

Understanding NICE guidance

Information for people who use NHS services

Management of a blackout (transient loss of consciousness) in adults and young people

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the care they should receive.

This booklet is about the assessment, diagnosis and specialist referral of adults and young people aged 16 and over who have experienced a blackout (the medical term for this is 'transient loss of consciousness' or TLoC for short). It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence) for the NHS in England and Wales. It is written for people who have had a blackout, but it may also be useful for their families or carers or for anyone with an interest in blackouts.

The booklet is to help you understand the care that should be available in the NHS. It does not describe blackouts or the tests associated with them in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 15.

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The advice in the NICE guideline covers:

- the assessment, diagnosis and specialist referral of adults and young people aged 16 and over who have experienced a blackout (transient loss of consciousness).

It does not specifically look at:

- children under 16
- people who have had a physical injury, such as head injury or major trauma, before experiencing a blackout
- people who have collapsed without loss of consciousness
- people who have experienced prolonged loss of consciousness without recovery, which may be described as a coma.

Your care

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution

(www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm).

All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain blackouts and the possible tests associated with them. They should cover possible benefits and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss the tests you are offered, any diagnosis that is made about your condition, and the reasons for any referral to a specialist. This may include changing your mind about your care. If you are aged 18 or over, and have made an 'advance decision' (known as a 'living will' in the past), in which you have already given instructions about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All care should be given with your informed consent. If you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/consent) and the Code of Practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.publicguardian.gov.uk In Wales healthcare professionals should follow advice on consent from the Welsh Assembly Government (www.wales.nhs.uk/consent).

In an emergency, healthcare professionals may perform tests and give treatment immediately, without obtaining your informed consent, when it is in your best interests.

Blackouts

Blackouts are very common, affecting up to half of us at some point in our lives. The medical term for a blackout is 'transient loss of consciousness', and this is the term used throughout the guidance produced by NICE. There is a number of possible causes for a blackout, such as a reduced supply of blood to the brain caused by heart problems, conditions related to the brain and nervous system (such as epilepsy), emotional factors, or simply because you stand up for too long. Because of this, healthcare professionals may offer you a number of tests to find out what caused your blackout.

Initial assessment

Urgent care

The healthcare professional assessing you after a blackout might be your GP, ambulance staff, or staff in the Emergency Department. If you have injured yourself or have not fully recovered consciousness, or the healthcare professional thinks that you have a condition that needs immediate attention, they should arrange the care that you need.

Gathering information about your blackout

If you have had a blackout, the healthcare professional who assesses you should ask you and anyone who was there at the time to describe what happened. They should ask about:

- what was happening when you lost consciousness, such as whether you were sitting or standing
- any warning symptoms you had (for example, were you sweating or feeling warm or hot?)
- your appearance when you were unconscious (for example, your skin colour and whether your eyes were open or shut)
- whether you moved, bit your tongue or hurt yourself when you were unconscious
- how long you were unconscious for
- whether you felt weak down one side or felt confused while you were recovering.

Your description of what happened, and any information from witnesses, is really important and will help the healthcare professionals who are carrying out your assessment to confirm whether you have had a blackout and may also help them decide what could have caused it.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

Questions you might like to ask your healthcare team

- Why did I have a blackout?
- Will a blackout cause any long-term problems?
- What should I do now?
- Can I drive?
- Can I continue to work?

What you can do to help if you have had a blackout

(you may be able to get checklists to help you with this from the organisations listed on page 15)

- Describe clearly what happened when you lost consciousness.
- Give as much detail as you can about your blackout, for example, how long you were unconscious for, and how you felt before and afterwards.
- If you can, provide contact details for anybody who was there when you had your blackout so that they can also describe what happened.
- Give as much information as you can about:
 - any previous blackouts
 - your medical history
 - any medicines you are taking and why
 - any family history of heart problems.
- Follow the advice you are given by healthcare professionals, for example, on what you should do if you have another blackout, how active you should be, and whether or not you can drive.
- If you haven't yet had a diagnosis, or if your healthcare professional asks you to, try to get someone to record any future blackouts that you have (for example, by getting a video recording of your blackout using a camera in a mobile phone or a detailed description of your blackout from a witness).
- If you have fainted or been diagnosed with 'situational syncope' (see pages 7 and 8), keep a record of your symptoms, when they occur and what you were doing at the time so that you can understand what causes you to faint. You may be able to avoid trigger events.

