

This 2-part article is a synthesis of the work of Denys Cope RN, and her book *Dying A Natural Passage*.

Part 1

Introduction

We, the living (which we all are until we take our last breath), owe it to ourselves, our loved ones, and our society to learn about the process of dying. We need to understand that death is a natural part of life. In fact, we need to become as familiar with dying as we have with pregnancy, labor, and birth.

There was a time when pregnancy was not openly discussed, and certainly nursing mothers were seldom seen in public. We did not see pregnant women portrayed on television until *I Love Lucy* in the 50's it was all a mystery kept behind closed doors. Now, pregnant women are often viewed on television, and actresses are seen fully pregnant in skintight, revealing dresses. In sitcoms, we have seen a woman's water breaking and even witnessed certain aspects of labor and birth. Mothers now nurse their children in public. It has become a normal part of our culture. It is out of the closet.

Now death must come out of the closet. As a society, is it not time for us to stop pretending it does not exist for us? Death is not a failure, and we are all going to experience it. We are part of nature's cycle, just as is every living organism on earth. We are born, we live, and we die. Ideally, we will become as familiar with the stages of dying as we are with those of pregnancy and birthing. Then, when we are faced with death in our personal lives, we will read about and learn the finer details of the process. We will gather support around ourselves just as we do when pregnancy becomes a personal reality. In this way, shame, fear, and uncertainty are less likely to arise.

As we learn to accept dying as a normal, expected, unavoidable part of life, we demystify it and understand the hard work it is, as well as embrace the gifts that accompany it. When we learn how to best be with each other during this most poignant of times, to offer true peace and comfort, we will have changed ourselves as individuals and as a society.

Too often, we are not comfortable around a dying person. We are afraid for many reasons but most frequently because we are dealing with the unknown. We are not sure what to say, what to do, or how to be with someone who is dying, afraid that we will say or do the wrong thing or somehow cause harm. We frequently believe something is going wrong and we are responsible for fixing it. Many times people who are dying feel guilty for having or causing their illness. They may feel shame for being ill or letting loved ones down or creating discomfort in other people. They may fear suffering or being a burden. And they might experience grief at leaving loved ones, or anger at having life and loved ones taken away. These feelings are all a natural reaction to a process that, for the most part, is foreign and therefore is often entered into blindly and with many misconceptions.

Sadly, although most Americans express a desire to die at home, only 30 to 35 percent actually do. The remainder die in accidents or in the hospital, either due to irreversible conditions that have arisen, or by choice, for one reason or another. Sometimes this is because family members are frightened and feel totally ill-equipped to care for their loved ones. Even when there is some acceptance of death, many people feel completely inadequate to deal with the process. It is

hard to be around pain, to see apparent discomfort and suffering, and to feel so helpless. Occasionally, being in the hospital is the choice of the dying person, who sees those fears and does not want to be a burden to family members who are already overwhelmed. Fortunately the steady increase in hospice care is making it possible for more people each year to die at home or in a hospice inpatient facility.

As a registered nurse since the mid-sixties and a hospice nurse for more than half of that time, I have learned that one of the most important parts of hospice care is teaching family and friends about the dying process, to allow them to become comfortable being with and caring for their loved ones. With education and support, especially from hospice staff, a peaceful death at home or in an inpatient hospice facility can be facilitated. And when a person does die in a hospital or nursing home, hopefully with support from hospice or palliative care, that death can also happen in as peaceful and supportive an environment as possible.

What helps is to become familiar with the actual dying process, the physiology of it, and the spiritual aspects that emerge, to know what is really going on. As you read you will learn what happens when people are counting their life in weeks or months rather than years. It is based on what I have learned from the many individuals with whom I have been involved during the last days of their lives. Taking care of a loved one who is dying presents some of the most difficult, demanding, and rewarding work we will ever do. Always the challenges are unique—to the course of the disease, our loved ones' relationship to their own death, and our connection with them. Understanding how to be with loved ones in their last days is one of the most life-affirming—and life- and death-altering gifts we can give them and ourselves.

About Dying

Overview

We have a cultural myth that dying is filled with pain and suffering and that is why we as a culture are taught to fear it. The truth, known by most people who have been with loved ones as they die, especially with hospice support, is that it is a very normal, predictable, natural, exquisitely well-orchestrated physical and spiritual experience, just like the pregnancy, labor, and birth process that it parallels. There is a pregnancy to the dying process, a labor, a transition phase, and then the “deathing,” instead of birthing.

No matter what brings one to the dying process, whether it is cancer, lung disease, heart disease, Alzheimer's, or any other disease, or simply old age the process eventually becomes the same, except in the cases of sudden or traumatic death. The dying process is like being in a funnel; everybody comes to this time from different conditions, and then they move into the same physiological process. This becomes a very recognizable phenomenon.

Like labor and birth, the dying process can vary from an easy, quick experience to a very long and difficult one to a rich and peaceful experience, or any combination of these. The experience ultimately is unique to each person, just as our birth is.

