

STARS

Syncope Trust And Reflex anoxic Seizures

Frequently Asked Questions



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

www.stars.org.uk

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Frequently Asked Questions

1 What is a Reflex Anoxic Seizure?

Reflex Anoxic Seizures occur mainly in young children but can occur in adolescents or adults. The sudden shock of pain (however slight), or indeed any unexpected stimuli, causes the heart to stop, the eyes to roll up into the head, the complexion to become deathly white, the jaw to clench and the body to stiffen with arms and legs jerking. After 30 seconds or so the body relaxes and the heart restarts. The sufferer may remain unconscious for one or two minutes or for well over an hour. The sufferer often sleeps for 3-4 hours after an attack.

RAS is often mis-diagnosed as simple breath-holding or more seriously as epilepsy.

2 How old was the youngest and oldest known person with RAS?

The youngest had his first attack during his first day of life. There are people with RAS in their 50s and 60s.

3 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.

4 Does the person's heart stop during a 'near miss'? (We understand near-miss to refer to an incident when the person stops breathing after a fright or other stimuli, but starts to breathe again before unconsciousness lost)?

Recordings from the King of Hearts Monitor now shows medical evidence that yes, the heart does stop during a near-miss, albeit briefly.

5 Will the heart weaken through time?

No

6 Placing the person 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 results 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.

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

No. The 'fail safe' mechanism in the brain restarts the heartbeat and breathing before the oxygen level is low enough to cause damage.

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

There should never be a situation where resuscitation is needed, because of the 'fail safe' mechanism in (7) above. 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.

9 When do children grow out of attacks and what percentages of children continue attacks after school entry age?

Children's attacks tend to lessen as they get older, but they may never 'grow out' of them fully. Unpublished data shows that 75% of children 'grow out' of RAS at a median age of 6 years; however 1: 4 continue to have attacks albeit less frequently.

10 Do you know of any adults with RAS?

Yes

11 Is there a support group for them?

Yes. **STARS**, Syncope Trust And Reflex anoxic Seizure, provides support wherever they maybe in the world. (www.stars.org.uk) Due to high demand **STARS-US** has been established to provide support and information for those sufferers in the USA and Canada. (www.STARS-US.org).

12 When a child becomes too old to attend the children's hospital, which hospital do they attend and will they know about RAS?

The patient would be referred onto the nearest 'adult' hospital or department should it be necessary and all information forwarded. An individual hand-over plan would need to be made, sometimes to a cardiologist, sometimes to the GP, depending on the individual case. When a child is no longer under the care of a paediatrician, some consultants will refer to the condition as Vasovagal Syncope (VVS). This is the adult version of RAS.

13 Why do some children regain consciousness after an attack quicker than others do?

Children are very different in their ability to recover from attacks, partially because of the severity of the attacks, and partially due to their own body's reaction to the attack.

14 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 easily using an electrocardiogram read out, and parents are encouraged to have this done, to rule out this diagnosis.

15 Why does a child with RAS have more attacks when with parents?

There are two theories, one that the child has most attacks as a toddler, when he would normally spend most of his day at home with a parent. Another theory is that the child feels more relaxed in his home environment, he is not anticipating a fright, and will therefore be more likely to have an RAS attack because the fright/bump was unexpected.

16 What are the problems facing a person with RAS during anaesthesia?

The vagus nerve can be stimulated to produce an RAS attack by pressing the eyeballs [the ocular compression test] and, in anaesthesia when the tube is pushed down the throat. If the person is anaesthetised lying flat, after being given a pre-operation dose of atropine, there will be no further complications.

Complications arise where, particularly in dental anaesthesia, the RAS sufferer is anaesthetised sitting up. The intubation causes the RAS attack, and because the body is upright the blood falls to the legs. When the fail-safe mechanism restarts the heart the lack of blood in the heart could cause a cardiac arrest. Complications, including brain damage could then ensue.

The advice is always tell the anaesthetist that the child or adult has, or did suffer from RAS, and insist that all anaesthesia is administered while the patient is lying flat.

17 What does the child with RAS feel and experience during the stages of an attack?

A few older children have been able to describe what they experience during an attack and mention that voices sound far away, but that it felt nice. They do say that it is not pleasant coming out of an attack back to consciousness.

