



YOUR GUIDE TO SUPPORT SERVICES

FOR YOU AND YOUR FAMILY

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Introduction

The Fox Chase Cancer Center is committed to a comprehensive approach to dealing with cancer diagnosis and treatment. Medical services are of course the main reason that people choose Fox Chase as their treatment facility. Fortunately, Fox Chase, being a comprehensive cancer center, is able to provide support services (help with emotional and family problems) to you and your family. Often these services are not available in community hospitals due to constraints imposed by insurance providers or budget issues. This often short-changes people who may need help in dealing with an illness that is experienced as "catastrophic" by many. Finding these services in the community is often difficult, as it may be hard to find counselors who specialize in oncology. So if you have chosen Fox Chase as your primary provider of medical care, you can be assured that support services are part of the package of care that is available to you and your family.

Cancer is a very complicated disease and requires the help of a variety of specialists in managing it. Just as patients need the services of a surgeon, medical oncologist or radiation oncologist, there may be times during your experience with cancer that psychosocial support services may be helpful. By psychosocial support services, we mean those services that will help you to deal with the emotional, family and practical problems that can occur in dealing with a chronic illness. Cancer is often called a "family disease" because it affects more than the person who is diagnosed. Patients and their families have a powerful influence on how each deals with cancer diagnosis and treatment. It is not possible for patients and those important to them to act in isolation from each other and in fact, to try to usually make the situation even more complicated. Cancer is no longer an inevitably fatal disease; many types are curable and all are treatable, enabling patients to live many long and fulfilling years after their diagnosis. Psychosocial support services may enhance the quality of your life and help you with whatever difficulties and special challenges you may be encountering.

Why Would People Need Support Services In Dealing With Cancer?

Most people struggling with a new diagnosis feel as if this is the most serious situation they could possibly face. The word 'cancer' still evokes images of death and/or suffering even though heart disease actually is responsible for more deaths than cancer. This fear and anxiety that patients describe makes the emotional burden of cancer greater than for many other diseases.

A person's reaction to cancer is influenced by a number of factors. Some of these are age, culture, family beliefs about illness, finances, philosophy of life and the nature of the cancer itself. Younger people have different struggles than older people; optimistic people may find stress easier to cope with than pessimistic people; people with financial problems may have fewer choices than those with higher incomes. So there may be factors over which you have no control that may make a cancer experience especially difficult.

A cancer diagnosis means learning a whole new body of information to understand what is happening physically and emotionally. Many decisions will be made in the first few weeks and months of your diagnosis. Different decisions will need to be made as your experience with cancer continues. In addition to learning and understanding the language of cancer, decisions will be made about where to be treated, choosing a physician, treatment options, and managing treatment side effects. In addition to the medical issues confronting you, it will be useful to learn what you can about emotional responses to cancer so you are in the best position to help yourself and your family.

What Can I Expect From Fox Chase Cancer Center?

The Department of Social Work Services is available to any patient or family member who needs our services. You can access these services at the beginning of your diagnosis or at any point along the way in your experience with cancer. The advantage of getting help in the facility where you are being treated is that it saves you the emotional energy it takes to be going to multiple places to get help. It also assures

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you that the professionals you will be dealing with are specialists in oncology and how it affects patients and their loved ones.

Of course, you can also seek help from professionals in the community who may be closer to your home or possibly where you have gotten help in the past. (Finding someone who is experienced with cancer in your community is addressed in a later section). You can also find help from support groups in your community, telephone services, and through the Internet. **(See item ** for help with Internet)**

The Department of Social Work Services is staffed by oncology social workers who possess a master's degree in their chosen field and have often had additional training in oncology. Sometimes people think that social workers only work with poor people and wonder how they could be of help with a cancer problem. Actually the field of social work is very broad with people working in child welfare, medical and psychiatric hospitals, family service agencies, schools, mental health agencies and as private counselors. Fox Chase understands that dealing with cancer is more than blood tests and medical appointments. It also includes dealing with the worries and fears that are a natural part of being diagnosed with a serious illness.

At Fox Chase, there are 9 oncology social workers available to you and your family. Social workers are assigned to particular diagnoses or groups of diseases so that they become specialists in the problems of that particular diagnosis. For instance, a young woman with breast cancer will face different challenges than an older man with prostate cancer. You can expect that the social worker on your treatment team knows about the problems that come up with your particular diagnosis.

Fox Chase also consults with a psychiatrist who is on the staff at Jeanes Hospital with which we share a campus. Referrals to the psychiatric staff can be arranged through your doctor or by a social worker. We can also help you find a psychiatrist experienced with cancer in your own community. Referrals to a Fox Chase social worker are discussed below.

"Crisis intervention" is the term that describes most of the support services that occur in hospitals. An example is what happens when someone is first diagnosed with cancer. Patients facing a new diagnosis describe feelings of being numb or "in shock". They have trouble concentrating and absorbing medical information so that decisions can be made about treatment. Feelings of anxiety, sadness and even panic are common. Sometimes patients are so overwhelmed by fears about the future that they have trouble focusing on the "here and now". An oncology social worker can help people absorb accurate medical information so that wise decisions about treatment can be made. We will help you prioritize your concerns, prepare for treatment and develop a kind of roadmap to help you and your family deal with the first weeks or months of treatment.

At Fox Chase, oncology social workers are part of a larger team of people including doctors, nurses, rehabilitation specialists, radiation technologists, nutritionists, etc. Sometimes oncology social workers meet every patient particularly if the patient is being evaluated for a complex treatment. More typically, other members of the treatment team refer patients to us. A referral may be made for help with the emotional impact of cancer or for more practical problems like how to get transportation services or where to buy a wig. If you think you would like to talk to a social worker, call 215-728-2668 to arrange an appointment.

The oncology social worker will want to know how you and those close to you are reacting to the illness and what problems may have come up for you or your family. Health care professionals understand that cancer is a complex disease with the potential to cause significant family stress. Just learning about some of the issues from people who have worked with other families dealing with cancer may be helpful. An example might be how to explain a cancer diagnosis to young children in such a way that fosters confidence and hope. The more that you are prepared for the challenges that may occur, the easier it will be to avoid getting into trouble emotionally.

How Will I Know If My Family Or I Need Support Services?

