

Take STARS to Heart

Syncope Trust And Reflex anoxic Seizures®

Providing information and support on Syncope, RAS and PoTS



2014 will celebrate ten years of progress in syncope and arrhythmia care

2013, STARS' 20th anniversary year, was memorable both professionally and personally and this year we celebrate ten years of progress in syncope and arrhythmia care. We will be working alongside our sister charity, Arrhythmia Alliance, during **Heart Rhythm Week**, 2-8 June 2014 and I hope that many of you will join us.

I am heartened by the amazing progress that has been made across arrhythmia technology with devices and medication, and the increase in resources, including arrhythmia nurses, electrophysiologists and new heart rhythm clinics. You will read on pages 6 and 7 the exciting news regarding the latest devices to help diagnose and treat syncope as well as other heart rhythm disorders. Both these new devices, a new mini pacemaker and a miniature insertable cardiac monitor (ICM), are considerably smaller than their predecessors. They will be virtually invisible to the naked eye, be more comfortable and certainly less intrusive. Already the medical profession are talking about them and I was invited to appear on BBC Breakfast to explain the benefits and show how far technology has progressed with the miniature ICM.

STARS is involved in the NICE quality standard on transient loss of consciousness which is currently being developed, the result of which will be posted in October. I very much welcome this much-needed

initiative which will provide support for those who are struggling to obtain a credible diagnosis for their unexplained loss of consciousness.

I was delighted to be elected as a Fellow of the Royal College of Physicians of Edinburgh in December. It is in recognition of STARS' commitment to improving the diagnosis, treatment and quality of life for all those affected by arrhythmias and syncope. I was also fortunate to be awarded Runner Up in the 2014 Directory of Social Change Awards in the Lifetime Achievement category.

Personally, I am extremely honoured to receive these awards, but I am very aware that it is the work of STARS and the support you afford us that has enabled me to receive this prestigious recognition.

Finally, as many of you will know my elder daughter Charlotte who has worked for STARS for over ten years, (and as a proud mother) I want to share a day in October last year when she was married to Nigel D'Souza. Charlotte is now an anaesthetist and Nigel a surgeon. They are currently working in the rural areas of South Africa and Charlotte still works for STARS!

I would also like to share some further happy news, Fiona our fundraising officer gave birth to a beautiful baby boy, Thomas James Vince on 9th December. Mum and baby are doing well.

My best wishes

Trudie Galbraith



Charlotte and Trudie on her wedding day in Portugal.

Fainting is a symptom not a condition



Dr Nick Tullo, cardiac electrophysiologist from the New Jersey Center for Fainting in the US, explores syncope as an indicator for other conditions.

Fainting, or “syncope,” is an extremely common symptom that affects one out of three individuals in their lifetime. Since most people wake up quickly after a fainting spell, they often shrug it off as not being serious, and frequently do not even mention it to their doctor. However, fainting may be a sign of a serious underlying condition.

The most common cause of fainting is a temporary imbalance in the brain’s control systems that manage heart rate and blood pressure. In that case, fainting occurs because of a sudden drop in blood pressure or slowing of the heart rhythm, resulting in a decrease in blood flow to the brain tissue and loss of consciousness.

In people who are prone to fainting, the normal reflexes that maintain proper circulation can be thrown off by certain “triggers” like pain, stressful circumstances, dehydration, standing for long periods of time, and even warm environments. This condition is referred to as “vasovagal syncope.” Most of the time, the victim has warning signs – they may feel unwell, sometimes nauseated, a hot sensation, lightheadedness, sweating, and progressive symptoms that eventually lead to a brief period of unconsciousness, which usually ends within a minute after the person falls over.

