## **COMFORT**

## Comfort @ 2021 by Hunter's Hope Foundation

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## **Authors**

Families who have lost a child or have a child with a serious illness, who have been comforted by our Lord Jesus Christ, and with that comfort desire to comfort others through Christ.

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Praise be to the God and Father
of our Lord Jesus Christ,
the Father of compassion
and the God of all comfort,
who comforts us in all our troubles,
so that we can comfort those in any trouble
with the comfort we ourselves
receive from God.

## Introduction

It has been almost 16 years since my son, Hunter left this earth for his heavenly home. Sometimes it feels like just yesterday when we said, "goodbye". Sometimes it feels like a thousand years. I guess that's the ebb and flow of grief. I'm not really sure, but what I do know is that it still hurts. All these years later I still feel the pain of losing my one and only son. I just feel the emptiness that his presence used to fill. I still miss his handsome face and beautiful green eyes. I miss everything about him, and I imagine I always will.

Not too long ago, I was having one of those mornings. Harder than I've had in a really long time. Of course, hard days come and go, but this particular day was different. I did what I usually do, but my usual coping mechanisms weren't helping. So, I decided to go for a walk.

As I walked down the street I started crying. You know, the ugly kind of cry. My tears were mixed with frustration, fear, and deep sorrow. I was praying and asking God lots of hard questions. "Where are you, God? Do you see what's going on? Why haven't You intervened yet?

Do you even care about all of this pain?" I just kept walking and crying and praying until I was completely exhausted. I accumulated over 10,000 steps that day for all of you step trackers, LOL.

When I finally arrived back at our driveway, I had cried every last tear and poured out everything on my heart. I walked over to our mailbox

to grab the mail and much to my surprise there was a small pot of flowers sitting there with a note. The note read, "I'm thinking of you and praying for you..." And in that moment, standing in front of my

mailbox, holding a small pot of flowers and note of encouragement in

mailbox, floiding a small pot of flowers and flote of effcodragement in

my hand, I was comforted.

You are not alone in what you're going through.

God sees you and knows exactly what you need

and when you need it.

He hears every cry and cares about every tear.

He is the God of all comfort.

Comfort - that's what this book is about.

And it's my hope and prayer that as you read these pages you'll not only be comforted, but you'll want to know the Father of all Comfort that much more.

We're all in this together my friend and fellow sufferer.

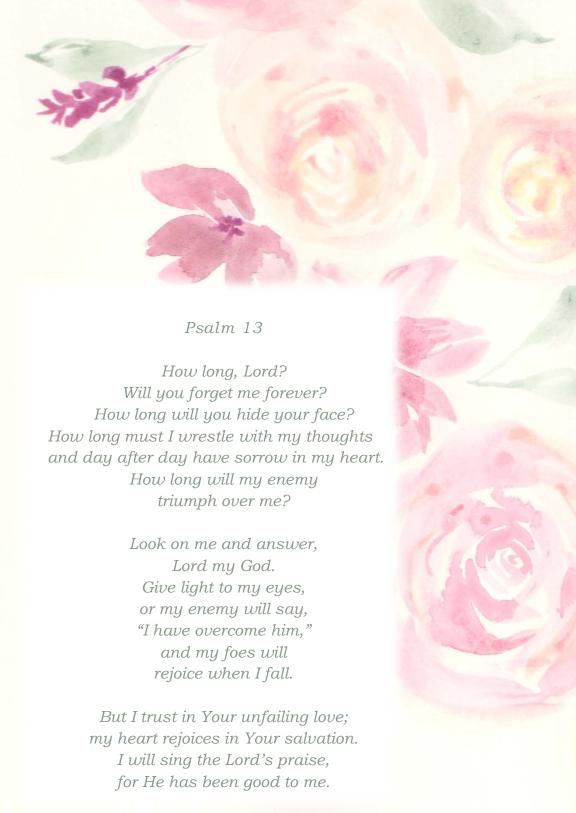
One day at a time.

One prayer at a time.

All in God's perfect timing.

~ Jill Kelly

Mother of Hunter Kelly (2/14/97-8/5/05)



## How Long?

How long...
Will the pain ever end?
Will the sorrow cease?
Will the grief give way?
How long, Lord?
How long?

I've been waiting for what seems like an eternity to receive the answer to this desperate cry.

I was 10 years old when my brother went to heaven.

I was 17 when my dad was diagnosed with cancer for the first time, 18 the second time, and 22 the third time.

I was 23 when depression, anxiety, and an eating disorder took over my life.

I was 24 when I was diagnosed with Lyme disease.

I'm 25 years old, and I'm still crying out to God – "How long, Lord? How long?"

In the midst of one of my darkest days I prayed ...

"How long Lord?

How long? How long will I have to continue to bear this brokenness? How long will I wake up only to want to fall back asleep and never awake again? How long will the darkness last? Will the light ever fully break? Will it stay? I can't live this way forever. I'm not meant to. You have a plan for my life. You have more in store."

## How Long?

You may feel like your suffering will never end.

Maybe you're at the end of your rope, waiting for God to rescue you.

You're not alone in your suffering and you're not alone in your waiting.

The God who promises to never leave you, nor forsake you, will meet you there.

When you're waiting for healing... He is there.

When you're waiting for an answer... He is there.

When you're waiting for the darkness to lift... He is there.

When you're waiting for deliverance... He is there.

When you're waiting for freedom... He is there.

When you're waiting for life to return to your bones... He is there.

When you're waiting... He. Is. There.

I don't know how long, but I know it won't last forever. No matter what you're going through, it won't last forever. 1 Peter 5:10 says, "And the God of all grace, who called you to His eternal glory in Christ, after you have suffered a little while, will Himself restore you and make you strong, firm and steadfast."

I don't know how long.

But I know that God is there in the waiting... and that is enough.

~ *Erin Kelly Bean* Sister of Hunter Kelly (2/14/97-8/5/05)

## Prayer

Lord,

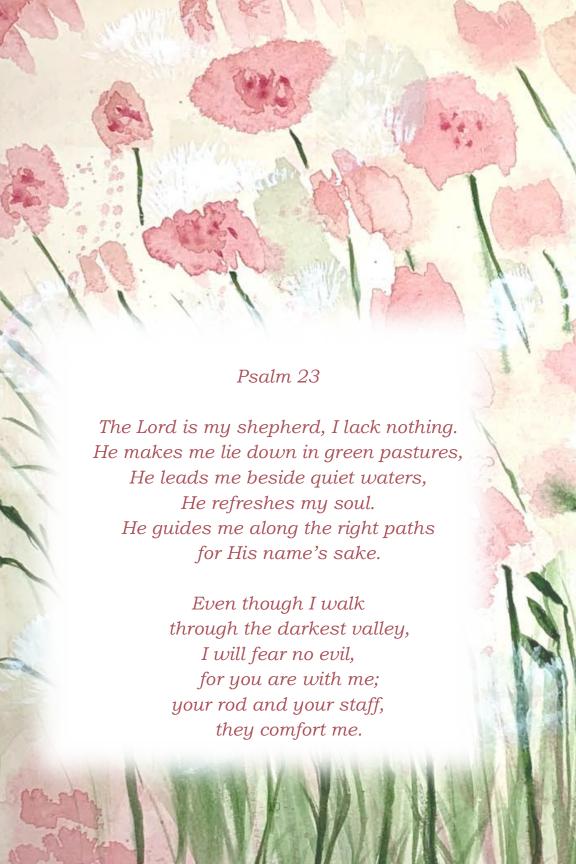
Thank you that you meet me in the waiting.
You meet me in my wandering.
You meet me in the midst of every why I bring before You.

