**Alan Frew**
Lead singer, Glass Tiger, stroke survivor

Photo: **Denise Grant**

# Different Strokes

## Recovery triumphs and challenges at any age.

**2017** Stroke Report

Heart&Stroke™

# Stroke recovery across the ages

Every stroke is unique, as is every stroke recovery journey. Age, stroke severity, the part of the brain affected, and other factors play a role. Yet people of all ages who experience stroke and their families encounter personal triumphs and face common challenges as they navigate through the healthcare system and reintegrate back into their life roles and activities.

The Canadian population is aging, and age is the strongest risk factor for stroke. At the same time, stroke in younger people is rising – at a rate faster than older adults. Due to increased awareness of the signs of stroke and improvements in early stroke management most people – 80% – now survive a stroke. Together this is resulting in more Canadians living with the effects of stroke and requiring services and support as they recover, especially those who return home or to a community setting.

"We know stroke can happen at any age," says Yves Savoie, CEO, Heart & Stroke. "We need to ensure all Canadians who experience stroke and their families receive support and that they are at the centre of care, their personal goals are understood, and they are involved every step of the way as recovery progresses and their needs change."

**More than 400,000**
Canadians are **living with the effects of stroke.**

## Placing the patient and family **at the centre of care**

The **Heart & Stroke 2017 Stroke Report** looks at the stroke recovery journey across the ages, highlighting common challenges and issues that occur at specific life stages. It examines the essential role of the family caregiver, highlights the importance of placing the patient and family at the centre of care, and identifies areas where system improvements could support the changing profile and needs of people who experience stroke. This is not an exhaustive review of all rehabilitation and recovery needs or existing services and supports but it profiles main themes across ages and life stages.

For this report we talked to people who have had a stroke, family members and experts, and reviewed the latest research studies and data from the Canadian Institute for Health Information (CIHI) and other sources. We also drew on consultations we carried out with 600 people who have experienced stroke or heart disease and their caregivers, and polled Canadians around their understanding of stroke recovery and caregiving.

## Heart & Stroke milestones in stroke research

**2017** RecoverNow is the first mobile tablet-based rehabilitation intervention to help patients recover their language and motor skills. **2016** A Heart & Stroke funded program, Timing it Right Stroke Family Support Program, addresses the changing needs of family caregivers as their loved ones move through the stages of recovery. **2016** The INTERSTROKE study, co-funded by Heart & Stroke, identifies 10 risk factors that account for 90% of the risk of strokes worldwide.

# The stroke story in Canada

In big picture terms, there are more than 400,000 Canadians living with long-term disability from stroke, and this number will almost double in the next 20 years. The effects range from mild to severe disability, and can be obviously physical limitations or more subtle such as memory changes. Recovery can take months or years, even for milder strokes, and many people never fully recover.

**In the next 20 years,** the number of Canadians living with **stroke will almost double.**

**Help needed**

Half of all Canadians living with stroke need help with daily activities such as eating, bathing, dressing, going to the washroom and getting around. About 60% of stroke patients are left with some disability and more than 40% are left with moderate to severe disability that requires more intense rehabilitation and support in the community.

The most troubling part of the stroke recovery picture: **overall many needs are not being met**. As an example, of the stroke patients who leave inpatient acute hospital care, only about 16% get into inpatient rehabilitation right away, and only 19% within the first month after leaving hospital. This is considerably lower than the *Canadian Stroke Best Practice Recommendations* target of greater than 30%. There is considerable variation across regions in access to rehabilitation as well.

"More people are surviving strokes which is cause to celebrate," says Dr. Patrice Lindsay, Director of Stroke at Heart & Stroke. "Acute care for stroke patients has improved dramatically but unfortunately the rest of the system has not kept pace. There are gaps in rehabilitation and community services and supports for stroke survivors of all ages, especially outside of urban centres."

## Where you live matters

There is general agreement that while some excellent resources are available in communities, they are too few and mostly in major centres. Barriers exist around awareness, access and cost. Some challenges are specific to particular ages but others are consistent across life stages, especially the disparity between urban and rural areas.

Dr. Mubeen Rafay is a pediatric stroke expert covering a huge area: all of Manitoba, Northern Ontario, Nunavut, and parts of Saskatchewan. She acknowledges that services and support are superior in bigger cities compared with northern areas, including access to specialized professionals such as speech therapists.

"Many patients along with their families move to larger cities for a few years because there are limited or no resources close to home," she says. "It is also important for the patient to be followed after diagnosis and remain connected with resources in the community or things can fall apart, especially in remote areas."

There is a tremendous opportunity to expand telestroke – which uses telecommunication technology to link referring and consulting healthcare sites together – to increase access to stroke rehabilitation across the country.

## Heart & Stroke milestones in stroke research

**2015** ESCAPE, a Canadian-led, international clinical trial co-funded by Heart & Stroke, shows remarkable results in the treatment of major strokes caused by blood clots, and heralds the most significant change in stroke treatment in 20 years.
**2015** Heart & Stroke researchers discover 10 genes associated with stroke and are working to isolate the genes that put apparently healthy young people at risk of stroke.

