

# LIFE IN HEARTS

ISSUE 04  
2024



## CANADIAN WOMEN WITH MEDICAL HEART ISSUES

LIVING BRAVELY. LOVING BOLDLY.

# LIFE IN HEARTS

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Canadian Women With Medical Heart Issues Facebook Support Community



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Cover Photo Credit: Lise Burgess, BC - Pending Heart Transplant

Issue 04 · August/September

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# A FEW J.R. NOTES



HAPPY SUNNY AUGUST AND WELCOME SEPTEMBER!

I am always surprised how quickly summer flies by in Canada ... well it certainly does in Winnipeg/Winterpeg!

This is a special issue with 3 women with lived/living experience articles and one powerful REFLECTIONS also by a WWLE (please note it is an emotional one and could be triggering.)

The opening article and the Lighthouse article are by inspiring women living with Hypertrophic Cardiomyopathy (HCM) - some of you may recall Lise Burgess's article in the first issue was also HCM leading to pending heart transplant. This condition has been on the radar lately with new research and understandings being published. Hope is in the air for those with this condition.

The other article written by a WWLE is our feature article this issue. It is an editorial and personal story of what can happen when we are not believed. Bobbi-Jo has a powerful heart journey that has been frustrating, and debilitating to her and honestly should be unacceptable in our Canadian health care system. While it is difficult to read, it is important we do not shy away from thinking about how to make it better, how can change happen in a broken system... Sue Robins discussed this in our previous issue and her book "Ducks In a Row" delves into this topic deeper. We also had a "How Do I Get Heard" tips article by Risa Mallory in the last issue that can be helpful if you are not getting answers in your own care,... an info sheet is also available for download or print at [LifeInHearts.ca](http://LifeInHearts.ca)

Annie and Cheryl are back! Annie to provide guidance for getting moving and Cheryl will share "5 food routines" to ease your way into a busy back to school September for many.

I would love to hear how you are finding our e-magazine. What would you like to see? What don't you read? Any and all suggestions are welcome! Shoot me an email [LifeinHearts@HeartLife.ca](mailto:LifeinHearts@HeartLife.ca)

  
EDITOR-IN-CHIEF

# I HAVE A REALLY BIG HEART - NO REALLY I DO.

“I spent years taking care of my physical health to avoid heart issues. It didn't matter.”



By SANDRA NAUFAL, Ontario  
Hypertrophic Cardiomyopathy, 2021

**P**ivot - that became my word of 2020. I was immersed, and enjoying my role as an educational consultant, even though it could be overwhelming. I suspect I did not notice subtle physical changes happening during this time. The move/pivot, in late 2020, from in person work to online work was a huge 'pivot for me in my day to day.

In August 2021, as I was preparing for this pivot to be longer term, I bought a desk for home only to have it come crashing down on my foot, causing a serious fracture. That meant no time for exercise, or gardening, and preparing for the school year was limited as I navigated healing.

The pivot became a jolt with physical impacts. Rude nightly awakenings with my heart doing some sort of dance that wasn't familiar to me. Not the happy dance it did when I exercised. It became a flutter followed by pounding, like lightning jolts and mini earthquakes.

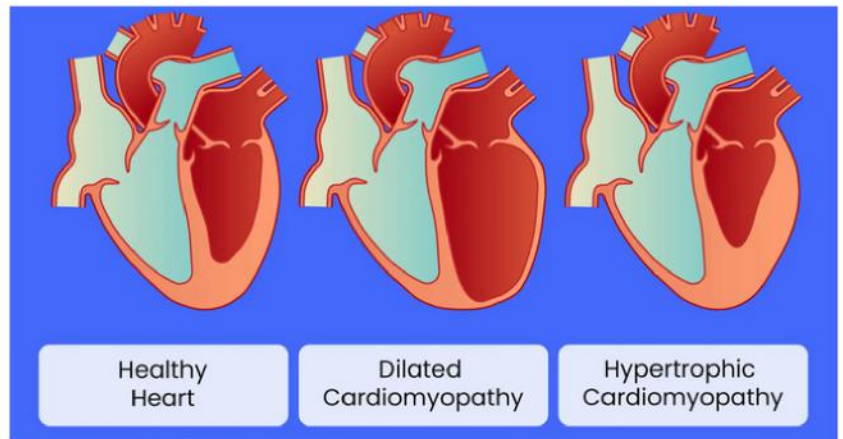
I called my family doctor. A discussion about my age and the changes I was experiencing. You know "the age"? Menopause? Is this normal? My father was a heart patient. I saw how he suffered and had to become a fierce advocate for himself, finally having open heart surgery to fix his heart. I watched in disbelief as this all unfolded for my dad - it did not prepare me for my own heart issues.

I still remember clearly my dad and all the tubes, his recovery, and his need to continue to work in some capacity because it was all he knew. He worked hard with long hours. He did his best providing for his family. But I knew there was more, much more to living (or at least hoping) for something better.

I called my Endocrinologist. He wholeheartedly listened to me when nobody else would. I told him something was not right. "You can't blame your thyroid", he said. He knew my history with autoimmune disorders and sensed my worry. He referred me to a cardiologist. I kept thinking this must be nothing.

My first appointment was for an echocardiogram. Some rudeness from the technician and in-house cardiologist had me in disbelief. When I questioned the contrast dye, I was met with "You are afraid of needles?" I would have hoped there was a template to describe all the tests. The teacher in me needed a plan. Further testing at the hospital in September 2021 indicated that there was thickening in my heart..

The call came in November 2021. "You have Hypertrophic Cardiomyopathy." I heard some words after that. "You need to be seen in person ...There's medication ... Do you work? ... Is it hard work? ... Does it involve lifting? ... Have you fainted yet?.... It isn't too bad ... Stop aerobic activity ... Exercise in moderation..."



Source: HealthCentral.com - By Elizabeth Millard / Medical Reviewer David M. Axelrod, M.D. (May 30, 2024)

I spent years taking care of my physical health to avoid heart issues. It didn't matter. I was told I did nothing wrong. It was most likely genetic. It could have developed over time. Looking back, there were clues: frequent palpitations, shortness of breath with exertion, and dizziness. These were never taken seriously when I questioned them. I was told, "It's your age." and "This is normal." or "Your job is overwhelming."

Hypertrophic Cardiomyopathy (HCM) has taught me a few things. There is no timeline. Every person has different symptoms, burdens, and experiences. HCM is a condition affecting the left ventricle (the main pumping chamber of the heart). The walls of the left ventricle become stiff and thick. Over time, the heart cannot take in or pump enough blood during each heartbeat. Simply put, the body's needs are not being met. There is no cure. There is medication or surgery if you are obstructed to remove the thickness. These are not ultimate solutions but treatment options. In my case, I take beta-blockers to help support my heart. For me, the side effects include hair loss, weight gain, and fatigue but they keep my heart from doing its jolted dance.

*“But I knew there was more,  
much more to living (or  
at least hoping) for  
something better.”*



Working with textiles  
and signing off  
with a heart.



Painting birds and  
enjoying the new  
species that visit my  
garden.



Turning art into key  
chains.



Printing artwork into  
stickers.

Sandra is multi talented - working in many  
mediums to express her love of art.

