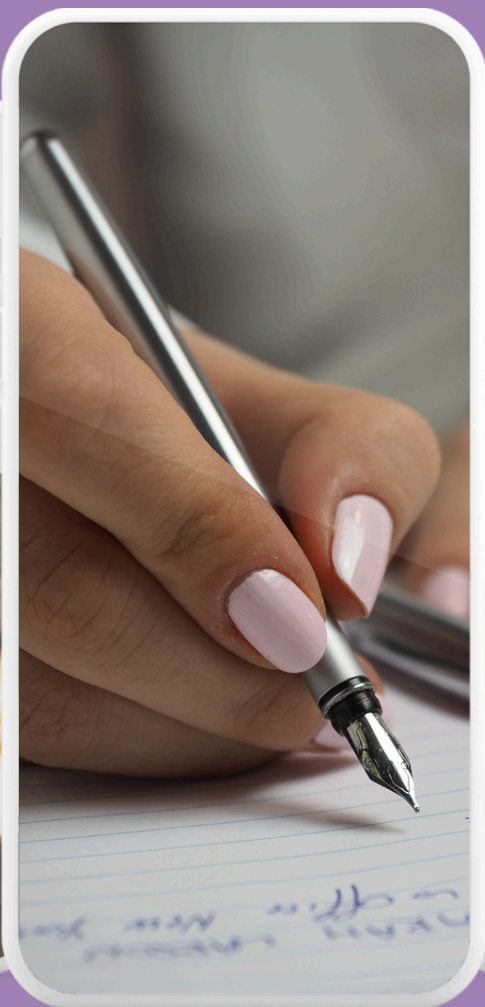




How to Share Your Story

Through various forms of storytelling, explore your journey and learn how to express your emotions, challenges, and victories.





My story. My voice

This digital toolkit is designed to help individuals with epilepsy or seizure disorders share their stories in a variety of engaging and impactful ways. The toolkit includes tools, resources, prompts, and step-by-step guidance for expressing personal experiences, whether through written, verbal, or visual storytelling.



How Do I Share My Story?

There are many storytelling formats that allow you to reach a variety of audiences. Below are a few we will focus on in this toolkit.



Written Stories

Personal Essays
Journaling
Blogging

Visual Stories

Photography
Painting
Collage
Drawings
Video



Verbal Stories

Presentations
Speeches



Social Media Stories

Personal Narratives
Awareness Facts & Myths
Education
Interactive Stories
Advocacy & Fundraising

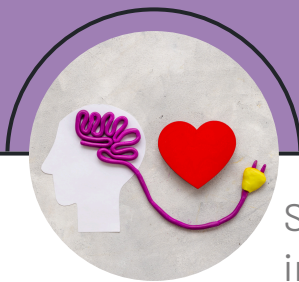


The Impact of a Story



LEGISLATIVE ADVOCACY

Sharing your epilepsy story can have a significant legislative impact - both locally and federally - by humanizing the issues surrounding the condition and encouraging lawmakers to take action on policies that affect people impacted by seizures.



AWARENESS

Sharing an epilepsy story can be a powerful tool in raising awareness, educating, and giving a clearer picture of what life is truly like for someone living with seizures.



CALL TO ACTION

Personal stories evoke empathy and can serve as a call to action by urging people to get involved in supporting those with epilepsy.



Written Stories

Sharing your epilepsy story through writing can help raise awareness, combat misinformation, and inspire change. Whether you're sharing it with friends and family, a support group, or even the wider public, your story can be a source of education, comfort, and empowerment for others.

1. Begin with Your Why

Are you trying to raise awareness, seek support, or give a voice to those who may not be able to speak for themselves? Understanding your purpose will help you shape your narrative and make it more impactful.

2. Start with Your Diagnosis or Early Experiences

Share when you first learned about your epilepsy. How were you diagnosed? Describe the impact it had on your life at that moment.

3. Describe the Impact on Your Daily Life

Talk about how it has influenced your day-to-day life, including school, work, social interactions, or hobbies. Be specific and let your readers see what it's like to live with epilepsy.

4. Include Moments of Struggle and Strength

Be open about the difficult moments while also highlighting moments of resiliency and strength.





Written Stories

5. Share the Emotional Journey

Share the difficult feelings that can often accompany an epilepsy diagnosis - fear, anxiety, embarrassment, or loneliness.

6. Talk About Support Systems

Sharing how a support network has made a difference in your journey can show others the importance of community and encouragement in managing epilepsy.

7. Discuss Treatments and Management

Share your personal experience with various treatments - medication, therapy, lifestyle changes, surgery - including what's worked for you and what hasn't.

8. Educate the Reader

Many people may not understand what epilepsy is, so providing information on its causes, symptoms, and treatment options can help raise awareness.

