“Jolene Philo is like a trusted friend who anticipates our questions and supplies us with answers. She’s done all the heavy lifting—tracking down resources, exploring websites, recommending books and blogs. The resulting book is both a tool to be used and a testament to be savored.”
Holly Miller, Editor, The Saturday Evening Post

“Different Dream Parenting is full of practical strategies, tactics, and wisdom to help parents tap into medical professionals, the community, family, friends, and the faith-based community, to not only navigate the world of different dreams, but to embrace it and live life to its fullest according to all God has to offer. This book is not only informative but also inspiring for families. A must-read for any special family.”
Jackie Mills Fernald, Director of Access Ministry, the disability ministry of McLean Bible Church in Vienna, VA

“This book is a blessing to families with loved ones experiencing special physical or emotional needs. Different Dream Parenting offers sound and practical advice to families during experiences when clear thinking is difficult. Her book is a wonderful gift to families in the midst of crisis.”
Stephen Grcevich, MD President, Board of Directors, Key Ministry

“Different Dream Parenting is a critically needed resource for parents facing the unique responsibilities of parenting special needs children. This book overflows with practical information, medical resources, parenting stories, and spiritual wisdom rooted in Jolene’s experiences as the mother of a child born with medical challenges. Those who read it will come away equipped, encouraged, and feeling that they’ve found a friend who, too, envisions God’s dreams for their precious child.”
Shelly Beach, award-winning author of Precious Lord, Take My Hand: Meditations for Caregivers and Ambushed by Grace: Help and Hope on the Caregiving Journey
“Three cheers for Jolene Philo! Different Dream Parenting is chock-full of practical information, balanced advice, and insightful spiritual reflections. This easy-to-read book is a must-have resource for Christian parents who are embarking on the journey of raising a precious child who has special needs.”

Stephanie O. Hubach, Special Needs Ministries Director, Mission to North America, Presbyterian Church in America
Author of Same Lake, Different Boat: Coming Alongside People Touched by Disability

“When parents receive the news that their child has a special need, they are frozen in shock, not knowing which way to turn. Jolene’s latest book comes alongside parents when they are in their hour of greatest need. Offering spiritual as well as practical help, this book is a must-have on the shelf of every mom and dad who faces such challenges.”

Barb Dittrich, Executive Director, Snappin’ Ministries, www.snappin.org

“Jolene Philo has done an excellent job of researching and compiling a wealth of information in Different Dream Parenting, and yet it is presented in an interesting, easy-to-read manner. I recommend this book to anyone involved with children with special needs.”

Susan Osborn, author of thirty books
Different Dream Parenting

A Practical Guide to Raising a Child with Special Needs

Jolene Philo
To my father, who lived joyfully and with dignity in the face of disability, and to my mother, whose love for Dad never flagged during thirty-eight years as his caregiver.
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Introduction

I Didn’t Sign Up for This, God!

Have you ever had one of those dreams where you can’t move? The car is racing toward the edge of a cliff and you can’t lift your foot to press the brake pedal. An attacker is breaking down the door to your house and you can’t raise your arm to dial 911. Your child is about to run in front of a truck and you can’t open your mouth to scream.

My bad dream became a reality in 1982. My husband and I stood beside our son’s isolette in the neonatal intensive care unit. An IV needle pierced Allen’s tiny arm, and angry red scars crisscrossed his chest. One end of his feeding tube hung on a pole beside his IV bag. The other end rose from the soft skin of his tummy. Pain etched his wide forehead and tugged at the corners of his perfect rosebud mouth.

More than anything, I wanted to reach out and take his hurt away. But I was trapped in a bad dream. Immobilized. Inadequate. Helpless. Though God had assigned me to love and care for this
beautiful child, I could do nothing to minimize his pain. My thoughts were an inward scream. *This isn't what I signed up to do, God! I don't want to be a helpless onlooker. I want to parent my child. How can I care for him? What can I do?*

As the parent of a child with special needs, you’ve probably experienced the same sense of helplessness. Whether your child is critically or chronically ill, mentally or physically impaired, developmentally or behaviorally challenged, you want to do something. You want to ease your child’s pain, but you don’t know how. You want to help your child realize his or her full potential, but you don’t know where to begin. You want to ask God about your child’s suffering, but you don’t want to be condemned for questioning His wisdom. You want to believe God is with you, but you don’t know how to find Him.

