



Osteoporosis Canada

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***COPING***  
**The E-newsletter of the**  
**Canadian Osteoporosis Patient Network (COPN)**  
**November 2005**

***COPN – Dedicated to representing people with osteoporosis on all issues related to the disease.***

***COPING: One Year Old***

The first issue of *COPING* (we didn't have a name then) was published in November 2004. With your support, we have grown tremendously in the year since then. Our subscribers have more than doubled, and the list continues to grow every month. Thank you all very much.

We want to be sure we are meeting your needs. Please drop us an email [copn@osteoporosis.ca](mailto:copn@osteoporosis.ca) or phone 416-696-2663, ext. 229, and give us your answers to the following:

1. Have you enjoyed receiving the newsletter?
2. What have you enjoyed the most?
3. What have you liked the least?
4. What areas of interest to people with osteoporosis would you like us to add to the newsletter?
5. Any other comments?

We look forward to hearing from you.

**What Does It Mean to Live with Osteoporosis?**  
**Negotiating a New Sense of Self**  
**By Richard Hovey**

A version of the following article was presented at **New Perspectives: International Conference on Patient Self-Management** in **Victoria, BC, September 2005**.

Richard Hovey is a doctoral candidate at the University of Calgary, Alberta. This article is adapted from his PhD thesis and is based on interviews with Priscilla Cole and Gail Lemieux, COPN members. Richard has been a member of the national Board of Directors of Osteoporosis Canada and recently joined the Steering Committee of COPN.

The experiences presented in this paper come from people who have learned to live their lives fully again in spite of a diagnosis of osteoporosis. A diagnosis of an illness such as cancer, diabetes or osteoporosis turns lives upside down. Coming to understand what this means within the context of a life is the task of my research. To understand my role as a researcher, consider a three-way relationship wherein one person comes to an understanding with another person about something they consequently both understand. When two people

understand each other, they always do so with respect to something and, in this case, the “something,” or the topic being understood, is the experience of living with osteoporosis.

This approach provides an opening for both the participant and the researcher to find common ground on which to have a conversation where questions can be asked that explicate how lives that are permanently changed by a chronic illness can be healed. Someone’s suffering from the pain and discomfort of osteoporosis can be amplified by their sense of loss of self, where a person living with a chronic illness witnesses a previously held concept of “self” dissolve into another less positive vision. Priscilla recounts finding out that she had osteoporosis: *“You know undoubtedly when you are first diagnosed it is traumatic. Have you ever seen Snow White and the Seven Dwarfs? Remember when the queen diverted to the witch? She looked exactly how it feels.”* People without the capacity to develop an equally valuable and meaningful alternative self-concept are more likely to succumb to the powerful emotions associated with loss of independence, social isolation, perceived changes in social identity and thoughts of being a burden to others. Thinking about the self in this negative light creates profound psychosocial suffering that is not often recognized within the biomedical view of the patient.

It is not enough to merely acknowledge the significance and the existence of the psychosocial suffering associated with chronic illness. We need to learn from those who have already experienced osteoporosis, to discover how they became able to live with their illness. We need to ask questions that enlighten and inform, questions that prevent answers from being suppressed by the dominant opinion, or, in this case, to counter the objective medical discourse of disease and illness. These questions open up the discourse of how people manage their physical symptoms, and how people learn to negotiate a new sense of self.

Although we are tempted to look to the experts for knowledge and inspiration, everyday inspiration is best found in the people who live next door to us, shop at the same stores, and walk with us along our neighbourhood streets. Unfortunately, we aren’t always able to recognize these individuals because they are not whom we may consider “experts,” even though they carry within them the key to improving our over-all understanding of living with osteoporosis. We should consider the experiences people accumulate throughout their lives as “expert” knowledge that can be used to guide our approach in the development of health policy, education, health care practices and recovery strategies for the chronically ill.

