

# Cancer Ministers Advocacy Training

IMMERSION – INTO THE FUTURE





# SELF ADVOCACY Training

For Cancer Care Ministers

# introduction

If you are taking this training, it is likely that cancer has become an unwelcome intruder in your life, a family member or someone connected with your community.

We at IMMERSION for Cancer Survivorship (ICS) believes that cancer becomes a much lesser foe when faced by an individual who is informed and knowledgeable and who knows how to communicate their needs to those who can be helpful to them as they experience cancer.



# introduction

This training is intended to help you become such an individual – a cancer advocate – to lessen the fear, dispel the myths, and reduce the anxiety, so that you can make the best decisions about survivorship.

While each one of us (Cancer Care Ministers) experiences cancer as an individual, there is some collective wisdom to be derived from what they have learned as a community of advocates for people who are living and dying well with cancer.



# introduction

This training is, however, a primer intended to encourage and enable you to become an active participant as you or a family member, friend or a member of your community deal with a diagnosis of cancer, no matter what the life circumstances.

Many phrases and expressions found in this training are repeated throughout. This is intentional, to reinforce the importance and purpose of the term self-advocacy and advocacy.

This training focuses on self-training steps and tools to assist and empower individuals dealing with cancer. If you are at the beginning, middle, or end of your decision-making about dealing with a diagnosis of cancer, the materials in this training will add value to survivorship.



The background features a light grey base with large, overlapping organic shapes in muted green and brown. Stylized foliage patterns, resembling ferns or pine needles, are scattered across the top and left sides. A thin white line curves across the bottom right.

# Getting Started

# Getting Started

Some would say that, ideally, upon a diagnosis of cancer or other life-threatening illness, a person would be provided a patient advocate.

Unfortunately, our society is far from using this model. Therefore, IMMERSION disseminates materials, programs and skill-building tools to enable individuals and their supporters to become effective self-advocates. You can think of these as your advocacy tools as you begin your journey of survivorship.



# Getting Started



- The materials and tools in this training are based on the experiences of many survivors and are intended to help you “become your own best advocate.” **Cancer survivorship** as defined by IMMERSION is an ongoing process – one that begins at diagnosis and continues for the balance of your life.
- Every journey begins with a single step. No matter where you are in your cancer journey, the step you take now may be your first to become **more informed** and feel **more empowered** to adjust to this diagnosis. Ideally, you are dealing with cancer with the **support** of many friends, loved ones and compassionate caregivers.



# Getting Started



- Too often, people experience cancer in isolation, without financial or emotional support and with few resources to tap into.
- No matter what your circumstances, always keep in mind that you can always do something – even if that something just gets you through the next hour or the day.
- And remember, no matter where you are along the path of your survivorship, having good skills to negotiate and communicate your needs are some of your best weapons to use against cancer.

# 3 Terms Defined

1

Three words appear often throughout this training: **survivor**, **survivorship** and **advocacy**.

2

From the moment of diagnosis and for the balance of life, an individual diagnosed with cancer **is a survivor**.

3

Put the term **survivor** into your dictionary of terms to **replace “patient” or “victim”** to describe someone diagnosed with cancer.



## SURVIVOR

The word **survivor** is often debated, but IMMERSION persists in using it because of the proactive approach it emphasizes when living with a diagnosis of cancer.

# Survivorship



The term **survivorship**, as defined by IMMERSION, is the experience of living with, through and beyond a diagnosis of cancer.



IMMERSION includes the process of dying well as the last stage of survivorship.



It is IMMERSION's belief that by living and dying well with cancer, an individual and all those who care for him/her, will pass on a legacy of **survivorship** to all those they come in contact with..

# Advocacy



The term advocacy is frequently used to encompass activities carried out in the name of **supporting a cause**. The dictionary defines advocacy as “**active support**, as of a cause, idea or policy.”



Advocacy, as IMMERSION defines it, is a continuum that begins when an individual is diagnosed with cancer. IMMERSION believes that at this defining moment, an individual with cancer (and/or a significant person in his or her life) must play a very active role in assuring that they receive quality care.

# Advocacy

---

The term advocacy is frequently used to encompass activities carried out in the name of **supporting a cause**. The dictionary defines advocacy as “**active support**, as of a cause, idea or policy.”

---

**Advocacy**, as IMMERSION defines it, is a continuum that begins when an individual is diagnosed with cancer. IMMERSION believes that at this defining moment, an individual with cancer (and/or a significant person in his or her life) must play a very active role in assuring that they receive quality care.

# Advocacy | Advocacy for Others | Advocacy in the Public Interest



This marks the first step in the cancer advocacy continuum. **The next step** in the continuum is what IMMERSION defines as “**advocacy for others.**”



This is where some of the most effective advocacy occurs for individuals with cancer and it is where many people with cancer find a role for themselves as advocates in their own community.



At the other end of the continuum is **advocacy in the public interest**, or national health care advocacy, and this is the chief role of organizations like IMMERSION.



This training touches on all three areas, but **focuses principally** on **self-advocacy**, and explains how you can become the most effective advocate when you or someone you care about has cancer.

# Becoming A Self Advocate

Self-advocacy **does not mean** that you have to wave a banner, give speeches or take to the ramparts.

In the personal context, it means that you arm yourself with the tools and skills necessary to feel comfortable about asserting yourself and communicating clearly about your cancer care needs.

It ultimately means that you are **taking responsibility** and assuming some **control** of your life circumstances with cancer.

.



# What is Self-Advocacy & How Does It Apply To Me?

Knowing as much as possible about your disease, its treatments and its potential effects on your body can empower you to take charge of your health and help you make the most of your survivorship experience.

It is imperative that survivors, their health care providers and other supporters become effective advocates in the current environment of rising health care costs and restrictive referral policies.

