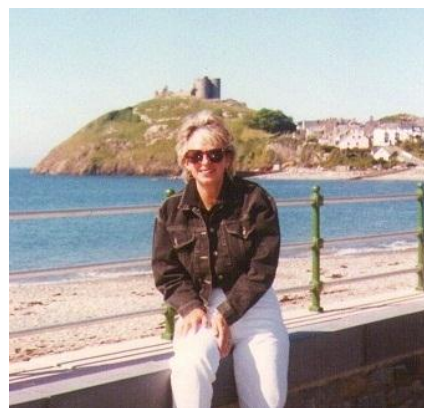


Living with the Rare heart rhythm disorder “Inappropriate Sinus Tachycardia”

It was in February 2007 I woke up as normal but after being up for a few minutes I had a cramping feeling in my chest , I did not know what it was I felt ok, I have arthritis in my spine and thought maybe it could be this, but as the morning wore on I became unwell, feeling nauseous and so tired, I went to the doctors and he said I had had an angina attack, I didn't know what that was, he gave me some medication to take and said come back to see me in few days and we will check your BP and pulse see how you are feeling, but I didn't get that far, the next couple of day I kept getting palpitations and on around the third day after the initial even I got palpitation every time I moved, so odd !.. my heart was galloping madly, when I check it it was 160 bpm, but I was not doing anything in particular it would not stop, it was as though it was stuck, this was the beginning of the road to my diagnoses of IST and a life changing illness ...



Nothing has ever debilitated my life to this degree ...I have always had a fast heart rate in my younger years and never new why, but it did not seem to be an issue, nothing to concern me as I had to work hard to get my heart rate up just like any other normal person, knowing the parameters used in the gyms (aerobic mode and anaerobic mode) and that these sort of parameters being quite hard to achieve under normal circumstances. But now with IST it does them without even trying..... I did suffer with an awful lot of unexplained tiredness, I suffered blackouts in my teens again no explanations for this, I seemed to grow out of them by the age of sixteen I had a normal life, worked, married, raised a family, looking back I wonder if the blackouts could have some link to what has happened to me now, did I have this condition but to a milder degree?...

Inappropriate sinus tachycardia is a debilitating chronic heart rhythm disturbance whereby your heart rate gives huge exaggerated responses to normal activity and is constantly fluctuating for what seems to be no reason ... it rapidly accelerates with minimal exertion, it makes trying to live a normal life very difficult, you are constantly compromised by your heart rate and bodies inability to adjust normally... It gives rates in the realms of SVT levels every time you move and try to be active, it is erratic and life altering, It literally means you have no endurance levels and find sustaining activity very difficult **IST**, is a difficult condition because it is difficult to control even with medications ... it is quite surreal, you can hardly believe what is happening, a heart rate that is so exaggerated it does not seem possible, research is needed into why this happens, it is as though you heart cannot regulate itself anymore, it's constantly fluctuating

An overview of what a typical day is like for me, when I get out of bed my heart rate will accelerate very quickly to 130 bpm and will continue to give bursts of high rates of up to 150 plus bpm with pounding, galloping, palpitations and breathlessness whilst doing the most simplest of things, like walking to the kitchen, making a cup of tea, trying to get washed and dressed, you hit the ground running all of the time, you have had your heart rate in (anaerobic) mode on multiple occasions throughout the day without even trying ... (it is uncomfortable and unpleasant) ... also hard for your body to sustain because you are not actually exercising, your body feels like it is running a marathon and is exhausted all of the time ... I need to lay down and rest frequently because the severe tachycardia leaves you very fatigued and laying down periodically to help alleviate the symptoms, it is also a coping strategy and coping strategies have been my only ally... It is a tiresome situation, something happened to me to change the way my heart reacts, it went from normal to inappropriate over night ... (It has blighted my life)...

