

Dear Friend:

Thanks for taking the time to pick up this copy of the *Resource Book for Cancer Patients in New Jersey*. I want to thank our friends on the Joint Psychosocial and Nursing Advisory Group to the New Jersey Commission on Cancer Research for making this book possible. Originally published in 1991, with over 120,000 books distributed to date, the booklet has been revised to reflect additional issues and resources now available.



Unfortunately, the issue of cancer is one that many New Jersey families face. We have tried to make this guide as user-friendly as possible and several sections have been updated.

Because the world of health care is complex and ever-changing, this booklet provides detailed information on medical topics ranging from cancer symptoms, treatment approaches and side effects, to selecting and communicating with your health care team, and home health care needs for advanced cancer patients. It includes sample medication charts, treatment plan forms, schedules, and space to record office visit questions. This resource book also lists the addresses and telephone numbers of all acute care hospitals and provides internet addresses to reputable cancer resource web sites.

Medical issues are only one aspect of the problems cancer patients face as they cope with their disease. This is why several chapters in the revised booklet are devoted to psychosocial issues such as coping with cancer, special needs for children and older adults, and cancer survivorship.

Please call my office at (609) 292-6000 or the New Jersey Commission on Cancer Research at (609) 631-4747 for further information.

Sincerely,

A handwritten signature in black ink, which appears to read "Jon Corzine". The signature is fluid and cursive.

Jon Corzine
Governor

The New Jersey Commission on Cancer Research

The New Jersey State Commission on Cancer Research (NJCCR) was created in 1983 with the goal of eradicating cancer through scientific research. Towards that end, the NJCCR supports the following activities:

- Research projects that focus on the causes, detection, treatment and prevention of cancers at non-profit New Jersey research institutions
- Training fellowships aimed at attracting talented young people to careers in cancer research at New Jersey institutions
- Professional and community educational programs, publications, workshops, and conferences

The NJCCR also administers the New Jersey Breast Cancer Research Fund and the New Jersey Prostate Research Fund, fueled by check-off boxes on the New Jersey State Income Tax form, and the Conquer Cancer License Plate, the first specialty license plate dedicated to cancer research in the country.

The Joint Psychosocial and Nursing Advisory Group

The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the NJCCR of special research needs pertinent to nursing, psychology, sociology and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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The Joint Psychosocial and Nursing Advisory Group to the New Jersey Commission on Cancer Research is pleased to provide this booklet about coping with cancer to you and your family and friends. We hope that you will use it to help identify some of the issues that might be ahead for you, and to assist you in locating the support and resources you might need.

This book is not the final word; it is meant to help begin the journey of getting information and services and to alert you to some important issues ahead.

The Joint Psychosocial and Nursing Advisory Group to the New Jersey Commission on Cancer Research gratefully acknowledges the Resource Book's past editor, Elizabeth J. Clark, PhD, MSW, MPH and past contributors, Regina Cunningham, PhD, Joanne Hayes, MA, RN, OCN, Shirley Hwang, MA, Gail Hilbert, DNSc, RN, Ann de Jong Hodgson, RN, PhD, Barbara Hoffman, JD, Linda Kennelly, PhD, RN, Elise Lev, EdD, Diane Byrnes Paul, MS, RN, Barbara Rainear, MSW and Laurie Miller. Special thanks are given to The American Cancer Society, and the National Coalition for Cancer Survivorship for granting permission to reprint parts of their publications within the book. The advisory group also thanks patient advocates, Frank Reedy and Norma Almanza, as well as the New Jersey Department of Health & Senior Services for their assistance. The 1990-91 Montclair State College Research Program provided initial seed money for this project. Since its first printing, over 120,000 Resource Books have been provided to New Jersey citizens at no charge.

NEW JERSEY COMMISSION ON CANCER RESEARCH NEEDS YOUR HELP!

You have the opportunity to make a difference:

- by purchasing the **Conquer Cancer** license plate;
- by donating to **Breast Cancer** or **Prostate Cancer** Research on your State Income Tax Form.



JOIN THE DRIVE TO CONQUER CANCER!

*Purchase your plate at your local
Division of Motor Vehicle office.*



HELP SAVE LIVES!

*Donate to breast or prostate cancer
research on your state income tax
return!*

Monies raised through the Breast Cancer & Prostate Cancer Research Fund, the Conquer Cancer License Plate or from private contributions do not finance the NJCCR's operating expenses. **ONE HUNDRED PERCENT** of these contributions go directly to an approved cancer research project in New Jersey and are tax deductible.

To date, the NJCCR has provided more than \$29 million dollars for over 675 research projects on cancer. For every dollar the NJCCR has awarded, over \$10.00, on average, has been returned to the state for continued research, strengthening the scientific infrastructure and New Jersey's economy.

**FOR FURTHER INFORMATION OR TO ORDER COPIES
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to the New Jersey Commission on Cancer Research.
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Acknowledgement

The Commission and its staff would like to recognize the major contribution that Denyse Adler has made to this book. She has given generously of her time, knowledge and talent to assure that cancer patients, families and friends have the support and resources needed to face the challenges ahead.

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Introduction

If you are reading this book, it is likely that you, or someone you love, has been diagnosed with cancer - whether recently or sometime in the past. Given current advances, cancer treatment will be successful for the majority of people, and the disease will be cured. For others, while the cancer may not be totally eliminated, they may look forward to many years of a satisfying and productive life, perhaps coping with some ongoing treatment or symptoms. For still others, the treatment may not work, and lives will be cut short.

For many people, however, just hearing the word cancer can create a crisis that can be frightening, fearful, uncertain and often, very confusing. You may feel that life is “out-of-control,” or that everything has somehow changed.

The course of your disease, treatment and the way that you respond to it will only be known as you progress through this journey. While certainly no one seeks this disease or welcomes its intrusion, many people feel that they grow in response to the challenges it presents. It is important to do everything in your power to maintain the best quality of your life during your treatment and where ever this journey takes you.

There are a few very important things to remember as you embark on this journey.

YOU ARE NOT ALONE.

Many friends, professionals, organizations and resources are available to help you through the cancer experience, by helping you to cope with your feelings and concerns after treatment. *Use these resources: they will make all the difference to you.*

YOU ARE STILL THE SAME PERSON YOU WERE BEFORE THE WORD “CANCER” WAS SPOKEN.

While some might call you a “cancer survivor,” this does not define who you are, what is important to you or what you want for your future.

GETTING GOOD, ACCURATE AND RELEVANT INFORMATION IS CRITICAL.

While you may feel bombarded with well meaning people bearing information from web sites and articles, most people do find it helpful to learn as much as possible. Be sure that the information comes *from trusted, reputable and reliable* sources. Please remember that while it can be helpful to hear about others experiences and advice,

each person's case is different and your disease and response may not be the same. Knowledge can give you a sense of control and help you face the many choices ahead. Selecting someone to be your partner in getting information and helping you listen is a good strategy.

YOU ARE YOUR MOST IMPORTANT ADVOCATE; ONLY YOU ARE AN EXPERT ON - YOU.

While your healthcare team has medical expertise, *only you* know how *you* feel, how the treatment or symptoms affect your life, what is most important to you, and how you want your information provided. Some people want to know every detail; others feel more comfortable leaving the decision-making to others in the family. This is up to you. Your friends, family and health professionals need to hear from you; don't assume that they know what you think and feel.

SELECTING A HEALTHCARE TEAM THAT YOU LIKE AND TRUST IS VERY CRUCIAL.

You will encounter many health professionals: doctors, nurses, social workers, therapists, dieticians, clergy and others. Make use of all of them and seek out the ones that you find most responsive to your concerns. Some national organizations have developed recommended guidelines for treatment for each kind of cancer. You might want to ask your healthcare team about these and how your care fits into those guidelines.

WHAT YOU CAN DO...WHEN YOU HAVE CANCER?



- Speak up for yourself.
- Listen and ask questions.
- Tell people how you feel.
- Get the facts.
- Keep good records.
- Don't be afraid to ask for help and take it when it's offered.

ASK QUESTIONS AND LISTEN TO THE ANSWERS.

You are a partner in your care, and should feel comfortable with your health care providers. You are entitled to have your questions answered and information provided in a way that is clear to you; keep asking until it is. If you are more comfortable with information in another language, ask to have an experienced interpreter provided for you. It is always good practice to bring a family member or friend to sessions with healthcare providers; remembering and understanding information when you are nervous or upset is often quite difficult.

KEEP GOOD RECORDS OF YOUR TREATMENT PLAN, CURRENT MEDICATIONS AND YOUR SYMPTOMS.

Remember that people undergoing cancer treatment also get the flu, colds, and other, unrelated medical problems. It is always important to provide a new healthcare provider, or the emergency room staff with the full information about what you are taking/have taken, and your treatment dates. Keep a good record of the way you respond to treatments and questions you have for the next visit.

While you will find valuable information in this booklet, remember it is just a beginning point, and much more help is available. Please let the people who want to help do so, and use all of the assistance you need. ***This booklet is just a first step.***

Notes

Chapter 1

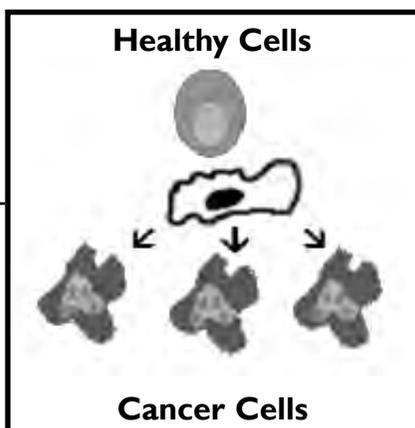
WHAT IS CANCER?

All living things are made of cells, the smallest unit of life. Cancers are diseases in which cells go out of control, growing rapidly and constantly. In recent years, research has identified more about what happens inside a cell when it turns cancerous. There are a number of steps that occur to the basic building blocks (DNA) found within normal cells. These building blocks give cells their structure and function and join in unique patterns to form codes that produce an individual's characteristics, including eye color, skin shade or body size.

When cells are working properly, they grow, perform their assigned function and then die to keep the body alive and healthy. In cancer, damage done to the cell over time can cause it to get the wrong messages and change behavior. The damaged cell begins to crowd out or invade nearby healthy tissue. It also starts to break away from its first location or primary tumor and travel through the body, forming new tumors called metastases (See the Glossary for a definition of terms used in this book). There are more than 100 known types of cancer, which can be found in almost any organ or tissue of the body, and in people of all races and ages. Some cancers are caused by damage due to lifestyle behaviors such as diet, smoking, alcohol, and sexual history. A very small percentage (2-5%) is related to environmental exposures. Approximately 5 to 10% of all cancers are inherited - meaning damaged building blocks are passed down through the family putting those people at risk of getting certain forms of cancer. Other factors that may cause cancer include infectious agents, medical drugs and exposure to ionizing radiation.

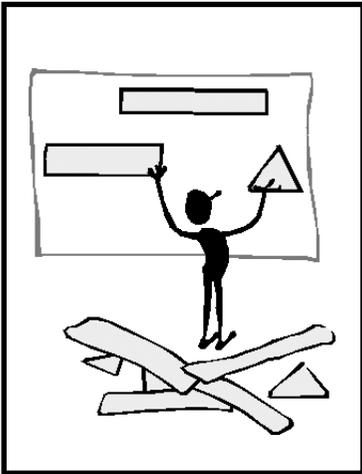
What is Cancer?

All living things are made of cells. In cancer, your cells break down and don't work right. They keep growing and making copies of themselves. Then, they spread and attack other parts of your body.



CANCER DIAGNOSIS

The first step in treating your cancer is to get a complete and accurate diagnosis. Blood tests, biopsies and scans, among other tests, may be needed to help doctors know exactly what type of cancer you have. A biopsy is an examination of tissue under a microscope to determine whether cancer cells are present. The tissue might be removed by surgery or may sometimes be obtained using computer guided needles. Your blood may contain special proteins called tumor markers that may point out that certain cancers are in the body. Scans such as Computerized Axial Tomography (CAT scan), Ultrasound, Positron Emission Test (PET) and Magnetic Resonance Imaging (MRI) provide different pictures of cancer in your body. These tests not only show the exact type of cancer (histology), but the tumor's size, its nature and may be able to identify whether the cancer remains in its original site or has traveled to other parts of the body. Understanding the extent of your cancer through these tests is known as staging. Knowing the cancer stage helps the doctor determine which option appears to be the best treatment plan.



How is cancer found?

There are many tests to help the doctors find what kind of cancer you have and if it has spread. Once this is known, you and the doctors can make the best choices for your care.

Chapter 2

TREATMENT APPROACHES

When all of the necessary information is gathered about your cancer diagnosis, you will meet with your health care team to discuss the findings and consider all treatment options. Your doctor may seek the advice of other physicians or health care professionals. You may also wish to talk to another doctor who may review your records and provide a second opinion. It is your right to talk to another doctor about your case.

What treatments do we have for cancer?

Those used most often are:



- Surgery or cutting the cancer out.
- Radiation or using energy rays aimed at the cancer cells.
- Chemotherapy or using drugs that kill cancer cells.
- Hormones or blocking the cancer cells from growing.

Cancer is a serious disease and you deserve to have all options in front of you.

You and your health care team, working together, will decide upon a treatment plan. This may include one or more of the following methods of treatment: surgery, chemotherapy, radiation therapy, hormonal therapy or biological therapy. Each can be used alone, but often two or more of these treatments are combined.

SURGERY

Surgery has long been accepted as a method of curing or controlling some types of cancer. Surgery often is effective in removing cancer that is limited to an organ or area of the body. It involves cutting out all, or as much of the cancer as possible. In many cases, surgery is combined with other treatments to give you the best chance of removing all the cancer cells. Surgery may result in the loss of a portion, or all of a body part, or alter a bodily function. In recent years, strides have been made to reduce the amount of surgery necessary to remove the cancer. Newer techniques using lasers and computer aided technologies are becoming more common. When surgery is more extensive, reconstruction can sometimes be used to replace what the surgery removes. Also, new and more advanced prosthesis and artificial limbs can help patients function effectively despite the loss of a limb or other body part.

CHEMOTHERAPY

Like many other diseases, cancer often is treated with drugs or chemotherapy. These drugs can kill or stop the growth of your tumor, as well as cancer cells that may have spread from the original tumor site. Chemotherapeutic drugs may be used alone, or combined with other treatments. You may be given one drug or a combination of drugs that work in different ways to kill cancer cells. Schedules for receiving chemotherapy vary considerably, depending on the drugs and the specific plan for your diagnosis. These drugs usually attack cells that are dividing rapidly. For this reason, they sometimes can also affect similar healthy cells like the lining of your digestive track, blood cells and hair follicles. This can result in eating problems, anemia or hair loss. These side effects are usually temporary and can often be addressed with medication or other methods.

Most people receiving chemotherapy live normal or nearly normal lives at home, going to their jobs or school, and participating in many of their regular activities. Chemotherapy affects each person differently. How you respond may depend on other medical conditions, your general health, the stage of your disease, and your body's disease fighting ability. Your health care team can help you overcome most of the difficulties associated with chemotherapy.

Chemotherapy can be given in several ways:

- By mouth, in pill or liquid form.
- By injection into muscle or tissue in your arm, buttocks, or thigh.
- By inserting a small needle into a vein in your arm. This is also known as intravenous infusion. Many intravenous infusions can be completed in a matter of minutes, while others may take longer. Each type of drug requires a different schedule; some require a daily intravenous infusion for several days, others are once a week or one time a month.
- By devices called ports or pumps that are temporarily implanted in your shoulder or elsewhere in your body, which allows for easier injections or continuous treatments.

RADIATION THERAPY

Radiation treatment is the use of high-energy rays to kill cancer cells. Radiation therapy may be used alone to try to cure the cancer or to reduce some of the discomfort created by your tumor. In the past decade, radiation therapy has been increasingly used together with surgery and/or chemotherapy. The decision about

radiation therapy will depend on the type of tumor, its location and the goals of the treatment.

Radiation treatment can also cause some unpleasant side effects, depending on the location of the treatment. These can include mouth, stomach or bowel distress, skin irritation or other problems. However, increased accuracy in treatments, as well as more effective remedies for these problems, has significantly reduced the side effects from radiation.

Radiation treatments may be administered in several ways:

- **External:** While the patient lies on a treatment table, radiation beams are focused on the tumor. Computer technology may be used to help aim the beams to the exact location of your tumor. Although this sounds frightening, there is no pain and side effects can generally be controlled. Treatments are typically given on a daily basis five days per week, with each treatment lasting only a few moments. The total number of treatments will be determined by your radiation oncologist and will depend on many factors.
- **Internal:** Another approach to radiation therapy is to insert the radioactive material directly into the body. This may be done in one or several sessions, and occasionally requires a short hospital stay. There are many new advances, including seed implants and special immune cells called monoclonal antibodies. Seed implants use tiny capsules full of radioactive material that are inserted into the area of the tumor. Monoclonal antibodies can act like armed missiles bringing the radiation directly to the cancer cells.

HORMONE THERAPY

Some types of cancer depend on hormones, such as estrogen and testosterone for their growth. Hormones are chemicals produced by glands in your body that cause a specific effect on cells or organs. Since some hormones can make the tumor grow, doctors may suggest treatment that prevents cancer cells from getting the hormones. This treatment may include the use of drugs to block the production of certain hormones or their effects on the body. Sometimes surgery is performed to remove the hormone-producing organ. Hormone therapy most often is used to treat cancers located in the breast, prostate, or uterus. Hormone therapy may have a number of side effects depending on which drugs or surgical procedures are used. However, as with other treatment side effects, these usually can be controlled or minimized.

Watchful Waiting

Watchful waiting may also be an option for patients who are diagnosed with slow growing tumors and who do not have any symptoms from their cancer. Your health care team may keep you under observation and not actively treat your cancer until symptoms appear or the cancer changes its behavior. You will receive regular medical checkups and be monitored carefully for any progression of your cancer.

Circumstances when your doctor might recommend watchful waiting include:

- Early and low grade prostate cancer in older males
- Chronic lymphocytic leukemia
- A very slow growing form of advanced non-hodgkins lymphoma

BIOLOGIC THERAPY

Biologic therapy (sometimes called immunotherapy) is one of the newest areas of cancer treatment. It can boost or restore the body's own immune or defense system. One form of biologic therapy, called monoclonal antibodies, uses cells that can locate the cancer and attach to it. Another uses interferon, a protein made by white blood cells that helps the body to fight cancer cells. A third uses interleukins, proteins that control immune cell growth. Recently, a new vaccine was approved to prevent cervical cancer and other vaccines are showing promise in cancer treatment. There are many other types of new biologic therapies that are in development and may be available through clinical trials.

COMBINATION THERAPY

Because some cancer cells might have spread throughout the body, doctors often combine surgery, radiation and chemotherapy together to improve results. Studies have shown that using these combinations in some cases could cure more cancers and increase survival in many others. While single types of treatment are still appropriate, you should not be surprised if your doctor recommends chemotherapy or radiation after surgery, or a combination of all three. This approach is called adjuvant therapy. More recently, doctors are finding that it might be helpful to give chemotherapy, hormones or radiation treatment before surgery in some situations. This can shrink the size of tumors, making surgery easier and can also kill cancer cells that might have spread. This approach is called neoadjuvant therapy. When you are undergoing combination therapies, it's important to follow the treatment plan or protocol that the doctor gives you so you receive all of the benefits.

BONE MARROW TRANSPLANTATION AND PERIPHERAL STEM CELL TRANSPLANTATION

Other new treatments that might be suggested are bone marrow or peripheral stem cell transplant. These transplants are most often used in leukemia, lymphoma, and other blood related cancers and some pediatric cancers. Your bone marrow is a spongy material found inside your bones. Stem cells are also found in your bone marrow but may also be found in the blood stream or umbilical cord blood. Bone marrow and peripheral stem cell transplantation are procedures that restore stem cells that have been destroyed by very high doses of chemotherapy or radiation in certain cancers. In some cases it might be possible to remove your own bone marrow or stem cells, separate the cancer cells and return the healthy cells back to you (autologous). For others, stem or marrow cells can be obtained from another person whose cells closely match your own (allogenic). Research on transplantation in other types of cancer is ongoing.

GENETIC TESTING

Genetic testing involves the study of a person's genes for abnormal changes that may increase the risk for developing certain diseases or conditions. Because genes are shared with relatives, certain diseases, including cancer, may run in families. The abnormal genes may be inherited from parents and passed on to children. While family members might wish to be checked to identify their risk for your type of cancer, careful thought should be given to this decision. You need to consider whether it will be helpful to have this information, and what you or your family members will do about it once you have it. If having the information will increase an awareness of the need for earlier screening (i.e. mammograms, colonoscopy), this could be valuable information to have. However, if there are no screening tests, or other interventions that can prevent the cancer, this information can simply increase anxiety. There are many risks and benefits with genetic testing. So talking to a qualified genetic counselor is important.

REHABILITATION

Rehabilitation can often help to restore loss of functions including strength, speech or the ability to conduct activities of daily living. Appropriate rehabilitation might include a short stay in a facility, where you would receive physical, speech, respiratory, occupational or other therapies. Some of these same services can often be provided in your home. Discuss your specific needs and wishes with your healthcare team and insurance provider. In either case, such therapies can help you continue to enjoy well-being and the fullest functioning possible.

PALLIATIVE CARE

Palliative care is treatment directed at comfort, quality of life, pain and symptom control and general well-being. It is not a new concept, but one that has been getting more and more attention in recent years. Today people recognize how important it is to maintain the best possible quality of life throughout treatment, from diagnosis onward. People who feel well, can maintain activities of daily living, and experience some contentment or satisfaction, tend to stay with the treatment and may have a more positive attitude. This means paying attention to methods of staying well during treatment and afterward. In the past, attention to pain and suffering was the main focus at the end of life. Now a focus on well-being is part of ongoing treatment to cure the cancer. However, it is important to let your healthcare team know how you feel and what causes you distress.

COMPLEMENTARY AND ALTERNATIVE CANCER TREATMENT

Additional kinds of treatments, called complementary and alternative medicine (CAM) are the subject of much discussion. CAM is a group of health practices, products or systems that are not currently part of conventional medicine. There are many types of CAM therapies and many have not been scientifically tested or assessed. For this reason, it is important for you to get all the information available before making a decision about using any of these methods.

While complementary and alternative are linked together under the heading of CAM, they are actually quite different from one another.

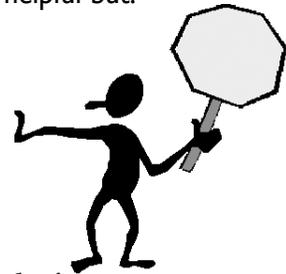
- Complementary or integrative therapies are used together with conventional medicine. One example of a complementary therapy is using massage therapy to help lessen stress before surgery.
- Alternative medicine is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy that has been recommended by a conventional doctor.

