

Breast Cancer Education Intervention

Teaching and Support Materials

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Overview of Fatigue

Fatigue is one of the most common and distressing symptoms experienced by breast cancer survivors. Cancer-related fatigue can have a considerable impact on self-care activities and quality of life. The degree of fatigue experienced following breast cancer varies according to the type of treatment received.

Cancer-related fatigue is an unpleasant feeling of weariness, exhaustion, or lack of energy that interferes with a person's daily activities. Cancer-related fatigue is a very common side effect of many cancer treatments and can persist long after treatment has ended.

Everyone feels some tiredness and expects it to go away after a good night's sleep. Fatigue occurs when one feels more tired than usual or tires more quickly after completing the usual activities. It may also occur when not doing anything.

Fatigue can be more than just a feeling of being tired. The person may have some trouble doing everyday activities such as housework, showering, and cooking. A person also may have some difficulty in walking, talking, concentrating, and making decisions. These are all symptoms of fatigue. Sometimes you may not feel like yourself. It may be hard dealing with family members or other people who may be trying to help you.

With fatigue you may feel weak after physical activity, bored, or sleepy during the day, unable to concentrate and pay attention, teary or weepy when you don't usually feel this way, and irritable. Even everyday tasks such as housework, bathing and showering, walking up or down stairs, food shopping, paying bills, or driving may be more tiring or harder to do.

Some women may talk more slowly or give shorter answers to questions. Some may feel that they're sleeping too much or too little. Some individuals say they feel "fuzzy" or "droopy." Many are surprised that fatigue is so intense. Others may feel angry and frustrated because they are unable to do what they used to do. Without balanced nutrition, exercise, and adequate rest, your body can become chronically fatigued.

Remember:

it is normal and expected that persons with breast cancer will feel fatigued even after treatment is over.

Problems Associated with Fatigue

Fatigue can influence one's sense of well-being. Some women may be unable or less able to function at home after treatment is over. Some may experience changes in their relationships with family and friends. Others may feel changes at work such as being too tired to concentrate or feeling depressed.

Lack of Sleep or Insomnia

Changes in sleep or a lack of sleep (called insomnia) can cause fatigue, and fatigue can cause insomnia. This may surprise you because you may think that if you are fatigued you will be able to fall asleep easily. Insomnia can be either a problem of falling asleep or staying asleep.

Symptoms of insomnia include:

- Taking 30 minutes or longer to fall asleep.
- Waking up several times during the night.
- Taking at least 30 minutes or longer to return to sleep after waking up during the night.

Anemia

Anemia, an abnormally low level of red blood cells, is a common complication of cancer and its treatments such as chemotherapy. Both cancer and its treatments can interfere with the supply of red blood cells by inhibiting the production of new red blood cells by the bone marrow. Although it is seldom life threatening, cancer-related anemia can cause fatigue, and may have a severe impact on the quality of life. Signs and symptoms of anemia depend on how fast it develops and how severe it is.

If anemia develops rapidly, people most likely will experience a rapid heart rate, lightheadedness, and shortness of breath. Chronic anemia, (i.e., persistent anemia) causes fatigue, headache, dizziness, faintness, sensitivity to cold, paleness, and loss of skin tone. Loss of energy associated with anemia can limit a person's ability to perform everyday activities, including work, social and leisure activities. If an individual is severely anemic, no amount of exercise will help.

Severe anemia can be treated with a transfusion of red blood cells or the administration of medication to stimulate the body to make more red blood cells.

Nutrition and Fatigue

Maintaining good nutrition is important to offset fatigue. Eating foods that are rich in iron such as green leafy vegetables and liver, and maintaining good caloric intake are helpful in fighting fatigue. Many women are also surprised to find that weight gain is a side effect of chemotherapy and the hormone Tamoxifen. They find it distressing that they are not able to lose weight as quickly as they would like after treatment ends. Eating several small meals a day and regular exercise may be helpful in managing weight and fatigue after treatment ends.

Medications and Fatigue

Certain kinds of medications and medication interactions may contribute to worsening of fatigue. For example, combinations of different classes of medications, such as antidepressants, pain medications, antiemetics (medications for nausea and vomiting), and/or anti-histamines (e.g., Benadryl®) may contribute to excessive drowsiness. If you are taking any of these medications, it is important to talk to your oncology team and see what you can do to minimize your fatigue. If possible, take these medications close to bedtime when you are ready to sleep.

Low Energy

Fatigue can affect your mood and how you think and function. People, who suffer from mental fatigue often report that they are easily overwhelmed and have difficulty being organized and efficient in their daily activities. In addition, people report that activities that once were automatic now require more effort.

Mental fatigue differs from physical fatigue

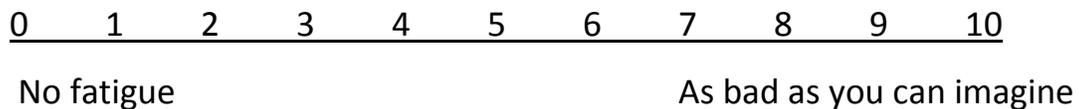
in that it involves a reduced capacity to exert mental effort rather than physical effort. Thus, a person with mental fatigue may not be physically tired but may have difficulty in doing activities that require directed attention such as problem solving, planning, carrying out purposeful activity, and self-monitoring of behavior. The ability to concentrate is fundamental for effective functioning, particularly in demanding life situations. In people with cancer, a loss of concentration can reduce ability to learn important information, and resume valued family roles.

Fatigue may interfere with a person's ability to work. Making adjustments in work schedules, decreasing hours and responsibilities, or even in a few instances, discontinuing work or going on disability may be necessary. However, the large majority of people with cancer continue to work. It is important to communicate with your employer and co-workers about cancer-related fatigue. Talking with your employer and your co-workers about your fatigue may dispel their uncertainty or uneasiness regarding your lack of energy. The more they know and understand about cancer-related fatigue, the better they can support you in the workplace setting.