There are a few things I would suggest from my own experience:

1. If something does not feel right, advocate for yourself. HCM is not recognized enough within the medical community. I looked for resources to help me understand the disease and how best to cope. Thankfully there are support networks such as The Hypertrophic Cardiomyopathy Association. Although this is based in the U.S., I find knowledge and support in the Facebook community of people around the world who have “big hearts”.

2. The Women@Heart Peer Support Program has a 10-week session run by the Canadian Women’s Heart Health Centre. The modules focus on becoming an empowered patient.

3. When I had no answers on what “moderate exercise” meant, I found resources through Peter Munk’s Heart Health by Designs Series.

4. Finally, ensure family members are tested. It’s important to rule out the disease or at least prepare for it should symptoms emerge.

I retired earlier than planned. I could not be the best version of myself for the students I served. I have the gift of time to spend with family. My days are spent focusing on my art. If you look closely enough, many of my creations have a heart included somewhere in the designs because a big heart can be a powerful thing.





# CARDIOMYOPATHY -HYPERTROPHIC (HCM)

**PURPOSE:**

A brief introduction to the heart condition being featured in the current issue of Life In Hearts E-Magazine.

## INTRODUCTION:

(The heart is a muscle that works like a pump. The main job of the heart is to pump blood throughout the body. Cardiomyopathy is a condition which affects the ability of the heart muscle to pump effectively. There are different types of cardiomyopathy and different causes. The main goal of treatment is to reduce symptoms – cardiomyopathy is not curable. Most types of cardiomyopathy are treated with medications and lifestyle changes. In some cases, there are surgical options which may help to reduce symptoms and protect you from life-threatening abnormal heart rhythms.

The different types are : Dilated cardiomyopathy, hypertrophic cardiomyopathy, restrictive cardiomyopathy, arrhythmogenic right ventricular cardiomyopathy, enlarged heart plus others.

## HYPERTROPHIC CARDIOMYOPATHY

Muscles in the heart become abnormally thickened, and the heart has to work harder to push the same amount of blood through the body. In obstructive hypertrophic cardiomyopathy, the thickened muscles push into a chamber of the heart, blocking blood flow and sometimes causing the mitral valve of the heart to leak.

## Potential Causes of Cardiomyopathy

There are many causes of cardiomyopathy. Some types are inherited. They are caused by genetic conditions passed from parents to their children. In addition, many other medical conditions can cause cardiomyopathy, including:

- Congenital heart disease
- Coronary artery disease
- Chronic high blood pressure
- Previous heart attack, causing damage to the heart muscle (called ischemic cardiomyopathy)
- Heart valve disease
- Viral or bacterial infections of the heart
- Excessive alcohol consumption
- Use of cocaine or other street drugs
- Treatment with some types of chemotherapy or radiation therapy for cancer
- Diabetes and other metabolic diseases or disorders
- Some nutritional deficiencies
- Complications from pregnancy

Cases in which the cause cannot be determined are known as idiopathic cardiomyopathies.

The cause of cardiomyopathy does not need to be known for a patient to undergo treatment.

For more information on HCM, visit  
[OttawaHeart.ca](http://OttawaHeart.ca) and  
the Heartlife Academy @ [HeartLife.ca](http://HeartLife.ca)





## Editorial Feature

# THE BATTLE TO BE BELIEVED



By BOBBI-JO GREEN, Alberta

Official diagnosis: Coronary Artery Spasms, 2020

**H**ave you ever wondered how many women have received an incorrect diagnosis before receiving a correct one? Have been told their symptoms were anxiety when they were not? Have had to fight to be heard? Or how about being harmed by a doctor, institution, intervention or medication? What about being gaslit by a physician - told your symptoms were all in your head? Are you still searching for answers and/or appropriate care?

You might be surprised how often the above happens. I hear about these stories often because I am living it. Some people reach out to unite, some to judge, some to try and help, and others to solicit help. Honestly, I welcome all of it. I have been fighting to be heard for over a decade.

I initially received a diagnosis of Coronary Vasospasm in 2020 after searching for answers for over 8 years. In the early years, test after test would come back within “normal” baselines but I just

knew something was seriously wrong. I would suggest to my clinician that my normal testing results did not mean that I was fine but instead maybe meant that the science was not yet advanced enough to find it. My comments would often result in a psychiatry referral.

In fact, it was a new type of test that finally caught my vasospasms in 2020. Unfortunately, my health took a tough turn in 2023 and I have once again been battling to be believed.

Disbelief in women's symptoms is REAL and has a long deep-seated history in medicine. Gender stereotypes affect how doctors treat illnesses and how they approach their patients. For example, a 2018 Canadian study <“Brave Men” and “Emotional Women”: A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain> observed that doctors often perceive men with chronic pain as “brave” or “stoic,” and “reluctant to admit weakness”, whereas women with chronic pain were viewed as “emotional, hysterical, not wanting to get better” and “fabricating the pain”. In comparison to males, females reporting pain are more likely to be told that their pain is driven by



A bad day... too many to count.

emotional factors or mental health concerns rather than a physical condition.

In a 2018 survey of physicians and dentists similar results regarding pain were found < The roles of gender and profession on gender role expectations of pain in health care professionals> In summary, many of these participating healthcare professionals - of which 40% were women - believed that women regularly exaggerate their pain.

I found it interesting that the same Canadian study mentioned earlier also found that general practitioners and specialists (no gender breakdown of participants) regarded fibromyalgia patients as “malingerers, time consuming, and frustrating”. Some clinicians surveyed even went so far as to blame the patient for their pain.

None of these findings are surprising to me. I have spent the last year of my life, crying, begging and pleading to be listened to. I have had a physician roll his eyes at me and tell me it is all in my head. I have been yelled at, told I am not feeling what I am feeling - I only “think” I am feeling it. I’ve had a doctor note in my chart that



A good day... fighting for these.

I need to put my Apple Watch on the charger and spend time with my children (this was right after I pointed out that my heart rate rises alarmingly when I stand or move). I have had nurses smirk at me. I have cried on the phone to my internist telling her I can no longer feel any type of adrenaline after a medication injury - to which she replied “why is that a bad thing?” I have pointed out obvious issues with my blood gas results only to be told I am being “hypersensitive” and needed to see a psychiatrist. I was told over and over that I don’t know my own body.

When a society and specifically the medical community perpetuates sex stereotypes of women being hysterical, anxious, and attention

“I don’t think the medical system realizes the harm that a default diagnosis of “anxiety” does to a patient and the down stream effects it has on their support systems.”

seeking or exaggerating their symptoms, it only further widens the gender equality gap and leaves women sick, dismissed or worse. I don’t think the medical system realizes the harm that a default diagnosis of “anxiety” does to a patient and the down stream effects it has on their support systems and future reassessments.

I have lived in this body for 42 years and I know my own bodily experience. I know when something is good and I know when something is wrong. Over the years, some of my tests have not been within “normal” baselines. I have had abnormal tests that when I ask no one can explain these to me and often tell me they are not worrisome.

I think it is unprofessional and short-sighted to attempt to step into someone’s experience and discredit it. What benefit comes from painting women as unreliable narrators in their

own experiences? Devaluing someone’s struggle and pain is a habit we need to break. How unrealistic to believe that, with the vast expanse of medical knowledge we continue to discover, that in practise we have already discovered everything there is to know? Why is it acceptable to believe that lack of evidence becomes proof it is in our head?

