



*Patient and Family*

Symptom Control and  
Palliative Care  
Acute Inpatient Unit

THE UNIVERSITY OF TEXAS  
MD ANDERSON  
CANCER CENTER

*Making Cancer History®*

The Symptom Control and Palliative Care Acute Inpatient Unit Handbook is made possible by a generous donation from Patricia D. Bohan. It is a fitting tribute to the exceptional skill and compassionate care that Pat received from the Symptom Control and Palliative Care Acute Inpatient Unit staff, while she was a patient in 2005.

Pat left her creative imprint in every corner of M. D. Anderson during 20 years as an accomplished graphic designer in the Department of Medical Graphics & Photography. As a young adult, the experiences she gained working as a licensed vocational nurse inspired Pat to serve others throughout her life.



# Palliative Care

## *Improving Quality of Life*



The World Health Organization defines palliative care as: *“The approach to care that improves quality of life for patients and families facing a life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.”*

When facing advanced disease or severe pain, quality of life becomes precious. The Symptom Control and Palliative Care Acute Inpatient Unit at The University of Texas M. D. Anderson Cancer Center is dedicated to helping patients have the best quality of life.

M. D. Anderson operates the largest cancer symptom control and palliative care program in the United States. Our research programs strive to find new ways of assessing and managing severe physical and psychosocial symptoms in advanced and terminal cancer patients. We also offer continuing education opportunities for cancer specialists, community health care workers, medical students and residents who want to learn the latest in palliative cancer care, end-of-life care and cancer rehabilitation.

It is our goal that this booklet will help you and your family understand how to cope with and treat your symptoms. We are here to help you make life with cancer as best as it can be.

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PATIENT GOALS/COMMUNICATION BOARD	
Room No. <b>209</b>	Room Telephone No.
Unit No. <b>61249</b>	Target Discharge Date/Time
Patient Name <b>W. M.</b>	
Daily Goals Needs	
1. <b>Urinary cath</b>	<input type="checkbox"/>
2. <b>Decrease Morphine</b>	<input type="checkbox"/>
3. <b>Start Helder know the clock</b>	<input type="checkbox"/>
4.	<input type="checkbox"/>
5.	<input type="checkbox"/>
6.	<input type="checkbox"/>
Care Team	
Name <b>Pranee</b>	Signature
M.D. <b>Dr. Neil Finkbein</b>	
Nursing Agent <b>F. Santisca</b>	
Other Information	



# *Palliative Care Service*

We believe that approaching your care from different aspects will benefit you greatly, so we work as an interdisciplinary team. This means that your health care team members have different medical areas of expertise. Since they also have specific training in palliative care, they work together to plan your treatment and care for you.

We strongly encourage you and your family to be involved with all levels of your care. You can arrange meetings with your health care team to address symptoms, comfort levels and any complications you may be having.

## **Three levels of care make up the Palliative Care Service**

One or more of the following health care teams will treat you:

1. Supportive Care Center (for patients who do not require 24-hour care)
2. Inpatient Unit (for patients who stay in the hospital, requiring more than 24-hour care)
3. Mobile Team (for inpatients and outpatients)

### **Outpatient Center**

The Supportive Care Center is where palliative care doctors see patients on an outpatient basis. Even if you do not have an appointment, please contact us if you would like to get more information or receive care. Our nurses and staff will listen to your needs to help you. We are open Monday through Friday, 8 a.m. to 5 p.m. Our phone number is 713-792-6072.

### **Inpatient Unit**

This specialized unit has 12 private rooms for patients who receive care on an inpatient basis. Specially trained staff cares for patients and families who are experiencing physical and emotional distress.

Your medical team meets daily to discuss your plan of care. They will assess your condition to make sure your needs are being met. (On the weekends, you may have a different medical team, but they will be aware of your plan of care.)

### **Mobile Consultation Team**

This team of doctors, fellows and advanced practice nurses respond to patient referrals by visiting patients in inpatient and outpatient settings.



# *Interdisciplinary Team*

In many cases, symptoms may be complex. For example, if you have shortness of breath and at the same time you have anxiety, you may feel the shortness of breath more than the patient who has shortness of breath without anxiety. At the same time, shortness of breath by itself may cause anxiety. In addition, anxiety may be caused by other factors, such as worries about the cancer, the future, the family or financial issues. To be able to treat your symptoms well we need to know more about you, the different symptoms you have and your overall goals. This will require many questions to you and your family by different members of our team. This team is called the interdisciplinary team and its members meet regularly to discuss your condition and try to help you achieve your goals.

The interdisciplinary team is made up of the following members:

## **Doctors**

You may meet different types of doctors.

- The attending physician is a doctor with specialized training in symptom control and palliative care. This person leads the medical team and will visit you daily to assess your condition and approve any changes in your care.
- Fellows are doctors who have completed a medical residency and are completing additional specialty training.

## **Pharmacist**

A pharmacist will make daily rounds with your care team, and will review your medicines and discuss any medicine-related issues you may have.

The pharmacist is also involved in the discharge process. When you are discharged, you will receive information on the medicines you need to take.

## **Physical and Occupational Therapists**

Physical and occupational therapy will help you attain the best quality of life possible. Therapy treatments are designed to improve your ability to do the things that are meaningful to you.

Physical and occupational therapy is helpful to all patients. Although you may not be able to do demanding exercises, you can still benefit from receiving therapy. Our team works with patients on all skill levels, and they will create a routine that works best for you.



## Nursing Team

Another element of your clinical care team is the nursing staff. The Palliative Care nursing team is made up of nurses and other clinicians.

