PATIENT EXPERT PERSONAL STATEMENT

FOR MRS MICHELE ROSE TURNER

AUGUST 2014

I have been nominated by **STARS** as a patient expert.

My answers to your questionnaire are as follows:-

- **Do you wish to agree with your nominating organisation's statement?**

To my knowledge STARS have not submitted a statement, therefore I am unable to comment on this.

Are you a patient with the condition, a carer of a patient with the condition, a patient organisation employee or volunteer?

Yes - I am a patient with the condition.

- **Do you have experience of the treatment (s) being appraised (that is, those included in the title)?**

Yes - I have a dual-chamber pacemaker for treating symptomatic bradycardia. As for the sick sinus syndrome without atrioventricular block I cannot comment on this. I was never told what exactly was causing my collapses. I was, however, informed my condition to be that of malignant syncope.

LIVING WITH THE CONDITION

- **What is your experience of living with the condition as a patient or carer?**

On reflection I probably had issues with syncope long before I knew anything about the condition.

Initially I would feel quite tired, nauseous and light headed. Sickness and diarrhoea followed which left me feeling exhausted, extremely cold and very dizzy. At this point I would collapsed. If I were alone I would have to stay where I lay. I simply did not have the strength to move myself to a safe and warm place. The only way to describe this is to say it was like having a switch and someone turned it off. All my energy would seep away as if slipping down a drain. From here on in I would fall in to a sleep which could last for hours. My first recollection of these symptoms goes as far back as 2006.

When somebody finally found me an ambulance would be called. It then took the paramedics quite a while to stabilise me. My blood pressure would be really low, I would be hypothermic and my heart rate very slow. Upon arrival at hospital I would have a drip

connected and blood taken. Following this I eventually came round. I would then be allowed home feeling fine.

After this had happened a couple of times I was finally admitted to hospital. It was thought I may have Addison's disease. I was tested and the results were negative. The Doctor who admitted me did say if the problems were caused by a slow heart I need not worry as a pacemaker could be fitted.

The following is what occurred over the next few days and months:-

Sunday 14 August2014 (Bradford Royal Infirmary)
I woke up fine and was ok until lunchtime. Once again I started to feel dizzy. I called for a nurse. The diarrhoea started but no sickness. From there on in I have no recollection of what happened to me apart from what others told me.

Apparently a number of Doctors and Nurses were in attendance trying to stabilise me. I was attached to a 12 lead ECG and my heart rate was really slow. Drugs were administered in order to deal with this. My blood pressure went through the floor and I was hypothermic. I was put on a drip containing a warm solution to help with the hypothermia. I had another drip attached with antibiotics (no one seemed to know what was going on or what was wrong with me) as a precaution. Oxygen was also given as I had breathing difficulties. I also had the feeling that a large heavy weight was pressing on my chest.

For clarification this can be verified in my medical records.

Monday 15 August (BRI)
24 hour heart trace monitor attached.

Tuesday 16 August (BRI)
Around 5:00am I felt dizzy and nauseous and had diahorrea. I think I slept until the doctor arrived. I managed to stay awake and speak to him although I was extremely tired. Slept for rest of the day.

Wednesday 17 August (BRI)
Went for a CT scan of brain and bowel. When I had to drink the fluid for the scan I became really cold once more and had to be moved from the wheelchair to a trolley as I was shaking uncontrollably.

Thursday 18 August (BRI)
Discharged.

Saturday 20 August
Early hours of the morning I went to the toilet. I felt sick and really cold. I managed to get back to my bed and promptly fell asleep until the following morning.

Tuesday 23 August
Mid morning I felt sick and dizzy. I went to lie on the bed with my feet raised. Once again I became really cold and had to get under the duvet. I awoke an hour and a half later.

Monday 12 September
I returned to work (part time legal secretary) but was really tired when I came home.

Tuesday 13 September
Went to work but had to return home early as I felt so ill and tired.

Wednesday 14 September
Around 9:30 I had diarrhoea and lost all my energy. On this occasion I did not lose consciousness and managed to crawl on my hands and knees to reach for my mobile phone. Rang the Doctor who sent an ambulance. Was taken to BRI A&E. Discharged around lunchtime after being checked over.

Thursday 15 September
Attended the GP's. She put me on the sick for 2 months as she was seriously worried by my extreme exhaustion.

Tuesday 27 September
Attended Sheffield Northern General Hospital for food allergy testing. Results were ok. Also had blood tests for tryptase and this too was ok.

