



# **(Dis)connected:**

**How unseen links are putting us at risk**

2019 Report on Heart, Stroke and Vascular Cognitive Impairment





Cover photo: Cheryl MacKenzie, stroke and heart attack survivor  
Photo credit: Michelle Doucette

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# Introduction

The heart, brain and mind are inextricably connected. They work together and are dependent on each other; if something happens to one, the others are affected.

A new in-depth analysis, conducted by Heart & Stroke, of the interconnections between our hearts, our brains and our minds has revealed that the relationship is much stronger and more complex than previously thought, and the impact of the connections on the already overloaded health system — and on people's lives — is profound. The analysis uncovered gaps in the health system that have resulted in delays in diagnosis and secondary prevention, leading to unnecessary suffering in thousands of people in Canada. There is great opportunity to better coordinate care and improve outcomes for people living with our diseases.

The new knowledge is raising the stakes on the risks and impacts of these conditions for all people in Canada.

“The heart, brain and mind are at the core of everything, including our health,” says Yves Savoie, CEO, Heart & Stroke. “We mapped the connections between heart, brain and mind diseases and conditions for the first time and found even stronger links and a much greater impact than anticipated. People managing these conditions are overwhelmed and the system is overloaded. This is a crisis and it is not sustainable. We need to find solutions now.”

Heart & Stroke is continuing its support of people living with heart, brain and mind conditions. It is also sharing its research, raising awareness and calling out for health system leaders to work together to improve integration and coordination of care and save lives.

Heart, brain and mind diseases and conditions share many things: they are physically connected, and they have many of the same risk factors. Further, the impact of the connection is often cumulative: If you prevent one condition, you can prevent many others. Unfortunately, at the same time, if you develop one condition, you are at significantly higher risk of developing others. With nine in 10 people in Canada having at least one risk factor for heart conditions, stroke or vascular cognitive impairment, the impact is even further amplified.

And yet the health system that manages heart, brain and mind conditions can be disjointed. Each specialty focuses on specific parts of the body and on specific conditions. Addressing multiple needs requires additional referrals, dialogue and collaboration between specialties. Wait lists and increasing demands for specialty services create hardships for patients and their families who experience the human costs. For many, this means serious illness and early death that might have been prevented if access to all needed services were more readily available.

## What we mean by mind

In this report, Heart & Stroke is using the term “mind” for the first time. By mind we refer to the ability to be aware, to think and to feel. The mind is affected by vascular cognitive impairment, which may be caused by tiny clots that block small vessels in the brain, resulting in a lack of oxygen and damage to brain cells. It consists of a range of cognitive impairments associated with cerebrovascular disease, including problems with attention, memory, language, and executive function (e.g., problem solving). The severity can range from mild problems with concentration and thinking, to more severe and widespread problems termed vascular dementia, causing difficulty performing even basic tasks such as getting dressed and bathing. While there are many other diseases and conditions that affect the brain and mind, Heart & Stroke's interest is in the areas of stroke and vascular cognitive impairment.

Patients can enter the healthcare system through many different points. Whichever way they come in, most share common needs for understanding and managing their underlying health risks and risk factors, for lifestyle change, for access to medications and tobacco control. This points to the pivotal role of family doctors and primary health teams, who provide referrals to more specialized care and who maintain the relationships that support a wholistic approach to patient well-being.

Even when they have a diagnosis, patients and their families must navigate a complicated network of health-related services, usually involving multiple providers to meet their often-increasing medical needs. They do this with little understanding of what should happen, what is available, what will happen next and where they need to go. This is a startling reality given that 2.6 million hospitalizations in Canada over the past decade involve people with at least one of these conditions.

We have made tremendous gains in increasing survival rates from heart conditions and stroke through improvements in diagnosis and treatment, and we have started to slow the progression of vascular cognitive impairment, of which dementia is the most severe form. But these gains are only half the story. As the population ages, and as more young people develop these conditions, we see an increasing number of people living with heart conditions, stroke or vascular cognitive impairment — often more than one — and having to cope with them for a longer period. Their growing numbers and complexity increase the need for medical, rehabilitation and community-based health services.

Despite healthcare providers' best efforts, timely access to multiple specialty and supportive care services remains elusive. The higher demand created by the growing number of people with these conditions and their increased complexity outweighs the current capacity of our healthcare system, a system that was designed to manage individual conditions and risk factors. The fragmented system creates a significant time and financial burden for patients and families, and results in increased stress and frustration, decreased quality of life and poorer outcomes.



“I was lucky once my diagnosis finally came; I had surgery within three months. But the follow-up did not go well,” says **Caroline Lavallée**, who had surgery for supraventricular tachycardia, a heart rhythm disorder. “I was released from hospital and did not know what to expect. Yet I consider myself lucky compared with others. I can’t imagine the psychological distress that some people must feel — not only the patients but also their families. They don’t know what to do, what’s happening, what’s coming or how to support their family member.”

# 1. The big picture

**This report explores the many connections among heart diseases and conditions, stroke and vascular cognitive impairment, and the challenges faced by people who experience one or more of these. The challenges occur from the onset of conditions through diagnosis, treatments, prevention of further damage, rehabilitation and ongoing self-management of these conditions in their community and facing end-of-life.**

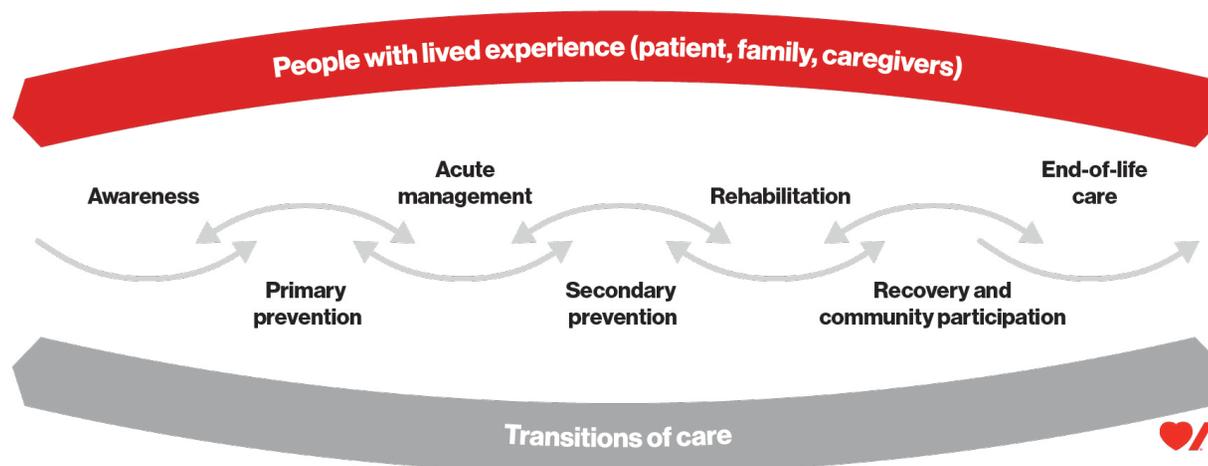
For the first time, the connections between a broad set of heart, brain and mind conditions have been systematically mapped, revealing their complex interconnectivity and the real magnitude of this crisis in Canada. By examining available data and published studies through the lens of interconnection, we found many strong associations between these conditions, the challenges and impact on the people experiencing them and their families, and how the health system supports them through their journeys from recognition and diagnosis to prevention of further damage, treatment and longer-term recovery and management. Some notable differences between men and women surfaced.

