

A PIECE OF MY MIND

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Where Do You Put the Pain?

When I was a resident, I worked with a young physician who had horrible luck. She was one of those doctors reliably in attendance for the presentation of the sickest patients. So, as a very young physician, she saw many heartbreaking things and was present for the deaths of many children, in spite of her brilliance and hard work. Near the end of our training together, she asked me, "Where do you put the pain?" She went on to explain that she understood her role as a physician at the end of someone's life, and she wanted to be present for the children and their families in these terrible times. She just didn't know how to cope with the human aspect of the experience. Physicians are not supposed to feel as much as our patients and their families feel. At least, not in public. And, I suppose, we do not. How would we ever return to work if one patient's death hurt us as much as if it were actually our own child? No one could do that over and over again. But we do feel the pain. It isn't our child, but it is a human life, and it hurts like hell to watch them suffering and dying.

So, where do you put the pain? She was speaking of the anguish of watching, again and again, when all the science, learning, and technology of humankind is worthless, when a child is just not going to survive, no matter what. Since then, she and I have both grown as physicians, and we both care for children fated to die. I haven't figured out why a child should have such a fate, and I think I will always struggle with the idea that any child should. Nevertheless, I know it is true. There are children whose diseases are simply so terrible that we have no medical cure for them. I could write about the philosophy of this for pages and pages. But that is not the point. This is about the psychological impact of caring for dying children and how we, the physicians, cope with the pain.

The pain cannot stay inside us. *That* I have learned for sure. If we attempt to simply bottle up the pain and move forward as if we don't feel it, we experience burn-out (also termed *compassion fatigue*). This is what happens when the pain of watching people suffer becomes so great you simply turn a blind eye to it. (Is this what happened to Dr House?)

How do we cope? I have come up with one of the strangest ways I know of: I travel to the homes of my dying patients. That's right, I make house calls. I see my dying patients as often as I can, driving hours in all kinds of weather, all around my state. I learned this from a wonderful palliative care physician I trained with before I became an attending physician. He told me it was good for *him*, and I didn't understand. Now, I do.

The driving ... hours alone in a car. South Carolina is a beautiful state. But I'm pretty much alone with my

thoughts. People know it's my "out of town" day, so they don't page me much. None of my family or friends call, because they know I'm working (like most people do in the middle of the week). So I can listen to music, muse on the nature of life, think angry thoughts at God, or just drive. For hours!

Then, I see my patients in their element. I meet their cats. I see the playhouse someone built for them. I watch their siblings run through the grass in the sun and rain, too young to focus on the tragedy their family faces. I see life. Life in the face of death, when children are at their most vulnerable, when their parents are tired and scared. I see the bravery of those parents, acting like nothing is wrong when their children can no longer walk.

We talk about medications, adverse effects, changes to come, what things might mean, how much time they might have. We talk about siblings, churches, last trips, family reunions, jokes the families have, what another family member's death might have been like, and how that might be similar or different from what they're now facing. Then we just sit in silence for a little while. I stay for 20 minutes or 2 hours, depending on the mood of the moment.

Sometimes, I do "house calls" in the hospital. Some families decide their child's death would be most appropriate in a hospital. However, if the child lives somewhere for which my hospital is too far for the family, I make arrangements with other hospitals to care for him or her at the end of life. I visit the physicians and nurses, tell them a little about what makes *this* child so special, since they didn't get to know the child when they were healthy or speaking. I talk with the family about what is happening in the hospital and why. We have the same conversations we did in the house, sometimes. Other times, we say very little, and I just put my hand on a shoulder while they watch their child breathe quietly and comfortably.

Whatever happens, I spend the time I spend, and then I get back in my car. I think it's the drive away where I do most of my coping. I almost never cry. I often listen to loud, angry music, singing along out of tune and out of beat. I listen to the rain on my windshield (it rains an awful lot in this state). That drive home is a lot of alone time. It's just me and my thoughts, which I alternately drown out and listen to. I just kind of sit in the pain for a while.

In the end, I let the pain wash through me, and I let it leave. I think of the children I've cared for, those who live and those who do not. I think of them often. I hurt for them and their suffering, but I don't put the pain anywhere. I let it wash through me and go wherever it goes.

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Conflict of Interest

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