Barrow Neurological Institute Stroke Education Manual





St. Joseph's Hospital and Medical Center

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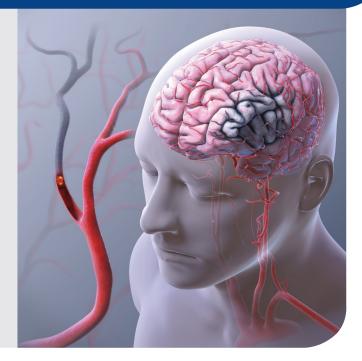
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Introduction

This guidebook will help you understand your diagnosis and treatment plan for your stroke recovery. The information presented here may answer many of your questions, but please speak to any of our staff if you have further questions or concerns. We are here for you.

This guidebook should stay in your room so that the health care team may add materials that are specific to your care. This guidebook is intended to be an introductory resource and to serve as a part of your comprehensive rehabilitation program.

Thank you, Your Health Care Team



Some information contained within was taken from:

- 1. The clinical practice of neurological and neurosurgical nursing (7th ed.) Livesay, S.L & Hickey, J.V. (2014). Philadelphia, PA: Lippincott Williams & Wilkins;
- 2. The National Stroke Association
- 3. American Heart and Stroke Associations
- 4. Centers for Medicare and Medicaid Services
- 5. Canadian Heart and Stroke Foundation

This information is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Consult your doctor or healthcare provider with any specific medical questions.

Barrow Neurological Institute St. Joseph's Hospital and Medical Center 350 W Thomas Road Phoenix, AZ 85013

Treatment Information

Diagnosis:	
Team member name:	Specialty:

Procedures Performed

Date:	Procedure:	Purpose:

Your Stroke Recovery Team

Patient: You are the most important member of the recovery team and will be included in the decision making when appropriate. If you are unable to assist with decision making, then an alternate decision maker will be identified, based on hospital policy, until you are able to make decisions for yourself.

Family/Caregiver: With the patient's consent, you will be included in the decision making processes to help with discharge planning. You will be included in family teaching/education, and you should be an advocate for the patient's current and future care.

Below are some of the team members that you may meet during your stay.

Care Management/Case Management*: The nurse case manager is a registered nurse who works together with social work to help with post hospital care planning in cooperation with insurance coverage and community options for patients and families.

Chaplain Services: The chaplains provide emotional and spiritual support during your recovery at your request.

Neuropsychology: Neuropsychologists specialize in how changes in the brain affect thinking skills, mood, and behavior. They can provide neuropsychological testing to assess memory, attention, language abilities, visuospatial functions and problem-solving skills. Neuropsychologists can provide education to you and your family regarding cognitive and behavioral effects of stroke. They may also help provide emotional support and education to patients who are adapting/adjusting to life after stroke.

Nursing: Nurses have special education and training to care for patients with stroke. They are responsible for planning your care, helping you understand your medications, watching for side effects of medicines, treating your pain and keeping you as comfortable as possible. Nurses make decisions about your care, watch your vital signs (heart rate, blood pressure, and breathing) and supervise care given to you by other staff such as nurse's aides. The nurses work closely with the doctors and therapists to teach you about your illness, medication and therapies so you can take an active part in your recovery.

Nurse Practitioners (NPs) are registered nurses with graduate education and advanced clinical training. Our NPs work collaboratively with the physicians and other members of the health care team to assist in providing high quality, individualized care.

Occupational Therapy (OT)*: Occupational therapy works on returning you to daily life through occupation (an occupation is anything that people do during the course of everyday life). This will include the physical and cognitive skills to engage in activities in your environment and resume your life roles which include self care, productivity and leisure. They will also address, as needed, your neuromuscular recovery, vision, visual perceptual issues, positioning, splinting, sensation, tone management, adaptive equipment use, range of motion (ROM) and strengthening in attempt to return you to your everyday life.

Physical Therapy (PT)*: Physical therapy focuses on functional mobility training, gait/assistive device training, seating/positioning, tone management, therapeutic exercise to enhance strength and ROM, pain management, balance and neuromuscular re-education to assist with restoration of function and prevent disability.

Physicians (MD or DO): The physicians who will work together in managing your care may include specialists in multiple areas including, neurology, neurosurgery, internal medicine, physiatry* and other specialties depending on your specific needs.

Registered Dieticians: These professionals ensure that you receive nutrition to promote healing and help with any issues that stem from lack of appetite or difficulty eating. Rehabilitation Psychology: Rehabilitation psychologists will assist you and your family with adjustments to medical conditions and provide education related to emotional, physical, cognitive and behavioral correlates of injury/illness.

Rehabilitation Technicians/Aides: They work alongside the nurses to assist you with basic care that you may be unable to do for yourself. This may include helping you get in and out of bed, going to the bathroom and assisting with your personal daily needs.

Respiratory Therapy (RT): Respiratory therapy includes the assessment and treatment of breathing disorders and lung conditions. Respiratory therapists are experts in airway management, including tracheostomy/stoma care for you, if you're having difficulties managing your airway.

Social Worker (SW)*: The social worker is a valuable resource for you and your family. With a vast knowledge of benefits and services offered, the social worker's primary focus is helping you smoothly transition out of the hospital to the next level of care and helps you address social problems. Speech Language Pathology (SLP or ST)*: Speech Language Pathologists or Speech Therapists assess and treat swallowing, cognitive issues and communication skills, including understanding (receptive) and using (expressive) language skills, swallow assessment and intervention, clarity of speech, and alternate communication methods.

Therapeutic Recreation (TR): Therapeutic Recreation includes educating you and your family on the importance of continuing leisure interests after discharge. TR will incorporate community reintegration therapy, adaptive sports/recreation, leisure skill building and education, aquatic therapy, community resources, assistance with peer mentors and practice of the skills you learn from other therapists in the clinic to translate those to real life settings.

