Listening to you

Arthritis Consumer Experts is pleased to share with you another consumer's experience about living with arthritis.

My arthritis resume

I am a 54 year old married woman and mother of two teenage girls. I worked as a professional researcher and consultant in international development and environment until my surgeries in 2002. I now manage a real estate brokerage. I speak four languages. My career and community have afforded me a wide range of activities where I've been an advocate on a broad range of issues: French Immersion which was successfully implemented here in our County, International Aid Budgets - a nation-wide campaign that I designed and managed, a French

This issue of JointHealth™ monthly provides another consumer perspective about living with osteoarthritis. In addition, articles about foods and arthritis – does what we eat make a difference, and the 10,000 Steps ... a walking program. Next month ACE will announce its new workshop format for 2006. The topics covered in this issue are:

Listening to You

 My arthritis resume – another consumer experience

Education

- Exercise and walking: 10,000 steps ... a walking program
- Food and arthritis does it make a difference?

Arthritis Consumer Experts

- Who are we
- Guiding principles and acknowledgement
- Disclaimer

Arthritis Consumer Experts

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School that was established in the County, a nature conservancy that has acquired multimillion dollar properties for lifelong preservation, as well as arthritis issues where I have raised the issues that plague those living with arthritis in the media - print, television and radio.

I was diagnosed with primary osteoarthritis about five years ago although I've suffered from incremental pain for about 25 years - the first persisting symptoms being noticed in the carrying of my last child who is now 18 years old. In the early days of running, at about age 27, I noticed knee pain after 2 miles, an issue that I eventually partially resolved for a while. I was a runner until about 2000 when I had to stop due to debilitating pain. This was after many types of orthotics and the close supervision of a sports physician. I substituted the running with long distance swimming and later water exercises. In June 2002, I was given a first total hip replacement in Halifax and a second total hip replacement at the Orthopedic and Arthritic Institute in Toronto in November of 2002. From 2002, my health consistently improved until 2004. Unfortunately, especially in the last year, my arthritis has gotten worse. I have maintained a rigorous regime of swimming and water exercises I've returned to all of my previous activities except for running. I have skied the past 2004 and 2005. I doubt I will ski again as the pain has become too intense in my lower and

During my worst pain, I took all of the

NSAIDS and anti-inflammatories for about four years. Celebrex became the preferred one but eventually resulted in hypertension. I now live without NSAIDS and take Tylenol Arthritis to manage my pain. I have two other chronic diseases, moderate asthma and hypothyroidism which I control with medication. I also had a fainting episode with convulsions pre-hip surgery. I have been advised by several medical professionals that I should be on opioids but I have been unable to agree to that. What happens after the glow of opioids?

Today, I continue with persistent ongoing arthritic pain in my lower and upper back, neck and sciatica in my hips, fevers on an almost daily basis, insomnia and occasional headaches/migraines.

When I was fourteen years old, I suffered with rheumatic fever and was kept in hospital for two weeks. Subsequently I received penicillin shots on a regular basis for years. Following on this, my immune system weakened and I suffered from many pneumonias, several times a year for several years afterwards. Another health professional thought I made have had a mild form of JIA. Who knows? I'm documenting this for research.

"I've returned to all of my previous activities except for running ... I doubt I will ski again as the pain has become too intense in my lower and upper back."

I can now identify an arthritis flare up because the symptoms and pain are also accompanied by a rash and itchiness, worsening of my chronic asthma (for which now I take Flovent and Serevent as prescribed daily). I've been aware of this for the last four years. The more severe the arthritis, the greater the severity of the asthma.

Throughout this entire health decline, I

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managed to maintain an international career until my first surgery in 2002. By that time, I could no longer cope with the demands of the work nor the international travel and really could not work at the requisite capacity. I then resolved to obtain both surgeries as I really could not function with one hip alone being unable to walk, nor sustain the daily activities while living with pain. Throughout this period, I became well-versed in the disease and acquired an in-depth knowledge of the medical system that serves arthritis patients. I am well aware of emerging trends in arthritis treatment and also have knowledge of pain management and the complexities of auto immune diseases.

