

Resources for Accessing Whole Person Cancer Care

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This is produced as an educational resource. All health decisions should be made in consultation with your health care team.

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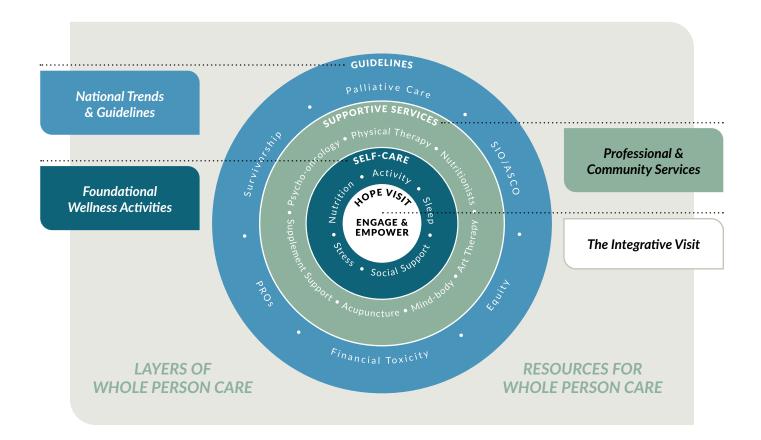
Introduction

his booklet provides tools and resources that can be a part of a whole person approach to cancer care today. The evidence-informed approaches we included in this guide may help to relieve cancer symptoms and reduce treatment side effects when used alongside conventional cancer treatments.

If you are interested in a breast cancer specific guide to integrative oncology, please see our Integrative Breast Cancer Guide.

You will find succinct summaries of the evidence and applications for these care tools in addition to answers to some of the questions you might have about each one. We will also point to the best sources for credible information to explore each further.

The figure below shows the "layers" of care these tools are drawn from, with the HOPE Toolkit (used by the care team) in the center, followed wellness and self-care, integrative and supportive care services, and national and international guidelines that support and broaden the type of care a person receives. Tools and resources from each of these layers will be summarized with links included to sources of additional information.



Self-Care: What can I do to support my own healing through self-care and behavior change? How can my own health journey help me lead people facing cancer to new levels of health and healing? What are the foundational wellness activities that I should consider to feel my best?

- Activity (movement/exercise, yoga, tai chi)
- Nutrition
- Sleep
- Social support
- Environment/healing spaces
- Spirituality
- Herbs and supplements

Supportive Services: What non-drug and integrative practices can I safely tap into to reduce side effects? Are these modalities affordable? What, if anything, is covered by insurance? Where are the best places for me to learn about these modalities?

- Acupressure and acupuncture
- · Psycho-oncology, mind-body and energy medicine
- Mindfulness, meditation, relaxation
- Massage
- Music therapy
- Art therapy

ART THERAPY POCKET GUIDE

FAST FACTS

- In addition to being used for treating psychological and medical conditions, art therapy has been shown to produce general benefit by reducing everyday stress and increasing self-esteem and quality of life.
- To heal the invisible wounds of war such as mild and moderate traumatic brain injuries and post-traumatic stress disorders, the military and VA offer art therapy in many centers such as the National Intrepid Center of Excellence Healing Arts Program.¹

WHAT IS ART THERAPY?

Art therapy is a form of clinical intervention that uses art as the primary mode of expression and communication. The art therapist uses creativity to help achieve personal and treatment-related goals. The patient uses and makes art as a way to convey feelings at that moment or about a particular experience or situation.

When people are experiencing intense, complex or confusing emotions, the use of art in a therapeutic setting can help them manage and communicate their feelings in ways that language cannot always accomplish. You do not have to be good at or an experienced artist to enjoy the benefits of art therapy.

What can I expect to happen during art therapy?

Although art therapists are trained to treat a number of different psychological or emotional issues, some therapists will specialize in certain conditions. Confirm that your therapist is equipped to address your particular concern.

Art therapy can be done in groups or in individual sessions. Before you seek treatment, make sure that you are choosing what you or a trusted healthcare practitioner believes will work best for you.

Is there evidence that art therapy works?

In the last 20 years, as patients increasingly integrate art therapy into their treatment plans, more and more literature is being published exploring and confirming the positive impact of art therapy for treating certain conditions. This includes for:

- Trauma²
- Depression, anxiety and phobias³
- Burnout, fatigue and quality of life for End of Life/Hospice Care Workers⁴
- Physical and psychological symptoms relating to cancer⁵
- Anxiety and quality of life in children with asthma⁶

What conditions does art therapy treat?

Art therapy is used to treat both physical and mental health conditions and address symptoms related to chronic health concerns including:

- Post-traumatic stress disorder/trauma recovery
- Grief/loss treatment
- Addiction recovery
- Depression
- Panic disorder
- Anxiety
- Asthma
- Cancer symptoms
- Neurodegenerative diseases
- Managing undesired behavior

Are there precautions, side effects or safety concerns I should be aware of before I start art therapy?

Art therapy is widely considered a safe way of addressing physical and mental conditions when delivered by a well-trained certified art therapist. Any form of therapy can unearth uncomfortable emotions and may cause you to experience increased levels of psychological discomfort. Reliving traumatic experiences is difficult and if it isn't handled correctly can negatively impact an individual's psychological and/or physical health.

What training/certifications/licensing does an art therapist need on order to practice?

Currently, there isn't a nationally recognized unified set of required guidelines and certifications an individual must obtain to act as an art therapist.

Licensure Guidelines

Thirty-nine states regulate the licensure of art therapists, and these requirements vary by the state in which the therapist is practicing. Typically, art therapists are licensed as an art therapist, creative art therapist, or professional or mental health counselor. To find out your state's current licensing requirements of art therapists, visit arttherapy.org/stateadvocacy

Educational Requirements

To be recognized as an art therapist, an individual must have completed graduate level education in art therapy or in a related counseling or psychological field. The American Art Therapy Association also requires that students have completed certain courses during their graduate program in order to apply for licensure. To find more information on recognized graduate programs and the courses art therapists are required to take, visit arttherapy.org/educational-standards

Board Certification and Registration

• Currently, the American Art Therapy Association oversees and certifies the registration of art therapists. In order to be registered, a therapist must have completed a graduate program in art therapy from an accredited university, completed an internship/clinic hours supervised by a professional clinician and pass a nationally recognized exam. To learn more about the certification process, visit www.atcb.org/ Public/AboutTheCredentials

How do I find an art therapist?

The best place to locate a certified art therapist who meets the certification and educational requirements of the American Art Therapy Association is to visit arttherapy.org/art-therapist-locator

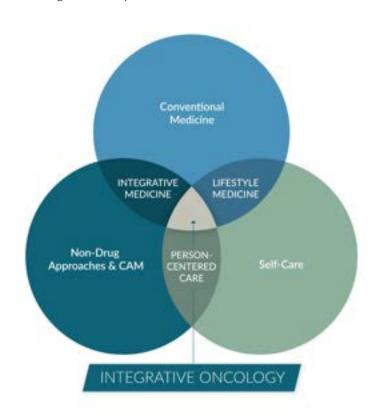
Will my insurance company cover the cost of seeing an art therapist?

A therapist who strictly identifies as an art therapist is most likely not going to be covered under your insurance policy. Whether your insurance company covers your art therapy is mostly dependent on your therapist's training, license and how your state classifies art therapy as a profession (see training/certifications/ licensing section).

Some insurance companies will cover treatment and recognize the services of therapists trained in particular therapeutic interventions that accompany the art therapy such as traditional therapy services.

Should I inform my primary care physician that I am seeing an art therapist?

It is important when deciding to see an art therapist to let your primary care physician and any of your other healthcare providers know that you would like to include art therapy in the tools you are using to address your medical condition or concern.



- 1 National Intrepid Center of Excellence. The NICoE Healing Arts Program. http://www.nicoe.capmed.mil/Shared%20Documents/Healing%20Arts%20 Program(AEM)_Fact%20Sheet%20FINAL2_2012%2006%2018.pdf Accessed October 17, 2017.
- 2 Schouten, K. A., de Niet, G. J., Knipscheer, J. W., Kleber, R. J., & Hutschemaekers, G. J. M. (2014). The Effectiveness of Art Therapy in the Treatment of Traumatized Adults. Trauma, Violence, & Abuse, 16(2): pp. 220-228.
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YOUNG ADULT AND TEEN **CANCER POCKET GUIDE**

Coping with cancer between 15 and 39

FAST FACTS

- In 2020, there were approximately 89,500 new cases of cancer among people aged 15-39.1
- Teens and young adults are more likely to be diagnosed at later cancer stages than older people. Reasons include not having insurance, not having routine tests to look for cancer, and being younger than the age when most people develop cancer.

WHEN TEENS AND YOUNG ADULTS HAVE CANCER

For the most part, cancer happens in older adults. According to the American Cancer Society, only about one in 20 people with cancer is a young adult aged 20–39.2 The broader category called "adolescents and young adults" includes people who are diagnosed with cancer between the ages of 15 and 39. So, if you feel like you wandered into the wrong waiting room at your oncologist's office, you're right—most people with cancer are older. Help and support are available, but you may need to look for it. This pocket guide and the tools that go with it are designed to help you do just that.

THE BEST CARE STARTS WITH YOUR QUESTIONS AND NEEDS

Health-care providers and researchers know that adolescents and young adults, or AYAs, face unique challenges. These are mostly related to dealing with a disease during the life stages where you would normally focus on building your adult life through school or training, work, relationships, and family.

Jennifer Bires, MSW, LICSW, OSW-C, is a certified oncology social worker who specializes in working with adolescents and young adults. She is executive director of life with cancer and patient experience for the Inova Schar Cancer Institute in the Washington, D.C., metropolitan area. She suggests each person ask the following questions of their health-care providers:

- How will treatment impact by ability to work or go to school?
- What side effects should I expect, and how will they impact my quality of life?
- Will any of the treatments I am being prescribed impact my fertility?
- How can I reduce the risk of long-term side effects from treatment?

It can be hard to find information about prognosis since so few people are diagnosed as young adults, which may mean the statistics you can find online represent a group of patients who are typically diagnosed at a later stage in life. If this information find in the literature might apply or not apply to your situation.

is important to you, don't be afraid to ask your doctor for more information or help in understanding how the statistics you can

	How will my parents, siblings, boyfriend, girlfriend, or spouse
C	ope? What about my young children?

Other questions that might be on your mind:

- How can I relate to staff and other patients at the hospital or cancer clinic? If my cancer is common in children, I might be seeing a pediatric cancer specialist (pediatric hematologists/ oncologists). If it is more common in older adults, I could be the youngest person in the waiting room. Where is my peer group?
- Should I choose a doctor who specializes in my cancer/ cancer subtype?
- How can I reduce the risk of long-term side effects from treatment?
- How will cancer and treatment affect my ability to find a partner and have children (if desired)?

"It's important to bring up topics that are important to you, otherwise your treatment team may not know they are on your mind," says Bires.

You may want to reread the list above and place a check mark by any questions you have. Then feel free to share them with your health-care provider or a social worker on your cancer care team.

Integrative health solutions for AYA challenges

Feeling isolated

No matter where you are in life—a college athlete, pregnant mom, or a young professional—all face the challenge of isolation in dealing with cancer. Cancer can put you out of sync with the people around you. Friends, neighbours, and co-workers don't understand the fear, fatigue, and hours of appointments. And because of their ages and differing life stage, they probably know few other people your age with cancer. Who can you talk to?

Social connection is the solution for this AYA cancer challenge. You can:

- Ask your health-care team to refer you to a support group for people your age.
- Join an online group, search a hashtag on social media that relates to your cancer (i.e., #BreastCancer) or visit a website specifically for younger people with cancer. See the Resources section below for a list of organizations.
- If you don't have online access, talk with a social worker on your health care team. They can help you find resources for equipment, Wi-Fi connections, or in-person support.

Want to engage your friends but don't know how to start the conversation?

- Consider writing a journal online or creating a blog that outlines your cancer journey. You can simply share a link without having to verbally tell people how you are and where you are in treatment again and again.
- Identify needs such as meals, help with housework, and other areas where friends and family can help. Appoint a close friend to communicate these areas of need with your social circle.

Read our blog post <u>How Emotional Connections Can Help</u> You Heal.

Planning your family

Bires says cancer specialists may not bring up the fact that for adolescents and young adults, cancer treatment could affect their ability to have children in the future. "They may not feel comfortable talking about it, there may not be time to do anything because treatment needs to start right now, or finances may be a concern," says Bires.

However, simply talking about cancer treatment's effects on future fertility can be reassuring, even if no practical steps (like banking sperm or freezing eggs) are possible. Asking specific questions about your fertility can help you get the information you need to know what's ahead. You can ask:

- Will my cancer treatment affect my ability to have children?
- I want the option of having children later. How can we protect my body during treatment or preserve eggs, ovarian tissue, or sperm for the future?
- How much does it cost to freeze eggs, ovarian tissue, or sperm? Who can help me learn more about these procedures, costs, and timing?
- What are my options if biological children are not possible?

Jenny Leyh, a breast cancer survivor who was diagnosed in 2016 while pregnant with her daughter, worried about the health of her baby and wondered how treatment may affect her ability to have more children once treatment ended.

"The diagnosis alone was terrifying, but I also worried that the treatment would make me infertile," said Leyh, who was 33 years old at the time of diagnosis. "My doctors brushed it off, saying 'you're young, there's no reason to think your body won't bounce back.' But the fact is many women go into early menopause after treatment for breast cancer. I was lucky that I was able to naturally conceive another baby a few years after cancer treatment ended, but not everyone has this experience. I wish my doctors had listened to my concerns and included a fertility specialist in my care team. Because of the aggressive nature of my cancer (triple negative breast cancer) treatment could not wait, and there wasn't time to discuss options, and that just added to an already high level of stress."

Dealing with sex and relationships

The book and movie The Fault in Our Stars include physical intimacy between two teens with cancer. Having sex, marrying, and having children are important emotional and physical milestones that many teens and young adults with cancer worry about missing. Depending on your beliefs and wishes, this can be a worry or regret.

You may also wonder, "Who will ever want to be with me if I have these scars, look like this after treatment, or have a permanent medical device attached to my body (such as a colostomy bag)?" Education and talking with peers can both help. You will likely be surprised at how many people live active lives and meet new partners even when they have colostomies and scars. We created a free, downloadable Cancer and Sexuality Pocket Guide to point you to educational resources and options for supporting this important part of your body, mind, and spirit.

Risky behavior

Having a life-threatening illness can lead to risky behavior, especially for teens. The desire to escape reality can also lead to overuse of alcohol and other substances—but some of these can cause severe side effects when taken with cancer medications.

Acknowledging that you might want to take physical risks or use substances is important. So is asking, "Why?" An organization like First Descents or Epic Experience can help you find adventures

and activities that boost your mood and provide excitement and meet other young adults with cancer with fewer negative consequences.

Talk with your health-care team about whether drinking alcohol or using marijuana or other substances is safe and how much. "There's 'completely unsafe, not recommended, but safer, and possibly safe," says Bires. Having the information can help you make better choices.

Insurance

Teens and young adults are often without the same insurance coverage as older or younger people with cancer. Before the Patient Protection and Affordable Care Act was passed in 2010, as many as 1 in 3 young adults with cancer did not have health insurance coverage.³ The age range of 15 to 39 includes people who still use a parent's insurance coverage, those who may not have coverage through a job or spouse, and those with job- or school-related insurance that can change if the job ends or they graduate.

Looking at all your potential sources of health insurance coverage can be helpful. Also, talk to your health-care team. Most hospitals and clinics have financial counselors who can work with you to meet the cost of care even if you have a high-deductible insurance plan or need to apply for state insurance coverage. They can also connect you with many discount programs from drug manufacturers.

Work

Can you work when you have cancer? Will you keep your job during treatment? Having cancer can affect your job prospects and earnings for many years.4 If possible, plan what to do ahead of time. Options include:

- Using long-term disability insurance.
- Staying with a friend or family member.
- Applying for Social Security disability income if you cannot work.
- Simply taking time off, if you have financial support from someone in your household.

Being a survivor

When you start cancer treatment, you may be concerned with possible health issues that may arise later in life due to effects of chemotherapy, surgery, or radiation. Survivors of adolescent and young adult cancer can face "late effects" including:

- Reduced ability to have children.
- Health problems, including later cancers and problems caused by cancer treatment, such as heart problems from radiation therapy.
- Hormone problems.
- Nerve damage.

Ask your health-care team about what late effects your cancer and its treatment can cause. It's never too early to say you want a "survivorship" plan, with appointments, tests, and preventive medicine in order to thrive after cancer.

Resources

Most of these resources are free or low-cost.

- Camp Kesem Support for children of cancer survivors during and beyond cancer treatment.
- Colontown An online community for people living with colon or rectal (colorectal) cancer, their caregivers, friends, and family members. Apply to join.
- Dana-Farber Cancer Institute Websites for Young Adults with <u>Cancer</u> — Links to many websites, including support for college students with cancer, career support, information on fertility, and more.
- For the Breast of Us For women of color diagnosed with breast cancer, many of whom are younger than age 40.
- Stupid Cancer Welcome to the club you didn't ask to join. Many types of support, from groups to how to be your own advocate and more. Specifically for teens and young adults.
- <u>Teen Cancer America Resources</u> From financial and educational help to wigs and outdoor adventures, Teen Cancer America provides a huge list of organizations offering support.
- Young Survival Coalition For young adults facing breast cancer, with many resources, workshops, and opportunities to connect with fellow survivors and thrivers.

Fertility Support

Looking for an onco-fertility specialist in your area? The OncoFertility Consortium includes a search option on their website where you can locate specialists in your state.

