

When the Sun Rises Without You

by Barbara Joyce-Hawryluk

Her chest rises and falls, hitching a little as her eyes track the second hand of the clock until it reaches twelve. In twenty-nine minutes, she'll be dead.

A question aches inside Julie Silke, a grim tear bleeding down a sallow cheek. How do you close your eyes for the last time? Let the lids fall, little by little, as the person in front of you, the one you loved from the second you felt her kick inside your womb, slowly vanishes from sight. Forever.

She doesn't want to leave her only child. She doesn't want to die.

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Julie, her mind still in reasonable working order, had cut through the squabble of hope and despair and made a choice. *You may not control all the events that happen to you, but you can decide not to be reduced by them.* It was her favourite Maya Angelou quotation, and it had supplied fuel during a two-year stand-off with her neurologist, Dr. Sand, and with her daughter, Rae, over Medical Assistance in Dying. She wanted MAiD. They didn't.

Rae was an idealist, offering an optimistic flurry of Dr. Google advice, but it was Julie, not Rae, being buried alive inside a coffin of skin and bone from Relapsing-Remitting Multiple Sclerosis. RRMS had been stealth in its attack ten years earlier—lazy foot nicking the edge of a scatter rug, cups and plates slipping from her hands. The insidious assault had escalated to roaring debilitation—total dependency, visual perversions, and over the last two years, a tenacious fog infiltrating her brain, leaving her forgetful and at

times confused. Scrambled thinking triggered panic, which led to the first, second, and then final MAiD application, the first two rejected because of the neurologist's report.

"Who owns my life anyway?!" The desperate cry stuttered between gulps of saliva and air, foam bubbling from her lips as she sat, wheelchair-bound, in Dr. Sand's office for the third time, Rae dabbing sticky white paste from the corner of Julie's mouth.

A question with no clear or simple answer. Not when the law permitting death with medical assistance was new and rules and requirements were still being sorted. Not when the diagnosis and prognosis didn't tuck neatly into the criteria. Not when human beings were being human.

Dr. Sand, a study in practiced authority and clinical efficiency, didn't see it the way Julie did. From the inside. He wasn't hostage to the inevitable devolution, piece by piece, of body and mind—communication lost, thinking disordered, ventilator wheezing into withering lungs, tubes force-feeding wasting cells, bags and machines encrusted like barnacles on a sinking ship. All to keep the horror show running, for how long, no one could predict for certain, not even a seasoned neurologist.

"You know the criteria for acceptance," he said, ticking the points off with his fingers. "A medical condition that's considered grievous and irremediable, incurable and in an advanced state of decline. Intolerable physical or psychological suffering that can't be relieved under conditions considered by you as acceptable. *And,*" he added, widening his eyes over the top of his glasses, "natural death is presumed to be reasonably foreseeable in the next two years, or thereabouts."

He'd paused and she knew why. He was waiting for the words, third time delivered, to take hold, as if repetition would shake her resolve.

Her unyielding stare returned his.

“Ms. Silke,” he’d sighed. “You’re only fifty-eight years old. I can’t, in good conscience, answer the MAiD doctor’s question the way you want me to.” He read the question aloud as if she hadn’t heard it before. “Would you be surprised if Julie Silke dies of natural causes in the next two years?” He removed his glasses. “My answer is still yes, because it’s the truth. With your particular diagnosis, you could be alive two years from now, maybe even much longer.”

Once again, Julie knew that Dr. Sand’s prognosis would be the single factor denying her the right to assisted dying.

A contorted claw of knotted fingers trembled helplessly in her lap as panic raged inside. *I’ll be incompetent soon! MAiD won’t even consider me then! You know this!* Her lips quivered in fury and then flattened. She had neither the strength nor endurance for the same tired argument.

Silence filled the space between mother and daughter as Rae drove back from Dr. Sand’s office to Julie’s assisted living suite, until Rae pulled into a side street, collapsed against the steering wheel, and began to sob. “Can’t you delay? Just for a while. Please!” Rae wiped her tears with the back of her hand. “I’m pregnant, Mom. Your first grandchild.”

Julie’s heart soared and collapsed in the same moment. *Can I wait a little longer?*

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The summer passed, MAiD application put on hold as her medical condition declined, forcing three emergency admissions to hospital for pneumonia, lungs wheezing ragged bursts of breath while drowning in mucus and despair. Answering her question.

Boxes on the MAiD application were once again ticked and answer blocks completed. How long had Julie considered MAiD? What were the details of her physical and

psychological suffering? Why MAiD versus palliative care or natural death? Why now? If MAiD wasn't an option, what then? Was there anything that would change her mind? Was she aware of other options—withholding or withdrawing life sustaining treatments, or palliative care? Was she of sound mind? Depressed? Were there any contraindications in the file forwarded from her family doctor? Were the important people in her life aware of her decision and did they support it?

As expected, the final part of the assessment, the one requiring input from the neurologist, remained unchanged. In Dr. Sand's professional opinion, natural death may not occur in the foreseeable future.

"Begging you," Julie wept. "Can't do this ... Please ... Another neurologist?" The words came in desperate punches after the MAID physician, Dr. Walker, delivered the news.

"Getting a second opinion will take a lot of time and there are no guarantees. Before I make a referral, I want to explore one other option," the MAID doctor said.