Give me hope, give me courage, give me strength as I wait. When I cry out in desperation, be my Comforter. When I can't see past the darkness, be my Light. When I doubt, be the Truth I stand on.

Lord, today I choose to trust in Your unfailing love.

I worship you in the waiting... for you have been good to me.

In Jesus Name, Amen



## The Valley

I have lived through my worst nightmare. Truth be told, my nightmares never even came close to the reality of watching my son suffer through a terminal disease. Deep down, I think I had a very naïve assumption that life pretty much works out if you "work hard" and "do the right thing". There are all the catchy sayings that add up to "be a good person and your life will turn out ok." We think we can control our lives, but control is an illusion, friends.

I was rolling along just fine with my husband and three sons, when my world imploded. My youngest son, Dylan, was diagnosed with a terminal illness called Krabbe Disease. I thought we had passed the risky part of having another child. My pregnancy was good. Dylan was born perfect. There was no bad news from his newborn screening. He was the easiest, happiest baby of the three. When Dylan was 8 months old, our world came crashing down because we were told to take our son home to watch him die a horrific death. We were told that his death was "certain by age 2". However, Dylan lived 4 years, 3 months and 2 days after his diagnosis. That was the longest, darkest valley of my life. But God was with me during it.

There is hope because God is still **with us**, even in the darkest valley. We must find HOPE in Him, not in our circumstances or our own abilities to "control" our lives.

Our beloved 23<sup>rd</sup> Psalm says: Yea, though I walk through the valley of the shadow of death, I will fear no evil; for thou art with me; thy rod and thy staff, they comfort me. Psalm 23:4

## The Valley

Even though I walk **through** the darkest valley, I will fear no evil; for You are **with me**.

There are 3 very important points in this scripture.

- 1. We walk **through** the valley. God did not send a helicopter to pluck us out of that dark valley. We walked through it day by day and it was a long, painful journey.
- 2. I'll say it again. We walked **through** it. Therefore, we came out on the other side. That means it was not permanent. (That does not mean that you "get over" this experience. It means the pain decreases, and joy is more readily available).
- 3. "Thou art with me". Thank you, God, that you are with me. I very desperately wanted God to send the helicopter to pluck me out of the valley and save me from the pain. But He didn't. However, He did promise to be with me. And He was. And He still is. And He can be with you also.

~ *Amy May* Mother of Dylan May (1/16/04-1/6/09)

## Prayer

Father God,

We praise You for who You are and the promises You have made to us.

We thank You for Your promise to be with us, during our darkest valleys. We claim that promise now, Lord. We ask You to meet us where we are now, in our pain.

Please fill us with Your presence and Your peace.

Walk with us, Lord, and hold our hands.

Lift us up when we are not strong enough to go on.

Carry us Lord, through this dark valley, to the other side.

In Jesus' Name we pray,

Amen.



## Jeremiah 33:3

Call to me and I will answer you and tell you great and unsearchable things you do not know.

## *Romans* 15:13

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.

## Our Jackson, Our Story

Our Jackson was born a beautiful and healthy baby boy. Full term, no complications. So as new parents of a perfectly healthy baby, when we started to notice unusual behaviors 5 months later, we naturally assumed this must be a result of simple childhood illnesses. Irritability and discomfort came at the expense of mundane everyday diseases, and we trudged on believing he'd come out of it as soon as he acclimated to living in this harsh world. This too is just a step in the journey of life, of growing up, and even for myself and my husband, a step in parenting.

I was completely derailed at his 6 month check up when I was told my perfectly ordinary little boy was potentially seriously ill. Heart sinking, stomach turning, I tried to grapple with what I was hearing. "This is an indication of something very serious, but I don't want to

speculate. We need to get brain imaging."
"You need to contact a specialist right away."

Days later after extensive testing and not being able to eat or sleep, a diagnosis: Krabbe Leukodystrophy. "Terminal by 2 years of age. There is no treatment, just supportive care."

Just like that our lives shattered.

Terror, powerlessness, dread, confusion, and isolation. The enemy had more than a foothold. I was in the midst of personal despair as all the plans I had for Jackson came crashing down around me. All the things I had dreamt of for this precious little boy were being threatened. Spiraling, I began to play all the firsts in my head that I'd never get to witness: first words, first steps, first time he would call me Mama, first day of school, first ball game, first love...and on and on.

Confused and angry at God, I demanded "Why?! He's brand new. He's done nothing wrong. It's not like this is the consequence of a bad decision he's made. He's literally done NOTHING wrong."

## Our Jackson, Our Story

With an almost audible voice, God so lovingly and graciously answered my desperate cries, "Jenna, those are good and right things for you to want for your son, but they are ordinary things. And what I have planned for Jackson's life is extraordinary."

It was then in that profound moment that my mind began to shift focus. I was no longer focusing on all the things I was going to miss out on because Jackson was terminal, but rather all the things I was going to miss out on if I didn't set my sights on the One who created him. God had a different plan for Jackson than mine. It was clear that my vision of his life was small and ordinary in comparison to what the Creator had planned it to be. God was going to use my beautifully broken boy to do MIGHTY things. It would be scandalous because God would use a boy who would never speak a word to grow His kingdom, and bring others to Christ through his story.

God was doing the very thing He had done throughout history. He was exercising His strength through the humble and seemingly weak.

And the truth is that the darkest parts of our journey have shaped us and prepared us for what has come. The pain has not been in vain because God does not waste our sorrow—He uses it. God made our story, so we can sit with others and lean into their darkest moments, and it's a true gift to get to show up for others in those moments.

Because of Jackson being born with krabbe, God called us into starting a foundation. This has allowed our family to love on and care for a rare community of people who need to know and hear of God's goodness amidst tragedy. He continues to ask us to be His hands and feet, bringing glory to His name by making this disease known to our local community, and by supporting a community of individuals who are real life heroes. When this all started, God was moving and reconciling broken things before our very eyes, and he was asking us to come along and be a part of His team.

## Our Jackson, Our Story

God's very movements in our journey remind me that the story is never over. You might believe it is when the pain feels like it's going to swallow you up, but it isn't over. God is always working even when we can't see or feel it. And you may argue and wrestle with God, maybe even in a disrespectful way as I did, but He's going to show up because He has promised His presence through it all.

But not only did He give us purpose in this tragedy, He never abandoned us. He grew our joy, loved us, comforted us and carried us through one of the most beautiful and difficult seasons of life that we were to ever experience.

God tenderly held us close by giving us so many sweet graces during Jackson's life. We met dear friends with similar stories who have guided and loved us through all parts of the journey.

We truly experienced life with our boy, drinking in every moment, and appreciating every breath he took. We gained perspective and strength from Jackson's quiet strength and stillness. We learned and we loved deeper than ever before.

God gave us 3 years with our extraordinary boy, and we are better for having been called to be his parents. He will always be Our Jackson, the boy who truly lived.

~ *Jenna Wallace* Mother of Jackson Wallace (4/18/13-7/4/16)

## Prayer

Dear God,

Please continue to give me faith to believe in You, even in uncertain times.

Thank You that You are right here.

Please help me see that all I need, I already have.