Your feelings about what is happening to you may be a useful yardstick to use in evaluating how you are doing emotionally. In the beginning of a cancer experience, most patients go through a period of turmoil, characterized by feelings of anxiety, sadness, and fear about the future. You may have questions about why this has happened to you, the meaning of life in relation to your illness, your relationship to God, along with worries about your job, finances, insurance or other practical matters. Gradually, as you move through the first stages of treatment, you will be dealing with these feelings and concerns and figuring out how to begin addressing them. If you have close relationships with other family members or friends, they will play a part in helping you figure out how to manage the experience. *If these concerns are not addressed or you find yourself feeling very sad or preoccupied much of the time or unable to make decisions, it may help to talk with us.* Your goal will be to gradually feel more in control of the situation and able to manage yours and your family's worries. Chronic feelings of hopelessness, anxiety, and fear will deprive you of the energy to cope with your current situation. The advantage in talking with a professional can be to find quicker solutions to the problems you are worried about rather than struggling on alone.

Other family members will have their own concerns as a result of your illness. If you are married or in a long term relationship, your partner will be trying to figure out the meaning of your illness in relation to his or her own life. Sometimes couples have a very difficult time communicating about a new diagnosis. This is usually because of unspoken fears about the future and how life may be different as a result of the cancer. It is normal to want to protect the people we love from difficulty but sometimes this results in people feeling very isolated from one another. It is also to be expected that people will sometimes feel angry about what has happened but be troubled about having such feelings. Gradually people learn ways of communicating and find safe ways of expressing their concerns. If this process seems to be stuck and you and/or your partner can't figure out how to meet each other's needs, it can be helpful to talk with someone outside of your relationship to gain some perspective.

These issues can feel more burdensome if you are single or you are in a relationship that was already troubled before the cancer. Single people may need to identify other ways of getting support. Friends or extended family members may be more important during this time. Or a single person may want to seek out an oncology social worker or join a support group in order to meet others who are dealing with the same issues.

With troubled marriages or relationships, it will be important to find help so that your problems don't interfere with your ability to handle the illness. Dealing with a new cancer diagnosis along with a troubled relationship can feel quite stressful. Sometimes people worry that marital disagreements or unresolved stress will interfere with their ability to get well. *There is no evidence that stress causes cancer or interferes with positive treatment results.* However, it will affect your quality of life and make it harder to cope with day-to-day problems.

Why Would People Be Reluctant To Seek Help With Emotional Or Family Problems?

For many people dealing with cancer, just sorting through the medical decisions that need to be made is an enormous challenge. They may not have the energy to cope with much more so dealing with emotional issues gets ignored or put off until later when life feels more settled. This is understandable as people can only cope with so much at one time.

One of the important concerns for people needing support services is how they feel about asking for help. People somehow have the idea that they should know how to handle every emotional problem that comes up, even though they have never been confronted with a crisis like cancer. Sometimes, people see needing help with a problem as a sign of weakness. This is not true-in fact asking for help can be a sign of strength. There is no way you can be expected to know all there is to know about coping with cancer until you have had experience with the

disease. Think about what it would take to play the piano—most of us would find a piano teacher. Athletes usually get a coach in order to be really competitive. Learning about what you might expect from yourself and other family members can help you to solve problems quicker than attempting to solve them alone.

There are other reasons to ask for help early. During periods of active treatment, you may feel tired and overwhelmed with all there is to cope with physically. In addition to your physical needs, family members will have their own reactions and worries that you will need to respond to. This takes energy and you will need to preserve yours as much as possible to deal with all that is happening. If family problems are worrying you, it may be harder for you to feel in charge of the situation. The Fox Chase staff wants to help families maintain a reasonable "quality of life" in the face of cancer treatment. *This means making good choices about managing the illness, preserving your hope for the future, and taking charge of the situation.* What you don't want to have happen is to feel victimized by the disease or feel that the disease has taken over your life. You will always have choices about how to feel and think about the situation.

What Kind Of Support Services Should I Consider?

Support services for people with cancer are usually available as individual counseling, family counseling, support groups, complementary/alternative treatments and even on the telephone or Internet. Making a decision about what support services might be helpful depends on a number of factors, such as what services are available from your hospital or community, the cost or location of these services and what kind of insurance coverage you have. Support services in the hospital where you are being treated are usually free while community agencies or practitioners typically charge a fee. Agencies sometimes have a sliding scale meaning the charge is based on your income. In some communities, there are organizations like the "Wellness Community" or "Gilda's Club" that offer free support services to cancer patients and their families.

Deciding what kind of help to get depends on your understanding of how your reaction to the cancer is affecting you and your family. For example, if you are a young parent and are feeling sad or depressed, it may be hard to find the energy to respond to young children. You may be feeling too preoccupied and worried to deal with all that is going on. Or you may be an older person who is finding it difficult to accept the help of your adult children in managing your illness. Talking with a counselor may help you put a new perspective on the situation and find ways to solve problems that you may not have thought of. Often, feeling more in control of your own feelings and reactions may be all it takes to help your family to get back on track.

Sometimes people need to do more than one thing to begin to feel better. For example, counseling combined with an antidepressant medication may be worth a try. The point is that there are many kinds of help available---if what you are doing doesn't seem to be helping, you may need to experiment with other strategies in order to feel better. The vast majority of people are able to learn to cope with cancer.

You may feel that you are doing fine emotionally but have worries about how to get to the hospital, concerns about your insurance, where to buy a wig or other prosthesis or what to tell your employer. We can help with these kinds of practical problems also. As we have said before, it's easier to get this kind of information from people who know about the resources available to you than to use up your valuable energy finding them yourself.

What About Support Services And Confidentiality?

As all services are confidential, you may want to talk to your social worker about what will be documented in your medical record. Usually what is documented concerns how you are dealing with the cancer and whatever else is going on which will help you cope or might make it more difficult. If you have particular worries that you don't want shared with your treatment team, tell your social worker. Your needs for

privacy are important and you will need time to develop trust in the health care team caring for you. You are in charge of what you want people to know about you or your family.

The exception to this is when someone is suicidal as the counselor has a legal and moral obligation to try and protect that person. In that kind of situation, the social worker would explain to the patient that they must share that information with their doctor so that we can help the patient get relief from such a terrible burden. Also if medications are suggested to help people get over the rough spots, the doctor needs to know about that so that these drugs are compatible with other medications you are taking. The next sections discuss other kinds of counseling that may be helpful to you and to the people you care about.

