THE CARE COURIER



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WILL I EVER GET OVER THE LOSS OF A CHILD?

Lingering grief is like a beautiful fragrance, or a stinging stench, memories will linger for years. The intensity is determined by allowing yourself to express your feelings now in order to heal. Grief may be triggered by a song, an object, or flavor, and that is normal. Even sixty years from now. It's a bittersweet grief that has healed over time and tenderly reminds us of the deep love that endures and is treasured.

In the wake of several infant deaths, we at Locke did our best to care for their mothers and fathers: "What do you write to someone who lost a baby?" I scribbled in my journal, hoping for an answer. Suddenly I was writing a letter to the parents:

Dear Ones, there is nothing I can write. Nothing I can say to you. Except to tell you I am here, and I care. And I am so sorry. You are grieving the loss of a child, and I am at a loss for words. Perhaps that is a blessing, for so many say trite phrases meaning well, but they shoot straight into your heart.

I talked to my mother last week. She is now 91. And I asked her about Martin, the child she carried over sixty years ago with no complications. The son she delivered after full term. The son she held only once. The son who died the next day. Martin Lindley. His name blends the names Austin and Margaret Lindley, his parents.

I was only a child myself, five years old. My sister Teri was three. But I can vividly remember Mom returning from the hospital with empty arms. I can remember her crying. I can remember nothing of my father's grief as he poured himself into teaching and tutoring at the high

school. I cannot know or understand all they felt for I am very sure they hid most of it from us.

Many years later, the whole family gathered for her birthday. The younger sisters never "knew" Martin. They never patted Mommy's tummy, anticipating their little brother. They never stood at the bedroom door, helplessly watching her sob. They never listened to Mom's resignation as she tried to comfort herself and us with the belief that Martin was in heaven, and one day she would see him again. They only knew our family without him. But for Mom, Martin was never far away. The memory of him lingered. It still does six decades later.

Mom enjoyed her party, surrounded by her daughters and grandchildren who plied her with questions about her life as a social worker, teacher, massage therapist and world traveler. She entertained us with inspiring and funny stories to the delight of all. She lived through many sorrows, mistakes, and hard things in life along the way. None of her life is suppressed or repressed — but she moved forward through several losses one step at a time, all those decades. She had to.

She had to. She had a home, a husband, children. There were meals to cook, a house to clean, gardens to tend, cakes and cookies to bake, clothes to sew, weight to lose, hands to pray, books to read, daughters to encourage,

friends and family to laugh and cry with. A life to live.

"Do you ever think of Martin?" I asked during a recent phone call.



"Every day," Mom answered. Mom now lives in Assisted Living. She's survived miscarriages, surgeries, and mini strokes. She fights cancer. The chemo treatments take a toll, but she's determined and uses her walker. The days seem long.

She anticipates Heaven. Not a death wish, but a clear anticipation of her ultimate destination. Perhaps Jesus will be there with the promised "Well done good and faithful servant." Mom will relish that. But to tell you the truth? I think she'll he looking over his shoulder, sorting through the loved ones gathered to welcome her home. Then she'll find my dad. A smile will pass between them as she sees him holding the hand of their son, her Martin.

And Jesus? He will be forgotten (sorry Jesus) as she runs over to Martin, bear hugs him, delighted in knowing they will have eternity to laugh, sing, talk, listen, and love.

He will know her. She will know him. A son. A mother. Reunited.

You are moving forward with your grief. Talk to trusted friends, even years later. Pull out the pictures and videos; tell their story, your story. Today may you treasure the lingering memories of your loved one, young or old, with the hope of one day being reunited. If you are still struggling, I am glad to help you on your journey. Please feel free to call me at 319-233-6138.