As we advance our understanding of the connections between the heart, brain and mind, most people are unaware of these connections, and the extent of their impact is only starting to become clear:

- **91,524 people** in Canada died of heart conditions, stroke or vascular cognitive impairment in 2016. This equates to one out of every three deaths.
- **One person dies** in Canada every five minutes from heart conditions, stroke or vascular cognitive impairment.
- **40% of people** admitted to hospital with a heart condition, stroke or vascular cognitive impairment will be readmitted at least once more for another similar event or a different heart, brain or mind condition.
- There is a **negative impact** on health outcomes for people with multiple conditions, including decreased quality of life and increased mortality.
- People with more than one of these conditions are up to **eight times more likely to die** in hospital compared to those with only one condition.

## The continuum of care:

Stages that may be experienced by people living with one or more heart, brain or mind conditions.



## Heat map of associations between heart conditions, stroke and vascular cognitive impairment

Review along the horizontal rows to understand the strength of the associated risk of each condition on the left to all other conditions listed across the top columns.

Strength of Association: ● No Known Association ● Weak ● Moderate ● Strong

		POSSIBLE ASSOCIATIONS								
Read across rows		Atrial Fibrillation	Heart Failure	Stroke	Vascular Cognitive Impairment	Congenital Heart Disease	Heart Valve Disease	Myocardial Infarction (Heart Attack)	Coronary Artery & Vascular Disease	Cardiac Arrest
CONDITIONS	Atrial Fibrillation		Strong	Strong	Moderate		Weak	Weak	Moderate	Moderate
	Heart Failure	Strong		Strong	Strong		Strong	Moderate	No Known Association	Strong
	Stroke	No Known Association	No Known Association		Strong		No Known Association	Weak	Strong	No Known Association
	Vascular Cognitive Impairment	No Known Association	No Known Association	Moderate			No Known Association	No Known Association	No Known Association	No Known Association
	Congenital Heart Disease	Strong	Weak	Strong	Strong		Weak	Strong	Weak	Strong
	Heart Valve Disease	Strong	Moderate	Moderate	Weak			Weak	Strong	Weak
	Myocardial Infarction (Heart Attack)	Strong	Moderate	Strong	Moderate		Weak		No Known Association	Moderate
	Coronary Artery & Vascular Disease	Weak	Moderate	Weak	Strong		Moderate	Strong		Strong
	Cardiac Arrest	No Known Association	No Known Association	No Known Association	Moderate		No Known Association	No Known Association	No Known Association	



## 2. Mapping the heart, brain and mind connections

**The heart, brain and mind are connected by the vascular system, but not the healthcare system.**

The links between heart conditions, stroke and vascular cognitive impairment occur at the basic physiological level and they share common risk factors. This gives us insights into how we should approach prevention, diagnosis, treatment and management, as well as the ongoing needs of those who experience these conditions. The connections are multidimensional and complex and not yet well understood.

Sarah Lansdown had her first stroke at her desk at work. It took a second stroke before the cause was identified; it turned out to be a relatively common congenital heart defect that rarely causes stroke. See her story at right.

The brain is the control system for the whole body. When there is stress on this system, the heart can be negatively affected. The heart is the muscle that pumps blood with oxygen and other essential nutrients throughout the body — including to the brain. When it does not function properly, the brain is at risk. The heart and brain are connected by the vascular system — the blood vessels that carry the blood throughout the body. When there is a decrease in blood flow or oxygen, everything is negatively affected — the heart, the brain and the mind.

“Interruptions in blood flow to either the brain or heart can have dire consequences. They are co-dependent ... for life,” says Dr. David Hogan, a professor of medicine who specializes in geriatric medicine in Alberta.



“They found a PFO (patent foramen ovale) — a hole in my heart — and it was repaired,” says **Sarah Lansdown**, who had two strokes before this cause was identified. “I was

told I would not have any cognitive issues because of the two strokes. But I find that I cannot multitask the way I used to. My job as an executive assistant requires memory and organization and I struggle more now with both. Also, my speech sounds fine to most people, but I find that sometimes I misconjugate verbs in conversation and know it right away and cringe. My balance is still an issue.”

# 3. Five conditions examined

There are many heart, brain and mind conditions and risk factors. This report focuses on conditions where the connections are the strongest or least understood, and where there is new information to report.\*

## In this report we examine the interconnections between:

- Heart failure
- Heart rhythm disorders including atrial fibrillation (Afib)
- Stroke including ischemic and hemorrhagic stroke and transient ischemic attacks (TIAs)
- Structural heart disease including heart valve disease and congenital heart disease
- Vascular cognitive impairment (VCI) — including dementia as its severest form.

## Definitions

- Heart failure refers to the heart being unable to pump adequately to meet the needs of the body.
- Heart rhythm disorders refers to fast, slow, or irregular heart rhythms due to disruption of the normal electrical impulses of the heart.
- Structural heart disease refers to defects in the heart valves, major heart vessels, heart walls or chambers.
- A stroke happens when blood stops flowing to a part of the brain or bleeding occurs in the brain, leading to damage to brain cells.
- Vascular cognitive impairment is an array of cognitive deficits, ranging from mild problems (e.g., attention deficits, forgetfulness, problem-solving difficulties) to more severe vascular dementia caused by a lack of oxygen to blood vessels in the brain.

\* The data presented in this report includes coronary artery and vascular disease (CAVD). However we are not highlighting CAVD in this chapter or in the hospitalization data (p. 15). Recent advances have led to a 9% decrease in hospitalization for CAVD over the past decade. Find more data on CAVD, plus all our target conditions and their interconnections, at [heartandstroke.ca/what-we-do/media-centre/report](http://heartandstroke.ca/what-we-do/media-centre/report).

