

STARS

Syncope Trust And Reflex anoxic Seizures

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

Do you suffer from unexplained...



The Blackouts Checklist

Affiliated to Arrhythmia Alliance



www.stars.org.uk

Registered Charity No. 1084898 © 2009
Published October 2009

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The Blackouts Checklist was prepared under the guidance of STARS' expert Medical Advisory Committee. Its principal aim is to help you and your doctor reach the correct diagnosis for any unexplained loss of consciousness (blackout).

The Checklist gives you information and advice on the major reasons for experiencing a blackout, helps you prepare for a doctor's appointment, and provides information on what to expect if you have to attend a hospital appointment.

CHECKLIST: What do you need to know?

✓ **A blackout is a temporary loss of consciousness**

If someone loses consciousness for a few seconds or minutes, they are often said to have had a blackout.

✓ **Every patient presenting with an unexplained blackout should be given a 12-lead ECG (heart rhythm check)**

It is important that the ECG is passed as normal.

✓ **Most unexplained blackouts are caused by syncope**

Many people, including doctors, assume that blackouts are due to epileptic seizures, but much more commonly they are due to syncope (pronounced sin-co-pee) – a type of blackout which is caused by a problem in the regulation of blood pressure or sometimes with the heart. Up to 40% of the population will lose consciousness at some point in their life due to syncope. Syncope can affect all age groups but the causes vary with age, and in older adults multiple causes often exist.

✓ **Many syncopal attacks only require reassurance from your GP**

Many syncopal attacks require only explanation and reassurance from a GP or trained nurse regarding the likely absence of anything being seriously wrong. Consultation with a specialist will be necessary, though, if the cause of the syncope remains uncertain or if there are particularly concerning symptoms or there is a family history of a heart condition.

✓ **There are three major reasons for why people may experience a blackout(s):**

- **Syncope: a sudden lack of blood supply to the brain.** Syncope is caused by a problem in the regulation of blood pressure or by a problem with the heart.

- **Epilepsy: an electrical 'short-circuiting' in the brain.** Epileptic attacks are usually called seizures. Diagnosis of epilepsy is made by a neurologist.
- **Psychogenic blackouts: resulting from stress or anxiety.** Psychogenic blackouts occur most often in young adults. They may be very difficult to diagnose. 'Psychogenic' does not mean that people are 'putting it on'. However there is often underlying stress due to extreme pressure at school or work. In exceptional cases it may be that some people have experienced ill treatment or abuse in childhood.

✓ **Misdiagnosis is common but avoidable:**

- Many syncopal attacks are mistaken for epilepsy.
- However epilepsy only affects slightly less than 1% of the population.
- UK research has shown that approximately 30% of adults and up to 40% of children diagnosed with epilepsy in the UK do not have the condition.
- Many elements of a syncopal attack, such as random jerking of limbs, are similar to those experienced during an epileptic seizure.
- It can be difficult to tell the causes of the blackout apart.

✓ **Syncope causes falls:**

- Syncope causes a significant number of falls in older adults, particularly where the falls are sudden and not obviously the result of a trip or slip.
- Many older adults will only recall a fall and will not realise they have blacked out.
- Greater awareness of syncope as a cause of falls is key to effective treatment and prevention of recurring falls.

CHECKLIST: Preparing for an appointment with your GP

- Before visiting your doctor, it is important to write down what happens before, during and after a blackout or fall, including any symptoms you may experience.
- If there are any questions you want to ask your doctor or specialist, make a note of them on the Checklist as it can be easy to forget to ask them during the consultation.
- Try to take along a family member or friend who has seen your blackout(s) or fall(s) to your appointment. If they cannot accompany you, ask them to write down exactly what they saw in the Checklist or ask them how the doctor could contact them if necessary. If they can video an attack this is often very helpful.
- Check that both syncope and epilepsy have been considered. Ask for 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. You could ask about possible referral to local rapid-access clinics for blackouts, falls or arrhythmias.
- Family history; check with relatives whether there is any family history of blackouts, faints, epilepsy, or sudden/unexplained deaths. This is important as it can often provide a clue to the possible cause of your blackout.
- Make detailed notes – use the space later in the Checklist.
- Take the Checklist and your notes with you to your appointment.

CHECKLIST: Questions to ask your GP

During your GP appointment it can be hard to remember everything. Here are some suggestions of questions which you may find useful to ask during your appointment. There is a section on the Checklist for you to make a note of any questions for your GP.

- Can I still go to school or work whilst I am waiting to see the specialist?
- What is the likelihood that a diagnostic test will deliver a definitive result?
- Can I go to the gym/play sport whilst I am waiting to see the specialist?
- What will the treatment involve? Do you think I will have to visit the hospital frequently or stay overnight?
- Can I still drive whilst I am waiting to see the specialist?

