2016 REPORT ON THE HEALTH OF CANADIANS



THE BURDEN OF HEART FAILURE

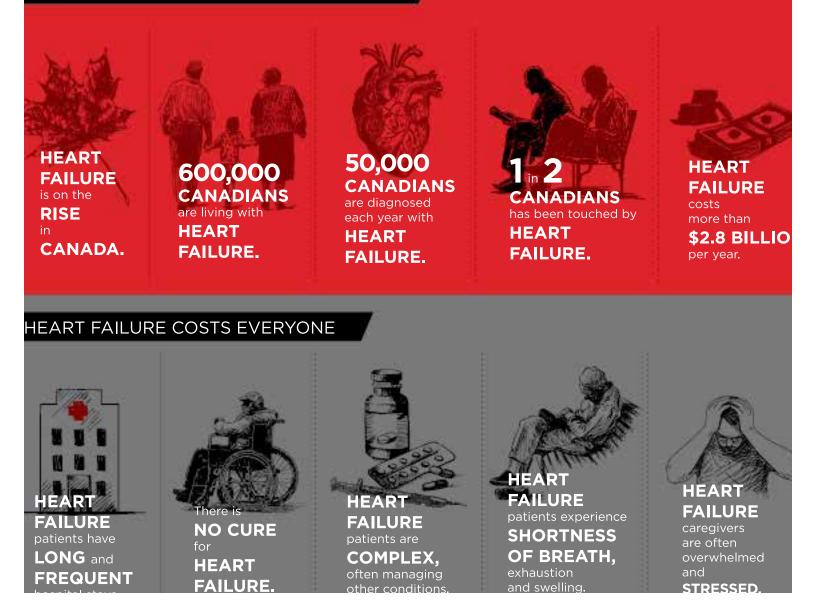
BURDEN OF HEART

FAILURE

Heart failure means the heart muscle is damaged or weakened, unable to pump blood efficiently. It is a significant health issue for hundreds of thousands of Canadians and their families, and its reach is expanding. It is often the last stop for Canadians who experience a journey through cardiovascular disease.

Because more Canadians are surviving cardiovascular disease, more are developing heart failure. With improved diagnostics and better medical management, heart failure patients are living longer with their damaged hearts but not without challenges.

HEART FAILURE IS A GROWING EPIDEMIC



CONFRONTING A GROWING EPIDEMIC

Heart failure is a growing — and all too silent — epidemic in Canada. It is a significant health issue for hundreds of thousands of Canadians and their families, and its reach is expanding. It is often the last stop for Canadians who experience a journey through cardiovascular disease. As Dr. Paul Fedak, a cardiac surgeon at the University of Calgary, explains, "Heart failure is the end result of all cardiac disease. You get heart failure from everything that goes wrong with your heart — all roads lead to heart failure."



This is a sobering thought considering that well over a million Canadians have heart disease and 50,000 new cases of heart failure are currently diagnosed each year.

More Canadians are living with cardiovascular disease, which means more of them are developing heart failure. With improved diagnostics and better medical management, heart failure patients are living longer with their damaged hearts.

The Heart and Stroke Foundation 2016 Report on the Health of Cana-

dians takes a critical look at the growing burden of heart failure in Canada, as well as innovative new research that points to hope for the future.

For this report we interviewed health professionals who work with heart failure patients, and, in partnership with the Canadian Cardiovascular Society, surveyed 69 heart failure experts across the country. We also polled Canadians to find out how they have been affected by heart failure, and how much they understand it, and we analyzed Canadian Institute for Health Information (CIHI) hospitalization data.

HOW TO EXPLAIN A FAILING HEART

Heart failure is often misunderstood by the public. According to our poll, more than one-quarter of Canadians believe that heart failure means your heart has completely stopped beating.

In fact, heart failure means that the heart muscle is not pumping blood as well as it should, resulting in the body not getting the amount of blood, oxygen, and nutrients it needs. Even when presented with the definition, one-fifth of the Canadians polled admitted they were not sure or did not know this is what heart failure is.