You’re stuck in a bad dream. You can’t move. You can’t speak. You want someone to shake you awake and tell you everything will be okay. Instead, you wake up and must become the parent you never expected to be. You doubt that you’re up to the task. You’re worried about your child’s future. And you’re wondering, *Does anyone understand what I’m experiencing?*

The answer is yes, many parents understand your situation. In the United States,

- 10–15 percent of newborns, or 431,000 annually, spend time in neonatal intensive care according to the March of Dimes.
- 12 percent of children between ages 1 and 17 had medical conditions serious enough to require hospitalization between 2004 and 2006, the most recent years for which statistics are available at the Centers for Disease Control and Prevention.
- 13.6 percent of students between ages 6 and 21 were enrolled in some kind of special needs program according to the National Center for Educational Statistics. That’s 706,000 of our country’s school-aged children.
Lots of kids mean lots of parents, dads and moms who are valuable sources of information and advice. In this book, dozens of them share with you the wisdom they gained while parenting kids with special needs.

Support can also come from the surprising number of professionals who work with families of kids with special needs. These professionals—and the resources they’ve created—are available at hospitals, medical facilities, government agencies, private organizations, businesses, schools, churches, and more.

This book brings you advice from professionals around the country and provides information about national organizations and resources. It also gives tips about where to start searching for state and local resources. More often than not, your problem won’t be a lack of resources, but a lack of awareness of them or inability to access them.

Different Dream Parenting contains six sections: Diagnosis, Hospital Life, Juggling Two Worlds, Long-Term Care Conditions, Losing a Child, and Raising a Survivor. Each section is divided into four chapters. Three chapters address practical issues. The last chapter in each section addresses spiritual concerns.

Parents of kids with special needs often wrestle with prickly spiritual questions. I sure did. Sometimes I still do. So do all the parents interviewed in this book, and most of the professionals, too. Every day, we continue to ask questions about our kids’ lives and futures. Gradually, we learn more about how to trust God’s timing and wait for His answers.

As you read this book, please ask your faith questions. Read about how parents and professionals learned to ask questions, wait, and listen. Consider the answers they have discerned and their suggestions about how to find comfort and courage in God’s Word. When you are ready, try out their ideas about how to pray and use Scripture to hear God’s answers to your hard questions. The
thirty-day prayer guides in appendix A are designed to help you engage in conversation with Him.

But even with prayer guides and Scripture to guide you, I know how hard it can be to trust the God who is allowing your child to suffer. So I won't condemn you for asking prickly questions. Instead, I'll encourage you, cry with you, and support you when your faith grows weak. When you can't hang on a minute longer, I'll hold you close until your strength and your faith return.

I hope this book helps you break out of your bad dream, wake up, and move forward with joy and confidence. I pray that the stories of parents and professionals in this book will give you hope and strength.

Most of all, I hope you discover the truth God has revealed to me and many other parents. Raising a child with special needs isn't a bad dream. It's just a different dream. And surprisingly, a different dream can be the best dream of all.
Section

1

Diagnosis

From Ambushed to Advocate
Unexpected Advocate

When I get really afraid I come to you in trust.
Psalm 56:3

From the very beginning, put everything in God’s hand. Crawl right into His lap.
Cindy, mother of adopted son, Peter, who has fetal alcohol syndrome

Eric and Cheryl knew their two-year-old son’s speech skills weren’t developing as rapidly as his older brother’s had. Joel rarely spoke. When spoken to, he didn’t seem to process what was said. The public school provided early intervention speech services beginning at age two, but it took five long years before doctors diagnosed the causes of Joel’s delays and behaviors.

