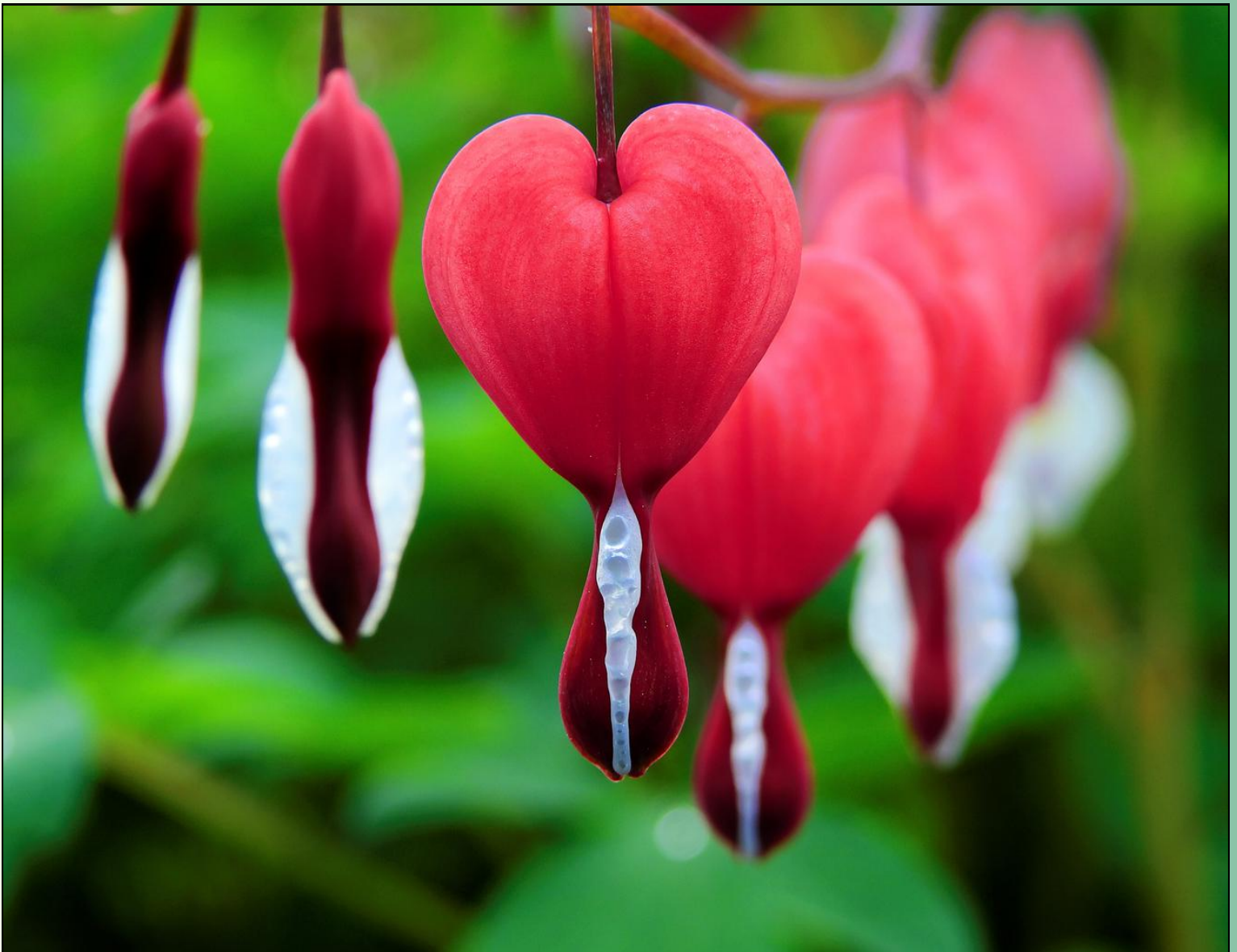


LIFE IN HEARTS

ISSUE 08
MAR/APR
2025



CANADIAN WOMEN WITH MEDICAL HEART ISSUES
LIVING BRAVELY. LOVING BOLDLY.

LIFE IN HEARTS

www.LifeInHearts.ca · LifeInHearts@HeartLife.ca · @LifeInHearts
Canadian Women With Medical Heart Issues Facebook Support Community



EDITOR &
FOUNDER

Jackie Ratz, MB
Heart Failure, 2017

J.R. NOTES:

I am so excited to share our Special February issue had the highest readership of all our issues - we had 1,100 plus reads. This is a testament to how valuable and special sharing our heart journeys are. The feedback received on the February issue and many other past issues encourages me to keep going.

BUT this is not possible without your participation. I would love to hear how we can improve, add value or make this e-magazine more relevant to you. please send me an email. Jackie@Heartlife.ca

Thank you for being on this journey with me... we are Heart Warrior Queen strong together!

LIFE IN HEARTS TEAM



Rachel Charron, ON



Louise Koch, AB



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Charlotte Girard, QC



Lorraine Stratkotter, AB

CANADIAN WOMEN WITH MEDICAL HEART ISSUES TEAM

PROUDLY AFFILIATED WITH:



HeartLife Foundation
of Canada
heartlife.ca



Canadian Women's Heart
Health Alliance
cwhha.ca / wearredcanada.ca



Global Heart Hub
globalhearthub.org

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Issue 08 · March / April

CONTENTS



Be Curious, Not Furious...

Heart Journey Share

- Laura MC Avelar, ON

5



Prescriptions, Vitamins & Supplements.

Tips & Strategies

- Chris Mendoza, BSc, BscPharm, CDE, MB

12



Patient Engagement & Involvement.

Learning & Information

- Sue Robins, BC

15



Best Before Date.

Mental Health Lighthouse

- Aubyn Baker-Riley, ON

18



Good-Bye My Friend... Thank you!

Reflections

- Lise Burgess, BC

21



Why Heart-Healthy Eating Habits Don't Always Stick.

Eating For Heart Health

- Cheryl Strachan, AB

22



Achieve Your New Years Goals with Grace.

Fitness For Every 'Body'

- Annie Smith, ON

28



Colour Me Beautiful.

- Contest

33

HEARTLIFE FOUNDATION OF CANADA



by MARC BAINS, British Columbia
Heart Transplant, 2018
Co-founder



JILLIANNE CODE, British Columbia
Heart Transplant X2, 2014 & 2018
Co-founder

Founded in 2016, HeartLife began as a support network for Canadians living with heart failure. What started as a personal mission for Marc Bains, a heart failure survivor and heart transplant recipient, and Jillianne Code, a two-time heart transplant recipient, has since evolved into a national advocacy organization dedicated to improving heart health across the country.

HeartLife's mission is simple yet powerful: to engage, educate, and empower people affected by

cardiovascular disease. While the organization was founded with a focus on heart failure, its work now spans the full spectrum of heart health—because, as they put it, all roads lead to heart failure.

Heart failure affects 1 in 3 Canadians over their lifetime, yet awareness, education, and support remain limited. HeartLife is changing that by working directly with patients, caregivers, healthcare professionals, researchers, and policymakers to push for better access to care,

innovative treatments, and stronger government action.

Through digital education initiatives, patient-driven research, and advocacy efforts, HeartLife ensures that the voices of those living with cardiovascular disease are heard. At the heart of everything they do is a belief that it's about life, not failure.

Join the HeartLife community and learn more about their work at www.heartlife.ca.



ABOUT US

HeartLife has evolved from a heart failure organization into one of North America's leading patient-led cardiovascular charities — because all roads lead to heart failure. Our mission is to raise public awareness of cardiovascular diseases, empower patients, families, and caregivers through education and support, and advocate for better care for everyone.