The American Cancer Society has described five broad categories of complementary medicine.

- Mind, Body, and Spirit Methods focus on the connections between the mind, body, and spirit, and their power for healing. *Examples include:* aromatherapy, art and music therapy, biofeedback, hypnosis, meditation, Native American healing, naturopathic medicine, psychotherapy, Qigong, spirituality and prayer, Tai Chi, and yoga.

- Manual Healing and Physical Touch Methods involve touching, manipulation, or movement of the body. These techniques are based on the idea that problems in one part of the body often affect other parts of the body. *Examples include:* acupuncture, chiropractic, craniosacral therapy, massage, reflexology, Reiki, and therapeutic touch.
- Herb, Vitamin, and Mineral Methods may include plant-derived products that are used as treatments, as well as everyday vitamins and minerals. *Examples include:* Chinese herbal medicine, green tea, marijuana (to relieve nausea and vomiting), saw palmetto, and the use of individual herbs, vitamins, and minerals.
- Diet and Nutritional Methods include dietary approaches and special nutritional programs related to prevention and treatment of disease. *Examples include:* intake of specific vegetables such as broccoli, maitake mushrooms, shiitake mushrooms, soybeans; macrobiotic diet; diets high in vegetables and low in red meats.
- Pharmacological and Biological Treatment Methods include substances that are made from chemicals or extracted from plants and other living things. These are not the same as the raw plant or a plant in its natural state. *Examples include:* homeopathy, coenzyme Q10, and various therapies that are unproven or disproven such as shark cartilage, Revisi's guided chemotherapy, laetrile, and anti neoplaston therapy.

You may hear claims about “miracle” or “natural” cures. **BEWARE** of things that sound too good to be true. They often are!!! Some new approaches can be helpful but:



Get all the facts...

- Talk to your doctor or nurse.
- Keep getting your regular treatment.

EVALUATING ALTERNATIVE OR COMPLEMENTARY TREATMENTS

Friends and relatives may offer information and suggestions about these types of treatment, and it may be difficult to sort out what is fact and what is not. There may be talk about “miracle cures” and even suggestions of rejecting traditional medicine recommended by your doctor. When making decisions it is important to evaluate any treatment based upon the levels of scientific evidence that supports each approach. While conventional medicine has undergone scientific review for

safety and effectiveness, many CAM methods have not been studied and are still unproven or may have serious side effects. The National Center for Complementary and Alternative Medicine (NCCAM) is conducting studies to help scientifically evaluate CAM and also has designed a system to help you make decisions based on good evidence. You can also call or go online to the NCCAM Clearinghouse, <http://nccam.nih.gov/> for further information.

Some other things to keep in mind include:

- Beware of anyone who steers you away from proven treatments. Using only unproven methods can delay or prevent effective treatment. Choose your practitioners carefully to minimize risks.
- Be suspicious of unrealistic claims, including guarantees of cure. Ask to see scientific studies that back up these claims, and read them carefully.
- Consider the costs associated with these treatments, and consult your insurance carrier regarding reimbursement.
- Remember that just because a substance is “natural” does not mean it will automatically be good or safe for you.

CLINICAL TRIALS

Advances in medicine and science result from new ideas and approaches developed through research. Cancer treatments that are currently in use are known as standard therapies. Although these treatments are effective for some patients and some cancers, scientists continue to search for new ways to find

cancers earlier, treat them more effectively, improve the way you feel when you have cancer and even prevent them from starting. Clinical research studies also known as clinical trials are an important part of the search for new ways to overcome cancer.

What are Clinical Trials?

Clinical Trials are studies in people that try to:

- find cancer earlier
- stop it from growing
- get rid of it easier
- keep it from ever starting
- make you feel better when you have it.



There are several types of clinical trials.

- Prevention trials, which involve individuals without cancer, look for ways that prevent the development of cancer.

- Screening trials may look at new ways to find cancers earlier.
- Treatment trials often compare new drugs or medical devices with standard treatment or compare new combinations of drugs or approaches.
- Quality of life trials seek to keep patients feeling well with their disease or treatment.

First, scientists identify new ideas and test them in the laboratory using cells and animals. When they are as sure as possible that the new drug or approach is safe and effective, they must still see how well it works in people. Each clinical trial is designed for a specific type of cancer. To be considered for the trial, a person must meet certain criteria to be included. This is necessary to be sure that the outcome of the trial is accurate. The trials proceed in a very carefully organized and monitored step-by-step fashion. There are three categories of cancer treatment clinical trials: **Phase One** trials involve only a handful of people and focus on safety. **Phase Two** trials include more patients, and are designed to see if the drug or approach actually works against the cancer. Once the drug or device has been considered safe and shows some ability to affect the cancer, many more patients are enrolled into **Phase Three** trials, that compare the new approach to the standard treatment usually used. If there is a trial available for your specific type and stage of cancer, your team will tell you about it, and might ask you to participate. You may also seek information on the web yourself to find out about studies that might be of interest to you.

In the past, clinical trials relied upon white adult males as participants. Because drugs and new approaches often work differently in certain groups of people, this did not give a very accurate picture of how the treatment would work for women or other diverse populations. For this reason, women, children, ethnic minorities and older adults are encouraged to participate in studies. Some people are very interested in being a part of clinical trials, both for the opportunities for themselves, and for the chance to advance what is known about cancer. You might have some concerns about what exactly is ahead when you enter a study, and you should discuss these with the treatment or research team. It is natural to be somewhat fearful of the unknown or wonder if there will be any special discomfort, pain, or additional costs.

What to Expect as a Participant of a Clinical Trial

Before you or family members participate in a clinical trial, the study must be fully explained and you must agree to join. A written consent form explaining all participants' rights will be provided and explained to you. If you do not understand something, need the information translated into another language or are not sure

about the medical terms, your doctor or research nurse will help you. If you agree to join the study, then you will be asked to sign the informed consent.

The government provides strong protections to make sure that you are treated fairly and that the consent form is clear and accurate. You will be kept informed about the study and nothing can be done to you or given to you without your knowledge. You can choose to leave the study and you will continue to receive treatment for your cancer.

The cost of clinical trials is often a concern to cancer patients. Several of New Jersey's leading health

insurers have agreed to cover the routine costs of care when you are participating in an approved clinical study. Coverage applies only to those trials that are sponsored by the National Institutes of Health, the U.S. Food and Drug Administration, the U.S. Department of Defense and the U.S. Department of Veterans Affairs. Coverage may vary depending upon your specific contract and you should contact your insurer to see if you are covered. (See appendix K for additional information on this program.)

WHERE CLINICAL TRIALS ARE CONDUCTED

Clinical trials are conducted in many places in New Jersey. If you are interested, ask your physician or call the **New Jersey Commission on Cancer Research at (609) 631-4747**. **New Jersey Cancer Trial Connect** provides current information on clinical trials in your community (www.njctc.org or call 1-866-788-3929.) For additional information, you can also call the Cancer Information Services of the National Cancer Institute at 1-800-4-CANCER. Many other websites are also available. (See the listings in appendix B for more information.)

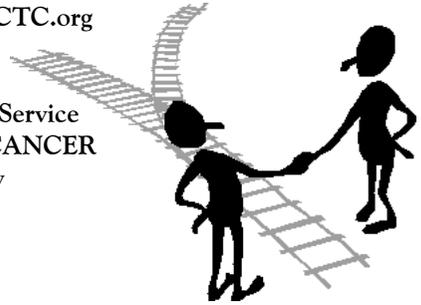
Have all the choices in front of you.

For listings of cancer clinical trials, call:

**The New Jersey Commission on
Cancer Research at 609-631-4747
or online at NJCCR.com**

**The New Jersey Cancer
Trials Connect
866-788-3929 or
online at NJCTC.org**

**The Cancer
Information Service
at 1-800-4-CANCER
or cancer.gov**



Chapter 3

CONTROLLING YOUR SYMPTOMS AND TREATMENT SIDE EFFECTS

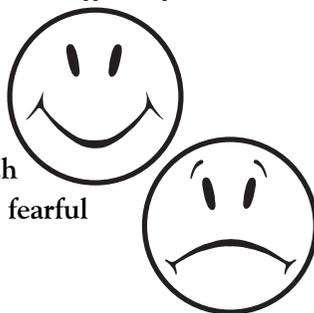
Symptoms and side effects from the cancer and treatment can affect your daily life or cause discomfort. Pain, nausea, fatigue, sleeplessness, poor appetite, constipation, tingling in hands or legs, mouth sores, depression and anxiety are all possible side effects of treatment or from the cancer itself. However, there are many ways to control these difficulties and there is no purpose to suffering in silence. Your health care team can help you develop sound strategies to deal with many of these concerns.

NAUSEA AND VOMITING

Most people worry about nausea and vomiting. This side effect might be caused by treatment, the cancer or other factors like infections, medications or other illnesses. Very effective medications are now available to help reduce or even eliminate nausea and vomiting.

What are the side effects from cancer treatment?

Pain
Tiredness
Upset Stomach
Feeling sad or fearful



But your doctors and nurses can help you...
IF YOU TELL THEM HOW YOU FEEL.

While most work well, they may need to be adjusted to find the combination that works for you. The medication you receive first will be based on the type of chemotherapy drug you are receiving. However, if it doesn't work, there are many other drugs that can be used, and the team will continue to work to find the best solution.

In addition to drugs that control nausea and vomiting, other approaches such as muscle relaxation, biofeedback, guided imagery, and music therapy can reduce nausea and vomiting. These techniques promote relaxation, can distract attention and help you feel more in control. These methods may be used alone or in combination with anti-nausea medications.

FATIGUE

Fatigue is a frequent problem for patients undergoing treatment. Chemotherapy, bone marrow transplants, and radiation therapy may all cause fatigue because they

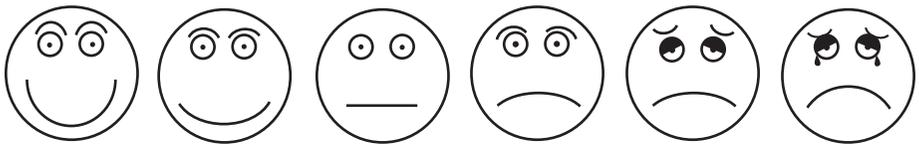
destroy rapidly dividing healthy cells, especially the cells in the bone marrow. Too few red blood cells (called anemia) may result in too little energy to meet the body's needs. Also, the body may have to work harder to clean up all of the cells that the drugs have killed.

Many other problems can contribute to fatigue, such as pain, emotions, sleep problems, low thyroid gland function, medications, nutrition, other medical problems or lack of exercise.

Because there are many causes, treatment for cancer-related fatigue may involve many approaches. A variety of new drugs are available that may help overcome anemia and build up blood counts. Education and counseling are also part of the treatment and can help you learn to conserve energy, reduce stress, and use distraction to think about things other than the fatigue. Your doctor and healthcare team have a number of other methods to help. You do not have to accept being tired as a normal part of your treatment.

PAIN

Another common problem for cancer patients is pain. Pain can affect all aspects of our lives and may prevent participation in regular activities, reduce sleep and appetite and cause depression or feelings of isolation from friends and family. People with cancer may have pain for a variety of reasons: treatment; changes in body functions; the spread of cancer into soft tissues, organs, or bone; nerve injury or pressure exerted on a nerve; or increasing pressure in the head. Pain can be treated effectively and there is no reason to suffer. It is important to tell your health care team when you are in pain.



The image shows a horizontal row of six circular faces, each representing a different level of pain. From left to right: 1. A smiling face with wide eyes and a large open mouth. 2. A slightly smiling face with wide eyes and a small open mouth. 3. A neutral face with wide eyes and a straight horizontal line for a mouth. 4. A frowning face with wide eyes and a downward-curving mouth. 5. A frowning face with heavy, closed eyes and a downward-curving mouth. 6. A frowning face with heavy, closed eyes and a downward-curving mouth, with a single tear visible on the right cheek.

1 NO PAIN **2 MILD PAIN** **3 DISCOMFORTING** **4 DISTRESSING** **5 INTENSE** **6 EXCRUCIATING**

One type of pain assessment tool to help you let the doctor or nurse know how much pain you are having.

Before starting a plan to reduce the pain, your doctor will gather information, a process known as pain assessment. You may be asked to describe the location of the pain, when it began, how long it lasts, how much it hurts, what it feels like, what

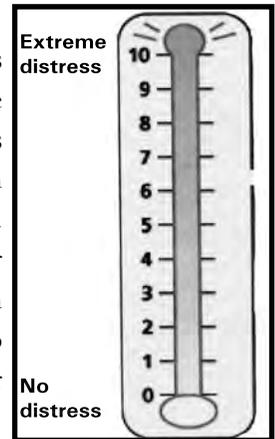
makes it better or worse, and how it affects your life. A treatment plan can then be developed and discussed with you.

Cancer pain can be treated in several ways. Treating the underlying cancer with chemotherapy, radiation therapy, surgery, or other therapy might reduce the pain. For some, medications are the main way to treat cancer pain. They include the use of opioids (such as morphine, oxycodone) or, non-opioids (such as acetaminophen and non-steroidal anti-inflammatory drugs). Patients and their families sometimes worry about using too much pain medication because of a fear of addiction. Studies show that people in pain from diseases like cancer do not get addicted to pain medications.

Keeping pain under control is very important for many reasons. It is easier to stay with a treatment plan when you are not suffering with painful side effects. In addition, being pain free can help you to continue to keep active and reduce the impact on other parts of your body. Other therapies such as relaxation techniques, biofeedback, physical therapy, anesthesia procedures, and surgical procedures can also be very helpful in treating cancer pain.

EMOTIONAL DISTRESS

Often, coping with cancer can cause some emotional distress for both patients and caregivers at some point during the cancer experience. Distress can range from normal feelings of vulnerability, sadness, and fear to conditions that can become disabling, such as depression, anxiety and panic. Without treatment, anxiety and depression can make other side effects feel worse. Untreated anxiety and depression can also make it difficult to continue with treatment and to make sound decisions about your cancer care and your future.



Sometimes depression, anxiety or distress, are mistaken for symptoms of cancer or its treatments. Some people assume distress is an expected reaction to having cancer. Many of the symptoms of distress are normal expressions following the diagnosis of cancer, or ongoing treatment. When they are continuous or prevent a person from taking treatment or enjoying normal life activities, they should be brought to the attention of the treatment team. ***The signs that treatment might be needed include:***

- Profound sadness, hopelessness, guilt, worthlessness, irritability, or anxiety

- No interest in or pleasure from activities and people you recently enjoyed
- Difficulty concentrating and remembering
- Thoughts of hurting yourself
- Crying easily
- Difficulty falling asleep or staying asleep
- Decreased appetite
- Not wanting to be with other people or refusing to leave home

Fortunately, treatment for depression and anxiety are generally effective for persons with cancer. Medication such as anti-depressants, and non-medication treatments, such as individual psychotherapy and support groups, can make a big difference and can help to continue your everyday activities and relationships. Some of the emotional reactions to cancer are discussed in more detail later in this book.

THE ROLE OF NUTRITION

Nutrition plays an important role in maintaining health. A balanced diet promotes physical well-being by strengthening muscles and bone, and keeping thoughts and energy levels high. Further, a balanced diet helps maintain a healthy weight and limits fat intake; important steps to promote and maintain overall health.

With a diagnosis of cancer, the role of nutrition is even more important. Yet, keeping up good nutrition may be a special challenge. While not all people have eating or digestive problems, the cancer or its treatment and side effects may make it difficult to maintain body weight. In addition, loss of appetite, anxiety, changes in taste, difficulty swallowing, altered sense of smell, mouth sores or sensitive gums, nausea, vomiting, diarrhea or a lack of energy to prepare meals can play a large part in reducing appetite.

It is most important to build your strength to help cope with the cancer and its treatment. According to the National Cancer Institute, recommendations for nutrition during cancer treatment can prove to be very confusing, because they

Cancer can make eating and drinking water more difficult. Some helpful tips are:

- **Try simple soups or light meals several times a day.**
- **Keep water, crackers or snacks close by.**
- **Eat many small meals during the day.**
- **Let friends help by cooking some of your favorite foods for you.**
- **Stay positive and keep trying.**



might be different from what people generally consider healthful. For example, during treatment, it might be suggested that you focus on eating higher calorie foods with more protein. The recommendations might even suggest more dairy, increasing sauces and gravies, or discovering new foods that you have not tried before. Your team may suggest you temporarily eat less of certain high fiber foods during treatment because they can make some of the side effects worse.

You may not have any eating problems, or difficulties might vary during your treatment. You will have to wait to see how you react. A lot of information is available to you, and the dietician on your healthcare team can make specific recommendations. There are no absolute rules about eating; find out what works for you. Keeping a positive attitude and being willing to try food will go a long way in solving some of these problems. Some people feel better in the morning so this is a good time to gain a few more calories. If you can't eat on a particular day, don't worry about it - just try later or the next day. You might even find some new things that you enjoy!

Some Additional Suggestions:

- Prepare some simple, nutritious, non-spicy meals and freeze them before your treatment.
- When you do eat, try to make sure that you are eating high protein snacks.
- Keep water nearby when you work or relax. This can serve as a reminder that fluids are important, and make it easy to keep drinking.
- Call upon friends who want to help by letting them prepare simple soups and foods that you like. Freezing such dishes is a practical way for family and friends to help.
- Have nutritious but easily digested snacks on hand during the few days that follow chemotherapy when you have little appetite. If you are allowed to have fresh fruit, washed, chilled grapes are nutritious and ready to eat. Chicken or beef broth provides a good source of protein and is easy for many people to digest. The broth can be taken with crackers if desired.
- Eat several small meals rather than a few large meals; this may work best for you. It will be important to know what time(s) of the day are best for you to eat as well as what types and specific foods you enjoy, tolerate, or must avoid.
- Try crackers or other dry foods to control nausea from chemotherapy. Simple cereals, dry toast, or rice cakes may also be accepted.
- Some nutritional supplements can be frozen like ice pops to provide both fluid intake and cooling refreshment for the mouth.

NUTRITIONAL SUPPLEMENTS

If you think that you or a family member may need a nutritional supplement due to poor appetite, nausea, vomiting, or diarrhea, ask your health care provider about the brands and types of supplement that might be best for you.

Chapter 4

IMPORTANT FIRST STEPS

GET ORGANIZED

At a time when everything around you seems disorganized and random, establishing a system for keeping track of your medical care and questions can provide a reassuring port in the storm. This is not the time to rely on your memory for anything!

Keep a notebook handy to write down questions for your doctors and health care team. Of course, emergencies must be handled promptly, but many concerns arise during the days or weeks between visits. Call if you need some immediate help. Otherwise, you will want to remember the questions during your next visit. Don't be shy about asking the questions; it does not help to leave questions unanswered about what to do or what something means.

Always ask the doctor or nurse what you might expect in the way of side effects from the treatment and make a note of these. In this way, you will avoid the panic and uncertainty in the middle of the night, and will be prepared to cope with the problems in advance.

Get Organized!!!

- Write down your questions for the doctor right when you think of them.
- Ask how a drug treatment might make you feel.
- Keep good notes about your care.



Keep a record of all your medications, dosages and current treatment handy. Remember, people with cancer also get the flu, colds, break bones or sprain ankles. It is important to have the information available in the event of any emergency or treatment for other conditions.

SELECTING YOUR HEALTHCARE TEAM

Just as your need for familiar faces and old connections seems the greatest, you will have to consult specialists you don't know and meet a whole group of new professionals. Understanding the role of each person you meet can be confusing: nurses, social workers, therapists, case managers, psychologists, dieticians, clergy and

others are all there to help with your care. ***If you are not sure where to go for good cancer care, you might:***

- Ask your primary care doctor or other doctors that you know.
- Call your local hospital, which may also offer cancer clinics if you do not have insurance.
- Call your state medical society or physician specialty association.
- Visit a federally qualified health center in your area, or community and health agencies.
- Ask friends or colleagues who are involved in health care.

In this age of consumerism, many people are accustomed to researching almost every purchase. We consult consumer reports and reviews for the best new refrigerator, ask our friends their opinion, and inquire about reliability and durability. Unfortunately, when it comes to our health care providers, most of us know less about our doctor than we know about our appliances. So, even if your insurance coverage limits you to a list of participating physicians, find out how much experience each has with your specific cancer. Feeling comfortable with your physician is essential. It is always a good plan to ask a family member or friend to accompany you and to share information and impressions later. Remember, you cannot be expected to understand everything when you or your loved one are still just trying to get used to the word cancer.

You should feel comfortable asking:

- Did the doctor train at a major university or cancer center, and does he or she hold Board Certification (passed a special test) in this specialty?
- Who is on your treatment team and how often do they deal with your type of cancer?



How to find the best doctors to take care of you...

ASK IF THE DOCTOR:

- is well trained and studied at leading cancer centers?
- has taken care of many other people with your type of cancer?
- is part of a cancer team that can give you special treatments or care if you need them?
- takes the time to answer your questions and calls you back if you need something?

- Do the physician and team members listen to your concerns, return phone calls promptly and answer your questions in clear, understandable language?
- How does the physician respond when you request a second opinion?
Doctors should encourage you to get all the information that you want.
- Does the team have access to advanced treatment options, including clinical trials and investigational drugs?
- Can you get the specific type of help you need when you need it? For example, are the services of a dietician, physical therapist, social worker or other specialized provider easily available?

It will be important to consider the schedule of treatments you will need and how easily you will be able to get to the facility. If necessary, ask about transportation options or getting your treatments closer to home.

COMMUNICATING WITH YOUR HEALTHCARE PROVIDERS

Coping with cancer - your own or that of a family member or close friend - can feel like being hit by a 18 wheeler truck. Facing all of the possible complications of the disease and the treatment; physical, emotional, financial, spiritual, and psychological issues, can be overwhelming. Services and information are available; but unfortunately, no one will know you need them unless you tell them. It is hard to ask for help, few of us are accustomed to it and we all prefer to offer help rather than ask for it for ourselves.

It is very important to remember that getting information, making decisions, and relieving troubling or painful symptoms requires clear and precise communication and that is the responsibility of both you and your healthcare team. Creating a productive and comfortable working relationship with your healthcare team must be a two-way road. While you should demand understandable and accurate information, you must also be prepared to provide a clear description of your concerns and needs. The team cannot guess what is important to you or how you are responding to the treatment.

