STARS

Syncope Trust And Reflex anoxic Seizures™

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STARS HEALTHCARE PIONEERS REPORT

SHOWCASING BEST PRACTICE IN SYNCOPE 2020

In memory of Dr Adam Fitzpatrick

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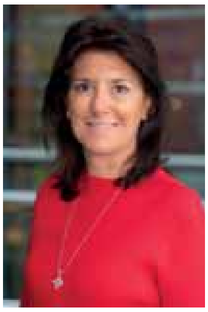
UK Registered Charity No. 1084898

FOREWORD



Trudie Lobban

TRUDIE LOBBAN MBE, FRCP (Edin)
Co-Founder & CEO, STARS

PROF. RICHARD SUTTON,
STARS Medical Advisory Committee Member

In order to encourage excellence in syncope care, STARS is proud to launch the Syncope Healthcare Pioneers Report comprising of case reports illustrating innovations and quality in the care of syncope patients. It is anticipated that this report will continue in years to come. The STARS Syncope Healthcare Pioneers Report is in honour of Dr Adam Fitzpatrick who sadly passed away early this year. His work on syncope and arrhythmias has been outstanding.

In 2000, Adam met Trudie Lobban MBE, who had founded STARS (Syncope Trust And Reflex anoxic Seizures), and together they achieved a great deal including constructing the Blackouts Checklist which was launched by Sir Roger Moore, Patron of STARS. Its value was to enhance the patient consultation by prompting conversation between the patient and consultant. It also prompts the doctor to seek answers leading to a correct diagnosis. This checklist was the first of its kind. Following the success of STARS Blackout Checklist, Adam founded a 'Rapid Access Blackout Clinic' in Manchester, the first anywhere in the world. Patients could be referred and seen in less than two weeks, thereby reducing long waiting times, misdiagnoses and even sudden cardiac death from undiagnosed cardiac arrhythmia. This concept has now been widely adopted and has improved outcomes for these patients.

Adam and Trudie were also successful in 2004, by pressing for an additional chapter to National Service Framework on heart disease in the NHS to include arrhythmias. This was followed by establishment of the Arrhythmia Alliance charity of which Adam was a founding Trustee, and three years later the patient-oriented AF (Atrial Fibrillation) Association was launched. Adam had remained as chairman of the Medical Advisory Committee of STARS, as well as being Medical Director & Trustee of the Arrhythmia Alliance and member of the AF Association Medical Advisory Committee.

Adam strived for perfection and always put the patient first. His dedication to the STARS community and to improving patient outcomes was always paramount in everything he did. Thus, this new activity of STARS is thought to be a proper tribute to Adam's great achievements, once again to the benefit of patients.

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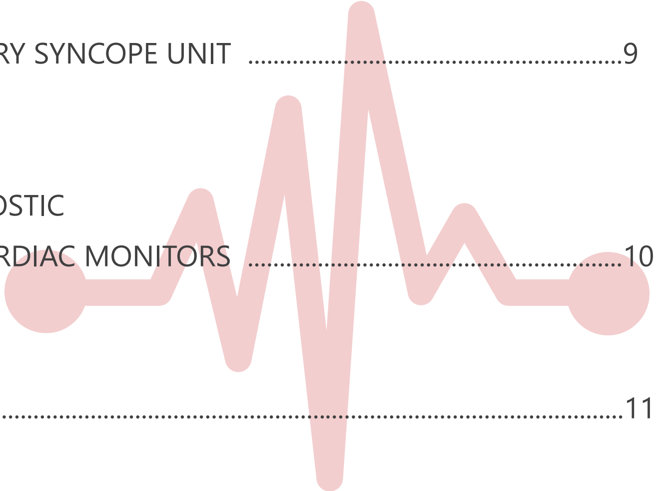


ATOMOXETINE FOR THE PREVENTION OF VASOVAGAL SYNCOPE: A NEW AND EMERGING THERAPY

Dr Satish R Raj MD MSCI, Lucy Lei BSc, Professor Robert S Sheldon MD PhD
LIBIN CARDIOVASCULAR INSTITUTE OF ALBERTA, DEPARTMENT OF CARDIAC SCIENCES, CUMMING SCHOOL OF MEDICINE, UNIVERSITY OF CALGARY, CANADA

BACKGROUND: There are few effective therapies for vasovagal syncope (VVS). Pharmacological norepinephrine transporter (NET) inhibition increases sympathetic nervous system tone and decreases tilt-induced syncope in healthy subjects. Atomoxetine is a potent, and highly selective NET inhibitor. We tested the hypothesis that atomoxetine prevents tilt-induced syncope. We also report on an open-label experience with atomoxetine in patients with frequent VVS.

METHODS & RESULTS: We designed and conducted a proof-of-principle, randomized, placebo-controlled trial of the efficacy of atomoxetine to prevent VVS on tilt tests. VVS patients (n=56; 35±14 years [73% F]) underwent tilt testing having received either atomoxetine 40 mg x 2 doses, or placebo. Continuous non-invasive beat-to-beat blood pressure monitoring allowed us to assess the mechanism of atomoxetine's efficacy. Fewer VVS patients fainted with atomoxetine than with placebo 10/29 vs. 19/27; p=0.012 (Figure left). The benefit of atomoxetine was not due to an effect on vascular resistance or on stroke volume, but to preserve blood pressure by preventing bradycardia, in turn preserving cardiac index. Atomoxetine basically prevented cardioinhibitory (VASIS 2B) syncope. NET inhibition significantly decreased the risk of tilt-induced syncope in VVS subjects by blunting reflex bradycardia, and maintaining cardiac index and blood pressure.

