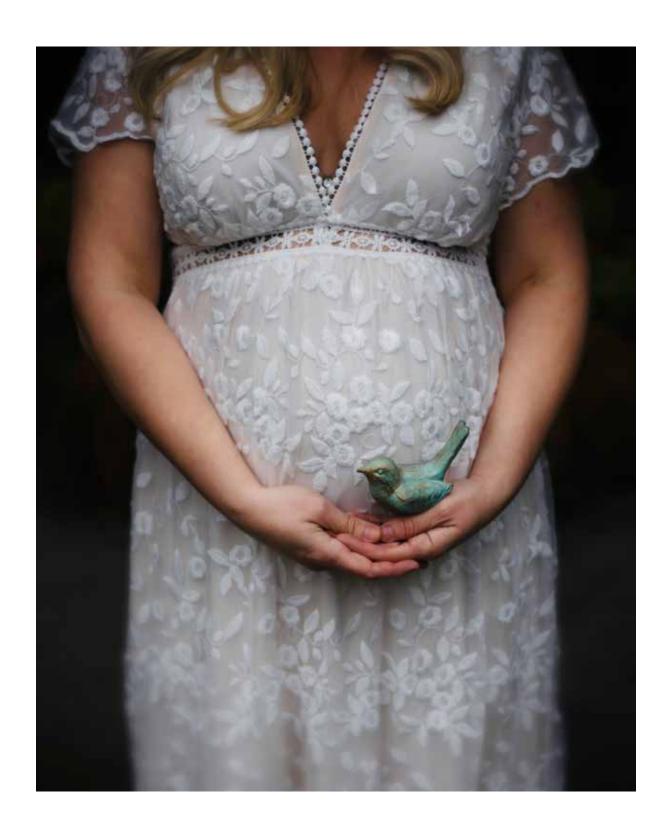
IIONE in the face of ISS

A JOURNEY OF SURRENDER

This is a collection of writing that follows our family's journey with our son James through pregnancy, birth, death, grief and integration. Most of the writing found inside is written by Rebecca with the addition of quotes that provided companionship, validation and healing along the way. Thank you for taking the time to witness our journey. We hope you may be able to find some personal inspiration or reflection through our family's story of love and loss.



BEAUTY in the BREAKING



Words For My Sweet Baby Blue Jay

I lay here every night feeling you... Listening to you Talking to you Sensing you.

I keep searching for a personality I can hold onto...

A life story I can embellish.

But every time, I am led back to the utter gift of your simple presence.

A luminous experience of love.

Since before we even conceived you, I felt your soul was of two worlds.

The essential truth of us all I guess...

But how often we forget after we are born.

I had a sense that this knowing was going to be strong in you.

That I would learn from your connection to the world beyond who we are here in human form.

But never did I think that world might not include you here in human form...

Some days and many nights I desperately want to know what your story will be.

How exactly it will unfold...

How long will you be here

Will we get the privilege of meeting you earth side

Will I be able to bear it

Will I be able to let you go when you're ready...

The unknown brings me to my knees over and over.

It steals my breath in fear

Fills my body with shaking doubt

Exhausts my every cell.

But then ... every time

Your presence returns

A kick

A roll

A sense

A Blue Jay sighting

A song

A little whisper ... it's ok mom. Just breathe. That's it

... one more ... a little deeper this time.

Here we are together.

It's pretty amazing.

Be here with me.

Pure presence...

A gorgeous gift of surrendered blue ethereal light

energy

Love.

This is who you are to me.

This is who I know you will always be to me.

Even in my darkest days, I raise my hand to my heart in gratitude that you choose me to be your mother.

That I have been gifted the privilege of carrying you.

Feeling you.

Loving you.

Honoring you.

And even as the waves of pain, grief, sadness, anger and confusion shatter and pummel me daily, they also lead me back to the greatest experience of surrender and mercy I have ever known.

The waves ... they lead me back to grace. They lead me back to love. They lead me back to you.

I sense and I hope that even as the pain and desperation relentlessly take me to the edge of who I have known myself to be ... that I will always be led back.

One desperate and deeper breath at a time. To the rawness of what it means to truly, just be.

And that from this tingling place of pure presence, I will be softened and nourished by a palpable experience of love and know that no matter where our bodies reside our souls will always be together.

I deeply trust that my soul is evolving through the miraculous and painful gift of being your mother. That nothing can be wrong.

But instead that this whole experience is in fact, just as Gibran says ... life's longing for itself.

The soul's wild journey of growth.

Yet another generous invitation into the beautiful presence of love.

And for that my sweet Baby Blue Jay I will be ever grateful and forever changed by you.