For the AYA cancer patient, this fund specifically addresses that population: www.thesamfund.org/get-to-know-us/about-us

More Pocket Guides and Tools

- The Pocket Guide to Nutrition and Cancer
- The Pocket Guide to Movement and Cancer
- An Integrative Approach to Your Reproductive Health
- Your Healing Journey: A Patient Guide to Integrative Breast Cancer Care
- Your Healing Journey: A Patient Guide to Optimal Healing **Environments**
- How Healing Works: Get Well and Stay Well Using Your Hidden Power to Heal [book] by Dr. Wayne Jonas

My notes and questions			

Conventional Medicine INTEGRATIVE LIFESTYLE MEDICINE MEDICINE PERSON-CENTERED CARE Non-Drug Approaches & CAM INTEGRATIVE ONCOLOGY

References

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- JCO Oncology Practice 2021 17:6, 302-304Ketterl TG, Syrjala KL, Casillas J, et al. Lasting effects of cancer and its treatment on employment and finances in adolescent and young adult cancer survivors. Cancer. 2019;125(11):1908-1917. doi:10.1002/cncr.31985

BIOENERGY MEDICINE POCKET GUIDE

FAST FACTS

- Cancer Treatment Centers of America has integrated energy medicine into their treatment options for patients and self-care for hospital staff.
- Reiki is a form of bioenergy used on military bases to assist veterans coping with post-traumatic stress and addiction.
- Therapeutic touch was recognized in 2005-2006 as part of NANDA International's guidelines (NANDA-I was previously called North American Nursing Diagnosis Association).

WHAT IS BIOENERGY MEDICINE?

Bioenergy medicine includes a number of different therapeutic interventions where a therapist helps to harness or manipulate a patient's subtle energy in order to help restore the body's balance and improve the body's ability to heal. These "subtle energy" therapeutic interventions have been described and used for thousands of years by systems such as Traditional Chinese Medicine and Traditional Indian Medicine, and by faith healers through approaches like "laying-on-of-hands." The most commonly used bioenergetic therapeutic interventions are Therapeutic Touch/Healing Touch, Reiki, Qigong, and the laying-onof-hands.

How does bioenergy medicine work?

We don't know. Current understanding of subtle energy medicine diverges from accepted principles in physics, chemistry and biology. Until an understanding of the practice can be accepted that is in line with current science, it will continue to be called pseudoscience by skeptics in the field.

Explanations often focus on the makeup of the human biofield (detectable or undetectable amounts of light that the body emits), but the medical and scientific fields have not yet accepted subtle energy healing as a valid form of medical treatment in part because there is no known mechanism by which it works.

Different theories include quantum mechanics, biophotons, intention and suggestion, placebo and unmeasured energy fields.

Advocates of the therapy say that because scientists don't know how it works, they may not be controlling for proper factors or have the right instruments to measure it. This creates issues with being able to reproduce results of studies; reproducibility is a major issue when studying energy medicine.

What are the different types of bioenergy medicine?

Qigong

• Qigong is an ancient Chinese practice that uses gentle movements, meditation and controlled breathing to restore energy or "qi." According to the National Qigong Association, Qigong practices can be classified as martial, medical or spiritual. All styles have three things in common: they all involve a posture (whether moving or stationary), breathing techniques and mental focus. Some practices increase the qi; others circulate it, use it to cleanse and heal the body, store it, or emit qi to help heal others.

Reiki

• Reiki is a practice along the lines of meditation, yoga and tai chi. Reiki was formulated to be a practice primarily for selfcare. The hands-on practice can also be offered to others to gently encourage self-healing.

Healing Touch

 Healing touch is a form of energy medicine in which practitioners consciously use their hands and mind in an intentional way to promote healing by manipulating the human biofield. The goal of Healing Touch is to restore balance and harmonies in the energy system, placing the client in a position to self-heal.

Therapeutic Touch

• Therapeutic touch is a form of energy healing by which the healer places his or her hands on or near a patient's body and detects and manipulates the healee's energy.

Laying-on-of-hands

Laying-on-of-hands is a spiritual practice that appears in Christian, Jewish, Muslim and other faith traditions throughout the world. Hands are placed on an individual in conjunction with prayer to provide healing or blessings.

What can I expect to happen during my session with a bioenergy medicine clinician?

Do Your Research

Make sure you research the different types of bioenergy medicine to be sure you are choosing the practice you believe is right for you. When you call to set up an appointment, speak with the practitioner to see if you are comfortable with their demeanor and how they conduct their practice. It is important you feel comfortable with your chosen practitioner.

Is there evidence that bioenergy medicine works?

In the last 20 years, as patients increasingly integrate complementary and alternative medicine into their treatment plans, more and more literature is being published exploring the impact of bioenergy for certain conditions. The following is a short summary.

Reiki for Burnout

Reiki in comparison with a sham intervention significantly decreased burnout symptoms of community mental health workers.1

Reiki for Cancer Patients

A program evaluation of a Reiki program of 213 patients collected pre- and post-program surveys from them about their experience with Reiki and their symptoms following participation in the Reiki program. The program evaluation found that participants reported a decrease in distress, anxiety and pain, and 173 of the patients would continue using Reiki and most of them would recommend it to others. When patients were interviewed they reported that Reiki cultivated a feeling of relaxation and enhanced spiritual well-being.²

Healing Touch for Pediatric Oncology Patients

Pediatric oncology patients who received Healing Touch experienced significant decreases in the scores for pain, stress, and fatigue.3

Healing Touch on Postsurgical Adult Outpatients

• A prospective pilot study found that postsurgical adult outpatients who received Healing Touch reported decreased anxiety and pain and a trend toward a decrease in the use of narcotics.4

Biofield Therapies for Palliative and End-of-life Care Patients

A structured review of bioenergy medicine therapies including Healing Touch and Therapeutic Touch for managing symptoms experienced by palliative and end-of-life care patients found that studies supported the use of bioenergy medicine in these populations; these studies reported that patients were better able to manage their pain, improving their quality of life and decreasing physiological indicators of stress.5

Healing Touch and Post-Traumatic Stress Disorder (PTSD)

• A randomized study of Healing Touch combined with relaxation imagery CDs vs usual care in 100 Marines with PTSD found that Healing Touch and relaxation imagery CDs reduced symptoms and improved the wellbeing of Marines compared to usual care alone.6

If you or your healthcare provider would like to read more, visit www.ncbi.nlm.nih.gov/pubmed

What conditions does bioenergy medicine treat?

Note that you may find claims that bioenergy can cure cancer and other major diseases on the internet. There is no reliable data that this is true and to use bioenergy instead of proven treatments for these conditions is dangerous. Primarily, different Bioenergy medicine practices are used to improve wellbeing and help reduce symptoms related to chronic health concerns and not to cure the disease. Examples of conditions in which Bioenergy has been used for symptom management include:

- Fibromyalgia
- Sleep apnea
- Restless legs syndrome
- Allergies
- **Bronchitis**
- Addiction
- Lupus
- Alzheimer's disease
- Chronic pain
- Cancer symptoms
- Anxiety
- Depression
- Burnout
- Fatigue
- Insomnia

Are there concerns I should be aware of before I start bioenergy medicine?

Bioenergy medicine is widely considered safe when delivered by a well-trained certified bioenergy practitioner, provided it is not used as a substitute for a proven treatment.

Potential

Precautions

- Psychotic illnesses such as schizophrenia
- Swelling/Inflammation
- Pain that is undiagnosed
 - Including joint pain and pain where there is cancer present

Side Effects

- Increased thirst
- Restlessness
- Anxiety
- Fever
- Mental "spacy-ness"

How often should I seek treatment from a bioenergy medicine clinician? How long is each session?

How often and for how long you will seek treatment from a bioenergy medicine clinician depends on why you are seeking help and the type of therapy you are seeking. Sessions with your practitioner can run anywhere from 20 minutes to an hour.

What training/certifications do bioenergy practitioners need to have?

Currently, there are no nationally nor state-recognized certification, training or licensure programs for a majority of the bioenergy practices. There are many independent organizations that lead trainings and provide certifications to individuals who either take their courses or meet their qualifications. Before seeking the treatment of a bioenergy medicine practitioner, ask for their qualifications and research the organization where they received them.

Healing and Therapeutic Touch Certification

The Healing Touch Certification Program (www.healingtouchprogram.com) has been recognized or endorsed by the National Commission for Certifying Agencies (NCCA), the American Holistic Nurses Association (AHNA), National Certification Board for Therapeutic Massage & Bodywork, the NANDA and both the American Nurses Credentialing Center and it's Canadian equivalent.

To certify as a healing touch practitioner, individuals must complete the Healing Touch Program's coursework levels 1-5 and receive a certificate indicating that they have passed and completed all of the coursework (www.healingtouchprogram.com/ classes). Additionally, practitioners must also take and pass The Healing Touch Certified Practitioner Entry Level Proficiency Exam.

To maintain certification, the practitioner must complete a renewal packet every five years indicating and providing proof that s/he has not faced any ethical violations, continues to regularly practice and has participated and completed continuing education classes.

Although there are no official training guidelines, the following websites can help you ask the right questions and address the training qualifications prior to seeing a practitioner for your first session.

- www.umm.edu/health/medical/altmed/treatment/ therapeutic-touch
- www.takingcharge.csh.umn.edu/explore-healing-practices/ reiki/how-can-i-find-qualified-reiki-practitioner

How do I find a bioenergy practitioner?

Depending on the type of bioenergy treatment you are seeking, visit:

Reiki

- iarp.org/find-reiki-practitioner-teacher/
- www.reikimembership.com/MembershipListing.aspx

Therapeutic Touch

- therapeutictouch.org/
- www.umm.edu/health/medical/altmed/treatment/ therapeutic-touch

Healing Touch

• www.htpractitioner.com/find-a-practitioner

Qigong

- www.qigonginstitute.org/directory
- www.nqa.org/index.php?option=com_mcsearchresults&view= search&uuid=cfe925f8-fa56-4fda-9d85-be4a1dba5d54#/

How much will a bioenergy session cost me?

The cost of receiving bioenergy treatment will vary based on location, provider and extent of services needed.

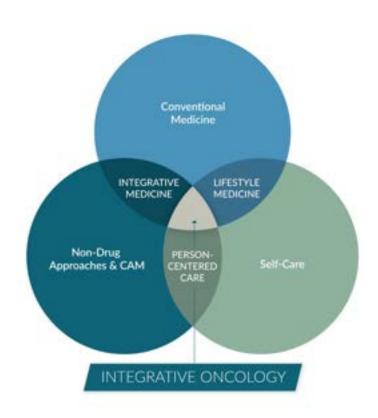
Will my insurance company cover the cost of seeing a bioenergy medicine clinician?

Currently, bioenergy medicine is not covered by most insurance. Nevertheless, there are certain clinics and hospitals whose nurses and/or employees are trained in bioenergetic medicine practices and their services are offered for free. You should ask about this at your hospital or clinic.

Should I inform my primary care physician that I am interested in receiving bioenergy treatments?

To receive the best treatment and effectively address your psychological or physical condition, it is best to openly communicate with all of your healthcare providers. Open communication can help you and your healthcare providers properly integrate care, avoid complications that may arise from interactions between therapies and improve provider-patient

Bioenergy medicine can be used alongside any conventional treatments you are receiving; bioenergy medicine is not meant to take the place of proven conventional care. Any decisions regarding treatment should be discussed with your doctor(s) prior to making changes to your treatment plan.



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THE POCKET GUIDE TO CANCER PAIN

FAST FACTS

- Pain is a common cancer side effect. At least 20 to 50 percent of people with cancer report having pain.¹
- Cancer pain can be caused by injury to the nerves, cancer spreading to the bones or other structures in the body, and inflammation.²

MEDICATIONS FOR CANCER PAIN

Medications are the most common solution offered for cancer pain. These may be over-the-counter pain medications such as acetaminophen (Tylenol) or ibuprofen (Advil) or strong prescription pain medications called opioids, such as oxycodone (OxyContin). Some medications can also help treat chemotherapy-induced peripheral neuropathy (CIPN).

You might be concerned that taking opioids will cause addiction. But this is not always true with cancer pain. In fact, undertreating pain because of fear of opioids might be more harmful for some than using them. If you have a history of drug or alcohol dependence, be sure to discuss it with your doctor before you start taking opioid medications. Read about the <u>3 Keys to Avoiding Opioid Dependency</u>.

Medications are not your only option. Ask your doctor about ways to manage cancer pain besides medications. It's OK to think outside the box when it comes to cancer pain.

Other ways to manage cancer pain

All medications have side effects, and these can be different for different people. If you do not like the side effects of your medication, talk to your doctor or someone else on your health care team. They may be able to change the dose or the medication to keep you more comfortable while relieving pain.

You can also try other ways of managing pain. Mind-body treatments such as guided imagery have been shown to lower the intensity of cancer pain and to help in other ways.³ You can try these techniques to manage pain whether you take medication or not.

- Massage
- Guided Imagery
- Breathwork
- Meditation
- Music Therapy
- Using sensory methods, such as <u>scrambler therapy</u> ⁴
- Exercise This can relieve muscle pain and tension.
- Acupuncture

Choose a mind-body pain relief solution using this free tool.

It might not be possible to control all your pain without medication. However, you may be able to reduce the amount you take, take less powerful medications or take them less often. For example, even if you have bone pain from cancer, you might still need opioid medication, but you might be able to take less of it.

Consider tracking your symptoms

The American Cancer Society has a <u>free pain tracker</u> to help you understand your cancer pain. This can help you talk with your doctor or health care team about options for pain relief.

FAQs about cancer pain

Does all cancer cause pain?

Not necessarily. Many people with cancer do have pain at some point in their disease or treatment, but not everyone does.⁵ Talk with your doctor if you are concerned about whether your type of cancer is likely to cause pain or what treatments might be painful.

Can cancer pain be controlled?

Almost always. From medication to relaxation, there are many ways to manage pain from cancer and its treatment. This guide and information at HealingWorksFoundation.org gives you information on pain that you can share with your doctor and health care team.

How can meditation or breathwork help my pain?	My notes and questions
These practices cause something called the "relaxation response" in your body. It cn lower your stress, calm fear and anxiety, and reduce tension and pain. Learn more in our <u>Pocket Guide to Breathwork</u> , available as a free download. You can <u>try meditation with Dr. Jonas</u> here.	
I'm afraid to be physically active when I have cancer. Is it really safe?	
Check with your doctor first. But studies show exercise can help relieve pain and has other benefits, too. ⁷ Learn more about increasing your body's ability to heal with exercise. You can also download a free Pocket Guide to Movement and Cancer.	
Find information on <u>Physical Activity and the Cancer Patient</u> from the American Cancer Society.	
Can I use cannabis products, like medical marijuana or CBD, for cancer pain?	
Medical cannabis products are legal to use for medical purposes in most U.S. states, but the U.S. federal government still considers them to be mostly illegal to use.	
Talk with your doctor or health care team about cannabis products. Under U.S. federal law, your doctor or other health care provider is not allowed to prescribe these for you but can <i>recommend</i> them. Research has shown that cannabis products are helpful in reducing pain and most oncologists believe they are useful but do not feel like they have enough information to discuss with their patients. Some people can effectively lower their opioid medication dose when they add cannabis.	
How is palliative care different from hospice care?	
If you have pain during active cancer treatment or are experiencing pain after treatment ends, it can be very helpful to work with a health care provider who specializes in "palliative care."	
Many people think palliative care is the same as hospice care because both focus on relieving symptoms and helping you have the best quality of life possible. Hospice care starts after cancerdirected treatment is stopped, and includes palliative care. A person receiving hospice care is not expected to survive their illness.8 But palliative care is possible at any time. It can help you find solutions to cancer symptoms, treatment side effects and even	

the stress and anxiety of going through treatment.

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CANNABIS AND CANCER POCKET GUIDE

FAST FACTS

- As of January 2022, more than 35 U.S. states and four U.S. territories allow medical use of cannabis products. Non-medical (recreational) use is legal in 18 states.² Learn more at the National Conference of State Legislatures website.
- Pharmaceutical companies had cannabis products available for doctors to prescribe in the U.S. until 1942.1

SUMMARY

Cannabis is a plant (botanical) substance that can help relieve symptoms of cancer and is used during its treatment, including for:

- Anxiety
- Insomnia
- Nerve problems (neuropathy) and other pain

The cannabis plant contains more than 400 chemical substances, including over 100 called cannabinoids. The effects of most of these are not yet studied. The substances most readily available in integrative health products are THC (delta-9tetrahydrocannabinol) and CBD (cannabidiol).3

THC is responsible for the "high" found in some cannabis products, while CBD does not produce this effect.4 Other cannabinoids you may hear about include CBN, CBG, and delta-8-THC.

So far, research has not found that cannabis helps destroy or reduce cancer cells in the human body, though some test tube research has been promising.

Definitions

Understanding cannabis can be overwhelming for cancer patients to navigate, especially considering the different terms. Here's a breakdown of some of the top and most common terms with their definitions.

A dispensary is a shop where cannabis is sold for medical or recreational use.

A **budtender** is an employee of a dispensary and should be able to answer your questions about cannabis and refer you to products that may address your specific needs.

There are three **strains** or types of cannabis. A strain is categorized as an indica, sativa, or hybrid. Within those categories, there are many different strains with names like OG Kush, Acapulco Gold, and Pineapple Express, which have different effects.

Indicas generally have a relaxing effect on the user while sativa is known to have an energizing effect. A hybrid is a combination of the two.

Tetrahydrocannabinol (THC) is an active ingredient found in cannabis that produces the "high" sensation that many users describe.

Cannabidiol (CBD) is the second most prevalent active ingredient found in cannabis and does not cause a high.

What is cannabis?

Cannabis is a species of plant that includes both hemp and marijuana. The plant likely originated in Asia, then spread to Europe between 1 and 2 million years ago.⁵ It may also have been used as a cancer treatment for thousands of years. A woman who lived almost 3,000 years ago in Siberia was found buried with cannabis. An MRI of her body showed she had metastatic breast cancer that had spread to her bones.¹

Cannabis and cancer

"Cannabis use has always been fairly prevalent in cancer," says Greg Garber, LCSW. Garber is the director of Patient Support Services at the Sidney Kimmel Cancer Center at Jefferson Health in Philadelphia, Pennsylvania. The center developed a clinical cannabis program after Pennsylvania legalized medical cannabis in 2016.

"With broader legalization, the stigma has begun to disappear," Garber says. "The increased dialogue allows us to educate people with cancer, reassure them, and talk through the evidence-or lack of it-for cannabis products."

For many patients, the use of cannabis to combat some of the side effects of cancer treatment, such as nausea or insomnia, is a welcome therapy. April Stearns, founder and editor of Wildfire Magazine, a publication dedicated to sharing the stories of young breast cancer patients, has found cannabis useful through treatment and beyond. Stearns, now a 10-year survivor, says that the great thing about cannabis now is that there is a wide range of products available-from edibles to tinctures to salves-allowing for different methods of consumption beyond smoking. There are also different concentrations available so that patients can explore and find what works best for them.