Throughout the dying process, a person naturally begins to do things that conserve energy. Our body is programmed for survival, to live as long as humanly possible. Energy conservation is one of the ways we do this. We eat less and lighter food because our body cannot utilize the food as well. We do less and less physically as we turn inward toward an internal focus. Very often these same changes in lifestyle are also common in elderhood, and, in themselves, do not necessarily indicate someone has started to die. It is when several factors come together that one can see, most often in retrospect, that the person had been in the early stages of dying for a while.

One patient, Elaine, told me that, in looking back, she realized she had had cancer for much

longer than she had known. It was early springtime when I met her, and she had been newly diagnosed with pancreatic cancer. Elaine said: "You know, now that I think about it, last winter I didn't feel like going to church as much. And for the first time in my life I didn't feel like building a fire this winter." She just did not have the energy to do the things in life that normally mattered to her. It was only in hindsight that she could see she was withdrawing from the world and spending more and more time resting and conserving energy. It was also interesting that when, a month before she was diagnosed, Elaine did find the strength to go out with her son and granddaughters during their visit from Hong Kong because they nurtured her energetically. Another very important awareness to hold is that throughout the dying process, we, living, tend to project on our dying loved ones what we think they are going through. Trying to put ourselves in their place, we invariably imagine they must be in discomfort or pain because it looks like it to us. In fact, the dying person is usually having a very different experience of his or her body, one that does not involve the level of suffering we believe is happening. Many people associate dying with pain. They think the more pain someone is in, the closer to death he must be. They do not realize that increased physical pain is associated with the advancing illness, not dying, and can in fact be effectively managed. In reality the actual dying process is not painful, especially in the absence of disease, and it has its own timing, regardless of the presence or absence of pain. This is not to say there may not be pain and suffering because there can be. But this relates to the illness, not to dying. The actual dying process, which entails the closing down of the body's functions, is not painful.

Societal Views

As a society, it is our challenge to understand that death is not a failure. Death may come as the result of actions or events that appear to have failed, but death itself is not a failure. It is something we each will go through, and it is as much a part of life as birth.

We all have our time, and yes, most of us would fight for life if we were diagnosed with a terminal illness. We would do everything within our power to facilitate a cure. However, once we had given every effort and it had become clear a cure was not happening, then it would be time to look at the ending of our life. Even if a cure gave one a second chance, it would still be time to consider the end of our life. After all, it is going to happen at some point.

When we turn and face our mortality, we are making a difficult choice. Yet repeatedly, when people make that choice, it is because they have done everything they could to cure their illness but it has become too much and thus death has become something to surrender to.

Ken Wilber wrote a remarkable book about his wife's dying process, *Grace and Grit*, which captures this very movingly. One can do all the spiritual work and all the physical work, yet if the time has come to make the transition from this world, then this fact must be accepted on some level, even if it is only in the unconscious. In Wilber's book, his wife did all she could to heal from her cancer over several years, and then one day she said, essentially, "Enough. I have given it my all. I am tired." And she surrendered to her dying process. By dying when and as she did, she left a gift that helped the world become a better place

In many cultures, especially the Eastern traditions, meditating on one's death is part of a daily spiritual practice. As a result, when a person's time comes, it is something very familiar and known, and it is therefore not likely to engender deep fear. This is certainly true of the Buddhist traditions. Among others, His Holiness the Dalai Lama, spiritual leader of the Tibetan Buddhists, speaks of this practice. In addition, many indigenous cultures have, as a rite of passage from adolescence into adulthood, a ritual in which people actually experience their own death on a mystical level. This is done with the understanding that as one faces one's fear of death, there will no longer be a fear of living life fully.

We have heard of other indigenous cultures in which it was traditional for elders to leave the tribe and go out into the wilds alone when they knew it was their time to die. Perhaps we modern folk tend to imagine the elders went out there and were eaten by animals, froze to death, or starved to death, or in some other way went through great physical suffering. Yet I have come to understand, as I learn more about indigenous cultures, that it is more likely they knew of a way to bring about their own death naturally. With an intuitive knowledge, they understood it was time, knew where to go, knew what to do, and did it. They knew how to close their bodies down energetically.

If this capacity exists among some people, then it must be available to all of us. One thing seems certain: it usually means a strong connection to a spiritual practice and the ability to enter into a deep meditative state. Thankfully, in this day and age it is not necessary to separate oneself from loved ones to die. On the other hand, we, as a culture and individually, have a long way to go before death is integrated into our everyday life as a normal, natural part of living.

Relationships — A Time for Healing

The dying often go through dramatic changes in the way they live their lives when they know they have little time left. One fellow I took care of, Paul, was among the angriest people I have ever met. He was fifty-one and dying of bladder cancer. With a wry sense of humor, he said of his disease: "Well, what do you expect from someone who has been pissed off all his life?" And evidently he truly had been angry for all his life. He had been abandoned at 3 months of age, which explained a great deal. Paul was a complex, sometimes delightful, often very difficult person to be around. He was experiencing quite a bit of pain in the course of his disease. To help manage this pain, pain specialist physicians were continually involved in his care. Paul would get one kind of pain under control and another would pop up. We would work on that one, then another would develop; he could never get comfortable for long.

