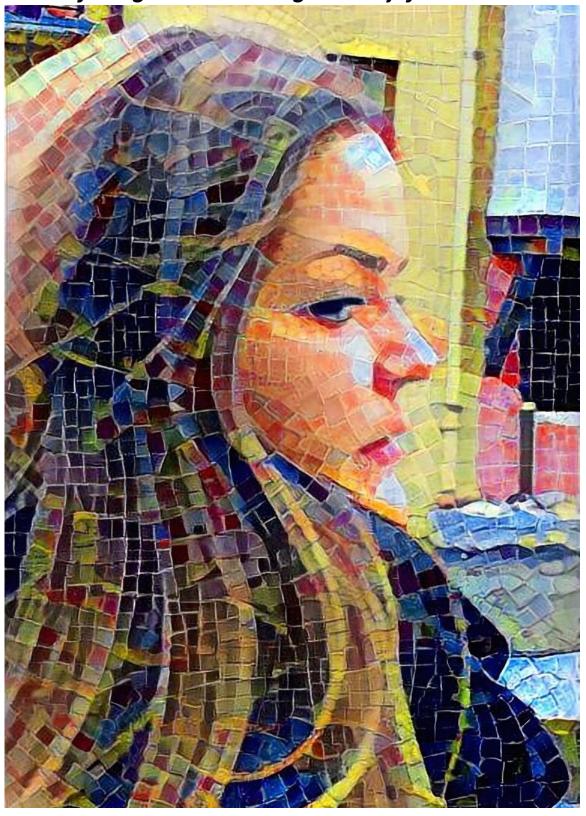


To my daughter Alex who gives me joy.



# Prologue

On a beautiful June morning in 2008, with the wind in his hair and the sun on his face, my son Max was riding his bicycle as if there would be no tomorrow.

For him, there wouldn't be.

He miscalculated a sharp turn, hit a parked car, severed his trachea and died within minutes. He had just celebrated his  $20^{\rm th}$  birthday.

Max's short life followed the trajectory of a dazzling firework: ablaze with intense heat, radiance, and color. Before the thrilling "Ooohs" and "Ahhhs" of family and friends had a chance to fade, his time on this earth was over leaving only faint puffs of smoke and colorful memories trailing into the obsidian sky.

This story seems to begin with catastrophe but in fact it starts – and ends – not as tragedy but as a tale filled with love. And although it was Max's death that unexpectedly catapulted me into the journey I'm on now, this is not his story. It's mine. I am not a doctor or a therapist, but I know of what I speak. I've stood by the abyss and know its depth and pull. No one can completely *understand* this journey unless they've experienced it themselves.

While each loss is different, among grieving parents there are shared pitfalls and patterns. There are also similar pathways of hope. With the passage of time and incredible courage, the desolate feelings begin to soften allowing fewer tears because your child's life is over and more smiles because it happened. Experiencing softened feelings about loss doesn't mean the

gut-wrenching pain never existed. Or that it's gone completely. It means it no longer controls your life. You've created a new kind of home – *a new you* - in the midst of the anguish.

The fact that one of my children has died doesn't alter the truth that I am still the parent of two children. The fact that no word or acronym exists to define the parent of a child -or children - who have died doesn't change that. When a husband dies, he leaves a widow. When parents die there may be an orphan. When someone is medically trained she is a doctor. People who are divorced have a name. But there is no instantly recognizable name for parents whose child has died.

Without a name, our role as the parent of a deceased child seems diminished somehow. I propose that when a child dies, one becomes a "Parent or Parents of a Deceased Child or Children". The acronym is PDC. Having a name for who we are is important. It validates our truth and enables others to immediately understand our situation. "I am a PDC". No further explanation is necessary unless I choose to give it.

This, then, is my story about loss, hope, love and living life as a PDC in the best way I can. If you are also a parent of a deceased child you may be walking a similar path. Perhaps you're not a PDC but know and love someone who is. You want desperately to help but don't know how. *Going On* may give you some ideas. The life of a PDC is a story of an ending, of death, yet it is also a story of beginning where one can come to realize that the only feeling stronger than loss – is love.

Love to the max.

### **At First...**

YOU ARE an un-whole, incomplete person. Aching and unwell. You will never be the same because you've experienced every parent's worst nightmare: **Your child has died**.

YOU ARE alone and lost in the dark. When the child you love disappears, it's like the sun is obliterated behind a cloud leaving you shivering in deep, desolate shadow. In your darkness, you can't see where to go or what to do. The entire world is shrouded in grey mist. You try to do what people tell you: put one foot in front of the other, keep busy, pray, sleep. But the simplest tasks seem surreal and take far more energy than you have to give them. You feel as if you are carrying a boulder on your shoulders and that you might be crushed into dust by its weight.

