

AMERICAN UNIVERSITY OF BEIRUT

EDUCATIONAL PROGRAM FOR FAMILY CAREGIVERS OF  
STROKE SURVIVORS

by  
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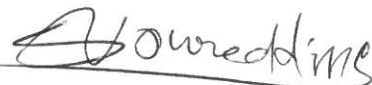
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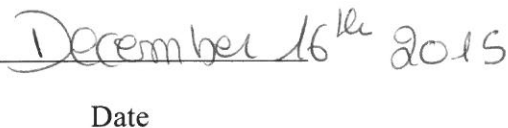
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## AN ABSTRACT OF THE PROJECT OF

Ingrid Antoine Corbani for Master of Science

Major: Nursing

Title: Educational program for family caregivers of stroke survivors

Stroke is a leading cause of disability in the adult population. Complications due to stroke account for a significant proportion of admission into Lebanese hospitals, as it does in many other countries. It leaves the survivors with impairments and disabilities; these may include the loss of body functions and structures, activities limitations, and participation restrictions. Family members become an integral part of the long-term care of these patients who continue to require the assistance of a caregiver.

The caregiver burden following stroke is increasingly recognized as a significant health care concern. Family caregivers need to be supported by the multidisciplinary team to get involved in treatment decisions, assessed for their learning needs in their new responsibilities, contacted after discharge for follow up and referrals as needed, attended to their physical and emotional health, and provided with the needed information for them to care for their beloved stroke victim

The designed educational program for caregivers of stroke survivors is a combination of psycho educational interventions, skills-building interventions as well as support interventions. The program integrates guidelines and recommendations related to stroke caregiver education and preparation into clinical practice. It motivates them to take on their new role by providing them with all the necessary information about stroke and how it affects the survivor, the caregivers, and the family as a system, and by developing and strengthening their management skills. Moreover, it allows the multidisciplinary team of healthcare professional to offer support, thus helping the caregivers to properly cope with all the physical and emotional stress resulting from the experience.



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## CHAPTER I

### BACKGROUND AND SIGNIFICANCE

#### **Definition of stroke**

The World Health Organization defined “Stroke” as “*rapidly developing clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin*” (World Health Organization, 2000, p. 1, 2). Since then, many advances and developments have been made in the knowledge about the etiology, pathophysiology, and symptomatology of stroke. According to a consensus document by experts from the American Heart Association/American Stroke Association, the term “Stroke” is now broadly used to include central nervous system infarction, intracerebral hemorrhage, subarachnoid hemorrhage, and cerebral venous thrombosis as follows (Sacco et al., 2013):

1. Central nervous system infarction: Brain, spinal cord or retinal cell death attributable to ischemia, as identified by pathological imaging or other objective evidence of injury in a defined vascular distribution, and based on clinical evidence of symptoms persisting more than 24 hours or until death.
2. Intracerebral hemorrhage: Focal collection of blood within the brain parenchyma or ventricular system noted on neurological imaging or neurological pathological examination that is not caused by trauma.
3. Subarachnoid hemorrhage: Bleeding into the space between the arachnoid membrane and the pia mater of the brain and spinal cord.

4. Cerebral venous thrombosis: Infarction or hemorrhage in the brain, spinal cord or retina because of thrombosis of a cerebral venous structure.

Injuries attributable to vascular causes are usually focally localized in the brain, except when they lead to an increased intracranial pressure in the cases of massive infarcts, intra cerebral hemorrhages and sub-arachnoid hemorrhages. The general evaluation of an acute stroke depends on the following questions (Jauch et al., 2013): Is the lesion caused by ischemia, hemorrhage or one of many other stroke mimics? What are the localization, size, shape and extent of the lesion? What is the nature and severity of the vascular lesion? Are there any brain perfusion abnormalities related to the lesion? In the modern era, the confirmation of the diagnosis of stroke relies heavily on brain imaging (Jauch et al., 2013).

Some stroke risk factors are hereditary; others are a function of natural processes. Still other factors result from a person's lifestyle. The factors can be classified into modifiable and non-modifiable. Modifiable risk factors that can be treated, changed, or controlled include: high blood pressure, cigarette smoking, diabetes mellitus, carotid or other artery disease, peripheral artery disease, atrial fibrillation, sickle cell disease, high blood cholesterol, poor diet, physical activity, and obesity. Non-modifiable risk factors cannot be changed, and include: age, family history of cerebrovascular disease, race, gender and prior stroke, transient ischemic attack (TIA) or heart attack. Other risk factors are less documented in the literature and include drug abuse, alcohol abuse, socioeconomic factors, and geographic location (Sacco et al., 2013).

### **Stroke Epidemiology**

Due to differences in exposure to risk factors and in stroke management practices, there is a considerable variability between countries and regions in the reported prevalence and mortality

rates of stroke (Thrift et al., 2014). The worldwide prevalence of stroke is 33 million, with 16.9 million people having a first stroke, making it the second leading global cause of death in the world following ischemic heart disease. Stroke accounts for 11.13% of deaths worldwide; that is more than 6.15 million deaths each year (Go et al., 2014). During the first 3 to 4 weeks after stroke, patients are at the highest risk of death; 20 to 50% of them die within this period of time, that is, depending on age, severity and type of stroke, health status, and medical history (Thrift et al., 2014).

In the United States, about 795,000 people have a stroke each year. It is the fourth leading cause of death, claiming 129,000 lives per year. African-Americans have nearly twice the risk for a first-ever stroke than white people, and a much higher death rate from stroke (Go et al., 2014)

The prevalence of stroke is 5.2% in the Lebanese population (Jurjus et al., 2009). It is also one of the leading causes of death in the country, since it accounts for 10.3% of total deaths (World Health Organization [WHO], 2011). Post stroke complications account for a significant proportion of admission into Lebanese hospitals (WHO, 2011), as it does in many other countries, thus placing a high economic burden on the health care system (Thrift et al., 2014).

Stroke leaves 40% of survivors with moderate functional impairments, and up to 30% with severe disabilities (Duncan et al., 2005). Impairments and disabilities include, but are not limited to, the loss of body functions and structures, activities limitations, and participation restrictions. The loss of body functions and structures include impairment of structures and physiological and psychological functions such as hemiparesis, contractures, spasticity, shoulder pain, muscle weakness, cognitive dysfunction, dysphagia, bowel incontinence, bladder incontinence, pain, and aphasia. Activity limitations reflect the difficulties stroke survivors experience in functional task performance, including activities of daily living such as dressing, self-feeding, toileting, bathing,

grooming, ambulation, and writing; and instrumental activities of daily living such as shopping, meal planning and preparation, cleaning, financial management, driving and use of public transportation, handling medication, making medical appointments, and having access to recreational activities. Participation restrictions refer to problems the stroke survivors encounter when re-establishing social interactions, such as exercising, returning to work, and driving (Miller et al., 2010).

Depending on the cerebral territory affected, neurological symptoms of stroke could be classified as follows (Sacco et al., 2013):

1. Left hemisphere: Left gaze preference, right visual field deficit, right hemiparesis and right hemi-sensory loss.
2. Right hemisphere: Right gaze preference, left visual field deficit, left hemiparesis, left hemi-sensory loss and neglect (left hemi-inattention).
3. Brainstem: Nausea and/or vomiting, diplopia, dysconjugate gaze, gaze palsy, dysarthria, dysphagia, vertigo, tinnitus, hemiparesis or quadriplegia, sensory loss in hemi-body or all four limbs, decreased consciousness, hiccups and abnormal respirations.
4. Cerebellum: Truncal/gait ataxia, limb ataxia and neck stiffness.
5. Hemorrhage: Focal neurological deficits, headache, neck pain, light intolerance, nausea, vomiting and decreased level of consciousness.

### **Stroke Management**

Stroke management requires a high priority status, since functional outcomes depend on early recognition of stroke symptoms, an important factor in successful delivery of possible acute therapies. Early care delivered in both the pre-hospital setting and the emergency department

setting is defined as the hyper-acute care. The main goals during this phase are to immediately identify patients with possible stroke, identify conditions requiring immediate interventions, determine potential causes, initiate early secondary prevention, access neurology and/or neurosurgery services, and initiate stroke management pathways, if applicable. Care consists of emergency triage and initial evaluation, diagnostic tests and brain and vascular imaging, general supportive care, treatment of acute complications and the initiation of acute therapies (Jauch et al., 2013).

Stroke survivors are transferred to critical care units, intermediate care units, stroke units or general medical units. Care during this phase is defined as the acute care, which aims at stabilizing the survivors, establishing the etiology, preventing stroke-related complications, preventing therapy-related complications and maintaining the ongoing secondary prevention strategies. Later during this phase, a comprehensive rehabilitation plan for discharge will be developed. A multidisciplinary team of physical therapists, occupational therapists, speech therapists, nutritionists, psychologist and social workers will assess survivors and their families. The team's goal is to ensure a safe transition while maintaining a continuity of care between the hospital setting and the rehabilitation setting (Jauch et al., 2013).

Some survivors may not be candidates for rehabilitation interventions; these include: *“patients who have had a severe stroke, who are maximally dependent in their activities of daily living and have a poor prognosis for functional recovery”* (Duncan et al., 2005, p. 25). The care of these patients would include the following: Prevention of recurrent stroke; prevention of complications; medication administration; assistance in activities of daily living such as transfers, bathing, positioning, feeding, toileting and grooming, nutrition; care of indwelling bladder catheters; skin care; the use of feeding tubes; and home exercises. Such patients also require special

psychological care and psychiatric assistance, since many studies have suggested that anxiety, depression, bipolar disorders and pathological affect, are all very common among stroke survivors (Duncan et al., 2005).

Family members become an integral part of the long-term care of these patients who continue to require the assistance of a caregiver. Bakas et al. (2014) defined a family caregiver as “*a relative, partner, personal friend, or neighbor who provides assistance to an adult with a chronic or disabling condition such as stroke*” (p. 1). Prior to discharge, both patients and the caregivers should be given information and provided with an opportunity to learn about risk factors, causes, consequences and possible complications of stroke, and about the prognosis and care plan goals.

With the aim of minimizing impairments, maximizing functions and preventing complications, rehabilitation must be started as early as possible after stroke, as soon as the survivor’s medical condition becomes stable, and all life-threatening problems are managed (Duncan et al., 2005). Rehabilitation guidelines have been developed to provide clinicians and health care providers with a structured approach to care, and to guide them with determining the ultimate interventions and timing of care. Later after the acute phase, the focus of care turns to assessment and recovery of physical and cognitive deficits, as well as compensation for residual impairments. Abiding by these guidelines has been associated with improved patient outcomes (Duncan et al., 2005). Eventually, stroke patients will be home, and cared for by the family.

### **Family Caregivers of Stroke Patients**

Miller and colleagues (2010) stated that all healthcare professionals are “*Strongly urged to respond to not only the needs of stroke survivors but also those of family caregivers throughout*



*all the phases of the rehabilitation process”* (p. 29). Family caregivers need to be supported by the multidisciplinary team to get involved in treatment decisions, assessed for their learning needs in their new responsibilities, contacted after discharge for follow up and referrals as needed, attended to their physical and emotional health, and provided with the needed information for them to care for their beloved stroke victim (Miller et al., 2010).

### **Significance**

The caregiver burden following stroke is increasingly recognized as a significant health care concern (Candido et al., 2012; Draper et al., 2005; Hung et al., 2012; McPherson, Wilson, Chyurlia & Leclerc, 2011). In a review of the literature, family caregivers were shown to demonstrate high levels of psychological distress and depression; increased rates of physiological illness and suppressed immune responses; lower rates of engaging in preventive health behaviors; disruptions in paid employment; and personal, financial, family, and social problems (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Therefore, caregivers need a lot of support in order to provide adequate care to their stroke survivor and maintain a satisfactory quality of life themselves.

A descriptive study was undertaken by Ang et al. (2013) to explore the health care professionals and caregivers' perception of educational needs. The study took place while the stroke survivor was still being cared of in an acute hospital in Singapore. The qualitative analysis of the caregivers' perspectives led to the emergence of many themes, among which are the meaning of stroke, self-awareness of knowledge gap, empathy for the stroke survivors, lack of readiness to care, desired information, educational needs (Sources of information, training needs, venue and format of training), positive views about support groups, and finally the caregiver's level of

involvement when a foreign domestic worker is available. Caregivers expressed the need for information concerning the illness itself, as well as the practical and emotional aspects of caring. They wanted to learn more about stroke, what to do in case of a recurrent stroke, how to prevent the recurrence of stroke, and the signs or indications of improvement. Moreover, caregivers wanted to learn how to assist the survivors in activities of daily living, motivate, and emotionally support them. Concerning the sources of information, health care professionals were identified as the main source. Some caregivers mentioned that booklets and pamphlets are useful; however, the majority expressed preference for oral presentations and hands-on training in the physical aspects of care, and that training should begin as soon as possible and should be a continuous process (Ang et al., 2013).

The above findings echo those obtained by Hafsteinsdottir, Vergunst, Lindeman, and Schuurmans (2011) in their review of 21 studies that addressed the educational needs of patients with stroke and their caregivers. The information needs identified in the review are related to the stroke, its causes, symptoms, and treatment; physical care; moving and lifting; exercises; and psychological considerations, as well as nutritional and sexuality issues. Both patients and caregivers wanted information to be provided verbally and in writing; they all wished to have the information tailored to their own situation.

In the chronic phase, patients and caregivers expressed the need for information on resources available in the community, local agencies, and support services. The findings of this review highlight the importance of integrating the knowledge and the educational needs of patients and caregivers into specific intervention programs and the importance of developing generalizable educational interventions for the provision of active information, as well as the importance of a

better coordination of information provided by different professionals within the multi-disciplinary teams through improved documentation of information and communication.

In Lebanon, rehabilitation services for stroke survivors are limited, thus placing the burden of the care on the family. Moreover, only few hospitals have specialized stroke units where the staff is equipped to provide the needed education to help caregivers prepare for their caring activities at home, following discharge. The aim of this project is to develop an educational program for family caregivers of stroke survivors in Lebanon.

## CHAPTER II

### LITERATURE REVIEW

As family caregivers of patients with stroke carry on the responsibility of providing care to facilitate recovery, they need a lot of education and support in preparation for their task. This chapter reviews the literature on the outcomes of caregiver education, guidelines and recommendations related to what needs to be taught, and methods of delivery of the educational programs.

#### **Effectiveness of Educational Programs**

With the purpose of critiquing and synthesizing the available evidence on the impact of family caregiver interventions, Bakas and colleagues (2014) reviewed 32 intervention studies. Of these 32 studies, 17 were interventions that focused primarily on the caregiver and 15 were dyadic interventions that involved both survivors and caregivers as active participants. All of the included studies used quasi-experimental or experimental research design, revolved around provision of stroke caregiver interventions, included stroke survivor outcomes and/or stroke family caregiver outcomes, and were implemented during any part of the stroke care continuum.

Concerning the survivor-related outcomes, the results of several studies reported significant improvement in intervention groups compared to control groups in terms of: physical functioning (Burton & Gibbon, 2005; Grasel, Biehler, Schmidt & Schupp, 2005), anxiety and depression (Smith, Egbert, Dellman-Jenkins, Nanna & Palmieri, 2012), health-related quality of

life (Burton & Gibbon, 2005; Louie, Liu & Man, 2006), social functioning (Burton & Gibbon, 2005), and the use of health care services (Forster et al., 2009; Grasel et al., 2005; Pierce, Steiner, Khuder, Govoni & Horn, 2009; Shyu, Kuo, Chen & Chen, 2010; Tilling, Coshall, McKeivitt, Daneski & Wolfe, 2005), as well as knowledge and satisfaction (Forster et al., 2009; Louie et al., 2006).

Concerning the caregiver-related outcomes, the results of several studies also reported significant improvement in intervention groups compared to control groups in terms of preparedness (Grant, Elliott, Weaver, Bartolucci & Giger, 2002; King, Hartke & Denby, 2007; Shyu, Chen, Chen, Wang & Shao, 2008; Shyu et al., 2010); reduction in burden, stress, and strain levels (Bakas et al., 2009; Burton et al., 2005; Draper et al., 2007; King et al., 2007; Perrin et al., 2010); anxiety and depressive symptoms (King et al., 2007, 2012; Smith et al., 2012; Wilz & Barskova, 2007); health-related quality of life (Bakas et al., 2009; King et al., 2012); social functioning and coping abilities (Bakas et al., 2009); use of health care services (Grasel et al., 2005); knowledge (Franzen-Dahlin, Larson, Murray, Wredling & Billing, 2008; Mant, Winner, Roche & Wade, 2005); and satisfaction (Mant et al., 2005; Shyu et al., 2008; Smith et al., 2012).

In the same vein, Oupra, Griffiths, Pryor and Mott (2010) developed and implemented a nurse-led educational program for 140 family caregivers (SELF) of the stroke survivors in Thailand and evaluated its effect on the caregivers' strain and quality of life. Those admitted to the intervention hospital received the SELF, while those admitted to the comparison hospital received the usual care provided at the hospital. The data were collected prior to discharge of the patients and after 3 months. The quality of life was measured using the Thai version of the General Health Questionnaire GHQ-28 (Oupra et al., 2010). The level of strain was measured using the Caregiver Strain Index (CSI) translated into Thai language (Oupra et al., 2010). The findings

revealed that providing education and support to the family caregiver of stroke survivors could reduce caregiver strain and enhance the patient's quality of life. The family caregivers of stroke survivors in the intervention group had a significantly better quality of life than the comparison group (GHQ-28 at discharge: Mean of control group = 22.6 versus Mean of the intervention group = 17.2,  $t_{138} = 2.82$ ,  $P = 0.006$ ; and GHQ-28 after 3 months: 16.4 versus 8,  $t_{135} = 6.80$ ,  $P < 0.001$ ) and they also reported less strain (CSI at discharge: 8.6 versus 5.1,  $t_{138} = 6.73$ ,  $P < 0.001$ ; and at CSI after 3 months: 5.9 versus 1.6,  $t_{135} = 7.67$ ,  $P < 0.001$ ) (Oupra et al., 2010).

### **Guidelines about the Involvement of Caregivers in the Stroke Survivors' Care**

In a comprehensive overview of the literature on nursing and interdisciplinary rehabilitation care for the stroke patient (Miller et al., 2010), the American Heart Association (AHA) stressed the importance of the role of family caregivers during the recovery trajectory and recommended their involvement in six domains (Miller et al., 2010).

The first domain discusses viewing caregivers as efficient members of the multidisciplinary team, that is by encouraging them to participate in the goal setting and the decision-making processes. Their input regarding the survivor's pre-stroke life is desirable and valuable; therefore, they should be very well prepared to offer support. The second domain discusses the assessment of the caregivers' perspective of needs and concerns. The assessments should be comprehensive and multi-dimensional, and the entire family system should be taken into consideration. The third discusses follow-up contacts and referrals to smoothen the transition from the hospital setting to the home setting. Follow-up contacts with the caregiver should be scheduled at one, four, six, and 12 months after discharge; this follow-up care should be arranged during the survivor's in-patient

stay. The fourth domain discusses the promotion of problem solving, coping, and support-seeking behaviors through counseling, as it improves the caregiver's knowledge, preparedness, and health-related-quality-of-life, as well as the entire family's functioning. The fifth domain discusses paying adequate attention to the emotional and physical health of caregivers, who should be regularly assessed and reminded about the importance of taking self-care.

Caregivers' stress and strain can impede the stroke survivor's recovery process and can lead to long-term stroke survivor institutionalization. The last domain discusses the provision of stroke-related care information and stresses the importance of healthcare professionals in providing information to caregivers using variable formats as appropriate (Individual face-to-face education, written formats, conferences, training sessions, etc.). Provision of information should occur in both the in-patient and out-patient settings and should cover stroke warning signs, lifestyle changes, and risk factors for secondary stroke prevention. Additional areas of education and training should include medication management, the survivor's condition and treatment plan and prevention and management of post stroke complications (Miller et al, 2010).

The guidelines and recommendations for the care of people with stroke and transient ischemic attacks, published by the stroke council of the Irish Heart Foundation in 2010, stated that the caregiver of every patient with stroke should be involved in the management process from the outset, specifically as an additional source of important information about the patient, both clinically and socially. Caregivers should be as well involved in all important decisions as the patients' advocate if necessary (Doyle, Collins, Harbiston & Donnellan, 2010). Moreover, the guidelines state that stroke caregivers should be actively provided with timely, up-to-date information, in conjunction with opportunities to learn from members of the multidisciplinary team and other appropriate community service providers (Doyle et al., 2010).

## **Guidelines Concerning the Design of Educational Interventions for Family Caregivers**

A critical review of the literature on family caregiver interventions provided the basis of the statement by the AHA for healthcare professionals regarding the care of stroke survivors and their caregivers (Bakas et al., 2014). The statement addressed the following elements: Type of intervention, target, design, mode of delivery, frequency of sessions, timing and dosage of interventions, and access to experts. Recommendations for practice were designated as class I (evidence and/or strong agreement about the usefulness of the intervention), class II (conflicting evidence about usefulness of the intervention), or class III (intervention not recommended due to evidence of harm). The levels of evidence for the recommendations were classified as A (randomized controlled trials and meta-analysis), B for a single randomized trial or nonrandomized trials, or C for consensus of experts, case studies or standards of care (Bakas et al., 2014).