"It doesn't have to be 100% one thing," says Stearns. "So, you can get the effect you want and minimize any reaction you don't, such as wanting pain relief without feeling high. Or if you had problems with paranoia in the past, you would want to emphasize indica over sativa. I mention this because I tend toward paranoia when high, so I had sworn off cannabis because I didn't realize I could get the benefits without the paranoia."

Your provider may not be able to answer all your strain-specific questions, but a qualified budtender at a dispensary should be able to lead you in the right direction. Not all dispensaries are equal, so take your time finding one that makes you feel comfortable and has knowledgeable staff that can help you find the products that will work for you.

For more information about cannabis use as a cancer therapeutic, review the National Cancer Institute's 2020

Is cannabis safe?

Donald Abrams, MD, an integrative oncologist at the UCSF Osher Center for Integrative Health and professor emeritus of medicine at the University of California San Francisco, has observed cannabis and researched use by people with cancer, AIDS, and other conditions for more than 30 years. He notes that cannabis has a relatively good safety profile. No deaths from overdose have been reported, and the chance of physical addiction is low.

However, Garber and Abrams agree that you may want to skip cannabis or use extra caution if you:

- Have a condition that raises your risk of falling.
- Have a heart condition.
- Had a bad reaction to cannabis in the past, such as paranoia.¹
- Are preparing for a bone marrow (stem cell) transplant (smoking plant products that could lead to lung infection).
- Receive immunotherapy, which cannabis may make less effective.7

How will cannabis affect you?

"Start low, go slow" is the mantra for first time cannabis users. Start with a low percentage THC content, and try it in small amounts.

"The effect on everyone's body is different," says Garber. "At the Sidney Kimmel Cancer Center, we start by asking 'What, if any, has your experience with cannabis been, and what symptoms are causing you distress?' whether that is pain, nausea, anxiety, insomnia, loss of appetite, or neuropathy."

Cannabis certification programs, like the one at Sidney Kimmel Cancer Center, can help you learn about the current available evidence, routes of administration (vaporization, ingestion, topical, suppository, etc.), and various products available.

To learn more about cannabis for the treatment of side effects of cancer treatment, visit Cancer Choices.

To date, the center has helped more than 1,000 people, including those with low digital and health literacy. Garber notes that most patients are in their early 60s and new to cannabis use. The program offers education on various forms of cannabis and their CBD/THC content, dosing, potential risks and benefits, cannabis and the law, travel, work, and keeping children and pets safe. The program works with patients over time to help refine a plan to address their symptoms and try to reduce some of the trial and error and cost that is inherent in the process.

Increasing legalization leads to cannabis research

The Controlled Substances Act of 1970 placed cannabis on the United States Drug Enforcement Administration's list of Schedule 1 drugs, with no accepted medical use and a high potential for abuse. Drugs on this list are considered unsafe even with medical supervision.

However, state-by-state legalization has allowed more studies under state laws. Pennsylvania has a provision for academicindustry research partnerships in its medical cannabis law.

How research benefits patients

"With state medical cannabis programs," says Garber, "we can create more standardization, consistency, and quality in the cannabis used for medical care. Standardization enables patients to better access what is helpful or not and enables us to conduct more controlled studies knowing that the products being studied are consistent."

Cannabis for specific symptoms¹

Cannabis is shown to be helpful for specific symptoms of cancer and treatment. Talk with your oncologist or other health-care provider before trying cannabis for any of the symptoms listed below.

Nausea, vomiting, and lack of appetite

The pharmaceutical drugs dronabinol and nabilone were formulated during the 1970s and have been FDA-approved since 1986. They are a synthetic form of delta-9-tetrahydrocannabinol.

Inhaled cannabis does not cause constipation, as some prescription anti-nausea drugs do. Some people prefer cannabis to the antinausea drugs that are usually prescribed. It can also make you feel more like eating through the well-known effect of "the munchies." Some people report that using cannabis before going to chemotherapy makes them feel less of the nausea that just thinking about chemo can cause (anticipatory nausea).

Pain from neuropathy (nerve problems)

Cannabis has been shown to help people with HIV who have nerve damage (neuropathy).8 Studies in rodents have suggested that cannabis compounds may not only treat but could also prevent nerve damage related to chemotherapy (chemotherapy-induced peripheral neuropathy). You may want to talk with your healthcare provider about cannabis if you have chemotherapy-induced peripheral neuropathy.

Sleep problems

A prescription medicine called nabiximols is a whole plant extract of cannabis that contains THC and CBD in a 1-to-1 ratio. Nabiximols was found to improve sleep in people with cancer, including those who have chronic pain that is not helped by other medications.

Anxiety

Cannabis products make some people anxious and paranoid, while others feel calmer. If a health-care provider approves trying it, cannabis products could help with anxiety. People who are new to using cannabis, however, should be aware that paranoia is a potential side effect of this botanical.

Jenny Leyh, a five-year breast cancer survivor, says that cannabis was helpful during cancer treatment but has also helped ease symptoms of anxiety and depression before cancer and now after. "I've tried a number of different antidepressants to help combat depression and anxiety," says Leyh. "Cannabis not only helps me to feel like myself and pulls me out of a rut, but it also doesn't come with the side effects that some antidepressants can create. Through trial and error, I have found particular strains that work best to treat my depression and help me get back to my life."

Does cannabis cure cancer?

In laboratory studies involving cell cultures in test tubes and in non-human animals, cannabis has been shown to kill cancer cells. These studies give many people hope that using cannabis products will cure their cancer. However, the National Academies of Sciences, Engineering, and Medicine's latest report (2017) concluded that there is not yet enough evidence that cannabis will kill cancer cells in the human body.6

Unfortunately, the internet includes many reports of people who used products such as high-THC cannabis oil (aka "Rick Simpson oil") to attempt to cure their cancers. When these reports cite evidence that the product "kills cancer cells," it generally refers to studies in cell culture or non-human animals. As yet, no cannabis product has been shown to eliminate cancer in humans. "One of the most painful things that I see is a patient using high-dose cannabis oil in hopes of curing their cancer and coming to me with metastatic disease because they have waited to start standard cancer therapy," says Dr. Abrams.

To be used properly, cannabis should be used as part of a whole-person approach to cancer. While cannabis can help ease some of the side effects of cancer treatment, it should never be used as a cure for cancer.



In fact, high-dose cannabis oil preparations can make cancer treatments more toxic to the body, and the U.S. Food and Drug Administration released a warning about these products several years ago. People taking extremely high doses of THC may also be too disoriented to spend quality time with loved ones at what may be the end of life.

However, new studies may lead to better outcomes, at least when cannabis products are used along with standard chemotherapy. In 21 people with recurrent brain tumors, 12 received nabiximols along with their chemotherapy, and nine received a placebo. After six months, two-thirds of the people in each groupnabiximols plus chemotherapy versus chemotherapy alone-had recurrent tumors. However, more than 80 percent of those in the nabiximols group were still alive after 12 months. Their survival rate was better than that of the patients who received standard chemotherapy alone. 8 "Although very small, without really enough power to make a definitive statement, this is the first study to show a survival benefit," says Dr. Abrams.

Questions to ask your provider

You may want to start by listing symptoms you would like to improve. Then, you may want to ask these questions:

- Who on my health-care team can help me learn more about using cannabis?
- How and where can I register to use medical cannabis? Is there someone on my health-care team who can help me register?
- Will using cannabis affect other health conditions besides my cancer symptoms? How?
- Is a different medication or approach safer or more effective?

Other questions to consider

- What is the difference between an indica and sativa? CBD and THC? Terpenes and other compounds?
- How can I properly dose cannabis to ease my symptoms?
- Do I know the legal status of cannabis in my state?

Resources

- National Library of Medicine Medline Plus. Cannabidiol (CBD).
- National Cancer Institute Office of Cancer Complementary and Alternative Medicine
- US Food and rug Administration warning letter to companies marketing high-dose cannabis
- National Cancer Institute Cannabis, Cannabinoids, and Cancer Research Symposium (For health care providers)

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CHEMOTHERAPY-INDUCED PERIPHERAL **NEUROPATHY (CIPN) POCKET GUIDE**

FAST FACTS

- Chemotherapy most often affects the nerves that run to the legs, feet, hands, and arms.
- Nerve toxicity is the second most common cancer treatment-induced side effect.1

WHAT IS PERIPHERAL NEUROPATHY?

Peripheral neuropathy (PN) is numbness, tingling and pain in the hands, feet, fingers and toes. It is often caused by cancer treatment. You pronounce it "purr-IF-err-ull nurr-AW-path-ee." It is also called CIPN for "chemotherapy-induced peripheral neuropathy."

WHAT CAUSES PN AND HOW CAN I AVOID IT?

If you need certain types of chemotherapy drugs to treat your cancer, PN is possible. These drugs include:

- The platinum drugs, such as cisplatin and oxaliplatin.
- The taxanes, such as paclitaxel and docetaxel.
- The vinca alkaloid drugs, such as vincristine, vinblastine, and vinorelbine.
- Drugs used to treat myeloma, such as bortezomib or thalidomide.

If you need one of these drugs and develop CIPN, talk with your doctor. They may lower the recommended dose or even stop treatment with that drug. Adjusting the dose or treatment schedule can reduce your neuropathy.²

Cool down to prevent CIPN

Cooling your hands and feet before and during your chemotherapy infusion may help prevent CIPN. You can use frozen socks and gloves or buy special cooling equipment. Talk with your doctor or other health care provider about cooling during treatment.3

Compression, or wearing gloves that are too small, may also help prevent CIPN. Talk to your doctor about this option.4

Acupuncture for CIPN

Several small studies have reported that acupuncture at specific points slowed down the progression or severity of CIPN when performed soon after chemotherapy.^{5,6} Ask your oncology team if acupuncture is available at your hospital or clinic. Acupuncture combined with reflexology, a specialized form of massage focused on the feet, also helped some patients in another small study.⁷

Other ways to manage PN

Several treatments can help with PN and the secondary effects of neuropathy, such as balance problems. Treatments to talk with your doctor about include:

- Physical and occupational therapy to help with movement, balance, and everyday challenges in fine motor function, such as gripping and lifting objects.
- Yoga or tai chi to help improve your balance.
- Mindfulness training to keep track of where you are walking, how you set your feet down, and more.

Managing pain from PN

PN is not just about numbness and tingling. You may also experience pain, which may be a burning sensation, or even pain from a gentle touch or other stimulus that you would not normally expect to hurt. You may also have difficulty walking normally or feeling your toes.

If you have painful CIPN, duloxetine (Cymbalta) is the only medication recommended so far by the American Society of Clinical Oncology.8 This is based on a modestly positive result in one randomized controlled trial. Other possible treatments include:

- · Applying a combination of numbing cream and capsaicin cream.
- Using CBD (cannabidiol) cream.
- Using a "scrambler" device.
- Acupuncture.

Unfortunately, not many large, well-controlled studies have been done to evaluate treatment options, and larger studies are needed to confirm the benefits of these treatments. However, these treatments may have benefits for some individuals.

Exercise and diet can make a significant difference in your overall well-being, and reducing inflammation in your body with diet and supplements may also help. Download our free guide to optimizing your healing even when you live with pain. Please review and discuss any supplements you are taking or considering taking with your oncologist.

FAQs about PN

Do all cancer treatments cause CIPN?

No. These nerve problems are typically caused by specific types of chemotherapy. The most common chemotherapy drugs that cause CIPN are listed at the start of this Patient Pocket Guide ("What causes PN and how can I avoid it?").

Can my doctor tell me for certain whether my treatment will cause CIPN?

Because CIPN is most common with specific chemotherapy drugs, your doctor should be able to tell you if this side effect is likely.

You can also discuss things you might do to prevent or reduce CIPN. There are no medications to prevent it. But you may prevent or reduce symptoms by wearing cooling socks and gloves during treatment, having acupuncture after treatment, or receiving a reduced dose of chemo if you experience severe neuropathy.

Can I take pain medications or supplements for CIPN?

Yes. Pain medications (both over the counter and by prescription) can help with pain, including CIPN.9 Your doctor should be able to help you decide on the right ones to use. Although less studied, some natural products may be helpful for certain types of CIPN.¹⁰ Ask your doctor to investigate the appropriateness of these compounds for you.

Does CIPN ever go away?

Sometimes. It depends on many factors, including the chemotherapy drugs used in your treatment, your personal health, and more. About eight out of every 10 people who have chemotherapy with taxanes and oxaliplatin therapy have CIPN six months to two years after treatment. 11-13 With CIPN from other chemotherapy drugs, your symptoms are likely to improve with time.

Doctors know that certain chemotherapy drugs are very likely to cause CIPN, but we do not yet know very much about effective ways to treat this side effect. When talking with your doctor about your treatment plan, it's important to balance consideration of side effects with a discussion of how much the treatment is likely to benefit you.

Signs of CIPN won't change my chemotherapy plan, right? I have to stick with it even if I do develop nerve problems.

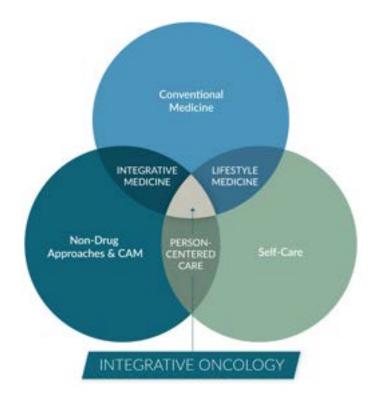
Not necessarily. Talk with your doctor about what you do for a living, your hobbies and interests, how severe the CIPN is, and anything else you think is important for them to know. They may be able to adjust your treatment to reduce the chances or side effects of PN.

Tell your doctor and health care team about any side effects you experience. Ask how they can help and what you can do to relieve symptoms.

My notes and questions

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FINANCIAL IMPACT OF CANCER POCKET GUIDE

Patient Pocket Guides

FAST FACTS

- In one large survey, approximately 4 in 10 people with cancer said their out-of-pocket (self-paid) expenses were higher than they expected.1
- People with cancer spend more on massage, supplements, and other complementary and alternative medicine treatments than people who do not have cancer and tend to pay out of pocket for these treatments.2
- People with cancer or a history of cancer may be more likely to skip filling a prescription or skip doses to cut costs than people without cancer.3

THE FINANCIAL IMPACT OF CANCER

If you or a loved one are diagnosed with cancer, financial worries may be the last thing on your mind. Learning more about the cancer, treatment options, and expected outlook are probably first. So, it might surprise you to learn that cancer and its treatment can have serious, sometimes lasting effects on your finances.

This pocket guide is designed to help you assess your situation, spot financial pitfalls, and avoid what many health-care providers call "financial toxicity."

"Financial toxicity" - A lesser-known side effect

Financial toxicity happens when the cost of having cancer including treatment, sick time, or in some cases being unable to work—causes problems for you and your family. Problems can include:

- Having difficulty paying regular bills (food, housing, utilities).
- Losing income if you are not able to work or need to take medical leave.
- Going into debt to pay regular bills, treatment costs, or both.
- Losing health insurance if you lose your job.
- Selling assets or spending your savings on treatment.
- Additional costs such as transportation, parking, cost of medications.

The financial effects of cancer can affect your family and future plans, whether you are paying for ongoing treatment or receiving care for post-treatment side effects, called late effects.4

Raymond Wadlow, MD, is a medical oncologist at the Inova Schar Cancer Care Institute in Fairfax, Virginia. "I see a lot of variation in how cancer affects people's finances," he says. "Some have insurance but not enough to prevent them from having financial difficulty from the cost of care. Others have no insurance."

Each U.S. state has options for people without insurance, such as a state-funded plan or high-risk insurance pool. Your cancer center may also be able to help with payment plans, reduced rates, patient assistance, or connections with charitable organizations.

No health insurance?

People without health insurance may apply for public insurance, such as care through the state where they live, Medicaid, or Medicare. However, applying and being accepted takes time and quite a bit of work. This can be difficult for someone who is not feeling well, has relatively low health literacy, is not a fluent English reader and speaker, or is not a computer user. Waiting to be accepted into an insurance program can also cause risky delays in getting cancer treatment, according to Dr. Wadlow. Many cancer centers have financial counselors on staff who can help walk patients through their options to pay for cancer care and connect them to resources for additional support. Some health-care systems have charity care, so that may be worth exploring before deciding where to receive treatment.

An oncologist's advice

Dr. Wadlow offers this advice to reduce or avoid financial toxicity:

- First, learn what financial toxicity is. Even if you have health insurance, don't assume cancer and treatment cannot affect vour finances.
- Then, talk with your health-care team about what your cancer care may cost. They want to know if you have financial concerns regarding treatment! If you have other specific financial needs, such as paying for a child's college tuition or being on a fixed income in retirement, share this with your cancer care team. A social worker or financial counselor may be able to assist.
- Finally, understand that integrative treatments, which support the mind and spirit as well as the body, are an important part of cancer care. Your health-care team may be able to help you find these types of treatments free or at low cost, such as from a community acupuncture clinic. You may also receive financial assistance for your regular cancer care, such as a discount on medications from the pharmaceutical company that makes them. Some arrangements make it easier to incorporate integrative health options into your treatment plan.

"You're much better off bringing the question of finances to your health-care team's attention than trying to avoid it," says Dr. Wadlow. This is particularly true if you are already facing some financial challenges, such as going without insurance or coping with another health condition. Dr. Wadlow says, "There are resources available! It is much easier for us to personalize your care for maximum benefit if we hear about your needs and concerns."

More finance and insurance tips

Our top tips to lessen the financial impact of cancer include:

- 1. If you're insured, check out your benefits online. Learn what your deductible, co-payments, co-insurance rate, and cancer care benefits are, and let your main health-care providers
- 2. Ask to talk with a financial counselor (they are also called financial navigators) at the hospital, clinic, or cancer center where you will be treated. They can go over your insurance information, help you apply for public insurance if you need it, and help you find other ways to pay for care. For example, you may qualify for financial assistance from the hospital or clinic if you have financial need. This can reduce the amount you need to pay out of your personal funds.
- 3. WWTalk with a social worker at the cancer center or clinic. They can help you find low-cost or free options for everything from transportation to integrative care. For example, some hospitals offer free yoga classes for people with cancer. Many organizations offer free or low-cost rides, which can help cut the cost of going to treatment.