History taking, examination and tests

The healthcare professional should ask you about any previous blackouts, your medical history, any family history of heart disease, and any medicines you are taking. They should also offer you some tests to help them find out what caused your blackout.

What the healthcare professional should do

- Take a history.
- Examine you (for example, by checking your vital signs such as your pulse rate, breathing rate and temperature, and by listening to your chest).
- Offer a 12-lead ECG (ECG is short for electrocardiogram; this is a test to record electrical signals from your heart and check for any problems).
- Offer other tests depending on your condition.

The tests you are offered will depend on your condition and whether or not you have any other problems that are not connected to your blackout. You should not normally be offered a test called an EEG at this time (EEG is short for electroencephalogram; this is a painless test that records the brain's electrical activity).

The healthcare professional should discuss these tests with you and explain what they are for. A record should be kept of all of the information that you and any witnesses provide.

If an ambulance was called for you when you had your blackout, the ambulance staff should take you to the Emergency Department unless they are sure you fainted (see page 7) or had a type of blackout called 'situational syncope' (see page 7) (in which case they should suggest you see your GP).

Copies of your records should be given to you and whoever is taking over your care. You should receive a printout of the ECG recording and copies of the results of other tests with your records.

Urgent referral

In certain circumstances you should be referred within 24 hours for a specialist cardiovascular assessment (this is an assessment of the heart and blood vessels; further information about this assessment can be found on page 11). This applies when:

- your ECG shows that something may be wrong with your heart
- you have heart failure (reduced efficiency of the heart's pumping), or have had heart failure in the past
- you have a heart murmur (an extra or unusual sound during a heartbeat)
- there is an inherited heart condition in your family, or any family members have died from heart problems at a young age (under 40)
- your blackout happened during exercise, **or**
- you have new or unexplained breathlessness.

If you are over 65 and had no warning symptoms before you lost consciousness, you may be referred for a specialist cardiovascular assessment within 24 hours (further information about this assessment can be found on page 11).

Diagnosis after the initial assessment

It may be possible to make a diagnosis of one of the following conditions after the initial assessment and without further tests.

Blackouts that are faints

You may be diagnosed as having fainted if your assessment doesn't show any other reasons for your blackout and if:

- you were standing for a long time, or felt warm or hot or began to sweat before you lost consciousness
- there were factors that may have triggered the blackout, such as pain or a medical procedure, or
- you have been able to prevent previous blackouts by lying down.

Blackouts caused by specific situations

Sometimes blackouts occur in specific situations, for example, when coughing or swallowing, or straining when passing urine – this is known as 'situational syncope'. If this happens to you, and your assessment doesn't show any other medical reasons for your blackout, you may be diagnosed as having this condition.

Blackouts caused by a change in posture

Sometimes when a person changes posture from lying to sitting, or from lying or sitting to standing, they have a large drop in blood pressure. The medical term for this condition is 'orthostatic hypotension'. This may cause light-headedness (dizziness), a fall, or a blackout. If the healthcare professional suspects that you have this condition because of your history and your assessment, they should offer further tests that involve checking your blood pressure while you are lying down and standing to help them with the diagnosis.

What happens next

You won't need any further tests or treatment if you have fainted or been diagnosed with 'situational syncope' and your healthcare professional isn't concerned about anything else. If the person you saw about your blackout was not your GP, you should be given a copy of your patient report form and your ECG printout to take to your GP. Your GP should offer to arrange an ECG within 3 days if you have not already had one.

However, if you have been diagnosed with 'orthostatic hypotension', you may be offered further tests and treatment; the healthcare professional should discuss these with you.

If you fainted or have 'situational syncope'

You should be given some information on what may have caused your blackout. You should also be advised:

- about possible trigger events and how to avoid them
- to keep a record of your symptoms, when they occur and what you were doing at the time so that you can understand what causes you to faint
- to see your GP if you haven't already done so or if you have another blackout.

If you have 'orthostatic hypotension'

You should be given some information on what may have caused your blackout. The healthcare professional should also discuss with you the possible causes, especially any drugs you are taking that may be causing your blackouts.