18 Is there a genetic factor in RAS?

Yes. It can run in families and can affect siblings to a lesser or greater degree. More research is needed to establish what gene actually carries the susceptibility to RAS.

19 Will my son pass RAS onto his children?

It is quite possible.

20 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?

STARS now produce Alert Cards, which are the size of a credit card and clearly show the key information on what to do in the event of a syncopal attack. They are useful to give to teachers, close friends and family. They are available in packs of 20 at a cost of £1. If you would like to order these, please send £1 coin or cheque (payable to **STARS**) together with your address, to **STARS**, PO Box 175, Stratford-upon-Avon, Warwickshire. CV37 8YD. MedicAlert pendants or wristbands are also appropriate for an RAS/Syncope sufferer. Leaflets and applications forms are available from **STARS**.

21 Is there a link between RAS and other medical conditions, e.g. early childhood illness, heart murmurs or developmental delays, Autism/Asperger’s Syndrome?

To date there is no medical evidence to prove a link to other conditions.

22 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 could be aware of at least the sound of voices.

23 What problems are associated with vaccinations [in respect of both the actual injection and the immunisation mechanism]?

None, other than it is possible to bring on an attack with the fright of an injection. Try to talk to your child and alert them so that they anticipate the pain. On balance, it is in the child’s interest to have the immunisation rather than the risk of contracting the disease.

24 Has a person with RAS 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.

25 What problems are associated with dental surgery?

The problems with dental surgery lie in the method of induction of anaesthesia (see Question 16). There is an information leaflet available from **STARS** (www.stars.org.uk)

26 Why does a child with RAS cry for hours after an attack?

Doctors are unsure. It could be due to chemical imbalance in the body after a period of anoxia, or might be due to the child's experience as they come out of the unconscious state. Perhaps the child's subconscious is coping with the emotion and shock of the seizure.

27 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.

28 Is there a connection between a complicated birth and the development of RAS?

No

29 What information should be given to playgroups and schools to ensure that staff know the risks?

Nursery and teaching staff should be directed to the **STARS** website, www.education.stars.org.uk. There is a wealth of information on the condition, including downloadable sample care plans. **STARS** also offers a free in-school presentation to any interested educational establishment about RAS, VVS and syncope by **STARS** Information Representatives (SIRs). **STARS** representatives have all been CRB checked. Educational establishments and parents can contact jo@stars.org.uk to find out more or to book a visit.

30 What is the longest time some one with RAS has been free from attacks before they experienced attacks again?

10 years

31 Can an RAS attack be controlled, once the child has experienced fright/ other stimulus?

A child has no control over the process. Some parents find in the early stages that they can avert an attack by a combination of reassuring the child, talking and placing them down in the recovery position. Different children respond differently.

32 Any advice on how to cope day to day with family life and a child with RAS?

It is important for the child with RAS to lead a normal healthy life. However, adults in charge of the child at any given time should be aware of the condition and perhaps given a STARS Alert Card (see Question 20) Further information is available from STARS website, www.stars.org.uk and www.education.stars.org.uk

33 A parent has been advised not to cuddle a child during an attack and let them come round themselves. Is this good advice?

The best advice is to have the child lying in the recovery position (lying on their side), speaking calmly and reassuringly to them, with physical contact where appropriate [rubbing child's back, patting their arm]. Your voice should sound calm and reassuring.

34 Why does a child'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.

35 Why does a child with RAS sleep for so long after an attack?

Unsure. It is probably the brain recovering from the shock of the attack. During a RAS attack the heart stops beating for normally 5 - 30 seconds, after about 9-10 seconds lack of blood supply to the brain makes the normal electrical activity in the cerebral cortex (the thinking, conscious part of the brain) turn off. When the heart starts beating again, the cerebral cortex comes on again but is sleepy for up to a couple of hours, as it gets over the 'shock'. This does NO damage to the brain.

36 What triggers are involved in later years?

Stimuli in later years often differ from the bumps and falls of a toddler with RAS. They can include trapping fingers, stubbing toes etc, long-term research is needed to discover what other stimuli causes these attacks.

37 Where is the vagus nerve, what is its normal function and what is its involvement in the RAS attack?

There is a full diagram and information sheet available from **STARS**, www.stars.org.uk

38 Could the vagus nerve cause other symptoms, feeling faint, sick, or affect the blood pressure?

The vagus nerve has many functions within the body. An information sheet is available (see 35).