Doctors who specialize in fainting must rely on the history and circumstances surrounding the faint in order to surmise the cause. Vasovagal syncope can be diagnosed when the history is similar to that described above. However, when the circumstances differ significantly the doctor may suspect a more serious cause of sudden loss of consciousness, such as a heart rhythm disturbance (arrhythmia). Sudden slowing or stopping of the heart for more than a few seconds can cause syncope. Furthermore, a rapid heart rhythm disturbance can force the muscle to beat so erratically that it cannot contract effectively. Arrhythmias can

result in a precipitous drop in blood flow to the brain, and can cause loss of consciousness without warning. Sometimes, patients describe a feeling of very rapid heart palpitations that precede the faint. Serious arrhythmias can cause collapse of the circulation, and can cause loss of consciousness even when a patient is lying down.

Syncope during exercise can also be a sign of a serious cardiac condition, because the movement of the muscles should normally be associated with an increase in blood pressure. Vasovagal syncope, on the other hand, can occur after exercise, because if someone stops moving the muscles can remain engorged with blood, reducing the amount available for the heart to pump to the brain.

“Syncope is never “normal.” An expert consultation may save the patient from serious injury or even cardiac arrest in the future.”

Doctors have to explore various facets of the history to gain clues to the cause of a faint, especially if someone is taking medications (which can affect blood pressure or heart rate), whether they may be dehydrated from a recent illness, or if there is a family history of fainting or sudden death. Certain heart rhythm problems can actually be caused by a genetic abnormality of the heart muscle, such as the congenital long QT syndrome or hypertrophic cardiomyopathy. In that case, a fainting spell can be a warning that the patient is at risk of dying suddenly. Finally, syncope in a patient with a history of heart attack or in someone with heart muscle weakness should never be ignored, as it could be due to a life-threatening heart rhythm disturbance.

Syncope is never “normal.” Therefore, medical professionals experienced in establishing a proper diagnosis should evaluate any fainting spell. An expert consultation may save the patient from serious injury or even cardiac arrest in the future.

Nicholas Tullo, MD, FACC, FHRS
New Jersey Center for Fainting
www.njfaint.com

Rise of the patient support group

Dr Diane Bruce, consultant cardiologist from Poole Hospital and medical lead for the Dorset Patient Support Group, shares her experience of the first ever syncope and PoTS support group meeting earlier this year.

"The first meeting of the Dorset patient support group for PoTS/Vasovagal Syndrome (VVS) took place in January 2014. Despite the adverse weather conditions and the mobile MRI scanner blocking the entrance, twenty people attended and several others left messages to say they would like to in future.

The attendees soon started chatting amongst themselves until the meeting got underway.

I gave a brief overview of the condition, including a background of Joint Hypermobility. Up to a third of people with Joint Hypermobility Syndrome/ EDS type 3 can have typical symptoms of PoTS and or VVS.

I explained how a whole spectrum of symptoms can be explained and possible forms of treatment. The group soon moved on to talking about their own experiences and what they would like the group to achieve.

It soon became obvious that many patients felt isolated and frustrated with their condition and the length of time required to obtain a correct diagnosis. Concerns were focussed on the lack of knowledge about PoTS and VVS in primary care and where to get specialist advice and financial support.

All ages attended the meeting, from teens to patients in their 60s, including a patient who had been diagnosed almost 18 years ago when her cardiologist came back from an overseas conference and announced "I think I know what's wrong with you - you have PoTS!"



There was unanimous support to continue with the group and raise awareness of these conditions, whilst educating patients how best to manage themselves.

The meeting ended on a really positive note with lots of patients laughing and chatting away as they headed back into the cold rainy night again looking forward to their next meeting."

**Dr Diane Bruce, Consultant Cardiologist
Poole Hospital**

Interested in becoming a local patient support group lead in your area?

Local support groups can provide an invaluable service to patients and one of the greatest advantages of a group is that it helps patients and carers realise they are not alone.

Email Daisy Harris communications@stars.org.uk or telephone 01789 451 829 if you are interested in leading a group in your area.

