



“What Shall I Say...?”

Answering The Big Questions In Palliative Care

Some questions posed by patients pull at the heart of the doctor, causing fear and anxiety as to how best to answer.

By Elizabeth J. Latimer, MD, CCFP, FCFP

“Hope is to see in the eyes of another that you are understood.”

— *Henri J. Nouwen*

Effective interpersonal communication is, for the most part, a complex art. For this reason, it can be difficult to write about. There are some straightforward approaches to communication, however, which can help clinicians at the bedside, particularly when answering questions within the context of serious illness.



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The big questions in palliative care

Some questions posed by patients pull at the heart of the doctor, causing fear and anxiety as to how to answer. These are usually questions that relate directly to future prognosis, dying or what will happen. Physicians may have a natural desire to sidestep such questions with a generality such as, “We are going to make you feel better,” or an answer that does not relate to the question, such as, “We will change some of your medications today to see what we can do.”

Answers like these are not satisfying for the patient because they avoid the question and they may leave the doctor feeling uneasy. In addition, the doctor misses an opportunity to further clarify the goals of care and direction of the illness, to identify and plan to meet the needs of the patient, and to solidify the doctor-patient relationship as

Six patients — six questions

- Mr. J has advanced renal cell cancer and is very breathless. He asks: "Can you make me better, doctor?"
- Mrs. R, who is hospitalized with advanced breast cancer, asks: "You have seen other people like me, doctor. What happened to them?"
- Mrs. B has newly diagnosed amyotrophic lateral sclerosis (ALS). She asks: "Am I going to die, doctor?"
- Mrs. M, with advanced liver failure secondary to cirrhosis, asks: "How long do you think I have, doctor?"
- Mr. W, with advanced cardiac failure, asks: "Is there no hope for me, doctor?"
- You have a long talk on Tuesday with your patient, Mrs. Y, about her new diagnosis of widely disseminated bowel cancer. On Wednesday morning, she doesn't seem to have heard what you said, and asks: "Do you have the results of my operation, doctor?"

one of openness and trust where questions can be asked and gentle answers given.

How can we address the big questions in a more effective way? How can we communicate better?

Understanding interpersonal communication

Communication is a complex process. In many ways, it is remarkable that it works as well as it does most of the time. It is a two-way transmission of information between senders and receivers — a process of observing, listening and speaking. We often place too much focus on the speaking and not enough on the important components of listening and observing. The development of skills in observing and listening more effectively before we speak would be of great help in health care generally, and in the emotional situations encountered in palliative care, particularly. A good way to remember this is to keep in mind we have two ears and one mouth. Perhaps nature intended us to listen twice as much as we talk!

The filter between people

I find it very helpful to conceptualize a space of "filter" between myself and those with whom I wish and need to communicate. Figure 1 illustrates the filter through which the words, gestures and overall demeanour of the communicator must pass in order to be "heard" by the receiver. This filter is rather like a semi-permeable membrane which can be closed, partially or completely, by such factors as pain, worry, fear and anxiety, fatigue, depression, personal values, cultural beliefs and practices, information overload, and other factors. These factors influencing the in-and-out flow of information are common to both the patient, the family and the physician. For example, the stressed or fatigued physician may not accurately hear what the patient is asking. Similarly, frightened patients may not be able to let the information in. They may not be able to hear what is being said because their filter is closed by fear and anxiety.

For the patient and his/her family, the semi-permeable membrane, or filter, can be opened by a supportive and relaxed atmos-

here, plain language and a gentle approach by the doctor. A physician's filter can be opened through self-knowledge of the factors which might be affecting one's ability to communicate. For example, the physician can recognize he/she is fatigued and take a few minutes to clear one's mind and re-establish an emotional "centre."