The heart is a two-sided pump. Heart failure can affect the right side of the heart that pumps "used" blood from the body to the lungs, where it gets replenished with oxygen. Just as easily, it can affect the left side of the heart that pumps "fresh" blood full of oxygen to the rest of the body.

There are two main types of heart failure. The heart can get large and floppy and the muscle becomes weak; or the heart muscle becomes stiff and cannot relax to fill with blood between beats. Both types of heart failure reduce the blood flow and oxygen to the body.

Heart failure symptoms include increased shortness of breath, sudden weight gain, bloating or feeling full all the time, cough or cold symptoms that last longer than a week, loss of or change in appetite, and swelling in the ankles, feet, legs, base of spine or stomach because of fluid retention. Symptoms become more pronounced as the condition advances.

WHAT CANADIANS KNOW ABOUT HEART FAILURE ACCORDING TO OUR POLL

- More than one-quarter believe that it means your heart has completely stopped beating.
- Even when presented with the definition, one-fifth admitted they were not sure or did not know what it is.
- Almost one-fifth mistakenly believe that it is a normal part of aging.
- Almost three-quarters know it is on the rise.
- Nine out of 10 know that heart failure can be managed and treated.
- Almost half mistakenly think that it can be cured.
- Fewer than three-quarters believe heart failure patients can lead a normal, full life.
- Almost half have been touched by it either diagnosed with it themselves or having a family member or close friend with the condition.



One of the most important things I learned is you can be a person with chronic illness and still be quite healthy and active. There is hope. There are places to go for support. You can rebuild your life.

Karen Nicole Smith

43, living with heart failure and kidney disease. **READ Karen's story.** Find this story and more at: blog.heartandstroke.ca/heartfailure

THE JOURNEY TO HEART FAILURE

Heart failure develops after the heart becomes damaged or weakened by heart disease, including heart attacks and other medical conditions. Our poll revealed that a significant number of Canadians — almost one-fifth believe that heart failure is a normal part of aging. It is not. Unfortunately heart failure usually goes hand in hand with heart diseases such as a heart attack or coronary artery disease.

"If you have significant heart disease, the longer you live with it, the greater the chances of developing heart failure over time," says Dr. Fedak.

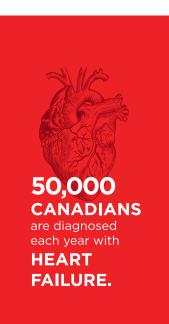
Heart failure has many causes or underlying risk factors. The most common is damage to the heart muscle caused by a heart attack and the second most common cause is high blood pressure.

Heart failure is not an event; it is a long-term chronic condition that usually gets worse over time. There is currently no cure. Many patients can improve with lifestyle changes — by reducing salt and improving their diet, becoming physically active and quitting smoking. There are also good medications and medical devices that can help manage the symptoms and improve quality of life.

"Many heart failure patients can do well, but the condition tends to go in waves," says Bonnie Catlin, heart failure clinical nurse specialist with Cardiac Services BC, an agency of the Provincial Health Services Authority, and BC's Heart Failure Network. "Patients will be doing well, then they deteriorate. You make changes to their medication, they rally and get better, then they deteriorate again. If a patient is on optimal medication therapy and meets other criteria they could be given the option

of having a device implanted to improve the pumping of their heart, but it gets to a point where the only option left is to offer the patient palliative or supportive care to ensure the best quality of life as they move closer to the end of their life."

Depending on the severity of symptoms, heart dysfunction, age and other factors, half of those diagnosed with heart failure will die within five years, and most die within 10 years.



DAMAGED HEARTS ARE A TAX BURDEN

Heart failure patients are no strangers to hospitals. They visit, they stay, and they come back.

"There is a huge economic cost associated with heart failure," says Dr. Justin Ezekowitz, director of the Heart Function Clinic at the University of Alberta. "The biggest driver of costs is hospitalization and emergency room visits."

It is estimated that heart failure results in direct costs of more than \$2.8 billion per year in Canada.



