CAREGIVER
Participant Handbook

March of Dimes Canada, After Stroke
Community Engagement & Integration Services
How to use this Handbook

Welcome to the 7-week Caregiver Workshop!

The intention of this handbook is to:

- Guide you through each session
- Act as a resource for information even after the program is ended
- Act as a discussion prompt throughout the sessions
- Be a place to write down your questions, notes, doodles, or items to follow up with

The handbook is yours to take away and keep as a resource throughout your caregiving journey. Feel free to add more information and share additional resources with the rest of the participants of the program.
Program Objectives

Session 1: Sharing Your Story
● Be introduced to the 7 week caregiver workshop
● Share some of your caregiving stories and hear from others and their respective stories
● Learn about self-management and identify what it means in the life of a caregiver

Session 2: Changing Roles in your relationship
● Learn about relationship changes after a stroke
● Practice identifying the roles you embody
● Discuss how your roles have changed since the stroke and their impact

Session 3: Behaviour Changes & Managing Your Emotions: Mood, Thought and Perception
● Learn how stroke affects cognition, mood and perception
● Practice strategies of care (Activity)
● Learn about the stages of grief
● Practice an anger release strategy
● Discuss reactions to emotions and strategies of care

Session 4: Community Connections
● Reflect on topics from Session 1
● Learn about stroke services in the community
● Share experiences about services already known in the community
● Learn about navigating the healthcare system as a caregiver

Session 5: Stress Management: Managing the Rollercoaster
● Learn about the different aspects of stress
● Practice a stress self-awareness activity (Activity)
● Discuss self-care stress strategies

Session 6: Communication: Key for Caregivers
● Learn the different components of communication
● Practice listening skills (Activity)
● Discuss how communication changes after a stroke
Session 7: How to be “Caregiver Smart”
- Learn about navigating the system as a caregiver
- Develop a Caregiver Emergency Preparedness Plan
- Discuss questions about how to be an advocate for yourself and the stroke survivor
SESSION 1: SHARING YOUR STORY
Objectives

- Share caregiving stories with peers
- Learn about self-management
- Know that this program is about YOU

Welcome and Introductions

- Thank you for taking the time and effort to be here today!

Housekeeping Items

Before we get started, let’s go through some basic housekeeping items.

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<tr>
<th>Name of Facilitator:</th>
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<tbody>
<tr>
<td>Contact information:</td>
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<tr>
<td>Location of Washrooms</td>
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<tr>
<td>Parking Instructions</td>
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<tr>
<td>Smoking Policy</td>
</tr>
<tr>
<td>Other housekeeping Items:</td>
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Sharing your Story

Let’s get to know each other.

Take a moment to reflect on why you are here. When it’s your turn, answer these questions out loud and share your story with the group:

Your Name

Who are you caring for? What is your relationship with them?

When was their stroke?
Let’s Discuss!

Tell us a bit about your journey since their stroke.

Remember, as caregivers yourself, you are the experts on what it means to be a caregiver. Take this opportunity to learn from each other, as caregiver experts.
What is Self-Management?

Recovery after stroke is a lifelong process, not only for a survivor, but also for the caregiver. Although stroke often causes sudden changes, the road to recovery is slow. It takes patience, strength and determination as a caregiver.

The path of recovery provides the opportunity for stroke survivors to be self-managers of their health and life, as well as caregivers to be self-managers of their health and life.

You have been given the task of living well as a caregiver.

Self-management includes:

- Health management
- Role management
- Emotional management

Components of Self-Management

As a caregiver, you have many components to contribute to your health and well-being:

- Problem solving skills
- Goal setting
- Social support
- Emotional health
- Individual assessment
- Links to community resources
Components of Wellbeing in Self-Management

When thinking about self-management in regards to your well-being, a holistic approach is necessary. Consider these six areas of your health.

