

# Transitions in Care for Patients with Brain Tumors: Palliative and Hospice Care



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# Overview

The goal of this handbook is to provide an overview of what a patient and his/her family and caregivers may expect when facing a progressive, life-threatening brain tumor. This handbook is specifically focused on providing effective care at home and at the end of life.

Cancer involving the brain can either be primary, meaning that its origin was in the brain, or secondary, meaning that the cancer started elsewhere and spread to the brain. The incidence of secondary brain cancer is rising because treatment options for many cancers have expanded, sometimes resulting in improved survival, but also increased rates of spread to the brain.

*Some of the problems caused by brain tumors are in common with many other forms of cancer; however, there is a subset of challenging problems unique to brain tumors. We aim to address these unique issues in this handbook.*



# Introduction to Palliative Care

Although treatments for high-grade brain tumors are advancing, cancer arising from the brain is frequently incurable. There are treatments that may improve symptoms and prolong life, but unfortunately, cancer involving the brain will frequently lead to the patient's eventual death. Some of the major concerns of patients as they face the end stages of their illness include uncontrolled symptoms and feeling as though they are a burden. There is increasing recognition that patients benefit from receiving their standard oncologic care alongside palliative care.

*Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious and/or life-threatening illnesses. Palliative care focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness. The goal of palliative care is to improve quality of life for both the patient and their family.*

Palliative care is provided by a team of doctors, nurses, social workers, and other health care professionals who work together with a patient's care team to provide an extra layer of support. Importantly, palliative care is appropriate at any age and any stage of a serious illness and can be provided alongside curative treatment. Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea,

loss of appetite, difficulty sleeping, and depression. By successfully managing these symptoms, patients are ideally able to more fully participate in and enjoy daily life. Palliative care can improve the ability to tolerate medical treatments and can help patients better understand treatment choices, which often allows them to feel an enhanced sense of control around their medical care.

Palliative care teams are present in some hospitals; an increasing number of outpatient palliative care clinics exist as well. If you are interested in seeing a palliative care doctor, ask your oncologist about services available in your area.

It is important to note that palliative care and hospice care are not interchangeable terms. Hospice is a specific type of palliative care aimed at people with a life-limiting illness who have a prognosis of six months or less and who have elected to forgo aggressive treatment. Hospice care can be provided at home, at a hospice facility, or a nursing home. The goal of hospice care is to give patients control, dignity and comfort. Typically, patients in hospice are not admitted to the hospital in an emergency, unless the hospice team is unable to get a patient comfortable at home. Hospice care also provides support and grief therapy for patients' loved ones.

Both palliative care and hospice care include a focus on the emotional and spiritual aspects of facing a life-limiting illness for both patients and families. This may include engaging family and community to provide support, or offering ideas and resources that help a patient to find meaningful ways to say goodbye and leave a legacy. Some patients find meaning in writing legacy letters to family members, or in creating audio or video recordings.

# Specific Symptoms

In the following section, we describe some of the possible symptoms patients living with a progressive brain tumor may experience. In general, the most common symptoms experienced by patients include: difficulty walking, cognitive and personality changes, difficulty moving various parts of the body, seizures and delirium (confusion and difficulty thinking). Some patients may have several of these symptoms, while others may have none. Some of the factors that influence the presence and severity of symptoms are the tumor's location and size, progression of the tumor, and swelling in the brain.

## Motor and Sensory Problems

Brain tumors can affect the parts of the brain that control movement and physical sensations.

Depending on the location and growth of the brain tumor, potential problems include:

- Balance and coordination
- Impaired coordination of arms, legs, and hands
- Fine motor control (writing, eating)
- Awkward or stiff movements in arms and legs
- Numbness or tingling
- Falls
- Asymmetrical (lopsided) facial expressions
- Muscle weakness on one side of the body.

Symptoms vary from patient to patient. For some patients, mild symptoms may lead to minimal interruptions and inconveniences in daily life. For other patients, symptoms may be so severe they affect their life on a daily basis.

Symptoms can progress to the point that it may be difficult to walk, feed oneself or maintain regular bowel function.