Allow me to find the joy and beauty even in confusing and trying times.

Awaken me to Your presence in all the big and small moments.

God thank You for all the graces You have given me in my life.

Allow those graces and the beauty of Your creation to point me back to You.

Amen.



Psalm 118:1

Give thanks to the Lord, for he is good; his love endures forever.

## Anna

When our daughter, Anna, was diagnosed with Krabbe Disease, it felt like all of my months of parenting experience completely went out the window. As her primary caregiver at home, I struggled with how to bridge the gap between helping her live her life and preparing for the health changes to come. Coupled with my own grief regarding her diagnosis, how could I help my child thrive when the whole world told me she was dying?

I was watching a cartoon with Anna one day when one of the characters said, "A grateful heart is a happy heart." It was a lightning bolt moment. From that instant, I began to find the gratitude in each moment, which in turned helped me to be the capable parent she needed. Seeing Anna's face light up when the wind tickled her toes, having a pain-free day, squishing her hands in finger paint, lying on the beach with her friend; it all became an example of God's grace on earth through her life.

Seeing those day-to-day examples of grace and goodness helped me seek them out even further. And when she passed, that gratitude became harder to find on some days, but never completely went away. I've had many moments of self-pity and absolute ungratefulness, and I know I'll have many more. But God gave me Anna. Though she is no longer here in my arms, I will always praise Him for the 23 months I had with her here on Earth.

~ Sarai Taylor Mother of Anna Taylor (4/28/13 – 4/2/15)

## Prayer

Dear Lord,

Thank You for the love and grace You pour out, even on those days I have been less than thankful.

You make a way in the desert places and Your mercy is unending.

Lord, I know when I sing my song of broken praise, that You give these barren arms holy purpose.

You give me hope for a future in You, when this weary world seems hopeless.

May that hope in You never depart my heart.

In Jesus' name,

Amen.



## Strong and Courageous

As parents, we just dive in and do our absolute best in providing the ultimate care for our child's medical needs. I lived everyday knowing that my daughter's care came first. But I also failed to look at myself; my physical and emotional wellbeing.

Knowing that I did not give myself the care that I needed, I thought about the "oxygen mask" analogy. When the flight attendant tells you to "put your oxygen mask on first" before helping others. We do this action so we can physically provide help to others. This applies wholeheartedly to caretaking. As parents, we need to take care of ourselves so that we can continue to give the BEST quality of care to our children. Always remember this analogy. It's what helped me through my days of caretaking.

~ Lisa Borodychuk Mother of Olivia Kay Borodychuk (10/10/08 – 4/28/17)

## Prayer

Dear Lord,

I ask for Your healing over every part of our lives. Physically, emotionally, mentally, spiritually.

I ask that You make us strong and resilient for the days ahead and prepare us for whatever trials we are faced with.

I know You are the ultimate comforter; the ultimate healer. I lean fully on You Lord, for You alone are able.

Thank You, Lord that no matter what we go through, You will always be there.

We pray this in Jesus' precious name,

Amen



### Christ in the Journey

You are not alone.

I wish I could be there to hold your hand and listen. I wish I could be there to give you a hug, pray with you and tell you it will be alright and that I understand.

My son Stephen was 3 ½ years old when he suffered a traumatic brain injury due to a rare disease called Isovaleric Acidemia (IVA) that could have been detected at birth through newborn screening. It left him with severe disabilities and complex medical issues. I have come to realize that life is not always fair, but my family is blessed and our Stephen is a blessing. His life has taken us on a path far from what we imagined, but one where Christ was waiting to walk by our side. He did not promise that the journey would be easy, but that we would not be alone.

Life has been quite different, one full of fears and uncertainties amidst the joys and milestones. The hardship and sadness of raising a child with a life-threatening illness is real as we endure what I call an eternal grief... Grief of what we lost in Stephen, grief of all of the things we missed out on with him, and fear of one day losing him. What has not changed is God's presence in our lives. He has always been with us... Every step of the way. Know that He is with you. He even sent His own son to be with us.

I reach out to Christ during the most difficult moments knowing He has full control of every aspect of our lives, especially Stephen's. God is there and it takes great strength to feel Him and trust in Him. Oh, how comforting it is when we can truly hand it all over to Him.

### Christ in the Journey

Clinging to faith in God allows me to see His presence and greater purpose for my son's life and how perfect Stephen is in God's eyes.

As a mother, I will always worry, but while I worry, I will pray and I will pray for you. Prayer helps us draw strength and brings us back to hope, which enables us to feel God's perfect and unconditional love. God bless you.

~ *Jana Monaco* Mother of Stephen Monaco

Heavenly Father,

I ask You to please lift these parents You have chosen for Your most precious and vulnerable children, created in your likeness.

Help them to feel Your loving arms around them during the most difficult and sad days.

Open their eyes to the blessings You bestow on them each day.

Strengthen them when they are physically and emotionally weak.

Fill them with Your grace, peace, love and mercy.

Please comfort their hearts and minds. May they feel Your everlasting love and presence each day.

In Jesus' name,

Amen.



I was mesmerized when I first laid eyes on Tori. My heart was bursting with joy and pride as I admired her beautiful features and praised God for her health. Never did it occur to me that her time with us would possibly be short. In fact, even as her symptoms began to appear and we inched closer to a diagnosis, losing her wasn't my predominant thought. But, as much as we protested our reality, she was with us just twenty short months before Krabbe sealed her fate.

About a month post-diagnosis, we made the decision to embrace what time we had left with Tori and to be joyful. We handed the reins over to God, ever praying for a miraculous healing, and decided to give her the best earthly life we could.

The loss of a child is devastating, but even so, there can be joy. Even so, there can be abundant life. Even so, it can be well with your soul if you trust Him who loves you completely. Being well in your soul doesn't mean that things are perfect, or that you pretend to not be in pain. It simply means that you trust Jesus more than you fear your circumstances. After all, if we can trust Him when things are good, we should trust Him even more when things are less than ideal!

You may never understand on this side of eternity why your precious baby left you so soon, but you can have full faith and confidence in the One who knows all, and you can know without a doubt that He loves you deeply. He is the only One who can provide the comfort you seek.

Some days are truly a struggle and we have to make a choice to be joyful, to remember their life with gratitude. In those moments, I find it helpful to focus on who God is and to remember that God is still God, even when we have no idea what His plan may be. I do this in two ways: by remembering what God's Word says is true, and by focusing on eternity.

### Remembering What is True

The enemy tries to make us feel afraid, overcome with sorrow, and filled with guilt and regret. He wants us to feel like failures, like we are unworthy of God's love and grace, like somehow this is our fault. It's easy to allow our minds to focus on what might have been instead of what actually is, but when we remind ourselves of God's truth and His promises, when we speak truth in the middle of our fear and sorrow, we can overcome these things.

### We must remember...

- To choose to focus on what is true (Philippians 4:8), including the reality of your child's presence in Heaven - and that YOUR future residence is also in Heaven (John 3:16).
- That everything God does is for **good** (Romans 8:28).
- That God is sovereign, faithful, loves you, and IS love.
- That He is **still God** even when you can't see His hand working.
- To set our minds on things above (Colossians 3:1-3).
- To choose joy and be grateful in all circumstances (1 Thess. 5:16-18).
- That **God knows** the number of days we will live on earth (Job 14:5, Psalm 139:16) and that death is inevitable (Revelation 21:4; Ecclesiastes 3:1-2a., 8:8). We cannot stop it.

