

Sunflower Syndrome

A P H O T O S E N S I T I V E E P I L E P S Y

A Guide for Patients, Families, and Schools



The purpose of this guide is to explain Sunflower syndrome (SS) and provide advice about how to help individuals living with SS.

This guide can be distributed or used by anyone seeking more information on SS to better support individuals living with SS.

This guide was created by the Pediatric Epilepsy Program at Massachusetts General Hospital.

Introduction to Epilepsy

Before we dive into Sunflower syndrome (SS), it is helpful to understand what epilepsy is.

- A **seizure** is a sudden abnormal burst of electrical activity in the brain that causes an alteration of sensation, behavior, or consciousness.
- **Epilepsy** is defined as having 2 or more unprovoked seizures in a person's lifetime.
- An **electroencephalogram (EEG)** is a noninvasive diagnostic test used to measure and record the electrical activity of the brain. An EEG shows normal brain activity or it may show abnormal brain rhythms which may be indicative seizure activity. An EEG is used to help locate the origins of seizures and help diagnose epilepsy.
- An **epileptiform** change is a pattern on an electroencephalogram (EEG) that shows abnormal electrical activity in the form of spike waves, sharp waves, and slow waves, which may be observed on EEGs of people with epilepsy.
- Dr. Jo Sourbron reviews EEG basics before showing the seizure activity of an individual with Sunflower syndrome in the video titled, [Ictal EEG Provoked or Unprovoked Seizures?](#)

Definitions are from the [MGHfC Epilepsy Education Glossary](#)

What is Sunflower Syndrome?

- Sunflower syndrome (SS) is a rare form of photosensitive epilepsy.
- Individuals with SS have seizures triggered by light, most often the sun, but may also be triggered by artificial light.
- Their seizures are typically accompanied by handwaving in front of the face.
- Individuals with SS may compulsively and involuntarily turn their head toward the light source, which makes it difficult to control the seizures.



Image from [The Boston Globe Interview with Dr. Thiele \(2019\)](#).

Quick Sunflower Syndrome Facts

There is a lot of misinformation on the internet about SS.

*Here are the **facts** you need to know:*

Handwaving

The handwaving and the seizure occur simultaneously. The handwaving does **NOT** cause the seizure. This has been proven by EEG tests.

- Visit [TODAY highlight on Dr. Thiele and SS \(2019\)](#) for handwaving examples and more background

Frequency of Seizures

The frequency of seizures may differ from one individual with SS to another. Exposure to the sun and other light sources may impact the length and duration of a seizure.

Cognition

Individuals with SS can have varying cognitive abilities. This syndrome may interrupt learning and may lead to academic and/or behavioral challenges.

Awareness of Surroundings

Although individuals with SS often continue to play or work during a seizure, they may briefly be unaware of their surroundings, which may impact safety in certain situations.

Survey Results: How Individuals with SS Describe Their Seizures

A RedCap survey was completed by 68 patients with Sunflower syndrome. Below describes how patients with SS reported feeling before, during, and after their seizure (Barnett et al., 2021 & [Clinical Features of SS](#) video).

Feelings Before, During, or After Handwaving

Before handwaving a person may feel:

- Drawn to turn their face towards the sunlight or light source
- Normal or fine before the handwaving
- A compulsion to handwave
- A tingling or buzzing in the front of the head or neck immediately before handwaving

During handwaving a person may feel:

- Normal or unaware that handwaving had occurred
- A negative or unpleasant feeling such as dizziness
- A pleasant or euphoric feeling

After handwaving a person may experience:

- Fatigue
- Nausea
- Headache
- Relief
- Another seizure type after handwaving, especially if it occurred for an extended period of time



How to Support Individuals with Sunflower Syndrome

SS is a generalized epilepsy. Below are some medications and treatments that may be helpful for treating SS. Please contact your provider to learn more about the medications and dietary therapies listed below and to discuss if a treatment would be a good fit for you or your child.

Treatments

- Medications
 - Divalproex Sodium (Depakote)
 - Levetiracetam (Keppra)
 - Clobazam (Onfi)
 - Lamotrigine (Lamictal)
 - Recent studies have demonstrated that Fenfluramine (Fintepla) may also help
- Diet
 - Classic Ketogenic Diet
 - Low Glycemic Index Treatment (LGIT)
 - Modified Atkins Diet (MAD)



How to Support Individuals with Sunflower Syndrome

A multidisciplinary approach between administrators, teachers, and parents is essential to make home, school, and the community safe for the individual with SS.

Suggested Modifications

Some individuals benefit from the use of modifications to help reduce seizures.