This loss of mobility and need for increased assistance can be very distressing for patients and their caregivers. We encourage you to ask your health care providers for help thinking about what assistive devices and therapies may be helpful for you. Depending on your particular symptoms, your doctor may recommend that you see a rehabilitation specialist (physical or occupational therapist) to learn range of motion exercises and help to improve your walking,

strength, and balance. An assistive device such as a cane, walker or wheelchair may be prescribed to ensure safety and help with mobility. If mobility becomes severely impaired and walking to the bathroom becomes challenging, you may require either a bedside commode (portable toilet) or bedpan.

## Changes in Behavior and Thinking

The brain is organized, broadly, into compartments. Each compartment controls specific mental and emotional functions. These functions can be affected by brain tumors, which damage surrounding brain tissue. For this reason, many patients experience some change in behavior and/or thinking during their illness.

Possible changes depending on the size, location, and progression of the brain tumor include:

- **Emotion and Personality Changes:** Depression, anxiety, obsessive-compulsive behaviors; changes in emotional control, irritability, mood swings, withdrawal; socially inappropriate behavior
- **Attention and Concentration:** Confusion, easily distracted, difficulty multitasking and planning
- **Learning and Memory:** Difficulty processing, storing, and retrieving information; short-term memory loss
- **Executive Functioning:** Decreased reasoning and organizational ability, impaired judgment

Some patients may have insight into the behavior and thinking problems they are having, while others will not. In some cases, changes in thinking and behavior are so subtle that patients themselves are more aware of their difficulties than those around them. Changes in thinking, behavior, personality, and/or mood can make some family members and caregivers feel the person whom they know and love is no longer the same person—that they have already “lost” their loved one. It is normal to mourn these changes, especially because this is a time when you most need the support of your loved one. Expressing this loss can be difficult, and people often feel guilty about having such feelings. Additionally, troubleshooting and coping with new, and sometimes hard to manage, behaviors can be frustrating for caregivers. Ensuring that caregivers have the support they need and occasional respite will allow them to have the capacity to compassionately care for their loved ones.

Some symptoms may be addressed with a combination of cognitive rehabilitation therapy, psychotherapy, problem-solving therapy and medications. Unfortunately, with brain tumor progression, these symptoms can worsen as well and become more difficult to manage or treat. Seizures, infections or other medical problems can precipitate or worsen these symptoms. This raises the importance of taking advantage of and enjoying the more lucid moments, since we are unable to predict the future.

## Communication Challenges

Language and communication can be affected by brain tumors. Patients may experience problems with finding the right words to use, speaking words in a logical pattern, reading and/or writing, depending on the location of the tumor. Patients may also have difficulty understanding language. Adjustment is difficult and challenging for the patient with aphasia and their family. There can

be feelings of frustration, guilt, anger and embarrassment as well as helplessness on the part of both the patient and caregiver. Speech and language therapy or cognitive rehabilitation therapy may be helpful. In addition, there are some strategies that family members can follow to help cope with these changes.

- Give the person time to talk. Speak slowly, use simple terms and remain calm.
- Use visual props to help get the message across.
- Acknowledge and verbalize the frustration your loved one feels at not being able to communicate effectively.
- Participate in support groups for caregivers that can suggest coping strategies and help you feel less alone.

## Seizures

A seizure is a sudden attack or convulsion caused by an abnormal burst of electrical activity in the brain. Seizures – a common and distressing problem for patients with brain tumors – are caused by pressure on the brain from the tumor, in combination with brain swelling or inflammation, also from the tumor. Seizures occur in approximately 60 percent of brain tumor patients.

There are several types of seizures. Myoclonic seizures involve single or multiple muscle twitches, jerks or spasms. Tonic-clonic (or grand mal) seizures may involve sudden onset, loss of consciousness followed by body twitching, tongue biting, periods of no breathing and possibly turning blue. After-effects, including sleepiness, headache, confusion, muscle soreness and sometimes brief periods of weakness or numbness, can be seen following a seizure.

Seizures can be dangerous for patients. For this reason, during a seizure, the primary focus should be on making sure your loved one is safe.

- Clear the area of sharp or dangerous objects
- Protect the head from being bumped
- Do not put anything in the mouth
- Do not attempt to restrain the limbs during the seizure since it could result in injury
- After the seizure, try to lie the person on his or her side in order to keep the airway open
- Help with reorientation by telling your name, where you are and what happened
- Allow time for recovery and encourage the person to rest until he/she feels like him/herself again

When the seizure subsides, call your neuro-oncologist, hospice agency, or other treating provider for advice about what to do next. The provider may recommend you take the patient to the emergency department for further evaluation, or they may adjust the seizure medications by changing the doses or adding a new medication.