### Focusing on Eternity

And that's the beauty of our faith, the beauty of knowing that we weren't created for this world: **there's more to come**. Death is only the beginning for us! Scripture repeatedly discusses death as something to be celebrated, something we as believers should anticipate with "eager hope" because it means we will be with Jesus and other believers FOREVER.

One of the truths I remember daily is that Tori is no longer confined in a broken body that couldn't function properly—as her mother,

knowing that she is free makes me so happy! The course of Krabbe in her life was inevitable, so the hope and joy of heaven is indescribable (1 Corinthians 15:42–44, 50–58). We live daily with the assurance that Tori is more alive now than she ever was! She is healed, she is whole, and she is healthy. Praise Jesus.

By keeping our focus on eternity, by remembering that we were never meant to stay on earth forever, by embracing our future home and choosing to look forward to it with expectation, then, as a result, death becomes a little less sad.

"I consider that our present sufferings are not worth comparing with the glory that will be revealed in us. For the creation waits in eager expectation for the children of God to be revealed. For the creation was subjected to frustration, not by its own choice, but by the will of the one who subjected it, in hope that the creation itself will be liberated from its bondage to decay and brought into the freedom and glory of the children of God.

We know that the whole creation has been groaning as in the pains of childbirth right up to the present time. Not only so, but we ourselves, who have the firstfruits of the Spirit, groan inwardly as we wait eagerly for our adoption to sonship, the redemption of our bodies." (Romans 8:18-23)

When we, as followers of Jesus, are living with eternity in mind, our earthly perspective on death will shift from sorrow to joy. How is this possible? Because we also know that this earth isn't our home; it isn't where we belong. Death is NOT the end of our existence. We are only here for a short time to form a relationship with God and to preach the Gospel so that all might be saved through Him. We are here to prepare for eternity.

The anticipation of my reunion with Tori brings such excitement, even though I have no idea how long it will be until we are together again. All I know is that it will feel as if no time has passed at all since heaven doesn't operate within the rules of time we know.

Does all of this mean that I shouldn't cry when I miss her? Of course not. However, I do believe that having a biblical perspective on death and heaven eases the blow of her absence, and it brings me peace that cannot be otherwise explained. Heaven, along with the knowledge that we'll be reunited with our loved ones (who also knew Jesus), removes the sting of death, one thorn at a time.

Praise Jesus for His grace and mercy that make this possible.

~ Lesa Brackbill

Mother of Victoria "Tori" Brackbill (7/30/14 – 3/27/16)

Jesus,

Thank You for the promise of eternal life with You in Heaven for those who follow You.

Thank You for Your sacrifice on the cross that made this our reality and our hope.

Thank You for the beautiful children You have placed into our care, even if just for a short time.

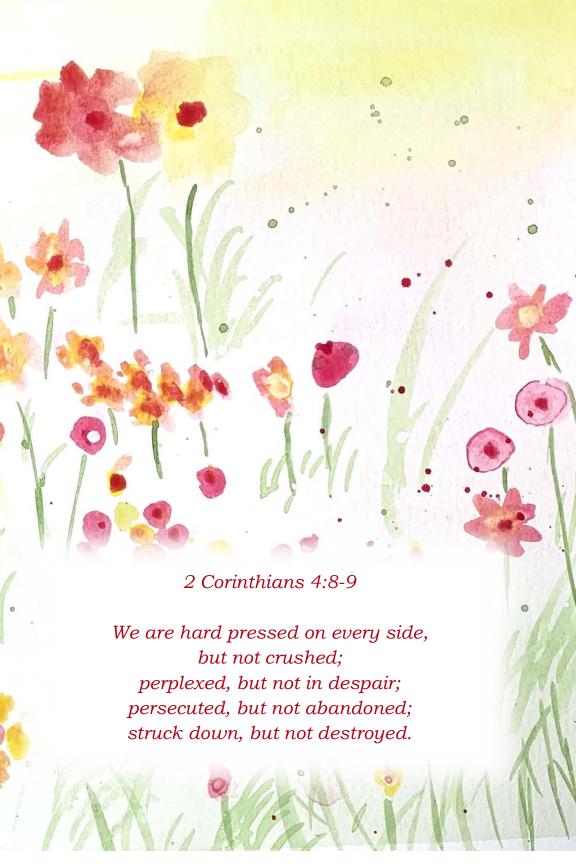
In the moments when we feel that the burden is too much, please bring us peace and comfort that only You can provide.

Remind us of who You are, what You've done, and what's in store for us.

Lord, continue to teach us about what's to come, about the incredible place we will call home for eternity.

May we allow Your Word to guide us in all things, especially death.

Amen



### Letting Go of "Why?"

My son Dylan died 12 years ago today (January 6<sup>th</sup>). Dylan was diagnosed with Krabbe Disease when he was 8 months old, and he lived to be almost 5 years old. During that four-year period, I railed at God. I was angry. Why? Why him? Why me? Why us? Why haven't you healed him? Why won't you take this burden from me? We finally realized that we could not, with our earthly minds, fathom an answer that would satisfy us. God could have miraculously spoken audibly to me personally and said "Because \_\_\_\_\_" and it still would not have satisfied me. There would never be a good enough reason, something that would make me say, "Ok. You're right. Take my son." So, after much ranting, I tried to let go of the question.

James Dobson wrote an excellent book entitled *When God Doesn't Make Sense*. Dobson says that God's purposes are beyond the reach of mortal man. It is an incorrect view of scripture to say that we will always comprehend what God is doing and how our suffering and disappointment fit into His plan. When times get desperate, it may appear that God has lost control – or perhaps, interest – in our lives. That is only an illusion, but one with dangerous implications for our spiritual and mental health. Interestingly, it is not pain and suffering that do the greatest damage to our faith. It is confusion. So, my friends, let us not be confused. God IS with us and He DOES love us, even when we are not receiving the answer we want.

There are many Biblical examples of God's children suffering through traumatic experiences. But that does NOT mean that God has abandoned us. There is sometimes a greater purpose to pain than being relieved from it. God uses that pain – it is not wasted. Here are some of the by-products of suffering: it humbles us, it makes us more

### Letting Go of "Why?"

dependent on God, it weans us from the allurements of the world, it vitalizes our prayers, and it makes us more compassionate toward others in pain. We can take a measure of comfort in knowing that our suffering is not wasted.

Practically speaking, many of our questions (especially those that begin with "Why") will have to remain unanswered on this earth. So, dear friend, I encourage you to try to let go of the question.

~ *Amy May*Mother of Dylan May (1/16/04-1/6/09)

Dear Lord Jesus,

Please be with me today.

I turn my circumstances over to You because I cannot do this on my own. I need You in the midst of this pain.

Fill me with Your presence and Your peace.

You know my thoughts and feelings of anger and frustration. Thank You for loving me anyway.

Please help me to use my strength and energy where it is needed, and not to struggle in vain. I am being pressed on every side, but don't let me be crushed. I am perplexed, but don't let me despair. I am struck down, but help me to know that I am not destroyed.

Help me to know that You are in control and will never abandon me.

Please help me carry this burden, Father.

Amen.



### Goodbye For Now

April 29th, 1997, was a warm spring day that brought sunshine and hope for warmer days to come. How could I have ever imagined I would have to say, "Goodbye for now," to our dear sweet Benjamin, our baby son who was just 6 1/2 weeks old and was taken from us in a horrific auto accident in which I was the driver and our two eldest children survived?