# Understanding needs

Heart & Stroke consulted with more than 600 Canadians who experienced stroke or heart disease and their caregivers and families to understand their needs during recovery. The results highlighted changing needs over time and common challenges:

- Needs vary according to several factors including severity of the event, age, and availability of and access to appropriate local programs.
- Stroke survivors have important psychosocial needs as many live with the effects for the rest of their lives.
- The transition from acute care back to the community is difficult. They go from a high level of personal care to uncertainty and feelings of isolation.
- They report feeling anxious, vulnerable, isolated, lonely and depressed.
- They experience a sense of loss: of independence, social connection, work and family roles.

The consultation also revealed specific gaps in support for both survivors and caregivers:

- Social and emotional needs are not being met. Survivors and their caregivers have a high need to connect with others who are going through or have gone through similar challenges for mutual support and information sharing.
- Caregivers also need support developing the skills needed to navigate the health system and advocate on behalf of the patient.

# What is a stroke?

A stroke happens when blood stops flowing to any part of the brain. This interruption causes damage to the surrounding brain cells which cannot be repaired or replaced; 1.9 million brain cells die every minute during a stroke.

**Ischemic stroke** is the most common form of stroke, caused by a blood clot. A **transient ischemic attack (TIA)** is sometimes referred to as a mini-stroke. TIAs are caused by a small clot that briefly blocks an artery and stops blood flow to part of the brain for a short period. However TIAs are an important warning that a more serious stroke may occur. **Hemorrhagic stroke** occurs when a blood vessel ruptures, causing bleeding in or around the brain. Anyone who experiences a stroke or a TIA must seek medical help immediately.

**Act FAST**

Recovery from stroke starts right away. The quicker the signs are recognized, and the patient is diagnosed and treated, the greater likelihood of a good recovery, with less chance of another stroke, and decreased healthcare costs. The first few hours after stroke are crucial, affecting the recovery journey for years to come.

## Learn the signs of stroke

**F**ace is it drooping?
**A**rms can you raise both?
**S**peech is it slurred or jumbled?
**T**ime to call 9-1-1 right away.

Act F A S T because the quicker you act, the more of the person you save.



## Heart & Stroke milestones in stroke research

**2014** Heart & Stroke researchers discover a better way to better detect atrial fibrillation, one of the most common and treatable risk factors for stroke. **2011** *Quality of Stroke Care in Canada* is released, the first report to document availability of and critical gaps in stroke services across Canada, co-led by Heart & Stroke. **2006** Heart & Stroke co-leads the development of the *Canadian Stroke Best Practice Recommendations*, leading to increased consistency and standardization of stroke care in Canada. **2003** Heart & Stroke leads development of the Canadian Stroke Strategy, which will revolutionize stroke prevention, treatment and care. **2000** A Heart & Stroke-funded project discovers that ACE inhibitors significantly reduce the risk of heart attacks and strokes.

# A family affair

"It is not just the patient who experiences a stroke; it is also the family, significant others, and the community," says Dr. Theresa Green, Adjunct Associate Professor, University of Calgary.

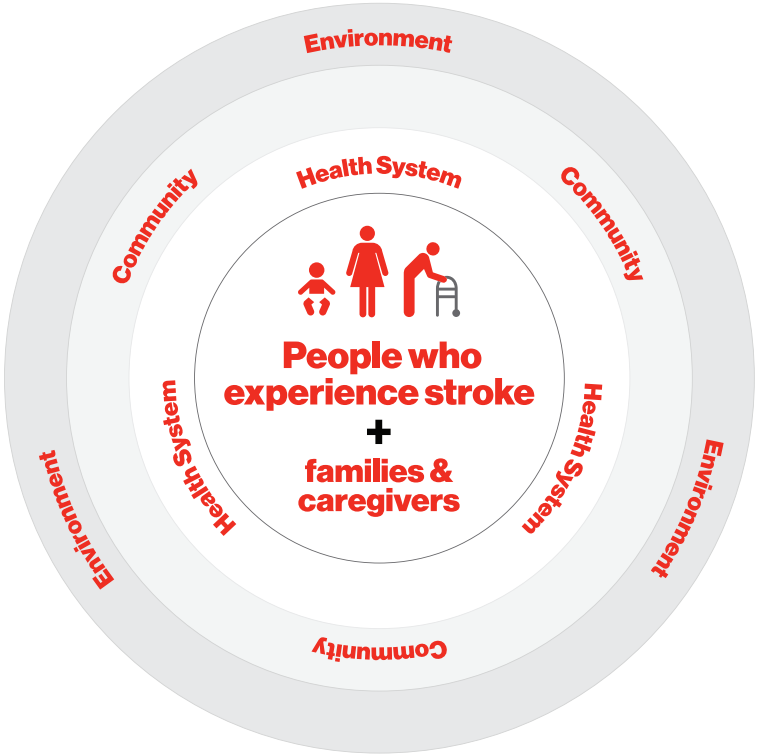
An estimated 58% of stroke patients return home after being hospitalized and 68% after receiving inpatient rehabilitation. About 10% of patients are admitted to long-term care. This highlights both the need for ensuring adequate care in the community is available and the important role of family caregivers.

