

8. CARING FOR THE DYING

To the yogi death is the sauce that adds spice to life.

—B. K. S. IYENGAR

THE NEEDS OF THE DYING

by Christine Longaker

AFTER YEARS of listening to many people who are dying, hearing them try to articulate what they need during this most difficult passage of their lives, I will try to speak for them to you, their loved ones and caregivers. I will speak with one voice representing their many voices, communicating the emotional, practical, and spiritual needs of a human being facing imminent death.

I need to talk about my thoughts and fears. I am going through so many changes; I feel so uncertain about my future. Sometimes all I can see in front of me are those future things I am afraid of. And each day, my fear ignites a different emotion. Some days I can't take it in and I need to believe it isn't happening. So there might be days or even weeks that I will feel sad, or act irritated. If you can listen and accept me, without trying to change or fix my mood, I will eventually get over it and be able to relax, and perhaps even laugh with you again.

Until now, you may have always expected me to be emotionally strong and in control. Now I'm afraid that if I honestly reveal myself, you will think less of me. Because of the extreme stresses I am going through, it might happen that the very worst sides of my personality, the real dregs, will get stirred up. If that happens I need permission to be "lost in the woods" for a while. Don't worry, I will come back.

Do you know that I'm afraid to express my true thoughts and feelings? What if everyone I care about runs away and leaves me all alone? After all, you might not believe how hard this really is. That's why I need you to reassure me that you understand my suffering, and that you are willing to stay with me through the process of my dying. I need to know that you will listen to me, respect me, and accept me, no matter what sort of mood I am in on any particular day.

Here's the most important thing: I want you to see me as a whole person, not as a disease, or a tragedy, or a fragile piece of glass. Do not look at me with pity but rather with all of your love and compassion. Even though I am facing death, I am still living. I want people to treat me normally and to include me in their lives. Don't think that you cannot be completely with me. It is okay to tell me if I am making your life harder, or that you are feeling afraid or sad.

More than anything, I need you to be honest now. There is no more time for us to play games, or to hide from each other. I would love to know I am not the only one feeling vulnerable and afraid. When you come in acting cheerful and strong, I sometimes feel I must hide my real self from you. When we only talk of superficial things, I feel even lonelier. Please, come in and allow me to be myself, and try to tune in to what is going on with me that day. How healing it would be for me to have someone to share my tears with! Don't forget: we're going to have to say goodbye to each other one day soon.

And if we have a rocky history between us, don't you think it would be easier if we could start by acknowledging it? This doesn't mean I want you to rekindle the same old disagreements. I would like it if we could simply acknowledge our past difficulties, forgive each other, and let go. If we don't communicate like this, and instead stay in hiding from each other, then whenever you visit me we will feel the strain of that which remains unspoken. Believe me, I already feel much more aware of my past mistakes, and I feel bad about the ways I might have hurt you. Please allow me to acknowledge them and say I am sorry. Then we can see each other afresh and enjoy the time we have left together.

Now more than ever I need you to be reliable. When we make plans and you are late, or do not come at all, you don't realize how much you've really let me down. Thinking that I will have one visitor on a given day can make all the difference in how much I am able to bear my pain or emotional distress.

Each moment spent with a friend who really cares and accepts me is like a warm light shining in a very difficult, lonely, and frightening existence.

When you come into the room, can you meet my gaze? I wish you would take the time to really look into my eyes and see what I am truly feeling. I long for friends to embrace me, or at least touch my shoulder, hold my hand, or gently stroke my face. Please don't hold back your affection and your love. In the hospital, I sometimes feel more like an object or a disease rather than a human being. Please, bring in your humanity and kindness to ease my suffering. Because no matter how I might seem on the outside—gruff, withdrawn, cheerful, bitter, or mentally impaired—inside, I am suffering and I am very lonely and afraid.

Even though this is a difficult time in my own life, often my main worry is about how my condition is affecting my loved ones. They seem so lost, so burdened, so alone with all of the changes they are experiencing and all the responsibilities they shoulder. And what about *their* future? How are they going to cope after I am gone? I'm afraid I am leaving them stranded and alone. Some days, when everyone comes in with different emotions and needs, I am too weak to handle it all. I can't possibly listen to everyone and all of their burdens. I would be so relieved if someone could help my closest family members contact a counselor, or an organization like a hospice, who could support them, listen to their needs and their sadness, and maybe even help out in practical ways.