What Can I Expect With Individual Counseling?

Individual counseling offers an opportunity for you to talk with one of our staff about what is worrying you and to figure out how to tackle those worries. We will ask questions about how you and your family are coping and what is worrying you the most. You might find that talking about the situation puts a different perspective on things. Focusing on how you have dealt with problems in the past may help you to figure out what to do next. We will help you prioritize your needs so greatest needs can be addressed first. You may talk about different ways to approach the situation before deciding what to try first. It is important not to get impatient or frustrated if your first approach doesn't seem to be working. Problem solving is often a stop and go process--you may try out a variety of possibilities before arriving at an approach which is right for your family.

We will probably also ask you what you understand about your medical situation to be sure that your information is accurate and sufficient enough to make treatment decisions. People need different amounts of information so our goal is not to tell you everything that is known about your diagnosis but to be sure you have the right information for you. In this regard, you may also be experiencing problems talking with your doctor or another health care professional. We can also help you sort out sensitive problems like that. Remember that all of the information you choose to share is confidential.

You may feel very much better after one or two sessions with an oncology social worker. While that is a good thing and probably means you have found the right match for you, it doesn't usually mean that your problems are all solved. It may be that what you are feeling is the relief that comes from sharing your worries with another person. Human behavior is very complex and not easy to change. Also, understanding why we feel and/or behave in a certain way doesn't necessarily mean we will be able to quickly feel or act differently. So give the counseling process adequate time in evaluating how useful it is for you.

Problem solving is a complex process and is influenced by a variety of factors. These include your feelings about the situation, personality characteristics and relationships among family members, your ability to be flexible and to try new things, and the effects of other life events. For example, if you are having problems at work, this may interfere with your ability to cope with what is going on at home. If you are experiencing difficult treatment side effects, you may have less energy to cope with a spouse's expectations.

It is easy to be critical of yourself, but when dealing with a diagnosis of cancer it may not be possible to feel in control of every thing going on in your life. Understand that you are probably doing the best you can and that it will take time to feel like yourself again. Cancer is both physically and emotionally taxing and people often underestimate the toll it can take on them and their families. Don't be hesitant or afraid to seek the support you need in order for you and your family to begin to feel better.

Suppose My Family Doesn't Think I Need This Kind Of Help?

If you decide that you would like to try meeting with an oncology social worker, you will probably find yourself talking this over with the important people in your life. Hopefully, those people will be supportive

of the idea but sometimes patients are surprised to discover that this may not be so. If you are married or in a long-term relationship, your partner may be worried that your desire to get help means there is something missing in your relationship together. If you are a young adult still living at home, your parents may feel they have failed in some way. Or it may be that your family wants to be included and you would prefer to sort things out for yourself. These situations can be very stressful, as the decision to try counseling is not an easy one. People have a hard time with the notion that they can't easily solve any problem that comes along. While this reaction is understandable, it's not necessarily logical or helpful. No one questions the fact that we are not all auto mechanics and can't take a motor apart to solve a car problem. The same applies in asking for help. The point is that there are many different support services available. If one isn't right for you, chances are something else will be. If you see a counselor, we suggest that you give it two or three sessions to decide if it's helpful.

When Might Family Counseling Be A Better Option?

Fox Chase social workers also see patients along with their family members. We very much believe that families are essential to dealing with this experience and no one operates in isolation from the other people who are important to them. Family members have their own reactions to this kind of a crisis and even if they are not sharing their worries, they are there. Medical care that is only oriented to the patient is not very useful; as people exist in a world with other people they care about, not in hospitals. This is not to say that all families are harmonious and able to throw themselves wholeheartedly into the experience. However, whatever the relationship, they should be included so that the patient gets the chance to benefit from all of his or her resources.

Some professionals think that family counseling is the best way to cope with cancer because a diagnosis of cancer always affects other family members. Behaviors among family members are influenced by many things--life experiences, personality, feelings, the quality of relationships, the family's stage of development (composed of young, middle aged or elderly people), cultural and racial characteristics, finances and family belief systems, to name a few. For instance, if a family believes that problems should not be shared with outsiders, that family might have difficulty accepting help. If a family believes that children should be spared any exposure to the painful realities of life, that family would probably not be comfortable telling a child about a parent's diagnosis. These two belief systems can make a cancer diagnosis more difficult than it needs to be and counseling may be helpful in trying to think about a problem in a new way.

One of the ways to decide about family counseling is to look at what is going on among the people you care about. Ask yourself the following questions:

- Can I talk to my spouse about how I feel?
- Is my spouse or partner able to listen to what I am saying or does it seem to be too painful for them?
- Does it help to talk to the important people in my life when things are going badly?
- Do my partner and I always end up in a fight about how we expect each other to be reacting?
- Do my children seem more worried, sad or lonely than before the cancer?
- Do they tell me how they feel?
- Are my children misbehaving more than usual?
- Do we seem unable to enjoy being together as a family?
- Are we fighting among ourselves more often?
- Are my children backsliding in their development? (For example, having more difficulty separating from you, maintaining toilet training, being unable to play by themselves or being unusually dependent on you.)
- Is my family able to accept help from others?
- Do I resent it that people outside of the immediate family seem happy?
- Do I feel angry a lot of the time that others don't have this burden to deal with?

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- Are my constant feelings of sadness or anxiety affecting those people I care about?
- Are financial or insurance problems interfering with my ability to deal with the situation?
- AM I or my partner less interested in sexual intimacy?
- Do my family members have problems that are making it more difficult for me to cope?

The issues described above happen in all families, to some degree at different times in our lives but may be more troublesome now. In the typical family with its mixture of different personalities and ways of behaving, change is often difficult. Recognizing a problem and understanding why you or your loved ones behave in a particular way are important steps in figuring out how to get along better.