After several weeks of this pattern, it became clear to those of us caring for Paul, including his partner, that at some deep unconscious level Paul needed his pain and he needed to suffer. It was, we supposed, part of the way he was trying to atone for a lifelong pattern of what he saw as pretty poor behavior on his part with many people. The last three weeks of Paul's life were very interesting. His twenty-five-year-old son, John, and Paul's partner, Sarah, did not get along; they were like oil and water. Paul finally requested a family conference and asked me to mediate the meeting. A few minutes into the discussion, he said to John and Sarah, "You know, up until now I've been sick, but something has shifted and I know I'm dying and we don't have time for this anymore. We have got to learn how to get along." From that moment on, the peace that enveloped their household was remarkable. Paul really seemed to stop suffering. And while he had a tube in his kidneys and still needed quite a bit of pain medication, he had come to a place of incredible peace. In his last three weeks of life, Paul became a very soft and loving partner and father, and died quite peacefully. We can change and grow, even in our final days, hours, and minutes.

Transforming Guilt

So often when we are diagnosed with a serious or life-threatening illness we think something has gone terribly wrong and wonder: "What have I done to deserve this? How can I fight it?" How many times have you heard someone say, "I am going to beat this"? Yet there is a different, more gentle, more loving way to be with our illness and ourselves rather than to see it as a punishment or something to fight. Stephen Levine describes this beautifully. He says people

get caught up in the idea that we are responsible for our life-threatening illnesses. To be responsible for an illness means that you believe you have somehow caused it. The underlying message is that if you just do your spiritual work, tend to your emotional clearing, eat healthy food, and do everything right, the illness will disappear and you will not have to die.

The belief that illness results from something you did wrong leads to feelings of guilt. Seen differently, the minute you start thinking you are responsible for your illness, Levine notes, you have made an enemy of it and begin to send fear to that illness. He concludes, "We are not responsible **for** our illness, we're responsible **to** our illness." Therefore, if illness shows up, we must ask ourselves what it is we need to do for ourselves in response to it. That way we can move in concert with the illness and see the lessons it holds for us, see the experiences that are there for us and for those we love.

The reality is that all of us on this earth right now will die within the next 110 to 130 years. Death is going to be part of our experience. So what are our choices in response to this reality? We can feel responsible for our situation and say, "Oh my God, I caused my cancer because I ate the wrong thing" or "I'm sick because I'm angry at this person or because I haven't been spiritual enough." We can be like Paul, who said, "I've been pissed off all my life, no wonder I have bladder cancer." He believed he was being punished and had created the whole situation. Now illness can indeed serve as a metaphor, and certain lifestyles do contribute to the development of particular diseases, but Paul wasn't speaking in metaphorical terms; he was feeling responsible for his disease.

Our other choice, as Levine says, is to become responsible to the situation in which we find ourselves. This means saying to ourselves, "Okay, I've got this illness. Now what can I do to gain the most from whatever this illness has to teach me?"

Further, we can put another question to ourselves: "Is this a time for me to really, in a heartfelt way, say, 'Thank you, God?'" I recall a woman who had cancer, and as a response she understood it was time for her to reprioritize and reorder her life, which she did. Subsequently, her cancer went into remission. Later, the cancer came back a couple of times, and she said, "You know, it's been a real friend to me, because it keeps coming back and reminding me, 'Which way are you walking? What life choices are you making?'"

Cancer has become her barometer. Eventually, it will probably become her teacher about how to leave this world. So, feeling responsible for leads to feeling guilty, as though you must get rid of things, while feeling responsible to means looking at how you can respond to whatever has come into your life.

This 2-part article is a synthesis of the work of Denys Cope RN, and her book *Dying A Natural Passage*.

Part 2

Stages of Dying

Pregnancy of Dying

The beginning stages of pregnancy in a new mother often go unrecognized. And it is only in hindsight the mother is able to acknowledge the subtle signs have been there for a while. The same is true at the end of life. So often it is only retrospectively that the family or the person dying is able to recognize the process has been unfolding for a time, as Elaine mentioned earlier.

Physical Nourishment

Many people ask, "How do I know if my loved one is dying?" One of the first considerations is whether the person has changed his or her relationship to food. In the early stage of pregnancy, a new mother's first clue that something is occurring is a change in her relationship to food, which is usually marked by morning sickness, which is actually protective. In the beginning of dying, the change in one's relationship to food is marked by a diminished appetite. In both cases, decreased energy is usually part of the picture as well. Because a change of appetite can be caused by many factors it is important to work with one's doctor and look at the whole picture. Loss of appetite and low energy can also be signs of other physical problems, including depression. A medical examination, along with any tests that are indicated, is an important part of determining one's actual state of health. When dying begins, the body naturally withdraws from nourishment, from that which sustains physical life. It is protective of the body living as long as humanely possible. The person, over time, is switching from a physical energy source to a spiritual energy source, so usually there is a natural diminishing of appetite with accompanying weight loss.

There are many physical reasons for this change in eating habits. People eat less and lighter food because their bodies cannot digest nutrients as well as before. In addition to losing weight, their metabolism is slowing down, their activity level decreases, and they grow weaker. Significant weight loss is one of the criteria considered when a person is being assessed for hospice.

