



**EPILEPSY**  
FOUNDATION®

MINNESOTA

# ADVOCACY ACTION GUIDE



RESOURCES FOR EPILEPSY ADVOCACY

EPILEPSY FOUNDATION OF MINNESOTA | [EFMN.ORG](http://EFMN.ORG)

# Epilepsy Foundation of Minnesota's 2026 Advocacy Action Guide

This resource is designed to help you learn more about EFMN's advocacy work and build confidence in sharing how epilepsy-related issues impact individuals, families, and communities across Minnesota.

Inside this packet, you'll find background information on key epilepsy-related issues, tools to support conversations with elected leaders and their staff, and guidance to help you advocate in a way that feels meaningful and comfortable to you.

When you connect with elected officials, you help increase awareness, deepen understanding, and lay the groundwork for future policy change.

By engaging with this toolkit, you're supporting EFMN's mission to empower Minnesotans impacted by epilepsy and help ensure individuals and families have the care, resources, and support they need on their journey.

## What's Inside

- Fact Sheet: Epilepsy in Minnesota..... pg. 3
- Overview of EFMN's Key Issues..... pg. 4-6
- How to Engage your Legislator..... pg. 7
- How to Email your Legislator..... pg. 8
- How to Send a Letter to your Legislator..... pg. 9
- How to Call your Legislator..... pg. 10

# EPILEPSY IN MINNESOTA

## WHAT IS EPILEPSY?



Epilepsy is a neurological (brain) condition that causes people to have recurring seizures.

Seizures are bursts of uncontrolled electrical activity in the brain that can cause a person to behave or feel differently than they typically would.



## WHO HAS EPILEPSY?

- Epilepsy can affect people of all ages.
- It is the fourth most common neurological condition among adults and the most common among children.
- 3.4 million Americans are living with epilepsy.

An estimated **55,000+** Minnesotans live with epilepsy

**1 in 10**

people will have a seizure in their lifetime

## IMPACT OF EPILEPSY

- People with epilepsy, their family, friends, and caregivers are all impacted by epilepsy.
- Unpredictable seizures can disrupt daily life.
- People with epilepsy also face increased rates of:
  - Anxiety and depression
  - Isolation and stigma
  - Unemployment and financial stress
  - Transportation challenges

**1 in 26**

people will develop epilepsy their lifetime

## MANAGING EPILEPSY

- **7 out of 10** people manage seizures with medication.
- Seizure Alert Devices are designed to alert caregivers or medical personnel, providing improved safety and peace of mind for people living with epilepsy.
- For those who cannot control seizures with medication, surgery and implant devices may be alternative options.

# ADVOCATING FOR THE EPILEPSY COMMUNITY

## Quick Look at EFMN's 2026 Key Issues

### ACCESS TO AFFORDABLE PRESCRIPTIONS AND MEDICAL SUPPLIES



- Minnesotans with epilepsy may not be able to afford medications and medical devices due to high co-pays and coinsurance.
- Missing medication is the leading cause of seizures and can lead to injury, hospitalization, and in rare cases, death.
- Uncontrolled seizures can impact a person's education, employment, and overall quality of life.

**EFMN supports efforts to limit cost-sharing on medications and medical supplies used to treat epilepsy, helping ensure care remains affordable and accessible (HF 3652, SF 3786).**

### RAISING AWARENESS OF SUDEP & EARLY MORTALITY



- Sudden Unexpected Death in Epilepsy (SUDEP) occurs in 1 in 1,000 people with epilepsy. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.
- Conversations between health care providers and the epilepsy community can help minimize risk for SUDEP.

**EFMN is building awareness among legislators about SUDEP and early mortality to emphasize the need for more education, prevention, and healthcare incentives to reduce the occurrence of SUDEP across Minnesota.**

### ENSURING ACCESS TO ESSENTIAL HEALTH SERVICES



- EFMN's advocacy work is guided by our commitment to ensure that all Minnesotans with epilepsy have the tools, resources, and support they need to thrive.
- For people living with epilepsy, health services extend beyond medical treatment to include supports such as transportation, case management services, financial resources, caregiver services, residential housing with on-site support, service animals, and mental health support.

