Palliative Care Patient Education
## Palliative Care Patient Education

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Domain 1- Physical Well Being: Patients

Domain 1 Introduction
Physical well-being is focused on how much the symptoms you have affect your quality of life and everyday activities. People with lung cancer often have symptoms that are a result of their cancer and/or treatments. Some of your symptoms may be new, and some you may have had for a longer time. It is important to make sure that all of your symptoms are treated so that you are able to take part fully in your everyday activities.

Some symptoms that are common in people with lung cancer can be treated with medicines. Most symptoms can be treated with a combination of medicines and other supportive treatments. Often there are many things that can make you feel better that you can do alone (self-care) or with the help of family or friends at home.

In this session, we will give you information about some of the most common symptoms faced by many people with lung cancer. For each, we will discuss key things to know about the symptoms, how to assess and talk about the symptoms to your doctor/nurse, how to manage the symptoms, and self-care tips that you can use to manage your symptoms. We will help you develop a personal action plan that identifies ways to manage your symptoms. Finally, at the end of the session, we will give you some resources that help with managing the symptoms.

In each of our sessions we will begin with asking you to rate your level of distress. This helps us to know overall how you are coping with lung cancer. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

My Overall Distress ________
Domain 1- Physical Well Being: Patients

It would be helpful if you would tell us what physical symptoms/needs you would like to learn about during today’s session. We find that asking you to identify which physical symptoms are most important makes the teaching more relevant to your personal needs.

Below is a list of physical symptoms/needs that are common for patients who face lung cancer. Please pick three symptoms/needs that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

- ______ Breathing Problems (pg. 4)
- ______ Cough (pg. 7)
- ______ Pain (pg. 8)
- ______ Constipation (pg. 10)
- ______ Fatigue (pg. 12)
- ______ Sleep Problems (pg. 14)
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BREATHING PROBLEMS
(dyspnea, difficulty breathing)

Key things to know:

- Causes:
  - Cancer blocking airways
  - Cancer treatments (such as effects of radiation)
  - Low levels of red blood cells
  - Infections of the lung
  - Fluid in the lungs

How to assess and talk about breathing problems:

- Call your doctor/nurse if:
  - Your breathing problem is new or getting worse
- Keep track of the following:
  - When your breathing problem started
  - What makes your breathing problem better/worse

How to treat your breathing problem:

- Type of treatment is based on what caused your breathing problem:
  - Oxygen therapy
  - Medicines that are inhaled to open up small airways in your lung
- Supportive care professionals that can help:
  - Pulmonary rehabilitation doctor
  - Physical/occupational therapist
  - Palliative care team

Self-care tips:

- Follow directions when taking any medicines for your breathing problems. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Pursed-lip breathing and/or leaning positions can be very helpful (see following handout, pg. 9)
- Use a fan to blow cold air against your cheek or through your nose
- Relaxation and meditation (see following handout, pg. 10)
- Conserve energy:
  - Prioritizing activities
  - Balancing rest and activity
  - Asking family/friends for help
Domain 1- Physical Well Being: Patients

Pursed Lip Breathing

Pursed lip breathing is one of the easiest ways to control shortness of breath. It is a quick and easy way to slow your pace of breathing, making each breath more effective.

Use this technique during the hard part of any activity, such as bending, lifting or stair climbing. Practice 4-5 times a day at first so you can do the technique correctly.

**Technique**

1. Relax your neck and shoulder muscles.

2. Breathe in (inhale) slowly through your nose for two counts, keeping your mouth closed. Don't take a deep breath; a normal breath will do. It may help to count to yourself: inhale, one, two.

3. Pucker or "purse" your lips as if you were going to whistle or gently flicker the flame of a candle.

4. Breathe out (exhale) slowly and gently through your pursed lips while counting to four. It may help to count to yourself: exhale, one, two, three, four.

5. Breathing while bending forward can help you breathe better. Lean forward at the waist, and keep your back straight. People often use a table or the back of a chair for this. You can also use this breathing method while you are sitting down.
Domain 1- Physical Well Being: Patients

Breathing: Relaxation Exercises

The following relaxation techniques can help with the tension and anxiety that may be caused by your breathing problems. By learning to relax your mind and body, you may feel better.

☐ To begin, lie down on a comfortable surface and place pillows under your head and knees. If you are more comfortable on your side, use pillows under your head and between your knees.

☐ Relax

☐ Lie quietly in a comfortable position. Take a slow deep breath through your nose. Hold the breath for several seconds; purse your lips, and slowly exhale. Relax.

☐ Take another deep, slow breath through your nose. Hold your breath and pull your toes towards your head and tighten your leg muscles (no longer than a count to 3). Feel the tension. Purse your lips, exhale slowly and relax your legs. Relax.

☐ Take another deep slow breath through your nose. Hold your breath and make a fist with both hands and tighten your arm muscles. Feel the tension. Purse your lips, exhale slowly and relax your arms and hands. Relax.

☐ Take another slow, deep breath through your nose. Hold the breath and bite down as hard as you can and tighten your jaw muscles. Feel the tension. Purse your lips, exhale slowly, and relax your jaws. Relax.

☐ Take a slow deep breath through your nose. Hold your breath and lift up your head and tighten your neck muscles. Feel the tension. Purse your lips, exhale slowly, let your head rest back on the pillow, and relax your neck muscles.

☐ Lie still and enjoy the relaxed feeling you are experiencing. You should do this relaxation technique several times a day, even if you simply do it while sitting in a chair.
Domain 1- Physical Well Being: Patients

**COUGH**

**Key things to know:**
- Chronic cough is common in lung cancer and can:
  - Keep you from sleeping
  - Make breathing problems worse
  - Be painful

**How to assess and talk about cough:**
- Call your doctor/nurse if:
  - Your cough is new or getting worse
  - Your cough keeps you from doing your everyday activities
- Keep track of the following:
  - When your cough started
  - What makes your cough better/worse
  - If you have mucus with the coughing
  - If your mucus changes color, and you have a fever (signs of possible infection)
  - How long your cough lasts

**How to manage your cough:**
- Type of treatment is based on what caused your cough:
  - Treating your cancer to make it smaller
  - Medicines that control cough and/or mucus
  - Antibiotics that can treat infections
- Supportive care professionals that can help:
  - Pulmonary rehabilitation doctor
  - Pulmonary medicine doctor
  - Palliative care team

**Self-care tips:**
- Follow directions when taking any medicines for your cough. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Cough medicines such as codeine can cause nausea or constipation. Call your doctor/nurse if you are experiencing these side effects while taking codeine to manage your cough
- Stay away from or minimize doing anything that makes you cough
- Elevate head of bed
- Use a humidifier
- Drink enough fluids
- Ask family/friends for help if you have trouble doing your everyday activities
Domain 1- Physical Well Being: Patients

PAIN

**Key things to know:**
- Best to control pain before it becomes severe
- You deserve the best pain relief

**How to assess and talk about pain:**
- Rate your pain using a 0-10 scale (0 = no pain to 10 = worst pain)
- Call your doctor/nurse if:
  - Your pain is new or getting worse
  - Your pain keeps you from doing your everyday activities
- Keep track of the following:
  - When your pain started
  - What makes your pain better/worse
  - Where your pain is located
  - How you describe your pain (sharp, shooting, dull, burning)
  - How long your pain lasts

**How to manage your pain:**
- Type of medicine used is based on what caused your pain:
  - Many medicines can be used to treat pain
  - Medicines can be given in many ways
  - If one medicine doesn’t work well, other kinds can be tried
- Opioids (morphine-like medicines) are used to treat pain
- What to know about opioids:
  - Definitions to understand
    - **Tolerance**- When your body adjusts to the current pain medication requiring an increase in the dosage. This is normal and is not addiction
    - **Physical Dependence**- Anyone taking on opioid for a long time is likely to become physically dependant on it. If you stop the opioid abruptly, you will experience withdrawal symptoms (e.g. shaking, agitation, fear, chills). Do not stop the opioid abruptly. Physical dependence is normal and is not addiction.
    - **Psychological Addiction**- Addicts crave drugs to satisfy their physical, emotional, and psychological needs, not for pain relief. Drug addicts focus on getting and using drugs despite consequences of any kind, including legal.
  - Opioids can be long-acting or short-acting
    - **Long-acting medicine** controls pain that continues throughout the day. They need to be taken around the clock
    - **Short-acting medicine** controls unexpected episodes of pain (breakthrough pain). They need to be taken as needed.
  - Opioids will still work if taken over months and years
- Common side effects:
Domain 1- Physical Well Being: Patients

- Constipation – if you take pain medicines on a regular basis, you should take stool softeners and/or laxatives daily (see page 16 for more details).
- Sedation (feeling sleepy)
  - Supportive care professionals that can help:
    - Palliative care team

Self-care tips:
- Follow directions when taking any medicines for your pain. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
  - Have side effects from your pain medicines
  - Have concerns or questions about using your pain medicines
- Use other supportive methods:
  - Massage
  - Heat/cold
  - Relaxation/meditation
  - Distraction
- Ask family/friends for help if you have trouble doing your everyday activities
Domain 1- Physical Well Being: Patients

CONSTIPATION

Key things to know:
- Can be caused by pain medicines such as opioids
- Many other medicines can also cause constipation (including chemotherapy)
- Prevention is important!

How to assess and talk about constipation:
- Call your doctor/nurse if:
  - Your constipation is new or getting worse
  - You are not having soft bowel movements at least every other day
  - Your constipation keeps you from doing your everyday activities
- Keep track of the following:
  - Bowel movement patterns
  - When your constipation started
  - What makes your constipation better/worse

How to manage your constipation:
- Type of treatment is based on what caused your constipation:
  - Pain medicines:
    - Use bowel regimen to prevent constipation (pg. 18)
      - Laxative and/or stool softener
  - Supportive care professionals that can help:
    - Palliative care team
    - Pharmacist

Self-care tips:
- Follow directions when taking any medicines for your constipation. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Try to have a bowel movement whenever you feel you need to
- Drink enough fluids
- Eat foods high in fiber
- Avoid foods and beverages that cause gas if they cause you distress
- Stay active (i.e. walking):
  - Work at your own pace
  - Only do what you can
- Ask family/friends for help if you have trouble doing your everyday activities
Domain 1- Physical Well Being: Patients

Bowel Regimen for Constipation
Start with Senokot S (laxative) – 2 tablets at bedtime

If you have bowel movement:
Take Senokot S – 2 tablets at bedtime on a regular basis when you are taking morphine-like pain medicines. If you start having loose stools, call your doctor/nurse

If no bowel movement on day 1:
Take your pain medicine in addition to Senokot S - 2 tablets twice a day.