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





**KEEP
CALM,
REMAIN
CURIOUS
BUT NOT
FURIOUS.**

**I KNOW MY
BODY BEST!**

by LAURA AVELAR, Ontario

Idiopathic Dilated Cardiomyopathy & Congestive Heart Failure, 2014

Exercise Induced Pulmonary Hypertension, 2022

If someone told me one day that I would be living with heart disease, I would not believe it, but it has become a reality for me. Heart disease affects all women differently. There is a gap when it comes to diagnosing, treating, rehabilitating, and supporting women with heart disease. There is also a lack of awareness of the symptoms and risk factors faced by women among the public and healthcare professionals. Recent research on women's heart health is promising, yet we need to continue to improve women's survival rates, quality of life, outcomes, and

decreasing recurrence rates. I firmly believe that "sharing is caring" so I would like to share my story to help women become advocates for their heart health, believe in their symptoms, voice their concerns to their healthcare providers, and become more assertive with what they know they are feeling. I also would like to express the importance of being involved in all of the support services available to them throughout their cardiac health journey and the significance of setting and maintaining goals for a healthy lifestyle and prognosis.

My name is Laura and I am a woman living with heart disease.

My heart journey started at the age of thirty-eight, although it possibly started before then. I am a mother, wife, daughter, sister and a friend. I had a beautiful childhood, growing up in Little Italy in Cambridge, Ontario. I moved to Ottawa to follow my long-time dream of becoming a Registered Nurse, a career that I have loved and continue to enjoy.

While in nursing school, I met the love of my life. We eventually got married, and have two beautiful children. I would not have been able to go through this journey without their support and love.

Communicating, and providing support and care to patients most respectfully and compassionately is a big part of being a nurse. As a healthcare professional, you never imagine yourself being on the other end of that line, or your life completely changing. This is my personal story.



In 2008, I remember going home after a busy day shift. While sitting at the dinner table and talking with my family about our day, I remember feeling my heart beating fast. I thought nothing of it at the time, until I started to feel shortness of breath and pressure in my left arm and chest area. I went on with our usual family discussion, not revealing how I truly felt. I thought the feeling I was experiencing would go away, and believed that I was simply overtired.

My husband could tell that I was not my usual self, so he asked me if I was okay. It was then when I quietly told him how I was really feeling, and he insisted on taking me to the Emergency Department.

I hesitated at first, but eventually decided to go to make him happy and to have some peace of mind.

Upon arrival, I was immediately taken in and was followed up for a heart attack. After careful observation, I was told that I did not have a heart attack; however, there was an abnormal finding on my electrocardiogram, where a left branch bundle block was seen.

I was instructed to follow up with my family doctor and to cut down on my coffee intake. Not having Cardiac Nursing experience I was not quite sure what this meant.

All I knew was that I was not feeling well. When I went to see my family doctor I was sent to Cardiology for a follow up assessment. I was told that the left branch bundle block was just a finding and that I had nothing to worry about as I lived a healthy lifestyle, was not overweight, a non-smoker, consumed no alcohol, and used no drugs.

As the months and years went on, I expressed concerns about my ongoing symptoms, which now included increased fatigue, shortness of breath, irregular heartbeats, bloating of my abdomen, fluttering feeling at the back of my throat, and chest pressure which radiated to my left arm and mid-back area. I asked to see cardiologists for a second consultation in 2009, and a third in 2010. I was told the same thing as at my first consultation.

A few years passed and I progressively became more and more tired. I continued to work and look after my family, but I could feel the increasing signs of my ongoing symptoms.

In the summer of 2013, I returned to my family doctor. As I was sitting in the office, my emotions overwhelmingly took over as I expressed my concerns. I wanted another assessment as I truly knew that my symptoms were real.

I was told that I was stressed and that some time off would be beneficial for me until I was reassessed, so I took a few weeks off as suggested.

After repeating my story to the fourth Cardiologist, I was told the same thing. I was also told that I was young with teenagers, aging parents, and a stressful work environment, all of which the doctor believed were the sources of my stress and possible depression.

I did not believe that I was depressed so I expressed that I was able to handle the stress of aging parents and work very well, and that my children (although teenagers) were of no concern. I expressed how fortunate I was to have a wonderful and supportive husband and children. I was discharged back to my family doctor. At my next follow up, I was encouraged to start antidepressants as my family doctor also felt I had depression.



I filled out the prescription at the pharmacy as I started to wonder if maybe my symptoms were not real and I possibly was depressed.

Although I started to have my doubts, deep down my gut intuition was telling me that something was truly wrong with my heart. I did not start the antidepressants and decided to monitor my symptoms.

In February 2014, my symptoms progressed and worsened. I had an episode of bradycardia and tachycardia while resting after a busy day at work. I felt as though I was going to faint. The next day I went to my family doctor and began to cry in the office.

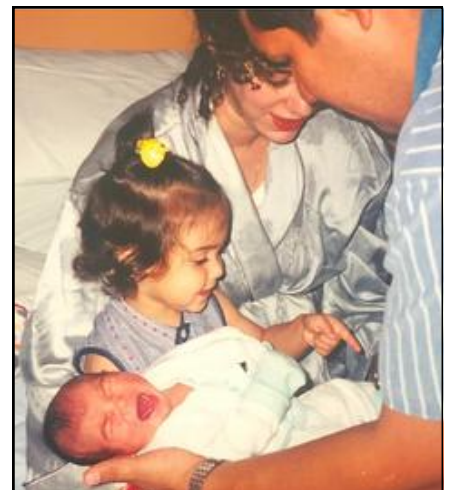
Once again, I was told that I was depressed. I finally expressed that I was crying not because I was depressed or stressed, but because I truly was not feeling well, that

the fatigue and shortness of breath was worsening, especially when climbing just one flight of stairs.

I reviewed how I was concerned about the weight gain and bloating that I was experiencing in my abdomen. I could not understand why my weight kept increasing even though I had not changed my diet and was in fact eating less. Again, my family doctor sent me back to Cardiology to clarify that nothing was being missed.

I saw Cardiology in April 2014 and a MUGA Scan and Cardiac CT Scan were ordered at that time.

In June 2014, my care was transferred to the Heart Function Clinic where I was diagnosed with Idiopathic Dilated Cardiomyopathy and Congestive Heart Failure. My ejection



“I remember feeling a sense of relief knowing that everything I had been feeling over the past eight years was real...”

fraction was 32%, with my left ventricle moderately dilated. Besides the reality of my diagnosis, I remember feeling a sense of relief knowing that everything I had been feeling over the past eight years was real and not in my imagination, and that I definitely was not depressed.

My frustration of not being heard by my medical team was very stressful for me. Despite being angry at first, I am now very thankful for the patience that all the health care providers had with my persistence and voicing of my concerns.

Throughout my years of feeling unwell, I continued to work and give my all to my patients and their families. I also continued to work through my medical treatment until September 2014, when I finally hit a wall.

I realized that it was time to think of my journey and rehabilitate my heart. I began to attend Cardiac Rehab which helped me focus on my self care, improve my healthy lifestyle, strengthen my heart and promote lifestyle change. I received



support from various professional staff. I learned how to exercise properly with the Physiotherapists.

I gained confidence as the nurses monitored my vital signs and provided support for my symptoms. I received guidance for healthy eating by the Dietician. I also received support while I was off on disability until my return to work by the Vocational Therapist. The Social Worker and Psychologist were able to help manage and cope with my diagnosis.

On November 1, 2016 I was able to return to work gradually, until I successfully reached my full time hours in February 2017. My main goal has always been to be strong for my family. Being able to return

to work has shown my family that everything is possible with perseverance and hard work. My return to work has been successful because of the ongoing support and care I received from the whole medical team. My ongoing patience has given me lasting strength and courage.

