

CHAPTER 9:

DON'T LET FEAR OF THE FUTURE INTRUDE ON LOVE IN THE PRESENT

When caring for an ill parent, it's so easy to become wrapped up in the million minor details that come with your role. Are the finances handled? Is your other parent doing okay? Is your spouse doing all right with your frequent absences? How are your children doing with all this? So many plates spinning in the air, all of them filled to the brim with extra servings of fear and guilt. Guilt over what you have done and fear over what is to come. It can be devastating on the psyche.

The trauma on my entire family surrounding my father's illness and passing was profound. It touched every one of us. Emotionally of course, but financially as well. To pay for the care my dad needed so desperately, we had to sell off pieces of the life he had built piece by piece. First, we sold my parents' Florida condo, where we'd all had so many happy summers and Dad had so generously (foolishly) given me my first taste of true independence. Even worse, we had to sell my parents' house that they had built and we had all enjoyed for so many years together.

The memories of our Sunday lunches and the cookouts we enjoyed on the beautiful deck were filled with laughter. This wasn't just a house, a commodity. It was our home and where our hearts lay. But no matter where we lived, those memories were just that... memories. Though I can still summon the smell of Mom's famous steak tenderloin and Dad's grill, those days are gone.

In the wake of my father's passing, the happiness he carried with him wherever he went seemingly evaporated. Left behind were the lawsuits against the facility that had so grievously wronged him, the loans my Dad took out without understanding the impact, and my grief-stricken mother who was now being asked to manage the crushing debts of my father's estate.

The sharp decline of my mother's health was another punch in the gut, though not at all unexpected. A lifetime spent with one man, her high school sweetheart, only to have to watch him change into someone else, suffering terribly along the way.

“I miss him so much,” she said to me. “But in a way, it’s a relief. He was so confused and so damned scared and angry. Just knowing he’s at peace now is the only thing that lets me sleep at night.”

I could only nod when she said it, not even needing to agree. Because in that moment, we both remembered what Dad had taught us and shown us through his own example throughout his life. How when he’d laid his own mother to rest, he’d encouraged us all to remember her laugh, her voice, and be happy with the times we spent with her.

Even when he knew Grandma didn’t have long left, he didn’t turn away from her to tend to his own grief. He leaned into the time he had left with her. Through all he did, [DADNAME] showed us all how to live our lives, taking extra care to impress his most important lessons on us throughout our lives:

1. Don’t let anyone decide who you’ll be: People try to make decisions for how you live your life based on shallow things, like your income, your gender, or even your hair color. Dad never let that happen in his life, and he taught us never to either.
2. Let life be uncivilized sometimes: You’ll have plenty of time to sit in a rocking chair and knit. Go ride a motorcycle while you can. And if you’re really brave, put your barefoot daughter on the back.
3. Quick thinking can save your hide: Boldness can only get you so far. Sharpen your intellect so you can see threats before they come over the horizon.
4. Never let the big stuff slide: Dueling with pistols at dawn has been illegal for some time. But that doesn’t mean you should suffer an affront to yourself or your family.
5. What is best isn’t always what you want: Look at the big picture, rather than the small list of things you want and hope for.
6. Care for your family, always: This is non-negotiable
7. You only know your strength when its tested: We all have an idea of what we’d do in a hypothetical situation. But when reality comes for you, we find out who we really are.
8. Listen to your gut: Sometimes it’s wrong. But most of the time, it isn’t.
9. Don’t let fear of the future intrude on love in the present: Don’t be so crippled by the eventuality of death that you can’t enjoy life.

Tia Walker said, “To care for those who once cared for us is one of the highest honors,” and I couldn’t agree more. The strength we all found to care for the man who gave us all so much, right up to the end, only came because he had planted the seeds in us. Our bravery, our wildness, our absolute commitment to doing right by our family—all of it came from our dad. And I can only hope as he looks down on us, clear-headed at last, that we have done him proud.

My hope for this brief memoir of [DADNAME] and his battle with dementia is for others to be able to work through their own grief when faced with an ill parent. It can be so easy to focus on the minutia, the administrative tasks of life, and miss out on actually spending time with your parent. Yes, the bills need to be paid and the dog needs to be walked. And all of those things are helping your sick parent. But what helps the most can sometimes feel like a waste of time...to sit beside them and just be.

I will forever cherish those days my sister and I spent with Dad, just holding his hand and playing oldies, remembering happier times and cherishing every breath we could hear him take. There’s a tendency in modern life to try to make everything positive, to snap that perfect social-media-friendly image of life. The problem with that is that when the time comes to stare down something scary, so many people flee from it. And maybe I would have too...if not for my dad’s lessons that prepared me for it.

Maybe others didn’t get the benefit of that life-long instruction. It is my wish to give it to you now, in abbreviated fashion of course. I survived balancing kids and a husband and an ailing mother, all while helping my father in every way I could. And so can you. It pushed us all to our limits, with many of us (me included) developing health issues of our own in the wake of the stress.

Just like when I was a child and was sick with the flu, my parents cared for me. They sat in the room with me, putting a cool cloth on my head, and encouraged me to drink ginger ale, all while reading me stories. They did this knowing full well one or both of them would catch my flu and would have to take their turn laid up in bed. This is what parents do, all day, every day, never asking for help or even thanks. Our thanks to them should be (must be) to care for them in their later years, to help them

remember who they were, even if only for brief moments, and to let them know unceasingly that they are loved. They deserve nothing less.

Anticipatory grief in particular can be challenging, that is, grieving for them while they are still physically here. It can descend upon you so unexpectedly, turning your attention from your parent, where it belongs, to your own pain. With time so short, I would encourage everyone to do battle with this impulse. There will be time—so much time—to grieve for them when they are gone. Let the time they're here be spent with you fully present.

If you're getting help from a memory care or other facility, the staff there can be great allies, giving you guidance on how to “redirect, not correct” when your parent becomes confused. When they ask for their deceased loved ones, you just hold their hand and explain "they are busy but will see you soon." You're not lying after all. When they become confused and don't know where they are or cry because they want to go home, all you can do is comfort them, just like they did for you when you had to get a shot, or take a test, or one of the millions of other things you were scared to do...but had to.

Just holding their hand and sitting quietly or watching their favorite movie can mean everything in the world. Talk about the good old times, and listen to them talk about their childhood, even if they think they are living it at the moment. Laugh at their silly stories. But most of all, love them and support them. We owe it to them.

More than anything, we owe them our advocacy. There are so many super-hero doctors, nurses, and other caring professionals who help our parents day in and day out. But as I found out the hard way, there are also sharks in the water, and it is so important to be your parent's voice. This is especially true in later stages when they can't remember if they've eaten that day if or they've taken their medication. It is up to you to pay attention, to ask questions, and to watch your parent like a hawk, just like they watched you when you came home with unexplained scrapes or bruises.

Even with all the trials that came with his illness and death, I am filled to the brim with pride at being my father's daughter. Proud of time he smiled at me, gave me a mischievous wink, or let me drive to Florida with beer in my back seat. All that I am comes from him, from the united team he and my mother formed to raise us with love, logic, and just a touch of wildness.

And I am so endlessly proud that my father, with his generous heart, allowed me to return the favor.