

Survivors Speak: Jane and Frank

When Jane picked up her recorder and began playing, her husband Frank knew she was going to be okay.

Jane was in the hospital, just weeks after suffering a stroke that doctors described as devastating. She'd been left with 'irreversible brain damage.' Both Jane and Frank agree: it was a scary diagnosis.

At first, Jane couldn't speak at all. A nurse suggested that bringing in familiar objects might be helpful, so that's what Frank did. One of the objects was Jane's recorder. The first time he gave it to her, she just looked at it, then set it aside, so Frank took it home.

(continued on page 2)



Frank Ingold, Jane Adshead, Captain Kelly, and Andria Spindel at the 16th Annual Ability and Beyond Dinner

Preventing Another Accidental Fall

By Michael Izzo, Airgo Mobility

It was an ordinary evening in early March, when my grandmother fell down the stairs of the two-story house where she lives with my grandfather, independently with the occasional help of their three children. After walking up no more than five or six steps on her way to her bedroom she lost her balance, and took a terrible backwards fall down the stairs. My grandfather rushed to her side when he heard the commotion, and found her on the floor unconscious. He called her name and when she wasn't responsive, he called 9-1-1.

The fire department were the first responders to aid my grandma, and then an ambulance brought her to Montreal's Royal Victoria Hospital. It was determined she had broken ribs, hurt the back of her head, her lower back and tail bone, and chipped two or three vertebrae near her neck. This was, by far, her worst fall.

(continued on page 3)

In this issue...

- **Survivors Speak** p.1
- **Preventing Another Accidental Fall** p.1
- **May is Stroke Recovery Awareness Month** p.2
- **Stroke Recovery Guide** p.4
- **March of Dimes Canada's Aphasia Camps** p.4
- **My Liberty:** Surviving a stroke and reclaiming your life p.5
- **Planned Giving** p.6
- **Canada Cares** p.7
- **Caregivers – Tips and Tricks** p.7

Survivors Speak: Jane and Frank (continued from page 1)

A couple of weeks later, though, he took the recorder back and gave it to Jane again. This time, she played it.

That was nearly six years ago, and Jane has come a long way since then. She's now able to make herself understood and, while she still lives with some aphasia, communicating is much easier than it used to be. For his part, Frank has gotten better at listening and understanding her. Both credit March of Dimes Canada's Aphasia and Alternative Communication Services.

Jane has benefited greatly from relating to and helping other people in the program – it has helped to boost her confidence post-stroke. Frank, too, appreciates the way the program integrates

caregivers into the recovery process. In fact, Frank calls the Aphasia and Alternative Communication Services program 'instrumental' in Jane's progress and their shared journey.

A doctor told them Jane's recovery was miraculous. "And you don't often hear doctors speaking in terms of miracles," Frank smiles.

For more information on March of Dimes Canada's Stroke and Brain Injury services, please call 1-888-540-6666, visit www.marchofdimes.ca/src, or email src@marchofdimes.ca.

May is Stroke Recovery Awareness Month in Ontario!

Every 9 minutes a Canadian will have a stroke. There are almost 400,000 stroke survivors in Canada. May is Stroke Recovery Awareness Month. March of Dimes Canada's Stroke Recovery Canada® is putting stroke survivors in touch with the support they need. Local support groups have been set up across the province to help. Stroke Recovery Canada® is the leading service provider of education, information and peer support to stroke survivors in Ontario. Stroke Recovery Canada® helps stroke survivors across the country to more easily re-engage in their communities, and affirm that they can have a meaningful and quality life after a stroke. Through its work with local peer support groups, March of Dimes Canada offers survivors the tools to survive and thrive after a stroke.

This year we are going to hit the streets of Toronto to tackle the common "myths" surrounding stroke and stroke recovery – stay tuned for informational videos and testimonials!



Debby & Shawn, Stroke Recovery Canada® Program in Winnipeg

For information or to join Stroke Recovery Canada® call the Warmline® at 1-888-540-6666 or visit the Stroke Recovery Canada® website at www.marchofdimes.ca/SRC

Preventing Another Accidental Fall (continued from page 1)

By Michael Izzo, Airgo Mobility



Not long after, she was transferred to the Montreal General Hospital trauma unit, which was not available to my grandmother at the Royal Victoria. Her stay at the Montreal General lasted about a week, and she was let out on the recommendation that she use a walker in the house, and a sturdy rolling walker with wheels for the rugged and

unpredictable outdoors. She was also asked to join an outpatient program for physical therapy at the Royal Victoria Hospital.