November 2021, my family physician had some concerns with my increasing symptoms of shortness of breath, chest pressure, and increased swelling in my extremities. Also, a split S2 and S3 heart sound was heard which was a new finding for me.

My family and friends would tell me I looked tired, my face was puffy and my colour was off. I started to monitor my oxygen saturations on my watch.

In August 2022, My cardiologist ordered a stress echocardiogram to rule out a Patent Foramen Ovale which was not seen but it was noted that I had signs of Pulmonary Hypertension with exercise. My diuretics were increased and a nitro patch was ordered with a referral to the Pulmonary Hypertension Clinic where a right sided heart catheter

was ordered. I had the test and then was sent to Toronto to have this test repeated while doing exercise. My diagnosis of Exercise Induced Pulmonary Hypertension was confirmed.



Throughout my heart journey, I have learned that my heart disease is a chronic, lifelong disease and it is a disease that affects men and women differently.

Women have smaller hearts, we test differently, and our symptoms are different. Women have traditional risk factors but we also have non-traditional risk factors such as preterm labour and delivery, gestational hypertension, preeclampsia and diabetes during pregnancy. Women are also understudied as most testing has been done on

men. This is why awareness and communication is so important. Communication is a key element when developing and maintaining a partnership with our Health Care Team. It is a team effort.

Although I was young and healthy, my risk factors included a family history of heart disease, stroke, diabetes, thyroid disease and hypertension, as well as preterm labour, delivery of a late preterm infant, and hypertension during pregnancy.

As women, we should not feel isolated or feel alone with our struggles with our heart condition, or any condition. Take initiative with whatever symptoms you may be experiencing. Do not quit or ignore your symptoms because once the damage has been done, it will change your life and the lives of your loved ones.

I have realized that age and appearance sometimes can be deceiving. It is important to remember that even with normal values at first, there still can be something truly wrong, as was in my case. I want other women to look at my story and see not only a mother, wife, daughter, sister and friend, but a goal setter who doesn't quit when things get

rough. I did not let this disease control my life, but instead, I have learned how to control it. My disease does not define me. I am strong.

Please remember that your health comes first. If we don't have our health we then have nothing. If we don't look after ourselves first, then how can we look after others and most importantly our loved ones and families.

Where am I today? My heart disease has not disappeared. I continue to not be the textbook patient and I continue to struggle with my ongoing symptoms of shortness of breath, feeling very fatigued, retaining fluid and chest pain/pressure.

The word idiopathic in my diagnosis still makes me wonder why I got cardiomyopathy and heart failure at such a young age. That question will never go away. I am now able to manage these symptoms the best that I can and avoid a hospital admission. My ejection fraction is preserved.

I have lived to the age of fifty six and look forward to many more years. I have traveled and hope to travel more with my family. Laughter is part of medicine.

I have learned that life does not stop. The word “reality” has a strong meaning. Advocacy, raising awareness, and offering support is important to me.

I have completed two cardiac rehab sessions and one cardio pulmonary rehab session. I continue to navigate the healthcare system and keep advocating for myself because on the outside I am told I look great, but internally it is a different picture.

I have a wonderful Cardiologist and Family Physician that are on my team and I am happy to have their ongoing support and exceptional care. Most importantly, I am able to have the time with my husband and children, time I wasn't sure I would have. I live for them and I am alive!!

How can we as women feel empowered? The voice of the women with lived experience is critical in understanding our journey.

We must focus on knowing what is most important and what our needs are, if these needs are being met and also the challenges we face. The importance of support



from our families, friends, peers and our healthcare team is key to promoting recovery, understanding of our new normal and continued compliance with our medical regime.

We do not need to remain silent or feel shame in how we feel or what we are experiencing. Taking charge, advocating, and sharing our experiences will help healthcare professionals recognize our signs and symptoms as well as bring awareness and understanding of our journey.

Always keep in mind that knowledge is power. By attending programs, participating in research, and becoming more educated women will learn to be accountable, listen to their bodies, and become advocates through their own recovery. You are your

greatest advocate. Everyone's story is different and each is unique. You are much more than your disease.

Our voices and experiences are key in making a difference so we are not misunderstood, not understudied, not underdiagnosed, not undertreated, not under supported and not unaware.

Over the years, I have learned the importance of keeping an open communication with my health care providers, to keep calm, remain curious but not furious, and that I know my body best.

Our voices are important and we must always remember that the women with lived experience are actively living that experience!





Excerpt from the [Heart and Stroke](#) website under:
Home/Heart disease/26 Conditions/Cardiomyopathy
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HEART CONDITION SUMMARY

PURPOSE:

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

DILATED CARDIOMYOPATHY

What is Cardiomyopathy?

Cardiomyopathy (cardio-my-op-a-thee) is a disease of the heart muscle that reduces the heart's ability to pump oxygen-rich blood to the body. This can lead to Heart Failure.

What is Dilated (Congestive) Cardiomyopathy?

This is the most common form of cardiomyopathy. It often occurs as a result of restricted blood flow to the heart muscles (cardiac ischemia). It weakens and thins the walls of the heart chambers.

The disease often starts in the left ventricle, which is the main pumping chamber of the heart. When the walls dilate and become thin, the inside of the chamber gets larger. The left ventricle beats with less force, so it pumps blood less effectively to the rest of your body. The problem can then spread to the heart's right ventricle and the atria.

Dilated cardiomyopathy mostly affects middle-aged men. Causes may include viral infection of the heart muscle, excessive alcohol consumption, cocaine and the abuse of antidepressant drugs. In rare cases it may be caused by pregnancy or connective tissue disorders such as rheumatoid arthritis.

In most cases of dilated cardiomyopathy, the cause is unknown (idiopathic).

Treatment?

The goal of cardiomyopathy treatment is to reduce your symptoms. Your treatment plan will depend on what type of cardiomyopathy you have, how serious it is and what symptoms you are experiencing. Your doctor will suggest medications, surgery, lifestyle changes or a combination of the three to manage your condition.





Tips & Strategies

PRESCRIPTIONS, VITAMINS AND SUPPLEMENTS; OH MY!



By CHRIS MENDOZA, BSc, BScPharm, CDE

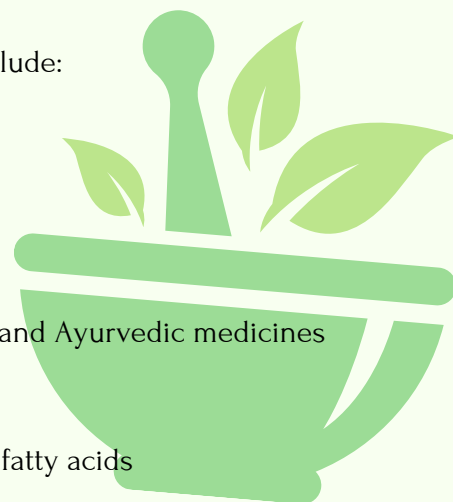
Community Pharmacist, Certified Diabetes Instructor and Applied Pharmacy Practice Instructor at the College of Pharmacy at the University of Manitoba

In a world where information is readily available at our fingertips, it can be easy to get lost in the immense online data when searching for answers about our health. Would supplements be beneficial? Are all vitamin brands equally effective? What is ashwagandha used for? As a community pharmacist, I recognize the importance of examining this online data with a critical eye to help patients navigate through this information. Pharmacists are a great resource for guidance on many health-related topics and are the most accessible health care professionals. We have a wealth of knowledge regarding prescription medications, over-the-counter medications, vitamins and natural health products.