Whilst on my 2 month sick leave I felt very tired and found doing everyday things exhausting. I did manage to do some things with the help of lots of rest time and warm drinks.

Tuesday 1 November
Appointment with Cardio Respiratory Department. It was arranged for me to have a tilt table test.

Wednesday 30 November
This took place on the above date.

The standing for a length of time did not cause a response, however the administration of a substance under the tongue did result in me collapsing. Again I was left feeling extremely cold. I was also put on a drip and left to recover in a side room. Later that evening my husband came to collect me.

2 December
Appointment with Neurologist. All was well here.

5 January 2012
When I went to discuss the results with the Syncope Nurse she informed me that what happened was exactly what they expected. She informed me that she would need to speak with a cardiologist, however in her opinion it was probable it wouldn't happen again and I needed to learn to live with it. The cardiologist came to speak with me. Upon speaking with him I was alarmed to learn that I did not need to go away and learn to live with it and I would actually require a dual chamber pacemaker. I was told however, he could not do it immediately. He went to check when I would be able attend for surgery. He returned and told me he would do the surgery one week later. This came as quite a shock to me. He also informed me that the pacemaker would stop the collapses however it would not stop the low blood pressure and that I may still experience problems relating

to the low blood pressure. I was told if I should feel unwell I should stop what I am doing and take a rest and warm drink. If I do this immediately, it usually takes around an hour before I feel back to my normal self. However, if I am out and about when I feel unwell and cannot sit down and rest I must get home as soon as possible. It usually then takes around 24 hours to recover and leaves me feeling tired for a few more days.

12 January 2012
I had surgery to implant my dual chamber pacemaker.

This concludes my history of Malignant Syncope.

The following are my replies to your bullet points in the hints and tips leaflet.

- **The benefits and downsides of the therapy:-**

  The benefit of having my pacemaker is that it enables me to have a better quality of life.

  Without the therapy my life would be very unstable. I do not wish to think about what could have happened to me if I did not have my pacemaker.

- **How does the therapy compare with other therapies:-**

  I cannot comment on this as I have had no other treatment other than my pacemaker.

- **What difference (if any) has the therapy under appraisal made to you?**

  It has given me back a better quality of life.

- **What would be the implication if the therapy was not available?**

  I can only guess at this and I presume I would either have an intolerable life where by I would be collapsing all the time (and probably bed bound) or may even die.

- **What is the impact on your home life, social life and your ability to work?**

  The impact on my home life is that my husband is always close by. Since having my pacemaker I have had a couple of occasions where my blood pressure has gone very low and I have been left with exhaustion and needing to rest. Some times it is enough to sit in a chair and have a warm drink and on other occasions I am left where I cannot even get out of bed. I am able to have a social life providing I have someone with me to ensure I arrive safe and are able to get home alright. As regards work this is an issue of contention. The job centre feel I am not willing to comply with their regulations when I say I would be unable to travel for 60 to 90 minutes on my own. Driving any distance makes me stressed and tired and leaves me needing to rest. This is a much larger issue which I feel does not need to be discussed in this meeting unless deemed appropriate by the committee. I would be prepared to discuss this in confidence if necessary. As things stand I currently do not work, nor do I receive any benefits. My husband and I live off his state pension.

- **What is the impact on your family and friends?**

  This has a very big impact on my husband as I rely on him greatly when I have an episode of low blood pressure. My family and friends are more aware of my health now and are constantly watching me when in their company to see if I am becoming tired and need to rest.

CURRENT PRACTICE IN TREATING THE CONDITION

- **Which treatment outcomes are important to you? (That is, what would you like treatment to achieve)? Which of these are most important? If possible, please explain why.**

  I feel treatment needs to achieve a better quality of life for the individual.

- **What is your experience of currently available NHS care and of specific treatments? How acceptable are these treatments - which did you prefer and why?**

  When it was realised that I would require a pacemaker this was provided within the space of one week. I most certainly could not have received better treatment from my Cardiologist. This treatment had to be acceptable to me as I believe I had no other choice if I wanted to stay well.

WHAT DO YOU CONSIDER TO BE THE ADVANTAGES OF THE TREATMENT (S) BEING APPRAISED?

- **Please list the benefits that you expect to gain from using the treatment (s) being appraised.**

  Benefits of a treatment might include its effect on:
  The course and/or outcome of the condition

  Pain - After the initial surgery I was left with some pain in my shoulder. I would consider this to be the usual amount of pain following the procedure.