Oncology social workers understand how the behavior of an individual affects the family as a whole. The problem may be the way family members communicate with one another. Or it may be a lack of understanding among family members about behaviors that are hurtful or get in the way of people receiving support from each other. Sometimes tension in a relationship will prevent people from understanding each other so the same hurtful behaviors continue. It is often easier for someone outside the family to help family members look at a situation differently and try new ways of behaving that may make it easier to give and to receive support. As in any kind of counseling, the important thing is to find a counselor that you and your family trust. If that cannot be established within a reasonable time frame (a matter of 1-3 months), talk to the social worker assigned to you if you feel comfortable doing that. Social workers understand that not every relationship "works" and we are primarily interested in getting you the right person that you feel comfortable with. If you don't feel comfortable bringing this up, call the department (215-728-2668) and ask to speak with someone about changing social workers.

Social workers go about helping people in a variety of ways. Some always see whole families together; others may mix up the sessions with some devoted to the whole family and others with an individual. The nature of your problems will influence the approach used. There may be times when your worries are directly related to the experience of having cancer. There may be other times when family relationships are affected by the cancer in ways that make you unhappy. The social worker will try to help you and your family understands what is going on and what you may need to feel better. You must give your permission to have your family involved. For instance, if your family does not come with you to your appointments and we have the sense that their input is necessary, we would ask you if it was OK with you for us to contact them.

When Should I Consider A Support Group?

The Social Work Services department offers a variety of group programs. Some meet in the evenings and others during the day. Some are open to everyone with different diagnoses while others are composed of the same people, dealing with the same diagnosis or age group, for instance. If we don't have a group that seems to meet your needs, we will try to start one if enough people are interested or refer you to one in the community.

The purpose of a support group is to help people share their concerns with one another and to learn new ways of tackling difficulties. Participants can expect to learn more about the disease itself in addition to getting new ideas from other group members. For instance, a woman with breast cancer can learn from other women about breast reconstruction. Young adults can hear how others have approached problems with dating from those who have "been there".

Support groups for people with cancer can be organized in several different ways. Open-ended groups are set up to allow anyone with cancer or their family members to attend as many sessions as they find helpful. Or people might attend during periods when the course of the illness is changing, decisions need to be made about new treatment options, or new family concerns come up.

Closed groups are those in which the same group of people agrees to meet for a prescribed period of time, like for six or eight sessions. They can be organized in a number of ways like for people with the

same diagnosis, the same sex or age range, the same stage of disease, or by the kind of treatment people are receiving. Our group for people with esophageal cancer is one example.

Groups can be organized by topic, meaning different issues will be discussed each week or they can have a free-flowing agenda where participants can discuss whatever topic they choose. Regardless of the kind of group you attend, confidentiality should always be discussed. You should feel free to discuss your concerns with others and know that what is discussed will remain confidential among group participants.

What Kind Of Group Should I Attend?

Sometimes people wonder what kind of group they should attend, one organized by a professional or by a cancer survivor. Professionals include oncology social workers or nurses, psychologists, psychiatrists, or clergy. Professionals should be licensed in their respective fields and have skills in group "facilitation". This means they will have had training in how to go about setting up a group and how to help members get their needs met. This is the case with Fox Chase group facilitators. Professionals also know how to deal with difficult group members. Examples might be someone who is so upset that they monopolize the conversation or are unable to listen to the worries of others. If a cancer survivor is facilitating a group, that person may or may not be able to deal with those difficult issues. Or they could find themselves getting uncomfortable or overwhelmed by what is being discussed in the group.

People may have strong feelings about the kind of group that they want. Some will feel that only someone who has "been there" will make a good group leader. Others want a professional who might be able to offer more education about cancer or emotional issues. Professional facilitators are available at Fox Chase and groups run by cancer survivors may be available in your own community. You might consider trying both types of groups to identify what type is right for you. Your "comfort level" is usually a good indication that you have found the right group for you. If you feel comfortable sharing your experiences and are better able to address your problems, the group will probably be helpful. If not, consider another group or another kind of counseling until you figure out what is best for you or your family.

What If I'm Worried That A Group Will Be Too Depressing?

Some people are more comfortable in groups than others. It may be easy to imagine sharing your feelings with others or it could seem like a real invasion of your privacy. There are few "rights or wrongs" about how people feel about participating in a group. Some people find them very useful at the point of diagnosis or changes in treatment because there is so much information to sort through in order to make decisions. Patients with more experience with cancer can help new patients know what to expect and how to avoid troublesome situations. If you don't know if a group is right for you, we will try to help you figure that out.

Sometimes people reject going to a support group because they think that it will be "too depressing" to listen to other peoples' problems. This does happen occasionally but for the most part, patients are very good at helping a discouraged group member feel better. Everyone has down times—the trick is to figure out how to stop the negative thinking from taking over. It's all too easy to imagine the worst. Other patients have "been there" and can offer the kind of encouragement and even 'inspiration' to keep fighting when times are tough. Sometimes new group members are surprised at how much humor is expressed in a support group. Finding something funny in a situation is a very good way of moving past a difficult time.

It may take time to determine how much of yourself to share with others. Some group members will be very talkative while others learn better just by listening. Usually, group members will gradually feel more comfortable in discussing their concerns and will get satisfaction from helping others in the group.

A listing of Fox Chase groups can be found at the end of this document.

Does Everyone Benefit From Attending A Support Group?

Sometimes patients will experience pressure from family or friends about attending a support group. This happens because people often don't feel comfortable talking about cancer; they think that they have to say something to "fix" the problem or to help you to feel better, when really they just need to listen. The nature and seriousness of your needs should help you decide whether to try a support group. Some needs lend themselves to being addressed in a support group. Examples are the need for information, such as how children typically react to a parent's diagnosis, how to explain your diagnosis at work, or how to communicate better with your doctor. Other problems, such as severe marital or psychological problems, may seem too "private" or complicated to share with others.

The intensity of your feelings about a situation will also help you to decide about attending a group. You may feel so upset about your situation that the idea of discussing it with others makes it worse. Your own distress may make it impossible to listen to the problems of others. In this kind of situation, an individual counselor can concentrate on you and help you to feel better more quickly. Once you feel less anxious or overwhelmed, you may be in a better position to benefit from a support group.

Occasionally, people dealing with serious medical problems get so desperate that they think about suicide. This is not a usual response to having cancer but can happen to people who may have other stresses in their lives in addition to the cancer. Sometimes people can feel so depressed and hopeless that they can't imagine how the situation will ever get better. If this is how you or a family member is feeling, you need immediate help. This is not the kind of situation that joining a support group will help. A psychiatrist should be consulted who can evaluate the severity of the situation and prescribe medications if necessary.