There are some questions that might come up at some point during your care, and it is helpful if you give them some thought and talk to your family. Then, be sure to tell your team how you feel about them. Remember, the answer to these questions may change over time.

- Some people want a lot of information about their condition and want it delivered only to them. Other people would rather not hear it all, and prefer to have information about their treatment given to someone else in the family. It is generally best if there is only one person in the family selected

to talk to the doctor, and that person can keep everyone else informed.

- What kinds of treatment are you willing to have? For example, do you want to try more aggressive treatments, no matter what the side effects might be? How long should a new treatment be continued if it is not working? At some point you may need to decide if you want to continue to keep trying new treatments if they don't seem to be working.



***Getting Good
Cancer Care is like a
two way street***

Make sure **you understand what the doctor or nurse** are saying when they talk to you about your cancer. Bringing someone along to listen can help.

And...**YOU** have to **let them know how you feel** and what you want.

- Would you be interested in participating in a clinical study?
- You might have to make some decisions about types of treatments that offer you pain or symptom relief. For example, some medications might make you more drowsy or unclear in your thinking. You have to decide if the relief offered is more important than being able to think clearly all the time. Your healthcare team will discuss these options, or you can ask them about the way you might respond to certain medications.

- Although it is often hard to talk to your family about this, give some thought to what kind of treatment you want if you become unable to speak or are unconscious. You might want to fill out an “Advance Directive for Health Care,” available through the hospital or found in Appendix F. This is an official document that clearly outlines your wishes and lets your family and physician know what you want for yourself. Having this document can reduce confusion and distress for your family and for the healthcare team. It also allows the hospital and doctor to follow your wishes.
- Be sure to let your family and team know if you change your mind about these things.

INFORMED CONSENT

Informed consent is a very important principle of medicine and law. Informed consent means that you are entitled to know and **understand** all of the procedures, treatments and methods that will be used to treat your cancer. The health care team

must tell you what you can expect and any ways the treatment might affect you. Do not sign any documents that say you understand the information if you do not. Asking for the information to be translated into another language, reworded, or drawn into a diagram is your right, if this will help you to understand.

CHOOSING A HOSPITAL

While many diagnostic tests and treatments may now be done in your doctor's office or other outpatient centers, cancer may involve some kind of hospitalization. It can be difficult to know which hospital may be best for you. Most hospitals are able to provide the general services cancer patients need, but some special services might also be necessary. Some hospitals specialize, just as physicians do. Many hospitals have cancer centers that bring together all the types of doctors and specialists that you might need under one roof. Some have specialized centers for certain kinds of cancer. For example, breast centers will have trained staff, equipment and therapies to deal with that specific cancer. Other centers may focus only on children with cancer and offer special pediatric services. For this reason, learning about the quality of cancer care provided at the hospital you choose is important.

The American College of Surgeons, is a well known national organization that sets standards for quality cancer care in hospitals. You may wish to call your hospital to see if it has this special certification.

In addition, the National Cancer Institute (NCI), the main research arm of the federal government, selects certain research centers for the title of "NCI Designated Cancer Center." These are research institutions that are recognized for their scientific excellence and the many cancer services and specialized programs offered. The Cancer Institute of New Jersey is an NCI designated comprehensive cancer center located in New Brunswick with partners throughout the state. There are also a number of NCI designated centers nearby in New York and Pennsylvania. You may obtain information about NCI designated cancer centers by calling the Cancer Information Service of the National Cancer Institute (1-800-4 Cancer). Additional numbers are listed in the Appendix B.

You may be limited in your choice of a hospital because of the type of insurance you have, or because that is the only place where the doctor you have selected practices. Most Health Maintenance Organizations (HMOs) will allow second opinions and provide referrals to specialty hospitals. However, you need to work carefully with your primary care physician or health insurance representative to obtain the type of care you want.

HOME CARE

Home healthcare services can help you to carry on your regular routine at home. For older patients, especially those with frail caregivers, or minimal support at home, it can make the difference between remaining comfortably at home, or requiring admission to another facility. For younger families, it can assure that the daily needs and special care of family members are met. ***Some of the things that home care support might provide include:***

- Disease management & monitoring
- Chemotherapy infusions
- Pain and medication management
- Symptom control & palliative care
- Referral to other services such as physical, speech or respiratory therapy
- Assessment of your home to eliminate obstacles to effective care
- Training and support for activities of daily living
- Nutritional counseling
- Respite care to relieve caregivers; and other services
- Home health aides
- Hospice & bereavement counseling

Home care agencies involve teams, including nurses, doctors, social workers, dietitians and other professionals. Some have volunteers available to help with your daily activities. It is important to let the healthcare team know of your specific living situation; floors to walk up, if you live alone, or other special concerns. It is also a good idea to make sure your hospital discharge planner or doctor coordinate your care and inform the home care agency of any needs that might require special attention.

FINDING INFORMATION

It is important to be involved in your own healthcare, even if you attend a clinic or do not have a regular doctor. Cancer is complex and getting essential care can be challenging. If you are uninsured or under-insured, you may feel that getting help and answers are especially hard. This is not a time to let your frustrations with red tape or bureaucracies take over your life. Speaking up for yourself is the key to making sure that you get the best care possible. You might wish to ask your hospital or clinic if a case manager or patient navigator might be available to help you find your way through the health system. Cancer organizations can provide online or telephone assistance to help guide you through decision making.

You might also wish to look at some guidelines that have been established by cancer organizations that have reviewed scientific evidence to guide treatment for most cancers. These guidelines describe the treatment steps that are generally considered the standard for the type and stage of cancer that you have. The National Comprehensive Cancer Centers Network (NCCN) in collaboration with the American Cancer Society (ACS) has developed easy to understand practice guidelines that may help you make informed decisions. These are available in English and Spanish. The website is www.nccn.org for downloadable versions or call 1-800-ACS-2345 for printed copies. You may also receive the latest treatment information from the National Cancer Institute website (www.cancer.gov) or by calling the **Cancer Information Service** at 1-800-4-CANCER. Remember that each person's cancer is different and there may be reasons that your doctor does not recommend following general practice guidelines in your specific case. It may be helpful for you to have this information when you discuss your options with your health care team.

Your healthcare team is the major source of information about your specific cancer and treatment options. Ask as many questions as you need until you feel that you understand. It may be helpful to seek additional information, which should then be checked out with your healthcare team.

SUPPORT GROUPS CAN HELP

Support groups can help you cope with your cancer by offering you a chance to share feelings, learn ways to deal with challenges and gain valuable strategies for managing your cancer. Emotional and practical support is provided in a shared and comforting environment. Family members are often included and special groups for caregivers, children or family members themselves may be also available.

Many organizations and hospitals offer support groups. You can call your local hospital or many of the organizations listed in the back of the book for meetings near your home.

THE MEDIA

The media, including, television and magazines, offers considerable information about cancer. Often, reports of cancer studies from science journals are described, because the public is very interested in learning about new “breakthroughs” in cancer. But journalists do not have to use the same standards as scientists for reporting such research findings. Their descriptions might not be as clear, accurate or complete. If you feel that the news might relate to your cancer or treatment,

bring the article to the doctor at the next visit and ask about it. Often the science reported is early in development and the related treatment may be years away.

Other times the media will present inspirational stories about cancer patients. These can be very positive, and help share new ways to deal with common experiences. Other stories might describe unsuccessful attempts at a cure. Remember, your cancer may not be the same as those described in the articles, even if it sounds similar. Also, keep in mind that while the media provides information and news, it is also used to sell products through advertising. Sometimes an advertisement can look like a new cancer research report. It is important to be very wary of claims that might sound too good to be true.

THE INTERNET

The growing popularity of the Internet has made it easier and faster to find health information. You may search a wide variety of sites to obtain current medical information, listings of available research studies and a broad range of online patient support services. Much of this information is valuable; however, the Internet also allows anyone to put false and misleading information on the web. It is important to consider the source of the information so that you can decide if it may be real and accurate.

Government, university, medical school or recognized physician association sites are usually good sources for scientific and medical information. Web sites by individuals, describing their own case, or pushing a particular interest of their own may be more suspect. A good site should also give you links to other sources of health related information and should be updated on a regular basis. A wise consumer will check out the information carefully with other reputable sources. Feel free to talk to your health care team about such information.

Knowledge is power.



**Get all the facts about
your cancer...**

but beware...not everything you
hear about cancer is true. Check
with your doctor or nurse or other
health care team member.

The National Cancer Institute provides an excellent fact sheet on ***“How to Evaluate Health Information on the Internet: Questions and Answers”*** (http://cis.nci.nih.gov/fact/2_10.htm). Also, remember that even if you do not have a computer, your local library may provide access to the Internet through public terminals.

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Chapter 5 - Coping With Cancer

You or your family member may have just heard the word cancer for the first time, or you may have been living with the diagnosis for months or years. In either case, it is hard to know exactly what is ahead for you. For the majority of people, new and improved treatments will cure the cancer and it will not return. For smaller groups of people:

- The cancer may go into “remission” or go away temporarily only to return at a later date, even many years after the first treatment.
- The cancer may remain in your body in some form for many years but still permit a satisfying and productive life.
- The disease may progress and limit the number of years or months ahead.

In all these situations, there are steps that you can take to help you through the cancer experience and to be as positive as possible.

As you and your family learn to deal with your cancer, the immediate fear, confusion and anxiety may give way to determination to find the best care and prepare for the challenges ahead. Responding to the initial shock of the diagnosis may have revealed much strength you did not know you had, and support from many people and groups you might not have anticipated. Some people react by finding themselves frozen in place and seemingly unable to make decisions. Preparing yourself and your family to cope effectively with the special challenges ahead will take some thought and consideration.

COPING WITH CANCER

When you are diagnosed with cancer, it is natural to have some strong feelings like anger, fear, distress, hopelessness or anxiety. These feelings might appear, increase, and then disappear for a time, only to reappear unexpectedly. Finding and taking support is not a sign of weakness or failure, but rather an indication of your strength and maturity in coping with what might feel like an overwhelming threat.

It is difficult to know what will trigger these feelings, and hard for those around you to know how to help. These up and down feelings are normal and letting yourself have these reactions is important, as is telling your family and friends how you feel. Sharing your concerns can reduce their power. *Some of the more typical reactions include:*

ANGER

It is not unusual to feel instantly angry about this news. You may feel betrayed, believing that this should not happen to someone who has tried to be good and responsible. Some people resent those around them who can simply go on with their lives. The anger might be directed at your healthcare team, family, God, co-workers, or even directed toward yourself for something that you think you did or did not do that made this illness happen.

ANXIETY AND CONFUSION

You and your family have now entered an unknown world, complete with professionals, words, ideas and decisions that are new to you. It is natural to be fearful about the way the disease will progress, how you will react to treatment, what your family will do, how you will overcome financial concerns and if you will be in great physical distress. It's important to try not to let these fears take control and keep you from moving forward. Remember that information and support is available each step of the way.

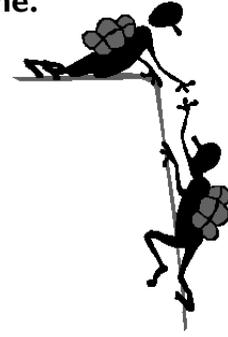
DEPRESSION AND HELPLESSNESS

Each person reacts to bad news in an individual way. Some are energized to overcome the obstacles ahead; others feel depressed and sad. Often the same person may move back and forth between these emotions. They are an expected part of coping. Talking to friends and family can often help. Support groups, professional counselors, peer advisors, and other methods such as meditation, physical activity and biofeedback, among others, can be used to address depression. Depression does not have to be a part of your cancer experience. Your healthcare team may be able to offer suggestions or medication to help you deal with the depression.

GRIEVING

Coping with any kind of loss can be distressing. With the diagnosis of cancer, the loss of your health and well being can be especially difficult. Your dreams, ambitions and expectations may all be threatened. You might find some changes in

There is no prize for going it alone.



When you have cancer, finding and taking help from others is important.

your body or the ability to function as you did before. It is important to allow yourself to grieve over these losses, even if they are temporary.

Just as you seek help for symptoms of the disease and treatment, it is important to seek relief and support for the psychological and emotional concerns which may accompany diagnosis, treatment, rehabilitation and beyond. This need may begin the day of diagnosis and can extend far beyond the completion of the treatment phase. Just as you are urged not to accept physical pain as an automatic part of cancer, unrelieved emotional pain does not have to be an automatic part of cancer treatment.

HELPING FAMILIES COPE

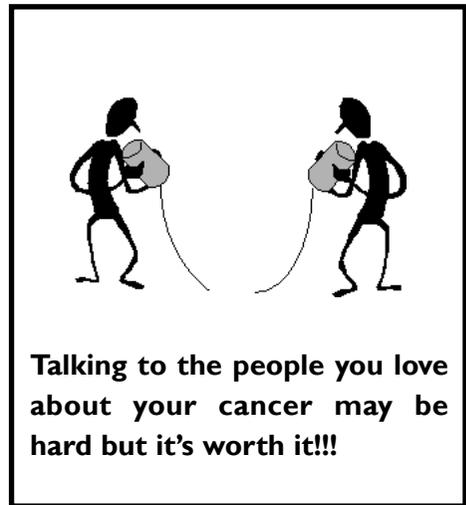
A cancer diagnosis affects not only the individual, but the family as well. Today, the definition of family can be very broad. It might include a partner, extended relatives, and close friends. Each family unit has a personality and style of coping. Each individual within the family also has different ways of dealing with new information or a crisis situation. These differences can create stress within the family.

There are many factors that might influence how people react to cancer in the family. ***These include:***

- The age of the patient at diagnosis, and the ages of family members will have a major impact on how the family copes. If you are an elderly person, living alone, or with a frail spouse, this may require different services and support than if you are the family wage earner or the main caregiver for young children. The response may be completely different if the patient is a child.
- Every family has a “style” of handling emergencies. The way families handle emergencies may be based on their previous experiences, religious or cultural traditions or personalities. Some people chose to rely on community leaders or clergy for decision-making; for others, the tradition is to maintain a stoic, “stiff-upper-lip” approach. In many traditions, family members do not feel free to share feelings or information about cancer. Your family traditions and culture will impact on how you all deal with the diagnosis, and will make a significant difference in the way the family will deal with the cancer and treatment concerns.
- Finding help with household chores or transportation can be more difficult if funds are limited. Many situations can increase the stress: the lack of a job or car; many floors to walk up to an apartment; family members who are scattered around the country; or, an elderly or frail spouse. Some resources are available

to help meet these needs, so ask your treatment team or case manager, your church, neighbors or other organizations listed in this book.

Your family and friends cannot help you if they don't know what you need. Sometimes it is the practical aspects of life that are the hardest to manage; picking up the children at school, doing the grocery shopping, a load of laundry or a meal prepared on a treatment night. Other times, you may just need a quiet conversation, or just a hand to hold. Your family and friends want to help. **There is no prize for going it alone.**



COMMUNICATION WITHIN THE FAMILY

In the face of cancer, talking to one another may become strained or uncomfortable. It sometimes becomes difficult to share thoughts and feelings. Some people worry about upsetting or depressing others. Some find it hard to use the right words. For most families, sharing makes the disease easier to endure, so it is worth the effort to search for a way to keep communications flowing.

Keeping secrets may make family members feel left out or leave them feeling that they are not important to you. Sometimes, it is easier for people to deal with the truth than what they might imagine. How you include your family in the decisions and course ahead will be different for each member. It will depend on how old they are and how you think they need to hear the information.

Some very popular approaches to cancer treatment emphasize the importance of a patient's "positive attitude" in achieving a cure. While a positive attitude can help increase your sense of well-being, there is no evidence that an optimistic attitude cures cancer. Not letting a person share fears and doubts can create feelings of being alone and isolated. It is important for family members to understand that if the treatment fails, this is not because the patient didn't really try hard enough or because he or she does not want to live.

CHANGING FAMILY ROLES

Each member of the family has specific jobs and responsibilities. Family members may need to pitch in to accomplish tasks usually performed by the person with cancer. This may be difficult, both for the one taking on the task, as well as for the one who must give up the usual chores. These may include money management, household upkeep, decision-making, and the physical care of children and elderly relatives. It is important not to ask children to take on tasks that are too difficult for their age or ability. Changes in the household may cause disruption, anger, fear or resentment, as each person still must attend to their own traditional responsibilities, as well as take on new ones. In light of the new situation, perhaps a new way of doing things would make more sense. An immaculate house may no longer seem so important and simpler meals may become acceptable. Flexibility, open communication, and a sense of humor can help families make these changes.

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Chapter 6 - Help is Available

HOW CAN FRIENDS AND FAMILY HELP?

When someone we care about has cancer, it is hard to know how to help and what can make a real difference. The diagnosis can make family members and friends also feel very vulnerable. *There may be many confusing and conflicting thoughts:*

- What is going to happen? Will my loved one survive?
- If so, will he or she be different in some way?
- How will this change my life?
- What do they expect of me?
- If it can happen to them, could this also happen to me?
- What do I say? How do I keep from crying?
- How do I help?
- Why do I feel guilty that I am healthy?

These concerns are very normal and may feel stronger at some times and less so at other times. The best thing is to treat the person with cancer in the same way you always have. While you cannot and should not ignore this new threat, it is important to remember that this is the same person you always knew and loved; the diagnosis of cancer does not change who this person is.

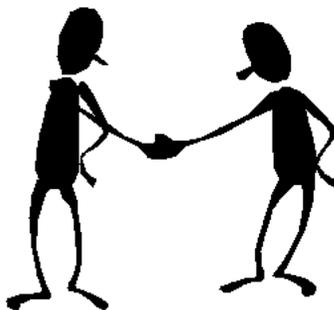
Some of the ways you can be helpful include:

Listen

The person newly diagnosed with cancer will go through many stages in dealing with this new crisis. He or she may need to talk, to cry or yell, to consider all of the issues, to ask “*why me.*” Many questions are not asked in hopes of an answer, they just need to be heard. Let the person with cancer set the agenda; at times they may need to talk about the disease or

How can you help someone you love with their cancer?

- Listen.
- Just be there.
- Get information.
- Offer to do the every day things like fix a meal or drive to the doctor.
- Take care of your own worries and fears.



treatment, and at others, they may want to talk about everyday things and not about the disease. Try to follow this lead and let the discussion go where your friend or family member wants it to be.

Remember that everyday events continue, and sometimes, it is a relief to be concerned with other topics. Don't assume that the things that were important to this person before are no longer of interest - ask; otherwise you are denying them the right to continue to be a part of life.

Just Be There

Many people are reluctant to visit or call a person with cancer because they feel that they don't know the **"right"** thing to say or they worry that it might be uncomfortable to see someone cry or be tearful. Remember that your presence is the most important thing that you can offer. Very few things are **"wrong"** to say if you are there with a hug and a hand to hold. Sometimes quietly sitting together or simple everyday chitchat is just the ticket.

Offer Specific Help

People are reluctant to ask for help, and saying, **"Let me know how I can help,"** may not result in a request. It might be best to ask specific questions: **"Can I pick up the children from school today; What time shall I bring dinner over; Can I drive you to your treatment; Is the laundry ready for pick up?"** etc. Offer to go to the doctor or treatment appointment with your friend, if they would like. It is often helpful to the patient to have someone else hear the instructions and information.

Gather Information if Asked

You can help by gathering information from the sources described in this booklet such as the Internet, library, organizations and other places. Be sure that the facts are reputable and accurate, and try to organize what you find so that you are not just throwing a big stack of materials at an already confused and bewildered patient.

Stories about people who survived a similar diagnosis may be helpful. Suggestions about unproven or unorthodox methods might not be helpful. Bombarding people with many unknowns may only be more confusing. Finding out about support groups or informational gatherings can be helpful information to the person with cancer. However, it is important to let this person decide if they want to participate.

Allow Yourself to be Sad, Fearful, Confused and Angry

Confronting cancer can cause you to worry and feel sad for your friend/family member and yourself. This is normal. You might want to talk to someone about

your own feelings. While you do not want to change how you behave around the person with cancer, you also don't want to burden them with your own anger and anxiety. Support groups are available for family and friends of persons with cancer. You might want to consider this for yourself.

Families Need Support Too!

Your healthcare team can help to find support groups for family members in your area. If your family is approached to join such a group, encourage them to give it a chance. If things become especially difficult at some point, consider individual or family counseling with a professional. This can help the family and the patient over the rough spots and strengthen your ability to adjust and grow in the future.

As with adults, children are unique in the way that they react to new events. To some extent the reaction will relate to their age, whether they are in school or working, what else is happening at this time and their own emotional development. While there is an understandable impulse to try to shield children from the news of a cancer diagnosis, it is generally obvious to even the youngest child that something is going on; they may overhear telephone conversations, hear friends or neighbors talking, or see the anxiety and fear around them. Remember, children are not small adults and are extremely sensitive to change.

When they don't get information, a child's fantasy can be more frightening than reality. It is important to share clear, honest, information with the children, geared to their age and what they are able to understand. They need to feel they can trust you and what you tell them. They may need information in small doses, in a manner appropriate to their age, and to hear the story as often as they request.

It may help children for you to tell them:

- Nothing you did caused the disease;
- Someone will always be there for you;
- You can still do the things you like to do;

How do I talk to my kids about cancer?

Be honest.
Keep it simple.
Include them.
Assure them.



- Cancer is not contagious;
- You can always talk about your feelings.

It is important to be sure that the children are not becoming isolated from their friends and family. Children thrive on consistency so family members should try to keep activities and plans as normal as possible. It is helpful for you to prepare them for your anticipated treatment side effects, like hair loss or fatigue, possible hospitalizations, and visits by health care team members. Young children do not cope in the same way as adults. They may appear more interested in getting to football practice than going to visit an ill relative. This is normal and does not represent a lack of interest or concern. It is not unusual for a child to become clinging, develop nightmares, throw a tantrum or try other attention getting activities.

Adolescents may worry about their likelihood of developing cancer, the impact of the disease on their emerging need for independence or changes in their parents. You might find it helpful for someone in the family to devote some extra time and special attention to them, so they do not feel left out or isolated. Teachers should be informed of what is going on in the family so they can provide some extra support and be on the lookout for signs of changes in the children.

A non judgmental approach to a child's or adolescents' own style of coping will help. Finding ways that they can be helpful and involved, such as a young child drawing a picture for the patient, or an adolescent assuming some new task, can help them to cope. Special programs are available for children to meet with others who have similar experiences. Seek out these opportunities.

Chapter 7 - Special Needs

CHILDREN WITH CANCER

All of the information in this booklet about the biology of cancer, treatment methods, and the need for communication among caregivers, family and community applies to cancer in children. Yet, children with cancer have special needs that require the comprehensive services of many healthcare providers and supportive services.