They should discuss with you what this diagnosis means for you and treatment options available to you.

You should also be given some advice about what you should do if you have another blackout.

If you have not been diagnosed as having fainted or as having 'situational syncope' or 'orthostatic hypotension' (see pages 7 and 8) after your initial assessment, you may need to see a specialist.

Referral to see a specialist

Most blackouts that may mean you need to see a specialist are caused by one of three possibilities: cardiovascular problems, epilepsy or emotional factors. You should be offered a referral to see the most appropriate specialist depending on your symptoms and the results of any tests that you have already had.

Waiting for a specialist assessment

You should be given some advice while you are waiting for your appointment to see a specialist, for example, about what to do if you have another blackout or how active you should be. You should be advised that you must not drive while you are waiting for your appointment and that the specialist will advise you further about your future driving.

Referral to a specialist in epilepsy

If healthcare professionals think that your symptoms suggest that you had an epileptic seizure (that is, you had one or more of the features listed in the box below), you should be offered a referral to a specialist in epilepsy for an assessment and seen within 2 weeks of your blackout.

Features that suggest an epileptic seizure

People who are having an epileptic seizure may:

- have an intense sensation of having experienced something before, or that a situation that should be familiar is completely new to them, before losing consciousness
- not remember their actions before, during or after a seizure that other people noticed were unusual
- have an unusual posture or prolonged jerking of arms and legs during a seizure
- turn their head to one side or bite their tongue when they are unconscious
- experience confusion and disorientation when they regain consciousness.

Some people may also have blackouts or attacks that look like epilepsy but are caused by emotional factors (see page 14). These types of blackouts are very real and can be difficult to distinguish from epilepsy, and are therefore best assessed by a specialist in epilepsy.

Referral for specialist cardiovascular assessment

You should be offered a referral for a specialist cardiovascular assessment and further tests (see page 11) if healthcare professionals aren't sure of the cause for your blackout after your initial assessment, and they don't think you have epilepsy.

Questions you might like to ask your healthcare team

- What tests will I have? Can you tell me why you are recommending them?
- Where am I going to have these tests? Can any of these tests be done by my GP?
- Will I have to go into hospital?
- Will the test hurt? How long will it take?
- Will there be any after effects? Should I take somebody with me?
- Will I have to take any drugs?

Specialist cardiovascular assessment and diagnosis

Cardiovascular assessment is carried out by a specialist team, which includes healthcare professionals who are experts in diseases or disorders of the heart and blood vessels.

Assessment

If you have a specialist cardiovascular assessment (to look at your heart and blood vessels), the specialist team should ask about:

- your blackout and any previous times you lost consciousness
- your medical history and any family history of heart disease or inherited heart condition
- any medicines that you were taking at the time of your blackout, and whether you are still taking them.

You should also be offered an examination, which may include having your blood pressure measured when you are lying down and standing, and another 12-lead ECG. Any previous ECGs that you have had should be reviewed.

This assessment may suggest what caused your blackout and will determine any other tests you may be offered (see below).

Further tests that you may have

Exercise testing

Exercise testing involves having changes in your heart rate, breathing and blood pressure measured while you are doing different levels of exercise. If your blackout happened during some form of physical exercise (and not after exercising), you should be offered exercise testing within 7 days to try to find out why you had a blackout during exercise. This may help with your diagnosis. However, you shouldn't be offered exercise testing if there is a medical reason why this type of test is not suitable for you (for example, if it is suspected you have certain heart conditions). Your healthcare professional should discuss with you what kind of exercise you normally do, and how much is appropriate for you until you have had further assessment and have been told that it is fine to exercise again.

If testing shows how exercise triggers your blackout, you should be offered further tests or treatments according to your particular condition.

Some tests may not be suitable for you, depending on your exact circumstances. If you have questions about specific tests and options covered in this booklet, please talk to a member of your healthcare team.

Ambulatory ECG

An ambulatory ECG is a test that uses a device to monitor and record your heart activity over a period of time to find out if you have an abnormal heart rhythm. This device will not stop you from having another blackout, and is only used to record your heart activity.

You should be offered this test if the specialist team thinks that your blackout may have been caused by a change in your heartbeat (also known as a 'cardiac arrhythmia') or if they are not certain what caused your blackout.

