



Syncope Trust And Reflex anoxic Seizures

Psychogenic Loss of Consciousness



Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures

www.stars-us.org

Non-profit organization 501(c)(3)

Glossary of terms

Counsellor is a person trained to listen to people's problems and help to find ways of dealing with them.

Electrophysiologist is a medical specialist who is a heart rhythm expert.

Epilepsy is a medical term for various disorders in which attacks are caused by abnormal electrical signals in the central nervous system (brain).

Neurologist is a specialist in the branch of medicine dealing with the nervous system and disorders affecting it.

Postural tachycardia syndrome (POTS) is defined as an increase in heart rate of over 30 beats per minute when standing upright but without a postural fall in blood pressure.

Psychogenic loss of consciousness is a medical term for a faint that can look like reflex syncope or an epileptic seizure but is not related to either. A Psychogenic loss of consciousness can mimic any cause of syncope but is not related.

Psychological is a term used to describe a condition relating to or arising from the mind or emotions (brain).

Reflex syncope is one of the most common forms of syncope.

Syncope is a medical term for loss of consciousness that is caused by a sudden lack of blood supply to the brain.

Trigger is something that sets other events in motion. An event, situation, sensation or emotion that sets off a non-epileptic attack.

Contents

What is psychogenic loss of consciousness?

How is psychogenic loss of consciousness diagnosed?

How do you feel about your condition?

What causes psychogenic loss of consciousness?

How can stress be the cause?

What about other symptoms?

Talking about psychogenic loss of consciousness

How is psychogenic loss of consciousness treated?

Who can help?

What can I do to help myself?

Should I stop doing anything?

Will I recover?

Tips to remember



What is psychogenic loss of consciousness?

Psychogenic loss of consciousness is a medical term for a faint that can look like reflex syncope or an epileptic seizure but is not related to either.

During these attacks, people lose some control of their body.

Attacks may involve:

- Passing out and falling to the floor.
- Jerking movements of your arms or legs.
- Losing control of your bladder or bowel.
- Going blank or absent.
- Feeling out of touch with your surroundings.
- Not being able to remember the attack.

Some of these symptoms may lead people to confuse these attacks with other causes of loss of consciousness such as reflex syncope or epilepsy.

This booklet is for individuals who have been diagnosed with psychogenic loss of consciousness.

It has been written to provide information on the cause, diagnosis and treatment of this condition.

It may also be of interest to families, friends and carers of people struggling with this condition.

Psychogenic loss of consciousness can sometimes be referred to as non-epileptic seizures or pseudoseizures.



How is psychogenic loss of consciousness diagnosed?

Psychogenic loss of consciousness can be difficult to diagnose. Most often it can occur in young adults, as a result of stress or anxiety. However, the link between loss of consciousness and stress may not be obvious. 'Psychogenic' does not mean that people are 'putting it on'. In most cases psychogenic loss of consciousness is an involuntary reaction of the brain to pressure or distress. This can sometimes develop after people have experienced ill treatment or trauma.

Specialists in treating loss of consciousness (such as specialised physicians, electrophysiologists or neurologists) can sometimes make a clear diagnosis when you, or someone who has seen an attack, describe it in detail. Although psychogenic loss of consciousness does resemble an epileptic seizure or reflex syncope, there are small but important differences between these types of attacks:

- Psychogenic attacks tend to be numerous, often occurring several times a day, or at the same time each day. This differs from reflex syncope (vasovagal syncope, neurocardiogenic syncope) which is typically no more frequent than four or five times a year.
- During an episode, the eyes may be tightly closed with a lid flutter, whilst during reflex syncope or epilepsy the eyes are often open.
- Patients can experience psychogenic loss of consciousness when they are lying on their back.
- Typical symptoms associated with reflex syncope (such as looking pale or becoming sweaty) may be absent.
- Psychogenic loss of consciousness often lasts much longer than reflex syncope.

When the diagnosis is unclear doctors can use a number of tests:

Tilt table testing can be used to help establish the cause of fainting by inducing syncope symptoms. In people prone to reflex syncope, heart rate or blood pressure are likely to change on the tilt table. Heart rate and blood pressure do not change in psychogenic loss of consciousness.

Prolonged heart activity monitoring with an **implantable loop recorder (ILR)** can be used to look for heart-related causes of syncope. The heart rate would be abnormal in cardiac syncope but not psychogenic loss of consciousness.

Video-EEG observation of typical attacks may be used to see whether loss of consciousness is associated with abnormal electrical activity in the brain. This would be expected in epileptic seizures but would not be found in psychogenic loss of consciousness.