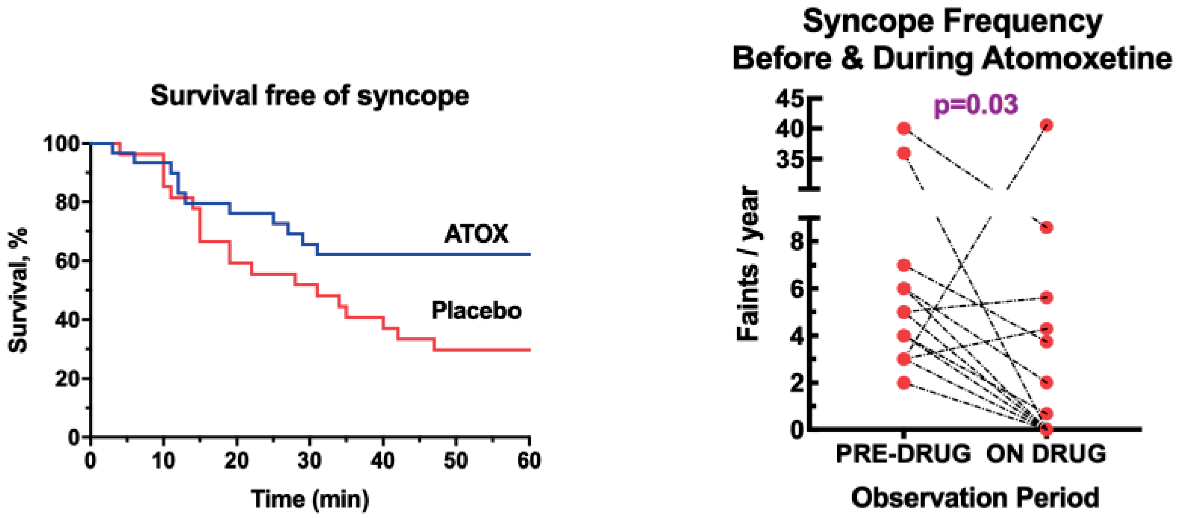
Following the tilt-based study, we have started using off-label atomoxetine in some of our refractory VVS patients. Atomoxetine 60-80 mg daily. To date, 13 VVS patients (8F; median 56.5 yr) have been treated, with a decrease from a median of 4.5 faints/yr PRE-atomoxetine to a median of 0.34 faints/yr WITH-atomoxetine. As seen in the Figure (right), 10 patients were "responders".

CONCLUSIONS: We conclude that atomoxetine seems to be a very promising medication to prevent VVS. These findings need to be confirmed in a placebo-controlled randomized control trial.

Figure Legend:

Left: Survival free of syncope in patients in the atomoxetine (ATOX) and placebo arms during drug-free tilt table testing.

Right: Open-label atomoxetine deceased the burden of clinical vasovagal faints in 9 of 13 VVS patients.



INTRAVENOUS GAMMAGLOBULIN THERAPY FOR THE TREATMENT OF RECURRENT SYNCOPE DUE TO SEVERE REFRACTORY POSTURAL TACHYCARDIA SYNDROME

Professor Blair P Grubb MD FACC FAHA
COLLEGE OF MEDICINE AND LIFE SCIENCES, OHIO, USA

CASE STUDY:

A 33-year-old woman was well until two months prior to presentation, when she developed a severe febrile upper respiratory tract infection.

Shortly thereafter she began to experience episodes of lightheadedness, near syncope and syncope. Over the next several weeks she began to experience syncope every time she attempted to stand. She was admitted to a local hospital and it was documented that upon standing, her heart rate would go from 70 bpm to 170 bpm beats per minute while at the same time her blood pressure would fall from 110/70 mmHg to unobtainable levels, at which time she would lose consciousness and display convulsive activity.

She did not respond to midodrine, droxidopa, fludrocortisone, pyridostigmine, octreotide nor erythropoietin. She was then transferred to the University of Toledo Medical Center where she was thought to have severe postural tachycardia syndrome, most likely due to an auto-immune process.

She thereafter underwent therapy with intravenous gammaglobulin. Within a week, for the first time in over a month, she was able to sit up in a chair without losing consciousness. Intravenous gammaglobulin therapy was continued on a biweekly basis while at the same time she underwent inpatient physical therapy and rehabilitation.

By the time of discharge, she was able to walk for the first time in months without losing consciousness.
This case illustrates the potential autoimmune basis of some patients suffering from syncope due to Postural Tachycardia Syndrome, as well as the potential role for immune modulating therapy as a treatment modality.

INTRODUCTION OF THE SYNCOPE GUIDELINES AND SETTING UP A DEDICATED SYNCOPE SERVICE IN A UNIVERSITY TEACHING HOSPITAL NHS TRUST

Dr Mehran Asgari MD
WIRRAL UNIVERSITY TEACHING HOSPITAL NHS FOUNDATION TRUST, MERSEYSIDE, UK

INTRODUCTION: Syncope is the cause of non-traumatic Transient Loss of Consciousness (TLoC) that is typically characterised by its short duration, abnormal motor control, loss of responsiveness and amnesia for the period of TLoC. It is a global problem with an estimated lifetime incidence of 20%. It can often pose a significant diagnostic and management challenge to the physician.

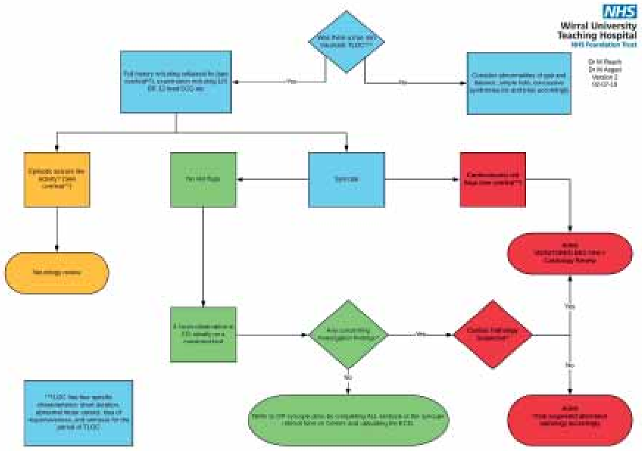
Admission rates vary between 28% to 76% in some studies. We recognised that no structured guideline was being applied to the patients presenting with syncope in Wirral University Teaching Hospital NHS Foundation Trust, which serves a population of around 333,000, with annual ED (emergency department) admission rate of 75,784 in 2017-18. A retrospective study confirmed the clear evidence of delay to the diagnosis, prolonged inpatient stays, unnecessary and often costly investigations.

AIMS: We therefore set up a working group including specialists in ED, Acute Medicine, Stroke, Cardiology and Primary Care to write the first syncope guidelines for the Trust. We reviewed the syncope management programs in several centres including UK, North America and Italy. We also set up a dedicated outpatient syncope clinic to see the non-urgent cases upon discharge from ED.

SERVICE DESCRIPTION: After several meetings with various stakeholders, the first syncope guidelines for the Trust finally became available on the hospital intranet. Red flag features which require patient admission are clearly defined for the physicians in the guidelines. When the patient is found to be safe to discharge - mostly on the same day, a simple syncope referral pathway is filled in and the completed form is sent to the “syncope expert” who will in turn facilitate the relevant outpatient investigations and timely patient follow up in a dedicated syncope clinic.

Syncope management can be complex and thus education of the physicians has been found to be inadequate. We have been therefore organising regular educational meetings, including “The North West STARS Syncope Symposium” with the target audiences of specialist doctors, nurses and other healthcare professionals.

