

*Care*livingSM

Caring for **YOURSELF**
and a Stroke Survivor

CARELIVING GUIDE

www.stroke.org





Dear Reader,

Welcome to Careliving Guide, a resource for caregivers of stroke survivors.

Caregivers are invaluable in their role of continuous planning and facilitating a stroke survivor's care. But, being cognizant of the need for self-care is another critical element to consider. National Stroke Association is committed to equipping caregivers like you with the knowledge, resources, strategies and tools to navigate the post-stroke caregiving journey.

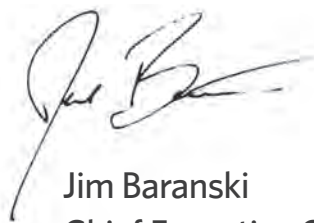
This guide is one asset offered through **Careliving: Caring for Yourself and a Stroke Survivor**—a multifaceted initiative designed to support caregivers while they care for stroke survivors.

Caregiving is not easy. This guide is designed to help you address issues, make decisions and maintain a high quality of life no matter where you are in the caregiving journey.

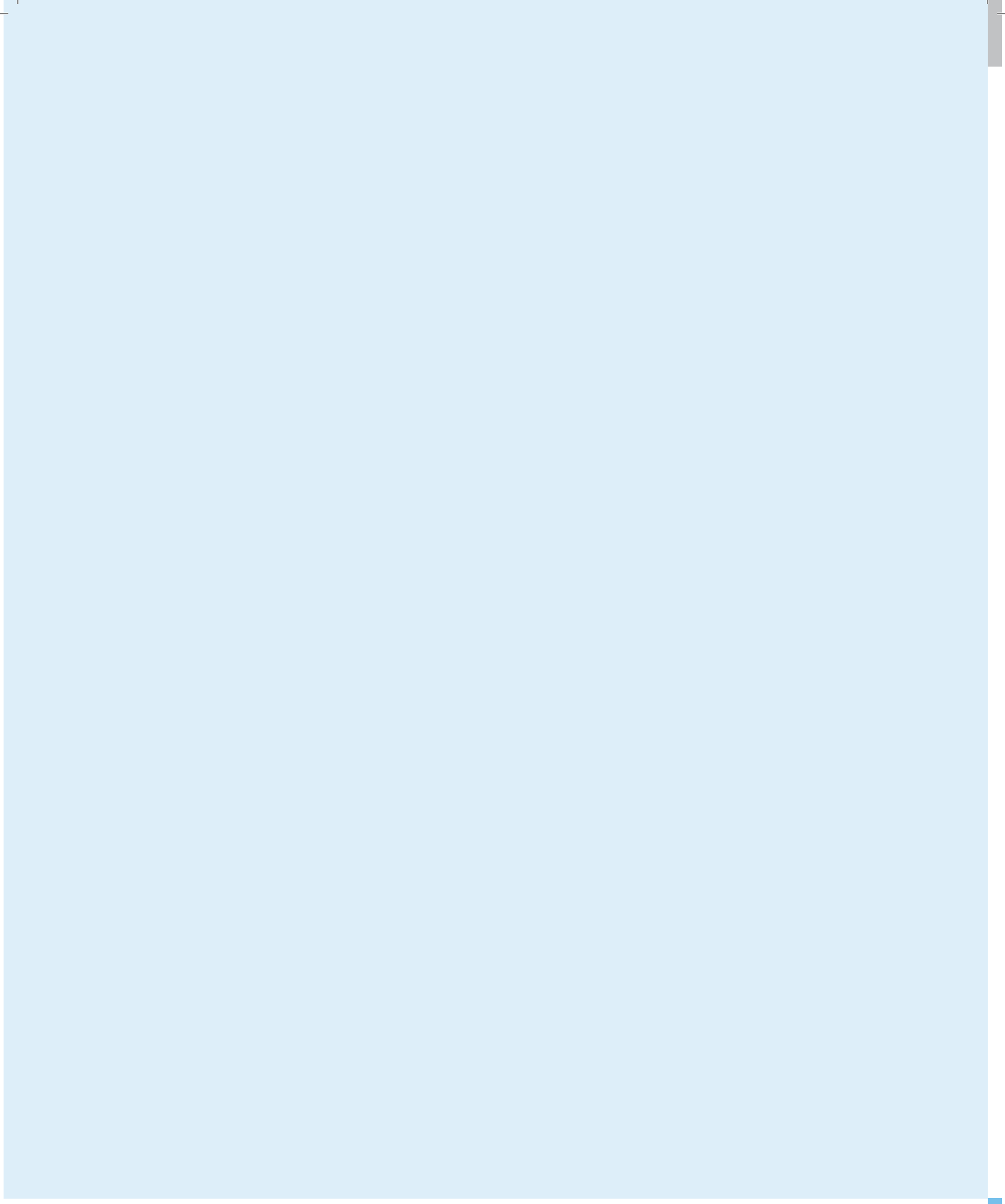
Learn more about the **Careliving** initiative and join a free online social network exclusively for you and other loved ones of stroke survivors at www.stroke.org/careliving.

We wish you the best of luck in your caregiving experience.

Sincerely,



Jim Baranski
Chief Executive Officer
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ACKNOWLEDGEMENTS

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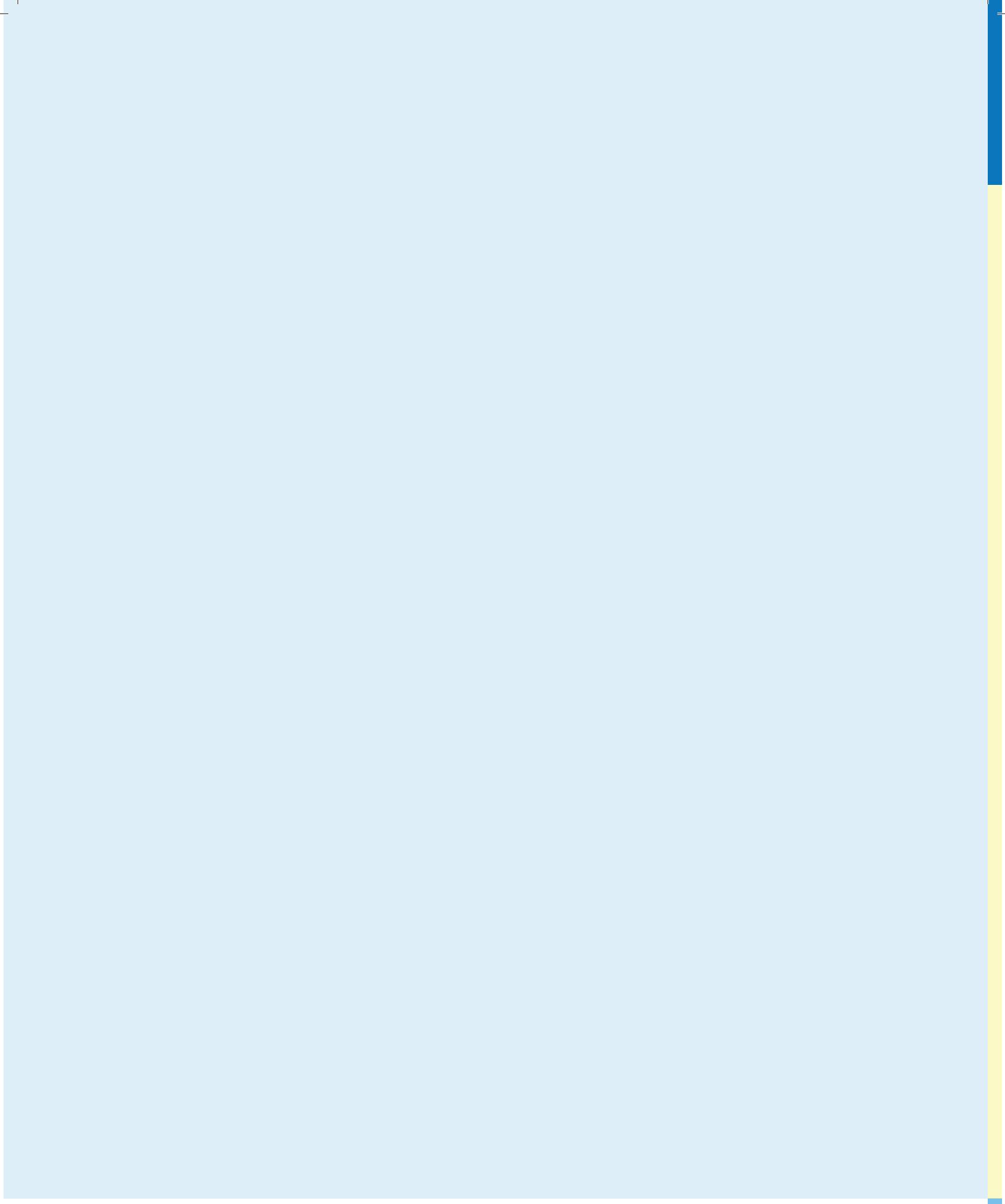
National Stroke Association also wishes to thank:

- Easter Seals Rehabilitation and Stroke Day Program
- National Stroke Association staff
- Rocky Mountain Stroke Center

National Stroke Association's mission is to reduce the incidence and impact of stroke, and is the only national organization in the U.S. that focuses 100 percent of its efforts on stroke by developing compelling education and programs focused on prevention, treatment, rehabilitation and support for all impacted by stroke. Visit www.stroke.org for more information.

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INTRODUCTION

A caregiver's role may start immediately post-stroke or may have evolved over time as it becomes clear that a stroke survivor can no longer manage all his/her daily needs. No matter when or how your role as a caregiver begins, it can be challenging, and you may have questions and concerns. National Stroke Association is committed to assisting caregivers during their journey alongside stroke survivors.

Recognize that caring for your loved one IS caregiving.

Many of you will be directed to this guide when your loved one has just survived a stroke or you may find this guide days, weeks, months or even years into your caregiving journey. This guide is designed to walk you through the caregiving process.

The guide will help you:

- **Prioritize tasks and develop a plan** for the stroke survivor's care.
- Access resources, tools, templates and suggestions to **keep you organized**.
- **Adapt to changing roles** and relationships post-stroke.
- **Prevent recurrent stroke**.

INTRODUCTION

Strokes can be sudden and complex.

Caregivers' roles are multifaceted and unique to each person. There are many things for a caregiver to think about when determining their stroke survivor's care. Just as no two stroke survivors have the same experience, there is no standard way to care for a stroke survivor. Because this guide includes worst-case scenario information and advice, not all sections may apply to your situation. Read the sections that apply to you and modify them as you see fit.

Caregivers may need to assist their stroke survivor with a wide variety of tasks and activities. Caregivers often:

- Plan out the stroke survivor's care, including setting routines and managing the care team.
- Observe the stroke survivor's medical needs, communicate with healthcare professionals and advocate (medically) for the stroke survivor.
- Provide the stroke survivor with physical, mental and emotional support.
- Assist the stroke survivor with daily activities such as personal care and hygiene.
- Manage financial matters and transportation.