It is interesting that in a recent study published May, 2024 < [Comparison of Hospital Mortality and Readmission Rates by Physician and Patient Sex](#) >



The reasons why I fight to be believed.

found that patients with female doctors have a lower risk of death or serious complications. In hospitals where over 35% of its anesthesiologists and surgeons are women, patient outcomes were significantly better, showing a 3.0% lower odds of mortality or morbidity!

This finding is consistent with the preferences expressed anecdotally by many women, who often seek female physicians or specialists for their care. Many women report that female healthcare providers are more likely to listen to them and understand their concerns.

Unfortunately the latest data indicate that women constitute approximately 22% of practicing cardiologists. < [Women’s Health Collective Canada Is Addressing the Gap in Women’s Health](#) > For many women, finding a female cardiologist accepting patients is like trying to find a needle in a haystack.

It becomes quite clear why, as women, we are largely 'unbelievable'. Medicine has historically been dominated by male physicians, male scientists; including male research which has led to significant gaps in understanding and addressing women's health needs. This gender bias has permeated into medical culture, reinforcing stereotypes and biases.

As a result, women are under aware and under-studied which can lead us to being under-diagnosed, mis-diagnosed and dismissed both in the doctor's offices and in our own social and family networks with potentially devastating consequences.



Interview to raise awareness on REAL TALK with Ryan Jesper (2023)

For many people, they believe the paradigm of illness looks like this; you get sick, you go to the doctor, they order some tests, they figure out what is wrong - you get treatment. You get better. But that is not how it goes for many of us - especially if you are a woman experiencing an understudied or orphan illness. Many of us have to fight to be heard, fight to be taken seriously and fight to be believed. We leave with a requisition for some bloodwork and walk out the door just another number, another chart slid across the desk at the end of a long day.

When the bloodwork comes back normal or close enough, we are often offered an antidepressant and if we complained about chest pain, we will receive an antacid for our stomach. If there are no obvious indications of disease in our bloodwork or other diagnostic tests,



Bobbi - Jo and her kids raising awareness - Feb 13

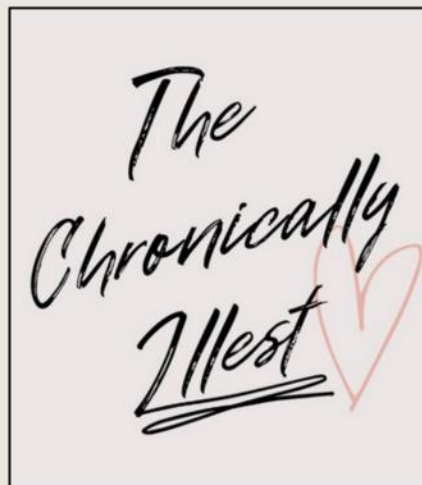
anxiety should not be the default diagnosis. It begs the question: why do physicians often struggle with acknowledging uncertainty when it comes to female patients? What inherent harm lies in the simple admission of "I do not know?" When medical testing fails to yield a definitive diagnosis, there is a tendency to default to assumptions that the patient is either dishonest or experiencing psychosomatic symptoms and many women end up suffering as a result. It is quite ok to admit to not having all the answers at this time and declare the diagnosis as "Uncertain".

Sadly, over the years I have learned to employ strategies (game play) for my clinical appointments, which of course I should not have to, but seem to work:

- Take a man with you
- Dress nice but not too nice as you can not look like you have energy to put into your appearance but you also can't look like a derelict
- Best not to wear make up!
- Do not suggest a potential diagnosis (lead them to come up with it on their own)
- Do not appear too educated on your symptoms
- Do not suggest tests
- Do not mention you have read peer reviewed articles or studies on the internet
- DO NOT mention the internet as Dr. Google is not welcome
- Do not resist medications (you could become labelled a 'non-compliant' patient).
- Do not point out inconsistencies in testing results (this makes you hypersensitive and needing a psychology consult)
- Avoid using medical jargon when describing your symptoms

Through my decade long journey as a 'professional patient', I have not seen any overt attempts to change the way women are treated in healthcare. I have heard my story over and over - sure the name and details are different, but the narrative is the same. We are being gaslit, neglected, patronized, dismissed and misdiagnosed. It is devastating when women's lives depend on physicians learning how to listen, have permission to be curious and have the time to build trust. It is even more devastating to realize the healthcare system failed me by design and it will continue to fail women every time we seek medical help until some drastic changes are made to the system.

While I understand that many patients have no idea how



Bobbi-Jo's Personal Blog on Facebook

broken, hostile and unforgiving the medical system can be (thankfully) ... sometimes ignorance IS bliss but for those responsible for the system, ignorance is just ignorant. Until the health system takes a hard look at itself and finds ways to change course, women will continue to suffer needlessly.



### Note from Editor:

Bobbi-Jo's personal heart journey may be difficult for many to read. It is hard to read about her struggles but shying away from the difficult will not help reshape our health systems to provide better care to us.

There are efforts by many people in medical education, volunteer organizations, and within our health systems to change the dialogue, to encourage and empower both patients and health practitioners to rethink current models. Unfortunately it is slow going. We will do our best to share some of these efforts to influence meaningful change in a future issue.

- Jackie Ratz, Editor



## Tips & Strategies

# WHEN YOU CAN'T

## Why it can be difficult to get a diagnosis and

Article excerpt reprinted from [www.verywellhealth.com](http://www.verywellhealth.com) - Written by [Trisha Torrey](#) - Fact checked by [Nick Blackmer](#)  
Updated on May 22, 2023

**EDITOR NOTE:** This article is from an American source. The content however is relevant and applicable to our Canadian health system. Please visit 'VeryWellHealth.com' for the full article.

**M**edical conditions can be difficult to diagnose for a number of reasons. For example, you may have overlapping conditions or a rare disease that isn't on your healthcare provider's radar.

When your doctor can't diagnose you, it may help to ask questions about additional testing, seek a referral to a specialist, or get a second opinion. Failure to get an accurate diagnosis can delay treatment and potentially worsen your condition.

This article explains what to do when doctors can't diagnose you. It also discusses possible reasons why something may be overlooked and offers examples of conditions commonly missed.

### Why Your Doctor Can't Diagnose You...

The science of medicine may be highly advanced, but that doesn't mean that it is always exact or perfect. Your doctor may not be able to reach a diagnosis when:

- The symptoms themselves are difficult to identify. For example, an occasional headache may be just a headache, or it could be a symptom of a larger problem.
- The body system causing the symptoms is not clear. The patient may find they are seeing the wrong specialist, leading to a delay in diagnosis.
- The patient may have more than one medical problem, which makes the diagnosis process confusing. There may be conflicts among the drugs or supplements the patient already takes, leading to symptoms caused by those conflicts.
- There are no definitive tests used to identify a condition, or the diagnosis cannot be confirmed until a patient has died (upon autopsy). In these cases, healthcare providers must use combinations of symptoms, often vague ones, which can lead to a lack of diagnosis.
- The real medical problem may be highly unusual. The healthcare provider might not consider a diagnosis that is very rare in general or for the age of the patient. For example, lung cancer in a younger person would be highly unusual.
- A rare disease is so rare that few medical professionals know much about it.
- The patient is not entirely truthful about symptoms. For example, cirrhosis of the liver may not be immediately considered in someone who

# GET A DIAGNOSIS.

what can you do to improve your odds...



has pain in the region of the liver but claims not to drink alcohol.