* Team members required to meet criteria of IRF (Inpatient Rehabilitation Facility) admission.

About Stroke

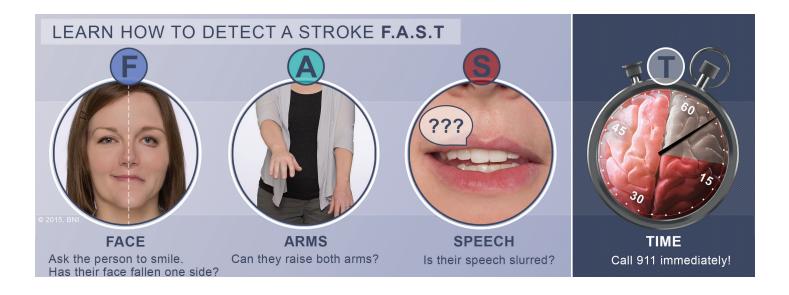
A stroke is an emergency, just like a heart attack, and medical help is needed right away. The brain controls important functions like movement, breathing and sensory perceptions (for example, sight, touch and taste). It also controls higher functions like thinking, learning and emotions. The brain needs an adequate supply of oxygenated blood in order to operate.

Strokes usually give warnings.

Warning signs of a Stroke

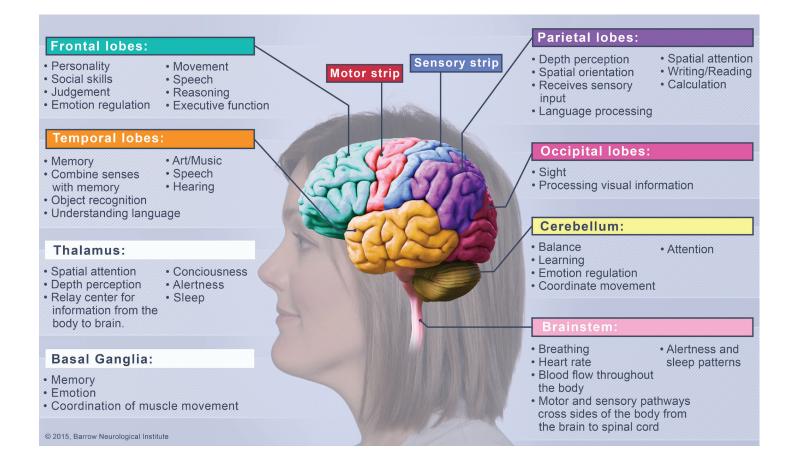
- Sudden numbness and tingling or weakness of the face, arm or leg, usually on one side of the body
- Sudden loss of speech, trouble speaking, or understanding
- Sudden vision problems
- Sudden unexplained dizziness, unsteadiness or sudden falls, especially with any of the other symptoms
- · Sudden severe headache with no apparent cause, described as the "worst headache" of your life

If you notice one or more of these signs, call 911 and say you are having a stroke. Seek appropriate medical attention immediately at a qualified hospital with a stroke center.



Anatomy of the Brain

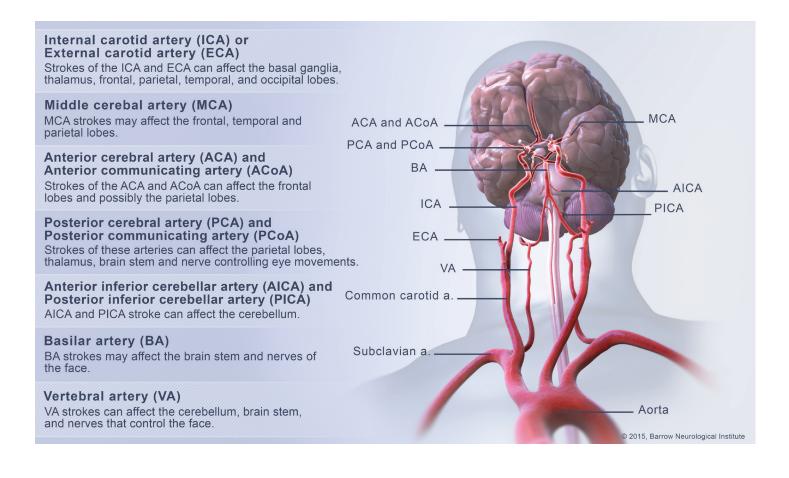
The brain controls important functions like movement, breathing and sensory perceptions. It also controls higher functions like thinking, learning and emotions. These functions maybe associated with specific parts of the brain. A stroke causing damage in one of these parts of the brain, may affect function associated with the damaged area.



Ventricles: A set of four (4) cavities in the brain where cerebral spinal fluid (CSF) is produced, responsible for the production and flow of the CSF from the brain to the spinal cord. If this stops working it can cause fluid

buildup, pressure and trapping of CSF and blood which needs to be drained by a device such as an external ventricular drain (EVD) or shunt.

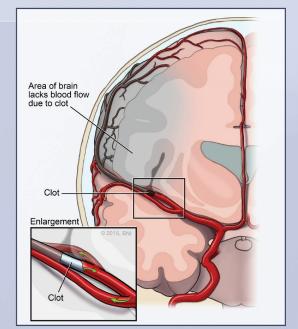
Arteries of the brain



Types of stroke

Types of stroke

There are two types of stroke; ischemic and hemorrahagic



Ischemic stroke

Ischemic

Ischemic strokes occur when blood flow through an artery in the brain becomes blocked by plaque on the wall of an artery or by a blood clot.