Assessment and Self-Evaluation

Measuring fatigue is based on the person's self report. The best way to talk about fatigue is to learn a common language and have a common scale to measure your fatigue. Using this same language with your family members and friends can help them too.

- Communicate your true feelings about your fatigue; don't try to hide them.
- Tell your family members your level or degree of fatigue using a scale from 0 = no fatigue, to 10 = as bad as you can imagine.



- Answering these questions may help you to understand your fatigue and communicate with others:
 - When did the fatigue start?
 - When did you first notice that you were fatigued?
 - Has the fatigue become worse?
 - How is fatigue affecting your daily living?
 - How is fatigue affecting the activities that give meaning and enjoyment to your life?

- Are there times when you feel confused or cannot think clearly?
- Do your arms and legs feel heavy?
- Do you sleep more than usual? Do you sleep less than usual?
- Have you changed your bedtime routines?
- Are you able to participate in family activities?
- Have you changed your eating habits?
- Have you changed your exercise and activity habits?
- Are routines getting harder?
- Have you stopped doing anything because of fatigue?
- Does it take more mental effort to perform usual activities than before your treatment?
- Do you have difficulty with multi-tasking and become overwhelmed when too much is going on at once, such as socializing with several people talking at once or working in an environment with multiple distractions?
- Do you have difficulty sustaining your attention and concentrating for any period of time, or have problems meeting deadlines and efficiently performing work activities?
- Are you experiencing generalized slowing of your thinking so that you're missing points in a conversation or cannot take notes during a lecture?
- Are you anemic or taking medications that can cause anemia and worsen emotional fatigue?

In talking with your family, these tips may be useful:

- Tell your family members how your fatigue is affecting your emotions.
- Ask your family members how your fatigue is affecting them.
- Ask your family members for suggestions in managing your fatigue.

Communicating About Fatigue

It is very important to communicate with your family and oncology team about your fatigue. Your oncology team needs to know your concerns about fatigue so that any changes in treatment or medication may be made. It is also important to communicate your concerns to help you have the strength and focus to maintain your health. Cancer-related fatigue is real. It should not be ignored. Be aggressive and expect that your fatigue can be treated. Talk to your oncology team about what can be done to preserve your quality of life.

The following are some questions you can ask yourself about your fatigue:

- When did your fatigue start?
- How long does the fatigue last?
- What does the fatigue feel like?
- What makes it worse?
- What makes it better?
- What prescriptions are you taking and what other treatments are you using to relieve the fatigue?
- Am I doing too much at home? At work?
- Am I eating properly?
- Have I changed my eating patterns?

- Am I exercising?

Lack of understanding within a family about cancer fatigue can lead to communication problems, resentment and feeling guilty. Sometimes women may assume that they just have to live with it. Here are some things to consider in communicating with your family:

- Tell your family members how your fatigue is affecting your emotions.
- Tell your family members how your fatigue is affecting daily activities.
- Communicate your true feelings about your fatigue; don't try to hide it.
- Discuss how fatigue is affecting the activities that give meaning and enjoyment to your life.
- When I don't feel like doing anything, how do I tell my family?
- If I am unable to continue my prior level of activities, how do I tell my family?
- How do I tell my family that fatigue may last a few more weeks or months?
- How do I respond to my children/grandchildren when they want me to participate in their activities?
- How useful do I feel in general?
- Do I feel a sense of isolation because of my fatigue?

Homework

Over the next few weeks, work on the following areas as homework exercises:

- Read through your workbook section on fatigue
- Try the following interventions:

- Call the BCEI Research Team for any questions
- Communicate with your family about the following fatigue issues:

- Communicate with your oncology team about the following issues:



Overview of Pain

Pain is an unpleasant and uncomfortable feeling and an emotional response related to actual or possible tissue damage. Pain is perhaps one of the hardest things for other people to understand. Unlike some symptoms pain is invisible, and no one else can “feel your pain.” Therefore, it is very important to remember: *pain is whatever you say it is, happening whenever you say it does.*

People describe pain in many ways. Sometimes they describe it by where the pain may be coming from. Pain can be aching, gnawing and localized to one area of the body, or it can be a vague and generalized aching. Pain can happen suddenly and feel sharp and intense, it can be intermittent or constant, or it can be tingling, numbing or burning. Pain can be acute, meaning that it comes on suddenly but goes away, or it can be chronic, meaning that it persists for months or years. People who have chronic pain can also have episodes of very intense pain, which is called break through pain.

Breast cancer pain is a common symptom and can occur during surgery, radiation therapy, chemotherapy, and throughout long-term survival. Pain may last for only a short period of time (e.g., after surgery), or it may persist for many years. After mastectomy, pain may be caused by lymphedema or phantom limb pain. When breast cancer metastasizes to the bone it is often associated with

severe pain. The effects of pain from breast cancer are not just physical. It also has an impact on social, psychological, and spiritual aspects of life. Pain causes physical effects such as decreased activities, difficulty sleeping and symptoms such as nausea. Pain causes psychological effects such as anxiety or depression. Pain also may affect spiritual issues by diminishing hope or increasing suffering.

Causes of Pain in Breast Cancer

Pain can be a result of tissue damage from surgery or radiation therapy. It can also result from nerve compression, such as with a tumor. Nerve pain can also result from direct nerve damage from chemotherapy (called neuropathy). Tumors can press on surrounding tissue and also cause pain.

Breast cancer treatment and side effects that can contribute to pain include:

- Surgical procedures such as mastectomy/node dissection.
- Lymphedema or swelling in the affected arm after surgery.
- Breast conserving surgery procedures (also called lumpectomy or segmentectomy).
- Radiation therapy causing shooting pains, breast edema and heaviness.
- Neuropathy from chemotherapy.
- Infection after surgery.

