

## CHAPTER SIXTEEN PAIN MANAGEMENT

By  
Dr. Aubrey Pilgrim and Several Survivors

If you are in pain, it may seem difficult to believe, but pain has a purpose. An example is the "hot stove reflex". If you accidentally put your hand on a hot stove, you know immediately that you should take it off. It serves as a warning that you should not be so careless and keeps you from being further harmed. But if you are in chronic and constant pain it may be difficult to believe that it has any purpose other than being something evil and sadistic.

The International Association for the Study of Pain defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."

Pain from recurrent and advanced cancer is present in 60 to 80 percent of patients, according to the World Health Organization (WHO). However, the Outpatient Pain Needs Assessment Survey conducted in 1994 by the Eastern Cooperative Oncology Group revealed that 42 percent of those experiencing pain did not have adequate pain management. Sixty-two percent of the patients who experienced pain stated that it was severe enough to prevent participation in activities of daily living (ADLs). Poor pain assessment was determined to be the greatest obstacle to effective pain management by 76 percent of physicians surveyed.

Competent pain assessment is paramount for effective pain control. When assessed inadequately, pain is undertreated. That is a shame because pain can be effectively diagnosed and treated. Proper analgesics and adjuvant medications can relieve pain in approximately 95 percent of patients.

There are some doctors who specialize in pain management. If you are in pain, you might try to find one.

Pain is strictly subjective. Only the patient knows how much pain he or she has and where it hurts. As a result, the patient self-report is the *gold standard* for pain assessment. The relationship between pain and tissue injury may not be uniform or constant. We are all different. Some people can withstand more pain than others.

The description of the pain should describe its intensity, say on a scale of 1 to ten. It should describe its location and anything that might make it better or worse. The caregiver should do a detailed history, physical examination, and review of laboratory and imaging studies. This can often clarify the relationship between the pain and the disease. This assessment can help determine the therapy needed.

Pain has been arbitrarily assigned to several different categories.

**Transient pain** is usually minor pain such as that felt when you stub your toe. It is related to insignificant tissue damage and is not a major clinical problem.

**Nociceptive pain**:- (Noci is from Latin nocere, to injure, ceptive means to receive). This type of pain is usually caused by tissue damage and inflammation in response to trauma. The resulting pain may not be well localized. It usually responds to opiates.

**Acute pain**- may be similar to that seen after a major operation. It may also have minor or major neuropathic and psychological contributions. This pain may require potent systemic therapy including opioids.

**Chronic pain**- (Chronos is Greek for Time). Chronic pain is usually a persistent pain of long duration. Inadequate pain management may contribute to the progression to a chronic pain state. Early diagnosis and effective treatment are a priority since chronic pain, once it occurs, can substantially reduce a patient's productivity and quality of life.

Chronic pain syndromes may result from a direct effect of the cancer. Some chronic pain may be therapy-related or represent disorders unrelated to the disease or its treatment.

**Neuropathic pain**- (Neuro is Greek for nerve, pathos is Greek for disease or suffering). Neuropathic pain is that caused by direct stimulation or injury to peripheral or central nervous system (CNS) nerves. The pain may be localized. It is often burning or shooting. It responds poorly to opioids.

**Psychological pain**- This component of pain may be caused by depression and cancer treatments. Personality, mood, and comorbid psychiatric disorders can strongly influence the perception of pain.

**Idiopathic pain**-(Idio is Greek for own- pathic is pain) This pain is defined as pain that persists in the absence of an identifiable physical or psychological cause. It may be one of the first sign of occult disease progression.

## **Bone Pain**

**Editorial Note:** I Aubrey, have been most fortunate in that I have never had to experience bone pain so I can't really write about it. Below are a couple of Internet posts from men who have experienced it.

Reply-to: berky@NANOSECOND.COM (Maynard Berkowitz)

To: PROSTATE-HELP@HOME.EASE.LSOFT.COM

My bone pain started easily enough. My first pain was in the rib cage. Kind of felt like I had a broken rib. Didn't do anything about it. This was before I was diagnosed. The pain got progressively worse, and eventually felt like I had a rope or belt around my chest, and someone was pulling it tighter and tighter.

That was when I went to the ER at a local medical facility. It seems that everyone is so attuned to heart problems, when you walk in the door, and say chest pain, they are quick to respond. At any rate, the doctor thought it was congestive heart failure, and they took me by ambulance to the nearest hospital.

After five days of intensive heart checks, the Cardiologist said: "Your heart is OK". Went back home, and several weeks later, the pains were fairly severe, and again I went to the ER at a different medical facility. This time prostate cancer was diagnosed. The chest pain was perhaps most noticeable at night, probably due to sleeping on my side.

