

Through Sickness and Health: A Couple's Love Perseveres in the Face of ALS

At home with Jeff and Darlene Sutherland

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The first thing one notices upon walking into Jeff and Darlene's airy bungalow is the feeling of warmth and love that reaches into every corner: it's present in the family photos that adorn the walls and the tasteful trinkets carrying messages of friendship and hope. And it's a stark contrast to the second thing that's evident: the soft, motorized whir of the breathing machine that keeps Jeff alive. It's a constant reminder of the thin line between life and death – a line with which Jeff and Darlene are all too familiar.



We are at Jeff and Darlene's home in a quiet community north of Toronto to shoot an awareness video. It's 7am, and Darlene is in her dressing gown – Jeff and Darlene have offered to carry out their morning routine in the usual way, so it can be captured for the video. They're willing partners, wanting to share the reality of living with amyotrophic lateral sclerosis,

though Jeff admits in an email that they've been living like this for so long that they're a bit immune to the harshness of the disease.

And ALS is indeed harsh – it's a thief that takes and keeps on taking. Disease symptoms and progression can vary from person to person, but the outcome is always the same: walking, talking, swallowing, and ultimately breathing become impossible. The problem lies in the motor neurons – the internal wires that send signals from the brain to the muscles. In ALS, motor neurons gradually break down and die, which results in the muscles weakening throughout the body. For most, the breakdown happens quickly: 8 out of 10 people diagnosed with ALS will die within five years.



Jeff was diagnosed 12 years ago at the age of 41. First, he lost the ability to walk, then to talk. In 2011, no longer able to swallow, he decided to have a feeding tube inserted to provide him with nourishment. In 2014, when his respiratory muscles weakened to the point that breathing on his own was no longer possible, he had tracheostomy surgery, which resulted in an opening in his windpipe for a tube to be inserted, allowing the ventilator to breathe for him. The decisions one must make when living with ALS are highly personal, emotionally-charged, and life-changing – but then again, so is the disease.

Today, the only muscles Jeff can fully move are in his eyes, so that's how he communicates – a text-to-speech device gives him the ability to type with his eyes at a rate of about 15 words per minute. That's how he wrote his memoir, *Still Life*, which was released in October 2019. A close-up of an eye makes for a fitting cover.

According to Jeff, *Still Life* has four prominent themes. He summarizes each in an email. The first: his experience and his family's experience with ALS.

"I decided to give the reader an intimate, raw, look into this disease," he says. "It is our experience only, but I hope that some of my words are relatable to other families who have had ALS enter their lives so that the all-encompassing nature of living with this terminal disease will have impact and hopefully, through the 'Still life challenge', more fundraising will occur to find treatments for this disease."

The second theme, of profound grief, is about the loss of Jeff and Darlene's eldest son, Zach, and his partner, Kaya, who died at the age of 21 in a tragic kayak accident in 2016.



"This is a horrible tragedy for any family, but in a family that is already living with a terminal disease, it's even more cruel and takes you to the

darkest of places,” says Jeff. “It is something that exists with a person throughout their lives. With deep, personal work, and through connections and purpose, we have found a way onto a healing path.”

The third theme, hope and resilience, is defined by Jeff as not only being able to survive after profound adversity, but to thrive, too: “I hope that by showing our path for becoming more resilient after profound loss, that others who are going through difficult times, may be helped through their adversity.”

The final theme is the one Jeff says is perhaps the most important: love. Specifically, the love that keeps a family functioning and thriving through the darkest times.

“It is the love that Kaya and Zach enjoyed in their lives and I believe still share in the afterlife,” says Jeff. “It is the love that parents have for their children, in our case, our love for Ben, Nathaniel and Zach. It is the love from friends, through connections and shared community that helps build resiliency and we are so grateful to our network of friends who have freely given this to us, through the good times and bad times. Most importantly, It is the love between husband and wife, through sickness and health. “

Does sending your memoir out into the world make you feel vulnerable, to know so many people will be reading your story? I ask him. Conversations with Jeff tend to be punctuated by lengthy pauses as he types each character. “Not really,” he responds through the device that gives robotic voice to the words he has typed on the screen. In an email exchange, he goes on to explain his hope that sharing his experiences will help others.

It has been an intense morning of shooting video. Jeff and Darlene have been gracious in giving the camera crew access to their most intimate moments: Darlene climbs into bed to face Jeff for their daily meditation session; Dorothy, the personal support worker, moves Jeff’s body through a series of exercises to keep his muscles active; using a Hoyer lift, Darlene and Dorothy move Jeff from the bed to his chair and wheel him to the bathroom for his morning shower; after drying him off, they clean his

stoma and moisturize his body. The full morning routine usually takes them 2 hours, when a camera crew isn't there to slow things down.



Throughout the entire morning routine, the love that Jeff and Darlene share is clear. High school sweethearts, they've experienced so much as a couple. Their life together may not be what they once imagined, but they accept it, take things day by day, and experience joy along the way, appreciating one another and the support of their community of friends who have stuck by them.

Jeff hopes that his book and the awareness videos will help people to understand the reality that they live with. "Getting stories of ALS into the general public is important," he says in an email. "These stories help raise awareness and with more awareness, compassion is raised."

Order your copy of *Still Life: A Memoir* on [Indigo](#) or [Amazon](#) today.