



# 2025-2026

# CAREGIVER RESOURCES

# AND EDUCATION BOOKLET

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A quick reference guide of resources and education for caregivers who provide long term support during a loved one's recovery and rehabilitation after experiencing a stroke.

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# TABLE OF CONTENTS

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Caregiver Resources.....pages 2-5  
Respite Care.....pages 6-7  
Transportation.....page 8  
Communication Tips.....page 9  
Medications.....page 10  
Rehabilitation.....pages 11-12  
Stroke Effects.....page 13  
Life After Stroke.....page 14  
Understanding Fatigue.....page 15  
Emotional Wellbeing.....page 16  
Support Group Resources.....pages 17-18



## UofL TRAGER INSTITUTE CAREGIVER PROGRAM

The UofL Trager Institute's Caregiver Program supports individuals caring for a loved one that is 60 or older or someone under 60 diagnosed by a doctor with dementia or Alzheimer's in Bullitt, Henry, Oldham, Shelby, Spencer, Trimble and Jefferson County in Kentucky.

### CONTACT INFORMATION:

Call Caregiver Hotline: (502) 557-0550

Email: [misty.kupka@louisville.edu](mailto:misty.kupka@louisville.edu)

Learn More: [www.tragerinstitute.org/caregivers](http://www.tragerinstitute.org/caregivers)

Scan this QR code or visit

[www.tragerinstitute.org/trager-caregiver-survey](http://www.tragerinstitute.org/trager-caregiver-survey) to fill out an online interest survey



## NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

The National Family Caregiver Support Program offers flexible benefits and support services to informal caregivers of people 60 years of age or older, an individual with Alzheimer's disease or a related disorder and also for grandparents and relatives age 55 or older caring for a relative child no older than 18 years of age related by birth, marriage or adoption. The services include:

- Information about available programs and services.
- Assistance accessing services.
- Counseling, support groups and training to help caregivers make decisions and solve problems related to their caregiver role.
- Respite care to give caregivers time off from care giving responsibilities.
- Supplemental services on a limited basis, to supplement caregiving tasks

### CONTACT INFORMATION:

Call Department for Aging and Independent Living (DAIL):

(502) 564-6930

Learn More:

[www.chfs.ky.gov/agencies/dail](http://www.chfs.ky.gov/agencies/dail)



## AARP FAMILY CAREGIVER RESOURCES FOR KENTUCKY

AARP developed this family caregiver guide with you, the caregiver, in mind and as a starting point to help you find the services and support you might need throughout your journey.

### CONTACT INFORMATION:

To order a print copy of this online guide, call the toll-free AARP Family Caregiving Resource Line at 877-333-5885 and indicate which state(s) you would like to receive. A copy will be mailed to you. Scan the QR code below for list of resources that can be offered through AARP.

[www.aarp.org/caregiving/local/info-2021/state-caregiver-resources.html](http://www.aarp.org/caregiving/local/info-2021/state-caregiver-resources.html)



## DIVISION OF LONG-TERM SERVICES AND SUPPORTS

Kentucky Medicaid's Division of Long-Term Services and Supports (LTSS) oversees programs for Kentuckians who need ongoing support due to their age, a medical condition, or a disability. LTSS offers a variety of options to meet each individual's unique needs.

Check out the wavier programs:

- Acquired Brain Injury (ABI) Acute and Long-Term Care Waivers
- Home and Community Based Wavier
- Model II Wavier
- Michelle P Wavier
- Supports for Community Living Wavier

### CONTACT INFORMATION:

Call: (502) 564-7540

Learn More:

[www.chfs.ky.gov/agencies/dms/dca](http://www.chfs.ky.gov/agencies/dms/dca)



## PERSONAL CARE ATTENDANT PROGRAM

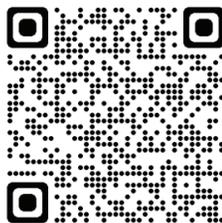
The Personal Care Attendant Program helps severely physically disabled adults at risk of being institutionalized to live in their own homes and communities by subsidizing costs of personal attendant services. Participants must be 18 or older, severely physically disabled with permanent or temporary recurring functional loss of two or more limbs, need at least 14 hours but no more than 40 hours of attendant care per week, be mentally capable of instructing and supervising attendants and be capable of preparing payroll and required employer tax statements.

