



Do's and Don'ts

My friend or loved one has cancer . . . What should I say? What should I do?

This is a common question we have. Anne Coscarelli, Ph.D., Executive Director of the Ted Mann Family Resource Center in L.A. presents a well rounded answer below:

When a friend or family member is diagnosed with cancer, questions frequently arise, "What should I say? What should I do? How should I respond?" Unfortunately, there is no simple answer because patients with cancer are not a generic entity. Rather, they are a diverse group of people with unique issues and concerns and each person brings his or her own needs to the experience. There is probably only one universally accepted sentence that everyone with cancer might like to hear and that is, "Oh, it was a mistake, you don't have cancer after all." Short of that, responses must be tailored to the needs of the individual. That being said, however, over the years I have accumulated a wealth of information from professionals and patients about the wonderful things that people have said or done, as well as a few horror stories. In this process I have developed a catalogue of responses, behaviors and suggestions to help friends and families think about the ways in which they might be helpful, and thoughts about avoiding difficulties. I encourage you to use this list as a starting point for communication.

I also invite patients to review this list, to think about what makes sense to them and to identify items that they want to share with friends and family. I encourage everyone to read and integrate these suggestions into practice. The most important gifts that anyone can offer a loved one who is diagnosed with cancer are presence, commitment to assist at all phases of the illness and a desire to help. Communication is the first and most important part of this process.

THINGS TO THINK ABOUT DOING:

- ❖ Communicate interest in understanding what the patient is experiencing. Living with cancer can be an emotional rollercoaster. This is a time when expressing your understanding is especially appreciated from those closest to the patient.
- ❖ Sometimes a person with cancer may want to protect friends and family and may censor communications. Invite them to share their fears as well as hopes and assure them of your continued presence.
- ❖ Know how to listen actively and without judgment. Be open to hearing what the patient has to say. Show understanding by nodding, making eye contact, and acknowledging the meaning of their words.
- ❖ Recognize that the experience of living with cancer and its treatments can be isolating. Encourage the patient to join a support group, maintain social

contacts and involve his or her faith community in the circle of healing.

- ❖ Recognize that intense emotions are appropriate responses to this experience. Communicate your willingness to "hear" these emotions without judging them.
- ❖ Reach out, even if the person is not your closest friend.
- ❖ Remember that this person is more than a patient with cancer. Some people want to talk about the cancer experience a lot, others less so. Recognize and respect the limits that a person sets regarding how much or how little to talk. Be cognizant that their comfort in talking will be bolstered by open and honest communication.
- ❖ Talk about normal, non-medical life, if the patient is interested. Sometimes patients feel that their whole lives have been consumed by cancer. When a patient feels this way it helps to be distracted by other things going on in other people's lives. It may provide them with new topics to discuss with their partner or family. Take cues from the patient about how much talk there should be about cancer and non-cancer topics.
- ❖ Bring humor. Remember jokes or go to the Internet as an additional resource. Help to bring levity to a difficult situation and allow the patient to connect to those things in life that are not usually associated with cancer.
- ❖ Bring joy into the patients life. Plan a special outing if the patient is up to it. Bring an old movie and offer to watch it together. Host a "Mad Hatter Tea Party" in which the guests wear hats and bring a hat or scarf for the patient. Get creative and come up with ideas that are fun.
- ❖ Provide physical comfort. Offer to give a massage of the hands, feet or neck and shoulders. Fluff pillows, offer to change the sheets or re-make the bed while visiting.
- ❖ Offer concrete assistance such as running errands, preparing a meal, driving to the doctor's office, or picking up prescriptions. Be as specific as possible.
- ❖ Consider organizing a "dinner club" in which a group of families makes home cooked meals and delivers them each night of the week.
- ❖ Organize transportation. Identify key people who are available to drive to and from the medical center and work out a rotating schedule so the patient and family do not have to do this.
- ❖ Create a phone pool so when the patient is not feeling well enough to talk, everyone can share information. This takes the burden off the family household. Make certain that this does not become a means to gossip. Allow the patient and family to dictate who is called and what information is shared.

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- ❖ Offer to read books, stories or even the newspaper out loud. Sometimes a patient will enjoy the company and the relaxation of being read to.
- ❖ If the family has young children, think of all of the creative ways you might be able to help. Some suggestions are:
 - ❖ Offer childcare for when the patient is getting treatment or isn't feeling well, or for the patient and spouse to have some special time alone.
 - ❖ Help the children to attend birthday parties and other event by providing transportation or purchasing and wrapping the gift and providing the card.
 - ❖ Take pictures of the patient's children at events to record moments that the parents might miss. When the pictures are developed, use them as upbeat non-cancer topics.
 - ❖ Offer to transport the children to and from school, doctors, dentists, tutors, athletics, or whatever else needs to be done.
 - ❖ Communicate that there is a community of support to help the family.
 - ❖ Be considerate. Call before you visit. Be aware of fatigue and notice if a patient becomes restless, seems anxious or shows signs of discomfort. If the person closes his or her eyes, this may be a cue to leave, but if uncertain, ask what the patient wants. It may not be a cue to leave and the patient might like company even if there is no interaction.
 - ❖ Sit near the patient and greet him or her normally with a kiss on the cheek, a handshake or pat on the shoulder or leg, if appropriate. Touch can be an important soother and a powerful form of communication. If the patient is comfortable, offer a hand for holding.
 - ❖ Be honest. When feeling nervous or unsure of what to say, tell the patient. It is okay to say, "I am scared of saying or doing the wrong thing, but I really care about you and I want to be here for you. I'm open to helping you in any way you need."
 - ❖ Recall pleasant memories. If there are favorite stories or shared experiences that have brought closeness, see if they continue to be comforting, helpful or uplifting.

