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The hands I've been dealt

When I think of hands, I think of my mother's hands. They were the 'immaculately clean, with nicely trimmed nails' type of hands. They could do anything from working a knot out of a shoelace or with a flash, wipe a runny nose, or fix a zipper that was hopelessly stuck. They were immensely strong hands that could open any jar or package; pull you back from imminent danger or settle on your own hand with an ever-tightening grip when you waded into spoken territory that she thought bordered on 'cheek'. They were the hands that could envelop your own and warm them when you came in from play or stroke your brow when you were sick. In later years they were the hands that pulled you up to dance with her when the mood struck, whether you wanted to or not. I loved her hands, they told you everything you needed to know about her, at times fierce, playful, or loving.

In life, you get the 'hands' you are dealt, and my 'hand' resulted in my being the third generation on my father's side of the family to be diagnosed with rheumatoid arthritis (RA), all of us around the age of 36. I had an acute onset that had the immediate effect of throwing my life and work into chaos. In retrospect, I was fortunate that very early on I was referred to hospital-based physio and occupational therapy specifically for my hands. I wouldn't have been that lucky if my primary diagnosis had been hand osteoarthritis (OA). The pain and swelling, particularly in the metacarpal-phalangeal (MCP) joints, proximal interphalangeal joints (PIP's) and distal interphalangeal joints (DIP's) made gripping a toothbrush or a hairbrush or holding and using a utensil such as a fork or a knife virtually impossible. Eating was therefore almost impossible to manage and I lost 30 pounds within a few months. The hospital OT fitted me with custom-made orthotic devices; for resting and sleeping, and ones I could wear in water for showering or rinsing dishes. All with the intended outcome of settling and protecting the joints until the medication prescribed had a chance to work its' magic. There was no discussion about how or whether I would be able to use my hands going forward even though they realized that a diagnosis like RA at that time meant eventually I would see substantial deviations in the joints of my hands. It's astonishing what we take for granted in our day-to-day lives. Doing small daily tasks around the house, or in my office became an exercise in futility, with a heaping helping of frustration, anger, and an overwhelming sense of helplessness. Turning on a lamp, opening a tin and getting food out to feed my cat, or even turning a key to unlock the door became a contortionist's feat. I stopped wearing

anything that had buttons, and on more than one occasion had to ask someone else to tie my shoes for me. I was demoralized.

The hospital-based PT and OT didn't last long, once they've provided you with exercises like walking my fingers back and forth on a flat surface or touching each finger to my thumb; and basic splinting, you're pretty much left on your own to figure out the rest. The Arthritis Society here in Ontario, Canada where I live ran, and still run an arthritis rehabilitation and education program (AREP) where a PT, an OT, and a social worker will come into your home and provide the tools to help you learn to manage your arthritis and manage daily activities in your home. I was able to self-refer and the most amazing women came to my home regularly for the next 6 months or so. I was given different sizes of foam handles to fit over things like my toothbrush, hairbrush, or utensils to help me grip better. There was a special key holder for my house key and a large plastic triangle that fit over a lamp switch so I could turn the lamps on or off as well as large rubber bands for the doorknobs for better grip. There was a stress ball for maintaining my grip (which I still use) and some microwaveable putty to heat and knead to strengthen my hands and work my joints. Wherever I went I brought my trusty 'bag of tricks' with me. My bag full of custom-made orthotic devices with Velcro straps has since been replaced by a pair of Robbie's leather bowling orthoses and a special-order thumb orthotic device. What those ladies gave me, aside from and maybe more than the assistive devices and exercises, was the realization that there was a way to manage everything and if I put my mind to it, I could learn to live well with this disease that had been thrust upon me. But I also had to be at the point where I was ready to hear that. They gave me the support and confidence to take back my life.

Over that first year, I got a lot of help with what the professionals saw as obstacles to work around, all activity-specific, and exercises to maintain the range of motion in my hands. And while I'm sure they delayed the inevitable changes in my hands, as the disease continued uncontrolled the deformities started to occur. Exercises alone cannot stop the march of RA, but exercises used in conjunction with medications can be very effective. And then once again, I was left to get on with my life. To be fair, in RA it's about treating (with powerful medications) to a target of a low disease state or if you are lucky, remission. In the grand scheme of things, the hands tend to take a back seat. You can do a total joint arthroplasty for many joints; knees, hips, shoulders, elbows, or fuse complex joints like wrists but there isn't a lot of long-term

success with hands. The joints are small, ligaments and tendons stretch, you get deviations like ulnar drift, swan necks, boutonnières and subluxations, and dislocations. You can have surgery to realign your MCP's, but it involves a rather lengthy recovery and no guarantee that it will be effective long term.

Research is making big strides in developing better therapies and modalities, but research results remain largely inaccessible to patients who don't have access to the medical journals that publish the latest knowledge. Open access is starting to change that but unless you have an affiliation with an institution like a university, you don't have access to the novel, evidence-based research that is being produced. Over the last 20 years, arthritis patients have become an integral part of all arthritis research, and many funding agencies mandate having a patient on the research team and involving them in a meaningful way. Organizations like COCHRANE regularly develop reviews that are evidence-based and have lay summaries, but COCHRANE is not a widely known organization to most patients, or even health care practitioners in general.