- **Thrombosis** is a blood clot that forms in the artery at the site of the stroke
- **Embolism** is a blood clot that forms in a different part of the body, usually in the heart, and travels into an artery in the brain.
- **Transient ischemic attacks (TIAs)** are short episodes of ischemia with stroke-like symptoms that resolve in less than 24 hours. TIAs are still emergencies since there is a high risk of experiencing a permanent stroke in the future.
- **Stenosis** occurs when blood vessels become narrow and do not allow enough blood to flow to the brain.
- **Moya-Moya** is an inherited condition that causes stenosis in many vessels throughout the brain and neck.
- **Watershed** strokes occur in areas of the brain that receive the furthest supply of blood flow. Any disruption in flow to larger blood vessels or blood flow can cause watershed strokes.
- Lacunar strokes happen in deep blood vessels of the brain leaving a small cavity within the brain tissue.

Hemorrhagic

Subarachnoid – hemorrhage (bleeding around the brain tissue)

Cerebral hemorrhages occur when a blood vessel in the brain bursts, bleeds, and causes rapidly increasing pressure in the brain. The sudden bleeding causes stroke symptoms like headache, nausea, vomiting, and often rapid loss of consciousness.

Hemorrhagic stroke

ntraparenchymal hemorrhage (bleeding within the brain tissue)

- **Intraparenchymal hemorrhage (IPH)** is bleeding that occurs within the brain tissues.
- **Intraventricular hemorrhage (IVH)** is bleeding that occurs within the ventricles, which are fluid filled spaces in the middle of the brain.
- **Subarachnoid hemorrhage (SAH)** occurs when an aneurysm (bulge of the wall of an artery) ruptures over the surface of the brain, creating an explosive burst of blood between the brain and the skull, causing a build-up of pressure that damages the brain.
- Arteriovenous malformations (AVM) are tangles of abnormal blood vessels. The direct connection of high pressure arteries to thin-walled veins can cause ruptures. AVMs may occur anywhere in the body, not just the brain.
- **Cavernous malformation** (**cav mal**) is a group of fragile, thin-walled veins. Since the blood flow is lower cav mals usually bleed at a slower rate than other types of hemorrhages.

Tests and Treatments

Common Diagnostic Tests

Computed tomography (CT) scan	Special x-ray equipment to make cross-sectional pictures of your body. CT scans quickly identify strokes and hemorrhages
Magnetic resonance imaging (MRI) scan	A technique that uses a magnetic field and radio waves to look at organs and structures inside your body
CT angiography (CTA) and MRI angiography (MRA)	Scans that identify the blood vessels in the brain by injecting dye through an IV. These scans help identify aneurysms, AVMs and narrowed blood vessels
Angiogram	Dye is injected into the bloodstream and x-rays are taken to visualize the blood vessels
Electrocardiograms (ECG or EKG)	Records the electrical activity of the heart that is used in diag- nosing some heart abnormalities
Echocardiogram	An ultrasound of the heart that identifies blood clots and assess blood flow through the heart
Blood tests	Are assessed in the laboratory to check for high cholesterol, di- abetes, abnormal clotting, risk for bleeding, and overall health.

Medical Treatments for Stroke

The goal of care during hospitalization is to support and maximize recovery. The treatment options depend on the type of stroke. For ischemic strokes returning blood flow takes priority. For hemorrhagic strokes stopping the bleeding and stabilizing intracranial pressure (ICP) generally take priority. Then patients are evaluated for any surgical needs.

Ischemic

- **Tissue plasminogen activase** (**tPA**) is a thrombolytic, a medication that restores blood flow by dissolving blood clots.
- **Medications** such as anticoagulants and antiplatelets are given to prevent strokes from occurring again.
- **Thrombectomy** is mechanically removing the blood clot.
- **Angioplasty** is using a small balloon to open a blood vessel.
- **Stenting** is implanting small mesh tubes into blood vessels to keep the vessel open or divert blood away from an aneurysm.
- **Carotid endarterectomy** (**CEA**) is the surgical removal of fatty plaque from the carotid arteries.
- **Surgical bypass** of the carotid artery increases blood flow to the brain by connecting the superficial temporal artery (STA) or another vein to a branch of the middle cerebral artery (MCA).

Hemorrhagic

- External ventricular drain (EVD), also known as a ventriculostomy, is a catheter that is surgically placed into the ventricles of the brain to monitor pressure and drain cerebral spinal fluid and blood.
- **Evacuation** of blood clots is to surgically remove a blood clot from a vessel.
- **Clipping aneurysms** the goal is to stop blood flow within the bulging area of the artery by placing small titanium clips around the base of the aneurysm.
- **Coiling or Stenting** of an aneurysm during angiogram physicians place titanium coils within the aneurysm or use a stent to divert blood flow from the aneurysm.
- **Embolization** of small blood vessels for treatment of AVMs during angiogram.
- **Resection** is surgical removal of AVMs, cav mals to prevent future bleeding.
- **Vasospasm** occurs due to the irritation of the blood on the brain tissue. Physicians use extra fluid to increase blood volumes and blood pressure to keep the vessels open. Severe spasm may require angioplasty.

Effects of Stroke

Aphasia: Difficulty with any or all of the following: speaking, reading, writing and understanding language.

Altered midline: The perception of sitting upright is affected causing you to lean to one side or the other. This can result in a "Pusher" syndrome.

Apraxia: Strokes may impair the ability of a person to carry out movements the way they intend to. This may include initiating movements, coordinating their mouth and tongue properly when talking, completing movements, or using an object correctly.

Balance: The inner ear, somatosensory system, and visual centers contribute to balance. Patients with impairment to one or more of these areas can experience dizziness or vertigo.

Bladder dysfunction: Strokes can affect muscles and sensations that are used in bladder function. Weak muscles can cause urine to leak from the bladder. Strong muscles may not relax and can cause retention. Patients may need to urinate often because they feel the bladder is full.

Bowel dysfunction: Constipation occurs when patients are not aware of their bodily needs or do not eat enough fruits or vegetables, drink enough water or exercise.