Medications called anti-epileptics are frequently prescribed to prevent recurrent seizures. Sometimes these medications will be started after a first seizure; other times they may be started in patients without a history of seizures if the risk of seizures is high enough. Steroids (usually dexamethasone) are often given to decrease brain swelling and reduce symptoms.

Typically, as brain tumors progress and patients approach the end of life, they lose the ability to eat and swallow. Even towards the end of life, seizure prevention is important because we think seizures can be uncomfortable for patients. Therefore, when patients lose the ability to swallow anti-seizure medications, providers may recommend changing the patient's seizure medication to a rectal suppository, an oral dissolving tablet that dissolves into the blood stream through the cheek, or sometimes an intravenous injection if the patient is in the hospital or a hospice setting.

If seizures are frequent, debilitating, and not responding to typical medications, palliative sedation may be considered. Palliative sedation involves using medications, to the point of

sedation, to control difficult-to-treat symptoms (in this case, seizures). The goal is comfort and the relief of suffering. Medications that are typically used include lorazepam (Ativan), phenobarbital, or midazolam (Versed).

## Delirium

Delirium is an acute change in mental status associated with confusion, disorganized thinking and a change in the level of consciousness (i.e., very sleepy or very agitated). Delirium can be caused by the tumor itself, by medical problems such as infection or electrolyte abnormalities, and by medications.

If infection or other medical problems are identified, treatment of these issues may help resolve delirium. In these instances of potentially reversible causes of delirium, it is important that patients keep to their regular sleeping pattern. For most patients this means sleeping during the night and being awake during the day. Long (>1 hour) naps during the day should be avoided and family, friends and caregivers should try to interact with the patient during the day. A quiet environment and minimal interruptions are encouraged at night.

Within the few hours or days before death from a brain tumor, some patients become delirious. There may be a role for medication if the delirium causes significant distress or agitation. It is critical your loved one is safe and supported. Sometimes, ensuring a safe environment may require 24-hour assistance.

## Problems with Eating and Drinking

Food and drink, in addition to being basic human needs, carry great social meaning, and are also equated with nurturing and caring. As such, the inability of a loved one to eat or drink is often very distressing to family members, caregivers and medical providers alike.

Nausea can be a common symptom that limits food intake. This can be due to increased brain

pressure and may be associated with headaches. Medications can also contribute to nausea. Patients can become dehydrated because of decreased fluid intake. There are several medications that can be used to relieve the symptoms of nausea, including steroids.

Progression of brain tumors may cause difficulty eating, chewing or swallowing. This may result in choking, gagging or food or liquid going down into the lungs instead of the stomach. These problems may be lessened by offering assistance with feeding, and offering small bites of pureed or soft food or thickened liquids. A speech or swallow therapist may be able to make recommendations about what type of diet to offer and suggestions about how to make it as easy and safe as possible to eat and swallow. Unfortunately, for most patients, when a brain tumor causes eating and swallowing problems, it is likely to get worse over time.

When a person is not able to eat or drink due to progression of a brain tumor, it is likely that other symptoms (such as inability to communicate, altered level of consciousness, or seizures) will worsen as well, and that the end of life is approaching.

Sometimes patients or families wonder about providing food and liquid through a feeding tube (in the nose or the stomach) or through an intravenous line. Artificial nutrition and hydration will not treat the cancer, and, importantly, have not been shown to improve quality of life or prolong life. Furthermore, providing artificial food or fluids near the end of life may worsen secretions, swelling or breathing difficulty. Most patients who are actively dying do not experience hunger or thirst. The sensation of thirst is most likely related to having a dry mouth, which can be addressed by using moistened swabs or ice chips.

## Headache

About half of all brain tumor patients experience headache at some point during their illness. Patients' headaches can be variable in frequency, intensity and quality. Typically, headaches that

are caused by the build up of pressure in the skull from the brain tumor are worse in the morning (or at night) and can be worsened by bending over or coughing. Headaches from the tumor itself and from increased brain swelling can be any type of headache – the most common being a dull ache. Steroids are the mainstay of treatment for increased brain pressure and the dose should be adjusted to maximize pain relief and minimize side effects.