The body has wisdom of its own. When a person has a growing cancer, much of the food taken in feeds the cancer. When the appetite diminishes and less is eaten, the cancer receives less fuel, and in a basic way, does not grow as quickly. Nevertheless, it is very important that people with cancer not be afraid to eat. In fact, for anyone pursuing curative treatment, nourishment is vital to support healing. For a person moving into the dying process with cancer food becomes a quality of life rather than a quantity of life issue. If the person has an appetite and feels like eating, food is to be enjoyed, not feared.

When a person has advanced cardiac or lung disease, the body wants to conserve energy, so the tired heart or lungs do not have to work any harder than necessary. Eating and digesting food takes energy. When the appetite and eating decrease, the body can conserve whatever energy

is available for the more important job of keeping the heart beating or taking the next breath. When people are dying and losing their appetite, we often project onto them our need for them to eat. We want them to eat because feeding our loved ones is our way of nurturing them. Normally if people are not eating very much, it means they are sick. We want them to eat because if they do, we believe, they will be “better,” and they won’t die. As we watch people eat progressively less and less, we may be afraid they are “starving to death.” The truth is, people who are dying have a natural and gradual loss of appetite and do not need the same quantity of food. Often they will tell you clearly that they just don’t have much of an appetite. They may occasionally have a craving for some food and will enjoy it—in small amounts. At other times, they think they want something and may even bring it up to their mouths, but then they stop. They just are unable to put it into their mouths. Sometimes they know that if they eat it, they will get sick. Other times they just suddenly become aware they don’t want it. Eating, again, at this point is about quality of life, not quantity. Sometimes people who are dying may eat anyway, in order to take care of loved ones who need them to eat. When they do eat, however, they often become nauseated because their metabolism and digestion have slowed down and they truly do not need the food.

The father of Kay, a friend of mine, was dying. Kay’s mother was having a very hard time accepting his decline. She kept encouraging him to eat. This was her way of loving him. Once Kay’s father had finished eating and his wife had left the room, he would ask Kay to clean his dentures, which of course she did. When he took them out, she saw that her father had packed all the food on top of the dentures as a way of appearing to eat without really doing so. He knew how much it meant to his wife to see him eat.

The work of the family, therefore, is to have the courage and wisdom to listen to our dying loved ones, let them set the pace, and respond sensitively and appropriately. When we do this, we are faced with accepting the fact that we can no longer nurture them through food. We need to be aware that we are also acknowledging that they are dying. This can be a very difficult point in the early stages of the process. As we experience the grief that comes with that reality, we need to look for other ways to nurture and relate to our dying loved ones. We also need to find ways to nurture and sustain ourselves as we go through this very challenging and often difficult work with them. As people are withdrawing from food, they move away from heavier, harder-to-digest foods, even foods that used to be their favorites. The first things to go are meats and fats, cheeses, and fried foods. More easily digested foods such as potatoes, rice, toast, and eggs become more appealing. Then, at some point, they may only want soft foods, such as applesauce and yogurt, and perhaps ice cream, milkshakes, and health drinks. Soon, they may only want juices, then only Gatorade and water, maybe ice chips, and then just sips of water. Finally they stop drinking altogether. When they reach this stage, they usually have three to five days left. Many people will lock their lips at this point, and will not allow you to put anything in their mouth. On the other hand, some people continue to eat until the day they die. This whole process can go very quickly or very slowly. Just like labor and birth, it is entirely individualized. As the dying person gradually withdraws from eating and drinking, the question of a feeding tube and intravenous drips comes up as part of the family’s desire to keep their loved one comfortable. This is often the case when family members are afraid the patient is dying of starvation or thirst or both. It is so very important to realize that the withdrawal from food and fluids is a natural process that actually supports the dying person’s comfort. It does not create suffering because the dying body’s needs do not entail physical healing and ongoing life. The withdrawal from food and fluids in our loved one’s last days has a sedative effect leading to an enhanced sense of well-being and diminished illness-related pain. As the body withdraws

from nutritional sustenance it naturally goes into a fasting mode. Fasting generally supports one of two purposes. The first purpose most people think of is cleansing, which creates its own sense of well-being, but an additional reason for fasting is enhancement of spiritual experiences. Therefore, as the dying person moves into a fasting mode, he or she also is able to open to an altered state of consciousness that promotes an inner experience of disconnectedness from the body and facilitates connection to the spiritual realm. Thus, withdrawal from food and fluids actually supports the dying process.

Attempting to override this biochemical state in the hope of providing comfort actually creates the opposite effect. Giving intravenous fluids at this point will bring them back into their body and out of the natural comfort-creating altered state. With the reconnection to the physical, they once again become more aware of any physical discomfort.

Meanwhile the body, which is shutting down, cannot effectively use these fluids, which are then likely to lead to swelling in the body and eventually may fill the lungs and cause respiratory distress. The challenging work of caregivers is to learn to trust the body's wisdom, respond to the needs of their loved one rather than to their own projections of what is needed, and take care of themselves during this profound transition.

When nourishment cannot take place through food and fluids, there are other ways of being with, nurturing, and sharing love with them. These include playing and listening to music together, reading to them, talking with them, going through photo albums, looking at memorabilia, or simply sitting quietly in the room.