Cognitive Deficits: Cognition refers to the brain's thinking abilities, such as the ability to learn and remember information, to pay attention, to think quickly and process information and to solve problems.

Diplopia (double vision): Weak eye muscles, dry or scratched corneas, or impairment of the brain's visual centers can cause double vision.

Dysphagia: Difficulty swallowing food and liquids. This can result in aspiration (entrance of food or liquids into the airway) and lead to pneumonia.

Dysarthria: Weak muscles cause slow or slurred speech. Dysarthria and dysphagia often occur together.

Emotional Changes: Emotional changes can occur due to biological changes in the brain itself, adjustment to having a stroke, or both. Some people with stroke experience pseudobulbar affect, such that they experience uncontrollable or rapid shifts in emotions (including tearfulness or laughter) which may or may not be consistent with their internal experience. Changes in emotional expression and perception of others' emotions or body language can occur and may result in miscommunication.

Executive Functions Deficits: Executive functions include higher-level and complex thinking skills. Injury to the frontal lobe can impact executive function, including cognition and behavior.

- 1. Behavioral: Poor judgment and loss of inhibition can cause patients to act before thinking about the consequences or act in a socially inappropriate manner.
- 2. Cognitive: Patients may be easily distracted, get stuck on one thought, have difficulty understanding abstract ideas, and struggle with using logic to solve a problem.

Foot Drop: Inability to lift the foot up which causes you to drag your foot when walking.

Hemiparesis: Weakness of one side of your body.

Hemiplegia: Paralysis of one side of your body.

Hypertonicity: Stiffening of the muscles at rest.

Hypotonicity: Having lower muscle tone which results in muscles being limp.

Insight: Individuals may lack the awareness of changes in cognition or physical limitations following stroke.

Intracranial Pressure (ICP): High Intracranial Pressure may be related to one of the following reasons:

1. Brain edema: Swelling of the brain, causing it to

push against other contents in the skull. This is a major cause of brain injury and can cause death if not treated.

- Hydrocephalus: The enlargement of the cerebral ventricles due to a blockage of cerebral spinal fluid (CSF) flow.
 Extraventricular Drain (EVD): A drain that may be placed within the brain to monitor ICP and helps to relieve pressure by draining CSF.
 Ventricular-Peritoneal Shunt (V-P shunt): a drain that moves the extra fluid from the brain to the peritoneal cavity where it can be absorbed and this helps relieve pressure by draining the CSF.
- 3. Brain Herniation: When some of the structures of the brain are pushed across or through other structures of the skull due to very high ICP. Brain herniation is life threatening and can result in permanent neurological damage and disability.

Neglect/Inattention: Hemispatial neglect is the lack of awareness of one side of your body or a lack of response to stimuli on one side. Hemispatial inattention is a difficulty with attention to stimuli on one side of the body. This may occur with or without visual field cut. Pressure Sores: Damage to the skin and underlying tissues, due to decreased blood flow, resulting from prolonged pressure. Other factors that may contribute to this are friction, poor nutrition and moisture. This pressure commonly occurs in areas where bones are close to the skin.

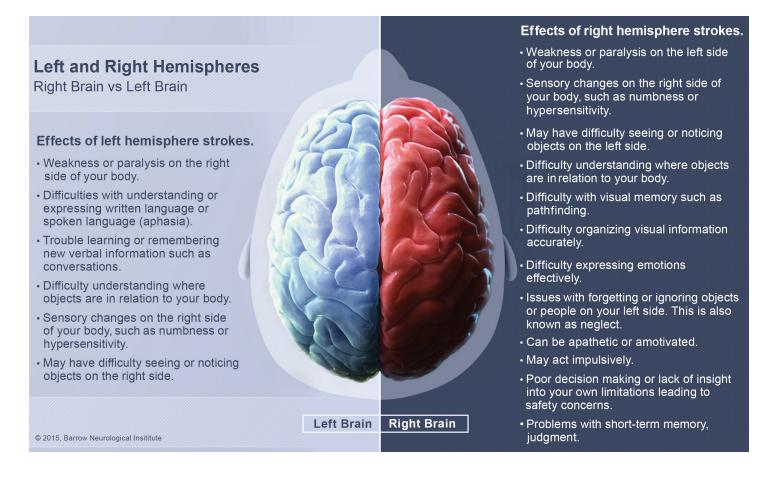
Sensory changes: Altered sensation of touch, deep pressure, pain, temperature, vibration, hearing, awareness of body in space, and/or sensitivity to light. People can be more sensitive to overstimulation (too much noise, too much light) after stroke.

Sleep Issues: Feeling tired after stroke is normal. Recovery from stroke requires a lot of effort and frequent rest periods or naps may be required.

Spasticity: Involuntary stiffening of the muscles related to movement.

Visual field cut: This is a type of partial blindness resulting in a loss of vision in one or both eyes. A typical type of visual field loss in stroke patients is homonymous hemianopsia where the person loses half of the field of view on the same side in both eyes.

Stroke Recovery



Stroke Recovery is a lifelong process. This begins with the medical personnel providing the best care after you suffer a stroke. When you are medically cleared, rehabilitation will start and assist you with improving physical, mental and emotional functions and restore quality of life and functional independence as much as possible. Each survivor's functional outcomes may be different, even if they had a stroke in the same area of the brain. It is important to continue to learn as much as you can about stroke and the recovery process. The goal of stroke rehabilitation is to relearn and resume the skills that you lost. Use the resources available to you to optimize your understanding of what stroke is, managing post stroke effects, advocating for the stroke survivor's and caregiver's needs and prevention of another stroke.

Examples of national resources include the National Stroke Association and the American Stroke Association, but these are not the only resources available to you. See page 19 for further resources.