- Advance practice nurses (APNs) are nurses with advanced degrees who work closely with the other members of the medical team and treat patients during the week.
- The advanced practice nurse counselor is a nurse with an advanced degree and extensive experience in counseling and supportive care. This team member becomes involved in care particularly when patients and families are struggling with emotional crises.
- The clinical nurse specialist (CNS) is a nurse with an advanced degree and extensive clinical experience. The CNS focuses on supporting clinical nurses in care planning and implementation.
- A clinical nurse will admit you to the inpatient unit by completing a nursing assessment. He or she will be in charge of your daily care and is the primary coordinator of care for the team. A clinical nurse not only provides medicines and treatment, but also is a specialist in physical and emotional symptoms.
- The certified nursing assistant (CNA) helps the clinical nurse in your daily care, particularly by monitoring your vital signs, helping you wash and bathe, and providing treatment to make you feel more comfortable. The CNA is knowledgeable about hospital resources and procedures, and he or she will help you communicate as needed with the team.
- The inpatient service coordinator (ISC) sits at the front desk in the nursing station. The ISC helps patients and team members by coordinating requests for help, and also is responsible for scheduling tests and procedures and managing patient charts.

An associate director and two assistant nurse managers lead the unit. Each shift also has a charge nurse. The nursing managers assure that adequate resources are available for excellent patient and family care.



## Social Worker

The social worker is highly skilled and can provide free short-term counseling. He or she serves as a link between you, the health care system and the community, and can help identify appropriate resources for your specific needs. The social worker arranges family meetings, counsels patients and families, and helps with requests for work release letters, airline letters and advance directives.

## Chaplains

Chaplains at M. D. Anderson have advanced degrees in theology and clinical pastoral education and specialize in hospital ministry to support you spiritually. A chaplain will visit your room to get to know you and your family, and is available for prayer, pastoral guidance and to facilitate any spiritual practices you have. The chaplains' training prepares them to counsel all people regardless of faith or tradition.

## Massage Therapists

If you wish, you may receive a massage treatment that may help ease physical and emotional pain. The massage therapists can also show your family and caregivers how to use touch to relieve your stress and frustration.

Two registered and certified massage therapists are part of the palliative care team. They will consult with your doctor and other health care providers about your care. The massage therapist is available two days a week.

This is a free service.

## Music Therapist

A board-certified music therapist uses music therapy to achieve therapeutic goals and improve quality of life. The music therapist develops goals tailored to meet your unique needs. Prior musical training is not required to benefit from personalized sessions. The important factor for you and your family is to choose music you enjoy. The music therapist has many instruments if you choose to play a selection.



## Pediatric Outreach Liaison

Illness, especially cancer, can be very confusing to children. They may not fully understand what is happening to their loved one.

The role of the pediatric outreach liaison is to help you discuss difficult issues with children, such as the diagnosis and coping with the hardships of treatment and side effects.

Children usually have many questions that may be hard to answer. The pediatric outreach liaison can teach you how to talk openly and honestly with them.

Patients and family members with children frequently ask:

***“I want to protect my children. How do I share this information with them?”***

Children know when something is going on in their family. While the cancer diagnosis is indeed devastating, children can imagine things much worse, and at some ages may even feel responsible for the “bad” things that are happening in their family. Honesty is the most important factor in helping children deal with the cancer diagnosis of a loved one.

***“Why should we contact the pediatric outreach liaison?”*** In order for children to understand what is happening, it is important that they know you respect them as valued members of your family. Therefore, it is important to openly discuss the illness with them. Additionally, having an honest dialogue helps to set the stage for ongoing open communication.

The pediatric outreach liaison will help you and your family determine how to best help the children and what approach to use, at whatever stage of the illness. They can talk with the children and assess their understanding of your illness and prognosis, and their emotional response to the illness and treatment. The liaison can also be present to help you talk with your children about your cancer.

The pediatric outreach liaison is available Monday through Friday, 8:30 a.m. to 5 p.m. and by appointment. For information or an appointment, please call 713-792-2489 or tell your nurse.

## Case Manager

The case manager may visit you and your family while you are in the hospital to discuss possibly continuing care or discharge needs for when you leave M. D. Anderson. He or she also provides information to your insurance companies about the care you are receiving, to justify payment for services.



## What to Expect in the Palliative Care Unit

The goal of your admission to the Palliative Care Acute Inpatient Unit is to improve your quality of life. We will help you and your family manage your symptoms and make decisions about your care.

Since we measure your discomfort based on what you tell us, we often may ask you questions about your symptoms. We rely on you to inform us if you are in pain, for example, or if you feel nauseated. If you think that we are not addressing one of your symptoms, please let us know.

It is likely that we will need to give you medicine on a regular basis to treat most of your symptoms. If your symptoms get worse, be sure to tell your nurse. We may be able to increase the dose or try a different medicine that works better for you.

### **To make your stay in the Palliative Care Inpatient Unit more pleasant, try to:**

- Stay active. If you are able, leave your room for a walk. Places for relaxation include The Park on Floor 2. Physical and occupational therapists can help improve your activity level.
- Take advantage of resources. Many programs and services are available to support and encourage you.
- Bring items from home like pictures and personal keepsakes.
- Ask people to visit you. Enjoy a meal with your friends or family. You may order food from outside the hospital, too.

Include your family in your care plan. With your permission, they will meet with you and your health care team to discuss your condition and care.



# *Understanding Symptoms and Their Management*

## **Pain**

Pain is an unpleasant sensation happening in varying degrees of severity. In cancer patients, pain is usually caused by direct effect of the tumor on tissues, bone or nerve. Sometimes radiation therapy or chemotherapy may cause pain. Anxiety or delirium sometimes increases the perception and expression of pain. Opioids are the main treatment for pain in patients with advanced cancer.

When pain is not treated properly, it may interfere with:

- Daily activities and function
- Sleep
- Appetite
- Enjoying friends and family

When pain is managed properly, you can:

- Be active
- Sleep better
- Enjoy food
- Interact with family and friends

## **Types of Pain**

- Somatic pain (pain in the bone/soft tissue) is usually a well localized, gnawing, dull, aching or occasionally cramping pain. It may be constant or come and go. Pressing over the affected area causes pain or makes it worse. Movement usually makes this type of pain worse.
- Visceral pain (pain in the organs) is a constant, deep aching, squeezing or cramping that is usually widespread. It can happen in an area of the body away from the organ.
- Neuropathic pain (pain in the nerves) is severe pain, often described as a constant burning pain that radiates or as a sharp or shooting pain that comes in waves.