## Heart failure

As people with damaged hearts are living longer, they become more susceptible to heart failure. More than 5,000 people die of heart failure each year. Of these, 23% more women die than men. Today heart failure is on the rise as more people in Canada survive heart attacks and other acute heart conditions. In fact, at least 600,000 people in Canada are living with heart failure and 50,000 new cases are diagnosed each year. This puts heart failure in a new light; no longer the end of life, it is now seen as a risk factor for other conditions.

## Connections by the numbers:

- People with heart failure have triple the risk of stroke.
- Women with heart failure have a six-times increased risk of Afib — a 25% higher risk than men.
- People with heart failure are complex, with 45% managing five or more other health conditions.

“Heart failure is a complex and challenging condition. Patient engagement is crucial in order to achieve the best outcomes,” says Dr. Heather Ross, a professor of cardiology and heart failure specialist in Ontario. “Sometimes we may have unrealistic expectations of our patients, especially those with cognitive impairment. They have so many things to worry about when it comes to self-management that at times they can’t remember them all.”

## Heart rhythm disorders

Atrial fibrillation (Afib) is abnormal heart rhythm caused by irregular or fast beating of the upper chambers of the heart. It is the most frequently occurring heart rhythm disorder. One of its main complications is stroke. Generally, the risk of developing Afib increases with age and with other risk factors, such as high blood pressure. Afib is also associated with vascular cognitive impairment and many other heart conditions.

## Connections by the numbers

- People with Afib have 2.4 times the risk of stroke. This is higher in women than men.
- People with Afib have five times the risk of heart failure.

## Stroke

Stroke is on the rise. Ischemic stroke, caused by a blood clot, occurs in 85% of all stroke patients. A hemorrhagic stroke occurs in the remaining 15%, when a blood vessel ruptures, causing bleeding in the brain. A transient ischemic attack (TIA) — sometimes referred to as a mini-stroke — is caused by a small clot that briefly blocks an artery. More than 62,000 strokes occur in Canada each year and that number continues to rise, leaving more than 405,000 people in Canada living with the effects of stroke.

Women are disproportionately affected by stroke: 45% more women die of stroke than men in Canada, and because they live longer, more women are living with the effects of stroke.

### Connections by the numbers:

- 10% of people who have a stroke already have some vascular cognitive impairment.
- Another 10% will develop vascular cognitive impairment after their stroke.
- 30% of people who experience a second stroke are at risk of developing vascular cognitive impairment.
- Women with stroke related to Afib have worse outcomes than men.

## Structural heart disease

Structural heart disease includes heart valve disease and congenital heart disease.

Structural heart defects that occur later in life are referred to as acquired structural heart disease. These may include an abnormality of a heart valve that results in the valve becoming stiff and not opening properly (valvular stenosis) or a valve that does not close tightly and becomes leaky (valvular insufficiency or regurgitation). Between 2007 and 2017, there was a 68% increase in hospitalizations across all age groups for heart valve disease, according to Heart & Stroke's analysis of Canadian hospitalization data.

### Connections by the numbers:

- People with aortic valve disease have a 33% increased risk of stroke.
- Men with heart valve disease have double the risk of Afib; women with heart valve disease have triple the risk of Afib.
- People with heart valve disease have a 20% increased risk of heart failure and this risk increases over time.

- 30% of people with heart valve disease return to hospital for Afib.
- The number of people who die in hospital within 90 days is 3 times higher for those with heart valve disease and Afib in comparison to heart valve disease alone.
- One-third of people with heart valve disease were previously in hospital for heart failure.
- The number of people who die in hospital within 90 days is 7.6 times higher for those with heart valve disease and heart failure in comparison to heart valve disease alone.

## Congenital heart disease – A lifelong challenge

Congenital heart disease is a condition that people are born with. About one in 100 children in Canada are born with a congenital heart defect, putting them at risk for many other heart, brain and cognitive conditions. This is the most common congenital anomaly among newborns.

Successful treatment of congenital heart conditions has resulted in more adults living with the disease. In fact, two-thirds of the estimated 257,000 people in Canada living with congenital heart disease are adults. This is a new and complex problem that urgently needs study, so healthcare professionals can provide specialized care for these adults living with congenital heart defects across their lifespan.

### Connections by the numbers:

- People with congenital heart problems (including children) have 10 times the risk of stroke; one in 11 men and one in 15 women with adult congenital heart disease experience a stroke.
- People with congenital heart disease have a 20% increased risk of heart failure.
- People with congenital heart disease have a 60% increased risk of vascular cognitive impairment.

## Vascular cognitive impairment

All roads can lead to dementia.

The overlap between stroke and vascular cognitive impairment is not surprising given both are conditions of the brain. Vascular cognitive impairment is often a further result of stroke damage, from either one or more larger strokes or many smaller ones accumulating over time. Surprisingly, this link goes both ways — people with vascular cognitive impairment are at increased risk of stroke.

Now, strong evidence is emerging around the link between heart function and cognitive function. When the heart is not functioning properly it can cause decreased blood flow to the brain. For example, conditions such as atrial fibrillation and heart failure put people at significantly increased risk for not just stroke, but also for premature cognitive decline.

“Healthcare efforts to better manage vascular risk factors such as hypertension, high cholesterol and diabetes, are paying off by delaying onset of heart disease and stroke,” says Dr. Sandra Black, professor of neurology and director of the Hurvitz Brain Sciences Research Program in Ontario. “As the population continues to age, we will see more people developing heart and brain conditions, all of which can eventually lead to vascular cognitive impairment. In its most severe form, it is called dementia, and results in a person becoming dependent on others for activities of daily living.”



All roads  
can lead to  
**dementia.**

### Connections by the numbers:

- People with vascular cognitive impairment have up to a 68% increased risk of fatal stroke.
- People with stroke are 2.2 times more likely to experience vascular cognitive impairment.
- People with heart failure are 2.6 times more likely to experience cognitive impairment.

- People with atrial fibrillation are 1.4 times more likely to experience vascular cognitive impairment.
- People with heart valve disease have a 25% increased risk of vascular cognitive impairment.
- Congenital heart disease may triple the risk of early onset vascular cognitive impairment (under age 65) and increase the risk of late onset vascular cognitive impairment by 30%.

## Action required

“There is a critical need for better understanding of the complex heart-brain-mind connections. This will inform our approaches to prevention as well as streamline more integrated health system design and delivery,” says Anne Simard, Chief Mission and Research Officer, Heart & Stroke. “Ultimately we want fewer people to be diagnosed with these conditions. For those who do experience them, we hope they can use their energy to focus more on their own recovery and experience a better quality of life rather than having to navigate a fragmented health system.”