Although still relatively rare, cancer is the second leading cause of death in children. Types of cancers common to children are leukemia, central nervous system cancers (brain tumors and spinal cord), lymphomas, bone cancers, and soft tissue cancers. Substantial advances have been made in the treatment of childhood cancers and today many children diagnosed with cancer are cured.

Treatment for children must be designed specifically for their unique and changing developmental, physical, and emotional needs. Pediatric cancer centers offer specialized teams and a comprehensive approach that are essential for children with cancer. The team will help you to identify your child's and family's unique needs in many areas such as home, school, workplace, and community. Children also need access to clinical trials designed specifically for them. Many of the advances in pediatric cancer care have occurred because so many children have been enrolled in cancer studies. So, you should not be surprised if you are offered a clinical trial very soon after diagnosis of your child.

Families of children diagnosed with cancer face physical, emotional and financial demands that can disrupt family life significantly. Parents may feel responsible for not having noticed the signs of the disease earlier, or that something they did might have caused the disease. It is important to remember that childhood cancers are not the result of actions, or inactions, by parents.

Finding ways to talk to your child with cancer can be difficult for some people. What to say, when to have the discussion and how much should be explained will vary with each child. Of course, you know your child and what he or she can understand better than anyone. Sometimes, our protective instincts often lead us to try to shield children from difficult information. However, children generally can sense distress and changes in the household, and do need to have some answers.

Honesty is usually the best approach when talking to your child about cancer, targeted to what your child is really asking, and responsive to the age and life stage. Your own cultural and religious background may have some role in how to approach your child. It is important to help your child understand that he or she is not to blame for the illness and has not done something to cause the cancer. Your treatment team can help you assess the most appropriate way to respond to questions.

Your child may have fears about separation, pain or other issues. You will want to be alert to these concerns and discuss them, reassuring your child that you will be there and that there are ways to keep them comfortable and secure. Siblings, grandparents, other children and adults in the extended family, even schoolmates have their own needs and may require some help in coping with cancer. This is a good time to draw in extended relatives and friends to help. Parental support may also be needed and groups are available to help you cope with your feelings. Find friends and/or counselors to whom you can turn for guidance.

Cancer in adolescents can present even greater challenges. Of course, teenagers are more aware of the issues that cancer poses, and may have a more difficult time adapting to the limitations and side effects of treatment. Just when they are attempting to gain some autonomy, cancer may dictate dependence on parents and doctors. At an age when peer pressure and the need to fit in is most important, the loss of hair, body mass or other side effects of cancer can isolate them and assault their self-image. Special attention should be paid to these concerns. Your child's treatment team can offer or refer you to counseling, peer support groups or materials to help both you and your adolescent through this period.

Just as with adults, adolescents and children may be treated with a whole host of methods; surgery, radiation, chemotherapy, biologic therapy, bone marrow or stem cell transplant, or other procedures. Each type of treatment is designed to take into account the developmental stage of the child to minimize any impact on the child's growth and development. Of course, treatment and survival are the primary concerns following a cancer diagnosis. However, since the majority of children and adolescents with cancer are being cured, increasing attention is being paid to the long-term impact of the disease and its treatment on their survivorship.

Important steps to be considered for survivors of childhood cancer are:

- Ask your pediatric oncologist about the known impact of the treatment on your child's physical, emotional and learning capabilities. Reproductive health should also be discussed.

- Arrange to get regular follow-up information to monitor your child's physical and emotional health. The team will help you identify ways the treatment or the disease might have had an impact on growing systems, look for delayed effects of the treatment, and address emotional, educational, and career concerns.
- Seek follow-up services in a pediatric oncology clinic or one of the newly developed special programs designed specifically for childhood cancer survivors.
- Assure that the treatment team develops a plan for a smooth entry into adult medical care.

Information about pediatric cancer centers in New Jersey may be obtained from the New Jersey Commission on Cancer Research. The Cancer Information Service of the National Cancer Institute has complete information on treatment centers throughout the country. (See appendix B for more information).

THE OLDER ADULT WITH CANCER

Cancer is more common among older adults; more than half of all cancers are diagnosed in people over the age of 65. This may be the result of longer exposure to cancer-causing elements in the environment, or because cells are not as efficient in fighting off disease as they age. Little is also known or understood about the relationship between cancer and aging. How cancer in older people might be different from younger patients is also poorly understood. For example, medications and treatment methods may work differently in older patients. Active research is seeking answers to help understand these and other questions.

Such a lack of answers may make the care offered to older adults more variable. If you are older, you may not be encouraged to participate in screening or prevention efforts. Studies also show that you may also not get a referral to a cancer center, recommendations for aggressive new therapies or offers to participate in a clinical trial. Often, those over 65+ years get lumped together into one big category. Newer definitions describe the “*young old*,” about 65-75, “*older old*” from 75-85, and “*oldest old*” who are beyond age 85, a fast growing population. It is also important to understand that individual people vary in their abilities and physical condition within each of these categories. Some people are still playing tennis at 80, while others are inactive at age 50.

It is clear that treatment for cancer can become more complex with age, especially as people often have a number of other health problems that complicate the diagnosis and treatment of cancer. You might have ignored some symptoms, assuming that they are just a natural part of aging. Some older adults may be frail and not able to get out on their own. In some cases, memory and thinking may not

be as clear. Some older adults may be isolated and need more support. Coping with the complexities of cancer and understanding the choices may be an especially difficult challenge.

Many of the long held beliefs about cancer and aging are no longer valid:

- Everyone over 65 is not the same; each person must be evaluated individually;
- Most older adults can receive the full schedule of cancer treatments with appropriate supportive measures;
- People of any age want and need information that is clear, understandable and accurate;
- Depression and confusion, if they are apparent, can often be treated;
- Patients of any age have the right to make their own decisions about initiating and declining treatment, when they are capable;
- Financial concerns are real for many older adults with limited income and a reliance on Medicare (which may not cover all necessary treatment) as well as the pressure of other disease-related costs;
- Cancer among older people of minority populations is even less understood and often access to essential care is a problem.

Your family members might be geographically distant and unavailable to help with care giving and transportation. Often spouses or siblings of older cancer patients are themselves frail or suffering from medical conditions and are less able to provide support. For these reasons, a special *geriatric assessment* is important to help the health care team understand your specific level of care. You may want to find a health care team with experience working with older patients.

Older adults may have different physical responses to disease and treatment than younger patients. These differences may include more digestive problems, skin changes, the need for more fluids and better nutrition, changes in how well kidneys are working and drug interactions. Pain medication and other drugs might work differently and/or last longer in your system. Hearing or eyesight might be less acute; if you need to hear the information in another, more comfortable language, or prefer written materials in larger type, ask for this help. ***When treatment options are made available, you might want to discuss some of these issues with your family and other personal advisors as well as the treatment team:***

- How will the treatment impact on my continued ability to be independent?
- How important is being physically independent?
- Am I willing to undergo very intense treatment that might result in

- moderate or severe side effects?
- Do I have a caregiver to help with treatment side effects?
 - Where can I find additional help to meet your special needs?
 - What costs will be covered by Medicare or Medigap insurance?
 - Whom do I want to designate to make medical decisions if I cannot?
 - What are the specific instructions in the event I cannot communicate my decisions?

There are resources available to help. The “**Cancer Survival Toolbox**” is available through the National Coalition for Cancer Survivorship. The Toolbox has a special audiotape with a variety of topics for older adults with cancer. Cancer Care, Inc., the American Cancer Society, local hospitals and county offices on aging all offer additional information to help.

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Chapter 8

NAVIGATING INSURANCE, WORKPLACE ISSUES & OTHER CONSIDERATIONS

Cancer can be a considerable financial burden for both you and your family. While you may have insurance that covers many of the medical costs, there are still many expenses that are not covered. Often, insurance companies require you to get approval in advance of your treatment.

In addition, they may have a long list of requirements and considerable paperwork adding much stress to an already difficult time. It is very important to understand your health insurance coverage and what your limitations and rights are. Read the descriptions of your coverage and discuss it with your healthcare team. If you do not understand fully, call your workplace benefits person, your insurer or the Medicare hotline (if a Medicare Beneficiary) to ask questions until you are clear. Sorting out all this information is something that a knowledgeable friend or family member can also do.

It can be a considerable challenge to cope with the healthcare system and find the care you need, especially if you have no insurance. With or without insurance, there are a number of government programs and social organizations that can help. These are described below and in the Appendices at the end of this book. It is important to try to get as much information at the very beginning as possible, as many programs require some pre-approval.

Because today's health care system is so complicated, this book can only cover some of the essential information. Please use this as a guide to continue to get assistance.

- Ask for information from your insurance company, union, or workplace insurance office, social worker or case manager where you are getting care.

How do you deal with the costs of cancer?



- Find out ahead of time what costs your insurer covers or if okays or referrals are needed for doctor visits.
- If you have no insurance, talk to someone at your hospital or call the cancer help lines in the back of the book.
- Don't give up or take NO for an answer.

- If you have Medicare or Medicaid, call the office or use the web sites listed in the Appendices in the back of this book to have your questions answered. Be persistent.

If you feel that you have been turned down for care unfairly, each insurance company and the State Department of Insurance and Banking as well as Medicare and Medicaid have appeal processes you can try. Find out the steps involved and be tenacious. Do not accept **NO** for an answer. Ask your physician to help by giving you a written explanation of why you must have a certain procedure or treatment.

HEALTH INSURANCE

Health insurance is complex and changes rapidly. Many insurers have case managers to help you get all of your benefits. However, it will save you much trouble and frustration if you understand the type of coverage you have and what responsibilities you have for approvals and referrals.

There are several broad categories of health care insurance contracts:

- One type of plan is the **INDEMNITY PLAN**, or fee for services. In this type of insurance, you can choose any physician and hospital and the bills are paid according to the specifics of the policy, usually at 70% or 80% of what the insurance company considers “usual and customary” charges for your area. Please note that generally, the “usual and customary” fee is often considerably less than the doctor actually charges. You will be responsible for the difference. These plans generally include an initial deductible each year.
- The **MANAGED CARE PLAN** is another type of insurance, in which you may be offered a broad range of services for a small fee, but choice is limited to the specific physicians, hospitals and services within the system. Several types of managed care plans are now available:
 - ❖ **Health Maintenance Organizations (HMOs)** are plans that require you to choose a primary care physician in the network who takes care of you. In these plans, the primary care physicians must give you a specific referral for special services that the primary care physician does not handle.
 - ❖ **Preferred Provider Organizations (PPOs)** are plans that do not require you to have a primary care physician and referrals, but you generally pay a co-pay to see doctors and to use hospitals in their network. In

these plans, using doctors or hospitals out of the network will result in higher costs to you. Trying to find doctors in the network can represent considerable savings. You can also ask your referring doctor to be sure that any new services he/she recommends are part of your plan.

In past years, once a person was diagnosed with cancer, it became difficult to obtain or maintain affordable health insurance. Now, you are protected by federal and state discrimination laws that may help you keep your group plan at work. In New Jersey, you can also purchase individual health plans with no waiting period for pre-existing conditions if you have **continued insurance coverage, with no gap in coverage** from one plan to another. A fee-for-service insurance company or an HMO offering individual or small group plans must charge the same price and provide the same benefits and services without regard to a person's age, gender, occupation, geographic location or health status. A list of current premiums charged by participating carriers is available by calling the New Jersey Individual Health Coverage Program Board at 609-633-1882.

If you leave your job, the **Comprehensive Omnibus Budget Reconciliation Act of 1986 (COBRA)** allows you and your dependents to continue to pay for your group health benefits for up to 18 months or in some cases of disability up to 29 months. Your employer may charge you the full premium for your coverage plus 2% and charge an even higher premium if you continue to extend your benefits because of a disability. This may create a considerable burden, so you might want to compare the costs and benefits of the COBRA coverage with the individual plans provided by the state. The cost of these individual policies may be less than your COBRA benefits, but the coverage may be more limited and the deductibles higher.

If you have **Medicare**, "**Medigap**" plans can pay some of the deductibles and co-pays. New Jersey insurance companies offer a number of plans but all must offer at least the basic plan. Be sure to read the information carefully and know services are included. Ask questions. Appendix B includes organizations to call or write to get more details on these plans.

The state has a program that offers low cost, affordable health coverage to families who are not able to afford health insurance. It is not a welfare program, but does require a certain level of income to be eligible. For more information, call 1-800-701-0710 or visit the website www.njfamilycare.org.

MEDICARE

Medicare is a government sponsored health insurance program for individuals 65 years and older who receive social security or railroad retirement benefits, those who are disabled under social security or have certain other health conditions. It includes Part A that provides hospital coverage, Part B that includes medical coverage for doctors visits, test and other services and starting in 2006, Part D that offers a prescription drug benefit.

Part D is a newly expanded benefit that requires that you choose and join a medicare drug plan. These vary significantly so you should do your homework when you are making this choice. Things to consider include the type of overall medicare coverage you presently have, the costs that the different plans involve and the convenience that you desire. You can find information to guide you in your decision by visiting www.medicare.gov or by calling NJEASE at **1-800-792-9745**.

If your income is limited, you may qualify for extra help with premium costs. Contact social security at 1-800-772-1213 to obtain more information about eligibility.

MEDICAID

Medicaid provides health insurance for certain very low income citizens. It pays for hospital, doctor, prescription drugs, nursing home and other healthcare needs. You must be a resident of New Jersey, a US citizen or qualified alien (certain residency requirements exist for immigrants), and meet specific income and financial resource levels. The program is administered through the New Jersey Department of Human Services. The program is separate from New Jersey's welfare reform program, Work First New Jersey (WFNJ). When you apply for WFNJ benefits through your local County Board of Social Services, your caseworker will also determine your Medicaid eligibility. As your income changes, so will your Medicaid eligibility.

If you have dependent children, your family may be eligible for Temporary Assistance to Needy Families (TANF) and/or health benefits through Medicaid based on your income and situation. For more information, call the Medicaid hotline at **1-800-356-1561** or inquire at your local County Board of Social Services.

WORKPLACE ISSUES

The vast majority of working people with cancer continue to work, or return to work after their initial diagnosis or treatment. It is clear that cancer survivors are productive workers and have no higher rate of absenteeism. However, almost one in every four survivors face job barriers because of a cancer history. Problems most frequently reported are dismissal, failure to hire, demotion, denial of promotion, undesirable transfer, denial of benefits and hostility in the workplace. Under both federal and New Jersey law, an employer cannot treat you differently from other workers in job-related activities. *You are protected by these laws only if:*

- You can do the major duties of the job in question.
- Your employer treated you differently from other workers in job-related activities because of your cancer history.

FEDERAL DISCRIMINATION LAWS

The Americans with Disabilities Act (ADA) and the Federal Rehabilitation Act prohibit some types of job discrimination by employers, unemployment agencies and labor unions against people who have or have had cancer. Employees of state and local governments, federal agencies and Congress are also covered. The ADA covers private employers with 15 or more employees, state and local governments, unemployment agencies and labor unions. The Equal Employment Opportunities Commission (EEOC) enforces your rights.

NEW JERSEY DISCRIMINATION LAWS

The New Jersey Law Against Discrimination prohibits some types of job discrimination against people who have or have had cancer. Every public and private New Jersey employer, regardless of size, must obey the Act. For more information, you may contact the Division of Civil Rights in the New Jersey Department of Law & Public Safety.

Most people with cancer can still work and do their jobs well. There are laws that:

- keep you from being fired or treated unfairly.
- let you take unpaid time off if you or someone in your family are sick for up to 12 weeks.

Talk to your HR office about your rights, or call the phone numbers listed in the back of the book.



GENETIC TESTING AND DISCRIMINATION

The New Jersey Genetic Privacy Act of 1996 controls genetic testing and the use of genetic information. The Act is designed to protect people from being unfairly discriminated against by employers and insurance companies because of genetic information. It assures that your genetic information remains private and confidential. Anyone who feels that insurers have unfairly discriminated against them should call the New Jersey State Department of Insurance. For more information about the Genetic Privacy Act, please call the New Jersey Commission on Cancer Research.

FAMILY LEAVE

You may feel the need to take a leave from work for your own treatment or to help a family member. Both federal and state laws provide for unpaid leaves. **The Family and Medical Leave Act of 1993 (FMLA)** requires employers with 50 or more employees to provide up to 12 weeks of unpaid job-protected leave for family members who need time off to address their own serious illness or a seriously ill child, parent or spouse. This law is defined and regulated by the U. S. Department of Labor, Employment Standards Administration Division and can be contacted at 1-866-4US-WAGE or by visiting their website at www.dol.gov/esa.

The New Jersey Family Leave Act of 1990 guarantees job security and certain benefits for employees who need to take up to 12 weeks of unpaid leave to care for a family member with a serious health condition. You should check with your employer to see if you are eligible. Employees may be eligible if they have been employed for at least one year and worked at least 1,000 base hours during the immediate preceding 12-month period. Family leave is separate from, and in addition to, any disability leave for which the employee may be eligible, including disability leave authorized under the Federal Family and Medical Leave Act. This law is defined and regulated by the N.J. Office of Attorney General, Division of Civil Rights and can be contacted at (609) 292-4605 or by visiting their website at www.state.nj.us/lps/dcr/law.html.

MEDICATION ASSISTANCE

Some people with cancer may not be able to afford some of the more expensive drugs that are available now. For example, the newest anti-nausea medication or long-acting pain medicines may be quite expensive.

Some of the organizations that can help include:

- **The Pharmaceutical Assistance to the Aged & Disabled.** (See Appendix B)
A State program that may be available if you are over 65 and meet certain income eligibility levels or are disabled and on Social Security Disability.

- **The Senior Gold Prescription Plan** provides prescription drugs to eligible New Jersey residents for \$15 per prescription plus one half of the cost of the prescription. You must be a New Jersey resident 65 years of age or older or receiving Social Security Title II disability benefits. This program also limits the amount of income you can have to be eligible. Applications are available at senior centers, pharmacies and county offices on aging.
- **The Pharmaceutical Manufacturer’s Patient Assistance Programs** may help you obtain certain drugs at reduced cost if you are not able to afford them. This is open to all patients but there is a limit on how much income you can have and still be eligible. The program assists you in coordinating these benefits with the new Medicare-approved drug discount cards. Ask your physician about it, as the physician must apply for you. Companies now use a centralized toll free number to streamline the process. RX4NJ is a clearinghouse for New Jersey patients. For more information call (1-888-RXFORNJ) or www.rx4nj.org.
- **Rx4NJ (www.rx4nj.org)** - Rx4NJ is a voluntary partnership formed to help people all across New Jersey gain access to free and low-cost prescription medicine programs. The coalition is led by a wide range of patient advocacy and community organizations and New Jersey’s pharmaceutical and medical technology industry. Phone 1-888-RXFORNJ.

VIATICALS & LIVING BENEFITS

You may have an immediate need for financial help to take care of the costs of medication or treatment. In many states, you can use your life insurance policy through something called a Viatical. This means that you can get some of your life insurance dollars when you need them. Be sure you understand how the program will affect your benefits and read the fine print before you sign anything. In this case your beneficiaries would not get the part of your benefits that you have already used before your death.

Another option might be a “reverse mortgage” in which you can collect some of the money that you have invested in your house. It must be then repaid when the house is sold.

A whole host of financial options may be available to you. Be sure to **get advice from your lawyer or accountant before you make any of these decisions.**

Other programs that may help you cope with the financial stresses that might accompany illness include:

- **The New Jersey Temporary Disability Benefits Law may cover disability- if you work in New Jersey.** You may be eligible if an illness or injury keeps you from working. Your employer may participate in New Jersey's Temporary Disability Insurance Program or may offer a private plan. This insurance can continue for up to 26 weeks. Your employer also may offer long-term disability insurance. Discuss your benefits with your benefits manager if you have to take time off from work. For information on the state's program, see Appendix B.
- **SSD - SOCIAL SECURITY DISABILITY** - Under some circumstances you might be eligible for Social Security Disability. You may be eligible if you expect to be out of work for longer than a year; have been contributing into Social Security; have worked five out of the last ten years; and are under 65 years old. You must meet all of these criteria to qualify. The application process may be done at any Social Security office or by phone and usually takes six months to complete.
- **SSI - SUPPLEMENTAL SECURITY INCOME** - This is another program offered by Social Security for the person unable to work due to illness or injury. It is based on financial need, and if you qualify, automatically grants New Jersey Medicaid coverage, the health insurance program for low-income families and disabled individuals.
- **TEMPORARY ASSISTANCE** - The state also has a program for single adults and couples without children, known as Work First New Jersey General Assistance (WFNJ/GA). WFNJ limits assistance to a maximum of five years over a participant's lifetime. If you are a single adult or couple without dependent children you may also be eligible for medical coverage while you are receiving cash assistance.
- **MUNICIPAL WELFARE** - If you have no job, no income and no money or you need help while you are waiting for some benefits to begin, municipal welfare can help with prescriptions, some doctor's office visits, some home care and a little money. Every municipality has a welfare office that may be open every day or only once a week. Call your local municipal offices for information.

Chapter 9 - What Lies Ahead: Cancer Survivorship

Each year, many thousands of people become cancer survivors. This rapidly growing group of people is attracting a lot of attention, research and interest. The National Cancer Institute has created a special Office of Cancer Survivorship, dedicated to looking at issues that face people who have had cancer. This office, like many other groups in the country, is focused on assuring a high quality of life and continued well-being for those who have a history of cancer. While you are not a different person after a cancer diagnosis, there may be a unique set of issues due to your cancer that will need to be considered during your life time.

LOOKING AHEAD

The National Coalition of Cancer Survivors defines a person as a “cancer survivor” from the day of diagnosis. How you cope with that survivorship will be influenced by many things: your age; whether you are married, single, widowed or divorced; have children or aging parents; your physical strength; cultural traditions; how you feel during treatment; and the response of the cancer to the treatment.

There are a number of crossroads ahead. In earlier chapters, we addressed some of the first steps following your diagnosis. There are other points along this journey that can present some new challenges and require special attention.

COMPLETING YOUR TREATMENT

For many people, completing the course of cancer treatment may cause a crisis all of its own. When you started treatment, everyone was mobilized and ready to help. When the treatment is finished, your family and friends return to their own lives. However, a whole new set of concerns may arise for you. Friends and family may expect you to be happy and relieved, but instead of relief, you may continue to feel fearful, depressed or sad. Or, you might see the end of treatment as an opportunity to change the way that you look at your life.

Some very common questions, you might have, include:

Did they get all the cancer out of my body? Will it come back?

This is a question that often cannot be answered immediately, and the waiting may be very difficult. Each regularly scheduled test causes anticipation and fear until the results are in; this may be true for many years following the end of treatment. This is a normal reaction and it is helpful if you can tell family and friends of your concerns, so they are aware of your periods of high anxiety.

