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Writing Sample: Essay

Family Secrets: On Hiding a Diagnosis

Was I better off not knowing how little time my dad might have to live?

It was a question I asked myself every day after my father was diagnosed with pancreatic cancer. He found out at the start of September. I didn't know until the first week of October. I had suspected severe illness when, two weeks after his bout of "strange stomach flu," my mother Skyped me from a hotel room in Boston to tell me my father had just woken up from a 12-hour surgery.

She hadn't said anything before that. It was only when he was leaving the hospital a week and a half later that she mentioned the c-word. She didn't tell me the type, how far along he was, how much time he had. All she said was he had "something called a whipple" and that everything was going to be fine.

Knowing nothing but grasping for reassurance, comfort, knowledge, something, anything, I did what any 21-year-old does nowadays: I Googled it.

Invasive. No cure. Dangerous.

Three to six months. I thought knowing was supposed to make me feel better, that having a timeline would help me prepare. But all I could think was that my dad might not even make it to my graduation in May.

Was it better that my mom avoided the diagnosis, that she tapped into maternal instinct to protect me from fear and heartbreak? Her decision waylaid an anxious conversation, but I was left with an even bigger fear: what else about his sickness might they tell me? How could I stay calm about what was going to happen next if I thought I was missing so many important details?

Not knowing where to turn for advice, I began researching and contemplating the cancer process, how it affects families on an emotional level, and how I might better prepare for what would come next.

Protective Instinct

Psychologists refer to the process of hiding one's feelings as emotional buffering. It is common for patients and families to hide details about sickness so that they might also hide their pain.

When a family member is diagnosed, parents face not only the anxiety of treatment but also the stress of relating the news to family and friends. A cancer diagnosis unleashes anxiety and fear; by waiting to share the news, patients may feel that they can suspend their loved ones' grief and give them more time to carry on with normal routines. Some people feel uncomfortable relating what they know because they don't have a clear, certain understanding of what will happen next.

Dr. Melanie Bone, a cancer survivor and gynecologist in Miami, Florida, believes that it is not only the fear of death that pushes patients and caregivers to hide the truth, but also the perception of pain and the stigma related to the disease.

"Wouldn't it be nice if one day the word cancer was as scary as the common cold?" she writes in her blog. "Then, being diagnosed and treated wouldn't be as traumatic. Certainly, there wouldn't be a need to hide the diagnosis if the norm was a good prognosis."

Dr. Michael Constantine, a professor at Harvard University and an oncologist at the Dana-Farber Cancer Institute in Boston, stresses to his students the importance of honesty in

assisting patients with their treatments. He strongly believes that open discussion can alleviate patients' and caregivers' apprehensions.

“People are fearful of the unknown,” he says. “So the two most important aspects of discussing a diagnosis with a patient and his or her family are honesty and developing a plan of care. If you are always honest with them, and you have recommendations for a plan to care for them, then most of the fears and concerns are diminished.”

Oncologists consider family members as “second-order patients” and do their best to cater to families' unique needs. A strong demand for answers can distract caregivers and thus destabilize normal routines, an important piece of maintaining strength during treatments.

Even children who live apart from their parents face serious emotional effects. In a recent study titled “Parental Cancer: Catalyst for Positive Growth and Change,” Australian psychologists Janelle V. Levesque and Darryl Maybery surveyed adult reactions to parental cancer, further supporting and calling for research related specifically to how adults handle a parent's cancer.

“It should not be concluded that the impact of parental cancer is minimized simply because the dependent child-parent relationship is no longer present,” they write. “For some participants the realization that their parent was not infallible...challenged their sense of security and place in the world.”

Maintaining a Dialogue

Hiding details about the diagnosis might initially keep loved ones from emotional stress, but it also might affect a family's ability to provide care. Following a diagnosis, a caregiver faces intense grief but also takes on an intensely active role in the patient's treatment. In the beginning,

he or she will go with the patient to new places for treatment and help make decisions about a treatment plan. The caregiver's role increases throughout treatment as he or she takes on more household duties, manages hospital visits, and provides emotional support for others.

Dr. Myra Glajchen, social worker and creator of the Family Caregiver Program at New York's Beth Israel Medical Center, notes that family caregiving becomes more and more important as more effective treatments develop. In a recent study, she writes that care for patients has shifted from the hospital to the home because of the increased use of outpatient services, shortened hospital visits, and longer and greater chances for survival.

"The cancer experience affects not only the patient but also the caregiver, and in profound ways," she says. "Caregivers have their own emotional responses to the patient's diagnosis and prognosis and may require coaching and emotional support separate and apart from the patient...Family members of seriously ill patients have been found to experience as much, or more, distress than even the patient suffers."

When I returned home for break the first time after my dad's diagnosis, caregiving started with establishing our normal routines. Our fight against my dad's disease began with something as simple as watching a Patriots' game.

Nestled under his red fleece, I couldn't see the strings and gadgets at his stomach. I didn't notice the weight he'd lost. But his face was drawn, his eyes were tired, and I realized what he and my mother had tried to hide from me, the ordeal from which they had spared me.

In that moment, I did all that I could: I offered them some tea.

"Two scoops of sugar, please," he replied as the camera panned to Bill Belichick storming on the sidelines. "Thank you, sweetie."

I'm not a doctor. I'm a twenty-something. I can't work miracles. I can't change that my dad got sick. But I can try to make things a little easier. I've learned to vacuum when mom and dad go for their weekly chemo date at Dana Farber. I'll actually remember to put the dishes in the dishwasher. When we go to treatments, I can grab fruit cups from the fridge, sit with him and mom, and watch home makeover shows.

It might not be a normal Monday afternoon routine, but it's *our* routine. As long as I know what's going on with dad and as long as I don't hug his stitches too hard, it's all okay.