



Syncope Trust And Reflex anoxic Seizures

www.stars.org.uk

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

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Launch of First NICE TLoC Guidelines hailed as breakthrough by STARS - Blackouts charity

New guidelines launched today (**August 25th 2010**) aimed at improving the diagnosis and treatment for people experiencing blackouts is being hailed as a breakthrough by the charity STARS.

The STARS charity (Syncope Trust And Reflex Anoxic Seizures) also known as The Blackouts Trust, is welcoming the first ever Guidelines on Blackouts from NICE, the National Institute for Health and Clinical Excellence. STARS is congratulating NICE on responding to the charity's request to provide guidelines which it's hoped will dramatically improve the diagnosis and treatment for thousands of people suffering from unexplained blackouts and fainting (syncope).

They will also help the 30% of adults and 39% of children who are being misdiagnosed every year and told they have epilepsy, when in fact they may have cardiac syncope – loss of consciousness causing blackouts.

Until now, diagnosis has been a challenge for the 120,000 patients a year who experience unexplained loss of consciousness **Transient loss of Consciousness (TLoC)** in the UK. The NICE Guidelines will aid medical professionals to determine the cause of the symptoms and decide whether a person is suffering from a life threatening arrhythmia (irregular heart beat), which may be the cause of blackouts and fainting (syncope).

In line with the new Guidelines, STARS has launched a new ***Blackouts Checklist*** – available free to download from www.stars.org.uk. The Blackouts Checklist has been designed to help doctors work together with their patients to reach the correct diagnosis for any unexplained loss of consciousness. The Checklist gives information and advice on the major reasons for experiencing

www.stars.org.uk info@stars.org.uk www.education.stars.org.uk

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Trustees: Mrs Susan Broatch, Mr Andrew Fear, Prof Rose Anne Kenny, Mrs Cathrine Reid, Dr William Whitehouse.

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a blackout and helps patients prepare for a doctor or hospital appointment increasing their chances of being properly diagnosed and treated.

Blackouts are associated with a number of different causes. For the majority, these will not be serious, for example triggered by dehydration or even standing for long periods. However blackouts can more seriously be caused by cardiac arrhythmias or epilepsy, with many adults and even children being misdiagnosed and given epilepsy drugs over long periods when their condition is heart related.

Trudie Lobban, Chief Executive and Founder of the charity STARS says, *“It is clear from my own experience with my daughter who suffered from blackouts and from the thousands of people who have contacted STARS, that we need to improve the diagnosis and management of TLoC in the UK which is why we have developed the STARS Blackouts Checklist. Following these Guidelines, health professionals will be better able to accurately and quickly diagnose the cause of a blackout and they should go some way to reducing Sudden Cardiac Death which is the number one killer in the UK. I would now like to see the roll out of rapid access blackout clinics so that people who experience a blackout are seen and diagnosed within two weeks of their first blackout episode. These new NICE Guidelines will help enormously.*

*“We have produced a self-help tool for anyone who has suffered a blackout in the form of a **Blackouts Checklist** and form which you can obtain online, from us at www.stars.org.uk and take to your GP.”*

Dr Adam Fitzpatrick from the Manchester Royal Infirmary, pioneer of the Rapid Access Blackout Clinic said,

“As many as 30% of adults and 39% of children are misdiagnosed with epilepsy, when in fact they usually have convulsive syncope (loss of consciousness due to complex fainting causing

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blackouts). Parliament acknowledges that at least 74,000 patients are misdiagnosed with epilepsy in England, with up to 125,000 in the UK. Over the first two years in our clinic, out of the 327 patients with epilepsy type symptoms who attended the Rapid Access Blackout Triage Clinic, only 9% needed to be referred to a neurologist to test for epilepsy”.

Professor Richard Sutton, from St Mary's, Imperial College Healthcare NHS Trust, said,
“Blackouts can be a symptom of a hidden killer. These new Guidelines will ensure that patients are properly assessed and all potential causes of their blackouts are examined. We believe this will speed up and improve diagnosis of TLoC (Transient Loss of Consciousness) and save lives.”

Crucial to accurate diagnosis is the report of the TLoC event as this can give vital clues to the actual cause of the blackout. Information about the posture of the person who has fainted, their appearance before the event, duration of the event and length of time taken to recover can all be vital clues in helping diagnose the reason for the blackout.

The NICE guidelines also highlight the importance of new technology such as implantable loop recorders, a device inserted under the skin to record the heart rhythm of the heart for up to three years.

Editor's Notes

- For more information, contact Syncope Trust And Reflex anoxic Seizures (STARS). 01789 450 564 or email info@stars.org.uk

Key Facts

- 120,000 people experience unexplained blackouts or loss of consciousness each year.
- 30 per cent of adults and 39% of children are misdiagnosed with epilepsy and put on a treatment of drugs which can last a lifetime, when in fact they have a heart rhythm disorder.

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- 100,000 people die of sudden cardiac death each year in the UK. Experts say that 80% of these are preventable if blackouts are diagnosed and treated.

About the STARS Blackouts Checklist

- The STARS Blackouts Checklist was prepared under the guidance of STARS Medical Advisory Committee. Its principal aim is to help the patient and the professional establish the specific circumstances that occurred before, during and after the suspected blackout, either directly from the person, or from any witnesses to reach the correct diagnosis for any TLoC.

About the Rapid Access Blackouts Clinics

- Rapid Access T-LoC Clinics (RATCs) are designed to ensure patients are always diagnosed and treated by the appropriate expert. They achieve this by taking referrals from all parts of the health system when patients present with a blackout/T-LoC or a fall. Often nurse-led, the clinic combines several disciplines to develop 'blackout/T-LoC experts' who will direct the patient to the most appropriate specialist.
- **Case Studies, STARS Spokesperson and Medical Experts all available for interview on Monday, Tuesday and Wednesday of this week.**

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