The Loneliness of Mental Illness at the End of Life

Eileen Ahearn, MD, PhD

hen we first met her, it was about hospice care. She was a small, elfish woman, 75, with thin spindly legs and sunken eyes. Standard-issue green nonslip hospital socks pointed out from underneath an old crocheted afghan. Her daughter, worried and tearful, sat at the foot of the bed. The room was late American nursing home: beige with reprints of placid winter scenes on the walls. The decor was a wan attempt to warm up an unmistakably clinical setting.

She said she was trying to make the best of it. The news was barely 2 weeks old. Someone noticed a strange yellow tint to her skin, then there came ultrasounds, CT scans, visits with surgeons and the oncologist, and the diagnosis of advanced pancreatic cancer. "I don't want to do all that," she said. "I am ready to go." We told her we were there to help her have a good death, her way, with some dignity and as little pain as possible.

She told us of her miserable marriage, her belittling husband, her tormented life. She had done everything to be a good wife and mother, raised 4 children, cooked, cleaned, kept the house going. But it was never good enough for him. She had been trapped for years. Finally, 4 months ago, she had gotten the courage to escape. She moved to a shelter for abused

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Corresponding Author: Eileen Ahearn, MD, PhD, William S Middleton VA Hospital, 2500 Overlook Terrace, Madison, WI 53705; phone 608.280.7084; fax 608.280.7204; email eileen.ahearn@va.gov. women, at a secret location. She wanted to make a clean break, and decided to break from her husband, from her entire family.

The people at the shelter helped her to get an apartment and plan for divorce. They were wonderful, she said. They really understood her. And, she loved having her own place. It was liberating. She got a small dog named Sam and she planned their days around walks and watching TV, side by side. She could make her own schedule, go out with new friends. She started going to a local Lutheran church with some neighbors down the hall. She was a Catholic, but it didn't make much difference to her. Church and then lunch afterwards. She was happy and safe, finally shed of her abusive husband.

But then the cancer diagnosis. She was shocked at first, but then it seemed in accord with the harshness of her life. She settled into the news. She contacted her daughter to drive her to her appointments and move her into the nursing home. The other siblings came by to visit. The family was invited back into her life, except of course for the abusive husband.

After our visit, the daughter followed us out of her mother's room. We walked down the hall, past milling patients with walkers, past the nurses' station and the portable medicine carts. There is something you need to know, she tells us. Her mother's story is "not quite right."

"None of what she said about my father ever happened. He was a devoted husband who never was mean to her. She remembers her life all wrong." As it happens, none of her adult children nor her husband know what started this derailment in thinking. "Now she wants us back in her life, as if nothing has happened. And there is hardly any time left."

We are drawn up short. We can't be cer-

tain of the cause, we tell her, but we will try to shake loose these false beliefs. We offer words of support, a medication to try, a promise to return, and the hope that there is still time to reunite the family. The daughter looks at us. She is worn out and doesn't seem hopeful. The terminal cancer diagnosis was hard news, but the ongoing rupture of the family has been devastating. It has all been too much.

Cancer may ravage the body, but there is a known trajectory of treatment options and outcomes. People understand what terminal cancer means and they come by to visit: the minister, the old neighbor, the former colleague. They come and go as you lie in bed and your spouse sits quietly nearby. In the end, you can hope to experience the end of your life surrounded by family and friends with soothing words and gentle care as you take your last breath.

Her cancer death will be a sad passage, but all the more so if she remains lost in a delusion that has rewritten her life, taken her family from her, erased her husband, and left her utterly alone. Her children do not recognize the person she has become. The husband will not be there at the end; the daughter will do what she can between shifts at work. Perhaps the minister can stop by. The staff will show kindness, but it will be a lonely death if she does not return to her right mind. Mental illness has a cruelty all its own.

Postscript

The patient was admitted to hospice care and an antipsychotic was tried with no improvement. The hospice team focused on comfort measures and helped the family through this complex goodbye. The patient died peacefully 2 weeks later and the entire family, including the husband, was present at her funeral.



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