

MEMORIAL HOSPICE
INFORMATION AND POLICY
TRAINING MANUAL

574-3600

MEMORIAL HOME CARE SERVICES

302 South 10th Avenue
Yakima, Washington

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HOSPICE CONCEPTS OF CARE

Hospice care is based on twelve concepts, which form the foundation of our work. For the sake of discussion these concepts are listed separately, however, in actual practice they are inseparable. The concepts are interdependent parts that, when woven together, form the whole of Hospice care.

Before we can work effectively and compassionately, not only with our patients but with one another and our community, we must integrate the Hospice concepts of care into all parts of our lives. If we truly recognize our own need for autonomy, we will recognize that same need in our co-workers and in our patients and their family members. If we are able to recognize the importance of quality in our own lives and understand the need to respond to our own physical, emotional, social and spiritual needs, we will be able to recognize those same needs in our patients and their families. In order to respond to the grief of our patients and their family members, we must also honor our own grief and that of our co-workers.

Integrating the concepts of care into our lives helps us become more authentic in our relationships with our patients. We try to incorporate the twelve concepts into our daily lives, whether we are at work or at home.

Overview of the Hospice Concepts of Care

As we consider the twelve concepts, take a moment to think about how you can apply each of them to various aspects of your life.

- Patient and family autonomy are emphasized in Hospice.
- The unit of care is comprised of the patient and the family.
- Hospice care is palliative with emphasis on pain control.
- Hospice recognizes death as a natural part of the cycle of life.
- Hospice care is holistic with emphasis on quality of life.
- Hospice care is interdisciplinary.
- Hospice uses volunteers.
- Hospice provides services 24 hours a day.
- Admission to Hospice care is based on need.
- Hospice provides bereavement care.
- Hospice provides continuity of care within a wide scope of services.
- Hospice emphasizes quality patient care, education, and research.

Concept One

Patient and Family Autonomy are Emphasized in Hospice

Hospice programs recognize and emphasize patient and family autonomy (self-governance) by encouraging patients and family members to take an active role in defining the goals of care and participating in all decision making.

In his article on Hospice care, Douglas MacDonald notes that the principle of autonomy in the Hospice setting means patients and their family members have the right not only to refuse a particular course of treatment but also to modify treatment to meet other needs they might be experiencing, such as the need for privacy or mental alertness or care in a particular setting or at a specific time. The preferences of the patient and family are an essential concern in the delivery of care.

Three factors work together to ensure autonomy: informed consent which implies correct information presented in a manner the patient and family can understand; recognition of patient and family rights; and respect for patient self-determination.

In more traditional medical settings patient autonomy is often limited to the patient's right to refuse a specific treatment recommended by a physician. In Hospice however, patient autonomy has been greatly expanded to include patient and family participation in all aspects of decision-making. In Hospice care the patient and family have the final word about what is done – they “call the shots.”

If, as sometimes happens, a patient's decision conflict with those of his or her family, the patient's decisions are paramount. When conflict occurs, qualified members of the Hospice staff act as information conduits, providing further information about the goals of Hospice care and the effects of particular treatments. In the midst of conflict, qualified staff also provides support to both the patient and the family, acting in a mediation capacity.

Staff members, both experienced and un-experienced, are frequently challenged by the patient's and the family's expanded role in making treatment decisions. Relinquishing control can be difficult, particularly when we have been trained to be the professional in charge.

Concept Two:

The Patient and Family are the Unit of Care

Hospice care recognizes that each member of the family belongs to a family system that needs support during times of crisis, particularly a crisis involving the death of one of its members. Since the patient and family are such interdependent parts of the system, a terminal illness affects not only the patient but also every other member of the family system. All need support as they learn to redefine their roles, adjust to loss, examine family issues, address spiritual concerns and financial matters, and determine how best to care for the one who is dying. After the death occurs, family members often need on-going support and care during the time of bereavement.

When providing care, we need to remember Hospice defines the word “family” in terms broad enough to include relatives, close friends, lovers, and others vitally important in the patient's life. The National Hospice Organization defines family as, “a group of two or more individuals related by ties of blood, legal status, or affection who consider themselves a family.”

In many other components of the health care delivery system, the patient is the unit of care and family members are tolerated only when necessary. While exclusion of the family may speed things up and make care more efficient, it ignores the interconnections that give meaning to our lives. Patients and family members often need one another on such a deep level that severing those connections during the dying process interferes with quality of life and any opportunity for emotional healing.

Hospice recognizes these interconnections and works to enhance them on a deep and meaningful level.

Goal of Team Care: Care and support for both the patient and family members.

Concept Three:

Hospice Care is Palliative with Emphasis on Pain Control.

Hospice care is palliative, or comfort care, rather than curative care. Palliative, or comfort care, involves a change in treatment goals from cure of the patient's underlying disease to the provision of comfort and relief from distressing symptoms. Because palliative care emphasizes the management of symptoms, with special attention given to the control of pain, Hospice care requires its medical and nursing staff to become highly skilled specialists in the control of pain and other symptoms. Quality of life demands that physical symptoms be adequately controlled enabling patients to devote their energy to other important issues, such as family reconciliation and spiritual concerns.

In traditional health care settings where cure is the primary goal, symptoms receive much less attention because care is focused on curing the underlying disease. However, in Hospice care, treatment is re-focused. Symptoms which interfere with quality of life become the focus of treatment.

Pain and many of the other frightening and distressing symptoms that may accompany a terminal illness, such as nausea, vomiting, constipation, and weakness, interfere with quality of life by creating discomfort, anxiety, fear, and worries about loss of control, not only for the patient but also for family members. Even members of the Hospice staff may experience anxieties about symptom control, anxieties that surface when we ask ourselves, "What happens if I can't control my patient's pain? Does it mean that I am incompetent? What will I do then?"

The patient's quality of life depends on the skill of the entire Hospice team as each member works in unison to alleviate pain and suffering.

Concept Four:

Hospice Recognizes Death as a Natural Part of the Cycle of Life.

While Hospice care neither hastens nor postpones death, it accepts death as the last phase of life, just as birth is the first. When the prospect of cure is no longer realistic, members of the Hospice team work together to ensure that the dying process is as satisfying and fulfilling as possible so patients can experience a peaceful and appropriate death with dignity.

Traditionally a patient's death has been viewed as a failure on the part of the medical profession. Since cure was the only acceptable outcome, death was forbidden to enter the halls of the hospital or nursing home. If a patient persisted in dying, he or she was isolated and ignored. Call lights went unanswered for as long as possible. None of the staff members wanted to be reminded that death could defeat all the latest medical technology. Because dying patients also reminded staff members of their own helplessness and inability to control what was happening, staff frequently responded to such patients with anger, distancing, or the silence of denial.

In Hospice care, a death with dignity sometimes referred to as an "appropriate" or "good" death, is not seen as a failure, but as a successful completion of the cycle of life. Instead of letting our tears of uncontrolled pain or loss of control rush us into ending life prematurely, or on the other hand, letting our fear of death lead to the prolonging of life as long as possible, regardless of its quality, the acknowledgement of death as a part of the cycle of life allows us to accept life's natural ending.

Concept Five:

Hospice Care is Holistic with Emphasis on Quality of Life.

The concept of Hospice care emerges from the principle of holism – the understanding that anything that deeply affects one aspect of a person’s being has an effect on all other parts of that person’s being. As we learn more about the complex interconnections that make up our lives, we develop a greater appreciation as to how our physical, emotional, social, and spiritual lives are interwoven. We must take into account the effect that a planned therapeutic intervention will have on the entire person.

In order to help us understand the concept of caring for the whole person, Hospice philosophy classifies the needs of the dying patient and his or her family into physical, emotional, social, and spiritual needs. While the categories help us assess and discuss patient and family care issues, they can’t be separated from one another—the boundaries always blur. We need to remain focused on understanding the entire person.

When, as caregivers, we have integrated the concept of holistic care on both a personal and professional level, we no longer respond to a patient as the “breast cancer in Room 314 who gripes and complains a lot.” Instead we see Mrs. Bailey, a school teacher who raised four children and is now dying and in great physical and spiritual pain. We are sensitive to her physical pain as well as to her fear and loneliness. We recognize that her body is translating the emotional pain of fear and loneliness into additional physical pain and that she may feel more comfortable asking for more medication than acknowledging her own sense of fear and helplessness. Amid the frenzy of an intensive care unit it is difficult to say, “I’m lonely and afraid. Please stay with me.”

Responding to a patient holistically means responding to that person’s need for quality of life. Quality of life can mean, among other things, freedom from pain and other distressing physical symptoms, finding meaning in our lives, and healing broken relationships. It can also mean birthday parties and family reunions, a beer with dinner, or privacy for cuddling, snuggling, enjoying sex, or praying. For most of us, quality of life includes a caring human touch.

Concept Six:

Hospice Care is Interdisciplinary.

Because Hospice provides comprehensive care, a team of highly trained and compassionate professionals from several different disciplines is needed to meet the patient’s and the family’s physical, emotional, spiritual, and social needs. Physicians, nurses, social workers, clergy, home health aides, pharmacists, physical and occupational therapists, and others work together to ensure the needs of both patient and family are met as completely as possible. Although each professional has a specific area of expertise and an important and irreplaceable role, each must also be able to communicate with the rest of the team to provide the best possible care.

In the past, professionals were more likely to focus on just one aspect of a patient’s needs. Physicians might write prescriptions without asking, “Can this patient afford the prescriptions I’m writing?” Hospital chaplains might focus on praying or making communion available without also considering the effects of unrelieved pain on a patient’s ability to cope with spiritual matters. Care was disjointed because professionals were concerned with only one aspect of the patient’s life.

When caregivers work together as a team and communicate information vital to a patient’s quality of life, the result is coordinated care that better meets the needs of the

patient and family. More information on the interdisciplinary team's role is included in Module Two.

Goal of Team: Care for the Physical, Emotional, Spiritual, and Social Needs of the Patient and His or Her Family.

Concept Seven:

Hospice Uses Volunteers.

Hospice programs rely on trained, compassionate volunteers to provide extra sets of hands and ears for both the patient and the family. With their varied interests and special talents, volunteers can greatly expand both the number and scope of services a Hospice program is able to offer.

A Hospice volunteer works in many capacities. These include helping in the office, fund-raising, providing transportation for patients, cooking or assisting with yard work, and providing caregiver relief. Volunteers also act in a liaison capacity with the community to maintain and increase community awareness and support of Hospice care. Most importantly, volunteers act as loving companions who listen with "long ears" to their patient's and the family's concerns, anxieties and joys.

In most other health care settings, volunteers help by delivering mail and assisting with clerical work or fundraising. They are rarely considered integral parts of the patient's health care team. In Hospice, volunteers are an important part of the care team and have the opportunity to contribute greatly to a patient's quality of life. Because patients and their family members are sometimes more comfortable talking to a "regular person" volunteers can act as extra ears and eyes for paid staff. And by working without financial remuneration, volunteers help contain the rapidly escalating costs of health care.

Many Hospice programs in the United States were developed by members of the community who volunteered their time to plan and deliver Hospice care for the terminally ill. To encourage the continued use of volunteers, Medicare requires Hospice programs to provide documentation proving that volunteers provide the equivalent of 5% of the paid staff's hands-on patient care time.

Goal of Care: Enhancement of quality of life for the patient and the family.

Concept Eight:

Hospice Provides Services 24 Hours a Day.

Hospice recognizes dying patients and their families continue to need care and support throughout the night and during the weekend; their needs can't be put on hold until Monday morning. Anyone who has experienced a serious illness or injury, surgery, or a stay in the hospital knows pain and discomfort seem to increase once the sun goes down. In the darkness of an empty room, anxieties take on lives of their own. Our fears become the bogeyman of our childhood, keeping us awake and restless with apprehension. Symptoms such as pain or itching become intolerable.

Hospice recognizes the need for extra care and support by making on-call services available throughout the night and weekend. Staff members are on call at all times, with backup staff available in case the on-call staff is simultaneously responding to a call. The on-call number is given to patients and family members, who are encouraged to use it whenever a problem or concern arises. Sometimes just knowing a nurse is on-

call is enough to allay a family's fears. When a family member does call, Hospice staff can often handle the problem over the phone but some situations require a personal visit. Calls or visits last as long as necessary to resolve the problem, whether five minutes or five hours.

Goal of Team Care: Provide high quality patient care and caregiver support and assistance at all times.

Concept Nine:

Hospice Care is Based on Need.

Hospice offers palliative care to all terminally people regardless of age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, ability to pay, or place of residence. Sometimes it is hard for us as Hospice staff to remember the incredible relief experienced by terminally ill patients and their family members when they discover the only requirement for admission to Hospice is need. After trying to qualify for program after program, after using up all their financial resources and "spending down" to become eligible for Medicaid, after experiencing tremendous anxiety about the costs of caring for a dying family member, they at last are referred to Hospice.

As Hospice programs are faced with providing care for an increasing number of patients with complicated illnesses, some of which are more chronic than terminal, the concept of need-based admission presents a great challenge. In the United States more than 38 million people lack health insurance. Others have been impoverished by the costs of treating a serious illness or injury. In this situation, Hospice programs are constantly challenged by ethical issues.

Goal of Care: Hospice Care for All in Need.

Concept Ten:

Hospice Provides Bereavement Care.

After the death of a loved one, family members often need support and reassurance as they experience the sometimes overwhelming emotions of grief and learn to adjust to a world that no longer includes the person who died. Bereavement can be a difficult time, not only because our culture denies death but also because we deny the intensity and length of the grieving process. As a society we have forgotten what grief feels like and how long its pain can last. Those in mourning are expected to get on with life just days or weeks after the death of a loved one. When the normal but powerful emotions of grief overpower us, we think we're going crazy.

As part of their bereavement services, Hospice programs help normalize the grieving process by providing supportive care and educating those in mourning about the process of grief.

In most other components of the health care system, a patient's death signals the end of all interaction with the family. However, providing ongoing support for family members for at least a year following the patient's death is a basic concept of Hospice care. Bereavement services can include bereavement or grief support groups, memorial services, visits from the bereavement coordinator and/or bereavement referrals for other services, including referrals for treatment of complicated grief and periodic notes to let the family know they haven't been forgotten.

Goal of Team Care: Successful Accommodation to Grief.

Concept Eleven:

Hospice Provides Continuity of Care.

Most Hospice patients receive most of their care at home. Although stays in a hospital or skilled-care facility may be necessary to control a particular symptom, they tend to be infrequent. In fact, Hospice Medicare requires that 80% of the annual number of aggregate patient days of care be delivered in the patient's residence.

For many patients, home is the ideal setting because it's familiar and comforting and filled with the day-to-day activities of life. Unfortunately, home care is not always possible. Some patients may require more intensive treatment for symptom control than can be provided at home. Sometimes, for family reasons, home care is not an option. When home care is not possible, each Hospice program is faced with the challenge of ensuring that Hospice's loving care follows its patients wherever they go.

Since most Hospice programs don't operate inpatient facilities, our constant challenge is providing continuity of care for all our patients. When Hospice patients are transferred from home to another setting to receive short-term treatment for a symptom that can't be controlled at home, or when they reside in a long-term care facility, how can we ensure both continuity and quality of care? How can we ensure continued Hospice care in so many different settings when the staffs in most health care facilities have little or no training in providing palliative care? How can we ensure adequate pain and symptom control when facility staffs are unfamiliar with the treatment protocols and drug dosages commonly used in Hospice care?

The goal of team care is:

A safe and coordinated program of palliative and supportive care; from the time of patient admission through the family's bereavement.

Concept Twelve:

Hospice Emphasizes Quality Patient Care, Education, and Research.

In her work with terminally ill patients, Dr. Cicely Saunders emphasizes the need for continued research and education to improve the quality of patient care. Her commitment to maintaining detailed records of the efficacy of various pain and symptom control techniques allowed her to determine which treatments actually worked and which did not. The results of her research led to tremendous improvements in the quality of life of her patients.

As members of the Hospice team we need to follow Dr. Saunders example and remember her commitment to detail and to the use of scientific methods to determine whether the treatments we offer actually work, or if we just think they are working. Research is essential to continued improvements in the relief of pain and suffering.

Dr. Saunders also emphasizes the importance of continued education concerning the management of terminal illness and the scope and availability of Hospice services, not only for Hospice staff but also for other health care professionals, patients, family members, and the community. Educating other professionals about pain and symptom control is crucial because it contributes to better management of dying patients, regardless if those patients receive terminal care from an official Hospice program. Educating patients, family members and the community about Hospice-related issues

contributes to better understanding of the dying process and decreases fear of a subject usually left unspoken. An educated community results in an increased interest in Hospice care, more effective use of hospice services, and broader support for Hospice concepts of care.

VOLUNTEERING IN HOSPICE

Hospice is a special kind of care designed to provide comfort and support to patients and their families in the final stages of terminal illness. This care seeks to enable patients to carry on their remaining days in an alert and pain-free manner, with symptoms under control so their last days may be spent with dignity at home or in a home-like setting.

Hospice care neither speeds up, nor slows down the dying process.

Bereavement care is critical to supporting family members.

Volunteer Policies

Volunteers will adhere to the policy of strict confidentiality regarding names of and information about the patient and families served by Memorial Home Care Services.

Hospice volunteers will maintain contact with the appropriate staff coordinator about each client and document each visit with appropriate and timely charting.

Hospice volunteers will visit the patient and families as directed by coordinating staff.

Volunteers will wear their name badge and appropriate attire at all times when representing the agency or assisting in the Memorial Home Care Services.

Volunteers will attend at least four scheduled in-service training meetings each year.

Volunteers are required to show evidence of a negative Tuberculosis (TB) test in the form of a skin test or chest X-ray. This test is given at no charge.

Bereavement volunteers will attend bereavement activities when appropriate, i.e., educational opportunities, etc.

Volunteer performance evaluations will be conducted annually by the staff and reviewed by the volunteer.

At staff discretion, volunteers can be deemed inappropriate for a service at any time.

Why Hospice needs Volunteers

In addition to the special kind of care volunteers can bring, Medicare requires that 5% of patient care hours be provided by volunteers.

What do Volunteers Do?

Volunteers will have an opportunity to share their time in a variety of ways including: Caregiver relief, companionship, emotional support, life review, clerical office support, light meal preparation, yard chores, medication deliveries, leisure activities, errands and bereavement support.

Some things to Consider:

Volunteers often find they must go to extra lengths to make their own families understand why they make the personal sacrifice to be a volunteer. It can also serve as an opportunity to teach your children that other people besides them need the help of a family member.

If you wonder whether being a Hospice volunteer is for you, ask yourself the following questions:

- Can I handle the loss of people I help?
- Am I comfortable with my own mortality?
- Am I flexible enough to accept others' views of death without being judgmental?
- Am I willing to help others in the way they want me to help?
- Am I independent enough to work on my own?
- Do I have a sense of humor that will help me see the funny side of situations as well as empathize with more painful aspects?
- Do I work well as a team member?
- Can I respect others' lifestyles and cultural differences without being judgmental?
- Is my personal life sufficiently stable that I can make a commitment to be there for others?
- Am I open enough to continue learning about myself as I learn the Hospice volunteer experience?

Volunteers and Families

Volunteers are indispensable in helping families cope. In some cases, patients are more comfortable speaking about dying with a volunteer trained to listen than to their own families.

Remember, your presence and enthusiasm can make a difference in how a dying person approaches what could be the most challenging experience in his or her life. You have a chance to support not only those living with a terminal illness, but their families as well.

Guidelines for Hospice Volunteers

Many volunteers feel anxious before their first visit. It is normal to have such questions as “Will the family like me? What will I do? Will I be able to help?” This is often a new experience for both the patient and the family and the volunteer. An attitude of openness and receptivity to the needs of the patient and their family will enable them to communicate their needs. In turn, the volunteer can then indicate clearly what she or he can offer. The relationship unfolds step by step in a very natural way. The following guidelines may help:

Genuineness: Be yourself. People who are ill appreciate being treated naturally, and this way are reassured that their illness has not set them apart any more than in the obvious way. Relate to the patient, not to the illness. This holds true for family members as well. The volunteer role is that of friend and supporter, not expert and authority. The volunteer is not expected to know all the answers. It does not take long to clarify for the family that medical and technical questions can be best answered by the nurse and physician, and that the volunteer is there to facilitate this communication and to provide other, less technical support. This role definition comes about most easily when the volunteer feels comfortable from the beginning just being herself or himself.

Team communication: Clear communication between Hospice staff and volunteers is very important. Every member of the Hospice team can be of help to one another and to the patient and the family by maintaining regular contact and by keeping one another current with what is happening. Written reports of visits should go to the Volunteer Coordinator for inclusion in the patient’s chart. When necessary or appropriate, a telephone report should be made. Exchange schedules and phone numbers, and clarify mutual expectations at the start. A working relationship is essential to maintaining continuity and stability, as well as providing quality care.

Communication with the family: The volunteer responds to a specific request for help from the patient or the family. It is then the volunteer’s responsibility to state clearly to the family what can and cannot be offered in terms of time and availability. It is helpful to clarify with the family their needs and expectations at the beginning with the understanding that these may change as the patient’s condition changes. Regular phone calls to “check in” are often appreciated as an indication of continued support. These contacts may give the patient and the family an opportunity to share their feelings. Some people are comfortable calling the volunteer for help, while others find it easier to respond to contact initiated by the volunteer. The volunteer most often must take the initiative in communicating and developing the relationship with the patient and the family. The volunteer must also always be sensitive to those times when help is not needed or wanted.

Confidentiality: References to the patient or the family by name should be confined to contacts with the Hospice team, either individually or at meetings. Information of extreme confidentiality divulged by a patient or family member should not be shared in a group session unless it bears directly upon the designing of a care plan. Such information should be shared directly with individual team members, especially when it affects the care of the patient or the family.

Physical contact: Some people like to touch and be touched. Others don't. It is helpful for the volunteer to be flexible with this issue in order to cue in on the needs of those being served. In most instances, patients welcome handholding and other appropriate physical gestures as a means of communicating, caring and connection without the necessity of tiring conversation. Family members will often respond to a hand on the arm or across the shoulders as a gesture of "I'm here. I care."

It goes without saying that this dimension of the relationship evolves naturally with the passage of time and the intensity of events. Be open. Do what feels right. Again, your comfort or discomfort will communicate itself clearly, so it is important to be yourself.

Meet them where they are: Over and over again in the volunteer training the concept of tuning in to the family and meeting them in terms of their own values and life patterns is stressed. Regardless of how much a volunteer may be uncomfortable with a family's way of dealing with their situation, it is never appropriate to give unsolicited advice. Patterns of interaction between family members, no matter how counterproductive they may seem, have been formed over years of association. The volunteer's responsibility is to work as helpfully and harmoniously as possible within the given structure, not to try to change it.

Little things mean a lot: Here are some things, perhaps obvious or common sense, to think about:

- Your personal grooming and manner of dress can affect a patient's mood. Color and attractiveness can help lift the spirit. Be casual.
- Perfume or after-shave can be unpleasant to people on medication. Use in moderation.
- A positive attitude and pleasant expression mean a lot. This does not mean phony cheerfulness and bright chattiness, but a clear message of caring and personal attention.
- Volunteers should not smoke while visiting a patient, unless the patient invites them to do so and they are smokers.
- Please wear your Hospice name tag when doing Hospice work.
- Personal problems of the volunteer are not appropriate topics for discussion with the patient or the family.
- The patient's right to privacy is important. Lifestyle and personal beliefs should be respected.
- Religious beliefs are very personal. Religious discussions should be undertaken carefully, and only when initiated by the patient. Sharing faith can be a positive and important part of your relationship. However, this is not the time for evangelizing or proselytizing.

Limits of Care

In addition to common sense and insurance restrictions, there are some limits within which a volunteer must function. After participating in the volunteer training program, volunteers may provide direct patient care as necessary, only to relieve the primary caregiver for respite purposes. Volunteers may assist someone in and out of a chair,

wheelchair, from bed to commode or toilet, provided the volunteer has determined it is safe to do so. After training, volunteers may also administer fluids and assist with feeding the patient. Volunteers may also perform light household chores, prepare meals, relate to children in the family, run errands, etc.

Volunteers may not provide skilled nursing care, personal care such as bathing, tube feeding or dispensing medications. However, volunteers may assist a family member or other caregiver in these tasks when it would be helpful and safe to do so.

Medications

Medications are never administered by the volunteer: If a question of a medication need occurs, contact the Hospice staff at the office. 574-3600.

