CHAPTER 3

COMMUNICATION SKILLS

We should all know this: that listening, not talking,
is the gifted and great role, and the imaginative role.
And the true listener is much more beloved,
magnetic than the talker, and he is more effective
and learns more and does more good.
And so try listening.
Listen to your wife, your husband, your father, your mother,
your children, your friends; to those who love you and those who don't, to those who bore you, to your enemies.
It will work a small miracle. And perhaps a great one.

— Brenda Ueland
From a collection of her essays,
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> **Perhaps the most important thing we bring** to another person is the silence in us, not the sort of silence that is filled with unspoken criticism or hard withdrawal. The sort of silence that is a place of refuge, of rest, of acceptance of someone as they are. We are all hungry for this other silence. It is hard to find. In its presence we can remember something beyond the moment, a strength on which to build a life. Silence is a place of great power and healing.
>
> **— Rachel Naomi Remen**

I. OVERVIEW

As a Hospice SLO In-Home volunteer you may be asked to provide a variety of services: respite care for the primary caregiver, shopping, preparation of meals, running errands, light housekeeping, providing companionship, life review, and supportive listening. This last area, your ability to listen and communicate, may very well be the most important thing you can offer your client and family.

As a family member approaches death, there can be a litany of differing responses and emotions. The family may or may not be willing to talk about their experience; they may want to do a "life review" or reminisce or they may not. As a Hospice SLO volunteer, you will need basic skills in communication, and listening, so you may provide support for the patient and the family in their journey. When we listen, we need to hear with our heart, as the poet, author and teacher Stephen Levine writes:

> You are with one...in the same way you are with yourself. Open, honest, and caring. You are simply there, listening with a heart that is willing to hold the joy or pain of another with equal capacity or compassion. With a mind that does not separate death from life, that does not live in concepts and shadows, but in the direct experience of the unfolding. If it hurts, it hurts. If it makes you happy, it makes you happy. Not trying to change things. Not trying to make something or someone other than it is. Just hear the truth that the moment has to offer.

II. THE COMMUNICATION PROCESS

This chapter considers four principle concepts of communication which apply to the In-Home volunteer: The Art of Listening, Practical Suggestions on What to Say and What Not to Say, the Concept of "ENUF" and the Non-Verbal Cues of Communication.

A. The Art of Listening

Listening is an art, for it is a developed craft which, for most of us, does not come naturally. Usually, when we are communicating with someone, we are not completely focused on what *they are saying*, but on what ***we*** *are going to say*. Therefore, we need to look at our "craft" and evaluate our own capacity to listen to others. Although it sounds easy in practice, listening is often very challenging.

It is important to remember that the client and family's communication needs come first. You will be offering a stable, caring presence and an opportunity for the family to talk about their concerns. To listen means to make a conscious effort to hear. For most of us this will be similar to the development of any craft and will require practice. To improve your listening skills, where can you begin? Here are a few ideas and suggestions you can use:

1. **Exercise active listening skills.** Try asking more questions. If you need clarification ask the speaker to say more, give an example or to explain further. Give feedback or paraphrase what you've heard: "Are you saying such and such? What I heard you say is this. Is this what you meant?" Nod your head to show interest, or ask a question of interest to demonstrate that you are really listening to what is being said. Try making eye contact with the speaker. Sitting and listening quietly may not be enough for the speaker to feel that they are truly being understood.

2. **Become aware of your personal opinions and judgments**. Each of us is a product of our upbringing, culture, life experiences and anything and everything that makes us unique as human beings. Our uniqueness can sometimes be an obstacle to being an effective listener. As you listen, try to remain open to what you are hearing and withhold evaluation or judgment.

3. **Observe your own and other people's listening habits.** Ask yourself what it feels like when someone really listens to you and when they don't. Notice the listening habits you have that work well for you. Pay attention to the things you do that impair your ability to listen. Thorough self-exploration is a way to learn about any barriers you create to being a good listener. Once you identify and reduce what gets in the way of your ability to hear, you'll increase your effectiveness as a listener.

