SYNCOPE AND YOUR CHILD
INCLUDING REFLEX ANOXIC SEIZURES

“Working together with individuals, families and medical professionals to offer support and information on Syncope and Reflex Anoxic Seizures”

www.stars-us.org

Non-profit organization 501(C)(3)
STARS (Syncope Trust And Reflex anoxic Seizures) was founded 16 years ago in England by Trudie Lobban after her daughter, Francesca, was diagnosed with Reflex Anoxic Seizures, a form of syncope. Trudie was dismayed to find there was no support or information regarding her daughter's condition. Her pediatric neurologist suggested she start a support group for others who were experiencing the same frustrations. In her quest to support and educate others on syncope conditions, STARS was created. Because of the tremendous growth in demand for support and information from sufferers in the United States, STARS-US was established.

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Please remember these are general guidelines and individuals should always discuss their condition with their own Doctor
What is SYNCOPES?

SYNCOPES (pronounced sin-co-pee) is a medical term for a ‘blackout’ or a ‘common faint’ that is caused by a sudden lack of blood supply to the brain. This is very common, and occurs in roughly half of all individuals during their lives. There are many causes of syncope; the most common is vasovagal syncope, also known as neurocardiogenic syncope or reflex syncope.

Other medical names for Syncope:
• Reflex Asystolic Syncope
• Vasovagal Syncope (VVS)
• Reflex Syncope
• Neurally Mediated Syncope (NMS)
• Neurocardiogenic Syncope (NCS)
• Pallid Syncope
• Stephenson’s Syndrome
• Vagal Cardio-Inhibitory Fainting Fit
• White Breath-Holding Attacks
• Reflex Anoxic Seizures

They are not:
• Epilepsy
• Blue Breath-Holding Attacks
• Valsalva Syncope
• Apnea attacks caused by the stoppage of breathing
• Prolonged Expiratory Apnoea (PEA)
• Simple Faints or Pseudo-Syncope
• Pseudo-Seizures
• Other cardiac causes with arrhythmia (abnormal heart rhythm, such as Long QT, etc.)

With some children who suffer from a syncope condition, any unexpected stimulus, such as pain, shock or fright, causes the heart and breathing to stop; the eyes to roll up into the head; the complexion to become deathly white, often blue around the mouth and under the eyes; the jaw to clench and the body to stiffen; and sometimes the arms and legs to jerk.

After what seems like hours, but is probably less than 30 seconds, the body relaxes and the heart starts beating (sometimes very slowly at first). The sufferer is unconscious. One or two minutes later the person may regain consciousness but can appear to be unconscious for over an hour. Upon recovery the person may be very emotional and then fall into a deep sleep for two to three hours. He or she looks extremely pale with dark circles under the eyes. Episodes may occur several times per day/week/month, they also appear to come in batches.
Because of the symptoms, syncope is often unfortunately misdiagnosed as temper tantrums, cyanotic breath-holding (prolonged expiratory apnea), or epilepsy. Therefore, one of the aims of STARS is to bring about both professional and public awareness of syncope conditions.

**Diagnosis**

A correct diagnosis of a syncope condition is aided by a good description from a witness, establishing the trigger, keeping a diary of events, and consulting a doctor who is fully aware of the patient’s condition, and takes a detailed history. Videotaping an attack will also help in a speedy, accurate diagnosis.

Routine tests (mainly to rule out any other underlying condition) may include:

- **Electrocardiogram (ECG/EKG):** These tests are based on wires placed on the chest to monitor the heart and hopefully record an attack.
- **Electroencephalogram (EEG):** This test is based on wires placed on the head to read the electrical output of the brain.
- **Event monitor worn in an attempt to record an attack occurring naturally.**
- **Implantable Loop Recorder (ILR):** This monitors and records events.
- **Tilt table test:** This test induces an attack while being monitored with ECG and EEG.

“I just wanted to wrap her up in a blanket, sit and play jigsaws all day, knowing that she was unlikely to have an attack if she didn’t move.”

(Parent of sufferer)

Such a response while caring for a child with a syncope condition is natural; however, parents need to balance the understandable need to protect their child from harm with the long-term problems caused by this attitude.

Excluding children from everyday activities and risks can stunt their normal emotional and psychological development. Discipline and limit-setting are particularly difficult for families of these children, but they remain essential for the child’s healthy development.

**Avoiding Attacks**

- Allow a child to stand, watch and survey and then become accustomed to and gain confidence before participating in activities such as games, parties or just entering a crowded room or new environment.

- Don’t stop your child from doing anything (unless dangerous), but warn him/
her ahead of time about any danger, so if an accident happens, it is not such a shock.

- Allow your child to participate in athletic programs, but warn about possible dangers. A typical example may be a girl suffering with severe attacks, but she never has an episode while at gymnastics. She knows she is likely to hurt herself, so when it happens, it is not such a shock.

