



Survivorship:

Living With, Through and Beyond Cancer

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER
Making Cancer History[®]

www.mdanderson.org/topics/survivorship

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“My survivorship started the minute I decided that this wasn’t going to be the end for me, that I was going to beat the disease.”

— Rita, survivor

“When I first got this disease, I thought that I would get back on the bike, so to speak. And it’s really taken me a long time to accept — you know — that that’s really not going to happen. I’m still having a good life, and I still have an opportunity to find fulfillment as a human being, but it’s under a different set of parameters than it was before. “

— Max, survivor

To the patient and family

This booklet is for people who have been diagnosed with cancer. If you have questions that are not answered in this booklet, please ask your health care team.

For more information, visit www.mdanderson.org/topics/survivorship.

Words that may be new to some readers appear in *italics*. The glossary section in this booklet gives the meanings of these terms.

For an at-a-glance look at M. D. Anderson’s resources, refer to the table in the back of the booklet.

What is a survivor?

A cancer survivor is often defined as anyone who has been diagnosed with cancer, from the time of diagnosis and treatment through the remaining years of life. Recently, some groups have widened that definition to include the people in a cancer patient’s life. This would include family members to friends and caregivers. In this guide, however, the term cancer survivor refers to anyone who has been diagnosed with the disease.

At M. D. Anderson, your health care team will provide you the best possible care. On your team are specialists from every field related to the diagnosis and treatment of cancer. They will combine their knowledge and skills to develop your treatment plan and ongoing care.

You are also a member of your health care team. As an active member of this team, your role is to ask questions when you need more information.

If you have any questions about M. D. Anderson’s resources and services, ask a member of your health care team.

Stages of survivorship

There are three stages of survivorship.

Living with cancer begins at the moment of your diagnosis. The focus is on treatment, getting rid of the cancer, if possible, or controlling the cancer to the point where you can live with it long term. During this time, you may be offered treatment options such as surgery, chemotherapy and radiation therapy as well as medications to manage side effects of the treatments. You may be asked whether you would like to join a clinical trial, in which new cancer drugs and treatments are studied. You also may be offered services to help you and your caregivers cope with emotional and practical concerns.

Living through cancer refers to the period following treatment in which you are at a relatively high risk of a recurrence of your cancer. At this stage, you

Sometimes I feel down, and other times I feel great, but I'm trying to keep on the great side so it's not much of a roller coaster."

— Frank , survivor

"It has put faith back into the medical professional for me, that I can actually talk to doctors, and to nurses, and we're just people figuring out the same problem ... We're part of a team, and you're not alone, you are not alone."

– Carolyn, caregiver

"I would say that one of the strongest tools that cancer patients have is themselves and their team."

– Sergio Giralt, M.D.,

Professor,

Stem Cell Transplantation

may feel relieved that treatment is over but anxious about the fact that you no longer see your cancer doctor on a daily, weekly or monthly basis. During this stage, you typically see your cancer doctor every three, four or six months, depending on your treatment plan. This is also a time of rehabilitation, especially if treatment included surgery that physically changed your body.

Living beyond cancer refers to post-treatment and long-term survivorship. You may find your life returns to what you knew before you had cancer. Or, you may find that physical, psychosocial or financial concerns continue as a result of earlier treatments. This is often referred to as a *new normal*. During this stage, you may develop a plan for your ongoing health care with your cancer doctor and community health care provider.

Communicating with the health care team

Your care at M. D. Anderson is based on a team, or *interdisciplinary approach*. This means that specialists from various areas and disciplines will be involved in planning your treatment. The team includes your doctor, nurse, case manager, pharmacist, therapist, dietitian and social worker to name a few. You may meet with the members of your health care team one-on-one or in a group.

Communicating with your health care team is important. It's your patient right and responsibility to ask lots of questions. Keep asking questions until you understand what your health care team is saying and what you need to do to take care of yourself.

To make a visit with any of your health care team members easier, here are a few tips.

- Prepare a list of questions to ask your doctor.
- Bring a friend or family member with you to take notes during the appointment.
- Report any new or different symptoms to your doctor.
- Repeat instructions back to your health care team to make sure you have the right information.
- Speak up. Before you leave your appointment, make sure you address any questions or concerns.
- Follow up. If you have any questions after your appointment, contact your health care team.
- Keep a journal or a notebook to record your medical history in your own words and for your own use.

It's important to communicate with your health care team through every stage in your cancer experience. Some survivors may need more information than others depending upon their diagnosis and treatment. If you have questions or concerns, don't hesitate to contact your health care team. Interpreters are also available through Language Assistance at 713-792-7930.

Physical changes of cancer treatment

Physical changes cancer patients go through can be caused by the cancer itself and/or the therapies used to treat cancer.

- **Short-term side effects** occur during treatment.
- **Long-term side effects** are those that begin during treatment and continue after the end of treatment.
- **Late side effects** are symptoms that appear months or years after treatment has ended.