A personal care attendant, hired by the physically disabled adult, helps with personal care, housekeeping, shopping, travel, self-care procedures, meal preparation and other day-to-day activities.

### CONTACT INFORMATION:

Scan QR code below to find your Regional Personal Care Attendant Program Coordinators or send an email to [PCAP.HSL@ky.gov](mailto:PCAP.HSL@ky.gov)

<https://www.chfs.ky.gov/agencies/dail/Pages/pcap.aspx>



## AMERICAN STROKE ASSOCIATION CAREGIVER SUPPORT

As a caregiver, you provide the most important long-term support for your stroke survivor's recovery and rehabilitation. But who takes care of you?

You're not alone in facing the challenges to balance your caregiving with family, work, personal time and other commitments. More than 53 million Americans are caregivers — as diverse as those they care for: spouses, partners, adult children, parents, siblings, grandchildren and family friends. At the American Stroke Association, we're only a click or a phone call away to assist you.

### CONTACT INFORMATION:

Learn More:

<https://www.stroke.org/en/help-and-support/for-family-caregivers>



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## APHASIA RECOVERY CONNECTION

CONNECT TO COMMUNITY WITH VIRTUAL CONNECTIONS: AN ENTIRE APHASIA COMMUNITY AT YOUR FINGERTIPS

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Often, it can be difficult for people with aphasia to receive consistent speech therapy due to issues with insurance or accessibility. Virtual Connections offers online meetups where people with aphasia from all over the world can practice their conversation skills multiple times per day, every day of the week. Our sessions, which are led by speech pathologists and rehab experts, provide a wide range of activities including singing, dancing, yoga, reading, poetry, conversation, and so much more! These daily Zoom sessions are offered to people with aphasia and their care partners at no cost.

### CONTACT INFORMATION:

Scan QR code below OR GO TO  
<https://aphasiarecoveryconnection.org/virtual-connections/>



## ACQUIRED BRAIN INJURY (ABI) WAIVER

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Acquired Brain Injury (ABI) waiver: The ABI waiver is for adults with an acquired brain injury who can benefit from intensive rehabilitation services. The services are designed to help participants re-enter the community and function independently.

Acquired Brain Injury Long Term Care (ABI LTC) waiver: The ABI LTC waiver is for adults with an acquired brain injury who have reached a plateau in their rehabilitation level. They require maintenance services to live safely in the community.

If you are interested in applying for ABI or ABI LTC waiver services, you must first obtain financial eligibility for Medicaid. You can apply for Medicaid online using kynect (see page 8), by calling the Department for Community Based Services (DCBS) at (855) 306-8959 or in-person at a DCBS office.

### CONTACT INFORMATION:

Learn More: (844) 784-5614  
Email: [1915cwaiverhelpdesk@ky.gov](mailto:1915cwaiverhelpdesk@ky.gov)

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# RESPITE CARE

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Formal and informal, in-home and out-of-home respite options may exist in your locality. Respite programs may utilize an available bed in a health care facility for families who require extended respite options and whose family member or friend requires skilled care; whereas, other respite programs may only offer time-limited (a few hours) services in the family's home. In addition, respite services may be available to families through formal programs that hire and train their staff or may be available to families through informal networks (e.g., volunteer or faith-based initiatives, parent cooperatives, or cash subsidies from states to purchase respite through relatives and friends).

Many families prefer respite that is provided in the home. There are several advantages to in-home respite:

- The care recipient may be most comfortable in the home setting and does not have to adjust to a different environment.
- The parents/caregivers may be more comfortable if the care recipient does not have to leave the home.
- The home is already equipped for any special needs the child/adult may have.
- The cost is relatively economical (especially if you hire and train your own provider rather than using an agency).
- Transportation barriers for the care recipient are eliminated.

## CONTACT INFORMATION:

Learn More: <https://archrespite.org/caregiver-resources/respitelocator/>

## TRAUMATIC BRAIN INJURY (TBI) TRUST FUND

The TBI Trust Fund is committed to helping people with a brain injury maintain the highest quality of life possible through its services and supports. The program encourages individuals to regain their independence through case management, local programming, and services. This fund assists individuals in accessing opportunities, resources, and services needed to remain in their homes.

