

# Beyond Measure

*Participant Guide*





THIS BOOK BELONGS TO:

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In the *Beyond Measure Collective*, you'll find a community of mothers who all share unique and truly special children. This is a journey that you'll make together, as you are invited to walk through the very real challenges and extreme joys of being a parent of a special needs child.

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## ABOUT THE AUTHOR

*TyiaLynn Scott* is the mother of three wonderfully unique children, ranging from college to kindergarten. Her 19-year-old daughter, Celia, is one of six children in the United States diagnosed with a rare form of life-threatening internal bleeding; causing Celia's childhood to be spent in and out of the hospital. Professionally, TyiaLynn was co-owner of a small consulting firm for 16 years. Then in 2015, she shifted her focus and founded Critically Loved, a nonprofit providing support to families of critically and chronically ill children. TyiaLynn now puts all of her professional energy into Critically Loved where she works full time. To learn more about the free support they provide to parents, visit [\*\*criticallyloved.org\*\*](https://criticallyloved.org).



## GROUP EXPECTATIONS

1. I will keep everything shared in this group confidential.
2. I will not judge other women in this group.
3. I will respect myself and those around me.
4. I will not give advice or try to “counsel” other participants.
5. I will keep my phone on “silent” and only answer in case of an emergency.
6. I will show my commitment to my group by attending every session and doing my homework.

Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_



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# WEEK 1: STEP BY STEP

## AGENDA

Welcome & Check-In  
Group Expectations  
Special Needs Parent  
Break Out Exercise  
The Next Three Steps  
Putting It Into Practice  
• Attributes of God  
Prayer



# WEEK 1: STEP BY STEP

*“The difficult road is managed  
by a continued determination  
to take the next step.”*

- TYIALYNN SCOTT

## *Special Needs Parent*

“Special needs parent.” What does that phrase mean to you? Do you cringe at the title others have cast over your life? Do you claim it as a banner to what your life is now? Do you wish, with every ounce of your being, it simply did not apply to you? Whatever your reaction is to this “name,” the road you are on is undeniably more difficult than the one traveled by most of your friends.

How many times have we, moms of EXTRAordinary children, been at our wits’ end and not fathom traveling this road any longer? We probably have never said the words out loud, because what kind of moms would we be if we admitted our lack of faith, strength or perseverance? The answer is an honest one: If we are being real with ourselves and those in this room who are walking alongside us, we need daily encouragement, wisdom beyond our years, a supportive community, and most of all – Jesus! The reality is that we need all of these more desperately than our friends with typical children.

*Are you there right now? Are you completely exhausted and overwhelmed by the thought of raising a special needs child? Yes or No*

Who came up with the phrase “special needs parent”? It doesn’t even come close to carrying the weight associated with the responsibility. Do others in our lives really understand all that goes into raising a special needs child? Do they know the stress level associated with endless doctor and therapy appointments, dealing with denied medical insurance claims (*Can I get an AMEN?*), and high pitched screams that you can’t bear to hear. One. More. Time. Let’s not forget the endless nights of crying (and I’m not just talking about our children). Of course they don’t. No one can understand what you are going through until they have walked in your shoes. Now, look to your left and to your right; these moms understand the struggle. They feel your hurt, your overwhelmedness, your emotional and physical exhaustion. You are not here by accident and you certainly are not alone in this struggle. The women sitting in this room can be amazing sources of support for you!



**BREAK OUT GROUP**

Find 2-3 women whom you don't know well and take 10 minutes to share your story and exchange a prayer request for this week. Write down their prayer requests:

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*Therefore encourage one another and build each other up, just as in fact you are doing.*  
**- Thessalonians 5:11**

**THE NEXT THREE STEPS**

Even with the best support system, looking down the long-term road for our special children can be overwhelming. This is especially true when we focus on what their future as adults will look like and how long we will be their caregivers. How in the world can I do this the rest of my life or scarier yet, for the rest of *her* life? Will I outlive my child? These are the questions that make it hard to breathe.

So, instead of standing on our toes trying to see the end of this hard road, let's focus on just the next three steps.

Several years ago, my brother, Chris, set a goal to run a marathon. While he trained for the Chicago Marathon, he ran for hours at a time. After about 15 miles, his body would start to give out because he was overwhelmed by just how much further he had to go. So, he took his focus off of the next 11 miles and started to focus instead on the next three steps. Three steps at a time, then the next three. Chris accomplished his goal and completed the Chicago Marathon – three steps at a time!

Knowing the very long road ahead of medical challenges for my daughter, Celia, can be overwhelming. I, too, must stop looking for the finish line and just focus on the next three steps.

What are ways you can focus on just the next three steps in caring for your child?

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## PUTTING IT INTO PRACTICE

When it comes to adversity and hardships, how does faith play a role in handling those difficult situations or seasons?

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If you have a relationship with Jesus, how does that help you in raising a special needs child?

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What attributes of God will help build your perseverance and dependence on him?

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Include scriptures or quotes that solidify the attributes of God you chose. See examples below:

### **God is ever-present.**

*Where can I go from Your Spirit? Where can I flee from Your presence? If I go up to the heavens, You are there; if I make my bed in the depths, You are there. If I rise on the wings of the dawn, if I settle on the far side of the sea, even there Your hand will guide me, Your right hand will hold me fast. - Psalms 139:7-10*

### **God is all-powerful.**

*O Sovereign LORD! You have made the heavens and earth by Your great power. Nothing is too hard for You!*

- Jeremiah 32:17

### **God is love.**

*For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord. - Romans 8:38-39*

### **God is faithful.**

*Let us hold unswervingly to the hope we profess, for He who promised is faithful. - Hebrews 10:23*

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## Your Chosen Attributes of God:

*When we trust God with the long term,  
it is much easier to take the next three steps.*

(If you need help mustering the strength to take even the next step, God can do that, too!)