Family members (and this can include close friends) are key facilitators of stroke recovery. With their vital role, the family or friend caregiver should be a core member of the care team, at the centre alongside the person who had the stroke. Evidence shows patient and family-centred care results in improved health outcomes.

"What helped was I have a family that knows I do not need hand holding. I need strong, grounded understanding that what I am going through we are all going through together," says Alan Frew, lead singer of Glass Tiger. Alan had a stroke in 2015 at age 58, worked hard to recover and is back performing and touring.

Primary care providers – family doctors, nurse practitioners or other professionals – also have a vital role to play. They can coordinate care and help access available services and supports. People have a variety of different needs post-stroke including:

- practical
- emotional
- physical
- social
- psychological.




Stroke affects quality of life and influences family relationships in areas such as communication, problem-solving, emotional support, sexuality, closeness and empathy. While there are many challenges and life changes associated with stroke, both stroke survivors and family caregivers report some positive consequences: awareness of the other's contribution and a sense of mutual gratitude; shift in attitude around what is important in life; a deeper appreciation for meaningful relationships with family and friends; and strengthened connections.

"One thing I have learned over the years is in the Indigenous community, there is a significant lack of proper resources at the community level. I feel lucky that when I had a stroke I was living in an urban area because if it had happened to me in some of the communities where I have traveled over the years I would have suffered significantly from the lack of appropriate medical care, particularly urgent medical treatment."

**– Senator Murray Sinclair, stroke survivor**

# Stroke in babies and kids

It is still surprising to some that stroke can happen at a very early age, including in infancy. In fact, the risk of stroke in children is greatest in the first year, especially in the first week of life.

Perinatal stroke refers to strokes that happen between the middle of pregnancy through birth and the first month of life. In Canada there are more than 10,000 children (0 – 18 years) living with stroke. There is one neonatal hemorrhagic stroke for every 6,300 live births; this is double what was previously estimated and means one full-term baby is born in Canada each week with stroke. The rates are higher in premature babies (1 in 1,500). Perinatal stroke is a leading cause of early brain injury, cerebral palsy, and lifelong neurological disability.

Causes for perinatal strokes are not always clear. One of the only established risk factors, accounting for about 20% of perinatal strokes, is congenital heart disease. These are usually severe cases and easy to diagnose.

"One of the most important pieces of information I give to new mothers is to let them know that it is not their fault. When I spend just a few minutes explaining this, there is a huge sense of relief, it has a big impact and helps them do better," says Dr. Adam Kirton, Director, Calgary Paediatric Stroke Program.

**Difficult to diagnose**

Diagnosing a stroke in a newborn can be difficult and therefore often delayed; compared with adults, it often takes longer. Some babies have symptoms right after birth such as seizures, but for others symptoms do not appear until later. There is a lack of awareness of stroke in the very young and the signs are not always identified by pediatric healthcare professionals and caregivers. As with adult stroke, faster treatment may translate into better recoveries, fewer recurrent strokes, decreased healthcare costs and likely better long-term outcomes.

**Effects that last a life time**

Babies' brains are more adaptable than those of adults and therefore have great potential for recovery. They can sometimes rewire themselves as they are still developing and nerve cells are forming connections. But stroke at a young age brings with it some unique issues.

"The earlier in life you have a stroke, the longer you deal with its effects," says Dr. Kirton. "If you have a stroke as a baby you will be living with stroke your entire life."

Outcomes from childhood stroke vary. Most children will improve over time although it is estimated that more than 60% will have some long-term disability. Potential complications from childhood stroke include:

- permanent weakness on one side of the body
- epilepsy
- speech and language disorders
- coordination and movement disorders
- musculoskeletal impacts
- cognitive, behaviour and learning challenges
- mental health issues.

When talking about kids and stroke recovery, the term should really be "habilitation" not "rehabilitation." Their brains are growing and recovering at the same time; it is more often new learning instead of re-learning how to do things.

"At the baby stage you do not know the outcome of stroke until they do not meet developmental milestones,

"At the baby stage you do not know the outcome of stroke until they do not meet developmental milestones, so therapy is often delayed."

**– Laura Lenz, mother of Nolen (left) who had a stroke at birth**

so therapy is often delayed," says Laura Lenz, whose son Nolen had a stroke at birth. "Young kids who have strokes can have all the same symptoms and outcomes as adults, but there are musculoskeletal differences as their bodies grow into their stroke."

Rehabilitation for young stroke is an under-researched area and the existing evidence is weak. There are gaps in treatment and expert care and treatment guidelines are lacking. There is also little evidence-based therapy and disability support available to families.

