

HOW TO RAISE A CHILD *with Special Needs*



A GUIDE

KAMERON MOODY

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On February 18, 2011, I began a very unexpected and challenging journey: being a mom to a child with special needs. That was the day our son, John Austin, was born, and the day we found out he had Down syndrome, or Trisomy 21.

To say the news rocked our world is an understatement. John Austin came into the world with a host of issues, including having to spend five weeks in the Neonatal Intensive Care Unit (NICU) battling breathing and feeding challenges. He also was diagnosed with transient myeloproliferative syndrome, a form of leukemia that occurs in about 10 percent of babies born with Down syndrome.

My husband, Caleb, and I spent those five long weeks racing back and forth between home (and our fifteen-month-old daughter, Avery) and the hospital. The weeks seemed an endless procession of tests, blood work, occupational therapy, and watching and waiting to see how he progressed.

There were discussions about a bone marrow test and possible chemotherapy, and a recommendation that a feeding tube be surgically placed. We were overwhelmed by what seemed an insurmountable list of medical decisions that had to be made. But throughout all the stress, frustration, and sadness, we were constantly encouraged by the strength our son showed during his time in the NICU. He was, and is, a little warrior. It is heartbreaking to see so many tubes

and wires attached to anybody, let alone a seven-and-a-half-pound infant. But John Austin was “strong,” “determined,” and “resourceful” — words used by his nurses and occupational therapist to describe him.

Over the five weeks he spent in the hospital, the transient leukemia resolved itself, and we were able to take John Austin home needing only a small amount of oxygen. The feeding tube surgery was not necessary, as our son worked so hard to learn how to breast- and bottle-feed that he gained four ounces in a day, proving he could eat on his own.

The day we brought him home from the hospital was one of the happiest days of my life. We jumped right in, learning how to treat Down syndrome, what therapies he needed, what kind of supplements he could take, and just enjoying getting to know him.

As I write this, John Austin is a thriving three-year-old boy who loves his family, books, Mickey Mouse, buses, trucks, dancing, and playing music. He lives a very full life, including preschool and a lot of therapy.

Raising a special little person takes the same skills necessary to raise any child, and more. My son is only three years old, so I don't have all the answers. My husband and I will continue learning and growing as our son grows. There will be new challenges and new opportunities. I am certain that what I have learned so far will come into play as we move through life together.

Here are some of the most important skills I have learned that allow me to be the best parent possible to my son with special needs, and to my daughter, too. My goal in sharing these with you is to give you hope, encouragement, and tangible tools to help on the wonderful, inspiring, and deeply rewarding adventure of raising your child.

1. *Become a Superhero*

It's time to activate the superhero powers you have.

Omnipresence (being able to be in multiple places at one time)

Yes, you can learn to juggle the demands of your new life, but it will take some adjustment. You will eventually learn how to make it to your child's therapy appointment(s), take your other child to a play date or birthday party, have lunch with a friend you hardly ever see since becoming a mom, research the latest treatment options for your child, go to the grocery store, do laundry, shower, make dinner and tomorrow's lunches — all in one day. The key is to become a master at scheduling. Make a list, a plan of what needs to be done each day and when appointments are scheduled. Prioritize the list. Then work your plan. Stay realistic, patient, and flexible. Know that in the beginning it will all feel overwhelming, and start small. You may not be able to do everything you want, but try to get the most important things accomplished. Put yourself and your needs at the top of the list at least once a week.

Learn how to let go of unnecessary stress. You might have to set some boundaries with people in your life who are “energy suckers.” You simply do not have time to keep up with everyone in the same way you used to. This might apply to friendships, family members, even work relationships. This “cleaning house” of all the extra, unwanted stress in your life will make more room for you and your child's needs.