1. **Physical** – taking care of your body through proper nutrition, activity and fitness
2. **Emotional** - becoming aware of how emotions affect your body and recognizing their effects
3. **Intellectual** - examining one’s opinions and judgments, and the connections to life
4. **Spiritual** - developing a set of values, principles and beliefs that give a sense of meaning and purpose in life.
5. **Social** - creating and maintaining healthy, satisfying relationships that are mutually loving and supportive.
6. **Environmental** – creating an environment that is conducive to living well

**Take a moment to rate (on a scale of 1-10) each aspect of your wellbeing. Reflect:**

**What area needs the most work?**
How does self-management help?

Self-management is a decision you make when you are faced with being a caregiver to a stroke survivor.

Some people manage by withdrawing, isolating themselves and becoming depressed and overwhelmed.

Caregivers must make the decision to live well and remember, “YOU are the manager”

Why is self-management important for caregivers?
Activity: What are your Self-Management Strategies?

1. Scan the list below.
2. **Check off** the coping strategies that you currently practice.
3. **Circle** three of the coping strategies that you checked off that you view as healthy self-management techniques.
4. **Underline** three strategies that you practice that may not be viewed as healthy self-management techniques.

- Take a nap
- Talk with friends or family
- Do something for yourself that you enjoy
- Exercise
- Take part in a hobby
- Pray for help
- Smoke cigarettes
- Go to church, synagogue, mosque, temple, etc.
- Meditate
- Yell or raise your voice in frustration
- Go for a walk or run
- Think about your problems all the time
- Count to 3, 5, or 10
- Take an educational class
- Watch T.V. or a movie or go online
- Avoid thinking about your problems
- Write down your thoughts in a journal
- Decide to do nothing about the situation
- Go shopping
- Go for a massage
- Practice some breathing exercises
- Joke about the situation to a friend
- Laugh with your partner about a situation
- Decide to avoid the person that is irritating you
- Cry
- Listen or play music
- Research stroke and caregiving
- Play a game
- Take medications or drugs
- Take a bath or shower
- Talk to other people in similar situations, other caregivers
- Talk with the person receiving your care
- Read a book
- Go to a counselor, social worker or other health professional
- Have a drink or two
- Day dream about leaving your situation
- Join a support group

**Let’s Discuss!**

What do you struggle with most when it comes to being a caregiver? What works? What isn’t working?
What are healthy self-management techniques that you could adopt in your caregiving role moving forward?

Suggested Readings and Resources


- Getting on With the Rest of Your Life After Stroke - Canadian Stroke Network – www.canadianstrokestrategy.ca

- The Patient and Family Guide to Best Practice Recommendations for Stroke Care – www.canadianstrokestrategy.ca


- The Healthline - Enter your community name or a postal code to find health and community services in Ontario. - https://www.thehealthline.ca/
SESSION 2: CHANGING ROLES IN YOUR RELATIONSHIP
Objectives
- Learn about relationship changes after a stroke
- Discuss how your roles have changed since the stroke and their impact
- Learning to balance the changing roles and responsibilities that caregivers play can be a challenging aspect of caregiving

Introduction
The roles you and your care partner play in each other's lives have most likely changed in many ways since the stroke.
It is also important to note that the role of caregiver is not your ONLY role!

What are some of the roles that you play in your life?
(for example: father, husband, friend, caregiver, employee, volunteer, etc.)
What changes in these relationships have there been since the stroke?

Responsibilities and Tasks

- After a stroke, caregivers suddenly find themselves having new responsibilities and tasks to do which they never thought they would encounter.

What new responsibilities have you taken on since becoming a caregiver?
Which of these responsibilities do you find the most challenging? Ask yourself why these seem to be the most challenging to you?