- Encourage a child to swim, but allow him or her to sit on the side of the pool with their feet in the water and gently wet the face, hand and arms to get used to the temperature before jumping in. Again, it takes away the shock element.

These are general guidelines and individuals should always discuss their condition with their own Doctor.

- Warn a child that vaccinations will hurt, but re-assure and explain what is about to happen as it happens, while the nurse/doctor injects. This reduces the chance of an attack brought on by the sudden pain of the needle.

- In a matter of fact way, inform all teachers/care-givers/babysitters that your child has a problem coping with pain and sometimes passes out.

- Stress the importance of informing those responsible for the child not to overreact. For more information, please contact STARS.

- If you know a certain situation will bring on an attack (i.e., eating cold ice cream), then avoid these situations for a while.

- Maintaining a balanced diet and hydration has proved to reduce the frequency of attacks. Poor hydration appears to be linked with fainting. Some doctors recommend increasing fluid intake (water, energy drink, not carbonated drinks).

- Remember the child is a normal healthy person and should not be excluded from any “normal” activity.

During and immediately after an attack:

- Stay calm, at least outwardly, even if you are panicking within.

- Make sure the child is safe.

- The child should lay flat, whether on lap, bed, floor or sofa. Parents often feel better if you say “recovery position” as it gives them something to focus on.

- Check to make sure nothing is in the child’s mouth.

- Try to time the attack. It will be much shorter than you imagine.

- If possible, video the attack to show doctors.
• When the child regains consciousness, allow him or her to sit up when they are ready and able. Re-assure, cuddle, and give lots of tender loving care, as they are often very emotional.

• If an older child has been incontinent, don’t make a fuss.

• Allow them to sleep. They often sleep for 2 – 3 hours. Some however are just drowsy and dizzy/disorientated. Reassure and just be there for them because they often feel afraid and insecure.

• Many sufferers report that noise is amplified after an attack. Keep the environment calm and quiet around the sufferer.

• The sufferer is often very emotional for hours/days. Be understanding and reassuring. Slowly encourage them to get back to normal and allow them some time.

• Sufferers and parents report night terrors and pains in legs a few days before, during, or just after an attack. Awareness is vital.

• It is unlikely that they will actually remember the attack. If they don’t want to talk about it, do not force the issue.

Management:

• Even with very young children avoid discussing “their problem” in their presence. It makes them feel odd, different and can make them become withdrawn.

• Don’t avoid disciplining your child because you are afraid of an attack.

• Give the child an explanation of their condition and answer any questions he or she may have, appropriate to their age.

• Siblings often feel they are the cause of the attack. Reassure and explain to them. Don’t blame the sibling for an attack. This can lead to resentment and anger.

• If attacks continue after the age of 5 years old, be aware of any bullying from fellow classmates.

• Families with children who have been diagnosed within a short period of time and have had contact with the support group normally cope better in their management and understanding of this condition.

• Telephone the STARS group for reassurance. Know you are not going through this alone.

• Finally, if an attack happens, don’t blame yourself, don’t feel guilty.
“The lack of information was incredibly frustrating, but then I found STARS. The information and resources they gave me were invaluable.”
Mary from Maryland, whose 5-year-old daughter, Claire, has swallowing syncope.

Treatment Options

Although as yet, there is no cure, advances have been made with the use of the following:

Pacemaker: Cardiac pacing as a treatment to improve the quality of life for some individuals with a syncope condition.

Atropine: Atropine sulfate/methonitrate is an inexpensive, safe, effective drug that prevents most attacks, but can cause harm in overdose. It is used in the short-term for young children having severe and frequent attacks.

Side effects of atropine may include:
• Dry eyes, eye irritation
• Blurred vision
• Dry mouth
• Excessive thirst
• Hot and sweaty feelings
• Difficulty in passing urine
• Affects ability to learn
• Long-term effects not fully known
• Must be given daily whether attacks are occurring or not

“Caitlin has seen Dr. Blair Grubb in Ohio. From a parent’s perspective, he is a godsend. He listened — really listened.”
Deb Blevins, North Carolina

A SPORTING CHANCE
Caitlin leads a full life with her family, friends, church, school and every sport imaginable, including soccer, league basketball and baseball. To keep up with her demanding schedule, Caitlin has been wearing her pacemaker since she was 4 years old to help deal with her condition.

Night Terrors

Night terrors are brief periods (about 10 to 20 minutes) of screaming/crying and distress in the middle of the night. This normally occurs in toddlers up to the age of 4 years to 5 years. Night terrors occur typically in the first half of the night. It is
very difficult, if not impossible, to arouse a child from a night terror. The child may have his or her eyes open, but will “stare straight through you” as if not seeing you. In fact, the child does not see you and will not remember anything about the night terror in the morning.

A night terror is a disorder of incomplete arousal from deep sleep. Most of the brain is shut down, but certain motor (muscular movement) circuits are active when they should, in fact, be quiet. The result is thrashing around, screaming/crying out, walking up and down, kicking, unintelligible speech and apparently terrified feeling. The child will not respond to voice, touch, or reassurance.

