

30 Prayers for Special-Needs Parents

edited by Sandra Peoples
and Caroline Flory



Join us at specialneedsparenting.net and remember you are **Not Alone!**

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30 Prayers for Special-Needs Parents

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Diagnosis Day
Sarah Broady

*"I cry out to God Most High,
to God who fulfills His purpose for me."
Psalm 57:2 (ESV)*

December 20, 2007. I finally made the appointment for an autism evaluation. We went just to "rule it out" at the suggestion of a friend who happened to work with special-needs kids and had concerns about my twenty-seven month old son, Samuel. I took tests that I felt completely unprepared to take as I answered questions about his development—how and when he talked, how he played with toys, "what-if" scenarios such as, "If you gave him a baby doll and a bottle, would he feed the bottle to the baby?" "Probably not," I answered, "considering I only have boys and we don't own toys like baby dolls and bottles." But her pencil was already scribbling away. Hours later, the psychologist showed me his evaluation results, coloring over the line on the graph that separated "moderate" and "severe" on the autism spectrum. She had given him the most benefit of the doubt, yet he still fell on the edge of the severe end of the spectrum.

I had entered the doors of the regional center with my two-year old boy. But I left with a two-year old boy *with autism*. That sounds strange, since *he* didn't change in those four hours. He was the same kid I had dressed and fed that morning. But now he wasn't just my son. It was official. He was my *broken son*. And I wanted my boy back—unbroken.

There are a host of emotions that we parents of kids with special needs go through when our child's disability becomes "official." All the pictures in our heads of our children going through life disappear, like the picture in *Back to the Future*. Dreams we had for our child die and are replaced with emptiness because we have no idea what to expect. Fear replaces typical parental anxiety. Confusion sets in as we try to get a grasp on what this diagnosis really means. We desperately try to understand it so we can control it. We figure if we can control it, we can change it—like watching the newspaper heading change back to normal in the movie. But we know it's out of our control. Obviously so, because we sure wouldn't have chosen disability for our kids. That doesn't make sense. We only want the best for them. Disability doesn't fit that description. And we struggle for years to accept this "new normal" we didn't ask for.

Our world is broken, and disability is part of that brokenness. But God is working to make it unbroken. He has a plan for each of us, and that plan doesn't exclude our children with disabilities, or even the disability itself. God created each of us uniquely in His own image. Disability might appear to mar that image like a reflection in a shattered mirror; but in fact, God is shining His light on the broken pieces to reveal more of Himself to us and to the world. A lot more light reflects off a broken mirror than a whole one.

I wish I had been able to think and feel what I do now about autism when Sam was diagnosed. But that's not how grief works. There's a process to go through; it's not immediate. I've come to learn that my son *isn't broken*. Autism is the result of brokenness, and Sam struggles with

how it affects him. My job isn't to "fix" him. My job is to do everything I possibly can to teach him how to love, obey, and glorify the God who created him. I can help him learn how to live with autism and cope with the challenges he faces because of it so that he can reach his fullest potential and fulfill the plans God has for him. And in the meantime, I anticipate the day when Jesus fully restores all of His creation and makes everything new and whole again. Join me, won't you?

Father, I mourn the loss of the child I thought I had. I grieve the dreams for the future I had for him before I even saw his face. Help me to accept this gift You've given me, despite his disability. Teach me to see the heart of my child and not his disability. Strengthen me to face my child's special needs with grace and love, and the wisdom to lead my child in the true knowledge of his Lord and Savior, Jesus Christ. Fulfill Your plans in him. May he come to love You, serve You, and honor You with his life. Amen.

When You're without a Diagnosis

Caroline Flory

*"I cry out to God Most High, to God, who vindicates me."
Psalm 57:2 (NIV)*

When our firstborn was born, my husband and I fell hard and fast in profound love. From his intense stare and his wrinkled forehead to his flailing limbs and his deep dimples when he sleep-smiled, we were in love. My pregnancy was unsurprising and very "textbook."

That was the last thing "textbook" about our son.

At one month old, we found out about an irreparable (but, so far, manageable) heart condition. At least it's a diagnosis, right?

That was pretty much the last official diagnosis for our son so far.

A little before he was two years old, we were thrown in the medical world of genetics. A simple chest x-ray to check for a respiratory infection showed some skeletal malformations and then hundreds of tests after that, some of which are ongoing.

The first doctor told us our son would likely not live past his teenage years because of what this doctor thought was a degenerative condition.

I was halfway through another pregnancy at the time. You can imagine the tears.

Thankfully, subsequent doctors do not believe our son has this group of degenerative conditions. But, as doctors have told us since then, science hasn't caught up with our son yet.

With apraxia, stomach issues, chronic lung disease, heart conditions, skeletal changes, aspiration, and more, our son definitely has *something*. But, no one knows yet what to label that *something*.

So, we wait.

What would a diagnosis do? Would it really *solve* any issues?

No, it wouldn't make his medical and developmental conditions disappear. It wouldn't spell out all the best treatments. It wouldn't necessarily even convince insurance to cover more of his therapies and medications.

But, it would provide *some* ideas on treatments, dole out *some* hope, and perhaps offer a chance to find community with other families.

Waiting is not easy, is it?

Even though we wait, we still see God's hands in our situation. We see our son's innate joy and how he thinks hospital stays are to make new friends. We see our therapists always willing to change their strategies to match our son's development and needs. We see the timing of new tests becoming available and doctors who look for those chances.

God is in this situation, even in this waiting.

If you and your family are waiting for a diagnosis, it's okay to cry out to God in frustration, fear, or despair. It's okay to ask yet another question to yet another doctor *just in case* it leads to new answers. It's okay to need a day of downtime just to recoup from this chaos in life.

It's also okay to cheer for every new goal met and progress made.

It's okay to see how doctors and therapists work for the best care they know how to give even *without* a diagnosis.

It's okay to cry out to God one second, and praise Him the next.

God is here, even in this, every step of the way.

God, we lift up all of the families without diagnoses and all the hassles and heartaches that accompany these situations. Help us pray Psalm 57:2 when we cry out to You, and help us remember Joshua 1:9, that You are here. Thank You for being with us through every day. Amen.

Choosing Joy Because We Are His (Even on Evaluation Days)

Caroline Flory

*“Know that the Lord is God. It is he who made us, and we are his;
we are his people, the sheep of his pasture.”*

Psalm 100:3 (NIV)

One of my favorite writers, [Sara Frankl](#), fiercely adopted the phrase “Choose [Joy](#)” through her too-short life as she battled extremely rare, painful, and degenerative medical conditions.

It’s a phrase that constantly appeared in her writing, in her art, and, subsequently, in her friends and readers.

It’s a phrase we all might need more and more, through exciting times and through trials, including on evaluation days.

Evaluation days in the special needs world can be *tough*, particularly initial ones. As you’re just beginning to learn about your child in ways you couldn’t have prepared for, teams of people enter to tell you *even more* you probably weren’t expecting.

My son’s initial medical evaluations always brought stress of the unknown. We didn’t know *what* the doctors would say since no one can figure out exactly what conditions he has.

During those same months of initial medical evaluations, my son began having numerous developmental evaluations. There’s nothing like a (well-meaning) team of people who are just meeting your child to then tell you how “behind” and delayed your child is from normal milestones. (If you’re at this point now, know this: after the sting, you and your wonderful team *will* find ways to support your child. The stumbling block becomes a stair step.)

Maybe you, like I did, feel overwhelmed at the responsibility of so many new therapies and “shoulds” and “need-to-dos” to help your child grow. Maybe you grieve over lost dreams and more obstacles. Maybe you feel like *something* has to be your fault because, if it was, that means you must be able to do *something* to “fix” it.

At these points, I try to remember verses like Psalm 100:3 – we are created by God *for a reason*. We are His, *on purpose*. The verses before and after this one in Psalm 100 shout joy and praise. Why? Because God loves and He loves *forever*. Because we are God’s, we can remember what Sara always shared, through happiness and through challenges: choose joy.

God made my son different, but that doesn’t stop his joy and it doesn’t have to stop mine, regardless of what any evaluation says. God made my son and forever loves him because he is His, and I’m eternally joy-filled that God chose him to be mine in this life.

God, we lift up all of our children's evaluations to You. Help us see the good amongst the challenging, and help us choose joy through it all because we are Yours, and You are good. Thank You for creating us uniquely, beautifully, and lovingly. Amen.

Preparing for an IEP (ARD)

Sandra Peoples

*“For you are great and do wondrous things;
you alone are God.” (Psalm 86:10 ESV)*

For Christmas my husband got me a t-shirt I call my IEP shirt (or ARD now that we live in Texas). It says, “I may be wrong, but I doubt it.”