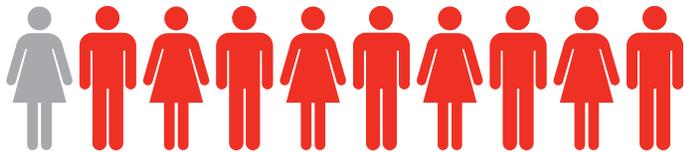
# 4. Prevention is critical

## There is a greater need for prevention measures than ever before.

This needs to start at the national level, with policies that enable healthy environments and help people in Canada make healthy choices. Examples include strong legislation to restrict marketing of unhealthy food and beverages to children, mandatory front-of-package nutrition labelling and measures that address inequities and reduce barriers to health for those most vulnerable or at risk.

Prevention — the adoption of healthy lifestyle changes — at the individual level is also critical. This report demonstrates that healthy choices do not just benefit the heart or the brain or the mind — they benefit all three and more. For example, daily exercise, even just a brisk walk for at least 10 minutes, will help the heart and increase blood flow to the brain, reducing the risks for heart conditions, stroke and dementia.

And yet, prevention has traditionally been a struggle in Canada. Healthcare professionals are discouraged because they know their coaching isn't working as well as they would hope. Many people in Canada have tried to change their habits, such as drinking less, quitting smoking, losing weight and exercising regularly. Some simply don't understand how to change or why it is important. All too often their good intentions fade and old habits return.



**90%** of people in Canada have at least **one risk factor** for heart conditions, stroke or vascular cognitive impairment.

We know from our public opinion research that people in Canada understand some of the risks for heart conditions, stroke and cognitive impairment, but overall awareness is low. According to a poll commissioned by Heart & Stroke, less than half of Canadians were very aware of their specific risk factors. The most recognized risk is poor diet at 41%, followed by smoking at 28% and lack of exercise at 27%. Only 10% of Canadians recognize high blood pressure as a risk, even though it is one of the most significant risk factors for these conditions.

The challenge now is to use our new knowledge about heart, brain and mind connections to motivate people in Canada — particularly those who have already had one condition diagnosed. Surprisingly, our polling revealed that only 38% of Canadians said they would be more motivated to make lifestyle changes even if those changes would have multiple health benefits and not just reduce the risk of one condition.

With the benefits increasingly clear, there is an urgent call to act. Primary care teams, who have the ongoing relationship with individuals and families before and after a condition emerges, are pivotal to supporting action. This includes educating and supporting patients and families, coordinating access to appropriate specialty services and managing all aspects of health for optimal quality of life.

Supporting behaviour change will be an area of research for Heart & Stroke in the coming years. Currently, we are evaluating a pilot program in Ontario, called *Activate*, that engages people who are at risk of high blood pressure and provides them with personal coaching. If the approach is successful, it may provide a model for future programs.

## Risk factors and the need for prevention

Heart conditions, stroke and vascular cognitive impairment have many risk factors in common, although their importance can vary with each condition. Each condition has some specific risks, and men and women can face unique risks, as can certain groups in Canada including Indigenous people and people of African, Asian or South Asian descent. In addition, once a person experiences a heart condition, stroke or vascular cognitive impairment, it too becomes an additional risk factor for other heart and brain conditions.

Having multiple risk factors often leads to worse outcomes including increased mortality when they co-exist with a heart condition, stroke or vascular cognitive impairment. Notable lifestyle risk factors include waist-hip ratio, physical inactivity, unhealthy diet, and smoking. Only 15% of people in Canada get the recommended



amount of physical activity. Among those who smoke — an estimated 18% of the population — there is a 25% greater risk for coronary heart disease in female smokers compared with male smokers, and it is more likely they will die as a result.

“We know what the common risk factors are and what needs to be done. Millions of deaths and much disability could be averted over the next decade if what is already known is applied,” says Dr. Vladimir Hachinski, a neurologist and expert in stroke and dementia in Ontario.

People with heart conditions, stroke and vascular cognitive impairment often have more than one risk factor. Managing multiple risk factors becomes a balancing act for healthcare providers — to ensure that all risk factors are optimally managed, and treatments complement one another.

Hypertension (high blood pressure), diabetes, and atrial fibrillation are common medical risk factors for heart, brain and mind conditions. In fact, according to Heart & Stroke’s analysis of Canadian hospitalization data from 2007 to 2017, more than

half of individuals with a diagnosis of a heart condition, stroke, or vascular cognitive impairment also have hypertension. More than one-quarter also have diabetes. Afib is present in 15% of these admissions. These risk factors are on the rise in Canada according to Statistics Canada. First Nations, Métis and Inuit people are more likely to have high blood pressure and diabetes than the general population.

Patients and their families experiencing multiple health issues must engage with several specialists, an increased number of medical appointments and multiple medications. They often report feeling very overwhelmed.

“Our heart and brain have a remarkable ability to compensate. These vital organs will often work harder to adjust for the effects caused by a disease in the short term. But over time the compensation can add stress to our body and cause irreversible structural damage. Primary, secondary and tertiary prevention are essential to avoid the development of long lasting damage,” says Dr. Cindy Yip, Director of Data, Knowledge Management and Heart, Heart & Stroke.

# 5. Challenges for the health system

Three in five people in Canada or someone close to them has faced at least one heart, brain or mind condition.

One person dies in Canada every five minutes from heart disease, stroke or vascular cognitive impairment. This outpaces other diseases; 13% more people die of heart-, brain- and mind-related conditions than die from all cancers combined.

Heart conditions, stroke and vascular cognitive impairment account for 270,204 hospitalizations in Canada in 2016-17. Seventy per cent of patients will be discharged home from inpatient care and may rely on community services to support them.

Significantly, 40% of patients — two out of five — experience more than one heart, stroke and/or vascular cognitive impairment event requiring rehospitalization. And hospitalizations for these conditions are increasing. The greatest increases over the past decade were for structural heart disease (50%), vascular cognitive impairment-related conditions (35%) and heart failure (25%). (See graph on p. 15.)

About 7% of people experiencing these conditions will spend time in inpatient rehabilitation where they receive intensive services to help them recover more function. Of these, 26% will not be able to return home to live, due to complex health needs associated with multiple risk factors for heart, stroke or cognitive conditions. Many others will receive outpatient rehabilitation as appropriate to their condition.



In Canada, **one person dies every 5 minutes** from heart conditions, stroke or vascular cognitive impairment.

People who survive must adjust their lifestyles and establish a “new normal.” Fear, anxiety, depression and generally being overwhelmed are magnified while they are still dealing with healing and trying to overcome fatigue. They also face ongoing medical, psychological, emotional, social and spiritual needs. People with these conditions and their caregivers are at higher risk of emotional and mental health issues.

“Surviving a heart attack is emotionally traumatic. Managing guilt, uncertainty, and anxiety about the future can be overwhelming,” says Alex Smith, who had a heart attack at age 33.