### **A childhood incident and its deeper meaning**

At first glance, Priscilla’s telling of an incident that occurred in her childhood seems unrelated to the question of what it means to live with osteoporosis. However, this part of her story had an important place in how Priscilla chose to tell me about her life. Priscilla’s topee (a sunhat worn by children in India) was symbolic of protection in her childhood. More than just a hat, it was indeed her protection, a source of security, a friend, and a connection to her life in India. The experience of loss and adaptation presented itself early in her life through the devastation of having her symbol of protection and security tossed overboard during her return voyage to England: *“It was chucked over into the water, and of course I did not have my parents for a year when I was with my grandparents.”*

Our conversation revealed to me the importance of objects – those that remind us of important life experiences and their connectedness to an object, an individual, or a powerful emotion. While we learn to be in the world, we create multiple strands of interconnections, with all their secrets and hidden personal associations and emotions. Our conversation was

about the lived experience of suffering with osteoporosis and the impact of that change on the individual's life. What I was given back was much more than just an answer to a question. I received valuable insight into the meaning of objects, experiences and interactions. The loss of the topee was the event for Priscilla, but her connection with the object was as it symbolized protection, and what it meant to be protected (from more than just the sun). The loss of this object is associated with being left behind by her parents. Priscilla's childhood story about her topee reflected her first experience of facing life's challenges as she went through the change of being without her parents. Many years afterward, her memory of this early adaptation to a stressful event helped her to learn how to manage and adapt to osteoporosis.

The task that I set for myself was to find within something small something that was hidden, and then bring it out into full light, to view it in its proper status. Narratives provide the words that are then open to be interpreted, to allow movement from what is said to what is meant. When the interviewee gives expression to the lived experience of their illness, the researcher does not attempt to interpret these experiences as something factual, as psychological, social or historical events that need explanation. We want to focus on the understandable meaning of these experiences.

### **The three "acts" of living with osteoporosis**

In my attempt to contextualize the experiences of Gail and Priscilla, I was led to consider their illness experience as comprising a three-act play, where their intended path was interrupted by an unexpected, unplanned and unwelcome character - osteoporosis. Illness became the diversion from a normal and predictable life to an episode within that same life that involved suffering, courage, commitment and recovery.

Consequently, Act 1, a **shattering** of their bones, became the metaphor for their shattered lives. The "shattering" was not just about fracturing but also about being forced to live their lives differently as they became overwhelmed by fear, apprehension, rapid changes to their self-perception and social identity, and the frustration that came from living for many years with something unnamed before their osteoporosis was diagnosed and treated. Priscilla states the importance of getting the information at the time of diagnosis: *"There is very little sharing of information. The doctor who sits down and shares information with the patient will be more successful in getting the patient on line to make themselves better than one who just tells the results."*

Characteristically, the initial fractures came as a surprise: *"The fall was nothing."* They were unusual: *"I was only lifting a box that I had always lifted."* - a minor fall or a sudden apparently insignificant turn that resulted in a disabling fracture. Medical intervention had its place after the shattering; doctors and other health professionals eventually made the correct diagnosis, which then led to the appropriate treatment that promoted healing and maintenance of their bones. The seriousness of osteoporosis was illuminated by Gail: *"I fell down one winter and I had to lie in the snow bank because I could not get up. Every time I tried to get up the pain was excruciating, and I would pass out from time to time. I thought this was a really dangerous situation, the wind was howling like mad, coming across the driveway onto the lane and sidewalk, and I was getting covered with snow."* Although Gail's and Priscilla's medical needs were eventually met, finding support for their psychosocial needs was somewhat more difficult. A sense of not being heard resulted in stress, depression and frustration, all of which have been felt by many individuals when time was not taken to fully explain the situation.

Act 2 was a critical period of transition for Priscilla and Gail as they began to experience their world as people living with osteoporosis. Act 2 became the **surrendering** to the disease. This was not giving up, but rather giving in to the functional reality of their situation and the difficulty of piecing the fragments of their life back together. During the “surrendering” phase, adaptation to change became the key element that influenced the reconstruction and perceived quality of their life. Faced with limitations, it became essential to make new experiences and activities meaningful. The past needed to give way to the present. The old, comfortable life was assessed, and a new perception of quality of life negotiated.

