

Fact Sheet

End-of-Life Choices: Holding On and Letting Go

Introduction

Our culture tells us that we should fight hard against age, illness and death: “Do not go gentle into that good night,” the Dylan Thomas poem says. “Rage, rage against the dying of the light.” And holding on to life, to our loved ones, is indeed a basic human instinct. However, as the end of life approaches, “raging against the dying of the light” often begins to lose importance, and “letting go” may instead feel like the right thing to do.

This Fact Sheet discusses the shifting emotions and considerations involved in “holding on” or “letting go.” Addressing these sensitive issues ahead of time will allow a person with a chronic illness to have some choice or control over his or her care, help families with the process of making difficult decisions, and may make this profound transition a little easier for everyone concerned.

The opinions of the dying person are important, and it is often impossible to know what those beliefs are unless we discuss the issues ahead of time. Planning ahead gives the caregiver and loved ones choices in care and is kinder to the person who will have to make decisions.

First, this Fact Sheet will present the principal concerns. Then it will discuss planning ahead, and some of the related matters that come up during chronic illness. Finally, it will present some ideas on actually making the decisions when the time has come.

Holding On

As people, we have an instinctive desire to go on living. We experience this as desires for food, activity, learning, etc. We also feel attachments to loved ones, such as family members and friends, and even to pets, and we do not want to leave them. We do not so much decide to go on living, as find ourselves doing it automatically. Robert Frost said once, “In three words I can sum up everything I have learned about life: It goes on.” Even in difficult times, it is our nature to hold on for better times.

When we realize that the end of life may be approaching, other thoughts and feelings arise. The person who is ill will want to be with loved ones, and may also feel a sense of responsibility towards them, not wanting to fail them nor cause them grief. He/she may have unfinished business. For example, the person may want to reconcile with estranged family members or friends and will find it both easier and more important to do. Fears arise, and may be so strong that they are hard to think about or even admit: fear of change, of the dying process, of what happens after death, of losing control, of dependency and so on. Both the person who is ill and the caregiver might also experience resentment, sadness and anger at having to do what neither wants to do, namely face death and dying.

In one way or another, hope remains. The object of hope may change. As death comes closer, the family may hope for a restful night, or another visit with a particular friend, or just a quiet passing from this life to whatever we hope follows it. Often, as the end of life nears, we keep two incompatible ideas in our

minds at the same time. The Jewish prayer of the gravely ill puts it well for both the person who is ill and the loved ones caring for him/her: "I do not choose to die. May it come to pass that I may be healed. But if death is my fate, then I accept it with dignity."

Letting Go

As death nears, most people feel a lessening of their desire to live longer. This is not a matter of depression. Instead, they sense it is time to let go, perhaps as in other times in life when one senses it is time for a major change. Examples might be leaving home, getting married, divorcing or changing jobs. Some people describe a sense of profound tiredness, of a tiredness that no longer goes away with rest. Others, who may have overcome many adversities in their lives, reach a point where they feel they have struggled as much as they have been called upon to do and will struggle no more. Refusing to let go can prolong dying, but it cannot prevent it. Dying, thus prolonged, can become more a time of suffering than of living.

Family members and friends who love the dying person may experience a similar change. At first, one refuses to admit the possibility of a loved one dying. Then one refuses to accept the death happening. Lastly, one may see that dying is the better of two bad choices, and be ready to give the loved one permission to die. As mentioned, the dying are distressed at causing grief for those who love them, and, receiving permission to die can relieve their distress. There is a time for this to happen. Before that, it feels wrong to accept a loss, but after that it can be an act of great kindness to say, "You may go when you feel it is time. I will be okay."

Other Concerns

Letting go gets mixed up in our minds with a person wanting to die, although these are really separate situations. There are various reasons a person may want to die, reasons quite separate from those for letting go. Depression is one response to finding life too painful in some way. Some people cannot tolerate losing control, so they want to take control of dying. It can be unpleasant to be disabled, or in a place one does not want to be, or isolated from the important people and things in one's life. Very often, a severely ill person feels like a burden to family and friends, and may wish to die rather than let this continue. Fears of the future, even of dying, may be so

great that a person wants to die to get away from that future. Inadequately controlled pain or other symptoms can make life seem unbearable. For many of these problems the right sort of help can make a great improvement, and replace the desire to die with a willingness to live out this last part of one's life.

Chronic Illness

So far, this Fact Sheet has been about the very end of life. Many, or even most, people go through a period of chronic illness before they die. Along the way there are numerous choices to make. Caregivers and people they care for have to decide whether or not to get a particular treatment or procedure. How long can one keep trying to do usual activities, including work, and when must they admit that that phase of their lives is over? Most of us have things we have dreamed of doing, but never got around to. Now may be the time to do that thing, no matter how difficult, or it may be time to let it be just a beautiful dream. Chronic illness brings up one situation after another where caregivers and care receivers must decide either to hold on or to let go.

Planning Ahead

Planning ahead means thinking about what is important, and what is not. It also means talking about this with those close to us. Even though we think we know what someone else thinks and believes, we really do not know until we ask. You cannot read other people's minds.

When we think about the last part of our own or someone else's life, consider these questions: What makes life worth living? What would make it definitely not worth living? What might at first seem like too much to put up with, but then might seem manageable after getting used to the situation and learning how to deal with it? If I knew life was coming to an end, what would be comforting and make dying feel safe? What, in that situation, would I most want to avoid? Some matters to consider would be: being able to talk with people, activity, physical comfort, alertness, the burden of care on others, being at home (or not being there), how much distress it would be worth in order to live another month, what medical procedures are not worth enduring, what I think is the best way for a person to die, how important it is to be in control of how one lives and how one dies, whose opinion should be sought in making choices about end of life care.