When life feels too difficult to handle and our circumstances become too heavy to carry, turn to the promises in scripture that remind us that we don't have to take on these burdens alone.

Write out Psalm 55:22.

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When God tells us to CAST our cares on him, he doesn't tell us to lay them down gently. To CAST our cares to the Lord is literally a transfer of the weight. It is throwing with **all of our might** all that burdens us onto him.

Do you see the promise God provides in his word? Let's make the promise of Psalm 55:22 more personal: *When I cast my cares on the Lord, He will sustain me; He will never let me be shaken.*

This is the promise of God that I am claiming today. Will you claim it with me? Type out Psalm 55:22 on your phone as a recurring reminder to pop up every morning this week. Let's start each day claiming his promise.

God will not let you be shaken or moved. He has you; rest in that, my friend. We are in this together.

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*Praise be to the Lord,  
for He has heard my cry for mercy.  
The Lord is my strength and my shield;  
my heart trusts in Him,  
and He helps me. My heart leaps for joy,  
and with my song I praise Him.*

**- Psalm 2:6-7**

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# WEEK 2: FAITH OVER FEAR

## AGENDA

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Welcome & Check-In

Joy in the Midst of Fear

Break Out Exercise

Three-Step Approach

Putting It Into Practice

- Perfect Love

Prayer



# WEEK 2: FAITH OVER FEAR

## JOY IN THE MIDST OF FEAR

Where do you find yourself at this moment in time? Are there parts of your life that you wish were different? Let's be real. Life. Can be. Overwhelming. Some people seem to have more than their share of chaos thrown at them, and if I'm not careful, I can lose sight of the joy and peace that is available to me. It's easy to have peace when life is sailing along smoothly on calm seas, but when the waves begin to roar and the boat is barely afloat, you will discover where your joy is rooted. I'm not talking about happiness; happiness is a surface emotion, an "in the moment" feeling that is based very much on circumstances. But joy? Joy is hidden in the depths of your soul – far beneath the surface, unable to feel the changing winds of life. Joy is the very thing that settles who I am in God and steadies my life. I assure you, happiness cannot be found in the ER trauma unit at 3 a.m. with your child. But joy can. I don't know what the days and weeks ahead will bring to our lives, but I do know this – God is good. The God who provides life also provides indescribable joy, calming comfort and overflowing peace. And for that, I am eternally grateful and joyful.

How would you describe the difference between joy and happiness?

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*Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which surpasses all understanding, will guard your hearts and minds in Christ Jesus.*

**- Philippians 4:6-7**

I wrote this in the fall of 2018 from my daughter's hospital room. She was 18 at the time and had the biggest internal bleed of her life which took us to the ER trauma unit. After receiving four units of blood to stabilize her, she was taken by ambulance to ICU at Cincinnati Children's Hospital where her specialists were. The event also included receiving platelets, iron infusions, multiple blood clotting treatments and a week in the hospital.

*So how could I write about joy at a time like this and not have been completely fearful for the life of my child?*

It took years to work through my anger, fear and anxiety to come to a place of total dependence on God. I wish I would have learned how to lay down all of the internal struggles years before when my daughter was young. I also wish that I would stop picking them all back up again.

## GOD SPOT

I can't get back the years that I spent angry at God for my daughter's condition, however, what I learned during that time was invaluable. Here's the simple truth:

***Control is an illusion.***

Fear comes when we feel out of control, but the simple truth is that we control very little in our lives. Try as we may, we can't control other's actions, life-changing events, our children's conditions, consequences of people's choices, and the list goes on. The only things we can truly control are our own actions, choices, heart and mindset. We control who and what our lives are centered around: Is it our child's condition? Our spouse? Our other children? The church? God?

*Be honest, what consumes your thoughts most of the time? Do not write what you think the Christian answer "should be," write what it actually is. If I'm being real, my answer many times would be work, relationships with family and friends, and my daughter's condition.*

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As Executive Director of a small nonprofit, I have to give many presentations to raise community awareness about the services we provide. The groups I present to have become larger, and I have found myself getting very nervous speaking to large audiences. I didn't share this with anyone, in spite of it getting worse. In the summer of 2018, it finally came to light. I was at a prayer meeting with pastors from all over the city and one of the prayers spoken landed so profoundly in my soul: "Someone here has lost their confidence in Christ and it's time to regain it." I had never thought of my struggle in that way before, but the anxiety I felt was actually me losing my confidence in Christ. The pastor rebuked the attack and claimed victory over it; unbenounced to him he was praying for me. Immediately, peace flooded my whole body.

As I left that prayer meeting, I realized that I had taken over the "God spot" in my life. I had started caring about what people thought of me, and that took the focus off of God and placed it on me. I had placed a tremendous amount of pressure on myself for the nonprofit to become sustainable so it could help more people; believing that if I failed, then the nonprofit would fail. I had to re-acknowledge God's authority; if God had called me to this ministry, then he would provide for it. **It's not about me; it's about what God will accomplish.** When we take our eyes off of him and try to control the uncontrollable, that's when fear comes in.