As we are currently auditing the new service, short term results in terms of avoiding multi-specialty referrals, and reduction in the number of unnecessary test requests become apparent. We feel that the front line doctors are seeing syncope patients with more confidence now. Application of the syncope guidelines is helping to identify patients for a safe discharge without the need for prolonged stay. This has certainly helped the “patient flow” whilst we face increased pressure on hospital beds.



YOUNG PATIENTS WITH SYNCOPE

Professor Richard Sutton and Dr Phang Boon Lim

HAMMERSMITH HOSPITAL, SYNCOPE UNIT, IMPERIAL COLLEGE HEALTHCARE NHS TRUST, UK

ABSTRACT: Female, 16 years old, presented frequent syncope. Tilt-testing: vasovagal (VVS) tendency, excessive heartrate. Diagnoses: VVS, psychogenic pseudo-syncope, postural orthostatic tachycardia. Ivabradine and close supportive follow-up completely resolved symptoms.

INTRODUCTION: Presentation of syncope is never simple, requiring diligence in history-taking and analysis of the case.

SERVICE: Our service aims to provide full clinical care of syncope including diagnosis and therapy.

CASE: A schoolgirl aged 16 presented syncope up to six per day seriously affecting her school attendance including sport being disallowed. A neurologist had already eliminated epilepsy.

Treatment with fludrocortisone 100mcg/day had no effect. Full history revealed no additional information except that she claimed that she enjoyed school but was approaching exams. Physical examination, supine/erect blood pressure and ECG normal.

Tilt-testing showed a panoply of findings (see image below).

A vasovagal (VVS) tendency was revealed from the BP oscillation and it was considered by the staff that syncope was imminent. The heart-rate changes are compatible with postural orthostatic tachycardia (PoTS) but the patient had no other features of this condition. The frequency of syncope suggested psychogenic pseudo-syncope (PPS). Thus two diagnoses were made PPS and VVS.

Her condition was discussed with her and her family. It was agreed that she would take Ivabradine 5mg daily increasing in 2 weeks to 5mg twice daily. She had close and supportive follow-up with the full benefit of education about both VVS and PPS. She had no side-effects of medication. Her symptoms subsided progressively. Her school attendance increased back to normal. Syncope ceased. After six months treatment it was possible to phase it out over a further six months. She again took up sport with success for her school. She passed her exams with credit.

IMPLICATIONS OF THIS CASE:
Frequent syncope is very often PPS but its origin is usually VVS so both conditions exist together and evidence of this can be seen on tilt-testing. Even a diagnosis of PPS does not require a referral to a Psychiatrist as close supportive care based on patient education and empowerment can achieve excellent results. Not every patient with excessive heartrate on tilt has PoTS.

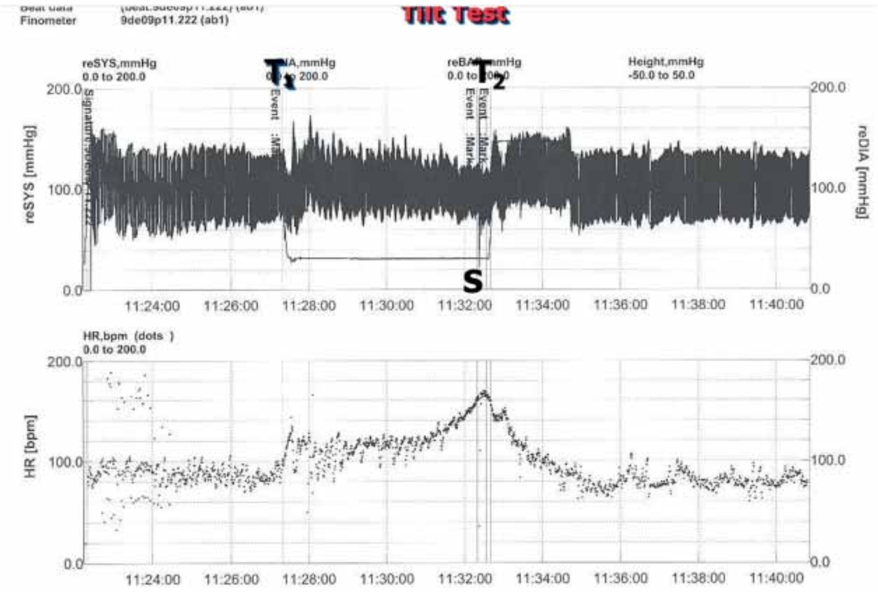


IMAGE: TILT-TEST
The Tilt-test shows a resting heart rate of 95bpm. On tilt-up (T1) heart rate increases to 120 bpm for 4 minutes rising again to 170bpm as symptoms of distress and pre-syncope occur (S). During tilt marked oscillation of blood pressure (BP) is shown; on commencement of symptoms BP falls but only to 115 systolic from a maximum of 150. Tilt-down (T2) is conducted on basis of symptoms. No syncope.

STREAMLINING THE SYNCOPE CARE PATHWAY THROUGH A MULTI-DISCIPLINARY BLACKOUT SERVICE

Jayne Mudd, Professor Nick Linker & Dr Andrew Turley
THE SOUTH TEES BLACKOUT SERVICE, UK

INTRODUCTION: The South Tees Blackout Service was established in 2010 and provides rapid, standardised clinical assessment and management for patients experiencing Transient Loss of Consciousness (TLoC).

The service is delivered across two sites by nurses specialising in cardiac rhythm management and epilepsy with same day access to a consultant neurophysiologist and cardiologists. Close liaison with the emergency department (ED), falls team, elderly care and psychogenic services are integral. Referrals are both triaged and seen by specialist nurses within two weeks of referral.

The service offers a nurse-led implant and explant service for implantable loop recorders (ILR) including follow up via remote monitoring systems. Referral sources include ED, general practice and in-patient specialities. Monthly multidisciplinary team meetings allow for complex case review whilst providing a platform for education.

NHS
South Tees Hospitals
NHS Foundation Trust

CASE STUDY

- 62 year old gentleman with a history of diabetes, ischaemic heart disease and asthma presents to emergency department with sudden, no warning blackout. Two episodes in three months with significant facial injury sustained. Referral made to blackout service and patient discharged.
- Nine days later: Blackout clinic, clinical assessment by the nurses, witness account obtained. Examination: unremarkable, Active stand: no significant postural drop in BP, ECG, 72 hour holter – no arrhythmias identified. Transthoracic echocardiogram: mildly impaired LV function.
- Discussed with cardiologist and recommendation for ILR made. ILR implanted by nurses seven days from initial assessment in blackout clinic. Patient monitored via remote monitoring service - checked daily by the nursing team.
- 94 days later: Automated event via remote monitor demonstrates a 12 second ventricular pause. Patient contacted immediately by the nurses and confirms another sudden no warning blackout that correlates with the automated event. Discussed with cardiologist on the same day and listed for permanent pacemaker implant.
- 25 days later: Permanent pacemaker implant performed. On-going care provided through the pacing clinic.

