# ***Sue's Sinus***
# ***Update reports***

## ***Update 1 - 23 February 2016***

Sue went to Kidderminster hospital today, expecting to have surgery to remove the nasal polyp and flush out her sinus. In the event, the surgeon decided not to remove the polyp, but to take tissue from the lining of her nose and from her sinus, so that a biopsy can be performed on them.

The procedure has left her with some bruising and swelling around her eye, but she is recovering reasonably well from that, although she looks somewhat strange with an enormous 'moustache' of bandages, which will have to be in place for a few days. She actually feels quite well this evening, with no pain, although she is very tired.

The surgeon will be sending her an appointment for next Monday, which we presume will be to discuss the biopsy results.

Unfortunately, this has not been as conclusive today as we had expected, and we hope to hear more detail next Monday.

Sue thanks you all for your concern, and hopes that whatever treatment is deemed necessary will be done as promptly as she has experienced so far.

## ***Update 2 - 26 February 2016***

After Sue's nasal/sinus biopsies on Tuesday, she appeared to be progressing, but her right eye was giving cause for concern yesterday (Thursday). On instructions from Kidderminster hospital, we went to Worcester hospital for further investigations. CT scans were taken of her eye and facial area. A review by an ophthalmologist specialist concluded that no operation was necessary to relieve the pressure behind her eye. However, the CT scans of her sinus area revealed cancer, with the bone already eroded.

The CT scans of yesterday showed the extent of the eroded bone, which had not been apparent only seven weeks earlier.

She is currently in Worcestershire Royal Hospital, where she is being give intravenous antibiotics and steroids (to reduce the inflammation). We have no idea how long she will be there, but her case notes and CT scans will be sent to the QE hospital in Birmingham, so that its cancer team can analyse them to work out the best way to proceed.

## ***Update 3 - 7 March 2016***

Sue has been to see the ENT consultant at Worcester today, having had multiple CT and MRI scans last week, and the cancer team at the QE hospital has given its opinion.

It seems that it's not as clearcut as it had previously been thought, and that it is actually a malignant melanoma (skin cancer) which is attacking Sue's sinus. This is very rare, and checks now need to be done to find out if it is the primary tumour, or a secondary one - spread from elsewhere.

A consultant dermatologist checked Sue immediately after the ENT consultant, and she will have an ultrasound scan later this week.

Also, a Positron Emission Tomography (PET) scan will be done later this week at Cheltenham.

We will be going back to the consultant at Worcester next Monday for further developments, but at the moment, no news is possibly good news.

## ***Update 4 - 14 March 2016***

The PET-CT scan was accomplished at Cheltenham last Friday, but the results are still unknown.

Sue saw a respiratory consultant today, who stressed (once more) that this is a rare type of cancer and that his job is to look at some strange shadows on her right lung. He will be performing a bronchoscopy on Wednesday morning - that's a thin tube with a camera at the end to see inside the lung, it will also gather some material, either by washing it out, or as a biopsy.

The ultrasound scan and biopsy on a small lump on her thigh will now be performed on Friday of this week, although this is not expected to show anything untoward.

The theory is still that this is almost certainly a secondary tumour in her sinus, so a primary tumour needs to be found.

We will be going back to the consultant at Worcester next Monday for further analysis of test results.

Sue is generally upbeat about her situation, and continues with her raw food diet, yoga and reiki.

### ***Update 5 - 18 March 2016***

The situation has now changed, and there is some reasonably hopeful news.

Sue's bronchoscopy on Wednesday was satisfactory, although results from and internal 'wash' may take three weeks.

The ultrasound on a small lump on her thigh was carried out today and it was benign.

The results of the PET-CT scan had evidently arrived mid-week, and Sue was immediately give an appointment today with a consultant oncologist who specialises in melanomas. The outcome of the appointment is that immunotherapy has been offered in conjunction with radiotherapy, if required. [The specific immunotherapy offered being the newly-licenced Pembrolizumab, also known as Keytruda.]

### ***Update 6 - 30 March 2016***

Sue has started her immunotherapy course today, which will require a treatment every three weeks until it is decided to stop - which may be some months.

The doctors have been concerned that the tumour is growing at a rapid rate, and has already spread to other areas. To give the slow-acting immunotherapy some breathing space to work, it has been decided to act very quickly with radiotherapy treatment. We think the radiotherapy will commence next week, and be a short, but intensive course every day for two weeks (except the weekend in between). There are dangers with this, as the sinus tumour is very close to sensitive areas. Despite this, it is hoped that it will buy some vitally-needed time.