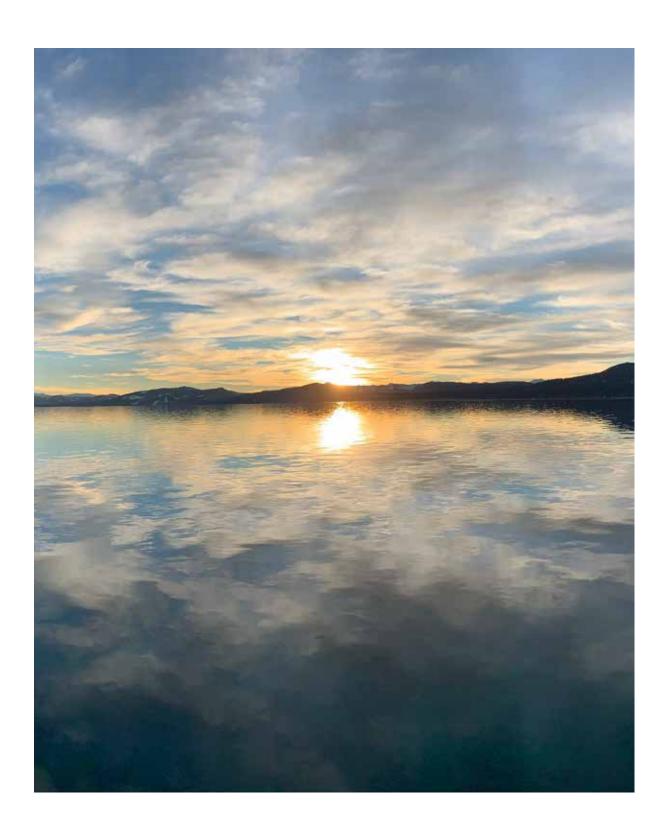
From my broken but expanded mama heart to yours....

I love you.

I trust you.

I promise to always carry you with me.





A Prayer To Rise

People have told me that I am strong.

That I am the embodiment of "mother."

That my acts of courage inspire a state of "awe."

I would be lying to say that I didn't enjoy these praises or that they didn't lift me on days that I didn't think I could carry on. Hell, I have even thought these things about myself. Oh how our egos love a good "pump me up."

But please don't be fooled...
If I have any ounce of strength in this pregnancy
Any kernel of courage
Any resemblance of mother
The cold hard truth is that it is being born out of
a brokenness that has me on my knees crawling
through the glass shards of my shattered heart daily.

Yes this journey was a calling and a choice or sorts. Funny how those calling... choice lines lie.

Many days I have wondered if I bit off more than I can chew.

More than my heart, mind and body can bear Sometimes, I wonder if I have denied my capacity, in a false belief of my so-called "strength."

I'm still not sure.

Every day at the moment feels like an endurance event.

Full to the brink with challenges, pain, emotionally flailing and more.

My heart breaks for our beautiful family

Why us?

I ask.

Over and over.

With no answer that seems true, other than the divine truth that our family includes this precious baby's soul, and therefore also includes this devastating and sacred journey we are walking with him.

But it's not easy.

My heart breaks for my son.

For my living children.

For my husband.

For my own mama heart.

I'm tired. So so tired.

We all are.

I see it in our eyes.

Feel it in our home.

Know it in my bones.

The exhaustion runs deep and old forms of resiliency often feel like ghosts.

I pray for help.

May hope come and provide rest for our weary hearts.

May resilience return and dance in our cells.

Please... please...

grace me with some shadow of energy and speck of courage

again by morning.

So that I may meet another day.
Find my will to surrender.
Keep my heart open in love.
And learn once again,
how to be present
with the fullness, beauty and heartbreak of life.



MIRACLES in the MYSTERY



Blessings For You

For the day you come
For the day you go
And for all of the days, moments and breaths
between now and then.
I pray...

That your journey is sacred.

That it is honored

That it is beautiful

That it unfolds in your own perfect divine right time.

I pray...

For strength
For courage
For willingness
For surrender
I pray...

That a warm golden light surrounds us all.

Comforts our tears

Expands our hearts

And brings even more beauty, joy and presence than

we ever thought possible.

I pray...

That love will be at the center of it all.

That the pulse of connection will be palpable.

That we will all be changed for the better.

And feel peace as we learn to live courageously

Surrendering to life's twists and turns.

Over and over In memory and honor of you.

These are my prayers...

May they be so
As we walk
One day
One step
One breath at a time.

To an end
But not a goodbye
Instead, the beginning of a new knowing

A beautiful experience
And a powerful relationship
That transcends this lifetime
And connects us forever through the divinity of all things.

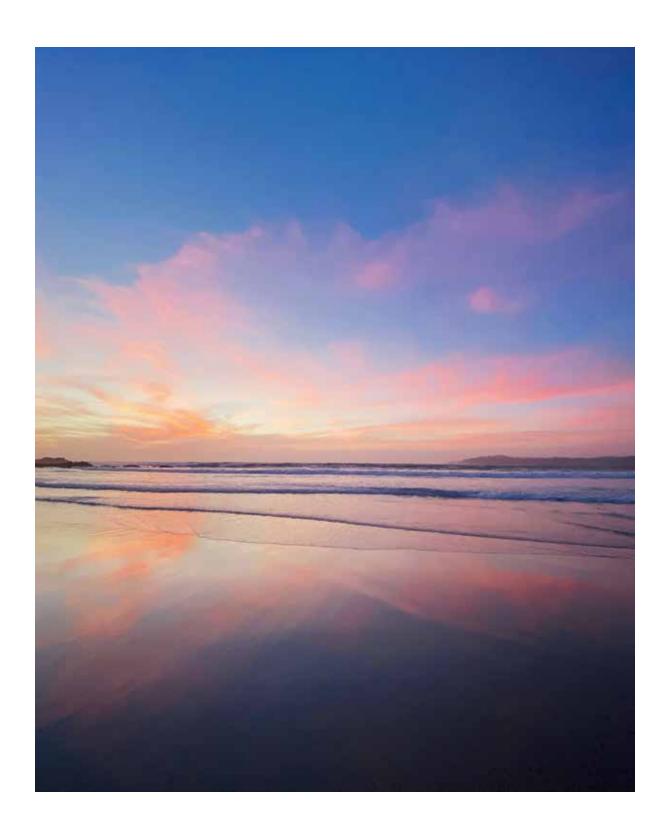
Amen



Where there is sorrow there is holy ground

Oscar Wilde





Caught Between Two Worlds

I remember...
Oh how I remember
The memories are like stains and treasures in my
mind
Many, so painful I can barely look..
Others I desperately want to hold onto and pray I
never forget.