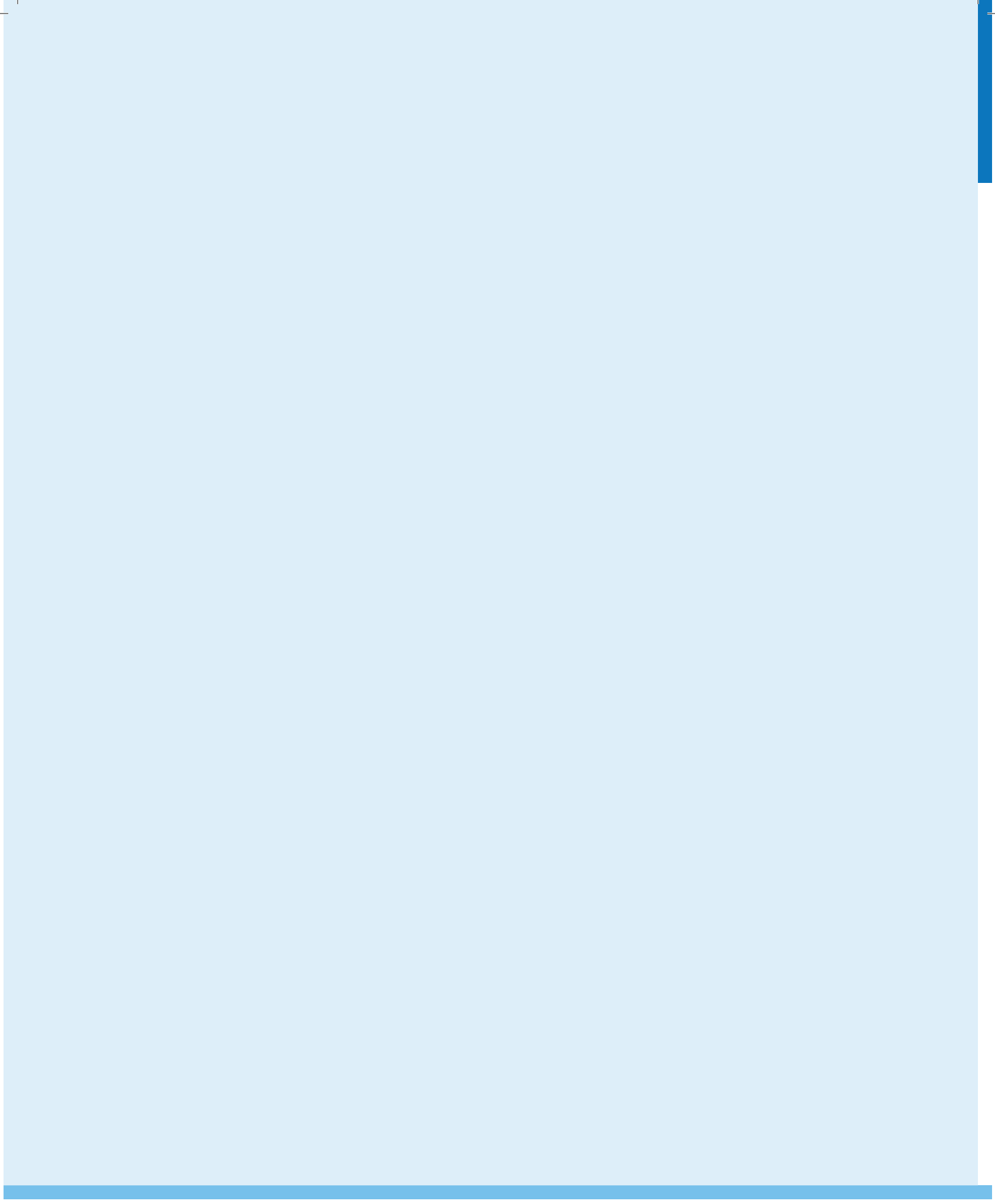
**Keep in mind—you don't have to do it alone.
If someone offers to help, let them!**

It's important to take care of yourself too!

Join National Stroke Association's new online social network, **Careliving Community**, to connect with other caregivers about self-care and share successes and challenges. **Join today at www.stroke.org/careliving.**

The screenshot shows the Careliving Community website. At the top left is the National Stroke Association logo. The main header features the 'careliving' logo and the tagline 'Caring for YOURSELF and a Stroke Survivor'. Below the header is a navigation menu with 'Main', 'Discussion Forum', 'Events', and 'Live Chat'. The main content area is divided into two columns. The left column contains a 'Welcome to Careliving Community' message with 'Sign Up or Sign In' buttons and social media sign-up options. The right column has an 'About Careliving' section explaining the community's purpose and a 'Blog Posts' section featuring a post titled 'Screaming for help with my "Inside voice"' by Lori Ramos Cavallo, dated January 25, 2012, with 3 comments and 6 likes.

If you are unfamiliar with stroke signs and symptoms, stroke risk management or conditions post-stroke, refer to fact sheets that provide information on issues that may affect your caregiving. Visit www.stroke.org/factsheets.



CHAPTER 1—WHERE TO BEGIN?

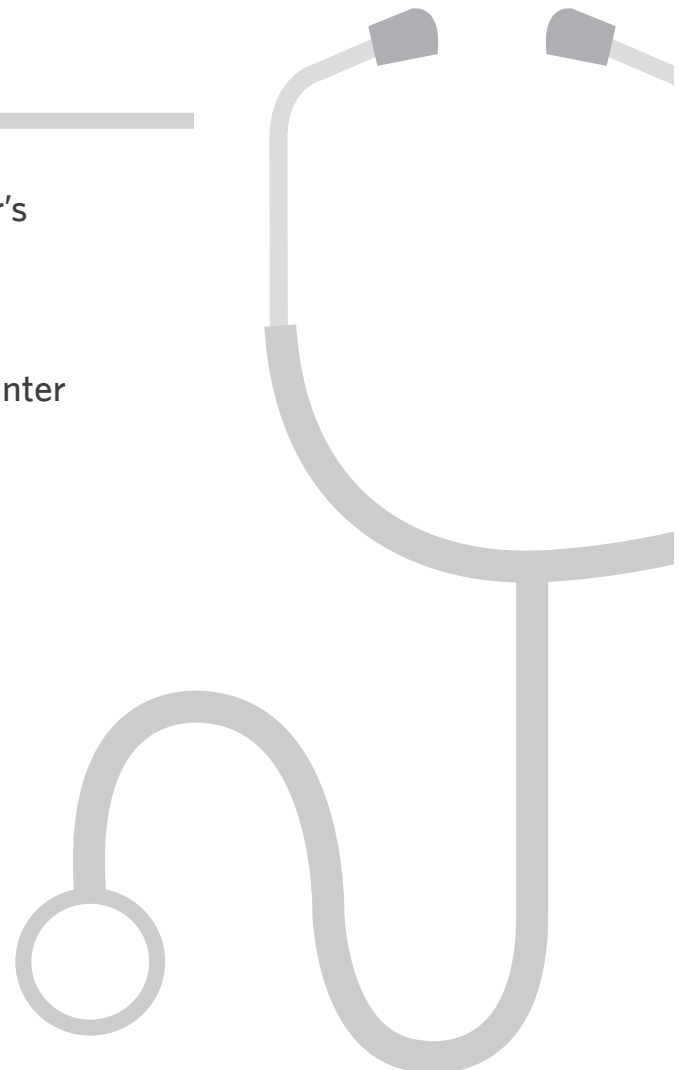
Your loved one has just survived a stroke. A great deal of information will be coming at you at once. Focus on the stroke survivor's immediate needs. This section outlines important things to note during a hospital stay.

MEDICAL HISTORY

Provide the healthcare team with the stroke survivor's medical information:

- History of previous stroke(s).
- Current medications (including over-the-counter medications, supplements and vitamins).
- Past surgeries.
- Allergies.
- Family medical history.
- Health insurance.

If you do not know this information, have someone go to the stroke survivor's home and retrieve all medications. Find a Medication Tracker Template in Appendix A.



WHERE TO BEGIN?

COMMUNICATE WITH HEALTHCARE PROFESSIONALS



Communicating with healthcare professionals is essential. If the stroke survivor cannot advocate for himself/herself, be sure to find out whether there is a designated medical power of attorney (MPOA). If not, make sure there is someone available to advocate for the stroke survivor.

MEDICAL POWER OF ATTORNEY—AUTHORIZING DECISION-MAKING

WHAT IS AN MPOA?*

An MPOA designates a person to make healthcare decisions for the stroke survivor if he/she is unable to do so for him/herself. (See Appendix B for a printable MPOA Form.) An MPOA document provides the specified person the authority to make decisions and fulfill the stroke survivor's wishes. This document gives the designated representative legal authority, which eases the flow of information between the healthcare professionals and the care team. It is necessary to have an MPOA if your loved one becomes unable to make his/her own medical decisions.

TAKE NOTES

Write down questions and concerns as you think of them. If they are written down, you will be less likely to forget to ask these questions when meeting with healthcare professionals.

Take notes or record meetings to confidently relay information to other family members, friends or healthcare professionals. Recording meetings with healthcare professionals avoids miscommunication.

Keep the stroke survivor involved in decision making as much as he/she is able.

**This guide does not replace legal council. Consult with a lawyer for all questions and/or concerns.*

QUESTIONS TO ASK

Here are some important questions to ask at the hospital:

- What caused the stroke?
- What type of stroke was it?
- Where in the brain did it occur?
- What types of challenges are typical after this type of stroke?
- What kinds of tests have already been done?

(See Appendix C for a printable version of Questions to Ask Healthcare Professionals.)

Ask for explanations. If you feel a test is needed and has not been run yet, ask the healthcare professionals about it and to explain why it hasn't been done.

Ask for copies of test results for future doctor appointments. Many hospitals can provide this information on a CD or will email your doctor directly. Having copies of the test results, such as the stroke survivor's CAT scan (computerized axial tomography), will come in handy when working with different healthcare professionals.

Be aware that healthcare professionals may not have answers to every question, especially those that start with "why." Try to be patient and trust that everyone is giving it their best.

Holding your loved one's hands during tests and procedures is an easy way to be supportive.

WHERE TO BEGIN?

IMPORTANT CALLS

Stroke is an emergency and things happen quickly. Once a diagnosis has been made, you may need to make important calls to:

- Your employer.
- The stroke survivor's employer.
- Other family members.
- The stroke survivor's primary care provider, family doctor or other healthcare professionals currently treating your loved one.
- A neighbor or friend to make arrangements for children or pets.

After making these important calls, come up with a way to regularly update people. Setting up a personal blog, mass emails or a phone tree will save you time and energy. Lotsa Helping Hands and CarePages are great resources for this and can be found at www.stroke.org/care.

When discussing critical issues, having a meeting with friends and family may be necessary.

IMMEDIATE NEEDS

There are a variety of issues that may impact the stroke survivor’s immediate recovery. Take note of any issues concerning the stroke survivor’s immediate needs. The following chart lists some common concerns, why they are important and what you can do about them.