YOU ARE standing on the edge of a giant abyss looking down into the black, bottomless depths. Numb and cold, you feel nothing. Swaying on the edge, you could easily fall forward and allow the darkness to swallow you. People would understand. Heads would nod, as even the most optimistic would acknowledge that losing a child could be enough to make anyone stop their own journey. Unable to go on.

YOU ARE wishing you could trade places with your child so that your life is the one cut short. After all, parents are supposed to die before their children. That is the correct order of things. The way things are supposed to happen. Right? You'd surrender to death so that the pain would stop. You'd be the one transitioning into the bright forever and your child would live a long and happy life.

YOU ARE aware of a faint light – a glimmer really – of what life was like before. It brightens then disappears like a boat's light bobbing on a bruised night sea. There, then gone again. A shimmer of light shining always just out of reach.

YOU ARE longing for things-which-no-longer-are and feelings of acute nostalgia are so strong they are smothering your heart and dragging you to a desolate, lonely, soul-less place.

YOU ARE wondering WHY THIS HAPPENED TO YOU? What bad things could you possibly have done to deserve this? You lean over the abyss and long to be swallowed whole. You know that if you allow yourself to fall, you will never get up again. For a long time you stand statue-like, cold as marble, looking into the pit, feeling nothing. You are unable to hear, taste, see or feel. You float in a daze not wanting to face the truth.

YOU ARE dreaming about the life you had with your child and family and you think it's not far away. You hope at any moment you can reach out and grab it. Feel safe again. Hold on and never let go. But when you wake up, you know *that* life - *that you* – is gone forever. All the more scary because you don't know what lies ahead. And you don't much care.

Friends and family are devastated and want to help but they have no idea what to say to you. They are well intentioned but clueless. So they often end up feeling desperate while stammering the wrong things.

Here is a list of things I encourage you <u>not</u> to say to bereaved parents or siblings:

- Time heals all wounds.
- At least you have another child.
- You need to be strong for others who are also grieving.
- I know someone else who lost a child and she's fine now.
- Your child is in a better place.
- Tell me what you need.
- Having another baby might make you feel better.
- This is God's will.
- At least you had him in your life for a while.
- I know just how you feel.
- Isn't it time for you to get over this?
- I felt this way when my dog died.
- At least you have a job to take your mind off this.
- Is all this crying really helpful?
- I miss the person you used to be.

Here is what I would say to PDC and their families:

- I am so terribly sorry for your loss.
- I wish I could spare you.
- Feel what you will and be damned with anyone who tells you otherwise.
- It. Just. Hurts.
- Be gentle with yourself: snivel when you need to, sleep when it takes you, eat so you still have strength left to scream and throw things if that's what you want.
- Talk about your child and encourage others to do the same. Tell them you want to hear your child's name. You might hear something you didn't know before. A bittersweet new memory.
- Don't let others forget that your child *lived*.
- Take peacefulness when it comes. Accept any calm feelings like windfalls in the tempest and let the breeze soothe.
- The dead don't need to be perfect. Remember the child you loved for whom he/she was.
- You are a good person to whom something terrible has happened. If you have doubts, forgive yourself. If you can't today, try again tomorrow. And again the day after that. Keep trying.

- There is no compliment in mourning forever. Repeat that and keep moving. Keep going on.
- "How many children do you have?" Don't hesitate. You are always the parent of your child. You are now a PDC.
   The fact that your child no longer has a physical presence on this planet that he has shed his "earth suit" makes no difference. You are always the parent of your child.
- Accidents happen. Illnesses overtake. Please feel the goodness in yourself and know that you did the best you could whatever the circumstances. You now have a chance to become the person you are meant to be not in spite of, but because of what has happened to you.
- You won't believe me (I wouldn't have believed you in the beginning) but there are gifts that can come to you out of your loss. Try and be open to receive them. Understand that this is both an end and a beginning. It will be what it needs to be.
- Profound grief is not a sign of weakness or lack of faith. It is the price of the deep love.

## As Time Passes...

YOU ARE obliquely aware that life is going on around you whether you like it or not. You begin to be able to hear what people are saying. Take in their words. Feel their love. And then one day, the call of the abyss is less strong. The weight has shifted. You've been standing on the edge for such a long time you're afraid to move. But you do. You take a step away from the gaping, black hole. Then another. You stand in a haze of blue-black days never knowing for what you are waiting.

