Reducing Barriers to Pain & Fatigue Management

Introduction
Pain and fatigue can impact all dimensions of a person’s life including physical, psychological, social and spiritual well-being. The attached cards were adapted from a study funded by the National Cancer Institute (NCI) to test an innovative model of reducing barriers to managing pain and fatigue in cancer patients using evidence based guidelines from the National Comprehensive Cancer Network (NCCN). While this information was created for cancer patients initially, we have adapted it to meet the needs of patients with any quality of life limiting illness.

Adapted from City of Hope’s “Passport to Comfort”

How to Assess and Treat Your Pain

Key points:
- It is best to control pain before it becomes severe and hard to manage.
- Patients deserve the best pain relief.

How to Assess Pain:
- Rate it – use a 0 – 10 scale (0 = no pain to 10 = worst pain)
  Describe it (Is it sharp? Shooting? Dull? Where is it? What makes it better or worse?)
- If your healthcare providers forget to ask you to rate your pain, please tell them because it is important to know if you are in pain.

How to Treat Pain:
- There are many kinds of medications available and many ways of giving them.
- If one doesn’t work well for you, other kinds may be tried.
- Addiction occurs rarely in people who are taking medications for pain. Addiction is psychological need. Tolerance means you may need to increase doses of your pain medication. Physical dependence is normal and predictable, but this is NOT addiction. Withdrawal symptoms may occur when the medication is stopped abruptly.
- Pain medications can be taken over months and years and they will still work.
• The most common side effects of pain medications are constipation and sedation.
• Side effects of pain medications can be controlled and treated.
• Please tell your healthcare providers before side effects become severe.
• There is no ceiling dose above which morphine class medicines can not be prescribed.

---

**How to Manage Constipation from Pain medication:**

- The best way to manage constipation is to prevent it.
- Make sure you drink enough fluids
- Make sure you get some form of exercise each day (i.e. walking). Even a little bit helps.
- Eat foods high in fiber.
- Use a bowel regimen (stool softeners and laxatives) as instructed by your healthcare providers.

**Suggested Bowel Regimen:**

- Start with Senokot as a stimulant and Colace as a softener. May increase to 4 tabs twice a day. If no BM in 2 days add a laxative (Ducolax, Miralax, Milk of Magnesia).
- If still no BM, **contact your MD or pharmacist.** You may be asked to use an enema or suppositories.
Preventing and Managing Constipation

What to do:
- Drinking lots of fluids is very important. Drink eight to ten cups of liquid each day (if allowed by your doctor)
- Try to eat at the same times each day.
- Eat foods high in fiber (e.g. uncooked fruits (with the skin on), vegetables, whole grain breads and cereals, fresh raw fruits with skins and seeds).
- Add one or two tablespoons of unprocessed bran to your food. This adds bulk and stimulates bowel movements. Sprinkle on food at mealtimes.
- Avoid foods and beverages that cause gas such as cabbage, broccoli, cauliflower, cucumbers, dried beans, peas, onions, and carbonated drinks if these items cause you distress.
- Get as much exercise as you can, even if that means only walking a very short distance.
- Try to have a bowel movement whenever you have the urge.
- Use stool softeners and laxatives only as instructed by your doctor or nurse.
- Use a rectal suppository only after checking with your doctor or nurse.
- If you are confined to bed, try to use the toilet or bedside commode when you have a bowel movement, even if that is the only time you get out of bed.
- Use an enema to provide immediate relief from constipation, but first check with a doctor or nurse. Enemas should be the last step for relieving constipation. They evacuate the lower bowel and help the upper bowel move as well.

Do not:
- Strain or use extreme force when trying to move your bowels.
- Use over-the-counter laxatives or enemas unless first discussed with your doctor.
- Use laxatives and enemas if you have a low white blood count or low platelet count.
Managing Fatigue

What is Fatigue?
• An overwhelming sense of exhaustion physically, mentally, emotionally.
• Can occur with cancer or cancer treatment
• Can persist over time and interfere with usual activities
• Differs from the tiredness of everyday life, which is usually temporary and relieved by rest
• More distressing and not always relieved by rest
• Can vary in its unpleasantness and severity
• Can make being with friends/family difficult
• Can make it difficult to follow your treatment plan

