

Help for Caregivers

A stroke can permanently alter the mind and body of a survivor, but also the lives of an entire family. Day to day family life may be changed forever. A stroke means that caregivers must somehow set aside their own shock and fear to support their loved one, whose needs may seem to far outweigh those of the caregiver.

Caregivers, however, must meet the enormous challenge of caring for the physical and emotional needs of their care recipient **without** neglecting their own needs.



Information and Education

“Lack of information heightened our grief. I had the feeling nobody cared.”¹

In the event of a stroke, caregivers of a stroke survivor need:

- **Information** about stroke and its impacts, prognosis and the rehabilitation process
- **Education** about the physical and psychological needs of stroke survivors
- **Practical assistance** in enhancing caring and coping skills
- **Increased awareness** of available attendant care (outreach), therapeutic, social service, and respite supports
- The **opportunity to share** ideas, information, and coping methods with others dealing with similar issues

Sources of support include:

- After Stroke – provides programs and services, information and resources, and navigational support
- Information produced by hospitals, regional information services, seniors’ directories, municipalities, regional health councils, and libraries
- Caregiver support groups based in community centres, churches, synagogues, mosques, etc.

¹ *Quotes contained are from participants from a caregiver workshop held in Burlington in 1995, involving the Community Health Services Centre, Burlington SRA, Fellowship of Stroke Survivors, and the United Way.

The Work of Caregiving

Caregiving can be physically, emotionally, and financially straining. Too frequently, little thought is given to a caregiver's ability to deal with the burden of providing care.

Caregivers, their family and friends must consider:

- **Financial** status
- **Preparing** the home – i.e. bath rails, shower chair, non-skid mats
- The **ages and health** of the caregiver and care receiver
- The **gender** of the caregiver – men are not often as socialized to give care as women
- The **safety** concerns of caregiving, including the ability of the caregiver to handle emergencies such as a fall

Family caregivers must learn to ask for and accept the help they need to fulfill their role. It is very important to not take on the full responsibility of caregiving alone.

Help yourself by helping the care recipient:

- Organize a realistic and flexible schedule for the care recipient, incorporating down time for yourself
- Set specific and viable goals - this will boost the stroke survivor's confidence and self-esteem
- Help your loved one stay in touch with the world he or she has known
- Encourage the survivor to be more responsible and less dependent
- Remember that greater independence is good for a stroke survivor's well-being and reduces demands on the caregiver



Caregivers need to look after themselves first.

Otherwise, the quality of care that they are capable of giving, their relationship with their care recipient, and their own quality of life can suffer greatly.

Relationship Change

Physical disability, communication problems, and personality changes in a stroke survivor may cause profound relationship changes. This can place great **stress** on caregiving relationships.

After a recent stroke, a survivor might not be able to respond to anyone’s needs but his or her own. They may show little appreciation for another’s needs or efforts. Spouses and caregivers must often come to terms with what may be permanent changes in their partners such as depression, fatigue, lack of strength, frustration, egocentricity, and thoughtlessness. The partnership the caregiver once shared with the care recipient may also be changed forever. They may now be the primary shopper, cook, nurse, financier, chauffeur, handyman, and more.



The Stress of Caregiving

For a stroke survivor, the experience of stroke may be terrifying and disorienting. The spouse and family, however, are thrown into a situation that is no less frightening. Often, they must suspend grief, fear, and frustration in order to help the survivor.

Caregivers generally have very demanding expectations of themselves. After the initial shock has passed and the caregiver and stroke survivor have settled into a new routine, the stress of caregiving may emerge and the caregiver may exhibit **irritability, anxiety, numbness, or fatigue**. They may also feel that they just can’t manage. Caregivers may become **distant and detached, or experience health problems** of their own.



The occasional expression of these feelings is **natural and normal**. The caregiver should not feel guilt or embarrassment by these feelings- it is a warning sign that it’s time to reduce stress.

There are many ways to manage stress:

- Talk to someone (a friend or professional) about your feelings
- Journal about your feelings
- Take time to take out your frustrations by being physically active
- Take a break – find some time away from the situation

Cognitive Distortion

A useful way of clarifying your thoughts is to have someone you trust listen quietly as you explain your situation to them. In this way, any distorted ways of thinking will become clearer to you.

Different types of distorted thinking are listed below. Do you recognize any of them?

- **Overgeneralization** – thinking that an isolated event or decision makes you a poor caregiver
- **“All-or-nothing” thinking** – seeing your efforts either as only successes or only failures
- **Negative thinking** – ignoring the positive and focusing only on the negative
- **Catastrophizing** – exaggerating the importance of your own failures or someone else’s successes; making a situation seem much worse or severe than it is

Many avenues of research show that **flexibility** is the key to successfully dealing with the tremendous stress imposed by a stroke in the family. Don’t be a martyr. Give yourself encouragement, compassion and understanding and, whenever needed, a break.

Caregiver Survival Checklist

- Take one day at a time
- Accept your limitations
- Learn to ask for and accept help
- Have a daily routine and stick to it
- Don’t bottle up negative feelings – talk about them with someone you trust
- Take time for yourself every day and stick to it
- Keep your sense of humour
- Look after your health – get plenty of rest, exercise daily, eat a nutritious diet, and see your doctor
- Take advantage of local support groups like those offered by Stroke Recovery Canada
- Remain socially active
- Find a caregiver respite program in your community