- There may be no name for the symptoms someone is experiencing. Medical science may not yet have determined a named diagnosis.

## What Is “Failure To Diagnose”

“Failure to diagnose” is the terminology used by healthcare providers (and lawyers) to indicate a missed diagnosis. This means a patient has a set of symptoms that have gone undiagnosed.

## What to Do When Doctors Can’t Diagnose You...

Having troubling symptoms without a diagnosis for an extended period of time can be extremely frustrating. Tactics for solving your undiagnosed disease or condition include:

### ***Ask probing questions.***

Phrases that might prompt your doctor to pause and reflect further include: What might this be? Are there other things that may be causing these symptoms? What should I do if my symptoms get worse? Might other testing be helpful?

### ***Request a referral to a specialist.***

If your primary care provider is unable to determine the cause of your symptoms, ask to see a specialist.

### ***Organize your medical records.***

Putting together a binder of your medical records makes it easier for a new healthcare provider to

review them. Include previous test results, after-visit summaries, correspondence with your provider’s office, and prior treatments.

### ***Seek a second opinion.***

If a specialist is unable to pinpoint a diagnosis or you are not confident in the diagnosis given, consider seeing another specialist for a second opinion.

### ***Check the Undiagnosed Diseases Network.***

Funded by the National Institutes of Health and a part of Harvard University, the Undiagnosed Diseases Network offers resources for people with difficult-to-diagnose conditions.

### ***Consider genetic testing.***

Medical genetic testing is often an important part of the diagnostic process, especially when it comes to rare diseases.

*“Ruling diagnoses out, rather than confirming what you have, can be frustrating. However, it can help narrow the possibilities and get your healthcare provider closer to finding out exactly what is wrong with you.”*



## ABOUT US

The HeartLife Foundation is a patient-driven charity whose mission is to transform the quality of life for people living with heart failure by engaging, educating, and empowering a global community to create lasting solutions and build healthier lives.



**ENGAGE • EDUCATE • EMPOWER**



**HeartLife**  
FOUNDATION

- **FB Community**
- **Academy**
- **Advocacy**



Learn more:



# Global Heart Hub

Learn more:  
[www.globalhearthub.org](http://www.globalhearthub.org)

Global Heart Hub is the first global non-profit umbrella organisation established to provide a voice for those living with, or affected by, cardiovascular disease.

**A unified global voice...  
we are a network of  
heart patient organisations  
and advocates.**







# FINALLY A DIAGNOSIS... UMM... HCM?

By Joanne Green & Ethan Green, Ontario  
Hypertrophic Cardiomyopathy (HCM), 2017



***“I did my best to fight through my health issues as I wanted so badly to do what my friends were able to do...”***

I have struggled a lot since I was around 18 with various health challenges. (I am now 50!) It all started with asthma, and shortness of breath, but the various inhalers given to me didn't prevent me from having asthma attacks. Another notable was that socializing and partying was difficult for me as many of my nights resulted in ER visits and hospitalization at the end of the night.

I did my best to fight through my health issues as I wanted so badly to do what my friends were able to do, but new symptoms arose (ankles swelling and occasional chest pain). After being admitted to hospital yet again, my dad reached his boiling point with the lack of insights and understanding of why I was so sick. He demanded I remain in hospital until we had an accurate diagnosis.

Finally, I was seen by a wonderful cardiologist from the United Kingdom who diagnosed me with a pericardial effusion on my heart, and this would also be the first time I heard the term Cardiomyopathy.

I was diagnosed with having a rare syndrome called Churg Strauss, now known as EGPA, and the doctors started me on daily prednisolone, and suddenly life started to settle again. I was now 21 years old and a 'rare breed' apparently. I was even asked me to stand in front of a medical team in England whilst they asked probing questions, and they learned about this condition.

With the medication and regular consultations, I was able to enjoy most of my 20's back socializing with friends, although I continued to struggle with their pace, but at least I was enjoying life even if it meant I needed three or four days to recover from nights out. By my mid 20's, friends were ramping up partying and starting to tease me about not being able to keep up. It was so confusing as to why I couldn't keep up, given my age and everything, what was wrong with me. I felt I had to push on and adapted.

I met my husband in my 30s, we got married, I was able to be active, and we enjoyed socializing, yet again a time came that I was struggling to keep up. I just thought it was 'me' - I was weak. I became pregnant and despite being poorly throughout, we had our beautiful son. Three years later we made the decision to relocate to Dallas.

Life in Dallas was good. We made new friends, I was a regular gym goer and even took a high impact class - proud that I was in my early 40's and kept pace with the group. The day after one such class is a day that I will never forget, I had pains in my leg that were excruciating. My 6 yr old son was inconsolable as my husband ushered paramedics into the house. In the ambulance they asked how long I had suffered with Atrial Fibrillation ... that was news to me! I had a serious Pulmonary Embolism in my leg and we were faced with an emergency catheter procedure to avoid

the amputation of my leg, a thought I could not mentally reconcile. From a high impact workout one yesterday to today a possible leg amputation and no understanding of why. This was the first time that it really hit me, something was not right, and I could even die. Doctors were asking my husband to give consent of emergency procedures and confirming that I was to be resuscitated as it was a real risk.... I am a survivor.

The next year in the USA was emotionally and mentally challenging for our family. Our son constantly panicked if he heard me say I felt unwell, my husband was concerned about going on work trips in case I was taken ill, and specialists were flexing and changing medications to stabilize me so I could enjoy life again. At this point, I was told again I had Cardiomyopathy.

Mental anguish was kicking in, and with the evolution of the internet, I was now self-diagnosing and established in my own head that I had 5 to 10 years to live, because that is what is said on "Dr. Google".



Family cycling at Niagara on the Lake



Flour fight evidence!

## “She (cardiologist) reassured me that people live with HCM for decades, with her patients living well into their 80’s ...”

We had amazing friends who had become like family and offered help, but I wanted to be the one to care for my husband and my son ... he was so young to be dealing with the loss of his Mummy or seeing his Mummy constantly sick and visiting hospitals! It was scary. I was panicking.

My husband was and is my support and my rock. He constantly picks me up, and pushes us on, but I do not think he really understands what I go through personally with this at times. He has a busy career and travels a lot, and I feel so guilty for the added stress on him. I felt so sad. I felt anger. Why had I been dealt this card?

2017 we relocated to Canada for my husbands work - my heart (both emotionally and physically) broke leaving Texas. Still learning about this condition, leaving our friends and support network behind, and being on our own again was a lot to process.

As soon as we arrived in Ontario, I found a great primary doctor and shared all my medical woes, she recommended my current Cardiologist who is incredible. I firmly believe her experience, knowledge, compassion and support has helped save my life, and put me on a path to recovery.

She listened attentively and quickly ordered a number of tests - CT Scan, MRI, Angiogram, and blood. She diagnosed me with Apical Hypertrophic Cardiomyopathy. She reassured me that people live with HCM for decades, with her patients living well into their 80s with relatively normal and enjoyable lifestyles. The most important support I received

was being fortunate to find a cardiologist who took the time to listen to me, who helped me unpack the mental and emotional trauma that I was going through (much centred around our son seeing his mum be so poorly and regularly being admitted to hospital and undergoing cardioversions and other medical procedures). She helped me to understand that while I can enjoy life, I need to do so at a pace that makes sense for my body.



Making memories in Turks and Caicos.