### **Types, targets, and design of the interventions.**

Three types of interventions were described in the literature: skill-building, psycho-educational, and support (Bakas et al., 2014). Skill building interventions focus on the strategies that facilitate problem solving, stress management, goal setting, communication with the patient and healthcare professionals, as well as hands-on training in skills and techniques required to assist the survivor in activities of daily living. The psycho-educational interventions focus on the provision of information concerning the warning signs of stroke; life style changes; managing the survivor's emotions, behaviors, medication and personal care; managing finances and transportation; managing one's own emotions and healthcare needs; and access to community resources. Support interventions are those that help both survivors and caregivers engage in peer interaction for advice and support.



Interventions that combine skill building with psycho-educational strategies and support should be chosen over interventions that only use one of the three strategies alone (class I recommendation, level of evidence A). Those that involve only psycho-education, only support, or a combination of support and psycho education are not recommended (class III level B) and might jeopardize social functioning in some survivors and caregivers (Bakas et al., 2014).

Many interventions discussed in the literature targeted the caregivers alone; these interventions did address the needs of the survivors, but without them being active participants. Few interventions targeted the survivors alone, whereas others targeted the survivor-caregiver dyad in which both survivors and caregivers were active participants in the intervention (Bakas et al., 2014).

When stroke caregiver outcomes are most desired, caregiver interventions are recommended in preference to dyadic interventions; however, when survivor outcomes are most desired, dyad interventions are recommended in preference to stroke caregiver interventions (class IIa, level A). If addressing both, then the intervention needs to include specific content to meet both survivor and caregiver needs (Bakas et al, 2014).

Concerning the delivery design, two types of design are discussed in the literature: Those that are individualized and tailored to the caregiver and survivor's needs, and those that are generalizable or the "one size fits all" format (Bakas et al., 2014). Individualized tailored interventions should be chosen over the non-tailored one-size-fits-all group interventions (class I level A). Post-discharge assessments with tailored interventions based on changing needs across the continuum of care and recovery should be performed (class I level C) to improve caregiver outcomes (Bakas et al., 2014).

**Mode of delivery.**

Caregiver interventions are delivered in one of three modes: face-to-face interventions, combination of face-to-face and telephone interventions, and Web-based interventions (Bakas et al., 2014). Interventions that are delivered face to face and/or by telephone are recommended (I, A), as they have strong evidence for improving outcomes for both stroke survivors and caregivers. Those delivered completely by telephone might be useful, only when face-to-face access is not possible (IIa, B). Concerning the web-based interventions; the fact that they require computer skills and resources might limit their access for some; however, they seem to be effective and promising (IIb, B) in some cases (Bakas et al., 2014).

The number of sessions reported throughout the literature ranged from 1 to 15 (Bakas et al., 2014). Interventions consisting of 5 to 9 sessions are recommended (I, A), as they show the best evidence for improving survivor and caregiver outcomes. Those with a large number of sessions are not recommended (III, B), as they tend to have worse outcomes (Bakas et al., 2014).

The timing of interventions varies considerably throughout the literature, with the distribution of sessions over time ranging from few weeks to a number of months after stroke. Part of this variation may be accounted for by the fact that some interventional studies included caregivers caring for stroke survivors later in the trajectory of recovery, whereas others were initiated during the acute phase (Bakas et al., 2014). No recommendations have been issued concerning that matter; however, more research is needed in this regard (Bakas et al., 2014).

Access to experts is available and mentioned in several interventions throughout the literature, but not clearly identified in many others (Bakas et al., 2014). Experts include case managers, nurses, therapists, social workers, psychologists, and in some cases, expert caregivers.

Access to such individuals during the intervention is a key component throughout the course of the program (Bakas et al., 2014).

### **Guidelines Concerning the Content of Educational Programs**

The content of education related to stroke should cover all aspects of stroke care and recovery (Lindsay et al., 2014). Depending on the needs and phases of care of the survivor, topics may include: a description of the roles of all members of the healthcare team involved in the survivor's recovery; the role of the patient, family and informal caregivers as members of the team and as participants in decision-making and planning; stroke symptom awareness and risk of recurrent stroke; treatment goals within each care setting and environment; medical information regarding type and cause of stroke, physical, psychological, functional and emotional impact of stroke and expectations for recovery; changes in social and family roles and relationships; prevention of recurring stroke including risk factor modification; availability of and access to community services; seeking help if problems develop; and the potential benefits of local stroke groups (Lindsay et al., 2014).

The guidelines published by the council of stroke of the Irish Heart Foundation, 2010, state that: *“Carers should be encouraged to participate in an education program that explains the nature of stroke and its consequences, teaches them how to provide care and support, gives them opportunities to practice care with the patient, and emphasizes advice on secondary prevention, especially lifestyle changes* (Doyle et al., 2010, p. 55).

Based on literature review and clinical experience, Ostwald, Davis, Hersch, Kelley and

Godwin (2008) developed multidisciplinary evidence-based educational content guidelines for stroke survivors and their caregivers after discharge home. In the immediate post-hospital phase, especially stroke survivors and caregivers, need information about the effects of the stroke on the survivor, assistance with special nursing and therapy techniques, suggestions for adapting the home for safety and independence, support for day-to-day issues, and ways to access community resources. Later, after several months, they require information related to stress management and coping with chronic illnesses, as well as developing and maintaining a healthy lifestyle (Ostwald et al., 2008).

The educational program designed by Oupra and colleagues (2010) included didactic education sessions, hands-on training sessions, a booklet, and follow up phone calls. Group education sessions were chosen as the main teaching method; they provided an opportunity for family caregivers to share their opinions and support each other. Caregivers in the intervention group attended three interactive sessions. Each session was approximately 120 to 150 minutes duration including time for group discussion. The number of caregiver/patient pairs was limited to six in each session. During the practice component of each session, family caregivers were separated into three groups (two in each), who practiced with their relatives under the supervision of the researcher and two research assistants (Oupra et al., 2010). The first session focused on the causes and risk factors of stroke, its complications and methods to prevent or reduce them. The second session covered swallowing difficulties and feeding, and maintaining adequate hydration and nutrition. The final session included urinary catheter care, preventing urinary tract infections, techniques for bladder and bowel training, positioning, mobility and transfer, the role of the family caregiver and caring for themselves. Family caregivers were supervised practicing activities such as adjusting the patient's position to prevent pressure ulcers, feeding, catheter care, lifting and

handling technique, and mobility and transfer with the stroke survivors (Oupra et al., 2010). Each family caregiver was given written information on the content covered in the form of a booklet before attending the education sessions. After discharge, the caregivers in the intervention group were telephoned on an agreed day and time during the third week of each month, for three months, in order to discuss problems, provide suggestions for care and provide support to the caregiver (Oupra et al., 2010).

The above-mentioned guidelines about the involvement of caregivers, the design of the educational intervention and their content, will be tailored to create comprehensive and feasible interventions that will help integrate the concerns and expectations of healthcare professionals with those of the survivors and their caregivers. The proposed educational program is based on the reviewed literature and adapted to the Lebanese context.

## CHAPTER III

# EDUCATIONAL PROGRAM FOR FAMILY CAREGIVERS OF STROKE SURVIVORS

This chapter describes the application of the previously discussed guidelines in the design and implementation process of the program, the components of the educational program, and its objectives and overall implementation of the program.

### **Overview of the program**

The program will target the family caregivers of patients who have had severe stroke, and are not candidates for rehabilitation. The content of the program will be delivered through individualized face-to-face sessions offered at the Neuro-Medicine unit of the American University of Beirut Medical Center, where stroke survivors spend approximately 5 to 6 days prior to discharge, after being stabilized and transferred out of the Neuro-Intensive Care Unit

The sessions will be based on a standard elaborated outline, used as a reference. However, the specific information or content that will be communicated and its mode of delivery may be modified depending on the needs of the survivor, as well as on the caregiver's priorities and concerns. The design of the sessions will be flexible enough for caregivers to discuss individual problems.

The program will combine psycho-educational interventions, skills-building, and support interventions, thus a mix of education and counseling. A multi-dimensional approach will be adopted in delivering the information and in assessing and dealing with arising problems.

An advanced practice nurse, the Neuroscience Clinical Nurse Specialist (Neuro-CNS), physical therapists, psychologists, social workers, speech & language pathologists, and of course the treating physicians will all take part in the program.

Each session will follow a fixed schedule that will commence with an introduction to the topic, and proceed according to the designated teaching approach, with hands-on training as needed. Each session is structured to accommodate questions and evaluations by the caregivers. It will take approximately four days for completion. The content will be divided into eight sessions, with two sessions per day, if possible. The first six sessions, namely those that provide family caregivers with information about stroke, promote understanding about the nature and level of impairments, and prepare them to effectively manage the care of the survivor at home, will be offered at the hospital. The remaining two sessions, including those that address post stroke depression and the caregiver's burnout, will be offered at the patient/caregiver's house after discharge. Each session is expected to last one to two hours depending on the content.

This program is structured to accommodate: (1) Family caregivers of those who have had a severe stroke and are not candidates for rehabilitation services once they become medically stabilized and ready to be discharged home and (2) Family caregivers of those admitted to the medical center for treatment of any complication related to stroke, such as urinary tract infections, aspiration pneumonia, pressure ulcers, etc...

**Recruitment of caregivers**

The nurse-manager of the Neuro-Medicine unit would inform the Neuro-CNS when a patient with a diagnosis of stroke is admitted. Additionally, the CNS would also visit the unit on a daily basis to check for admissions. After the acute phase, once the survivor is medically stabilized, the CNS would check the patient and the family caregiver for program eligibility; accordingly, an explanation and a description of the program in details will ensue. Eligible family caregivers will be asked if they are interested in participating in the program.

The selection of the family caregivers is based on the assessment of the stroke survivors using the National Institute of Health Stroke Scale (NIHSS) It is a systematic assessment tool that provides a quantitative measure of stroke-related neurologic deficit (Duncan et al., 2005). It is composed of 11 items, rated between 0 (normal function) and 4 (severe impairment). The individual scores from each item are summed in order to calculate a patient's total NIHSS score: A score of 0 indicates no stroke symptoms, a score of 0 → 4 indicates a minor stroke, 5 → 15 a moderate stroke, 16 → 20 a moderate to severe stroke and 21 → 42 a severe stroke (Duncan et al., 2005). Moreover, the scores strongly predict the likelihood of the patient's recovery: A score below 5 is strongly associated with discharge home; a score between 6 and 13 is strongly associated with discharge to rehabilitation; and finally a score above 13 is strongly associated with discharge to long term care (Duncan et al., 2005). Appendix A shows the NIHSS.

The family caregivers would be eligible to enroll in the program if their stroke survivor scores above 13 on the NIHSS

The Neuro-CNS would then inform the multidisciplinary team about the family caregivers who have met the criteria and agreed to receive the interventions. Each member of the team would



then visit the family caregiver to perform assessments and evaluations prior to the delivery of the program. Assessments would cover the following areas: comorbidities and baseline health status, prior and current functional status, risk of complications (skin breakdown, swallowing problems, bowel and bladder dysfunction, malnutrition and pain), impairment determination (cognitive, communicative, motor and psychological impairments), and psychosocial status (family, social support, financial and cultural support). The members of the multidisciplinary team would then meet together to identify, adjust, and finalize the content of the sessions.

The Neuro-CNS coordinates between the family caregiver, the concerned member of the multidisciplinary team, and the registered nurse/nurse aid taking care of the patient the day of the session, in order to decide on a perfect timing for the delivery of each session. The timing should be convenient to all three parties. The program should neither increase the workload of the registered nurses/nurse-aids on duty, nor hinder the work of the physical therapist, the speech & language pathologist, the psychologists or nutritionists on the days of the interventions. At the end of the program, the readiness of the family caregivers to take on their new role and responsibilities will be assessed, prior to the discharge.

On a later stage, caregivers of chronic stroke survivors who follow-up with the treating neurologists at the Neuroscience Outpatient Center at AUBMC will also be included in the program. The registered nurses working at the clinics would inform the neuro-CNS when a stroke patient presents for a follow-up consultation. The CNS would check the patient and the family caregiver for program eligibility; explain and describe the program. Eligible family caregivers will be asked if they would like to receive the education. For those caregivers, all eight sessions will be delivered at home. The members of the multidisciplinary team would visit the caregivers at home, so that they may assess the health status of the survivors as well as the home environment.

They will then meet together to identify, adjust, and finalize the content of the sessions to be delivered on an agreed time and date.

## **The proposed Program**

### **Description**

This eight-session-program prepares family caregivers to take care of their loved ones with stroke at home. It combines psycho educational interventions, skills-building as well as support interventions.

### **Time and location.**

The first six sessions will be held at the Neuro-Medicine unit at AUBMC. Power point presentations will take place at the unit's conference room, whereas hands-on training and return demonstrations at the patient's room. The last two sessions will take place at the patient/caregiver's house, on an agreed date and time.

The first six sessions will be distributed over 4 to 5 days of the patient's stay at the unit, yet prior to discharge. The last two sessions will be offered one week after discharge.

### **Instructor(s).**

Several healthcare professionals will participate in teaching and training; each will provide his/her contribution based on his/her specialty and expertise. These include: Neuro-CNS, physical therapist, speech & language pathologist, nutritionist, psychologist and social worker.

For a detailed description of the role of each instructor, please refer to appendix B.

**Teaching methods.**

Different teaching methods will be adopted, depending on the content of each session: Slides presentation, discussions, demonstrations, and hands-on training.

**Program goals.**

The “Stroke Family Caregivers Program” would:

1. Provide family caregivers with information about stroke and how it affects the survivor, the caregivers and the family as a system.
2. Develop and strengthen the family caregivers’ practical skills.
3. Promote the family caregivers’ understanding of the nature and level of the stroke. survivor’s emotional and cognitive impairments, to provide helpful strategies for dealing with these impairments.
4. Motivate the family caregivers to effectively manage the care of the stroke survivor at home.
5. Introduce family caregivers to ways of coping with the stress emanating from the experience.

**Content outline**

Session 1: Brain, Stroke, and the multidisciplinary team

Session 2: Stroke survivor daily hygiene and skin care

Session 3: Bladder and bowel control

Session 4: Meal assistance, Special diet, and hydration

Session 5: Mobility, positioning and transfer

Session 6: Communication and cognition after stroke

Session 7: Post stroke depression

Session 8: Caregiver Burnout

### Description of the sessions

#### *Session 1: Brain, stroke and the multidisciplinary care.*

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Definition of stroke and its causes</li> <li>2. Effects and complications of stroke</li> <li>3. Members of the multidisciplinary team and their role</li> <li>4. The caregiver's important role</li> </ol>
<b>Duration</b>	30 minutes
<b>Instructor</b>	Neuro CNS
<b>Teaching methods</b>	Lectures / Slides presentation - Discussion
<b>Learning outcomes</b>	<p>At the completion of the session, caregivers should be able to:</p> <ol style="list-style-type: none"> <li>1. Define stroke and list its types</li> <li>2. Identify the risk factors for stroke</li> <li>3. List the possible consequences of stroke</li> <li>4. Identify the members of the inter-professional care team</li> <li>5. Describe the role of each member within the team</li> <li>6. Appreciate the caregiver's role within the team</li> </ol>
<b>Assessment of learning</b>	Oral Evaluation: Family caregivers will be asked questions concerning the topic discussed
<b>Content of the</b>	<b>APPENDIX C</b>

<b>session</b>	
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*Description of the session.*

This first session will focus on defining stroke and its effects, introducing the multidisciplinary care team, and explaining the importance of the caregiver's role within this team. The power point presentation addressing these issues will be followed by a discussion that will allow caregivers to select the information that is applicable to their stroke survivor. At the end of the session, questions will be asked to make sure that the pre-set learning outcomes are achieved.

***Session 2: Stroke survivor daily hygiene and skin care.***

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Bed bath and oral hygiene for the stroke patient</li> <li>2. Development of pressure ulcers in the stroke patient</li> <li>3. Common sites for pressure ulcers</li> <li>4. Progression and complications of pressure ulcers</li> <li>5. Prevention of pressure ulcers</li> <li>6. Control management of pressure ulcers</li> </ol>
<b>Duration</b>	60 minutes
<b>Instructor(s)</b>	Neuro-CNS, in collaboration with the nurse-aid
<b>Teaching methods</b>	<ol style="list-style-type: none"> <li>1. Lecture / Slides presentation – discussions</li> <li>2. Video tutorials</li> <li>3. Hands-on training</li> </ol>
<b>Learning outcomes</b>	At the end of the session, the caregiver should be able to:

	<ol style="list-style-type: none"> <li>1. Identify the factors that affect a stroke survivor's ability to maintain hygiene</li> <li>2. Demonstrate the ability to give the stroke survivor a complete bed bath including mouth wash</li> <li>3. Demonstrate changing the linen with the stroke survivor in the bed</li> <li>4. Describe how pressure ulcers develop in stroke survivors</li> <li>5. Identify the common sites and manifestations of pressure ulcers</li> <li>6. List the complications of pressure ulcers</li> <li>7. Identify the preventive measures of pressure ulcers</li> <li>8. Describe the management strategies to control the development of pressure ulcers</li> </ol>
<p><b>Assessment of Learning</b></p>	<ol style="list-style-type: none"> <li>1. Bed bath return demonstration</li> <li>2. Oral care return demonstration</li> <li>3. Demonstration of preventive and treatment measures for pressure ulcers</li> <li>4. Oral evaluation</li> </ol>
<p><b>Content on the session</b></p>	<p><b>APPENDIX D</b></p>

*Description of the session.*

This second session is divided into two parts:

1. The first part discusses the importance of providing hygiene care, and teaches the family caregivers how to provide such care. The caregiver will be exposed to a tutorial video that will be repetitively paused, so that elements would be discussed and explained thoroughly, and that discussion would occur. The videos are chosen as media support for learning, since clinical skills are best taught through visual demonstration. For the evaluation of this part, caregivers will be asked to perform a complete bed bath return demonstration on their patient at the hospital, in agreement with, and in the presence of the registered nurse and the nurse-aid on duty, so that it will not hinder their work flow.
2. The second part discusses skin integrity and pressure ulcers. The power point presentation addressing these issues will be followed by a discussion that will allow caregivers to ask questions and to identify the risk factors and possible preventive measures applicable to the case of their stroke survivor. At the end of the session, questions will be asked to make sure that the pre-set learning outcomes are achieved.

***Session 3: Bladder and bowel control.***

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Loss of normal bladder and bowel functions after stroke</li> <li>2. Physical and emotional effects of bladder and bowel incontinence</li> <li>3. Management of bladder and bowel problems</li> <li>4. Urinary catheters</li> <li>5. Urinary tract infections (UTIs) and how to prevent them</li> </ol>
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<b>Duration</b>	60 minutes
<b>Instructors</b>	Neuro-CNS
<b>Teaching methods</b>	<ol style="list-style-type: none"> <li>1. Lecture / Slides presentation – discussions</li> <li>2. Video tutorials</li> <li>3. Hands-on training</li> </ol>
<b>Learning outcomes</b>	<p>At the end of the session, caregivers should be able to</p> <ol style="list-style-type: none"> <li>1. Describe the loss of bowel and bladder functions after stroke</li> <li>2. Discuss the physical and emotional effects of bladder and bowel incontinence of the survivor</li> <li>3. Adequately identify bowel and bladder problems</li> <li>4. Describe the management of bowel / bladder problems</li> <li>5. Demonstrate the care for an indwelling urinary catheter</li> <li>6. Identify the signs of a urinary tract infection</li> </ol>
<b>Assessment of learning</b>	<ol style="list-style-type: none"> <li>1. Oral evaluation</li> <li>2. Return demonstration of Care of an indwelling urinary catheter</li> </ol>
<b>Content of the session</b>	<b>APPENDIX E</b>

*Description of the session.*

This third session exposes the caregivers to urinary and bowel problems resulting from stroke. It will begin by a power point presentation that will teach them how to properly identify



and manage possible problems, and how to avoid and recognize urinary tract infections. Afterwards, questions will be asked to make sure the pre-set learning outcomes. The caregivers, whose stroke survivor might be discharged home with an indwelling urinary catheter, will be exposed to a tutorial video that teaches them how to properly handle and care for catheter. It would be repetitively paused, so that elements would be thoroughly discussed and explained. For the learning assessment, caregivers will be asked to perform a return demonstration on how to perform perineal care and manipulate the catheter.

