

USER'S GUIDE



L I V I N G

with dying



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"When a guy tells you, 'Hey you only got two months or one month to live', I don't know, it's kind of a hard thing to take. Very, very hard. Holy smokes, that's not very much. I was pretty emotionally upset.."

Albert Kerestes



The Terminal Diagnosis

The diagnosis of a terminal illness comes as a shock. In a society which values the physical and intellectual dimensions of our beings, we are often emotionally and spiritually ill-prepared to cope with death. But the questions posed by impending death are inescapable: What happens in death? How should I live now? What is the meaning of my life? We are confronted with the loss of all we have known and loved in life. We begin to grieve the loss of our physical abilities, our accumulations, and our relationships. The future fills with uncertainty.

Our family members accept the news in differing degrees. Each one struggles to adjust to the changes occurring to their loved one, make decent and intelligent choices about their involvements with the dying person and negotiate a workable relationship with the health care system.

Chronic illness is a burgeoning challenge to the health care system. We are being forced to recognize that a flexible combination of community services and care in the home is a desirable alternative to institutional care.

The Palliative Home Care Option

Palliative home care can be initiated when medical treatments aimed at curing a disease are no longer effective and the patient wants to live with dying at home. As required, the home care nurse will call upon the services and disciplines available in the community to relieve pain, alleviate symptoms, maintain abilities and provide support to patient and family alike. This allows the terminally ill person to remain at home for as long as is humanly possible. By sustaining the family's quality of life, home care enhances the possibility of a comfortable, peaceful death.

Choosing The Home Care Option

Having control of our lives is healthy. Self esteem is what helps us to achieve a sense of well being. For the terminally ill person, the best way to die is to live; to embrace what is enjoyable and meaningful; to discover in one's own faith what is spiritually sustaining; to take unfinished business to completion; to come to an understanding of one's own body, its afflictions and its changes; to find a way of accepting care in the place of cure; to share pain and fear of anticipatory grief; to love, to laugh, to feel at home and remain a person.

Family members will want to care for and about their loved one. They will make time to be with their

terminally ill kin. They will listen, love, share, hold, celebrate, reminisce, discover, enjoy, grieve, organize, doubt, affirm...they will live, honestly and openly, with the dying. They will find ways of identifying and managing day-to-day stresses of caregiving. And, because caring is both rewarding and exhausting, they will take time to restore themselves.

The health care system can reinforce family home care for the terminally ill by providing the services of a palliative home care nurse. The home care nurse will be a professional trained to identify the needs of the aggrieved family and help them to maintain a quality of life in the home. The home care nurse is sensitive, open, informative, practical and committed to keeping the terminally ill and their families in control of their circumstances. He or she will facilitate the efforts of patient and family to resolve relationship issues and help them connect with the supports and services available in the community.

The caring family that has the good will and support of the community is a stronger, more sustainable, home care unit.





“If he did not have Margaret, Albert would have been in a hospital and that would have led to considerable problems with his morale. The love and care give Albert a desire to live. We all need something to live for.”

Dr. S.K. Khullar
Family Physician

Questions From the Film For Discussion

- What are some of the personal resources that Albert called upon in responding to his terminal diagnosis?
- Why might he prefer home care to hospitalization?
- What are some of the losses he experienced? How did he respond to these?
- What were some of his hopes and fears; his concerns and desires?
- What provides meaning in Albert's life?
- The caregiver's feelings, needs and stresses are as important as those of the patient. Indicate why you would agree or disagree.
- What are some of Margaret's feelings and needs? How does she care for herself?
- "Dennis and Tim try to get Albert thinking about happy times they've shared." How might reviewing memories be helpful to the family?
- What do Albert and Margaret describe as supportive in their relationships with friends and family?
- Suppose Margaret had not been able to care for Albert at home. What other choices might they have made?

- What services from the palliative home care program did the Kerestes use? What health care workers were involved?
- How were the members of the palliative home care team sensitive to the unique and evolving needs of the Kerestes family?

