



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - October 2012

Editor's Note: The following article was written for the Polio Outreach of Washington State. It is reprinted with permission. Although some of the material is specific to the State of Washington, the article contains valuable information for anyone trying to manage chronic pain.

New Rules for Pain Management

By Janet Bliss

Janet is Secretary of the Polio Outreach of Washington, www.poliooutreach.com

As a Polio survivor, I've experienced chronic pain for the past ten years and have used opiates. Recently, I was asked to complete a lengthy, in-depth questionnaire and to provide a urine sample before receiving my prescription for pain medication. I was surprised and even a little offended. I also experienced some fear: was I going to be denied medicine that helped me get through the day?

My physician explained that the urinalysis and pain study are now a part of his requirements when prescribing opiates. If you are also among the many polio survivors regularly using opiates for chronic pain, then you may soon experience changes in the way that your doctor is prescribing medications. In Washington State, the [Opioid Dosing Guidelines for Chronic non-cancer Pain](#) is a voluntary attempt to correct medical problems with overdosing of opioids.

Commonly prescribed opioids include codeine, hydrocodone, oxycodone, fentanyl, hydromorphone, morphine, methadone, Demerol, and Darvon. Some of these opioids are combined with Tylenol and aspirin. Too often, patients may self-medicate with additional

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doses of over-the-counter pain medicines, thus increasing their chance of damaging internal organs. Methadone, in particular, is an opioid that accumulates with repeated doses and can become toxic to the kidney and liver. Opioids are highly addictive, with the result that the individual will often require increased frequently and/or stronger dosage to be effective.

All of this can lead to overdosing and the State of Washington is attempting to reduce accidental deaths with the voluntary usage of the Opioid Guidelines. When the pain is not improving and/or the individual's dosage is increasing to above 120mg/day, the guidelines recommend a second opinion or reevaluation of the cause of the chronic pain. The system, including physician and patient, are now being scrutinized and everyone has more responsibility for the safe use of pain medication.

Patients, who are currently taking an opioid for chronic pain, may also face new requirements. Drug tests, given before providing prescription refills, and completing personal medical questionnaires, may become the norm, rather than the exception.

Washington State, as part of its Medicaid program, is currently monitoring practitioners who prescribe high volumes of narcotics. In addition, Medicaid recommends the use of one doctor/practitioner for prescriptions. This has reduced "doctor shopping" for multiple narcotic prescriptions, with the result of fewer deaths caused by inadvertently combining and/or providing higher dosages of pain drugs. This can happen when an individual visits multiple physicians for the same condition. For example, someone experiencing chronic pain may be working with a Primary Physician, an Orthopedic Physician, and a Naturopath. If these physicians are not a part of the same medical provider, then a record of all the prescriptions and supplements, written for the individual, will not be known.

Prescriptions for opioids can, and do, act adversely when combined with muscle relaxants, sleep aids, and antidepressants. Drinking alcohol and using recreational drugs in combination with pain medications can also contribute to adverse reactions and is often the cause of accidental death and/or renal failure. Hundreds of patients die each year from accidental overdoses of prescription pain drugs.

Is there a connection between emotional pain and physical pain?

Sadness, unexpressed anger, anxiety, shame and guilt, increase the physical response to an inability to do things independently. Polio survivors have experienced many of these feelings as they have aged, and these often times exacerbate their chronic fatigue and pain.

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Pain management or pain rehabilitation may be in your future...

If your doctor is refusing to provide you with stronger doses of opioids, your level of emotional pain is increasing and you feel out-of-control, then you are a candidate for pain management. Generally, a clinic that offers pain management has a team of at least three medical specialists (Coordinating physician, physical rehabilitation specialist, and a psychiatrist) who will work together to design a personal program for the individual. Other medical specialties may also include neurosurgery, anesthesiologist, internal medicine, occupational therapists, social workers, and/or alternative medicine practitioners.

The goals of pain management are to minimize pain, rather than eliminate it, improving function and increasing the quality of life. People with opioid addictions usually require a chronic pain rehab program, rather than a pain management program.

What else can you do?

If you are experiencing chronic pain, then thinking about the future is difficult. Suddenly being faced with drug tests, to prove that you're only taking as much as being prescribed, or being asked to complete a mental health questionnaire to determine your fitness to take pain medicine, is daunting.