Even when resources exist, they are not always timed with children's development. For example, speech might be delayed for a child with stroke but they might be too old to qualify for speech-language therapy by the time they are ready for it. Families often have to pay out of pocket for different services. Children phase out of publicly funded therapy at different ages and stages, and the types and level of support available at schools varies.

Dr. Gabrielle deVeber, Director of Children's Stroke Program, The Hospital for Sick Children estimates that only 10% of pediatric stroke patients have access to specialized care. "All kids with stroke need medical care, 50% have significant moderate to severe disability that develops over time and 80% require support such as physiotherapy, occupational therapy, speech-language therapy and extra educational support."

**Behaving like kids**

The experts interviewed for this report and the evidence reveal that some of the biggest challenges facing kids with stroke are cognitive and behavioural issues such as attention deficit disorder, poor decision making, and social isolation. These become big barriers to psychological well-being, social interaction and functional independence as children get older, and anxiety and depression can compound normal adolescent challenges.

Parents need to learn how to navigate through various services within the healthcare and education systems and between healthcare professionals. This takes time and puts a strain on family finances.

> Some of the biggest challenges facing kids are **cognitive and behavioural issues**

"The parent has to become the expert and the advocate. There are so many appointments and they spend so much time bringing each health professional up to speed," says Laura Lenz.

Ideally children with stroke should receive the additional supports they need from the healthcare and educational systems throughout their childhood and adolescence. These supports should be tailored to their development, with particular attention at transitions, for example, as they start school or higher education. Some children with stroke will require life-long follow-up and will be transitioned to an adult clinic once they turn 18, though this process has not been well studied and transition clinics are scarce.

Everyone in the family requires support including siblings, as the entire family dynamic is impacted. Establishing networks with other families and peer-to-peer support groups can help. **The Canadian Paediatric Stroke Support Association** (cpssa.org) provides support, education and resources for children and their families impacted by stroke.

## Heart & Stroke milestones in stroke research

**1999** Heart & Stroke researchers pioneer organized stroke care and systems change in Canada to enable more patients to get tPA, a clot-busting drug that can erase the effects of stroke. **1997** Human genome is mapped with Heart & Stroke funding, including identification of more than 84,000 DNA sequences related to heart disease and stroke. **1983** Heart & Stroke researcher Dr. Robert Côté develops the Canadian Neurological Scale, which is now used around the world to measure neurological deficits following an acute stroke. **1976** Dr. Henry Barnett conducts the first clinical trial using Aspirin to prevent strokes. Dr. Barnett was instrumental in increasing funding for stroke research.

## Subtle and lasting effects

**Depression** is very common after stroke. It can be caused by injury to the areas of the brain that control emotions, or as an understandable response to this difficult, life-changing event. Research estimates that one-third to one-half of people who have had a stroke will develop depression and some survivors report they can deal with the physical consequences of stroke better than the psychological and emotional aspects. Screening for depression should be included in care for stroke patients of all ages and in all settings.

**Post-stroke fatigue**, a condition of feeling very tired even after resting, is also commonly reported, with estimated rates between 38% and 73% in people who experience stroke. This type of fatigue can last for months and even years and does not seem to be related to size, location or severity of the stroke. It may be associated with sleep disturbances or low mood in some cases and it can negatively impact a person's ability to participate in rehabilitation or engage back in their community.

According to the poll we commissioned, the majority of Canadians understand that there are lasting effects associated with stroke. The two most identified issues were speech and communication problems (52%) and mobility problems (48%). However, fewer than 3% of poll respondents identified fatigue or depression, yet these are the issues that impact survivors and caregivers the most.

# Stroke in younger adults

Stroke in younger adults is on the rise. According to the most recent data from the Canadian Institute for Health Information, 19% of hospital admissions for stroke and TIA were for patients between the ages of 20 and 59, up from a few years ago. A new stroke happens in about one in 10,000 young adults under the age of 64. Because they are generally more robust physically, younger adults can recover somewhat better than the elderly, but their odds of dying in the first week following a stroke are the same.

There are various causes of stroke in young adults such as heart problems and congenital factors, and one-third of stroke in young adults (18 – 45 years) is cryptogenic, meaning the origin is not known. However, typical vascular risks such as high blood pressure, diabetes, and unhealthy lifestyles are on the rise in this younger age group.

Similar to babies and children, stroke in young adults is less common than in the elderly and misdiagnosis can result in a missed opportunity for proven therapies such as clot-busting drugs and clot removal procedures.

Younger adults face distinct challenges as they recover from stroke. Dr. Richard Swartz, Director, University of Toronto Stroke Network, reports that younger adults more often face both practical and philosophical matters. They may be concerned with being able to drive again, returning to work or school, young families, and long-term finances. They also struggle with questions such as "Why did this happen? Why me? How do I make sure it does not happen again? What do I do now? How do I get my life back?"

