
Something to Live With

*This can't be happening to me.
What could I have done to prevent it?*
—Norma, parent

*The pain of one child's disability
reshapes every life in unexpected ways.*
—Helen Featherstone, *A Difference in the Family*

Lisa reached for the car door handle as I released her seat belt. She made the hard scoot toward the edge of the seat and pulled on the metal handle with a few grunts. The door opened, but that was only the first step. Now she had to push it open. It took three hard pushes before the heavy door budged. Next, she worked small side steps to move her feet toward the door. A few more scoots, and one leg was out. Another hefty push, and the other foot found ground. That allowed gravity to pull the rest of her body out of the car and into a standing position.

I sat in the car, as I did every time this happened, feeling frustrated, helpless, in an internal war. Should I help or not? Sometimes I did. I would put the car in park, get out of the driver's seat, walk around to her side, open the door, release her seat belt, and let her use my hands for leverage to get her out of the car in a more timely fashion. I'm sure the long line of parents waiting to drop off their schoolchildren appreciated it. But I always wondered. Was I helping her or myself? Was making life easier her goal or mine? And what were the implications for the future? What would she do when I wasn't around?

That's when I began thinking about empowerment issues. I never used the word, but I understood the goal. Lisa needed to learn how to deal with life without my cues or all-too-quick interventions. She needed to learn what she could handle in spite of the unique set of limitations in her life.

Our story

It wasn't the way her father or I had envisioned her life. Lisa smiled her way into my heart when I accepted her father's proposal to marry "them," as Lisa always described it. Her mother, Mark's first wife, died too young, when Lisa was three and a half. From the beginning, I knew Lisa had some physical issues. She had been on medication to control a seizure problem for about a year. She moved slowly and complained of aching legs,

waking up multiple times during the night. However, there was nothing that signaled the complicated, unpredictable, and confusing journey we would all take in the years to come.

Just three months into our marriage and adjustment as a family, Lisa's neurologist suggested hospitalization to find the cause for unexplained muscle weakness. We all feared a debilitating, life-threatening, degenerative disease. I'll never forget the night before we left for the hospital. I couldn't sleep. I walked to the patio window, hoping it would give me the distance I needed from the bedrooms to muffle my sobs. I was scared about everything I didn't know and might find out. I cried to God for help. I rehearsed what He already knew that I did not: what the tests would reveal, what would happen next, what our lives would be like. The more I rehearsed what He knew, the calmer I became. When I realized that God already knew what I did not and was preparing answers for all of us, I learned my most important lesson.

I don't think I realized then how critical that moment was for everything that would follow. What I understand now is that because I let God's knowledge be enough for me in that terrifying night of not knowing, it prepared me for the numberless times of uncertainty that awaited me in the future. The answer to my "What will happen?" questions is always the same: God knows, and He'll reveal the answer at the right time.

We made it through a week of difficult testing, still new at being family to each other. At the end of the week, there was a diagnosis. Besides the seizure issue, Lisa had juvenile rheumatoid arthritis. We viewed the information video that told us how we could help our child. We learned the exercises we needed to do twice daily after a warm bath. We learned about medications the doctors would prescribe. I remember the two-hour ride home from the hospital trying to process everything. At one point in our debriefing, I turned to Mark and with a great sigh of relief said, “Well, at least arthritis is something we can live with.”

I didn’t know how prophetic those words would become. Lisa’s joint-limiting development, her daily pain, her medication and exercise regimen, her lack of endurance, her unpredictable inflammation flares, her extra doctors’ appointments, and her loss of mobility were all part of the “something” to live with. Unfortunately, her challenges didn’t stop with seizures and arthritis. More challenges continued to surface. There were severe learning disabilities, the depth of which was not effectively identified until late in high school. Add to that the complications that necessitated a life-threatening double heart valve replacement surgery and two hip replacements. Lisa’s special needs have changed our lives *every day*. They change how we live and where we live. They change vacations. They change leisure activities. They change mealtimes. They affect *everything*.

Something to live with

That's the nature of chronic emotional, mental, and/or physical issues. They give us something to live with. Sometimes they're like shadows, dark and scary. Sometimes they offer opportunities to learn resilience and endurance we might never have learned otherwise. Sometimes they give us good reasons to celebrate small victories. But whatever they do, they don't leave us the same. In fact, they don't leave us—they're always there.