***Session 4: Meal assistance, special diets and hydration.***

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Stroke and eating/swallowing problems</li> <li>2. Signs and symptoms of swallowing problems</li> <li>3. Safe feeding and modified diets</li> <li>4. Enteral tube feeding (if needed by the patient)</li> <li>5. Signs of dehydration</li> <li>6. Measures to avoid dehydration</li> </ol>
<b>Duration</b>	60 minutes
<b>Instructor(s)</b>	<ol style="list-style-type: none"> <li>1. Speech and swallow pathologist</li> <li>2. Nutritionist</li> </ol>
<b>Teaching methods</b>	<ol style="list-style-type: none"> <li>1. Lecture / Slide presentation – discussions</li> <li>2. Video tutorial</li> <li>3. Hands-on training</li> </ol>
<b>Learning outcomes</b>	At the end of the session, the caregivers should be able to:

	<ol style="list-style-type: none"> <li>1. Discuss the impact of eating / swallowing problems on the overall health status of the patient</li> <li>2. Recognize the signs and symptoms of eating / swallowing problems</li> <li>3. Describe the principles of safe feeding</li> <li>4. Describe the principles of modified diets</li> <li>5. Demonstrate the ability to administer food through enteral measures: a gastrostomy/Jejunostomy (if needed by the patient).</li> <li>6. Demonstrate the ability to care for a stoma gastrostomy</li> <li>7. Describe the causes and effects of dehydration in stroke survivors</li> <li>8. Appreciate the importance of maintaining adequate fluid intake for stroke survivors</li> <li>9. Identify the signs of dehydration on stroke survivors</li> <li>10. Discuss measures to prevent dehydration in stroke survivors</li> </ol>
<p><b>Assessment of learning</b></p>	<ol style="list-style-type: none"> <li>1. Verbal evaluation</li> <li>2. Return demonstration of food administration through a gastrostomy</li> <li>3. Return demonstration of oral feeding of the stroke patient</li> <li>4. Gastrostomy care return demonstration</li> </ol>

<b>Content of the session</b>	<b>APPENDIX F</b>
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*Description of the session.*

This session discusses the possible eating and swallowing problems after stroke. Both the speech and swallow pathologist and the nutritionist would participate in the delivery of the information. The speech and swallow pathologist would first expose the caregivers to the signs and symptoms of swallowing problems and to the principles of safe feeding and the reasons for the modified diet, using a power point presentation followed by discussions and evaluation. The pathologist would then help the caregivers identify the best types of diet and feeding applicable to their stroke survivor.

The nutritionist would then discuss the impact of eating and swallowing problems on the overall health status of the survivor, and will discuss the signs & symptoms, effects, prevention and management of dehydration. These topics will be covered by a power point presentation, followed by an interactive discussion and evaluation.

The caregivers, whose survivors have a gastrostomy or a Jejunostomy, will be exposed to a tutorial video that will teach them how to properly administer food through the tube, properly handle the tube, and clean and monitor the insertion site in collaboration with registered nurses and the nurse-aid on duty. The caregivers will be evaluated while performing a return demonstration of food administration and tube handling.

***Session 5: Mobility, positioning and transfer.***

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Mobility after stroke</li> <li>2. Performing range of motion exercises</li> <li>3. Moving a stroke survivor towards the head of the bed</li> <li>4. Turning the stroke patient in bed</li> <li>5. Positioning of the stroke survivor</li> <li>6. Transfer techniques applied to the stroke patient</li> <li>7. Assisting the stroke survivor in ambulating</li> </ol>
<b>Duration</b>	60 minutes
<b>Instructor(s)</b>	Physical therapist
<b>Teaching methods</b>	<ol style="list-style-type: none"> <li>1. Lectures / slide presentations – discussions</li> <li>2. Tutorial videos</li> <li>3. Hands-on training</li> </ol>
<b>Learning outcomes</b>	<p>At the end of the session, the caregiver should be able to:</p> <ol style="list-style-type: none"> <li>1. Describe how stroke affects mobility of the patient</li> <li>2. Demonstrate range of motion exercises applied to the stroke survivor</li> <li>3. Demonstrate moving a stroke survivor toward the head of the bed</li> <li>4. Demonstrate assisting the stroke survivor in walking</li> <li>5. Demonstrate turning a stroke survivor in bed</li> <li>6. Demonstrate the correct positioning technique</li> <li>7. Demonstrate the transfer of a stroke survivor between bed and chair</li> </ol>

<b>Assessment of learning</b>	<ol style="list-style-type: none"> <li>1. Oral evaluation</li> <li>2. Return demonstration</li> </ol>
<b>Content of the session</b>	<b>APPENDIX G</b>

*Description of the session.*

Through developed power point presentation, the factors that affect mobility after stroke will be discussed and explained. The caregivers would then watch tutorial videos that demonstrate range of motion exercises as well as proper positioning, turning, lifting, transferring and walking assistance techniques. The videos will be repetitively paused for discussion and explanation. Afterwards, the caregivers will practice all techniques on the survivor, with the help of the physical therapist and nurses on duty.

***Session 6: Communication and cognition problems.***

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Definition and effects of aphasia</li> <li>2. Communication with the aphasic patient</li> <li>3. Role of the speech therapist in aphasia</li> <li>4. Cognitive problems post stroke and means of dealing with these problems</li> </ol>
<b>Duration</b>	60 minutes
<b>Instructor(s)</b>	Speech pathologist and Neuro-CNS
<b>Teaching methods</b>	Lecture / Slides presentation
<b>Objectives</b>	At the end of the session, caregivers should be able to:

	<ol style="list-style-type: none"> <li>1. Discuss the impact of aphasia on stroke survivors</li> <li>2. Identify the different types of aphasia resulting from stroke</li> <li>3. Discuss ways to facilitate communication with the stroke survivor</li> <li>4. Cite possible cognitive problems occurring after stroke</li> <li>5. Discuss ways to deal with the stroke survivor's cognitive deficits</li> </ol>
<b>Assessment of learning</b>	Oral evaluation
<b>Content of the session</b>	<b>APPENDIX H</b>

*Description of the session.*

This session will cover communication and cognitive problems after stroke, and will teach caregivers how to manage and deal with such problems. The power point presentation addressing these issues will be followed by a discussion that will allow caregivers to select the information that is applicable to their stroke survivor. At the end of the session, questions will be asked to make sure that the pre-set learning outcomes are achieved.

***Session 7: Stroke and depression.***

<b>Outline</b>	<ol style="list-style-type: none"> <li>1. Post stroke depression</li> <li>2. Signs of post stroke depression</li> </ol>
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	3. Measures by the caregiver to deal with depression
<b>Duration</b>	30 minutes
<b>Instructor(s)</b>	Neuro-CNS
<b>Teaching methods</b>	Lecture / Slides presentation
<b>Learning outcomes</b>	At the end of the session, caregivers should be able to: <ul style="list-style-type: none"> <li>1. Identify signs of post stroke depression</li> <li>2. Describe the potential measures that will help the caregiver deal with the depressed stroke patient</li> </ul>
<b>Assessment of learning</b>	Oral evaluation
<b>Content of the session</b>	<b>APPENDIX I</b>

*Description of the session.*

This session will address post stroke depression, its signs and symptoms, and possible treatment options. The needed presentation equipment –The projector, Laptop computer, cables and connections- would be provided by the medical center. The power point presentation of these issues will be followed by a discussion that will allow caregivers to select the information that could be applicable to the case of their stroke survivor. At the end of the session, questions will be asked to make sure that the pre-set learning outcomes are achieved.

***Session 8: Caregiver burnout.***

<b>Outline</b>	1. Burnout among the stroke patient caregiver
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	<ol style="list-style-type: none"> <li>2. Signs of burnout among the caregivers of the stroke patients</li> <li>3. Avoidance of caregiver burnout</li> </ol>
<b>Duration</b>	30 minutes
<b>Instructor(s)</b>	Neuro-CNS
<b>Teaching methods</b>	Lecture / Slides presentation
<b>Learning outcomes</b>	<p>At the end of the sessions, caregivers should be able to:</p> <ol style="list-style-type: none"> <li>1. Recognize the signs of burnout developing from caring for the stroke survivor</li> <li>2. Demonstrate ways that help to prevent burnout in the caregiver of the stroke patient</li> </ol>
<b>Assessment of learning</b>	Oral evaluation
<b>Content of the session</b>	<b>APPENDIX J</b>

*Description of the session.*

This final session will target the caregivers themselves. The Neuro-CNS will introduce the concept of caregiver burnout and the related signs and symptoms. The needed presentation equipment (The projector, Laptop computer, cables and connections) would be provided by the medical center. The power point presentation addressing these issues will be followed by a discussion. The discussion will focus on the self-care needs of caregivers. The neuro-CNS will emphasize the importance of taking care of one's own physical and mental health to better care for



others. Practical skills for effective coping, stress reduction, improving self-confidence, and communicating effectively will be taught and reinforced.

### **Home visits.**

As previously mentioned, the Neuro-CNS will visit the caregivers at home to deliver the last two sessions of the program. These visits will provide the, caregivers with the opportunity to discuss arising problems with the CNS and will allow the CNS to reinforce the content of the sessions, give suggestions and provide the needed support. Further visits would be scheduled by the social worker if needed.

### **Booklet and handouts.**

Caregivers will be provided with a booklet that contains all the information figuring in the slide show presentations. This booklet will serve them as reference and will be prepared in English then translated to Arabic at a 5<sup>th</sup> grade reading level. In addition to the booklet, they will also be provided with the following:

1. A handout, entitled “Body Mechanics for Caregivers”, which summarizes what was already discussed during the sessions, in relation to moving, positioning and transferring stroke patients. The handout contains images and illustrations that simplify steps that should be followed by caregivers during execution. Please refer to Appendix K.
2. A handout that illustrates the basics of bed bath and general hygiene. Please refer to Appendix L.
3. A contact list of companies and Lebanese associations that provide useful mobility-aids and healthcare equipment such as hospital beds, wheelchairs, etc

## CHAPTER IV

### PROGRAM IMPLEMENTATION AND EVALUATION

#### **Program Implementation**

A proposal outlining the program significance and main components, along with proposed mode of delivery and evaluation will be prepared and presented to the collaborative practice team, CNS council, and the nursing director. Once approved, the program structure and content will be presented to those involved in the teaching (nutritionists, speech therapists, physical therapists etc...) for finalization. Then the educational material will be sent to the patient education coordinator at AUBMC who will assess its level of readability. The approvals of the patient education committee will be sought. The material will be translated from English to Arabic. A pilot test of the program on five stroke survivors and their family caregivers will be made. Modifications will be made based on feedback from the five stroke survivors then full implementation will follow. Documentation of the program shall be integrated in the patients' medical record.

#### **Program evaluation**

Evaluation of this educational program occurs at various levels: (1) evaluation of learning by the caregivers, (2) evaluation of the quality of the program from the perspective of participants, i.e. the caregivers, and (3) organizational evaluation of the impact of this program on the outcomes of stroke survivors. Evaluation of learning was addressed in chapter 3 where stroke survivors will

be asked questions at the end of each session and/or asked to return demonstration to assess cognitive learning and psychomotor skills acquired through the program.

### **Program Evaluation From the Perspective of Caregivers**

Written questionnaires will be handed out to caregivers at the end of each session, as well as at the end of the overall program; which will allow them to give feed back on the content and the execution.

At the end of each session, caregivers will be asked to fill a 5-minute-questionnaire, in which they indicate their level of agreement with a set of statement concerning the content and execution of the modules. Two open-ended questions are added at the end. Please refer to appendix M.

The overall program evaluation questionnaire will be given at the end of the last session of the intervention. It was developed based on the learning objectives, to assess the extent by which caregivers perceived the program as beneficial, useful and effective in meeting their needs. The caregivers will be asked to fill a 10-minute-questionnaire, to indicate their level of agreement with a set of statement concerning the program and its application. Open-ended questions are also added to better understand the experience of the caregivers. Please refer to appendix N.

### **Organizational Program Evaluation**

The institution (AUBMC) shall evaluate the program in more than one way. Patient satisfaction questionnaires are already available for in-patients and outpatients and done on a

quarterly basis. Similarly, adapted caregiver satisfaction questionnaires can be used. Stroke patient outcomes can be measured before and after implementation of the educational program to see whether it had an impact. Outcome measures to be used may include stroke readmissions rates - due to stroke complications (pressure ulcers, urinary track infections, aspiration pneumonia, dehydration, malnutrition, etc...). Such measures would be compared prior to and after the implementation of the program. A cost analysis shall be carried out including cost of health care with and without the program versus the cost of the program itself (remuneration for staff, etc...).

### **Limitations**

The educational program for caregivers of stroke survivors could be faced with several limitations:

1. This educational program targets family caregivers of those who are not candidates for rehabilitation. The program was not designed to meet the needs of family caregivers of patients with mild, moderate, or even moderately severe stroke. Perhaps these caregivers do not need to undergo such a comprehensive program; however, they do require specific interventions so that they may be able to accompany their survivor through the phases of recovery. At an early stage, only caregivers of those who have had a severe stroke will be targeted. At a later stage, the content of the program would be expanded to target the caregivers of those that are candidates for rehabilitation interventions, as well as the survivors themselves.

2. For this program, the individualized interventions with individual approaches were chosen over non-tailored, one-size-fits-all group interventions due to the large amount of the information delivered, the complexity of the skills taught, and the complexity of the stroke survivor's physical and emotional needs. The disadvantage is that such program may consume extra money, time, and resources. It would add to the heavy workload of the nursing team in charge of the concerned patients, as well as that of the healthcare professional providing the education.
3. The hospital itself is a very stressful environment, and the idea of having to suddenly drift into the role of caregiver could be tense and upsetting. Stress affects learning and memory; it interferes with a person's capacity to encode memory and the ability to retrieve information. However, conducting this educational program outside the hospital, and offering the sessions at home after discharge would not be feasible due to the unavailability of all the members of the multidisciplinary team, and their heavy workload. In order to overcome this issue, information will be delivered in a very simple and concise manner. Information would be repeated several times and caregivers themselves would be asked to repeat and summarize the communicated information to make sure that the learning process had occurred. Finally several pamphlets and brochures would be handed out to facilitate the retrieval of the information. Alternatively, providing the education in the hospital shall provide support and resources that may not be available at home if the teaching has to be done there.
4. In addition to the hospital being a stressful environment, offering 6 sessions prior to discharge may be challenging, for both the caregivers and the instructors, since the patient's stay is short, around 3 to 4 days as previously mentioned. However the program will be

pilot tested, and caregivers will be assessed prior to discharge. If, based on the assessments conducted after each session, the instructors feels that the caregivers are not yet ready to take on their responsibilities, additional sessions will be programmed to be delivered after discharge.

### **Conclusion**

The designed educational program for caregivers of stroke survivors is a combination of psycho educational interventions, skills-building interventions as well as support interventions. The program integrates guidelines and recommendations related to stroke caregiver education and preparation into clinical practice. It motivates them to take on their new role by providing them with all the necessary information about stroke and how it affects the survivor, the caregivers, and the family as a system, and by developing and strengthening their management skills. Moreover, it allows the multidisciplinary team of healthcare professional to offer support, thus helping the caregivers to properly cope with all the physical and emotional stress resulting from the experience.

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## APPENDICES

### Appendix A

#### The National Institute of Health Stroke Scale (NIHSS)

Instructions: Administer the stroke scale items in the order listed. Record performance in each category after each subscale exam. Do not go back and change the scores. Follow directions provided for each exam technique. Scores should reflect what the patient does, not what the clinician thinks the patient can do. The clinician should record answers while administering the exam and work quickly. Except where indicated, the patient should not be coached (i.e., repeated requests to patient to make a special effort)

Instructions	Scale Definition	Score
<p><b>1a. Level of Consciousness:</b> The investigator must choose a response if a full evaluation is prevented by such obstacles as an endotracheal tube, language barrier, orotracheal trauma/bandages. A 3 is scored only if the patient makes no movement (other than reflexive posturing) in response to noxious stimulation.</p>	<p>0 = <b>Alert;</b> keenly responsive.                      1 = <b>Not alert;</b> but arousable by minor stimulation to obey, answer, or respond.                      2 = <b>Not alert;</b> requires repeated stimulation to attend, or is obtunded and requires strong or painful stimulation to make movements (not stereotyped).                      3 = Responds only with reflex motor or autonomic effects or totally unresponsive, flaccid, and areflexic.</p>	<p>_____</p>
<p><b>1b. LOC Questions:</b> The patient is asked the month and his/her age. The answer must be correct - there is no partial credit for being close. Aphasic and stuporous patients who do not comprehend the questions will score 2. Patients unable to speak because of endotracheal intubation, orotracheal trauma, severe dysarthria from any cause, language barrier, or any other problem not secondary to aphasia are given a 1. It is important that only the initial answer be graded and that the examiner not "help" the patient with verbal or non-verbal cues.</p>	<p>0 = <b>Answers</b> both questions correctly.                      1 = <b>Answers</b> one question correctly.                      2 = <b>Answers</b> neither question correctly.</p>	<p>_____</p>
<p><b>1c. LOC Commands:</b> The patient is asked to open and close the eyes and then to grip and release the non-paretic hand. Substitute another one step command if the hands cannot be used. Credit is given if an unequivocal attempt is made but not completed due to weakness. If the patient does not respond to command, the task should be demonstrated to him or her (pantomime), and the result scored (i.e., follows none, one or two commands). Patients with trauma, amputation, or other physical impediments should be given suitable one-step commands. Only the first attempt is scored.</p>	<p>0 = <b>Performs</b> both tasks correctly.                      1 = <b>Performs</b> one task correctly.                      2 = <b>Performs</b> neither task correctly.</p>	<p>_____</p>
<p><b>2. Best Gaze:</b> Only horizontal eye movements will be tested. Voluntary or reflexive (oculocephalic) eye movements will be scored, but caloric testing is not done. If the patient has a conjugate deviation of the eyes that can be overcome by voluntary or reflexive activity, the score will be 1. If a patient has an isolated peripheral nerve paresis (CN III, IV or VI), score a 1. Gaze is testable in all aphasic patients. Patients with ocular trauma, bandages, pre-existing blindness, or other disorder of visual acuity or fields should be tested with reflexive movements, and a choice made by the investigator. Establishing eye contact and then moving about the patient from side to side will occasionally clarify the presence of a partial gaze palsy.</p>	<p>0 = <b>Normal.</b>                      1 = <b>Partial gaze palsy;</b> gaze is abnormal in one or both eyes, but forced deviation or total gaze paresis is not present.                      2 = <b>Forced deviation,</b> or total gaze paresis not overcome by the oculocephalic maneuver.</p>	<p>_____</p>

<p><b>3. Visual:</b> Visual fields (upper and lower quadrants) are tested by confrontation, using finger counting or visual threat, as appropriate. Patients may be encouraged, but if they look at the side of the moving fingers appropriately, this can be scored as normal. If there is unilateral blindness or enucleation, visual fields in the remaining eye are scored. Score 1 only if a clear-cut asymmetry, including quadrantanopia, is found. If patient is blind from any cause, score 3. Double simultaneous stimulation is performed at this point. If there is extinction, patient receives a 1, and the results are used to respond to item 11.</p>	<p>0 = <b>No visual loss.</b></p> <p>1 = <b>Partial hemianopia.</b></p> <p>2 = <b>Complete hemianopia.</b></p> <p>3 = <b>Bilateral hemianopia</b> (blind including cortical blindness).</p>	<p>_____</p>
<p><b>4. Facial Palsy:</b> Ask – or use pantomime to encourage – the patient to show teeth or raise eyebrows and close eyes. Score symmetry of grimace in response to noxious stimuli in the poorly responsive or non-comprehending patient. If facial trauma/bandages, orotracheal tube, tape or other physical barriers obscure the face, these should be removed to the extent possible.</p>	<p>0 = <b>Normal</b> symmetrical movements.</p> <p>1 = <b>Minor paralysis</b> (flattened nasolabial fold, asymmetry on smiling).</p> <p>2 = <b>Partial paralysis</b> (total or near-total paralysis of lower face).</p> <p>3 = <b>Complete paralysis</b> of one or both sides (absence of facial movement in the upper and lower face).</p>	<p>_____</p>
<p><b>5. Motor Arm:</b> The limb is placed in the appropriate position: extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine). Drift is scored if the arm falls before 10 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.</p>	<p>0 = <b>No drift;</b> limb holds 90 (or 45) degrees for full 10 seconds.</p> <p>1 = <b>Drift;</b> limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support.</p> <p>2 = <b>Some effort against gravity;</b> limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity.</p> <p>3 = <b>No effort against gravity;</b> limb falls.</p> <p>4 = <b>No movement.</b></p> <p>UN = <b>Amputation</b> or joint fusion, explain: _____</p> <p><b>5a. Left Arm</b></p> <p>_____</p> <p><b>5b. Right Arm</b></p> <p>_____</p>	<p>_____</p> <p>_____</p>
<p><b>6. Motor Leg:</b> The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.</p>	<p>0 = <b>No drift;</b> leg holds 30-degree position for full 5 seconds.</p> <p>1 = <b>Drift;</b> leg falls by the end of the 5-second period but does not hit bed.</p> <p>2 = <b>Some effort against gravity;</b> leg falls to bed by 5 seconds, but has some effort against gravity.</p> <p>3 = <b>No effort against gravity;</b> leg falls to bed immediately.</p> <p>4 = <b>No movement.</b></p> <p>UN = <b>Amputation</b> or joint fusion, explain: _____</p> <p><b>6a. Left Leg</b></p> <p>_____</p> <p><b>6b. Right Leg</b></p>	<p>_____</p>