Health care professionals are also experiencing ongoing pressures such as nursing shortages and restrictive reimbursement policies for health care services. These all have an adverse impact on the care we receive and the system in which it is provided.



## WHAT IS SELF-ADVOCACY & HOW DOES IT APPLY TO ME?

Our interdependency on one another for responsible advocacy can strengthen the health care environment in which we are treated for cancer.



## WHY IS SELF ADVOCACY IMPORTANT

By being a proactive, educated cancer consumer/advocate, you can impact the quality of your life and the health care you receive.

# Why Self-Advocacy Is Important

- Advocacy gives you some stability and a feeling of regaining some control in your life.
- Advocacy is confidence building in the way it helps you face challenges that seem insurmountable.
- Advocacy is a way of reaching out to others. It can be as simple as asking your doctor or nurse for the name of someone to talk with who has survived your particular type of cancer.
- Advocacy can improve your quality of life.
- Advocacy for yourself may be the difference that turns feeling hopeless and helpless into feeling hopeful



# Why Self-Advocacy Is Important



- Stated in another way, self-advocacy is a synonym for what some might otherwise call “control” or “empowerment.”
- Self-advocacy implies strength, both physical and mental.
- Self-advocacy requires participation in the decision-making process.
- Given our tremendous access to resources for information and support today, a self-advocate need not go to a medical provider and say, “What would you do,” or “I’m in your hands” or “just cure me.”
- Commitment to shared responsibility with your medical team can contribute to the goal of physical, emotional, and mental health.

# Who Are Cancer Advocates



We are all cancer advocates – ourselves, our families, friends, health care professionals, and caregivers. It is anyone taking the necessary steps to play an active role as an informed, communicative decision-maker about treatment and quality-of-life after a cancer diagnosis.

It is anyone reading and using the suggestions in this training. It is anyone empowered by IMMERSION adopted Cancer Survivors' Bill of Rights.

It is anyone advocating on behalf of themselves, or others, at the personal, community, state or national level. We are part of a growing constituency of people living with, through and beyond cancer.

# The Demographics of Cancer

As we examine the faces and voices of cancer survivorship, we see many disparities – disparities in age, ethnicity, literacy and socioeconomic status.

Consider this compelling statistic: approximately 77% of all cancers are now diagnosed in people age 55 and older.

Too many of those diagnosed are culturally and economically underserved – both uninsured and underinsured.

It is projected that by 2030, one in five people will be age 65 or older. Our aging population is significant because cancer occurrence increases with age.



# 4 Self-Advocacy Skills

Based on a review of survivorship research and writing, IMMERSION identified four primary, but interconnected areas, in which self-advocacy skills are essential: information-seeking, communication, problem-solving and negotiation. Although there are differences, these skills each serve to reinforce one another.





# 1. Information Seeking Skills



Information Seeking skills are developed by educating yourself as thoroughly as possible about your cancer, your treatment options, possible side effects and available support services.

You have probably heard the tagline for a national retailer that states “an informed consumer is our best customer.” This is especially true when dealing with cancer.

## 2. Communication Skills



Communication skills development is designed to help you organize your thoughts before you speak.

Your communication skills can be applied to thoughtful interactions with your family, friends and caregivers, thereby increasing your knowledge and avoiding unnecessary misunderstandings.

Information about Teamwork is provided in Resources at the end of this Training.

# 3. Problem Solving Skills

Problem-Solving skills can be also thought of as decision-making skills and are essential to the process of becoming an active, rather than passive, survivor.

It is important to identify the problem and know how to articulate it – whether or not to have treatment and, if so, what type of treatment; considering a clinical trial; what physician to choose; and so on.

Do not feel that you have to make decisions alone. The team approach often serves as the best way to tackle a problem.



# 4. Negotiation Skills

Negotiation skills are necessary in every aspect of life, whether dealing with cancer or any other challenging life circumstances. Some of us are better at negotiation than others, but all of us can achieve some degree of skill in this area.

Negotiating in order to get your needs met may require you to step out of your normal comfort zone.

This does not mean that you become confrontational, but rather that you negotiate about issues that are of personal importance such as the accommodation of unconventional hours at your office or persuading your insurance company to cover a test or procedure.



# Other Types of Advocacy

You need not confine your advocacy to a personal context. After a cancer experience, many people or their family members and friends feel a need to “get involved.” You can expand your participation in many ways.

**Community advocacy** can begin simply by assisting others through the cancer experience – “the veteran helping the rookie” – or by speaking about your experience to others. It can include public speaking or writing, distribution of flyers, assistance with fundraising for your support group or hospital, or having a cancer survivor’s day petition signed by the mayor or governor.



# Being Proactive: Applying The Skills

Now that you know why self-advocacy is important and how to acquire the necessary skills, you must actively apply them to your personal experience.



**BRAVER  
STRONGER  
SMARTER**  
Fighting Childhood Cancer

# BEFORE DIAGNOSIS

What follows are some steps to reduce your misunderstanding and to increase the opportunity to get the best care, if and when you learn that you or someone you care about is diagnosed with cancer.



# Study and Understand Your Health Insurance Coverage



It is important to fully understand your choice of facilities and health care providers when selecting a health plan. Those who advise you to seek second opinions, find another doctor, go to a major cancer center, etc., may believe that they are providing sound advice. However, you may face barriers to accessing this type of care based on your insurance coverage. If you think that you might want to get an opinion or treatment at a major cancer center and/or specialist out of your area (if you are diagnosed), make sure that you fully understand your “out of network” benefits. If you don’t, contact your health plan or your employer’s benefits administrator.