The Worcestershire Royal Hospital has continued to act amazingly fast, in a most professional manner, and we are very grateful. There have been 14 appointments in 37 days, with some booked at a day's notice - such has been the urgency. We are very impressed with the NHS.

Sue continues to be hopeful and determined to beat this cancer, particularly as her treatment has now started, and in conjunction with her own methods - which the doctors don't mind, but can't give them any credence!

### ***Update 7 - 16 April 2016***

Sue continued on her regime of diet, yoga, reiki and keeping busy. The diet includes 2 to 3 pints of organic carrot juice* per day. Morrisons must be wondering why sales of organic carrots have shot up.

The immunotherapy drug is given once every 3 weeks, with the second one being due next Wednesday. The radiotherapy is an intensive course of 10 consecutive days (excluding weekends), with the last 3 being next week.

Early side effects were not expected from the immunotherapy, other than increased inflammation. Side effects from the radiotherapy were not expected until at least after the 5th session. What happened is that Sue had an increase in thirst and her inflammation has reduced. This has surprised the medics. We wonder if it's the carrots! Sue is still expecting some very uncomfortable side effects from the radiotherapy over the next few weeks, as they often occur after the course has finished.

Whilst there is hope that something is unusually good is happening from the various treatments, we also feel it is still early days.

## ***Update 8  -  1 May 2016***

Since the last report, Sue has had a challenging time.  The side effects of radiotherapy to zap the tumour have occurred, with 100s of ulcers covering her mouth/lips/gums.  This is the radiotherapy 'sunburn' effect.  Eating has been impossible, and drinking has been unbelievably painful - even water.  So much so, that the carrot juice has had to stop, and 'complan-type' compounds have been necessary as food.

However, the ulcerated membranes have now generally been discarded (not a pleasant topic) and the pinkish new membrane underneath is looking healthy, although sensitive.  Soups are starting to be acceptable in minor amounts.  Pain is being partly controlled with painkillers, although not fully.

Sue's face is still rather red (sunburnt), she looks drawn and is tired.  Generally, the swelling has gone down on her face, and her eye is starting to move back into position.  Nevertheless, we feel she has now turned the corner, and hope that she will be better within the next two weeks.  She has even done a small amount of driving, as her two eyes are now looking in roughly the same direction.

## ***Update 9  -  15 May 2016***

After the last, somewhat unpleasant update, this one is mostly good news, as the last two weeks have shown a decided improvement in Sue's health.

The ulceration of Sue's mouth has generally cleared up, and she has started to be able to eat mashed or liquidised food without too much discomfort.  In the last couple of days, she has avoided all painkillers.

Sue's right eye is now back to normal, we think, and she has started to drive again.  Breathing has started through her (previously blocked for six months) right nostril, although the left one is now intermittently blocked!

Putting on weight is now Sue's primary ambition.  She has lost about 1·5 stones (9·5 Kg) since the troubles began, and now feels the cold.

In the meantime, Sue's health is certainly looking better, but she will be happier when she can put on some weight, whilst still continuing with immunotherapy treatments every three weeks.

## ***Update 10  -  29 May 2016***

Sue has continued to try to put on weight, but even with five small meals daily, she is only maintaining her weight.  She is now eating normal food, as the mouth ulcers have gone.   She has odd (health) experiences, which are possibly caused by the immunotherapy drug, and appears to be becoming somewhat yellow - probably caused by her high carrot intake!  A blood test two days ago showed her liver to be fine.

Sue is generally getting back to normal life - playing the recorder, getting involved in committees, gardening, etc.  She's also had the OK to start playing the bassoon again.

In two days' time (Tuesday), Sue will be having a CT scan to find out about the effectiveness of the immunotherapy course, but we do not know when the results will be available.  In the meantime, she will continue with immunotherapy every three weeks.

## ***Update 11  -  12 June 2016***

Sue's health has continued to improve, with a very slight gain in weight.

The annual visit to the ophthalmologist found that the dire problems in her right eye of a few months ago have all corrected themselves.

The CT scan was performed nearly two weeks ago, but no results have been reported to Sue. This may be because the consultant is on holiday, or the results are good. We are assuming that no news is good news.

Sue still continues the yoga, reiki and strict diet, including carrot juice.

The next meeting with the consultant is in eight days' time.

