



# Jeanne's Hands

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LISA PICKER

Everyone noticed her hands. They were delicate but worn. Her pale Irish skin had been protected from the sun most of her life, but there were signs of how she exposed them to useful pursuits. They had been productive hands, engaged in the activities a devoted daughter, sister and aunt as well as a beloved art teacher and follower of God could offer. They were hands that regularly turned the pages of her worn bible, brushed away tears from the faces of her students, nieces and nephews. Her hands knew how to get dirty with paint and plaster or found objects she could turn into something beautiful or fun. She was what Mr. Rogers would classify as “a helper.” She taught and nurtured many children at a local school, barely making enough to provide for herself. Her name was Jeanne, and she was my sister-in-law.

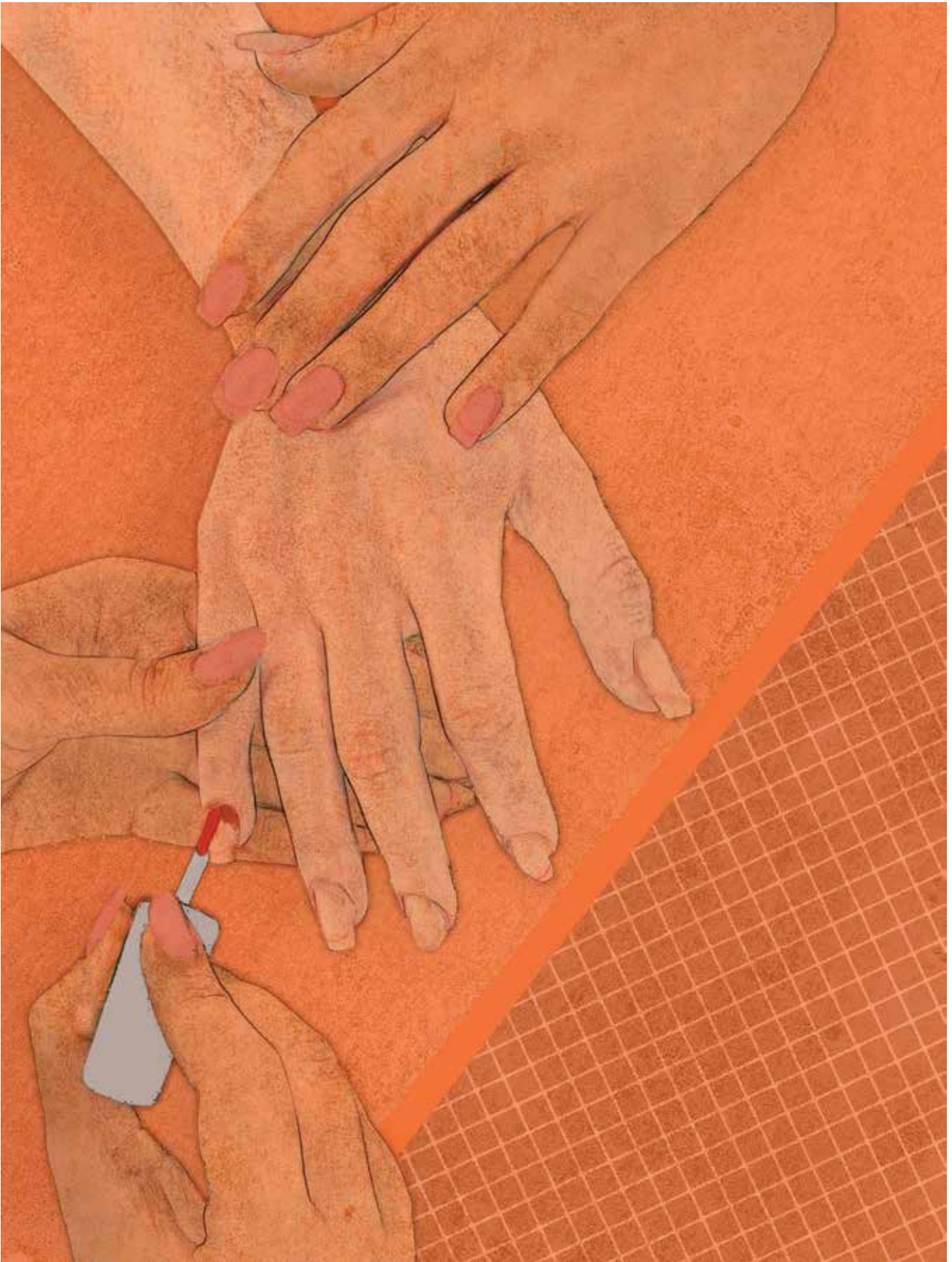
We began noticing a change in Jeanne around the time the coronavirus hit. Slight lapses in her memory, increased anxiety and an inability to concentrate on even the smallest things left her frustrated. Crying spells and sadness replaced the positive, quirky attitude we had always known. These changes could not be ignored, as on the day she tried to make a simple bank deposit and couldn't. “I know how to do this,” she protested. “I have done this a thousand times.” This time, however, was different.