Never directly call the patient's physician: You must convey any concerns you may have to the Hospice staff, particularly to the Volunteer Coordinator or team members, i.e. nurse, social worker.

TOOLS FOR HOSPICE VOLUNTEERS

STRESS MANAGEMENT

What is Stress?

- A physical and psychological response to a demand.
- A response to a perceived threat, challenge or change.
- A state of physical and psychological arousal.
- The interaction between what happens to you and how you take it.
- Wear and tear on the body as it adapts to change.
- A non-specific response to a demand.
- A perception that events or conditions have challenged or exceeded your ability to cope.
- Cause of emotional or physiological strain, usually resulting from a perceived struggle or mismatch between what a person wants to happen and what the world delivers.
- Reality is the leading cause of stress among those in touch with it. (Lilly Tomlin)
- **Self Talk Questions to Consider:**
- Do I need to think about this event or person in this way?
- What am I telling myself that might be mistaken or irrational?
- What is the worst thing that could happen?
- What are the real chances that it will turn out as badly as I imagined?
- If it does turn out as badly as I imagined, will I survive?
- How will I survive?
- How much can the situation or person really hurt me apart from the meaning I give it?
- What could I say to myself that would reduce my stress?
- If I cannot change the situation or outcome, how could I see it differently and accept it?
- How can I change my expectations, demands and “should’s” to preferences?
- What is the impact of negative self-talk to positive self-talk?
- Am I willing to be responsible for my thoughts, feelings, and stress level?

Strategies for Managing Stress

Each of us has our own comfort levels of stress. A stress level that seems exhilarating and conducive to good work to one member of the team may be frightening and overwhelming to another. Each of us comes to Hospice with our own vulnerabilities to stress, our own genetic makeup, and our own developmental history. Our ability to cope with stress at work and home may change over time as we experience additional stress in one or more areas of our lives. When illness strikes, a level of stress that was comfortable may suddenly seem overwhelming. Each of us has our own methods for managing stress, some of which may not be very effective. The following are several strategies for managing the stress in our lives.

Know Yourself

All of us have different abilities to cope with stress. We need to know ourselves well enough to recognize the levels of stress we find satisfying and recognize when stress levels begin to overwhelm us. We also need to accept ourselves as we are. Not being able to cope with the same amount of stress as another team member does not mean we are inferior or lacking value as a member. One of the important lessons in life is learning to accept ourselves. We need to let go of the desire to be someone or something we are not.

Identify the “Stressors” in Your Life

Take time to identify and label the stressors in your life and prioritize them. If uncertainty about something is creating stress, ask for clarification. If lack of knowledge about an aspect of your job or assignment is creating stress, ask for help and additional training. If personal stressors are contributing to your volunteer assignments, discuss the situation with your coordinator. A temporary reduction in responsibilities or a personal leave could be arranged while you cope, for example, with a family crisis. Ask family members for more assistance with responsibilities at home.

Set Limits

Each of us needs to recognize the limits of our knowledge and expertise and learn to say, “I don’t know.” Each of us also needs to recognize the limits of our physical and emotional stamina. We have to learn when to say “no” to requests to take on additional responsibilities at work, at church, at home, or in volunteer groups.

Express Yourself

We must also learn to speak up and ask for help when we need it. People can’t read our minds. We must speak up for ourselves and request assistance with stress management.

Recognize Your Own Physical Needs

Exercise, good nutrition, and adequate sleep contribute greatly to our ability to cope with stress. Take time out for meals, regardless of how busy you are. One of the responsibilities of the Hospice program is to ensure a healthy environment for all team members. While caring for others we may forget our own needs for physical comforting through touching, stroking, hugging and other physical contact.

Recognize Your Own Social and Emotional Needs

Responding to our emotional and social needs is an important strategy for managing stress. Long-range effectiveness in Hospice may depend more on our ability to nurture ourselves emotionally outside of Hospice than on the knowledge and skills we bring to Hospice. While our social and emotional sources of support can include our volunteer group, they should also include people who are not associated with Hospice.

Recognize Your Own Spiritual Needs

Working with the dying creates an atmosphere which we inevitably ask our own questions about the value and meaning of our lives. Once again, we need to remember that working with the dying means working on ourselves and sometimes results in spiritual crises that are normal and to be expected. On occasion we may question all of

our spiritual and religious values and beliefs. Questioning can be an unsettling experience, but the process can lead to growth. Sometimes, as a result of what we learn from our dying patients, our religious beliefs change, expand and grow.

15 Proven Stress Reducers

- 1) Get up 15 minutes earlier in the morning. Don't start the day feeling frazzled.
- 2) Do nothing which, after being done, leads you to tell a lie.
- 3) Act now. Procrastination is stressful. Whatever you want to do tomorrow, do it today; whatever you want to do today, do it now.
- 4) Schedule a realistic day. Allow ample time between appointments so you don't have to rush, worry, and apologize for being late.
- 5) Exercise! An instant cure for most stress is 30 minutes of brisk walking or other aerobic exercise.
- 6) Talk it out. Discussing your problems with a trusted friend can help clear your mind of confusion so you can concentrate on problem solving.
- 7) Make time for solitude every day.
- 8) Get enough sleep. If necessary, use an alarm clock to remind you to go to bed.
- 9) Turn needs into preferences. Our basic needs are food, water and keeping warm.
- 10) Stop worrying. If something concerns you, do something about it. If you can not do anything about, let it go.
- 11) Count your blessings. For everything that goes wrong there are 50 to 100 blessings. Be grateful!
- 12) Forget about counting to ten. Count to 100 before you say anything that could make matters worse.
- 13) Stop and think. The next time someone cuts you off in traffic, stops suddenly, etc., instead of getting mad, think of instances when you have intentionally (or un-intentionally) done a similar thing.
- 14) Write your thoughts and feelings in a journal. This can help clarify and put things into perspective.
- 15) **Letting Go:**
 - To "let go" does not mean to stop caring. It means I can't do it for someone else.
 - To "let go" is not to cut myself off. It's the realization that I can't control another.
 - To "let go" is to admit powerlessness, which means the outcome is not in my hands.
 - To "let go" is not to try to change or blame another. It's to make the most of myself.
 - To "let go" is not to care for, but to care about.
 - To "let go" is not to fix, but to be supportive.
 - To "let go" is not to judge, but to allow another to be a human being.
 - To "let go" is not to be in the middle, arranging all the outcomes, but to allow others to affect their own destinies.
 - To "let go" is not to deny, but to accept.
 - To "let go" is not to nag, scold, or argue, but instead to search out my own shortcomings and to correct them.
 - To "let go" is not to adjust everything to my desires, but to take each day as it comes and cherish myself in it.

- To “let go” is not to regret the past, but to grow and live for the future.
- To “let go” is to fear less and to love more.

LIFTING AND TRANSFER TECHNIQUES

Lifting techniques

- Use your thigh muscles.
- Keep your spine straight.
- Divide weight between two hands.
- Use firm, natural footing.
- Get as close to the object or person being lifted as possible.
- Squat or bend knees, then straighten up.
- Bring weight up against your body.

Pivot transfer technique:

First explain clearly to the patient what you are going to do and how the patient can help. Sometimes it is helpful to demonstrate how you want the patient to move.

Also make sure wheelchair brakes are on before transfers. If possible, transfer the patient with him or her moving toward his or her strong side.

Stand in front of the patient. Place your hands around the patient's waist and lock your fingers or wrists. Place one foot between the patient's feet and your other foot to the side and back a little.

Have the patient place his feet back and slightly under the chair. Lean the patient forward as you lean your body forward also. Keep your back straight and knees bent.

Counting to three together, slightly rock the patient forward. Then pull his or her forward as you tell the patient to push with his or her feet and with his or her hands on the chair arm rests.

As the patient rises, his or her head must stay forward and up. After the patient is standing and balanced, the helper pivots with the patient to turn so that the patient now stands in front of the second chair. The helper assists in lowering the patient into the chair slowly by bending his knees as the patient sits. The patient puts his or her strong hand on the arm rest to assist in lowering his or herself slowly into the chair.

Sitting Up in Bed

The patient is near the edge of the bed. Keeping your back straight, bend only at the hips and knees. Put one hand under the patient's head and neck. Put the other hand behind the patient's knees. The patient puts the strong hand on the helper's shoulder, not around the neck.

The helper straightens his or her hips and knees, at the same time lifts the patient's head and neck, and pulls their legs over the side of the bed. The patient can help by pulling himself up with their strong hand on the helper's shoulders.

Wheelchair Instructions:

- Brakes must always be set before placing or moving a patient from the wheelchair. Check brakes on both sides of the wheelchair. When locking the brakes, be sure to release all the way to prevent drag.

- Be sure leg rests are out of the way before a patient gets into or out of a wheelchair.
- Assist the patient into the wheelchair.
- After the patient is seated, put pedals and leg rests in place. Make the patient as comfortable as possible.
- When going down a ramp or incline, move the wheelchair backwards.
- When going up a ramp or incline, push the wheelchair forward.
- Be sure the patient's elbows are out of the way so that they are not bumped.
- To assist the patient in getting out of the chair, put on both brakes. Put foot pedals and leg rests up and out of the way. Assist the patient in getting out of the wheelchair.

MEDICAL EMERGENCY SITUATIONS

Medical Emergency Situation

Policy: It is the responsibility of the volunteer to inform the volunteer coordinator of any significant changes in the patient's medical condition. It is also the responsibility of the volunteer to be informed of the patient or families plan for emergency care.

Responsibilities:

When assigned to a patient or family, the volunteers will receive information on their plan for care in a medical emergency.

When providing respite care, the volunteer will inform himself or herself of how to contact the absent caregiver in the event of a medical emergency.

Whenever a volunteer observes noticeable changes in a patient's condition, the volunteer will call the Hospice office immediately and ask for assistance from the nursing staff. If it is after office hours, the volunteer will call and ask for the on-call nurse.

If it is determined by the nurse and volunteer that a medical emergency exists, the volunteer will proceed to carry out the patient or the family plan. If there is no plan covering the emergency, the nurse will direct the volunteer regarding appropriate actions to be taken.

If a Seizure Occurs

Remain calm.

Move furniture and any sharp objects away to avoid injury to the patient.

Don't place anything in the patient's mouth. Putting something in the person's mouth could cause more harm than good. The person's jaw muscles clamp shut and a hand or pencil between the teeth could prove disastrous. The person could break his or her teeth on an object, or fragments could be lodged in the throat. It is impossible to swallow your tongue.

If possible, lay the person on his or her side. This keeps saliva from accumulating in the throat and possibly choking the person.

Let the seizure run its course. The person is temporarily unconscious and is in no pain.

Try to provide a calm atmosphere when the individual regains consciousness. The seizures usually last a short time. It is unnerving for the person to wake up and find a group of frightened looking people standing around.

Call the Hospice office immediately. 574-3600.

When Death Occurs

Policy: In an effort to meet the needs of the Hospice family, Hospice personnel will be available to assist by phone or to visit at the time of death. A volunteer who is present with the family at the time of death; or is alone with the patient will follow these guidelines.

Procedures:

When the volunteer is present with the family and funeral arrangements are prearranged.

Notify the primary nurse or on-call nurse through the Hospice phone number.

Assist with necessary phone calls if the family desires.

If death occurs while the volunteer is alone with the patient:

Call the primary nurse or on-call nurse for assistance. Tell the nurse what has happened. 574-3600.

Call family members to inform them of the death. Always have a phone number and location of family member when providing respite care.

Assist family with phone calls if desired.

Guidelines for Writing Volunteer Progress Notes:

As volunteers, we observe, help patients and caregivers, record the factual information and our observations, and report to Hospice staff members when needed or when we have questions.

Progress notes are an integral part of the permanent patient file. Telephone conversations and patient visits should be documented on the progress notes which are provided by the Hospice office. These notes should provide a clear, concise record of telephone conversations and visits. They should include all or some of the following, depending on the situation.

Date each entry.

Print or write legibly with black ink.

Remember to put the patient's name at the top of the progress note.

Record your observations about the patient. How does the patient appear? What does the patient talk about? What is his or her demeanor? Do they speak freely, remain quiet unless prompted to talk, converse appropriately, or seem to be in another world? Do they appear to be happy or sad? Are they sleeping? Reading? Watching television? Does he or she have an appetite? What is the patient telling you he or she needs?

Are there any specific concerns? What do you observe about the patient's physical condition? Does he or she express a need to visit with someone in the family, or a chaplain? Do you observe any problems or complications with regard to medications? Concerns should be related to the MSW or Volunteer Coordinator as soon as possible. Rate the patient's pain level.

Report immediately to the MSW in charge or to the Volunteer Coordinator if you observe anything you think is unusual or bothersome in what is said or done during your visit. Document in your progress notes that you called and reported your concerns.

All reports and the information contained therein are confidential.

Record your observations and document your visit or telephone call as soon as possible after the visit or call. The longer you wait, the less you will remember.

Progress notes are to be submitted to the volunteer coordinator within 72 hours of patient visit. Prior to mailing the progress notes, take a moment to review and make certain it is complete. Remember, if it is not documented, it is not done! The dynamics within the home are equally important to document whether or not there is patient contact.

HOSPICE VOLUNTEER – VISIT CHECKLIST

- Clearly state how long you can stay.
- Request a phone number where the primary caregiver can be located if an emergency occurs. In addition, make certain the phone number for our agency is posted where you can see it in the event of any emergency.
- Inquire about any medications the patient will need to take or about any unusual needs the patient may have (example: toilet use). When was the last pain medication given?
- Inquire about incoming phone calls; are any expected? Should the volunteer answer the phone?
- Inquire about bathroom arrangements for the volunteer, television rights, and access to the refrigerator if you brought snacks or drinks.
- Inquire about the patient's ability to communicate and whether the patient prefers to converse or to be left alone.
- Explain that the Hospice office (or the nurse on duty) will be contacted FIRST if an emergency regarding the patient occurs. The phone number for the office is 574-3600 and if it is after business hours this number will ring directly to the answering service.
- If you have additional concerns or questions and if it is not an emergency, call Hospice Volunteer Coordinators Branden Johnson 575-8053 or Kathryn Holman 574-3655

COMMUNICATION TECHNIQUES

ACTIVE LISTENING

Active listening is a means of communication that involves interaction with family members and provides them with proof of the volunteer's understanding and acceptance. In active listening, volunteers feed back only what they feel the family members want reflected back to them.

The following are guidelines for active listening:

Know when to use active listening. Remember that active listening is only a technique so you can better communicate your acceptance and empathy. Use it when you are free enough of your own problems to feel accepting and want to help families with their problems.

Competence only comes with practice. Volunteers won't become competent at active listening without lots of practice. Practice with your family members and friends.

Don't give up too quickly. It takes time for families to realize that you really do want to understand and are accepting their problems and feelings. Remember, they might be accustomed to hearing family and friends warn, preach, teach, advise, and interrogate.

Accept that active listening will feel artificial at first. It undoubtedly feels more gimmicky to you than to families. With practice, you'll feel more natural and less clumsy.

Try using other listening skills. Passive listening, acknowledgement response and door openers can be effective. Every response of a family member does not need feedback. Use active listening primarily when feelings are strong and the family member's need for talking or sorting out feelings is apparent.

Avoid pushing or imposing your active listening on family members. Listen for clues that tell you they don't want to talk or have finished talking. Respect their need for privacy.

Don't expect families to arrive at your preferred solution. Remember, active listening is for helping families with their problems and a tool for helping them find their own solutions. Be prepared for times when no solution surfaces, they might not even tell you how they later solved the problem.

What to Listen For

Words or phrases used to express feelings:

- "Everyone has gone home." (I feel alone.)
- "We used to go out all the time".
- It isn't the same without her.
- Friends don't come over anymore.

Voice Inflection

- Monotone
- Tearful
- Angry
- Matter-of-fact
- Judgmental
- Hyper
- Agitated
- High pitched voice

Willingness to Participate in Conversation.

The responses go beyond yes and no answers.

Expression of Need:

- I don't drive.
- I don't know how to balance the checkbook.
- The sink is broken and I don't know who to call.

Active Listening Won't Work if:

- The behavior of the family member is causing you a problem in any way;
- You fail to approximate the tone or intensity of the feeling of the sender. If this happens, simply relay back, "Do I hear you saying that..."
- You are concerned with problem solving for the family rather than reflecting their feelings back to them so that they can solve their own problems;
- You are in a hurry;
- You are focusing on the subject of concern rather than the person; and
- Your mind is on personal problems.

Storytelling

Story telling goes hand in hand with listening, remembering that the patient (or in some cases a family member) is the teller of stories, and we, the listeners. Think of recent movies like Forest Gump, Fried Green Tomatoes, and Titanic, all of them are simply a person telling their story.

The benefits of storytelling can be enormous. Some of them include:

- Alleviating loneliness and depression;
- Appreciating family heritage;
- Communicate values;
- Creates perspective in loss;
- Entertainment;
- Humor;
- Reminiscing (a grief tool);
- Building community;
- Emotional catharsis;
- Connects past, present, and future;
- Diversion from pain;;
- Gives focus to life;

- Primary source of information; and
- Validation of one's life.

There are great topics to spark storytelling:

- Children
- Parents
- Jobs
- Scars
- "Hard times"
- Pets
- "Hometown"
- Yard
- Church
- Food
- WWII
- Travels
- Hobbies
- Photographs
- School experiences
- Meeting their spouse

Start with less threatening topics at first. Be attentive with your eyes and ears. Explore the details within the story. Place stories in historical context. If someone says they moved here in the 1940's, there is a story there. Share your own stories only to serve as a bridge to help them relate to you, or to introduce a new topic.

Non-verbal Communication

Some of the non-verbal behaviors that help people to feel "listened to" include:

- Eye contact;
- Occasional head nodding to show that the practitioner is tracking what the patient says;
- Varying facial expressions in response to what the patient says;
- Smiling at appropriate points to demonstrate warmth and understanding;
- Occasional hand gesturing;
- Sitting in close proximity to the patient; and

Leaning slightly towards the client to indicate your interest and concentration.

The English Language

An essay by Rachael Williams of Excell Data Corporation, 1999

Let's face it – English is a crazy language. There are no eggs in an eggplant or ham in a hamburger; neither apple nor pine in a pineapple. English muffins weren't invented in England or French fries in France. Sweetmeats are candies while sweetbreads, which aren't sweet, are meat.

We take English for granted. But if we explore its paradoxes, we find that quicksand can work slowly, boxing rings are square and a guinea pig is neither from Guinea nor is it a pig. And why is it that writers write but fingers don't fing, grocers don't groce, and hammers don't ham? If the plural of tooth is teeth, why isn't the plural of booth beeth? One goose, two geese. So one moose, two meese? One index, two indices?

Doesn't it seem crazy that you can make amends but not one amend, that you comb through annals of history but not a single annal? If you have a bunch of odds and ends and get rid of all but one of the, what do you call it? If teachers taught, why didn't preachers praught? If a vegetarian eats vegetables, what does a humanitarian eat?

Sometimes I think all the English speakers should be committed to an asylum for the verbally insane. In what language do people recite plays and play at recitals? Ship by truck and send cargo by ship? Have noses that run and feet that smell? Park on driveways and drive on parkways? How can a slim chance and a fat chance be the same, while a wise man and a wise guy are opposites? How can overlook and oversee be opposites, while quite a lot and quite a few are alike? How can the weather be hot as hell one day and cold as hell another?

Have you noticed that we talk about certain things only when they are absent? Have you ever seen a horseful carriage or a strapful gown? Met a sung hero or experienced requited love? Have you ever run into someone who was combobulated, grunted, ruly, or peccable? And where are all those people who are spring chickens or who actually would hurt a fly?

You have to marvel at the unique lunacy of a language in which your house can burn up as it burns down, in which you fill in a form by filling it out, and in which an alarm clock goes off by going on.

English was invented by people, not computers, and it reflects the creativity of the human race (which, of course, isn't a race at all). That is why when the stars are out, they are visible, but when the lights are out, they are invisible. And why, when I wind up my watch, I start it, but when I wind up this essay, I end it? Why is it when we are ill, we are referred to as being 'poorly', but when we are well again, we're never referred to as 'richly'? Or, if an airplane has a near-miss, surely that would mean it was hit?

And finally – if in England they speak 'English', why don't they call it 'American' in America, or 'Australian' in Australia?

INTERPERSONAL COMMUNICATION

By Warner Burke

Communication, by definition, involves at least two individuals, the sender and the receiver. Consider yourself, first of all, as the sender of some message. There are certain filters or barriers (internal) which determine whether or not the message is actually transmitted. These barriers may be categorized as follows.

Assumptions about yourself – do I really have something to offer? Am I safe to offer suggestions? Do I really want to share the information? Will others really understand? How will the communication affect my self-esteem?

Attitudes about the message itself – is the information valuable? Do I see the information correctly, or understand it well enough to describe it to others?

Sensing the receiver's reaction –do I become aware of whether or not the receiver actually understands? Or in other words, can I “sense” from certain cues or reactions by the receiver whether or not we are communicating?

Now consider yourself as the receiver. As a receiver you may filter or not hear certain aspects (or any aspect for that matter) of a message. Why? Because the message may seem unimportant or too difficult. Moreover, you may be selective in your attention. For example, you may feel that “this guy has never made a point in his life and never will!”

Many times the receiver never makes use of his “third ear.” That is, trying to be sensitive to nonverbal communication. The sender's eyes, gestures, and sometimes his overall posture communicate messages that the insensitive listener never receives.

There may be barriers that exist between the sender and the receiver, e.g., cultural differences. Environmental conditions may also cause barriers, e.g., poor acoustics. More common, however, are the differences in frames of reference. For example, there may not be a common understanding of purpose in certain communication. You may ask me how I'm feeling today. To you the phrase, “How ya doing?” is nothing more than a greeting. However, I may think that you really want to know and I may tell you – possibly at length.

Now that some of the problems in interpersonal communications have been mentioned, let us delve somewhat deeper into this process of transferring a message from the brain and emotion of one person to the brain and emotion of another human being.

In communicating a message effectively to another person, there are several obvious factors which are beneficial. Such things as correct pronunciation, lack of distracting brogue, dialect, or accent, or a pleasant resonance in one's voice usually facilitates the sending of a message.

Assuming the sender of a message really has a desire to be heard and understood and not just speak for the sake of speaking, he wants some assurance that he has communicated. The key to effective communication on the part of the speaker, then, is to obtain some feedback, of one form or another, from his listener(s). Some bright people who really have something to say are ineffective speakers, be it lecturing or speaking to someone at a cocktail party, because they are unable to tell or care whether their listener(s) is understanding, or they do not make any effort to check on their effectiveness as a communicator. For example, many lecturers in a classroom situation

are often unaware of when a listener is sound asleep, unless there is interaction of some type between the speaker and his listener(s) or the speaker is susceptible to “losing” his listener. Often the speaker must take the initiative in order to receive any feedback regarding the effectiveness of his communication. When speaking before a large group, I often resort to the simple act of requesting my audience to shake their head “yes” they understand what I have just said, or “no” they did not understand. Even though this technique is simple, I usually get considerable feedback quickly and I know immediately what I must do at that point to make my speech more effective or whether to continue on with my next point.

Even when talking to just one other person the speaker must often take the initiative, in an interactive sense, to determine whether his message is being understood. Even though I sometimes take the risk of “bugging” my listener, I often stop and ask him if he understands what I mean or I occasionally ask him to tell me what he thinks I meant in my message.

There is a fairly small percentage of people who speak articulately and clearly enough to be understood most of the time. Most of us have to work at it, especially when we are attempting to communicate a message which is fairly abstract or when we want to tell something which is quite personal or highly emotional. In sending the message effectively, we must do two things simultaneously; (1) work at finding the appropriate words and emotions to express what we want to say, and (2) continually look for cues from the listener to get some feedback even if we must ask our listener for some.

In considering interpersonal communication, we might, at first thought think that listening is the easier of the two functions in the process. If we assume, however, that the listener really wants to understand what the speaker is saying, then the process is not all that easy. The basic problem that the listener faces is that he is capable of thinking faster than the speaker can talk. In their Harvard Business Review article, Nichols and Stevens state that the average rate of speech for most Americans is about 125 words per minute. Most of our thinking processes involve words, and our brains can handle many more words per minute than 125. As Nichols and Stevens point out, what this means is that, when we listen, our brains receive words at a very slow rate compared with the brain’s capabilities.