- 4. If you get Medicare, sign up for Part D, which helps with the cost of prescription drugs. You may want to purchase insurance that supplements Medicare, too. This can pay for things Medicare does not cover or pick up the remaining cost after Medicare pays their part.
- 5. Ask if group visits are available to access supportive services. Some organizations offer free or reduced-fee acupuncture, nutrition counseling, exercise, or Zumba classes. Some services are even available online.
- 6. You may be eligible for disability benefits. The Social Security and Supplemental Security Income disability program is an option for those who have paid into Social Security. Up to \$1,200 per month is available, and those who are dealing with cancer may have their application processed more quickly.

The impact of out-of-pocket costs

Many people with health insurance are accustomed to paying a modest amount for appointments, tests, and prescriptions. But cancer is one of the most expensive medical conditions to diagnose and treat.⁵ Staging scans alone may run thousands of dollars, and these tests occur well before any expensive treatment is delivered.

Factors that make cancer treatment especially costly include:

- Newer chemotherapy and other treatments are more expensive than in the past.
- New drugs enter the market at higher price points, with many cancer medications priced in the most expensive "specialty" tier of prescriptions.
- Prices continue to increase after drugs and treatments are on the market.
- Insurance companies charge consumers higher insurance premiums, deductibles, co-payments, and co-insurance rates.6

Providers may assume that because someone with cancer has health insurance, the cost of treatment won't be a concern. Unfortunately, it can be, even for people with "good" insurance. Someone with a high deductible may have to pay \$3,000 to \$6,000 out of their own pocket before insurance begins paying any part of the cost. With a short-term health insurance plan, the policy may pay very little.

Co-insurance is the percentage of each bill the insured person must pay (the insurance company pays the rest). If someone's co-insurance rate is 20 percent, their out-of-pocket cost is modest for a treatment that costs \$100. But if a cancer medication costs \$10,000 per month, the person with cancer just acquired a new monthly bill of \$2,000—more than the average mortgage payment in some parts of the country. According to the National Cancer Institute, prices higher than \$10,000 a month for individual drugs are "common."

Talking with health-care providers

Asking questions about cost can help you avoid overwhelming financial impacts. You may need to bring this up with your oncologist and other team members. Dr. Wadlow says most providers don't realize how big a financial burden cancer places on the people they care for.

"Doctors don't know much about this, and patients often don't tell them much," he says. "People may be apprehensive about sharing financial concerns with the cancer care team because they are wary of having the 'budget' option recommended. They want to hear about the best care, not the lowest-cost option, because that may seem like it's less effective."

Financial toxicity may lead some to skip supportive services, such as physical therapy or nutrition counseling, without first talking with their doctor. This may be an opportunity to ask about integrative options that are low cost or even free. See our chart, Free and Low-Cost Integrative Health Resources, for examples of services that support healing.

Integrative care and finances

Research shows that most people who choose integrative health options such as massage, acupuncture, chiropractic, or biofeedback pay for them personally. Insurance often does not cover them. In addition to buying higher-quality foods, such as fresh fish and organic produce, paying for these types of care takes a bite out of the family budget.

"There is a barrier to leveraging the benefits of integrative medicine if you have financial stress," says Dr. Wadlow. "You have stress related to paying for your regular care. This may keep you from taking advantage of integrative approaches that would help your stress—so even more stress builds up."

Bringing integrative care further into the mainstream can help. When insurance companies begin to cover these treatments, doctors are more likely to prescribe them in addition to standard cancer care. "Integrative treatment should be integrated into the care plan, so everyone understands that it is every bit as important as chemotherapy or surgery in terms of whole-person care—not an added luxury," says Dr. Wadlow. "When that happens, financial stress can be distributed across the whole spectrum of treatment, so it is less likely to prevent people from choosing integrative modalities." Doing this will require changing some government rules. For example, Medicare does not cover treatments it considers "alternative," such as acupuncture, except for very specific purposes.

More financial assistance options

Some cancer centers offer financial assistance programs. One such program at the Karuna Precision Wellness Center in Indiana offers financial assistance to clients regardless of income level.

Unite for HER, a Philadelphia-based organization, recently launched a wellness program that covers the cost of integrative health services for breast and ovarian cancer patients. The national program is available for those within 18 months of diagnosis or who have been diagnosed with metastatic disease. Patients receive a care box with educational resources as well as a \$2,000 passport that covers the cost of integrative therapies such as nutritional counseling, virtual fitness and yoga classes, sexual health counseling, and meditation.

Crowdfunding

Many patients use crowdfunding platforms such as GoFundMe to ask friends, family, coworkers, and others to assist with the costs of cancer treatment. This provides the patient with an easy link to share through social media, text, or email that can be an easy and non-awkward way to ask others for financial assistance.

Another way that friends and family can offer help is through Meal <u>Train</u>. This platform creates an easy, organized tool for friends and family to plan meals for a loved one who is going through cancer treatment or surgery or just needs help planning meals.

Free and Low-Cost Integrative Health Resources					
Good nutrition	Mediterranean Diet Pocket Guide	The Nutrition Cancer Center	Pocket Guide to Nutrition and Cancer		
Better sleep	Guided meditation via HealthJourneys	CBT-i Coach app			
Journaling	Journaling through Pain and Trauma	Healing with Words: Journaling and Reflecting Throughout Treatment from www.cancercare.org	<u>CaringBridge</u> – offers free, private and ad-free personal health journey website		
Mindfulness meditation	Breathing Healing Meditation with Dr. Wayne Jonas	Free mindfulness courses via Mindfulness Exercises			
Acupuncture	Search "community acupuncture near me" online	Ask your health-care provider for an acupuncture clinic recommendation	Explore whether your community offers acupuncture in a group setting for a reduced fee		

Free and Low-Cost Integrative Health Resources				
Art therapy	Art Therapy Pocket Guide	Oncology on Canvas from Lilly Oncology	Smith Center for Healing and the Arts	
Music therapy	Free music therapy library from the University of Michigan Rogel Cancer Center			
Pain relief	<u>Curable</u> app	Nutrition for Chronic Pain Guide	Watch For Grace's free event on "The Pain-Cancer Connection"	
Therapeutic yoga	Therapeutic Yoga Pocket Guide	Healing Yoga Foundation	<u>Yoga4Cancer</u>	
Moving meditation (tai chi or qi gong)	Moving Meditations: Tai Chi and Qi Gong Pocket Guide	Tai Chi Video with Dr. Wayne Jonas	Memorial Sloan Kettering Cancer Center Tai Chi Instructional Video Series	
Connection to social services	Call 211 — Help with food assistance, health expenses, and more - www.211.org	American Cancer Society Support Programs and Services	National LGBT Cancer Network	
Exercise	Maple Tree Cancer Alliance free online workout videos and YouTube Channel			
My notes				

For health-care providers

Let everyone with cancer know that financial counselors or navigators are available and can be helpful in planning to meet the cost of cancer care. Also let them know social workers can help them locate free or low-cost care resources and practical support connect them with other organizations that offer free or low-cost help for people with cancer.

Knowing that the very latest chemotherapy drug or treatment is extremely expensive "creates a lot of anxiety," says Dr. Wadlow. His approach? Talking about financial options with every person who needs treatment, without guessing who might face financial challenges. "I simply say, 'We could do this treatment, or here are some other less costly options." This can help start a discussion about which treatment is the best choice overall.

A cancer survivor's advice

Jenny Leyh, a breast cancer survivor and mother of two, felt the strain of financial toxicity after having to quit her job following her diagnosis in 2016. Her advice is to keep a binder of important documents and tap a family member to play the role of patient advocate and manage the medical bills.

"A cancer diagnosis is an overwhelming experience and cannot be solely managed by an individual. It's important to ask for help in areas where you need assistance. Explore free or less expensive options such as online yoga classes, going for walks, imagery and mindfulness apps, or books on meditation. Complementary practices are so important in supporting healing during treatment, and they do not have to add to the financial burdens of cancer care," says Leyh.

Resources

CancerCare.org offers a Helping Hand tool — a searchable database of organizations that help people with cancer. You can search by your type of cancer and the type of assistance you're interested in, such as meal delivery, help paying for prescriptions, and much more.

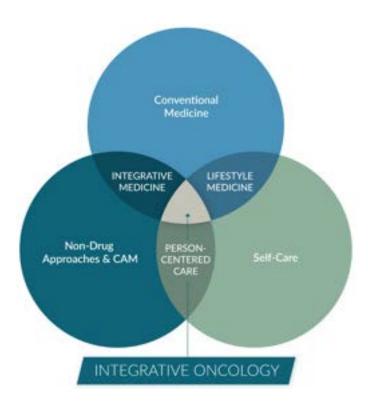
A magazine called **CONQUER**: the patient voice, from the Academy of Oncology Nurse and Patient Navigators, offers a wealth of information on financial issues and cancer.

The <u>HealthWell Foundation</u> offers assistance to people who are underinsured and dealing with a serious illness. They also provide coverage for some medications.

Triage Cancer offers a tool to help guide patients through the potential financial burdens of cancer care.

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INTEGRATIVE ONCOLOGY SELF-CARE GUIDE

What follows is a summary of some basic behaviors shown to facilitate healing. They involve changes you can make in everyday life to feel and function better. Food, movement and social connection can be powerful medicine. Read on for more information to support healing.



BASIC NUTRITION PRINCIPLES

EAT MORE

- Eat breakfast-start the day fueled.
- Drink more water-flavor with a twist of citrus or slice of cucumber.

PROTEINS AND FAT SOURCES

- · Cold water fish such as salmon, sardines, herring, black cod (sablefish), or mackerel
- Fish oil, olive oil, coconut oil, grapeseed oil, flax oil
- Nuts and seeds: pumpkin seeds, ground flax seeds, almonds, walnuts, etc.

FOODS WITH A LOW GLYCEMIC LOAD*

- Whole grains: barley, bulgur, brown rice, quinoa, oats (steel cut or rolled)
- Legumes: beans, chickpeas, lentils
- Whole wheat tortillas, pumpernickel bread, 100% whole grain bread

VEGETABLES AND FRUITS HIGH IN ANTIOXIDANTS

- Make a rainbow on your plate
- Yellow, orange and red vegetables
- Dark leafy greens
- · Broccoli, Brussels sprouts, cauliflower, cabbage
- · Onions and garlic
- · Berries and pomegranates
- · Citrus fruits (not juices)

HEALTHY SPICES, HERBS, SWEETS AND OTHERS

- Herbs and Spices with anti-inflammatory properties
 - Cinnamon: ½ tsp. daily for blood sugar control
 - Ginger: 1 gram per day, fresh or dried
 - Turmeric: 1-3 grams per day of powder
 - Garlic: 1-2 grams per day, fresh, or aged and deodorized
 - · Green and white teas
 - Others: rosemary, cayenne, pepper
- Dark Chocolate: 1-2 ounces daily of 70% cocoa content or greater
- · Probiotics-discuss with your provider
- Fermented Foods: kombucha, miso, sauerkraut, yogurt, kefir. and kimchi
- Try These: 28 Anti-Inflammatory Recipes

EAT LESS

- Don't eat dinner too late-don't eat for a period of 10-12 hours, if possible.
- Avoid added sugar—in drinks and in food (check labels)

PROTEINS AND FAT SOURCES

- · Red Meat
- Dairy products (made with cow's milk)
- Partially hydrogenated oils such as margarine or shortening
- · Soybean, corn, safflower and sunflower oils
- · Processed and fried foods

FOODS WITH A HIGH GLYCEMIC LOAD*

- White bread
- · Instant rice and instant oatmeal
- · Rice and corn cereals
- High fructose corn syrup
- Soda and sugary beverages
- · Fruit juices
- · Sweets: cookies, cake, pastries, donuts

FOODS KNOWN TO TRIGGER INTOLERANCE REACTIONS

- Wheat**
- Dairy** (especially from cows)
- Eggs
- Corn
- · Artificial colors and flavors
- Sucralose and aspartame

*GLYCEMIC LOAD (GL): The measure of quality and quantity of a carbohydrate. This uses the glycemic index in combination with the amount of carbohydrate in a serving of that food to assess the impact of eating it on glucose production and insulin release. A goal is to eat more food with low glycemic load and less with a high load. Glycemic Index (GI): The measure of how fast a food turns into sugar once you eat it. You can look up the glycemic index of foods at www.glycemicindex.com

**INTOLERANCE REACTIONS: An abnormal physiologic response to a particular food or compound. It can result from an abnormality in the body's ability to digest or absorb nutrients. It is a non-allergic food hypersensitivity that is different form true food allergies. Best test is to eliminate the food and see how you feel. For many patients they feel much better very rapidly when they are able to do that. This is called and "Elimination Diet" and takes some supervision and guidance.



Exercise (Physical Activity)

- At least 150 min per week of moderate-intensity
- 2 or more days per week of muscle-strengthening activities

Social Connection

- Who do you rely on in times of need who hasn't heard from you lately? Reach out today.
- Who do you need to support you in achieving your health goals? Let them know.

Behavior Management

- Plan ways to increase fun, time spent in nature and exposure to art and music
- Seek support to break addiction to sugar, smoking, alcohol and drugs

Supplements

 Always discuss any supplement use with your provider preferably before you buy them! If you do purchase supplements, always be sure to purchase quality supplements from reputable brands. Look for the NSF International, US Pharmacopeia or Consumer Lab seal. These organizations verify what's inside the product.



HEALTHY MIND AND STRESS MANAGEMENT

The goal is to learn how to induce the "relaxation response" for 20 min, 1-2 times a day. This can be done through prayer, meditation, breathing/yoga practice, etc. Like physical exercise, mental fitness practices enhance health. Consider these resources others have found useful in managing stress and improving mental resilience and social happiness.

Guided Imagery: Guided imagery is a mind-body practice that uses the imagination and sensory memory to induce a state of relaxation and physiological, emotional and attitudinal responses. Visit healingworksfoundation.org/ guided-imagery to access free tracks to reduce stress, promote healing, sleep soundly, lessen pain and more. www.healthjourneys.com

Meditation/Mindfulness: Meditation and mindfulness typically go hand-in-hand. Sometimes, mindfulness is frequently attached to movement practices.

- Recharge Your Mind and Body with Therapeutic Yoga
- Meditate with Dr. Jonas: Breathing Healing Meditation
- Enhance your mind-body connection with a Tai Chi video from Dr. Jonas

Journaling: Journaling techniques can help you heal, grow and thrive.

- Creates a safe space to write private thoughts
- A healthy habit to take time for yourself
- 15 journaling exercises to help you heal, grow, and thrive

Sleep: Sleep plays an important role in our health and wellness.

- Benefits from a healthy sleep habit
- Your surroundings can impact how well you sleep

LIFE AFTER CANCER POCKET GUIDE

FAST FACTS

- It has become more common to live a substantial portion of your life after having cancer. Nearly 7 in 10 cancer survivors have lived more than 5 years since their diagnosis, and almost half have lived more than 10 years.
- The number of cancer survivors is growing. More than 5% of the total U.S. population were cancer survivors in early 2022. The National Cancer Institute projects a 25% increase in the next 10 years.

SUMMARY

- Having cancer can be a traumatic experience. You may experience mental, physical, and emotional effects for years after treatment ends. Care and support are beneficial.
- A survivorship appointment can help you learn how to care for your general health, and plan for post-treatment appointments and tests.

The challenges of life after cancer

The stress of a cancer diagnosis can be overwhelming, even if you have completed active treatment. After you ring the bell signaling the end of chemotherapy or radiation, you may be surprised by the feelings that come up. Friends or family members might act as if your cancer is behind you while you feel like a new phase of the cancer journey has begun. This is the phase of the journey that often comes without a roadmap, and one in which you feel physically and emotionally exhausted from the side effects of cancer treatment.

"Cancer doesn't end when treatment is over," says Yolanda "Yoli" Origel, founder and executive director of the organization Cancer Kinship, which offers peer-to-peer mentorship for anyone facing a cancer diagnosis. "Survivorship is a lifelong experience."

During this period of recovery and adjustment, you slowly get your energy back and adjust to a schedule that is no longer filled with appointments. You are no longer under the medical microscope. You may miss seeing the people on your health care team or feel survivor guilt if someone you met in treatment died. All these reactions are normal, and caring for yourself is critical as you heal your mind, body, and spirit after a cancer diagnosis.

Learning what you need in survivorship

It may help to think of nature's seasons when you think about life after treatment. Every season has its own weather, including storms and times of surprising beauty. You may be surprised by physical symptoms that crop up or by changes in your own attitude and perspective.

"There's still a lot happening after treatment ends," Ana Maria Lopez, MD, MPH, says. Lopez is professor and vice chair of medical oncology at the Sidney Kimmel Cancer Center at Thomas Jefferson University in Philadelphia, Pennsylvania. "You may be getting your hair back, feeling better, eating better, but you are not the same person you were before. And even when you look better on the outside, you may still be healing."

Common physical symptoms after treatment include fatigue, sleep problems, and difficulty with balance and concentration. (See the Resource list at the end of this guide for links to more information.) Some people have nerve pain, stiffness from surgery, or are adjusting to a prosthesis.

Emotional aftereffects can be just as noticeable as the physical symptoms. "The diagnosis of cancer can cause something like PTSD," Lopez says. "People talk about their heart racing every time they drive by the cancer center or feeling nauseated every time they go to a medical appointment."

In the past, providers and care teams didn't concentrate their efforts on the phase that comes after active treatment ends. Their focus was on killing cancer cells, not the invisible wounds that come with a cancer diagnosis and follow into life beyond the treatment phase. However, this is changing. Many medical institutions have established survivorship programs. Your health care team will probably connect you with survivorship care, either through the cancer center or your primary health care provider.

"In the past, we focused on 'You're alive! Go live your life," Lopez says. "Now we have the opportunity to help people live well, whatever that means to them."

"Vigilance is key when you are trying to remain cancer free," Origel says. "It's important to have a plan of action when treatment ends, especially if you have genetic or other risk factors." Your personal survivorship plan may cover:

- Physical health after cancer, such as movement recommendations (yoga, walking, etc.).
- Healing the emotional side effects of a cancer diagnosis, either through support groups, individual counseling, or a combination of the two.
- Spiritual support.

The resources at the end of this guide give you a place to start.

Survivorship and your health

Lopez often suggests the American Cancer Society's survivorship information to patients.

"To me, 'life after cancer' begins the moment someone learns of their cancer diagnosis," says Lopez. "Before that moment, you did not know you had cancer. After that moment, you became a survivor."

The American Cancer Society defines "survivor" the same way. Anyone in treatment, living with cancer, or finished with active treatment is living a life after cancer. This guide is designed for the adjustment that happens after active treatment ends, but you will still find it useful if you are undergoing treatment now.

