



Distress in People With Cancer

What is distress?

Distress is a word that has many meanings. Here, we use “distress” to describe unpleasant feelings or emotions that may cause problems for you as you cope with cancer and its treatment.

Distress is also common in the family members and loved ones of people with cancer. It can make it harder to deal with all the changes in your life caused by cancer in someone you love.

Saying that you are distressed can mean that you feel:

- Sad
- Hopeless
- Powerless
- Afraid
- Guilty
- Anxious
- Panic
- Discouraged
- Depressed
- Uncertain

The stress of dealing with cancer may affect areas of your life other than your feelings. It can affect your thoughts, your behavior, and how you interact with others.

Some distress is normal.

A certain amount of distress is normal when you or a loved one has cancer. This distress is caused, in part, because of the attitudes and fears people have about cancer. For example, one of the big fears people have is that cancer means death. But the idea that

cancer always leads to death is wrong. Today, there are nearly 12 million Americans alive who have had cancer.

Of course, people are upset when they learn they have cancer – no matter how much progress has been made in treating it. There are many things that suddenly seem uncertain. People have fears and concerns about what may happen to their bodies. They worry about how their loved ones will cope with cancer and all the things that may happen. And they have fears about what the future will be like. People often wonder, “Am I going to die?” and “Why is this happening to me?”

Once you learn that you or a loved one has cancer, you may no longer feel safe. You may feel afraid, exposed, weak, and vulnerable. Such feelings often last through treatment, and you may feel anxiety and sadness, too.

It’s normal to worry when you are waiting for the first treatment. “The worst time for me was waiting for that first chemo treatment,” said one patient. “Once it was over, and it wasn’t as bad as I thought it would be, I was OK. I actually felt better because I was finally doing something about the cancer.”

Waiting for surgery is another time of major concern. People often worry about the operation itself, but also about whether the cancer is growing while they wait. Fears about the changes that surgery will cause can be a major source of distress, too. Then there are concerns about work and home life and how they may change. Insurance and financial issues often add to the worries.

For some people, one of the hardest times is after cancer treatment. Rather than feeling happy that treatment is all over, they feel even greater distress. One patient put it this way: “I’m on my own now – and I’m just waiting to see what will happen next.”

Seeing the oncologist (cancer doctor) after treatment can feel quite scary. Nearly everyone has some fear the cancer will come back (recur). This is normal, too. “Every time I have aches and pains, I’m convinced it’s the cancer coming back – even if it is a pain in my big toe,” one patient said.

Everything about cancer is stressful

Dealing with the side effects of treatment – such as tiredness (fatigue), hair loss, weight changes, and how disrupted your life seems – is also stressful. In fact, everything about having cancer is stressful. Being upset and worried are part of it, so a certain amount of distress is expected when you find you have cancer. But sometimes distress can go from the expected level to one that interferes with your treatment, makes it hard for you to cope with the illness, and affects all parts of your life.

It’s not a sign of weakness that you become so distressed that it interferes with your ability to do your usual activities. Here, we will try to explain the range of distress – from normal to very high – and offer some ideas about how to handle your feelings in ways that are likely to be helpful.

Your first line of defense in coping with distress is having a doctor and cancer care team you feel safe with. Talk to them about how you feel. They can usually direct you to the help you need. Remember that they are treating YOU, not just the cancer, and they count on you to tell them how you are doing and what you are feeling. Remember, no one can do that except you.

Even though most of the information here may seem like it's for the cancer patient, it also applies to the loved ones of the person with cancer. These people are a strong source of support, and their well-being is important, too. If you are a loved one and feel distressed, it's OK to let the cancer care team know that you need help.

How do you know when your distress level is normal or more serious?