As you have experienced many times, you know that you can listen to what someone is saying and think about something else at the same time. As the “cocktail party” phenomenon illustrates, the human brain is truly remarkable in its ability to process a considerable amount of input simultaneously. Sometimes, at a cocktail party, I want to hear not only what the person in my small gathering is saying, but also what that lovely creature is talking about in the group about six feet away. If the overall noise level is not too loud, I can hear and understand both conversations.

The problem with listening then is that we have “spare” time in our thinking processes. How we use that spare time determines the extent of our listening effectiveness. It is easy for us to be distracted in listening, especially if the speaker talks slowly or haltingly or if he says something that stimulates another thought. For example, suppose you are listening to a friend who is telling you about a problem he is having in his department. In the process of describing the problem, he mentions a person whom you know, whereupon you start thinking about the person at length. Later, when your friend asks you what you would do about his problem, you’re apt to respond, “What problem?”

Thus, a fundamental problem the listener must consider in the communicative process is the fact that his brain is capable of responding to a speaker at several different levels simultaneously. Naturally, this can be an asset to the listener rather than a problem. For example, the listener can attend to nonverbal cues the speaker gives, e.g., facial expression, gesture, or tone of voice, as well as listen to the words themselves.

Besides a highly active brain, an effective listener has another factor to consider in the communicative process. This factor involves the process of trying to perceive what the speaker is saying from his point of view.

Barrier and a Gateway

According to Carl Rogers, a leading psychotherapist and psychotherapy researcher, the major barrier to effective communication is the tendency to evaluate. That is, the barrier to mutual interpersonal communication is our very natural tendency to judge, to evaluate, to approve or disapprove the statement or opinion of the other person or group. Suppose someone says to you, "I didn't like what the lecturer had to say." Your typical response will be either agreement or disagreement. In other words, your primary reaction is to evaluate the statement from your point of view, from your own frame of reference.

Although the inclination to make evaluations is common, it is usually heightened in those situations where feelings and emotions are deeply involved. Thus, the stronger our feelings and emotions are the more likely it is that there will be no mutual element in the communication. There will be only two ideas, two feelings, two judgments, missing each other in the heat of the psychological battle.

If having a tendency to evaluate is the major barrier to communication, then the logical gateway to communication is to become an active listener, to listen with understanding. Don't let this simple statement fool you. Listening with understanding means to see the expressed idea and attitude from the other person's point of view, to see how it feels to him to achieve his frame of reference concerning his subject. One word that summarizes this process of listening with understanding is "empathy".

In psychotherapy, for example, Carl Rogers and his associates have found from research that empathetic understanding – understanding with a person not about him – is such an effective approach that it can bring about major changes in personality.

Suppose that in your next committee meeting, you were to conduct an experiment which would test the quality of each committee member's understanding. Institute this rule. "Each person can speak up for himself only after he has first related the ideas and feeling of the previous speaker accurately and to that speaker's satisfaction." This would mean that before presenting your own point of view, it would be necessary for you to achieve the other speaker's frame of reference – to understand his thoughts and feelings so well that you could summarize them for him.

Can you imagine what this kind of approach might mean if it were projected into larger areas, such as congressional debates or labor-management disputes? What would happen if labor, without necessarily agreeing, could accurately state management's point of view in a way that management could accept, and management, without necessarily approving labor's stand, could state labor's case in a way that labor agreed was accurate? It would mean that real communication was established, and conditions would be more conducive for reaching a workable solution.

Toward More Effective Listening

Some steps the listener can take to improve interpersonal communication have been stated. To summarize and be more explicit, let us consider these steps.

Effective listening must be an active process. To make certain that you understand what the speaker is saying, you, as the listener must interact with him. One way to do this is to paraphrase or summarize for the speaker what you think he has said.

Attending to nonverbal behavior that the speaker is communicating along with his verbal expression usually helps to understand the oral message more clearly. Often a facial expression or gesture will “tell” you that the speaker feels more strongly about the subject than his words would communicate.

The effective listener does not try to memorize every word or fact the speaker communicates, but, rather, he listens for the main thought or idea. Since your brain is such a highly effective processor of information, spending your listening time in more than just hearing the words of the speaker can lead to more effective listening. That is, while listening to the words, you can also be searching for the main idea of the message. Furthermore, you can attempt to find the frame of reference for the speaker’s message as well as look at what he is saying from his perspective. This empathetic process also includes your attempting to experience the same feeling about the subject as the speaker.

These three steps toward more effective listening seem fairly simple and obvious. But the fact remains that we don’t practice these steps very often. Why don’t we?

Moreover, according to Carl Rogers, it takes courage. If you really understand another person in this way, if you are willing to enter his private world and see the way life appears to him without any attempt to make evaluative judgments, you run the risk of being changed yourself. This risk of being changed is one of the most frightening prospects many of us face.

Moreover, when we need to utilize these steps the most, we are likely to use them the least. When the situation involves a considerable amount of emotion. For example, when we listen to a message that contradicts our most deeply held prejudices, opinions, or convictions, our brain becomes stimulated by many factors other than what the speaker is telling us. When we are arguing, with someone especially about something that is “near and dear” to us, what are we typically doing when the other person is making his point? It’s certainly not listening empathetically! We’re probably planning a rebuttal to what he is saying, or we’re formulating a question which will embarrass the speaker. We may, of course, simply be “tuning him out”. How often have you been arguing with someone for 30 minutes or so, and you make what you consider to be a major point for your point of view, and your “opponent” responds by saying, “But that’s what I said 30 minutes ago!”

When emotions are strongest, then it is most difficult to achieve the frame of reference of the other person or group. Yet, it is then that empathy is most needed if communication is to be established. A third party, for example, who is able to lay aside his feelings and evaluation, can assist greatly by listening with understanding to each person or group and clarifying the views and attitudes each holds.

When the parties to a dispute realize that they are being understood, that someone sees how the situations seems to them, the statements grow less exaggerated and less defensive, and it is no longer necessary to maintain the attitude, “I’m 100% right and you are 100% wrong.”

Summary

Effective communication, at least among human beings, is not a one way street. It involves an interaction between the speaker and the listener. The responsibility for this interaction is assumed by both parties. You as the speaker can solicit feedback and adjust your message accordingly. As a listener, you can summarize for the speaker what you think he has said and continually practice the empathetic process.

One of the joys of life, at least for me, is knowing that I have been heard and understood correctly and knowing that someone cares enough to try to understand what I have said. I also get a great deal of satisfaction from seeing this same enjoyment on the face of a speaker when he knows I have understood him.

STEPS TOWARDS GOOD LISTENING

Listening is a skill that can be learned and improved. In order to create good listening habits, choose one activity from the following list to concentrate on for one week. After one week of practice each activity will become a habit. Remember, even a small effort will bring remarkable results.

- Reduce talk.
- Don't jump to conclusions leaving the conversation early.
- Leave judgments for later.
- Don't panic when you hear a moment of silence—be patient—wait.
- Concentrate and evaluate.
- Have intensity, be alert and alive.
- Listen from the speaker's perspective—step in their shoes.
- Don't provide words or complete another's sentences.
- Listen for ideas and concepts.
- Paint a mental picture of what you hear.
- Don't interrupt.
- Motivate speakers to tell you more—you might be surprised by what you learn.
- Don't respond with a change of subject.
- Mentally distinguish between fact, opinion and assumption—when in doubt, ask questions.
- Forget the urge to “set the record straight.”
- Be an equal opportunity listener.
- Do something about what you hear.
- Use questioning techniques.
- Use nonverbal behavior.
- Know when to call it a day.
- And last—Seek First to Understand---Then to be Understood.

From *The 7 Habits of Highly Effective People* by Stephen R. Covey

Seven principles for selecting the right words.

- Choose words precisely. Consider both denotations and connotations.
- Use short rather than long words.
- Use concrete rather than abstract words.
- Economize on the use of words.
- Avoid overused or hackneyed phrases and jargon.
- Use positive words that convey courtesy. Avoid sexist and discriminatory language.
- Use a conversational style; but not too informal.
- Five principles for organizing words for effect.
- Keep sentences relatively short. Express one main point.
- Prefer the active to the passive voice.
- Develop effective paragraphs.
- Develop coherence.
- Edit and rewrite.

INFECTION CONTROL

Personal Protection Equipment (PPE)

It is important to always carry PPE with you whenever you go into a patient's home. It is your responsibility to replace used items. Put on gloves anytime you have personal contact with a patient when assisting with changing the sheets, turning, assisting on and off the toilet, etc. It is not necessary to put on gloves for casual contact.

Wear gloves, gown, and mask in situations where the patient is coughing and it is necessary to stand less than three feet from the patient. Do not allow sputum to get on the front of your clothing, face hands or eyes. Use face shield masks if necessary.

Remember that most infectious organisms are spread by contact and not through the air. Always wash your hands upon entering the patient's home, immediately after personal intimate contact with a patient, and right before leaving the home.

Hand Hygiene:

When hands are visibly dirty or contaminated with proteinaceous material or they are visibly soiled with blood or other bodily fluids, wash hands with a non-antibacterial soap.

If hands are not visibly soiled, use an alcohol-based hand rub for routinely decontaminating hands in all other clinical situations.

Decontaminate hands before having direct contact with patients.

Decontaminate hands after contact with a patient's intact skin (e.g., lifting a patient).

Decontaminate hands after contact with bodily fluids or excretions, mucous membranes, non-intact skin, even if hands are not visibly soiled.

Before eating and after using the restroom, wash hands with a non-antibacterial soap.

When washing hands with soap and water, wet hands first with water, apply a handful of foam soap and rub hands together vigorously for at least 15 seconds, covering all surfaces of the hands and fingers. Rinse hands with water and dry thoroughly with a disposable towel. Use towel to turn off the faucet. Avoid using hot water because repeated exposure to hot water may increase the risk of dermatitis.

The floor is dirty. Keep items off the floor.

ABUSE AND NEGLECT

REPORTING SIGNS OF ABUSE

As a volunteer of Hospice you are required to make a report whenever any of the following occurs:

- The volunteer observes or has knowledge of an incident that reasonably appears to be abuse;
- The volunteer is told of an incident by the victim; or
- The volunteer reasonably suspects abuse.

All of the following types of abuse must be reported: physical abuse (including sexual abuse), abandonment, mental or emotional mistreatment, exploitation, financial abuse, and neglect, including self-neglect.

Immediately following an incident, or learning of an incident, the volunteer is to contact the YVMH Hospice Volunteer Coordinator. Upon contact, the Volunteer Coordinator will ask the volunteer to write a report that will contain information on the incident(s), when, where, and who was involved, and if the incident was witnessed, or the volunteer was told of the incident by the victim.

How does the volunteer make the report?

The Volunteer Coordinator will immediately take the volunteer's written report to the Hospice Director, where the necessary follow-up will take place. The Hospice Director may contact the volunteer for additional information.

What will happen if I do not report an incident?

We understand that volunteers have the best intentions for the patient and the patient's family. When a volunteer fails to report an incident no matter how small it may seem, the volunteer is no longer acting in the best interests of the very people they set out to serve. The failure to report an incident, no matter how small it may seem, can result in the permanent termination of that volunteer.

SIGNS AND SYMPTOMS OF ABUSE

Physical Abuse

Physical abuse is intentional bodily injury. Some examples include slapping, choking, kicking, shoving or the inappropriate use of drugs or physical restraints.

Signs of Physical Abuse

- Bruises, black eyes, welts, lacerations and rope marks;
- Broken bones;
- Open wounds, cuts, punctures, untreated injuries in various states of healing;
- Broken eye glasses or frames, physical signs of being subjected to punishment and signs of being restrained;
- Laboratory findings of either an overdose or under-dose of medications;
- Individuals report of being hit slapped, kicked or mistreated;
- Vulnerable adult's sudden change in behavior; and
- The caregiver's refusal to allow visitors to see vulnerable adult alone.
- Sexual mistreatment

Sexual abuse is nonconsensual sexual contact. Examples include unwanted touching, rape, sodomy, coerced nudity and sexually explicit photographing.

Signs of Sexual Abuse

- Bruises around the breasts or genital area;
- Unexplained venereal disease;
- Unexplained vaginal or anal bleeding;
- Torn, stained or bloody underclothing;
- An individual's report of being sexually assaulted or raped.

Abandonment

Abandonment occurs when a vulnerable adult is left without the ability to obtain necessary food, clothing, shelter or health care.

Signs of Abandonment

- Desertion of an individual in a public place
- Desertion of an individual in own home
- Individuals report of being left alone

Mental Mistreatment or Emotional Abuse

Mental mistreatment is deliberately causing mental or emotional pain. Examples include intimidation, coercion, ridiculing, harassment, treating an adult like a child, isolating an adult from family, friends, or regular activity, use of silence to control behavior, yelling or swearing that results in mental distress.

Signs of Mental Mistreatment

- Being emotionally upset
- Being extremely withdrawn and non-communicative or non-responsive
- Unusual behavior usually attributed to dementia (e.g., sucking, biting or rocking)
- An individual's report of being verbally or mentally mistreated

Exploitation

Exploitation occurs when a vulnerable adult or the resources or income of a vulnerable adult are illegally or improperly used for another person's profit or gain.

Signs of Exploitation

- Sudden changes in bank account or banking practice, including an unexplained withdrawal of large sums of money by a person accompanying the individual.
- The inclusion of additional names on bank signature card.
- Unauthorized withdrawal of funds using an ATM card.
- Abrupt changes in a will or other financial documents.
- Unexplained disappearance of funds or valuable possessions.
- Bills unpaid despite the availability of adequate financial resources.
- Forged signature for a financial transaction and for the titles of possessions.
- Sudden appearance of previously uninvolved relatives claiming rights to affairs and possessions.
- Unexplained sudden transfer of assets to a family member or someone outside the family.
- The provision of services that is not necessary.
- Individual's report of exploitation.

Neglect

Neglect occurs when someone, either through action or inaction, deprives a vulnerable adult of care necessary to maintain physical or mental health.

Indicators of Neglect

- Dehydration, malnutrition, untreated bed sores, and poor personal hygiene
- Unattended or untreated health or dental problems
- Hazardous or unsafe living conditions or arrangements (e.g., improper wiring, no heat or no running water)
- Unsanitary and unclean living conditions (e.g., dirt, fleas, lice on person, soiled bedding, fecal or urine smell, inadequate clothing)
- An individual's report of being mistreated

Self-neglect

Self-neglect occurs when a vulnerable adult fails to provide adequately for themselves. A competent person who decides to live their life in a manner which may threaten their safety or well-being does not come under this definition.

Indicators of self-neglect

- Dehydration, malnutrition, untreated or improperly attended medical conditions and poor personal hygiene
- Hazardous or unsafe living conditions or arrangements
- Unsanitary or unclean living quarters (e.g., animal or insect infestation, no functioning toilet, fecal or urine smell)
- Inappropriate and or inadequate clothing, lack of the necessary medical aids
- Grossly inadequate housing or homelessness
- Inadequate medical care, not taking prescribed medications properly.

UNDERSTANDING PAIN

DEFINITION OF PAIN

In Hospice care the definition of pain is both simple and profound:

“Pain is what the patient says it is.”

Tom West. MC

St. Christopher’s Hospice

Pain is one of the most feared symptoms of the dying process and is a major cause of the anxiety, depression, and helplessness, loss of self-esteem, guilt and anger commonly experienced by patients with advanced cancer. Up to 95% of cancer-related pain responds to treatment.

Chronic Pain vs. Acute Pain

The signs and symptoms of chronic pain differ from those of acute pain. Health care workers are trained to recognize and treat acute pain.

Acute pain is recognized by hyperactivity of the autonomic nervous system---sweating, rapid heart beat (tachycardia), hypertension---and the patient’s grimacing, crying or anxious face.

Patients suffering from chronic pain may exhibit few of the usually attributed symptoms of pain. The autonomic signs are absent in chronic pain and the patient’s face may show very few signs of distress. After long periods of unrelieved pain the patient’s face may no longer exhibit anxiety, but instead show exhaustion and or depression. Suffering may be hidden beneath a brave, stoic face. The lack of objective signs of chronic pain, coupled with the patient’s depressed, sleepy face, can lead to a misdiagnosis or an under-diagnosis of pain.

The burden of pain is often magnified by its interaction with other common symptoms of advanced disease. Unrelieved pain can add to anorexia, insomnia, immobility, and weakness as well as preventing patients from making recommended changes in position, leading to the development of painful bed ulcers. In addition, pain relief therapy may in itself contribute to other kinds of pain, such as the pain of constipation which is often caused by the use of narcotics. Adequate knowledge about the control of pain and its side-effects is the responsibility of the Hospice staff.

HOSPICE CONCEPTS OF PAIN CONTROL

Pain control is a much brighter picture today than in times past. A wider array of options such as new drugs, new ways to administer them, long-acting and short-acting liquids, injectable and suppository medications, is allowing patients greater freedom in the design of their pain management plan. As a result, many Hospice patients are achieving their goal of significant physical comfort and pain relief.

Some important things to remember about pain control are:

In case of the need of continuous pain control it is important to use pain medication such as M.S. Contin on a regular schedule.

Pain control is more easily achieved and maintained if medication is used before the pain becomes severe or out of control.

“As needed” pain medication is to be taken when pain comes up between doses, or is not controlled by the scheduled medication. This is called “breakthrough pain.”

Medicines taken by mouth take 20-50 minutes to begin to work and give noticeable relief of pain.

Almost all pain medicines cause constipation.

The following list includes some of the most important Hospice concepts of pain control.

- Diagnose cause(s) and type(s) of pain.
- Select appropriate medication for specific kind of drug.
- Know the pharmacology of prescribed drug.
- Adjust route of administration to patient’s needs; use oral whenever possible.
- Keep it simple.
- Manage medications according to patient needs.
- Give analgesia at regular intervals.
- Maintain pain control throughout 24 hour period.
- Use adjuvant medications (medications which enhance the effectiveness of other medications) to improve analgesia and reduce side effects.
- Avoid drug combinations that increase sedation without enhancing analgesia.
- Anticipate and treat side effects and complications.
- Continue to evaluate and manage emotional, social, and spiritual pain.
- Remember that no one optimal dose or maximal dose exists for morphine.
- Remember that addiction and tolerance are not clinical problems in terminally ill patients.
- Remember that break-through pain is common; provide for relief.
- Treat insomnia vigorously.
- Offer cognitive and behavioral therapies when appropriate.

TYPES OF PAIN

Four types of Pain as described by Dr. Cicely Saunders:

- Physical
- Social: financial, security, relationships
- Psychological or emotional: fear, anger, depression
- Spiritual: God, church, meaning of life

No amount of morphine will provide relief from spiritual pain, just as no amount of counseling will provide relief from the burning “pins and needles” of nerve pain. Excellent assessment skills are needed, not only to determine the category of pain but also to determine which types of pain are causing distress.

Most cancer patients suffer from several types of pain. Studies have found that 80% of advanced cancer patients suffered from more than one type of pain and 34% experienced four or more types of pain, each of which demanded a different set of treatments.

PAIN ASSESSMENT

Intensity: The person should rate the pain on a scale of 1-10.

(0-10)		Behavior
0	No Pain	Relaxed, calm expression
1	Least Pain	Stressed, tense expression
2		
3	Mild Pain	Guarded movement, grimacing
4		
5	Moderate Pain	Moaning, restless
6		
7	Severe Pain	Crying out
8		
9	Excruciating Pain	Increased intensity of above
10		

(Volunteers will also document on progress note whether pain is acceptable or not acceptable to patient and refer to RN if it is not acceptable).

Location: Have the patient indicate where in the body the pain is located and whether it is deep or closer to the surface. Does it radiate anywhere?

Describe the pain in the person's own words (e.g., prick, ache, throb, pull, or sharp). The patient may need you to provide a list of words to pick from (see Patient Description of Pain).

Frequency of pain interfering with patient's activities of daily living.

Patient has no pain or pain does not interfere with activities of daily living.

Less often than daily.

Daily, but not constantly.

All of the time.

How does the person express pain? (Wincing, crying, and moaning?)

What relieves the pain or makes it better?

What causes or increases it?

What effects does the pain have?

Has accompanying symptoms (e.g., nausea)

Affects relationships with others (e.g., irritability).

Affects concentration.

Impact:

On sleep

On mood

On activity

On appetite

Page

MYTHS AND MISCONCEPTIONS ABOUT MORPHINE

Many health care professionals and members of the community are reluctant to use morphine and other narcotics because of the widespread myths and misconceptions about their effects. The following are some of the most common myths about the use of morphine to treat pain in the terminally ill patient.

Morphine Equals Respiratory Depression

Clinically significant respiratory depression is extremely rare in patients who receive optimized doses of morphine. When morphine is carefully titrated, it is a safe analgesic even in patients with respiratory disease. In fact, low doses of morphine are an effective management when dyspnea appears to be increasing.

Morphine Equals Addiction

Addiction does not occur when morphine is administered regularly at individually optimized doses in the patient experiencing pain.

Morphine Equals Rapid Tolerance

Some physicians are reluctant to use morphine because they fear the drug will become ineffective over time. Clinically significant tolerance is unusual. The plateau of dose requirements is usually seen and the need to increase morphine is based on disease progression, not on tolerance.

Morphine Equals Euphoria

The use of morphine does not produce euphoria in the terminally ill patient. Mood may improve because of pain relief and the ability to eat and sleep.

Morphine Equals Narrow Effective Dose Range

Morphine has a very wide effective dose range. Two mg. every four hours may be an effective dose for some patients while 300+ mg. every four hours may be an effective dose for others.

Problems with Morphine

- Drowsiness—wears off
- Nausea—30% experience
- Constipation—very common
- Tolerance—rare
- Addiction—extremely rare
- Acute urinary retention

Pain Management – A Patient Guide

Dear Patient and/or Caregiver:

Your health care provider from Memorial Home Care Services will teach you about pain control. You can use this Teaching Guide as a reminder. If you have questions or concerns about your pain, the phone number for Memorial Home Care is 574-3600.

What is pain?

Pain is an unpleasant sensation caused by different stimulations of the sensory nerve endings. Pain, regardless of the type and source, is a complex syndrome that encompasses both physical manifestations and emotional responses. Pain is one of the most common reasons people consult a physician. When pain is managed appropriately it can mean an end to lost productivity, needless suffering and excessive healthcare expenditures. Pain is what you say it is, existing when and where you say it does.

What are your rights in relation to pain? They are:

- That your reports of pain will be believed;
- To receive information about pain and how your pain can be relieved;
- Our commitment to your pain prevention and management;
- To have our staff respond quickly to your reports of pain;
- To have the best possible pain control for you and your circumstances; and
- Pain medication information for drugs ordered by your doctor (side effects, precautions) and education regarding techniques to manage your pain effectively.

What are your responsibilities in relation to your pain control? They are:

- To provide complete and accurate information regarding your pain and how you have attempted to relieve symptoms in the past and currently.
- Ask the nurse what to expect regarding your pain and pain management.
- Discuss pain relief options with your nurse.
- Work with the nurse to develop a pain management plan.
- Ask for pain relief when pain first begins.
- Help the nurse assess your pain.
- Tell the nurse if your pain is not relieved.
- Tell the nurse about any worries you have about taking pain medications.
- What will the health care professional need to know about your pain?
 - Location (where it occurs).
 - Frequency (how often it occurs).
 - Duration (how long it lasts).

- Intensity (describe the pain on a scale of 0-10; 0 = no pain; 1- = worst possible pain). There are other scales available if this scale is difficult for you to use.
- Character (use your own words to describe the pain).
- Things you do that help you get rid of the pain.
- Things you do that make the pain worse.
- Effects of pain on your daily life (appetite, sleep, emotions, activities, relationships, etc.).
- Knowing the nature and characteristics of your pain helps health care professionals determine the best course of treatment for you.
- **What kinds of barriers are seen to managing pain?**
 - Not understanding the pain.
 - Thinking pain cannot be relieved.
 - Thinking pain is a normal part of the disease and should be present.
 - Thinking that you are not a good patient if you complain of pain.
 - Thinking that medicines cause addiction.
 - Not being able to afford to pay for pain medicine.
 - Side effects of pain medicine are too hard to manage.
 - Hard time getting pain medicine refills.
 - Hard time telling others about your pain.

Please tell the health care professional or other home care worker if those barriers (or others) are true for you so that we can help you overcome them.

What are some other ways to relieve pain, in addition to my medicine?