You will probably be asked to identify when you are most likely to experience your worst level of pain. What level of pain are you experiencing at the time you are completing the office visit? Is it worst in the morning, afternoon or night? How can you help your doctor identify your level of pain? Swelling? Elevated blood pressure? Depression? Fatigue? If you are prescribed "one pill" and you take two, or three, then the levels of the opioid will be shown in your urinalysis.

Learning effective coping strategies can help you deal with the anxiety that you face on a daily basis. Polio survivors, as a group, tend to be demanding! If you want to control your chronic pain, you have to ACCEPT that chronic pain is never going to be completely eliminated. We all experience levels of grief as we find ourselves being faced with additional bracing, wheelchairs, crutches, and home aids for bathing and housekeeping. It is okay, and necessary, to express your grief about these losses. Take the time to cry, yell, talk to your support group, best friend and/or spouse about your feelings. You are not helping yourself by denying what you are experiencing.

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Your daily schedule can often be a trigger for increased levels of pain. Planting primroses may be fun in theory, but in fact the reaching, bending over, and then trying to stand, from a sitting position, may cause you more pain than folding clothes! Vacuuming one room or vacuuming two rooms? Sitting for more than an hour or getting in and out of the car doing errands? Grocery shopping? Who hasn't experienced more levels of pain when doing tasks that tend to be more physically demanding? Do we continue to push ourselves unnecessarily, with the thought that we can always take another pain pill?

You've grieved your loss(es), you've discussed pain, and now you've identified which tasks cause you increased levels of pain. Your doctor has probably asked you to identify the level of your pain, from 1 being the lowest, to 10 being excruciating, intolerable pain. You can do this for yourself as you go through your daily schedule. Common sense has to prevail – even for polio survivors! You may also be asked to identify your current level of pain when you see your doctor, so this is a habit you will need to develop.

If you know what increases your pain, you usually know what you can do to make yourself feel better. Having a rigid schedule makes no sense when you wake-up feeling tired, stiff, and when you can't turn your head to the left or right! Give yourself a break and relax. Do the exercises that you learned from your massage or physical therapist, add a hot towel to your neck and change your schedule. You are still in control. If you're at a personal pain level of 7, then don't start doing a task that is going to make it increase to a 9 or 10! This is certainly easier and healthier, than taking another pain pill. Try doing less, before you self-medicate.

Being aware of **what** triggers your pain, can help you to make better, more informed decisions, as you negotiate your daily behaviors and habits. **You determine what, when and how you do something, based on how you think it will affect you.**

Prescriptive use of opioids in the State of Washington is being justifiably scrutinized because of the high incidence of misuse and deaths resulting from overuse. A substitute, like methadone, a drug that has proven to have the potential of staying in your system, is not a recommended solution. The latter may be less expensive, but it is also inherently more dangerous. It is imperative that if you are experiencing chronic pain, you need to explore your current prescriptive program. Combining prudent usage of pain medications, with coping strategies, is the first solution. Once you adopt a "reasonable" daily schedule, and you still feel that your pain level requires more opioids, you may require a pain management component.

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For further reading, please refer to the series of articles by Michael J. Berens and Ken Armstrong, Seattle Times staff reporters. Pain management programs, and addictions, are also represented by Medscape.com, and About.com. The website for AMDG (Agency Medical Directors' Group) has also provided their dosing guidelines at: www.agencymeddirectors.wa.gov/opioiddosing.asp

We thought the following article from our 2000 newsletter would be appropriate now because our December 8, 2012 joint meeting with the Post-Polio Support Group of Orange County will focus on bathroom challenges for both men and women. Our special speaker will be polio survivor Dr. Donna Barras, a good friend and member of both the Rancho Los Amigos and Orange County Support Groups. She will lead us in a candid discussion of toileting issues that face both sexes.

Is There Any Relief In Sight?

By Richard Daggett

I accepted the picnic invitation without reservation. It sounded like it would be fun, and I had been to this park several times over the years. I knew the ground was level, the grass was not too high, and there were plenty of shade trees. However, I forgot one important factor. During my previous visits to this park I was walking. Now I used an electric wheelchair full time.

I arrived at the park just before noon. Some of my friends were already there and others were trickling in. We visited as we spread our food on the tables. There was plenty to eat and drink. The weather was a little cooler than anticipated, but the hot coffee warmed my insides.