If no bowel movement on day 2:
Take your pain medicine in addition to Senokot S - 3-4 tablets twice a day or three times a day.

If no bowel movement on day 3:
Call your doctor/nurse
Domain 1- Physical Well Being: Patients

FATIGUE

Key things to know:
- Fatigue in cancer is a sense of feeling tired/weak that affects people physically, mentally, and emotionally.
- Fatigue in cancer is different from tiredness of everyday life, which usually gets better with rest.
- Causes:
  - Low red blood cell count
  - Other symptoms (i.e. pain)
  - Chemotherapy
  - Emotional distress
  - Sleep problems
  - Poor nutrition
  - Lack of physical activity
  - Other illnesses (i.e. heart problems)

How to assess and talk about fatigue:
- Rate your fatigue using a 0-10 scale (0 = no fatigue to 10 = worst fatigue).
- Call your doctor/nurse if:
  - Your fatigue is new or getting worse
  - Your fatigue keeps you from doing your everyday activities
- Keep track of the following:
  - When your fatigue started
  - What makes your fatigue better/worse
  - How you describe your fatigue (worn out, exhausted, sadness)
  - How long your fatigue lasts

How to manage your fatigue:
- Type of treatment is based on what caused your fatigue:
  - Treating other symptoms (i.e. pain)
  - Treating emotional distress
  - Treating sleep problems
- Supportive care professionals that can help:
  - Physical/occupational therapist
  - Psychologist/psychiatrist
  - Dietitian
  - Palliative care team

Self-care tips:
- Conserve energy:
  - Prioritizing activities
  - Balancing rest and activity
• Establishing a structured routine
• Ask family/friends for help

❖ Stay active (i.e. walking):
• Work at your own pace
• Only do what you can

❖ Eat well:
• Save favorite foods for non-treatment days
• Eat small meals throughout the day
• Include protein/high calories in your diet
• Call your doctor/nurse if you have problems swallowing. A referral to a speech pathologist is helpful for assessment and recommendations for managing swallowing problems
Domain 1- Physical Well Being: Patients

SLEEP PROBLEMS

Key things to know:

- Causes:
  - Emotional factors (anxiety, depression)
  - Other symptoms (i.e. pain)
  - Cancer treatments
  - Other illnesses

How to assess and talk about sleep problems:

- Call your doctor/nurse if:
  - Your sleep problem is new or getting worse
  - Your sleep problem keeps you from doing your everyday activities
- Keep track of the following:
  - When your sleep problem started
  - What makes your sleep problem better/worse

How to manage your sleep problem:

- Type of treatment is based on what caused your sleep problem:
  - Treating emotional factors (anxiety, depression)
  - Treating other symptoms (i.e. pain)
  - Treating other illnesses that make sleep problems worse
  - Medicines can help
- Supportive care professionals that can help:
  - Physical therapist
  - Psychologist/psychiatrist
  - Palliative care team

Self-care tips:

- Follow directions when taking any medicines for your sleep problem. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Stay active (i.e. walking):
  - Work at your own pace
  - Only do what you can
- Sleep hygiene methods:
  - No coffee, tea, chocolate, soft drinks before bed
  - No exercising 2-4 hours before bed
  - Sleep in dark, cool, quiet, and relaxing rooms
  - Use bedtime rituals (i.e. warm milk before bed, warm baths, soothing music)
  - Bed only for sleep and intimacy
Domain 1- Physical Well Being: Patients

- Go to bed at the same time each night
- Sleep restriction methods:
  - Add one extra hour of sleep if feeling sick or cannot get up
  - Limit naps to less than one hour and no more than two every day
- Ask family/friends for help if you have trouble doing your everyday activities
Domain 1- Physical Well Being: Patients

NAUSEA AND VOMITING

Key things to know:

- Types:
  - Anticipatory
    - Happens before treatment
    - Response to triggers in the environment (such as objects, odors, tastes)
  - Acute
    - Happens minutes to hours after treatment
    - Stops within 24 hours
  - Delayed
    - Happens around 24-72 hours after treatment
    - Can last 6-7 days
- Prevention is important!

How to assess and talk about nausea and vomiting:

- Call your doctor/nurse if:
  - Your nausea/vomiting is new or getting worse
  - Your nausea/vomiting keeps you from doing your everyday activities
- Keep track of the following:
  - When your nausea/vomiting started
  - What makes your nausea/vomiting better/worse
  - Whether your nausea/vomiting is related to eating

How to treat your nausea and vomiting:

- Medicines are very effective if taken properly. Most can be taken by the mouth or given through a vein during your treatment
- If you have delayed nausea, your doctor will give you medicines after chemotherapy to prevent nausea
- Supportive care professionals that can help:
  - Dietitian
  - Palliative care team

Self-care tips:

- Follow directions when taking any medicines for your nausea and vomiting. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Nutrition tips:
  - Try eating when you are best able to eat
  - Eat foods that are easy on your stomach and/or bland if strong odors and tastes cause nausea (See page 38 )
Domain 1- Physical Well Being: Patients

- Drinking enough fluids
- Eat food cold or at room temperature
- Eat small, frequent meals
- Ask family/friends for help if you have trouble doing your everyday activities
Domain 1- Physical Well Being: Patients

APPETITE PROBLEMS/WEIGHT LOSS

Key things to know:
- Causes:
  - Problems swallowing
  - Depression
  - Mouth problems from chemotherapy
  - Changes in taste/smell
  - Feeling full early
  - Other symptoms (i.e. nausea/vomiting, constipation)
- It is important to keep your weight stable during chemotherapy
- Avoiding sugar and red meat for lung cancer is a misconception

How to assess and talk about appetite problems/weight loss:
- Make sure you are checking your weight regularly to monitor weight loss
- Call your doctor/nurse if:
  - Your appetite problem/weight loss is new or getting worse
  - Your appetite problem/weight loss keeps you from doing your everyday activities
  - You are having problems swallowing
- Keep track of the following:
  - When your appetite problem/weight loss started
  - What makes your appetite problem/weight loss better/worse

How to manage your appetite problem/weight loss:
- Medicines can help. Most can be taken by the mouth.
- Treating other symptoms (i.e. nausea/vomiting, mouth problems)
- Supportive care professionals that can help:
  - Dietitian
  - Psychologist/psychiatrist
  - Palliative care team

Self-care tips:
- Follow directions when taking any medicines for your appetite problem. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Ask for a dietary consult if you have questions
- Nutrition tips:
  - Stock up on foods that you can eat even when you feel sick
Domain 1- Physical Well Being: Patients

- Stock up on foods that need little or no cooking (i.e. frozen dinners, ready-to-eat cooked foods)
- Cook foods ahead of time and freeze
- Eat small frequent meals whenever you feel hungry
- Eat foods high in calories and protein (See page 34)
- Increase calories and nutrition by adding gravy, sauce, butter, cheese, peanut butter, or cream to your food – if you can tolerate them
- If you don’t feel like eating solid foods, drink lots of fluids, such as juices, soups, liquid meal replacements, and/or milk. (See page 36)
- Drink liquids between meals, not with meals because you may feel full faster
- Try eating when you are best able to eat
- Use plastic forks and spoons (helps if you have metal taste in your mouth)
- Change your routine. This may mean eating in a different place, eating with other people instead of eating alone, or trying new foods and recipes.
  ❖ Small amount of physical activity before meals to help increase appetite (i.e. walking)
  ❖ Ask family/friends for help if you have trouble cooking/preparing meals
  ❖ If you are having problems swallowing, ask for a referral to see a speech pathologist
Domain 1- Physical Well Being: Patients

SKIN, NAIL, HAIR CHANGES

Key things to know:
❖ Causes:
  • Some cancer treatments (chemotherapy, radiation, targeted therapies)
  • May be painful and annoying, but most are minor and will get better
  • Major changes (i.e. infections) must be treated
❖ Skin and nail changes:
  • Itching, dryness, redness, rashes, acne-like pimples, and peeling (face, upper body)
  • Nails may become dark, turn yellow, or become brittle and cracked
  • Blisters in skin around nails
  • Eyelashes grow abnormally long
  • Skin sensitivity to sun
  • Radiation effects:
    ▪ Chemotherapy may cause skin in area where you had radiation therapy to turn red
    ▪ Skin may blister, peel, or be very painful
❖ Hair loss:
  • Often starts 2 to 3 weeks after chemotherapy begins
  • Hair may fall a little at a time or in clumps
  • Takes about 1 week for all hair to fall out
    • Hair typically grows back 2 to 3 months after chemotherapy is over
    • Hair may be very fine when it starts growing back
    • New hair may not look or feel the same as it did before (hair may be thin instead of thick, darker/lighter in color)

How to assess and talk about skin/nail changes:
❖ Call your doctor/nurse if:
  • Your skin/nail changes are new or getting worse
❖ Keep track of the following:
  • When your skin/nail changes started
  • What makes your skin/nail changes better/worse
  • If your skin/nail changes are painful

How to manage skin/nail changes:
❖ Medicines can help. Most can be taken by the mouth. Antibiotics may be used to treat skin infections
❖ Supportive care professionals that can help:
  • Positive image center consultants
Domain 1- Physical Well Being: Patients

Self-care tips:
- Follow directions when taking any medicines for your skin/nail/hair changes. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Skin changes:
  - Take quick showers/sponge baths
  - Pat (do not rub) dry after bathing
  - Wash with mild, moisturizing soap
  - Use cream/lotion while skin is still damp after washing
  - Do not use topical acne medication to treat your rash
  - No perfume, cologne, or aftershave lotion that has alcohol
  - Try oatmeal bath powder when body itches
  - Keep skin clean and dry
  - Wear gloves when washing dishes to protect hands
  - Protect skin area that received radiation from the sun
  - Wear clothes that are made of cotton or soft fabrics
  - Talk about your feelings. Many people feel angry, depressed, or embarrassed about hair loss. If you are very worried or upset, you might want to talk about it with your doctor/nurse.
- Hair loss:
  - Be gentle when washing hair (use mild shampoo)
  - Dry your hair by patting (not rubbing) with a soft towel
  - Avoid items that can hurt scalp (straightening/curling irons, curlers, or perm products)
  - Protect scalp by wearing a hat, turban, or scarf
  - Buy a wig while you still have hair
    - Can match wig to color and style of your hair
    - Take wig to hairdresser to style it to look like your own hair
    - Choose wig that feels comfortable and does not hurt your scalp
  - Cut hair short or shave head (use an electric shaver)
  - Talk about your feelings. Many people feel angry, depressed, or embarrassed about hair loss. If you are very worried or upset, you might want to talk about it with your doctor/nurse.
  - Look Good Feel Better
    American Cancer Society
    (800) 227-2345
    http://lookgoodfeelbetter.org/
Domain 1- Physical Well Being: Patients

DIARRHEA

Key things to know:
- Diarrhea is not uncommon in lung cancer. Causes include:
  - Infections, surgery, anxiety, side effects of chemotherapy, radiation therapy to the abdomen, or medicines.
  - Diarrhea caused by chemotherapy or radiation therapy may last for up to 3 weeks after treatment ends.