My husband Dan was my knight in shining armor on that day, my family and friends deeply ministered to me, and my God and my Savior were my breath and my HOPE. Jesus, my very best friend, restored my sanity, which I had lost for what felt like an eternity, but in reality, was just a few hours of time. You may think it odd that I included the 1/2 when mentioning his age. Does it really matter? Oh, yes it does! The truth is that every day, every hour, every minute that we spent with our Ben counts from now, until we'll meet him again one day in that place we call Heaven.

Bereavement is a life long journey. We'll never forget those whom we knew, loved and bonded with. The loss of a child is, no doubt, one of the most complicated grief journeys to navigate through. No! Strike that—to struggle through. The struggle in the loss of a child, and for any loss of a loved one for that matter, centers around what I believe to be this one word that will determine whether we will embrace the very precious gifts God has given us to survive, in whatever circumstances we'll encounter, on this side of eternity. Acceptance.

In the 23 years that we have been on this journey of accepting the loss of our dear sweet Ben, my hubby, Dan and I have found what it means to be surrounded with the peace that passes all understanding (Philippians 4:7,) the God of all comfort, which comforts us in all of our affliction so that we will be able to comfort others who are in any affliction (II Corinthians 1:3-4). We've also learned to train our minds to steer away from the trauma of that day, to instead see, to truly see, through our Father's eyes—all that He wants us to behold, which

### Goodbye For Now

is true, honorable, right, pure, lovely, of good repute, excellent and worthy of praise (Philippians 4:8-9). Yes, even when experiencing a traumatic loss.

If you're not familiar with these verses from the Bible, then dive into their depth and beauty. Write them on your heart and use them as weapons against the enemy of God, who seeks to rob you from your JOY. Make no mistake that this enemy is on the warpath to steal your JOY from your past, present, and future. His greatest desire is to render you useless in your number of years, months, and days left on this earth. He wants to prevent, destroy, alter and/or distance your relationship with your Heavenly Father. If he's successful, he dances in victory. He wins! May it never be!

If I can leave you with any words, thoughts or deeds, on this very day in this moment of time, as I'm sharing my inward thoughts, it is to grieve well! Do not die inwardly which will affect your very being. Emotions can make us ill and they can drive us to become distant. It's no surprise that one can actually die from a broken heart. Whether it's from giving up on maintaining your body and shrinking away to nothing (your body is a temple of the Holy Spirit), or from giving into that desire to just end your life (trust me, I can empathize here), you can live to survive but miss out on living! I believe with great certainty that living without the JOY that comes from Jesus is missing out on living! Please grieve well. Fight for your JOY! JOY in your past, present, and future! JOY from the past... Are you choosing to see it as God sees it?

~ Pam Waterman

Mother of Benjamin Waterman (3/6/97 - 4/29/97)

Heavenly Father,

You are amazing God! You rule over all of the Earth and nothing goes unnoticed by You. Nothing! You are omnipotent, omniscient, and omnipresent. We are so very thankful for these truths.

On the day that we lost our Ben, and on the day that all those who may have suffered the loss of a child or a loved one—we know that is a day of remembrance for a lifetime for all of us. These loved ones are not forgotten! Indeed, every soul, whether they breathed on this earth or only in the womb of their mother, is ordained, sanctified and intimately known by You.

We ask for Your divine gifts that will allow us to carry on in our bereavement journey. We ask that You will help us to come to the very place of acceptance that will allow us to be free from the sorrow of separation from our loved ones.

We thank You for the HOPE that we will be able to reunite or become unified for the first time with these dear loved ones. We are delighted in the HOPE that they are in Heaven waiting for us. Who would want to miss this glorious reunion? My prayer is that no one would! My prayer is that every and any grieving soul on this Earth comes to know You and Your forgiveness through Your Son, Jesus!

While we await our time to join these loved ones in Heaven, give us Your amazing peace, comfort, and the strength promised to us in Philippians 4:13, "I can do all things through Him who gives me strength." Help us to JOYFULLY count every moment, every breath we are given, as Your gifts to us. May we shine the light of Your beauty and Your grace to the world around us. May we never hold our emotion(s) in, but may we talk and let others talk to us—even if it brings tears.

Remind us of Psalm 56:8 which says, "You have taken account of my wandering; put my tears in your bottle. Are they not in your book?" May we truly understand that our tears from our wanderings are collected in Your bottle and put in Your book. What book is that? Oh, dear Jesus, may we come to know and come to find out that this book is Your Book of Life and may we have great JOY in knowing this truth!

May we never miss an opportunity to smile and to bring a smile to another soul in our corner of the world. May Your enemy be defeated in his attempts to rob us of our JOY—past, present and future. Give us eyes to see that our past has taught us how to have complete trust in You, our present is filled with opportunities to do good, and our future is awaiting blessings to behold. Though there will be trials and tribulations that we must overcome, let us know down deep in our hearts that we are never alone. You will carry us when the burdens are too heavy to endure. Your strength is just what we need to grieve and to grieve well!

Thank you, dear Jesus, and forever remain in our steadfast hearts and minds.

Amen!



### The Lord Provides

I'm sure this finds you in the trenches of unbearable pain that feels like you're drowning over and over again, without any hope of coming up for air. I could say that I am deeply sorry, this isn't fair and that your loved one does not deserve the hand they've been dealt. And each of those things are true. But as someone who has stood where you're standing and also felt the soul crushing heartbreak no person should experience, I want to tell you something different. Yes, this journey will undoubtedly be hard, but God will cover you in ways you least expect. He will fill you with gratitude and competence and a spirit of resilience. You may lose some relationships along the way, but you will form bonds with those in this rare disease world that feel like family. Your loved one may face daily struggles, but they will also redefine what uncontainable joy looks like.

So right now, sit with your emotions, cry, work through your grief, anger and confusion. But please know, this pain won't last forever. Make no mistake, your grief will forever come in waves. It's a part of you now, but please don't let it consume you. Eventually, you will come up for air again. And it's there the Lord will provide you with strength and you will delight in the unexpected joys that lie ahead.

~ *Karlita Blackwell*Mother of Ezra Blackwell (Born 10/8/16)

Dear Lord,

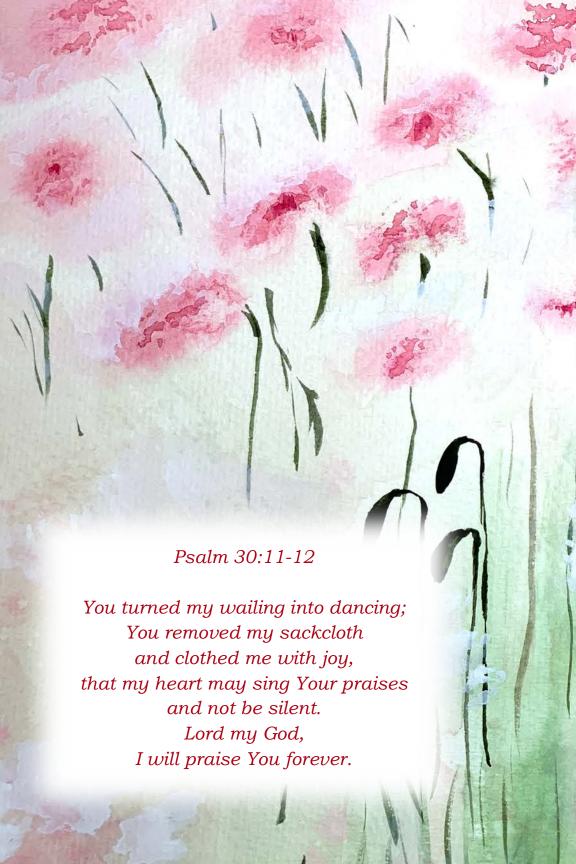
In a time of pain and uncertainty, we ask You to remind us that Your work is not done.

