

Living with Epilepsy

By: Alex Houston

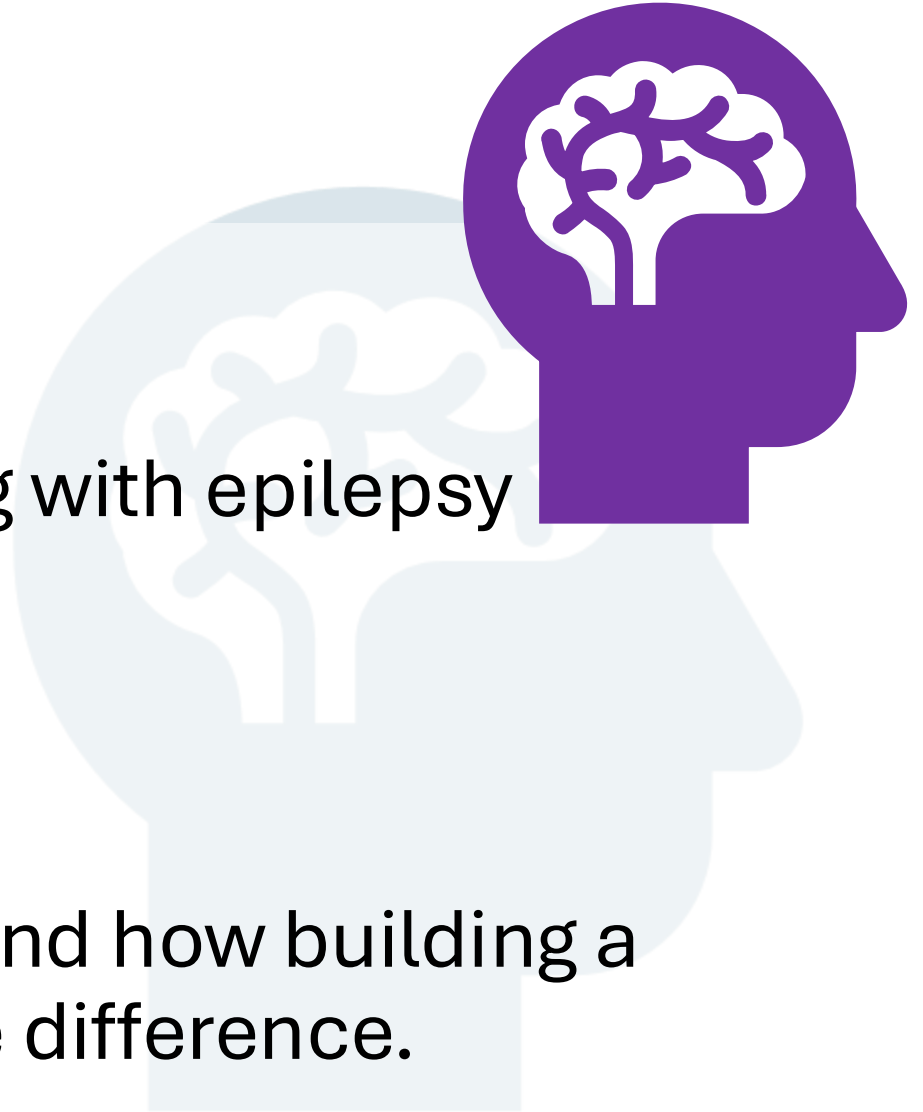
Community Education Specialist

Epilepsy Foundation of Greater Chicago (EFGC)



Learning Objectives

- Understanding Epilepsy
 - Building your community
- Navigating daily challenges of living with epilepsy
 - Learning of available resources
- What it's like to live with epilepsy, and how building a strong community can make all the difference.



What is a seizure?

- A brief, excessive discharge of electrical activity in the brain that alters one or more of the following:
 - Movement
 - Sensation
 - Behavior
 - Speech
 - Awareness
 - Memory
- More than 20 different types
- Not all seizures are medical emergencies



Phases of a Seizure

- **Prodromal** – Behavioral changes seen hours or days before a seizure.
- **Aura** – First symptom of a seizure, often called a ‘warning’, most commonly seen with partial seizures.
- **Ictus** – What is seen/felt during a seizure.
- **Postictal** – What is seen/felt after the seizure, until the brain recovers to baseline.

