2 • Communication & listening

Communication skills in caregiving

Adapted from Home Hospice of Sonoma County

The first visit is always hard. “Will they like me?” “Will I be able to help?” “What will I do?” These questions are natural. Just remember at these times that you have been selected to serve as a team member because people experienced in the field have confidence in you. Just plunge in, taking with you an attitude of openness and receptivity to the needs of the patient and family to whom you have been assigned. They will let you know what they need, and you, in turn, will let them know what you can offer. The relationship unfolds step by step in a very natural way. The following are some guidelines that may help:

Genuineness

Be yourself! Say what you mean, mean what you say, be who you are, let your words and the way you act and how you feel all match, and respect your own and the other person's right to be unique, different, and human.

Value openness. Respect privacy. People who are ill appreciate being treated naturally, and in this way are reassured that their illness has not set them apart any more than in the obvious ways. Relate to the person, not the illness.

This holds true for family members as well. The volunteer's role is that of friend and supporter, not expert or authority. You are 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 non-medical 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 himself or herself.

Dependability

To people in crisis, whose lives are subject to so much unpredictability, it is essential to know that they can count on someone or something. It is your responsibility to state clearly to the family what you can and cannot offer in terms of time and availability.

Never offer more than you know you can deliver. It is helpful to ask the patient and family to outline their needs and expectations at the beginning (with the stated understanding that these may change as the patient's condition changes), and to indicate how you can help fill these needs, given your own life pattern. Regular phone calls to “check in” are often appreciated, and sometimes result in meaningful and substantive conversations.

Listening

Always remember that your function as a volunteer is to first meet the needs of your patient and family, rather than your own. In most instances this means listening more than talking.

It may mean listening to the same stories over and over again – stories that, for whatever reason, satisfy a need of the patient or the family member in the telling. It may mean listening non-judgmentally to outbursts of anger, frustration and resentment that serve to release tension.

You may even be the target for some of these negative feelings. Don't take it personally. Don't return anger. It may be appropriate to let the patient know that you would be angry too if you had a life-threatening illness.

Be tolerant of behavior that seems inappropriate or may be difficult for you to handle. Remember that this behavior may be adaptive responses to severe emotional strain.

Allow the person to talk about his or her dying and illness if desired. If not, don't push. Be alert to verbal and non-verbal cues. Expect that the patient will not always want to talk about dying even if very close to death. Don't put your agenda onto the patient and family.

Communication

Stay with NOW and HERE instead of talking about another time or a different place. Don't say “it” when you mean “I” or “you” when you mean “me.”

Own your feelings. Take responsibility for what you are doing, saying, and feeling, and allow your real self to be known. WHAT and HOW are more important questions than WHY. Talk to people, not about them. Address people by name.

Pay attention to your language. Use whole sentences instead of starting in the middle or leaving them unfinished. Recognize that “yes, but” means “no”; that “trying” means “not doing or not succeeding,” that there is a difference between what you feel and what you think.

You are real and the other person you are talking with is real. Don't turn yourself or the other person into a thing or an object. Respect your reality and your humanity and get as close as you dare.

Physical contact

Some people like to touch and be touched. Others don't.

It is helpful if you can be flexible with this issue yourself, so that you can cue in on the needs of those you are serving. In most instances, patients welcome handholding and other appropriate physical gestures as means of communication, caring and connection without necessity for tiring conversation. Family members, too, 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 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 you may disagree 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 to you, have been formed over years of association, and are rooted in a history of which you are not a part. Your responsibility is to work as helpfully and harmoniously as possible within the given structure, not to try to change it.

Initiative

At the outset of a relationship, the family will usually look to the volunteer to set the pattern of interaction. Regular phone calls and brief visits to see how things are going are usually appreciated and serve to break the ice.

Don't assume that someone doesn't need to talk to you just because they haven't called you. On the other hand, be sensitive to the possibility that you may not be needed, and never prolong a conversation in which you are doing most of the talking.

Sharing

Allow for the creative expression of feelings through paintings, drawings, music, stories, dramatic play, etc.

Details

Your personal grooming and manner of dress can affect a patient's mood. Color and attractiveness can help lift the spirit. Noisy, jangling jewelry, however, may be annoying, and large earrings, brooches and necklaces may hurt the patient in a hug.