The majority of headaches can be treated with either acetaminophen (Tylenol) or non-steroidal anti-inflammatories (NSAIDs; Ibuprofen or Advil) on an as needed or scheduled basis. Headaches may become more severe as the cancer progresses at which time opioids are used. Some headaches may be associated with other neurological changes, such as changes in strength, sensation, ability to speak, etc. If your loved one is experiencing fevers, chills or neck stiffness, you should call your provider, who, under appropriate circumstances, may recommend you go to the Emergency Room as these symptoms can signal an infection.

## Fatigue

The side effects of brain tumor treatment as well as the cancer itself can cause patients to be fatigued. Fatigue can manifest in a variety of ways including poor concentration, irritability, sleeping more, and participating in fewer activities. It is important that patients listen to their bodies and rest before becoming overtired. Rest/nap periods should be routinely built in to allow the patient to store up energy to participate in the activities they enjoy. Gentle exercise is encouraged if the patient can safely participate. It is natural that as the brain tumor progresses, the patient will likely become increasingly tired and spend much of his or her time sleeping. For some patients, a stimulant medication (methylphenidate) can improve energy level and mood. Activities and enjoyable experiences, at this point,

may need to be creatively reconfigured to meet the patient's energy level, mobility and desires in their final days.

## Bowel and Bladder Problems

If a patient has a tumor in their lower spine or a tumor in the front part of the brain (frontal lobe), they may lose control of their bowel and/or bladder. When patients are close to the end of their life, they also often lose the ability to control these functions and/or simply have difficulty getting out of bed to walk to the bathroom. Sometimes, patients will have difficulty urinating or having bowel movements voluntarily; other times they will experience difficulty controlling these functions, resulting in accidents. Coping with bowel and bladder problems can be a major cause of caregiver burnout.

Urine retention occurs when a patient has a large amount of urine retained in the bladder. This can be quite uncomfortable for the patient.

Patients with brain tumors may lose the ability to sense when they need to urinate, leading to retention. Certain medications can also lead to urinary retention. When this happens, your health care provider can do an evaluation and select the appropriate management. Sometimes for comfort, they may recommend a Foley catheter, which drains urine from the bladder into a bag close to the patient's bedside. Patients who experience incontinence (accidents related to urine or bowel movements) should also be evaluated by their healthcare provider to address any reversible problems (for example, a urinary tract infection leading to incontinence). Commodes at the bedside, bedpans (in which the patient can urinate or have a bowel movement while lying down on the bed into a special pan), and incontinence briefs may be utilized to help with this important and distressing problem. Attention to skin care is important because of the risk of breakdown and ulceration, which can be painful and become a source of infection.

## *Caring for the Caregiver*

**C**aring for a loved one with a terminal illness is extremely difficult, and carries with it intense and prolonged physical and psychological stress. The cognitive, personality and communication changes that can arise for patients with brain tumors are particularly challenging for families and caregivers.

The stress of caregiving may lead to difficulty sleeping, excessive fatigue, difficulty concentrating, and even physical problems including colds, flu and other upper respiratory illnesses.

It is important for caregivers to find coping strategies to help sustain their well-being in the midst of stress. The UCSF *Orientation to Caregiving Handbook* has some excellent suggestions. Find it online at: [www.osher.ucsf.edu/patient-care/self-care-resources/caregivers](http://www.osher.ucsf.edu/patient-care/self-care-resources/caregivers) (or <http://tiny.ucsf.edu/caregivers>)

# Children in the Home

*Parenting when there is a tumor recurrence or the disease becomes terminal.*

One of the hardest things about having recurrent cancer is thinking about how and what to tell your children. It is normal for parents to want to spare their children from pain, but that is not always possible. One thing you can do is give your children the tools to succeed and lay a firm foundation that will see them through life's trials and troubles. By preparing your children for what is ahead you have a chance to make a real difference in how they handle the experience and how they deal with serious illness in the future.

Wanting to protect children from difficult news is natural. That said, children are smart and sense change. If you choose not to talk to your children they may:

- Feel frightened because they don't know what is going on
- Feel alone with lots of worries and no one to talk to
- Worry that something they have done or thought has caused the cancer to come back
- Imagine something worse than the reality
- Think that cancer is something too terrible to be talked about
- Misunderstand the situation and get the wrong idea.

In addition, if children learn the news from others outside of the family, it can jeopardize their trust in you. They also may find information online that is inaccurate. It is very important to include them in understanding the status of the disease and the plans.