This question can be hard to answer because some distress is “normal” (or expected) when you have cancer. But certain signs and symptoms can warn you that your distress level is too high and is becoming serious. Some of these are:

- Feeling overwhelmed to the point of panic
- Being overcome by a sense of dread
- Feeling so sad that you think you cannot go through treatment
- Being unusually irritable and angry
- Feeling unable to cope with pain, tiredness, and nausea
- Poor concentration, “fuzzy thinking,” and sudden memory problems
- Having a very hard time making decisions – even about little things
- Feeling hopeless – wondering if there is any point in going on
- Thoughts about cancer and/or death all the time
- Trouble getting to sleep or early waking (getting less than 4 hours of sleep a night)
- Trouble eating (a decrease in appetite, or no appetite) for a few weeks
- Family conflicts and issues that seem impossible to resolve
- Questioning your faith and religious beliefs that once gave you comfort
- Feeling worthless and useless

Sometimes, things from the past may put you or your loved one in danger of greater distress and in need of help. Here are some examples of past events that can cause distress to be worse when you have cancer:

- Having a loved one who died from cancer

- Having a recent serious illness or death of someone close to you
- Having had depression or suicidal thoughts in the past
- Memories of painful events from your past that come back as nightmares or panic attacks

If any of these describe you or a loved one, talk to your doctor or nurse. You may need help dealing with distress.

Today, doctors, nurses, and other health professionals realize that emotional distress is a part of having cancer, and that it should be treated along with the physical symptoms of cancer. The best cancer treatment centers are starting to ask every patient about distress.

Tools to help measure distress

Sometimes it's hard to talk about distress in a way that helps your cancer care team understand how much distress you are having and how it's affecting you. There's a distress tool (see the example below) that is much like a pain scale to help measure your distress.

The pain scale works like this: When asking about pain, the doctor or nurse might say, "How is your pain right now on a scale from 0 to 10, with 0 being no pain and 10 the worst pain you can imagine?" This has proved to be a helpful way to measure pain. A score above 5 is a sign of significant pain, and tells the cancer care team that the patient needs more help to manage it.

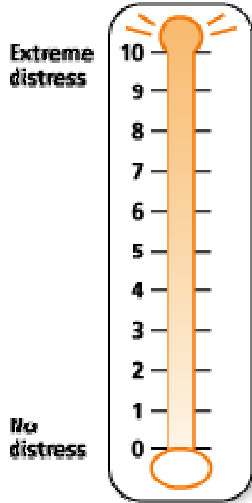
Some cancer teams measure distress in the same way, using a 0 to 10 scale. Just as with the pain scale, you are asked to choose the number from 0 to 10 that reflects how much distress you feel today and how much you felt over the past week. Ten is the highest level of distress you can imagine, and 0 is no distress. Most people can use this scale to rate their distress in a way that helps the cancer team. If your response is 4 or above, you likely have a moderate to high degree of distress. Your doctor or cancer team should find out more and offer some help with your distress.

Not only does this tool tell your team about your emotional health, but it also gives you a chance to talk and work out problems during your visit. Surveys done in cancer clinics have shown that up to 4 in 10 patients have significant levels of distress. You are not alone in your distress.

Another part of the distress tool is the "Problem List," or a list of things that may be causing your distress. For this, you read through a list of common problems and mark possible reasons for your distress. This helps your doctor or nurse know whom you need to see to get help. The list of physical problems helps you remember those you should tell your treatment team about.

Distress screening tool: the Thermometer and the Problem List

Please circle the number (0-10) that best describes how much distress you have had during the past week, including today.



Please read the list below. Have any of the following problems been a cause of your distress in the past week, including today? Be sure to check NO or YES for each.

NO	YES		NO	YES	
		Practical problems			Physical problems
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue (feeling tired)
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		Family problems	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
		Emotional problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
			<input type="checkbox"/>	<input type="checkbox"/>	Constipation
			<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea

- | | | | | | |
|--------------------------|--------------------------|-------------------------------------|--------------------------|--------------------------|-------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Fears | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness | <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Spiritual/religious concerns | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Memory or concentration |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Sexual |

Other problems:

Once your cancer care team knows that you are having problems in certain areas, they can work with you to address those concerns. A nurse will often talk with you in more detail after you have filled out the distress scale and Problem List. The nurse may ask you more questions and can refer you to other health care professionals, like a social worker, nutritionist, or chaplain, if needed.