<p><b>7. Limb Ataxia:</b> This item is aimed at finding evidence of a unilateral cerebellar lesion. Test with eyes open. In case of visual defect, ensure testing is done in intact visual field. The finger-nose-finger and heel-shin tests are performed on both sides, and ataxia is scored only if present out of proportion to weakness. Ataxia is absent in the patient who cannot understand or is paralyzed. Only in the case of amputation or joint fusion, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. In case of blindness, test by having the patient touch nose from extended arm position.</p>	<p>0 = <b>Absent.</b></p> <p>1 = <b>Present in one limb.</b></p> <p>2 = <b>Present in two limbs.</b></p> <p>UN = <b>Amputation</b> or joint fusion, explain: _____</p>	<p>_____</p>
<p><b>8. Sensory:</b> Sensation or grimace to pinprick when tested, or withdrawal from noxious stimulus in the obtunded or aphasic patient. Only sensory loss attributed to stroke is scored as abnormal and the examiner should test as many body areas (arms [not hands], legs, trunk, face) as needed to accurately check for hemisensory loss. A score of 2, "severe or total sensory loss," should only be given when a severe or total loss of sensation can be clearly demonstrated. Stuporous and aphasic patients will, therefore, probably score 1 or 0. The patient with brainstem stroke who has bilateral loss of sensation is scored 2. If the patient does not respond and is quadriplegic, score 2. Patients in a coma (item 1a=3) are automatically given a 2 on this item.</p>	<p>0 = <b>Normal;</b> no sensory loss.</p> <p>1 = <b>Mild-to-moderate sensory loss;</b> patient feels pinprick is less sharp or is dull on the affected side; or there is a loss of superficial pain with pinprick, but patient is aware of being touched.</p> <p>2 = <b>Severe to total sensory loss;</b> patient is not aware of being touched in the face, arm, and leg.</p>	<p>_____</p>
<p><b>9. Best Language:</b> A great deal of information about comprehension will be obtained during the preceding sections of the examination. For this scale item, the patient is asked to describe what is happening in the attached picture, to name the items on the attached naming sheet and to read from the attached list of sentences. Comprehension is judged from responses here, as well as to all of the commands in the preceding general neurological exam. If visual loss interferes with the tests, ask the patient to identify objects placed in the hand, repeat, and produce speech. The intubated patient should be asked to write. The patient in a coma (item 1a=3) will automatically score 3 on this item. The examiner must choose a score for the patient with stupor or limited cooperation, but a score of 3 should be used only if the patient is mute and follows no one-step commands.</p>	<p>0 = <b>No aphasia;</b> normal.</p> <p>1 = <b>Mild-to-moderate aphasia;</b> some obvious loss of fluency or facility of comprehension, without significant limitation on ideas expressed or form of expression. Reduction of speech and/or comprehension, however, makes conversation about provided materials difficult or impossible. For example, in conversation about provided materials, examiner can identify picture or naming card content from patient's response.</p> <p>2 = <b>Severe aphasia;</b> all communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. Range of information that can be exchanged is limited; listener carries burden of communication. Examiner cannot identify materials provided from patient response.</p> <p>3 = <b>Mute, global aphasia;</b> no usable speech or auditory comprehension.</p>	<p>_____</p>
<p><b>10. Dysarthria:</b> If patient is thought to be normal, an adequate sample of speech must be obtained by asking patient to read or repeat words from the attached list. If the patient has severe aphasia, the clarity of articulation of spontaneous speech can be rated. Only if the patient is intubated or has other physical barriers to producing speech, the examiner should record the score as untestable (UN), and clearly write an explanation for this choice. Do not tell the patient why he or she is being tested.</p>	<p>0 = <b>Normal.</b></p> <p>1 = <b>Mild-to-moderate dysarthria;</b> patient slurs at least some words and, at worst, can be understood with some difficulty.</p> <p>2 = <b>Severe dysarthria;</b> patient's speech is so slurred as to be unintelligible in the absence of or out of proportion to any dysphasia, or is mute/anarthric.</p> <p>UN = <b>Intubated</b> or other physical barrier, explain: _____</p>	<p>_____</p>

<p><b>11. Extinction and Inattention (formerly Neglect):</b> Sufficient information to identify neglect may be obtained during the prior testing. If the patient has a severe visual loss preventing visual double simultaneous stimulation, and the cutaneous stimuli are normal, the score is normal. If the patient has aphasia but does appear to attend to both sides, the score is normal. The presence of visual spatial neglect or anosagnosia may also be taken as evidence of abnormality. Since the abnormality is scored only if present, the item is never untestable.</p>	<p>0 = <b>No abnormality.</b></p> <p>1 = <b>Visual, tactile, auditory, spatial, or personal inattention</b> or extinction to bilateral simultaneous stimulation in one of the sensory modalities.</p> <p>2 = <b>Profound hemi-inattention or extinction to more than one modality;</b> does not recognize own hand or orients to only one side of space.</p>	<p>_____</p>
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Duncan, P., Zorowitz, R., Bates, B., Choi, J., Glasberg, J., Graham, G., ... Reker, D. (2005). Management of adult stroke rehabilitation care: A clinical practice guideline. *Stroke*, 36, 100-143.

## **Appendix B**

### **Roles of the instructors**

#### The Neuro-CNS

The CNS will play an essential role in planning, preparing and leading the multidisciplinary team, evaluating the implementation of the program and following up with the stroke survivors and their caregivers afterwards. He/she will do the following:

- Recruit participants
- Ensure coordination and communication between members of the team
- Assess comprehensively the needs and concerns from the caregiver's perspective
- Set clear, well defined, care goals
- Participate in the functional and psychological assessment of the survivor (bladder and bowel function, skin integrity and risk of breakdown, etc....)
- Participate in the delivery of the following program modules: (1) Brain, stroke, and multidisciplinary care, (2) The bladder and bowel control and (3) Daily hygiene and skin care
- Monitor the progression of the program
- Evaluate the overall program
- Ensure proper documentation and
- Arrange follow up contacts and/or visits periodically after discharge.

#### The physical therapist

The Physical therapist would provide baseline assessment of balance, gait, locomotion, joint integrity and mobility, movement patterns, coordination, strength, power, posture, range of motion and reflex integrity; deliver the Mobility, Positioning & Transfers module; and provide the assistive and adaptive devices needed such as wheel chairs, canes, hospital beds, etc...

#### The dietitian

The dietitian would evaluate the nutrition and hydration status; monitor the food/fluid intake, and body weight; recommend a variety of methods to maintain and improve food and fluid intake; and collaborate with the speech & language pathologists in presenting the Meal Assistance & Special Diets module, and the Hydration module.

#### The Speech and language pathologist

The speech and language pathologist would perform swallow screening and examination; discuss food consistency with the dietitian; identify areas of cognitive and communication impairments, be in charge of the communication and cognition modules; and will collaborate with the dietitian in the delivery of the Meal Assistance, Special Diets and Hydration module.

#### The psychologist

The psychologist would assess the survivor's risk for depression; and participate in the delivery of the program, as he/she will be responsible for the stroke and Depression and the Caregiver Burnout modules.

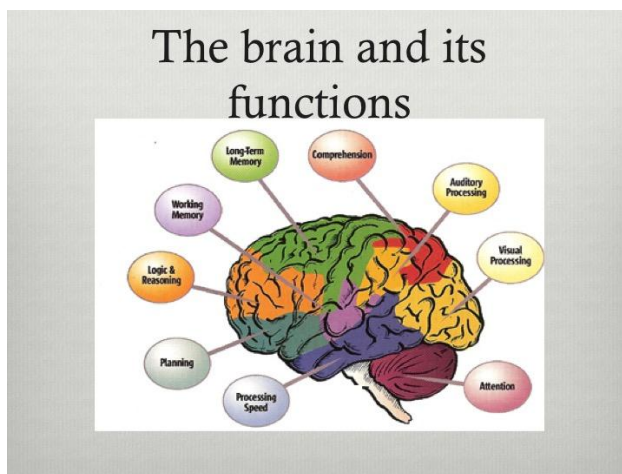
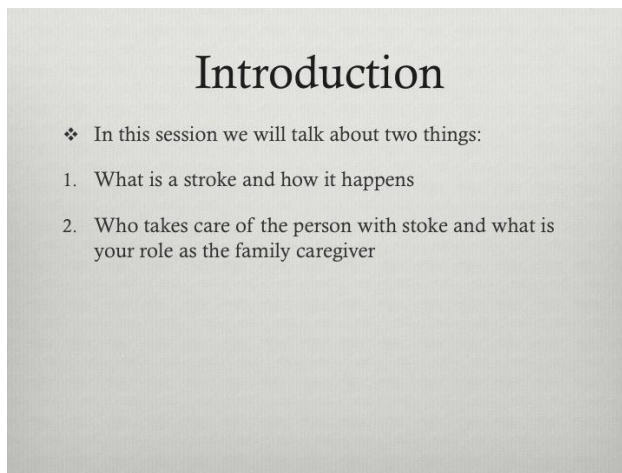
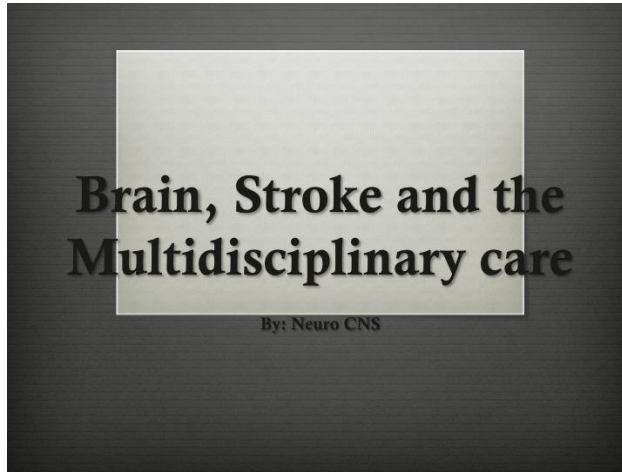
#### The social worker

After discharge, the social worker would visit the family caregiver at home where he / she would perform comprehensive assessment of the family's psychosocial functioning, environment, resources, goals, and expectations; inform the family caregivers about all aspects of healthcare and safety needs; assist the family caregiver in obtaining financial support; and encourage their participation in leisure activities.

#### The treating neurologist

The treating neurologist would meet with the rest of the members of the team for routine evaluation; treat possible complications or any conditions that would alter the plan of care; and

## Appendix C



The complex human brain controls who we are: how we think, feel, and act. It gives meaning to our world and our place in it. The brain also controls all the major functions of our body

**Movement:** Moving and the coordination of movement

**Perception:** How we interpret the information around us with our senses

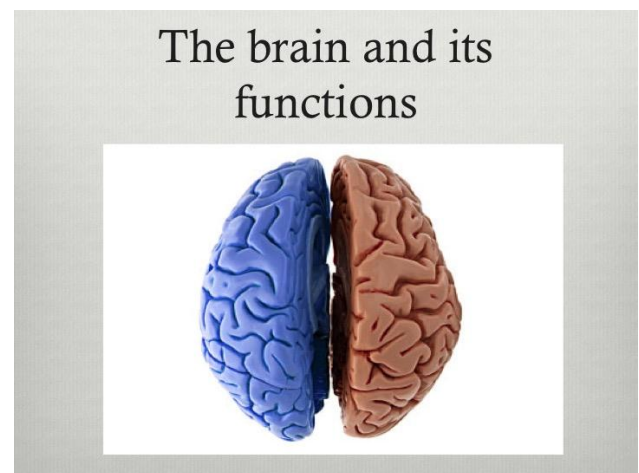
**Sensation:** Such as touch

**Vision:** How we see

**Cognition:** Thinking, remembering, understanding, planning, reasoning and problem solving

**Communication:** Speaking and understanding what others say to us

**Personality:** Including our emotions and behavior



The brain is divided into two parts. These are called the left and right **hemispheres**. Each hemisphere is divided into regions, which control different functions



### Right Side Brain




- ☞ Sequential thinking
- ☞ Insight
- ☞ Imagination
- ☞ Face recognition
- ☞ Art/Color
- ☞ Spatial Orientation
- ☞ Drama
- ☞ Metaphor/Poetry
- ☞ Music
- ☞ Meditation/Prayer
- ☞ Rap/Rhyme

**The right hemisphere of the brain controls:** Movement and feeling of the left side of the body; Artistic functions: music, art awareness, and awareness; Perception: being aware of, and making sense of the surrounding environment


### Left Side Brain

- ☞ Sequential thinking
- ☞ Sees Details
- ☞ Logical: Cause & Effect
- ☞ Language functions
- ☞ Uses Facts
- ☞ Speaks well
- ☞ Good with numbers
- ☞ Word puzzles
- ☞ Analyzes
- ☞ Names things



**The left hemisphere of the brain controls:** Movement and feeling of the right side of the body; Talking; Understanding written and spoken language; Number skills; Analyzing and thinking in sequence

### Definition and Types of Stroke

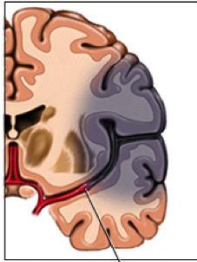


The brain is full of specialized cells called neurons that need a constant supply of oxygen and nutrients.

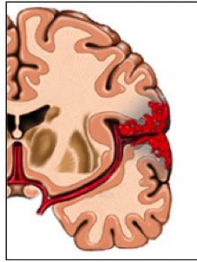
A complex network of blood vessels called arteries carries blood to all parts of the brain. Each blood vessel supplies oxygen and nutrients to a specific area of the brain.

Stroke is a sudden injury to part of the brain caused when blood flow in an artery stops. The affected area of the brain then will not receive enough oxygen and nutrients. This damages the neurons and the functions they control in that area of the brain. If blood flow is not returned within minutes, the damaged neurons start to die. Neurons that die cannot be replaced or restored.

### Definition and Types of Stroke



A clot blocks blood flow to an area of the brain

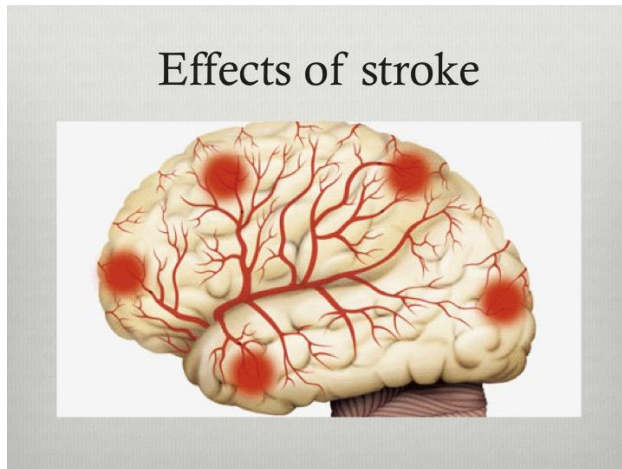


Bleeding occurs inside or around brain tissue

Stroke can occur in two ways:

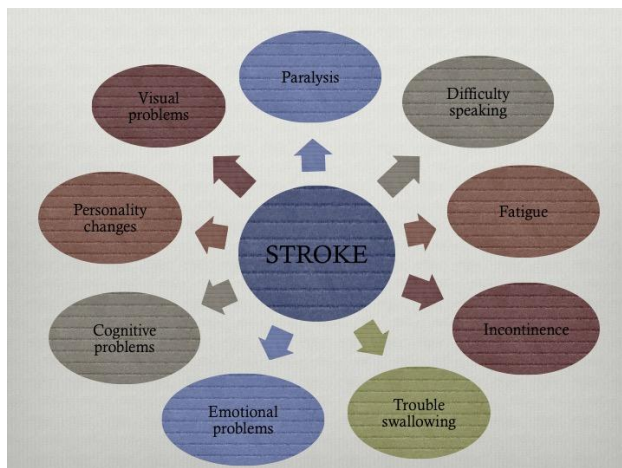
Rupture of an artery causes a **hemorrhagic stroke** (stroke due to bleeding in the brain tissue).

Blockage of an artery causes an **ischemic stroke** (stroke due to a clot blocking blood flow)



The effects of a stroke depend on the location and size of the area of brain that is damaged, and the functions that the area controlled. Strokes that are large enough to affect several areas of the brain affect many functions. For example, a large left hemisphere stroke may damage motor, sensory, and language areas.

This may affect the survivor’s ability to move, feel, and communicate



Common effects of stroke include:

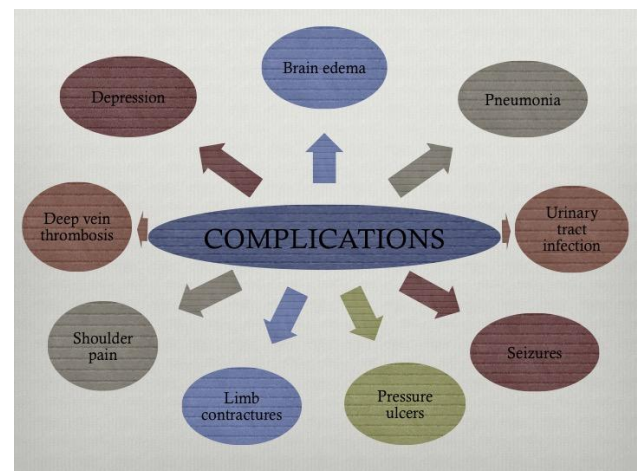
Paralysis or weakness on one side of the body; Difficulty speaking or slurred speech; Fatigue; Incontinence: Loss of bladder and/or bowel control; Trouble swallowing; Emotional problems: Loss of emotional control and changes in mood; Cognitive problems: Problems with memory, judgment, problem solving; Personality changes, improper language or actions; Decreased field of vision, or trouble with vision

### Complications after Stroke

The highest priorities after a stroke are to:

- ❖ Prevent complications from the stroke, and
- ❖ Prevent another stroke.

Some things happen as a direct result of the injury to the brain due to the stroke; and others are because of the changes in the survivors’ abilities



**The most common complications of a stroke are:**

Brain edema, which is the swelling of the brain after a stroke

Pneumonia or infection of the lungs, which causes breathing problems. Common swallowing problems after stroke can lead to

pneumonia that is caused by food or fluid going into the airway.

Urinary tract infection

Seizures, an abnormal activity in the brain causing convulsions

Bedsore or breaks in the skin that result from decreased ability to move and from pressures on areas of the body because of immobility

Limb contractures, or abnormal position of extremities caused by shortened muscles in an arm or leg from reduced range of motion and a lack of exercise

Shoulder pain, from lack of support of an arm due to weakness or paralysis

Deep venous thrombosis, or blood clots that form in veins of the legs because of immobility from stroke

Clinical depression or sad mood, which is a treatable illness that often occurs with stroke and causes unwanted emotional and physical reactions to changes and losses.



The team is made up of the stroke survivor, their family caregivers and their health care providers.

The group designs a care plan for each stroke survivor. The team shares information. They also work together to develop care strategies. They report on how your relative is doing. They tell each other about changes in the survivor's care.

Sharing what you know about the stroke survivor with the team will help improve the survivor's quality of life.

### Members of the team

The make-up of the team depends on how severe the stroke was and on the loss of functions. Each member of the team has knowledge and skills to add, so that the survivor gets the best care. In most cases the team includes Doctors, Nurses, Physiotherapist, Speech and language pathologist, Psychologist, Social worker, Dietitian, as well as the family caregivers



As a member of the inter-professional care team, you can make a difference in the life of your relative who has the stroke.

Each survivor has his own values, preferences, and needs. What you know about the stroke survivor is important; it helps the team understand your relative's needs and his/her physical, mental, and emotional status.



There is no one “Job Description” that explains what all caregivers do. Each caregiver’s responsibilities vary according to the unique needs of the stroke survivor. You may need to learn new skills and have changes in your role



**The responsibilities of caregiving include:**

Providing your relative with physical help with personal care and transportation

Managing financial, legal and business affairs

Monitoring your relative’s behavior to ensure safety

Managing housework and making meals

Coordinating healthcare and monitoring and giving medication

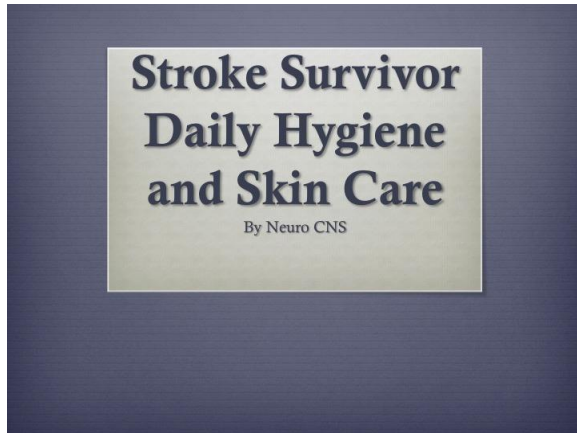
Providing emotional support for the stroke survivor and family members

Encouraging the stroke survivor to work towards being as independent as possible.

## References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pvI3IeNWJwE/b.5384179/k.B2BB/HCP.htm>

## Appendix D



### Stroke survivor and daily hygiene

Helping a stroke survivor with his daily hygiene care means letting the survivor be as independent as his/her abilities will allow.

Your challenge is to make sure the task is not too hard, tiring, or frustrating.

All the while, you must keep safety in mind.