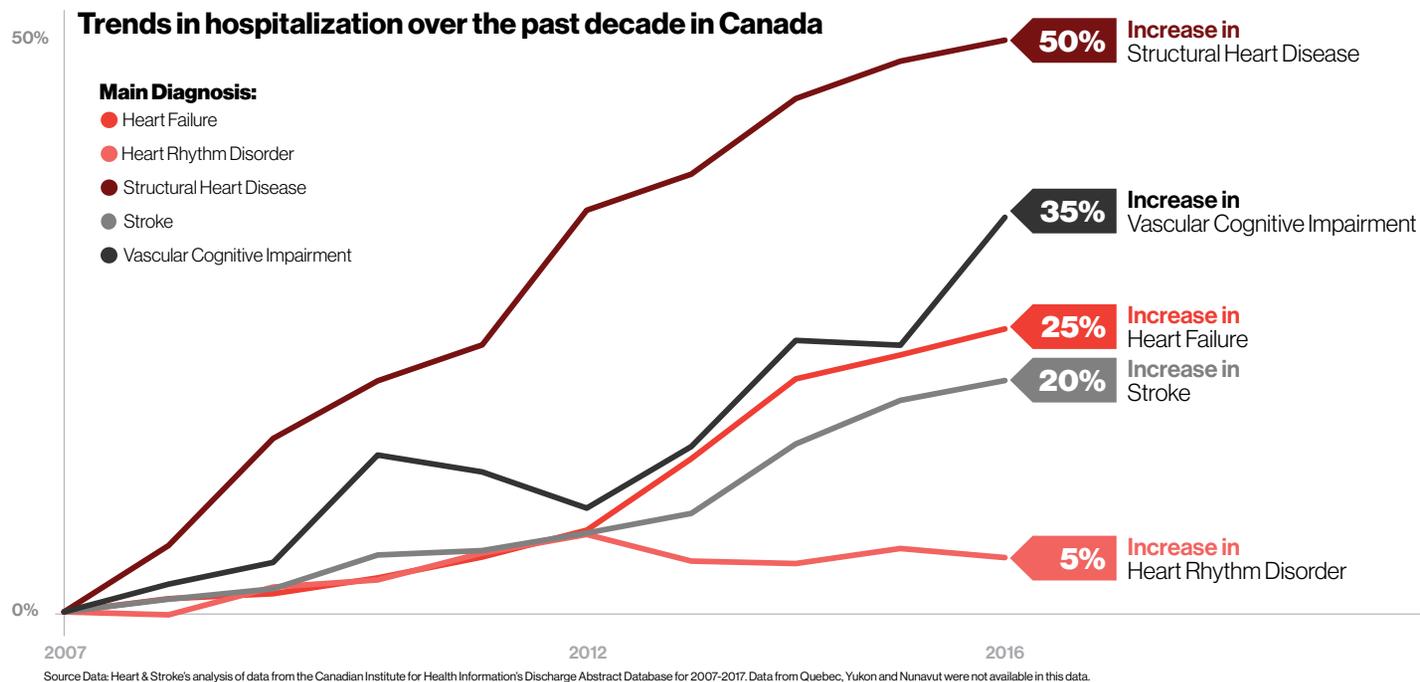
The burden of heart conditions, stroke and vascular cognitive impairment on the healthcare system is immense. Cardiovascular disease alone is the most costly disease in Canada, totaling \$21.2 billion in direct (medical) and indirect (lost earnings) costs. Stroke costs the Canadian economy \$3.6 billion a year in physician services, hospital costs, lost wages and decreased productivity. In addition, the combined direct and indirect costs of dementia total \$33 billion a year. If nothing changes, this number will climb to \$293 billion a year by 2040.

The more heart-, brain- and mind-related conditions people have, the more care they need and the more they utilize health services, driving costs even higher. At present, we can only estimate the collective costs, but all indications suggest these are substantial. As we begin a deeper exploration of the heart-brain-mind connection, understanding the health solutions to prevent connections from leading to medical emergencies will be an imperative.

## Perplexing age impacts

People are living longer with heart-, brain- and mind-related conditions. The population is also aging; seniors in Canada are a rapidly growing segment. According to the 2016 census more than six million people in Canada were aged 65 or older (16% of the population); this number is projected to grow to over 9.5 million by 2030 (23% of the population). This means a growing number of people will be affected by these conditions. Women, who continue to outlive men, will be even more disproportionately affected.

Surprising and more worrisome is that these conditions are also manifesting at an earlier age, with a growing number of people in their 30s, 40s and 50s experiencing them prematurely. This is partly due to risks such as low physical activity, poor



diets and higher stress. In addition, medical risk factors are also appearing earlier: hypertension, diabetes, and atrial fibrillation. With earlier onset, and knowing that these conditions are interconnected, the magnitude of the impact is exponential. People are having to self-manage the conditions for more years of their lives.

“At 39, you’re not prepared for a heart attack,” says Annie Richard, who is living with a heart condition called vasospastic angina. “Unfortunately, heart disease can strike anyone, anytime. I cried a lot, but now it’s behind me. The illness was an opportunity to take stock of my life.”

Together our aging population and the increase in younger age of onset of our conditions demand urgent action for prevention before risk factors even manifest, or before they lead to heart, brain and mind dysfunction.

### Everything not being equal

While the cost of these conditions to the healthcare system is enormous, the burden on individuals and families is daunting, with some more heavily impacted than others.

Social determinants of health such as poverty, lack of education, lack of access to affordable food and safe drinking water and unsafe living conditions have created a widening health gap and further contribute to heart, brain and mind health risks. Once risk factors or conditions do appear, people in remote and isolated communities face additional challenges accessing basic treatments and recovery support, leading to potentially worse outcomes. Access to specialist care close to home is even more of a challenge. These are issues disproportionately faced by Indigenous communities.

# Women deserve an equal chance

Heart & Stroke published reports on heart disease and stroke in 2018 demonstrating that women in Canada are under-researched, under-diagnosed, under-treated, under-supported during recovery and under-aware of their risks.

In this report, where we expanded our examination to focus on additional conditions of the heart, brain (stroke) and mind (vascular cognitive impairment), we again discovered notable differences between men and women, showing that women are at even greater risk than we previously knew. This reinforces the inequities highlighted in 2018 and strengthens our resolve to reduce the impact of all heart, brain and mind conditions on women's lives.