A social worker can help with the practical, family, and emotional issues. A mental health counselor, psychologist, psychiatrist, psychiatric social worker, or psychiatric nurse may also be able to help you with painful emotions. A pastoral care counselor or chaplain is skilled in helping you with your spiritual concerns. (These professionals and what they do are described in more detail in the “Counseling services you may need” section.) If your distress is mild, the cancer team may choose to work with you themselves, or recommend a support group.

Another way to help you decide whether you need extra support for your distress is to use a questionnaire. A cancer treatment center may use something like the one here when you first start going there for treatment.

“Do I Need Professional Support?” Self-Assessment Questionnaire for Patients

The following questionnaire may help you figure out whether professional counseling would be helpful to you. Every patient has some of these symptoms. Circle the answer that fits best for you, from 1 (not at all) to 5 (all the time) or one of the numbers in between. There are no right or wrong answers. Answer the questions honestly. If you try to cover up how you feel, you might not get the help you need.

During the past 2 weeks:

I have felt anxious or worried about cancer and the treatment I am receiving.

Not at all	1	2	3	4	5	All the time
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I have felt depressed or discouraged.

Not at all	1	2	3	4	5	All the time
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I have been irritable or unusually angry, and I have not controlled it well.

Not at all	1	2	3	4	5	All the time
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My sleeping habits have changed.

Not at all	1	2	3	4	5	All the time
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I have noticed a change in my appetite.

Not at all	1	2	3	4	5	All the time
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I have had trouble focusing at work or at home, or on routine things such as reading the newspaper or watching television.

Not at all	1	2	3	4	5	All the time
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Cancer and its treatment have interfered with my daily activities.

Not at all	1	2	3	4	5	All the time
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Cancer and its treatment have interfered with my family or social life.

Not at all	1	2	3	4	5	All the time
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Cancer and its treatment have interfered with my sex life.

Not at all	1	2	3	4	5	All the time
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Pain and discomfort have caused me to limit my activities.

Not at all	1	2	3	4	5	All the time
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Cancer has caused physical, emotional, or financial hardship for me.

Not at all	1	2	3	4	5	All the time
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Cancer and its treatment have caused changes in how I look, and this concerns me.

Not at all	1	2	3	4	5	All the time
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I have had trouble coping with the stress I have been having.

Not at all	1	2	3	4	5	All the time
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My quality of life during the past 2 weeks has been:

Excellent	1	2	3	4	5	Very poor
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If you find that many of your answers are 4s or 5s, you may be having serious distress and should think about talking with a counselor or other mental health professional.

Source: Developed by the Department of Psychosocial Resources, Tom Baker Cancer Centre, and the Division of Psychosocial Oncology, Department of Oncology, Faculty of Medicine, University of Calgary, Calgary, Alberta, Canada. Derived in part from the Functional Living Index: Cancer, and from the EORTC Core Quality of Life Questionnaire. Published with permission.

How can I help myself cope with cancer?

People value the care they get from their cancer care team, but many also want to take an active role in dealing with their illness. Dr. Jimmie Holland has spent more than 30 years caring for patients at Memorial Sloan-Kettering Cancer Center in New York, and offers some ideas on helpful ways to cope with cancer. They are divided into those attitudes and beliefs that clearly are helpful (the Do's) and those that are harmful (the Don'ts).

Do –

- **Rely on ways of coping that have helped you solve problems and crises in the past.** Know that almost everyone needs to have people around them who they can count on to help when needed. Find someone you feel comfortable talking with about your illness. When you would rather not talk, you may find that relaxation, meditation, listening to music, or other things that calm you are helpful. Use whatever

has worked for you before, but if what you're doing isn't working, find a different way to cope, or get professional help.

