

Support from Family and Friends

Cancer can be a terrible burden in its physical aspects alone, but to face it without support is far worse. Cancer can be an isolating experience for the patient, because for others, it calls to mind issues that many people dread, such as chronic pain or the surrender of physical independence. Many people, especially younger people, have never experienced any form of long-term illness in their families, much less the chronic and very serious aspects of cancer or cancer treatment.

Cancer counselor and non-Hodgkin's lymphoma survivor Nan Suhadolc points out that those we must deal with tend to fall into three categories—nurturing, supportive, and toxic—whether they're family, friends, or acquaintances. In other words, your closest family members, upon whom you may hope to rely, might be negative and unsupportive, emotionally toxic to you. Those who are less close actually may be more nurturing than family members. In the discussions that follow, the term “loved ones” implies those who are nurturing, even if they are not related to you by blood or marriage.

Specific needs

The word “support” means different things to different people, or different things on different days, depending on what you're dealing with at the moment. Support can include very tangible, instrumental ways of helping such as:

- Offering to locate and interpret medical information about your illness
- Offering their points of view for your decision-making process
- Organizing blood donor or marrow donor drives
- Helping you move around at home after surgery
- Offering to do some of your cooking, cleaning, laundry, or shopping
- Driving you to and from treatment visits
- Acting as an advocate for you when you're not well enough to express your needs or demand better care
- Keeping track of medications you must take if you're too groggy to do so on your own
- Monitoring your reactions to specific medications and your health in general
- Organizing fundraisers
- Calling insurance companies, medical offices, or employers to iron out misunderstandings
- Being a surrogate parent to your children
- Offering to stay overnight with you if you need nursing care
- Offering to temporarily assume some or all of your workplace responsibilities
- Understanding that fatigue is the most common long-term effect faced by cancer survivors, often lasting for years, and remaining constant in their efforts to help and understand as time unfolds

Next, there are ways that others can provide emotional support:

- Empathizing, at least in principle, with the terror of facing a life-threatening illness
- Attempting to understand how you feel, however alien it may seem to them
- Just being around when you want company
- Sending gifts and cards if you're housebound or hospitalized
- Attending to your children's emotional needs
- Not assuming they know how you feel
- Avoiding asking nosy or inappropriate questions, offering instead to listen when you're ready to talk
- Saying, “I'm sorry this happened to you. Please let me know what I can do for you.”

Typical reactions of others

In an ideal world, we would be surrounded by people who come forward as soon as we need help. But often others are only partially aware of what we're going through. Nausea? Fatigue? While they may have had nausea and fatigue in the past, it's likely that they were

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quickly remedied. They may not realize what it's like to experience nausea for days each week, even before the chemotherapy treatment has begun. They don't truly understand what it's like to be tired all day, every day, as soon as they wake in the morning. Most people may have considered their own mortality, but seldom have they done so with the sense of immediacy that a cancer diagnosis entails.

At times, others would like to offer support but don't know what to do or say. They may say the wrong thing. In some instances, others find it easier just to avoid discussing the issue of your illness. They hope—it is presumed—that if they dwell on other topics you (and they) will feel normal again.

In very rare cases, the motives of others are not at all honorable, and they may say or do things that are despicable.

Frequently there are good explanations for what you may perceive as the failure of others to provide adequate support. Other people, being mortal, have finite logistic, emotional, and financial resources. They still have their own responsibilities and needs to address.

If they are loved ones, they may have assumed some of your responsibilities as well. They might be attempting to manage this on a reduced income if the cancer survivor is unable to contribute financially. They may be concerned that the time they're missing from work to provide care will jeopardize the family's only remaining source of income. The thought of losing a loved one is probably highly threatening to them, perhaps causing anger, terror, sadness, and a host of other debilitating feelings. None of these issues justifies unkind behavior, of course, but hidden concerns might cause loved ones to seem distracted, inattentive, overly controlling, or insensitive.

Fortunately, it appears that many cancer survivors receive most of the support they need when they need it, with just an occasional bump along the way—if they make their needs known. A nurse with cancer discusses the wonderful support she received from family and friends:

One of the most amazing things that happened to me during this disease was learning how much people cared. I had friends call and visit me in the hospital that I thought were mere acquaintances. When I was finally diagnosed, I learned that I wouldn't be allowed to return to work during treatment. This meant that I would need to go on disability but there was a thirty-day waiting period.