Stroke Management and Prevention of Secondary Stroke

You can prevent or reduce damage from a stroke by knowing and reducing your risk factors. There are two kinds of factors: modifiable and non-modifiable. Non-modifiable include age, gender, race/ethnicity and family history.

Modifiable Risk Factors

Heart Disease

Atrial fibrillation (a-fib) is an abnormal heart rhythm that may cause blood clots to form in the heart. Blood clots can travel to the brain, causing a stroke.

Heart valve disease is damage to or a defect in one of the four heart valves which may cause blood clots to form in the heart. Blood clots can travel to the brain, causing a stroke.

To lower your risk: Take heart medications prescribed by your health care provider and have your blood tested on a regular basis.

Hypertension (High Blood Pressure)

Prehypertension: 120-139/80-89 Hypertension: Higher than 140/90

Why is this a problem: High blood pressure hardens and weakens blood vessels, and causes the heart to work harder leading to cardiac disease.

To lower your risk: Have your blood pressure checked regularly. Take the medications as prescribed by your health care provider.

Atherosclerosis / Artery Disease

Arteries in the heart, head, and neck are narrowed by cholesterol or hardened by high blood pressure.

Why is this a problem: Plaque forms in artery walls and blocks blood flow.

To lower your risk: Have your cholesterol levels and blood pressure checked regularly. Take medications as prescribed by your health care provider.

High Blood Cholesterol Levels

Total cholesterol over 200mg/dL

LDL over 100mg/dL

HDL under 40mg/dL

Why is this a problem: Cholesterol is deposited in the walls of arteries where it reduces blood flow leading to stroke.

To lower your risk: Eat a low cholesterol diet and exercise regularly. Take the medications prescribed by your health care provider.

History of stroke or TIA (TIA sometimes called a mini-stroke)

Previous stroke or TIA, especially in the recent past

Why is this a problem: A person who has had a TIA is more likely to have a stroke within 90 days. Those who have had a stroke are 20 percent more likely to have another stroke within the next five years.

To lower your risk: tell your health care provider

Diabetes

Fasting blood sugar over 126mg/dL on two separate days

HgbA1c over 7

Why is this a problem: Diabetes contributes to atherosclerosis and heart disease, and increases the risk of stroke.

To lower your risk: Keep your diabetes under control by proper diet, medication as ordered and exercise.

Tobacco Use

Smoking cigarettes or cigars, use of chewing tobacco, use of e-cigarettes

Why is this a problem: Smoking increases the risk for blood clots and is a strong risk factor for carotid and coronary arteries disease.

To lower your risk: Stop smoking. Talk to your health care provider about resources for quitting smoking

Alcohol Consumption

More than two drinks a day for men and more than one drink a day for women

One drink equals: 12 ounces of beer

1 glass (5 ounces) of wine

1¼ to 1½ ounces of liquor

Why is this a problem: Clots are more likely to form and arteries become narrowed.

To lower your risk: Abstain or limit alcohol consumption.

Excessive Weight

Being more than 20 pounds over ideal weight.

Why is this a problem: more likely to develop diabetes, high blood pressure and stroke than those who are not overweight.

To lower your risk: Work together with your health care provider to develop a diet and exercise plan that meets your needs.

Medications Used to Reduce Risk Factors for the Stroke Patient

Lowers Blood Pressure

ACE Inhibitors (Angiotension Converting Enzyme) and ARB (Agiotension II receptor Blockers): These prevent the body from narrowing the blood vessels so that the blood vessels remain wide open and blood pressure remains low

Examples include: lisinopril, valsartan and losartan

Side effects: cough, dizziness, headache and high potassium.

Alpha Blockers: lowers blood pressure by relaxing the heart muscles and causing he heart to beat slower.

Examples include: doxazosin and clonidine *Side effects*: cough, dizziness, headache and fatigue.

Beta Blockers: cause the heart to beat in a slower, more regular rhythm. This places less stress on the heart and lowers blood pressure.

Examples include: propranolol, metoprolol, carvedilol, atenolol

Side effects: a heartbeat that is too slow, dizziness, fatigue, cold hands and feet.

Calcium Channel Blockers: Cause the heart to relax by slowing the movement of calcium into the muscles

Examples include: amlodipine, nifedipine, diltiazem

Side effects: swollen feet, headache, flushing

Diuretics ("water pills"): removes water and salts from the body by increasing the formation of urine

Prevent Blood Clots

Anticoagulants/AntiThrombotics (Blood Thinners): which prevent blood clots from forming or getting bigger.

Examples include: Pradaxa, Xarelto, warfarin, heparin

Side effects: bleeding, bruising, anemia and heartburn

Antiplatelets: These prevent platelets form sticking together. When platelets stick together a blood clot forms.

Examples include: aspirin, Plavix, Aggrenox and Ticlid.

Side effects: bleeding, bruising, anemia and stomach ulcers

Lowers Blood Sugar

Insulin: natural hormone that reduces blood sugar.

Examples include: insulin, Lantus, Humalog

Side effects: low blood sugar, injection site reactions, weight gain, low potassium

Oral Agents: Reduced blood sugar by helping the body tissue absorb sugar from the blood or helping the pancreas make more insulin.

Examples include: metformin, glipizide

Side effects: diarrhea, flatulence, nausea, vomiting, dizziness

Lowers Cholesterol

Statins: Prevent the liver from making more cholesterol.

Examples include: atorvastatin, simvastatin, rosuvastatin

Side effects: joint pain, muscle pain, diarrhea

Discharge Planning and Disposition

The Case Manager/Social Worker and other team member's work together to ensure your health care needs are being met within the covered benefits of your health insurance plan after you are discharged from the hospital. They help you pick the most appropriate setting for your discharge. If you need follow up inpatient or outpatient services a summary is provided below.