Now that I am finished with the treatment, will the same healthcare team continue to take care of me? Whom do I ask?

Your healthcare team remains concerned about your care. Feel free to continue to ask them questions. Generally, you will continue to see your oncology team for follow-up for many years after treatment, even while you resume your relationship with your “pre-cancer” physicians. It is important to tell any new physicians or healthcare providers about your cancer history, type of treatment, status of care and other details about your treatment. They will want to monitor your health after your treatment is completed.

When might I need extra help in dealing with my cancer?

When you:

- Get the news that you have cancer.
- End your treatment.
- If the cancer comes back.
- If the treatment does not work.

While these times may be harder, you can do things to make them easier. You are not alone, so ask for help.



Why does it seem harder now to talk to family and friends, especially those who always seemed to understand me before?

For many people, the diagnosis of cancer can alter your view of the world. The end of treatment may be energizing and may prompt you to want to experience a whole range of new activities. Some people may reconsider their work or life style, and may begin to seek a new job, change careers, or quit altogether. Some may chose to gather family and friends around and even renew relationships with long lost friends. Often some of the “small stuff” that used to be important really does not matter so much. The dents in the fender, a son’s lower math grade, the national news, no longer make such an impression.

You may need more time to absorb the impact of the diagnosis and take some **“time out”** to withdraw and consider what this all means. There are some people who pull away from family and friends for a time and need to be alone. Whatever your response, your family members and friends may not be changing their view of the world at the same pace, or at all. They may be surprised that things that upset, or pleased you before, now do not get the same reaction. They may become confused about how to meet your new needs and feelings. In addition, the extra energy that they needed to cope with the immediate emergency may have left them feeling drained and exhausted. Talking or writing about your feelings can help.

Will my health be different now? What do I have to do to stay healthy?

New and advanced treatments have improved your chances of surviving your cancer. However, some of the methods that are used to destroy cancer cells can also damage healthy cells and organs. Most of this damage is temporary. Your hair will grow back; your energy should return and many functions return to normal. However, some treatments may leave more permanent changes to your body and your functioning. Learning to live with these changes may take some time and you might want to get assistance in adapting to your daily routine.

For some people, cancer treatments may increase the risk for some other long-term complications that can occur months to years after treatment. These late effects may range from very minor ones to more serious problems. Although rare, some cancer treatments may increase your risk of getting a second, new malignancy in later years. Some minor heart or lung damage may occur. Fortunately, your doctor understands these risks and can check you regularly for any problems.

What this means for you is paying more attention to any changes in your health, continuing regular examinations, and maintaining healthy habits in diet and exercise. Your doctor will advise you about whether the drugs that you have taken have a history of long term effects. Ask your healthcare team which tests and examinations would be important for you to schedule on a regular basis.

While for many people the cancer is not likely to return, it is very normal to worry about the possibility. Scheduled tests and new symptoms can cause anxiety and fear. This is not unusual and generally gets easier over time. Nonetheless, many people continue to count the years from diagnosis: one, five, ten, and twenty, as milestones and to celebrate each one.

BECOMING AN EFFECTIVE ADVOCATE

You have been encouraged throughout this booklet to become an active and assertive advocate for your own needs, concerns and care. This is essential for you. In addition, you might want to consider using your knowledge and experience to help make changes in the way government or workplace organizations deal with cancer. Joining a cancer advocacy group, such as the National Coalition for Cancer Survivors, the American Cancer Society, or some of the others listed in the appendix can help you to find new meaning in your own experience, while also helping others by pressing for more funding for research, changes in the treatment coverage and for new laws to help protect survivors.

SEXUALITY, REPRODUCTION AND CANCER

The diagnosis of cancer can impact every part of your life. For many people, uncertainty about how the disease and treatment will affect their ability to continue, or start, a sexual relationship can be of concern. Unfortunately, in our society, many people feel reluctant to discuss this topic with their treatment team, or anyone else.

Remember, many people now view cancer as a chronic disease. Even after treatment is completed, you might feel some physical or emotional impact from your cancer experience. Consequently, addressing concerns about your sexual life is important. Maintaining communication with your partner about what matters to you, and discussing what adjustments in thinking or physical behavior might be needed will help.

THE IMPACT OF CANCER ON SEXUALITY

The word “*sexuality*” refers not just to intercourse, but other actions and feelings related to sex, even to our own self-image. It is not unusual for our self-esteem to suffer as we face changes in our bodies and our lives. At times, the cancer, or cancer treatment, can change how we function, how we feel and respond, and how a partner views us. Sometimes the cancer or the surgery, radiation therapy, chemotherapy or hormone treatments can have an actual effect on your body’s ability to function sexually. In other cases, your emotional reactions to cancer or its treatment can have an impact on sexuality. Adjusting both to the diagnosis of cancer and the changes that treatment may bring about can be exceptionally difficult. Keep in mind that there are many ways to express and to receive sexual satisfaction, and these can make a significant difference in your general happiness and well-being. Don’t assume that your doctor or nurse will ask you about your

sexuality. Take the initiative and raise your concerns with them, and don't wait until you are in a crisis.

TALKING ABOUT YOUR CONCERNS

Couples often go a long time not talking about their intimate/sexual relationship. It may be difficult to find the words to express these feelings. It can be risky to ask questions that might produce upsetting answers. While this is generally true, it can be even more difficult for the cancer patient. It is important to know that although you may experience some changes in your usual sexual experience, there are ways that you can continue to share sexually with your partner.

BEING SINGLE HAS SPECIAL CHALLENGES

For single people, thoughts about how to cope with new relationships may be of special concern. Choosing when to tell a potential new partner about the cancer experience is a delicate decision. Talking this through with a counselor or a volunteer from a cancer support group who has had this experience may be helpful.

HELP IS AVAILABLE

People can continue to be active sexually in spite of changes from surgery or other cancer treatment. For those who may have stopped or decreased sexual activity before the cancer diagnosis, this may not be an issue of concern. However, if sexuality and sexual function are still important, you can reestablish a satisfying level of intimacy. Just as there are new ways to help with other symptoms and problems from your cancer, new medications, devices, counseling and educational materials are all available to help maintain or establish a satisfying sexual life. Learning about the phases of sexual response, and how the cancer or its treatment might have affected these can be helpful.

THINKING AHEAD ABOUT REPRODUCTION

Younger patients may be concerned about their ability to have children in the future. Some cancers and treatments may have a significant impact on reproduction. Reproduction should be discussed with the healthcare team at an early point. Technologies such as sperm banking and others might be an option. If you are at especially high risk for reproductive problems or infertility, referral to appropriate specialists is essential. Assisted reproductive techniques have improved the outlook for fertility, but there may be a limited window of opportunity for you to successfully conceive and bear children.

Notes

Chapter 10 - Changing Needs and Concerns

RECURRENCE

For some people, the cancer will come back (recur) at some point after treatment. While this can be disappointing, you can face this new challenge with more knowledge and skills than you had before. Your healthcare team will be able to help you consider the new or different treatment options. New drugs are now able to slow cancer growth and keep it under control for long periods, even for many years. Coping with recurrence can create some additional challenges. Some of the “*fighting spirit*” you and your family felt at the first diagnosis might be harder to draw on again. You may still be tired or have other side effects of the earlier treatment. More energy will be necessary to mount this new effort. Sharing your concerns with family, friends and healthcare team will help. It may take some additional patience and understanding, especially dealing with your own feelings. However, as before, taking one step at a time can help you get organized and ready for the new demands.

You may have less physical strength than you did when you started the first course of treatment, so your response to new drugs or methods of treatment might be more difficult. Newer medications and treatments can help to address the fatigue and side effects. Many options are available, so if one does not do the trick, the healthcare team will try another.

You may need to cope with symptoms and any new adjustment in quality of life and functioning. There are many options available for care. Remember that it is very important to ask for supportive care to reduce pain and other symptoms that can diminish quality of life and make the treatments more difficult to tolerate.

It may take some additional work to find the resources you need including finances, friends, and community support. If you are working, you may face some additional issues maintaining your regular schedule. Ask for an opportunity to discuss your treatment and work schedule needs with your workplace representatives. In addition, seek the help of counselors, accountants and others to help relieve your fears and worries. Use all of the sources described in this book to help you get the assistance you need.

Your second course of treatment will hopefully remove the cancer, or provide a respite of many years. It is possible that additional treatment might be necessary

down the line. You might be offered a clinical trial specifically for people embarking on a second course of treatment. All these possibilities offer you the chance to continue to live a meaningful life with your cancer.

WHEN TREATMENT DOES NOT WORK.

When treatments designed to cure no longer work, you may start to think of cancer more like a chronic disease, like cardiovascular disease, asthma or diabetes. This means that, you may face many years, coping with treatments aimed at controlling your cancer and attention to side effects. This may require some adjustments in your life style, how you feel, and your general sense of well-being. It is generally impossible to predict the course of disease or how long you will continue to experience new bouts of the disease.

There are many options available for your care and attention to supportive or **“palliative”** care to reduce pain and other symptoms that can diminish quality of life is important. The healthcare team will continue to provide care and attention to assure that you and your family receive all of the services and treatments needed to assure this quality. You may continue to be offered clinical trials designed for people for whom other treatments have not been effective. You will have to evaluate each option that is presented.

ADVANCE DIRECTIVES

It is important for everyone to consider and complete an **“Advance Directive for Healthcare.”** This document identifies what kind of care you want in the event that you are unable to participate in the discussion at any point. In addition, you can designate whom you want to make health decisions for you when you cannot.

When you have cancer, it is especially important for you to make your wishes about your care known. For example, you may need to decide if quality of life is a higher goal for you than extending your life through any means. Do you wish to have life

If my treatment is not working, what do I do?

- Don't suffer from pain and other symptoms.
- Think about joining a clinical trial.
- Think about using hospice, it gives you the care you and your family need at the end of your life.
- Make your wishes known about your care to your family, doctor and hospital.



support applied when your cancer becomes advanced? Discussing your feelings with your family before the need arises will assure that your wishes are followed, and will make things easier for everyone. Having a clear written description of your intentions available to everyone will avoid misunderstandings and family discord. Since it is not possible to anticipate all of the decisions that might arise, the best plan is to discuss this with your family members and to designate one person to act on your behalf. Be sure that this person understands what is important to you.

You can complete an Advance Directive by yourself. You do not need an attorney or professional advisor to write your wishes. Remember that you can change these documents at any time if your feelings or thinking changes. Your health team will respect the wishes outlined in your **Advanced Directives** so be sure that a copy is in your physician's chart, and filed with the hospital. In some cases, the hospital cannot honor your wishes unless they have a written statement of them. A sample form for New Jersey is available in Appendix F.

HOSPICE

If the cancer cannot be successfully treated, and your life expectancy can be measured in months, you may wish to consider hospice care. In the United States, the word hospice is used not only to mean a place, but more importantly, to describe a philosophy of care emphasizing the needs of the dying patient and family. The hospice philosophy makes the family the unit of care. It helps you to live in the most alert, pain-free manner possible and reduce other symptoms of the illness. This service is limited to patients considered to have less than six months to live, and may be provided either at home, or in a hospice facility. Very often families are reluctant to ask for hospice because they see it as a sign of giving up and giving in. Unfortunately, this attitude tends to delay and minimize the benefits that a hospice team can provide to all of you. Hospice programs can help the most if they become involved earlier. Hospice services assure that you and your family will not be abandoned. Experts will attend to the pain, symptoms and other problems that prevent using whatever time is available to the best extent possible.

A team of caregivers, including doctors, nurses, social workers, clergy and volunteers, can assist you and your family with physical care and provide a support system to improve the quality of life. Some patients may elect to remain at home with a family member when this is possible. In many cases, families may be unable to provide the care at home, or the patient may prefer another setting. For the family that cannot provide care at home, a hospital or nursing home hospice unit or in-patient hospice setting, where available, may best meet your needs. Some

families use “*respite care*” where a patient stays in a hospice to let the family have a brief rest from the day-to-day care.

Hospice units differ from the traditional hospital setting in various ways. One way is that some rules may be more relaxed in hospice settings. Visiting hours are more flexible, often children, and even pets, are among the visitors. The focus is on comfort and relief from symptoms, and all activities promote this goal.

There are many kinds of hospice programs, and often several serve the same geographic area. Ask your physician, healthcare team or friends and co-workers for recommendations. *Some frequently asked questions about hospice include:*

Does the patient have to know that he or she has a limited life span?

Generally, Medicare patients will need to sign a Medicare approval form that includes information on a patient’s limited life span in order to enter a hospice program. Insurance providers may have different requirements. However, family members should discuss with the hospice staff the best approach to presenting this form to the patient.

Can the patient continue radiation or chemotherapy if he or she is admitted to a hospice?

Comfort and support are the goals of hospice care. The goal of the treatment is the deciding factor: if the therapy produces a reduction in pain and suffering, most hospice programs provide such treatment. Hospice is not the right program if aggressive curative treatment for the disease is still the goal.

Can a patient be admitted to a hospice program if he or she lives alone?

Some hospices require a primary care person in the home who accepts responsibility for care. Hospice staff can teach family members about the necessary care, and serve as a support system. Hospice programs have nurses and other staff members available on a 24-hour, seven day a week basis. Often, staying at home is not an option: there may not be anyone who can function as a caregiver; an elderly spouse may not be capable of the care; the home might not have the necessary space or facilities; or the care needs might be too complicated. When staying at home does not appear to be possible, it is important to seek other programs that are geared to the individual without home support.

Can the patient continue to see his or her own doctor?

Some hospices require the use of their staff doctor, while other hospices maintain a relationship with the patient's physician. It is important to ask this question. The hospice medical director will remain in touch with the patient's physician.

Can the patient use the hospital of his or her choice?

Some hospices require a patient to deal with only one hospital while others care for patients from different hospital settings.

Remember, the driving force behind hospice, is the desire to transform the experience of dying. Today, far too many people die in avoidable pain and distress. In hospices, multi-disciplinary teams strive to offer freedom from pain, dignity, peace and calm at the end of life.

In summary, you will find a range of services in hospices - pain control, symptom relief, skilled nursing care, counseling, complementary therapies, spiritual care, art, music, physiotherapy, reminiscence, beauty treatments and bereavement support. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice.

The hospice philosophy values the basis of respect, choice, empowerment, holistic care and compassion. Hospices care for the whole person, aiming to meet all needs physical, emotional, social and spiritual. They care for the person who is dying and for those who love them, at home, in day care and in the hospice.

IN CLOSING

We hope that you have found some help and hope as you embark on your journey coping with your own cancer or that of someone you love. These pages are only a starting point - it will be up to you and your family and friends to seek out the sources that can provide the information, assistance and support that can make all the difference as you move forward. The New Jersey Commission on Cancer Research, as well as all of the organizations and groups described and listed in this booklet want to help - don't hesitate to ask. We wish you all the best.

LIST OF COMMON MEDICAL ABBREVIATIONS

NPO	Nothing by mouth
p.o.	By mouth - taken orally
IM	Intramuscular - into a muscle
IV	Intravenous - into a vein
sc or sq	Subcutaneous - under the skin
sl	Sublingual - under the tongue

+	one
++	two
+++	three

q.d.	Once every day
q.o.d.	Once every other day
tid	Three times a day
qid	Four times a day
h.s.	At bedtime
q3h	Every 3 hours
q4h	Every 4 hours
q6h	Every 6 hours
Prn	When needed
ac	Before meals
pc	After meals

BP	Blood Pressure
CA	Cancer
CNS	Central nervous system

M.D.	Medical Doctor
O.N.S.	Oncology Nurse Specialist
D.O.	Osteopathic Doctor
R.N.	Registered Nurse
L.P.N.	Licensed Practical Nurse
M.S.W.	Social Worker
O.T.	Occupational Therapist
P.T.	Physical Therapist

Appendix A - Glossary

The terms and definitions listed have been compiled to provide you with a better understanding of words frequently used in cancer care.

A

Acute - A sudden start of symptoms or disease.

Adjuvant therapy - Treatment used in addition to the main treatment. It usually refers to hormonal therapy, chemotherapy, radiation therapy, or immunotherapy added after surgery to increase the chances of curing the disease or keeping it in check.

Adrenal glands - Two small organs near the kidneys that release hormones.

Allogenic - From a donor whose tissue type closely matches the patient's. For leukemia, the patient usually has an allogenic transplant.

Alopecia - The loss of hair, which may include all body hair as well as scalp hair.

Alternative Treatment - The use of unproven remedies alone to the ruling out of standard treatment. A broad term which includes treatment methods which are outside the range of established Western medicine, and refers to treatments that do not have the approval of the United States Food and Drug Administration.

Analgesic - Any drug that relieves pain. Aspirin is a mild analgesic.

Anemia - A condition in which a reduced number of red blood cells may cause symptoms including tiredness, shortness of breath, and weakness.

Angiogenesis (An-JEE-o-gen-i-sis) - The way tumors develop new blood vessels to provide nourishment so they can grow.

Antibodies - A substance formed by the body to help defend it against infection.

Antigen - Any substance that causes the body to produce natural antibodies.

Antineoplastic agent - A drug that prevents, kills, or blocks the growth and spread of cancer cells.

Autologous - Patient's own cells.

B

Benign - Not cancerous; does not invade nearby tissue or spread to other parts of the body.

Biological Therapy - Treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also called immunotherapy.

Biopsy - The removal of sample tissue which is then examined under a microscope to check for cancer cells. When only a sample tissue is removed, the procedure is called incisional biopsy; when the whole tumor is removed, it is called excisional biopsy. Removing tissue or fluid with a needle is called needle biopsy or needle aspiration.

Blood cells - Very small structures produced in the bone marrow; they consist of red blood cells, white blood cells, and platelets.

Blood count - The number of red blood cells, white blood cells, and platelets in a sample of blood.

Bone marrow - The spongy material found inside the bones.

Bone Marrow Transplantation - A procedure in which doctors replace bone marrow that has been destroyed by treatment with high doses of anti-cancer drugs or radiation. The replacement marrow may be taken from the patient before treatment or may be donated by another person. When the patient's own marrow is used, the procedure is called autologous (aw-TOL-o-gus) bone marrow transplantation. When another person donates marrow that is compatible with the patient, it is called allogeneic (al-lo-gen-ic).

Bone scan - A picture of the bones using a radioactive dye that shows any injury, disease, or healing. This is a valuable test to determine if cancer has spread to the bone, if anticancer therapy has been successful, and if affected bony areas are healing.

Breast self-examination (BSE) - A manual self-exam of the breasts.

C

Cancer - A term for disease in which abnormal cells divide without control. Cancer cells can invade nearby tissue and can spread through the bloodstream and lymphatic system to other parts of the body.

Cancer in situ - The stage where the cancer is still confined to the tissue in which it started.

Cancer Survivor - The National Coalition for Cancer Survivorship maintains in its charter: *“From the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor.”*

Carcinogen (kar-SIN-o-jin) - A substance or agent that is known to cause cancer. For example, nicotine in cigarettes is a carcinogen that causes lung cancer.

Carcinogenesis (kar-SIN-o-jin-o-sis) - The steps that lead to cancer. Theories indicate that multiple steps are necessary for a cell to become cancerous including initiation and promotion.

Carcinoma - A cancer that arises from the lining of an organ or system. They are the commonest cancers.

CAT scan or Computerized Axial Tomography (CT scan) - A test using computers and x-rays to create images of various parts of the body.

Catheter (KATH-e-ter) - A thin plastic tube. When a catheter is placed in a vein, it provides a pathway for drugs, nutrients, or blood products. Blood samples can also be removed through the catheter.

Chemoprevention - A strategy to prevent or intervene at a very early stage in the development of cancer through the use of a drug or natural substance.

Chemotherapy - Treatment with anti-cancer drugs.

Chromosomes - Structures in the cell nucleus that are made up of genes; the carriers of heredity.

Chronic - Continue over a long period of time.

Clinical trials - Research studies that involve patients.

Colonoscopy - A process to look at the colon or large bowel through a lighted, flexible tube.

Colony-stimulating factors - Substances that stimulate the production of blood cells. Treatment with colony stimulating factors (CSF) can help the blood-forming tissue recover from the effects of chemotherapy and radiation therapy. These include granulocyte colony stimulating factors (G-CSF) and granulocyte-macrophage colony-stimulating factors (GM-CSF).

Complementary Treatment - The use of non-traditional treatments in combination with approved therapies.

Computerized Axial Tomography (CAT Scan) - Detailed pictures of areas of the body created by a computer linked to an x-ray machine. Also called computerized tomography scan (CT Scan).

Cryosurgery - Use of extreme cold to freeze and destroy cancer cells.

Cyst - A buildup of fluid or semisolid material within a sac.

D

Deoxyribonucleic Acid (DNA) - The information code or blueprint of life; the building blocks of genes.

Diagnosis - Identification of a disease in a person's body.

Differentiation - The development of form, function and specialization in a cell or tissue. Cancer cells range from well differentiated (look close to normal and are less aggressive) to less differentiated (look very different from normal cells and are usually more aggressive).

Drug resistance - The result of cell's ability to resist the effects of a specific drug.

E

Edema - The buildup of fluid in part of the body.

Electrocardiogram (EKG or ECG) - A test that takes recordings of the electrical activity of the heart.

Endoscopy (en-DOS-ko-pee) - A procedure in which the doctor looks inside the body through a lighted tube called an endoscope.

Enzymes (EN-zimes) - Proteins that stimulate cell functions.

Estrogen - A female hormone.

F

Fine-needle aspirate - A method in which a needle is inserted, under local anesthesia, to get hold of a sample for the evaluation of suspicious tissue.

Frozen section - A method in which tissue is removed and then quick-frozen and examined under a microscope by a pathologist.

G

Genes - Units of inherited material made up of DNA.

Gene Therapy - Treatment that changes genes (the basic units of heredity found in all cells in the body). In early studies of gene therapy for cancer, researchers are trying to improve the body's natural ability to fight the disease or to make the tumor more sensitive to other kinds of therapy.

Genetic Information - Information about genes, gene products, or inherited characteristics that may be derived from an individual or family member.

Genome - The complete set of hereditary factors in all the chromosomes of an organism.

H

Hematologist - A doctor who specializes in the problems of blood and bone marrow.

Histology - The microscopic structure of organic tissues. The branch of biology dealing with the study of tissues.

Hodgkin's disease - A cancer that affects the lymph nodes.

Hormones - Chemical produced by the endocrine glands of the body. Hormones control the actions of certain cells or organs.

Hormone Therapy - Treatment that prevents certain cancer cells from getting the hormones they need to grow.