Pain after Mastectomy

Patients with breast cancer who are recovering from surgical procedures such as mastectomy and breast conserving surgery may experience pain. Pain at the incision site usually goes away with time. "Phantom limb pain" refers to feelings

and pain in the chest wall even after the breast has been removed by mastectomy. This feeling can occur immediately after surgery or weeks or months later.

After surgery, many women want to hold their affected mastectomy arm bent across their waist and feel more comfortable when they stoop over. Unfortunately, this results in elbow and shoulder soreness, pain, and muscle contraction (i.e., shortening of the muscle). When you are in a sitting or standing position, you may need to support your arm at first, but you can gradually allow it to hang straight by your side.

Try not to stoop. Remember to keep your body in an upright posture with your shoulder held back when sitting, standing, or walking. While this may be difficult at first, it will help to prevent future problems as you recover from surgery. After a mastectomy, the difference in weight may cause back pain. Exercises may help with this pain.

Pain and Lymphedema

Lymphedema is swelling due to a fluid build-up caused by the blocking of the lymphatic vessels. In breast cancer patients it usually occurs in the arm on the affected side. The obstruction is caused by the removal of lymph nodes during surgery. Lymphedema causes pain and decreased mobility in the arm and shoulder. It may occur immediately or several months or years after breast cancer surgery. Factors that contribute to lymphedema include post-operative wound infection and being overweight.

Signs or symptoms of lymphedema to watch out for include: a full sensation in the limb(s), skin feeling tight, decreased flexibility in the hand, wrist or ankle, difficulty fitting into clothing in one specific area, or ring/wristwatch/bracelet tightness. If you notice persistent swelling, it is very important that you seek immediate medical advice as early diagnosis and treatment can prevent lymphedema from worsening.

Pain After Radiation Therapy

Women receiving radiation therapy after breast conserving surgery often report a 'shooting pain' through the breast. It may be accompanied by swelling, and intermittent aches and pain in the treated breast. Some patients experience continuing shooting pains and aches in the treated breast that last for several weeks to months after radiation therapy has ended.

It is helpful to know that shooting pains can happen. If they occur, you may try using medications as described in the next section. Wear a sport bra with good support and no underwire. Shooting pains will generally resolve spontaneously.

Treating Pain with Medication

There are different types of analgesics (medications for the control of pain). Some of these drugs such as aspirin, acetaminophen and ibuprofen are used for mild to moderate pain. These drugs can be bought over the counter. Stronger analgesics such as morphine and oxycodone are used for moderate to severe pain and need a prescription by a physician. There are many medications that were not developed for pain relief but which are now known to be very helpful for pain.

These are both useful for nerve pain in the hands or feet caused by chemotherapy.

Some people do not want to take pain medications because they make them feel “fuzzy” or “droopy”. Talk with your doctor if you are concerned about the side effects of your pain medication.

Sometimes people are reluctant to take pain medications as directed because of the common misconceptions about pain relievers. They may think, *"If I take this amount of medication now, there won't be a strong enough dose later when I really need it,"* or *"It is better that I should wait until the pain gets really bad before I take my pain medication, that way I won't take it as often and I won't become addicted."*

Neither of these statements is true. Studies show that pain medication is more effective when taken early. If you wait until your pain is severe, you will need more medication to relieve it. When people take medicine regularly, they use less medication.

For these reasons, most physicians order pain medicine to be taken around the clock. Around the clock means taking the medicine at regular intervals during the day and night. By taking pain medicine around the clock, you maintain a more consistent level of pain control. For most patients, pain can be relieved using appropriate analgesics (pain medicine) and co-analgesics (other medications that also add to pain relief).

You may have heard that people taking pain medication can become addicted, develop a physical dependence or a medication tolerance to their pain medicine. These three terms are often confused with each other and actually represent three different medication issues.

Drug Addiction

Drug addiction means a person takes medication in order to get "high," not to gain pain relief. It is important to understand that it is unlikely someone will become addicted to pain medication when they are using it appropriately. If your family has concerns about the medications you are taking and is afraid of addiction, explain that severe pain requires strong medications. Explain how pain can interfere with even the simplest of tasks and that you would not be taking pain medication if you did not need it.

Physical Dependence

Physical dependence can sometimes occur when you take analgesic medicines over a long period of time. *Physical dependence is not addiction.* Physical dependence on a medication means if you stop taking the medication suddenly, you may experience some cold sweats, chills or muscle aches. If you do not need pain medications, your physician and nurse will help you to slowly decrease the amount that you are taking over a period of time to avoid symptoms of physical dependence.

Medication Tolerance

Occasionally, over time, your body gets used to the pain medication and you may require a higher dose or a stronger medication to maintain the same level of comfort. This is called medication tolerance. The length of time necessary for tolerance to develop can vary from person to person. Medication tolerance is normal and is **not** an indication that you are becoming addicted to pain medication. Remember, stronger medications and larger doses of medicine

are available if you need them, so be sure to discuss medication tolerance with your oncology team.

Side Effects with Pain Medication

Side effects such as nausea, constipation, and drowsiness can occur when you take pain medications. If you are having side effects from taking your pain medications, we have Tip Sheets available to help you manage them.

General Use Non-Drug Pain Relief

Another way of relieving pain is through the use of non-drug methods such as the application of heat, cold, massage, relaxation and distraction. For many reasons, women are sometimes hesitant to try these non-drug methods. For instance, some women may have tried one of the methods in the past and found it was not helpful. They may think that if it worked their doctor would have mentioned it, or they may be afraid that it will harm them in some way. Like pain medication, each non-drug method works differently for different people and different types of pain.