The hip pain began shortly after diagnosis, followed by knee pain. I don't know that I could relate it to any other kind of pain that I had, and within 6 weeks, I couldn't walk without crutches. These pains seemed to lessen when I took my weight off my hips and knees. Sitting in a recliner helped a lot.

A fairly common place for pain to appear with metastasis is in the back. I never had that. In fact, I have had back pain since I was a teenager, but since prostate cancer, it has not bothered me.

As far as relief, I was using aspirin at first, then Percodan, aspirin based with oxycodone, and Vicodin, acetaminophen based with hydrocodone bitartrate. They helped the pain by doping me up. Eventually, I graduated to Duragesic patches along with the Percodan and Vicodin. Duragesic patches contain Fentanyl, and according to my Uro, it is supposed to be 40 times more powerful than Morphine. In fact, I was taking all three for about 2 months.

I had severe pain in April 1998. My Uro recommended palliative radiation which I started about May 1st. After 1 week of radiation my pain went from severe to twice as bad. The radiation continued to May 21, and the Rad Onco was looking every day to a reduction in pain, but it never came. By July, I was on Duragesic plus about 4 Percodan and 4 Vicodin per day. The pain never let up.

Finally in July, I fell and broke both hips. After hip surgery (one replaced, and one with a plate and pin), I started improving. This all happened in 1998. By December 1 1998, I stopped all pain medications, and have felt good ever since.

If you need pain medications, don't be afraid to ask for them. Don't be afraid of using them. When you don't need it, you won't crave it.

Berky  
Folie à Deux

**Note:** Berky is 70 years old, had a PSA of over 1600 when first diagnosed.

Subj: Re: [PHML] Bone pain

From: rvy99@YAHOO.COM (Robert Young)  
To: [PROSTATE-HELP@HOME.EASE.LSOFT.COM](mailto:PROSTATE-HELP@HOME.EASE.LSOFT.COM)

I've read Berky's posts and thought I'd offer my own experience, since my PCa had metastasized into bone cancer and was causing considerable pain.

I was 61 when I was diagnosed (Dx) on 11/23/99. My Dx showed not only very advanced PCa (PSA at 1000+ which was as high as their test equipment went) but the bone scan showed it had metastasized into the pelvis, spine, ribs and shoulders.

My initial pain (that I disregarded) was in the hips and legs. My mom had bad hips (3 replacements) so I thought my pain was just inherited osteoarthritis. Besides, an anti-inflammatory such as naproxen (e.g., Alleve) brought relief. (Meanwhile I also disregarded growing urinary problems, such as getting up frequently.) But the pain grew considerably worse and eventually the naproxen didn't help. Prior to my diagnosis, some of my ribs became sore, as if they were bruised. It was a mild ache but also sore to the touch. There was also a sore spot on my lower spine. Well, that was all bone cancer, found in hips, spine, ribs and shoulders.

I was put on Zoladex and Nilandron (Nilutamide). The chronic pain was so bad that I could barely walk, hardly sit and couldn't find a comfortable position at night. It all finally disappeared after being on CHT for about 6 weeks. Since then I've been pain free and my mobility has returned.

While most of the pain I suffered was similar to arthritis or just an ache, there was another pain that would rack my body that I've never been able to describe. It would occur when I would be walking, such as in the store. It would grip me so badly through the legs and hips and back that I would have to stop and lean on the cart to rest. My body would shake and I had trouble breathing. It would hurt like hell and yet it didn't. I know this sounds strange but it was such a peculiar "pain." It was as if I had all of the debilitating effects without the agony. And yet there was agony. That has now disappeared.

The main warning I can give anyone is the one you hear often: don't disregard a pain that won't go away. I did it for over a year, stupidly thinking it was something else.

I've been struggling with some deep issues of masculinity from the effects of my hormone therapy that go beyond mere lack of sex drive and into my ability to even show affection.

Before my Dx I was becoming impotent from a combination of some personal problems and the growing pain that made even sleeping difficult. Erections were becoming more infrequent and often difficult to maintain. Zolodex was implanted

in the stomach tissue and I was started on nilutamide. I was told that I would lose my sex drive but I figured it was already dying, so no big deal.

Within days, the pain that was crippling me started to diminish and within a couple of weeks it was gone completely. I started to not only sleep through the night but could on occasions not even have to get up to urinate. (It had been nearly hourly or more frequent before then). In the last couple of weeks, I've felt physically better than I have in over a year. There is no pain, no painkillers, walking and climbing stairs is returning and even urine flow is nearly normal. On that side, I'm thrilled. (The only side effects have been light-to-dark vision adjustment and alcohol intolerance. This is a side effect of Nilutamide).

