

# **Elevating Life After Stroke**

Resource Guide for Stroke Survivors and Caregivers

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## Introduction

Recovering from a stroke can be challenging, but having the right information can make it easier. This guide was created for individuals who have experienced a stroke and for those closest to them.

It provides information to help you understand your stroke, the changes that may occur after a stroke, and what you can do about it. It serves as an educational tool during your recovery here in the hospital and support resource when you return home. Every stroke is different, but there are steps you can take to navigate your recovery safely and prevent another stroke.

This comprehensive guide was carefully written and edited by Peterson Regional Medical Center's (PRMC) Acute Rehab Unit Staff who wishes you the best in your recovery journey and the hope of a fulfilling life after stroke!

## What is a **Stroke**?

A stroke occurs when a blood vessel that carries oxygen and nutrients to the brain either bursts or is blocked by a clot. When that happens, part of the brain cannot get the blood or oxygen it needs. The part of the body controlled by the damaged area of the brain does not work properly.

Stroke is the 5th cause of death in the United States. It is a leading cause of disability. About 80% of strokes are preventable.

#### **TYPES OF STROKES**

**An ischemic stroke** is caused by a clot blocking the flow of blood to the brain. About 87% of all strokes are ischemic strokes.

- The protein Tissue Plasminogen Activator (r-tPA) is the gold standard in the US to treat ischemic strokes because it can save lives and reduce long-term stroke effects. The r-tPA is given intravenously in the arm (i.e. IV). It dissolves the clot and improves blood flow to the part of the brain being deprived.
- According to American Stroke Association's 2018 "Get with the Guidelines", it is recommended to receive the r-tPA less than 3 to 4.5 hours from the time symptoms first appear. Many people do not get to the hospital in time to get it, so it is important to identify stroke symptoms and get help quickly by calling 911.

A hemorrhagic stroke is caused by a blood vessel bursting and preventing blood flow to the brain.

About 13% of strokes are hemorrhagic strokes.

A TIA (transient ischemic attack) or a mini stroke is caused by a temporary blood clot. TIAs share the same symptoms as strokes, but usually only last a few minutes. Because TIAs do not cause permanent damage, they are often ignored by patients. Do not ignore them. TIA's precede about 15% of strokes, so seek treatment quickly.

#### RISK FACTORS FOR STROKE

Manageable vs. Non-Manageable

Knowing your risk factors for a stroke is the first step in preventing a stroke. There are many ways to reduce your likelihood of having another stroke.

Controlling your blood pressure is the single most important way to lower the risk of having a stroke.

#### **Manageable Stroke Risk Factors:**

- Smoking
- Atrial fibrillation (irregular rapid heartbeat)
- Heart disease
- Diabetes
- High cholesterol
- Excessive consumption of alcohol
- Illegal drug use
- Excess weight and lack of exercise
- Stress

Regular visits to your healthcare provider, a healthy diet, and exercise program are the best ways to manage these risk factors.

# Non-Avoidable Stroke Risk Factors (Non-Manageable)

- **Gender:** Men are 30% more likely than women to have a stroke. However, stroke kills more women each year than breast cancer.
- Age: The incidence of stroke increases with age. Approximately, 25% of all stroke survivors are under the age of 65, so it is not just a disease of the elderly.
- Race: African-Americans have twice the risk for stroke than Caucasians.
- History of prior stroke or TIA
- Family history of stroke

#### PREVENTING ANOTHER STROKE

In the previous section, you can see that there are multiple risk factors for stroke – some are manageable and even preventable, and some are not. This section will discuss some of the most common manageable risk factors:

#### **HIGH BLOOD PRESSURE**

High blood pressure occurs when force of the blood pushed out with a lot of force against your artery walls for a long time.

- If the force is high enough, it may eventually cause health problems, such as heart disease and stroke.
- This pressure can cause your arteries to get hard and thick, which can cause a stroke and other medical problems.

The **harder your heart pumps** and the **more narrow your arteries**, the higher your blood pressure can be.

Symptoms of high blood pressure are not very specific - headache, trouble breathing, nosebleeds. A lot of people with high blood pressure can have no symptoms at all, even when their blood pressure is dangerously high.

#### **Managing High Blood Pressure**

- Take your medicine as prescribed! Consistently follow up with your doctor.
- Exercise
- Eat a well-balanced, healthy diet
- Maintain a healthy weight
- Avoid too much salt or alcohol
- · Quit smoking

#### HIGH CHOLESTEROL

Cholesterol is a waxy substance found in your blood. Your body needs cholesterol to build healthy cells, but high levels of "bad" cholesterol can increase your risk of heart disease and stroke.

- Low-density lipoprotein (LDL). LDL, or "bad" cholesterol, transports cholesterol particles throughout your body. LDL cholesterol builds up in the walls of your arteries, making them hard and narrow.
- High-density lipoprotein (HDL). HDL, or "good" cholesterol, picks up excess cholesterol and takes it back to your liver.

With high cholesterol, you can develop fatty deposits in your blood vessels. Eventually, these deposits grow, making it difficult for enough blood to flow through your arteries. Sometimes, those deposits can break suddenly and form a clot that causes a heart attack or stroke.

#### **Managing High Cholesterol**

- Eat a healthy, balanced diet full of fiber, fruits and vegetables, whole grains, and lean protein.
- Follow your doctor's orders for medications, and follow up regularly.

#### **DIABETES**

Diabetes affects the body's ability to create insulin or use it properly. Since insulin plays an important role in pulling glucose (sugar) into cells from the bloodstream after eating, people with diabetes are often left with too much sugar in their blood.

Over time, this excess sugar can contribute to the buildup of clots or fat deposits inside vessels that supply blood to the rest of the body. (atherosclerosis). If these deposits grow, they can cause a narrowing of the blood vessel wall or even a complete blockage, which can cause a stroke.

Eat a healthy diet and stay physically active to prevent diabetes. If you already have diabetes, monitor your blood sugar regularly, take your medications as prescribed, and maintain a healthy diet with plenty of exercise.

#### **Managing Diabetes**

Eat a healthy diet and stay physically active to prevent diabetes. If you already have diabetes, monitor your blood sugar regularly, take your medications as prescribed, and maintain a healthy diet with plenty of exercise.

#### **SMOKING**

Tobacco smoke contains more than 7,000 toxic chemicals. These chemicals are transferred from your lungs into your blood stream, changing and damaging cells all around your body - these changes can lead to a stroke.

Cigarette smoke can affect your body's cholesterol levels, too. Smoking reduces the 'good' cholesterol (HDL) in your blood stream and increases 'bad' cholesterol (LDL). Having low 'good' cholesterol in your body increases your risk of stroke.

Nicotine makes your heart beat faster and raises your blood pressure, causing a risk of stroke. Smoking can also trigger an episode of AFib, which can cause a stroke.

The chemicals in smoke also make your blood cells more likely to stick together. This increases the chance of a clot forming.

Smoking can also increase your risk of having hardened and narrow arteries, which reduces your blood flow and can cause a stroke.

#### **Managing Smoking**

\*\*\*SMOKING CESSATION IS KEY\*\*\*

Smoking cessation is critical to preventing a stroke. Speak to your doctor about options available to help you stop.

#### DIET

A healthy diet can help reduce your risk of heart disease, diabetes, stroke, TIA, and cancer.

Many strokes can be prevented and healthy eating is one important way to reduce your risk.

Even making small changes to your eating habits can make a difference to your overall health, particularly if you have been told that you are at risk of having a stroke or TIA.

#### **Managing a Healthy Diet**

- Fruit and vegetables eat the rainbow! Eating 5+ portions of fruit and vegetables a day can reduce your risk of stroke up to 30%.
- Choose whole grain carbohydrates over simple and processed carbohydrates.
- Cut down on full-fat milk, cream, cheese, fatty meat, processed meats, and takeaways.
- Limit salt intake. Be aware of hidden salt that can be found in frozen meals and as preservatives in 'off the shelf' foods.
- A dietitian can give you advice on healthy eating if you are unsure of what to eat, need to lose weight, or have diabetes. Your doctor can refer you to one.

#### WEIGHT MANAGEMENT

Controlling your weight is an important way to lower stroke risk. Excess pounds strain the entire circulatory system and conditions, including high blood pressure, diabetes, high cholesterol, and sleep apnea.

Losing as little as 5% to 10% of your starting weight can lower your blood pressure and other stroke risk factors.

#### **Managing a Healthy Weight**

Exercise is great for your health and can help you keep a healthy weight. It also plays an important role in reducing your risk of stroke and can improve your overall wellbeing.

Regular exercise can help lower your blood pressure and help you maintain a healthy weight. Research shows that regular moderate exercise can reduce your risk of stroke by 27%.

## Changes & Complications Following Stroke

#### COMPLICATIONS

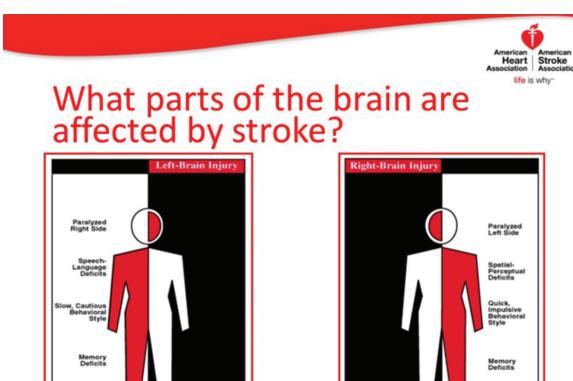
Every stroke is unique, but strokes tend to affect people in common ways. Depending on the intensity of the stroke, you may have major or minor difficulties that are sometimes temporary or possibly permanent.