- Women with heart failure have a six-times increased risk of atrial fibrillation (Afib) — a 25% higher risk than men.
- Women are disproportionately affected by stroke: 45% more women die of stroke than men in Canada, and because they live longer, more women live with the effects of stroke.
- Women with heart valve disease have a three-times increased risk of Afib (50% higher risk than men).
- In 2016, 12% more women than men died of heart conditions, stroke or vascular cognitive impairment.
- In 2016, twice as many women than men died of causes related to vascular cognitive impairment.

Heart & Stroke is working to ensure women in Canada have the knowledge to recognize and reduce their risks and advocate for the care they deserve. We are investing in research that addresses sex/gender inequities to close the research gap so that we can better understand why heart conditions, stroke and vascular cognitive impairment affect women disproportionately. And, we are calling on all people within the health system — researchers, funders, healthcare workers, system leaders, governments, organizations like Heart & Stroke, and the community — to band together to level the playing field so all women in Canada have an equal chance to survive and recover.



“Women need to take health into their own hands. In this day and age, there shouldn't be different treatment for men and women. Women need to be strong. If you get dismissed, you need to go back to the hospital or back to the doctor. If you have family history, get checked and if you have an event, go to rehabilitation,” says **Cheryl MacKenzie**, who had a first mild stroke at age 22, a second at 37 and a heart attack at 48.

# 6. Complicated by complexity

Heart & Stroke's analysis of Canadian hospital admission data confirms that many people experience more than one condition or risk factor associated with heart conditions, stroke and vascular cognitive impairment, complicating their treatment, care and recovery.

## Connections by the numbers:

- Of all people admitted to hospital for heart conditions, stroke or vascular cognitive impairment, up to 40% were readmitted at least one other time for another similar event (such as another stroke) or for a new heart- or brain-related condition (such as someone who has heart valve disease subsequently admitted for heart failure).
- One person in five will have two hospital admissions for new heart- or stroke-related conditions and another one in five will have three or more admissions for new heart- or stroke-related conditions.
- More than half of patients admitted to hospital with vascular cognitive impairment have more than one other heart- or brain-related condition.

Multimorbidity — having more than one condition — has been estimated to affect up to 95% of people aged 65 and older who access primary care. Women appear to be at even higher risk of having multiple conditions compared with men — as much as 50% higher, partly because they live longer.

Despite this reality, much of the health system is set up to deal with individual conditions, and multimorbidity places further stress on that system, as well as those people experiencing them. Even with one condition, moving through the system from diagnosis to treatment and care can involve multiple points of entry and different providers. But for patients with multiple conditions, the siloed approach to care is particularly challenging. This fragmented and less efficient approach can be frustrating and at times overwhelming for patients and family members, and places heavy demands on primary care providers to coordinate care in a complex system.

Complexity and multimorbidity negatively affect outcomes. Heart & Stroke's analysis of Canadian hospitalization data found that people with multiple conditions are more likely to die in hospital. Further, despite added complexity, a significant number of people with multiple conditions are discharged home from hospital without referrals or support for homecare services.

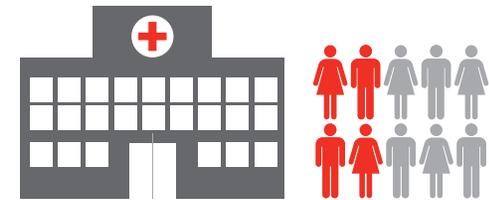
One study revealed that approximately 80% of people who survive a stroke have on average five other conditions and a wide range of psychosocial issues. Stroke rehabilitation studies have found that multiple conditions increase

rates of complications, lead to longer hospital stays, and negatively affect patient outcomes. These factors result in higher costs and reduced efficiency of rehabilitation.

Another study of patients with multiple conditions revealed their caregivers are frustrated with poor communication between care providers, a lack of care coordination and long wait times. Patients were challenged with managing multiple conditions and symptoms, and adherence to treatment recommendations.

As noted above, the onset of these diseases is happening earlier, adding to the complexity of care over a longer lifespan. This leaves millions of people having to self-manage chronic conditions for more years in their lives. We have observed a notable increase in hospital admissions with a diagnosis of heart conditions, stroke or vascular cognitive impairment for people under 30 years old in the past decade. The most affected age group is between 30 and 39 years old, with a 35% increase for ischemic stroke, 68% increase for vascular disease, 52% increase for heart failure, and 31% increase for heart valve disease.

“All the heart, brain and mind conditions require adherence to health behaviours to best manage them, such as making changes to diet, increasing physical activity or restricting fluids,” says Dr. Adrienne Kovacs, a clinical psychologist who works with people who have congenital heart disease. “Other examples include coordinating multiple medical appointments and following instructions for taking medications. Effective recovery requires people to problem solve, to plan, to make decisions. Navigating the health system is really challenging when they are at a physical and or cognitive disadvantage.”



**40%** of people who were **discharged** following a heart, stroke or cognitive condition were **re-admitted to hospital** with a **second** related event or condition.

# 7. Lost in transition

Our health system — what is really many different systems within a larger system — was designed to manage people with individual conditions. For example, there are hospitals that specialize in heart conditions or stroke. There are centres with concentrated expertise in vascular cognitive impairment, and clinics for heart failure, stroke prevention, and adult congenital heart disease. These experts play an important role in ensuring each condition is managed appropriately. Primary health teams are often expected to serve as the integrator for patients and families.

“Even with one condition, patients can have a confusing and frustrating experience. They still must transition between different services and specialists as they try to get diagnosed and treated, and move through recovery, much of which takes place outside hospital walls,” says Dr. Patrice Lindsay, Director of Systems Change and Stroke, Heart & Stroke. “People with less knowledge of the system or who have fewer resources and support are at even greater disadvantage. Further, language and cultural barriers can add additional layers of challenges as people try to reset their lives and recover.”

## Access always a challenge

The challenges not only exist in access to care and rehabilitation that individuals require to achieve their recovery goals. Many people in Canada also face challenges accessing necessary medications, regardless of their insurance coverage. In fact, more than one in five people without insurance has difficulty paying for prescription medications; even one in 10 people with coverage has difficulty.

“You have to be your own advocate 100%. If I didn’t have money, resources, education, language skills and a strong will, I would not have gone anywhere. I worry about others not having the support and resources they need,” says Sarah Lansdown, who had two strokes and had to advocate for herself throughout her diagnosis, treatment and recovery.

Heart & Stroke manages [online peer support communities](#) and an e-registry that includes people with heart conditions, stroke and vascular cognitive impairments and their caregivers. An analysis of their online discussions, as well as responses to an email questionnaire, highlighted how common these themes are related to their collective experiences.

