

Fading Away

When you were still painting watercolour scenes - the cheeky orange and turquoise aspens at Canmore, the indigo and emerald mountains at Kananaskis, or the prairie snow scenes that capture Alberta's sunny winter days with their shadows of amethyst and lilac - you did a painting of Dane. You didn't usually do paintings of people, so this was a new endeavour. Dane was a work colleague and although the two of you were not best friends or anything like that, you did have an enjoyment of painting in common.

One beautiful windy, sunny summer day, Dane invited us to visit him at his cottage on the lake to paint en plein air. The conditions were not ideal for painting outdoors as the sun dried the watercolours too quickly and the wind kept blowing the plastic water cups over and whipping the paper into the yard, chasing the butterflies. But Dane said, "Never mind the painting; it is a perfect day for sailing." He wanted to demonstrate how well his sailboat worked. It was a one-person vessel that he had built. It had a small but mighty sail that could carry him across the lake at a leisurely clip while he sat back and enjoyed the ride.

When he slipped into his boat and pushed off, you photographed the scene. Dane had his back to us as he left the shore. His beige Tilley hat was anchored securely to his head with a tight knot under his chin; his windbreaker billowed behind him.

Although we knew Dane was unwell, it turns out he was sicker than we thought, and he died later that year. After he passed, you did a painting of that day. From your photograph, you created magic. The sheer sail glowed as the sun shone through, the waves

sparkled with little spritzes of light on their crests. You painted Dane at peace, determined, heading to the far shore, and donated the art piece to the University hospital where Dane had been in palliative care for a short time. You titled it *Sailing Away*. It is a powerful memorial.

After you retired, you continued painting, switching to acrylics. You took painting workshops, bought art you admired and produced lovely works yourself. And then, over a several years, you slowly stopped painting. You lost interest. Were no longer motivated to paint or do much of anything. Skipped going to the gym. Found it a major effort to go for a walk. Didn't laugh anymore. Or smile. Spoke so softly, I could barely hear you. Of course, my being hearing challenged did not help in that case. You were fading into invisibility, oblivion. You were leaving me, sailing away, like Dane.

I thought it might be your fear of another atrial fibrillation episode caused when you got up too quickly or moved too fast. Then I thought I might be the problem. I thought you were unhappy. Maybe you were. People get old, and retired men often are depressed. I didn't know what was going on. And you didn't either. This went on for a long while with no idea of the underlying cause of the change.

We got by until the fall, when things declined further. I insisted we investigate your health. You were referred to the Senior's Clinic at the University of Alberta, where you underwent a thorough work-up and assessment with a gerontology specialist. At the end of that half-day session, we learned you most likely had Parkinson's disease (PD). At a follow-up consultation with a neurologist in mid-November, 2020, you received confirmation of the preliminary diagnosis and started on medication. The only signs we had known

associated with people who had Parkinson's were tremors and shaking. Since you had shown none of these symptoms, we were shocked by this diagnosis.

Once we learned about other symptoms, the diagnosis explained so much. Loss of smell, shuffled walking, balance problems, slow gait, lack of enthusiasm for anything, need for lots of sleep, loss of weight, decline in strength, bent-over posture, vision problems, unexplained shoulder pain and difficulty finding some words, although we thought the latter was just part of normal aging for both of us.

Turns out, it wasn't only aging. It was predominantly a lack of dopamine, a neurotransmitter in the brain that coordinates the body's muscles and movement. We learned that by the time most people are diagnosed with Parkinson's, up to 70% of the dopamine-producing cells are damaged or have died. Dopamine affects motivation, the get-up-and-go attitude. Your not laughing or smiling was because your brain was not making enough dopamine which affects the muscles in the face. Since being on medication, I have seen you laugh and smile. That wee change brings me joy.

The encouraging news is that your executive functions are still spot on, although the processing is slower, and daily living functions are not impaired. And, at the most recent medical consult, the neurologist said there was definite improvement in movement. In many cases, the progress of the disease is slow, so I am being as optimistic as I can.

Now, after almost five months, this is my wish from this day forward, for better or worse, in sickness and health.

Dear Matt.

Come back. Or, at the very least, stay here. At this time. In this moment.

I am here when you need me. I will honour your independence and not step in when you can still manage although I just want to fix things for you. You are still capable of doing so much and I am grateful you're trying. I want the colour to come back into your life for as long as you can make that happen. I want you to lay down a brush load of cobalt blue and lemon yellow and maybe even a stroke of scarlet lake or opera pink in your daily activities.

I will try to accept *what is* while pushing with all my might against the blurring, muddling, pixelating, clouding, evaporating, disappearing and waning that will come from now on as PD progresses. I will help you hang on to *some* sharp edges, *some* clear outlines, *some* bright moments. Together, let's embrace the tints and shades of life and stave off any further erosion and dimming for as long as possible.

I offer my hand and my love. Every day, I will strive for my own patience and understanding and hope. As I learn more, I will share more with you, but for now, I am documenting my concerns and thoughts and holding a big space in my heart for you.

You have always been there for me with no complaints. I appreciate and am grateful for having you in my life and for everything you have done for me and our family. Now I want you to know I am doing the same for you. So lean on me whenever you need to.

March 2021

[NOTE: The names in this document have been changed for privacy reasons. Since this writing, PD-related dementia has caused additional difficulties].