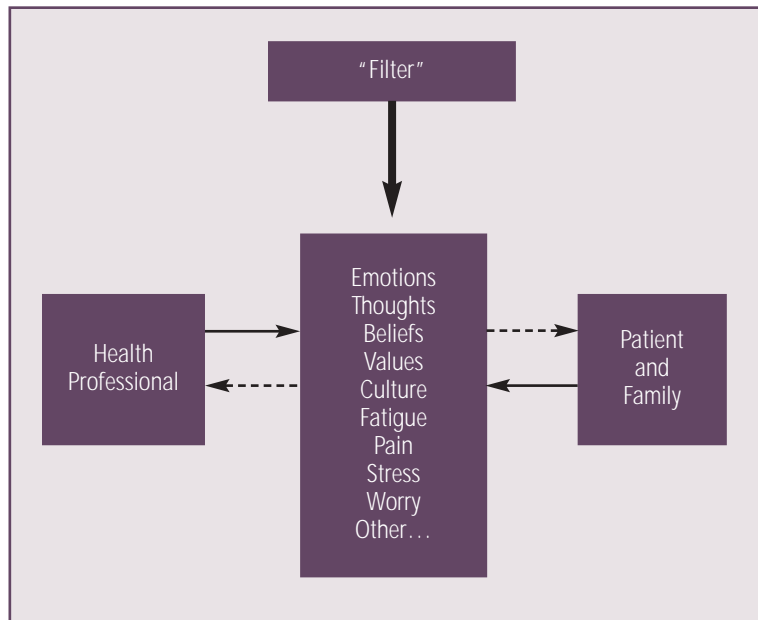


Figure 1. Communication in serious illness.

Verbal and non-verbal communication

We are communicating non-verbally all the time. What proportion of our communication is non-verbal? It may surprise you to learn this makes up 80% of our communication! We communicate non-verbally through our facial expression, eye contact, body posture and in a myriad of other ways. A lot of non-verbal communication reflects who we are as a person. We convey caring, compassion, respect and professionalism through our positive way of being. We show who we are, the knowledge and skills we possess and the integrity we maintain. Once we recognize this, we can use these very powerful communication channels to our advantage. We can convey messages that are helpful in clarifying what we are saying and in supporting very sick people and their families.

The physician as communicator

"Know thyself." This is very good and timeless advice, and a lifelong journey for most of us in our role as doctors. Because we have the potential to be therapeutic agents and play a pivotal role in influencing people for good, we are advised to strive to enhance our self-knowledge. In this task, we will want to reflect about ourselves in several areas:

- In general:
 - What are our life's values and beliefs?
 - What are our usual reactions to certain questions, situations or people?
 - How do we feel in emotional situations, for example, when people cry, or express grief or anger?
 - What are our particular interpersonal strengths? In what situations do we function particularly well?



- What are our past life stressors and losses and how might these influence our communication in life-threatening and other clinical situations?
- What are our present life stressors? Are we worried about a loved one? How full is our own life stress “plate”?
- What are our areas of particular vulnerability? Do particular people or situations evoke feelings in us and, perhaps, influence our ability to communicate effectively at that time?
- What is our philosophy about the practice of medicine and our role as a physician?
- Are we feeling good about our work? Do we feel a sense of affirmation in what we do?
- On this particular day:
 - How am I feeling today?

As physicians, we probably don't ask ourselves this last question as often as we should. Our work is very stressful and we are human beings. It is good to acknowledge we will have our days of vulnerability. A particularly good time to assess how we are on a given day is while driving in to work. Am I tired? Am I nearing an overdue vacation? Do I feel

a cold coming on? Am I worried about a home situation?

If the answer to any of these questions is “yes,” this self-knowledge can help us prepare for the day. We can plan to be gentle with ourselves. We will be aware we may be more vulnerable to feelings and difficult situations. Can that particularly difficult interview be done tomorrow? If not, perhaps it would be a good idea to ask the social worker, chaplain or nurse to join us in the interview for our own support and for help in conducting the interview with the patient and his/her family. Advanced self-knowledge will also help in clinical situations on any given day. For example, if we are tired, we may have a tendency to react to things that would not ordinarily bother us. We can be vigilant about this. We also can get some interpersonal support from our interdisciplinary team colleagues by sharing how we feel.

Addressing and answering the big questions in palliative care

I would like to share a simple approach that has worked for me when answering “big questions” — those that are emotive and are usually about the future, dying or what will happen.

