Daring to Dream

Category: Stories
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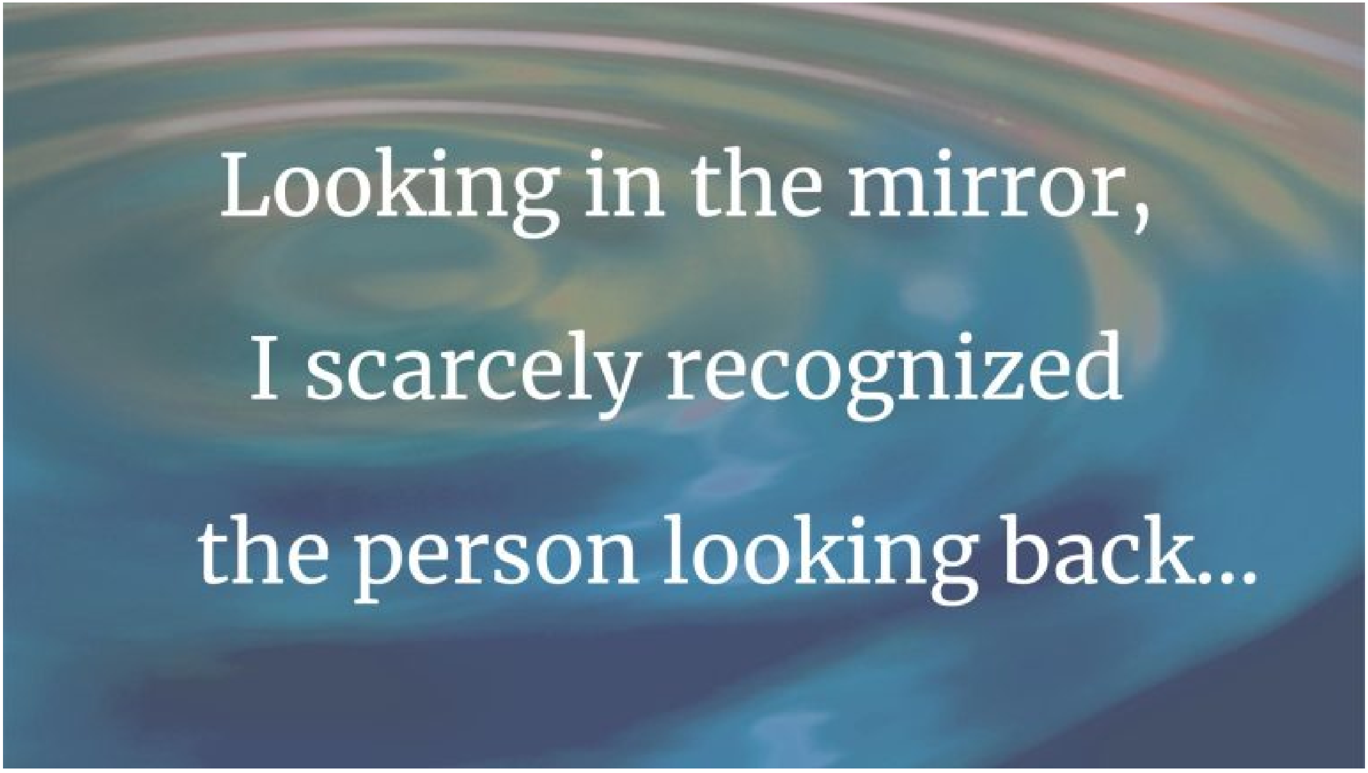

Looking in the mirror,
I scarcely recognized
the person looking back...

For the past three years, I worked as a rural primary-care doctor. Two months ago, I resigned to pursue further training in hospice and palliative care. My patients were the inspiration that illuminated every step of my way towards this new path.

Marly came to me for a workup of her persistently elevated liver enzymes. Together, we navigated her new diagnosis—liver cancer—and a series of failed treatments. Eventually, Marly's thoughts turned to facing her mortality.

I remember our frank discussion about the mystery surrounding our earthly timeline. I asked her what she wanted from the rest of her life.

Her first priority surprised me: "I want to keep my nipples from showing through my shirts." Her bulging abdomen, distended by her disease, made it impossible to wear a bra without discomfort. "I want to be able to enjoy lunch with my friends and go shopping with my daughter without worrying about my top."

The only remedy I could think of was pasties. Together we researched options on Amazon. I will never forget how much Marly laughed about that; we both learned that people can find joy in any moment.

Marly also shared her fears. "If I take my pain medications now, I'm worried that the pain will be so bad near the end that they won't work anymore," she said.

We discussed this. I reminded Marly that, although the doctors had given her one to two years to live, we didn’t actually know how much time she had left.