With a family history of anxiety and depression, it was easy to first chalk it up to all things COVID. After all, everyone seemed to be afraid and overwhelmed and to have increased levels of uncertainty. When the security rug of life is pulled out from under an entire country, these things happen. I know this because I've worked in adult medicine for years. The number of patients calling for help with anxiety, mood changes and sleep issues was off the charts this year, and it was concerning. Understandable, but unusual. It's not uncommon to see such spikes around the holi-

days, with a death or a divorce, a major life event. Unfortunately, I am personally acquainted with mental health issues. In my 2018 article in this magazine, “His Name was Liam,” I wrote about our struggles and the loss of my son to suicide. The effect of the coronavirus pandemic on our society worries me.

Jeannie came by those delicate pale hands naturally. She was born into a large, complicated, loving Irish family with five sisters and two brothers. It is a family I was lucky enough to marry into. Everything and every day provided reasons to celebrate. We all loved deeply and lived life as if no accomplishment or event was too small to go unnoted. Family is everything to this group. So, when we noticed changes in Jeanne, we needed to find out why.

One of the first things clinicians are taught while studying and diagnosing is when you hear hoofbeats, don't go looking for zebras. It means when presented with a list of symptoms, you research and entertain the most obvious reason for the patient's symptoms before jumping to the



worst-case or most outlandish scenario. Why? Because nine times out of 10 it is there in the obvious that you'll find the answer. Unfortunately for Jeanne, that wasn't the case. Our family was about to deal with a huge unknown.

After weeks of tests that included imaging, lab tests, EEG and lumbar punctures, we finally received a confirmed diagnosis from the Cleveland Clinic. Jeanne had not had a stroke, which we had thought most likely, nor was she suffering from situational anxiety, early onset Alzheimer's or the stress of COVID. Any of these would have made sense from her health history. The diagnosis was Creutzfeldt-Jakob Disease, or CJD. What is this disease with a funny name? How did she get it and how is it treated? Why is it affecting her memory? Those questions swirled in our minds, but one thing was certain: this diagnosis was a zebra.

CJD is a fatal neurodegenerative disease caused by abnormal protein in the brain. The disease usually claims its victim within 6-12 months after the onset of symptoms. We felt shock and disbelief. The sadness was palpable. Some professionals describe CJD as Alzheimer's on steroids. A similar condition known as Mad Cow disease appeared in the late 1980s in the United Kingdom, where a panic ensued as cattle literally began keeling over and dying from Bovine Spongiform Encephalitis, which was later found to be caused and transmitted by infected cattle feed. CJD is the human form of Mad Cow.