However, there has been an unexpected downside. Yes, what was left of the sex drive has been lost and disappeared. I dealt with the male ego thing on it. But it continued further to the point now that I can't even express physical affection.

I have been living with my girlfriend who was supportive of me even before my diagnosis. Sex was seldom, but at least I had interest and we might flirt or play around. After all, there are ways that a guy can enjoy a woman or make her feel good even if he can't perform right then (smile). But as the CHT took effect, as the pain diminished and my physical well being returned, even that sexual interest fell away. It is to the point now that the best I can do with her is a hug or just snuggling lightly on the couch. Any serious physical expression of affection is gone. She's commented on it and said how much she misses the physical expressions that I used to do. But I can't conjure them up and I don't understand it. It is as if something inside died along with the libido.

It is like the alcohol intolerance side effect that came with the nilutamide. While I seldom drank, I enjoyed a glass of wine now and then. But after a few weeks on nilutamide, I would get a headache with alcohol. Then my interest in even having a drink fell away. Now it's more basic than I can't drink. I don't want to. That's sort of what happened with me and sex, except it has moved further. Now I can't even include physical signs of affection that I used to have, other than those of just friendship. I don't understand. Is that the way we guys (or some of us!) are really wired?

This morning my GF (girl friend) and I went to a Starbuck's and after I paid and as we were walking out, I was laughing out loud. She asked what was so funny, since I hadn't been feeling that well this morning. I said that when I paid, I noticed my wallet was getting old and I might consider a new one. Then I imagined being in a store and a clerk trying to sell me one with a "lifetime guarantee". I found that incredibly funny, given that I might have only a few months or at most a few years to live.

Robert

**Editorial Note:** In the paragraph above, Robert demonstrated that there is more than one way for one to feel pain. It appears to me that Robert may be suffering

from depression. Cancer and its treatments can have a lot of unpleasant side effects. One of the most prevalent is depression. Depression can be treated. Just as we should not live with treatable pain, we should not live with treatable depression.

Here is an update on Robert:

The lack of pain and loss of potency and libido has continued but the ability to be affectionate has returned with little moments of libido, as if the body is trying to rewire the function. After months of nothing, I find it encouraging. - Robert

Robert has set up a web site at <http://www.phoenix5.org>. Here is his description: "It was created to help men and their companions with the deeply personal issues created by prostate cancer, most of it from the treatment of PCa, such as impotency and incontinence and the effects on the relationship. The site draws heavily from first-person accounts by both men and women that I gathered from the individuals, although there are professional articles and abstracts. However the emphasis is not on treatment, but deals with the effects of the treatments and how men and women have dealt with them, successfully and unsuccessfully. The purpose is not to advise but to let people know that they are not alone in this fight and to see how others have dealt with it."

Robert mentioned the loss of his libido when he started on the combined hormone therapy. Libido is a very important facet of life. It can be suppressed by a host of things such as drugs, depression, environment and many, many other things. But we know very little about the libido. There is no literature about it.

### **Government Agencies**

There are several government agencies that have been set up to regulate and protect us consumers. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) Standards formulated a set of standards. Below are some of the things patients should receive from hospitals, home care agencies, long-term care facilities, behavioral health facilities, outpatient clinics, and health plans. It is much like a patients bill of rights. Health care organizations:

1. Recognize the right of patients to appropriate pain assessment and management
2. Assess pain in all patients
3. Record the results of the assessment in a way that facilitates regular reassessment and follow-up
3. Educate relevant providers in pain assessment and management
4. Establish policies and procedures that support appropriate prescription(s) and/or medication orders
5. Assure that pain does not interfere with participation in rehabilitation
6. Educate patients and their families about the importance of effective pain management
7. Include the need for symptom management in the discharge planning process

## **Government Agencies and Pain Medications**

Pain is manageable. No patient should have to suffer pain, especially a terminally ill cancer patient. There are several medications that a doctor can prescribe. However morphine, and many other effective drugs for pain, are on the Government's list of controlled substances. The Federal Drug Enforcement Agency (DEA) closely monitors all prescriptions for controlled substances. If they find that a doctor is writing too many prescriptions for these drugs, they can file charges against him. The CBS show, 60 Minutes recently did a story about some medical doctors who were writing many prescriptions for pain drugs. The DEA raided their offices, shut them down and had the doctors licenses revoked.