4. **Listen without formulating a response to the speaker.** As listeners we think about 500 words per minute while the normal speaking rate is about 125 to 150 words per minute. That creates a lot of room for communication to break down or for your mind to wander! Try to hear everything that is being said, listen to the entire message. You can even allow some silence as you think about how to respond. The temptation is to fill the extra space with our own thoughts or to

anticipate our responses to what is being said. But filling this space with your own thoughts or responses takes you out of the current conversation. And, you may miss valuable information. Really listen first, respond second.

5. **Listen with empathy.** Most people drawn to hospice work are empathetic. Empathy is a respectful understanding of what others are experiencing. True empathy is the ability to fully understand and accept another, complete with all their feelings, thoughts and opinions. It is often frustrating for someone needing empathy to have us assume they want reassurance or "fix-it" advice. Try to notice: What's not being said? What's in the way? What's missing? What's needed right now? What's most important to the speaker?

6. **Become aware of the speaker's non-verbal communication.** One estimate has it that 75% of all communication is non-verbal. Beyond the words is a host of clues as to what the speaker is communicating. Is their posture rigid or relaxed? Do they maintain eye contact? Does their vocal tone match the words they are using? Are their movements tense or relaxed? Is the verbal and non-verbal communication consistent? Listening includes observation. The more you practice, the better you will become at picking up on non-verbal cues.

7. **Create an environment for the listening to occur.** Remove distractions. For example, if the television or radio is on, you may ask to reduce the volume if you are not able to turn them off altogether. Also, if you are feeling stressed, you just won't be available to hear what the speaker is saying. Spend a moment or two before walking up to the door, relaxing or meditating on your role as a support person. Bring your full self to your client and do your best to be fully present.

We all need to feel that we are being heard and understood. It is a basic human need that is as primary a need as having enough water, food or air to survive. So, try out any of these suggestions and you will experience more of a connection to those around you. And, if all else fails just remember these words by Epictetus, an ancient Greek philosopher, and you are guaranteed to improve your listening skills: *"Nature gave us one tongue and two ears so we could hear twice as much as we speak."*

B. Practical Suggestions on What to Say and What Not to Say

Listening to your clients will be one of the greatest gifts you can give. But what if they have difficulty opening up to you? Certainly, if they do not want to talk, that's fine. Yet, there may be some very benign, non-invasive things you can say that will "break the ice," and begin to develop an opening to relate together.

As with the section on listening, it might be best to start with some of the *Roadblocks to Communication*. These communication "stoppers" might inhibit others from feeling safe about talking with you.

What Not to Say

1. **Directing, Ordering** - To tell someone to do something in such a manner that gives the other person little or no choice ("Oh, don’t say that!")

2. **Warning, Threatening** - To tell the other person that if the behavior continues certain consequences will occur ("Stop making fun of me or I'll leave.")
3. **Moralizing, Preaching** - To tell someone things they ought to do ("I have to tell you, I often believe that we bring illness upon ourselves. Try to be more positive!")
4. **Persuading, Arguing** - To try and influence another person with facts, information, and logic ("What I read was that terminally ill people who keep a 'positive attitude' last up to 6 months longer.")
5. **Advising, Recommending** – To provide answers for a problem ("If you worked on developing your faith, you would handle your mother's illness a little better.")
6. **Evaluating, Criticizing** - To make a negative interpretation of someone's behavior ("You really should not be so angry with your wife. She's doing her best.")
7. **Sympathizing, Identifying** - To try and talk the other person out of his or her feelings or to deny another person's feelings ("You poor dear." Or "I've been there. I know just how you feel.")
8. **Diagnosing** - To analyze the other person's behavior and communicate that you have their behaviors figured out ("I've been coming here for weeks and I think you're really angry because you're feeling a lack of control over your life now.)
9. **Diverting, Bypassing** - To change the subject or to not talk about the problem presented by the other person. If someone is trying to express a fear or concern or even the truth, "I'm going to die," ("No, you're not. You shouldn't think that way, keep a positive outlook!") We don't take away a person's need to express whatever they're struggling with.

