

# There's Sunshine *Behind* the clouds



Surviving The Early Years As a Special Needs Mom

By Andi Sligh

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For more information and other queries, contact  
[andi@bringingthesunshine.com](mailto:andi@bringingthesunshine.com)

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## Introduction

Have you ever boarded a flight when the weather was nasty? From the ground, the sky was dark and it may even have been storming. It was one of those dismal, gloomy days when all you want to do is go back home, climb in bed, and wait for the sun to come out again. The last thing you wanted was to get on a plane with turbulence.

But once that plane took off, soared up through the clouds, and leveled off at a safe cruising altitude, what did you see? Blue skies and sunshine for miles and miles, with beautiful puffy clouds beneath your feet like a bed of cotton. The weather didn't change, but your mood did, as you gazed across that beautiful sky. What was the difference?

Perspective.

# 1

## The Why Behind This eBook

In the early morning hours of December 22, 2002, five days before my daughter was born ten weeks premature, my husband and I sat alone in a small room in labor and delivery. The solitude wouldn't last long - my situation was too precarious and fast-moving for us to be without the requisite doctors, nurses, and other medical staff coming in and out - but it was long enough for things to feel as if they were crashing down around us. My husband leaned over, put his head in his hands, and said, "I can't do this again."

I had suffered a miscarriage four years earlier, given birth to a stillborn daughter with triploid syndrome the following summer, and struggled with infertility for the next three years. We had almost given up on having children of our own when I became pregnant with our daughter, Sarah Kate. We had rushed to the hospital because of sudden unexplained loss of blood that we learned later was due to a placental abruption.

More than a decade has passed since that night, and while I empathize with those younger versions of ourselves, age and experience have shown me that the devastation we felt was overblown and naive. Yes, our daughter has spastic diplegia cerebral palsy - a condition that means the muscles in her legs will remain contracted permanently. But instead of suffering and pain, she brought us joy and blessings.

### **Seven years later, I gave birth to my son, Nathan.**

We chose his name in advance because it is derived from Nathaniel, a Hebrew name which means “God has given.” After Sarah Kate was born, we gave up on our dream of having multiple children. We counted ourselves lucky to have her, and we were afraid that with her challenges we wouldn’t have the resources to devote to a second child. Sarah Kate and God had other plans, however. When we turned down her requests for a sibling, she took the matter up with God, and he answered her prayers.

Nathan was born by Caesarean section in March of 2010 on his father’s fortieth birthday; my husband followed him to the nursery while I was moved to recovery. He was ecstatic about his new son, who had arrived quite unexpectedly and slightly premature, and he was probably already looking ahead to baseball and fishing trips. When he reappeared a short time later, he had a faraway look and a somber expression, and sat down slowly in the chair next to me. I knew something was wrong, which he at first tried to deny. While he was in the nursery, he had overheard the nurse speaking quietly to the pediatrician on the phone.

## "They think he may have Down syndrome."

In the three years since then, I've read stories of mothers who were devastated when their child was born with Down syndrome, and stories of fathers who refused to accept their child for months or even years. A part of me understands this feeling. Nathan's diagnosis was a shock, to be sure, and the little we knew about Down syndrome was negative.

I can still remember that night and how I felt when the pediatrician came in to talk to us. I could see the fear in her eyes as she tried to cushion the blow by using words like "may" and "might." I didn't make it easy for her, either. I asked her directly what she meant by "might" - what did her gut tell her? She responded that she was pretty sure he did.

## I was shocked but not heartbroken, concerned but not devastated.

Nathan was alive, he seemed to be healthy, and we had done the whole "special needs" thing before. The challenges and the experiences would be different, but we had weathered the first storm of a child with disabilities, and I knew we could do it again.

## However, my husband's outlook was very different.

For the first 36 hours, my husband withdrew into a dark place inside himself. Late that first night, while he was sleeping, I emailed a few close friends and begged them to pray for him. I was fearful of what might lie

ahead. Because Nathan needed an oxygen hood, rooming in wasn't possible, but the hospital was small and the nursery wasn't far away. In the middle of the second night, I lay awake in my bed, filled with anxiety. I wondered if my husband would ever be able to bond with his son. I thought of my tiny baby boy and feared that his father would never be able to love him.