**EFMN is increasing awareness and elevating lived experiences on how gaps in care impact individuals and families across Minnesota.**

# EFMN'S 2026 KEY ISSUES

## ACCESS TO AFFORDABLE PRESCRIPTIONS AND MEDICAL SUPPLIES

- Currently, there is no cost-sharing limit for epilepsy-specific prescriptions and medical supplies, meaning that people with epilepsy may have to pay high co-payments and coinsurance for life-saving prescriptions or related medical supplies.
- When people with epilepsy cannot afford medication, they may miss or ration doses, which can lead to seizures.
- People with epilepsy must often trial several medications or combinations of medications to find what works best – meaning the cost of medications can add up quickly.

**Talk with your legislator about why affordability matters, and ask if they would support limiting cost-sharing on epilepsy medications and medical supplies.**

## RAISING AWARENESS OF SUDEP & EARLY MORTALITY

- Sudden Unexpected Death in Epilepsy (SUDEP) occurs in 1 in 1,000 people with epilepsy. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.
- Status epilepticus, unintentional injuries, and suicide also contribute to early mortality (death) in people with epilepsy
- These causes of death are underestimated in Minnesota due to poor recognition and reporting

### What work is already being done to address SUDEP and early mortality?

In 2025, legislation was passed to start the Epilepsy Program at the Minnesota Department of Health (MDH) to improve data collection around epilepsy and related issues including SUDEP and early mortality.

### How can SUDEP be prevented?

More research is needed to fully understand what causes SUDEP, which is why it is important to raise awareness. Because SUDEP occurs most frequently among people with uncontrolled seizures, the best way to minimize risk is to optimize seizure control.

Risk counseling is a conversation between healthcare providers and people with epilepsy about their individual risk for SUDEP and how to lower it. It may involve assessing the frequency and type of seizures they experience, their medications, and lifestyle factors.

- Conversations between health care providers and the epilepsy community can help minimize risk for SUDEP, but lack of awareness and inconsistent reimbursement for post-diagnosis education and case management services makes it challenging for healthcare providers and the epilepsy community to have transparent conversations about SUDEP.
- EFMN is building awareness among legislators about SUDEP and early mortality to emphasize the need for more education, prevention, and healthcare incentives to reduce the occurrence of SUDEP across Minnesota.

**Talk to your legislator about the importance of increasing awareness of SUDEP and early death in epilepsy.**

# EFMN'S 2026 KEY ISSUES CONT.

## ENSURING ACCESS TO ESSENTIAL HEALTH SERVICES

- EFMN's advocacy work is guided by our commitment to ensure that all Minnesotans with epilepsy have the tools and resources they need to thrive, address gaps in care and education, and reduce stigma surrounding epilepsy
- We will advocate to protect and advance access to health care, especially life-saving services for Minnesotans with epilepsy. We will educate lawmakers and key decisionmakers on the public policy changes that are needed to support people living with epilepsy and understand epilepsy's true impact on individuals and families.

**Talk with your legislator about why ensuring access to essential health services is important for Minnesotans living with epilepsy and their families.**

### What types of services do people with epilepsy need?

People with epilepsy need specialized medical care. Additional services depend on how well seizures are controlled and other conditions - transportation, case management services, financial resources, caregiver services, residential housing with on-site support, service animals, and mental health support are other services people with epilepsy may need.

### What gaps in care do people with epilepsy often encounter?

Medication costs, inadequate transportation, and lack of knowledge of and access to specialty medical care are some issues most frequently experienced within the epilepsy community.

For more information scan the QR Code or  
visit **EFMN.ORG/advocacy-2026**



# ADVOCATING FOR THE EPILEPSY COMMUNITY

## HOW TO ENGAGE YOUR LEGISLATOR

### STEP 1: Find Who Represents You

Knowing who represents you is the first step to building relationships and advocating effectively.