Some people need for you to open the door for a frank conversation. Simply asking, "Do you want to talk about it?" invites that conversation. Other people would rather talk about something mundane – the weather, a ballgame, or television programs. For them, it's important to keep things as normal as they can.

While maintaining a sense of humor or helping your client by validating *their* estimation of their relationships or illness can be supportive, we encourage you to be cautious in diving right in. Listen and learn about your client's personality and needs, allowing you to skillfully offer words of encouragement at the appropriate times.

What to Say

The way we communicate can encourage our clients and families to open up with us. Discussing an interest held in common, asking them to describe their career, or hearing fond memories re-told builds a relationship of trust.

1. "**Can You Tell Me?**" **–** "Can you tell me how many children/grandchildren you have. For each one – "How old are they? Where do they live, what do they like to do?" "Tell me about your work, what did you like best about it?"
2. **The Honest (not overdone) Compliment –** "That robe is such a beautiful color **—** it really brings out the blue in your eyes." "Your home is very comfortable, I especially like……"

3. **Mutual Interests –** "Did you refinish that table yourself? I'm working on a chest of drawers." "The garden is coming in, I would love to bring the family some tomatoes."
4. **External Events –** "What did you think of that article in the paper this morning?"
5. **The "Here and Now" Environment –** check in – "How are you doing this morning (afternoon / today)?" "Can I get you some water?"

When you do speak, take your cue about what to say from your friend. If he wants to talk about dying, let him. And don't try to gloss over bad news.

Additionally, there are some helpful things to remember when initiating conversations with your In-Home clients, such as:

- "Big Talk" usually starts with "small talk."
- Try to avoid feeling frustrated with "the same old conversations" about the weather, sports, etc. as these often produce a level of trust.
- When moving to more "difficult" topics, the two rules are:

  -Ask permission to talk about the topic.
  -Give the person an "out" at your expense.
  ("Is it okay to talk about this, or is it too painful?" or
  "Can I ask a personal question, or am I being too nosey?")

C. The Concept of "ENUF"

Dr. Ken Moses is a psychologist who has done an extensive amount of work in the area of grief counseling. Dr. Moses has developed an acronym, ENUF, which he uses to remind us of how to be present when listening. The letters represent the words: Empathy, Non-Judgment, Unconditionality and Feeling Focus.

Empathy - Dr. Moses defines this as "the concerted effort to gain an accurate perception of another's experience, and then to share that perception in one's own words." Empathy, then, is not simply parroting someone's words back to them, or repeating "um-hum." It is an attempt to get a sense of what the person is going through, to "walk in their shoes."

Empathy should be distinguished from both sympathy and identification. Sympathy implies feeling sorry for, which often can be interpreted as pitying or condescending. Identification can also be inappropriate, because it often "takes away" from the client's experience, i.e., putting the focus on you, the volunteer. "I know what that's like because I once..."

Dale Larsen, in his book *The Helper's Journey* (1993), uses the metaphor of a pit to describe the differences between identification, sympathy and empathy.

> Imagine that the person you are helping is in a pit and you are on the edge of that pit. If you identify with that person's problems, what happens? You fall into the pit! Most important, people stuck in pits don't like to have their helpers in the pit with them; it can be terrifying for them, and it can deepen their feelings of hopelessness and helplessness. If you empathize, you *feel*

with the person in the pit...you must find a way to reach down in the pit and help the suffering person out — without falling in yourself.

Non-Judgment - Being non-judgmental is something the volunteer attempts to do to erase the element of positive and negative. It is not our job to determine if our clients are functioning "well" or "poorly." We attempt instead to keep ourselves clear of judgment in order to enhance our ability to gain an accurate perception of their experience.

Unconditionality - This term comes from what Carl Rogers termed "unconditional positive regard," which refers to caring for someone simply because they are a unique human being. We respect them just for "being," without putting our value judgments on what they think or feel. We especially don't judge them by what they can or cannot do at this stage of life.