Whether you are offered a device that you wear, or a small device that is implanted under the skin during a hospital operation, will depend on your history and how often you have a blackout. If you are offered a device that is implanted under your skin, you and your family or carers should be shown how to use it. If you have another blackout after the device has been fitted, you should be advised to see a member of the specialist team as soon as possible so that the details that have been recorded by the device can be checked.

Questions you might like to ask about devices used to monitor heart activity

- Will I need an operation? If so, why can't I have one of the devices that you wear and doesn't need an operation?
- Will I have to have the device fitted in a hospital? Will I have to stay in hospital? If so, how long for?
- How long will I have to wear the device, or have it in for?
- Can I take a bath while I have the device?
- Will it bleep and what do I do if it does?
- Are there any risks associated with wearing one of these, or having one put under my skin?

Carotid sinus massage

If the cause of your blackout is unexplained and you are aged 60 or over, or if the specialist team thinks you may have had a blackout due to an over-sensitive artery in your neck (this is also known as 'carotid sinus syncope'), you should be offered a test called carotid sinus massage.

This test involves a trained healthcare professional pressing on an artery in your neck while watching an ECG monitor, and this may cause a blackout. Reproducing your blackout may help to show that it is caused by a drop in your heart rate triggered by pressure on the artery in your neck. If this test does not lead to a diagnosis, you should then be offered an ambulatory ECG (see page 12).

Tilt test

A tilt test involves having your heart rate and blood pressure monitored while being tilted (head up) on a special examination couch in the hospital to see if this leads to you having a blackout. You may be offered this test if the specialist team knows you keep having blackouts and thinks they are affecting your quality of life or could cause you harm.

Cardiac imaging and other tests

If it is suspected that you have a condition known as 'structural heart disease' (where the structural parts of your heart, such as the muscle or valves, are abnormal), you may be offered tests such as cardiac imaging where pictures of your heart are taken and examined.

You may be offered some other tests that the specialist thinks will help with your diagnosis, for example, if there is an inherited heart condition in your family, or any family members have died from heart problems at a young age (under 40).

If the cause of your blackout remains uncertain

Sometimes people have blackouts that happen for psychological or emotional reasons – these blackouts may look like epileptic seizures (and are known as ‘psychogenic non-epileptic seizures’ or PNES) or may appear to be like other types of blackouts (also known as ‘psychogenic pseudosyncope’). The specialist team should consider these if you keep having repeated blackouts and if, for example, the nature of your blackouts keeps changing or they last for a long time, or you have a number of other unexplained symptoms.

You should be advised to try to record any future blackouts (for example, by getting a video recording of your blackout using a camera in a mobile phone or a detailed description of your blackout from a witness).

If the cause of your blackout remains uncertain after further assessment, or treatment you have been receiving isn’t working, the specialist team should then consider other causes for your blackout, including the possibility that there is more than one cause.

Information and advice

The healthcare professional should discuss with you the possible causes of your blackout, the reasons for any tests that you are offered (including the risks and benefits of tests), and the results of any tests you have had. They should also discuss with you whether there is any uncertainty in your diagnosis.

Driving

Your healthcare professional should give you advice about driving when you see them for the first time after having a blackout. If you have been referred for a specialist assessment, you should be advised that you must not drive while you are waiting for your appointment. After a specialist assessment, you should be advised whether to report your blackout to the Driver and Vehicle Licensing Agency (DVLA). Check the DVLA website (at www.dft.gov.uk/dvla) for up-to-date information about driving after a blackout.

Work

You should be advised about how your blackout may affect health and safety at work, and what action you must take to keep yourself and others safe.

More information

The organisations below can provide more information and support for people who have had a blackout (or transient loss of consciousness). NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Cardiac Risk in the Young (CRY), 01737 363222
www.c-r-y.org.uk
- Syncope Trust And Reflex anoxic Seizures (STARS), 01789 450564
www.stars.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see

www.nice.org.uk/AboutGuidance

*This booklet and other versions of the guideline aimed at healthcare professionals are available at **www.nice.org.uk/guidance/CG109***

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2271). The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.

We encourage NHS and voluntary organisations to use text from this booklet in their own information about blackouts (transient loss of consciousness).