### ***Update 12 - 26 June 2016***

Sue continues to feel and look well, although she could do with putting on more weight.

The last two weeks have provided bad and good news.

The bad news is that the CT scan of nearly three weeks ago showed the very small tumour in her liver had grown to about 25mm (1") diameter, and other tumours have appeared in her spleen, together with more in her liver. Sue was also aware of two more just below the surface of her skin - one on her shoulder and one close to her navel.

The good news is that the consultant was pleased with the reaction of the two below the surface of her skin, as inflammation and bruising around them indicated that the immunotherapy is working. Her body's own immune system (encouraged by the immunotherapy) is attacking those two tumours. Although the tumour close to her navel had grown since the CT scan, it is now reducing in size, as is the one on her shoulder.

The consultant is pleased with the situation, and another CT scan in 12 days' time will indicate what is happening to the other tumours in her inner organs. We should know the results of that CT scan on the same day.

Sue still continues with the intravenous course of immunotherapy (every three weeks), as the slow accumulation of the drug appears to be working.

### ***Update 13 - 10 July 2016***

As with the last update, this has good and bad news.

Sue had a CT scan on Friday. There was not time for the radiographer to give a full report, so the consultant had to analyse it himself in a fairly basic manner, about three hours later. His brief analysis was that there appeared to be no new tumours, but the previous ones were still there, and the 25mm (1") diameter liver tumour had grown by another 50%. He was expecting the immunotherapy to have reduced this particular tumour (the most obvious one), and so he is disappointed - although he did add that some of the apparent 'growth' may be inflammation from the immunotherapy.

Sue will continue with the next immunotherapy treatment (in four days' time), but the consultant may well suggest a change of drug at the beginning of August, when the full CT scan report is available. It could mean having some chemotherapy in the short term, whilst waiting for another drug combination to be licenced for use in the UK.

Overall, this was not good news. However, characteristic of Sue, she is still determined to beat it, and has decided to make yet more changes to her diet.

Sue continues to look and feel well, and is holding her weight, but not adding to it.

### ***Update 14 - 24 July 2016***

There has now been the customary two weeks since the last progress update, but there really is nothing new to report.

Sue continues to look and feel well, and is still holding her weight, but not adding to it. She has enjoyed and coped very well with a visit of her son and his family from Peru for a week.

In the next progress update, we should have the official results of the CT scan of two weeks ago, and the consultant's thoughts on future treatment.

### ***Update 15 - 7 August 2016***

Once again, this update has a mixture of good and bad news.

Sue still continues to look and feel well, and is still maintaining her weight, although about a stone (14 lbs/6·5 kg) lighter than a year ago.

The main good news is that the three lumps just under the surface of Sue's skin have come and gone, so it is considered that the immunotherapy is working to some extent.

However, Sue has now had the official results of her CT scan of four weeks ago, which showed that there were no new tumours in her liver, but confirmed that the one large one had grown by 50% since the scan of ten weeks ago. Unfortunately, two new tumours had also appeared - a small one in the head of her pancreas, and another in her left adrenal gland (an adrenal gland is on top of each kidney), measuring 1·4cmx1·8cm (0·5"x0·7"), which is about 10% of the size of the adrenal gland. The adrenal gland is a common site for a tumour, as it is has a good supply of blood. These are causing the consultant to consider a change of drug. He has asked for a new body and head CT scan to be done during the next week, and to see him again for a review in a week's time.

Sue had the usual immunotherapy treatment last week, and the next one has been booked, but this could change beforehand.

Sue continues to be optimistic about conquering her cancer and is planning a long-distance walk in the autumn.

### ***Update 16 - 21 August 2016***

The CT scans of Sue's head and body were done, but the radiographer's report was not available for the consultant on Monday. As the consultant has previously stated, he is not qualified to analyse the scans, but he considered that they did not show any new tumours in the body scan, the existing tumours had not grown, and the largest of the liver tumours had shrunk slightly. He could not analyse the head scan.

Additionally, Sue's blood test of her thyroid function showed that she now has an under-active thyroid. The consultant concluded that the immunotherapy drug is now working, as her auto-immune system is attacking her thyroid gland, as well as the tumours showing signs of improvement. He had always stressed that her cancer(s) would become worse before getting better, although four months was longer than expected. Consequently, he has decided to continue with the present immunotherapy drug, which is a big relief to Sue. The under-active thyroid problem can be treated with thyroxine pills - although Sue is not happy about having more drugs.