A coworker who I thought of as a friendly acquaintance I shared my commute with took up a collection for me at work. Coworkers in my immediate unit have also gone grocery shopping for us three times now. I protest, but they seem to receive joy in doing it. It really has helped too. They call occasionally for a status update, and sometimes I fax a letter to them. I am now anxious to return to work. I need the companionship and to get my life back to normal.

My family also became a haven of support. The cancer strengthened ties that were slipping by the wayside. I spent more time with my mother; the days I had chemotherapy treatments, my mother took off work so she could take me. My father moved back to the northwest from Missouri. I have also heard from extended family members who live out of state. My cousin has called his mom with information he got from the Internet. I started writing to family members that I hadn't talked with in years.

Some of the most interesting friendships I've developed because of this illness have come via the Internet. I joined a support group for lymphoma patients and have been overwhelmed by the caring and support that "strangers" can offer each other. Most of all, I feel this has made me closer with my daughter. She has been such a help, even scolding me for not taking my medication or "overdoing it."

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How to communicate about needs

There's no one way to communicate successfully with others about your needs. Even among people who believe they know each other well, misunderstandings and hurt feelings arise because of daily variations in mood or circumstances of which they're unaware. Your own skills in dealing with cancer come into play, too, when what was not upsetting yesterday may be upsetting today, if you're sick, tired, and discouraged.

Despite these ups and downs, many cancer survivors have learned by experience about communicating with others. Details regarding how to discuss your illness will be touched on in each section below, but some very general guidelines are:

- With your closest loved ones, be as honest as possible, as gently as possible.
- With those to whom you're not very close, use your judgment about what, and how much, to say in order to protect yourself and them from undesirable consequences until you can assess the quality of their responses. You may choose, for example, to tell some family members, social acquaintances, and coworkers a few things about your treatment while avoiding lengthy, painful discussions or topics they're likely to misunderstand.
- For that group in the middle comprising good friends and perhaps some other family members, try to sense the boundary. Just as you have limits to what you can bear, few friends are able to absorb all of your pain all of the time. Asking, "Are you in the mood to listen to this today?" or "Do you have the time and energy to be my sounding board?" are two possible approaches. And the reverse is true: you need to be clear but tactful if you don't feel like discussing your circumstances, for instance, or if you aren't feeling sturdy enough to have visitors.

Exceptions to the rule

The general suggestions above are probably no surprise to you. Nor will be the fact that there are exceptions to every rule.

The general guidelines of telling your closest loved ones the most, with greatest honesty, may not hold. For example, you may have a close relative who handles bad news better if you joke about it a little, but who will never be able to react appropriately to the rawer emotions. He or she may turn tail and run if you cry, for instance. Conversely, you may have a casual friend with a medical background who is a skilled listener, and who can at times provide you with more objective support than your family can. From such an interaction a very deep friendship may grow.

At times, you just can't predict how someone else will react. This experience is retold by a survivor puzzled over the reaction of her husband:

When I was in the hospital with pneumonia six months after my stem cell transplant, my legs began to swell because of the fluid I was receiving by IV. My blood pressure rose from its normal 120/80 to near 200. I was getting scared. I rang for the nurse and insisted that someone consult with the doctors for a diuretic. My husband stood up and said, "I'll be back in an hour." Who knows what was going through his mind?

Although most loved ones will support you, it's not unheard of for some family members and friends to disappear when they discover you have cancer. There's no one solution to this very painful problem. Often, cancer survivors just move on to find new friends, but some justifiably neither forgive nor forget. Sometimes the absentee friend will reappear and apologize, perhaps not until years later.

Loved ones

Some families work better as a team than others. It's rare for any team of people to respond perfectly when it comes to dealing with a crisis. We see these lapses often in the workplace, but we are especially hurt when our families fail to respond appropriately.

Owing to the many variations in group behavior, it's not possible to cover in this section all family behaviors with which you might have to contend. Instead, the most common problems and solutions are discussed.

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For many people of all ages, a new crisis tends to elicit behaviors that worked well in the past, especially at first. These reflexive behaviors might be arguing, escapism, intellectualizing the problem, or taking control. For children in crisis, we might see a return to the dependent behaviors they had outgrown. The overall impression in a crisis may be that those around us are reverting to immature, maladaptive behaviors. Keep in mind that cancer is a brand-new experience, and that learned coping behaviors can be hard habits to change, especially in a time of great stress.