I remember my heartbeat

Lying arms spread on the operating table moments before he was born

Caught in a world between my life and his Would he come out alive?

Would I?

Was this the moment we would meet each other on the other side?

Or the moment we would be separated...

Just a veil of consciousness between us.

Would he breathe?

Would I stop bleeding?

I remember his sweet hands
His little nose
The way he strained to open his eyes and look at me
with such wonder and pain
We are so limited as humans
I hate that about being human

I remember that I was in my body and I was out
I remember his father's sorrow
The weight of heartache on his shoulders
In the doctor's eyes
In the nurse's hands

I remember feeling strong and broken
Questioning myself...
Am I here?
Am I present?
Don't mess this up.
Don't be distracted.
This will be your only time with him.
Don't miss it.

Why must my inner bully follow me everywhere?

Go the **** away!

I am here with my son doing the best I can.

There is nothing perfect about these disappearing minutes...

And yet everything is perfect.

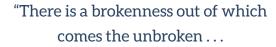
It will never be enough...
And yet my whole being knows it already is.

I remember knowing it was time to pull the ventilator
But not wanting to know
Wanting to question my knowing
Looking desperately like a child for someone to tell
me it wasn't true.

I remember catching the reflection of my eyes in the mirror
You can do this.
He needs you.
But how?
You already know that...
Be his mother.
And so I was

I still am.





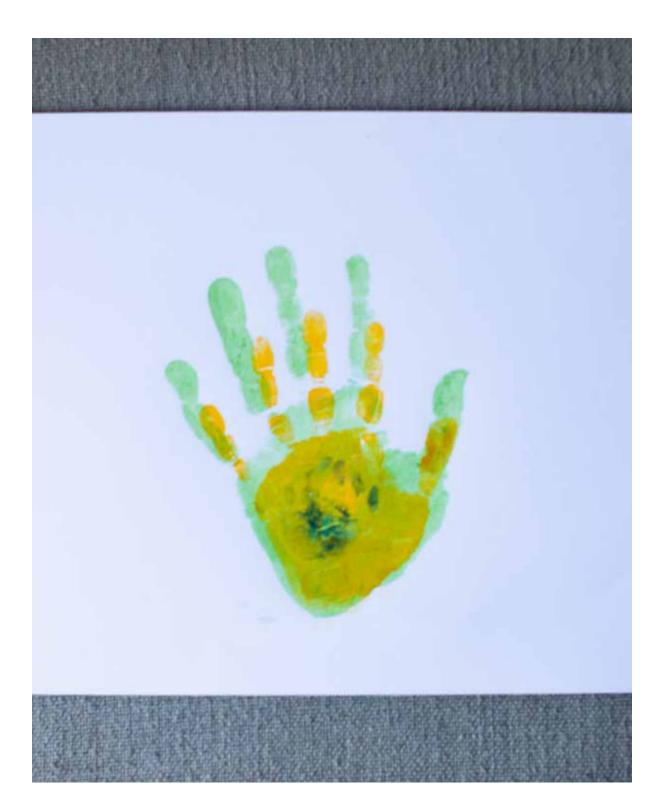
A fragility out of whose depths emerges strength.

There is a hollow space too vast for words through which we pass with each loss, out of whose darkness we are sanctioned into being.

There is a cry deeper than all sounds whose serrated edges cut the heart as we break open to the place inside which is unbreakable and whole . . ."

Rashani Rea

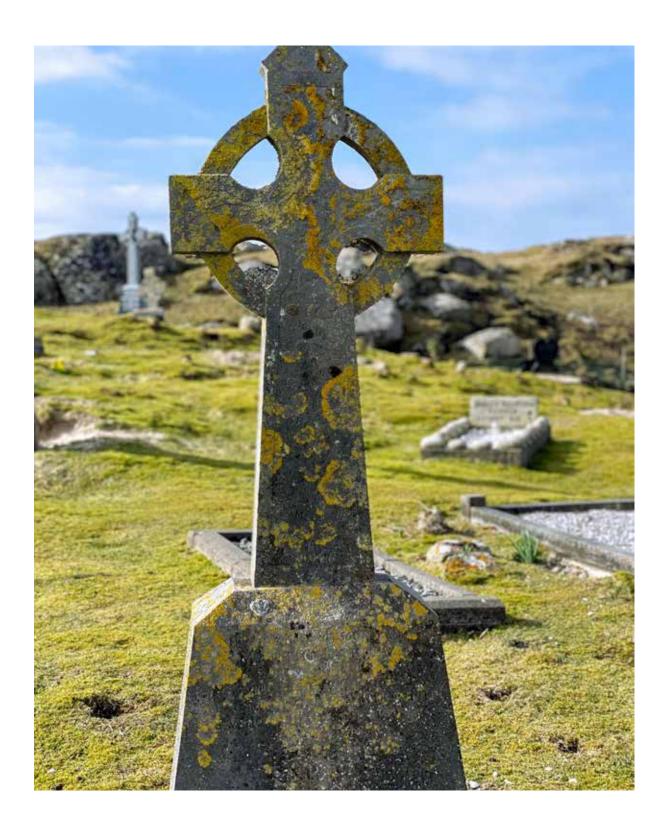
LOVE in the LETTING GO





I feel lucky with James. I know it sounds strange but if you look at the unknowns we faced throughout the pregnancy... the possibility of never meeting him alive or potentially enduring a life of great suffering...I think we were lucky. We got everything we hoped for given who James was. We got to meet him alive. We got to hold him. He got to meet Ciarán and Áine. We got time as a family. And James didn't suffer. He passed peacefully in our arms and we got to lay him to rest in Cleggan... a place he will be remembered. Besides wishing he never had Trisomy 18... I think we were fortunate with how everything unfolded for him.

