

Listening to You

This first issue of JointHealthTM monthly in 2006 is all about sharing

and listening to you. The people contributing to this issue have all, in one way or another, helped to move the arthritis cause forward over the past decade. Arthritis Consumer Experts is so very grateful to them for their enormous contributions of energy, expertise and passion to help 4 million Canadians with arthritis. We hope you benefit from the wisdom and insights of the amazing individuals who contributed to this month's JointHealthTM monthly. Along with many others across the country, they have learned to live, and win, with arthritis.

Disease weeds out the nut bars from your life

As a friend of mine once told me, "The wheel chair screens out the bad ones." I never thought of it that way, but I guess disease does as well.

My disease has made me sit down and really think out what I feel really is important to me and what is fluff. People tell me, "Why didn't that make you freak out?" I tell them that it is not that big of a deal. The truth is that in the back of my mind most issues are not worth getting upset about. When one hears that there maybe a 25% chance you may not walk, most other problems become trivial.

Disease has taught me that it is important to laugh. Everyone has a choice how they want to react to life, the other choice was unacceptable to me.

I am as bored as I want to be. (When I think life sucks, life usually does when I am not busy doing something constructive)

*Anonymous
Person with adult JIA*

My Arthritis Experience

Recently I listened to author, Joan Didion, talking about her book, "The Year of Magical Thinking" – an almost unbearably painful memoir about coming to terms with the sudden deaths of her husband and her daughter.

Most of us with arthritis have formulated our own type of "magical thinking" – our own way of working through pain and sadness to come through the disease experience with something positive and life enhancing.

My disease has made me reflective, something nature did not intend me to be. It has also made me far more empathetic to others than was 'pre-disease me' – but above all, it has induced in me a rich vein of contentment.

Why contentment? Maybe it's the "Yin-Yang" principle, the play of opposites; "white" needing "black" to express the essence of "whiteness". The presence of pain brings genuine joy when that same pain lifts – like the old saw about hitting yourself over the head with a hammer because it feels so good when you quit!

So every day that arrives without pain is a day for the tabulation of blessings. I know that I owe my ability to count and savour those blessings to my disease. For that very special gift, I am hugely grateful – and genuinely, robustly content – in a way that I know I could not otherwise be.

*Gordon Whitehead
Person with rheumatoid arthritis and
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Today is a good day

I try very hard, to remind myself, that today is a Good Day.

Every day, I self-talk my way through it.

It is too easy to be negative.

Sharing stories, with friends, family or my kids.

It reminds me that my life is good, and full.

Somedays it's enough for me to feel good, that I did the dishes, or made a meal, or took a nap.

Sharing a smile, or a few words with someone, can make their day better, and yours.

Trying to understand, that we are all different, but all the same.

Arthritis, has been the best gift, I've received, besides my kids.

My life is better, beyond description, because of the people, that

I am truly inspired by. My arthritis family, gives me the strength and determination, to be a better person.

I am truly thankful every day, for all that I have received.

Smile and the world smiles with you.

Joyce Greene

Person with rheumatoid arthritis

Aboriginal representative on the Consumer Advisory Council of the Canadian Arthritis Network

A beneficial side effect to having RA

It's funny what benefits having arthritis can bring. Some of the strongest, smartest, nicest, most productive, entertaining, understanding and compassionate people I have ever had the pleasure to know, deal every day with the pain and disability caused by their arthritis. I've learned a great deal from each of them, and I'm lucky to call each one my friend. I call it a beneficial side effect to my having RA.

Anne Dooley

Person with rheumatoid arthritis

President, Canadian Arthritis Patient Alliance (CAPA)

I turned this lemon into lemonade

Twenty years ago my life took a hard right turn: I was diagnosed with rheumatoid arthritis. Within 5 years I had to quit my job, could barely walk, had major stiffness and fatigue every morning and evening; my joints were progressively being damaged. I cycled in and out of depression.

But I turned this lemon into lemonade. I got on a drug regime that stabilized my disease and then I got involved in arthritis advocacy and research!

I share my passion, experience, and knowledge, and contribute to improve the lives of people with this disease. And the bonus for me is that I feel better. Now instead of being depressed, I find the more I do, the better I feel; and the better I feel, the more I can do. My lemonade tastes sweet.

Pam Montie

Person with rheumatoid arthritis

Member, Consumer Advisory Board of the Arthritis Research Centre of Canada

Making a good poker hand with bad cards

For me, getting a diagnosis of rheumatoid arthritis was like being dealt a very bad hand of poker. You know, the one where you want to throw all of the cards back into the pile and ask for new (hopefully better) ones from the dealer. Unfortunately, rheumatoid arthritis doesn't work that way. So like millions of other Canadians did when they were diagnosed with arthritis, I tried to figure out how to make a good hand with bad cards.

In the early going, I faced constant setbacks. The more I learned about rheumatoid arthritis the more afraid and depressed I got – mostly about my life as I once knew it being over. I learned that as a former competitive athlete, I wasn't going to be out crashing down a mountain on a bike, or running a marathon, or doing other things that came as second nature to me. But to my surprise, as my health care team and I got control over my disease, I learned that there were still many things I could do. That with care and some creative problem solving, I could still play tennis, swim, workout in the gym, among other physical activities. That I could still be in meaningful relationships with family and friends – that I could still be Cheryl, not Cheryl + rheumatoid arthritis.

What amazes me today, sixteen years after receiving my diagnosis, is that I don't view myself as ever having had a bad hand of cards. I feel good inside when I think in these terms and that makes me want to start a new day, with a smile in my heart and on my face.