- Relaxation (deep-breathing exercises, abdominal breathing).
- Distraction (watching non-stressful or comedy TV; spending time with friends and family; reading or participating in another hobby).
- Music therapy (listening to peaceful music or recordings, such as waterfalls, ocean sounds, or other environmental sounds that are relaxing to you).
- Massage (with medicated cream or ointment as ordered by your doctor or with your favorite lotion).
- Heat (check with your doctor or nurse to be sure that wet or dry heat will not make the pain worse or cause problems with other ailments that you may have).
- Cold (check with your doctor or nurse to be sure that cold will not cause problems with other ailments that you may have).
- Aroma Therapy (oils or candles that you find soothing and comforting).
- TENS (transcutaneous electrical nerve stimulation). This can be ordered by your doctor. It can be obtained from your medical equipment supplier.

What are some of the side effects of pain medication and how can they be controlled?

- Nausea/vomiting.
- Other medications can be ordered to control or prevent this.
- Check to see if you should avoid taking the pain medicine on an empty stomach.
- Increase your activity level if you are safely able to do so.
- Increase your fiber intake.
- Increase your fluid intake.
- Modify your diet, (BRAT diet, soft or bland diet. Your nurse can make recommendations).
- Sedation.
- Drinking coffee or other caffeinated beverages will not aggravate any other ailment you may have.
- Having the doctor adjust the dose for daytime use, or having the doctor order two different medicines – one for mild pain and one for severe pain.

Diarrhea

- Other medicines can be ordered to control or prevent this.
- Decrease fiber intake.
- Must still drink plenty of fluids to prevent dehydration.

Constipation

- Increase your fluid intake.
- Increase your fiber intake.
- Increase your activity level if you are safely able to do so.
- Fruit paste. The nurse can provide a recipe.
- Senna tea.
- Other medication either prescribed or over the counter can be ordered to control or prevent this.

Dry mouth

- Sip fluids.
- Suck on hard candy.
- Lip balm.
- Mouth moisturizers.
- Mouth rinses.

Special Consideration for Elderly People

- Elderly people often suffer multiple chronic, painful illnesses and take multiple medications. They are at greater risk for drug-drug and drug-disease interactions.
- Aging need not alter pain thresholds or tolerance. The similarities of pain experience between the elderly and younger patients are far more common than are the differences.
- Cognitive impairment, delirious, and dementia are serious barriers to assessing pain in the elderly. Sensory problems such as visual and hearing changes may also interfere with the use of some pain assessment scales. However, as with other patients, the clinician should be able to obtain an accurate self-report of pain from most patients.
- Elderly people may be more sensitive to analgesic effects of opiate drugs. They may experience higher peak effect and longer duration of pain relief.

Special Consideration for Infants and Children

- Infants, especially premature or those with neuralgic abnormalities or pulmonary disease, are more susceptible to apnea and respiratory depression with use of opioids. However infants and children do experience pain and adequate pain control is necessary and possible.
- Careful assessment and reassessment are necessary to determine optimal dose and interval of administration to decrease risk of apnea and respiratory depression.
- With infants and children, the initial dose of medication is reduced and titrated in small increments to achieve optimal pain relief.

Special Consideration for Substance Abuse Disorders

- If alcohol or other non-prescribed substances are part of your life, it is important to share this information with your physician and home health care worker.
- If you use alcohol or other non-prescribed substances you have the same right to pain relief as any other patient.
- The goal of providing pain management is twofold. To relieve pain and prevent withdrawal symptoms.
- Larger than usual doses of opiates may be necessary to get adequate pain control.
- When you are experiencing pain, you are the authority about your pain.

PAIN ASSESSMENT SCALES

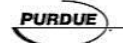
Choose a number from 0 to 10 that best describes your pain

CHOOSE THE FACE THAT BEST DESCRIBES HOW YOU FEEL

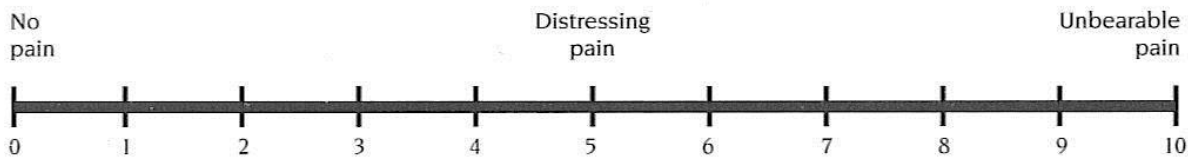


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CHOOSE A NUMBER FROM 0 TO 10 THAT BEST DESCRIBES YOUR PAIN



Jacox A, Carr DB, Payne R, et al. *Clinical Practice Guideline Number 9: Management of Cancer Pain*. Rockville, Md: US Dept of Health and Human Services, Agency for Health Care Policy and Research; 1994. AHCPR publication 94-0592.

Key subjects to ask patients about their pain:

INTENSITY • LOCATION • ONSET • DURATION • VARIATION • QUALITY

For more information about pain and pain management and prevention, visit our Web site: www.partnersagainstpain.com

FLACC PAIN ASSESSMENT TOOL

	Face	Legs	Activity	Cry	Consolability
0	No particular expression or smile	Normal position or relaxed	Lying quietly, normal position, moves easily	No cry (awake or asleep)	Content, relaxed
1	Occasional grimace or frown, withdrawn and disinterested	Uneasy, restless, tense	Squirming, shifting back and forth, tense	Moans or whimpers, occasional complaint	Reassured by occasional touching, hugging, or "Talking to" distractible
2	Frequent to constant frown, clench quivering chin	Kicking or legs drawn up	Arched or rigid, or jerking	Crying steadily, screams or sobs, frequent complaints	Difficult to console to comfort

PCA (Patient Controlled Analgesia) Patient Instructions

What is a PCA Pump?

One method of giving pain medications through a pump is called a PCA (Patient Controlled Analgesia). The PCA pump allows you to give yourself pain medication by pressing a button connected to the PCA Pump. When you press the button, you will hear a beep and the pump will deliver a specific amount of pain medicine. If you press the button, but you do not hear a beep, that means that you have already received the maximum pain medicine set for the pump for that time period.

Your physician and Healthcare team determines the amount of medicine you will receive based on your size, age, and diagnosis. Patients are able to receive small doses of medicine frequently and quickly using this method. The PCA Pump has safety features which help prevent you from getting too much medicine.

ASSESSING YOUR PAIN

You are the only one who knows how your pain feels. To help your caregiver and nurses understand your pain, they will ask you to rate your pain using a 0-10 scale. Zero is no pain and 10 is the worst amount of pain possible. You will be asked frequently about your pain using this scale or the Wong-Baker face scale. Always tell your nurse or caregiver about any pain which is new, changed, or does not improve with pain medication.

When you become non-verbal, the FLACC scale may be used. Not all pain is the same. Describing your pain in words such as "aching" or "shooting" may help your nurses and caregiver to administer the most appropriate

medication. There are other medications that could be used in combination with the PCA to alleviate your pain.

MEDICATION SIDE EFFECTS

The most common side effects which may occur with patients receiving PCA pain medications include:

Sleepiness or feeling drowsy

Nausea

Difficult urination

Itchiness

Constipation

Let your nurse or caregiver know if you experience any of the side effects listed above. Your caregiver and nurses will also assess you regularly for side effects from the pain medication.

WHEN SHOULD YOU USE YOUR PCA?

The degree of pain a person experiences may vary from very little to very much. However, with the help of the PCA, we would like to keep your level of pain at a comfortable level. You should press the PCA button before your pain becomes severe or when it first begins. If your pain is not relieved to your satisfaction, please contact your nurse. Other methods of pain control, such as proper positioning, decreasing environmental noises, heat and ice or other adjunctive therapy can be used to enhance the effects of your pain symptoms.

Please remember that your comfort is important to us. Your input is very helpful. Please don't hesitate to ask your nurse or healthcare team questions.

SAFETY INSTRUCTIONS

When possible, you are the only person who should push the PCA button. Your family or caregiver may press the PCA button if you become physically unable to do so.

Do not eat or drink if you feel very sleepy or drowsy. Do not allow visitors to feed you while you are feeling sleepy or drowsy. Wait until you are more awake.

If you feel dizzy or weak, ask for assistance before attempting to walk or get out of bed.

SPIRITUALITY, RELIGION, RITUALS AND CULTURAL DIVERSITY

American Indians

Preferred term: People refer to themselves by tribal name. When referring to all tribes, older adults strongly prefer “American Indians” to “Native Americans.”

Communication: Most speak English. American Indians often use anecdotes or metaphors to discuss a situation. Telling about a neighbor who became ill may signal that a patient feels similarly. Verbal disclosures may be carefully constructed to provide precise meaning through examples, metaphors, etc: **DO NOT INTERRUPT SPEAKER.** Long pauses are part of normal conversation.

Non-Verbal Communication: Respect is communicated by avoiding eye contact; keeping a respectful distance is recommended.

Greetings: Light touch handshake. Do not refer to men as chiefs and women as squaws.

Orientation towards time: Present orientation explained as “Indian Time,” which is flexible and conflicts with rigidly timed schedules. When asking a question that requires a yes or no answer, be patient; expect careful consideration before answering. Rushing an elder is considered disrespectful.

Family Relationships

Gender issues: Varies between tribes; in some clans or bands, women may make important decisions. Male roles include ritual to protect family and community well-being.

Expectations of children: Children are expected to respect their elders, take pride in their culture and develop natural talents while maturing. While autonomy is generally valued, “independence” is expected to be tempered by responsibility to the community, family, and tribe. Children are not encouraged to seek outside help.

Modesty: American Indians are modest but not prudish.

Special Clothing or Amulets: If a medicine bag is worn, every effort should be made not to touch, examine or admire it.

Serious Illness: Some tribes prefer not to openly discuss terminal status because negative thoughts may hasten inevitable loss, while other tribes may use information to make appropriate preparations.

Death Rituals

Preparation: Most American Indian cultures embrace the present. Some tribes avoid contact with the dying. When the family wants to be present 24 hours a day, this will include immediate and extended family and close friends. Atmosphere may be jovial with eating, joking, playing games and singing. Small children are also included. Although the outcome is tacitly recognized, positive attitude maintained and family may avoid discussing impending death. Sadness and mourning are done in private, away from the patient. Some patients will prefer to have an open window, or to orient the patient’s body toward a cardinal direction prior to death.

Care of the Body: Care varies with the tribe and Christian beliefs. Traditional practices include turning and/or flexing the body, sweet grass smoke (smuggling), or other purification; family (women) may want to prepare and dress the body. Family may choose to stay in the room with the deceased for a time. Some families take the body home from the funeral home the night before the burial to be cleansed and dressed, “spend the last night on earth”, and for visitation for family and friends.

ARAB AMERICANS

Preferred Terms: Identified by region, such as Arab Americans or Middle Eastern Americans or by country of origin. Ask about country of origin.

Communication: Arabic, however variations exist in dialects, words and meanings in different Arab countries.

Non-Verbal Communication: Expressive, warm, other-oriented, shy and modest. Their communication may have a flat effect to protect others from accessing inner feelings. More traditional women may be reserved and non-expressive. When they trust and feel accepted, they tend to be more expressive. Arabs respect elders and professionals and are reluctant to take up their time. Arabs are comfortable in touching with like gender. Traditional women may avoid eye contact with non-acquaintances and men. They tend to prefer closeness in space with same sex, and when comfortable with others tend to be in close proximity to build a trusting relationship. They tend to be very polite and may not disagree outwardly and may respond in ways they think others want them to respond.

Greeting: Greet using the title and first name. Approach by shaking hands and acknowledge country or origin and something personal about patient or family. Smiling and eye contact helps.

Orientation towards time: More focus on past and present, rather than future. Tend to follow two different concepts, “on time” for official business and “spontaneous” time kept for social events. Human contact tends to be more valued than adhering to a clock.

Family Relationships

Structure: Family oriented structure, not usual to have extended family living in the same household. They are less tolerant of alternative structures such as Gay and Lesbian couples. Decisions are made by the collective family, including extended family. Father, eldest son, or elderly uncles are usually the family spokesperson.

Gender issues: Men in the immediate family are expected to be responsible for logistics of patient transportation, financial arrangements and funeral plans. Caring for daily needs is usually delegated to women in the family.

Caring issues: Mothers, grandmothers, sister-in-law, or daughters assume caring functions in the family. Caring for patients may include preventing self-care and early ambulation, believing that energy needs to be conserved for healing.

Children: Children are sacred. Families sacrifice money, time and country of origin to raise children who are well-educated and well-provided for. Childrearing based more on negative than positive reinforcement and on what can be perceived as permissiveness in some aspects (roaming, loud voices, demanding behavior) and very strict in other aspects (respect for adults, prohibited from speaking back, friendships approved by the parents). Parents are stricter with girls than boys.

Elders: Elders expect to be respected. Use title and first name. Ask family how a person is addressed by friends or distant relatives.

Visitors: Visitors may be treated as family or acquaintances. Those considered family may be incorporated into care of the patient.

Modesty: Very modest. Most need a long gown and robe, particularly in the presence of the opposite gender.

Toileting: Toilet paper not purifying enough. Most prefer to wash up after every urination and bowel movement. They may insist on using a bidet to wash up after urination and bowel movement. Respect their privacy.

Special clothing and amulets: Depends on country of origin. For many women scarves are important and essential. Blue beads or other amulets may be on hand to ward off the evil eye.

Meals: Three meals per day, the largest is usually preferred about 2 pm. They do not mix milk and fish, sweet and sour, hot and cold or sweet with meals. No ice with beverages.

Prohibited food: Most Moslems do not eat pork, ham or food cooked in alcohol. They do not consume alcohol. No cold beverages in the morning, no icy beverages when sick. They will not eat raw fish, and will only eat meat cooked well-done. The sharing of tea, coffee, and chocolates indicates reaching out, trusting and caring. Receiving and accepting these offers demonstrates acceptance and trust.

Death Rituals:

Care of the body: Special rituals followed after death, such as washing the body and all of its orifices.

Special needs: Arab Christians may request a minister to visit. Moslems do not need an Imam to be present. An Imam reads the Koran after the death, not before or during the dying process. Families tend to express their grief in a very open way.

Black/African Americans

Preferred term: Several terms are used depending on the individual's age and socialization. It is best to ask what they prefer: colors, Negro, black, Afro-American or African American.

Communication: English. Some traditional dialects are spoken in Carolinas, Alabama, and Louisiana. Black English is a very expressive dialect, spoken mainly in inner cities. People may switch between Black and Standard English depending on the situation.

Non-Verbal communication: African Americans are affectionate people. Affection is shown by touching, hugging, and being close to friends and family. Maintain eye contact to show respect, and to establish trust. Silence may indicate lack of trust.

Greeting: On the first meeting, address as Mr. or Mrs. Or by professional title and last name. Handshaking is appropriate.

Orientation towards time: Flexible time frame, not linear. Life issues may take priority over keeping appointments. Primarily present-orientated by individual. Older persons tend to be more punctual and more willing to wait.

Family Relationships

Gender issues: May be separate male and female roles, however, very egalitarian (equality of all men). Father or eldest family member is usually the spokesperson.

Caring role: Usually wife or eldest sister is the family caretaker, but this depends on the family structure. Sons often care for ailing parents. Institutions for elder for any reason are avoided.

Children: Early walking and toileting encouraged. Children are expected to help with household chores, attend and complete schooling. Developing talents in music and sports are encouraged to develop a socioeconomic base.

Elders: Elders are a source of wisdom and demand respect. They are often involved in the care and raising of their grandchildren.

Spiritual orientation: Baptist, other Protestant sects, Muslim.

Modesty: Respectful approaches accepted by either gender; may prefer female nurse. Muslim women prefer to have their head covered at all times. Daily washing is common; hair is washed every seven to ten days and may use hair oils daily.

Meals: Three meals daily, traditional large meal at late afternoon (supper). There are frequently practices on Sunday's after church.

Usual diet: Hearty meals with meat, fish, greens, rice or potatoes, other starches such as corn or yams.

Food prohibitions: May have religious restrictions (Islamic, Seventh Day Adventist, etc.); otherwise generally not a problem.

Death rituals

Preparation: Report to the oldest family member, spouse, or parents. There is often an open and public display of grief.

Care of the body: Family members usually want professionals to cleanse and prepare the body for burial. The deceased highly respected; cremation is avoided. It continues to be taboo to donate organs or blood.

Mexican Americans

Preferred term: Hispanic

Communication: Some speak Spanish exclusively. Many are Bilingual. Often elders will not attempt to speak English to a stranger. In Spanish, there are no differences in word usage depending on the home region.

Non-verbal communication: Strongly influenced by respect. Direct eye contact avoided with authority figures or with those perceived with class difference. Family may all stand when an authority figure enters the room as a way of showing respect. Touch by strangers is generally unappreciated and can be very stressful or perceived disrespectful. Handshaking is considered polite and usually welcomed.

Greetings: It is considered respectful to address individuals formally, especially with elders and married women. They generally tend to be very warm and expressive with family and close friends. Embracing is common.

Family Relationships

Structure: Family comes first. Help is first sought within immediate and extended family. There is a strong sense of loyalty, reciprocity, and solidarity among members. Behavior of individual members is mediated by a concern for the reputation of the entire family. Traditionally the father or oldest male is head of the household and holds ultimate decision-making authority. Mothers, while publicly deferential to husbands and elders, hold a great influence over their children throughout their lifespan. They are generally respected for cultural wisdom and life experience.

Gender issues: Males tend to have the cultural trait of machismo (macho). It is a trait that is viewed stereotypically as a brutish and controlling attitude toward women. Mexican American men are expected to be strong and in control and a provider for the family. Mexican American women are stereotypically submissive, although as mothers they have considerable influence over the family.

Care issues: Women are primarily the caregivers.

Children: Children are raised in a protective environment. Hard work and achievement are encouraged; next generation is expected to “do better” than the previous one.

Elders: Elders are treated with respect and in a formal manner. Elders are active in care and education of children. Avoid using first names when addressing elders.

Visitors: There may be large numbers of visitors; generally quiet and respectful.

Spiritual: Approximately 80 to 90% are Roman Catholic.

Modesty: Especially pronounced in women, prefer health care from women. Mexican Americans bathe daily; pay close attention to grooming and appearance. Presentation of self is probably related to the family reputation.

Special clothing and amulets: Religious items, such as rosaries are frequently kept on person. Respect for elders may enhance the use of the special items among acculturates Mexican Americans.

Meals: Mexican Americans usually have three meals a day. They prefer to eat meals together. In traditional agriculture settings men eat first. If snacks are eaten between meals, they are usually of poor nutritional value.

Usual diet: Beans, tortillas, and rice are staples in most meals. They prefer their vegetables cooked. Tomatoes and chilies are used for a variety of sauces. Meat is used much more in the United States than in Mexico, probably because of the higher standard of living in the United States.

Death Rituals

Preparation: The extended family is obligated to tend to the sick and dying and pay their respects. Pregnant women usually prohibited from caring for the dying person or attending the funeral.

Care of the body: Death is a very important spiritual event. The family will generally ask for extra time to say their good-byes before the body is taken to the funeral home.

Day of the Dead: Is an annual celebration held on November 2nd to honor the spirits of the dead? Day of the Dead coincides with All Soul's Day, to commemorate the deceased so that they can rest in peace. According to popular belief, on the Day of the Dead the spirits of the dead return so they can commune with the living. Families leave offerings for these spirits, attend festivals in costumes, and clean and decorate graves of deceased family members. Most of the Day of the Dead activities takes place in the

home where a shrine is made in honor of the deceased with offerings of food and decorated with yellow or orange flowers Cempasuchil (Flower of the Dead) and (Mano de Leon) Lions Paw. According to custom, ill fortune such as sickness or death may befall those who do not make offerings.

Notes: Do not give a Hispanic person a yellow or orange flower, the color symbolizes death.

RUSSIANS

Preferred term: Russian

Communication: Russian is a Slavic language with few dialect differences. Russian language is very rich and expressive.

Non-verbal communication: Typically, direct eye-to-eye contact is used. Russians are very respectful to elders. Use touch freely with family and close friends. Personal space varies such as close for friends and family; more distant until a feeling of friendship or familiarity is established. Nodding is a gesture of approval.

Greetings: They are taken very seriously. They may shake hands, or kiss each other on the cheek, depending on the relationship. Elders are highly respected and greeted with titles of "Mr." or "Mrs." or with "Uncle" or "Aunt" even in the absence of a blood relationship. Their tone of voice is sometimes loud, even in pleasant conversations.

Orientation towards time: Most try to be on time for appointments and may even arrive early. At times they may arrive late.

Family Relationships

Structure: Extended family with strong family bonds and great respect for elders. They are family-oriented. Gays and Lesbians are not acknowledged.

Gender Issues: There are no major gender issues. Although husband and wife will consult each other some wives may eventually give way to their husband's opinion. The more dominant personality will eventually prevail.

Caring Role: The whole family pulls together during a crisis for support and strength.

Expectations for Children: Children are taught to behave, be obedient, be very respectful to their elders, to study hard and obtain a higher education. Children are also expected to take turns in caring for an ill family member.

Expectations for elders: Elders are highly respected and expected to also care for the ill if possible. Elders live in extended families; they are family oriented and expect their children to also be family oriented and to produce offspring. Elders are expected to rear their grandchildren, especially when the parents work.

Expectations of visitors: Family members and friends are expected to visit the sick. Russians have strong bonds and provide strength and support for the sick.

Spiritual: Primary religions are Jewish and Eastern Orthodox. Other religions include Molokans, Seventh Day Adventist, Pentecostals, Old Believers and Baptist.

Modesty: Mildly modest. Patient may prefer opposite gender family members to leave the room when changing clothing or while the nurse assesses a urinary catheter.

Special clothing or amulet: Some elderly women may prefer to wear warm clothing on top of hospital gowns for fear of catching cold or pneumonia. Some orthodox

individuals may want to wear a religious cross, necklace or have pictures of saints near by.

Meals: Three meals a day with lunch being the heaviest. Russians may snack in between meals with Russian spiced tea (spiced orange pekoe tea) or fruit.

Usual Diet: Russian food is high in starch, fat and salt.

Food Rituals: When ill, they may prefer hot soups, such as borscht (beet soup), or various light broth soups; and soft bland foods such as boiled potatoes. Drinks include spiced tea or milk with honey.

Illness Beliefs

Causes of physical illness: Poor nutrition, not dressing warmly, family history, stress, not taking care of self or ingesting too many medications. Some Christian faiths believe illness is “the will of God” or “God’s punishment” or a “test in one’s faith in God”.

Folk Remedies: Russians will treat themselves before seeking medical attention and believe that excessive drug use can be harmful and that all drugs are poison in some way. Home remedies include rubbing of camphor ointment, and other various mixtures, oils, and ointments. Placement of hot glasses on bare back, enemas, light exercise with fresh air and some sunlight, sweet liquor, and herbal teas with lemon and or honey.

Death Rituals

Preparation: The head of the family is generally in charge of communicating the prognosis to the patient and may not want the patient to know of a pending death to ensure a peaceful death.

Care of the Body: Depending on the religion, family members may want to wash the body and put special clothing on the deceased. Some Jewish persons believe the body should remain intact. Most Russian Christians do not believe in cremation.

VIETNAMESE

Preferred term: Vietnamese people.

Communication: The three major languages are Bac, Nam, Hue dialects, French and Chinese. However, they may be able to speak only French and or Chinese. They may speak English as a second language.

Non-verbal communication: A gentle touch may be appropriate when having conversation. However, touch in communication is more limited among older non-traditional people. The head may be considered sacred and the feet profane. Be careful in what order they are touched. Respect is shown by avoiding eye contact with those of higher status. Respect is portrayed by slightly bowing the head and using both hands in giving something to another. Personal space is more distant than in Euro-Americans.

Greetings: In formal settings, the family name (last name) is mentioned first; however, in casual conversation, they prefer to be called by giving name plus title (Mrs. Plus first name). Elderly people are shown respect by gentle bow. One should not shake a woman’s hand unless she offers her hand first. Vietnamese greet others with a smile and a bow.

Orientation toward time: Frequently fashionable to be late but they understand the importance of keeping appointments.

Family Relationships

Structure: High family oriented; may be an extended or nuclear family. Sometimes there are two or three generations living in one household. They may not be tolerant or supportive of Gay or Lesbian siblings.

Decision Making/spokesperson: The Father or eldest son is the family spokesperson. Wives who are not wage earners demonstrate more subordinate patterns of decision making. Women tend to have the attitude that the husband has the right to make final decisions. They may withdraw from a spousal conflict to maintain harmony in the family.

Gender Issues: Men are the decision makers and the support for the family. Their job is to carry out heavy duty chores unless the children are old enough to help. Women prepare all the meals, whether employed or not. They do most of the house chores unless the children are old enough to help. It will usually strain the marriage when a woman has a better job than her husband.