Common Causes of Cancer-Related Fatigue
• Anemia (low red blood cell count)
• Pain
• Emotional distress
• Sleep problems
• Poor nutrition
• Lack of exercise
• Other illness such as infection, hypertension, diabetes

Common Words Used to Describe Cancer-Related Fatigue
• Feeling tired, weak, exhausted, weary, worn out
• Having no energy, not being able to concentrate
• Feelings of heaviness in arms and legs, feeling little to no motivation, sadness and/or irritability, and unable to sleep or sleeping too much

What to Tell Your Doctor
• When did the fatigue start?
• Has it progressed over the course of your treatment?
• What makes your fatigue better?
• What makes your fatigue worse?
• How has the fatigue affected your daily activities?
Energy Conservation Principles

- Prioritize your activities in order of importance
- Ask for help and delegate tasks when you can
- Place items you use often within easy reach
- Establish a structured routine
- Balance rest and activities, performing activities during times of higher energy
- Establish a regular bedtime
- Whenever possible, sit instead of stand when performing tasks

Principles of Exercise

- Your heart, lungs, and muscles require a daily workout. When you are less active, especially while in bed, your heart, lungs, and muscles have very little work to do. Overtime, your heart pumps less forcefully, your lungs expand less fully, and your muscles will become weak and tight. This causes a drop in your energy level, which affects your ability to carry out your daily routine.
- The following tips should be considered:
  - Check with your doctor before exercising
  - Do exercises slowly and completely
  - If too tired to finish exercises, do what you can
  - Always work at your own pace, do not rush
  - Work within your own target heart rate (see your doctor for details)
  - Remember to breathe while you exercise
  - Walk!

no problem       1       2       3       4       5       6       7       8       9       10       severe problem
Nutrition to Manage Fatigue

Managing and Optimizing Your Nutrition Can Help to:

- Prevent or reverse nutrient deficiencies (For example, too little calcium or vitamins)
- Preserve lean body mass
- Better tolerate treatments
- Minimize nutrition-related side effects and complications (nausea, vomiting, and dehydration)
- Maintain strength and energy
- Protect immune function, decreasing risk of infection
- Aid in recovery and healing
- Maximize quality of life

Poor Nutrition – Its Effects

In people with cancer, certain changes in nutrition can affect fatigue levels. These changes include the ability to process nutrients, increase energy requirements, and decrease intake of food, fluids, and some minerals.

The changes can be caused by:

- Changes in the body’s ability to break down food products (metabolism)
- Competition between your cancer and your body for nutrients
- Poor appetite
- Nausea/vomiting
- Diarrhea or bowel obstruction

Fatigue can affect your interest in food, ability to shop, and to prepare healthy meals. Some suggestions include:

- Be familiar with your treatment and possible side effects
- Make sure you get enough rest
- Save favorite foods for non-treatment days so they won't be linked to an unfavorable event
- Poor nutrition and not eating can increase your fatigue
- If unable to eat regular sixe meals, eat small meals more often
- Include protein in your diet (fish, beans, milk, cheese)
- Drink plenty of fluids (8-10 cups per day)
- If unable to eat, drink high calorie/protein drinks (milk, juices, smoothies, milkshakes, nutrition supplements)
- Stock your pantry to avoid extra shopping trips
- Keep foods handy that need little to no preparation (pudding, peanut butter, tuna fish, cheese, eggs)
- Do some cooking in advance and freeze meal-sized portions
- Eat larger meals when feeling better
- Talk to family/friends about help with shopping/cooking
Please ask your physician to refer you to a dietitian if you:

• Have had minimal food intake for 5 days or more
• Have difficulties with chewing or swallowing
• Are receiving tube feedings or IV nutrition (TPN)
• Have a pressure ulcer or skin breakdown
• Are not able to maintain weight
• Wish to see a dietitian about your nutrition concerns
Strategies to Help with Promoting Sleep

**Sleep Hygiene Strategies:**
- Avoid coffee, tea, chocolate, soft drinks, and tobacco before going to bed
- Avoid exercise 2-4 hours before bedtime
- Sleep in a dark, cool, quiet, and relaxing room
- Develop a bedtime ritual (i.e. warm milk before bedtime)
- Use your bed only for sleeping and intimacy
- If possible, go to bed at the same time each night

