

The
Longest
Goodbye

Endorsements

“LOSING A PARENT IS ONE of life’s most difficult moments and, in some cases, a difficult season. Shelly’s heartwarming, poignant, personal account of her decade-long journey of saying goodbye to her mom who suffers from memory loss will be a source of comfort and hope to anyone going through a similar experience.”

Carey Nieuwhof

Bestselling Author, Speaker, and Host of the *Carey Nieuwhof Leadership* Podcast

“IN *THE LONGEST GOODBYE, SHELLY* gives us hope and help to navigate when a loved one faces memory loss. Shelly shares her decade-long journey watching her mother decline with Alzheimer’s disease. Through heartfelt stories and reflections, she gives her readers a glimpse into the pain of seeing a loved one slowly fade away while at the same time looking for hope-filled moments along the way. Shelly expresses how joy and pain can co-exist and where to look when everything feels lost. And most of all, her experience shows how the bonds of family and unconditional love carried her through. This book isn’t about the clinical part of the disease; it’s about the heart and how to hold on through all the seasons of memory loss.”

Kevin Scott

Author, Leadership Expert, and Co-founder of ADDO

“IT’S MUCH EASIER TO WRITE fiction than to share a hard, human story of love and loss for others to read. Shelly has brilliantly authored pages that share the hard and the good of loving someone fiercely, while losing them slowly to Alzheimer’s. Shelly is both honest and honoring with her words as she draws the reader into the journey of the one thing she feared most—her mother’s diagnosis and slow decline due to Alzheimer’s. Shelly’s words paint

a stunning picture of a brave and tender response to human suffering. Be moved in the reading of this beautiful remembrance.”

Cathie Ostapchuk

Author of *Brave Women, Bold Moves*

Co-Founder and Lead Catalyst for Gather Women

Host of *The Strong Way* Podcast

“IN *THE LONGEST GOODBYE*, SHELLY invites her readers into the journey of her mother’s battle with Alzheimer’s disease. From the strong bonds of their special mother and daughter friendship to becoming a stranger to the mother who cannot remember, Shelly writes with the honesty and insight of a daughter processing the frozen grief of Alzheimer’s and the long thawing of emotion, awaiting death’s second chill. If you or someone you know is dealing with the pain of losing someone before they are gone, this book is a companion on your journey. Written as a friend who understands and with the wisdom of a faith holding on to hope, this book is for you.”

Matt Tapley

Lead Pastor, Lakemount Worship Centre

“SHELLY LEADS HER READERS THROUGH the stages of saying goodbye to someone who is still physically present as they live with dementia. Woven throughout the book are firsthand stories of how her family wrestled through the realization that life was going to look different and how God met them in the joy and in the pain. Shelly beautifully describes her deep assurance she is still known, seen, and loved by her mom. What a gift this journey will be to so many others as they navigate Alzheimer’s disease with their loved ones. Shelly’s words will be comforting, relatable, and hope-giving to others walking this same road.”

Melissa McEachern

Chief Operating and Content Officer at Crossroads Christian Communications

A FAMILY'S HOPE-FILLED
JOURNEY THROUGH ALZHEIMER'S

The
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Goodbye

SHELLY CALCAGNO



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The Longest Goodbye

A Family's Hope-Filled Journey Through Alzheimer's

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Mom,

I never wanted to write a book about losing you.

I didn't want to say a long goodbye.

But I'm grateful for all these moments and all your love.

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Foreword

I WASN'T PREPARED FOR HER to go. To have her sit right beside me yet be so far away. It's been the longest goodbye. And I keep asking this question—how do we love through the hardest of days? Through the pain and the loss? Listening to the slow ticking of the clock as we sit watching everything slip away? There's no easy answer to my questions, and I've come to realize that we do the best that we can. We look for glimmers of hope, reach for deep grace, and collect all the precious memories and moments into a big pile of legacy love. We treasure each goodbye like it's the most important moment we've ever had.

Because it is.

CHAPTER 1

Yellow Flowers

I REMEMBER WHEN I FIRST learned about Alzheimer's disease. My parents moved to Ontario when I was three years old, leaving their home and families back in Newfoundland. Because of the distance, we didn't see our grandparents and extended family often. But I remember all the times we visited; they are written into my heart as some of my favorite childhood memories. Running up my grandma's hill that overlooked the bay, her freshly-baked bread toasting on the stovetop, my beloved cousins who lived down the lane, the china jug and washbasin in the room where I slept with the cupboards in the wall, family jigs, and getting into trouble for picking all the strawberries from the garden with my cousin. Many memories, considering the distance between us all.