Never wear perfume, cologne, or other scented materials in the office or in the presence of a patient. Perfume or aftershave can be unpleasant to people on medication.

A positive attitude and pleasant expression mean a lot. This does not mean phony cheerfulness or overly bright chattiness, but merely a clear message of caring and attention.

Silence

Sometimes not talking but just sitting with a patient and letting him or her know you care by being there is the greatest gift of all. Sometimes there is nothing “to do” to or for the patient except give your quiet presence.

Non-verbal communication

Be aware of non-verbal language – your own as well as those of your peers, patients, and families.

For example, if you walk into your patient’s room and stand at the foot of the bed and glance at your watch frequently, you may communicate to your patient either discomfort with him or her, or lack of time. They probably will not feel comfortable and confident in talking with you during the visit. If you give them this same message each time you see them, they eventually will know not to share on an intimate level with you. They may even protect you by always seeming happy and “well adjusted.”

Symbolic language

People with life-threatening illnesses frequently use a symbolic approach to deal with some of the heavier issues of death and dying.

It is sometimes less threatening to talk in parables. If a person talks to you in symbolic language, respond in the same symbolism. Don't interpret the symbolic language unless the person asks you if you understand what they are really saying. It's better not to interpret: your interpretation could be wrong, and the other person would probably have been more direct with you if they were ready for that. You might scare them off by pushing.

Belief systems

Be aware of religious beliefs, and see to it that patients and families get the appropriate support, priest, minister, rabbi, etc. Don't impose your belief system onto the patient and family. Allow the patient and family their beliefs – they can have powerful positive effects on healing.

Personal reactions

The relationship a volunteer has with a patient and family can be deeply personal. Often the volunteer is involved in helping to support the family members immediately following the patient's death.

The volunteer may feel the same grief that would be expected in the death of a friend or any other important person in his or her life. Sometimes these reactions are immediate and easily identified. Others may be delayed for some time, perhaps making it more difficult to identify the source.

It is important to understand that these reactions are normal and to realize that the Mission Hospice team stands ready to support you through the grieving process.

Frustrations

Becoming involved as a volunteer may present unexpected frustrations for some people. The team approach is delicately balanced, and it depends more on the needs of the patient and family than it does on the relationship of the individual caregivers.

In some cases, the nurse assumes the primary support role in the team. This may be because the patient sees no need for a non-medical volunteer or does not wish to share his or her personal life except in a professional way. In other cases, the patient might need a friend more than professional nursing. Bear in mind that the nurse's role is more defined, and often more easily accepted, particularly in the beginning of a case.

Availability

Sometimes the family will emotionally withdraw from the patient as they approach death. At this time, you can be most helpful by increasing your time with the patient. They will appreciate your being able to share in their pain and loneliness.

Expectations

Remember that death acceptance and the lack of it are both valid. Seeing the acceptance of death as a virtue is a value judgment. We each choose to die as uniquely as we live. Leave your expectations of the patient with a life-threatening illness at home.

Conflicts

Another area that may cause frustration is personality conflict. There might be a conflict between the patient and/or family and the volunteer. Remember, this is OK – we are all human. The conflict might be temporary, as the family or patient might resent needing anybody. In time, the initial rejection can turn into deep friendship. In truth, you will become very involved with some patients, and remain relatively untouched by others.

Listening to others: Person-to-person listening

Stop talking. You can't listen while you are talking.

Empathize with the other person. Try to put yourself in the patient's place so that you can see what they are trying to get at.

Ask questions. When you don't understand, when you need further clarification; be careful not to ask questions that might threaten or embarrass the patient.

Don't give up too soon. Don't interrupt the other person; allow time for the patient to say what they have to say.

Concentrate on what the patient is saying. Actively focus your attention on the words, ideas, and feelings related to the subject.

Look at the other person. A patient's face, mouth, eyes, hands, all help to communicate; they help you concentrate, too; this will reassure the patient that you are truly listening and are interested.

Share your own reactions, such as smiling or crying, when it's appropriate for you.

Leave your emotions behind (if you can). Try to push your worries, your fears, your problems, outside the room – they may prevent you from listening well.

Be aware of your feelings of anger. They may arise when listening to another person; understand your own anger, rather than judging the patient's; your anger may prevent you from understanding the patient's meaning.

Get rid of distractions. Put down any papers, pencils, etc.; they may distract your attention.