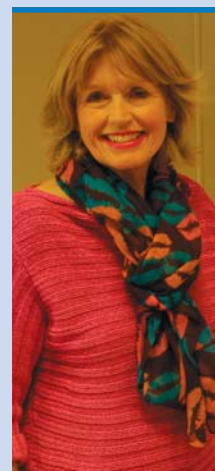
STARS Patients Day 2014

Sunday 5 October 2014, International Conference Centre (ICC), Birmingham

Already members are registering their interest for 2014. As we go to press some presenters have yet to confirm their attendance, but we can promise another stimulating agenda with international speakers, including a PoTS expert. There is no financial commitment at this stage, but when the final agenda is confirmed we will email those on the list who will have an opportunity to confirm their registration.

Topics will include:
Situational syncope;
Causes of falls in the elderly;
New and experimental treatments for syncope and related conditions;
POTS;
Patient experiences;
Paediatric syncope;
Questions and Answers.

To register your interest email jenni@stars.org.uk or telephone 01789 450 564



Together we shall overcome



Tania Tirraoro.

Author and journalist Tania Tirraoro shares her family's challenging journey to diagnosis with STARS.

The first time my son, Giorgio, lost consciousness and stopped breathing in 2000, he was just 13 months old.

I was halfway up the stairs when he let out a strange cry. I froze for a second on the stairs, listening. Then the cry abruptly stopped and I ran back down, finding him in the arms of my husband, eyes closed, grey and not breathing, looking as if he had suddenly died.

Horrified, I took him in my arms and instinctively laid him flat, blowing on his face trying to bring him round, while my husband called the ambulance. I didn't realise it at that moment, but his heart had stopped for a short time as well as his breathing.

As the ambulance arrived, Giorgio came round and seemed perfectly fine. At A&E he was his usual happy, smiling self and the staff could find nothing wrong.

He continued to have these strange attacks. We were lucky with the paediatrician we were referred to. He diagnosed "White Anoxic Seizures". He didn't seem at

all concerned. "Harmless", he said. He would probably grow out of them. No information, just advice to lie him flat until it passed.

I searched the internet. It brought up a few medical results and a small volunteer patient support group called STARS. I called and chatted with a sympathetic lady, Trudie, who posted me information.

I was so grateful that I offered any help I could.

I have worked with STARS, most notably in 2004, when we all worked together as Trudie led an amazingly successful campaign to include heart rhythm disorders in the National Service Framework for coronary heart disease.

It was a brilliant example of patient power that led Trudie to launch Arrhythmia Alliance and, as they say, the rest is history.

Meanwhile, Giorgio's RAS attacks tailed off, and he was virtually free of them by the time he started school although he still had near misses.

"I didn't realise at that moment, but his heart had stopped for a short time as well as his breathing."

Looking back, it was an extraordinarily fraught time, especially as Giorgio's older brother, Luca who was big, strong and mischievous, was usually the trigger for a seizure. I would have to dive in as Giorgio collapsed and comfort him while simultaneously reprimanding Luca, who was only 18 months older, because it seemed he had deliberately provoked his brother. It was a relief when he started school but by Year 2 Luca was diagnosed with attention deficit hyperactivity disorder (ADHD).



Luca and Giorgio.

I now realise that Giorgio's trigger was anxiety and this is still a feature of his daily life. He was a delicate child who seemed to spend half his life away with the fairies. He could read before he got to school but had enormous difficulty writing.

He would regularly zone out and he had an EEG in case he was having absence seizures (petit mal). It came back normal, but we knew something wasn't right and continued to seek answers. Within a year, he had a diagnosis of Asperger Syndrome and attention deficit disorder (ADD). ADD is ADHD without the hyperactivity. I researched parenting a child with Asperger's and realised that Luca too had Asperger's Syndrome. We needed statements of special educational needs.

"I knew something about PoTS from my work with STARS and it fitted with his difficulties."

Both boys received a statement of their needs that was legally enforceable, and I also secured placements and funding at a specialist boys' school where they have been for six years.

A happy ending? Not even close!

In 2012, Giorgio was 13 and he began to get mysterious leg pains, and feel very dizzy and fatigued. I knew he suffered from Raynaud's Syndrome, as did I, which is a circulatory disorder that leads to cold hands and feet.