Feeling-Focus - Sometimes we feel called to try to "fix" others, to "solve" their problems. However, this rarely proves satisfying for either the client or volunteer, as people typically end up doing what they want. What usually proves most helpful is to validate what people are feeling. For example, a caregiver might share with you, "It feels like I haven't had a day's rest in weeks..." You may at some point want to try and fix this by finding overnight respite care. However, it might also be important to just let the caregiver share what they are feeling, giving them the opportunity to express themselves, "It must get very overwhelming for you." If you do want to offer additional support, contact the Volunteer Director for current services available in the community.

D. Non-Verbal Communication

It is said that non-verbal communication accounts for about two-thirds of the communication between two people or between a speaker and his audience. There are a number of elements that constitute non-verbal communication such as dress, eye contact, and body position. In each communication there is both content and a *process* message. The content message refers to the meaning of the words being communicated, while the process refers to the non-verbal elements of the interaction. Although it is important to focus on the content of *what* is being said, it is also important to have an understanding of the process of *how* it is being said.

Non-verbal issues to be aware of with your In-Home client may include the use of touch, eye contact, height (relative to the client's position), voice and body position.

Touch is a powerful communication tool, and should be used with sensitivity. Often people with incurable diseases are not touched as often as they once were, and your willingness to provide some physical touch can be both soothing and reassuring to your client. However, some people have difficulty being touched. Therefore, don't assume everyone will respond positively to touch. If you are unsure, ask them.

In an interview with Bill Moyers in 1993, Rachel Remen, a doctor who has been working for more than twenty years with people who have terminal illnesses, and the author of *Kitchen Table Wisdom and My Grandfather's Blessings*, speaks of touching as a way of healing. She acknowledges that we don't touch each other a lot and, when we do, that it's often misunderstood or sexualized. Physicians are taught that they should touch people

only to make a diagnosis: If they touch their patients in any other way, even as a means of comforting them, it might be misunderstood.

As Bill Moyers writes, "Touch is deeply reassuring and nurturing. It's the first way a mother and child connect with each other . . . what a mother is saying to her child with that touch is 'Live . . . your life matters to me.'"

Remen also describes how people with cancer often feel when they're touched by health care providers. They say they feel as though they are merely a 'piece of meat.' She reports that one woman said, "Sometimes when I go for my chemotherapy, they touch me as if they don't know anybody's inside the body."

Making eye contact and looking at someone can demonstrate a willingness to listen and communicate. Sometimes, however, in our desire to be connected, the client may find this intrusive. Be attentive and interested, but not overbearing in your efforts to make eye contact.

"Height" is power. When we communicate with young children, it is often helpful to crouch down and get to their level. Similarly with a bed-ridden adult (or a client experiencing confusion, such as with Alzheimer's patients), it provides more "even ground" if we attempt to communicate with them from a seated position.

Finally, your voice and body position will also determine your relationship with your client. Speak clearly and inclusively. When your client has difficulty hearing, make sure you have their attention and are speaking at a volume that can be heard but is not too much.

We can get bogged down in trying to remember all of these suggestions. Remember that "leading with our heart" is the most important characteristic. We know that at whatever level, we do communicate, and although our clients may not always appear to be as perceptive as they once were, they will usually detect our level of caring.

III. COMMUNICATION ABOUT LOSS AND GRIEF: ISSUES OF THE CLIENT AND FAMILY

In your role as a volunteer, you may become a safe haven for the client, caregiver, or family to confide in concerning their fears and anxieties about the process of dying. To be available in this capacity, it will be important for you to have some knowledge of your own personal feelings about loss (see Chapter 11) as well as some understanding of the issues central to grief. In this section we will touch on some of the particular issues that may be affecting the client, caregiver, and family during this process. Chapter 9 of this manual presents more information regarding bereavement. Again, be aware that our role is not to change these patterns, but to understand and support. This section ends with an addendum on "being yourself."

