

Arthritis Awareness Month Series



Part III Recovering from Joint Replacement Surgery, a patient's perspective

Part I and II of the Arthritis Awareness Month JHI Series covered new research on osteoarthritis and heart health and the road to joint replacement surgery. The third and final part of this series consists of an in-depth interview with Cheryl Koehn, Founder and President of Arthritis Consumer Experts (ACE) and person living with rheumatoid arthritis and osteoarthritis. In July, Cheryl underwent a total knee replacement (TKR) and kindly agreed to share her surgical journey with ACE's members and subscribers. In the ["Total knee replacement – Preparing for surgery" video](#), Cheryl explained the different aid devices that would be needed in recovery. Then, just over 2 weeks after her surgery, Cheryl answered some questions about her recovery and rehabilitation process thus far and talked about the challenges faced by someone who also has an autoimmune disease.



To give some context to our readers, can you tell us about the type of surgery that you had done and how you felt going into it?

After doing all the things my surgeon told me to do, to try and keep the knee I got at birth going as long as possible, it got to a point where the joint was just a complete failure. I then knew it was time to get a total right knee replacement. The surgery happened just over two weeks ago.

// Like most people with arthritis who have to undergo a surgery of this type, I went in with some anxieties but with very high expectations because I knew that both the surgical technique and the actual prosthetics that are used have advanced quite a bit and I was diligent about my “pre-hab”.

This gave me confidence that there’s a possibility this new knee could last the remainder of my life.

Keeping in mind that everyone has a different recovery timeline, where are you currently in your recovery journey?

I had a slightly extended stay in hospital because in addition to osteoarthritis, I also have rheumatoid arthritis (RA). In the setting of RA, it is particularly true that recovery timelines can vary compared to a person getting a joint replacement without an existing autoimmune disease. I was in hospital for 5 nights, mostly because of post-surgical vomiting and a left shoulder flare. I had someone stay over at my house for that first night home which is recommended. The first few days home were pretty brutal. I was in a lot of pain and it was difficult to distinguish whether it was RA joint pain or not, given that it’s a new knee and not a joint with RA anymore. So, I did have some concerns about the pain I was experiencing, but with a call to my surgeon’s office I was assured that it was quite normal.

The first week at home was all about recovery and less to do with rehab. A lot of people without RA go straight into rehab following their departure from the hospital, but in my case, I had to really focus on just recovery and pain management. This means focusing on getting over the anesthesia and just feeling well enough to eat and do the things one needs to do to feel “healthy”. I also had quite a lot of lower leg swelling, from my groin all the ways down my leg and into my ankle and bottom of the foot – it was almost completely purple from bruising. It was a bit scary looking! Then, the last few days have been more about trying to take my knee through greater range of motion. At first, you feel like you’re going to break your incision, it’s so tight with blood inside the joint from surgery and inflammation from the RA. I was a bit nervous about trying to bend my knee but trying is a good thing – it flushes the swelling and takes some of the blood away with it from the joint. So, in my recovery process, I now feel like I have gotten over that initial big hurdle, I feel kind of



like my old self. I feel like eating a meal again – I didn't have a sense of taste or a desire until the last day or two. I've now had my second physio appointment and I've learnt so much from my physio. She's been fantastic at showing me how to use my core, like pelvic floor muscles, that help you lift your leg, instead of relying on muscles in my operated leg.

Are you able to see a physiotherapist who has experience treating patients with rheumatoid arthritis (RA)?

Yes, I'm seeing a physiotherapist who is trained in arthritis and knows a lot about autoimmune types of arthritis and joint replacements in people like me. Most people with autoimmune arthritis in Canada have access to an arthritis trained rehab specialist because our cases are a bit more complicated and we have this underlying autoimmune disease process going on. Rehab is handled a little bit differently, for example, the rehab timeline is not as compressed as for a patient with osteoarthritis.

For you, what have been some of the most important parts of rehab, after getting through the recovery process?

I'm a bit of a type A personality, I was a high-performance athlete in my teens and 20's. In other words, I had really high expectations that I would be doing more than I have been able to do, in terms of rehabilitation. I was expecting to be able to do a lot more with the muscles in my operated leg, but that has not been the case.

// So, my rehab this past week has been all about – well, sort of non-rehab. It's been about loving myself and not feeling pressured that I have to bend my knee at a 90-degree angle two weeks post-surgery, even though that might be a reasonable expectation for another patient in a different situation.