National Jump Rope competition.



Good old days of riding.



Proud mummy - Grade 8 grad 2024.

It is this element that is probably the hardest for me and my family to accept, my husband and I are now late 40s early 50s and our 14 year old teenage son is as active as we once were, so it is so hard for him to see me going to bed at 7 or 8 pm, exhausted and not feeling great, I know it has impacted him emotionally and mentally, despite our best efforts to protect him. I see a psychologist to help with the trauma and to learn how to help my son cope.

I have educated myself and become an advocate to myself which is a must, I understand what medication can help me, what surgeries are available, and what diets and supplements can help. I have seen a HCM specialist at Toronto Peter Munk Centre. I have seen Nutritionists, Naturopaths, Therapists, all in an effort to help myself. I also have other specialists due to side effects of medication now impacting other organs in my body and causing concerns there. I have found wonderful support groups and people living through this as well that have lifted my spirits when I needed it.

Atrial Fibrillation continues to cause the most issues for me. When I am in Sinus, I am able to control

things and enjoy life. However, four cardiac ablations later and many cardioversions, how many more of those I can have due to the scarring taking place on my heart is questionable. The specialists feel that my only next option would be a heart transplant. I am not ready to face that journey, and so I am doing all I can to remain positive to live for today. We now thankfully have many scientists and medical minds in the world that are working towards helping our hearts with treatments and many other things to keep us going. We must remain hopeful... in ten years so many things have changed. So I wonder what is another 10 years going to offer? This thought brings constant hope.

I am proud of my son Ethan, as he is now fairly resilient. He has held my hand and hugged me when he sees my struggles and reassures saying 'We got this Mama.' He is what drives me thankfully and makes me fight. We were given this life for a reason. We must try make the most of it no matter what curve balls get thrown at us.

Lastly, this condition has given me an appreciation of life that I know I didn't have before. Every single day is precious. I try make sure I make my son laugh and smile EVERY SINGLE DAY. We goof around, we make tik toks, we have the baking flour fights, we laugh, we cry, we hug, we take the vacations, we spend time together. We love on each other, and we try help others when we can, if that is helping someone else in the FB groups with words of encouragement, or just being kind to a stranger or a neighbour, whatever it is, maybe we can make a difference, like so many others have to us. It is not a death sentence; I have had it for 30 years so far. I am ready for another 30! However, there are many layers to HCM, but finding the right medical team, support, and really understanding the condition and medications available are vital. We got this!

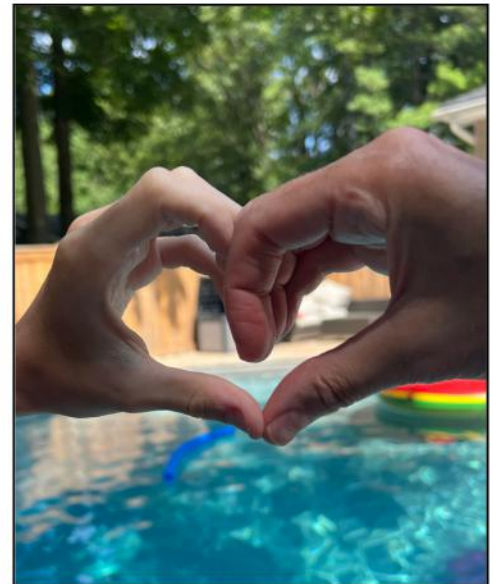


SPECIAL ADDITION - KIDS POINT OF VIEW

# WHAT IT IS LIKE... MY MOM HAS HCM.

A quick question & answer  
between mom Joanne & son Ethan

*A big thank you to Ethan (and his mom) for his willingness and candour in contributing to our understanding from a young person's lense.*



**Joanne:** What is the earliest memory you have of mummy being sick? How did you feel?

**Ethan:** The earliest memory I have of mummy being sick is when she had a blood clot. At this time I was around 6 years old so I probably didn't understand what was going on. I think I remember feeling confused and sad and scared because I didn't want her to be sick.

**Joanne:** As a teenager now, do you understand mummy's condition? What is HCM?

**Ethan:** As a teenager now I think I can understand my mummy's condition well. HCM is when the heart is larger and stiffer than normal. This causes blood to pump around the body less effectively and can lead to the side effects Mummy has I believe. However with medication and procedures this condition can be managed.

**Joanne:** Does having a parent with heart issues make you worry about developing heart issues yourself?

**Ethan:** A parent with heart issues makes me only slightly worried of developing heart issues myself. I get annual check ups to check if my heart is ok. However if my mummy can deal with it so can I.

**Joanne:** What would you say to other kids who have a parent that has heart issues?

**Ethan:** Something I would say to other kids who have a parent with heart issues is that many people sadly suffer with heart issues. In saying this there are many times when challenges are faced but support is available and can be dealt with well by the medical teams that support patients like Mummy.





# REFLECTIONS

This Reflection is a very difficult but special feature. In mid July a strong, loving and courageous woman made a heart journey decision that was right for her – Jennifer made the decision to use Medical Assistance In Dying (MAID). While a legal choice in Canada, it is not without stigma and controversy. I thank Jennifer for being willing to share a glimpse into her world.

Jennifer was born as a blue baby. Born with serious congenital heart issues she faced numerous heart struggles over her years. She faced them bravely and made the decision early on that a transplant journey was not to be her story. Over recent years (since 2018), I was incredibly privileged to learn from her as she lived her life her way. Jennifer loved her Blue Jays, along with fishing & travelling – nothing stopped her from seeing and trying new things ... we did not however agree on football or hockey teams but ever a sportsperson, she cheered the Bombers when they won the grey cup!

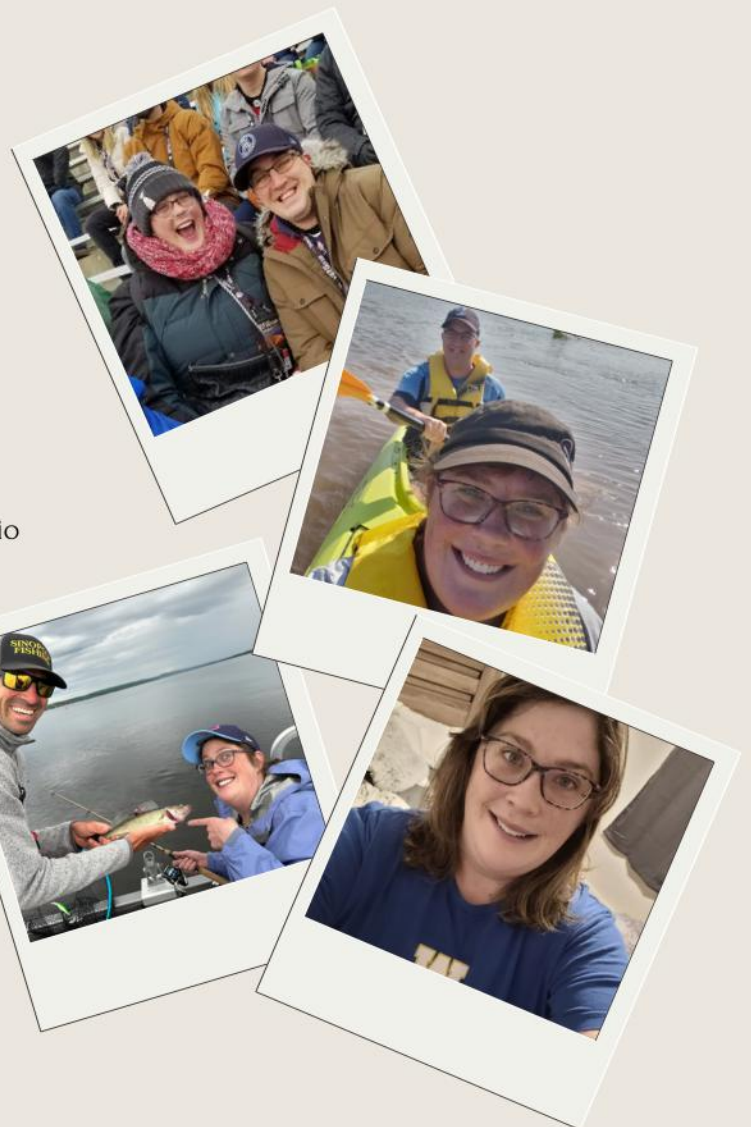
Rest now Jennifer knowing you have left a beautiful legacy of Living Bravely and Loving Boldly. I love you and will miss you.