## Management

The palliative medical team will review your case on an individual basis and prescribe the appropriate plan to relieve the symptom of pain. This plan will be reassessed frequently to assure the best possible pain control.

- Opioids such as morphine are needed to control pain in most patients.
- Sometimes weak opioids like hydrocodone may control pain if it is not severe.
- Your doctor may add some medicine to help in pain control. These include anti-inflammatories, antidepressants, anticonvulsants or corticosteroids.
- Pain medications are given by mouth if possible. If this is not possible, medicines can be given through the rectum (suppository), IV or under the skin.
- In very rare cases, anesthesia or epidural may be needed to control the pain.

Your doctor or nurse may recommend that you try non-medicine treatment for pain, along with your medicine, to give you more pain relief. Your family members may want to help you use these treatments. These treatments will help to make medicines work better and relieve other symptoms, but do not use these instead of your medicine.

- Breathing and relaxation exercises
- Guided imagery
- Massage, pressure and vibration
- Music therapy
- Distraction
- Heating pads and cold packs
- Rest/Immobilization

## Side Effects of Opioids

All opioid medicines can have some side effects, but not all people get them. Most side effects happen in the first few days of treatment and gradually go away. Some of them are:

- **Constipation**
  - Most patients on opioids experience some constipation. Your doctor will place you on a bowel regimen that you will need to follow carefully at discharge.



- **Nausea and vomiting**
  - When this happens, it usually only lasts for the first few days after starting a medicine. Tell your doctors and nurses about any nausea or vomiting. They can give you medicine to stop these side effects.
- **Sleepiness in the first few days**
  - For most patients, this side effect usually disappears within one to three days. Talk to your doctor or nurse if this is a problem for you.
- **Slowed breathing**
  - This rare complication sometimes happens when a pain medicine is started. Your doctor will decrease the dose or rarely stop the medicine for some time.
- **Serious complications like hallucinations (seeing things that are not there), muscle twitches or confusion and delirium may occur.**
  - These usually happen in patients who have been on the same pain medication for some time. They are believed to be due to the products of pain medication. Treatment is to change to a different type of pain medication.
  - When a tumor is pressing on nerves or other body parts, operations to remove all or part of the tumor may help relieve pain in selected instances.

If you have any of these side effects, you should contact your doctor or nurse immediately.

## Concerns

Some patients have pain that is not relieved by medicine. In these cases, the following treatments can be used to reduce pain:

- **Radiation Treatment**
  - Radiation reduces pain by shrinking a tumor. A single dose of radiation may be effective for some people.
- **Nerve blocks/implanted pumps**
  - Temporary or permanent nerve blocks may help relieve some painful conditions. Implanted pain pumps are also available, which can be of benefit in selected instances, also are available.
- **Surgery**
  - When a tumor is pressing on nerves or other body parts, operations to remove all or part of the tumor may help relieve pain in selected instances.



***“I can only take medicine or other treatments when I actually have pain.”***

You should not wait until the pain becomes severe to take your medicine. Pain is easier to control when it is mild than when it is severe. You should take your pain medicine regularly (if your pain is present most of the time) and as your doctor has instructed you. This usually means taking it on a regular schedule and around the clock, even when you are not feeling the pain. You can also use other treatments such as relaxation, breathing exercises and hot/cold packs, as often as you want.

***“I will become ‘hooked on’ or ‘addicted to’ pain medicine.”***

Studies show that getting “hooked on” or “addicted to” pain medicine for cancer pain is very rare. Remember, it is important to take pain medicine regularly to keep the pain under good control.

***“If I take too much medicine now, it will stop working, and I may need it later.”***

The medicine will not stop working; sometimes, however, your body will get used to the medicine. This is called tolerance. Tolerance is not usually a problem with cancer pain treatment because the amount of medicine can be adjusted or other medicines can be added. Cancer pain can be managed, so do not deny yourself good pain relief.

***“If I complain too much, I am not being a good patient.”***

Controlling your pain is an important part of your care. Tell your doctors and nurses if you have pain, if your pain is getting worse, or if the pain medicine you are taking is not working. They can help you manage your pain.



## Loss of appetite and Weight Loss

Loss of appetite is a decrease or complete loss of interest in food, eating or drinking. Anorexia happens in 80 percent to 90 percent of patients with advanced cancer. The complications of decreased appetite, weight loss and loss of muscle mass can cause serious fatigue.

When cancer is advanced, anorexia or the loss of appetite is due to overwhelming disease in the body and commonly does not respond very well to therapy.

### Causes

#### **Many factors cause anorexia:**

- Toxins produced by the tumor (They cause changes that block carbohydrates, fats and proteins from properly being used by the body.)
- Nausea
- Constipation
- Dry mouth or change of taste
- Difficulty swallowing
- Depression
- Abdominal bloating or shortness of breath
- Confusion

### Management

#### **The aim of the medical team is to improve quality of life by:**

- Controlling symptoms
- Stimulating appetite
- Consulting with a dietitian to improve nutrition

#### **Tips to help with loss of appetite:**

- Eat small, frequent meals.
- Eat larger quantities of food in the morning.
- Avoid spicy foods.
- Avoid food aromas.
- Try to make food a pleasurable social event and not a necessity.
- Encourage the eating of favorite foods for comfort and enjoyment that they give.
- Resist the desire to force-feed. This may cause other problems.



## Anxiety

Anxiety is a feeling of apprehension, fear or nervousness.

### Causes

**Many factors can cause or increase anxiety, such as:**

- Diagnosis of cancer
- Progression of cancer
- Fear of the future, talking to family about the cancer
- Pain and difficulty sleeping, especially if untreated
- Change in mental status (thinking process)
- Reactions to medicines (or side effects)
- Difficulty breathing or shortness of breath

### Signs

**You may experience the following if you are feeling anxious:**

- Tense and worried feelings or expressions
- Restlessness
- Irregular or fast heartbeats
- Chest pain
- Sweating
- Difficulty concentrating
- Feeling of suffocation
- Rapid, difficult breathing

### Management

The first step in managing anxiety is to determine its cause. Anxiety can often be treated without medication.

