

Eileen's Story

October 2018

My dad loves maps.

For as long as I can remember, there were atlases and road maps in his cars. He loved looking at them and navigating from them. He recognized places and roads that none of us remembered traveling.

I'm guessing that maps made him wonder how someone did the work of making a map. That's something my dad would wonder about. He had a great sense of direction and could give good directions. And he didn't need Google maps to do it.

We use maps to show us the way to a new destination – one we may have heard about or read about. We use them to help us find our way to important places. We sometimes need maps to make our way home. We use a map, so we won't get lost.

Sometimes though, we do get lost. Even when we have a map.

We might not consult it, thinking we've been there before and we know this way. We might think we have it all figured out, and we don't need a map. The map could be wrong, we could be looking at the wrong part of it or even holding it upside down (which is totally something I would do and still do, even with Google Maps) and misinterpreting it.

Sometimes the map becomes hard to read – it's unfamiliar. It begins to look different than we remember. The landscapes it portrays are foreign and different. The compass doesn't point north anymore. And the words seem to be in another language.

Getting lost and unable to read your map seems to me a lot like having Alzheimer's. As I watch my dad pace the house from the front door to the back, looking for something he can't remember, waiting to go home while he's already home, it's easy to see that he's lost. His compass doesn't point north.

While there's a lot we don't know about Alzheimer's, there are some parts that don't seem so bad – no one wants you to drive any more, people make you dinner, you're happy to see someone every time they bring a bag of groceries in from the car, or when they walk in the room.

Clearly, though, there are less wonderful things about Alzheimer's and about getting lost. When you're lost, you're unsettled. There's no comfort. You can't find home.

You're in a constant state of wondering: Where am I? Where am I going? Who's there? Who's here? What's going on? Did I eat yet? What's today? Why is it cold out? When will we be there? How will we get there? Who are these people?

Many of us have had the experience of being lost. Time moves slower when you're lost – the minutes seem like hours and the days like weeks. The saying about time flying when you're having fun is true – and being lost is not fun.

When you're lost, it can feel like being hungry and not knowing what will satisfy that hunger, so you try all different things and they just make your stomach hurt. And sometimes just being lost gives you a stomach ache and makes you lose your appetite.

When you're lost, the sounds are strange. The voices, the alerts, the bings and bongs – they're all foreign – and they elicit alarm, rather than checking a phone, or answering the door.

Seeing my dad without his map is gut-wrenching. Sitting on the couch in his living room, he tells me it's time for him to go home. Or he gives me a dollar from Belize that he's been hoarding in his sock full of money for years. I take it, knowing I'll give it back to him in a couple of days and he'll be thrilled – and I will be thankful for his simple pleasure at the coin.

Watching my dad be so lost makes my heart hurt, it makes me wish for one more time when I could call and ask him a question about some hard situation, or have him beam with pride at how successful his kids are, or admire the garden he dug at my house before he was lost.

I want to ask him what it's like to lose your way, to recognize that those around you love you, but you don't know that they're your children. I want to remind him of when we were kids and he did things like buy us Easter corsages, take me to movies and for Mexican sundaes (whose names have hopefully changed by now).

Mostly though, I just want him to find his way home.

January 31, 2020

My dad is in the hospital. Earlier this month, he moved to an assisted living residence that specializes in memory care – undoubtedly there's a growing need for this, but the work is definitely for people with the patience of a saint.

He's here because he told one of the other residents not to eat the food, or take her pills and, when confronted, shoved a butter knife up his sleeve, went into the bathroom and locked the door.

My sister wanted to know what they thought he was going to do with it?

There's no telling what his plan was, assuming he even had one. One of my brothers suggested that maybe he had rolls and butter stashed somewhere and was just going to eat, which sounds exactly like my father.

My father has been diagnosed with Alzheimer's for more than a dozen years, or as my mother says, 'we've been doctoring for years.' This 'doctoring' as it were makes one think there might be a solution, an answer, a cure. There's not.

For years, they've been going to appointments, participating in studies, trying new medications to help researchers find a cure for this disease.

During some stages of Alzheimer's, some patients are paranoid, and my Dad has started saying demons are trying to get him. He's not wrong. Alzheimer's is the worst kind of demon. It starts by taking your memory, just yours.

It seems mild at first, annoying to your friends and family by forgetting a date or repeatedly asking what time we're leaving, what time is it now, who's coming, where are we going again. Slowly though, it shrinks your world.

You can't drive because you don't know where you're going. Then you can't decide what to wear because you don't know how to dress for the weather. Then you forget you smoked, and don't do it anymore.

After that, you pace around your house, as if you're waiting for a bus that's never coming to take you home, but you are home. And none of it is recognizable. And your people are nice, but you don't know they're your family or how you got to be here with them.

And that's just how it affects you.