As I lay in the darkness, I was struck with the urge to get up and go to see Nathan. I struggled out of bed and headed down the hall, fighting the pain of my incision and dragging my IV pole alongside me. I didn't want my baby boy to be alone, and I was determined that he would know the love of one parent. In that moment, I loved him with a fierce passion that would have given me the power to do whatever it took to protect him, even if it was from the indifference of his own father.

By the next morning, I was beginning to worry about my husband's mental health. The entire day before he had given me absolutely nothing to go on, spending hours sitting in a chair barely speaking or even making eye contact with anyone. When he left the room for a moment, I called the nurses' desk and begged them to call our church for me and ask for someone to come. A short while later, one of our deacons arrived. My husband barely acknowledged him, but within moments after his departure, he stood up and told me he was going to work.

I couldn't fathom what would motivate him to go to work. I was certain he had flipped out completely. I briefly wondered if it was possible that he might not come back - that he would abandon us. But then he reminded me

that he impresses upon his employees that it's up to them to choose their response to what life throws at them. He said that it was time to walk the walk. From that moment on, he was a different person. A renewed person. A loving, doting father.

**Over the past decade, I've asked myself "Why?" too many times to count.**

It doesn't seem fair that our parenting pathway has been so rocky and I will admit to some envy from time to time of parents who have one or more...or a dozen...typical children. But that question no longer haunts me, because I've reached the point in life where I understand that "Why?" is a question without an answer; the why doesn't matter anymore. What does matter is that I embrace the two precious gifts I've been given, and that I look beyond myself to see and appreciate the meaning and purpose in shaping these special little people.

**If you're a parent of a young child who has just been diagnosed with a disability, please know that I GET IT.**

I have been where you are, and the view is frightening. You have probably been inundated with information about your child's condition, his need for interventions, possible treatments (or the depressing lack thereof), and his longterm medical prospects. It can be overwhelming and difficult to hear those things when not so very long ago you were dreaming of a very different child and a very different life for yourself.

In the pages ahead, I want to tell you what I've learned in over a decade as a parent of not one, but two children with disabilities, and share with you some suggestions of how to not only cope, but embrace your new life.

**It is only through experiencing sorrow that we know true joy - I want to help you find the joy.**

There is, indeed, sunshine behind the clouds.

## 2

### *Hang in There. It Gets Better.*

I'm not going to lie to you. It's going to be rough for awhile.

Whether you learned it from reading the books during pregnancy or from watching your other children develop, you probably had expectations of this child before he was born. You knew what he would be able to do and when he'd be able to do it, accepting that most developmental milestones fall along a spectrum. You were probably looking forward to the first smiles, first steps, and first words, and if you were anything like me, you may have envisioned exactly how those firsts would happen. You probably didn't expect your child's first steps to be taken in a therapy office amid wailing and promises of stickers, with you sitting on the sidelines. You probably didn't expect your child's preschool to send home his folder day after day with the word "nonverbal" circled.

You probably weren't expecting to take your child to a three year old birthday party with a walker, or to a daycare where he was the only kid not yet talking. You probably expected to spend your days out-and-about with

your child, but instead you stay home most of the time because it's so difficult to leave, even for a short time.

### The early years are tough.

I remember going to McDonald's with a group of moms who had children Sarah Kate's age and watching them sit around and drink coffee while their children ran loose in the Playplace. Rather than enjoying my own cup o' joe, I had my shoes off, following Sarah Kate through the equipment, lifting her because her legs couldn't, and wishing I were anywhere else but there. Backyard birthday parties were only marginally better. She could navigate a flat grassy yard in her walker with less assistance, but a two-hour party would cause a two-day exertion hangover. It was no fun.

Tougher still, though, was watching the other kids effortlessly run, climb stairs, carry large toys, and dance along to The Wiggles. While her peers were doing all of those things, Sarah Kate sat quietly at a table or on the floor. It was tough to see how much further along the developmental path they were, and how quickly they seemed to be traveling down that path. The comparisons were inevitable, and so was the question in my mind, "Will she ever catch up?"