Hospital visits due to heart failure have gone up every year for the past several years, with 60,000 reported in 2013-2014 according to CIHI data. In fact, the relative increase over the past six years has been 13 per cent. There are currently 600, 000 Canadians living with heart failure, and these numbers are only expected to go up as the population ages and more people develop and live with cardiovascular disease. Hospitalizations - and associated costs - will grow accordingly, placing increased

burden on our healthcare system. Most Canadians know that heart failure is on the rise — almost three-quarters of those polled confirmed this troubling fact.

The condition has the regrettable distinction of being a leading cause of hospitalization. Leaving out childbirth, heart failure is the third most common reason for hospitalization according to CIHI – trailing only respiratory disease and heart attack, both of which are associated with heart failure.

Heart failure patients are usually complex, often managing other issues — referred to as comorbidities — such as kidney or lung complications, as well as mental health issues. This makes them "high touch" patients, meaning they need more time and care. They can require repeated and expensive diagnostic testing and multiple medications that need to be frequently adjusted.

If they are so sick that they become hospitalized, the average length of stay for heart failure patients is long at



It was a hard job taking care of my dad the sheer number of appointments and trying to coordinate care. There were different systems and different specialists. He fell a lot before he went into extended care and there were lots of ambulance calls.

Sue MacDonald

Caregiver for her father, who died at 76 from heart failure and multiple health issues. **READ Sue's story.** Find this story and more at: blog.heartandstroke.ca/heartfailure

HEART AND STROKE FOUNDATION RESOURCES FOR HEART FAILURE PATIENTS

The Heart and Stroke Foundation has adopted and adapted heart failure patient education resources developed by Cardiac Services BC and BC's Heart Failure Network. These resources ensure patients and caregivers have the knowledge to self-manage their heart failure. Topics include:

Understanding Heart Failure

Heart Failure Zones

Limiting Sodium When You Have Heart Failure

Limiting Fluids When You Have Heart Failure

Daily Weights

Why People with Heart Failure Should Keep "Active"

Why People with Heart Failure Should Exercise

These resources are available in English and French (printable PDF). Find them and more at heartandstroke.ca/heartfailure. eight days according to CIHI data. Advanced heart failure affects many, if not all, parts of the body and these need to be managed together. Patients often arrive at hospital overloaded with fluid and it takes time to "get them dry."

REPEAT CUSTOMERS

Heart failure is often referred to as a "revolving door condition," with high rates of hospital re-admission. Various sources estimate that one in every five heart failure patients find themselves back in the hospital within 30 days either for heart failure specifically (in about half of those cases) or for another related cause.

Repeat visits are a stress on the patients and on the healthcare system. Almost 60 per cent of the heart failure experts surveyed consider re-admission rates one of the biggest issues related to heart failure that needs to be addressed.

Managing a heart failure patient's health is a delicate balance. Along with comorbidities patients can face a host of challenges that land them back in hospital — challenges they are not able to manage effectively on their own.

Once the symptoms are under control, the majority of heart failure patients are discharged from hospital, and of these about four in five return to their homes or a home setting, according to CIHI data. Unfortunately of those who return home, only one in four have home care support services. Patients can have a difficult time controlling their fluid intake, reducing sodium, and managing their medications — which often require adjustments to get right, as well as keeping up lifestyle changes such as physical activity and eating a healthy diet.

According to Dr. Ezekowitz, while there are various reasons for re-admissions there are also strategies to reduce them. "Heart function clinic nurses are excellent and counsel patients, as do family doctors," says Dr. Ezekowitz. "Often small changes and telephone counselling can help them avoid being re-admitted."

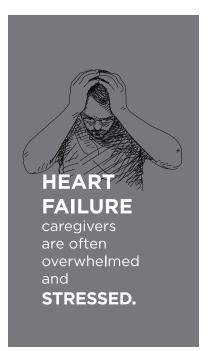
The Canadian Cardiovascular Society Heart Failure Management Guidelines state that heart failure patients should be seen by a care provider ideally within two to four weeks of being discharged from hospital as it is a particularly vulnerable time for complications and rehospitalization. Unfortunately this does not happen often enough. The heart failure experts point to the lack of continuity of care from the hospital to the community as a significant gap.