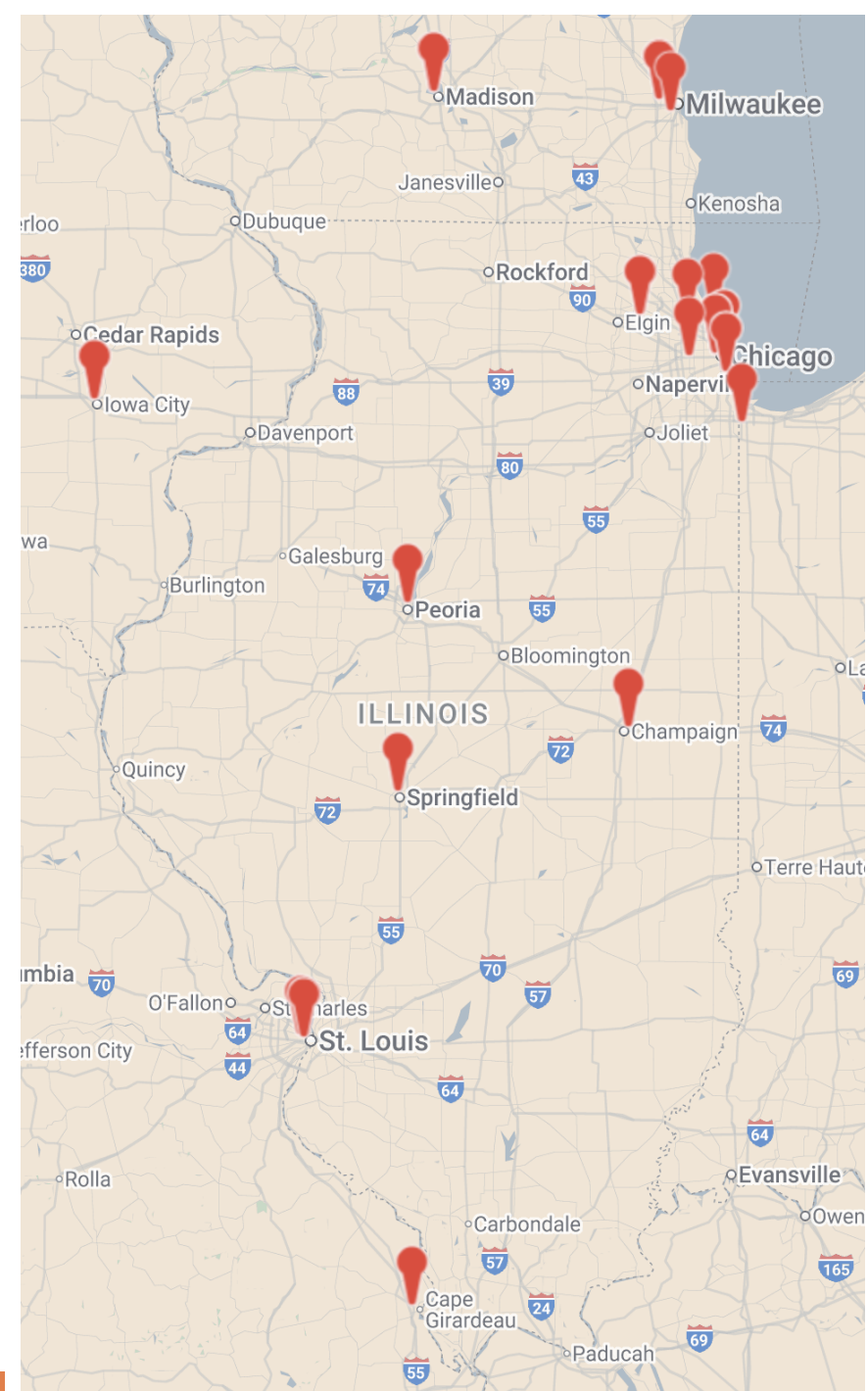
What is Epilepsy?

- *Chronic* neurological disorder characterized by a tendency to have *recurrent* (2+), *unprovoked* seizures
- Many “types” of epilepsy
- Also known as “seizure disorder”

What causes Epilepsy?

- For 30% of people with epilepsy common identifiable causes include:
 - **Traumatic brain injury (TBI)**
 - Stroke
 - Brain tumor
 - Infections of the brain (e.g. meningitis, measles, malaria)
 - Genetics (2,000+ genes)
 - Brain injury at birth
 - Abnormal brain development
- For the remaining 70% the cause is unknown

- Currently 12 **Level 3 and 4** Epilepsy centers in Illinois



Your Brain

FRONTAL LOBE

- Concentration, planning, problem solving skills
- Orientation
- Motor control of voluntary muscles

TEMPORAL LOBE

- Memory of visual and auditory patterns
- Hearing

Motor-Sensory Strip

PARIETAL LOBE

- Sensations of touch, temperature, pressure, pain from skin
- Use of words, understanding language, speech

