

Good Palliative Care, Bad Palliative Care: A Tale Of 2 Doctors

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As a Stage 4 colorectal cancer patient, I have had experience with palliative care doctors. Fortunately, I haven't had the need to meet with one in a few years.

But recently, I started experiencing pain that didn't go away with my normal methods. I have a high pain threshold, and when I do have pain, I view it as a message from my body and I do my best to work with it. I also have a number of mind-body methods that I use to manage the pain.

I can't recall ever taking drugs for pain. Even after my mastectomy, I didn't need any pain medication.

But when this recent pain couldn't be managed by my usual approaches, I resorted to taking two Tylenol, which I considered to be strong medicine (well, outside chemotherapy drugs!).

Still, the pain, even after taking Tylenol, was debilitating, so I decided to ask for something stronger. Asking for pain medication was new territory for me, and a big step.

I wrote a piece about on how wonderful I found palliative care doctors, and I made the assumption that they were all the same. So when my palliative care doctor couldn't see me for a week, I agreed to see a different palliative care provider.

In this case, she was a nurse, though I don't think that is the relevant difference. I walked into her office, nervous about starting on pain medication. Here are some assumptions I had about pain meds and cancer patients:

- 1. It isn't a temporary situation and the dose only increases until you die.*
- 2. You can't drive while taking them, so your life is even more restricted than it already is.*
- 3. They can be addictive.*
- 4. Pain gives me a message about how my body is doing, and without feeling that, I would be out of tune with my body.*
- 5. You are to take pain medication before you really feel the pain, to "stay ahead of it." But what if I take it when I don't really need it, when the pain would not actually get worse?*
- 6. Narcotics cause constipation, which is a problem for me to begin with.*

I explained all this to the nurse, and the fact that I really don't take pills. I also explained that I tend to vomit during chemotherapy, which makes it difficult to swallow pills. I told her that I wanted to understand more about what I might be taking.

She sat quietly and let me speak, then she said, "You need to take this" and wrote out a prescription for a narcotic.

I was stunned and didn't know where to begin.

"Is there something I can try that is between regular strength Tylenol and a narcotic?" I asked her.

"I believe this is the best for you," was her firm reply.

“Is it true that I won’t be able to drive when I am on this?” I asked. I could feel myself trembling. (This on top of not feeling well anyway, which makes it hard to think clearly, and harder still to advocate for myself.)

“You shouldn’t be driving if you are in pain,” she countered.

At this point, I was shaking. I told her that I have trouble swallowing pills, and she told me they weren’t that big. That didn’t help. I have trouble swallowing tiny pills.

She just stared at me and, **although I wanted to understand more, I couldn’t form the questions and she wasn’t talking. She was a large, fixed object that I couldn’t move or even get around.**

Since September 2007, when I was first diagnosed, I have probably cried fewer than 10 times. I left her office shaking and in tears. I held onto the prescription like a child who was following orders they didn’t want to obey, and I was about as scared.

Over the following days, I realized that I couldn’t fill the prescription. **I knew that every time I took one of those pills, I would think of that meeting and feel powerless,** which isn’t good for my own health.

I continued to live with the pain, regrouped and booked an appointment with my palliative care doctor. I didn’t care if I had to wait.

The appointment day finally arrived. When my doctor walked into the office, she smiled and asked if she could hug me. I immediately felt uplifted and the pain receded into the background. I kid you not.

We talked. We caught up on life -- how my kids are doing, how my husband is handling everything, how my spirits have been.

We soon got to the reason for my visit. She had read the notes that I had seen someone else in palliative care and asked why I was there to see her so soon afterward. I recounted the story as she watched me and listened carefully with her entire body.

When I was done, I told her that even if she prescribed the same drug, I wanted a new prescription because I would feel better taking it.

She understood. She explained that, at the dosage she prescribed, I would not get addicted to these drugs. She told me that they are not a one-way street to death, and certainly not in my case.

She explained that **painkiller can be used to improve your quality of life, they can be used as needed, and she would monitor me. She acknowledged that pain can be an indicator of how I am doing, but we decided that a good time to take a painkiller would be when pain interfered with my sleep. I didn’t need to receive messages in the middle of the night.**

She explained why she choose a narcotic rather than a stronger version of Tylenol, and I felt ready to explore options.

We tore up the prescription I had and deleted it from the electronic system. She looked for something that might come in a liquid or dissolve in my mouth. Then we narrowed it down to the least-constipating option.

We decided on Tramadol and she told me to get a pill cutter to take one-fourth of the pill. She smiled when she told me that she was only going to prescribe 10 pills rather than a full prescription because she knew I wouldn’t use them all. She asked me to let her know how it went, and to book a follow-up appointment.

I left her office walking on air. My pain was gone without any pills, and although it did return over time, it was intermittent and bearable. I have been able to manage it without narcotics, though it is nice to know that I have something to take if I needed it, and a caring doctor to listen to me as well.

Since my initial diagnosis, I have been through much testing, many surgeries, countless rounds of chemotherapy and some radiation. I have been under the care of a variety of doctors, some of whom I adored and some who had me running scared. But after eight years, I started to feel like I could handle anything thrown at me.

I was wrong.

My visit with the nurse I just met and my visit with the doctor I love took approximately the same number of minutes. But after the former, I felt weak and disempowered. After the latter, I felt strong and full of life.

This experience reminded me of the importance of my relationship to my physician, and that I cannot handle everything alone. My doctor or provider's attitude, his or her words and connection to me as a human makes a physical difference in my well-being. This may not be true for everyone, but for me, it helps when I am heard, and when my concerns, which may not seem like much, are taken to heart.

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