#### **Common Stroke Complications**

- **Brain Edema:** Swelling of the brain
- **Pneumonia:** A stroke can cause breathing problems. Pneumonia can occur as a result of not being able to move after a stroke. Swallowing problems after stroke can sometimes result in food or liquids going into the lungs. leading to aspirational pneumonia.
- **Urinary Tract Infection (UTI):** This can occur as a result of having a foley catheter placed to collect urine when the stroke survivor cannot control bladder function.
- **Seizures:** Abnormal electrical activity in the brain causing convulsions. These are common in larger strokes.
- **Clinical Depression:** A treatable illness that often occurs with stroke and causes unwanted emotional mood swings.

#### **Functional Changes**

Depending on what part of the brain is affected by the stroke, you may present with some of the following deficits:



## Identifying Signs & Symptoms of Stroke

# Spot a stroke F.A.S.T.



**Face Dropping:** Ask the individual to smile, and identify if their face is drooping on one side. Does their face feel numb?

**Arm Weakness:** Ask the individual to raise both arms to identify if she or he has weakness on one side of their body. Does one arm drift downward?

**Speech Difficulty:** Ask the individual to speak a simple sentence to identify if it is hard for them to speak or if their speech is slurred

**Time to Call 911:** If an individual has any of the symptoms mentioned above even if they go away, call 911 as soon as possible because every minute matters!

The American Heart Association also asks individuals to look out for the following stroke signs and symptoms in addition to those included in FAST:

- Confusion or trouble understanding
- Trouble seeing out of both or one eye
- Trouble walking, loss of balance, and coordination
- Dizziness
- Sudden severe headache without no known cause
- Sudden weakness or numbness of leg

## Post Stroke Medications

As a stroke survivor, you may leave the hospital or rehab with at least one medication and possibly more new medications which can be surprising and cause confusion.

Follow the healthcare team's recommendations. Take your medications as prescribed. Complying with the medications reduces your risk of another stroke. It may take time to adapt, especially if you have not been on medication before. Never quit taking a prescribed medicine without talking to your healthcare provider first. They can work with you to minimize difficulties with any of your medicines.

Understand the purpose and potential side effects of your medications, both prescribed and over the counter. Get to know the risks of not taking your medications as directed. Be mindful of your recovery and the role of the medications.

#### **COMMON MEDICATION THERAPIES**

Anti-platelet medications work to prevent a stroke by improving blood flow. When we get a cut, platelets in the blood release a chemical that signals other platelets to form a clot, closing the wound with a scab. Anti-platelet medications limit the release of that chemical signal, preventing platelets from clotting as easily. Anti-platelet medications including aspirin, clopidogrel, dipyridamole, and ticlopidine allow blood to flow more easily.

Your healthcare provider may prescribe aspirin or other anti-platelets, alone or in combination, to help prevent clots from forming in the blood vessels and causing another stroke. Your provider will determine the right dose and combination of medications for you based on several considerations, including your particular risk factors.

Anticoagulant medications work by interfering with the production of clotting factors made in the liver. Because of this, your healthcare provider must test your blood as often as every six weeks,

to check the effect of the medications on the liver. Your healthcare provider will adjust dosage amounts based on these tests. Anticoagulant medications include Warfarin and Heparin. These medications work to decreased blood clotting, but not to prevent clotting completely.

Warfarin patients need to adjust their diet and intake levels of certain foods high in Vitamin K, including cabbage, cauliflower, spinach, and other leafy green vegetables. Vitamin K can affect the ability of Warfarin to do its job. Your physician may recommend avoiding foods high in Vitamin K entirely when on Warfarin.

Newer anticoagulants, such as Rivaroxaban, Apixaban, Edoxaban, and Dabigatran, provide a simpler treatment as they do not require frequent blood tests.

Each stroke is unique. Your healthcare provider will create a medication regimen unique to you. Keep records of your medication schedule and follow the regimen.

#### **STATINS**

Statin medications work in the liver to prevent cholesterol from forming. Development and buildup of cholesterol in the blood vessels can narrow the vessels, particularly in the brain. This buildup is called atherosclerosis, (i.e. hardening of the arteries) and high levels of cholesterol in the blood may contribute to ischemic strokes.

Several medications lower cholesterol levels. However, many healthcare providers recommend statins for patients because they significantly reduce the risk of a stroke.

#### **BLOOD PRESSURE MEDICATIONS**

Blood pressure medications can treat high blood pressure (HBP), a risk factor for recurrent stoke and other cardiovascular conditions. Many types of HBP medicines work in different ways to reduce your blood pressure. It may take more than one medication with many changes in dosage before your blood pressure becomes controlled. Take your blood pressure medications consistently. Talk to your doctor about getting a blood pressure regimen that you can perform every day. Be sure to monitor your blood pressure regularly at home, and report it to your healthcare provider.

#### **DEPRESSION MEDICATIONS**

You may experience a depressed mood after a stroke. Many stroke survivors report symptoms of depression. Estimates on the incidence of post stroke depression vary. However, when you experience depression after a stroke, it can prevent participation in daily activities, therapy, and impact recovery.

Physicians may use antidepressants, including selective serotonin reuptake inhibitors (SSRIs) to treat depression. Small trials have demonstrated that SSRIs might improve muscle motor recovery after stroke, in addition to mood recovery (Mead, et al. 2012).

#### **FOLLOW THE PLAN**

Take your prescription medications only as directed. Your healthcare provider prescribes medications in the specific dosage and times that scientific research has shown them to work best. Always discuss any deviation from these instructions with your healthcare provider. Do not assume that taking more will increase the effect or taking less will give you the same result with fewer side effects. Never stop a long-term medication unless advised to do so by your healthcare professional.

You can avoid many side effects by taking the drug at a certain time of day. For example, if a medication makes you sleepy, take it at bedtime to assist with sleeping. Drugs can also be absorbed differently if taken on an empty stomach or with food. Even with full understanding of the purpose and benefits of post stroke medications, you may experience challenges taking the medications as directed. Review your new medications with your pharmacist, and report the side effects to your physician (Caswell, 2017).

## **Swallowing, Communication, & Cognition**

Stroke survivors will often receive speech therapy services. A Speech Language Pathologist (SLP) will work to improve communication, cognition, speech, and swallowing after your stroke. Each of these abilities is controlled by a different part of the brain. The area of your stroke damage will determine which of these abilities may be difficult for you. The SLP will prioritize care based on the severity of your deficits and quality of life concerns.

#### **SWALLOWING**

Many stroke survivors will have swallowing problems. Reduced swallowing ability is known as dysphagia. A person who has swallowing problems may have facial droop, reduced ability to chew, tongue weakness and problems with food remaining in their mouth. Your stroke may cause weakness to your throat muscles and increase your aspirational risk. Aspiration is defined as food or liquids going into the lungs. Noticeable signs of aspiration can cause sudden coughing, hoarse voice, or wheezing, Aspiration can possibly cause a form of pneumonia. This type aspirational pneumonia can be a life threatening medical issue.

A bedside swallowing evaluation and a Modified Barium Swallow Study (MBSS) may be completed. These evaluations assess the following abilities:

- Chewing
- How food is controlled inside the mouth
- How food is moved to the back of the mouth
- Initiation (trigger) of a swallow/delay of swallow reflex
- Residue of bolus (small round mass of chewed food)/liquid
- Aspiration into the lungs and silent aspiration (aspiration with no signs such as coughing)

The SLP may recommend a modified diet to allow you to eat with reduced risk of aspiration or choking. Your diet recommendation is also based on your attention, fatigue, dentition (how

many teeth you have, how teeth are arranged in your mouth, dentures, etc.), and issues of low oral intake (amount of food or liquid the individual is able to take in by mouth).

The SLP will often teach functional dysphagia strategies to improve swallowing and increase oral intake. These swallowing strategies often include the following:

- · Sit upright for all meals
- Big Chewing
- Small bites and sips
- Alternate bites of food and sips of liquids
- Use of a hard swallow
- Monitor for food left in mouth
- Use of chin tuck or chin in neutral position

# PERCUTANEOUS ENDOSCOPIC GASTRONOMY (PEG) TUBE

If your swallowing is severely impaired or you are clearly aspirating, a PEG may be recommended. The PEG is a feeding tube inserted into the stomach to allow liquid nutrition to be given. The SLP will continue to perform swallowing treatments after PEG placement. The Physician, Dietician, and SLP will work closely together to make decisions regarding nutritional choices and swallowing safety.

Most patients recover their ability to swallow and take food orally (via their mouth). It is a process of recovery that is based on your improved attention, cognition, and swallowing ability. You and your caregivers may undergo training for strategies to improve swallowing in order to achieve the ability to eat a regular diet and drink normal liquids again.

#### SPEECH AND VOICE

Based on the location of the stroke in the brain, your voice may be impaired or have less clarity. You may show a reduced vocal loudness, hoarse voice, or slurred speech. The SLP will work with you on improving articulation, vocal quality, and respiratory (breathing) support. With speech therapy, you have an excellent ability to regain clear and normal speech.