Please know you are not alone. You may feel it but you're not. There is a silent legion of parents just like you – other PDC – who are living their own nightmare while lost in the dark. Such terrible suffering. It eased my pain somewhat when I realized I was not alone. Seeing others with a smile on their face who were further along the grieving path than I made me wonder: would I ever feel joyous again?

YOU ARE overwhelmed with the hugeness of your love for your child. But your grief feels bigger and it's killing you. Waking up in a world without your child is like waking up in a world without the sun or stars: unimaginable. You can't breath, think, eat or work. Everyday tasks are left undone. You sleep and sleep and hope never to wake up. How can you possibly bear another day? How can you survive this? How is it possible for you to continue going on?

Survival is a painful, arduous, lonely process – but it is possible. When depression overtakes, try to get through an hour. If that's too long, make it a minute. Time will pass. Just hold on until it does. Be gentle with yourself yet don't bypass the desperate feelings you're experiencing. Move with them. Feel them. Breathe. Keep going on. The only way forward is by being open to life just as it is.

YOU ARE reading about the stages of grief and feel off-track. One day you are on schedule, busy, doing what you need to do. The next day you can't get out of bed. You try to hide your sadness in order to make others feel more comfortable. But that doesn't work well. Despair comes out through your eyes, in the way you walk, dress and the way you talk to people. You have a black aura around you that scares people away. Sometimes you scare yourself.

There is no set calendar for the grieving process. Your journey through the emotional sludge of feelings is yours alone. Don't judge yourself if after months and months and months tears still take you by surprise. In the early days, expect that there will be no good days. I was surprised in my very early grieving that things were so violently cyclical. Some days were grey; others black and it was impossible to tell when I woke up in the morning what the day would be like or if it would be a confusing mix of colors.

Healing isn't a race. And you're not obliged to follow someone else's timetable. For me, there were no "stages" of grief. I experienced "emotional platforms" on which I stood in erratic and unpredictable ways that changed from day to day. I took deep breaths and tried to forgive as much as I wanted to be forgiven. I doggedly continued to move forward in my own way and at my own pace. The goal during the early months after loss was simply to keep going on.

YOU ARE surrounded by well-intentioned family and friends who want to help but don't know what to do. Or, you find yourself amongst others who slowly back away from you afraid that somehow the death of a child is contagious. You feel so sad and completely shut off from the world. Desperate. Afraid. Wrapped in a dark cocoon. Your soul is sobbing. Where has everyone gone?

People are just people who are doing the best they can given this tragic situation. Some will not be able to be strong for you. Often, you will have to give much of your energy to them while telling them you're "just fine." You simply don't have the strength to explain all the ways in

which you are not all right. And they wouldn't want to hear them anyway. There are other people who are desperate to be there for you with no clue what to do. Make it easier for them so that it can be easier for you. If you're lucky enough to know what you need – tell them. And for times when you truly would rather be alone, have a trusted gatekeeper for those well-intentioned visitors you'd rather not see.

YOU ARE afraid you're going crazy. Becoming a lunatic. Giggles come at the strangest moments and then, just as quickly, they turn to tears. In a one -hour time frame you may want to rage, sulk, blame, laugh, scream, pray, die, sleep, run, eat, and forget. What is happening to you?

You are not losing your mind. You are grieving. Emotions will become more stable -- even out -- given enough time. It's true that you can find yourself laughing at the strangest moments. The giddy bubbles can feel a bit too close to madness but they help heal, purge, purify and remind you that life is still life - challenging, unfair, messy, funny. The swing of emotions is what grieving looks like for many of us. You are blessed if you have a sister or close friend with whom you laugh. Or cry. If despair overtakes when you're alone, tell your dog everything and let her lick away your tears. Dogs know.

YOU ARE experiencing grief like a part you have to play without knowing your lines or rehearsing. You'll meet others who play their part while sympathizing. You don't know how to do this. They don't know what you need.

Grief requires acquainting yourself with the world again and again; each "first" causes an emotional upheaval that breaks open the scab. This causes you to anticipate the feeling of pain and suspense, an unknowing dread, never recognizing what occasion will bring you to your knees. Being real about what you're feeling could be the bravest thing you ever do. You might just find strength in yourself you never knew was there. A warrior-soul deep within your core. Let the tears and emotions flow. I came to find that a good cry released the built up angst, fear and sadness I held inside. Be gentle with yourself and let it out.

YOU ARE starting to regain some feelings and you just want to move on – stop feeling so wretched. Put the intense, tragic truth of your loss in a different place. But you're afraid that if you stop being sad your love for your child will somehow be invalidated. Grief's moods make you melancholic, estranged from the normal and everyday events of life. Set apart. You wonder what "feeling normal" is supposed to mean to you now.

