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

SYNCOPE TRUST AND REFLEX ANOXIC SEIZURES (STARS)

INFORMATION AND RESOURCE BOOKLET

Registered Charity No. 1084898

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Founded in 1993 by:
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The aims of this booklet

- ☆ To inform and reassure you.
- ☆ To outline the ways a school can effectively manage a student with syncope / RAS so as to provide support and enable inclusion.
- ☆ Provide you with the information, materials and support with which you can plan and then action, a whole school strategy on the care and management of a student with syncope/ RAS.



Definitions

- ☆ It is believed that about two thirds of loss of consciousness is due to syncope. Syncope (sin-co-pee) is the result of the temporary cutting off of the supply of oxygenated blood to the brain.
- ☆ This is quite different from epilepsy, where the problem begins in the brain itself, and the blood flow during an attack may be completely normal.
- ☆ Reflex Anoxic Seizures (RAS) is the childhood version of Vasovagal Syncope (VVS).
- ☆ Vasovagal Syncope is similar to RAS, but is more commonly diagnosed in older patients.



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Key points to remember

- ☆ This is a NON-life threatening condition and there are no known long term ill effects.
- ☆ The frequency of attacks varies with each individual – they may occur several times per day/ week/ month or year.
- ☆ While RAS more frequently occurs in young children, it is not uncommon for it to occur at any age.
- ☆ Good management of the student is the key to inclusion.



What will I see when someone is having an attack?

Each patient is individual so symptoms may differ slightly

- Triggers:** Unexpected stimulus – such as pain, shock, surprise or fright.
- Signs:** May include off colour/ a marked pallor of the skin / emotional; keeping a diary can help predict episodes.
- Symptoms:** The heart and breathing momentarily stop the eyes roll up into the head, the complexion becomes deathly white, while the skin may appear blue around the mouth and under the eyes, the jaw clenches and the body stiffens.



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What will I see when someone is entering the recovery stage?

Recovery:

The body relaxes, the heart starts beating (sometimes very slowly). Consciousness is usually regained within one or two minutes, occasionally it may be longer.

Upon recovery:

The person may be very emotional and fall into a deep sleep for two or three hours. They may also look extremely pale with dark circles under their eyes.

Think of a hedgehog! Whenever the hedgehog faces danger it curls into a ball shutting itself off from the world to protect itself and only uncurls when it is sure it is safe to do. This is very similar to children with RAS, their body shuts down until the 'nasty thing' has gone away.

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What should I do if someone has an attack?

DON'T PANIC

An unexpected syncopal attack can be alarming,
just remember that the patient
WILL recover.

Recovery position – roll the patient into this.

Are there any dangers which could cause them harm?
If so, make the area safe.

Stay with them, talking quietly and reassuringly.
To the recovering child everything can appear
disorientated and noisy, so try to keep the room
calm, quiet and be reassuring!



The Recovery Position

1. Place arm nearest to you at a right angle.
2. Move other arm, and place the back of their hand against their cheek. Then get hold of the knee furthest from you and pull up until foot is flat on the floor.



3. Pull the knee towards you, keeping the person's hand pressed against their cheek, and position the leg at a right angle.
4. Make sure that the airway remains open by tilting the head back and lifting the chin, and check breathing.
5. Monitor the casualty's condition until help arrives, if help is needed.



How do I help to avoid attacks?

- ☆ Share information with ALL staff who come into contact with the child.
- ☆ Keep a note of days of poor concentration, it can be a forewarning of possible episodes.
- ☆ Maintain good hydration – drink lots of water.
- ☆ Pre-warn the student of possible dangers, to reduce unexpected shock.
- ☆ Allow the student to watch, survey and become accustomed before participating in any activity whether that be a game, party or even a crowded room.
- ☆ Swimming: encourage them to participate, but allow them time to enter the water gradually.



