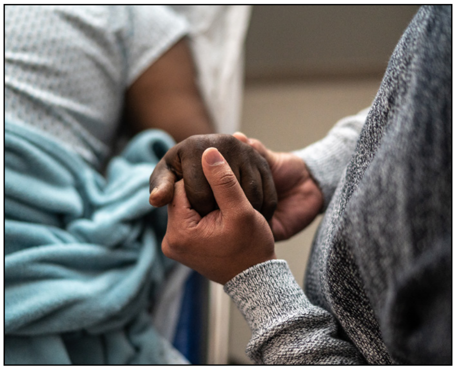
Chapter 7: For the Care Circle Members

What to Consider About Visitors

Your loved one may or may not want to have visitors during the hospital stay. Respect your loved one's wishes about when they would like to see members of their care circle.

Each hospital has different visitor rules. Ask your loved one's health care team about rules for your area.

How to help your loved one



- Limit visitors to no more than 2 at a time to protect your loved one from too much stimulation.
- Limit visits to 10 to 15 minutes, unless you are just sitting with your loved one and not talking or doing an activity.
- Keep your conversations brief and clear. Give just 1 piece of information at a time.
- Speak slowly with a calm, quiet voice. Give your loved one time to respond.
- You may put up a few family photos in your loved one's room. Limit cards, balloons and flowers. Consider putting photos and cards in a small album.
- Do not use your phone when your loved one is in the room. If you need to use your phone, go into the hallway.
- If the room phone keeps ringing, talk with a nurse about your options.
- Keep the television, music and computer off unless you know your loved one enjoys it. Limit screen and music time to no more than 20 minutes to protect your loved one from too much stimulation.
- Remove clutter in your loved one's room.
- Check with staff before giving your loved one anything to eat or drink.
- Share these tips with others who visit.
- Talk with any member of your loved one's health care team if you have any questions or concerns.

Just for the Caregiver

Your loved one will have specific needs after a stroke. This means you may need to learn new skills or change your role with them.

It is important that you learn about your loved one's safety, physical and emotional needs.

Here are some tasks you may do:

- Keep notes about discharge plans. Ask about anything that is not clear.
- Help to make sure your loved one takes their medicines the right way at the right time.
- Help to make sure your loved one follows recommendations for eating, exercising and resting.
- Help your loved one practice the skills learned in rehabilitation.
- Help your loved one solve problems and learn how to do things.
- Help your loved one with tasks done before the stroke. This includes using tools, buttoning a shirt and doing housework.
- Help your loved one with personal care if needed.
- Help your loved one's speech if needed. Include them in family activities even if they cannot actively participate.
- Arrange for any needed community services.
- Help your loved one schedule and attend follow-up appointments.
- Help keep your loved one safe. Be aware of your loved one's limitations (such as cooking, driving or returning to work).

Preparing to Care for Your Loved One

Important

You are not alone. Help is available to help you care for your loved one.

See the resources on pages 113-115.

Think about how your role may change with your loved one. This can help you prepare to provide care. Ask yourself the following questions:

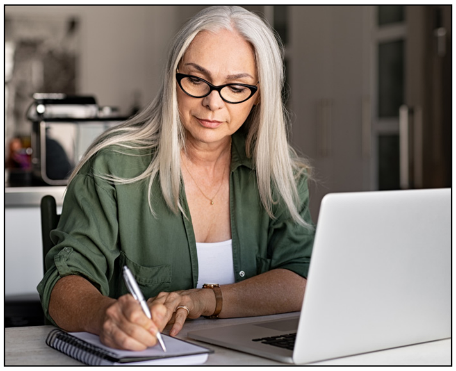
- What are my loved one's needs?
- Who can best help meet my loved one's needs?
- Am I ready or able to help my loved one recover?
- What resources will I need to care for my loved one? Do I know where to go for those resources? (See pages 113-115.)
- Will this care need to be scheduled around my work or other activities?
- If others are helping care for my loved one, who will be the main person providing care?

You will have time to talk with your loved one's health care team before discharge (leaving the hospital) to make plans for care after discharge.

Your loved one's brain injury and needs are unique. It is important that you learn about your loved one's safety, physical and emotional needs.

