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When Patients Don't Want to Know

BY JOANNE KENEN

Denial places added burden on caregivers.

Don Fisher was crushed when his wife, Susan Duffy, was diagnosed with sarcoma in the spring of 2000. She was 50; they had been together nearly 30 years. They were an unusually close and loving couple. They talked about everything. Except her prognosis.

Fisher, a professor in the department of mechanical and industrial engineering at the University of Massachusetts in Amherst, liked knowing the facts, the odds, the statistics that form the matrix of survival. Duffy, a professor of psychology, did not.

“I think,” Fisher recalls, “she lived on hope.”

At first, her odds were pretty good—a 75 percent five-year survival rate for her form of sarcoma. But Duffy got sicker. The doctors at Massachusetts General Hospital recognized that she did not want or could not talk about it, and for the most part, they matched their vocabulary to her attitude.

“They would tell her that they would take ‘very good care of her,’ ” Fisher says. Even when they eventually eased her into hospice care at home, they found a way to continue chemotherapy. She would lie on a mattress in the family minivan, too sick, too weak, and too afflicted by bed ulcers to endure sitting for the 90-mile drive to the hospital. Still, it was all about hope.

Don Fisher could talk to his wife about chemotherapy and radiation. They could talk about their two daughters, Annie and Jenny, who were 10 and 15 at the time. But they never discussed the end. They didn’t discuss where she would be buried or what kind of memorial service she wanted, other than one quick comment about wanting to thank family and friends.

She dismissed her husband’s suggestion that she leave letters for her daughters to open someday, maybe for a graduation or for their weddings. Too hard, she said. And it was only years later that Fisher learned she had pulled aside that curtain of hope, at least once, to tell a social worker she hoped Don would find

someone else someday.

““ The key is finding the right moment to bring these questions up, and for the patient, family, and health care team to work through them together. ””

—Richard Hara, PhD

Hoping for the Best, Preparing for the Worst

For caregivers of cancer patients, life is a demanding balance of preparing for the worst, while hoping for the best. It can be even harder when the caregiver knows the story won't end happily ever after, but the patient is adamant about not wanting to know his or her own prognosis.

“Family caregivers want to plan, they want to anticipate, they want to know what they have to do, how to get ready. They are driven by just the pragmatic demands of caregiving, which are huge. It is just so much work to be taking care of someone who has cancer,” says Anthony Back, MD, an oncologist at the Fred Hutchinson Cancer Research Center in Seattle.

Physical caregiving may be hard, but so is the emotional work.

“Closure work is hard, in a different way,” says Back. Not all couples are as happy and affectionate as Fisher and Duffy were; most have things to say (or unsay) toward life's end. But if one person won't acknowledge that time is running out, it makes closure even more difficult.

That doesn't mean a degree of denial doesn't have its place. It can even be healthy. Ira Byock, MD, director of palliative medicine at Dartmouth- Hitchcock Medical Center in Lebanon, New Hampshire, likes to envision denial as a spigot on a faucet: “It allows just enough bad news to flow as you can stand or tolerate.”

Usually, the flow changes as the patient and family adjust, striving anew for that balance of preparation and hope. But when the spigot stays too close to the “off” position, denial can become a hurdle. It makes it harder for the caregiver to tackle the mundane but necessary financial and legal tasks. It makes it harder to shift gears from aggressive treatment to more palliative care or eventually hospice. And it can make it so much harder to do the sad, hard, but often healing work of what Byock calls “relationship completion,” the emotional closure and goodbyes that can yield unexpected moments of grace and clarity even in a time of piercing grief.

Families who find themselves at polar opposites on the “facing reality” spectrum aren't all that common, but they aren't unheard of, either. Usually patients do know at some level that time is running out. Many doctors and social workers believe people have a sense of when their health is failing, even if they don't articulate it.

“The dying process sort of shows you,” says Richard Hara, PhD, a social worker at CancerCare, a nonprofit support organization for patients and caregivers. “They

know that something serious is going on, that larger questions are there. The key is finding the right moment to bring these questions up, and for the patient, family, and health care team to work through them together.”

A Bit Out of Sync

Even if most families arrive at common emotional terrain by the end of life, they may travel there at different speeds and communicate (or fail to communicate) in different ways.

“It seems like they are often out of sync a little bit. Family members and patients want to know different things, from the time of diagnosis all the way to end-of-life care,” says Back. Sometimes husbands and wives may both know the score but each one pretends, trying to protect the other in what Byock calls “a conspiracy of denial.”

“I can talk to a patient who will say, ‘I know I’m dying but don’t tell my wife. It will kill her.’ Then I go out in the hall and his wife will ask me how he is doing, and I’ll say, ‘Not very well’ and she’ll say, ‘I know he’s dying but don’t tell him. It will kill him,’ ” says Byock, whose book *The Four Things That Matter Most* helps guide people through difficult but necessary conversations.

A clinician with tact, wisdom, and experience can help people bridge that gap, and can also gently move them toward some choices and decisions about health care proxies, advanced directives, and end-of-life care.

Lack of open communication doesn’t mean a lack of love.

“I had a patient, a middle-aged woman dying of colon cancer,” says Lidia Schapira, MD, an oncologist at Massachusetts General Hospital Cancer Center. “She wanted to talk about it. She wanted to choose the dress she’d be buried in, she wanted to choose her plot. But her husband couldn’t do it. There was no hidden agenda. There was lots of love. He knew. They even had called home hospice. But he just couldn’t talk.”

The patient asked Schapira to help. “Not to force him to talk. But to try to explain to him how important it was for her to have an honest and completely sincere conversation.”

As a social worker, Hara says he tries to work on family communication early, soon after diagnosis, to promote good communication through the course of the disease and to avoid getting to that stressful point where everyone is afraid to say out loud what everyone knows is true. Some cultural or ethnic groups have more taboos about discussing cancer, or death. Some families are just more fragile. Doctors and social workers agree the caregiver shouldn’t force the patient to “accept reality.” But the caregiver should seek help.

“It’s not the family member’s job to give the prognostication—it’s never the family member’s job. That is too hard,” says Back. “But if you are not sure what to do or say, that’s a good time to ask someone for help.”

If a family isn’t comfortable talking to the oncologist, or they sense the oncologist is not a great communicator or doesn’t understand the family’s cultural mores

and traditions, they can approach the nurse, who may know how to best get help from a social worker, psychologist, chaplain, or other spiritual adviser.

James Avery, MD, senior medical director at Visiting Nurse Service of New York hospice, has worked with countless cancer patients and has developed a seven-step program to help physicians break bad news and give patients and caregivers what they need to plan, to prepare. Part of his process is to explicitly ask, “How much do you want to know? Do you want to know everything?”



Don Fisher with his daughters, Jenny and Annie (right), and their dog, Fudge. Photo by Joseph Kushick.

Schapira says there are parameters in oncology. “If somebody is really in denial, you better respect that denial. That person honestly cannot deal with the information.”

Most patients, however, are not in denial, she says. “They choose to defer accepting that they know something, or they downplay it, or they don’t want to let you know they know. We can gently—gently—chip away at that. They may be terrified or extraordinarily sad, but with a good approach, a good constant presence, they will come around. And they are relieved. Relieved that they don’t have to bear it alone.”

Don Fisher and Susan Duffy were never alone; they had a supportive family and a close community who helped them right up to her death on Valentine’s Day 2002.

“Did she know she was dying? I still don’t know,” her still grieving husband says. “But she was a very happy person. We had no regrets.”