Hospice - A place for supportive care for the terminally ill patient that is based on a philosophy stressing the physical and emotional needs of the patient and family.

I

Immune system - The complex group of cells and organs that defend the body against infection and disease.

Immunosuppression - Weakening of the immune system that causes a lowered ability to fight infection and disease.

Immunotherapy - The artificial stimulation of the body's immune system to treat or fight disease.

Informed Consent - The medical and ethical principle that a patient should only consent to treatment after he/she fully understands the treatment or procedure, his/her rights and all of the medical options.

Interferon - A type of biological response modifier (a substance that can improve the body's natural response to disease). It slows the rate of growth and division of cancer cells, causing them to become sluggish and die.

Interleukins - A type of biological response modifier (a substance that can improve the body's natural response to disease). They stimulate the growth of certain disease-fighting blood cells in the immune system.

L

Lesion - A lump or abscess that may be caused by injury or disease, such as cancer.

Leukemia - Cancer of the blood. White blood cells may be produced in excessive amounts and are unable to work properly.

Lumpectomy - Removal of the lump and a small amount of surrounding breast tissue.

Lymph - An almost colorless fluid that travels through the lymphatic system and carries cells that help fight infection and disease.

Lymph nodes - Small, bean shaped organs located along the channels of the lymphatic system, also called lymph glands.

Lymphatic system - The tissues and organs, including the bone marrow, spleen, thymus, and lymph nodes, that produce and store cells that fight infection and disease. This system also has channels that carry lymph.

Lymphoma - A cancer of the lymphatic system. Doctors differentiate the different lymphomas by the type of cell that is involved in the makeup of the tumor. Treatments depend on the type of cell that is seen.

M

Magnetic Resonance Imaging (MRI) - A procedure using a magnet linked to a computer to create pictures of areas inside the body.

Malignant (ma-LIG-nant) - Cancerous.

Mammogram (mammography) - A low-dose x-ray / picture of the breasts to determine whether abnormal growths or cysts are present.

Mastectomy - The surgical removal of the breast.

Melanoma - A cancer of the pigment-forming cells of the skin or the retina of the eye.

Metastasis (ma-TAS-te-sis) - The spread of cancer from one part of the body to another. Cells in the metastatic (secondary) tumor are like those in the original (primary) tumor.

Monoclonal Antibodies - Substances that can locate and bind to cancer cells wherever they are in the body. They can be used alone, or they can be made to deliver drugs, toxins, or radioactive material directly to the tumor cells.

Mutation - A change in the cell that is permanent and can be passed on to offspring.

N

Nausea - The feeling of sickness.

Neoplasm - Any abnormal growth of cells or tissues. May be benign or malignant but the term usually is referring to a cancerous growth.

Non-Hodgkin's lymphoma - A cancer of the lymphatic system. Non-Hodgkin's lymphoma is related to Hodgkin's disease but is made up of different cell types.

Nucleus - The part of the cell that holds most of the DNA and other organelles that control the cell.

O

OCN (Oncology certified nurse) - A registered nurse who has met the requirements and successfully completed a certification examination in oncology.

Oncogenes - Genes in the cell, that when switched on, cause abnormal cell growth and division.

Oncologist - A doctor who specializes in treating cancer. A radiotherapist specializes in treating cancer with radiation, and a medical oncologist specializes in treating cancer with drugs.

Oncology - The study and treatment of cancer.

Orally - Given by mouth.

P

Palliative treatment - Treatment aimed at the relief of pain and symptoms of disease but not intended to cure the disease.

Pap (Papanicolaou) smear - A test to detect cancer of the cervix.

Pathologist - A doctor who identifies diseases by studying cells and tissue under a microscope.

Pathology - The study of disease by the examination of tissues and body fluids under the microscope.

Peripheral stem cell support (per-IF-er-ul) - A method of replacing blood-forming cells destroyed by cancer treatment. Certain cells (stem cells) in the blood that are similar to those in bone marrow are removed from the patient's blood before treatment. The cells are given back to the patient after treatment.

Placebo - A mock-up substance often used in clinical trials for comparison.

Primary tumor - The original cancer site. For example, breast cancer that has spread to the bone is still called breast cancer.

Progesterone (pro-JES-ter-own) - A female hormone.

Prognosis - The probable outcome or course of a disease; the chance of recovery.

Proteins - Combinations of amino acids (the basic building blocks of life that make up DNA) that carry out most of the work needed to live.

Protocol - A carefully thought out and well organized treatment plan.

PSA (Prostate-specific antigen) - A marker used to determine prostate disease; it may be benign or malignant.

R

Radiation therapy - Treatment with high-energy rays to kill or damage cancer cells. External radiation therapy is the use of a machine to aim high energy rays at the cancer. Internal radiation therapy is the placement of radioactive material inside the body as close as possible to the cancer.

Radioactive - Giving off radiation.

Radiologist - A doctor who specializes in the use of x-rays.

Radionuclide scanning - An examination that produces pictures (scans) of internal parts of the body. The patient is given an injection or swallows a small amount of radioactive material. A machine called a scanner then measures the radioactivity in certain organs.

Randomized - In a clinical trial, eligible patients (those that meet the strict criteria of the research project) are randomly placed in one of the treatment plans so that the study is not biased.

Recurrence - The reappearance of a disease after a period of remission.

Regression - The shrinkage of cancer growth.

Relapse - The reappearance of a disease after its apparent cessation.

Remission - Disappearance of the signs and symptoms of cancer. When this happens, the disease is said to be **“in remission.”** Remission can be temporary or permanent.

Risk factor - Something that increases a person’s chance of developing a disease.

S

Sarcoma - A malignant tumor of muscles or connective tissue such as bone and cartilage.

Side effects - Problems that occur when treatment affects healthy cells.

Sigmoidoscopy (sig-moy-DOS-ko-pee) - A procedure in which the doctor looks inside the rectum and lower part of the colon (sigmoid colon) through a lighted tube. The doctor may collect samples of tissue or cells for closer examination. Also called proctosigmoidoscopy.

Sperm banking - Freezing sperm before cancer treatment for use in the future. This procedure can allow men to father children after the loss of fertility.

Stage - The extent of cancer, especially whether the disease has spread from the original site to other parts of the body.

Standard therapies - The measures or steps taken to treat a disease.

Stem Cells and Stem Cell Transplant - A variation of bone marrow transplantation in which immature blood cells called stem cells are taken from the patient's blood and later, in the lab, stimulated with growth factors to produce more stem cells which are returned to the patient by transfusion.

Systemic disease - A disease that affects the entire body instead of a specific organ.

T

Testicular self-examination (TSE) - A simple manual self-examination of the testes.

Tissue - A group or layer of cells that together perform a specific function.

Toxins - Poisons produced by certain animals, plants or bacteria.

Tumor - A mass of excess tissue with no useful bodily function.

Tumor markers - Substances found in abnormal amounts in the blood, in other body fluids, or in tumor tissue of some patients with certain types of cancer.

Tumor suppressor genes - Genes that constrain cell growth. These genes act as brakes on the growth of malignant cells.

U

Ultrasound/Ultrasonography - An examination in which sound waves are bounced off tissues and the echoes are converted into a picture (sonogram).

V

Virus - A tiny infectious agent that is smaller than bacteria.

W

White blood cells - Cells that help the body fight infection and disease.

X

X-rays - High-energy radiation used in low doses to diagnose disease or injury, and in high doses to treat cancer.

Appendix B - Cancer Resources

THE INTERNET

The growing popularity of the Internet has made it easier and faster to find health information. You may search a wide variety of sites to obtain current medical information, listings of available research studies and a broad range of online patient support services. Much of this information is valuable; however, the Internet also allows rapid and widespread distribution of false and misleading information. With the proliferation of numerous Web sites, it is important to consider the source of the information to evaluate the quality of these sites. The most important feature of a good web site is its content. Government or University run sites, without marketing, social or political agendas, are usually good sources for scientific and medical information. A good site should also link to other sources of health related information and should be updated on a regular basis. A wise consumer will cross check information carefully with other reputable sources. Also, do not be afraid to talk to your health care team about such information. The National Cancer Institute provides an excellent fact sheet on “How to Evaluate Health Information on the Internet: Questions and Answers” (http://cis.nci.nih.gov/fact/2_10.htm). Also, remember that even if you do not have a computer, your local library may provide access to the Internet through public terminals. Linkages to other sites are also possible through these websites.

SELECTED CANCER RELATED WEB SITES & CONTACT INFORMATION

Government Sites

Centers for Disease Control and Prevention (www.cdc.gov)- Provides on-line access to the Morbidity and Mortality Weekly Report, to CDC WONDER (a single point of access to CDC reports, guidelines, and published health data) and to the National Center for Health Statistics. Phone: 800-311-3435.

Equal Employment Opportunities Commission (www.eeoc.gov) -

With its headquarters in Washington, D.C., and through the operations of 51 field offices nationwide, EEOC coordinates all federal equal employment opportunity (EEO) regulations, practices and policies. The Commission interprets employment discrimination laws, monitors and conducts hearings in the federal sector employment discrimination program, sponsors outreach and technical assistance programs, and provides funding and support to state and local Fair Employment Practices Agencies (FEPAs) charged with enforcing anti-discrimination laws on state and local levels.

Phone: 1-800-669-EEOC.

National Cancer Institute (NCI) Information Center

(www.cancer.gov) Provides the latest and most accurate cancer information to patients, their families, the public, and health professionals. Provides on-line access to the National Cancer Institute's CancerNet resource database and information on cancer trials in English or Spanish.

Phone: 1-800-4-CANCER.

NCI - Office of Cancer Survivorship (<http://survivorship.cancer.gov>)-

The mission of the Office of Cancer Survivorship (OCS) is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship.

Phone: 1-301-402-2964.

NCI - PDQ or the Physician Data Query

(http://www.cancer.gov/search/clinical_trials) - A comprehensive database produced by the National Cancer Institute, that contains the latest information about cancer treatment, screening, prevention, genetics, and supportive care, plus clinical trials. Phone: 1-800-4-CANCER.

National Center for Complementary and Alternative Medicine

(<http://nccam.nih.gov/>) - One of 27 institutes and centers that make up the National Institutes of Health (NIH) dedicated to exploring complementary and alternative healing practices in the context of rigorous science, training complementary and alternative medicine (CAM) researchers, and disseminating authoritative information to the public and professionals.

Phone: 1-888-644-6226.

National Institutes of Health (www.nih.gov) - Provides on-line information about cancer through the National Cancer Institutes CancerNet resource; access to PDQ (physician data query) information summaries on treatment, supportive care, screening and prevention, and investigational drugs; on-line access to the NIH Guide to Grants and Contracts; access to on-line scientific journals; links to 24 separate NIH Institutes, Centers and Divisions. **Phone: 301-496-4000.**

New Jersey Commission on Cancer Research

(www.njccr.com) - Mission is to ensure that the citizens of New Jersey receive the fullest benefit of our nation’s fight against cancer through the promotion and funding of research into the causes, prevention, and treatment of cancer. **Phone: 609-631-4747.**

New Jersey Department of Health & Senior Services

(www.state.nj.us/health) - Mission is to foster accessible and high-quality health and senior services to help all people in New Jersey achieve optimal health, dignity and independence. Work to prevent disease, promote and protect well-being at all life stages and encourage informed choices that enrich quality of life for individuals and communities.

General Phone:

(609)292-7837

SENIOR Hot Lines:

NJ EASE

(877) 222-3737

Pharmaceutical Assistance

to the Aged and Disabled (PAAD):

(800) 792-9745

New Jersey Family Care:

(800) 701-0710

Cancer Initiatives in the NJ Department of Health and Senior Services. The Center for Cancer Initiatives contains four units:

Cancer Epidemiology Services (CES) is responsible for the New Jersey State Cancer Registry, collection and analysis of cancer statistics, cancer patterns and trends, and cancer research activities.

New Jersey Cancer Education and Early Detection Program (NJCEED) provides breast, cervical, colorectal and prostate cancer education, outreach, screenings, case management and follow-up services to low-income, uninsured and underinsured residents of the state.

New Jersey Commission on Cancer Research (NJCCR) was established in 1983 to promote and fund innovative cancer research into the causes,

prevention and treatment of cancer, and to bring the benefits of such research to patients in New Jersey through education and outreach.

The Office of Cancer Control and Prevention (OCCP) is dedicated to implementing the New Jersey Comprehensive Cancer Control Plan by coordinating statewide and local activities designed to reduce the incidence, illness and death due to cancer in New Jersey.

Center for Cancer Initiatives

Cancer Education and Early Detection Service (CEED):

(800) 328-3838 (*Screening Services*)

Office of Cancer Epidemiology:

(609) 588-3500

Office of Cancer Control and Prevention:

(609) 588-5038

New Jersey Commission on Cancer Research:

(609) 631-4747

Social Security Offices (www.socialsecurity.gov) - SSI, or Supplemental Security Income, is a federal program that provides monthly cash payments to people in need. SSI is for people who are 65 or older, as well as for blind or disabled people of any age, including children. **Phone: 1-800-772-1213.**

Surveillance, Epidemiology, and End Results (SEER) Program (<http://seer.cancer.gov/>) of the National Cancer Institute is an authoritative source that collects and publishes cancer incidence and survival data from 11 population-based cancer registries and three supplemental registries covering approximately 14 percent of the US population. **Phone: 1-800-4-CANCER.**

United States Department of Justice (www.usdoj.gov) - Information about employment discrimination. **Phone: 1-800-541-0301.**

United States Department of Labor (www.dol.gov) - Information about your rights under the Federal Rehabilitation Act. **Phone: 202-514-3933.**

United States Food & Drug Administration (www.fda.gov) - provides on-line information about new drugs in development. **Phone: 1-888-INFO-FDA.**

NCI DESIGNATED CANCER CENTERS

The following centers have been designated by the National Cancer Institute as either clinical or comprehensive cancer centers. They are engaged in multi disciplinary research efforts and a wide range of NCI approved clinical trials.

NEW JERSEY:

The Cancer Institute of New Jersey

195 Little Albany Street
New Brunswick, NJ 08901

Phone: 732-235-6777

comprehensive

Memorial Sloan Kettering Cancer Center at Basking Ridge

136 Mountain View Boulevard
Basking Ridge, NJ 07920

Phone: 908-542-3400

comprehensive

NEW YORK:

Memorial Sloan Kettering Cancer Center

1275 York Avenue
New York, NY 10016

Phone: 800-525-2225

comprehensive

Kaplan Cancer Center

New York University Medical Center
550 First Avenue
New York, NY 10016

Phone: 212-236-6485

Herbert Irving Cancer Center

Columbia Presbyterian Medical Center
550 First Avenue
New York, NY 10032

Phone: 212-305-8610

PHILADELPHIA:

Fox Chase Cancer Center

7701 Burholme Avenue
Philadelphia, PA 19111

Phone: 215-728-6900

comprehensive

Kimmel Cancer Center

Thomas Jefferson University
1025 Walnut Street
Philadelphia, PA 19107

Phone: 215-503-4500

clinical

University of Pennsylvania Cancer Center

3400 Spruce Street
Philadelphia, PA 19104-4383

Phone: 800-383-8722

comprehensive

CANCER RELATED ORGANIZATIONS

Aging With Dignity: (www.agingwithdignity.org) - A nonprofit group that provides information and tools to draft health directives. This group publishes - Five Wishes - a 12 page living will document that prompts individuals to consider five questions and issues: who your health-care agent should be; what kind of medical treatment you want in various situations; how comfortable you want to be; how you want people to treat you and what you want your loved ones to know. **Phone 1-888-594-7437.**

American Association for Cancer Research: (www.aacr.org)

A scientific society of over 21,000 laboratory and clinical cancer researchers, was founded in 1907 to facilitate communication and dissemination of knowledge among scientists and others dedicated to the cancer problem; to foster research in cancer and related biomedical sciences; to encourage presentation and discussion of new and important observations in the field; to foster public education, science education, and training; and to advance the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world. **Phone 215-440-9300.**

American Cancer Society Web Site: (www.cancer.org) - A nationwide,

community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service. Web site provides information about cancer as well as information about the American Cancer Society, its publications, programs and local offices. **Phone 1-800-ACS-2345.**

BBB Wise Giving Alliance (www.give.org)- A non-profit organization that monitors and ranks national charitable organizations. They can also be reached by USPS 19 Union Square West, New York, NY 10903-3395 or call (212) 929-6300.

Black Health Net (www.blackhealthnetwork.com)- Provides information through a search engine on health for African-Americans. Provides a means for patients to locate a minority physician near the area closest to their home.

CancerCare Web Site (<http://www.cancercare.org/>)- A national non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance. **Phone 1-800-813-HOPE.**

Cancer Hope Network (www.cancerhopnetwork.org) - a not-for-profit organization that provides free and confidential one-on-one support to cancer patients and their families. **Phone 877-HOPENET.**

CARESOURCE (www.caresource.com) - Caresource is a full service healthcare information and communications company with a top-rated team of communications and publishing professionals specializing in health care and aging services. **Phone 1-800-448-5213.**

Cancer Trial Connect - New Jersey (www.njctc.org) - New Jersey Cancer Trial Connect is a web-based cancer clinical trials matching service created to help you find innovative research trials, at your fingertips. **Phone 1-866-788-3929.**

Center Watch: Clinical Trials Listings (www.centerwatch.com)- provide information services used by patients, pharmaceutical, biotechnology and medical device companies, CROs and research centers involved in clinical research around the world. **Phone 617-856-5900.**

Coalition of National Cancer Cooperative Groups, Inc. (www.cancertrials-help.org) - The Coalition of National Cancer Cooperative Groups, Inc. is a national premier network of cancer clinical trials specialists. The coalition was created to address serious issues facing the cooperative groups, such as improving the clinical trials experience for patients and physicians, regulatory requirements, and providing professional support services. **Phone 1-877-520-4457.**

Gilda's Club (<http://www.gildasclub.org>) - A special place where the focus is on living with cancer. And where men, women and children with any kind of cancer and their family members and friends can plan and build life-changing emotional and social support. **Phone 1-888-GILDA-4U.**

HelpingPatients.org (www.helpingpatients.org) - A web site by PhRMA and 48 of its member companies, which is designed to help you find patient assistance programs for which you may qualify. Patient assistance programs can help patients receive assistance in acquiring their needed medicines. This online service is free and completely confidential.

National Charities Information Bureau (www.give.org) - Non-profit organization that monitors and rank national charitable organizations. They can also be reached by USPS, 19 Union Square West, New York, NY 10903-3395 or call 212-929-6300.

National Childhood Cancer Foundation Web Site (www.nccf.org) Dedicated to reducing the devastating impact of cancer on infants, children, adolescents and young adults by supporting clinical and laboratory research on cancer causes, treatments, and cures, and by education and advocacy for the needs of children with cancer and their families. **Phone 1-800-458-6223.**

National Coalition of Cancer Survivors

(<http://www.canceradvocacy.org/>) - Survivor-led advocacy organization working exclusively on behalf of people with all types of cancer and their families, advocates for quality cancer care for all Americans. **Phone 301-650-9127.**

New Jersey Hospital Association (www.njha.com) - publishes a Woman's Resource Guide to Breast Cancer Services in New Jersey, as well as other useful information. **Phone 609-275-4000.**

ONCOLINK (<http://www.oncolink.org>) - Helps cancer patients, families, health care professionals and the general public get accurate cancer-related information at no charge. Provides comprehensive information about specific types of cancer, updates on cancer treatments and news about research advances.

The Patient Advocate Foundation Co-Pay Relief program (www.patientadvocate.org) is a co-payment assistance program for insured

Americans. The PAF CPR is a program offered through Patient Advocate Foundation, a 501(c) 3 non-profit organization which provides professional case management services to Americans with chronic, life threatening and debilitating illnesses. **Phone 866-512-3861.**

Pharmaceutical Research and Manufacturers of America (PhRMA) (www.phrma.org) - The PhRMA represents the country's leading research-based pharmaceutical and biotechnology companies, which are devoted to inventing medicines that allow patients to live longer, healthier, and more productive lives.

Rx4NJ (www.rx4nj.org) - Rx4NJ is a voluntary partnership formed to help people all across New Jersey gain access to free and low-cost prescription medicine programs. The coalition is led by a wide range of patient advocacy and community organizations and New Jersey's pharmaceutical and medical technology industry. **Phone 1-888-RXFORNJ.**

U.S. Living Will Registry (www.uslivingwillregistry.com) - Will store an electronic version of your health-care directive and provide copies as needed, 24 hours a day, to health-care providers anywhere in the country. There's no charge for the service. **Phone 1-800-548-9455.**

Wellness Community of Central New Jersey (www.thewellnesscommunity.org/cnj) - is located in Bedminster New Jersey and is part of a national organization that provides support, education, and hope to people with cancer and their loved ones. Through participation and free classes, people affected by cancer learn vital skills that enable them to regain control, reduce isolation and restore hope regardless of the stage of their disease. **Phone 908-658-5400.**

WEBSITES FOR SPECIFIC TYPES OF CANCERS ---

Brain Tumors

American Brain Tumor Association (ABTA) (www.abta.org) Provides publications, support group lists, physician lists, pen pal program and social service consultation by telephone. **Phone 1-800-886-2282.**

National Brain Tumor Foundation (NBTF) (www.braintumor.org)

Provides patients and family with information on how to cope with having a brain tumor. Phone 1-800-934-CURE.

Breast Cancer

AVON Breast Cancer Crusade (www.avoncrusade.com) - The Avon Foundation is funding the fight against breast cancer through this unique multifaceted initiative. Knowing that breast cancer is the most commonly diagnosed cancer among women, the goal of the Avon Foundation Breast Cancer Crusade is to benefit all women through research, clinical care, education and support services. Phone 1-866-505-AVON.

Breast Cancer Resource Center (www.bcrcnj.org) - The Breast Cancer Resource Center (BCRC) at the YWCA Princeton is dedicated to increasing breast cancer awareness in the community, and to provide information and emotional support to those affected by breast cancer. Programs and services are free and include breast cancer awareness talks, an educational seminar, a guest speaker series, a lending library, a telephone hotline, support groups, a woman-to-woman telephone network, a wellness program and a prosthesis & wig bank. Phone 609-497-2126 or toll free 1-866-497-3507.

Inflammatory Breast Cancer Research Foundation

(www.ibcresearch.org) The Inflammatory Breast Cancer Research Foundation is dedicated to the advancement of research of inflammatory breast cancer (IBC), leading to finding its causes and increasing the effectiveness of its treatment. Increasing awareness of IBC symptoms, leading to earlier and better clinical methods of detection and diagnosis, is the other principal activity to which the foundation is dedicated.