It is important to remember the following advice:

- Non-drug methods should be selected for the type of pain you have. For example, heat may be most helpful for muscular pain such as a stiff shoulder or neck pain from positioning your arm related to lymphedema.
- Often a non-drug method may require a "trial and error" period. Choosing the right method for your pain and the correct placement of heat or cold is important in achieving the best relief possible.

- Sometimes a person may be reluctant to try a non-drug method of pain relief because of a mistaken belief that even partial success with the non-drug method will result in pain medicine being decreased or withheld.
- Non-drug methods are to be used in addition to your pain medicines, not to replace them.
- It is important to use whatever method you choose before the pain becomes severe so that while your body is absorbing the pain medicine, you may be able to achieve additional pain relief from the non-drug method.
- Although usually safe, be sure to check with your oncology team prior to beginning any of these non-drug pain relief methods.

More information about non-drug treatments for pain is included in the Tip Sheets.

Assessment and Self Evaluation of Pain

The following are some questions you can ask yourself about your pain. Thinking about these questions will help you to communicate with your family or health care providers about your pain. Ask yourself the following questions:

- When did your pain begin?
- Where are all the areas that hurt?
- How long does the pain last?
- What does the pain feel like (achy, stabbing, cramping, dull)
- What makes your pain worse?

- What makes it better?
- What prescriptions are you taking and what other non-drug remedies are you using to relieve the pain?

Since you are the only one who can feel your pain, it is very important to communicate with your family and oncology team about your pain. Report pain as soon as it begins and whenever it changes to help keep it under control.

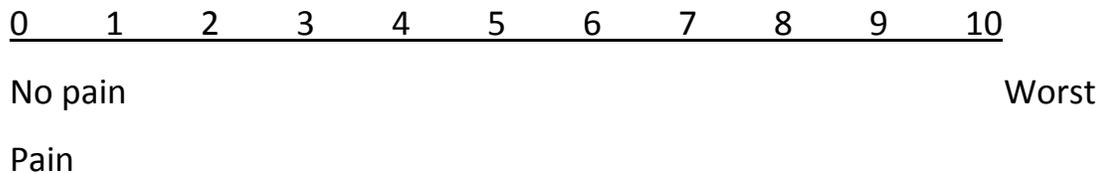
Sometimes women are concerned that reporting their pain will distract the physician away from focusing on the breast cancer. Don't worry about that, it is very important to make pain relief a priority so that you can have the strength to regain your health, continue your treatment and focus on survivorship.

Sometimes women believe that if their pain is worse, they must be getting sicker. This is not necessarily true. Pain is common after breast cancer treatment and often only indicates a short-term problem that will resolve or a chronic problem (i.e. neuropathy after chemotherapy) that is not related to spreading cancer. The most important thing is to remember you are the only one who knows how much pain you are experiencing. You must be assertive and communicate your pain symptoms to your healthcare provider. Expect that your pain can be treated!

Communicating About Pain

The best way to talk about pain is to learn a common language and use a common scale to measure your pain. Using this pain language with your family members and friends as well as your health care providers is the first step toward improved pain relief. Some key principles are:

- Communicate your true feelings about your pain; don't try to hide them.
- Describe where your pain is located.
- Describe the intensity of your pain on a scale from 0 = no pain, to 10 = the worst pain imaginable.



- Tell your family members how your pain is affecting your emotions.
- Ask your family members how your pain is affecting them.
- Ask your family members for suggestions in managing your pain.

Aspects of your pain that are important to communicate to your oncology team are:

- Pain that is not relieved by your current pain medication.
- Pain that is new or different than when you last saw the doctor or nurse.
- Pain that is increasing in severity and intensity.
- Pain that is accompanied by nausea and vomiting.
- Pain from constipation or abdominal distention.
- Severe side effects from pain medication.

Homework

Over the next few weeks, work on the following areas as homework exercises:

- Read through your workbook section on Pain
- Try the following treatments: _____

- Call the BCEI Research Team for any questions
- Communicate with your family about the following issues: _____

- Communicate with your oncology team about the following issues:



Overview of the New You

Breast cancer changes the way women see themselves and how they appear physically to others. These are common and universal concerns that can be faced realistically. Because these concerns can affect your quality of life, this module was designed to help you understand them.

Physical Changes - Menopausal Symptoms

Chemotherapy can induce menopause during or after treatment. During menopause, the ovaries no longer produce sufficient quantities of female hormones (e.g., estrogen and progesterone). The lack of hormones causes menopausal symptoms such as, hot flashes, sleeplessness, vaginal dryness, and infections of the vagina and urinary tract. Chemotherapy-induced menopause tends to cause more severe symptoms than natural menopause. Hot flashes occur frequently at night while women are sleeping but can occur at any time of the day. They can occur more than ten times a day and can last from a few seconds to a few minutes. When hot flashes occur at night, sleeplessness may also occur which can lead to daytime fatigue. Women find hot flashes very bothersome and disruptive and seek the advice of their physician for medication relief. The standard treatment of hot flashes is estrogen replacement therapy, but its use in women with a history of breast cancer is controversial.

The risk of cardiac disease increases with menopause. Women who are obese, have a sedentary lifestyle, and smoke are at an increased risk of developing cardiac disease after menopause. Thus, it is important to maintain good cardiac health through exercise, good nutrition, and smoking cessation.

The risk of osteoporosis also increases with estrogen loss. Calcium is depleted with poor reabsorption. Women with osteoporosis have a higher risk of developing hip and spine fractures. For this reason, it is very important to prevent osteoporosis through good nutrition, exercise, and calcium replacement therapy.

The risk of urinary tract infections and vaginal dryness occurs with estrogen loss. Women experience a decrease in vaginal lubrication, an increase in pain during intercourse, and an increase in urinary discomfort and urinary infections. These distressing outcomes of estrogen loss may be managed through good personal hygiene and other self-care treatments. A special Tip Sheet provides more information.