Sue's immediate reaction was to see if she could help to treat her under-active thyroid gland with diet, but quickly discovered that it would conflict with some of her anti-cancer diet. Consequently, she has resigned herself to eating a balanced, more normal diet, but to keep up the carrot juice.

The immunotherapy course is now continuing, and we will find out about the radiographer's CT scan report at the next appointment with the consultant, in 2·5 weeks' time (after the next update).

As the consultant seemed pleased with the new developments, we have now booked a cottage with the aim of embarking on Sue's long-distance walk.

### ***Update 17 - 4 September 2016***

We had thought that there would be no particular news for this update.

However, Sue had a strange fall last Sunday. She was doing yoga early in the morning, as usual, and had vertigo. She hit her head on the wall and broke the radiator valve with her elbow. We are not sure if she knocked herself out or just fainted, but she has no recollection of the next 30 to 50 minutes. Paramedics attended and could find nothing wrong, but her cancer consultant (who had been alerted by the hospital) telephoned to ask her to go to A&E.

All sorts of tests have been done this week, with still more to come, to discover the initial cause. A&E had wondered about a heart attack, but ruled that out, and concluded that she might possibly have had an epileptic seizure - the first in her life - but was not worth doing anything about it. The consultant is concerned that one of the possible side effects of the immunotherapy drug is a weakening of the heart muscles, so that is the basis of many of the current tests.

In the last week, Sue has felt a little 'distant' with vertigo very slightly on a few occasions, but generally has continued as usual, although she has a very black eye and bruising on the left of her face - all considered to be from her head hitting the wall.

We did glean a small amount of information about the report of the CT scans of 3·5 weeks ago, and the rough impression is that the tumours had not changed very much, compared with 5 weeks earlier.

### ***Update 18 - 18 September 2016***

After the last update, this one has very encouraging news.

The bruising from Sue's fall of three weeks ago has all but gone. The consultant has also concluded that the vertigo was caused by the new course of thyroxine for her under-active thyroid gland, and that her body was simply getting used to it. It was nothing to do with heart problems or epilepsy, and all blood tests are normal. She has stopped doing yoga early in the morning since then, just as a precaution.

In further discussion about the recent CT scans, the consultant has told Sue that no new tumours have appeared anywhere, and the existing tumours have not increased or decreased in size or number. He feels optimistic that the immunotherapy treatment has turned the corner and is now working.

Sue is very upbeat about her treatment, and is continuing to play her bassoon and recorder - she is about to play in her first concert for 10 months, which is a real turning point. She is also doing much more around the house and garden, and near-enough back to normal. She is very much looking forward to starting on the long-distance footpath next month.

### ***Update 19 - 2 October 2016***

The roller-coaster ride of Sue's cancer still continues.

Sue has been very healthy over the last two weeks - behaving in a normal way and looking very healthy. Last night, we both played in a really enjoyable concert - the first for Sue since last November.

Nearly two weeks ago, Sue had an MRI scan of her head, requested after her vertigo and fall at the end of August. The scan shows two small brain tumours and a few pin-prick-size ones. Unseen on a CT scan in mid-August, these were a complete surprise to us all, including the consultant. We have no idea how long they have been there. The consultant has referred Sue's case to the Queen Elizabeth Hospital (QE) in Birmingham. This is the largest centre of excellence for cancer in the UK, outside London. It has a 'CyberKnife' (the only one outside London), which can give radiotherapy very accurately to small areas within the brain. The consultant has asked the QE if the CyberKnife could be used. We all laughed about this 'Star Wars' reference!

The vertigo and fall had been put down to Sue's new thyroxine course, but these new findings may change that conclusion.

Sue has been advised by the consultant not to drive for 12 months, in view of this latest development. However, she is still thinking very positively, as the immunotherapy has appeared to have been working well, with other tumours having disappeared or stabilised. This new development may be a set-back, but the immunotherapy could still conquer all. Sue is still determined to continue to lead a normal life.

### ***Update 20 - 16 October 2016***

There is mixed news for this update.

The QE Hospital cancer team has reported back about Sue's newly-discovered tumours, and various options were put forward. The one favoured by Sue and her consultant is to have another MRI scan in about three weeks' time, to see if the tumours have changed in size - in comparison with three weeks ago. If they have shrunk or stabilised, then the immunotherapy drug will be deemed to be doing its work, and Sue will continue down that track. If they have increased in size then the other options from the QE will be considered.

