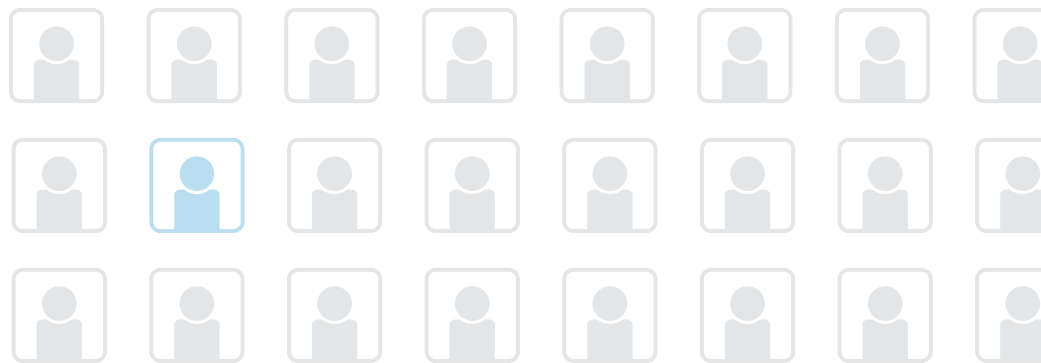


CHAPTER 6—MANAGING RECOVERY

Stroke recovery is not a linear process. The stroke survivor's needs may change, and as a caregiver, your role will change along with them. It is helpful to be open to these changes. As the stroke survivor regains strength and independence, your role may lessen, but it may also increase if new challenges arise. Keep open communication with the stroke survivor to make sure you are tuned in to their changing needs and concerns. Over time, you and the stroke survivor may need to re-establish boundaries and figure out new ways to communicate.



Many caregivers find that support groups/clubs are helpful in connecting with other caregivers to share advice, stories or tips. National Stroke Association has a number of caregiver-focused support groups in its Stroke Support Group Registry at www.stroke.org/supportgroups and a new online network for caregivers—**Careliving Community**—at www.stroke.org/careliving.

HOME MODIFICATIONS

Home modifications may be necessary depending on the stroke survivor's needs. Making appropriate modifications will enable the stroke survivor to regain independence throughout recovery. If facing financial challenges, be creative and seek help with your home modifications from friends, neighbors, faith communities, veterans groups and community organizations. Look for stores and/or websites that sell affordable new/used adaptive equipment and medical supplies. See the Managing Life at Home fact sheet at www.stroke.org/factsheets for more detailed information.

Examples of home adaptation include:

- Installing ramps that can be built or purchased.
- Rearranging or removing excess furniture and rugs to avoid falls.
- Checking lighting to ensure that walkways are well lit and to determine whether current window coverings need to be changed.
- Modifying the kitchen to ensure safety and accessibility.
- Checking the stair and wall rails for sturdiness.
- Installing grab bars, shower chairs and raised toilets in the bathroom.
- Acquiring medical supplies and assistive living devices (e.g., gait belts, adaptive cups and utensils and safety monitors to listen to someone in another room).
- Determining whether an emergency alert device is necessary.
- Having a key for emergency access. Install a lockbox or leave a key with your neighbor. This avoids the need for personnel to knock down your door in case of emergency.

RESPIRE CARE

Throughout caregiving, remember that you have options. **Respite care refers to short-term relief services for the stroke survivor so you, the caregiver, can take a break.**

Caregivers providing unpaid care are eligible for respite care under the 2006 Federal Lifespan and Respite Care Act. Online registries, newspapers and yellow pages can be helpful in finding respite providers, or ask your medical and rehab care team members if they can make a referral.

ARCH National Respite Network and Resource Center is an online resource center that connects caregivers and healthcare professionals with local respite services. Visit www.archrespite.org/respitelocator to find services near you.

When choosing a respite care provider, it can be helpful to:

- Screen and interview each respite provider.
- Ask for work and personal references.
- Discuss payment in advance.
- Conduct background checks if possible.

HelpGuide.org is a nonprofit online resource with great tips for picking a respite care provider. Visit their site at www.helpguide.org.

[Include the stroke survivor in the respite care planning as much as possible. A printable consumer guide to respite care is available at \[www.archrespite.org\]\(http://www.archrespite.org\).](#)

Paying for respite care will be similar to paying for rehab. Not all insurance programs cover respite care but some states use waivers to offset costs. Check the federal government's Administration on Aging (www.aoa.gov) and/or your state's agency on aging (www.n4a.org) to determine your options.

