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Understanding Psychosocial Support Services

Having cancer is hard and going through it can be a very involved and complicated process. It affects the person with cancer and each family member or loved one socially and emotionally. This is known as the *psychosocial effect* of having cancer.

Just as there are cancer treatment teams and surgical teams, there are also teams of experts, each with a different focus on mental or social health, who understand how cancer affects a family. A psychosocial team can offer the patient and the family support during this time.

Psychosocial support can include mental health counseling, education, spiritual support, group support, and many other such services. These services are usually provided by mental health professionals, such as psychologists, social workers, counselors, specialized nurses, clergy, pastoral counselors, and others. These professionals might also refer you or your family to other sources if they identify other needs.

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Types of Support Services

In cancer centers, universities, or city and community hospitals, psychosocial services are likely to be offered along with medical care.

A team of people, including doctors, nurses, social workers, rehabilitation specialists, and nutritionists usually deliver cancer treatment. In some treatment centers, a social worker, clinical nurse specialist, member of the clergy, or counselor may be able to help with family issues.

In some hospitals, you might be referred to the department that offers psychosocial support services. You can also contact them yourself or ask your cancer care team where you can get this kind of help.

If the hospital where you are getting your treatment does not offer these types of services, you may find the services you need from agencies in the community, private counselors, places of worship, or peer support programs.

Support service options

- Individual (one-on-one) counseling
- Family counseling
- Groups

You may find you need just one or a combination of all the services above. Individual therapy gives a person a chance to focus on their own emotions and challenges. While family therapy focuses on the family system.

Deciding what's best for you depends on a number of factors, like what's available in your area, the cost of services, and how the cancer seems to affect your whole family.

Individual (one-on-one) counseling

Individual counseling offers a chance for you (or you and your child) to sit down and talk with a counselor about worries and concerns. If your child is seeing a counselor, the counselor may meet with the child individually and bring you in as needed.

The counselor may ask some questions about you and your family and help you figure out what is bothering you the most.

For some, just talking about problems may not seem as helpful as doing something to solve the problem, especially people who are used to working things out for themselves. The best ways of dealing with and even talking about cancer require patience and time.

Problem-solving can be affected by many factors. These include:

- Your feelings about the situation
- Your personal traits and qualities, as well as those of your family members
- Relationships between family members
- Your ability and your family's ability to be flexible and to try new things
- All of the other things that are going on at the same time in your life besides cancer

For example, worrying about your job or money concerns may make it hard to focus on your children or family at home. If you have treatment side effects, you may not have the reserve to deal with your child's behavior as you did before cancer.

Try not to get discouraged. Problem-solving often requires some trial and error. You may try a number of strategies before you find an approach that is right for your family. Remember, sometimes the goal is just to talk it out and clear your head of worries so that you and your family can work together to do all the things you need to do during this time.

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Remember to go easy on yourself—you are going through a really hard time—and realize that as much as you would like to, you just can't control everything the way you would like. Find a professional who wants to help you feel less alone and overwhelmed. No one can or should try to handle cancer by themselves.

Counseling for children and teens

If your child has a counselor, you will meet with the counselor, too. You will either go along with your child, or you may meet with the counselor alone for an update on your child's progress. Counselors who specialize in helping young children often use play therapy to figure out what's worrying the child and help him or her express what they are feeling.

Children have strong emotions, but are usually not able to express them in words like adults can. Their feelings are often shown in actions, or in artwork and play. A certified art therapist may be a good fit for school age children and teens as well.

Teens often talk more easily about problems with a therapist. Finding someone experienced in working with teens is very helpful. Even so, your teen might resist the idea of counseling. After all, it can be hard for any of us to accept the idea that getting help and changing our old habits may help us.

Teens must also fight normal feelings of uncertainty about who they are along with their need to separate from adults as a normal part of growing up.

Sometimes your teen may need an extra push to get started in counseling, but don't give up—they might thrive under the individual attention and support of a counselor.

Psychoeducational counseling

There's a special form of counseling called *educational counseling* or *psychoeducational counseling*. Major cancer centers have been using this approach for the past 30 years or so. If you live in an area that is able to do psychosocial research or offers programs based on research that has been done in the past, you might be able to take advantage of such a program. Some such programs might even be offered at low or no cost to you.