  Level of disability - After taking the initial amount of time recovering and following instructions regarding lifting and reaching, I was left with no disability in connection to the pacemaker.

  Mental Health - Personally having a pacemaker has not caused any issues with my mental health.

  Quality of life - Without my pacemaker I consider I would not have a good quality of life. I would be unable to participate in any activities or events for fear of collapsing.

Other people - Please read above in my statement.

Ease of use - A permanent pacemaker does not fall into this category as once it is in place there is nothing further to be done. The pacemaker will require replacing at some point in the future.

Where the treatment has to be used (for example, at home rather than in the hospital) - Again this does not apply to pacemakers with the exception of the yearly checks in pacing clinic.

- **Please list the benefits that you expect to gain from using the treatment (s) being appraised.**

  Having a better quality and longer life.

- **Please explain any advantages for the treatment (s) being appraised compared with other NHS treatments in England.**

  I am unable to comment on this as I have received no other treatment. Therefore I am not in a position to compare with having my pacemaker.

- **If you know of any differences in opinion between you and other patients or carers about the benefits of the treatment (s) being appraised, please tell us about them.**

  Not applicable

WHAT DO YOU CONSIDER TO BE THE DISADVANTAGES OF THE TREATMENT (S) BEING APPRAISED?

Disadvantages of a treatment might include:-

- Aspects of the condition that the treatment cannot help with or might make worse - In my particular case the pacemaker will not help with my low blood pressure.

- Difficulties in taking or using the treatment (for example, injection rather than tablets) - This does not apply to pacemakers.

- Side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate) - With the exception of initial pain at the surgery site and the limitations after surgery such as stretching and reaching I would not personally say there are any side effects.

- Where the treatment has to be used (for example, in hospital rather than at home) - Again this is not applicable to the pacemaker itself only the pacing checks which are done in hospital.

- Impact on others (for example, family, friends and employers) - I do not consider there are impacts on others with the exception of they are more aware of my health conditions.

- Financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying for a carer) - As I now only have to attend pacing clinic once a year this does not impact greatly on our finances.

Please list any concerns you have about current NHS treatments in England

My treatment thus far has caused no concern regarding current NHS treatments.

Please list any concerns you have about the treatment (s) being appraised.

I am not sure I fully understand the purpose of the appraisal of dual chamber pacemakers. If the appraisal is that they will not be used in the future obviously this is of great concern to me. Without mine I would probably have no quality of life of even face the fact that I could die. As regards to using a different product I would be unable to comment as I do not understand why one is used as opposed to another. This is beyond my scope of knowledge.

If you know of any differences in opinion between you and other patients or carers about the disadvantages of the treatment (s) being appraised, please tell us about them.

Not applicable

PATIENT POPULATION

Do you think some patients might benefit more from the treatment (s) than others? If so, please describe them and explain why.

Once again this is beyond my knowledge.

Do you think some patients might benefit less from the treatment (s) than others? If so, please describe them and explain why.

Again this is beyond my knowledge.

RESEARCH EVIDENCE ON PATIENT OR CARER VIEWS OF THE TREATMENT

Are you familiar with the published research literature for the treatment (s)

No

If you answered no, please skip the rest of section 7 and move on to section 8.

EQUALITY

NICE is committed to promoting equality of opportunity and eliminating discrimination. Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, who they are and why.

Surely if a person requires a pacemaker and it is a cardiologist that has reached this decision then it should be available to each individual regardless of any other factors.

OTHER ISSUES

- **Do you consider the treatment (s) being appraised to be innovative?**

  Again I am only a patient expert and would know nothing of these matters.

If yes, please explain what makes it significantly different from other treatments for the condition. (If this applies to more than one treatment that is being appraised, please give reasons for each one).

- **Is there anything else that you would like the Appraisal Committee to consider?**

  Have any of the committee got a pacemaker in order to be able to understand how it feels to live without one and the difference once one is fitted.

KEY MESSAGES

- **In no more than 5 bullet points, please summarise the key messages of your submission.**

- The appraisal of a pacemaker does not really apply to some of the points listed on your document DUAL CHAMBER PACEMAKERS FOR TREATING SYMPTOMATIC BRADYCARDIA DUE TO SICK SINUS SYNDROME WITHOUT ATRIVENTRICULAR BLOCK, (PART REVIEW OF TECHNOLOGY APPRAISAL 88)

- Pacemakers are fitted for different reasons for each individual

- Impact on life if they were not available