One especially important matter is to complete the Advance Health Care Directive for both the person who is ill and the caregiver, so that there is an official spokesperson when one is too sick or too confused to speak for him/herself.

If, as caregivers, we haven't had the necessary conversations—whether due to reluctance, dementia, or a crisis—we might have to think about the issues raised above without a lot of information. Some questions that might help in thinking about this are: What has that person actually told me? How can I find out for sure about her or his wishes? Turning now to myself as the caregiver, what would be important to me? What would I especially like to know about that person's wishes? What would be the limits of what I could do? Could I take time off work? How much? What physical limitations do I have? What kinds of care would be just too much emotionally for me? Am I willing to accept the responsibility of being someone's official spokesperson? If that person has relatives who would be especially difficult to deal with, how would I manage being the official maker of decisions?

All of these questions may sound very difficult to discuss now, when the time for decisions is still in the future. However, they are harder to discuss when someone is really sick, emotions are high, and decisions must be made quickly. Dementia soon takes away the ability to discuss complicated issues. The earlier everyone sits down to talk, the better. The best way to start is simply to start. Arrange a time to talk. Someone else's death or illness may offer a good opportunity to bring up thoughts you had about their choices. Perhaps you could say you want to talk about things that might happen in the future, in case of serious illness. Have some ideas to bring up. Be prepared to listen a lot, and to ask questions. Do your best not to criticize what the other person says. If you know the other person will not want to talk much about this topic, have just one or two important things to say or to ask about. Be prepared to break off the conversation, and to come back to it another time. Write down the important things people say. Eventually, you can use your notes to prepare a statement of wishes and make this statement part of an "advance directive" about health care decisions, whether or not the formal document has been completed.

Making the Decision

Is it time to let go? Or time to give a loved one permission to die? There are three ways to help decide. First, look at the medical situation. Has the illness really reached its final stages? When it has, the body is usually moving on its own toward dying, with strength declining, appetite poor, and often the mind becoming sleepier and more confused. Treatments are no longer working as well as before, and everyday activities are becoming more and more burdensome. In a sense, life is disappearing. Second, talk with people you trust. Discuss the situation with the family members and friends who seem to be able to see things as they are. You might also talk with people who are not personally involved. Choose the people whose judgment you trust, not just those with an official role of giving advice. Most importantly, what does the dying person think? Third, listen to your heart. Try to see beyond your fears and wishes, to what love and caring are saying to you. What is really best for the one who is dying, and for the others around? Given that death is unavoidable, what is the kindest thing to do? It might be holding on. It might be letting go.

Credits

Albom, Mitch, *Tuesdays with Morrie*, Doubleday, 1997.

Byock, Ira, *Dying Well*, Riverhead Books, 1997.

Dying Unafraid

Fran Johns

Synergistic Press

3965 Sacramento Street

San Francisco, CA 94118

(415) 387-8180

www.synergisticbooks.com

Kubler Ross, Elisabeth, *Death, The Final Stage of Growth*, Prentice Hall, Inc, 1975.

Levine, Stephen, *Who Dies*, Anchor Books, 1982.

Handbook for Mortals

Joanne Lynn, MD and Joan Harrold, MD

Americans for Better Care of the Dying

4200 Wisconsin Ave. NW, Suite 418

Washington DC, 20016

(202) 895-2660

www.abcd-caring.org

Malcolm, Andrew, *This Far and No More*, Times Books, 1987.

Nulland, Sherwin, *How We Die*, Alfred A. Knopf, 1994.

Rabbi Nosson Scherman, *The Complete Art Scroll Siddur*, Mesorah Publications, 2000.

Shannon, Thomas and Charles Faso, *Let Them Go Free*, Sheed and Word, 1987.

Thomas, Dylan, "Do Not Go Gentle Into that Good Night", *The Collected Poems of Dylan Thomas*, New Directions, 1957.

Webb, Marilyn, *The Good Death*, Bantam Books, 1997.

Resources

Family Caregiver Alliance

180 Montgomery Street, Suite 900
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106

Web Site: www.caregiver.org

E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating disorders that strike adults.

Compassion in Dying

1275 Fourth St. #615
Santa Rosa, CA 95404
(707) 544-5993
www.compassionindying.org

Hospice Foundation of America

2001 S St. NW, #300
Washington DC, 20009
(800) 854-3402
www.hospicefoundation.org

National Hospice Foundation

(800) 338-8619
www.hospiceinfo.org

National Hospice and Palliative Care Organization

A Pathway for Patients and Families Facing Terminal Disease
1700 Diagonal Rd. Suite 625
Alexandria, VA 22314
(703) 837-1500
www.nhpco.org

Partnership for Caring, Inc.

1620 Eye St. NW, Suite 202
Washington DC 20006
(800) 989-9455
www.partnershipforcaring.org
www.lastacts.org

Finding Your Way and Talking it Over

Center for Healthcare Decisions
3400 Data Drive
Rancho Cordova, CA 95670
(916) 851-2828
www.chcd.org

Five Wishes

Aging with Dignity
P O Box 1661
Tallahassee, FL 32302
(888) 5-WISHES
www.agingwithdignity.org/5wishes.html

Five Wishes is a document that helps you express how you want to be treated in the event you become seriously ill and unable to speak for yourself.