

North of Here

There is a magical place, just north of here. In the winter, snow crystals leave an imprint on the trees and grasses before evaporating into blueness. The air is luminous and diffused with a golden clarity. Here, a quiet stillness lands, enveloping everything with a sense of balance and peace.

Alice did not live in this place anymore. She and her family had left, relocating for a better job. It was a move they did not regret; yet there were moments, once in a while, when a weariness overtook her. In the mornings, after her husband left for work and the children were at school, it took her a long time to get up from the kitchen table where she sat, drinking her coffee. In the late afternoon, she stared at the play of light as it danced through her front bay window. Throughout the day she was tired, constantly tired. This was not the sort of tired that would go away after a long night's sleep, this was deeper. She was tired in her skin and often dreamed of floating away.

"Come home," her aunts begged her, phoning every week to catch up on the happenings in the family. Alice was careful to sound cheerful, to outline the achievements of the children and the success of her husband at work. "It is a wonderful neighborhood," she told them. "We have everything we could possibly want here."

"Come home," they said again. "You need to rest. Bring the children, we'll look after them. Let someone care for you."

Alice didn't want to hear anyone tell her that she needed rest. Rest was for others. Rest was for later. Motion was comfortable, preferable to the accusing sound of silence. Making her life a conveyor belt of backpacks, nutritious meals and housework was what needed to be done, sitting in silent introspection was not. And yet her balance had slipped, leaving her to sit immobile and silent, not where she wanted to be.

There is always a starting point for these things. How does a confident, capable woman lose her way so easily? Perhaps it was the eclipse of larger circumstances. The illness of her mother. An unexpected moment, a phone call. "Honey, can you come help me? I think I'm getting a little sick again," changing things in a forever way. Alice did

not know—how could she, her mother Jenny had never told anyone—about the invading disease. And then came the time her mother never went home again.

She tried to talk to her father about it. “Dad, I have to tell you something. I spoke with the doctors today, and...” Alice tried to take a deep breath. She did not want to do this, she did not want to be the one responsible for this, yet here she was with no real choice in the matter at all. “Dad, they don’t think Mom is going to make it.” Alice started to cry, unable to hold herself back.

After a moment she looked up at her father. He was immobile, standing in front of her, eyes filled with uncertainty. “Dad, do you know what I’m trying to say? They told me that mom is going to die.”

She tried to give her father a hug, whether for her reassurance or his she didn’t know, and she felt him absently patting her on the back. “Are you okay?” she asked him, pulling away to look at him.

“Oh yeah, sure, I’m okay, honey. Are you ready to go now?”

Alice stared at him for a moment, telling herself he was fine. Everybody processes things differently, and maybe her father needed some time alone to think about everything.

Six weeks later Jenny quietly left this world and crossed into the next.

Alice expected her father, James, to be devastated. She thought he simply would not be able to function without his wife. Instead, her father simply allowed himself to be absorbed into his own illness.

James had been diagnosed by a neurologist Alice had chosen. She found it difficult to believe that anything was wrong with her father; after all, he had always been so big, larger than life, and so capable. He was the kind of man who existed in a room long after he left.

The day of the appointment was cold. The previous week there had been a terrible ice storm and the counties were just starting to crawl out from under the frozen mess. As the doctor sat at his desk, continually pushing his round black glasses up the bridge of his nose and fiddling with the papers on his desk, Alice spent a few moments gazing out the window behind him, watching the play of light on ice.

“Lewy Body Dementia.”

The weight of the words produced a moment's pause, followed by Alice asking, "What? What is that?"

"A degenerative dementia, characterized by increasing hallucinations, tremors and bodily disturbances. It won't get better from here," the doctor answered.

"Typical, arrogant doctor," Alice told her husband later that day. "He thinks he can sit behind his desk and make these pronouncements. He didn't even run any tests or take blood or anything!"

