



THE SURVIVOR VOICE

A PUBLICATION OF THE
 NEW ENGLAND COALITION
 FOR
 CANCER SURVIVORSHIP

PAIN: YOUR FIFTH VITAL SIGN

Along with taking your blood pressure and other vital signs, when you visit your hospital, doctor's office, or outpatient clinic, you should be asked: **Are you in any pain?** When you answer this question, do not answer just for that moment. Make sure that your answer includes any pain you have felt since your last visit. If you answer "yes", you should be asked to rate your pain.

Education about pain is an important key to patient empowerment. It is important to understand that cancer pain – whether caused by the disease, its treatment or by treatment side effects – can be controlled and relieved at a satisfactory level.

Here are some things to keep in mind, whether you are newly diagnosed, in active treatment, a survivor, or a family member/caregiver:

- Pain does not always accompany a cancer diagnosis.
- Escalating pain does not always indicate that treatment is not working or that your cancer is getting worse.
- Your pain should be relieved, not tolerated. Pain is not a punishment. Suffering is not a measure of courage.
- Poor pain management may slow down your recovery.

- Pain affects the quality of your life and can lead to depression.
- Do not fear addiction when you are taking medication under your physician's supervision. Addiction usually involves taking medication for non-medical reasons.
- There is a cause for your pain. If the precise cause cannot be pinpointed, your pain can still be alleviated.
- Talk with other survivors about what has helped them manage their pain. Veteran survivors are an important resource.

To get the pain relief you need and deserve, work actively with your health care team. **Believe that you can find relief.** Until you find the most effective combination of medicines and complementary therapies, **DO NOT GIVE UP.** If you are not getting the help you need from your doctor, ask for a consultation with a pain specialist or clinic. There are medical experts within your reach who want, and know, how to help.

"I tried not to complain too much about my pain. Big mistake! I should have shouted about it until my oncologist really listened. Keeping up a strong front only made my problem worse."

-Cindy Troidle, Survivor

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NECCS AWARDS

An opportunity to acknowledge the special people who help those on their cancer journey.

The NECCS Lorin Lavidor Caregiver of the Year Award honors someone who has provided outstanding care for you or someone you know during the course of treatment/illness.

The NECCS Health Care Professional of the Year Award honors a professional who has shown outstanding support to patients/survivors. This could be a doctor, nurse, social worker or any professional who goes above and beyond to help those on this cancer journey.

For nomination process—see last page.

The Medical Profession's Commitment

Pain assessment has finally become an integral part of patient care because organizations across the country have lobbied for the American Pain Society's concept of pain as "**The Fifth Vital Sign.**" Since 2001, the Joint Commission on Accreditation of Health Care Organizations (JCAHCO) has focused on pain management standards. To secure accreditation, institutions and programs must use tools which measure their patients' pain. They must also record methods of pain treatment and educate their staff on the principles of pain assessment and management.

How to Help Your Medical Provider Help You

1. Open and honest *communication* with your health team is crucial. Your nurse and doctor are not mind readers. They need you to articulate what is happening to you. *You are not a complainer* when you talk about your pain.
2. The earlier you tell your health team, the easier it will be to treat. Don't allow your pain level to escalate.
3. If no one asks, *bring the subject up*. If it is hard for you to do that, talk with your caregiver or a friend and have him/her with you at your next appointment.
4. *Keep a pain journal*. This should include a record of when you take your pain medication, how you felt before and after, pain levels in between doses, and all side effects.
5. Side effects can be managed and should not cause you to stop taking medication.
6. Ask your nurse to help you with vocabulary. There are many words to describe pain with different treatments for different types of pain. Pain can be sharp, intense, dull, stinging, persistent, nagging, gnawing and so on.
7. Take all medication as directed. Don't skip doses. Work with your team to adjust doses and timing to maximize effectiveness and minimize side effects.
8. If one medication or treatment doesn't work, there are others. Don't be afraid of developing a tolerance to a particular drug therapy. There are new drugs and combinations that can be tried.
9. Ask your providers about *alternative therapies*. Many health insurance companies will cover some of these treatments, which include acupuncture, meditation, exercise, herbal medicine, vitamins, support groups, prayer, psychotherapy, visualization and relaxation therapies, hot and cold treatments, massage, and aroma therapy. Do not begin alternative therapies without consultation with your health team.