Your loved one's health care team will help you decide what type of care and how much care your loved one needs. You may need to learn new skills or change your role with your loved one.

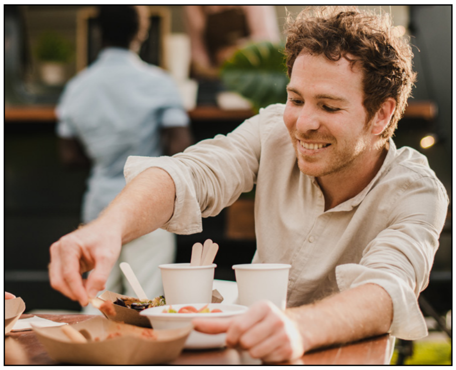
Your Role in Providing Care



Below are some tasks you may need to do.

- Keep notes about your loved one's care plan after leaving the hospital. Ask about anything that is not clear.
- Help make sure your loved one:
  - takes their medicines correctly and on time
  - eats well, exercises and rests (see pages 61-64).
- Help your loved one:
  - practice the skills learned in therapy
  - solve problems
  - learn or relearn how to do things
  - with personal care such as bathing or using the toilet
  - with tasks they did before the brain injury. This may include using tools, buttoning a shirt and doing housework.
  - communicate if needed. Include them in family activities even if they cannot actively participate.
- Arrange for any needed community services.
- Learn all you can about brain injury symptoms, treatment and care.
- Check out education classes or information in your community.
- Talk to your loved one's health care team if you have any questions or concerns.

Taking Care of Yourself

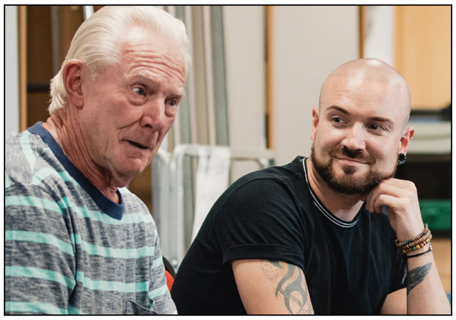


Taking care of yourself is just as important as taking care of your loved one.

Continue to take care of yourself. Consider the following.

- Take time each day to be by yourself, or take 1 or 2 days off during the week. This can refresh you and help you provide better care.
- Get out of the house for a quick break such as having lunch, going for a walk with a friend, or going to the gym.
- Take time to do activities you enjoy.
- Ask your loved one's care circle for help.
- Ask about community agencies, volunteer groups, churches, respite care or nursing agencies that can help you.
- Talk to a psychologist about how your life has changed.
- Join a support group to talk with other caregivers about their experiences and feelings. (See page 115.)

Support Groups



Support group members share common experiences about caring for a loved one. Members "lend an ear" so you can share your feelings with others who may have similar needs and feelings.

Support groups can also give you ongoing education, tips and sources of help in the community.

Support group members can become your new friends or give you support. See page 115.

Tips for Reducing Stress

- Take stroke recovery one day at a time. Be hopeful for a successful recovery.
- Appreciate each small gain your loved one makes. Your loved one's emotions and ability to do things may vary day to day. They may need to learn how to do things in different ways or try new ways of doing tasks, talking, speaking and organizing their social life.
- Expect that your skills and knowledge of how to provide care will improve. This is a time of learning for both you and your loved one.
- Plan for breaks so you and your loved one are not together all the time. Time apart is important for both you and your loved one. Try to do activities that get you both out of the house.
- Ask your loved one's care circle to help.
- Try relaxation, massage, exercise or meditation to cope with your stress. Ask a nurse about your options.
- Learn from others who have had similar experiences. Read about them or join a support group.
- Be patient with and kind to each other. You may feel frustrated some times. Do not take your frustrations out on others. Talk with a family member, friend, professional or support group about your feelings.

Tip

Visit the Penny George® Institute for Health & Healing at allinahealth.org/pennygeorge to learn more about services, classes and programs.

Progressive Muscle Relaxation

Progressive muscle relaxation is a short and easy exercise to help you relax.