The irony was I had written an entire curriculum on how to combat fear and I had taught multiple studies on this topic, yet, it never occurred to me to use this knowledge to fight this particular battle in my own life.

*Take up the shield of faith, with which you can extinguish all the flaming arrows of the evil one.  
Take up the helmet of salvation and the sword of the Spirit, which is the Word of God.*

**- Ephesians 6:16-17**

## **BREAK OUT GROUP**

Break up into small groups of 3-4 and share what fears you have relating to your child's condition.

Write out your own fears below:

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Come back together as a large group.

*Have you ever thought about having fear around your child's condition as being a result of losing your confidence in Christ? What is your initial reaction to this idea?*

*Have you considered that this fear is actually just a result of feeling the need to control the uncontrollable? What is your initial reaction to this idea?*

The good news is that we don't have to live this way. We can practice recognizing where our fear comes from, being patient with ourselves, and doing the work to feel peace in the midst of hard circumstances.

## **THREE-STEP APPROACH TO REMOVING FEAR**

### **1. Walk confidently in Christ.**

This means giving up control (or the illusion of it) and placing Jesus at the center of every area of your life. Be aware of the times you take over the "God spot," and put him back in his rightful place – right at the center of your life so he takes the focus off of our inability and places it on his all powerful ability. This means walking confidently in the peace, love and joy of who Christ is. It means knowing that God's got you, even when you don't feel it.

### **2. Cast your cares on God.**

*How can God handle any situation better than me?* Read Psalm 55:22 from last week. God can be trusted with every area of your life and with every trial. Be mindful that we often continue to pick up areas of our lives that we surrender, especially when it starts to feel out of control again. You may have to cast your fear onto Jesus daily. And that's OK.



### 3. Use the sword of the Spirit.

“The sword of the Spirit” is a poetic way of saying that the Bible is seriously powerful. It’s the weapon God has provided to remind us of who he is, who we are, and why we are here. Speak scripture out loud. Speak God’s promises over your situation, your children, your doctors. Read Ephesians 6:10-17 as a reminder that we need the whole armor of God for battle. Then write it down and put it in a place where you can see it daily.

*“Fear must have thought I was faithless  
when it came for my heart.”*

- Hillsong UNITED (“Not Today”)

*Submit yourselves, then, to God. Resist the devil, and he will flee from you.*  
**- James 4:7**

### PUTTING IT INTO PRACTICE

Write down 1 John 4:18.

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Circle “perfect love” in the verse. What does “perfect love” look like? Be specific.  
There are no right or wrong answers.

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When I think of “perfect love,” I think of God. The Bible tells us in 1 John 4:18 that God is love. The only one who can truly love perfectly is the creator of the universe, and I am so glad he does! How awesome to know that God pursues us endlessly, provides for us tirelessly, loves us completely. And that type of “perfect love” casts out fear. When we place God in his rightful place in our lives, it removes the pressure of having to do anything on our own.

*Does this mean life will be free of pain and suffering?*

Winning the battle doesn’t mean the war is over. **The longer we put off dealing with fear makes it even more overwhelming to face.** However, as long as we know how to fight against fear, we have victory over it as soon as the attack comes.



Write out three verses on the subject of fear that resonates with you.  
(Search on the web, *Bible verses on fear*, if none come to mind.)

1. \_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
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3. \_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

This week when you start to feel fear creep in, practice using the three steps to combat fear: walk confidently in Christ, cast your cares on God, and use the sword of the Spirit.

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*"So do not fear, for I am with you;  
do not be dismayed,  
for I am your God. I will strengthen  
you and help you; I will uphold you with my  
righteous right hand."*

**- Isaiah 41:10**

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# WEEK 3: BEAUTY AMONG THE ASHES

## AGENDA

Welcome & Check-In

Kiss the Wave

Break Out Exercise

Putting It Into Practice

- Things I'm Thankful For

Open Letter to My Friends

Prayer



# WEEK 3: BEAUTY AMONG THE ASHES

## KISS THE WAVE

Our church did a sermon series called, “Kiss the Wave.” Kissing the wave is a concept that helps us see hardships as opportunities to be drawn close to God, to build your character, to help others. It is a realization that God does not waste the waves (hardships) in our lives. Whether you are facing small waves, big waves or tidal waves that change the trajectory of your life, learning to see them as a blessing that draws you closer to Jesus is life changing. This brings a whole new light to seeing trials as opportunities.

I’m sure many of us are all too familiar with the “count it all joy!” phrase shared during hardships within our Christian circles. I suppose that I knew hardships should be counted as such and it is scriptural, however, moving truth from your head to your heart can be a long journey.

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*Consider it pure joy, my brothers and sisters, whenever you face trials of many kinds, because you know that the testing of your faith produces perseverance. Let perseverance finish its work so that you may be mature and complete, not lacking anything.*

**- James 1:2-4**

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*“I have learned to kiss the waves that throw me against the Rock of Ages.”*

- Charles Spurgeon

I know it sounds crazy to be thankful for your child’s health condition; I used to think so too. Only after I had released the anger about my child’s condition was I able to feel God’s embrace and begin to see the beauty among the ashes. It was the hardships themselves (the waves) that made me lean on Jesus like never before. This closeness and dependence on him was something to be thankful for. This was the first blessing that had come from my child’s condition.