HOW PAIN IS DEFINED

Chronic pain: An unpleasant sense of discomfort that persists or progresses over a long period of time. Chronic pain persists over time and is often resistant to medical treatments. Chronic pain tends to interfere with the ability to perform activities of daily living and affects *quality of life*.

Acute pain: Pain that comes on quickly, can be severe, but lasts a relatively short time.

Breakthrough pain: For people who suffer pain all of the time, the concept of breakthrough pain addresses the fact that the level of pain can "spike" throughout the day because of different activity levels, medication wearing off, or the nature of the illness. The goal in addressing breakthrough pain is to provide enough sustained release medication to meet the patient's baseline needs, and then provide supplemental short acting medication when the pain spikes occur.

Palliative Care: Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called comfort care, supportive care, and symptom management. Palliative cancer therapies are given together with other cancer treatments, from the time of diagnosis, through treatment, survivorship, recurrent or advanced disease, and at the end of life.

A SURVIVOR'S EXPERIENCE OF SELF-CARE – Marion Merrill

“Pain is inevitable, suffering is optional.”

– Dalai Lama, Nobel Prize Winner and Spiritual leader of Tibet

For Marion, her attitude has been a huge factor in managing the recurrence of her breast cancer. Marion was first diagnosed in 1996 with Stage II breast cancer. In 2001, after five years on Tamoxifen and being cancer free, she learned that her cancer had metastasized to her bones. She is currently undergoing a regimen of chemotherapy (Taxol and Avastin) with Fosamax injections to strengthen her bones. Working with the same medical team since her first diagnosis, she has responded well to her treatment and she feels tremendous gratitude for the commitment and dedication they share in her fight. “They offer a lot of incentive to be strong,” she said, “I feel that they are fighting just as hard as I am to beat this. I couldn’t ask for a better team.”

As opposed to her first diagnosis and treatment period, this time around, Marion made the decision to stop working and devote 100% of her energy to doing what’s best for her own wellbeing. A self-described Type-A, she’s allowed herself the luxury of slowing down her pace and giving herself time to take care of herself.

“For me, fighting this illness has become my main purpose.” she said.

After going through an adjustment period to get the dosages effective and in balance, her treatment is going very smoothly. And while she counts herself lucky for the positive response, she does experience chronic and acute bone pain, primarily in her back. Her pain increases when she’s been physically active and she’s had to recognize boundaries for herself, acknowledging that she can’t “do it all”. Her sister helps her with household chores and her “to-do” list is shorter. An informed patient, Marion clearly under-

stands the clinical impact that the disease has on her body which contributes to her capability in managing her pain as well as she does. Generally, her moderate chronic pain is managed with Tylenol, an acetaminophen which has an analgesic effect and reduces fever. She also takes Oxycodone, a stronger pain reliever that is a narcotic, using discretion because of the side effects which are primarily constipation and some

drowsiness. She encourages others in treatment to talk about their pain symptoms with their doctors and to include every aspect, no matter how depersonalizing it seems at first. “You’re talking to your doctor and nurses about things you don’t even talk to your mother about,” she modestly admits. But because of her candor, her side effects are successfully addressed. When she has breakthrough pain, she takes Percocet, which is a fast acting narcotic-type drug with a shorter duration of effectiveness. To be sure that she doesn’t lose track of her doses of medications, she carefully measures them out each day. And she is always aware of any side effects that inhibit her

ability to react alertly and accommodates extra fatigue with the luxury of a nap.

Marion, who at 52, has practiced yoga for many years prior to her diagnosis, continues to use her yoga practice as a way to keep physically active. The stretching portion of yoga allows her to exercise her muscles without straining her bones and helps with her endurance. The relaxation aspects of yoga contribute to the reduction of tension in the muscles and overall stress, which she feels is a key component in



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successfully living with her diagnosis. Additionally she has taken up Reiki (a form of energy healing) and meditation, incorporating positive visualizations into her routine. She uses visualization to create calming mental images and reduce anxiety. In a South Korean study, sixty breast cancer patients undergoing chemotherapy filled out questionnaires about side effects and quality of life. The patients who received guided imagery and muscle-relaxation training reported significantly less nausea, vomiting, anxiety, and depression than those who did not receive adjunctive therapies.