Several of the patients who were receiving the pain medications were interviewed. They were devastated because they could not find other doctors who would prescribe the amount of pain medication that would make them comfortable. Because of the threat of the DEA, other doctors are overly cautious.

## **Pain Management: Are Patients Suffering Because of Strict Regulations**

<http://www.medscape.com/medscape/features/spotlight/sep/jc-0997.spotlight.html>

The Medscape web site above has a lot of very good information about cancer and treatments. They also have an area for comments and letters.

## **Bone Pain**

Prostate cancer causes very little pain in the early stages. But it can be very painful in advanced stages. Prostate cancer often metastasizes to the bone. The pain can be very difficult to control, especially if it is in the spinal vertebrae. The effects of some treatments may also cause pain and discomfort. There are several pain killers available. However, the government still has policies that may prevent one from getting the necessary drugs or make it very difficult to do so. A person may be dying and suffering horrible pain, but the government is very fearful that a person may become addicted. Even if the person is dying, it seems that they would rather see him die in pain rather than become an addict for the short time he may have to live.

Dr. Marc B. Garnick wrote a book, "The Patient's Guide to Prostate Cancer". On page 234, he says "It is extremely important for both the physician and patient to recognize that addiction is almost never a problem...In my twenty-plus years of caring for patients with metastatic prostate cancer, I have never seen one of these patients abuse pain medicines. A fear or perception of addiction, on the part of physician, patient, or family, may lead to underdosing, leaving the patient in a state of constant pain. Pain relief is the goal, and unless it is achieved, the physician has not performed his or her job satisfactorily."

Below is a portion of a note that was posted on the Internet:

From: Diana Morison <dicymor3@CONNECTNET.COM>  
Subject: Pain Management

<Some of you may remember my husband, Rod, who has been fighting the monster since 1989. He is now 78 and tiring of the battle. As the result of a recent cystoscopy and TRUS by Dr Barken, we have been told that there is a tumor invasion from the prostate into the rectum. The only remaining option, for a variety of reasons which I will not go into, is palliative. He is now seeing an anesthesiologist who specializes in pain management. Oxycontin (codein without the aspirin or acetaminophen) has been tried with unacceptable side affects.

The doctor is now proposing a spinal narcotic pump which is implanted in the abdomen with a catheter leading to a strategic place in the spine. The pump is loaded with morphine (usually) which is dispensed at a predetermined rate. This implant will be preceded by trial injection(s) to ascertain the success of the medication.

Both procedures require hospital stays as well as pre-approval by Medicare. The Medicare pre-approval involves a psychiatric evaluation which has Rod (and me) very unnerved. There must be a better way.

Diana>

Note that for Rod to get the pain medication, he would have to undergo a psychiatric evaluation. The Government and Medicare should be pleased to know that Rod did not become addicted. Diana and Rod thought about all the trouble it was to get the drugs and decided that it wasn't worth it. Rod died less than two months later.

The Circle is a group of people on an Internet list who offer hope, love, encouragement and support to all. Here is an account that was on the Internet Circle:

< From: TSShep@aol.com

<Hello to all - this is not an easy thing I am doing, communicating with so many people, but I know I need to and I know there are a lot of friends out there, so here goes.

Tom was diagnosed almost two years ago (on our 35th anniversary) with a PSA reading of 255. His testicles were removed in April and the cancer was dormant for almost a year. The Urologist said that he probably had had the cancer for at least 5 years before diagnosis, but the doctor he was seeing for checkups never told him there was a problem.

Last June his PSA tests started rising (we got them down to about 2.8 at the best) and we watched that for about six weeks and then put him on a hormone therapy called Casodex. About the same time we looked into finding an oncologist. Both doctors said watch for any changes, and I said what should we be looking for. To back up a bit he had cat scans, bone scans, and I did ask the Uro if the cancer was in his bones and he said yes. Tom didn't hear this, so I let

it lie because I knew that would really scare him, and at that point he didn't really need to know. Anyway, they told us to look for pain in the back, paralysis. Scared the life out of me.

The end of September (on his birthday) he got up from a nap and had a sharp pain in his back. I called the Uro office, talked to the secretary and said we think it is a muscle strain and would like to go to a chiropractor, is that ok? Call back if not. No call back, so we went. Did nothing to help the pain, so Tom asked to see his primary physician, which we did. He said I will prescribe a pain killer, but you have to have an MRI to see if this is a muscle strain or is it the cancer.

Of course the MRI showed it was the cancer. It had metastasized in his lower back, and when I saw the picture I could see that one vertebra was really eaten away and you could see the tumor poking out of it. So we immediately went into radiation.