"The individual components of the system are not aligned. We are working in silos," says Dr. Sean Virani, provincial heart failure physician lead at Cardiac Services BC. "We need a strategy and a robust system to integrate these pieces. We need patients, providers and healthcare systems to work together in developing a path forward."

HEART FAILURE COSTS EVERYONE

Heart failure is a strain on Canadian families. According to our poll, almost half of Canadians have been touched by heart failure — either diagnosed with it themselves or having a family member or close friend with the condition.

The challenges facing heart failure patients and their caregivers can be overwhelming. "They face a huge psychological and physical burden. Depression



and anxiety are common for people with heart failure," says Bonnie Catlin. "Around 30 per cent of heart failure patients experience depression with wide ranging symptoms including feeling sad, sleeping too much or not enough, not eating enough and losing interest in activities they used to enjoy."

Many heart failure patients are frail and elderly. They cannot carry out daily living activities to the extent they used to; they're faced with multiple

appointments to attend and medications to manage. The complexity and amount of health information they receive can be overwhelming. They are often physically and emotionally exhausted.

For caregivers, the stress of supporting a loved one with a condition that is complex to manage and whose deterioration is difficult to predict can take its toll.

Patients and caregivers require support and education to manage the condition, slow its progression, and ensure the best quality of life possible. The heart failure experts surveyed identified a multitude of issues that need to be addressed, including better patient and health professional education, improving continuity of care and providing resources in the community.

THE TROUBLE WITH DIAGNOSIS

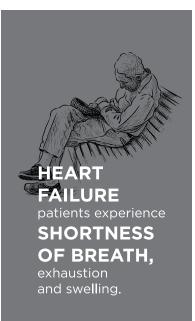
Several decades ago, it was hard to diagnose heart failure because heart function was difficult to evaluate. Consequently the heart failure progressed unchecked and patients had a poor quality of life and did not survive. We have come a long way since then. In fact the heart failure experts surveyed ranked diagnosis as one of the top areas where progress has been made around heart failure in Canada.

Dr. Fedak points out that diagnosing heart failure is still challenging, especially in the early stages. The longer it takes to diagnose, the more damage is done and the sicker patients eventually become.

Some symptoms, such as shortness of breath, are not specific to heart failure. Many patients have more than one condition

or disease with overlapping symptoms — such as lung disease. The comorbidities or additional medical conditions with their accompanying symptoms can cloud a diagnosis.

The causes can also lead to confusion. While most heart failure is due to coronary artery disease, other causes include inherited conditions and genetics, faulty heart valves, alcohol and drug abuse. Cancer survivors can end up with damaged hearts from cancer therapies.



Diabetes and high blood pressure are also risk factors, and by controlling these two conditions heart failure can be prevented. Early screening for patients with diabetes or high blood pressure would help diagnose more patients in early stage heart failure.

Heart failure patients typically show up in the emergency department or are first seen by a primary care or family doctor, adding another challenge to receiving a prompt and specific diagnosis. According to the expert survey, there is an opportunity to improve awareness of heart failure signs and symptoms with healthcare providers who are most likely to be the first point of contact with heart failure patients. An added complication for early diagnosis is that patients can be asymptomatic — meaning they do not show symptoms — or have only mild symptoms for several years. Ejection fraction (EF) is a measurement used to assess how well a person's heart pumps blood. A normal measurement is between 55 and 70 per cent, meaning the heart pushes



out between 55 and 70 per cent of the total amount of blood in the left ventricle with each heartbeat. A low EF can be an indication of heart failure. However, a significant number of heart failure patients have what is referred to as "preserved" EF, which means their reading is normal.

The heart failure expert survey revealed that preserved EF poses a substantial challenge to diagnosis. In some patients the heart chamber walls get thicker, resulting in a smaller volume of blood in the heart. The heart then seems to be pumping

out a normal percentage of blood, but in reality the heart is working harder than it should and is not pumping out enough blood to meet the body's requirements.

There are now several diagnostic tests to identify heart failure. For example imaging has become more precise and has helped identify heart failure patients earlier, paving the way for earlier intervention through treatment and management. Other tests include:

- Blood tests and BNP (brain natriuretic peptide) tests, which can indicate heart failure development
- Electrocardiogram (ECG) to look at electrical activity of the heart
- Chest X-ray to look at heart size
- Echocardiogram to create a picture of the heart and measure ejection fraction
- Stress test to see how the heart responds to exercise.