It is important to realise that the diagnosis of psychogenic non-epileptic attacks and other seizure disorders is often a gradual process rather than a single event. The information available to the doctor following loss of consciousness for the first time is often limited. The diagnosis may become clearer as more events are observed and described.



How do you feel about your condition?

You may have a range of emotional reactions on finding out that you have been experiencing psychogenic loss of consciousness. This is normal and understandable.

- **Confused?** It can be confusing to receive a diagnosis of psychogenic loss of consciousness, especially when YOU KNOW that you have experienced 'real loss of consciousness'. Reflex syncope is a common clinical condition caused by a sudden lack of blood supply to the brain, perhaps as a result of low blood pressure or even slow heart rate. There is a lack of present understanding about psychogenic loss of consciousness and this can be very difficult to accept.
- **Angry?** People may feel angry that they have had a different diagnosis and treatment in the past. Some people also become angry because they do not accept that the cause of their attacks is not a physical condition.
- **Having doubts?** Some people struggle to accept the diagnosis and continue to believe they have reflex syncope or postural tachycardia syndrome (POTS).
- **Relieved?** Some people are glad to have a definite diagnosis of psychogenic loss of consciousness. They can then begin to understand their condition, try to reduce the stress factors and anxiety levels in their lives. They can also start appropriate treatment for the attacks.

What causes psychogenic loss of consciousness?

The medical profession are gradually beginning to recognise and understand what causes psychogenic loss of consciousness. It is accepted that there are no definable physical problems and that it happens for different reasons in different people.

It is likely that psychogenic loss of consciousness can happen when there is a temporary problem with the way the brain is working. The brain may become “overloaded” and “shut down” for a short while when faced with some kind of threatening feeling, situation, thought or memory. Although it is thought that stress plays an important part in these attacks, people can pass out at times when they do not feel particularly stressed.

Sometimes the first attacks are related to an upsetting or frightening experience, or some other great loss or change. These experiences may be recent or in the past. Sometimes it isn't clear why attacks have started, or they seem to have started just as some life stress was getting better. Stress can also make it difficult for a person to get over their attacks once they have started. Examples of this include relationship problems, ill health, bereavement and money worries and even just the stress of living with psychogenic loss of consciousness.

In recent years, it has become clear that psychogenic loss of consciousness is not uncommon amongst students struggling with the stresses of examinations and school life, peer pressure and the worries of getting that first job. These sorts of loss of consciousness often become much less of a problem after college or university life.

Individual attacks can be set off by many different things. Something that brings on an attack is called a *trigger*. Common triggers include unpleasant memories, upsetting thoughts or feelings, and stressful situations such as arguments.

Sometimes attacks can happen without any obvious trigger or warning, **even when you may be feeling calm and relaxed**, particularly when attacks have been happening for a long time. This can make it difficult to work out what has triggered a particular attack.



How can stress be the cause?

It is very common for people to think that there must be a physical cause for psychogenic loss of consciousness. This is a physical symptom after all. However, there are many examples of how emotional stress can cause physical reactions in the body. These include blushing when you are embarrassed, feeling “butterflies” in your stomach when you are nervous, and getting a headache when you have been worrying or have had a bad day. Another familiar idea is someone fainting when they are shocked.

When emotional stress is particularly severe or has been going on for a long time, more serious physical problems can arise. In some cases this leads to disability. There are many conditions where stress is thought to play a part, including chronic fatigue, postural tachycardia syndrome, non-cardiac chest pain, fibromyalgia and irritable bowel syndrome.

For some people it is relatively easy to identify stresses that might be related to their psychogenic loss of consciousness. Others will say that they don't feel particularly stressed or upset, or that they feel calm and relaxed before an attack. This can make it very confusing if you have been told that your attacks are caused by stress. It may be that not all psychogenic loss of consciousness/non-epileptic attacks are caused by stress but further research is needed to answer this.

Even though stress may be an important part of this condition, this does **not** mean that you are “mad” or “crazy”. It also does **not** mean that the attacks are your fault, that the problem is “all in the mind” or that you are doing it “on purpose”.

Psychogenic loss of consciousness is a real physical symptom that can cause real problems.

Some people feel that they are not believed by their friends and family or by doctors and nurses. Many people, including doctors and nurses, can find it difficult to understand that attacks can be caused by stress. This could lead them to wrongly believe that people presenting with psychogenic loss of consciousness have control over their attacks.

However, specialists who diagnose and treat psychogenic loss of consciousness know that the attacks are real and take them seriously.



What about other symptoms?

There are many different symptoms that can occur in people with psychogenic loss of consciousness. Confusingly, many of these symptoms can be found in other conditions such as POTS (Postural Tachycardia Syndrome) or depression.