The pain never stopped. He was on so much codeine and morphine that I was starting to fall apart. I hated the pain. So after radiation, but before we could tell how effective it had been, he had another MRI which showed that the tumors had reduced in size, but one vertebra was so eaten away it had collapsed and that might be the cause of the pain.

He sleeps in a hospital bed because his back and knees can never be flat, I sleep on the couch next to him because he is on too much morphine to leave him alone.

He has just had his second dose of chemo, he handles it well, no bad side effects and he is doing better. We are off MSIR (morphine which is similar to Tylenol 3) for five days - first time since 9/30/96 - and today he was really dopey which tells me that the long acting morphine (MS Contin) dose is I think too strong. The radiologist explained that when you take dope and have pain, the dope goes directly to the pain to kill it, but without the pain it goes directly to the brain. That is why I think even the long term morphine is too strong, it is going to his brain, so I hope within the next week we can start reducing the dose and let this guy come back to normal.

I'm glad my daughter, Mindy, told me just to get on the Internet and tell it all, but I guess I am pretty long winded. I am in some emotional problems now - my nerves are very frayed, but I am strong - have talked a lot with Myrt and she has been heaven sent, plus a couple of other people, Lisa, and all. This is a wonderful support group and it will get us through these tough stages. We all need support.

Thank you all for listening to me. I hope to participate more in the future. Love you all - this is a wonderful networking group.

Love and God Bless - Susan Shepard>

Notice in the two notes above how many times the wives said "we". If anyone had any doubt, cancer is a family thing. It affects everyone, especially those who love you.

Note this sentence in her post: "The Uro said that he probably had had the cancer for at least 5 years before diagnosis, but the doctor he was seeing for checkups never told him there was a problem."

It is too bad that Tom was not diagnosed earlier. He might have had fewer complications and lived longer. The answer to cancer is early detection.

Here is a followup note from Susan:

Subj: Tom's Update  
From: TSShep@aol.com

<It is just over two years since my husband, Tom, died. It seems like the right time now to give a final accounting of our fight against this disease. My first letter in January, 1997, written to the Circle, told about Tom's diagnosis (2/95) and the treatments he had through until 5/97. When he was done with his chemotherapy (Novantrone), he was out of pain - off all pain medication - and his PSA had dropped from 287 (start of chemo) down to 34.5. What a wonderful relief! We had a terrific summer in June of 1997, travelling, seeing special friends and places.

However, even though the pain was gone the PSA was still rising and the doubling time was becoming shorter and shorter. Here are some readings:

6/6/97	34.5
7/16/97	62.1
8/27/97	244.2
9/19/97	456.2

After consulting with the radiologist and oncologist it was decided that Tom would go through another session of radiation. He was "tattooed" the middle of September and we were told that before the treatments started it would be fine for us to travel from our home in Massachusetts to San Diego, CA to a prostate cancer conference. We would stay for a week and then start the treatments when we returned. This was a very special trip because our son was a Captain in the Marine Air Corps and stationed in San Diego. We hadn't seen him in over a year and now, in hindsight, that was the last time he got to see his Dad healthy.

We started the radiation treatments about the 10th of October. At the same time he was put on Ketoconazole. The pain had returned but not very severe at this

time. He was still able to get around with the help of two canes. But it was too late, the cancer was advancing faster than we could stem it.

I have heard a number of times from others that the end comes very quickly - this was so with Tom. He was up and about, joking with his doctors, having tests run, doing what he did every day, then one day he wanted to sleep and by that night he was in a coma. I called for an ambulance and we got him into the hospital. He died 5 days later on October 22, 1997.

I don't know how I would have survived the 2+ years that we fought this disease or the 2 years since he died without the love and caring of family, friends, and most especially, the Circle.

I have stayed with the Circle. I have found that helping others has been a great help to me, has aided the healing process. My greatest wish, hope, desire, is that a cure is found for this dreaded cancer and that the day will come when families won't have to experience the pain and suffering that comes with this disease. It exacts a terrible toll.

Love and blessings to all, Susan>

To subscribe to the Circle that Susan mentioned, send e-mail to:  
majordomo@prostatepointers.org  
Subject: (blank or a dash)  
Message: subscribe circle

Here is a message posted by Sipora about her husband Mike:

<Subj: [PP] Oxycontin for Pain Relief

Hello

A subscriber wrote to me with questions about Oxycontin. I responded privately, and I figure I might as well write to the list, as this information might be interesting to others, as well.

