

COPN: Proudly Celebrating our 10th Anniversary Stay Properly Informed but... Self-diagnose and Self-treat off the Web "at Your Peril"

This is a revised and updated version of an article published in the December 2006 and July 24, 2009 issues of COPING.

Do you use the Internet to search for information, particularly medical and health related information? Are you ever tempted to self-diagnose or even self-medicate because of something you have read on the Internet? This can be a very dangerous practice, as illustrated by the following example: A woman had self-diagnosed chronic fatigue syndrome after reading about it on the Internet. Without consulting her physician, she started self-medicating with oral steroids that she was able to purchase over the Internet. She developed cataracts and glaucoma in both eyes as a result of the steroid use. Clearly, self-diagnosis and self-medicating are risky and NOT recommended.

If you enter the word "osteoporosis" into Google, you will get 40 pages of sites, or about 10,600,000 results, in 0.20 seconds. These sites may be hosted by national osteoporosis organizations, government agencies, allied health professional associations, pharmaceutical companies, hospitals and clinics, special interest groups or companies trying to sell you a product under the guise of providing information. Sometimes it is not clear who is hosting the site.

In addition to these organizational websites, we now have personal blogs, Facebook, Twitter and YouTube, where individuals can post their questions, responses to questions, their experiences, comments and opinions. There are even sites offering online self-diagnosis for medical conditions. The amount of electronic information available is overwhelming, frequently contradictory and very often wrong. How does one navigate through this jungle of information and filter out items that are not credible, scientifically accurate and appropriate?

To help determine the reliability of information you find on the web, ask yourself the following questions:

- 1) **Who runs the website?** Are they concerned about health and wellbeing; are they reputable? You can usually find this under the "About Us" section on the site (the heading may be different, so look for the section whose purpose is to tell you about the host organization).
- 2) **What is the purpose of the website?** Is it to provide information or to sell products and/or raise funds? Remember that anything that seems too good to be true probably is.

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Fracture Fact:
"Drugs don't work in patients who don't take them." – C. Everett Koop, M.D.

- 3) **What are the suffixes (endings) of the website names?** For instance, websites that are sponsored by the U.S. government end with ".gov"; universities end with ".edu"; not-for-profit organization end with ".org"; and Canadian sites end with ".ca" As an example, Health Canada's website is www.hc-sc.gc.ca; Osteoporosis Canada's website is www.osteoporosis.ca.
- 4) **Is the information current and evidence based?** Reliable websites are frequently reviewed and updated. Check the copyright date on the bottom of the home page and the publication date of the articles posted.
- 5) **Are the links to other websites also reputable?** If the answer is "yes", the information being shared is usually accurate and your privacy is being protected.

While COPN and Osteoporosis Canada recognize that the Internet can often be a valuable tool to gather information, no resource is better than your doctor. Because everyone is different and unique, personalized health care from your doctor who knows you best cannot compare with general information you get off the Internet. The Internet cannot have a confidential discussion with you and formulate an individual approach to your healthcare plan that is personally tailored to your unique needs – but your doctor can.

Even after gathering information from the Internet, ALWAYS discuss your health issues with your healthcare professional. It is important for you to receive up-to-date and scientifically sound information and advice from a professional who is trained to assess your individual needs, who knows your medical history, any other medical conditions you may have, and what medications you are taking. All of these factors are very important as each can impact on the other.

While information gathering is often encouraged, self-diagnosis and self-medication are NOT recommended. COPN wants to reassure you that the medical and scientific information on the web pages of Osteoporosis Canada and in *Coping* is checked for medical accuracy by Osteoporosis Canada staff and our Scientific Advisory Council.

“Medication Adherence: An Ongoing Challenge in the Management of Osteoporosis”

If you are on a medication for osteoporosis, are you ever tempted to stop taking it? If you answered "yes," you are not alone. Studies indicate that especially for those with chronic conditions, such as osteoporosis, many patients do not take their medication as directed or for as long as they should.

What is meant by medication adherence? **Adherence** to medication involves two factors: **compliance**, which is taking a medication *as directed*, and **persistence**, which is taking a medication *for as long as necessary*. Osteoporosis is a growing problem worldwide, with the greatest burden resulting from broken bones. There are several treatment options available that are effective in reducing fracture risk, but in order to see the benefit, patient adherence is required. However, similar to other chronic diseases, especially those with no symptoms, adherence to osteoporosis therapies is poor. Some articles have suggested that in general, rates of non-adherence can be as high as 50%. In a recent study that looked at people on Ontario Drug Benefits, only 63% of patients given a bisphosphonate prescription were still taking it after one year, and this dropped to 46% after two years.

Why don't people take their medications as prescribed? Possibilities include:

- **Memory loss** The individual forgets when and how to take the medication.
- **Psychological problems** such as depression. The person is not motivated to take care of her or himself and therefore does not take their prescribed medication(s).
- **Lack of symptoms**. The need for and benefits of a medication are not felt. This is true of osteoporosis, which is often called “the silent thief” because there are no symptoms unless and until one has fractured.
- **Fear** of immediate or longer-term potential side effects.
- **Uncertainty** about the benefit of drug treatment or preference for a “natural” approach.
- **Lack of understanding** of the disease and the value of medication.
- **Poor relationship** between the patient and their healthcare provider.
- **Cost** of medication.
- **Difficulty following the instructions** for use.
- **Complexity of treatment**, especially if the patient has multiple conditions requiring multiple drug therapies.

Not taking your medication as prescribed has far-reaching consequences. Poor adherence means that the drug will not be as effective and health will decline. In addition, medical costs will rise. In 2009, it was estimated that non-adherence cost the US healthcare system \$290 billion. There is little data available for Canada, but in 1995 the cost of medication non-adherence was estimated to be \$7-9 billion annually.