Today my grandma is still recovering from her accident, and still has trouble with her balance. She never had to use a walker or rollator before the accident, but when she's using the rollator, she says her back doesn't hurt because the rollator helps her posture. Also, she feels secure and doesn't fear falling.

My grandmother is in better condition than she was in March, and I'm happy she's made this much progress, but it hurts to see her suffer the pain she still has from her injuries. When the accident first happened my family and I were all worried for my grandmother, but we're all so thankful my grandfather is almost always at her side, or he could not have called for help.

Using her rollator makes her feel independent, however she still requires something to help her control her balance, such as a cane, when going up and down the stairs. She also always has her hand on the railing, and usually someone will help her up the stairs.

To help prevent future accidents, my grandparents have sold their house and will move to an apartment or condo with an elevator instead of stairs. Although my grandfather is still her constant companion, everyone has some peace of mind knowing she has a rollator for extra support.

Stroke Caregiver Guide

It's important for stroke survivors, their families, and their caregivers to know what resources are available to support them during recovery. They also need to know what to expect, and that they aren't alone.

A Caregiver's Guide to Stroke Recovery provides all this and more.

The Guide includes personal stories of surviving and thriving after a stroke, as well as information on peer support groups, rehabilitation programs, drug coverage, and Stroke Recovery Canada.

Specifically, you'll find:

- Personal stories of caring for a stroke survivor, including young adult children
- The 7 steps to stroke recovery
- Help for spasticity

- March of Dimes Canada's Aphasia Camps
- Working through grief as a caregiver
- Tips for caregivers
- March of Dimes Canada's DesignAbility program
- Drug coverage in Canada
- Services offered by Stroke Recovery Canada

You can access the latest version of **A Caregiver's Guide to Stroke Recovery:**

- **online** at <http://www.marchofdimes.ca/EN/programs/src/Pages/StrokeResources.aspx>
- **by e-mailing** src@marchofdimes.ca
- **by calling** 1-888-540-6666

March of Dimes Canada's Aphasia Camps

Aphasia Camps are an opportunity for people living with aphasia, and their caregivers, to have physical, social, and educational fun in an environment that is physically and communicatively accessible. The goal is to help participants live more successfully with the communicative disorder known as aphasia.

March of Dimes Canada started offering these unique camps in 2008, in partnership with the Adult Recreation Therapy Centre in Brantford, Ontario, and the University of Western Ontario. They've been available every year since. This is a list of upcoming Aphasia Camps across Canada:

- Nova Scotia Aphasia Camp at Brigadoon Village: September 4th – 8th
- Alberta Aphasia Camp in Edmonton: September 16th – 18th
- BC Sea to Sky Aphasia Camp in Squamish: September 16th – 18th



Ellie and Marc in Geneva Park for the Summer Recreation Program

- Ontario Aphasia Camp (Location TBD): September 23th – 25th
- Manitoba Aphasia Camp: Details TBD

For more information, please visit www.marchofdimes.ca/aphasiacamps.ca

My Liberty: Surviving a stroke and reclaiming your life

By Stacey Diffin-Lafleur

Surviving a stroke and reclaiming your life

A conversation with Barbara Moore,
March of Dimes Canada ... part one

No one wakes up in the morning and says, yes, today is the day I'm going to have a stroke. No one. But it happens every day to people across Canada, and it's not just the elderly. The average age range for strokes in Canada is 26 to 50 years of age.

What is a stroke?

Stroke is an injury to a part of the brain. It causes a pattern of symptoms that arise when something obstructs blood flow to parts of the brain and deprives cells of the oxygen necessary to stay alive. If blood supply to the brain is interrupted for as little as four minutes, brain cells begin to die. They are not replaced. A stroke is a medical emergency.

