



Pathways

at Louisville East

Family Resource Guide

Compiled by:
Megan Orton, M.A.
&
Brittany Donna, M.A.

Local Contacts

Non- Exhaustive list of contacts

Pathways Brain Injury Program 4200 Browns Lane Louisville, KY 40220	Tel. 502-459-8900 Fax 502-451-6123 Email info@louisville-east.com https://pathwaysbraininjuryprogram.com/
Brain Injury Alliance of Kentucky 7321 New LaGrange Road, suite 100 Louisville, KY 40222	Tel. 502-493-0609 Email info@biak.us https://biak.us/
Kentucky & Southern Indiana Stroke Association 3425 Stony Spring Circle, #102 Louisville, KY 40220	Tel. 502-499-5757 Email info@strokekyin.org https://www.strokekyin.org/
Brain Injury Association of Kentucky	Tel. 800-444-6443 Email braininjuryinfo@biausa.org https://biaaky.org/
NeuroRestorative	Tel. 800-743-6802 Email Nrinfo@sevitahealth.com https://neurorestorative.com/
Department for Community Based Services 275 E. Main Street Frankfort, KY 40621	Tel. 502-564-5497 https://www.chfs.ky.gov/agencies/dcbs/Pages/default.aspx



Caregiver Burnout

What is Caregiver Burnout?

- Caregiver burnout is a state of physical, emotional, and mental exhaustion that happens while you're taking care of someone else.
- Caregiver burnout is very common. Studies show that more than 60% of caregivers experience symptoms of burnout.



Caregiver burnout may feel like:

Anxiety or Fear	If you do something wrong, it will harm someone within your care.
Anger or Frustration	The person within your care doesn't accept, want, or appreciate the care you're providing.
Denial	The severity of the person's condition you're caring for "isn't that bad."
Guilt	Spending time taking care of yourself is less important than the person within your care. You might feel bad doing things to care for yourself because they benefit you and not others.
Negativity	Your caregiving journey started positively but now feels like a dark cloud is following you. Your feelings toward your responsibility are passive or you don't have the desire to do your job well.
Secluded or Alone	You feel like you don't have support, no one wants to help or asking for help is a sign of weakness.

What causes Caregiver Burnout?

- Caregiver burnout happens when you devote the majority of your time, energy, and resources to taking care of others that you neglect, forget, or aren't able to take care of yourself.



Other Factors can contribute to burnout as well:

Role Confusion	Quickly stepping into a caregiver role can cause confusion. It can be difficult to separate your role as a caregiver from your role as a spouse, friend, or child.
Varied Expectations	Many caregivers believe that their involvement will have a positive effect on the health and happiness of the person within their care and themselves. Caregiving is challenging. It can also be extremely rewarding while also being stressful.
Lack of Control	You may feel frustrated or held back by a lack of finances, resources or skills needed to effectively plan, manage, and organize your loved one's care.
Too Many Responsibilities	Sometimes, caregiving can feel like you're juggling too many obligations at once. Many caregivers experience stress because they see their role as their sole responsibility, even if it's too much for one person to realistically handle.

Burnout Self- Assessment

- Taking a self-assessment may help provide insight and aide in tracking your symptoms.
- <https://www.healthinaging.org/sites/default/files/media/pdf/Caregiver-Self-Assessment-Questionnaire.pdf>

How to manage burnout:

- You will likely need to employ multiple strategies to help manage caregiver burnout.



Non- Exhaustive list of recommendations:

Talk to a healthcare provider	The amount of stress and emotional weight associated with being a caregiver can be overwhelming. It helps to reach out to a healthcare provider, psychologist, social worker, or mental health professional to discuss what you are feeling. There are also many support groups for caregivers that can improve feelings of connection with others.
Make time for self-care	It is not selfish to take care of yourself while you are taking care of someone else. Don't skip or put off personal appointments. Eating a well-balanced meal, getting enough sleep, participating in exercise, yoga or meditation is also recommended.
Ask for help	Asking and/or accepting help can be difficult. Sometimes, your support system does not recognize the need unless you ask for it. You may need to practice saying "yes" when someone offers you help and saying "no" when more tasks fall on your plate.
Find local resources.	Organizations within your community may offer services and support when you are in need. This may include in-home care, adult day care centers, or community meal programs.