One of the newer methods is called a *problem-solving approach*. Using this method, you might work with a counselor for a limited period of time (for example, three 50-minute sessions) about one certain problem that you and the counselor have identified as something that you would like to tackle.

You and the therapist will be working on problems you are having right now, short-term issues, not long-term issues that seem as if they will go on and on. And the problems you work on are directly linked to your cancer, not other unrelated problems.

Several studies have shown that this type of problem-solving helps the patient or family member work with the counselor as a team. They can break up a problem into manageable steps with actions that really make a difference in changing the outcome of a problem. This approach seems to reduce levels of psychological distress as shown by the follow-up research.

Family counseling

Some experts think that family counseling is the best way to address all the issues that come with cancer in the family. Families are unique. Each family has its own differences in life experiences, personalities, feelings, the quality of relationships, beliefs, stage of development, and culture.

For instance, if a family believes that their problems should not be shared with outsiders, they might have a lot of trouble taking part in counseling. If a family believes that children should not have to deal with any of the painful realities of life, they will have a hard time talking about a parent's diagnosis with their children. Secrets can harm any

family, and having cancer is an almost impossible secret to keep.

One of the ways to decide on family counseling is to look at what's going on in your family. Ask yourself the following questions:

- Can I talk to my spouse or partner 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? For example, do they change the subject when I bring up a serious issue?
- Does it help to talk to my spouse or partner when things are going badly?
- Do we often end up in a fight about how we expect each other to react?
- Do my children seem worried a lot, or are they less involved with friends or school activities?
- Is it harder to get my children to listen? Do they tell me how they feel?
- Are my children misbehaving more than usual?
- Do my children seem sad or lonely?
- Do we seem unable to enjoy being together as a family?
- Are the children fighting among themselves more often?
- Are their grades much lower than usual?
- Am I getting more complaints from my child's school?
- Are my children suddenly acting younger than their age? (For example, are they having more trouble leaving you, unable to toilet train, or unable to play by themselves? Does it feel like they are suddenly more dependent on you?)
- Is my family able to accept help from others?
- Do I resent that other people seem happy?
- Do I feel angry that others can lead normal, cancer-free lives?
- Are financial or insurance problems making it harder for me to deal with my family?
- If you answer yes to any of these questions, it does not mean you or your family is in trouble. However, bad times may seem to last longer, and your efforts to change things for the better may not seem to be working.

Recognizing a problem and understanding why you or your family members act in certain ways are important steps in figuring out how to get past the hard times. A family counselor knows how the behavior of one person in the family can affect the family as a whole. A family counselor will work with the family to improve communication, help the family resolve conflict, and give ideas to improve family functioning.

Support groups

The purpose of a support group is to help people in similar situations share their concerns with each other and learn more about coping and problem solving. People in a support group can also expect to learn more about their cancer and get new ideas from others.

We have listed information below about the different types of groups and factors that can affect your choice of group. Before you start with any group, you will want to think about these factors and how they may affect your work with a group.

Open-ended groups

These groups often allow anyone with cancer or their family members to attend for an indefinite period of time. People might come only during times of stress or need, such as when the course of the illness is changing, when deciding about new treatment options, or when new family concerns come up.

These groups might allow new people to come in at any time, which can make attendance uncertain. No one knows who will show up from one meeting to the next. It's important that even one-time attendees agree to keep what goes on in the meeting confidential.

Closed groups

In this type, the same group of people meets for a set period of time. These groups may be organized for people with the **same diagnosis**, the **same stage** of disease, or by the kind of **treatment** people are getting. Some groups are for women or men only. Some groups are only for people with cancer, while others are for the people who support or care for the person with cancer. In general, they do not allow people to join the group after the group has started.

Groups can be organized by topic, which means different issues will be discussed each week. On the other hand, the group may have a free-flowing agenda where group members can discuss whatever they would like to talk about.

No matter what kind of group you go to, the group leader should address the issue of keeping all the information private. In any support group, you should feel free to discuss your concerns with others and know that what you talk about will not be shared or discussed with anyone outside the group.

Group leadership

Groups can be led by **professionals** or by **cancer survivors**. There are advantages and disadvantages to both types of groups. Professionals include oncology social workers, psychologists, psychiatrists, psychiatric or oncology nurses, or clergy. These experts should be licensed in their fields and have skills and/or experience in leading groups. An experienced group leader has been trained in setting up groups and knows how to help group members get their needs met. They should also know how to deflect group members who tend to take over the conversation or deal with people who are upset or angry.