It's been 30 years since I was first diagnosed with RA and over the last 10 years or more, I have developed OA as well, particularly in my hands. I retired three years ago and have found since that time that my manual dexterity is deteriorating rapidly, and my fine motor skills have become almost non-existent. I have toyed with the idea of going back to physiotherapy but feel that I need to do so with an ask. What do I hope to achieve? Here in Ontario, services like PT and OT were delisted by our government some years ago so I have to pay out of pocket for a consultation and any sessions I attend. If you are fortunate enough to have medical benefits insurance through your employment, it is often covered, but not always and there are a lot of uninsured people in this Province. If you have a total joint arthroplasty (TJA) or joint fusion surgery, a number of hospital-based sessions may be covered, and then either you or your insurance have to assume that ongoing responsibility. For many if not most people, like so many other extra-ordinary expenses, it becomes about family priorities like someone needing new running shoes vs a PT consult. In an ideal world, a person living with a chronic MSK disease like arthritis should be entitled to the benefit of an assessment by a PT and OT once a year to address any ongoing or new changes to their joints and the management challenges that that presents, and then a follow-up to assure that recommendations of assistive devices, exercises or treatment modalities are being done/used properly, that they are making a difference and that they are well managed within the parameters of the patient's life.

To a person living with any type of arthritis, it's all about pain, and function. I've learned to manage my pain but the function is directly related to the ongoing damage in my hands that both RA and OA have caused. I think that services like PT and OT are largely about managing expectations. What you want to achieve vs what can be achieved. Balancing what I want vs what I need. Where do the patient's priorities and even preferences fit in? That conversation between patient and practitioner must take place and the decisions around treatment must be shared and agreed on with mutual respect and understanding. A person's therapy needs directly reflect what their day-to-day living challenges are and should be the target of treatment for both physio and occupational therapy. Do they have young children to dress and get off to school each day? Do they have older parents to care for? Do they work in an office and have to use a keyboard all day? Does their job require them to handle money? Do they play the piano or a stringed instrument? Do they work in a dental practice and have to handle small instruments? Some of these activities can be accommodated with assistive devices and some represent a great loss of time and money invested without the lifetime of enjoyment or fulfillment of a career realized.

My priorities have changed over the last 30 years. You learn to live with a lot, and you learn to manage. Now I have a constrictor as they use on your car to take the oil filter off, and that will open a jar or anything large that is screwed on. I wither when a cashier puts my change down on the counter for me to pick up and put in my wallet. At the pet food store one day the man behind the counter said my hands looked "like a monster's hands" and once a young salesgirl told me my ring orthosis was 'awesome'. I told her I had RA and the ring was really a orthosis and she said "Bummer, but cool ring!". The way I manage to accomplish daily activities isn't always pretty, but it generally gets the job done.

Thirty years on I still get frustrated when I can't get the top off an orange juice bottle, and I hate those safety strips inside the top of over-the-counter medications that you have to grip and peel off. I struggle to use scissors but can't open a package of instant oatmeal, or anything else that tears open without them. I won't even start on the hard plastic packaging that so many products come in nowadays. Putting on gloves and getting one finger into one finger hole takes a few tries. It would be really nice if I could do up the clasp on a necklace, or put earrings on without dropping them two or three times. I struggle to get bills, coins, or credit cards out of my wallet while a cashier waits, sometimes impatiently. It would be a relief to type an article like this without having to make corrections because my fingers no longer have the reach on a keyboard that they once had. And just for once, I'd like to be able to walk hand in hand with my partner Shaun with our fingers laced together instead of just holding a finger or two. I know none of these things are life-threatening or life-altering but they are things that are important to me and I would like my frustrations over them heard and acknowledged whether there is a 'work around' for them or not.

Three years ago, I took a tumble off a step stool and managed to fracture my right shoulder and break my left thumb. The thumb was displaced, the break occurring just inferior to the CMC, and required surgery and pins to put it back together. My hospital-based 'physiotherapy' for my shoulder was no more than a resident telling me to bend at the waist and let my arm hang, and to lift my arm straight up over my head. I accomplished both handily as I was highly motivated to reclaim the use of at least one of my arms unimpeded. My thumb healed slowly but the pins were eventually removed and I went to three physiotherapy sessions at the hospital which involved hydrotherapy, and some instructions to try to stretch open my hand until my thumb and forefinger formed a perfect 'L' and then the exercise to touch each of my fingers to my thumb. I was also urged to purchase a stress ball to work on my grip. The MCP in that thumb has been fused by the disease process for some years now so this break has definitely impacted the grip in my left hand and plays a part in the loss of both my manual dexterity and fine motor skills. I keep thinking that this can't get any worse, but clearly, it can and how quickly will it happen? Do I want to risk that? I was still having some pain in my shoulder and a noticeable decrease in my range of motion, so I decided to seek out a physiotherapist to treat my shoulder. By this point in time, it was rather seized up from me not using it in an attempt to try to avoid pain and it took a few sessions of dry-needling to convince the muscle to release and though I quickly improved from there, it still took about four months of weekly visits to get the full range of motion back. In fact, it's now better than it was before I fell! That experience and knowing the advances that have been made in physiotherapy over the last 30 years encourages me to at least book an assessment for my hands. I may manage well to my own way of thinking, but could I be managing better, with less pain and less frustration? Time to find out.

My mother lived with Alzheimer's Disease (AD) for the last 15 years of her life. She was blind, wheel-chair bound, and non-verbal

for the last 5 years. I got her an iPod and loaded on all her favorite music from the 40s, 50s, and 60s and we spent many hours, both plugged into that iPod, sharing music. And we held hands. Despite how AD had ravaged her body and her mind when the music started playing, she would reach out for my hand and hold it in that oh so familiar death grip and we were connected. For that short time, she was my mom once again. Hands are that important, they provide the touch that can bring you back home again.

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