How to assess and talk about diarrhea:
- Call your doctor/nurse if:
  - You have 6 or more loose bowel movements per day for > 2 days
  - You have blood in/around the anal area or in your stool
  - You have a fever
  - You are suddenly puffy or bloated in the abdomen
  - You have constipation for several days accompanied by a small amount of diarrhea or oozing fecal material
- Keep track of the following:
  - When your diarrhea started
  - An increase in number of stools per day
  - What makes your diarrhea better/worse

How to manage your diarrhea:
- Type of treatment is based on what caused your constipation:
  - Chemotherapy, Targeted therapy, Radiation therapy
    - May require Imodium, Pepto-Bismol, Kaopectate, or if indicated, something stronger requiring a prescription from your doctor. Check with your doctor before using any medications.
  - Supportive care professionals that can help:
    - Palliative care team
    - Pharmacist

Self-care tips:
- Follow directions when taking any medicines for your diarrhea. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Try a clear liquid diet (avoid acidic drinks) as soon as the diarrhea starts.
- Eat frequent small meals
- Try small amounts of low-fiber foods (rice, bananas, applesauce, mashed potatoes)
- Eat foods high in potassium (bananas, potatoes, apricots) which is an important mineral often lost through diarrhea.
- Avoid foods that stimulate/irritate the digestive tract (whole grain breads/cereals or bran, fried/greasy food, nuts, raw fruits/vegetables, spicy foods, caffeine, milk/mild products, very hot/very cold foods),

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City of Hope
May 9, 2016
Physical Well Being: Patients
Domain 1- Physical Well Being: Patients

Information on How to Quit Smoking

What to do if you would like to quit smoking:

- Talk to your doctor/nurse if you are interested in quitting
- Resources for quitting:
  - 1-800-No-Butts
    http://www.tobaccofreeca.com/where_to_get_help_resources.html
    Also at http://www.nobutts.org (available in 6 different languages.)
  - American Cancer Society: Guide to Quitting Smoking.
    http://www.cancer.org/Healthy/StayAwayfromTobacco/GuidetoQuittingSmoking/index
  - National Cancer Institute: Smoking http://www.cancer.gov/cancertopics/smoking
  - http://smokefree.gov/
  - http://women.smokefree.gov/
  - Kaiser Permanente Wellness Coaching- Quitting Smoking
    (866) 862-4295
    https://healthy.kaiserpermanente.org
## Domain 1 - Physical Well Being: Patients
### Action Plan

### Symptom #1:

<table>
<thead>
<tr>
<th>Achievable Goal:</th>
<th></th>
</tr>
</thead>
</table>

#### Actions Taken:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>□ Yes</td>
</tr>
</tbody>
</table>

### Symptom #2:

<table>
<thead>
<tr>
<th>Achievable Goal:</th>
<th></th>
</tr>
</thead>
</table>

#### Actions Taken:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>□ Yes</td>
</tr>
</tbody>
</table>

### Symptom #3:

<table>
<thead>
<tr>
<th>Achievable Goal:</th>
<th></th>
</tr>
</thead>
</table>

#### Actions Taken:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>□ Yes</td>
</tr>
</tbody>
</table>
# Domain 1- Physical Well Being: Patients

## Foods and Drinks That Are High in Calories or Protein

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Soups</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cream soups</td>
</tr>
<tr>
<td></td>
<td>Soups with lentils, dried peas, or beans (such as pinto, black, red,</td>
</tr>
<tr>
<td></td>
<td>or kidney)</td>
</tr>
<tr>
<td><strong>Drinks</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Instant breakfast drinks</td>
</tr>
<tr>
<td></td>
<td>Milkshakes</td>
</tr>
<tr>
<td></td>
<td>Smoothies</td>
</tr>
<tr>
<td></td>
<td>Whole milk</td>
</tr>
<tr>
<td><strong>Main meals and other foods</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beef</td>
</tr>
<tr>
<td></td>
<td>Butter, margarine, or oil added to your food</td>
</tr>
<tr>
<td></td>
<td>Cheese</td>
</tr>
<tr>
<td></td>
<td>Chicken</td>
</tr>
<tr>
<td></td>
<td>Cooked dried peas and beans (such as pinto, black, red, or kidney)</td>
</tr>
<tr>
<td></td>
<td>Cottage cheese</td>
</tr>
<tr>
<td></td>
<td>Cream cheese</td>
</tr>
<tr>
<td></td>
<td>Croissants</td>
</tr>
<tr>
<td></td>
<td>Deviled ham</td>
</tr>
<tr>
<td></td>
<td>Eggs</td>
</tr>
<tr>
<td></td>
<td>Fish</td>
</tr>
<tr>
<td></td>
<td>Nuts, seeds, and wheat germ</td>
</tr>
<tr>
<td></td>
<td>Peanut butter</td>
</tr>
<tr>
<td></td>
<td>Sour cream</td>
</tr>
<tr>
<td><strong>Sweets</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Custards (soft or baked)</td>
</tr>
<tr>
<td></td>
<td>Frozen yogurt</td>
</tr>
<tr>
<td></td>
<td>Ice cream</td>
</tr>
<tr>
<td></td>
<td>Muffins</td>
</tr>
<tr>
<td></td>
<td>Pudding</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
<tr>
<td><strong>Replacements and</strong></td>
<td>Liquid meal replacements</td>
</tr>
<tr>
<td><strong>supplements</strong></td>
<td>Powdered milk added to foods such as pudding, milkshakes, and</td>
</tr>
<tr>
<td></td>
<td>scrambled eggs</td>
</tr>
</tbody>
</table>
### Domain 1- Physical Well Being: Patients

#### Foods That Are Easy on a Sore Mouth

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main meals and other foods</td>
<td>Baby food</td>
</tr>
<tr>
<td></td>
<td>Cooked refined cereals</td>
</tr>
<tr>
<td></td>
<td>Cottage cheese</td>
</tr>
<tr>
<td></td>
<td>Eggs (scrambled)</td>
</tr>
<tr>
<td></td>
<td>Macaroni and cheese</td>
</tr>
<tr>
<td></td>
<td>Mashed potatoes</td>
</tr>
<tr>
<td></td>
<td>Pureed cooked foods</td>
</tr>
<tr>
<td></td>
<td>Soups</td>
</tr>
<tr>
<td></td>
<td>All foods softened with gravies or sauces</td>
</tr>
<tr>
<td>Sweets</td>
<td>Custards</td>
</tr>
<tr>
<td></td>
<td>Fruit (pureed or baby food)</td>
</tr>
<tr>
<td></td>
<td>Gelatin</td>
</tr>
<tr>
<td></td>
<td>Ice cream</td>
</tr>
<tr>
<td></td>
<td>Milkshakes</td>
</tr>
<tr>
<td></td>
<td>Puddings</td>
</tr>
<tr>
<td></td>
<td>Smoothies</td>
</tr>
<tr>
<td></td>
<td>Soft fruits (bananas and applesauce)</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
</tbody>
</table>
## Domain 1- Physical Well Being: Patients

### Liquid Foods

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Soups</td>
<td>Cheese soup</td>
</tr>
<tr>
<td></td>
<td>Soup that has been strained or put through a blender</td>
</tr>
<tr>
<td></td>
<td>Soup with pureed potatoes</td>
</tr>
<tr>
<td></td>
<td>Tomato soup</td>
</tr>
<tr>
<td>Drinks</td>
<td>Eggnog (pasteurized and alcohol free)</td>
</tr>
<tr>
<td></td>
<td>Fruit juices</td>
</tr>
<tr>
<td></td>
<td>Milk (all types)</td>
</tr>
<tr>
<td></td>
<td>Milkshakes</td>
</tr>
<tr>
<td></td>
<td>Smoothies</td>
</tr>
<tr>
<td>Fats</td>
<td>Butter</td>
</tr>
<tr>
<td></td>
<td>Cream</td>
</tr>
<tr>
<td></td>
<td>Margarine</td>
</tr>
<tr>
<td></td>
<td>Oil</td>
</tr>
<tr>
<td></td>
<td>Sour cream</td>
</tr>
<tr>
<td>Sweets</td>
<td>Custard (soft or baked)</td>
</tr>
<tr>
<td></td>
<td>Frozen yogurt</td>
</tr>
<tr>
<td></td>
<td>Ice cream with no chunks (such as nuts or cookie pieces)</td>
</tr>
<tr>
<td></td>
<td>Ice milk</td>
</tr>
<tr>
<td></td>
<td>Pudding</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
<tr>
<td>Replacements and supplements</td>
<td>Instant breakfast drinks</td>
</tr>
<tr>
<td></td>
<td>Liquid meal replacements</td>
</tr>
</tbody>
</table>
Domain 1- Physical Well Being: Patients

These items may also be helpful if you have nausea or diarrhea, but they are not high in nutrients

Bouillon
Broth
Carbonated beverages
Coffee
Fruit drinks
Fruit punch
Fruit purees that are watered down
Gelatin
Honey
Jelly
Sports drinks
Syrup
Tea
Water
## Domain 1- Physical Well Being: Patients

