

Cancer and the Family's Needs

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Individuals who are diagnosed with cancer need, in addition to good medical care, useful information about what to expect and help in coping with and making sense of the turbulent emotions that can accompany a cancer diagnosis. Often the major focus is, understandably, on the person diagnosed with cancer. The result may be that the family's information needs and help with emotional reactions are overlooked. In general, it is rare to find skilled health professionals who are responsible for the care and well-being of the family once a member has been diagnosed with cancer.

I first became aware of the needs of the children of cancer patients some years ago when I began to provide cancer risk information to adult women whose mothers had been diagnosed with breast cancer some many years before. I was surprised at the depth and often raw quality of the emotions these daughters expressed about their mothers' breast cancer diagnosis and the effect it had had on their own lives. Even many years later, these daughters were living what might be called blighted lives. That is, they were living the shadows of lives they might have had, and made statements such as "I feel like a walking time bomb," "I'm living as if there is a sword over my head," "I still feel separate and different from other people," and "I have trouble feeling close to others."

As a group, I found that adults of either sex whose parent was diagnosed with

cancer when they were children often felt that they were doomed to follow the same course as their parent, were anxious about their own cancer risks, and even blamed themselves for worrying. Many felt unsure about how to proceed to set up a health care program that would keep them as safe as possible and help them to feel safe. I often heard words such as "I just feel in my bones that it will happen to me, too." As a consequence of their strong emotions about cancer, which often included hopelessness and despair, many had no medical follow-up or had inadequate medical care. In fact, some felt so sure that they were "hypochondriacs" that they had less care than women without a family history of cancer.

The parents and the spouses of those diagnosed with cancer told me of their confusion, of their feelings of loneliness, and of feeling excluded from the person with the cancer diagnosis. Some spoke of feeling betrayed by modern medicine or of being overwhelmed by the need to assume new responsibilities for such major tasks as finances and child raising.

These families benefited greatly from the following:

- ***Information About and Help in "Navigating" the Medical Care System*** Many do not know where to turn to get their questions answered. They do not realize that these days it is highly unlikely for any one physician to provide all of a person's treatment. Until the families

knew which specialists provided what services, they were very confused. Some felt abandoned by doctors who did not provide what they had expected, though they had not verbalized their expectations or ever known what to ask. Once individuals understood the system, they could proceed with more confidence and could request what they wanted. And once they had a better understanding, a great deal of their anxiety was reduced.

- **An Accurate Assessment of the Risk of Cancer to Family Members** Most cancers are not due to strong hereditary factors. In fact, only about 10 percent of each of the common cancers is thought to be due to strong hereditary factors. Nevertheless, when close relatives are diagnosed with cancer, many quite naturally feel that they are now at “high risk.” A family-history assessment by a geneticist to determine individual risk can be most useful, even for very young children, whose risk may not be imminent or is far less than they had imagined.

- **Information About Individual Risk Given in Concise Terms** A great deal of the information we read and hear is in a format designed for scientists, not for concerned individuals. This format is far less useful or may even be confusing when individuals attempt to apply it to themselves. Generally, risk information is more likely to be useful to an individual when it (a) involves a time frame (for example, a 10 percent risk in the span of one year is very different from a 10 percent risk that is spread evenly over the next ten years) and (b) is expressed in actual or absolute terms instead of as a comparison of one group's risk with that of another. (For example, learning there is a 10 percent risk that is spread over ten years is more useful than hearing that the risk is twice as high as or is 35 percent less than another risk.) When risk is presented in comparison terms, individuals don't learn what they

most want to know—the actual risk—so it is hard to make intelligent decisions based on what they have heard.

- **Information About How a Cell Becomes a Cancer Cell** An understanding of the origin of cancer can greatly reduce the mystique about cancer and help individuals think about cancer more clearly.

- **Information About the Importance of Communication with Others and How to Communicate Needs and Concerns Effectively** The more family members are able to communicate with each other and share information and their feelings about what is happening, the happier, healthier, and stronger they are and will be in the future.

Children Who Have a Parent with Cancer

The parents I see frequently underestimate the fears and questions their children have. Many worry that by talking to their children about cancer, they will frighten them. Parents may not realize how easily children pick up on the emotions of the adults around them. In most instances, there is no way to hide the fact that *something* is different once a parent has been diagnosed with cancer. Many of those I see who were children when their parents were diagnosed with cancer were either not told about their parents' cancer diagnosis or were told very little. These adults are far more likely to feel anxious and less trusting than those whose parents kept them informed about what was happening and were honest about their feelings.