RESULTS: Audit pre and post service demonstrates significant reductions in a number of outcomes: wait for first assessment, diagnosis and treatment times. Hospital admissions for TLoC were reduced from 64 to 23 per month. Diagnostic yield increased from 10% to 17% following introduction of the nurse-led ILR service.
72% of patients receive diagnosis at first appointment.
99% of patients reported high levels of satisfaction.

CONCLUSION: The multi-disciplinary service allows for prompt access to appropriate specialists enabling provision of high quality care through a standardised approach to investigation and management.
Investigations are appropriate and kept to a minimum.

HOW TO DIAGNOSE THE UNDIAGNOSED IN A TERTIARY SYNCOPE UNIT

Dr Frederik J de Lange MD PhD
AMSTERDAM UNIVERSITY MEDICAL CENTER, THE NETHERLANDS

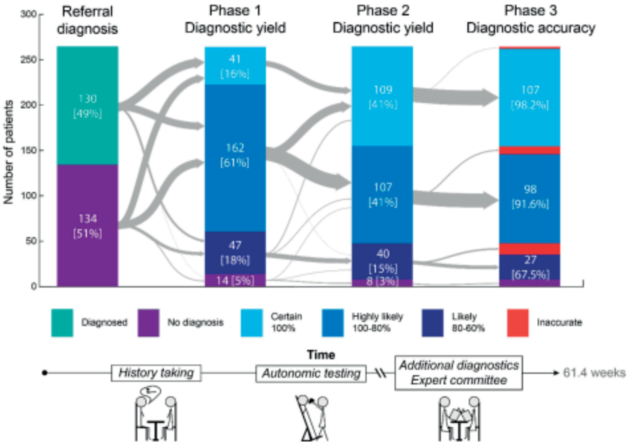
BACKGROUND: Patients with syncope often remain undiagnosed and untreated. As syncope is a symptom with potentially lethal as well as benign causes, it is important to make a diagnosis. However, due to specialization and subsequent fragmentation in secondary care, physicians often fall back on ruling out causes in their own field. In addition, the most prevalent cause of syncope; reflex syncope, has not been claimed by any specialty. This results in a low diagnostic yield and lots of untreated patients. The yield in emergency departments and secondary care hospital-wide has been studied, and is highly variable. The diagnostic yield of a tertiary syncope unit has yet to be determined. We assessed for the first time the diagnostic yield, accuracy, and safety of a tertiary syncope unit with a dedicated structured approach of three diagnostic phases.

METHODS: Consecutive syncope patients presenting to our tertiary syncope unit were included. The consultation consisted of phase-1: history taking followed by phase-2: autonomic function testing. After each phase-1 and phase-2 a diagnosis was made and the physician's subjective probability of the diagnosis was recorded: certain (100%), highly likely (80-100%) and likely (60-80%). The diagnostic yield was defined as the rate of patients that received a certain, highly likely and likely diagnosis after both phase-1 and phase-2. Phase-3 consists of critical follow up by a multidisciplinary expert committee reviewing the Phase-1 and Phase-2 diagnoses by protocol. This critical follow up was used as a gold standard to assess the diagnostic accuracy and safety. During Phase-3, patients filled in a questionnaire after 3-6 months and after 1-1.5 years, assessing the number of recurrences, changes in treatment, outcomes of testing, and changes in diagnoses.

RESULTS: 264 patients were included. Mean age was 51y (IQR: 34-64y), patients experienced six (IQR: 3-20) life-time syncopal episodes and three (IQR: 1-6) episodes last year. Patients underwent a median of 11 diagnostic tests and consulted a median of 6.5 specialists before the syncope unit consultation. Prior to consultation 134 patients still did not have a suggested diagnosis of the referral physician. After history taking in tertiary SU, 250 out of 264 (94.7%) patients were diagnosed. Autonomic testing yielded six additional diagnosis after Phase-1, did not change the phase-1 diagnosis but increased the subjective probability of the physician (Figure). After phase-3 the overall accuracy of the tertiary diagnoses appeared to be 90.6% compared with diagnostic accuracy of 47% of the referral physician in the secondary care. No cardiac syncope was missed. Three patients were diagnosed with epilepsy after follow-up whom all were seen by neurologist.

CONCLUSION: A tertiary syncope unit has a high diagnostic yield with a high accuracy, and is safe. Patients underwent many tests prior to the consultation of the tertiary syncope unit resulting in a low yield by the physician in secondary care. History taking is the most important diagnostic tool as additional autonomic testing tailored on history taking, 1) did not change the phase-1 diagnosis after history taking but increased certainty of the diagnosis 2) increased yield in patients with unexplained syncope after history taking. This study emphasizes the need for taking time for thorough history taking in case of highly complex patients with unexplained syncope. Earlier referral to a syncope unit may result in a shorter time to the correct diagnosis with less costs. Accuracy by an expert committee should be assessed in every study focussing on diagnosing patients with transient loss of consciousness, although this is seldom done currently.

LEGEND Figure: The diagnostic yield and accuracy of Phase 1 (history taking) and Phase 2 (autonomic function testing) in a tertiary syncope unit sorted by physician's certainty of the diagnosis (level of subjective probability). Phase 3: follow-up with expert committee. Grey arrows indicate patient flow. Thickness of arrows indicate relative number of patients.



UNEXPLAINED SYNCOPE IN AGING PATIENTS: DIAGNOSTIC PERFORMANCE OF TILT TESTS AND IMPLANTABLE CARDIAC MONITORS

Professor Robert S Sheldon MD PhD, Roopinder Sandhu MD MSc, Dr Satish R Raj MD MSCI

LIBIN CARDIOVASCULAR INSTITUTE OF ALBERTA, DEPARTMENT OF CARDIAC SCIENCES, CUMMING SCHOOL OF MEDICINE, UNIVERSITY OF CALGARY, CANADA

BACKGROUND: Syncope in aging patients is common, leads to admissions to emergency departments and hospitals, triggers expensive investigations, and has a persistently high inability to establish a diagnosis. Partly this is due to uncertainty about how to proceed with investigation.