Caring Role: Women in the family are responsible for the ill patient. Women act as the primary care provider at the bedside, regardless of the patient's sex. Women are expected to pamper the patient with daily bath and meals.

Children: When children are young the parents look after them. When parents get old the children look after them. Children are usually well sheltered by the parents and are expected to obey and honor their parents and respect the elders. They are taught to be honest and polite.

There is a strong emphasis on education. Parents push their children to the highest level in education, especially when they did not have the opportunity themselves. Some intergenerational conflicts arise with the children's acculturation to American norms, or when a child must serve as a spokesperson or interpreter.

Expectations for elders: As mentioned above, female family members are expected to stay at bedside for comfort and support. A private room is recommended. Because Vietnamese are family centered, many family members come to visit.

Spiritual Practices: Catholics recite the rosary and read prayers. The Buddhists practice of Dana (or generosity), is believed to return to them in the future as karma. Theravada Buddhism holds that individuals must seek their own salvation. They believe in reincarnation and in an ultimate Nirvana. They pray silently among themselves.

Illness Beliefs

Causes for Illness: There are four types of explanation for illness. A "natural" cause attributed to natural or immediately visible circumstances such as rotten food. The Chinese-Vietnamese explanation for illness is based on traditional Chinese philosophy of a balance between ying and yang, hot and cold. Supernatural explanations include punishment for a personality fault or a violation of a religious taboo. Western biomedical causes, such as "germs" can also explain illness. Mental illness is believed to be caused by disruption of the harmony in an individual or by an ancestral spirit coming back to haunt them because of past behavior.

Home Remedies: Treated with herbal medicine, spiritual practices and acupuncture. Other practices include inhaling aromatic oils such as eucalyptus, drinking herbal teas or by wearing strings tied to the body.

Death Rituals

Care of the Body: The body is highly respected. Certain families may want to wash the body themselves. Others may want it left as it is. A spiritual or religious rite usually takes place in the room.

Special Needs: For Catholic families, religious medallion, rosary beads or other spiritual objects such as figures of saints are to be kept close to the patient. For Buddhist families, incense is lit in the room and a Monk is present to start the religious ritual. It is not uncommon for families to cry loudly and uncontrollably.

Diversity among Spiritual and Religious Beliefs

Adventist (Seventh Day)

Names by which the particular sect is known: Adventist, Church of God, Seventh Day Adventist and Advent Christian Church.

Spiritual and Religious Implements: Prayer and anointing with oil. No special sacraments or rituals at birth or death.

Daily Practices: Some sects consider Saturday the Sabbath, a day of worship and rest.

Food Requirements and Prohibitions: A vegetarian diet is encouraged. Many groups prohibit meat, shellfish and some birds. Alcohol, coffee and tea are also prohibited.

Illness: There are no restrictions of medications blood or blood products, or vaccines. Some groups prohibit narcotics and stimulants because the body is a temple for the Holy Spirit and should be protected. It is not uncommon for refusal of any medical interventions on Friday evening or on Saturday's (Sabbath).

Dying and Death: They believe in prolonging life but may allow someone to die in some cases. Euthanasia is not practiced. Autopsy and donation of body organs is acceptable. Disposal of the body and burial are individual decisions.

Buddhist

There are many forms of Buddhism. Some forms are based on the country of origin.

Spiritual and Religious Beliefs of Health and Illness: According to Buddhist traditions, Siddhartha Gautama, the Buddha who lived in India during the 6th century B.C., discovered that life is basically unsatisfactory when conditioned by a mind full of greed, hatred and delusion. An unclear mind produces suffering and bad karma, leading to repeated rebirths in unsatisfactory worlds. One transcends this existence through the Eightfold Path: right understanding, right thought, right speech, right action, right livelihood, right effort, right mindfulness and right concentration. The central focus of most Buddhist practice is the attainment of a calm mind, undisturbed by worldly actions and full compassion.

Illness is a result of karma (law of cause and effect), therefore an inevitable consequence of actions in this or a previous life. Illness is not due to punishment by a divine being. Buddhism teaches ways to overcome fears and anxieties. Healing and recovery promoted by awakening the wisdom of Buddha, which results in spiritual peace and freedom from anxiety.

Spiritual and Religious Implements: Incense burning, flower and fruit offerings, altars in temples and homes with images of Buddha and ancestors, and prayer beads.

Daily Practices: Buddhism does not dictate dogma or any specific practices. Individual differences are expected and are respected. Individuals may chant or meditate to observe their rites and rituals.

Food Requirements and Prohibitions: Extremes are to be avoided. There are no prescriptions for foods. Many Buddhists do not eat meat.

Illness: Buddhists do not believe in healing through faith. There are no restrictions on blood, or receiving health care on holy days. Buddhists often refrain from using medications, but in great discomfort, medications are acceptable as long as they do not affect the mind.

Dying and Death: Enlightenment can be achieved by accepting the inevitability of death and opportunity for improvement in the next life. A dying person's state of mind at the moment of death is believed to influence the rebirth.

Each Buddhist group has its own ritual requirement after death (e.g., last rite, chanting at the bedside or soon after death, family members remaining with the body until cremation or burial). The body is considered a shell. Autopsy and disposal of the body are an individual rather than a religious decision. The body must be treated with respect. Cremation tends to be more common than burial.

Pregnant women should avoid funerals to prevent bad luck for their baby. Suicide, violent, unexpected death or the death of a small child may necessitate monks, soothsayers, or special rituals to counter the negative impact of the lack of preparation or the wrong condition at the time of the death.

Catholic

Spiritual and Religious Beliefs of Health and Illness: Illness may be God's punishment of sinful thinking or behavior. Suffering is part of one's fate and relates to religious implements. Sacred oils and incense are used only during official rituals.

Spiritual and Religious Implements: Many signs, symbols (especially the name Jesus Christ, the cross, the crucifix (cross with Jesus' fixed on it), music, images, colors, natural crafted objects, holy water, candles, and statues serve as religious implements. Sacred oils and incense are used only during official rituals.

Food Requirements and Prohibitions: Use foods in moderation, not injurious to health. Some Catholics abstain from meat on Fridays. At particular times of the year fasting is common.

Illness: Transfusions are permissible. Medications may only be taken if the benefits outweigh the risks. Most surgical procedures are permissible except abortion and sterilization. An amputated limb may be buried in consecrated ground. Healing practices include Sacrament of the Sick (which includes anointing, communion, and blessing by a priest), burning candles, laying on of hands, offering prayers. The Eucharist (a wafer of flour and water) may be given as food of healing. The sick may also want the Sacrament of Reconciliation (confession).

Dying and Death: Obligated to take ordinary, not extraordinary, means to prolong life. It is permissible to refuse treatment that carries risk.

Euthanasia is forbidden. Sacrament of the Sick is mandatory. Autopsy is permissible. The body is to be treated with respect. Burial is usual although cremation is acceptable.

A Catholic who commits suicide may be denied burial in consecrated ground or in a Catholic cemetery.

Islam

Names by which the particular sect is known: Islam, a word meaning peace or complete submission, is the name of a monotheistic religion preached by the Prophet Mohammed around Mecca approximately 1,400 years ago. Muss élan, Muslim, or Moslem are names given to the people who profess Islamic faith.

Spiritual and Religious beliefs on Health and Illness: Belief in only one God, or Allah, is the most important principal in Islam. Other guiding principals are: to believe in the prophet Mohammed and the Holy Koran, to make a commitment to fast; to believe that there is a judgment day and life after death; to perform duty or give with generosity to poor people; jihad - to fight for the sake of Allah and to pray five times each day. Principal object of faith is show the straight path by which people's faculties are brought to perfection and individual souls may experience full self-realization. The law of Islamic state is the law of the Koran. Since life is a gift of God, disease, pain and suffering are manifestations of God's will. Pain and suffering are part of expiating sin.

Spiritual and Religious Implements: Holy Koran (word of God) and hadith (traditional sayings and acts of the Prophet Mohammed). Individual may wear a chain with the symbol of Islam, use a prayer rug, or wear a taawilz (Koranic verses wrapped in a small cloth).

Daily Practices: Prayer five times per day facing Mecca, after ritual within (dawn, mid-day, mid-afternoon, sunset, nightfall). Days of observances occur through out Muslim lunar calendar. There are no sacraments.

Illness: There are no restrictions on transfusions. Faith healing is generally not acceptable unless it is done to prevent deterioration of the patient's psychological and moral condition.

Most surgical procedures are permitted. Older or conservative Muslims may not adhere to therapy because of fatalistic view.

Dying and Death: Euthanasia or any attempt to shorten life is prohibited. Autopsy is only permitted for medical or legal reasons although devout people may be concerned about desecration of the human body. As the moment of death approaches, the dying person, if they can, should recite, with help from others, the Islamic Creed, or Shahadah (La Illa- Allah Muhammadur Rasuulullaah), meaning there is no God but the Almighty Allah and his messenger is Muhammed. Confession of sins and begging for forgiveness must occur in the presence of the family before death.

It is very important to follow the five steps of the burial procedure which specifies washing, dressing, and positioning of the body. After death, the individual's eyes should be gently shut; the mouth closed with a bandage running under the chin and tied over the head, arms and legs straightened. The surrounding people can grieve tears, but are forbidden to wail, beat the breast, slap the face, tear hair or garments or complain or curse.

With minimum delay the body should be thoroughly washed, shrouded in a white cloth sheet, a funeral prayer (salaatul Janaazah) is held for the deceased asking God's mercy and blessings, as soon as the prayer is over the body is taken to the grave for burial. The grave must be positioned so that the body, when turned on its right side, faces

Mecca. The body is lowered with the utmost respect and dignity. The grave is filled with earth, starting with the head. Every person helps, using both hands. Finally, water should be sprinkled over the grave.

Jehovah's Witness

Names by which a particular sect is known: Jehovah's Witness, Watch Tower Bible, and the Tract Society.

Spiritual and Religious Beliefs on Health and Illness: Opposition to "false teachings" of other sects, often extending to science and medicine. The conversation of others is important. Some are conscientious objectors to war and do not participate in nationalistic ceremonies (e.g., saluting the flag) or give gifts at holidays nor do they celebrate traditional Christian holy days. Full allegiance is give to Jehovah's kingdom. It is believed that after the world has been restored to a state of paradise, beneficiaries of Christ will be resurrected with healthy, perfected physical bodies and will inhabit the earth.

Spiritual and Religious Implements: The Bible.

Daily Practices: Prayer and reading of scriptures.

Food Requirements and Prohibitions: Abstain from tobacco. Moderate use of alcohol is permitted, but drunkenness is a sin.

Illness: Faith healing is forbidden. Reading scriptures is believed to comfort the individual and lead to mental and spiritual healing. Blood transfusions are not permitted. Surgical procedures are permitted as long as there is no blood administered.

Dying and Death: Euthanasia is forbidden. Autopsy is acceptable if it is legally required. Burial is determined by individual preference and local custom. In the Tri-Cities the Jehovah Witness's generally will cremate and scatter the remains. Any services are held in the Kingdom Hall (church).

Mormon

Names by which the particular sect is known: Church of Jesus Christ of Latter Day Saints (LDS), and Mormonism.

Spiritual and Religious Beliefs on Health and Illness: One of the central purposes of life is procreation. The power of God can be exercised to bring healing. Faith healing (faith in Jesus Christ and the power of the priesthood to heal), medical treatment and care are used together. Medical intervention is viewed as one of God's ways of using humans to heal. Mormons believe that life continues beyond death.

Spiritual and Religious Implements: After being considered worthy to enter a temple, Mormons wear a type of underclothing called a garment which signifies a promise to God. Blessings of sick use consecrated oil.

Daily Practices: Sacrament meetings are held on Sunday which is the Sabbath. Baptism is at eight years old or after - never at infancy or at death.

Food Requirements and Prohibitions: Alcohol, tobacco, coffee and tea are prohibited.

There is counsel against caffeine but caffeine containing soft drinks are not prohibited. Fasting is required once each month. Ill people are not required to fast.

Illness: There is no restriction on blood transfusions. Many may use herbal or folk remedies. Healing practices include blessing of the sick which consists of two Elders anointing with oil, sealing the anointing with a prayer and blessing, and laying hands on the head of the patient.

Dying and Death: Euthanasia is not practiced because people must not interfere with God's plan. The belief is to promote a peaceful and dignified death if death is inevitable.

Burial preparations start by the funeral home cleansing the body and by members of the church who are of the same gender as the deceased and then dressing the deceased in temple cloths. The deceased will be taken to their ward (church) where a public viewing may be held in the Relief Society room. About 20 minutes before the funeral service is scheduled to start, as the family gathers in the Relief Society room where a prayer is given and a veil (female) or cap (male) is placed over the deceased's face. The funeral is traditional with songs, prayers, and eulogy. The deceased is taken to the cemetery where there is a dedication (prayer) of the grave and the casket is lowered.

Tahara: An Ancient Jewish Ritual for the Dead

By Lisa M. Halpern, MSN, APRN, BC

She was know to God by her Hebrew name, Baila bat Sarah. The tag on her toe identified her as Bessie Cohen, a resident—until that morning—of the Jewish Home. Her birthday, also on the tag, was January 7, 1921.

That evening I was one of three women from my community's chevra kadisha (Jewish Burial Society) who had gathered at the Jewish mortuary to perform the tahara, the traditional purification ritual of preparing a body for burial. My experience as a nurse enhances my participation in this religious ritual.

Quietly, in observance of universal precautions, we gowned and gloved, softly, in observance of ritual traditions, we recited the introductory prayers asking Baila bat Sarah for her forgiveness for any indignities we might subject her to. We wanted to avoid any action that could cause a living person to feel disrespected—carelessly handling the limb, for example, or having a mundane conversation during the purification ritual.

We prepared her for her final bath, gently removing gauze and IV tubing. On a paper towel, we gathered loose hairs and bits of bandage stained with her blood, preparing, according to religious requirements, to bury even these tiny bits of her body with her. As I performed these tasks, my mind was busily, unnecessarily, assessing the indicators of her clinical state in her final days and developing a differential diagnosis for the cause of her death. O still those thoughts; I wondered instead what joys she had known, whom she had loved, how she had struggled, who wept for her now.

We washed her body in sections, safeguarding her modesty with a bath towel, uncovering parts of her body only as we attended to them. Once, as we rolled her onto her side to wash her back, she slipped down the mortician's table. Bending my knees slightly to protect my back, I helped to reposition her. We cleaned beneath her fingernails and toenails, careful not to dislodge the onychomycotic toenails on her right foot. Using acetone, we removed her chipped pink fingernail polish; evidence of someone's loving attention in recent weeks. One of us removed debris from her deeply

indented umbilicus. Together we prepared to return her to the God who had created her, as clean and unadorned as she had arrived in this world.

Three times we poured water over her, from head to foot, as she lay propped on boards that allowed the water to flow over and around her. As we did so, we murmured in Hebrew a message from the Book of Ezekiel: “will pour upon you pure water and you will be purified of all your defilements, and from all your abominations I will purify you.” She could no longer pray for herself, so by reciting these ritual passages we prayed on her behalf—just as nurse’s care for patients who are unable to care for themselves.

We dried her, tenderly, with clean white sheets. I noticed her hands—soft; white, competent—and wondered how many baths she had given. I thought about her mother, who might have bathed her first.

Plain white burial garments (tachrichim) awaited her on a stainless steel table. We shook them out. Taking turns, we helped one another pull on her trousers, shirt, and jacket, struggling a bit with her limbs stiffened by rigor mortis. Before tying the shroud’s belts with the special knot representing the name of God. We cut open a tiny plastic packet of soil from the Holy Land and sprinkled the earth inside Balia bat Sarah’s garments. As one of us cradled her head and another stood alongside to assist, the third arranged Balia bat Sarah’s headdress and veil. According to ancient custom, her eyes and mouth were covered with shards of broken potter, and the veil was pulled over her face.

Gathering at Balia bat Sarah’s side, we again requested her forgiveness for errors we had committed or omissions we had made. We spoke in unison, two in an undertone, one of us aloud. Our activity ceased. My breathing was slow and even, my diagnostic mind stilled.

We summoned the morticians into the room to move Balia bat Sarah into her simple pine casket. They joined us, speaking everyday voices that sharply contrasted with the hushed tones we had been using. The sudden glare of fluorescent bulbs seems to overwhelm the faint glow of our ritual candle. The morticians worked with care but with less compassion than we of the chevra kadisha. We, and perhaps she, were jostled from our sanctified hour. We stood aside as the men lowered her body into the box cushioned with straw. The closing of the lid resonated throughout the room.

DEATH AND DYING

NUTRITION

Obtaining adequate nutrition can be challenging for the patient suffering from an illness. The following sections may be helpful in providing nutritional care for the patient or assisting their caregivers.

- Loss of Appetite
- Loss of appetite may be short-term or it can be very severe and long lasting and may lead to severe tissue loss, malnutrition, and dehydration. Some of the following suggestions may be helpful in promoting food and fluid intake.
- Make meal times relaxing and pleasurable.
- Listen to soft music, make the meal more attractive by using a place mat and candlelight (if determined to be safe and appropriate).
- Eat with friends or family members whenever possible.
- Eat slowly and take a break during your meal, no need to rush.
- Try eating six or more small meals instead of three large ones.
- Use ready-to-eat and easily prepared foods to conserve energy.
- Add flavor to food by using spices and herbs, mustard, barbeque sauce, lemon wedges, ketchup or hot sauce.
- Prescription medication may be used to stimulate appetite; consult the physician.
- Eat what sounds good and eat throughout the day.

Nutrient Dense Food

A patient may be limited in the total volume of food which can be tolerated perhaps due to a decreased appetite. The nutrient density of foods can sometimes be successfully increased without adding to the portion sizes of food. If the patient is diabetic, intake of high sugar foods may be monitored closely to avoid any problems with blood sugar.

Mouth and Throat Problems

Experiencing a dry or sore mouth or throat may inhibit proper food intake. Some of the following suggestions may help alleviate some discomfort.

Dry Mouth or throat

- Moisten food with sauces, gravy, broth or melted butter or margarine.
- Eat moist foods such as pudding, yogurt, and ice cream.
- Try sugarless candy (lemon drops) or mints to stimulate saliva production.
- Artificial saliva may be used in extreme cases.

Sore Mouth or Throat

- Try eating a softer diet. A blender may be used to modify the texture of regular foods to make it easier to swallow.
- Soft foods such as mashed potatoes; well cooked, scrambled or poached eggs, cooked cereals, milk shakes, puddings, gelatin, macaroni and cheese and bananas may be well tolerated.
- Foods at room temperature or slightly chilled are more soothing.
- Avoid highly acidic foods such as citrus fruits, juices, and tomatoes.

- Avoid spices such as pepper, chili pepper, cloves and salt to avoid a burning sensation.
- Avoid rough or coarse foods.
- Avoid smoking and drinking alcoholic beverages as they can irritate the mouth and throat.

Swallowing or Chewing Difficulty

- Cut foods into smaller pieces or use a blender or food processor.
- Use liquids, gravy or sauces on foods.
- Consume a meal supplement such as Ensure, Sustacal or Carnation Instant Breakfast.
- Recommend an evaluation from a speech pathologist to determine the appropriate consistency of foods which are better tolerated.

Altered Sense of Taste and or Smell

- Taste sensations can change during an illness or treatment. A condition referred to as “mouth blindness” or “taste blindness” may give foods a bitter or metallic taste, especially for meat or other high protein foods. Many foods will simply have less taste. Sometimes a patient begins eating a type of food he previously disliked or craving a certain food.
- There is no ultimate way to enhance the flavor or smell of food because each person is affected differently.
- A metallic taste may be reduced with tart foods such as citrus or cranberry juice, and pickles (caution needed if the patient has a sore mouth or throat).
- Use plastic utensils instead of metal.
- Add sugar to reduce salty flavor; add salt to decrease sweetness.
- If red meat tastes or smells bad, eat chicken, turkey, well-cooked eggs, dairy products or fish.
- Serve foods at room temperature. Cold foods may also be well-tolerated (macaroni salad, cold cuts, cold drinks).

Nausea and Vomiting

Nausea may occur with or without vomiting and may be caused by some medications. The following suggestions may help in managing symptoms.

- Eat small, frequent, dry meals; eat slowly and chew food well.
- Drink any liquids between meals, not with meals.
- Avoid eating greasy, fried or spicy foods.
- Choose dry foods such as boxed cereal, crackers and Melba toast.
- Remain sitting upright for one to two hours after eating.
- Eat food cold or at room temperature; hot food can worsen nausea.
- Anti-nausea medication may be prescribed by a physician.

HYDRATION

In a landmark 1983 article, this Hospice nurse questioned the practice of giving IV fluids to terminally ill patients. Since then, she reports, evidence has grown that in many cases artificial hydration is misguided mercy that neither gives comfort nor prolongs life.

By Joyce V. Zerwekh, EdD, MA, BSN

Introduction

The Hospice movement has led nurses to challenge many long-held assumptions about the care dying patients receive. Consider, for example, the belief that terminally ill patients need fluids, even if they must be given through an IV line or other artificial means because the patient can't drink.

Before I joined the Hospice movement in 1979, I too assumed that hydration was good for all patients, even those at the end of life. Dehydration, I believed, would cause suffering. But in the home Hospice care, my colleagues and I saw many patients who remained comfortable despite prolonged periods of dehydration. When these patients were hospitalized for symptom relief, we found, they were routinely administered artificial hydration, and they developed many signs of symptom overload, such as ascites and peripheral edema.

My experience led me to write an article, published in 1983, that challenged the prevailing belief that hydrating the dying patient was more merciful than allowing dehydration. The article has been cited widely in the debate over withholding and withdrawing IV fluids in the terminally ill.

Since 1983, my observations have been supported by reports from Hospice oncology, and gerontology specialists. Yet many clinicians continue to administer artificial hydration to terminally ill patients inappropriately.

Knowledge gathered from clinical experience and research indicates that dehydration has physiologic effect that may relieve a dying person's suffering. Conversely, artificial hydration, rather than being merciful, may do the patient more harm than good. As I'll explain in this article, the available evidence suggests that fluids shouldn't be routinely administered to dying patients—or automatically withheld from them. Instead, the burdens and benefits of artificial hydration must be weighed for each individual after careful assessment.

Your role is to share your nursing expertise and unique understanding of the patient with the care team so that an informed decision about hydration can be made. You'll also be challenged to correct misconceptions about dehydration that may cause emotional distress to both patients and families.

Physiology of Dehydration in the Dying Patient

When a patient with advanced terminal disease comes within days of death, we expect that a fluid deficit will develop. The patient typically drinks less because of dysphagia, nausea, anorexia, diminishing energy, a reduced level of consciousness, or emotional withdrawal from activities of living, or a combination of these factors. At the same time, the patient may be losing fluids through bleeding, vomiting, diarrhea, or drainage from wounds and fistulas. Because fluids play such a critical physiological role, you can actually anticipate death by observing the progression of reductions in fluid intake and urine output.

The expression "terminal dehydration" is commonly used to refer to the process that occurs when a dying person's condition causes him to gradually reduce fluid intake. As the patient's fluid intake drops, a decrease in circulating blood volume and, eventually, dehydration follow. Signs of terminal dehydration include dry skin and mucous membranes, postural hypotension, thickened secretions, oliguria, and reduced tissue perfusion with cerebral hypoxia. The electrolyte and acid-base changes associated with

terminal dehydration are poorly understood. Knowledge of physiology leads us to expect:

Hypernatremia due to water intake inadequate to maintain serum dilution;

Asotemia resulting from perenal renal failure;

Acidosis due to perenal acute failure, lactic acid accumulation, ketosis from starvation and hypoventilation;

Hyperkalemia caused by asidosis, tissue catabolism, and renal failure;

Hypercalcemia due to immobility, increased concentration of serums, and bony metastases.

These physiological changes are indeed common, but they are by no means inevitable, as has been widely believed. Research studies, such as that by John Ellershaw and colleagues at St. Christopher's Hospice near London, have found surprising normal blood chemistries in dehydrated dying people. Why this is so remains unknown.

The most consistently seen change is azotemia with elevation of urea, creatinine, and uric acid. Since electrolyte levels don't necessarily change in the expected manner, any symptoms seen in patients near death who are dehydrated, such as weakness, lethargy, or neuromuscular irritability, can't automatically be attributed to electrolyte imbalance. Similarly, abnormalities in cardiac rhythm or, indeed, cardiac arrest can't be ascribed to hyperkalemia from dehydration.