#### **APHASIA**

Aphasia is the loss of your ability to understand language as well as express language caused by brain damage from your stroke. If you have experienced aphasia, you may have trouble understanding language (receptive aphasia), verbalizing language (expressive aphasia), reading, writing, and completing math. Certain areas of the brain (usually in the left side of the brain) can influence your ability to communicate and understand language.

#### **Effects of Aphasia:**

- Trouble speaking or no ability to speak
- · Reduced ability to verbalize needs and wants
- Non-sensible speech
- Poor ability to nod/shake your head to express yes or no correctly
- Trouble finding words
- Problems understanding what others say to you
- Reduced ability to understand complex words and sentences

Your SLP will work with you to regain your language abilities or to develop new ways of communicating. The severity of aphasia may vary from person to person. You may have some emotional changes related to your reduced ability to communicate. Frustration, disappointment, and anger may be common emotions. The reduced ability to communicate needs and wants is hard on you and your family. You are encouraged to share these feelings with your SLP, your physician, and a counselor. Your family members will receive training in techniques and strategies to improve your language abilities. Be encouraged!

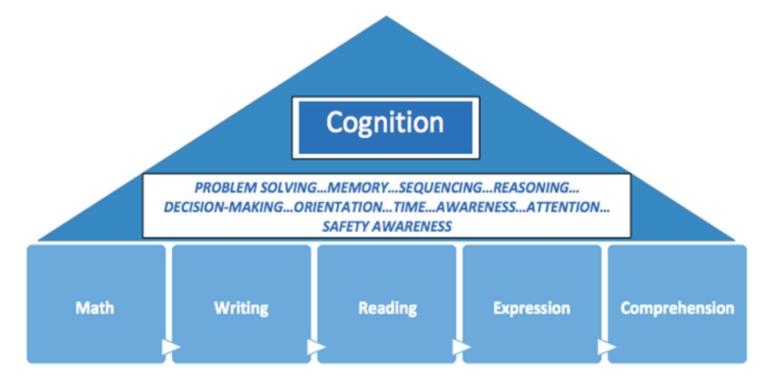
#### MEMORY AND COGNITION

The five language areas of understanding, math, writing, reading, expression, and comprehension serve as a base (the pillars) for your memory and cognition. Cognition is the mental action or process of acquiring knowledge and understanding through thought, experience, and senses. You may experience a loss of memory and cognition. Your memory and cognition are the abilities that serve as an "umbrella" over the language areas that allow you a high level of thinking and understanding for you to do activities safely and efficiently.

You may experience reduced ability to maintain attention after a stroke. You may have difficulty understanding directions. You may not remember things quickly. You may be impulsive and do things too quickly. This reduced cognition may cause you to have reduced problem solving ability and decreased safety awareness. You may show reduced ability to follow steps in the correct order for activities of daily living. For example, you may try to take off a shirt before unbuttoning it first. You may also show reduced understanding of cause and effect. For example, if I walk without my walker, I may not realize this is unsafe, and I may fall. The SLP will work with you on improving your memory and cognition.

#### Tools to improve memory function:

- Use self-talk to remember to do something
- · Repeat what is said or ask for clarification
- Focus on one task at a time
- Practice a new task over time
- · Go slow and take your time
- Monitor fatigue as you are less likely to remember things when tired
- Use a consistent routine and schedule
- Use visual aids like a clock, dry erase board, or written schedule
- Use a pill box for medication management
- Have a consistent place for things
- Use a day calendar for planning activities
- Use a notebook and take notes



## Caring for Your Arms & Legs

#### MANAGING YOUR AFFECTED ARM

If you have an affected arm with limited movement and strength, you must protect your arm after a stroke to prevent pain and further injury.

#### **POSITIONING**

- · Never let your affected arm hang freely.
- Support your arm on your lap or on a surface such as armrest, chair, lap tray, etc.
- You may need to use a sling to prevent your shoulder from dislocation (shoulder subluxation) especially when walking or moving between different surfaces such as from bed to a chair.

#### **ARM SWELLING**

- Keep your hand above your heart to prevent fluid from building up in your arm:
  - Use a lap tray or a specialized arm trough when seated in a wheelchair to keep your arm elevated.
  - Use pillows under your arm while sleeping.
     Pillows may be more comfortable for elevating your arm.
- Compression gloves/sleeves may be used to prevent swelling.
- Swelling can prevent your ability to move your arm.

# INCREASED MUSCLE TONE (Muscle Tightness or Tension)

- When you have increased tone, the muscles in your arm or hand become tight and may be harder to move.
- Use your affected arm as much as you are able to keep your joints moving.
- Doing slow movements are better than fast movements.
- Splints may prevent a contracture in your arm/ hand as you recover. Contracture means a

permanent inability to move a joint due to tight muscles that have shortened.

#### **SWELLING PREVENTION**

- Swelling can be common after experiencing a stroke, especially in your arms and legs.
- After doing exercise or sitting up for a long time, it can be good to elevate your legs to prevent swelling.
- Wearing compression socks on your legs can help keep swelling from accumulating in your feet, ankles, and lower legs.

#### PREVENTING BLOOD CLOTS

- Preventing blood clots is very common after a stroke. If a clot forms, it can travel through your veins and to other areas such as your lungs or brain causing serious damage or possibly another stroke.
  - Wearing TED hose or compression socks on your legs can help prevent clots in your legs.
  - Exercise is also a good way to prevent clots because your muscles act like a pump that helps your blood flow better.
    - Ankle pump exercises provide an easy way to keep your blood flowing.

## **Helping You Move**

#### **BED MOBILITY**

Bed mobility involves moving to/from a lying position in bed to sitting up at bedside. It also involves rolling and scooting in bed for comfort. Your therapist can show you the safest way to do this as it may differ based on your individual strengths and deficits. One the most effective ways is rolling on to your side and sitting up. This helpful way allows you to use your stronger side to control your body. Bed rails may also be beneficial with bed mobility.

#### **TRANSFERS**

Transfers involve moving from one place to another such as from bed to a chair or from a wheelchair to a car.

- Your therapist will show you the safest way to transfer.
- Practice this with your caregiver as much as needed.
- As much as possible, transfer towards your stronger side so that you can use your nonaffected arm to reach for your target.

Always wear shoes or non-slip socks when transferring or standing up so that your feet do not slip out from under you.

#### **WALKING (AMBULATION)**

- Your therapist will practice this with you based on your abilities.
- Always use your assistive device (e.g. walker or cane) when you are walking, if your physical therapist (PT) instructs you.
- Pay attention to objects around you while you are walking, so you do not fall. As much as possible, try to keep floors clear of clutter and rooms well lit to eliminate tripping hazards.
- Pay attention to changes in ground surfaces and move slowly and cautiously.
  - Every surface has its own set of obstacles.
    - For example, tile can have grooves that can catch on your assistive device or toe, and carpet can be thick and hard to walk over. The edge of a large area rug can curl up and cause you to catch your foot on it and trip.
  - The area where one surface leads to another can often be hard to see or have a slight incline that can catch on your toe or assistive device. If this is hard to see, adding a colored or reflective piece of tape can be a good way to remind you to pay attention when you are walking over that area.

#### **ASSISTIVE DEVICES**

As a stroke survivor, you may require a device to assist you with walking safely. Many devices provide support and assistance. Your therapist will help you decide which assistive device is best for you based on safety and your abilities. During therapy, you will practice with the assistive device to improve your ability to walk.

#### **Types of Assistive Devices**



**ROLLING WALKER** 



**PLATFORM WALKER** 



4 WHEEL WALKER



SINGLE **POINT CANE** 





**HEMI WALKER** 

#### **ANKLE FOOT ORTHOSIS (AFO)**

This item helps those who have trouble clearing their foot when they walk.

- The AFO is placed under your foot and around your calf for support when you are moving around. It should be worn with a sock and shoe.
- AFO's can be bought as a standard size off the shelf or they can be molded to your foot by a professional. They are made from plastic and metal materials as well.

Speak to your physical therapist (PT) about whether an AFO may be beneficial for you.

#### **WHEELCHAIRS**

Wheelchairs can be helpful for getting around in your home or out in the community. Ask your therapist if a wheelchair is a good option for you!

- Talk to your therapists about the layout of your home. Your home may not be wheelchair accessible if you have narrow doorways. Ask to have a home evaluation to prepare your home before discharge.
- Use a wheelchair out in the community to help you conserve your energy.

#### **Wheelchair Management**

- Have your therapist assess your wheelchair if you plan to use one.
- A good fitting wheelchair fit is key to increasing your comfort and helping to prevent unwanted pressure against areas of your body, especially on areas where your skin is thinnest or bones are prominent.
  - Adding an appropriate cushion based on your particular needs can help you be more comfortable in your wheelchair.
  - Pressure relief is also key to prevent skin breakdown from sitting for too long.
     Discuss with your therapists whether you will need help doing this.

#### **GOING UP AND DOWN STAIRS**

Going up and down the stairs can be tricky. Practice with your physical therapist (PT) to find the safest way to use the stairs.

Stairs can come in many forms. There can be several stair steps, flights of stairs, stairs with handrails, stairs without handrails, curbs, threshold steps leading from one room to the next, or threshold steps to enter into a doorway.

- Use the handrails whenever possible to help you with balancing.
- An assistive device (such as a cane or walker)
  is helpful to use when going up or down a curb
  or threshold step.
- Go up the stairs, leading with the strong leg.
- Go down the stairs, leading with the weak, affected leg.

