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“Seeker of Freedom and Joy”

(inspiring life journeys of an enlightened heart)

Chapter 1

Dad’s Advocate

What I remember most about my dad are his bright, clear, sky-blue eyes. How those eyes smiled at me! I could feel his soul smiling back at me, his heart embracing mine. Dad had a strength about him, an inner force I could feel around him, filled with love. He was full of fun, humour, and knew what freedom felt like, as he enjoyed being in the great outdoors with nature. I remember him as the heart of our home in the early days, and I adored him. Then an event in his life changed him, and us, irrevocably.

Have you ever seen a loved one struggle for their life? How did that feel for you?

It can be daunting, scary to watch, or a blessing and honour to be present with a loved one as they move on and change form. We do not talk about death enough in Western society, unlike many ancient and indigenous cultures who celebrate and accept death as part of life. We struggle, even though death is what we

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are all moving toward every day. It does not matter your age or race — we are all equal in the eyes of death when it is time to leave Mother Earth. I remember my first experience of death. As a trainee nurse of only two months’ experience, I was placed on a ward where an elderly patient had just died. I was instructed to help a senior nurse lay the poor lady out. When we moved the patient onto her side, the last air in her lungs came bursting out in a huge sigh. This sent me into hysterical laughter, and I had to be taken outside the ward to settle down. It was not that I was being disrespectful, I just had not seen a dead person before. My mind went into overload, unconsciously sending me into an almighty laugh. I realised later it was my coping mechanism. I had used it before — in my school years in situations to which I did not know how to react. Some fifteen years later in my nursing career I had seen a good deal of death, but I was about to experience it from an entirely new perspective — watching death from a very personal and emotional connection, of a loved one I knew well. I watched my father struggle for his life in a hospital bed, while his spirit was slipping away from his body. This became one of those extremely challenging journeys life throws at you, forcing you to look at your own mortality and make some really big changes in your life. For me, that involved transforming into a new version of myself, to find answers to those life questions of who am I really and why am I here? This does not happen in a hurry. It takes time and trusting your own inner compass — our heart — to guide you.

My Dad at fifty-five years of age had been suffering for twenty years with Alpha-1 Antitrypsin deficiency (A1AD), a severe lung disease. There was no cure, and he was getting progressively worse. A1AD is due to a protein enzyme deficiency in the blood. It affects the lungs and/or liver and allows the lungs to be damaged by air pollution and smoking. The symptoms are similar too Congestive Obstructive Pulmonary Disease (COPD): shortness of breath, wheezing, chronic coughs, lots of sputum, recurring colds and pneumonia, allergies, and low tolerance to exercise. Basically, Dad could not breathe normally. He struggled to get air in and out of his lungs and was at high risk for lung infections. From its onset, the condition was a slow decline into poor health and would eventually take his life. To this day, no cure has been found. A1AD is a genetic condition. My father's family carries the genes, and my grandfather died of the same disease after he had a serious motor-vehicle accident while working as a fireman. There was not much known about A1AD then, nor is there now. Apparently, it had been dormant in my father's body, so he experienced no symptoms and did not know it had been passed on to him. A serious car accident in his early thirties caused dangerous injuries, including broken ribs that punctured and collapsed Dad's lungs, shocking his body system and activating A1AD. Dad spent the next twenty years in and out of hospital with lung infections, struggling to breathe. In his late forties, Dad reluctantly surrendered to using an oxygen cylinder, as he could not push himself any longer to get oxygen into his lungs. In the later years, leading up to the lung transplant, doctors would

regularly say on hospital admissions, "He may not make it this time." Dad always proved them wrong, as he had such a strong will and determination to live. I wonder if I got that stubborn determination from Dad's genes? In 1990, aged fifty-five, Dad was offered a place on the lung transplant list by Dr. Chan, a specialist heart/lung surgeon. Dad agreed to the operation if they could find a donor. They did, and in 1991 Dad became the first man in Australia to have a lung transplant. When the call came, Mum and Dad had moved just three days earlier to a new house purpose-built for Dad's condition. It overlooked the north coast beaches, only ninety minutes from Sydney. Ironically, the land was paid for by the small compensation Dad had received twenty years earlier for the motor-car accident which had caused A1AD to be activated. Dad was told to go straight to the hospital; if he was a match with the donor (a middle-aged woman who had just died in a car accident) they would operate immediately. Dad was lucky to find a donor so quickly. On the day of the transplant, we were taken to the visitors' room where we would wait for many hours, not knowing if Dad would survive the operation — he was a test case, as the first man in Australia to have a lung transplant. When Dad was being anaesthetised, Dr. Chan came out to let us know he would not be doing two lung transplants, he had changed his mind and would now only be transplanting one lung, Dad's other lung would be left in place.