# Headlines are meant to sell newspapers and Magazines and can be misleading.



Hardly a day goes by without a news story heralding some breakthrough or major finding about cancer. One headline tells us certain foods may increase our risk for cancer, while another study and story may dispute that evidence. Our knowledge of cancer risks is constantly changing and may be more or less significant than current literature would suggest. Scientific knowledge about what puts us at risk for cancer evolves constantly.



Keeping up with this kind of news helps you remain an “active” rather than a “passive” consumer. Never hesitate to raise questions with your health care professionals about your risk for cancer based on current evidence.

# Engage in practices that reduce your risk of exposure to known cancer causing agents.

We all look forward to the day when we will know for certain what causes cancer. Two very difficult cancers are largely, though not always, caused by lifestyle choices – lung cancer and skin cancer. You can lessen your risk of developing these cancers by not smoking or using tobacco products and by limiting sun exposure.

Guidelines regarding screening for the most common cancers are constantly evolving. Check with your physician to determine how the most current evidence regarding screening for breast, prostate, lung and colorectal cancer may apply to you.

# History is not destiny.

If you have a family history of cancer, ask your physician what role genetics or other risk factors may apply to your particular health profile.

Understanding “**relative risk**” versus “**actual risk**” marks an important distinction when dealing with genetic or heritable risk factors for cancer.



# Know and trust your body and your instincts.

See your physician with any unusual symptoms that do not clear up in two weeks.

If you are unsatisfied or instinctively sense that something is wrong, seek another opinion.



# Diagnosis

After persons receive a diagnosis of serious illness, the support they need varies as widely as humanity itself.

Some want to have family gathered around them, others need to be alone.

Some need assurance of immediate medical intervention, others have to have some time to decide what treatment they want.

A physician may help one person by rushing in, another, by backing off. The caregiver's art is finding a way to allow the ill person to express his needs.

# Diagnosis

The field of health care that deals with cancer is called oncology. The people treating cancer are chiefly medical oncologists, surgical oncologists, radiation oncologists, oncology nurses and oncology social workers.

Cancer is many diseases with one thing in common: the uncontrollable growth and accumulation of abnormal cells. Cancer growth and development has so many phases that physicians use terms that specify where the cancer is (site) and the type of tissue involved.



# Diagnosis

Because there are so many different types of cancer, it is vitally important that you understand your diagnosis and prognosis – a prediction of the probable cause and outcome of the disease – so that you can make informed treatment decisions.



# Become educated about your type of disease and the treatments available.

Rarely is there only one treatment option to consider. If you are emotionally or physically unable, ask a friend or family member to do the research for you.

Consider that a high quality clinical trial may be your very best treatment option. Be sure to ask your physician about this option.





# Be sure that you understand the stage and grade of your cancer.

For most cancers staging is based on a scale of 0-5 that identifies the size of the tumor and the extent of its spread.

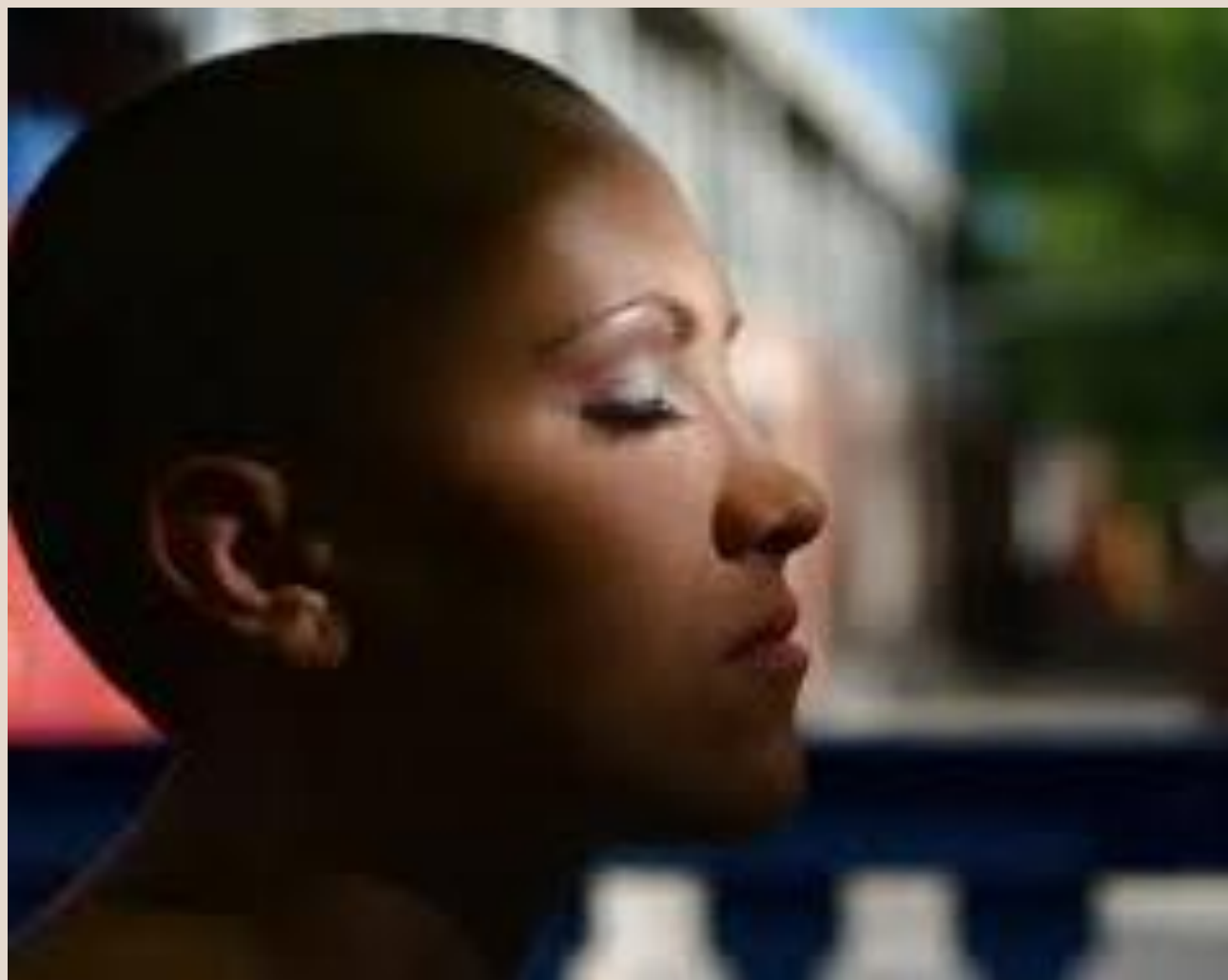
Grade compares the cancer cells characteristics to that of normal cells. These factors may determine treatment options.