During and after an attack

- ☆ Stay calm!
Make sure the student is safe.
Lie the patient down flat – on your lap / floor / bed or sofa and put them into the RECOVERY POSITION.
Check their airways to make sure nothing is in their mouth.
- ☆ When the student regains consciousness allow them to rest, and only move them when they feel ready. Talk to them in a quiet voice constantly reassuring them – even give them a cuddle.
- ☆ If they wish to sleep, allow it (they may sleep for 2 – 3 hours). Or they may feel dizzy, afraid and disorientated, try to reassure them.
- ☆ Many report that noise is amplified, so try to keep the environment around them as quiet and calm as possible.
- ☆ The student may be emotional for quite a while – on an individual basis, decide whether they need to be sent home.
- ☆ If an injury is sustained, or you are concerned, or the student is unconscious for an unusually long period, please call the emergency services.



How do I manage behaviour of a pupil with RAS?

Knowing that unexpected bumps and shocks can trigger an attack, it is understandable that some parents and teachers alike find managing behaviour worrying. However it should be remembered that:

- ★ Students with RAS or syncope have a medical condition but should be expected to behave as any other pupil.
- ★ Occasionally a loud, unexpected shout or noise could trigger an attack, such as the sound of the fire alarm or being startled by a shout.
- ★ Anxiety can also trigger 'dizzy' spells.
- ★ After an attack it is best if they can recover in a quiet area. For some it may be necessary to be sent home, however once they have recovered and returned to the class they should be able to return to all normal class activities and follow usual codes of conduct.
- ★ If uncertain, seek advice from the family or contact **www.stars.org.uk** or 01789 450564 or **jo@stars.org.uk**



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How can I enable inclusion?

- ☆ Share the student's care plan with all staff who will be responsible for the care of the pupil.
- ☆ Maintain regular communication with the student's family.
- ☆ Educate other students about RAS and syncope.
- ☆ Plan ahead time to share information with the pupil - for example when an alarm is due to ring.
- ☆ Allow time to acclimatise - to gently slide into a swimming pool or watch an activity before joining in.
- ☆ If uncertain, seek advice from the family or contact **www.stars.org.uk** or 01789 450564 or **jo@stars.org.uk**



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What should be included in a Care Plan?

- ☆ Student Name
- ☆ Student DOB
- ☆ Student Photo
- ☆ Background of medical condition
- ☆ Triggers & Warning Signs
- ☆ Management Strategy

Download a care plan from the **STARS** Education web site:
www.education.stars.org.uk

Important Information

- ☆ Emergency Contact Details:
 - Parent/Guardian
 - Doctor
- STARS:** Telephone: 01789 450 564

Other information

- ☆ Signed & Dated by:
 - Head Teacher
 - Parent/Guardian
 - Student

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Frequently Asked Questions

- ★ **What is Reflex Anoxic Seizures?**
RAS occur mainly in young children but can occur at any age. Any unexpected stimulus, such as pain, fright or shock, causes the heart and breathing to stop, the eyes roll up into the head, the complexion to become deathly white, often blue around the mouth and under the eyes, the jaw to clench and the body to stiffen. Sometimes the arms and legs will jerk. After about 30 seconds the body relaxes and the heart and breathing restarts slowly but the sufferer is unconscious. One or two minutes later the person may regain consciousness but can appear to be unconscious for over an hour. Upon recovery the person may be emotional and sleep for three to four hours, RAS attacks can occur several times a day/ week/ month and often come in clusters. RAS is often misdiagnosed as simple breath-holding or, more seriously, as epilepsy.

- ★ **What is the age of the youngest and oldest known RAS sufferer?**
The youngest known sufferer had his first attack during his first day of life. There are RAS sufferers in their 50s and 60s.

- ★ **What causes RAS in children?**
Reflex Anoxic Seizures are caused by the vagus nerve being over stimulated due to an unexpected stimulus such as pain/shock/fear. It is not known why this should happen in some children.

- ★ **Will the heart weaken through time?**
No, an RAS attack puts no strain at all on the heart.



Frequently Asked Questions

- ☆ **Placing the student into the recovery position immediately after the fright or other stimuli and before loss of consciousness seems to lessen the severity of the attack, or result in a near miss. Is there any medical foundation for this?**

This does seem to be the case, although the doctors are unsure why. It should be noted that the person does not always have to be placed in the recovery position. (Possibly it reduces the effect of the drop in blood pressure which occurs after the heart stops.)

- ☆ **Does an RAS attack cause any damage to the brain, short term/ long term?**

There is no evidence whatsoever that RAS causes brain damage. The 'fail safe' mechanism in the brain restarts the heartbeat and breathing before the oxygen level is low enough to cause damage.