The physical changes you may experience depend upon your cancer type and the treatment you receive. Some specific side effects may include:

Bladder and bowel changes

Cancer and its treatment may change the way your bladder and/or your bowels work. These changes can affect your everyday tasks.

You may have incontinence (a loss of urine) while coughing, sneezing, straining or sleeping. Depending on what bladder changes have occurred, you may see a Wound, Ostomy and Continence (WOC) nurse or you may require a referral to a urologist.

Bowel changes may include *constipation* and *diarrhea*. Ask your doctor or nurse for a referral to a dietitian to learn more about how food affects your bowels. For help with bowel changes, you can attend the Bowel Management class. For more details, call the Patient Education Office at 713-792-7128.

You can also ask your health care team for a referral to:

- Department of Clinical Nutrition
- Department of Gastroenterology, Hepatology and Nutrition

Cancer that returns or second cancers

Most cancer patients live with the possibility their cancer may return or spread. Some types of cancer may increase the risk of you getting a second cancer. Please ask your doctor or nurse if you have any questions.

Diabetes

Some drugs taken during your treatment may cause your blood sugar levels to rise. If your blood sugar levels stay high after treatment stops, you may be at risk for *diabetes*. If you have questions or concerns about diabetes, ask your health care team for a referral with the diabetes educator in the Internal Medicine Center. For help with diabetes, you can attend the Diabetes and You classes. For more details, call the Patient Education Office at 713-792-7128.

Eyesight, hearing, speech and dental

Your cancer and its treatment may affect your eyesight, hearing, speech or mouth. Examples of how these areas of your body can be affected are as follows:

Radiation around the area of the **eye** may increase the risk of eye problems such as *cataracts*. Taking steroid medications also can increase your risk for cataracts. For children, radiation to the bones near the eye may slow bone growth and stop them from forming correctly. In addition to steroid medications and radiation, other cancer drugs can lead to problems such as blurred vision, double vision or *glaucoma*. If you have problems with your vision during or after your treatment, your doctor may refer you to an eye specialist, called an ophthalmologist, in the Department of Head and Neck Surgery.

Certain chemotherapy drugs and antibiotic medications may cause **hearing** loss. Radiation to the brain or ear may lead to hearing loss as well. Hearing aids may help correct problems caused by your treatment. If you have problems with your hearing, you may be referred to a hearing specialist, known as an audiologist, in the Department of Head and Neck Surgery.

After certain surgical procedures to the head and neck, your **speech**, your ability to swallow and your ability to communicate may be affected. If you have problems with your speech, your doctor may refer you to a specialist, called a speech pathologist, in the Department of Head and Neck Surgery.

Chemotherapy may affect tooth enamel and increase the risk of long-term **dental** problems. High-dose radiation to the head and neck area can change tooth development and cause gum disease. Or, it may cause tooth decay or loss and decrease the amount of saliva (spit), causing a dry mouth. Mouth or throat soreness and/or ulcers may result from your cancer treatment as well. These side effects can be painful and can make it difficult for you to eat, talk and swallow. You may be referred to a specialist in our dental clinic in the Department of Head and Neck Surgery if you have problems with your teeth, gums or mouth.

“Anyone who is living with and through, and after the cancer is a survivor. There are just different problems to deal with at each of these stages.”

*— Alma Rodriguez, M.D.,
Professor, Lymphoma*

Cancer survivors should have regular check-ups to help find or prevent any eyesight, hearing, speech or dental problems. If any of these issues need attention, ask your doctor to refer you to the appropriate specialist.

Hormone changes

Sometimes cancer treatment can change the body's natural hormones. For women, menstrual periods may suddenly stop (early menopause). Other side effects for women may include hot flashes, vaginal dryness, pain during sexual activity, fatigue, mild depression and problems sleeping. Men may have less testosterone. Men may also experience hot flashes, problems sleeping, fatigue and mild depression. They may also have a loss of interest in sex and erection problems. Please tell your doctor or nurse if you have any hormone-related side effects that are bothering you.

Women may need to make an appointment with their gynecologist or ask for a referral to see a gynecologist in the Gynecologic Oncology Center. Men may need to ask for a referral to meet with a doctor in the Endocrine Center.

Fatigue

Fatigue is the most common side effect of your cancer and its treatment. You may feel very tired no matter how much sleep you get. If you are feeling overly tired, ask for a referral to the Fatigue Clinic. You may find new ways to relax and save energy. You can also attend the Cancer-related Fatigue class. For details, call the Patient Education Office at 713-792-7128. Or, you can attend relaxation classes offered at the Place ... *of wellness*, 713-794-4700.

Hypothyroidism

Some cancer treatments cause your *thyroid gland* to make too little thyroid hormone. This is called hypothyroidism. When this happens, you may gain weight, become constipated, have dry skin or always feel cold. This health problem can be treated with medicine. To learn more, ask your doctor or nurse.