Jackie



By JENNIFER HART-MULDER, Ontario  
Congenital Heart Failure  
(1983 to 2024)

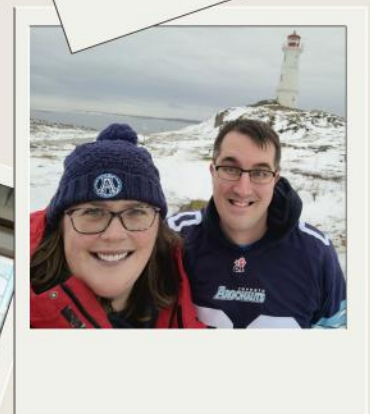
*" ... I am at peace with this decision and am so proud and happy with the life I've lived. All of you have made it that much better."*



# DEAR HEART...

*Thank you. Thank you for beating all these years. Thank you for allowing me to live a full and wonderful life. Things started off rough for us, you were broken when I was born. The doctors told my parents that you would be problematic for me. Causing me to have a difficult life and a shorter lifespan, but you didn't listen. You had your own plans for us. Plans that included education and 3 post secondary diplomas. Plans that included travelling the country and seeing the beauty that is our own back yard. Plans for me to fall in love with the most spectacular man and become his wife. Plans for me to give so much love and in return, be so loved back. Some would argue that 41 years is not enough, and most of the time I would agree with them, but I know what we've been through and it's never been easy. The fact that you have pumped for as long as you have has always amazed me. But my darling heart, it's time now for us to rest. We have fought a long, hard, challenging battle, and there is nothing left we need to prove. We're both exhausted and it's okay for us to stop. You did your job and you did it to the best of your ability. And for that, I love you.*

*With sincere gratitude  
towards you,  
Jen*





## 3 ROUTINES THAT CAN HELP MAKE HEALTHY EATING HAPPEN...

As fall approaches, are you itching to return to your regular routines? Summer adventures are grand, but after a while, it's nice to put some aspects of life on autopilot, making healthy living easier.



By CHERYL STRACHAN, RD - Alberta  
Author of 'The 30 Minute Heart  
Healthy Cookbook'  
[SweetSpotNutrition.ca](http://SweetSpotNutrition.ca)



Now is the perfect time to assess whether your healthy eating routines could use a tune-up. How are you doing with the following?

- 1 Weekly meal planning and shopping
- 2 A weekly meal prep session
- 3 A lunch-packing habit

If you're regularly doing all of them, high five! If not, which one would make the most difference for you? Focus on that before you tackle the next.





## 1

## Weekly Meal Planning and Shopping

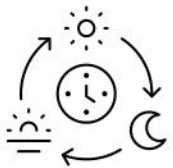
### Why it matters:

Eating well is grounded in home cooking, and a little planning can help you do it with less time, money, and stress. No more 5pm stops at the grocery store, no more calling for takeout.

### How to make it routine:



First, think about your schedule. Is weekly best or would you rather go every 2-3 days? What day(s) are best for you? Can you go midweek and avoid the crowds? Will you meal plan earlier that day or the day before? Would online shopping work for you?



Second, develop a meal planning routine. Keep it simple by rotating 2-3 breakfasts and using leftovers for lunch. That way meal planning just means picking 3-5 main dishes for supper, assuming you're doing a whole week.

For best results, start by checking the calendar to look for anything that will affect what or when you eat, like your in-laws coming for dinner or a 6pm hockey game.

Next, check the fridge to see if you have any perishable ingredients to use up. If you have time, check the freezer and pantry too.



Third, think about whether a weekly theme night or two would mean fewer decisions for you every week. You could do meatless Mondays, Taco Tuesdays, or fish on Fridays.

For the plan itself, any format will do, from the back of an envelope to a [google sheet](#).

### If you need more help:

Book a consultation with a dietitian for help with this. Or try a meal kit service like HelloFresh or Goodfood. They send you fresh ingredients for several wholesome meals and you just cook.

## 2 Weekend Meal Prep Sessions

### Why it matters:

If you're low on time or energy during the week, spending even an hour on the weekend can pay big dividends. How nice would it be to have food ready to warm up and eat after a busy day?

### How to make it routine:

Start with your calendar. When will you do this? Do you have more energy early in the morning, or later, while you're making dinner? Schedule it so it happens.

Next, check with family and friends to see who might want to join you. Or is this your time to listen to music or catch up on Netflix? Make it fun!

Then, try whichever of these you might enjoy when things get busy:



- A big batch of chili or soup. Have it for dinner on your meal prep day and then freeze leftovers in single-serving containers. Build up enough inventory in the freezer and you won't have to eat the same thing three days in a row.



- A hearty whole-grain and/or bean salad. A favourite in our house: Julie Van Rosendaal's [Lentil & Barley Salad](#).
- A pot of steel-cut oats, which can simmer while you do other things. Once ready, freeze in small containers. This works for other long-cooking grains, like brown rice or wheat berries too.



- A pile of pre-chopped vegetables. Clean and prep raw veggies for snacking, or roast them if you like, for easy addition to scrambled eggs, pasta, or wraps.
- Extra servings of lean meat or chicken, to help you get protein at lunch without having to rely on processed meat.
- Individual portions of yogurt, cheese, milk, nuts, and other snacks. Move them from wallet and planet-friendly big packages to reusable individual containers. You are now a lunch-making ninja.



**TIP:** Don't feel like you have to spend 3-4 hours doing all of this. Just one or two can help the following week, without making a big dent in your weekend.

## 3

**A Lunch-Packing Habit***Why it matters:*

Your cooking is almost guaranteed to be healthier than a restaurant meal. Plus you can save money!

*How to make it routine:*

Again, decide what works for your schedule. Can you pack leftovers into lunch containers while you're cleaning up supper, or do you have more time in the morning?

You'll need a good protein source or two, a couple of fruits and/or vegetables, and a whole grain. If your days are long, a snack will help too.

This is where your weekend meal prep pays off. Say you have leftover chicken from dinner. Add the roasted veggies you prepped and a container of brown rice from the freezer. That's lunch. A yogurt, bag of nuts, apple, and orange will round out the day. Easy peasy.