## Adjusting to a new normal

People with lived experience voiced the realities of dealing with life “after” their diagnosis or event: the need to reduce isolation, maintain relationships and strive



to return to work; the challenge of making lifestyle changes and embracing a “new normal;” side effects from medication; and the frustration of not being taken seriously by healthcare professionals. Mental health issues such as anxiety, fatigue and depression were also frequently noted. People who experienced both heart conditions and stroke identified delays in diagnosis and treatment, and feelings of stress, frustration and grief.

“When I went from one cardiologist or hospital to another, they did not talk to each other, so I’m the one who had to ask for and pay for my dossier. I had to tell my story over and over again every time there was a new person,” says Caroline Lavallée, who had symptoms of supraventricular tachycardia, a heart rhythm problem, for five years before she was finally diagnosed.

For patients and healthcare providers caring for them, access to electronic health records is imperative. Everyone within the circle of care, regardless of entry point, should have the same information available, improving continuity and quality of care.

The impact of these conditions extends to family members. Caregivers can face isolation, stress and lack of support, as well as advocacy fatigue.

"I couldn't get out of the house, to exercise, run errands, I couldn't even go grocery shopping," says Barbara Toohey, caregiver to her husband Jim, age 65. He was discharged from the hospital after a stroke with little information about what they should expect. "We had to wait for an appointment with the case manager for six weeks after we got home. I had no idea of the help I would eventually get. Was this my life, my future? I was feeling desperate, anxious and hopeless," Barbara says. Jim had also previously experienced a blood disorder and high blood pressure.

People in Canada understand that these conditions can significantly impact those who experience them. In fact, 86% of respondents to our poll believe that people who survive continue to be impacted in their day-to-day lives. Specific challenges cited by poll respondents who have experienced these conditions include mobility problems and not being able to get around on their own, getting access to the medical care they need, losing their independence, changes in lifestyle and eating habits, and the impact on their families.

### **A difficult system despite caring providers**

Healthcare providers themselves spend many additional hours helping patients make their way through the system and through each step: initial assessment to diagnosis, treatment and care, and continued recovery. Unfortunately, they also operate within a system that is fragmented, and face the added demands of increasingly complex patients. Rapid access to services and specialists is not assured, wait lists grow longer and patient outcomes suffer, such as the success of a treatment or therapy, quality of life and stress levels.

According to our poll, only 38% of men and 32% of women stated they were confident that the healthcare system would be there for them completely if they experienced a heart condition, stroke or vascular cognitive impairment.

Dr. Leanne Casaubon, a stroke neurologist in Ontario, says the system is not yet optimized for either patients or healthcare professionals. Doctors, nurses and other healthcare professionals want to provide the best care but there are challenges in assisting patients through a complex journey. There are many tools and protocols to support stroke care; but when patients require more collaborative care with other disciplines, like cardiology, there are fewer established mechanisms to efficiently and effectively connect patients with these services. There is a large opportunity within the healthcare system to develop such connections to optimize care, patient experience, and clinical outcomes.

"We use the term navigation, but we could do better for both patients and providers to help them find their way," says Dr. Sharon Mulvagh, a cardiologist in Nova Scotia. "Patients need clearly defined expectations and direction around next steps — who is going to do what, what are they waiting for, what they might experience next, and they need to be provided with a record of this information. Doctors, nurses and other healthcare team members want to provide the best comprehensive, interdisciplinary care but it can be a real challenge to do so without adequate resources or communication."



"We use the term patient-centred care, but it is not how we deliver care," says **Dr. Mike Sharma**, a stroke neurologist in Ontario.

"We need a health record structure that follows the patient. Data is not always available at the point of care." Dr. Sharma agrees that the will is there to support patients, and many clinicians have tried to make improvements, but the structure is not always sufficient nor would it always be feasible.

# 8. Towards solutions and better outcomes

As we navigate through the crisis of managing people experiencing heart, brain and mind conditions, there are some shining examples of the way forward. New integrated and wholistic approaches that simplify access to care are emerging across Canada.

Dr. David Hogan, a specialist in geriatric medicine in Alberta, says his practice is defined by the age of his patients — not by whether they have a particular disease. As every patient is an individual, “It is important to consider the whole person. Their values and beliefs play a significant role in planning and decision-making about their health care. You need to treat the person with the disease, rather than just the disease a person might have.” The geriatrics model is one we can study.

A surprising result of more advanced and more specialized care — especially in bigger, densely populated centres — is that it can also become more divided. Rural and remote areas can be forced to provide more integrated vascular primary and secondary prevention services out of necessity, due to a lack of resources and space. But they can also serve as a valuable model for aligning services.

The Vascular Health Program in rural Renfrew County in Ontario combines clinics for cardiac arrest, heart function, stroke and diabetes management, providing an example worthy of study. “We recognized the overlap between risk factors for these conditions and at the same time we had to accommodate our limited resources, so we created a vascular clinic,” according to Dr. Debbie Timpson, a specialist in physical medicine and rehabilitation and the chief of rehabilitation at the Pembroke Regional Hospital.

Canada’s publicly funded health system provides universal coverage for medically necessary healthcare services, but according to experts, while acute care is critically important, it should not come at the cost of everything before and after it. “There are phases before the hospital and after the hospital. These bookends are important, but we spend the most on the little space between. For patients that is the shortest part of their journey,” says Sacha Arseneault, provincial director, Stroke Services BC.

The Cardiovascular Health and Stroke Strategic Clinical Network (CvHS SCN), was launched in Alberta in 2012. Recognizing the overlap between heart conditions and stroke, one of its core areas of focus is vascular risk reduction. Among its current priorities is a commitment to reducing inequities and improving the patient journey.

Balraj Mann, executive director of the CvHS SCN, explains that the success of the network is in great part due to its collaborative approach: “Our superpower is the ability to influence and bring people together. We leverage what we learn from one community and bring it to another to move innovation into practice across the system.”

For example, recognizing that people visit pharmacies much more often than they visit doctors, a screening and education project was set up in collaboration with pharmacists to screen for blood pressure, lipids and blood sugars. The result: a 21% reduction in cardiovascular risk, benefitting the heart, brain and mind.



“When I was living in Victoria but still seeing a heart failure team in Vancouver on an alternating basis, I insisted that my cardiologist in Victoria be part of any consultation that involved my case. So she would call in for those discussions. I advocated for that; with advanced heart failure it was important to keep everyone in the loop,” says **Jillianne Code**, who was diagnosed with heart failure at age 28. Now 42, she has had two heart transplants and volunteers with Heart & Stroke; Jillianne is co-founder and president of the HeartLife Foundation of Canada, a patient-led advocacy and support organization focused on heart failure.

# 9. Where do we go from here?

## Heart & Stroke's role

A key role for Heart & Stroke is to be a catalyst for change. We provide the new knowledge, data and energy that bring together diverse organizations and people to improve prevention and management of heart, brain and mind conditions and support people living with them. This work takes place within the health and public policy systems and at the individual level.