- **Deal with cancer “one day at a time.”** Try to leave worries about the future behind. The task of coping with cancer often seems less overwhelming when you break it up into “day bites,” which are easier to manage. This also allows you to focus on getting the most out of each day in spite of your illness.
- **Use support and self-help groups if they make you feel better.** Leave any group that makes you feel worse.
- **Find a doctor who lets you ask all your questions.** Make sure there is a feeling of mutual respect and trust. Insist on being a partner in your treatment. Ask what side effects you should expect and be prepared for them. Knowing what problems may come often makes it easier to handle them if and when they happen.
- **Explore spiritual and religious beliefs and practices, such as prayer, that may have helped you in the past.** If you don't consider yourself a religious or spiritual person, get support from any belief systems that you value. This may comfort you and even help you find meaning in the experience of your illness.
- **Keep a personal notebook of your doctors' numbers, dates of treatments, lab values, x-rays, scans, symptoms, side effects, medicines, and general medical status.** Information about the cancer and your treatment is important to have, and no one can keep it better than you.
- **Keep a journal if you find a need to express yourself without holding back.** It can help you process the journey, and you may be amazed by how helpful it can be.

Don't –

- **Believe the old saying that “cancer equals death.”** There are nearly 12 million Americans alive today who have had cancer.
- **Blame yourself for causing your cancer.** There is no scientific proof linking certain personalities, emotional states, or painful life events to getting cancer. Even if you may have raised your cancer risk through smoking or some other habit, it does not help to blame yourself or beat yourself up.
- **Feel guilty if you can't keep a positive attitude all the time, especially when you don't feel well.** The saying “you have to be positive to beat cancer” is not true. Low periods will come, no matter how great you are at coping. There is no proof that those times have a bad effect on your health or tumor growth. But if they become frequent or severe, get help.
- **Suffer in silence.** Don't try to go it alone – get support from your family, loved ones, friends, doctor, clergy, or those you meet in support groups who understand what you are going through. You will likely cope better and take care of yourself better with people around who care about you and can help encourage and support you.

- **Be embarrassed or ashamed to get help from a mental health expert** for anxiety or depression that disrupts your sleep, eating, ability to concentrate, ability to function normally, or if you feel your distress is getting out of control.
- **Keep your worries or symptoms (physical or psychological) secret from the person closest to you.** Ask this person to come with you to appointments and talk about your treatment. Research shows that people don't often hear or absorb information when they are very anxious. A close friend or family member can help you recall and interpret what was said. As a practical matter, your friend or loved one can also help you get home from a doctor's visit or medical test.
- **Abandon your regular treatment for an alternative therapy.** If you use a treatment that your doctor didn't recommend, use only those that you know do no harm. Find out if the treatment can be safely used along with your regular therapies (as a *complementary therapy*) to improve your quality of life. Be sure to tell your doctor which treatments you are using with the medical treatment, since some should not be used during chemo or radiation treatments. Discuss the pros and cons of any alternative or complementary therapies with someone you can trust to look at them more objectively than you may be able to when you are under stress. Psychological, social, and spiritual approaches are helpful and safe, and doctors generally encourage their use. Things like relaxation and meditation are good ways to deal with distress.

Other coping methods: Exercise

Exercise is not only safe for most people during cancer treatment, but it can also help you feel better. Moderate exercise has been shown to help with tiredness, anxiety, muscle strength, and heart and blood vessel fitness.

Most people with cancer can do some form of exercise. For example, walking is a good way to get started and a good way to keep moving when you are feeling stressed. Talk with your doctor about your exercise plans before you start. Depending on your level of physical fitness, you may need help from a physical therapist to get started on a program that will work for you and is safe.

Keep in mind that even though exercise may help lower distress levels in some people, exercise alone is usually not enough to help people with moderate to severe distress.

Do you need extra help for your distress?

Some people have a higher risk of serious distress; for example, if they:

- Have had depression or other major mental health problems in the past
- Have made a suicide attempt in the past
- Suffer from other serious medical problems besides cancer

- Have communication problems (such as a different language, trouble reading, or hearing problems)
- Have some type of social or family problems
- Have ever been physically or sexually abused
- Are younger
- Are female
- Live alone
- Have limited access to medical care
- Have young children in the home
- Lived with very high stress levels (even before the cancer)
- Have ever abused alcohol or drugs
- Have financial problems
- Have spiritual or religious concerns
- Have uncontrolled symptoms

If any of these are true for you, it is more likely that you may need help from others – your cancer care team can refer you to the right people.