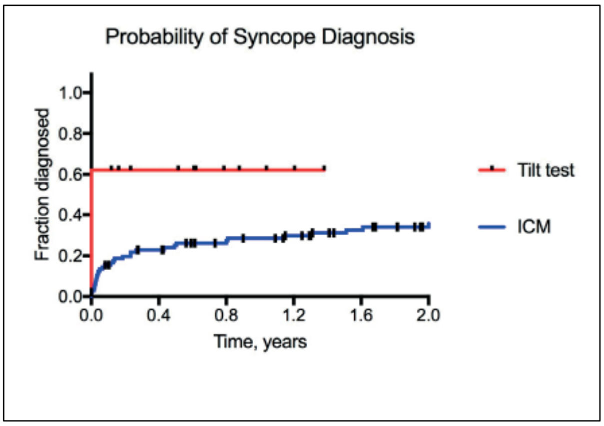
There are two competing diagnostic techniques; implantable cardiac monitors (ICMs) and headup tilt tests (HUT), and international guidelines are silent about which to perform first. Two early randomized studies reported the diagnostic yield of an early ICM strategy compared to conventional testing. RAST and EASYAS2 were conducted 15-25 years ago and used technology no longer current, and neither one randomized patients to HUTs versus ICMs. RAST had a positive HUT rate of 8.6%, far below representative rates then or now. The English EASYAS2 study had a primary outcome based on ECG documentation and used a device no longer marketed.

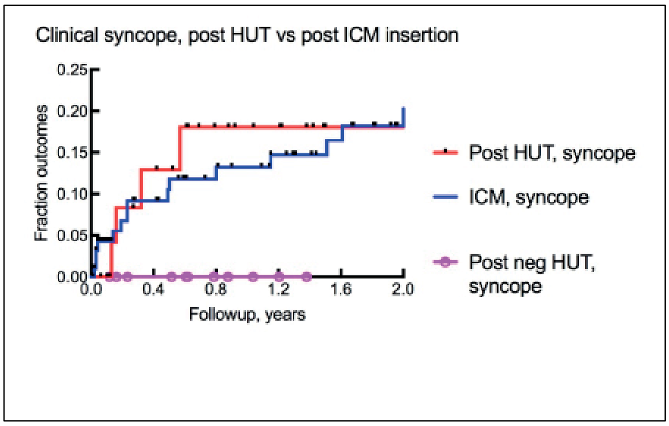
METHODS & RESULTS: We examined the diagnostic outcome rates for syncope patients >50 years old in the Calgary Syncope Clinic for ICMs (n=98) since June 2006 and HUTs (n=29; Italian protocol) since August 2017. The two groups had the same mean age (69 years), sex distribution (40% women), and median number of faints in the previous year (one). The primary outcome of both tests was syncope or clinically reminiscent presyncope. HUTs were positive in 62% (95% CI 44, 77%), and ICMs yielded a diagnosis in 29% of patients after one year and 35% after two years (see figure, left panel). The median times to a diagnosis by HUT and ICM were one day and 2.8 months, respectively. The patients were followed after diagnosis to assess safety and syncope recurrence in each strategy. Our preliminary data (see figure) suggest that syncope recurs in the HUT arm at the same rate that it occurs in the ICM arm. In this small and selected population, the recurrence rate following a negative HUT is very low.

These data suggest that the current understanding that early ICM compared to HUT provides more and earlier diagnoses may be incorrect.

CONCLUSIONS: A strategy of first performing a tilt test to diagnose the cause of syncope in older patients appears to provide an earlier, higher diagnostic rate implanting an ICM. A randomized controlled pragmatic pilot trial (POST 8) is underway.

FIGURE LEGEND: Left, probability of making a diagnosis of syncope in HUT or ICM arms; right, probability of a first clinical faint in HUT or ICM arms.





The Blackouts Checklist

The Blackouts Checklist was prepared under the guidance of STARS' expert Medical Advisory Committee. Its principal aim is to help you and your doctor reach the correct diagnosis for any unexplained loss of consciousness (blackout).

The Checklist gives you information and advice on the major reasons for experiencing a blackout, helps you prepare for a doctor's appointment, and provides information on what to expect if you have to attend a hospital appointment.

CHECKLIST: **What do you need to know?**

☑ **A blackout is a temporary loss of consciousness**

If someone loses consciousness for a few seconds or minutes, they are often said to have had a blackout.

☑ **There are three major reasons for why people may experience a blackout(s):**

- **Syncope: a sudden lack of blood supply to the brain.** Syncope is caused by a problem in the regulation of blood pressure or by a problem with the heart.
- **Epilepsy: an electrical 'short-circuiting' in the brain.** Epileptic attacks are usually called seizures. Diagnosis of epilepsy is made by a neurologist.
- **Psychogenic blackouts: resulting from stress or anxiety.** Psychogenic blackouts occur most often in young adults. They may be very difficult to diagnose. 'Psychogenic' does not mean that people are 'putting it on'. However, there is often underlying stress due to extreme pressure at school or work. In exceptional cases it may be that some people have experienced ill treatment or abuse in childhood.

☑ **Every patient presenting with an unexplained blackout should be given a 12-lead ECG (heart rhythm check)**

It is important that the ECG is passed as normal.

☑ **Witness information is vital for the evaluation of blackouts**

Make sure a witness (family or friend) who has been with you during a blackout or fall is present during any meeting with a doctor.

☑ **Most unexplained blackouts are caused by syncope**

But much more commonly they are due to syncope (pronounced sin-co-pee) – a type of blackout which is caused by a problem in the regulation of blood pressure or sometimes with the heart. Up to 50% of the population will lose consciousness at some point in their life due to syncope. Syncope can affect all age groups but the causes vary with age, and in older adults multiple causes often exist.

☑ **Many syncopal attacks only require reassurance from your GP**

Many syncopal attacks require only explanation and reassurance from a GP or trained nurse regarding the likely absence of anything being seriously wrong. Consultation with a specialist will be necessary, though, if the cause of the syncope remains uncertain or if there are particularly concerning symptoms or there is a family history of a heart condition. Also, if the blackouts happen on several occasions, you may be referred to a specialist.

☑ **Misdiagnosis is common but avoidable:**

- Many syncopal attacks are mistaken for epilepsy.
- However, epilepsy only affects slightly less than 1% of the population.
- UK research has shown that approximately 30% of adults and up to 40% of children diagnosed with epilepsy in the UK do not have the condition.
- Many elements of a syncopal attack, such as random jerking of limbs, are similar to those experienced during an epileptic seizure.
- It can be difficult to tell the causes of the blackout apart.

☑ **Syncope causes falls:**

- Syncope causes a significant number of falls in older adults, particularly where the falls are sudden and not obviously the result of a trip or slip.
- Many older adults will only recall a fall and will not realise they have blacked out.
- Greater awareness of syncope as a cause of falls is key to effective treatment and prevention of recurring falls.