Positive outcomes of being open and involving your children and teens include:

- Making them feel more secure and less anxious
- It gives them permission to talk. They can ask questions and say how they feel
- It shows you trust them and you don't need to be on guard with what you say all the time
- It can make you feel closer. Your children can help support you and you can support them
- They will learn how to cope when life isn't going according to plan.

It is important to be honest. Children need to be prepared to know how the treatment or illness will affect their lives. They need to know what the side effects might be, what changes in family routine are anticipated, and when life might return to normal again (if that is possible). They need to be included so that they can prepare themselves for what happens next. Research shows that children with a relative who has cancer recurrence learn to be more sensitive to peers with family troubles. In addition, the process of letting them feel some of life's painful realities often leads to a more mature outlook. They learn that you can trust them to deal not only with the happy parts of life, but the hard parts as well.

## What Should You Say?

You can always start by asking questions to the child and determine what their understanding is and what they think is going on. You can use those answers to correct any misinformation that they have and gently offer the new information. You can say something like, "the tumor has come back and more treatment is needed. The doctors are doing everything that they can." Try to be honest and still offer hope.

## Terminal Illness

It is important to let your children know if the treatment is not working and no further treatment is to be given. Do spend some time thinking about how you will answer questions. Know how you will answer possible questions that may come up, such as 'What will happen to me?' 'Am I going to die too?' 'Will other people I love die too?' 'Is it my fault?'

Explain that the treatment is no longer working. Doctors have tried their best but the cancer is not going away. What everyone hoped for is no longer possible. The cancer is still there and is growing and spreading and this means that the parent may not live that much longer.

## Children's Responses

Your child may react to your illness with behavior you wouldn't normally accept. Some children may have problems with eating, sleeping, or bed-wetting, or problems at school. They may seem sad or withdrawn or have physical symptoms, like losing appetite, headache or stomachache. These behaviors are normal responses in and of themselves, but if they persist or interfere with your child's ability to participate in normal activities, he or she may need help. There are lots of people to help support your child. Check with your pediatrician. Speak with the school, teachers, counselors, a social worker, your oncologist, or try the psychological services at the cancer center.

Children who are under 3 years of age know something serious is happening, but don't understand death or the permanence of it.

Children age 3-5 years have heard of dying, but don't really understand it. They think of it as living somewhere else and need reminders that that person will not come back, as well as reminders of the nice things they did together.

Children age 6-12 years have an understanding of death, but not all the emotions that go with it. By 9 years they understand it like adults.

They worry that death is frightening or painful.

Teens have the hardest time coping. That is in part because of the normal developmental milestone, the process of establishing independence from their parents. They understand what it means to have major change and loss. Some pull away and some pull close. Everyone should remember that there is no right or wrong way to feel. They may get angry with you, spend more time with their friends, and feel guilty about both. Teens are already having a lot of emotional ups and downs as part of their development. Knowing that a family member has cancer or is dying can make things even harder. Teens are often not comfortable talking to their parents about their emotions. They may have support from their friends or other adults. It is important to make sure they have someone to talk to outside of the family, maybe a support group or online chat group.

## When to Tell Them

Many factors influence when a child should be told that a parent is going to die. The first depends what a child has been told to date. Make sure they know it is ok to talk. They may have worries about who will take care of them. Make sure the kids know you have a plan. You can call it a back-up plan or a just-in-case plan, and you can review it with them, ask what they think, and give them time for questions. In not preparing a child for a parent's death, you run the risk of a child feeling like they are not important enough to share it with, that death is so terrible they will not be able to cope, or they may believe it is their fault.

Ideally children can be given gradual explanations about what has happened and why and what to expect next. Older children often want more information. Children's concept of time is different from adults, so children don't cope well with lots of lead time, waiting for a parent to get worse and or die. Present information gradually, only when you are fairly certain it will happen in the near future, as in days to weeks.

## Good Strategies for Talking about Dying

- Be honest, use straightforward language.
- Use the words death or dying, avoid words like lost, passed away or going to sleep.
- Reassure them that they are not responsible for the illness or the death.
- Don't hesitate to get or use outside support

*If you are having trouble sorting through all the emotions that surface at this time, think about talking with an expert who has worked with other families facing similar problems.*

While you may be able to solve some of these difficult issues on your own, you may lose valuable time if you depend only on yourself. Oncology social workers, nurses, psychologists, and other cancer care counselors have experience and education that prepares them to work with families in your situation. Let yourself be helped by their experience and what they have learned with coping with the problems of serious illness.