If a cancer survivor runs a group, that person may or may not be able to deal with these tasks very well, simply because they have not had group skill training and experience. Still, many cancer survivors are comfortable dealing with difficult behaviors in a group and have had enough life experience to run a group well. Others may find themselves feeling ill at ease or overwhelmed by what's being discussed in the group or by group members' behavior. It helps if the leader has experience in going through groups and received special training to be a peer leader.

You could consider trying both types of groups to learn which feels right for you. Your comfort level is usually a good gauge of the health of the group and how well it fits with you. If you feel OK sharing your feelings and believe that your problems are being addressed, the group will likely be useful. If not, try another group or another kind of counseling until you figure out what's best for you and/or your family.

There are few rights and wrongs about how people react to being in a group. Some people find groups helpful at certain times, like when they are first diagnosed or when their treatment changes.

Groups can be a good source of information to help patients make decisions. Cancer survivors help new patients know what to expect and what situations to avoid. Sometimes only a cancer survivor will have that perfect little tip that ends up making a big difference in how you get through the cancer experience and sometimes a professional group leader will point to something in the big picture that helps you and your family.

Personal preference

People often have strong feelings about the kind of group they want to attend. A person may feel that only someone who has had the experience will make a good group leader.

Others want a professional who will offer more education about cancer or emotional issues and will know how to handle in upsetting situations or conflict in the group. You could consider trying both types of groups to learn which feels right for you.

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For some people, it's easy to share feelings with others and they feel comfortable in group settings. Other people find that this kind of sharing feels like an invasion of their privacy. There are few rights and wrongs about how people react to being in a group. Some people find groups helpful at certain times, like when they are first diagnosed or when their treatment changes.

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Phase of illness

Sometimes a support group might be perfect for one phase of the illness, but no help at all for another phase. It's best to look for a group with members who are in the same phase that you are in.

For instance, people with cancer who have been encouraged to go to support groups when they are first diagnosed may be overwhelmed in a large group of people who are going through a cancer recurrence. Recurrence is not what a new cancer patient needs or wants to focus on at the start of their cancer treatment.

Check out the groups carefully. Make sure that your needs or those of your family members are enough like those of the group you are considering. This type of research ahead of time may save you or your loved one time and unnecessary distress.

Special support for special needs

Some needs are best addressed in a special type of support group. Examples are groups that give parents information on how children typically react to a parent's diagnosis, how to explain your diagnosis at work, or how to talk more easily with your doctor.

Other problems, like ongoing marriage problems or serious psychological problems (like

depression) are not best handled in a support group format. For people struggling with these kinds of issues, one-on-one counseling is a better choice. Once you feel less anxious or overwhelmed about your situation, you may be in a better position to be helped by a support group.

The intensity of your feelings about a situation may also help you 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 or your family's distress may make it impossible to listen to anyone else's problem. You could also feel overwhelmed by listening to others. This is another example of when it's probably not the best thing for you to join a group.

Support groups for children and teens

The main goal of a child's support group is to give children the chance to meet other kids whose parents have cancer. Support groups for children and teens are usually divided by age.

Support groups for children and teens should always be led by professionals. School teachers, guidance counselors, art therapists, music therapists, and oncology social workers or nurses with experience with children are examples of possible group leaders. The best kind of support group for children is often one that offers a support group for parents as part of the same program. A group should also teach healthy coping skills for children and teens.

Few children will be eager to attend their first cancer support group. Confronting your own pain and fear is hard for everyone, but once the child goes and has some fun and feels supported, he or she may be quite eager to go again. And at the very least, your child has a chance to be with kids who are like him or her, so the loneliness of the experience is lessened.

Some people resist getting help

Some people refuse to get professional help for emotional or family problems, no matter what their needs may be. They feel that needing help means that they are weak or that it's a sign they are unstable or even "crazy." The American culture tends to value independence or "pulling yourself up by your bootstraps." Sometimes this attitude may cause more harm than good.

One of the issues that comes up when you need support services is how you feel about

asking for help. People sometimes think they should know how to handle every problem that comes up even though they have never had cancer.

Although some feel asking for help is a sign of weakness, in fact, the opposite is true. **Asking for help is a sign of strength.** Learning what to expect from yourself and other family members can help you solve problems faster. Helping your children cope with your illness will teach them that while we cannot control everything that happens in life, we can control how we choose to deal with problems. People sometimes think they should know how to handle every problem that comes up even though they have never had cancer.

