The impact of stroke on the survivor’s family

A stroke affects the whole family. Family members may have strong feelings and go through many changes. They may feel they are on an emotional roller coaster, making it hard to cope.

Each family member will react differently, depending on the relationship they have with the stroke survivor and their own personality. One family member may be afraid for the future of a loved one. Another might worry about how they will care for the survivor. While each family is unique, their reactions could include:

**Stress from:**
- The disruption of household routines
- The need to cope with new issues or problems

**Worry that:**
- Their loved one will fall
- Their loved one will have another stroke or die

**Sadness, anger, or frustration about:**
- The loss of their social life or time at work
- The loss of time for themselves

**Guilt about:**
- Living in their own home while their loved one is in a hospital or long-term care home
- Taking time for themselves instead of spending all their time with their loved one

**Grief:**
- Intense sadness, just as if the survivor had died
- Feeling they have lost the person the stroke survivor used to be

**What you can do to help**

Here are some ways you can help the stroke survivor’s family:

- Ask family members how they are being affected by the stroke
- Be supportive. Offer information and assistance
• Give encouragement and positive feedback when the family is managing well. The family often needs to know that others appreciate their efforts. Show them that you know they are doing their best.
• Encourage family members who wish to help with the survivor’s care to get involved.
• Encourage family members to make time for themselves. They need to balance care for themselves and care for the survivor.

Watch family members for signs of stress or other negative emotions. Report your concerns about a family member’s mood to someone on your team who can help.

Stresses on the informal caregiver

The informal caregiver is the person who has the main responsibility for looking after the stroke survivor. This person could be the spouse, an adult child, a sibling, a close friend, or a neighbour. Caring for a stroke survivor can be difficult, stressful, and time-consuming. The caregiver may have some of these feelings:

Anxiety about:
• How they will be able to keep caring for the survivor. This is especially true if the caregiver has health problems or is older.
• Their role. Depending on the culture they grew up in, caregivers may feel it is their duty as spouse, child, or family member to care for the survivor single-handedly. This is stressful, but failing to care for the survivor would be an even greater source of stress.

Worry about:
• Money – being able to keep providing financially for the survivor

Fear of:
• Social isolation: Initial offers of help and support from friends and relatives often decrease over time
• Others judging the quality of care the survivor is getting

Guilt about:
• Being unable to care for the survivor
• Placing the survivor in a long-term care home

Frustration at:
• Seeing the survivor struggle to cope
• Seeing no improvement, or less improvement than hoped

Anger about the stroke:
• How it affected both of their lives
• How it affected their plans – “This isn’t the retirement we planned”

Exhaustion from:
• Caring for the survivor. Extreme fatigue may make the caregiver seem apathetic towards everything else
• Exhausted caregivers may appear uncaring or cold
• Care giving often consumes all their energy and emotion

Confusion about:
• A role reversal in a relationship. The main caregiver, usually the wife, may now be cared for by her husband, or a parent may now be cared for by a child
• The role reversal may increase the stress felt by both the survivor and the caregiver

What you can do to help
You can play an important role in identifying caregiver stress. You can also encourage and support the informal caregiver. Here are some ways to help:

Listen to the caregiver.
Caregivers may need to share their worries. Suggest a tea or coffee break and listen to the caregiver. They may need to talk repeatedly about their fears for the survivor. However, they may be uncomfortable discussing the stress and fatigue of care giving, due to fears of being judged or criticized.

Observe the caregiver.
Weeping, anger, poor eye contact, and withdrawal from others are signs of stress. Share these observations with your team.

Learn about the caregiver’s support system.
This may include family members, friends, neighbours, the family doctor, and members of the caregiver’s faith group. Encourage the caregiver to seek help from their support system.

Reassure them about the survivor’s care.
Demonstrate your ability to meet the survivor’s needs for care.

Communicate clearly and consistently with caregivers.
Ask them directly what can be done to decrease demands placed on them. Do not lecture them about what they should or should not be doing.

Encourage the caregiver
Help the caregiver to have a realistic sense of hope about the future. Encourage them to believe that they will be able to adjust to the new reality.

Refer the caregiver to helpful resources.
A very helpful resource is “Let’s Talk about Stroke: An Information Guide for Stroke Survivors and their Families”, published by the Heart and Stroke Foundation.

Report your concerns
If you feel that a caregiver is not doing well and needs more support, report your concerns to your case manager.
Upon reflection

What are some signs of caregiver stress or burnout?

Think about an informal caregiver you have met while caring for a stroke survivor.

What kind of stress were they feeling?

What did you do to support the caregiver? Can you think of anything else you could have done?