Cheryl Koehn

President, Arthritis Consumer Experts

Coping with osteoarthritis

Although it's a relatively slow progression until osteoarthritis insidiously wrecks damage enough that you realize it's a downhill, chronic affliction you ultimately recognize there are effective rearguard strategies that can postpone the inevitable crippling of joints and loss of musculature and the concomitant pain. My experience trifled with medication, diet, massage therapy and positive thinking but it finally came together with health promotion and the need to help others suffering with my predicament. So ten years ago I initiated an aqua-exercise program for a small group of senior volunteers which has evolved into an amazing success story for we now have 130+ participants in the pool thrice weekly and year round. The loyalty/bonding/socialization, camaraderie of the group is such that we are partnering with Dalhousie University on a scientific study to try and elucidate pertinent factors which culminate in this success story. At the same time the physical/psychological fitness, from the buoyancy and resistance of the water exercise has brought about abeyance of the arthritis in a significant portion of our 'mermaids'.

George McKiel

Person with osteoarthritis and

Past Co-chair, Canadian Arthritis Network Consumer Advisory Council

A long struggle to success

It took me a long time to talk and write about my “Struggle/Success” with arthritis because for so long in my life I have hidden the problem from everyone (except family). Even my son did not know I had anything “wrong” with me until he was 13 years old. He just thought all women had to be treated/touched with great care. So here it is: Until four years ago, every decision in my life has secretly revolved around my health issues related to arthritis, - where I lived, worked and holidayed, how I traveled, even when and if I would have children. “Arthritis” was a word for “old people” and I was not old. Four years ago I could hide it no longer, I divulged my secret and heaved a sigh of relief. I was older and thankfully the rights of disabled people had improved. My world opened up! I have many new friends, have gained wonderful support from the local “arthritis community” and have met some incredibly dedicated people in the national arthritis “arena”. But the old fear still lingers, because of government health care cut-backs and cost savings – will I, one day, live to regret being so open about my arthritis? NO, this must not happen! Together we must fight to make life for people with arthritis better, to change attitudes about this disease and to promote and implement the Standards for Arthritis Prevention and Care!

Delia Cooper

Person with rheumatoid arthritis

for over 30 years

Leader of the The Arthritis Society group, “Hang Tough”

My fight against arthritis

Arthritis, this disabling illness which affects over 4 million Canadians and strikes without warning. Six feet 2 inches tall and weighing 210 lbs, I’m not exactly frail! And yet, rheumatoid arthritis came knocking on my door 21 years ago. My fight began on January 2, 1985 when I woke up with excruciating pain in my hands and wrists. I remember that my hands were very swollen. I was 38 years old at the time. Since that day, it has been a constant fight to maintain my autonomy, my dexterity, my strength and my endurance. There have been several battles against this illness, some I won and some I lost, just like in any war. In February 1993, one of these battles put me in a wheelchair and on my way to the hospital. I could no longer walk. However, this series of battles against the invader has allowed me to get to know myself better and to capitalize on my strengths. My most significant fight and the one that brought me the most self-gratification was succeeding in ensuring recognition of a new category of medication – biological agents – by the Quebec Health Insurance Plan. Since then, I have been able to take this innovative drug and my illness is under control. My quality of life is more than acceptable and the constant pain has almost disappeared. There is definitely hope!

Jean Légaré

Neuville, Quebec

Member, Consumer Advisory Council of the Canadian Arthritis Network

Giving something back

With every negative experience something positive happens. For me, after many years of living with undiagnosed osteoarthritis (OA), I finally found out the constant pain and disability was OA. Within a short period of time, I had bilateral hip replacements, no limp, and moreover, no pain. I was able to combine my education and disease into a career that involves helping people with arthritis. Without arthritis, I may not have found this job or met many wonderful people all with their own arthritis experience and who are advocates for all Canadians with arthritis. I am glad to have the opportunity to give something back. The worst part of the whole disease was getting a diagnosis. I would like to see better education for detecting early OA. Perhaps, if I was diagnosed years before I wouldn’t have needed to have surgery. I hope that research for early detection of OA continues and one day, the need for surgery is no longer a need.

Sandy Lockwood

Person with osteoarthritis

Allied member, Consumer Advisory Council of the Canadian Arthritis Network Office manager, Arthritis Consumer Experts

“Never look down or back! – move forward with a positive attitude – it will affect the outcome”

This was my parents’ mantra growing up and it has helped me deal with the challenges of osteoarthritis (OA). I choose to believe my OA is a gift that has helped me to stop long enough to see and feel myself, my loved ones and world around me in a sharper focus. It has helped me clarify my life’s priorities like no other time before this. I realized I was living according to my parents words when my husband laughed one day and said, “You have no rear-view mirrors”! I remain active physically, emotionally and mentally and continue to challenge myself to become a more thoughtful person. I would like to see more work and research done in arthritis prevention and care in the area of methods for people with arthritis to retain the mobility they have at the onset of the disease.

Céline Pitre

Person with osteoarthritis and

Member, Consumer Advisory Board of the Arthritis Research Centre of Canada

Lessons Arthritis has taught me

I’ve learned that a change in life’s circumstance provides a second chance. I’ve learned that family encouragement turns disability into ability. I’ve learned that true friends never tire of asking, “How are you?”. I’ve learned that elderly counsel is rich in kaleidoscope colours. I’ve learned that a kind word in the face of doubt is strong currency. I’ve learned that sharing successes begets sweeter rewards. I’ve learned that laughter fuels my well-being, And that a positive outlook sustains me year after year.

Colleen Maloney

Person with rheumatoid arthritis

Vice President, Canadian Arthritis Patient Alliance (CAPA)

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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