We were surprised to receive this comment from the doctors, and it seeded some doubt in our minds for Dad's success. Later, we were told the change in plans gave Dad a better

chance to recover. Dad came through the operation, and we could all breathe again, I say in jest. It was a long operation and many hours had passed before we were told it was successful. Dad spent time in an Intensive Care Unit, and later moved to a rehabilitation ward for activities and monitoring before he went home. The doctors were really pleased with his progress and stated how he had exceeded their expectations. What were they expecting? I did not ask, we were just glad to have him back. Dad's strength kept him going through all sorts of challenges; he just never gave up. Finally, Dad went home to enjoy the new lung and freedom from the oxygen cylinder! However, he still had to go to the hospital for frequent check-ups and drug adjustments. What made him happy was a small sense of freedom returning. Little activities, like walking to the local shop to get the newspaper, had not been possible before the transplant. After, he could enjoy a slow walk to the shop, giving him a wonderful sense of achievement. We were privileged to see the biggest smile on his face when he walked, taking his two-year-old granddaughter with him. Something my father shared with our family, which intrigued me at the time, was that he was experiencing the old memories from the donor's lung. He would say he was getting memories from incidents that were not part of his life previously, as a

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female. He was certain they were memories held in the lung he had received. Twenty-seven years on, I know it is highly possible he was picking up on the memories of the donor lung at a cellular level. This is what I have learnt and experienced through therapy trainings — trauma memories are actually held in the body, so healing the body through conscious movement therapy can release the memory. Dad also had a sense of the donor around him, energetically. He could not explain it; it was more of a knowing. I know from living in an Australian Aboriginal community that they are very keen to take all the belongings of a person who has died to be burned, so the person can be released and not held back spiritually on this earthly plane. Maybe this opens up a whole new cultural discussion around organ transplants?

Do you know of anyone who has shared similar feelings from an organ transplant? When Dad talked about it, I had not heard this before, or at least not anyone admitting to having these feelings after a transplant. I had a lot to learn!

Sadly, almost twelve months to the day after Dad received the lung transplant, he acquired a severe cold in his old lung. This quickly turned into pneumonia, due to his very low immunity from being on immune-suppressant drugs. Dad was taken to hospital and his body rapidly turned from serious infection to septic (full body infection). After six weeks of struggling to stay alive, Dad's body slowly shut down, causing kidney failure. I was

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there every day and watched him struggle and lose his strength, going steadily downhill. The doctors thought Dad would be a good candidate for the lung transplant because his other organs were very strong, but his time to leave this life was closing in on him. Unfortunately, on his last admission to hospital with pneumonia, his body had already gone through so much with the lung transplant and heavy medications that he could not fight the infection

any longer. It changed my life to see him go through that horrible, painful experience over six weeks. He had always been a proud and very private man who looked after himself with great dignity. To be at the mercy of hospital staff, bathing, and toileting him in bed, would have been very upsetting for him. Dad had really suffered, but always said, "It will help science, even if it is not successful for me." My mum, sister, and I had not been all that keen for him to have a transplant. From my previous nursing experience, I knew the road would be challenging. But we all wanted to support his decision, his need to feel freedom — without the oxygen cylinder. He shared with me one day, "Maybe I will play golf again, Deb." I just smiled. I could not dampen his hope. One morning, leading up to the day he left his physical body, I remember especially well. I arrived to find him bombed out on many drugs. Approaching, I saw him have an involuntary full-body shaking fit, something he had never suffered from before. I felt helpless. What was going on? My heart broke, feeling his discomfort and the lack of privacy with all the medical team around his bed. Was Dad ever going

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to have peace? That was it for me — I had to do something. I needed to be dad's advocate. I was ready to battle with the doctors for Dad's peace. It was time to tap into my old nursing experience and assertively get to the bottom of this bizarre event my father had suffered. My gut feeling said something was amiss. Confronting the doctors, I eventually found out they were not communicating with one another and had given him two drugs that were contraindicated and not compatible, causing him to have seizures. That was insane! His whole body was already struggling to keep the infection under control, this made me so angry. The specialist doctor was not there, but when he arrived the next morning, I cornered him in the corridor with his entourage of medical specialists, residents, and registrars. "If that was your father dying in that bed, would you be giving all these drugs? What good are you doing? You know he is dying you have told us. Please let him die in peace with just pain relief," I implored. The doctors heard me and had a meeting, resulting in only one specialist being responsible for Dad's medical treatment instead of a group of specialists who were not working as a team. The problem was, each specialist had focused only on their own speciality body system, prescribing medications without consulting with the other specialists, thus causing my father's seizure event. I did not know until my mother told me later, but when Dad was offered the transplant my parents had signed many papers. They had agreed for the doctors to basically do what they liked

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to his body — it would no longer be his body it was now seen as research. I am glad I did not know that at the time! After my confrontation with the medical team they suggested my mother, sister, and I go for counselling with the chaplain. Why? To soothe their own guilt? We were not deluded in our attempts to help Dad find peace in his last days. Specialist doctors are not used to families speaking up and questioning their actions. Of course we were stressed, who wouldn't be under the circumstances? But I was not going to stop making those doctors accountable for their actions, and I kept watching over my dad. This I feel is the problem with our medical system — doctors do not see the whole person in the

bed. In comparison, in complementary therapies the whole person is seen and treated in an integrated approach with the patient. I have seen the medical model cause patients so much harm with treatments, and now I was witnessing my father in the same position. On the day of my thirty-third birthday at 11 am, my father passed away. It was 1991, the year I will not forget. He was fifty-six years old.