These tools continue to improve but they are not as widely available as they could be. Cost and accessibility issues mean not enough patients are accessing them quickly enough.

The resulting lag between onset and diagnosis allows heart failure to progress, resulting in a heavier burden of sicker patients, more hospitalizations and higher costs to the system.

CARING FOR A DAMAGED HEART

More Canadians are living with damaged hearts. While heart failure cannot yet be cured, it can be treated and managed. Canadians understand part of this equation; according to our poll, nine out of 10 know that heart failure can be managed



and treated. However Canadians are mistaken about the severity of the disease, as almost half think it can be cured.

While heart failure cannot be cured, people can learn to live active, healthy lives depending on the severity and duration of their symptoms, their mental health and the services and support available to them. Patients themselves have to be involved and active participants in the management of their disease. They need to pay particular attention to their fluid and salt intake, manage their diets, take their medication as prescribed, be smoke free and be active. Fewer than threequarters of Canadians believe heart failure patients can lead a normal, full life according to our poll.

WHEN THE SYSTEM FAILS

Heart failure patients are being let down by the healthcare system in many ways. The heart failure experts surveyed were clear that there are challenges facing heart failure patients, and the system that is there to support them is riddled with gaps. There are not enough heart failure specialists for the number of patients, so not enough patients are being seen by the people who have the best skills to manage them. The experts surveyed revealed that family physicians are often the care providers for heart failure patients, but they can lack the specialized knowledge and training to deal with the more complicated patients. The experts also pointed to the initiation of specialized heart failure clinics as progress, but noted that access to these specialized services is very low.

The system itself does not support the best, most integrated and timely care for heart failure patients. It does not provide enough individualized treatment demanded by this complex condition, nor does it adequately match patients with the best type of care provider through the progression of their disease. Heart failure patients are diverse and some need more time and services with access to specialists, while lower risk, less complex patients can be well cared for by a primary care team.

"We have lots of work to do around early diagnosis and treatment. We provide care in silos and we need to involve

others and work in interdisciplinary teams," says Dr. Serge Lepage, director of the Heart Failure Clinic in Quebec. "Everyone in health care works hard for the patient, but we are not working together."

New — and existing — treatments show promise to improve the lives of heart failure patients, but there are barriers around access and not all patients are receiving optimal therapies and timely care. Even more than diagnosis, the heart failure experts surveyed pointed to treatment as the area where the greatest gains have been made in heart failure, followed by management.

Dr. Virani points out that developing new therapies is not enough; the system must be in place to get them to the people who need them, starting with a plan to manage the potential number of patients who could benefit. "We can come up with new techniques, but we need to deliver and manage them effectively and ensure they are affordable."

MEDICATIONS AND DEVICES

There are several medications available to manage heart failure, and new and better drugs have recently been approved for use in Canada. Because patients often have other conditions, medications need to be closely monitored and adjusted.

Devices exist that can help failing hearts, and there is room to improve and innovate, as well as broaden access. For example, an implantable cardioverter defibrillator (ICD) is a device implanted to regulate irregular heart rhythms. A left ventricular assist device (LVAD) is a mechanical pump that helps a weakened heart pump blood.

Heart transplant surgery is the removal of a failing heart and its replacement by a donor heart to treat severe end-stage heart failure. The results can be dramatic but it is a resource-intensive procedure with many possible complications, and there are too few donor hearts available for too many patients. In Canada fewer than 200 heart transplant surgeries are performed each year.

SPECIALIZED CLINICS FOR BEST CARE

Referred to variously as heart function, cardiac function or heart failure clinics, these specialized facilities are more established in some regions than others; for example there are 47 clinics in Quebec and 22 in British Columbia. They support heart failure patients to assess and manage their symptoms, manage medications and support positive behaviour changes such as diet and physical activity. They also allow heart failure patients to receive regular followup by cardiologists, internists and GPs, as well as access services quickly if they encounter problems, thus avoiding trips to the emergency department.