From a rehab perspective, my focus with the physio has been on non-weight bearing, and muscle recruiting range-of-motion exercise. There are some exercises I can't do, that technically I should be able to do at 2 weeks, and there are other exercises I can do that would actually be considered more advanced. For example, I've been putting my leg up on an exercise ball and not using the muscle to promote range of motion but actually gravity, rolling my leg from side to side. I've also been using a transcutaneous electrical nerve stimulation (TENS) machine, which is a little electronic machine that creates muscle stimulation through sensors on your leg. We've been trying to work with the muscles in my upper and lower leg, without disturbing the joint. Doing those things in two separate steps has been a great learning experience, not just for me but my physiotherapist.



It seems very important that patients, particularly those with an autoimmune arthritis, are kind to themselves in times when they're unable to meet their rehab expectations. Is that correct?

Absolutely. If you're going in for joint replacement surgery you get handed this booklet on exercises you are expected to do as part of your rehabilitation process, in weeks 0-6 after surgery. And then you look at the timelines in the booklet and you think, "well, I can't do this one, I'm a loser" [Cheryl laughs]. My physiotherapist said to me, "okay Cheryl, let's not freak out about what you can't do but focus on what you can do and build on that". In my case, there are certain muscles that are not working well enough to do some exercises earlier on in the booklet but then I'm doing some that are supposed to be further on. I learnt quickly that it's all contextualized. That was a really good lesson for me.

What has been the most challenging part of your recovery process? What do you do to help overcome these challenges?

// For me, the most challenging part is something I had to overcome even before the surgery and that's the recognition that I was going to need help.

I'm not the greatest person at asking for help. I like figuring things out on my own and have always been independent. I would like to say to all the readers, if you're not good at asking for help, try your best to overcome that.

When my close circle of friends found out I was getting surgery, they immediately began offering help. I started to think about which of my friends would be good at certain stages of recovery. For example, who won't be squeamish seeing the stuff that happens in hospital?

Looking for help and organizing the help you will get are quite critical to your recovery process and we don't think enough about them. We think about them sort of just in time, when you need the help – but then it's much harder to organize. Organizing that stuff beforehand is really helpful to you and your helpers because you don't have that extra burden when you're in huge pain and discomfort. There are fewer surprises. Help arrives when you need it.

Now that I'm home, I'm still receiving help. I've got friends and colleagues getting groceries for me and bringing me to appointments. When you are prepared mentally and socially, your physical and functional recovery will be better.

Would you say that in a sense, these friends and colleagues become an important part of your post-surgery healthcare team?

They become more important than your surgeon was, that's for sure. I have absolute worship for the surgeon who did my surgery. He is highly skilled, has incredible bed-side manner, etc. but the surgeon is now out of the picture, so it's my friends and family members who become

more important than my surgeon and I think this is a really important point to underscore about healthcare. For example, face-timing with my sister who lives in a different city has been the best medicine ever. Having my friends come in and bring me a pastry and a coffee has been the best medicine ever. So, absolutely, the role that my friends play has risen up in importance for me and my recovery process. And also, my physio. She's my goddess – I can't imagine having gone through the last few days without the excellent pieces of advice she's given me.



What is something that you wish someone had told you before surgery?

Well, it was only after the surgery when I was in so much pain that every healthcare provider I encountered would say “yea, the knee replacement surgery is far more painful than the hip replacement surgery”. I wish someone had told me beforehand that this is a super painful surgery and even more so in the setting of RA. I would have rather known and not thought something went wrong with the procedure or prosthetic. I could have been prepared for my post-surgery pain.

// I also wish I knew that patients in the recovery process and initiation of rehab are not little cookie cut-outs of one another; we all move at different paces. Even though we address this all the time in our ACE education programs, I fell prey to this notion that I would be like everybody I've read about in these booklets. We are snowflakes in how we respond to a new joint being put in our body. I wish that I was told, “Cheryl, you maybe aren't going to be like these little line drawings in this booklet. You aren't going to be able to do exercise 1 but you might be able to do exercise 5 and we'll modify those things”. I wish I could have been kinder

to myself in not having this expectation that I would be like everyone else in the recovery and rehab process. Knowing this beforehand would have made things easier for me and caused me less anxiety about being “behind” in my recovery. I was thinking to myself “what is wrong with me?”. I thought something went wrong in the surgery and my knee wasn’t working right.

