

STARS

Syncope Trust And Reflex anoxic Seizures®

www.stars.org.uk

Take Fainting to Heart

There is no such thing as a simple faint...

Reflex Anoxic Seizures (RAS)



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

www.stars.org.uk

Registered Charity No. 1084898

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Glossary of terms

12-lead Electrocardiogram (ECG) Used to record heart rhythms in hospital

Heart monitor is used to record heart rhythms whilst away from hospital or to activate during an episode.

Insertable cardiac monitor (ICM) is a device used to monitor heart rhythms for months at a time if the episodes are less frequent than every two weeks. The device can remain in place for up to three years.

Reflex Anoxic Seizures (RAS) Sometimes called Reflex Asystole Syncope is a term used for a fit which results from a brief stoppage of the heart through excessive activity of the vagus nerve

Tilt Table Test An autonomic test used to induce an attack whilst connected to heart and blood pressure monitors

This booklet is for families, friends and individuals who care for a child who has been diagnosed with Reflex Anoxic Seizures (RAS).

RAS occurs mainly in young children but can occur at any age. Unexpected stimulus 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.

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

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General Information



What is Reflex Anoxic Seizures (RAS)?

"Reflex Anoxic Seizures (RAS) was first clearly distinguished in 1964 ("type 2 hypoxic crises", Maulsby & Kellaway). The term is used for a particular fit which is neither epileptic nor due to cyanotic breath holding (prolonged expiratory apnoea), but which rather results from a brief stoppage of the heart through excessive activity of the vagus nerve. I have used the term reflex anoxic seizures (RAS) to describe the convulsions which accompany this particular type of syncope."

Syncope (sin-co-pee) is derived from the Greek word to cut off. Syncope is the result of the temporary cutting off of the supply of oxygenated blood to the brain. The mechanism of the syncope in susceptible individuals includes reflex cardiac standstill (always reversible) commonly following a surprising bump to the head or elsewhere. Associated marked pallor of the skin has led to these attacks being called pallid syncope. In more recent times these attacks have been referred to as reflex asystolic syncope."

**Prof. J B P Stephenson MA. DM. FRCP. FRCP.
(London & Glasgow) Hon. FRCPCH. DCH.
Founder & STARS Patron**

They are not...

Temper tantrums

Epilepsy

Reflex Expiratory
Apnoea Syncope
(RES)

Blue breath holding
attacks

Prolonged Expiratory
Apnoea (PEA)

Valsalva syncope

Apnoea attacks due
to stopping breathing

Simple faints

Pseudo-syncope

Pseudo-seizures

Other cardiac causes
with arrhythmia
(abnormal heart
rhythm such as
Long QT etc)

Deliberate behaviours



Reflex anoxic seizures (RAS) occur mainly in young children but can occur at any age. Any unexpected stimulus, such as pain, shock, or fright, causes the heart and breathing to stop. The eyes roll up into the head, the complexion becomes deathly white, often blue around the mouth and under the eyes. The jaw will clench and the body will stiffen, sometimes the arms and legs will jerk. After what seems like hours but is probably less than 30 seconds, the body relaxes, the heart starts beating (sometimes very slowly at first) and throughout this the person is unconscious. One or two minutes later the person may regain consciousness but can appear to be unconscious or asleep for over an hour.

Upon recovery, the person may be very emotional and then fall into a deep sleep for two to three hours. They may look extremely pale with dark circles under the eyes. RAS attacks may occur several times per day/ week/ month. The attacks appear to come in batches.

Unfortunately, because of the symptoms, it is known that RAS is often misdiagnosed as temper tantrums, breath holding or as epilepsy. It is one of the aims of STARS to improve both professional and public awareness of RAS.

Reflex Anoxic Seizures are also known as:

- Reflex Asystolic Syncope (RAS)
- Infantile Vaso/Vagal Syncope (IVS)
- Vaso-Vagal Syncope (VVS)
- Reflex Syncope (RS)
- Cardioinhibitory Neurally Mediated Syncope (NMS)
- Neurocardiogenic Syncope (NCS)
- Pallid syncope
- Stephenson's syndrome
- Vagal cardio-inhibitory fainting fit
- White breath holding attacks

What is the difference between RAS and breath holding?

