Improving the syncope pathway from a Patient Perspective

Trudie Lobban MBE FRCP (Edin), Founder and CEO
Developing an Effective Syncope Service
• What do patients face?
• What do patients want?
• How can the patient experience be improved?
Problems patients face

- Misdiagnosis
- Long waiting times for appointments
- Lack of awareness
- Lack of understanding
- Psychological impact of blackouts

"I was blacking out ten times a day and didn't know why."

'I kept blacking out'. Ella's condition had doctors baffled

Jane tells of mystery illness

'I am NOT a drunk': Teenage girl has rare fainting condition which means she collapses after 30 minutes of standing

Lincolnshire mum of four battling a fainting disorder to help charity

STARS helped Abi, 4, receive correct diagnosis

Man whose heart stopped beating 817 times in a single month, and why TV presenter Matt's story is a dramatic warning to us all

When even a simple walk outside can result in fainting, the world can seem a dangerous place. But for one Moray woman who can collapse up to three times a day, it is now just a horrible fact of life
What the clinician says

“I see patients in my clinic who are at the end of their tether, lost and discouraged; they might have been pushed from pillar to post after an incorrect referral to a psychiatrist by their GP.”

- Arrhythmia Care Coordinator, Sheffield Teaching Hospitals NHS Trust
Learning from the patient perspective

STARS has learned that patients need:

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

...which should bring an improved quality of life
The system that patients face...

- Tens of thousands of patients churning in the healthcare system not properly diagnosed
- Thousands treated but no support mechanism
The challenge of effective diagnosis: the facts

• Syncope has a lifetime risk estimated at 39% and it affects women (47%) roughly twice as frequently at men (24%)

• Misdiagnosis – accurate diagnosis is often not achieved
  Each year around 40% of patients with epilepsy are misdiagnosed and around 60% of these have been found to have syncope

• Non-diagnosis – timely diagnosis is not often reached
  50% of patients with T-LoC leave hospital without a diagnosis
Threats in primary and secondary care

• Syncope is poorly investigated and diagnosed
• Uninformed GPs who are dismissive
• Lack of awareness of syncope by A&E
• Shortage of heart rhythm specialists
• Recognition by geriatricians that not all falls in the elderly are due to ill-fitting slippers and tripping on a mat!
• Recognition by medical professionals that syncope is a debilitating condition that should be addressed and not dismissed
Support from STARS

STARS provides information on the diagnosis, treatment and management of syncope for all age groups

- Checklists
- Information booklets
- Information sheets
- Posters
- Online resources
- Patient meetings
- Blackouts app
FINALLY I KNOW WHAT IS WRONG WITH ME

Three years ago I had a brilliant job that I loved but because of my falls and other symptoms I was accused of having a drinking problem by people who would gain financially if my reputation was damaged. Although the allegation was completely without foundation we could not find a doctor who could explain why I fell so often without warning. I thought I was going insane. Finally, I was made redundant despite the support from clients and friends who knew me well and, of course, my wonderful husband of 35 years.

"Not once was I ever referred to a cardiologist."

We finally found out what was wrong in January, the week I turned 60. Just before Christmas I was riding my bike along the Thames path from Barnes to Putney. I fell off my bike to cross at the pedestrian crossing to go into Richmond Park. The next thing I remember was lying on the road surrounded by people. I was helped up and someone wheeled my bike over to the gates. I thanked my helpers then got back on my bike and rode the four kilometres home.

When I got home I told my husband. He said he had had enough of these falls and that he would go to the doctor with me. We have been at this practice for almost 20 years although I had always seen other doctors not my husband's GP. I had been suffering from severe vertigo from time to time and awful visual disturbances, weakness, tiredness, inability to climb stairs and nausea which was very distressing. On several occasions I had been rushed to hospital only to be told there was nothing wrong or that I had a virus.

I was referred to neurologists, ENT consultants, audiology department and asked for CAT scans. I was suffering from "migraines without headaches"! I think this is a medical shorthand for "neurotic woman". I had a very high profile job, was regularly interviewed in the media and, as an expert witness in international courts, I had to remain calm and collected at all times. That is difficult if you fall over without warning. My colleagues had teased me about falling off my beautiful Christian Louboutin shoes but I knew my shoes were not the cause. More often than not I fell when I was standing still. I thought I was clumsy.

"More often than not I fell when I was standing still. I thought I was clumsy."

The visit to my husband's GP was a revelation; I can't help but believe all women should take their husbands to the doctor with them. Finally someone took me seriously. After hearing my story he said I wanted to keep all my records and that I should come back the next day. We did and he referred me to a cardiologist and advised me to stop taking the beta blockers. He said "I think you have syncope".

Experiencing unexplained falls or blackouts?

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

Prevention and treatments are available

By investigating unexplained blackouts appropriate treatment can be given to prevent further falls

Helplines: 01780 480 564
www.stars.org.uk

STARS
Syncope Trust And Reflex anoxic Seizures

www.stars-international.org

Arrhythmia Alliance
The Heart Rhythm Charity

www.aa-international.org
How to achieve change...
Raising public awareness of syncope

- STARS aims to ensure that anyone with unexplained loss of consciousness receives timely and accurate diagnosis, effective treatment, support and signposting to an appropriate medical professional.

- Our work is guided by a multidisciplinary medical advisory committee. The committee comprises a panel of international medical experts, including cardiologists, EPs, geriatricians, paediatricians, GPs and neurologists.

- Empowering patients with the STARS Blackouts Checklist.
Supporting Healthcare Professionals

- The establishment of Rapid Access TLoC Clinics, including syncope and PoTS

- Scientific syncope agenda at the annual Heart Rhythm Congress, which has a footfall of over 3000 delegates across three days

- Awareness campaigns on syncope and heart rhythms
  - Syncope and Falls in the Elderly (SaFE)
  - Take fainting to heart
  - Syncope education for schools (DVD)
  - Know Your Pulse
Improving the patient journey – the STARS experience

What do patients want?

• Improved understanding
• Greater awareness
• Information and empowerment
• Support and reassurance
• A multidisciplinary approach to investigation of T-LoC
STARS helps patients through their treatment journey

- **Patient support**
- **Helpline** - providing advice, guidance and continued support
- Information **resources** on syncope, reflex anoxic seizures and postural tachycardia syndrome for all ages
- Signposting to **heart rhythm specialists**
- Online **forums**: Facebook, Twitter and HealthUnlocked
- Sharing **stories**
- Annual **Patients Day** and an opportunity to meet and listen to international specialists
- **Bi-annual newsletter** and **monthly eBulletins** keep our syncope patients informed on current information, medication and guidelines
Invaluable support needed

- Syncope is poorly investigated and diagnosed
- It remains unexplained in about 35% of causes
- 50% of population are affected by syncope at some stage of their life
- 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 are due to syncope
- 23% of elderly in nursing homes
- Impact on daily life is immense

Provide access to a dedicated blackout clinic to improve care journey...

Blackouts clinics present clear benefits to patients:

- **Clear referral pathway** – less misdiagnosis
- **Thorough and appropriate investigations** – fewer emergency hospital admissions
- **One point of access** – speedier journey along the pathway and greater patient satisfaction
Education, support and accurate treatment leads to improved quality of life...
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