More than 80% of Canadians consume natural health products (NHP) and in the third quarter of 2023, sales amounted to nearly 1.45 billion Canadian dollars. According to Agriculture and Agri-Food Canada (AAFC), growing consumer interest, combined with a greater understanding of food-health relationships, rising health care costs and an aging population, are factors driving the market for natural health products in Canada. Natural Health Products are defined as naturally occurring substances used to restore or maintain good health. They are often made from plants, but can also be made from animals, microorganisms and marine sources. They come in a wide variety of forms, such as tablets, capsules, solutions, creams, ointments, tinctures and drops.

NHPs, often called "complementary" or "alternative" medicines, include:

- Vitamins and minerals
- Herbal remedies
- Homeopathic medicines
- Traditional medicines, such as traditional Chinese and Ayurvedic medicines
- Probiotics
- Other products such as amino acids and essential fatty acids



Before adding any Natural Health Product to your regimen, it is important to consult with your health care team to assess the safety of these products and to determine if it is appropriate for use with your other medications. Products that are labelled "natural" does not implicitly mean they are safe to use. Some of these products may interact with prescription medications or have dangerous side effects. There are some NHPs that should be completely avoided in those with certain medical conditions.

Some common examples of NHPs that should be avoided due to interactions with heart medications:

COENZYME Q-10

Potential antioxidant properties but may affect:

- How warfarin works
- Blood pressure

HAWTHORNE

Health claims for heart disease, high blood pressure and anxiety but may affect how these medications work:

- Beta Blockers (atenolol, propranolol), calcium channel blockers (diltiazem, nifedipine), nitrates, digoxin

ST. JOHNS WORT

Promoted for depression, ADHD, menopausal symptoms but may affect the way certain medications work:

- Calcium channel blockers
- Statins (atorvastatin, rosuvastatin)
- Warfarin
- Digoxin
- Immunosuppressant medicine, such as cyclosporine

EVENING PRIMROSE, GARLIC, GINKGO BILOBA, SAW PALMETTO, ST. JOHN WORT

Can all increase the risk of bleeding if paired with any of these medications:

- Aspirin
- Clopidogrel
- Warfarin

With some NPHs, the interaction lies in the timing of when you take the supplements and prescription medication. Sometimes they shouldn't be taken at the exact same time and must be separated by a few hours to ensure that each are being absorbed by the body properly. For example, calcium and magnesium supplements may interfere with the way that some antibiotics work. By taking them at least 2-4 hours apart from each other, this ensures that the antibiotic is absorbed by the body properly and will work to treat the infection. Another example is where certain minerals may affect the way thyroid medication works and should not be taken at the same time.

Food may also play a role in interactions with prescription medications. Grapefruit juice is not recommended for use with certain cholesterol-lowering medications. This combination may result in increased levels of the prescription medication potentially causing more side effects. Licorice seems like a harmless snack, but if digoxin for congestive heart failure and abnormal heart rhythms is being used, some forms of licorice could increase the risk of digoxin toxicity. It may also reduce the effects of blood pressure drugs or diuretics (water pills).

What is the best way to avoid drug interactions?

- 1 • Avoid the assumption that all natural supplements are safe.
- 2 • Consult with your health care team before taking any supplements or other medications.
- 3 • Use the same pharmacy for all your prescriptions.
- 4 • Keep a list of all your medications and supplements and share it with your healthcare providers.

With numerous Natural Health Products claiming health benefits, it is important to speak with your pharmacist to ensure that these products are safe and appropriate. Pharmacists are medication experts who will take the time to answer questions and provide education. We have been trained to help prevent and manage chronic illnesses and are an essential part of your healthcare team.



Over The Counter (OTC) Cold/Flu Treatments...

General Recommendations:

- Consult your doctor or pharmacist before using OTC cold or flu medications if you have a heart condition.
- Avoid medications containing decongestants if you have high blood pressure, arrhythmias, or heart disease.
- Use acetaminophen for pain relief, and avoid NSAIDs unless directed by your doctor.
- Monitor for side effects such as dizziness, increased heart rate, or blood pressure changes, and seek medical advice if any occur.

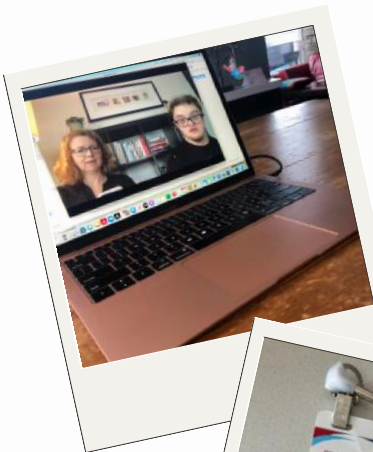
more info >



Learning & Information

Why Be a Patient Partner

5 tips to set yourself up for success.



By SUE ROBINS, British Columbia
Patient Engagement Advocate, Speaker
Author 'Bird's Eye View' and "Ducks in a Row"



My youngest son Aaron has Down syndrome.

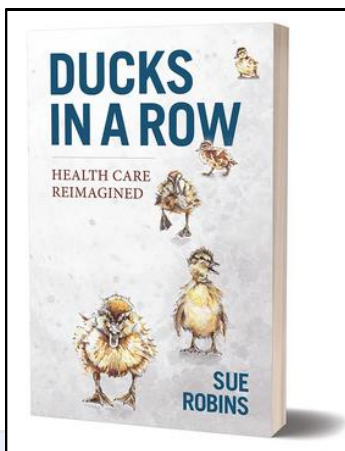
When he was a baby, he had many appointments at pediatric rehabilitation centres and children's hospitals. I experienced this world as his mom and spent hours sitting in waiting rooms, clinic appointments and beside his hospital bed.

I observed what went right and what could have been better. I wanted to do something with that newfound wisdom, so I joined a family council. I gave talks and sat on committees. Eventually, I was hired to do family engagement with a children's hospital. This meant going out to families in the community to bring their voices into the hospital through a family council.

These experiences taught me that the healthcare system will only improve if patients and families are given a seat around the decision-making table. Partnerships between clinicians and patients at the point of care – at the bedside, in the Emergency department, at a clinic – are crucial to improve individual patient outcomes through shared decision-making. The next level of engagement is partnering at an organizational level to influence system-wide change.

Since Aaron was born 22 years ago, the language around partnering with patients has changed. What started as a movement in children's hospitals (then called family-centred care) expanded to children and youth (patient-centred care) and evolved into adult health care (patient and family-centred care). The language changed to patient partnership and now patients are often called people with lived experience or people with lived expertise.

I know you've had many experiences in health care – good, the bad and the ugly. Perhaps you've experienced a medical error, given feedback or escalated concerns in the system. Often patients don't hear back when they speak up, so they search for other ways to make meaningful change.



Sue Robins's latest book, *Ducks in a Row: Health Care Reimagined*, is a scrappy challenge to the established health care world. Her first book, *Bird's Eye View: Stories of a life lived in health care* is a poignant memoir of her experience as a caregiver and cancer patient.

Sue has also written for *The New York Times*, *Canadian Medical Association Journal* and *The Globe and Mail*. She consults with health organizations about best practice in patient engagement and is a frequent plenary speaker at health conferences.

Why get involved as a patient partner at the system level? Why join an advisory group, be a patient representative on a committee, or share your story with health professionals?



Everybody has their own 'why.' It is important to identify why you want to be involved before you begin. This goes beyond 'to make a difference.' For me, my purpose is to motivate professionals to create healing health care settings. My patient experience, especially when I had breast cancer a few years ago, was lacking in compassion. Encouraging humanity in healthcare is my 'why.'