My body is in total chaos every day, it brings incapacitating fatigue, exercise intolerance, breathlessness, heat intolerance, dizzy spells, chest discomfort and numerous symptoms.... Some days I cannot even leave the bed because the tachycardia will not relent and the fatigue is all consuming.... family and friends go about a normal life, they have no problems sustaining activity, they glide from one project to another, whilst I have to keep stopping and resting, I have to pace myself now in everything I do because I cannot keep up anymore, I miss out on so much in life, I used to enjoy going on walks with my husband and normal activity was never a major problem like it is now, it's also hard when wanting to socialise as you are always over tired and feel the need to rest and lay down and so decline offers

Forgetting what normal is - a type of evolving! After suffering for so long, you find you have evolved into a different way of life, after going through so many stages of frustrations and grief for the life you once had, no longer having the freedom to just get up and go out at a moment's notice, everything has to be carefully

planned, no more shop till you drop!. always feeling to unwell to join in with any activities or offers or invites, struggling so much, I am lucky if I can achieve a visit to just one shop without encountering problems ...

lower my expectation, it has been better to take each day as it comes because the symptoms can be quite incapacitating the fatigue can render you housebound, even bed bound if you have tried to over exert yourself even by a small amount, exercise intolerance is a very disabling feature to IST...I found I was becoming more secluded, housebound, feeling vulnerable, I had to lower my expectations, adapt my life massively to cope...I find it has altered my attitude to what is important in life.....

My Story seems to be typical of IST - I underwent all the usual tests for tachycardia, the twenty four hour urine test to check for a tumour called a phycromocytoma, I had ECG monitors on for 24hour periods and then I had monitors on in the hospital, I had treadmill tests, also a telemetry ECG recorder on many occasions whilst on the ward to monitor your movements, whilst on this type of monitor the nurses were concerned when they could see that my heart rate soars to 155 bpm whilst having a simple wash and cleaning my teeth standing at the sink (they said this is clearly not normal) ...but this is how your heart behaves with IST, high rates for minimal activity, (it does this every time not just occasionally) very debilitating, it is as though your autonomic nervous system is broken ...

I was in and out of hospital on numerous occasions all of the monitoring showed very unrealistic high heart rates for my activity, I was eventually diagnosed after they felt they had excluded other causes that could be causing the severe tachycardia , my cardiologist informed me that IST is a rare rhythm disturbance ... my story seems to be typical of IST patients, presenting at the hospital with high heart rate and no explanation as to why ... the doctors struggle to find answers because IST is rare ... the IST patients stories I have read, it seems that the same scenario ensues, (a severe unrelenting tachycardia) a very persistent type of rhythm disturbance... I was told that IST is closely linked and is an overlapping syndrome with Postural Orthostatic Tachycardia Syndrome (POTS)

Gaining help and Support I was fortunate enough to come across a support group which was set up by a patient with this condition and this is where I started to gain help and knowledge of IST, and how to begin to cope with this condition, I learnt that IST is difficult to treat for many and so coping strategies became a huge part of my life There are people who are affected to varying degrees, which makes me think I could have had this in my younger years but not to this very severe degree as mentioned earlier in my story .. Some of us are very disabled by the condition and this is where I feel I fit in because I have been quite debilitated by the severe and incessant unrelenting daily tachycardia, whilst others maintain some normality and are helped by the medications Some have had ablations and pacemakers with varying degrees of success.... Procedures like this may not to be recommended for all ...

Coming to terms and having to accept what is! the symptoms have remained the same throughout, but I cope with it differently, I have evolved in to this (new normal) which is way out of line with normality, your new normal literally means you are living a very different life from what you grew up with, a very limited lifestyle that means you have to cope with chronic illness, like I said you seem to evolve, come to expect less of yourself and accept what is! ... I feel the most disabling feature to IST is the exercise intolerance because you are already compromised from the outset ... you can't afford to stress and waste precious time looking back, life now has to be different to cope with this condition, over the past four years I have had help from the cardiac specialist nurses, my family and husband have given me a huge amount of much needed support and help.

It is very debilitating how the tachycardia and fatigue limit what you can do and make you feel tired all of the time, trying to be more active just floors you when you try to sustain activity and I mean the most simplest of activity ... the frustrations can get to you having to adapt your life, it has been a life changing experience, I have to plan more carefully now, how far I have to walk, can I achieve what I am expecting to do !... do things slowly and try to ask for help if I need it, it is such a debilitating condition, You have no normality anymore

As said earlier, my coping strategies are my only ally, there was something that changed my life in 2007 and whatever caused this to happen it was very like throwing a spanner in the works...

Kathy