Spiritual Nourishment

It is important to address the dying person's spiritual beliefs or questions. The person may have been raised in a formal religion, and been away from that tradition for many years. Yet when it comes time to die people may want to reconnect with their religion. As one woman put it, "Well, I think I'd like to talk to a minister, just in case there really is a God and I need to be on his good side." Even when a person has not followed any particular religion, it is still natural, especially at this stage in life, to have questions and concerns about spiritual matters, perhaps about the meaning of their life. It is important to explore these concerns with the dying person and to provide any support she requests in this area. The chaplains and spiritual care coordinators on the hospice team are experts at supporting the dying and their loved ones from a non-denominational viewpoint in such situations, and also work closely with various spiritual leaders, such as pastors, priests, and rabbis in the community, for support of the patient and their family.

The use of rituals aligned with the dying person's belief system can be powerful at this time. Some traditions, for example, encourage the use of oils, incense, particular prayers, sacred music, or special readings to reinforce the spiritually nourishing environment.

People often ask me, "Well, what if you don't believe in that kind of stuff?" In response, I tell the story of Will, a wonderful man and a well-known, much-loved botanist. He was very much the scientist. When I first met him, he was adamant about only believing in the physical world, in things that could be seen, touched, tasted, measured and tested. We would have long, philosophical discussions on such things.

As he grew close to the end of his life, he seemed to be taking an inordinate amount of time to die. I say "seemed" because, in truth, people die according to their own perfect timing. All of us who were caring for Will—his family and hospice staff—were projecting upon him what we believed his situation to be, that his quality of life had gone. He was relatively young, in his early

fifties, and had prostate cancer. He had a catheter. He was bleeding from his urinary tract, so he was weak with anemia; his lower body was very puffy and swollen with edema (extra fluid in his tissues); he was too weak to walk and needed help with all his toileting; he was often constipated and, at times, was in pain. We could see him becoming thinner and thinner, and closer and closer to the end, and we as hospice caregivers, thought, “This guy is suffering, why doesn’t he just let go? What is going on? Why is he hanging on?” We, the living were projecting suffering on to him. He was my great teacher about this, as I was a young hospice nurse at the time. At one point, his other hospice nurse said to him, “Will, is there anything that you are afraid of? Anything that is keeping you here?” Do you have unfinished business? This is something to explore with people when they seem to be hanging on: whether there is anything they are afraid of, or if there is any unfinished business or something they are waiting for. He said, “Oh no, I’m not afraid. I’ve been given the gift of seeing where I’m going, and it’s so warm and so beautiful; it’s just that I don’t want to leave here yet.” He, the scientist, was having an experience of something beyond the physical, in spite of his beliefs up to that time. His dearly, beloved partner, his ex-wife, and his daughter were all there with him—his three favorite women. It was a time of deep intimacy, and he was not quite ready to leave them. It was a real lesson for us as caregivers. We realized that we had been projecting onto him a poor quality of life, seeing only the physical while he, in his view, still had such extraordinary quality of life that he wanted to stay as long as possible. When I spoke with Will’s partner five years later, she said, “I just want you to know that was a very special time.” She told me that Will, who had lived a very full life, had said to her when he was close to the end, “I am happier than I have ever been in my life.” He was quite a teacher for all of us.

Pain and Symptom Control

One of the first things to address in creating comfort and quality of life for the dying person’s remaining time is to be sure there is sufficient pain control. Hospice physicians and nurses are experts at pain and symptom control. With physical discomfort, quality of life is greatly affected, and suffering is present. Without adequate comfort, it is very difficult to address any of the other areas of the dying process. Very often, by the time people come to hospice they have been on inadequate pain or symptom control. Sometimes, if it is very late in the dying process, providing adequate pain control is all that is needed to allow the person to let go and die. When this happens, loved ones often think that maybe the stronger, or new, medicine, especially if it is morphine, killed the person. Actually quite the opposite is true. Pain tends to keep a person in their body, and adequate pain relief allows them to relax and let go. Even when people have stopped eating and drinking, medicines can be administered without IVs or injections. Medicine can be given sublingually (under the tongue, or inside the cheek), transdermally (rubbed on the skin, or in a patch that allows it to be absorbed through the skin), rectally, or via the nasal passage. The hospice doctors, nurses, and your physician will help determine your needs as the dying progresses.

When attempting to create comfort, morphine is one of the primary medications to be considered. This is an invaluable medication that is rarely used soon enough. So often the patient or family members or physicians are afraid of the problem of addiction. Out of this fear, many people believe morphine should be saved “until it is really needed.” In reality, as long as there is pain or trouble breathing and morphine is used to alleviate the distress, it is not being used in an addictive way. Drug abusers use morphine or other addictive substances in order to alter their consciousness, often as a way of coping with emotional difficulties. Yes, there will probably be a gradual need to increase the dose of morphine during

end-of-life care, but that is not because the person is becoming addicted. Rather, it is because the condition creating the discomfort is advancing, causing increasing pain. There is also a tolerance to the medication that develops over time, which requires a gradual increase in dosage.

Basically, there are three different kinds of pain, visceral, neurological, and somatic. For each of these kinds of pain, there are different types of medications that are most effective. The physician will know which medications are indicated. What is important is to have prescribed the right type of medicine and the right dosage for sufficient pain control. This will make all the difference in the quality of life dying people experience during the remainder of their time.