SPENDING TIME IN NATURE CAN HELP YOU HEAL

Casting for Recovery: This organization connects women with breast cancer with fly fishing organizations and guides around the country so that they can benefit from the healing, calm, and camaraderie of spending time in a beautiful natural setting.

First Descents: Outdoor experiences for adults aged 18-39 whose lives are affected by cancer and other serious illnesses. Includes some events for caregivers and health care workers.

Working with a patient advocate

"Patient advocates are very important in providing support, navigating the complex health care system, asking questions, and clarifying concerns," says Celeste Vaughan-Briggs, LCSW, manager of the Breast and Cervical Cancer Screening Program and an oncology social worker at the Sidney Kimmel Cancer Center at Jefferson University in Philadelphia, Pennsylvania.

Origel agrees. "A professional patient advocate can use their experience to help support you." Advocates can help with:

- Getting access to health care, including coordinating your care and communicating with your care team.
- Getting practical information about your disease and treatment.
- Paying for treatment, including financial aid and health insurance.
- Paying for living expenses.
- Getting transportation to and from medical appointments.
- Referrals to community resources.
- Information about complementary treatments.
- Support in lifestyle changes.

Where to find an advocate

Professional patient advocates are sometimes called patient navigators. Cancer centers and hospitals often have them, though Origel notes that "especially since COVID, patient navigation programs have been reduced. Not all have increased their capacity to pre-pandemic levels, and some programs only serve people who are in active treatment."

If you need to seek out a navigator or health care advocate on your own, check local and national nonprofit organizations, federally qualified health centers, government agencies, insurance companies, and for-profit patient advocacy firms. In addition, some patient advocates are self-employed. Compassion is a key quality in a professional patient advocate.

Family members or friends can also act as informal patient advocates.

Drawing strength from supporting others

Volunteering to mentor others is an important way to find meaning in the experiences of cancer and survivorship.

"A year after treatment ended, I started mentoring patients at my breast surgeon's request," Origel says. What surprised her was that most of the people she worked with wanted to give back, too.

"For every 10 people I mentored, nine probably asked me, 'How can I do what you are doing? How can I help someone when I finish my treatment?" Origel says helping others "gives you a greater sense of self-efficacy, purpose, and usefulness." When the time is right, consider lending the knowledge you have gained from cancer and treatment to support someone else's healing.

For many cancer survivors, life after cancer means "establishing a new normal." Your life has been significantly impacted by your cancer diagnosis, and after active treatment ends, you may find yourself wondering "what do I do now?" It may take some time, but establishing a routine and exploring ways to heal your mind, body, and spirit will help you to move forward in your life.

More free pocket guides

- Pocket Guide to Cancer and Sexual Health
- Pocket Guide to the Financial Impact of Cancer
- Pocket Guide to Nutrition and Cancer
- Pocket Guide to Supplements and Cancer
- Trying Mind-Body Medicine for Whole Person Cancer Care

Resource list

Use these resources to make life after cancer easier.

General Cancer Survivorship Resources

- American Society of Clinical Oncology Patient Website, Survivorship Resources: Resources for every aspect of life. from finances and work to mental health and stress relief. Includes links to resources for children and teens.
- Cancer Kinship: Mentoring, support, and education for anyone facing a cancer diagnosis. You can be paired with a volunteer mentor, take a workshop, and much more.

Mental and Emotional Support After Cancer

- **HopeWell Cancer Support**: Free virtual cancer support community. Based in Baltimore, Maryland, but currently offering many resources online.
- Mayo Clinic: Managing Your Emotions After Cancer **Treatment**: Learn about common emotions in cancer survivors and how to manage them.
- Why Do I Need Support? Cancer Support Community: This nonprofit organization offers ways to connect by phone, online, and in person with a support person or group during or after cancer treatment.

Physical Health After Cancer

- **American Cancer Society Living Well After Cancer Treatment:** Information on nutrition, being physically active, going back to work, cancer rehabilitation, and much more.
- **American Cancer Society Long-term Health Concerns for** Cancer Survivors: Learn which medical records to keep, what later side effects of treatment to watch for, and the importance of survivorship care and screenings. Includes information for survivors of childhood and young adult cancers.
- **LiveStrong at the YMCA:** Free and low-cost physical activity programs tailored to your needs, energy level, and limitations by a professional fitness trainer experienced at working with cancer survivors and their families.

Spiritual Support After Cancer

Stanford Medicine-Cancer: Religion and Spirituality: Article on how cancer can affect us spiritually, questions that come up, and ways to cope and find meaning during and after treatment.

Transportation

• American Cancer Society Road to Recovery® program: Trained volunteers that drive patients and families to hospitals and clinics for treatment. Available in some areas.

Housing During Treatment

- Hope Lodge®, American Cancer Society: A free place to stay if cancer treatment is far from home.
- Healthcare Hospitality Network: Free or low-cost housing for families getting medical treatment far from home.

Integrative Cancer Care

- The Center for Mind-Body Medicine: Programs that support those who have been through psychological trauma through a model of self-care, social support, and community building.
- Commonweal: Integrative cancer support programs for patients and health care workers.

Health Insurance

- Health Insurance, Triage Cancer: Guides and information.
- Legal & Financial Navigation Program, Triage Cancer: Free one-on-one help in health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more.
- **Health Insurance Options, American Cancer Society:** Information about types of health insurance and where to find it.

Other

- Managing Your Care, American Society of Clinical Oncology.
- Work and Employment, Triage Cancer: Guides and other resources.
- Dating, Sex, and Reproduction, American Society of Clinical Oncology: Information on dating and intimacy, sexual health, fertility, pregnancy, and more.
- Cancer Survivorship Checklist: A Cancer Survival Toolbox that can be used at any time during the cancer journey.
- **Support:** Living Beyond Breast Cancer for breast cancer patients.
- Young Survival Coalition: Support for breast cancer survivors diagnosed before age 40.

CANCER:

Using therapeutic writing to manage issues both during and after treatment, around physical and emotional distress tolerance, identity, and shifting priorities

A Patient Tool



OVERVIEW

Therapeutic writing is a kind of structured journal writing. It is a self-care tool to encourage deeper and clearer reflection, processing, and discovery. Therapeutic writing can help you heal, grow, and thrive.

- Writing prompts are offered as frames—it's up to you to decide which content is most useful to examine through these frames.
- In therapeutic writing, the **process** is more important than the product: not the sentences that you craft on the page but the **experience** of writing.
- You can also refer to your journal entries later, as a resource, to read what you've written and track your progress.
- Therapeutic writing, like any form of journal writing, is a place where you can have a conversation with the person who knows you best: you.
- Some people find further healing and insight through sharing their reflections with others. But whether you share your work is up to you. Therapeutic writing is a deeply personal process, so for it to be profound and meaningful just to you is enough.

MANAGING STRESS THROUGH WRITING

Writing has been found in many studies to reduce feelings of depression, anxiety and stress that can come when you're facing the challenge of cancer. This includes managing thought patterns and emotions prompted by uncertainty, and grappling with your identity both during treatment and afterward: "what ifs," fear, anger, sadness, helplessness, loss of your full sense of self. Learning to tolerate and decrease these feelings of distress can have physical, psychological, and emotional benefits - including improving sleep, reducing bodily expressions of stress (headaches, stomach pain/digestive issues, rapid heart rate, neck and shoulder tension, etc.), managing the physical toll of treatment, resisting catastrophic thinking, developing more rational thought reframing, and deescalating emotional responses to more manageable levels.

If you are ready, grab a journal and a pen and start writing with the help of the prompts that we have provided. Take the first step on your healing journey today!

THERAPEUTIC WRITING PROMPTS

Cancer and identity: Facing a cancer diagnosis and undergoing treatment can overwhelm your mental and emotional bandwidth. It can even take over your entire identity. During this experience, you might feel like you

Loss and gain: When you're challenged by cancer, you might sometimes focus only on what you've lost. Try to shift

need to reach out to them? The letter could take the form of a warning, a reassurance, or a yearning for when things were better. Note your voice, the tone in which you address yourself. Keep in mind that your thoughts and feelings now are likely different from your thoughts and feelings then, which is the point of the exercise—to gain perspective on your experience and your own evolution.					
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Letter to yourself: Address the letter to a former self—perhaps before your cancer diagnosis or right after it, if that's far enough in the past. What does this particular self need to hear from you now? And why do you, now,

a s of one	Expectation/reality: Write about an event or incident (e.g, your first chemotherapy infusion, when you first told a significant loved one about your diagnosis, or someone offering or denying support) where your expectation of it was different from how it actually turned out. You can write two pieces—one expectation, one reality—or one piece comparing and contrasting the two. The expectation versus reality may be around your own behavior, emotional state, etc.						

emotion through its external, physical manifestations—that is, what was happening in your body (palms sweating, heart racing, head throbbing)—and/or how you experienced and interacted with your environment through all your senses (e.g., shadowy or sunny, stuffy or breezy, sounds and smells, tactile sensations, etc.). Use all the senses o express the emotion as vividly as possible. You don't need context/plot/explanation of what was happening; just get right to the emotion in the moment and describe it physically. By expressing our emotional state through our physical experience of it, we're able to delve into the heart of it.						

Emotion made external: Reflect on a moment when you felt a strong emotion or combination of emotions—for example, when you first received your diagnosis—writing in the present tense for maximum immediacy. Explore the

b in b	Shifting priorities: Identify three to five formerly "small" things that have become "big" and "big" things that have become "small" for you, emotionally, as you've embarked on this cancer experience. More specifically, you could investigate three to five things that used to be emotionally challenging that no longer are and things that have become challenging that weren't before. In any case, try to resist judgment in your exploration and simply remain open and curious to these changes.						

whe and phy	Safe place visualization: Think of a real or imaginary place (or real place that you improve upon however you like) where you feel safe and at peace. Create that place in your mind using all your senses: sight, hearing, smell, touch, and taste. Similar to "Emotion Made External," this exercise draws upon that connection between the external/ohysical and the internal/emotional. You may also find that you conjure a specific time in your life, as well as a place, when you felt utterly safe and at peace.							

n certain ways or means that you depend on others more. Perhaps you can't be as involved in your children's ctivities as you used to and worry about their disappointment. Perhaps you struggle with asking for and accepting telp, feeling undeserving. Identify three situations in your life where you feel this guilt arising, and for each explore what feels "imperfect" due to cancer, investigating—without judgment—the very real reasons for this mitation or your need. Can you allow for the possibility that your engagement is enough and that your requests or help aren't a burden? Can you accept what you cannot change—cancer and its effect on your life—to let go and orgive yourself?						
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Good enough/self-forgiveness: When you are undergoing sometimes physically debilitating treatment for cancer, guilt feelings can arise if your current physical condition sometimes limits your ability to engage in relationships

Trying Mind-Body Medicine for Whole Person

Cancer Care

Mind-body therapies can be great resources during and after cancer treatment and are safe for most people in most situations. If the treatment or activity you choose involves a health care professional, make sure they are trained and certified. Most post their qualifications on their websites, but don't be afraid to ask.

If you try something that's not a match, there are other options. Like <u>physical exercise</u>, the "mental exercise" provided by mindbody practices comes in many varieties. If the therapy involves physical activity, such as tai chi, please check with your regular doctor or health care provider before starting.

Here's a graphic to help you figure out which mindbody therapies might be right for you.

I'd like to	Mind-body options to try	What to know first	Can I do while I'm on "stay home" orders?
Know right away if what I'm doing is working.	 Biofeedback to monitor your heart rate or track how relaxed your muscles are. 	 You may need to buy a device or download an app. 	Yes, if you order a device from HeartMath or another company.
Talk to a human being Learn if my feelings/ responses are helpful/healthy.	 Cognitive behavioral therapy. Biofeedback or progressive muscle relaxation with professional coaching. 	 Insurance plans pay for mental health care such as CBT. Check if insurance plan covers biofeedback. 	 Try CBT through BetterHelp.com or Online-Therapy.com. Or find a therapist in your area.
See if hypnosis works I've always been curious.	 Hypnosis with a therapist. Self-hypnosis with an app or podcast. 	 A licensed hypnotist cannot make you do anything you would not normally be OK with doing. Never use an app or recording while driving, exercising or using power equipment. 	 You can find a therapist who offers hypnosis online, or use an app such as Uncommon Knowledge.
Relax I'm stressed all the time, and my cancer treatment and pain makes me even more anxious.	 Meditation with an app or video. 	 There are different ways to meditate—walking meditation or moving meditation. You can do it no matter what faith you practice, and you do not need to practice a faith at all for meditation to help. 	 Apps such as Calm and Headspace can teach you to meditate at home. Free videos are also available on YouTube and other channels.
Try meditation but I'm not religious. Is there a non- spiritual kind?	 Progressive muscle relaxation. 	 Learn to fully relax by tensing your muscles first. Some experts say this is best learned from a coach, but there are many programs available. 	 Watch my Breathing Healing Mediation video.
Improve my fitness while reducing pain and undergoing treatment.	 Tai chi. Helps with balance, arthritis pain and other physical problems. Yoga. Extensive research shows the pain and stressrelieving powers. Qi gong. It is based on the principle of moving energy more easily through the body. 	 You probably need to find a class or group near you, at least when you are starting out. Many cancer treatment centers offer movement or exercise programs but you may have to ask. 	 Free videos online and DVDs are available for purchase. Some studios and gyms may be streaming classes. Here is a popular online yoga class for beginners. Access more resources in our Pocket Guide to Movement and Cancer.



If you like to be active

Moving meditations, such as tai chi, yoga and qi gong.



If you like immediate feedback and data

Biofeedback. A sensor or app gives you information on how you're doing, and a physical therapist can help you interpret what you are hearing or seeing.



If you like being quiet

Classic seated meditation, guided imagery, or progressive muscle relaxation. All these can be done alone in a quiet space.



If you're looking for a therapist or other caring practitioner

Cognitive behavioral therapy with a therapist or hypnosis with a certified hypnotherapist. If you also want to be active, try a tai chi, yoga or qi gong class or group. Some physical therapists provide biofeedback training and coaching.



If you prefer to be with others

Tai chi, yoga and qi gong are often practiced in groups, and you can talk after the class or session. If you want to work with just one person, a cognitive behavioral therapist, hypnotherapist or physical therapist practicing biofeedback might be for you.

Note: during the COVID-19 (coronavirus) pandemic, being together in person isn't possible for many of us. But you can try these with your family members or roommates as a way to relieve stress and possibly laugh at yourselves as you learn new moves and poses – laughter is a great stress and pain reliever, too.

Two mind-body practices I'd like to try:

Learn more about different mind-body practices

Biofeedback

- Association for Applied Psychotherapy and Biofeedback, Find a Practitioner
- HeartMath® tools available to the public include the emWave2, a portable, hand-held device that can be connected to a personal computer, and the Inner Balance™ Trainer, a sensor with an app (Android and Apple) that helps you increase heart coherence, rewards you for progress and includes guided stress management practices.

Cognitive Behavioral Therapy

- Association for Behavioral and Cognitive Therapies, Find a CBT **Therapist**
- Psychology Today, <u>Find a Cognitive</u> Behavioral (CBT) Therapist

Guided Imagery

• Health Journeys

Hypnosis

- American Society of Clinical Hypnosis, Find a Member
- Society for Clinical and Experimental Hypnosis, Members
- Uncommon Knowledge app for Apple and Android

Meditation and Mindfulness

- Free meditation tracks
- Meditation and mindfulness: Several online centers and courses. You can even do your own training program free online at palousemindfulness.com
- International Mindfulness Teachers Association, Teacher Directory

Progressive Muscle Relaxation

• A quide to the practice from the University of Michigan.

Qigong

- Qigong Institute, Directory of Qigong Teachers and Therapists
- Institute of Integral Qigong and Tai Chi
- National Qigong Association

Tai Chi

- Tai Chi for Health Institute
- Supreme Chi Living
- Tai Chi Foundation

Yoga

- Yoga for back pain from Yoga with Adriene
- Yoga, meditation and Pilates from Glo.com
- Yoga for Beginners video from Yoga Journal
- Many apps for Apple and Android, including 5 Minute Yoga and Simply
- Healing Yoga Foundation offers free live and recorded yoga sessions.

POCKET GUIDE TO MOVEMENT AND CANCER

FAST FACTS

- Exercise during cancer has been shown to improve fatigue, mood, muscle strength, and pain tolerance.1
- The American College of Sports Medicine recommends some level of physical activity for all cancer survivors.2
- Just 30 minutes of moderateintensity movement, such as walking at four miles per hour three times a week, can reduce cancer risk3.

PHYSICAL ACTIVITY AND CANCER

Resting to conserve energy may seem like the right thing to do when you have cancer. After all, the body and mind are facing the stresses of diagnosis, treatment, and side effects. In the past, doctors did not generally recommend physical activity for people with cancer. But that has changed. Today, your treatment plan is much more likely to include some form of exercise.

You know your body best, so listen to it. Some days you will feel able to do more than others. If you are looking for ways to be active when you have cancer, the American College of Sports Medicine offers practical tips.

Aerobic endurance, strength, and flexibility are important benefits of being physically active during and after treatment. Endorphins released during exercise can reduce pain,4 while fresh air and solitude can provide a break from feeling like a patient rather than a person.

Yoga, tai chi, and other gentle forms of exercise can restore and even boost energy. Today, physical movement is recommended to virtually everyone who is receiving treatment or is a cancer survivor.

THE EXAMPLE OF LYMPHEDEMA

Lymphedema is a painful swelling that can happen in an arm or leg after removal of lymph nodes to treat cancer. In the past, doctors advised people to avoid arm exercises after underarm lymph node removal to decrease risk of lymphedema. Now we know exercise is not only safe but also preventative.5

Where can I learn more about cancer-specific movement, aka exercise oncology?

Maple Tree Cancer Alliance (www.mapletreecanceralliance.org) employs certified exercise oncology instructors to serve patients at over 40 clinical sites across the United States. It also offers virtual services for those who do not live near a Maple Tree program. Memberships are available for less than \$10 per month and include customized exercise plans, recipes, and healthy eating tips. The program Maple Kids is specifically designed for children with cancer. The Maple Tree site also offers some faith-based resources to support patients spiritually, if desired.