**The nursing staff and family can:**

- Provide a safe, supportive environment
- Teach you about the disease and treatment
- Tell you about upcoming tests and procedures
- Answer questions and provide time for you to reflect
- Encourage you to talk about fears and worries



### **The health care team will:**

- Help you identify anxiety-provoking triggers
- Help you identify positive and negative ways to cope
- Assess current and past coping mechanisms
- Encourage you to talk about your fears and worries
- Teach you coping techniques, such as relaxation exercises
- Provide positive reinforcement for adaptive coping strategies
- Give you and your family information about how to access support groups and community resources
- Teach you and your family about the purpose and effects of prescribed medicines

### **Tips for management**

At times, patients with cancer may appear agitated or restless because of underlying problems including:

- Pain
- Nausea
- Shortness of breath

Careful assessment by the medical team will ensure that the correct medicine is being prescribed to treat the appropriate symptom.











## Management

It is much easier to prevent constipation than to treat it. The medical staff will ask you about your bowel pattern history, and an abdominal examination by palpation will be done. A medical staff member may perform a digital rectal examination. The doctor will insert a lubricated gloved finger into the anal opening to examine the rectum for hard stool. A flat abdominal X-ray may be used to determine the severity of constipation or to rule out a bowel obstruction.

- Initial treatment may include a combination of stimulant and stool softener taken daily.
- The dose may be increased to two to four tablets four times a day if necessary.
- If constipation is an ongoing problem, the doctor may prescribe Lactulose (a syrup laxative). Usually, Lactulose is taken every six hours until a bowel movement happens.
- Treatment for severe constipation may require a suppository, Fleet® enema or a milk and molasses enema.
- A member of your care team may need to break up the stool manually.
- Your nurse or doctor may discuss with you other ways to treat your constipation.

The key to managing constipation is prevention. The palliative care team will develop a prevention program that will be easy for you and will ease discomfort.



## Dehydration

Dehydration is “the excessive loss of water from the body.” Fluid loss may even be severe enough to become life-threatening. Adequate hydration is important both as a comfort measure and in symptom management. All palliative care cancer patients admitted to acute care facilities receive fluids by IV or injection into the skin because the patient is unable to take in fluids by mouth.

### Signs and Symptoms

- Fatigue
- Nausea
- Confusion
- Thirst
- Restlessness
- Opioid accumulation (build up of medicines in a person’s system)
- Low blood pressure
- Dizziness
- Dry loose skin on arms and legs
- Sluggishness
- Less urine output
- Dry mucous membrane



## Management

Treatment is individualized, and your palliative team will assess the need for hydration. Your clinical status will be monitored daily, and infusion volumes will be adjusted to prevent over-hydration.

## Family Concerns

*My family member has edema (is swollen).*

*Why did the doctor order IV fluids?*

Edema is not a good indicator of the hydration status in patients with advanced cancer. Edema more often is a result of poor nutritional status.

*My family member is always asking for water or complains of thirst.*

*Why does his/her mouth look so dry and cracked?*

Thirst or dry mouth is not a reliable indicator of dehydration but more frequently results from taking pain medicine and other drugs, oral thrush, viral infections or mouth breathing. You can offer ice chips and do frequent oral care.

*Why would the doctor slow down the IV on my family member?*

Very ill patients generally require less fluid than other patients.

## Delirium

Delirium is a problem with thinking related to complications of cancer and its treatment. You may have difficulty concentrating, remembering things, and you may be confused. The goal is to treat the underlying cause of delirium.

### **Delirium is more likely to happen in patients who:**

- Have advanced cancer or another serious illness in addition to cancer
- Are elderly
- Have had a previous mental disorder
- Have low levels of albumin (protein) in the blood
- Have an infection
- Are taking medicine that affects the mind or behavior
- Are taking high doses of pain medicine or other medicines that interfere with thinking, such as tranquilizers, anti-anxiety medicines, antihistamines and sleeping pills

## Signs and Symptoms

Patients experiencing delirium may fall in and out of consciousness. This means that they may not be fully awake or alert for a continuous amount of time.

They may have problems with memory. They may get sleepy during the day and get restless or have anxiety at night. In severe cases, some patients may remove clothes, catheters or IV lines. Sometimes patients may be at risk of hurting themselves or family members and nurses. Sometimes patients may see things, which are not there, or experience muscle twitches or purposeless movements. This situation may change from time to time and most patients will alternate between agitation and being quiet and coherent.

## Causes

**Many factors can contribute to delirium, including:**

- Cancer or its treatment
- Organ failure (for example, kidney or liver failure)
- Dehydration
- Imbalances of important minerals like salt, potassium, calcium and phosphorous
- Infection
- Medicines, including some pain, antidepressant, antipsychotic and antihistamine medicines (these side effects usually go away after the drug is stopped).

## Other Problems

**Patients with delirium are more likely to:**

- Fall
- Be incontinent (unable to control bladder and bowels)
- Become dehydrated (drink too little water to maintain health)
- Have trouble communicating well with family and health care providers

## Management

Delirium makes it more difficult to assess your needs. For example, a health care provider or family member may think you are highly emotional because of extreme pain when you may actually be experiencing delirium.

Your mental status is assessed using a brief survey. The health care team will periodically repeat this examination to discover problems as early as possible. By doing so, corrective measures can be taken quickly to address these issues.

### **To treat you, the health care provider may:**

- Stop or reduce medicines that may cause delirium
- Give fluids intravenously (into a vein) or subcutaneously (under the skin) to help hydrate you
- Give medicines to correct hypercalcemia (too much calcium in the blood)
- Give antibiotics for infection
- Give medicines that sedate (calm) you
- Ask a family member to stay with you all or part of the time while you are hospitalized

### **Tips for Caregivers**

- Place a clock or calendar where the patient can see it.
- Have a family member present if possible.
- Have the patient in a quiet, well-lit room with familiar objects.
- Limit number of caregivers.

Although many patients with delirium can be successfully treated, delirium may persist in some patients, even when they receive proper treatment. It may mean that the patient is near death. The goals of care become comfort rather than prolonging life when this happens.