When a parent is diagnosed with cancer, both parents may feel that their children are “just fine” or not that interested in what is going on. Some say, “Whenever I bring up the cancer, they say they don't want to hear about it, that everything will be just fine, or they leave the room.”

In such cases, it may be helpful to put an arm around the child while explaining what is happening. There is no need for a long discussion, but there are some essential points to get across

- Mom/Dad was diagnosed with cancer.
- Not all cancers are alike.
- New and better treatments are being discovered every day.
- Mom/Dad is having good care and treatment.
- Sometimes the treatments and the diagnosis are stressful and scary, so there may be tension in the house and even sorrow or crying. This is normal for such a time. The doctors say that in a few months, life will be a lot easier, and that we will all feel much better. You can help by remembering that this is a stressful time, that it will change, and that we love you very much.
- The type of cancer Mom/Dad has is not found in children (most cancers are not). Most cancers do not run in families. By the time you are grown, doctors will be able to stop many cancers or treat them in easier ways than is possible right now.
- Mom/Dad is fine at present. The treatments are proceeding the way they should. If there is a problem in the future, we will tell you right away. I hope that if ever you don't feel well, you will tell us also. Meanwhile, it is important for you to keep doing all of the things you do every day and to tell me if you are worried. We want you to go on about your life as much as you can.

Obviously, these comments need to be modified for the age of the child and the family situation.

The Spouse or Partner of a Cancer Patient

Few appreciate the pain, fear, and confusion endured by the spouse or partner. And while attention and treatments are

being given to the person with cancer, the spouse is sometimes shunted aside. Little or no time is spent giving the spouse of the cancer patient tips about how to proceed, leaving many to tell me they felt they had to "reinvent the wheel." For example, many of those who were diagnosed with cancer say that when they try to tell their partners about some of their fears, the response is, "Oh, don't worry about it. I'm sure everything will be okay." When this reply is repeated several times, the person with cancer may refrain from communicating his or her fears about the cancer diagnosis and the couple may draw apart.

Instead of remaining quiet and suffering, the person with cancer might find it useful to tell the spouse what is actually needed in direct terms, such as, "I've noticed that when I tell you I'm scared, you tell me not to worry. I'm thinking you say that because you care for me and you don't want me to worry. But when I tell you how worried I am, what would help me most is a hug and to hear you say how much you love me and that you worry sometimes, too."

In general, the more the couple can talk about the areas in which they feel they are not communicating and the more they can be direct about their wishes and needs, the more the relationship will be strengthened. Also, the more the spouse can participate in the ongoing decision making and discussions and the more experiences the couple can share, the less likely it is that they will drift apart. When it is not possible to share the experience, talking about it together later can help spouses to stay in touch. Unless this ongoing communication occurs between the person with cancer and his or her partner and children, family will be unable to know what the person with cancer is experiencing and feeling. In time, the person with cancer can begin to feel like Marco Polo—coming from afar with fantastic stories and

having feelings that are hard for others to understand.

Many spouses of cancer patients are greatly helped by having an opportunity to get away from their home responsibilities on a regular basis and having someone other than the person with cancer with whom they can speak.

Friends and Relatives

After a cancer diagnosis, many people tell me that friends and even relatives don't call as often as they used to. Some even appear to be avoiding them. In time, the person with cancer may conclude that those who haven't stayed in touch just don't care. In such cases, it is not uncommon for a breach to occur in a family or for old friendships to end. It is important at such times to be aware that friends and relatives may sometimes need to be educated. Some may not call because they are afraid of saying the wrong thing or of calling at the wrong time, or because they just don't know what to say. Many of those with cancer have great success when they call a friend or relative and say straight out, "I haven't heard from you in a while and thought it might be because you don't know what to say or you thought that I might be resting. Well, you don't need to watch what you say now any more than

you did before. I'm the same person in many ways and I'm getting good care. Sometimes it's hard, but I am not too busy or too tired for old friends. I hope you won't let this come between us. Would you like to go to a movie [take a walk, etc.]?"

An Approach That Meets Families' Needs

Some of the families I've seen were fortunate enough to obtain some or all of the types of help discussed here. Others, who had less or none of this help available, endured more pain. A comprehensive service is needed for *all* families in which a parent has been diagnosed with cancer. Ideally this service would utilize the expertise of an oncologist, a geneticist, and a psychotherapist to supply information and support. In this way, questions and concerns could be addressed as they arose, before any became troublesome to the workings of the family or to the normal growth and development of the children. Spouses would have their needs met in a timely manner as well, which would enable them to provide more comfort to the person with cancer and to the children. Even when a diagnosis of cancer has occurred some years before, families would benefit by having access to this service.