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## FAQ: What might I expect to happen when someone I'm caring for is dying?

This is a difficult topic for many people to think about, and especially to bring up in a public forum, but people still want and need to know what they might expect as they or someone they care for are declining. It is understandable to fear the unknown, and to fear suffering. I would say that there are a few leading points here:

- 1) Most patients don't suffer much as their cancer progresses and as they transition through the dying process.
- 2) This process is quite variable from one person to another, but we typically have a good idea of what a patient's leading problems will be weeks to months before a person is experiencing a more rapid decline.
- 3) Engaging hospice services/palliative care can help guide expectations and generally manage many of the problems effectively by anticipating them, rather than waiting until very late to accept palliative care.

While I would never want to romanticize or minimize the challenges of the dying process, I find that the majority of my patients experience a controlled decline in which they really don't suffer. The most common pattern I see is that someone with a progressing cancer will slow down, eat less, begin to lose weight more steadily, and just gradually become less and less active. They no longer go out on walks, then leave the house less often, then spend more time alternating between sleeping and getting up in a chair, then eventually get to a point where they are sleeping most of the time and are pretty much bed-bound. They have less interest in eating, which is sometimes frustrating to the patient but often more so to the family and supporters of the person, who may pressure the patient to force down food that they have little or no appetite for (the danger is that some patients describe distress from the unyielding pressure from well-intentioned but nagging loved ones). Soon, they are sleeping more and more, to the point that they eventually sleep all of the time and are no longer communicative; this is followed by irregular breathing, more prolonged pauses between breaths (called *agonal* breathing, though it isn't uncomfortable for the person, just a reflex — the last phase of the dying process), and then they stop breathing. It's important to remember that this common pathway of progression isn't a lack of will on the part of the person with progressing cancer: they would eat and be more active if they could, but the cancer pours out toxic proteins that mediate this inexorable process.

It's true that some patients have pain, or a terrible cough, or shortness of breath, agitation, and other problems, but I would say that most of the time, we have signals that these are going to be issues for a long while before the later stages, and it's advisable to deal with them as aggressively as possible *before* these symptoms become a crisis. Secondly, I most commonly see problems emerge when people (patients and/or their doctors) are very resistant to enlisting hospice support, which typically does a very good job of addressing symptoms proactively, before they become a crisis, and also being able to provide the comfort of helping patients and

families/caregivers to understand what to expect in the near future. Just as on a plane, turbulence is much easier to understand if you know to expect it, what it represents, and how you'll get through it.

About 20 years ago, I spent some time in medical school doing home visits with the very compassionate and thoughtful Medical Director of a Boston hospice. I asked him about his feelings on euthanasia, and he told me that he didn't actually feel that it was a pressing need in almost any cases. Specifically, he noted that it was most common for people to fear two things about dying: being alone in being in pain. Though being a primary caregiver is a very hard job, it is a great blessing to have someone there to help as a caregiver to a terminally ill patient — something that even attentive medical care can't substitute for. That care and the ability to ensure that people aren't alone is incredibly helpful. But a medical team today can usually do a good job to minimize the physical suffering of the process — to relieve pain and other symptoms. And most of the time, what we see is a patient gradually withdrawing and eventually passing comfortably.

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