Learning and memory problems

Cancer treatment may cause problems with learning and memory. For example, you may forget a word, name or thought in the middle of talking to someone. These changes, which may occur during or right after treatment, are sometimes called chemobrain. Cancer itself may also affect learning and memory. Memory loss may improve in long-term survivors. For help with these changes, ask for a referral to visit a neuropsychologist in the Neuropsychology Service. Or, you can attend the Chemobrain: Is it real? class at the Place ... *of wellness*, 713-794-4700.

Lymphedema

Lymphedema is swelling that occurs in the arms or legs. It is caused when lymph nodes are removed by surgery or damaged by radiation. Fluid builds up in the tissue in the arms and legs, which leads to swelling, pain and limited motion. Lymphedema may occur several months after surgery or radiation or many years later. If you notice swelling in your arm or leg, contact your health care provider. Early treatment will help prevent problems. For help, ask for a referral to Rehabilitation Services.

Neuropathy

One of the most difficult treatment side effects is neuropathy. Neuropathy is a tingling, burning or numb feeling in the hands and/or feet due to nerve damage. Neuropathy can be caused by radiation, surgery and chemotherapy. This side effect may improve when your treatment stops and may get better over time. It also may last for many years. For help with your neuropathy symptoms, you may be referred to Rehabilitation Services or the Department of Neuro-Oncology.

Acupuncture services are also available at the Place ... *of wellness*, 713-794-4700.

Ask your doctor or nurse to help you understand your lab reports. For more information about how to read your lab reports, visit The Learning Center.

Organ damage

Certain types of cancer treatment can age or damage your heart, lungs, liver or kidneys. This damage may cause long-term health problems. These problems may appear as you age or have other health problems .

Some cancer treatments can cause **heart failure**. Certain types of chemotherapy medicine can be harmful to the heart. Heart failure symptoms can include shortness of breath, feeling weak and tired after regular activity or while at rest, chest discomfort or feeling the heart beat fast. Your doctor will screen you for heart failure during your treatment and may refer you to the Cardiopulmonary Center.

Certain drugs can damage the **lungs and airways**. These drugs can include some antibiotics, chemotherapy medicines or some types of biotherapies. Common symptoms of lung damage can include problems breathing, coughing or pneumonia. It is important that you tell your doctor if you experience any of these symptoms.

Some chemotherapy medicines can damage your **liver**. Symptoms of liver damage may include dark urine, pale stools, yellowing of your eyes or skin, swelling or pain in your abdomen (stomach area), flu-like symptoms or severe fatigue. When taking some chemotherapy drugs, you will have regular blood tests to check how your liver is working.

Other chemotherapy medicines can damage your **kidneys**. Symptoms of kidney damage include decreased urine flow or bladder irritation and bleeding. You may also have a change in urine color or a burning feeling while you urinate. Your doctor will check your kidney function closely.

Should you experience any of the above symptoms, tell your doctor or nurse.

Osteoporosis

Osteoporosis (bone loss) occurs when bone mass is lost faster than it can be replaced. This results in weaker bones that may break more easily. Your cancer, cancer treatment or other side effects may cause bone loss. To speak with a doctor about osteoporosis, ask for a referral to the Internal Medicine Center.

Pain

Cancer pain takes many forms. It may be short-lived or long-lasting. It also can be mild or severe. It can affect your bones, nerves or organs. Each patient's pain is unique. Pain does not always mean the tumor has grown or returned. Your cancer or its treatment may cause pain. You also may have pain that has nothing to do with your illness or its treatment. Talk to your doctor or nurse about signs and symptoms to watch for and what you can do to reduce the chance of recurrence or second cancers. Also, see the "Guidelines for follow-up care" section on page 10 in this booklet.



Hospice Care

As hard as it may be for you to approach the end of life, there may come a time when you ask yourself, “What if I do not recover from my cancer?”

“What can I do to prepare myself and my family?”

“Will I be in pain?”

“Will I be afraid?”

You can plan to have the best possible end of life.

Hospice care or end-of-life care provides medical, psychosocial, and spiritual support to terminally ill patients and their loved ones. Hospice is about quality of life — peace, comfort and dignity.

The goal of hospice care is to control pain and other symptoms so the patient can remain as alert and comfortable as possible. Hospice care is available for patients who can no longer benefit from curative treatment. The typical hospice patient has a life expectancy of six months or less.

Hospice programs provide services in various settings: the home, hospice centers, hospitals or skilled nursing facilities. Patients’ families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need.

The following resources may offer help for people seeking hospice care and information:

- Chaplaincy, 713-792-7184
- Department of Social Work, 713-792-6195
- Supportive Care Services and Rehabilitative Medicine, 713-792-6085

For help with these concerns, ask for a referral to the Pain Management Center at 713-745-PAIN (713-745-7246). You can also attend the Pain Management class. For more information, call the Patient Education Office at 713-792-7128. *Acupuncture* services are available at the Place ... *of wellness*, 713-794-4700.

If the pain is sudden and new, like pressing chest pain, call 911 or go to the nearest emergency room. If you have pain with fever, nausea, vomiting or bleeding, you also need emergency help.