In the months after the diagnosis, there was no noticeable change in James. He was still full of life and laughter. Once in a while he did seem a bit confused, but Alice wondered if she was projecting her own fears onto the situation, a situation she felt entirely unequipped to handle.

He'll get better, Alice thought. He has to...

Nobody gets better from Lewy Body Dementia, as Alice soon discovered. There is the task of dispensing medications, completing household chores, preparing meals and locking doors. There is the task of childproofing the house for an adult. There is weariness and tears, not in that order.

After reading all the information she could find about this disease, Alice was scared. But the only thing for her to do was continue with the job of caregiving. Really, what choice did she have?

When her husband received an offer for a better job in another state they could not refuse. It is more expensive to live north of here and the winters are very long. Being practical, they moved her father, James, with them. James would live in the same house, and Alice would take care of him.

Alice proceeded to pack two houses, hers and her father's. They purchased a new house with an in-law apartment, they enrolled the children in their new school, and they began their new life in a different state, away from the family and friends they had known for a lifetime. James moved with them and their lives moved forward.

Shortly after, during a phone conversation her aunt Dahlia told her, "They don't call you the 'sandwich generation' for nothing, you know."

"I've never heard that," Alice answered, "What does it mean?"

“Well, you’re sandwiched in between everyone. You’ve got children to take care of, the younger generation, that is. And you’ve got a parent to take care of, the older generation. You’re in the middle, you’re the meat of the sandwich. You’re the one doing all the work, aren’t you?”

“No, actually my husband Adam is amazing. I don’t know how I could have done this without him.” It was true. Her husband had been extremely supportive, helping her to dress, bathe and move her father when necessary. The doctor had been correct on that cold day, it was not getting any better.

“We’ve had to put him in diapers,” Alice quietly told Dahlia. “It’s just—there were so many times...”

“I know, I know. You are going to do what you have to do, honey, and none of us can tell you anything different or help you through this. You’ll be fine, we support you all the way.”

“I just didn’t think it would be so quick,” Alice whispered.

“Listen, kiddo, this is just the beginning. Have you started looking at nursing homes yet?” Dahlia asked.

“No, I don’t think it’s time. I mean, he still recognizes me, and while he still recognizes me and the kids, I don’t want to put him somewhere that will make him worse. I’ve got a routine with him, I can handle him for now. I can’t bear put my father away.”

Dahlia’s voice was gentle. “I know you can’t, honey. But there will come a time when you have to do what you have to do. Like I said, we support you. You’re the one doing all the work. Do what you have to do, and if that means putting your father in a home, that’s okay with all of us.”

But it was not okay with Alice. The days rolled by and still she could not bear the thought of placing her father in a home.

James knew that his memories were dripping away and that the world that appeared to him was not the world that others saw. On a mild Friday, the week before Thanksgiving, he took his daughter’s hand. “I can’t hold on much longer,” he told her. “It’s just getting so hard... I can’t do it anymore. I love you.”

It would be four long months before James actually died. In many ways, however, he was gone to his family. He no longer recognized anyone and usually did not make

sense when he did speak. He could not feed himself and sometimes could not walk. Alice, with her husband and a home health aid, tended to her father's needs.

When Alice looked at her father she could hear a shattering, a sound of thousands of tiny glass shards falling onto the concrete floor of her heart. When her children asked why grandpa was crazy all she could remember was a young man swinging his toddler daughter high in the air. "He can't help it," she told the children quietly. The youngest, Jeremy, solemnly nodded, telling her, "We know. He's got the forgetting disease."

Still, she could not bear to place him in a nursing home. Doctors, nurses and hospice helped as Alice stood by, unable to alter the outcome in any way.

In the final ten days of his life James did not eat or drink. At night, Alice slept on the couch next to his bed, not wanting her father to die alone. She held his hand as he took his final breath.

Nobody told her how guilty she would feel. Everyone said that what she and her husband did was a wonderful thing, and her aunts and uncles were so proud of them. But there was an overriding sense of guilt, a feeling that she had failed.

