

The impact of stroke upon the family

The Acute Stroke Patient

Although strokes are such a common occurrence in our society – some 50,000 in Canada each year – each one comes as a bolt from the blue, nearly always unexpected, often involving a spouse who may not be in the best of health and who by reason of age may have limited capacity to adjust to such a crisis. For the first few days, the main concern is whether the patient will survive. Then, for a few weeks, the question is how much the patient will be able to recover. As the situation becomes clearer, the family must learn to adjust to a loved one who may have trouble understanding them, who may not be able to communicate thoughts and feelings, is often emotionally labile (*has a loss of emotional control due to brain injury*), who probably has problems getting about, has visual deficits, who needs help even in the simplest activities of daily living, and who tires out easily.

The Importance of Support

As the patient begins to recover, he or she may become very depressed. To some extent this is a good sign, in that it shows understanding and an awareness of what has happened. This is when the husband or wife, family, or friends can play a crucial role in assuring the patient that he or she is still loved and wanted, and there are those who care and want to help. Therapists, nurses, physicians, and volunteers can show they care and can provide technical help and support.

Rehabilitation

As the patient moves from the active or acute care area to the rehabilitation area, family members may be confused by the changes in care that the stroke survivor receives. Family members may interpret efforts of the team to get the patient to do more for himself or herself and to be more independent as signs of poor nursing. The family can speak to their loved one's therapists about ways that they themselves can best promote and assist in the stroke survivor's recovery. They can play an important role in keeping the stroke survivor motivated and encouraging him or her to try new things without assistance.

Stroke Education

When the stroke survivor enters rehabilitation, stroke education for the patient, family and friends is vital. Family members can speak to various health care professionals and can contact Stroke Recovery Network to find out more about the different elements of stroke and stroke recovery.

They may wish to know more about:

- The causes and mechanisms of stroke
- The process of recovery, prognosis, and risk factors such as cardiac arrhythmia, hypertension, diabetes, and weight that must be brought under control and monitored to prevent a recurrence
- The role that nurses, occupational therapists, and speech/language pathologists play in stroke rehabilitation
- The emotional impact of stroke
- The medications used by stroke survivors
- Outpatient and day programs for stroke survivors in your area

The Progression of Care

It is common for a stroke survivor to spend two to three weeks on the active side (*acute care*) of the hospital, where the rehabilitation team sees the patient and initiates therapy. Treatment will then continue in a rehabilitation unit where the patient's reactivation is accelerated. Here the survivor has one-to-one sessions with physiotherapists, occupational therapists, and speech pathologists as well as group therapy. Some care centres have a recreation worker who arranges social events, such as pub night, shopping trips, or parties to mark special days.

The family is encouraged to see the patient in therapy so that they can receive instructions in transfers and at home care. Family members can help in areas such as speech therapy.

After 10 to 12 weeks in a rehabilitation unit, the patient will usually move into an outpatient clinic where the patient will engage in therapy, group exercise, recreational activities and lunch. While the survivor is at the Day Hospital, the nurse can monitor blood patient, blood chemistry, and pro-thrombin times and change dressings and catheters. The doctor may see the patient regarding any concurrent illness or arrange consultations with any of the medical specialists as indicated. Family conferences are frequent during this time and, as in the other conferences in the rehabilitation unit, the family doctor is encouraged to attend.

Sexual Adjustment after Stroke

Stroke survivors may have a diminished self-image after their stroke and may doubt whether they are still lovable. The love, patience and understanding of the family are all important at this time.

Stroke survivors may also face a sexual adjustment following their stroke. Usually stroke does not diminish the libido or potential for organism. However the resumption of sexual intercourse is a major milestone in the rehabilitation process. Dr. Charles Clay Dahlberg, an American psychiatrist, describes his own stroke and recovery in an excellent book entitled, "Stroke", published by Norton and Company. He writes. "One morning about three weeks post-stroke, I woke up with an erection and it was a pleasant sensation. Life was coming back to me, so very shortly after I was cleared by the latest brain scan, we decided it was the time for action. I think we were both nervous but all went well and afterward Jane asked me how I felt. I replied, "Good". I asked her the same question and received the same reply."

Alex Comfort in his book, "Sexual Consequences of Disability", writes in summary that far too little is known scientifically about sexual dysfunction related to stroke. Some sexual difficulties relate to emotional causes: ongoing anxiety about a potential recurring stroke, overwhelming fear after the catastrophic event, anxiety about sexual failure or performance, possible unresolved guilt, or clinical depression. These difficulties can be managed with an explicit, clear discussion of sexual function, sex counseling, or an appropriate antidepressant. Families are encouraged to work through post-stroke challenges together so that the quality of life for both the stroke survivors and their loved ones can be maximized.

The Long Slow Road

People's reaction to a stroke can often parallel their reaction to death, with the same stages as described by Elizabeth Kubler-Ross: denial, anger, bargaining, depression and acceptance. Family and friends must recognize that these do not necessarily follow each other in order, however. There are frequent reversals to denial and anger and depression on the way to eventual acceptance, and then the long slow road to recovery and readjustment to a different way of life. Family members must also go through a similar process of acceptance, as they too must learn to live with many significant life changes.

Many spouses and families faced with the responsibility of caring for and sharing a life with someone who has had a stroke can rise to levels of love, devotion and understanding that they never thought possible. Doctors and nurses alike have said how inspired they felt watching families cope with the effects of stroke, work together, and support each other through recovery and beyond.