At the moment, Sue does not want to think beyond the next MRI scan, as she feels perfectly well, and getting back to all the activities she was doing before the start of the problems, nearly a year ago.

### ***Update 21 - 30 October 2016***

There is very little news for this update.

Sue has started on her challenge of a long-distance walk in Norfolk, and covered the first 36 miles (out of 93) in five days. She still appears to be very fit and well, although her drug-caused psoriasis is becoming more widespread.

An MRI scan of Sue's head and a CT scan of her body will be done tomorrow, although there may be no report on this for another two weeks. In the meantime, Sue has continued to receive her immunotherapy drug every three weeks.

### ***Update 22 - 14 November 2016***

There was no significant news, so this update was delayed for a day.

We went to see the consultant today, knowing that he would have results of the head and body scans. The body CT scan has shown a marked reduction in the sizes and numbers of tumours, which were in Sue's major organs. The head MRI scan has shown that one of the two brain tumours is about the same size, but the other has reduced. The consultant is pleased about this, as it indicates that the immunotherapy drug is working.

On the other hand, although Sue's drug-caused psoriasis has actually improved in the last few days, the consultant is concerned about it, particularly on her shins. Consequently, he has decided to delay the next immunotherapy dose, which was due this week, and put Sue on a strong course of steroids for a week, together with other drugs (to counteract the steroid's effects!) and another to reduce the possible effects of the existing brain tumour. Sue is not happy about taking so many drugs.

Another appointment has been made to see the consultant next Monday, to see how her skin is improving and with a view to returning to the immunotherapy drug.

### ***Update 23 - 28 November 2016***

Unfortunately, Sue's immunotherapy drug has not been resumed, because her psoriasis has not improved enough.

In another twist of the story, Sue suddenly developed an itchy rash, with the spots joining up over 24 hours to look like sunburn. She was taken off some of her very recent drugs, which were considered to be the culprits. Antihistamine has now mostly calmed the rash, and more drugs have been deleted from Sue's list, as her consultant, who we've seen today, is convinced there is a reaction from these recent drugs - which were meant to be counteracting the effects of the immunotherapy.

A blood test has shown a raised level of a liver enzyme, so more blood tests have been done today, with possibly more in the pipeline. Another MRI scan of Sue’s head has been ordered in about two weeks' time, to check on the tumours.

### ***Update 24 - 12 December 2016***

Sue's severe reaction to one of her drugs wore off, and her liver enzyme level was nearing a normal level. The consultant concluded the reaction was to one of two drugs - an antibiotic or an anti-seizure medicine (in case a brain tumour could cause trouble). To test his theory, he instructed Sue to take one single pill of the antibiotic, as that was the least likely culprit. She took one the next morning, and the symptoms started in under 25 minutes. A very uncomfortable 24+ hours ensued, with many telephone calls and another hospital visit. Sue avoided being hospitalised. We now know what Sue's allergy is, but it may only be because she also has the immunotherapy drug in her system - this is nearly uncharted territory for drug compatibility.

On seeing Sue's consultant again today, he was pleased with Sue's skin, which has now mostly cleared the antibiotic reaction and the drug-caused psoriasis. The steroid dose is continuing to be cut, and Sue should be back on the immunotherapy next week, just before Christmas.

After a few difficult weeks of skin reactions, Sue will be back on course, once the MRI head scan results are known in seven days' time.

### ***Update 25 - 20 December 2016***

This update is a little earlier than expected, as the Christmas period would have been two weeks since the last update, and because Sue's events of the last few days have changed the scenario.

Two days ago (Sunday), Sue suffered a series of major seizures, which lasted for about three hours. These were similar to epileptic seizures, but slightly different, and were caused by her brain tumour(s). Luckily, Sue doesn't remember the event, but eventually came round in hospital, having been given many doses of drugs to calm down her system. She was discharged from hospital the following day (yesterday/Monday).

Also yesterday, Sue had an appointment with her oncology consultant to discuss the seizures and the MRI brain scan of three days previously. We were aware of two significant tumours (and many very small ones), and one has receded with the immunotherapy treatment. However, the other has continued to grow, and is now about 1.5 inches (35mm) long and lozenge-shaped. This growth has meant that the immunotherapy is deemed not to have been completely successful, and so the consultant has concluded that he cannot justify continuing with the (very expensive) immunotherapy course at the moment.

