A STARS perspective: What are the most common questions asked by patients with syncope?

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Global outreach

- It all started with Francesca...

- STARS has undergone rapid expansion and the support and information group that was originally established is now an international charitable organisation.
Why we do what we do...

- Syncope is poorly investigated and diagnosed
- Syncope remains unexplained in about 35% of causes
- 40% of population are affected at some stage of their life by syncope
- As many as 30% of (A) 39% (C) are misdiagnosed with epilepsy, many of these patients have cardiovascular syncope
- Syncope accounts for:
  - 1-6% of all hospital admissions
  - 10% of falls in elderly
  - 23% of elderly in nursing homes
- Impact on daily life is immense
Stories show that patients face...

- Misdiagnosis
- Long waiting times for appointments
- Lack of awareness
- Lack of understanding
- Psychological impact of blackouts
What do patients want?

➢ Accurate diagnosis and treatment
➢ Information and understanding
➢ Advice and support

...leads to improved quality of life
Common questions

Of course the first questions include:

- why me?
- what is syncope, RAS, PoTs etc?
- what does it mean for my child, parent, husband/wife?

For those further along the ‘patient journey’ questions tend to be more specific, such as:

- Can I drive?
- Can I drink coffee?
- Can my child go on a school trip?
Common questions - RAS

➢ How do I explain the condition to my child’s teacher or siblings?
Use STARS resources and website!

➢ When will my child grow out of RAS?
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 Unpublished data shows that 75% of children ‘grow out’ of RAS at a median age of 6 years; however 1 in 4 continue to have attacks albeit less frequently.

➢ 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.
Common questions

➢ What can I do to prevent syncope attacks?
Physical actions include fluid intake, diet, salt intake, exercise, medications, posture, clothing. For others it may be recognising the triggers, reducing stress or CBT. Immediate advice may include sit down, squat, clenching exercises, lie down.

➢ Can I go on holiday?
Yes of course, but we have some practical tips for before, during and after holiday, as well as a list of insurers whom STARS has found to be sympathetic to travellers who have a heart condition.
Common questions

➢ What can increase my chance of fainting?
1. Chronic medical problems, long term problems such as diabetes, congestive heart failure, coronary artery disease, strokes and mini strokes and Parkinson’s disease. 2. Multiple medications, this may be due to part of their own action or how they affect one another

➢ Why is my syncope not being diagnosed?
Syncope is often misdiagnosed in the event of a fall because there are many risk factors for falls in older adults. People are very aware of deteriorating eye sight or ‘a knee giving way’ in older age as causes, but syncope should also be investigated as a cause of falls. It is recommended good practice that people with recurrent unexplained falls should be given a medical review.
The work of STARS

STARS **bridges the gap** between patients, healthcare professionals, and government policy makers

- Promotes accurate & rapid diagnosis and treatment
- Offers information on Syncope for all age groups
- Provides advice and continued support
NICE TLoC Guidelines 2011

Quick reference guide

Issue date: August 2010

Transient loss of consciousness

Transient loss of consciousness (‘blackouts’) management in adults and young people

Quick reference guide

NICE clinical guideline 105
Developed by the National Clinical Guideline Centre

STARS
Syncope Trust And Reflex anoxic Seizures®
The Blackouts Checklist

Features:

➢ Advice on the major reasons for experiencing a blackout

➢ Helps prepare patients for a GP appointment

➢ Provides information to patients on what to expect should they have to attend a hospital appointment

➢ New Checklist section for patients to fill out about their blackouts to take along to their doctor’s appointment
Information resource
Patient Information -
Syncope and Falls in the Elderly

Syncope Causes Falls in

What is Syncope?

Syncope is the medical term for a blackout that is caused by a sudden lack of blood supply to the brain. This is very common, and occurs in roughly half of all people during their lifetime.

There are many causes of syncope, but the most common is Reflex Syncope (also known as Vasovagal Syncope or Vasodepressor Syncope).