Palliative care

Palliative care helps patients with advance disease or severe side effects to attain the best possible quality of life. A team of specialists in the Supportive Care Center works together to assess and manage severe cancer-related symptoms. For additional help, call the Department of Social Work at 713-792-6195.

Premature aging

Some of your treatments may cause health problems that are more often seen in older people. These may include bone loss, arthritis (joint pain), early menopause, infertility and sexual health changes.

Sexual health

When you find out you have cancer, your sexual health may not be high on your list of worries. Because you are dealing with big choices and coping with stressful changes, the topic of sexuality may be the last thing on your mind.

Your sexual health is a personal topic, and your feelings and needs are unique. At some point, you may find that cancer has affected your sexual health. These effects can be temporary or permanent. Some of these changes may include:

- Struggles to feel normal or attractive
- Loss of desire to have sex or difficulty being sexually responsive or intimate with your partner
- Physical changes to your body (e.g., removal of one or both breasts or testicles)
- Hot flashes (men and women)
- Not being able to get or keep an erection (erectile dysfunction)
- Trouble enjoying sex because it is painful or vaginal dryness
- Trouble being able to have children (infertility). For more information about fertility, visit www.fertilehope.org
- Concerns about the safety of a pregnancy after cancer

Intimacy is not just sex. It is also touching and closeness with someone. It means caring about someone. It includes sharing your hopes and feelings. Finding ways to be intimate with your partner during and after treatment is very helpful. Talking to your partner is key to good sexual health during and after treatment.

It's hard to know what will happen because every person is different. But no matter what, you deserve the best quality of life, and this includes your sexual health.

“It has an emotional impact on who you are, and how you conduct yourself intimately and what is this going to mean [to me].”

– Rita, survivor



“Individuals who maintain their health are going to be able to face second challenges of cancer if they do, unfortunately occur. So it’s important that the patients have an overall focus on health.”

*— Alma Rodriguez,
M.D., Professor,
Lymphoma*

By learning more about how cancer can affect your sexual health, and how to deal with these changes, talk with your doctor or nurse before treatment begins. Patients may be unsure about how to talk about their sexual health with their doctor or nurse. If your doctor or nurse seems uncomfortable talking about your questions or concerns, ask to see a specialist. This could be a doctor or mental health professional trained to treat changes and issues related to your sexual health.

To meet with a sexual health specialist, ask your doctor for a referral to the Psychiatry Service at 713-792-6600.

For help with erectile dysfunction, ask your doctor for a referral to a urologist.

Sleep loss

Being able to fall asleep or stay asleep can be a problem for cancer survivors. While sleeping, you may have hot flashes, night sweats, breathing problems or feel worried. For help with these concerns, you may be referred to the Sleep Center, Internal Medicine Center or Psychiatry. You also can attend relaxation classes offered at the Place ... of wellness, 713-794-4700.

For a list of the most common health problems by cancer type, visit our Web site at www.mdanderson.org/topics/survivorship.

Guidelines for follow-up care

After treatment, you will most likely see your local doctor for follow-up care. Your local doctor may know little about your cancer and treatment. Before going home, your cancer doctor will give you a follow-up plan of care. You can share this plan of care with your local doctor.

This plan should include:

- The type of cancer you had
- The treatment you had for your cancer
- Possible side effects of your treatment
- When to come back for follow-up visits
- The type of follow-up tests you will need
- Tips for staying healthy

Most follow-up plans focus on the first five years after treatment. There are suggested yearly tests and procedures for each type of cancer. You can visit our Web site for suggested yearly tests and procedures. www.mdanderson.org/topics/survivorship.

Survivors often have questions about their genetic risk for cancer. They also may be concerned about the cancer risk for their children. Genetic counseling and testing can help answer these questions for you and/or your children. In genetic counseling, a counselor reviews your personal and family history of cancer. This is used to estimate your personal cancer risk. If your history suggests that the cancer in your family may be hereditary (runs in your family), you can then choose to have genetic testing. Genetic testing involves taking a blood sample to see if you have a genetic mutation that may increase your risk for cancer.

Call Clinical Cancer Genetics at 713-745-7391 for more information or to make an appointment.

Tips for healthy living

A healthy way of life is important for everyone. Healthy choices should be a part of each day. Cancer survivors must focus on their health even if they feel fine after treatment.

A self-care plan is a tool that can help you make healthy lifestyle choices. Your own self-care plan can include your daily diet and exercise needs. This plan may lower your risk for illness and help improve your quality of life.

A healthy way of life may not always stop cancer from coming back or spreading. But, healthy choices can make you feel your best every day. Follow your plan, but be sure to talk to your doctor if any problems arise. Together, you and your health care team can develop the best self-care plan.

Your self-care plan will include five parts:

- Exercising
- Eating well
- Reducing stress
- Getting regular check-ups
- Avoiding tobacco

Every self-care plan is different. So, it is vital that you talk with your health care team about your health when making your self-care plan. Here are some healthy ways to start your self-care plan.