Talking About Dying

Often family members ask, “Does my loved one know they are dying?” Determining whether or not someone is aware of his or her impending death is not easy. What we realize in hospice is that in the last days, if not weeks, of life, dying people usually know they are approaching death, whether they talk about it or not. Sometimes they refrain from speaking about it to spare their family from “facing needless suffering”; other times, it is because they are not ready to deal with it. Sometimes family, friends or caregivers avoid the topic of approaching death because they do not know what to say or how to say it. What is most helpful is get support from hospice or palliative care to provide gentle openings for the topic to come up and then respect the desires and comfort level of the person who is approaching the end of life.

Fear Of Dying When first faced with the fact they are dying, many people experience a tremendous amount of fear. Often, I am told, it is not death but the process of dying that is frightening. Many times people who are dying need to talk about some of their fears to work through them. Some might need to hear their loved ones tell them they will be okay after they die. They may need to speak to a minister about unresolved “wrongs” from their past. They may have fears of being a burden, or “too dependent,” like Morrie in *Tuesdays With Morrie*. He was dying of ALS (Lou Gehrig’s disease) and talked about dreading the day when “someone’s gonna have to wipe my ass” because it was the “ultimate sign of dependency.”

So many of our fears are related to the future, and I have seen time and time again the fears that are expressed in the early stages of dying melt away into the reality of the actual experience when it occurs. In Morrie’s case, he admitted it took some getting used to because “it was a complete surrender to the disease.” And he felt “a little ashamed because our culture tells us we should be ashamed” to have to be cleaned by others. Once he did surrender and let go of his shame, he began to enjoy his dependency and was able to actually revel in the experience of being turned, cleaned, rubbed with cream, and massaged, and he died a very peaceful and comfortable death

Visioning As people withdraw from food and fluid and go into a natural fasting state, as well as spending more time sleeping, they begin to report experiences of seeing loved ones who have already died. Time and again family members have told me things like: “Oh, she’s been talking to her brother who has been dead for thirty years. She’s very confused.” This is another instance of the caregivers and family projecting from their limited perspective what they think is going on. To the caregiver, it may seem that the dying person is out of their head, confused, or hallucinating. However, those of us who work with the dying will tell the family, “This is normal. She really is experiencing her brother.” This is a process called “visioning.” It is an expected

occurrence as one is dying. It is observed, by hospice staff I work with, about 98 percent of the time, and it usually begins about several weeks before a person dies.

In reports of visioning, we, in hospice, find approximately 90 to 95 percent of the time the dying person mentions speaking to or seeing a loved one who has died. A small percent of the time they mention seeing a living relative, but normally they speak of seeing people who have passed on before, who seem to show up in a reassuring and supportive manner. Other reported visioning have been of angelic beings, favorite pets, strangers who seem to offer a comforting presence, or, as in Will's case, a beautiful place. Very rarely, the vision can be a disturbing presence. If the visioning is disturbing, be supportive by inquiring about who they are seeing and why it is disturbing; then reassure them that this is a normal occurrence at this time in their life. And if the presence is truly disturbing, they can simply ask it to leave. Often they just need reassurance.

Elaine had chosen to spend her last weeks at a nursing home. During a visit about two weeks before she died, I asked her how she was doing. In a very frustrated tone she said, "Oh, I'm losing my mind. I'm seeing people who aren't really there." I said, "Are they people you know or people you don't know?" And she replied, "Well, for the most part I don't know them." When I asked her to tell me about the people she did know, she repeated, "For the most part, I don't know them." This told me she did not want to talk about the people she knew. I continued, "Tell me about who you are seeing." She told me, "There are these three young men, sitting up over there," and she pointed high up on the wall of her room. Not wanting to impose my value system on her experience, I asked, "Are they a comfort, or are they distressing?" Elaine said, "Oh no, they're great. I am glad they're here." She happened to be a woman who liked men and, as a rule, did not like women, so it was perfect she was seeing three young men. I said, "You can just relax. They are really here, and they are here for you. That is part of your process." She sighed with great relief and said, "Oh thank God! I thought I was losing my mind." And then she relaxed into her experience.

Families repeatedly report these kinds of experiences, regardless of the dying person's beliefs. So it is undeniable that there are spiritual interactions taking place that are comforting and that there is spiritual assistance being given as the dying person is preparing to make the transition. If both the dying and the caregivers understand that this is expected, that nothing is going wrong—and, in fact, everything is going right when visioning happens—they can relax into it.

Labor Stage of Dying

Up to this point, I have described what I call the "pregnancy" stage of dying: the withdrawal from food, distancing from the physical world, and moving into the inward world of the dying person. Following this is the "labor" stage. Just as labor during birth is marked by rhythmic changes in the body felt as patterns of contractions of the uterus, so is labor during dying marked by rhythmic changes in the body, only in this case it is in the breathing patterns.