Helping you and your doctor reach the correct diagnosis following unexplained loss of consciousness or falls



CHECKLIST: Preparing for specialist tests at the hospital

- ✓ Following your appointment with the doctor you may be referred for some tests with a specialist to discover the cause of your blackouts. 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
- ✓ The latest guidelines on the diagnosis of syncope state that patients suspected of having syncope should receive one of the following tests. Make sure that you receive the right test based on the nature of your symptoms.
- ✓ There are information sheets on the following diagnostic tests available from www.stars.org.uk

Every patient presenting with an unexplained blackout should be given a 12-lead ECG

- **12-lead Electrocardiogram (ECG) for heart rhythm analysis** – Every patient presenting with an unexplained blackout should be given a 12-lead Electrocardiogram (ECG). If there is uncertainty about diagnosis the ECG should be reviewed by a heart rhythm specialist (Electrophysiologist).

Tests aimed at syncope:

- **Lying and standing blood pressure recording** – Drops in blood pressure with changes in posture can cause dizziness, falls and blackouts, particularly in older patients and those on blood pressure and water tablets.
- **Tilt Table Testing** – This procedure can be used to induce a syncopal/fainting attack whilst connected to heart and blood pressure monitors.
- **Heart Monitor** – This is used to record heart rhythms whilst away from the hospital or to activate during an episode. A 24-hour/7 day 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.
- **Implantable Loop Recorder (ILR)** – This device should be used to monitor heart rhythms for months at a time if the episodes are less frequent than every 4 weeks. The device can remain in place for up to 3 years.

Tests aimed at epileptic seizures:

- **Electroencephalogram (EEG)** – For brain activity analysis to check for epilepsy. The EEG cannot be used to diagnose epilepsy, but it is helpful to neurologists to decide which type of epilepsy is happening. The EEG is much less useful over the age of 35 years.
- **MRI or CT-scan** – These are not aimed at showing that someone has epilepsy, but are used to seek the cause when epilepsy is likely.

CHECKLIST: Questions to ask your specialist

During your GP appointment it can be hard to remember everything. Here are some suggestions of questions which you may find useful to ask during your appointment. There is a section on the Checklist for you to make a note of any questions for your GP.

- ✓ Can I continue to drive?
- ✓ What is the likelihood that a diagnostic test will deliver a definitive result?
- ✓ If treatment is offered you may wish to ask whether it will completely stop you having blackouts or falls. If no treatment is offered be sure to ask the best way to manage your condition.



Preparing your own CHECKLIST

Sometimes during a consultation it can be hard to remember everything. The checklist is designed for you to complete. If you have a friend or family member who has been with you during a blackout or fall, it may be useful to ask for their help in filling out parts of the form. This will help your GP to refer you to the appropriate specialist and the consultant to whom you are referred to make the right diagnosis.

To give the doctors the best chance of making the right referral or diagnosis you should provide as many details as possible about your blackout(s) or fall(s).

Name: _____

1. List any medication(s) you are currently taking: _____

2. Do you experience blackouts, falls or both? *(Tick as appropriate)*

- Blackouts Falls Blackouts and Falls

If you experience falls, are they unexplained or due to a slip or trip?

- Unexplained Slip or trip

3. Do you always lose consciousness? *(Tick as appropriate)*

- Yes No

How long are you unconscious for? _____

4. How frequent are your blackouts or falls? *(Tick as appropriate)*

- Daily Weekly Monthly
 Less frequently than every 4 weeks

5. Before a blackout or fall did you have any warning signs? *(Tick as appropriate)*

- Light-headedness Sweating Nausea
 Looking pale Palpitations Other *(give details below)*

6. Is there anything that triggers your blackout or fall?

(Tick as appropriate; if one trigger occurred at one time and another at another time, tick both)

- | | | |
|---|--|--|
| <input type="checkbox"/> Pain or a fright | <input type="checkbox"/> Not eating | <input type="checkbox"/> Alcohol |
| <input type="checkbox"/> Lack of sleep | <input type="checkbox"/> Stressful situation | <input type="checkbox"/> Flashing lights |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Going from sitting or lying to standing | <input type="checkbox"/> Standing for a long time |
| <input type="checkbox"/> Being very hot | <input type="checkbox"/> Exercise | <input type="checkbox"/> Other <i>(give details below)</i> |

7. Describe what happens during your blackout or fall

If you are not conscious or cannot remember ask someone who was with you at the time to describe what happened.

Your description _____

Friend or family description _____

Do your limbs move whilst you are unconscious? Do they jerk about randomly or rhythmically?*

Randomly Rhythmically

Do your arms move around your head?*

Yes No

Do you know whether your eyes are opened or closed?*

Don't know Open Closed

If open, how do your eyes move? _____

8. After your blackout

Following your blackout or fall how long before you regained consciousness?* _____

After the blackout or fall are you confused on coming around? How long does the feeling last?

How do you feel after a blackout or fall? _____

Are your blackouts or falls affecting your daily activities or quality of life?

Yes No

* You will need to ask someone who was with you during your blackout

9. Family History

Is there a history of loss of consciousness in your family?

Yes No

If there is, who/what relation? _____

Have there been any reported sudden deaths in your family under the age of 55 years? Is the cause known?

Any other questions you would like to ask the doctor or specialist: _____