It is a very strong narcotic. Oxycontin is strictly a pain reliever. It must be prescribed by a doctor with a written prescription (not on the phone, obviously). It comes in doses of 20mg., 40mg. 80mg. (no 60mg. for some reason).

You start with a small dose, say 20mg. twice a day, and see if it works. Then you adjust it accordingly. At one point last year, Mike started with 20mg. twice a day, and we quickly realized that it was not enough to control his pain. Over time, with his doctor's guidance and permission, Mike had to up the dose to 300mg. in the morning and 300mg. at night. This was a huge jump, but it happened gradually, and that's what it took to control the pain. Then, after surgery, radiation, and chemo, his pain subsided, and he was able to reduce the

dose back to 60mg. twice a day. Now, with chemo failing and the PSA climbing, the pain has increased, and Mike now takes 240mg. twice a day.

At the beginning, when the body gets used to the dose, the patient sleeps a lot for a day or two. Once he reaches the condition of no pain (not even breakthrough pain), the patient takes that dose, as long as it works. Once there is breakthrough pain, the dose is raised by 20mg. If the patient feels lightheaded or "high", he might try and cut back on the dose, say 20mg. less at a time, and see if the new dose still controls the pain. If not, raise it again by 20mg. All this needs to be done under the guidance of a doctor, of course.

Side effects of Oxycontin are minimal. Constipation, which is helped with 4 pills per day of a laxative/stool softener. And, as I said, sleepiness at the beginning, before the body gets used to the Oxycontin. We try and raise the dose on a Friday night, so that Mike has the whole weekend to adjust to the new dose. This seems to work best for us.

Regards

Sipora>

Here is another post by Sipora about Mike:

Subj: [Circle] Mike Meschino - The Watch  
Date: 04/14/2000 5:11:50 AM Pacific Daylight Time  
From: MEMeschino@aol.com  
To: circle@prostatepointers.org

Hello Circle Family

Well, we're still here, still....

Mike hasn't eaten in 3 days, and the only liquid he gets is some ice chips that we place on his lips and in his mouth. I learned the ice-chip trick on Circle a while ago, good idea. I put some chapstick on his lips, because they are so dry. The oncologist, when asked if Mike was going to make it to Easter, said that he probably won't.

Mike's kids were supposed to come Easter, but instead, they came yesterday. Mike is in his own world, but he acknowledged his daughter, Yvonne. His son, Travis, just touched him, and it was enough. Today, Mike's mom is coming. She, too, was supposed to come for Easter. This is the part that sucks the most, that she has to see her oldest son like this.

Mike has developed a gurgling sound when he breathes. A while ago, someone on Circle mentioned that it was more bothersome to the relatives than to the

patient. I explained to everyone that it was mucous, but I ordered a drug to dry him up some, because it sounds like he is suffering, and also so his mom doesn't get too upset. We had a family reunion at Christmas, and Mike was still the picture of health.

The morphine was upped to 50 mg., with Ativan (sp) to stop agitation. Unfortunately, the nurse ignored my handwritten order to "do not wash and do not move" because Mike's sheets were crumpled. Now, there is a "do not wash and do not move", written by the doctor himself.

Mike developed a fever, 102, last night. Since he can't swallow, the nurse was going to give him a suppository, and she would have to move him to the side to do this, but I said over my dead body.

P.S. I found out accidentally that the hospital has an apartment for patients' relatives. The apartment is practically on hospital grounds, and it has a living room with 2 Bermuda beds and a bedroom with 2 double beds. We decided to rent it. There is no time limit as to how long we can have it. I think we'll stay there this weekend, as the drive back and forth is wearing me out.

Thanks for your love and prayers.

Sipora>

I am very sorry to say that Mike died just a few hours after Sipora sent this post. He was a young man, still in his 50s. He left a young son and daughter and a loving wife.

For the last three years, Sipora was on the Internet almost daily, trying to find ways to help Mike. She had never met most of the people on the Circle, but she was family.

Here is a post from Mary about some of the drugs used for pain:

From: LeonMary@AOL.COM (Leon Bresloff)

I've been forwarding some of the pain management posts to my daughter who has been a certified hospice nurse for the past 12+ years. I've been interested in her feedback and thought some of you might appreciate it also so I'm sending it on.

Regards from Maine  
Mary

From daughter, Mija:

"Decadron is also used for bone mets. Aredia and Strontium injections are very effective in decreasing bone pain. Opioids are not so good in the long run. They usually need to be used with NSAIDs. (NSAIDs: non-steroidal anti-inflammatory drugs such as Ibuprofen, Naprosyn, Naproxen, Ketoprofen, etc) at the same time to decrease inflammation from mets in bone). Aredia gives better results than Strontium 89.