I have worked on HIV/AIDS in South Africa – another area of research in health care where the country had to campaign to change not only citizens' attitudes but those of the government in order to acquire the treatments and drugs available to other parts of the world.

My experience with arthritis has made me a more compassionate and empathetic human being. I now have knowledge of the disease as well as the health system and its response to this growing epidemic. With my experience in the Canadian Arthritis Network Consumer Advisory Council and the Tooling Up for Early Osteoarthritis Project, I can better contribute to other research endeavors in the arthritis. I only know that information about the disease has made a world of difference in my ability to cope.

Anne Fouillard

Person with osteoarthritis Member, Consumer Advisory Council of the Canadian Arthritis Network

To read more about consumer experiences with arthritis refer to the January 2006 JointHealth™ newsletter in print or go to the on-line version:

http://www.arthritisconsumerexperts.org/news/2006-january.cfm. Please contact ACE if would like a print copy mailed to you. 《

Listening to You

We hope you find this information of use.

Please tell us what you think by writing to us
or emailing us at:

info@arthritisconsumerexperts.org

Through your ongoing and active participation, ACE can make its work more relevant to all Canadians living with arthritis.

Education

Exercise and walking: 10,000 steps ... a walking program

Exercise has general benefits such as improved heart and lung function, weight control, decreased stress and improved self-esteem and self-confidence. For arthritis, exercise helps to minimize joint pain and stiffness. If you are considering starting an exercise program, formal or informal, it is important to speak to a health professional trained in exercise for arthritis.

Walking is a great form of exercise and something we do everyday as a part of our daily routines. The 10,000 step program encourages people to keep track of how many steps they walk, using a pedometer, and then increases the number of steps each week until they get to 10,000.

The 10,000 step lifestyle approach to exercise began in Japan to encourage people to walk more as a lifestyle change. The program requires a pedometer and a good comfortable pair of walking shoes. Pedometers are inexpensive and can be purchased at most sporting goods stores and stores that specialize in running shoes and clothing.

Pedometers need to be attached to your waist area near the front of the hip and in a line above the kneecap. It can also be worn at the side or at the back of the waistband. The important part is the pedometer must be in an upright position to work properly.

How to use the pedometer:

attach the pedometer to your waistband, set it to zero

- walk 20 steps in a row without looking at the pedometer
- check the pedometer to see that it reads 20

How to start the 10,000 step program:

- Wear the pedometer for one week and record your total daily steps. One week is a good time frame as it should include both work and leisure times.
- Total the number of steps for the 7 days and take the average number of steps/day.
- Try to increase the number of steps each week by 500 until you reach 10,000, which is considered an active level of activity. See the activity chart below.

Exercise is as individual as you are, so listen to your body when exercising. If increasing the number of steps by 500/week is too much, try 250 and increase at your own pace until you reach the 10,000 steps. Some helpful hints to promote more walking steps are things like taking a short walk at lunch time, or walk to the mail box down the street instead of drive, and think about other times where you could walk instead of taking the car or public transit.

Keep track of your progress and how you feel each step of the way. If you are interested in a walking program or walking indoors, get in touch with your local recreational centre or ask at the local malls. Often the large centers have informal indoor walking paths that provide a safe walking space that is free from outdoor elements like the rain and snow.





inactive average active

Education

Foods and arthritis – does it make a difference?

Diet plays an important role in our overall health. There is evidence to suggest that there is a connection between foods and heart disease, stroke, and both colon and breast cancer, but what about arthritis?

Rheumatologists, up until recently, did not believe there was a relationship between food and arthritis symptoms. Now, this possible connection between diet and disease is getting more attention in the scientific community. More research is needed to see if there is a link between diet and the over 100 types of arthritis. Gout is the only type of arthritis that has scientific proof that the disease is linked to diet.

There is a growing body of evidence that suggests that diet may affect not only the symptoms of rheumatoid arthritis (RA) but perhaps the progression of the disease. Scientific research in this area is just beginning, however, scientists believe that diet may affect the many types of arthritis in the following ways:

Food sensitivities may either trigger symptoms of RA or make existing symptoms worse in a small number of people

A diet that is high in saturated animal fats and popular vegetable oils may play a role in joint and tissue inflammation

*Of Joint pain from arthritis can be so painful it's difficult to walk around, drive and lift and carry item like groceries. This might limit ones ability to shop, load in groceries and prepare nutritious food.

