

Call me Heather – A day in the life of a radiotherapy patient

I am in the middle of a six-week stay in London, where I am having fractionated stereotactic radiotherapy for a low grade non-malignant brain tumour. I say 'non-malignant' as I refuse to use the word benign because mine has certainly not been benign in effect. It's cost me a thirty-two-year career in nursing and has left me with a constant sensation of vertigo, fatigue, occasional disorientation, facial pain (as it is compressing one of the facial or 'trigeminal' nerves a bit), and occasional *petit mal* and absence seizures.

My day starts at about 8:30am. I am staying at a friend's apartment in Ladbroke Grove, which is about 40 minutes to an hour away from the Royal Marsden Hospital in Chelsea, where I am having my radiotherapy as an out-patient. I come from Penzance in Cornwall, about 400km away. The hardest part of this is having to live away from my home and my husband for so long. Getting up is not too much of a problem, but with fatigue as one of my symptoms sometimes I really have to drive myself out from under the bed covers.

I have managed to set up a daily routine, and so far have really enjoyed my time in London and am making the most of it as I do not know how the radiotherapy will affect me over time. Certainly there will be side effects and there is already a stabbing pain at the top of my head, and the prickling, numbing and sometimes sharp sensation of pain I started to get down the right side of my face, as a symptom of my tumour, has intensified. As a result, I have recently been prescribed a drug specifically for nerve or 'neuralgic' pain.

My brain tumour is called 'Algernon' or Algy for short. I first became aware of him back in 2010, when I collapsed at work, ironically on a medical ward at the local hospital where I worked as a Registered Nurse in the town where I live. I had begun to suffer from dizzy spells for about three weeks beforehand, and had not been terribly well over the previous winter. Looking back, I remember the number of times I had falls, usually from tripping over something or just seeming to lose my balance, over the years. There was something else I was occasionally getting which was suddenly feeling faint or if waking up from a doze, the sensation of not being able to move and my blood pressure dropping through my boots.

After a consultation with an ear, nose and throat (ENT) clinic, a problem with my core balance was identified and so I was referred for a CT (Computed Tomography) scan. This was done at the hospital where I was working at the time and I knew the radiology staff there. The procedure was explained clearly, including any risks, because although different to standard x-rays, it is still a radiological procedure that uses x-rays with computer technology.

After explanations, I was assisted on to the scanner table; a cushion was placed under my knees to keep me comfortable as the table moved under the scanner, taking not very long. If I remember correctly, it took about ten minutes, something like that. Afterwards, the staff kindly helped me up on to my feet. The results at the time would be sent to my ENT consultant after review.

What the CT picked up was a 'mass' impacting on the right side of the pons, which is part of the brainstem. As a result, I was referred for an urgent MRI (Magnetic Resonance Imaging) scan at RCH Treliske Hospital in Truro and also for a neurology appointment at Derriford Hospital in Plymouth.

The MRI scan experience was different to the CT scan. Beforehand, I was sent information about the appointment and also a request to see my family doctor for a blood test to see if my kidneys were ok, as I will need to be injected with contrast medium, which needs to be excreted. On arriving at the department, I was given a questionnaire to fill out about whether I had had any recent surgery, metal implants and so on, in case there was anything that could be affected by the magnet in the scanner.

The scan itself involved being placed in a much narrower and longer 'tube', which I found very claustrophobic. Also, because the scanner at Treliske is second-hand, it is very loud as the magnet spins, well deserving of the name 'Old Clunker'! I was given a set of headphones and a choice of music, or I could bring in my own music, which I did, but not even my loudest heavy rock music could drown out or lessen the intensity of the noise! Also, my head was encased in a frame which for some might add to the discomfort, so it *is* important to speak to the staff beforehand about any difficulties you may have. There is a microphone inside the machine and the staff can speak to you, and will stop the scan at the slightest hint of trouble.

An MRI scan is important as a 3D image can be taken of the tumour, which can provide more detail if needed. I also needed a liquid 'contrast medium' injected in to a vein in my arm, which highlights certain areas and the tumour itself. This wasn't always an easy process, as my veins tend to be reluctant to have a cannula pushed into them, and the experience varied over five sessions in three different hospitals. You have a scan first then the contrast is injected half way through, then the scan repeated. After that, the cannula, which is the tube through which the medium is injected, is removed.

From my own nursing experience it is very important to take your time placing the cannula, by making the patient more comfortable, preferably sitting with their arm resting on a pillow or support. Some hospitals have special chairs for this. In my case, this didn't always happen, and on one occasion the cannulation was very painful.