As in any healing, the first step towards a healthier life is a desire to be healed and Marion's desire is compelling. "I wouldn't wish this on anyone," she said, "but no one can say that there is only so much time for any of us. Since my recurrence, if I had thought I only had a short time left, my ability to go through this successfully would be affected, but I'm treating it like a chronic disease and I'm living with it."

Her circle of support has been a tremendous source of strength for her, especially her sister who has steadfastly attended all of Marion's doctor appointments with her. "It's so important to have another set of ears listening," she said, "Many times I will hear something and get caught in a thought, and my sister will hear something important that followed and remind me about it later." In addition to having an extra set of ears, the moral support of friends and family has been a tremendous gift. "At first it was difficult for me to ask for help in doing things that had been routine, but they have made it genuinely clear that they want to help me." They have offered helpful hints and suggestions for dealing with pain, like the friend who introduced her to the use of heating pads that can be wrapped around the midriff and worn throughout the day to provide relief. And if Marion finds herself getting down, her friends offer a safe place to reflect. They also help her find her way back to a more positive place and to the things in her life she is grateful for. "There is always someone who has it worse off than you do," she selflessly reflects.

Her advice to those newly diagnosed: "It is un-chartered territory when you first hear this diagnosis. You must think of yourself as a special patient from now on. You are not the ordinary patient. If you

have an ache or pain, address anything that's uncomfortable with your team member so that she/he can deal with it." No matter what the subject is, hair loss, pain, complications from medications, never hesitate to bring it up.

As Marion prepared to leave for a trip to New Mexico to visit friends, she conveyed tremendous hope. "I think of myself in recovery. I'm grateful to be alive."

COMPLEMENTARY AND ALTERNATIVE MEDICINE

These approaches to the diagnosis, treatment, and care of cancer are used in conjunction with (complement) conventional cancer treatments or are used in place of (alternative) conventional cancer treatments such as surgery, chemotherapy and radiation. Always consult with your health care professional before beginning any treatment on your own. In many cases health insurance companies may cover some of these treatments.

ACUPRESSURE

A system of massage in which finger pressure on acupuncture points is used in place of needles.

ACUPUNCTURE

In traditional Chinese medicine, the practice of placing needles at key points along "energy pathways," or "meridians" on the body in order to "restore the energy balance." Best known in the West as a system of pain control.

AYURVEDA

The traditional Indian system of medicine that uses herbs, yoga, and various other techniques to bring the body into a state a harmony with its environment.

BEHAVIORAL THERAPIES

Also known as cognitive, holistic and alternative therapies these encompass hypnosis, meditation, autogenic training, progressive relaxation, and biofeedback. By far the most widely used technique in cancer is relaxation therapy. It promotes an altered state of awareness by reducing distressing emotions and producing a physiologically quiescent state.

BIOFEEDBACK

The use of instruments to induce awareness of the ability to achieve responses, such as relaxation, previously thought to be beyond conscious control.

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PROVIDER PERSPECTIVES

A CONVERSATION WITH THREE NURSES

Some of the newest information and best advice can be gained from talking with your providers. They are able to draw from experience, training and current publications. They can be a resource directing you to books, websites and other materials that you, your caregiver, and your support network may find helpful.

The three providers interviewed for this article are all working in the fields of pain management and oncology. The conversations were structured around the following questions.

What Do You See As the Current Issues/Concerns in the field today?

Access is the biggest concern, according to all three. Access, as an issue, is twofold. The first part is **access to medication**. Not all medications are available to all patients.

The FDA may have approved a drug for one certain use, but not another. Insurance, including Medicare, may not cover all expenses. Access may not be impossible, but this roadblock makes it much harder.

Some insurance companies have preferred drug lists, which limit payment to those drugs alone. These preferred drug lists may also not allow the use of a drug for all diagnoses. So a patient whose doctor wishes to try a different medication may be faced with paying for a drug without an insurance co-pay.