#### **SERVICE ANIMALS**

Service dogs can be trained to help you after having a stroke by assisting with mobility. A well-trained large dog can help keep you steady. A service dog can encourage you to get up and walk. Service dogs can pick up an item from the floor or fetch an item. A dog can also provide companionship for you if you live alone or do not leave the house often. Note that service dogs can be expensive and waiting lists can be long.

If interested in finding out more about service animals, look at the Assistance Dogs International (ADI) website which lists ADI accredited organizations and locations.







ELECTRIC WHEELCHAIR

# Self Care: Activities of Daily Living (ADLs)

#### **SELF-FEEDING**

- Utensil Ideas:
  - Use utensils with larger, built up handle grips when you have limited hand strength.
  - Weighted utensils can increase the stability of your hand when you have shaky hands or tremors.
  - Rocker knives allow you to cut food one handed.
  - Swivel utensils help to keep food on the utensil if your hand is shaky or if you have impaired coordination.
  - Curved utensils help to get food closer to your mouth if you have limited movement in your arm.
- Plate guards and high sided or scoop dishes help with getting food onto the utensil and prevent spilling food on the table when you have limited hand movement.
- Other items to assist with self-feeding:
  - Non-skid rubber coated dishes or mats can stop your dish from moving around.
  - Bottles or cups with lids and handles can prevent spilling liquids.
  - Universal cuff can make feeding yourself possible when you are unable to hold a utensil in a typical way.

Please work with your occupational therapist (OT) in identifying the best items for you to use to feed yourself more independently.

#### **Examples of Adaptive Utensils**



ROCKER KNIFE



CURVED SPOON WITH BUILT-UP GRIP



SWIVEL FORK



WEIGHTED FORK WITH BUILT-UP GRIP

#### **DRESSING GENERAL TIPS**

- Get dressed while seated if you have good sitting balance. If not, you can get dressed while lying down in bed.
- It is easier to put on and take off clothing on your affected side first.
- Knit fabrics wrinkle less than woven fabrics.
- Clothing made of or lined with slippery fabrics are easier to put on then unlined garments.
- Longer strings or rings can be added to zipper pulls to for easier use.
- Snaps and Velcro straps are easier to use than buttons and shoelaces.
- Label clothing such as shoes boldy with "R" for right side or "L" on left side if you have difficulty placing your limbs in the correct side of the clothing.

#### **LOWER BODY DRESSING**

- When putting on pants and underwear, cross your affected leg over your unaffected leg first and then place the pant leg and/or underwear opening onto the affect leg. Do the same for your stronger leg. Lastly, stand to pull up underwear and pants. Hold on to a grab bar or a sturdy surface such as counter for balance and to steady yourself.
- You can put your foot on a stool or box while putting on shoes/socks.
- Shoes without shoelaces are easier to manage.
   Elastic shoelaces (available in all colors online)
   do not require tying but can allow the shoe to
   stretch when putting it on but also give a snug fit.
- Lower body clothing with elastic waistbands are much easier to put on than clothing with zippers and buttons.

#### **UPPER BODY DRESSING**

- Practice buttoning/unbuttoning a shirt on your lap first.
- Button a shirt (or jacket) from the bottom up.
- Use clip on ties as an easier option for a formal event.
- Use front closing or pull over bras that are easier to fasten than back closing bras.

Other adaptive tools such as a buttonhook, reacher, dressing stick, sock-aid, and "Bra Angel" (a device to help you fasten a bra from the front) can help with getting dressed if you need more assistance.

Please work with your occupational therapist (OT) in identifying the best method for you to get dressed and obtaining appropriate items as needed.

#### **BATHING**

Your risk of falling increases when you bathe due to the wet, slippery surfaces.

- Have someone close to assist with bathing for safety.
- Take a shower instead of a bath because you do not have to get up and down from a low tub surface.
- Check the temperature of the water before getting into your bathing area. If you cannot identify if the water is too hot or cold yourself, have someone check and set the water temperature for you.
- Use a shower chair or tub transfer bench to sit while bathing. A tub transfer bench can help with getting in and out of a tub without having to step over a high surface but it can be used in some larger walk-in showers.
- When getting in and out of walk-in showers and tubs, use grab bars to further help you to steady yourself during bathing tasks.
- To direct the flow water with more ease while seated for bathing, use a handheld showerhead.
- Non-skid rubber mats or bath mats with suction cups can be used in the shower or tub to prevent a fall.
- Wear slippers or socks with non-skid bottoms (such as hospital socks) to prevent a fall after bathing.
- A long handle sponge can allow you to wash hard-to-reach places.
- Bath mitts can allow you to wash body parts when you have limited arm and hand movement.
- When you are washing your stronger side while seated, it may be easier to place a soapy washcloth in between your legs and move your arm back forth over the washcloth.
- If drying off after bathing is too tiring, use a terry cloth robe to dry skin instead.

#### **TOILETING**

If you are unable to install grab bars near your toilet, place a bedside commode over your toilet (without the bucket or bottom container) or get a toilet safety rail to assist with getting on and off the toilet.

If you are unable to wipe after voiding due to not being able to reach far enough behind you, you can use a long handle toileting aide that holds toilet paper or a wipe at the end. Bidet toilet seat can also help to clean your private area.

Please work with your occupational therapist (OT) in identifying the best items for you to use the toilet safely.

#### HANDLING INCONTINENCE

Bowel and urine accidents happen and are unavoidable. Here are helpful things to consider:

- Add a bedside toilet or commode next to your side of the bed, so you can relieve yourself quicker without going to the bathroom.
- Keep this toilet in a closet during the day, so visitors will not see it.
- Get waterproof pads to place under bed sheets.
- Get furniture covers to put over the waterproof pads or use plastic covers to protect furniture that you frequently use.
- Keep a clean set of clothing for the stroke survivor in all bathrooms.
- Get car seat covers to hide blue pads in vehicles.
- When taking a patient out of house, plan for a longer travel time to allow for frequent bathroom stops.
- Use disposable underwear or protective underclothing.
- When taking longer trips outside the home, bring a small carry-all or suitcase packed with extra clothes.
- Keep a spare set of clothes in the car at all times for emergencies.
- Keep a spare set of clothing at places where you may visit regularly, such as homes of family members or friends.
- Keep packaged hand wipes and liquid hand sanitizer handy.

#### OTHER PERSONAL CARE ACTIVITIES

#### **Cleaning Teeth**

- Toothpaste tubes with flip tops are easier to open when you have limited hand movement.
- Tooth flossing aides can further assist with cleaning teeth.
- If it is hard for you to grip your tooth brush, build up the handle of the toothbrush with tape.

#### **Shaving**

- Use an electric shaver to remove hair from your face, underarms, and legs with less effort.
   Electric shavers are particularly recommended for those who are on blood thinning medication.
- When using a standard razor to shave your face, puff your cheeks out.
- It may be easier to shave your legs on an elevated surface such as in bed to prevent bending down and losing your balance.

#### **Hair Grooming**

- Use a wall mounted hair dryer or a hair-drying stand.
- Sit to complete hair-grooming tasks to prevent getting tired.

#### **Other Toiletries**

Use pump or roll on bottles for deodorant, lotion, body wash, shampoo, conditioner, etc. as they are easier to use than squeeze bottles or bottles with screw tops.

Please work with your occupational therapist (OT) in identifying the best items for you to use for grooming tasks.

## Sex after Stroke

Sex is a healthy part of life. It can be enjoyed in a safe way after having a stroke. Studies have reported that as many as half of patients and their partners experience dissatisfaction with their sexual life after stroke. Sex can be adapted after stroke just like every other activity using safe positions and methods to enjoy sex after stroke.

It is very common to have tightness (see the spasticity and tone section) after having a stroke. This tone may limit the positions you can get into comfortably. Perform gentle stretches prior to participating in sexual activity, so you can be most comfortable.

Always consider your balance. If your arm or leg has been affected by the stroke, position yourself in a manner that supports those areas. Speak to your occupational therapist (OT) and physical therapist (PT) about finding a position that is safest for you. They will be happy to share ways to keep you safe and healthy.

Remember to take your medication as you normally would when participating in sexual activities!

If you have any questions at all about how to perform sex safely, please ask your Occupational therapist (OT), physical therapist (PT), and/or you doctor for safe ways you can do this. They have knowledge that can help you find what is best for you and your partner.

## Preparing for **Discharge**

Discharge planning actually starts the day of admission!

The Peterson Regional Medical Center's Acute Rehab Unit (ARU) staff assists in planning your discharge to help you experience a trouble-free transition to a new level of care. You and your caregiver will be involved in the plan. Going home depends on your ability to move around, communicate your needs, follow medical advice, and care for yourself. Family and loved ones should help when needed.

#### **ARU Discharge Planning involves:**

- Determining your functional ability and how much you can do for yourself
- Providing caregiver training or other support to your caregiver
- Making referrals to a home care agency, outpatient therapy, or community agency when needed for further treatment and resources
- Scheduling follow-up appointments or tests
- Discussing other resources/services you and your family may need after leaving the hospital. It is important to consider how much care will be required for you and your family's finances when determining appropriate care, items, and services needed post-discharge.

On the day of discharge, the nursing staff will provide a packet of all the information you will need to ensure a smooth transition to home.