A. Interacting with the Terminal Client

In many cases, the client will continue to function in the capacity he or she did prior to the illness. The same mannerisms, the same defenses, similar interests, will all continue to be present throughout this process. There can, however, be a great deal of denial regarding the

current issues. This denial is typically healthy and necessary as the individual struggles with acknowledgment. Other feeling states that may be present for the patient include depression, anger, guilt, anxiety, and fear. It is important to remember that at Hospice SLO we recognize *the need for all of these feelings without judging them as either good or bad.*

In the book, *Choices*, Van Bommel (1987) lists three things that dying people often need:

1. **To be accepted and respected** as the people they are rather than the dying person other people see;
2. **Permission to die** from all the important people in their lives. Pretending often puts up barriers to communication. People end up isolating themselves because they cannot talk about their loneliness, hopes, fears, and feelings of love; and
3. **To voluntarily let go** of every person and possession that they hold dear. People need to say goodbye to their families, friends, and material possessions.

The key words in Van Bommel's writing are *permission* and *voluntarily*. Our job as listeners is to provide the space for the client to do these things, yet understand that they may not choose to seek permission nor voluntarily let go of their friends and family.

As a volunteer, it is helpful to see yourself as a "tracker" rather than as a "guide," allowing the client to show you where they want to go, what they are comfortable talking about, as opposed to having an agenda that you feel they need to follow. (Inappropriate: "He needs to get his affairs in order and break out of his denial.")

B. Interacting with the Caregiver

Usually, when you go into a home of a terminally ill client, there will be someone serving as the *primary caregiver* for the client. When interacting with this person, remember that, typically, they are not trained for this task and often find themselves thrust into this position suddenly and unexpectedly. Secondly, although caregiving can be rewarding, it can also be physically and emotionally stressful.

Communicating with the caregiver is as important as it is with your client. Understanding the stress that they are going through, and the myriad of emotions that they are experiencing will be helpful in supporting them. The caregiver may begin to resent the dying person, as they are forced to face the inevitable loss and the burden of caregiving. Having these feelings of resentment often stimulates a feeling of guilt. The person then begins to feel a great deal of ambivalence about the impending death. It may prove helpful, if these feelings arise, to validate them by simply acknowledging that they are normal, or by saying, "I understand why you might feel that way," or “This is a stressful situation.”

C. Interacting with the Family

As you will hear throughout your hospice training, the family is viewed as the unit of care. Therefore, it is often necessary to communicate with other family members and attempt to offer them support. Like the terminal client, the individual family members will probably be dealing with the loss in their own unique ways. Similarly, your job will not be to change

their perspective or encourage them to confront their fears, but to support them in whatever they are going through.

One area to be aware of is what is often referred to as *family myths*. This term refers to a family's defenses or system of denial that operates to allow them to stay intact (healthy or not). The myth refers to the idea that the family will collude to pretend that "Dad will get better" or "If it weren't for the doctors..." as other areas to focus on rather than the reality. Be sensitive to the family's need to protect themselves, knowing that this sort of behavior has gone on historically, and is probably not just occurring here for the first time.

D. "Being Yourself"

Perhaps the most important ingredient that you can bring to a family is YOU. Your willingness to be caring, trusting, and "real" will generally override any other "technical" mistake you may make. Volunteers often wonder if it is okay if they cry when they are sitting with a client, or if they should share their own losses. The answers are "yes" and "it depends." Often we have heard clients say that they really felt the presence of the volunteer when he or she began to cry with them. Similarly, sharing your own personal stories with the client sometimes makes it easier for them to feel safe enough to talk with you at a deeper level. This is probably the litmus test for you if you are wondering about the appropriateness of crying or sharing something personal with the client: if it provokes them to speak more openly, then it is probably positive; if, however, they pull back or begin to distance themselves from the conversation, you may want to refrain from this level of sharing.
Remember to trust yourself, and if you are left wondering about the appropriateness of some interaction with a client or family member, run it by the volunteer director or present it during the In-Home support meetings.

IV. CULTURAL SENSITIVITY IN COMMUNICATION

A. Cultural Sensitivity Tips for Hospice SLO Volunteers

1. Assess whether you can be open and nonjudgmental with your prospective families. We all have prejudices — decide whether yours will affect the relationship you have with your clients. If you cannot reconcile these thoughts, consult with your volunteer director to help you process any issues you may have. In some cases you may find you need to ask to be transferred to a different assignment.