As a group, let us brainstorm ideas to make these tasks more manageable.
Which idea seems most realistic? What steps need to be taken to put this idea into action? Who can help?
SESSION 3: BEHAVIOUR CHANGES & MANAGING YOUR EMOTIONS

ANGER GRIEF, LOSS
Objectives

- Learn how stroke effects cognition, mood and perception
- Learn about the stages of grief
- Practice an anger release strategy
- Discuss reactions to emotions and strategies of care

Stroke Effects to the Brain

A stroke is an injury to the brain. The brain is the headquarters of the body, not only for physical aspects, it also houses a person’s character and personality. A stroke can affect both physical and behavioural changes of a person. Often the behavioural changes may be the most emotionally challenging to manage or adjust to as a caregiver.

How a person is affected by a stroke depends on:

- Location of the damage
- Severity of the damage
- How well the body repairs the blood supply to the brain
- How quickly other areas of the brain tissues take over the damaged cells

According to the information above, what type of stroke did your care partner experience? What behavioural functions were affected by the stroke?
Have you experienced any changes in your care partner related to mood, perception or thought? Give some examples.
Activity: Strategies of Care

Now that you’ve learned about the different changes in the brain after a stroke, let us apply it to a real situation.

Scenario:
Martha lives with her husband Henry, a stroke survivor. Henry had a stroke two years ago, and physically he is walking again. He was near retirement so decided not to go back to work. Martha finds that it is a real challenge having Henry at home all the time, especially because now it seems that he questions Martha about EVERYTHING in detail. Before the stroke, Tom didn’t seem to even notice that there was any housework at all but now he has become a micromanager. Martha tries to be patient most days, but now Henry even criticizes the way she does laundry.

OR - Think of your own ‘real life’ scenario…

Ask yourself these questions:

● What are the underlying issues here? How to go about uncovering them?
  ○ STOP
  ○ BREATH Deeply
  ○ THINK:
  ● What is going on?
  ● What is the cause?
  ● What can I do about it (if anything)?
    ○ Some things you can change, some things you cannot
Let’s Discuss!

When difficult situations arise where mood, thought or perception are affecting the behaviour of your partner, what can you do?

What are some strategies that have worked for you before?
When nothing seems to be working, what do you do?

Managing your Emotions:

A caregiver, just like everyone, feels a range of emotions throughout day to day life.

No amount of preparation can prepare you for a stroke. It occurs suddenly without warning, affecting the individual as well as the family. An overwhelming feeling of loss, anger and grief resonate.

Describe how you feel about being a caregiver?
What is Grief and Loss?

Kubler-Ross, a well-known psychologist, described the feelings of grief and loss after a sudden event, like a stroke. By looking at grief and loss in different stages and how people characteristically react in times of sudden change, caregivers may have a better awareness of their thoughts and emotions, and which stages they may recognize in themselves.

According to Kubler-Ross, the stages of grief and loss include:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance
## Stages of Grief, according to Kubler-Ross

### Denial

"I feel fine."; "This can't be happening, not to me."; “I will be okay.”

Characterized by:

- Avoidance
- Confusion
- Fear
- Numbness
- Blame

Denial is usually only a temporary defense for the individual. This feeling is generally replaced with heightened awareness of what will be changing because of the loss.

### Anger

"Why me? It's not fair!"; "How can this happen to me?"; "Who is to blame?"

Characterized by:

- Frustration
- Anxiety
- Irritation
- Embarrassment
- Shame

In this stage, the individual recognizes that denial cannot continue. Because of anger, the person is very difficult be around due to misplaced feelings of rage and envy which may alienate people who try to help.
**Depression**

"I'm so sad, why bother with anything?"; "What's the point? All my plans for the future are changed/gone."; "I miss my loved one, why go on?"

Characterized by:

- Overwhelmed
- Blahs
- Lack of energy
- Helplessness

A person begins to understand the certainty of the situation and begins to feel hopeless. The individual may become silent, refuse visitors and spend much of the time crying and grieving. This allows a person to disconnect from things of love and affection. Attempts to cheer up an individual are often not successful.

**Bargaining**

"I'll do anything to have my life back to normal."; "I will give my life savings if..."