### Foods and Drinks That Are Easy on the Stomach

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Soups</td>
<td>Clear broth, such as chicken, vegetable, or beef</td>
</tr>
<tr>
<td>Drinks</td>
<td>Clear carbonated beverages that have lost their fizz</td>
</tr>
<tr>
<td></td>
<td>Cranberry or grape juice</td>
</tr>
<tr>
<td></td>
<td>Fruit-flavored drinks</td>
</tr>
<tr>
<td></td>
<td>Fruit punch</td>
</tr>
<tr>
<td></td>
<td>Sports drinks</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
</tr>
<tr>
<td></td>
<td>Water</td>
</tr>
<tr>
<td>Main meals and other foods</td>
<td>Cheese</td>
</tr>
<tr>
<td></td>
<td>Chicken (broiled or baked without its skin)</td>
</tr>
<tr>
<td></td>
<td>Cream of rice</td>
</tr>
<tr>
<td></td>
<td>Eggs</td>
</tr>
<tr>
<td></td>
<td>Fish (poached or broiled)</td>
</tr>
<tr>
<td></td>
<td>Instant oatmeal</td>
</tr>
<tr>
<td></td>
<td>Noodles</td>
</tr>
<tr>
<td></td>
<td>Peanut butter (creamy)</td>
</tr>
<tr>
<td></td>
<td>Potatoes (boiled without skins)</td>
</tr>
<tr>
<td></td>
<td>Pretzels</td>
</tr>
<tr>
<td></td>
<td>Refined cold cereals (e.g. Rice Krispies)</td>
</tr>
<tr>
<td></td>
<td>Saltine crackers</td>
</tr>
<tr>
<td></td>
<td>White rice</td>
</tr>
<tr>
<td></td>
<td>White toast</td>
</tr>
<tr>
<td>Sweets</td>
<td>Angel food cake</td>
</tr>
<tr>
<td></td>
<td>Bananas</td>
</tr>
<tr>
<td></td>
<td>Canned fruit, such as applesauce, peaches, and pears</td>
</tr>
<tr>
<td></td>
<td>Custard</td>
</tr>
<tr>
<td></td>
<td>Gelatin</td>
</tr>
<tr>
<td></td>
<td>Ice cream</td>
</tr>
<tr>
<td></td>
<td>Ice milk</td>
</tr>
<tr>
<td></td>
<td>Popsicles</td>
</tr>
<tr>
<td></td>
<td>Sherbet or sorbet</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
</tbody>
</table>
Yakima Fruit Paste Recipe
Dose: 1-2 tablespoons per day

1 pound prunes
1 pound raisins
1 pound figs-pitted
4 oz. senna tea
1 cup brown sugar
1 cup lemon juice

1. Prepare tea-use about 2 ½ cups boiled water added to tea and steep 5 minutes
2. Strain tea to remove tea leaves and add only 1 pint tea to a large pot, then add fruit
3. Boil fruit and tea for 5 minutes
4. Remove from heat and add sugar & lemon juice. Allow to cool.
5. Use hand mixer of food processor to turn fruit mixture into smooth paste
6. Place in plastic container and place in freezer. (Paste will not freeze but will keep forever in freezer).
7. Spoon out what you require each day.

Enjoy eating fruit paste straight off the spoon.
Spread it on toast or add hot water and make a drink.

- If the fruit paste is not working (no bowel movements) then increase the amount of fruit paste each day.
- If the fruit paste induces very loose stools, cut down on the amount of fruit paste intake. Consider taking it every other day in some cases.
- For questions or problems with the fruit paste, contact your home care or hospice nurse.

Caution-Dietary changes, including fruit paste, could potentially lead to alteration of electrolytes. For example, it is possible that a patient with underlying renal insufficiency could develop hyperkalemia when dietary changes are made.
Domain 2- Psychological Well Being: Patients
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IV. Worry and Fear .................................................................................................. D2-5
V. Depression............................................................................................................ D2-9
VI. Anger................................................................................................................... D2-11
VII. Cognitive Changes ............................................................................................ D2-12
VIII. Action Plan........................................................................................................ D2-13
IX. If You’ve Just Been Diagnosed ........................................................................... D1-14
Domain 2- Psychological Well Being: Patients

Domain 2 Introduction

Psychological well-being is focused on how much your cancer and its treatments affect your emotions and feelings. You've probably felt a range of feelings during your cancer experience. You may have had these feelings at other times in your life, too, but they may be more intense now.

You may relate to all of the feelings listed in this session or just a few. You may feel them at different times, with some days being better than others. It may help to know that others with lung cancer have felt the same way that you do.

There is no right or wrong way to feel. And there is no right or wrong way to react to your feelings. Do what is most comfortable and useful for you. There are many, medicines and other treatments, to help with your feelings. In many cases there are many things that can make you feel better that you can do alone (self-care) or with the help of family or friends at home.

In this session, we will give you information about some of the more common feelings faced by many people with lung cancer. For each, we will discuss key things to know about your feelings, how to assess and talk about those feelings to your doctor/nurse, and how to help cope with the feelings. We will help you develop a personal action plan that identifies ways to manage your feelings that best fits your needs. Finally, at the end of the session, we will give you some resources that help with managing emotions and feelings.
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In each of our sessions we will begin with asking you to rate your level of distress. This helps us to know overall how you are coping with lung cancer. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

My overall distress _____
Domain 2- Psychological Well Being: Patients

Below is a list of emotional symptoms that are common for patients who face lung cancer. Please pick three symptoms that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

_____ Worry and Fear (pg. 5)
_____ Depression (pg. 9)
_____ Anger (pg. 11)
_____ Cognitive Changes (pg. 12)

*Resource: If you’ve just been diagnosed (pg. 14)
Domain 2- Psychological Well Being: Patients

WORRY AND FEAR

Key things to know:
- Worry, fear, or anxiety are common and normal feelings when coping with lung cancer and its treatments
  - Facing the unknown can be hard
  - Feel scared of losing control of life
  - Afraid to rely on other people
  - Fear of dying
- Worry (anxiety) is a feeling of uneasiness, tension, or fear that happens when bad news or harm is expected
- May have physical symptoms such as trembling, sweating, fast heart rate, or heart pounding
- Other symptoms and concerns, such as breathing problems or money issues, can make worry and fear worse

How to assess and talk about your worry and fear:
- It is better for your health to talk about feelings, rather than hold them in
- Call your doctor/nurse if:
  - Your worry and fear is new or getting worse
  - Your worry and fear keeps you from doing your everyday activities
- Keep track of the following:
  - When your worry and fear started
  - What makes your worry and fear better/worse
  - How long your worry and fear lasts
  - What are the main reasons for your anxiety

How to manage your worry and fear:
- Type of treatment is based on what caused your worry and fear:
  - Treating other symptoms, such as breathing problems, that make worry and fear worse
  - Medicines are available for anxiety and can help. Talk to your doctor/nurse about them
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social workers
  - Spiritual counselors (chaplains)
  - Pain and palliative medicine

Coping tips:
- Follow directions when taking any medicines for anxiety. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
Domain 2- Psychological Well Being: Patients

- Feel that your medicine doesn’t work
  - Identify what triggers worry/fear
  - Keep a journal of your feelings and experiences
  - Do activities that you enjoy and try to stay physically active
  - Join a support group
  - Use methods that may have helped you in the past, such as relaxation, prayer, and meditation
  - Listening to music
  - Asking family/friends for help
Domain 2- Psychological Well Being: Patients

Relaxation Techniques and Mind/Body Practices

How They Can Help You Cope With Cancer

Cancer and its treatment can be stressful for people with cancer and their caregivers. Relaxation techniques and other mind/body practices can help calm your mind and sharpen your ability to focus. These techniques offer creative ways to reduce stress caused by cancer and to maintain inner peace. For example, some people use these techniques to help them relax as they wait for treatments or test results.

Here are some techniques that can help you cope with the challenges of cancer:

Deep Breathing Exercises:
At the core of life is breath. Laughing and sighing are the body’s natural ways of getting us to breathe deeply. That is why we often feel calmer or rejuvenated after these experiences. Anxiety and stress can make us take short, shallow breaths. Shallow breathing, which does not allow enough oxygen to enter our bodies, can make us even more anxious.

Try this four-step breathing exercise. It can be done anywhere, anytime:

1. Take in a deep breath from your diaphragm (this is the muscle between your lungs and abdomen).
2. Hold the breath for several seconds – however long is comfortable for you – and then exhale slowly.
3. Repeat steps 1 and 2 two more times.
4. Afterwards, relax for a moment and let yourself feel the experience of being calm.

Meditation
Repetitive prayers are a form of meditation. Two other traditional forms of meditation include “one-pointed” and “two-pointed” meditation.

One-pointed meditation focuses on a word or sound called a mantra. Many people create their own mantra from an affirming word, such as “peace,” “love” or “hope.” The goal is to relax the mind, which has a natural tendency to jump from one idea to the next – and from one worry to the next. Do not try to force your mind back to your mantra when you notice it has wandered. Simply guide it back gently, accepting that it will stray again.

Two-pointed meditation is also called “mindful” or “insight” meditation. With this technique, you relax your mind by focusing on your breath. As your mind jumps around, practice “non-judgmental awareness” – simply observe the pattern of your thoughts and gently guide them back to focus on your breath. Non-judgmental awareness allows you to separate yourself from
Domain 2- Psychological Well Being: Patients

emotions and sensations rather than getting pulled into them. One benefit of this type of meditation is that you can practice it while seated quietly or when doing daily activities.

**Guided Imagery**
This stress-reducing technique combines deep breathing and meditation. As you practice deep breathing, imagine a peaceful scene or setting, perhaps from a memory. Once you are relaxed, you can create a “wakeful dream” in which, for example, you envision pain being washed away or your body becoming stronger.

Many people practice guided imagery exercises while listening to recordings of “ambient” sounds. These are usually music or sounds from nature, such as waterfalls or ocean waves. Sometimes just listening to ambient sounds is enough to relax your mind and briefly transport you emotionally to a place in which you feel safer and more secure.
Domain 2- Psychological Well Being: Patients

**DEPRESSION**

**Key things to know:**
- It’s normal to feel sad. It is normal to grieve over the changes that lung cancer brings to your life
- Depression is common in serious illness such as lung cancer
- Signs of depression:
  - Feeling hopeless or helpless, or that life has no meaning
  - Having no interest in things you used to enjoy
  - Feeling short-tempered and grouchy
  - Not being able to get negative thoughts out of your mind
  - Crying for long periods of time or many times a day
  - Thinking about hurting yourself or others
- Depression needs to be assessed and treated

**How to assess and talk about depression:**
- Call your doctor/nurse if:
  - Signs of depression last for more than 2 weeks
  - Your depression is new or getting worse
  - If you are thinking about hurting yourself
  - Your depression keeps you from doing your everyday activities
- Keep track of the following:
  - What part of your illness or treatment seem to make you most depressed
  - When your depression started
  - What makes your depression better/worse
  - How long your depression lasts

**How to manage your depression:**
- Depression can be treated with medicines. Talk to your doctor/nurse about them
- Other treatments which help depression include talking about your feelings or anxiety
- Treat other symptoms, such as pain, that make your depression worse
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)
  - Pain and palliative medicine

**Coping tips:**
- Follow directions when taking any medicines for depression. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
Domain 2- Psychological Well Being: Patients