For Personal Reflection

Your doctor has just told you that you have weeks, perhaps months to live.

- What is your immediate reaction?
- What questions do you want to ask?
- Who is the first person you will want to talk with?
- Who is the last person you will want to tell?
- How will you tell your family? Individually?
Together?
- Is there anyone you won't tell?
- How will you spend your last days?
- How will you want health care professionals to treat you?
- How will you want to be treated by friends and neighbours?
- Would you be able to offer palliative care in your home?

- What considerations would you have to take into account in reaching your decision?
- Are there palliative options other than homecare that you would want to explore?
- What palliative home care services are offered in your community?
- How are they organized and administered?
- How would you change your local home care program?

Anticipatory Grief is a time of simultaneous holding on to and letting go of a loved one who is dying. It encompasses losses past, present and future. Forthcoming detachment is not so much from the other person but from the hopes, dreams and expectations of the future. A host of personal, financial and lifestyle concerns plague those struggling to cope with the consequences of their impending loss. By definition, the grieving person is pulled in opposing directions with each concern. At this time, each family member will want to make good their relationship with the loved one they are losing in order to clear the way to an effective period of bereavement in the future.

Some Points to Consider

Shock and disbelief are common reactions to a terminal diagnosis.

“How long do I have?” is the most frequently asked question. As the film illustrates, the answer sometimes has more to do with the individual than the disease.

Some will accept the diagnosis as the end and ask, “What about pain?” Others will look for a way out by asking, “What treatments are available?”

We will usually talk first with those people we know will be supportive. Those we support will be told last. For this reason, it is important that our family members allow us to determine who we will tell first. We may make choices quite different from theirs, and for quite different reasons.

Men will often tell their wives so she can tell others.

If a number of people are told at the same time, they may not hear the same thing. They may want or need to be told a second and third time using different approaches.

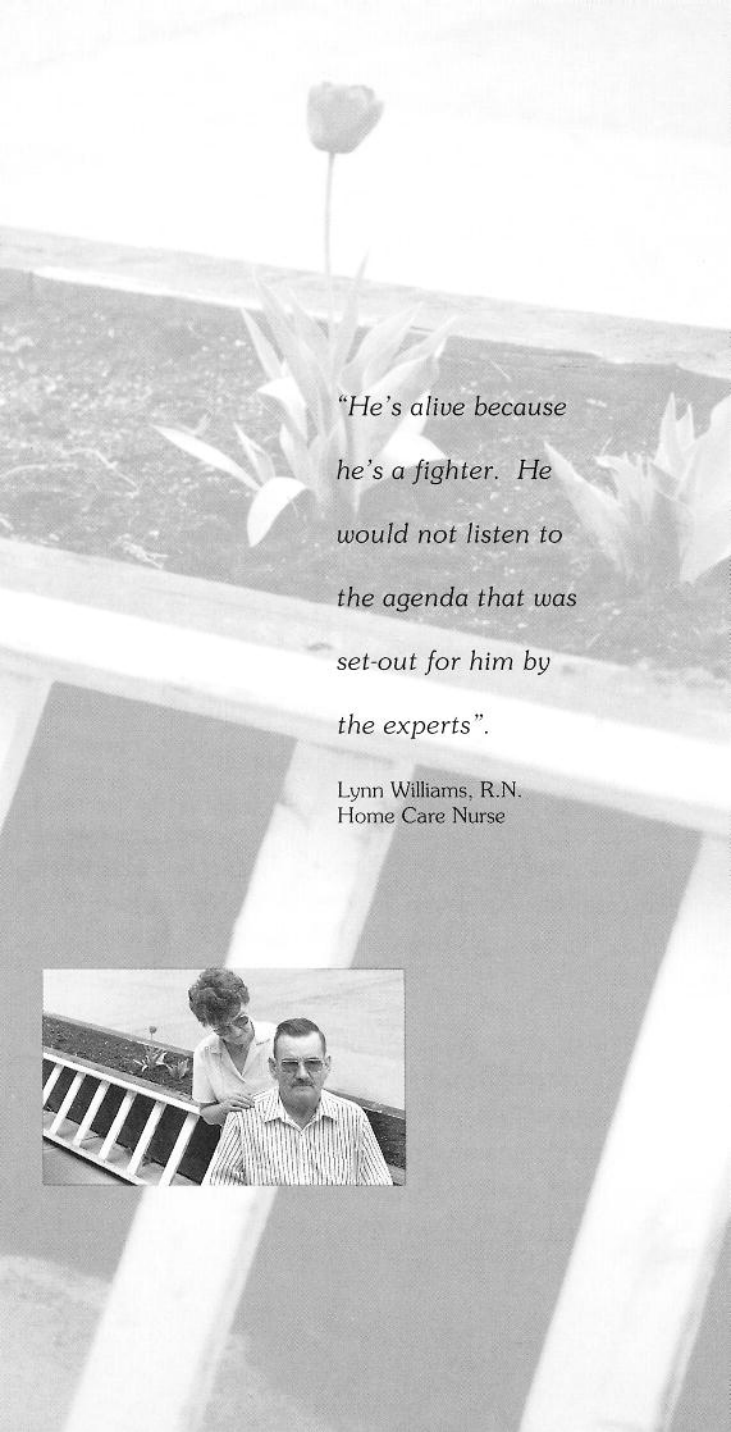
If family members are the first to learn of the terminal diagnosis and choose to withhold the information from that patient, the potential for conflict, distrust and alienation are enhanced. The family members enter a period of anticipatory grief while the patient becomes totally mystified by their changed behavior. The decision to protect the patient from the bad news

