The Lodestar

To tell you where I'm coming from – and maybe who I really am – I have to set off a little bomb:

I am the mother of a dead child.

Forgive the brutality of that, but there is no word in the English language for this condition. Children who survive dead parents are orphans. But what are parents of dead children?

The death of my eldest child, Jessica, is not the center of my life. Yet it is undeniably the lodestar that has helped me align the crucial losses and limits I've faced and assign them meaning and purpose. This, I now know, is the overriding task of survival.

As life-ordering experiences go, few are as shattering as the death of a child. You need a tight hold on the essentials of existence to know how to bury your child. And how to survive it.

Miraculously, I've survived.

Saying flat out that my daughter died is explosive because death that close tends to startle people. They tense up, they look away, they struggle to find a word, any word that can stand up to the verbal assault of that news. “Sorry, I'm so sorry.”

Sometimes they take a step back from me, as if to create distance between my tragedy and theirs. But here's the thing: Everybody knows the pain of loss and the struggle of limits, and everyone experiences them in their own way.

At first you are too stunned to do anything with “the tragedy,” whichever one you’re hit with. Not that it matters. They all come down to loss. And there is no comparing losses because your pain is yours alone. The reality of that has seared me, as you'll see. We are all suffering in some way, and we all have to figure out how to survive. It's not easy.

When my four children were little, struggling with the not-small issues children face (mean friends, scary tests), I would say, “It’s hard being you.” And while that statement sometimes took on a bit of snark when whining was involved (“My friends don't have to be home so early. . . .” “No one else has to do chores. . . .”), in general it was empathy. Life *is* hard.

Of course, those early losses and limits were just the beginning. My youngest, Caitlin, was fifteen years old when Jess died, and she asked me: “Is this the worst thing that will ever happen to me? Is this the last bad thing?”

The possible answers ricocheted in my brain as I tried to determine the best one, the right one. I wanted to soothe her and say, “Yes, the worst is over. The rest of your life may be tough, but not this tough.”

But another part of me didn’t want to accept that my child had to endure such a crushing loss at all.

Ultimately, I recoiled at the thought of denying her pain, which brought me to what I think was the right answer: “You definitely will be happy again – I imagine very happy – but a happy life is destined to include suffering and heartbreak. It just is.”

There’s simply no getting around the fact that we pay dearly for our deepest joy, intimacy with others. When someone you've risked loving dies, a part of you dies with them. That's the bargain you strike when you boldly choose to love.

But when the severance involves your child, the loss – the amputation, if you will – is not surgical in any way. When you lose a child, that child is ripped from you. There are thousands, perhaps millions, of frayed edges where the child was torn out.

Yet there are myriad other losses and limits, and they are inevitable, despite our frantic efforts to avoid them. You hear a lot about unlimited possibilities, yet our options *are* limited, by everything from genes to circumstance.

But here’s the inscrutable part: To succeed you need to *embrace* the limits that confront you, including all the losses that make you who you are – the slop of overshooting, the brokenness of falling short, the desolation of despair.

Surviving losses and living with the limits thrown at you is so central to making it through life intact that I’m amazed families spend so little time addressing the inevitable encounters with pain that are essential to a life. Perhaps the same optimism that draws us to produce children also permits us to think they can somehow escape unscathed.

But that is a disservice to children. No one is ever spared.

The truth of that makes me want to extend comforting arms into my children's suffering. Not to pull them out, but to help them proceed with gratitude and hope.

Limits, the loss of things – conditions, people we love – don't so much define our lives as empower us to shape them. I want my children to have that power. Harnessing it comes down to seeing the value of the good and the bad in our lives and assigning proportion to each. One helps us see the other, the good and bad are inextricably linked.

As Jessica's mom, I learned about that linkage amid all the challenges and joys she brought us as a person – our person – with developmental, cognitive and neurological differences. Families of people with disabilities know this split-screen life well. Among all the scream-out-loud moments, there are important lessons to be learned – not only for us but for the larger world we are helping create.