Younger adults as part of the "sandwich generation" may be busy caregivers to children, elderly parents or both. A stroke forces them to contemplate decisions typically faced later in life including a change in living

"There are some good things that have come from my stroke, weird as that sounds. It's made me incredibly more aware of the time frame we are on as human beings; in a blink of an eye you can be gone or devastated. So I treasure my time more."

**– Alan Frew, lead singer of Glass Tiger and stroke survivor**

accommodations and help with daily activities, finances, and end-of-life planning.

Richard Wilson counts himself lucky that he has a loving family, including his wife Sharlene and their two children who were 7 and 16 at the time of his stroke, but they all faced challenges during his recovery, he says. "It was hard for the kids. The first couple of years I would get very frustrated with things I couldn't do. It was very emotional, trying to do things. Anger was hard to deal with."

A big issue for this age group with multiple work, family and other responsibilities, can be the hidden nature of some of their deficits. Patients can look well, but be dealing with ongoing issues such as thinking and memory problems, fatigue or depression. "It can be challenging because these deficits can be subtle so others do not recognize them. Even patients may not recognize these issues at first, but if the pace of return to function, to work, and to family becomes too fast it can lead to frustration and setbacks," says Dr. Swartz.

Dr. Annie Rochette, a researcher at the Université de Montréal and the Center for Interdisciplinary Research in Rehabilitation of Greater Montreal, examined activities of daily living after stroke. "We looked at how they were walking, dressing, eating, and doing chores around the house. Individuals who have had a stroke told us that they were doing OK when we looked at each thing individually. But when we looked at everything together it was a challenge to do everything that needs to be done in one day. They were exhausted and had less patience, and this often caused conflict in the home."

## Aphasia

Aphasia is a language problem that masks a person's inherent competence affecting the ability to talk with and understand others, and read and write. It affects all relationships; conversation is the currency for engaging in life.

One in three stroke survivors **is diagnosed with aphasia**

One in three stroke survivors is diagnosed with aphasia and there are more than 100,000 Canadians living with the condition, ranging from mild to severe. This number is expected to increase significantly as the population ages and the number of stroke cases increases accordingly. Speech problems are the most recognized sign of stroke onset, yet aphasia is not well recognized or understood during recovery.

Aphasia creates barriers to accessing services and information in stroke care and recovery. It often brings increased depression, a loss of self-esteem and social isolation; research shows that people with stroke and aphasia are spoken to less, eroding human connection.

Unfortunately there are gaps in treatment and services for individuals and families living with stroke and aphasia. Too many people with aphasia are discharged home with no supports or training — either for themselves or their circle of family and friends — that could help enable meaningful communication.

Ky Pruesse had a stroke at 39 while traveling on business. He woke up in his hotel room and was literally at a loss for words. He could see clearly what he wanted to say but the words would not come out of his mouth. An editor-in-chief in the publishing industry, his world was communication: speaking, reading and writing, and suddenly that was stripped away. Five and a half years after his stroke, his speech fluid and trouble searching for words minimized, Ky returned to work at his previous company in a different role.

"I had a very specific path and I was fortunate; I had rings of support around me," says Ky. "Not everyone has access to what I had." That support included his wife Andrea and other immediate family who navigated the system and helped him advocate; friends and neighbours who helped with practical matters such as driving him to rehabilitation; access to excellent professionals such as a speech-language pathologist and a social worker; good private healthcare coverage; a supportive workplace; and programs at the Aphasia Institute.

**The Aphasia Institute** (aphasia.ca) helps people with aphasia learn how to communicate in new ways.

# Drive safely

Driving is considered by many to be an essential component of independent living as well as a pleasure. People depend on it to maintain their social lives and recreation, work and other activities. Having this privilege revoked after a stroke (by provincial ministries of transportation) can be a particularly sensitive and emotional issue and difficult to accept.

Many stroke survivors who regain functional independence can return to safe driving and those who do are usually better able to re-integrate into their lives. They often must overcome or adapt to deficits, for example, weakness, loss of sensation and fatigue, which must be addressed as part of the rehabilitation plan. Guidelines for assessing a stroke survivor's ability to drive vary by province. Waits for assessment are often long and fees can be high, and few rehabilitation programs address issues specific to driving.

"There is tremendous frustration for patients in getting their license back," says Dr. Hillel Finestone, Director of Stroke Rehabilitation Research at Elisabeth Bruyère Hospital. "It can also affect the doctor– patient relationship as patients feel they are safe drivers and want to resume driving yet there is no specific office test and assessments are not standard."

Physicians and healthcare professionals have numerous paper-and-pen tests at their disposal which help to better understand their patients' physical, cognitive and perceptual states but a road test is still the gold standard.

**Stroke**
can happen
**at any age.**

**Community and connection**

Isolation can also be pronounced in young stroke survivors because it is still primarily a condition associated with older adults. It is difficult for young people to connect with a community of their peers who have also experienced stroke and they may perceive a stigma attached to their situation more than older adults would.

Getting back to their lives before stroke is a high priority for younger stroke survivors. Returning to either work or school can require accommodations as they are faced with fatigue and may have issues with working memory, concentration and attention. They can experience difficulty re-establishing their roles in their families, in the community, and in their professional lives.