Are There Support Groups For Children?

Fox Chase was one of the first cancer centers across the country to offer groups for children. We have been offering *"Kids Night Out"* for close to 25 years and are committed to helping children deal with this experience. Since children don't intuitively understand what a cancer diagnosis in their family will mean to them, a group offers basic information about cancer (not specific to their parent) and introduces them to other children whose parents are being treated.

Since Fox Chase does not treat children as patients, the groups we offer are for children with a sick parent or grandparent, if that relationship has been particularly close. The need for children to meet others who are in the same situation as them is a very real one. Cancer is different from other problems that children experience. Children who have a parent with cancer are not likely to know others with a sick parent, in contrast to children whose parents are divorced for instance. For this reason, children with a sick parent often feel very isolated and different from their peers. When they meet other children who are dealing with cancer in the family, it is very comforting to realize that others have the same worries. Some of these worries include the following:

- Why has cancer happened to my parent?
- Is it something I did that made it happen?
- Did my parent "catch" cancer from someone else?
- Will my other parent get sick?
- Can I get cancer?
- How will my life change?
- Will my parent still be able to take care of me?
- Will my friends at school know about my parent's cancer?
- Should I talk to my friends about it?
- Will people treat me differently?

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- Will my parent die?
- Who would take care of me if my mom or dad dies?
- Will I still be able to do things I enjoy?
- Will mom or dad still do "fun things" with me?
- Will I have to take care of mom or dad?

While these questions may not be asked directly, we know from experience with other families that these are questions children think about. While you will not know the answers to all of these questions, especially when you are first diagnosed, these are issues that may need to be addressed at some point in your experience.

Support groups for children should be facilitated by professionals--people like oncology social workers or nurses, schoolteachers or guidance counselors, art therapists or music therapists. The professional should be knowledgeable about cancer and the issues it raises for families along with being comfortable working with children.

The success of a group for children will depend on the professional's use of play therapy or activities that help children to address tough issues. Adults can receive help by talking about a problem whereas children are less able to verbalize their feelings and worries. A professional should be experienced in getting children to open up through play, drawing, and games. Typically we will try to organize a group with children in the same age range so that they are all interested in similar activities. Groups are usually in the late afternoon or early evening, lasting for 1 to **1 1/2** hours. We will want to meet you and your children ahead of time in order to explain what to expect and to decide together if the group is right for your child. It also is useful for you to meet us as we know it is difficult to entrust your children to people you don't know well. Don't expect that your child will be thrilled about the idea of attending a support group. People usually resist doing something new and children are no exception. Usually, once the child experiences the fun a group offers, they are quite eager to participate.

The support groups for children at Fox Chase offer a corresponding group for parents. Parents are a child's best teachers and you will learn from other parents about ways to deal with your children. When the group is over, we will meet with you to give you feedback about your child's participation in the group and if necessary, give you suggestions on how to continue to help your child understand and deal with the situation. People often worry that their child will be damaged by the cancer experience and won't be able to cope with it. In our experience, this is certainly not true. Children can cope with cancer when their parents give them the help they need. If you need help knowing what that is, we will help you figure it out, especially if you are new to the experience and have no way of knowing how children react to this kind of crisis. Most parents, upon learning about how children cope with cancer, can easily move in and help their children manage their worries.

Sometimes parents worry that in a support group, children will learn that people can die from cancer. Most of the time, children know this already. If a child brings this up, we will acknowledge that people can die from cancer but that the purpose of treatment is to control, and in many cases, cure people of it. The emphasis is always on hope for the future. We will also encourage children to talk to you if they are worried and offer advice about how to deal with your children's fears about the future. We hope that parents will be able to feel confidence in our ability to get to know your children and you as a family and to offer guidance that will result in your child feeling reassured, not frightened.

We have also produced a videotape oriented to helping parents explain a cancer diagnosis to children. These are available to any Fox Chase family at no charge and can be located in 3 display racks in Ambulatory Care, (one close to the registration area, the other in Area B and the third in Radiation Oncology). The video is called "Talking About Your Cancer: A Parent's Guide to Helping Children Cope". Please pick one up if you have not already done so. We also have a journal for children called "Kid's Night Out" and this can be obtained from your social worker or by stopping in at our office (4th floor of the hospital building).

Should I Consider Complementary/Alternative Therapies?

'Complementary' therapies are typically those that patients utilize *along with* their cancer treatments. Examples might be meditation and relaxation techniques, hypnosis, massage, yoga or changes in diet. Many centers offer "mind/body" groups in which patients are taught how to use these techniques to feel more in control of their fears about cancer. A group can also help you to change automatic "negative thinking" into a more positive way of approaching the cancer experience. These approaches often help people deal with the side effects of cancer treatment as well and thereby improve their quality of life.

'Alternative' treatments on the other hand, are usually thought to be those that people utilize *instead of* standard treatment. Examples might be supplements produced by people outside of mainstream medicine who claim to have found the cure for cancer, macrobiotic diets or the use of vitamins, herbal remedies or faith healers, instead of medical treatment. Obviously, the medical community does not support the use of "alternative" treatments instead of cancer therapy. Complementary therapies are more easily accepted as they are thought not to interfere with a person's chance for survival.

There is much written in the popular press about these new or alternative cancer treatments. Some of these treatments are harmless while others can complicate or interfere with your cancer treatment. Some alternative treatments are said to be "natural" substances implying that nothing negative can result from their use. Herbal remedies are sometimes considered to be pretty benign since they're "only herbs" but in fact, there are no clear guidelines about safe dosages so patients are often on their own about how much to take. Also, a strictly macrobiotic diet can seriously interfere with your nutritional status and if combined with chemotherapy, cause real physical problems. So it's very important that your doctor know if you are using alternative treatments in the event that complications occur.

Many people are reluctant to discuss complementary or alternative treatments with their physicians as they expect they will get a negative response or jeopardize their relationship with their doctor. Actually, most of the Fox Chase physicians know about these approaches and will be happy to discuss them with you. There is more acceptance of these treatments than ever before especially if patients are not rejecting medical care. If you want to consider adding a complementary treatment to your standard therapy, tell your doctor and ask for his or her advice. Some patients need to do "something extra" in order to feel more in control or to cover all the bases. If this is the case, explain this to your doctor and discuss the pros and cons. Most will be understanding once they see that you are not questioning their medical competence or compromising your chances that treatment will be effective. If your doctor does not understand your need to try a complementary or alternative treatment, it is still your right, as the person in charge of your life, to use it. But we hope that you will not do anything that will interfere with conventional treatments, since they offer you the best chance of a cure or long-term control of your disease.