Who is eligible for the TBI Trust Fund?

- Kentucky Residents
- Individuals who have a medically documented brain injury
- Open to all ages
- Open to all income levels

### CONTACT INFORMATION:

Call toll-free: 1-855-816-9577

or call: 502-564-6930 Option #2 (8:00 a.m. - 5:00 p.m. EST)

<http://chfs.ky.gov/dail/braintrust.htm>

## FAMILY CAREGIVER SUPPORT PROGRAM (KIPDA)

The National Family Caregiver Program provides vouchers for medical supplies and equipment that assist caregivers in their needs to support their care receivers. The caregiver could also choose to use part, or all, of the funds to pay for a person of their choice who can provide them with respite caregiving breaks.

The National Caregiver contract requires that the care receiver be age 60 or older or have a written medical diagnosis of a form of dementia or have a significant disability. All three types of care receivers must need a combination of care tasks completed by the caregiver for their activities of daily living (ADL's) and instrumental activities of daily living (IADL's) in order to qualify.

This program is available to caregivers who live in one of the 7 counties in the KIPDA region or to caregivers whose care receiver lives in one of the 7 counties in the KIPDA region; Jefferson, Oldham, Henry, Trimble, Spencer, Shelby, or Hardin counties.

### CONTACT INFORMATION:

<https://www.kipda.org/social-services/family-caregiver-support-program/>

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## KYNECT RESOURCES

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Kynect is your one-stop shop for the programs and assistance you need no matter who you are, or where you are in life. Get connected with health and dental coverage and find out if you qualify for zero-cost or reduced cost health insurance monthly costs. You can also find out about resources such as food, transportation, utilities and other assistance. Kynect is a program of the Kentucky Cabinet for Health and Family Services.

The Kynect website ([kynect.ky.gov](http://kynect.ky.gov)) can be used to access:

- Health coverage ([kynect.ky.gov/healthcoverage](http://kynect.ky.gov/healthcoverage))
- Assistance programs ([kynect.ky.gov/benefits](http://kynect.ky.gov/benefits))
- Local resources ([kynect.ky.gov/resources](http://kynect.ky.gov/resources))

### CONTACT INFORMATION:

General phone number: 1-855-459-6328

Kynect health coverage: (855-4kynect)

Kynect benefits: 1-855-306-8959

Website: [kynect.ky.gov](http://kynect.ky.gov)

## MEDICAID TRANSPORTATION

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Non-emergency medical transportation (NEMT) provides rides for Medicaid recipients who do not have access to transportation to a medically necessary appointment, including trips to the doctor, hospital, pharmacy, dentist, adult day services, counseling, or any other Medicaid-covered service.

The ride is provided by a broker, and brokers are regionally assigned by the state. Rides are paid by Medicaid, and you should not be charged for the ride.

### CONTACT INFORMATION:

Learn More:

Transportation Delivery

(502) 564-7433

8:00 a.m. - 4:30 p.m. EST, Monday-Friday

<https://transportation.ky.gov/TransportationDelivery/Pages/Human-Services-Transportation.aspx>

## COMMUNICATION TIPS TO REMEMBER

- Speak directly to each other, face-to-face. This helps eliminate distractions and keeps the focus on the conversation and nonverbal cues.
- Use gestures, pictures, or other nonverbal cues to help them understand.
- Limit unnecessary noise, bright lights and distractions, which can be difficult for a stroke survivor to tolerate.
- Memory might be impaired, so you may need to remind of dates and times.

## COMMUNICATION MISTAKES TO AVOID

- The term “stroke victim” may be perceived as negative. Some prefer the term “stroke survivor”. Follow the lead of the person who has had the stroke for their term of choice.
- It isn’t necessary to raise your voice unless asked to do so. Please speak as if you are understood, even if you don’t receive a response.
- Please speak one person at a time. It helps the stroke survivor hear each person and process the conversation.