# Knowing The Diagnosis

Write out your questions in advance of your visit to an oncology professional.

Some physicians will let you submit questions in advance of your first visit to allow for a more focused discussion..



# Investigate living wills and advanced directives

Investigate living wills and advanced **directives** so that your wishes are carried out throughout the entire course of your life.



# Take Time To Investigate

Take some time to do the necessary research to make the choices that are best for you.

Don't let anyone pressure you into making an immediate decision about your treatment options.



# Other Types of Advocacy

You can also get involved with an advocacy group in your town or city – many national organizations have state and regional offices that work locally – at the grassroots level to accomplish change.

You can be active at the community level by participating in support groups, planning informational programs and Survivors Day events and by planning or participating in a Town Hall meeting.



# Other Types of Advocacy

National advocacy or Public Policy on behalf of social issues is referred to as **Public Interest Advocacy**.



# Assuring Quality Cancer Care

“I was overwhelmed by all the information I was receiving and by the choices and decisions that I had to make, but I knew that my survival could depend on the knowledge and experience of the physician and the health care team that I chose.”



# Assuring Quality Cancer Care

When diagnosed with cancer, you deserve the best possible care through your diagnosis, treatment, recovery and long-term follow-up. Ensuring Quality Cancer Care, a report of the Institute of Medicine and the National Research Council, found that a substantial proportion of cancer patients do not receive the best quality care.

The report recommends systems changes to improve the likelihood that more people will receive high-quality cancer care in the future.



# How Do I Find Experienced Care Providers?

Choose a doctor with experience treating your type of cancer. Such a doctor will often be a board-certified oncologist, but other types of health care providers may specialize in the treatment of certain types of cancer. For example, urologists often treat prostate cancer and dermatologists treat many skin cancers.

Doctors involved in research may be able to offer you promising new treatments and provide access to clinical trials and other experimental programs.

# How Do I Find Experienced Care Providers?

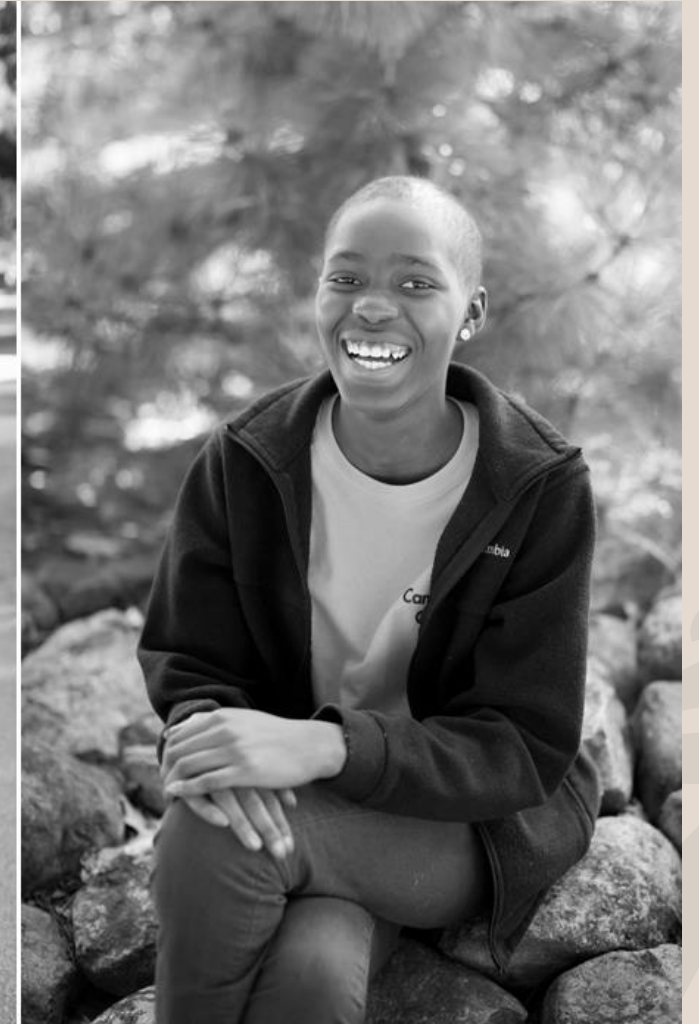
Oncology researchers have devised many treatment plans and protocols based on the best available scientific evidence. Their use helps to ensure that you receive the best care supported by the latest scientific advances. Check to see if your health care providers are using the guidelines and protocols that are available for your situation.

If you need surgery or care that is considered “high-risk” – for example, surgery for cancer of the pancreas, esophagus, or for some types of lung cancer – consider getting care at facilities/hospitals with extensive experience in such procedures because they tend to have better outcomes



# How Do I Select and Evaluate My Doctor or Specialist?

By extension this also relates to your nursing care and the hospital or facility at which you will receive treatment.