Both you and your cancer care team may also notice there are times when you are at risk for greater distress during the course of illness and treatment. Cancer is often said to be “like being on a roller coaster.” These times for more distress are often at points of change in the illness and treatment:

- Finding a suspicious new symptom
- During work-up and diagnosis
- Waiting to start treatment
- Changing treatment
- Going home from the hospital
- Finishing treatment
- Going back to your cancer doctor for follow-up visits
- Going back to a “normal” life after treatment
- Cancer comes back
- Treatment doesn’t work

- Cancer gets worse or becomes advanced
- Nearing the end of life
- Going into hospice care

If your distress reaches moderate to severe levels at these times, you may need extra help.

Counseling services you may need

The kind of problems you have and your level of distress will help decide what services can best help you.

Social work

In most places, the social worker is the “first responder,” and the first support person you may see. When the cancer care team wants to refer you to someone for your distress, a social worker will see you and find out whether your distress falls into the area of psychosocial or practical problems.

Psychosocial problems. The word “psychosocial” combines psychological, or mental, health with social conditions or aspects. Some psychosocial problems are:

- Trouble adjusting to illness
- Family and social isolation
- Family conflict
- Problems with treatment decisions
- Concern about the quality of life
- Problems adjusting to changes in care
- Making decisions for future medical care (advance directives)
- Abuse or neglect in the home
- Trouble coping or problems communicating
- Changes in how you think and feel about your body and your sexual self
- Grief problems
- End-of-life issues
- Cultural concerns
- Caregiver issues or the need to prepare for caregiving and set up caregiver support

Social workers work with patients and families with psychosocial problems by:

- Teaching patients and families
- Offering support and education group sessions for patients and families
- Giving you resource lists and finding community resources where you can get needed help
- Counseling patients and families about relationships and grief

The above options work best when the distress level is fairly low (4 or less).

If the problems are more severe, patient and family counseling or psychotherapy may be used. Patients and/or families or loved ones may also be referred to psychosocial or psychiatric treatment or pastoral counseling, and certain problems may involve sexual or grief counseling. The social worker may offer community resources that can help families and loved ones with serious issues, such as organizations that help women who are abused at home.

At this level, social workers teach you how to approach and resolve the problem in the way that works best for you. There are also times when the social worker must speak up for the patient who has no close family, or refer a family member to protective services if there is neglect at home. All patients are taught about how to better cope with their illness.

In some places, the social worker is the only resource and handles all practical, psychosocial, and psychological problems. These services are usually covered as part of your total care. Social workers also know a lot about community resources, so that along with counseling, they can connect you to other sources of help nearby.

Practical problems. These can range from day-to-day needs, such as food and clothing, to professional needs, such as job issues. Listed here are some of the more common practical problems that a social worker can help you and your family or loved one manage:

- Illness-related concerns (for example, how to get to treatment every day, how to pay for parking, or where to stay for out-of-town overnight hospital visits)
- Financial concerns
- Job concerns
- School concerns
- Food costs and preparation
- Help with daily activities
- Cultural or language differences (culture or language not the same as those around you)
- Finding help for family and caregivers

For practical problems that are causing only mild distress, the social worker might use patient and family education, suggest support group sessions, and offer resources. For more severe distress due to practical problems, social workers provide patient and family counseling. They may also be able to link people to community agencies, teach problem-solving approaches, help you get needed care, and offer education and support group sessions.

Mental health

Mental health services are used to evaluate and treat distress that is moderate to severe (4 or more on the distress scale). This distress may be caused by other emotional or psychiatric problems the person had before cancer was found. Some problems that can make it harder to cope include:

- Major depression
- Dementia
- Anxiety
- Panic attacks
- Mood disorders
- Personality disorders
- Adjustment disorders
- Substance abuse

All of these may be worsened by the distress of cancer.