Choosing A Cancer Counselor

Your comfort level and the counselor's experience are probably the most important factors to think about when choosing a counselor. People who work in cancer treatment centers usually have more knowledge and experience with the usual emotional responses to cancer than counselors who work with people without cancer. A counselor's experience with cancer, whether personal or professional, helps you see that your reactions are normal and can help you make sense of your situation.

For example, an experienced cancer counselor knows that a patient might feel depressed after treatment is finished. This might happen for some people because being in treatment and going to the cancer center means "I am fighting the cancer." Once treatment is over, patients are sometimes surprised to find they are more worried than they were when they were getting treatment. A cancer counselor knows this is a normal response for many people.

The counselor can help the person with cancer see how this makes sense and not feel so strange and alone at times. And, an experienced cancer counselor will also be able to tell the difference between the normal sadness and loss you feel and a major depression that may require treatment. (For more on this, see [Anxiety, Fear, and Depression¹](#).)

It's also important to consider **training or credentials** when choosing a counselor. Your counselor should have at least a bachelor's degree in one of the counseling fields. They

might also have a master's or doctoral degree. Counselors come from the fields of social work, psychology, psychiatry, psychiatric nursing, or pastoral counseling.

While credentials describe a person's formal education in their chosen field, **experience** with cancer care is also important. And **personality** is important, too. Ideally, your cancer counselor will be warm and caring. Often the best sources for counselors come from someone who has had a good experience with the professional: **word-of-mouth references**. Just as you want to be sure the people on your medical team are competent, you should also apply the same standards to your psychosocial care. You should not feel shy about checking out your potential mental health counselor. Professionals who are secure in their abilities should be happy to give you information about their credentials and experience.

Sometimes people feel that unless a counselor has had cancer, they may not be able to help. A personal experience can certainly add to the counselor's expertise, but living through the cancer experience with many cancer patients and family members is valuable as well. Even if a counselor has never had cancer, we have all experienced life crises and losses. A personal experience with cancer is only one factor to think about in choosing a counselor.

Do you feel safe sharing your concerns with this person? Do you trust their ability to help you? Do you feel that the counselor listens to you and understands who you are as a person? Do you think your family could relate easily to this person? Your reactions may be hard to understand or describe, but trust your instincts. If somehow you just don't feel comfortable after a few sessions, it would be wise to try someone else.

Paying for counseling services

Most health insurance plans have some coverage for counseling, but coverage is often more limited than it is for medical services.

Mental health coverage is supposed to be available to most people with health insurance, but you may find that your coverage still doesn't meet your needs. Some policies only pay for a limited number of sessions.

A managed care policy may limit your choices about whom you can see. Your insurance may have contracts with certain mental health providers, but not with others. Smaller employers may not be required to cover mental health treatment at all. Check on your co-pay and how much you will be reimbursed for your mental health provider.

If there are no free counseling services in the hospital or clinic where you are being

treated, staff can usually help you get clear information about your insurance plan and what services are covered. Your oncology team should also know of services in the community that may use a sliding scale fee that adjusts to your income. They may be aware of services in the community offered at low or no cost to you, too.

How to know if counseling is working

Here are some ways to decide whether counseling is helping you and your family. Keep in mind that it takes some time to get to these results, and you have to do the emotional work for most of them:

- Am I getting more insight or understanding into my problems? Is it easier to see the overall picture, not just the details?
- Do I feel less anxious or worried?
- Is it easier to make decisions?
- Do I have a clear idea where I am now emotionally, what I need to work on now, and what can wait until later?
- Am I OK with how I am feeling and acting?
- Do I have a goal for completing counseling?
- Could I put into words how counseling is helping me or a family member?

Your family should be asking (and answering) the same questions if they are involved in the counseling sessions. If your answers to these questions are mostly yes, you are probably on the right track. If you don't feel good about your answers to these questions, discuss them with your counselor. If the relationship with the counselor feels right, it may be that what you expect to get is different from what you are getting. It's always possible that the counselor is not the right one for you. This may mean you need to find someone who is a better match for you. You may also need different types of support throughout the process and at different stages. The extra effort this takes could make the difference between a good outcome or a more painful one for you and/or your family.