**Sleep Restrictions Strategies:**
- Add one additional hour of sleep if you feel ill or feel unable to get up at the scheduled time in the morning
- Limit naps to no more than two everyday, each lasting less than an hour

**Relaxation Strategies:**
- Take a warm shower or bath before going to bed
- Listen to soothing music
- Use meditation, message, progressive relaxation, or other strategies to decrease stress
- Place dried lavender in your presence before going to sleep

**Other Strategies:**
- Keeping yourself as active as possible during the day will help with promoting sleep at night (discuss with your health provider what forms of exercise is safe for you).
- Having other symptoms, such as pain or fatigue, can affect your sleep. If you are currently experiencing other symptoms, please talk to your provider about how to best manage these symptoms.
- If you are worries, depressed, or anxious, talk to your provider about resources to help you cope with these concerns.
- A variety of sleep medication (over the counter or prescribed) are available to help you sleep. Please ask your provider about which sleep medications would be best for you to take.
Nausea and Vomiting

**Nausea and Vomiting:**
- Can often occur together
- **Nausea** is an unpleasant feeling in the back of the throat and stomach that may result in vomiting. Increased saliva, dizziness, light-headedness, difficulty swallowing, skin temperature changes, and fast heart rate are symptoms that may occur during nausea.
- **Vomiting** (emesis) is a forceful contraction of the stomach muscles that causes the contents of the stomach to come up through the mouth. Nausea may or may not be present.
- **Retching** is the attempt to vomit without bringing anything up from the stomach (gagging or dry heaves).

**Causes of Nausea and Vomiting**
- Chemotherapy
- Radiation therapy
- The cancer itself
- Certain medications
- Constipation
- Other: anxiety, infections, other diseases, or illnesses

**Types of Nausea and Vomiting**
- **Acute nausea and vomiting** usually occurs a few minutes to several hours after chemotherapy and goes away within 24 hours.
- **Delayed nausea and vomiting** occurs around 24-72 hours after chemotherapy and can last 6-7 days.

**How is Nausea and Vomiting Treated?**
- Anti-nausea/vomiting medications
  - Based on your condition, ability, preference
  - By mouth is most common
  - For severe vomiting or for those unable to swallow, medicines can be given into a vein
- Nondrug treatments such as relaxation, distraction, imagery, and meditation

**Managing Side Effects:**
- Try to eat small frequent meals instead of 3 larger meals
- Eat foods higher in calories and protein
- Try eating when you are best able to eat. Some people are more hungry at breakfast time
- Let your doctor or nurse know when eating is a problem for you
- Let your doctor or nurse know if you would like a referral to see the dietitian
- Let your doctor or nurse know when your nausea or vomiting are not relieved

**To Help Manage or Reduce Nausea and Vomiting**
• Key is to try and prevent nausea. Take medications for nausea on a regular schedule.
• Eat foods and drink beverages that are easy on the stomach or made you feel better when you had the flu, such as ginger ale, bland foods, sour candy, dry crackers or toast.
• Do NOT force yourself to eat when you feel nauseated.
• Restrict fluids with meals.
• Eat food cold or at room temperature.
• Ask someone else to make the meals if you are nauseated.
• Try aromatherapy with mint, ginger and other scents.

Please ask your physician to refer you to a dietitian if you:
• Have had minimal food intake for 5 days or more
• Have difficulties with chewing or swallowing
• Are receiving tube feedings or IV nutrition (TPN)
• Have a pressure ulcer or skin breakdown
• Are not able to maintain weight
• Wish to see a dietitian about your nutrition concerns
Dyspnea (difficulty breathing)

**General Principles**

- Dyspnea means difficulty breathing, a sense of breathlessness, or a feeling of shortness of breath.
- Dyspnea is very different for each person.
- Dyspnea can be very upsetting. It is normal to feel anxious or distressed when you have difficulty breathing. Controlling anxiety is an important part of treating dyspnea.
- Your doctor may prescribe medications to help your breathing or reduce your anxiety.
- It is important to describe your dyspnea to your doctor.
  - Does it come on suddenly?
  - Does it come with activity?
  - What makes it better or worse?
- One way to communicate your difficulty breathing is on a scale:

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>none</td>
<td>slight</td>
<td>moderate</td>
<td>severe</td>
<td>very severe</td>
<td>maximal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Treatment**

There are many things you can do to reduce your feelings of dyspnea.

