



Toolkit For Advocates

Share Your Epilepsy Journey

on International Epilepsy Day!

Epilepsy affects over 50 million people globally, yet we still have much to learn about its full impact on individuals and communities.

That's why this #EpilepsyDay, building on 2024's "My Epilepsy Journey" theme, we're asking you to share your personal experiences that shed light on the unmet everyday needs of people with epilepsy.

Your stories will bring greater context to the findings of IBE's [Global Epilepsy Needs Study \(GENS\)](#) and ILAE's newly developed [Clinical Care Pathway](#).

Our goal is to use these insights to ensure people with epilepsy receive not only the best possible medical care but also the support they need to thrive in all aspects of their lives.

Call For Stories

We want to hear YOUR story. How has epilepsy affected your daily life? What unmet needs have you faced? What support have you needed along the way?

By sharing your epilepsy journey, you will:

- Help us understand the real-world impact of epilepsy.
- Contribute to improving epilepsy care worldwide.
- Join the global epilepsy community in advocating for change.

How to share your story

1. **Choose your format:** Tell your story in writing (200-300 words) or create a short video (2-3 mins max)
2. **Select a domain:** The Global Epilepsy Needs Study (GENS) highlights key areas of life impacted by epilepsy. Choose **one** of these domains to focus your story.

Knowledge and Advice	Safety and Survival	Healthcare and Wellbeing	Learning and Education	Work and Income
Safe Transport and Driving	Community and Household	Mental Health and Wellbeing	Sexual and Reproductive Health	Achieving Your Goals

*Refer to [this chart](#) for more details on each domain.

When describing your experiences, consider the following:

- **What specific needs have arisen related to your chosen domain?** (e.g., Did you need flexible work arrangements due to seizures? Did you require specialised educational support?)
- **How did these needs impact your everyday life?** (e.g., Did it affect your social interactions, your independence, or your emotional well-being?)

3. [Submit your story via this Google Form](#)

If you cannot access the Google Form, submit your story using this [Word document](#).

Closing Date: Friday, 31st January, 2025.

Need some inspiration?

Use the following story prompts as a springboard for sharing your unique experiences, but don't feel limited by these prompts – your own experiences and perspectives are what matter most!

- 1. Knowledge and advice:** Have you had access to reliable information about epilepsy? Do the people around you have the knowledge to support you?
- 2. Safety and survival:** Have you experienced seizures in public? How did people react? Did you feel safe and supported?
- 3. Healthcare and wellbeing:** Share your experiences navigating the healthcare system to manage your epilepsy. Have you faced difficulties accessing health services or treatments for epilepsy?
- 4. Learning and education:** Have you experienced any cognitive challenges related to your epilepsy, such as difficulty with memory, attention, or learning?
- 5. Work and income:** Have you encountered challenges with finding or maintaining employment, disclosing your condition to employers, or dealing with workplace accommodations?
- 6. Safe transport and driving:** What challenges have you encountered in accessing transportation, whether through driving or public transportation? How has this affected your independence, social life, or ability to access essential services?
- 7. Community and household:** Has your epilepsy affected your relationships with others? Have you withdrawn from social situations or avoided activities due to fear of having a seizure, feeling different, or facing stigma?
- 8. Mental health and wellbeing:** Have you experienced anxiety, depression, or other emotional challenges related to your condition? How have these challenges impacted your daily life and overall quality of life?
- 9. Sexual and reproductive health:** Have your epilepsy medications affected your hormones, menstrual cycle, or sexual function? Has epilepsy affected your ability to be intimate or have children?
- 10. Achieving your goals:** Reflect on your overall quality of life. How has epilepsy affected your self-esteem, happiness, and ability to pursue your goals and dreams? What kind of support or resources would help you reach your full potential?

Virtual Art Exhibition

Our Virtual Art Exhibition is back for International Epilepsy Day 2025!

This is your chance to use the power of art to highlight the unmet needs across the GENS life domains through art.

Here are some thematic starting points to inspire your creative exploration. Again, these prompts are here to inspire you, but don't feel limited by them!

- 1. Knowledge and Advice:** Create a piece of art that challenges common misconceptions or stereotypes about epilepsy.
- 2. Safety and survival:** Depict the importance of safe environments and seizure first aid.
- 3. Healthcare and wellbeing:** Express the challenges of navigating the healthcare system to get an accurate diagnosis and effective treatment.
- 4. Learning and education:** Illustrate the impact of epilepsy on the educational experience. Capture the need for understanding and support from teachers and peers.
- 5. Work and Income:** Highlight the challenges of navigating workplace accommodations, and achieving financial security.
- 6. Safe transport and driving:** Create a piece of art that advocates for accessible and affordable transportation options for people with epilepsy.
- 7. Community and household:** Explore themes of isolation, connection, belonging, and the search for acceptance.
- 8. Mental health and wellbeing:** Capture the invisible struggles of anxiety, depression, and other mental health challenges associated with epilepsy.
- 9. Sexual and reproductive health:** Explore the impact of epilepsy on intimate relationships, body image, and family planning.
- 10. Achieving your goals:** Represent the diverse experiences of living with epilepsy and striving for a fulfilling life.