Fainting may be simple, where the person gently collapses to the ground usually after feeling dizzy and weak. It may be more complex when patients experience symptoms like vision changes, slurred speech, or loss of consciousness. A fall may occur with or without the sensation of fainting.

As a rule, older adults are at greater risk than younger adults, and a fall can result in a visit to the hospital or even death.

What can increase my chances of fainting?

1. Chronic Medical problems, long term problems such as diabetes, congestive heart failure, stroke, kidney disease, and Parkinson’s disease.

2. Medications, these may be due to an interaction with other medications or due to the side effect of one medication.

3. Syncope causes falls

Though it is not commonly known, syncope causes a significant amount of falls in older people. Syncope, and falls are the most common reasons for hospital visits and for emergency services.

For further information about Syncope, contact:

www.stars.org.uk
How My Heart Works

Your heart

Your heart is very special. It makes your blood flow all around the body and lungs. It is inside your body, but you can feel it working, just place your hand on the left hand side of your chest; can you feel it beating?

It continually works, even when we are asleep. Did you know your heart beats 100,000 times a day?

Your heart rate

Your heart rate is the number of times your heart beats each minute. It changes depending on what you are doing. If you are watching TV or lying down your heart rate will be slower. If you are running around and playing or you get excited, your heart rate will be faster.

How your heart works

Your heart is a muscle which pumps blood to all parts of your body. It produces its own electricity to make the muscle work.

Your heart pumps by relaxing and squeezing. When it relaxes it fills up with blood and when it squeezes it pushes, or pumps the blood out.

Your heart has two chambers in the top half, the atria (ay-tree-a) and two in the bottom half, the ventricles (ven-tri-cals).

Each side of the heart has a different job to do. The right side of the heart pumps the blood through the lungs so it can pick up the oxygen from the air. Then the left side of the heart pumps this blood around the body, brain and muscles so they can use the oxygen it carries. The blood then gets back to the right side of the heart to do all this again.
Brand new booklets

Identifying the undiagnosed person
How mobile devices can make a difference

Which ECG is Right for You?
Implanted Devices - Infection

Did the wound become infected?

- Yes (14.90%)
- No (85.10%)

5.4% of those surveyed had their devices removed and re-implanted in another position.

28.5% out of those had an infection after their second implant.

Mobile ECG Devices

Just 8% were provided the device by their cardiologist or other specialist at the hospital.

And 83% purchased the device themselves.

3 out of 4 doctors used the results to make a diagnosis.

www.stars.org.uk
STARS Medical Advisory Committee

➢ STARS work is guided by a multidisciplinary medical advisory committee

➢ Committee comprises a panel of international medical experts made up of Cardiologists, Electrophysiologists, Geriatricians, Paediatricians, GPs, and Neurologists

➢ Committee acts as an advisory, support and management committee to STARS
Resources for healthcare professionals

➢ Care pathways

➢ STARS ‘Heart of Syncope’ website
  www.heartofsyncope.org.uk
  (in development)

➢ Syncope symposium at Heart Rhythm Congress

➢ Syncope specialists database
STARS Care Pathways

• Arrhythmia Care Coordinator (ACC)
• Point of Care A&E
• Point of Care Ambulance Service
• Management of child presenting with Transient Loss of Consciousness (TLoC)
• Point of Care GP (&OOH)
• Point of Care – Rapid Access to Blackouts Clinic

www.stars.org.uk
Provides advice and support through...

Channels:

➢ Patient helpline
➢ Website [www.stars-international.org](http://www.stars-international.org)
➢ Newsletters
➢ Educational videos
➢ Social media – active Facebook & Twitter and message forums
➢ Patient and professional meetings
➢ STARS Patients Day & Regional Meetings
Awareness campaigns

- Syncope and Falls awareness
- Take Fainting to Heart
- Syncope Education in Schools
- Know Your Pulse

Top tips to prevent faints:

1. Increase fluid intake
2. Counter Pressure Maneuvers
3. Exercise
4. Avoid excess carbohydrates
5. Review medication

Experiencing unexplained falls or blackouts?

