Managing Expectations

When I was in training many years ago, I struggled with the knowledge that most of my patients would succumb to their disease while I was also trying to partner with them to “get better” to whatever extent treatment would allow. I remember asking a beloved senior mentor what to say when my patient with metastatic pancreatic cancer tells me they hope they will be cured. She responded quickly and simply: You say, you hope so, too! That lesson has helped me over and over again throughout my career.

When we meet a new patient, we have a lot of teaching to do. What does the diagnosis mean? What are the goals of treatment? What treatments are available? What are the side effects? Is cure possible? If not cure, can we make this a chronic condition? The list goes on.

Often, a patient looks me in the eye and asks directly, “How long will I live?” They ask as though I have a crystal ball on my desk and that I’m a fortune teller. My answer is always the same: I don’t know. I can tell a patient the average lifespan for a group with their disease and the range of possibilities. But, in fact, lifespan for any given patient depends on the outcome of treatment and perhaps a bit of luck.

Although I don’t think we should ever sugarcoat a grave prognosis, I also don’t think it’s wise to steal hope away entirely. In fact, I think that can drive a patient to explore alternative therapies that often have no foundation and can actually be harmful. To be clear: I don’t dismiss all alternative therapies, but many are promoted with outrageous claims and often come with a very high price tag.

And I teach trainees that you do need to be open to miracles. I follow several patients who have outcomes that you would not think possible. These patients with bona fide pancreatic cancer and biopsy-confirmed metastatic liver or distant nodal or lung disease are in complete remission for years. My record holder is 10 years at the moment. Did my treatment do this? Did some alternative practice that my patient didn’t tell me about do this? Is it just a divine gift?

I’ll never know.

The point is, it can happen. So when patients ask me if I have ever seen someone with their diagnosis survive, I can honestly say, yes. Not often, of course. But emphatically, yes.

The other point about hope is that a better treatment may be just around the corner. Over the years, we have seen new drugs or better treatment strategies emerge that made the impossible possible. A case in point is curative immunotherapy in metastatic melanoma. Although that might not have been such a stretch of the imagination, how about immunotherapy in metastatic lung cancer? Bet you never saw that coming!

So, I leave you with a parting thought. Sick or not, we should all have our affairs in order in case a calamity occurs. But if it does, remember this, too: It is okay to hope, even for a miracle.

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