Since all patients respond differently to different



“Unrelieved pain causes needless suffering and destroys quality of life. But this doesn't have to happen. Nearly all cancer pain can be relieved.”

- Susan Richter, RN,
Caregiver

medications, restricting drugs in this way can limit success in alleviating pain.

Access in the community may also be limited by pharmacies which don't carry certain drugs or which don't provide enough privacy to patients, causing potential embarrassment on the patient's part about the need for certain medications.

The second part is **access to knowledgeable providers and to pain clinics**. To begin with, there are too few pain centers. For those in rural or underserved areas or without the ability to get to metropolitan centers, going to a facility that specializes in pain management with highly trained providers may be impossible.

When the access problem to a pain center is insurance coverage, it may be due to the restrictions placed on the need for pain management. Procedure based management, such as surgery, is usually covered. Less well reimbursed, if at all, is chronic, functional pain management - a big concern for cancer survivors.

Also not reimbursed or under reimbursed, is counseling by a nurse. Because there is no well defined diagnostic code for such treatment, a thorough workup and follow-up by a nurse is not always available.

Education is the second major concern raised by these providers. There is a great deal of ignorance on the part of the public as to the need for pain management. While cancer patients often get sympathy during the course of treatment, **long term effects, especially pain, are not well understood**.

The public also needs more education about the use and abuse of various drugs. The negative media focus on some new and extremely effective drugs such as Oxycontin® makes patients and families anxious about

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their use. Such media focus is on those who use and abuse drugs who are not being treated by a doctor for pain. But the worry that the stigma of using such drugs will spill over is very hard to dispel.

The majority of physicians, nurses and pharmacists have little or no training about pain. They tend to pass on misperceptions, myths, and old ingrained fears. Providers need more in depth training based on science. They need to learn how to use pain scales and how to do an effective pain assessment. There is a great need to learn more about interdisciplinary approaches to manage pain, such as occupational therapy, physical therapy, nursing counseling, and alternative therapies. A provider may not know about newer drugs or the new uses of currently available drugs, such as the use of anesthetic drugs for intractable pain.

What are some of the new developments in the field?

Some of the most exciting research is being done in the understanding of the basic mechanisms of pain and the nervous system. Learning how pain is transmitted has led to understanding that **pain is harmful**. Research is showing that pain delays healing, it suppresses the immune system, that it **rewires or causes permanent damage to the nervous system**, and that it **makes the patient more likely to have pain later**.

Current studies are being done to learn how patients respond individually, and as a group, i.e. men and women, different ages, to different classes and doses of drugs. People respond differently to different medications, even in the same family of medicines. A cookbook approach to treatment does not work.

New drugs are on their way. New delivery systems such as the nasal delivery of opiates are coming onto the market. Expanded use of already available drugs, such as methadone, is being studied for cancer pain. It is inexpensive, works like morphine, but uses other pathways to block pain signals. It works especially well with neuropathic pain— pain involving nerve damage— which is a huge issue with cancer patients.

Even though there has been a great deal of progress in pain research, there is a long way to go to understand and manage complex pain syndromes.

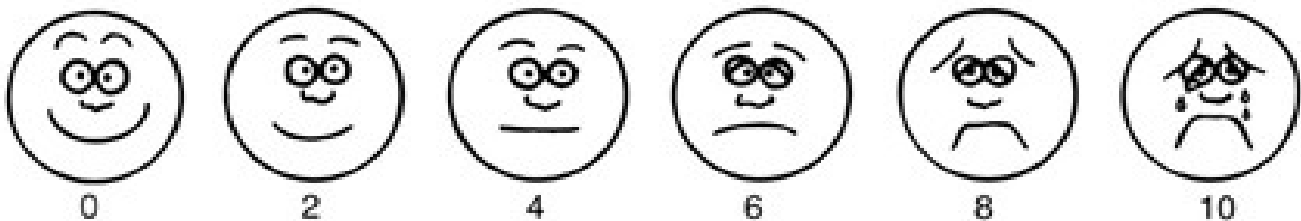
Why is pain such an emotional issue?