Before losing my son, I had my own idea of grief. I thought it was a sad time that had to be endured to get to the other side. The goal was to push through and "get over it". Now I know that for PDC, there is no other side. There is no pushing through anything. But rather, there's absorption, adjustment and acceptance. Grief is not something you complete or a task to finish and move on. Acceptance of our loss isn't something you can choose off a menu, like meatloaf instead of chicken salad. Moving through grief is a passage you endure. It becomes an element of yourself, a part of your being. A new way of seeing and living. It colors every single thing in your life. Living with your loss is your new normal.

YOU ARE encountering family and friends whose lives are joyous. They're celebrating birthdays, weddings and holidays with their children and everyone is flourishing. You feel angry, jealous, sad, uncertain and so guilty about these feelings. You desperately want things to be like they used to be for you and your family but recognize this yearning as futile.

There is no right or wrong way to handle family gatherings or holidays. The first ones after your loss will be painful no matter what you do. Some PDC may not want to celebrate anything for a long, long time. Some may wish to follow family traditions while others may choose to change things. Each parent may have a different idea of what to do and their plans may differ from what the surviving siblings want. Thinking ahead as to where and how you will spend your time during family events is important. Scale back on activities if you want. Redefine and reframe your plans. Communicate with each other. This can be a transition time where new traditions are begun and others let go. Ask for what you need without apologies... simply ask. It's all right, too, if you have no idea what you may need and express that.

YOU ARE crying all the time and your husband hasn't shed a tear. You want to talk about your child's death with the hope that you can make some sense out of an act that makes no sense. You suggest counseling and it falls on deaf ears. Your husband seems to be focused elsewhere and is busy doing things. "Talking won't change what happened," he might say.

Grief is very personal and no two people grieve in the same way or at the same pace. And this can be ok. There is no right or better way to experience the loss of a child.

There are different ways and realizing these differences is important. Many things contribute to the way PDC react to their loss. One important factor is gender. Men may be unsure how to respond to emotional displays as grieving openly is not seen as part of the "male character." Men are usually focused less on talking and more on doing. In general, women talk their way through grief. They need to process it by verbalizing their feelings. The goal is to nurture and support one another -- despite the different ways in which you grieve -- with as much love and understanding as possible.

YOU ARE consumed by blinding anger. Your rage might be aimed at yourself, your child, your spouse, God, your family other people, life. You've never before experienced the vehemence of anger like this. It feels like you might explode spewing hot embers in all directions. There is a tightness in your chest as if a fist has grabbed hold of your heart, clamped down and killed all other feelings you might have.

Anger and the guilt it causes can be a really huge part of our grief and healing process. Many women are taught that anger is not okay and to never express it openly. And for some men, anger is the only emotional expression they feel is permitted. While anger is a natural feeling we must allow ourselves to experience, it's not good to wrap ourselves in it and not move on. In order to heal, we must allow ourselves to feel the anger and then move past it. Sometimes the support of a therapist, friend, or healer is necessary to help discover ways of easing into, around and beyond our raw feelings.

One thing that helped me work through my anger was learning to forgive myself. For what did I want to be

forgiven? For not being there to stop the accident; for the missed chance of holding my son in my arms as he took his last breath; for not feeling something in my soul at the exact second he left this earth; for not telling him I loved him one more time. My list for forgiveness was long. With time and attention, I learned to be patient with myself, to love myself and to recognize that it would be a very, very long time before I would feel anything other than despair. These feelings are all part of grieving.

"How are your parents doing?"

Please do not ask this question of the surviving siblings. It takes away from their personal grief making it seem like nothing. And in order to make you feel better, they might have to make light of their own grief. Siblings are commonly referred to as the "forgotten" grievers. While sympathizers are focused primarily on the PDC, siblings are often left alone. In their aloneness, many siblings feel the burden of the impossible task of doing something to make their parents feel better. As well, they can be filled with anger at their sibling for dying and "ruining everything".

After the loss of their sibling, children need to see their parents and be with them in some way. They need to know that they have not lost everyone, that they are not to blame, and that they are still loved. Families heal best together. Being there to listen to the sibling's fears and thoughts as they emerge is crucial as it bears witness to their loss. It also gives them permission to feel what they're feeling, to embrace the memories and to move forward with their own living.

What can make sense especially during the early days after the loss is for the PDC to have a family member or close friend be responsible for the siblings' daily needs; driving them where they need to go, doing laundry, making meals, checking homework, etc. There is no shame in recognizing that you may need to seek outside, professional help for your living children.