As advocates and supporters of people with lived experience, and as educators and influencers for systems change, we act where we can have impact, and serve as a catalyst where we cannot act alone — all with a sense of urgency — in order to reduce suffering and save lives.

## Influencing and supporting people:

- Raise public awareness of the complexity and connections associated with heart, brain and mind conditions to help people make informed decisions about their health.
- Provide guidance to patients and families to help them advocate for themselves when talking about heart, brain and mind connections with their healthcare professionals.
- Engage and support people with heart conditions, stroke and vascular cognitive impairment and their caregivers by:
  - Facilitating and improving health and recovery knowledge through effective online support (peer support)
  - Enabling and encouraging effective self-advocacy and self-management of chronic disease
  - Providing health information and supportive resources.

## Influencing governments:

- Advocate for policies that enable and support healthy environments and choices, such as:
  - Strong legislation to restrict unhealthy food and beverage marketing to kids
  - A revised Food Guide
  - Mandatory front-of-package nutrition labelling
  - Tobacco control policies
- Public policies that address inequities and reduce barriers to health for those most vulnerable or at risk.

- Advocate for a national, universal pharmacare program with equitable and timely access to proven and safe medically-necessary prescription drugs for all people in Canada regardless of domestic geography, socioeconomic status, age, ethnicity or sex/gender. Ensure public funders are the first payers.
- Invest in research around heart, brain and mind connections and ensure gender-based analysis and reporting.
- Raise awareness and understanding and work to address inequities in awareness, support, diagnosis, treatment and research around women's heart, brain and mind health.

## Influencing health systems, services and providers:

- Build awareness and understanding of the connections between the heart, brain and mind with health professionals, decision-makers, researchers, and educators:
  - Partner with key health professional bodies to influence curricula, education and clinical practice guidelines
  - Provide professional educational events that address these connections and solutions for improving integration and continuity of care
  - Integrate heart, brain and mind concepts and complexity into clinical practice guidelines.
- Work with provincial health authorities to plan systems of care that are evidence-based and informed by reliable data.



- Work with the research community to identify questions around heart, brain and mind connections to address gaps in understanding and data.
- Invest in research around heart, brain and mind connections and ensure gender-based analysis and reporting.
- Raise awareness and understanding and work to address inequities in awareness, support, diagnosis, treatment and research around women's heart, brain and mind health.

### What can health systems, services and providers do?

- Develop and follow a wholistic model of care.
- Facilitate more streamlined and supported patient and caregiver navigation through the health system and services.
- Talk to patients and families about prevention, risk factors, and signs for heart conditions, stroke and vascular cognitive impairment.
- Improve communications with patients, families and caregivers so they understand what to expect, where to go and what to do.
- Use common assessment tools, common language and electronic medical systems to facilitate communication between providers.
- Increase services and support for northern, rural and remote communities.
- Commit to equitable care for women, Indigenous people, and complex patients.

### What can individuals do?

- If you have any condition affecting your heart, brain or mind, make sure your doctor is checking for other signs of illness. You should be checked and followed for other conditions that might be developing.
  - Find tips to help you at [heartandstroke.ca](http://heartandstroke.ca).
- Recognize that prevention has never been more important. Healthy lifestyle choices, such as quitting smoking and increasing exercise, do not just help your heart or your brain or your mind — they help all three and more.
  - Find information on healthy lifestyle changes at [heartandstroke.ca/get-healthy](http://heartandstroke.ca/get-healthy).
- Share with your peers. Learn from other people who have had similar experiences to yours by joining our online Community of Survivors or our Care Supporters' Community at [heartandstroke.ca/connect](http://heartandstroke.ca/connect).
- Raise your voice. Partner with Heart & Stroke in advocacy initiatives or get involved in research. You'll find opportunities in our [Community Connect newsletter](#).

# 10. Data sources

- The poll with Canadians was conducted by Environics Research Group. A total of 2,850 respondents 18 years and older were interviewed by telephone between Oct. 29 and Nov. 15, 2018.
- Information in the report was identified through structured literature reviews of online medical research databases, up to December 2018, and through expert interviews with researchers and clinicians.
- Administrative data was obtained from the Canadian Institute for Health Information (CIHI) and analyzed by Heart & Stroke. Parts of this material are based on data and information provided by the Canadian Institute for Health Information for the years 2007-2008 to 2016-2017. However, the analyses, conclusions, opinions and statements expressed herein are those of the author and not those of the Canadian Institute for Health Information.
- Statistics Canada CANSIM tables 102-0529, 102-0525, 102-0526, 102-0527, for the years 2000 – 2016.
- Interviews were carried out with stroke experts, and people with lived experience. Heart & Stroke is greatly appreciative of their contributions.

# 11. Resources

Heart & Stroke provides resources to support individuals and their families, most of which are available at [heartandstroke.ca](http://heartandstroke.ca).

- **FAST signs of stroke** [heartandstroke.ca/fast](http://heartandstroke.ca/fast)
- **Signs of heart attack and cardiac arrest** [heartandstroke.ca/heartsigns](http://heartandstroke.ca/heartsigns)
- **Working with your doctor:** [Practical tips](#) to help you understand and manage your risk factors
- **Community of Survivors and Care Supporters Community:** Members-only Facebook groups for those living with heart disease or stroke, or caring for someone who is. [heartandstroke.ca/connect](http://heartandstroke.ca/connect)
- **Time to See Red:** Women are under-researched, under-diagnosed and over-dying. Learn more at [heartandstroke.ca/women](http://heartandstroke.ca/women).
- **Living with Heart Failure:** Resources to help you manage your heart failure ([PDF](#))
- **Living Well with Heart Disease:** A guide for people with coronary artery disease ([PDF](#))
- **Your Stroke Journey:** A guide for people living with stroke ([PDF](#))
- **Post Stroke Checklist:** A resource to help you and your care team manage your recovery ([PDF](#))
- **Stroke Best Practices:** This site for healthcare professionals includes resources for patients and families. [strokebestpractices.ca](http://strokebestpractices.ca)
- **Activate:** A free six-month wellness program in the Greater Toronto Area that helps you manage your blood pressure for a healthier life. [heartandstroke.ca/activate](http://heartandstroke.ca/activate)

# 12. Acknowledgements

## Experts and health professionals

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## People with lived experience

Cheryl Beattie, Kate Bell, Jillianne Code, Sarah Lansdown, Caroline Lavallée, Cheryl MacKenzie, Trish Pollock, Debra Ramage, Annie Richard, Alex Smith, Barbara Toohey



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Together, we're committed to saving women's lives by advancing women's heart and brain health in Canada.

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