That's good news and bad news. The good news is that as parents of children dealing with a variety of chronic issues from learning disabilities to mental health issues to multiple physical challenges, we have time to learn coping, nurturing, and empowering skills. That's really very good news.

The bad news is that no matter what we do, we can't get rid of these issues. Medication and therapies may help manage them, but they don't cure them. That's why we need to learn how to live with them. One way we do that is to ask God to help us empower our children to live with their challenges. And we can't do that unless we ask God to empower us to live with the challenges as well.

To empower

- To give authority, power, or freedom to an individual

- To promote or influence self-actualization
- To give strength and inspire with confidence
- To equip or supply with an ability

From the beginning of diagnosis

From the beginning of a diagnosis, life changes. Whether or not you like it, your life has a new reality and a new set of boundaries. These boundaries affect family schedules, interactions, resources, energy, and social involvement. Learning disabilities mean tutoring and extra help with homework. A physical diagnosis means doctors' appointments, watching for symptoms, and often dealing with medication issues. A mental health issue means counseling, learning coping strategies, and balancing medication. Each changes how you expected life would be for you and your family. How do you take it all in?

*At first we were in shock; then we faced guilt;
finally our lives became all about survival.*

—Dianne, parent

You don't. You take in only today's reality and look for ways to prepare for tomorrow. That's all you can do. There are no helpful answers for tomorrow. But God has promised enough answers for today. As the parent of a special-needs child, you have the opportunity to learn that lesson on the front line.

*Your heavenly Father already knows all your needs,
and he will give you all you need from day to day.*

—Matt. 6:32-33, NLT

After diagnosis

Several processes are involved when beginning the journey of parenting a special-needs child. They remind us that we're part of a complicated and unfolding life. They help us realize that a myriad of responses are normal.

Discovery and confirmation. It may become apparent through recognizable symptoms, a doctor's diagnosis, or a test's confirmation. Shock often paralyzes our decision-making and processing abilities at first. Then a desire for information motivates parents to get it wherever they can: pamphlets, the library, the Internet, or others living with the same diagnosis.

A search for meaning. Questions like "What does this mean?" can easily overwhelm. Here's what I've found true. The meaning or purpose isn't in the diagnosis or disability. The meaning and purpose surface in our responses. God creates extraordinary answers in our submission. They are purposes that cannot exist without His intervention and creativity. The more confidence we have in what God wants to do in our lives *because* of our context, the more confidence we pass on to our child. Our submission to God *becomes* an empowering response.

Time to refocus. We begin to recognize that this is not just a childhood disease or crisis that will go away. We start to understand that this is long-term. It's the understanding that helps us to stop looking for some change that takes all the bad stuff away. We start asking how we need to do this. That is an empowering focus.

Assimilate and keep going. Adjustment to a chronic diagnosis is not a one-time event. Each time there is a change or new understanding, we have to find a way to accept it into our lives and keep going.

Celebrate answers and growth. Celebrate the first word, even if it comes at age 10. Celebrate the day your child puts his or her socks on without assistance, even if they're twisted. Celebrate a new attitude or trust that helps you face a new crisis without as much panic as before. A life of celebration is an empowered life.

Empowering vs. enabling

If we're going to empower our children to live life to their fullest potential, we have to begin empowering strategies early. They're not black and white. They're not one-size-fits-all. They're principles to help us consider empowering issues as we develop our parenting patterns.

This isn't just about setting goals. It may involve some goals, but empowerment is a lifestyle of various strategies. It involves how you talk about the challenges, when and why you help. It especially involves developing an affirming and secure context in which your child can

learn how to deal with his or her challenges at an appropriate level of independence. It's a process of continuing education and evaluation. Empowering involves encouraging your child to act and speak for himself or herself appropriately. Empowering means preparing your child to accept the realities of his or her life.

Parents hold two sometimes incompatible goals: to arrange their child's world so that he feels, and is, as normal as possible, and to protect him from harm.