## Depression

Depression is a deep feeling of sadness or hopelessness for a prolonged period. Although individuals with cancer will experience different levels of stress and emotional distress, only 10 percent will experience serious depression. Many patients with cancer who feel sad or upset are not experiencing real depression. The majority will have difficulty adjusting to the cancer and its complications. Most of the time in these cases, medication for the treatment of depression is not needed.

## Signs and Symptoms

### Patients with depression may:

- Feel sad, blue or cry a lot for no reason
- Feel guilty, unworthy, helpless and lack self-confidence
- Feel life is meaningless or have a negative outlook on the future
- Experience a loss of interest in activities once enjoyed
- Exhibit social withdrawal
- Be irritable and have a tendency to overreact
- Experience difficulty falling asleep or sleeping too much
- Have a preoccupation with thoughts about dying
- Have suicidal thoughts

## Management

Although depression may go away on its own, some people cannot lift themselves out of their depression alone. Treatment for depression usually includes psychotherapy, medicine or both.

Your doctor or the unit counselor will assess you to find if you have depression. If depression is diagnosed the doctor will decide if you need to receive medication for depression. In many cases, counseling and support will control the symptom of depression. The unit has a nurse counselor to support you. You may request to see the nurse counselor, or the health care providers can request a consult for you. With therapy, many people are relieved after their first session to find that someone understands and can help.

Most patients who are treated for depression continue to function well. However, if you or your loved one is having thoughts of suicide, tell your doctor or nurse immediately. Suicidal thoughts should always be taken seriously.

## Dry Mouth

Dry mouth means dryness of the mouth due to a decreased production of saliva. Dry mouth can be permanent or temporary.

Saliva is important because it helps to remove food, debris and plaque from tooth surfaces, helping to prevent dental decay. Saliva also helps to neutralize acids and digest food. Saliva makes it possible for you to chew and to swallow.

### Causes

- Treatments
  - Radiation therapy, which can permanently damage the saliva glands
- Narcotics
  - Decongestants
  - Antihypertensives
  - Antidepressants
  - Antihistamines
  - Diuretics
- Nerve damage (Injury or surgery to the neck or head can damage the nerves that work with the salivary glands to make saliva.)

### Signs and Symptoms

- Burning sensation of the tongue
- Sticky, dry feeling in the mouth
- Difficulty chewing, eating, swallowing, especially with dry food
- Difficulty speaking
- Frequent thirst
- Difficulty wearing dentures
- Dry, cracked lips or dryness at the corners of the mouth
- Infection in the mouth

## Management

- Keep sugar-free fluid nearby and at the bedside at night
- Suck ice chips
- Sip water and sugar-free drinks often
- Sip water or sugar-free drinks during meals  
(This will help you chew and swallow.)
- Avoid drinks with caffeine, such as coffee, tea and some sodas  
(They will dry your mouth.)
- Avoid tobacco and alcohol
- Chew sugar-free gum or suck on sugarless hard candy (citrus, cinnamon or mint-flavored) to simulate saliva
- Avoid spicy or salty foods since they cause pain in a dry mouth
- Use a humidifier while sleeping
- Use artificial saliva
- Try acupuncture
- Ask your health care provider (He or she may prescribe medicines to help the dry mouth if the dry mouth is temporary or partial.)

## Shortness of Breath

Shortness of breath or “air hunger” is difficulty in breathing and a feeling that you “cannot get enough air in your lungs.”

### Causes

- Pain
- Airway obstruction by tumor.
- Emotional distress, including fear or anxiety
- Infection such as pneumonia
- Fluid in the lungs
- Pressure of enlarged abdominal organs
- Collection of fluid in abdomen pressing on diaphragm
- Anemia
- Anxiety

## Management

Here are some ways to help provide quick relief from dyspnea:

- Controlled breathing
  - Shortness of breath is a common side effect of some cancers. It can easily begin a vicious cycle of breathlessness. It is very important to relax and break this cycle as soon as possible.
- Pursed lip breathing
  - Start by taking a normal breath, counting the seconds it takes you to inhale through your nose. Exhale, through pursed lips, for twice the number of seconds as you inhaled. For example, if you inhaled for three seconds, exhale for six seconds. Try to make a slight whistling noise as you exhale. Do not force the air out. Breathe out in a controlled manner, through your lips.
- Relaxation
  - Because tense muscles use oxygen faster than relaxed muscles, it is important to relax. Rotate your shoulders a few times, or shrug them up and down. You should practice relaxing your shoulders and arms throughout the day. Try to be aware of times when you are tense so that you can relax before you become short of breath.
- Visualization techniques
  - Find a comfortable position and take a few controlled breaths. Begin to imagine a setting that relaxes and calms you. The setting can be anywhere or anything from watching the waves at the beach to relaxing in your bed at home. Stay focused on the setting; breathe, and relax your body. Feel the tension leave your body.
- Bedside fan
- Supplemental oxygen
  - Oxygen may help you manage shortness of breath. Your doctor, nurse and respiratory therapist will monitor and supply you with the proper oxygen therapy when required. Having a fan in the room and blowing air on your face may help.
- Medicines
  - Morphine and other pain medications decrease the feeling of shortness of breath the same way they decrease pain
  - Steroids sometimes help with inflammation and shortness of breath
  - Medicines to lower anxiety levels
  - Antibiotics if there is infection
  - Medicines given in breathing treatments to dilate the bronchial tubes
  - Diuretics

## Fatigue

Fatigue is excessive feelings of tiredness that may not be relieved by extra amounts of sleep or rest. Fatigue is controllable.

### Causes

- Pain
- Emotional stress/ lack of sleep
- Infection
- Low red blood cell counts
- Inactivity/deconditioning
- Advanced cancer or cancer treatment
- Difficulty breathing

### Management

#### Strategies to help manage your fatigue:

- Reassess your daily goals to make them realistic and reachable
- Control treatable causes such as pain, infection or dehydration
- Exercise regularly
- Have a blood transfusion
- Address emotional issues
- If no correctable causes can be found, your doctor may consider giving you stimulants during the day



## Insomnia

Insomnia is insufficient sleep, difficulty falling and staying asleep, interrupted sleep, or poor quality or “non-restorative sleep.” Data suggests that sleep may be disturbed in 50 percent or more of patients with advanced cancer.