#### **Discharge Packet Information will include:**

- Your medical and functional status
- Activities you might need help with
- Medications, prescriptions, and the pharmacy where they were filled
- A safe diet for your condition
- Extra, required equipment
- Referrals to post-discharge appointments and physicians

## Just for Caregivers

Caregivers provide day-to-day help for stroke survivors. Everyone involved in helping a person who has survived a stroke is a caregiver. It can be a spouse, family member, or friend. It can also include an employee of an agency. Often one person will provide most of the care. As a caregiver, strive to partner with your stroke survivor in their recovery. Although challenging, the change in roles can produce highly effective results in recovery. Share decision-making as much as possible. Try to share your feelings honestly without taking anything personally.

#### WHAT SHOULD A CAREGIVER DO?

Your stroke survivor's condition will determine how much care you will have to provide. Rehab therapists will train you on how to assist your loved one with daily activities and mobility. They will also provide home safety and fall prevention education. Nurses will provide education on medication and blood pressure management.

Social workers will further provide resources for medical equipment and further caregiver assistance (e.g. respite care and private caregiver agencies) to ensure a smooth transition to home post-discharge.

As you become more involved in your survivor's training, you will learn the skills you need to support the survivor and understand their new needs. It is recommended to monitor the stroke survivor's fatigue levels during activities, keep a record of symptoms, and note their mood.

Be willing to ask for help from other support systems and use the resources in your community.

#### **Common Responsibilities of Caregiving:**

- Coordinate health care appointments.
- Monitor and/or give medications.
- Provide help with the survivor's self care and grooming.
- Provide transportation.
- Manage financial, legal, and business affairs.
- Manage home responsibilities and meals.
- Help the survivor maintain functional skills learned in rehab
- Work to improve participation in daily activities.
- Provide emotional support for the stroke survivor and family members.
- Encourage the stroke survivor to continue working toward recovery and to be as independent as possible.

#### ASSISTANCE FOR CAREGIVERS

Many people find caring for another person very rewarding, but there may be times when a stroke survivor's needs are too much for you. Sometimes you just need a break. These community resources may be helpful:

- Home Health Aide Service: In home personal health care assistance
- Adult Daycare: Professional supervision of adults in a social setting during the day
- Meal Programs: Meals on Wheels is a federally sponsored nutrition program, but there are other meal programs.
- **Homemaker Assistance:** Supervised, trained personnel who help with household duties
- Respite Care: People who come into the home for a limited time to give caregivers a break.
   Some nursing homes also provide short-term respite care.

# WHAT CAN CAREGIVERS DO TO RECAPTURE LANGUAGE?

- Use gestures and visual aids when you speak.
- Ask only one question at a time.
- Ask yes or no questions.
- Give the survivor time to respond.
- Always assume that the survivor with difficulty understanding and expressing language can hear and understand what you are saying and doing.
- Reduce distractions and noise to help the survivor understand and communicate.
- Encourage all types of communication: speech, writing, drawing, gestures, choices, facial expressions.
- Encourage socialization and avoid isolation.

# WHAT CAN CAREGIVERS DO FOR ENERGY CONSERVATION?

- Note the time of day when energy is higher for the survivor and assist the survivor in planning activity around that time.
- Reduce stimulation such as noise, lights, and other distractions.
- Change your expectations of the stroke survivor.
- Be aware and responsive to the actions of the survivor.
- Be patient!

# WHAT CAN CAREGIVERS DO FOR EMOTIONAL EFFECTS?

The shock of the stroke and all its changes can take a serious, immediate, and emotional toll. Your loved one's level of daily independence has completely changed; and hope for recovery may seem distant and frustrating.

Be patient and sympathetic with both yourself and your loved one. Your survivor may experience a sort of personality shift, due to both changes in the brain and the emotional weight of what has taken place. Both laughter and tears may seem to emerge out of nowhere. This can be shocking at first, but remember that both the physical and emotional areas of the brain may have been affected by the stroke. Your loved one is still there, despite confusing changes.

The repetitive nature of post-stroke rehabilitation can lead to early burnout, but the mind is a powerful tool. Prevent emotional fatigue by incorporating personal interests into the stroke rehab routine. Play your loved one's favorite music during their rehabilitation time, or utilize family photos for exercises that involve writing or moving objects around a table. Blend rehabilitation tasks with recognizable items, such as organizing favorite personal items into a box, helping to prepare a favorite meal together, or engaging in a game, all while using the affected arm as much as possible. This acts as a reminder that you are moving toward independence and familiarity with each day.

## **Household Chores** & Other Activities

#### **GENERAL TIPS**

- Use a walker basket or tray to transport items needed for activities around the home.
- Complete home management tasks seated as much as possible.
- Clearly label items with big letters, bold colors, bump dots, or other tactical markers if you have difficulty seeing small print after your stroke.

#### **LAUNDRY**

- Wash smaller loads to avoid moving large, heavy laundry baskets.
- Use a rolling laundry basket or a backpack to transport items that need to be washed.
- If your balance is good enough, you can carry your laundry by hand.
- If you are using a walker and want carry heavier or bulker items, use a large plastic bag (such as one you would get from a clothing store). Place one plastic bag strap around one hand grip of your walker and the other plastic bag strap around the opposite hand grip of your walker. The bag should drape over the outside of the walker for you to drop items in easily.
- Once you have reached your laundry destination, place your laundry container on top of your appliances or near them on another elevated surface such as a chair or stool.

#### **CLEANING**

- Instead of hand washing dishes, use a dishwasher.
- Load the dishwasher while seated.
- Use disposable dishes and utensils to avoid washing dishes.
- Use community resources, family, and/or friends if able to help with cleaning tasks around the home.

#### COOKING

Prepared meals such as Meals on Wheels, microwavable meals, or meals prepared by family/ friends are easier if you get tired quickly from making your own meals.

Watch out for hot surfaces and items to avoid burns/injuries. It may be harder for your weaker side to feel heated surfaces and items.

#### Items that can assist with cooking:

Electric appliances, such as an electric can opener, are easier to use but may require both hands for proper use.

#### Tools that only require the use of one hand:

- Easy Squeeze® can opener
- Solo Grip® non slip jar opener or panda grip jar opener
- Adaptive cutting boards
- Home craft clamp-on vegetable peeler

#### **OPENING APPLIANCES**

To open the **refrigerator**, move your walker to the side of the door you want to open. While staying inside of your walker, use the hand closest to the handle to open the door. To collect items, you may need to move yourself and walker closer to the area so you can reach items safely before the door shuts.

To open an **oven or dishwasher**, move your walker to side of the appliance. While staying inside of your walker, put one hand on the counter or a non-heated surface to support yourself and use the opposite hand to open an appliance door from the side.

When using the **sink or stove top**, stand directly in front while staying inside of your walker.

Please work with your occupational therapist (OT) in identifying the best items and techniques for you to complete in-house home management tasks safely.

#### YARD WORK

- Do not work outside when it is really hot or cold.
- Avoid using motorized lawn tools and equipment such as an edger or lawnmower.
   They may not be safe for you to use due to their fast and powerful movements.

#### **PETS**

- To prevent falling, do not let pets jump on you or walk close to your feet.
- Interact with pets while seated to prevent falling.
- Use a long handle poop scoop to prevent bending down when cleaning up after your pets.
- Ask a family member or friend to walk your dog if they are likely to pull on their leash.

Please work with your occupational therapist (OT) in identifying the best items and techniques for you to complete yard work and for you to interact with your pets safely.

# SPENDING TIME WITH YOUNG CHILDREN

- To prevent falling, do not let children jump on you while standing.
- Hold babies only while seated.
- Instead of playing games on the floor, play them while seated at a table.
- If you are going to interact with young children on the floor, make sure you can get up safely or get assistance from someone.

Please work with your occupational therapist (OT) in identifying the best items and techniques for you to interact with younger children safely.

#### **MONEY MANAGEMENT**

It may be harder to manage your money after your stroke due to memory loss and vision changes.

- To help you remember, keep your financial records, such as bills, receipts, etc. in easy to reach places. Keep a calendar of when bills are due regularly.
- Mobile apps or websites (such as Mint, Prism, or BillGuard) may help you to manage your money, if you are comfortable using them.
- It might be helpful to consolidate multiple bills into one payment or credit card bill each month.
- Most credit card issuers and banks have credit monitoring tools, budgeting assistance and other helpful resources.

## **Home Safety**

#### **FLOORS**

- Remove throw rugs and mats at sinks; instead, bolt down any area mats or rugs if you must have them and put down anti-slip bat mats when needed.
- Remove clutter such as cords and other objects from the floor to prevent tripping and causing a fall when walking.
- Secure carpet or treads on stairs.
- Be alert when walking across changes in floor surfaces such as between carpet, tile, and wood flooring.

#### **FURNITURE**

- Remove furniture with low seating surfaces as it is much harder to rise from a lower surface.
- Use chairs with armrests to make it safer/ easier to sit and stand. Reach back for the armrest when sitting and push off from them when rising to stand.
- It may beneficial to have chairs with armrests in the rooms where you spend a lot of time, such as the kitchen, bedroom, and living room.
- Do not use chairs with wheels or casters unless the chairs with wheels can be locked such as a wheelchair. Chairs that roll and do not have breaks may slip away from you, causing a fall.

#### STAIRS, RAMPS, & LIFTS

- In a two story home, move your bed to the first floor to eliminate frequent stair climbing, if possible.
- If you cannot go up/down stairs safely, consider putting a ramp in place of stairs or installing a mechanical chair lift for the stairs.
- General guideline for a safe ramp is 1 foot for every 1 inch of height.