It may be harder for your loved ones to help you if you don't communicate clearly about your circumstances. With this group, don't be shy or proud. Ask for all the help you need, even if it embarrasses you. Many family members express chagrin at the seeming reluctance of cancer patients to "trouble" them. They in turn hesitate to invade the patient's privacy by prying or being dominant. Consequently, the already upsetting cancer experience can transform into an even larger menace than it is, because nobody will talk about it.

On the other hand, if your family is closely knit, sharing and verbalizing just about everything, the stresses associated with cancer might appear to be taking a greater toll than one might see in a family with fewer emotional ties and more independent members. The telling point is the success of your family's long-term adaptation, not any temporary disequilibrium, emotional flotsam, or distancing you may experience.

What you need from loved ones may change as your experiences evolve from diagnosis through treatment. Different relatives and loved ones may prove good at handling different things. Unlike coworkers and casual acquaintances, close family members and loved ones probably won't surprise you too often with their reactions, because it's likely you already know their weaknesses and strengths. You may find yourself occasionally disappointed, but perhaps not surprised.

Communicating needs to adults

Ideally, communicating with the loving adults in your life about your needs should be relatively easy. Honesty, gentleness, and especially gratitude should

serve well. With a couple of exceptions, such as a relative who's mentally ill or otherwise frail, adults who are nearest and dearest should be trusted to handle every aspect, even the worst aspects, of your illness appropriately.

But cancer challenges a family's beliefs and myths about their family unit and may alter the established dynamics of the family. If the father, mother, husband, or wife has always been a wise and strong provider, for example, the balance of power may shift temporarily during treatment for cancer. If the partner without cancer has developed an untoward reliance on the strong one, it may be a difficult transition to assume control for a while. The partner with cancer may suffer lowered self-esteem when roles shift. It's important to keep in mind that often these shifts are temporary.

Many cancer survivors note that their loved ones become ill, too, while trying to help them deal with treatment and emotional issues. Upper respiratory infections such as sore throats, persistent GI tract problems such as diarrhea, emergence of autoimmune disorders, and worsening of certain other chronic illnesses such as herpes or diabetes often go hand in hand with the extreme emotional stress associated with a loved one's having cancer. At times, though, cancer survivors report that a relative seems to want to be sicker than the person with cancer. This does indeed happen in some families, and if it happens in yours, chances are you've seen this kind of behavior before from that individual. The deciding factor is whether the ostensibly ill person continues to provide help to the best of his or her ability, or uses the illness as an excuse not to help—or even to punish you.

If you find that the adult loved ones in your life are reacting to your needs in unhelpful ways, do ask why. It may be a simple thing to put right. If they seem angry, of course you needn't apologize for having cancer, but it's likely some older, unresolved issues are being forced to the fore by the stress of dealing with cancer. They may feel, for instance, that they owe you little because in the past you were not supportive of them when they needed help. Communication, humility, and open-mindedness may work to break the impasse.

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If attempts to communicate don't make much difference, it may be a disappointment to realize that the strength you thought existed in the relationship does not—or at least not for this set of circumstances. Perhaps you could rely on someone else temporarily for what you need. Sometimes loved ones just need some time to settle down and get used to the changes and increased responsibilities that cancer brings.

Avoid asking a third family member to intervene if you have difficulty getting along with a loved one. Triangles such as this seldom succeed because they hint at two against one, and talking behind each others' backs.

If reasonable attempts to get the help you need fail, you might discuss attending family counseling with the person who seems to be acting out of character.

If none of these attempts works, then finding alternate support or finding ways to live without such people, temporarily or permanently, is in your best interest. Because of the seriousness of cancer, your concerns must be put first, at least for the time being. You may be surprised to find that, in spite of cancer, your life is more serene and enjoyable in the absence of such difficult people. A decision not to deal with someone is also a means of dealing with them.

Communicating with children

Communicating needs to young children has different goals than communicating with adults. While it's true that children sometimes provide major instrumental support if no other family members are available, generally it isn't necessary or fair to expect a great deal of help from children. More often, they can be asked to help with small, safe chores in order to make them feel part of the solution and to reinforce the honest relationship they've grown accustomed to.

Human children are inclined by biology to think the world revolves around them. Very young infants do not understand, for instance, that Mommy is a separate person who can leave them with Daddy and go grocery shopping, and they may become quite upset when they discover that Mommy is gone. This bonding trait is probably essential to survival for a species whose young

have a long and vulnerable nurturing period, such as humans and some other mammals have.