Characterized by:

- Reaching out to others
- Desire to tell one’s story
- Struggle to find meaning for what has happened

This stage involves the hope that the individual can somehow change their situation. Usually, the negotiation for life before the incident is made with a higher power in exchange for a reformed lifestyle. Psychologically, the individual is saying, "I understand that this happened, but if I could just have more time..."
Acceptance

"It's going to be okay."; "I can't fight it, I may as well prepare for it."

Characterized by:
- Exploring options
- A new plan in place

In this last stage, the individual begins to come to terms with the situation that the incidence has left with them and make plans to live successfully at a new normal.
Let's Discuss!

Do you recognize any of these stages, thoughts or emotions in yourself?

How do you respond to these emotions related to grief and loss?

Have you given yourself permission to feel these emotions?
Activity: Emotional Release – Journaling

Are ready to explode? Too tearful to carry on? Here’s a release technique that can be helpful in many situations.

Things you'll need: *Pen, Paper, Quiet Time*

- **Day One:** Find a quiet spot, get pen and writing paper. Don't skimp on size or quantity-you don't want to run out of paper and you DO want a large enough writing surface on which to vent.

- **Day Two:** Set a timer for ten minutes or place your watch nearby. Begin writing-pour your wrath, your frustration, your bile about this person onto the page. DO NOT STOP YOUR HAND, DO NOT STOP TO THINK-these are the keys to this exercise. Then when the time is up, put away the anger-soaked pages. Go about your day, no need to explain what you just did.

- **Day Three:** Find your quiet place again, get out the pages you wrote the day before and read the entire thing, word-for-word. Set your timer again and go for another ten minutes. Same thing, keep that hand moving with no stopping. Then put the pages away again.

- **Day Four:** Read the entire piece and then find a place where you can SAFELY burn it or destroy the pages. As it burns, envision your rage being released. As the smoke billows away, let your anger go with it.

Now with a clear head and your bags emptied of rage, you can have a talk with the person or not talking if you’ve realized it’s does not warrant a conversation.
SESSION 4: COMMUNITY CONNECTIONS
Objectives

● Learn about stroke services in your community
● Share experiences about services you already use in the community
● Learn about navigating the healthcare system

Community Service Providers

Community stroke service providers have been invited to the group today. Each service provider will give a 15 minute overview of the services they offer to stroke survivors and their families as they transition from hospital to home and home to community. Participants will learn about health system navigation and resources will be provided during the session.

Service Provider #1

Name:

Contact Information:

Services:

Notes and Questions:
Service Provider #2

Name:

Contact Information:

Services:

Notes and Questions:
<table>
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<tr>
<th>Service Provider #3</th>
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<tbody>
<tr>
<td><strong>Name:</strong></td>
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<td><strong>Contact Information:</strong></td>
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<td><strong>Services:</strong></td>
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<td><strong>Notes and Questions:</strong></td>
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Questions and Discussion

Here are some sample questions you might have as a caregiver.

1. What services does your organization offer? What is the purpose of the program and does it involve for the participants?

2. What is the eligibility of the program?

3. How do I access the program? Are there any costs associated with the program?

4. How can caregivers be involved for their own education and support?

5. Can you suggest any other programs or services in the community that may be of interest to me?

6. How can I advocate for myself and my partner within the system?

Other topics you might want to ask about?

1. Advocacy for caregivers
2. Financial assistance
3. Referral process
4. Where to find this information
5. How would the service providers take back what they learned tonight and apply it to their programs? (Accountability)
Objectives

- Learn about the different aspects of stress
- Practice a stress self-awareness activity (Activity)
- Discuss self-care stress strategies

What does stress mean to you?