According to the heart failure experts surveyed, these clinics provide excellent care, but there are far too few to serve the broad — and growing — heart failure population.



After my heart attack, the left ventricle in my heart was so damaged that it now only works at 12% capacity; the LVAD (left ventricular assist device) has taken over pumping blood through my body, which keeps me alive from day-to-day while I wait for a heart transplant.

Barb Kolomi

50, living with heart failure **READ Barb's story.** Find this story and more at: blog.heartandstroke.ca/heartfailure



The heart failure journey does not follow the same course as a cancer patient.

End-of-life care for heart failure patients is almost non-existent.

Bonnie Catlin

Heart failure clinical nurse specialist

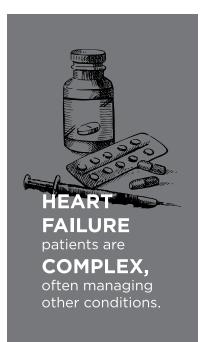
FACING END-OF-LIFE ISSUES

When a chronic illness such as heart failure progresses to a point when medical or surgical treatments don't work, palliative care, also known as end-of-life care, helps patients achieve the best quality of life until the end. Palliative care is a system of support services which may involve healthcare and home care services. It can include pain and symptom management, psychological, social, spiritual and practical support.

Unfortunately, the unpredictable progression of heart failure — punctuated by deterioration and then improvement — makes it difficult to access palliative care. As Bonnie Catlin explains, "The heart failure journey does not follow the same course as

a cancer patient, for example, where criteria diagnosing a patient palliative can be better identified and end-of-life care can be planned. Endof-life care for heart failure patients is almost non-existent."

To fill this gap in care, Cardiac Services BC helped establish the first provincial heart failure end-of-life program in Canada. Heart failure and palliative experts from across BC developed tools and guidelines to support healthcare professionals in caring for heart failure patients.



The 2011 Canadian Cardiovascular Society Heart Failure Management Guidelines Update acknowledges that the majority of palliative care recipients are cancer patients.

To address the significant gaps that heart failure patients face around end-of-life care and access to services, the guidelines strongly recommend that care providers initiate regular discussions with patients and their family. Further, the guidelines stress the importance of providing palliative care to heart failure patients based on assessment of their needs, rather than on an estimate of remaining life expectancy.

The heart failure experts surveyed ranked palliative care as one of the top three areas where progress can be made for heart failure patients.

NEW RESEARCH IS PROVIDING NEW HOPE

Improvements in diagnosis and treatment have helped heart failure patients live longer and live better. Exciting new research is reaching even further by looking at ways to stop heart failure in its tracks or to replace damaged tissue.

FINDING THE OFF SWITCH

FOR HEART DAMAGE

Heart failure can cause the heart muscle to increase in size (hypertrophy) and to develop scar tissue. Although this helps the heart cope with damage, eventually hypertrophy places added strain upon the heart and it starts to fail. For the heart to hypertrophy and develop scars, genes must be turned "on" by a series of chemical switches. How these switches work is poorly understood.

Dr. Kim Connelly is leading Foundation-funded research at St. Michael's Hospital in Toronto to understand why certain switches are turned "on" and "off" when a heart starts to fail, and to develop new drugs that will stop these switches from turning on, preventing the heart from failing. In previous research, Dr. Connelly identified a drug which activates the genes, and now he is testing its safety. This research will increase understanding of how heart failure develops and how to prevent it.

HEARTS THAT CAN HEAL THEMSELVES

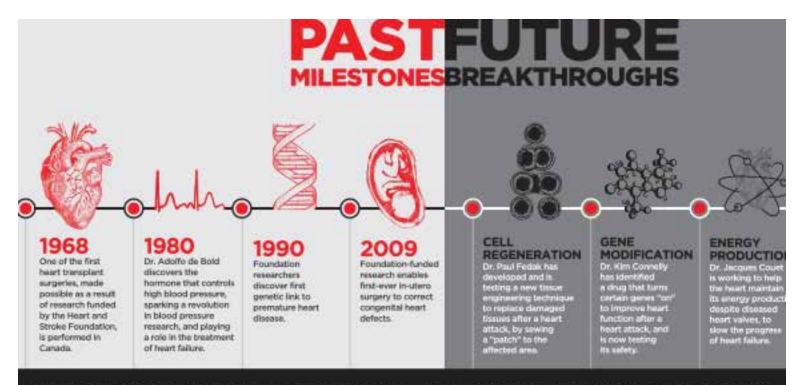
Heart muscle cells and brain cells do not regenerate like other cells. Once the heart muscle has been damaged because of a heart attack or other condition and it begins to fail, it cannot be repaired. Yet.