*Has your child’s condition strengthened your relationship with God? Yes or No  
If yes, how? If no, why?*

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I believe that my daughter started to see the beauty among the ashes before I did. Somehow, these trials our children face, force them to become spiritually mature well beyond their years. I hear this time and again from parents of special needs children. It seems that pain has a way of bringing wisdom. If this is the case for your child, you have just discovered a second blessing that has come from your child's condition.

The following was written by my daughter as part of a school assignment in April 2018:

*I struggle with multiple medical issues, the most serious being internal bleeding problems that cause me to need blood transfusions often. To give some context to that, I have received over 50 units of blood in the last three years. However, this is just one piece of my story. I am a young woman who truly wants to make an impact on this world. I hope to lead a life full of love, courage, and, most importantly, faith. I don't ever want to let my health challenges or the rough parts in my history stop me from doing that. Some advice I'd like to give to other young girls (and something I'm still working at myself) is to remember that those broken and difficult pieces of life are still a part of your story, and those scars they leave are a map of what you have survived and conquered. I know it's really hard to have that mindset; it is for me too, but every chapter in our stories shapes us into who we are and who we will become. I'd like to end with this saying: "Speak life, love hard, live victoriously." - Celia, age 17*

This is the child I have much to learn from. So, here is the third blessing that has come from my child's condition: she inspires me. Her strength, perseverance, witness, love, endurance, outlook. It all inspires me! I want to encourage you to watch daily for ways your child inspires you. Be mindful to verbalize this to her even if she is not able to respond.

What is one encouraging thing you can tell your child this week about how he inspires you?

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## **BREAK OUT GROUP**

Break up into small groups of 4-5. Everyone share one really hard thing about their child's condition (examples: doctor visits, up at night, nonverbal, isolation because of child's social issues). Then share one positive thing that has come as a result.

Come back together as a large group.



## PUTTING IT INTO PRACTICE

It's good to take pause and look for the beauty among the ashes. Write down things you can be thankful for that are a direct result of your child's condition. To help get you started, see mine below. Circle any that apply to you, then add at least three more.

### The things I'm thankful for that are a direct result of my child's condition:

Building my strength, perseverance and dependence on my Creator

Growing the spiritual maturity of my child

Inspiring me

Shaping who i am

Shifting my focus off of material things and onto relationships

Preparing me for other challenges

Enabling me to support others walking a similar road

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_

Let's focus this week on the beauty among the ashes. Any time you think of another blessing that is a direct result of your child's condition, come back to this page and write it down.

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*We also glory in tribulations, knowing that tribulation produces perseverance; and perseverance, character; and character, hope. Now hope does not disappoint, because the love of God has been poured out in our hearts by the Holy Spirit who was given to us.*

**- Romans 5:3-5**

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*"I will fix my eyes on the blessings of this  
ridiculously hard life that I call mine."*

- TyiaLynn Scott



## AN OPEN LETTER TO MY FRIENDS

As the parent of a special needs child, I'm sure you have heard the phrase, "I don't know how you do it!" more times than you can count. People are often in awe how we manage other children, friends, family, running a household and our child's healthcare. I don't know about you, but I have just about had my fill of hearing that phrase.

*To my friends who are not special needs parents:*

"I don't know how you do it," you say.

"Do you honestly think I have a choice?" I didn't choose for my child to have a life-threatening condition. I didn't choose for my child's condition to alter the life of my family – completely.

Here's the honest truth: if **your** child suddenly acquired a life-altering condition, you too would learn how to do it!

You would figure out juggling your work schedule with three-hour specialist and therapy visits.

You would learn all about school medical intervention plans and IEP's so your child could graduate.

You would learn to prioritize making time for your other children away from hospital rooms, therapy sessions and doctor appointments.

You would learn how to fight denied medical claims and get out-of-network facilities approved for your child's care.

You would become an expert in your child's condition by doing hours of research.

You would figure out how to function on little sleep because you were up all night again with your child.

You would learn to squeeze in date nights with your spouse because protecting your marriage is vital and even harder for special needs parents.

You would learn that venting your frustrations about your child's condition to God is healthy.

You would find out that it is OK to not have it all together.

You would learn that grieving the loss of plans for your child doesn't make you a bad parent.

You would figure out well-meaning friends don't always say the right thing and you would muster the grace to look past the harsh words and see their hearts.

**But** you would also learn how to be still with God in a way you never have before.

You would spend hours on your knees petitioning God on behalf of your child.

You would learn to sift through the ashes to discover the beauty in life.

You would see your child mature well beyond their years and teach you incredible life lessons.

You would witness kindness in the hearts of nurses and doctors who care for your child.

You would learn to appreciate the exhales in life, when you can rest for just a moment.

You would learn to treasure the simple things of life, because possessions would no longer matter.

You would cherish each moment you have with your child because you would have a keen awareness that there may not be many more.

You see, my friend, I am the one who doesn't know how **YOU** do it! If I had not the trials I currently walk in, I would not feel so tremendously blessed by this ridiculously hard life that I call mine.