- Visit the “Who Represents Me” webpage to identify your state representative and senator. Take note of their names, email addresses, phone numbers, and mailing addresses so you can reference them later.

### Step 2: Choose How You’d Like to Reach Out

There’s no one “right” way to engage. All of the options below are effective, so choose what works best for you.

#### Send an Email

Sending an email is a great way to introduce yourself, share your story, and communicate your priorities as a constituent.

Use this email template to send separate emails to each of your legislators.



#### Tips:

- Use your own words whenever possible.
- Send separate emails to each legislator.
- Focus on one or two key points to keep your message clear.

#### Write a Letter

Writing a letter allows you to be thoughtful and reflective when sharing your experience.

Use this letter template to send separate emails to each of your legislators. Encourage family members, caregivers, or friends to write their own letters as well.



#### Call your Representative

#### What to expect:

- You may speak with a staff member or leave a voicemail.



#### Before you call:

- Review your key points or personal story.
- Keep your message brief and focused.

# HOW TO SEND AN EMAIL TO YOUR LEGISLATOR



**Subject: [Brief summary of the issue or topic. Include bill numbers, if applicable. See example below.]**  
Constituent perspective on epilepsy care, access, and safety

Dear Representative/Senator [Last Name],

My name is [Your Name], and I live in [City/Town]. I'm writing as a constituent and as someone connected to the epilepsy community.

**[Make Your Point - Identify the issue and why this issue is important to you. If you are writing about a specific bill, mention it. See examples below].**

I wanted to share perspectives on a few epilepsy-related issues that are important to individuals and families across Minnesota, particularly access to affordable care, essential health services, and education around epilepsy-related risks.

Many people living with epilepsy rely on life-saving medications and medical supplies. When out-of-pocket costs are high, it can create barriers to consistent treatment. Missing medication is one of the leading causes of breakthrough seizures, which can result in injury, hospitalization, and, in rare cases, death. Affordability plays a critical role in helping people manage their condition and maintain stability.

In addition to medical care, people with epilepsy often depend on access to essential health services such as transportation, case management, mental health support, caregiver services, and, in some cases, residential housing with appropriate supports. These services are fundamental to safety, independence, and quality of life.

I also want to highlight the importance of education and awareness around Sudden Unexpected Death in Epilepsy (SUDEP). SUDEP occurs in approximately 1 in 1,000 people with epilepsy, and when seizures are uncontrolled, the risk increases to more than 1 out of 150. Increasing awareness, education, and access to appropriate care can help reduce risk and save lives.

**[Optional personal paragraph: Share your connection to epilepsy and how these issues affect you, your family, or your community.]**

**[Make the Ask - what do you want your representative to do —vote a certain way, make sure a certain policy is included in a piece of legislation, or raise a certain issue? If applicable, suggest potential solutions or policy recommendations.]**

I appreciate your service to our district and encourage continued consideration of how policies and decisions impact people living with epilepsy. I would welcome the opportunity to share additional perspective or stay engaged on these issues in the future.

Thank you for your time and for listening to constituents like me.

Sincerely,

[Your Name]

[City/Town or County, State]

[Optional contact information]

# HOW TO WRITE A LETTER TO YOUR LEGISLATOR



(Month) (Day), (Year)  
The Honorable (First Name) (Last Name)  
(Legislator's Street Address)  
St. Paul, MN 55155

Dear Representative/Senator (Last Name):

My name is (your first and last name), and I am a (person living with epilepsy / family member / service provider / advocate / community member) who resides in your district. I am writing to share perspectives on issues that are important to people living with epilepsy and their families across Minnesota.

**[Make Your Point - Identify the issue and why this issue is important to you. If you are writing about a specific bill, mention it. See examples below].**

Many individuals with epilepsy rely on life-saving medications and medical supplies to manage their condition. When out-of-pocket costs are high, it can create barriers to consistent care. Missing medication is one of the leading causes of breakthrough seizures and can result in injury, hospitalization, and, in rare cases, death. Affordable access to care plays a critical role in supporting health, stability, and quality of life.