Breath holding is different to RAS in that during breath holding the heart continues to beat normally, but the breathing stops temporarily. Breath holding is not done on purpose but is also a reflex.

It is normal when crying, or when very upset, to have some difficulty 'catching your breath'. In breath holding the child makes an expiratory loud cry (breathes out with the crying noise), then is silent before gasping breath in. Sometimes, especially in some toddlers, they get stuck in the expiration and lose consciousness at that point. Typically, a child may look distressed and go very blue during the silent phase, then collapse unconscious, either floppy or stiff. This can look just like RAS. However, RAS results from a brief stoppage of the heart through excessive activity of the vagus nerve. Although there are treatments for RAS when it is severe and frequent, there are no treatments for breath holding. As with RAS, it is frightening to witness but is not in itself dangerous, the loss of consciousness (syncope) is brief and recovery complete.



"...just to know that other parents are going through the same emotions and stresses you are makes a big difference"

Kerry,
Mum of a toddler



How is RAS diagnosed?

A correct diagnosis can be obtained by a good description from a witness and establishing a trigger to at least some of the attacks. This can be aided by keeping a diary of events. Try to ensure that your chosen doctor is familiar with the condition. If you are able to video an attack e.g. on your phone, this also helps towards a speedy, accurate diagnosis.

- **12-lead electrocardiogram (ECG)** is done to check for any features on a resting ECG that might suggest a genetic, inherited or familial heart rhythm disorder, and for heart rhythm analysis.

The following tests are sometimes used to help doctors make a diagnosis:

- **Heart rhythm monitor** to record heart rhythms for up to a week, or more whilst away from hospital.
- **Implantable loop recorder (ILR)** is used to monitor heart rhythms for months at a time if the episodes are less frequent than every two weeks. The device can remain in place for up to three years. They are not commonly used in children.
- **Tilt table test** is a test used to induce an attack whilst connected to heart and blood pressure monitors. Ideally, this test should be performed with other tests as these aid diagnosis and also help in treatment.

If the tilt test fails to trigger an attack, other triggers can be tried, e.g. ocular compression. This involves the doctor pressing on the child's eyes for ten seconds. It is a strong trigger for RAS, is safe when done by an expert in a controlled setting, but is quite painful, so is not done routinely.

What should I do if my child experiences an RAS attack?

1. Stay calm! At least outwardly even if you are panicking within. There have been reports of children going into a second attack as they recover from the first attack because a parent was hysterical and the shock of that triggered a second attack. Older children sometimes report that they can still hear during an attack. It is therefore important to remain calm and reassure the child.
2. Make sure the individual is lying in the recovery position in a safe environment ensuring nothing is blocking their airway. This can be on your bed, floor or sofa. (Family and friends will feel better if you say 'recovery position' as it gives them something to focus on and reassures them that what they are doing is correct). The child normally starts to regain consciousness during that time.
3. Check to make sure nothing is in the mouth to choke on, being careful not to get fingers clamped in the jaws of the child.
4. Try to time the attack - it will be much shorter than you imagine (in most cases).
5. Talk reassuringly (it is known that the individual can sometimes hear but is unable to answer) and comfort them upon recovery.
6. Video if possible to show doctors if necessary.



7. When the child regains consciousness, allow them to sit up when they are ready and able. They may feel weak for some time, so leave them to lie down if they prefer. Reassure, cuddle and give lots of tender loving care, as they are often very emotional.
8. If an older child has been incontinent, do not make a fuss, and help them to change as quickly as possible. The older the patient the more embarrassing it is for them.
9. If they wish to sleep, allow it. They often sleep for 2-3 hours. Some however are just drowsy and dizzy or disorientated. Reassure and just be there for them. They often feel afraid and insecure.
10. Many people report that noise is amplified after an attack - everyone appears to be racing around and shouting or being very loud. Keep the environment calm and quiet around the patient. They may feel 'fragile'.
11. They can be very emotional for a few hours or days - be understanding and reassuring. Slowly encourage them to get back to normal but do not force the issue at first. Allow them time.
12. Some patients and parents report night terrors and pains in the legs a few days before, during or just after an attack - reassurance and awareness is vital. Massaging legs sometimes helps.
13. It is unlikely that they will actually remember the attack so if they don't want to talk about it do not force the issue.

