him to improve you and your family by your joyful surrender and acceptance.

### **What You Can Do: Reaching Acceptance**

Acceptance is a choice you make to leave the grieving process behind. There will still be tough times ahead. However, with acceptance, the emotions you wrestled with during the grieving process (denial/fear, bargaining, anger, depression) no longer determine how you tackle difficulties. You can make decisions from a place of love with a peace of mind not consumed with fear, sadness, or anger. You can advocate and fight for a cure or new, innovative treatments, or pray for a miracle, but be happy with your child as he is right now. If you are lucky, you will start to see the beauty of life through his eyes, and learn from



his perspective rather than your own. If you have other children, look to see how they interact with their special-needs sibling. Do they model unconditional love and acceptance that you can learn from?

If you've struggled with your faith during the grieving process, hopefully now you can begin to rebuild trust in God's plan for your family, even without knowing or understanding all the whys. If you fell away from attending Mass and the sacraments, or stopped praying and practicing your faith, now is the time to ease back in. Go to confession and admit your struggles, past and present. Attend Mass with a contrite heart and admit to God that you're doing the best you can. Look up saints related to your child's diagnosis and create a family litany of saints to call upon when you're tempted to return to anger, denial, or grief.

If you continued to practice your faith, but were only going through the motions as my husband and I did, make the effort to reengage with your faith through increased participation and attention at Mass, and a more mindful attempt at prayers and regular devotions. Pick up a spiritual classic, or spend more time meditating on Scripture, to help reorient and reinvigorate your faith. Improving your faith may not lead to a miraculous cure, but you will see how it leads to the graces you need to thrive as the parent of a child with special needs.

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## KEY TAKEAWAYS

- Acceptance means you now accept the reality of your child's diagnosis, and no longer need to cope with that reality through denial, bargaining, anger, or depression.
- Moving through the stages of grief is a normal healing process, but choosing to stay stuck in any one stage rather than moving into acceptance can prevent

you from enjoying your child and your family life.

- Don't let grief define your life as a special-needs parent.
- Life with a child who has special needs will be different than the life you envisioned for your child pre-diagnosis, but it can still be a good life.
- Put forth a renewed effort into practicing your faith. Meditate upon having childlike faith and humility.

### **Prayer of Abandonment, by Blessed Charles de Foucauld**

Moving into the stage of acceptance may not feel easy at times. Recite this brief prayer to help you surrender yourself with love to God's plan.

Father,  
I abandon myself into your hands;  
do with me what you will.  
Whatever you may do, I thank you:  
I am ready for all, I accept all.

Let only your will be done in me,  
and in all your creatures —  
I wish no more than this, O Lord.

Into your hands I commend my soul;  
I offer it to you with all the love of my heart,  
for I love you, Lord, and so need to give myself,  
to surrender myself into your hands without reserve,  
and with boundless confidence,  
for you are my Father.  
Amen.\*

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<sup>\*</sup><https://www.ewtn.com/catholicism/devotions/prayer-of-abandonment-361>.



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