Saying goodbye is so very hard for both of us. But if we don't, and if you are resisting my death when I have begun the process of dying, it will be even harder for me to let go. I would like to live longer, yet I cannot struggle anymore. Please do not hold this against me, or urge me to fight when all my strength is gone. I need your blessings now, your acceptance of me and of what is happening to me. Tell me it is all right for me to die, even if I appear unconscious or in great pain, and tell me you are letting me go, with your warmest wishes and all the courage you can muster in this moment.

One of my deepest, most powerful fears is that I will be reduced to the situation of an infant, helpless and incoherent. I fear that you will forget who I am and treat me with disrespect. Even thinking about others taking care of my most intimate needs makes me feel ashamed. And every step closer to death makes me realize I will soon be totally dependent on others. Please try to understand when I resist giving in to one more change, one more loss.

Help me to take care of myself, even in little ways, so that it will be easier to tolerate the bigger changes which are coming. *Speak directly to me*, rather than over my head, or as though I were not in the room. Find out what my wishes are for my medical care during the time of dying while I can still articulate them. And please honor and respect my wishes, ensuring they get written down and communicated.

When everyone treats me as though they know what is best for me, I get so angry. *Aren't I the person who is ill?* Isn't this my life, and my body? Don't I have a right to know what is going on, to know if I am living or dying? I need to know what my condition is. I need to know, in the doctor's best estimate, how much time I have left. If you find the courage to tell me what is going on, then I can decide which type of care is right for me; then I can make decisions about my life. If we stop hiding the truth about my imminent death, I will be able to wrap up the details of my life and prepare my family to survive after I'm gone.

You know, the pain can be unbearable sometimes. On other days, the pain is just there, like a bad toothache, and I get tense and irritable. Please forgive me when I am in a bad mood; you may not know what it is like to live with constant pain and discomfort. What is hardest is when no one believes the amount of pain I am having; that makes me feel crazy. I need to be believed and I need to have my pain relieved. But please don't knock me unconscious to do it. I would rather experience a little pain, and still be conscious—to enjoy my life and my family, and to do my spiritual practice—while I am in the last few weeks of life.

One of the most important ways you could offer practical help would be to act as an advocate for my needs. When I am ill and weak, I may lose my ability to communicate what I want and need. Perhaps some hospital rules can be relaxed to accommodate my lifestyle, my family, and my personal needs. My loved ones might need reassurance, or encouragement to take a break from caregiving duties when they become too emotional or stressed. And legally, help me to plan ahead of time whatever practical arrangements are necessary so that I can prepare for a peaceful atmosphere at the time of my death.

And what happens if my mind starts to disintegrate? How long will you visit me then? I hope you will not give up communicating with me when my words come out garbled, or when I can't speak at all. Do not forget that underneath the seeming confusion—or unconsciousness—I am still there, I can still hear you, I can even feel the quality of our relationship. I might be

feeling lonely and afraid, though. I always need your love and your reassurance. In order to help me, I hope you can learn to be deeply peaceful inside and receptive, so that you can sense what I am feeling and needing and know how to respond appropriately.

As my body and mind disintegrate, remember that inside I am still the person I was when my life was at its peak—and thus I am always worthy of kindness and respect. No matter how far gone I appear to be, trust that your love and heartfelt prayers do get through and deeply reassure my entire being. Please don't give up on me when the going gets rough. This is our last chance to heal our relationship, and to give to each other our last gifts of love, forgiveness, and wisdom.

Being in the hospital makes me feel so restricted. It's hard to give up the patterns of my normal lifestyle—my ability to enjoy the company of my friends, my favorite activities, and even my usual waking and sleeping patterns. It's hard to lose my privacy; in the hospital I feel so exposed and vulnerable. I miss the home-cooked meals, the family celebrations, and my favorite music. It's hard, in this controlled and public environment, to find a space to share our intimacy and our grief without fear of being interrupted. When I'm hospitalized, I yearn to have a connection to the outside world, to nature, to the beautiful changes of weather and seasons and wind. Do I have to be cut off from all that I love and cherish even while I am living?

I might prefer to die at home. If you called a hospice program, they could show you how to arrange for me to be cared for at home as long as you can manage it. Being at home would make the process of dying more bearable. I understand that if you have the responsibilities of work and raising your family, you might have to put me in a hospital. But please, do not abandon me there! Help make the hospital environment more like home; try and spend the night when you can. And, even if I have to be hospitalized for most of the period of my dying, I would be grateful if you could arrange with the hospice nurses to bring me home for at least the last few days of my life. What a relief that would be, to be cared for in my familiar surroundings, with family and friends keeping vigil—meditating, praying, or simply talking with me, to help relieve my fears and my loneliness.