Seán



A Prayer On The Eve Of A Burial

Strength is courage in action.... Strength is courage in action....

I don't have to be strong.

I just have to find courage.

I have found it before

Please please help me find it again

Strength is courage in action.... Strength is courage in action....





To James...

Your life was short but you were known you were loved you will forever be remembered.

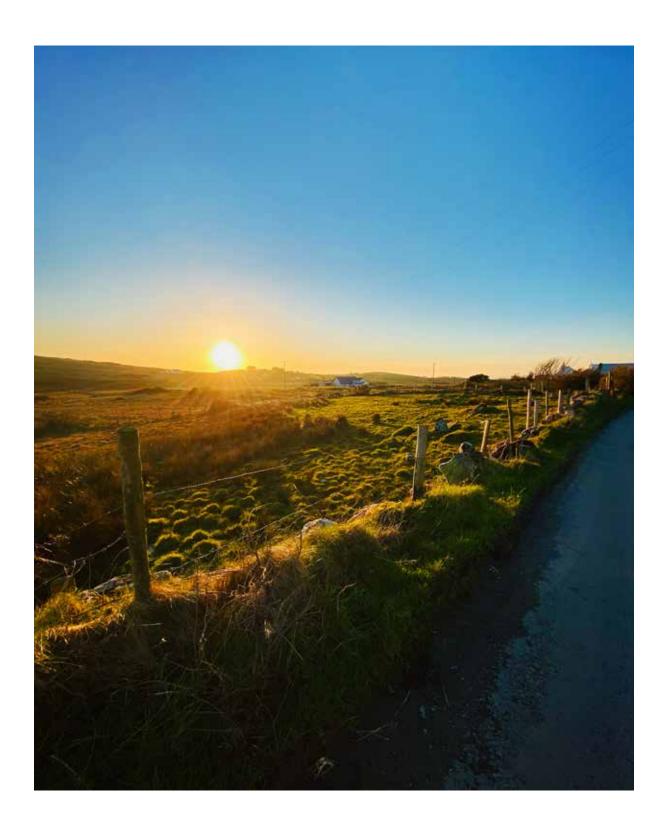
May you rest in precious peace sweet boy.

We love you.

We miss you.

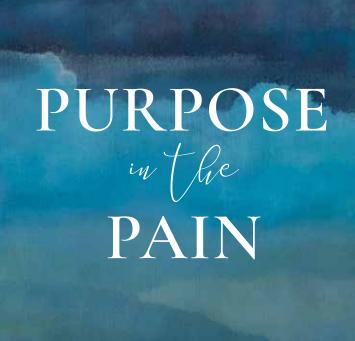
We will always carry you with us.

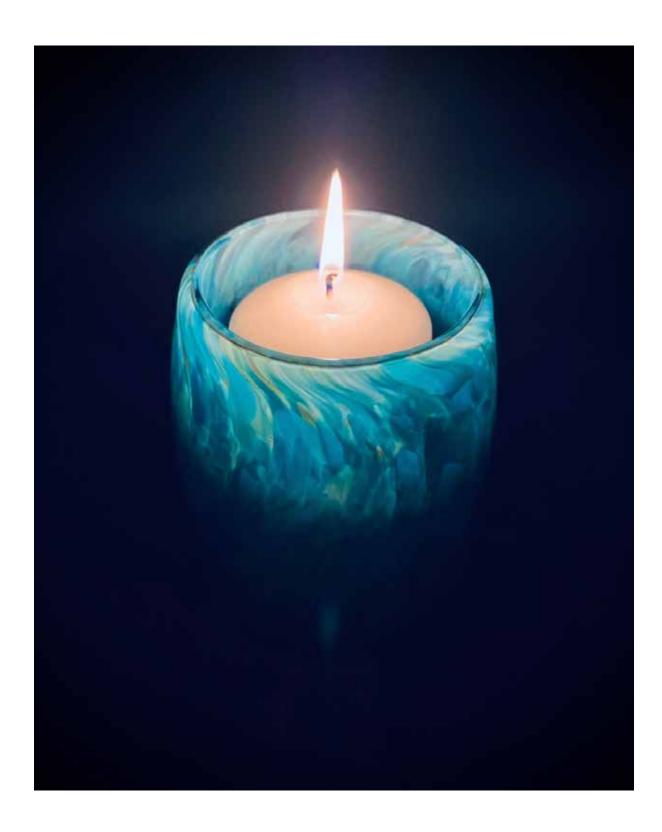




May the light forever shine upon you.

Prayer For Eternal Rest





The Darkness is Holy Too

Hey grief!

You have been a lot lately

From the outside it almost appears as if nothing is

happening

Or perhaps, there might even be a "problem"

On the outside, it is true...