Arthritis pain and the tired feeling that results from chronic pain can decrease the appetite and affect nutritional intake.

How to check for food sensitivities....

First, keep a food diary of everything you eat and drink and leave a space to write down any symptoms, like increased pain or less pain. Stop eating one food at a time for two weeks. This does not mean a food group such as vegetables but one type of vegetable, for example potatoes. After two weeks reintroduce that food into your diet and note any changes in your arthritis symptoms.

It is also important to remember that, if you cut out dairy products, you get your calcium and vitamin D from other foods or by a supplement. For information on calcium and vitamin D requirements, refer to JointHealth™ monthly, June 2005 or click on: http://www.arthritisconsumerexperts.org/news/2005-june.cfm.

Remember, it is important to let your doctor or dietician know you are cutting out some foods from your diet. Do not cut out a food for more than two weeks. If you find a food that you think triggers an arthritis symptom, it is recommended you see a dietician or an allergist.

If you have noted that certain foods affect your arthritis more than others, either increasing or decreasing your arthritis symptoms, and would like to share this information with ACE, please write or email us at: www.arthritisconsumerexperts.org.

Getting better mileage out of your joints with an oil change (Horstman, 1999)

The research suggests that the type of oil we eat in our diet may either increase or decrease inflammation and arthritis pain. Fast food and processed foods contain the omega-6 fatty acids that can increase inflammation. Omega-3 fatty acids found in cold water fish and certain cooking oils help fight inflammation.

The following information are recommendations from the Arthritis Foundation's guide to Alternative Therapies, by Judith Horstman.

Fast food, restaurant foods and prepared foods are cooked with linoleic cooking/salad oils. These types of oils are considered 'bad oils' and include: corn, safflower and sunflower oils. Instead it is recommended to use canola, olive and flaxseed oils, that are considered 'good oils' as they contain fatty acids that are good for our diets.

Use flaxseed oil in your diet either oil, seeds or meal. For oil, use 1-3 tablespoons each day. For seeds and meal use about one quarter of a cup each day. The oil can be used as a part of a salad dressing and seeds on the salad. The meal can be used on cereal, soups, casseroles, yogurt, as well as in salads.

Limit your intake of meat or poultry to 4–6oz in any one day

*Eat broiled or baked cold water fish, 2-3 times/week. Cook without fat or use a very small amount of fat.

Limit fat intake to 20-30 percent of daily calories.

Gout: facts and myths

Years ago gout was thought to be a disease of the rich. It is now known that gout happens because either too much uric acid is produced (in about 20% of people with gout) or the body's inability to get rid of it through the kidneys (in about 80% of people with gout). The myth formed because the foods that break down to form the uric acid are alcohol, meats and seafood's like anchovies, mackerel, and sardines, frequently consumed by the rich.

In gout, the uric acid builds up in the bloodstream and forms crystals that settle in the joints and soft tissues, most commonly the big toe, causing inflammation in these areas. Kidney

> stones can also form. The pain can be excruciating. Although gout is common in men, women can get it after menopause.

Prescription medication like allopurinol and probenecid control and often cure gout so well, most physicians don't recommend dietary changes as well. However, lowering the uric

acid level can help the effectiveness of these medications.

What can you do to help avoid gout attacks?

No beer – some alcoholic drinks can increase the amount of uric acid in the bloodstream. Wine in moderation is apparently fine, and possibly helpful.

Limit the foods that increase uric acid in the bloodstream like meats and seafood's (anchovies, scallops, mackerel, herring and sardines)

*On't fast because this elevates the uric acid level in your bloodstream and may cause a gout attack. If you want to lose weight do it slowly to help prevent uric acid build up in the blood

Prink water to promote elimination of uric acid through the urine, drink 8-12 glasses of water/day

Choose non-fat dairy products in preference to others

Remember – talk to your physician before eliminating foods or taking steps to lose weight.

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the

influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

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ACE thanks these private and public organizations.

Disclaimer

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 never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.

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