Women champions battling arthritis

Arthritis affects two-thirds more women than men. In this issue of JointHealth™ monthly, Arthritis Consumer Experts (ACE) profiles the work and lives of women who actively battle arthritis. Two of the women we present here are people who live with the disease and are driven by their experiences to advocate for others with arthritis. The other is a researcher in the field of rheumatology (study of arthritis and related diseases). All three women are working toward improving the lives of people who live with arthritis.

Q What kind of work do you do?
A As a physiotherapist, I work in two locations. I work in a private orthopedic clinic, which is like a private physiotherapy clinic that you would just walk into if you had an injury.
I also work in the hospital, at the Mary Pack Arthritis Centre, which is also an outpatient clinic. People make appointments to see us because they have been referred by their doctor. They come in for any type of arthritis. We assess them and treat them for anything from post-surgical knees and hips (knee and hip replacements) to inflammatory arthritis to chronic osteoarthritis.
At the private clinic, the physiotherapists can diagnose and treat any musculoskeletal problems. About Karen Tsui
Karen Tsui is a certified Pilates instructor and a practicing registered physiotherapist with a special interest in rheumatology. She lives with undifferentiated spondyloarthropathy (spondylitis) and her father has ankylosing spondylitis. Also, she is a board member on the Consumer Advisory Board of the Arthritis Research Centre of Canada (ARC).

Q What’s interesting and different at the clinic is that people will come in and we don’t know what they have. But in the hospital the diagnosis is already established. So in the clinic we have to figure out what’s wrong and develop a treatment plan. Also, if people are coming to us before seeing their doctors, we try to screen for any medical red flags that we might need other healthcare providers to address.
Q Would you have focused your work on arthritis if you didn’t have it yourself?
A I don’t know if I would have gone into working in arthritis if I didn’t have it myself.
I think it helps when you’ve gone through the experience that the patient is also going through—it helps you to connect with the patient and address their needs better. So, I think it’s natural for a lot of physios to go into the field because of an experience they had themselves where they were injured and needed physiotherapy. The areas they tend to focus on will be related to their own background. Because we understand what patients are going through, it’s that much more satisfying to help them through their rehabilitation.
Q As a women with arthritis, what special concerns do you have?
A Axial spondyloarthropathies, or inflammatory arthritis types that happen in the spine, tend to be less common in women. For myself, it took 9 years to be diagnosed—the average time to diagnosis is roughly 8 to 10 years—and so my concern is that symptoms not get overlooked simply because they are in women.
About Linda Wilhelm:

Linda Wilhelm is a mother, a grandmother, and an arthritis advocate who has lived with rheumatoid arthritis for over 30 years. Her advocacy work includes the following:

- Atlantic Canada representative and Co-Chair for the Consumer Advisory Council
- Operations committee member of the Best Medicines Coalition.
- Frequent participant on Health Canada's advisory panels and conferences on access and drug safety.
- Two term member of The Expert Advisory Committee for Vigilance of Health Products
- Member of the Drug Safety and Effectiveness Network’s steering committee.
- Active advocate for treatment access and quality of care both regionally and nationally.
- Past board chair for the New Brunswick Division of The Arthritis Society.
- President of the Canadian Arthritis Patient Alliance

The interview:

Q Please tell us a bit about your arthritis advocacy work.

A I finally acknowledged I was disabled and unable to work in 1998 when I could no longer walk and was spending most of my time in a wheelchair. Then, I spent 3 years trying to regain some measure of health after getting access to a biologic in 1999, followed by back to back surgeries until I got my mobility back.

I became involved with The Arthritis Society as a volunteer in 2001, which gave me a new purpose. I soon learned that arthritis advocacy was my passion. I could take all my experiences, good and bad, and put them to use to help improve the lives of people with arthritis.

It came as a shock to me that governments did not know everything there was to know about healthcare and especially about inflammatory arthritis. I also quickly figured out that the only way they could learn was for them to listen to those living with the disease and experiencing the system. That is when I started writing letters to the editor and to government. I also mentor other patients who need help with navigating the healthcare system and I regularly dialogue with the New Brunswick Department of Health on the needs of patients.