## WHAT NOT TO SAY TO A YOUNGER STROKE SURVIVOR AND WHY

“You are too young to have had a stroke.”	Approximately 25% of stroke occurs in those under the age of 60.
“You don’t look like you’ve had a stroke.”	What does looking like you have had a stroke really mean?
“Are you better now?”	Most survivors don’t “get better” so to speak and instead they learn to live with and manage the long term effects of a stroke.
“It could have been worse! It must have been a mild stroke.”	A stroke is a major health even and is usually traumatic and life changing.
“I know someone who had a stroke and they ran a marathon last week/got back to work, etc.”	The intention can be good but total recovery is not possible for everyone and comparison can be the thief of joy.

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# UNDERSTANDING MEDICATIONS AND DIRECTIONS FOR MEDICATIONS

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Every stroke survivor is unique. In order to prevent another stroke, work with your health care provider and rehabilitation team. They'll tailor a medication program that's best for you.

Be sure to take your medications as directed. Never stop taking them without talking with your health care provider.

Don't be afraid to ask questions.

Some medications that may be part of your treatment plan include:

## **ANTITHROMBOTIC:**

These are anti platelet medications which keep the platelets in the blood from sticking together. Because these medications increase the risk of bleeding, seek medical attention if you notice any signs of major bleeding. Be sure physicians are aware that these medications are prescribed prior to any medical procedures. A few antithrombotic medications are: Aspirin, Clopidogrel (Plavix), Ticagrelor (Brilinta), and Prasugrel (Effient).

## **ANTICOAGULANTS:**

These medications are used to prevent strokes by thinning the blood by slowing clot formation. Because these medications increase the risk of bleeding, seek medical attention if you notice any signs of major bleeding. Be sure physicians are aware that these medications are prescribed prior to any medical procedures. Common anticoagulants used are:

1. Warfarin (Coumadin): While taking this medication, frequent lab work is needed to ensure the correct dose is prescribed and consistent Vitamin K intake is important. Vitamin K is found in foods such as green, leafy vegetables and grapefruit juice.
2. Rivaroxaban (Xarelto), Apixaban (Eliquis), Dabigatran (Pradaxa), Endoxaban (Savaysa), Enoxaparin (Lovenox), Heparin: These medications may also be used to prevent strokes in patients with irregular heart rhythms or who are high risk for developing blood clots.

## **CHOLESTEROL MANAGEMENT:**

Statins help decrease LDL levels, which is the "bad" cholesterol in the liver. They also reduce inflammation in the body. Stroke survivors will be prescribed this medication even if you don't have high cholesterol. Statins reduce the risk of another stroke, heart attack, or death. These medications include Atorvastatin (Lipitor), Simvastatin (Zocor), or Rosuvastatin (Crestor). Other LDL lowering medications include ezetimibe (Zetia), evolocumab (Repatha) and alirocumab (Praluent). Your doctor may prescribe one of these in addition to, or instead of, statins to reduce risk of another stroke.

## WHAT TO EXPECT AT REHAB LEVELS:

<b>WHERE?</b>	<b>WHO IS IT FOR?</b>	<b>WHAT DO PATIENTS GET?</b>
Inpatient rehabilitation facility (IRF)	Patients who are expected to benefit from intensive, 24 hour-a-day rehabilitation care under the direct supervision of a rehabilitation physician and will receive rehabilitation therapy (physical, occupational and speech therapies) at least three hours per day, five days a week.	Hospital level of care that is physician directed with 24-hour specialized nursing care. A comprehensive team of specialty trained physicians, therapists, nurses and case managers who develop a personalized plan of care. Daily physician visits are typical.
Skilled nursing facility (SNF)	Patients who need daily skilled nursing or rehabilitative care and will not tolerate the intensity of an Inpatient Rehabilitation Facility.	Skilled nursing and/or therapy services with no minimum therapy requirement. Services are commonly performed by or under the supervision of a registered nurse. Periodic physician visits but no minimum number of physician visits is required.
Long-term acute care facility	Patients with multiple complex chronic medical conditions.	Hospital level of care with highly specialized medical care and rehabilitative services.
Nursing home	Patients who don't require skilled nursing.	Long-term care for patients who can't live independently.

## WHAT TO EXPECT AT REHAB LEVELS:

<b>WHERE?</b>	<b>WHO IS IT FOR?</b>	<b>WHAT DO PATIENTS GET?</b>
Outpatient clinic	Patients who don't require inpatient care and are able to leave home for therapy.	Hospital-based or free-standing sites; care transitioned to primary care provider; occupational, speech and/or physical therapy, and possibly other services.
Home health agency	Patient must be homebound, except for medical appointments or occasional personal outings.	Care transitioned to primary care provider; skilled nursing; speech, physical and occupational therapy; health aide; and social services as needed.