Research says that partnering with patients can improve the quality of care. This includes improving patient safety and the patient experience. Partnering also positively impacts staff satisfaction.ⁱ



The healthcare sectors that are engaging with patients at the organizational level are growing beyond a hospital council or committee. Research, pharmaceutical companies (also called life sciences), health technology assessment agencies, national organizations, primary care, health faculties in universities have all subscribed to the notion of patient engagement.

Your own region may have an organization that shares patient partnership opportunities, like Health Quality BC's Patient Voices Networkⁱⁱ, or Healthcare Excellence Canada.ⁱⁱⁱ Some universities offer 'patients as faculty' programs where patients share their stories with medical, nursing or other health faculty students to help them better understand the patient perspective before they go into practice.^{iv}

READY TO BECOME INVOLVED AS A PATIENT PARTNER?

Here are a few tips so your experience is successful.

1

First of all, be picky. The experience of being a patient partner on a committee or council should not cause you additional harm.v

2

Only work with organizations who have a good reputation or who have demonstrated that they respect your perspective. There is a tendency for patient engagement to be tokenistic, also known as the ‘checkmark’ phenomenon. Ask the organizers how patient feedback is used in a meaningful way.

3

Telling our healthcare stories can bring up traumatic or painful experiences and memories. Are you in a healthy place for that?

For instance, I can talk about the disclosure of my son’s diagnosis from two decades ago, but I still have a hard time speaking about my patient experience in oncology from 7 years ago. I skirt around this by talking generally about compassion in health care, and only share stories that I’ve either written about before or rehearsed until most of the emotion has faded away. Patient partnerships can also bring up grief about loss of health, illness experiences, abandonment of friends and family, and other issues.

4

While it is rewarding, patient partnership work can be lonely. Make sure to connect with other patient partners and build your own community of support. Your colleagues can help you find opportunities and share their own stories about organizations that are good (and bad) to work with.

5

Finally, the thing nobody wants to talk about: money. Best practice in patient engagement means that partners are offered compensation right at the beginning of an opportunity. Remember that this work has great value to an organization. I do make time to volunteer (for instance with non-profit patient support group work), but a large health organization should be paying us an amount that is equitable to what the professionals who are sitting around the table receive.vi

I’ve learned many things doing this work to influence system-change. The main hard-earned lesson is that this work is generational, meaning you might not see change in your lifetime. Patient partners can plant seeds for future generations to build upon. We might not see a difference in our lifetime, but it is my belief that patient partners create a ripple effect that leads to positive action long after we are gone.

References >





Mental Health Lighthouse

“Best Before” Date...



Aubyn (L) and Taegyn (R).



By AUBYN BAKER-RILEY, Ontario
Congenital Heart Disease, 1963
& Heart Failure

I was born in December 1963, the youngest of three girls. Very early on after my birth, my parents became aware that something was wrong with me. I would turn blue at night trying to breathe. After testing, it was found that I had Congenital Heart Defects (CHD). Specifically, Coarctation of the Aorta and a Bicuspid Aortic Valve. My parents were told that there was not much they could do for me but to take good care of me, to monitor my heart and I was put on one medication, Digoxin. They needed to wait till I was older, if I lived that long, to “fix” my heart. So that is what they did.

I was not allowed to participate in gym class or any sports. I spent time visiting doctors, hospitals, having tests, taking meds, even staying away from school when there were viruses going around.

At 7 years old (October 1971), I went to the Vancouver General Hospital to have my Coarctation of the Aorta “fixed”. Or so we were told then, I was fixed, I was normal now.

I had my surgery through the TAVI approach (no broken ribs or zipper scar down my chest). I don’t really remember much about pre or post surgery other than my mom making it as FUN as she could for me. She read to me sitting beside my bed, she brought my favourite food into the hospital in a thermos (Spaghetti O’s in case you are curious) and she even brought our cats into visit me in the hospital ward room, to the dismay of the nurses. My recovery was long and hard and as I said to my family, “I feel worse coming out of the hospital than I did going in”.

*“COULD IT BE YOUR HEART AUBYN?”
SHIT, I THOUGHT, SHE COULD BE RIGHT.*

After getting home from the hospital, I was treated differently, “normal”. I was given the opportunity to take gym classes at school, to learn sports, to learn how to skate. I was followed annually through to my 18th birthday at the Children’s Hospital of Eastern Ontario in Ottawa. Unfortunately, as medical protocol dictated, at 18 I was discharged from their care but was then not followed by a cardiologist at all in my 20s or 30s.

I led a happy, healthy busy life in this time frame, with no indication that there was any problem with my heart. I truly almost forgot about it and didn’t in any way let it dictate how I lived, what I did or didn’t do. The only indication that something was wrong with my heart came when I had my first born son at age 29. I should state that I was not being followed as a high risk pregnancy, everything was fine throughout my pregnancy, but I ended up in Super Ventricular Tachycardia (SVT) in labour. I can remember a rush of people entering the labour room. I believe I was given oxygen and possibly some medication (I honestly don’t remember).

Thankfully my beautiful son was born safely, his heart was healthy and I recovered well. Again, I was given no heart follow-up.

Five years later when I was pregnant with my second son, I was followed as a high risk pregnancy. I was given tests throughout my pregnancy to check on my heart health and the baby’s. I birthed my second son in an operating room, not a birthing room, in case anything happened to me during labour. Thankfully again, my son was born safely, heart healthy and I recovered well. I again was given no heart follow up. I didn’t think about it again after that. To be honest, most people who knew me didn’t even know I had a heart issue. I didn’t talk about it, mention it, or really think about it again.



Aubyn (L) and Jeanette Smith (R)

Fast forward 8 years, I was a wife, a mom, working part time, house owner, juggling many roles at the same time. Life was moving along as it should.

However, I started to notice that I was getting tired quickly, had some shortness of breath issues, and could not keep up with all my responsibilities. But the big tell happened one day as I was taking out the garbage, and my elderly neighbour was doing the same. He was twice my age but having no issues talking to me while he was rolling his garbage cans down the driveway. I on the other hand was having difficulties breathing well enough to do both, so I just waved.

This upset me enough that I made a comment to a friend of mine later that day about it. She was aware of my heart condition and asked “Could it be your heart Aubyn?” SHIT I thought, she could be right. I called my GP, and from there the testing, poking, prodding from my youth came back into my life.

This would have been in the early 2000s and we as a generation of CHD patients were just beginning

to emerge as adults with issues. Eventually I saw the CHD doctor at the Ottawa Heart Institute who when meeting me said “We don’t know what to do with 40 year old CHD patients, you guys didn’t live that long!”

For the record, he was a paediatric CHD doctor they had borrowed from the Children’s Hospital of Eastern Ontario and who admitted he was out of his depth but this was the beginning of the adult CHD clinic.

Ultimately, I feel very lucky to have not had my CHD affect me over my lifespan, other than the last 20 years or so. I have had three ablations, the first one giving me 12 years without many symptoms at all.

I have been followed by the CHD clinic since they began and given the opportunity to learn more about my CHD, to attend cardiac rehab a few times and meet others with CHD and/or HF. YES I have that now too although it is in remission.

I am taking various medications to support my heart health, some that I have reacted better to than others. It is an ongoing discussion with my cardiologist.

My mental health has taken a toll over the last twenty years, first as a wife and mom who felt like she was betraying her husband who did not sign up for having a chronically ill wife. He knew about my CHD but not the implications of it as I got older, either did I.

I felt guilty that I could not be there as I wanted to be for my family. That cleaning the house at times has been too hard for me to do and we have had to at times get a cleaning lady. Financially, I have never held down a full time job since the heart issues started. Every time I tried to do something else would happen.

I have thankfully been able to access mental health supports, some through Ottawa Heart Institute, but most privately, paid for by my husband’s health plan.