—Helen Featherstone,
A Difference in the Family

The opposite of empowering is enabling. Enabling builds a trap for both parents and children. Enabling renders the child so self-focused that he or she has trouble fitting into a larger circle of life. It develops unnecessary patterns of dependency, which does little to prepare the child for adult life. It traps the parents into caregiving that others could and should supply.

Enabling

- Prevents or interferes with acquiring empowering skills
- Reduces a person's sense of control
- Reinforces old or nonadaptive behavior (such as procrastination or whining)

Empowering

- Promotes personal growth and increases skills
- Increases a sense of control
- Encourages new coping abilities to replace non-adaptive behavior

—Adapted from Lynchburg Area Center for Independent Living <www.lacil.org>

I remember the pamphlet I took to heart as I began dealing with Lisa's disability. "As normal as possible," the literature kept repeating. I have come to change that phrase to "as normal as is *realistic*." It's possible to raise special-needs children with a false sense of "normal." The result does not help them adjust to a world where others have a different set of abilities. A realistic picture is absolutely necessary. That's where empowerment begins.

I would like people to treat me as normal as possible. —Renea, young adult

Empowering strategies

1. Accept the realities. What you refuse to know *can* hurt you and your child more than whatever the reality is. Use any available avenue of research to identify the basic realities of your child's special needs. Don't overdose on extreme stories. Look for middle-of-the-road, basic information. If you use the Internet, use reputable

sites for your primary information. Don't get basic information from someone's personal Web site. Compare what you see and what others see in your child with the symptom description you uncover. This helps you confront the reality picture. How is this diagnosis, these symptoms, real for you and your family? This discovery isn't about what you're afraid is going to happen. This is about what's really going on. Always start there. That's where God's help begins too.

It took a long time for the entire reality to set in and the likelihood that nothing could change it.
—John, parent

2. Don't pretend. Honesty begets honesty. Be honest with your spouse about how you're dealing with the pressures, the fears, the unknowns, the challenges. As it is age-appropriate, be honest with your child. God inhabits truth, not pretense. That's why honesty about your fears, your emotions, your endurance, your own limitations is key. Since God already knows the whole truth and nothing but the truth, He can help you find it if you ask Him to.

3. Encourage honest talk about special-needs issues. Answer any question from any family member with the truth as you understand it. Sometimes the most honest answer is "I don't know—we'll have to find out." If your child believes you hide information about his or her challenges, it increases his or her fear instead of di-

minishing it. Our kids are stronger than we give them credit for. Many times we're trying to protect ourselves when we don't encourage open and honest talk about uncomfortable challenges. Understand that I'm not suggesting that you push information on your child that he or she isn't ready for. Ask questions: *What do you understand? Do you have any questions? Did you hear anything that upsets you or makes you afraid? Could we talk about it?*

4. Adopt language that affirms, encourages, and inspires. Let me share what it doesn't mean to use language that affirms, encourages, and inspires. It doesn't mean to be positive at all costs. You and your child could face some very difficult situations. To speak positively about a negative situation won't empower anyone. To speak honestly will. To give opportunity to vent feelings so that energy can be redirected is an empowering process. To model language that helps a child express feelings is an empowering process. Use phrases like "You can," "You are," "You amaze me," "You have what it takes," "You make a difference," "I believe in you." Write them down. Slip them into daily conversation. Commit yourself to this kind of language with the same fervor you apply to medication regimens. These words empower.

Finish the following sentences for your child. Communicate at least five a day. Every week make a new list. Is it possible to run out of affirmations? Ask God for new ideas.

You are _____

You will _____

You can _____

You have _____

You trust _____

You choose _____

You create _____

You enjoy _____

You know _____

5. Never do for your child what your child can do for himself or herself. Doing too much for our special-needs child is the greatest temptation most of us face. Life is harder for a child with special needs. We want to make life easier. So we overhelp. That's the opposite of empowering. We all know that sometimes we do things for our children because we're in a time crunch and it's just easier. I'm not talking about those times. I'm talking about trying to even the score by overhelping. It doesn't empower—it enables. It makes your child more dependent, not more independent. Start small, and start early. It's the story of helping the struggling chick out of the egg and rendering it helpless to survive outside its protective shell. This is not an all-or-nothing proposition. And it involves a lot of trial and error. I've done my share of overhelping. I find that it usually comes from my own guilt and discomfort concerning the challenges our Lisa faces. But overhelping enables dependence. Dependence

does not help your child live life to his or her fullest potential.