Immediate Post-Stroke Concerns

Atrial fibrillation (Afib)	Afib is a condition many people have but may not be aware of. Afib is an irregular rapid heartbeat, and specific medications can be taken to manage it.
Breathing	It is often helpful to request an “incentive spirometer,” which is a device that helps stroke survivors practice breathing and improve lung functioning.
Balance	After a stroke, the area of a stroke survivor’s brain that controls balance may be damaged. Make sure your loved one has assistance when moving and going about their daily activities (e.g., going to the bathroom).
Cognition (thinking) and emotions	It is often more difficult to diagnose and measure cognitive and emotional conditions. It is not uncommon for a stroke survivor to have feelings of depression, shock, confusion and/or anxiety after such a life-altering event. These changes are very common. Pay attention to how the stroke survivor is coping.
Deep venous thrombosis (DVT)	DVT (blood clots in the legs, pelvis and/or arms) can cause swelling and pain. Not all stroke survivors experience DVT, but be aware of the possibility.
Dehydration	Stroke survivors can become dehydrated during hospitalization. Monitor the stroke survivor’s fluid intake.

WHERE TO BEGIN?

Diabetes	Diabetes increases a stroke survivor's risk of having another stroke. Get the stroke survivor tested for diabetes. If he/she is found to have diabetes, medication and changes in diet and lifestyle are usually recommended.
Dietary restrictions and allergies	Discuss any dietary restrictions and/or allergies with a nutritionist or nurse because diet can affect some medications.
Digestive issues	After a meal, be aware that many stroke survivors experience digestive issues such as incontinence, gas, constipation, vomiting and diarrhea. Ask a healthcare professional how to manage these symptoms.
Eating	Your attentiveness during meal times is important in helping prevent further complications. Some stroke survivors have issues swallowing and can choke easily. Lifting the cover off the plate and cutting food may be difficult if there is upper limb weakness or paralysis. Hospital kitchen staff only deliver the food; they do not stay to make sure these issues are resolved. You will want someone present who is aware of these issues and can assist the stroke survivor.
Hypertension (high blood pressure)	Hypertension is a major risk factor for stroke. A blood pressure reading of 140/90 indicates hypertension. Medications can help a stroke survivor manage their blood pressure.
Muscle weakness	Paralysis and weakness in arms and legs may make it difficult for a stroke survivor to move around freely. For management of muscle weakness and paralysis see Chapters 3 and 6.

<p>Seizures</p>	<p>Seizures may last seconds or minutes, but loss of bladder or bowel control and tongue biting can accompany the convulsions. See Chapter 6 for what to do if someone is having a seizure.</p>
<p>Skin and pressure ulcers (bed sores)</p>	<p>Skin and pressure ulcers may not be an immediate concern, but if your loved one is in the hospital for an extended period of time, make sure he/she is moved regularly to prevent skin wounds.</p>
<p>Speech/aphasia</p>	<p>Many stroke survivors struggle with speech-related issues post-stroke. Aphasia is an impairment of language that results from brain damage. Aphasia affects a stroke survivor's ability to use and comprehend words/numbers. You may need to adapt how you communicate with the stroke survivor. Management tips are available in Chapter 6.</p>
<p>Swallowing/dysphagia</p>	<p>Just like with breathing, some stroke survivors have difficulty swallowing. If not diagnosed, dysphagia may result in aspiration (when food or liquid gets caught in the lungs) pneumonia, dehydration or malnutrition. Ask a healthcare professional to assess this.</p>
<p>Vision/hearing issues</p>	<p>Vision and/or hearing issues may be an indication of other medical issues, so it is good to pay attention to the stroke survivor's vision and hearing and report concerns to a healthcare professional.</p>

Watch and listen to National Stroke Association's *iHOPE: Depression and Other Emotional Issues Post-Stroke* webinar as well as the accompanying Ask the Experts session at www.stroke.org/ihope.

SELF-CARE FOR THE CAREGIVER

You may be spending many hours or days at the hospital, depending on the health of your loved one. While this may be a stressful time, taking care of yourself will enable you to provide better care for your loved one. Remember to:

- **EAT AND NOURISH YOURSELF.**
- **REST, NAP AND SHOWER**—See whether the hospital has an area for your use.
- **EXERCISE**—Go for a walk to relieve stress and clear your mind.
- **JOURNAL**—Write down your thoughts, feelings and concerns (for information on the benefits of keeping a journal, visit www.carepartnersresource.com).

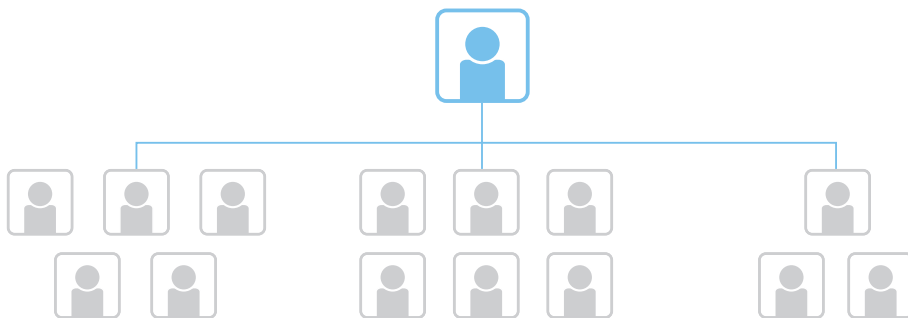


CHAPTER 2—SETTING UP YOUR CARE TEAM

Whether the stroke survivor is still in the hospital, going to a rehabilitation (rehab) center, transitioning home or going to an assisted living facility, set up an organized team of support.

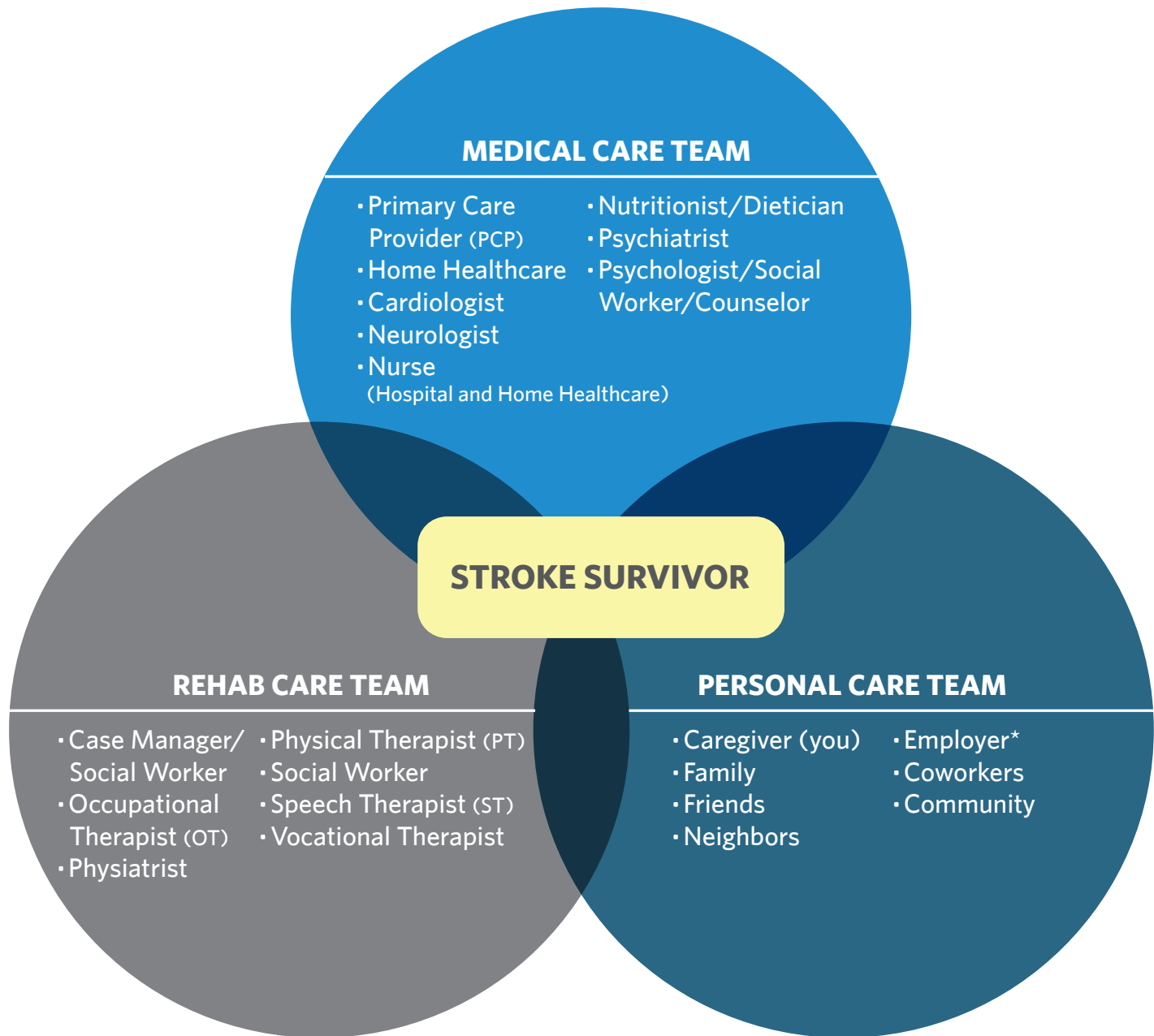
WHAT IS A CARE TEAM?

A care team is a group of people assembled by the stroke survivor, caregiver(s) and/or family of the stroke survivor. The care team may consist of family members, friends, neighbors, employers, coworkers and healthcare professionals. This Guide splits the care team into three parts: the **medical care team**, **rehab care team** and **personal care team**. These teams can share the workload and allow you, the “main” caregiver, the time to focus on the stroke survivor, his/her recovery and daily needs and your own self-care.



SETTING UP YOUR CARE TEAM

CAREGIVING IS A BIG JOB, SO IF SOMEONE OFFERS TO HELP, LET THEM.



*It can be helpful to inform your employer of your new situation and caregiving responsibilities. This will let them know about the new challenges and pressures you are facing. Many companies have plans in place for caregiving and family emergencies. Ask your company's human resource department. You may be eligible for the Family and Medical Leave Act (FMLA).

MEDICAL CARE TEAM

The medical care team includes the neurologist, primary care provider (PCP), home healthcare worker(s) and other specialists involved in the stroke survivor's medical tests and procedures.

PCP Oversees coordination of care through referrals, prescriptions and testing.

Home Healthcare Often certified nursing assistants (CNAs) are prescribed to provide additional support. Visit Care Partner Resource's Hiring a Caregiver Guide for tips and questions to ask agencies at www.carepartnersresource.com.

Cardiologist Involved in diagnosis, management of symptoms post-stroke and referrals for post-hospital care related to disorders of the heart.

Neurologist Involved in diagnosis, management of symptoms post-stroke and referrals for post-hospital care as it pertains to neurological involvement.

Nurse (Hospital and Home Healthcare) Assists with immediate health needs and managing health problems that affect stroke.

Nutritionist/Dietician Provides guidance to help manage healthy eating and special diets.

Psychiatrist Provides prescriptions for antidepressant medications.