This egocentric thought process lingers well through childhood, though, and causes children to think that the bad things that happen are their fault. They may think that you developed cancer because they were very angry with you when you once punished them, for example. They may even have wished you were dead, and now it appears to be coming true. Depending on their religious upbringing, they may believe that God saw them misbehave and is punishing them.

For many reasons, our children see us differently from our view of ourselves. Lack of experience with emotions, fear of abandonment, or just plain being shorter than we are means their perspective is truly different. Often small children can't distinguish a sad adult face from a grouchy one, for example, and because we are all-powerful from their perspective, unconsciously they hedge their bets by tailoring their actions to forestall anger instead of sadness, which from their perspective is the worse of these two in terms of the consequences for the child.

This difference of perspective may also cause efforts to explain cancer to backfire. If you try to compare cancer to any illness they've had, it may create an extreme fear that becomes obvious when the next normal childhood illness strikes them.

For these and other reasons, honesty with children about cancer is essential. The following story describes the fear and confusion that Nan, a childhood non-Hodgkin's lymphoma survivor, experienced after her family excluded her from the truth about her diagnosis and thus from the emotional cohesiveness and goal-oriented mindset of the rest of the family:

My parents didn't tell me that I had cancer when I was a teen. Back then, cancer was the "c" word, and they were petrified. I'd been given three months to live, and mom and dad were determined that by not saying that aloud, we'd all be better protected. So, for five years, I imagined I had "reactive/viral lymph nodes"—until I read my chart upside down in the oncologist's

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office, then looked up “lymphoma” in the dictionary!

It was confusing. If all I had was some sort of virus, why couldn't I go to camp? Why was I spending all summer at the Mayo Clinic in treatments that made me violently ill and caused my golden hair to fall out? And why did everyone in line for the experimental radiation look like they were dying? My parents, my source of trust and safety, told me I was okay. My external cues and my own devastating side effects challenged my parents' assurances. Inside somewhere, I knew...

Today, I forgive my parents. I know how terrified they were. I also, however, believe in disclosure, and I help others communicate with loved ones about their disease. Doctors need to inform their patients, even children, about the facts. Parents can tell even the youngest kids, with age-appropriate discretion, what is going on. But even the wisest among us needs help, since in our roles as doctor, parent, caretaker, we are not accustomed to creating sadness and fear in those we love.

Nan was cured of aggressive childhood non-Hodgkin's lymphoma, but developed a low-grade form of the disease twenty years later. Today, Nan is a licensed counselor specializing in cancer survivorship issues. She offers these thoughts based on both experience and training:

Disclosure is linked to fear. So often I hear, “Nan, I can't tell my daughter about my illness. She will be so afraid. And why burden her?” No doubt there is an element of protectiveness. I feel that myself to this day with my kids. But an additional translation might be, “Nan, I can't tell my kids because I am so afraid of their fear. What do I say when they ask me if I am going to die?”

There are specific circumstances which might create the exception to the “tell” rule: the age of our kids and their emotional stability...our specific patients we work with.

But the key question I ask of all who say “no way” is, “What are you afraid will happen if you tell them?” Usually the fears are about us, not them.

Communicating needs to teenagers

This is a topic on which an entire book could be written. An adolescent trying to break away from the family and become independent is likely to experience quite ambivalent feelings if a parent is diagnosed with cancer. Just at the time in his life when he'd rather avoid talking to any adult, circumstances may force him to become very intimate and empathic with a parent. He must be patient and caring toward one of the people most likely to make him angry by holding him to high standards, enforcing rules, denying him privileges, or restricting his freedom. Some find that teens turn surly or run amok when faced with the physical, emotional, and financial hardships associated with cancer.

Nonetheless, some people find that their adolescent children are extraordinary in their ability to comprehend what's needed, and that they follow through with a maturity that's well beyond their years.

But—even more so than younger children—teens can appear to be knowledgeable and well-adjusted when in fact they are not. This group may have an intellectual maturity that is beyond their level of emotional maturity. A willingness to overlook unexplainable lapses and an honesty that is geared to their level of understanding are wise. Frequent offers to chat candidly are a good tactic. These offers confirm their belief that they can approach you about difficult subjects.