We know that in all things You are good and that You will redeem what is broken.

Lord, we ask that You cover those who are grieving and suffering with Your peace and restoration of the mind and the body.

Bless us with a spirit of serenity that only You can provide.

Amen.



### Now I See

It was a beautiful summer day in 1996, when I looked up to the endless blue sky, wondering if this life I was living was all there was. I had everything I'd ever hoped for - a beautiful family, home, career - all the things I thought were important for a good life with purpose. But, in that moment I knew in my heart something important was missing. I just didn't know what it was.

I forgot about that moment until June of 1997 when my grandson, Hunter, was just four months old. He was born a beautiful healthy boy; but, within a few weeks of his life, he became increasingly inconsolable. After a four-month search for answers, he was diagnosed with Krabbe Leukodystrophy, a painful progressive genetic disease with a life expectancy of 13 months.

At that moment, everything I had ever hoped for didn't matter. How could anything matter when my daughter's son was dying? In my desperate search for medical help, it didn't take long to realize there was no help for Hunter, there was no hope for his life.

There was no place to turn, but to God. I cried out to Him... A God I grew up knowing about, but never knowing. Every minute outside of helping Jill and Hunter was spent crying out to God, studying the Bible, and learning from Christians. I needed help. I needed hope. Hunter needed healing.

Over time God answered my prayers, not with healing for Hunter or answers as to why this happened to him and our family. But, through His amazing grace, He filled my heart and life with Himself. He was

### Now I See

what was missing in my life, and now I know Him. I was blind and now I see.

Yes, I continued to pray for healing for Hunter, but now I trusted God with his life. And, if God chose not to heal Hunter this side of heaven, it was okay. I knew I would see Hunter in the next life, for all eternity. Now I had hope. Hope in eternal life, where there is no sickness, no tears.

I still miss Hunter deeply with a sadness that overwhelms my soul. But, I am no longer alone in my sadness, God holds me and reminds me of a jubilant life to come for all eternity.

~ *Jacque Waggoner* Grandma of Hunter Kelly (2/14/97 – 8/5/05)

Heavenly Father,

I didn't know what I needed, but You did.

You were there for me.

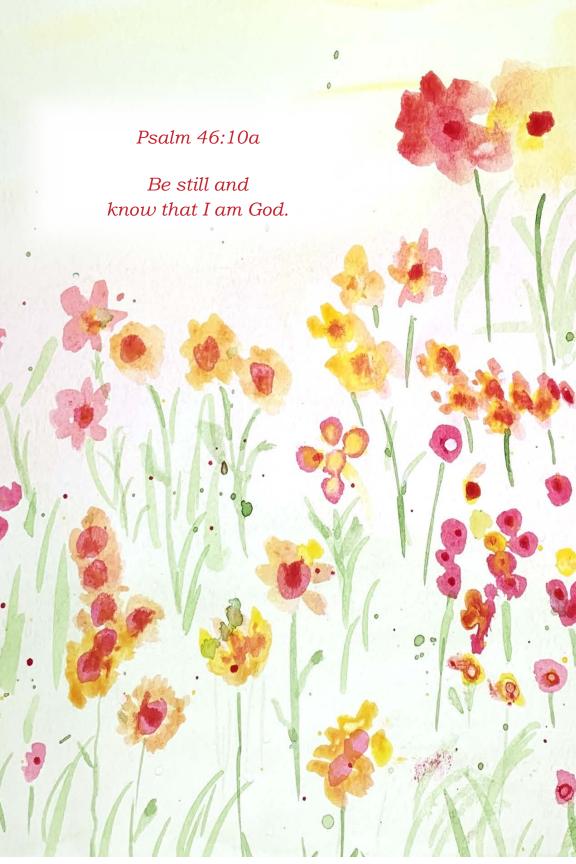
You saved me.

Lord, I ask that You be there for those who need You. Show them who You are and light their hearts with more of You and Your Glory.

Comfort them as they need You so.

In Jesus' Name,

Amen



## Jody

From the time our daughter, Jody, was diagnosed at nearly the age of two until her last breath, I knew that the future of our family would be devastating, incomprehensible and uncertain. We were fortunate to live near the University of Iowa Hospitals and Clinics in Iowa City, Iowa. The department head of Pediatric Neurology had a sterling reputation, sent blood samples from Jody, her dad and me to the biochemist who had diagnosed other individuals with Leukodystrophy. There was no second opinion. He WAS the second opinion. God, please help us.

With an accurate diagnosis of Krabbe Disease, the information we were given taught us that this was a degenerative brain disease, affecting the white matter of the brain. There was NO CURE. Typically, children do not live a year past diagnosis. We said our goodbyes many, many times. When she was three years old, it seemed clear that she would not survive another week. Funeral arrangements were made, the first of three times. I remained in a prayerful, yet in a fight or flight state of mind. Jody's dad and I took turns anticipating her cares throughout each night, taking one-to-four-hour shifts. The interrupted sleep affected our functioning at work, eating habits and concentration, to name a few.

Enter in-home, skilled care for Jody. We were adamant that Jody continued to live at home. She was eligible for eight hours per week of RN and LPN care. Eventually, it was increased to 24-hour care. A few nurses continued to care for Jody for eighteen and eleven years. We considered hospice care. That was in place three separate times. I leaned on God's direction. Our family grew. We made the decision to have two more children. Jody's brothers, Joseph and Sam, who were not affected with Krabbe Disease, lived their entire lives with no privacy, being parented by two stressed parents. They had a sister that had a serious illness she wouldn't survive. These siblings played, sang, loved and developed tight, inclusive relationships. Joe and Sam have grown into genuine, courageous, compassionate and humorous men

## Jody

with the most extraordinary coping skills... More than most people I know, myself included.

In younger years, Jody developed many friendships through her day program, attended public Jr. High School, earned a High School diploma and socialized at Employed Systems. She had her own responsible and encouraging associates in each program. There were opportunities for school dances, modified bowling, and even a road trip to Camp Courageous with her classmates for a weekend. This mother/daughter time seemed to be one of the most memorable times of our lives! Jody wasn't able to walk, talk, eat or move, but she never lost her ability to smile and laugh. And that's just what she did while she zip lined, loved the animals, as both of us canoed, went for strolls, made candles and danced to music. Arrangements were made ahead of time for a hospital bed with an egg crate mattress, specialized formula, a feeding pump, cotton linens, abundant sizes and shapes of pillows and pads, as well as pages of detailed care instructions, documentation and medications. I felt immense gratitude for this time, while Jody's face told me she was truly happy. Her blue eyes twinkled. Shiny, chestnut hair framed her face. Ruby lips formed a deliberate smile and her beaming, fair skin looked like porcelain.

Eventually, the illness attacked Jody's body enough to diminish vital organ functions. Angel Jody lived to be twenty-six years old. Even though her death occurred nearly ten years ago, writing about the days leading up to this, finalizing arrangements and the memorial service produces incredible sadness and deep anguish.