Psychologist/Social Worker/Counselor Provides mental health therapy.

SETTING UP YOUR CARE TEAM

REHAB CARE TEAM

The rehab care team is involved in facilitating the stroke survivor's post-stroke recovery therapy. These experienced professionals specialize in rehab.

Case Manager/Social Worker Involved in discharge planning, coordination of services and connecting stroke survivors with local resources.

Occupational Therapist (OT) Works with stroke survivors to regain skills for daily living activities and increased independence.

Physiatrist Specializes in rehab therapy and helps determine appropriate treatment plans to manage pain and disabilities involving muscles, nerves and bones.

Physical Therapist (PT) Engages stroke survivors in exercise techniques to increase mobility, reduce pain, prevent disability and restore independent functioning.

Social Worker May be involved in discharge planning, continuing care and connecting stroke survivors with resources.

Speech Therapist (ST) Works with stroke survivors with aphasia and apraxia issues to regain and improve language skills.

Vocational Therapist Assists stroke survivors who want to return to work, volunteering and other social activities.

PERSONAL CARE TEAM

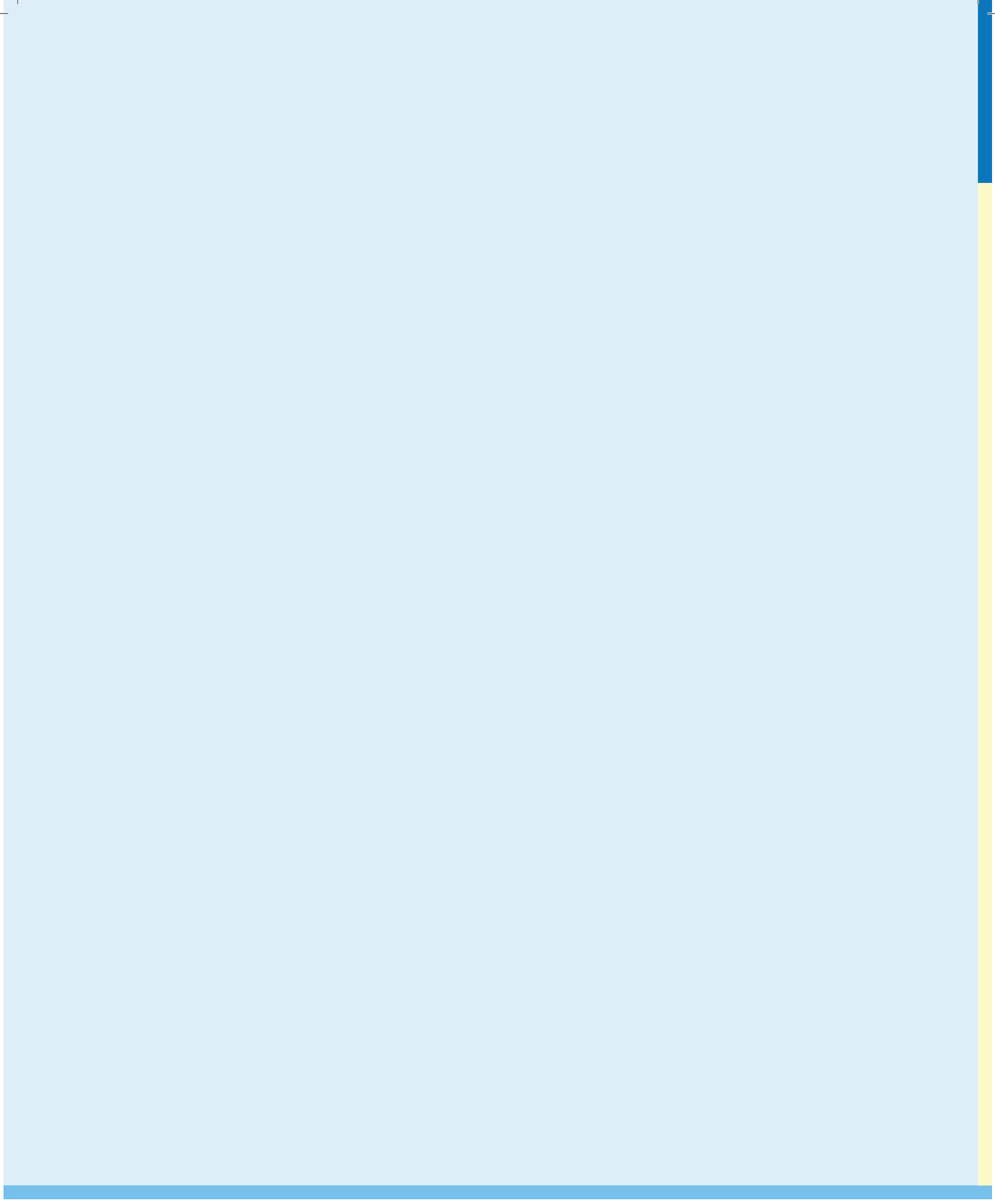
The personal care team can be made up of friends, family, neighbors, coworkers, employers and other members of the community who want to help with the stroke survivor's care.

Schedule a meeting with the personal care team members to address immediate concerns and assign responsibilities in managing:

- Child care—Car-pooling, homework, play-dates, etc.
- Cleaning the house.
- Meal preparation—Hospital food can be repetitive and eating out can be expensive.
- Grocery shopping.
- Laundry.
- Lawn care.
- Pet care.

It is also beneficial for you or the stroke survivor to educate the personal care team members about stroke and the rehab process, as well as the stroke survivor's needs and goals.

Your stroke survivor's care team will be unique to your and the stroke survivor's particular wants and needs.



CHAPTER 3—REHABILITATION (REHAB)

The primary care provider (PCP) usually provides the prescriptions for ongoing rehab therapy. Ask whether rehab should be part of your stroke survivor's recovery because it is not always necessary. It may be necessary to contact your insurance representative to find out what your benefits package covers.

The rehab care team will begin rehab as soon as it is prescribed by the ordering physician. Rehab is essential in helping stroke survivors regain independence and life skills. While rehab does not cure a stroke survivor or completely repair damage to brain tissue, it can help a stroke survivor regain skills and promote recovery.

Whether a stroke survivor is one day or ten years post-stroke, rehab can help.

REHABILITATION

Be sure to call for an appointment as soon as the prescription for rehab is written. A physical therapist, occupational therapist, speech therapist or counselor will be involved at this stage of your loved one's care. Ask these professionals how your personal care team can be supportive with prescribed physical and mental exercises at home. (See **iHOPE: Rehabilitation at Home** at www.stroke.org/ihope.) Studies have shown that supportive caregivers have consistently helped in achieving better outcomes for the stroke survivor's rehab process. Successful rehab often leads to better mental health and quality of life for stroke survivors.

Educate yourself about stroke and your loved one's symptoms and challenges as much as possible.

Conducting your own assessment of your loved one's progress enables you to keep track of their advancements and assists you in communicating with their medical and rehab care teams.

Observe the following to determine whether your loved one needs more support with their:

- Independent movement or mobility.
- Mood and behavioral changes.
- Recovery of physical and mental skills.
- Accessibility of physical environment.
- Social support network.
- Financial status.
- Health insurance coverage.

PICKING A REHAB PROGRAM

Rehab programs are not created equal. Some programs are better than others; consult with your medical care team when choosing a rehab program. Healthcare professionals, friends and family may be able to recommend a rehab program or therapist. If you can, visit potential rehab facilities to learn about their programs and decide whether it's a good fit for the stroke survivor.

Look into specific stroke-certified rehab centers through the Joint Commission on Accreditation of Healthcare Organizations (TJC) and the Commission on Accreditation of Rehabilitation Facilities (CARF). TJC evaluates healthcare facilities and programs on their care and certifies those that meet all industry standards for safety, accountability and quality. CARF certifies stroke rehab facilities to ensure they are comprehensive, person-centered and use best practices in their care.

For assistance in picking a rehab facility that is best equipped to manage the stroke survivor's needs, see our Finding a Rehabilitation Program Checklist in Appendix D.

Information concerning board certification and consumer reviews is available online. Visit www.qualitycheck.org to find a facility certified by TJC and www.carf.org/providersearch to find one certified by CARF.

Continue monitoring the stroke survivor's progress. A stroke survivor should be re-evaluated regularly to ensure that his/her needs are being met.

Once you have decided on a rehab program, consider the rehab facility's geographic location. Find a facility that is easily accessible because therapy can often be several times a week.

GETTING TO REHAB

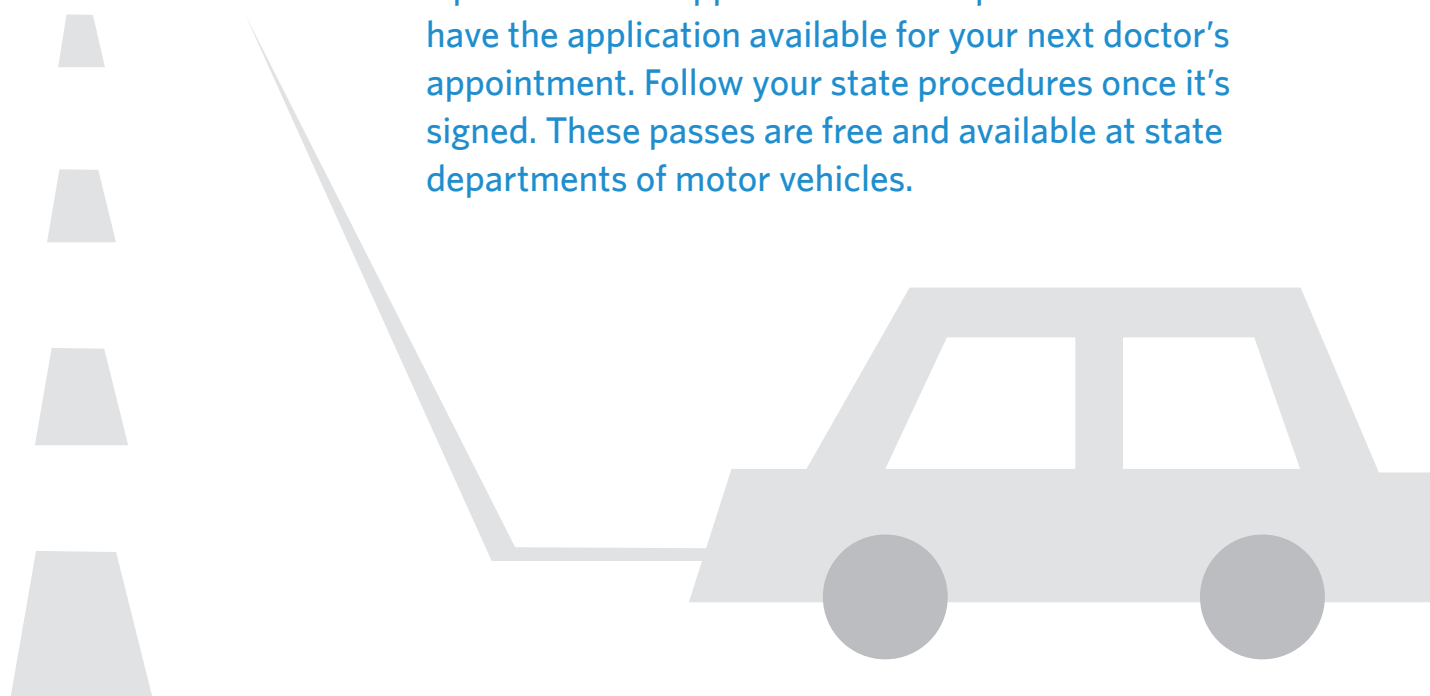
If the stroke survivor is not able to drive himself/herself and you are unable to provide transportation, ask the members of your personal care team for help or look online for a list of alternative transportation resources.