Dr. Walker scoured all three-volumes of Julie's medical files and reviewed the medical literature. What she discovered was a point of possible dispute. Julie's EDS score, a measure of disability and progression, had jumped from level 7 to 9 since her last application a year earlier. She was one point from level 10, death from MS. With three pneumonias in less than two months, the recalculated trajectory of decline deserved consideration, not just the nature of RRMS, because it meant that Julie might well experience natural death within two years.

"Living is tough ... dying harder," Julie managed to spit out after hearing that the third application was reviewed and accepted.

"It's not quite over yet," Dr. Walker cautioned. The lawyers agree that you meet the criteria but a second MAID team is required to make an independent assessment.

Fire flashed in Julie's eyes.

"I'm sorry, I can only imagine how exhausting and frustrating this is for you. We're not trying to make this any more difficult than it already is, but we have a protocol to follow, especially since your situation isn't as clear as others. Another set of eyes will ensure the right decision is made."

Findings from the second team concurred. Natural death was imminent, probably measured in months, not years.

Julie finally had agency over her dying body. No more pneumococcal waterboarding, pharmaceutical straightjacketing, bedsores, infections, and freefalling into the hands of caregivers, some who coupled care with giving, some who didn't.

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Her eyes shift in the direction of a curio cabinet—a gift from her long-deceased husband—where the clock sits, along with a swath of medical aids and supplies. Fifteen more minutes. The nurse inserts the first and then backup IV cannula.

"How you do this?" she whisper-stutters.

"Like I said before, the first medicine is a sedative. It'll make you sleepy and relaxed. Before I administer it, I'll ask you again if you're sure."

A switchblade look cuts across to the doctor.

"I know. If you hear— 'Are you sure?'— one more time, you'll ... well ... I can't imagine what you'd do to me if you could." Smiles circle the group, the widest one breaking through Julie's shrunken features, brightening her cheeks with a flush of colour.

“The second medication will put you into a coma, a deep sleep. You won’t feel a thing by the time the drug from the last syringe goes in. It’s a neuromuscular blocker and it stops your lungs from breathing and your heart from pumping blood. There’s no gasping or shaking. It’s a peaceful transition.”

“Not what I mean.” Julie works hard between bursts of hacking and gagging to make her tongue fold around the words and push them out. “Your job.”

“Ah, I see what you’re asking.” Dr. Walker crimps her lips and gathers her thoughts.

“Not easily and not lightly. I think about how I want to be treated when it’s my time. What would I want if I had a condition like ALS, terminal cancer, or MS?” Her thoughtful eyes rest on Julie. “The answer’s always the same. I’d want to be heard and respected.”

A gentle purr vibrates in Julie’s throat. Appreciation.

“And so,” the doctor continues, “I do my best to listen and try to be respectful, reminding myself always that this is about you, Julie, not me. Really, it doesn’t feel like a job, not for any of us. I know it sounds cliché, but it feels more like a calling. Hard, very hard. But right, very right. If that makes sense.”

Another purr.

The social worker pulls a book from her bag. “We helped your mom make this for you, Rae. It’s a Legacy Book and it comes as part of the MAID program.”

Rae dabs her eyes with a soggy tissue and opens the memoir, fifty pages abbreviating fifty-eight years of living—the exquisite and the ordinary, highlights and lowlights. She reads the first page; a poem Julie wrote during the dark days following her diagnosis:

Life moves the years through you

Crafting a story

Until one morning
The sun rises without you
And in the seconds before it breaks dawn
You look at who you were
And who you are
And wonder if your story
Made any difference at all

At the bottom of the page, there's a note in unfamiliar cursive.

"Your mom asked me to write that for her," the social worker explains.

You, my precious girl, have been my story, my purpose. I hope I've made even half the difference in your life as you've made in mine. My story might be ending here but yours is being crafted with the gift of new life. Please tell my grandchild that I knew. I had the joy of knowing that he or she was coming as I was leaving.

Julie's nystagmus stalls and permits her eyes to stop shifting and circling for a brief moment, to rest inside her daughter's tearful gaze. Mother and daughter living and dying together *in a lullaby for suffering with a paradox to blame*, as Leonard Cohen once said.

Briny tears pool in the nape of Julie's neck as Rae whispers in her ear. "Good-bye, Mom. I love you forever."

"Love ... you ... too," Julie gasps, weary but peaceful regard drifting to Dr. Walker with an answer to the question she knows the doctor is obliged to ask: "Are you sure?"

Her head jerks a nod and Dr. Walker releases the first plunger.

"Thank you," she whispers, as eyelids, little by little, drift to a gentle close.



Barbara Joyce-Hawryluk shifted gears from academic writing as a social worker to crime fiction in 2013. *Wounded*, her first book in the Scarlet Force series, won bronze in The Independent Publisher Book Awards for Best Western Canadian Fiction, and finalist in the High Plains Book Awards for Best First Novel and Best Woman Writer. The second book, *Bad Elf*, will be released in 2020. Inspired by real events and people, the series features Royal Canadian Mounted Police Constable Debrah Thomas and her husband, Major Crimes Investigator Liam Thomas. Barbara is a member of Crime Writers of Canada and Sisters in Crime. When she's not writing, she's reading, running, and enjoying her grandkids. Her website is <https://scarletforce.com/>