## How Do I Select and Evaluate My Doctor or Specialist?

Research the credentials of the professional(s) that will be handling your care. Check their board certification(s) in the Official Directory of the American Board of Medical Specialties (ABMS) (available in the reference section at most libraries) or online at [www.abms.org](http://www.abms.org).

The American Society of Clinical Oncology (ASCO) has a Website especially for consumers at [www.cancer.net](http://www.cancer.net), which features an option to find certified oncologists by name, location and specialty (click on ASCO Resources, then Find an Oncologist).

# Assuring Quality Care

Check with your State Medical Board – listed with the Federation of State Medical Boards at [www.fsmb.org](http://www.fsmb.org) – or your local medical society.

Ask about their education, specialty training and experience – in years and number of procedures or cases similar to yours.

Ask for referrals to other patients with a similar diagnosis who have given permission to be contacted. Although it's tempting to ask a relative, neighbor, or friend for a referral, it is always best to do your own research to find a physician and/or cancer center that is suited to your illness and situation.

# Assuring Quality Care

Call the Cancer Information Service toll-free at 800-4-CANCER (800-422-6237) for a listing of the National Cancer Institute's (NCI) designated Cancer Centers.

Seek a second opinion. Ask your physician for a referral to another specialist or do your own research to find one.

Other things to consider when making this decision: your support system (family, friends), which may affect location, transportation, and access to other supportive care services such as counseling, rehabilitation and support groups.

# How do I Effectively Communicate with my Health Care Team?

- **Evaluate the health care team's responsiveness** to your questions and their ability to effectively communicate about your diagnosis, treatment and other concerns.
- **You are entering into a partnership with this team.** Ask who will coordinate your care—surgeon, medical oncologist, radiologist, or other specialist.
- **Ask about accessibility.** Ask for a contact person (and phone number) of a case manager, nurse, or nurse practitioner who can speak with you during non-business hours.

# How do I Effectively Communicate with my Health Care Team?

- Be sure that you or your designated advocate understands the medical terminology and the significance of scans, blood counts, other lab tests, and pathology reports.
- Ask about follow-up office policy: How frequently will you be seen? where (in office, by phone)? when will lab tests and





# Understanding Your Diagnosis and Treatment Plan



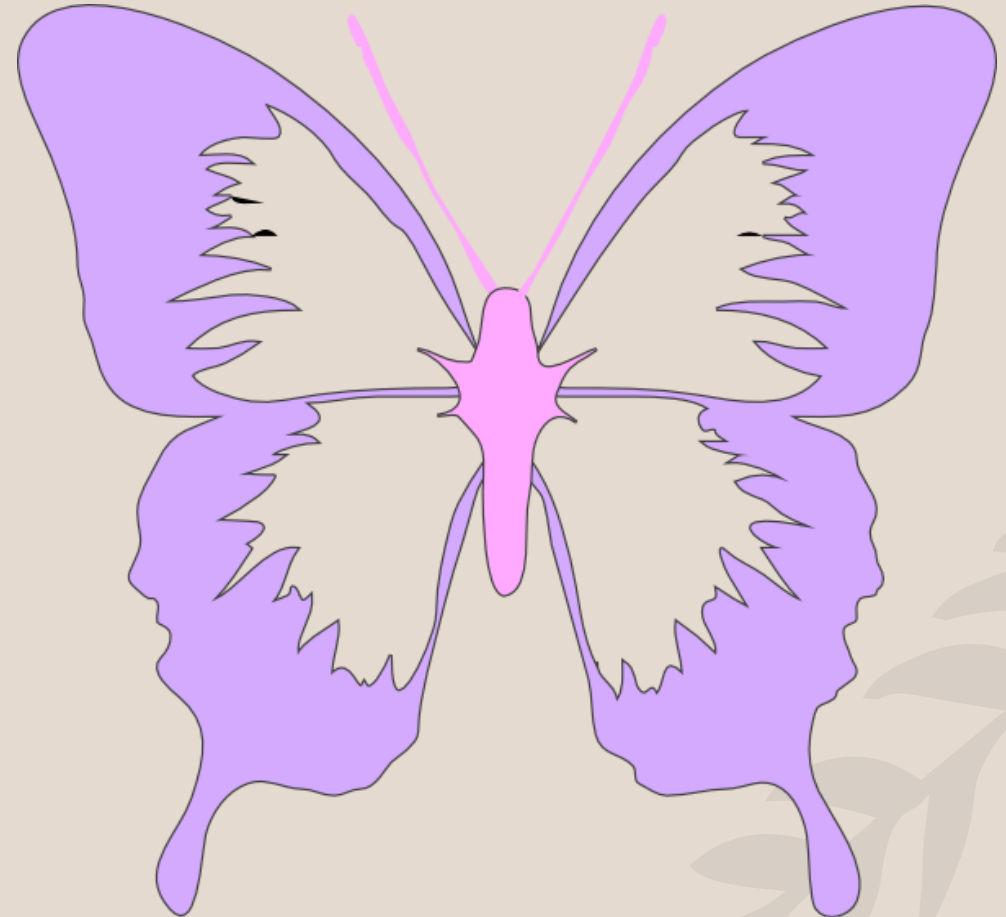
“I was so frightened when first diagnosed. But I couldn’t stand feeling helpless so I decided I had to actively participate in the treatment I received.

Doctors tend to treat symptoms; I insisted that my doctor treat me, the patient – the person. I insisted on a dialogue. When treatment was determined, I wanted to know the purpose, the side effects, and the alternatives. Then I researched everything. I don’t know if it can be measured, but I know it helped my recovery.”