The families of people with disabilities are so important. All of us grow and recede in relation to those we know most intimately and they, in turn, reflect back to us what we are. I suppose that's why the members of families can both love and hate each other with such passion – we see ourselves in each other.

By sheer proximity over time, family members bear witness to one another's lives – the mundane and the major, the quotidian and extraordinary. And what we see provides us with meaning and agency to help change the world. What we experience is important.

When Jess drowned – twenty years later, the specifics still cut me – I struggled mightily to make sense of what had happened to me, to my family. I needed someplace to put The Hole, the excruciating burden of negative space – the grief. I wanted to keep it within eyeshot, but not so close as to risk falling in, consumed by grief. It was tricky. Dangerous, even.

Standing wide-eyed in the blaring light of personal catastrophe, I learned that losing a relationship – losing love – is the cruelest burden we bear. No wonder estrangement and death are our deepest fears.

The first challenge was mere survival. One breath at a time, one night that led to a full day that led to another night and yet another day. Day Two. Somehow we, The Grieving, were still here. I imagined that it would take some specific action to continue, but it didn't. Time just washed over and past me. I was no longer the actor but the acted upon.

The first 133 days after Jess's death were treacherous. I made myself cry on each one of them. Every morning. For more than four months.

Then I started to write. I imagined that by attaching words to my grief I could give it shape and volume and mass, and that by creating it in time and space I could make it transportable – make it gone.

Where, I'm not sure.

Away, definitely, I wanted it away.

But strangely I also wanted it here forever. I wanted a record of my struggle with it. Like Jacob who wrestled with God and forever limped. I wanted my children to know that I endured grief at its most devastating. It diminished me to just a heartbeat and a whisper of breath on some days. On others

I tried to defy it, angrily beating my fists against . . . what? Fate? Happenstance? I was doing an amazing job being Jessica's mom, so why was that work taken away from me?

Ultimately, I realized my grief needed to declare itself: This happened, this tragedy happened *to me.* The telling was important because it allowed my isolated story to resonate as part of the shared human experience – bigger than me, bigger than you, bigger than everyone who stands to be consumed by grief.

After survival, learning how to proceed was my greatest challenge. I had to force myself to see beyond my grief, to the secrets emerging from my battle to survive. I had to break the secrets free from the struggle, so I could put them to work in my life.

I didn't want my grief to endure as tragedy, as a sad, unending story. And I definitely didn't want my children to see the loss of their sister, and their experience of that great loss, as tragedy. Tragedy requires an unhappy ending.

But Jessica's death was really just the beginning, the foundation for what I wanted to tell my children about learning to live with loss and limits. It's important because it's the key to a happy life.

Mining my own experience with loss and limits was grueling. And self-revealing. I initially tried to tell this story without acknowledging the lasting limitation of my own life: my stutter. I thought I was avoiding self-absorption, but, in fact, I was being less than brave.

I discovered that all my life I've feared being seen as “damaged,” not quite right. So, I've defiantly cast myself as not only undamaged but the one who can walk through fire unscathed. It is much, much harder for me to say that I have regularly been burned. Hence my reluctance to acknowledge my battle with stuttering.

We all have to wrestle with our own limits, in a solitary battle we wage in our heads: How do I feel about this person who is me? We alone determine the impact of the events that comprise our lives.

Human beings have miraculous power to do this. We have survived for millions of years, not because we are smart or strong or even lucky, but because we are resilient. When bad things happen to us, we don't crumble, we adapt. We can even thrive. We have enormous capacity for happiness. In that, we truly *are* amazing.

What’s extraordinary is when people don’t survive. And there is some of that in this story. No denying, I’m the oldest of three siblings and the only one still here. My sister's and brother's stories showed me what a precarious balancing act it is to carry our experiences across the tightrope that is our life. Not everyone finds the equilibrium, the context that allows them to survive what happens to them.

Somehow, I did.

Essential truths can arise from the telling of our individual stories of adapting to loss and limits – the relentless but never mundane struggle to live as well as we can. This is mine.