The oncology social work staff will also be able to help you make decisions about this issue. We can also help you to figure out if an alternative or complementary medicine practitioner's credentials are legitimate, whether they practice in an accredited institution and direct you to research about survival. When you hear about alternative treatments, keep in mind that, unless a treatment has been tested scientifically, there is no way to know whether it helps control cancer. Clinical trials are the only way to prove whether treatments are effective. The vast majority of alternative treatments have never been evaluated scientifically.

People sometimes turn to alternative treatments if they have a kind of cancer that is difficult to treat or if it has been established that cure is no longer possible with standard treatment. Well-meaning friends and relatives may suggest that you have nothing to lose by seeking such help. You may be quite eager to pursue this, since the idea that the disease is no longer curable may create a sense of helplessness, depression, and even panic. While these feelings are understandable, a cancer that is not being treated medically can be extremely difficult to live with. Even treatment that is considered "palliative", (to relieve suffering instead of cure), is still important to a patient's quality of life.

There are some excellent materials available to help you to understand and evaluate complementary and alternative therapies. (See reference list for these publications). We suggest that patients and their families learn as much as possible about these treatments in order to decide if and when they could be helpful. Both the American Cancer Society (1-800-ACS-2345) and the National Cancer Institute (1-800-4-CANCER) can direct you to other sources of information.

Fox Chase also has a relationship with the Center for Human Integration, which is located very close to the center. The center, operated by the Medical Mission Sisters is one of the very early groups to study how people could promote their own healing through complementary treatments. We feel very comfortable that the staff of this center is fully qualified to be offering these services and would encourage you to use them if you are interested in supplementing your cancer therapy. The costs are reasonable and might help you feel more in control of your emotions and reactions to what you are going through. If this center is not convenient for you, we can help you to locate other resources, perhaps closer to your home. Ask one of the social workers about it or call our department (215-728-2668).

What Should I Look For In A Cancer Counselor?

In addition to the counselor's education and credentials, the two other important factors to consider when choosing a counselor are a person's experience in helping people deal with cancer and how comfortable you feel with that person. People who work in cancer treatment centers tend to have more knowledge and experience with emotional responses to cancer than counselors who work outside of a medical facility. Their experience with cancer is important because it will give them a way to understand how your reactions and feelings will help you deal with your situation.

For example, an experienced cancer counselor will know that a newly diagnosed patient might become depressed *after* treatment is completed. This is because the medical facility represents a feeling of safety and that the treatment is fighting against the cancer. Once the treatment is over, patients may find they are more worried than they were when they were "doing something" to control the disease. A cancer counselor will recognize that this is a normal response for many patients and can help you deal with this. If your depression is long lasting or you find that talking about your feelings is not helping, a cancer counselor might suggest a trial of an anti-depressant medication to help you get back on track. An experienced cancer counselor will be able to help you more quickly than someone who doesn't know what patients normally experience.

Another important factor to consider in selecting a counselor is the person's professional training or credentials. At a minimum people should have a bachelor's degree in one of the counseling fields and often, will have a master's or doctoral degree. Counselors often come from the fields of social work, psychology, psychiatry, psychiatric nursing, or pastoral counseling. While credentials will demonstrate a person's formal education in their chosen field, they ideally should be combined with their experience of helping people cope with cancer. You should not feel shy about checking all of this out. Professionals who are secure in their abilities know that people need to find the most knowledgeable source of help and should not be reluctant to give you this kind of information.

Sometimes people feel that unless a counselor has had cancer or "been there", that they will not be able to help. While a personal experience will certainly add a dimension to the counselor's expertise, it's important not to underestimate the value of experience with other patients and families. Even if a counselor has never had cancer, we have all experienced life crises and losses of one kind or another. Cancer counselors have usually worked with a great number of families and that experience is invaluable in learning how people cope. So a personal experience with cancer is not a necessity in figuring out if a counselor is the right person for you.

Always consider how you feel with the person you are seeing. Does it feel safe to share your concerns with this person? Do you trust their ability to help you? Do you feel that the counselor is really able to listen to you and understand you as an individual? Do you think your family could relate easily to this person? The quality of your relationship with a counselor may be hard to understand or describe.

However, trust your instincts—if somehow you just don't feel comfortable after a few sessions, it would probably be wise to try someone else. You will know when you have found the right "match".

Will My Insurance Pay For Counseling Services?

At Fox Chase, oncology social work services are free and available as part of your comprehensive treatment plan so insurance is not a worry. If you are seeking services in your home community, you will need to learn what your policy covers for mental health services. Many health plans have some coverage available for counseling but often, this is more limited than it is for medical services. Most people have no idea what their insurance covers for support services until they develop a serious illness. Legislation is being considered to achieve mental health "parity" meaning an appreciation that mental health coverage is as important as coverage for physical illness. However, this is not universally accepted by the insurance industry so you may find that your coverage is inadequate for your needs. Some policies only pay for a limited number of sessions or if it is a managed care policy, it may limit your choices about whom you can see. Your insurance may have "contracts" with certain mental health providers, but not with others.

If you are having trouble understanding your coverage, ask a hospital social worker to help. They also know about services in the community that may operate with a sliding scale adjusted to your income. The hospital billing department may also be able to examine your policy and determine your coverage.

It is important that you get the kind of help you need when you need it. You will learn a great deal about cancer as a result of having the experience. Give yourself the opportunity to learn what you might need in order to manage the impact of cancer for yourself and for those you love.

Does Medication Help People Cope With Cancer?

Feeling positive about the future helps many people with cancer get through the bad times. It also helps to enjoy life with those who are important to you. Hope is an essential ingredient in coping with cancer; if people feel hopeless, coping with cancer is very difficult. If you are feeling this way most of the time, you are probably quite depressed and anxious. An antidepressant medication may be what you need to help you get on with day to day living. Antidepressants usually work better if you are also talking with someone about how you are feeling.