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## EFFECTS OF STROKE:

The brain is an extremely complex organ that controls various body functions. If a stroke occurs and blood flow cannot reach the region that controls a particular body function, that part of the body won't work as it should. The effects of a stroke depend primarily on the location of the obstruction and the amount of brain tissue affected.

### LEFT BRAIN

If a stroke occurs in the left side of the brain, the right side of the body will be affected, producing some or

all of the following:

- Hemiparesis/hemiplegia (paralysis/weakness on the right side of the body)
- Aphasia (trouble speaking or understanding others)
- Dysphagia (trouble swallowing)
- Dysarthria (slurred and slow speech)
- Slow, cautious behavioral style
- Cognitive-linguistic disorder (memory loss and concentration)

### BRAIN STEM

The brain stem is the area of the brain that controls all of our involuntary, life-support functions such as breathing, blood pressure and heartbeat. The brain stem also controls eye movements, hearing, speech and swallowing. Since impulses from the cerebral hemispheres must travel through the brain stem on the way to the rest of the body, people with a brain stem stroke also may have paralysis in one or both sides of the body. Every stroke is unique, but strokes tend to affect people in common ways.

### CEREBELLUM

When the cerebellum is affected by stroke, coordination and balance problems, dizziness, nausea and vomiting often occur.

### RIGHT BRAIN

If the stroke occurs in the right side of the brain, the left side of the body will be affected, producing some

or all of the following:

- Hemiparesis/hemiplegia (paralysis/weakness on the left side of the body)
- Neglect (unawareness of the left side of body or environment)
- Perseveration (the repetition of a particular response)
- Visual/spatial problems
- Problems with attention span (unable to focus attention on a conversation or task)

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# LIFE AFTER STROKE

## PLANNING ACTIVITIES

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- Keep it simple.
- Talk to your doctor about any problems you are having and when you can return to your usual activities.
- Do as much as you can for yourself at home; take breaks and rest before getting tired.
- Practice the skills and exercises that you learned in the hospital.
- Use your weak limbs as much as possible.
- Do important things first or in the order of most importance.
- Combine motions and activities.
- Limit work that requires lifting and pushing.
- Alternate sitting and standing.
- Set a reasonable pace rather than rush through activities.
- Ask others to help or give a task to others when needed.
- Breathe evenly; do not hold your breath.

## PERSONAL CARE AND SAFETY

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- Take all medications as ordered.
- Follow up with your primary care provider.
- Place things within reach in all rooms.
- Use all assistive devices properly.
- Avoid using a bath rug in the bathroom and remove any rugs that are not nailed down.
- Clear away all barriers in your room, the hall and doorways.
- Check for good lighting in and around your home.
- When sitting, use a supportive chair.
- Avoid temperatures that are too hot or cold.
- Let others do things you cannot or are too tired to do.
- Learn ways to relax.
- Exercise to help reduce stress.
- Take the time to do the things you enjoy.
- Know the signs and symptoms of stroke.
- Call 911 or use a Lifeline® in an emergency.

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## UNDERSTANDING FATIGUE:

Many stroke survivors experience overwhelming fatigue, both physically and mentally. Symptoms can include difficulty with self-control, emotions and memory. Some report feeling tired even after a good night's sleep. Others say they feel tired when they perform a task requiring physical or mental focus. Most report that fatigue occurs without warning and makes it harder to do daily, routine activities.

### TIPS FOR ADDRESSING FATIGUE:

- Check prescriptions for potential side effects, including fatigue.
- Ask for treatment options if experiencing anxiety, depression or difficulty sleeping.
- Family support and understanding can also help. Let your family know post-stroke fatigue can be overwhelming.
- Try to eat healthy and exercise to prevent other health problems that also can affect your energy level.
- Talk to your physical therapist to understand fitness, balance disorders, uncoordinated movement and walking related to fatigue. Balance and coordination exercises will help you perform tasks with less energy, increase your confidence and decrease your anxiety.
- Try to schedule demanding physical or mental activities throughout the day or week. That way, you'll plan to take rest breaks before you feel tired.
- Consider modifying your home and work environment to make them more efficient. Use assistive technology when possible.