Settings for Stroke Care - Inpatient Services

Rehab Program	Criteria for Admission	Type of Setting	Services Provided	Frequency of Therapy
Acute Care (inpatient)	 Requires admission to a hospital and order for therapy services. Needs 24 hour nursing care. Medical needs requiring daily physician visits. 	Hospital Based	24 hour medical care and a full range of therapy services.	Therapy provided according to the needs of the patient and physician orders
Inpatient Rehabilitation Facility (IRF)	 Able to tolerate three hours of therapy per day, five days a week. Needs for at least two of the following therapies (PT, OT, ST). Needing 24 hour nursing care. Medical needs requiring rehab physician or physician with specialized rehab training at least three times per week. Must show practical, measurable improvement in a prescribed period of time. 	Free standing or special unit of a hospital with designated rehab beds.	24 hour medical care and a full range of therapy services.	One of the more demanding settings from a therapy perspective. At least three hours per day, five days per week.
Skilled Nursing Facility (SNF)	 Require skilled therapy services. Require skilled care nursing Frequent on-site evaluation by a physician, nurse practitioner, or physician assistant. 	Free standing or special unit of hospital with designated SNF beds for short term nursing care, sub acute	Provides daily nursing care and a wide range of rehab services.	Less demanding than an IRF, but the program may continue for a longer length of stay.
Long -term care facilities (LTC)	 Requires 24 hour nursing care. Medically stable. Physician visits. Provide the required services from a written order by a physician by qualified personnel 	Free standing facility Nursing Home	Provides long term nursing care and limited rehab services as ordered.	Therapies provided as prescribed by physician.

Settings for Stroke Care - Outpatient Services

Rehab Program	Criteria for Admission	Type of Setting	Services Provided	Frequency of Therapy
Outpatient Facilities	 Order from a following physician including diagnosis, type and frequency of therapy. A skilled medical need. 	Outpatient center, outpatient department of a hospital or doctor's office.	All therapy services. Social worker and neuropsychologist as available	Therapies usually provided in one hour sessions, two to three days per week as prescribed by physician.
Home Health Care Agencies	 Requires a need for specific rehab services in at least one of the therapy services (PT, OT, ST). The person must be considered "homebound". 	In the persons place of residence	Nursing and wide range of therapy services.	Therapies usually provided in one hour sessions, two to three days per week as prescribed by physician.
Adult Day Care	 • Able to participate in group activities • Requires supervision. • Depends on focus of adult day care center. 	In the adult day care center	Nursing is available and group type activities. May have some restorative services.	No skilled therapies provided.
Group Home	 Depends on clinical assessment, medical necessity, and inability to live alone in the community. Fit of the patient to the group home. Ability to communicate by some means. 	In the persons group home or outpatient facility	Limited nursing, brought is as needed. No therapy provided, must either have home health or go to outpatient for therapy services.	Therapies as prescribed by physician. Home program followed by group home staff as set up by the therapist.
Assisted Living	• Those who need help with activities of daily living.	In the persons assisted living facility or outpatient facility	Limited nursing if any. No therapy provided, must either have home health or go to outpatient for therapy services.	Therapies as prescribed by physician.

Community Resources and Websites

Resource	Contact
The Barrow Stroke Center	www.thebarrow.org/Stroke/
American Stroke Association	http://www.strokeassociation.org/
National Stroke Association	http://www.stroke.org/
National Aphasia Association	http://www.aphasia.org/
Brain Injury Alliance of Arizona	http://biaaz.org/
Joe Niekro Foundation	https://www.joeniekrofoundation.com/
National Institute of Neurologic Disorders and Stroke (NINDS)	http://www.ninds.nih.gov/disorders/stroke/stroke.htm
Arizona Bridge to Independent Living (ABIL)	http://abil.org/
Arizona Technology Access Program (AzTAP)	http://aztap.org/
City of Phoenix Adaptive Recreation	http://www.phoenix.gov/parks/adaptiverec/index.html/
2014-2015 Barrow Connection Community Recreation and Resource Guide	http://www.thebarrow.org/stellent/groups/public/@xinternet_con_bni/doc- uments/webcontent/211140.pdf
Virginia G. Piper Sports & Fitness Center	http://www.spofit.org/
Valley Metro Mobility Center	http://www.valleymetro.org/accessibility/mobilitycenter/
Arizona Disabled Sports	http://www.ArizonaDisabledSports.com/
Care pages	http://www.carepages.com/

Support Groups

Support Group	Contact
Barrow Stroke Survivor & Caregiver's Support Group at Outpatient Rehab	602-406-6688
Barrow Grief Support Group	602-406-3275
American Stroke Association	http://www.strokeassociation.org/STROKEORG/strokegroup/public/zip- Finder.jsp
Brain Injury Alliance of Arizona	http://biaaz.org/coping-with-brain-injury/support-groups
Joe Niekro Foundation	http://www.joeniekrofoundation.com/patient-caregiver-support/sup- port-groups/
National Stroke Association	http://portal.stroke.org/a_supportgroupsearch

Caregivers

Caregivers are essential to the recovery of a person affected by stroke; however, the caregiver must be sure to balance the demands of their role with their personal needs. The needs of the stroke survivor may change over the course of their recovery as will the role and needs of the caregiver. Keep open communication with one another to ensure the ever-changing needs of one another are being addressed.

Rights and Responsibilities of a Caregiver:

- Take care of yourself.
- Accept help from others.
- Maintain aspects of your life that do not necessarily include the person you care for.
- Know it is okay to get angry and to express other difficult emotions while monitoring for signs of depression.
- Take pride in what you are accomplishing and recognize the courage it takes to meet the needs of another.
- Educate yourself on stroke and deficits specific to your loved one.
- Seek support and guidance from others.
- Monitor for signs of "caregiver burnout".