Having a bath, brushing your teeth, or shaving, are things most of us do without thinking.

A stroke can change that. These factors affect a person's ability to complete these activities of daily living: Loss of movement on one side; Impaired ability to grasp; Lack of sensation; Difficulty planning tasks

### Stroke Survivor and Daily Hygiene

The following 5 strategies can help you help your relative with the hygiene as needed:

- Prepare the tools
- Position the patient properly
- Encourage your relative to use his/her good limbs
- Cue and guide him/her during the hygiene care
- Use assistive devices

### Bed Bath

How to give a bed bath and change the bed sheets?

<https://www.youtube.com/watch?v=UaoZ17al-yU>

Stroke can change bathing from a private pleasure into an unpleasant experience.

Fear of injury and invasion of your relative's privacy may change his/her view of bathing.

It is important to recognize your relative's fears and concerns and to use patience when helping with bathing.

## Oral Hygiene

How to perform oral care?

<https://www.youtube.com/watch?v=ODCy8fjQSuM>

A clean mouth and clean teeth are essential to comfort and good health.

Bacteria from diseased gums may travel through the bloodstream and cause infections.

Bacteria and food particles in the mouth can be especially dangerous if aspirated into the lungs.

A clean mouth and teeth are important whether the survivor takes food orally or by tube.

Without these essential nutrients, skin cells and tissues are damaged and may eventually die.

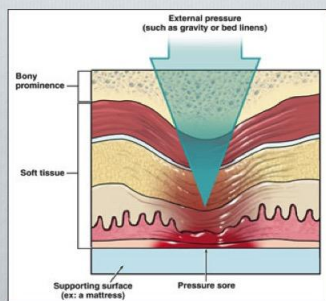
Pressure ulcers most often develop on the skin that covers bony areas of the body, such as the heels, ankles, hips and tailbone.

People most at risk of bedsores are those with a medical condition that limits their ability to change positions, requires them to use a wheelchair or confines them to a bed for a long time – such as stroke.

## What are Pressure Ulcers



## What are Pressure Ulcers



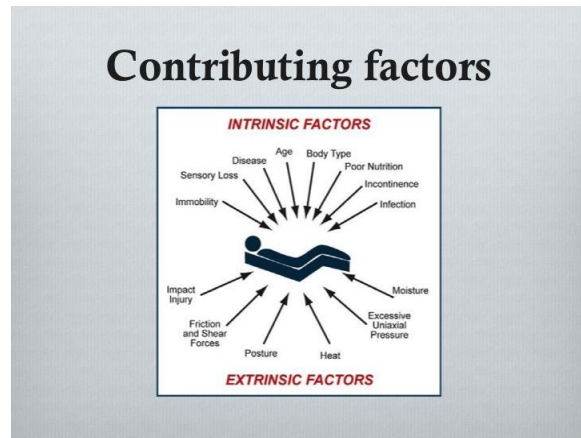
Pressure ulcers are injuries caused by pressure against the skin that limits the amount of blood that delivers oxygen and nutrients to the skin and nearby tissues.

## Contributing Factors

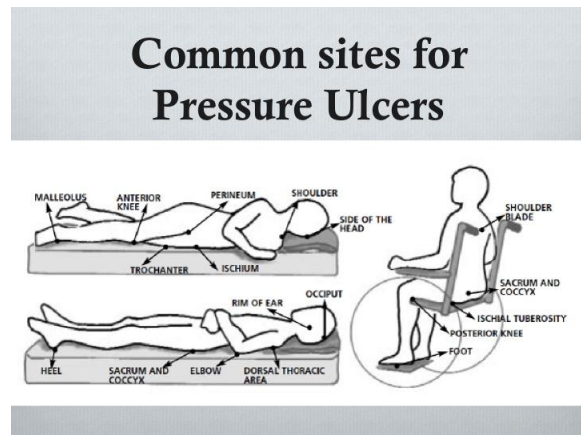
Three primary factors contribute to the formation of pressure ulcers: sustained pressure, friction and shear.

1. **Sustained pressure** is when the skin and the underlying tissues are trapped between bone and a surface
2. **Friction** is the resistance to motion. It may occur when the skin is dragged across a surface
3. **Shear** occurs when two surfaces move in the opposite direction.



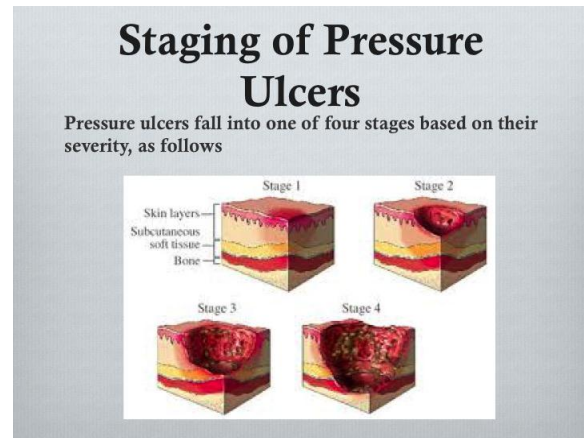


Stroke survivors face skin breakdown because of: Decreased activity and mobility; Decreased or absent sensation; Increased moisture from incontinence or perspiration; Poor nutrition, dehydration, and dry skin; Inability to communicate pain and discomfort; Improper positioning, causing friction



For people who use a wheelchair → Tailbone or buttocks, shoulder blades and spine, and the backs of arms and legs where they rest against the chair

For people who are confined to a bed → Back or sides of the head, rim of the ears, shoulders or shoulder blades, hip, lower back or tailbones, and heels, ankles and skin behind the knees



#### Stage I:

The skin is not broken; The skin appears red, and does not briefly lighten when touched; The site may be tender, painful, firm, soft, warm or cool compared with the surrounding skin.

#### Stage II

The outer layer of skin and part of the underlying layer of skin is damaged; The wound may be shallow and pinkish or red; The wound may look like a fluid-filled blister or a ruptured blister.

#### Stage III

The loss of skin usually exposes some fat; The bottom of the wound may have some yellowish dead tissue; The damage may extend beyond the primary wound below layers of healthy skin.

#### Stage IV

The wound may expose muscle, bone or tendons; The bottom of the wound likely contains dead tissue that is yellowish or dark and crusty; The damage often extends beyond the primary wound below layers of healthy skin.


## Complications of Pressure Ulcers

Complications of pressure ulcers include mostly infections of the skin and connective tissue, or even the bone and joints if the pressure ulcer is deep.

In stage IV pressure ulcers, infection may spread to the bloodstream through the broken skin, a condition called sepsis.

## Prevention of Pressure Ulcers

### Clean




**Clean:** Gently wash, do not scrub skin regularly, using mild cleansers; Rinse the skin thoroughly; Cleanse soiled skin promptly. This removes irritants and maintains the skin's natural barrier.

Let's take the  pressure off!

## Prevention of Pressure Ulcers


### Moisturize



**Moisturize:** Treat the dry skin with moisturizers; Dry, flaky or scaling skin can bring about pressure ulcers, infection and irritation; Do not massage bony prominences or reddened areas; Massage in these areas reduces blood flow and skin temperature and slows healing

## Prevention of Pressure Ulcers

### Inspect and report



**Inspect and report:** Check your relative's skin carefully every day; Pay special attention to bony prominences – heels, hip bones, and elbows; Search for redness and cuts; Report concerns or signs of skin irritation

## Prevention of Pressure Ulcers

Positioning the stroke survivor correctly



Positioning the stroke survivor correctly : Position the survivor in bed in a 30 degrees side-lying position; Do not position the survivor completely on their side; Use foam wedges or pillows; Use pillows between the knees and ankles to separate bony prominences; Use a water pillow, thick foam, or specialty boot to relieve pressure on the heels; Do not use doughnut devices. They decrease blood flow and increase tissue breakdown

## Prevention of Pressure Ulcers

Reduce friction forces



Reduce friction forces: Use dressings and padding can protect delicate areas; Use linens to lift the survivor when you move them; Do not pull or drag the survivor; Lift the head of the bed no more than 30 degrees and limit the amount of time in this position

## Prevention of Pressure Ulcers

Move often



Move often: Write up a plan for moving the survivor at least once every 2 hours and follow it; If the survivor can move himself, maintain or improve their current activity level, mobility, and range of motion,

## Prevention of Pressure Ulcers

Use pressure-reduction devices



Use pressure-reduction devices

Such as pressure-reducing mattresses, Alternating air mattresses, Elbow pads, or Pressure-reducing seat cushions for wheelchairs



## Prevention of Pressure Ulcers

Hygiene and incontinence



Hygiene and incontinence: Wipe from front to back after voiding; Change underwear daily or more often if soiled; Always provide thorough peri-care after urinary or fecal incontinence; Do not use deodorant sprays, powder, or perfumes on perineal skin

## Prevention of Pressure Ulcers

Provide nutritional support



## Treatment of Pressure Ulcers

Stage I and II pressure ulcers usually heal within several weeks to months with conservative care of the wound and ongoing, appropriate general care. Stage III and IV pressure ulcers are more difficult to treat.

Strategies include:

1. Reducing pressure
2. Cleaning and dressing wounds
3. Removing damaged tissue (Surgical debridement, Mechanical debridement)

## Treatment of Pressure Ulcers

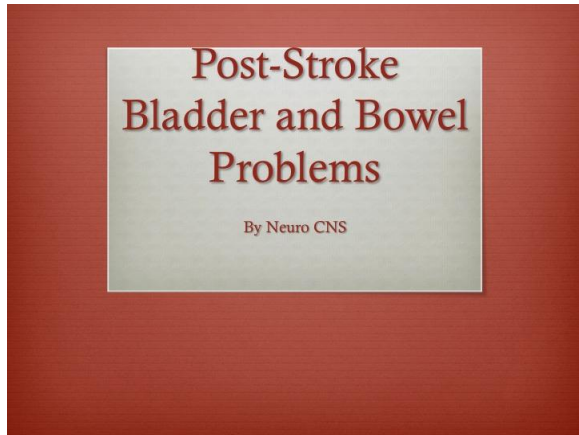
Other interventions include:

- ❖ Pain management.
- ❖ Antibiotics.
- ❖ A healthy diet.
- ❖ Management of incontinence.
- ❖ Muscle spasm relief.
- ❖ Surgery

## References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pv131eNWJwE/b.5384179/k.B2BB/HCP.htm>

**Appendix E**



### Stroke and loss of bladder control

Normal bladder function requires coordination between the nervous system and the lower urinary tract.

The lower urinary tract is made up of the bladder, urethra, and internal and external sphincters. The urethra is the tube that the urine passes through. The sphincters are muscles that close to hold urine in or open to let it pass through the urethra.

### Stroke and Loss of Bladder Control

**Urinary incontinence**

The stroke survivor may have lost the ability to identify and respond to the need to urinate.

Many stroke survivors lose bladder control right after a stroke but get it back within eight weeks, or the incontinence may come and go or be permanent.

### Stroke and Loss of Bladder Control

**Urinary retention**

Stroke may interrupt nerve pathways that control bladder emptying. If this happens, the survivor does not feel an urge to urinate. The bladder fills, but the person cannot empty it.

Urinary retention causes the urine to back up. This can increase the risk of urinary tract infection and damage the kidneys.

### Stroke and Loss of Bladder Control

**Urge incontinence**

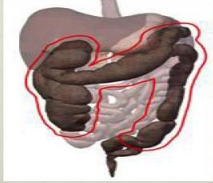
Stroke may cause involuntary bladder contractions. This causes the stroke survivor to feel a strong urge to urinate and lose control before reaching a toilet.



## Stroke and Loss of Bowel Control

**Constipation**

Constipation happens when the bowels don't move often enough and the body passes hard, dry stools after a long time.




It is the most common bowel problem among stroke survivors. Stroke can weaken the muscles that expel the stools. This can cause constipation or make it worse.

Constipation reduces the stroke survivor's quality of life, comfort, functional ability, and social life.

Causes of diarrhea can range from viral infections, such as the flu, to more serious medical problems, such as Crohn's disease.

People can mistake fecal incontinence for diarrhea, when in fact the survivor has severe constipation.


## Physical and Emotional Effects



Stroke survivors experience physical and emotional problems as a result of their lack of control over their urination and defecation. ...etc

## Stroke and Loss of Bowel Control

**Common Causes of Constipation**



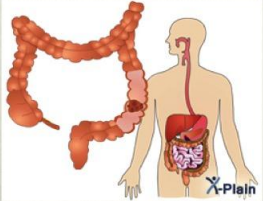
## Physical Effects

Skin breakdown and infection	Urinary tract infection	Pain and discomfort
Falls and injuries	Dehydration	Toxicity

## Stroke and Loss of Bowel Control







**Diarrhea**

Stroke survivors may experience frequent, watery stools that mark diarrhea.



Physical problems: Skin breakdown and infection; Urinary tract infection; Pain; Falls and injuries: A survivor with poor mobility or coordination may fall while hurrying to the toilet; Dehydration: A stroke survivor may restrict fluid intake in an attempt to manage incontinence

## Emotional Effects

-  Incontinence dramatically affects the stroke survivors' feelings of self-worth and wellbeing, as well as their lifestyle.
-  Patients may feel the need to stay close to a toilet.
-  Their activities are interrupted by frequent bathroom visits.
-  The survivor may socialize less and stop taking part in activities or travel.
-  Having to help a stroke survivor go to the bathroom can strain family relationships.
-  It might even limit family visits and reduce outings with the survivor

## Managing Bowel and Bladder Problems







Managing bladder and bowel problems is critical to the stroke survivor and the family caregiver. It increases the stroke survivor's self-esteem and quality of life, cuts down on the use of continence products such as pads or diapers, and most importantly, it can prevent complications, such as urinary tract infection, skin breakdown, pain and falls caused by rushing for the bathroom

## Identifying Urinary Problems

Watch for these signs and symptoms of incontinence and notify any healthcare provider as soon as possible if you see:

Any change in the survivor's normal pattern of going to the bathroom	A weak or interrupted urine stream	Loss of small amounts of urine.
Urinating more than eight times per day or twice per night	Frequent urinary tract infections	A sudden urge to urinate followed by loss of large amounts of urine (urge incontinence).
		The survivor's bladder still feels full, even after urinating.

## Assessment of Bowel and Bladder Problems

					
Urination	Bowel habits, stool color, and consistency	Straining and discomfort with bowel movements	Diet and fluid intake	Mobility, activity or exercise	Any signs of skin breakdown around the anus, scrotum, and vulva, such as swelling, redness, oozing or crusting

## Identifying Bowel Problems

Constipation or other bowel problems may be part of a serious, underlying health condition. If you see any of these signs, inform your healthcare provider, including

Sudden change in bowel pattern or stool	Abdominal pain	Sudden onset of constipation, such as constant straining with bowel movements or no bowel movements in at least 3 days
Rectal bleeding	Weight loss	Liquid stools
		Fever

Your careful and accurate observation provides much of the information needed for assessment.

You can keep a voiding diary to organize the information for the team. The diary usually includes details about

## Managing Bladder and Bowel Problems

The treatment for urine and bowel problems might include:

- ❖ Reviewing the survivor's medications and laxative use
- ❖ Increasing the stroke survivor's activity levels
- ❖ Habit training – drawing up a routine toileting schedule
- ❖ Setting up best positioning on the toilet
- ❖ Increasing fluid intake or changing the diet



Increasing fluid intake or changing the diet :  
The dietitian can create a diet that helps with constipation – for example, by increasing fibers and fluid intake

### Managing Bladder and Bowel Problems

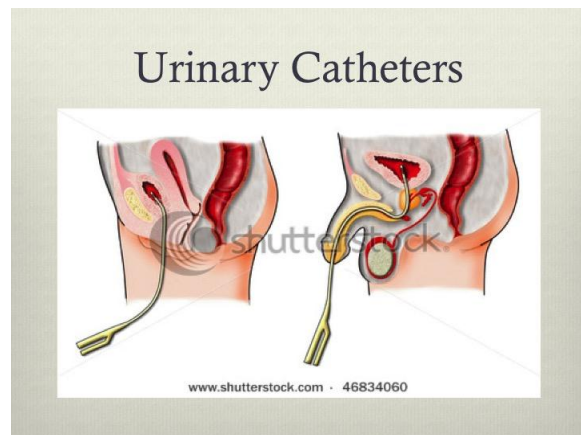
The team can also apply proper bladder and bowel care programs. These include:

- ❖ Habit training
- ❖ Prompting the survivor about scheduled trips to the bathroom
- ❖ Redirection
- ❖ Urinary catheters

**Habit training:** A process where a regular routine of toileting is established with the goals of having regular bowel movements

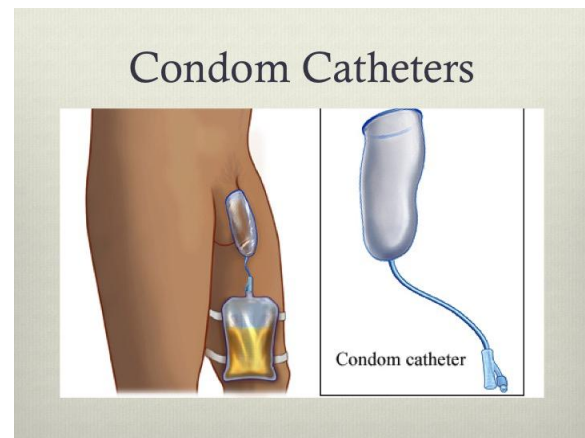
**Redirection:** Particularly for stroke survivors with cognitive impairment.

Redirecting might mean, for example, distracting the survivor with a TV program they like, so that they can control their need to go the bathroom a little longer and stay on their schedule.



A urinary catheter or condom catheter for males may be needed on a temporary or permanent basis.

A urinary catheter is a tube placed in the body to drain and collect urine from the bladder. It increases the risk of urinary tract infection. Appropriate catheter care can reduce this risk.



A condom catheter is a rubber sheath that is put over the penis.

The condom is attached to a tube.

Urine drains through the tube and into a drainage bag.

A condom catheter drains urine without putting a catheter into the bladder.

### Urinary catheters

- ❖ How to manage a urinary catheter:

The video shows how to manage your catheter and prevent urinary tract infection

- ❖ <https://www.youtube.com/watch?v=Ow-vQKxevFQ>

## KEY POINTS

### Catheter care

- Ensure the stroke survivor drinks 6 to 8 cups of fluids daily (1-2 liters).

Adequate fluid intake keeps the catheter draining well and free of sediment.

- Ensure the drainage bag is positioned below the level of the bladder. This prevents the urine from backing up into the bladder.
- Position the catheter tubing so that it does not kink or pull on the catheter.
- Secure the tubing to the patient's leg with tape to prevent accidents.
- Empty the urine bag every 8 hours.

#### **Patient monitoring:**

Report the following

#### **Urine output:**

- Any change in output in 24 hours
- Decreased output, with the survivor reporting feeling of a full bladder

#### **Pain:**

- In the abdomen, pelvis, or at the catheter insertion site
- Restlessness or agitation (this could be a sign of pain or discomfort especially in older adults)

#### **Urine:**

- Change in color or consistency
- Blood
- Foul-smelling drainage around the catheter
- Urine leakage around the catheter
- Any signs or symptoms of urinary tract infection as described below

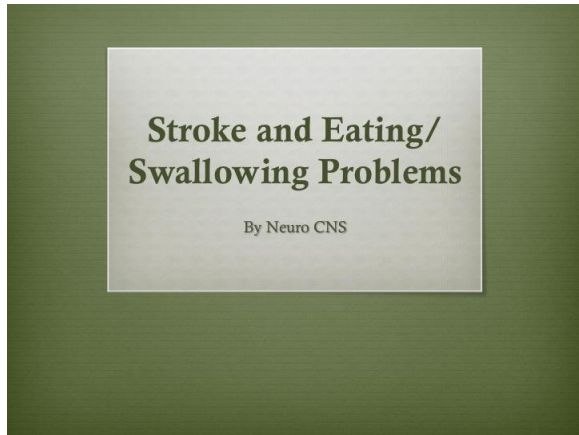
#### **Urinary tract infections and how to prevent them**

- A lower urinary tract infection untreated can move up to the kidneys and cause serious problems.
- Watch for these signs and symptoms.
- Temperature above 37.9° C
- Blood in the urine
- Burning or pain with urination
- Chills or shaking
- Delirium or confusion
- Urinary urgency
- Urinary frequency
- Urinary incontinence
- Pain in the lower abdomen or at the side
- Change in urine color or odor
- Urethral or vaginal discharge

## References




Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pv13leNWJwE/b.5384179/k.B2BB/HCP.htm>

**Appendix F**



Eating and drinking are a necessary and pleasurable part of life. Stroke can change that. A stroke can leave survivors unable to feed themselves or to swallow food or liquid safely

Effects of a Stroke that Make Meals Challenging

-  Difficulty getting the food or drink to the mouth or difficulty chewing and moving food in the mouth.
-  The loss of the cough reflex so he/she is unable to cough when choking and may silently aspirate (inhale) solid or liquid food into the lungs.
-  Decreased alertness and attention. Normal level of alertness and attention to eating protects against choking. Stroke survivors may be vulnerable to choking.