Kids can never have any degree of independence if parents don't teach them to take care of themselves.

—Bruce L. Baker and Alan J. Brightman
Steps to Independence

6. Be realistic about time, energy, and resources.

This is just another way to look at the new realities of your life. It may take more patience, more endurance, and more physical energy to meet your child's needs on a daily basis. You're not a bad parent if you need help. Talk with your spouse or other family members who can support you. Take time away. Don't think you can meet all the needs all the time. Use whatever time management devices help you, but don't just try to get more done in a day. Sometimes you need to stop, put your feet up, and let someone else help. And sometimes you have to help your child understand that you can't meet every need, go to every meeting, and still give the support other family members need. It's another part of the reality picture. Empowerment says, *I can't do it all for you. Other people will have to learn to help, and you'll have to learn how to let them.*

7. Start somewhere. Empowering strategies evolve; they don't happen overnight. In the same way a toddler takes trial-and-error baby steps to learn to walk,

you can do the same. Think about how to give your child choices. Think about how to sequence the steps for difficult skills and focus on only one of the steps. Applaud every success no matter how small. Don't wait for completed skill mastery.

Empowering questions

- How much protection does our child need?
- How much independence should we allow?
- Where should we set limits?

Learn when to give comfort, compassion, and sympathy and when to make the child quit feeling sorry for himself or herself.

—Dianne, parent

The tightrope

Empowering special-needs children is like walking a tightrope. If you protect them too much, you disable them for the future. However, if you allow too much independence too soon or without the right skills and boundaries, you set them up to fail. The good news? There's always middle ground. Find what that middle ground means for your child. It will change as age and skills change. It could change as the mental, emotional, or physical issues get better or get worse. Just commit yourself to help your child live the life God has given him or her the potential to live.

Truth brings freedom

Truth is not always the same as your opinion or perception. We can commit ourselves to a wrong perception and reject truth. Early in dealing with Lisa's learning problems and the labels I feared would isolate or restrict her, I reviewed John 8:32, which became my basic philosophy: *You will know the truth, and the truth will set you free* (John 8:32).

Using this verse, I constantly ask God to help me sift through impressions, observations, and information in order to know what's true. Sometimes God has counseled me to defer judgment about what I'm hearing or seeing until other details surface. I want to act on truth. I want to build empowering strategies based on what's true. Only God can help me do that. His truth always empowers and always frees.

Not impossible

Does it sound like an impossible journey? It's not. Empowering is an exciting, rewarding, affirming, and God-pleasing journey. It means increasing your trust in God's love for you and your child. It means the difference between struggle and freedom. It isn't a panacea that gets rid of all the difficulties and fears. However, with an empowering focus, even difficult times have new meaning.

Will you join me in this journey to learn what empowering means in your life as a parent and what it could mean in the life of your child? Remember—it's a

journey toward freedom. That's God's gift for anything you must give up along the way.

Empowering questions

1. What do you do for your child to make things easier? Does this empower or enable?
2. What experience or activity have you denied your child because of your fear? Did this empower or enable?
3. What behavior do you overlook because life is harder for your child? Does this empower or enable?

Empowering strategies

- Accept the realities.
- Don't pretend.
- Encourage honest talk about special-needs issues.
- Adopt language that affirms, encourages, and inspires.
- Never do for your child what your child can do for himself or herself.
- Be realistic about time, energy, and resources.
- Start somewhere.

An empowering prayer

Dear God,

You knew the challenges my child would face from the moment of conception and before. While this reality has changed

our lives in ways I don't even understand, there's nothing about it that surprises you. Thank you for your empowering words: "Do not be afraid," "I am with you always," "Nothing is impossible with me," "Do not let your heart be troubled," "I am the way," and so many more. Empower me to be your instrument of hope and stability in the life of my child.

I pray this in the power of the One who broke through life and death for me and who will do the same for my child.

Amen.

The truth will set you free.

—John 8:32