Many PDC do this. Especially since you may simply not be able to provide the support for them until you feel stronger.

Men, women and siblings may find an extra challenge in understanding the grief experienced and expressed by each other. And it's important to know that families, even strong, loving, close families, don't always necessarily grieve together or in the same way.

# These reminders might be helpful:

- Don't blame or judge
- Stay emotionally and physically close
- Talk to each other and, as importantly, listen to each other without interrupting
- Give appropriate space, patience and gentleness to each other
- · Apologize if you make a mistake or misunderstand
- Love to the max
- Keep going on
- Repeat

### **Little Songs From My Great Sorrow**

Being Max's Mother while he lived taught me many things and took me places I never thought I would see. But the truth is

he's still teaching me and I refer to what I learn now as "*little songs from my great sorrow.*" I've come to believe that Max's life purpose was to jump start mine. It's in searching for the inner courage to get up again and again – to living the life I have now -- that my mettle is tested every day.

What have I learned? What changes have I made that help me stay upright through this storm? Most definitely, I am a work in progress. I haven't arrived at a final destination but am continuing to process and learn. And I continue to seek the courage it takes to gaze as squarely at death as I do at life. What follows is a list of things I've incorporated into my life which have been helpful as I continue to transition into existence without my son.

#### Let Go of Perfect

It's crucial to our well being to release all expectations and not think of what life could have been. This is a tough one and I frequently fall back into old patterns. But if you allow *life to happen to you*, you will begin to see a difference. My goal is to stop trying to control people and things around me. Having your child die lays it all bare. Among the most painful realities for me was how quickly death severed the direct link between my effort and outcome – the creed around which I'd built my life. One of the ideas I'd lived by was that if I just tried hard enough things would work out. If I toed the line, all would be well. I would get what I wanted and find the safe path while escaping the bad things.

Max's death taught me that in life, things just happen. In my case, the worst possible thing -- Max's death -- happened and there was nothing I could do to change the outcome. Believing this helped me begin take my hands off the controls and try to accept *what is*. I now experience the world with far less fear

and more clarity, strength and resilience. Instead of asking "Why me?" I now think "Why not me?" I don't live in a protective bubble or think I'm better than anyone else. And I certainly can't control life. Better for me to accept "what is" and keep going on.

#### Take Care of Your Soul

Parents don't usually make much time for themselves. Losing my son forced me to stop my "busy-ness" to try and figure out who I was, what I was feeling, and what I needed to do in order to feel better. Surrendering and letting myself truly feel the pain as I stood still is what began to lessen the hurt. I was determined to learn continue going on. To transform my loss into something bigger than the loss itself.

Recognizing the need to shower as much loving-kindness on myself as I showered on others made sense intellectually. But I quickly discovered that I had few ideas about how to nurture myself. Take care of "me". Through suggestions from friends and through my reading, I tried the following activities that helped. None of them in and of themselves make dramatic changes in my day-to-day life, but collectively, they gently remind me to continue breathing and be grateful. To keep going on.

- Take a walk
- Meditate
- · Talk to a friend
- Let housework go
- Sing a song
- · Perform random acts of kindness
- Watch a movie
- Drink a cup of tea

- Listen to a favorite piece of music
- Attend a yoga or tai chi class
- Write in a journal
- Smell the flowers
- Read a good book
- Do some gardening
- Take a nap
- Eat healthy food someone else prepares
- Get a massage
- Take a bubble bath
- Be compassionate and gentle with yourself

## **Practice Being Grateful**

I believe the most courageous of parents are those of us who have had to give our children back. My hope is that we PDC, each of whom have experienced this most devastating loss, can use our found courage to move through the pain and embrace the possibilities. There are so many things for which to be grateful. The single most powerful source of help for me in learning to live with my loss is an online bereavement group for women called "ForMomsOnly" (www.formomsonly.org).

For MomsOnly was started by a PDC named Barbara Smith. She lost her oldest child, Evan, in a motorcycle accident in 2006. Barbara recognized that losing a child either destroys you or becomes the impetus for you to build something out of the loss. "Building" is exactly what Barbara did in uniting mothers in support and love when she created the safe haven of For MomsOnly. Barbara had a vision to unite grieving mothers so they could reach out to each other offering comfort and support. In Barbara's own words: "I am not For MomsOnly. I am simply a woman who needed a way to save herself from a pain only another grieving mother could know. "Barbara

recognized that grieving Moms need each other and can support each other in unbelievable ways.