- Have problems getting your medicine
- Have side effects from your medicine
- Feel that your medicine doesn’t work
  - Avoid drinking too much alcohol
  - Try relaxation, meditation, and/or massage
  - Join a support group
  - Keep a journal of your feelings and experiences
  - Do activities that you enjoy and increase the activities as you can
  - Use methods that may have helped you in the past, such as prayer or sharing your feelings
  - Ask family/friends for help
Domain 2- Psychological Well Being: Patients

ANGER

**Key things to know:**
- Anger can help by moving you to take action, such as to become more involved in your care
- It is normal and healthy to feel angry when facing a serious illness
- Anger is an emotional reaction that may happen when you feel threatened or feel that you have no control
- Anger may come from other feelings such as fear, worry, or helplessness
- Anger doesn’t help if you hold it in too long or take it out on others

**How to assess and talk about anger:**
- Call your doctor/nurse if you feel that your anger is out of control or that you need help from a counselor
- Keep track of the following:
  - When your anger started
  - What makes you angry, such as any key reasons for your anger

**How to manage your anger:**
- Medicines, such as those used to treat worry (anxiety), can help with anger. Talk to your doctor/nurse about them
- Treat other symptoms such as pain that triggers anger
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)

**Coping tips:**
- Follow directions when taking any medicines to help with anger. Call your doctor/nurse if you:
  - Have questions about how to take your medicine
  - Have problems getting your medicine
  - Feel that your medicine doesn’t work
- Focus your frustration from being angry to exercise, participate in physical activity, art, or other activities you enjoy
- Sometimes it helps to just hit the bed with a pillow or shout!
- Try relaxation, meditation, and/or massage
- Join a support group
- Keep a journal of your feelings and experiences
- Do activities that you enjoy and increase the activities as you can
- Use methods that may have helped you in the past when you felt angry, such as prayer or spiritual support
- Ask family/friends for help. Talking about your anger can often be the most helpful thing
Domain 2- Psychological Well Being: Patients

COGNITIVE CHANGES

Key things to know:
- May be described as “mental fog” or trouble thinking clearly
- Include:
  - Trouble remembering (i.e. names, dates, events)
  - Trouble concentrating (“space out”)
  - Short-term memory loss
  - Forgetting things easily
  - Trouble doing more than one thing at a time
  - Trouble finding right words to finish a sentence

How to assess and talk about cognitive changes:
- Call your doctor/nurse if:
  - Your cognitive changes are new or getting worse
  - Your cognitive changes keep you from doing your everyday activities
- Keep track of the following:
  - When your cognitive change started
  - What makes your cognitive change better/worse

How to manage your cognitive changes:
- Treat problems with emotions or feelings (i.e. depression) that may make cognitive changes worse
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Neurologist
  - Social worker

Coping tips:
- Talk with your doctor/nurse about changes in your memory and concentration
- Review your medicines with your doctor/nurse to see if any are making your cognitive changes worse
- Use tools such as post-its and/or a daily planner so you can keep written reminders of activities/responsibilities
- Concentrate on one thing at a time
- Exercise your brain. Take a class, or do word puzzles
- Get enough rest and sleep
- Stay active, such as through daily walking:
  - Work at your own pace
  - Only do what you can
- Set up and follow routines
- Try to keep the same daily schedule
- Ask family/friends for help
## Domain 2- Psychological Well Being: Patients

### Action Plan

#### Symptom #1:

**Achievable Goal:**

**Actions Taken:**

- Medicine
- Dose
- How to take it

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<thead>
<tr>
<th>Did it work?</th>
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<td>Yes</td>
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<tr>
<td>No</td>
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#### Symptom #2:

**Achievable Goal:**

**Actions Taken:**

- Medicine
- Dose
- How to take it

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<thead>
<tr>
<th>Did it work?</th>
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<td>Yes</td>
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<td>No</td>
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#### Symptom #3:

**Achievable Goal:**

**Actions Taken:**

- Medicine
- Dose
- How to take it

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<th>Did it work?</th>
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<tr>
<td>Yes</td>
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<td>No</td>
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Domain 2- Psychological Well Being: Patients

If You've Just Been Diagnosed... (from CancerCare)

"You have cancer." While these are possibly the most devastating words we can hear from a doctor, many of us who receive a cancer diagnosis come to learn that there are options. There are treatments. Most of all, there is hope.

When you receive a cancer diagnosis, we recommend the following course of action:

- **Form a good health care team.** The doctor who diagnosed your cancer will be one of many professionals who will become part of your team. Medical oncologists, nurses, social workers, and psychologists, as well as nurses’ aides, home care professionals, nutritionists and the clergy, can all play significant and unique roles in your healing process. Your family and friends are a crucial part of your health care team.

- **Understand the roles played by each member of your health care team.** Your oncologist is the member of your team that organizes your treatment plan. He or she may work with an oncology nurse who helps you manage treatment side effects, gives more information about the treatment you will be receiving, and schedules your next diagnostic procedure.

- **Understand what your insurance will and will not cover.** Only when faced with a medical crisis do many people learn how their HMO, other health coverage or entitlements work, what services are covered, and what reimbursement procedures to follow. To anticipate any problems, use the toll-free number provided by your health insurance carrier. Find out whom you should call in your doctor’s office or hospital when your insurance company has a question about a procedure or specific charge for medications or tests.

- **Be an advocate.** You must remember that as a cancer patient, you are a consumer of services, and are entitled to the best care possible. Ask questions about the care you are getting and who is providing it. Make lists of questions before speaking with your medical team. Write down their answers and read back what you wrote to check for accuracy. Tape record the sessions so you will not forget any of the information. Seek second opinions so that you feel well-informed and confident about your decisions.

- **Most importantly, take care of yourself.** Though you may have others around you who are supportive, you must make sure that you take the best possible care of yourself. The better you care for yourself, the better able you will be to cope with your diagnosis. Consider joining a support group for people with cancer or a program near to your home or treating hospital. Keeping a journal, expressing feelings and thoughts artistically, getting appropriate exercise, and joining a yoga or tai-Chi class are examples of activities other people diagnosed with cancer have found helpful.
Domain 3- Social Well Being: Patients
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Domain 3- Social Well Being: Patients

**Domain 3 Introduction**

Social well-being refers to how people carry on relationships with family, friends, colleagues at work, and the general community. Lung cancer doesn't affect just one person. It affects couples, families, and friends. Lung cancer changes the way you relate to your family and friends, and the way they relate to you.

Although the effects of lung cancer are different for everyone, there are some common social changes. Lung cancer changes roles in relationships, often in unexpected ways. A person who in the past was the caregiver may have trouble being taken care of. Being a parent with lung cancer presents unique challenges as you may now rely on your children to care for you. Lung cancer also causes changes in responsibilities, such as chores and/or your job. You may also find that some physical and emotional needs changes as you, your family, and your friends cope with lung cancer.

In this session, we will give you information about some of the more common social changes faced by many people with lung cancer. For each, we will discuss key things to know about the changes, how to assess and talk about the changes, and tips that you can use to help cope with these changes. We will help you develop a personal action plan that identifies ways to cope with social changes that fit your needs best. Finally, at the end of the session, we will give you some resources to help with social well-being.
Domain 3- Social Well Being: Patients

In each of our sessions we will begin with asking you to rate your level of distress. This helps us to know overall how you are coping with lung cancer. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

![Thermometer Image]

**My overall distress**

It would be helpful if you would tell us what social or family concerns you would like to learn more about during today’s session. We find that asking you to identify which social concerns are most important makes the teaching more relevant to your personal needs.

Below is a list of social topics that are common for patients who face lung cancer. Please pick three topics that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

- Changes in Relationships (pg. 4)
- Communication (pg. 5)
- Sexual Changes (pg. 6)
- Social Support (pg. 10)
- Financial Burdens (pg. 12)
- Healthcare Planning (pg. 13)
Domain 3- Social Well Being: Patients

CHANGE IN RELATIONSHIPS

Key things to know:
- Isolation from lung cancer or lack of social interactions may lead to feelings of loneliness
- Sometimes changes in your roles and responsibilities may cause tensions in your relationships
- Sometimes relationships become stronger because of illness
- Spouses/partners:
  - Both partners may have feelings of sadness, anxiety, anger
  - Changes in responsibilities can become overwhelming, and may lead to feelings of frustration, resentment, and guilt
  - Lung cancer can change the dreams and hopes that couples share for the future
- Children/parenting:
  - Demands of lung cancer make it difficult to care for young children (younger children may become overly clingy; older children/teenagers may be angry, distant, withdrawn)
  - There is sometimes a role reversal of adult children becoming caregivers for a parent with cancer. This can be difficult for both parents and children

How to assess and talk about relationships:
- Since your lung cancer diagnosis, what kind of changes in your relationships have you noticed?
- It is important for both partners to communicate their needs
- Keep in mind your children’s or grandchildren’s ages and give them truthful and correct information they can understand. Your social worker can help you think about your family’s special needs

Coping tips:
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)
- Accept outside help from family/friends
- Work together with your family to meet short-term goals, such as finishing cancer treatment
- Re-evaluate your priorities. What is really important to you at this time?
- If you have children, try to keep your child's daily schedule as normal as possible
- Spend extra time with your children and with your family or others who provide you with support
- Join a support group
- Use methods that may have helped you in the past, such as prayer and spiritual support
- As much as possible, try to continue doing social activities with your friends and family
Domain 3- Social Well Being: Patients

COMMUNICATION

Key things to know:
- Lack of communication can lead to isolation, frustration, and unmet needs
- Talking about and sharing feelings and needs lets couples, families, and friends work together to cope with cancer
- Talking about feelings and problems with honesty and openness can reduce the stress that cancer places on relationships

How to assess for communication issues:
- Since your lung cancer diagnosis, have you noticed changes in the way you talk with your family/friends?
- It is important for both you and your family member to communicate your needs
- Keep in mind your children’s or grandchildren’s ages and give them truthful and correct information they can understand

Communication tips:
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social worker
  - Spiritual counselor (chaplain)
- Take the lead in talking. Some friends and family members may avoid talking with you because they just don’t know what to say
- If you feel like talking about your cancer, bring the subject up with your friends and family and let them know that it’s okay for them to talk about it
- Reassure family/friends that you don’t expect them to have answers; you just want someone who will listen and understand your feelings.
- It is also okay to tell people when you just don’t want to talk about your cancer—sometimes you might just want to talk about normal things or just laugh with your friends
- Don’t assume that your family/friends know what you need
- You and your family members may need extra reassurance that they are still needed and loved. You may think your family caregivers know how much you love him or her, but he or she may need to hear it more often
- Encourage your children or grandchildren to ask questions and talk about their feelings and fears
- Join a support group
- As much as possible, try to continue doing social activities with your friends and family
Domain 3- Social Well Being: Patients