But the one trip that stands out in my mind as I think of those days is the visit after my grandfather was diagnosed with Alzheimer's. I remember being a little apprehensive as we prepared for our trip, being a young girl and not really understanding fully what he was going through and what to expect. But our mom assured us it would be okay. It just meant Poppy was forgetful, but we didn't need to be afraid, so we bravely went with open hearts to see her family again.

Most of the visit, he sat quietly, and he didn't really know we were there. He was always a gentle, sweet man, yet I wasn't sure how to act around him in this new stage. I remember my mom being sad and having conversations with her sisters, as they tried to figure things out and work on a plan to support my

grandma. I'm sure it was hard for my mom, living so far away and coming back to see her father in his declining state and not being part of the day-to-day care as his illness progressed.

I have one vivid memory when I think of that trip. After I became more comfortable and felt less fearful, I would often sit beside him—he in silence and me trying to be close and present. I remember I was wearing a blue sweatshirt and my black Adidas track pants in all my awkward, preteen glory. We sat quietly that day as I leaned up against him, across from the cuckoo clock in the room with the red carpet and all the family pictures and treasured dolls—in the house where my mom was raised. And out of nowhere, he said my name.

“Shelly.”

The joy that spread through me was instant. I remember running to my mom and grandma and saying, “He knows who I am.”

I wasn't forgotten, and that filled me with joy. In that moment, he was who I always knew him to be, and I was his granddaughter who had traveled far to visit. And he remembered me.

That was the last time I saw him, the last visit we made before he further declined. I remember when he died and how hard it was for my mom; yet in the middle of our grief, we never could have imagined what was still to come.

A few years later, my mom's brother was diagnosed with Alzheimer's—another gentle and beautiful soul. They had always been close throughout their lives. I remember him bringing me chocolate bars and playing classic Newfoundland songs during our visits. He loved music and had an instrument I'd never seen called a zitter, and I would sit and listen to him play it for hours. He brought life and light to each room he entered. I would feel so loved when I saw him, and I would get so excited when we would drive across the island and make the stop to see him and his family. Then, I learned he wasn't well. That was devastating for my mom; she loved him so much. She took his passing hard, especially after losing her father to the same disease. I can remember her sobbing, her heart broken at another loss.

But that wasn't the end.

Her oldest brother was diagnosed next—another one of my favorites with his big, loving personality and sparkling eyes. I would always be so thrilled to see him, too, when we would visit. I'd wait at my grandma's house in her little mudroom, almost holding my breath until he would burst through the door to see us shortly after we'd arrived. He'd laugh, give me a big hug, and call me the special nickname he had used for me since I was a little girl. The patriarch of the family. The brother they all looked up to. Unfortunately, Alzheimer's had become part of his story, too.

The last time I saw him—maybe a year before he passed away—he held my hand, and we walked together around the bay in the little Newfoundland town where he had lived his whole life. I can still feel his hand in mine. In many ways, his memory was going, but he knew every detail of everything we passed and told me all his stories. Those are precious memories stored in my heart forever.

When he passed away, my mom didn't get a chance to grieve him properly. I know she would have; she loved him dearly, too. But she couldn't remember him. Or me. Or anyone anymore. My sweet mom has Alzheimer's, too.

The fourth one in her family. It's enough to break your heart—the unfairness of it all that one family would have to bear such heartache. And now I sit beside her in the small room at my parent's house that has been her world for the last couple of years. Miles and miles away from her Newfoundland home and the longest goodbye journeys that happened in her absence. She missed the passing of her older brother, then her mother, and a thousand other moments and memories that happened in her presence that she never even knew.

I call it the longest goodbye—this losing of the one you love. Piece by piece. Stage by stage. Hour by hour. So slow, yet so fast that it all doesn't seem possible when you look back and realize that it's been almost ten years.

And now, she sits in silence on her chair, with pretty, rose-colored pillows surrounding her. I hold her hand; and I say her name; and I help her walk. I

stay so that my dad can go and breathe and have some space. I sit by someone I don't know anymore, but whom I've known forever. All my life is wrapped up in her, and she's here. But she's also gone. And she's still my mom.

Sometimes, I think back, and I wonder if she was aware of what was happening to her. She was a nurse. She must have noticed she was forgetting things. She knew it was a chance, given her family history. I remember the first time my brother wondered if something was wrong. We were at my parents' cottage, and it was spring. Dandelions were sprouting up across the lawn, and she was trying to talk about them. She couldn't remember what they were, so she called them yellow flowers, and my brother noticed. And he had a thought that maybe it was happening to her, too.

