

## Living with SVT, treating it with ablation and complications later needing a pacemaker



I've had supra-ventricular tachycardia (SVT) since I was 10 (first attack a complete surprise, after a primary school swimming lesson) and am now 35. The attacks continued through my teenage years, sometimes more frequent, sometimes less. I had the classic symptoms – sudden onset racing heart pounding throughout my body, feeling clammy, sick and sweating. If I talked, I would be breathless.

I was referred to a cardiologist as a teenager, but we never managed to capture my attacks on 24-hour monitor or ECG. As my blood pressure, general health and 'usual' ECG were all fine, doctors were sure it was SVT and reassured me that it was harmless and I'd probably grow out of it. In the early years, the attacks stopped easily, normally as soon as I lay down.

As I got older, the attacks continued. I never smoked, but general triggers for me were more than two drinks a day containing either caffeine or alcohol, bending over more than a couple of times to pick things up, jetlag (though maybe that was also because I tended not to be able to avoid caffeinated drinks on planes or when tired!) and laughing too much (which was quite a shame!). After one particularly bad attack, I gave up caffeine for a year and didn't have a single attack. Gradually though, even though I stayed off anything with caffeine, the attacks came back. I never let it stop me though – I had medicals regularly, checked my blood pressure, never smoked and avoided caffeine (wasn't quite so good at avoiding alcohol!). When an attack happened, I just dealt with it, taking myself away somewhere to lie down until it stopped. In the meantime, I learnt to scuba dive (which I still love, and have never had an attack during), travelled very extensively (only very occasionally having an attack in a difficult place, once on a plane mid-Atlantic, another time in the back of minibus in Kosovo!) and living and working overseas (Kosovo, Sierra Leone, Philippines, Pakistan and the Caribbean). I was so used to the SVT attacks and had had them for so long that they didn't scare me. I was calm when they happened, and they always stopped eventually.

Over the years, however, my SVT attacks were getting more frequent, often lasting a couple of hours and generally harder to stop. Just lying down didn't work, and I'd be banging my chest, splashing cold water, holding my breath, bending over, standing up, walking around and then lying down again etc to get them to stop. They always did stop eventually though, with that strange lurch where you can feel your heart stop racing and just stop, then quietly start up again, a bit irregular and then back to usual again.

I was also starting to notice more symptoms with or after attacks, including migraines and flashing lights in front of my eyes. I went to my GP for reassurance that the attacks were still harmless. The additional symptoms and the increasing frequency of the attacks (every two weeks at that point), however, rang alarm bells and I was referred to a cardiologist.

### Cardiology assessments

I got an appointment (7 weeks' wait because of summer holidays) and knew that the first thing would be to be fitted again with a 24-hour monitor, and how difficult it would be to catch an attack during that time. Then, the morning after I made the appointment, I had an

SVT attack and, with the agreement of NHS Direct, went straight to our local hospital to get them to take an SVT ECG. As luck would have it, it was a Saturday morning, and I was the only patient in our local Accident and Emergency (A&E) unit. They did the ECG during the SVT attack, and a range of other tests (blood tests, blood pressure, chest X-ray etc). It turned out that what I'd got used to during attacks was actually very fast indeed (my pulse rate was around 250 beats per minute (bpm)). My blood pressure was also high during the attack. In the end, they decided that the SVT had to be stopped with Adenosine, and it worked like a charm – within two minutes, my pulse was down to 80-ish and blood pressure was falling back to normal. As I'd had Adenosine, I had to be admitted to a ward for observation for a few hours, and they fast-tracked my appointment with the cardiologist to the following Tuesday.

My appointment with the first cardiologist was straightforward – I had an ultrasound of my heart (normal) and he had copies of all my A&E test results. He explained, that at 250bpm, my heart was going so fast during attacks that I should seriously consider ablation to stop the condition entirely.

Ablation is not offered at our local hospital, but within ten days of being referred to our regional centre, one of the specialist arrhythmia nurses phoned me and we had an initial discussion about the procedure, benefits and possible risks. She talked through the process, referred me to the A-A website for further information and remained on call to answer questions I had (I emailed and phoned her three times with small questions pre-procedure and she always replied within a day). I decided to go ahead and was given an appointment for ablation as a day procedure about eight weeks later (August 2008). In the meantime, I returned to work.

Five days before the procedure, I went to the hospital for a pre-assessment (another ECG, blood tests, a detailed discussion with the arrhythmia nurse, including going through the consent forms and checking that I wasn't pregnant as the procedure involves X-rays). She explained everything in as much detail as I wanted and accompanied me to the various tests. I left the hospital confident about the procedure the next week.