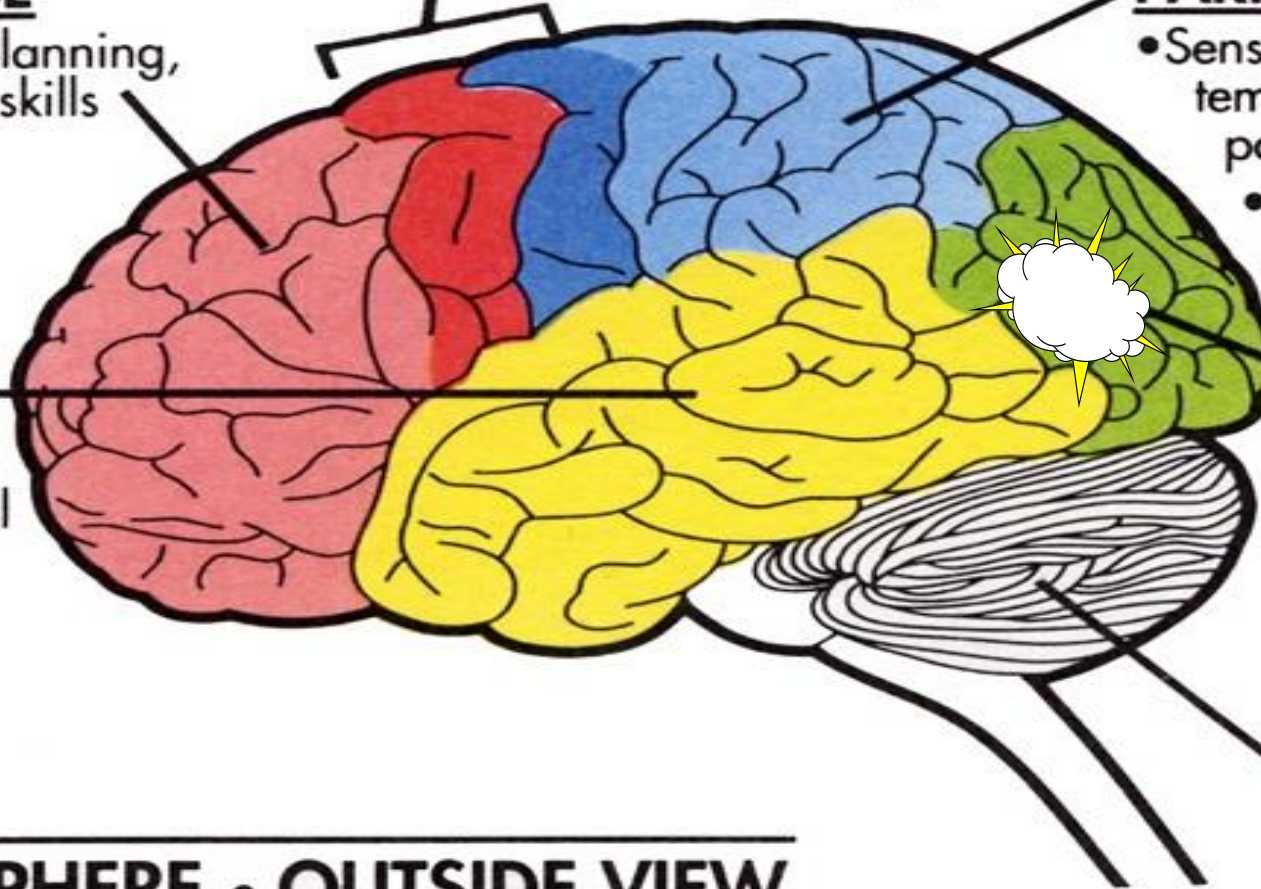
OCCIPITAL LOBE

- Visual capabilities, recognition
- Combining visual images

CEREBELLUM

- Coordination of voluntary muscular movements
- Balance

LEFT HEMISPHERE • OUTSIDE VIEW



Epilepsy Disease Burden

- Worldwide: 65 million worldwide live with active epilepsy
- United States and Illinois:
 - 3.4 million individuals (1.2% of the US population)*
 - 470,000 are children
 - **13+ million individuals**
 - **200,000 identified by the CDC**
- 1 in 26 will develop epilepsy their lifetime*
- 1 in 3 have uncontrolled epilepsy
- Chicago-metro area: **136,000** people
- CDC recognizes nearly 200,000
- Barriers exist in society impact access to care
- The risk is higher in children with comorbidities



Learn More about Epilepsy & Seizure First Aid

Monthly Public Seizure
First Aid Training



Visit EFGC Website at www.epilepsy-chicago.org

Connect with your local Epilepsy Organization

Seizure First Aid

How to help someone having a seizure

1

STAY with the person until they are awake and alert after the seizure.

- ✓ Time the seizure
- ✓ Remain calm
- ✓ Check for medical ID



2

Keep the person **SAFE**.

- ✓ Move or guide away from harm



3

Turn the person onto their **SIDE** if they are not awake and aware.

- ✓ Keep airway clear
- ✓ Loosen tight clothes around neck
- ✓ Put something small and soft under the head



Call
911
if...

- ▶ Seizure lasts longer than 5 minutes
- ▶ Person does not return to their usual state
- ▶ Person is injured, pregnant, or sick
- ▶ Repeated seizures
- ▶ First time seizure
- ▶ Difficulty breathing
- ▶ Seizure occurs in water

Do
NOT

- ✗ Do **NOT** restrain.
- ✗ Do **NOT** put any objects in their mouth.
- ✓ Rescue medicines can be given if prescribed by a health care professional