- Sit upright supported by pillows or lean over a bedside table.
- Use a fan or open a window to circulate air.
- Use oxygen if recommended by your doctor.
- Use medications as ordered by your doctor to help relieve dyspnea.
- Use relaxation, meditation, and breathing exercises such as pursed lip breathing to decrease your anxiety and improve your breathing.
- Activity often makes dyspnea worse. Use methods to conserve energy or use medications before activity.
- It is important to let your doctor know if your respiratory symptoms change, you are coughing more, you have fever, or you have any blood in your sputum.
- The American Board of Internal Medicine supports the use of morphine-class medications as well as sedative medications for the treatment of dyspnea.

**Pursed Lip Breathing**

Pursed Lip Breathing is a simple technique to help control shortness of breath. It works by slowing the pace of your breathing making each breath more effective.

**When to Use Pursed Lip Breathing**

- During activity such as bending, lifting, climbing stairs, or any activity that requires extra effort.

**How to do Pursed Lip Breathing**

1. First, relax your neck and shoulder muscles.
2. Then breathe in slowly through your nose with your mouth closed, taking in a normal breath.
3. Purse your lips together like you are blowing out a candle or whistling.
4. Breathe out slowly through your pursed lips while counting to four. Breathing out should take 3-4 times longer than breathing in.
5. Repeat steps 2 through 4 until shortness of breath is relieved.

**Activity/Energy**

1. Plan important or fun activities first. Limit unnecessary activity.
2. Take rest periods during activities.
3. Perform grooming activities while sitting.
4. Keep frequently used items within easy reach.
5. Use a wheelchair as needed.
6. Wear flat shoes.
7. Wear loose, easy to put on clothes.
8. Avoid warm temperatures, unpleasant odors or fumes.
9. Establish a regular routine.
10. Ask for help and delegate tasks when you can.

If dyspnea continues to be a problem, please contact your doctor.
Managing Diarrhea

Diarrhea is the passage of loose or watery stools three or more time a day with or without discomfort. It happens when the water in the intestine is not being absorbed back into the body for some reason. Sometimes diarrhea can be caused by an overflow of intestinal liquids around stool that is lodged in the intestine (impaction). Other causes can include infections; surgery; anxiety; side effects of chemotherapy, radiation therapy to the abdomen, or medicines; supplemental feedings containing large amounts of vitamins, minerals, sugar, and electrolytes; and tumor growth. Diarrhea caused by chemotherapy or radiation therapy may last for up to three weeks after treatment ends.

**What the Patient Can Do**

- Try a clear liquid diet (water, weak tea, apple juice, peach nectar, clear broth, popsicles, and plain gelatin) as soon as diarrhea starts or when you feel that it’s going to start. Avoid acidic drinks such as tomato juice, citrus juices, and fizzy soft drinks.
- Eat frequent small meals.
- Try small amounts of low fiber foods, e.g. rice, bananas, applesauce, yogurt, mashed potatoes, low-fat cottage cheese, and dry toast when the diarrhea starts to improve.
- Eat foods high in potassium (bananas, potatoes, apricots) which is an important mineral often lost through diarrhea.
- If diarrhea last longer than 2 days, start a liquid diet and add low-fiber foods as tolerated.
- Monitor the amount and frequency of your bowel movements.
- Clean the anal area with mild soap after each bowel movement, rinse well with warm water, and pat dry.
- Inspect anal area for red, scaly, broken skin.
- Apply a water-repellent cream, such as A&D ointment to the anal area.
- Take medicine for diarrhea or skin irritation as recommended by your doctor.

**Do Not**

- Eat foods that may stimulate/irritate the digestive tract
  - Whole grain breads/cereal or bran
  - Fried or greasy food
  - Nuts
  - Raw fruits or vegetables
  - Rich pastries/candy, or jellies
  - Strong spices/herbs
  - Caffeinated, alcoholic, or carbonated drinks
  - Milk/milk products
  - Very hot/very cold foods

**When to Call the Doctor**

- 6 or more loose bowel movements per day, for > 2 days
- Blood in/around anal area or in stool
- Weight loss of 5 lbs or more after diarrhea starts
- New abdominal cramps/pain lasting 2 or more days
• Inability to urinate for 12 or more hours
• Refusal (inability) to drink liquids for more than 2 days
• Fever
• Sudden puffy or bloated abdomen
• Constipation for several days accompanied by a small amount of diarrhea or oozing of fecal material.