These symptoms include:

- Numbness
- Tingling
- Fatigue
- Pain
- Headache
- Dizziness
- Blurred vision
- Bladder problems
- Bowel problems
- Limb weakness or paralysis
- Poor concentration
- Memory problems
- Worry
- Panic
- Anger
- Frustration
- Low mood
- Trouble sleeping
- Speech problems
- Feeling distant or “unreal”

Talking about psychogenic loss of consciousness

The most **important** treatment for psychogenic loss of consciousness involves speaking with friends and family and sharing your emotions. Telling people that you have a condition such as reflex syncope, POTS or even panic attacks is difficult. However, many people have heard of these problems and know something about them, which can make it easier to explain what’s wrong.

Telling people about psychogenic loss of consciousness can be much harder. Most people (including some doctors and nurses) have not heard of this and it can be difficult to explain what it is. Having a good understanding of the condition can make it easier to explain to others.

Here are some useful phrases that may work for you:

"I have faints that I cannot control. They are like reflex syncope but are not caused by the same things. They always pass without any special treatment."

"I have attacks similar to faints, which means that I can sometimes pass out."

"I sometimes have loss of consciousness which can be brought on by stress."

"I have attacks which are similar to panic attacks, except that I can pass out with them."

It may be useful for you to discuss this booklet with friends and family so that they know about your attacks and can support you.

How is psychogenic loss of consciousness treated?

The first step is to understand the condition and why it is different from reflex syncope and POTS. Psychogenic loss of consciousness can stop altogether. In some cases, treatment may help you to have fewer attacks and/or cope better with them. The best form of treatment is talking treatment.

One common type of talking treatment is psychological therapy. There are different types of psychological therapy and they may be offered by people with slightly different types of training, including psychologists, psychiatrists, psychotherapists, counsellors, cognitive behaviour therapists and some specialist nurses.

Depending on the nature of the person and the problem, a number of things may be discussed during therapy.

These might include:

- Understanding why these attacks are happening.
- Spotting triggers for attacks.
- Learning specific techniques to control and reduce the impact of attacks where possible.
- Identifying and exploring stresses or problems that are contributing to attacks and developing ways of relaxing and managing them.
- Coming to terms with events in the past that may be related to attacks.
- Viewing situations in more positive ways.
- Increasing activity levels.

Some people are reluctant to take up psychological therapy because they fear being thought of as unbalanced/ disturbed. However, research shows that psychological therapy can help people learn to cope with all kinds of illnesses, such as cancer, diabetes and heart disease. As stress is often an important part of psychogenic loss of consciousness, psychological therapy is likely to be particularly useful for people with this condition.

Therapy or counselling can be a very positive experience. It's a chance to talk things through, and explore your own thoughts and feelings about things that matter to you.



Who can help?

- **Your consultant specialising in syncope** (for instance an electrophysiologist, a cardiologist or a neurologist) who will explain the diagnosis to you. He might also advise you about types of medication that may help.
- **A clinical psychologist or cognitive behaviour therapist** may be able to offer talking treatments.
- **A syncope specialist nurse** may be able support you in understanding your diagnosis, and help you to cope better with your attacks.
- **A social worker or welfare rights officer** can give you information about benefits and job schemes that may be available to you.
- **Your Physician** can give advice and support and can let you know about local counselling services.

What can I do to help myself?

- **Feel comfortable and clear about the diagnosis.** If you understand and accept the diagnosis you are more likely to get better. Feeling comfortable with the diagnosis may also help you to discuss the condition with your friends, family or colleagues.
- **Use the specialist help on offer.** Talking treatments can help in a number of different ways including reducing stress, learning to control attacks, and addressing important issues in your life. You can find what specialist help is on offer in your area by talking to your doctor.

- **Look for your triggers.** Think about what is happening before or during an attack. Are you frightened? Are you worried about something? Understanding what triggers your attacks, can help to prevent them. If your attacks seem to be brought on by a certain situation, then talking it through with someone can help to overcome the problem. However, it is not always possible to identify what has triggered a particular attack.
- **Learn to stop your attacks.** If you get a warning that an attack is going to happen you can learn to use breathing and stress reduction techniques. You can ask your family doctor about local services where you can learn stress management or relaxation. This may help to reduce the number of attacks.
- **Talk to friends and family.** They are more likely to stay calm during an attack if they know what is happening. This can help to make the attacks shorter.
- **Remain positive.** Give yourself time to get better and remember that psychogenic loss of consciousness can be overcome.
- **How can I find out more?** There is only a limited amount of information about psychogenic loss of consciousness available but you may find that some of the things which help people diagnosed with nonepileptic disorder (NEAD) can also help you. www.nonepilepticattacks.info

Should I stop doing anything?