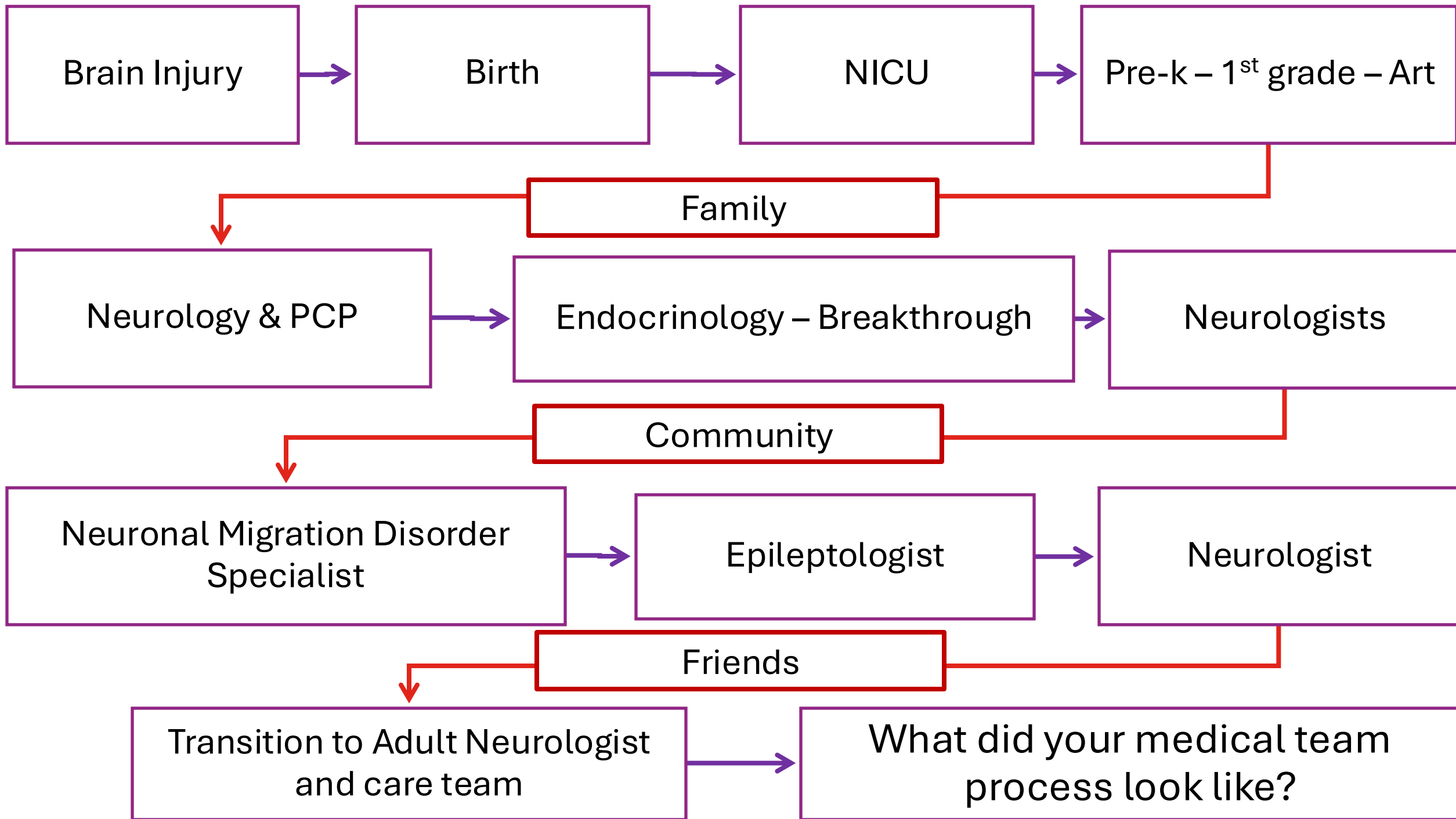
Building your
community



Each story is Unique

- Each person has their own experience
- Each Condition
- Each Experience
- Each Diagnosis
- Each Perspective
- Each Timeline of “When”
- This does not define us
- My Diagnoses is only part of what has shaped who I am today





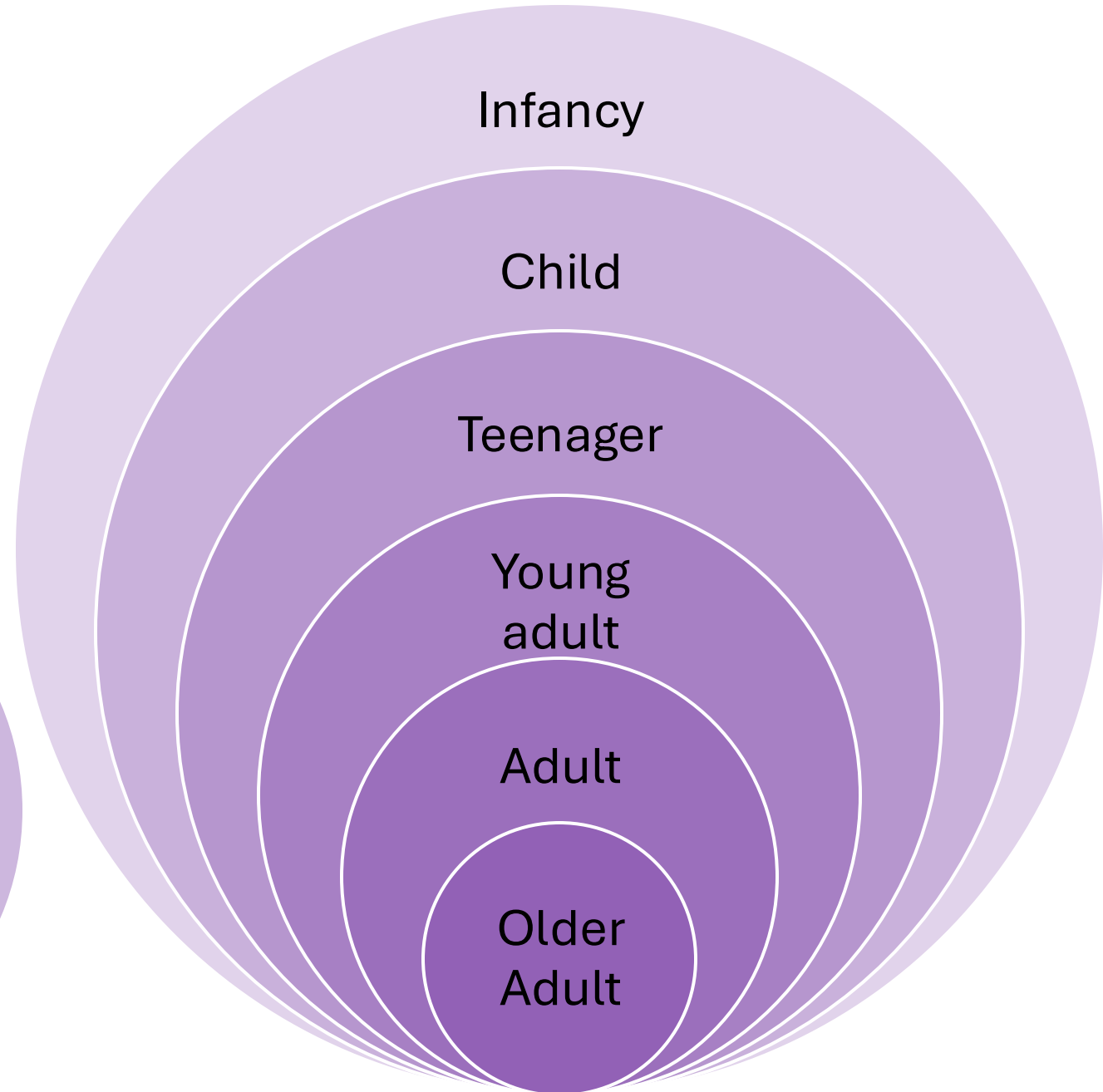
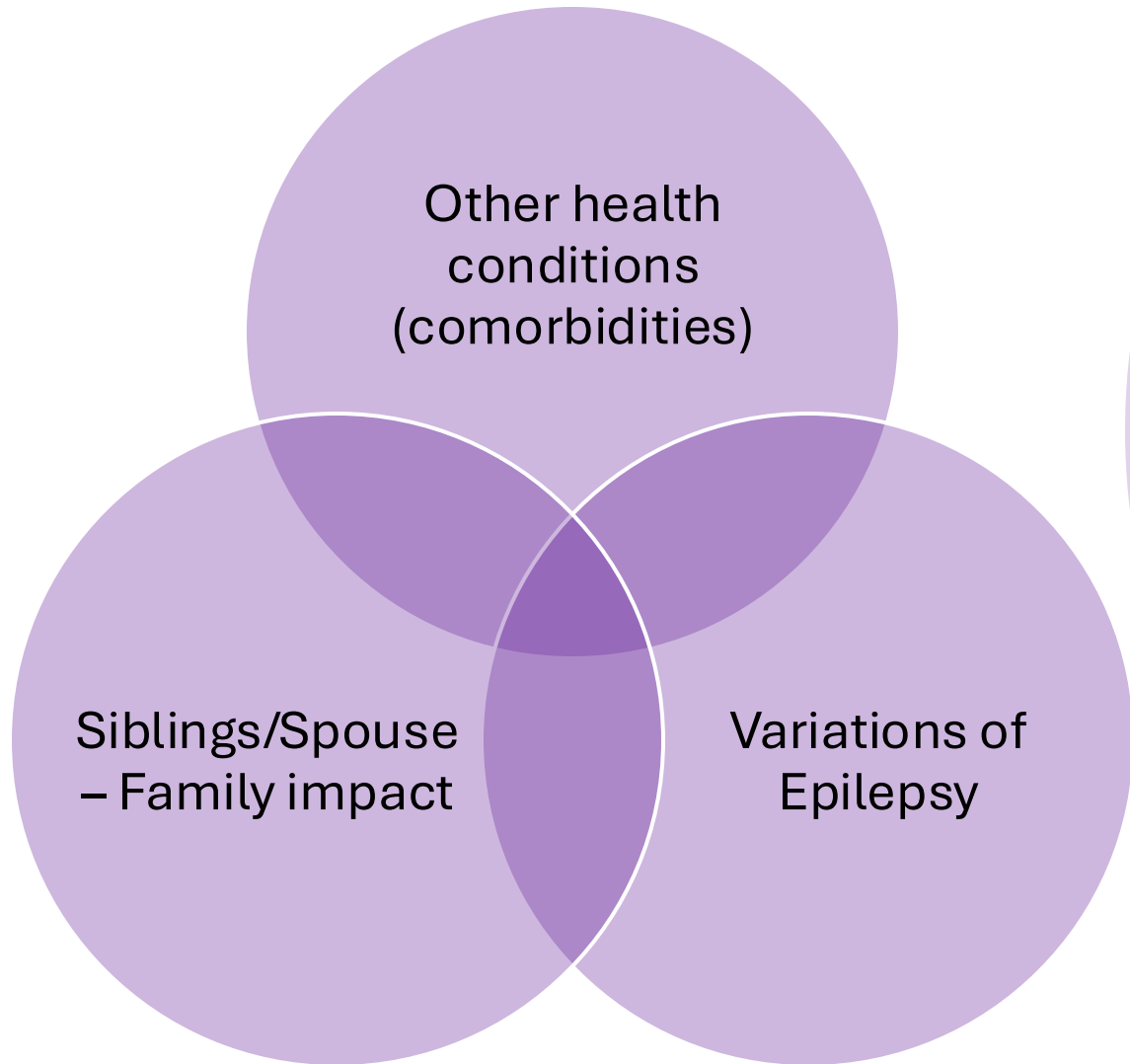