Eyes in the back of your head (self-explanatory)

This is a must all the time. And it's especially helpful when your child begins walking, makes a mad dash out of the Gap Kids store, and heads straight to

the child-swallowing escalator and into the arms of a very nice, middle-aged woman, where he stays for the two-to-four minutes it takes you and your husband to realize that the other one doesn't have him like you both thought. If your child has what behavioral therapists so cutely call "elopement" issues, this is the power to activate. Elopement means your child will often choose to do what he or she wants without knowing the possible dangers involved. That means the child might wander off or run away from you in places like parking lots, busy streets, parks...the kind of thing that literally stops your heart from beating. Get used to watching carefully, paying attention to where your child is and what he or she is doing at all times. For the first time in my life, I understand why those parents at Disneyland had their children on leashes. I used to be horrified at the sight, but if my husband were okay with it, I would buy one today. Until then, behavioral therapy is very helpful with treating elopement. We have John Austin in this type of therapy several times a week.

Stoicism (the ability to turn off emotions at any given moment and just accept what is happening)

This is a must-have skill. It comes in especially handy when a developmental pediatrician who assessed your child for less than 30 minutes tells you that despite the 13 therapy appointments a week you drag your child to, his fine motor skills are those of a 15-month old, not those of the 35-month old he is. The best way to stand up for your child and to support yourself is to remain peaceful and detached from the opinions of others, even health care professionals. Get used to responding with, "Thank you so much. I will work harder with him." Then smile and walk away calmly.

Trust me on this. I know from experience that yelling at said developmental

pediatrician, pointing out how things have changed since the 1950s when she started practicing, so she needs to update her assessment tools and her attitude toward your child, and then turning into a blubbing mess and going home to rush through bath and bed so you can open a bottle of wine, throw a pity party, and watch mind-numbing reality TV while eating chocolate (organic of course), are not nearly as satisfying as they seem. Instead, get really good at taking deep breaths and walking away. You have enough stress, so don't intentionally create more for yourself. Also, remember that the people assessing your child are only seeing him or her for a limited amount of time, are using standardized tests, and have to make their assessment based primarily on what they observe. They aren't there during those precious moments when you witness your child achieve something that he or she has been struggling with, if only just for that one time, not to be done again for months. Celebrate the little things with your child and try not to get discouraged by the many assessments a child with special needs unfortunately has to go through in order to keep receiving services. Assessments are part of the deal, but they do not define your child and are not indicative of what your child is capable of achieving.

2. Accept that none of the above is completely possible and allow yourself to be human.

You can't be everywhere at once. Things will slip through the cracks and you might accidentally lose track of your child for a brief moment. Accepting that you cannot be everywhere at once and that things will happen beyond your control is a big lesson for all parents, not just for those of kids with special needs. I pray daily for John Austin's guardian angels to surround him, and so

far they have been doing a pretty great job.

Let go of the idea of being the perfect parent. Throw out the manuals you downloaded from the Baby Center web site when you were pregnant (especially the one that outlines the milestones and at what age your baby should reach them). Realize you are raising a very unique child and that you and your partner will have to figure it out as you go.

Sometimes having a so-called “imperfect” child is what finally breaks our pressure on ourselves to be perfect, because we realize just how much we can love a little being who isn’t fitting into the societal mold that we had envisioned and who might not be developing at the rate of the typical child, but who in his or her own way is “perfect” to us and all who meet him or her. It’s okay to not always have everything figured out and to make mistakes. There is beauty in the imperfections, so let yourself off the hook. It will feel very freeing. This is one of the biggest lessons my son has taught me.

3. Let yourself feel everything when you feel it

You will be surprised at the range of emotions that will overwhelm you after getting any kind of diagnosis, or even after realizing that your child isn’t developing typically and needs extra support. The depression, anger, denial, and acceptance we go through are all feelings that accompany the stages of grief. It is normal and healthy to go through these, because when you realize you are the parent of a child with special needs, you experience grief.

It took me a while to come to terms with this. At first I had guilt about feeling depressed or angry about my son’s diagnosis. I wanted to celebrate him, accept him completely, and love him unconditionally. And I did feel all those

things, and still do, but it isn't rainbows and unicorns all the time.