Finding the right community helps. FMO was and continues to be my anchor, my trusted guide and my lead line to other grieving Moms who fostered in me the belief that I could not only live through my loss but also thrive in its aftermath. Journaling with my "sisters of the heart" on this site was a safe, private way to release my darkest fears and bare my soul with people who knew exactly what I was going through at any given time. I always know that these women - all of whom are PDC - would never judge or give unwanted advice. The site provides an always-available forum to speak words of love, truth and encouragement. When there are no words, other Moms on FMO are there to simply listen. And love. My own desire to heal myself combined with the heartfelt thoughts of the mothers on FMO and the passage of time were the most significant factors in helping me become the peaceful memorykeeper of my son that I am today.

While FMO's support was hugely important to me, it's only for women. There are other bereavement groups and reading materials that are helpful for men and siblings as well. You can find a listing of recommended resources for men, women and children on the ForMomsOnly website. It's worth the effort to do your own research and find a group of other PDC with whom you can connect. Being with others who have personally experienced the devastating loss of a child can be extremely powerful. As well, a grief therapist or member of the clergy might be beneficial to you. I read every book about loss and grief that I could find and found nuggets of hope in the printed word. None of these things are a panacea, but the messages and information wash over us with time and like a gentle rain they help to nourish and encourage growth.

## **Do Things to Help Others**

In the early days after my loss all my energy was directed inward. I had nothing left to give anyone and it took all my strength to just *be*. After a period of time, I realized I was ready to think beyond myself and reach out in an effort to help others. In spite of many set backs I came to understand that although I was broken I was not so broken that I couldn't pick myself up and accomplish things that made me proud. And in helping others I honor my son. Life did not always seem fair given what had happened but it could still be good.

I've learned that I can sit silently at a friend's side and help ease their tremendous burden just by being there. It never feels like enough. But I remember those who were there for me in this way and it can be a most meaningful connection. When suffering, empathy can be a salve that helps soothe the pain of deep hurt.

### **Embrace the Person You Are Now**

When Max died, my soul shattered into a million shards of glass. I was unrecognizable to my family, friends and, most frighteningly, to myself. Over a very, very long period of time, along with a lot of work the pieces began to slowly, sometimes painfully, come back together although not in the same way as they had before. Some fit differently, and some no longer fit at all. Eventually, at my core, I came to recognize parts of my original self. But while my original essence existed, it was surrounded by new pieces that were unrecognizable. *One of the hardest parts of healing after you've lost a dear one is to recover parts of "you" that disappeared with them.* Part of my ongoing journey is to continue to rediscover myself and learn to like this new, altered me.

I now know what heartbreak is. Realizing its inescapable nature in the life of a PDC, I've come to see it not as the end of the road and not as the elimination of hope. But rather, heartbreak is the close embrace of the essence and emotion of what we have lost. Heartbreak is the cost of loving deeply and feeling that love disappear for a time. Becoming lost in sadness. But I now know with the strongest of convictions that love is the deepest emotion we have and that it endures and always outlasts heartbreak and loss. Love is immortal. And because of this fact, I'm discovering an invincible light inside myself that outshines the darkness of loss.

## Love to the Max and Keep Going On

For me, writing has always been a way to clear my head and stay balanced. I keep a notebook and a pen close by to record favorite sayings, thoughts, and dreams. I began writing more after losing Max and shared my thoughts in journals on the ForMomsOnly website. That's how this book began. A significant reason I chose to make this book easily available to others is because I want my experiences to help as many people as possible. I want the opportunity to touch every PDC – and those who know and love a PDC – and give them a sense that even though life is black during the early months after loss, there is hope. It is possible to enjoy life and people again. This reaching out beyond myself has been extremely cathartic. And if reading *Going On* has helped you in any way, I feel that Max's death was not entirely in vain.

In re-reading my journals, certain recurring themes that helped me begin to see the goodness in things again are evident. I want to share these themes with you:

- Live in the now as it's the only guarantee we have
- Breathe in the present moment
- Shower yourself with patience and loving-kindness
- Appreciate the small things that make life beautiful
- Do things you love
- Acknowledge all feelings
- Anticipate frequent setbacks
- · Accept the death of your child
- Realize your life is forever changed
- Be with people who give you joy
- Keep going on
- Love to the max
- Repeat

#### **How Am I Different Now?**

Losing my child forced me to accept death as well as life, and to acknowledge that they always go hand in hand; two halves of a whole. We all think about the "life" half of the circle but choose not to dwell on or talk about the "death" half. The most important thing I've learned from Death is that although it has taken my child and part of my soul, it does not wound without giving back something in return. Yes, the price is exorbitantly high and not one I would have willingly paid had the choice been mine. But my loss has actually lifted me toward a better understanding of myself. I've learned so many things about life and my place in it since Max has been gone. Taking what I've learned from my child's death and applying that wisdom to my daily living is powerful. A salve of sorts.