Most of the time, mental health services are provided by psychologists, psychiatric nurses, psychiatric social workers, and psychiatrists. Oncology nurses and social workers are often very skilled and experienced in these areas as well. Ideally, one of these professionals is a member of your cancer care team.

Mental health professionals use a range of counseling and therapy approaches to help you cope. They often start by helping you figure out what has worked well for you in the past. They will respect your coping style and try to help you strengthen it. They can help you understand how past problems or experiences may be making it harder to deal with cancer. They may also teach you techniques like relaxation and meditation to help control distress.

Costs. Mental health services are not free as a part of your medical cancer care, but they are usually covered in part by health insurance. Call your health insurance company to find out which professional services are covered and the dollar amount it will cover. An increasing number of cities and towns have free support groups sponsored by local hospitals, religious organizations, or cancer advocacy groups such as the American Cancer Society.

Medicines. Usually, psychologists and social workers work with psychiatrists who can prescribe medicines to help manage distress. Sometimes a drug is needed to reduce distress related to cancer, or distress caused by a medicine to treat cancer or another

serious symptom. For example, steroids (like prednisone or Decadron[®]) may cause mood swings. Opioid pain medicines (like morphine or fentanyl) in higher doses can cause confused thinking. Medicines may be needed to counter these symptoms.

Medicines to treat depression (anti-depressants) or to treat anxiety (anti-anxiety medicines) are options that may reduce distress and help with poor sleep and appetite. Many patients fear taking these medicines – “I will be a zombie” or “I will get addicted.” These concerns are often exaggerated, much like the unreasonable fear some people have of taking narcotics for cancer pain. Many people also fear that seeing a psychiatrist means they are “crazy” or “weak.” But like other mental health professionals, psychiatrists can help reduce severe distress through counseling and helping choose the best medicines.

Remember that your mental health is as important as your physical health, so work with your cancer care team to get all the care you need.

Pastoral services

In a time of crisis (like when you, a family member, or a loved one has cancer), many people prefer to talk with a person from their spiritual or religious group. Today, many clergy have training in pastoral counseling for people with cancer. They are often available to the cancer care team and will see patients who do not have their own clergy or religious counselor.

Pastoral services are important because finding out you have cancer can lead to a crisis of faith or belief. Some people may question the purpose of their life or wonder why God “gave” them cancer. Others may feel that God is punishing them or that God has left them. Still others may use their religious and spiritual resources as a means to cope with their illness and help them sort through these kinds of questions.

The clergy may help you address any of these symptoms or concerns:

- Grief
- Concerns about death and the afterlife
- Conflicted or challenged belief systems
- Loss of faith
- Concerns about the meaning or purpose of life
- Concerns about the relationship with a higher power or God
- Isolation from the religious community
- Guilt
- Hopelessness
- Conflict between beliefs and recommended treatment
- Need for certain types of rituals

Special issues

Some situations call for special skills. Examples are grief counseling and sexual counseling.

The Association for Death Education and Counseling is useful for grief counseling. They have many resources for people who are looking for help or who wish to offer support to someone who is coping with a loss.

The American Association of Sex Educators, Counselors, and Therapists can help you find a specially trained expert in sexual counseling and sex therapy. See the section called “To learn more” for contact information for these 2 groups.

Choosing the right counselor

When you wish to see a counselor, it is important to find one who has had some training and experience in taking care of people with cancer. Your cancer care team is the best way to get names of counselors in your area. Another resource, the American Psychosocial Oncology Society (APOS), can connect you to someone within 2 business days through their toll-free service at 1-866-276-7443. They will help you find a qualified professional in your area who can counsel people with cancer. If you see a counselor and do not feel comfortable or safe talking with that person, call APOS and ask for other names.

More resources to help you

Cancer organizations

A broad range of psychological support services for patients is available. Some provide group and telephone support, as well as information through the Internet and written materials. Contact your American Cancer Society anytime at 1-800-227-2345 or at www.cancer.org for information on what you need. We can connect you to other resources, including those in your area that may best meet your needs.