I came across a case study of a young woman with similar symptoms. She had something called Ehlers Danlos Syndrome and Postural Tachycardia Syndrome. I knew something about PoTS from my work with STARS and it fitted with his difficulties.

I researched EDS and within weeks we had the diagnosis of EDS type III, also known as Hypermobility Syndrome. This explained his difficulty with handwriting – it was nothing to do with his Asperger's – he had hypermobile fingers!

I mentioned to Giorgio's specialist I also had the same symptoms. He offered to see me too, but I declined – I could manage, always had!

A tilt table test for Giorgio was positive and a diagnosis of PoTS was added. They also included vasovagal syncope as well for good measure.

Is this the end of the story? Nope!



Giorgio and husband, Marco.

A month after Giorgio's EDS diagnosis, I started to have a racing heart when I went upstairs with burning pain in my legs and pains in my lower abdomen. Symptoms worsened and I was in excruciating pain, with a heartbeat of 140 after just having a shower. I couldn't stand for long and walking even a short distance left me exhausted. Test after test came back negative.

You might be shouting at the newsletter "go and see the professor yourself" but how could the symptoms I had managed all my life suddenly flare up into a virtual disability? Well I did go and, with a diagnosis of EDS and PoTS, my whole life made sense. It occurred to me that I had been in pain and had dizzy spells for much of my life but thought everyone was like that. Doesn't everyone get a 'head rush' when they stand up too quickly? Well maybe, but not like I did, apparently!

Since then, Giorgio and I have taken beta-blockers to slow the heart. Until I have had proper autonomic testing other medication cannot be prescribed and I now use a wheelchair.

I won't be beaten – Giorgio needs me, especially as he is approaching his GCSEs in 2015.

I'm now waiting for a three-week inpatient rehabilitation course to help me learn to pace and work with my condition.

So we're not at the end of the story, but we are up to date...

Tania Tirraoro

To read Tania's full story, go to www.stars.org.uk.

2014 heralds arrival of revolutionary

New miniature implantable cardiac monitor



Dr Nick Linker compares the devices.

Dr Nick Linker, consultant cardiologist, James Cook University Hospital and member of the STARS medical advisory committee recently implanted, for the first time in the UK, the smallest version of an insertable cardiac monitor (ICM).

He describes the role and advantages of the new device.

The ICM is a diagnostic tool that monitors your heart's electrical activity and helps a heart rhythm specialist identify the cause of your symptoms. This device offers the same benefits as a traditional implantable loop recorder (ILR) but is a tenth of the size. Virtually invisible to the naked eye, it is more comfortable and much less noticeable under the skin.

How is the ICM fitted?

As this miniature monitor is so much smaller and easier to implant, it is intended that the procedure could be performed in a treatment room rather than a theatre setting. Implanting the device requires an

incision of less than 1cm which is closed very simply with medical adhesive, steri strips or a suture. It is anticipated the procedure will take about ten minutes. It is hoped that the new procedure will reduce the waiting lists for this diagnostic device to be fitted and in some cases the procedure could be undertaken in clinic, saving delay in reaching a diagnosis and the inconvenience of repeat visits.

How is an episode captured?

The ICM is remotely monitored, wirelessly, through a receiver in your house. Any unusual heart activity will be transmitted via a 3G signal to a secure system which will alert your heart rhythm specialist. You would then be contacted if necessary.

Removal of the ICM

Once the reason for your heart rhythm problem has been identified, the device can be removed with another simple procedure.