Surrendering to that which could not be changed opened up other possibilities. For Gail, this meant meeting someone who was an empowered advocate for awareness of and support for people with osteoporosis. *“I met someone, a person named Eleanor Mills who was doing a walk across Canada. My company was sponsoring her. I helped with the walk, got to meet Eleanor and speak to her, and got myself straightened out. She helped me to put things into perspective - what I should be doing, how I could do better. Well, it was very fortunate that I came to this understanding because Eleanor opened up for me a different and more hopeful vision of what it means to live with osteoporosis.”*

Act 3, the **dance**, has to do with being in control of your life. As Priscilla explains: *“The patient has to take charge. As an osteoporosis patient, you must take charge of your health, get all the information you can and then put it all together as a lifestyle for yourself. And it seems to work for me.”* Priscilla’s “dance” with the reality of her osteoporosis reflects her becoming an empowered patient: *“Patients don’t understand - they think they have to be told what to do, they have to be compliant. I can be compliant, but I am not, because I question why I am doing anything. I don’t do something unless I know why.”* Priscilla also talks about the “gifts” of living with osteoporosis: *“The gift of very great friendships. I met so many wonderful people because of my osteoporosis. While working with Osteoporosis Canada, many of us supported each other and created a strong network of women helping others. We were a very experienced group sharing what we knew about osteoporosis.”*

Part of the dance is to let go of some parts of your life while being open to others. Gail comments: *“You can choose to dwell on your losses, or you can choose to do something positive. There are things I will never be able to do again. I would love to go skating, or play golf. My husband and I used to golf all the time. Now I am scared to death to do it - one mighty swing and I am back to where I was. I choose to do more positive things, assessing the risks of what I do. I also choose to know what my losses have been and say, okay, but I can also still do so many things.”* Living well with osteoporosis means becoming a partner in the dance of life, no longer being led by the disease. For those who manage to adapt and see beyond the restrictions, life continues, but differently.

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### **Navigating Winter: Things to Remember**

The memory of the time I slipped and fell on some ice in front of my home, in the middle of a blizzard, still produces fear in my mind. Every time I head out to do something, I am very

aware that people with osteoporosis need to be extra alert and aware of the dangers that can present themselves at this time of year.

When I fell, I fractured two vertebrae. The fall was so painful that I lay there on the ground, slowly being covered with snow, as I couldn't get up because of the severe pain in my back. I had to lie there until quite some time later when someone out for a walk found me. They thought I was a garbage can on the ground, covered with snow!! I have learned not to take navigating the winter lightly. Here are some precautions - I'm sure you can add your own to this list.

1. Always prepare yourself to be alert to the winter weather conditions. Ask yourself, is it really necessary to go out today? Sometimes it is; otherwise, stay in.
2. Do you have on the proper walking boots? Will they keep you on your feet or do they have slippery soles and higher heels? If they aren't appropriate, put on another pair.
3. Be alert for hidden ice. Is the road/sidewalk/driveway/parking lot cleared out, free from ice, sanded and easily travelled? Where are you going, and will the destination have clear and safe access?
4. While in a car, are you belted in? While getting on/off a bus or in/out of a car, can you get on/off easily, and has the access point been cleared?
5. While clearing the snow from a car, consider if the snow is too heavy for you to sweep off and are you putting yourself in an awkward position that puts undue stress on your back?
6. Some days it is just not smart to be out. You can always do something else – such as writing to us and telling us your experiences of winter!
7. I have learned that the pain, disability, and risk to my future are much more deserving of consideration than going out on days when the weather tells me I should stay in.

### **Winter Can Be Fun for People with Osteoporosis**

There are many things that people with osteoporosis can do in the wintertime, but keep the following considerations in mind.

#### **If you have osteoporosis or have had fractures:**

1. Pick your outing days very carefully.
2. Know your limits for walking and how steady you are on your feet.
3. Make sure you are wearing the right footwear and clothing.
4. Consider whether your doctor has placed any limits on your activities.
5. Do you usually need assistance in walking - a cane, a person, a walker?
6. Do you tell people where you are going and how long you might be gone?
7. Outdoor sports activities may not be the best activities for you in the winter.
8. Always remember, fractures can change how you lead your life. They can change your life in an instant.
9. On great days, take that walk and enjoy the snow.
10. Do the activities that interest you, but know your limits.
11. Exercise for people with osteoporosis is important. Just know your limits and keep an eye out for your safety.

#### **If your bone density is in the osteopenia range:**

1. Choose your activities wisely. Fractures could still happen.

2. Exercise in the out-of-doors can be great to build bone density. If it is an activity that you have always participated in, and that you have a level of skill at, you will probably be ok. Check with your physician just to be sure.
3. Winter is a wonderful time to be outside and enjoy the season. Just be aware, be careful, and build those bones.