Your story is your own

- Think of who has helped you.
- Who is in your life right now?
- Who do you want in your life?
- Who do you turn to for support or understanding?
- **Silence is easy, sharing is a strength.**
- Each diagnosis, experience, and timeline shapes who we are—but does not define us.
- Building your community means surrounding yourself with people who understand, support, and empower you.



Living with Epilepsy



Growing up with Epilepsy – Birth/Childhood

Early
Development

Social Skills

Self-Advocacy

Independence

School
Challenges

Accommodations

Hormones

Transition Periods

Parent/Caregiver
Perspective

Resources

Toolkit – A Perspective to Adult Care

- Toolkits are created by various organizations connect with your local Epilepsy Foundation
 - Children's Neurology Foundation (CNF) and the American Academy of Pediatrics (AAP) – Young Adult Council created a Toolkit
 - Start early when diagnosed – Differs for everyone
 - Special Needs Planning
 - After life care/Adult care
- Self-Advocacy (Find your Voice for your role)
 - Self / Caregivers / External Support
- Medical Access
 - How does this impact you, let's connect

Understanding Transitions

Educational transitions

- IEP/504
- College Prep

Medical transition –
learning more of your
condition

Hormonal transitions

- Knowing more of your
body

Pediatric to Adult Care

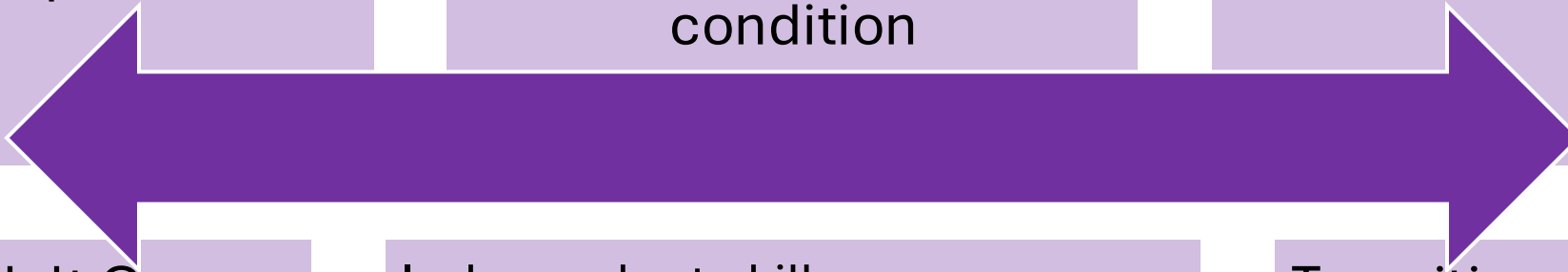
- Toolkits (CNF)