Keep moving beyond cancer

Researchers have studied the benefits of physical activity after cancer treatment for approximately 40 years.⁶ A review of exercise effects for women treated for breast cancer found increased stamina, increases in natural "killer" cells that fight cancer, and improvements in mental and emotional health, from greater life satisfaction to improvements in depression and anxiety.7 For people who had other cancers, studies have shown improved muscle strength and improvements in mental and emotional health, including feeling better about their physical appearance.

Many hospitals and clinics offer exercise programs for people who have been through cancer treatment. You may also want to talk with your oncologist or a physical therapist about creating a personalized exercise program to address specific side effects, such as loss of bone strength from hormone therapy.

A sense of control

Physical activity can provide a greater sense of control for people dealing with the uncertainties of cancer.8 One study showed that simply doing arm exercises after breast cancer treatment benefited some women in this way.

Tailoring a routine to help with specific side effects or choosing new or different activities to strengthen the body or relax the mind—all can give you a sense that you are taking steps toward healing. Feeling stronger can also help you feel more capable as you go through treatment.

Cancer survivor Jenny Leyh has written extensively on integrative approaches to cancer, treatment, and survivorship. Five Steps to a New Normal: Life After Cancer includes a discussion of "work conditioning": gaining back the physical strength, coordination, and stamina to return to work through exercise and other rehabilitation activities.

All about you

As with any movement, exercise, or nutrition program, it is important to learn what works for you. Keeping a written log of your progress can be motivating, whether it's as simple as checking off days on a wall calendar or using a phone app to track health metrics and movement sessions. You can even use your phone to schedule exercise "appointments." Try an activity tracker on your smart phone like MyWellnessCoach. Of course, it's also important to discuss your plan with your health care team to ensure what you are doing is not only effective but also safe.

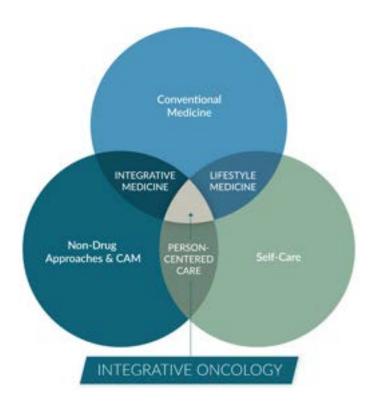
Learn more about increasing your body's ability to heal with exercise.

Free resources

- Physical Activity and the Cancer Patient from the American **Cancer Society**
- Cancer Council Australia offers a free booklet, Exercise for People Living with Cancer
- Healing Yoga Foundation, free live and recorded events
- Video from Dr. Wayne Jonas offering an introduction to tai chi
- Video from Dr. Wayne Jonas on The Three Best Exercises That You Can Do Right Now
- **Nutritious Movement website and resources**
- Maple Tree Cancer Alliance website and resources

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THE POCKET GUIDE TO NUTRITION AND CANCER

NOTE: With this guide, we tried to address the impacts of food on multiple areas of a person: their physical body, social body and emotional body.

FAST FACTS

- Food choices following a cancer diagnosis can feel as important as treatment decisions.
- Eating well during treatment and beyond means listening to your body's healing intuition.

CANCER AND NUTRITION—WHY IT MATTERS?

The question, "What should I eat?" is common after a cancer diagnosis. It may be prompted by concern about side effects or the search for a cancer-curing diet.

"Whatever you feel like eating—it doesn't really matter" is often the answer. Oncologists see many patients lose their appetites, struggle with nausea, and lose weight during treatment. However, physicians receive little training in nutrition. Research shows many connections between diet and cancer, from the strong association of obesity and alcohol consumption with cancer risk to the potential benefits of carotene- and sulforaphane-containing foods such as broccoli. Eating during and beyond treatment may mean considering your common sense amid messages from many "experts."

Food can help heal the body, mind, and spirit. It can convey the message "I care about you" from a caregiver and help people dealing with cancer focus on self-care. Foods that fight cancer and inflammation contribute to whole-person healing regardless of the ultimate treatment outcome.

The body's response to food

A changing sense of taste

Both chemotherapy and radiation can change your sense of taste. This may be due to changes in both the taste buds and the brain, where taste sensation is perceived. The most common changes are to the sensations of sweetness and bitterness.⁵

Changes in taste mean favorite recipes and foods may no longer taste good, or at least not taste the same while you are on treatment. You may crave sugary foods or want to sprinkle everything with lemon juice to cut the sweetness.

It may help to think, "My sense of taste is new." As when you try a new dish, expect it to take a couple of attempts to get used to tastes and modify them as needed.

Add cancer-fighting foods to the diet

Research shows many fruits and vegetables, and some other foods, are filled with cancer-fighting compounds that support the idea of food as medicine. These include:²

 Carotenoids, found in carrots, squash, sweet potatoes, broccoli, kale and more.³

- Sulforaphanes and other substances found in broccoli, cabbage, cauliflower, and other cruciferous vegetables.4
- Protease inhibitors, found in whole grains, apples, bananas, spinach, and more.

Learn more about <u>cancer-fighting foods</u> at <u>HealingWorksFoundation.org</u>. There are many ways to add cancer fighters to your regular diet—replacing a mid-morning cup of coffee with green tea, adding berries to a smoothie or bowl of oatmeal, and roasting vegetables like broccoli and cauliflower or eating them raw for a satisfying, stress-relieving crunch.

Food safety during treatment

Chemotherapy causes neutropenia, a decrease in white blood cell count that leaves a person more vulnerable to infection. This makes food safety even more important than usual. Keeping hot foods hot, cold foods cold, and cutting boards and utensils germfree is vital when someone in the household has a weakened immune system. Memorial Sloan Kettering Cancer Center has a free guide to food safety.

IS THERE "ONE BEST WAY" TO EAT WHEN YOU HAVE CANCER?

Despite books and websites touting "the cancer diet" or specific food cures, research has not yet shown that any specific diet prevents or treats cancer. Oncologist Alyssa McManamon, MD, says, "No single diet is best for every patient. Eating is social and emotional as well as physical, and the mind-body connection is very important for well-being during cancer treatment, just as it is when we are healthy."

Foods to Fight Cancer by biochemist Richard Beliveau offers a comprehensive look at foods, spices, and beverages that do contain cancer-fighting compounds. Cookbooks from the American Cancer Society include many of the foods listed in Beliveau's book. Check out What to Eat During Cancer Treatment for recipes that work for the family during the stress of cancer treatment, as well as for people getting treatment and managing side effects.

You may want to ask for a referral to a nutritionist. They can talk with you about balancing healthy choices, your family's tastes, what you feel like eating, and what will nourish you most.

Are dietary changes effective?

Yes. Changing your diet can pay off, as a study of more than 8,000 women from the well-known Nurses' Health Study shows. Researchers found that women following a diet designed to reduce the risk of developing diabetes reduced the risk of dying from breast cancer by 17 percent compared to women who didn't follow the diet.6

The diabetes risk-reduction diet meant making the following adjustments:

- Eating more cereal fiber (whole grains).
- Drinking more coffee.
- Eating more nuts and whole fruits.
- Eating more polyunsaturated fats than saturated fats.
- Eating lower glycemic-index foods, meaning foods that have reduced impact on blood sugar, and fewer foods with trans fats.
- Drinking fewer sugar-sweetened beverages and fruit juice.
- Eating less red meat.

Women who followed the diabetes risk-reduction diet were also 33 percent less likely to die from any cause (not just cancer) compared to women who did not follow the diet. This large study shows that diet can be a highly effective intervention for cancer, diabetes, and other conditions.

Quality matters

The modern grocery store contains many items that are actually harmful to our health. Prime examples are sodas and other sugary drinks, processed meats, and foods that contain no or very few natural substances, such as packaged snacks and fast-food fare.

High-quality food typically does cost more than low-quality food. However, it is possible to focus on avoiding the foods most likely to be harmful. The non-profit Environmental Working Group publishes two lists, the Dirty Dozen and the Clean 15, detailing the foods least and most likely to contain pesticides, updated regularly. Get a free, downloadable version of both lists at www.ewg.org.

You can also watch How to Make Smart Food Choices with food expert Mark Hyman, MD, author of What the Heck Should I Eat? and numerous other research-based resources on food and nutrition.

Sugar and Cancer

The idea that cancer cells feed on sugar comes from the work of Otto Warburg, MD, who nearly 100 years ago studied how cancer cells metabolize sugar. The Warburg Effect, as this is called, leads some patients to feel guilty if they do not give up all sugarcontaining foods during cancer and treatment.

Research does show that cancer cells metabolize sugar avidly. Cutting back is a good idea for people whose diets include significant added sugar, often found in condiments, bottled sauces, yogurts, and other foods we might not expect to be as sugary as desserts. Some tips:

- Look for prepared foods with no added sugar.
- Keep the American Heart Association guidelines for added sugar in mind—just 25 grams per day for women, 36 for men. When you check the label on your favorite yogurt and see 18 grams of sugar, understand that you can still eat it, but sticking with the guidelines will mean avoiding almost all other foods with added sugar that day if you want to stick with the guidelines. 7 Soda and coffee drinks can also contain a great deal of sugar. Some regular sodas may have more than 40 grams in a single 12-ounce can.

Researchers continue to study the role of sugar in cancer. For now, eating a healthy, balanced diet and adding known cancerfighting foods is likely the best—and most sustainable—approach.

Should you go keto? Or fast?

Many people with cancer are interested in a ketogenic diet. The Academy of Nutrition and Dietetics explains what this diet involves, who should avoid it, and the pros and cons. You can also learn more from Harvard Health.

Is "keto" necessary if you are serious about fighting cancer? Is fasting linked to survival? Current research shows keto or shortterm fasting may help chemotherapy and radiation work more successfully.8 However, research is still ongoing and, particularly for fasting, in its infancy.9

It is important to note that the heavy emphasis on meat protein intake in ketogenic diet plans is not aligned with cancer prevention guidelines. As an alternative, the Mediterranean diet includes animal protein sparingly and has been extensively studied for its anti-inflammatory properties. Download our free Mediterranean Diet Pocket Guide.

Food and emotions

Moving past shame and self-blame

Many patients come to treatment with the idea that they caused their cancer. While it is certainly possible that exposure to smoking, processed meats, and other potential carcinogens played a part, self-blame does not support healing.

The opposite idea is that making the right changes, such as giving up sugar or red meat, will effect a cure. The patient mistakenly feels that they have failed if the cancer does not disappear or go into remission.

In fact, while many cancers are cured, some are not. No dietary intervention has been reproducibly shown to cure cancer. People are not at fault if the malignancy does keep growing. Dr. Jonas' book How Healing Works offers a deep dive into what it means to create health for mind, body, and spirit.

The comfort of food and drink

Food can be medicine—and it can provide comfort and pleasure. Those are at least as important during the stress of cancer and treatment as when we are feeling healthy. Dr. McManamon agrees: "If you are depressed and craving a comfort food, this might be the time to eat it without guilt. If you are a caregiver, you might fix a favorite food the person with cancer feels like eating, even if it is a 'bad' or sugary food." The nutritional value of food is emotional as well as physical.

Some tips for comfort eating with cancer:

• Try a new comfort food that may be a cancer fighter. Green tea with honey, creamy scrambled tofu, or a side of caramelized roasted sweet potatoes can all be comforting and easy to eat and are loaded with important nutrients. Also consider adding herbs and spices. These can boost flavor and, in some cases, decrease inflammation.

• Check the lists of cancer-fighting food and come up with your own ideas.

The social side of eating and cooking

More than 40 percent of Americans are now unmarried, and many live alone. Whether or not a caregiver is present, self-care is just as important for people living solo with cancer as for those in families. Nutrition tips include:

- Planning specific meals and snacks. Instead of grabbing whatever is on hand, breakfast might become the time for a smoothie.
- Dr. McManamon advises patients who live alone to make a big pot of soup once a week to have something healthy and easy to prepare on hand.

Patients may have a caregiver who prepares meals for them, or they may be the primary cook for a family group. Cooking can be challenging if the smells of certain foods are nauseating, or fatigue might make it difficult to be present at every family meal. Helpful questions to consider include:

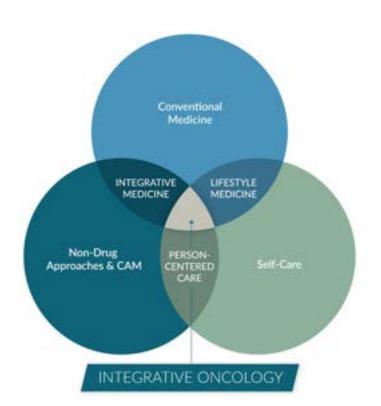
- What can be stocked in the pantry to make it easy for you to eat and for family members to prepare their own meals?
- How can you talk with young children who are distressed that family patterns are disrupted?
- Who can help you shop or cook, if necessary?

My notes and questions

• Do you need help cleaning up the kitchen? Can you maintain appropriate food safety and kitchen hygiene for yourself or someone you care for who is immunocompromised?

Author Rebecca Katz offers a complete online course, The Cancer Fighting Kitchen, that caregivers and cooks may want to check out. Katz is interviewed in our article "Navigating Nutritional Information as a Cancer Patient and Beyond."

Believing that what we take in is nourishing us also helps us get used to new foods. Instead of thinking of vegetables as "diet food," focusing on the nutrients that give them their brilliant colors can help. The nutrition advice to create a "colorful" plate can double for creating a cancer-fighting plate. As you eat to benefit your body, you may find yourself discovering some new favorite foods, experiencing pleasure when you may not have expected it, and creating a new level of health for body, mind, and spirit.



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THE POCKET GUIDE TO PATIENT **ADVOCACY IN CANCER**

FAST FACTS

- Patient advocates are personal guides who help you get the right care at the right time during your cancer journey. They can take the form of a friend or family member, a social worker, nurse navigator, a former cancer patient, or yourself.
- A patient advocate can help you find ways to pay for treatment and living expenses, access health insurance, get transportation to visits, access to community resources, and more.

HOW PATIENT ADVOCATES CAN MAKE YOUR CANCER JOURNEY EASIER

Having cancer or any serious life-changing disease is overwhelming. At a time when you're anxious and afraid, you are faced with navigating the complicated health care system to get the treatment you need. You and your family also face practical challenges, including paying for and getting to treatment. "Getting told you have cancer is like getting hit by a bus," says cancer survivor Lou Lanza. It's almost essential to have some that can help you get back on your feet.

You don't have to—and you shouldn't try to—do this all on your own. A patient advocate can help make your cancer journey easier.

What is a patient advocate?

A patient advocate is someone who helps you get the care and support you need. This can be a professional patient advocate, a support group, a family member, or a friend. Get the best care and support by working with both a professional patient advocate and a family member or friend. Also, you can advocate for yourself.

What does a patient advocate do?

"Patient advocates are very important in providing support, navigating the complex health care system, asking questions, and clarifying concerns," says Celeste Vaughan-Briggs, LCSW, manager, Breast and Cervical Cancer Screening Program and oncology social worker at the Sidney Kimmel Cancer Center at Jefferson University in Philadelphia, PA. .

A professional patient advocate can help you with:

- Getting access to health care, including coordinating your care and communicating with your care team.
- Getting practical information about your disease and treatment.
- Paying for treatment, including financial aid and health insurance.
- Paying for living expenses.
- Getting transportation to and from medical appointments.
- Referrals to community resources.
- Information about complementary treatments
- Support in lifestyle changes

A family member or friend who knows you well can listen during appointments, write down and organize what the care team says, and ask questions. They can let your care team know about things you might not mention, such as your symptoms and how you're feeling. "A family member or friend can be a connecting bridge for the care team, providing crucial information," says Vaughan- Briggs.

You should also ask questions. "There is no stupid question. Everybody has different questions, needs, and requirements," says Lanza. When Lanza was being treated for non-Hodgkin's lymphoma at the Sidney Kimmel Cancer Center in 2005, professional patient advocates weren't common. But he got help from his wife and friends who drove him to treatments, gave his kids rides, made meals, and helped in other ways. Now Lanza helps other cancer patients, including by being part of the Sidney Kimmel Cancer Center's Buddy Program, where he supports newly diagnosed cancer patients.

Where do professional patient advocates work?

Professional patient advocates are sometimes called patient navigators. Cancer centers and hospitals usually have patient navigators. Sometimes, patient advocates are also called health care advocates.

Local and national nonprofit organizations, Federally Qualified Health Centers, government agencies, insurance companies, and for-profit patient advocacy firms also have patient advocates. Some patient advocates are self-employed.

What qualities and skills should a patient advocate have?

Compassion is a key quality in a professional patient advocate, say both Lanza and Vaughan-Briggs. Other qualities and skills to look for are:

- Knowledge of your disease and the health care system.
- Ability to communicate effectively.
- Empathy.
- Good time management.
- Ability to do research to solve problems.
- Patience.

Also, if possible, look for a professional patient advocate who is like you: someone of the same race, ethnicity, age, gender, and setting (urban, suburban, or rural) who speaks your primary language, recommends Vaughan-Briggs. The patient advocate will understand your life and be able to make your care team aware of any barriers to care based on your life.

A family member or friend who serves as your patient advocate should know you well, be comfortable asking questions, and be organized and assertive.

How do I find a patient advocate?

If your cancer center doesn't assign a patient navigator or advocate to you, ask for one. Your care team can help you find a patient navigator or advocate if the cancer center doesn't have any on their staff. You can also use a directory of patient advocates (see the Resources at the end of this guide).

As my needs change, how can the patient advocate help me?

A professional patient advocate understands your needs during your cancer journey and can provide support and resources tailored to where you are. For example, when you're newly diagnosed, your patient advocate will focus on relieving your anxiety, working with you and your care team to develop a care plan so you know what to expect, and helping you navigate the health care system.

During treatment, your patient advocate will continue to provide support, can help coordinate your appointments, and help you communicate with your care team. After treatment, your patient advocate will work with you and your care team to develop a follow-up care plan and continue to help with your emotional, financial, and other needs.

If you need end-of-life care, your patient advocate will support you and your family and continue to coordinate your care. They will work with your care team to ease your pain and help you organize practical matters while respecting your advance directive and your wishes.

Is a patient advocate different than patient advocacy?

Patient advocacy organizations and some patient advocates don't work directly with patients. Instead, they promote policies to help people with cancer, raise awareness of cancer, advance cancer research, and improve the quality of cancer care at the local, state, and national levels.