I have had to try to explain my chronic illness to family and friends. In 2018, I was set up to go back to school part time, work part time and again my heart said otherwise. So, at 54, I finally applied for Canadian Pension Plan disability. My application was initially declined and it was a tough decision to appeal, but in the end I did and I got it.



Bandit - my comforter.

It is so important to take care of ourselves, and let others help us along the way. For most of us, we cannot do this journey well on our own. It takes a village to raise a child they say. I think it takes a village to be on this journey of living well with a chronic illness.

I have a solid village around me... Family, friends, other heart patients, clinicians and of course pets (can’t forget to mention my corgis). They have my back: some because they allow me to vent and cry, others raise me up, and of course my heart community who understand what I am going through cause they have been there too.

I hope my journey story helps one person to feel less alone, helps one person to remember that we are worth it, we are still here. I am still here ... beyond my BEST BEFORE DATE!



INSPIRED WRITINGS & ART

REFLECTIONS



Good-bye my heart... Thank you.



By LISE BURGESS
British Columbia
Heart Transplant, Dec 2024

As I hold my heart in my hands I know, with tears streaming down my face, that it's time to say goodbye. You were always there for me, you kept me alive for 57 years. You took me on so many amazing adventures, allowed me to learn life's lessons, to become a mom to two amazing children, to meet beautiful souls (who came and went or stayed). You've seen me cry, be frustrated, have deep sadness, feel joy, laugh and fall in love (and painfully fall out of love). You did all of this while you were damaged and struggling to keep me alive, you were amazing. I didn't realize just how precious you were to me until you stopped being a part of me.





EATING FOR HEART HEALTH

Why Heart-Healthy Eating Habits Don't Always Stick



By CHERYL STRACHAN, RD - Alberta
Author of 'The 30 Minute Heart
Healthy Cookbook'
SweetSpotNutrition.ca



If you've committed to eating for heart health in the past, but then slipped back into old habits, you're not alone!

Researchers found that the percentage of people in a cardiac rehab program whose eating habits were rated "good" jumped from 30% before to 91% during the program, but then dropped to 49% a year later. Three years after the program it was down to 42%.

WHY IS IT SO HARD TO BE CONSISTENT WITH HEART-HEALTHY EATING?

Even if you know what you “should” do, actually following through is another matter. There are many possible reasons:

1. Fear doesn't last.

A cardiac event or related diagnosis is frightening, and fear can be a powerful motivator. Thankfully for most people, the fear fades away. But once it's gone, you'll need something else to motivate you - maybe eating a certain way gives you more energy, or you have a sense of pride in the healthier habits you've formed.



2. Lack of time.

This is one of the most common barriers to healthier eating. Planning, shopping, and preparing healthier food does take time, and you undoubtedly have other responsibilities.

3. Fatigue after a heart event.

This can be a bigger problem than people expect, depending on what happened to your heart. You may struggle to find the energy to cook.



4. Heart-healthier food might not taste as good to you!

Preferring satisfying, pleasurable food is only natural. After eating the same way possibly for decades, you may find it hard to adjust to new flavours and textures.



5. Competing family preferences.

You want to eat fish, everyone else wants steak. You want homemade, they want to eat out.

6. The cost of food.

Can be serious obstacle. It can push some heart-healthier choices out of reach, and it's getting worse.

7. Unnecessary restrictions.

Sometimes people take heart-healthy eating to an unsustainable extreme. Declaring “No sugar, no salt, no fat” is understandable after a health scare, but a moderate approach may work better in the long run.

8. Emotional eating.

is another frequent challenge. Eating to relieve stress or other difficult emotions isn't necessarily a problem, but if you feel it's affecting your health, then you may decide to address it.



SO WHAT CAN YOU DO ABOUT IT?



First of all, give yourself grace. Self-compassion, treating yourself like you would treat a friend, is actually associated with greater motivation to make needed changes in your life, among [many other benefits](#).

Second, decide which of the barriers listed above is most relevant to you right now. (Or is it something else?) Focus on one problem at a time.

Then brainstorm ways to address that problem. Reach out for help if you can. A loved one or health professional might be able to see your situation more objectively. If you're able to access cardiac rehab, is there a nurse, dietitian, or counsellor you can work with? Does your doctor's office have anyone?

You're welcome to join my "[Sweet Spot Heart-Healthy Cooking Club](#)" Facebook group, where committed heart-healthy cooks share ideas and support people who are newer to this way of eating.

Changing lifelong eating habits means addressing the barriers above, experimenting in the kitchen, and persevering. It takes time, but it's doable!

Every day is a day to choose differently!



Heart Friendly Pasta

Crunchy Chickpea and Sun-Dried Tomato Pasta

BY CHERYL STRACHAN, RD

Prep Time: 10 minutes

Cook Time: 45 minutes (this is for the chickpeas to roast, but you won't be hands-on in the kitchen for that long)

Total Time: 55 minutes

6 servings

INGREDIENTS:

CHICKPEAS

- 1 can chickpeas (no salt added)
- 4 cloves garlic
- 1/3 cup olive oil

PASTA

- 1 pound scoobi doo pasta, rotini or fusili
- 5 oz pre-washed spinach (140g)
- 1 cup oil-packed sun-dried tomatoes, drained
- 1/2 cup feta cheese crumbled
- 1 can light tuna in water, drained

INSTRUCTIONS:

CHICKPEAS

1. Preheat the oven to 400F.
2. Rinse the chickpeas in a strainer. Give them a couple of minutes to drain well, and then dry them off with a paper towel.
3. Meanwhile, peel the garlic and add the cloves (whole) to a baking sheet along with the oil.
4. Add the chickpeas and mix to coat well.
5. Roast for 30-40 minutes, stirring a couple of times. Remove when they're golden brown. Discard the garlic cloves.

Heart Friendly Pasta

Crunchy Chickpea and Sun-Dried Tomato Pasta



INSTRUCTIONS CONTINUED:

PASTA

1. Meanwhile, cook the pasta in a large pot according to package instructions, then drain and return to the pot.
2. Add sun-dried tomatoes, tuna, and spinach, stirring to combine. Put a lid on the pot and keep warm on the lowest setting.
3. When the chickpeas are brown and crispy, add them to the pasta. The spinach should be wilted by now. Stir once more to combine. Top with feta cheese and enjoy

NUTRITION: Per serving: 424 calories, 20g fat, 3g saturated fat, 48g carbohydrates, 7g fibre,
(Approximate) 3g sugar (0g added/free sugar), 19g cholesterol, 331mg sodium, 17g protein.

NOTES:

· **SUN DRIED TOMATOES** - If you're making this with heart health in mind, take a look at the sodium when you buy sun-dried tomatoes, because there is a huge difference from brand to brand. See if you can find one with no more than 45 mg of sodium per tablespoon (15g).

If the oil in the sun-dried tomatoes is olive oil, it may get cloudy and solidify in the fridge. Don't worry about it - olive oil does that. Take it out for a few minutes and it will clear right up.

· **CANNED TUNA** - I used tuna packed in water for the nutrition analysis, but this would be good with tuna packed in oil too.

· **WHOLE WHEAT PASTA** - I didn't write this recipe with whole-wheat pasta because personally I'm not a fan. You get plenty of fibre from the chickpeas, spinach, and sun-dried tomatoes, so I let this one go. But if you like it, of course, use it.





HEART RETAIL & THERAPY PRODUCTS

There are so many great products available to help us live better and products that make us feel good or support a cause that is close to our hearts... here are a few:

1

SELF LOVE RING

[Zaleska.ca](https://www.zaleska.ca)



Here's the truth: good love starts from within. It's a practice, and it helps to have a (cute & wearable) reminder. Back after a wee makeover, this ring is a love letter to YOU from YOU. It's got a hint of Art Déco detailing with a faceted rose quartz gemstone and a sneaky little carving on the back. It's an everyday piece to remind you to be soft with yourself, to enjoy your company, to look in the mirror and say something nice, and to build confidence with every tiny step along the way. Wear it knowing you are deeply capable of living a life full of love.