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INSPIRATIONS

"Only people who are capable of loving strongly can also suffer great sorrow, but this same necessity of loving serves to counteract their grief and heals them." — Leo Tolstoy

"Deep grief sometimes is almost like a specific location, a coordinate on a map of time. When you are standing in that forest of sorrow, you cannot imagine that you could ever find your way to a better place. But if someone can assure you that they themselves have stood in that same place, and now have moved on, sometimes this will bring hope." — Elizabeth Gilbert

"How lucky I am to have something that makes saying goodbye so hard." — Winnie the Pooh

"What we once enjoyed and deeply loved we can never lose, for all that we love deeply becomes a part of us." — **Helen Keller**

"Grief can be the garden of compassion. If you keep your heart open through everything, your pain can become your greatest ally in your life's search for love and wisdom." — Rumi

"The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you'll learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again, but you will never be the same. Nor should you be the same nor would you want to." — Elisabeth Kubler-Ross

WHAT IS ANTICIPATORY GRIEF?

Grief masks and manifests itself in many life situations, from a life-threatening diagnosis, the loss of a relationship, downsizing, or the kids going off to college. Long term caregivers, trying to give years of love and care, may not realize they are grieving even while their loved one is still alive.

Vivian stroked a strand of silver hair from her face. Her eyes glistened as she looked around the table at her Grief Group. "I can't get anything done. Sometimes all I do is sit on the couch, staring out the window. I feel tired and unmotivated. I've always been able to take care of things even as George's Alzheimer's got worse and worse," Vivian finally admitted, "What is wrong with me?" she asked, turning to the group leader, Margaret.

"You're grieving his death, but you've been

grieving for years," Margaret said kindly.

Vivian's brow furrowed, confused. "What do you mean? Are you telling me that even when George was

alive, I was grieving?"

"Yes, we call it Anticipatory Grief. It's a very deep sorrow that comes with a loss or an impending death. It can begin with a diagnosis of cancer, losing a part of your body, a divorce, a terminated pregnancy, or downsizing as you move into senior living care. It can come as one faces their own death, even watching a beloved dog or cat age. The grief comes before the loss, that's why we often don't recognize it as grief.

"As a Long-Term Caregiver, you have lived with a grief that was long and progressive. You not only anticipated the death, but with the Alzheimer's, you've experienced the loss of your relationship, your way of life. Would you like to tell us about it?" Margaret and the group waited, letting the ever-optimistic Vivian finally gather the courage to tell her truth.

"It was scary, and I didn't want to tell anyone about George getting up so often during the night with hallucinations. I didn't know my husband anymore. The kids tried to get me to put him in a nursing home, but he's my husband and I just had to try to take care of him." Vivian paused as Ted handed her a tissue.

"Is that how you both moved off the farm and into Senior Living?" Ted asked softly.

"Yes. The kids were so worried. Not just about George, but me too. We sat down one night and shared our feelings and fears. They helped me see it was time to face reality and make plans." Vivian looked around the table. "That's a lot different from the rest of our group who faced sudden deaths. I never thought that I was grieving. More frustration and anger in the midst of love."

What Could I Feel during Anticipatory Grief?

Vivian fiddled with the tissue, blotting the tears as they dropped onto the table.

"I married George when he got back from the war. I was seventeen. He was such a good man, so kind and gentle. But as the disease progressed, he turned into a different person. I was scared and powerless. Sometimes he knew me, sometimes not. He started getting mean and seeing things. I was losing control. Frankly I tried to be loving and kind, but it was hard. I began to resent him, to get angry. I pushed it down. I felt guilty. He's the one dying. He's the one in pain."

She began to sob, but continued, choking on the words she had held in for so long.

"I vowed 'for better for worse, in sickness and in health. It was my turn to care for him. But sometimes I felt like I was the one dying. The burden was so heavy. I missed my husband. I missed our conversations. Pretty soon I wasn't his wife, just his nurse, finally a stranger. My friends tried to understand, but for some it was too uncomfortable, so they stopped coming by. It's a very lonely time.

"You don't think things will go this way. You believe you'll grow old together. We still had a lot of living to do!" She looked at her friends. "Ted, I'm so

sorry your wife died of Covid."