POST-STROKE CONCERNS

Damage to brain tissue from a stroke can cause a variety of challenges for a stroke survivor. Seek advice and guidance from your medical and rehab care team members on managing the varying effects of the stroke.



APHASIA

Aphasia is an impairment of language that affects the ability to use and comprehend words. A common problem for roughly one quarter of stroke survivors, aphasia may make it hard to:

- Talk.
- Understand what others say.
- Read.
- Write.
- Use numbers and do calculations.

Aphasia affects people in different ways. Stroke-related aphasia can improve with speech therapy. Ask your speech therapist for exercises you can do with the stroke survivor. Computer and word games and puzzles will promote improvement (depending on the level of ability, children's learning tools can be very helpful).

The webinar ***iHOPE: Aphasia*** at www.stroke.org/ihope discusses how aphasia is related to stroke and offers practical management strategies for stroke survivors and caregivers.

COGNITION (THINKING)

Memory, attention span, self-awareness and comprehension skills may be diminished in a stroke survivor after the stroke. Your loved one may lose the ability to learn new tasks, remember things, problem-solve, understand things, make plans or acknowledge the reality of his/her physical limitations. There are a variety of ways to manage cognitive deficits as well as improve them:

- Break up tasks into simple steps.
- Set a routine.
- Keep things the stroke survivor regularly uses (such as a toothbrush) in the same place.
- Use prompts and reminders.
- Repeat exercises.
- Read.
- Play card games, memory games, puzzles and crosswords to improve memory, focus and thinking skills.
- Consult with a speech therapist and/or an occupational therapist for more exercises.

CONFINEMENT (LIMITED MOVEMENT)

If the stroke survivor is confined to a bed, move him/her often to protect against bed sores and skin irritations. Range-of-motion exercises and leg lifts will help with muscle strength, and installing bed rails is an essential safety feature. Safety monitors and walkie-talkies can also help you communicate with the stroke survivor when you are in another room.

INCONTINENCE

Incontinence refers to the inability to control the bladder (urinary incontinence) and/or bowels (fecal incontinence). Incontinence is more common in the early stages post-stroke. Both types of incontinence are characterized by involuntary leakage.

Having a nurse conduct an evaluation and assessment will be very helpful in determining individualized strategies.

Behavioral and physical therapies such as kegel exercises and bladder training, known medically as “prompted voiding,” includes exercises to help the stroke survivor regain control of his/her bladder and/or bowels. Work with a healthcare professional to set up a “voiding schedule,” assigning times to use the bathroom. The training involves adhering to the schedule as closely as possible with planning, deep breathing and mental exercises. Adjusting the stroke survivor’s diet, disposable undergarments, a bedside commode, catheters and some medications may also help with this.

Limited mobility and activity, depression, anxiety, dehydration and diet can lead to constipation. Narcotic medications often cause constipation, which can be aided by the use of stool softeners.

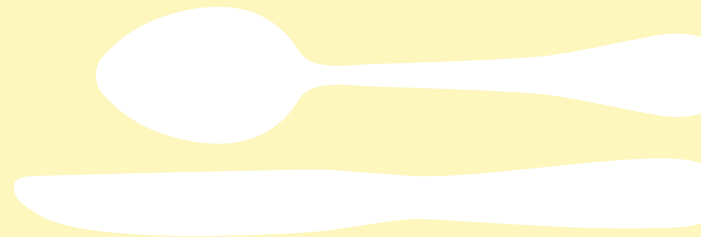
For treatment descriptions, management suggestions and available supplies see the Bladder and Bowel Function fact sheet at www.stroke.org/factsheets.

Incontinence issues may be uncomfortable to deal with and/or cause embarrassment, so try to be sensitive.

MEAL TIME

Depending on the stroke survivor, paralysis, one-sided weakness and/or dysphagia (trouble swallowing) can make feeding oneself difficult. Pay close attention to breathing and swallowing issues to avoid choking. Paralysis can also make it difficult for the stroke survivor to feed him/herself. Here are some suggested meal-time aids:

- Adaptive utensils with foam handles/grips.
- Plate guards.
- Cups with handles.
- Liquid thickeners.



MEDICATION ADHERENCE AND COMPLIANCE

Medication adherence is a prevalent issue surrounding recurrent stroke prevention. Many patients report not taking their medications exactly as prescribed. Additionally, 50 percent of aging patients on multiple prescription medications admit that they forget to take their medications at varying degrees, with some patients habitually missing their medications. Taking medications as prescribed is central to recovery post-stroke and recurrent stroke prevention.