Some alternative forms of transportation are:

- State or county resources such as Access-a-Ride.
- Discounted taxi tickets.
- Public transportation.

You can also talk to local community groups about transportation options (e.g., churches, senior centers).

A handicap pass can be beneficial to a stroke survivor if his/her mobility is limited. A PCP will need to complete a portion of the application for this pass. Be sure to have the application available for your next doctor's appointment. Follow your state procedures once it's signed. These passes are free and available at state departments of motor vehicles.



PAYING FOR REHAB

Paying for the stroke survivor's care and services will depend upon insurance, financial standing and the local programs available to you. Check out the Recovery After Stroke: Health Insurance fact sheet at www.stroke.org/factsheets.

FINANCIAL ASSISTANCE

Insurance often has limitations. Speak to your insurance representative to learn specifics about benefits. Hospital discharge planners, case managers and social workers are also good resources when trying to figure out health insurance coverage.

Information about Medicare, Medicaid or Social Security Disability Insurance (SSDI) benefits and eligibility is available online. Visit www.cms.gov for information on Medicare and Medicaid and www.socialsecurity.gov for information on SSDI. For information that is specific to stroke and SSDI, see the Stroke and Social Security Disability Insurance brochure at www.stroke.org/brochures. The process of applying and obtaining SSDI and/or Medicare benefits can be complicated and overwhelming. Allsup is a company that specializes in helping people navigate these programs. Allsup advisors and representatives assist with the process from application to benefits selection. To learn more about these services, visit www.allsup.com.



REHABILITATION (REHAB)

Long-Term Care Insurance often covers at-home care, assisted living or nursing homes. For information on cost, state partnership programs, benefits and eligibility, visit the Long Term Care Insurance National Advisory Center at www.longtermcareinsurance.org.

The Family and Medical Leave Act (FMLA) offers eligible employees job protection should they require leave for family and/or medical reasons. This program allows caregivers to take time off of work without losing their jobs. The U.S. Department of Labor website includes information about eligibility, forms, news and guidance at www.dol.gov.

The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a program that provides healthcare under the Americans with Disabilities Act. COBRA helps workers and their families with health coverage should they lose health benefits due to job loss, job transition, divorce, death or reduced work hours. Contact the stroke survivor's employer for more information. The U.S. Department of Labor's Employee's Guide to Health Benefits Under COBRA is available at www.dol.gov/ebsa/publications/cobraemployee.html. The guide provides information on eligibility, benefits, tax credits and more.

Some communities have **free assistance programs** such as the state or county department of aging, senior resource centers, faith communities, Boy Scouts of America or veterans groups. Be creative and diligent in your search.


Some states provide **tax credits** or **medical deductions** to caregivers. Although these can relieve some financial stress, eligibility and benefits vary in individual states.

In addition to financial assistance, it is beneficial to locate important documents such as 401(k) (retirement savings) account(s) statements or a living will and keep all bills, statements and medical receipts in an organized place.

Try to exhaust all free resources.

CHAPTER 4—AFTER THE HOSPITAL

Not everyone will be ready to return home post-stroke. Be thoughtful and talk with your medical and rehab care teams to determine the best living environment for your loved one. These decisions will depend on finances as well as the stroke survivor's needs that may change during recovery.



There are a variety of options for daily care. If you and your loved one haven't discussed this yet, you will need to decide the best place for the stroke survivor to continue care.

DAILY CARE OPTIONS

Adult Day Services Structured, supervised day programs that provide nonmedical care and social services, as well as recreational and educational activities.

Assisted Living Facilities Residential communities where a stroke survivor can live independently. They often coordinate health services for residents and provide assistance with activities of daily living such as bathing, dressing and grooming. These facilities differ from nursing homes because they do not provide medical services.

Home Healthcare/Professional Caregivers Nurses, social workers, physical therapists, occupational therapists and other professionals can be prescribed to do home visits.

Live-In Family Caregiver A stroke survivor may prefer to live in his/her home with a family member or a family member's home to assist with recovery.

Nursing Homes Residential facilities that provide acute medical care and therapy for stroke survivors who are currently unable to live independently.

Take the stroke survivor's needs and finances into account when making these decisions.

Support groups may be beneficial for you and your loved one as you navigate through the recovery journey. Groups can help you connect with other stroke survivors and caregivers as well as share advice, resources and tips. Visit National Stroke Association's Stroke Support Group Registry at www.stroke.org/supportgroups to find a group near you.

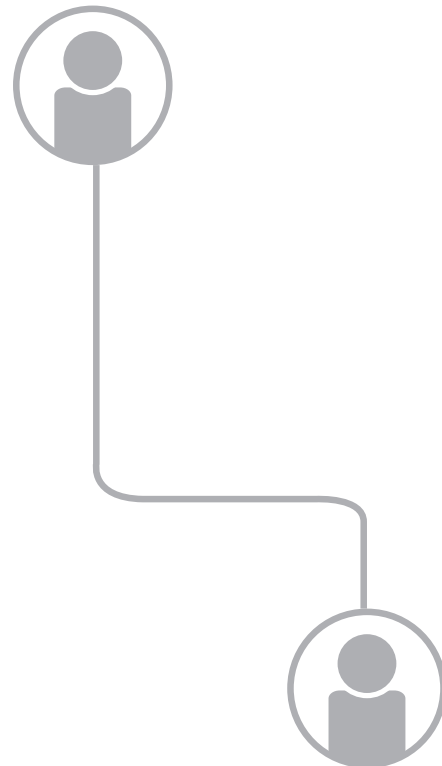
OUTPATIENT SERVICES

When preparing for outpatient services, talk with the stroke survivor's medical and rehab care team members (physicians, nurses, stroke coordinators and/or social workers). They can connect you with discharge information, prescriptions for medications and home care. They can also provide you with information about rehab and companion caregiving services.

Easter Seals Disability Services is a national organization with more than 500 centers throughout the country. Find a location near you at www.easterseals.com. Easter Seals locations may offer rehab services, information about local resources and may be able to make appropriate referrals.

It is very important that you schedule all follow-up appointments as soon as possible. Appointments may include but are not limited to:

- Primary care provider.
- Neurologist.
- Cardiologist.
- Physical therapist.
- Occupational therapist.
- Speech therapist.
- Social worker.



AFTER THE HOSPITAL

Searching for a healthcare professional in your area can be frustrating. However, resources are available to assist you in choosing a healthcare professional that meets your needs. The American Medical Association has a database of member physicians at www.ama-assn.org. Find a physician in your area with the DoctorFinder application. The website, www.ratemd.com allows you to search for professionals in your area and view reviews on their knowledge, experience, punctuality and helpfulness. In addition, consult with the stroke survivor's health insurance company; companies often have registries of local physicians in the stroke survivor's network.

It is important to know how to appropriately assist the stroke survivor; ask your medical and rehab care team members to demonstrate how to move the stroke survivor, administer treatments/medications and follow the recovery plan.

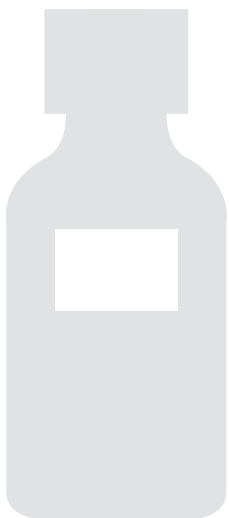
Your medical and rehab care teams may change after discharge from the hospital. Refer to Chapters 2 and 3 to help you plan your loved one's care.

MEDICATIONS

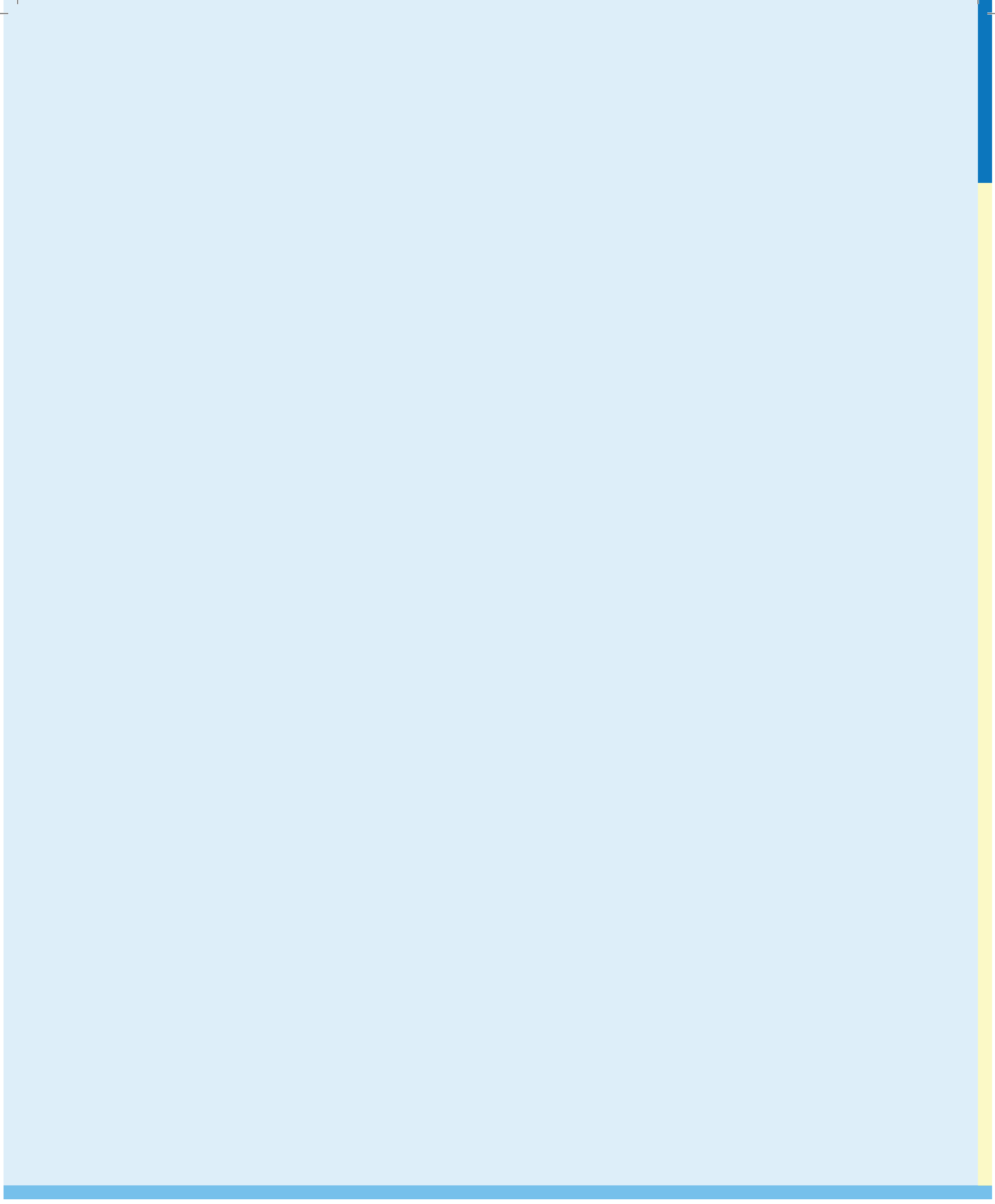
Before leaving your healthcare professional's office or the hospital, make sure to get all prescriptions and have a clear understanding of what each medication/prescription is for. The average stroke survivor is prescribed 11 different medications. These medications may be prescribed to manage pre-existing conditions prior to the stroke, to prevent another stroke or to manage new post-stroke conditions such as depression, chronic pain or seizures.