Sue had been having very minor hints of seizures for a few weeks, but the recent major event has meant a very quick change of action is required. Two options appeared to be available - open surgery or radiotherapy. In 'Update 19' (2nd October), the 'CyberKnife' was mentioned as a possibility, but the tumour is now too large for that. Open surgery is still an option, but the consultant radiotherapy oncologist (at an appointment today) considers that the 'electrical damage' to Sue's brain during the seizures would need to calm down for a reasonable length of time before it would be undertaken. The remaining option is for 'whole brain' radiotherapy to ensure that as many secondary melanomas can be treated as possible. There are side effects, of course, but as this is the least invasive option, Sue has decided to accept it.

A mask (a 'shell') will be made to fit Sue's head, to hold her head in exactly the same position each time for ten radiotherapy treatments. The shell will be made in nine days' time, and the ten-day radiotherapy course will start almost immediately after that.

In the meantime, Sue is quiet and still slightly affected by the various drugs which were administered over a very short period. She is well, at home and in no discomfort. She has a new arsenal of drugs.

We hope this news does not affect your enjoyment of Christmas, and send our good wishes to all around the world. Hopefully, the next update will have more positive news.

### ***Update 26 - 3 January 2017***

Sue has certainly improved since her seizures of two weeks ago. She has not yet resumed her normal, cheerful character, but sleep and time are helping her to heal. She is rather quiet and has some problems with dexterity and coordination. Typing emails has become a challenge, as this requires dexterity and coordination, but she is still trying her best, and I help out when necessary. She knows that she is getting things wrong, but doesn't know how to correct them. This could be a consequence of the seizures, brain tumour(s) and/or drugs.

Sue's radiotherapy head mask/shell was made last week, and the course of 'whole brain radiotherapy' is starting tomorrow. That will be for ten consecutive days, excluding weekends.

Carrot juice* continues to be part of her diet and 90% dark chocolate. Although she has previously enjoyed a glass of wine, Sue has decided to cut out all alcohol, as it really doesn’t mix with radiotherapy or tumours.

It is time to reiterate the absolutely excellent care and attention that Sue has received from the NHS at Worcestershire Royal Hospital (at Worcester), and the ambulance service. Nothing has been too much trouble, and the immediate attention, which Sue has received at some urgent times, could not have been bettered, even if we had been paying for private treatment.

### ***Update 27 - 17 January 2017***

Sue has now had most of her 'whole brain radiotherapy' course, with the final treatment being tomorrow. We now know that the first five treatments were for the 'whole brain', aimed at her many pin-prick-size tumours. The second five treatments are specifically for the larger tumours, including the two significant ones, and probably also a large, benign meningioma, which had suddenly changed in some way - this was a surprise to the medics.

Since the start of the radiotherapy, Sue has slept well, but not particularly during the day. She is finding activities requiring coordination and dexterity to be difficult, because her right hand and arm are now not functioning properly - like fitting her safely belt, doing up her coat zip, tying laces and dressing. This has become markedly worse. She is also much more quiet and finds it difficult to cope with questions or making decisions. She is rather vague and distanced from reality. I'm now writing almost all of her emails, and have taken over most domestic duties, with cooking instructions being given by Sue.

Sue's mental capacity definitely suffered since her major seizure(s) a week before Christmas, and has now become significantly worse. We are unsure whether this is because of the tumours, the radiotherapy or both, and hope that the radiotherapy will slowly work to restore her normal self.

On the positive side, Sue does not have headaches or nausea and has lost none of her hair - all of which were likely side effects of the radiotherapy. She is not unhappy, as life continues around her. Interestingly, although Sue's right hand is a real handicap for many necessities of life (luckily, she is left-handed), it still works well when playing the piano and recorder.

### ***Update 28 - 31 January 2017***

Sue had her last 'whole brain radiotherapy' treatment two weeks ago, and a review with the radiotherapy consultant. He advised her that he had delivered the maximum permitted amount of radiation to her head for life, and that he had done all that he could do. He was hopeful that he had been successful, but there was no guarantee. He was very definite that Sue should consult her GP to make her wishes known about resuscitation and to contact the local Macmillan cancer nurse. This was somewhat demoralising, but he meant it sincerely, offering practical measures whilst Sue was capable. By this time, the radiotherapy and/or the pressure of the tumour had made her very distanced from reality, and she calmly accepted the advice. We made efforts to sort out Sue's wishes over the next couple of days. (To correct a statement in the previous update, the radiotherapy in the second five treatments was actually only aimed at the single tumour, which had continued to grow during immunotherapy.)

