

## [Track 6: Survivor Stories: Living with Dying]

[Narrator]

Dr. Ira Byock, author of the book, *Dying Well: The Prospect for Growth at the End of Life*, describes the difference between *death* and *dying*. “Death” is about a lifeless state – inert, static and unchanging. But the term “dying” describes a specific time of living.....the months and moments toward the end of one’s life. Dr. Byock uses the term “dying well” to describe the sense of a living experience where conversations can still be had, where emotional wounds can be mended, and where values can become crystal clear. This includes addressing issues of forgiveness, appreciation, love, and saying goodbye. The experience of “dying well” may not suit everyone, and there surely are many good reasons for some of us to fight off impending death. No judgments are being made if this is what is right for you. But dying also can be peaceful and dignified, and viewed as a normal and natural process.

Let’s join Lupe, a hospice nurse, as she teaches a session on symptom control when someone is dying so that the person is as comfortable as possible.

[Lupe (Female #12)]

First, I’d like to thank you all for coming to another session on what to expect in the last months of life. Sometimes talking about what we’re afraid of – taking these things apart and looking at them in a factual way – can make us more comfortable and less fearful. In this way, the unknown becomes known to us.

Today we’re going to talk about symptoms that either you or your loved one may experience in the future or may have right now. Many symptoms, such as losing your appetite, are normal and part of the dying process. Others may be specific to the type of cancer or other problem that you have, such as difficulty in breathing. My hope is that you will learn about what to expect while dying and what you might be able to do in order to feel more comfortable.

Let’s start by saying that symptoms are not only physical – those that impact the body – but they can also be emotional or spiritual. Our first task is to identify the symptom. Then we can discuss ways to deal with it. So, who would like to describe a symptom they’re having or are concerned about? Or...what are your fears?

[Female #13]

I’m really afraid of pain. My aunt died of cancer and had a lot of pain, but no one talked about it back then. Also, a neighbor was treated for cancer, and toward the end she said she just wanted it to be over because of the pain. We all felt so helpless around them, and we never knew what to do. We tried distraction, back rubs, chicken soup and, of course, pain pills. But they didn’t seem to work. So pain.....my fear is pain.

[Male #8]

I am afraid of dying alone. What if no one’s there with me? What if I need help and no one’s around? Where will I be.....in my own home or a hospital? And will my kids have enough time to get there to say good-bye? I have a strong faith and believe there is an afterlife, but who will help me pass over? My fear is being alone.

[Female #14]

My fear is not being able to breathe. Since I'm on oxygen almost all the time now, I know when I'm anxious I have more trouble getting air into my lungs. It's really scary to feel that I can't get air. So my fear is suffocating.

[Male #9]

I'm afraid of being confused, not knowing loved ones, of being alive, yet not knowing what is going on around me. What if I have to make the decision to cut down on pain medicine so that I'm more alert? I don't know what troubles me more – having pain or being confused. So I guess I have more than one fear.

[Lupe ]

You've mentioned some of the most common fears people have when they're nearing the end of their lives. Let's look at a few of these fears. The fear of being in pain is really widespread, so let's start with that.

Many people – even those who have some type of cancer – have absolutely no pain when they are dying. They take no medicines whatsoever. Pain is not an automatic part of dying from cancer. At the other end of the spectrum, many people who are dying do have pain, yet do not get adequate pain control. There are many reasons for this, such as:

- You don't want to take too much medicine in case your pain gets worse later on and you think you'll need a higher dose.
- You feel that if your doctor thought you needed more medicine, he or she would order it, so you don't ask for more.
- You don't want to sleep too much or get confused with the amount of medicine you need for total pain relief.
- You or your family – or even your doctor – are afraid you will get addicted.
- You're afraid that too much pain medicine, especially morphine, will hasten your death.

What I want you to take away from this session is this: something can be done about ALL pain. There are many different types of pain, and there are many types of pain medicine. Doctors and nurses, and those who work in palliative care and hospice, know how much medicine is enough and how to combine drugs and other methods to relieve your pain. Often people don't get referred to hospice until a few weeks, days, or even hours before their death. This can result in needless suffering if treatment goals are not met or if treatment is delayed. This can be avoided.