

## Anita's Story



My problems with pre-syncope spells began 13 years ago when I was 16. I had multiple dizzy spells when standing up the kind that most people have had at some point in their lives, maybe when standing up from a hot bath. Everything closes in and goes black and blurry. The GP put it down to hormones and being a teenager. The spells became more frequent and caused me to collapse to the floor, though I never lost consciousness. I was referred to a neurologist who also dismissed it as the result of being a young female.

So I left for University in Newcastle, and when the problem didn't seem to settle down I again saw a GP. Fortunately she'd just heard of a "Blackouts and Falls Clinic, run by an eminent Professor. I had multiple tests – MRI brain scan, echocardiogram, ECG, 24-hour ECG tape, 24-hour BP, tilt test etc. It was embarrassing being the only person under 60 in the waiting room but I was glad it was at least being investigated!

I was treated for postural hypotension with fludrocortisone, but not before I'd tried all the conservative measures first – drinking 2-3 litres of water daily with 6 cups of coffee, as much salt as I could eat, wearing strong support tights at all times and no alcohol...none of which was any mean feat for an 18 year old at university!

The problem improved a little, though there were always peaks and troughs. I finished my English degree and decided to train to be a nurse: not a conventional career move, but I have no regrets! However, as I progressed through the course in Liverpool, I had a lot of problems as the shift-working – especially the night shifts – seemed to exacerbate my symptoms.

I was referred to a pharmacology team at Liverpool, where a consultant said, "I have no interest in your condition" (his exact words). I was devastated that my dream of becoming a nurse might be over, simply because a medical professional couldn't help me and refused to refer me to someone who could. He indicated on many occasions that he thought it was just "stress" and that I was "highly strung". I couldn't make him see that the cause of my stress was simply that I couldn't stop falling over or going very faint in specific circumstances, such as standing up, yawning or shouting. There are many other strange triggers such as take-off and landing on air flights and blowing up balloons, but these are easier to avoid and don't affect my daily life!

One traumatic day I was working on coronary care and ended up in A&E myself, where the doctor gave me drugs for vertigo. After this I finally managed to get a referral to the Cardiothoracic Centre in Liverpool. The consultant here took my condition more seriously, reassuring me it was a medical problem and not one I was making up. He repeated some tests, tried me very briefly on a low dose of midodrine, and then inserted an arterial line in my arm for a few hours to prove that it was my heart rate rather than my blood pressure that was causing the main problem. This was embarrassing as CTC was my base hospital as a student nurse, so I went from following these doctors and nurses around to being on the receiving end of their care! But the end result was that he put me on a beta-blocker and things did improve so that I could qualify as a nurse.

Unfortunately, though the beta-blockers helped the problem never went away. I still had bad days and good days, and really acute periods as well as great weeks where it didn't bother me too much. However, after a while things got out of hand, partly due to the side effects of the beta-blockers. I was really upset at having to take time off work sick for the first time, had no consultant in Manchester and a GP who didn't seem to know what to do. That is when I contacted STARS after a desperate web search for ideas. I was given the name of an appropriate consultant and finally managed to see him in May. He was very supportive and I was so grateful that he understood the impact this was having on my life – not just my job, but my ability to do hobbies or even day-to-day activities like climbing a flight of stairs. He also promised to help me enjoy my forthcoming wedding rather than just “get through” it without falling over.

I was really appreciative that it was being taken seriously after so long, and I'm pleased to say I had a wonderful wedding and honeymoon! I was put back on the fludrocortisone but am currently coming off it for a repeat tilt test. I would just like a definite diagnosis, though I've been warned this may not be possible. While I am very glad the condition - whether it is postural hypotension, POTS, Vasovagal Syncope, bits of all three or something else – is not life-threatening, it does have an impact on my life and it's hard accepting that I can't do everything that I want to do. But I try to carry on and not let it stop me having a go!