Pain has a dramatic effect on the quality of life. When it is associated with a life threatening illness, pain becomes magnified and its meaning is layered. While cancer patients generally have better access to pain management during treatment (surgery, radiation, chemotherapy), the longer term management of the effects of treatment is not as good. Since nobody benefits from unabated symptoms, it is crucial to understand the dynamics of the emotions involved.

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UNIVERSAL PAIN ASSESSMENT

Wong-Baker FACES Pain Rating Scale has been developed to assess pain in adults and children over 3 years old.



Numeric Rating Scale

<http://www.med.umich.edu/pain/>

Pain intensity is rated on a scale of 0 (no pain) to 10 (the worst pain imaginable).

At the time of diagnosis, practitioners, patients and caregivers expect that there will be pain and that there will be a need for the relief of pain. However there is fear on the part of everyone if the need for pain relief becomes long term.

The patient fears that worsening pain might mean worsening disease and be reluctant to discuss it. Often, of course, **the pain may be a side effect of the treatment and not the disease at all.** Providers need to counsel on the symptoms of the disease and the side effects of treatment so the pain can be treated appropriately. Generally pain as a result of treatment can be tolerated better.

Pain is a culturally laden issue. Patients are supposed to be strong and optimistic. They don't want to distract the doctor from working to cure them and don't wish to be seen as chronic complainers. Families and friends don't understand chronic pain: haven't you gotten over that yet? It has been a long time since your surgery, radiation, or chemo.

Everyone is concerned that pain treatment will dull thinking and functioning. But in fact, pain treatment is all about increasing functionality, especially when the doses and medications have been fine-tuned. Part of this misconception has to do with end of life issues. Understanding the dying process, that the body begins to shut down and the patient may drift in and out of consciousness, can be confused with the effects of medication. For properly treated pain, the patient will be able to think more clearly.

Studies have shown that most pain medication is prescribed PRN, or as needed. Physicians tend to underprescribe. In the hospital, nurses tend to underadminister. At home patients are reluctant to take the pills and often take less.

Since pain slows the healing process and can be treated, it is up to providers, patients and caregivers to work hard at communicating with each other to allow for the most effective treatment.

And of course, the biggest fear of all is that of addiction. This risk is overstated. There has been a great deal of media hype about drug use. The right of patients to treatment must be protected. Cancer patients have a low risk of becoming addicted. Only 8-13% of

the general population has addictive potential. Many of those with risk factors have already been identified. Cancer patients are closely monitored and there is help available at all times. Patients are anxious to get off the medication once the pain is gone. If a patient becomes addicted, it is not because the individual is a weak or bad person. Good communication with your providers is your best defense.

Part of the fear on the part of providers is potential diversion of the drugs. This means that another person may use or sell the drugs. It may be a family member or other caregiver who has access to the drugs. Keeping the drugs in a safe place is important for this reason, as well as for the safety of children.

What advice would you give to patients and caregivers?

1. Expect help. Do not take "no" or "I don't know" for an answer.
2. You have a right to effective pain management. Someone at your doctor's office should ask you about your pain. If they do not, volunteer the information.
3. When asked how you are, don't bite the bullet and respond "I'm fine". Sometimes you feel better just being in the office and getting attention. If you are better at that moment, make sure to talk about the rest of the time.
4. Expect a thorough work-up, a treatment plan and follow-up.
5. If you are not getting effective treatment, ask for a referral to a pain clinic.
6. Expect to be a partner. Keep a diary. Carry a little wire notebook with you. Include the following:
 - a. **Pain.** What does it feel like, when does it occur? Is it achy? Sharp? Does it come and go? Use the various scales, but make sure that you just don't indicate a number or a face!
 - b. **Relief.** What works? (Not just medication, for example exercise, massage, heat etc) When does it work? How long does it last?
 - c. **Functioning.** What does the pain prohibit you from doing? Include things you normally enjoy doing, not just basic functions.

7. Look for a multimodal approach, not simply a prescription. Alternative therapies can be very effective.
8. Look for a multidisciplinary approach. Nursing visits are very important. Physical therapy may be needed.
9. Take responsibility to educate yourself and to communicate. If you are unable to do so, talk to your caregiver or ask a friend to help.
10. Remember that discussion about your pain should be an ongoing communication between you and your providers.