**What Caregivers Can Do**
• See that the patient drinks about 3 quarts of fluids per day
• Keep a record or bowel movements to help decide when to call the doctor
• Check with the doctor before using any over the counter medicine. Many of these contain compounds that are like aspirin, which can worsen bleeding problems.
• Check anal area for red, scaly, broken skin
Spiritual Care at Hoag Hospital

The staff, at Hoag, is committed to caring for our patients…body, mind, and spirit. We truly believe that the mind and spirit are every bit as important as the body. So while our medical, nursing, and psychological staff are working to heal the body and mind…our spiritual care department is committed to the spirit and addressing the suffering that is part of facing cancer.

Many people are very faithful to a particular tradition and would describe themselves as religious. Others might not be affiliated with a religious institution, but do consider themselves quite spiritual and connected to something greater than themselves.

Spiritual Care at Hoag isn’t limited to those who identify with a particular religious tradition or teaching. Our chaplains provide spiritual care to each individual, providing support in whatever way best serves the patient and family.

What do Chaplains do?
• Offer compassion and presence
• Listen to your concerns
• Address spiritual or religious concerns
• Reflection

When should I ask for a chaplain?
• If you’re asking yourself, “Why is this happening to me?”
• If you’re trying to find meaning in the experience.
• If you’re experiencing distress related to religious or spiritual matters.
• If you have fears about your own mortality.
• If you would like to tell your story.
• If you feel alone and lonely.
• If you’re struggling with making decisions.
• If prayer and or meditation might be helpful.
• If you would like to see a clergy person from your faith tradition.
• If you want the rituals or sacraments from your faith tradition.
• If you’re feeling your faith, or world view, is being challenged.

How do I contact a chaplain?
• Call the Spiritual Care Office at 48358
• Let your nurse know you want to see a chaplain.
• Let your physician know you want to see a chaplain.
• Use channel 12 on Skylight TV
• Prayer boxes on the units
• Call the operator
Coping with Emotional & Social Impact of Pain & Fatigue

Cancer symptoms such as pain and fatigue can affect your emotional, social, and spiritual well being. **Distress** is a term used to describe unpleasant feelings or emotions that may interfere with your ability to cope with cancer. It is **normal** to be distressed when you receive a diagnosis of cancer.

**Distress** covers a wide range of feelings, including:
- Depression
- Anxiety
- Panic
- Fear
- Stress

**Distress** can occur at different times. Times that patients often find most stressful include:
- Hearing the initial diagnosis of cancer
- Waiting for the first treatment to begin
- Dealing with side effects of treatment
- Completing cancer treatment and facing an uncertain future
- Follow-up visits with doctors
- Hearing news of recurrent or advanced illness
- Facing advanced stages of cancer

**Distress** can sometimes become more serious. Certain signs of **depression** include:
- Persistent sad or “empty” mood almost daily
- Loss of interest or pleasure in activities
- Loss of appetite or overeating
- Disrupted sleep or oversleeping
- Decreased energy almost everyday
- Feeling of guilt, worthlessness, helplessness
- Difficulty concentrating, remembering, making decisions
- Thought of death or suicide
- Inability to cope with pain or fatigue
- Questioning your faith or religion

**Signs of anxiety include:**
- Feelings of panic, loss of control
- Anger or irritation
- Increased muscle tension
- Trembling and shaking
- Sweaty palms, racing pulse, difficulty breathing

**What you can do**
- Talk with your doctor or nurse about these feeling or emotions and possible ways to treat them.
- Seek help through counseling (pastoral care, social workers, psychologists, psychiatrists)
or support groups.
• Use prayer or other types of spiritual support.
• If possible, identify the situations that may be adding to your anxiety.
• Try deep breathing exercises to help relieve anxiety.
• Keep a personal journal to help you express yourself.

**Contact your Doctor or Nurse if the Following Occur:**
• You have thoughts of suicide
• You cannot eat or sleep for several days
• You are having trouble breathing and you feel shaky
• Nothing you do seems to help