Diagnoses: Pervasive Developmental Disorder (PDD), Attention Deficit Hyperactive Disorder (ADHD), Auditory Processing Disorder, and Sensory Integration Disorder
Todd and Barb’s four-year-old daughter Jenny had always been a healthy, active child. But suddenly, the little girl didn’t have any appetite. She grew tired and pale. Her joints hurt. Because they had recently moved to a rural area, Barb took her to a doctor they had never met before. He said Jenny had the flu, arthritis, or leukemia. The doctor dismissed the first two diagnoses based on Jenny’s suspicious blood test results. A bone marrow test confirmed the third diagnosis. Jenny had leukemia.

Diagnosis: Stage 3 Acute Lymphocytic Leukemia (ALL)

Alice’s adopted daughter Nicole was an emotionally sensitive baby, overly anxious when her mom wasn’t around. By age two, Nicole threw frequent, huge tantrums. By age five, she often said she wished she wasn’t alive. Alice began to read books and research mental illness. The list of bipolar symptoms matched Nicole’s behavior, so Alice searched for a child psychiatrist qualified to diagnose and treat her daughter. Nicole’s been seeing her psychiatrist since age eight, and he continues to refine her treatment.

Diagnoses: Bipolar Disorder, Anxiety Disorder, Attention Deficit Hyperactive Disorder (ADHD), Post-traumatic Stress Disorder (PTSD)

Allen was born around midnight in a small town hospital. He was a tad small for a full-term baby, but looked perfect otherwise. Through the night his breathing grew labored. An early morning chest X-ray was inconclusive, so he was transferred to a nearby regional medical center for further tests. The newborn had a birth defect, or congenital anomaly, requiring immediate surgery at a hospital seven hundred miles away. Without it he would die.

Diagnosis: Esophageal Atresia/Tracheoesophageal Fistula (EA/TEF)
From Ambushed to Advocate

Four different kids. Four different sets of symptoms. Four different timelines. Four different diagnoses. But the moms and dads of these kids have one thing in common. Even before the diagnosis was made, as soon as they suspected something wasn’t quite right, they began the transformation from ambushed and shocked parents into extraordinary advocates and decision-makers for their children.

Since you’re reading this book, more than likely you know or suspect something is amiss in your child’s life. You want to fix it, but you also know your child’s condition requires more than typical parental first aid. More than a bandage to cover a boo-boo. More than a kiss and a reassuring hug to make it all better. Your child needs you to be an advocate. But, you wonder, what do advocates do?

The answer is simpler than you might think. Advocates speak on behalf of those who lack the ability to speak for themselves. They use their strengths to champion the rights of the powerless. Which sounds a whole lot like what parents typically do for their kids. You’re already trying to parent your little one well and make the most of the different dreams that accompany the diagnosis. But as a parent ambushed by a diagnosis, your advocacy duties are out of the ordinary, and your season of advocacy may be longer, more complex, and filled with unexpected challenges. So you are wondering how to go from ambushed to extraordinary advocate.

The answer is simple. Start where you are and move forward one step at a time. After receiving a diagnosis, you should develop a working knowledge of the diagnosed condition. To do that effectively, you have to listen carefully to what the professionals say and ask questions to fill in the gaps and clarify your understanding. This will prepare you to make pressing decisions. You’ll also be better equipped to explain the diagnosis to family and close friends. But for now, concentrate on the first things first: developing that basic understanding of your child’s condition.
Develop a Basic Understanding

Your child’s diagnosis could be a complete shock to you or the confirmation of long-held suspicions. Whatever the case, coming up with good questions in the wake of diagnosis can be hard. Hard, but not impossible.

If a diagnosis doesn’t require immediate action, you’ll have time to think and pray, research, and consult with others. You can schedule follow-up appointments, or get the doctor’s e-mail address or phone number to communicate when you’re ready. In the intervening time, prepare a list of questions with your spouse or someone you trust. Be sure to ask about

- Standard treatment and side effects
- Alternative or experimental treatments
- Cure or success rates
- Where to get a second opinion
- Practitioner’s familiarity and level of experience with condition
- Insurance considerations
- Locating families or support groups familiar with the condition