But what if the heart could heal itself?

The exciting field known as regenerative medicine is about repairing or replacing human cells to help the body selfheal. Regenerative medicine is game-changing. It has the potential to heal damaged tissues and organs, offering solutions and hope for people who have conditions that today are beyond repair — like heart failure.

"There are lots of ways to aid a failing heart, either through prevention, medical therapeutics, artificial pumps, or tissue engineering or regenerative medicine," says Dr. Fedak. "It is a fixable problem if we could turn scar back into muscle or if we could grow someone a new heart using a pig heart and stem cells."

Using artificial heart technology and cell-engineering platforms, Dr. Fedak and his Foundation-funded research team at the University of Calgary are using their advanced understanding of the heart matrix — the proteins that glue the beating heart muscle cells together — to develop an organic "patch." This unique solution could allow the matrix of a scarred heart to regenerate, and the damaged heart could be reshaped and strengthened. For so many Canadians, this work could mean a new lease on life.



HEART AND STROKE FOUNDATION FUNDED RESEARCH IS MAKING A DIFFERENCE FOR HEART FAILURE

IMPROVING THE LIVES OF HEART FAILURE PATIENTS

What can Canadians do?

- Patients and their caregivers should be actively involved in decision-making and management of heart failure.
- Patients should follow the directions of their healthcare providers regarding medication and lifestyle changes.
- Patient and their family caregivers can be their own best advocates to improve diagnosis, treatment, management, end-of-life planning and palliative care.

What can healthcare providers do?

- Follow the Canadian Cardiovascular Society Heart Failure Management Guidelines.
- Improve early diagnosis for heart failure patients.
- Ensure heart failure patients access the best treatment and care.
- Improve patient education around managing heart failure.

What can governments and healthcare system decision-makers do?

- Support integrated systems of care.
- Improve, expand and coordinate services across the continuum of care from prevention to diagnosis, treatment, management, end-of-life planning and palliative care.

What the Heart and Stroke Foundation is doing:

- Funding research that will save more lives and improve the quality of life for heart failure patients.
- Developing patient education resources, available at heartandstroke.ca/heartfailure.
- Developing innovative programs to support those living with heart failure.
- Advocating for healthy environments to help Canadians reduce their risk of heart disease.

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DATA SOURCES AND ACKNOWLEDGEMENTS

Canadian Institute for Health Information (CIHI) administrative data including Discharge Abstract Database (DAD) for fiscal years 2009-10 to 2014-15.

The poll with Canadians was conducted by Environics Research Group. A total of 2,012 respondents 18 years and older were interviewed by telephone during the period Oct. 5–18, 2015. The margin of error for a sample of this size is +/- 2.2%, 19 times out of 20. The results were weighted to match the demographic makeup of the Canadian population.

A survey of 69 heart failure experts was carried out Oct. 19-Nov. 5, 2015. The Heart and Stroke Foundation gratefully acknowledges the input from the experts as well as Susan Oliver from the Canadian Cardiovascular Society for administering the survey.

The Heart and Stroke Foundation is greatly appreciative of the experts who agreed to be interviewed for this report and the expertise they provided:

Dr. Justin Ezekowitz, Associate Professor, University of Alberta; Co-Director, Canadian VIGOUR Centre; Director, Heart Function Clinic; Cardiologist, Mazankowski Alberta Heart Institute Dr. Paul Fedak, Associate Professor, Section of Cardiac Surgery, Department of Cardiac Sciences, Libin Cardiovascular Institute of Alberta, University of Calgary

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