There is a sadness that accompanies the journey of a parent who has a child with any kind of issue. You have to mourn the loss of the child you had envisioned — the child with no health problems or developmental delays. Parents dream of their children as being perfect, healthy, and normal. That was my daily prayer when I was pregnant with both my children. No parent wants to see their child suffer, or be different, or get made fun of, or feel left out. Unfortunately, this can happen to kids who have special needs, and it can happen to typically developing kids too. It can feel isolating to you as the parent.

It's tough when you're at the park, for example, to see children your child's age doing things your child can't do yet, or may never be able to do. To catch the stares of people who notice something different about your child. It can leave you holding a ton of messy, ugly feelings that may or may not make sense.

It is important to allow the feelings to come up, talk about them with someone you trust, or journal about them, and do not judge yourself for having them. Accept that you will not be able to harness all the multi-layered emotions that accompany being a parent, especially a parent of a child with special needs. Feel what you feel, because everything you are feeling is real and normal. It is healthy to honor your emotions.

4. Take care of yourself

In the three years since my son's birth, I have felt just about every emotion known to man, and I have dealt with them in healthy ways — and sometimes not so healthy ways (like wine, chocolate, and bad reality shows). You have to find what works for you and do it, often.

A lifesaver for me in the beginning was to see a counselor. Also, it was vital for me to get support by connecting with other parents who had a child with similar issues. Exercise helped tremendously to release stress and maintain my health. It also helped to pamper myself, like with a manicure or massage or long lunch or dinner with a good friend.

Get support even if you don't think you need it. It's easy to forget about or ignore yourself when you are dealing with the challenges your child is facing. We all experience denial. Stress is a big killer, so accept that you will live with the strain that can come with raising a child who has special needs. You must make it a priority to take care of yourself.

Remember what they tell you on an airplane: In the event of an emergency, if you are traveling with a child, put the oxygen mask on yourself first, then your child. You are no good to your child if you aren't alive or have passed out from too much wine. Find healthy ways to love yourself and do not feel guilty for taking the time to care for you.

Having a supportive partner will really help you to do this. Part of maintaining the healthy relationship you and your partner have is to encourage each other to focus on yourselves, too. If you don't have a partner, seek out the support of a close family member, friend, or neighbor who can step in on occasion to give you a break. If none of those options is available, check with

your pediatrician for support that might be obtainable through nonprofit organizations that offer help to families who have a child with developmental disabilities. It varies by country and/or state, but most cities now have some sort of program to offer assistance. Often there are services that provide in-home care for your child at no cost to you, so you can take care of yourself.

5. Keep expectations high for your child

It's easy to become discouraged with the way others might perceive your child. I remember when John Austin was born, I Googled Down syndrome and read about many of the dire possibilities that could happen to him: early Alzheimer's, cognitive decline, heart issues, thyroid issues, never having a job or getting married or living independently.

In my Googling phase, however, I thankfully came across a site called Einstein Syndrome. It was started by a woman who has a daughter with Down syndrome. She writes about how different it would be if, when our children were born, instead of hearing the doctors say "Your child has Down syndrome, and these are all the things you need to be concerned about..." we heard instead, "Your child has Einstein syndrome!" "Your child will be so smart!" "Your child is so advanced!" We would automatically have high expectations for that child. Instead, what we hear from doctors the moment we realize that our child has special needs is all the negative things about that diagnosis, or what to watch out for.

Surrounded by negativity, you tend to let go of the dreams you had for that child, and those dreams get replaced by worries and sadness and thoughts about all the things your child won't do. What the Einstein Syndrome listserv

encourages parents to do is to set high expectations for their child, believe in his or her potential, and not be limited by what modern science might say. Look at alternative treatments and always keep an attitude that your child can achieve.