# Understanding Your Diagnosis and Treatment Plan

Your doctor should tell you the kind of cancer you have, your prognosis and what you can expect from treatment. Your doctor should describe options for treatment and clearly set forth a treatment plan for you.

Understanding what cancer is and how your type of cancer can be treated will help you communicate with your health care providers and make decisions with confidence. Reliable information on cancer, its treatment and local supportive and treatment programs is available at no cost.



# Understanding Your Diagnosis and Treatment Plan

Cancer-related treatment usually consists of surgery, chemotherapy, radiation or a combination of these therapies.


Newer, more targeted treatments for some diseases may have fewer side effects. Other new and emerging treatments – including hormones; biologics (cellular, protein and enzyme levels); immuno-suppressors and others – are being researched in the laboratory and within clinical trials (see section on Clinical Trials).

# Understanding Your Diagnosis and Treatment Plan



Be sure that you understand all of your treatment options before starting any therapy. In most cases treatment doesn't have to start immediately after diagnosis.

Don't rush to a decision or let anyone else rush you. **Your first treatment usually** offers the best chance for cure, so it is important to know all of your options and the possible benefits and risks before that first treatment.



Input from patient advocates, lists the following questions for consideration before beginning treatment.

Is there any evidence the cancer has spread? What is the stage of the disease?

What are my treatment choices? Which do you recommend for me? Why?

What new treatments are being studied? Would a clinical trial be appropriate for me?

What are the expected benefits of each kind of treatment?

What are the risks and possible side effects of each treatment?

Input from patient advocates, lists the following questions for consideration before beginning treatment.

- Is infertility a side effect of cancer treatment? Can anything be done about it?
- What can I do to prepare for treatment?
- How often will I have treatments?
- How long will treatment last?
- Will I have to change my normal activities? If so, for how long?
- What is the treatment likely to cost?



## Understanding the Role of Clinical Trials in Quality Cancer Care



“I read about a promising new treatment for my cancer. When I asked my doctor, she told me that a clinical trial was being conducted to compare this drug to the standard treatment. If I agreed to participate I would receive the same quality of care (perhaps even better, because I would be very closely monitored) and I would be randomly assigned to receive either the standard drug or the new treatment.

After reviewing the material she provided, comparing other potential treatments and trials and reading the informed consent document, I decided that this trial presented the best option for me and I agreed to participate.”

# Understanding the Role of Clinical Trials in Quality Cancer Care



High-quality cancer clinical trials are an important component of quality cancer care. Before a new treatment method is made available to the public, it must undergo a clinical trial.



**Clinical trials**, also called cancer treatment or research studies, test new treatments in people with cancer.



**Clinical trials** test many types of treatment such as new drugs, new approaches to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy.



# Understanding the Role of Clinical Trials in Quality Cancer Care

Clinical trials are strictly monitored and carefully evaluated to test the therapy's safety and efficacy (effectiveness).

Any new treatment must successfully complete three phases of trials (see [www.cancer.gov/clinical-trials](http://www.cancer.gov/clinical-trials) for a complete guide and description of Phase I, II and III trials) before the federal Food and Drug Administration (FDA) approves it for general use.



# Understanding the Role of Clinical Trials in Quality Cancer Care

It's important to know that every patient in a Phase III trial receives either the standard treatment for a specific cancer or the treatment being investigated.

The common misperception that some patients receive placebos has kept many patients from participating in cancer clinical trials.



## Is it right for me?

Of course, there is no guarantee that a new treatment being tested or a standard treatment will produce good results. New treatments also may have unknown risks.

In the past, clinical trials were sometimes seen as a last resort for people who had no other treatment choices.

Today, patients with common cancers often choose to receive their first treatment in a clinical trial.



## How do I decide?

A number of excellent publications and Websites address this question. Reference the Patients section of the Coalition of National Cancer Cooperative Groups at [www.cancertrialshelp.org](http://www.cancertrialshelp.org).

Before making a final decision, review the National Cancer Institute booklet *If You Have Cancer: What You Should Know About Clinical Trials* or check the information and questions at [www.cancer.gov/clinicaltrials/learning](http://www.cancer.gov/clinicaltrials/learning) and click on *Participating in a Trial: Questions to Ask Your Doctor*.




# How do I decide?

These important questions must be asked and answered to your satisfaction before you can make this decision.

If you agree to participate, you will receive a copy of the written description of the trial.

You will also be provided with an informed consent document that you must sign, indicating that you understand the trial and what will be required to participate..





## Insist on Comprehensive, Coordinated and Continuous Care

**Good cancer care involves** doctors, nurses, social workers and other providers working as a team throughout your care.

**Make sure** that one member of your medical team is designated as your advocate to coordinate your care and guide your progress throughout treatment.

**If you experience pain or symptoms** such as fatigue or nausea, ask for assistance. Effective treatments are available for many of the symptoms of cancer and for the symptoms caused by cancer treatment.

**Psychological counseling, social services and rehabilitation** are among the support services that should be available to you. Maintain contact information to access the support you may need.



## Demand a Lifetime of Excellent Care

You should feel comfortable asking questions and talking to your medical providers. Make sure they listen to you and respect your point of view. Your decisions and your dignity should be respected.

If you need assistance in finding care or alleviating medical costs, you may find help through support and volunteer groups such as Cancer Care, Inc., and the American Cancer Society.

# Demand a Lifetime of Excellent Care

If your doctor tells you your cancer is incurable, ask questions. Even if a cure is not possible, there may still be treatments that can prolong life significantly, as well as procedures to reduce pain and other symptoms. In fact, most symptoms associated with cancer care and treatment can be managed well.

This is one area where your advocacy may require persistence as these symptoms vary from individual to individual.