Exercising

Daily exercise will help you feel your best every day. Examples of exercise include:

- Walking
- Swimming
- Cycling
- Gardening and outdoor work
- Playing sports you enjoy

The Learning Center offers materials about fitness and exercise such as yoga, Pilates and strength training. The Place ... *of wellness* offers classes such as yoga and tai chi. Classes are free of charge. Call 713-794-4700 to learn more.

Eating well

There are many ways to eat healthy. Guidelines for eating well include:

- Eating at least five servings daily of fruits and vegetables
- Eating plenty of fiber (such as beans, peas and whole grain foods)
- Drinking eight to 10 glasses of water per day
- Avoiding salted, pickled or smoked foods
- Limiting red meat
- Drinking little or no alcohol

You also can meet with a dietitian to learn about good food choices. Ask your doctor or nurse for a referral to a dietitian. The Learning Center offers materials about nutrition and healthy living. Cooking classes are also offered by the Place ... *of wellness*, 713-794-4700.

Reducing stress

It is not always possible to keep a stressful change or event from happening in your life. Many changes are out of your control. But you can control how you react to these changes. Learning to cope with stress can improve your health and make life more enjoyable.

The following tips can help you cope with stress:

- Do things you find fun and that make you laugh
- Do things that make you feel relaxed
- Take classes, like music or painting
- Write in a journal
- Pray or meditate
- Attend support groups, seek counseling or share your feelings with close family or friends
- Accept what you cannot change

The Place ... *of wellness* offers many classes for cancer survivors and their family. Classes are offered on journaling, meditation, music, scrap booking and much more. Call 713-794-4700 to learn more.

The Department of Social Work provides counseling free of charge for patients and their families. Support groups are also available. Call 713-792-6195 to learn more.

Patients and family members can meet with a chaplain at any time. Chaplains offer prayer and spiritual support for all faith traditions. Call 713-792-7184 to learn more.

Getting regular check-ups

As a cancer survivor, maintaining your health care is important.

- Take your medicines as directed.
- Have regular check-ups.
- Know what signs and symptoms to look for and when to call a member of your health care team.

During and after treatment, there are still things you can do to improve your health. It may mean learning new ways to exercise, eating a healthy diet and reducing stress.

Talk to your doctor about what you can do to stay healthy. You can also visit the following services:

- *askMDAnderson*, 1-877-MDA-6789 (1-877-632-6789)
- Cancer Prevention Center, 713-745-8040
- The Learning Center, 713-745-8063

If you'd like a copy from your medical record such as lab reports, call the Release of Medical Information office at 713-792-6821.

Avoiding tobacco

Tobacco use is the single most preventable cause of death in the United States. Smoking or using chewing tobacco puts you at risk for several types of cancer. Tobacco use increases the risk of your cancer coming back or getting a second type of cancer.

By quitting smoking, your treatment outcomes may improve.

If you've tried quitting before, but were not successful, don't give up. It's never too late to improve your health by kicking the tobacco habit. For free counseling and medication, call the Tobacco Treatment Program at 713-792-QUIT (713-792-7848) or email quitnow@mdanderson.org.

Psychological, social, emotional and spiritual impacts of cancer

As a survivor, cancer and its treatment does not only affect your body. You also may have *psychological, social, emotional and spiritual changes*. It is not easy to see these as separate because they are closely connected. These changes can affect your quality of life and may continue to be felt after your treatment is over.

There are no guidelines on how to be a survivor. These changes may come and go and may be different during and after treatment.

Psychological, social and emotional changes

You may have fear, anxiety, anger, guilt, grief or depression. You may see a change in your self-image and/or self-esteem. You also may have a change in family roles. At the end of this section, M. D. Anderson resources are provided to help you with these emotions.

It is normal to be **angry** when you have cancer. It affects your job, school and relationships. Let your anger out in a positive way. Some survivors find it helpful to talk to a counselor or support group or to a good friend. Other survivors find it helpful to write about their anger or to paint or draw.

Uneasiness or **anxiety** is a common feeling when dealing with cancer. You may have many questions about your health, finances and loved ones. For example:

- How serious is my illness?
- Will my health insurance cover my care?
- Who will take care of my family?

It is common to feel sad and **depressed** about your illness. At some point, many cancer survivors feel depressed. However, please talk to your doctor or nurse if you feel bad for more than a couple of weeks or feel so sad that you can't do normal, everyday things. Joining a support group may help. Exercise

“I have had to learn to not be so scared. You know, everything does not have to be perfect in life to be happy. Be real and if you're not able to handle it, get some help. If you're not able to handle it, it's ok.”

– Carolyn, caregiver



and spending time with friends or family also may make you feel better. It is not uncommon for cancer survivors to have **fears**. You may fear the unknown. You also may fear that your cancer will come back. Fear can be good and bad. Fear is good if it makes you talk with your doctor when you have a new ache or change in your body. Fear is bad if it keeps you from making decisions.

Grief is a normal process that helps people heal after loss. Many losses may come with cancer. These losses can be simple or complex. Losses can include a change in your health and independence. You may want to avoid the feelings of grief. Instead, it's important to seek help.