“Suffering From Dehydration: Rhetoric versus Reality

Those who insist we are morally mandated to provide fluids to all terminally ill patients to prevent “suffering” often paint a gruesome picture of dehydration: a parched, skeletal victim, burning with fever, convulsing, and retching from a dried-out stomach. This picture is based on findings of studies of healthy people deprived of fluids. These individuals do report headache, abdominal cramps, nausea and vomiting, and dry mouth they feel awful.

But the physiology of the living differs from the physiology of the dying. The horrifying scene some have imagined isn't what I and other Hospice caregivers have observed over years of practice. Since my 1983 article, others have reported studies finding that terminally ill patients don't suffer discomfort as a result of dehydration. In a 1989 survey of Hospice nurses, conducted by Maria Andrews and Alan Levine, 82% of respondents disagreed with the statement, “Dehydration is painful.” Hospice nursing researcher Shirley Ann Smith has reported a high comfort level in a group of 19 patients she studied who were severely dehydrated near death.

How thirsty are they?

The symptom clinicians most often associate with dehydration is thirst. Yet there's scant evidence that dehydration causes thirst in many terminally ill patients. In the Hospice nurse survey, 63% of respondents agreed that “Dying patients who are dehydrated rarely complain of thirst.” A 1994 study by Robert McCann and colleagues of terminally ill patients on a comfort care unit of a Rochester, New York, hospital found that 62% either experienced no thirst or were thirsty only initially during their admission for terminal illness care. The patients in the study received no forced hydration.

Another study, by John Ellen Shaw and colleagues at St. Christopher's Hospice, did find that a large percentage of patients who could respond to questions (20 or 23 patients)

said they felt thirst. And in a 1993 survey by Frederick Burge of patients on palliative care units at two hospitals in Halifax, Nova Scotia, respondents rated their thirst moderate in severity on average. The St. Christopher's researchers concluded that artificial hydration to relieve symptoms may be futile.

One symptom that has been seen consistently in dehydrated terminally ill patients is dry mouth. This may lead to cracking of oral mucosa and inflammation. As the oral surface barrier is compromised and immunity lowered, the patient may become more susceptible to candidacies or bacterial or viral infection. However, dehydration isn't the only cause of dry mouth in terminally ill patients. Medications — opioids, phenothiazines, antihistamines, and antidepressants — may contribute, as may mouth breathing or food debris and dried sputum coating the dry oral mucosa.

Discomfort from dry mouth can be relieved for one to several hours with sips of the patient's favorite beverage, ice chips, or hard candies. Meticulous mouth care can help prevent problems related to dryness. Remove debris from the mouth with frequent water and peroxide rinses. Brush the gums, teeth and tongue with a soft toothbrush, if the patient can tolerate this.

It might be argued that even if dehydration doesn't cause discomfort, it may hasten death. Aren't we then practicing euthanasia by allowing a patient to become dehydrated?

Let's put aside for the moment the ethical arguments about what constitutes euthanasia. There's evidence that terminally ill patients who don't receive artificial hydration die sooner than those who do. Shirley Ann Smith cites two studies that in fact found longer survival times in patients who didn't receive artificial hydration. There's been to my knowledge no clinical trial showing that artificial hydration prolongs survival in patients with terminal illness.

Benefits of Dehydration

Dehydration may actually have some benefits for the terminally ill patient. For example, with decreased urine output, the patient will have less need for the bedpan, urinal, or commode, or for catheterization. There may be fewer episodes of incontinence. With this particularly true of patients with bowel obstruction, in whom vomiting may diminish to only once or twice a day. Tubes and suctioning won't be needed for decompression. (Narcotics may still be needed, though, to relieve peristaltic cramping and anti-emetics may be useful.)

Numerous Hospice clinicians have reported diminished respiratory secretions in dehydrated patients, although the St. Christopher's Hospice study saw no relationship between degrees of hydration and secretions. Reduction of pulmonary secretions relieves coughing and congestion; morphine may still be necessary for dyspnea or cough. A decrease in pharyngeal secretions can afford some relief to the patient who's had difficulty swallowing secretions and has been experiencing choking and drowning sensations. However, anticholinergics may still be useful in controlling secretions.

Louise Printz has asserted that blood chemistry changes subsequent to terminal dehydration produce a natural analgesia in the last days of life. If this is so, presumably dying people throughout history have benefited from the process—that is, until medical technology made it possible to alter the course of death. Just what blood chemistry changes underlie the process is unclear, especially given the evidence of largely normal electrolyte profiles in dehydrated dying patients. But studies in rats have suggested that

terminal dehydration and starvation may lead to increased production of natural opioid. In addition, ketosis due to starvation has been demonstrated to have an anesthetic effect in animals. If dehydration is indeed a natural analgesic, then allowing it to occur at the very end of life far from being cruel can be considered to be palliative and compassionate.

Pros and Cons of Artificial Hydration

Now let's consider the possible benefits and burdens of artificial hydration. Intravenous or subcutaneous (an old administration route rediscovered by Hospice nurses) infusions can sometimes correct a fluid and electrolyte imbalance, stabilizing the patient's condition and reversing symptoms. In the person whose disease hasn't quite reached the end-stage, dehydration due to such causes as hypercalcemia, diarrhea, or diuretic therapy may be reversible, and hydration may be able to prolong life. In addition, Robin Fainsinger and colleagues in Alberta, British Columbia, have found that hydration reduces some patients' disorientation and restlessness. Again, however, there's been no trial or other study demonstrating that hydration improves comfort at the very end of life.

For some clinicians and observers, there are ethical grounds for giving fluids to dying patients, however, uncertain the clinical benefits. They argue that fluids have a symbolic meaning (the giving of water to the sick) and that artificial hydration shows caring and commitment by health professionals. I would counter that it's a human presence that conveys caring—not an IV line or other form of medical technology.

The amount of fluid in the GI tract may also increase. This is a major problem for a patient whose vomiting is difficult to control, especially when there is a bowel obstruction. Such a patient may need a nasogastric tube connected to suction in order to relieve pressure from excess fluid in the stomach.

When the patient has a respiratory problem such as pneumonia or pulmonary edema, or a pulmonary or tracheal obstructive disease, artificial hydration often increases respiratory secretions, many clinicians have observed. The patient may find it more difficult to cough or catch his breath, and suctioning may be hard to avoid.

Parenteral fluids can also worsen edema, cause a return of ascites and increase fistula drainage. A consequence of end-stage heart, liver, and kidney failure is fluid moving out of the blood vessels into tissues and third spaces. In other words, fluid given to dying people with end-stage organ failure collects where it can't be physiologically useful. If the patient has a tumor, the fluid can expand the edematous layer around it, increase pressure on surrounding organs (possibly causing ischemia), and aggravate symptoms, particularly pain.

These adverse effects may be avoided by infusing a limited amount of fluid, perhaps one liter daily. But any IV or subcutaneous fusion can be burdensome to the patient and family. Unless a central line is used, it involves painful needle insertion and immobilization to maintain the line, perhaps leaving the patient to spend his last days tied down so that he doesn't pull out a needle.

In the home, maintaining the infusion takes skill on the part of the family caregivers, who may continually worry whether everything is "all right." In addition, the cost of infusion technology may be high or even prohibitive for the family. Maintaining artificial hydration may preoccupy professional and family caregivers, consuming energy and

resources that would be better focused on the patient's family's emotional and spiritual needs as the patient's death draws near.

Finally, what may be for some patients a benefit from artificial hydration may be for others a burden. Presuming that hydration might improve levels of alertness, it may interfere with the natural analgesia that appears to occur near death.

Making an Informed Choice

The question of whether to initiate artificial hydration in a terminally ill patient can arise when a patient is being cared for on a hospital unit and is approaching death, when a patient who can no longer drink is transferred to the hospital or nursing home, or when a patient is dying at home.

SIGNS AND SYMPTOMS OF APPROACHING DEATH

Not all of these symptoms will appear at the same time and some may never appear.

The Hospice staff realizes that this particular period of time may be one of the most difficult times you and your family will have to live through. Our approach in all matters affecting you during this time is to be as honest and straightforward as possible. Your Hospice Team is your best resource to help you clarify your concerns about this information. These are meant to be a guideline. As each person is unique, so is his or her death.

The following signs and symptoms may actually begin:

One to Three Months before Death:

- Withdrawal – seen as an increase in sleeping
- First from the world – no interest in reading the newspapers or watching television;
- Then from people – not wanting to see friends and neighbors; and finally from children, grandchildren and even spouses.
- Increase in the number of naps every day, staying in bed all day and is asleep more than they are awake.

Food Changes

The body has less and less need for food and fluids as it begins to save energy for dying. The person may have difficulty swallowing and it will be noted that meats are the first to stop being eaten, then vegetables and other hard to digest foods.

- Allow the patient to choose whatever “sounds good” to eat and or drink.
- Don’t force them to eat!
- Frequent mouth care and small sips of water, or other liquid will help prevent a dry mouth.

One to Two Weeks before Death

Food Changes

- A need for food and liquids continues to decrease until the patient is no longer eating or drinking anything.
- Do not force your loved one to eat.
- Confusion – about time and place plus more sleeping; and
- Sleeping will be most of the time but the person is easily awakened.
- They may seem to be confused, i.e., talking to people who aren’t there or who have already died. This may be very comforting to them.
- Keeping a small light on in the room may help prevent some of the confusion.

Physical Changes

- Blood pressure, pulse, and body temperature may go up or down.
- Increased sweating while the body feels cold and wet.
- Breathing changes:
- May increase up to 40 to 50 breaths a minute; with puffing or blowing through the lips when letting out their breath.

- 15 – 45 second periods of no breathing (called apnea).
- Congestion may be noticed, raise the head of the bed and position on one side or the other. This may help this problem.

Skin Changes:

- Cool feeling hands, feet, arms and legs.
- Color changes – the skin may turn a bluish color with purplish splotches (called mottling).
- The underside of the body may be much darker (a bluish-purple) than the skin on the top of the body.

Changes in Urine and Bowels:

- Adult incontinence pads may be placed on, or under the patient to help their skin remain clean, warm and dry.
- If the person has a catheter in place to drain their urine, the urine will become dark in color and will decrease in amount, as death is closer.

One or Two Days, to Hours before Death

- Signs noted Under One or Two Weeks are more noticeable.
- Restlessness.
- Breathing – may become more irregular.
- Congestion – can be very loud and sound like a “rattle”. Placing the patient on one side or the other may help. A special patch to put behind the ear is also available from your Hospice nurse.
- Eyes – have a “glassy” look and may be open but not focusing. There may appear to be extra water (tearing) in the eyes.
- Hands and Feet – mottling may increase.
- Surge of Energy – Rarely, a patient may speak clearly, ask for something to eat, want to see and talk to friends or other family members.
- Non-Responsive – harder and harder to awaken; may or may not be able to wake up at all.

It may be very helpful for family members to take turns sitting with the dying person. It may be helpful for each family member to spend some time alone with the dying person telling him or her that you love him and that you will be OK after he or she dies; and that it is OK to die, even though you will miss him or her. Even if you cannot say these words to your loved one, an attitude of letting go and releasing can be very helpful to the dying person. That will allow him or her to die when he or she is ready and not have to “hold on” to take care of you. Sometimes a patient does die alone, and this is a natural event.

Minutes before Death

- Quiet, very shallow breathing
- Cannot be awakened
- Signs that Death has Occurred
- No breathing
- No heartbeat
- May lose control of bowel and bladder
- Eyelids slightly or totally open

- Eyes fixed on a certain spot
- Jaws relaxed with mouth slightly open

At this time those with the patient may have feelings of powerlessness and helplessness, and the desire to “do more.” Accept and know that all feelings are OK. It is all right to express your feelings. The Hospice staff is here to listen and support you.

Even though this may all sound frightening, the goal of the Hospice team is to help prepare you for what to expect. Remember, the Hospice nurse is only a phone call away. As you notice more imminent signs of death, notify your Hospice nurse.

If your loved one dies without the Hospice nurse present, notify her at once at 574-3600.

Please leave the phone line open until after the nurse returns your call. DO NOT call 911 or an ambulance. The nurse will come as soon as possible.

SOME THOUGHTS FROM TERMINALLY ILL ADULTS

The following is from the American Cancer Society Hospice

When someone we know is facing an illness, especially a serious illness, we often feel helpless. We stammer the weak phrase: "Just call me if you need something." Have you gotten a call lately? Here are practical tips to really help someone facing an illness—from people who have been there.

- Don't avoid me. Be the friend...the loved one you've always been.
- Touch me. A simple squeeze of the hand can tell me you still care.
- Call me to tell me you're bringing over my favorite dish and what time you are coming.
- Bring food in disposable containers so I won't worry about returns.
- Take care of my children for me. I need a little time to be alone with my loved one.
- My children also need a little vacation from my illness.
- Weep with me when I weep. Laugh when I laugh. Don't be afraid to share this with me.
- Take me out for a pleasure trip, but know my limitations.
- Call for my shopping list and make a "special" delivery to my home.
- Call me before you visit, but don't be afraid to visit. I need you, I'm lonely.
- Help me celebrate holidays (and life) by decorating my hospital room or home, or bringing me gifts of flowers or other natural wonders.
- Help my family. I am sick, but they may be suffering. Offer to come and stay with me to give my loved ones a break. Invite them out. Take them places.
- Be creative. Bring me a book of thoughts, taped music, and a poster for my wall, cookies to share with my family and friends...an old friend who hasn't come to visit me.
- Let's talk about it. Maybe I need to talk about my illness. Find out by asking me: "Do you feel like talking about it?"
- Don't always feel we have to talk. We can sit silently together.
- Can you take my children somewhere? I need transportation to the store...to treatment...to the doctor.
- Help me feel good about my looks. Tell me I look good, considering my illness.
- Please include me in decision making. I've been robbed of so many things. Please do not deny me a chance to make decisions in my family, in my life.
- Talk to me of the future. Tomorrow and next year. Hope is so important to me.
- What's in the news? Magazines, photos, newspapers, verbal reports, keep me from feeling the world is passing me by.
- Could you help me with some cleaning?
- Just send a card to say, "I care."

THE DYING PERSON'S BILL OF RIGHTS

I have the right to be treated as a living Human being until I die.

I have the right to maintain a sense of hopefulness however changing its focus may be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right to participate in decisions concerning my care.

I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.

I have the right not to die alone.

I have the right to be free from pain.

I have the right to have my questions answered honestly.

I have the right not to be deceived.

I have the right to have help from and for my family in accepting my death.

I have the right to retain my individuality and not be judged for my decisions which may be contrary to beliefs of others.

I have the right to discuss and enlarge my religious or spiritual experience, whatever these may mean to others.

I have the right to expect that the sanctity of the human body will be respected after death.

I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death

Marilee Ivars Donovan and Sandra Girton Pierce, Cancer Care Nursing

GOING HOME

The hospital couldn't save Jack's life. But Hospice gave him something to live for.

Jack Smith looked up from the evening news to see two old buddies bounding down the steps to the basement den of his northeast Philadelphia home. At once his tired face broke into a wicked smile. "There's beer behind the bar," he called out, pointing to the refrigerator full of Meister Braus. Then he turned to his daughter, Danielle Carpenter "Get me a drink," he said good naturedly. "A whiskey and water. No ice."

Brews in hand, the two men plopped on the sofa, all shouts and laughter. This was where Jack held court. A cavernous clubhouse for overgrown boys, its low ceiling plastered with triangular pennants. Notre Dame. Chestnut Hill College. San Jose Sharks. Philadelphia Eagles. A glass case displayed an "Archie Bunker for President" mug; laminated certificates honored the Cardinal Dougherty High School soccer team, which Jack had coached during its championship streak in the 70's. Jack's friends were guys whose histories, like his own, were intertwined with Philadelphia's Catholic schools. Florian Kempf had been one of his star players. Father Ron Ferrier, a science teacher at Dougherty, had presided over the weddings of both of Jack's daughters.

More recently, Father Ferrier had administered last rites to Jack, but instead of succumbing to esophageal cancer, Jack had come home from the hospital, climbed into his blue terry cloth robe, cranked up the space heater, and thrown open the basement to visitors.

As the men settled into drinking, Jack launched into a well-worn story about the time a much-younger Danielle came home with a friend, plastered for the first time. "Those two idiots drank a fifth of whiskey, then proceeded to throw up all over me," he exclaimed as his friends howled with laughter. Jack recounted how he ordered Danielle to change her clothes – and goddamn it, she comes back in her goddamn St Hubert's school uniform?" Jack loved to swear, even in front of priests.

Everyone in the room knew Jack was dying. But the retired coach and maintenance supervisor had decided he wouldn't spend his final weeks in the hospital, chasing an unlikely cure. Instead, he would make his remaining time as joyful as possible. He'd settle into his basement. He'd surround himself with family and friends. Back when Jack and his wife, Peggy, were engaged, they would listen to the Beatles sing, "Will you still need me, will you still feed me, when I'm 64?" Jack's 64th birthday was coming up, and he intended to be needed and fed – at home.

What made this scenario possible was the Hospice program at Philadelphia's Fox Chase Center; whose care team focused on maximizing Jack's comfort. The nurses, along with an aide, and a social worker, visited regularly, making sure that all problems—pain, nausea, sleeplessness, even despair and family grief—were addressed. So were the tasks of daily living, like helping Jack bathe. That freed Jack to do what he really wanted. To sit in his den with his loved ones, drinking whiskey and talking about old misadventures.

"I tell our families that the goal of Hospice is to help a patient live—underline as best as they can -- with their illness," says Debbie Seremelis-Scanlon, Hospice liaison for the Fox Chase program and a registered nurse. "If you're having a good day, great; if you're having a bad day, call us and tell us what's making it bad."

That's the revolutionary concept in this country, where death too often comes in a hospital room filled with machines and tubes—desperate and often futile attempts to eke out a few more weeks of survival. Knowing no alternative to this decades-old model, many patients believe Hospice is a euphemism for giving up treatment—and hope. “The first question I always ask is, “What’s your understanding of what’s happening now?” says Fox Chase Hospice social worker Rhoda Goldstein. “A lot of times they say, “They sent me home to die.” Well, maybe they sent you home to live.

A hundred years ago, people typically died at home, often abruptly and quite young, of epidemics, infectious diseases, and injuries. That started to change with the 20th century’s staggering advances in medical science. As one break-through followed another, doctors grew excited by the prospect of keeping sick patients alive for longer with the right combination of medication and surgery. Lives indeed became lengthier—but in the process death in America was transformed into an institutional and technological affair. “People were dying in the hospital’ they were dying in circumstances where the process was hidden and painful, and suffering was justified by the fight to cure whatever was causing the death,” says Linda Emanuel, M.D., Ph.D., director of the Buehler Center on Aging at Northwest University. “Denial was so great that patients and families ended up suffering a great deal physically, socially, psychologically and spiritually.”

It was the U.S. Civil Rights Movement that set the stage for a reexamination of how to die. As Americans learned to question authority, they began to doubt the doctor-driven high tech model. Some looked to London, where in 1967 Dame Cicely Saunders had set up St. Christopher’s Hospice, a residence for the terminally ill that focused on relieving pain and other symptoms rather than trying to prolong life. Visitors to St. Christopher’s were surprised by what they found. “Instead of a terminal-care or ‘death house’ environment with narcotized, bedridden, depressed patients, I found an active community of patients, staff, families and children of staff and patients,” reported one doctor in a 1975 issue of the Journal of American Medical Association.

The first U.S. Hospice opened in Connecticut about that time, but it wasn’t until recently that the American movement really took off. In 1992, U.S. Hospice programs served 246,000 people. Ten years later, the figure had reached 885,000. Today, even though most Hospice patients remain in their own homes, the original principle is the same: A Hospice team focuses on “palliative care,” working to make the patient’s days as symptom-free as possible. Everything is provided for. Nurses dispense medication for pain control. Social workers help patients and their families prepare for the end of life. Clergy members provide spiritual counseling. Volunteers fill a variety of niches, from quietly sitting with patients to helping clean and maintain their property. Some Hospices offer massage or music therapy; nearly all provide bereavement services for relatives. There’s even the possibility of expensive medical procedures—blood transfusions, chemotherapy, radiation—as long as the purpose is to control pain, fatigue, or shortness of breath. In Jack’s case, care was covered by private insurance—most policies have a benefit—through the majority of patients are covered by Medicare, and they never see a bill. Benefits are portable: They apply to wherever the patient calls home, including a relative’s or friend’s house or an inpatient facility.

The goal is to allow patients to live fully, even during their final weeks. “If what matters to you is to go fishing, for heaven’s sake, go fishing, and figure out how to take the oxygen tank to the end of the stream,” says Joanne Lynn, M.D., director of the Washington Home Center for Palliative Care Studies in Washington, D.C. Many

Hospice patients use the time to review their lives, mend broken relationships, and find spiritual peace. “It’s trying to undo what Descartes did by separating the mind and body,” says Michael H. Levy, M.D., Ph.D., medical director of the Fox Chase Hospice. “It’s not just DNA that’s sick, it’s the human being.”

When Fox Chase’s Debbie Seremelis-Scanlon met the Smiths for the first time in November 2001, she found a family whose high emotional tide had cranked up to a frantic rev. At 63, Jack had already completed treatment for lung and bladder cancer with few complications. The first time, after his surgery, he threw a “goodbye, lung” party and kept right on smoking. But this new illness, a rare soft-tissue sarcoma first discovered in his esophagus, had taken a deeper hold on his body. His life had become a revolving door of chemo treatments and hospital discharges, and he dreaded each new round. He looked like a skeleton. He had pneumonia. He had trouble swallowing, and his feeding tube leaked. When he grew delirious and the hospital staff tied him to his bed, his family had had enough. “I felt so angry over what they did—the hole in his stomach, this bag of bones that looked nothing like my father,” says Melissa Kuchler, the younger of Jack’s two daughters.

He wasn’t getting any better, nor would he. Still, when Seremelis-Scanlon suggested Hospice, the family was torn. Melissa and her brother, Matt, wanted to stop the treatment and bring him home. “I wanted not one needle put in that man. Not one more,” says Melissa. “Not one more ounce of pain.” But Danielle, a medical assistant in the oncology department of another hospital, wasn’t ready. “I just didn’t want him to die,” she says. “I said, ‘There’s got to be something else you can do.’ I thought if we went on Hospice, there was no turning back. I felt like we were saying it’s okay to die. It’s not okay to die.”

For her part, Peggy Smith didn’t really understand what the nurse was suggesting to her husband. “To me, Hospice was when you admitted you were dying and that was a final decision you made,” she says. “I thought they would check up on him occasionally and take his blood pressure.” Delicately choosing her words—she saw the family’s frustration—Seremelis-Scanlon explained to Peggy that the program was far more comprehensive and that Jack could change his mind any time. At this, Peggy did a double take. “Did you say that if he feels better, he can resume treatment?” she asked, surprised. “Absolutely,” the nurse said.

Jack himself made the final decision. “I’ve had enough,” he declared. Immediately, Hospice went into motion. A hospital bed and a small oxygen machine arrived at the Smith’s home the day of his enrollment. A team of experts began meeting weekly to discuss Jack’s care. They brought him morphine for the pain, thickened liquids to help him swallow. A social worker talked with the family about how to explain death to the grandchildren. Every weekday, an aide came to bathe Jack, wrapping him in extra towels afterward to keep him warm. The aide massaged Jack’s back, changed his bed sheets and chatted with him. “It was like she was caring for someone in her own family,” Melissa says.

As Jack rested at home, his pneumonia cleared up and he began to return to his old self. “Within a week, he got a lot stronger,” Seremelis-Scanlon says. “We were really surprised.” For a while, he was able to climb stairs. The family celebrated Thanksgiving together, then Jack’s birthday. They played Trivial Pursuit. They gathered in the basement to watch a Neil Diamond concert on T.V. Friends visited Jack in the basement hideaway, where they’d smoke cigarettes and reminisce—“like a living

wake,” his wife says. And Jack, a man not usually given to introspection, began settling up his emotional debts.

“My father totally opened up and changed,” Danielle says. “He would say things just to get them off his chest—family secrets—because he didn’t want to die with anything left unsaid.” For the first time, Jack regretted aloud that he and his brother didn’t have a closer relationship. He wished too, that he could have been a better father. And he reflected on what a homebody he had been, even when Peggy was itching to go out. “I wish I could have done more things with your mother instead of giving her a hard time,” he confided to Danielle. Still, whenever he saw one of the women in his family break down, his toughness came back to the fore. “Knock that off,” he’d say. “What the hell are you crying for?” “That last month of his life,” says Peggy “was incredible.”