Although it should not be necessary to call a doctor, if the person has had a particularly nasty bump, it may be wise to seek medical advice.



Avoiding attacks in given situations

Remember the child is a normal healthy person and SHOULD NOT be excluded from any normal activity; however a responsible adult should be made fully aware of the condition and the action to take if necessary.

In general, we encourage carers to allow a child to stand, watch and become accustomed, and gain confidence before participating in an activity whether that be a game, party or just entering a crowded room or new environment.

Sports: Allow a child to participate in gymnastics, karate, football, etc. Let the supervising adult(s) know about it, just in case. An example, is a girl suffering with severe RAS but has NEVER had an attack while at gymnastics. She has had many falls and bumps but she knows she is likely to hurt herself, so when it happens it is not a shock. Equally, she has arrived home and just knocked her elbow on a door handle and passed out immediately.

Swimming: Encourage your child to swim but allow them to sit on the side of pool with feet in the water and gently wet the face, hands, arms, to get used to the temperature before jumping in. Again it takes away the shock element. One child with RAS jumped in a pool and had an attack because the water was so cold. Now she always sits on the side, gets used to the temperature, eases herself in and then once used to it she is fine jumping or even diving in.



Vaccinations: Warn a child that it will hurt (a little), reassure, explain what is about to happen as it happens – while the nurse or doctor injects. This reduces the chance of an attack brought on by the sudden pain of the needle. This has proved to help; not only does it stop an attack happening but also reassures the parent because they feel they are doing something to help the situation.

Teachers, Carers & Dentists: Inform all that the child is susceptible to unexpected stimulus such as pain, shock or fright and will sometimes pass out. Advise them to make the child safe and put them in the recovery position. You could give them the **RAS booklet** which explains the condition and what to do.

Triggers: If you know a certain situation will or may bring on an attack in your child (e.g. eating a cold ice lolly, playing in snow, playground rides etc.) then avoid for a while until the child is slightly older and gradually re-introduce them.



"As a child I did horse riding, swimming lessons, school trips, in fact everything a boy of my age should be allowed to do"

Oliver, school boy



Managing a child with RAS

1. Do not avoid disciplining your child because you are afraid of an attack. If the attack was triggered because you had shouted or disciplined, do not then allow the child to later continue to do whatever he was originally doing. RAS is not caused by bad behaviour but if not handled correctly it can lead to behaviour problems later. Do not give in to the child because of the RAS.
2. Do not stop your child doing anything! (Unless dangerous). Pre-warn the child of danger so that if an accident happens it is not such a shock. For example, falling off the bottom of a slide at the park. The child is perfectly capable of going on the slide...when he does hit the bottom it is not a shock. It may still hurt but it is not unexpected.
3. Do attempt to give the child an explanation of RAS and answer any questions they may have, appropriate to their age. STARS has a useful booklet for children called **Jack has RAS**, which can also be shared with siblings, to aid their understanding.
4. Even with very young children, avoid discussing 'their problem' in their presence, it makes them feel 'odd', 'different' and can make them become withdrawn. Try to make light of it but be aware of their concerns. Siblings can often feel they are the cause of the attack. Reassure and explain to them.



"We are sure she will have a happy and fulfilling university life, just as we did"

Cathy, Mum of university student



Associated conditions

Night terrors

Night terrors are brief periods (about 10-20 minutes) of screaming/crying and distress in the early part of the night. These normally occur in toddlers up to the age of four to five years. Night terrors occur typically in the first half of the night. It is very difficult, if not impossible, to arouse a child from a night terror. The child may have their eyes open, but will 'stare straight through you' as if not seeing you. In fact, the child does not see you and will not remember anything about the night terror in the morning.

A night terror is a disorder of incomplete arousal from deep sleep. Most of the brain is shut down but certain motor (muscular movement) circuits are active when they should in fact, be quiet. The result is thrashing around, screaming/crying out, walking up and down, kicking, unintelligible speech and the child apparently terrified. The child will not respond to voice, touch or reassurance. It is known that children with RAS tend to have night terrors just prior, during or immediately after a batch of attacks.

Unfortunately, we have yet to discover why. Similarly, children often complain of unexplained pains in their legs and occasionally their chest, but the medical profession have yet to discover the reason for this.