I feel and look depressed

Flat

Lonely

Disconnected

As if I am moving through the motions of life and

not fully here

I am

It's awful

So uncomfortable

Frustrating

Sad

Lonely

And yet I know,

from somewhere deep in my soft belly that this apparent dullness is not the full story....

Deep down, below the surface of my life everything about me is being reconfigured into

something new.

Shifted

Expanded

Transformed from the inside out.

Something about me is being remade on a cellular

level

But who am I becoming?

I don't know yet

A mystery still claimed by the dark

Some days I surrender
And let the waves of grief and pain pass over me
Others I get overwhelmed with impatience, fear and
despair

Desperately trying to hold on to pieces of my old self as they fall away one by one

It's hard

Excruciating most days
Will the heaviness I feel at the center of my being

ever lift
Will I ever feel light again
Yes.

Yes you will....a strong quiet voice whispers to me
But now is not that moment
Now is the moment to descend into the dark waters
of your soul's journey

To cloak yourself in trust and faith for the long road ahead

And to feel it all
But have no fear.
Even in the darkness
There is nourishment for you
Growth for you
Aliveness for you
Trust it
Yes you will rise again
But for now, you sit here

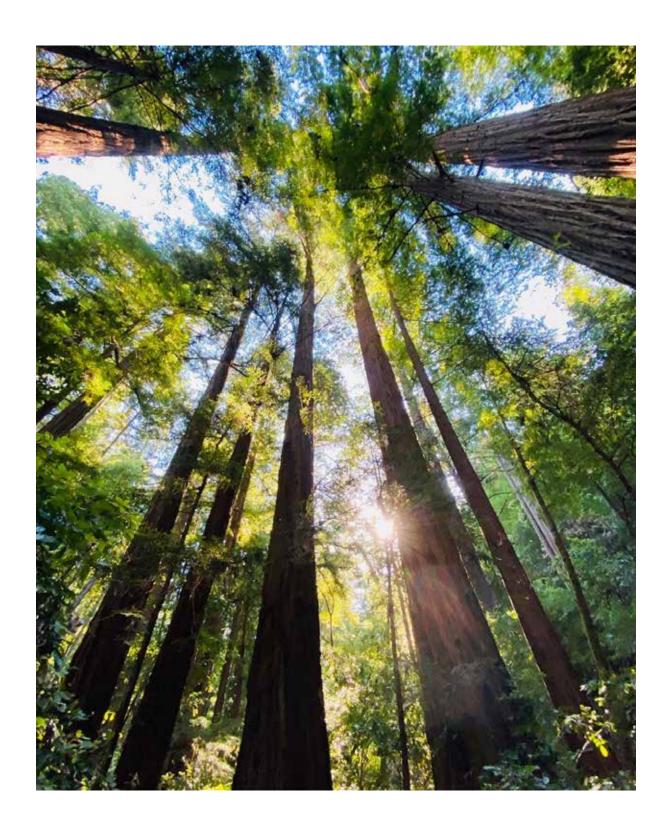
This is your soul's work
Surrender to the invitation
Be curious
The darkness is holy too.



The healing from the pain is in the pain.

Rumi





You Have Permission

You have permission to go slow
To grieve deep
To let the life-altering earthquake of loss
Change you
Slowly

You have permission to feel lost
Heavy
Blown open with your endless questions
Your regrets
Your what ifs

You have permission to pull back
To sit in the corner of the party
To not go at all
To crawl into bed instead
And let your tears cleanse yet another painfully
survived day

You have permission to make meaning out of you suffering
Or to refuse to believe any meaning exists at all

You have permission to be...
With the contradictions of your mind
The strength and the weakness of your heart
The blessing and the brokenness of your body

You have permission to laugh and to cry
At the same time
In joy
Or in pain

You have permission to feel inspired and to want to give up

To breathe and to want to stop breathing

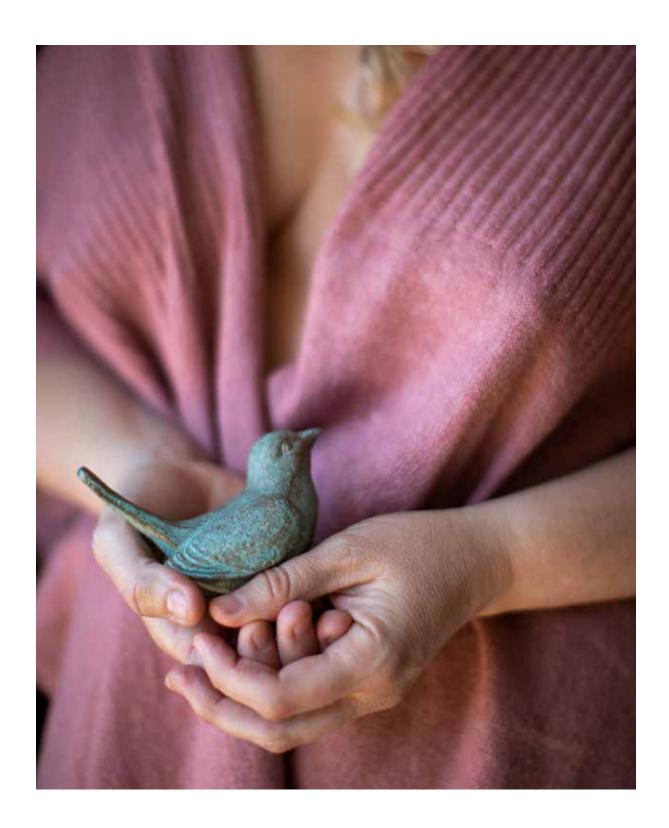
To live and to fear what life will bring next.