These modifications might include but are not limited to:

- Glasses with dark or blue-tinted lenses
- Blue-tinted contacts
- Hats or visors
- Putting down shades or blinds
- Putting up light filters
- Seating individuals away from windows when possible
- Alternatives for outdoor play on sunny days
 - Talk with parents about options for outdoor recess, physical education classes, and field trips
 - Consider allowing the student to play indoors with some friends during recess



How to Support Individuals with Sunflower Syndrome

Creating, Distributing, and Following a Plan

- It's important to have a medical plan in place for an individual with SS
- To create a medical plan, communicate with the doctor, nurse, and other specialists involved
- It's equally important to share the plan with **all** the adults who will be working with the individual, including the teachers, nurses, counselors, lunch and recess monitors, bus drivers, and service providers
- Check in periodically with the care team involved to ensure the plan is being followed as recommended and if amendments need to be made

Seizure Action Plan

- A **seizure action plan** is a plan of care should a seizure occur
- A seizure action plan includes important information about the individual's medical history, epilepsy syndrome, seizure type, and information a person would need to know to keep the individual safe
- For more information on seizure action plans and example plans go to [EF Seizure Action Plans](#)



How to Support Individuals with Sunflower Syndrome

Individuals with SS may experience academic difficulties which can be supported by a 504 plan or Individualized Education Plan (IEP).

Monitor for Academic Needs

504 Plan

- Includes specific accommodations, supports, or services for an individual living with a disability
- Is created by the individual's parent/guardian, teachers, and the school principal
- Typically updated annually and re-evaluated on an as-needed basis that can vary by state
- Example [504 Plan](#)

IEP

- Includes the individual's skills, education goals, services needed to meet goals, and accommodations to support the individual who has 1 or more of the disabilities supported by the Individuals with Disabilities Education Act (IDEA)
- Is created by an IEP team which includes the individual's parent/guardian, teacher(s), special education teacher(s), school psychologist, and a district representative
- Is reviewed annually and re-evaluated every 3 years

Which plan is better suited for my child?

- It depends. A breakdown of choosing the 504 plan or IEP is outlined by [EF of Minnesota](#) or [Understood](#)



How to Support Individuals with Sunflower Syndrome

Sunflower Syndrome and Bullying

Unfortunately, school bullying is not uncommon for children with SS because of the associated hand-waving with their seizures. It is important to put necessary supports in place to address bullying and harassment that may occur.

- **It's crucial for teachers to have conversations with their students to increase awareness, understanding, and empathy for peers with SS**
 - Useful resources: [Understanding Epilepsy Basics](#), [Explaining Epilepsy to Kids, Teens, or Adults](#), [Sunflower Syndrome: Patient Experiences](#)
- Communicate with parents and educators about any signs of not doing well in school: not spending time with friends, frequent stomach aches or headaches, anxiety, or depression

Individuals with SS can lead rich and rewarding lives. It is important that their family, friends and community understand how to best support them.

Resources: [Bullying- How to Support Your Child](#), [Bullying and Youth with Special Needs](#), stopbullying.gov, [MGHfC](#)



How to Support Individuals with Sunflower Syndrome

Sunflower Syndrome and Mental Health

- SS may place individuals at a greater risk of experiencing mental health and behavioral issues
- Research has shown that individuals with SS often experience low self-esteem, bullying due to handwaving, school performance issues, anxiety, and depression
- There are many reasons why individuals with SS may have a greater likelihood of experiencing mood and behavioral dysregulation. These may include:
 - Diagnostic journey can be lengthy and may involve previous misdiagnoses
 - Multiple challenges of adjusting to and living with a chronic health condition
 - Changes to daily life, which may include: possible need to take medication and/or adapt diet, maintain regular sleep patterns, and alterations in independence such as finding alternative modes of transportation
 - Areas of the brain controlling emotions and behavior may be impacted by seizure activity
- It is important to remember that mood and behavioral challenges may be managed through a range of effective treatments such as therapy, lifestyle changes, and medication

To learn more on epilepsy and mental health, please refer to [Childhood Epilepsy: Mental Health and Behavior](#), [Epilepsy and Psychological Disorders](#)



How to Support Individuals with Sunflower Syndrome

Anxiety is a common mental health issue seen in individuals with SS. Anxiety may take the form of chronic, generalized worrying; acute, overwhelming panic attacks; social phobias; specific phobias; and obsessive-compulsive tendencies.

Symptoms of Anxiety

Emotional and Behavioral

- Difficulty controlling feelings of worry
- Difficulty with concentration
- Fatigue
- Feelings of impending danger, panic, or doom
- Irritability
- Feeling nervous, restless, or tense
- Sleep disturbances

Physical

- Changes in blood pressure and heart rate
- Rapid breathing (hyperventilation)
- Headaches
- Muscle aches
- Stomachaches
- Unexplained pain

If you have concerns about the ways in which SS may be impacting a person's mental health, encourage the person to speak with their doctor and ask for a referral to a mental health professional treating these conditions.

Resource: [Mental Health Challenges](#)



How to Support Individuals with Sunflower Syndrome

Common Triggers of Anxiety in Individuals with SS

- Unpredictable nature of seizure activity
- Fear of being bullied at school and in the community
- Fear of handwaving in public
- Feelings of embarrassment for wearing sunglasses and hats
- Worries of transitioning to independence, particularly during adolescence
- Fear of medical procedures

Strategies to Help Reduce Anxiety

- Self-care: exercise, nutrition, sleep hygiene
- Coping strategies: listening to music, being creative, using mindfulness exercises
- Avoiding oversaturation of visual impacts i.e. tv, video games, and social media
- Open dialogue about anxiety at home and at school
- Social and emotional supports in place at school

Resources: [Anxiety and Executive Functioning](#), [Anxiety and Epilepsy](#).



