

Questions to GP/Paediatrician:

- ♥ What causes RAS in children?
- ♥ Is RAS a serious condition?
- ♥ Is RAS genetic?
- ♥ Is there a link between RAS and Autism and Asperger's Syndrome?
- ♥ What should I do when my child has an RAS attack?
- ♥ Is it dangerous to perform CPR if I am worried about my child's heart and breathing restarting?
- ♥ Will my child grow out of RAS?
- ♥ Are pains in the legs and sometimes in the chest linked to RAS?
- ♥ What else could these episodes be? How can we tell the difference between epilepsy and RAS?
- ♥ Is it safe for my child to still have their vaccinations?
- ♥ Can my child attend school?

Want to Know More?

"I just wanted to wrap her in cotton wool, sit and play jigsaws all day, knowing she was unlikely to have an attack if she did not move"

Trudie Lobban MBE, Founder & CEO STARS

If you have any questions, would like further advice or information, please contact our Patient Services Team:

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It is important to remember that although RAS is frightening to witness, it is NOT life threatening.



FOR PATIENTS & CAREGIVERS

Reflex Anoxic Seizures (RAS) Discussion Guide

This Discussion Guide is to help families and individuals diagnosed with RAS or awaiting a diagnosis who are struggling with the issues raised by this condition



FAQ Questions

What is RAS?

RAS occurs mainly in young children but can occur at any age. Unexpected stimuli such as pain, shock or fright can cause the heart and breathing to stop with RAS often being misdiagnosed as breath-holding or, more seriously as epilepsy. Your doctor will take the history of your child's attacks and may perform an ECG (monitoring of the heart) to confirm a diagnosis of RAS or a different condition

It is important to remember that although RAS is frightening to witness, it is not life threatening.

What is the difference between RAS and breath-holding?

Breath-holding is when the heart continues to beat normally but the breathing stops temporarily, and the child briefly loses consciousness; often as a result of the child being frustrated and cross and resorting to intense crying. RAS is the result of an over-sensitive vagus nerve being stimulated by pain, shock, or fear. When this nerve is 'irritated' the heart rate will slow and sometimes stop momentarily – resulting in the child losing consciousness. The heart will always restart.

Can an RAS attack occur whilst the individual is asleep?

It would be unusual for this to be RAS. If this occurs, however, it is important to discuss it with your GP as it could be a symptom of another, more serious condition such as Long QT syndrome. An ECG will hopefully help rule this diagnosis out.

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

No! The 'fail safe' mechanism in the brain restarts the heart and breathing before the oxygen level is low enough to cause damage. Again, in the very unlikely event (and this is not RAS) that breathing is not restored after two minutes, contact emergency services.

How is RAS diagnosed?

- In preparation for your doctor's appointment, obtain a good description from a witness and have a note of triggers leading to some of the attacks.
- Keeping a diary and videoing an episode on your phone will help towards a speedy and accurate diagnosis.
- A referral to a paediatric cardiologist should confirm a diagnosis.
- A full family medical history should be requested, together with a description of the circumstances surrounding an RAS attack and a 12-lead ECG to preclude any underlying heart rhythm disorder.
- If there is a family history of epilepsy, an EEG may be requested.
- The most important information is 'history, history, history' so go well prepared with history of when and how the attacks are triggered and what happens during the attack. Do the arms go up over the head or down by the side? What colour does the complexion of your child turn during an attack? Are they sleepy after an attack?

Treatment options for RAS

- ♥ Currently there is no 'treatment' for RAS. Children's attacks tend to lessen as they grow older although they may never 'grow out' of them completely. They can return at any time. From young adulthood, an episode may be recognised as reflex syncope or vasovagal syncope by medical professionals.
- ♥ Iron supplements may be beneficial. There is evidence that suggests iron deficiency may result in episodes being more frequent. Please discuss with your doctor.
- ♥ Increasing fluid intake (NOT carbonated drinks or those containing caffeine) as poor hydration can also lead to an RAS attack.
- ♥ Increasing salt intake (a packet of crisps) can also help.

Associated Conditions

Night terrors are brief periods of screaming/ crying and distress, normally linked to toddlers up to the age of four to five years. The child will not remember the night terror in the morning. Attempting to wake a child from this is rarely successful. It is known that children with RAS tend to have night terrors just prior, during or immediately after a cluster of attacks.

Leg pains: Children can complain of unexplained leg pains and sometimes chest pains. Although acknowledged, the medical profession has yet to discover the reason for this.

Anoxic-epileptic seizures (AES) are epileptic seizures triggered by RAS or syncope. They are uncommon as most RAS episodes in the majority of children do not trigger an AES.

Key points

- ✓ RAS is a non-life threatening condition with no known long term ill effects.
- ✓ Frequency of episodes varies with the individual – they may occur several times per day/week/month or year with long periods of time between attacks. Often, they present in clusters.
- ✓ RAS more frequently occurs in young children, but it is not uncommon for it to occur at any age. In adults it may also be called reflex syncope (vasovagal syncope).

Remember

**RAS is not an illness.
Do not stop your child enjoying
their young life!**