- Interview the several individuals/facilities to determine how their services align with you and the stroke survivor's needs.
- Include the stroke survivor in the interview and decision making process.
- Research funding for care. Check with your insurance. Determine if your state provides waivers to offset the cost. Options can be found through the federal government's Administration on Aging (www.aoa.gov) and/or your states agency on aging (www.n4a.org) to identify your options.

Assistance for Caregivers:

- Respite Care: short-term, temporary relief to those who are caring for family members who might require permanent placement in a facility outside the home. Caregivers providing unpaid care are eligible for respite care under the 2006 Federal Lifespan and Respite Care Act.
- Adult Day Care: professional supervision of adults in a social setting during the day.
- Home Health Aide: in-home personal health care assistance.
- Get assistance from family and friends to give you time to do required tasks or engage in leisure pursuits.

Rehabilitation Services

Choosing the Right Rehabilitation/Facility

Making the choice of where you or your family member will do their rehabilitation is an important decision. Insurance coverage may play a role in this decision but by doing some research and advocating for the patient you can help get the patient to the most appropriate rehabilitation setting. To make the choice best suited to the patient's needs, you may consider asking the following questions:

- 1. Is the facility accredited by CARF and/or The Joint Commission?
- 2. Are there doctors on staff who are board certified in rehabilitation medicine?
- 3. Do the therapists have specialty training/certification in dealing with specific conditions or diagnosis?
 - a. Some of these may include but not limited to NDT, Neuro-IFRAH, PNF, Certified Brain Injury Specialist (CBIS), Certified Stroke Rehabilitation Specialist (CSRS) or specialty certifications from discipline specific licensing boards (i.e. PT has NCS – Neurologic Clinical Specialist, OT's may have board certification in Physical Rehabilitation as examples)
- 4. Does the nursing staff have a majority of Certified Rehabilitation Registered Nurses (CRRN) on staff?
- 5. What equipment/technology do they have at their disposal?
- 6. Do they have aquatic therapy?
- 7. Do they have appropriate physical space and exercise equipment available?
- 8. How many days of therapy will the patient receive (they need at least three hours a day, five days a week)?
- 9. How much one on one therapy will the patient get? Do they use groups to meet the three hour rule? If so, how?
- 10. Will they have a team of therapists/nurses or random therapists/nurses on a daily basis?
- 11. Can you get a tour of the facility?
- 12. Do they have dedicated stroke programs and what are their outcomes?
- 13. Does your insurance cover the place you choose, and if not, what is your out-of-pocket cost?
- 14. Does the program have options for you to go to for the next level of care (outpatient rehab or day treatment)?
- 15. Is there medical care available at the facility if you need it?

- 16. Does the program offer stroke support groups for the survivors and caregivers?
- 17. Do they have neuropsychologists, rehabilitation psychologists or counseling available?
- 18. What are the facilities' outcomes?

Hospital Based Acute Care Rehabilitation Services

The priorities for inpatient acute care are management of stroke deficits to improve recovery, prevention of post-stroke complications that many interfere with their recovery process, and the prevention of stroke recurrence. Early therapeutic intervention is an important component to stroke recovery and, when appropriate, will be ordered by the physician. Occupational, physical and speech therapies will complete their assessments preferably within 24 to 48 hours of receiving an order. Evidence based practice shows patients admitted with a diagnosis of acute stroke should be mobilized as early as possible. Treatment plans will be set individually by the therapist based on what is necessary and tolerated. Once the assessments are completed, discharge planning will be initiated. Therapies are an important part of the discharge planning process to help identify the most appropriate next level of care. Family, friends and other support systems are also important during this planning as they will help guide interventions, education and plans for assistance that will be required during transition from the hospital.

Inpatient Rehabilitation Facility (IRF)

Currently to be classified as an Inpatient Rehabilitation Facility by Medicare, that facility must have at least 60 percent of a facility's total inpatient population meet IRF criteria and have one or more of 13 defined conditions (examples are stroke, brain injury, spinal cord injury, neurological disorders, amputation, congenital deformity, major multiple trauma, fracture of the femur, and burns). For those facilities that designate them as "Neurorehabilitation", they will specialize in the care of people with neurological conditions.

What are CARF and The Joint Commission Certification?

Commission on Accreditation of Rehabilitation Facilities (CARF) and the Joint Commission accredit health care organizations. They are an independent, nonprofit organizations focused on meeting a high quality of services and standards of care. They strive to help facilities put in place a system of care that will meet the needs of the patient and family and provide them with the best possible care.

The Therapy Team

The team will work towards helping you increasing functional independence, provide pertinent education to the patient and family, decreasing the burden of care and prepare for discharge to the community. They work in an interdisciplinary team with a patient centered approach, which includes the patient, the caregiver and health care professionals as detailed on "Your Stroke Recovery Team", page 4-5.

The Rehabilitation Process and the Expectations of the Patient and Family.

One of the primary goals of an IRF is to send the patient home with family or a caregiver in the safest and most efficient manner possible. Patients may not achieve complete independence or return to their prior level of function at the time of discharge from the IRF. The team will work to get the patient to the highest functional level in the restraints of time and progress before moving to the next level of care. The patient may need physical assistance, cognitive assistance or both upon returning home. The level of assist will vary depending on the patient and the severity of their deficits. It is recommended that the family/caregiver play an active part in the rehab process.

By agreeing to come to the IRF the family or caregiver has agreed to help or obtain the help necessary to meet patient's needs. The patient, family and/or caregiver(s) should let the team know what their needs and goals are so an individualized plan of care can be established. The amount and timing of family training will be conveyed by the team based on the patient's needs.

Interdisciplinary team meetings occur at least once a week to discuss the resolution to any problems that may affect the patient's plan of care, review the patient's progress towards their rehabilitation goals, and modify the plan of care to meet the their needs.