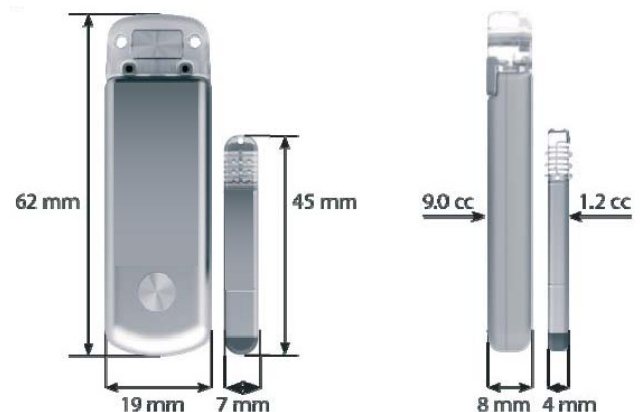


Image illustrates the size of new ICM compared to the traditional ILR device.

cardiac devices for syncope patients

New pacemaker is size of AAA battery

Early this year, alongside the first miniature cardiac monitor implant, the world's first retrievable leadless pacemaker was implanted at St. Bartholomew's Hospital in London by Professor Richard Schilling.

The leadless pacemaker is designed to be placed directly in the heart without the visible surgical pocket, scar and insulated leads required for conventional pacemakers. The device offers a less invasive approach for patients compared to traditional pacemaker procedures and is fully retrievable.

"Nanostim™ is one of the most significant advancements in cardiology and pacemaker technology. This miniature pacemaker offers the potential for reduced complications like infection and aesthetic benefits over conventional pacemakers, in addition to quicker recovery times."

Professor Richard Schilling,
Consultant Cardiologist and Electrophysiologist,
St Bartholomew's Hospital, London

Nanostim™ is less than a tenth the size of a conventional pacemaker which improves patient comfort and can reduce complications, including



Nanostim™.

device pocket-related infection and lead failure. The elimination of the visible lump and scar of the conventional pacemaker's implant site, in addition to the removal of patient activity restrictions, will potentially improve the quality of life for patients by allowing most to continue living active uninhibited lifestyles.

Total implant procedure time is around half an hour. Even with miniaturisation, the device battery is expected to have an average lifespan of more than nine years at 100% pacing, or more than 13 years at 50% pacing.

The Nanostim™ leadless pacemaker recently received "CE Mark" approval and will be rolled out in the UK in the coming months.

Founder & CEO on BBC Breakfast News

Many of you will be aware that STARS Founder & CEO, Trudie Lobban MBE, was invited to share news of the ICM on BBC Breakfast News on Wednesday 5th February. Interviewed by Bill Turnbull and Louise Minchin, Trudie demonstrated the simple procedure used to implant the device and highlighted the benefits of the new device for syncope patients. If you missed it, you can still view Trudie's interview footage on the STARS website.



For further information on the ICM or Nanostim, please contact STARS.

Our Fundraising STARS

Besides the following wonderful donations, there are some supporters who send cheques or make donations requesting anonymity – they are still 'STARS' and we say thank you. If we have missed you off on our list of 'STARS', we are sorry but still very grateful to all of you. Without this support, STARS would not be able to provide the personal contact that our helpline gives.



Abi Marshall and Cherish Ayres at the Tollgate Toddle.

Cherish Ayres with four year old Abi, Sammy, Paco and Hayley joined the Tollgate Toddle to walk 5k on a murky November day and raised £250. The Ayres family and friends are one of our most prolific fundraisers. Thank you Team Ayres.

Josette Ward organised three 'Host a Heart' boards for her colleagues to use for Christmas instead of sending cards. A brilliant idea and she raised nearly £65 for STARS. A big thank you!



Josette Ward and colleagues promoting their 'Host a Heart' board.

Anita Kiernan asked for a donation to STARS in lieu of her 'Secret Santa' present! What a great idea! Your colleagues are great supporters of STARS, we know. Thank you!

Rebecca Phippen raised nearly £200 on 27 October when she participated in the Great South Run. She chose STARS because she became a childminder for a young girl with RAS. Aware of the support mum had received and appreciative of all the information on the website which makes such a difference to the families, she just knew she wanted to support us. Rebecca – thank YOU!

Ashley Cooper made a donation to STARS instead of giving a present to Lynette Lewis in celebration of her 50th birthday bash. Thank you for thinking of us.