Ask your pharmacist about food or medication interactions, including herbs and vitamins, and how to administer medication (e.g., time of day, before or after meals). You may want to ask a variety of questions. Refer to page 40 for a list of recommended questions to ask your pharmacist and/or healthcare professional.

Many insurance companies recommend filling prescriptions by mail and for three months at a time. In the beginning, try to fill prescriptions monthly because medications and dosage may change. Prescriptions can be filled in many ways. Talk to your pharmacist about your options and choose what will work best for you and your loved one.



To help you track your loved one's medications, check out our Medication Tracker Template in Appendix E.



CHAPTER 5—CREATING YOUR CARE BINDER

A care binder is a personalized tool to store important information concerning your loved one's care. It should also be used to help other caregivers who do not know the stroke survivor's routine and/or daily needs. Keeping this information easily accessible (e.g., near the refrigerator) is beneficial in case of an emergency. You should also carry emergency numbers, medications list and insurance information with you at all times.



CREATING YOUR CARE BINDER

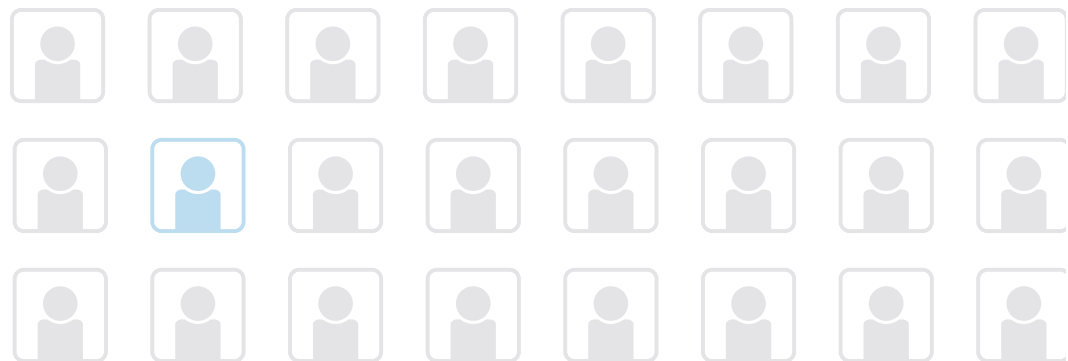
A care binder should include

- **Emergency numbers**, including 9-1-1, caregivers, family members, friends, neighbors and “in case of emergency” people. List the numbers in the order you would like them called.
- **List of medications/medical information**, including allergies, blood type and details for administering medications.
- **Medical history**, including diseases, surgeries, previous strokes and any other important information.
- **Contact information for healthcare professionals**, including therapists, home healthcare agencies and the pharmacy.
- **Copies of the stroke survivor’s driver’s license, social security card and health insurance card**. Having these with the stroke survivor is beneficial when going to the hospital.
- **Copies of Do Not Resuscitate (DNR) or other state-related forms** for the stroke survivor. Have a copy in your car and on the fridge.
- **A copy of the medical/financial power of attorney (MPOA or FPOA)**.
- **Daily routine instructions**, including meal times, medication times and activities.

See Appendices A through G for templates to help you create your care binder and get organized. Download and print the templates applicable to you and your needs.

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.

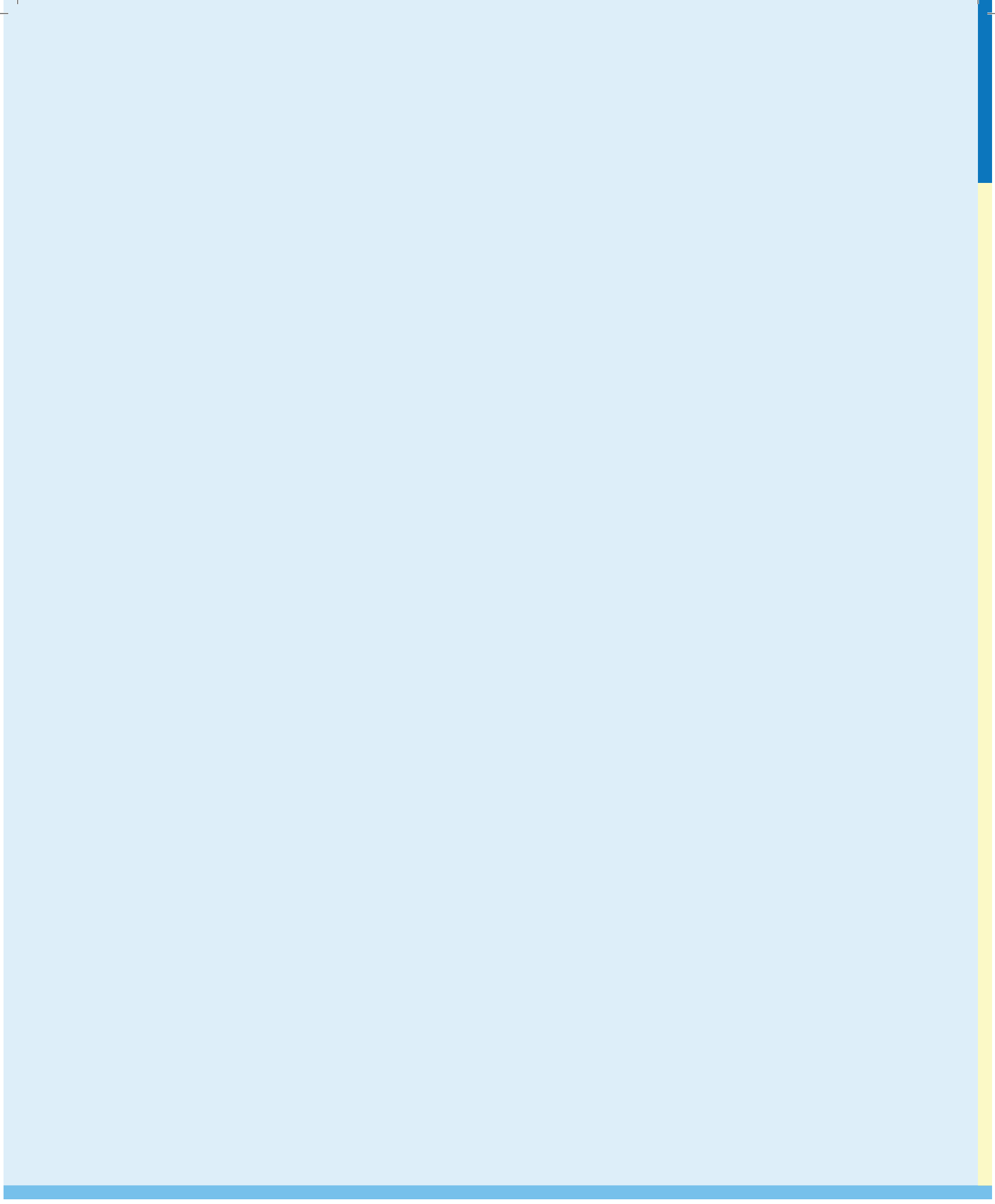
Pseudobulbar affect (PBA) is a condition characterized by episodes of uncontrollable laughing and/or crying that may be inappropriate, unrelated to the situation at hand or not reflecting the person’s actual mood. The condition is known by other terms, including emotional lability, emotional incontinence 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:

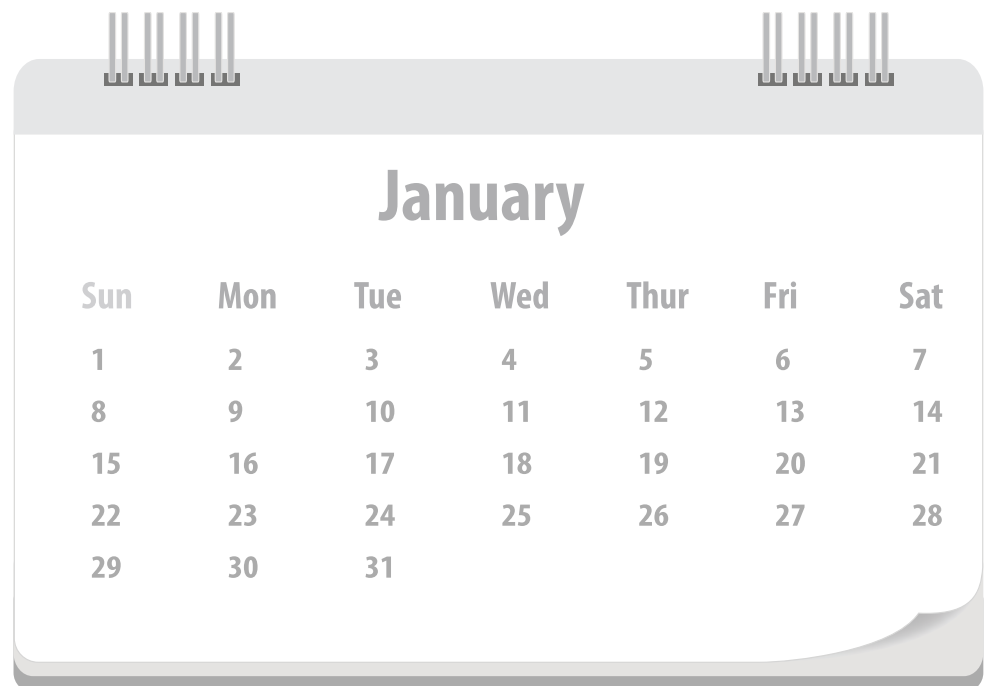
- Treat your loved one with patience; take one day at a time.
- Maintain open communication and involve the stroke survivor in as much decision-making as possible.
- Encourage independence as much as possible. Promote self-acceptance and celebrate even the smallest victories.
- Establishing a routine 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.