Getting started

Find a relaxing position. You may sit down or lie on your back in bed. Be sure your legs and hands are not crossed.

You may close your eyes. If you prefer, you can keep your eyes open, but focus on one spot in front of you.

Bring your attention to your breathing. Think about where your breath comes in and out of your nose or mouth. Think about how your chest moves up and down with each breath.

Imagine a gentle, safe wave of relaxation that will slowly and warmly flow through your body. The wave can help you find those places that need to relax and give them permission to relax.

You can also imagine this wave in any way you find most comfortable. You may see it as light, water or just a feeling.

If your mind wanders, gently bring it back to your breathing.

Relax from your head to your feet

- Bring your attention to the top of your head and begin to imagine a wave.
- With your next breath out, feel the wave flow through your head. Feel your jaw soften and relax.
- Breathe in.
- With your next breath out, focus on the back of your neck. Let it soften and relax.
- Breathe in.
- With your next breath out, imagine the wave moving through each arm all the way to your hands. Feel your hands become slightly heavier where they are lying.
- Breathe in.

- With your next breath out, imagine the wave of relaxation roll gently and safely down your spine. Let all of your back muscles relax and soften.
- Continue to breathe. Feel the wave flow as you breathe out.
- Let the wave flow through your pelvic area and hips into your upper legs and thighs.
- Breathe in.
- With your next breath out, allow the wave to find those areas in your legs and knees that need to relax. Give them permission to relax.
- Breathe in.
- With your next breath out, feel the wave move into your calves, then your feet. Feel your feet become a little heavier.
- Take two deep breaths. Imagine any remaining stress gently flowing out the bottoms of your feet.

Take a moment to observe the still place you created. With practice, relaxation will become easier.

Guided Imagery

You can use your imagination to help you breathe easier. Guided imagery helps manage distress and gives you a better sense of well-being.

- Think about a pleasant or restful place. It can be anywhere: a beach, a cabin, the woods or a safe place at home.
- Let happy thoughts of your favorite scene or place relax you.
- Close your eyes and picture that scene or place.
- Focus on the sights, sounds and smells of your favorite scene or place as you relax.
- Let your body relax and your breathing become deeper.

How Aphasia Affects Your Loved One's Speech and Understanding

Medical Term

Aphasia (a-FAY-zha) is a language problem.

Aphasia means your loved one has problems understanding language and speaking. They may be unable to find the right words or put sentences together. Not all strokes cause aphasia.

This means your loved one's brain may have problems with:

- speaking
- listening
- reading
- writing
- dealing with numbers.

Tip

Just because your loved one has problems using language does not mean they cannot think clearly.

Most people know what they want to say, they just have trouble putting their thoughts into words.

Some people with aphasia:

- are unable to use nouns or verbs while others have trouble with little words like *the* and *of*
- speak easily while others struggle to make a sound (Sometimes they are hard to understand.)
- may be unaware that their speech is unclear
- have trouble retrieving the right words they want to say
- know the right words but cannot form them with their lips, tongue and teeth (may cause stuttering or slurred speech)
- have problems understanding simple commands and more complex material.

Tips to Help You and Your Loved One Communicate

☐ Do not assume your loved one cannot understand what is being said. Never say anything you would not want your loved one to hear.

☐ Work closely with the speech-language pathologist. You can help improve and maintain your loved one's communication skills by following the home program.

☐ Learn when is the best time of day to work on communication skills. Try to use that time whenever you can. Good times are when your loved one is well-rested. Mornings can be a good time after a good night's sleep.

☐ Set up a routine.

☐ Let your loved one rest several times each day.

☐ Respect your loved one's wishes about when they would like to see members of their care circle. Your loved one may want to wait until they have adjusted or improved their communication skills. Slowly get your loved one back into social situations.

☐ Include your loved one in communication even if they seem unable to speak or understand.

☐ Let your loved one share in life-affecting decisions.

☐ Encourage your loved one to be as independent as they can.

Helping your loved one listen

☐ Reduce distractions. Close the door. Turn off the TV or radio. Pull the curtains.

☐ **Limit the number of people in the conversation.** Try to avoid large groups.

☐ Sit down so your loved one can see you. This will help them be more relaxed.