So far in your knee replacement journey, are there any gaps in the healthcare system that have stood out to you?

For sure. The big one is that I was feeling really pressured by the care team on the ward to get out of the hospital. That was really disappointing. I kept saying to them, “I have RA, I’m not the same as other people on this ward that don’t have RA. I feel really sick; I can’t be discharged right now”. I think it would have been good to go in beforehand and educate my healthcare providers in the ward that I was going to be in. I would tell them about my autoimmune disease before I went there.

Also, they do say that you should have an advocate with you in hospital, and I didn’t. I absolutely wish I had someone in my room with me all day the first couple of days. I needed someone to speak on my behalf because the second you put the hospital gown on, you lose your power. It doesn’t matter how ‘in the know’ you think you are, or your personal and professional experience in healthcare. The fact that I need an advocate in the room with me shows there are gaps in the healthcare system. I think healthcare providers do the best they can, but some of the nursing staff even told me that they couldn’t come at certain times when I really needed their help or care because they were overwhelmed with their other responsibilities. I think that’s a problem.

In reference to your experience, how can healthcare providers make patients feel more welcome or at ease?

I think they can be more empathetic. I think they have sympathy for you, but that’s very different than empathy. Sympathy is feeling badly for someone and wishing they felt better. Empathy is about putting yourself in that person’s shoes and actually trying to feel what the person is going through.

// Scientific evidence actually shows that there’s a strong correlation between physician empathy and patient satisfaction. Empathy lowers patients’ anxiety and distress and ends up delivering significantly better clinical outcomes. I didn’t feel a lot of empathy when I was in hospital.

Sometimes when I was trying to suggest that I needed something other than what they were offering me, I was treated in a demeaning way. For example, one nurse kind of spoke to me like I was a child. I may have been sick and on medication, definitely feeling vulnerable, but I’m still a grown adult who made the decision to have a joint replacement. I do have to say I had some

care in hospital that was superb and other care that was far less than superb. I had some interactions that left me in tears. That was hard.

You did a lot to prepare for surgery, including patient education, strengthening exercises and making your home as accessible as possible. Now that you've had the surgery, what preparation do you think was the most helpful?

I rode my bike a ton before surgery. It was one of the things I could still do, even with all the mobility issues in my knee. It allowed me to be and feel really healthy, at my ideal body weight, and build strong leg muscles before surgery and I felt emotionally and psychologically ready. I think this was very important and helped make me a good surgical candidate. I also did a lot of reading about the process and I talked to other people who had knee replacement surgeries.

As ACE members know, I equipped my house in advance with everything I would need after surgery. The one thing I under planned for was the toilet seat. I thought just a little small one that would sit on top of the toilet would be sufficient, but there is no way. There is no way I could have survived in the hospital or at home without having one with arms where you roll the seat overtop of your existing toilet. I would strongly suggest that people kind of overestimate what's required rather than under-estimate what is required in this case.

Do you have any other final words of wisdom for people going into a knee replacement or thinking about getting a knee replacement?



My biggest piece of wisdom that I can give my fellow patients is to think positively. Even when you're in pain, think positively. Pain is an indicator; it tells you if you've done too much or if you're not quite ready for something. Don't think of it as an enemy but as your friend and as a guide. Be positive because the latest research shows that joint replacements now last between 15 and 25 years. It's an incredible technology and after being in pain from a knee that was just worn out and couldn't do anymore, I view it as a great gift for the rest of my life. I don't think of a joint replacement as me being broken or weak, rather, I think of myself as being stronger.



Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power 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, scientific and medical experts on 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 amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional colleagues,

collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- 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.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Scientific Review

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.



Disclosures

Over the past 12 months, ACE received grants-in-aid from: Amgen, Arthritis Research Canada, Canadian Biosimilars Forum, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Hoffman-La Roche Canada Ltd., Knowledge Translation Canada, Merck Canada, Novartis Canada, Pfizer Canada, Sandoz Canada, Sanofi Canada, UCB Canada, and the University of British Columbia. ACE also received unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks funders for their support to help the nearly 6 million Canadians living with osteoarthritis, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and the many other forms of the disease.

Disclaimer

The material contained in this publication 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. Please contact your physician for your own health care related questions.

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