2. Speak the language that comes naturally to you. Using a group's slang or dialect to fit in may backfire and you may lose trust.

3. Remember, "white" or "Caucasian" does not necessarily mean "Anglo"; Ukrainian immigrants may be white yet speak no English.

4. It is always respectful to defer to the head of household in initial introductions. You will figure out the family's expectations and people's styles and hierarchies soon enough.

5. It may be appropriate to accept small gifts when offered (non-monetary). Among many groups it is considered impolite to refuse a gift. When in doubt, consult with the volunteer director.

6. Don't assume that because a particular tradition or practice works for you, it will work for the family to which you have been assigned. Try not to generalize. Asian-Americans, for example, represent a wide variety of cultures, languages and traditions. Honor their uniqueness.

7. Some people will express feeling of fear, hopelessness, and lack of knowledge or trust about hospice. Educate but be sensitive to their struggles.

8. What person wouldn't accept a compliment? Emphasize the family's strengths and resourcefulness.

9. Build a knowledge base of, and respect for, traditions other than your own. Learn about different groups, go to festivals, watch foreign movies, read articles about other groups and cultures.

10. BE CURIOUS AND INTERESTED in learning about others. If you are authentically interested in learning about someone who is different from you and approach that learning from an open place, more times than not they will welcome the opportunity to educate you rather than being offended by your lack of knowledge. The key is authenticity and interest in learning.

B. Cultural Assessment

While a full cultural assessment of every client would be extremely time consuming and impossible to achieve, the following are some questions that can be answered during the first visits and will be useful in gaining basic information to help you interact with your client and their family. Some of these questions can lead to a discussion between the volunteer and the client/family. Others may be answered through the volunteer's observations.

- Where was the client born? If an immigrant, how long has the client lived in this country?

- What is the client's ethnic affiliation and how strong is the client's ethnic identity?

- Who are the client's major support people: family, neighbors, friends, church members?

- What are the primary and secondary languages, speaking and reading ability?

- How would you characterize the nonverbal communication style of client/family?

- What is the client's stated religious affiliation, its importance in daily life and current practices?

- What are the client's food preferences and prohibitions?
- What are their health and illness beliefs and practices?
- What are the customs and beliefs around such transitions as birth, death and illness?

C. Communication and Interpretation

Language differences pose a barrier to even the most basic cultural assessment. Family members who are pressed into service as interpreters may be unable to accurately assist health care providers because of role conflicts or lack of medical vocabulary. They often base their messages to both the client and the providers on their own perceptions and may withhold information because it could "embarrass" their family member.

Conversation Style and pacing - Silence may indicate respect or acknowledgment that the listener has heard the speaker. In cultures where "no" is considered rude, silence may mean no. A loud voice or a repetitive statement may mean anger or simply emphasis. Style of conversation varies between blunt and to the point to indirect or providing information hidden in stories.

Personal Space - Cultural patterning often creates erroneous assumptions about individual personalities. People react to others based on their own cultures, rarely recognizing that cultural conceptions of space differ. For example, someone may be perceived for being too aggressive for standing too close or as distant for backing off when approached.

Eye Contact - Culturally appropriate eye contact may vary from intense to fleeting. Avoiding direct eye contact may be a sign of respect, an effort to refrain from invading someone's privacy, or an appropriate behavior between men and women. It may also indicate evasion or shyness.

Touch - Every culture has norms about how people should touch each other and in what situation touching is appropriate. We cannot assume our norm is that of everyone. For example, in Southeast Asia, touching the head is prohibited by those who believe the soul of the person resides in the region of the person's head.

V. INTERACTING WITH THE HOSPICE SLO STAFF

Your Needs are Important

Going into a home will provide a different experience each time and we will be affected differently by these experiences. With one family we may form an immediate bond, while with another we may feel some resistance or even resentment. This is why it is important that you stay in contact with Hospice SLO staff throughout your stay (typically this will be the Volunteer Director). It is important to have a place to process your feelings about the terminal client and family. In this way, you can "recharge your batteries," get some support for yourself and receive feedback on the proper care to be given. We realize that going into the home as a support person typically mandates that you keep your needs in check while being attentive to the needs of others. Therefore, having avenues in your life to take care of

your needs will be vitally important. As trite as it may sound, the better we take care of ourselves, the more available we can be to take care of others. (We'll address self-care thoroughly in Chapter 8.)