For example, the American Cancer Society's Cancer Action NetworkSM works with elected and appointed officials, policymakers, and candidates to ensure that cancer remains a top priority. Lanza provides his perspective as a cancer survivor for patient advocacy work at the American Society of Clinical Oncology, the American Association of Cancer Research, Patient Power, and other organizations.

Resource list

Use these resources to make your cancer journey easier.

Education

- Cancer A-Z, American Cancer Society: Information on specific types of cancer along with cancer basics.
- Guides for more than 120 types of cancer, American Society of Clinical Oncology
- Guidelines for different types of cancer, National Comprehensive Cancer Network

Patient navigation, case management, and patient advocates

- Patient Navigation programs, Susan G. Komen Foundation Helpline: For breast cancer patients: 1-877-465-6636 or helpline@komen.org.
- Case Management, Patient Advocate Foundation: Free help, including access to care, paying for treatment and living expenses, and employment for patients and families living with a serious or chronic health condition.
- Case Management, CancerCare: Free telephone case management from oncology social workers.
- AdvoConnection Directory: A directory of private patient advocates you can pay to help you. They are all members of the Alliance of Professional Health Advocates.
- Advocate Directory, National Association of Health Care Advocacy: A directory of private patient advocates you can pay to help you.

Financial Resources

- ASCO Financial Resources, American Society of Clinical Oncology: Links to organizations that provide financial support to people with cancer. Types of support include financial aid, grants, and help with specific services or products, such as travel or medications.
- Programs and Resources to Help With Cancer-related Expenses, American Cancer Society: Includes information on housing needs or mortgage payments, transportation, food costs, and other expenses.

- Help Paying for Prescription Drugs, American Cancer Society: Public and private programs that help with the cost of medicines.
- Legal & Financial Navigation Program, Triage Cancer: Free one-on-one help in health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more.
- Cancer Finances tool, Triage Cancer.
- Co-Pay Relief Program, Financial Aid Funds and Scholarships, Patient Advocate Foundation: financial assistance to insured patients who meet certain qualifications to help them pay for the prescriptions and/or treatments; small grants to patients who meet financial and medical criteria and for patients living with a serious or chronic health condition; and scholarships for college students with cancer or another chronic illness.
- National Financial Resource Directory, Patient Advocate Foundation: National and regional resources dedicated to improving access to quality care and decreasing the financial burden of medical treatment.
- Financial Assistance & Insurance, Susan G. Komen Foundation: For breast cancer patients.

Transportation

American Cancer Society Road To Recovery® program: Trained volunteers that drive patients and families to hospitals and clinics for treatment. This is available in some areas.

Housing during treatment

- Hope Lodge® program, American Cancer Society: A free place to stay if cancer treatment is far from home.
- Health care Hospitality Network: Free or low-cost housing for families getting medical treatment far from home.

Integrative Cancer Care

- The Center for Mind-Body Medicine, programs that support those who have been through psychological trauma through a model of self-care, social support and community building.
- Commonweal, integrative healing programs for patients and health care workers.
- Beyond Conventional Cancer Therapies, a database of evidence-based integrative practices that can support patients going through cancer treatment.

Legal services

- Legal & Financial Navigation Program, Triage Cancer: Free one-on-one help in health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more.
- Advance Directives, American Cancer Society: Information about advance directives and how to develop one.
- Putting Your Health Care Wishes in Writing, American Society of Clinical Oncology: Advance directives and decisions for urgent or emergency care.

Health Insurance

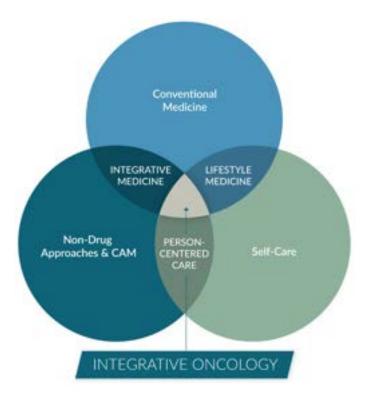
- Health Insurance, guides and information, Triage Cancer: Guides and information.
- Legal & Financial Navigation Program, Triage Cancer: Free one-on-one help in health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more.
- Health Insurance Options, American Cancer Society: Information about types of health insurance and where to find it.
- Cancer Insurance Checklist, Cancer Support Community.

Other

- Managing Your Care, American Society of Clinical Oncology.
- Work and Employment, Triage Cancer: Guides and other resources.
- Dating, Sex, and Reproduction, American Society of Clinical Oncology: Information on dating and intimacy, sexual health, fertility, pregnancy, and more.
- Cancer Survivorship Checklist, Cancer Survival Toolbox and more, National Coalition of Cancer Survivorship.
- Support: Living Beyond Breast Cancer for breast cancer patients.

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CANCER AND SEXUAL HEALTH POCKET GUIDE

FAST FACTS

- 87 percent of cancer survivors say that they experienced sexual side effects and that these issues were not addressed by their oncologist. Female patients were especially unlikely to be asked about sexual disfunction following chemotherapy, radiation, and/or surgery.^{1,2}
- More than 6 in 10 women report effects on sexuality and sexual response following cancer treatment.3
- More than 7 in 10 men who have prostate cancer surgery report problems getting an erection.

SEX AND CANCER

Your sex life doesn't have to end when you are diagnosed with cancer. What's likely, though, is that it will change, just as it changes with other life events. Cancer has physical, mental, and emotional effects on your sex life. It's important to emotionally prepare for the changes that may occur and eventually adjust to the change that you have experienced because of cancer treatment.

How cancer affects sexuality

The cancer itself may affect your sexuality physically and emotionally, but often it is the treatment that has the largest impact on sexual function. Erectile dysfunction (ED) is often an immediate post-operative side effect of surgery for prostate cancer that may last 18 to 24 months post-surgery, but it may also happen before cancer treatment. For women, surgery that removes the uterus or ovaries or chemotherapy and other medications, like aromatase inhibitors for breast cancer, that cause menopause affect sexual health. Loss of breast tissue, nipples, and feeling in the breast area following a mastectomy can also impact sexuality. Radiation to the pelvis, surgical scars, gaining or losing weight, and even losing or growing hair all affect how your body feels and how you feel about it.

On an even deeper level, Jennifer Bires, MSW, LCSW, OSW-C, executive director of the Life with Cancer and Patient Experience department at Inova Schar Cancer Institute, says fatigue has a major effect on sexuality when you live with cancer. "Fatigue can be crushing at times," she says. "People with cancer are more likely to be depressed or anxious, which also lowers libido." If you are taking antidepressants as part of your treatment, you should know that these also can cause changes in desire, arousal, and orgasm.

The emotional impact of cancer can include "changes in your relationship, changes in roles for you and your partner, or changes in your interest and capacity to date or form new relationships," Bires says. "Whether on the emotional side or in physical activity, there is likely to be a pause in sexual activity and a change in how you feel about your body and your sexuality."

The oncologist's view of your sex life

"The impression I get from my provider is that I should be lucky to be alive," says Steve, who is struggling with the physical effects of cancer treatment—but wants to stay connected with his wife. Steve says his oncologist's view of sex seems to be, "Why would you care about that right now?"

Derrick faced a similar attitude from his surgeon. "His attitude was, yes, you will probably have ED, but in your sixties, how much does

that matter?" In fact, maintaining a healthy sex life with his partner was very important to Derrick and not something he was willing to give up. He sought treatment advice from two more surgeons before choosing one who understood the need to treat him as a whole person with cancer, not just a cancer patient.

Feeling empowered to search for solutions for changes in sexual health is an important first step in advocating for yourself. This means keeping what matters to you front and center in conversations with your care team.

Health-care providers who can help

Your cancer care team can include health-care providers to help with sex, relationships, and sexual rehabilitation, including:

- A gynecologist (specialist in women's sexual and reproductive health).
- A urologist (specialist in the urinary system, for men and women).
- A pelvic floor physical therapist (specialist in assessment and rehabilitation of your body's strength and function).
- An endocrinologist (hormone system specialist).
- A counselor, marriage and family therapist, or sex therapist (emotional and behavioral specialists).

Because energy and appearance are important to sexuality, you may also consider the following team members:

- Personal trainer or exercise class instructor (including free and low-cost online instruction)
- Meditation or wellness coach (including free and low-cost online instruction)
- Massage therapist (consider group sessions or partner training for reduced fees)

The Maple Tree Cancer Alliance has exercise and nutrition programs specifically designed for people with cancer who are going through treatment.

For appearance, Fighting Pretty and Look Good, Feel Better (for women) and Look Good, Feel Better (for men) have helpful resources.

Ask your health-care provider about sex

"What's important to you should be important to your healthcare provider," says Bires. "Shared decision-making is important, especially when treatment will affect your quality of life as much as sexual side effects can."

If your provider makes a gendered assumption about you—for example, that you are interested in fertility preservation but in reality don't plan on having children—speak up! It's important that they have all the information possible so that they can tailor your treatment options for your unique needs.

You may want to ask your health-care provider some of the questions below:

- Will this cancer affect my interest in sex, my desire for sex, or ability to have children in the future, if I want them?
- How will treatment affect the way I look? Will these changes be permanent?
- Of the treatment options for this cancer, which would impact my sexual health the least?
- How can I cope with side effects such as early menopause?

My relationships [spouse / dating life / desire to get married / desire to have children] are very important to me. What's the best way to maintain those connections and plan for the future?

For more examples of questions for providers, see this <u>article on</u> WomanLab.

For men, Penn Medicine's Onco has a guide to sexual health with information on how particular chemotherapy agents can affect sexual partners and a list of questions to consider when speaking to your provider.

Sex will change, and that's OK

It's easy to accept the media ideal of sex as something we constantly desire and are constantly ready for. However, expectations meet reality in many life stages. Consider the following situations:

- The teen, longing for connection and experience, who doesn't have or may never have had a partner.
- The young adult, single and starting out in the working world.
- The parent with a newborn who has little time, desire, or energy for sex.
- The military service member who is far from their spouse or partner.
- The divorced adult who is getting back into dating.
- The adult who has a passionate relationship with their partner.
- The senior citizen who is unexpectedly widowed.

If sex isn't possible for the short or long-term, what are other ways of exploring intimacy with a partner?

- Hand-holding, resting your head on your partner's shoulder, or hugging—the healing power of touch is a powerful tool in intimate relationships.
- Non-sexual massage—reiki or therapeutic touch are other ways to harness the healing power of touch.
- Regular check-ins with a partner—taking time to tell your partner why you love them.
- Date nights—making time to be together and have conversations that don't involve kids, work, or household duties.
- Attend a relationship workshop or see a counselor. Couples therapy isn't just for relationships that are in trouble. Talking through some of the issues that come up as you navigate cancer will help you to develop the tools you need to have meaningful conversations with the people you love. Whether you struggle with asking for help or you need space, being able to have an honest conversation can strengthen your relationship.

Accepting change and loss

Cancer creates an undeniable experience of the inevitability of change, and all change involves some loss. "A lot of sexual health work involves grieving," Bires explains. "With cancer, your sex life may not go back to where it was before. You need to grieve for sex as you used to define it and grieve your expectations for what sex will be like."

Acknowledging that things have changed and grieving that loss is necessary before you "put your sex life back together," says Bires. She is clear, however, that a new sex life is very possible. "It will look different, but it could be very satisfying," she says. "Having cancer and dealing with changes means you have to work with your own body, talk to your partner, and become more aware of what's important to you sexually."

Single, with cancer

Should you date? Are you healthy enough, and do you even want to? What do you have to offer a partner—and when do you tell them about the cancer?

Marcus solved the problem by responding to one of the datingprofile questions—things you can't live without—with "Velcade," the name of his chemotherapy drug. He figured that potential partners who responded to his dark humor might be good matches. "I also got a lot of hate mail," he says. "People who couldn't believe I'd be so callous or that I was even dating when I'm living with cancer."

Dating and relationship decisions

- Do I want to date now?
- When do I share that I have (or have had) cancer? How much information is too much? Do I need to share this right away? There is more to me than cancer.
- How will I respond if someone says something insensitive about my cancer diagnosis and/or treatment?
- What is my goal for dating?

Resources

In one study, more than half of the patients who were asked about sexuality during cancer asked for "practical tips." This section has tools, resources, and tips to help you understand and nurture your sexuality during cancer and treatment.

- Scientific Network on Female Sexual Health and Cancer
 - A collated list for female cancer survivors covering various aspects of sexual health.
- American Association of Sexuality Educators, Counselors, and **Therapists**
 - Choose "Find a Professional" to search for a professional in your home state.
- Herman & Wallace Pelvic Rehabilitation Institute's low-cost download "Orthopedic Considerations for Sexual Activity" (Low cost download)
 - Shows sexual positions appropriate for when you are tired, had surgery, or have other physical needs.

- The Prostate Recovery MAP by Craig Allingham
 - Low-cost book on recovering sexual function and ability to control urine after prostate cancer treatment.
- Unite for HER
 - Enriches the health and well-being of those diagnosed with breast and ovarian cancers by funding and delivering integrative therapies.

Tips from an oncology social worker

Jennifer Bires has these tips to help you appreciate, rest, and rehabilitate your sexuality:

- Take the time for full recovery. Chemotherapy, surgery, and radiation all take a toll on the body. Keep your expectations for sexual activity modest and reasonable.
- Try "sensate focus" exercises, where you touch your partner without the goals of specifically being sexual or having an orgasm. Massage or extended sex play can count as "sex," too!
- Plan to be sexual when you know you have energy and feel your best. Don't hesitate to take pain medication, enjoy a warm bath, and experiment with new positions to see what works best.
- If culturally appropriate, don't be afraid to explore your own body. It is hard to tell other people what feels good if you don't
- If you have a longtime partner, remember that you have started many new chapters as a couple, and cancer or survivorship is just one more.
- Creativity and laughter can be key. There are endless ways to be sexual and intimate. Changing your mindset to one of exploration rather than one of loss can be helpful in regaining sexual satisfaction.

Bires also has a word of advice for caregivers. "You may want to be sexual and miss your partner's touch. But you may also be afraid to injure them or tire them out. Don't ignore your needs-ask them! If you're caring for them a great deal, they may be happy to do something for you, even a simple massage or kissing."

Sample script for talking with your partner about sex

Talking about sex can be scary, but communication is key. It is often helpful to have this conversation in a neutral space without distraction—not when someone is trying to initiate a sexual experience. When you are ready to talk about sex with your partner(s), it can be helpful to use a model similar to the one below.

- Fact: We haven't had sex since your cancer diagnosis.
- Belief: I think you might feel you're not attractive to me right now.

- Feeling: But I feel sad, and miss being with you sexually.
- Need: I need to feel close to you physically. Would you be OK talking about some ways to do that again?

Using a model like this allows your partner(s) to understand why you may be thinking or feeling the way you do without blaming, and it can help them open up about their point of view without becoming defensive.

More Pocket Guides and Tools

- The Pocket Guide to Nutrition and Cancer
- The Pocket Guide to Movement and Cancer
- Fertility: An Integrative Approach to Your Reproductive Health
- Your Healing Journey: A Patient Guide to Integrative Breast **Cancer Care**
- Your Healing Journey: A Patient Guide to Optimal **Healing Environments**
- How Healing Works: Get Well and Stay Well Using Your Hidden Power to Heal [book] by Dr. Wayne Jonas
- The Caregiver's Companion: Caring for Your Mind, Body and Spirit

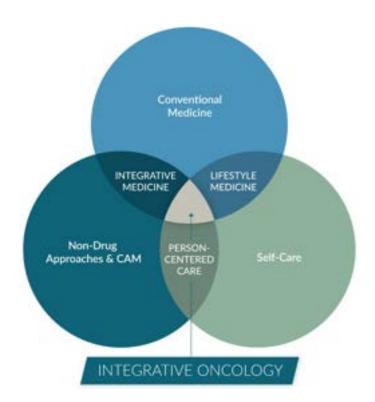
Website

savemyfertility.org

Notes and questions					

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SPIRITUAL LIFE AND **CANCER POCKET GUIDE**

Patient Pocket Guides

FAST FACTS

- More than 9 in 10 American adults believe in a higher power.1
- In one study, more than 7 of 10 hospitalized adults wanted to discuss spiritual issues, and nearly half wanted health-care team members to pray with them.2

WHAT IS SPIRITUAL LIFE?

When we talk about spiritual life, we usually mean a connection to something beyond ourselves—the higher power that 90 percent of Americans believe in. You can be spiritual whether or not you are also religious, belong to a faith group, or follow specific principles and beliefs. Spirituality and religion both help us answer the big questions of existence: Why am I here? What is the meaning of life? What matters?

Cancer and other serious illnesses tend to draw our attention to these questions. They focus our life. For that reason, many people with cancer say spirituality and religion—or faith—are particularly important during illness and treatment. Many studies show that having a spiritual or religious practice helps people with cancer cope with challenges from depression and anxiety to pain management and recovery.3

A deepened connection to ourselves, whether through religion, spirituality or mindfulness will help in navigating a serious medical trauma, such as cancer. Here are a few definitions to consider when we are talking about spirituality:

Mindfulness: Presence in the here and now and acceptance of one's illness within the context of the world we live in physically.

Spirituality: Existential concerns about life after death, what happens to one's soul, or will one see their loved ones again, etc.

Religious: Social-cultural systems of designated beliefs, behaviors, morals, and practices that relate humanity to supernatural, transcendental, and spiritual elements.

How does spiritual care help in cancer treatment?

Cancer and its management can open new spiritual support addressing needs you may have never been aware of before. Raymond Wadlow, MD, is a medical oncologist at the Inova Schar Cancer Care Center in Fairfax, Virginia. In Dr. Wadlow's experience, common questions include:

- Why me?
- Is cancer my fault?
- Is God or the universe punishing or testing me?

- Did this happen because I smoked, drank alcohol, ate certain foods, or did something bad in the past?
- Will I die soon?
- What will happen to my spirit after I die?
- Has my life mattered?

Worrying about these questions can have a negative effect on one's physical, social, and emotional quality of life. On the other hand, spiritual care has been found to positively 4 impact quality of life and be especially helpful at the end of life.5 Honoring and accommodating each person's belief system and spiritual practices is important.6

A spiritual care plan is designed to help people do the following things and more:

- Understand how they are struggling and talk about their needs.
- Cope with anxiety, worry, grief, and anger.
- Talk about change, loss, and death and dying when appropriate.
- Gain acceptance of their situation and develop a sense of peace
- Die with dignity, in a chosen manner (when possible).⁷

Talking with your care team about spiritual care

In whole person care, we often refer to three dimensions: body, mind, and spirit. But if you rely on your oncologist as the main source of treatment resources, finding spiritual care may take some extra effort.

