

[Track 8: Survivor Stories: Symptom Management]

[Lupe]

We already spent some time talking about managing pain. Let's talk now about other symptoms that might worry us. How about breathing? One of you mentioned you were afraid of not being able to breathe?

[Female #14]

Oh, yes, this really scares me. I can't imagine not having my oxygen at all times. When I feel like I can't get enough air into my lungs, I panic and find it even harder to breathe. What if there comes a time when I just can't get enough oxygen?

[Lupe]

As you know, oxygen helps you function with less strain on your lungs and heart. You can sleep better, and thus take fewer naps. This allows you to be more alert and active, and feel more independent. You can get as much enjoyment as possible out of each day. Yet, you may still have times where you feel anxious. This is where medicine might be helpful. Or you might need to combine medicine with some meditation for an enhanced calming effect.

In Tani Bahti's book, *Dying to Know: Straight Talk About Death and Dying*, she describes the need for oxygen. She writes about the oxygen levels in your body decreasing as you near death, and says: "When the oxygen in your body gets low enough and the carbon dioxide in your system builds up, it promotes a sense of calm as you slip into a coma. When this happens, all struggles leave you, and you breathe easier. You will essentially have "gone to sleep," and your loved ones will be happy to see easier breathing and no agitation. Increasing the oxygen or using a high-tech oxygen mask will only delay this natural and peaceful process."

Another symptom we may need help understanding is confusion and whether or not it is from medicines or from the body shutting down. Also, as death nears, there are changes in body temperature, notably cold hands and feet, as the body directs blood to vital organs. Again, the hospice staff can help us understand what is happening.

[Male #9]

My appetite is changing. I wonder if I need to force myself to eat and drink when I really don't feel like it. My family is so afraid that if I don't eat enough I will continue to lose weight and die sooner. So they say "Eat, eat. You must keep up your strength!" I wish they'd stop.

[Lupe]

This is one of the hardest issues for loved ones, as it's something they feel they can do to help. But foods may not taste the same, and you get full with just a few bites, or you have dry mouth and trouble swallowing, or feel nauseous. This is not unusual. Your body is telling you it doesn't need so much food now, and it probably can't use it either. As a matter of fact, you may make yourself uncomfortable by eating more – like feeling bloated or even vomiting.

When you don't eat much at this time of nearing death, your body goes into a state called "ketosis" – that is, it's using fat and protein for energy. This change in metabolism is associated with a release of natural endorphins that actually may cause a feeling of mild euphoria or well-being. Your healthcare team can help your family and loved ones understand this process better so they don't feel the need to force you to eat. You may also want to have them read the patient

and family education sheets that describe how to manage symptoms from the Hospice and Palliative Nurses Foundation (www.hpnf.org). Is there anyone else with other concerns?

[Male #8]

I wonder about drinking enough fluids. If we can feel better by not eating, should we try to stay hydrated? Or should we have IV fluids so we're more comfortable?

[Lupe]

When someone with a life-ending illness is no longer able to eat or drink, it usually means the body is beginning to prepare for death. If this is the case, then stopping fluids won't necessarily hasten your death but will probably make you more comfortable. Too much fluid could put an extra strain on your heart and cause your body to retain fluids and swell, especially your hands and feet, or your buttocks, where you can get pressure sores. Fluid could even build up in your lungs and make it harder for you to breathe. So you and your caregivers need to understand what is happening to your body, not force fluids, and let the natural release of endorphins again help you feel more comfortable. You might want to take a look at the National Hospice and Palliative Care Organization's tips on Artificial Nutrition (Food) and Hydration (Fluids) at the End of Life at www.caringinfo.org.