Here are a few other lunch-packing staples you can keep on hand:

- Mini cans of tuna
- Individually wrapped cheeses (eg. Babybel)
- Whole-grain crackers (eg. Triscuits or Ryvita)
- Small containers of hummus or guacamole
- Cherry tomatoes
- Snap peas
- Healthy-ish frozen meals. Perfect isn't the goal with healthy eating. These are better than restaurant fare, if you can find one with a whole grain, some veggies, and less than about 600 mg of sodium.

**TIP:**

Can you make a list of your favourite lunch foods? It will make grocery list and lunch making a cinch.

---

Don't feel like you have to do all of these if you're not already. Start with one that feels doable and build on that. Ultimately, you'll end up with more time, because you aren't scrambling around all disorganized. Plus you'll eat better. Say goodbye to last-minute stress and hello to wellness.

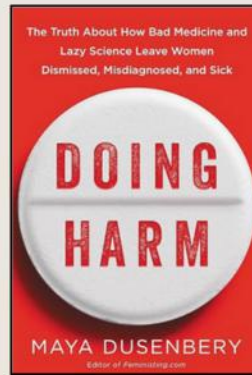


# HEART RETAIL & THERAPY PRODUCTS

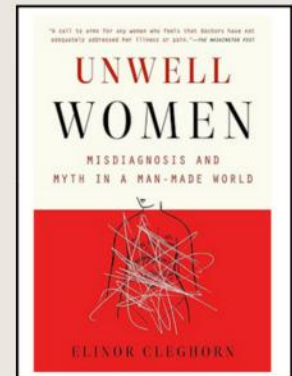


There are great products available to help us live better, to be safer or help us advocate for ourselves. There are also products that are just pretty or make us feel good or support a cause close to our hearts... let's share them all so everyone can benefit.

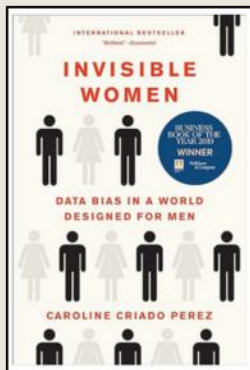
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5



For those interested to read more on why the health system is failing women, these books come recommended and are all available on [amazon.ca](https://www.amazon.ca):

1. **Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick - 2018** - by author [Maya Dusenbery](https://www.amazon.ca/author/MayaDusenbery)
2. **Unwell Women: Misdiagnosis and Myth in a Man-Made World - 2022** - by author [Elinor Cleghorn](https://www.amazon.ca/author/ElinorCleghorn)
3. **Invisible Women: Data Bias in a World Designed for Men - 2021** - by author [Caroline Criado Perez](https://www.amazon.ca/author/CarolineCriadoPerez)
4. **OMRON Bronze Blood Pressure Monitor, Upper Arm Cuff, Digital Blood Pressure Machine, Stores Up To 14 Readings / amazon.ca**
5. **Stress Balls (5 Pack) - Stress Relief Balls with Motivational Quotes - Hand Exercise Balls to Relieve Anxiety, Stress and increase strength / amazon.ca**



# CREATING FAMILY MEMORIES WITH PLAY

Consistency Creates Change .....  
show them how with laughter!

**HELLO!** BIG SMILE! I hope you are having a fantastic summer and are living life with intention and always having FUN for your heart health, body, mind and spirit!




By ANNIE SMITH, PTS, FIS, RAB II,  
Ontario - Cardiac Sarcoidosis, 2015  
All the Right Moves Personal  
Training & Fitness



GAMES and more! Previously we discussed FUN through Play with your children (or grandchildren/any family members and friends as well). Have you achieved joy and excitement of 'playing like a child', bear crawling around (that's not so easy) and laughing out loud (LOL!) while lighting up the faces of your loved ones? Did you hunt for sticks/ropes to make a ladder-on-the-ground to hop, jump and perhaps skip through with your family? If not, start today! Finish the summer off strong with commitment to health, while making plans to continue the routine once school commences in September. Create an after-dinner routine of movement together for 30 minutes 2-3x/week – small, achievable goals with movement being the key! Adding play to exercise keeps it FUN, exciting, interactive, definitely interesting and

challenging as well. I teach a segment of play in all of my classes for these reasons, while shifting the focus off the difficulty of the exercise. Hmm sneaky. But it works! And it can work for you and your family! You're creating amazing memories for them to pass on once they're grown. As parents


we're always looking to set a great example for our children. Learning how to keep the 'greatest machine' alive is #1 on my list of most important lessons, otherwise we wouldn't be able to do anything! So have FUN while doing that! Life is too short not to. I believe we all agree with that.



## APGA update from Annie:

In Issue 2 and 3 I shared with you about **Annie's Pace Global Adventure (APGA)**. I am very pleased to share that APGA raised \$3,377 this year for heart failure research and cardiac transplantation for UHN in Toronto. That's \$25,196 to UHN in 6 years! How fantastic!

**SAVE THE DATE**  
for the 7th Annual APGA  
**MAY 23-26, 2025!**



Please help by continuing to spread our message and reach out and ask how you can help APGA 2025 make a difference for other heart warriors!



### TIC TAC TOE

Put music on as it helps motivate movement! Get 4 ropes. Place them on the ground making a BIG Tic Tac Toe game (as shown in picture). Get a collection of 2 different types of pawns, Eg., soup cans & tennis balls or socks & shoes, etc. Create 2 teams. Decide what each team uses as pawns. Line up approx. 20-30 feet away from the Tic Tac Toe game. Have a referee. Rock, paper, scissors to see who goes first. The referee counts down, "Ready, Set, Go! And they're off!" The first person from each team runs (or walks fast) and positions a pawn down on the game, runs back and slaps hands with the next player in line, initiating their turn. Continue playing like this until the game is won. Have the referee keep track and play the best out of 10 (or 5). Communicate as a group and change the game any way you like, eg, when it's the 3rd or 4th team players turn, have them run up without a pawn and move one of their own players to a better spot on the game instead. HAVE FUN with it!



## 2 FUN BALANCE GAMES

Supplies needed: Small stacking cups & 2 small balls/per person - I bought medium 'red cups' and soft balls at the Dollar Store.



Balance Game #1 - bouncing balls on one leg.

### Game #1

Put some music on! As per the picture on the left, stand on one foot with a ball in each hand. To balance on one leg, connect your mind to your body. If lifting the leg first without doing this, chances are great that you will fall. This is a mind-body connection. Lift right leg off the floor slowly and think about your supporting left leg (Option: keep toes of right leg lightly on the floor, maintaining contact with floor, until feeling confident to lift leg fully off floor). Engage your left buttocks (aka your glutes) by tightening them, ground to the floor by spreading your toes making a wide foundation, tighten your quad (front of your thigh) and stand tall. Watch that your knee of the left leg does not turn in. Goal is to maintain the direction of your knee cap in line with your second-third toes. While maintaining balance (squeezing buttocks the entire time), bounce one ball at a time. Then bounce both at same time. Do this 15x each leg. Repeat all lifting left leg off floor. Have fun with it. Create partners and bounce balls to each other while balancing. Maybe bounce to the rhythm of a song. Be creative working together.



Tic Tac Toe with ropes and any items around the house!

### Game #2



Same single leg balance form as above, now hold 4 stacking cups. Bend forward from the waist and place 1 cup down on the ground. Stand tall. Bend forward and place another cup down beside the first cup. Stand tall. Continue this until all 4 cups are in a line in front of you.