Studies have found that a significant number of mild stroke patients experience challenges around mobility, relationships, work, and recreation up to a year after stroke, yet the majority indicated receiving little in the way of post-stroke rehabilitation. Although services vary across the country, funding for recovery support services for younger adults is limited; in general services exist for those under 18 and over 65 but not for those in between. Lack of benefits to cover rehabilitation for young adults can be financially devastating.

"Acceptance was the biggest challenge. Once I learned to accept it [the stroke] then I realized I was continuing to ignore my obligations to take better care of myself, I wasn't taking recovery very seriously. So I made an effort to lose weight, to monitor what I eat and to get more exercise, to keep physically busy. And I continue to take my medication."

**– Senator Murray Sinclair**

# Stroke in older adults

Age is a strong risk factor for stroke; the older you are, the higher your risk, and 80% of all strokes happen to those over the age of 60. Although older stroke patients face many of the same challenges as younger ones, a unique and major factor facing stroke in the elderly is they are also living with other chronic conditions. These are called co-morbidities and the average stroke patient has five, such as high blood pressure, diabetes and atrial fibrillation. This adds a layer of complexity to their care both in hospital and after they are discharged.

Further complicating elderly stroke care is that the primary caregiver is often elderly as well and is likely dealing with other chronic conditions. Many older stroke patients and their caregivers face issues around isolation and depression.

Surprisingly age also matters when it comes to research. In a recent review of stroke rehabilitation trials, the reported mean age was just shy of 65 and several of the studies excluded older participants. The result is not only a likely disconnect between the patient population and existing evidence on rehabilitation, but also the ability of older stroke patients to access emerging treatments and trials.

According to the recently released report *Better Home Care in Canada: A National Action Plan*, the number one challenge identified by all home care programs is the impact of our aging population on demand and service complexity. Older adults living with frailty have the greatest need for home care services. In 2013 more than 1.8 million Canadians received publicly-funded home care services, the majority of whom were seniors.

**Fractured care**

According to experts who work with older stroke patients with multiple conditions, care is fractured, many healthcare professionals don't communicate with each other or take a team-based approach, and services are not available throughout recovery. Family caregivers are not being involved as part of the team. There is inconsistency in assessment tools used and there is no common language across the disciplines and among care providers. Important members of the team such as personal support workers, who provide most of the day-to-day care, are not actively engaged as part of the team and may feel under-valued.

**Half of people** who experience stroke **need help with daily activities.**

"After a stroke it can take a full year or more to re-engage back into their communities. People are given limited professional services, for example nursing, occupational and physical therapy, and consistent follow-up over the critical first six months to a year post-stroke is lacking," says Dr. Maureen Markle-Reid, Research Chair in Aging at McMaster University. "Support is front-end loaded but people will often reach a plateau and then make additional gains and therefore need ongoing support."

Age is a benefit when it comes to stroke recovery and marriage, as life experience is an asset. Older couples in long relationships tend to adapt better to the caregiver and patient roles because they often have spent years developing adaptive behaviours in their relationship.

**Living with Stroke™ is a community-based support and educational program designed for stroke survivors and their care partners**
**heartandstroke.ca/livingwithstroke**

"I am still affected by it. My hand will never be the same; my arm will never be the same. I have good days and bad days. I will never be the guy I was pre-stroke. He's gone. I can only be this guy. But I am still singing at the top of my game."

**– Alan Frew**

# Helping the helpers

The role of family and friends in stroke recovery is central. It is no surprise that parents are the primary caregivers for babies and children with stroke, but family members and sometimes friends provide support to stroke survivors of all ages, from young and middle-aged adults to the elderly.

At a practical level the regular presence of another person in the home allows people who have had a stroke to return home and for some to avoid institutionalization. Two-thirds of stroke survivors return home after being in hospital or after receiving inpatient rehabilitation. Family caregivers coordinate medical care and services, help with activities of daily living, navigate through the healthcare system including transitions between care environments, and support ongoing rehabilitation, emotional well-being and re-engaging with the community.

> "I was paralyzed completely on my right side and I thought my life was over until I heard these words from my wife: 'This is not you.' It began a very personal, internal quest to say I am not going to let this define me and I am going to come back."
>
> **– Alan Frew**

The demand for home care is increasing and family caregivers and volunteers are being relied on more heavily, yet the number of volunteers is decreasing.

Despite family caregivers' essential role, they rarely receive the preparation they need and commonly experience negative impacts on their mental and physical health. The more care they provide, the harder it becomes to look after themselves.

Some of the negative effects identified by family members include a sense of burden, feeling their skills are inadequate, feeling captive, fear of another stroke, increased responsibilities, less time for leisure and social activities, and financial worries. Caregivers can feel isolated, and experience stress and depression. Young caregivers (ages 18 – 25) face unique challenges compared with older caregivers since many are themselves at a transitional stage in life. Some report challenges keeping up with school, establishing careers and social relationships, and say they feel isolated from friends and peers who do not understand their situation.