"Physicians are not taught to discuss spirituality," explains Dr. Wadlow. He says that talking about spiritual life and religion is still "somewhat taboo, and often delegated to other team members."

Your cancer care team may be hesitant to bring up spiritual life because they don't want to intrude on your personal beliefs. They may even believe it is not ethical to talk about these issues with you. However, most are willing to talk with you if you ask.

Your doctor or another person on your cancer team may also be willing to talk with your pastor, faith healer, or spiritual leader, especially if they understand the importance of spirituality and religion in cancer care. They can also help you find spiritual care by connecting you with a chaplain, a therapist, a support group, or meditation class at the hospital or cancer center.

Requesting a spiritual assessment

A spiritual assessment is another way to include spirituality and religion in your cancer care plan. An assessment is a tool, similar to an outline or list, that allows you or your health-care provider to consider spiritual beliefs, concerns, and desires. While the tools listed below were designed for used by chaplains and other providers, you can use them for yourself or a loved one, changing "the patient" to "you."

Spiritual assessment tools include:

The Joint Commission Spiritual Beliefs and Preferences questions

You may use this whether you are receiving treatment, acting as someone's caregiver, or treating patients with cancer.

The FICA Spiritual History Tool

Developed for providers to assess spiritual or religious preferences of a patient and how they may apply to mental well-being and medical care. Patients with cancer and their families may find it helpful.

The HOPE Questions for Mind and Spirit

- Questions that address a patient's reason for living—their purpose in life. These questions are designed to reveal what the patient finds meaningful, what motivates them, and what provides them with a sense of joy. Here are a few examples:
 - What brings you joy?
 - How has your illness impacted your life?
 - Why do you seek healing?
 - What are your plans and aspirations in life?

Personal Health Inventory

• Based on work developed by the Veterans Health Administration, the <u>personal health inventory (PHI)</u> establishes what matters to the patient and examines the personal determinants of health. This assessment helps a person to uncover where they are in their personal health and where they would like to be.

Drawing on many types of care

Ask any three people with cancer what "spiritual care" means, and you're likely to receive different answers. These may include:

- "Praying with the hospital chaplain and having people at my church pray for me."
- "Using traditional herbs and having a sweat lodge ceremony."
- "Meditating more often and going to therapy."

Not all spiritual interventions look the same. For example, a study conducted at the Kyoto University Graduate School of Agriculture found that a set of treatments based on time in nature, or "green space," were beneficial and considered spiritual. The treatments included gardening, "forest-bathing," yoga, and meditation.8 Although the study was small, the people who took part clearly showed benefit, including an increase in immune cell activity.

Talking with a therapist is another way to address spiritual needs. Having cancer may lead people to explore cognitive behavioral therapy with a counselor available through the cancer treatment center or the patient's workplace. Spiritual care for cancer may also include meditation or mindfulness-based stress-reduction techniques. Art and music therapy are other helpful therapeutic

The Inova Life with Cancer Center, where Dr. Wadlow practices, has courses in mindfulness and related practices and is even beginning to require that physicians and other providers taking advanced specialty training to participate in the courses. Many cancer centers have similar programs, and training providers to participate is becoming more common.

How chaplains can help

A chaplain is a trained spiritual leader who works at a hospital or for another organization such as a branch of the military service. Most service members are familiar with chaplains, who may come from any faith and are generally trained to help people of all faiths or none.

Your hospital or cancer center may have a chaplain who can support you. They can:

- · Read spiritual material to you.
- Talk with you about your concerns and about making healthcare decisions.
- Help family members with spiritual needs.
- Support members of the health-care team and providers at the hospital or clinic.
- Help you, your family, and your health-care team communicate with each other.9

Spiritual care beyond the hospital

Chaplains are generally available in the hospital. For support when you (or your loved ones) are at home, you may want to contact your spiritual community, even if you have not been active recently or ever. You may feel awkward at first, but nearly every organization will welcome a request to talk about essential life questions or provide help.

A hospital chaplain can also help you connect with a local organization for spiritual care, including organizations for those with no specific religious faith such as the American Humanist Association.

Here are some ways to ask for spiritual support:

- I have cancer, and I'd like to talk to someone.
- My family is looking for a supportive community during
- We used to attend [church, temple, mosque, dojo]. We'd like to get involved again, especially since [I, a family member, my partner] am/is having cancer treatment.
- I would like to be added to a prayer group.

Other health-care team members who can connect you with a spiritual or religious organization include social workers, nurses, and therapists.

Tips for finding spiritual care

Based on his experience caring for people with cancer, Dr. Wadlow suggests:

- Being open to exploring your questions about faith and spirituality.
- Recognizing that taking care of your spiritual side can help you heal as a whole person, whether the cancer is cured or not.
- Introducing your physician and other team members to your spiritual leaders or mentors if they visit or are involved in your
- Knowing that you can still discuss fears, worries, and questions of meaning and purpose if you do not have a spiritual bent or aren't religious. You may find hope or peace in nature, movement, meditation, art, or a support group.

"Most health-care providers are extremely dedicated and looking for ways to help you," says Dr. Wadlow. "But they may also feel sensitive because spirituality can be so private, so don't hesitate to ask if you are looking for guidance in this area." When you are seeking help to support and mend your spirit, it's important to ask—and be open to receiving the help and support you need.

To learn more about the connection between medicine and spirituality, read Healing Words: The Power of Prayer and the Practice of Medicine by Larry Dossey, MD. In it, Dossey explores the link between medicine and spirituality and concludes that prayer and spirituality are a critical part of a person's ability to heal.

Resources

Online articles

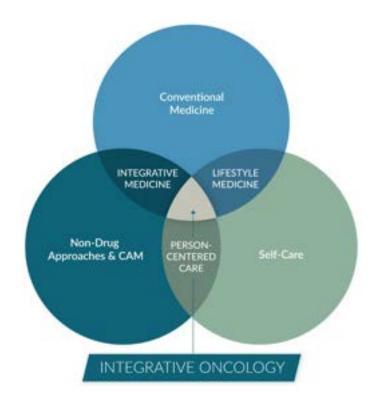
- "Cancer: Religion and Spirituality" from Stanford University
- "Feed Your Faith, Not Your Fears," article from Cancer Treatment Centers of America
- "My Wife Susan's Response to Cancer," from HealingWorksFoundation.org

Books

- When Things Fall Apart by Pema Chodron
- Picture Your Life After Cancer, edited by Karen Barrow
- Finding a Cancer Support Group from the National Cancer Institute
- Kitchen Table Wisdom by Rachel Naomi Remen, MD
- Spirituality in Healthcare edited by Mark Cobb, Christina Puchalski. Bruce Rumbold
- Healing Words: The Power of Prayer and the Practice of Medicine by Larry Dossey

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SUPPLEMENTS AND CANCER POCKET GUIDE

FAST FACTS

- About half of Americans who take dietary supplements believe the U.S. Food and Drug Administration has approved them as safe and effective.1
- The U.S. Food and Drug Administration does not have the authority to approve dietary supplements, but can remove them from the market if shown to be unsafe.²
- In a 2021 survey, fewer than 5 in 10 respondents had talked with their health-care provider before taking supplements.1

SUMMARY

For people in treatment or survivorship, dietary supplements may:

- Help relieve symptoms and side effects of cancer and treatment.
- Boost strength and immunity.
- Help mind and body heal after treatment.

Always talk with your health-care provider and cancer team about any supplements you take. If you are interested in taking supplements, check with your health-care team first.

Supplements can be part of an integrative health plan that includes a nutritious diet, exercise, rest, social support, and other healing practices. So far, no supplement is proven effective as the sole treatment for any cancer or as a cure.

Dietary supplements and cancer

If you or a loved one has cancer, you may have considered taking dietary supplements, are already doing so, or are wondering if you should. Between 60 and 80 percent of people with cancer take supplements before, during, or after their treatment.3

Reasons for taking supplements include:

- Boosting the immune system.
- Aiming to reduce side effects or symptoms of cancer and treatment, such as nausea or fatigue.
- Trying to regain some control by fueling the body as it undergoes cancer treatment.

Experts agree that in general, a holistic approach to diet, exercise, rest, and stress relief is the best way to improve health and potential outcomes, including in those with cancer.3

"It's best to get the nutrients you need from food," says Donald Abrams, MD, an integrative oncologist at the UCSF Osher Center for Integrative Medicine. "However, as you age or when you have certain conditions, you may consider taking supplements."

An integrative approach to cancer treatment can include supplements when conventional treatments do not work well. Jeffrey White, MD, who directs the Office of Cancer Complementary and Alternative Medicine of the National Cancer Institute, says, "People seek dietary supplementation for fatigue and other issues, including sleep problems, low energy, and chemotherapy side effects such as nausea, vomiting, and neuropathy."

What are supplements?

Simply put, supplements are anything you take to boost your body's level of vitamins, minerals, hormones, or other nutrients.

You might hear them called dietary supplements because they are intended to supplement, or add to, the nutrients you get from food and drink.3

Supplements come in many forms, including tablets, capsules, gummies, liquids (including teas), and powders.

Supplements are very popular. One study showed that more than 80 percent of adults in the United States take supplements. But only 24 percent take them because tests showed they were lacking in a certain vitamin, mineral, or other nutrient.⁵ In other words, many people are taking supplements they may not need.

Are supplements harmless?

"What can it hurt?" you might think. After all, getting the vitamins, minerals, and other nutrients you need must be especially important when you have cancer. However, there are important reasons to talk with your cancer care team about supplements.

- Supplements vary in quality. Some are made in clean, controlled laboratories, and others are not. In the United States, supplements are not regulated for safety or effectiveness before they go to market.²
- Labels may not be accurate. Some supplements have clear, accurate labels. Others do not. Your supplement may contain substances that are not listed on the label. "You have to be wary about the quality of any products you get," says Dr. White. "The bottle may say it contains the product you're interested in, but you really have no idea what is in that bottle."

The herbal supplement PC-SPES, used by many patients with prostate cancer, was taken off the market after being found to contain the drugs DES, warfarin, indomethacin, and alprazolam, none of which were listed on the label.4

- The same supplement may go by several different names.³ This can be confusing and even lead to overdosing.
- Supplements can interact with medications and treatments. Substances in your supplement can interact with your regular medications or cancer treatments, making them less effective or even toxic.
- You may not need everything in the supplement. Even if everything is listed on the label, the supplement may contain

- substances you don't need or that are harmful based on your age, sex, or other health conditions.
- Supplements can interact with medications and treatments. Substances in your supplement can interact with your regular medications or cancer treatments, making them less effective or even toxic.
- Your body might not be able to absorb the active ingredient. For example, curcumin is beneficial but very little enters enter your bloodstream unless it is combined with dietary fats or a compound found in black pepper.6

How to talk with your health-care provider

"It's incredibly important to stay honest and open about what you're interested in, taking now, or want to try," says Dr. White. "A lot of people are concerned about expressing things to their doctor. Some physicians are not as open to discussion as others, so this can be challenging, but I always recommend keeping the information exchange open on both sides."

Ways to bring up supplements with your provider include asking:

- Will taking a supplement interfere with any of my current medications or treatments?
- Will my cancer or treatment lower my level of any necessary nutrients?
- Would taking a supplement help me stay healthier during
- Would taking a supplement boost my immune system? Is that a good idea right now?

If you already take supplements

A Harris poll of more than 2,000 U.S. adults found that more than one-third "didn't think their health care provider was interested" in whether they took supplements or not. In fact, they are. To start the conversation, you might share something like

I take	and	$_{}$ for my health (e.g.,
calcium for	bone health and vitamins t	for my eyesight).
I also drink	tea (e.	g., echinacea)

Supplements for specific symptoms

Enough scientific evidence exists for some dietary supplements to recommend taking them for specific symptoms and side effects, provided there are not specific reasons you should not be taking

Talk with your oncologist or other health-care provider before trying any of these. They may recommend a specific dose or formula.

Safer supplements for cancer and treatment				
Supplement	Why try it?*	Things to watch out for		
Ginger	Nausea and vomiting	Can work like a blood thinner. You may bleed too much if injured, if you have a bleeding risk, or if you take aspirin, ibuprofen, or other medicines that can cause bleeding.		
Ginseng	Fatigue	Could cause a dangerously fast heartbeat and increase the risk of bleeding for people taking Coumadin® (warfarin).		
Probiotic containing Lactobacillus and Bifidobacterium	Diarrhea from chemo drug 5-fluorouracil	Dr. Abrams recommends a refrigerated product for best effect.		
Coenzyme Q10 (CoQ10)	Beneficial to the heart, if radiation was given in that region	Only take after radiation therapy ends.		
Vitamin B ¹²	Nerve problems (neuropathy) from B ¹² deficiency	Ask your health-care provider if this is important for you.		
Vitamin C	Wound healing, stress relief	Discuss high-dose IV therapy with vitamin C, but avoid if said to "cure" cancer.		
Zinc	Treating common cold symptoms or for symptoms related to radiation therapy (unproven)	Chronic use of zinc supplements can lead to copper deficiency and lowered blood counts.		
Lion's mane mushrooms	Neuropathy, "chemo brain"	Only take after chemotherapy ends. Consult your doctor if you have mutation of gene CDC73. Avoid mushrooms if receiving immunotherapy.		
Melatonin	Sleep	Avoid high doses said to "cure" cancers, as this is not proven. Some people experience undue drowsiness or headaches with use.		

^{*}Please note that many of the comments in this column are not derived from results of clinical trials. Consult your doctor if you are taking any of these or other supplements.

Avoid these supplements



St. John's wort - It can make chemotherapy drugs less effective and increase skin problems from radiation therapy.

Acetyl-L-carnitine, or ALC – It makes nerve damage from chemotherapy worse. Previously, it was thought to help with this.

Vitamin E – Patients who took vitamin E during treatment for head and neck cancers had higher rates of cancer recurring (coming back) and eventual death. Vitamin E can also increase the risk of prostate cancer in men.

Beta-carotene - In a large study, beta-carotene increased the risk of lung cancer in men who smoked.

Supplements and your treatment plan

Supplements contain powerful substances, including harmful ones. They also come in and out of vogue, often touted online by non-medical websites.

"Vitamin C is something many people are interested in and consume," says Dr. White. "Nowadays, it seems to be mostly highdose IV vitamin C as opposed to pills. That's not really a dietary supplement—that is more like a drug."

"Social media has a big impact," Dr. Abrams says. "Someone goes online and says, 'This cured my cancer.' Even laetrile, which was debunked in the 1960s, is back as 'apricot pits' or 'vitamin B¹⁷."

How supplements can affect you

- Some supplements can make your skin more sensitive. This can lead to severe skin reactions during radiation therapy.
- Some herbs make chemotherapy drugs less effective, like St. John's wort, listed in the box. They can also cause side effects such as bleeding.
- Some herbs and natural compounds, including ginkgo and grapefruit, block the liver enzymes that break down chemotherapy drugs. This can lead to toxic effects.
- Taking antioxidants may make some chemotherapy drugs less effective. "Antioxidants fight free radicals, but the point of radiation and some chemotherapy is to create free radicals to kill cancer cells," says Dr. Abrams.

"Foods with antioxidant properties are fine," Dr. Abrams says. "People ask me, 'Can I eat blueberries? They contain antioxidants.' The answer is yes, because blueberries do not contain such large amounts that they will interfere with chemotherapy, and they contain many other health-building compounds."

Can supplements cure cancer?

Are supplements effective at destroying cancer cells or shrinking tumors? Not that we know, according to Dr. Abrams. "For the most part, that idea is more wishful thinking than based in evidence. With many supplements, we simply do not have a body of evidence from placebo-controlled trials."

Dr. White offers this advice: "If you hear that a supplement kills cancer cells, ask, 'Did this happen in a petri dish? Did it happen in laboratory animals? Where are the studies showing that it works in humans?"

"I see many patients extrapolating from what happens in test tubes and animals to what happens in their bodies, particularly if they hope that supplements will cure their cancer," says Dr. Abrams. "But the human body is more complex than cells in a laboratory dish."

How to evaluate supplements

When considering any supplement, Dr. White says, "First ask, 'What is the scientific evidence?' If it is all anecdotal—personal stories-you don't have much."

Ask your oncologist if studies have shown the supplement or product is effective for your concern. Nurses and pharmacists can also help you find reliable information.

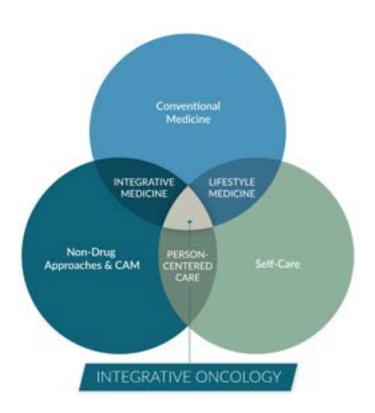
Questions to ask

- Do I take medications that lower the level of nutrients in my body? Do I need supplements to replace these nutrients?
- Does everyone on my cancer team know what supplements I take?

- Will my supplements affect my cancer treatment?
- Do my supplements contain high-quality ingredients? Are there any dangerous ingredients?
- Do high-quality research studies show this supplement works for my concern? Or, does an experienced health-care provider recommend it?
- Will the supplement affect other health conditions besides my cancer? How?
- Is a different medication or approach safer or more effective?

Resources

- Look for products with the NSF International, USP, or Consumer Laboratories seal.
- Check the U.S. Pharmacopoeia information on dietary supplements and food at qualitymatters.usp.org/topics/ dietary-supplements.
- See the Dietary and Herbal Supplements guide at the National Center for Complementary and Integrative Health.
- Subscribe to ConsumerLab.com for reviews of supplements and other health products.
- Check the FDA Dietary Supplement Ingredient Advisory List, and sign up to get alerts when new ingredients are added.
- Check the FDA's What's New in Dietary Supplements page for the latest news and actions.
- Your Healing Journey: A Patient's Guide to Integrative Breast Cancer Care Guide
- Chemotherapy-Induced Peripheral Neuropathy (CIPN) Pocket Guide
- Physician Data Query (PDQ®), National Cancer Institute
- About Herbs (MSKCC)
- Natural Medicines database
- Search Wellkasa to find science on supplements and information on drug-supplement interaction.



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This is produced as an educational resource. All health decisions should be made in consultation with your health care team.