“I’m going to have to live with an amputation for the rest of my life ... I think I was really concerned about, you know, am I going to be normal after this. Am I going to look normal, am I going to walk normal?”

–Shelby, survivor

During treatment, you may see changes to your body. These changes may bring feelings of low **self-esteem** and **self-image**. Some may have extreme weight loss or weight gain. Marks on the body such as radiation tattoos, eye patches or scars are hard to deal with for some people. There is sometimes a feeling of loss. It may be a loss of a body part (amputation). Or, it may be a loss of bladder control. Some who have a urostomy (an opening to get rid of urine) or colostomy (an opening to get rid of body waste) feel unsure in public. It may be a loss of feeling like a man or a woman. Some have issues being intimate with their partners. This is often common for women who have a mastectomy (removal of breast) or men who had a prostatectomy (removal of the prostate).

Some survivors feel a **sense of guilt for surviving** their cancer while others may not. As a survivor, you may ask, “Why am I the one to survive?” You may then struggle with another question: “If I have survived, what is the meaning of my life now?” This may cause you to take a closer look at your life, rethink your goals, and how you want to live your life or spend your time. If your sense of guilt lasts for a long period of time, there are people who can help you talk through your feelings.

There are things you can do to help yourself cope with your emotions.

- Write down your thoughts and feelings in a journal
- Try yoga, tai chi or meditation
- Share your concerns with a friend or support group
- Learn the difference between normal body changes and serious changes
- Know when to call your doctor
- Coach yourself to think in a positive way

Spirituality means different things to different people. It is about having feelings of faith, hope and love. You may be looking for life's meaning and purpose, or you may want to reach out and help others. Many people also follow a religion and join a community of a certain faith. These and many other ways show how people connect with each other and life in a spiritual way. M. D. Anderson's chaplains can guide patients on their spiritual journey, whatever path it may take.

If you'd like to talk with someone about any of these or other feelings, ask for a referral to the Psychiatry Service. For other resources, call:

- Your doctor or nurse
- Anderson Network , 713-792-2553 or 800-345-6324
- Chaplaincy, 713-792-7184
- Department of Social Work, 713-792-6195
- Place ... *of wellness*, 713-794-4700

Spiritual changes

Like many survivors, you may find that your life takes on new meaning after cancer. Your values may have changed. Your ties to others may have become stronger. Some survivors rely on their spiritual beliefs to help them through illness. On the other hand, you may feel abandoned. You may wrestle with the question, "Why me?"

More and more survivors are following a holistic approach. A holistic approach considers the whole person — body, mind and spirit. There are many places to learn more about the ties among body, mind and spirit.

For more details, visit the following:

- Chaplaincy, 713-792-7184
- Place ... *of wellness*, 713-794-4700

Returning to your daily life

You may have a hard time returning to your daily life and work. This may cause stress.

Some worries may include:

- Risk of infection
- Lack of energy during the day
- Memory loss or "chemobrain"

You may have dealt with life-and-death questions. This may cause you to feel alone. Talking to other survivors may be helpful. To be matched with a survivor, call Anderson Network at 713-792-2553 or 800-345-6324. For additional help, call the Department of Social Work at 713-792-6195.

Talking about your cancer with others

In the past, most people did not even want to use the word cancer. If cancer was talked about at all, it was done so in hushed tones and often called the "Big C." Because little was known in the past about how you get cancer, people feared what others would think if they talked about their illness.

While times have changed, you may fear you will be seen differently. You may be afraid to tell your employer or coworkers you are being treated. You may fear losing your job or health insurance. This fear adds to the emotional stress of having cancer.

“Today, many types are either curable or chronic, and patients will live through the cancer, or with the cancer for years.”

*— Alma Rodriguez, M.D.,
Professor, Lymphoma*

One of the hardest things to face is how the people closest to you will react. Often friends, coworkers and family members don't know how to talk to you about their own fears. Some may use humor to avoid serious talk about cancer. Others may not know what to say or how to act. They may pretend nothing has happened. This can lead to silence. With this silence, you may begin to feel abandoned. Still others may continue to treat you like a sick person well after your treatment. They may ask you questions about your health. Since cancer can be a long-term illness, talking about it early is an important step. But, you do not need to share anything that makes you uncomfortable.

Resources that can help you talk to others about your cancer include:

Books

- *The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer* by Micheal Feuerstein, 2006.
- *Cancer Survivorship: Today and Tomorrow* by Patricia Ganz, 2007.
- *From Cancer Patient to Cancer Survivor: Lost in Transition* by Maria Hewitt, 2006.

Brochures

- Facing Forward: Life After Cancer Treatment, National Cancer Institute, 2006.
- When Someone You Love Has Completed Cancer Treatment, National Cancer Institute, 2005.
- The Road to Survivorship: Living After Cancer Treatment, Lance Armstrong Foundation, 2006.