Phone 1-877-stop-ibc (1-877-786-7422).

Men Against Breast Cancer (www.menagainstbreastcancer.org)

A national organization whose mission is to target and mobilize men to be active in the fight to eradicate breast cancer. Phone 1-866-547-MABC.

National Breast Cancer Coalition Internet Web Site

(www.natlbcc.org) - The nation's largest breast cancer advocacy group.

Committed to ending breast cancer, NBCC, work to educate and train individuals to be effective activists and to influence the public policies that affect breast cancer research and treatment. **Phone 202-296-7477.**

National Alliance of Breast Cancer Organizations (NABCO)

(www.nabco.org/support.htm or www.nabco.org) - Is the leading non-profit information and education resource on breast cancer in the U.S. A network of organizations that provide information, assistance and referrals
Phone 1-800-719-9154, Phone 1-800-986-9595.

National Breast Cancer Foundation (www.nationalbreastcancer.org)

Provides Information about early detection, symptoms and cancer news for patients and caregivers.

Sisters Network, Inc (www.sistersnetworkinc.org) - Focuses on increasing local and national attention to the impact that breast cancer has in the African American community. **Phone 1-866-781-1808.**

South Jersey Breast Cancer Coalition - (www.southjerseybcc.org)

The SJBCC provides breast cancer information and education, increases public awareness through outreach efforts, and improves access to cancer screenings, diagnosis, treatment, care and clinical trials through legislation and regulation. **Phone 856-768-9028.**

The Susan G. Komen Breast Cancer Foundation (www.komen.org)

Global leader in the fight against breast cancer through its support of innovative research and community-based outreach programs. **Helpline 1-800-I'M AWARE (1-800-462-9273)** Northern NJ Affiliate 908-277-2904 Central/South NJ Affiliate 609-896-1204.

Y-ME National Breast Cancer Organization Web Site

(www.y-me.org) - Provides 24 hour national hotline for women with breast cancer and their families, as well as educational materials, support groups and workshops so that no one faces breast cancer alone.

Phone 1-800-221-2141.

Young Survival Coalition (www.youngsurvival.org) - Survivors and supporters dedicated to the issues of woman under 40 who are diagnosed with breast cancer. **Phone 1-212-916-7667.**

Childhood Cancer

Candlelighters Childhood Cancer Family Alliance (www.candle.org)

A national non-profit organization whose mission is to educate, support, serve, and advocate for families of children with cancer, survivors of childhood cancer, and the professionals who care for them.

Phone 800-366-2223.

Children's Catastrophic Illness Relief Fund Commission - To obtain information about financial assistance for families who have extraordinary uninsured medical expenses for children with acute or chronic illness. Phone 1-800-335-FUND(3863).

Children's Hospice International (www.chionline.org) - Lists hospices that will accept children as patients. Phone 708-684-0330.

Emmanuel Foundation - Provides in-home counseling support for children with cancer and their families. Regional Directors from six locations throughout the state and case workers insure that ECF children and families receive emotional and material support (food, clothing, toys and even appliances) and in some cases emergency financial assistance. For more information visit our website at: www.emmanuelcancer.org or call 908-322-4323.

Kristina's Rainbows of Hope (www.kristinasrainbowsofhope.org) Dedicated to creating public awareness for childhood cancers and blood disorders, offering hope and support to children and families that are presently coping with a diagnosis of cancer, and funding research to find the cure for these life-threatening illnesses.

Colorectal Cancer

Colorectal Cancer Network (www.colorectal-cancer.net) - A national advocacy group that raises public awareness about colorectal cancer and provides support to patients with colorectal cancer. Support groups, e-mail and Internet information is provided, as well as a service that connects patients with long-term survivors. Phone 301-879-1500.

Untied Ostomy Association, Inc. (www.uoa.org) Aimed at supporting patients by providing information to patients and the public. Volunteers are available to visit new ostomy patients.

Phone 1-800-826-0826 (6:30 - 4:30 pm EST).

Lung Cancer

Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE) (www.alcase.org) - Offers programs aimed at improvement of quality of life for patients with lung cancer and their families. Education, psychosocial support and advocacy are some of the programs provided.

Phone 1-800-208-2436.

It's Time to Focus on Lung Cancer (www.lungcancer.org) Offers education, resources, clinical trial information, support groups, teleconferences, news updates and newsletter. Phone 1-800-646-5864.

Lung Cancer Circle of Hope (www.lungcancercircleofhope.org) - To eradicate the myths surrounding lung cancer through educational symposia directed at the public, health officials and public policy makers; to be a resource in NJ for patients, their families and those at risk. 732-363-4426

Lymphoma, Leukemia and Myeloma

International Myeloma Foundation (IMF) (www.myeloma.org)

Supports education, treatment and research for multiple myeloma. A toll-free hotline is available as well as educational sessions and materials for patients and family members. Phone 1-800-452-2873.

Lymphoma Research Foundation (LRF) (www.lymphoma.org)

Provides educational information about lymphoma and a hotline. Referrals to other resources such as clinical trials and support groups are available. Phone 1-800-500-9976.

The Leukemia and Lymphoma Society

(www.leukemia-lymphoma.org) Provides patients with leukemia, lymphoma, Hodgkin's disease or multiple myeloma with potential financial aid for specified treatment expenses and transportation, family support groups and school re-entry materials.

Phone 1-800-955-4572,

Northern New Jersey 908-654-9445,
Southern New Jersey/Shore Region 888-920-8557

Ovarian Cancer

National Ovarian Cancer Coalition (NOCC) (www.ovarian.org)

Raises awareness about ovarian cancer and promotes education. Support groups and specialized physician database is available.

Phone 1-800-682-7426

Ovarian Cancer National Alliance (OCNA) (www.ovarian.org)

Distributes educational materials and sponsors an annual advocacy conference for survivors and families. Phone 1-202-331-1332.

SHARE: Self-help for Women with Breast or Ovarian Cancer

(www.sharecancersupport.org) - Provide support groups, educational forums, wellness programs, events, newsletter, and a toll-free hotline.

Phone 1-866-891-2392.

Pancreatic Cancer

Pancreatic Cancer Action Network (www.pancan.org) - A non-profit advocacy organization that educates health professionals and general public about pancreatic cancer. Information about support networks, clinical trials and reimbursement for care are also available. Phone 1-877-272-6226.

Prostate Cancer

National Prostate Cancer Coalition Internet Site (www.4npcc.org)

Dedicated to ending the devastating impact of prostate cancer on men, families and society through awareness, advocacy and outreach.

Phone 202-463-9455.

Prostate Cancer Coalition of New Jersey (www.pcc-nj.org)

PCCNJ is a private non-profit organization committed to eliminating suffering and death from prostate cancer for all New Jersey men and their families. It seeks to do this by increasing public awareness, education and outreach; improving the quality of life of those affected by prostate cancer; increasing research and funding; eliminating disparities in highrisk populations and mobilizing advocates for a cure. E-mail contactus@pcc-nj.org

Prostate Cancer Foundation

(<http://www.prostatecancerfoundation.org>) - The Prostate Cancer Foundation (PCF) is the world's largest philanthropy supporting prostate cancer research. PCF was founded in 1993 with an urgent mission: to find better treatments and a cure for advanced prostate cancer.

Phone 1-800-757-CURE.

Us Too Prostate Cancer Education and Support

(<http://www.ustoo.com>) - Provides information, counseling and educational meetings to assist men with prostate disease (and their spouses /partners) in making decisions about their treatment with confidence and support.

Phone 1-800-808-7866.

APPENDIX C
NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES
NEW JERSEY CANCER EDUCATION AND EARLY DETECTION

ATLANTIC COUNTY

Marge Scanny-Proj. Coord.

Shore Memorial Hospital
1 E. New York Avenue
Somers Point, NJ 08244

Contact: Bobbi Nevin/Sandra Dutra

Phone: (609) 653-3484

Fax: (609) 653-3699

BERGEN COUNTY

Elizabeth Burton-Proj. Coord

Bergen Cty. Dept of Hlth Svcs.
327 Ridgewood Avenue
Paramus, NJ 07652

Phone: (201) 634-2660

Fax: (201) 986-1068

BURLINGTON COUNTY

Calvin James-Proj. Coord

Burlington County Health Dept.
Raphael Meadow Health Center
15 Pioneer Blvd. PO Box 6000
Westampton, NJ 08060

Contact: Kelly Lathrop

Phone: (609) 267-1953

Fax: (609) 265-1382

CAMDEN COUNTY

Evelyn R-Rodriguez-Proj. Coord

Cooper Hospital/Univ/Med/Center
3 Cooper Plaza, Suite 220
Camden, NJ 08103

Contact: Lillian Ubarry-Rivera

Phone: (856) 968-7308

Fax: (856) 338-0628

Joan Lombardi-Proj. Coord

Virtua Health
6 East Clementon Road, Suite F-1
Gibbsboro, NJ 08026

Phone: 1-888-VIRTUA-3

Fax: (856-355-6161

CAPE MAY COUNTY

Carol Porter-Proj. Coord

Cape May County Health Dept.
4 Moore Road
Cape May Court House, NJ 08210

Contact: Diane Notorfrancesco

Phone: (609) 465-1200

Fax: (609) 465-3527

CUMBERLAND COUNTY

Carol Treston-Proj. Coord.

SJH Bridgeton Health Center
333 Irving Avenue
Bridgeton, NJ 08302

Contact: Christine White

Phone: (856) 575-4434

Fax: (856) 575-4428

ESSEX COUNTY

Catherine Marcial-Proj. Coord

SAVE Program
UMDNJ-NJ Medical School
Stanley Bergen Bldg. Suite GA 207
65 Bergen Street
Newark, NJ 07103

Phone: (973) 972-7007

Fax: (973) 972-2290

Aretha Hill-Forte-Proj. Coord

St. Michael's Medical Center
268 Dr. Martin Luther King Jr. Blvd.
Newark, NJ 07102

Contact: Contina Gray

Phone: (973) 877-2987

Fax: (973) 877-5215

GLOUCESTER COUNTY

Helene Lynch-Proj Coord.

Underwood Memorial Hospital
509 N. Broad Street
Woodbury, NJ 08096

Contact: Mary Ann Basileo

Phone: (856) 686-5036

Fax: (856) 251-0383

HUDSON COUNTY

Elsa Arellano Proj. Coord

Metropolitan Family Health Network
935 Garfield Avenue
Jersey City, NJ 07304
Phone: (201) 478-5800 Ext. 5882
Fax: (201) 946-6489

Edna Velez/Richard Ward Proj Coord

Hoboken Family Planning
Second and Grand Streets
Hoboken, NJ 07030
Phone: (201) 963-0300
Fax: (201) 963-0303

HUNTERDON COUNTY

Jacqueline Allen-Proj. Coord

Hunterdon Regional Cancer Center
2100 Wescott Drive
Flemington, NJ 08822
Contact: Marge Vellotti
Phone: (908) 237-5409
Fax: (908) 788-6106

MERCER COUNTY

Linda Johnson-Proj. Coord

Capital Health System-Mercer
446 Bellevue Avenue
PO Box 1658
Trenton, NJ 08618
Contact: Jackie Petronie
Phone: (609) 394-4045
Phone: (609) 599-5382 (Spanish)
Fax: (609) 394-4046

MIDDLESEX COUNTY

Michele Canfield-Proj. Coord

Middlesex County Public Hlth. Dept.
75 Bayard Street, 5th Floor
New Brunswick, NJ 08901
Contact: Connie Menafro
Phone: (732) 745-3127
Phone: (732) 745-3107 (Spanish)
Fax: (732) 745-2568

MONMOUTH COUNTY

Nina Goossens-Proj. Coord

VNA of Central Jersey
176 Riverside Drive
Red Bank, NJ 07701
141 Bodman Place (Mail Address)
Red Bank, NJ 07701
Contact: Celise Hayward
Phone: (732) 224-6723
Fax: (732) 224-0843

MORRIS COUNTY

Martha Lehlbach-Proj. Coord.

Breast and Cervical Cancer
Screening Program
Morristown Memorial Hospital
100 Madison Ave, Box 18
Morristown, NJ 07962-1956
Contact: Jigisha Kotheri
Phone: (973) 971-5870 (English)
Contact: Laura Sanango
Phone: (973) 971-5707 (Spanish)
Fax: (973) 290-7138

OCEAN COUNTY

Karen Purcell-Proj. Coord

Center for Women's Health
Community Medical Center
99 Route 37 West
Toms River, NJ 08755
591 Lakehurst Road (Mail Address)
Toms River, NJ 08755
Contact: Susan Putkowski
Phone: (732) 341-1400 (English)
Phone: (732) 557-3207 (Spanish)
Fax: (201) 557-3209

PASSAIC COUNTY

Debbie Delesantro-Proj. Coord

St. Joseph's Hospital & Med. Center
703 Main Street
Paterson, NJ 07503
Contact: Jessica Cardenas
Phone: (973) 754-2778
Fax: (973) 754-2707

Jacqueline Williamson-Webb-Proj. Coord.

PBI Regional Medical Center
350 Boulevard
Passaic, NJ 07055
Contact: Graciela Vega
Phone: (973) 365-4356
Fax: (973) 365-4695

SALEM COUNTY

Marilyn Bickle-Proj. Coord.

Salem County Department of Health
98 Market Street
Salem, NJ 08079-1995
Contact: Dorothy Robinson
Phone: (856) 935-7510 Ext. 8474
Fax: (856) 935-8477

SOMERSET COUNTY

Erica Saliu-Proj. Coord

Women's Health & Counseling Center

71 Fourth Street

Somerville, NJ 08876

Contact: Sandra Chalarea

Phone: (908) 526-2335 (Ext. 110)

Fax: (908) 725-7274

SUSSEX COUNTY

Pam Geiger-Proj. Coord.

St. Clare's Hospital-Sussex

20 Walnut Street- Linn House

Sussex, NJ 07461

Phone: (973) 702-2740

Fax: (973) 702-2633

UNION COUNTY

Kimberly Best-Parris-Proj. Coord

Plainfield Health Center

1700-58 Myrtle Avenue

Plainfield, NJ 07063

Phone: (908) 753-6401Ext. 192

Fax: (908) 753-6278

WARREN COUNTY

Sue Pappas-Proj. Coord.

Warren Hospital-Health Education

185 Roseberry Street

Phillipsburg, NJ 08865-1629

Contact: Tawny Youtz/Sarah Price

Phone: (908) 859-6757

Fax: (908) 859-6848

Appendix D - NEW JERSEY HOSPICES

ATLANTIC COUNTY

Atlantic City Medical Center Hospice

PO Box 1626
Pleasantville, NJ 08232
(609) 272-2424

Samaritan Hospice

5 Eves Drive, Suite 300
Marlton, NJ 08053
(800) 229-8183

BERGEN COUNTY

Hospice Program of Hackensack University Medical Center

30 Prospect Avenue
Hackensack, NJ 07601
(201) 342-7766

Hospice of Bergen Community Health Care

400 Old Hook Road, Suite G-6
Westwood, NJ 07675
(201) 358-2900

Valley Hospice

15 Essex Road
Paramus, NJ 07652
(201) 291-6000

BURLINGTON COUNTY

Caring Hospice

133 Gaither Drive
Mount Laurel, NJ 08054
(856) 439-0012

Samaritan Hospice

5 Eves Drive, Suite 300
Marlton, NJ 08053
(800) 229-8183

CAMDEN COUNTY

Lighthouse Hospice

4 Executive Campus, Ste 101
771 Cuthbert Blvd
Cherry Hill, 08002
(856) 661-5600

Compassionate Care Hospice

58 Mill Street
Mt. Holly, NJ 08060
(609) 267-1178
1-800-844-4774

Samaritan Hospice

5 Eves Drive, Suite 300
Marlton, NJ 08053
(800) 229-8183

CAPE MAY COUNTY

Holy Redeemer Visiting Nurses

1801 Route 9 North
Swainton, NJ 08210
(609) 465-2082

Samaritan Hospice

5 Eves Drive, Suite 300
Marlton, NJ 08053
(800) 229-8183

CUMBERLAND COUNTY

Hospice Care of South Jersey

2848 South Delsea Drive
Vineland, NJ 08360
(856) 794-1515

Trinity Hospice

226 W. Landis Ave, 2nd Floor
 Vineland, NJ 08360
 1-800-255-8986

ESSEX COUNTY**The Center for Hospice Care**

187 Millburn Avenue
 Millburn, NJ 07041
 (973) 429-0300

Hospice of New Jersey

400 Broadacres Drive 4th Floor
 Bloomfield, NJ 07003
 (973) 893-0818

Unity Hospice

17 Academy Street, Suite 606
 Newark, NJ 07102
 (973) 596-9661

GLOUCESTER COUNTY**Samaritan Hospice**

5 Eves Drive, Suite 300
 Marlton, NJ 08053
 (800) 229-8183

HUDSON COUNTY**Christ Hospital Home Health Services**

176 Palisade Avenue
 Jersey City, NJ 07306
 (201) 418-6800

Hospice Program of Bayonne VNA

325 Broadway
 Bayonne, NJ 07002
 (201) 339-2500

HUNTERDON COUNTY**Hunterdon Hospice**

c/o Hunterdon Medical Center

2100 Wescott Drive
 Flemington, NJ 08822
 (908) 788-6600

MERCER COUNTY**Community Hospice**

171 Jersey Street
 PO Box 44
 Trenton, NJ 08603
 (609) 695-3461

Hospice c/o Medical Center at Princeton

253 Witherspoon Street
 Princeton, NJ 08540
 (609) 497-4900

Samaritan Hospice

5 Eves Drive, Suite 300
 Marlton, NJ 08053
 (800) 229-8183

MIDDLESEX COUNTY**Barbara E. Cheung Memorial Hospice****Roosevelt Hospital**

1 Roosevelt Drive
 Edison, NJ 08837
 (732) 321-6800

Haven Hospice JFK Medical Center

65 James Street
 Edison, NJ 08818
 (908) 321-7769

Hospice at RW Johnson University Hospital

One Penn Plz, 2nd Floor
 New Brunswick, NJ 08901
 (732) 828-8884

Odyssey HealthCare

140 Campus Drive
 Edison, NJ 08837
 (732) 346-9276

Rahway Hospital Hospice

865 Stone Street
Rahway, NJ 07065
(732) 499-6151

Raritan Bay Medical Center Hospice

530 North Brunswick Avenue
Perth Amboy, NJ 08861
(732) 324-5173

MONMOUTH COUNTY**CentraState Medical Center**

Hospice/Oncology
901 West Main Street
Freehold, NJ 07728
(732) 294-2870

Meridian Hospice

615 Hope Road, 2nd Fl
Eatontown, NJ 07724
(732) 935-1797

VNA of Central New Jersey Hospice Program

1100 Wayside Road
Asbury Park, NJ 07712
(732) 493-2220

Riverview Medical Center Hospice

One Riverview Plaza
Red Bank, NJ 07701
(732) 530-2382

Trinity Hospice

111 Union Avenue
Long Branch, NJ 07740
(732) 229-0816

MORRIS COUNTY**The Center for Hospice Care**

Morris County Division
282 West Hanover Avenue
Morristown, NJ 07960
(973) 539-6121

Garden State Hospice

70 Jackson Drive
Cranford, NJ 07016
(908) 931-9080

Visiting Nurse Assoc of Northern New Jersey

38 Elm Street
Morristown, NJ 07960
(973) 539-1216 x2702

PASSAIC COUNTY**Compassionate Care Hospice**

66 Mt. Prospect Avenue
Clifton, NJ 07013
(973) 916-1400

Passaic Valley Hospice

783 Riverview Drive
Totowa, NJ 07512
(973) 785-7457

Tri Hospital Home Health & Hospice Program

70 Parker Avenue
Passaic, NJ 07055
(973) 365-5200

OCEAN COUNTY**Great Bay Rehabilitation and Nursing Center**

151 Ninth Avenue
Little Egg Harbor, NJ 08087
(609) 294-3200

Medical Center of Ocean City

Supportive Care Dept.
2121 Edgewater Place
Point Pleasant, NJ 08742
(732) 295-6427

Van Dyke Hospice

99 Route 37 West
Toms River, NJ 08753
(732) 818-6800

Ocean Community Memorial Hospice Program
Route 37 West
Toms River, NJ 08753
(732) 349-3450

SALEM COUNTY

Hospice of Salem County
390 N Broadway, Ste 900
Pennsville, NJ 08070
(609) 678-8500

SUSSEX COUNTY

Karen Ann Quinlan Center of Hope Hospice
99 Sparta Avenue
Newton, NJ 07860
(201) 383-0115

SOMERSET COUNTY

Somerset Medical Center Hospice
110 Rehill Avenue
Somerville, NJ 08876
(908) 685-2972

Community Care Hospice
586 East Maine Street
Bridgewater, NJ 08807
(908) 725-9355

Somerset Hills Hospice
219 Main Street
Gladstone, NJ 07934
(908) 234-2220

UNION COUNTY

Atlantic Homecare & Hospice
33 Bleeker Street
Millburn, NJ 07041
(908) 379-8400

Center for Hope Hospice & Palliative Care Inc.
176 Husa Street
Linden, NJ 07036
(908) 486-0700

Hudson House
111 DeHart Place
Elizabeth, NJ 07202
(908) 353-6060

Muhlenberg Regional Medical Center Hospice Program
Park Avenue Randolph Road
Plainfield, NJ 07061
(908) 668-2253

Theo House
851 N Broad Street
Elizabeth, NJ 07208
(908) 351-6507

Visiting Nurse and Health Services Hospice
354 Union Avenue
Elizabeth, NJ 07208
(800) 717-2273

New Jersey Hospice Organization
175 Glenside Avenue
Scotch Plains, NJ 07076
(908) 233-0060

National Hospice Organization
1001 Pennsylvania Ave
Washington, DC 20004
800-658-8898

Appendix E - NEW JERSEY HOSPITALS

Listing of acute care hospitals which provide cancer services. Hospitals listed in bold have indicated that they offer clinical trials for certain cancers.