What comes to mind when you hear the term ‘caregiver stress’?
Different Aspects of Stress

- **Stressor** – an event or situation that an individual perceives as a threat that causes us to either adapt or initiate a stress response
  - your find out that your partner has been taken to the hospital; a homecare worker fails to show up at the specified time

- **Distress** – negative effects of stress that can drain us of energy and surpass our capacity to cope
  - Heart starts to pump faster with feelings of anxiety; start to grind your teeth at night; become short tempered with little patience

- **Eustress** – positive, desirable stress that keeps life interesting and help to motivate and inspire
  - A busy day focuses you to get all your tasks done in record time; with your help your care partner is able to shower on their own

- **Acute Stress** – results from a short term stressor. It appears suddenly, is usually quite intense and disappears quickly

- **Chronic Stress** – long-term, continuing stress provoked by unrelenting demands and pressures that go on for an extended period of time
Caregiver Stress

How do you know when you are in distress?

- Cardiovascular disease
- Muscle tension and pain
- Headaches
- Fatigue
- Upset stomach
- Difficulty sleeping
- Bruxism (grinding, gnashing or clenching of teeth)
- Poor immune system
- Anxiety
- Difficulty concentrating
- Worry
- Fear
- Guilt
- Frustration
- Anger
- Exhaustion
- Turn to poor coping mechanisms (smoking, drinking, etc.)
- Other: __________________________
Let’s Discuss!

What are some of the symptoms of distress that you experience as a caregiver?

What are some of the symptoms of distress that other members of your family or household experience? What does your care partner experience?
As a caregiver, what ‘stresses you out’ the most?

What behaviours or actions do you automatically resort to when you are ‘stressed out’?

Are these the healthiest way to react? How can you better plan to face these situations?
10 Cs for Thriving Under Pressure

1. **Conditioning** - nutrition, exercise, sleep

2. **Caring** - supportive, caring relationships

3. **Challenge** - interpret difficulty as a positive challenge
   a. See **challenge**, don’t see a problem

4. **Confidence** - believe… ability to master

5. **Commitment** - positive involvement

6. **Control** - believe in ability to influence events

7. **Coping** - ability to respond constructively

8. **Calmness** - maintain moderate arousal in the face of difficulty

9. **Creativity** - ability to generate innovative solutions

10. **Competence** - ability to handle demands of a task effectively
SESSION 6:
COMMUNICATION
KEY FOR CAREGIVERS
Objectives

- Learn the different components of communication
- Practice listening skills (Activity)
- Discuss how communication changes after a stroke

Let us discuss first what communication means to you. Why is the topic of ‘communication’ important for you as a caregiver?
What is communication?

- A shared experience
  - It takes (at least) two people to talk or have a conversation
- It is uniquely individualized
  - No two people communicate in the same manner
- It reflects an accumulation of attitudes, values, beliefs and experiences
  - What is your talking saying about you?
- It can have as much of an impact on the environment as the environment has on communication
  - Even though similar words may be said, the message is subject to interpretation

Communication is...

50% Visual

40% Vocal

10% Verbal
What are the components of communication?

- Talking
- Facial expression
- Body language
- Gesturing
- Writing
- Understanding
- Reading
The mechanisms of communication and speech:

Understanding
Making sense of the message.

Responding or Expressing
Coming up with a response.

Hearing
Voice
Seeing
Brain processing

Facial muscles
Hands/arms gesturing

A stroke can affect many components of communication. How has stroke impacted communication with your partner?
Communication Barriers

Who do you find most challenging to communicate with as a caregiver?
Activity: Learning to Listen

Instructions:

1. Find a partner in the room to share with.
2. One partner will talk first; the other will listen. Each person will have 3 minutes to talk WITHOUT interruption, asking questions or providing advice. At the end of 3 minutes, switch roles and repeat the exercise.
3. The questions you will be focusing on will be on personhood:
   - The person you are caring for:
     - What are the strengths of the person you are caring for?
     - What are some of the things that really bother you about the person you are caring for?
4. As a group, let’s discuss these questions:
   - How did the exercise feel for the listener?
   - How did it feel for the person being listened to?
Reflection

True listening involves both the physical aspects of listening – both ears, eye contact etc. – but also the underlying emotional aspect of listening – the empathy and heart. Was it hard just to listen for 3 minutes without interrupting, asking questions or offering an opinion? Often when listening we are so busy planning what we are going to say, we don’t actually listen to what is being said to us.