Important Facts

- The child will not remember the night terror in the morning
- Parents are advised not to even mention it to the child
- Attempting to wake the child during the night terror is rarely successful
- The child is NOT ill
- There are no known long term ill effects
- Usually, night terrors occur only once per night and not every night
- Changes in routine and overtiredness can make them worse



What can be done to help?

- Stay calm during the night terror
- If the child is thrashing around and walking back and forth, speak reassuringly
- If possible, comfort and hold your child close until it passes
- Only attempt to restrain the child physically to prevent self-injury
- Place anything harmful out of reach
- If necessary lock doors and windows
- Reassure siblings that the terrors will do no harm and will go away
- Your reaction, and those of the siblings, may upset the child who is having the night terror. Reassure the child
- Remember that the child will have no memory of the incident the next day and should not be made aware of the incident as this can cause distress

"I just wanted to wrap her up in cotton wool, sit and play jigsaws all day, knowing that she was unlikely to have an attack if she didn't move.

Such a response to caring for a child with RAS is natural, however parents need to balance the understandable need to protect their child from harm against the long term problems this can cause. Excluding children from everyday activities and risks can stunt their normal emotional and psychological development. Discipline and limit setting is particularly hard for families but remain essential for the child's healthy development."

Trudie Lobban, MBE
Founder & CEO

Anoxic-epileptic seizures (AES)

Anoxic-epileptic seizures (AES) are epileptic seizures triggered by syncope or RAS. They are uncommon as most syncope episodes in the majority of people do not trigger an AES. However, these can occur in some individuals if they have a severe syncope episode, typically during the recovery phase. They usually last a few minutes and are not normally dangerous.

AES are now being identified in some children who have RAS. They start as the RAS episode is coming to an end but before the child has recovered. If an AES is brief, lasting LESS than five minutes, no specific treatment is necessary. However, prolonged AES lasting more than five minutes should be treated to reduce the risk of status epilepticus (this is an epileptic seizure lasting more than 30 minutes). If no emergency treatment has been prescribed, or if the treatment does not stop the AES within ten minutes of administering it, then an ambulance should be called.

One or all of these treatment approaches can help and may be prescribed by the paediatrician if considered necessary:

- Emergency treatment for the convulsive epileptic seizure that has gone on for more than five minutes: buccal midazolam. A paediatrician may decide that initially a test dose should be tried in hospital.
- Treatment to prevent or reduce the frequency of RAS, and consequently AES: regular or occasional glycopyrronium, atropine or similar medication. Very occasionally cardiac pacing may be considered.
- A regular anti-epileptic drug (AED) to prevent or reduce the severity and duration of the AES. This would have no effect on RAS: e.g. sodium valproate or other AED.

If you feel your child may be experiencing anoxic epileptic seizures following the RAS episode, then you should discuss this possibility with your GP who would refer you back to your paediatrician or another specialist.

What are the treatment options for RAS?

Although currently there is no cure for RAS, advances have been made with the use of:

Pacemakers: Cardiac pacing can be provided as a treatment to improve the quality of life for some individuals who are more severely affected with RAS. A pacemaker is a device that is directly connected to the heart and begins working when an RAS attack is sensed, preventing the heart from stopping completely and thus avoiding the loss of consciousness and associated symptoms.

Glycopyrronium, Atropine Sulphate or Methonitrate, and Hyoscine are inexpensive, safe and effective drugs that prevent most reflex anoxic seizures but can cause harm in overdose. A doctor may prescribe one of these in the short-term for young children having severe and frequent attacks that cause distress to the child and their parents. They must be given daily whether attacks are occurring or not. Little is known about the long term effects of these drugs.

Side effects may include:

- Dry eyes – eye irritation
- Blurred vision and enlarged pupils
- Dry mouth
- Excessive thirst
- Feeling hot and sweating
- Difficulty in passing urine

Iron supplements may be beneficial. There is suggestive evidence that a shortage of body iron (iron deficiency) may allow episodes to be more frequent. Ask your doctor if iron supplements might be prescribed.