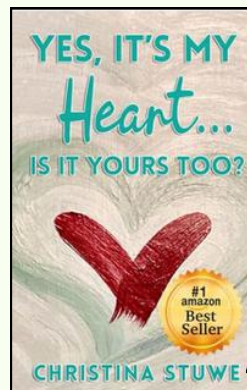
2

"YES, IT'S MY HEART... IS IT YOURS TOO?"

By: Christina Stuwe | Feb 7 2023

[Amazon Link](#)

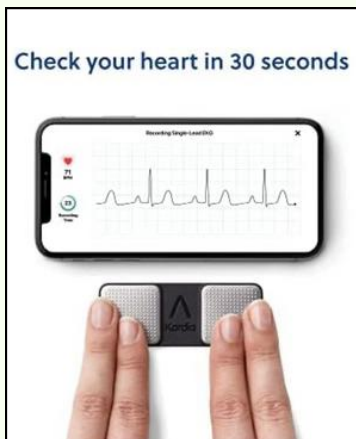
In this book, you will read the story of one woman's journey with heart disease. Her story is not just full of heart, but it will guide yours as well. Impactful yet informative, sincere yet serious, it provides a candid and intimate look at heart health in women, what to expect, and what needs to change.



3

KARDIAMOBILE ECG MONITOR

[Amazon.ca](#)



- ECG ON THE GO: Take unlimited medical-grade ECGs anytime, anywhere in 30 seconds.
- ECG HISTORY: Store your ECGs on your phone, and email to your doctor.
- TRUSTED BY DOCTORS: Cleared to detect Atrial Fibrillation, Bradycardia, Tachycardia or Normal Heart Rhythm
- EASY TO USE: Simply place your fingers on the sensors—no wires, patches or gels required.
- Works with most smartphones & tablets.
- Not recommended for use with pacemakers and ICDs and does not detect heart attack
- NO SUBSCRIPTION REQUIRED.



FITNESS FOR EVERY 'BODY'

ACHIEVE YOUR NEW YEARS GOALS WITH GRACE



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



Hello and Happy Fit Year!!

It's amazing that it's March already! The 3rd month, out of 12 months. Take that in for a moment..... Are you thinking: 'Where has the time gone! Is it too late to start exercising now for my New Years Resolution (NYR)?' You might also have thoughts about starting other important healthy lifestyle choices such as journaling, reading, eating and sleeping better, and drinking more water daily.

Unfortunately, there is much hype and pressure about making New Years Resolutions, that it causes more stress and anxiety than results. The majority of these resolutions are related to starting a fitness program.

Research shows that 80% of New Year's Resolutions fail! That means only 20% of people actually keep their resolutions. That's not great results at all!

So why is there so much failure to achieve these resolutions? Mainly because most resolutions are made just to have one; looking for a new experience, but the commitment to real change has not been taken seriously. For example, exercise makes the NYR 'list' approximately 50% of the time. With thoughts/goals, 'to be fit', 'healthy', 'look better', 'feel better', 'lose weight', 'fit into certain clothing for a certain event', etc.

MAKE A PLAN BY CREATING ACHIEVABLE AND SUSTAINABLE GOALS!

To achieve these goals it takes a plan, dedication, consistency and follow through. Unfortunately, once the realization of the effort required to achieve these fitness goals becomes known, the goals become altered and slowly, slide off 'the list' by March. The goals may have been too challenging. Not Fun. Boring even. Or simply, there was no plan set to achieve them.

Exercise should be Fun, have variety and an element of challenge in order to be successful. Did I just say Fun and challenging in the same sentence? You bet I did! To challenge the mind and body together, keeps your brain constantly learning and literally forms the mind-body connection.

And when the brain is stimulated while moving your body, you are entertained, smiling and even laughing. Hello endorphins! Exercise releases endorphins which are brain chemicals that help to improve mood and reduce pain and stress. That's an amazing reason to get moving!

Your mindset must be positive in order to achieve your goals. It is never too late to start anything. Plan it out. Create, set a plan and make your goals achievable and sustainable. And just move on it. Simply put, exercise = movement. Daily movement. Of. Any. Kind. Whatever you can do to move your body; any which way possible! Simple. Right? Yet it still causes stress and anxiety with most, because the mindset isn't positive.

Once you wake up (that's a bonus right there, so keep moving in the right direction) with the attitude, 'I'm so grateful for this body and I want to show it my appreciation and not take it for granted', trust me, things will turn around for you. Our bodies are the greatest machine ever and we get to house them and take care of them. What an honour. They are so easily taken for granted, in what they need to sustain life. As most readers here understand exceptionally well, there are many things that we haven't done 'to our hearts', and yet our hearts are still 'challenged'. So, let's be calm and kind to ourselves, find some kind of happy within and say thank you to our hearts for continuing on when we didn't think we could, and let's keep moving, with a smile the best that we can. I believe in you and so should you!

Please remember to HAVE FUN! Our hearts are working so hard for us heart warriors. Let's take time to fully appreciate that and give back, the best that we absolutely can. You can do absolutely anything that you set your heart and mind to!

Whenever I'm asked what my NYR is (because people do ask), I simply say, 'I don't set 'NYR', because every day is an opportunity to become a better version of myself than the day before'.

Here is a selection of exercises to do either inside or outside. Set your plan by choosing your exercises for the days/times each week and get moving. Put some music on and smile all the way! A reminder that the previous Life in Hearts issues host a variety of exercises as well!



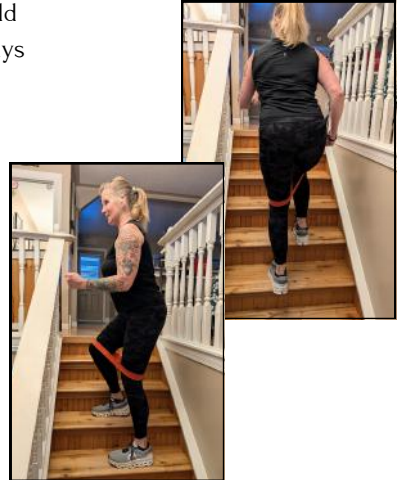
1

Get some steps in by walking (or dancing!) up and down a hallway, forwards, backwards and side-step. Pump your arms while doing this. Do you own a booty (rubber or fabric) resistance band? Put it on as seen in the pictures and add some resistance to your muscles. When moving side-ways make sure your knees are slightly bent.
Goal: 10-15 minutes.



2

Walk up and down a staircase for 10 minutes. Incorporate different muscle groups and also side-step up and down the stairs. Can use booty resistance band here as well.



3

Walk-out to Bear - Standing with hands on hips, bend forward shooting hips back, and having back parallel with floor. Bend knees, place hands on floor and walk them out so that they are beneath shoulders and bring knees to just above the floor (beneath your hips).



Think of pressing the floor away from you with your hands. Pull your navel towards your spine, engaging your core muscles. Hover knees off floor as long as possible - eg. start with 5-10 second intervals. Then walk hands back to feet and round back up to standing and start again. Goal: 5-10 times down and up from floor. Also, try to hover longer in bear position each day you try.



4

'Good Morning': Standing tall, arms crossed at your chest, knees slightly bent, bend forward from your hips, pushing your hips back, maintaining a flat back, take chest parallel to the floor. Then start to stand back up, squeezing your buttocks and top of your thighs once you stand tall. Repeat 10-12 times. Can use booty resistance band here as well.