Stroke Recovery Canada® – March of Dimes Canada Program

“What we do is enable stroke survivors to re-engage in their life and their community by helping them connect to the services they need,” says Barbara Moore, Community Coordinator at Linking Survivors with Survivors. “It's going to be a new normal for them and our role is to link experienced stroke survivors – people who have already adjusted to their new life style – to new stroke survivors, as soon as possible, to help them reclaim their life and their place in community.”

Strokes are not the same for everyone, but sharing recovery experiences can help people understand they don't have to journey down this long path on their own. Others have been there before.

Is incontinence an issue in stroke recovery?

Very much so. For both women and men, incontinence is one of the many challenges for survivors to get used to and in many places,



Barbara Moore

overcome. But it takes work. The level of leakage depends on where the stroke path is. For example, muscle density and tone is impacted by the stroke, so personal mobility can be an issue. Stroke survivors are often not able to get to the bathroom quickly or without assistance. So using incontinence

products such as briefs or pull-ons can be necessary at the beginning of recovery.

Is incontinence forever?

With some stroke survivors managing incontinence absolutely improves as time goes by; in others, incontinence can be part of the new way you embrace life. Knowing you are not alone and that incontinence is here forever can help you plan your future needs. Remember surviving strokes is very individual, and based on your ability and your recovery path. Stroke survival is a lifelong path, it is not a quick fix.

Barbara Moore is a Community Coordinator with the Linking Survivors with Survivors Program at the March of Dimes Canada. She loves her job and the work she does in the community. Watch this space as she will share more experiences working with stroke survivors in future blog posts with MyLibertyLife.

What will your Legacy be?

When we donate to a charity, we naturally want to make sure our money does as much good as possible, whether it's a small monthly donation, a larger yearly contribution, or something in between.

Two very useful and effective ways to donate money are a gift in a Will and Registered Retirement Savings Plans or Registered Retirement Income Fund gifts.

Leaving a Gift in a Will

These are donations that are bequeathed through your Will, and they can make a lasting statement about what was important to you in your life. However, many people shy away from this option because they worry they'll reduce the overall amount of their estate, leaving children and other loved ones inadequately provided for.

This isn't necessarily the case. In fact, a gift in your Will can entitle you to income tax savings that may actually increase the amount you can leave to your heirs.

Another misconception about legacy gifts is that only large donations are appropriate. This isn't true, either. Any amount of money you are comfortable, bequeathing is greatly appreciated, and will help ensure that March of Dimes Canada continues to positively impact the lives of Canadians living with disabilities.

RRSP/RRIF Fund Gifts

Retirement funds are excellent ways to grow wealth during your lifetime, but terrible ways to transfer wealth to children or other heirs. Why? Because they are among the most heavily taxed assets you possess.

Registered funds can be rolled over to a surviving spouse, but are taxed if left to anyone else. An alternative is to donate all or a portion of your retirement funds to March of Dimes Canada. You'll have the satisfaction of:

- Providing a useful gift to a worthwhile cause, while retaining use of the funds during your lifetime
- Donating to a charity you believe in

- Being able to provide for your family as well, by naming more than one beneficiary
- Off-setting estate taxes and reducing probate fees
- Obtaining a charitable tax receipt for your estate

For more information about legacy gifts, please contact Daniella Sretenovic at 1-800-263-3463 ext. 7338 or dsretenovic@marchofdimes.ca

OPEN UP A FUTURE OF POSSIBILITIES.
Make March of Dimes Canada part of your legacy today.



THE BENEFITS OF LEGACY GIVING

- A gift in your Will is a way to do even more for people with disabilities in a cost-effective and meaningful way.
- You can designate your gift to a local community program, chapter or initiative of March of Dimes, that is personal to you.
- Setting up a gift in your Will is very simple, and you can make changes at any time.

Canada Cares

Behind every person recovering from, or living with, a disability is at least one amazing individual who helps them live as fully as possible.

Every year, Canada Cares celebrates these extraordinary Canadians with their Caregivers Awards. The purpose is to acknowledge the family members, friends, and health care professionals who support these people in recovery and everyday life.

Meet the remarkable folks who were honoured in 2015:

One Wish Award Winner: Barbara Aris

Barbara was acknowledged for the support and care she provides to her husband Mike, who was diagnosed with Parkinsons' in 2004, and also lives with PTSD. Beyond her caregiving duties, Barbara has become a very active leader in her community.