CHAPTER 7—ADJUSTING THE ROUTINE

You and the stroke survivor can continue to do things you love; however, what was “normal life” pre-stroke is not always the same as “normal life” post-stroke. There are things you need to remember when scheduling activities and appointments. Change can be difficult, so keep in mind that recovery is a process.



ADJUSTING THE ROUTINE

Remember, respite care may be an option to give you a break every now and then.

Between 70 and 90 percent of stroke survivors experience some difficulty with mobility. A stroke survivor with limited mobility will require more assistance with not just walking, but personal care, getting from place to place and other daily activities. Progress is possible with perseverance and the continuation of rehab exercises at home. All activity needs to be adapted to the stroke survivor's pace.

Be creative in the ways you keep the stroke survivor's recovery moving forward:

- Outdoor or mall walking.
- Exercise videos (yoga, stretching, chair exercises).
- Computer games.
- Trips to the grocery store.

Maintaining daily activity and using adaptive tools to meet current needs will help to continue improvement. To learn more, visit www.stroke.org/ihope for information on:

- ***iHOPE: Mobility***
- ***iHOPE: Rehabilitation at Home***

FATIGUE

Post-stroke fatigue, the “invisible symptom”, affects between 40 and 70 percent of stroke survivors. Fatigue is often confused with “being tired.” It is important to know that fatigue is not necessarily the same as tiredness, because it arrives without warning and rest does not always make it better. Fatigue can occur days, weeks, months or even years post-stroke. It occurs differently in every individual, making a person feel physically, cognitively and/or emotionally exhausted. Fatigue can greatly impact daily life and limit recovery. As caregiver, you need to be prepared to help your loved one manage their fatigue.

Fatigue can make it difficult to perform daily tasks or stay motivated. Many stroke survivors report that they feel like they’re “hitting a wall.” Communication is vital to managing fatigue—ask the stroke survivor questions and encourage them to let you know when they feel tired.

- **Physical fatigue**—Motor deficits or muscle weakness and spasms.
- **Cognitive fatigue**—Memory loss, mental exhaustion and/or difficulty focusing.
- **Emotional fatigue**—Can co-exist with mood disorders, loss of motivation.

**Many factors can influence a stroke survivor’s level of fatigue.
Pay close attention to the stroke survivor’s:**

- Medications and medication side effects.
- Physical post-stroke symptoms such as upper limb weakness.
- Diet—Certain foods induce drowsiness.
- Sleep patterns.
- Pain.

To learn more about post-stroke fatigue, watch and listen to **iHOPE: Fatigue** at www.stroke.org/ihope, and check out the **Managing Fatigue** fact sheet at www.stroke.org/factsheets.

FATIGUE MANAGEMENT STRATEGIES

Keep a fatigue diary to record time, places and environments when fatigue occurs. To remain active while managing fatigue, consider an activity's location, the logistics required for the activity, how much time the activity will take and the stamina needed for the activity as well as diet.

Location—When planning an outing with your loved one, it can be helpful to visit the location first to check accessibility. The Americans with Disabilities Act (ADA) requires facilities to have accessible utilities, but some locations do not always allow for two people in the same space. When you have a stroke survivor with one-sided weakness, parking, entering the location and using the bathroom can be extremely challenging.

Logistics—Plan your activities around the stroke survivor's needs and abilities as much as possible. If you will be gone during medication or nap times, plan ahead and bring medications along. Make time so the stroke survivor can rest. Ask yourself: what kinds of skills/resources will be involved? What you will need to bring with you?

Time—Be aware of how long an activity will take. Consider your surroundings. Outside stimulation such as crowds, music and background noise can be overwhelming for a stroke survivor. It is best to do outings involving these factors for limited amounts of time.



Stamina—Determine what activities have the greatest impact on energy level. Try doing activities when the stroke survivor is most energetic and alert. Some people are “morning people,” and some are “night owls.”

If you are planning to go to a restaurant, make sure the menu has choices that are not only pleasing to everyone, but also meet the stroke survivor’s nutritional needs.

Diet—Eating certain energy-packed foods may reinforce the strategies above. Foods that help fight fatigue include:

- Dark chocolate.
- Pumpkin seeds.
- Red bell peppers.
- Tea.
- Walnuts.
- Watermelon.
- Wheat bran cereal.
- Whole grains.
- Yogurt.

Thinking ahead is worthwhile, yet a little overwhelming. Invite a friend along for added support. To learn more on managing post-stroke fatigue, watch and listen to **iHOPE: Fatigue** at www.stroke.org/ihope.

CHAPTER 8—PREVENTING RECURRENT STROKE

The best defense against recurrent stroke is good offense. Equip yourself, the stroke survivor and family members with information and tips for preventing another stroke.

NATIONAL STROKE ASSOCIATION RESOURCES FOR PREVENTING ANOTHER STROKE

MULTIMEDIA



- Explaining Stroke Interactive
- *iHOPE*: Medication Adherence and Compliance
- *iHOPE*: Preventing Another Stroke

BROCHURES/FACT SHEETS



- African Americans and Stroke
- Fact Sheet Series
- High Blood Pressure and Stroke
- Medication Adherence
- Steps Against Recurrent Stroke (STARS)
- Stroke and Cholesterol

TOOLS



- Medication Adherence Tracker
- Stroke Risk Scorecard

Download at www.stroke.org

RISK FACTOR MANAGEMENT

Be aware of your loved one's symptoms and challenges. Helping them manage their health will help reduce their risk of recurrent stroke.

CONTROLLABLE RISK FACTORS

Alcohol

Reduce or eliminate alcohol consumption. Drinking more than two alcoholic drinks in one day raises a person's risk for stroke by 50 percent. Alcohol can negatively affect many organs and systems. Alcohol depresses the central nervous system and inhibits the liver's ability to produce proteins that regulate blood clotting. This thins the blood, which can be a good and a bad thing. Alcohol also influences platelet (irregularly shaped cell fragments that circulate in the blood) function. Too many platelets cause excessive bleeding and too few cause blood clots. Alcohol contributes to platelet activation; activated platelets are more "sticky" than normal ones, causing blood clots. One drink of alcohol increases platelets a little, but excessive drinking causes too many platelets to activate, thus increasing risk for clots. Over time, excessive alcohol use can lead to long-term increases. Alcoholic beverages usually contain a lot of calories as well, which can contribute to weight gain.

The influence alcohol has on an individual depends on the person's age, gender, height, weight, genetics, level of hydration and medications. While some research says that drinking a small or moderate amount of alcohol can be beneficial in reducing risk of stroke, always consult with a healthcare professional. Heavy drinking can also increase the risk for atrial fibrillation in men.

Atrial fibrillation (Afib)

Afib is an irregular, rapid heartbeat that impairs a person's heart functioning because it slows blood to the heart. Afib is a major risk factor for stroke with no visible symptoms. A person with Afib is five times more likely to have a stroke. However, 75 percent of Afib-related strokes can be prevented with the use of anticoagulant medications that thin the blood. Because the risk of blood clots increases in those with Afib, anticoagulants are essential to prevention. Learn more about Afib by watching ***iHOPE: Atrial Fibrillation*** at www.stroke.org/ihope.

Diabetes

Diabetes is a group of chronic conditions where a person has high levels of sugar in the blood because of the body's inability to produce and/or use insulin. Medical treatment and dietary changes will be essential to manage diabetes, which increases the risk for stroke. To learn more about diabetes, visit www.stroke.org/diabetes.

Drug use

Illegal drugs like cocaine and amphetamines raise the risk for stroke as they narrow blood vessels and increase blood pressure.

Exercise

Staying active and exercising for 30 minutes five times a week can help a stroke survivor stay healthy and reduce risk factors. Exercise doesn't necessarily mean walking, running or lifting weights. Talk to the stroke survivor's medical and rehab care teams for exercises that can be done at home. For more information on rehab at home, watch and listen to ***iHOPE: Rehabilitation at Home*** at www.stroke.org/ihope.

PREVENT RECURRENT STROKE

High cholesterol

Cholesterol is a fat that is present in the outer layer of every cell in the body. It is produced by the liver and is necessary for normal bodily functioning. A cholesterol level of over 200 is considered high and raises the risk for recurrent stroke. High cholesterol can be caused by smoking, drinking too much alcohol, being overweight, not exercising and eating foods that are high in saturated fat. Medical treatments and diet changes are effective in lowering cholesterol. Talk with the stroke survivor's medical care team about appropriate treatment for high cholesterol.

Hypertension

High blood pressure, or hypertension, is another major risk factor for stroke. A blood pressure reading of 140/90 indicates hypertension. Talk with the stroke survivor's medical care team about effective strategies to lower blood pressure. Medical treatments, diet changes and exercise are most common.

Nutrition

Low-sodium, low-fat diets with lots of fruits and vegetables are best. Watch and listen to **iHOPE: Nutrition** to learn more about eating right to prevent stroke at www.stroke.org/ihope. Refer to the Post-Stroke Concerns section in Chapter 6 of this guide for websites that have healthy recipes and help with meal planning.

Smoking

Stop! Nicotine raises blood pressure. Smoking cigarettes reduces oxygen in the blood, making the blood thicker and more likely to clot. Ask the stroke survivor's primary care provider for tips for quitting smoking.

Weight

The combination of an active lifestyle and healthy diet will help reduce weight gain. Not only does maintaining a healthy weight reduce the risk of stroke, but it can also reduce the risk for obesity, diabetes, heart problems and more.

UNCONTROLLABLE RISK FACTORS

Age

Strokes can occur at any age. The risk for stroke, however, doubles every 10 years between the ages of 55 and 85.

Family history, gender and race

Take note that:

- Stroke risk factors run in families.
- The risk for stroke is higher among men.
- African Americans and Latinos are twice as likely to have a stroke as Caucasians.

STROKE WARNING SIGNS

Once someone has had a stroke, he/she has a higher risk of recurrent stroke than the general population. Helping the stroke survivor manage his/her health is important but you should also know the warning signs of a stroke so you can identify one immediately if it occurs.

Some sudden signs of stroke:

- **Dizziness, including trouble walking or standing.**
- **Numbness or weakness of the face, arm or leg.**
- **Confusion, including trouble speaking or understanding.**
- **Severe headache with no known cause.**
- **Trouble seeing.**

Warning Signs of Stroke

Learn the many warning signs of a stroke. Act **FAST** and **CALL 9-1-1 IMMEDIATELY** at any sign of a stroke. Use **FAST** to remember warning signs:

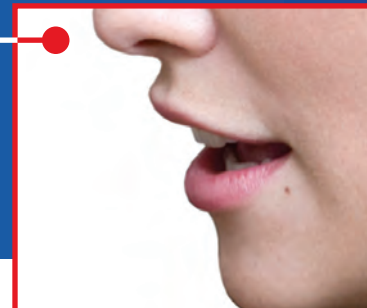
F **FACE:** Ask the person to smile. Does one side of the face droop?



A **ARMS:** Ask the person to raise both arms. Does one arm drift downward?



S **SPEECH:** Ask the person to repeat a simple phrase. Is their speech slurred or strange?



T **TIME:** If you observe any of these signs, call 9-1-1 immediately.