Ted nodded. "We all expect to be holding hands as we walk into our twilight years or being with each other in death and saying goodbye. Covid stole that from us, I couldn't even be with Tina in the hospital." He paused and patted her shoulder. "But yours was a long progressive loss. This is helping me understand what so many people experience. I have been so ignorant. I want to be kinder. Vivian how can I help others facing this?"

Vivian wiped away her tears and breathed deeply. "It simply helped to be loved, and accepted, not judged. We all had to learn not to challenge the hallucinations. My neighbor put in alarms in case George left the house at night. Mary came and took me out, while her husband stayed with George. That was such a gift, since I could never leave to get my hair done or do my gardening. My kids started taking turns, asking George to spend the day. That gave him time with grandkids, and time for me to rest and return to normal life."

"You returned to normal life?" Margaret asked.

Vivian forced a smile. "Ok. Not really. What is normal? It gave me a chance to catch my breath, to take care of everyday things without looking over my shoulder worried where he was. But looking back I realize I needed to let him go sooner. It really was too much for me. Still, I feel so guilty about it anyway."

What Are the Benefits of Anticipatory Grief?

"Guilt and regret can play a huge role in all forms

of grief," said Margaret. "It's important that we don't buy into the shame and beat ourselves up. But there are some benefits if we use the time well. Vivian already told us how her family planned ahead. Ted would you be willing to share about what you and Tina did when you couldn't see her at the hospital?"

Ted breathed deeply. "As soon as Tina got Covid, we both started anticipating she could die. As a nurse, Tina "knew" the time was short. She still was able to talk on the phone. It gave us a chance to forgive and resolve some things in our marriage. She handled all our financial matters. She coached me on where to find the Emergency file she had created with all the accounts, codes, and documents. We prayed she would survive but we prepared for her death."

"I'm so glad you and Tina were pro-active with the time you had to end your marriage well by not only dealing with your relationship, but also financial and home issues. Many avoid this, but frankly it's a chance to 'end well." Anticipatory grief is more than grieving early, it's multi-dimensional. It's so important to deal with reality rather than avoid the pain by ignoring the details that must be addressed," Margaret said.

Ted leaned back with resignation. "Tina was the breadwinner. It was difficult to start thinking about the future without her, not just the love, but paying the bills and raising the kids. It's really awful right now. I not only lost my wife, but my lifestyle. I'm a dad and mom now too. Thank God the kids at least got to say good-bye over the phone. Some people didn't get that chance." Ted paused, "Margaret, the grief morphed. What I felt then is different from what I feel now."

Anticipatory Grief vs. Grief After Death: What Are the Differences?

"Both forms of grief share the same emotions, but with Anticipatory Grief it's more of a conceptual rollercoaster of thoughts and fears anticipating the loss. If you are a long-term caregiver, you may feel increasing concern for the person dying. Some imagine what the death will be like, or what their life will be like once the other has gone. One moment things can seem normal, other days are consumed with either hope that something will change, or fear of what you expect might happen next.

"For some, it is much more stressful to go through the time before the death, than after the death. Some hold their breath, not allowing themselves to grieve until after the loss. Others may even deny reality. Many survivors feel relieved that 'it's finally over,' then feel guilt that there were times they wished "it were over." It is okay to desire the pain and suffering for themselves or their loved one to end. If you are feeling shame or blame, forgive yourself. You did everything you could, and assuredly with much loved," Margaret comforted them.

What Are the Stages of Anticipatory Grief?

Continuing, she added: Dr. Elisabeth Kubler-Ross identified the five stages of death when a person is dying: denial, anger, bargaining, depression, and acceptance.

According to Dr. Lynne Eldridge, lung cancer physician and author of <u>Avoiding Cancer One Day at a Time</u>, the stages of anticipatory grief differ if you are the caregiver. She identifies these stages in her article at https://www.verywellhealth.com.