Maintaining a balanced diet and hydration

in adults has been proven to reduce the frequency of attacks. Poor hydration and anaemia increase the risk of syncope (fainting). As yet it is not clear if this helps children with RAS, although some doctors recommend increasing fluid intake (water, milk, energy drinks, NOT carbonated drinks or drinks containing caffeine).



General Information

Information for anaesthetists and dentists

There is no reason why a child diagnosed with RAS should not be anaesthetised for a procedure but special care should be given during general anaesthesia due to triggering of the vagus nerve during intubation.

The following guidance should be shared with the anaesthetist or dentist managing your child's treatment.

- Induction of anaesthesia especially by endotracheal intubation causes rapid increase in vagal discharges
- It is common to find a precipitating cause for syncope and reflex anoxic seizures as people are susceptible to them when anaesthesia is being induced.
- This is often prevented by pre-medication with atropine, a drug which increases the patient's heart rate. A more 'gentle' anaesthetic can be given to minimize the drop in blood pressure.
- The anaesthetist should be informed in simple terms that the patient has syncope or reflex anoxic seizures and the heart can stop due to increase in the vagal tone for up to one minute. It is advisable that the anaesthetist is advised at the surgery pre-assessment appointment so they are prepared and aware of the individual's condition ahead of time. They may request extra tests such as an ECG or a letter from the patient's cardiologist.
- RAS is not a contraindication to anaesthesia and, with normal, careful monitoring, the anaesthetic should cause no problems as the heart will restart spontaneously. It is recommended to inform anaesthetists of the condition so the appropriate anaesthetic can be planned.
- The only danger is giving an anaesthetic to a person in an upright posture when, during the period the individual's heart has stopped, the blood can pool in the legs causing problems when the heart normally restarts.
- Thus, ALL those with syncope and reflex anoxic seizures should be anaesthetized lying down rather than sitting and may be given atropine or a similar pre-medication.

Healthy eating for children and young teens

Children

It is acknowledged that an iron deficiency (anaemia) in young children can be a contributory factor for RAS. If you feel this may be related to your child's episodes, then we suggest you discuss with your GP. If your child is shown to be anaemic then a diet rich in iron will help. Green vegetables like broccoli, cabbage and watercress are recommended, as well as red meat and eggs, pulses and beans. It is important that a child is encouraged to drink plenty of fluids and has some salt in their daily diet, equivalent of a small bag of salted crisps.

Young teens

Fluids It has been known for some time that if one is dehydrated you can be prone to fainting. A young person entering puberty who is affected by syncope or RAS is advised to drink at least 1.5/2 litres of fluids a day. Urine should be a very pale yellow colour. **Monitoring:** It may be helpful to drink from a refillable sports bottle. This allows you to keep track of how much has been consumed as it is very easy to underestimate when you are busy.

Food It is generally better to eat little and often i.e. graze all day long! Symptoms are often worse if one is hungry or have eaten a large heavy meal. Save those stodgy foods for the evening when you can lie down and rest afterwards! **Carbohydrates:** Meals rich in refined carbohydrates (e.g. sugars and white flour) can make symptoms worse. If you like to eat carbohydrate foods, try brown rice and pasta and wholegrain bread. **Fibre:** It is important to avoid constipation as straining on the toilet can cause fainting. Eat high fibre foods such as bran cereal, fresh and dried fruits, vegetable, beans and lentils. **Salt:** Some of you with a tendency to low blood pressure, which can trigger syncope, may have been advised to increase your salt intake. It is important your doctor clarifies the amount of extra salt you need. **Favoured foods to increase salt intake:** Crisps, salted nuts, feta cheese, olives, Marmite, instant noodles, packaged soups.

Note: Fast foods like burgers, chips and pizza are often salty but contain unhealthy fats and should be limited. It is important to keep your weight within normal limits. Being overweight may increase blood pressure but can cause other health problems. Low body weight can lower blood pressure and make you prone to fainting.



Education Information

Key points to remember when it is time to talk to school

- The frequency of attacks varies for an individual – they may occur several times a day/week/month.
- Whilst RAS more frequently occurs in the younger child, it is not uncommon for it to occur at any age.
- Good management of the child within school is the key to inclusion.
- You cannot stress too strongly that whilst RAS is frightening to witness, it is NOT life threatening.