**Unfortunately, the doctors and therapists didn't make things any easier.** Behind that first nagging question was another one: What will her future look like? Doctors should know these things, right? They should be able to make some kind of projections, right? But most of the time, the

answer was no, because they simply didn't have the answers.

If I have learned nothing else, I know this: doctors don't have the ability to predict what your child's future will look like, and if they say they can, find another doctor. Doctors often speak (and think) in terms of limitations, but there's no way to know what your child's limits are until she pushes them. Even if the doctors are right, a child is much more than her limitations.

Between the inevitable comparisons to typical children and the medical professionals with few answers, those early years may seem to stretch out before you like a bottomless pit of frustration and sorrow.

### **But it does get better, I promise.**

As for those other, typical kids? After a few years, their development will slow to the point where they are mostly just getting bigger, but your child will keep progressing at her own pace. **She may never catch up, but the chasm will stabilize for awhile, and when that day comes, you'll be able to breathe again.**

## 3

### *Replace Your Dreams with New Ones.*

Before the diagnosis, you didn't just look forward to those first steps and first words. You dreamed of soccer practice or ballet recitals or baseball team photos or the first high school dance. Like me, you may have hoped that your child would be able to do the things you were either never allowed to do or were never very good at - playing the guitar, swimming, or maybe even winning a photo contest. Your child was a blank slate upon which you could realize your own dreams, or, if you were more laid back, a child that you could nurture and encourage to discover her own dreams and make them a reality.

**It's time to let those dreams go.**

If they were dreams you wanted for yourself, then there's a good chance your child wouldn't have embraced them in the same way, even without the diagnosis, because she's a different person with different likes and dislikes and a different personality. But what about the smaller dreams - the ones

most people take for granted - the ordinary things like sports and school plays? It's okay to let those go, too. You don't have to bury them forever, but put them in a metaphorical box and put that box away.

**Accept that your child's big accomplishments may not be home runs or pirouettes, but ten unassisted steps or a twenty-word vocabulary of sign language.** Those things may seem small or insignificant now, but when they do come they'll be huge and hard-won. After weeks, months, or possibly even years of work and perseverance, each of those hard-won milestones will taste sweeter than any ordinary soccer goal or base hit.

Remember what I said about putting away those old dreams in a box? There's a tendency when your child is young to think in terms of what they'll never be able to do or what you'll never get a chance to experience. I didn't have brothers (or even an athletic sister) when I was growing up, so before Sarah Kate was born, I hoped for boys that I could shuttle around with all of their equipment to this game or that game. Even when I found out I was having a girl, I wanted her to experience sports - as a child in the 1970s in rural Alabama, sports opportunities were limited for me - and that was one opportunity I wanted to give her. Sarah Kate's diagnosis of cerebral palsy changed all that; I buried my dream of a daughter who would play sports.

**But a funny thing happened.**

At age seven, Sarah Kate asked if she could join the swim team. She had

just learned to swim the summer before, and she propelled herself mostly with her arms, not her legs, so we were reluctant. But for reasons I still don't quite grasp, I pushed outside my comfort zone and contacted the coach. She was the P.E. teacher at Sarah Kate's school, so she knew her and her limitations well, and she'd seen her swim a few times at the public pool the summer before. She urged me to let Sarah Kate swim, and we did. She's now in her fourth season of swim team. She'll never be an Olympian, and all of her swimming awards are rainbow-colored participant ribbons, but she has never once quit or failed to start, unlike some of her able-bodied peers.

A year and a half ago, she surprised me again by asking if she could play softball - not Miracle League, but regular rec league girls softball. It didn't seem possible to us that she could be successful, but we recalled how reluctant we were to allow her to join swim team and how well that had turned out, so we pushed past our fears and let her try. She's a slow runner - painfully slow - and grounds out a lot because it's rare for her to be able to beat the ball to the first baseman. However, she's a consistent hitter with a long list of RBIs to her credit, and she understands the game better than many of the other girls.