Discharge planning starts as soon as the patient is admitted to help ensure a smooth transition home. On admission, the family should understand that they may need to provide 24 hours a day, 7 days/week supervision for the patient on discharge. On some occasions, this may not be necessary at the time of discharge, but it is for the vast majority of the patients especially those discharging from a Neurorehabilitation Center. It is recommended that you start making plans to have someone to assist the patient once you initiate rehabilitation. Most insurance policies do not cover this type of custodial care, and family members or caregivers at the time of discharge usually have to provide it. The team will assist you in this process by helping you understand your insurance benefits, by providing family teaching for the physical and cognitive limitations of the patient, assist in recommending and obtaining any equipment needed, and help develop the necessary skills needed to go home. It is recommended that you do not wait until the end of the stay at the IRF to start preparing for discharge.

What Do the Different Levels of Supervision Mean?

The amount of supervision upon discharge will be determined by the rehabilitation team and conveyed to you.

- **24**/7 **supervision** means the patient will require 24 hours a day, 7 days a week supervision. This means that you have to provide constant and direct supervision physically and/or cognitively to assist the patient. When this level of supervision is recommended you cannot leave the patient alone. You need to be aware of the patient's needs and are responsible for the patient at all times.
- **Close supervision** means that you do not have to have constant direct supervision of the patient, and you can leave them alone for short periods of time (an hour or less) as long as the patient has a way to contact you if a need arises prior to your return.
- **Distant/Intermittent supervision** means you can leave the patient alone for short periods of time and check on them occasionally. These times will be recommended by the therapy team.

What is FIM Scoring?

We rate the patient by Functional Independence Measure (FIM) scores. FIM scores are the accepted method of describing a patient's functional ability (both physically and cognitively) in an IRF. It is a measure of disability not impairment. It is a basic indicator of the patient's current burden of care and a requirement by most insurance payers. For more information please ask your rehab team member.

Outpatient Rehabilitation

It is recommended you contact prospective outpatient facilities to ensure you select a facility that has a team of therapists that works with patients who have had a stroke. Your outpatient team may consist of a speech therapist, occupational therapist, physical therapist, social worker, nurse and neuropsychologist. Your plan of care will be established with each therapist, with individualized goals to focus on mobility, self-care, home management, return to work/school, community/recreational activities and return to driving.

The patient will typically be seen for an hour session with each therapist, two times per week. Discharge from outpatient therapies is based on whether the patient has met the goals, and the insurance plan coverage. The patient may be discharged from outpatient rehab when there is a medical set back as well.

Return to Work

Return to work considerations should be discussed with your physician and therapists. Throughout your course of treatment, your physicians and therapists will continue to re-evaluate your status for return to work.

• You may want to explore your options for the Family Medical Leave Act (FMLA) and disability pay options (short-term & long-term disability) with your employer.

www.dol.gov or call 1-866-487-2365

- Neuropsychological evaluations, functional capacity evaluations and/or physicals through your employer may be required prior to your return to work.
- You may need some accommodations in your work place and may need to utilize your rights under the Americans with Disabilities Act.

www.ada.gov or call 1-800-514-0301

- Although not required by all employers, it is highly recommended that you get cleared by your physiatrist or neurologist before returning to your regular work duties, and consider a gradual return to work.
- If you anticipate that you will be unable to return to work within a 12 month timeframe, you may want to apply for Social Security Disability benefits.

www.ssa.gov or call 1-800-772-1213

• If you're unable to return to your previous work position, the Arizona Vocational Rehabilitation Program and Services may provide assistance with looking into alternative work positions.

https://www.azdes.gov/rehabilitation_services or call 602-266-6752

Return to School

An individual with a stroke may have physical and/ cognitive changes that may affect the return to school. Once the student is cleared by their doctor to return to school, the parent/legal guardian should contact the school to request an evaluation to determine their student's educational needs. A team of individuals at the school will evaluate the student as well as obtain any outside evaluations (such as therapy evaluations, medical records). Once the school evaluation team has all the appropriate information to determine the student's educational needs, a meeting with everyone will be held to discuss the best plan for the student to have a successful return to school. Students who may need special education services may need to be served under the Individuals with Disabilities Education Act (IDEA) for services available for return to school.

- Per the 504 section of the Rehabilitation Act of 1973, a student is allowed classroom modifications that may include environmental, curriculum, methodology, organizational, behavioral and presentation strategies (extra test time, typed notes).
- An individualized education plan (IEP), allows a student to have therapy services at school, transportation, one on one aide, and time spent outside of the regular education classroom, in a classroom more specialized for a student with a disability.

Return to Driving

Depending on the location and severity of the stroke, the stroke can affect skills that are important for safe driving such as reaction time, ability to multi-task, visual perceptual skills, and judgment. The state of Arizona is a self-reporting state for when a person has a change in their medical condition such as stroke. It is the responsibility of the driver to report, in writing or by phone, to the Motor Vehicle Department that they had a stroke that may affect the ability to safely operate a motor vehicle. To return to driving, talk with your physician and contact the Arizona Medical Review Board for Motor Vehicle License to obtain a packet of information with the forms and assistance if needed.

http://www.azdot.gov/mvd/MedicalReview/ MedicalReviewProgram.asp or call 602-771-2460

An occupational therapist can assess the individual, who has had a stroke for their driving skills. The driving assessment is shared with the physician who will assist with deciding the best plan for return to driving. Sometimes it is recommended that a more extensive driving evaluation be conducted at a facility that specializes in driving evaluations after a stroke. Neuropsychological testing can also be helpful in evaluating cognitive skills relevant to safe driving. www.drivingtoindependence.com or call 480-449-3331

drsolutions@qwestoffice.net or call 602-840-2323

http://www.bannerhealth.com/Locations/Arizona/ Banner+Good+Samaritan+Medical+Center/ Programs+and+Services/Rehabilitation/ Rehab+Institute/Adapted+Driving+Program.htm or call 602-839-2317



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