Other factors related to chemotherapy treatment, not typically associated with natural menopause, include general pain, discomfort, fatigue, changes in energy level, hair loss, and weight gain. All of these can have a significant impact on physical health.

Body Image/Loss

Body image is the term used for the way women view themselves and their body. Breast cancer treatment changes one's perception of body image. For example, the loss of the breast after mastectomy can significantly alter a woman's body image because breasts may symbolize femininity and womanhood. The

mastectomy scar and the permanent markings on the breast used for radiation therapy can be a constant reminder of the disease. Breast cancer treatment may have other effects on how a woman views herself and how she feels about her body. For example, *surgery* causes decreased sensation, numbness on the inside of the arm and accumulation of lymph fluid in the arm (lymphedema). These problems may contribute to pain and physical discomfort. *Radiation therapy* may cause skin changes in the breast or surgical scar site. Some women describe less physical sensations in the breast after radiation therapy. Other women are concerned about temporary 'shooting pains' occurring in the breast after radiation treatment.

Feelings of loss and grief may linger for months or years after treatment ends. The life you knew before breast cancer has been changed in some way for the rest of your life. Finding a way to cope with feelings of loss are important for healing and recovery. It is very important to look at the impact of the losses in one's life. Are they motivating you to go on with your life? Or are they creating a feeling of being overwhelmed, making coping difficult?

Feeling sad or depressed at some point in your illness is common. You have not failed if you experience these feelings, feel distressed or have intrusive thoughts. Everyone has these feelings at times. Success is achieved by managing feelings of loss, and dealing with distressing thoughts and emotions, expressing them, and then seeking extra help or support if needed.

Intimacy

A woman's desire and need for intimacy may change after cancer. There are many ways in which cancer can affect one's intimacy. For example, physical

activity and energy levels may change. Women may not desire or feel desirable immediately after treatment. Other women may worry about stressors such as pain, sadness, financial concerns, and treatment side effects.

It is very difficult to predict how breast cancer and its treatment will personally affect you, but usually there are changes that require you to adapt and develop new ways of seeing yourself. For example, during treatment, your husband or partner may have assumed some of your roles. He may have taken on household chores that were once your responsibility or he may have become a caregiver to you. Grown children may also have taken on some of your previous roles and they may not easily give them up now that your treatment is over. Some women experience conflict in their roles as a result. Now that your treatment is completed you may want to resume your previous roles. Resuming these roles after treatment may have an impact on your family life.

Sexuality

Feeling apprehensive about the need for intimacy and sexuality after breast cancer treatment is normal. A woman might feel undesirable and avoid physical intimacy, fearing that her husband or partner is not interested. On the other hand, some husbands and partners are overwhelmed by the disease and may fear showing sexual interest, assuming that their loved one is not interested. Others may be anxious about seeing the surgical scar for the first time. It is important to reveal these physical changes to your husband or partner in a relaxed and unhurried manner.

Breast cancer can affect your ability to feel good about yourself and can influence the degree of need for physical closeness. Some women may feel the need for more opportunities for hugging, touching, and physical closeness. Other women may feel the need for less physical contact because of pain, tiredness or fatigue. It is helpful to understand that some changes may be temporary and may return to normal in a few weeks. If these changes concern you, you may want to take things slowly by first spending time enjoying your husband or partner's company, holding hands, touching, and resuming social activities together. As time goes on you'll be ready to move forward with greater intimacy.

Most of all, it is important to realize that any and all reactions are normal. Good communication between partners can help improve your adjustment to the New You.

Assessment and Self-Evaluation of the New You

To help you discuss any questions or concerns that you may have about the New You after breast cancer, ask yourself the following assessment and self-evaluation questions.

- ❑ Are you experiencing hot flashes?
- ❑ Do you have symptoms of vaginal dryness?
- ❑ Do you have symptoms of a urinary tract infection?
- ❑ If you have become menopausal, how does this affect your appearance and body image?
- ❑ If arm swelling or lymphedema is present, does it interfere with your appearance and body image?

- ❑ If you have had a mastectomy, how satisfied are you with your overall appearance?
- ❑ If you have had a mastectomy, would you want surgical reconstruction or other cosmetic improvements?
- ❑ How do you feel about the surgical scar?
- ❑ What impact has treatment had on your body image?
- ❑ If you have had radiation therapy, do you have shooting pains in your breast?
- ❑ How comfortable are you with the physical changes in your body? How comfortable are you with hugging and touching?
- ❑ What other ways can you express your need for physical closeness?
- ❑ How sexually desirable do you feel?
- ❑ Do you have pain of any kind during sex? If so, how intense is the pain? Where is the pain located? How long does the pain last?
- ❑ If taking medications, review the list with your doctor or nurse. Tell them how long you have been taking these medications and discuss how other medications (if any) could be affecting your appearance/body image.

Communicating About the New You

Good communication about the changes in physical appearance, body image/loss, intimacy, and sexuality is very important. Having a trusted confidant available to discuss your feelings will help. Problems in any of these areas can be difficult for some women to discuss openly, however failure to discuss them with

health professionals and husbands or partners can cause delays in resolving these problems. Even though you may feel frightened, awkward, and/or uncomfortable with the New You, it is important for you to communicate your feelings.

Communicate openly with your husband or partner and your oncology team.

Breast cancer is a family illness, and therefore it also affects your husband or partner. It is important to keep the lines of communication open and to acknowledge your husband or partner's needs. Sometimes, your husband or partner may share your concerns about the New You. Here are some areas to consider in communicating with your husband or partner:

- Create a safe time and place to talk about your concerns. Find a place where you can have privacy and few interruptions. You and your husband or partner may need to make time for talks about your concerns. Reconnecting is crucial and will open the door to talking about other issues.
- You may be the one to bring up the subject of physical changes, body image/loss, intimacy, or sexuality. Your husband or partner may not know what to say for fear that such a discussion will be too painful for you. Talk about what is important to you - your feelings about the changes in your body. Ask and listen to what is important to your husband or partner.
- Have realistic expectations. Select one or two objectives to discuss rather than a laundry list of your entire concerns. Be specific in your discussion.
- Focus on the positive. Define your goals in a positive light.