Breathing Patterns Once someone has come to the point of not eating solid foods and drinking very little and experiencing visioning, he or she is in the early stages of the "labor" of dying. As this phase progresses it is marked by distinct changes in the person's breathing, which becomes seemingly irregular but is actually rhythmic. The person breathes, breathes, breathes, and then there is a pause in the breathing, called "apnea," which means "without breath." Then the person starts breathing again, and then there is another pause in the breathing. This pause, or period of apnea, can last anywhere from ten seconds to a minute and a half. This phase of apnea can be very upsetting for loved ones because during the pauses it can seem as if

the person has stopped breathing altogether. Family members may be on the edge of their chairs, wondering, is this the last breath?

It is very important to know that this is an expected, normal part of the labor phase of dying— it is not the time of the person's final breaths. This rhythmic pattern of apnic breathing can last a couple of hours or several days. Eventually, the dying person will move out of it and into what is called the transition phase, marked by what is described as "terminal restlessness." Finally, the person will move into a very deep, regular breathing pattern, then a shallower and slower breathing pattern. It is from this regular breathing that he or she will eventually cease to breathe. Do not be frightened by the rhythmic, apnic breathing pattern; it is normal.

Non-Responsiveness vs Coma Another experience in the labor phase of dying is profound weakness that results in the dying person becoming non-responsive. This is often mistaken for, and described as "going into a coma." Yet it is important to know that in most cases a dying person does not go into a coma. A comatose person is not able to switch, at will, between being responsive and nonresponsive. The dying only seem as if they are comatose because they no longer have the life energy to respond. But they are certainly aware, able to hear, and able to process what they hear, up to the end, and are sometimes able to find the energy to respond in certain special situations, such as when a loved one arrives from afar, or in the last minutes of their lives.

Julian's father, who lived in another state, was dying and had not responded to anyone for days. When Julian arrived at his father's bedside and began talking to him, his father opened his eyes and smiled. The two were able to exchange a few words, and then the father died very peacefully. He was able to become responsive for Julian and, in fact, might well have been waiting for Julian to arrive before dying.

One way to be with people who cannot respond, for any reason, is to ask the same questions mentioned previously in the "Turning Inward" section—What are some of the things you are glad for or feel blessed about in your life? What regrets might you have? How might you resolve them? and let them know you are going to be quiet and leave space for them to silently reflect. Also playing some favorite music or reading to them from their favorite poet or author. Many people experience a great deal of comfort in hearing passages from the Bible or readings from whatever spiritual teachings they have followed. In these ways, we can be with people who are not able to respond, and we can create an environment that is comforting and healing to their inner world and process. The most healing way to be with a non-responsive dying person is to sit in silent, deep loving presence. The closer people are to dying, the more being quietly with them supports the peaceful environment that develops in the last days and hours.

The Sense of Hearing When we are dying, hearing is the last of the physical senses to go. Everything spoken in a dying person's room must be said with the awareness that it will be heard and may affect the dying person. Many people had actually been in a coma, sometimes for years, and when they eventually awakened, they were able to describe who said what and how various people had handled them. So it is crucial to be aware that no matter what people's ability to respond is, or what their level of consciousness appears to be, they are able to hear. We must speak at all times as if they were fully awake and responsive. Along the same lines, when the end is near and the dying person is too weak to respond, if a loved one is unable get there in time, it can make a vital difference for all involved if the loved one can call and the phone is put up to the person's ear. It is important that the one dying be able to listen to what the caller wants—or needs—to say. It may be the very words or connection required for letting go to be possible, or it may be what the caller needs to feel complete.

The Transition Phase During labor in childbirth, there is a time called the transition phase where the woman, just before moving into the active birthing process, feels as though she just cannot get comfortable. She is restless, feels as if she won't be able to stand the labor another minute, and is about to jump out of her skin—and then she moves into active birthing.

A very similar experience happens during the dying process. After the period of rhythmic, apnic breathing, which marks the labor phase, the person moves into the transition phase or terminal restlessness. In this stage, there is usually agitation, restlessness, moaning, and groaning. The person seems quite uncomfortable. This can be a very distressing time for loved ones because it seems as if something is going terribly wrong. It is often assumed that there has been a sudden increase in pain or discomfort and that this pain must be alleviated. Indeed, there appears to be a definite increase in discomfort compared with the peaceful state the person was in during the period of rhythmic breathing. What is actually causing the discomfort is hard to say. From the observations of those of us who work with the dying, this stage seems to be akin to the restlessness at the end of labor. In this sense, it may be related to the confinement of the body as the dying person is trying to leave. Some spiritual teachers, in fact, have likened this restlessness to the person's soul's last struggle to get out of the body.

There are some effective medications that can be given at this time to help the person relax through this very agitated period. Among these are morphine and lorazepam (Ativan). Just as with labor, the role of the one observing the process is to be supportive of the dying person through this natural phase. This is an expected, transitional stage. Nothing is going wrong. Being with them in loving presence, trusting the process, and remembering this is to be expected are some of the most effective ways to go through this time. It can be hard to watch, but it will pass. Also, giving yourself breaks from the bedside can support you in supporting them.

When I was twenty-eight, my mother was dying of pancreatic cancer. As a young nurse, to whom the natural process of death and dying had not been taught, I was unaware that she was going through predictable phases. Hospice was not available in those days to provide supportive care and information. When she started moaning and groaning, it terrified me. I was afraid something terrible was going on, she seemed to be in such pain. I didn't know what to do, and I didn't know it meant she was very close to death. I only knew she seemed in distress, and I had no idea why or how to help her. I decided I would have to take her to the hospital in the morning because caring for her was beyond anything I knew how to do at that point. She died four hours later very peacefully and easily. It would have been so helpful for me to know that the restlessness was a natural, temporary phase and an indication she was very near to death.