Patients who do not take their prescribed medication do not receive the benefits of that medication. Patients who only partially follow their medication regime may receive some benefit but are also at risk for serious complications. Patients who do not stick with their treatment plan are more likely to end up in hospital. Studies suggest that for people taking bisphosphonate therapy for osteoporosis, those that take 75% of their medication do not have the same reduction in fracture risk as those who take the medication as prescribed 100% of the time; and when patients take only 50% (or less) of their pills, no benefit is seen (it is the same as not taking any bisphosphonate).

Over 80% of fractures in people over 50 are due to osteoporosis. There are effective medications available to reduce the risk of fracture from 30 - 70% *provided they are taken properly and 100% of the time*. If you are at high risk of fracture, it is very important that you take your osteoporosis medication regularly and as recommended. If you have concerns, talk to your doctor, and ALWAYS talk with your doctor before making any changes to your medications.

FUNNY BONE: A positive attitude may not solve all your problems, but it will annoy enough people to make it worth the effort. - Herm Albright

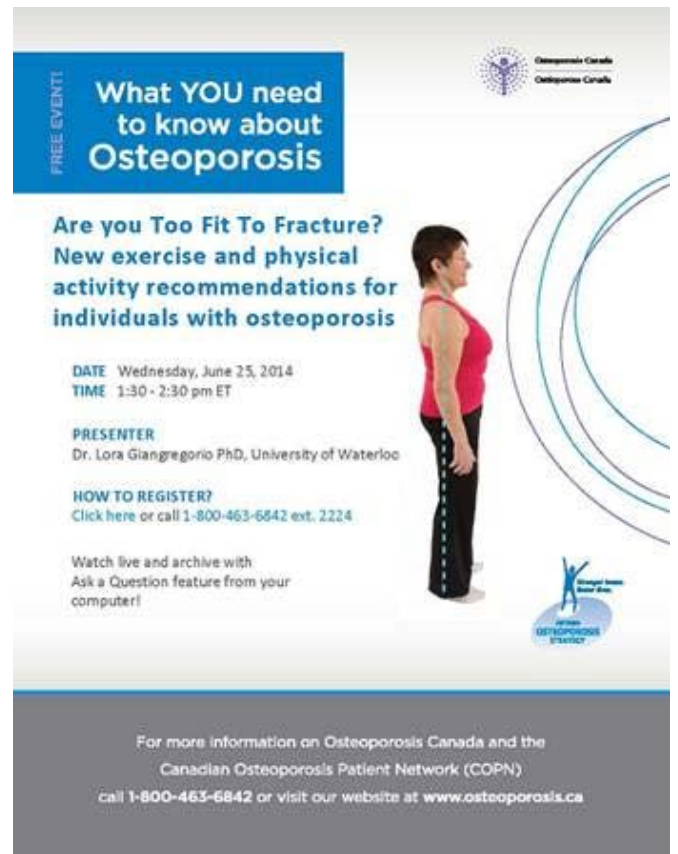
June 25, 2014

**Are you Too Fit To Fracture?
New exercise and physical activity
recommendations for individuals
with osteoporosis**

Learn what the experts think you should include in your exercise program to prevent bone loss and falls, and increase muscle strength. Get some tips on how to put the latest research into action. Understand how to practice “spine sparing”, and avoid or modify the movements that might not be safe for someone with osteoporosis.

Registration is NOW OPEN! -

<http://www.osteoporosis.ca/osteoporosis-and-you/copn/virtual-forum/>



FREE EVENT What YOU need to know about Osteoporosis

Are you Too Fit To Fracture?
New exercise and physical activity recommendations for individuals with osteoporosis

DATE Wednesday, June 25, 2014
TIME 1:30 - 2:30 pm ET

PRESENTER
Dr. Lora Giangregorio PhD, University of Waterloo

HOW TO REGISTER?
Click here or call 1-800-463-6842 ext. 2224

Watch live and archive with
Ask a Question feature from your computer!

For more information on Osteoporosis Canada and the Canadian Osteoporosis Patient Network (COPN) call 1-800-463-6842 or visit our website at www.osteoporosis.ca

A Recipe from our Sponsor

Barbequed Curried Chicken Burgers with Yogurt Sauce

Course: *Main Dishes*

Preparation Time: *15 mins*

Cooking Time: *12-15 mins*

Yields: *4 servings*

*1/2 milk product serving(s)
per person*

For more information
about this recipe:

<http://www.dairygoodness.ca/getenough/recipes/barbequed-curried-chicken-burgers-with-yogurt-sauce>



Ingredients

Burgers:

1 lb (454 g) ground chicken
1 French shallot or green onion, chopped
1 clove garlic, finely chopped
1/2 tsp (2.5 mL) ground turmeric
1-2 tbsp (15-30 mL) curry powder
1/4 cup (60 mL) fresh coriander, chopped
a small drizzle of olive oil

Yogurt sauce:

1 clove garlic, finely chopped
1/4 tsp (1 mL) fresh ginger, grated
1 1/2 tbsp (22 mL) maple syrup
the juice and finely grated zest of one lime
1 1/4 cup (310 mL) **plain Greek yogurt**

Preparation

Sauce: Stir all sauce ingredients together in a bowl. Adjust seasoning to taste and set aside.

Patties: In another bowl, combine chicken with remaining ingredients. Lightly oil hands and form 4 patties. Oil patties and season surface. Barbecue 12 to 15 minutes or until chicken is cooked.

This issue of COPING is sponsored by Dairy Farmers of Canada

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These newsletters are not intended to replace individualized medical advice. Readers are advised to discuss their specific circumstances with their healthcare provider.



NUTRITION
DAIRY FARMERS OF CANADA



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