Now bend forward, pick up one cup and stand tall. Repeat until you have all 4 cups in your hand. Repeat the entire balance on the other leg.



### CRAB CRAWL



Choose who selects music choice for this game. Laugh out Loud on this one!

Sit on the ground, bend your knees and keep your feet flat on the ground. Place your hands behind you on the ground, fingers facing forwards. Lift your butt off the ground by putting the weight in your feet (picture 1) and hands and crab crawl forward opposite hand and foot 10 steps, then backwards 10 steps (picture 2).

Take breaks anytime by placing your butt on the floor. Roll your wrists in slow, big circles 5x each direction before, during and after the exercise.

GOAL: 5 mins on/off. Build strength by using your own body weight and improve your coordination and core strength. Take 10 second breaks whenever you need. Be creative as a family!



1 - starting position



2 - initiation of the movement.



## SEPTEMBER MOVEMENT CHALLENGE

Let's join together for 30 days and create the habit of intentional movement for a minimum of 30 minutes a day (or less if your health dictates that). Get your kids/family involved once again!

Journal down your plans each weekend for the week ahead which helps with accountability. If it's walking each day, have someone in the family choose the route. It may be in the daytime or after dinner when everyone is home from work or school. Or choose any of the exercises you have seen in any of these first 4 issues or any of my exercise videos on [www.hearthub.ca](http://www.hearthub.ca). Whatever works for your family, but be consistent!

Keep moving daily even with unexpected circumstances. Consistency creates change! Remember, the kids are always watching and learning from you. Challenge yourself daily for the month! If you want to do more at any time, go for it! This is goal setting and creating the habit. I'd love to hear how you do! Feel free to post on the Canadian Women with Medical Heart Issues or HeartLife FB support communities. Use the hashtag #30DayChallenge.

### TIPS FROM ANNIE !

**T**IME - Make the time because 'Your life is worth 1 hour a day!'

**I**NTENTION - Have intention with every workout!

**M**USIC - Music stimulates the part of your brain that controls motivation. This can cause you to work harder and faster than without music. So put the music on and SMILE!

**E**XTRAORDINARY - You are absolutely extraordinarily amazing! Remember that!

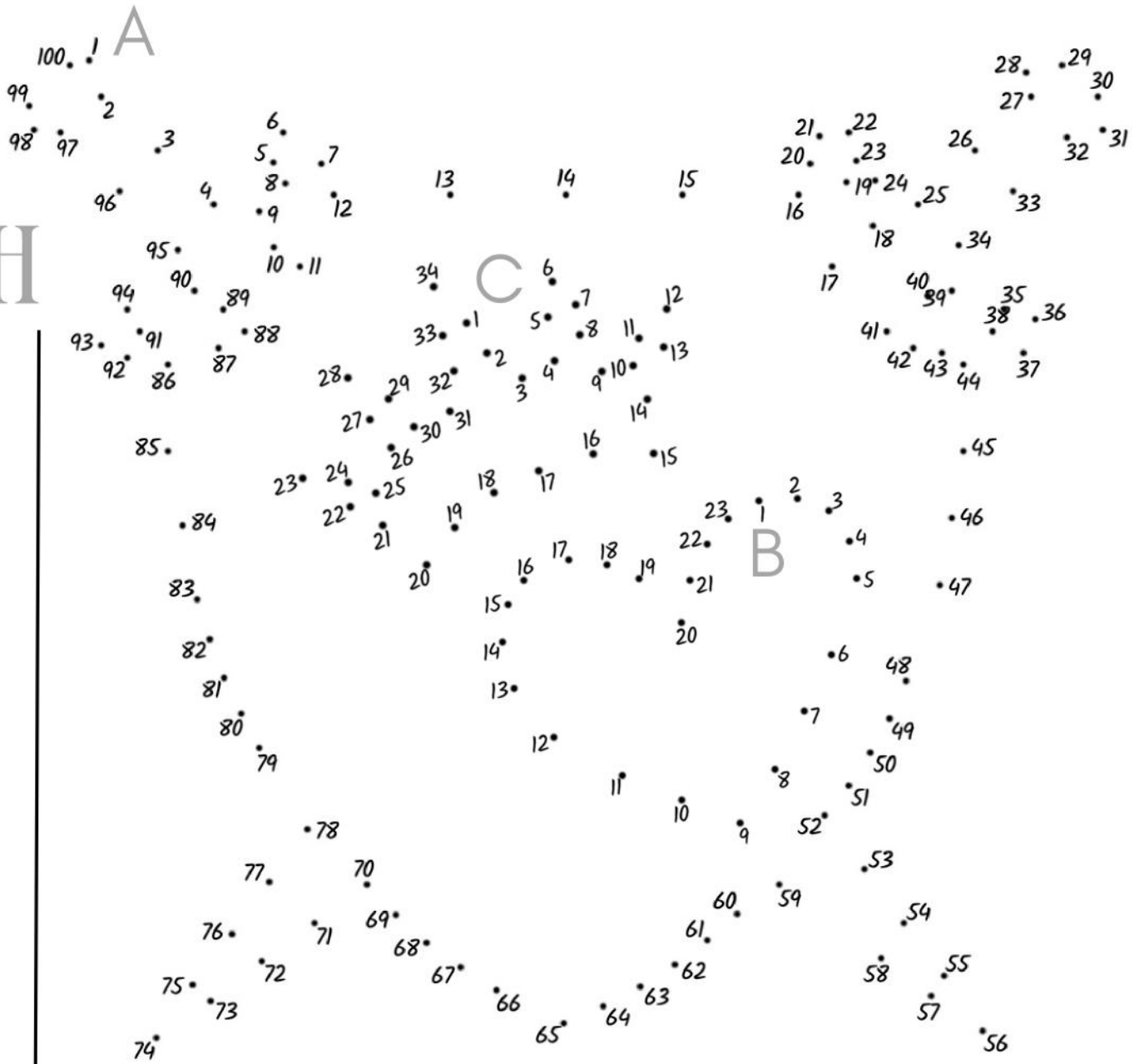
*Congratulations on showing up for you and choosing to start creating a healthy lifestyle of physical fitness and mindfulness. I am so proud of you! See you next time! Namaste.*

Annie is a regular contributor to the Ted Rogers Patient information website. Her "HEARTFIT" videos can be found at [OurHeartHub.ca](http://OurHeartHub.ca)



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A - 1 to 100 / B - 1 to 23 / C - 1 to 34

*Live Bravely. Love Boldly.*

**W O R D L E**

A DAILY WORD GAME

Are you a member of our online groups (Canadian Women and/or HeartLife)?  
Come join us in our daily play of a fun word game to keep our minds sharp!  
[www.nytimes.com/games/wordle](http://www.nytimes.com/games/wordle)



# ALL ABOUT YOU!

## Happy Little Things

CONSCIOUSLYKAY



stacks of books



handwritten notes



beams of sunlight



sweet colorful fruits



morning walks



wildflowers



cozy coffee shops



belly laughing



spontaneous road trips



a good song



the sound of rain



freshly baked bread

Do you have feedback or a quote or a suggestion for the magazine?

Would you like to donate to the costs of the magazine?

Email me! [Jackie@Heartlife.ca](mailto:Jackie@Heartlife.ca)

# LIFE IN HEARTS

Living Bravely. Loving Boldly.

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