STARS
Syncope Trust And Reflex anoxic Seizures®
www.stars.org.uk

FAQ for Reflex Anoxic Seizures (RAS) (Paediatric Syncope)





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

1. What is Reflex Anoxic Seizures (RAS)?

Reflex Anoxic Seizures occurs 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 misdiagnosed as simple breath-holding or more seriously as epilepsy. Some medical professionals may recognise or use the term Paediatric Syncope.

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?

RAS is caused by the vagus nerve being over stimulated due to an unexpected stimulus such as pain/shock/fear. The vagus nerve inhibits the heart and slows it down or temporarily stops it completely.

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

Heart monitor recordings show that the heart does stop beating during a near-miss, albeit briefly.

5. Will the heart weaken through time?

There is no evidence that the heart will weaken over time as a result of RAS attacks.

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. Contact emergency services if the person does not start breathing and if their heart does not restart within two minutes.

8. If the cessation of the heartbeat 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 have not restarted after a period of two minutes, attempt resuscitation in the normal manner.

9. When do children grow out of attacks and what percentage 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 in 4 continue to have attacks albeit less frequently.

10. Do you know of any adults with RAS and is there a support group for them?

Yes, to both questions. STARS, Syncope Trust And Reflex anoxic Seizures, provides support wherever they may be 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 (www.stars-us.org).

11. 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 or 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 (reflex syncope). This is the adult version of RAS.

12. 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.

13. 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 whilst 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.

14. 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 or she would normally spend most of his day at home with a parent. Another theory is that the child feels more relaxed in their home environment, is not anticipating a fright, and will therefore be more likely to have an RAS attack because the fright/bump was unexpected.

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

If the vagus nerve is stimulated by compressing the eyeballs during eye surgery, or when a breathing tube is inserted, an RAS attack may result. It might therefore be necessary to give a pre-medication of atropine to avoid these complications. Make sure the anaesthetist and surgeon are aware of RAS before the day of surgery.

16. 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.

17. 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.

18. 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 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 and available to order via our 'Online Shop' on the STARS website www.stars.org.uk Medic Alert pendants or wristbands are also appropriate for an RAS/Syncope sufferer.

19. 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.

20. 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.

21. 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 best interest to have the immunisation rather than the risk of contracting the disease.

22. 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 adult supervision at all times whilst in the pool.

23. 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.

24. 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.

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

No.

26. 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.stars.org.uk. There is a wealth of information on the condition, including downloadable sample care plans. Educational establishments and parents can contact info@stars.org.uk to find out more.

27. What is the longest time someone with RAS has been free from attacks before they experienced attacks again?

10 years.

28. 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.

29. 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 18). Further information is available from STARS website, www.stars.org.uk.

30. 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.

31. 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.

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

It is probably the brain recovering from the shock of the attack. During an 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.

33. 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.

34. What is the vagus nerve?

This is the longest nerve in the human body, connecting the brain to the heart. When the vagus nerve is stimulated, the heart rate slows.

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

The vagus nerve has many functions within the body. Common symptoms include low blood pressure, feeling faint, nausea etc.

36. 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.

37. 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.

38. 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. Pacemakers should be used only *very* rarely. Some consultants will prescribe Midodrine for young adults.

39. 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.

40. Is there a link between dietary allergies and RAS?
No.

41. How do I obtain a diagnosis for my child's attacks?
STARS has prepared a Blackouts 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 their diagnosis. STARS can supply information material for doctors.

42. 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 company 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 an RAS attack.

43. Is there a pattern to the frequency of the attacks?

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

44. Is RAS more common in boys than girls?

Girls.

45. Is it possible that a child could have an RAS attack during their birth?

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

46. How can I talk to other carers?

Please visit our online forum: www.healthunlocked.com/stars
Facebook: www.facebook.com/blackoutstrust
X (formerly Twitter): www.x.com/blackoutstrust

Notes

This booklet has been written to support those diagnosed with syncope and their carers, who struggle to find information on this condition. Without donations and fundraising, we would not be able to provide support through our award-winning resources and helpline.

Please donate to support our vital work at
www.stars.org.uk/donate

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"This has become my go to source when I worry about RAS"

Fiona S, a new mum

To view our patient resources, scan the QR code below:

Please remember that this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional. If you would like further information or would like to provide feedback, please contact STARS.

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