

COPING

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Remember: You can live well with osteoporosis!

What Does It Mean to Live with Osteoporosis?

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The following is an excerpt from an article originally published in COPING, November 2005, which was based on interviews with COPN members Priscilla Cole and Gail Lemieux. Its insights into how a diagnosis of osteoporosis can turn one's life upside down are still relevant. At the time of publication, Richard Hovey was a member of the national Board of Directors of Osteoporosis Canada and of the COPN Executive Committee.

What Does It Mean to Live with Osteoporosis?

Negotiating a New Sense of Self

By Richard Hovey, PhD

The experiences presented in this paper are those of two individuals, Gail and Priscilla, who have learned to live their lives fully again after a diagnosis of osteoporosis. A diagnosis of a serious or chronic illness such as cancer, diabetes or osteoporosis turns lives upside down. Priscilla recounts her feelings when she learned she had osteoporosis: “*You know undoubtedly when you are first diagnosed, it’s traumatic. Remember when the evil queen morphed into the witch in Snow White and the Seven Dwarfs? That was exactly how I felt when I was first diagnosed with osteoporosis*”

Although we tend to look to the experts for knowledge and inspiration, everyday inspiration is sometimes best found in the people who live next door to us, shop at the same stores and walk alongside of us in our neighbourhood. Unfortunately, we are not always able to recognize these individuals because they are not whom we may consider “experts,” even though they carry within them the essence of living well with osteoporosis.

The three “Acts” of living with osteoporosis

In my attempt to contextualize the experiences of Gail and Priscilla, I was led to compare them to a three-act play, where the main characters’ intended path was interrupted by an unexpected, unplanned and unwelcomed character – osteoporosis. Illness was the episode that caused the departure from a normal and predictable life to a life that involved suffering, courage, commitment and eventual recovery.

In 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 and uncomfortably as they became overwhelmed by fear and apprehension with rapid changes to their self-perception and social identity. They tried to cope with the added frustration that came from living for many years with something unnamed,

until their osteoporosis was finally diagnosed and treated. Priscilla states the importance of getting the right information early on at the time of diagnosis: “*There is very little proper sharing of information. The doctor who sits down and discusses the information with the patient in some detail will be more successful in getting the patient on board with treatment than the doctor who just tells the patient their results.*”

Characteristically, the initial fractures came as a surprise because they were due to “*a minor fall*” or “*lifting a box that I had always lifted*”, in other words, events that do not normally cause fractures. 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. It was Gail who drove home the seriousness of osteoporosis when she relayed her fall. “*I fell down one winter and I had to lie in the snow bank because 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, the struggle to find support for their psychosocial needs was more difficult. A feeling of “not being heard” resulted in stress, depression and frustration, all of which have been felt by many individuals when the health profession failed to take the time to fully explain the situation.

Act 2 represents the critical period of transition for Priscilla and Gail when 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 difficult task 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 reassessed, and a new perception of quality of life was 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 Eleanor Mills, who was doing a walk across Canada, because the company I worked for was sponsoring her. By helping with the walk, I got to speak with Eleanor, and got myself straightened out. She helped me 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 is the **dance**, which has to do with taking control of one’s life. As Priscilla explains, “*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. This approach seems to work well for me.*” Priscilla’s “dance” with the reality of her osteoporosis symbolizes her becoming an empowered patient. “*Patients don’t always understand - they think that to be good patients, they have to be told what to do, and then they have to be compliant with what they are told. I can be compliant, but I won’t be compliant if I am questioning everything I am told I should do. Knowledge is power because I won’t do anything unless I understand why I should do it. To me, a good patient is someone who does as they should because they understand why.*” Priscilla also talks about the “gifts” of living with osteoporosis, such as “*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 accepting newer aspects, much like changing partners. Gail comments: “*You can choose to dwell on your losses, or you can choose to do something positive with the changes in your life. 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 try it - one mighty swing and I am back to where I was. I choose to do safer activities, assessing the risks of what I do. I also choose to know what my losses have been and say, okay, I accept those losses, but I can still do so many other things.*”

Living well with osteoporosis means becoming an active partner in the dance of life and no longer being led by the disease. For those who manage to adapt and see beyond the restrictions, life continues, differently, but still well.

Dr. Hovey is an Associate Professor in the Division of Oral Health and Society with the Faculty of Dentistry, McGill University; as well as an Adjunct Professor in Community Rehabilitation and Disability Studies with the Faculty of Medicine at the University of Calgary. His research approach utilizes philosophical hermeneutics and phenomenology in strengthening our understanding of the experiences of vulnerable and underserved populations, like those living with chronic illness, cancer, disability, or the affects of medically induced trauma. Topics of interest include patient and health professional education, communication, leadership, and interdisciplinary practice.

E-mail: richard.hovey@mcgill.ca

For the extended academic version of this article please see:

Hovey, R., & Craig, R. (2012). Learning to live with osteoporosis: A metaphoric narrative. *Journal of Applied Hermeneutics, Article 3.*

A Recipe from Our Sponsor

Frosty yogurt Shakes

Cool and refreshing, whip up these frosty drinks for a treat, post-workout replenisher or as a super-quick dessert.

Course: Beverages and snacks **Prep. Time:** 5 mins

Yields: 2 to 4 servings

Ingredients:

Berry Banana Shake:

2 cups (500 ml) **milk**
1 cup (250 mL / 2 scoops) vanilla frozen **yogurt**
2 frozen bananas
1 cup (250 ml) fresh or frozen raspberries or blueberries

Chocolate Almond Shake:

2 cups (500 ml) **chocolate milk**
1 1/2 cups (375 mL / 3 scoops) chocolate frozen **yogurt**
1/2 cup (125 ml) ice cubes
1/2 cup (125 ml) toasted almonds



Creamsicle Shake:

2 cups (500 ml) **milk**
1 cup (250 mL / 2 scoops) **vanilla frozen yogurt**
1 cup (250 ml) ice cubes
1/3 cup (80 ml) frozen orange juice concentrate, undiluted

Directions

In blender, combine **milk**, frozen **yogurt**, frozen fruit or ice cubes and flavourings (as called for); purée until smooth. Pour into tall glasses.

Tips: If you don't have frozen **yogurt**, freeze an equal amount of vanilla-flavoured yogurt in a plastic container, stirring occasionally, for about 4 hours or until firm. For the *Chocolate Almond Shake*, add 2 tbsp (30 mL) chocolate syrup with **yogurt**. For a smoother texture in the *Chocolate Almond Shake*, substitute 1/4 cup (50 mL) almond butter for the whole almonds.

For more information about this recipe:

<http://www.dairygoodness.ca/getenough/recipes/frosty-yogurt-shakes>

FRACTURE FACT: Osteoporosis can result in disfigurement, lowered self-esteem, reduction or loss of mobility, and decreased independence.

FUNNY BONE:

It's good to have a friend you can trust, but even better to have one who trusts you.

This issue of COPING is sponsored by Dairy Farmers of Canada



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