Independent skills

- Higher Education
- Independent/Accessible living
- Working
- Adult care

Transitions vary through the ages

- Long-term
- What to do now for the
future



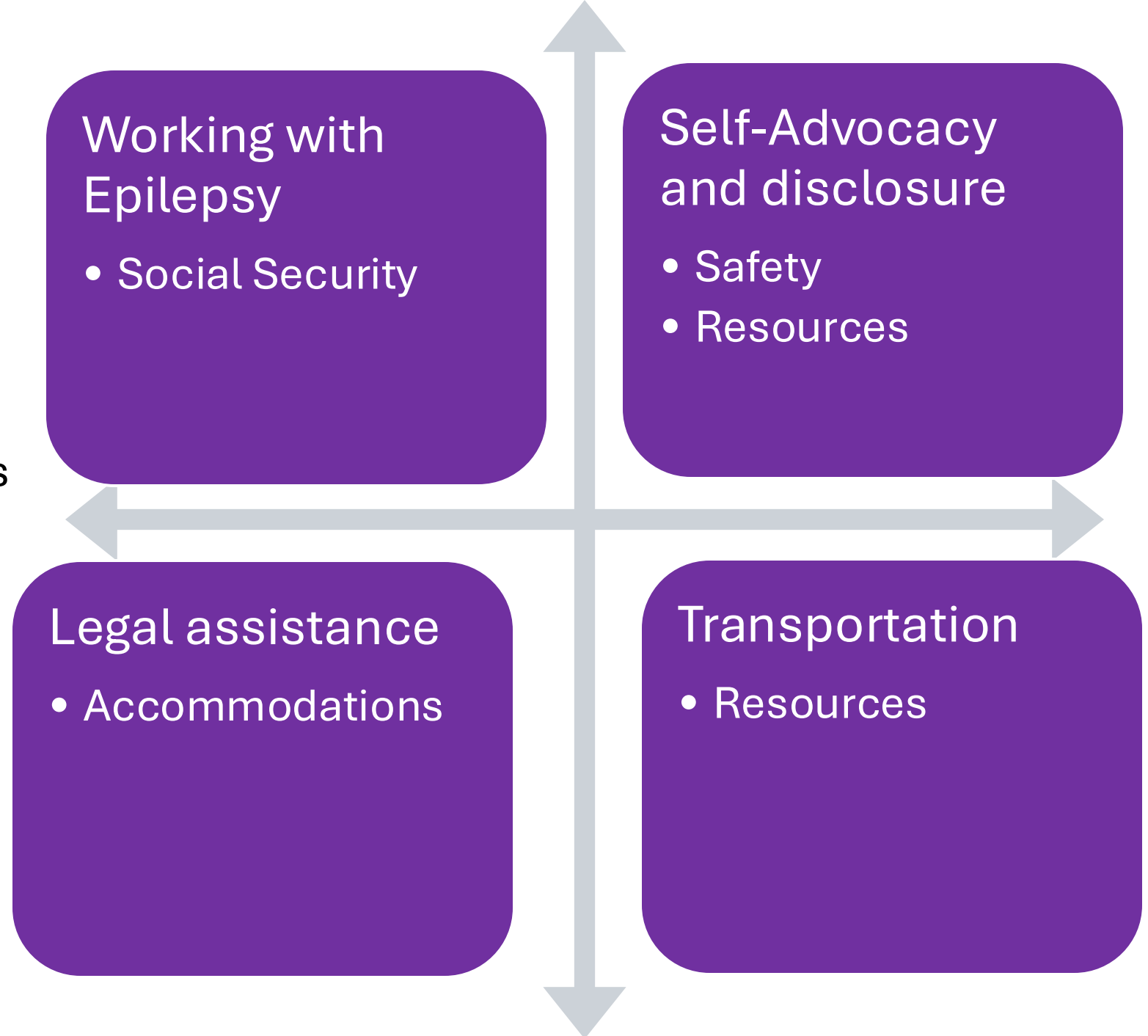
Adult-Onset

It's important to find a balance

Diagnosis can happen at any age. Each person's path looks different.