[Submission Guidelines and Google Entry Form](#)

If you cannot access the Google Form use this [Word document](#).

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Share Your Event With Us!

Are you planning an event to mark International Epilepsy Day?

[Please share the details with us here](#)

Events will be featured on the official International Epilepsy Day website, and may also be included in the International Epilepsy Day annual report.

Be sure to share posts and pictures from your event on social media, using the #EpilepsyDay hashtag. We will do our best to promote and reshare your content.



facebook.com/intepilepsyday



twitter.com/IBESocialMedia

twitter.com/llaeWeb



instagram.com/international_epilepsy

instagram.com/ILAE_Epilepsy



linkedin.com/international-bureau-for-epilepsy

linkedin.com/international-league-against-epilepsy

#EpilepsyDay Campaign Toolkit

Campaign resources are freely available for use by individual advocates or non-profit organizations. Commercial companies who wish to use the campaign resources should contact us for approval. If you have any questions about the campaign or issues with downloading the graphics, please contact Marie Ennis O'Connor, Head of Communications at marie.ennis@ibe-epilepsy.org

Icon and Logo



[Download icon](#)



[Download logo](#)

Social Media Graphics

Download Graphics Set 1: #MyEpilepsyJourney



In the lead-up to #EpilepsyDay, promote awareness on social media with these customizable graphics. Add your own logo to these pre-sized images for Twitter/X, Facebook, Instagram, LinkedIn and Tik Tok.

[Download zip file of images](#)

Download Graphics Set 2: #MyEpilepsyJourney: I Need

On Monday, February 10, 2025, there will be a worldwide effort to get #epilepsyday to trend on X (formerly Twitter) and other social media sites.

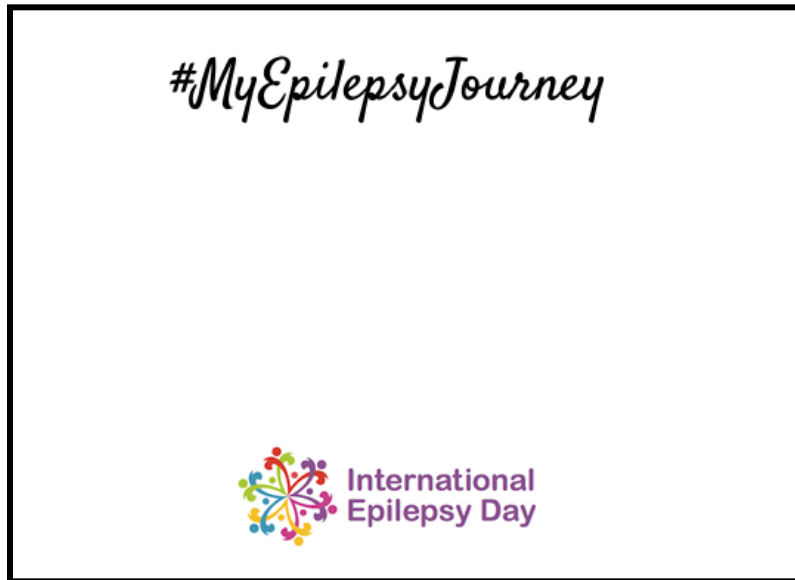
Here's how you can participate:

1. **Grab a card:** Print off one of the #MyEpilepsyJourney templates below (or the plain version on page 9 of the toolkit)
2. **Write your message:** What do YOU need to live well with epilepsy? Write your #INEED message on the card.
3. **Snap a selfie:** Take a selfie with your #INEED card.
4. **Share it online:** Post your selfie on social media using the hashtags #EpilepsyDay and #MyEpilepsyJourney.



[Download zip file of images](#)

Plain Card



[Download plain card](#)

Seeking inspiration for your message?

Check out the suggestions below to prompt your imagination.

#INEED understanding	#INEED to feel safe in public
#INEED support	#INEED to live without stigma
#INEED acceptance	#INEED mental health support
#INEED to achieve my dreams	#INEED to live my life to the fullest
#INEED affordable medication	#INEED access to specialists