Sleeping medicines are associated with many problems in patients with advanced cancer and may lead to delirium or increased fatigue. The medical staff must weigh the benefits of these medicines against the potential for complications and side effects.

### Causes of Insomnia

- Uncontrolled pain
- Anxiety
- Delirium
- Grief
- Medicines
- Depression
- Disease process
- Unfamiliar surroundings

### Management

The cause of insomnia must be carefully assessed before treatment begins.

- Maintain as regular a sleep-wake schedule as possible.
- Avoid unnecessary time in bed during the day.
- If you are confined to bed, try to receive as much cognitive and physical stimulation during daytime hours as possible.
- Nap only as necessary and avoid napping in the late afternoon and evening whenever possible.
- Keep as active a daytime schedule as possible. (This should include social contacts and light exercise when able.)
- Minimize nighttime sleep interruptions due to medicine, noise or other environmental conditions.
- Avoid lying in bed for prolonged periods at night in an alert and frustrated or tense state. Read or engage in other relaxing activities out of bed (when appropriate) until drowsy.

- Remove unpleasant stimuli from your environment, such as clocks.
- Identify problems or concerns of the day before trying to sleep, and address these issues with a problem-solving approach.
- Avoid stimulating substances (caffeine or nicotine), particularly in the hours just before bedtime.
- Maintain adequate pain relief through the night.
- Physical and occupational therapists are available to help you with exercises and activities.
- Nurse counselors are available and have audio relaxation tapes and other materials to help you with the treatment of insomnia.
- If these interventions were not successful, your doctor may consider giving you sleeping medications.

## Nausea

Nausea is an uneasy, uncomfortable feeling in your stomach, which may or may not lead to vomiting or “throwing up.”

### Causes

- Radiation therapy or chemotherapy
- Some medicines, especially pain medication
- Constipation
- Blockage of the bowel
- Unrelieved pain
- Infection
- Fluid and mineral imbalances
- Pressure on the brain
- Anxiety
- Kidney or liver failure
- Anesthesia

## Management

- Do not force yourself to eat.
- Avoid lying down flat immediately after eating. If you wish to rest, sit or recline with your head elevated for at least 30 to 60 minutes.
- If you are coughing and gagging due to thick secretions, and this triggers nausea and vomiting, rinse your mouth with warm salt water before and after eating. Ask your doctor for cough medicine.
- Distraction may help. Focus your attention on music, handwork, crossword puzzles, games, television, jigsaw puzzles, letter writing or reading.
- Learn relaxation techniques to help you control nausea.
- Move slowly to maintain your sense of balance.
- Constipation can cause nausea. Make sure you have regular bowel movements.
- Metoclopramide (Reglan) is an excellent medicine to control nausea in the majority of patients. Other nausea medicines may control the nausea also, but most of them cause severe sleepiness.

### *What should I eat when I am nauseated?*

- Try eating toast, crackers or other dry foods.
- Eat small, frequent meals throughout the day.
- Cold or bland foods, such as sandwiches, fruit, cottage cheese and ice cream, offer good nutrition without a strong odor.
- Drink fluids, such as ginger ale, sports drinks and fruit-flavored drinks made from dry mixes, frozen fruit bars on sticks, ice chips and carbonated drinks. Gelatin desserts or ice cubes can be made from these fluids.

### *What foods should I avoid?*

- Avoid fatty and fried foods because they are harder to digest. Foods high in fat will cause a feeling of fullness and possibly trigger nausea.
- Avoid spicy, highly seasoned foods. Eat bland foods instead.
- Avoid food with a strong odor, which may trigger nausea.

## Tips on Eating

- Take your nausea medication 30 minutes to one hour before you eat.
- Avoid an empty stomach.



# Emotional Needs

## Coping

During a time of crisis, it is normal to feel emotionally distressed. In fact, between 35 percent and 45 percent of all cancer patients experience distress. (This might include depression.)

### *How common is it for family members to feel emotionally distressed?*

It is very common for family and friends to feel distressed. It is scary for families to think about their loved one dying. Sometimes they feel more stressed than the patient does. They may also feel lonely and helpless.

### *How do I know if my family or I need professional counseling?*

Most people will experience emotional stress; however, it is different for each person. Below is a list of questions you can ask yourself or your family to help you decide whether to contact a professional counselor:

#### Answer using this scale:

1	2	3	4	5
<i>Not at all</i>		<i>Some of the time</i>		<i>All the time</i>

#### During the past two weeks:

- I feel anxious or worried about my loved one's cancer diagnosis and treatment.
- I feel depressed or discouraged.
- I have been irritable or unusually angry, and I have not controlled it well.
- My sleeping habits have changed.
- I have experienced a change in my appetite.
- I have had difficulty concentrating at work, home, school or while doing routine things, such as reading the newspaper or watching television.
- My loved one's diagnosis/treatment interferes with my daily activities.
- My loved one's diagnosis/treatment interferes with my family or social life.
- My loved one's diagnosis/treatment interferes with my sexual life.
- My loved one's diagnosis/treatment has caused financial hardship to our family.
- I have difficulty keeping up with my caregiving activities.
- I have difficulty coping with the stress that the entire family is experiencing.

If you find that most of your answers are fours and fives, and you are having difficulty dealing with your situation on your own, you may want to discuss your feelings with the Palliative Care clinical nurse counselor, chaplain or social worker.

### ***Should I feel ashamed for seeking support?***

Many people feel ashamed or weak for seeking support. Going to someone for help does not mean that you are weak; actually, seeking help is a sign of strength. You know that you cannot cope with a difficult situation alone. Seeking professional support gives you, your family and your caregivers a way to find solutions and maintain control over the things you can control.