#### **GRAB BARS**

- Metal grab bars designed to bear human weight is an option for use in your bathroom to help with balance. Grab bars can help you with sitting down or standing up from surfaces such as a toilet in your bathroom.
- Avoid using suction cup grab bars. Suction cup grab bars can be unsafe and have the potential to be positioned improperly to the wall. They are unpredictable and may come off a wall surface especially a tile surface when you are using it.
- Place grab bars on walls and/or floors at a height you would be naturally reach for comfortable. For example, while seating in the shower, reach out in front of you and to your side. Measure the height from the floor to the location of your hand. This is the preferred level to place you grab bar.

# TRANSPORTING ITEMS WITH A ROLLING WALKER

When using a rolling walker, it is important to keep both hands on the walker every step of the way. **Do not carry items in hands while using a walker**.

- Use a walker basket or tray that can connect to outer surface of the walker to transport items around the house or when out in the community.
- You can also drape small, light items over your walker (like clothing) or hang a large plastic bag over your walker to transport bigger items for short distance such as to a laundry area from your bedroom in your home. If these items are too long or affect you ability to walk safely, do not drape them over you walker.
- More pressure on one side of the walker can cause the walker to tip over. Distribute weight over your walker as evenly as possible.

#### **LIGHTS**

- Make sure areas are well lit.
- Turn on lights before going into a room.
- Use nightlights to provide a visible path to the bathroom at night.

If there is ever a doubt in your mind whether you are able to do something – DO NOT RISK IT! Ask for help first, and then practice that task with your occupational therapist (OT) and/or physical therapist (PT) to ensure it will be safe for you to do alone.

If possible, it may be beneficial to have your therapist(s) assess your home environment and give you tips about changes that can be made to make sure your home is as safe as possible for you.

## Feeling Tired After a Stroke

After your stroke, your brain and body are healing. The recovery process takes up a lot energy, so it is normal to feel tired or fatigued. Fatigue can affect you both physically and mentally. Symptoms can include difficulty with self-control, emotions, and memory.

Some stroke survivor's feel tired even after a good night's sleep. Often times, the fatigue occurs without warning and makes it harder to do daily activities. You may feel like you have to work harder to make up for the loss of normal functions.

#### WHY AM I SO TIRED?

Find out what is causing you to be tired. Consult with your doctor to rule out any medical conditions or medications that might cause tiredness or make it worse. Below are some reasons you may feel extra tired:

- You may experience less energy because of poor sleeping, not getting enough physical activity, or poor nutrition.
- You may be using your energy differently than before your stroke. The effects of your stroke may cause daily activities like dressing, walking, or even talking to take a lot more effort. Changes in thinking and memory take more concentration. You have to stay "on alert" all the time, and this takes energy.
- You also may feel fatigued due to emotional changes. Coping with frustration, anxiety, anger, and sadness can be draining. Often, loss of energy, and interest occurs along with a depressed mood.

#### **ENERGY SAVING TIPS**

Take a look at your daily routines and consider the energy saving tips below to find ways to reduce the amount of effort needed for tasks and make the most of your energy. **Remember: Energy** is like money. You only have so much, so think about how you spend it!

#### **Rearrange Your Environment**

- Keep frequently used items in easy to reach places.
- Use lighter items instead of heavier ones.
- Raise a tabletop to prevent awkward positions.
- Install long handles on faucets and doorknobs.
   Long handles or levers require less effort especially when you have less hand strength after your stroke.
- Install pull-out or swing-out shelving and cabinets.

#### PREVENT UNNECESSARY EFFORT

- If possible, sit instead of stand when completing any activity, especially for those that require more time such as cooking.
- When sitting, keep your feet on the floor. If the chair is too high or deep, use a footstool.
   Dangling feet can take away energy and can cause lower back pain.
- Use adaptive equipment and devices as needed to make tasks easier. This guide has some ideas for adaptive devices for you to use in the self-care and home management sections. For further ideas on adaptive equipment and devices to use, please ask your therapists.
- Use a rolling cart to transport items around the house or out in the community if you are not using a rolling walker.
- Doing activities above shoulder level can create an extra burden on your heart and use more energy. These activities may also cause you to have a loss of balance. Do these activities for short periods when you have more energy.
- Avoid working in a bent posture for long periods.
- Try to avoid holding items especially for long periods of time.

#### **PRIORITIZE**

- Eliminate or reduce tasks that are not important to you.
- Ask friends, family members, or caregiver to help with tasks that are harder to complete.
- Consider hiring professionals to cut down your workload.

#### **PLAN AHEAD**

- Gather all supplies you need for a task or project before starting.
- Plan harder activities for times in the day when you feel least tired, such as in the morning, after taking a nap, or after along rest break.
- Do an activity before meals or after a rest breaks if you have eaten.
- Work rest breaks into activities. Take a break before you get tired.
- Schedule enough time for activities. Rushing takes more time, can cause more mistakes, an injury, or even a fall.
- Break up activities into 5-15 minute intervals as needed.

#### OTHER ENERGY SAVING TIPS

- Learn to relax. Sometimes the harder you try
  to do something, the harder it is to do. You
  become tense, anxious, and frustrated. All of
  these feelings take more energy. Being relaxed
  allows you to use your energy more efficiently.
- Do not hold your breath while lifting or exercising. Breathe normally.
- Be cautious about over doing a lot of activity in hot or humid weather.
- Avoid excessively hot or cold showers. Hot showers require more oxygen.
- If you become tired while walking or going up stairs, stop momentarily until you can continue without great effort.
- Support your arms on a counter, table, armrest, or handrail when doing activities such as reading a book or newspaper.
- When resting, eliminate the extra "white noise" which may include TV, music, cell phones, or bright lights. This will help your brain experience full rest.
- Participate in physical activity. With permission from your doctor, consider joining a health and wellness program or exercise class.
- Do something you enjoy every day. Celebrate your successes in your stroke recovery. One day, you will see how far you have come. A Positive attitude or experience helps to boost energy levels.
- Be social. Interact with friends/family that you enjoy being around and encourage you to do your best.

### **Emotions & Stress**

# HOW DOES A STROKE CAUSE EMOTIONAL CHANGES?

As a result of a stroke, you may experience difficulty controlling emotions due to physical or psychological changes to the brain. You may feel challenged, fearful, and frustrated with the effects of the stroke on your abilities. At times, you may feel like you have lost control over the ability to connect your feelings with how you show them.

# WHAT ARE COMMON EMOTIONAL CHANGES AFTER A STROKE?

- You may have exaggerated changes in mood and behavior. Your may have emotions that do not appear to match your mood.
- You may burst into tears for no obvious reason, then stop crying and begin to laugh at unusual times or longer than what seems appropriate. For example, you may laugh at something sad or cry at something funny. Please refer to the glossary for more information on other terms such as pseudobulbar affect or emotional lability to describe the emotional and mood changes.
- You may experience impulsive behavior such as acting without thinking and making risky, unsafe decisions.
- You may feel frustrated.
- You may experience anxiety symptoms such as fear, worry, panic, restlessness, and shortness of breath.
- You can feel angry and behave more aggressively at times. You may shut down and not share your feelings.
- You may experience apathy, which is a lack of emotional expression or interest and concern about something.
- You can lose motivation.
- You can feel depression or sadness.

#### **RECOGNIZING DEPRESSION**

You may be suffering from depression if you have the following symptoms:

- Act sad or nervous for long periods.
- Think that every day is "empty" or has no purpose.
- Feel that everything is hopeless. Giving up on life.
- Feel that you are valueless, not important to others.
- Feel helpless and unable to contribute to positive actions to daily life.
- Feel that you are guilty or responsible for something bad or wrong.
- Lose interest in any hobbies or previous pleasurable activities, including sex.
- Feel tired all the time, lacking energy, or enthusiasm.
- Feel that it takes longer to get through each day.
- Have trouble concentrating, remembering, or making decisions.
- Have difficulty sleeping through the night or waking up in the morning.
- Experience changes in appetite or weight.
- Feel restless or irritable all the time.
- Think about death/suicide, or make suicide attempts.

If you (or your loved one) has suicidal thoughts or plans, please notify your doctor or healthcare professional immediately.

#### **HEALING EMOTIONS AFTER A STROKE**

Emotional treatment for stroke can provide longterm benefits, improve your motivation, and help you continue your path to recovery.

A neuropsychologist or psychiatrist may recommend antidepressant medication. Your doctor may prescribe antidepressants to treat depression or anxiety. Take your medication as it has been prescribed to you, and try these tips:

- Seek therapy and counseling. Talk with a psychologist or counselor to help you learn good ways to handle the emotions you are experiencing.
- Eat a balanced diet. Good nutrition will help you feel better. Speak to a dietician for more details about a heart healthy diet.
- Stay Active. Physical activity boosts your mood and helps your brain regenerate. Get involved in activities that help get your heart rate up.
- Get fresh air and time outdoors. It will do wonders for raising motivation. A change of scenery can keep exercise fresh and interesting. Try walking a new path in a park or visiting an old but familiar vacation spot.
- Find a support group. Share with other stroke survivors and caregivers, whether in person or online, to help you feel less alone. Survivors provide experiences and advice to help face the challenges you are experiencing.

