Finding Peace in a Painful Journey

Below is the story of a family who requested to remain anonymous,but wanted to share their experience with families who may be in similar circumstances.

For years, she lived with a body that hurt every day.

Diagnosed in 2005 with Ehlers-Danlos syndrome, a rare connective tissue disorder, she endured chronic pain, fatigue, joint dislocations, and a steady loss of independence that reshaped nearly every part of her life. Once a gifted artist and dedicated social worker, she gradually found herself unable to work, drive, or care for herself. By 2013, the illness had forced her to stop working entirely.

Her parents became her caregivers.

“She never knew a day without pain from the time she could talk and walk,” said Mom. “She struggled every day.”

What followed was a long and exhausting search for relief. The family consulted specialists, tried therapies, traveled to different parts of the country, and held tightly to hope. But as the years passed, her condition continued to worsen. The pain intensified. Sleep became impossible. The life she had imagined for herself—a career, a family, independence—grew more distant.

At the same time, she remained deeply thoughtful about the future. Mom describes her daughter as kind, genuine, and deliberate, someone who researched everything carefully and approached life with quiet clarity.

“She was clear-headed and focused,” Mom said. “She knew what she was facing, and she understood what mattered to her.”

That clarity led her and her parents into difficult but honest conversations about quality of life, dignity, and choice. Mom said those discussions were not impulsive. They unfolded slowly, over time, as her suffering deepened and her options narrowed.

In spring 2021, the reality of her condition came into sharper focus. “I said to her, ‘We need more help,’” Mom recalled. “And she looked at me and said, ‘No, Mom. I don’t want to live the rest of my life like that.’”

The family explored traveling to Switzerland and even submitted a deposit. But the process proved extraordinarily complicated, emotionally draining, and, ultimately, impossible. COVID-19 restrictions, international travel requirements, financial hurdles, and her fragile condition all combined to make the trip unworkable.

That is when Final Exit Network became more central to the family’s thinking.

Mom said what mattered most was not just logistics, but the sense that their daughter was being heard. After years of medical frustration and feeling as though others did not fully understand the magnitude of their daughter’s pain, the family found comfort in conversations with people who did.

“She found peace and comfort in knowing that there were organizations out there that could help,” Mom said. “And that supported her.”

For Mom and Dad, that support made an enormous difference during one of the most painful periods of their lives. Mom described the people they encountered at FEN as compassionate and steady at a time when their daughter needed calm, not judgment.

“FEN turned out to be magic,” Mom said. “Her passing, if one can put it this way, could not have been more perfectly orchestrated.”

This young woman, who loved the color purple and butterflies, died in early 2022 at home, wearing her favorite pajamas, with her dog on her lap and her parents by her side.

For Mom and Dad, the loss remains profound. Mom speaks openly about grief, and about how even a decision made with love and conviction does not erase heartbreak. “Losing a child is not the natural order of things,” she said.

Still, she remains certain that their daughter’s choice came from a place of thoughtfulness, not despair, and that honoring it was an act of love.

“Mom, it’s not something I want to do,” Mom recalled her daughter saying. “It’s something I have to do. I cannot go on like this.”

Today, Mom remembers her daughter not only for the suffering she endured, but for the tenderness and authenticity she brought to the world. “Kind, genuine, authentic,” she said. “A person that everybody liked.”

And in the end, Mom said, the family’s decision came down to one thing: giving their daughter the dignity, peace, and agency that illness had taken from so much of her life.

For them, it was the right—and only—choice.