Because stroke is a sudden occurrence the family caregiving role starts abruptly. Like the patients they are supporting, caregivers' needs evolve over time as they move from the emergency situation and diagnosis through treatment, rehabilitation and the ongoing recovery process.

"Caregiving for stroke is such an unknown. Stroke onset is sudden and people do not know what to expect. They do not know about the extent of recovery or what they are going to get in terms of support if any, and the types of care offered to caregivers is not consistent across the country and between urban and rural areas," says Dr. Jill Cameron, a stroke researcher at the University of Toronto.

To carry out their central and constant function across the illness trajectory, caregivers need:

- **information and education** about all aspects of stroke at different stages
- **training** around needs at different stages including medication management, communication, occupational therapy and physiotherapy, navigating the healthcare system and transitioning between services and providers
- **emotional support** from healthcare professionals, family, friends and peers
- **feedback** from health professionals to provide validation.

When caregivers are supported they report improvements in their well-being and are able to provide better care, including accessing more community services for the stroke survivor. Yet there is a glaring lack of services and resources for families, especially beyond the primary caregiver, resulting in teens and young adults being all but forgotten.

When asked to what extent they would feel capable of personally caring for a family member who experienced stroke, 31% of respondents to our poll said they would not feel capable. When asked to list their biggest concerns around taking care of someone close to them who had had a stroke, they identified as the top three issues their own lack of skills and ability to provide care, financial concerns, and not having free time or help from others.

In response to how confident they would be that family and friends would be available to care for them after a stroke, only 45% are very confident about this.

# Resources and programs

**Heart & Stroke provides resources to support stroke patients and their families, most of which are available on the Heart & Stroke website at heartandstroke.ca/what-we-do/publications.**

- **Your Stroke Journey** – If you or your loved one has had a stroke, this comprehensive handbook can help you and your family understand stroke and the recovery process. This resource answers questions most stroke survivors ask.
- **Family Guide to Pediatric Stroke** – This guide provides basic information about stroke and stroke care to families of children who have had a stroke. It is based on the *Canadian Stroke Best Practice Recommendations* and was developed by stroke professionals and families.
- **Living with Stroke™** – This is a community-based support and educational program designed for stroke survivors and their care partners (and currently being updated). The 6–8 week program will help you gain confidence to manage the challenges of living with stroke, and to meet others going through a similar journey. Meetings are led by either a healthcare professional, trained peers or a combination of both. They are highly interactive, focused on building skills, sharing experiences and supporting one another.
- **TIA fact sheet** – This fact sheet is a quick look at the causes of TIA, and how to manage your risk factors.
- **Post-stroke checklist** – A two-page list of common issues and concerns after stroke. It is a tool for healthcare professionals, patients and family members to ensure all important topics are addressed during follow-up visits.
- **Taking Action in Community and Long Term Stroke Care (TACLS)** – Closely linked with the Canadian Stroke Best Practice Recommendations, TACLS is an evidence-based resource that provides guidance around how to provide safe care for people who have had a stroke and are living in community and long-term care settings. Developed primarily for healthcare workers it provides additional information for family caregivers.
- **Stroke in Young Adults** – A resource for patients and families – Every person and every stroke is different and no single resource can meet all needs. This guide is designed for young adults, their families and caregivers and intended to complement other stroke resources.
- **Taking Charge of Your Stroke Recovery: A Survivor's Guide to the Canadian Stroke Best Practice Recommendations** – This resource offers patients and families key information about evidence-based stroke best practices at each stage from emergency and acute care to long-term recovery. It helps people to *Be Aware, Be Informed, and Take Action* for their stroke, follow-up and recovery by providing explanations about care and helpful questions to ask of the stroke care team while considering individual circumstances and needs. Available at strokebestpractices.ca
- **Heart & Stroke Community of Survivors** – The Heart & Stroke Community of Survivors supports the fullest recovery possible for Canadians diagnosed with stroke, heart disease or heart failure. The Community offers a helping hand by way of practical advice on day-to-day challenges such as healthy eating, exercise and dealing with stress, as well as expert information, a chance to learn about the most recent heart and stroke research and, importantly, the opportunity to have input into our plans. Community members take part in focus groups and surveys that help us better understand what survivors need to optimize their recovery. We are creating new initiatives built on this feedback, such as an online place where survivors can connect and get social and emotional support from others living the same experience. The community welcomes anyone who has experienced stroke or heart disease as well as their care partners and/or families. To register, go to heartandstroke.ca/connect
- **Heart&Stroke Risk Assessment™** – This e-Tool helps people know and manage their stroke risk factors. heartandstroke.ca/risk