I worked with others like me to help create and sustain patient driven organizations—only when we organize in large numbers do we get heard.

Also, I ran in the riding of Fundy Royal for the Liberal Party of Canada in the 2011 federal election.

Q As a woman with arthritis, do you feel your experience is very different from a man’s?

A I was diagnosed 30 years ago when I was 23 and had one baby, and another on the way. I put my own needs on the back burner to take care of my children and that included my diagnosis of rheumatoid arthritis (RA). It was important to me to be able to contribute equally to our household and that meant taking care of the house, meals, cleaning, laundry, and children while my husband worked outside the home.

I tried numerous times to return to work once my children were in school but by this time the disease was so advanced that every time I tried, I ended up in the hospital within 6 months.

I manage quite well in the home now. There are times when it is very difficult, but I value my independence and I find it difficult to ask for help. I am fortunate—my husband has a good job and we have good health insurance. I get frustrated with my limitations but always push myself as much as I can.

I was very unhappy about the physical changes caused by my RA. I didn’t feel like the same person with a different shaped face, dry, sore eyes, twisted hands/feet and a stiff, immobile neck. I wanted to feel attractive, but I felt very old at the relatively young age of 38. Now that I am ten years off prednisone my face has returned to its original shape but I have so many scars from 14 joint surgeries. It’s a trade off—function and mobility for scars—I guess I’m okay with that.

I still am a very active woman. I spend a lot of time on online groups helping people with their questions. I think of this as my second career.

What scares me the most is becoming totally disabled and unable to care for myself. Will I be able to continue to live in my own home? Will I be able to drive my car, walk, enjoy retirement, or travel?

I cannot wear pretty shoes, have trouble putting on makeup, jewelry, some clothing, and blow drying and styling my hair.

I am concerned that one of my children will be diagnosed with RA. My daughter is pregnant. I was diagnosed when I was pregnant.

Q What ways do you accommodate your arthritis in your work and daily activities?

A Rheumatoid arthritis is woven through every part of my life that I cannot imagine living a life disease free.

I am on long term disability and can no longer work. I have to plan every aspect of my life to accommodate my disease: cooking, cleaning, laundry, travel, exercise, personal hygiene, social activities, and walking my dogs. I plan my day in the morning and have to factor in frequent rest times. I avoid activities that aggravate the disease, like washing windows, painting, and spring cleaning.

My husband helps me to participate in activities that I really enjoy but can’t do without help, such as kayaking, riding a motorcycle, and hiking.

I can still function well in our current home. In the future I may not, so we are taking steps now. We are in the process of getting our home ready to sell and are planning to build a new, open concept, accessible home with no stairs.

Our vehicles are purchased with my RA as a consideration. I have power locks, power windows and higher seats for ease of entry and exit, as well as good visibility to help with my neck restrictions.

Every day I make time to do the exercises given to me by my physiotherapist to strengthen my core and improve balance.

Q As a woman with arthritis, what special concerns do you have?

A My children’s spouses are not confident I can handle caring for my grandchildren, so I do not get to spend as much time with them as I would like. I hope this will change as the kids get a little older and don’t require as much hands on care. But I worry whether they will know me well enough to want to spend time with me then.

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Dr. Mary de Vera is a health services researcher with expertise in pharmacoepidemiology (the study of the use of and the effects of drugs in large numbers of people), epidemiology, and perinatal (during pregnancy) epidemiology. She currently holds a tenure track position in the Faculty of Pharmaceutical Sciences at the University of British Columbia. She also works with the Arthritis Research Centre of Canada (ARC). To learn more about Dr. de Vera, please visit http://www.arthritisresearch.ca/trainees-menu/63-devera

My research interests fall under two main areas. First, I am interested in medication non-adherence. Either voluntary or involuntary. This may include not filling a prescription to begin with, not refilling prescriptions, skipping doses, or stopping medication altogether.