Get the main points. Concentrate on the main ideas and not the illustrative material: examples, stories, statistics, etc., are important, but are usually not the main points; examine them only to see if they prove, support, define the main ideas.

Share responsibility for communication. Only part of the responsibility rests with the speaker; you as the listener have an important part; try to understand and, if you don't, ask for clarification.

React to the content, not the person. Don't let any reactions you personally may have to the patient interfere with what is being said; be aware of your own biases.

Don't argue mentally. When you are trying to understand the other person, it is a handicap to argue mentally as they are speaking; this sets up a barrier between you and the speaker.

Use the difference in rate. You can listen faster than the person can talk, so use the rate difference to your advantage by trying to stay on the right track; anticipate what is going to be said; think back over what they have said. The rate of speech is about 100 to 150 words per minute; the rate of thinking is about 250 to 500 words per minute.

Reflections

Try to use many different reflections. The following examples from Hospice of Buffalo may be helpful:

Sounds like…

Seems as if…

I hear what you're saying…

I wonder if…

I get a sense that…

I imagine…

I think I hear…

What I seem to be hearing…

I get the feeling…

It feels as though…

Sounds to me like…

Am I right in thinking…

You seem to be…

So you're feeling…

So it's…

"It gives me joy to spend time with a person who is willing to share their life experiences. I'm getting more than I'm giving – I'm seeing life through their eyes."

– Ida Young
Mission Hospice Direct Care Volunteer

Helpful phrases

Establishing your willingness to listen

- I'm listening.
- I'm here.
- Would you like to talk about that? Do you feel like talking about that?
- Yes-s-s?
- Could say more about that?
- That (listening) is what I'm here for.
- Sounds like talking about that will be hard for you. It's going to be hard to get started (talking) ...

Recognizing the person behind the words, hearing and acknowledging feelings

- It sounds like you are angry about that.
- How did you feel when that happened?
- What kinds of feelings are you having right now? You must have felt very hurt.
- I can't tell you how you feel about that...
- Are you still upset when you think about that?
- Have you had these feelings at other times? Are you feeling a little confused by all of that? You sound very lonely...
- You wish things could be different?
- You feel things are pretty hopeless right now? Do you have a trapped feeling?

Helping the person think, discovering what they already know or feel, and what is going on

- What ideas have you already considered?
- You seem to have several ideas about what would help.
- You've tried ideas that didn't work?
- Can you tell me what you have already done about that situation?
- Has this type of thing happened to you before? ... What did you do then?
- Have you talked to anyone else about this? ... What did they think?
- How long has this been happening to you?
- Have you thought about why this happened to you? What thoughts did you have? Sometimes it's hard to decide on these things ...
- Can you think back to when this began and tell me about that?
- I don't understand what you mean exactly ...
- Do I hear you saying that ... ? (summarize)
- A minute ago you said," ... " Would you explain more about that?
- Can you tell me when all this began?
- How do you act when that happens?
- Where do all those feelings go? What do you do with them?
- What part of that problem is really yours — something you can control?

Roadblocks to communication

Directing, ordering, commanding

You must...

You have to...

You will...

Warning, threatening, admonishing

You had better...

If you don't, then...

Moralizing, preaching, obliging

You should...

You ought…

It is your duty…

It is your responsibility…

You are required…

Persuading with logic, arguing, instructing, lecturing

Do you realize…

Here is why you are wrong…

That is not right…

The facts are…

Yes, but…

Advising, recommending, providing answers or solutions

What I would do is…

Why don't you…

Let me suggest…

It would be best for you…

Evaluating, judging negatively, disapproving, blaming, name-calling, criticizing

You are bad…

You are lazy…

You are not thinking straight…

You are acting foolishly…

Your hair is too long…

Praising, judging or evaluating positively, approving

You're a good boy…

You've done a good job…

That's a good drawing…

I approve of…

That's a nice thing to do…

Supporting, reassuring, excusing, sympathizing

It's not so bad…

Don't worry…

You'll feel better…

That's too bad…

Diagnosing, psychoanalyzing, interpreting, reading-in, offering insights

What you need is…

What's wrong with you is…

You're just trying to get attention…

You don't really mean that…

I know what you need…

Your problem is…

Questioning, probing, cross-examining, prying, interrogating

Why…Who…Where…

What... How… When…

Diverting, avoiding, by-passing, digressing, shifting

Let's not talk about it right now…

Not at the dinner table…

Forget it…

That reminds me…

We can discuss it later…

Kidding, teasing, making light of, joking, using sarcasm

Why don't you burn the hospital down?