Louisa and Callum Browning after their Big Fun Run.

Louisa and Callum Browning participated in the Big Fun Run in Lee Valley in September and then took on the Majors Challenge in October – all in support of the Morgan family who are very close friends and have a young son with RAS. They raised the magnificent sum of £245. Congratulations to you all and thank you.



Debbie Bishop gearing up for the Cardiff Half Marathon.

Debbie Bishop undertook the Cardiff Half Marathon as a thank you to STARS because we supported her and her family during a difficult 3 years, raising £185. Thank you very much Debbie and the best prize of all is that you are now able to run 13 miles!



Sally Hamilton-French at her open day at Freshfields.

Sally Hamilton-French raised an amazing £345 when she held an open day at Fresh Fields, her stables for retired horses in Shropshire. Sally is a great supporter of STARS and she knows how much we appreciate her fundraising activities. Thank you.

ETZ Chaim Jewish Primary School

sent us a cheque for £100. We are very grateful to Mrs Baron, her staff, pupils and families for their support. Thank you so much.



Gini Dellow's poetry gift cards.

Gini Dellow's name will be recognised by many of you because in 2013 she began her year-long challenge to write a poem a day to raise funds for STARS.

She has also used her talent to produce Christmas cards for STARS, raising £80 through sales. A specially big thank you to Gini and also thank you to all our members who supported us by buying them. Gini also made Valentine cards and has supported Mother's Day with a special poem.

See page 10 for Gini's full story.

Share your fundraising stories

Why not let us highlight your fundraising achievements in the next newsletter! Already **Chris Tennison** is training hard for the 'Tough Mudder, Midlands' on 13 July and **Megan Summers** and four friends are swimming in a 25-hour relay in March. WOW!!

Caroline Stewart is organising a Classic Car show in her village of Harworth, near Doncaster, in June. **Cherish Ayres** has organised an evening of clairvoyance with Peter Langhorn in Tilgate, Crawley in March. All proceeds from the raffle are being donated to STARS.

All in support of STARS. A big thank you, it is really appreciated. If you have felt inspired by our fundraisers and would like to participate in your own activity on behalf of STARS, then we are here to support you with T-shirts, collecting tins, leaflets and posters. We can also produce press releases to highlight your event in the local media. Email info@stars.org.uk with details of your event.

Our raffle

STARS' Spring Raffle is now open and our top prize is an incredible one night stay with dinner, bed and breakfast for two at any Hand Picked Hotel, worth £250!

The winner can pick any of the stunning country houses, chosen for their distinctive personality and luxurious surroundings.

- First prize – One night stay for two in a Hand Picked Hotel
- Second prize – Family ticket (2+2) to SEA LIFE aquariums
- Third prize – Monsoon Estates, artisan roaster will send you your favourite fresh coffee once a month for six months
- Fourth prize - Nando's Chicken cheque for one full platter meal and bottle of Cara Viva wine.

Look out for your raffle tickets enclosed with your newsletter.

Heart Rhythm Week, 2-8 June 2014

For this year's Heart Rhythm Week we are working alongside our sister charity Arrhythmia Alliance to celebrate ten years of progress in syncope and arrhythmia care.

Heart Rhythm Week 2014 will look to celebrate the amazing progress that has been made across arrhythmia technology, resources, and policy guidelines as well as share good news patient stories to illustrate the changes.

Have you received a new device or medication to treat or manage your condition, or been treated and cared for at a clinic that was not available ten years ago?

To register your interest in receiving communications about Heart Rhythm Week or to share your story to help raise awareness during the week, email andrew@stars.org.uk or telephone 01789 520 311.



Living a fulfilled life with chronic illness

Living with a chronic illness is hard work. It is too easy to be consumed by it as you focus on seeking answers and the best available medicines in search of a cure. But often there is disappointment because the answers you seek and that miracle cure you hoped for cannot be found. You may not get better. So you have a choice. Do you allow the illness to defeat you and drag you down, or do you choose to fight and get on with your life? Focusing on your emotional wellbeing and understanding the power of the mind will help you manage your chronic illness.