The sheer frequency of psychogenic loss of consciousness attacks can be frightening and you may feel worried about carrying on with your usual activities. Whilst this is understandable it is important to live your life normally as much as possible.

Many people try to carry out their normal daily activities without help. You should not assume that you can't do something just because of your attacks. Indeed, stopping activities can actually make the problem worse in the long term.

If you feel that you may be at risk of injury during an attack, discuss this with your friends and family. They may be able to help you think about ways to keep yourself safe without giving up too much. For instance, there may be no need for you to stop going out if your attacks only happen at home.

You may not need to stop daytime activities if your attacks only happen in the evenings or when you are really tired. You may be able to keep up activities such as jogging or shopping by joining up with others rather than doing them by yourself. It may be entirely reasonable for you to go swimming if you have never had an attack doing this. Just remember to warn the life guard!

Try to do as much as possible for yourself and be as independent as you can.

It is better if your friends and family encourage you to do things for yourself, and do not become more protective than they need to.

If you find your life is restricted by your attacks (for example, you have given up doing things or you no longer do things on your own), you should discuss this with your GP, counsellor or therapist. Even if your attacks don't stop, it is possible for a professional to help you think of ways to reduce their effect on your life.



Will I recover?

People diagnosed with psychogenic loss of consciousness can recover fully and lead a normal life. Recognising that the attacks are not caused by reflex syncope or other medical disorders is the first, and often most important, step on the road to recovery. It means that the right treatment can be started if necessary. It also means that unhelpful treatments (for instance medications for reflex syncope) can be stopped.

Sometimes just receiving and accepting the diagnosis can be enough for some people to get better. For other people, recovery comes about as a result of psychological therapy. Psychological treatment can be a long process, and it can take weeks or months before the attacks improve. However, if treatment is started, attacks often improve over time. Over the course of a year many people's attacks reduce a lot or stop completely.

In some cases, attacks can become a long-term problem. Some people with psychogenic loss of consciousness find it very difficult to accept the diagnosis and take up psychological treatment. People who have this problem often continue to seek medical answers and go from one expert to the next. Their disappointment about not finding the answers they are looking for can cause them to become depressed and more severely affected.

Even if the attacks continue, people can still lead a full and active life. It is possible to learn how to cope with attacks in a similar way to how people deal with other conditions causing loss of consciousness, for instance uncontrolled epilepsy.

The following STARS booklets and information sheets are available at www.stars-us.org

- Postural Tachycardia Syndrome (POTS)
- Reflex Syncope

Tips to remember

- Psychogenic loss of consciousness is not caused by changes in heart rate, blood pressure or other medical conditions, but it is real and can have a big impact on your life.
- Having psychogenic loss of consciousness does not mean you are faking or going “crazy”.
- Having psychogenic loss of consciousness does not mean the attacks are your fault; they are not done “on purpose”. You may, however, be able to learn how to stop the attacks from occurring.
- The attacks do not cause damage to the brain, even if they go on for some time.
- Having a longer attack does not mean that the condition is more serious. Attacks of psychogenic loss of consciousness will typically go on for longer than those of reflex syncope or epilepsy.
- Accepting and understanding the diagnosis is the first step to recovery.
- Psychological help can be very useful in finding out the cause of psychogenic loss of consciousness and help people control or stop their attacks.
- Psychogenic loss of consciousness can be easier to deal with if your friends and family have a good understanding of the problem. It may be useful for them to read this booklet and to discuss the attacks so that everyone knows what is happening and what to do.

STARS

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STARS US, PO Box 5507,
Hilton Head Island,
SC29938

☎ 843.785-4101

@ info@stars-us.org

➔ www.stars-us.org

Non-profit organization 501(c)(3)

© STARS Published
September 2012,
Planned Review Date
September 2014



Please remember that this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional.

Author:

Dr. Markus Reuber Consultant Neurologist

Reviewed by:

Dr A P Fitzpatrick Consultant Cardiologist

Prof. Richard Sutton Professor of Clinical Cardiology

Board of Trustees:

Daniel Beach

Blair Grubb

Linda Kadesh

Carlos Morillo

Robert Sheldon

J Phillip Saul

Cindy Tobin

Fetnad Mahmoud Fouad-Tarazi

Vera Novak

David Benditt

Richard Sutton

Founder & Chief Executive

Trudie Lobban

Patient Services

info@stars-us.org

If you would like further information or would like to provide feedback please contact STARS.