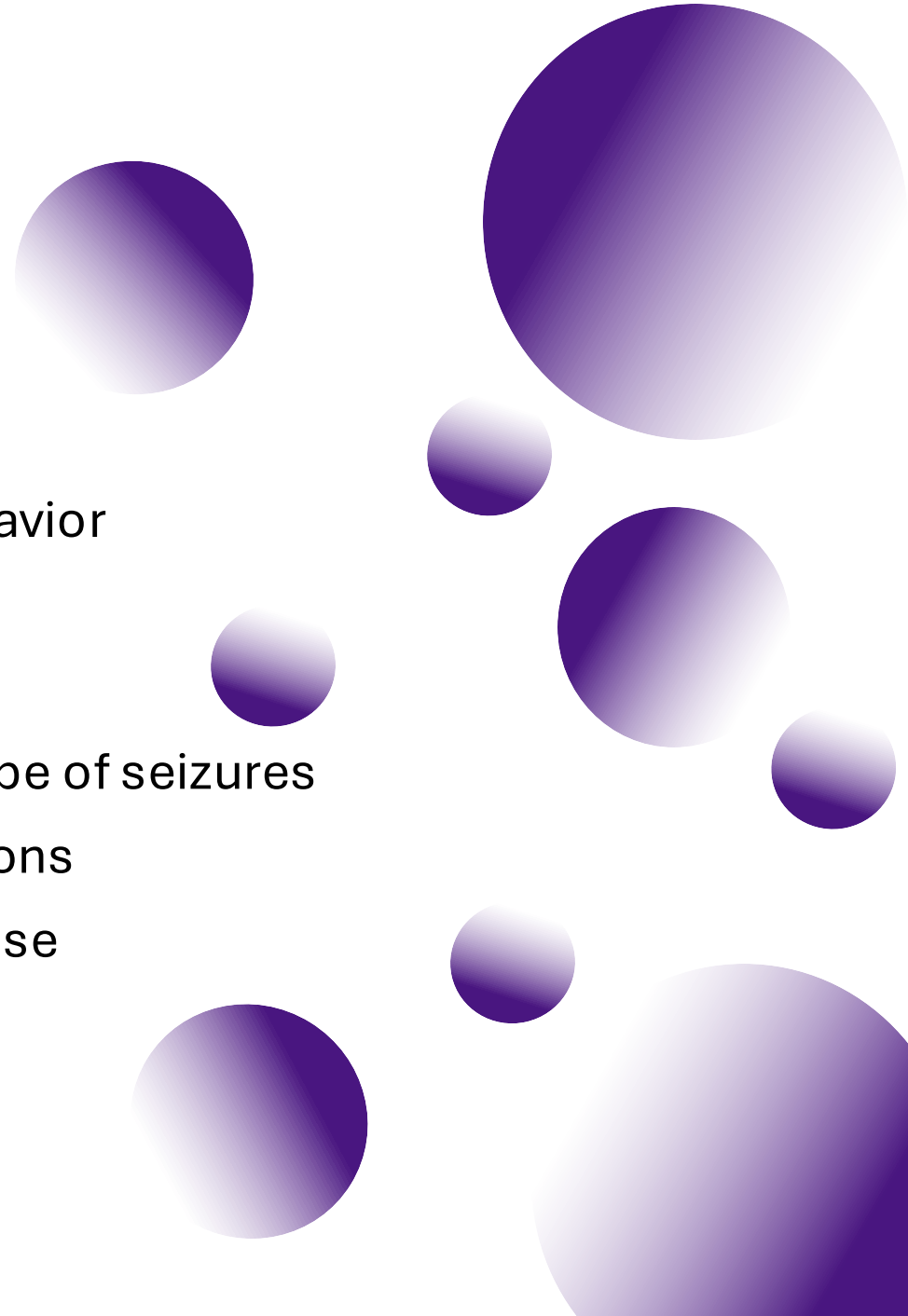
There is no one-size-fits-all approach

Senior Care: Older adults may experience additional challenges, higher fall risks and overlapping conditions

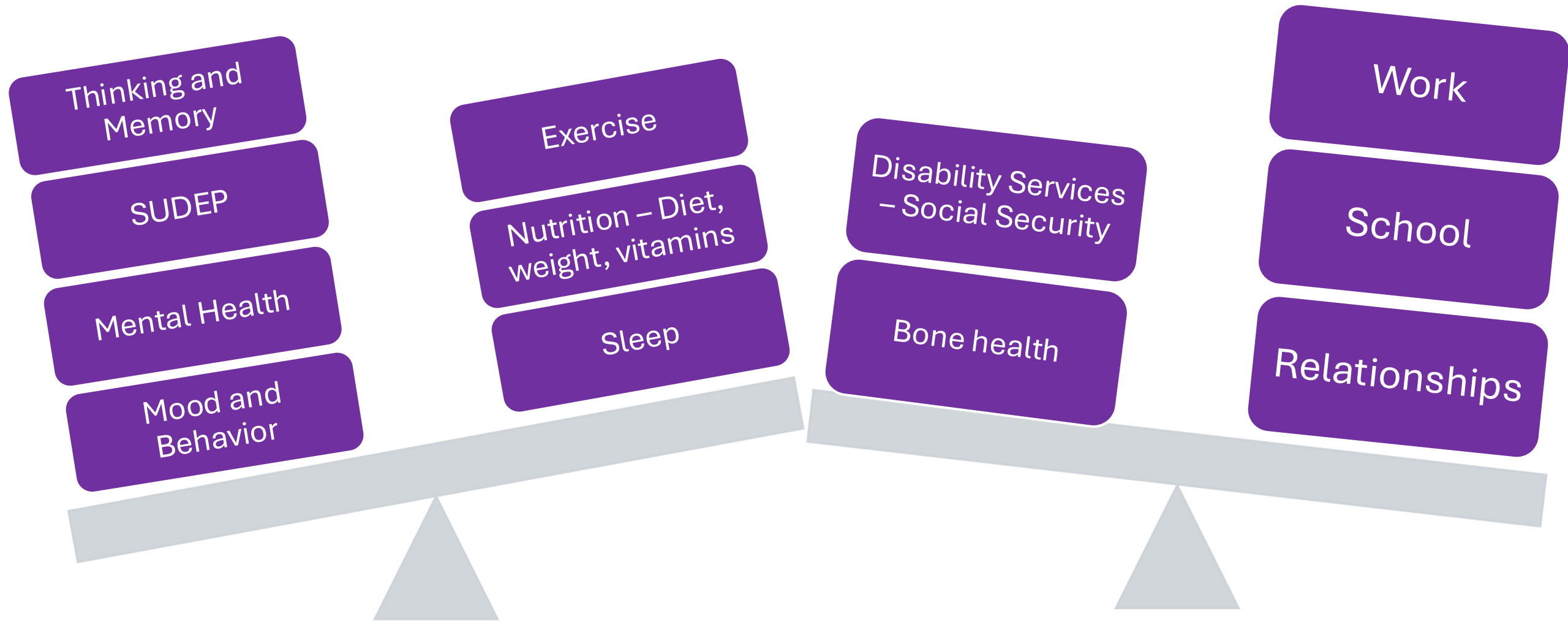




Impacts on Daily Life

- Race / Ethnicity
 - Gender / Biological Sex
 - Age
 - Education
 - Neurologist / Epileptologist
 - Memory
 - Employment
 - Social Security
 - Finance
 - Stigma
 - Housing
 - Mental Health
 - Mood and behavior
 - Medications
 - Daily tasks
 - Frequency / Type of seizures
 - Accommodations
 - Diet and exercise
 - Sleep
- 