## **Relaxation and Coping Resources**

The Learning Center is a free consumer health library with the latest information on cancer care, support, prevention and general health and wellness issues. The Learning Center provides skilled, personalized service to M. D. Anderson patients, caregivers and the public. Resources include:

- Health and medical reference books
- Brochures
- Medical journals, health magazines and newsletters
- Audio and videotapes
- Access to online medical and consumer health databases

### **Theodore N. Law Learning Center**

Main Building  
Floor 4, Near Elevator A, Room R4.1100  
Monday-Friday, 9:00 a.m.–4:00 p.m.  
713-745-8063

### **Holden Foundation Learning Center**

Jesse H. Jones Rotary House International  
Floor1, Room RHI1.103  
Monday-Friday, 7:00 a.m.–8:30 p.m.  
Saturday, 10:00 a.m.–4:00 p.m.  
Sunday, 1:30 p.m.-8:30 p.m.

### **Levit Family Learning Center**

Mays Clinic  
Floor 2, near The Tree Sculpture,  
Room ACB2.1120  
Monday-Friday, 9:00 a.m.–4:00 p.m.  
713-563-8010

### **Proton Therapy Center Learning Center**

Proton Therapy Center  
Floor 1, Room PTC1.1015  
Self-serve during normal Proton Therapy  
Center hours

## **Videos**

Selected videos are available for viewing through MDA-TV, an in-house cable television system, by calling extension 5-3223.

You can find a current list of videos in the “Patient Education Guide.” If you do not have this guide, ask your nurse for a copy. Available videos include:

- *The Relaxation Tape* (30 minutes) - #183
- *Life Journeys: Coping with Cancer* (20 minutes) - #207
- *Bernie Siegel: Out of Mind* (74 minutes) - #206
- *Caring for the Cancer Patient: The Caregiver’s Perspective”* (25 minutes) - #177

The Relaxation Channel is also available on Channels 80 and 81.

# Spiritual Resources

People come from around the world to visit M. D. Anderson, and each person has a different culture, religion and belief system. It is important that you and your family are respected physically, emotionally and spiritually.

Spirituality is more than a particular religion. It is what gives ultimate meaning to our lives. It is a sense that there is something larger than ourselves, from which we can draw comfort, hope, courage and strength.

Take a moment to think about what this is for you. Organized religion, prayer, meditation, nature, music, art and community are some of the many ways people connect to their spiritual selves.

## Questions About Your Spirituality

The loss of connection to one's inner strength, wisdom, God or spirituality can be one of the most frightening and painful parts of the cancer journey. Beliefs and assumptions that you have held dear all your life may change, and priorities may shift. For example, material things may become less important, while family and relationships take on a greater priority.

For some, this new perspective reinforces and strengthens their beliefs. Others may find themselves struggling since this is a time when many have spiritual concerns or issues.

A chaplain will visit you in your room to get to know you and your family, and a chaplain is available 24 hours a day to talk with you about any of the questions below, or other issues that are important to you.

- How have I used my life?
- What helped me through other tough times in my life?
- What is meaningful to me?
- Is there a purpose to my life in this experience?
- Are my beliefs, family and friends helping me cope or adding to my burden?
- What have I learned, and how can I share that with others?
- Whom do I need to forgive, and who do I wish would forgive me?
- What do I need to “let go of” or “clear up” in order to feel more peaceful?
- What are the blessings in my life, and why am I thankful?
- What are my sources of hope, strength, comfort and peace?



*Wedding was held in the Palliative Care Unit.*

# Other Resources for Your Mind and Spirit

## Place ... of wellness

At M. D. Anderson, we realize that physical healing is only part of the puzzle. The Place ... of wellness is an environment where all persons touched by cancer may enhance their quality of life through programs that complement medical care and focus on the mind, body and spirit. More than 75 complementary therapy programs are available to help manage symptoms, relieve stress and enhance your quality of life. Most programs are free, except acupuncture and full body massage, which are provided at a nominal fee.

## Thanksgiving Tree

Pick up a card, write down something you are thankful for, and hang it on the Thanksgiving Tree. This is a way of reminding us of the many blessings in our lives. Please feel free to read the other cards as well.

## Maps

There are two maps on the unit: one of the United States and one of the world. Take a minute to place a pin on either map (or both) to show your home. You are not alone in this experience.

## Discharge Planning

Discharge planning is a complex process. It may involve increasing symptom management and treatment. The case manager, discharge nurse and social worker will work together to help you and your family in determining the best course of action concerning the discharge instructions.

The discharge planning process begins the day you are admitted to the Palliative Care Acute Inpatient Unit. The discharge planning team assesses your medical needs. At each step of the planning process, the team takes into account the following points:

- Cancer treatment plans: whether there is further treatment for the cancer or not. Sometimes we may need to contact your oncologist if this is not clear.
- Your wishes and your family's wishes. Whether you want to be at home or in a facility.
- Availability of family members or other resources to help take care of you after discharge.

### **The case manager and discharge nurse:**

- Work with the health care team, you and your family in the assessment and coordination of care needs and transition planning.
- Identify actual and potential problems in services and treatments, and relate those to the interdisciplinary care team.
- Are responsible for the coordination and education about options for care and available resources (along with the social worker).

### **The levels of care available at discharge include:**

- Home – family care or private paid help
- Home health care (nurse comes to your home)
- Hospice care – at home, the hospital or a nursing home/hospice
- Rehabilitation (short-term facility for physical therapy)
- Long-term hospital care (specific needs)
- Skilled nursing facility (specific needs)
- Transfer to another hospital near your home (requires accepting physician)
- Nursing home (custodial care)

### **Care Following Discharge**

The Symptom Control and Palliative Care staff recognizes that many discharged patients and their families typically want ongoing contact with a health care team. Therefore, you or a member of your family will receive a phone call from one of our inpatient discharge nurses within the week following discharge. Our goal is to find out how you are doing and to help with any care coordination issues. If problems are identified that require more help, the discharge nurse may refer you to our Palliative Care phone service, which allows you and your family to receive calls from our advanced practice nurses until concerns have been resolved.

Patients who are discharged to hospice have access to a 24-hour phone service operated by each hospice. Please arrange all calls for routine or emergency care, including hospitalization, through the hospice team. To assure that you and the hospice team have access to ongoing communication with the M. D. Anderson palliative care team, we encourage calls to our Supportive Care Center (713-792-6072). Our palliative care nurses will coordinate with our doctors to provide coordination of care following discharge.