Internet resources

A large amount of information about cancer is available on the Internet. This information can be very useful to those facing cancer. It can help them make decisions about their illness and treatment, and help them find support. But it's important to look at the credentials and reputation of the organization providing the information, since any person or group can post information online. Always remember, not all information is good information. Some information can even be harmful if you act on it.

Some people find that looking on the Internet increases their distress because of the overwhelming amount of information available. If this is true for you, it may help to ask someone else to “filter” the information and give you only that which pertains to your situation. See the section called “To learn more” for some Web sites that may be helpful.

It's best to stay with Web sites that are supported by well-known cancer organizations with good reputations, where information is reviewed on a regular basis. Avoid Web sites that are selling a product or that make claims that cannot be proven.

To learn more

More information from your American Cancer Society

The following information may also be helpful to you. These materials may be read online at www.cancer.org, or free copies may be ordered from our toll-free number at 1-800-227-2345.

Coping with cancer and treatment

Coping With Cancer in Everyday Life (also in Spanish)

Anxiety, Fear, and Depression (also in Spanish)

Pain Control: A Guide for Those With Cancer and Their Loved Ones (also in Spanish)

Chemo Brain

Guidelines for Using Complementary and Alternative Methods

Health care and insurance

Talking With Your Doctor (also in Spanish)

Health Insurance and Financial Issues for the Cancer Patient

Health Professionals Associated With Cancer Care

Relationships

Talking With Friends and Relatives About Your Cancer (also in Spanish)

Sexuality for the Man With Cancer (also in Spanish)

Sexuality for the Woman With Cancer (also in Spanish)

For loved ones of a person with cancer

What It Takes to Be a Caregiver

What You Need to Know as a Cancer Caregiver

When Someone You Know Has Cancer

Coping With the Loss of a Loved One (also in Spanish)

To find a counselor

American Psychosocial Oncology Society (APOS)

Toll-free number: 1-866-276-7443

(Leave a message with your name, phone number(s), patient's city and state of residence, area code of the town where you are searching for a referral, and the patient's cancer diagnosis. They usually find someone and call back within 24 to 48 hours.)

Web site: www.apos-society.org

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345**, or visit www.cancer.org.

References

Aaronson NK, Ahmedzai S, Bullinger M, et al. The EORTC core quality of life questionnaire: Interim results of an international field study. In: Osoba D. ed. *Effect of Cancer on Quality of Life*. Boca Raton, FL: CRC Press 1991:185-203.

Bultz BD, Holland JC. Emotional Distress in patients with cancer: The sixth vital sign. *Community Oncology*. 2006;3:311-314.

Holland JC. History of psycho-oncology: Overcoming attitudinal and conceptual barriers. *Psychosomatic Medicine*. 2002;64:206-221.

Holland JC, Lewis S. *The Human Side of Cancer: Living with Hope, Coping with Uncertainty*. New York: HarperCollins. 2000.

Institute of Medicine (IOM). *Cancer care for the whole patient: Meeting psychosocial health needs*. Adler NE and Page AEK, eds. Washington, DC: The National Academies Press. 2008.

Kushi LH, Doyle C, McCullough M, et al for the American Cancer Society 2010 Nutrition and Physical Activity Guidelines Advisory Committee. American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention: Reducing the Risk of Cancer With Healthy Food Choices and Physical Activity. *CA Cancer J Clin*. 2012;62:30-67.

National Comprehensive Cancer Center Network. *Clinical Practice Guidelines in Oncology: Distress Management, v.1.2011*. Accessed at www.nccn.org/professionals/physician_gls/pdf/distress.pdf on January 4, 2012.

Schipper H, Clinch J, McMurray A, Levitt M. Measuring the quality of life of cancer patients: the Functional Living Index-Cancer: development and validation. *J Clin Onc*. 1984:472-483.

US Food and Drug Administration, Center for Drug Evaluation and Research. *Fake Cancer Cures*. June 2008. Accessed at www.fda.gov/cder/news/fakecancercures.htm on March 31, 2009.

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For additional assistance please contact your American Cancer Society
1 · 800 · ACS-2345 or www.cancer.org