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Syncope Trust And Reflex anoxic Seizures

www.stars.org.uk

Helping you and your doctor reach the correct diagnosis following unexplained loss of consciousness or falls

CHECKLIST: **Preparing for an appointment with your GP**

☑ Before visiting your doctor, it is important to write down what happens before, during and after a blackout or fall, including any symptoms you may experience.

☑ Try to take along a family member or friend, who has seen your blackout(s) or fall(s), to your appointment. If they cannot accompany you, ask them to write down exactly what they saw in the Checklist booklet or ask them how the doctor could contact them if necessary. If it is safe to video an attack, this is often very helpful in making a diagnosis.

☑ Family history; check with relatives whether there is any family history of blackouts, faints, epilepsy, or sudden/unexplained deaths. This is important as it can often provide a clue to the possible cause of your blackout.

☑ If there are any questions you want to ask your doctor or specialist, make a note of them on the Checklist as it can be easy to forget to ask them during the consultation.

☑ Check that both syncope and epilepsy have been considered. Ask for a referral to a paediatrician (for a child) or a cardiologist/electrophysiologist (heart rhythm expert) if possible or, if you are unsure that the diagnosis is accurate, to both a cardiologist and neurologist. You could also ask about possible referral to local rapid-access clinics for blackouts, falls or arrhythmias.

☑ Make detailed notes – use the space later in the Checklist.

☑ Take the Checklist and your notes with you to your appointment.

CHECKLIST: **Questions to ask your GP**

During your GP appointment it can be hard to remember everything. Here are some suggestions of questions which you may find useful to ask during your appointment. There is a section on the Checklist for you to make a note of any questions for your GP.

☑ Can I still go to school, college or work whilst I am waiting to see the specialist?

☑ Can I go to the gym/play sport whilst I am waiting to see the specialist?

☑ Can I still drive whilst I am waiting to see the specialist?

☑ What is the likelihood that a diagnostic test will deliver a definitive result?

☑ What will the treatment involve? Do you think I will have to visit the hospital frequently or stay overnight?

CHECKLIST: **Preparing for specialist tests at the hospital**

☑ Following your appointment with the doctor you may be referred for some tests with a specialist to determine the cause of your blackouts. Being prepared for these can significantly reduce the anxiety of a hospital visit. Try to learn about these in advance at **www.stars.org.uk** and go to 'For Patients' section of the website.

☑ The latest guidelines on the diagnosis of syncope state that patients suspected of having syncope should receive one of the following tests. Make sure that you receive the right test based on the nature of your symptoms.

☑ There are information sheets on the following diagnostic tests available from **www.stars.org.uk**

Every patient presenting with an unexplained blackout should be given a 12-lead ECG

- **12-lead electrocardiogram (ECG) for heart rhythm analysis** – Every patient presenting with an unexplained blackout should be given a 12-lead electrocardiogram (ECG). If there is uncertainty about diagnosis the ECG should be reviewed by a heart rhythm specialist (electrophysiologist).

Tests aimed at syncope:

- **Lying and standing blood pressure recording** Drops in blood pressure with changes in posture can cause dizziness, falls and blackouts, particularly in older patients and those on blood pressure medicines and diuretics (water tablets).
- **Heart monitor** – This is used to record heart rhythms whilst away from the hospital or to activate during an episode. A 24-hour/seven day heart rate monitor is very unlikely to identify any problems if you experience blackouts once a week or less, so do not be afraid to ask about other options.
- **Insertable cardiac monitor (ICM)** – This device should be 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.
- **Tilt table testing** – This procedure can be used to induce a syncopal/fainting attack whilst connected to heart and blood pressure monitors.

Tests aimed at epileptic seizures:

- **Electroencephalogram (EEG)** – For brain activity analysis to check for epilepsy. The EEG cannot be used to diagnose epilepsy, but it is helpful to neurologists to decide which type of epilepsy is happening. The EEG is much less useful over the age of 35 years.
- **MRI or CT-scan** – These are not aimed at showing that someone has epilepsy, but are used to seek the cause when epilepsy is likely, and look for more sinister causes of blackouts and/or seizures.

CHECKLIST: **Questions to ask your GP and specialist**

During your GP or Specialist appointment it can be hard to remember everything. Here are some suggestions of questions which you may find useful to ask during your appointment. There is a section on the Checklist for you to make a note of any questions for your GP/Specialist.

☑ Can I continue to drive?

☑ What is the likelihood that a diagnostic test will deliver a definitive result?

☑ If treatment is offered you may wish to ask whether it will completely stop you having blackouts or falls. If no treatment is offered be sure to ask the best way to manage your condition.

The Blackouts Checklist

Sometimes during a consultation it can be hard to remember everything. The checklist is designed for you to complete. If you have a friend or family member (witness) who has been with you during a blackout or fall, it is VITAL to ask for their help in filling out parts of the form. Please ensure your witness completes their sections of the Checklist. This will help your GP to refer you to the appropriate specialist to make the right diagnosis.

Preparing your own CHECKLIST

To give the doctors the best chance of making the right referral or diagnosis you should provide as many details as possible about your blackout(s) or fall(s).

Name:

1. List any medication(s) you are currently taking:

2. Do you experience blackouts, falls or both? *(Tick as appropriate)*

☐ Blackouts
☐ Falls
☐ Blackouts and Falls

If you experience falls, are they unexplained or due to a slip or trip?

☐ Unexplained
☐ Slip or trip

3. Do you always lose consciousness? Please ask a witness *(Tick as appropriate)*

☐ Yes
☐ No

How long are you unconscious for?

4. How frequent are your blackouts or falls? *(Tick as appropriate)*

☐ Daily
☐ Less frequent than every two weeks
☐ Weekly
☐ Every one to two weeks

5. Before a blackout or fall did you have any warning signs? *(Tick as appropriate)*

☐ Light-headedness
☐ Looking pale
☐ Change in hearing
☐ Sweating
☐ Palpitations
☐ Other (give details below)
☐ Nausea
☐ Greying out or dots in vision

6. Is there anything that triggers your blackout or fall?

(Tick as appropriate; if one trigger occurred at one time and another at another time, tick both)

☐ Pain or a fright
☐ Lack of sleep
☐ Anxiety
☐ Being very hot
☐ Not eating
☐ Stressful situation
☐ Going from sitting or lying to standing
☐ Exercise
☐ Alcohol
☐ Flashing lights
☐ Standing for a long time
☐ Other *(give details below)*

7. Describe what happens during your blackout or fall. Please include whether your episodes are identical on each occasion or if there are differences.

If you are not conscious or cannot remember, ask someone who was with you at the time to describe what happened.

Your description

Friend or family description

WITNESS: Do the individual's limbs move whilst they are unconscious? Do they jerk about randomly or rhythmically?

