

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...

- falls?
- seizures?
- faints?
- blackouts?

The Blackouts Checklist

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.

✓ **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.

✓ **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.

✓ **Witness information is vital for the evaluation of blackouts**

Make sure a witness (family or friend) who has been with you during a blackout or fall is present during any meeting with a doctor.

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

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 50% 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. Also, if the blackouts happen on several occasions, you may be referred to a specialist.

✓ **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.
- ✓ 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 booklet or ask them how the doctor could contact them if necessary. If it is safe to video an attack, this is often very helpful in making a diagnosis.
- ✓ 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.
- ✓ 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.
- ✓ 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.
- ✓ 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?
- ✓ Can I go to the gym/play sport whilst I am waiting to see the specialist?
- ✓ Can I still drive whilst I am waiting to see the specialist?
- ✓ What is the likelihood that a diagnostic test will deliver a definitive result?
- ✓ What will the treatment involve? Do you think I will have to visit the hospital frequently or stay overnight?

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 determine 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 and go to 'For Patients' section of the website.
- ✓ 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 medicines and diuretics (water tablets).

- **Heart monitor** – This is used to record heart rhythms whilst away from the hospital or to activate during an episode. A 24-hour/seven 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 two weeks. The device can remain in place for up to three years.
- **Tilt table testing** – This procedure can be used to induce a syncopal/fainting attack whilst connected to heart and blood pressure monitors.

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, and look for more sinister causes of blackouts and/or seizures.

CHECKLIST: Questions to ask your GP and specialist

During your GP or Specialist 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/Specialist.

- ✓ 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 (witness) who has been with you during a blackout or fall, it is VITAL to ask for their help in filling out parts of the form. Please ensure your witness completes their sections of the Checklist. This will help your GP to refer you to the appropriate specialist 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? Please ask a witness (Tick as appropriate)

- Yes No

How long are you unconscious for? _____

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

- Daily Weekly Every one to two weeks
 Less frequent than every two 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)

- Pain or a fright Not eating Alcohol
 Lack of sleep Stressful situation Flashing lights
 Anxiety Going from sitting or lying to standing Standing for a long time
 Being very hot Exercise Other (give details below)

7. Describe what happens during your blackout or fall. Please include whether your episodes are identical on each occasion or if there are differences.

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

Your description _____

Friend or family description _____

WITNESS: Do the individual's limbs move whilst they are unconscious? Do they jerk about randomly or rhythmically?

- Randomly Rhythmically

WITNESS: Do the individual's arms move around their head?

- Yes No

WITNESS: Are the individual's eyes opened or closed?

- Don't know Open Closed

If open, how do their eyes move? _____

8. After your blackout

WITNESS: Following the individual's blackout or fall, how long before they regain 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

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: _____