When did you read a newspaper last?

Get up on the wrong side of the bed?

When did they make you President?

Snapshot

By Mission Hospice staff Gabrielle Elise Jimenez, LVN, CHPLN and Gary Pasternak, MD, MPH

By the time someone comes to us, they have lived their entire lives; we come in at the very end and only get a snapshot. We hear a lifetime of stories condensed into a short amount of time, like the *CliffsNotes* of a life. We may feel as if we've known them intimately for a long time. We take the bits and pieces that they generously share with us and using our imagination we create a tableau of the patient and family; the landscape of a life lived.

The telling of these stories is often an essential element of the dying experience.

> " 'Remember on this one thing,' said Badger," in the children's book *Crow and Weasel* by Barry Lopez. " 'The stories people tell have a way of taking care of them. If stories come to you, care for them. And learn to give them away where they are needed. Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memories. This is how people care for themselves.' "

Because of the way a couple is holding hands as those last breaths are taken, we assume the 70+ years together were full of so much love – without a moment of struggle, arguments, betrayals, or disappointments. We leave thinking, "I want a love like that", and "when I die, I want someone at my bedside who will have loved me that much, and will miss me that much." It becomes quite easy to create a life they may or may not have ever lived, simply with the glimpses we are given. We are humbled by how much we actually don't know about them.

Our understanding of people can be immediate and intimate, but it can also be influenced by the circumstances, their sickness, stress, our own biases and transference and the untamed wildness of our own imaginations. In the short time we have together, we must quickly build mutual trust and respect. And as psychologist Carl Rogers said, holding people with unconditional positive regard and accepting and respecting others as they are, without judgment or evaluation, is an essential element of all healing professions.

This is one of the main tasks of all hospice workers: to approach patients with objective empathy and compassion, without pitying, romanticizing, or judging. Being present for – and receiving – a life story is one of the great gifts of this work. We often call this active listening, but it is really another example of relationship-centered care. We are not passive receivers because we have a part, large or small, in creating the end-of-life experience for this patient and family. Simply sitting silently in a room with a dying person is an intimate relational act.

We took an oath to not pass judgment, to not refuse to care for someone because of choices they made and things they've done, despite how dark their past might have been. When we start to care for someone, those secrets may be shared with us, or we may only have a sliver of a story to give us a window into the person's life. At the end of the day, that doesn't matter to us, because we have learned to have respect for every human life when they are dying—all humans should be cared for kindly regardless of their past personal history. That is a right everyone should possess.

But often our snapshots do contain rich and helpful stories. Human beings are interesting, especially when there are dynamics within the family and people have stopped talking to one another, perhaps for something that happened many years ago. And when we are alone with a

family member or significant other, they may share something hurtful or awful the patient has said or done. We try to remind them that at this moment, if they are receptive to our suggestion, they have an opportunity to find a way to come together to provide comfort and support to the person lying in the bed, perhaps even forgive and comfort despite a difficult and hurtful past.

Human beings can be lovely and beautiful, and cruel and selfish. We are all only human with our imperfections and our emotions, and feelings have a tendency to get the best of us. However, one opportunity at end of life is the possibility for reconciliation of long- held challenging relationship issues and emotions. Grudges, hatred, slights, regrets as well as expressions of love long withheld are so often heard in these stories we witness. Often in the telling and facilitating of communication among family members we witness the transformation of the suffering from long held painful patterns into a more peaceful and graceful state. Not necessarily a perfect or "good death" but perhaps a better one. This often allows for a death that is not necessarily without grief but that is experienced with more peace and less anguish. This doesn't always happen but often does.

A terminal diagnosis removes the luxury of time, which reminds us of things we didn't say or do, or wishing we had let something go. We often see people wishing desperately that they had let go of their grudge or anger. A husband recently said, "I took advantage of the time we had together, I always thought we would have more time". He and his wife did have a wonderful love, but it was shorter than they had hoped, and both wished they made more of the time they had together. We can all learn from that.