The Active Stage of Dying — “Deathing”

Eventually, the dying person moves out of the transition phase into the last stage of dying, a very peaceful time marked by deep regular breathing, which becomes progressively slower and shallower. First the breathing is deep, down into the abdomen, then eventually the breath only goes to the chest, then just to the upper part of the chest. Very soon only the person's mouth and neck are moving, the mouth opening and closing in a “fish out of water” kind of breathing. Then, when the breath actually stops, you can hardly tell it has happened because it is so peaceful and easy.

Hollywood often shows a theatrical gasping for air, but that is not what happens at all. There is actually something called “the death rattle,” but it is not a horrible gasping for air, and it is not at the very end. The rattling sound is caused by secretions gathering in the back of the throat

because the person has become too weak to clear his or her throat. The dying person is breathing through the secretions, and caregivers may think the person is choking and needs to be suctioned in order to be able to breathe. Once again, we are projecting upon the dying person our discomfort. It is important to really see what is going on, to observe the reality that the person is breathing quite comfortably. They are not struggling for air or thrashing in the bed, “air hungry”; they are peaceful and comfortable. It is crucial to realize that the discomfort is in us. It is a natural reaction to what we are hearing, since we know that if we had that much secretion in our throat we would be uncomfortable. Be assured that the people who are dying in this situation are fine. As they are leaving their body, their experience of being in their body is different from what we, from the outside, might imagine it to be.

So often the remark heard from the family after their loved one has died is, “It was so peaceful; he looked so radiant. I could hardly tell when he took his last breath.” In most cases, though not all, there is deep peace at the time of death that is palpable to those at the bedside.

The Mystery of the Timing of Death It is clear to those who work closely with the dying that we very often choose our time of death. One of the greatest mysteries in this very complex and blessed event is how we make that choice. How is it that some individuals can leave their body easily, seemingly at the proverbial snap of their fingers, while others do not seem able to let go in spite of apparent readiness?

Maggie took an amazing amount of time to die. She was, a solitary soul, a very private person who had no family attachments to keep her here. Much of her dying time was spent alone, except for her dogs and a business friend who promised to be with her through the process. The friend and I could not figure out why Maggie was taking so long to die. To us, there seemed to be nothing in her life keeping her here. She finally died on August 4. Afterwards, when her friend was going through her papers, she discovered that Maggie’s beloved husband had died on August 4, fifteen years earlier. People very often hold on until a certain date: a birthday, an anniversary, a graduation, or some other date special to them.

On the other hand, some individuals are able to leave quite quickly. The mother of a very dear friend of mine had flown in from out of state to be tested to determine why she was not feeling well. She was admitted to the hospital on a Tuesday. On Wednesday, the doctors performed a biopsy that showed end-stage lung cancer. Obviously, this woman had not felt well for a while and had lost weight, but she had been able to make the flight and was still relatively strong. That night, as her family was leaving after visiting her in the hospital, they said, “Good night, Little Mama,” and she replied, “Good-bye, darlin’s.” They said, “Don’t say good-bye, Little Mama, say good night.” Again she replied, “Good- bye, darlin’s.”

At midnight, when the nurse made her rounds, Little Mama seemed to be okay. By 12:30 a.m., the next round, Little Mama had died. Elisabeth Kübler- Ross taught us about the importance of listening to the dying—but who would have thought Little Mama was that close to death? How did she do that??

The most common time of death is between 4:00am and 6:00 am, just as it is the most common time for birth. In some traditions, this is also the time when people get up to pray, meditate, or do other forms of spiritual practice. Spiritual traditions teach that this is the time when, in terms of energetics or nonphysical reality, the veil between this world and the next is thinnest. So it makes sense, given this framework, that these early morning hours are when many people come into this world and when they leave.

Some people seem to need privacy, or space, to die. They may wait until a loved one, who has been at their bedside for hours, leaves the room for a few minutes, and then they quietly let go. For others, it seems to be the opposite: they hold on until a certain person arrives, and minutes

after the arrival, die. It is hard to predict how it will be for each individual. It is very important for loved ones to not feel guilty for not being present at the time of death. Dying people choose their own time to leave. If someone you love dies without you being there, it may well be that he or she was protecting you from having to be present at the moment of death. Or it may mean they needed privacy to be able to let go, since the bonds of love and connection can hold us here when, otherwise, we are ready to move on.

References

Books

Cope, Denys, RN, BSN *Dying A Natural Passage*. Santa Fe, NM: Three Whales Publishing , LLC, 2008

Gawande, Atul, MD *Being Mortal: Medicine and What Matters in the End*. Deckle Edge, 2014

Moorjani, Anita, *Dying To Be Me: My Journey from Cancer, to Near Death, to True Healing*. Carlsbad CA: Hay House Inc , 2012

DVD

Adair, Camille and Grant Taylor. *Solace: Wisdom of The Dying*. Santa Fe, NM: Point of Light Productions, 2008