Patients who are discharged and plan to continue receiving palliative care services at M. D. Anderson will be given a follow-up appointment to our Supportive Care Center.



## Advance Directives

Quality of life refers to your level of comfort, enjoyment and ability to pursue daily activities of living. Advance directives allow you to state your choices for health care if you become too sick or unable to make decisions. An advance directive also lets you make your wishes known about medical treatment before you need such care. There may come a time, for a variety of reasons, when you might not be able to tell others what type of medical care you would like to have. This communication problem may be temporary or ongoing.

**There are three kinds of advance directives:**

- Medical Power of Attorney
- Living Will (Directive to physicians and family or surrogates)
- Out-of-Hospital Do-Not-Resuscitate Order (DNR)

### Medical Power of Attorney

By completing a Medical Power of Attorney, you can choose someone you know and trust to make health care decisions for you if you are unable to make them for yourself. Texas honors a Medical Power of Attorney from other states. If you do not choose someone to speak for you, and you do not complete other types of advance directives, your doctor and one of your relatives, as determined from a state designated priority list, will speak for you.

### Living Will (Directive to Physicians and Family or Surrogates)

You may sign a Living Will form if you are at least 18 years old, of sound mind and acting on your own free will. A Living Will allows you to state preference for full life-sustaining interventions or instructs your doctor not to use life support to extend the natural process of dying, as Texas state law allows. There are separate sections for patients with terminal illness and for those with incurable illness. This directive will take effect only when you are in the terminal phase of an illness. Parents may complete a Living Will for their child less than 18 years of age.

### Out-of-Hospital Do Not Resuscitate Order (DNR)

All medical care, procedures and tests are provided. Pain medications and other medication to improve comfort and quality of life will be given. Out-of-Hospital Do-Not-Resuscitate Order (DNR) is a form signed by the patient and the doctor indicating that when the patient is dying he or she should not receive cardiopulmonary resuscitation (CPR) or be placed on a breathing machine. He/she will be allowed to pass in peace and dignity. CPR or intubation at that time are usually not helpful and cause significant harm and family distress.

## Frequently Asked Questions

Patients often ask the following questions:

### *How do I complete advance directives?*

- Talk with your doctor, family and other people you trust.
- Complete the forms.
- An attorney is not necessary to complete the forms.
- Ask your nurse or social worker for copies of the forms. Social workers will help answer questions and with completion of forms if requested.
- Keep the original.
- Give copies to your doctor, hospital, lawyer and the person you choose to speak for you.

### **Other Important Matters**

When cancer is advanced or has spread, your health condition may change suddenly. Effects of the cancer or medicines can cloud thinking. It is important to take care of all legal and personal matters as soon as possible. These include:

- Will
- Financial Power of Attorney
- Funeral home selection
- Guardianship for minor children
- Direct deposit of Social Security or other income checks
- Co-signature on bank account
- List of accounts and assets
- List of where to find important documents
- List of distribution of sentimental and other property
- Arrangement for care of pets
- Forms and Letters:
  - Family Medical Leave Act (FMLA) physician statement
  - Visa letters
  - Work and school excuses
  - Travel rescheduling/cancellation medical statement

The Palliative Care social worker can help or provide information on taking care of many of these important matters. If you need help, please ask your nurse to contact the social worker.

# Hospice Planning

Most patients elect to go home after discharge from the Palliative Care Acute Inpatient Unit. If there are no further plans for treatment of the cancer, patients will continue to need medical care. Hospice care is provided at home by trained health care providers.

Our social worker is the professional on our team who is the best resource for learning about hospice care, and he or she is available to meet with families to discuss this option.

If a decision is made to consider hospice, our case manager will check your insurance to determine if hospice is a covered benefit and if specific hospices have been chosen by the insurance plan. The social worker will help your family in meeting with representatives from a hospice to discuss available services.

## **Some basic information about hospice includes:**

- Hospice is available as a benefit under Medicare Part A.
- Most insurers, including managed care plans, also cover hospice services.
- Most hospices provide care to patients who do not have insurance as a free service.

## **Hospice benefits, as defined by Medicare, are available to persons who:**

- Are certified by two doctors as having a life-limiting diagnosis with a life expectancy of six months or less. However, patients may live longer than six months, and certifications can be extended for multiple periods.
- Sign a statement choosing hospice care rather than curative treatment for their hospice diagnosis. (However, standard insurance benefits can still be used for treatment of other illnesses not related to the hospice diagnosis.)

**The hospice benefit typically covers the following services:**

- Physician services
- Home care visits by nurses to monitor the patient condition and to provide appropriate care to maintain patient comfort
- Home health aide and homemaker services, such as dressing and bathing
- Spiritual support if desired
- Social work or counseling services
- Medical equipment
- Medical supplies
- Medicines for symptom control and pain relief
- Volunteer support
- Physical, speech and occupational therapy and dietary counseling
- Bereavement counseling and support services for 12 months after the patient's death

***Where are hospice services provided?***

Most hospice care is provided in your home. The hospice team can arrange for you to stay in the hospital if needed. Nursing homes and assisted care living centers are also places for hospice. Respite care, another form of hospice care, involves allowing caregivers a break for daily responsibilities. Some short-term facilities (up to a five-day stay) may be available for payment if Medicare approved. If not, the family or insurance usually makes the payment for hospice care.

***What expenses must be paid by my family and me?***

Medicare plans pay for hospice services, but can require a \$5 co-payment for each prescription and may request payment of 5 percent of the cost of respite care. Many other insurers provide coverage similar to the Medicare plan. Our case manager is available to help you with benefit questions.





# CANCER IS SO LIMITED

It cannot cripple love.

It cannot shatter hope.

It cannot corrode faith.

It cannot destroy peace.

It cannot kill friendship.

It cannot suppress memories.

It cannot silence courage.

It cannot invade the soul.

It cannot steal eternal life.

It cannot conquer the spirit.

Cancer is so limited!

*Author unknown*

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