SEXUAL CHANGES FOR WOMEN

Key things to know:

- Causes related to cancer and its treatments:
  - Fatigue
  - Other symptoms (i.e. pain)
  - Depression
  - Changes in body image
  - Changes in self-confidence
  - Stress in relationships
- Common concerns:
  - Not being able to have sex as you did before
  - Partner won’t find you as attractive as before
- Most common changes for women:
  - Loss of desire
  - Vaginal dryness/tightness/thinning
  - Pain with intercourse (related to vaginal dryness)
  - Menopausal symptoms
    - Vaginal changes (dryness, loss of elasticity)
    - Hot flashes (especially at night)
  - Changes in body image may affect your sexual desire

How to assess and talk about sexual changes:

- Since your lung cancer diagnosis, have you noticed any sexuality changes?
- Ask your doctor/nurse if its okay for you to have sex during treatments
- Talk to your doctor/nurse before beginning treatments about fertility issues that you might have
- Call your doctor/nurse if you:
  - Notice pain during intercourse that is new or getting worse
  - Notice any bleeding during intercourse
  - Have any other sexual concerns
  - Have any questions concerning sexual activity

How to manage sexual changes:

- Water-based lubrication to control vaginal dryness
- Medicines can help with controlling menopausal symptoms (talk to your doctor/nurse)
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social worker
  - Gynecologist
Domain 3- Social Well Being: Patients

Coping tips:

- Sexuality is much more than intercourse. Intimacy and closeness through touch and spending quiet time together is very important.
- It is important for both partners to communicate their needs.
- Wait until you feel ready for sexual activity (do not push yourself).
- Understand that you are not contaminated:
  - You cannot give your partner cancer
  - You cannot pass chemo on to your partner
- Practice safe sex to avoid infections and/or pregnancy.
- Look for new ways to enhance your appearance (i.e. wigs, head scarf, new makeup or clothing).

- Coping with menopausal symptoms:
  - Dressing in layers
  - Stay active
  - Try yoga, meditation, or other ways to lower stress.

- Try other things if your usual sexual activities are uncomfortable.
- Both partners may need extra reassurance that they are still needed and loved. You may think your partner knows how much you love him or her, but he or she may need to hear it more often.
- Join a support group.
Domain 3- Social Well Being: Patients

SEXUAL CHANGES FOR MEN

Key things to know:

- Causes related to cancer and its treatments:
  - Fatigue
  - Other symptoms (i.e. pain)
  - Changes in body image
  - Changes in self-confidence
  - Stress in relationships
- Common concerns:
  - Worry about sex during treatment
  - Not being able to have sex as you did before
- Most common changes for men:
  - Loss of desire
  - Not being able to reach climax
  - Impotence (not being able to get or keep an erection)
- Even if your treatment doesn't show, changes in body image may affect your sexual desire

How to assess and talk about sexual changes:

- Since your lung cancer diagnosis, have you noticed any sexuality changes?
- Ask your doctor/nurse if it's okay for you to have sex during treatments
- Talk to your doctor/nurse before beginning treatments about fertility issues that you might have
- Call your doctor/nurse if you:
  - Notice any bleeding during intercourse
  - Have any other sexual concerns
  - Have any questions concerning sexual activity

How to manage sexual changes:

- Medicines and some devices can help with erection problems (talk to your doctor/nurse)
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Physical therapist
  - Social worker

Coping tips:

- Sexuality is much more than intercourse. Intimacy and closeness through touch and spending quiet time together is very important
- It is important for both partners to communicate their needs
- Wait until you feel ready for sexual activity (do not push yourself)
- Understand that you are not contaminated
  - You cannot give your partner cancer
Domain 3- Social Well Being: Patients

- You cannot pass chemo on to your partner
  ❖ Practice safe sex to avoid infections and/or pregnancy
  ❖ Try other things if your usual sexual activities are uncomfortable
  ❖ Both partners may need extra reassurance that they are still needed and loved. You may think your partner knows how much you love him or her, but he or she may need to hear it more often
Domain 3- Social Well Being: Patients

SOCIAL SUPPORT

Key things to know:
- Even though your needs are greater when you have cancer, it can be hard to ask for help to meet those needs
- No one needs to face cancer alone. When people with cancer seek and receive help from others, they often find it easier to cope
- Asking for support is one way you can take some control of your situation
- People feel good when they help others. But family/friends may feel more at ease when you ask them something specific, like to cook a meal or pick up your children after school
- Finding support with daily activities such as transportation, shopping, or house cleaning can be very helpful
- Social support systems can include:
  - Family members
  - Friends
  - Other people who have cancer
  - Support groups
  - Spiritual/church groups
  - Health care professionals
  - Caregivers
- Social support systems can provide lots of help such as:
  - Keep you company, give you a hug, or hold your hand
  - Listen as you talk about your hopes and fears
  - Help with rides, meals, errands, or household chores
  - Go with you to doctor's visits or treatment sessions
  - Talk about what it’s like to have cancer
  - Help each other feel better, more hopeful, and not so alone
  - Share tips about ways to cope with cancer

How to assess for social support needs:
- You may have already identified social systems that have been helpful to you since your lung cancer diagnosis. What types of social support do you find helpful?
- If you haven’t identified social systems for support, what types of support would you like to have?

How to find social support:
- Here at Kaiser, we provide many social support services for our patients and families. As part of this program, we recommend that you use these services. Your research nurse can discuss the types of services that are best to meet your social support needs
Domain 3- Social Well Being: Patients

Coping tips:

- Build a team of caregivers so that you don’t have to depend on just one person
- Find help where you live:
  - Look in your local newspaper
- Keeping your caregivers informed:
  - Making a list of important phone numbers, and keep copies of the list next to each phone at home (doctor, nurse, family members, neighbors, friends)
  - Make a list of all your medicines
  - Telling your caregivers about important paperwork (copy of insurance policies, social security papers)
- Take care of your caregivers
  - Encourage them to take time off so they can do errands, enjoy hobbies, or simply have a rest
  - Encourage them to also seek support (i.e. support group)
- Maintain close contact with friends, family, and social groups
Domain 3- Social Well Being: Patients

FINANCIAL BURDENS

Key things to know:
- Lung cancer can cause financial burden:
  - Treatment-related expenses (i.e. medical care, medicines, transportation)
  - There are many costs that insurance doesn’t cover
  - Not being able to work while being treated lowers income
- Money matters can be stressful

How to talk about financial burden:
- Since your lung cancer diagnosis, have you had problems with managing your money and finances?

How to find support for financial burden:
- Here at Kaiser, we provide many services for our patients and families. We have social workers and financial services professionals who can help with discussing outside help for everyday living expenses, and hospital financial counselors who can help with your medical expenses. As part of this program, we recommend that you use these services. Your research nurse can discuss the types of services that are best to meet your financial needs.

Coping tips:
- Access financial services professionals to help you manage financial burdens
- Identify who manages money in your family
- Develop a plan to cope with changing financial needs for daily expenses (i.e. medicines, housing, rent/mortgage, transportation, insurance, groceries)
- Organize a financial record-keeping system
- Learn more about your health insurance:
  - What will be covered and what you need to pay
  - Keep accurate and complete records of claims submitted, pending, and paid
  - Keep copies of all paperwork related to your claims (i.e. letters of medical necessity, explanations of benefits (EOBs), bills, receipts, requests for sick leave or family medical leave (FMLA), correspondence with insurance companies)
  - Send in your bills for reimbursement as you get them
  - If you become overwhelmed with bills, get help
- Learn about your company’s rules and policies related to use of “sick time”
- Maintain close contact with friends, family, and social groups
HEALTHCARE PLANNING

Key things to know:
- Everyone has the right to accept or refuse medical care
- What happens if you cannot make your own medical decisions?
  - Someone must decide when to begin or not begin treatment, or when to stop it
  - Sometimes family members and doctors may need to make medical decisions if you cannot
- People may not be sure what is best for you, and they may disagree about what they believe you would have wanted
- That’s when it would be good to know what you would have wanted and whom you would have wanted to make these decisions
- Advance Directives are legal documents that give information about your treatment preferences to your family and health care team (what you want done to you in case you cannot make your own medical decisions)
- Advance directives can help with the following:
  - Make sure that your wishes are respected even when you can’t make decisions yourself
  - Help prevent disagreements between those close to you
  - Take away some of the burden of decision-making which are often experienced by family members, friends, and health care providers
  - Gives you control over decisions on your medical care
- Types of advance directives:
  - Living will
    - Set of instructions documenting your wishes about medical care (such as use of breathing machines or ventilators) intended to keep them alive
    - "Do not resuscitate" orders - instructions not to use CPR or resuscitation if you have trouble breathing or your heartbeat stops
  - Health care proxy
    - A person appointed to make your medical decisions if you are unable to do so
    - Assign someone that you know well and trust
    - Durable power of attorney for health care - legal document that names your health care proxy
- Process of discussing and writing advance directives should be ongoing, and not a single event
- Advance directives can be changed as your situation changes
- Even after advance directives have been signed, you can change your mind at any time
- Advance directives can only be used for decisions about medical care
- Advance directives take effect only when you are unable to make your own decisions

How to talk about advance directives:
- Do you have an advance directive?
- Since your lung cancer diagnosis, have you thought about your medical care preferences if you cannot decide for yourself?
Domain 3- Social Well Being: Patients

How to get help for advance directives:
- Here at Kaiser, we provide many services for our patients and families. As part of this program, we recommend that you use these services. For more information on Advance Directives, please speak with a Social Worker (see following handouts for forms used for advance directives).

Coping tips:
- Talk to your family/friends about your wishes so they clearly understand what you want
- Learn all you can about advance directives before you begin
- Know your rights and the laws about advance directives in your state
- Decide what you want (i.e. living will, durable power of attorney for health care, and/or other advance health care instructions)
- Decide what you want your advance directive to say (be as specific as possible) and who you will choose to be your representative to make decisions on your behalf if you are unable to do so
## Action Plan

### Topic #1:

**Achievable Goal:**

**Actions Taken:**

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<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
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### Topic #2:

**Achievable Goal:**

**Actions Taken:**

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<th>Medicine</th>
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### Topic #3:

**Achievable Goal:**

**Actions Taken:**

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<th>Medicine</th>
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<th>How to take it</th>
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CALIFORNIA ADVANCE HEALTH CARE DIRECTIVE
Including Power of Attorney for Health Care

NOTE: The document meets legal requirements for most Californians, but might not be appropriate in special circumstances. If you might have special needs, consult an attorney.