If possible, talk to the parents of a child with the same diagnosis and ask them for advice. If no one’s available locally, then check the Internet for a parent support group, chat room, or website about your child’s condition. The diagnosis information page at the Seattle Children’s Hospital website (http://cshcn.org/diagnosis-information) is an excellent resource for researching specific illnesses or conditions. However, your doctor may advise against Internet research. If that’s the case, skip the online component until you and the doctor feel you’re ready for it. When that time comes, check out the research strategies and resources found in chapter 2.
As your research proceeds, write your questions in a notebook and take it to appointments. When meeting with professionals, listen carefully, reigning in your emotions and fears. Be calm and polite and ask more questions if you don’t understand what’s being said. Ask for information to be repeated until you understand. And take plenty of notes so you can refer to them later.

In some cases, every minute counts. My husband, Hiram, was taking a shower at a friend’s house when the doctor called to relay our son’s diagnosis. The doctor asked whether we wanted Allen life-flighted to Denver or Omaha for immediate surgery.

“Can I wait to decide with my husband when he returns?” I asked.

“No, your baby needs to go now, before complications can develop,” the doctor said.

I took a deep breath and answered, “Take him to Omaha.”

Alice faced a similar dilemma when Nicole picked up a kitchen knife and threatened her mother. “I had to decide,” Alice said. “Let them take her to the hospital and have her feel like I abandoned her, or try to deal with her at home?” Hospitalization was the only safe option.

How does a parent make good decisions when there’s no time to lose? Over the years, my husband and I have learned to do four things in urgent situations. First, we ask God to guide our thoughts. Second, we assess the options to see if one is obviously better than the others. (For example, Omaha was a better choice than Denver because it was closer to family.) Third, we choose to the best of our ability. Finally, we trust God to honor our decisions made in good faith.
Once urgent decisions have been made, it’s time to tell others about the diagnosis. What you say to your child depends on his or her age, intellectual ability, and maturity. “What Do You Tell Your Child?” suggests basic guidelines, but you may want to get the advice of a child life specialist before talking to your child. More information about how to locate a child life specialist is found in the resource section at the end of this chapter.

Allow your child to ask questions. Answer those you can. When you don’t know the answer or don’t know how to phrase it, tell your
child you need time to find the answer. In a reasonable amount of time, come back with an answer or admit you couldn’t find one.

Whenever possible, break the diagnosis to your spouse, close family, and friends in person. If you have to use the phone, consider how the person will react. If the news is upsetting, call a pastor, friend, or coworker and tell him first. Ask him to be with your loved ones when you call them.

Who you tell is your decision. Depending on age, it could be your child’s decision too. If the diagnosis could be misunderstood by others or your child has strong objections to going public, you may choose to tell only a few trusted people. But generally, the more people who know what’s happening, the more support you and your child will receive. That support will be crucial in your new role as an advocate for your child with special needs.

Consider Your Next Steps

In the following chapter, we’ll continue to talk about how to become a more effective advocate. But for now, take time to reflect on your child’s diagnosis. Talk to God about how you’re feeling. Use the prayer below if you’re at a loss for words. Consider what to do next and who will help you. When you’re ready, move on to chapter 2. One step at a time. You can do it.

Dear Creator, this diagnosis is not what I want for my child. I don’t know how to be an advocate. I don’t know what to do. All I can do is crawl into your lap. Frightened and helpless, I put my trust in you and wait for you to show me what to do next.
Which concerns demand immediate action? Which require thought and further questions? Who can help brainstorm good questions to ask the doctor? Who needs to know about the diagnosis? Who can help break the news to others?

Resources

• For more information about your child’s diagnosis, see “Diagnosis Information” at the Seattle Children’s Hospital’s Center for Children with Special Needs website: http://cshcn.org/diagnosis-information.
• To locate a child life specialist, contact the closest children’s or university hospital to ask for the child life department, or go to your hospital’s website to search for “child life specialist.”
• To locate parent support groups, type the words “parent support group” and the name of the illness or condition into a search engine like Google, and then follow the links. Another option is to create a Facebook account, if you don’t already have one, and search for a page about your child’s condition. Often you can post questions for parents and professionals on these pages.