Talk to your family doctor or oncologist if you think you are depressed. Sometimes people are reluctant to tell their doctors about depression because they worry that somehow it will take the focus off of getting rid of the cancer. Or that they will be considered "weak" or even emotionally unstable. Doctors are very familiar with human suffering and usually become physicians in order to help people. Your doctor will not think less of you if you ask for help—in fact you are taking active steps to take control of your life. There is a wide range of drugs available and your doctor probably has had experience in using them with other patients. Some of them take a few weeks to work so be patient. Sometimes people need to try several kinds of drugs to find the one right for them. If the drug doesn't seem to be helping, your doctor may refer you to a psychiatrist who is a specialist in using antidepressants. It may be that you need another class of drugs, need the dosage adjusted or a combination of medications may be the answer.

Depression is sometimes the result of chemical changes in the brain related to the cancer, treatment effects or chronic stress. If this is the case, there will be very little you can do to talk yourself out of it. If your depression is severe and not responding to medication, you definitely should have a psychiatric consultation. The same applies if you are having thoughts about suicide. Occasionally, people dealing with serious medical problems get so desperate that they think about suicide. This is not a usual response to having cancer but can happen to people who may have other stresses in their lives in addition to the cancer. If this is how you or a family member is feeling, you need immediate help. A psychiatrist should be consulted who can evaluate the severity of the situation and recommend

medications or perhaps a short hospitalization to help the person feel more in control. If you think seeing a psychiatrist would be helpful, ask your oncologist, nurse or social worker to recommend someone who has experience with people with cancer.

Why Do Some People Need Help And Others Don't?

There are people who need little or no help in dealing with the experience of cancer. These people may be blessed with "good genes", supportive families, resilience in handling stress, generous incomes and insurance resources, superior flexibility and problem solving abilities, strong spirituality and a history of successful coping over a lifetime. If these people possess accurate information about their cancer diagnosis and treatment, they will probably never seek out counseling services.

For many other people, counseling may be very useful. However, there is a built in barrier that needs to be overcome. This barrier relates to our attitudes about asking for help. As we discussed about help with depression, for many people, the idea of getting help for emotional or family problems is problematic. It is thought of as a sign of weakness or even that the person is unstable or "crazy". The American culture puts a high premium on being independent and able to solve any problem that comes along. This cultural norm leads to people suffering more than is necessary when a situation like cancer presents itself. It may seem to you that some people sail through the cancer experience, never revealing any stress or difficulty dealing with it. So people make all kinds of judgments about themselves and say things like "what's wrong with me that I can't seem to cope with my problems?" Or, "I should be able to just 'tough it out' until the trouble passes." While we all have this tendency to feel we should be able to manage just about anything, there will be times in this experience that toughing it out just doesn't work.

A person's ability to manage stress depends on a great many things. Some of these are genetic and related to physiologic factors like the influence of hormones on our ability to feel balanced in our reactions to stress. Most people believe that babies come into the world with a predetermined set of characteristics, which are part of our genetic makeup. This "personality" that we are born with doesn't change a great deal as we grow but is influenced significantly by our life experiences. These life experiences influence whom we become as adults, or our "self image." Other important factors are our relationships with people, especially our parents and siblings, cultural factors, how we were educated, intelligence, relationship to God or a "higher power", career success, finances, gender or sexual identity, and our physical and mental health. So human beings are extremely complex and will vary in their ability to understand themselves and their reactions to stressful experiences.

Your understanding of the cancer itself will also influence your ability to cope. In addition to learning information about your illness and treatment, you will need to understand yourself in relation to the experience. It will take time to absorb what you need to know medically along with what you can expect of yourself and others in your family. Asking for help in understanding cancer and what to anticipate physically and emotionally is not a sign of "weakness" but instead, a smart move to prepare yourself and your family for what is to come. *To struggle alone will make the experience more difficult than it needs to be. People **learn** how to cope with cancer-give yourself the benefit of our experiences with other families so that you can approach the situation with hope in your ability to manage the illness and get on with your life.*

How Will I Know If Counseling Is Working?

Deciding if you are benefiting from counseling is something you should try to figure out with the social worker or counselor you are seeing. It is perfectly all right to ask the social worker how he/she will know if it's helping. You will also decide on what problems you need to work on, as some are more bothersome than others are. The oncology social worker should also ask you periodically if you are getting what you need. Since we aren't mind readers, we will want you to be honest about what seems to be helping and

what is not. In general, if you are feeling more in control of your feelings and life is getting "back to normal", counseling is probably helping. You can also ask yourself the following questions:

- Are you gaining more insight into the nature of your difficulty?
- Do you feel less anxious or worried?
- Is it easier to make decisions?
- Can you act on those decisions?
- Do you have a clear idea where you are going, or what needs working on immediately and what can wait until later?
- Are you more in control over how you are feeling and behaving?
- Can you put cancer aside and focus on other things?
- Can the counselor give you some idea of how long you will need help?
- Could you tell your doctor how counseling is helping?

Your family should consider the same questions if they are involved in the counseling sessions. If your answers to these questions seem positive, you are probably on the right track. If you don't feel good about your answers to these questions, discuss them with your social worker. If the relationship with the counselor doesn't feel comfortable or trusting, the sooner you address that, the better. It may be that we may not have understood your expectations or something else is bothering you that is interfering with the process. Sometimes it's hard to understand what makes a relationship work. If it looks like what we are doing is not helpful, we will want to change that, or if that's not possible, to help you to get to someone else who is a better match for you. You may also call the department (215-728-2668) to request another social worker. Our goals and yours are the same--to help you and your family get the best services possible so that you can move on with your life.

Conclusion

We hope that we have given you a better understanding of the support services available to you and how they might make coping with your illness easier. Your emotional reactions to cancer are as important as what is going on in your body. Even when you're finished with your treatment and are feeling better, your mind and feelings are still there, sometimes interfering with your sense of well being. Certainly most people can and do cope with cancer without ever consulting with a social worker or counselor. However, we are interested in helping you prevent some of the problems that we know cancer can cause for people. It's really a question of energy--how much do you need to get through treatment and how much of it gets spent worrying about the future or being preoccupied with family troubles? We know that stress deprives people of the energy it takes to live and enjoy your life. If you find that the stress of dealing with cancer is using up yours and perhaps your family's energy, we hope you will call upon us to help you to figure out how to get your life back on track. Your doctor or nurse can refer you to us or you can refer yourself by calling **215-728-2668** during regular business hours. Services are free, confidential and available to you and/or your loved ones.