Weakness in facial muscles and drooling are easy to see. But other effects of stroke may be invisible to observers and unrecognized by the survivor. Swallowing problems may prevent survivors from safely taking in enough nourishment, especially during early recovery

Eating and Swallowing Problems can cause

- Dehydration** • Dry mouth, constipation, urinary tract infection, confusion, severe illness or death
- Malnutrition** • Weight loss, reduced energy, skin breakdown, impaired wound healing and lower resistance to infection
- Aspiration** • Choking, airway obstruction, respiratory problems and pneumonia
- Changes in quality of life** • Eating is often a social activity. Swallowing and eating problems can make the survivor reluctant to take part in-group meals. This can increase social isolation and decrease quality of life.

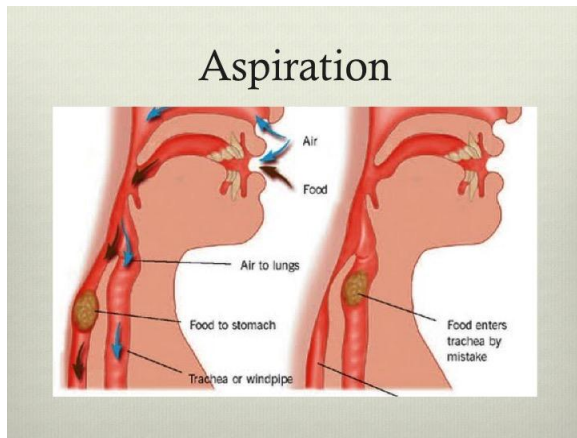
**Dehydration**→Dry mouth, constipation, urinary tract infection, confusion, and even severe illness or death.

**Malnutrition**→Weight loss, reduced energy, skin breakdown, impaired wound healing, and lower resistance to infection.

**Aspiration**→Choking, airway obstruction, respiratory problems, and pneumonia.







**Changes in Quality of life**→Eating is often a social activity. Swallowing and eating problems can make the survivor reluctant to take part in-group meals. This can increase social isolation and decrease quality of life.










Aspiration: The entry of saliva, solid or liquid food, or refluxed stomach contents into the airway






### Signs and Symptoms of Swallowing Problems

-  Coughing or choking during or after meals
-  Shortness of breath
-  No swallow reflex
-  Drooling
-  Poor lip closure, loss of food from mouth
-  Altered voice quality: wet or gurgling voice

### Signs and Symptoms of Swallowing Problems

-  Spitting food out
-  Pocketing of food in cheeks or under the tongue,
-  Slow chewing with difficulty
-  Difficulty swallowing pills rapidly
-  Low intake of solids or fluids

### Signs and Symptoms of Swallowing Problems

-  Weight loss
-  Tight throat, food sticking in throat, reflux or heartburn
-  Increase sin temperature shortly after meals
-  Watery eyes or runny nose when eating or drinking
-  Avoiding specific foods or fluids

### Management of Swallowing Problems



A **speech-language pathologist** assesses swallowing ability and then recommends safe diet textures and strategies for safe feeding and swallowing. He/she also recommends positioning strategies and adaptive equipment for feeding.

A **dietitian** ensures that the recommended diet texture or tube feed meets the survivor's nutrition and hydration needs

### Management of Swallowing Problems- Safe feeding

- Always use the best positioning: Keep the trunk (upper body) upright at 60–90 degrees, stabilized with pillows with Head in midline and slightly flexed forward
- Monitor feeding rate and amount: Provide small, frequent meals
- Give small amounts: ½ –1 teaspoon at a time (do not use a tablespoon). For medications, crush 1–2 pills at a time in food; and present one food item at a time if the survivor is easily distracted

### Management of Swallowing Problems- Safe feeding

- Check for complete swallow: laryngeal elevation that is the movement of the Adam's apple up and down
- Encourage swallowing twice
- Encourage napkin use if drooling
- Teach survivor to remove pocketed food with tongue, be aware of drooling and keep the patient upright at least 30 minutes after meal

### Management of Swallowing Problems- Modified diets

Common special diets for stroke survivors with swallowing difficulties

- Pureed foods
- Minced or moist minced foods
- Thickened fluids
- No dry particulates
- No bread products
- No mixed consistencies
- No thin fluids

### Management of Swallowing Problems- Safe feeding


- Perform mouth care after meals: Brush teeth, gums, and tongue with a toothbrush
- Encourage coughing to clear the throat
- Elevate head of bed 30 degrees to prevent reflux
- Encourage the survivor to wear loosely fitting clothes and to avoid tight belts

A stroke survivor who cannot manage adapted food textures may need to be fed through a tube.

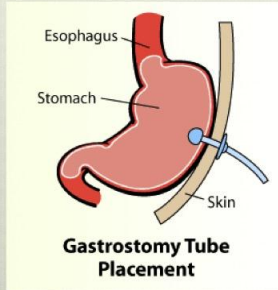
Tube feeding can provide the calories and nutrients needed.

If swallowing ability improves, survivors can often return to a soft or regular diet

### Management of Swallowing Problems- Modified diets



### Enteral Tube Feeding



**Gastrostomy Tube Placement**

To eat safely, stroke survivors with swallowing problems often need their food textures adapted.

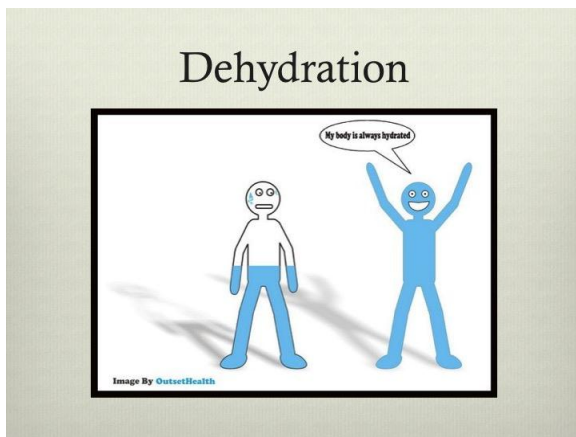
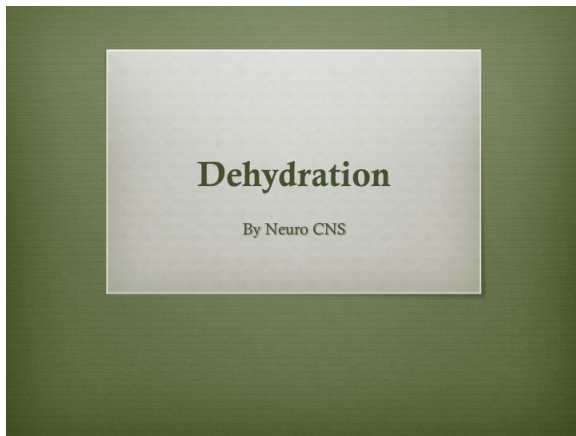
The type of swallowing problem determines the food textures a survivor can swallow safely.

### Enteral Tube Feeding

Please watch the correspondent video  
<https://www.youtube.com/watch?v=J66zizn8Pf0>



The following items is covered in the video:  
 What is an enteral feeding tube?; Benefits of gastrostomy tubes; How is a gastrostomy tube inserted and removed?; How to care for a gastrostomy tube?; Signs of infection; Gravity feeding; Syringe feeding; Medication administration through a gastrostomy tube; Cleaning supplies; Preventing blockage; What to do if the gastrostomy tube get dislodged?



Water is critical to life. You play a key role in helping stroke survivors drink enough.

It's your job to report if they are not drinking enough, as well as any signs of dehydration.

Dehydration occurs when the body loses more fluid than it takes in.

## Dehydration

This is a health risk that rapidly becomes life threatening.

When people are dehydrated they may lose physical, mental and cognitive function.

They have an increased risk for infection, falls, constipation and urinary tract infection

## Dehydration

Stroke survivors with swallowing problems may fear choking and avoid drinking fluids.

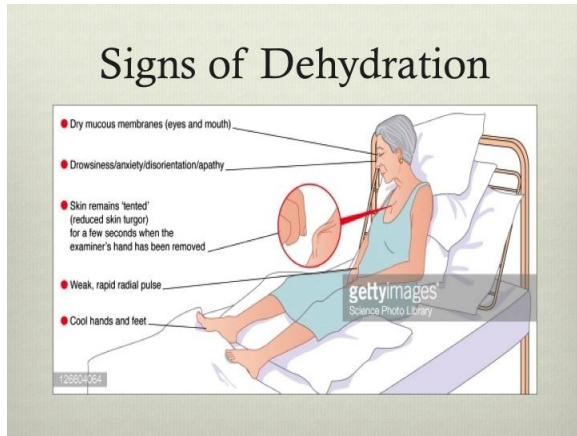
Survivors who fear incontinence may decrease their fluid intake in an attempt to prevent accidents.

## Dehydration

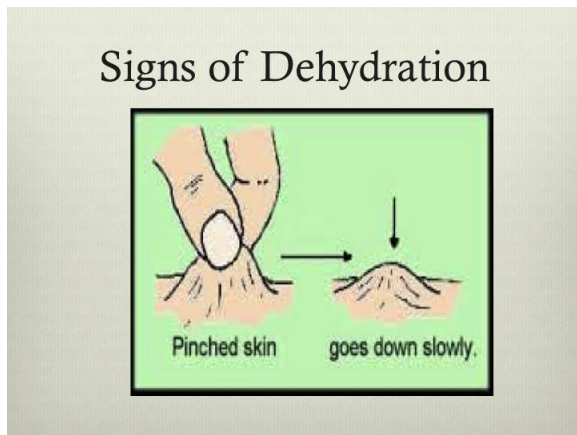
In addition, the risk of dehydration is increased if survivors:

- Are on a thickened fluid diet and do not take all the fluids provided
- Refuse fluids at meals or snacks
- Need help with eating and drinking
- Lack the feeling of being thirsty
- Are unable to communicate that they are thirsty
- Have memory problems or are forgetful
- Have an illness that increases fluid loss, such as vomiting, diarrhea, or fever and sweating





Watch carefully for these signs of dehydration: Decreased urine output; Dark, concentrated, or strong-smelling urine; Frequent urinary tract or bladder infections ; Thick, stringy saliva; Constipation; Dizziness when sitting up or standing; Confusion or a change in mental status; Weight loss of 1.5 kg in less than seven days; Fever; Decreased skin elasticity (Gently pinch the skin on the survivor's arm. If the skin remains pinched up when you release it, suspect dehydration)



### How to Avoid Dehydration?

Stroke survivors should be encouraged to

- Receive enough fluids such as 6 to 8 cups (or another amount, if prescribed) daily.
- Sip fluids during the day, rather than drinking large amounts at once
- Drink water, the preferred liquid.
- Limit caffeine intake to 2 to 3 cups or less per day

### How to Avoid Dehydration



You may need to provide the survivors with gentle reminders to drink.

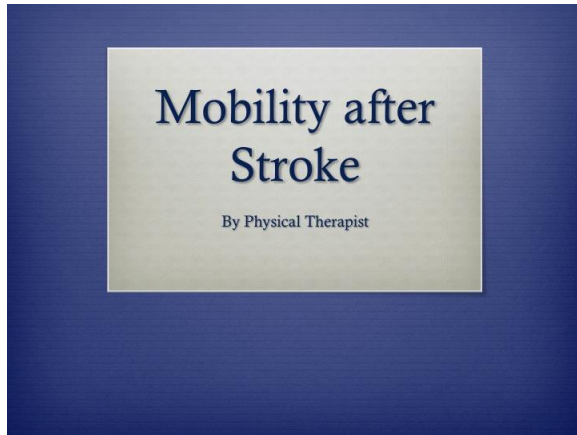
Try to give them liquids at the temperature they prefer.

Offer a variety of liquids such as popsicles and puddings.

### References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pv13leNWJwE/b.5384179/k.B2BB/HCP.htm>

Appendix G



### Mobility after Stroke

- Muscle tone**
  - Stroke can alter muscle tone, causing high tone (spasticity) or low tone (flaccidity). Changes in muscle tone can cause mobility problems.
- Balance**
  - Problems with sensation or motor control after stroke can impair balance, increasing the risk of falls.
- Posture**
  - Stroke may cause the survivor to put more weight on the unaffected side. The affected shoulder and hip may rotate backward.

### Mobility after Stroke

We move all the time – in bed, rolling, sitting up, standing, and walking.

You support stroke survivors as they move around throughout the day. How you help can have a direct influence on their safety, comfort, quality of movement, and independence

### Mobility after stroke

- Perception**
  - Changes in perception caused by stroke may affect mobility. These changes include:
    - Visual and auditory neglect (less awareness of the environment on the side of the body affected by the stroke)
    - Body neglect (less awareness of the body on the side affected by stroke)
    - Apraxia (difficulty making purposeful movements, even though the survivor has the ability and understanding to perform the task)
    - Impaired depth and distance perception (such as double vision, partial loss of vision in one or both eyes, and visual field loss).

### Mobility after stroke

Stroke can affect a survivor's mobility, depending on several factors:

- fatigue**
  - Stroke survivors often feel very tired. Even simple tasks may be exhausting. Fatigue can produce frustration, sadness and anger.
- Loss of sensation**
  - A stroke survivor may have less or no sensation in the affected part of the body after the stroke.
- Loss of motor functions**
  - A stroke survivor can lose the ability to move body parts.

The following videos show various mobility techniques for stroke survivors.

**How to perform range of motion exercises**

<https://www.youtube.com/watch?v=iDUCgZK7ckE>

**How to turn in bed?**

<https://www.youtube.com/watch?v=Mz-akrOY3gY>

**How to move a stroke survivor towards the head of the bed?**

[https://www.youtube.com/watch?v=yHMWfgC\\_UQc](https://www.youtube.com/watch?v=yHMWfgC_UQc)

**How to correctly position**

<https://www.youtube.com/watch?v=gnyiwPXSxkl>

**How to assist a stroke survivor in walking**

<https://www.youtube.com/watch?v=DCj6nKQOn7o>

**Transfer techniques**

**How to transfer a stroke survivor requiring maximal assistance**

[https://www.youtube.com/watch?v=\\_HbecwTgugc](https://www.youtube.com/watch?v=_HbecwTgugc)

**How to transfer a stroke survivor requiring moderate assistance**

<https://www.youtube.com/watch?v=pAJmtKqoKJc>

**How to transfer a stroke survivor requiring minimal assistance**

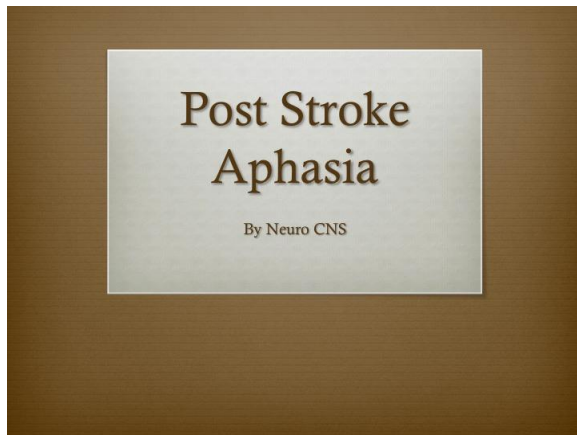
<https://www.youtube.com/watch?v=nxhI2Vg4xHE>

## References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pv13leNWJwE/b.5384179/k.B2BB/HCP.htm>

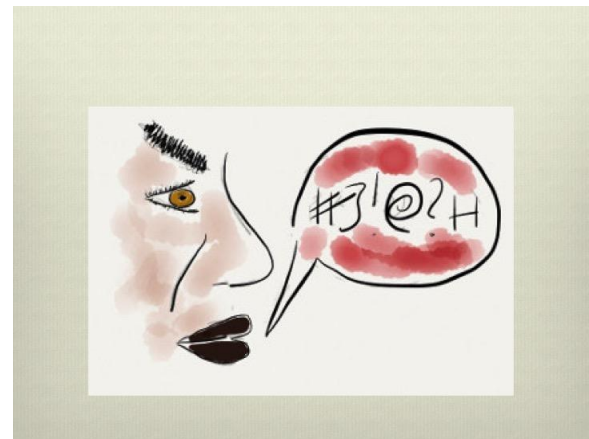


## Appendix H



Stroke survivors may remain mentally alert, even though their speech may be jumbled, fragmented or impossible to understand.

Some survivors continue to have: Trouble speaking, like “getting the words out”; Trouble finding words; Problems understanding what others say; Inability to process long words and infrequently used words



Aphasia is a language problem that affects the ability to communicate. It is most often caused by strokes that occur in areas of the brain that control speech and language

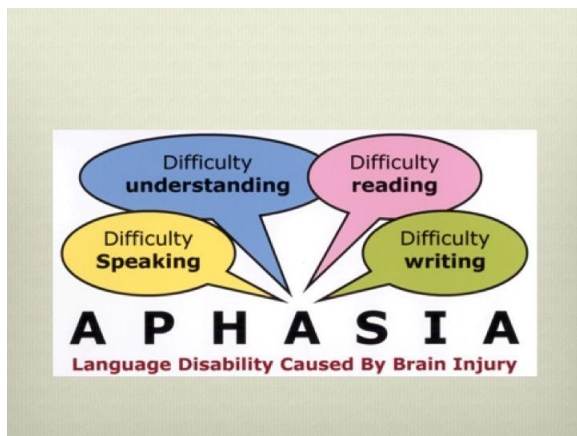
People with aphasia are often frustrated and confused because they can't speak as well or understand things the way they did before their stroke.

They may act different because of changes in their brain.

Imagine looking at the headlines of the morning newspaper and not being able to recognize the words.

Or think about trying to say “Put the car in the garage” and it comes out “Put the train in the house” or “Widdle tee car ung sender plissen”.

Thousands of alert, intelligent men and women are suddenly plunged into a world of jumbled communication because of aphasia



Aphasia does not affect intelligence.

## What are the Types of Aphasia?

There are several forms of aphasia. They include:

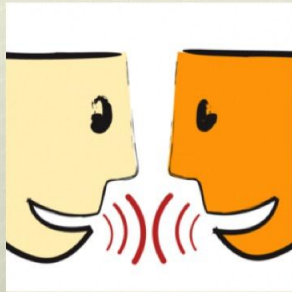
- Global aphasia → People with this aphasia may be completely unable to speak, name objects, repeat phrases or follow commands.
- Broca's aphasia → The person knows what he wants to say, but can't find the right words
- Wernicke's aphasia → The person with this aphasia can seldom understand what's being said or control what he is saying.

## Communicating with the Patient with Aphasia

### Set the stage:

- Talk face to face in a quiet room
- Give information in small amounts at a time
- Assure the patient you understand that he/she knows what he/she wants to say
- Introduce a change in the topic clearly: "I want to talk to you about family"

## Communicating with the Patient with Aphasia



## Communicating with the Patient with Aphasia

### Be patient:

- Speak slowly. Give the patient time to respond
- When a patient is struggling for a word, don't jump in too quickly
- Allow patients to express themselves to the best of their ability
- Supply the word only when the patient is too frustrated

As the family care provider, you may be the most important communication partner in the stroke survivor's life.

When you are developing a communication partnership with a stroke survivor, knowing the person is just as important as knowing the communication strategies.

Here are some ways you can help the person with aphasia communicate.

## Communicating with the Patient with Aphasia

### Provide specific choices. Avoid open-ended questions:

- Ask: "are you hungry or feeling ill?" Not: "what's wrong?"
- Ask: "would you like an apple or an orange?" Not: "what would you like to eat?"

### Break down longer questions into yes or no questions:

- Would you like tea? Would you like coffee? Would you like juice?
- Wait for a yes or no answer to each question
- If the answers seem inconsistent, explain what you understood.

## Communicating with the Patient with Aphasia

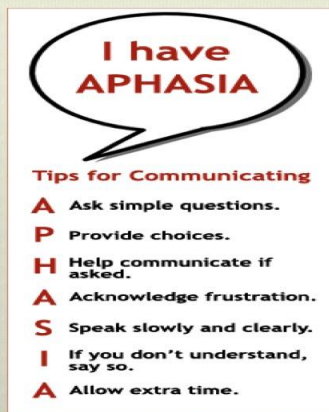
### Use pictures and objects:

- Use pictures and objects to show what you mean. Even drawings can help.
- Use maps, calendars, schedules, and clocks when talking about where and when.
- Print key words in large, clear letters on paper as you speak.
- Urge the patient to show you, to draw, or to print.
- Use photos or other materials as starting points for conversations with the patient.

## Communicating with the Patient with Aphasia

### Always include patients in any conversations that concern them:

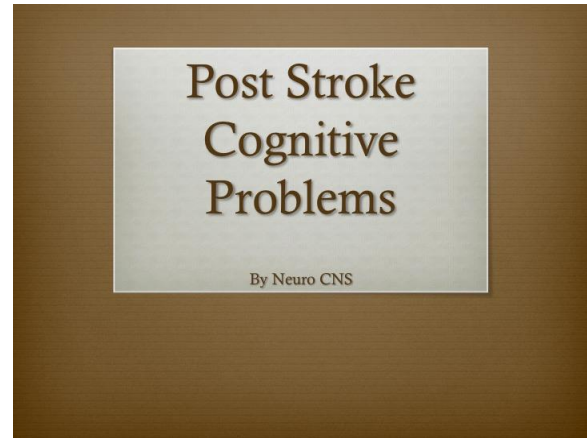
- Never underestimate the patient's ability to understand nonverbal information, especially when it is personally relevant.
- Expect communication ability to vary – patients have good and bad days, and good and bad times of day.



