

PASSAGES

Support and Education in End of Life Issues

Resources for End for Life Issues

There are many websites and books about various end of life issues. Below is just a small selection to help you begin your exploration.

Websites

- National Hospice and Palliative Care Organization
www.nhpco.org
- Hospice Foundation of America
www.hospicefoundation.org
- Growth House, Inc – Improving Care for the Dying
www.growthhouse.org

Books

- A Midwife Through the Dying Process – Stories of Healing & Hard Choices at the End of Life, Timothy Quill MD
- Being With Dying – Cultivating Compassion and Fearlessness in the Presence of Death, Joan Halifax
- Dying to Know – Straight Talk About Death & Dying, Tani Bahti
- Dying Well, Ira Byock, MD
- Ethical Dilemma at the End of Life, Ed. K Doka, B Jennings, C. Corr
- How We Die – Reflections on Life's Final Chapter, Sherwin Nuland, MD
- Learning to Fall: The Blessings of an Imperfect Life by Philip Simmons

Caregiving Resources

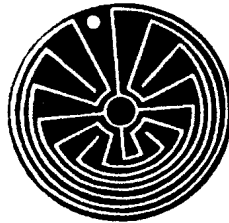
- Pima Council on Aging at 790-7262 - www.pcoa.org
- Pima Health System Caregiver Education & Support Program at 512-5599
- Caregivers Consortium – www.arizonacaregivers.org – community resource list
- Family Caregiver Alliance
www.caregiver.org
- Caring Connections (from NHPCO)
www.Caringinfo.org
- National Family Caregivers Association
www.nfcacares.org

Advocacy Websites

Patient Advocate Foundation
www.patientadvocate.org

American Pain Foundation
www.painfoundation.org

Be sure to check websites for organizations related specifically to your disease, e.g. Alzheimer's Association, American Cancer Society, Parkinson's Association, American Lung Association, etc.



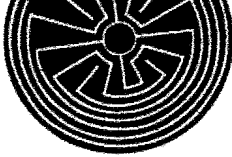
P A S S A G E S

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Important Questions for Making Treatment Decisions

- Is the goal of this treatment to cure, prolong life or relieve symptoms?
- What is the best I can hope for with this treatment?
- What is the worst I should prepare for if this doesn't work?
- Is this a standard treatment or experimental? What are the chances for success in my particular case?
- How and when will I know it's working?
- How will this impact my daily living, comfort and/or goals? What are the physical changes I may experience and how will you help me manage them?
- If I have side effects, how long might they last? What can be done to prevent or minimize them?
- Are there any potentially permanent side effects?
- Is this covered under my insurance? What will the cost be to me?
- Will I need extra help to manage at home, and if so, for how long?
- If I refuse this treatment, what can I expect to happen?
- If I refuse this treatment, will you still be my doctor?
- Is there a counselor, support group or someone I can talk to about this?
- Do you have material about this treatment that I can take home and review?
- Are there other ways to manage my disease and would you recommend them? Why or why not?

Although medicine doesn't have a crystal ball to know how you are going to respond to a particular treatment, it is important that you have enough information so you can make a decision. Consider your lifestyle, your beliefs, your goals and values. Consider your family, finances and spiritual beliefs. You always have the right to know and to choose.



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Important Questions for Yourself and Your Family When Making Treatment Decisions

- Do I have the information I need to make this decision?
- Is fear or lack of information pushing me towards a particular decision?
- What am I most afraid of?
- What are my goals at this time in my life and will this treatment help me reach them?
- Am I making a treatment decision based on what I believe someone else wants me to do or what I really want to do? Have I sat down with that person to clarify what each of us want?
- Who or what is my source of strength and support and have I utilized that?
- If I have a limited life expectancy, how do I want to spend the time I have?
- What does fighting the good fight mean to me? Seeking aggressive treatment until the end or allowing a natural death?
- Have I completed my advance directives (Living Will and Medical Power of Attorney), which declare my wishes for the extent of medical treatment I wish to receive in the event I cannot speak for myself?
- Have I talked with my family and physician about my advance directives?
- Have I asked all my questions, expressed all my fears, and shared what I truly feel with my family and physician?