Web site

- American Cancer Society Cancer Survivors Network
www.acscsn.org
- CureSearch National Childhood Cancer Foundation
www.curesearch.org
- M.D. Anderson Cancer Center
mdanderson.org/topics/survivorship
- National Cancer Institute
cancercontrol.cancer.gov/ocs
- National Coalition for Cancer Survivorship
www.canceradvocacy.org

Financial and legal impacts of cancer

Money issues can have a major impact on survivors. Survivors can be left paying for some or most of their treatment costs. If you are the major wage earner, there may be little or no income during treatment. Insurance coverage can also change after cancer treatment. Benefits may be reduced or lost. As a result, you and your family may face major debt.

At M. D. Anderson, you will get a patient statement for every month in which there are charges, payments, adjustments and/or open balances. You can also view your statements online at <https://myMDAnderson.org>. For help with your statements, call Patient Business Services Customer Service at 800-527-2318.

Many families need financial help after cancer treatment. For questions about the cost of your care or your bill, talk to your Patient Access Specialist in your center. If the cost of your care is beyond your financial means and you are a Texas resident, you may request an Application for Supplemental Financial Assistance. If you wish to apply for Texas Medicaid or disability, your Patient Access Specialist will refer you to our third party eligibility specialist. This service is provided free of charge. For non-Texas residents, talk with your social worker. He or she can tell you about programs that may help based on your specific needs. Call the Department of Social Work at 713-792-6195. Legal issues are also important to survivors. Your cancer history can affect your rights at work and your insurance options. You are encouraged to know your rights as a cancer survivor.

Survivors also should plan for the future. It is never too soon to make financial and legal plans. Prepare legal documents that will make your wishes known. Proper planning will make sure your wishes are followed and ease the stress of decision making for your loved ones.

Resources

The following resources can help you with financial, legal or job-related concerns.

Advance Directives

713-792-6195, Department of Social Work

Advance directives allow you to state your choice for health care if you become too sick or unable to make decisions. There are three kinds of advance directives:

- Living Will
- Medical Power of Attorney
- Out-of-Hospital Do-Not-Resuscitate Order

If you have questions or need help, contact the Department of Social Work.

American Association of Retired Persons (AARP)

888-OUR-AARP (888-687-2277)

www.aarp.org

AARP is a nonprofit organization for people age 50 and over. It offers information about finances and retirement planning. On its Web site, you can use the online money calculator and read financial news.

American Cancer Society

800-ACS-2345 (800-227-2345)

www.cancer.org, Search “Taking Charge of Money Matters”

The American Cancer Society offers the class “Taking Charge of Money Matters.” The class focuses on money issues for cancer survivors or those touched by cancer.

Americans with Disabilities Act

www.usdoj.gov/crt/ada

Know your civil rights as a cancer survivor. The Americans with Disabilities Act makes it illegal to be denied a loan or other financial service based on your cancer history. The U.S. Department of Health and Human Services Office of Civil Rights has basic information to help you understand the rules and process your complaints.

Cancer Legal Resource Center (CLRC)

866-THE-CLRC (866-843-2572)

www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm

With cancer, you may face many legal issues. These can include:

- Insurance coverage
- Job discrimination
- Access to health care
- Child custody
- Estate planning

These legal issues can cause worry, confusion and stress. If they are not addressed, you may find yourself dealing with the loss of a home, job, and/or insurance.

The CLRC provides free resources on cancer-related legal issues. All counseling is confidential. It is available to people with cancer, their families, friends and others coping with cancer.

Internal Revenue Service (IRS)

800-829-1040

www.irs.gov

In addition to tax information, the IRS offers helpful tips to start and maintain a retirement plan. On their Web site, you can view different types of retirement plans and the benefits of each.

Your retirement plan could be a source of cash and a way to fund a disability. Know your plan. Funds may be available if you are still employed and meet the plan's hardship conditions.

Life and Health Insurance Foundation for Education (LIFE)

202-464-5000

www.life-line.org

LIFE is a non-profit organization for information about life, health, disability and long-term care insurance.

Check to see what cash or loan benefits your life insurance can provide. Keep your policy if you leave your job. Some life insurance companies offer pre-death benefits.

Medicaid

877-267-2323

www.cms.hhs.gov/home/medicaid.asp

Medicaid is a government sponsored health insurance program for people with low income. Whether you qualify for Medicaid will vary from state to state. Check with your local Medicaid office for details.

Medicare

800-MEDICARE (800-633-4227)

www.medicare.gov

Medicare is a government sponsored health insurance program for people 65 and older. Medicare is divided into two parts, Part A and Part B. Part A pays for hospital, home health and hospice care. Part B covers medical services, such as physicians' services and home medical equipment. Part B also covers cancer screening exams.

Social Security Disability Insurance

800-772-1213

www.ssa.gov/disability

The Social Security Administration offers Social Security Disability Insurance. If you are disabled and have contributed to Social Security, you may be eligible to receive benefits.

Supplemental Security Income (SSI)

800-772-1213

www.ssa.gov/ssi

The Social Security Administration offers Supplemental Security Income (SSI). This program helps disabled persons with little or no income. Money is provided to meet the basic needs of food, clothing and shelter. Call or visit the Web site to find out if you qualify.