NOTE THE TIME WHEN ANY SYMPTOMS FIRST APPEAR. If given within *three hours* of the first symptom, there is an FDA-approved clot-buster medication that may reduce long-term disability for the most common type of stroke.

LEARN ABOUT MORE SIGNS OF STROKE AT

www.stroke.org/symp

In addition to these signs, women can experience unique and sudden symptoms that include but are not limited to:

- **Hiccups**
- **Shortness of breath**
- **General weakness**
- **Nausea**
- **Heart palpitations**
- **Face or limb pain**
- **Chest pain**

If your loved one is experiencing one or more of these symptoms, act FAST and call 9-1-1 IMMEDIATELY.

If the stroke survivor has another stroke, it will be helpful if you:

- Know which hospital/stroke center you and your loved one prefer. Choices should be based on previous care, location and reputation.
- Take your caregiver binder with you. It will have the stroke survivor's insurance information, identification cards, medication list, healthcare professional information and medical history information.
- Insist on an MRI (magnetic resonance imaging) or a CAT scan (computerized axial tomography) due to previous stroke history. An MRI uses magnetic and radio waves to take pictures of different body parts, and a CAT scan is a specialized x-ray.
- **Be assertive! Follow your instincts!**

APPENDICES

This guide was developed to assist you in organizing your loved one's care. The following appendices can be used to help you organize yourself. Pick the ones that fit your needs, and adapt them as you see fit.

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MEDICAL HISTORY TEMPLATE

Name: _____ **Blood Type:** _____ **Positive** **Negative**

Date	Medical Condition/Surgery/Injury	Comments



MEDICAL POWER OF ATTORNEY FORM*

DESIGNATION OF HEALTHCARE AGENT

I, (insert your name) _____

Appoint: (name) _____

Address: _____

Phone: _____

as my agent to make any and all healthcare decisions for me, except to the extent I state otherwise in this document. This Medical Power of Attorney takes effect if I become unable to make my own healthcare decisions and my physician certifies this fact in writing.

LIMITATIONS ON THE DECISION-MAKING AUTHORITY OF MY AGENT ARE AS FOLLOWS:

Designation of Alternate Agent

(You are not required to designate an alternate agent but you may do so. An alternate agent may make the same healthcare decisions as the designated agent if the designated agent is unable or unwilling to act as your agent. If the agent designated is your spouse, the designation is automatically revoked by law if your marriage is dissolved.)

If the person designated as my agent is unable or unwilling to make healthcare decisions for me, I designate the following persons to serve as my agent to make healthcare decisions for me as authorized by this document, who serve in the following order:

**This guide does not replace legal council. Consult with a lawyer for all questions and/or concerns.*

First Alternate Agent

Name: _____

Address: _____

Phone: _____

Second Alternate Agent

Name: _____

Address: _____

Phone: _____

The original of this document is kept at _____

The following individuals or institutions have signed copies:

Name: _____

Address: _____

Phone: _____

Name: _____

Address: _____

Phone: _____

**This guide does not replace legal council. Consult with a lawyer for all questions and/or concerns.*

Duration

I understand that this medical power of attorney exists indefinitely from the date I execute this document unless I establish a shorter time or revoke the medical power of attorney. If I am unable to make healthcare decisions for myself when this medical power of attorney expires, the authority I have granted my agent continues to exist until the time I become able to make healthcare decisions for myself.

(IF APPLICABLE) This medical power of attorney ends on the following date: _____

Prior Designations Revoked

I revoke any prior Medical Power of Attorney.

Acknowledgment of Disclosure Statement

I have been provided with a disclosure statement explaining the effect of this document. I have read and understand that information contained in the disclosure statement.

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY.)

I sign my name to this Medical Power of Attorney on
_____ day of _____ month _____ year
at _____
(City and State)

(Signature)

(Print Name)

Statement of Witness

I am not the person appointed an agent by this document. I am not related to the principal by blood or marriage. I would not be entitled to any portion of the principal's estate on the principal's death. I am not the attending physician of the principal or an employee of the attending physician. I have no claim against any portion of the principal's estate on the principal's death. Furthermore, if I am an employee of a healthcare facility in which the principal is a patient, I am not

**This guide does not replace legal council. Consult with a lawyer for all questions and/or concerns.*

APPENDIX B

involved in providing direct patient care to the principal and am not an officer, director, partner or business office employee of the healthcare facility or of any parent organization of the healthcare facility.

Signature: _____

Print Name: _____

Address: _____

Date: _____

Signature: _____

Print Name: _____

Address: _____

Date: _____

EXAMPLE

Source: Texas Medical Association. (1999). Medical power of attorney. www.texmed.org.

**This guide does not replace legal council. Consult with a lawyer for all questions and/or concerns.*

QUESTIONS TO ASK HEALTHCARE PROFESSIONALS

- What caused the stroke?

- What type of stroke was it?

- Where in the brain did it occur?

- What kinds of tests have already been done?

- What types of physical problems may arise post-stroke and how do we treat them?

- What types of emotional problems may arise post-stroke and how do we treat them?

- Is rehabilitation necessary? If yes, ask about specific prescriptions/referrals.

Add your questions here:

FINDING A REHABILITATION (REHAB) PROGRAM CHECKLIST

Name of Program: _____

About The Program	Yes	No	Notes
Does the program have a full-time physiatrist or other healthcare professional who is experienced in stroke and rehab medicine on staff?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program provide a wide range of therapy services? (Physical therapy, occupational therapy or speech therapy)	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program provide the specific services the stroke survivor needs?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program have a formal system for evaluating the progress made by its patients and the overall outcomes of the stroke rehab program?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program have any partners that offer rehab services at other levels of care that the stroke survivor may eventually need? (Day treatment, outpatient treatment or home care)	<input type="checkbox"/>	<input type="checkbox"/>	
Are staff members required to keep up with new information about stroke and rehab? How do they do so?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program match the stroke survivor's abilities, or is it too demanding or not demanding enough?	<input type="checkbox"/>	<input type="checkbox"/>	
Is medical care available at the rehab center if needed?	<input type="checkbox"/>	<input type="checkbox"/>	

APPENDIX D

Can the stroke survivor's healthcare professional visit him/her at the rehab center?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program have a stroke support group for survivors and their families? If not, can they make a referral to a local group?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program use outside groups (such as consumer advocacy groups) to get ideas for serving people with disabilities?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the program conduct home visits before checking people out of the center and releasing them to their homes?	<input type="checkbox"/>	<input type="checkbox"/>	
Has the program been in operation at least one year?	<input type="checkbox"/>	<input type="checkbox"/>	
TREATMENTS & SERVICES	Yes	No	Notes
Does the program provide the specific services the stroke survivor needs?	<input type="checkbox"/>	<input type="checkbox"/>	
Is the stroke survivor eligible for those treatments?	<input type="checkbox"/>	<input type="checkbox"/>	
Will there be bilingual staff members?	<input type="checkbox"/>	<input type="checkbox"/>	
Will there be sign language interpreters?	<input type="checkbox"/>	<input type="checkbox"/>	
Will medical information be explained in simple terms?	<input type="checkbox"/>	<input type="checkbox"/>	
Is help available with discharge? How does it work?	<input type="checkbox"/>	<input type="checkbox"/>	
What percentage of people will return home after discharge?	N/A	N/A	
What percentage of people will be placed in nursing homes?	N/A	N/A	

LOCATION	Yes	No	Notes
If it is an outpatient program, is transportation available?	<input type="checkbox"/>	<input type="checkbox"/>	
Is the location convenient?	<input type="checkbox"/>	<input type="checkbox"/>	
Is the location close to public transportation?	<input type="checkbox"/>	<input type="checkbox"/>	
HOURS	Yes	No	Notes
Are the days and times convenient for the stroke survivor?	<input type="checkbox"/>	<input type="checkbox"/>	
What are the visiting hours?	<input type="checkbox"/>	<input type="checkbox"/>	
Are the visiting hours convenient for family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	
Are the visiting hours long enough for a good quality visit?	<input type="checkbox"/>	<input type="checkbox"/>	
COST & INSURANCE	Yes	No	Notes
What is the estimated cost of treatment?	N/A	N/A	
Will the stroke survivor's insurance plan or government funding (Medicare, Medicaid, state health plans) cover all or part of the cost?	<input type="checkbox"/>	<input type="checkbox"/>	
Will the staff help with health insurance claims or appeals, if needed?	<input type="checkbox"/>	<input type="checkbox"/>	
What is the average total cost for the complete stroke program? (Acute rehabilitation, home care and outpatient)	N/A	N/A	

APPENDIX D

CUSTOMER SERVICE & SATISFACTION	Yes	No	Notes
Does the program collect information from patients and their families about satisfaction with the care received?	<input type="checkbox"/>	<input type="checkbox"/>	
If so, is the feedback generally positive?	<input type="checkbox"/>	<input type="checkbox"/>	
Can I talk to other people who have used the services?	<input type="checkbox"/>	<input type="checkbox"/>	
How long do most stroke survivors stay in the program?	N/A	N/A	

Notes:

MEDICATION TRACKER TEMPLATE

Mark the top of a medication bottle with the corresponding number to help manage and identify each medication.

Medications	Dosage	Morning	Noon	Afternoon	Night	How Does the Med Make You Feel?	Date of Last Med/Dose Change	Comments	Date of Next Refill
SAMPLE									
#1= Baclofen	10mg	X	X		X		12-2011	For spasticity	2-2012
1=									
2=									
3=									
4=									
5=									
6=									
7=									
8=									
9=									
10=									
11=									
12=									
As Needed=									

Patient Name: _____

Primary Care Provider: _____ Phone: _____

Pharmacy: _____ Phone: _____

Medication Allergies: _____

Food Allergies: _____

EMERGENCY CONTACT INFORMATION TEMPLATE

Patient Name: _____

Home Phone: _____

Address: _____

Who to Call

First Contact: NAME: _____

Number: _____ Home/Cell/Work

Number: _____ Home/Cell/Work

Second Contact: NAME: _____

Number: _____ Home/Cell/Work

Number: _____ Home/Cell/Work

Third Contact: NAME: _____

Number: _____ Home/Cell/Work

Number: _____ Home/Cell/Work

PHYSICIAN INFORMATION TEMPLATE

Patient Name: _____

Primary Care Provider:

Name: _____

Physician Assistant or Nurse Practitioner: _____

Phone Number: _____

Neurologist:

Name: _____

Phone Number: _____

Cardiologist:

Name: _____

Phone Number: _____

Nephrologist:

Name: _____

Phone Number: _____

Other (Type): _____

Name: _____

Phone Number: _____

Other (Type): _____

Name: _____

Phone Number: _____

National Stroke Association's mission is to reduce the incidence and impact of stroke by developing compelling education and programs focused on the prevention, treatment, rehabilitation and support for all impacted by stroke.

A stroke is a brain attack that occurs when a blood clot blocks an artery or a blood vessel breaks, interrupting blood flow to an area of the brain. Brain cells begin to die.

CALL 9-1-1 IMMEDIATELY IF YOU SEE ONE OR MORE SIGNS OF A STROKE.



1-800-STROKES
(787-6537)

www.stroke.org

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