# Advance Care Planning

Advance care planning involves conversations, decision-making and documentation of a patient's future medical care and end-of-life preferences. Advance care planning is important so that a patient's wishes can be known and respected in the event they become unable to speak for themselves. Advance care planning topics include: resuscitation preferences (code status), appointment of a Durable Power of Attorney (DPOA), and preferences regarding other medical interventions including antibiotics, artificial nutrition and hydration, and a focus on comfort care.

Thoughtful advance care planning is critically important for ensuring your loved one receives medical treatments that are in line with their own goals and values. If your loved one does get more ill, knowing your loved one's preferences ahead of time may make hard decisions around medical treatments that arise at the end of life easier.

Advance care planning should be done EARLY in a patient's illness to ensure they are able to participate fully in these conversations before becoming too sick. That being said, it is perfectly reasonable and expected that during the course of illness, a patient's preferences may change. If/when this happens, new documents related to advance care planning can be completed to reflect these preferences. Advance care planning conversations often start during a medical visit with the patient's health care provider and then continue with the patient and their friends and family after the appointment. Patients and caregivers should feel empowered to ask to discuss this important topic with a health care provider they trust.



## Key questions for patients to consider include:

- Who would they want to make medical decisions for them if they became too sick to make them?
- What medical treatments would they want or not want if they were close to the end of their life?
- What types of things would be important to them at the end of life (e.g., being at home, not being in pain, being lucid, etc.)?

These important preferences should ultimately be legally documented. The most common way to do this is by completing an advance directive. In their most basic form, advance directives include the Durable Power of Attorney (DPOA) and a section detailing a patient's resuscitation preferences. Some advance directives will also provide space for patients to document other medical preferences, including treatments like artificial hydration and nutrition and comfort measures.

In the Durable Power of Attorney (DPOA) section, the patient is asked to identify their health care proxy. A health care proxy is the person(s) the patient designates to make decisions regarding medical care if the patient is unable to participate in these decisions (i.e., he or she is too sick, too confused, or prefers not to). Typically a health care proxy should be someone who knows the patient and their wishes well, and will make decisions that are in line with the patient's hopes and wishes. The health care proxy is often a spouse or relative of the patient; people under 18 years of age as well as health care providers are unable to be health care proxies. The patient should make sure to ask this person if they agree to be the health care proxy.

The other portion of the advance directive allows patients to document whether they would like to have CPR (cardiopulmonary resuscitation, chest compressions) if their heart stops and be intubated (breathing tube placed through the mouth down into the windpipe) and placed on a ventilator in the ICU if their lungs fail ("full code"), or forgo these measures and allow natural death ("DNR/DNI" or "AND"). Patients and families are encouraged to discuss the options for resuscitation with their health care provider, with the goal of choosing effective interventions that are in line with their wishes and values.

Once the advance directives are completely filled out, they should be signed, dated, and copies should be kept at home and also included in the patient's medical records. Once they are signed, they become legal, official forms. It is important to note, however, that if the patient (or health care proxy if the patient has lost the ability to make decisions) changes his or her treatment preferences, these newly expressed wishes should typically supercede any past documentation.

*Advance care planning documents may vary by the state you live in, and you can obtain your state's version from your doctor, legal offices or state departments. Additional advance care planning resources can be found at the end of this booklet.*

# Role of Hospice

**H**ospice is a model of care that emphasizes comfort and quality of life for people with life-limiting conditions. Hospice provides highly skilled symptom management alongside comfort and support to patients and their loved ones. Patients are eligible for hospice care when a doctor deems their illness is expected to lead to death within six months. This does not mean that care will only be provided for 6 months; hospice can be provided as long as the person's physician and hospice team certifies that their condition remains life limiting. Also, if the patient gets better and/or would not like to be in hospice care anymore, they can always unenroll.

Hospice care takes a patient- and family-centered team approach. A hospice team typically includes a doctor, nurse, social worker, chaplain, home health aide, and trained volunteers. The team works together to address the patient and family's physical, psychological, social and spiritual needs. The goal of hospice is to keep the patient pain and symptom-free as long as possible; the goal is not to hasten death. Interestingly, there is some data to suggest that patients in hospice care may live longer, perhaps due to better symptom management. During this phase of the patient's illness, non-essential medications are discontinued and all medicines essential for optimal symptom control continued.