National Winner – Professional: Mary Lorraine Horlick

Mary transformed her personal residence into a care home for young women with persistent, severe mental illness. In addition to supporting her residents, Mary encourages them to participate in vocational rehabilitation activities and community events.

Caregivers – Tips and Tricks

Some of the common signs and symptoms of caregiver stress/caregiver burnout

- Anxiety, depression, irritability
- Feeling tired and run down
- Difficulty sleeping
- Overreacting to minor nuisances
- New or worsening health problems
- You have much less energy than you once had
- It seems like you catch every cold or flu that's going around

National Award Winner – Family: Chelsea Russell

Chelsea is a firefighter who took on a large, active, and willing role in the care of her step-children, Lauren and Wyatt, who both lived with Hypotonic Quadriplegia Cerebral Palsy. Sadly, Lauren passed away in 2012. Since then, Chelsea has done everything possible to maximize Wyatt's quality of life.

Do you know someone who works hard to make a difference in someone else's life? Then Canada Cares wants to hear about it! Nominations for their 2016 Caregivers Awards will open soon, and remain open until November 2016. Please keep watching caregiversolutions.org, and click on Contests and Awards, for updates.

For more information visit canadacares.org, call 416-421-7944, or by email info@canadacares.org

About Canada Cares

Caregivers can call the Canada Cares Caregiver Support Line at 1-855-619-5021 for emotional support and to request complimentary copies of Caregiver Solutions magazine and a resource kit. Our Awards Program and Canada Cares Teas celebrate and recognize the important role of caregivers from coast to coast.

- You're constantly exhausted, even after sleeping or taking a break
- You neglect your own needs, either because you're too busy or you don't care anymore
- Your life revolves around caregiving, but it gives you little satisfaction
- You have trouble relaxing, even when help is available
- You're increasingly impatient and irritable with the person you're caring for
- You feel helpless and hopeless

(continued to page 8)

Caregivers – Tips and Tricks

(continued from page 7)

Tip 1: Ask for help

- Speak up!
- Spread the responsibility
- Set up a regular check-in
- Say “yes” when someone offers assistance
- Be willing to relinquish some control

Tip 2: Give yourself a break

- Set aside a minimum of 30 minutes every day for yourself
- Find ways to pamper yourself
- Make yourself laugh
- Get out of the house
- Visit with friends and share your feelings

Tip 3: Practice acceptance

- Focus on the things you can control
- Find the silver lining
- Share your feelings
- Avoid tunnel vision

Tip 4: Take care of your health

- Keep on top of your doctor visits
- Exercise
- Meditate
- Eat well
- Don't skip on sleep

Tip 5: Join a support group! Stroke Recovery Canada® can help you!

Source: <http://www.helpguide.org/articles/stress/caregiving-stress-and-burnout.htm>

Reader's Survey

What did you think of this issue?

- Excellent! Keep up the good work
- Could use more information on (check the appropriate box)
 - Medical research and treatment
 - Sexuality and dating
 - Depression
 - Family caregiver issues
 - Rehabilitation options

Other: _____

Comments



Stroke Recovery Canada® is a program of March of Dimes Canada 10 Overlea Blvd., Toronto, Ontario M4H 1A4
Tel. No.: 1-888-540-6666

YOU ARE NOT ALONE. JOIN STROKE CANADA® NOW!

Are you a:

- Stroke Survivor
- Healthcare Professional
- Family/Friend
- Other

Name: _____

E-mail Address: _____

Address: _____

City: _____ Province: _____ Postal Code: _____

Your donation to Stroke Recovery Canada® will help us continue to provide education and support.

Here is my tax-receiptable donation of:

- \$250
- \$100
- \$50
- \$25
- I prefer to give \$ _____

My cheque is enclosed OR

- Please charge my: VISA MasterCard American Express

I prefer to give monthly

- \$5
- \$10 or
- \$ _____

Card No.: _____

Name on Card: _____

Expiry Date (mm/yy): _____

Signature: _____

Charitable Registration No.: 10788 3928 RR0001
www.marchofdimes.ca | 1-800-263-3463