Reading Materials

Books

- Armstrong, L. It's Not About the Bike. New York, Putnam, 2000
- Borysenko, J. Minding the Body, Mending the Mind. Reading, MA. Addison-Wesley, 1987
- Buckman, R. What You Really Need to Know About Cancer. Baltimore, MA, 1997
- Live Strong: Inspirational Stories From Cancer Survivors. Lance Armstrong Foundation. Broadway, 2005
- Spiegel, David. Minding The Body: Psychotherapy for Extreme Situations. Philadelphia, Institute of Pennsylvania Hospital, 1996
- Harpham, W.S. After Cancer: A Guide to Your New Life. New York: HarperPerennial, 1995
- Harpham, W.S. When a Parent Has Cancer: A Guide to Caring for Your Children. New York: Harper Collins, 1997. (Includes "Becky and the Worry Cup", an illustrated children's book that tells the story of a seven-year-old girl's experience with her mother's cancer)
- Heiney, Sue, Hermann, J. Bruss, K, Fincannon, J. Cancer in the Family: Helping Children Cope With a Parent's Illness. American Cancer Society, 2001
- Hoffman, Barbara (Ed.). A Cancer Survivor's Almanac. Minneapolis, MN: Chronimed Publishing, 1996
- Holland, Jimmie. The Human Side of Cancer. Living With Hope; Coping With Uncertainty, New York, Harper Collins, 2000
- Hermann, J. Cancer Support Groups: A Guide for Facilitators. American Cancer Society, 2003.
- Lauria, Marie, Clark, E. Hermann, J., Stearns, N. Social Work in Oncology: Supporting Survivors, Families and Caregivers. American Cancer Society, 2001.
- Lerner, M. Choices in Healing: Integrating the Best of Conventional & Complementary Approaches to Cancer. Cambridge, MA: MIT Press, 1996.
- Lynn, Joanne. Handbook for Mortals. New York, Oxford University Press, 1999
- McCue, K. How to Help Children Through a Parent's Serious Illness. New York: St. Martin's Press, 1996.
- Moyers, B. Healing and The Mind. New York: Doubleday, 1993.
- Remen, Rachel. Kitchen Table Wisdom. New York: Riverhead Books, 1996
- Schimmel, Selma. Cancer Talk. New York: Broadway Books, 1999.
- Spingarn, Natalie Davis. The New Cancer Survivors. Baltimore: The Johns Hopkins Press, 1999.
- Zinn, John-Kabot. Full Catastrophe Living. New York, Delacort Press, 1990

Patient Education Materials

Available from the American Cancer Society

(Call 800-ACS-2345 for a free copy, or visit their Web site at: www.cancer.org)

- After Diagnosis: A Guide for Patients and Families
- Breast Cancer Treatment Guidelines for Patients
- Caring for the Patient with Cancer at Home: A Guide for Patients and Families
- Colon and Rectal Cancer Treatment Guidelines for Patients
- Couples Confronting Cancer
- Nutrition for the Person with Cancer: A Guide for Patients and Families
- Prostate Cancer Treatment Guidelines for Patients
- Sexuality and Cancer: For the Man Who has Cancer and His Partner
- Sexuality and Cancer: For the Woman Who has Cancer and Her Partner
- Understanding Chemotherapy: A Guide for Patients and Families
- Understanding Radiation: A Guide for Patients and Families

Available from the National Cancer Institute—for information about a wide variety of cancers.

(Call 800-4-CANCER for a free copy, or visit their Web site at: <http://publications.nci.nih.gov>)

- Clinical Trials: A Blueprint for the Future
- Facing Forward: A Guide for Cancer Survivors
- Questions and Answers about Pain Control: A Guide for People With Cancer and Their Families
- Taking Time: Support for People With Cancer and the People Who Care About Them
- Talking With Your Child About Cancer
- What You Need To Know About Cancer
- When Someone in Your Family Has Cancer
- Young People With Cancer: A Handbook for Parents

Available from other organizations

- *The Cancer Survival Toolbox: Building Tools That Work For You.* Call 1-877-TOOLS 4 U. Offers free audiotapes and written material oriented to teaching newly diagnosed patients what they need to know in order to deal with diagnosis and treatment. It is a collaborative project of the Association of Oncology Social Work, the National Coalition for Cancer Survivorship, and the Oncology Nursing Society. Produced with an unrestricted educational grant from Genentech, Inc.
- Hermann, J. and Houts, P. *Helping People Cope: A Guide For Families Facing Cancer.* Pennsylvania Department of Health, 2003 Call 1-877-724-3258 for a free copy. These are also available at Fox Chase at no charge and can be found in the Resource and Education Center on the first floor of the Cancer Prevention Pavillion

Web Sites

There are multiple web sites that can be useful to patients and their families. Some of these will provide information about cancer and its treatment while others focus on support or advocacy services. In addition to obtaining information, it is also possible to locate an on-line support group or voice messaging system to connect with others who are dealing with cancer. While it is not possible to include an exhaustive listing, the following web sites may be useful and direct you to others for more in-depth information. Because patients will be talking with each other about their experiences, it will be important to check out any information you receive so that you understand how it might or might not apply to you. Remember that each person's cancer and response to treatment is different. If you are hearing information that is confusing or frightening, always check it out with your health care team. The following web sites will give you information you can trust:

- **American Cancer Society:** 800-ACS-2345; www.cancer.org
- **Cancer Survivors Network,** American Cancer Society. On-line support system to communicate with other patients and their families.
- **The Leukemia and Lymphoma Society of America:** www.leukemia.org
- **OncoLink:** www.oncolink.upenn.edu
- **Cancer Care, Inc:** www.cancercares.org
- **National Cancer Institute;** 800-4-CANCER: www.cancer.gov
- **National Coalition for Cancer Survivorship:** www.cancersearch.org

For the current list of Fox Chase Cancer Center Support Groups
Go to our web site under *Patient Center*, and see the **Support Group** page
under *Patient and Family Support*.

<http://www.fccc.edu/patients/support/groups/>