renders him or her a victim of ignorance. Honest, open communication is more likely to bring all the members of the family closer together prior to the loss of their loved one and clear the way for the healing that is meant to follow.

Terminally ill patients who tell everyone of their impending death may be sowing the seeds of regret. Not everyone knows how to respond. It is easy to interpret a clumsy response as a bad response and the patient comes away feeling badly treated.

People with terminal illnesses want to be treated as they always were, as friend and as family. They have every reason for wanting normal doses of candor, patience, understanding and wise counsel. They expect professional advice but want the important people in their lives to remain personable and accessible.

Like everything else in this life, dying is about changes and choices. Making your own choices about how you want to die and sharing that with family and friends, gives them the information they need to fulfill your wishes. With your support now, they will survive your passing with the knowledge they did the right thing. Without that knowledge, they will forever wonder, "Did we do the right thing?"



*“He’s alive because
he’s a fighter. He
would not listen to
the agenda that was
set-out for him by
the experts”.*

Lynn Williams, R.N.
Home Care Nurse



Services

Contact your provincial Department of Health, the Social Services department of your local hospital, or your Home Care office for information on palliative care/hospice services in your community. Your public library may carry some of the expanding body of literature on death and dying. Many community services, from churches to pharmacies, can provide you with support and information.

Suggested Readings

Kubler-Ross, E. *Questions & Answers On Death and Dying*
New York: MacMillan Publishing Co., 1974

Rando, T. *Grief, Dying and Death Clinical Interventions for Caregivers* Illinois: Research Press Co., 1984

Siegel, B. *Love, Medicine and Miracle* New York: Harper and Row, 1986

Segal, J. *Living Beyond Fear* New York: Balantine Books, 1989

Whiting, D.L. *Home Care for the Dying* Garden City, N.Y.: The Dial Press, Doubleday and Co., 1985

Jevne, R. and Levitan, A. *No Time For Nonsense - Self-Help for the Seriously Ill* San Diego: Lura Media, 1989

Jevne, R. *It All Begins With Hope* San Diego: Lura Media, 1991

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Pills Unlimited (VHS, 16mm) 28:43

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The Last Days of Living (VHS, 16mm) 57:52

Order Number: C 180 002

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Associate Director and Narration Writer
Susan Carnahan

Producer
Dale Phillips

Executive Producer
Graydon McCrea

Colour
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