## Additional resources

- **Canadian Stroke Best Practice Recommendations** provide comprehensive guidelines for healthcare professionals working with stroke patients and their families; patient and professional education resources have also been developed. strokebestpractices.ca
- **Stroke Engine** – Funded by the Heart and Stroke Foundation Canadian Partnership for Stroke Recovery and managed by research leaders at the University of Montreal, it is the go-to site for information on post-stroke recovery. Stroke Engine provides patients and families with answers to their questions about rehabilitation and recovery after stroke and delivers the latest reviews on interventions and assessments for clinicians working in the field. E-learning modules have recently been added to the site. strokengine.ca
- **Evidence-Based Review of Stroke Rehabilitation (EBRSR)** – Funded by the Heart and Stroke Foundation Canadian Partnership for Stroke Recovery and managed by research leaders at Western University, EBRSR reviews and synthesizes all the latest research evidence about stroke recovery. It is geared to researchers working in the field. EBRSR.com

# Supporting stroke recovery at any age

## What can Canadians do?

- Learn the signs of stroke and act FAST by calling 9-1-1 or local emergency medical services immediately. **heartandstroke.ca/FAST**
- Know and manage your stroke risk factors. Take the Heart&Stroke Risk Assessment at **heartandstroke.ca/risk**
- Participate in peer-to-peer networking and support groups.
- Join the Heart & Stroke Community of Survivors. To register, go to **heartandstroke.ca/connect**
- Familiarize yourself with the resources and supports within your community.
- Use the Heart & Stroke and Canadian Partnership for Stroke Recovery patient resources listed in the resource section.

## What can work places and educational institutions do?

- Ensure schools and work places are accessible for those with a disability as a result of a stroke.
- Employers should consider ways to support caregivers and stroke patients through flexible work arrangements as they navigate through the recovery process.

## What can healthcare providers do?

- Take a holistic approach to stroke recovery.
- Employ a multi-disciplinary team-based approach to stroke care and include all care providers.
- Support patient-centred care, including the patient and family as a central part of the care team.
- Engage patients and families in the design, delivery and evaluation of stroke treatment and care.
- Recognize that patients' and caregivers' needs change throughout the recovery journey and develop resources and supports to deliver at the appropriate time.
- Understand and raise awareness with other healthcare professionals and health education institutions that stroke can happen at any age and patient recovery goals and needs are partly age dependent.
- Understand, and raise awareness of the signs of stroke, including unique signs of stroke in babies and children.
- Ensure patients, family and other caregivers are supported across the continuum of care.
- Follow the *Canadian Stroke Best Practice Recommendations* for all ages.
- Expand telestroke capability to go beyond emergency stroke care and use to support rehabilitation and recovery especially in smaller, rural and remote communities.
- Provide culturally-sensitive care by recruiting Indigenous people to health careers and ensuring that all health providers working with Indigenous people have the required cultural knowledge, skills, understanding and respect.
- Respect traditional health knowledge, recognizing and incorporating traditional healers and Elders in health care. Ensure resources and compensation for healers and Elders are appropriate.
- Understand and determine the needs of complex patients, including those with multiple comorbidities, to provide optimal support.

## What can governments do?

- Ongoing development, implementation and evaluation of comprehensive provincial stroke strategies that leverage *Canadian Stroke Best Practice Recommendations*. Strategies and implementation should address the full system of stroke care and include prevention, awareness, emergency response, acute care, rehabilitation and community support.
- Invest in campaigns to raise awareness of the FAST signs of stroke across the country.
- Improve access to funded/subsidized stroke rehabilitation services for all age groups across the country including rural and remote communities.
- Improve transitions of care between acute care, rehabilitation and return to community.
- Develop a strategy to provide adequate home care for stroke patients and their families.
- Invest in telerehabilitation services to improve access to services across the country, including Indigenous, rural and remote communities.
- Provide financial support for family caregivers including through access to employment insurance.
- Recognize the important role of all family caregivers including those who live apart from the stroke patient and younger caregivers. Provide support for all stroke caregivers.
- Support peer-to-peer and other support groups and services for stroke patients and their families.
- Local governments should make public transit and transport solutions easy for stroke patients during throughout the recovery and rehabilitation journey

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- **Richard Wilson**, stroke survivor
- **Angela Wright**, stroke survivor

## Data sources

In 2015 Heart & Stroke consulted with 600 stroke and heart patients and their caregivers discussing their needs, barriers, challenges, coping strategies and supports in recovery. This included 28 focus groups in 22 towns and cities in nine provinces (237 participants), an online survey (282 respondents), one-on-one or small group conversations (89 participants), and conversations with key informants from national charities, academic institutions and service provider organizations (11 organizations).

The poll with Canadians was conducted by Environics Research Group. A total of 3,100 respondents 18 years and older were interviewed by telephone between February 6 - 21, 2017. The results were weighted to match the demographic makeup of the Canadian population.

Parts of this material are based on data and information provided by the Canadian Institute for Health Information. However, the analyses, conclusions, opinions and statements expressed herein are those of the author and not those of the Canadian Institute for Health Information.

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Dr. Barnett was a leading Canadian physician, stroke researcher, and pioneer of the use of Aspirin for stroke prevention.

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