Oxycontin is a form of long acting Percocet. It is similar to MS Contin which is also a form of long acting morphine. MS Contin can be given every 12 hours. Doctors seem to love it because the side effects are minimal. Few people have adverse reactions to Percocet.

The person may eventually need to convert to subcutaneous IV meds. He may be unable to swallow or the oral dose may be so high that the amount of pills needed becomes prohibitive. In this case the person could convert to Morphine/ Dilaudid.

VERY IMPORTANT NOTE: Do not crush, dissolve or alter the pills in any way otherwise they are no longer effective as a long acting medication and in essence become a short acting med.

NOTE: there is no set dose to ANY opioid used in chronic cancer/terminal pain management, not just this drug. Same with Morphine, Dilaudid, Fentanyl (Duragesic), etc.

The reason one gets better pain relief from bone pain by taking both a long acting opioid like MS Contin or Oxycontin or Duragesic patch and a NSAID like Naprosyn is this: the opioids work on the central nervous system to diminish the pain receptors and the NSAIDs affect the peripheral nervous system to decrease pain.. Since bone pain is a pain which crosses both, one needs to use dual meds to reach each system."

### **X-rays**

If a well defined the metastatic site can be identified, it may be treated with spot radiation. Often this will reduce or eliminate the pain for some time. Of course, if the patient has had radiation before, there may be a limit as to how much radiation can be given.

### **Metastron (Strontium 89)**

Mija mentioned Strontium 89 or Metastron. For more information go to:  
[http://www.amersham.com.au/Healthcare\\_Catalogue/PATINFO/sms2ppi.htm](http://www.amersham.com.au/Healthcare_Catalogue/PATINFO/sms2ppi.htm)

Metastron contains small amounts of a specially selected form of radioactive strontium, chosen because almost all its radiation is given to the area where it is absorbed. This allows it to deliver therapy precisely where it is needed.

Before starting the Strontium 89, a radiologist may ask the patient some questions and explain the test. An I.V. will be started with medicine given through the I.V. The treatment takes approximately 30 minutes in all.

Metastron is similar to calcium chemically. It locates all areas where bones are absorbing extra calcium and causing pain, then it stays there for several weeks and steadily provides pain relief. At first the patients may feel no effect at all. He may even feel a slight increase in pain during the two or three days after injection. This is quite normal and he may need to increase his dose of pain killers slightly until this subsides.

After about two weeks, sometimes a little longer, he should begin to feel the pain diminish. This reduction in pain should continue and the effect should then last for several months.

His doctor may advise him to continue to take pain-killing medicine until the pain starts to subside. The doctor may then suggest that he begin to reduce the dose gradually. He may continue reducing the dose and eventually he may not need pain killers at all.

Strontium 89 may give pain relief in about 80% of the patients and may last for up to six months. It has an affinity for metastatic bone metastasis and will bypass other sites to reach the cancerous bone sites. Once there, the radiation may actually kill off some of the cancer cells as it provides relief from pain. Strontium 89 has a fifty-one day half life so it remains in the body for some time. If a new metastatic site begins to form, the drug that is present in the body will rush to that site and stop any pain from it and possibly kill many of the cells by its radioactivity.

Strontium 89 can be used along with spot radiation for even greater effectivity. Strontium 89 treatment can be repeated in about 6 months if necessary. It may cause some bone marrow suppression, so the patient should be checked for blood levels.

Amersham is now a part of the Nycomed Corp. You can find more information at <http://www.nycomed-amersham.com>

### **Samarium 153 (Quadramet)**

Samarium 153 or Quadramet is a radioactive drug that is similar to Strontium 89. Here is some information from their web site at: <http://www.quadramet.com/>

Quadramet (Samarium Sm-153 Lexidronam Injection) is an agent to treat bone pain due to cancer. It targets the sites of new bone formation, concentrating in the areas where the cancer has spread

Once injected, Quadramet concentrates selectively in the areas where cancer has spread to the bone. Quadramet irradiates these sites, and in patients who respond, alleviates the pain associated with metastatic bone disease.

Patients who respond to Quadramet may begin to notice the onset of pain relief one week after injection. In general, pain relief reaches a maximum at three to four weeks after injection, and patients may be able to decrease their use of opioid analgesics. In controlled clinical trials, approximately one-half of the patients reduced opioid usage by week four.

Some patients have reported an initial increase in bone pain shortly after their injection of Quadramet (flare reaction). Usually, the increase is mild, transient, and occurs within 72 hours following the injection of Quadramet. These reactions are usually responsive to analgesics.