I need help reflecting on my life, so I can make sense of it. What meaning did my life have? What have I accomplished? How have I changed and grown? I need to know you will not judge me, so that I can honestly face and reveal my life to you. Encourage me to acknowledge my regrets, so that I can

make up with anyone I've neglected or harmed and ask for their forgiveness. Sometimes when I look back on it, my life seems to be one continuous string of mistakes, or a legacy of selfishness and disregard for others. Remind me of what I have accomplished, of any good I have done, so I can know that in some way I have contributed to your life.

Please don't feel you must have all the answers or wise words to assuage my fears. You might come to my side feeling anxious, not knowing what to say. You don't have to pretend or keep up a strong façade. To really offer me spiritual support, I need you to be a human being first. Have the courage to share with me your uncertainty, your fear, your genuine sadness for the immense loss we are facing. Going through these difficult feelings together, establishing a deep bond and trust, I will feel safe enough to begin letting go, and I'll be able to face my death with more equanimity and an open heart.

After you have listened to my painful stories or complaints, remind me that I am more than my fear or my sadness, my pain or my anger. Help me understand that whatever suffering I am going through is natural; it's part of the human condition. Remind me that my painful emotional or physical condition, no matter how seemingly solid and real, will pass.

If I seem to be lost in my own suffering, help me to remember that there is still one positive thing I can do: extend my love and compassion toward others. Tell me the ways my life has touched yours. In whatever way you can reach me, help me connect to the inner goodness which is the most essential part of my being.

How can my process of dying have meaning? When I am lying here, weak and helpless, I am tempted to feel that the remainder of my life is useless. Everyone has to do everything for me, and it's so hard to feel that I have nothing left to contribute. If you ask, you might find there is something I do have to offer you: the insights about life and about death that I've recently gained. Would you allow me to give you whatever final gifts I have?

Sometimes the thought of death terrifies. At the same time, I also feel strangely peaceful and even curious about the adventure that is ahead. Yet it is a journey for which I may not have prepared. It won't help if you try to give me your own beliefs and answers about death; I need you to help me discover my own philosophy, my own inner resources and confidence. But if you are grounded in a spiritual tradition which gives you strength, which helps you work through your own suffering, perhaps you can find ways to

open windows and doors of hope for me. Perhaps all you need to do is tell me your own story, without any expectations attached. With time, if you give me your love and your trust, I will work something out deep inside me.

What will happen to me after I've died? What will count then? Help me find images of death which inspire rather than frighten me, so I can trust that what I am going toward is good. What I don't like is to feel I must simply "give up" and die. Perhaps you can help me find a way to meet death in a more positive way, calling on the best qualities of wisdom and authentic compassion within me. Maybe, like the prodigal son, I have been wandering far away from my home and my truth. Dying might be the process to help me find my own way home, so I can make my peace with God or my inner truth.

Perhaps you could learn which spiritual practices—prayers or meditations, sacred readings or music—are inspiring for me, and sit by my side and practice with me whenever you visit. Finding a spiritual practice that fills my heart with confidence, devotion, and compassion will help me to feel more prepared for death. I would be grateful if you could arrange whatever is necessary with the hospital staff and my family, so that the atmosphere when I am dying is loving and peaceful, and will be conducive to spiritual practice.

And please do not worry or feel bad if I die when you are not by my side. Sometimes your presence is soothing, but sometimes your being there makes it harder for me to leave. Please say and do whatever you need to early on, and then you won't have regrets if I should die unexpectedly soon. And when you learn I have died, please let go of any guilt! Remember that I am grateful for all you have done—and what I need most is your kindness, your sincere and heartfelt prayers, wishing me well and letting me go.

THE FIVE PSYCHOLOGICAL STAGES OF DYING AND MEDICAL ISSUES AROUND DEATH by Mitchell Gershten, MD

The process of dying is neither easy nor simple. Disengagement from the body often requires significant effort and may be associated with pain or other discomforts that can limit our ability to be fully present for the process. For some, disentangling from the physiology that has supported and nurtured us is challenging, and those challenges frequently increase when clinging to this life is coupled with fear about what may happen after death.

I have observed many ways by which people undergo this process. In a