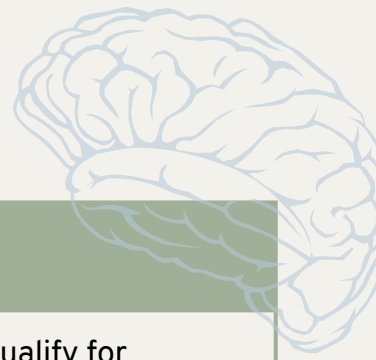
Information from <https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>

Respite Care:

- Respite care can be defined as short term care provided to a waiver recipient due to absence or need for relief of the primary caregiver. Depending on the person and their waiver involvement, this definition may change, as well as limits to the amount of respite allowed per year.



<https://archrespite.org/wp-content/uploads/2022/09/kentucky.pdf>



Non- Exhaustive list of resources:

Disability	<p>After brain injury, it is not uncommon for survivors to qualify for disability benefits, especially early on in recovery. The process of applying can take time. It is helpful to keep all documentation from disability and continuously follow up on the status of the claim. Some individuals choose to hire a disability lawyer to help them navigate the process. Social work services can also be helpful.</p>
Case Management	<p>Case management is a healthcare process where professionals helps survivors and their families coordinate care surrounding the individual's specific needs in the context of their insurance coverage. They can help coordinate appointments and referrals to ensure the survivor is getting their healthcare needs met.</p> <p>https://www.ncbi.nlm.nih.gov/books/NBK562214/</p>
Family & Survivor Support Groups	<p>Support groups can allow those with similar situations to provide one another with support, opportunities to share their experiences, and develop coping strategies. Different groups and their locations in KY can be found at https://biak.us/i-have-a-brain-injury/</p>
Educational Programs	<p>There are a variety of online and in-person education programs that can help you and your family better understand brain injury and life after a brain injury. The Shepherd Center has educational video that uses easy to understand language on what there is to know about brain injury and recovery (www.braininjury101.org).</p>
Assistive Devices	<p>An assistive device is any piece of equipment to help assist someone preform a particular task. Some assistive devices include mobility aids (wheelchairs, walkers, canes, etc.) hearing aids, cognitive aids (devices that help with memory, attention, etc.), and communication aids (augmentative and alternative communication (AAC) device to help those with speech or language impairments to communicate). Some waiver programs, as well as local charities, may be a good resource for assistance with home modifications.</p> <p>https://www.nichd.nih.gov/health/topics/rehabtech/conditioninfo/device</p>



Clinicians

Non- Exhaustive list of clinicians:

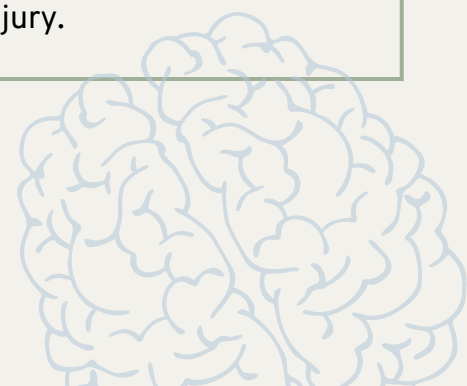
Neuropsychology	<p>Neuropsychologists are psychologists that specialize in understanding brain behavior relationships and cognitive functioning. Neuropsychologists will often perform neuropsychological assessments to better understand how brain injury has impacted the survivors' current functioning so that they can make informed recommendations for treatment. These exams can occur soon after injury, as well as up to a year+ after, to track changes in function. Neuropsychological assessments are also common in workers comp evals and are needed for supported employment/ return to work assessments.</p>
Speech & Language Pathologist (SLP or ST)	<p>After brain injury, some survivors may have trouble with understanding and producing speech, chewing and swallowing food, and may display difficulty with memory and problem solving. A Speech & Language Pathologist or Speech Therapist can help survivors learn strategies and exercises that address these concerns. Even if the survivor does not have an issue with speech, speech therapy is still important for strengthening memory and cognitive processes.</p>
Occupational Therapist (OT)	<p>Occupational therapists can help survivors improve thier ability to perform daily tasks after a brain injury. They often work with fine motor movements of the hands, which is helpful with tasks such as grooming. OTs may also target other tasks such as safely getting dressed, taking medication, toileting, shopping for groceries, etc.</p>
Physical Therapist (PT)	<p>The role of physical therapy after brain injury, is to help survivors regain movement and strength. This may look different from person to person, but may include passive range of motion, to building stamina, and assistance with walking or propelling wheelchairs.</p> <p><small>https://www.flintrehab.com/physical-therapy-interventions-for-traumatic-brain-injury/</small></p>





Non- Exhaustive list of clinicians:

Psychiatry/ Neuropsychiatry	After brain injury, it is not uncommon for survivors to experience changes in their personality, changes in their emotional control, and decision making. It is also common to experience anxiety and depression related to their situation. When these experiences start to impair the survivors' functioning, psychiatry/neuropsychiatrists may prescribe medication to assist with emotional control.
Social Work (SW)	Social workers often wear many hats. In the context of brain injury, SW will often help coordinate the care of survivors by connecting families with community resources, providing assistance with filling out waiver and disability applications, assist with setting up appointments, they can act as a liaison between the family and the treatment team, they assist with discharge and referrals, and in some contexts, SWs are able to provide some counseling services.
Neuro- ophthalmology	A Neuro-ophthalmologists is a doctor that specializes in visual problems related to brain function rather than eye function. After brain injury, it is not uncommon that people will experience a change in vision. This may include visual field changes, worsening acuity, double vision, etc.
Neurologist	Seizures and migraines are both common conditions that are associated with brain injury. Often, individuals who experience these conditions will be medically managed by a neurologist.
Neurosurgery	Depending on the nature of the brain injury, the role of neurosurgery is often to manage and prevent further injury. Some survivors require an operation to relieve pressure on the brain, typically as the result of blood or increased cerebral spinal fluid. Survivors often follow up with neurosurgery to ensure the stability of their injury.



Kentucky Waiver Programs

Acquired Brain Injury (ABI) Waiver:

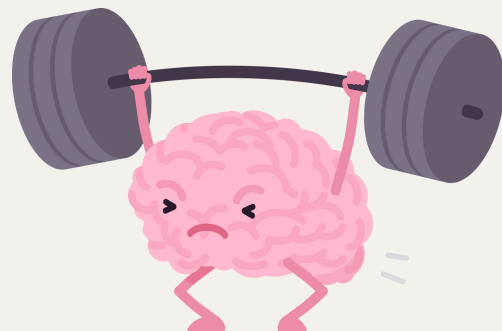
Different Types of ABI Waiver:	
ABI Waiver	The ABI waiver is for adults with an acquired brain injury who can benefit from intensive rehabilitation services. The services are designed to help survivors re-enter the community and function independently.
ABI Long Term Care Waiver (ABI LTC)	The ABI LTC 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.

Services Include:

- Adult Day Training
- Individual and Group Counseling
- Environmental and minor home modifications
- Respite Care
- Supervised Residential Care (ABI LTC only)
- Companion Services (ABI only)
- Personal Care (ABI)
- Community Living Supports (ABI LTC)
- Nursing Supports (ABI LTC)

Eligibility:

- Have an acquired brain injury
- Age 18 years or older
- Meet requirements for residence in a nursing facility.



Apply:

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

Once you are ready to apply for ABI or ABI LTC waiver services, you can complete your application online using kynect or in-person at an Aging and Disability Resource Center or a Community Mental Health Center.

For more info, go to www.chfs.ky.gov/agencies/dms/dca/Pages/abi.aspx, or call (844) 784-5614.

A Quick Guide to Legal Aspects of Brain Injury

This information does not replace legal advice.
You should consult with an attorney for legal advice.

Power of Attorney

- Power of attorney is a document that gives someone you trust the power to act on your behalf.
- In KY you can have a financial POA and a healthcare POA.
- When you sign a POA, you do not sign over or give away any decision-making ability.
- By law, your POA cannot overrule your decisions.
- You can revoke a POA at any time, given in tact decision-making capacity.

POA Types in Kentucky

Financial POA	A financial POA allows someone to handle your financial or business matters.
Health Care POA	A healthcare POA allows someone to make medical decisions on your behalf. In KY this is combined with a living will, which says what your wishes for medical treatment are. This is often called an advanced directive.

<https://www.kyjustice.org/topics/planning-ahead-elder-law/power-attorney-kentucky>

Conservatorship vs. Guardianship

- After brain injury occurs, some survivors require help managing their day to day needs. The amount of assistance someone needs can vary, below are some examples.

Conservatorship vs. Guardianship

Conservatorship	The conservator only looks after the financial affairs of the person. They have power over the estate, paying bills and managing income.
Guardianship	Limited guardianship would allow a guardian or conservator to only make decisions in some aspects of the person's life. Full guardianship would allow the guardian to make decisions about the persons day to day life, including medical decisions, financial decisions, who can have contact with them, and where the person resides.

<https://www.kyjustice.org/topics/planning-ahead-elder-law/adult-guardianship-and-conservatorship>