### **Struggling with a Diagnosis of Osteoporosis**

This is a two-fold story. I am 60 years old and always considered myself to be fit and trim, as I was raised on 58 acres of land with an abundance of fresh clean air and lots of physical activity. In April 2004, I slipped on a hardwood floor (I was wearing socks and I was running, definite “no-noes”). A visit to the emergency department confirmed that I had fractured my sacrum. Subsequently, I asked my family physician to refer me for a bone density test, which I had never had. That test diagnosed me as someone with osteopenia, a precursor to osteoporosis, but I still did not think I was in danger. I had been taking calcium for 10 years and felt safe.

It was a long, slow recovery from the fracture. As winter came and went, I started to feel my bones actually hurting, particularly when lying in bed and throughout the night. A pillow between my knees helped hip and leg pain. Leg bones on top of one another just didn't feel comfortable when I slept on my side. (I am required to sleep on my side as I have arthritis in my neck.) As spring rounded the corner, I felt worse and worse. Something told me to get another bone density test, but my doctor said I wasn't due for one until another year had passed. The thought of the delay scared me and I didn't want to wait, so I suggested to him that I would pay for the test for the sake of my peace of mind. He agreed. The test came back with a diagnosis of osteoporosis of the spine and a significant risk of fracture. What a surprise and shock this was to both me and my doctor! We agreed that the \$120 was well spent.

My doctor started me on a bisphosphonate right away. I am now in my 26th week of the medication and am so thankful that I had been proactive. After checking my calcium supplement, which I had taken for 10 years, I realized that I was not getting sufficient calcium. Therefore, I changed brands and am making sure I am getting 1500mg of elemental calcium, plus 800 mg of vitamin D (necessary in our gray, rainy climate), which are the Osteoporosis Canada recommended daily intakes.

This near disaster changed my life completely. I now have to be careful of bending and carrying heavy grocery bags. No more gardening, and certain sports like golf, tennis and skiing are no longer possible. These restrictions have been quite an adjustment. I have learned to pay close attention to what my body is telling me. When I begin to experience pain, I stop what I am doing and rest. I have taken up other hobbies, such as leisurely walks, card making and photography.

I realize that this is not a short-term fix. Osteoporosis is something I will have to cope with for the rest of my life, but at least listening to my body has put me in control of my destiny. And I am thankful for the cooperation of the health profession.

Pam Erickson, British Columbia

## **Tell Us Your Story of Living with Osteoporosis, Stories that Might Help Others**

Here are some topics that you may wish to consider. Email us at [copn@osteoporosis.ca](mailto:copn@osteoporosis.ca). Please note that stories you submit may be published in subsequent newsletters or on the COPN web site.

- How you have managed to increase your bone mineral density.
- How you are working (or not) with weight-bearing exercises.
- How you are managing to get enough calcium, especially if you are intolerant to dairy products.
- How you deal with the pain of osteoporotic fractures.
- What are your family's experiences with osteoporosis; how are you managing? How has your family been affected by osteoporosis?
- How are you helping your children to be aware of the osteoporosis in your family?
- Your struggle to be diagnosed with osteoporosis.
- Your surprise at the diagnosis of osteoporosis/osteopenia: what was your immediate reaction?
- Did you have problems getting an effective osteoporosis drug? What happened?
- Being a caregiver to someone with osteoporosis.
- Any other aspect of being a person with osteoporosis – tell us your story.

## **What's Happening in Your Area?**

COPN would like to know what is going on in your area that would be of interest to people living with osteoporosis. E-mail us at [copn@osteoporosis.ca](mailto:copn@osteoporosis.ca) with your report.

## **Volunteer with COPN**

Is your life in any way affected by osteoporosis?

Are you interested in representing people with osteoporosis?

COPN is a virtual network of people whose mandate is to provide the patient perspective wherever possible. We are a dynamic, growing network and we have many opportunities for you to join us:

- Steering committee members to provide leadership
- Publicists to spread the word
- Writers/editors to help put out the e-newsletter *COPING*
- Web-savvy people to work on our web site

Join our team. E-mail us at [copn@osteoporosis.ca](mailto:copn@osteoporosis.ca).

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