Much love,

*A Mom of a Special Needs Child*







# WEEK 4: ANGER

## AGENDA

Welcome & Check-In

Deep Seeded Anger

Spiritual Boot Camp

Putting It Into Practice

- Ask God the Question

Prayer for Peace and Restoration



# WEEK 4: ANGER

As a special needs parent, I think feeling betrayed or blaming God is a natural response – by natural, I mean a human response. When we encounter health challenges in our children, it is difficult to not blame God, especially when it appears that God has removed his shield of protection from our children. For there is nothing a child could have done to deserve a serious health condition or her life taken away. While we do not understand why God would allow these things in our lives, if we choose to honor him in the process, it can be a powerful witnessing tool. **We might not ever get the “answers” we’re looking for as to why our child has been dealt this hand, but we must remind ourselves that loving our babies is one of the greatest privileges of our lives, and an opportunity to mimic Christ’s love every day. And that is enough.**

## DEEP SEEDED ANGER

My daughter, Celia, is a people person; she feeds off of people’s energy even when her blood is dangerously low. She will use up all of her energy visiting with people, and will be completely wiped out when they leave. She would often times be lethargic all day at home and in the car ride over to the doctor’s office, then bounce back to life the minute she saw her beloved nurses and doctors. They would often think she was feeling great until they checked her blood levels and would have to send her straight to the hospital because her blood levels were so low.

I would often hear from friends and family, “Celia looks like she is doing great!” This started making me really angry. At first, I would say, “Thank you.” However, the more this happened, the madder I got; it got to a point where my response was, “WELL, SHE IS NOT!” I viewed other’s optimism as making light of the situation by making themselves feel better by thinking Celia was OK. When in reality, she was really struggling. Can anyone relate?

My deep-seeded anger that I allowed to seep into my heart several years before was now fully manifested. Not only was I dealing with anger about my daughter’s life threatening illness, but now a life-changing illness of my own. It was all I could do to keep my head above water, watching Celia struggle with the pain and bleeding, and unable to fix it or take it from her. I suddenly found that my joy was gone, and I had allowed anger to seep into my deep, fresh wound ... and it burned.

## SPIRITUAL BOOT CAMP

On recommendation from a couple of trusted friends and their guidance, I worked through my anger by getting real about it and beginning to understand where it came from and the true depth of it.

Now, it’s your turn. With your trusted group of women gathered around you, let’s get started: Time to get real. Before answering these questions, pray for God to reveal any hidden anger or issues you need to deal with. Search your heart.

*Do you think God wants your child to have a life-altering condition? Yes or No*

*Does God have the power to heal your child? Yes or No*

*Are you mad at God for allowing your child to have this condition? Yes or No*

The thing about anger is that it’s a secondary emotion. It comes as a result of something else – like fear, old wounds, or unmet expectations with God. The best thing we can do is get super honest with ourselves about the anger we might be allowing to fester, and recognize what’s going on below the surface. Discuss with your group the things that might manifest in anger or rage.



## PUTTING IT INTO PRACTICE

When we reflect on life-changing events and evaluate our responses to them, it can change how we respond to having our world shaken now and in the future. We need to be prepared for hard days ahead: disheartening doctor reports, beyond exhausting days, harsh words spoken by friends who can't fathom our struggle. Being prepared for these overwhelming times to come, can lessen the risk of anger being our response.

*Write down one life-changing event that shook the very ground you stood on? Think through the details.*

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*How did it make you feel?*

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*What were the circumstances leading up to this event? Was there something that happened prior to the event that prepared you for it?*

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*Did you respond by being angry at God?*

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*What lessons did you learn from the event? How has God used this event to grow your character, prepare you for something else or to help someone else?*

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There's no doubt as special needs parents that we are continually overwhelmed and that we have many reasons to be "rightfully" angry. However, if we instead choose to surrender our "right" to anger and learn to "kiss the wave" as we talked about last week, we will rest in God's peace much faster.

*When anger is out of the way, we can  
clearly see God's love for us.*



**ASK GOD THE QUESTION - PRAYER**

In the midst of managing Celia’s healthcare, my own health challenges resulted in weeks at the Mayo Clinic getting diagnosed, and then several years of rehabilitation to get back to a normal level of activity. This was the point where my anger had really set in. Thankfully, my friends recognized my need to lay the anger down. They prayed with me and encouraged me to ask this question: “Ask God if he wants you to be sick.” When I asked, God responded so clearly, so unexpectedly that I could not speak. My eyes spilled over with tears and I was already on my knees – all I could do was fall on my face before the God who loves me so much.

“What did God say?”

“God asked if I wanted Celia to be sick?”

I had blamed God for so long that all reason had escaped me. In that moment, I realized how much it hurt me to watch my child suffer so how could I ever think that God wanted me, his child, to suffer?

For me to blame God for sickness was sin because it pulled me away from him. I had to repent of this because it allowed anger in my heart and bitterness toward God. At the very moment of repentance, immediate healing ensued. Restoration. Healing of my heart where anger had been residing for so long was now filled with love, acceptance and peace.

Since the child you have been entrusted with is actually God’s child, it is unfathomable to think that God wants him to be sick. You know as a parent just how hard it is to watch your child suffer; God is with you in this. He is loving you through this. He does not want your child to suffer any more than you do.

Be willing to ask God “the Question.” Maybe it’s the same one as mine: “Do you want my child to be sick?” or you may have another question for him. There is no wrong question, nor any question that he can’t handle. This is your loving father, who cares deeply for you, and you are in a safe circle of women who share your anger and longing for restoration. Be bold to ask the Lord anything and then bravely wait for his answer.

**Ask God Your Question**

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**His Response**

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## PRAYER FOR PEACE AND RESTORATION

*Lord God,*

*I come before you now, a broken daughter of yours. I repent of the anger I have harbored in my heart and I lay it down at your feet. I know You can be trusted with every aspect of my life; and that includes my child. I'm sorry for blaming You for my child's condition and the distance that has caused in our relationship. I know You love my child even more than I do and it must break your heart to watch her struggle, just as it breaks mine. Open my eyes today, to see your blessings that are being poured out on my life and the life of my child. Help me to see how the uniqueness she possesses is making an impact.*

*Thank you for loving me through the hard days. Thank you for being my strength, my peace, my comfort. Remind me if I pick up the torch of anger again that you can quench it when I come to your peaceful waters. I rest in your trustworthy hands. In the holy name of Jesus, I pray.*

*Amen.*







# WEEK 5: OVERFLOW

## AGENDA

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Welcome & Check-In

Stress Expectations and Realities

The Three “BE” Practices

Break Out Exercise

- Fruits of the Spirit

Putting It Into Practice

- Joy and Peace

Prayer



# WEEK 5: OVERFLOW

## STRESS EXPECTATIONS AND REALITIES

De-stressing practices for moms, especially for moms like us, are a necessity. But many of us may come with preconceived notions or unrealistic expectations of how that should look and how much time we need for it. Here's two scenarios that I'm sure you'll be able to relate to:

**Expectation:** A long bubble bath in the quiet. Yes, the quiet that drowns out all the noise in my head, a tub just the right temperature to soothe my tight muscles, and scented candles to provide the only light. Sweet easy music plays for the second half of the bubble bath. Then exiting the tub, slipping into my PJs, and sliding straight into bed without waking up the entire night.

I have had a few times in my life that something very close to resembling the above did indeed happen. However, this is not the norm, but if I expect it to be I will be continually disappointed.

**Reality:** I spent the day at the hospital with my daughter for an iron infusion and blood clotting treatment. My laptop accompanied me to the hospital room so I could squeeze in some work, but a new doctor was on call and had to be brought up to speed on her condition. We wait longer than usual because there is an issue with insurance no longer wanting to cover the blood clotting treatment at the hospital. The doctor tells us it must be given at home tonight.

I call my mom and ask her to pick up my 3-year-old from preschool since the appointment is taking longer than expected. (This is the third time in two weeks that I've had to call in that favor). Finally, I make it home and rush around getting chores done early so I can take a long bath to end my hectic day. Dinner consists of leftovers for the fourth night in a row with much fussing from my 3-year-old who didn't get a nap today. After the fastest bath that will qualify for getting my child "clean," I rush my little one off to her room to read a book before bed. Getting her second wind, she emerges from her room for some cuddles, but I put her back to bed because I want my bath!

I quickly help Celia finish cleaning up the kitchen and then I rush to the bathroom and close the door. Finally, time to myself. I run the bath water and start to get out candles, but at this point I'm really just too tired for all of that effort. I slip into the bath and close my eyes, only to hear loud thumping music coming down the street. My teenage son must be home.

A few seconds later there's a knock on the bathroom door, "Mom, we have to do the blood clotting treatment tonight, remember? I will get the supplies out; let me know when you're ready."

*Shoot! I forgot.* There goes my plan for going straight from bath to bed. I drag my tired body out of the tub, not any more relaxed than when I got in. I exit the bathroom and mix the medicine that will stop Celia's internal bleeding. *I almost forgot to give it to her. Wow! I'm a great mom.* I slip on the medical gloves, insert the needle into her scared veins, and give lifesaving medicine to my child.

Defeated, exhausted and far from de-stressed, I finally go to bed.

This trap is so easy to fall into. Don't get me wrong; we can all use a getaway: long soak in the tub, early morning run, time to ourselves, but don't be dependent on those alone to lower your stress level. If we only look forward to the elaborate practices and unrealistic expectations to lower stress levels, we will be continually disappointed and ironically, become more stressed. Instead, if I choose to be present in each moment, be watchful and thankful for the blessings, my heart will be full and my stress level greatly diminished.

## THE THREE "BE" PRACTICES

This is no easy task, so let's work together on these three practices: **Be Present, Be Watchful and Be Thankful.** I've altered my above narrative to reflect what these three practices could have looked like:

*Renewed Reality:* When my 3-year-old came out of her room, I could have read a few more books and spent a few minutes of snuggling with her – *that would lower my stress level.* While cleaning the kitchen, I could have turned on some music and danced with Celia – *that would lower my stress level.* When my teenage son came home blasting his music, I could have focused on how responsible he is and thanked him for coming home on time – *that would lower my stress level.*



How would you rate your current stress level?

1    2    3    4    5    6    7    8    9    10

What are your three favorite activities to lower your stress level?

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

How often are you doing these? \_\_\_\_\_

What are some ways you can lower your stress level in your everyday routine?

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If anyone has justifiable stress, it is a special needs parent. Few would try to argue otherwise or see your plight as being one that is easy to bear. With that being said, I have to admit that I am a “pull up your bootstraps” kind of girl, and my children will tell you that one of my favorite sayings is “Suck it up, Buttercup!” However, I am well aware of the burden and stress level that a special needs parent carries, and at times, I allow stress to overwhelm my life and I feel defeated. We just need to be careful to not stay in that place or the stress will consume us.

When we are consumed by stress, there is little room for anything else including the fruits of the Spirit. Stress, anxiety and fear simply cannot coexist with joy and peace. The fruits of the Spirit are the very things that people are drawn to and can point others to Christ when they are evident in our lives. When stress overwhelms us, we miss that opportunity.

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*But the fruit of the Spirit is love, joy, peace, forbearance (patience),  
kindness, goodness, faithfulness, gentleness and self-control.*

**- Galatians 5:22-23**

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By being present in the moments and watchful for opportunities to be thankful for, it frees us up to focus on Christ. This allows us to not only lower our stress levels, but it allows room for joy and peace.



## BREAK OUT GROUP

*God is our refuge and strength, an ever-present help in trouble.*  
**- Psalm 46:1**

## PUTTING IT INTO PRACTICE

Last week, we talked about anger not being able to stay contained within a person. However, anger is not the only emotion that overflows out of your life, so does joy and peace. When you are radiating joy and are so filled with the peace that can only come from God, it spills over to everyone around you. Just as your anger is felt by loved ones, so is joy, and its impact can be even greater!

*Write down someone you know who is a true joy to be around.*

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*How does this person impact your life?*

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*May the God of hope fill you with all joy and peace as you trust in Him, so that you may overflow with hope by the power of the Holy Spirit.*  
**- Romans 15:13**

Write out the following verses:

Nehemiah 8:10

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John 15:11

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Psalm 16:11

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Psalm 92:4-5

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What is the common theme of these verses?

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Where does our joy come from according to these verses?

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Here's the truth: **We cannot have true joy apart from God.** Building on the past few weeks, first, we have to surrender to God, then cast everything on Him (including our anger). Only after this occurs, can we experience true joy; then the overflow of our God-given joy will make a tremendous impact on others.

*Have you thought about your child's condition being an avenue to impact others and a blessing to them?*  
Yes or No

The reason you can have an impact in such a way is because of this: the world sees your struggle and expects you to have the natural (human) response of being weary, disheartened and angry. So when someone has an upside down response, the world takes notice. Read what Jesus says about how our response as believers should be completely different than what the world expects.

*"You have heard that it was said, 'Eye for eye, and tooth for tooth.' But I tell you, do not resist an evil person. If anyone slaps you on the right cheek, turn to them the other cheek also. And if anyone wants to sue you and take your shirt, hand over your coat as well. If anyone forces you to go one mile, go with them two miles. Give to the one who asks you, and do not turn away from the one who wants to borrow from you."*

**- Matthew 5:38-42**

Jesus commands believers to respond in a way that the world will take notice and to love people well. You, my friend, have a unique opportunity to be a witness and a blessing to others by simply being on this "special needs parent" platform. If we choose to respond in the way Jesus asks us, we can make immeasurable kingdom impact, showing others the life-changing joy that Jesus offers.

*In the same way, let your light shine before others, that they may see your good deeds and glorify your Father in heaven.*

**- Matthew 5:16**

One final thought: You may not always see the harvest of joy overflowing in your life or others. Please do not get discouraged or think you have failed when you don't see the impact, yet. Remember to just stay focused on what you are called to do – allow joy to fill your heart which will overflow to those around you. Allow God to take care of the results.

Will you pray with me as we both strive this week to have an overflow of joy?

*Lord God, I pray that you will fill me up with the joy that only You can provide. I lay down all my pride that would hinder You from filling me completely. Thank you, Lord, for your joy that cannot be contained. I pray that everyone around me would be witness to my joy and would be drawn to You as a result. Thank you for this gift that You provide so freely.*

*In Your Awesome Name,  
Amen*







# WEEK 6: LOVE BEYOND MEASURE

## AGENDA

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Welcome & Check-In

Your Identity

Truths and Lies

Putting It Into Practice

- Three Lies and the Truth

Your Worth

Beloved Daughter Letter

Additional Resources

Prayer



# WEEK 6: LOVE BEYOND MEASURE

Most moms of young children will admit how exhausting it is to care for their little ones all day. Honestly, it's hard for me to sympathize with those moms. I would gladly welcome that level of tired! When you add in special needs, raising our children is a whole new level of exhaustion that most parents will never know.

## Discussion Questions:

How would you rate your average level of exhaustion? (1 = none, 10 = code red)

1   2   3   4   5   6   7   8   9   10

How about being overwhelmed? (1 = none, 10 = code red)

1   2   3   4   5   6   7   8   9   10

*“The world needs to see honest struggles,  
not pious pretenders.”*

- Nancy Groom (*Bondage to Bonding*)

## YOUR IDENTITY

### *Truths and Lies*

Caring for a child with a developmental or medical challenge can also be very isolating, whether your child is too sick to be in public, overwhelmed by too much stimulation, or you are just too worn out to do any more than caring for your family. Whatever the case, when we are isolated, worn out and overwhelmed, Satan sees an opportunity to diminish our self-worth and whispers lies to draw our attention off of who we are in Christ. Mamas, we are more susceptible to this than moms with typical children. When we believe the lies about who we are, we begin to live into them. When we reject the lies and claim God's truth about who we are, we become a light for God.