When asked a “big question”, take the following approach:

- **Stop, look and listen** before you begin to answer.
- **Pause for a moment.**
- **Take a breath or two in and out** to relax and focus.
- **Sit down if you are not already sitting.**

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- **Clarify what is being asked.** For example, say: “I am going to try to answer your question, but before I do, can you tell me what you are thinking?” or, “I am going to try to answer your question, but can you tell me what has been on your mind?” or, “It seems like you have had some thoughts on your mind. Before I try to answer your question, can you tell me what you have been thinking?”
 - **Establish that you have found the real question.**
 - **Answer the real question with a blend of gentleness, truth and hope.**

Of all of these steps, pausing to clarify the real question being asked is the most vital key to knowing how to answer.

When answering the question, remember the following:

- Be gentle.
- Choose ordinary “non-medical” words;
- Observe the patient for emotional reactions and provide support.
- Pause frequently to confirm the patient understands what you are saying.
- Put yourself in the patient’s place as to how it would feel when receiving such information.
- When talking about prognosis, avoid being blunt, foretelling the future, or using numbers for survival time. **Dx**

See over
for case discussions

Responding to our patients using the approaches listed above

- **Mr. J:** "Can you make me better, doctor?"

At first, Mr. J seems to be asking if we can take away his disease. Using the approach outlined above, however, we ask him what he has been thinking. He answers, "I know that I am not going to get well, but I am very frightened about this bad breathing. Can you make me more comfortable? Can you make this breathing better for me?" The doctor now knows a lot more about Mr. J's understanding of his situation, his real question, and his fears about his illness. Using palliative approaches to relieving breathlessness, the doctor can institute effective medication orders and reassure Mr. J that everything will be done to prevent him from suffering breathing distress through the provision of attentive on-going care.

- **Mrs. R:** "You have seen other people like me, doctor. What happened to them?"

Mrs. R also appears to be asking a prognosis-related question. On clarifying with her, however, she says something quite different. "I wondered if you have ever seen someone as sick as me be able to get home from the hospital. I would really like to have some time at home with my family." Identifying her real question opens all kinds of avenues to explore in trying to make her hope come true.

- **Mrs. B:** "Am I going to die, doctor?"

Mrs. B has asked a question which is very large in its potential scope. The physician is aware of the need to be gentle and truthful, but also to help Mrs. B. maintain hope that she can be relatively well for some time. Before answering, the physician asks what she has been thinking. In fact, she has heard from a friend that people die within weeks of a diagnosis of ALS. She wonders if she will have some time to do things and to prepare her family. Clarifying the question has revealed a misunderstanding on her part. The physician can give her more hopeful information about timing and how she might feel physically. He/she can also explore further what she knows about the disease and try to seek some reading material for her. Future discussions can focus on treatment approaches. The prognosis time can be addressed again from time to time in the course of the illness as she wishes to explore it.

- **Mrs. M:** "How long do you think I have, doctor?"

Mrs. M would seem to be asking a direct question about prognosis time. It is particularly important that the physician carefully explore a question like this before answering. The physician comments: "It sounds like you have been doing some serious thinking." Mrs. M replies, "Yes, I have some things I need to set right with my family; things I need to talk about." The physician can now listen to Mrs. M's concerns and call upon colleagues in social work and chaplaincy to facilitate healing in the family. Remember, a question about prognosis time should be handled with great care.

- **Mr. W:** "Is there no hope for me, doctor?"

Mr. W is asking about hope. The doctor can enter a conversation with Mr. W by saying: "Hope often means different things to different people. Can you tell me what hope means to you?" Mr. W. begins by saying he knows he is very ill. His granddaughter is expecting his first grandchild any day and he wonders if he will live to see the baby. Based on his/her knowledge of the patient's physical illness, the physician can answer in such a way as to keep the door open for the patient to hope for this. Physician and patient can also talk about the joy of a long-anticipated first grandchild and how meaningful this is for the family.

- **Mrs. Y:** "Do you have the results of my operation, doctor?"

The physician isn't sure what Mrs. Y is asking, given the long talk of yesterday. When asked "Can you tell me what has been on your mind?" she replies, "I know you talked with me yesterday, but I really don't remember what you said. There is so much going on and so many people coming to see me. I don't seem to be able to concentrate. I feel anxious." Mrs. Y's communication filter has been blocked with anxiety and information overload. She will need to be told again, perhaps with just short pieces of information at one time so that she can incorporate it. The physician can begin by asking, "Do you recall any of what I said yesterday?" and proceed from there.