If you have a teen who is developing behaviors that are a danger to herself or others, such as acting out rage, violating laws, or considering dropping out of school, find a counselor who specializes in the adaptation of children to serious illness. Attempts to handle these problems by yourself may risk compounding your health problems, may make of you a psychologically abused parent—and they may fail anyway. A teen may carry “cancer anger” formed during these especially rebellious years well into adulthood.

If you have a teen who is doing housework and assist-

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ing with medical care while continuing to carry his academic responsibilities, thank him at least daily.

Mary, a five-year transplant survivor, describes how easily she misinterpreted what her son was thinking and feeling:

My son was in high school when I was diagnosed. Those difficult years were just beginning. I tried to include him, without giving him too much information, so that he would not feel frightened that we weren't telling him everything. As time and treatment wore on, he withdrew more and more. I thought he didn't understand completely. What I didn't realize—because I was so understandably self-involved, I suppose—is that he was withdrawing in terror.

He visited me just one time in the transplant unit. My husband was careful to wait until I looked somewhat better before bringing him for a visit. At the time, the whites of my eyes were black with blood, and my skin was yellow and peeling all over. I was bloated and bald. My son had to wash with bacterial soap and put on a gown, mask, and gloves just to enter my room. I was so happy to see him it didn't register that what he was seeing was making it so much worse for him.

When I was released from the transplant unit and home a couple of days, we were sitting in the kitchen together. I was still only up for a few minutes at a time, and we hadn't had any time together before now. I sat smiling up at him as he sat on a stool, and suddenly I realized he was sobbing. I'll never forget the pain that flowed out of him. "Mom, I only had two things to worry about this year: whether or not I got my homework done and if my mom was going to die."

Good friends

We expect our good friends to stand by us while we're facing serious problems. Close friends can offer us help such as emotional support, occasional running of

errands, some cooking, household chores, babysitting, or an escapist night on the town. As with loved ones, we may occasionally be disappointed or surprised if they fail to live up to our opinions of them. On the other hand, many cancer survivors have discovered that good friends earn their wings in heaven by way of loyalty and selflessness, and that some come to mean as much to us as our families do.

Because they usually have a lower emotional investment in the relationship than family members do, good friends can be easier to deal with at times than family. They can be more objective about some of our problems.

This objectivity is purchased with their relative distance. Good friends, in order to remain good friends, may need an occasional vacation from us and our problems. If we give them space to refresh themselves, they are able to return to us with more emotional vigor.

Most people will find that at least some friends or acquaintances will have responses that are disappointing. We can't control how other people react to cancer.

When my husband was first diagnosed with lymphoma, I phoned my best friend to tell her. After my call, she didn't phone me for about a week, although we work on the same campus, used to speak about once a day, and usually had lunch once or twice a week. A few years prior, her father had died of acute leukemia. Several months after my husband's diagnosis, she admitted that at first it was just too difficult to face cancer again.

Mary, a survivor of a transplant, describes her experiences with friends who couldn't face her:

I had a number of friends disappear. What surprised me were which ones disappeared: I never would have imagined those particular people abandoning me—or anyone—under those circumstances. At first it was very painful. I kept thinking I had done something to offend them. Over time, I realized that, for whatever reason, they couldn't handle my being sick, or my not

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getting well faster. It didn't really matter because ultimately cancer was a wonderful tool for separating the wheat from the chaff. It was a gift in disguise, because the quality of the friends that stuck it out or surfaced during the crises far exceeds the quality of any of those that left. Maybe that sounds petty or mean, but I don't intend it in a vengeful way at all. It's simply the truth.

Your experience with cancer may be your most vulnerable, powerless experience since early childhood. Getting the support you need is critical to adequate recovery, especially during and after relatively risky procedures such as bone marrow transplantation.

We humans are imperfect. It's unfortunate but true that if we don't communicate clearly, if old resentments linger, or if altruism dries up, the formidable single problem of facing cancer might evolve into six or seven additional problems.

Many of your closest friends and family members may provide you with wonderful support. Whether they do or not, consider looking beyond your most intimate circle by participating in support groups as well as being open to support offered by other social acquaintances and your coworkers.

This fact sheet was derived from *Non-Hodgkin's Lymphoma: Making Sense of Diagnosis, Treatment and Options*, by Lorraine Johnston, © 1999 by Patient-Centered Guides. For more information, call **(800) 998-9938** or see www.patientcenters.com.