

COPING
'A newsletter from COPN'
October 1, 2010
Remember: You can live well with
osteoporosis!

If you have received this newsletter from the Canadian Osteoporosis Patient Network (COPN)
You are a COPN member

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Thought for Today - "If you don't know where you are going, you may end up someplace else." - Yogi Berra

Launch of the Osteoporosis Patient Bill of Rights

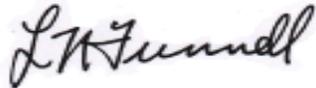
I am pleased to use this edition of the COPING Newsletter to officially launch the Osteoporosis Canada Patient Bill of Rights.

More than a year in the making, the Bill of Rights represents a significant accomplishment. It has been dissected and reviewed and rewritten more times than I care to count. Yes it has been a challenging process, but has it been worth it? Absolutely. I believe it accomplishes all those goals we set those many months ago. It is inspirational, it is achievable, and it does provide the foundation

for all that we do at COPN and Osteoporosis Canada on behalf of those affected by osteoporosis.

I would especially like to thank all of you who took the time to comment on the draft Bill of Rights. Without exception your comments were thoughtful and yes, some were thought-provoking too. They certainly did help shape the final document and I am sure now that you see the final result you will agree that it is much improved. We are proud, and you too should be proud of what we have accomplished.

The launch of the Bill of Rights provides an excellent segue to our next article *The Importance of Advocacy*. Read on to discover why advocacy is such a significant issue for us as patients, and how Kay, one of our members from Hanover, Ontario personifies advocacy in action.



Larry Funnell
Chair
Canadian Osteoporosis Patient Network

Osteoporosis Patient Bill of Rights

All Canadians have the right to live without osteoporotic fractures.

Bones weakened by osteoporosis break easily. These osteoporotic fractures can have devastating health consequences including pain, decreased quality of life, loss of independence and even death.

Because osteoporotic fractures are preventable:

We believe that all Canadians, wherever they live, have the right to effective bone care and fracture prevention programs that include:

- Regular, comprehensive assessments of the risk of bone fractures;
- Timely bone mineral density testing; and
- Medications that are proven to reduce the risk of fractures.

We believe that every Canadian who has experienced an osteoporotic fracture has a right to post-fracture care programs that include:

- Timely care and treatment including adequate pain control;
- Assessment of risks for future falls and fractures;

- Education about osteoporosis; and
- Self-management tools and strategies to reduce the risks of future fractures.

[Download a poster version of the Osteoporosis Canada Patient Bill of Rights.](#)

The Importance of Advocacy

When you or a loved one are faced with an illness, such as osteoporosis, your initial reaction may be shock and you may ask yourself, “how did this happen to me?” Once you have come to terms with your illness, it is important to get all the information you need and to take the necessary steps to make sure that you or your loved one are getting the best possible care. Our Osteoporosis Patient Bill of Rights acts as a guide to help you understand the type of care you should be receiving. If you are not receiving the best possible care you have the right to speak up and when you do so this is called advocacy.

According to the Canadian Oxford Dictionary, advocacy is *verbal support or argument for a cause or a policy*. Quite simply, it is telling your story to someone who can help make a difference. In the case of health care, that usually means speaking to the right people in government. It is a process that can take a long time to see the changes you would like and there is no one way to go about advocating. It is personal to your own style and comfort level, and can give you a sense of empowerment by taking some form of control and initiating some type of action around an issue that matters to you. Advocacy is also based on two fundamental things:

- your ability to tell your personal story, and
- the establishment and nurturing of relationships with those who have the ability to make a change.

You may initially be concerned or nervous if you’ve never before told your story about the challenges you may be facing living with osteoporosis, or if you don’t currently have any relationships with people in government. Both will get easier with time and practice. It is important to remember that without these two things, your ability to advocate effectively will be limited.

So why is advocacy important? The easiest answer, as the saying goes, is because the squeaky wheel gets the grease. Or rather, key decision-makers react to those credible groups or individuals who most effectively bring their issues to the forefront of the public agenda. But advocacy is also important because the alternative, not doing anything, is really no alternative at all. Inaction has never led to change or progress.

There are two different kinds of advocacy: personal and issue-based. Personal advocacy is the typical way one starts to get involved. An issue that affects you or a loved-one, such as those described in the Osteoporosis Patient Bill of Rights, compels you to take action. You're not looking to change the world, you just want to improve your situation. It's out of this personal need though, that some people start to realize that they have an opportunity to bring about larger public policy change by advocating for a broader based issue. They realize that by getting involved in issue-based advocacy they can not only help themselves, but help others who can't make their voices heard.

With that brief background in mind, you can now start preparing to advocate. As with most things in life, preparation is essential in advocacy. You need to have a clear understanding of the issues that you want to raise and the decision-makers in government that you need to contact. The more focused your issues are, and the fewer of them you have, the more likely you are to be successful. Again, you can use the Osteoporosis Patient Bill of Rights as your guide, but be sure to only focus on one issue at a time.

As you are preparing, take the time to write out your personal story. It usually helps to get it down on paper first. Whatever your situation, as a patient living with osteoporosis, you have a unique story to tell about the issues and challenges faced from your perspective. Make sure that you capture your thoughts and feelings. As noted earlier, it will be fundamental to your advocacy activities.

If you are interested in becoming involved in advocacy, please contact your local Chapter. Each province is working with Osteoporosis Canada to identify the issues that would help improve osteoporosis care and is developing an advocacy strategy to seek the necessary changes to address those issues. They would love to hear from you.

Advocacy in action. *Kay is retired and lives in the small community of Hanover, Ontario. She has osteoporosis. She has tried all the oral treatments but they resulted in bleeding ulcers and dangerous weight loss. Subsequently, her doctor prescribed a non-oral treatment. Kay was surprised to learn that the treatment required special approval from the provincial government. Kay's request was denied. Kay was not satisfied to leave it at that. She wrote to her Member of Provincial Parliament to request that the treatment be made available not only for her, but also for others with osteoporosis who cannot tolerate the oral medication. Since her initial correspondence, Kay has written two letters to her MPP and has had two replies - neither of which were satisfactory to her. One of her letters was recently sent on to the Ontario Minister of Health and Long-Term Care by her MPP. She is determined to continue working to raise awareness of this silent disease and is now participating in various advocacy activities with Osteoporosis Canada.*

Funny bone – Great Truths from Little Children:

- No matter how hard you try, you can't baptize a cat.
 - When your Mom is mad at your Dad don't let her brush your hair.
 - School lunches can stick to the wall.
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Notices/references

i. Osteoporosis Canada will have a special information supplement in the October 2010 edition of *Canadian Health Magazine*, featuring this fall's unique Osteoporosis Month 2010 theme

ii. Remember: It is important for you to eat a healthy diet, get some appropriate exercise, take your calcium and vitamin D and if your doctor has prescribed a medication don't forget to take it as directed.

iii. COPING Weekly will come to you every second Friday. We hope you enjoy it and find the information useful. Don't forget to log on to www.osteoporosis.ca for up-to-date information.

iv. The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any health care related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.

v. To have your name removed from the COPN mailing list please contact us at the email below.

You must provide the first and last name for which you registered in order to be removed from this list.

<cPatientNetwork@osteoporosis.ca>

vi. (1)<http://www.volunteerkw.ca/index.php?MenuItemID=180>