Additionally, not only will the Hospice SLO staff provide emotional support for you, they will also be available to help process your observations and insights about the family. If you have concerns or suggestions about the type of care the client is receiving, then you are asked to share these with the Hospice SLO staff.

In essence, please do not hesitate in sharing your experience with Hospice SLO staff and in the monthly In-Home support meetings. It is only by your feedback that we can get a true assessment of the progress of your client and an idea of what your needs are, so that we can support you best.

VI. SPIRITUAL DIMENSIONS OF COMMUNICATION

What does communicating or caring for someone's spiritual side mean? The following excerpt from an article published in the *California Hospice Report*, does a superb job of discussing your role as a volunteer.

SPIRITUAL CARE IN HOSPICE by Larry Beresford

In a sense, everyone has a spiritual life, whether or not that spirituality includes any specific or meaningful religious beliefs. Spirituality also relates to the feeling that there is more to life than the physical, emotional, or intellectual realms; that there is some larger mystery, whether or however one wishes to define or explain it.

Howard Bell, Hospice Coordinator at Abbott Northwestern Hospital in Minneapolis, Minnesota, has defined spirituality in an as yet unpublished article entitled, "The Spiritual Care Component of Palliative Care" as: "both the substance and the mystery in life," substance in its connection with the animate quality of life and as the source of the religious, artistic and philosophical impulse in people; and mystery in that it is unprovable and lacking a universal accepted definition.

The definition of spiritual care, based on interviews with spiritual caregivers, is both simple and complex, or rather, what is involved is so intuitive that it can be summarized simply but requires greater length and complexity to adequately explain. Simply, hospice spiritual care is "being" with the patient and family, not necessarily "doing" any specific tasks other than compassionate, active listening. The terminally ill patient and family are on a spiritual journey the same as the rest of us — but with an urgency posed by a looming mortality — and the spiritual caregiver is there to accompany, encourage and support that journey.

Ideally, the caregiver comes without an agenda or a specific spiritual message or answer and on the patient's terms, whatever the patient's wishes, beliefs, or questions, if any. However, there may be some exceptions to this requirement, as will be shown below. Often the patient asks "Why me?" "Why now?" or "What happens when I die?" The spiritual caregiver basically answers, "I don't know," acknowledging that these are indeed good, handy questions and encouraging the patient to make his or her own spiritual explorations.

There are other types of questions or problems that indicate when a patient may have spiritual needs or that there is a role for spiritual support. Some examples:

- "ultimate questions"
- what is going to happen to me?
- what does it all mean or matter?
- a loss of meaning in life
- how will my life be remembered?
- what do I leave to posterity — my work, my children, my creations?
- I wonder what life is worth?
- a sense of hopelessness
- a sense of abandonment
- the loss of a former belief system
- severe depression
- anger at God
- a resurrection of long dormant religious ideas and concerns
- a sense of guilt
- feeling like an outcast, or on the shelf
- loneliness, fear, unfinished business
- why is God doing this to me?
- how am I going to die?

Spiritual care has been described as easing pain in a broad sense; palliating distressing spiritual/emotional symptoms; helping to bring acceptance into the life of a dying patient; helping to facilitate the exploration and discovery of meaning in a dying patient's life; validating the patient's religious tradition, in language meaningful to the patient; communicating love or God's love to people in need; helping patients explore their life stories; encouraging the patient to live for the present moment; affirming the person's unique values; affirming life, not death; giving a patient room to say or ask anything; being a friend; providing substitute love and support for people without families or personal support systems; saying not in words but in action, "I accept you as a full human being."

At the same time it is important to acknowledge that there are issues and questions that relate to a spiritual realm apart from psychological and emotional considerations.