At the Royal Marsden there was more up-to-date equipment and more experience. As their sole speciality is in dealing with cancers, the staff are much more used to damaged or small veins, so cannulation was much more comfortable. The MRI scanner was not quite so claustrophobic and a little quieter, and there was maybe a little more space in the 'tunnel' as well. The scan, which could take anywhere from thirty to forty minutes at Treliske in Truro and Derriford in Plymouth, took not even twenty-five minutes to complete, even with contrast.

In all three hospitals, I was treated with courtesy by the radiology staff, there were no problems with answering questions and all tried their very best to make sure I was as comfortable as possible during the procedures.

Getting back to the diagnosis. Of course, after Algy was found, it became clear that the 'fainting spells' were nothing to do with having blood pressure problems but actually *petit mal* seizures where the tumour was impacting on the brain's temporal lobe from underneath.

The hardest part about receiving my diagnosis wasn't even the fact I have a tumour in my head, but the consequence of the eventual loss of my job, career, and financial independence. Having to go through the rigours of applying for financial support and a pension, as well as everything else, was very frightening, especially while also feeling unwell.

Initially, I was placed on 'watch and wait' surveillance for two years to see if Algy would progress. Even when the symptoms became more obvious, I felt there was a reluctance to start treatment due to the potential long term effects that can result from radiotherapy. Eventually the tumour had become large enough to cause the symptoms to intensify, including neuralgic pain, and the number of seizures – although not as intense, as I had started medication – certainly were becoming more frequent.

Cutting a very long story short, I was eventually offered radiotherapy, which I could have had done at Derriford Hospital in Plymouth, but I would have had to wait until November 2013, due to installation of new equipment. As a result, I was offered a referral to the Royal Marsden in London, and knowing the wonderful reputation they have, jumped at the chance.

So here I find myself now. I am sitting in a small café across from the hospital (Café Roma if anyone is interested) where I have a cup of hot chocolate and one of their wonderful sandwiches. When done, I head over to the hospital and down to the radiotherapy department for my session. The team there are very friendly and reassuring, willing to have a little chat when setting you up for your treatment.

Let me explain a little about the treatment I am having. Algy is considered inoperable because of his location, so radiotherapy has been offered, the intent of which is to prevent the tumour from getting any bigger and hope that also there could be some shrinkage. I had an initial consultation earlier in the year and it was determined that I should have the longer and more traditional radiotherapy treatment, or 'fractionated stereotactic radiotherapy' where a dose of radiation is prescribed, the dose divided and given over a number of sessions. There are various options and you may have heard the terms 'Gamma Knife', 'radiosurgery', stereotactic etc. These terms refer to the type of machine used, the intensity of radiation delivered and delivery time.

In my case, because of where Algy is in relation to some very sensitive areas of the brain, it was decided to deliver the dose of radiation prescribed over thirty sessions, which is not so intense and less likely to have an impact on the areas surrounding the tumour. For this I have had to be fitted with a mask before I started treatment, to keep my head completely still during the session, which is vital since the beams are targeted very precisely at the tumour and it would not do for the target to then suddenly move! This, for me, was the worst part, not because of any pain but because the mask itself can be claustrophobic to wear as it encompasses the whole head.

Fitting the mask was very quick and painless. It is made from a plastic type material which is heated in hot water, applied over the area to be treated – in this case over the front of my head and moulded around my face. A hole was quickly opened for my mouth and nostrils to enable breathing. Clips were then fixed on the edges of the mask as it is clipped on to the table to secure you.

I was hoping that the Royal Marsden would allow me to take pictures of the stages of fitting but sadly their policy is not to allow any, so I can only go on other people's accounts of the actual session, as I could not see it!

Now I have got used to the routine of going in, lying down and having the mask clamped to the table, I can feel quite relaxed as there is the option of having music played during the session, as with the MRI scans earlier. The session ends quite quickly and the mask is then removed, plus I am helped to sit up as I need to regain my balance before getting off the table. After a quick goodbye, I leave the hospital and depending on how I am feeling at the time, might go for a walk and some lunch, or head back to where I am staying if I am feeling very tired, which does happen.

In all, my experiences with radiotherapy have not been unpleasant so far, but everyone will have a different experience, depending on the type of radiotherapy offered and where. For me the worst will probably come later as the side effects become more noticeable and to that end, my husband will be joining me in London during the last week of my treatment as I have been warned that the fatigue and the disorientation could intensify for a while. I just hope this works and that Algy will no longer be trying to occupy more skull space in the future.