☐ If your loved one wears hearing aids, make sure they wear them, have them turned on, and the batteries are working.

Helping you speak

☐ Speak slowly.

☐ Use short, simple sentences.

☐ Pause between sentences to give your loved one time to "digest" what you have said and respond.

☐ Give your loved one directions, questions or one piece of information at a time.

☐ Talk about things your loved one can see. Use photos, hand movements or facial expressions.

☐ Write down any request you have for your loved one. This way they can read what you are asking.

☐ Watch for signs your loved one understands you. Repeat or rephrase what you are saying if needed.

☐ Do not ask your loved one to talk and do another task at the same time.

☐ Try not to switch topics too quickly or often.

☐ Keep conversations short and to the point.

Helping your loved one speak

☐ Allow at least 30 seconds for your loved one to respond, follow a direction or to tell you something.

☐ Remind your loved one to:

  — speak slowly

  — speak clearly.

☐ Encourage your loved one to use other ways of communication such as:

  — write it first and read it out loud

  — gesture the meaning or what someone would do with it

  — draw a picture

  — point to the picture, object or word on a chart

  — describe it in other words.

☐ If your loved one tries 2 or 3 times and gets frustrated, ask them to take a short break. Have them try again in a few minutes.

Helping you listen

- ☐ Be patient.
- ☐ Do not interrupt. Give your loved one at least 30 seconds to respond. Try to look relaxed while you wait.
- ☐ Let your loved one know when you do not understand. For example try saying, “I am not understanding you.”

Aspiration

Medical Term

When food, drink, saliva or vomit accidentally enters the lungs, it could cause an infection. This is known as **aspiration**.

After a stroke, some people are more likely to cough or choke on liquids or solids. This can cause aspiration. It is common for people who have dysphagia (see pages 78-79) to be at risk for aspiration.

Watch your loved one for signs of aspiration:

- a wet-sounding voice
- breathing you can hear
- struggling when breathing or swallowing
- shortness of breath
- a rattling sound in their lungs
- fever.

If you think your loved one has aspiration:

- do not try to stop the coughing. Coughing is the body’s natural protection against choking.
- have your loved one stop eating and drinking until they stop coughing and the airway is clear
- make sure you or your loved one talks about aspiration with a speech-language pathologist or doctor. They can check for aspiration and may give tips to reduce the risk of choking.

When to call 911

Call 911 if your loved one:

- has a blue or purple tinge to their skin color
- is not breathing for more than 30 seconds
- is unable to speak or cough.

Sexual Behavior and Sexual Activity

Important

Talk honestly with your loved one's health care provider about your questions or concerns.

If the health care provider doesn't know there is a problem, they can't help.

It is common for people with brain injuries to have a change in sexual behavior or sexual activity.

There are two common types of changes: hyposexuality and hypersexuality.

Hyposexuality

Your loved one may lose interest in sex, feel depressed, cry or get upset more easily or at the wrong times. This may be the result of sexual dysfunction or physical changes caused by the brain injury.

The most common types of sexual dysfunction are:

- lack of arousal and orgasm
- erectile dysfunction (ED or impotence). This is the inability to get or keep an erection long enough for sexual intercourse.

Fear about physical changes may keep your loved one from being intimate. They may feel anxious about:

- how they look
- changes in their relationship
- rejection.

Learn More

Visit the American Stroke Association to learn more about intimacy after stroke. Go to stroke.org > About Stroke > Effects of Stroke > Emotional Affects of Stroke.

It is important for you to know how to deal with hyposexuality.

- Talk openly with your loved one's health care provider about your loved one's hyposexuality. Talk about any questions or concerns you have.
- If your loved one is also your sexual partner, it may be helpful to talk with a licensed family or marriage counselor about any concerns you may have.

Hypersexuality

Your loved one may have increased sexual thoughts, feelings or behaviors.

Hypersexuality may cause inappropriate sexual behavior such as:

- talking explicitly about sex
- making offensive or bad sexual comments or gestures
- touching others.

It is important for you to know how to deal with inappropriate sexual behavior.