Don't be brave when you need to ask for help.

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THE HITCH OF PAIN MANAGEMENT—SIDE EFFECTS

Constipation

One of the most frequently reported side effects of the pain medication is constipation. Because opioids cause the stool to move more slowly along the intestinal tract, thus allowing more time for water to be absorbed by the body, stool then becomes hard. Constipation can often be prevented and/or controlled and should be candidly discussed with the patient's treatment team.

The most important step that can be taken to alleviate constipation is to drink plenty of liquids. Eight to ten 8-ounce glasses of fluid each day will help keep stools soft. Other steps that may help:

- Stool softeners. Ask the doctor to recommend a stool softener, and confirm how often and how much should be taken.
- Adjust diet. Discuss diet with the doctor and consider increasing foods that are high in fiber or roughage such as uncooked fruits (with the skin on), vegetables, and whole grain breads and cereals. In some cases this may not be an agreeable solution.
- Exercise. As much as you are able to—exercising and physical movement has many benefits.

Note—Two days or more without a bowel movement warrants a call with your doctor.

Drowsiness

Drowsiness is the second most frequently reported side effect of pain medication, especially opioids. This is usually temporary and goes away after a few days. And if the medication is alleviating pain that has been keeping sleep away, a few days of "catch up" sleep may be the simple solution.

Some ways to handle drowsiness are:

- Check to see if there could be other medications that may be compounding the symptom.
- Ask the doctor if a smaller dose more frequently or an extended-release opioid may be prescribed.
- If the medication is not relieving the pain, the pain itself may be wearing you out. Communication with the treatment team is the key to identifying if this may be the cause.
- Consider a mild stimulant such as caffeine.

Remember: if drowsiness is severe or if it occurs suddenly after opioids have been prescribed for awhile, call the doctor or nurse right away.

AVAILABLE PAIN THERAPIES

Non-steroidal anti-inflammatory drugs (NSAIDS)

Aspirin, ibuprofen, acetaminophen, etc. NSAIDS are used for mild to moderate pain. They work by blocking the cyclooxygenase enzymes (COX-1 and COX-2) that lead to inflammation. They may be used alone or in combination with opioids, depending on the patient's level of pain. Even though these drugs are commonly used, they must be taken with caution as they can interfere with blood clotting, may cause gastrointestinal ulcers and may impact on kidney function.

Opioids (narcotics)

Opioids are used for moderate to severe pain and should be taken with a stool softener. They work by suppressing the incoming messages of pain to the central nervous system. They provide the cornerstone for pain treatment in most cancer patients. Unfortunately, recent publicity about Oxycontin® and other potentially addictive opioids may make it hard for some patients to get. Also, some patients may not feel comfortable using it due to the fear factor. Side effects like mental confusion, sleepiness, itching and urinary problems either wear off or can be offset.

Anticonvulsants

Neurontin and other drugs can help calm over-sensitized nerves. Because Neurontin has a very low side effect profile, it is used commonly for neuropathic pain. Other anticonvulsants, such as Tegretol or Dilantin are also used but need to be monitored more closely for potential side effects like lowered blood counts or changes in liver function.

Tricyclic antidepressants

Amitriptyline, Nortriptyline, Desipramine and other antidepressants can be extremely useful in treating neuropathic pain. They augment the ability of the patient's own body to reduce pain. Possible side effects include sleepiness, dry mouth and constipation. Taking an antidepressant does not mean you are depressed or have a mental illness.

Complementary and Alternative Medicine

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MACROBIOTICS

A dietary approach derived from traditional Oriental philosophies whose goal is to live in harmony with the environment. The diet is grain-based and nondairy, primarily cooked, and can be vegetarian or vegan.

QI GONG

An ancient system of self initiated healing, combining movement with meditation and breath awareness, which has as one of its goals the conscious control of the body's energetic system.

REFLEXOLOGY

A system of therapeutic massage based upon the theory that pressure points affecting all of the body's organs and systems are located on the palms of the hands and soles of the feet.