When we lived in Pennsylvania, we couldn't have created a better class for James if we had been able to design it ourselves. I loved IEP meetings. Getting together with everyone who loved, taught, and took care of James—what could be better? We sat around and told stories of cute things he did or said, went through the paperwork I approved of 100%, and all left the room smiling.

But I can already tell our current situation is different. They don't do the same therapy here that James has had since he was three (behavioral therapy). The school psychologist told me over the phone he probably won't get as much occupational or speech therapy as he got before. I'm already planning to wear my IEP shirt!

It's hard to believe you know what's best for your child and to sit in a meeting with people who disagree. It's hard to feel like you have to fight for services your child deserves. It's hard to fear for your child's safety, future, or lack of opportunities and feel like you aren't on the same page with the people who control these for your child. But who ultimately has control over all these details?

“For you are great and do wondrous things; you alone are God.”

God has control. And He can do wondrous things. He can do them through an awesome team and a great IEP. He can do them in spite of an apathetic team and the most stressful meeting of your life.

Father God, we thank you for those who care for our children each day at school. For the teachers, therapists, aides, bus drivers, administrators, bus drivers, cafeteria workers, and everyone else. We thank you for the time we get to spend with our kids' teams in meetings like IEPs. We know that you control all things and do wondrous things. We ask for Your guidance in this meeting. We ask for Your control over what is said and how we react. We as You to do wondrous things so we can give You glory and praise. In Jesus' name, Amen.

When the Specialists Are More Than Just Specialists

Caroline Flory

*“For you formed my inward parts;
you knitted me together in my mother's womb. I praise you,
for I am fearfully and wonderfully made.”*

Psalm 139:13-16 (ESV)

“We have different gifts, according to the grace given to each of us.”

Romans 12:6 (NIV)

As parents of children with special needs, we interact with specialists of all kinds. From the medical specialists, like cardiologists, pulmonologists, and otolaryngologists, to developmental specialists, like physical therapists, speech therapists, and occupational therapists, many of our families work with a team of people.

In our family, we love having this kind of team. Each member plays a separate, but crucial part. But, what constantly amazes me is that each part influences another part, as well.

My son's physical therapy helps strengthen his core muscles, which in turn allows his body to focus on controlling his fine motor muscles around his mouth for speech improvement. The words we practice in speech give us a list of words to practice writing with different implements in occupational therapy. Our pulmonary and ear, nose, throat specialists consult on surgery implications and treatments. As parents, we work to inform the team about new developments, incorporate various therapy methods, and practice, practice, practice. Even our daughter has a part by helping her brother practice speech words and more.

Each member helps another member (and helps our son!) by doing his or her part and doing it *well*.

But, even more than the practical help, our specialists (particularly our developmental therapists) have become a part of our family.

We see each other weekly or more. We cheer over small steps and huge successes. We consult each other on new strategies. We listen to each other, and, most important, we observe and listen to my son. The care we receive means exponentially more because our specialists genuinely love our son.

Even if we encounter challenges or disagreements, knowing each member of our team has a meaningful, chosen part in our son's care reminds me that we all have value. I pray for wisdom and love when working together, and I praise God for giving us amazing options amongst the complexities of finding the best care for our son.

God, thank You for creating people for different roles in different lives. We lift up all of the specialists we encounter, and help us remember each other as gifts. Thank You for helping us see value in each person on our team. Amen.

Left Out

Debbie Sutherland

“You have given me greater joy than those who have abundant harvests of grain and new wine.”

Psalm 4:7 (NLT)

I see you with your child. You try so hard to look like everything is okay, normal; you are fine, your child is fine. I see your eyes dart around to make sure no one is staring, because there is always someone staring either at you judging your parenting or at your child. My heart breaks for you. I know the difficulty you face everyday, the financial challenges, the challenges within your family unit. The struggle to be all you need to be for this child and any other siblings. Just day-to-day caring for your child with special needs takes more time and presents more challenges than anyone can ever imagine. You are a hero! You need to know that God sees how you serve Him everyday by caring for this child He so lovingly gave you. God knows your struggles and He holds you and your family in His loving hands. You need to know that you have nothing to prove to anyone and that you are enough.

Take heart, your child was chosen. They were chosen before they were born. Their names are written on God's hand. They were created in the image of our Heavenly Father. God does not make mistakes. Your child was fearfully and wonderfully made. They were created for a purpose. Their lives have value. Without your child we are incomplete as the body of Christ. Watching you struggle to help your child learn to speak, I have learned the value of words. Our words have power and should be used carefully; Lord, I pray that my words are used to encourage and build up Your children. Watching you smile proudly when your child finally masters a task that their peers mastered long ago, gives me hope. Each small step your child takes is proof that our hope lies in God. God answers prayers; I see this in the small miracles God places in our lives each day. When we celebrate the small things with praise and gratitude we are living life the way God intended. God has given you a heart of courage; I see this every day in your perseverance, your patience, and your tenacity.

Abba, I pray that You give this parent the same courage You gave her child. For every battle we fight, we both need Your courage, Lord. Father, give me the strength I need to advocate for this child, to speak out about injustice and to encourage inclusion for all. Lord, work through me, let me be an example of Your perfect love for these amazing children. I pray that people are able to see how these children are not disabled; they are differently abled. We all have limitations and things we do really well; these little ones are no different. Let Your light shine through Your children, Lord; they are perfect examples of Your perfect love. You sent Your Son, Father, to earth; not to be served, but to serve. Help us to serve these children in love and wonder at Your perfect creations. Amen.

Experiencing Family Stress

Sandra Peoples

*⁹ Be gracious to me, O LORD, for I am in distress; my eye is wasted from grief;
my soul and my body also.*

*¹¹ Because of all my adversaries I have become a reproach, especially to my neighbors,
and an object of dread to my acquaintances; those who see me in the street flee from me.*

¹⁶ Make your face shine on your servant; save me in your steadfast love!

*¹⁹ Oh, how abundant is your goodness, which you have stored up for those who fear you and
worked for those who take refuge in you, in the sight of the children of mankind!*

Psalm 31 (ESV)

Romans 12:16a and 18 say, "Live in harmony with one another. If possible, so far as it depends on you, live peaceably with all." This isn't easy when you feel like the world is against you.

We need to have patience with others. We may not always get it in return, but we are Christ-followers. We are different. When we have reasons to get angry and don't, others notice. God notices. Of course, we stand up for our rights and the rights of our children, but we remember to display the fruit of the Spirit (Gal. 5:22-23: love, joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control). We know we will give an account to God for our actions and words. All we can do is our best and ask the Holy Spirit to work through us.

Situations with family members and friends are hard. One family we know deals with lots of hard issues with the husband's parents. They pay attention to the typical child in the family and ignore their grandson with cerebral palsy. They even buy gifts for the typical grandchild only, saying their special needs grandson doesn't know the difference. Even if he doesn't know, the parents know. The typical sibling knows. And it hurts them all.

You need to protect your child if you feel there is any danger (for example, if you have family members who don't understand your child and don't even try to, we wouldn't suggest asking them to babysit), but we can look to the example of Christ. Continue to have patience. Continue to love.

He had brothers who didn't believe in Him (John 7:5). But since His brother James went on to write the book of James, we know he eventually did believe Jesus was who He said He was. His family finally got it and yours may too.

Father God, I feel so lonely and misunderstood. The people who are most important in my life exclude me, misjudge me, and don't give me the support I need. I know Jesus experienced the same feelings with His family during His earthly life. Please help me follow His example of gentleness and patience. I know you can change hearts and minds. I ask you to give me strength. Help me to trust in You above anyone else. In Jesus' name, amen.

Marriage – It Takes Work!

Cindi Ferrini

“By wisdom a house is built, and by understanding it is established; and by knowledge the rooms are filled with all precious and pleasant riches.”

Proverbs 24:3-4 (ESV)

Marriage, as you’ve probably noticed - takes work. It takes a lot of work. It takes a whole lot of work to make a marriage *work*.

When speaking around the country on the topic, one of the things we most often see is how easily people tend to give up and quit. Hardships and challenges are in every marriage, but if we want our marriages to be strong, and especially in the midst of the unexpected journey we travel with a child (or children) with special needs, we must realize it will take some very special navigation. My challenge: MAKE YOUR MARRIAGE YOUR MINISTRY.

We make meals for others, watch other people’s children, help others when we can, and sometimes in the midst of ministering to others, we neglect the very ones within our own home. We get out of marriage that which we put into it. So how can we make our marriage our ministry? A few thoughts that come to mind, and then I’d like *you* to make it your own and add to it!

- Welcome my spouse at the door when they return home (whoever is home first!)
- Help my spouse with menial things like dishes, yard work, etc. – together
- Take walks and use those times to talk about today and look to the future
- Share something funny each day so we laugh together
- Kiss goodnight for thirty seconds ... and it might lead to ... a good night’s sleep!
- _____
- _____
- _____

Lord, we want to build our homes with Your wisdom, so we ask You to show us how to minister to our mate in such a way that our marriage is built up daily. Help us to begin understanding one another and what marriage is supposed to be. Help us to learn so that we would be an example to those around us even with the challenges of raising a child(ren) with special needs. Establish us in Your will and Your way so we can navigate this life together for the long haul. May we turn to You and Your word to gain the knowledge we need so that the rooms of our hearts and homes are filled with all precious and pleasant riches. We know there are things we might need to change in order to do things right and in the right way. Help us to see our sin, errors, and mistakes so that we can learn to ask for forgiveness and correct them. Guide us to right thinking, right motives, and right actions with our spouse and our family. We want to

please You in all we do, and we know that in doing so, we would please each other. May we do the work to make marriage our ministry! In the name of Jesus we pray. Amen.

Siblings – Exchanging Fighting for Unity

Cindi Ferrini

*“Behold, how good and how pleasant it is for brothers to dwell together in unity!”
Psalm 133:1 (NASB)*

The otherwise sweet and lovely little four year old had about enough of her seven year old brother with special needs. “Somehow” he landed mouth first into our wooded toy box. Tears, crying, yelling, and blood had the makings of a 911 emergency call at first. Upon further examination and a call to our dentist (my husband), I knew just how to secure the loose permanent tooth; but I soon learned I wasn’t as confident about how to maneuver the teaching of living in unity!

With years ahead of us I recognized the need to teach our girls how to handle our son with the firmness of a new mattress and the kindness of a well-worn one! I wanted our family life to be comfortable...not lumpy and bumpy and uncomfortable. Most of that teaching, I now see clearly in retrospect, was by way of explanation, example, and the end point in mind. We needed to be intentional!

My husband (Joe) and I showed our children how to disagree without getting angry and yelling. We cared for Joey and his needs so that our girls eventually followed in the way we cared for him. It wasn’t always easy. Sometimes as adults we were close to “losing it” but little eyes translate into little hearts and we want them to see what we also wanted them to be. Intentionality, not perfection, was the name of the game for us! When mistakes were made, when we did or said things we shouldn’t have, we apologized.

And interestingly ... that loose tooth incident is now over twenty-five years ago, yet we still continue learning with intentionality how to maneuver living in unity. Some days are better than others, but all days are better than they might have been had we not looked ahead to the end results we wanted to see.

Lord, we want to be an example of who You are to others. With that thought in our minds, may we live with intentionality of coming to You for all of our needs. We need You to help us see where we are not living in unity with our family members or others in our life. We need You to guide us to the right kind of living in our words and actions so our children will glean from us the same right kind of living. We need You to prick our hearts when we are not heading in the right direction so that we will listen carefully, fully, and then act quickly to follow Your lead. God, we know we can’t do it ourselves. Life can be frustrating when trying to “do” life “right” with the challenges of one with special needs. We want You to develop in us the right attitudes, the kindest of actions, and with the sweetest of dispositions. With that combination, we can show and tell others of our love for you and for our children. Then, may we see in our children, and with them and their siblings, the unity and love we’ve shown. In the name of our Lord, we pray. Amen.

When You Grow Weary from the Sameness

Sandra Peoples

*“Wait for the Lord;
be strong, and let your heart take courage;
wait for the Lord!”
Psalm 27:14 (ESV)*

“Bye James! Have a good day at school. I love you.”

“Love you. See you morning.”

“No, not ‘see you in the morning.’ It’s school time, not bed time.”

“James do you want an apple?”

“Want apple?”

“No, say ‘yes’ or ‘no.’”

“Yes or no.”

“No James, say ‘yes apple’ or ‘no apple.’”

“Yes or no.”

Some days I grow weary from the same-ness.

From teaching the same lessons. From working on the same goals. From hearing the same mistakes.

Every day feels the same. Like Habakkuk, I want to cry out “O Lord, how long ... ?” (1:2).

My son is seven years old and I’m still changing his diapers, still lining up trains, still watching Blue’s Clues every evening after dinner. In most ways, he’s just like he was three years ago when we got his autism diagnosis. I often think, “How long?”

But then God answers me as He answered Habakkuk: look and see, wonder and be astounded. “For I am doing a work in your days that you would not believe if told” (2:5).

Look and see.

Even though James goes through our bedtime routine when he’s getting on the school van, he now loves going to school and isn’t anxious about being away from me. Just like I’m there when he wakes up, he knows I’ll be there when he gets home from school. And even though he may not be able to say “Yes, I want an apple,” he can tell me if he wants “green apple” or “red apple.”

Wonder and be astounded.

Because even if James never progresses beyond where he is now, God is still at work. He's at work not only in James's life, but in my life, our family, and my ministry to other special-needs families. I am in awe of how God invites me to live out His purpose for my life through my calling of motherhood. That isn't same-ness. That is sanctifying.

Father God, today feels just like every other day. I'm growing weary from the sameness. I thank you for the reminder to look and see. To wonder and be astounded. And like Habakkuk, I want to rejoice and take joy. Thank you for your grace and strength. In Jesus' name, Amen.

High Alert and Pacing Prayers

Barbara K. Dittrich

How long will you forget me, Lord? Forever? How long will you look the other way when I am in need? How long must I be hiding daily anguish in my heart? How long shall my enemy have the upper hand?

Answer me, O Lord my God; give me light in my darkness lest I die. Don't let my enemies say, "We have conquered him!" Don't let them gloat that I am down.

But I will always trust in you and in your mercy and shall rejoice in your salvation. I will sing to the Lord because he has blessed me so richly.

Psalm 13 (TLB)

Pediatric hospital admission is an interesting convergence of discordant circumstances. Nowhere else on earth does a parent feel more on "high alert," and nowhere else does a parent wait hour after anxious hour than when their child is hospitalized. Heart racing with pent up adrenaline imprisoned in the body, no action to take as the holding pattern continues. Hours painfully pass with mind-numbing television containing sea creature cartoons and hillbilly animal shows. All the while thoughts spin over and over and over, nervously waiting for test results or treatment plans, whispering intercessions for precious offspring's safety and health.

Whether it is a planned surgery or a medical emergency, nothing drowns out the annoying sounds of rhythmically beeping IV alarms and intermittent staff pagers like the heavy, deafening, heartbreaking silence of God. Can't He see our tears? Doesn't He care about our languishing little one? Minutes melt into miles of seemingly endless high alert and pacing prayers.

I have learned through too many of these experiences that what feels like painful imprisonment is really time on holy ground. When I cry out to God in my anguish during these perpetual hours, I am really affirming Who He is, His unlimited power, His presence everywhere at all times, His overflowing goodness and love. My complaints about feeling His absence admit my absolute dependence upon Him for my very life and the life of my child.

Suddenly, my countenance lightens as I recall what defines my Savior. He has been faithful before. He will be again. Turning my eyes towards gratitude for the rich, simple blessings of a visitor, or a popsicle, or the knowledge that there is a much more comfortable bed at home, all put me in a better frame of mind.

God is near. He is in this sacred space, whether we can feel him within the confines of the anxious, isolating infirmary or not.

Jehovah Rapha, Healing God, mend our hearts and calm our minds when our child must be hospitalized. As our thoughts race, let them race towards memories of Your faithful goodness to

us in the past. Increase our trust in You. Remind us that You have proven Your lovingkindness to us in the past and will again. Thank You for how richly You bless us. Guide the doctors and medical staff You have so mercifully supplied to care for our child. Strengthen us to make good decisions on behalf of our child when hospitalized, and give us endurance to care for our child when they are discharged. Provide us with sweet sleep to help us all persevere. In the hours we feel silence and isolation, remind us to draw closer to You.

Father, You know our hurt. You grieved Your Son's agony. You saw Him treated as an outcast. Thank You for Your understanding. You are our very breath, keeping us alive when the suffering is long.

Missing Milestones

Faith Clarke

"You keep track of all my sorrows. You have collected all my tears in your bottle. You have recorded each one in your book."

Psalm 56:8 (NLT)

Fifteen years of assessments and IEP meetings have been depressing. The first time they said, 'He has autism,' though horrifying, didn't prepare me for what's been our life since then. At that time, his special quirks were just, well, special. Who knew they pointed to countless missed milestones ahead! Now, fifteen years later, there isn't a milestone in sight! They're all in the distant future. When people ask, "How's Jaedon doing? Is he making progress?" what should I say? I smile and say something bland and positive, while the infinitely distant developmental markers that a typical 2-year-old has already passed laugh at me and dance further out of sight. Though I hide it, grief, hopelessness, and despair all compete for active space in my mind and heart. *God, I get it! I'll help families, offer support, listen, and pray. We can move on now. Heal my son, please.*

*I'm healing **you**, He replies. I'm healing your eyes so you can see what I see. See his beauty and the wonder of how I made him. I'm healing your eyes to see yourself, your wounds that you finally allow Me to heal, so you can love him more fully. I'm healing your eyes to see others in pain, and your healing, helping them to see that they can be healed too.*

So, of elusive developmental milestones, I say, *I trust in God, so why should I be afraid (Psalm 56:11, NLT)?*

Thank You, Lord, for always hearing and embracing me, no matter how often I despair. I'm grateful for Your generous love that seeks me out wherever I am. Please help me to remember Your intense love for us, in the face of what doctors and therapists say about my son. Please help him continue to develop, and help me to be patient with Your healing process, even when the milestones remain points somewhere in the distance. Thank You for daily healing my eyes, so that I can see what You see, in my child, in myself, and in my community. Please remind me always of the beauty in my son, the fearful and wonderful way that You made him. I'm so grateful that You have trusted me with this treasure, Your child that You allow me to care for in this moment. Amen.

Socializing with Typical Peers

Debbie Sutherland

"It is not an enemy who taunts me—I could bear that. It is not my foes who so arrogantly insult me—I could have hidden from them. Instead, it is you—my equal, my companion and close friend."

Psalms 55:12-13 (NLT)

Hearing your child called names is never easy, and yes, it is a part of growing up and playground politics, but having a child with special needs being called names is a totally different matter. It makes the mama bear in you come out! Making fun of a kid who can fight back is one thing; making fun of a kid who doesn't even understand the concept and just wants to play isn't childish hijinks—it is bullying. These kids need to be shown the error of their ways but in the kindest way possible. By showing them God's love, they will come to understand the value and worth of life. We have to change the face of disability in our world and we can do this by teaching our children about acceptance and inclusion. Answer that stare with, "Hi, how are you? What's your name? This is my child ..." and give their name. This could be the start of a new way of thinking; or perhaps a new relationship. I know it doesn't seem fair to add another thing to your list of to dos, but we need to forge the trail, to teach the next generation to be accepting and inclusive.

Lord, I pray that you touch the hearts of the educators and the leaders in our schools. Inclusion begins at the top and filters down. Lord, let your love shine through us; let people see Your great love through serving and loving differently abled people. Father, we are all Your children fearfully and wonderfully made in Your image. Show us, Lord, how to fight injustice, how to create a world of inclusion, how to teach our children that everyone is our neighbour. Teach us Lord to be Your light in this world, to forge the path toward full inclusion and acceptance. In Jesus's Name. Amen.

Grace, Peace, and Mercy to Advocate

Caroline Flory

*“Behold, God is my helper;
the Lord is the upholder of my life.”*

Psalm 54:4 (ESV)

*“Grace, mercy and peace from God the Father and from Jesus Christ, the Father’s Son, will be
with us in truth and love.”*

2 John 1:3 (NIV)

Every parent knows the feeling of stepping up, perhaps even confronting a person or a system, to help or protect their child.

All parents are advocates for their children. *Often.*

Parents of children with special needs have to be advocates *even more often.*

This does not make anyone stronger, better, or more involved than anyone else.

It really just makes us *tired.*

Special needs parents advocate in expected situations, like doctor’s offices, schools, and therapies.

But we also have to remain advocates in many, many other places and situations.

You might have to turn down the offer of a popsicle from a well-meaning neighbor (without hurting that person’s feelings) because your child will aspirate it. Or call the insurance company yet again to resubmit for medication coverage. Or remind a family member that your child cannot ride in a car someone previously smoked in because of her lung condition. Or help others welcome and understand your child with a speech difficulty or autism. Or prepare your child himself for a new situation with practice and preparation.

Basically anywhere or anybody new (and sometimes those who aren’t new), we have to advocate.

It’s challenging standing up to people in certain situations and simply *tiring* advocating 100% of the time. It can be frustrating if people perceive your family’s choices as *limitations*, when, more of than not, those choices *create options* for your child to participate and grow while staying safe.

Many people respond positively, eagerly learning new ways to support. But, for those situations where people receive advocacy as punishment, I need to pray for grace, peace, and mercy.

Grace from me while I speak truth (in love, with God's strength), and grace for those hearing it.

Peace in all of our hearts for constant changes and new strategies.

Mercy to accept what reactions come, yet continue to forgive and love and grow.

But, I can't conjure that grace, peace, and mercy on my own. Thankfully, we can pray as John did in 2 John 1:3 and know that God offers all this with truth and love.

God, Thank You for Your never-ending grace, always-present peace, and life-giving mercy. Help us share it in every situation, including advocating for our children. And, when we're lacking, help us pray for Your grace, peace, and mercy to flow through us in truth and love. Amen.

Fear

Shannon Dingle

*“The LORD is my light and my salvation;
whom shall I fear?*

*The LORD is the stronghold of my life;
of whom shall I be afraid?”*

Psalm 27:1 (ESV)

“When I am afraid,

I put my trust in you.

In God, whose word I praise,

in God I trust; I shall not be afraid.

What can flesh do to me?”

Psalm 56:3-4 (ESV)

Brave. Fearless. Confident.

Those words are often used to describe me, which I find perplexing. Each time, I feel like I've fooled someone into buying into a façade. I'm not brave, far from it. I'm full of fear more days than not. Confident? More like self-conscious.

As I parent six young children, several with disabilities or early childhood trauma, one thing scares me more than any boogeyman did in my childhood: the future. I like answers, and the future is full of question marks. I like certainty; the future is anything but. I like control, but tomorrow isn't in my hands.

We just wrapped up an IEP meeting for our youngest child, and the entire team discussed how many unknowns are in front of us. Will she ever walk? Will she learn to speak more intelligibly? Will we see more results from her last surgery? How about the next procedure? How much will her visual impairments affect her education? What level of independence will she reach?

I hate the answers to each one.

I.

don't.

know.

I don't know the answers to any of those questions about the baby of our family, nor do I know when the next seizure will come for my son with epilepsy, what medical advances will be made by the time my child with HIV is an adult, or where our children's trauma from the past will trickle out (or explode forth) in the future.

But I do know a few solid truths: The Lord is my light and my salvation. The Lord is the stronghold of my life. When I am afraid I can put my trust in the one who does know the answers to every question and who promises that beauty will come from them, even in the midst of brokenness.

God, maybe when people call me brave and fearless and confident, they aren't being fooled by a façade. Maybe they're seeing Your Spirit who lives in me, the one in whom I place my confidence, confide my fears, and rest my soul when all the unknowns are simply too scary. May my fears be transformed into a testimony of You. I know I can trust You completely, even in the face of life's I don't know. Thank you for already making beauty out of my brokenness. In Jesus' name, amen.

The Autism Detour (on Fear)

Kathleen Deyer Bolduc

You direct me on the path that leads to a beautiful life. As I walk with You, the pleasures are never-ending, and I know true joy and contentment.

Psalm 16:11 (The Voice)

We ran into a host of orange barrels coming home from our third son's birth. Our daily route, parenthood-by-the-book, ended. No detour sign in sight. No big, black arrows pointing the way forward.

We drove in circles before pulling into a gas station to ask for directions. Funny, how gas station attendants, even ones with Ph.D. degrees, don't know the names of side streets leading back to well-traveled roads.

We got lost. Really lost. But we kept on driving, taking turns, two boys wrestling in the back, incessantly asking, "Are we there yet?" The third boy, the one with pervasive developmental disabilities and autism, repeating himself again and again, "Starving. Starving. Starving. Starving."

Thirty years later we're still driving back roads, this time, by choice. We love the not-knowing nature of these scenic byways—the lush, green landscapes of prayer; strangers who materialize out of mist hitching rides straight into our hearts, artist friends who make the invisible, visible, saying, "Here. I hope this helps."

The best part of all? The Word become flesh, riding right here beside us, steering the car around orange barrels like an Indy 500 driver.

Filled with praise there's no room for fear about trivialities like where we are going or when we will arrive.

It's time to sit back and simply enjoy the ride.

Oh Lord, thank you for the scenic byways on this ride with autism. Banish the spirit of fear and fill us instead with the expectation of beauty just around the next corner. You want good things for our children. You want good things for our families. You want good things for our marriages. Keep surprising us, Lord, with joy and contentment and beauty in the midst of the hard stuff. Amen.

Friends Who Get It

Sarah Broady

“A friend loves at all times.”

Proverbs 17:17 (NIV)

*“A man of too many friends comes to ruin,
But there is a friend who sticks closer than a brother.”*

Proverbs 18:24 (NASB)

Finally, after spending three years only ever able to talk on the phone, we got to meet. Liz lived in Florida, and I lived in Maryland. The first time I called after getting her number from my pastor who knew her, it was as if I had known her forever. I cried over the phone to a stranger, who was an instant friend simply because of the bond we shared as special-needs parents. I didn't have to explain all the intricacies of my emotional meltdown. *She knew*. When I would start to describe Sam's behavior that was hard to put into words, Liz said, “Sarah, *I get it*. My kid does that too.” There are a few different types of phone calls we have. Urgent: “Help me, I don't know what to do!” (she was also an autism therapist); Angry: “I hate autism/I'm losing my mind”; Depressed: “I can't do this anymore”; and Normal: “I'm actually only calling to say ‘Hi.’”

When Sam was diagnosed, I had no special-needs mom friends. We moved a year after diagnosis where I still had no close, strong special-needs mom friends. I prayed for seven years for a close friend who was a special-needs mom. Someone I could see often, maybe at church, or over a caramel macchiato on a regular basis. A friend whose kid could script Star Wars with mine while we chatted. A mom who could look me in my teary eyes, say, “*I know*,” and give me a tight hug. A mom who could rejoice over progress—in person—and sit with me in autism regression.

Six years after moving to Maryland, we moved again. God answered my long-awaited prayer for a special-needs mom friend even before moving. Our new church has several special-needs families, including the pastor himself who has a son with autism. His wife, Lisa, and I were instant friends over the phone and have been close since moving. But it took seven years for that prayer to be answered. God is faithful. He put people in my life who loved my son without an intimate understanding of autism through living it themselves. Our friends tried to understand, though they would never really *know*. I can't say how much it touched my heart that they did what they could.

Still, one can only truly understand if they have experienced it themselves. Christ Himself sympathizes with our weaknesses (Hebrews 4:15-16). This is why we draw near to the throne of grace with confidence, and why He is able to comfort our weary, hurting hearts, if we will only turn to Him in our loneliness and distress. He will never leave us; he sticks closer than a brother. He loves at ALL times.

Jesus, I praise You for understanding the joys and sorrows of raising a child with special-needs. Thank You for the friends You have given me; please strengthen those relationships and grant new friendships according to my needs. I pray that You will build up this community of parents and grant close or even long-distance friendships that will encourage our hearts and motivate us to persevere in this life raising special-needs children. Comfort us in our loneliness, and bring people into our lives who will love us and our children the way You do. Thank You for Your own friendship as You have called me "friend" (John 15:15). Amen.

When You Have Nothing Left

Cindi Ferrini

*“Blessed be the Lord, who daily bears our burden, the God who is our salvation.”
Psalm 68:19 (NASB)*

Like scraping the last bit of refreshing ice cream out of our dessert bowl and finding there is nothing left (but wanting more)—that’s how I’d find myself at the end of most days. I felt empty but wanted more of sweet refreshment in time and energy that was lacking at the end of most days! No energy, no happiness, no feeling of accomplishment, and sometimes no will to keep going. Depleted, exhausted, and discouraged were my days and heart—resembling a desert not a dessert ... dry, needing refreshment, parched, dead.

One particular day of non-stop care for Joey (ill with vomiting, a high fever, and one grand mal seizure after another) had me hanging by a fingernail at the end of my rope. Watching him through the seizures was like watching popcorn kernels popping in a clear-lidded pan. One would end and other would pop up. His seizures were frightening for both of us, so being at each other’s side was reassuring. Others needed reassuring too, so the rope I was hanging onto turned into a tug of war with daily responsibilities, meeting my two daughters needs, trying to get food on the table, and the list goes on!

As late night drifted into the next day so did my prayers to God. I finally sensed a cloud of comfort under my head as my head, prayers, and sleep hit the pillow at the same time, “Please, let me die. I have nothing left. Let Joe find a stronger woman to marry and do this. I don’t want to do it again tomorrow.” Instead of waking in heaven liked I’d hoped, God gave me a way to live and pray instead of giving up when I had nothing left.

Lord, like my son needs someone to lean on, may I learn to lean on You. You are always with me. You know my suffering and sadness. You know when I have nothing left to give or offer. I know I have choices to make, so I choose to live in each moment with You when I travel the rough roads of caring for someone long hours and without breaks or rest. Please help me to value what You value and help me to develop the right attitudes that will help others learn how to do this with grace, stamina, truth, and love. Show me the reality of my days in perspective to the perfection of the days to come when we meet You face to face. Give me the bigger picture of Your plan and the puzzle piece I am in the scene You want to portray to others. Let me go from hopeless to hopeful as I come to You in prayer, as I yield my will to Your will, as I relinquish my rights and cling to my responsibilities. As You give me endurance may I give that out in encouragement to others. Show me in Your word and as I come to You in prayer, the decisions You want me to make, the ways You want me to serve, the thanks You want me to give, the character You want to build in me, and let me live from a trial to a triumph. I pray this in the name and strength of my Lord and Savior, Jesus Christ. Amen.

Clobbered by Allergies

Ann Holmes

“God gives a hand to those down on their luck, gives a fresh start to those ready to quit. All eyes are on you, expectant; You give them their meals on time. Generous to a fault, You lavish Your favor on all creatures.”

Psalm 145:14-16 (The Message)

It's scary traveling into the sneaky world of allergens. They slip up on your blind side or they may languish long just leaving their footprints—those nasty allergens! It takes serious detective work to find the culprit and even more work to figure a path to deal with those allergens. Walking that road, especially for a special needs parent, is just packing more exhaustion onto weary and worn already. It's also hard on the heart. The emotional toll of allergies is staggering.

My son has struggled for years with terrible allergies. He probably hasn't had an uninterrupted night's sleep for twenty years. The itching is so horrendous that he often gets up during the night to take several showers just for a little relief. I have a good friend whose daughter is allergic to almost every antibiotic known to man—really scary! Sometimes I just don't know how my son can bear to get up and do it again—that same drill—day after day after itching day.

I don't know if the ancient sufferer Job had allergies, but he certainly understand the torture of relentless itching.

For sighing comes to me instead of food; my groans pour out like water. What I dreaded has come upon me; what I dreaded has happened to me. I have no peace, no quietness; I have no rest, but only turmoil (Job 3:24-26).

If only my anguish could be weighed and all my misery be placed on the scales (Job 6:2)!

When I lie down I think, “How long before I get up?” The night drags on, and I toss till dawn. My body is clothed with worms and scabs, my skin is broken and festering (Job 7:4-5).

It's a whole new level of despair—not being able to sleep, not being able to eat, not being able to wear certain fabrics or clothes, not being able to take certain practically essential meds, and the list goes on!

In Psalm 145:14-16, King David gives us a life preserver when we're drowning. The God who gives meals on time certainly cares and will give a fresh start even if only with emotional energy for the on-going battle as He lavishes His favor on you and me, on my son and yours.

*Lord Jesus, we need You! We need You in the bright light of day. We need You in the itchy night of pain. We need You when we have to search for foods and meds that will keep us safe because of allergies. We need You to give us strength to keep on. We need to know You will stick right in with us no matter what and **always!** We're counting on You to keep all Your promises. In Your strong name we pray. Amen.*

The Church
Mike Dobes

"How lovely is your dwelling place, O Lord Almighty! My soul yearns, even faints, for the courts of the Lord; my heart and my flesh cry out for the living God ... blessed are those who dwell in your house; they are ever praising you ... better is one day in your courts than a thousand elsewhere; I would rather be a doorkeeper in the house of my God than dwell in the tents of the wicked ..."

Psalms 84:1-12 (NIV)

What a powerful moment of praise from the lips of this Psalmist! We can feel his emotion and even sense his desperation to be in the house of the Lord. This is not a mere religious exercise, but rather it is the source of hope and life for him. How strong his relationship must be with God for even his flesh to cry out for more!

If you are anything like me, I find my heart and flesh crying out for so many other things than the living God. Coffee, a good burger, a fun book to read ... sometimes just five minutes of quiet with nothing to worry about. So what is it that causes the Psalmist to cry out for time in the house of the Lord and not so many temporal things? How is it better to be a mere doorkeeper than to own real estate? Is it really about the courts and keeping the doors ... or is it more about Who resides there? All too often, the Church does not seem to be a place we would yearn for. Yet, this is exactly what it should be.

When the Church is truly the body of Christ, the picture of yearning and crying out makes more sense. Church is to be a place of embrace and welcome, a place of respite and restoration, a place of love and acceptance. Church is the one place where we should be free to embrace transparency and celebrate each other on this journey called life. It is not about a fancy building or an impressive lobby or even a completely inclusive special needs ministry. Rather, it is about the people of God gathering in His name. His Word promises that He is present when this happens and it is the presence of God that our souls yearn for.

Throughout life, I have enjoyed moments where I have been completely surrounded by the presence of God. Time seemed to stand still and the peace I felt was truly indescribable. The problem comes when the scurry and hustle of life interrupts time in the courts of the Lord. But in the midst of the busyness, we can find rest when we seek the Lord, when we devour His Word, when we lean on others. The journey of life is one step at a time, seeking God and all His glory. This is what Church should be about...and this is what our hearts cry out for.

Lord, help me to find Your presence in the midst of my daily schedule. May I see Your Church, the gathering of Your people, as a place of refreshing and restoration. My heart cries out for Your presence and it comes most often in times of quiet and solitude. Grant me these times, both today and every day, that I may enjoy a day in Your courts. Amen.

Experiencing Change

Sandra Peoples

*When the cares of my heart are many,
your consolations cheer my soul. (Psalm 94:19)*

A few weeks ago we moved from Pennsylvania to Houston, Texas. We're in a new house, going to a new church, and about to start a new school. James is missing his favorite pizza place, Hershey Chocolate World, and the familiar faces at school and church. It's been tough. He's struggled with anxiety through these changes. He tries to control anything he can, by repeatedly closing all the doors in the house or asking to go to places he does feel comfortable (unfortunately we can't drive the thirty hours it would take to get back to what's familiar to him!).

I feel helpless. But I know who to turn to for help.

Jeremiah 29:11 says, "For I know the plans I have for you, declares the Lord, plans for welfare and not for evil, to give you a future and a hope." We can hold on to that hope when everything else seems out of control.

The changes in your life may feel like a storm. But like the anchor of a boat, no matter how tumultuous the storms rages above, the anchor continues to hold. God is your anchor so you can strive to be an anchor for your child—consistent, calm, and courageous.

Father God, my heart is heavy with all the changes our family is experiencing that I can't control. I continue to trust in Your control over the big and small changes we are going through. Please calm the storm around us. Remind us of the hope we have in You. Help me be strong because I trust in Your plan for our lives. In Jesus' name, amen.

Information Overload

Sarah Broady

*"I will bless the Lord who has counseled me;
Indeed, my mind instructs me in the night."*

Psalm 16:7 (NASB)

67,600,000. That's how many "relevant" websites Google found for a search on "autism." That is a *lot* of information. And we have immediate access at our fingertips to all of it—literally. Thanks to Google, Siri, and apps galore, we can read, hear, or see images about anything we want within seconds (0.40 seconds to be exact). On four-inch phones. Or 38mm *watches*. (Inspector Gadget, anyone?)

I am a hypochondriac. As such, I have to fight the urge to do a search on various "symptoms" that my brain is convinced is a fatal disease. I'm a lot better now than I used to be, but I was still an expert researcher when my autistic son, Samuel, was a baby. As he got older and I noticed things that seemed unusual to me, I turned to my computer. I typed in things like "15 month old, no words, lines up toys, major tantrums." Result after result showed autism. I tried re-wording things. "Toddler, picky eater, bangs head, loves water." More autism. No matter what I typed, I saw the "A" word everywhere. So I read. A lot. I learned about the three domains of autism, the autism "spectrum," and how it's diagnosed. I took online tests. I looked up all kinds of checklists for typical development and checklists for red flags. I felt that the more I knew about what might be, the better prepared I would be.

But compulsive research did more than just prepare me for the diagnosis that eventually came. It *consumed me*. I couldn't stop thinking about autism. I questioned every little movement or vocal expression out of fear that there was something wrong with my child. It sapped moments of joy I could have had with Sam. It terrified me. It threw me into a grief-stricken depression before he even had an evaluation. But once I had a diagnosis in hand, website by website, and book upon book, I built my intellectual repertoire on autism.

It's not wrong to do your homework. As parents, we have an obligation and responsibility to know how to help our child grow in every aspect. We should know "typical" expectations of kids as they grow, and it doesn't hurt to know red flags for the fastest rising developmental disorder in the country—especially since early intervention is so crucial. But there's a balance that must be preserved. If you perseverate on research, you'll miss out on life with your child. There's always a new link to a new article. But your child needs you to be with them more than they need you to constantly research their problems. Most everything I have learned about autism in my son that I truly needed, I learned "on the job." Research what you need, but walk that line carefully. Be sensitive to the Spirit who may be whispering that it's time to stop for now when your computer battery dies.

The Bible doesn't give diagnostic checklists. But it tells us about God who loves us and gives wisdom when we ask. Psalm 16:7 says that the Lord counsels us. We know that He did not give

us a spirit of fear, but of power, and love and a sound mind (2 Timothy 1:7). When our fears and anxiety prevent sleep, we can pray instead of scanning Google. We can ask for guidance from the Lord when we are confronted with possible problems. He is faithful to answer and grant peace for the night.

Father, I praise You for Your omniscience. You know all things and You have promised to give us counsel when we seek Your wisdom. Guide me in better understanding my child that I might best provide for his needs. Help me enjoy my child without constantly focusing on the challenges he faces. I pray that You will lead us to the right helps at the right time. Calm my fears and anxiety over the future that I might live fully in the present without worry. Amen.

When My Child Knows She's Different

Jennifer A. Janes

*"He determines the number of the stars
and calls them each by name."*

Psalm 147:4 (NIV)

I knew the conversation was coming, but it snuck up on me and surprised me one night during supper.

"Mom, I wish I wasn't different from my friends. None of them have to get infusions or go to therapy. They don't have to go to the hospital all the time either. I hate being different!"

I finished chewing, thankful I had taken a bite just as she started talking so I could have a few moments to think. I breathed a silent prayer as I swallowed. How do you handle self-loathing in a child so young, over disabilities she can't control?

"Honey, we're all different." I stopped her objection and asked her to let me finish. "Everyone struggles with something. Your friends have their own issues to deal with. Some people have to deal with things that are more visible. Others have challenges that no one can see. The important thing to remember is that all of us are made by God. Each of us is precious and special to Him. All of us are handling problems that cause us to draw closer to God and depend on Him.

"We should focus on God and growing in our relationship to Him, and we should treat everyone we meet with kindness because we don't ever know what someone else is going through. When others don't understand why you have to do some of the things you do, explain to them that your body works differently from theirs, and you have to take care of it differently."

I remind her of *The Crippled Lamb* by Max Lucado and point out that disabilities can become the very thing that places us exactly where God wants us to be for reasons only He knows and understands.

She thinks about this for a long time. She understands the explanation, but we both know that real life situations don't always play out nicely. There are still the questions there, asking "Why?" and shouting "It's not fair!"

But the topic is open now. It is a conversation that will continue in different ways and over a lifetime of suppers.

I don't have the answers to all of the questions she has, but I don't have answers to all of mine either. What I know, and what I try to instill in my daughter, is that God is good, and He is kind, and He is with us every step of every day.

The Creator who knows how many hairs are on the head of every person on earth, who has carefully counted the stars and named each one, is attentive to every detail of our lives, and He will be faithful to oversee each one, always.

For now, we laugh, cry, sing, dance, and pray our way through our days, both the bad and the good. We practice daily gratitude, finding God's small gifts in unexpected places. This makes the dark days more hope- and light-filled, and it reminds us that we're not alone. Not ever.

Father, thank You for being so caring that You have counted and named every star in every galaxy in the universe. Thank You for knowing my precious child inside and out. Help her to see her great worth in Your eyes—and in ours. Thank You for blessing our family with this precious gift. Amen.

Self-Care for the Special-Needs Parent

Kelli Anderson

*“A cheerful heart is good medicine, but a broken spirit saps a person’s strength.”
Proverbs 17:22 (NLT)*

God has written mankind a prescription: at least one day each week rest and have fun. In fact, the Great Physician carved it into His top ten must-do list not as a suggestion, but as a command. Why? As special needs parents we understand better than many, how our wellbeing impacts our ability to care for our children, marriages, friendships, and our relationship with God. God commands rest and restoration not because He needs it, but because we do. We need rest to stay strong.

Many of us check off the weekly box marked “Keep the Sabbath holy” if we successfully complete the dreaded Sunday obstacle from house to church and back again. It’s not so much a holy experience as a wholly exhausting one. So how are we supposed to rest? What can restore us as God intended?

Jesus is pretty clear: the Sabbath isn’t a don’t, it is a do. It is a gift God made for our benefit, not the other way around. Proverbs 17:22 prescribes the remedy for our exhausted souls: a cheerful heart. Literally, a rejoicing, delighted heart.

So what delights you? What makes the hands of the clock disappear, puts a smile on your face and makes you feel like you’re ten years old again? When I was asked that question two years ago I was stumped. My mentor prodded and asked, “What did you love to do as a kid?” Like a flashback montage from “The Andy Griffith Show,” images passed through my mind: wriggling tadpoles in the palm of my hand, drinking coffee with my grandpa after digging in his watermelon patch, singing like a rock star while banging on the out-of-tune ivories on an upright piano, and jumping off an Ozark bluff with my sunburnt cousins into the shocking cold of our spring-fed creek.

Nature, song, family, animals, gardens, friends, coffee. While the places and faces have changed over the years, my love for these things has not. And I have learned that I need to put them back in my life—to make space for them and delight in them with God by my side—as often as I can. Once a week, we try to take turns, my husband and I, giving each other the time and space. For my husband, it’s listening to music, riding his bike, and taking a blissfully long, uninterrupted nap. Once a year, I go on retreat; he goes on a bike trip with his brother. What restores your soul? What makes your heart sing? Make the space however you can. You’ll be glad you did. God will too. And besides—it’s doctor’s orders.

Father, thank You for permission to rest and that You take delight in my laughter, my passions and my fun. Help me to be that person I so seldom make room for. Please show me how we can do this together—to better care for myself—so I may better care for my children, love others and be closer to You in the way you always intended.

Hope for the Continual Cycle of Grief

Sandra Peoples

*“Then they cried to the Lord in their trouble, and he delivered them from their distress.
He made the storm be still, and the waves of the sea were hushed.
Then they were glad that the waters were quiet, and he brought them to their desired haven.
Let them thank the Lord for his steadfast love, for his wondrous works to the children of man!
Let them extol him in the congregation of the people, and praise him in the assembly of the
elders.” Psalm 107*

Special-needs parents experience unique grief. Instead of moving through the regular stages and finding resolution, we can be struck with grief at any moment. We go through the cycles again and again.

Each of us could tell stories of surprising grief. (We can also tell stories of surprising joy!) When I run up against the wall of grief, I open to the Psalms. Psalm 107 is my favorite. Look with me at the hope it presents:

- For those who are lonely and have no place to call home, He “satisfies the longing soul, and the hungry soul he fills with good things” (v 9).
- For those in darkness, in the shadow of death, He “brought them out of darkness and the shadow of death, and burst their bonds apart” (v 14).
- For those who were fools and suffered affliction, “He sent out his word and healed them, and delivered them from their destruction” (v 20).

We can follow this pattern from Psalm 107 when grief threatens to engulf us.

We can cry out. We can experience the peace He brings to our circumstances (even if the circumstances don't change). We can thank Him for His love. We can praise Him with others.

Wherever you are in the cycle of grief right now, know there is hope. Even if you are like me and experience that cycle of grief over and over again. Each time we feel ourselves going down with the sorrow ship, we know God will meet us there and offer the hand of hope.

God, I thank You for the many emotions found in Scripture. I know I'm not the first to feel wave after wave of grief. Thank you for being a constant source of peace and reassurance. I praise You for being my anchor. In Jesus' name, amen.

Anger
Jeff Davidson

“Take control of what I say, O Lord, and guard my lips.”
Psalm 141:3 (NLT)

For so many special needs parents, including myself, we wrestle with anger all throughout our journey.

Anger is a natural part of the grief process. As we experience the various aspects of life in our special-needs world, we will always find ourselves at various stages in dealing with our emotions and grief. Anger is one such emotion and stage.

I personally made the near-fatal mistake of letting anger and denial destroy me in the early years after receiving our diagnoses. I was acting out of my anger and I let it affect my relationship with my spouse, my family, and my friends.

Ultimately though, uncontrolled anger hurts ourselves as much, if not more, than others around us. Unbridled anger over our circumstances can lead to bitterness, despair, and chronic sorrow. If anger were a road, it would be a dead-end road leading us to nowhere.

Anger is a response, and we have a choice in how we respond to all things. We can choose to act, speak, and live out of anger. Or, we can choose to act out of joy, acceptance, and determination to rise above our circumstances.

When we choose the latter, our perspective begins to shift and change. God opens our eyes to His purposes, His presence, and His character. God can channel our anger into a “holy discontent” that He can actually use in our lives.

Our prayers will become more about asking God to use our circumstances than they are about asking Him to change our circumstances.

Everything in our lives can be perceived as a burden or a blessing. How we respond ultimately determines the choice we make in how we perceive it.

Uncontrolled or chronic anger robs us of the ability to make the right choices when determining how we will react and respond to our circumstances.

Surrender and confess your anger problems to God, and ask him for help. Don't let anger rob you of your joy, peace, and contentment as you go along the journey of being a special-needs parent.

Father God, please help me in dealing with my anger. I admit it is a struggle for me sometimes, and affect my thinking. I ask You to help me control my anger. Your word says You turn our sorrow into joy; help me see things from Your perspective and use my thoughts and actions for Your glory. Amen.

Traveling - Not for the Weary!

Cindi Ferrini

*"The Lord will guard your going out and your coming in from this time forth and forever."
Psalm 121:8 (NASB)*

As I begin to write this devotion, I'm also beginning the checklist in my mind of what we'll need to take as we travel with our son next week! Of course we need the usual things: medications, the endless list of movies for his CD player, his action figures (did I mention he's 34?), hand games, a few books he'll never look at but will insist to take, and then the all encumbering wheelchair—do we take it or leave it home? He's quite mobile, but sometimes too much walking and heat makes him cling to us like sweat on a hot and humid day.

We know better than to fight some of the list. It's not negotiable even if half of it is never used ... not unlike half the clothes my husband and I will take! But after the list is made of what we must pack in the suitcase, we know there's also things we must pack ... mentally.

We know that our travel, pace, and what we can pack into a day will be greatly altered having Joey join us. We've learned that pushing him beyond what is his limit, will cause us all to have a lousy time. We need to be sure his meals, meds, and movements are marked out ahead of time. It might mean:

- We meet with less people than we'd hoped
- He'll need to get to sleep earlier, so one of us will need to take him to the hotel
- We'll have to take more time to do things that we could do effortlessly and without much thought had we traveled alone—that would be everything!
- The pace will be considerably slower
- We'll have to go to Chuck E. Cheese if he's really good and earns it!

Dear Lord, You know when we travel, when we will come, and when we will go. You are acquainted with our agenda and the many times it will change in order for there to be peacefulness, good attitudes, happy faces, and content hearts! May we turn to You in the times of frustrations for the right words to encourage, the right actions to bring unity, and the right frame of mind to keep sane in the midst of many challenges. You already know how challenging our usual days at home are, so we ask You to go ahead of us—helping us to maneuver the road we travel; keeping us from big road blocks and detours in the "special needs" realm so that the usual daily difficulties aren't more challenging than usual. When (or if) we get off track, please remind us gently that we are to make wonderful memories and not take everything too seriously to ruin a good time that is planned. Help our child with special needs to enjoy in whatever ways they are able, the trip, the time away, and the time as a family. May we honor You—as others will be watching! In Your name we pray. Amen.

Guilt

Lorna Bradley

“My guilt overwhelms me—it is a burden too heavy to bear.”

Psalm 38:4 (NLT)

Guilt is insidious and virtually every special-needs parent struggles with it on some level. Birth mothers often carry guilt related to their self-care during pregnancy. Both parents can feel guilty about passing on a genetic difference. A father of an adult son with autism told me that he feels guilty over the weight of responsibility placed on his wife as they raised their son, “Somehow I won the lottery, and the most beautiful woman in the world married me. Raising our son has been so hard. I think she would have been better off in a different life, an easier life.” Guilt can be caused by our actions, by things we think we have caused or done whether that is true or not, and by things we have left undone. It is a no-win situation with a virtually endless list of possibilities.

It is safe to assume that all parents feel some measure of guilt related to their parenting, but it is even more so for parents raising children with special needs. Just as the role of parenting our children comes with a bigger measure of responsibility, so too the accompanying portion of guilt comes as a heaping side order on a plate already too full.

The journey to freedom from guilt must travel the road to forgiveness. Side tours to shame, isolation, and self-condemnation simply make the journey longer and harder. So how do we fully embrace forgiveness? Seeking forgiveness is threefold. We need to seek forgiveness from God, from others, and from ourselves. The psalmist is right: guilt does overwhelm and is a burden too heavy to carry. We need to learn from what is past and move on. God’s desire for us is for freedom from guilt. How do we know? *“If we confess our sins, he who is faithful and just will forgive us our sins and cleanse us from all unrighteousness”* (1 John 1:9, NRS). God’s desire is to forgive. Were it not so, would the crucified Christ have prayed from the cross for the forgiveness of those who mocked him? The weight of our guilt belongs at the foot of the cross in reconciliation with Christ. What if guilt is from wronging another person? Seek their forgiveness as well, if possible. Yes, it may be a hard conversation, but also potentially freeing and reconciling.

What about that third part, seeking self-forgiveness? For many, that is easier said than done. They work toward letting go of guilt and forgiving past mistakes only to find they are right back where they started a few days later. What breaks that cycle? Try talking with a trusted friend or family member, journal, pay attention to negative self-talk and redirect those thoughts positively, read scripture, and pray. Let God’s word guide you toward healing. *“Create in me a clean heart, O God, and put a new and right spirit within me”* (Psalm 51:10). *“As far as the east*

is from the west, so far he removes our transgressions from us” (Psalm 103:12). Whatever guilt you carry, God is bigger and wants you to release the burden that is too heavy to bear. God forgives, wiping clean the slate for a fresh start. Accept the gift and reclaim a life free from guilt.

Cleansing God, thank You for the gift of forgiveness. Please accept humble repentance for mistakes. Grant Your grace and mercy for reconciliation with You, with others, and within our own hearts. Close the door to guilt and open pathways to healing and wholeness. Amen.

When It's Just Too Hard

Sarah Broady

*"Seek the Lord and His strength;
Seek His face continually."
Psalm 105:4 (NASB)*

It was too late. There was no turning back now. The meltdown had begun, and once it starts, there is no stopping it, much less controlling it. Like so many other special-needs parents of children with autism who have severe meltdowns, I did what I needed to do to get him to his room to calm down. That meant putting my own self in harm's way as his body raged out of control. It meant holding his door closed until he calmed himself down enough so I could go back in. Once he started to cool off, I went in and wrapped him in his weighted blanket and pulled him to my lap on the floor while I squeezed him as tightly as I could. He was crying. I wanted to, but knew I couldn't because it would only upset him more. When it was all over, he resumed life as normal and went back to scripting Star Wars with his lightsaber. And then I fell apart.

My closet, the van, the bathroom, and the arms of my husband are all places of refuge I've sought after weathering severe meltdowns. Sometimes I just sit, shocked and traumatized. Other times the dam bursts and I cry to myself or to my mom or a friend over the phone as they listen to me grieve. I hate that my son can't completely regulate his emotions and that autism takes over and transforms him in an instant. I hate that I can't make it stop. HE hates that he can't make it stop, and I hate *that*.

There are days when it's just one thing after another, and by the end of the day, I am completely drained. I have no more to give. I'm empty. It's gone. *It's all gone*. I tell my exhausted self, "His mercies are new every morning" and go to bed, hopeful for a good day tomorrow, only to replay yesterday all over again: "Second verse, same as the first! A little bit louder and a little bit worse!"

I admit I don't always turn to the Lord or His Word when I am overwhelmed. I have tried before, but I can't focus enough to know what to read, or even concentrate on the words themselves. But that's exactly what Psalm 105:4 tells me to do. It's not wrong to hide away, cry, eat chocolate, or call someone to vent. I think having a place of solitude to go in order to calm down is necessary. Otherwise, emotions might be taken out on loved ones and cause further damage.

A friend gave me a verse that has been a tremendous help during those volatile times. Psalm 61:2 says, "*From the end of the earth will I cry unto thee; when my heart is overwhelmed, lead me to the rock that is higher than I.*" From the depths of my closet, I have cried out to God with an overwhelmed heart, asking Him for His strength. I admit out loud that I can't do this alone and I *need* Him. I pour out my heart to Him, trusting that He is listening: "This isn't the life I pictured. I hate this! I don't want this for my son or for our family." I certainly don't hate

Samuel; I hate the negative ways autism affects his daily life. I hate how hard he has to work to achieve something that comes so naturally to everyone else. And yes, sometimes it really is just too much to deal with. It's just too hard. But it's not an option to quit and walk away. At least, not one that I allow myself to consider. I don't have a choice. I *have* to do everything I possibly can to help him. I *have* to wrap him up and hold him for as long as it takes. I must. Because that's what love does. Love *never fails*.

Friends, Jesus loves you. His love truly never fails. He won't quit and walk away from us because we're crying out to Him yet again and it's just too much to deal with. He won't – He *can't* - because of the covenant He made with us. We can obey these words to "seek the Lord continually" because we know He is continually present. His strength is abundant and He lavishes His grace on us in our hurt. When it's just too hard, cry out to God.

Father, thank You for always being there whenever I need You. You know the pain, frustration, and sorrow I feel because of the challenges my child faces. Help me to seek You first when I can't handle it anymore. Comfort my heart and remind me that You are able when I am not. That Your strength is mine in Christ and I can do all things through Him. Thank You for loving my child and for loving me. I praise You that Your mercies truly are new every morning, and that Your grace is sufficient. When my heart is overwhelmed, lead me to the Rock that is higher than I. Amen.

Hope

Sarah Broady

*“O Israel, hope in the LORD;
For with the LORD there is lovingkindness,
And with Him is abundant redemption.”
Psalm 130:7 (NASB)*

Hope. There is something inherently beautiful about the word. For the believer, it is more than merely waiting for a desire to be fulfilled that may or may not happen. For instance, “I hope I get the grant to pay for therapy.” I have no way of knowing whether or not I will get the grant, and I have to wait to find out if we get it or not. So, I “hope” for the grant. But as one who trusts in Jesus, the *hope* I have is not an unknown. It is not wavering. It is an anchor of the soul, both confident and sure (Hebrews 6:19). And it has nothing to do with therapy grants at all.

A right understanding of hope results from a right understanding of the Lord’s lovingkindness. God’s lovingkindness refers to the covenant God has made with His people, Israel, who you are if your trust rests in Christ. A covenant is more than a vow or promise. A covenant grants certain promises, and can only be broken if the one who made the covenant dies. We know the Lord is eternal and cannot die; therefore, His covenant is forever binding and unbreakable. It grants us faith to believe in Christ who paid the price of death for our sin, that we may be forgiven and reconciled to God, to glorify and live with Him forever.

Sin has broken our world and wrought all kinds of suffering. As believers, we know the suffering sin imposes on our souls. The daily struggle to fight the good fight of faith. To be selfless, loving, gracious, and kind to our children and family when they are hard to be kind to and love. As special-needs parents, we know suffering as we watch the pain that disorders and dysfunction bring upon our precious children, and even ourselves. We see the frustration and agony behind glassy eyes and muted lips that cannot communicate their needs or desires. We watch society struggle to understand words like “inclusive” and “compassion” that we parents are so desperate for them to understand. We have cried enough tears to fill the ocean in between the precious few hours of sleep we get each night. For *years*. And we long – we yearn – for *hope*. For restoration. But there is hope! His covenant grants the redemption of all earthly and worldly brokenness. The Lord’s lovingkindness is our hope. *“Let us hold fast the confession of our hope without wavering, for He who promised is faithful!”* (Hebrews 10:23).

We can hope for grants and therapy and societal understanding and even cures. But this is not where our true hope lies. One day, there will no longer be depression, disease, disorders, or death. Jesus has overcome all brokenness through His own death and resurrection (Revelation 21:4) and He will wipe away every tear from our grief-weary eyes forever. True hope rests in the faithful lovingkindness of the one true God, Yahweh, through Jesus Christ His son, who is both now, and will forever make all things new (Revelation 21:5).

Father, thank You for Your lovingkindness toward me. I praise You that Your covenant is trustworthy and that You are faithful to Your promises. Thank You for my children and the privilege to raise them up to love and put their trust in You. Please give me wisdom as I parent my child with special-needs. Grant me strength and grace to deal with every situation in love. Comfort me, Father, as I weep over my children who have so many struggles and challenges to face. Help me guide them through the trials and victories of life with joy and continued hope in our Savior, Jesus Christ. I put my trust and hope in You alone. Amen.

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[Jeff Davidson](#) – Jeff and his wife Becky started Rising Above Ministries after realizing the incredible gift and blessing their own son with special needs (Jon Alex) was to their family. Jeff

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