☐ Randomly ☐ Rhythmically

WITNESS: Do the individual's arms move around their head?

☐ Yes ☐ No

WITNESS: Are the individual's eyes opened or closed?

☐ Don't know ☐ Open ☐ Closed

If open, how do their eyes move?

8. After your blackout

WITNESS: Following the individual's blackout or fall, how long before they regain consciousness?

After the blackout or fall are you confused on coming around? How long does the feeling last?

How do you feel after a blackout or fall?

Are your blackouts or falls affecting your daily activities or quality of life?

☐ Yes ☐ No

9. Family history

Is there a history of loss of consciousness in your family? ☐ Yes ☐ No

Is there a history of deafness in your family? ☐ Yes ☐ No

Has anyone suffered a sudden cardiac death in your family? ☐ Yes ☐ No

Have there been any sudden deaths in the family under 55 years? ☐ Yes ☐ No

If there is, who/what relation?

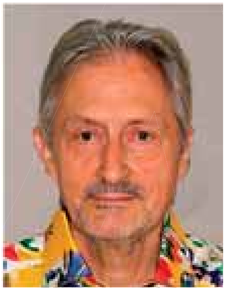
Is the cause known?

Any other questions you would like to ask the doctor or specialist:

DR ADAM FITZPATRICK
28 DECEMBER 1956 – 19 JANUARY 2020

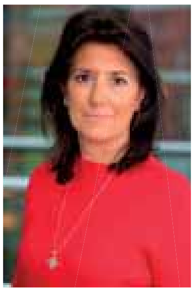
TRUSTEE – ARRHYTHMIA ALLIANCE
CHAIR – STARS MEDICAL ADVISORY COMMITTEE
MEMBER - AF ASSOCIATION MEDICAL ADVISORY COMMITTEE

"COLLABORATION IS KEY…"



Prof Richard Sutton
Medical

=



Trudie Lobban MBE
Patient/Carer

=

Pierre Chauvineau
Industry

The arrhythmia community suffered a great loss with the unexpected death of Dr Adam Fitzpatrick on Sunday 19th January 2020.

I first met Adam in 2001 at the launch of the ESC Syncope Guidelines in Nice, France. We immediately realised we had so much in common. We both knew there was so much work to do to prevent the unnecessary suffering and mis-diagnosis of syncope. Something so simple and yet so complex that all too many doctors 'got it wrong' when treating patients presenting with loss of conscious. That day I finally met a doctor as passionate about syncope as I was. From there on he became my partner in bringing about change, he did not hesitate when I asked him to become Chair of the STARS Medical Advisory Board.

By 2003 we realised that the problem was not just syncope but all arrhythmias (heart rhythm disorders). When I asked for his support to set about changing policy in the UK he committed 100%. Over the following months he helped and guided me through the complex and often disjointed arrhythmia world and by May 2004 he agreed to be a founding Trustee of Arrhythmia Alliance as we hosted our first ArrhythmiA Awareness Week (AAAW), later to become World Heart Rhythm Week. We succeeded in changing policy in less than nine months, often by working through the night drafting proposals, meetings in London, phone calls and thousands of e-mails (as those close to Adam know all too well – why write one e-mail when a hundred will do?).

Once we had our new chapter added to the National Service Framework for Coronary Heart Disease we set about ensuring it was implemented and Adam led the way in launching the Arrhythmia Alliance Cardiac Update Meetings, followed by A-A Heart Rhythm Congress (held annually in Birmingham, UK) – two previously unheard of concepts. Identifying local best practice and then bringing them to the national arena. A-A HRC is still the only event in the world that brings patients, healthcare professionals, policy makers and industry together to improve education, arrhythmia services and better outcomes for all those involved in or affected by cardiac arrhythmia.

Adam never wavered in his commitment to all three charities and forever working to deliver world class arrhythmia care to all patients. He established the worlds' first Rapid Access Blackout Clinic in Manchester based on the STARS Checklist we had developed. Never before had anyone thought of something so simple and so far-reaching. It changed the approach to identifying and diagnosing those presenting with unexplained loss of consciousness – others have gone on to adapt and copy and we now see more syncope services than ever before, due mainly to the foresight of Dr Adam Fitzpatrick – a very special, caring individual.

I think we all agree that the medical profession has lost a great man and the thousands of patients he treated will be forever grateful for his empathy, kindness and support. He has saved so many lives over the years; it is just so tragic that his own life could not be saved.

Arrhythmia Alliance and its sister charities have lost a passionate and committed member of our 'team'; the healthcare community have lost an exceptional doctor; and the arrhythmia world will be a poorer place without Dr Fitzpatrick – however his legacy will live on with the ground-breaking research he published and his unique way of improving and delivering first-class arrhythmia services.

Arrhythmia Alliance. STARS and AF Association are pleased to announce that his memory will live on through

Adam Fitzpatrick Lecture to be held annually at

A-A Heart Rhythm Congress (www.heartrhythmcongress.org).

STARS – Syncope HealthCare Pioneers Report – showcasing best practice in memory of Dr Adam Fitzpatrick; this annual report will be published to coincide with A-A World Heart Rhythm Week as Adam was one of the instigators of launching an awareness week in 2004.

Adam believed in collaboration – he was passionate in bringing people together to achieve greater results – he sought perfection and was never satisfied, always seeking new, innovative ways of improving healthcare.

Arrhythmia Alliance was founded on our ethos of collaboration – it is the only way to achieve the best for patients worldwide. Patients, healthcare communities and our industry colleagues working together to provide rapid diagnosis and access to appropriate treatments to restore the patient back to a person leading as active a life as possible. It only seems fitting therefore and right for the three communities, and those who knew Adam well, to share their memories of Adam.

Prof Richard Sutton trained Adam when he was a registrar in London. Pierre Chauvineau worked with Adam for many years supporting many of his research projects. Adam, Pierre and I became close friends and colleagues – The Three Musketeers as we jokingly called ourselves.

PROFESSOR RICHARD SUTTON:

I first knew Adam when he joined the Cardiac research team at Westminster Hospital in 1988. His arrival was not a breath of fresh air but more like a storm. Everything changed; he saw projects making no progress, took them and finished them. His productivity was huge.

He was always a good person to work with bringing humour and unique insights to every situation. He cared for patients in a way that they were his own parents, brothers, sisters or children. Together we published 16 papers and 28 abstracts, book chapters etc. in his four years at Westminster. He also wrote his MD thesis on Syncope which passed with flying colours; the only criticism made by the examiners was that it was too long, going into two volumes.