“REIKE” -THERAPEUTIC TOUCH

A practice from Eastern roots that stimulates the body's natural healing abilities, reduces stress and builds the immune system through the placement of the healer's hands above certain parts of the recipient's body to release and direct energy.

YOGA

A philosophical school of Hinduism that elaborates a system of physical, psychological, and spiritual approaches to the integration of the individual with the transpersonal. Yoga is best known as a physical discipline, including stretching exercises, breathing and relaxation techniques, and meditation practices.

Excerpts from Choices In Healing: Integrating The Best of Conventional and Complementary Approaches to Cancer by Michael Lerner, Ph.D., President and founder of Commonweal. Qi-Gong Awakening & Mastering the Medicine Within You, Video by Roger Jahnke. OMD

CAREGIVERS CORNER: THE HEALING VALUE OF TENDER LOVING CARE—Todd Richardson

Todd and Cindy share the life-changing experience of personally receiving a cancer diagnosis. They know how life can change in an instant. They met in 1999 at a cancer survivorship conference and have been looking out for each other ever since. Both diagnosed with cancer in their teenage years, Cindy was diagnosed with lymphoma in 1984 and was treated with chemotherapy and radiation. She had a recurrence which resulted in a bone marrow transplant in 1995. Todd was diagnosed in 1992 with leukemia and had a bone marrow transplant in 1994. Cindy most recently received treatment for a small tumor in her lung which likely resulted from the radiation she received for her earlier diagnosis. Due to ongoing, late effects, both receive social security disability. Todd is able to work part-time, usually 1-2 days per week.

Though Todd is also a cancer survivor, he sees himself more in the caregiver role, due to Cindy's continuous battle with pain. Cindy is never 100% pain free but Todd helps her manage her pain throughout the day by keeping track of her medications and keeping her spirits up. He knows that her pain is high in the morning as her medication has worn off during the night. He gets himself moving early, preparing coffee and preparing for the activities of the day ahead, including the multitude of phone calls that seem to have become part of their lives. They have learned to read each other very well. Todd can see Cindy's face relax and her body loosen as the day goes on and her medications begin to bring her relief. This is their quality time together - when they can easily talk and enjoy each other's company. Frequently their nieces and nephews come over and bring the joyful distraction of what Todd describes

as "kid therapy." Playing with them he says brings everything to the present moment and provides physical and mental relief from the snowball of worries and concerns that can mount up. He and Cindy also share a perspective that allows them to look beyond themselves to acknowledge that "there are always others who are worse off."

Cindy's pain originally started in 1992 due to her cancer. It is managed through the use of extended-release medicines (Oxycontin®). Rapid-acting pain relief for breakthrough pain is provided through (oxycodone). Occasionally she will take muscle relaxers, but the resulting drowsiness throws her off her



regular schedule and inhibits her ability to participate in daily activities. She has tried alternative therapies like acupuncture which brought some relief, but she wasn't able to continue because of limited insurance coverage. While the Oxycontin® and oxycodone had been cutting the pain fairly well, this is no

longer the case. Because cancer put Cindy into early menopause, she has suffered osteoporosis and bone density loss which has led most recently to swollen discs in her back causing her pain to increase dramatically. The result is their quality of life has been steadily deteriorating resulting in a dramatic change from how their life was just six months ago. Todd will not leave Cindy alone on days when her pain is really high. If he had plans to work on a project around the house, or go out to do errands, he will postpone it. The result is he feels that things aren't getting done. It has also had an impact on the amount of time they spend with the nieces and nephews. If Cindy is in too much pain, they won't have them over - cutting into something that usually brings them both a respite from it

all. Overall, they are more socially isolated from family and friends.

Todd feels Cindy's increased pain has been going on for a while, while Cindy thinks it has been just recently that it has gotten so bad. Todd thinks as the caregiver he has been able to notice the more subtle changes that started before the pain increased so dramatically. He tries to push gently and in supportive ways by presenting ideas as a "team effort" such as "let's try this" or "what if we tried this?"