You have permission to follow your grief
And to trust that wherever it takes you
is a worthy path
Of courage
Of love
Of loss



Since her first grief had brought her fully to birth and wakefulness in this world, an unstinting compassion had moved in her, like a live stream flowing deep underground by which she knew herself and others and the world.

Wendell Berry



A Journey of 6,323 oz

I pumped...

I pumped at first because I didn't know what else to do.

My empty arms and aching heart longed to stay connected to you... so I began a journey.

A journey in your honor.
A journey in your memory.
A journey to hold me in my grief.
And strangely soothe my broken heart.

I pumped because with each drop of milk that fell from my breasts I would think of you and feel your presence.

I like to think your essence was infused into every ounce

And that every baby who received your milk could feel the light of your sweet soul and the love of a mother.

I pumped...

I pumped for more hours than I could ever count In more places that I ever thought I could And for longer than I ever imagined.

I pumped because the moment your soul left your body my heart shattered

Because after we buried you the grief came over me like a thick blanket of fog

And for a long time I was unable to even sense the twinkling stars I hoped were just out of sight.

But I kept pumping

Even as the darkness descended over me

And the pain of navigating a life without you set in.

I pumped because sometimes the very act was the lantern I desperately needed, illuminating a path in the dark and lonely forest of grief.

A lifeline, that allowed me to keep putting one brave foot in front of the other

So I kept pumping
Kept making your precious milk
Drop after drop.
Bottle after bottle.
Donation after donation
I pumped because with every pump part I washed and bottle I sterilized
I was invited to face the loss of you fully.
To not push it all under the rug.
Tie up the unfairness of your short life with a shiny bow of gratitude.

Or become rigid with despair But instead...

To collapse fully under the weight of my sorrow Accept this initiation of love and loss And let it change me

And change me it has...
While the pain of losing you may never fully fade
I can feel the warmth of a new sun rising from deep
within

And I know now, that perhaps my life has been touched by the divine kiss of your grace and my grief ... for a purpose.

Your purpose My purpose Our purpose

So I pumped...

I pumped because I love babies
All babies
Healthy babies, Sick babies, Angel babies

I pumped for the miracle babies in the NICU For baby Levi who's mama passed away shortly after birth

For baby Robin who is bravely fighting a brain tumor
For babies Atlas, Axel and little Darragh
I pumped for many babies whose names I will never
know but whose precious souls I will forever hold
dear.

I pumped because this may be my last "breastfeeding" experience.

And although it was differentI have come to know it as no less beautiful.

I pray that every milliliter was nourishing and supportive in whatever way was needed for each family at the time.

I like to think that each baby who received your milk carries a speckle of your light in their cells and will be forever reminded that they too are an expression of pure love.

So I pumped ...

I pumped as an offering
As a prayer
As a hope
As a way of continuing to shine your light in the
world
Express my love
And let your legacy live on

I like to think your milk has magic in it
That it carries the gifts of your wisdom
Your teachings of love
Of surrender
Of trust

Of who we are beyond these limited bodies we live in.

I pumped and I am so glad I did. The journey has softened me. Gave me purpose in the pain.

And allowed me to transition the last threads of our earthly journey with tenderness of time.

So now, as I stand here on the threshold of completion ... Finally fully ready to release this last layer of our sacred physical connection....

I honor it all....

I honor the uniqueness of this journey
I honor the 49 gallons of miraculous milk we donated
I honor each precious baby it was blessed to feed
I honor my body
I honor my grief
I honor the offering of love we created together and all future offerings that are yet to unfold

But most of all I honor you my sweet James.

May your soul forever know my love and devotion
As your mother
Who although can not continue the journey in this
way forever
Promises to live as best I can with your legacy in my
heart and your wisdom in my life.



Embrace your grief. For there, your soul will grow.

Carl Jung



GRACE in the GRATITUDE



The Art of Losing

To Lose Let Go Release Say goodbye Surrender

We don't get to choose when death comes.

Things are taken from us

And come to an end

All the time

Life carves us at its will

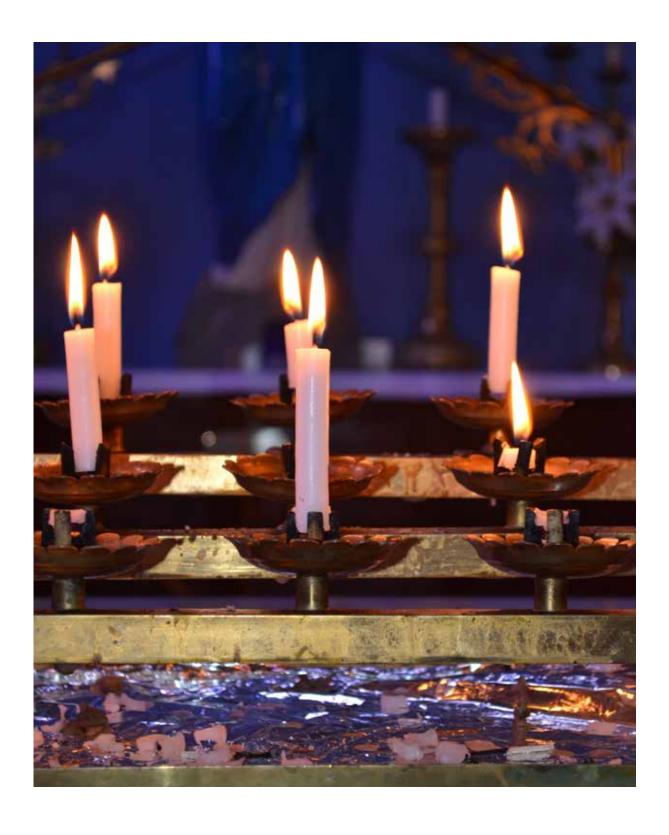
And we grieve

It's human

Art

Art is each of our unique expressions
How we choose to meet the mystery of loss
The way we show up to our sorrow
What we learn
How we grow
Who we become