Jack Smith was lucky, both to get into a Hospice program and to reap its benefits for a full month. For all of the Hospice movement’s growth, it still reaches only one in four dying Americans, and in many places considerably fewer. A terminally ill patient in Portland, Maine, for example, is less than one-tenth as likely to use Hospice as someone in Fort Lauderdale, Florida. There are many reasons for these variations. Florida has a state licensing process that encourages large Hospice organizations with the resources to advertise, do community outreach, and build relationships with doctors and hospitals. Maine has no similar process.

Ironically, when it comes to access, big cities aren’t always the best. New York, for example, has some of the lowest Hospice rates in the country. “It has something to do with a very academic and highly advanced health-care system,” says Carolyn Cassin, director of Jacob Perlow Hospice at New York’s Beth Israel Medical Center. “There’s more health care here than anyone can consume. That’s good for you and me when we are diagnosed with an illness that can be cured. It hasn’t, however, been a good system in which to be in the last phase of your life, when there isn’t a cure anymore.” Big-city doctors are so enamored of the medical razzle-dazzle available to them that they often don’t refer their patients to Hospice. “In 2002, 12.8 percent of patients who died of terminal illnesses in New York were assessed suitable for Hospice,” Cassin says. “Shameful! It should be up in the 60 percent range.”

Even for those who make it in to Hospice, there’s a trend toward shorter enrollments. In 1992, 21 percent of all Hospice patients died within one week of admission; a decade later, the figure has climbed to 35 percent. “One of the saddest things is when we have a patient who could have benefited from the Hospice program for several months—but by the time the doctor makes the referral, they only live three or four days,” says psychologist Dana Cable, Ph.D., board president of Maryland’s Hospice of Frederick County. “That’s not enough time to get them into pain control and work with the family to help them cope with death.”

Why are so many people steering clear of Hospice or waiting until their final days? Like Peggy Smith, many relatives equate Hospice with “giving up.” Or like Danielle Carpenter, they don’t want to forfeit the one last improbable shot at beating the disease. But patient and family attitudes are only part of the problem: there’s a whole set of barriers, from physician training to federal-funding formulas, which combine to depress the level of Hospice use in the United States.

Leading the list of obstacles are doctors themselves. They control a medical system that is focused on curing disease, not comforting the ailing. “Our entire system is designed to fix and to cure, and patients who aren’t cured are a failure,” says Bruce

Chamberlain, M.D., chief medical officer of Scottsdale-based Hospice chain Vista Care. The system is self-perpetuating: Today's physicians control medical school curricula, so tomorrow's doctors receive little or no training in end-of-life care. Without that training, even well-intentioned doctors find themselves tongue-tied when it becomes obvious that curative therapy will no longer work. "Only when the patient is days before dying does anyone think, oh, maybe we should call Hospice," says Betty Ferrell, Ph.D., a research scientist at the City of Hope National Medical Center in Los Angeles. "Physicians need to learn how to say, 'You know your mother has had a rough last few months. I, like you, am hopeful. However, I'd like us to consider what her care might be if she continues on this course.'"

While many medical schools have started teaching palliative care, many experts agree that they still have a long way to go. Even after a doctor graduates from medical school, the opportunities to learn about end-of-life care remain sparse. "When we have an oncology fellow come through our program and they have to do a bone-marrow biopsy, we train them how to do it," says Fox Chase's Levy. "Most doctors aren't trained how to sit down with a patient and talk about the difficult realities of what science has to offer, and give them choices about palliative care."

Physicians, of course, are human. Telling patients that they're dying is a gut-wrenching process, and many doctors will postpone the conversation as long as possible. So even those doctors who are well-trained find themselves faltering when it comes to the real world. "Some patients become these sequoias, the pillars of our clinical practice," says Christopher Dougherty, M.D., a clinical oncologist and medical ethicist at the University of Chicago. "You become more hesitant with those patients to disclose bad news. It happened to me yesterday: One of my patients with advanced leukemia was visiting the hospital, and I knew that I needed to see her. There was a perfect opportunity to say, 'There is no more therapy I can give you. But I didn't have the guts and fortitude. Who wants to give bad news?'"

Even if these human impediments were suddenly overcome, the federal government has created a system with yet more obstacles. The first is cost. The Medicare Hospice benefit, which covers the vast majority of patients, was passed during the Regan administration, which emphasized cuts in domestic programs. Regan budget director, David Stockman, agreed to support the Hospice benefit—on the condition that strict limits were placed on reimbursement.

Today, Medicare typically reimburses programs a flat daily rate of about \$125 per patient for routine home care rather than covering all costs. That's fine for those who need only periodic nurse visits and inexpensive medicine. But what about someone who requires a blood transfusion to combat fatigue? Or needs intravenous morphine for pain relief? What about a patient who lives alone and needs intensive nursing? Those services can cost considerably more than \$125 a day. Some large programs can absorb the added cost, but others need to turn away pricier applicants. The \$125 limit particularly frustrates rural Hospices, which have staggering transportation costs, and small Hospices, which don't benefit from economies of scale. "If you don't have enough patients, you don't receive enough federal money to run the office and hire the staff," says Levy.

Even more of an obstacle is Medicare's requirement that Hospice patients have six months or less to live. If the doctor is wrong and a patient outlives the diagnosis, doctors worry they'll be busted for Medicare fraud. In the mid-1990's, the feds began studying medical records in Puerto Rico, where patients were tending to live beyond the

six-month limit. The investigation spread to the U.S. mainland, and even though it didn't result in widespread prosecutions, it left a chilling effect on other physicians. As a result, to play it safe, doctors often wait until a patient is right at death's edge before making a Hospice referral.

The federal government has drawn a line in the sand," says Cassin of Beth Israel. "I can't take the patient who's dying of Alzheimer's, who is lying in a nursing home, and the family is desperate for Hospice. I can't sign her up till she's almost comatose—because until then, I can't say she'll die within six months."

Perhaps the most difficult aspect of Medicare funding is that, by law, patients must give up all curative treatments in order to claim the Hospice benefit. "The government will pay for you to live as long as you can, or die as comfortably as you can, but not both," says David Barnard, Ph.D., an ethicist and palliative-care specialist at the University Of Pittsburgh School Of Medicine. "That's a ridiculous bureaucratic distinction that makes no sense in the real world. Everybody who has a life-threatening illness wants both to live as long as they can and to die as comfortable as they can."

This is a terrible choice for anyone to make. Advocates say that removing such a choice---by lifting Medicare's either/or restriction---would dramatically increase Hospice access. Patients wouldn't feel forced to choose between accepting death and pursuing life. Doctors, too, would be more willing to refer patients to Hospice, because they wouldn't have to give up conventional therapies at the same time. While the jury's still out on cost, such a system might actually save money, because patients would feel better equipped earlier on to phase out expensive and futile medical treatments. More people would have access to the attentive care that Jack Smith had as he approached the last few days of his life.

The phone rang at 2:30 on the morning of December 13, 2001, in Debbie Seremelis-Scanlon's home in northwest Philadelphia. It was Melissa Kuchler, reporting to the Hospice nurse that her father had taken a turn for the worse.

For several days, Jack had known his life was coming to an end. So had his family, who had moved him upstairs and were scrambling to get the Christmas decorations hung while he could still appreciate them. The holiday lights were Jack's bailiwick: each year he would spend the Feast of the Immaculate Conception, a day off at Philadelphia's archdiocesan schools, turning the house into a spectacle that would lure people from around the neighborhood. Drivers would slow down on the Smith's block to catch a glimpse of the joyful excess.

This year, weakened, Jack couldn't do the honors, so his family took over. For the mantel, Peggy chose simplicity: a Hummel nativity scene offset by winter greens, with basic white lights. "That is so beautiful," Jack said when she finished. "I think that is the nicest I've ever seen the mantel." Danielle, the elder daughter, came over to decorate the tree with her niece. The Eagles were playing that day, but Jack forwent the televised football game, sitting back instead and watching his daughter and granddaughter animate the living room with holiday color. Only problem: when Danielle pulled out the five-pointed white star that topped the tree, one of the tips broke off. "I'll pick up another one," she promised her father.

The next day, though, the star-shopping plans got put aside when Jack suffered a setback. Walking to the commode, he was wobblier than usual. His wife offered to help, but Jack refused. Suddenly, he collapsed. Peggy caught him as he fell, and

reached for the phone to call Melissa and the Hospice for help in hoisting him back into bed. “That was the last lucid time,” she recalls. “That’s when I knew it was over.”

For the next two days, relatives came to visit the Smith home. Some gathered around the table while Peggy kept the coffee brewing. Others sat next to Jack’s bed as he slipped in and out of consciousness. Father Ferrier came by to administer last rites—again—but the solemnity was broken when Jack rallied and told the priest a racy joke. Grandchildren ran around everywhere. When the house finally emptied out on Tuesday night, Peggy immediately sunk into the livingroom couch too tired to worry about anything but slumber. Danielle slept fitfully in a dining room chair until her sister ordered her upstairs to their parent’s empty bedroom. Melissa snoozed in the recliner. Matt commandeered his father’s basement sofa. “We just wanted to be close to him,” Danielle recalls.

Then at 2:30, Jack’s breathing grew so rattly that the sound carried all the way upstairs and jolted awake his elder daughter. Danielle hurried downstairs and roused her mom. “We need to get up,” she said urgently. “This is the end.” Peggy pulled herself from her delirious sleep to find her three children agitated and uncertain about what to do. “We were petrified,” Danielle recalls. “How long was it supposed to take? Do we have an hour? It is minutes? I remember just shaking. I didn’t even want to go to the bathroom.”

Seremelis-Scanlon lived only a mile away, and she arrived at the house within minutes. She recognized the rattling sound as an inability to swallow properly. Had Jack been in the hospital he might have had his secretions aspirated mechanically, an invasive and noisy process. But with Hospice, Jack’s comfort was paramount. Seremelis-Scanlon gave him some medication to reduce his secretions, pain, and agitation. Gradually, he relaxed.

“Come on now, let’s let him rest, Seremelis-Scanlon told Jack’s children, who were crowded around their father. “Sometimes it’s harder for them to let go with their family in the room.” So the kids moved into the living room, where their mother was already sitting on the edge of the couch smoking. Peggy rose to fix coffee, and as she walked toward the kitchen she passed her husband. She stopped to look at him. Then, without planning to, she sat down at the edge of his bed.

“Jack, it’s okay,” she said, stroking his head. “If you want to go, it’s time. I’ll be okay. I’ll take care of the kids. Everybody’s all right. I love you. I know you’re afraid. Let the Blessed Mother take you. Go be with your mom, you dad, your brother, and be at peace.” Softly, she began to sing a favorite song from their long-ago days as young sweethearts:

When I get older, losing my hair, many years from now?

Will you still be sending me a valentine, birthday greetings, bottle of wine?

If I’d been out till quarter to three, would you lock the door?

Will you still need me; will you still feed me, when I’m 64?

Jack’s breathing grew calmer. Peggy sang some more. And then, as peacefully as anyone could muster, he just slipped into death. “There was no sound when he passed away,” says Seremelis-Scanlon. “It was just a breath. And a breath. And no breath.”

Jack had just 12 days earlier, celebrated his 64th birthday.

A few hours before dawn, as the hearse pulled away, Danielle walked outside and gazed up into the night sky. "Come here" she called to her family. "Look at that!" There, directly above the Smith's house, flickered the brightest of Christmas stars.

"Those were the best times I ever had with my father," says Melissa, sitting at her mother's kitchen table a year and a half later. "His mind was able to clear from all the medications. It put pride back in him. He could hold regular conversations. It restored his dignity."

Today, Melissa thinks of her father's last weeks not with unmitigated grief but instead with a stew of emotions that includes no small amount of joy. "Without that time in Hospice, I don't think he would have been able to let go," she says. She contemplates the misconceptions her family held in November 2001 and how grateful she is that they didn't deny themselves the opportunity for a meaningful final month together. "I thought we were going to sit in this house and have a death watch," she says. "It was so much more than that."

In Tragedy, When Is Humor Inappropriate?

June 14, 2006 from All Things Considered – National Public Radio

MICHELE NORRIS, host: An incident in an emergency room leads to some uncomfortable questions in this commentary from medical ethicist Katie Watson.

KATIE WATSON reporting:

My friend David told me this story.

When he was a resident in the emergency room, he and two other tired residents were wondering why the pizza they'd ordered hadn't come yet. A nurse shouted, GSW trauma one, no pulse, no blood pressure. The residents recognized the unconscious teenager. He was the delivery boy from their favorite all night restaurant. He'd been mugged bringing their dinner.

That made them work even harder. A surgeon cracked the kid's rib cage to expose his bullet torn heart, but they couldn't even stabilize him for the O.R. After 40 minutes of resuscitation they called it. Time of death, four a.m.

The young doctor shuffled into the temporarily empty waiting area. They sat in silence. Then David said what all three were thinking. Where's the food? Joe found their pizza where the delivery boy dropped it a few steps, away from the E.R.'s sliding doors. He sat it on the table. The overnight shift was brutal. The doctors were hungry, the delivery boy already dead. They stared at the food.

Then one of the resident's spoke. How much do you think we ought to tip him? They laughed, and then they ate. David finished his residency fifteen years ago, but he told me his story as if it happened last night. You're the ethicist, he said. Was it wrong to make a joke?

Gallows humor makes fun of serious or terrifying situations. And like every profession that confronts suffering or death, medicine has a strong tradition of humor around tragedy. As a non-physician, I found the whole story depressing. How can doctors make fun of the patients they're here to help?

Freud thought the jokes we make say as much about us as our dreams. In his book *Jokes and Their Relation to the Unconscious*, he argued that the more shame, repression and fear we feel about something, the harder we'll laugh at a joke about it. Freud's book reads like a Viennese manual for stand up comics, explaining that a good joke about death, not to mention sex, excrement, race or religion, produces pleasure by dodging our prissy, civilized super egos and releasing psychic tension through laughter.

But Freud also knew that jokes help us cope with external forces, like your boss or the king. When it's too dangerous to confront your oppressor directly, laughter is a more helpful response than anger. And what's more oppressive than death? David and his friends fought death with all they had and death won. The joke is the rock you throw after the bad guy is already gone. An omission of loss and a promise to fight again another day. To me the butt of the doctor's tip joke isn't the patient, its death.

Anyone who jokes to distance themselves from suffering risks becoming callous. But when a compassionate professional gets overwhelmed, gallows humor may be a psychic survival instinct. David and his friends talked about that night several times. The whole thing made them sad. How could we eat the food that poor kid dropped, they'd ask each other? In the process of trying to do good, did they become bad?

Depends who you asked. If I was the delivery boy's mother, I'd want to tear their eyes out. But if I was the person in the next ambulance hurling towards their emergency room after my heart attack, my car wreck, my rape, I'd be glad they made that joke, because they needed to laugh before they could eat. And they needed to eat to be at their best when it was my turn.

When a terrible joke is the only bridge between horror and necessity, gallows humor is a show of respect for the work that lies ahead. I'm glad David did what he needed to do to treat every patient he would see that night and I'm glad it still bothers him.

NORRIS: Katie Watson teaches medical ethics at Northwestern University's Feinberg School of Medicine.

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GRIEF, MOURNING AND BEREAVEMENT

AN INTRODUCTION TO GRIEF

Grief is the natural consequences of a loss. It is inherently and universally human, and is the normal healthy response to the death of someone important to you. Grief is an expression of the bond you have to the person who died. The bond is meaningful, and the severance of the bond is painful and disruptive. Grief is an inevitable part of living. Understanding, in and of itself, can be helpful to you. Though we all share common grief reactions each person's experience of loss and grief is unique. Personal growth can be one beneficial outcome of experiencing grief. Grief can be defined as the thoughts and feelings that are experienced within oneself upon the death of someone loved. In other words, grief is the internal meaning given to the experience of bereavement.

Differences between Grief, Mourning and Bereavement

"Bereave" is the experience of being deprived of a relative, friend, or other especially by death. Bereavement is the name given to this period of deprivation, the time after we lose someone important to us. It signifies that a momentous change has taken place and that our personal, financial and social status is different as a result of the loss. Life is irrevocably different.

"Grief" is the distinct personal experience we have after a loss takes place. Grief after a death is often intensely painful and disruptive, and encompasses our whole being. The pain and disruption is inclusive of emotions, physical sensations, mental ability, social interactions, observable behaviors, spiritual thoughts and questions, and extrasensory feelings and perceptions. The pain and disruption may be so intense that we become distressed with what we are experiencing and even question our sanity. Bereaved individuals will often make references to "having a breakdown" or "not handling it" or "going crazy".

As we cycle, and recycle through the process of grief, some of the more common reactions are shock (the feeling of "being in a fog"), disbelief, confusion, sleep and appetite disruption, stress, fatigue, sorrow, loneliness, anger, guilt, insecurity, and even relief. We may become forgetful, have difficulty concentrating, and be uninterested in normal activities. Some people no longer see a purpose in living and wish they would die too. Less frequent, but still not uncommon, are suicidal feelings. It is also not unusual to expect to see or hear from the ones who have died, wonder about their whereabouts and well-being, and to have experiences of sensing their presence. You may hear, smell, or see them, or feel their presence around you.

"Mourning" is defined as the expression of sorrow for the dead. It is what we do to demonstrate externally what we are experiencing internally. Privately and publicly we give expression to our grief. In this way we provide an outlet for, and the means to share, the pain and disruption caused by a death. If, as stated in the initial premises, grief is the natural and expected response to a death, then it becomes important to foster its natural and healthy progression toward an outcome of acceptance of, and adjustment to, the reality of the death. Too often in American society, bereaved individuals feel as though they must "act as if nothing has happened: and "move on with my life", as if the deceased never existed. Mourning is the method by which we

alleviate the pain and disruption of grief, and solidify the memory and meaningfulness of the life of the deceased in relation to our own life.

Grief is Individual

While grief descriptions are general, grief experiences are individual and deeply personal. Despite the quality of shared experience, each of us must ultimately experience and accept our grief, with the associated pain, as our own. The combination of who you are; who died, and the nature of your relationship with the deceased is one of the most powerful determinants of your individualized grief response. Your personality, how you view and cope with the lack of control over painful events in your life, and many other personal traits shape your response to a death. Your relationship to the deceased, his or her importance to your identity, joy and security whether the relationship was satisfying and up to date or discordant with unresolved conflict and other relationship variables will also personalize your grief. Because no two people or relationships are identical, we can see why people even in the same family, grieve differently. The death of a parent is different to the child than the death of the same person is to the spouse. In essence, different things are lost, and the effects on each respective bereaved individual will be different. Here again if the relationship to the deceased is the same for more than one bereaved, for example two children, we still have the unique personalities of each child to consider, and we must take into account that the nature of each child's relationship with the parent and its own specific character.

Inseparable from the death, timing and circumstance make up another substantial determinant of grief. A death by prolonged illness is different from a sudden, health-related death, as are those from accidents, catastrophes, suicides, and homicides. Your particular involvement with the dying process and death, and the timing in relation to your life make a difference. Witnessing a death, whether peaceful or tragic, anticipated or not, will have its impact on you.

Cultural, religious and personal beliefs also individualize grief. How you view the world, life and death, and how the experience of a death either affirms or contradicts this view will influence the course of your grief. Beliefs you adhere to may provide comfort and meaningfulness to your experience as well as the mourning rituals that foster grieving. On the other hand, sometimes a death has the effect of challenging our worldview and we meet with unexpected insecurity, fear, and anger as a result. This too, is part of grieving. A period of reflection, searching, or counseling may be required to find equilibrium with the experience of serious loss and what it means to you about the world we live in.

How much and what kind of support you have is crucial. Only you can experience your grief, but the support of others who are patient and understanding can make getting through the experience more tolerable. Support comes in many forms. Someone who brings a pre-cooked meal or provides childcare, or makes an invitation to take a walk may be as supportive to some people as a good listener is and organized support groups are to others. Support can come from family, friends, associates, clergy, counselors, and other people in bereavement.

Stages of Grief

The goal of a caring helper is to find a way to approach the bereaved and be friendly to them, without discomfort or fear. It is important to remember that grief begins from the moment a family member has been told that he or she won't recover. The impact of

loss can be dramatic; it can have a profound effect on our bodies and psyche. There are three general stages of grief and four tasks of mourning that most everyone moves through in their own way, according to their own grieving process.

1. Shock and Numbness (1st month)

This can include:

- Denial,
- Fear,
- Periods of panic,
- “I can’t believe it,”
- Death is not real; and
- Expectation that the deceased loved one will walk through the door

2. Suffering and Disorganization (1 month to 1 year)

This can include:

tremendous pain	restless over-activity
treasuring objects that belonged to the deceased	isolation
helplessness	guilt
lack of ability to concentrate	shock wave through entire family
loneliness	anger
symptoms of sleep disturbance	throwing oneself into work
yearning	social withdrawal
poor physical health	defenses are down
	40% mortality rate for survivor

3. Recovery and Readjustment

This can include:

- more good days than bad days;
- ability to talk of the deceased without pain;
- ability to look forward to the future;
- ability to reinvest in other relationships;
- profound change in the relatedness to the deceased; and
- ability to comfortably recall both the pleasures and disappointments of the relationship with the deceased.

The Tasks of Mourning

Below are the four basic tasks of the grief process that must be accomplished if a person is going to have a healthy recovery from the death of a loved one.

Task One: To Accept the Reality of the Loss

The first task of grief is to acknowledge the fact that the loved one is dead, believing the loss is a definite reality. Denial can be a positive coping

mechanism until the bereaved is able to incorporate the significance of the traumatic loss.

Task Two: To Experience the Pain of Grief

To fully accept the loss, the bereaved must first accept the painful feelings of sorrow that are associated with the loss. It is necessary for the bereaved to experience feelings of grief so as to be able to emotionally heal from the loss. Avoidance of feelings of grief only prolongs grief and makes recovery more difficult.

Task Three: To Adjust to Life without the Deceased

The bereaved will adapt to a new reality without their loved one. They develop new coping skills as well as abilities and strengths that will help them adjust to the demands of life after the loss.

Task Four: Withdraw Emotional Energy and Invest It in another Relationship

The task here is for the bereaved to find an appropriate inner emotional place for the deceased, while at the same time emotionally reinvesting in life again. They direct their energy in new interests, new places, and new relationships.

The goal is to essentially love again!

Mourning is Essential

Finding relief from the pain and disruption of grief is a primary wish of all bereaved. Just as grief is both universal and personal, many people need to feel that they are not alone with their pain, while also feeling that the loss of the person important to them is like no other loss.

Change is implicit in grief viewed as a process with cycles. Allowance is a necessary component if these cycles are to unfold naturally. Ideally you, and others around you, will make an allowance for the drastic change that has occurred and the grief that follows. Grieving requires a great deal of energy, so you may need to alter the expectations you have for yourself.

Remembering the deceased, experiencing your pain, and expressing your grief are essential to fostering the grief process. Most people want to remember the person who died and often fear that memories will fade. Usually it's comforting to share stories, look at photographs or take part in other activities that make us feel connected to the deceased. Remembering, however, makes us face the reality of the death, and can evoke the pain of grief. As natural as it is to grieve after a loss, it is also very human to try to avoid pain. Because we often experience painful grief when we face the fact of the death, a struggle can develop between the opposing wishes to remember and avoid pain. Ultimately, we cannot do both. Becoming tolerant of your grief, and finding meaningful ways to express it, eases this struggle. Designating specific times to remember, experience, and express are recommended. It is one way to make allowance for

the natural cycles of grief, and to provide an outlet for the abundance, of thought, feelings, and other grief reactions that build up inside of us.

Acknowledgement and validation do a great deal to diminish the suffering experience in grief. When you and others acknowledge the importance of the death, and grief is viewed as valid, the distress associated with grief tends to lessen. Historically, religious and cultural customs have provided the guidelines for acknowledging a death and validating the need to mourn. Direction is given and specific rituals are enacted to help the bereaved give expression to their grief. The community is also instructed on how to support the survivors. Many people in today's society lack this kind of structure or do not find comfort in traditional rituals, yet the need for acknowledgement and validations still exists. It is possible to acknowledge and validate your experience without traditional guidelines by engaging in meaningful moments of remembrance privately or with others. What is considered supportive may vary depending on the individual. Nonetheless, support can be vital to those cycling through the process of grief. People, who understand, allow and encourage remembering, tolerate your pain, or assist with concrete tasks to bolster your ability to weather grief. It is recommended that you establish a level of support that is adequate for your needs.