Jeanne was diagnosed with a sporadic case of CJD, which means it was neither transmitted nor inherited. We likely never will know how she developed it. Because of its ravenous nature and the rapid course of decline, particularly with memory and other cognitive functions, we had to move quickly. In Jeanne's case she knew what she wanted to say, she just could not find the words. People with CJD suffer with balance and gait problems. It can affect mood and perception. Some patients develop difficulty swallowing or become incontinent. The disease can cause blindness, hallucinations and seizures. At the end, patients generally lapse into a coma, and most die from cardiac arrest or complications from pneumonia.

We learned quickly that people are afraid or uneducated about the disease. We certainly were.

In theory you can only transmit sporadic CJD from an injection, through nerve tissue or spinal fluid, not from normal, day-to-day physical contact. Meeting the challenges of the disease as they were quickly multiplying was intimidating. We were told it was important to set priorities early in the disease process and come to agreements in advance about how to handle what was coming. We remained hopeful, but realistic.

There are wonderful support systems in place. Once the family learned more about Jeanne's disease, we knew what was likely to happen. We just did not know whether it would or when. We decided to try to control the things we could and allow each other the room we needed to try to process this tragedy. We had our work cut out for us when we all decided we would care for Jeanne ourselves.

After she was released from the hospital but before she could be settled into her sister's house as her new home, she stayed with her niece for a few weeks. Her two great-nieces, who had been close to Jeanne their whole lives, were built into the care plan. They wanted and needed to learn how to help care for their aunt, what that entails and how it is done. These are hard life lessons in grief and loss, living and dying. Even at the toughest times and in its most fragile state, the family unit can be a powerful force.

We held weekly family meetings to address difficult topics like what to do if Jeanne lost her sight or experienced terrible seizures. We talked about how aware she would be of what was hap-

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pening to her and for how long would she cognitively be able to understand what the changes meant. Should we tell Jeanne she was dying? Should we protect her from the knowledge that she was going to go through something none of us had personally experienced? The only certainty we had was that ultimately Jeanne was going to die, so everything else was an unknown. We came



up with a plan of care and put a calendar together. As a family we decided the best way to care for her and ourselves was to address her symptoms one at a time as they presented themselves. It was too overwhelming to think about all the things that could go wrong.

The lessons we learned from Jeanne's condition and suffering, how we tended to her care together, and her death were life-changing for me. The raw beauty I witnessed as our family tended to her needs and helped usher her into the next life was strong, woven with grace and love. All of our talents, all of our strengths, as well as our fears and frailties, were bonded together for her.

We were not given the 6-12-month window of the first diagnosis, it was just two months. Jeanne slipped over into God's arms on a beautiful Sunday morning. The church bells began to ring shortly after she took her last breath. How like Jeanne to wait for her favorite day of the week.

Because we were in the time of COVID and because of the concerns about transmission of Creutzfeldt-Jakob disease, the funeral home fulfilled the regular mortuary functions, but they were not able to dress or attend to the special grooming we wanted for Jeanne's body before burial. We did this ourselves. Tears of exhaustion and sadness mixed with the waters we used to wash her fragile body. We dressed her and brushed her beautiful thick hair. My daughter Zoe placed some fresh cut flowers around her. Finally, we painted her nails and placed those beloved hands gently together.

The hands that had lovingly cared for her family and students, that so often had reached out to the lonely and needy, were lifeless now. As I observed the love and care we were all taking to make sure Jeanne's body was treated with gentle dignity even after she died, I thanked God for bringing me into this family and their generosity in including me in Jeanne's care. While that lovely pair of hands would never touch or embrace any

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of us again, I realized they were at work in the rest of us. I saw them in my sisters-in-law, in my nieces and nephews, in my daughters, in my brother-in-law Mike, and in all the other family and friends that stepped up when they were needed.

I think of the saints of our time and of those from days past — Martha and the work she did with her hands. How both of the Marys tended to Jesus' body. How Jesus himself washed the feet of his own disciples. How his hands bore the nails that would save a world. I can't help but believe that hands are an extension of our hearts. I will never forget Jeanne's hands.

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IN MEMORY OF JEANNE M. HUNTER  
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