Dear James,

It has taken me the whole holiday season to finally find the courage to sit down and write this letter to you. I have thought about doing it every day but in different ways the pain of your absence has stopped me. I'm sorry. I hope you understand. I finally sit here tonight before our limp twinkling Christmas tree wishing for the millionth time that you were here. Tomorrow we will take it down and most of me still feels disbelief that it's been nearly a year since you were here. I miss you, my sweet boy. I miss you more than words could ever express. My heart literally aches for you and my arms still feel weak with emptiness. I long to hold you. To stroke your sweet little head, squeeze your perfect toes, kiss your button nose. Oh how I would cover you in kisses if you were still here.

I remember you in my belly this time last year. Your little kicks and rolls. I remember sitting for hours comforted by the eternal beauty of these same tree lights desperately trying to cherish each moment you were alive and well on inside ... and at the same time attempting not to focus on all that I intuitively knew I was very soon going to lose. Striving with everything I was not to brace myself but instead open my heart, surrender to your path and trust it.

I hope you know that despite all my pain and grief I do honor and trust your path. Grief is so complex. It touches every single part of you and literally turns a life inside out. Some days I think I am doing well. Others I come head to head with how truly broken I am and how torn apart our life really has become. It's been hard without you. It's been really really hard. We miss you so much.

We felt you with us this Christmas. I wanted your presence to be known and remembered. We hung your Blue Jay stocking right in the middle of ours. We placed an angel holding a bluebird at the of the tree and we toasted to you at Christmas dinner and again at New Year's. Your brother Ciarán and sister Áine talked about you often and your Daddy although he is a man of few words... I know he was aching for you too. We spoke about what it would have been like if you were here. You would have been just shy of a year old. Possibly crawling around the place, getting into trouble. We would have loved it. We felt the absence of the joy you would have brought by being here, but we also have gained a knowing of a love and devotion we could never imagine living without.

Despite our sorrow, we know that all has not been lost and you my precious James will always be remembered. I hope you can feel us carrying forward your legacy of love. Your teachings. Your wisdom. I know it deep in

my bones and hope that as time heals more of my pain I will be able to regain capacity and show up to offer your gifts to the world in honor of you.

Your life was short but the impact of your soul's light is eternal. There is so much more I want to say... I am realizing this is a thing.... It is actually impossible to express the magnitude of a heart's love. But I hope to continue trying. Because you, James have changed me and touched my soul in a way that I know was meant to be.

Merry Christmas and Happy New Year, my sweet boy.

I love you to the moon and back.

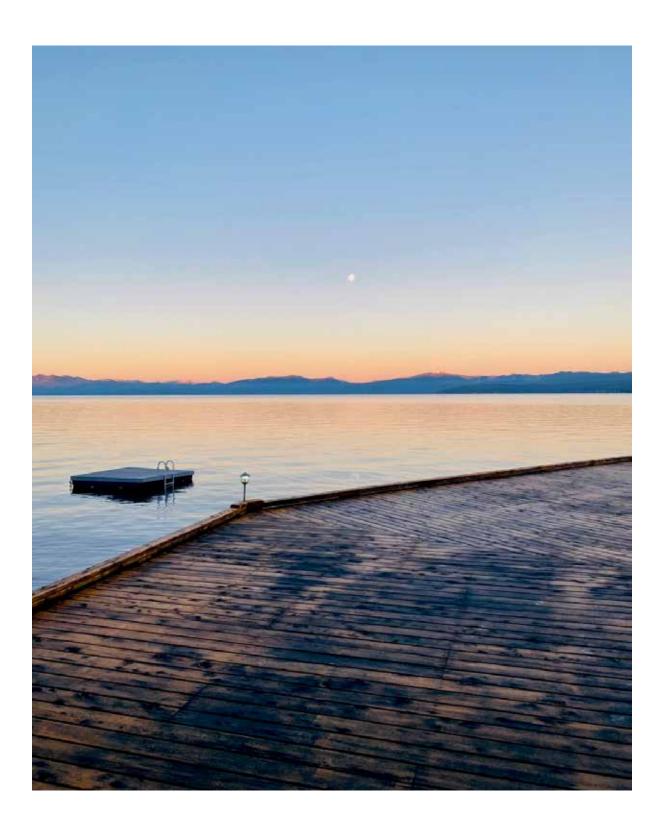
Truly. Always. And Forever.

Your Mama



Your children are not your children.
They are the sons and daughters of Life's longing for itself.
They come through you but not from you,
And though they are with you yet they belong not to you.

Kahlil Gibran



This Lake

This lake...

This stunningly beautiful lake.

The place I first connected with you.

The place our souls met and chose to dance.