Making an allowance for our grief, remembering and reviewing our life with the one who died, and experiencing and expressing the pain of our loss inevitably brings us to a pivotal point in our process: the acceptance of the irrefutable reality of the death. Acceptance of the adjustment to this reality is ultimately necessary for a healthy progression of grief. Whatever our religious or spiritual beliefs about what happens after death; the deceased is absent from our everyday life. To restore ourselves to a life not dominated by the pain and disruption of grief, we must come to grips with living without the person who died. Generally, it is a natural part of the grief process for disbelief about the death to diminish each day you confront the reality of being without the deceased. As acceptance of the death grows, the full scope of the loss is realized and your sorrow may deepen. Yet acceptance of the death does help to ease the suffering associated with grief. You will find more energy to focus on the adjustments necessitated by the changes to your life. By making the adjustments you will eventually be able to remember the one who died while having a greater sense of peace about being without them.

Anticipatory Grief in Patient

- Tell my Story
- Relive memories:
- What are my happiest memories...?
- What are my worst memories...?
- What was the best thing about being a _____ parent, spouse, sibling, friend, child, etc?)
- What was the worst thing about being a _____ (parent, spouse, sibling, friend, child, etc?)

- Say: “I love you”
- “Thank you”
- “I forgive you for...”
- “Please forgive me for...”
- Ask:
- What is the legacy I hope to leave behind?
- How do I feel about dying? What does dying mean to me?
- How do I feel about my life?
- The most important people in my life have been...because...
- The ideas, books, music, and poems that have influenced my life were...
- The things I care most about are...
- What I value most in my life is...because...
- I would like to be remembered as...
- I would like people to remember these things about me...
- What do I need before I die?
- Who do I need to forgive before I die?
- Where do I need to go before I die?
- Who do I need to talk to or reconcile with before I die?
- What is the most important lesson I have learned in life?
- What have I accomplished that I am most proud of?
- Where am I on my spiritual journey?
- Where do I want to get to on my spiritual journey before I die?
- What do I most regret?
- What business have I left unfinished?
- Have I worked through all my grief issues from the past?
- If not, Why
- Which ones need to be worked through?
- What would it take for me to allow myself to work through them?
- Am I ready to die? If yes, why _____? If no, why not _____?
- Anticipatory Grief in Family Members
- I daydream about how life with my loved one was before the diagnosis was made.
- I feel close to my loved one who has a terminal illness.
- I seem to be more irritable since my loved one was diagnosed.
- I am preoccupied with thoughts about my loved one and his or her illness.
- I have discovered new personal resources since my loved one was diagnosed.
- I very much miss my loved one the way he or she used to be.
- I have felt very much alone since the diagnosis was made for my loved one.
- I am able to move ahead with my life.
- I blame myself for my loved one’s illness.

- I find it hard to concentrate on my work since the diagnosis was made for my loved one.
- I have the personal resources to help me cope with my loved one and his or her illness.
- I have periods of tearfulness as I think about the course of my loved one's illness.
- I feel detached from my loved one.
- I feel a need to talk to others regarding my loved one's illness.
- I feel it is unfair that my loved one has this illness.
- I find it hard to sleep since the diagnosis was made for my loved one.
- No one will ever take the place of my loved one in my life.
- I avoid some people since my loved one was diagnosed.
- I feel I have adjusted to my loved one's illness.
- Since my loved one was diagnosed I find it more difficult to get along with certain people
- I wonder what my life would be like if my loved one had not been diagnosed with his or her illness.
- I feel more competent since my loved one was diagnosed with his or her illness.
- I get angry when I think about my loved one and his or her illness.
- Since the diagnosis was made for my loved one, I don't feel interested in keeping up with day to day activities (T.V., newspapers, friends, etc.).
- I am unable to accept the fact that my loved one has a terminal illness.
- I am now functioning about as well as before my loved one was diagnosed.
- I am planning for the future.
- Abnormal or Difficult Grief
- It is not easy to define what abnormal or difficult grief is, partly because there is so much variation within the normal grief process. It is easy to spot extreme examples, but there is inevitably a large overlap between what is basically normal grief and what is abnormal or difficult, which can complicate the grieving process. There are two useful ways of conceptualizing difficulties in grieving: in terms of the grief process and in terms of the tasks of mourning.
- In terms of the grief process:
- Absent grief: there appear to be no signs of grief in a person following a major bereavement.
- Delayed grief: the person puts off working through the grief process but then finds him or herself overwhelmed with grief after a number of months.
- Inhibited grief: there are some signs that the person is grieving but they are less than you might expect, given the nature of the loss.
- Unbalanced grief: the person is clearly grieving but may be only expressing one particular emotion.

- Chronic grief: the person appears to have been stuck for a long time in one particular part of the grief process.
- In terms of the tasks of mourning:
- Task One not tackled: The person has not acknowledged the reality of the loss.
- Task Two not tackled: The person has not allowed him or herself to experience the pain of grief.
- Task Three not tackled: The bereaved person is unable to adjust to living without the person.
- Task Four not tackled: The person is unable to let go and does not, therefore, have the energy to go forward and rebuild a life for themselves.

Disenfranchised Grief

Disenfranchised grief can be defined as grief that people experience when they incur a loss that is not or cannot be openly acknowledged, public mourned, or socially supported. The concept of disenfranchised grief recognizes that societies have sets of norms – in effect, “grieving rule” – that attempt to specify who, when, how, how long, and for whom people should grieve. (Dr. Kenneth Doka)

Contexts of disenfranchised grief include:

Relationships that are not recognized – friends, lovers, etc.

The loss is not recognized – abortion, peri-natal loss, divorce, etc.

The griever is not recognized – very old, very young, male patterns of grief, mentally disabled, etc.

Disenfranchised deaths – murder, suicide, AIDS, etc.

Complicated Grief

When the tasks of mourning are not successfully negotiated, the bereaved can experience what is known as complicated grief. Symptoms or experiences of complicated grief can include:

- Not being able to speak of deceased without intense grief
- Not wanting to move material possessions belonging to the deceased
- Minor events triggering strong grief reactions
- Imitation of personality traits and behaviors of the deceased
- Experiencing physical symptoms similar to the deceased
- Radical changes in lifestyle; out of the stream of life.
- Loss of support system
- Phobias about illness or death related to the loss of the loved one
- Self-destructive feelings and actions
- It is important to remember that ordinarily, pathological grief is rare.

Supporting the Bereaved through the Stages and Tasks of Grief

The experience of dying and grieving isn't as predictable and orderly as we would like it to be. Generally, grief has a pattern, but each individual's experience with grieving is unique.

Some additional thoughts on grief and loss to remember for the intervention:

- The bereaved can move in and out of the stages and tasks of grief
- Pay attention to what the person is experiencing
- Listen to the people you are caring for
- Grief is not a state, it is a process, it is work, it is exhausting
- Grief has its own timetable
- Grief is different for each individual
- Every experience of loss is different
- People grieve not only for the past, but the loss of the future with their loved one
- Different members of the family grieve differently, and therefore act differently
- Communicate that grief attacks are common
- One day at a time is a 'doable' timeframe perspective
- Encourage them to try something new
- Encourage them to practice stress management
- Always encourage them to seek additional support

Common Grief Reactions

The table below lists symptoms commonly expected during bereavement. Each person will experience a unique blend of some or all of the symptoms listed and perhaps some that are not included.

<p>Physical</p> <p>Pain</p> <p>Fatigue, exhaustion and low energy</p> <p>Sleep disturbances</p> <p>Loss of appetite</p> <p>Shortness of breath</p> <p>Tightness in chest or throat</p> <p>Hollow feeling in stomach</p> <p>Heartache, broken heart</p> <p>Dry mouth</p> <p>Tension</p> <p>Restlessness, irritability</p> <p>Increased sensitivity to stimuli</p> <p>“Grief attacks”</p> <p>“Sympathy pains”</p>	<p>Emotional</p> <p>Shock, numbness, emptiness</p> <p>Sadness</p> <p>Sorrow for the one who died</p> <p>Loneliness, longing, yearning</p> <p>Anger, resentment</p> <p>Guilt, regret</p> <p>“More I should have done”</p> <p>Fear, anxiety, insecurity</p> <p>Feeling of helpless, out of control</p> <p>Diminished self-concern</p> <p>Depression</p> <p>Desire to join the deceased</p> <p>Suicidal feelings</p> <p>Feelings of betrayal</p> <p>“Emotional roller coaster”</p> <p>Relief</p>	<p>Mental</p> <p>Disbelief</p> <p>Confusion</p> <p>Disorientation</p> <p>Absentmindedness</p> <p>Forgetfulness</p> <p>Poor Concentration</p> <p>Distraction</p> <p>Difficulty focusing and attending</p> <p>Low motivation</p> <p>Expecting to see deceased</p> <p>Expecting deceased to call</p> <p>Preoccupation with the deceased</p> <p>Need to tell and retell story</p> <p>Dreams or images of deceased</p> <p>Denial</p> <p>Memories of other deaths</p>
<p>Social</p> <p>Being isolated</p> <p>Withdrawal from social activities</p> <p>Diminished desire for conversation</p> <p>Being “widowed”, “single”, etc.</p>	<p>Behaviors</p> <p>Crying (sometimes unexpectedly)</p> <p>Searching</p> <p>Carrying special objects</p> <p>Going to grave site</p> <p>Making and keeping an altar</p> <p>Keeping belongings intact</p> <p>Looking at photos or videos</p> <p>Talking to the deceased</p>	<p>Spiritual</p> <p>Questions about God:</p> <p>Why would God allow this?</p> <p>Questions about the deceased:</p> <p>Where are they now?</p> <p>Are they Ok?</p> <p>Can they see me?</p> <p>Will I see them again?</p> <p>What will happen when I die?</p>

	Avoiding situations that arouse grief Changes in daily routine “Staying bust’ Assuming mannerisms of the deceased	Sensing the deceased’s presence Death affirms or challenges beliefs Awe, wonder, mystery
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Taken from “Understanding Grief” by Howard Lunche, LICSW

“COMPANIONING” THE BEREAVED

A note from Dr Alan Wolfelt

I invite you to consider the philosophy that under-girds my work with bereaved people as well as my writings. I believe in “companioning” the bereaved instead of “treating” them.

I have taken liberties with the noun “companion” and made it into the verb “companioning” because it so well captures the type of counseling relationship I support. Actually, the word companion, when broken down into its original Latin roots, means com for “with” and pan “bread”. Someone you share a meal with: A friend, an equal.

Companioning is about honoring the spirit;

It is not about focusing on the intellect.

Companioning is about curiosity;

It is not about expertise.

Companioning is about learning from others;

It is not about teaching them.

Companioning is about walking alongside;

It is not about leading or being led.

Companioning is about being still;

It is not about frantic movement forward.

Companioning is about discovering the gifts of sacred silence;

It is not about filling every painful moment with talk.

Companioning is about listening with the heart;

It is not about analyzing with the head.

Companioning is about being present to another person’s pain;

It is not about taking away or relieving pain.

Companioning is about respecting disorder and confusion;

It is not about imposing order and logic.

Companioning is about going to the wilderness of the soul with another human being;

It is not about thinking you are responsible for finding the way out.

ADDENDUMS

PERSONAL DEATH AWARENESS

One of the most helpful ways to understand your personal death awareness is to take a moment and recall the number of times today you've thought about your own --- not someone else's death or limited span of life. Maybe you thought about your age and evaluated your own progress toward certain life goals. Or perhaps you briefly experienced a fear of dying. If such a thought didn't occur to you at all, then you're probably in the low range today. If these ideas crossed your mind one, two or three times, then you moved up through the moderate range. If you seriously pondered your own death or mortality four or more times, or find it a preoccupation, then you're likely in the high range.

Your PDA is a fluctuating phenomenon, moving up and down daily. Some days, you may act and think as though you're going to live forever. The purpose of this is to ask you to raise your personal death awareness so that you can begin to perceive an entire range of choices about your life and death that you might not have been aware of before.

To test the level of your PDA, try this simple exercise. In the space below, draw a line that you think best represents your total life span. The line can be any shape or length that you think is most appropriate.

Some people choose to draw a line from one end of the page to the other; in effect a line without boundaries which ends only because the edge of the page forces the pencil to stop.

Now draw another line of any length, this time a straight one with a beginning and an end. Consider this line to be your total life span. Place a slash mark at any point along the line where you think you are today in your life's chronology

Now, complete the following sentences by filling the blanks:

I expect to live until age:

I am presently age:

When you compare your present age with the age at which you expect to die, how much of your life do you find you've already lived? A third; a half; two thirds, or more? Now look back at the line with the slash mark. How does your estimate of the time you have left to live on the life span line compare with your numerical estimate?

How did it feel to commit yourself to a definite life span? Some people worry that they may jinx themselves by doing this. Old superstitions rise up and haunt them. Does this concern you? Did you feel any other discomfort? If not, what do you think made you relatively comfortable in doing this? Take a minute and write down your responses below.

I was uncomfortable in estimating my remaining life span because:

I was comfortable in estimating my remaining life span because:

The death I would most prefer for myself would be:

The death I would least prefer for myself would be:

The reasons for my choices are:

You probably found it easy to pick the types of death that you would not want for yourself. But did you have difficulty picking a death you want?

Breaking free from fear. The last appointment of life with death is one that almost everyone, no matter how religious, elderly, or bored with life, would like to postpone. The reason that we're reluctant to confront the end of our existence is not simply that we enjoy life so much. For many of us, it's the fear of death and the process of dying that makes us avoid the subject.

Some fears may center on the event of death itself, but many people seem more concerned about the events that lead inexorably to death. People fear the dying process as much as death itself. Perhaps this is true of you. Think about it for a minute. Which do you fear the most?

- I fear death more than dying.
- I fear dying more than death.
- I fear neither.
- I fear both of them.
- I dislike thinking about either.

If you are in touch with your fears associated with dying as a process, what are they? The thing which most frightens me about dying is:

- The pain;
- Progressive deterioration and disability;
- Losing control over personal decisions;
- Being left alone;
- Overwhelming emotional feelings;
- Not knowing what is happening;
- Being buried before I'm dead;
- Getting inadequate medical care; and
- Other.

How important would it be to you to retain control over your personal decisions if you found you were dying? If you're afraid you may lose control over your last days of life, think for a moment how you can plan now to maintain some independence even though you may be confined to a bed. If you let your loved ones know NOW that you want to retain certain powers of decision over your life, you may succeed in keeping some control. Try answering the following questions:

When I learn my death is approaching, I would like to have a say about

To ensure that I maintain control over this/these area(s) of my life, I could notify my family about my wishes and enlist their support on my behalf. Other ways I can lay the groundwork now for keeping some control over personal decisions are

At this point consider what level of physical disability you might be willing to live with for an extension of life.

- one arm
- both arms
- one leg
- both legs
- my arms and legs

- a vital organ such as my heart, which would have to be replaced with a transplant
- my eyes
- my genital organs
- my entire body (complete paralysis)

My greatest fear in dying is:

My second greatest fear is:

As we continue to look at fear, use the words agree, not sure, or disagree to fill in the following blanks.

- _____ I would avoid death at all costs.
- _____ The total isolation of death frightens me.
- _____ I am disturbed by the physical degeneration involved in a slow death.
- _____ I would not mind dying young.
- _____ Dying might be an interesting experience.
- _____ I view death as a release from earthly suffering.
- _____ The pain involved in dying frightens me.
- _____ I am disturbed by the shortness of life.
- _____ The feeling that I might be missing out on so much after I die bothers me.
- _____ The fact that I don't know what it feels like to be dead doesn't bother me.
- _____ If I had a fatal disease, I would like to be told.
- _____ The idea of never thinking or experiencing again after I die does not bother me.
- _____ I am not disturbed by death being the end of life as I know it.
- _____ The intellectual degeneration of old age disturbs me.
- _____ I am disturbed by the thought that my abilities will be limited while I lay dying.

Free to recycle yourself, what will happen to your body after you die? Even after learning about the obvious benefits of organ donation, many people are still resistant to the idea. If you are also, try getting in touch with the source of your reluctance by looking at the resistances listed below. Check off the ones which apply to you.

I'm afraid I might not be dead when they remove an organ.

I'm chicken about doing unusual things.

Organ donation is a fad.

It's a sick perverted idea.

They wouldn't use my parts anyway.

My kind doesn't do things like that.

If I do anything with my body, I'll freeze it for possible use later.

I'm embarrassed and uncomfortable about having my dead body cut up or examined by doctors or medical students.

I want to be buried intact.

Removal of any organs might spoil my appearance.

It's too much trouble to arrange for organ donation before I die.

I really don't care about medical research or helping people who need transplants.

God wouldn't approve.

I need all my parts for the afterlife.

GLOSSARY OF MEDICAL TERMS

Word	Definitions
Alopecia	Hair loss
Anemia	A lack of adequate red blood cells, causing fatigue.
Anorexia	(In Hospice patients) Severe loss of appetite
Antibiotic	A substance produced by living organisms, such as bacteria or mold, which can destroy other bacteria. Penicillin is the most familiar. Some antibiotics have been shown to have effective anti-cancer activity.
Bed sores (decubitus ulcer)	Breakdown of skin, usually over prominences of bone.
Benign tumor	An abnormal swelling or growth that is not cancerous; usually harmless.
Bereavement	The period of time during which a person or group of people experiences, responds emotionally to and adjusts to the loss by death of a significant other.
Biopsy	The removal and microscopic examination of tissue for the purpose of diagnosis.
Blood count	Microscopic examination of the blood to count the number of white cells, red cells and platelets.
Cancer	A large group of diseases characterized by uncontrolled growth and spread of abnormal cells.
Carcinoma	A form of cancer which arises in the tissues that cover or line such organs of the body as skin, intestines, uterus, lungs or breast.
Catheter	A tubular surgical instrument for withdrawing urine from the bladder through the urethra.
Chemotherapy	Treatment of disease using chemical substances or drugs.

Word	Definitions
Disoriented	Confused
Dysphagia	Difficulty swallowing
Dyspnea	Labored or difficult breathing.
Edema	Presence of abnormally large amounts of fluid in the intercellular tissue spaces of the body.
Emesis	Vomit
Feces, fecal	Stool or containing stool (excretion from the bowel).
Force fluids	Encouraging the patient to take as many fluids as possible.
Gastric	Pertaining to the stomach.
Grief	Response to loss that often occurs in stages of varying length. These stages can, but do not always, occur in a predictable order but vary with the individual.
Hodgkins Disease	A form of cancer that affects the lymphatic system, the network of glands or nodes and vessels which manufacture and circulate lymph through the body to fight infection.
Incontinent	Loss of bowel or bladder control.
Intravenous	Within or into a vein.
Lesion	Abnormal change in tissue due to disease or injury
Leukemia	Cancer of the blood-forming tissues (bone marrow, lymph nodes, spleen) characterized by overproduction of white blood cells.
Lymphoma	Malignant growth of lymph nodes.
Malignant tumor	A growth of cancerous cells.
Mastectomy	Surgical removal of a cancerous breast to prevent spread of the disease. Simple mastectomy refers to removal of the entire breast. Radical mastectomy involves removal of the

Word	Definitions
	entire breast, underlying muscle tissue and lymph nodes in the armpit.
Metastasis “mets”	Cancer cells which have spread from the primary site by way of the lymph and blood system.
Metastasize	To form new foci (areas) of disease in a distant part by metastasis.
Oncology	Tumors. Oncologists are doctors who specialize in cancer management.
-ostomy	A surgical procedure which creates an artificial opening or a stoma. Example: colostomy – a new opening between the colon and the wall of the abdomen.
Palliative treatment	Providing relief from symptoms of a disease but not directly curing the disease; alleviating pain.
Primary	A term used in oncology to refer to the site where the cancer started.
Prognosis	Prediction of the course of a disease and future prospects for the patient.
Prophylactic	A preventative treatment to ward off possible disease.
Prosthesis	An artificial replacement body part (i.e., breast or, leg, arm, eye, etc.)
Radiation therapy	Treatment of cancer with radiant energy to damage or kill cancer cells. May be given with the goal of prophylactic, palliative, or curative treatment (i.e., cobalt, cesium implants, etc.)
Red blood cells	Small, disc-shaped blood cells which transport oxygen to the tissues.
Remission	Complete or partial disappearance of the signs and symptoms of the disease; the period during which a disease is “under control.”
Sarcoma	A form of cancer that arises in the connective tissue and muscles, such

Word	Definitions
	as bone and cartilage.

Common Medical Abbreviations

PRN – as needed

Sans – without

SOB – short of breath

-- with

MEMORIAL HOME CARE SERVICES

302 South 10th Avenue

Yakima, WA 98902

MEDICARE HOSPICE

I hereby request and consent to hospice care from the hospice program as ordered by my physician and provided by the hospice and interdisciplinary team of Memorial Home Care Services.

- The primary goal of hospice care is to provide relief from symptoms, emotional and spiritual support to me and my family. Hospice care is not curative.
- Eligibility depends upon a physician's statement that I have a life threatening illness, with a limited life expectancy, should the disease run it's normal course.
- I must have someone willing to act as primary caregiver who coordinates care with the Hospice Team.
- I understand the focus of my care is in the home. If I feel my condition has changed to warrant possible hospitalization, I will contact my hospice nurse or nurse on-call for further evaluation. I will not change my place of Hospice care without first notifying the Hospice Program.
- The Medicare hospice benefit is broken into four benefit periods:
First benefit period = 90 days
Second benefit period = 90 days
Third benefit period = Unlimited 60 day periods
- By choosing the Medicare hospice benefit, I understand only Memorial Home Care Services' Hospice program can bill and receive payment from Medicare for approved services related to my terminal illness or any other condition related to that illness. The exception to this is that my primary physician continues to bill Medicare in the usual way if my physician is not an employee of hospice.
- Hospice services will continue with these exceptions:

My condition significantly stabilizes or my prognosis changes and I no longer meet the Hospice program's criteria. Evaluation is done by the primary physician and hospice team.

I fail to notify hospice of changing my place of care, i.e., going from home to hospital.

I choose to have aggressive or curative therapy.

I move out of Yakima County area.

I desire to return to standard Medicare benefits.

- I can choose not to continue hospice care at any time. To discontinue care, I must complete a Revocation Statement. I can obtain this statement upon request. If I revoke my benefit in the middle of a benefit period, I give up the remaining days in the benefit period.
- I can choose to receive care from another Medicare certified hospice program. I must inform the Hospice program of Memorial Home Care Services so arrangements for transfer can be made.
- I understand that contracts with other community resources have been made by the hospice program to comply with Medicare regulation and assure continuity of my care. I agree to use these resources as directed by the hospice staff.

A. Patients may receive the following based on approval of the hospice interdisciplinary team:

- Hospice home care emphasis with consultation from the hospice interdisciplinary team.
- Twenty-four hour availability of consultation.
- Home health nurses, aides, pastoral care, social services, counseling, volunteers, rehab services, and dietary.
- Drugs, biologicals provided for control of symptoms purchased at contracted business.
- Rental of durable medical equipment needed for patient management from contracted business includes hospital bed (semi-electric), wheelchair (manual only), commode, suction machine,

I.V. pumps and related equipment (other equipment based on individual consideration).

- Respite care: provided on an intermittent, planned basis.
- General in-patient care with contracted hospital for acute medical crisis (i.e. pain not able to be controlled at home, severe uncontrollable symptoms).
- In lieu of hospitalization for an acute medical crises, a brief period of continuous care may be considered. The patient must require skilled nursing care (medical crisis may be initiating M.S. drip, frequent medication change for symptom management and observation). Daily evaluation is done to determine appropriateness of level of care.
- Continuation of Hospice care if the patient is still eligible and meets the criteria even after benefit periods are completed.
- Bereavement counseling for families/caregivers.

B. Type of expenses not covered:

- Custodial care of patient. The family is responsible for the primary care of the patient. Hospice team members will assist in making available resources for the family to explore additional help as needed.
- Personal comfort items and services, i.e. T.V., telephone, equipment that is not medically necessary.
- Those services which are not reasonable and necessary for the diagnosis or treatment of illness or injury (i.e. x-rays such as cat scan - brain scans are carefully evaluated as to whether or not they will affect the outcome of the illness and whether Memorial Home Care Services is responsible for payment).
- Ambulance transportation to and from the hospital or physician unless a medical need is authorized by the Memorial Home Care Services' Interdisciplinary Team.

MEMORIAL HOSPITAL
YAKIMA VALLEY MEMORIAL HOSPITAL

YOUR NOTES