Body mind connection

Our body and mind are connected; one will have a direct impact on the other. Therefore, focusing on your mind and emotional well being will have a direct impact on your physical wellbeing. Do you struggle with emotions such as anger, bitterness, fear, anxiety, worry, negative thinking, low self-esteem or grief? Do you have issues from the past which have not been addressed? These can have a detrimental impact on your physical health. For some, dealing with these emotions could be the cure, resulting in a return to good health.

Fear, stress, anxiety

There is increasing medical evidence that a significant number of conditions have their roots in fear, stress and anxiety. We live in a climate where pressure is high and time is short, and we push our bodies and minds to their limits. Stress can be positive and negative, physical and emotional, but it is still stress and will impact on our bodies.

Do you live in fear? Fear of what will happen tomorrow. Fear of failure. Fear of what people think of you. Fear of illness. Are you fearful of leaving the house in case you pass out? Are you anxious about everything, do you worry about anything? Again, these negative emotions are a form of stress which will have an impact on your wellbeing and ability to live your life.

Our emotions cause a physiological response, stimulating the autonomic nervous system to release stress hormones - adrenaline and cortisone (fight flight mechanism). Short-term stress is good, and needed in a life threatening situation. Long-term continuous stress will have physical consequences – the body damages itself.

Identity/sick role

How often do hear someone say “my condition” implying they have taken ownership of it and are at one

with it? Has your identity been formed around your illness? Have you become your condition? You need to separate yourself from your condition, and know who you really are. Do you want to live well despite having a chronic illness?

Positive self-esteem

How you feel about yourself will affect how you are physically. Do you feel good about yourself? Do you like yourself? If you do, you are more likely to have the confidence to step out of your comfort zone and try something new. If you are fearful, then your inner low will reflect your outer reality. The more energy you give to a thought, the more real it begins to feel, whether positive or negative, and will impact your health.

Beware that too much time with negative people, will encourage negative thoughts. More time spent with positive and inspiring friends will have a positive impact on your wellbeing.

Change your thinking

Don't let what you cannot do interfere with what you can do.

You may not be able to change your circumstances or condition, but you do have a choice how you respond, and how you choose to live life. Only you are responsible for your thoughts and only you can change them... if you want to.

Aim to think positively and when you have achieved this you will begin to act positively. Try not to dwell on your illness, but look outward rather than inward as much as possible. Focus on what you want in life, what you have, and what you can do in spite of your circumstances.

Your mind is powerful. If you convince yourself you can do something, you will succeed.

"There are millions of people out there ignoring disabilities and accomplishing incredible feats. I learned you can learn to do things differently, but do them just as well. I've learned that it's not the disability that defines you; it's how you deal with the challenges the disability presents you with. And I've learned that we have an obligation to the abilities we DO have, not the disability."

(Jim Abbott, Professional baseball player)

Lorna Nicholson RN

The full version of this article can be read on the STARS website, www.stars.org.uk

Poetry from the heart



Jenni, Ben, Gini, Kit and Nicholas.

Gini was diagnosed with autonomic dysfunction and PoTS in 2009. The impact of this condition left her unable to do simple things that many of us take for granted, but led her to rediscover her love of writing.

Gini Dellow started her ambitious poetry marathon in June 2013 and will continue to blog a poem a day until June this year to raise funds for STARS.

The 46-year-old poet battled to get a diagnosis for more than three decades, eventually being diagnosed with autonomic dysfunction and PoTS; autonomic disorders which make her prone to frequent spells of dizziness, fatigue and blackouts.

She recalls: "My unexplained fainting episodes started when I was eleven years old. I used to pass out in school assemblies.

"It was a nightmare trying to get a diagnosis. In school, I was told I was attention seeking, and then when I got married and had children I was told it was postnatal depression."