**I have APHASIA**

**Tips for Communicating**

- A** Ask simple questions.
- P** Provide choices.
- H** Help communicate if asked.
- A** Acknowledge frustration.
- S** Speak slowly and clearly.
- I** If you don't understand, say so.
- A** Allow extra time.



When you understand how a stroke affects the survivor's cognitive abilities, you can provide better care and support

## Cognitive Problems Post Stroke and How to Deal with Them



Cognitive problems are invisible. They are not as easily seen as physical problems. They can have a major impact on a survivor's function and level of independence.

## Attention

### Helpful tips

- Get rid of any distractions
- Give short, simple, step-by-step instructions.
- Make direct eye contact
- Give the survivor more time to think
- Slow down so the survivor doesn't feel pressured



Patients may have a short attention span. They may be easily distracted. This limits their ability to focus on a task. The survivor may need more time to finish

## Orientation

Helpful tips:

- Give gentle reminders like a clock and the correct information.
- Include the date when greeting the patient.
- Post a calendar to help the patient keep track of the day and date
- Use a bulletin board to list personal information and post family pictures
- Limit changes to the patient's schedule

After a stroke, the survivor may lose some awareness in time, place and/or person

## Memory

Helpful tips:

- Encourage the survivor to use memory aids like:
  1. Repeat the information to help the survivor remember it
  2. Store items in the same place.
  3. Label drawers and cupboards with the contents
  4. Provide simple, clear information.
  5. Present new information one-step at a time.
  6. Use signs or pictures as memory cues.

Memory problems can affect the stroke survivor's ability to learn new information and carry it over to everyday tasks

## Insight

Helpful tips:

- Make the environment as safe as possible.
- Have walking aids and other assistive devices close at hand for survivors
- Gently remind the survivor about the stroke and the resulting limitations
- Provide the necessary amount of supervision to ensure the survivor's safety

A lack of insight may lead a survivor to perform unsafe actions

## Judgment

Helpful tips:

- Discuss your concerns about the patient's safety with the health team
- With the health team, develop strategies to optimize safety and functioning
- Do not place the patient in difficult or challenging situations.
- Maximize the safety of the environment.

With impaired judgment, the patient may make choices that are not safe

## Sequencing

Useful tips:

- Give clear step-by-step instructions to help the patient understand the task
- Help the patient plan the task.
- Encourage the patient to think through the task.
- Explain the next step to the patient if needed
- Give the patient time to practice the task
- Repeat the task the same way each time

A patient with sequencing difficulties may be unable to start a task because the patient does not know where to begin.



The patient may do things in the wrong order

## Problem solving

Useful tips:

- Break tasks into small steps. Focus on one step at a time.
- Give verbal cues.
- Help the patient identify different ways of solving the problem.
- Talk about the different ways the problem could be approached.

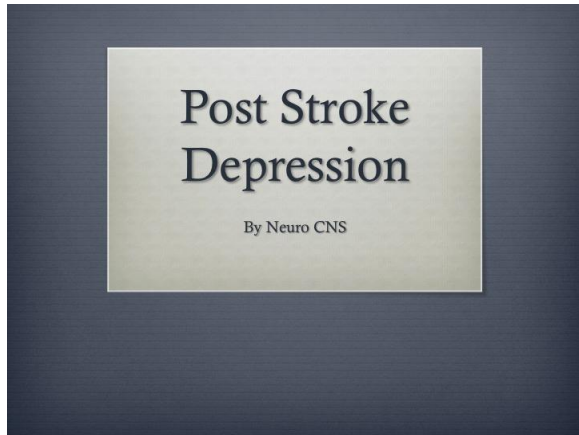
Problems with insight, sequencing, and memory can affect the patient's problem-solving ability.



## References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pvI3IeNWJwE/b.5384179/k.B2BB/HCP.htm>

### Appendix I



It disrupts a person’s ability to function. It is common among stroke patients. But depression can be treated. And the faster it is treated, the better.

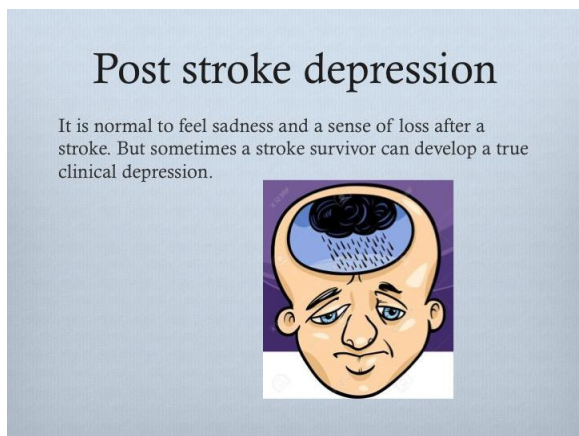
Depression gets in the way of physical and mental recovery. It can decrease energy, so the survivor participates less in rehabilitation. It can reduce the survivor’s ability to care for him/herself. Depression in a stroke survivor can also affect the health of caregivers at home.



### Signs of Post Stroke Depression

Physical signs	Attitudes	Emotions	Mental functions
<ul style="list-style-type: none"> <li>• Trouble sleeping</li> <li>• Weight loss</li> <li>• Decreased energy</li> <li>• Easily fatigued</li> </ul>	<ul style="list-style-type: none"> <li>• Not caring about anything</li> <li>• Loss of interest in things that were previously enjoyed</li> <li>• Negativity: Everything is gloomy</li> <li>• Self-focus</li> <li>• Difficulty connecting to others</li> </ul>	<ul style="list-style-type: none"> <li>• Feelings of hopelessness and worthlessness</li> <li>• Sadness and anxiety or nervousness</li> <li>• Thoughts of death and suicide</li> <li>• Difficulty coping, easily overwhelmed</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty concentrating</li> <li>• Problems making decisions</li> <li>• Confusion</li> <li>• Short-term memory problems</li> </ul>

Stroke has great physical effects on the survivor. It can also affect mood. Together, physical and mood changes may cause the person to become depressed



You are the team member who is the closest to the survivor.

Here are some things you can do

Depression is a sense of hopelessness.

**1. When you communicate with the patient, keep in mind that:**

- Depression is a medical illness. Always communicate with caring and hope. Be accepting, not judgmental.
- Learn how to communicate with patients who have communication problems
- Ask your relative how he/she is feeling. If he/she is feeling pain, make sure to give treatment to relieve the pain

**2. Observe the patient. Look for:**

- New symptoms
- Sudden changes in behavior or personality
- Signs of depression lasting more than 2 weeks
- Sleeping or napping more than usual
- No longer attending favorite social activities.

**3. Support your relative:**

- Find out what resources are available
- Let your relative know about activities and assistance
- Help him/her plan and structure the day. Routine can help people adjust

**4. Encourage patients to do things:**

- Help your relative get to activities he/she enjoys
- Spend time with your relative in activities such as playing cards or board games
- Find activities that make your relative feel better, such as listening to music, watching television and reading.

**5. Encourage emotional expression:**

- Allow your relative to express his/her grief and sadness about what he/she has lost
- Always give your relative hope that things can improve
- Share what you learn with the rest of the team

**6. Consult with the doctor for anti-depressant medication:**

- There are many different types of anti-depressant medications available, and everyone responds differently to them.

They are the most common treatment for depression; they affect the chemicals in the brain to lift the mood.

They do not cure depression; however they can ease some of the symptoms, which allow the person to take action and deal with it instead.

It is important to persevere with the treatment once started, because it may sometimes take weeks for the medicine to act.

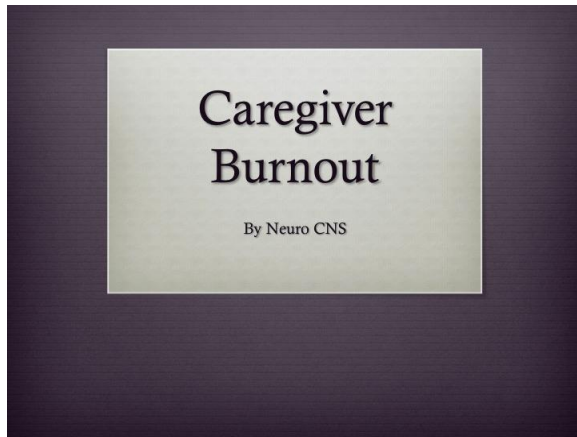
The choice and side effects of the medication should be thoroughly discussed with the caring physician

## References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pv13IeNWJwE/b.5384179/k.B2BB/HCP.htm>



## Appendix J



Many caregivers do not take time to care for themselves.

They begin to show signs of caregiver “burnout.” Your healthy body, mind and spirit benefit your loved one just as they benefit you.

Learn the signs of caregiver burnout and seek help if you are having them.

Caregiver burnout is caused by too much long-term stress.

It occurs when you feel overwhelmed and unable to meet constant demands.

As the stress continues, you begin to lose the interest or motivation that led you to take on a certain role in the first place.

Your emotional and psychological health can affect your physical health.

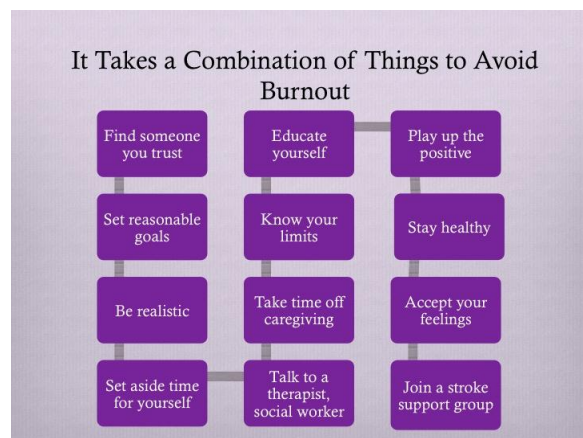
### What are the Signs of Caregiver Burnout?

As a caregiver, you’re under a lot of stress. It is common for caregivers like you to let your own health suffer. So, watch out for:

- Excessive use of alcohol, medications or sleeping pills
- Appetite changes — either eating too much or too little
- Depression, hopelessness, feelings of isolation, lack of energy to do new things

### What are the Signs of Caregiver Burnout?

- Losing control physically or emotionally
- Neglect or rough treatment of the person for whom you are caring
- Trouble falling or staying asleep
- Difficulty concentrating, missing appointments
- If you recognize the warning signs of burnout in yourself, remember that it will only get worse if you leave it alone. You need to take steps to get your life back into balance.



**How can burnout be avoided?**

**Find someone you trust** → Talk to a friend, co-worker, or neighbor about your feelings and frustrations.

**Set reasonable goals** → Accept that you might need help from others.

**Be realistic** → Set reasonable expectations about your stroke survivor’s condition

**Set aside time for yourself** → Even if it's just an hour or two, it's worth it. Remember, taking care of yourself is not a luxury, it's a need.

**Talk to a therapist, social worker** → They're trained to give advice on a wide range of physical and emotional issues.

**Know your limits** → Make sure you do a reality check and don't push yourself too hard.

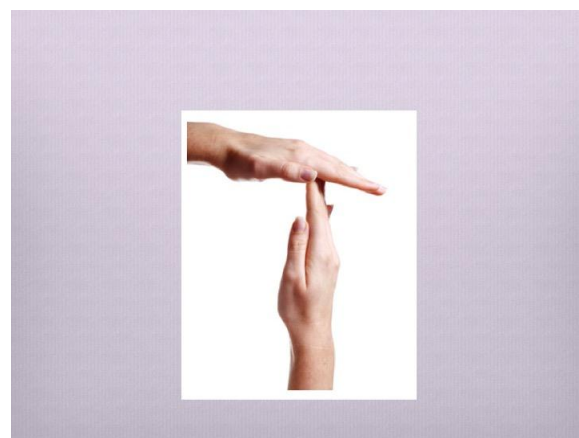
**Educate yourself** → The more you know about stroke, the better care you can give.

**Play up the positive** → Remember to lighten up when you can. Use humor to help deal with everyday stresses.

**Stay healthy** → Eat right and get plenty of exercise and sleep.

**Accept your feelings** → It's normal to have negative feelings such as frustration and anger. It doesn't mean you're a bad person or a bad caregiver.

**Join a caregiver support group** → Share your feelings and experiences with others in the same situation as you. It can help you manage stress, locate helpful resources, and stay connected with others.



## References

Bagg, S., Barr, L., Benton, J., Brown, G., Bruggenkate, I., Carques, T., ... LeDuc, L. (2013). *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*. Heart and Stroke Foundation of Ontario. Retrieved from: <http://www.heartandstroke.on.ca/site/c.pv13leNWJwE/b.5384179/k.B2BB/HCP.htm>

## Appendix K

### Body Mechanics Handout

## Moving the stroke survivor towards the head of the bed

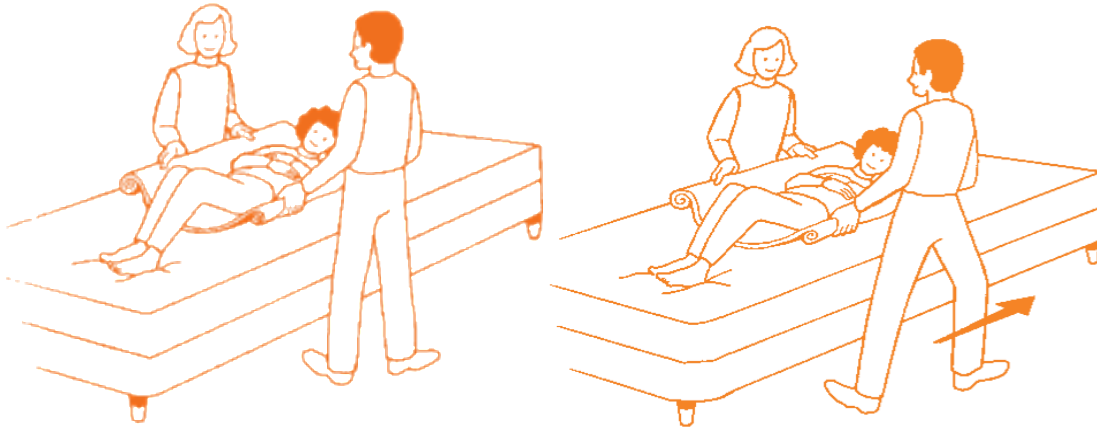
### When the stroke survivor can cooperate

1. Tell the person what you are going to do
2. Lower the head of the bed to a flat position and remove the pillow. Do not try to drag the person up
3. If possible, raise the bed and lock the wheels
4. Tell the person to bend his knees, place his feet firmly against the mattress and push himself up
5. Stand beside the bed and place one hand behind the person's back and the other underneath the buttocks
6. Bend your knees and keep your back in a neutral (arched naturally, not stiff ) position
7. Count "1-2-3" and get the person to push with his feet and pull with his hands toward the head of the bed
8. Replace the pillow under his head

### When the stroke survivor cannot cooperate, and you have help

1. Tell the person what you are going to do even if he seems to be unconscious
2. Remove the pillow
3. If possible, raise the bed and lock the wheels
4. Stand on either side of the bed
5. Stand at the side of the bed, with feet shoulder width apart, knees bent, and back in a neutral position
6. Roll the sides of the draw sheet up to the person's body
7. Hold on to the draw sheet with your palms facing up
8. Count "1-2-3" before shifting your body weight from the back to the front leg. Keep your arms and back in a locked position. Together, slide the person smoothly up the bed
9. Place pillows under the person's head
10. Ensure the person is in a comfortable position





### **When the stroke survivor cannot cooperate, and you don't have help**

1. If possible, raise the entire bed to a comfortable level and lock the wheels.
2. Remove the pillow
3. Stand at the side of the bed, with feet shoulder width apart, knees bent, back in a neutral (arched naturally, not stiff) position
4. Roll the sides of the draw sheet up to the person's body
5. Slide your arms under the draw sheet and support the person's shoulders and back
6. Count "1-2-3" and shift your body weight from one leg to another leg as you slide the person towards the top of the bed. Keep your arms and back in a locked position
7. Slide the person to the top of the bed
8. Replace the pillow
9. Position the person comfortably

### **Positioning the stroke survivor in bed**

#### **How to position the stroke survivor on his back...**

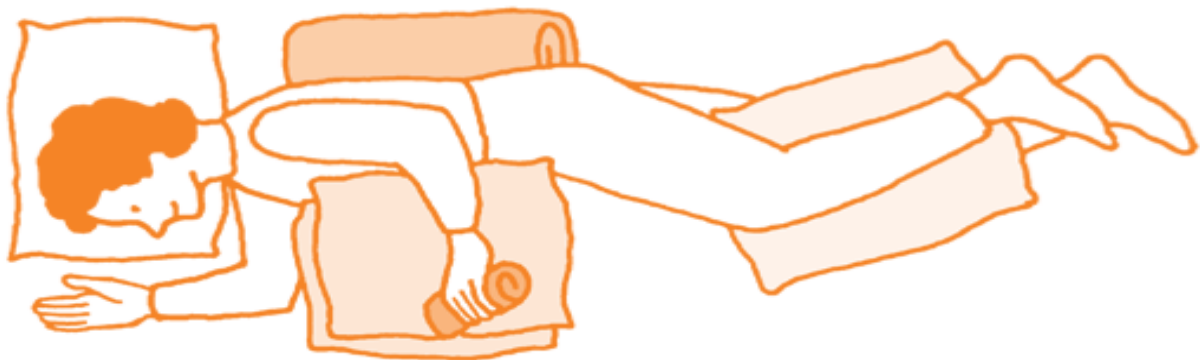
1. Place a small pillow under the person's head
2. Place a small pillow lengthwise under the calf of the weak leg. Let the heel hang off the end of the pillow to relieve pressure. If the person needs a blanket, make sure the blanket does not create pressure on the toes
3. Fold a bath towel and place it under the hip of the person's weak side

4. Place the weak arm and elbow on a pillow. The position of the arm should be higher than the heart



### **How to position a stroke survivor on his side...**

1. Place a small pillow under the person's head
2. Keep the person's head in alignment with the spine
3. Place a pillow at the back to prevent rolling
4. Place a pillow in front to keep the arm at the same height as the shoulder joint
5. Place a medium pillow lengthwise between the knees, legs and ankles. The person's knees may be kept slightly bent

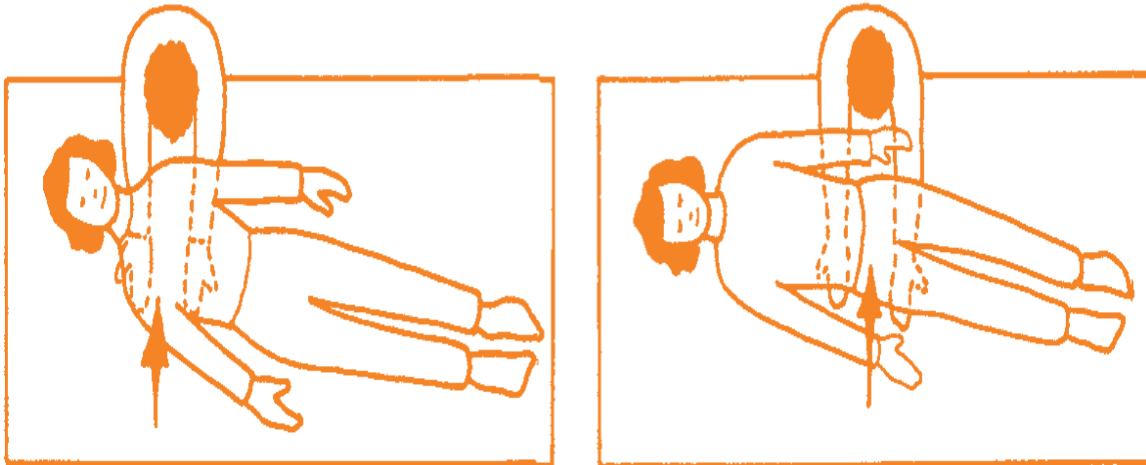


### **Turning the stroke survivor in bed**

#### **Moving a person to one side of the Bed on his Back**

1. Place your feet shoulder width apart, knees bent, back in a neutral (arched

- naturally, not stiff ) position
2. Slide your arms under the person's back to his far shoulder blade. Bend your knees and hips to lower yourself to the person's level
  3. Slide the person's shoulders towards you by shifting your weight to your back foot
  4. Use the same procedure to move the person's buttocks and feet
  5. Always keep your knees bent and your back in a neutral position