ATLANTIC COUNTY

Atlantic City Medical Center City Division

1925 Pacific Avenue
Atlantic City, NJ 08401
(609) 344-4081

Atlantic City Medical Center Mainland Division

Jim Leeds Road
Pomona, NJ 08240
(609) 652-1000

Shore Memorial Hospital

1 East New York Avenue
Somers Point, NJ 08244
(609) 653-3500

William B. Kessler Memorial Hospital

600 South White Horse Pike
Hammonton, NJ 08037
(609) 561-6700

BERGEN COUNTY

Bergen Regional Medical Center

230 East Ridgewood Road
Paramus, NJ 07652
(201) 967-4405

Englewood Hospital & Medical Center

350 Engle Street
Englewood, NJ 07631
(201) 894-3000

Hackensack University Medical Center

30 Prospect Avenue
Hackensack, NJ 07601
(201) 996-2000

Holy Name Hospital

718 Teaneck Road
Teaneck, NJ 07666
(201) 833-3000

Pascack Valley Hospital

250 Old Hook Road
Westwood, NJ 07675
(201) 358-3000

Valley Hospital

223 North Van Dien Avenue
Ridgewood, NJ 07450
(201) 447-8000

BURLINGTON COUNTY

Lourdes Medical Center of Burlington County

218 A Sunset Road
Willingboro, NJ 08046
(609) 835-2900

Virtua Memorial Hospital

175 Madison Avenue
Mount Holly, NJ 08060
(609) 267-0700

Deborah Heart & Lung Center

200 Trenton Road
Browns Mills, NJ 08015
(609) 893-6611

Virtua West Jersey Hospital-Marlton

90 Brick Road
Marlton, NJ 08053
(856) 355-6000

CAMDEN COUNTY

The Cooper Health System

One Cooper Plaza
Camden, NJ 08103
(856) 342-2000

Kennedy Memorial Hospitals UMC

Cherry Hill Campus
2201 Chapel Avenue
Cherry Hill, NJ 08002
(856) 488-6500

Kennedy Memorial Hospitals UMC

Stratford Campus
18 East Laurel Road
Stratford, NJ 08084
(856) 346-6000

Our Lady of Lourdes Medical Center

1600 Haddon Avenue
Camden, NJ 08103
(856) 757-3500

Virtua West Jersey Hospital-Berlin

100 Townsend Avenue
Berlin, NJ 08009
(856) 768-6006

Virtua Camden Hospital-Camden

1000 Atlantic Avenue
Camden, NJ 08104
(856) 246-3000

Virtua West Jersey Hospital-Voorhees

101 Carnie Boulevard
Voorhees, NJ 08043
(856) 325-3000

CAPE MAY COUNTY

Burdette Tomlin Memorial Hospital

2 Stone Harbor Blvd.
Cape May Court House, NJ 08210
(609) 463-2000

CUMBERLAND COUNTY

South Jersey Healthcare

Bridgeton Health Center

333 Irving Avenue
Bridgeton, NJ 08302
(856) 641-7632

ESSEX COUNTY

Cathedral Healthcare System

Saint James Hospital Division

155 Jefferson Street
Newark, NJ 07105
(973) 589-1300

Cathedral Healthcare System

Saint Michael's Medical Center

268 Dr. Martin Luther King Jr Blvd
Newark, NJ 07102
(973) 877-5000

Clara Maass Medical Center

One Clara Maass Avenue
Belleville, NJ 07109
(973) 450-2000

Columbus Hospital

495 North 13th Street
Newark, NJ 07107
(973) 268-1400

Department of Veterans Affairs

New Jersey Health Care System

385 Tremont Avenue
East Orange, NJ 07018
(973) 676-1000

East Orange General Hospital
300 Central Avenue
East Orange, NJ 07019
(973) 672-8400

Essex County Hospital Center
125 Fairview Avenue
Cedar Grove, NJ 07009
(973) 228-8000

Hospital Center at Orange
188 South Essex Avenue
So. Essex, NJ 07051
(973) 266-2000

Irvington General Hospital
832 Chancellor Avenue
Irvington, NJ 07111
(973) 399-6000

Montclair Community Hospital
120 Harrison Street
Montclair, NJ 07042

Mountainside Hospital
1 Bay Avenue
Montclair, NJ 07042
(973) 429-6000

**Saint Barnabas Health Care System at
Newark Beth Israel Medical Center**
201 Lyons Avenue at Osborne Terrace
Newark, NJ 07112
(973) 926-7000

St. Barnabas Medical Center
94 Old Short Hills Road
Livingston, NJ 07039
(973) 322-5000

**University of Medicine & Dentistry of New Jersey
University Hospital**
150 Bergen Street
Newark, NJ 07103
(973) 972-5702

GLOUCESTER COUNTY

Kennedy Memorial Hospital
Washington Township Division
435 Hurffville-Cross Keys Road
Turnersville, NJ 08012
(856) 582-2500

Underwood Memorial Hospital
509 North Broad Street
Woodbury, NJ 08096
(609) 845-0100

HUDSON COUNTY

Bayonne Hospital
29 East 29th Street
Bayonne, NJ 07002
(201) 858-5000

Christ Hospital
176 Palisade Avenue
Jersey City, NJ 07306
(201) 795-8200

**Franciscan Health System of New Jersey, Inc.
St. Francis Hospital**
25 McWilliams Place
Jersey City, NJ 07302
(201) 418-1000

**Franciscan Health System of New Jersey, Inc.
St. Mary Hospital**
308 Willow Avenue
Hoboken, NJ 07030
(201) 418-1000

LibertyHealth - Greenville Hospital Campus

1825 Kennedy Blvd.
Jersey City, NJ 07305
(201) 547-6100

LibertyHealth

Jersey City Medical Center

355 Grand Street
Jersey City, NJ 07302
(201) 915-2000

LibertyHealth

Meadowlands Hospital Campus

55 Meadowland Parkway
Secaucus, NJ 07096-1580
(201) 392-3100

Palisades Medical Center

7600 River Road
North Bergen, NJ 07047
(201) 854-5000

Clara Maass Medical Center

West Hudson Division

206 Bergen Avenue
Kearny, NJ 07032
(201) 955-7000

HUNTERDON COUNTY

Hunterdon Medical Center

2100 Wescott Drive
Flemington, NJ 08822
(908) 788-6100

MERCER COUNTY

Capital Health System-Fuld Campus

750 Brunswick Avenue
Trenton, NJ 08638
(609) 394-6000

Capital Health System-Mercer Campus

446 Bellevue Avenue
Trenton, NJ 08618
(609) 394-4000

University Medical Center at Princeton

253 Witherspoon Street
Princeton, NJ 08540
(609) 497-4000

RWJ University Hospital at Hamilton

One Hamilton Health Place
Hamilton, NJ 08690
(609) 586-7900

St. Francis Medical Center

601 Hamilton Avenue
Trenton, NJ 08629
(609) 599-5000

MIDDLESEX COUNTY

Robert Wood Johnson University Hospital

One Robert Wood Johnson Place
New Brunswick, NJ 08903-9802
(732) 828-3000

John F. Kennedy Medical Center

65 James Street
Edison, NJ 08818
(732) 321-7000

Memorial Medical Center at South Amboy

540 Bordentown Avenue
South Amboy, NJ 08879
(732) 721-1000

Raritan Bay Medical Center

Old Bridge Division

One Hospital Plaza
Old Bridge, NJ 08857
(732) 360-1000

Raritan Bay Medical Center

Perth Amboy Division

530 New Brunswick Avenue
Perth Amboy, NJ 08861
(732) 442-3700

St. Peter's Medical Center

254 Easton Avenue
New Brunswick, NJ 08903
(732) 745-8600

MONMOUTH COUNTY

Bayshore Community Hospital

727 North Beers Street
Holmdel, NJ 07733
(732) 739-5900

CentraState Medical Center

901 West Main Street
Freehold, NJ 07728
(732) 431-2000

Meridian Hospitals Corporation-Jersey Shore

Medical Center Division
1945 Route 33
Neptune, NJ 07754
(732) 775-5500

Monmouth Medical Center

300 Second Avenue
Long Branch, NJ 07740
(732) 222-5200

**Meridian Hospitals Corporation-
Riverview Medical Center Division**

One Riverview Plaza
Red Bank, NJ 07701
(732) 741-2700

MORRIS COUNTY

Chilton Memorial Hospital

97 West Parkway
Pompton Plains, NJ 07444
(973) 831-5000

**Carol G. Simons Cancer Center at
Morristown Memorial Hospital**

100 Madison Avenue
Morristown, NJ 07962-1956
(973) 971-5000

St. Clare's Hospital/Boonton

18 Powerville Road
Boonton, NJ 07005
(973) 625-6000

St. Clare's Hospital/Denville

25 Pocono Road
Denville, NJ 07834
(973) 625-6000

St. Clare's Hospital/Dover

400 West Blackwell Street
Dover, NJ 07801
(973) 989-3000

OCEAN COUNTY

Community Medical Center

99 Highway 37 West
Toms River, NJ 08755
(732) 349-8000

Kimball Medical Center

600 River Avenue
Lakewood, NJ 08701
(732) 363-1900

Meridian Health
Ocean Medical Center
425 Jack Martin Blvd.
Bricktown, NJ 08724
(732) 840-2200

Southern Ocean County Hospital
1140 Route 72 West
Manahawkin, NJ 08050
(609) 597-6011

PASSAIC COUNTY

Barnert Hospital
680 Broadway
Paterson, NJ 07514
(973) 977-6600

Beth Israel Hospital
70 Parker Avenue
Passaic, NJ 07055
(973) 365-5000

PBI Regional Medical Center
350 Boulevard
Passaic, NJ 07055
(973) 365-4300

St. Joseph's Regional Medical Center
703 Main Street
Paterson, NJ 07503
(973) 754-3004

St. Mary's Hospital Passaic
211 Pennington Avenue
Passaic, NJ 07055
(973) 470-3000

St. Joseph's - Wayne Hospital
224 Hamburg Turnpike
Wayne, NJ 07470
(973) 942-6900

SALEM COUNTY

South Jersey Hospital - Elmer
West Front Street
501 West Front Street
Elmer, NJ 08318
(856) 363-1000

Memorial Hospital of Salem County, Inc.
310 Salem Woodstown Road
Salem, NJ 08079
(609) 935-1000

SOMERSET COUNTY

Somerset Medical Center
110 Rehill Avenue
Somerville, NJ 08876
(908) 685-2200

SUSSEX COUNTY

Newtown Memorial Hospital
175 High Street
Newton, NJ 07860
(973) 383-2121

Saint Clare's Hospital/Sussex
20 Walnut Street
Sussex, NJ 07461
(973) 702-2600

UNION COUNTY

Children's Specialized Hospital
150 New Providence Road
Mountainside, NJ 07091
(908) 233-3720

Muhlenberg Regional Medical Center
Park Avenue & Randolph Road
Plainfield, NJ 07061
(908) 668-2000

Overlook Hospital

99 Beauvoir Avenue
Summit, NJ 07901
(908) 522-2000

Robert Wood Johnson University at Rahway

865 Stone Street
Rahway, NJ 07065
(732) 381-4200

Runnells Specialized Hospital

40 Watchung Way
Berkeley Heights, NJ 07922
(908) 771-5700

Trinitas Hospital

Trinitas Comprehensive Cancer Center

225 Williamson Street
Elizabeth, NJ 07207
(908) 994-5000

Union Hospital

1000 Galloping Hill Road
Union, NJ 07083
(908) 687-1900

WARREN COUNTY

Hackettstown Community Hospital

651 Willow Grove Street
Hackettstown, NJ 07840
(908) 852-5100

Warren Hospital

185 Roseberry Street
Phillipsburg, NJ 08865
(908) 859-6700

Appendix F - Sample Combined Advance Health Care Directive

This sample advance directive is included here for information and illustration. Advance directive forms vary from state to state, so check with your health care provider, and choose a form specifically approved for use in the state where you live.

BEFORE YOU SIGN: Read this form carefully. Choose which sections you wish to include, and fill in the blanks. If you want to add specific instructions in your own words, you may do so. If you need more space, attach extra sheets and sign or initial at the bottom of each sheet.

AFTER YOU SIGN: Have two witnesses sign, also. Witness requirements vary, so check to make sure your witnesses are right under the law in your state. If you are appointing a health care representative, sit down with him/her and talk about your wishes and goals for your care. Give copies to: (1) your health care representative, if you are appointing one; (2) your doctor and other health care providers, such as your hospital, home health care agency, or nursing facility; (3) close family members or friends. When you give them a copy of your advance directive, take some time to explain what it says and what your wishes are.

WORDS YOU NEED TO KNOW:

An **Advance Directive** is an instruction (usually in writing) that says how you want future health care decisions made for you if you can't make them yourself.

Artificial Nutrition and Hydration is when food and water are given to a person through a tube or needle because the person is no longer able to swallow.

Autopsy is an examination done on a body to find out the cause of death.

Comfort Care is care that helps to keep a person comfortable and control pain.

CPR (Cardiopulmonary Resuscitation) is emergency treatment that tries to restart a person's breathing or heartbeat after they have stopped. CPR can include pushing on the chest, putting a tube down the throat, and other emergency steps.

Health Care Appointment is an advance directive in which you appoint someone to make medical decisions for you if the time ever comes when you can't make them yourself. It is also called a "Health Care Proxy" or a "Durable Power of Attorney for Healthcare."

Life-Sustaining Treatment is any medical treatment that is used to keep a person from dying. A breathing machine, CPR, and artificial nutrition and hydration are examples of life-sustaining treatments.

Health Care Directive is an advance directive in which you say what forms of medical treatment you do or do not want if you become terminally ill or are in a persistent vegetative state.

Organ and Tissue Donation is when a person permits his/her organs (such as eyes or kidneys) and other parts of the body (such as skin) to be removed after death to be transplanted to another person or used for education or research.

Persistent Vegetative State is when a person is unconscious with no hope of regaining consciousness even with medical treatment. The body may move and eyes may be open, but as far as anyone can tell, the person can't think or respond.

Being **Terminally Ill** means having an injury or illness that has no cure and from which doctors expect the person to die, even with medical treatment.

This page intentionally left blank for notes.

COMBINED ADVANCE DIRECTIVE OF:

Name _____ Date _____

I. HEALTH CARE APPOINTMENT

I hereby appoint the following person as my health care representative. I intend for my representative to have the power to act for me in making health care decisions on my behalf if, in the opinion of my primary physician, I am incapacitated and unable to make such decisions for myself.

Name of person I appoint: _____

Address: _____

Home/Work Phone: _____

If the person I have just named is unable or unwilling to act as my representative, I appoint as alternate:

Name of alternate: _____

Address: _____

Home/Work Phone: _____

Special instructions or wishes concerning my future care:

II. HEALTH CARE DIRECTIVE

These are my wishes if I become **terminally ill** or am in a persistent **vegetative state** and cannot make decisions about my care:

I do or do not want **life-sustaining treatments (including CPR)** started or continued.

Other wishes: _____

I do do not want **artificial nutrition and hydration** started or continued if it would be the main treatment keeping me alive.

Other wishes: _____

Unless you specify otherwise, an advance directive will not limit or prevent **comfort care** as directed by your doctor.

III. ORGAN DONATION

- I do or do not want to be an **organ or tissue donor**.
- I want to donate **all** my organs and tissues
- I only want to donate the following organs and tissues:

Other wishes:

IV. AUTOPSY

- I agree to an autopsy if my doctor recommends it.
- I do not want an autopsy, if one is not legally required.

Other wishes:

V. GUARDIANSHIP

If it becomes necessary for a court to appoint a guardian for me, I nominate my health care representative acting under this document to be the guardian of my person, to serve without bond or security.

VIII. SIGNATURES

You and two witnesses must sign this document. If you are physically unable to sign your name, you may direct another person (but not one of your witnesses) to sign for you.

A. *Your Signature*

By my signature below I show that I understand the purpose and effect of this document and that I am signing it as an expression of my own wishes concerning my future care.

Signature: _____ Date: _____

Address: _____

B. *Your Witnesses' Signatures*

I hereby declare and affirm as true:

- I personally know the person who has signed above, or his/her identity has been clearly established;
- This person signed this document in my presence;
- This person appears to me to be of sound mind and not under any form of duress, fraud, or undue influence;
- I am qualified to be a witness; I am not: ► someone this person has appointed as health care representative or alternate; ► a relative of this person; ► someone who will inherit from or who has a claim against this person; ► this person's doctor or other care provider or an employee thereof; ► paying for this person's care. *[Note: Witness requirements vary from state to state. For example, if you are receiving care in a nursing facility, California and some other states require that one witness be an ombudsman or other type of patient advocate. Be sure to check on witness requirements in your state.]*

Witness #1

Signature: _____ Date: _____

Address: _____

Witness #2

Signature: _____ Date: _____

Address: _____

Appendix G - QUESTIONS TO ASK

QUESTION	DATE	RESPONSE
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		

Appendix I - EXAMPLE MEDICATION CHART

TIME	DATES						
DRUG NAMES & DOSE	SUN	MON	TUE	WED	THUR	FRI	SAT
BEFORE BREAKFAST							
1.							
2.							
AFTER BREAKFAST							
1.							
2.							
MID MORNING (10 A.M.)							
1.							
2.							
BEFORE LUNCH							
1.							
2.							
AFTER LUNCH							
1.							
2.							
MID AFTERNOON (3 P.M.)							
1.							
2.							
BEFORE SUPPER							
1.							
2.							
AFTER SUPPER							
1.							
2.							
AT BEDTIME							
1.							
2.							

Appendix J - IMPORTANT TELEPHONE NUMBERS

Many people will be involved in your cancer care. You may need to provide names and phone numbers of one specialist and agency to another. In the space below, keep a list of all persons and groups you are in contact with. Include your physicians and their specialties, your dentist, the nurse at the clinic or doctor's office, the social worker, physical and/or occupational therapist, nutritionist/dietician, local pharmacy, hospital pharmacy, local emergency service and ambulance company, medical equipment suppliers and any others you might need.

Name	Phone Number	Notes
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		

Appendix K - QUESTIONS AND ANSWERS ABOUT AGREEMENT TO PROVIDE HEALTH INSURANCE COVERAGE FOR CANCER CLINICAL TRIALS BY THE NEW JERSEY WORKING GROUP TO IMPROVE CANCER CLINICAL TRIALS

I. What is the New Jersey Consensus Agreement to cover cancer clinical trials?

As of December 16, 1999 members of the New Jersey Association of Health Plans (NJAHHP), which represents the state's nine largest health insurers, have agreed to voluntarily cover the routine health care costs of any of their members enrolled in a Phase I, II & III approved cancer clinical trial. NJAHHP members provide health plan coverage or administration to 4.8 million New Jerseyans and 98% of the state's HMO market. (See Appendix L for listing)

2. What is an approved cancer clinical trial as defined under this agreement?

The agreement strictly defines the type of cancer clinical trial approved under the plan. Strict criteria designed to assure scientific validity and oversight through national monitoring programs are required. Specifically, an approved cancer clinical trial is a trial authorized or approved by one of the following:

- a. The National Institutes of Health (NIH) including cooperative group trials, trials at NCI designated cancer centers
- b. The U.S. Food and Drug Administration (FDA)
- c. The U.S. Department of Defense (DOD)
- d. The U.S. Department of Veteran's Affairs (VA)

3. What costs are covered by this agreement?

Routine medical costs, or the costs that might normally be covered if you were being treated with standard care, will be borne by the health plans. All other costs (administrative, monitoring, and additional tests mandated by protocol) will be paid for either by the investigating sponsor, the institution at which the trial is being conducted, or some other party. Patients should be aware that the working group does not guarantee that all costs of clinical trials will be covered under this agreement. It tries to work with all parties to obtain the best coverage possible. A mechanism to determine up-front routine costs for trials may be available from the working group.

4. How can one determine if a trial is approved under the agreement?

New Jersey Cancer Trials Connect will allow access to such information for health care providers, health plan medical groups, and patients. Go to (www.njctc.org) and then follow steps to search for clinical trials.

5. Does the agreement cover only the HMO business of a health plan or other lines of business as well?

Because the agreement is voluntary, each individual health plan sets the lines of business included within the agreement. In many instances, PPOs, indemnity and HMOs plans are participating. For example, many self funded programs (ARISA) were offered the option to make the coverage provided in the consensus agreement available to their members. In addition, the year 2000 Medicaid contract includes this service for HCFA. Recently, President Clinton announced an executive memorandum that authorizes payment for the routine costs of clinical trials under Medicare. While the federal regulations may differ from the New Jersey agreement, this additional step means that New Jersey cancer patients have the broadest coverage for the routine costs of clinical trials in the country.

6. What if I do not have any insurance?

Medicaid beneficiaries may be covered by participating NJAHP HMOs under the agreement. Some hospitals in New Jersey will provide access to clinical trials for uninsured patients on a case by case basis. In addition, the Working Group is committed to work to increase access to cancer clinical trials through education, advocacy, and other interventions.

7. What if my doctor is not involved with clinical trials?

The New Jersey Commission on Cancer Research can provide information about hospitals in New Jersey where physicians offer access to clinical trials. Physicians who may wish to refer a patient to a clinical trial should be aware that contract relationships with specific insurers may limit where a patient may go for an approved clinical trial. You can find physicians who are offering the trial locally by displaying the trial that you are interested in and scrolling to the investigators listing.

8. Are all cancers included in this agreement? Are prevention and supportive care trials also covered?

All types of cancers are included within agreement. Prevention, treatment, and supportive care studies may also be included within the agreement as long as they fulfill the approved requirements.

9. How many clinical trials will be included?

The Coalition of National Cancer Cooperative Groups estimates that over 300 open trials are available to patients in New Jersey at any time. In addition, the Working Group estimates that The Cancer Institute of New Jersey has 70 NCI approved trials open in New Jersey.

10. While the agreement includes several major health insurers in New Jersey? What about other insurers who are not members of the New Jersey Association of Health Plans?

All insurers offering coverage in New Jersey have been invited to participate in the Working Group agreement. You should call your insurer to find out if they are part of the program.

11. What if I am insured in New Jersey, but want to participate in a trial outside the state? Will coverage be provided?

Insurers have agreed to cover the routine costs of approved clinical trials in New Jersey. Participation by any individual is still subject to contractual terms and benefit limitations of the member's plan including physicians and facility providers. Decisions about trials conducted at non-participating institutions or outside the state of New Jersey will be determined by individual companies. Patients should contact their insurer prior to starting any clinical trial to obtain specific information about their benefits.

12. How can a cancer patient find out more about this agreement?

Patients can call The American Cancer Society, Eastern Division 1-800-ACS-2345, the Cancer Information Service of the National Cancer Institute (1-800-4-CANCER), The New Jersey Commission on Cancer Research (609) 631-4747, and The Cancer Institute of New Jersey (732) 235-6777 for information about cancer clinical trials and the NJ agreement.

Appendix L - Member Companies of the New Jersey Association of Health Plans

Aetna U.S. Healthcare

AMERICHOICE

AMERIGROUP CORP.

AMERIHEALTH

CIGNA HealthCare of New Jersey, Inc.

Health Net

Horizon Blue Cross Blue Shield of New Jersey

Oxford Health Plans

United Healthcare of New Jersey

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