Around you, suggestions to your family like 'get a notebook and take some notes,' adult day care, more exercise, a different diet, stop smoking and play music all swirl around. And, your family – spouse, children, siblings, family – they all try to help. But Alzheimer's pushes them to their limit.

It makes them wonder: How long this will last, what else will he forget, will he hurt me or the kids? It pushes their patience, their ability to see you as the person you were. It causes worry about the caregiver's health. It frightens them into tests about themselves, healthy diets, more exercise, notebooks for remembering, brain games. Alzheimer's pushes its way into everyone else's life, too.

Alzheimer's is like a dark demon that eats you up from the inside out and makes you walk around looking fine, but you can't answer what year it is, who the president is (somethings are worth forgetting) and when your birthday is. Meanwhile, it creeps into your family and friends, stealing their patience, their rationality and their hope.

There are sparks of the past – a smile, a laugh, a joke or one liner that seemingly come out of nowhere, but those come less and less frequently. You become sad and angry, saying things you wouldn't ever say to the people you love the most.

You become engulfed by the demon that is Alzheimer's.

February 1, 2020

In a lot of ways, it seems that Alzheimer's diagnosis is like being handed a suicide bomber's vest. When it goes off, it shatters hope like the windows of a building impacted by the bomb. It leaves death, injury and confusion in its wake. It's not simple or straightforward. It's not easy to see, and can be misinterpreted as bad behavior, misaligned judgment or rudeness.

February 2, 2020

Getting a front row seat to someone's death is gut-wrenching. I don't understand when people say 'I feel lucky for this time.' I want my dad back, and I want him all back. I don't want him to die.

March 28, 2020

We knew this was coming. We've known it since my father was diagnosed with Alzheimer's more than 12 years ago. And, to be honest, lately I've wanted him to be free.

And then a pandemic took hold and it separated our sprawling family with its coronavirus, shelters-in-place, and social distancing.

And then my father died. Yesterday.

And all the feelings I want to share with those who knew him best – my mom, my six siblings – they're all done by phone and video. And I can't hug them, or hold their hand. And that's gut wrenching.

Word is already out that my dad is gone. People are sending sympathy notes and being sad. And, I want to scream, "Stop, he's my dad! You can't be sad! He's mine."

(Probably worth noting here that I'm the oldest. And in every oldest child's dreams, there seems to be some deep-seated thing about 'oldest' and 'only' being equal.)

The fact is, though, that my dad was generous. He helped when asked, he was quick with a smile, a laugh, a pat on the back, and sometimes even a joke. He was a good human and people were grateful for him, so I'm relearning the generosity of spirit that my dad taught me through his life. Anyone who knew him is sad for the loss, he made the world a better place.

And, he taught us a lot.

We were never considered well-off by any means, but he taught us to dream big. Somehow, he and my mom sent every one of us to Catholic schools and college. (Yes, a lot of loans and charity, but they worked hard.) When I wanted to work for the Olympics in 1996, he never said,

‘That dream is too big,’ or ‘Get real.’ Never. He believed I would. (I didn’t, but according to my dad, I could have..)

My dad taught us – through his actions – to smile and be good humored. Even through Alzheimer’s, he didn’t often lose his humor, and he often joked about losing his mind. Probably it was some type of defense mechanism, but it worked. It put all of us at ease. He told me I had a great smile and I told him I got it from him. We laughed and smiled at each other – probably one of my best, and most recent, adult moments with him.

My dad taught us to help out. For years, he volunteered at our high school, in the development office, coming up with new schemes for the school to raise money. And, then he raked the football field – pretty sure he was on a crew to do that – but in my mind’s eye, I see him there raking it all by himself.

My dad always said ‘God will provide.’ I thought that was a stupid thing to say when you had a pile of kids in a three-bedroom house. (I was a teenager at the time.)

He was faithful, as in the Mass-and-Church kind of faithful. He loved to be at Mass and sing, louder as he got older. I’m not sure he loved being at Mass with a bunch of misbehaving children. He was the elected ‘get that kid out of here before he does something to embarrass us’ parent. He didn’t always make it, but appreciated the stories he had to tell from a kid being hauled out of church screaming, ‘I want to see Jesus!’

He taught us that family comes first. With seven kids, there are bound to be some missteps. And, there were, but my father showed us that families stick together. He taught us that family loyalty was most important in tough times.

He was most loyal to my mom. His reliance on and love for her was a force. I’m sure, at the end, his reliance on her was anchor-like, but she was his rock. When he was with her, he was okay. Before his comfort of just having her there, was love – that’s what I saw.

Through his example, we learned to find the joy, or at least the good, in almost any situation. As a parent, I imagine he was often overwhelmed – seriously, with seven kids, how could you not be? He once described my sister as being able to smile if she was in a pile of shit. His analogies could use some work, but we learned to find the joy, see the good and keep smiling, from him.