Developmental Tasks of the Dying

Develop a renewed sense of personhood and meaning

- Find meaning in life through life review and personal narrative.
- Develop a sense of worthiness, both in the past and in the current situation.
- Learn to accept love and caring from other people.

Bring closure to personal and community relationships

- Say good-bye to family members and friends with expressions of regret, gratitude, appreciation and affection.
- Ask for and grant forgiveness to estranged friends and family members so reconciliation can occur.
- Say good-bye to community relationships (employment, civic and religious organizations) with expressions of regret, gratitude, forgiveness and appreciation.

Bring closure to worldly affairs

- Arrange for the transfer of fiscal, legal and social responsibilities

Accept the finality of life and surrender to the transcendent

- Express the depth of personal tragedy that dying may represent and acknowledge the totality of personal loss.
- Withdraw from the world and accept increased dependency.
- Develop a sense of awe and accept the seeming chaos that can prefigure transcendence.

From, "Tasks in Coping with Life-threatening Illness", *The Last Dance: Encounters with Death and Dying*, Lynne DeSpelder and Albert Strickland.

Should My Loved One Get a Feeding Tube?

ERIK FROMME, M.D.

Deciding whether or not to place a feeding tube in a loved one who cannot decide by him or herself can be one of the most emotional and difficult decisions that families face. Keeping a few things in mind can help:

Key Facts about Feeding Tubes

- ✓ If the goal is to prevent aspiration pneumonia, then be aware that a feeding tube will not prevent aspiration or pneumonia. Aspiration happens when food, oral secretions, or stomach contents get into the lungs. Sometimes this leads to fever, coughing, difficulty breathing, and pneumonia. It may be that feeding tubes actually increase the risk of aspiration pneumonia.
- ✓ If the goal is to provide comfort to a dying patient, feeding tubes are rarely necessary. Most patients who die over a period of days or weeks will drastically decrease the amount that they eat or drink as their bodies "wind down." It is actually uncommon for such patients to experience hunger or thirst, but when they do, small sips or bites of favorite foods or drinks are usually quite satisfactory.
- ✓ Withholding artificial food and fluids under these circumstances is not the same as starvation because a lot more is going on than just the inability to eat and drink. Ultimately, it is the underlying condition or disease (e.g., stroke, cancer) that prevents the patient from eating which is causing his or her death.
- ✓ Patients who suffer from dementia or other conditions where they are not thinking clearly may need to have their hands restrained after a tube is placed so that they will not pull out the tube by accident.

Questions to Ask Your Doctor/Nurse

- ✓ Your doctors and/or nurses should explain what the feeding tube is, why they think it might help, how it is put in, whether it will be temporary, the potential risks and benefits, and the alternatives to a feeding tube. They should also answer any questions you might have. Questions about prognosis or what the health professionals think will happen to your loved one are usually the most important but also the hardest to answer. Will the patient get better? How much better, and how long will it take? If not, how much worse will things get, and how soon will that happen? What will happen if the patient survives this episode? How long will he or she live, and what will his or her life be like?
- ✓ Remember that what health professionals give you are their opinions, and it is common for their opinions to differ on questions of prognosis and feeding tubes (and many other topics). Getting another opinion from a trusted health professional can help you get perspective and ease your peace of mind.