Acceptance: Coming to terms that the loved one's death is inevitable, the process of which may include sadness, anger, denial, and depression

Reflection: Coming to terms with feelings about the dying person, including regret,

guilt, remorse, or anger

Rehearsing the death: Anticipating your feelings and actions during and immediately after the death

Imaging the future: Providing yourself a roadmap through the bereavement process



How to Cope with Anticipatory Grief?

"Just like every form of grief, you must let yourself mourn. Mourning is externalizing the grief, "letting it out." Dr. Alan Wolfelt in his book <u>Understanding Your Grief: Ten Touchstones</u> emphasizes that we must "feel to heal." Talking to a friend, going to a counselor, joining a grief group always helps. Preparing for the loss or death is most important, be that spiritually, emotionally, physically, or financially. Making practical plans, deciding together on lifestyle changes, or exploring ideas at a funeral home, or meeting with a banker or trusted financial adviser will relieve you of many fears.

"As Christopher Reed, who after playing the role of Superman and now a paraplegic says: Once you choose hope, everything is possible. Never lose hope no matter what. Hope is powerful," Margaret concluded. "Let's take a break, Vivian, we are so glad you finally opened up." She grinned. "And I see, once again you made one of your blue-ribbon pies."

Vivian finally smiled, "Well, at least I got something done this week! Dig in!" The group took a break, offering hugs and words of encouragement.

Decide not only to survive, but to live. You must take care of yourself. Reach out if you feel isolated. Get outside whenever possible. Humor heals; watch comedies or whatever makes you laugh. Eat well. Avoid addictive behaviors and toxic people. Take walks. Pursue favorite hobbies. Be honest with yourself and others. Remember, that if a loved one is dying, share favorite memories, for those will never die.

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ADMINISTRATION

My late husband created an IN CASE OF EMERGENCY (ICE) file after several close calls in the ICU. He organized everything I would need in the event of his death, all in one place. Upon your death, your loved ones will be in shock and grieving, while taking care of enormous details. Through their tears they will thank you.

Create a file box, drawer, a notebook with pockets, or expandable file. Gather labels, page protectors, files, large envelopes, and permanent marker to print legibly.

- Will, notarized
- Living Will, notarized
- Medical Power of Attorney, notarized
- Financial Power of Attorney, notarized
- Accounts and Passwords (always update!)
- Friends & Family contact information
- Funeral/Celebration of Life instructions
- Funeral Preplanning & Contact information
- All deeds, titles and registrations
- Draft of Obituary
- Marriage Certificate
- Veterans' Papers
- Divorce papers
- Bank Accounts beneficiaries
- Life Insurance Policies beneficiaries
- Retirement Programs beneficiaries
- Investment Accounts beneficiaries
- Copy of Last Year's Taxes
- Car titles & Insurance
- Letters to Survivors: Love, Forgiveness, Blessing



What nobody tells you:

Upon death, KEEP CELL PHONES AND EMAIL ACCOUNTS OPEN.

Companies often send verification codes to the deceased persons phone when you are desperately trying to contact them through automated systems.

If you can't get through to a person, try hitting the #### or 0000 key several times.



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JOIN US EVERY THURSDAY!



Grief Support Daytime Meetings

TIME: 1:00—2:30 p.m.
LOCATION:

Cabin Coffee, 2040 Kimball, Waterloo

Grief Support Evening

Meetings

TIME: 5:00-6:30 p.m. **LOCATION:**

Locke at Tower Park, 4140 Kimball, Waterloo

DATES:

February 1, 8, 15, 22, 29

March 7, 14, 21, 28

April 4, 11, 18, 25

Please feel free to bring a friend

All groups are <u>free</u> and open to the public! Call with questions at 319-233-6138.

WEATHER ALERT: If schools are closed due to weather, the meeting is canceled.

Want to be on our mailing list? Call and we'll add you to our quarterly newsletter list.