- Keep in mind that your husband or partner may worry about pain and how to touch you for fear of hurting you. Make an agreement to let your husband or partner know when and if any activity causes discomfort.
- Although you may view your body in a different way, your husband or partner may or may not be having the same experience. Most husbands or partners of breast cancer survivors see the loss or alteration of a breast as less important than the fact that you survived.
- Be a good listener. At the end of your talk, summarize your husband or partner's and your concerns.
- How you express your sexual feelings with your husband or partner is important. Remember to be patient and give yourself time. Being uncomfortable and anxious are normal feelings. Confidence and comfort should return in time.

Although your oncology team may not bring up the subject, changes in appearance, body image, and sexual functioning are important areas of communication. It is helpful to identify someone on your oncology team such as an oncology nurse or social worker who can discuss these concerns with you. You may also ask them to give you a referral to a community support group.

Consider the following areas for discussion and communication

- Identify a member of your oncology team (oncologist, oncology nurse, or social worker) whom you feel comfortable discussing the concerns about these changes.

- Describe any physical pains that you are experiencing (including pain at the surgical site, shooting pains, and arm swelling). Ask your oncology team to suggest ways to relieve the pain.
- Describe any symptoms of menopause such as hot flashes and vaginal dryness. Ask about ways to manage vaginal dryness.
- Describe any symptoms of urinary tract infection you may have.

Homework

Over the next week, I will work on the following areas as a homework exercise:

- Read through my workbook section on the New You
- Try the following interventions:

- Call the BCEI Research Team for any questions
- Communicate with my partner about the following issues:



Overview of Dealing with Emotions

After treatment has ended, acute physical side effects such as hair loss, nausea, vomiting, discomfort, and fatigue gradually subside. Women face the task of moving on with their lives, making decisions about their future, and enjoying life fully after treatment has ended. The desire to get on with one's life and to live life as fully and meaningfully as possible without being overshadowed by a chronic or life-threatening disease can be a challenge for breast cancer survivors. Dealing with emotions ranging from fear to uncertainty is common after breast cancer but may make women feel overwhelmed. Yet, dealing with both negative and positive emotions is important in survivorship.

Because emotions such as fear, anxiety, and uncertainty can have a negative influence on your quality of life, this module was written to help you better understand and manage them, and encourage you to lead life more fully after breast cancer.

Anxiety

Feelings of anxiety and mood swings are common after breast cancer treatment. Intrusive thoughts and anxiety about what to do next with one's life may be bothersome. These feelings may not always be easy to manage, but there are ways to help yourself. Anxiety can be managed by making changes in your behavior like reestablishing routines, and adding structured activities and exercise

into your day. Changes in the way you relate to your friends and family and in the way you think about life events are also helpful.

Reestablishing old routines or starting new routines is a way to help normalize your life. During your treatment, family and friends may have taken on some of your responsibilities at home. After treatment, some women want to reestablish their former routines. Others may need to take it easy for a while. In either event, it is very important to talk with your loved ones about your desires and needs during this transition period.

Reconnecting with friends and social acquaintances may present a challenge. Often, friends look to you to give them clues as to what to say or how to act. Awkward moments should be expected. Again, having patience is very important while you move through the process of getting back to routines and getting on with your life.

You may have worked regularly while receiving breast cancer treatment or you may have reduced your work responsibilities. Take time to reestablish your work priorities if possible. Try not to rush into taking on the added burdens of work. Also, be careful not to start major work projects right after treatment ends. Keep in mind that you are recovering from breast cancer with its many physical, psychological, and social side effects.

Fear of Recurrence

Fears of recurrence (or breast cancer returning) and fears about the future are also common after treatment. While women with early-stage disease have a very low risk of recurrence, they often believe that their breast cancer will return. If you have these feelings, it is important to remember that you're not alone.

Other women have felt similarly about their breast cancer returning. Women fear that recurrence is associated with disabling pain and death. Thoughts and fears of recurrence may be triggered by the anniversary of one's diagnosis or treatment, awareness of symptoms, or simply by going for a routine check-up. Keep in mind, though, that early stage breast cancer is associated with a low potential for recurrence and there are many treatments available should your breast cancer recur.

Intrusive and unwelcome thoughts about cancer returning or spreading to other parts of the body are often heightened at the time of follow-up visits and anniversary dates (when breast cancer was first diagnosed). Other women describe these thoughts occurring in the evening or at night when it's quiet and they have more time to think about themselves. You may want to consider when these intrusive thoughts occur. If these intrusive thoughts are bothersome, there are many ways to help stop or minimize them. Strategies such as thought-stopping and refocusing your energies through relaxation, meditation, or writing in a journal are often helpful. Consider one of these strategies: keep a journal of your thoughts and feelings. When you are approaching your "anniversary date" or going to a follow-up appointment, be kind to yourself and ask a family member or friend to accompany you for the visit.

Another way of refocusing your energy and thoughts are to stay "in the moment." Enjoy each day and create special moments throughout the day. Enjoyment of family, friends and a pleasing environment helps to refocus your thoughts and gives you a larger perspective of your life. Refocusing your energy and thoughts takes time. Be patient with yourself while you go through this process.

Another fear that women are concerned with is that their spouse or partner will abandon them after breast cancer. We do know that breast cancer alone does not increase the incidence of separation or divorce. Sometimes the crisis of illness will help spouses and partners to work harder in the relationship. Sometimes the stress of illness on an unhappy relationship may be too much. After experiencing breast cancer, some women reprioritize their life and may choose to leave a relationship. If your relationship ends, try not to blame yourself or your illness as the only cause. If you are having trouble in a relationship you may want to consider counseling. Often a professional counselor can help sort through your relationship problems.