- ☆ **If the cessation of the heart beat and breathing continues beyond the student's normal reaction time at what point should resuscitation be attempted, and how should this be administered?**

It would be extremely unlikely that resuscitation would be needed, because of the 'fail safe' mechanism in the brain. However, if the person's heart and breathing has not restarted after a period of two minutes, then attempting resuscitation in the normal manner would do no harm.

- ☆ **Is there a support group for them?**

Yes. STARS, Syncope Trust And Reflex anoxic Seizures, support sufferers of all ages.



Frequently Asked Questions

- ☆ **Can an RAS attack occur while the person is sleeping?**
Probably not, however there are other heart stopping conditions, notably Prolonged QT Syndrome, which do occur during sleep, and while awake especially with exercise. Prolonged QT Syndrome can be diagnosed using an electrocardiogram (ECG), and parents are encouraged to have this done, to rule out this diagnosis.
- ☆ **Is there a genetic factor in RAS?**
Almost certainly. More research is needed to establish what gene actually carries the susceptibility to RAS. A team at Birmingham Children's Hospital is hoping to do research to identify the gene responsible for RAS.
- ☆ **Could the person with RAS carry a card like people with epilepsy or diabetes, with "RAS" on one side and instructions for first aid response on the other?**
Medic Alert pendants or wrist tags are appropriate for a person with RAS. STARS also offer an information card with the person's name on one side and medical instructions on the other.
- ☆ **Is there a link between RAS and other medical conditions, e.g. Early childhood illness, heart murmurs or developmental delays?**
As far as the medical experts know, the answer is no.
- ☆ **What can I say to a child to comfort them during an attack?**
It does seem to help to talk to your child calmly and reassuringly during an attack as it would appear that they are aware of at least the sound of voices.



Frequently Asked Questions

☆ **Has an RAS patient had an attack in a swimming pool? If so, what happened?'**

Yes - fortunately the parent noticed immediately so no harm occurred. The stimulus of cold water splashing in the face, is a particularly strong stimulus to the vagus nerve, and can result in an attack. The child with RAS must learn to swim but should always have close parental supervision at all times in the pool.

☆ **Are pains in the legs common amongst people with RAS?**

Yes, however many children suffer with pains in their legs even if they do not have RAS. Again it is hoped that proposed research may identify whether people with RAS are more susceptible to pains in their legs.

☆ **What is the longest time a person with RAS has been free from attacks before they experience attacks again?**

10 years.

☆ **Why does a patient's face in an RAS attack go white and not blue?**

During an RAS attack the heart stops beating, and breathing stops. Blood vessels constrict and the blood is not able to get to the skin. This results in white pallor to the face. The blood is lacking in oxygen and will be blue coloured; only noticeable on the lips in the early stages of the attack. During a blue breath-holding attack lack of oxygen from the lungs causes blood to turn blue. However, as the heart is still pumping, this 'blue' blood passes through the blood vessels of the face, causing the whole face and the skin of the body to have a blue tinge.



Frequently Asked Questions

- ☆ **What makes the heart restart after an attack?**
As the oxygen level decreases in the brain, there is a chemical release [the fail-safe mechanism], which induces the heartbeat and breathing mechanisms to restart.

- ☆ **How does an epileptic attack differ from an RAS attack?**
An EEG (brain wave activity) of an epileptic attack would show excessive elective spike or epileptic discharges, which are not present in an RAS attack. In an RAS attack the EEG goes slow for a few seconds then is flat as the cerebral cortex shuts down, then goes slow again during the drowsy recovery phase before returning to normal. An RAS attack is always precipitated by a shock trigger, albeit sometimes difficult to identify.

- ☆ **Are there any problems with insurance cover for RAS students?**
Schools, playgroups etc, should be made aware of the child's condition, and should advise their insurance companies accordingly. Travel insurance companies should be informed of the person's condition and may require a doctor's letter to certify that the person is fit to travel. This should not increase your premium.

- ☆ **Is there a pattern to the frequency of the attacks?**
It does appear that they occur in batches, but we do not know why.



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For further help and support

**For further information,
help and support please contact:**

www.stars.org.uk

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