5



Mobility: Getting down to the floor and back up: Standing, go down to the floor, 1 knee at a time, arms out to side for balance. Once on the floor on your knees, slowly stand back up again using your legs, 1 at a time (try not to put your hands on your thighs when getting up). Try 5, then 10 then goal to a number that challenges you, or, do as many as you can in a chosen time frame. Always try for a bit better each time.



Tips From Annie

- P Plan.** Make a plan and just go for it!
- A Attitude.** Attitude of Gratitude!
- T Time.** Prioritize the time for movement!.
- I Internal.** Feel within, your desire to feel better!
- E Example.** Be the example you want to see!
- N Nice.** Be kind and nice to yourself!
- C Consistent.** Consistency wins every time!
Keep moving!
- E Eager.** Be eager to learn how to move your body and reap the benefits of movement.

6

Bodyweight
Tricep Dips
Goal: 5-12 reps 3x



7

Modified Knee Push-Ups: Goal: 5-10 broken down to even 1 push-up at a time with small breaks. Easier version: Don't go as low to floor. Or, take it to standing position with a wall (shown in last issue).



Don't forget to get some Vitamin D and fresh air. Bundle up and head outside. In the winter I wear cleats on all of my winter boots for fall prevention. Realizing your body is the most important machine that you own and that it is your responsibility to take care of it the best way possible, you will do whatever you can to keep it moving and your soul happy!



Congratulations on showing up for you & 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

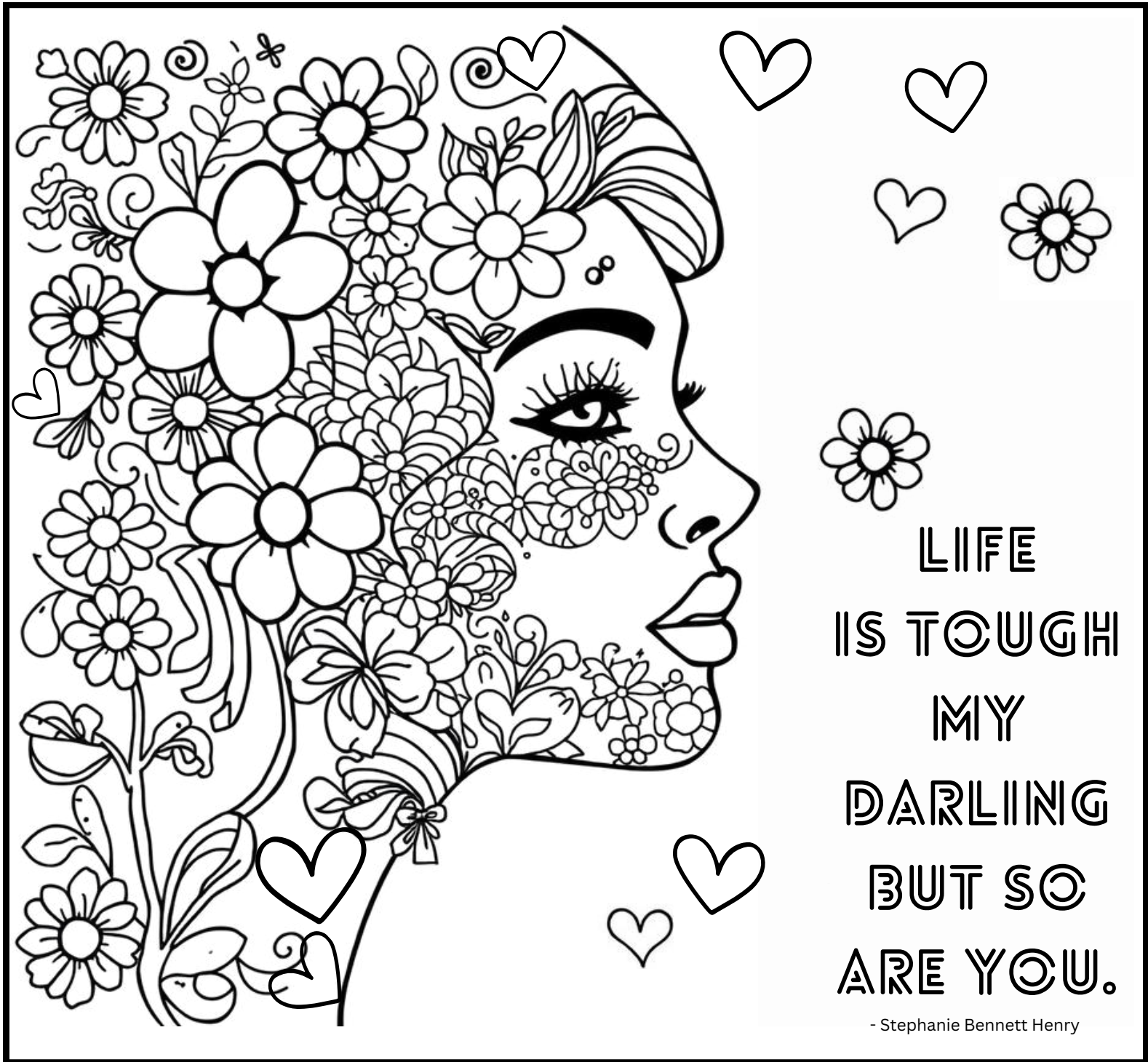


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email to LifeInHearts@Heartlife.ca by April 30, 2025

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Why Be a Patient Partner

5 tips to set yourself up for success.

By SUE ROBINS, British Columbia

Patient Engagement Advocate, Speaker

Author 'Bird's Eye View and "Ducks in a Row"

Reference i [https://www.mcmasterforum.org/docs/default-source/rise-docs/partner-resources/3-evaluation-guide-eng-\(002\).pdf?sfvrsn=82ecaebe_5](https://www.mcmasterforum.org/docs/default-source/rise-docs/partner-resources/3-evaluation-guide-eng-(002).pdf?sfvrsn=82ecaebe_5)

Reference ii



Reference iii <https://www.healthcareexcellence.ca/en/what-we-do/all-programs/patient-partnerships-and-engagement/patient-partner-network/>

Reference iv



Reference v

Statements Describing Patient Engagement Gone Wrong	Explanation	Questions for the Research Team to Ask Themselves
 Patients Partners as a Check Mark	Also known as tokenism, inviting someone's participation but not wanting their input or listening to their perspectives, and therefore not acknowledging their insights, contributions, or ideas.	1. How do we accept feedback from patient partners and integrate it into our work?
 Unconscious Bias Towards Patient Partners	Unlived experiences are often not viewed as that expertise and given less credence and respect. This may be subconscious and often relates to ethnicity, socioeconomic class, education, or other factors.	2. How can we ask more thoughtful questions of patient partners about their lived experiences?
 Lack of Support to Fully Include Patient Partners	Failure to provide physical and other supports to patient partners so they may fully participate as team members.	3. How can we create safer and more inclusive spaces for real and meaningful discussions?
 Lack of Recognizing the Vulnerability of Patient Partners	Failure to appreciate that patient partners often do not have the same knowledge or skills as the researchers or healthcare providers. This may lead to feeling vulnerable, especially when working with people who have less power or privilege.	4. How can we share our power and privilege with patient partners?

Reflections on patient engagement by patient partners: how it can go wrong - Research Involvement and...

As six patient partners in Canada, we aim to contribute to learning and to provide an opportunity to reflect on patient engagement (PE) in research and healthcare environments. Patient engagement refers to "meaningful...

Biomed Central Jun 32, 2023

Reference vi <https://pxjournal.org/cgi/viewcontent.cgi?article=1334&context=journal>