PART 1: APPOINTING AN AGENT TO MAKE HEALTH CARE DECISIONS

NOTE: You should discuss your wishes in detail with your designated agent(s)

My name is: __________________________ Date of Birth: __________________________

My address is: __________________________

In this document, I appoint an agent. That agent will make health care decisions for me in the future, if and when I no longer have the mental capacity to make my own health care decisions.

Optional: I want my agent to make my health care decisions now, even though I currently have the mental capacity to make my own health care decisions. [ ] (Do not initial here if you want to continue making your own health care decisions for as long as you are able.)

The following persons cannot be selected as your agent or alternate agent:
- Your primary physician
- An employee of the health care institution or residential care facility where you receive care (unless you are related to that person or you are co-workers).

PRIMARY AGENT:
Agent’s Name: __________________________
Address: __________________________

(Phone numbers – indicate home, work, pager, and cellular phone)

1st ALTERNATE AGENT (If Agent is not willing, able, or reasonably available to serve.)
Name of first alternate agent: __________________________
Address: __________________________

(Phone numbers – indicate home, work, pager, and cellular phone)

2nd ALTERNATE AGENT (If Agent and 1st Alternate are unavailable or unwilling to serve.)
Name of second alternate agent: __________________________
Address: __________________________

(Phone numbers – indicate home, work, pager, and cellular phone)
WHAT MY AGENT MAY DO
My agent will be allowed to make health care decisions for me just as I can presently make my own. For example, I give my agent my trust to make decisions (1) to accept or refuse treatment for me, including accepting or discontinuing food and fluid that is given through a tube into my stomach or into a vein; (2) to choose for me a particular physician or health care facility; and (3) to receive or review my medical information and records, or to permit release of my records for others’ review. ______(initial here)

WHAT MY AGENT MUST DO
My agent shall make health care decisions for me by considering what I have written here, and by considering my other wishes. My agent will try to find out as much as he/she can about my wishes. If my agent does not know my wishes, he/she shall consider my personal values as much as possible and make decisions that he/she thinks are in my best interest. I ask that when my agent is trying to consider my values and prior wishes, that he/she talk to other loved ones who know me and care about me. ______(initial here)

The following individual(s) are to be EXCLUDED from any part of health care decision-making for me:
☐ No Exclusions ______(initial here)

AFTER MY DEATH
My agent will be able to authorize an autopsy, donate all or part of my body, and/or determine the disposition of my remains. If I have written a will or made funeral arrangements, my agent should follow those instructions on what happens to my body after my death or other arrangements I have made. If I want to make exceptions to this authority, I write them here or in an attachment to this form:
☐ No Exceptions ______(initial here)

(Sign and date the attached pages when this document is witnessed.)

PART 2: HEALTH CARE INSTRUCTIONS (Cross out the sections that do not apply)
I have made additional written instructions to my agent and attached them. ______(initial here)

(Sign and date the attached pages when this document is witnessed.)

TRUST IN AGENT: The instructions I give to my agent are guidelines to assist him/her in making the best medical decisions for me. The subject of unacceptable treatments is a complex one. Whether I would or would not want a particular medical intervention might depend on context. At some point there might be a conflict between treatment instructions I have given and what my agent thinks best in circumstances that I could not have predicted. I trust that my agent will honor my goals and values. ______(initial here)

PERSONAL CARE DECISIONS: By my initials here I direct that my agent(s) named above authorize personal care on my behalf including, but not limited to, choice of residence, clothing, receipt of my mail, care for my personal belongings, care for my pet(s) if any, and all other decisions of a personal nature not included in the description of health care. ______(initial here)

DNR ORDER: I have completed a Prehospital Do Not Resuscitate Form. ______(initial here)
REVOCATION OF PREVIOUS DOCUMENTS: I revoke any previously-executed Power of Attorney for Health Care, Individual Health Care Instruction, or Natural Death Act Declaration. I have the right to revoke this directive at a future date by creating a new one.

PART 3: SIGNATURE OF PERSON WHO IS MAKING THIS DIRECTIVE
Sign the document in the presence of the witnesses or the Notary.

Date: __________________ Signature: __________________

If the person making this directive is unable to write, have the person make a mark have a witness write the name of the person making this directive and sign next page.

PART 4: THIS DOCUMENT MUST EITHER BE NOTARIZED OR SIGNED BY TWO WITNESSES ON THE NEXT PAGE.

WITNESSES: Certain individuals cannot serve as witnesses. Those rules are set forth in the following witness statements:

I DECLARE UNDER PENALTY OF PERJURY UNDER THE LAWS OF CALIFORNIA
(1) That the individual who signed or acknowledged this Advance Health Care Directive is personally known to me, or that the individual’s identity was proven to me by convincing evidence,
(2) That the individual signed or acknowledged this Advance Directive in my presence,
(3) That the individual appears to be of sound mind and under no duress, fraud, or undue influence,
(4) That I am not a person appointed as agent by this Advance Directive, and
(5) That I am not the individual’s health care provider, an employee of the individual’s health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness: __________________
Name (printed) __________________ Signature __________________
Date: __________________ Address: __________________

Second Witness: __________________
Name (printed) __________________ Signature __________________
Date: __________________ Address: __________________

ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:
I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the individual’s estate upon his or her death under a will now existing or by operations of law.

Date: __________________ Signature: __________________
Only if the person making this directive is unable to write, witnesses complete this section: ____________________________, being unable to write, made his/her mark in our presence and requested the first of the undersigned to write his/her name, which he/she did, and we now subscribe our names as witnesses thereto.

_________________________  __________________________
Signature of Witness #1      Signature of Witness #2

If the principal (the person appointing the agent) currently resides in a nursing facility, this document also must be witnessed by a representative of California’s Long-Term Care Ombudsman Program. If the two-witness method is chosen, the Ombudsman Program representative may serve as one of the two witnesses, or may serve as a third witness. If the notarization method is chosen, the Ombudsman Program representative serves as a separate witness.

DECLARATION OF OMBUDSMAN PROGRAM REPRESENTATIVE
(Required ONLY if person appointing the agent currently resides in a nursing facility.)
I declare under penalty of perjury under the laws of California that I am an ombudsman designated by the California Department of Aging and that I am serving as a witness as required by Section 4675 of the California Probate Code.

_________________________  __________________________  __________________________
Name (printed)              Signature                      Date

CERTIFICATE OF ACKNOWLEDGEMENT OF NOTARY PUBLIC
(Not required if two-witness method is followed)

State of California, County of ________________________________

On this _____ day of __________________, _____, before me, the undersigned, a Notary Public in and for said State, personally appeared ________________________________, personally known to me or proved to me on the basis of satisfactory evidence to be the person whose name is subscribed to the within instrument, and acknowledged to me that he/she executed it.

WITNESS my hand and official seal.

(seal) __________________________
Signature
Domain 4- Spiritual Well Being: Patients
Domain 4- Spiritual Well Being: Patients

Table of Contents for Domain 4-Spiritual Well Being

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Domain 4- Spiritual Well Being: Patients

Domain 4 Introduction

Spiritual well-being is focused on how living with a life-threatening disease such as lung cancer can impact a person’s spiritual or religious beliefs. Even people who don’t believe in a higher being have spiritual or existential questions when faced with a life-threatening illness such as lung cancer. An existential crisis is a point at which an individual questions the very foundations of his or her life: whether their life has any meaning, purpose or value. Spiritual values are important to many people coping with lung cancer. Many people use spiritual or religious beliefs and practices to help them cope with their lung cancer. We know that supporting spiritual well-being in people with lung cancer helps improve quality of life.

Although the effects of lung cancer are different for everyone, there are some common spiritual changes. Lung cancer may cause you to have doubts about your beliefs or religious values. This may cause much spiritual distress. Cancer may bring up questions that seem unanswerable, such as “why is this happening to me?” Some people may feel that they are being punished by God or may have a loss of faith after being diagnosed with lung cancer. Other people may have mild feelings of spiritual distress when coping with lung cancer, while others report that their illness experience has deepened their faith and heightened their sense of purpose in life.

In this session, we will give you information about some of the more common spiritual concerns faced by many people with lung cancer. For each, we will discuss key things to know about the concerns, how to assess and talk about the concerns, and tips that you can use to help cope with these concerns. We will help you develop a personal action plan that identifies ways to cope with spiritual concerns that fits your needs best. Finally, at the end of the session, we will give you some resources to help with spiritual well-being.

It is important to know to call your spiritual or religious counselor if you have any of the following:

- Feel that you deserve this life-threatening illness
- Feel that prayer or spiritual practices aren’t working
- Feel as though you have no hope
- Believe in God but feel spiritual pain because he doesn’t seem to be there
- Used to believe in God, but now not so sure
- Feel abandoned by God
- Have never believed in God, but now are beginning to wonder
- Worry about how your family/friends will get along without you
- Are scared
Domain 4- Spiritual Well Being: Patients

In each of our sessions we will begin with asking you to rate your level of distress. This helps us to know overall how you are coping with lung cancer. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

![Thermometer Image]

My overall distress _____

Below is a list of spiritual topics that are common for patients who face lung cancer. Please pick three topics that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

_____ Spiritual or Religious (pg. 4)
_____ Purpose and Meaning in Life (pg. 6)
_____ Hope (pg. 7)
_____ Redefining Self and Priorities in Life (pg. 8)
_____ Inner Strength (pg. 9)
_____ Uncertainty (pg.10)
_____ Positive Changes (pg. 11)
Domain 4- Spiritual Well Being: Patients

SPIRITUAL OR RELIGIOUS?

**Key things to know:**
- For many people, spirituality and religion have different meanings.
- Spirituality may mean a person’s sense of purpose and beliefs about the meaning of life, and/or their connection to others and the sacred (What does this mean, now that I have lung cancer?)
- Religion may mean a specific set of beliefs and practices, usually within an organized group.
- Spirituality may be found and expressed through an organized religion or in other ways.
- People may think of themselves as spiritual or religious or both.
- Spiritual and religious well-being can help improve quality of life:
  - Decrease the sense of feeling alone

**How to assess and talk about spirituality:**

- I would like to ask you a few questions about your beliefs using a simple tool called FICA, to help me understand your spirituality.
  - **F = Faith and Belief**
    - Do you consider yourself spiritual or religious? What gives your life meaning?
  - **I = Importance**
    - What importance do your beliefs or faith have in your life?
    - Have your beliefs influenced how you take care of yourself during this life-threatening illness?
    - What role do your beliefs play in regaining your health?
    - Do your beliefs influence your decision about your health care?
  - **C = Community**
    - Are you part of a spiritual or religious community?
    - Is this community of support to you and how?
    - Is there a group of people you really love or who are important to you?
  - **A = Address in Care**
    - How would you like your healthcare team to address spiritual issues in your healthcare?
    - What spiritual support do you need to support you through lung cancer?