Sometimes it's difficult seeing how far back she is in the swimming lane, or how awkward her running gait is after she makes contact with the ball. But as tough as those things are to watch, it isn't tough to hear other parents talk about how courageous she is or how much they admire her. [\*\*My daughter is not a star in the conventional sense, but she's a shining light on the\*\*](#)

field or in the pool, and that's better than any accolades she'd receive as a stellar athlete. Your dreams may be retired or revised, but you'll still have dreams. Keep reaching for them.

If, before your child was diagnosed, your dream was to have more children, don't feel that you must give up that dream. Many parents worry that their child with special needs will need so much of their attention that the other children will suffer, or that they won't have the resources to adequately provide for more children. Other parents worry that the next child could have the same condition or, as in our case, a different but still challenging one. If these are your worries, my best advice to you is to do as I say, not as I (tried to) do.

Nathan was a surprise gift, but not once since his birth have I worried about whether both of my children feel loved or whether their needs can be met. Some sacrifices have had to be made, and options weighed against each other, and those decisions are often tough and leave us second-guessing ourselves. But I have no doubt that my children - both of them - are better off with each other than either of them would have been as an only child. If more children is your dream, don't be afraid.

The decision to have more children isn't a utilitarian set of arithmetic or one that should be driven by fear - it's a decision that must come from the heart.

## 4

### Ditch the Books.

One of the most popular book series on pregnancy, baby, and child development is the *What to Expect* series. These books are a wealth of information on what to expect at each stage of pregnancy and a child's young life, and they are written in an accessible tone for a wide audience. Maybe you read one or more of these books or similar ones while you were expecting, or had them gifted to you at a shower before or after your child was born.

**It's time to throw them out - all of them.**

Once your child was diagnosed, you probably acquired literature on your child's condition - I know I did. When Sarah Kate was born, the neonatalogist gave us a book on preemies, which I promptly read cover to cover. Later, when she was diagnosed with cerebral palsy, I sought out information because I wanted to learn everything I could about spastic diplegia so that I could prepare, or treat, or seek out therapies, or do a thousand other things to

help my child. When Nathan was born, I ordered books on Down syndrome from Amazon.com. I keep them on my bookshelf, but I rarely look at them anymore.

Like all of those baby books, the books on my children's conditions have a valuable purpose, but they are written in clinical-speak and enumerate in excruciating detail all of the ways in which my children aren't like their typical peers. Talk about depressing! The problem is that none of them take into account that my children are special individuals with unique personalities and talents, and none of them could begin to describe the unique blessings we have received from having them in our family. If you want to read and learn more about your child's condition, seek out books, blogs, and articles written by people who live it every day. You only need to hear the same medical information a few times, but you will always want to hear from other people that you are not alone.

**Research your child's issues as needed, ask questions of professionals when you're searching for a specific solution, and make friends in the disability community, but don't read the books on typical developing children.**

## 5

### Prepare for Your Inner Circle to change.

Let's face it - some people are uncomfortable with disability. People often react in a negative way to things that they aren't familiar with or don't understand. I wish I knew why that is, but I don't. I imagine that there are a number of reasons: ignorance, fear, a need to feel superior, an unwillingness to face their own mortality, simple peer pressure, and countless others.

Some of your pre-baby friends will be nice to you, but will look through your child, not at her, or assume that they don't have anything in common with you anymore, and drift away. We all have character weaknesses, so I want to make it clear that I'm not saying that people who don't accept disability are bad people. But by the same token, I'd rather spend my time with friends and family who love and embrace my differently-abled children than those who do not. It's better for everyone.

We were fortunate when Nathan came along, because our friends were

people who had already accepted Sarah Kate. Since Nathan was born, we've felt an outpouring of love for him from our family and friends, and we've gained new friends along the way. Many moms and dads aren't as lucky.

**But when Sarah Kate was young, the dividing line between those who embraced her and those who didn't was clear.** After awhile, I began to see that most people could be classified into one of three categories: (1) people who had "been there" and truly got what we were going through; (2) people who hadn't been there and didn't get it, but expressed a desire to learn, understand, and empathize; and (3) people who didn't get it and made it clear they weren't interested in doing so.