By two o'clock we had all eaten too much, and I had consumed three cups of coffee. It was time to visit the "facilities." I drove my wheelchair across the grass toward my destination. As I approached I saw something I never noticed before. There was a six-inch high concrete step leading up to the door. I had used the same restroom when I was walking, and steps weren't a problem. I never really gave it a thought. Now my legs were much weaker. I could stand to transfer, but there was no way I was going to get up this step. And, even if I did, I could see from the outside that my wheelchair wouldn't be able to get near the toilet.

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What to do? What to do? I had given some thought to this possibility, but this was always while I was safely at home. And always in the abstract. Now the abstract had become reality. And the reality was that I had to go.

The only practical solution at the time was to leave the picnic. I wasn't too far from home and I knew I would be able to get there before my bladder burst. But it was fun visiting with my friends, and I didn't want to leave. I decided to give some serious thought to finding a solution. I didn't want to face this dilemma again.

I am male, so, at least in theory, that should make the urination problem a little easier. I could carry a urinal in my van. I've done that a few times. It's still a hassle. You have to get partially undressed to use one if you're seated in a wheelchair. At least I do. The van's tinted windows don't really provide much privacy either. And I'm always afraid I'm going to spill something.

There are female urinals available, too. But the ones I've seen require that the user be at least partially reclined. And women would have the same problems with clothing, spilling, and privacy.

Leaving an event and going back to my van might not always be practical either. When I was at a black-tie dinner in a well-known, older hotel the restrooms were not wheelchair accessible, and the only place I found to park was some distance from the hotel. It would have been aggravating and dangerous to dodge traffic if I returned to my van. Fortunately for me I didn't need to use the toilet. But the thought remained in the back of my mind all evening.

One solution if you are male might be an external condom-style catheter. I have many spinal cord injured friends who use them. They connect the catheter to tubing that leads to a leg bag. It's not usually visible if you wear the right kind of clothing. I could put the catheter and the other paraphernalia on if I anticipate that I'll be in an area without accessible toilets. But, now that I think about it, could I really put on an external catheter by myself? My arms and hands are much weaker now too. I can reach "down there," but not with much dexterity. And I'm not sure I would be able to ask for help with something like this.

If you are a woman you are presented with a whole different set of problems. I saw an article in an old issue of "The Disability Rag" about a woman who was trying to find a solution that worked for her. She found a female external catheter in a catalog. It had to

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be glued on. She said that it didn't work very well, and getting it un-glued was "very unpleasant." I've never seen a female external catheter in any of the many catalogues I receive, and I'll bet that "very unpleasant" is an understatement.

Of course, both men and women can dehydrate themselves in anticipation of going out. This might work occasionally, but cutting back on fluid intake on a regular basis is not a good idea.

The main reason for writing about this is that we hope you will begin thinking about these issues. You might not have any difficulty right now, but ... "what if?" Many of us are getting weaker. Some people who were ambulatory now use wheelchairs. Personal care tasks that were once routine are more difficult and time consuming. Using public restroom facilities is just one aspect of this, and we are often reluctant to discuss personal care issues with others. As a result, we miss the opportunity to learn from another person's experiences.

As you ponder "what if ..." please put your thoughts on paper. Bring these notes to our December meeting or, better still, send them to our address below. You can respond anonymously if you wish. We would really like to hear from both men and women. These are questions that need answers. Your questions and your answers may make life easier for others. Send your comments or questions to:

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or e-mail them to: RanchoPPSG@hotmail.com

**WE'RE
STILL
HERE!**
October 7-13, 2012
www.post-polio.org

We're Still Here! is a project of Post-Polio Health International and the estimated twenty to thirty million polio survivors around the world. Polio survivors are your neighbors, friends, and co-workers. We pioneered home care for those with severe disability. We pushed for equal rights for people with disabilities. We walked the walk, and fought the fight, and **We're Still Here!** Check out the many possibilities to celebrate at www.post-polio.org

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**FREE MATTER FOR THE
BLIND OR DISABLED**

MEETING NOTICES

Rancho Los Amigos Post-Polio Support Group

Saturday, October 27, 2012 - 2 p.m. to 4 p.m.

Smile, as We Focus on the Positive

Saturday, December 8, 2012 - 2 p.m. to 4 p.m.

Donna Barras, MD - Physician, polio survivor, good friend

The Post-Polio Support Group of Orange County will join us for this very special meeting.

Post-Polio Support Group of Orange County

Saturday, November 10, 2012 - 2 p.m. to 4 p.m.

Christine Phan, MD - Kaiser Physiatrist

NOTE: *You will receive a special mailing in November with more information about these very special meetings. Be sure to watch for it and mark your calendars.*