To this day, I pray for stamina, strength and peace of mind. Having something to look forward to and having fun are of utmost importance to me. I now use the words HOPE, OPTIMISM and ACCEPTANCE.

~ Sue Paulsen

Mother of Jody Lynn Vance (2/2/85 - 4/25/11)

## Prayer

I believe, without hesitation, in the power of prayer. As a child, I watched my mother pray silently. This role modeling affected my entire life by allowing me to talk to God about anything. I was convinced that He listened to my need for comfort, want for emotional stability, cries of desperation, which included tremendous anger, helplessness and hopelessness. Parallel to those, I experienced ongoing gratitude for the blessings I had been given and felt merciful towards others.

With Sam's permission, I would like to share one of the prayers he said immediately following Jody's passing. He was eighteen years old at the time.

Sam prayed, "Lord, this is something new for Jody. Please take extra good care of her, just like You do with all of Your other children. And please help us keep our family intact."

Joseph was working in California, while in the USAF. I prayed for him and safe travels to Iowa. He wrote a sincere expression of love for his sister, that was spoken at the memorial service.

Psalm 46:10
"Be still, and know that I am God."

This scripture praises Him for being a source of power and salvation in times of trouble. The meaning to "Be still" can be to stop striving, stop fighting and relax. A deeper meaning can also be to stop worrying, stop trying to control things, to wait and find contentment.

My hope is that you will consider God's words of direction, power and deep love for you. Imagine, gather scriptures and create a peaceful, quiet moment for yourself.



### He Chose Me

How did I become a mom to not just one angel... But two angels? I have asked that question so many times over the years. Then I remember; I am not supposed to question God.

### Romans 9:20 KJV

Nay but, O man, who art thou that repliest against God? Shall the thing formed say to him that formed it, Why hast thou made me thus?

So, what do I do to try to get some kind of peace? For me, I have learned to lean on God through prayer. I talk to Him. I ask Him to help me not to question His plan, yet to give me strength to face each day with thanksgiving. I thank Him that He not only gave me my two sons who are now back in His presence, but He also gave me four children who are here with me. They need a mother still. God gave all six of them to me to care for and I try to focus on that. Oh...there are days that I think to myself, how can I help my children when I can't help myself? I can only move forward knowing my sons are no longer in pain; they can walk, they can talk, they can see... They have a glorified body. Praise God!!!

I won't try to cover the ugly truth. Grief of a child loss is a journey that no one can really explain to someone who has never lost a child. (Even caring for a child with special needs cannot not be described in its full detail.) At first it feels like you are not breathing. You see everything moving around you as you remain stuck in that moment...The moment your child died. But.... There is good news! You don't have to stay there. With God, you learn to move forward one day at a time; one breath at a time. He will be there with you in those moments when you are not breathing. He is your breath. He has carried me when I just knew I could not go another day. He has opened my heart and my eyes to see joy again in the eyes of my four children here with me, my husband who despite the fact that he wants so desperately to "fix" me, is there to just hold me, and the rest of my family who are

## He Chose Me

also learning that some days are just too hard for me so they let me know they are there if I need them. He has given me hope and assurance that my sons did not die in spirit. They died an earthly death that gave them eternal life. For that, I am beyond grateful.

I know my life will never be as it once was. Why would I really want it to? My sons had a beautiful purpose that they each fulfilled here on earth. I don't want their life to be without meaning. I want to acknowledge they were here...That they existed. I speak their names, "Anthony" and "Dalton". They changed me for the better. They taught me how to be a better mother, wife and friend. They brought me to know God in a way I don't really know I would have without this journey. Whether it has been over thirty years since my Anthony earned his wings or the two and a half years since my Dalton earned his wings, I know I am forever changed.

So, how did I become a mom to not just one angel...But two angels? The only answer I have right now is this...God chose me to be the mother of two boys that would need a little more care than my other four children. He chose me to be their advocate. He chose me to love them with unconditional love. HE CHOSE ME! Thank You, God for my children.

### ~ Dianna Greene

Mother of Anthony (1/22/88 - 2/21/89) & Dalton Shell (10/3/96 - 6/25/18)

## Prayer

Gracious and Heavenly Father,

I ask You to please comfort my dear friends. Wrap Your merciful arms around us all and remind us who we are, Lord...we are YOURS.

Lord, give us compassion for others. Teach us to love one another. Give us words to say to help those who grieve. Lord, never let us forget to be a light to others.

Lord, I ask You to bless those who grieve. Give them beautiful memories of their loved one. Please comfort the brokenhearted. Be with us all as we face each day learning to move forward without our child and in some cases, our children. When the tidal wave of overwhelming grief feels like we will certainly drown, remind us that You are there, even in those moments when we just don't think You are. Help us to rebuke the enemy that tries to steal any joy we try to regain and keep us safe from his lies that sometimes make us question You, Lord.

Most of all Lord, thank You!!!

Thank You for being our comforter.

Thank You for allowing each of us to be the mother, father, sibling or just a friend to our loved one.

Thank You for giving us a way to reunite with them.

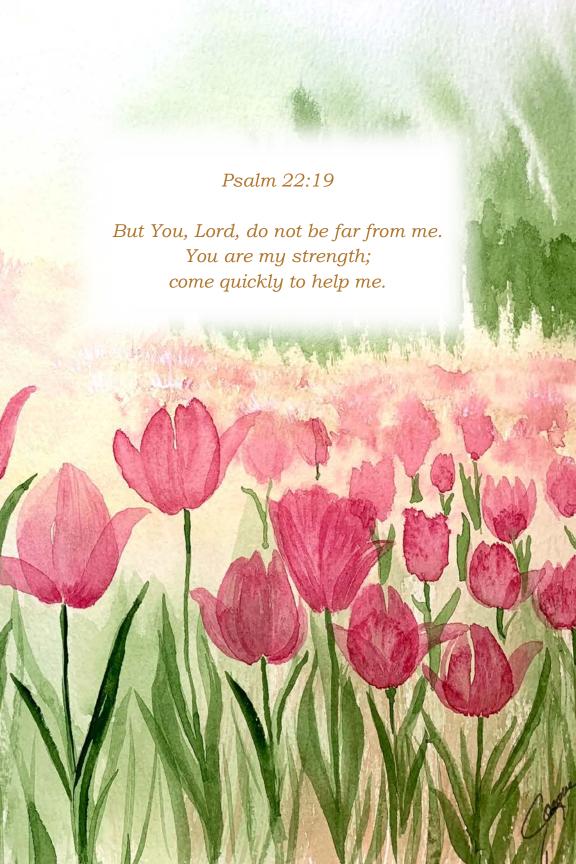
Thank You for Your mercy in grace and for Your son, Jesus!

I pray, dear Lord, for my family.

Please continue to give us the strength each day to move one step closer to You. Please give us peace in our hearts and joy in our lives as we go on remembering our child.

I ask these of You Lord, in Jesus' name,

Amen!



## God Feels Absent

In the darkness of Judson's disease and in his passing, there were many times I felt as though God was absent and my prayers were bouncing off the ceiling of our home, falling on deaf or distant ears. I found myself on my knees in tears, desperately hollering to God through the still air of my bedroom: Are You there? Do You even exist? Do You hear me? Why don't You answer? Where are You? Have You abandoned me? It was easy to grow weary in my prayers wondering why God seemed so distant as I called to Him in deep need.