In these "snapshots" we may see much about a person's essential nature and unique core qualities and we can experience their "nectar", the concentrated essence of the person in their wholeness. When we are witnesses with presence and clarity (when our own lens is not clouded by judgment and bias) these snapshots and stories become gifts to us and create opportunities for healing and the experience of a more peaceful dying. Mostly we feel lucky to be able to do this work

How to listen

By Rachel Naomi Remen, MD

Just listen

I suspect that the most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention. And especially if it's given from the heart. When people are talking, there's no need to do anything but receive them. Just take them in. Listen to what they're saying. Care about it. Most times caring about it is even more important than understanding it. Most of us don't value ourselves or our love enough to know this. It has taken me a long time to believe in the power of simply saying, "I'm so sorry," when someone is in pain. And meaning it.

One of my patients told me that when she tried to tell her story people often interrupted her to tell her that they once had something just like that happen to them. Subtly her pain became a story about themselves. Eventually she stopped talking to most people. It was just too lonely. We connect through listening. When we interrupt what someone is saying to let them know that we understand, we move the focus of attention to ourselves. When we listen, they know we care. Many people with cancer talk about the relief of having someone just listen.

I have even learned to respond to someone crying by just listening. In the old days I used to reach for the tissues, until I realized that passing a person a tissue may be just another way to shut them down, to take them out of their experience of sadness and grief. Now I just listen. When they have cried all they need to cry, they find me there with them.

This simple thing has not been that easy to learn. It certainly went against everything I had been taught since I was very young. I thought people listened only because they were too timid to speak or did not know the answer. A loving silence often has far more power to heal and to connect than the most well-intentioned words.

Generous listening

Generous listening means listening without deciding whether you agree or disagree with what is being said, or whether you like or dislike what is being said. It means listening without comparing the speaker to yourself: are they more or less highly trained, smarter, more or less competent than I am? It means listening without trying to 'fix' the person speaking or to offer advice. It even means listening without trying to understand why the speaker feels the way that they do.

Generous listening is listening simply to know what is true for another person at the time that they are speaking to others. When we listen this way, we offer a place of profound safety that allows for genuine connection and the open sharing and transformation of ideas.

Listening creates a holy silence. When you listen generously to people, they can hear truth in themselves, often for the first time. And in the silence of listening, you can know yourself in everyone. Eventually, you may be able to hear, in everyone and beyond everyone, the unseen singing softly to itself and to you.

Listening is the oldest and perhaps the most powerful tool of healing. It is often through the quality of our listening and not the wisdom of our words that we are able to affect the most profound changes in the people around us. When we listen, we offer with our attention an opportunity for wholeness. Our listening creates sanctuary for the homeless parts within the other person. That which has been denied, unloved, devalued by themselves and others. That which is hidden.

When we haven't the time to listen to each other's stories we seek out experts to tell us how to live. The less time we spend together at the kitchen table, the more how-to books appear in the stores and on our bookshelves. But reading such books is a very different thing than listening to someone's lived experience. Because we have stopped listening to each other we may even have forgotten how to listen, stopped learning how to recognize meaning and fill ourselves from the ordinary events of our lives. We have become solitary – readers and watchers rather than sharers and participants.

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.

Helping, fixing, and serving represent three different ways of seeing life. When you help, you see life as weak. When you fix, you see life as broken. When you serve, you see life as whole. Fixing and helping may be the work of the ego, and service the work of the soul.

Please Listen

By Leo Buscaglia

When I ask you to listen to me
and you start giving advice,
you have not done what I asked.

When I ask you to listen to me
and you begin to tell me why
I shouldn't feel that way
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something
to solve my problem
you have failed me,
strange as that may seem.

Listen! All I asked was that you listen.
Don't talk or do – just hear me.

Advice is cheap; 20 cents will get
you both Dear Abby and Billy Graham
in the same newspaper.

And I can do for myself; I'm not helpless.
Maybe discouraged and faltering,
but not helpless.

When you do something for me that I can
and need to do for myself,
you contribute to my fear and
inadequacy.

But when you accept as a simple fact
That I feel what I feel,
no matter how irrational,
then I can quit trying to convince
you and can get about this business
of understanding what's behind
this irrational feeling.

And, when that's clear, the answers are obvious and I don't need advice.
Irrational feelings make sense when we
understand what's behind them.

Perhaps that's why prayer works – God
is always there, LISTENING.

So, please listen, and just hear me.
And if you want to talk, wait a minute
for your turn – and I'll listen to you.