I am always encouraged when I see stories about a person with Down syndrome who owns his or her own restaurant, or has started a charity, or is married and lives independently. These are some of the things I want for my son, and letting go of the limits the diagnosis or the medical community places on him helps me to have hope for John Austin and his life ahead. My favorite Bible verse for him is Matthew 19:26: "But with God all things are possible." My child may have Down syndrome, but it doesn't have him. I believe that God has great plans for John Austin.

6. Get spiritual

Since I am on the subject of God, I will say this now. You cannot go through life with a child who has special needs without spirituality. I mean you can, sure, but it will be a lot more difficult.

Having our son brought me so much closer to God, and I am thankful for that. My faith is something much greater than myself. It is the one thing that got me through five weeks in the NICU. I lean on my faith during the regular blood draws to check that the leukemia hasn't returned, to make sure the leukemia hasn't returned, which is a risk until age 5 for a child who was born with transient leukemia. When I check the oxygen at night for his sleep apnea, and to get through the overwhelming amount of therapy and doctor's appointments he has to go to. I leaned on it during his hospitalization for pneumonia when he was eighteen months old.

It was necessary to entrust God with my son's care a long time ago. I pray daily for the wisdom and strength to get through whatever challenge we are dealing with, or just to be the best parent I can be to both of my children. I have seen God work in my son's life since birth. That first hour of life, when he grabbed my husband's finger and looked deeply into his eyes, as if to say that things were going to be rough, but that he would be okay. Being healed of leukemia at five weeks, when the blast cell numbers went down, with no treatment, until there was no trace of the disease left in his body. Rolling over for the first time at five weeks old, having just gotten out of the hospital and with low muscle tone — much earlier than what is expected of a typical child. Being diagnosed with severe obstructive sleep apnea at six months old, and with each sleep study, the sleep apnea improving to the point where it is now almost completely resolved. Severe acid reflux that required medication when he was an infant and toddler just going away, with no medication necessary now. Using words and sentences much earlier than they tell you to expect from a child with Down syndrome. And praying, with his little hands folded at his chin, as he lists off people in his family for God to bless before saying an adorable approximation of "Amen!" I can tell you with certainty that God works in John Austin's life, and by His grace our son has overcome so much, and will continue to.

For me, leaving God and spirituality out of our journey with our child would be like going through a 12-step program without doing the second step, believing there is a power greater than myself. I am not talking about religion, or saying one way is better than another. I am saying to look to something greater than yourself to help you raise your child and to trust in that divine love. For me, I derive a deep sense of peace and comfort in drawing close to

God and having faith that my son's life is in greater hands than mine.

7. Be a warrior parent

Before John Austin was born, I was the type of person who didn't like to ruffle feathers. It was hard for me to speak up at times, for fear of hurting someone's feelings if I didn't agree with them. Too often I remained in situations that were not best for me. All of that changed with the birth of my son.

My transformation into a warrior mom began in the NICU. Doctors were pushing hard for my son to have a feeding tube surgically implanted before we would be allowed to take him home. Something in my gut told me the feeding tube was unnecessary. Intuitively I felt certain that if we could just get him home, we could get into our own routine and he would be able to eat on his own for every meal. So I requested to stay overnight at the hospital, and my son and I worked very hard for 24 hours to see how much weight he could gain with just bottle- and breast-feeding.

I stayed up all night talking to him, telling him how important it was for him to stay awake long enough to eat so he wouldn't have to have surgery. I challenged his doctors when, even after John Austin gained four ounces in the first day, they still wanted to do the surgery. We were reluctantly told we could take him home, but that most likely he would be back. The pessimism of the physicians made me even more determined. Warrior mom and dad got busy. My husband and I are proud to say our son has not missed one meal since coming home from the hospital.

As a warrior parent, you are an advocate for your child. You research the

latest developments about your child's issues and take an active role in every aspect of his or her treatment. Warrior parents listen to our parental instincts and challenge recommendations the medical community makes that don't feel right. We educate ourselves about every treatment option, medical intervention, and alternative approach available.