# Demand a Lifetime of Excellent Care



Sometimes, in holding out hope, either doctors or patients may insist on very aggressive or controversial treatment when there is little chance that the treatment will prolong life.

The option of hospice care may be overlooked but should be considered because it can often offer individuals dying of cancer comfort and resources beyond what doctors and family alone can provide.

Once you reach a decision, based on sound knowledge and good research, don't second-guess yourself!



## INSURANCE AND EMPLOYMENT RIGHTS

“It was such a relief to know that there was information specifically for people with cancer available on insurance and employment issues.

Once I knew what my rights were in the workplace and under my state’s insurance laws, I could concentrate on getting the best possible cancer care.”

# INSURANCE AND EMPLOYMENT RIGHTS



The maze of bureaucracy and paperwork may seem overwhelming, but it is important to know and understand your rights as a cancer survivor under existing state and federal laws.



Be aware that health insurance coverage and employment protections are not consistent and may depend on your age, the state in which you live, the size of your employer and other variables.



However, an alphabet soup of federal laws, a few of which are presented below, may provide some protection. Other IMMERSION publications deal with these subjects at length. (See Resources)



# INSURANCE AND EMPLOYMENT RIGHTS

The Americans with Disabilities Act (ADA)

The Consolidated Omnibus Budget  
Reconciliation Act (COBRA)

The Federal Rehabilitation Act (FRA)

The Health Insurance Portability and  
Accountability Act (HIPAA)

# INSURANCE AND EMPLOYMENT RIGHTS



Read and understand your health insurance policy or check with your broker or benefits coordinator about your coverage.



If you do not have insurance, check with your state insurance office about other possible coverage, high- risk pools and other options.



To get information about coverage under Medicare and Medicaid, contact the Centers for Medicare & Medicaid Services (CMS) at 800-MEDICARE (800-633-4227).



## INSURANCE AND EMPLOYMENT RIGHTS

If you are a working woman with cancer, try [www.cancerandcareers.org](http://www.cancerandcareers.org) for additional information.

For both men and woman in the workplace, read the newly revised booklet *Working It Out:*

*Your Employment Rights As a Cancer Survivor.* We cannot overemphasize that although situations and conditions vary, state and federal laws and regulations may protect you if you know your rights.

# ONGOING SELF-ADVOCACY



---

“I thought when my active treatment was over, I would return to life as if nothing had happened. I now realize that I must be proactive and vigilant about my care and my health for the rest of my life.”

---

Although suggestions for being a **self-advocate** have been presented during and after treatment, in actuality you must now be an advocate for the balance of your life – not only to receive the care and monitoring that you require, but the social and support services that may be needed.

# DURING TREATMENT

There is no reason to unnecessarily suffer from the effects of treatment or from the disease itself.

There have been many advances in the management of nausea, pain, fatigue, weight loss and depression. Many side effects are not visible and, unless voiced by you, will remain untreated.

Doctors often say that these problems are not reported to them and are therefore untreated or ignored.





# DURING TREATMENT

It is important that you now monitor your body, your psyche and its changes during and after your treatment for cancer.

Keep a record or journal of your treatments and your physical, emotional and mental state – using a measurable scale.

This can be as simple as measuring the intensity of a symptom on a scale from 1 to 5.



# DURING TREATMENT

Ask if your doctor or hospital has already developed such a system for patients. A written record provides a basis of comparison or can indicate a pattern.

You can then take corrective action. For example, you may feel well and energetic in the morning, but end up getting your treatment in the late afternoon when you feel weakest.

Just by changing the time of your treatment, you may see an immediate difference in your reaction and rate of recovery.



# DURING TREATMENT

---

Survivors and their supporters report that you can improve your ability to cope and your quality of life if you:

---

Strongly insist on having a nurse and/or case manager assigned to you and available after hours.

---

Select one family member or friend as your representative if you are unable to speak for yourself. Be sure to inform your health care team in advance.

---

Articulate your symptoms to your doctor. Don't wait to be asked! If necessary, use your journal as documentation.

---

Avail yourself of professional and/or peer support and self-help groups.

---

# AFTER TREATMENT AND FOR THE BALANCE OF LIFE



Now, and for the rest of your life, you must be self-aware, as others cannot, about subtle and not so subtle changes in symptoms such as pain, weakness, fatigue, or loss of appetite.



Take advantage of cancer support services such as pain management clinics; insurance and financial aid- assistance, psychological counseling and therapy.



If such services are unavailable, then advocate for support and referrals in order to receive these services.

# AFTER TREATMENT AND FOR THE BALANCE OF LIFE



Stay informed about new research and developments in the treatment or late effects of your type of cancer. (See long-term and late-effects following this section)



Attend community cancer programs or participate in teleconferences and webcasts that provide credible and current information.



Ask your doctor(s) for a written summary of the treatment(s) received; drugs, dosage, amount of radiation, etc. Maintain this record with your health documents and present it to any new treating physician(s).



Be vigilant about monitoring your own health. Have regular check-ups and talk with your doctor about secondary prevention and monitoring for late effects of treatment.

# LONG-TERM AND LATE EFFECTS

Survivorship statistics are encouraging, but you may be unaware of potential delayed side effects of the illness and its treatment. This is increasingly important as the number of long-term survivors increases.

Currently, follow-up clinics exist primarily for survivors of childhood cancer.

Over the past several years the Institute of Medicine has published several reports on the status of survivorship research.

# LONG-TERM AND LATE EFFECTS



These reports include Childhood Cancer Survivorship: Improving Care and Quality of Life (2003); From Cancer Patient to Cancer Survivor: Lost in Transition (2005); and Cancer Care For the Whole Patient: Meeting Psychosocial Health Needs (2007).