Education booklet


The STARS Education Information booklet provides information for school staff on how to care for young pupils in their care with RAS. The booklet will inform and reassure staff and outline the ways a school can effectively manage a child with syncope/RAS to provide support and enable inclusion, thus ensuring your child is able to enjoy and lead a normal school life – the right of every child. To receive a copy, email info@stars.org.uk

Care Plans

All educational establishments now require care plans and this is available to download from the STARS website: www.stars.org.uk There is a form for the parent/carer to complete in conjunction with school together with an example of suggested wording if required. A care plan should be shared with all staff who will be responsible for the care of your child.

Alert cards

Every child should carry one of these cards and family and friends should ideally have one for



The image shows the cover of the STARS Education Information booklet and two alert cards. The booklet cover features the STARS logo (Syncope Trust And Reflex Anoxic Seizures) and the title 'Education information'. Below the title is a photograph of a group of diverse school children. At the bottom of the cover, it says 'Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures' and provides the website www.stars.org.uk. Below the booklet are two alert cards. The first card is for 'I suffer with Reflex Anoxic Seizures' and the second is for 'I suffer with SYNCOPE'. Both cards include a 'NAME:' field, a list of instructions (heart icon, 'Please make sure I am safe', 'Please put me in the recovery position', 'Please talk quietly to me and wait for me to regain consciousness (normally only 1 or 2 mins)'), a 'CALL IMMEDIATELY:' field, and a note at the bottom: 'If injured or concerned also call for EMERGENCY SERVICES - 999'. A small illustration of a person lying on their back in a recovery position is shown on the right side of each card.

STARS
Syncope Trust And Reflex Anoxic Seizures

Education information

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

www.stars.org.uk

NAME: _____

I suffer with Reflex Anoxic Seizures
(this is not connected to epilepsy and is NOT life threatening)

- ♥ Please make sure I am safe
- ♥ Please put me in the recovery position
- ♥ Please talk quietly to me and wait for me to regain consciousness (normally only 1 or 2 mins)

CALL IMMEDIATELY: _____

If injured or concerned also call for EMERGENCY SERVICES - 999

NAME: _____

I suffer with SYNCOPE
(this is not connected to epilepsy and is NOT life threatening)

- ♥ Please make sure I am safe
- ♥ Please put me in the recovery position
- ♥ Please talk quietly to me and wait for me to regain consciousness (normally only 1 or 2 mins)

CALL IMMEDIATELY: _____

If injured or concerned also call for EMERGENCY SERVICES - 999

reference. The size of a credit card they will provide immediate information and an emergency contact number in the event of an RAS/syncope episode. They can be purchased through STARS website: www.stars.org.uk

Syncope Education DVD for schools and colleges

This Syncope Education DVD has been produced to provide information for staff on how to care for young people who have been diagnosed with RAS and syncope. This is the perfect means to ensure that all the concerns that a school may have are addressed. This can be purchased through STARS website: www.stars.org.uk

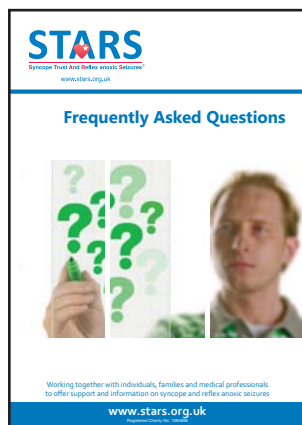
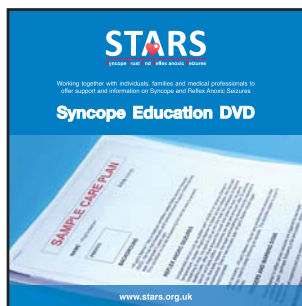
Other STARS resources to help family and friends in their understanding of RAS. These can be ordered through info@stars.org.uk

Frequently Asked Questions (FAQ)

Written to provide answers to the many questions that concern parents/carers of children diagnosed with RAS

Jack has RAS

A fully illustrated booklet, written to help parents explain RAS to siblings. Experience has shown that brothers and sisters who witness an RAS attack find it very frightening and worry that they have caused it. This book provides reassurance.



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

STARS would like to thank all those who have helped in the development and review of this publication. In particular, thanks are given to Prof. John Stephenson, and Dr William Whitehouse and Dr Charlotte D'Souza.

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