What did you discover about the person your partner is caring for? What were some of their strengths?

What are some of the common things that bother people about the person they care for? Which things can be attributed to the ‘disease’, the stroke?
Discussion and Questions

How has communication with your care partner changed since the stroke?

What strategies do you use to help improve communication with each other?

What acts as a barrier when it comes to communication with your care partner?
What can you do to help you to better communicate?

What can your partner, your friends and family, etc. do to better communicate with you?

What do they need to know about you in order to communicate more effectively with you?
SESSION 7:
HOW TO BE CAREGIVER SMART
Objectives

- Learn about navigating the system as a caregiver
- Develop a Caregiver Emergency Preparedness Plan
- Discuss questions about how to be an advocate for yourself and the stroke survivor

How do I Find My Way? The Art of Navigation...

Family members or friends often assume the role of caregiver with little or no preparation - they simply respond to a need. What they find very quickly is that while there may be some services available, in varying degrees, it is a difficult process to find what is 'out there'

Describe the situation when you first found out that suddenly YOU were the one begin described as the ‘caregiver’? How did that make you feel?
Navigation is the term that seems to best describe the process of finding one's way through a complex maze of jurisdictions, departments, services and programs. There are some tips that can demystify the process of navigation - offering some guidelines for seeking information and services - without adding unnecessary stress.

Like each stroke is different, so are the needs of each stroke survivor and caregiver. Define what the priorities are for you and your care partner and take one step at a time to reach your goals.
Case management – Becoming an advocate

When families are faced with the many demands of caregiving, the initial reaction can be overwhelming. Few people have had the experience of 'case management' which now becomes part of the caregiver role. They ask: How do I get some help? Where do I go for information? Furthermore, most caregivers are trying to juggle a multitude of responsibilities and, while they acknowledge that there may be help 'out there', they say: I don't even know the questions to ask!

Throughout this program you have been given some great resources on where to look and some ideas on how to make the system work for you.

What are some tips you’ve learned so far as a caregiver that you’d like to share with other caregivers?
Activity: Emergency Preparedness Plan

Part of being caregiver smart is planning for any further disasters. Often, caregivers come to realize that their care partner depends on them for so many things. What happens if a caregiver gets sick themselves? What happens if you need to access respite services? What happens in an emergency? Who is there to take care of you?

In cases like these, the best idea is to think ahead and be prepared.

Instructions:

- Take the time to read through the ‘Emergency Preparedness Plan’ in your handbook.
- Discuss with your care partner, family and friends any issues or questions that might come about as you fill out the form.
- Tell someone about it – once this plan has been filled out, make sure to make several copies and distribute them to your emergency contacts and close friends.
- Review the plan after any change in condition or on an annual basis (NOTE: A good reminder is to update every time you do your taxes!)
- Discuss with other caregivers any points or ideas they might have to add to the plan.
- What about account and computer passwords, important documents and financial information?
Discussion and questions

Being ‘caregiver smart’ means looking after yourself so you can look after your care partner.

What would you put in your own personal make-up bag or shaving ‘kit’ to look after yourself?
What would you advise a new caregiver to do based on your own experiences?

What is the most significant thing you learned as a caregiver?
“Caregivers must realize that you need to save you, first. Or there will be nothing left for anyone else.”

-Judy F.

TOLL-FREE WARMLINE
1-888-540-6666

Information line that connects stroke survivors with region-specific resources, information and support (Runs Monday to Friday from 9 a.m. to 4:30 p.m. EST)

Provides a safe, accessible options for stroke survivors looking for resources after they are discharged from the hospital

Receive our monthly e-newsletter by registering at: afterstroke.marchofdimes.ca