THINGS NOT TO DO:

- ❖ DO NOT burden the person with stories of people who have had cancer and what they did to manage their disease, unless the patient actively solicits this information. It can be overwhelming and not relevant.
- ❖ DO NOT relay stories of people that have died from cancer.
- ❖ DO NOT assume knowledge of how a patient feels or what course their life should take after a cancer diagnosis. How one experiences cancer is individual and can only be defined by that person.

- ❖ DO NOT offer the patient conclusions about the meaning of their experience unless they invite an opinion. Unsolicited opinions be irrelevant or even hurtful and may serve to halt much-needed dialogue between patients, family and friends.
- ❖ DO NOT be afraid to talk about their religious faith, but do not push views or beliefs onto them. A cancer diagnosis draws people back to the basic issues of life and core questions of existence to which all religious traditions speak. Cancer has deep spiritual implications and can mark the beginning of a new chapter in one's spiritual journey which may lead to a renewed and strengthened faith.
- ❖ DO NOT avoid the person because of personal feelings of helplessness, discomfort or lack of knowledge.
- ❖ DO NOT believe that having all the "right things to say" is what is most important. Communicating love and concern and willingness to be present is one of the greatest gifts.
- ❖ DO NOT give directions about the expression of emotion that discounts or invalidates a patient's feelings. Patients need to be allowed to feel. One of the best ways of doing that is by letting patients express their emotions and accepting them. Never tell someone the following:

*Don't cry
 Don't feel sad, depressed. Don't feel that way
 Crying never solved anything, crying won't help
 It's God's will
 Try and smile
 Buck up
 Get over it
 I know how you feel
 Don't worry, it will all be okay
 Don't be nervous
 Stop worrying
 You are over-reacting, it's not that bad
 Cheer up
 You aren't going to die*

- ❖ DO NOT trivialize, a person's feelings. This can happen when attempts are made to reassure someone. For example, for a patient who has lost her hair it may not be comforting to be told that her hair will grow back. It does not acknowledge the current feeling of loss. Instead, acknowledging that it must be, hard to have one's physical appearance change so drastically can provide the patient with the knowledge that his or her feelings are, understood and accepted. It can also open the door for communication. Follow up supportive statements can then be made about assistance that can be provided to adapt during this difficult time.
- ❖ DO NOT distract the patient from meaningful conversations about their life, what they want or their concerns about death. One of the biggest

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problems that exists in communication is the tendency of one party to deny the other party the opportunity to say what is on their mind.

- ❖ DO NOT be afraid to talk about death, advance directives, quality of life and funerals. Many times patients want to have these discussions even though they are frightening for everyone. It can sometimes be helpful to talk about the best case and worst case scenarios.
- ❖ DO NOT make promises that cannot be kept. Trust is an important issue in all relationships. The need for it can be heightened when a patient is feeling vulnerable.
- ❖ DO NOT assume that little things do not matter. A patient with cancer often feels like life is out of his or her control. One way patients manage this sense of being out of control is by organizing and orchestrating other issues that are in their control. They may have needs to have things in special places or for things to happen at special times. Sometimes this management may seem inappropriate to others and can lead to conflict. Communication becomes essential as well as an understanding of the importance of control. Whenever possible give the patient as much control as possible within the limits of the situation. If there are options, present them to the patient.
- ❖ DO NOT have a preconceived idea about how a person should respond to a cancer diagnosis. Expecting a patient to be crying and sharing their deepest feelings may be inappropriate as can having the expectation that they should be feeling optimistic and hopeful.
- ❖ DO NOT set preconceived timelines about a patient's emotional recovery, from cancer. There is no set time line for recovery and a mistake to assume that it will be anything other than on the patient's terms. On the other hand, if there are concerns, it may be appropriate to suggest that the patient seek professional consultation about their recovery from a mental health professional such as a psychologist, an oncology social worker, or other therapist familiar with cancer treatment.

- ❖ DO NOT do more for the patient than he or she is comfortable having others do. Being treated like an invalid when one is not can be degrading.
- ❖ DO NOT expect that the patient or his or her family will provide reciprocal emotional comfort. Patients and family are usually overwhelmed. Emotional support for friends will have to come from other resources.
- ❖ DO NOT assume that a patient who is quiet is not appreciative of companionship. Sometimes sitting in silence while someone rests or sleeps is consoling and comforting.
- ❖ DO NOT let a friend be emotionally abusive just because they have cancer. Try to find ways to talk to each other and reconcile difficulties. For example, "I really want to be here for you. Sometimes it is hard when I feel your anger directed at me. Let's talk about it. Is there something that you need from me that I'm not providing? I understand that you are really angry with this disease. I could provide more support to you if we could both direct the anger some place else." These kinds of conversations can lead to greater warmth and deepening of relationships if they are handled in loving ways.

Patients, friends and family have the opportunity to gain new insights and strengthen bonds during the cancer journey. It is important to look for possibilities to deepen relationships, to

Personally grow and to learn about living and dying. While cancer can have many difficult twists and turns, it presents the opportunity for great psychological growth for anyone willing to take the risks. While feelings of sadness and loss are often part of the experience, they can be bolstered by feelings that personal commitment and presence make, a difference in someone else's life. In my mind, making contributions to the quality of someone else's life, is the greatest gift that we give to others and, in the process, to ourselves.

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