Five days later, we went to see her normal consultant, and he painted a very different picture. He immediately decided that Sue should go back onto her immunotherapy. She had been off this for three months while the worrying psoriasis (caused by her immunotherapy) cleared up. He had some blood tests done on the spot, and Sue should be re-starting her immunotherapy this week.

Sue has progressed considerably in the last week. Her right hand and arm are now functioning again, and she has become far less distant. It does seem that she is on the road to recovery, although not yet fully right. Having mentioned in the last update that her hair had not dropped out, two days later it started to do so. The loss has now slowed and we are hopeful that it will not all go.

Sue will be having head and body scans in the next few weeks, to check on the state of the various tumours. Other than the one troublesome brain tumour, most had been receding before her immunotherapy was stopped.

### ***Update 29 - 14 February 2017***

Sue has continued to progress over the last two weeks. She is more cheerful and has put on weight, making her look healthier. Her recorder playing is now back to her old standard, and she is still working on the piano, oboe and bassoon.

However, the return to the immunotherapy course did not happen two weeks ago. No real reason was given, and then her psoriasis suddenly returned, which added a renewed concern about the immunotherapy drug.

Sue had an MRI brain scan a week ago, and we had the results two days later. The one troublesome brain tumour, which should have shrunk with the radiotherapy, has actually grown to 43mm x 43mm (1.75" x 1.75"), but with considerably less inflammation. The other brain tumour has near-enough disappeared, and the meningioma has returned to its original state. Consideration is now being given to removing the troublesome tumour surgically - possibly at Coventry Hospital, or the QE in Birmingham. We are currently awaiting more information about this, and expect more tests and consultations.

Needless to say, this is another difficult moment, which needs very careful consideration, as surgery was not really on Sue's agenda.

### ***Update 30 - 28 February 2017***

Sue has continued to be well, and is almost back to normal. She is still enjoying playing her musical instruments, which she finds good for rehabilitation.

The urgent scans of her head and body were delayed by some administrative errors at Coventry Hospital, to where Sue was referred. The scans were finally done four days ago, and we understand that Sue's case will be discussed at a meeting in three days' time. We have not been advised when or how we will hear the decisions from the meeting.

### ***Update 31 - 14 March 2017***

Sue's 'cat and mouse' events with her melanomas still continue.

The scan results from Coventry Hospital have described the troublesome brain tumour as "inert", which Sue's consultant has interpreted as 'not active'. It is thought that the 'whole brain radiotherapy' may have arrested it. Consequently, brain surgery was not recommended by Coventry Hospital. These results have caused some surprise, as some a previous scan - since the radiotherapy - showed the brain tumour had continued to grow. Consideration was being given to ask for further advice about the scans, this time from different hospitals. The scan results also showed that the liver tumours had continued to reduce, but the other tumours in the pancreas, spleen and adrenal gland are still there.

Unfortunately, a new tumour has appeared in abdominal lymph glands.

The revised strategy is for Sue to return to her immunotherapy course, in an effort to counteract the new lymph gland tumour. She has had an immunotherapy treatment today - after a break of some 4.5 months.

### ***Update 32 - 28 March 2017***

For the first time in the last 13 months, there is no real news to report.
Sue has continued to be well, and we have booked a week away to continue with her long-distance footpath ambition in Norfolk.
Over the next week, Sue has appointments for an MRI head scan, a visit to her consultant and the next immunotherapy treatment. We should know some more detail in the next update.
If you are interested in statistics, in the 12 months after Sue was first diagnosed, she had 112 appointments of various sorts connected with her cancer and its treatment - that's almost one every three days, with an average of about 4 hours out of the house per occasion.

### ***Update 33 - 11 April 2017***

Sue continues to be well, although sleeping more than usual, which has been put down to the continued effects of her 'whole brain radiotherapy' in January. This is a normal side effect, which can occur some time after brain radiotherapy.

The results of the brain MRI scan of a week ago showed that the large, troublesome tumour had shrunk, and is still considered to be inert/inactive. If Sue's body does not reabsorb it, thought may still be given to surgical removal at a later date.