The first two groups are the people that I surround myself with, and they are the rocks upon which I can rest when it's a struggle to press on. The last group are the folks I don't waste my time on. It may sound like I'm being harsh or judgmental, but I'm not. I harbor no ill will to those who are polite but distant - I just accept that they're not at a point in their lives where they are willing to be what I would need them to be in order to be my friend. As for those who aren't polite and pleasant, well...we're all better off without them, aren't we?

Some of your relationships will change. That's the bad news.

**The good news is that you'll become closer to other people who will replace those friends in your heart.** Becoming the parent of a child (or two) with disabilities helps you more clearly see who you want to spend

the precious hours of your life with, and it'll be the children of your friends who will be your child's friends as he grows.

People who were previously friendly acquaintances may become your closest confidants, and you'll become part of a heretofore-unknown "secret society" of people with family members who share your child's condition. You'll discover a kinship with others outside of your child's disability community, as well. Although our specific issues vary widely, we parents of special needs children have a common thread of empathy weaving us all together. We know what it's like to navigate the worlds of IFSPs and IEPs, clinic appointments, missed milestones, medical bills, and rude comments, and **friendships are forged in the foxhole.**

## 6

### Let Her Be who She Is.

Depending on the severity of your child's condition, the hours spent with a therapist can range from an hour or two a week to multiple hours every day - and that's only counting the time your child spends working with someone else. Therapists are indispensable, and because they spend more hours one-on-one with your child than most doctors, they know more about your child's personality, temperament, and condition than just about anyone outside of your immediate family. You need them to teach you how to work with your child to help him develop, to tell you how hard your child can be pushed, and to keep a watchful eye in order to spot improvements or setbacks.

Over the years, my two children have worked with a lot of therapists that I know have had high hopes and expectations for my children, and that I know have done everything in their power to improve their lives; I count many of them among my friends. Something I've had to remind myself time and time again, though, is that they aren't my child's parent and they don't live my life

(or my child's). Sometimes, they set expectations that are difficult to fulfill, and that's okay - in fact, it's their job.

## **But know that no matter how much therapy your child does, It Will Never Be Enough.**

Don't beat yourself up if you decide, "we just can't do it today." I'm not telling you not to push your child – you should – but life can't be only about therapy. You need to accept that there are limits to what she can do - but never define what those limits are. Don't hold her back, but don't push her so hard that you lose sight of the fact that she's just a child...and you aren't superhuman, either. It's okay to back off, take a break, or even stop therapy that isn't working (just be careful about that last one - sometimes it takes awhile to see progress).

Sarah Kate doesn't know what it feels like to run fast or bound up a flight of stairs; she is what she is and that's all she knows. She's old enough now where she not only doesn't enjoy physical therapy, but she says so, and has sometimes actively resisted doing it. We've taken a hiatus from therapy on a few occasions, and while it wasn't great in the short term, I believe that her emotional wellbeing was worth the cost. As I write this book, we have reduced her therapy schedule for the summer and she is riding a three-wheel bike and doing her own stretching most days. Incorporating functional activities and beneficial play into daily life is as good as - and often better than - therapy done in a structured clinic environment.

While it's true that the greatest benefit from therapy comes in the early years, it's also true that cerebral palsy never goes away, and that Sarah Kate will need to find ways to manage it for many years after I have relinquished control over her schedule. She needs to figure out what she can do now, so that she can be her authentic, healthy self for many decades to come.

7

Dont Miss Out on the Magic Moments.

Specialists.

Therapists.

IFSPs and IEPs.

Medical bills.

Insurance claims.

Research.

Medical equipment appointments.

Alternative therapy options.

All of the things listed above can suck up your time - and suck the life right out of you, on some days. Oh, how I wish I could get some of the hours back that I spent arguing with the insurance company, rehashing my children's medical history for the new resident who's learning to be a "real" doctor under the watch of the specialist, and sitting in meetings where my child's educational rights were relayed to me for the umpteenth time. But, alas, I can't, so best just to accept the lost time and move on, because those wasted hours were mostly out of my control.