The following norms defining the acceptable provision of spiritual care in hospice have been identified: (1) don't impose personal beliefs on patients and their families; (2) respond to patients out of their own backgrounds; (3) a deathbed scene is not a proper time for proselytizing; and (4) whatever a patient asks for in terms of spiritual support, do it yourself or get someone who can.

The spiritual caregivers interviewed for this article also described more specific approaches and attitudes toward providing spiritual care in hospice. Summaries of some of these approaches follow.

Walter Johnson, Chaplain at Peninsula Hospital in Burlingame: "There is a tendency to answer the ultimate questions with assurances that the patient has led a good life. If they ask why, say 'why are you asking why?' Your assurances may be another way of saying 'I don't want to hear this.' It's better to help draw out the depths of their feelings, even those of outrage, to help them move along, find a resolution, and take on a new depth in their spiritual existence."

Rev. Johnson also pointed to the characteristics of "accompanying" an ill person on a spiritual journey, such as "a willingness to travel into pain" and deal with painful questions.

John Golenski: "None of us have gone through this experience (dying), so we can't really teach people. In fact, they're teaching us. We assume we have something to give, but often the opposite is true. When you go into a situation not knowing what will happen or what you can do, a certain amount of humility can set in."

June Hartmann, Volunteer Coordinator, Mercy Medical Center Hospice in Redding: "I have a little cross in my lapel. Sometimes a patient will say, "That's pretty," and that will open the door for a spiritual conversation. Also, some patients may be uncomfortable about going to their pastors with emotional or spiritual garbage and the hospice caregiver can be accepting of this."

The kinds of encounters and attitudes described above should convey the idea that providing meaningful spiritual support involves getting down in the trenches with spiritually distressed patients — with the pain and suffering and doubt and questioning that accompany terminal illness. Although a cardinal precept of hospice spiritual care is being non-judgmental, avoiding your own agenda, and meeting the patient in terms of his or her needs and spirituality — it would be impossible and undesirable not to bring something of yourself and your values into the encounter.

In summary, the following is a description of one approach to spiritual care, from *Reflections of a Hospice Chaplain*, by the Rev. Paul Dawson (1980):

> Finally, we are brought to see again that the questions raised by terminal illness are profound and open ended — the kinds of questions relating to existence, suffering, and death that have plagued philosophers, theologians, and poets for as long as culture has existed. We cannot hope to be ready with answers for such questions, but we can offer a faithful presence, a caring heart, a listening ear, a discerning intelligence, and the eternal graces available in the fellowship of the spirit, prayer, scripture, and the sacraments... The best thing that we can do is bring to the hospice ministry the best that we are. If our ministry rests on a sure faith in a loving and caring God, this will come through in our sharing with the patients/families and staff.

VII.SUMMARY

One of the most important contributions you can make as a Hospice SLO In-Home volunteer is that of a listener and communicator. Your desire to be present, attentive, and responsive will make all the difference. As a person approaches death, they will usually be going through a myriad of changes. Your ability to listen is often a very stabilizing influence. Ram Dass comments on how difficult it is to achieve this goal:

> Reckoning, judging, evaluating, leaping in, taking it personally, being bored — the helping act has any number of invitations to reactiveness and distraction. Partly we are agitated because we so intensely want to help. After all, someone's in pain. We care. So part of our time we are listening, but we may also be using our minds to try to solve the problem. There's a pull to be efficient, to look for some kind of resolution.

Listening, caring, being compassionate, these traits are often difficult. We may want to try and "fix" the person or the situation. This is not our job. Rather we are to simply try and be present, to honor the needs of our client and family, and above all else, to listen with our loving hearts.

NAME: _____

CHAPTER 3 REVIEW
COMMUNICATION SKILLS

1. Please list at least four common roadblocks to effective listening.

2. Write down three suggestions on what you could say to possibly prompt a client to open up with you..

3. Why is the concept of "*being yourself*" important in a chapter on communication?

4. True or false: If a client is asking you to tell them whether there is a heaven or not, you should always say there is, whether you believe it or not (please explain).

5. After reading this chapter, what is the implied definition of "*spiritual care*"?