Making the Decision

- ✓ It may seem like *you* are being asked to make a decision all by yourself, but this is not quite right. Because you know the patient much better than any doctor or nurse could, you are being asked what you think *your loved one* would want if *he or she* were able to make the decision. The goal is not to burden you with a life or death decision; the goal is to ensure that the patient gets a feeding tube only if he or she would have wanted one. Often, the best decisions on difficult issues like this involve a collaborative effort between you and your loved one's professional caregivers.
- ✓ Some people believe that no matter what the prognosis for recovery, a feeding tube should always be used because food and water are basic human rights that should not be denied to anyone. Others believe that feeding tubes are medical treatments, which we are not obligated to use if we believe they would cause excessive burdens. (Dunn H: *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness*, 4th edition. Herndon, VA: A&A Publishers, Inc., 2001.) Try to imagine what your family member would say if he or she were thinking clearly. If it is not clear what he or she would want, or whether a feeding tube will help, or if the patient is going to get better, a "time-limited trial" can be the best solution. To do this you and the physician choose a goal for your loved one, then agree to try tube feeding for a limited time, such as 1 to 4 weeks. If there is little or no improvement or progress toward the goal, then the tube feeding can be stopped.
- ✓ Although tube feeding can be withdrawn after it is started, if a patient or family does not want a feeding tube it is psychologically easier not to begin the feeding than to face the difficult decision to stop feeding once it has been started.

Families who choose a feeding tube can find helpful information and support through the Oley Foundation, dedicated to patients and families who rely on tube-fed or intravenous nutrition. For more information call (800) 776-OLEY (in the U.S. or Canada) or 1-518-262-5079 (outside the U.S.), or go to www.oley.org

The information and recommendations appearing on this page are appropriate in most instances, but are not a substitute for medical diagnosis. For specific information concerning your personal situation or medical condition, JPM suggests that you consult your physician. This page may be photocopied noncommercially by physicians and other health care professionals to share with patients. Any other print or online reproduction is subject to approval by the publisher: Mary Ann Liebert, Inc. To purchase bulk reprints, call 914-834-3100 ext. 609.

Hard Choices for Loving People

Artificial Feeding and the Dementia Patient

By Hank Dunn

Alzheimer's disease and similar conditions are characterized by the deterioration of the person over a number of years. In earlier stages of the disease, it may be helpful to the patient to use a feeding tube as a temporary measure in the event of a decline in appetite or weight loss. The hope is that the patient will eventually be able to take in enough food and fluid by mouth to be able to discontinue the tube.

In advanced dementia, research has shown that a feeding tube does not offer benefit to the patient, even with temporary use. Dementia is a terminal disease. Like all terminal conditions, dementia has symptoms that indicate when the end of the disease process may be near.

One of the problems in the terminal phase of this disease may be swallowing difficulties that have sometimes been treated with feeding tubes. The truth is artificial feedings does not lengthen the life of an end-stage dementia patient and only adds greater burdens. The sign of end-stage dementia are well documented:

- Incontinence
- Progressive loss of speech
- Loss of intentional movement
- Complete dependence for dressing, eating and toileting
- Inability to recognize loved ones
- And finally, eating difficulties, possibly including the loss of the ability to swallow

One of the main hazards of hand feedings is the possibility for the patient to get food in the lungs and risk aspiration pneumonia. Some would rather start an artificial feeding tube to try and avoid the difficulties of hand feeding while hoping to reduce the possibility of causing pneumonia. Careful hand feeding (for example, keeping the head of the bed elevated and using soft foods) can reduce, though not eliminate this risk, but the risk is not eliminated by tube feedings either. Some research indicates that pneumonia is a greater risk with a feeding tube.

Many physicians, and others in healthcare, feel that because the feeding tube does not lengthen the life of the patient and causes greater burdens, careful hand feeding should be continued and artificial feeding is not appropriate. They see the swallowing difficulties as part of the end of a very tragic disease process and know that introducing artificial feeding does not cure the underlying affliction – dementia.

A review of 7 studies conducted over 33 years found that tube feeding of advanced dementia patients offered absolutely no benefit and even cause some harm. The researchers concluded, "We identified no direct data to support tube feeding of demented patients with eating difficulties for any of the commonly cited indications:

The facts:

- Tube feeding is a risk factor for aspiration pneumonia
- Survival has not been shown to be prolonged by tube feedings
- Feeding tubes have not been shown to prevent or heal pressure sores
- Improved delivery of nutrients via tube feeding has not been shown to reduce infection, but on the contrary, feeding tubes have been shown to cause serious local and systemic infection.
- Functional status has not been improved and demented patients are not more comfortable with tube feeding while dozens of serious adverse effects have been reported.