

STARS

Syncope Trust And Reflex anoxic Seizures

THE BLACKOUTS CHECKLIST

**DO YOU OR DOES YOUR CHILD
SUFFER FROM UNEXPLAINED LOSS OF
CONSCIOUSNESS (BLACKOUTS)?**

*HELPING YOU AND YOUR DOCTOR REACH THE CORRECT DIAGNOSIS
FOR UNEXPLAINED LOSS OF CONSCIOUSNESS*



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



www.stars.org.uk

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www.heartrhythmcharity.org.uk

These checklists are designed to help you and your doctor to reach the correct diagnosis. If someone loses consciousness for a few seconds or minutes, they are often said to have had a blackout. Many people, including doctors, assume that blackouts are due to epilepsy, but much more commonly they are due to syncope. The checklist below was prepared with the guidance of the Medical Advisory Committee of **STARS**

WHAT YOU NEED TO KNOW

There are two major reasons for why people may experience a spell of unconsciousness

- ★ The first is a sudden lack of blood supply to the brain. Commonly called a blackout, the medical term is syncope. Syncope is caused by a problem with the heart or by a problem in the regulation of blood pressure.
- ★ The second is an electrical 'short-circuiting' in the brain. This is called epilepsy and the attacks are usually called seizures.
- Doctors use the term "Transient Loss Of Consciousness" or T-LOC when describing these events.
- Up to 50% of the population will lose consciousness because of syncope (blackouts) at some point in their life. Epilepsy only affects slightly less than 1% of the population. Either condition can affect people of all ages.
- Many syncope attacks are mistaken for epilepsy. UK research has shown that approximately 30% of adults and up to 40% of children diagnosed with epilepsy do not have the condition. This mistake is probably because syncope may appear like an epileptic seizure, with random jerking of the limbs and even incontinence. It can be difficult, even for experts, to tell the causes apart. It is essential to provide a good history, and if possible a video, of your spell of unconsciousness.
- Every patient who experiences T-LOC should describe everything they can recollect about their symptoms to a doctor. The doctor will also try to obtain a description from an eye-witness.
- Diagnosis of epilepsy is made by a neurologist. It is based primarily on a patient's history.
- Every patient presenting with an unexplained blackout should be given a 12-lead ECG (heart rhythm check). If there is uncertainty about diagnosis the ECG should be reviewed by a heart rhythm specialist.
- When attacks are frequent, heart irregularities can be captured by a portable ECG device - which can typically be carried for up to two weeks.
- When attacks are less frequent, they might be captured with an Insertable Loop Recorder (ILR) which can constantly monitor the heart for a period of up to 18 months.
- Over 70% of sufferers of syncope endure depression or anxiety because of their attacks, and a similar number alter their daily activities to avoid the risk of blacking out in embarrassing or dangerous circumstances.
- After most syncope (blackouts), reassurance and education by a doctor or highly trained nurse is all that is needed; however, if attacks continue or become more frequent, consultation with a specialist is needed.

CHECKLIST: PREPARING FOR A DOCTOR'S APPOINTMENT

- Before visiting your doctor, it is important to write down what happens before, during and after an attack, including any 'feelings' you may have.
- Try to take along a witness of the attacks for your appointment. If a witness can't come along, ask them to write down what exactly they have seen or ask them how the doctor could contact them. If they can record any details using a camera or video on a mobile phone this could help.
- There are many terms used to describe a blackout or faint. These can be found in the terminology guide at www.stars.org.uk where there is a fuller description of syncope.
 - Have you read **STARS** "Syncope Terminology Guide"?
- Check that both syncope and epilepsy have been considered. Ask for a referral to a syncope expert if possible, or to both a cardiologist and a neurologist if you are not sure that the diagnosis is accurate.
- Remember to ask about possible referral to local rapid-access clinics for blackouts, falls or arrhythmias.
- Ensure you take this leaflet to your GP together with the **STARS** leaflet which you can pass on should he or she wish to make contact.
- Family History; check with all relatives to establish if there is a family history of blackouts/ sudden or unexplained deaths.

CHECKLIST: HOSPITAL APPOINTMENT

- Specialists use tests to decide whether or not you might have syncope. Being prepared for these can significantly reduce the anxiety of a hospital visit. Try to learn about these in advance at www.stars.org.uk
 - Take a list of all medication, prescribed and non-prescribed, that you are taking.
 - 12-lead Electrocardiogram (ECG) for heart rhythm analysis.
 - Electroencephalogram (EEG) for brain activity analysis.
 - Tilt table testing to induce a syncopal/fainting attack whilst connected to heart and blood pressure monitors.
 - Heart monitor to record heart rhythms whilst away from the hospital or to activate during an episode.
 - An insertable loop recorder which can monitor heart rhythms for months at a time if the episodes are infrequent.
- A 24-hour heart rate monitor is very unlikely to identify any problems if you experience blackouts once a week or less, so do not be afraid to ask about other options.

QUESTIONS YOU OR YOUR CHILD MAY BE ASKED

- There are several questions you should be ready to answer. In each case you should record as many details as possible and have these with you ready for the appointment:
 - Did something trigger your attack? (e.g. a bump or fright, not eating, alcohol, lack of sleep, stressful situation etc)
 - Do you have a clear description of the episode from a witness from trigger to complete recovery?
 - Do you remember everything that happens during your attack? How long were you unconscious?
 - Were you confused on coming round? If so how long did the confusion last?
 - Is there a history of loss of consciousness in your family?
If there is, who/what relation?
 - How frequent are your attacks? Daily, weekly, monthly, less frequent?
 - Have there been any reported sudden deaths in your family under the age of 55?
Is the cause known?
 - Are your blackouts affecting your daily activities or quality of life? How?
 - Do you definitely lose consciousness or do you collapse whilst remaining conscious?
 - If your limbs move whilst you're unconscious, do they jerk about randomly, or rhythmically? Do your arms move around above your head?
 - Do you know if your eyes are open or closed? If open, how do your eyes move?
 - Do you have any warning that something is about to happen?
 - Did you have early symptoms and signs like lightheadedness, sweating, nausea, looking pale?
- You should also be prepared to ask questions about how the process of confirming a diagnosis or getting treatment might affect you:
 - Will you be able to attend school or work? Will you be able to carry on sporting activities or driving? Will there be any restrictions?
 - What might treatment involve? Will you have to visit the hospital frequently or stay overnight?
 - What is the likelihood that a diagnostic test will deliver a definitive result?
 - What is the likelihood that a treatment will solve the problem?
 - After receiving treatment how soon will you be able to return to a normal life? School? Driving? Working?

**You will need to ask someone who witnessed your blackout*

GETTING MORE INFORMATION

- Please call **STARS** with any questions on +44 (0) 1789 450564 or please visit our website to find further information, including downloads and explanations of:
 - What is syncope? ○ Syncope terminology guide ○ What is reflex anoxic syncope?
 - What is vasovagal syncope?

Additional information can also be found on www.stars.org.uk

PO Box 175 Stratford-upon-Avon Warwickshire CV37 8YD UK

Tel: +44 (0) 1789 450 564 Fax: +44 (0) 1789 450 682

Website: www.stars.org.uk Email: trudie@stars.org.uk