## Anita's update

I used to be a community nurse. In September 2007, following deterioration in my long-term health condition (then treated as "postural hypotension and benign sinus tachycardia"); I had another collapse at work and was sent home until I could see the Occupational Health team. This was the beginning of the end for my nursing career – a job I loved and still miss. I was devastated and fought to come back to work. My employer did make the temporary "reasonable adjustments" as required under the Disability Discrimination Act, to allow me to work in clinics where I would not be alone. However, at another tilt test in October 07, I was given a diagnosis of postural tachycardia syndrome (POTS). I can remember driving home later, knowing it was probably the last time I might be allowed to drive, and aware that with the loss of my driving licence came the loss of my job. District

nurses can't travel to many patients without a car! In Retrospect, this was the push I needed to accept that, driving licence issue aside; my nursing role was untenable in my current state of health.

I continued to keep in contact with my line manager at the Primary Care Trust and she followed procedure while we waited a frustratingly long time for Occupational Health and cardiologist reports. But it was quite clear that we were now in the realms of re-deployment. By law, the employer has to try to offer an alternative role, if there is one available – not necessarily of the same level of responsibility or wage, only what is available and suits the employee's skills. Naturally I applied for other jobs while I was off sick as there was a very real possibility that there wouldn't be a suitable role with my current employer.

I got good feedback from an interview I had with a private firm, although I didn't get the job. However, there were many other roles for which I was very well qualified but was not invited for interview. Many of the application forms asked for information about disabilities; I cannot prove anything about why I was not selected for interview, but received no feedback when I requested it. The longer I was off sick, the more I started to lose confidence in myself and my abilities. I also felt my choices were now hugely limited by my disability.

I tried to stay as healthy as possible, physically and mentally, and so I made myself go for a short walk every day. I tried hypnotherapy, relaxation techniques and private therapy. I was lucky to have amazing support from my husband, friends and family. I logged on to the STARS message board every day and found huge comfort in knowing others understood my worries and could help answer my questions.

In January 08 I finally managed to have a meeting with my line manager and an HR representative, with my union rep present. It quickly transpired that my options were to drop 2 to 3 pay and responsibility grades. Despite the wage decrease, I decided that "a job" was infinitely better than "no job", and that returning to work, at whatever level, would help me re-build my confidence and increase my office-based skills. So I applied for one of these roles and had an informal interview. The lovely manager felt that there must be a role more suited to my qualifications and experience – so she looked at the vacancy list, found an office job at my previous level and arranged an interview.

Despite suffering pre-syncope spells during the interview, I was offered the post subject to a short probation period. I was so nervous when I started work again, partly as working in an office job was new to me, and partly because I couldn't expect my new colleagues to help and support me as my friends always did. It's not easy trying to make a name for yourself in a new career when you collapse or sway "drunkenly" on the way out of meetings! However, my colleagues have been extremely supportive and so has my manager: he changed the filing cabinets so I could avoid bending and crouching, ordered a fan to cool my side of the office and is

supportive of time off for medical appointments. I also received invaluable support from Access to Work, which is affiliated to Job Centre Plus, to help people with disabilities get back to work.

I believe I was helped by the fact that I was prepared to consider what I can do, rather than what I can't, even when that meant giving up my nursing career and some of my independence via the driving licence. The happy news is that a year after I first went off sick I am now very settled in my job and my health has improved somewhat. I still can't do all the things I used to do, but I am out of the worst phase (for now - I know it often goes in peaks and troughs). I recently saw an eminent professor in London who plans to carry out more investigations in order to nail the diagnosis and look at potential treatments again...but I'll have to wait a year or so as I found out recently that I am expecting a baby! I know I will have many more ups and downs and will need plenty of support and advice from STARS and its members on this particular journey to start a family, but I am so much more confident about dealing with it all than a year ago.

I have been truly fortunate that I have such an understanding manager and a supportive employer - I know everyone is not so lucky. I am also aware that many people with NCS, POTS and other conditions collapse more frequently than I do and are more incapacitated afterwards, which may make working much more difficult and a potential risk for an employer. So I just want to wish lots of luck to anyone else going through a similar situation. Keep positive, find out your rights, be prepared to adapt and change, and keep believing in yourself. You have skills and experience which will be valuable to an employer in some capacity – and you may even be able to work from home or start your own business, or work freelance if that suits you better. Don't give up hope! I try to carry on and not let it stop me having a go!

**Anita Kiernan Manchester**