For his own outlets, Todd plays the guitar, "as loud and as long as I can," and enjoys video games for a mental diversion. He credits the closeness of their shared family as one of the strongest support systems Cindy and Todd have. His father and he have an exceptionally tight connection and share the same sense of humor, regularly spinning off each other's sentences with one liners and punch lines. Todd's father finds the right thing to say when he's feeling overwhelmed and always provides an encouraging point of view. "My father can always let me know when it's okay to be freaked out by stupid stuff and when its time to get over it."

Todd and Cindy recently met with a specialist at the pain clinic associated with Brigham and Women's Hospital to address this new development in her pain. For Cindy this meeting was very affirming, which is so important when dealing with chronic pain. For Todd it was good, because he felt they were getting too socially isolated on the course they had been on. He also can go "mentally down hill" because no matter how much he does, he can't reverse the damage that Cindy has experienced. When her pain is fairly well managed he also does better.

The new plan gives them both some hope. The recommendations from the pain clinic will be submitted to Cindy's primary care physician. She and the PCP will discuss which recommendations to start with which include:

Trying an opioid rotation, so if she builds up a tolerance she can rotate back or go on to a different medication.

Trying a different medication that is more powerful, but then the dose could be lowered.

Physical therapy, exercise and some complementary therapies, such as massage, as a multi-level approach to her pain.

In addition Cindy is trying a TENS machine – a Transcutaneous Electrical Nerve Stimulator – which is very small and she can carry around with her. She places electrodes on her back and little pulses help to block the pain receptors.

A big tip that they both want to give to others - PERSISTENCE. There is no reason why pain should not be managed as best as possible. Also, don't try and deal with it by yourself. Todd states they are both feeling better because they have accessed a valuable resource to help them and they now have a direction to go in.

While they live with the specter of pain and cancer in their lives, Todd and Cindy feel fortunate that their paths crossed. Each day they face their challenges together, grateful that each is there for the other.

RESOURCES

Websites

Pain Relief Network www.painreliefnetwork.org

Mass Pain Initiative www.MassPainInitiative.org

Mass Compassionate Care Coalition www.massccc.com

American Cancer Society www.cancer.org 1-800-ACS-2345

American Pain Foundation www.painfoundation.org

National Cancer Institute www.nci.gov 1-800-422-6237

2007 Pain and Policy Studies Group ACS 2007 Pain and

Policy Studies Progress Report Card www.cancer.org

Reading

NECCS Complementary and Alternative Medicine Vol. 3 Issue 2

Mom's Marijuana, Life Love and Beating the Odds, Dan Shapiro. First Vintage Books Edition, 2001

The Complete Guide to Relieving Cancer Pain and Suffering, Richard B. Patt, M.D. and Susan S. Lang, Oxford University Press, 2004

Cancer Doesn't Have to Hurt. Pamela Haycock and Carol Curtiss. Hunter House, 1997

American Cancer Society's Guide to Pain Control: Understanding and Managing Cancer Pain, Revised Edition, 2005

THE SURVIVOR VOICE

A PUBLICATION OF THE
NEW ENGLAND COALITION
FOR
CANCER SURVIVORSHIP

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To nominate someone for the NECCS award, send a 400-800 word letter telling us the story of your hero and send it to our Framingham address or email it with Awards Committee in the subject line to: info@neccs.org. Be sure to include contact information • Awardees will be honored at the NECCS Annual Awards Luncheon.



NECCS is a non-profit organization comprised of patients/survivors, family, friends, caregivers and cancer related organizations. We are **the voice of survivorship**—the voice of experience and hope. Working together, we address the quality of life issues that affect all of us on the cancer journey.

CANCER SURVIVORSHIP

- As of January 2004, it is estimated that there are 10.8 million cancer survivors in the U.S., representing approximately 3.7 % of the population.¹ Approximately 14% of the 10.8 million estimated survivors were diagnosed more than 20 years ago.
- Three out of every four American families will have at least one family member diagnosed with cancer.²
- Today, 65 percent of adults diagnosed with cancer will be alive in five years. Among children, 75% of childhood cancer survivors will be alive after ten years¹.

¹SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, <http://seer.cancer.gov/csr/1975-2004>, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

²Cancer facts and figures 1996. New York, American Cancer Society 1996

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