# POSITIVE APPROACHES TO COPING AND REDUCING STRESS

- Talk to someone you trust and who may understand what you are feeling. Look at a situation with a different perspective through someone you trust.
- Learn to relax. Get involved in yoga, chair yoga, tai chi, and/or take a relaxation course.
- Breathe deeply. Correct breathing is key to stress reduction. Breathing slowly using all of your lung capacity helps restore calmness.
- Do activities you really enjoy and that make your heart happy and healthy.
- Develop skills to give you confidence and energy. Learn to say "no" without feeling guilty. Learn to give honest and clear messages to the best of your ability when communicating.
- Try to find a solution to problems before they become unmanageable.
- Allow extra time for you to complete activities.
- Get enough sleep.
- Recognize your own strengths and weaknesses.
- Learn to accept what you cannot change.
- Laugh. It reduces strain and tension.
- Learn to "talk" to yourself in a positive way.
   Allow yourself to make mistakes.



#### Stroke Support Group

Peterson Health's therapists host a Stroke Support Group once a month for stroke survivors and caregivers. Each session focuses on a different topic. If you and your caregivers would like to attend the group, please ask your therapist for more information.

#### STRESS MANAGEMENT

Some amount of stress is a natural part of life. However, it becomes harmful when it seems overwhelming and you feel helpless. Stress is often a result of coping with serious physical, emotional, psychological, social, and financial challenges. Recognize the signs/symptoms of stress, and learn how to manage them. The first step in gaining control over feelings of stress and anxiety is recognizing how each individual reacts during stressful situations.

#### **PHYSICAL SIGNS OF STRESS**

- Changes in sleep patterns
- Loss of appetite or eating too much
- Stomach pains or indigestion
- Changes in bowel habits
- Headaches
- High blood pressure
- Chest pain or tightness in chest
- Sweating
- Skin problems
- Allergies
- Loss of sexual desire
- Muscular aches and pains
- Emotional highs and lows
- Frequent colds or flu
- Shortness of breath
- Fatigue
- Shallow breathing

#### **EMOTIONAL SIGNS OF STRESS**

- Depression
- Anxiety
- Inability to relax
- Loss of concentration
- Poor memory
- Irritability / short temper
- Impulsive behavior
- Difficulty in finishing tasks
- No social desire
- Smoking / drinking too much
- Poor motivation
- Inflexible thinking
- Unable to organize your daily life

## **Community Activities**

It is important to still participate in activities outside of your home that your enjoy as much as you can. Your ability to participate in these community activities may look differently now, but remember, getting out and interacting with others in some form can also help you deal with the emotional changes after your stroke. Please consider the follow tips when going out into the community.

#### **GENERAL TIPS**

- Avoid busy times at places you would like to visit. Large crowds and loud noises can over stimulate and make you feel more tired.
- Keep your money organized to avoid frustration and confusion when paying for services and items.
- Make lists of what you need before you shop.
- If you are unable to participate in a former hobby, you can find a new one.
- Your occupational therapist (OT) can suggest ways to better access and enjoy activities.
- Join a stroke support and/or social group to find new fun activities and learn new hobbies to enjoy.

#### **SHOPPING**

- Hold cart handles to help with your balance while standing.
- Use gloves to grip items and carts with more ease.
- Use a reacher to get lightweight items from lower or higher shelves
- Make a list or use store apps on your phone or tablet to make your shopping process less tiring and easier.
- When finding items on shelves, scan in an organized way. Scan from left to right before moving to the next shelf.
- Check with your local stores for grocery curbside pickup or delivery.

#### **DINING OUT**

- Look at the menu ahead of time before going to the restaurant.
- Bring your adaptive utensils and equipment with you.
- Choose foods that require no cutting or that are easy to cut.
- If you would like to have a food cut into bite size pieces, ask the waiter to cut food into smaller pieces before it is brought to you.

#### **VACATION AND TRAVEL**

- Reserve a handicap accessible room, if possible.
- If hotel elevators are not available, get a room on the first floor.
- When booking your airline tickets, request wheelchair assistance, if needed.
- Schedule your flight in advance. Request an aisle seat towards the front of the plane to enter and exit with more ease.
- Ask if the attractions you would like to visit have handicap accessible options.
- Consult a community mobility specialist to assist with travel out of state or country if needed.

## **Driving** After a Stroke

In order to go out into the community, you must have some form of safe transportation. Individuals normally want to drive after having a stroke to participate in community activities. Discuss this with your doctor and therapists prior to discharging from the hospital or rehabilitation facility about driving. Driving after a stroke requires various skills that may have been affected by your stroke. It can take time to build these skills up after a stroke.

# POTENTIAL DEFICITS THAT COULD LEAD TO UNSAFE DRIVING:

- Vision changes, neglect, and/or visual field cut
- Decreased safety awareness
- One sided weakness
- Decreased coordination
- Decreased reaction time
- Delayed processing and problem solving
- Increased fatigue
- Decreased attention to tasks including being easily distracted

If you or a loved one notices any of the above deficits following a stroke, you should talk about this with your doctor and other healthcare professionals, such as your occupational therapist (OT), to identify any recommendations for referrals to a driving rehabilitation specialist and/or Neuro-Ophthalmologist for further evaluation and treatment.

#### BEFORE RETURNING TO DRIVING

According to the National Highway Traffic Safety Administration (NHTSA), it is dangerous and in some areas, it is illegal, to drive after a stroke without your physician's consent. Get further evaluation and treatment by a specialist for your safety and the safety of others on the road before returning to drive. Take these important steps before returning to drive:

- Get physician consent to drive
  - In your discharge packet from the Peterson Acute Rehab Unit, it will specify NO driving until cleared by your primary care physician with a referral for a driving evaluation as well
- Driving assessment with a driving rehabilitation specialist
  - Peterson Health Ambulatory Care Center (ACC) offers a driving evaluation with an OT as an outpatient service following your discharge home with a referral from Dr. Foster or Dr. Shaw
- Visual assessment with OT
- Follow up with Neuro-Ophthalmologist if you have visual deficits identified by your occupational therapist
- Continued therapy with occupational therapy (OT), physical therapist (PT), and speech language pathologist (SLP).

# Health Self-Management after Stroke

Keeping a history of your stroke care will be helpful to take with you when going to healthcare appointments and for other hospitalizations.

Below is an example of how you can record your care history since your stroke.

Date of Stroke	
Type of Stroke	
Was tPA used?	
Side of Brain Affected	
Hospital Where Treated	
Do you live alone?	
DATE	MILESTONES

## Questions & Tips for Medical Appointments

Plan ahead and get the most of your medical appointments!

#### **MEDICAL APPOINTMENT QUESTIONS:**

- What is my risk for another stroke?
- What is my blood pressure goal?
- What is my blood sugar level? Does it mean I am at risk for diabetes?
- What other screening tests for heart and stroke should I get?
- How often should I return for checkups?
- For tobacco users: what can you do to help me quit using tobacco?
- What is a healthy weight for me?
- What is a healthy eating plan for me?
- What is a healthy exercise program for me?

#### OTHER TIPS FOR MEDICAL APPOINTMENTS:

- Complete paperwork early. Some paperwork is available online. If you are completing paperwork in the doctor's office, allow time before the scheduled appointment.
- Understand the basics of your insurance (coverage, deductibles, co-payments, in-network providers, etc.).
- Identify what time of day is better for appointments.
- Ask for assistance in and out of doctor's office, if needed.
- Have a loved one or caregiver to take you to and from appointments.

## Planning Ahead for Emergencies

For stroke survivors with physical, cognitive, or communication changes, emergencies such as floods, storms, and utility failures can be difficult and perhaps life threatening. The only way to face these challenges is to prepare ahead of time.

The American Heart Stroke Association recommends the following steps to when planning ahead for emergencies:

**Step 1: Assess your situation.** Are you mobile? Does your medication require refrigeration? Are you in a flood zone? How far are you from emergency services?

**Step 2: Gather information** about community resources in your area. Is there an emergency shelter?

**Step 3: Make a plan.** Write it down. How can you evacuate out of your house/apt.? If the power goes out, what are your options for getting out of the building? How will you contact your loved ones? Keep lists in your phone or a printed copy in your wallet.

**Step 4: Create a support network** of family/ friends who can assist you in the event of an emergency. Keep their numbers in your wallet and close to your phone.

**Step 5: Make a plan for your pets.** Take your pets with you if you evacuate. However, be aware that non-service pets are not usually allowed in emergency public shelters. Prepare a list of friends, family, pet-friendly hotels, boarding kennels, or veterinarians that could shelter your pets in an emergency.

**Step 6: Assemble a disaster supply kit** to make you more safe and comfortable if you need to leave. This would include a cell phone charger, flashlight with batteries, food, water, medications in a portable container.

Review the items listed in these six steps at least once per year!

#### **OTHER TIPS**

- If you use an electric wheelchair, keep a manual one for back up.
- Learn the capabilities of your mobile device to receive emergency instructions and warnings.
- Keep vital records in a safe or safety deposit box.
- Buy and maintain a fire extinguisher and know how to use it.
- If you go to an emergency shelter, inform them immediately of any special needs that you have.

#### CONCLUSION

We hope that you enjoyed reading this guide and find it to be helpful and clear. It is our hope you will continue to use it as guide even after discharge from the hospital acute rehab unit. It may seem overwhelming, as a stroke is a major life change, but take your recovery one day at a time. Remember stroke recovery will be a long journey. Your life will be forever changed by it, but progress is still possible with your hard work, the help of therapists, family, and friends to support you. Celebrate the small the victories. Please do not hesitate to contact the acute rehab unit during your stay regarding the information in this guide and questions about the discharge planning process.