Impacting your lifestyle and Independence



Contact your Local Epilepsy Organization

Epilepsy Foundation of Greater Chicago (**EFGC**):

<https://epilepsychicago.org>

Epilepsy Advocacy Network (**EAN**):

<https://www.epilepsyadvocacynetwork.org>

Epilepsy Foundation of Greater Southern Illinois (**EFGSIL**): <http://www.efgreateril.org>

Key:

EFGC



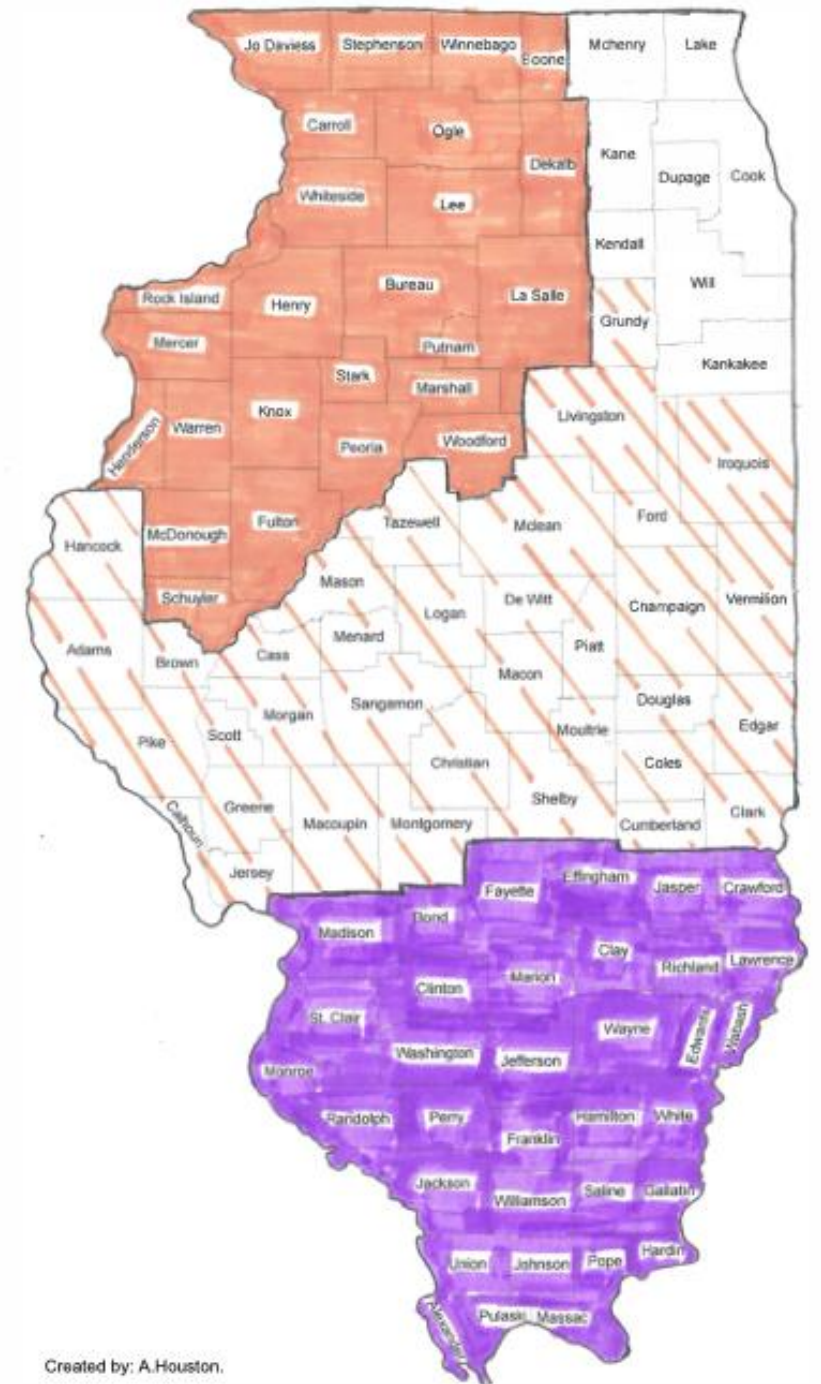
EAN



EFGSIL



Overlapping servicing area with EAN and EFGC



Created by: A.Houston.

You're Not Alone

- Epilepsy Foundation of Greater Chicago
- Epilepsy Foundation of Greater Southern Illinois
- Epilepsy Advocacy Network
- DannyDid Foundation
- Epilepsy Foundation
- Child Neurology Foundation
- Rare Epilepsy Network
- Arc of Illinois
- Mental Health - 988
- Nonprofits and agencies for every health condition and various needs
 - 211
 - Transportation
 - Rescue Medications
 - Transition of Care



Build a Community Together

Map your
community – Who
are your support
system:

List 1 to 2
agencies

List 1 person in your life you
could talk to

- Let's try to expand that to one more
- It's not for everyone but you want enough people around you to know

Stay Empowered – Advocacy and Confidence



**Learn about
your rights**



Ask Questions



**Speak up for
your care**



**Connect with
those who
support you**



**Connect with
nonprofits and
advocacy
organizations**

Advocacy begins with self-advocacy

Living Fully with Epilepsy

- *It's not about the seizures—it's about the strength to keep going.*
- Living with epilepsy isn't just about managing a condition. It's about creating a life filled with purpose, connection, and understanding. When we build communities that care, we build a world where epilepsy doesn't hold anyone back.

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