In addition to medical care, people with epilepsy often depend on essential health services such as transportation, case management, mental health support, caregiver services, and, in some cases, residential housing with on-site support. Access to these services helps individuals remain safe, independent, and connected within their communities.

I also want to highlight the importance of education and awareness around Sudden Unexpected Death in Epilepsy (SUDEP). SUDEP occurs in approximately 1 in 1,000 people with epilepsy, and when seizures are uncontrolled, the risk increases to more than 1 out of 150. Increasing awareness, education, and access to appropriate care can help reduce risk and save lives.

**[Optional personal story: Share how epilepsy has affected you, your family, or your community. Personal stories help policymakers understand the real-world impact of these issues.]**

**[Make the Ask - what do you want your representative to do —vote a certain way, make sure a certain policy is included in a piece of legislation, or raise a certain issue? If applicable, suggest potential solutions or policy recommendations.]**

Thank you for your service to our district. I appreciate your attention to these issues and would be grateful for the opportunity to discuss this matter further, and I look forward to hearing about your stance and actions on **[insert the issue]** in the near future.

Sincerely,

(SIGN YOUR NAME)

Print Name  
Street Address  
City, State, ZIP Code

# HOW TO CALL YOUR LEGISLATOR



Reminder: When you call, you may speak with your representative, a member of their staff, or leave a voicemail. Make sure to adjust your script accordingly.

## **[Introduction]**

“Hello, my name is [your name], and I live in [city or zip code]. I’m calling as a constituent and as an advocate with the Epilepsy Foundation of Minnesota.”

## **[Purpose of the Call. Identify the issue and why it matters, see example below.]**

“I’m calling to share why access to affordable care, essential health services, and epilepsy education are important to people living with epilepsy and their families.”

## **[Choose a few key points to share. You don’t need to cover everything. Pick one or two points that feel most important to you, see examples below.]**

### AFFORDABLE CARE

“Many people with epilepsy rely on life-saving medications and medical supplies. When out-of-pocket costs are high, it can make it harder to take medications as prescribed. Missing medication is one of the leading causes of seizures, which can lead to injury, hospitalization, and, in rare cases, death.”

### ESSENTIAL HEALTH SERVICES

“In addition to medical care, people with epilepsy often depend on essential services like transportation, case management, mental health support, and caregiver services. Access to these supports plays a major role in safety, stability, and quality of life.”

### SUDEP AWARENESS

“I want to highlight the importance of education and awareness around Sudden Unexpected Death in Epilepsy, or SUDEP. SUDEP occurs in about 1 in 1,000 people with epilepsy, and when seizures are uncontrolled, the risk increases to more than 1 out of 150. Education and access to care can help reduce risk.”

## **[Optional personal story: Share how epilepsy has affected you, your family, or your community. Personal stories help policymakers understand the real-world impact of these issues.]**

“For me / my family / someone I care about, epilepsy has meant \_\_\_\_.”

## **[Make the Ask - what do you want your representative to do —vote a certain way, make sure a certain policy is included in a piece of legislation, or raise a certain issue? See example below.]**

“I wanted to encourage continued consideration of how policy decisions affect access to care, essential services, and safety for people living with epilepsy. Would you be open to staying engaged on these issues moving forward?”

## **[Closing]**

“Thank you for your time and for listening to constituents like me. I appreciate the work you do for our community.”

# THANK YOU

Thank you for taking the time to engage with these materials. Sharing perspectives and experiences helps inform policymakers and contributes to a better understanding of how epilepsy affects individuals and families across Minnesota.

Whether your advocacy takes the form of a phone call, email, letter, or ongoing learning, these efforts help ensure epilepsy-related issues remain part of broader policy conversations. Over time, this type of engagement supports more informed decision-making.

We appreciate your participation and willingness to stay engaged on issues impacting the epilepsy community.

## Questions?

**Email:** [advocacy@efmn.org](mailto:advocacy@efmn.org)

**Scan the QR Code to learn more or visit**

[efmn.org/advocacy-2026](https://efmn.org/advocacy-2026)