- Talk with your loved one's health care team about what to do if there are inappropriate sexual behaviors. Common questions include:
  - What do I do if they touch someone inappropriately?
  - How should I react if they start talking sexually?
  - How should others respond to my loved one's inappropriate behavior?

  Talk openly with your loved one's health care provider about any other questions or concerns you have.
- Talk with your loved one's care circle about what kinds of sexual behavior are appropriate and what are not.
- If your loved one is also your sexual partner, it may be helpful to talk with a licensed family or marriage counselor about any concerns you may have.
- Talk with your loved one's health care provider about the risks of sexually transmitted infections.

Reducing Brain Over-stimulation

Over-stimulation

To help your loved one recover from a brain injury, it's important to help them not get over-stimulated.

Their brain is unable to make sense of all of the information coming in such as sounds, lights, touches and smells.

In the early stages of rehabilitation, it is important to provide an environment that reduces brain over-stimulation so they can participate in rehab.

Members of the health care team will work to keep your loved one on a regular schedule and plan their care in a quiet, dimly lit environment. Without this, your loved one may become overwhelmed and more confused. They may withdraw and shut down or even become aggressive.

The amount of stimulation your loved one receives will increase as they improve.

Signs to Watch for

Signs your loved one may be over-stimulated:

- being restless or trying to move around
- repeating the same words or sounds
- having a lack of attention
- being easily distracted
- being confused, irritated or being verbally aggressive
- being physically aggressive
- not wanting to be touched or withdrawing from interactions with staff or visitors.

Tell a member of the health care team if you think your loved one is over-stimulated.

How To Help Your Loved One

- Limit visitors to no more than 2 at a time.
- Limit visits to 10 to 15 minutes, unless you are just sitting with your loved one and not talking or doing an activity.
- Keep your conversations brief and clear. Give just one piece of information at a time.
- Do not use your phone when your loved one is in the room. If you need to use your phone, go into the hallway.
- If the room phone keeps ringing, talk with a nurse about options.
- Keep the television, music and computer off unless you know your loved one enjoys it. Limit screen and music time to no more than 20 minutes.
- You may put up a few family photos in your loved one's room. Limit cards, balloons and flowers. Consider putting photos and cards in a small album.
- Remove clutter in your loved one's room.
- Speak slowly with a calm, quiet voice. Give your loved one time to respond.
- Check with staff before giving your loved one anything to eat or drink.
- Share these tips with others who visit.

Talk with any member of your loved one's health care team if you have any questions or concerns.

Environmental Management System

Courage Kenny Rehabilitation Institute uses a system of communication that identifies how the environment should be managed for each person based on where they are in the rehabilitation process. This is called the environmental management system (EMS).

The system is based on a traffic light:

- red light: full restrictions
- yellow light: some restrictions
- green light: limited or no restrictions.

The level may change based on your loved one's needs and health care team's advice.

	Red Light	**Yellow Light**	**Green Light**
Lighting	■ dim/dark at night ■ natural light during the day	■ as they can tolerate	■ no restrictions
Noise	■ completely quiet	■ avoid loud, annoying, or ongoing noises	■ no restrictions
Room décor	■ none or very limited	■ a small amount is OK ■ avoid violent or sexual content ■ avoid busy or active posters	■ no restrictions
TV, video, music	■ none	■ no more than 20 minutes at a time (not during scheduled rest breaks)	■ no restrictions
Visitors	■ family only ■ 1 visitor at a time ■ limit visit to 10 minutes or less	■ family, close friends, and clergy ■ no more than 1 or 2 visitors at a time ■ limit visits to 15 minutes or less	■ no restrictions ■ must follow the hospital visitation policy
Touch, handling	■ limit touch and handling except as absolutely needed for medical care	■ as they can tolerate	■ no restrictions
Treatment location	■ in the room or in a private treatment area	■ in a private or semi-private treatment area	■ anywhere
Notes	These help prevent agitation later, help your loved one tolerate and benefit from rehabilitation therapies and keep your loved one safe and comfortable.	Red light restrictions will be used at the first sign(s) of agitation or withdrawal.	These provide cues to help your loved one recognize symptoms of overload, understand what adds to it and understand how to reduce stimulation.