Yellow flowers. That's when life started to fall apart.

For me, it was the combination of a few things. My mom loved Christmas, and buying gifts for everyone was always one of her favorite things to do. Each year, we'd plan a Christmas shopping day. We'd have lunch at our favorite steak sandwich spot and then spend the afternoon together tackling her Christmas list. This was one of our special yearly traditions. The fall after yellow flowers, we set up our shopping day and met at the mall. It didn't take long for me to notice that things weren't right. I was helping her get gifts for my nephews, and she couldn't remember what she had already bought for them. We wandered around the toy section for an hour, and no matter how I tried to help, she just didn't know what she needed to get. Then, I noticed when she went to pay for something, she would hesitate and was unsure of the pin code for her bank card; I had to help her. Then, I saw her struggle to pull the correct money from her wallet. I had knots in my stomach and felt like I was going to be sick each time we were paying for something in a store. I knew deep down that something was wrong.

The biggest thing I remember happening that day was when she had no idea where she had parked her car. Not a clue. I had seen her arrive, so I

knew the general area, but we literally had to walk up and down all the rows pressing the key alarm trying to figure out where her car was. I was relieved when we finally found it but concerned as she left to drive home, hoping she knew the way and praying she would be okay on the roads.

It wasn't our usual Christmas shopping spree. After that day, I was full of continuous stress and worry. I knew what was happening, even if I couldn't say it out loud.

Then, I started to see it more. When she made my favorite coffee cake, it didn't turn out because she missed some ingredients. When she came to babysit my children, she wasn't sure where their school was. I had to unwrap Christmas gifts she had already wrapped because she didn't know what was inside. Then I had to read her cards to her after her seventieth birthday party. When she went to Florida, she bought me three of the same kind of my favorite perfume. And I noticed she would ask me the same question a couple times.

We had moved on from yellow flowers.

I was in denial for a long time. I couldn't talk about it; I didn't know how to bring it up with my dad. I was afraid to have a conversation with my brothers. My beloved aunt came to visit from Newfoundland, and I didn't even see her while she was here. I knew she would know that her sister was different, and I didn't know how to process what was happening with words.

I read the book *Feeding My Mother* by Jann Arden that year, in preparation for what was ahead. It's a beautiful book, filled with endearing stories and lovely recipes; and while I loved the words and sentiment, it further scared me and made me want to curl up and hide away. I read it again a couple years later, and it felt different. I could see things more clearly, but at the time, I had to put it away on the back of the bookshelf and forget the words I had read. I needed to pretend that wouldn't be my story or my mom's story. Even though I knew it would be.

Avoidance was easier on my heart—on all our hearts—for a long time. I feel a peace now that she didn't know what was happening, that God allowed

that grace to her, because the thought that she did know and didn't want to tell us or talk about it is just too much for me to bear. That's a hard path to navigate alone. But maybe the slowness of the longest goodbye for her was so gradual that she didn't know she was slipping away. That's what I choose to believe because that's what I saw, and that's what my heart needs. It was painful for us, but it was seamless for her.

And now we sit together. I put her feet up. I play her music, switching between comforting hymns from the Gaither Vocal Band to the sentimental Newfoundland music of Shanneyganock. We watch a million Hallmark movies together and all the *Little House on the Prairie* episodes that we loved when I was a little girl. Most of the time, her eyes are closed, but she's not asleep. I know she feels my presence. It's been months since she's said my name and looked at me like I'm her girl. But I know I am. I am hers, and she has always been mine. And nothing can take that away. Her memories may be gone; but mine will live on, and she will live on through them.

It's spring right now, as I write this chapter. And outside the window of my office, our front lawn is filled with yellow flowers. Every year—and likely forever when I see them—I'll think of the year when we first realized that our mom was beginning to slip away. It's ironic that those yellow flowers eventually turn white, and then they just wisp off in the wind. They slowly let go, and they fade away in a gentle farewell as they trickle across the sky.

Yellow flowers blowing in the wind. Saying goodbye.

Reflection:

When you or someone you love begins a journey of illness, it's normal to take time to process. Change is hard. Relationships are complicated. Grief is real.

Take the time you need to sort out your feelings and emotions. If you don't know what the path ahead looks like, it's okay. You will get there. Be patient with yourself in the process.