Brochures

View online or visit The Learning Center for copies of these brochures:

- What Cancer Survivors Need to Know About Health Insurance, Kimberly Calder and Karen Pollitz, 2006.
www.canceradvocacy.org, under Find Resources/NCCS Publications
- Working It Out: Your Employment Rights as a Cancer Survivor, Barbara Hoffman, 2003.
www.canceradvocacy.org, under Find Resources/NCCS Publications
- Self-Advocacy: A Cancer Survivors Handbook, National Coalition for Cancer Survivorship, 2003.
www.canceradvocacy.org, under Find Resources/NCCS Publications
- Legal Guide for Cancer Patients, Texas Young Lawyers Association, 2006.
www.tyla.org/cancer_guide.html

Glossary

acupuncture – acupuncture involves the placement of metal needles in the skin to stimulate specific areas of the body. Research has shown that acupuncture may stimulate the natural healing process to restore health and well-being.

antibiotic – medicines used to treat infections caused by bacteria or fungi. Antibiotics are derived from living organisms such as mold.

cataracts – a cataract is a condition where the lens inside the eye becomes cloudy. When this happens, light entering the eye is not focused properly. This results in blurry vision that cannot be corrected with glasses or contact lenses.

chemotherapy – medicines that kill cancer cells. It works throughout the entire body, killing cancer cells that have spread to parts of the body far away from the original tumor.

constipation – when food moves too slowly through the body making it difficult or painful to have a bowel movement

diabetes – diabetes is a disease in which your blood sugar levels are too high. This may cause blindness, heart disease, kidney failure and amputations (the loss of a body part).

diarrhea – watery and frequent bowel movements

glaucoma – a disease caused by an increase in eye fluid pressure that damages the eye's optic nerve. Without treatment, glaucoma can cause blindness. There may be no symptoms of glaucoma, but a yearly eye exam can detect it.

infertility – the inability to have children

interdisciplinary approach – when specialists from various areas and disciplines are involved in treatment planning.

new normal – the normal you experience after cancer may be different than the normal you experienced before you were diagnosed. It is a “new normal.”

psychological, social, emotional and spiritual changes – see psychosocial definition

psychosocial – these changes can affect how you think, feel, behave, interact with others and how you find meaning and purpose in life

radiation – treats cancer by using high-energy rays. It pinpoints and destroys cancer cells in your body. Sometimes it is called radiotherapy. Although radiation is similar to an X-ray, the dose is much higher and is given over a longer period of time.

recurrence – cancer that has returned. The cancer may come back to the same place as the original tumor or to another place in the body.

rehabilitation – a process to improve physical activity lost to injury or disease. It helps you regain your strength, relearn skills or find new ways of doing things.

thyroid gland — makes and stores hormones that help control heart rate, blood pressure, body temperature and the rate at which food is made into energy. This gland is located in your neck.

Survivorship Resources

askMDAnderson

Anderson Network

Case Management

Cancer Prevention

Cardiopulmonary Center

Chaplaincy

Classes (Patient Education)

Clinical Nutrition

Emergency Center

Endocrine Center

Fatigue Clinic

Physical changes

Bladder changes										
Bowel changes							▲	●		
Dental										
Diabetes							▲			
Eyesight										
Fatigue							▲			●
Hearing										
Heart failure										●
Hormone changes										●
Learning & memory problems										
Lymphedema										
Neuropathy										
Osteoporosis										
Pain							▲		▲	
Palliative care										
Sexual health										
Sleep loss										
Speech										

Tips for healthy living

Alcohol use									●	
Exercising										
Eating well									●	
Getting regular check-ups	▲				▲					
Reducing stress							▲			
Tobacco use										

Psychosocial, emotional & spiritual changes

Anger		▲					▲			
Anxiety		▲					▲			
Depression		▲					▲			
Fear		▲					▲			
Grief		▲					▲			
Returning to daily life		▲								
Self-image & self-esteem		▲					▲			
Spirituality							▲			
Survivor guilt		▲					▲			
Talking with others about cancer										

Financial & legal impacts

Advance directives										
Billing										

● Referral needed ▲ No referral needed

Survivorship: Living With, Through and Beyond Cancer Booklet Evaluation

Date: _____

General Information (fill in the circle)

1. Are you: the patient the caregiver

2. What is your primary cancer diagnosis? (for example, breast cancer, skin cancer, etc.)

3. Based on the booklet you just read, please fill in the circle that best describes your opinion for each statement below.

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
a. The booklet gave me all the information I needed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. It was easy for me to learn from the booklet.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I learned a lot from reading the booklet.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. This booklet is high quality.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I would tell others to read this booklet.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

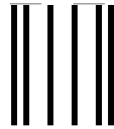
Thank you for completing this evaluation.

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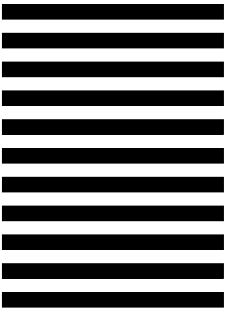
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