Medication non-adherence is an important health problem, especially for people with chronic diseases. The World Health Organization reported that non-adherence to medications occurs in about 50% of people with chronic disease. That is a staggering number, especially when considering the negative outcomes of not taking medications properly, which include hospitalizations, worsening symptoms, increased medical visits, need for more or other medications, and even death.

I showed this during my PhD, at UBC, research on people with rheumatoid arthritis who are taking statins (cholesterol lowering medications). I compared people who stopped taking their statin medications to those who continued. I found that stopping increased the risk of a heart attack by 67% and death by 80%.

In my new role as Assistant Professor (in Medication Adherence) at UBC’s Faculty of Pharmaceutical Sciences, I plan to continue this work by studying the reasons people do not take their medications properly, which include hospitalizations, worsening symptoms, increased medical visits, need for more or other medications, and even death.

My goal for my research is to improve outcomes for patients. Medications are amongst our strongest “weapons” against disease; however, it is important they are taken properly by patients. It is also important that we understand their effects across different patient populations, especially those who are excluded from clinical drug trials (with pregnant women being one group).

My interest in medication non-adherence is motivated by my own family members with chronic disease who struggle to take their medications properly. As caregiver to my grandmother who has many medical conditions including arthritis, I see the challenges of managing many medications and taking them in all forms. Also age, language, and a lack of understanding of why these medications are needed is a recipe for non-adherence.

In her, I see the challenges, but I also see where solutions may lie, including targeting not just the patient, but their caregivers and family to help improve adherence.

The interview:

Q Please describe the work you do in the areas of pharmacoepidemiology and perinatal epidemiology?

A My research interests fall under two main areas. First, I am interested in medication non-adherence. Either voluntary or involuntary. This may include not filling a prescription to begin with, not refilling prescriptions, skipping doses, or stopping medication altogether.

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My continued perinatal research represents the merging of my PhD and post-doctoral experiences. I plan to study how taking arthritis medications—including disease modifying anti-rheumatic drugs (DMARDs) and biologics—affect the health of the mother and her baby. This is an under-studied area but much needed, especially considering that arthritis disproportionately affects more women than men, and many types of arthritis strike during childbearing years.

Q How will your research benefit patients?

A My goal for my research is to improve outcomes for patients. Medications are amongst our strongest “weapons” against disease; however, it is important they are taken properly by patients. It is also important that we understand their effects across different patient populations, especially those who are excluded from clinical drug trials (with pregnant women being one group).

Q Have you always been interested in this area of study or did an experience during your education lead you to this point?

A My interests have been motivated by the combination of my education, training, and life experiences.

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My interest in perinatal research goes back to the early days of my career.

Ten years ago I started as a Research Assistant at BC Children’s Hospital working with babies and their mothers. They are a special population. Even back then, I knew that I was going to one day do research to help improve their health.

Finally, I myself am a new mother and understand that information during one’s pregnancy is so important to guide decisions. There is such little information on the impacts of medications, particularly arthritis medications, to help guide pregnant women with arthritis or women with arthritis who are planning to become pregnant. So, it is even more important to pursue this research and promote research on pregnancy issues in arthritis.

You can find more information about why most arthritis types are more common in women and how the disease affects life quality in the July/August 2011 issue of JointHealth™ monthly by:

- Visiting www.jointhealth.org to read it online.
- Contacting us at info@jointhealth.org or calling us at 604-974-1366 to get a print copy.
About 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 healthcare 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.jointhealth.org

Guiding Principles
Healthcare is a human right. Those in healthcare, 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 healthcare 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 website, or during any of its educational programs or activities.

Thanks
ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.

Acknowledgements
Over the past 12 months, ACE received unrestricted grants-in-aid from: AbbVie Corporation, Amgen Canada, Arthritis Research Centre of Canada, Bristol-Myers Squibb Canada, Canadian Institutes of Health Research, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Janssen Inc., Pfizer Canada, Takeda Canada, Inc., and UCB Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks these private and public organizations and individuals.

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