"It was a nightmare trying to get a diagnosis. In school, I was told I was attention seeking, and then when I got married and had children I was told it was postnatal depression. When you don't get the support, people buy into it and start labelling you."

"New avenues have opened up and through my limited lifestyle I have rediscovered my love of writing."

Misdiagnosis and non-diagnosis are common for syncope patients. Each year in the UK up to 40% of patients with epilepsy are misdiagnosed, with around 60% of these later found to have syncope.

In 2009, Gini's symptoms were taken seriously for the first time. She continued: "During a stay in hospital I passed out and fell down the stairs, and the next thing I knew I was in intensive care being monitored for a very slow heart rate.

"I then remained in hospital for a month and was fitted with a pacemaker to treat my slow heart rhythm. It was only after this that I was accurately diagnosed with autonomic dysfunction and PoTS.

"The impact of these conditions has left me unable to do the things that I used to do without a second glance. However, new avenues have opened up and through my limited lifestyle I have rediscovered my love of writing.

"Writing a poem a day is quite a task but it has proven to be really enjoyable, even if it is sometimes quite hard, particularly with having to fit in caring for four children, studying full time for a psychology degree, and dealing with variable blood pressure which can knock you down at any minute, but determination is a wonderful tool!

"The information I have received from STARS has been invaluable so I want to help them to be able to support other people with conditions like mine."

Gini's blog of her year-long poetry challenge can be viewed online: www.ginzandtonic.com

Searching for a special card? Gini has designed some unique cards featuring her poems to raise funds for STARS. Cards are available to purchase for

£1.50 (including post and packaging). Cards can be ordered directly through Gini Dellow: www.ginzandtonic.com, phone 07539 936464 or email ginzandtonic@live.co.uk



You can make a difference

With your help we can continue to support individuals and their families affected by syncope, RAS and PoTS. Your subscriptions enable us to maintain our daily helpline and essential services to patients and carers. Subscriptions are a suggested minimum donation of £15, \$25 or €25 a year.

- Make a difference straight away by making a one-off donation
- Sign-up for a direct debit and support us monthly – please call 01789 450 564
- Continue to support us and renew your subscription

In return for your donation, we will offer you:

- Access to the subscribers-only area on the STARS website
- Discounted rate for you and your family at STARS Patients Day.
£50 per person full rate/subsidised rate £25 per person (a saving of £25 per person attending)
- A full information pack
- Access to all STARS resources to download
- A printed copy of the STARS newsletter twice a year
- Access to 'Ask the Expert' when your query is forwarded to our STARS medical advisors for their opinion

Name		Address	
Telephone			
Email		Postcode	
I would like to make a donation/subscription to STARS of £ <input type="text"/> Please find enclosed a cheque made payable to STARS			

giftaid it Gift Aid is a government scheme which allows us to claim back from HMRC. For every £1 donated, we can claim an extra 25p. To enable us to claim gift aid you must be a UK taxpayer and pay an amount of income/capital gains tax at least equal to the tax to be reclaimed on your donations. I would like Syncope Trust And Reflex anoxic Seizures (Registered Charity No. 1084898) to reclaim the tax on all donations I make on or after the date of this declaration until I notify them otherwise.

Sign Date

Update your contact details

STARS is seeking to update records in order to ensure we offer the most relevant and up to date information to each of our members. Please complete the following form and return it to STARS. We would like to reassure you that we will not share personal data with any third party outside of STARS, its sister charity AF Association and our umbrella charity Arrhythmia Alliance.

Name		Address	
Email			
Telephone number			
DOB			
Ethnic origin	Diagnosis	Tests carried out	
GP practice		Name of GP	
Hospital attended		Name of Consultant	

Help us to help you

STARS relies on volunteer help and support. If you are able to support the charity – even with a few minutes of your time, please indicate below. **I would like to learn more about:**

- Sharing my case story
- Volunteering
- Involvement in awareness activities (eg Press and film interviews)
- Fundraising activities
- Joining the STARS Forum
- Reviewing patient literature
- Attending a STARS meeting
- Donating