Uncertainty About the Future

Women often wonder about the future and are concerned about the uncertainties of a future after breast cancer. Personal issues arise such as who will take care of my children and my husband? Will I be strong enough to go through another round of chemotherapy? Will I be around to take that vacation or finish that project? Feelings of uncertainty about the future are very common and concerns over how to manage these feelings are not unusual.

Women also report that they become more vigilant and over concerned about their health after their breast cancer diagnosis. They attend to every normal ache and pain as if their cancer has returned. Again, these feelings are very common. Talking about them with a trusted confidant helps. Being vigilant about your health is very important, but being overly concerned is stressful and a waste of energy. It is common to have some discomfort and fatigue after breast cancer

treatment, experiencing these symptoms is not necessarily a sign that your cancer is recurring. Some general suggestions to keep track of your health include:

- Keep accurate records of all your follow up blood studies, exams, and other procedures, particularly if you tend to move or change doctors frequently.
- Write down your questions and take them with you to routine check-ups.
- Stay in touch with a member of the oncology team who knows you well.
- Maintain regular contact with your oncology team and go for check-ups at the regularly scheduled times.
- Educate yourself about the different tests and procedures and the reasons why they are used in follow-up.
- Keep a journal of how you are feeling physically as well as emotionally.
- Talk to other breast cancer survivors; this will help you get another perspective on living with cancer.
- Stay informed about breast cancer news and developments.
- Understand the warning signs of recurrence.

Getting Accurate Information about Recurrence

Lack of knowledge about breast cancer recurrence or metastasis (the spread of cancer to other parts of the body) often leads to more fear about the disease. It is helpful to learn more about how breast cancer can behave to help you manage your fear. Getting accurate information about the real risk of recurrence can be reassuring. A special Tip Sheet provides general information about recurrence and what treatments are available. It is important to keep in mind that early-stage breast cancer has a low potential for recurrence.

It is very important to keep in mind that there are many treatments available for recurrent and metastatic breast cancer. Each person's treatment is very individualized and depends on the site and type of cancer involved.

Assessment and Self-Evaluation

Learning about recurrence and metastasis and managing your concerns about recurrence is an important aspect to your quality of life. To help you discuss any questions or concerns that you may have about recurrence after breast cancer treatment, ask yourself the following assessment and self-evaluation questions:

- Do you feel anxious?
- Do you feel tense?
- Do you have difficulty concentrating? Making decisions? Remembering things?
- Do you have difficulty sleeping?
- Do you feel tired all the time?
- Do you have fears about rejection by family?
- Do you have fears about rejection by friends?
- How often do you need to have check-ups after the end of breast cancer treatment?
- Who is responsible for monitoring your follow-up tests and procedures?
- What tests and procedures do you need after treatment ends?
- Will insurance cover the costs of the tests?

- What symptoms should you watch for?
- How often do you think about recurrence? Have these thoughts increased since the end of treatment?
- Do these thoughts interfere with your daily activities?
- Do thoughts of recurrence interfere with sleep?
- Do thoughts of recurrence interfere with decisions that you make?
- What thoughts come to mind about recurrence?
- What are your concerns about your future?
- What are your concerns about your family and friends?
- What are your concerns about your work?
- How uncertain do you feel about the present? Future?

Communicating About Your Emotions

Remember, your concerns are very normal. It may be difficult, however, to discuss these concerns openly. Maintaining good communication with your oncology team on a regular basis is vital. Your oncologist, oncology nurse, and oncology social worker can help you see the difference between any unrealistic fears you may have and valid health concerns that need to be followed up on. Good communication with your oncology team is helpful in creating a realistic appraisal of your potential for recurrence and to get support to help minimize your fears.

Don't forget to take time to talk about your concerns and fears with your family. Often you will find they are facing the same fears as you are. Sometimes family members hide their fears from their loved ones to "protect them".

Unfortunately this behavior can result in neither person getting the support they need. Talking things through can help to minimize fears.

Homework

Over the next few weeks, work on the following areas as homework exercises:

- Read through your workbook section on dealing with emotions
- Try the following interventions:

- Describe the effectiveness of the interventions
- Call the BCEI Research Team for any questions
- Communicate with your partner or spouse about the following issues:

- Communicate with Your oncology team about the following interventions:



Overview of Caring for your Soul and Body

After breast cancer, your life is changed. Because of the life-threatening nature of cancer, many survivors experience a change in their perspective of life. They have a changed outlook. They may search for some meaning in their illness and for answers to the question, “Why me?” These are very common concerns that can occur before, during or after treatment has ended. While the first four modules were very specific and were related to physical and emotional aspects of quality of life, this last module is designed to help you care for both your soul and your body, and to help you deal with the spiritual dimensions as you face life as a cancer survivor.

Caring for your soul and body, often called ‘spirituality’ is a broad concept and includes the need to find a purpose and meaning in life, have a sense of belonging, love and relatedness, maintain hope, and express faith. The purpose of this module is to help you explore some of the inner changes that you may be experiencing or have experienced as a result of having breast cancer and to discuss issues in caring for your soul as well as your body.

Faith: Religious Practice

After experiencing a life-threatening disease, many individuals question the meaning of their illness and the meaning of their life. Many may also question the meaning of their faith. Having had breast cancer may create loss and suffering which includes anger at God or a spiritual higher power. Others see their illness in different ways – as a challenge, an enemy, a punishment, or a weakness. These are common experiences. You might ask yourself, how does having had breast cancer affect you emotionally? Spiritually?