**Coping tips:**

- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
    - Can assist you as you sort through and process your cancer journey.
  - Call your spiritual/religious counselor if you:
    - Feel that you deserve this life-threatening illness
    - Feel that prayer or spiritual practices aren’t working
    - Feel as though you have no hope.
Domain 4- Spiritual Well Being: Patients

- Believe in God but feel spiritual pain because He doesn’t seem to be there
- Used to believe in God, but now are not so sure
- Feel abandoned by God
- Have never believed in God, but now are beginning to wonder
- Worry about how your family/friends will get along without you
- Are scared
  ❖ If available, accept help from your church community (spiritual/religious leaders, church members)
  ❖ If you do not belong to a spiritual community, perhaps begin to look for one if you are interested
  ❖ Contact a local spiritual director to assist you as you sort through and process your cancer journey from a spiritual perspective
  ❖ Use spiritual methods, such as prayer or reading spiritual writings, that may have helped you in the past
  ❖ Talk to your doctor/nurse about goals and options for care that honor your spiritual and/or religious views
  ❖ Retreat to spiritual spaces and natural settings in the outdoors that may help with feeling a spiritual sense of peace
  ❖ Keep a journal to express your feelings and thoughts (may help with process of self-discovery and spiritual development)
Domain 4- Spiritual Well Being: Patients

PURPOSE AND MEANING IN LIFE

Key things to know:
- Meaning in life focuses on searching for what changes are happening in your life as a result of your lung cancer diagnosis
- You may find yourself asking these questions:
  - What changes are going to happen because of cancer?
  - Does this mean my life is over?
  - What happens when life ends?

How to talk about purpose/meaning in life:
- What has given you purpose/meaning in your life before you had cancer?
- In what ways has this changed since your lung cancer diagnosis?

Coping tips:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
    - Can assist you as you sort through and process your cancer journey from a spiritual or religious perspective.
  - Talk with a close friend or a family member.
  - Keep a journal to express your feelings and thoughts (may help with process of self-discovery)
    - What are some experiences or moments when life felt particularly meaningful to you?
    - What is it about these experiences or moments that you find meaningful?
    - What helps you to feel alive and happy?
  - Contact a local spiritual director to assist you as you sort through and process your cancer journey from a spiritual perspective
Domain 4- Spiritual Well Being: Patients

HOPE

Key things to know:
- Hope is a way of coping during a life-threatening illness such as lung cancer
- Your hope may change as you go through your cancer treatments

How to assess and talk about hope:
- Looking at what you hope for will be important in helping with spiritual well-being.
- What are you hoping for today?
  - Are you hoping that your symptoms will get better?
  - Are you hoping that your treatment will end soon?
  - Are you hoping that you will be able to visit your family?
  - Are you hoping that you will be able to stay out of the hospital?
  - Are you hoping to attend a family event?
- What has given you hope in the past?

Coping tips:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
    - Can assist you as you sort through and process your cancer journey from a spiritual or religious perspective.
- Connect hope to things that you know will happen, such as hoping for relief of symptoms; make it tangible, something you can grasp.
- Talk with a close friend, family member.

- Keep a journal to express your feelings and thoughts (may help with process of self-discovery and spiritual development)
- Use spiritual methods, such as prayer or reading spiritual writings, which may have helped you in the past.
- If available accept help from your community (spiritual/religious leaders, or church members).
Domain 4- Spiritual Well Being: Patients

REDEFINING SELF AND PRIORITIES IN LIFE

Key things to know:
- Means to identify what is important to you as you experience a life-threatening illness such as lung cancer
- An illness like lung cancer can change your priorities and clarify what is really important to you

How to talk about self and priorities in life:
- What changes have occurred since your cancer diagnosis?
- When you look at your life now, what is important to you?
- What is important in relation to your family/friends?
- Do you have any unfinished business?
- Do you have any relationships that need adjusting?

Coping tips:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
    - Can assist you as you sort through and process your cancer journey from a spiritual or religious perspective.
  - Social Worker
- You may need to redefine your goals and priorities
- Remind yourself that you cannot control or know the future, but you can control your attitude about it.
- Be flexible and patient.
- Don’t compare yourself to how you were in the past.
- Know your physical limitations for today or the moment.
- Accept your limitations and know you can still find ways to live a fulfilling and meaningful life within these limitations.
- Talk to your family/friends about what you can and cannot do.
- Keep a journal to write down what your priorities are and to express your feelings and thoughts (may help with process of self-discovery and spiritual development).
- Stay connected with friends, family members and/or spiritual counselors.
- Use spiritual methods, such as prayer or reading spiritual writings, that may have helped you in the past.
- If available accept help from your community (spiritual/religious leaders, or church members).
Domain 4- Spiritual Well Being: Patients

INNER STRENGTH

Key things to know:

❖ Inner strength is what helps you face the day when you wake up in the morning and what keeps you going throughout the day.
❖ Looking at your inner strength means:
  • Examining your life and embracing what brings you meaning, and comfort.
  • Reflecting on that core of strength that you have used in the past to deal with difficult challenges.
  • Having courage to seek meaning in life despite adversity.
  • Accepting that life changes are inevitable whether we like them or not.
❖ This may be very hard work, but when your inner strength is there, it provides support for you each day

How to talk about inner strengths:

❖ What are the tasks for your life and how have they changed since your lung cancer diagnosis?
  ✓ Are these things that help you now?
  ✓ What is it about these experiences or moments that you find meaningful?
  ✓ What helps you to feel alive and happy?

Coping tips:

❖ Supportive care professionals that can help:
  • Spiritual counselor (chaplain)
    ✓ Can assist you as you sort through and process your cancer journey from a spiritual or religious perspective.
  • Social Worker
❖ Be flexible and patient
❖ Stay connected with friends, family members and/or spiritual counselors
❖ Keep a journal to write down your stories and to express your feelings and thoughts.
❖ Use spiritual methods, such as prayer or reading spiritual writings, that may have helped you in the past
❖ If available accept help from your community (spiritual/religious leaders or church members).
Domain 4- Spiritual Well Being: Patients

UNCERTAINTY

Key things to know:
- Uncertainty happens when you are not sure what is happening next
- When you are uncertain, you may worry a lot, feel frustrated, and/or angry

How to talk about uncertainty:
- What is causing you to have feelings of uncertainty?
- Do you have questions about what your doctor/nurse practitioner are saying?

Coping tips:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
    - Can assist you as you sort through and process your cancer journey from a spiritual or religious perspective.
  - Social Worker
- Ask your doctor/nurse questions when you do not understand what they have said.
- If possible, have a family or friend go to your medical visits with you so they can help you hear what is being discussed.
- Keep a journal to write down your questions and/or take notes during medical visits.
- Stay focused on what is happening right now
Domain 4- Spiritual Well Being: Patients

POSITIVE CHANGES

Key things to know:
- Many people find that a life-threatening illness such as lung cancer has given them a chance to do things not expected
- Since priorities change, doing things that are really important may be the focus
- Examples of positive changes:
  - Resolving family issues
  - Doing what one always wanted to do (i.e. travel, connect with friends)

Living with positive changes:
- Since your lung cancer diagnosis, have you experienced any positive changes? For example,
  - Have you gotten closer to a family member or loved one?
  - Have you planned or taken a long awaited trip?
  - Have you expressed your feelings to those you love?
  - Have you gotten closer to your spiritual community?
  - Have your beliefs been strengthened?

Coping tip:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
    - Can assist you as you sort through and process your cancer journey from a spiritual or religious perspective
  - Social Worker
- Keep a journal to identify and write down what positive changes happened since your diagnosis
- Use positive affirmations:
  - I am learning to accept responsibility for my own happiness
  - I do the best I can to make each day count
  - I have what I need to cope with today’s challenges
  - I have the courage and strength to do what I really need to do
  - I am learning to identify things I cannot change
  - I am learning to live within my limitations
  - I am focusing my energy on what I can do, rather than on what I can no longer do
  - I will forgive whoever I need to today, not for their sake, but for mine.
# Domain 4- Spiritual Well Being: Patients

## Action Plan

### Symptom #1:

**Achievable Goal:**

**Actions Taken:**

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

### Symptom #2:

**Achievable Goal:**

**Actions Taken:**

<table>
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<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

### Symptom #3:

**Achievable Goal:**

**Actions Taken:**

<table>
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<tr>
<th>Medicine</th>
<th>Dose</th>
<th>How to take it</th>
<th>Did it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>
Domain 4- Spiritual Well Being: Patients

**Spiritual Well-Being Resources**

**Spiritual Directors International** (to find a spiritual director)
http://www.sdiworld.org/find_a_spiritual_director

**Retreat Centers**
www.janjohnson.org/retreat_centers.html

**List of local gardens for reflection, meditation**

UC Riverside Botanical Gardens
http://gardens.ucr.edu/information.html

Fullerton Arboretum
http://fullertonarboretum.org/home.php

Moorten Botanical Garden and Cactarium
http://moortenbotanicalgarden.com/

Rancho Santa Ana Botanic Garden
http://www.rsabg.org/

UC Irvine Arboretum
http://arboretum.bio.uci.edu/

**Classes/groups/directed retreats**

Spiritual Growth Center (Catholic/Protestant) www.la-archdiocese.org/Pages/default.aspx

Center for Spiritual Development (Catholic/Protestant)
http://www.thecsd.com/

Holy Spirit Retreat Center (Catholic/Protestant)
http://www.hsrcenter.com/

Stillpoint (interfaith)
http://stillpointca.org/index.html

Labyrinth information
http://labyrinthsociety.org/resources
Domain 4- Spiritual Well Being: Patients

Cancer Resource List

American Cancer Society
www.cancer.org

CancerCare (Lung Program)
www.lungcancer.org
info@cancercare.org

Caring Bridge
www.caringbridge.org

Cancer Legal Resource Center (CLRC)
https://www.disabilityrightslegalcenter.org

Lance Armstrong
www.livestrong.org

Lung Cancer Alliance
www.lungcanceralliance.org

National Lung Cancer Partnership
www.nationallungcancerpartnership.org

Cancer Support Community (formerly known as the Wellness Community)
www.twc-wla.org