His ability to be happy with us, with my mom and his life, is one of the lessons I’m still trying to learn. He didn’t need us to change to be worthy of his love. He didn’t need us to make a certain amount of money, or have a certain type of job. He just loved us because we were his. I always knew my dad loved me. He was always happy to see us – virtually or in real life.

My dad wasn’t perfect – and we knew that. Turns out, you don’t have to be perfect to love those closest to you perfectly. You just have to keep showing up and working hard at it. And, that’s all we could ask of him. Thanks, Dad.

April 2020

Well, here we are, doing a ridiculous talent show virtually because we can't bear one more week without seeing each other's faces. I see Tom Casey at work here.

If my Dad died under some regular set of circumstances, we would have had a funeral, a few too many drinks, hugs and gone home. Now, though, we wait ... alone, with our nuclear families, holding tight to what he taught us was most important – family.

We find threads to keep us connected – holidays, talent shows, happy hours, birthdays for babies who won't remember him. But we will.

These are the days we will recall ... remember right after dad died and we had that talent show when Patrick did five tricks on his scooter, Kate danced to that song she's been drunk-dancing to for years ... and mom was the judge? Remember when Dennis made Fallyn *his* favorite cake for her birthday? And Kate and Eileen drank wine during lent because they couldn't take one more night without it? Remember?

I can't imagine these days trying to explain this 'unprecedented' unparalleled difficult challenging situation to dad, who just wouldn't be able to see his family – his 'chickens.' It would be torture – not just because he wouldn't understand, but because we'd have to tell him time and time again why, who, how, when ... and right, that doesn't make any sense, and I wish you could just go home too, dad. I do.

Truth is, my dad is right where he wants to be – watching all of his chickens, love each other in their imperfect ways – through their virtual talent show, their hugs, their dances and tricks. He gets to see it now, see all of it and be with all of us. Laughing until our sides hurt and our faces run hot with tears – he would LOVE this, and we do too.

Easter 2020

My parents' relationship ended exactly where it started in this world: Together, and alone.

That's how all the good ones start, isn't it?

We start off knowing that we'll conquer this world together, we'll figure it out, that our love will carry us through. And, that's how it started for Tom and Mary Kay.

I don't know what my father's in-laws, grandparents' in-laws, or anyone else thought of him but sooner than later, both time and consequence would make him a relied upon son-in-law, brother-in-law, and father figure – at least in Leroy, for the Callahan crew.

And all that was before he had children of his own.

We all struggle with the notion of what we should be or could be doing with our careers, our lives. But my father lived his life knowing that what and who he should be was the best father, brother-in-law, uncle, godfather, coach, brother and husband he could be.

He didn't think that if he accomplished more, people would listen. He led by example. He knew, innately, that love was the answer. Even when love seemed not enough – to pay the bills, to buy groceries, to get through one more teenager – my father knew that loving all of us for who and what we were at that exact moment in time was the most important thing he could do.

He wouldn't admit to, or even suggest, that he had some omniscient power to understand all of this. The best thing about my father was that he didn't know all of this – he just had the faith that if he loved enough, if he and my mom loved each other, and their children enough, it would be enough. Turns out it was.

He wouldn't ever hold us to things like – did you get all A's in school, or not wreck the car, or use drugs, or get stupid drunk or 'were you there when I died?' That's not how my father approached life. He woke up every single day, put his feet on the floor and worked hard for his family – regardless of how they showed up. He controlled what he could – himself – mostly. He didn't require us to look like something, to be an accomplished athlete, model or even a perfect child, or even ever to be a certain way – and that's about the only thing that was hard about being in a relationship with my dad. It was literally too easy to please him.

If you made pancakes with eggshells in them, he would just say, 'they're just a little crunchy;' if you struck out at the plate, he knew your next up would be the home run of your dreams. It was easy to please him because he saw the beauty of our lives before we could even fathom the gift we were given. My father knew how special it was to be in this world pinned together by the banner of family.

It's a lesson that some of us only realize now. But it's one we should be compelled to share.

It's the reason that even days before he died he would say he knew where these babies came from – heaven – and he was right. He saw us every day, in every way for who and what we were 'God's children' and he worked hard to treat us as such – to care for us as God would. While in Tom Casey's care, we would know how much we were loved.

I know there's a lot of water under the bridge here, and that I was far from the perfect child – believe me, I do. But I don't ever remember feeling resented, unwanted or unloved by my father. Maybe that's the same for everyone.

But I think that Tom Casey knew – in his giant heart – that we were all in his orbit for a reason. That he would, in his own way, take care of us – and if that meant tracking down the neighborhood low-life with a knife, standing up to a clerk in a store, paying our bail, dancing at our wedding, making our babies smile and burp, hugging our kids, or telling us that we had great smiles – that was his job and he was happy to do it.

I am so much the better because of my father, and while I didn't realize it in the moments, I know that he was in the stands my whole life cheering for me. Right where I was, when he died, with a whole lot more people cheering for him.