Prior to breast cancer, individuals may have practiced religious activities such as prayer, meditation, and attending a place of worship such as a church or temple. You may have started these religious activities after breast cancer. These individual practices can be a source of comfort and solace in facing the future. Some of your past faith-based or religious practices may be the same or may have changed dramatically. Think about your current religious practices and whether they have changed. Think about different religious activities and whether they may be helpful or useful in examining or understanding your spiritual life after breast cancer.

Faith: Other Forms of Spiritual Practice

After breast cancer, some survivors seek further understanding of faith and spirituality in their lives in other ways. While some begin or continue a search for God, a spiritual being, or higher power in their lives, others have identified a positive experience through everyday activities, enjoyment of family and friends, appreciation of nature and beauty, and development of creative talents and

abilities. Others reach out to their family and friends and create positive experiences in everyday activities. The ways in which women develop spiritual practices are as varied as the individuals themselves. Consider some of these practices and evaluate whether they may be useful in your spiritual life after breast cancer.

Seeking Meaning/Purpose in Life

The search for meaning is a basic human need for fulfillment. Often people delay the search to find meaning in life until they face a life-threatening illness such as cancer. Life-threatening illnesses create an increased sense of vulnerability and mortality. Having survived breast cancer may also create a sense of loss and suffering.

Women also experience many positive effects after breast cancer. These positive effects can be a review of one's life, developing a new attitude toward life, having an increased knowledge or change in oneself, and a reordering of life's priorities. Finding meaning in life after having breast cancer fosters positive coping and increased hopefulness. These positive effects occur in the process of identifying meaning and in coming to terms or gaining perspective on surviving breast cancer.

Developing or renewing a purpose or mission in life, and reordering of life, work, and personal priorities is not unusual after treatment. This is a process that occurs gradually over time. Many times breast cancer survivors feel a sense of gratitude in being alive and in living. Many want to share their positive experiences with other breast cancer survivors in creative ways such as through support groups, volunteer, or advocacy activities. Breast cancer survivors often

share that it is helpful to talk to others who have been through similar experiences to learn what has been helpful in coping. Times of sharing can help validate their experiences and affirm the meanings one has about breast cancer and its impact.

The process of seeking meaning after breast cancer does not mean ignoring the losses that have been experienced. Rather, identifying the losses that have occurred, acknowledging them, and properly grieving will enhance the healing process. Examine the losses that you have experienced and the impact of these losses in your life. Does the experience create a sense of being overwhelmed? Does the experience motivate you to go on with your life? What do you see as your purpose or mission in life?

Maintaining Hope

Hope is a vital part of our human existence. While hope is most often viewed as a positive virtue, it frequently springs from suffering and hardship. Yet, hope is resilient and can coexist with suffering. People view hope in many ways. Some ways in which people maintain and foster hope include:

- Having a meaningful, shared relationship where one feels a sense of being needed or being a part of something.
- Maintaining a feeling of delight, joy or playfulness; using humor in situations.
- Remembering joyous and meaningful events.
- Having one's individuality acknowledged, accepted and honored.
- Identifying positive personal attributes such as courage, determination, and serenity.

- Having beliefs that give one a sense of meaning in suffering.
- Focusing one's attention on the short-term future.
- Thinking about ways to direct one's efforts at short-term goals.
- Desiring serenity and inner peace.

Spend some time thinking about the comments about hope and the importance of maintaining hope in the presence of a chronic illness. Are you hopeful about your future? Strategies to maintain and preserve hope are listed in a Tip Sheet.

Assessment and Self-Evaluation of Caring for Your Soul & Body

The process of caring for your soul and body is a vital part of quality of life. To help you discuss any questions or concerns that you may have about the changes in your inner life after breast cancer treatment, ask the following assessment and self-evaluation questions:

- How do you feel about having survived breast cancer?
- What is your understanding of the course of your illness?
- How does breast cancer affect you emotionally? Mentally? Spiritually?
- Who provides you with emotional, physical, and spiritual support?
- Who do you confide in when you have a problem or concern?
- What gives you hope?
- How hopeful do you feel?
- Do you have spiritual or religious practices that help you?

- What are your personal goals in life? How have they changed after breast cancer?
- What are your professional goals? How have they changed after breast cancer?
- What are your priorities with your family? How have they changed?
- How ready are you to share your breast cancer experiences with others?
- Have you come to terms with any physical loss?
- Do you feel a sense of control in your life?
- What spiritual needs are important in your life today?
- How can you redefine your personal values and goals?
- What do you see as your mission or purpose in life?

Communicating about Caring for Your Soul & Body

Communicating your thoughts and feelings about having breast cancer and the meaning it holds in your life may not be easy. Often families, friends, and even your oncology team may be at a loss to respond. This is normal. Other times, they are waiting for you to broach the topic and start a discussion about your feelings. Often, it may be other breast cancer survivors who know and understand what you are going through.

You might also consider talking first to one individual such as your spouse, partner, or a friend in whom you can confide. The main goal is to understand your feelings and thoughts about breast cancer and how it has affected your life.

To help you communicate your thoughts and feelings, take some time out for yourself and think about the questions listed above. While all of our lives are

busy, think about taking some time out each day or every few days to focus your attention on these questions.

You may want to write down your thoughts and feelings about the questions in a journal or notebook. Any way that you want to write will do--long letters, short notes, or even phrases. Take a few minutes each day to write down your thoughts about these questions. The main goal is to think about how you feel about your life and the meaning or effect that having survived breast cancer has had in your life.

Homework

Over the next few weeks, work on the following areas as homework exercises:

- ❑ Read through your workbook section on caring for your soul and body
- ❑ Try the following interventions:

- ❑ Describe the effectiveness of the interventions
- ❑ Call the BCEI Research Team for any questions
- ❑ Communicate with your partner about the following issues:

- Communicate with your oncology team about the following interventions:
