FAMILY SUPPORT
Information for Patients and Families

What is family support?

Family support is the physical and emotional care and support that is given to individuals with stroke. Individuals who have had a stroke may require assistance with task and activities that they were previously able to do independently. Most often it is family and close friends who provide this support.¹
What support-based interventions are beneficial to individuals with acute stroke?

Evidence from scientific studies show that different types of support may be beneficial for individuals with acute stroke. These include:

**Intensive Discharge Transition Preparation**
Transition preparation programs aim to help patients return to home safely and in a timely manner. One study looked at the benefit of an intensive discharge transition service that included therapeutic weekend care at home before standard discharge, a training course and educational seminars for family carers, and telephone counselling. This program was found to improve patients’ health status. However, it did not have a significant impact on patients’ independence or emotional wellbeing.

**Group Education Programs**
Studies have shown that group education programs (e.g. lectures, seminars and discussion groups) can improve patients’ knowledge of stroke and their satisfaction with the intervention they receive during stroke rehabilitation. However, group education programs have not been found to improve patients’ emotional wellbeing, quality of life or independence.

Other interventions that have been examined by scientific studies include:

**Family Support Officers**
Several studies have looked at the benefits of support services such as a Family Support Officer or similar support worker. Family Support Officers provided services such as education, emotional support, home visits, telephone contact and assistance in accessing resources. It was found that these support services do not improve patients’ emotional wellbeing, activity/participation, quality of life or knowledge of stroke. However, there are mixed results as to whether these services can benefit patients’ satisfaction with the intervention they receive during stroke rehabilitation.

**Written Information**
Written information packages (such as brochures and educational leaflets on stroke) have been found to cause no significant improvement in patients’ knowledge of stroke or their satisfaction with the information provided to them about stroke. Further, written information packages have not been found to improve patients’ emotional wellbeing, quality of life, independence or ability to access community services.

**Integrated Care Pathways**
An integrated care pathway is a care plan that is developed by the multidisciplinary team to help with the patient’s recovery. Studies have found that integrated care pathways do not significantly improve patients’ satisfaction with the care they received, their quality of life, or their independence after stroke.
What support-based interventions are beneficial to family/friends of individuals with acute stroke?

A number of scientific studies have investigated the impact of support-based interventions for carers of individuals with stroke.

Group Education Programs
Participating in a group education program may improve carers’ knowledge of stroke. However, studies show that group education programs do not improve carers’ emotional wellbeing, quality of life or satisfaction with care.

Family Support Officers
Results regarding the benefits of family support services (e.g. Family Support Officers) are mixed. It was found that family support services may improve factors such as carers’ health status and quality of life, and their level of satisfaction with services. However no significant benefits were found in terms of carers’ knowledge of stroke, activity and participation, or emotional wellbeing.

Written Information
There is some research to suggest that written information (e.g. leaflets regarding stroke) may improve carers’ quality of life. Written information packages have not been found to benefit carers’ knowledge of stroke, satisfaction with the information they received, emotional wellbeing or quality of life after the patient’s stroke.

Cognitive Assessments
One study gave patients a thorough cognitive assessment and recommendations that were individualised according to the patient’s difficulties. Results from the study found that this treatment did not improve carers’ emotional wellbeing.

Intensive Discharge Transition Preparation
Studies show that intensive discharge transition services (i.e. weekend care at home before standard discharge, a training course and educational seminars for family carers, and telephone counselling) do not improve carers’ quality of life or emotional wellbeing.

Integrated Care Pathways
An integrated care pathway is a care plan that is developed by the multidisciplinary team to help with the patient’s recovery. Studies have shown that integrated care pathways do not improve carers’ satisfaction with care or emotional wellbeing.
How does providing support affect the caregiver?

Taking responsibility for the well-being of a family member or friend with stroke is often challenging. Because stroke occurs suddenly, there is often no time to get used to a change in health and functioning. Caregivers often experience sadness, anger, frustration, depression and loneliness, as the demands and stress of caring for your family member or friend increases. It is important to recognize and understand these feelings to prevent becoming too overwhelmed and experiencing “caregiver burn-out.”

Recognizing warning signs that you may be “burned-out” is important. If you are experiencing any of the following symptoms you should consider reaching out to others around you for help:

- decreased energy
- compromised immune system (getting sick frequently)
- constant exhaustion
- lacking in your own personal care
- constantly irritable
- impatient
- difficulty relaxing or taking time for yourself

You may find it beneficial to learn as much as you can about your loved-one’s condition, and be realistic in how much you have to give to someone (both mental and physical resources). Seeking help for yourself as well is essential, and there are a number of resources available to help you cope. Many people are in this situation. You are not alone.
Top 10 Tips for Caregivers²

The National Family Caregivers Association offers these 10 tips for family caregivers.

1. Choose to take charge of your life, and don’t let your loved one’s illness or disability always take center stage.

2. Remember to be good to yourself. Love, honor and value yourself. You’re doing a very hard job and you deserve some quality time just for you.

3. Watch for signs of depression and don’t delay in getting professional help when you need it. Download a printable depression self-assessment from the American Medical Association*.

4. When people offer to help, accept the offer and suggest specific things they can do.

5. Educate yourself about your loved one’s condition. Information is empowering.

6. There’s a difference between caring and doing. Be open to new technologies and ideas that promote your loved one’s independence and help you do your job easier.

7. Trust your instincts. Most of the time they’ll lead you in the right direction.

8. Grieve for your losses, then allow yourself to dream new dreams.

9. Stand up for your rights as a caregiver and as a citizen.

10. Seek support from other caregivers. There is great strength in knowing that you are not alone.
Where can I get information about assisting family members with stroke?

Your local hospital may be able to give you information about caring for a family member or friend with stroke. Here are a number of other resources that may help as well.

1. StrokEngine  
   www.strokengine.ca
2. Canadian Stroke Network  
   www.canadianstrokenetwork.ca
3. Heart and Stroke Foundation of Canada  
   www.heartandstroke.ca
4. Stroke Recovery Association of British Columbia  
   www.strokerecovery.bc.ca
5. American Stroke Association  
   www.strokeassociation.org
6. American Heart Association  
   www.americanheart.org
7. National Family Caregivers Association  
   www.thefamilycaregiver.org
8. The Internet Stroke Center  
   www.strokecenter.org
9. SAFE (Stroke Awareness for Everyone, Inc.)  
   www.strokesafe.org/
10. National Stroke Association  
    www.stroke.org

References

1. Anderson R. The contribution of informal care to the management of stroke.  
2. Top 10 tips for caregivers: http://www.americanheart.org

Information on this web site is provided for informational purposes only and is not a substitute for professional medical advice. If you have or suspect you have a medical problem, promptly contact your professional healthcare provider.