# LONG-TERM AND LATE EFFECTS



These reports demonstrate that after a diagnosis of cancer there is an increased risk of a recurrence (reappearance of disease) or metastases (transmission to other sites in the body), or of a second primary tumor.



There are also other increased risks that vary based on a particular diagnosis and treatment.



# LONG-TERM AND LATE EFFECTS



Familiarize yourself with the specifics of your treatment



Remain alert to the possibility of secondary medical effects



Plan to have regular follow-up visits for the rest of your life

# LONG-TERM AND LATE EFFECTS

Familiarize yourself with the specifics of your treatment

Remain alert to the possibility of secondary medical effects

Plan to have regular follow-up visits for the rest of your life

These suggestions are as true today. **There is now evidence** that treatment may cause or contribute to long-term or subsequent physiologic changes as long as 5, 10, or 20 plus years later.

This is not intended to frighten you, but rather to alert you to the potential problems so that you can be vigilant about your care.

# LONG-TERM AND LATE EFFECTS



Simply by aging, many of us experience these health problems. Organ damage, organ failure, premature infertility, premature aging, compromised immune system and a damaged endocrine system have been identified as some of the potential immediate, mid-range and long-term effects.

These effects may contribute to chronic illness, incontinence, swelling, reproductive problems and psychological conditions.

# SYMPTOM MANAGEMENT THROUGHOUT THE LIFESPAN

The concept of symptom control and adequate pain management from the moment of diagnosis, rather than only at the end stages of disease, is important and empowering for cancer survivors.

You can improve the quality of your life to the extent that you can alleviate and manage the side effects of your cancer and its treatment.

The most commonly used term to describe symptom management is palliation or palliative care. While many people associate these terms with end-of-life care, IMMERSION believes palliative care is essential from the moment of diagnosis through the balance of life.



# WHAT IS PALLIATIVE CARE?

In 2001, the National Cancer Policy Board adopted the World Health Organization (WHO) definition of palliative care in cancer “as active total care of patients whose disease is not responsive to curative treatment.”

The Board issued a groundbreaking report – Improving Palliative Care for Cancer.

The report went on to state that “palliative care focuses on addressing the control of pain and other symptoms, as well as psychological, social, and spiritual distress.”



# WHAT IS PALLIATIVE CARE?

But perhaps most importantly it focused “on the importance of palliative care beginning at the time of a cancer diagnosis and increasing in amount and intensity throughout the course of a patient’s illness, until death.”

Interestingly, the report identified six major skill sets for total and complete palliative care. With the exception of the last skill, you have been developing these skills throughout this training.

- Communication
- Decision-making
- Management of complications of treatment and the disease
- Symptom control
- Psychosocial care of patient and family, and
- Care of the dying



# WHAT IS PALLIATIVE CARE?

Although palliative care is beginning earlier and moving into the mainstream of quality cancer care, you may have to be proactive in demanding it for yourself or for loved ones.

Much of this care is not reimbursed adequately, which partially accounts for it being undervalued by treating professionals.



# END OF LIFE

While cancer survival has improved dramatically over the past few decades, a diagnosis of cancer often raises, for the first time, the prospect of a premature death.

In our culture, we have been reluctant to discuss death or plan for it. Our technological progress, medical training, and progressive health care mindset seek to save lives at almost any cost.





# END OF LIFE

Neither doctor nor patient nor family and friends feel comfortable raising the issue of dying. Consequently, when death appears to be an inevitable outcome of cancer that is no longer responding to active treatment, we often fail to provide a good way to help ourselves, or someone we love, die well.

IMMERSION has been actively addressing the issue of this last stage of survivorship.

**Inevitably**, with half of all cancer diagnoses, there will come a time when no treatment options exist or the prognosis for extended survival is poor.



# END OF LIFE

“**Hope is flexible**, and it remains open to various possibilities and the necessity to change the desired outcome as the reality changes.”

You Have the Right to Be Hopeful presents the many and changing meanings of hope – among which is the “hope for a dignified death.”

The **advocacy skills of information seeking, communication, problem solving and negotiation** take on special importance when making decisions about discontinuing treatment or how and where you wish to die.

# END OF LIFE

Recent studies show that people become more comfortable and appear to die more peacefully when they have planned for their death in advance and communicated these wishes to others.

At the end of life one can still be proactive if provisions have been made in advance.

In 1990, the United States Supreme Court ruled that the Constitution gives individuals the right to control their own medical care, however, you must provide **“clear and convincing evidence of your desires in the form of an advance health care directive.”**



# END OF LIFE

Educate yourself about end-of-life issues and advanced care planning (medical living wills and durable powers of attorney that vary by state). Contact Choice in Dying at 800-989-WILL (800-989-9455) or [www.partnershipforcaring.org](http://www.partnershipforcaring.org) for information and state-specific forms.

The National Cancer Institute and the American Cancer Society, among others, are updating materials for people with advanced cancer.

- Meet with experts in this type of planning: a peer counselor, hospital social worker, a spiritual or bereavement counselor, or a hospice representative.
- Prepare a will and put your affairs, legal and otherwise, in order.
- Make your wishes known in advance. Choose someone to act as your proxy that will be willing and able to carry out your wishes.



## END OF LIFE

Fortunately, many of us will go on to lead long, satisfying and meaningful lives after a cancer diagnosis. This opportunity may lead to interest and involvement in other kinds of cancer advocacy.



The background features a light gray base with a large, soft-edged olive green shape on the right and a large, soft-edged terracotta shape on the left. In the top left corner, there is a faint, stylized illustration of a leafy branch. The main text is centered and reads:

# thank you for attending the Immersion Cancer Advocacy Training

Knowing Is Everything  
Because Everyone's Journey IS Different!