

# Post Breast Therapy Pain Syndrome

## After Treatment & Talking To Your Medical Team About PBTPS

The effects of cancer and its treatment endure long after medical treatment ends. Some changes may actually be positive (i.e., you have a better appreciation of life, or you may have become closer to your family and friends). Other negative changes, such as: pain, scars, or lymphedema, are constant reminders that you have been diagnosed with cancer.

When pain symptoms persist, you may not always find sufficient compassion and empathy. Friends and family, and even health care personnel, may appear skeptical regarding your complaints, because post-treatment pain is not always visible and can't be easily measured.

Recognition of Post Breast Therapy Pain Syndrome (PBTPS) by the medical profession is in its early stages. Many professionals are unaware of this problem because they have little experience in making the diagnosis, and in treating this syndrome. You may, need to take a proactive approach to educate your health care team about this problem, and to seek effective solutions from them. PBTPS is best treated as soon as possible, because it becomes chronic and more resistant to effective treatment when diagnosis and initiation of therapy is delayed.

It is normal to have tightness around the incision (and under your arm if you have had lymph nodes removed from the armpit region) during the first few months after surgery. Sensory nerves are often intentionally cut during surgery to remove the lymph nodes. This may result in a tingling sensation during the first few weeks after surgery and, later, numbness of the affected areas. Constant severe burning or stabbing pain near the incision or in the arm, nerve spasms, or severe itching months after surgery is unusual. If pain interrupts your sleep at night or significantly impairs your daily life or if wearing clothing is uncomfortable, then you should ask your physician to refer you to a physical therapist and/or a pain management specialist.

### **Suggestions for Discussing PBTPS With Your Medical Team:**

1. Keep a daily symptom diary and make three copies. One for yourself. One copy for your doctor/caregiver to share your symptoms with him/her. You may also ask your doctor/caregiver to place an additional copy in your medical records.
2. Examples of noteworthy observations:
  - A) Time of pain or other symptom occurrence
  - B) Type of pain (i.e. stabbing, burning)
  - C) Pain duration whether chronic or sporadic
  - D) What triggers the pain?
  - E) Location of the pain
  - F) What helps to relieve the pain?

3. Address your needs for symptom management. Make sure that all of the members of your medical team are communicating with each other about your pain problem, and that a plan of action is established.

If your physician dismisses your pain with statements such as: *"It's just phantom pain"*, or *"You are anxious"*, etc., ask your medical team to read the beginning part of this information sheet which describes the symptoms of PBTPS. If the team is unresponsive to your complaints, seek a second opinion from a new medical team that understands PBTPS.

***The best advice to anyone who has Post Breast Therapy Pain Syndrome is that the pain is real and can be treated. Most importantly, remember the pain does not necessarily mean recurrence of your cancer!!!***

### **Suggestions For Alleviating PBTPS**

1. Your medical provider may prescribe: Anti-inflammatory agents (NSAIDs), narcotics or low dose antidepressants (SSRIs)
2. Physical Therapy: Early restoration of range of motion in the shoulder and arm is important to prevent a frozen shoulder or shoulder/hand syndrome. These two entities can cause pain separate from the neurogenic syndromes that can result from axillary lymph node dissections. Early movement and use of the arm will also help reduce the severity of lymphedema (chronic swelling of the arm).
3. Get a referral to a pain management specialist who is board certified by: The American Board of Anesthesiology-Added Pain Qualification or the American Board of Pain Medicine.
4. Supportive Care Approaches such as: Guided imagery training; biofeedback; acupuncture; massage; exercise (swimming, stretching); hypnosis; nutrition; topical salves (calendula, capsaicin, and mentholated creams); bed rest; a small pillow between you and the seatbelt; wearing of loose clothing.

***(Remember to consult with your medical team.)***