## Discussion Questions:

*What are some lies about yourself that you have believed or continue to believe?*

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On the worksheet below, circle the Lies and Truths that you relate to and then add your own in the blanks.

| LIES SATAN WANTS YOU TO BELIEVE | TRUTHS OF HOW GOD SEES YOU   |
|---------------------------------|------------------------------|
| Conditionally loved             | <b>UNCONDITIONALLY LOVED</b> |
| Untrustworthy                   | <b>TRUSTWORTHY</b>           |
| Unstable                        | <b>STABLE</b>                |
| Shamed                          | <b>ESTEEMED</b>              |
| Unworthy                        | <b>WORTHY</b>                |
| Unvalued                        | <b>VALUED</b>                |
| Isolated                        | <b>INCLUDED</b>              |
| Rejected                        | <b>ACCEPTED</b>              |
| Unprotected                     | <b>PROTECTED</b>             |
| Victim                          | <b>WARRIOR</b>               |
| Hopeless                        | <b>HOPEFUL</b>               |
| Resented                        | <b>FORGIVEN</b>              |
| Punished                        | <b>RESTORED</b>              |
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## PUTTING IT INTO PRACTICE

When we can get our eyes off of the enemy's lies and onto God's truth, it changes everything - most important, our perspective. Imagine what we can accomplish and the witnesses we can be when others see Jesus radiate from within us because we have a firm foundation of who we are in Christ. Most of us would not choose to be placed on a pedestal for others to view our spirituality. However, as parents of special children we are, like it or not. This is worth mentioning again; others are watching how you handle the struggle. Sister, when you know who you truly are in Christ, your confidence will be evident and although not perfect, your witness will be strong. Others will be drawn to Jesus because of you. Don't miss this opportunity; another beauty found among the ashes.

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*See what great love the Father has lavished on us,  
that we should be called children of God!*  
**- 1 John 3:1**

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## YOUR WORTH

Another part of realizing your worth in Christ is knowing how much he appreciates the job you are doing. Stay-at-home moms usually have few cheerleaders in their life. There are not performance evaluations, pay raises or awards at company parties. Let's face it, no one is shouting from the rooftops that we cleaned up poop from the bathtub (again), got the needle in our child's vein on the first try, or successfully avoided another public meltdown by our child.

Unfortunately, for moms of special children who need this encouragement even more, this necessity is vastly overlooked. Our husbands, friends and family may not applaud our efforts at the end of a long day. Here's the honest truth, Friend – even when no one else notices your tireless effort, sleepless night and endless prayer, your Creator notices.

## BELOVED DAUGHTER LETTER

See page 41 and read the letter out loud.

### *Your Creator Loves YOU Beyond Measure.*

This Collective, *Beyond Measure*, was titled not for the love that you have for your special needs child, although I'm sure that's an accurate description of how much you do, but rather it was my prayer that you would grab ahold of this truth:

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*The Lord your God is in your midst, a Mighty One who will save; He will rejoice over you with gladness; He will quiet you by His Love; He will exult over you with loud singing.*  
**- Zephaniah 3:17**

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It is not self-confidence that accomplishes a life lived in peace and joy. Instead, it is having our confidence firmly rooted in Christ that will make all of the difference in navigating this difficult road. It will provide a firm foundation on which we can stand. It will provide strength to endure. It will be the very thing that brings peace amidst the chaos and turns ashes into beauty. When we realize just how priceless we are to our Creator, we can rest in his ability, strength and love.



# *Beloved Daughter,*

*I see you and thank you for caring for your child.*

*When you have to leave the grocery store with a screaming child yet, again, I see you.*

*Visiting the emergency room at 3:00 a.m., restocking medication boxes at midnight, appealing the denied medical claim for the fourth time, I see you.*

*I see the hours spent organizing your child's healthcare, scheduling doctor appointments, and waiting in the specialist's office for two hours with your child. I see you.*

*I see the countless hours spent on your knees petitioning me on behalf of your child. I see the soft spoken word when you want to scream because your child is still crying. I see you.*

*I see your exhaustion, brokenness, and uncertainty of how you're going to do this another day. When you get back up and fight for the life of your child with my strength, I see you.*

*I thank you for caring for my child who I have entrusted to your care. I thank you for taking such good care of her and demonstrating my love. Thank you for being my hands and feet to care for the innocent. I see you.*

*Just as you love and appreciate your child, so I love and appreciate you. But even moreso, for my love is beyond your comprehension. I see you.*

*If no one else thanks you for the job of caring for your child today, I thank you. When no one else does, dear Daughter, I see you.*

*Love,*

## *Your Creator*



*this is motherhood.* NEVER FORGET THAT LOVE IS THE BEST THING WE DO. LOVE BIG, LOVE MESSY, LOVE LOUD. SLOW DOWN AND CUDDLE YOUR LITTLES, EVEN WHEN THEY'RE BIG. ABANDON THE LIE OF PERFECTIONISM. LEARN FROM YOUR KIDS AND COLOR OUTSIDE THE LINES, AND THEN STAND IN AWE OF THE MASTERPIECE YOU CREATE. SMILE KNOWING RIGHT NOW WILL TASTE EVEN BETTER AS A MEMORY. DECLARE GOODNESS; THE WORDS YOU SPEAK DICTATE THE LIFE IN FRONT OF YOU. REMEMBER THAT BAD DAYS COME AND GO. WHEN ALL ELSE FAILS, DANCE IT OUT. YOU ARE LOVED BY A GOOD GOD WHO CALLS YOU DAUGHTER. TEND TO YOUR OWN WOUNDS AS GENTLY AS YOU DO THE SKINNED KNEES AND THE JAMMED FINGERS AND THE HURT FEELINGS. BE THE FRIEND YOU NEED, EVEN WHEN YOU'RE BUSY. HUG PEOPLE TOO LONG. CATCH THE TEARS OF OTHER MOMS TOO. SPEAK UP FOR THOSE WHO DON'T HAVE A VOICE AND YOUR KIDS WILL DO THE SAME. SIT IN THE WARMTH THAT YOUR BABY WILL CHANGE THE WORLD SOMEDAY. STAND KNOWING THAT YOU CAN TOO.



THE MOMCO