



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: Advanced Illness: 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," Dylan Thomas wrote. And holding on to life and to our loved ones is, indeed, a basic human instinct. However, as an illness advances, "raging against the dying of the light" often begins to cause undue suffering; and "letting go" may, instead, feel like the next step.

This fact sheet discusses the shifting emotions and considerations involved in holding on or letting go. Exploring these 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. In caring for someone with memory loss, it is important to have the conversations as soon as possible while he/she is still able to have an informed opinion and share it. Planning ahead gives the caregiver and loved ones choices in care and is most considerate to the person who will have to make decisions.

This fact sheet presents principal concerns, then discusses planning ahead and some of the related matters that come up during a

chronic illness. Finally, it presents ideas on how to go about making the decisions when the time comes. All along the way, there are few, if any, right or wrong choices. This is a time to seek the answers that most respect the person experiencing advanced stages of an illness.

Holding On

Humans have an instinctive desire to go on living. We experience this as desires for food, activity, learning, etc. We 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, "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 toward 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. Fears arise and may be so strong that they are hard to think about or even admit to fear of change, of the dying process, of what happens after death, of losing control, of

dependency, and more. Both the person who is ill and the caregiver might also experience resentment, guilt, sadness, and anger at having to do what neither wants to do, namely face death and dying.

Even in facing death, 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 an illness progresses to an advanced stage, two seemingly incompatible ideas may arise in our minds. 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 different from depression or thoughts of suicide. Instead, they sense it is time to let go. Perhaps, as in other times in life, it's a sense that it's time for a major change like one might feel when moving away from home, getting married, divorcing, or changing to a new job. Some people describe a profound tiredness, a tiredness that no longer goes away with rest. Others may 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 of a time of suffering than of living.

Family members and friends who love the dying person may experience a similar change. At first, one may adjust to managing a chronic illness, then learn to

accept a life limiting illness, and then accept the possibility of a loved one dying. Some may refuse to accept the inevitability of death. Lastly, one may see that dying is the better of two choices and be ready to give the loved one permission to die. As mentioned, the dying may be 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 fear. Inadequately controlled pain or other symptoms can make life seem unbearable.

For many of these situations, 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. At this time, professionals such as mental health providers, a hospice team evaluation, or pain management specialist may be called upon for consultation.

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 does it seem time for one to face 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 do their best to communicate about beliefs and options and then decide to either 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?

Knowing what really matters to you is worth considering. How important is being able to talk with people, engaging in daily activities, physical comfort, or general alertness to you? What comes to mind when you think about the burden of care on others, being at home, or not being there? How much distress is it worth in order to live another month? And what medical procedures are not worth enduring? From your perspective, what is the best way for a person to die; and how important is it to you to be in control of how you live and how you die? Whose opinion should be sought in making choices about the care received when an illness has progressed to an advanced stage?

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 are my financial constraints?
- What physical limitations do I have?
- What kinds of care would be just too much emotionally for me?
- Might I provide more comfort if I let go of some of the daily hands-on caregiving and allow someone else, even a paid caregiver, to assume the role?
- 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. Chronic pain, frailty, and cognitive decline may take 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. You may 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.

It is also important to talk with your physician about treatment choices. You may ask the doctor to complete a Physician's Orders for Life Sustaining Treatment (POLST). (Visit www.polst.org to find out if your state offers a POLST program; or in states without a POLST, ask the doctor about a DNR order—Do Not Resuscitate.) This form is a set of medical orders similar to the DNR (allow natural death to occur). On this form, one can state that he/ she does or does not want to be resuscitated and whether or not one would want a feeding tube, ventilator, and other treatments. Decisions to provide or withhold life support are based on personal values, beliefs, and considerations for what a person might have wanted. Such decisions are painful. Family members should give themselves ample time to cope with these life and death decisions and to process feelings of doubt, guilt, or blame that may surface.

POLST is not for everyone. Only individuals with serious, progressive, chronic illnesses should have a POLST form. For these patients, their current health status indicates the need for standing medical orders. For healthy individuals, an Advance Directive is an appropriate tool for making future end-of-life care wishes known to loved ones (see fact sheet on Advanced Health Care Directives). Professionals in medical offices, hospitals, community-based services, and hospice teams are skilled to assist individuals or family groups at working with these very normal but painful emotions.

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. Consult with your physician. Ask for clarity on the prognosis or likely course of the illness or stages of dying.

Closer to death, there may be dramatic changes in the dying person's moods, behaviors, desire to take food or water, and capacity to verbalize wishes. All of this may be a normal part of his or her letting go. At this time, safety and comfort care are of utmost concern.

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. Most importantly, consider what the dying person has expressed or you know to be his or her desires.

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

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

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Resources

Southern Caregiver Resource Center

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Web site: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions, and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance National Center on Caregiving

235 Montgomery Street, Suite 950
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.

Aging Life Care Association

This professional group offers a listing of care managers nationwide.
<http://www.caremanager.org>

Compassion & Choices

PO Box 101810
Denver, CO 80250-1810
(800) 247-7421
<http://www.compassionandchoices.org>

National Hospice and Palliative Care Organization

1731 King Street Suite 100
Alexandria, VA 22314
(800) 646-6460
<http://www.nhpco.org/search/node/grief>

Hospice Foundation of America

1710 Rhode Island Ave, NW Suite 400
Washington, DC 20036
(800) 854-3402
<http://www.hospicefoundation.org/grief>

Finding Your Way and Talking it Over Center for Healthcare Decisions

3400 Data Drive
Rancho Cordova, CA 95670
(916) 851-2828
<http://www.chcd.org/>

Five Wishes

Aging with Dignity

PO Box 1661
Tallahassee, FL 32302
(888) 5-WISHES
<https://agingwithdignity.org/five-wishes>
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.

POLST

Objective information provided about this advanced care planning tool. Offers a current POLST program map by state and a downloadable POLST form.
<http://www.polst.org/>

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