“Whether you have six months, ten months or five years, why torture yourself during any of it?” I asked. By the close of our visit, her focus had shifted to dealing with the present, which included taking her pain medications as needed to keep herself comfortable and functional.

Marly passed away a few months later, but not in the way I’d expected. On her way to lunch with friends, she slipped and fell on the ice. I suspect that this caused internal bleeding. Later that night she passed away at home, with her husband at her bedside. The irony of this was not lost on me as I recalled our conversation about the unknown timing of “the end.”

Another patient, Beth, went to the emergency department after a fall. A CT scan revealed a mass that turned out to be pancreatic cancer. The cancer was advanced, and the treatments were palliative at best. She declined quickly and soon transitioned to hospice.

She had been my patient for two years, but our visits had been infrequent, and I knew very little about her as a person. Despite this, I felt a need to be present with Beth and her family during this time. I added her to my home-visit schedule, making sure that she was my last visit of the day.

My medical assistant and I walked into a very somber home. Beth lay in bed, skin mottled, face set in a grimace.

“The hospice nurse just left,” one of her daughters said. “She’s going to call you to approve giving her more morphine.”

I called the nurse on the spot, and we made the necessary adjustments. Then I sat beside Beth’s bed and held her hand, watching her face relax as her daughter administered the morphine, and listening as her family shared stories amongst themselves. They talked about her love for knitting, for cooking; how much she loved making things for her grandkids and her neighbors. I also learned of her love for cats, which had intensified after her husband’s death.

I spoke to Beth, even though I couldn’t be sure she knew I was there. I told her how strong she was, how much I could tell her family loved her and how honored I was to be her doctor. She passed away a few days later, and I was grateful to her family for letting me share that precious time with them.

Nancy was another patient whose situation influenced my future path. Over the last few years, she had spent more and more time lying down—a failed attempt to relieve her chronic pain. This pain, not well understood by her previous physicians, had undoubtedly eroded her quality of life.

Entering her apartment for a visit, I was pleasantly surprised to see her standing up without her walker. Unfortunately, this lasted only a moment, because she was on her way back to bed.

When we first met, Nancy went to the supermarket regularly and enjoyed weekly trips to the local thrift store. Sadly, within a few years, her pain had made even the ten-minute drive to my office too difficult, and she spent most days confined to her bedroom. She’d seen every specialist I could think of; all of their notes ended with some variation of “We have nothing further to offer this patient.”

I tried referring her to palliative care, but this was denied due to a lack of local providers. Even had it been accepted, I’m not sure that she could have tolerated sitting upright for the sixty-mile drive to attend the mandatory in-person initial consultation.

Nonetheless, I was determined to do whatever I could for her.

“I’m going to keep trying to find a way to treat your pain,” I told her. Even though I was unsure of what I could do, something in my tone of voice must have lifted her spirits. She rose from the bed to give me a tearful hug.

“It’s felt like everyone has given up on me,” she said.

“I’m not giving up,” I reassured her.

Every patient encounter unveils a lesson; sometimes, it’s an awakening. Marly, Beth, Nancy and others have opened my eyes to my passion for hospice and palliative care; they have sparked a burning desire to bring these direly needed services to rural communities.

At times over the last three years, I have also felt a different kind of burning: searing rage at a system that continues to fail so many of our patients. The list of injustices is long.

Unnecessary, drawn-out prior-authorization processes that delayed my high-risk obstetric patient’s receiving Makena, a hormone medication that reduces the risk of pre-term labor.

Insurance companies that refuse to continue covering diabetic medications that have kept my patient’s blood sugars well controlled.

Insurance companies that will pay for pharmaceuticals, but won’t pay for physical therapy. I could go on.

My encounters with the corporate profiteering model of modern medicine threatened my belief that this is my calling. Looking in the mirror, I sometimes scarcely recognized the person looking back at me. She was angry, confused; she felt stuck. Despite this, I remained determined to keep holding my values close to my heart: dedication to service, love for teaching, the importance of listening.

My experiences with patients like Marly, Beth and Nancy have reminded me that medicine and healing are indeed my calling. One of my hardest lessons has been learning to listen to myself as closely as I listen to my patients—to care for myself as much as I care for them.

As I look forward to beginning my new training, my goal is to bridge the gap between primary care and hospice/palliative care. I hope to teach other primary-care providers the palliative-care skills needed in rural communities like the one I served. Recently, I’ve been dreaming about starting my own home-based palliative-care practice.

My hope is that expanding my training will allow me to continue doing the work I love as a doctor without feeling like a cog in a wheel.

I must hold onto the dream of doing this work, both for the sake of my future patients and, just as importantly, for myself.

Because what is life without a dream?