Questions to ask the prescribing healthcare professional and/or pharmacist:

- What is the medicine's name and what is it for?
- When and how should the medicine be taken?
- What are the possible side effects?
- When should I expect the medicine to start working?
- Will the medicine interact with any of the stroke survivor's other medicines?
- Is it okay to take this with supplements (e.g., vitamins or omega-3s)?
- What should the medicine look like?
- What do I do if the stroke survivor forgets a dose?
- What are the repercussions if the stroke survivor stops taking it altogether?
- Besides time of day, is there any other thing I should know about the stroke survivor taking the medications (e.g., on a full stomach or with milk)?
- Are there foods to avoid?

Taking so many medications can become expensive. Many medications are available in generic form; you and the stroke survivor should talk to the prescribing healthcare professional about available options. There are also a number of patient assistance programs that can help with payment. Visit www.stroke.org/med_adherence to learn about medication adherence and for links to the patient assistance programs.

Forgetting to take medications can also cause issues with compliance. Many people find medication organizers, home delivery, auto-refills, numbering medications, medications trackers, pill boxes or alarms useful. See Appendix E for a Medication Tracker Template.

Watch and listen to *iHOPE: Medication Adherence and Compliance*, a webinar that provides strategies and tips for effectively managing medications.

NUTRITION

Be clear about dietary restrictions, needs and supplements. The stroke survivor may need to modify his/her diet to lower blood pressure and cholesterol levels, lose weight or control blood sugar if the stroke survivor has diabetes. Changing dietary habits can be a slow process but there are a many resources to help.

If you are unclear about the stroke survivor's dietary needs, consult members of the stroke survivor's medical and rehab care teams, or ask for a referral to a nutritionist. For example, stroke survivors with diabetes should avoid foods rich in sodium or processed sugar.

Healthy and delicious recipes and menus can be downloaded online. Some healthful websites are:

- www.cookinglight.com
- www.dailyhealthyfood.com
- www.diabetes.org
- www.eatingwell.com
- www.hearthealthyonline.com
- www.myfoodhealth.com
- www.wholefoods.com/recipes

Bringing stroke survivors on grocery store trips keeps them involved and allows them to gain a greater understanding of their nutritional needs.

iHOPE: Nutrition and ***iHOPE: Navigating Nutrition Labels and the Grocery Store*** offer tips to increase appetite, combat constipation, healthy food suggestions and instructions on reading nutrition labels. They are available at www.stroke.org/ihope.



PARALYSIS AND MUSCLE WEAKNESS

Paralysis refers to a person's inability to move a muscle or group of muscles voluntarily. When messages from the stroke survivor's brain to his/her muscles don't work properly after a stroke, a limb can become paralyzed or develop spasticity, which is when muscles become tight or stiff, restricting movement.

Stiffness in the arms, fingers or legs, painful muscle spasms or a series of involuntary rhythmic muscle contractions and relaxations can lead to uncontrollable movement or jerking. Upper and lower limb movement issues can make balance and coordination difficult, which increases the risk of falling.

Paralysis and weakness disrupt movement and make daily activities difficult. There are a variety of therapies available to help relearn motor skills and strengthen the arms and legs. Many physical therapists recommend stretching, walking or range-of-motion exercises. These are often referred to as "motor practice."

- **iHOPE: Spasticity** webinar at www.stroke.org/ihope offers information about treatment and management.
- **iHOPE: Rehabilitation at Home**—an educational webinar—will teach you strategies to make the most of physical therapy and other recovery services.
- The Hemiparesis brochure at www.stroke.org/brochures provides information on different types of one-sided weakness or paralysis and the types of treatment and rehab available.

**Circuits in the brain reconnect and heal over time.
Recovery is possible.**

PERSONAL CARE

You may help the stroke survivor in activities that include but are not limited to: getting in and out of bed, bathing, dressing and grooming. Shower chairs, hand-held showerheads, safety rails and adaptive dressing tools are helpful.

SEIZURES

Seizures are episodes of abnormal or disorganized electrical activity in the brain. Stroke is the most common cause of seizures in middle-aged and aging adults. Approximately 10 percent of ischemic (blood clot) stroke survivors experience a seizure post-stroke, while between 27 and 34 percent of hemorrhagic stroke survivors experience a seizure. Epilepsy, a neurological disorder characterized by recurrent seizures, is reported in 2 to 4 percent of stroke survivors. However, just because a stroke survivor has a seizure does not mean that he/she has epilepsy.