## **The ablation**

The ablation was booked for Tuesday. I had a lovely day out in London on the Monday with friends, had dinner that night (then no food after midnight) and then a couple of glasses of water at 6am on Tuesday (no water allowed after 7am). Day cases arrive at the hospital at 7.45am, and I was there a little early (I'm terrible for being late for things, so was determined to be on time!). There were eight patients in total, two of us there for SVT catheter ablation. We were checked in and talked through the day by the nurse assigned to us (there were four nurses for the eight of us) The doctor visited us briefly to introduce himself and check all was okay. I changed into my gown, had a canula put into my arm and a blood test, and was called into the lab by 8.45am. I walked down to the lab with a nurse and arrived as they were finishing setting everything up. Everyone was very friendly, introducing themselves and explaining what they were doing and why. I had the first dose of sedation and local anaesthetic and everything got underway. I was calm, and not in any pain (actually quite fascinated by what was happening) so I didn't have more sedation (although it was always on offer if I needed it). Instead, I stayed fairly awake to watch what was going on (pictures of heart and electrical traces were on a series of screens for the doctors, but they were all explained to me and turned so I could see them sometimes too). I could feel the catheters going into my veins initially (I had 5 in total, 2 in one leg, 3 in the other) but could not feel them actually inside my body, and there was no pain. I knew they'd try to trigger an attack to see exactly where the fault lay – and they did this using

electricity to simulate an extra heart beat, and then again also after they'd hooked me up to an IV drip of a drug to speed up my heart. My heart dutifully went into SVT and they were able to identify the second pathway in my AV node that they needed to work on. This was a huge relief for me as I was actually most worried that they wouldn't be able to trigger an attack and that the ablation would have to be aborted. They carried out the ablation (there was a separate room within the lab where the tests etc were assessed and the technicians were based, so the room I was in was very calm and quiet). They then tried to trigger another attack but couldn't, so were fairly sure they had fixed it. I was wheeled back to the ward, moved to a bed and not allowed to move my legs for 4 hours to allow the 5 small cuts in my groin from the catheter placement to seal up.

Overall, the procedure took about 3 hours – which is a bit longer than usual I think. The team were lovely throughout, with the sedation nurse staying in the room and chatting with me almost the whole time (except when he had to leave because of the X-rays) and the doctors coming in regularly to explain what was happening. If I'd wanted to be completely asleep and more sedated, I could have been – it was entirely my choice not to be, so if you wouldn't want to be awake, don't worry!

As soon as I got back to the ward, I had another ECG and was hooked up to a blood pressure monitor, then the nurses brought me water, a cup of tea and some jam and toast (after no breakfast, I was hungry!). Then I read for a few hours and dozed. After four hours, another ECG and more blood pressure tests, I was allowed to walk around. I only managed a few steps before one of my cuts started to bleed, so I had to stop and the nurse cleaned that up. All was fine after that though, and I had a couple more hours of relaxing, reading and talking to other patients. The doctors came round at about 5pm to talk through how everything had gone, any questions and concerns and what next, including that although they were confident they'd got the rogue pathway, ablation is not 100% guaranteed and I might need further follow-up treatment. After the procedure, the heart would also take 4-6 weeks to settle down back to normal and recover from the treatment. Overall though, they were happy with how it had all gone.

At 6.30pm, I went home, walking slowly because of the catheter cuts, but feeling OK.

### **An Update – three weeks later, needing a pacemaker**

About a week after the ablation, I started to have dizzy spells when I was eating (especially if I was standing up at the same time). At first, I ignored them but, when they got frequent and worse, with my vision blacking out, loss of balance, nausea etc, I reported them to the medical team at the hospital and they arranged for me to have a 24 hour heart monitor test. The monitor showed that I was having periods of heart block – short episodes where the atria of my heart were beating, but the ventricles were not for over 7 seconds at a time, before returning to normal. The hospital received the monitor back at 2pm, and reacted very quickly, calling me back in within a few hours. I was admitted as an in-patient that evening and put on to a heart monitor overnight. The doctors explained that I needed a pacemaker, which would sense when my heart was beating normally (and do nothing) but would know if my ventricle had failed to beat (and, if so, trigger a beat using a mild electrical current).

I had nothing to eat after midnight, and the pacemaker was implanted the next morning. It took about 90 minutes – and was more uncomfortable than the ablation had been (as the doctor had to make a hole for the pacemaker to go into) but not too bad, and the team were

lovely again. The doctor kept the cut quite small (about 3 inches) and neat. I was back on the ward for lunch, feeling fine but a bit sore and with a heavy left arm (you have to be careful not to move your left arm too much so as not to disturb the pacemaker). To avoid infection, I had two injections of antibiotics before the implantation and several sets of pills in the five hours afterwards.

The hospital staff were all great, other patients friendly and the food not bad. But it is hard to sleep in a ward where there were lots of heart monitors bleeping etc, so I was keen to go home that evening if I could. After lunch and a few hours rest, the cardiac physiologist came around to give the pacemaker recipients an ECG and pacemaker check, and then I was wheeled down to the X-ray department to have a chest X-ray. Both of these were fine, so the doctors agreed I could go home that evening (after dinner and the final set of antibiotics).

I'll need a check up 6 weeks after implantation and, after that, annually (checks are done by just placing a monitor over the site of the pacemaker). When the battery starts to decline, the pacemaker will need to be replaced (around 6-7 years, in my case).

The pacemaker will be my own little internal insurance policy, kicking in when I need it and allowing me to go back to a normal life without worrying about my heart. The hospital responded very quickly after my heart monitor test. Throughout this whole process, the NHS treatment I have had has been excellent – all the doctors, nurses and technicians lovely, responsive and thoughtful. The pacemaker was never what I expected before the ablation, but I always knew and understood that it was a risk, and the overall outcome (normal life, no SVT, no heart block) should be fine – and that is the most important thing.

#### **And the final update – after four months**



My pacemaker is doing its job well – I haven't had any dizzy spells or blackouts since it was implanted. It took a while to get used to (emotionally and physically), but I'm back at work overseas, travelling a lot and I've even been scuba diving recently, all with no problems.

Nicky, January 2009