Accessing Mental Health Services

Finding mental health services can be challenging and confusing. It is helpful to think about who provides these services, how to find these providers, and how to choose a therapist who is a good fit.

Mental Health Professionals

- Psychiatrists
- Psychologists
- Clinical Social Workers
- Mental Health Counselors
- School Counselors

See resources below for descriptions of mental health professional roles

Process of finding a therapist

- Call your insurance company
- Ask your primary care provider
- Ask people you trust for a recommendation
- Contact a therapy matching service
- Search online

A therapist is expected to listen, be respectful and supportive, give appropriate feedback, and help identify therapeutic goals and interventions. It can be helpful before making an appointment to ask about the therapist's training, license, and experience. Talk with a social worker or other health care team member for additional assistance to find a therapist that is a good match.

Resources: [Accessing Mental Health Services](#), [What Is the Difference Between Psychologists, Psychiatrists, and Social Workers?](#)

More information about Sunflower Syndrome can be found here:

Websites

- [MGHfC Epilepsy Education Glossary](#)
- <https://www.massgeneral.org/children/sunflower-syndrome>
- [EF Seizure Action Plans](#)
- [Example 504 Plan](#)
- [Epilepsy Foundation Minnesota: IEP vs. 504](#)
- [Understood: IEP vs. 504](#)
- [Understanding Epilepsy Basics](#)
- [Explaining Epilepsy to Kids, Teens, or Adults](#)
- [Bullying and Youth with Special Health Needs](#)
- [Stopbullying.gov](#)
- [MGHfC What to Do If You're Being Bullied](#)
- [Childhood Epilepsy: Mental Health and Behavior](#)
- [Epilepsy and Psychological Disorders](#)
- [Childhood Epilepsy: Learning](#)
- [Anxiety and Epilepsy](#)
- [What Is the Difference Between Psychologists, Psychiatrists, and Social Workers?](#)

Facebook Group

- Sunflower Syndrome - Photosensitive Epilepsy Peer Support:
<https://www.facebook.com/groups/565719590271542/>

Free Scientific Review Article

- Geenen, K. R., Patel, S., & Thiele, E. A. (2021). Sunflower syndrome: a poorly understood photosensitive epilepsy. *Developmental medicine and child neurology*, 63(3), 259–262.
<https://doi.org/10.1111/dmcn.14723>

Redcap Survey

- Barnett, J. R., Fleming, B. M., Doshi, S. P., Freedman, J., Ambrosio, N. R., Geenen, K. R., Bruno, P. L., & Thiele, E. A. (2021). Understanding Sunflower syndrome: Results of an online questionnaire. *Epilepsy & behavior: E&B*, 117, 107856.
<https://doi.org/10.1016/j.yebeh.2021.107856>

Videos

- Ictal EEG Provoked or Unprovoked Seizures?
 - https://youtu.be/4M3OqwoWm_o
- The Boston Globe Interview with Dr. Thiele (2019)
 - <https://www.youtube.com/watch?v=Ng4ne2D64aY>
- TODAY highlight on Dr. Thiele and SS (2019)
 - <https://www.today.com/video/sunflower-syndrome-causes-500-600-seizures-a-day-73531461619>
- Sunflower Syndrome: Patient Experiences
 - <https://youtu.be/cTbU2tzNeBI>

Videos

- Bullying- How to Support Your Child
 - <https://youtu.be/y17Y5jxtUCM>
- Sunflower Syndrome: Mental Health Challenges
 - <https://youtu.be/OPsptnra4HE>
- Sunflower Syndrome: Accessing Mental Health Services
 - https://youtu.be/Yo_1Ae1Gz-Y
- Anxiety and Executive Functioning in People with Sunflower Syndrome
 - https://youtu.be/uqzQVsC_Rls
- History of Sunflower Syndrome
 - <https://youtu.be/qhTy62mrlso>
- Clinical features of Sunflower Syndrome
 - <https://youtu.be/QfoCKr-JL9g>
- Sunflower Syndrome: OCD, Tics, and Related Disorders
 - <https://youtu.be/24wqsqwlyVY>
- Sunflower Syndrome: Parent Experiences
 - <https://youtu.be/F6sRQc2gt74>

Videos

- Epilepsy in Childhood: Types and Treatments
 - <https://youtu.be/KoAYGfGLtIA>
- Treatments in Sunflower Syndrome
 - <https://youtu.be/w3-se7-RMn8>
- Dietary Therapy for Sunflower Syndrome
 - [https://youtu.be/dZ\]cZ\]yacoU](https://youtu.be/dZ]cZ]yacoU)
- Benefits of Epilepsy Service Dogs
 - <https://youtu.be/o-TC3yqIWom>



Contact us!

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<https://www.massgeneral.org/children/sunflower-syndrome>

<https://www.massgeneral.org/children/epilepsy>



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