39 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.

40 How does an epileptic attack differ from an RAS attack?

An EEG 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. A trigger always precipitates an RAS attack, albeit sometimes difficult to identify.

41 How does Atropine prevent attacks, when should it be prescribed, and what are the side effects?

There is a full information sheet available from the RAS support group. Please send a SAE with your request. A small donation to cover administration costs would be appreciated.

42 What can be done to prevent a child having attacks?

In extreme circumstances medication can be prescribed but it is not always successful and has side-effects. Children should be encouraged to drink and eat regularly to avoid dehydration and low blood sugar, both of which are known to make a child more susceptible to attacks. Salt should also be included in their diet as this can sometimes help. Sufferers of frequent and severe attacks for whom medical treatment and preventative measures have failed could be fitted with a pacemaker. Some consultants will prescribe Midodrine for young adults.

43 When a child attends a 6-month pacemaker check what would happen if the pacemaker had not 'clicked in' at all, would it be removed?

No, not necessarily.

44 If the pacemaker was removed and then the attacks started up again would it be replaced?

Not necessarily, it would depend on the frequency and severity of the attacks and how it was affecting the individual. Pacemakers are used as a treatment, not a cure.

45 Why does RAS affect such a small percentage of children?

We do not know but it is believed that more children suffer with RAS than is recorded due to being misdiagnosed with epilepsy and/or breath-holding.

46 Do children in other countries suffer with RAS?

Yes, and many contact **STARS** for advice. Our website, www.stars.org.uk has increased awareness and provided information for sufferers of RAS/Syncope around the world. STARS recently launched STARS-US to support many members who live in the US. www.stars-us.org.

47 How many people are affected?

We know that syncope (fainting) affects 225,000 young people every year in the UK . There is no data available for individual conditions.

48 Is there a link between lack of iron in the blood and RAS?

Results of blood tests in some children with RAS have shown them to be suffering with low iron levels. Increased iron intake has shown to reduce the number of attacks in some children. This is something which should be discussed with your doctor.

49 Is there a link between dietary allergies and RAS?

No

50 How do I obtain a diagnosis for my child's attacks?

STARS has prepared a Blackout Checklist to help you and your doctor reach the correct diagnosis. This can be downloaded from www.stars.org.uk Your doctor then may decide to refer your child to a paediatrician; the consultant will write to your GP with his diagnosis. **STARS** can supply information material for doctors.

51 Is there a form that can be presented to your GP to prove your child has been diagnosed as having RAS?

The consultant writes to the GP after the consultation and diagnosis, but the GP may need further information on the condition. There is an information leaflet for medical professionals available from the RAS support group. Please send an SAE with your request. A small donation to cover administration costs would be appreciated.

52 Are older children aware of situations that might result in an attack?

Yes, it would seem that they are aware of potential hazards and try to avoid them.

53 Are there any problems with insurance cover for people with RAS?

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. Some private health insurance companies may refuse to cover any subsequent injury caused or related to a RAS attack.

54 Is there a pattern to the frequency of the attacks?

It does appear that they occur in batches, but we do not know why.

55 Is RAS more common in boys than girls?

Girls.

56 Is it possible that a child could have an RAS attack during its birth?

Yes, it is possible, but we do not know of any such incidents.

57 How can I talk to other carers?

My child has just become a teenager and wants to talk to young people with the same condition. STARS has two MODERATED message boards. The Syncope message board and the Youth message board. The former is used by STARS members to share experiences, swap information and just 'chat'. The Youth board is for young people (we advise 11+ years but it is up to the parent) to talk about their condition, share jokes and generally talk to other young people from all over the world. Visit www.stars.org.uk and click on 'Forum' for the adult moderated notice board; or young people (under 18 years of age) can join the Youth MODERATED Notice board via the education web site: www.education.stars.org.uk and follow the links from the Youth pages.

Syncope Trust And Reflex anoxic Seizures Group was originally known as the Reflex Anoxic Seizure Information and Support Group. It was founded in March 1993 after Francesca Lobban was diagnosed as having RAS and with the full support of Professor Stephenson, Consultant Paediatric Neurologist, Royal Hospital for Sick Children, Glasgow.

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