Only healthcare professionals can diagnose a person with epilepsy. Sometimes seizures and strokes can be confused for one another. Symptoms of a seizure depend on the type of seizure. Someone experiencing a seizure may spasm or convulse, stare into space or spontaneously start laughing. Epilepsy and seizures are manageable with medication, but missing a dose, not getting enough sleep and/or drinking alcohol can make the seizures worse. There are social and psychological effects of being diagnosed with epilepsy.



The National Institutes of Health has established guidelines for **WHAT TO DO IF SOMEONE IS HAVING A SEIZURE.**

- Roll the person on his/her side to prevent choking or vomiting.
- Cushion the person's head.
- Loosen any tight clothing around the neck
- Keep the person's airway open. If necessary, grip the person's jaw gently and tilt his or her head back.
- Do not restrict the person from moving if he/she is in danger.
- Do not put anything in the person's mouth, not even medicine or liquid.
- Remove any sharp or solid objects that the person might hit during the seizure.
- Note how long the seizure lasts and what symptoms occurred in order to inform a doctor or emergency personnel if necessary.
- Stay with the person until the seizure ends.

If your loved one experiences recurrent seizures, talk with his/her medical care team about what you can do to help during seizures to help prevent injuries.

SLEEP

Sleep disruptions are possible post-stroke, the most common of which relate to breathing. Sleep apnea is a disorder where a person's breathing is obstructed while they are sleeping. Loss of muscle, fat buildup or misfiring neurons can cause the windpipe to collapse when throat muscles relax during sleep. If a stroke survivor's wind pipe collapses—blocking air flow—the lack of oxygen to the brain can cause the stroke survivor to wake up with a headache, become irritable or lose cognitive function. Snoring is common among those with sleep apnea. The lack of oxygen to the brain can also increase blood pressure and increase the stroke survivor's risk for another stroke. This can be scary, so consult with the medical care team about the need for the stroke survivor to change sleeping position, lose weight or receive a medical intervention.

Other ways stroke effects sleep is changing sleep patterns, as in sleeping more during the day than at night, and insomnia. Insomnia refers to the inability to fall or stay asleep and can have a negative impact on the stroke survivor's recovery. Ongoing insomnia can be treated with sleeping medications, lifestyle changes or behavioral training.

See the Sleep Disorders fact sheet at www.stroke.org/factsheets for more detailed information.



EMOTIONAL REACTIONS POST-STROKE

Because stroke is sudden and often unexpected, many stroke survivors experience a variety of intense emotions such as anger, frustration, anxiety, depression, sadness, hopelessness and/or denial. They may also struggle with the sudden loss of control they feel or are experiencing. These feelings can be experienced at varying degrees at any phase of recovery.

A counselor, social worker or psychologist can assist with the emotional aspects of recovery. These professionals can be helpful as you and your loved one adapt to the “new normal” post-stroke. Recent studies show that antidepressant medication can help improve the emotional and physical health of a stroke survivor.

If the stroke survivor has been prescribed an antidepressant and there is little to no improvement after the time frame specified per the medication, speak with the prescribing healthcare professional.

There are many medications available. What works for one person may not work for another.

Keep communication with your healthcare professional open and clear to make sure the stroke survivor receives the correct medication(s) to manage their post-stroke symptoms, including emotional challenges.

Pseudobulbar affect (PBA) is a condition characterized by episodes of uncontrollable laughing and/or crying that may be inappropriate, unrelated to the situation at hand or not reflecting the person’s actual mood. The condition is known by other terms, including emotional lability, emotional incontinence and pathological laughing and crying. Talk to your medical and rehab care teams for more information on treatment options. Learn more about the condition at www.stroke.org/PBA.

STRATEGIES FOR NAVIGATING EMOTIONAL AND BEHAVIORAL CHANGES

Caring for a stroke survivor can be challenging when the stroke survivor experiences emotional and behavioral changes. Some suggested strategies:

- Treat your loved one with patience; take one day at a time.
- Maintain open communication and involve the stroke survivor in as much decision-making as possible.
- Encourage independence as much as possible. Promote self-acceptance and celebrate even the smallest victories.
- Establishing a routine will help you and the stroke survivor manage stress. Seek out a stroke support group in your area or online to connect with other caregivers and stroke survivors and share advice. Visit National Stroke Association's Stroke Support Group Registry to find a group at www.stroke.org/supportgroups.
- Stay active and exercise.
- Meet other stroke survivors at Stroke Camp. Visit www.strokecamp.com for events in your area.