If a patient decides to begin hospice care, he or she can remain at home and have regular visits from the hospice staff. Alternatively, when preferred by the patient and family (usually due to complex social and symptom management needs), the patient can be admitted to an inpatient hospice.

## **Specialized services provided by hospice include:**

- Manage pain and other symptoms
- Offer support with the emotional and spiritual aspects of dying
- Provide medications, medical supplies and equipment
- Teach family members skills to help them provide care
- Deliver special services like speech and physical therapy if needed
- Provide support and counseling to family members and loved ones
- 24-hour availability
- Short-term inpatient or respite care
- Bereavement services

Most insurance companies cover home hospice care, and it is covered by Medicare nationwide. Speak with your insurance carrier to determine your loved one's coverage and co-pay.

If coverage is unavailable, the hospice team may be able to use community or foundation funds to provide services. There is often a daily room and board fee for inpatient hospice.

*For more information about hospice, please talk with your health care provider. The social worker assigned to the patient's medical clinic is often very helpful in providing information about hospice care.*

# *What to Expect in the Final Hours*

The dying process involves a number of physical changes, which include increasing weakness and fatigue, decreasing appetite and fluid intake, decreased circulation, neurological dysfunction, pain, and loss of ability to close one's eyes. Some people become sleepy, which progresses to a coma, followed by death. Others become restless, confused and agitated. Noisy, labored or wet breathing is common. Other symptoms may include pain, shortness of breath, urinary incontinence, restlessness or nausea.

Noisy, moist breathing is caused by pooled secretions that the patient can no longer clear by cough or swallow. This is typically more distressing to family members than to the patient. Suctioning is not helpful for this symptom. Repositioning the person on their side may help secretions drain. Sometimes medication is used in attempt to decrease oral secretions.

The breathing pattern may also become irregular, with pauses in breathing sometimes lasting as much as a minute.

Delirium, or altered mental status, is a normal part of the dying process. Common themes include visitations, travel, crossing-over, unfinished business and fears. If these symptoms are distressing, they are addressed with caring support and reorientation. Sometimes sedating medications are used for severe distress or agitation.

As touch can heighten communication, you should show affection in familiar ways. It is okay to lie beside the patient in privacy to maintain as much intimacy as you feel comfortable with.

Loss of bowel or bladder control is common at the end of life. Sometimes a urinary catheter is used to minimize the need for changing and cleaning. However, it is not always necessary as urine flow is frequently minimal, and absorbent pads or surfaces can be used.



While many people fear that pain will suddenly increase during the dying process, there is no evidence to suggest that this occurs. Pain may be associated with grimacing and continuous facial tension, particularly across the forehead and between the eyebrows. Increased respiratory rate or labored breathing may also be an indicator of pain. Pain can be treated with medication, usually a concentrated oral morphine solution that is administered under the tongue and does not need to be swallowed. Adequate pain relief does not hasten death and all efforts should be made to ensure that the patient is comfortable and pain free.

Families will frequently find that their decreasing ability to communicate is distressing. We don't know for sure what unconscious patients can actually hear, but it is prudent to

presume that the unconscious patient hears everything. Families should talk to the patient as if he or she were conscious. Try to create an environment that is familiar and pleasant. Surround the patient with the people, children, pets, objects, music and sounds that he or she would like. Include the patient in everyday conversations. Say things you need to say. At times, it may seem that a patient may be waiting for permission to die. If this is the case, you should give the patient permission to "let go" and die in a manner that feels most comfortable. This may include statements such as "I know that you are dying; please do so when you are ready," or "I love you. I will miss you. I will never forget you. Please do what you need to do when you are ready."

## *What to Do When Someone Dies*

**W**hen someone dies, nothing needs to be done immediately. Take the time that you need to grieve. Some families want time to sit quietly with the body, console each other, and maybe share memories. Others may prefer to leave the room. During this time, you could ask a member of your religious community or a spiritual counselor to come. This is also the time to notify people who may want to visit before the body is moved.