C.S. Lewis similarly described how in the moment of his most profound need, the Lord who had seemed always available to him, "suddenly seemed distant and absent, as if God had slammed a door shut and double-bolted it from the inside."

David, who wrote many of the Psalms in the Bible expressed comparable feelings:

Why, Lord, do You stand far off?
Why do You hide Yourself in times of trouble? (Psalm 10:1)
My God, my God, why have You forsaken me?
Why are You so far from saving me, so far from my cries of anguish? (Psalm 22:1,2)

In the midst of his brokenness and pain David was desperate for God to intervene, to lift Him out of the pain; instead, it felt as though God was unavailable and far away.

I fought to reconcile the promises of God with my experience in the darkness of disease. Throughout Scripture He promises to never leave us or forsake us (Deuteronomy 31:6, Joshua 1:5, Isaiah 41:10, Matthew 28:20, Hebrews 13:5-6). In fact, God tells us He is especially close to the brokenhearted and saves those who are crushed in spirit (Psalm 34:18).

## God Feels Absent

So where is God when our child is suffering and our hearts are broken?

When Judson was sick and had lost all of his vision, I recall a time when he had been crying out in the middle of the night, distressed and afraid. I rushed to his side, stroking his hair to comfort him. In time, he settled. I continued to lie near him, just inches away, but no longer touching his frail body. Judson couldn't see me because of his blindness. And although I was right there—with him in every way—Juddy began to cry out again, afraid I had left him alone once more. Jud's inability to see, because of his suffering, kept him from recognizing I was totally near, face-to-face, fully present and caring for him.

Like Judson's illness, our pain can blind us to God's presence. We perceive He is absent and has left us, but He is, in fact, right there with us, face-to-face, present in every way.

Judson's instinct was to cry out, letting me know he needed my presence, and he trusted I would come. David, the psalmist, did the same.

But You, Lord, do not be far from me. You are my strength; come quickly to help me. (Psalm 22:19)

When God seems absent, he wants us to continue to call out to him like David did, similar to the way Judson cried out for me. And just as I reached out my hand to comfort my son, letting him know I was near, God is a faithful Father who will assure us of his presence too. Just keep crying out to Him!

~ *Christina Levasheff*Mother of Judson Levasheff (12/24/04 – 11/7/07)

## Prayer

Dear Lord,

Thank You for Your promises to be with me, my refuge, and alwayspresent in my troubles.

I am struggling to understand what You are doing in my life and Your purpose in this pain. I call out to You, asking You to intervene, and yet You seem so distant.

Where are You?

I am broken and hurting. I need You. I want to taste and see of Your goodness.

Will You show Yourself to me? Will You come and fill me with Your Spirit and allow me to see what You see? Will You keep me from being blind to Your presence?

Please respond to my cries, Lord, and remind me You are near. I ask for the strength to endure as I wait patiently for You. And as everything around me feels like it is shifting, please give me a firm place to stand. Help me to trust You.

Father, I thank You for this precious child you have given me. Continue to use them to shape me and the world around me. Please help me experience the heights of joy from their life, even in the depths of pain. May I walk in the hope of Your glory.

I will keep calling out to You. Come quickly, Lord Jesus.

Amen.



Isaiah 41:10;13

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.
For I am the Lord your God
who takes hold of your right hand
and says to you, "Do not fear;
I will help you."

## He Will Carry You

Have you ever read the poem that ends with this... "He whispered, 'My precious child, I love you and will never leave you; never, ever, during your trials and testings. When you saw only one set of footprints, it was then that I carried you."?

I don't exactly remember the first time I read or heard this, but I do know that when I was made aware of it I thought to myself that it sure was a comforting thought, in a figurative way. I never really thought about it in a literal sense, at least not until after losing my daughter.

The night our precious Mabry Kate passed away, we had ridden the ambulance to our local children's ER. We entered and exited the same ER entrance. We entered with our daughter and exited with empty arms, broken hearts, and shattered dreams of the future we had planned for her.

But how? How in the world did we manage to gather ourselves enough to exit the hospital empty handed? How could we put one foot in front of the other? How could we muster up the strength to get in a car without her? How could we even breathe?

As I'm six years out from losing her, I can't help but take a step back and ponder those recollections. It blows my mind, really. All the "how" questions flood my thoughts. The first few times I recalled that night, I didn't have answers. Then, one day it hit me...

We couldn't gather ourselves and exit alone. We couldn't put one step in front of the other. We couldn't muster up the strength to get in the car. We couldn't breathe. But Jesus could and did and does all those things for us. It was then that He carried us. It was then that He wrapped his loving arms around us. It was then that He breathed for us. He alone was our strength and our comfort in that moment and

## He Will Carry You

has continued to be as we wake up and put one foot in front of the other without her physical presence.

As I reflect on this in our lives, I begin to see it in the lives of others we know and love. I was reminded that Jesus also carries them and you through every battle, including those with leukodystrophies. I have heard brave and broken-hearted stories of other beloved children's "diagnostic odysseys" and hospitalizations and passings. I have heard parents struggles, cries, and heartaches.

BUT...I have also heard laughter! I've heard heartwarming and funny stories. I've seen love come from these families — which is exactly what Jesus is. He is love and He carries us all.

I hope that you know that you cannot face your trials and hardships alone. You can rest in the loving arms of Jesus Christ. I hope you see that Jesus never leaves nor forsakes you, and that He has and will continue to carry you through the times you don't think you can survive. He will. That's the ultimate comfort.

~ Christin Wehh

Mother of Mabry Kate (3/13/14 - 2/7/15) and Owen (3/30/15)

## Prayer

Heavenly Father,

We come to You with awe and thanksgiving of the comfort you provide to us in our trials and struggles. The comfort you offer our hearts is unmatched. Thank You for holding us when our world is crashing in, when we feel our hearts are shattered beyond all repair, and when we feel we cannot take another breath or another step. Help us to remember in the times we feel we are alone in our heartache, You are there.

I pray that You will comfort those reading and praying these words each and every moment of every day, even on the days when going through the motions seems like the only option.

We love you, and even in our confusion, anger, sadness, or whatever phase of life we are in, we trust You and Your sovereignty.

Help us to lean not on our own understanding.

Thank You for going before us and making a way to spend eternity with You and with our loved ones.

It's in Your precious and holy name we pray,

Amen.

## Hunter's Hope Foundation

All proceeds from the sale of this book will go to the Hunter's Hope Foundation.

Hunter's Hope Foundation was established to address the acute need for information and research with respect to Krabbe Disease and related Leukodystrophies. In addition, our mission is to strive to support and encourage those afflicted and their families as they struggle to endure, adjust and cope with the demands of these fatal illnesses.

Among the essential goals, founders Jim and Jill Kelly, seek to inspire an appreciation of all children and express a thankful heart towards God for these precious gifts of life. These bedrock values are categorically and vigilantly expressed throughout all of the Foundation's programs and activities.



The message of the Hunter's Hope logo is at the core of the Foundation mission and all we do. It is green representing Hope. It is a candle flame in a heart, meaning the light of Christ in our hearts.

"For God, who said, 'Let light shine out of darkness,' made His light shine in our hearts to give us the light of the knowledge of the glory of God in the face of Christ." ~ 2 Corinthians 4:6

To learn more about Hunter's Hope Foundation, please visit www.huntershope.org.