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Notes	

# Notes

# Appendix A: Portable Health Profile (PHP)

It is important that you know and keep track of changes in your own important health information. Because you see many different healthcare providers, it can be difficult to know all the details of your health information. A portable health profile (PHP) can you help you keep track of you health information with more ease. When you give healthcare providers the right information, you help them take better care of you!

Portable health profile includes basic health information, such as medical conditions, allergies, functional abilities, advance directives, and emergency contacts. It helps with organizing information from many different sources into one place. Take it to healthcare appointments, so it is easier for you to answer questions and provide information. It will also allow you to keep your important healthcare information together for emergencies.

There are various ways to keep this information. Some are "high-tech" and some are very basic, including paper profile, folders, wallet cards, medical ID bracelets, or flash drives. Tape a paper copy on the front of your refrigerator for emergency personnel or family members to be able to access quickly.

#### Websites that allow you to build a PHP:

www.onfile.com www.nomoreclipboard.com www.getmyid.com

# Appendix B: In-Home Safety Overview & Checklist

THROUGHOUT THE HOME	YES / NO
Is lighting sufficient?	
Are light switches near the entrance?	
Are cords placed out of flow of traffic?	
Are there enough outlets to accommodate all cords?	
Are throw rugs removed?	
Are smoke detectors in place and batteries fresh?	
Are walkways and hallways clear? Is clutter removed?	
Is there a phone in each room or a mobile phone available?	
Does the patient need a personal alert system?	
IN THE KITCHEN	
Are flammable things kept away from the range?	
Is there lighting over the stove, sink, and countertop areas?	
Are commonly used items within reach?	
IN THE BATHROOM	
Are there handrails and grab bars where needed?	
Are towels, shampoo, and soap within reach?	
Is there a portable handheld, showerhead, and/or shower seat if needed?	
IN THE BEDROOM	
Is there a well lit pathway from the bed to the bathroom including night lights?	
Is there a bedside table to place glasses, tissues, books, etc?	
Is there a bedside commode next to the bed?	

## Appendix C: Brain Games for Stroke Survivors

**Lumosity** is a cognitive training app that contains over 60 cognitive exercises. The app helps strengthen the brain's cognitive skills through games that are entertaining and prevent boredom.

**Constant Therapy** is an app specifically designed for stroke survivors. It contains various language and cognitive exercises to help rewire the brain after stroke.

**Tactus Therapy** is designed for stroke survivors and helps with aphasia. It also improves cognitive function.

**Aura** is a meditation app. Meditation has been shown to help improve attention, mental flexibility, and information processing, which are all important cognitive skills. Aura provides a different guided meditation every day.

**Board Games** like checkers, can serve as excellent cognitive training because they help stimulate the brain's problem-solving skills.

**Puzzles games** like Sudoku and crossword puzzles are excellent cognitive training games for stroke survivors. They provide challenges but help patients get better at them with practice.

**Music Therapy** helps improve cognitive function and attention span after stroke because music engages different areas of the brain and gives the brain a little workout.

**Creative Therapy** creative activities engage the creative part of the brain. When the creative activities involve fine motor skills, like painting, sculpting, or pottery, they engage many different parts of your brain.

## Appendix D: Local, State, & National Resources

**American Stroke Association:** Information and resources for survivors and caregivers, Laws related to stroke and stroke education needs, Advocacy and support groups, Free "Stroke Connection" Magazine (sign up online)

www.stroke.org

The Stroke Network: An online support group

www.strokenetwork.org

World Stroke Association: Advocacy Toolkit

https://www.world-stroke.org

Access Laws: Information and Technical Assistance on the Americans with Disabilities Act

https://www.ada.gov

**Dysphagia Diet:** Provides a variety of thickeners, thickened liquids, ready to eat purees, and other adaptive eating aids delivered to your home

www.dysphagia-diet.com

**Alamo Area Council of Governments:** Provides local information (including Kerr county information on transportation, legal assistance, and benefits counseling)

www.aacog.com

National Caregiver Alliance: Caregiver support and resources

www.caregiver.org

**Medline Plus:** Provides a lot of information about stroke. It has sections on medications, an illustrated medical encyclopedia, interactive patient tutorials, and the latest health news.

www.Medlineplus.gov

**Eat Right:** Provides information on health and nutrition. It is sponsored by the American Dietetic Association.

www.eatright.org

#### Online Websites that Sell Adaptive Equipment and Home Aides:

Alimed.com

Amazon.com

CaregiverProducts.com

Strokeaids.com

## Glossary

**Activities of Daily Living (ADLs):** Routine activities that you allow to take care of yourself that are essential to survival and well-being including feeding, swallowing/eating, bathing, toilet hygiene, brushing teeth, dressing, grooming tasks such as shaving or styling hair, functional mobility, personal device care, and sexual activity. An ADL is a type of occupation all humans can complete.

**Aphasia:** Reduced ability to understand or express language (i.e. to decreased communication ability) due to damage to specific areas of the brain

**Apraxia:** Inability to perform purposeful learned movements or activities even though there is no sensory or motor impairment that would hinder completion of the task

**Aspirational Pneumonia:** Type of pneumonia caused by food or liquid entering the lungs. It most frequently occurs in the right lower lobe of the lung

Ataxia: Inability to perform coordinated movements

**Bedside Swallowing Evaluation:** Assessment of an individual's swallowing ability at bedside or during a meal

**Bolus:** Food, liquid, or other material placed in the mouth for ingestion

**Cognition:** Mental action or process of acquiring knowledge and understanding through thought, experience, and senses. Types of cognitive processes are attention, orientation, and perception.

**Dysphagia:** Reduced ability to properly swallow

**Dysarthria:** Slurred and impaired speech due to weakness of the muscles used to speak

**Emotional Lability:** Characteristic of a right hemisphere stroke where there is an inability to control emotions. It includes outbursts of laughing or crying that are inconsistent with the situation.

**Executive Functioning:** Group of complex mental processes and cognitive abilities that control the skills required for goal-directed behavior. These skills help you be productive, manage time, pay attention, plan, organize, remember details, multitask, and to avoid saying or doing the wrong thing.

**Flaccid:** No voluntary muscle contraction (no muscle tone) with which tendon reflexes are decreased or absent causing a form of paralysis. An arm or leg can be flaccid due to a stroke.

Homonymous Hemianopsia: Loss of the right or left half of the field of vision in both eyes

Hemiparesis: Condition of weakness on one side of the body

**Instrumental Activities of Daily Living (IADLs):** Activities that support daily life either in the home or the community which require more complex skills such as cooking, money management, caring for others, caring for pets, social and religious activities, shopping, driving, etc. An IADL is a type of occupation a human can complete.

**Memory:** Ability to store or remember information for future use

**Modified Barium Swallow Study (MBSS):** Instrumental procedure/radiological procedure that assesses the oral, pharyngeal, and upper esophageal areas of the swallowing mechanism. MBSS also can determine if a patient is silently aspirating (aspirating with no sign of a cough).

**Motor Planning:** Ability to plan, prepare, and carry out a skilled movement in the correct sequence from the beginning to the end. Motor planning allows you to remember and perform steps to make a movement happen (e.g. brushing teeth, washing hands, and tying shoes).

**Neglect:** Inability to pay attention to things and activity in a person's environment on one side. In more severe cases of neglect, the individual may not be aware of their own body parts on the side of which they are experiencing neglect. The side of which a person experiences the neglect is often the opposite of where the stroke occurred in the brain. Left-sided neglect is most common with a stroke to the right parietal or temporal lobe of the brain.

**Neuroplasticity:** Ability of the brain to physically grow new connections and brain matter as well as reorganize new connections, especially in response to learning, experience, or following an injury (e.g. Stroke)

**Occupation:** Various kinds of life activities individuals or groups participate in such as self-care (ADLS), rest/sleep, education, work, play, leisure, and instrumental activities of daily living (IADL) such as cooking and driving

**Occupational Therapy:** Therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings

**Oral Intake:** In general, amount of food or liquid the individual is able to take in by mouth. More specifically, this describes the placement of food in the mouth; oral gestures used to prepare food for the swallow and gain pleasure from eating; and, tongue movement to initiate the oral stage of the swallow.

**Orthostatic Hypotension:** Form of low blood pressure that happens when you stand up from sitting or lying down. It can make you feel dizzy, lightheaded, and maybe even faint.

**Physical Therapy:** Focuses on mobility including gait training (walking), wheelchair mobility, stair training, transfers from bed to chair, reducing pain, improving balance, strength, endurance, and preventing future injuries.

**Perseveration:** State of repeatedly performing the same segment of a task or repeatedly saying the same word/phrase without purpose

**Proprioception:** The sense that you have of knowing where your body parts are in space. It is the sense that allows you to be aware of your body's posture, movement, and changes in equilibrium.

**Pseudobulbar Affect:** Nervous system disorder that causes inappropriate laughing and/or crying

**Spasticity:** An involuntary muscle contraction (increased muscle tone) that is not dependent on movement. It sometimes happens in your arms and/or legs after a stroke. It can be painful (like a charley horse), and it can create stiffness and tightness, resulting in decreased range of motion of your limbs.

**Speech Language Pathology:** Rehab service devoted to improve swallowing, voice, communication, and cognitive abilities of individuals

**Subluxation:** An incomplete or partial dislocation of a joint. When the bone moves out of the normal position, it may create pressure on ligaments, tendons, and nerves.

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