The death must be officially pronounced. This step makes it possible for a death certificate to be completed, which is a key step for many reasons, including life insurance and financial and property issues. A mortuary needs the death to be legally pronounced, in order to begin funeral arrangements. If the patient dies at home and hospice has been involved, hospice should be

called so that they can send a nurse to pronounce the death of the patient. If the patient dies at home without hospice care, either a doctor or nurse needs to come to the house to officially pronounce the death or you need to call 911. If you have an advance directive or medical order stating the patient's preferences for resuscitation, this should be presented to the emergency response providers. They may need to bring your loved one to the emergency room, so that the emergency room doctor can pronounce death. Arrangements should be made to pick up the body as soon as the family is ready. Usually this is done by a mortuary. The hospital or nursing facility, if that is where death takes place, may call the mortuary for you. If at home, you will need to contact the mortuary directly or ask a friend or family member to do that for you.

# *Grief and Bereavement*

**T**he diagnosis of a brain tumor can be a sudden, life-shattering event for all involved. The grieving process for families often starts at the time of diagnosis, since the personality and cognitive changes caused by a brain tumor can disrupt the very relationships you depend on for support during difficult times. The medical decisions and care involved can be overwhelming, especially if your loved one is not himself or herself due to the illness.

You may experience a wide range of emotions including sadness, grief, anger, frustration, relief, confusion, doubt, anxiety, isolation and guilt. It may be confusing to experience grief while your loved one is still alive. These are all normal things to feel. There is no right or wrong way to express and deal with all these emotions. Give yourself the permission and latitude to experience whatever emotions you may be feeling. It is not your fault. Do not feel guilty about your emotions, asking for help, or asking questions and wanting to be prepared for the end of life.

When your loved one dies, first and foremost remember: you neither need to be inspirational to others nor conquer your grief. Also, keep in mind that what one person finds helpful may be quite different for another person. It may take some trial and error to figure out how best to take care of yourself. Some people may find it helpful to talk with others about their grief, particularly others who have been through a similar experience. Others might find solace in their church or religious order, a bereavement group or individual counseling. Although not for everyone, some people find meaning in public speaking, advocacy or volunteer work. Though your life will never be exactly the same; typically, the emotions you experience as you grieve will get easier over time.

*If you find the intensity and frequency of grief does not begin to improve by six months after the death of your loved one, you should see your own physician to discuss possible treatment for a condition called “complicated” or “traumatic” grief.*



# *Suggested Resources*

## **General Information on Palliative Care**

- Center to Advance Palliative Care ([www.getpalliativecare.org](http://www.getpalliativecare.org))
- American Brain Tumor Association  
(<http://www.abta.org/brain-tumor-treatment/continuum-of-care/palliative-care.html>)

## **Brain Tumor Symptom Overview and Management**

- Cancer.net ([www.cancer.net/cancer-types/brain-tumor/symptoms-and-signs](http://www.cancer.net/cancer-types/brain-tumor/symptoms-and-signs))
- American Brain Tumor Association ([www.abta.org/brain-tumor-information/symptoms/](http://www.abta.org/brain-tumor-information/symptoms/))

## **Advance Care Planning Resources:**

- PREPARE Website ([www.prepareforyourcare.org](http://www.prepareforyourcare.org))  
Provides concrete examples on how to identify what is most important in life, communicate that with family and friends and doctors, make informed medical decisions, and choose a health care proxy.
- Caring Connections ([www.caringinfo.org](http://www.caringinfo.org))  
Information on Advance Directives; Download simple, state-specific Advance Directive forms.
- Go Wish ([www.gowish.org](http://www.gowish.org))  
Go Wish is a card game designed to help you find words to talk about what is important if you were to be living a life that may be shortened by serious illness. The Go Wish card game is an advance care planning tool developed by Coda Alliance to help people have conversations about end-of-life care.
- The Conversation Project ([theconversationproject.org](http://theconversationproject.org))  
This website offers help in expressing and communicating your end-of-life wishes with others.
- National Brain Tumor Society  
([www.braintumor.org/brain-tumor-information/#caregiver-resources](http://www.braintumor.org/brain-tumor-information/#caregiver-resources))
- UCSF Osher Center for Integrative Medicine Caregivers Project  
([www.osher.ucsf.edu/patient-care/self-care-resources/caregivers](http://www.osher.ucsf.edu/patient-care/self-care-resources/caregivers)).  
*Orientation to Caregiving* handbooks are available at the above website, in addition to other resources for caregivers.



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