One in ten falls in elderly people are caused by syncope (faints)

Prevention and treatments are available

Helpline: 01769 450 564

www.stars.org.uk

Know Your Pulse

IT COULD SAVE YOUR LIFE

www.knowyourpulse.org

STARS
Syncope Trust And Reflex enoxic Seizures

www.stars.org.uk
Impact of STARS – Outcome of real stories

“I phoned the support group 'STARS' and we were signposted to a professional with an interest in syncope.

Following Ella’s diagnosis of syncope and treatment she is now back dancing, horse-riding and swimming”.

Adi (Daughter Ella diagnosed with syncope)

“Jenni (STARS) signposted us to a paediatric cardiologist at Southampton Hospital who had an interest in RAS, and sent me The Blackouts Checklist to take with us to our GP.

We then went back to the hospital and we were commended by the team for throwing the Epilim away. The results of the heart memo confirmed Georgie’s diagnosis of RAS.”

Holly (Daughter Georgie diagnosed with RAS)
Education, support and accurate treatment leads to improved quality of life
There is no such thing as a simple faint...

The astonishing moment a man suddenly collapses and flips off a station platform and onto the tracks - before hero commuters rush to save him from an oncoming train

- The man stumbled toward Sydney’s Wynyard station and appeared to faint
- A customer service officer signalled for the train to stop as it approached
- Six members of the public rushed to the unconscious man’s aid
- Sydney trains discourages running to help because a live track is dangerous
Getting to the heart of fainting

STARS: Getting to the heart of fainting

There is no such thing as a simple faint – there is always an explanation and, if the work of Syncope Trust And Reflex anoxic Seizures (STARS) is anything to go by, that explanation could be because of an underlying arrhythmia (heart rhythm disorder). For Trudie Lobban MBE, CEO of STARS, she understands this better than anyone. With syncope (fainting) a condition that has affected her family for many, many years. After seeing her daughter seemingly losing consciousness from the age of ten months, and with seemingly no explanation as to why, she founded STARS to build a collaboration of patients, carers, healthcare professionals and policy makers – aiming to spread the word and reduce misdiagnosis.

If you have ever fainted and thought it was nothing, you could be mistaken, you could have an underlying arrhythmia (heart rhythm disorder) called Syncope. Trudie Lobban MBE, Founder and CEO of Syncope Trust And Reflex anoxic Seizures (STARS) understands this better than anyone, anyone is a condition that has affected her family for many years.

Fortunately, through the tireless work of Trudie Lobban MBE and her team of medical experts at STARS, these disorders are becoming more and more recognised and diagnosed thereby saving countless lives.

Starting at Trudie’s kitchen table back in 1993, STARS has grown from strength to strength over the years and, with the likes of Dr Elston and the late Dr Roger Mount, acting as celebrity patrons, the success looks set to continue. We spoke to Trudie about STARS recent accomplishments and discussed why common issues such as fainting are so close to her heart.

Hi Trudie! Can you tell us about your personal experiences with your daughter as a sufferer with syncope? It led to the foundation of STARS.

When my daughter was ten months old, she passed out in front of me and I rushed her to the doctors, but they said it was nothing to worry about. However, her loss of consciousness started happening regularly, up to eight times a day, which was both frightening and frustrating. The doctors couldn’t tell me what was causing it – she was fine.

39% of children and 30% of adults with epilepsy are wrongly diagnosed. They are not epileptic – they frequently have an underlying arrhythmia (heart rhythm disorder).
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My word is my Bond

& there is no such thing as a simple faint

Sir Roger Moore
1927-2017
HRC Heart Rhythm Congress

7-10 October 2018
International Convention Centre (ICC) Birmingham UK

www.heartrhythmcongress.org  info@heartrhythmcongress.org.uk