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Withering

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My dad is a strong man, physically and emotionally. He is kind, devoted, and he would do anything to protect us. His sallow skin enrobes a glorious forest of cells that collaborate to give him his strength. His brain dispatches information to his muscles along chains of cells called neurons. Everything he does requires this complex network to work synchronously. Dad is an avid gardener, nurturing a myriad of greenery at the back of our house. Easily my favourite, and the oldest of all the plants, is a burly lime tree that stands in the far-left corner of the lawn. He used to lift me onto his shoulders so I could pick fruit from the laden branches, and dotingly teased as I would wince at the tartness of the harvest of our labour. He still tends to his Eden just as fervently into his sixties; in fact, I think the only things he loves more than gardening are his children.

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Light creeps in through the blinds, which cast still shadows onto the kitchen wall. I have become acutely aware of the sound of my own breathing, no one says anything. My dad has just told us that he has been diagnosed with motor neuron disease. The only thing I know about this condition is that the life expectancy is short — very short. He tells us that he has been referred to a specialist who will provide him with physical, psychological and emotional support, and who will be visiting the house in the next few days. He smiles softly at us and tells us that everything is going to be fine. Everything does not feel fine.

The specialist is a man called Dr. Ward. He has a grey beard and smells of antiseptic. He perches on a chair at the kitchen table and tells us that our dad is suffering from the most common motor neuron disease, amyotrophic lateral sclerosis or ALS. I flinch at the words ‘neurodegenerative disorder’ which he explains means that the nerves controlling Dad’s movements will continue to degrade over time. The long trunk-like axons of the cells will wither and die in his brain and spinal cord. I glance at my dad; his face is soft and his eyes untroubled as he nods gently. There is a knot in my chest, vines tightly wind themselves around my heart as the droning voice of the doctor is obscured by the sound of blood pumping in my ears.

After Dr. Ward’s first visit things start to make sense: why Dad would mention aches in his legs, why he struggled to open doors and why he had started to become increasingly clumsy

— tripping over most days on his way out to the garden. He tends to laugh these instances off, pulling a face to make us laugh, and berating himself jokily for being so uncoordinated, but I can tell it's getting harder for him to do all the things he once found effortless. His immune system, the part of his body that should be protecting him, fighting on his side, has decided to launch an inflammatory attack on his nerves like a burning forest fire. He sits outside every day, and I recognise that it hurts him not to be able to water, weed, and prune his garden. As the air cools, the lime tree wilts and the fruits that were once a vibrant green, shrink and fall, rotting on the grass next to his lawn chair.

Porridge sits on the stove this morning, as it has most days recently; the only foods that Dad can eat are soft or pureed, lots of mashed potato and soup. The muscles he needs for chewing and swallowing, being skeletal, voluntary muscles, are declining. We all sit and eat at the table, family breakfasts, lunches and dinners; the only sound tends to be Dad's cutlery dragging shakily across his plate. He refuses any help with eating, saying he is feeling "very capable" at any offer, but his muscles are wasting as his nerves lose the power to send any signals to them and any tone they once had has diminished. His skin sags around his upper arms and thighs, unable to keep up with the loss of muscle mass. He struggles to bear any weight at all, an empty mug is about all he can manage; he can't even have tea anymore because Dr. Ward has warned that he could choke on anything as his mouth and throat muscles weaken. He said it was called bulbar degeneration and his words, "nothing too solid, nothing too liquid", discordantly echo in the kitchen. I hate porridge now.

I have been floating above my body every day since Dad's diagnosis, I feel hollow and the late autumn breeze rips right through me as I stand at the back door. I stare into the garden where I once ran, jumped and played, where my dad would hold my hands and spin me around, where my ribs would let my lungs breathe, where any tension would be replaced with laughter, and where I didn't need to consider why the branches of my dad's nervous system were breaking down. The uncertainty consumes me, even ALS experts can't say what is going on in his brain, their theories offer me little comfort. They say it's likely due to an excess amount of a chemical called glutamate, making nerve cells fire signals too often causing a buildup of toxic products that are killing his cells. I sway on the threshold. This thought makes me feel sick. The unmown grass seems to mimic me in the wind, ripples moving across it like a choppy sea. My dad is inside. Due to the nerve damage, his leg muscles have lost contact with his brain. No longer able to plant his feet on the ground, he stays in the house with constant nausea from his medication. The living room has become his bedroom as he can't get up or down the stairs. I smile as I walk in to see him, wrapped up in blankets in bed. I sit down softly next to him, and his warm, woody smell pricks the back of my eyes. My cheeks are suddenly sodden with tears, Dad reaches his hand out slowly and I can tell he is trying to squeeze mine as he holds it. He can't speak anymore — the thought makes me ache — but he smiles tenderly, and he is my dad again.

The lime tree's bark has turned pale and brittle, its spindly branches are barren and seem to be grasping for air. Maybe they, too, need a machine to breathe, a mask and tubes and a whirring box to stimulate the rise and fall of the lungs. Until even that cannot keep up with the demand for oxygen anymore.

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I have been putting off sorting my dad's things for months since the funeral, I feel raw as I walk into his room. I draw a deep breath into my chest and start on his bedside table and chest of drawers. Opened boxes of pills litter all the surfaces, their efforts to prevent the overwhelm of chemical toxicity couldn't keep Dad with me for more than a year. I wish that he had been granted more time to empty the boxes of pills. I make the bed, allowing myself to lay for a second on the blanket as I breathe in the soft woody scent that reminds me so much of him.

I stand up shakily and gently run my hand along the battered spines of the old books on his shelf. There is only one without tattered corners. I carefully slide it out and flick through the pristine pages — empty — there is only one page with any words. My dad's writing, still crisp and clear and so unlike what it had become after damage to the nerves controlling his fine motor skills caused his hands to twitch and tremor. A lump grows in my throat as I read the words "I'm scared of dying, I don't want to go yet" — suddenly the dad who was so indomitable, becomes so much more vulnerable in my eyes. It was all a façade.

My dad was a strong man, physically and emotionally. He was kind, and devoted and he did everything to protect us even when his body couldn't protect him.

Scientific Statement

'Withering' is a piece of creative writing about Amyotrophic Lateral Sclerosis or ALS, a condition that causes severe damage to nerve cells that control the body's movements. These nerves are called motor neurons — they transport information from the central nervous system to the muscles, allowing the body to move. Because ALS damages the motor neuron cells, the muscles become weaker as they can't receive any signals from the brain, and the person with ALS eventually loses control of all functions in their body, including eating and breathing. There are many different types of these conditions — they are known as motor neuron diseases — ALS being the most common among them. It is a progressive, degenerative disorder, which means that the damage it causes is irreversible and worsens over time. ALS is a terminal condition with no known cure; life expectancy after diagnosis is around two to five years and the condition worsens quickly causing severe disabilities. There is currently no cure for ALS, however there are therapies that target its symptoms, aiming to improve life quality and slow the progression of the disease.

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