While I've experienced the obvious feelings of loss there are other more positive feelings I have come to know as a PDC: courage, empathy, trust, the power of silence, vulnerability, grace, perseverance, thankfulness, compassion, spirituality, community, resilience, strength and hope. Mostly, I've learned about love. Loving to the max.

Suffering is caused by wanting life to be different than it is. All life is temporary yet we are designed to want to hold on. Keep things settled. When I began to accept that "things go away" I began to be able to see how I was trying to control the uncontrollable. One of the best things I did for myself was to release my expectations and make the most of my current situation. I urge all PDC to try and do this. Live more in the present. Don't get stuck in the past wondering "What if?" Or in the future. Children are a big part of our future and you've lost a huge part of yours. *Get used to your life now – just as it is – and live in the present.* If you are able to make this your mantra, miracles can happen.

Max's death gave me a second chance at living my life. When a child dies you're forced to reassess your picture of the world and how you fit in it. When we lose a child our brain goes blank and the world is on mute. For a time we, too, are dead inside. Our "life slate" is wiped clean. As our senses start to return in the aftermath of our loss we feel the need to reacquaint ourselves with things we had almost forgotten, old and important things we had been too busy to try and understand before. Insignificant things are now recognized as unimportant. We take time to better know certain more important things. Our broken pieces— the glass shards of our soul—come together in new ways.

I hope I've learned to listen more now. To lean in as the other person is speaking with a willingness to be changed by what I hear. I'd share my thoughts only if asked. In recollecting what it was like as I first stood on the edge of the abyss so alone and

sad I'm so very grateful for how far I've come since the early, dark years. And I will never again take anything for granted.

In working through my grief I've come to understand that the relationship I had with Max can continue, but I have to be open to experiencing it in new ways. When I see an eagle soaring in the cerulean sky I feel connected to Max's strength. When I spot a hummingbird hovering above a flower I feel Max's energy, speed, and joy. Whenever I am around water I recall how my son loved nothing better than a summer day spent sailing, swimming, eating and having fun with friends. As I hear Kermit the frog singing the song Rainbow Connection or the Terminator saying, "I'll be back" I recall Max's remarkable gift of mimicry. When I sing a song my soul flies high into the sky and joins my son, my "Little Prince", in his celestial home on a smiling star. Are these memories enough for me now? Do they allow me to remember my son and support my love for him? Yes. Because I've chosen to accept what I have and not yearn for what I do not.

I look back at the full ferocity of grief after Max's death as if someone other than myself went though it. I remember it, but it's as if it happened to me while I was dreaming while walking in a fog. Eight years into life without my son, I know exactly where the abyss of grief is. Over there. I can see the edge and still go there though I don't do so as often these days. It has become a part of my personal geography and I will always know how to find my way back to it.

The difference between today and the earlier years is that now I can choose to back away from the edge of the abyss when I've decided I've been rooted there too long. Move toward something else. I can also return when necessary and peer into the blackness letting my tears blind. Feeling the hole in my

heart. The ache. While the abyss remains, where I am in relation to it is, and always will be, my choice.

I'm not sure exactly how or at what point in time I came to believe I could continue *going on* without my son. Rather than being one single thing it was probably a myriad of feelings and events combined with the passage of time that helped me get to the peaceful place that is now my life. I do know that my eventual "acceptance" of Max's death was crucial in allowing me to move forward. To continue going on with grace.

Are there still moments of renewed despair, confusion, regret and longing? Oh, yes. Tears flow freely on occasion. But mostly, I'm able to work through the pain and enjoy the simple gifts life provides. My missing Max is more a wistful longing accompanied with a tender love for his *being*. I carry him in my heart wherever I go. He's always with me and he will always be safe. I still think about my son every day, but it's usually more comforting than painful now. He crosses my mind like a hummingbird seen out of the corner of my eye: amazingly fast, achingly lovely, then gone. Until the next memory or thought of him lands gently like a sweet melody on my heart.

I rest more peacefully now than I once did. I've learned to move forward as best I can. Some days I want to shout to the world that I had a son who is now a beautiful memory. Other days I like the anonymity of not being defined as "the mother of the boy who died." But most days I acknowledge the moments when I hear the birdsong, watch the sun's golden light dimple the water's surface and feel the soft breezes on my skin and the sand under my feet. I smile as I put my hand on my heart and appreciate the years I had with my boy. My Max. I'm reminded of how far I've come and how close I still am to being right back

on the edge of the abyss.

