

Palliative Care

Introduction

Palliative care has evolved significantly since it first emerged in the 1970s as a component of end-of-life care. Today, palliative care reflects a broad range of services that can provide comfort, care and support to you and your family. In fact, many physicians and health care professionals are choosing to specialize and receive certification in this practice, ensuring the highest standards of care.

The information that follows is designed to help you and your family understand what palliative care is, the difference between palliative care and hospice care, how palliative care can help you manage many of the challenges associated with a brain tumor diagnosis, the members of the palliative care team, and how to access palliative care services in your community.

What Is Palliative Care?

Palliative care is both a medical subspecialty and a philosophy of care. Its holistic or “whole person” approach to care focuses on helping you and your family achieve the best possible quality of life while living with a serious illness. Adopting a palliative care approach soon after diagnosis gives you a head start on developing strategies for coping with the many challenges you are likely to face throughout the course of your illness.

A major component of the palliative care philosophy is to empower you and your family to make informed treatment decisions—from establishing goals of care, to making decisions that will guide end-of-life care and planning, if necessary.

Because you and your family have unique needs and concerns, there is not a one-size-fits-all approach to receiving palliative care services. Instead, you are encouraged to choose those services that best suit your needs.



For example, early on a primary goal may be relief from symptoms. As treatment progresses, the palliative care team can also provide physical, emotional and spiritual support as needed.

You do not have to choose between palliative care and treatment intended to cure the disease. Palliative care can be provided simultaneously with curative treatment and, in fact, may help to manage treatment side effects.

How is Palliative Care Different from Hospice Care?

Palliative care is appropriate at all stages of a serious illness, whatever the prognosis. Hospice care, on the other hand, is available if you decide to no longer receive treatment to cure your illness. Both palliative care and hospice care strive to alleviate pain and other symptoms. While palliative care is a crucial component of hospice care, it is not limited to end-of-life care. When a cure is no longer possible, palliative care serves as a bridge to hospice care.

The Palliative Care Team

Members of a palliative care team work together with the neuro-oncologist and primary care physician to support you and your family’s goals for curative treatment, and to improve quality of life.

The palliative care team can also help clarify confusing medical terminology and procedures so choices for care are better understood and informed decisions can be made.



Because there are many services a palliative care program can provide, coordination of this care is important to ensuring that the level of provided services is appropriate for you, that your questions are being answered, and that your wishes are being respected.

For example, questions related to your symptoms, medical treatment or medications can be directed to your palliative care physician or nurse. In addition, you might want to seek counseling from a social worker to help you and your family cope with the emotional stress of your diagnosis and treatment. A chaplain is often available to talk through religious and spiritual beliefs and questions. Soothing therapies may be offered by healing arts practitioners specializing in music, art or massage therapy.

The palliative care team can also make you and your family aware of helpful resources in your local community. If necessary, they will work to coordinate care and ensure a smooth transition to different health care settings such as an outpatient clinic, home, hospice, or rehabilitation and long-term care facilities.

Your Palliative Care Team

Today, many of the top medical centers in the United States and abroad, including major teaching hospitals, offer palliative care programs. Physicians and health care professionals with board certification in palliative care may include:

- Emergency and Internal Medicine specialists
- Family medicine physicians
- Pediatricians
- Psychiatrists
- Neurologists
- Radiologists
- Radiation oncologists
- Physical medicine and rehabilitation specialists
- Surgeons
- Nurses
- Social workers

Your palliative team may also include:

- Chaplains
- Massage therapists/ art therapists/ music therapists
- Pharmacists
- Nutritionists/dieticians
- Trained volunteers who may provide emotional support and companionship.
- And most importantly, you and your family.

Palliative Care and Brain Tumor Symptoms and Side Effects

If you have a brain tumor, you may experience a variety of symptoms. Some of these symptoms can be directly or indirectly related to the brain tumor itself, while others may result from treatment methods such as chemotherapy, radiation therapy and surgery.

Two major goals of the palliative care team are to provide adequate symptom control, as well as psychosocial support to you and your family. Therefore, the palliative care team works with you and your family to help relieve the symptoms and side effects without interfering with treatment.

The following are a few of the most common symptoms and side effects associated with a brain tumor diagnosis and/or treatments:

- Headaches
- Seizures
- Dysphagia (difficulty in swallowing)
- Cerebral edema (an increase in water within the brain, resulting in an elevated intracranial pressure)
- Venous thromboembolism (blood clots in the veins)
- Fatigue
- Mood changes such as anxiety or depression
- Changes in cognitive function (such as attention and memory)
- Personality changes
- Nausea and vomiting, constipation
- Loss of appetite
- Sleepiness, irritability
- Neuropathic pain (pain due to malfunctioning of the nervous system; a brain tumor can affect the cranial nerves, causing headache or facial pain)
- Other pain (for example, if suppression of the immune system leads to shingles)



Enlisting Palliative Care Services

The first step in securing palliative care services is to talk to your doctor, nurse, or social worker as you will likely need a referral to receive this type of care. Let them know you are considering palliative care and ask what services are available in your area.

Your local hospital may offer palliative care services either in combination with hospice care or as a stand-alone program. Or, it may contract with an outside provider of palliative care.

If your local hospital or health care center does not offer palliative care services, you can check online for a list of programs. The Palliative Care Provider Directory of Hospitals is available at <http://www.getpalliativecare.org>. The National Hospice and Palliative Care Organization (<http://www.NHPCO.org>) also offers an online directory of hospice and palliative care providers, including non-hospital-based providers.

Palliative Care Resources

For Patients and Families:

Get Palliative Care.org
www.getpalliativecare.org

National Hospice
and Palliative Care Organization
www.nhpc.org

Palliative Doctors
www.palliativedoctors.org

For Health Care Professionals:

American Academy of
Hospice and Palliative Medicine
www.aahpm.org

Center to Advance Palliative Medicine
www.capc.org

The Initiative for Pediatric Palliative Care
www.ippcweb.org

The American Brain Tumor Association...

We're Here to Help

The American Brain Tumor Association offers a wide-array of education, information and support services for patients, families and caregivers.. These include publications and resources, compassionate support by a dedicated Patient Services team and regular updates on brain tumor treatment and care. For more information: info@abta.org; 1-800-886-2282; www.abta.org



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