9. End with Hope or a Call to Action

Conclude your story on a positive or hopeful note. Share the ways you've found strength, used your story to empower others, or important lessons you've learned.



Reflection Questions

Here are some thought-provoking prompts to help you reflect on your epilepsy journey and tell your story in a meaningful way.

How has living with epilepsy or seizures shaped your perspective on life?

Write your answer here

What were the biggest challenges or fears you had in the early days of your diagnosis?

Write your answer here

What are you most proud of achieving despite living with epilepsy?

Write your answer here

Reflection Questions

How have you learned to advocate for yourself, whether in healthcare or daily life?

Write your answer here

Can you think of a specific moment when you realized you were stronger than you thought?

Write your answer here

If you could go back to the time of your diagnosis and speak to your past self, what would you say?

Write your answer here

Sharing Your Story



BLOG

Your story could be shared on your own blog or personal website or you could consider submitting it to relevant blogging communities or websites focused on epilepsy.

SUPPORT GROUPS

Being able to share your story in a succinct and impactful way can benefit the group and inspire others to be more confident in sharing their own stories.



ARTICLES & ESSAYS

If you're looking to reach a larger audience, consider submitting your story to publications or advocacy websites focused on epilepsy awareness.



Visual Stories

Sharing your epilepsy story through visual formats can be a powerful and creative way to raise awareness, educate others, and express your journey. Visual storytelling can evoke emotions and provide clarity in ways that words alone may not.

Choose the Right Medium

Photography or Photo Essays: Capturing moments that reflect your journey with epilepsy.

Illustration or Artwork: Creating drawings, paintings, or digital art that symbolize your experiences.

Videos: Telling your story through video or slideshow, possibly including narration or interviews.

Social Media Content: Creating shareable content, such as graphics or reels, to spread awareness.

Define Your Message

Before you start creating your visual story, think about the message you want to convey. Is it about raising awareness, showing the emotional side of living with epilepsy, or educating others on the condition? Knowing your message will help you choose the most appropriate visual elements to communicate your story effectively.





Visual Stories

Other Visual Content Ideas

Photo Diary: A Day in My Life

Purpose: To visually document what it's like to live with epilepsy on a daily basis.

Include daily routines, safety precautions you take, images of your community or support system, physical activities, etc.

Video Journal

Purpose: To share your story through personal videos that show your personality and emotions.

Share a past seizure experience, how you manage your seizures, the emotional toll you experience, share advice, and encourage others to raise awareness.

Personal Illustrations or Portraits

Purpose: To create a direct visual representation of yourself and your journey, showcasing your identity and how it has been shaped by epilepsy.

Create a self-portrait that speaks to your experience with epilepsy or create portraits that incorporate visual metaphors such as themes of transformation, growth, or hope.





Verbal Stories

Verbal storytelling allows for emotional depth, personal connection, and the ability to directly engage with others.

Speech or presentation

Purpose: To share valuable information and educate about epilepsy in a structured format

Include attention grabbing statements, questions to encourage engagement, visual aids, personal anecdotes, and a call to action.

Interviews or panel discussions

(Podcasts, News segments, advocacy purposes)

Purpose: To raise awareness about epilepsy by sharing your personal story or knowledge in a public forum.

Be prepared to share your personal experiences as well as educate about the implications of living with epilepsy while advocating for better understanding, research, and support.

Host a support group or community meeting

Purpose: To create a safe space for people with epilepsy to share their stories and support each other.

Have discussion prompts and practical advice or tips prepared, provide resources and a non-judgmental environment.





Examples

Art

[Hidden Truths Project](#) (HTP) believes that the arts can become the narrative to engage and empower marginalized members of our society to promote dialogue and foster understanding and acceptance.

Advocacy

[Raise Your Voice: Epilepsy Association of Western and Central PA](#)

Our goal is to ensure that people with epilepsy have access to essential services, that their rights as individuals with epilepsy are protected, and that optimal treatment of epilepsy is promoted.

[International Bureau of Epilepsy's Advocacy Toolkit](#)

Provides a structured approach to prioritize epilepsy as a public health concern, empowering advocates to influence policy and drive impactful change

Blog Posts

[Epilepsy Research Institute UK](#)

[Beyond the In-Between: Breaking Free from the Guilt of Epilepsy](#)

[Tali's Story: Struggling with Epilepsy and Dravet Syndrome](#)

Social Media

[Why I Post On Social Media About Epilepsy](#)

Videos

[Why I have a Seizure Action Plan](#)

[Tina's Story - Carpe Diem](#)





*When we deny our stories, they define us.
When we own our stories, we get to write a brave new ending.
Brene Brown*

For more information, resources, or support, please reach out to
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