### **Novantrone or Mitoxantrone**

Here is some information from the Immunex web site at <http://www.immunex.com/>

In November 1996, the U.S. Food and Drug Administration (FDA) approved Novantrone (mitoxantrone for injection concentrate), the first chemotherapeutic drug for the treatment of advanced hormone-refractory prostate cancer pain when used in combination with corticosteroids.

According to a questionnaire, many Novantrone patients had less pain. Patients were asked to describe changes in: 1) their daily level of discomfort and the degree to which it interfered with daily activities; 2) the frequency of their pain; 3) the intensity of their pain; and 4) the duration of their pain. These questions were asked every 3-6 weeks after treatment began.

Also, when responding to these questions, patients reported having less intense pain and using fewer pain medications. In this study, patients taking Novantrone experienced a longer time until their disease progressed.

Researchers found that almost twice as many patients taking Novantrone had less bone pain or needed less pain medication. And pain relief lasted, on average, nearly eight months for many of the patients who received Novantrone, compared to around two months for patients taking prednisone alone. Novantrone delivered nearly four times longer pain relief. Of course, not everyone will respond to Novantrone plus corticosteroid therapy.

Immunex has established a toll free number (1-800-220-6302) to help patients and their families obtain the information they need about this treatment. Novantrone is the first chemotherapy drug approved for treatment of pain from advanced hormone refractory prostate cancer.

Strontium 89 or Metastron works on bone pain; Novantrone works on pain related to soft tissues. These two drugs can go a long way in eliminating pain.

Again, there are several ways to deal with pain. You should not have to suffer.

### **Pain Therapies**

Besides the many analgesic (From Greek, an- means not, -algos means pain) drugs that we have there are several mechanical and electrical devices that can help to alleviate pain. One system uses transcutaneous electrical nerve stimulation (TENS)- (Trans- is Latin for across, cutaneous is from Latin cutis for skin). TENS is the application of a mild electrical stimulation to skin electrodes placed over a painful area. It may cause an interference with the transmission of the painful stimulus.

### **Medical Marijuana**

The voters in California, Maine, Arizona and several other states have passed laws that will allow a doctor to prescribe marijuana for certain ailments. A search of the Internet with the word marijuana found 79 websites. Many of them were advocating legalization of marijuana.

Many patients claim that marijuana is the only thing that relieves their chemotherapy nausea problems. Chemotherapy often causes the person to lose their appetite. Marijuana is well known for causing a person to get the munchies. Many AIDS patients say that it is a tremendous help to them.

However, the Government says that Federal laws against marijuana preempts the state laws. They have said that any doctor who prescribed it would be charged with a felony. The New England Journal of Medicine recently came out in favor of doctors being able to prescribe Marijuana.

Marijuana is still illegal for most people in Canada, but the government has recently given the okay for it to be prescribed for AIDS and other patients who need it.

Dr. Dean Edell has a radio talk show. He has also written a book called "Eat, Drink And Be Merry". He says on page 202 of his book:

"There is no proved short-term or long-term damage to health from occasionally recreational use of marijuana by adults. Nor has there been a recorded death associated with its use, other than possible motor vehicle fatalities....Marijuana has unique pharmacological actions. It is a powerful antinauseant and stimulates appetite which explains why it is so valuable in the treatment of cancer and HIV. The list of conditions that researchers believe can be alleviated by marijuana is lengthy, including multiple sclerosis, seizures, strokes, breast cancer, PMS, and headaches".

He did not mention prostate cancer, but it has a lot in common with breast cancer so it should help.

Amsterdam is a beautiful city. It is one of the most liberal cities in the world, yet they have very little crime. If a person does get convicted of a crime, he can serve his jail time on the weekend, so that he can work during the week. Almost everything is legal there from prostitution to cannabis cafes. One can go into one of the cannabis cafes, order a cigarette and smoke it in peace.

One can also grow their own. Amsterdam has lots of canals and lots of houseboats. If a tourist takes one of the requisite boat trips through the canals, he or she will see almost as many marijuana plants as geraniums growing on the decks of the house boats.

It seems a shame that so much money is spent by the Federal Government in trying to eradicate marijuana. There are thousands of men in prisons because of marijuana. It is ruining the lives of these people and costing millions of dollars to keep them there.

This money could be better spent on cancer research.

### **Some Pain Information Resources**

The "Home Care Guide for Advanced Cancer Patients" How to Care for Family and Friends With Advanced Cancer at Home" is a Web-only publication, which can be found at [http://www.acponline.org/public/homecare/.](http://www.acponline.org/public/homecare/))