It is known that children tend to have night terrors just prior to, during or immediately after a batch of attacks.

**Important facts about night terrors**
- The child will not remember the night terror in the morning.
- Parents are advised not to even mention it to the child.
- Attempting to wake the child during the night terror is rarely successful.
- The child is not ill.
- There are no known long-term ill effects.
- Usually, night terrors occur only once per night, not every night.
- Changes in routine and becoming over-tired can make the child worse.

**What can be done to help?**
- Stay calm during the night terror.
- If the child is thrashing around and walking back and forth, speak reassuringly.
- If possible, hold your child close until it passes.
- Only attempt to restrain the child physically to prevent self-injury.
- Place anything breakable out of reach. If necessary, lock doors and windows.
- Reassure siblings that the terror will do no harm and will go away.
- Your reaction and those of the siblings may upset the child who is having the night terror.
- Remember that the child will have no memory of the incident the next day. He or she should not be made aware of the incident to avoid distress.

**Starting a new school or toddler group**

Starting school or a toddler group is an anxious time for parents and for young
children. This may be the first time the child had been separated from his or her mother.

Also, it may be the first time when the child has to learn to share and be given instructions from a “stranger.” All children have a settling in period. Many children find the transition from the home environment to a new environment a challenge. A child with a syncope condition, can be particularly vulnerable.

**Ways that a school can help**

- Many children find the transition from nursery to primary school and primary to secondary school a challenging time. A child with a medical condition can be particularly vulnerable.

- It is important that the child has equal access to all areas of the curriculum if at all possible.

- Set up a meeting as soon as possible with the parents/teachers/school nurse/classroom helpers so that all are fully aware and understand the child’s condition. Write an individual Care Plan (draft copy available from STARS) and review it each term with your parent/teacher/school nurse.

- Decide with the child how to handle telling the other children/students.

- Openness about their condition prevents it from becoming a weapon for bullies.

- It may help to ask the parent/guardian or a named contact to accompany the child on school trips or to swimming lessons to reassure parents and teachers when away from the school environment.

- In every other aspect the child is a healthy person and should not be excluded from any “normal” activity. However a responsible adult should be made fully aware of the condition and action taken if necessary. Remember that the older the child becomes, the less frequent the attacks will become and the chances of having a an attack while at school is highly unlikely.

**Advice for children starting middle school**

- Have early nights for the first few weeks of the term.

- Keep a diary of two or three things you like about school and two or three things you don’t like.

- If you have a problem, talk to your home-room teacher, advisor, or best friend. Do tell your parents.
• Give a copy of your school schedule to your parents.

• Talk to your friends about your condition.

• Reassure friends that you are just like them, but that your body “shuts down” unexpectedly after pain or shock.

• Tell friends that it is unlikely that it will happen; however, if an attack occurs, how they can help.

• If you have any fears or worries, please tell your parents or contact STARS. We can help and give advice. We could also put you in touch with another teenager to share your thoughts.

Always remember:

• Everyone starting the new school with you is feeling just the same.

• Don’t be afraid to ask for help. Teachers expect such requests in the first few weeks.

• Don’t get overtired. And remember to talk about your worries.

• Don’t let your condition prevent you from taking part in any activity.

• Complete your personal plan and hand it to the appropriate person in charge.

• Enjoy your new school.

**STARS PATRON:**

Sir Roger Moore is world-renowned for his work as an actor and ambassador for UNICEF. He also is a patron of STARS. Roger suffered his first syncopal attack while performing on stage in New York. Since then, a pacemaker has improved his condition.

“I know from personal experience how frightening and worrying this can be. I am very happy to be associated with STARS, which is a charity that does vitally important work by raising awareness, providing support and aiding research for this condition.”

Sir Roger Moore
Membership & Donations

Your membership allows STARS to continue to offer their vitally important services. Memberships are a minimum of $25 a year. Every dollar you contribute goes directly to support and education for sufferers and their families. Being a non-profit 501(c)3 organization, your donation is tax deductible. Your continuing support is vital to our mission.

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Mail to: STARS, P.O. Box 5507, Hilton Head Is., SC 29938
For more information: call (843) 785-4101 or email: info@stars-us.org
STARS is committed to improving the quality of life for individuals and their families coping with a syncope condition.

The main focus is education and supporting sufferers, their families, the medical community and general public by offering a support system where they can obtain knowledge and understanding of these conditions.
**STARS offers:**
- Information and reports
- Helpline
- Newsletters
- Monthly e-bulletins
- Moderated message board
- Ask the Expert
- Regional, national and international meetings
- Website - [www.stars-us.org](http://www.stars-us.org)

**Helpful Publications:**
- Syncope
- Syncope and Your Child
- Vasovagal Syncope (Neurocardiogenic Syncope)
- Blackouts Checklist

All of STARS’ literature has been approved by a panel of international medical experts.

**STARS**

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