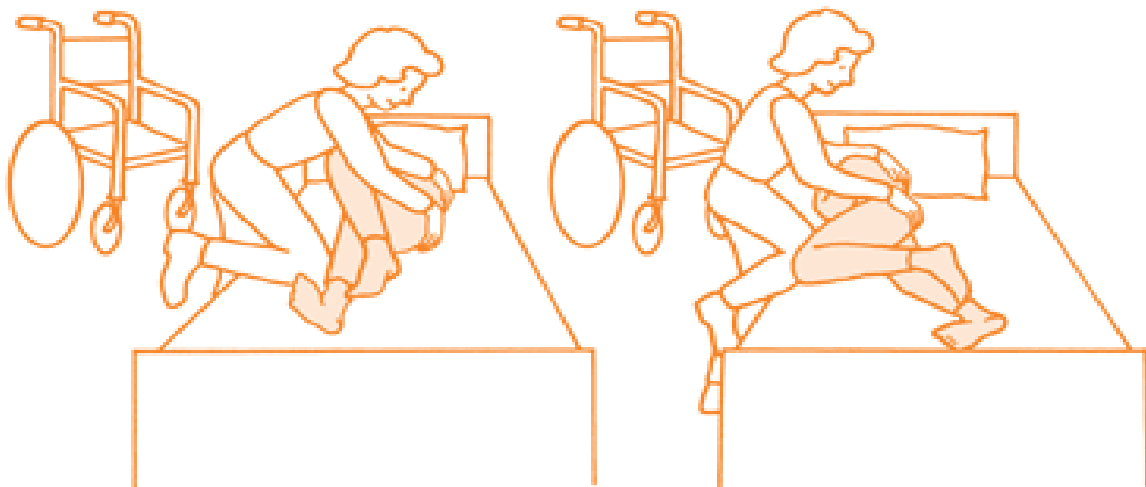
### Rolling techniques

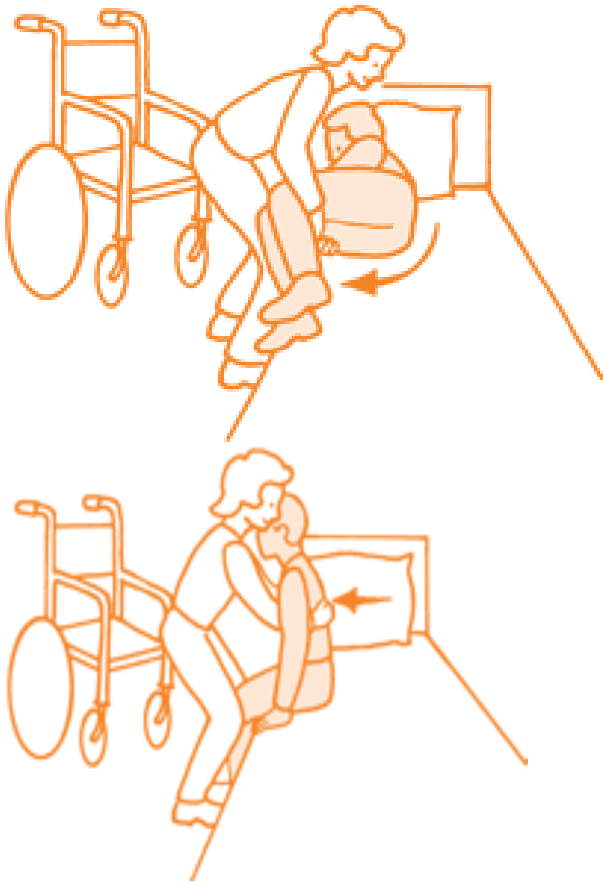
1. Move the person to one side of the bed as described before
2. Bend the person's knees
3. Hold the person at his hip and shoulder blade on the far side of the body
4. Keep knees bent, back in neutral position and lock your arms to assist the lift
5. Adjust the pillow

### Transfer techniques

#### **Transferring the stroke survivor from bed to wheelchair**

1. Place the wheelchair at a 45° angle to the bed so that the person will be transferring to his stronger side
2. **Lock** the wheels of the chair and bed, or use a wheel block
3. Tell the person what you are going to do
4. Bring him to a sitting position with his legs over the edge of the bed following steps a, b, c, and d as shown in the illustration
5. Let him rest a moment if he feels dizzy
6. Put his shoes on
7. Place the wheelchair at a 45o angle to the bed so that the person will be transferring to his stronger side
8. Lock the wheels of the chair (or use a wheel block) and the wheels of the bed
9. Tell the person what you are going to do
10. Bring him to a sitting position with his legs over the edge of the bed following these steps





11. Put your arms around his chest and hold your hands together behind his back
12. Support the leg that is farther from the wheelchair between your legs
13. Lean back, shift your leg and lift
14. Pivot your body towards the chair
15. Bend your knees and let him bend toward you
16. Lower the person into the wheelchair
17. Adjust his position so that he is seated comfortably

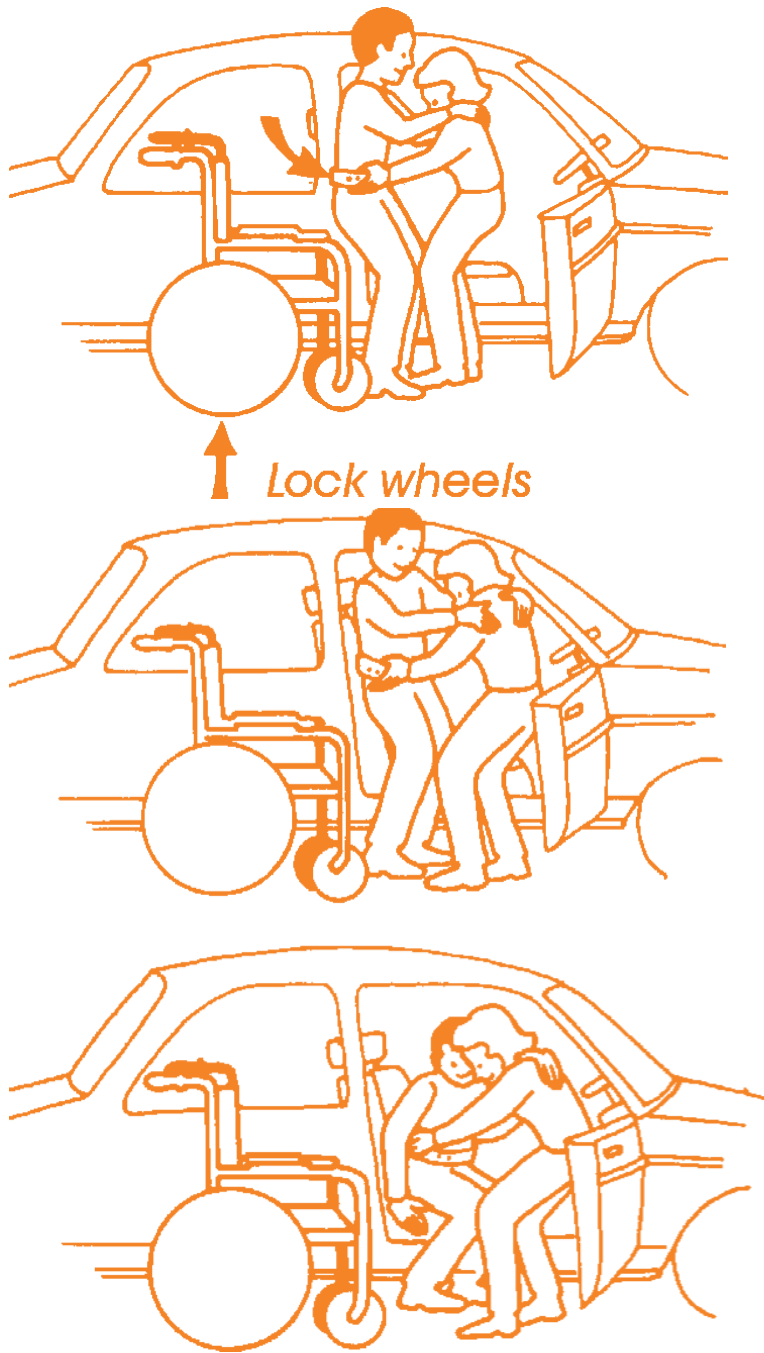


### **Transferring the stroke survivor from wheelchair to bed**

1. Reverse the process described in “Transferring from Bed to Wheelchair”
2. Place the chair at a 45° angle to the bed so the person is on his stronger side.  
Lock the wheels
3. Get into a position to provide a good base of support; use good body mechanics
4. Have the person stand, reach for the bed and pivot
5. Support and guide him as needed
6. Adjust the position of the person in bed with pillows

### **Transferring the stroke survivor from wheelchair to car**

1. Open the passenger door as far out as possible
2. Move the side of the wheelchair as close to the car seat as possible
3. Lock the chair’s wheels
4. Move both footrests out of the way
5. Position yourself so that you are facing the person
6. Tell him what you are going to do
7. Bend your knees and hips and lower yourself to his level
8. Hold on to the transfer belt around his waist to help him stand as you straighten your hips and knees
9. If his legs are weak, brace his knees with your knees
10. While he is standing, turn him so that he can slowly sit down on the car seat.
11. Make sure that he does not hit his head
12. Lift his legs into the car by placing your hands under his knees
13. Move him to face the front
14. Put on his seat belt
15. Close the door carefully



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## Appendix L

### General hygiene Handout

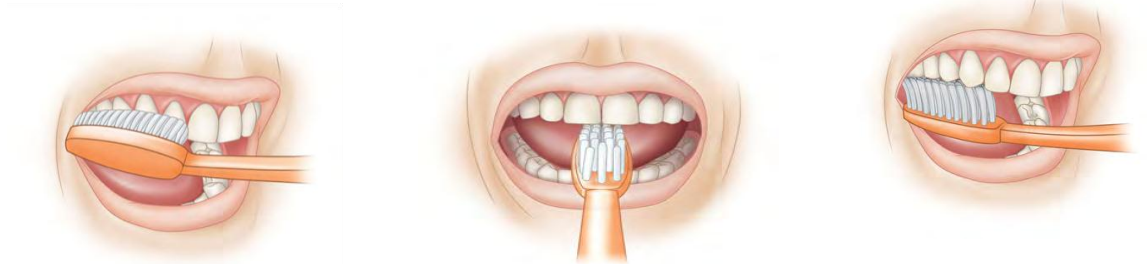
# Brushing and flossing the stroke survivor's Teeth

#### Preparation:

- 1- Wash your hands
- 2- Gather your supplies: Towel, gloves, paper towels, toothbrush, toothpaste, cup, emesis basin, mouthwash)
- 3- Explain the procedure

#### Procedure:

- 4- Prepare a solution of half water and half mouthwash.
- 5- Put the person in a seating position.
- 6- Unfold the towel. Place it across the person's chest.
- 7- Give the person a mouthful of the mouthwash mixture to rinse his mouth. Hold the emesis basin under the person's chin to catch the liquid. Dry the person's mouth and chin using the towel.
- 8- Wet the toothbrush by pouring mouthwash solution over it.
- 9- Put toothpaste on the wet brush.
- 10-Brush the upper teeth and gums



- 11- Brush the lower teeth and gums in the same way.
- 12- Brush the tongue.
- 13- Give the person a mouthful of the mouthwash mixture to rinse his mouth. Hold the emesis basin under the person's chin to catch the liquid. Dry the person's mouth and chin using the towel.

## Providing Mouth Care for an Unconscious Stroke Survivor

- 1- Wash your hands
- 2- Gather your supplies: Two towels, gloves, gauze squares, tongue depressor, cup, toothbrush and mouthwash
- 3- Explain the procedure
- 4- Prepare a solution of half water and half mouthwash.
- 5- Put the person in a seating position. Turn the person's head toward you.
- 6- Unfold one towel. Place it across the person's chest. Place the other towel under the person's head.
- 7- Put on the gloves.
- 8- Place the emesis basin on the towel near the person's cheek.
- 9- Pad the tongue depressor by wrapping the end in gauze and securing the gauze with tape.
- 10- Without using force, gently separate the person's upper and lower teeth. To do this, cross the middle finger and thumb of one hand. Put the thumb against the person's top teeth and the middle finger against her lower teeth and gently push the finger and thumb apart to open the jaw.
- 11- Insert the padded tongue depressor between the upper and lower teeth at the back of the mouth to hold the person's mouth open
- 12- Clean the roof of the mouth, the inside of the cheeks, the gums, under the tongue, and the lips with mouth sponges dipped in the mouthwash mixture.
- 13- Wrap a gauze square around your finger or use a mouth sponge to remove thick mucus or secretions.
- 14- Use a toothbrush moistened with diluted mouthwash to clean the person's teeth.
- 15- Apply lip balm or petroleum jelly to the person's lips.

16- Remove and dispose of your gloves.

17- Lower the head of the bed.



## Helping a Person with a Complete Bed Bath

### Preparation

- 1- Wash your hands.
- 2- Gather your supplies: Wash cloths, towels, bath blanket, bed protector, wash basin, bath thermometer, soap, paper towels, gloves, clean clothing, clean linens
- 3- Explain the procedure.
- 4- Fill the washbasin with warm water. Use the bath thermometer to verify that the water temperature is between 105° F and 115° F.

- 5- Lower the head of the bed as low as the person can tolerate.
- 6- Help the person move closer to the side of the bed where you are working.
- 7- Remove and fold the bedspread and blanket for reuse. Cover the person and the top sheet with the bath blanket (to provide privacy and warmth). Ask the person to hold the edge of the bath blanket (or tuck the edges under the person's shoulders) while you fold the top linens down to the bottom of the bed.
- 8- Put on the gloves.
- 9- Help the person to remove soiled clothing.

### Task 1: Wash the Person's Face, Neck and Ears

- 1- Place a towel on top of the bath blanket, across the person's chest. This helps to keep the bath blanket dry while you wash the person's face, neck and ears.
- 2- Wet the washcloth and make a mitt with it by holding a corner of the washcloth between your thumb and fingers, wrapping the rest of the cloth around your hand and holding it with your thumb. Hold the cloth over your fingers and tuck it under the fold in your palm.
- 3- Without using soap, use the washcloth to bathe the eye farther from you. Begin at the inner corner of the eye, near the nose. Then move the washcloth across the eye to the outer corner. Use the towel to dry the eye. Use the opposite end of the mitt and towel to bathe and dry the other eye
- 4- Using soap sparingly, wash, rinse and dry the person's face, neck and ears.



### Task 2: Wash the Person's Arms and Hands

- 1- Fold back the bath blanket to expose the person's arm that is farther from you. Place the towel lengthwise under the arm.

- 2- Wash, rinse and dry the shoulder, arm and underarm (axilla). Use the towel that was under the arm to dry the shoulder, arm and underarm.
- 3- Place a bed protector on the mattress near the person's hand, and place the washbasin on the bed protector. Place the person's hand in the washbasin. Wash, rinse and dry the person's hand.
- 4- Recover the person's arm with the bath blanket.
- 5- Fold back the bath blanket on the person's arm that is nearer to you. Place the towel lengthwise under the arm.
- 6- Wash, rinse and dry the shoulder, arm, axilla and hand
- 7- Remove the towel from under the arm, and cover the arm with the bath blanket.



### Task 3: Wash the Person's Chest and Abdomen

1. Place the towel on top of the bath blanket, over the person's chest and abdomen (stomach).
2. Reach under the towel that is over the bath blanket and fold the bath blanket down to the person's pubic area without exposing it. Leave the towel in place so that the person is not completely exposed.
3. Fold back the towel to expose the side of the person's chest that is farther from you. Wash, rinse and dry the person's chest. Inspect under the person's breast and skin folds as you work.
4. Dry the person's skin completely. Re-cover the chest with the towel.
5. Fold back the towel to expose the side of the person's chest that is nearer to you.
6. Wash, rinse and dry the chest
7. Wash, rinse and dry the person's abdomen in the same manner as the chest, doing the farther side first, and then the nearer side.
8. Pull the bath blanket back up to cover the chest and abdomen, and remove the towel from underneath.

9. Change the water if it becomes too soapy or cool.



#### Task 4: Wash the Person's Legs and Feet

1. Fold the bath blanket away from the person's leg that is farther from you. Place the towel lengthwise under the leg.
2. Wash, rinse and dry the leg. Use the towel that was under the leg to dry it.
3. Place a bed protector on the mattress near the person's foot, and place the washbasin on the bed protector. Place the person's foot in the washbasin. Wash, rinse and dry the person's foot.
4. Re-cover the person's leg with the bath blanket.
5. Fold back the bath blanket on the person's leg that is nearer to you. Place the towel lengthwise under the leg.
6. Wash, rinse and dry the leg and foot
7. Re-cover the leg with the bath blanket. Remove the towel from under the leg.
8. Change the water.



## Task 5: Wash the Person's Back and Buttocks

1. Help the person turn onto one side so that his back is facing you.
2. Place the towel on the sheet behind the person's neck, back and buttocks. Adjust the bath blanket so that it covers the person's chest, shoulders, abdomen and legs.
3. Wash, rinse and dry the person's neck, back and buttocks. Inspect the skin as you work.



## Task 6: Wash the Perineal Area

1. Place the towel so that it will be under the person's hips when you help the person back into the supine position. If the person is able to do his own perineal care, provide a fresh washcloth, soap and clean water. Give the person a few minutes alone to complete perineal care. If the person is not able to do his own perineal care, provide it yourself.
2. Remove and dispose of your gloves.

## Task 7: Help the Person Dress

1. Help the person back into the supine position.
2. Help the person to apply deodorant or antiperspirant (optional).
3. Help the person to put on clean clothing.
4. If the linens are soiled or wet, change the linens.

5. Pull up the top linens and remove the bath blanket.
- 

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American National Red Cross Association (2013). *Nurse Assisstant Training Textbook*. Retrieved from:

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<http://www.heartandstroke.on.ca/site/c.pv13IeNWJwE/b.5384179/k.B2BB/HCP.htm>



**Appendix M****Education session evaluation****TITLE OF THE SESSION:** \_\_\_\_\_

Offered by: \_\_\_\_\_ Date: \_\_\_\_\_

**Dear participant,**

We need your feedback about the session. Your answers will help us improve on future presentations.

**Please tick your chosen answer for each of the items below:**

1. The session increased my understanding of the topic:
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  
2. The session was presented in a way that was interesting
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  
3. The session was presented in a way that was easy for me to understand
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  
4. The content of the session was appropriate to my needs
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  
5. Now, I will confidently implement the information that was provided
  - Strongly agree
  - Agree
  - Disagree

- Strongly disagree
- 6. All my questions were answered
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
- 7. I was given opportunity to share my ideas and concerns
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
- 8. The environment and the overall set-up of the session were suitable for learning
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
- 9. The audio-visual aids used during the presentation helped better understand the information
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree

**Please answer the following questions:**

What aspects of the session did you like the most?

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What aspects of the session did you like the least?

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What aspects of the session would you like to see changed?

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**Thank you for your evaluation.**

**Appendix N****Overall program evaluation**

Dear caregiver,

We want to ask your opinion about the educational program that you attended. Your answers will help us improve it in the future.

**Demographic data.**

When did you attend the program? Please put the dates of the first and last sessions that you attended below:

- First session: \_\_\_\_\_
- Last session: \_\_\_\_\_

What is your gender?

- Male
- Female

How old are you?

\_\_\_\_\_

What is your relationship to the patient?

- Spouse
- Sibling
- Parent
- Child
- Grand-child

What is your marital status?

- Single
- Married
- Divorced
- Widowed

What is your work status?

- Self-employed
- Out of work and looking for work

- Out of work but not currently looking for work
- A housewife
- A student
- I work in the army
- I am retired
- I cannot work

What is the highest educational level that you completed?

- I can read and write
- High school graduate
- Bachelor's degree
- Master's degree
- Doctorate degree

Which sessions did you attend? Please put a tick (✓) next to the sessions you attended:

- Session 1: Brain, Stroke and the multidisciplinary team
- Session 2: Stroke survivor daily hygiene and skin care
- Session 3: Bladder and bowel control
- Session 4: Meal assistance, Special diets and hydration
- Session 5: Mobility, positioning and transfers
- Session 6: Communication and cognition after stroke
- Session 7: Post stroke depression
- Session 8: Caregiver Burnout

**Below we ask you if you agree or not on a number of statements. Please tick ✓ your answer of choice:**

1. The material presented was easy for me to understand.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  
2. The handouts I was given were helpful.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  
3. I have a clearer sense of the resources available to me.
  - Strongly agree

- Agree
  - Disagree
  - Strongly disagree
4. The program helped me to better understand about the care and treatment of my relative who has a stroke.
- Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
5. The presentations covered information that was important to me.
- Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
6. The timing of the program was convenient
- Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
7. The question and answer periods allowed me to ask about some of my specific concerns.
- Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
8. I feel more capable of providing care for my relative following this program
- Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
9. I feel more confident in my abilities as a caregiver
- Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
10. I feel less anxious about my role as a caregiver.
- Strongly agree

- Agree
- Disagree
- Strongly disagree

**Please answer the following questions:**

Which aspects of the program you found to be most helpful? Why?

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---

Which aspects of the program you found to be least helpful? Why?

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What aspects of the program do you recommend to be changed? Please comment.

- Timing \_\_\_\_\_
- Location \_\_\_\_\_
- Topics \_\_\_\_\_
- Instructors \_\_\_\_\_
- Number of sessions \_\_\_\_\_
- Sequence of sessions \_\_\_\_\_
- Teaching methods \_\_\_\_\_
- Others, specify \_\_\_\_\_

Thank you for taking the time to answer the survey.