He left a huge hole when he departed. He went to Bournemouth, Royal Brompton, then Southampton as Senior Registrar and these posts were followed by three years in San Francisco to work with Mel Scheinman, ultimately, being promoted to Assistant Professor. In the US and the other UK hospitals, he did equally well learning much that was not available at Westminster, especially ablation of arrhythmias in San Francisco, returning to the UK to be Consultant Cardiac Electrophysiologist in Manchester.

Again, he did an outstandingly good job there forming a busy Cardiac Electrophysiology Department. From my viewpoint, his great achievements were his approach to 'Blackouts' which had profound influence on the care of these patients not just in UK but also worldwide. This combined with his great enthusiasm and guidance for the STARS charity proved to be an excellent partnership. Another important step was discovering that there is a much greater overlap between arrhythmias and epilepsy than had previously been thought. This finding was quickly supported by evidence that he gathered. He was the first in the country to appoint an arrhythmia nurse specialist.

His health in the last three decades, unfortunately, attenuated his productivity contributing to his early retirement and, ultimately, to his untimely death. In Adam, we have lost a wonderful person, a superb physician, an excellent clinical researcher and a great friend to many of us.

PIERRE CHAUVINEAU:

Dear Adam,

I want to remember all that you brought to us as a friend and as a physician. We met as you moved back to Manchester after your experience in San Francisco. You quickly impressed me with your fast thinking and your holistic approach to cardiology. When you talked to us about your willingness to create a Rapid Access Blackout clinic in Manchester, you made such a good case that it was not difficult to find the investment required. You had already been partnering with the neurologists to ensure patients would be treated holistically. You had drawn the clinical decision tree as if it was already in your head for a long time. You had a view that a number of epilepsy diagnoses had a cardiac origin and you set out to prove it clinically.

Then I happened to cross Trudie's path in Oxford. The outcome of that discussion was that Francesca, Trudie's daughter who had numerous blackout episodes had not yet seen a Cardiologist. This is how I had the opportunity to introduce Adam to Trudie. From that connection came a long-lasting friendship between the three of us and a strong collaboration between the patients, the clinicians and the industry. Some of the outcomes of that friendship were the creation of the Arrhythmia Alliance, the development of a patient focused Arrhythmia National Service Framework, STARS Medical Advisory Board among many other things. You used to call us the three musketeers!

Adam, you always had a very witty and dry sense of humour. What mattered most to you was to ensure that everything you did went to improve patient care. You treated every one of your patients as if they were part of your family. You were always frustrated by all the processes and the internal barriers that prevented you from giving better care to your patients. When your health allowed, you had a relentless energy to remove barriers and obtain the data that would help you find the best way to treat your patients.

On the personal side, you were a gentle giant who had a passion for rugby. You used to play second or third row and we could see it from your ears! You were always there when we needed you with your expert opinion. You lacked confidence despite your exceptional intellect, work ethic and tiresome dedication. You were a committed family man.

Today, we are very sad you are no longer with us. However, over time we have built so many good memories and friendships with you that we will remember and value them. We will miss you as a friend and as a physician.

TRUDIE LOBBAN:

Adam was a personal loyal friend, he was committed, he was a professional, he was passionate about all that he did, he cared. Qualities that made him such a special person. Throughout the years he provided me with both professional and personal support and has encouraged and guided me through many challenges and difficult situations.

Adam you were so supportive when my husband, died – you wrapped your arms around my daughters and I in a huge, secure, comforting hug – reassuring us we would get through this… Every six months or so you, Pierre and I would meet – checking to see if I was OK and putting the world to right.

And of course the endless, infamous, Adam Fitzpatrick e-mails!

Adam - we first met in 2001 and I think we can say our lives changed for ever. We had each found our 'syncope' partner. We both had the same commitment and vision and, boy, what a force to contend with when we set our minds on something.

You had the expertise, knowledge and vision of what should and must happen to deliver first class arrhythmia services. You were like a tsunami, once you had the vision the solution just fell into place and nothing would get in your way until you achieved the unimaginable. People were blown away with your energy and passion.

However, I saw the other side of you, the one that agonised as to whether you were doing the right thing – not the right thing for yourself but for others. Perhaps that was your weakness – you cared too much for others and didn't put yourself first often enough.

There are too many achievements for me to list but I want you to know above all else, that you literally saved lives, not just the patients but their families as well. Any patient who was fortunate enough to be referred to you came away feeling they had been 'heard' someone had finally listened and more importantly understood.

We always kept in touch. Only a few weeks ago one of your famous e-mails arrived telling me you had lost your wallet but you were at the gym – you made me smile. Not quite sure why you shared that with me – but I am glad that you did.

Adam you never believed in yourself. I hope wherever you are, you will finally realise how many people believed in YOU. The difference you made to thousands, yes thousands, of lives – patients, colleagues, healthcare services, and to me.

Adam I will miss you but will always be thankful that I had the pleasure of knowing you and the honour of calling you my friend. My very special friend.

PUBLICATIONS LIST

Booklets

- Arrhythmias: Understanding your condition
- Cognitive behavioural therapy for chronic health conditions
- Devices for an arrhythmia
- Diagnostic tests for syncope
- Frequently asked questions
- Living with low blood pressure
- Pacemaker patient information
- Postural tachycardia syndrome
- Psychogenic blackouts
- Reflex anoxic seizures (RAS)
- Reflex syncope
- Syncope and Falls in the Elderly (SaFE)
- PoTS FAQs
- Bereavement: Life following the loss of a loved one
- Mindfulness and healthy living with syncope
- What can i do about sudden cardiac arrest?

Paediatric information

- Jack has RAS

Checklists

- Blackouts checklist
- Palpitations checklist

Factsheets

- Bradycardia
- Cognitive behavioural therapy (CBT)
- Syncope in older people:
  Common causes and advice
- Diagnostic tests for syncope
- Implantable loop recorder (ILR)
- Information for Anaesthetists, Dentists etc
- Inappropriate sinus tachycardia (IST)
- Long QT syndrome
- Midodrine
- Miniature insertable cardiac monitor (ICM) system
- NICE
- Pacemaker
- Postural tachycardia syndrome (PoTS)
- Reflex anoxic seizures (RAS)
- Reflex syncope (Vasovagal syncope)
- Syncope and falls in care homes:
  An introduction
- Syncope and diet: You are what you eat
- Syncope and diet: For teens
- Syncope causes falls in older people
- Syncope during pregnancy
- Syncope in care home residents
- Tilt table test
- Understanding your blood pressure

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To view case studies, centres of excellence, syncope healthcare pioneer reports or to submit a case study visit

www.syncopepioneers.org

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For a full list of publications on all arrhythmias including syncope, please contact us.

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