**What I can control is the quality of the time spent with my child, doing things that he likes - whether or not they qualify as therapy.**

It's a cliché to say that childhood goes by too fast, but it's true, and I think it goes double for families with special needs children. We have a lot to juggle, a lot to remember, and only a limited amount of time and brainpower to make it all work. Sometimes I'm too tired to fix dinner, much less hit the park for some playtime!

**Never forget that the first few years of a child's life can never be relived.**

Make time to do the fun things, even if you have to adapt them for your child's limitations. Take him to the park if he's able, or make up a different activity if he isn't. Don't shoehorn yourself into a place or an activity that's not suited to your situation, but also don't be afraid to take a chance on something you think may be out of reach. Your child may not remember a lot

of what happened in those early years, but you will.

### **Enjoy him while he's still small.**

And you know what they say during those airplane safety talks about putting your own mask on first before helping others? It's true down here at ground level, too. Eat, sleep, and take care of yourself so you can be a better parent to your child. It's easy to justify sacrificing your own needs for your child's, but you'll both be happier and enjoy each other more if you're rested and relaxed.

## 8

### Become who You Were Meant to Be.

Do you know who you were meant to be? That's a tough question for most of us to answer. I know that when I was growing up, who I was meant to be equated with what my occupation would be. I wanted to achieve something - to have something tangible I could point to and say, "I did that."

Before I became a mom, I worked for a little over a decade as an electrical engineer. At my first job, I designed lighting and electrical systems for commercial buildings such as churches, schools, and offices. Later, I worked for a large investor-owned electric utility company first as a distribution and transmission design engineer and then in commercial account management. Setting aside the personalities, pay, and work environment of each position, I can say without a doubt that the work I liked best was what I did at my first job. I could, literally, drive by a building, point to it, and say, "I did that."

I've now been out of the professional workforce for the same amount of

time I was in it, and I draw satisfaction from the drudgery of laundry and cooking and therapy by pointing to Sarah Kate and Nathan and stating proudly, "I did that." **My children aren't perfect, my life isn't perfect, and I'm certainly not perfect, but I think we've got it pretty good.** My children are loved, cared for, challenged (in the good ways), and happy, and that makes me happy.

But there's more to life than my children's happiness. All of those years that I asked myself, "Why?" were the precursor to the day when I would ask myself, "How?" - *How can I use this life that I've been given to become a better person and to enrich the world around me?*

Becoming a parent of a daughter with cerebral palsy and a son with Down syndrome has taught me patience, empathy, and compassion. I've overcome my fear of writing for the world to read, and I've become a staunch defender of those who are limited in their ability to defend themselves. As someone with a lifelong fear of rejection who has struggled with perfectionism and a need for approval, the changes in me are simply amazing. But even more than those things, I'm different now because I'm better able to appreciate all that I have and dwell less on what I do not. **I am a work in progress, becoming the best version of me that I can be.**

I challenge you to do the same.

## 9

### Conclusion

I'm not a doctor, a therapist, a psychologist, or anyone else with official-sounding credentials, so you can feel free to dismiss everything I've said in this e-book with a wave of the hand and a bit of snark about my audacity...and that's okay.

What I am is a mom who has been through the special needs ringer twice, has made some mistakes, and has come out on the other side with an attitude of gratefulness for my good fortune. I hope that within these pages you've discovered a gem or two that made your burden a little lighter or gave you a little more hope than before you started reading.

If you like this e-book and you know someone who could benefit from reading it, please [share it and spread the word!](#) If someone shared it with you and you would like to know more about our ordinary yet extraordinary family, visit me at my blog, [Bringing the Sunshine](#).

## About the Author

Andi Sligh is an ordinary mom living an extraordinary life on the gulf coast of Alabama with a daughter with cerebral palsy, a son with Down syndrome, an adventurous husband, a wild Westie, a rescued Schnoodle, a camera, and a worn out pair of running shoes. She blogs it all at [Bringing the Sunshine](#) and tweets a little [@AndiSligh](#). Her work has previously been featured in Dandelion Magazine, on WhattoExpect.com, and on BlogHer.



## Connect

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