Ours is a lifelong task of working and re-working – experiencing and re-experiencing -- the loss of our child. The erratic nature of my progress still surprises me: two steps forward and one back. I'll "move through" a certain experience thinking I won't have to face it again – and WHAM. The rug is pulled out from under me as I find myself in a different situation experiencing the same feelings again. And again. This is all part of our healing process. This is the life of a PDC.

Although my son's life was far too short, it was not, not even for a moment, in vain. I think many who knew Max got a priceless gift from him. After his memorial service, I received an email from a woman I hardly knew sharing this story: She was driving home from work and two birds flew out of the grass on the side of the highway; one flew high and the other flew low – right into her headlight and was killed. She felt so terrible that she pulled the car over and did a little ceremony with a prayer and laid the bird down under a tree. She returned to her car and her life but couldn't get that bird off her mind. She felt responsible for its life and didn't want it to have died for nothing.

A week went by and still she was haunted. Finally, she realized that energy can neither be created nor destroyed and that the bird's energy was existent inside herself (initially as anxiety and guilt). She knew that she needed to give that energy a different expression so she made four pieces of art. She liked the art she made and gave it away to friends who placed it in their homes where it had a pleasing effect on their everyday life. Through her act of creation in memory of the bird she allowed its energy to fly out into the world in a peaceful, positive way.

Like the bird, bits of Max's energy flew out into the world as his gift and became part of those who were affected by him. It's comforting to think of life's energy as a force that doesn't disappear but re-distributes at death. All life contains the same force and our great responsibility while living is to contain this energy for a while and then relinquish it upon death so it can be re-absorbed by others as love. Such a precious gift.

I think of the story about the bird when I think of Max's life. Through the years, people have shared stories with me about how his life – and his untimely death – have changed their lives. Some were given a fresh awareness of how precious life is. Some said they would always live in the moment and make the most of things. Some said Max's death caused them to tell their parents and siblings how much they loved them. Many stopped taking things for granted. These things are small when compared to a life. But when multiplied hundreds and hundreds of times as people incorporated Max's energy into their own lives in big and small ways, the ripple effect his life created in the hands and bones and breath of all these beings is huge and everlasting.

Without invalidating the deep melancholy I initially experienced when Max first died I now choose to invite the miraculous immortality of joy and love into my life. I've come to know that in the end, there is no end. I find all the support I need to live my life to the fullest within myself. For it's when I go deep inside my soul -- past the regret and pain and numbness of loss; past all the hopes and dreams of what my son could be but wasn't; past all the things I wish I'd done differently and the wonderful times we had together -- that I discover the one thing at my core that will always be there. *Pure love*. It's this feeling that keeps me going on.

Would I have found this tender, spiritual, loving place within myself if my son were still living? I'm not sure. I do know that it was through understanding and accepting the darkness that I came to perceive the light. Every bright shimmer I feel today is defined *because of* the darkness that surrounds it. And if I understand this as my truth I am compelled to tell my story with hopes that other PDC might benefit from it.

It can hurt to love deeply. To be vulnerable. To trust another with our feelings. To be open to whatever comes our way. But if you want to find love, there is no other way to be. Love is stronger than anything else and it's all that really matters.

My love for Max will always exist and belong to me. Those who love Max carry a significant piece of him in their soul. It's his gift to them. And nothing can touch that love, alter it or take it away. Ever. I've come to believe that the only feeling stronger than loss is love. The ultimate *love to the max* that will never die and will continue to grow and live for eternity. It is the strongest feeling I have now – stronger even than my feelings of grief and loss.

I love my husband, daughter, family and friends. I appreciate my life and try to make a positive difference every day. And I love my son whom I always carry in my heart until he's in my arms once again. art.

Death is nothing at all. It does not count. I have only slipped away into the next room. Nothing has happened. Everything remains exactly as it was. I am I, and you are you, and the old life that we lived so fondly together is untouched, unchanged. Whatever we were to each other, that we are still. Call me by the old familiar name. Speak of me in the easy way which you always used. Put no difference into your tone. Wear no forced air of solemnity or sorrow. Laugh as we always laughed at the little jokes that we enjoyed together. Play, smile, think of me, pray for me. Let my name be ever the household word that it always was. Let it be spoken without an effort, without the ghost of a shadow upon it. Life means all that it ever meant. It is the same as it ever was. There is absolute and unbroken continuity. What is this death but a negligible accident? Why should I be out of mind because I am out of sight? I am but waiting for you, for an interval, somewhere very near, just round the corner. All is well.

A' well.

-by Henry Scott Holland, 1847 – 1918. Regis Professor of Divinity at the University of Oxford, England