### TIPS FOR IMPROVING SLEEP:

- Keep the same bedtime and wake-up time each day.
- Exercise regularly, but not within a few hours before going to bed.
- Avoid caffeine and nicotine late in the day and alcoholic drinks before bed
- Relax before bed.
- Create a room for sleep – avoid stimulating bright lights and noise.
- Keep the temperature comfortable in the bedroom.
- Don't watch TV or have a computer in your bedroom.
- If you can't get to sleep, get out of bed to do something relaxing until you feel tired.
- Discuss your sleep issues with your doctor.

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# EMOTIONAL WELLBEING

After a stroke, survivors and their supporters are initially consumed by accessing the healthcare needed to survive and be stabilized. Then, the focus naturally shifts to rehabilitation (physical, occupational, speech, and other) to recover as many lost capabilities as possible. But there is another less visible and sometimes even more challenging aspect of recovery — the emotional journey to rebuild identities and rewarding lives.

## WHAT IS THE EMOTIONAL JOURNEY?

There are many aspects to emotional health and wellness after a stroke.

- Grieving the loss: As the emotional healing journey moves from the earlier stages of grieving towards acceptance, reflecting on meaning and purpose is an important step towards rebuilding.
- Rebuilding your identity: critical aspect of recovery is regaining or rebuilding that sense of self – who you are now. Even more important, a sense of who you want to be.
- Key factors about identity:
  - Identities are dynamic.
  - Our relationships impact our identities.
  - Identity is a choice.

Additional Resources:

- [strokeonward.org](http://strokeonward.org)
- [stroke.org](http://stroke.org)

## TIPS FOR THE EMOTIONAL JOURNEY:

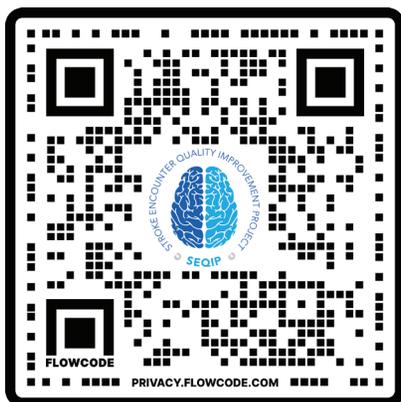
- Focus on deeper meaning and purpose - not roles, titles, and activities.
- Set reasonable goals and take time to appreciate small wins – recovery and rebuilding take time.
- Build Community – perhaps it’s through a religious community, volunteering, supporting a favorite sports team, or participating in a support group, but make sure to take time to connect with others.
- Adapting Activities – stroke can make it difficult to participate in many activities or types of recreation previously enjoyed, but there are often ways to adapt these activities.
- Redefining work – working after a stroke can look very different. For some, it may mean a return to full-time and for others, part-time is a better option. If returning to a paid position is not an option, consider volunteering for an organization you are passionate about.

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## SUPPORT GROUP RESOURCES: LOCAL LIST

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Scan the QR code or visit the webpage listed below to find the list of local Kentucky stroke support groups curated by Carrie Crockett, chair of the SEQIP subcommittee Navigating the Stroke Continuum of Care.



<https://khdstaskforce.com/wp-content/uploads/2023/05/2022-SEQIP-Support-Group-List.pdf>

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## SUPPORT GROUP RESOURCES: NATIONWIDE LIST

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Find a stroke support group in your area by using the Stroke Group Finder:  
Enter your zip code.  
Enter mileage radius.  
Your search will display registered stroke groups near you.  
Once a group or list of groups appears, you may click on any group for more details.

Many groups continue to experience difficulties post-pandemic. Some had to suspend meetings or change the format of their meetings. It's important that you use the contact information provided to check for meeting schedule changes before trying to attend any meeting. But the good news is that more groups are forming or restarting, so check back frequently as new groups register regularly.

## CONTACT INFORMATION:

<https://www.stroke.org/en/stroke-support-group-finder>

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This booklet was created by the SEQIP  
Continuum of Care Subcommittee:

- Carrie Crockett, Chair
- Breanna Walker
- Flannery O'Neill
- Margie Campbell
- Rosa Hart