As a warrior parent, feel free to change any doctor or therapist you don't believe is doing the best for your child. Get second and third opinions before making any big decisions. And don't be afraid to strike out on your own.

I have a friend whose child has a rare genetic condition about which very little is known. She became so frustrated with the lack of understanding among the mainstream medical community that she started a foundation and began fundraising to increase awareness, support research for her daughter's condition, find effective treatments, and create better understanding.

It is empowering to be an active participant in your child's treatment. And you will make a difference to the children within your community who have the same special needs as your child. Those types of contributions are always worth the effort.

8. Let your child be a kid, and let yourself enjoy being a parent

The everyday demands of life with a child with special needs can be overwhelming. Life can easily become a never-ending pursuit of the latest treatment or different therapies for your child. It is easy to lose sight of the fact that your child is still a kid who needs to just be a kid.

One thing that really helps me is to give John Austin a couple of days a week, usually on the weekends, free of therapy, supplements, or home exercises. We allow a little television — his favorite children's programs. We go to the park or to his favorite restaurant. We schedule play dates with friends or go to a movie or the beach. Not only does John Austin appreciate the time to enjoy being a child, my husband and I treasure just being a parent to our beautiful son.

It is important to forget about the diagnosis and just spend time connecting with each other. We take weekend trips to intentionally get out of the house. A change of scenery allows our minds a break from the constant physical reminders of our daily life as the parents of a child with special needs.

Part of being a parent to a child with special needs is to not let all that goes into raising him or her overtake your life. Your child's special needs are only one part of your life. While at times it can feel like there is no room for anything else, it is important to make time for fun, adventure, and just being together as a family.

9. Love your child's specialness

Our primary responsibility as parents is to shower our children with love. Loving means accepting everything about them, giving affection without limitations, and never diminishing that love, regardless of circumstances. We take care of their physical, emotional, mental, and spiritual needs. We do everything within our power to give them the best quality of life. And as parents of children with special needs, we love the specialness of our children — a specialness that may not have been the same if they had not been born as they were.

For example, John Austin is incredibly sensitive to the feelings of others. He knows exactly who needs hugs and gives them generously. He is a social butterfly, and loves to connect with people. He has no inhibitions when it comes to saying “hello” or “hola” to everyone he comes into contact with. He brings smiles to people wherever we go.

There is something different about John Austin in such a positive way because of his having Down syndrome. And I appreciate that about him. Maybe some parents of children with a disability do not feel that same appreciation. I certainly understand. I often struggle between acceptance of my son as a gift and wanting the Down syndrome to be miraculously taken away.

In the end, I believe God created my son exactly as he is for a reason. I think John Austin and other people with disabilities are blessings, here in the world to teach us acceptance, unconditional love, and the benefits of letting go of control. So I love my son and all the ways that Down syndrome makes him one of the cutest and sweetest little guys around. And I do everything I can to help him live the fullest and best life possible.

Regardless of how we'd love to have life be different for our children with special needs, the most important thing is to not let their disability get in the way of the love we have for them. It is true that love conquers all, so loving our



children unconditionally is the most important and easiest thing we can do as a parent.

My husband and I are still in the early stages of learning about raising a child with special needs. What I share above is what I have learned so far. This is what works for me. I am certain as time goes on I will be able to add to this list, because every day with my son I learn something new. Each day I realize some new way that being his mom has changed me, or something about me that I need to examine.

I am thankful for my son and feel blessed to have the privilege of being his parent. As my husband always says, "We are the ones with special needs. It is John Austin and others like him that are the ones with special gifts."

Resources:

National Down Syndrome Society

<https://www.ndss.org/Resources/>

Einstein Syndrome Listserv

www.einstein-syndrome.com

Trisomy 21 Talk

<http://trisomy21.discoursehosting.net/>



www.RomancingYourSoul.com