It was here on this dock I felt the call to be your mother.

Where you first visited me as a gorgeous Blue Jay.

Where I sensed your soul's light was ready to make its journey back to earth...

And that you had chosen us.

What an honor that moment was.

It still is.

This lake...

This stunningly beautiful lake.

It was here we came just a week after you were freshly planted in my womb.

I buzzed with excitement and anticipation sensing you were here, but not having confirmation yet. Your Dad and I shared special glances and long embraces all week.

Dreaming ... each in our own way, about what it would be like to have you join our family.

Our precious third child.

The missing piece in what we imagined would make our family complete.

We swam. We played. We laughed.

I knew you were already with us...

But there was so much I didn't know.

This lake...

This stunningly beautiful lake.

It was here where I first received the call.

The call that would change everything.

My doctor's voice etched painfully into my memory.

"I hate to be the bearer of bad news..."

The first time I heard the term "life-limiting diagnosis."

I called your Dad to tell him

Fell to my knees

Cried

Screamed

No. No. No.

How could this be happening?

What did I do wrong?

I saw the vision of you so clearly.

Looking back now, perhaps the vision was never lost just the picture changed.

This lake...

This stunningly beautiful lake.

Confused and desperate, it was here I prayed harder than I ever have before...

For strength

For hope

I prayed that the tests were wrong.

That you would be the miracle of a "false positive" result.

It was here on this dock your Dad and I held each other tightly and first descended into the dark world of considering terminating the pregnancy.

A decision we would wrestle to the core with for weeks.

But we didn't have all the information yet...

We needed to wait.

So there on the threshold of crumbling vision...

You spoke to me.

"Come on mom ... I may not have much time here.

Let's go jump into that gorgeous blue water together."

And so we did.

Every morning for the rest of the time we were here. It was cold but I also felt so alive with you. It is true that even in our darkest moments joy finds its way through the cracks of despair.

This lake...

This stunningly beautiful lake.

It was here we came last summer just six months after your earthly journey had ended but what felt like a lifetime since we were last lakeside.

The sun was shining but my world was dark with grief.

I remember trying to act normal.

Wondering if the warmth of summer would ever find its way back into my cold and broken heart.

Fun was had.

But I felt numb.

The lake looked dull.

You seemed so far away.

This lake...

This stunningly beautiful lake.

A portal that will forever connect the sacred threads of time and healing.

It is here we knew we wanted to celebrate the precious memory of your birth and the tender anniversary of your death.

So here we have come...

It's still winter

But the birds are chirping

There is a hope of spring in the air

And the water looks wider and deeper than ever before.

What a voyage we have traveled together...

There has been so much beauty in the breaking

Miracles in the mystery

And a love that has undoubtedly transcended the boundaries of loss and time.

I will never lay eyes on this gorgeous lake and not think of you.

It is true that our journey has come full circle But I know that our souls are still dancing on the dock.

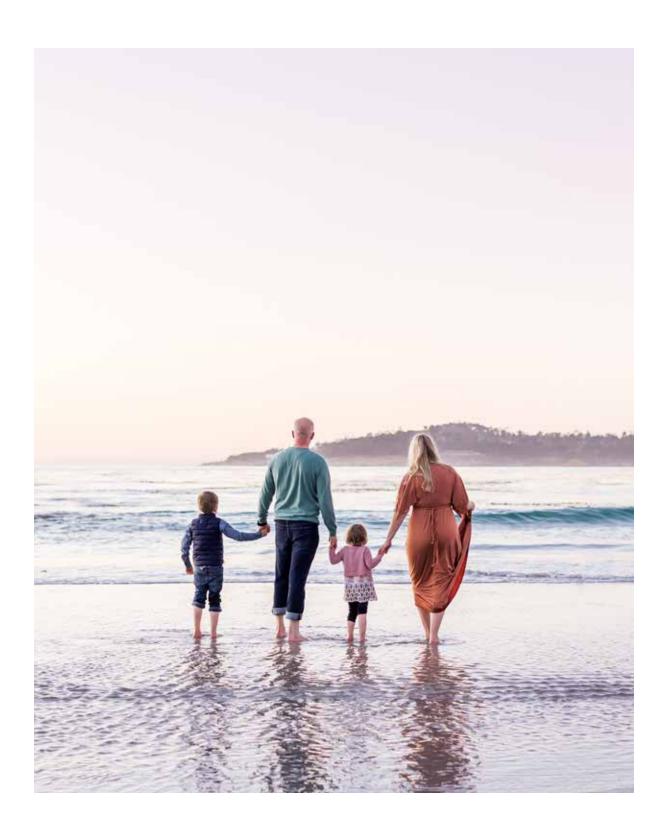
Forever connected in love.

Us as your family and you, our precious James, soaring just above.



No anguish I have had to bear on your account has been too heavy a price to pay for the new life into which I have entered in loving you.

George Eliot



I have no idea where life will take our family next but...

I deeply trust the path we have been asked to walk.

The darkness we have been called to sit in.

The pain that has broken our hearts open in love.

May we not fear the ways life will ultimately carve us all ... but instead, may we band together in rituals of courage and faith ... so that we will be able to meet the waves as they come and bravely answer the call to sit at the center of our own, and collective brokenhearts. Allowing our grief to deeply change us for the better. Moving us to create something beautiful

connected and peaceful world.

May it be so.

from the rubble and activating our souls' wisdom in the restoration of a more honest, compassionately



We love you



