

## **Enjoy a sample of “When I’m Not Me Anymore”:**

My mom took her last breath at ninety-three years of age. Unfortunately, the real Eileen left us years before in the form of a lost train of thought here or a forgotten word there. We thought it was a natural by-product of ageing but, in retrospect, it was dementia taking hold.

Near the end, when she lost interest in most of the world around her, it was hard remembering that she wasn’t always like that. She was once a toddler learning to walk; a vibrant young woman falling in love; and a strong, quiet force alongside my father in their sixty years of ministry. But when our conversations became shallow and bizarre and lacked connection, the painful realization that something had changed took hold. I wondered if there was anything she would have wanted to say to me, knowing that our time left together would be so short. Perhaps there was a secret she once thought she couldn’t tell, but I never found out because her jumbled thoughts were a mixture of facts and fiction by then.

It was a privilege for my sisters and me as we helped Dad keep Mom at home and care for her. Being a family means living each day without keeping score of who did what for whom; but that last stage of mom’s life allowed x us to give back to her, in a tangible way, the love and care that she gave us over a lifetime. Our lack of understanding about dementia meant we had to learn as we went along, and sometimes going through the same scenario again and again was the only way to discover the best course of action. This created frustration and aggravation before the reality and sadness of what was happening sunk in. The game for Mom had changed, and we girls were still using the old rules to make sense of things— which didn’t get us very far.

I don’t claim to be any kind of expert on dementia or Alzheimer’s disease, but I have seen firsthand the effects they had on my mom and our family. My goal for this book is to share thoughts from my heart to kindred spirits on a similar journey and to prepare my daughters for what may come. The fact that Mom had dementia doesn’t mean I will get it, but I’ve often thought about what my daughters may have to deal with if I go down the same path. What would I want them to know? If I could have another lucid conversation with my mom, what might she want to tell me, and what would I want to hear from her? With this in mind, this book is first and foremost for my daughters. Like many parents, I often wished children came with instruction manuals, but I also felt the same way when adjusting to the changes in Mom. I hope that down the road my girls will recognize the behaviors mentioned here and use that understanding to help them cope. This collection of thoughts and instruction is a love letter to

my daughters to express myself completely so that, if the day comes when words elude me, they will find my heart in these pages.

Even though everyone's journey is different, there is much about dementia that can be predicted and mitigated. With the staggering increase of dementia and Alzheimer's disease among baby boomers, I realized that I am not alone in this journey and that my experience could perhaps help others. For this reason, I am sharing these very personal musings with you in addition to my daughters. We will talk about the initial frustration of our loved one forgetting something we just told them or stopping midstory to say, "Now why was I telling you that?" Time loses meaning when our loved one has nowhere to go and all day to get there, forgetting that we still have commitments, appointments, and things to do. We experience a sense of time travel when where we are becomes when we are as their memories from the past get jumbled up in their happenings of today. We will look at how their language changes bringing about surprising and sometimes disturbing conversations as the filters from the past wane and we see them in their uncut glory.

Until there is a cure for dementia or Alzheimer's disease, there are ways to soften their effects on us; that's why you will find some tips and encouragement here as well. In the appendix, I offer journaling questions to encourage parents and their children to capture thoughts and stories before they are lost forever. My hope is that we can be remembered, even when we ourselves forget.