"I'm so sorry," she told her uncle, calling him to inform him of James' death. "I tried, you know, I really did..."

"What are you talking about? We knew this was going to happen. There's nothing you could have done about any of this," he told her.

Yet there was a strange belief within her, a sense that all her caring and love should have been able to hold back this disease, that her will alone should have been enough to save her father. She knew the efforts of her love had somehow failed her family.

"Come home," her aunts urged her. "We're all older, now, it's the way it is. Come visit, you'll feel better."

New spring leaves were beginning to appear when Alice, Adam, and the kids traveled north to visit the aunts. She took two boxes with her, boxes containing ashes and small bits of bone. Two lives, so largely lived, reduced to small rectangular boxes.

Thoughts raced through her mind while they traveled. "It will be nice to see everyone. I can't sleep, why can't I sleep? Did I leave the heat turned up? I hope they don't search my luggage."

There was no evidence of spring in the north. The ground was frozen, the trees bare. Through the cold, however, the approaching season was starting to emerge. There was a teasing scent in the air, a hint of the warmth to come mingled with the smell of fresh earth. *Soon*, she thought, *everything will become unfrozen*.

The aunts welcomed Alice and her family with love and food. There were hugs and tears, laughter and stories that lasted well into the late night. Later, the aunts told Alice, “You should go to the cemetery. Then you can see the headstone that has been engraved for your parents. Then you will know the spot they are in, you’ll have the picture in your mind. It’s important to know these things.”

Alice agreed. She would visit the cemetery to see her parents’ headstone before she gave the ashes over for burial.

The bright sun cut through the cold air that day Alice went to the cemetery. She braced herself before getting out of the car, uncertain what she would feel once she saw her parents’ names engraved in stone. She walked slowly through the rows of markers, counting. *It’s supposed to be row seven*, she thought, then abruptly stopped.

Slowly, she looked up and down all the rows she could see. The names, all those names. She read them in silence. DeGuerra, LaPorta, Kropp, DeRosa, LePine, Moffa, Guay, Levitt... these were names she knew. For as far as she could see, there were names that were familiar to her. These were families that she had grown up with, people whose stories she knew. And there, right in the midst of those names, were her parents. In an instant she saw her history as part of something else, something bigger. Her history was, in fact, rooted in a place and time. But more importantly, her history was rooted with those she loved.

Shaking her head slightly, it occurred to her that the names of the dead were also the names of the living.

Turning, she walked back to her car, climbed in, and drove back to the aunt’s house. The sun continued to shine as she sat at the kitchen table with her hands wrapped around a mug of hot tea. Aunt Dahlia sat next to her, waiting.

“I’m afraid,” Alice told her.

Her aunt nodded. “I know.”

“I did the best I could, yet it wasn’t enough. How can it not have been enough? What will I do if this happens to someone else in our family? What if it happens to Adam? What if I let someone else die?”

“You had to let your father die, honey. It was the only way he could be healed.”

There was silence as Alice processed that thought. Her aunt asked, “How was the cemetery?”

Alice gave an apologetic half laugh, looked at her and said, “Powerful. It was powerful seeing all those names, all those families. All those people I have a connection to...” She gazed inward, seeing rows and rows of headstones.

Dahlia nodded. “It’s important to see that and know your connections. Once you know where you come from you can go anywhere.”

It was true, Alice realized. Even though she would soon leave, she would always carry a connection to home within her. For the first time in over a year, Alice felt just a bit lighter.

Traveling south, Alice and her family took a nonstop flight home. She had time to think on the plane while Adam and the kids slept, time to think about who she was and where she came from. For the first time since she had moved, she thought about all the places magic and love exist. She thought about home and she thought about what she knew to be true, that we are made of all the things we came from, that we are part of the places we have been, and that sometimes we can choose to hold all of that magic of home within ourselves.