The immunotherapy course still continues - an intravenous injection every three weeks - and this is hoped to make the relatively new abdominal lymph gland tumour shrink (see Update 31). We now know that it measured 40mm x 24mm (1.5″ x 1″) about 6 weeks ago in a PET scan. In the same PET scan, the liver tumours had reduced significantly, but the other abdominal tumours were still there (also in Update 31).

### ***Update 34  -  25 April 2017***

During the last two weeks, Sue has continued with her ambition of a long-distance footpath, walking about 39 miles in a week.  She found the walking very tiring, but was determined and happy to be doing it.  Her general tiredness has continued, often having many naps during the day, and still sleeping well at night.  The tiredness is still regarded as a normal delayed effect of the 'whole brain radiotherapy' in January.

The consultant has requested another body scan, to discover the state of the tumours since the last body scan at the end of February.  This should be within the next two weeks.

In the meantime, the course of immunotherapy continues - in the hope that it will carry on being active against any tumours.

### ***Update 35  -  9 May 2017***

Within four hours of Sue's last update, another significant tumour was discovered - this one is in her spine, between her shoulder-blades.  It is not uncommon for melanomas to appear in the spine, and immediate steps were put in place for an MRI scan of Sue's body and head, which she had last week; and she had the PET scan of her body and head yesterday, which had already been planned.  The spine tumour is uncomfortable at times, particularly when reaching up into a cupboard or leaning backwards, but is fine the rest of the time.

We both played in a concert on Saturday - the first that Sue has played in since last October.  She coped really well and enjoyed it.  She is having less trouble with tiredness recently, although still has short naps.

We will see the consultant on Friday, and expect he will have the results available from both scans, with a revised action plan.

### ***Update 36  -  23 May 2017***

Sue's consultant said that the two scans indicated the various tumours were reducing, now that she is back on the immunotherapy.  The new one in her spine is odd, as the pain was not where the actual tumour was showing on the scan - contradictory to the previous doctor's opinion.  The thought is that the pain is being referred from the tumour further up her spine, although the pain is not constant.

The consultant is pleased with the way the immunotherapy is working and the course will continue.  Sue has been prescribed a bone-strengthening drug to help her spine.  It is given intravenously at the same time as the immunotherapy.

Sue had been instructed to reduce the steroids (which were to counteract her psoriasis, caused by the immunotherapy), and she had almost reduced them to zero, but the psoriasis then started to reappear, so she has increased the dose again, under instruction from a hospital doctor.

Sue seems to be very well, but tires easily and either has naps or goes to bed very early.

As Sue is now showing signs of being in a more stable period of her treatment, she has decided to lengthen the time between these updates.  The intention is to send the next update in three weeks' time.

### ***Update 37  -  13 June 2017***

In the last update, I said that Sue was showing signs of being in a more stable period of her treatment.  This may have been tempting fate.  During the next afternoon, she had a minor seizure, which was quickly over, but was the start of problems over the last three weeks.

Sue's right arm started to lose control again, and she has experienced rapidly worsening problems with coordination, dexterity, mobility, disorientation and mental ability.  She had a fall one night, on her way to the toilet, as she became disorientated in some way.  She is now doing even more sleeping/dozing than before.

She had another brain scan eight days ago, and when we arrived on the following day for the continuing immunotherapy dose, we learnt that the 'troublesome' brain tumour (of six months ago) had started to grow again, with considerable inflammation around it.

The immunotherapy dose was immediately cancelled, Sue was given a high dose of steroid to reduce the inflammation, and she was kept in hospital overnight. There has not been any obvious sign of improvement yet - in fact, very much the opposite.

We saw Sue's consultant yesterday to discuss the possibilities of surgery on the brain tumour and of radiotherapy on her recently-discovered spine tumour. Sue is not at all happy about brain surgery, but we will see the surgeon at Coventry hospital tomorrow for her to make a decision. We also had a hastily-made appointment to see the radiotherapy consultant. To buy some time, whilst possible brain surgery is being determined, a one-dose shot of radiotherapy to the spine tumour will be given on Friday this week.

In an effort to find something good in the last three weeks, Sue's psoriasis is now much better. Her consultant has been extremely helpful, kind and thoughtful, telephoning on two occasions to find out how she is. Sue is very subdued, but is not in any pain, nor on any painkillers.

### ***Update 38 - 23 June 2017***

Rather than wait a full fortnight for this update, I thought it wise to send it now, because so many people have enquired about Sue's sudden change of situation in the last cheerless update.

When we saw Sue's consultant a mere 11 days ago, he said that if surgery on Sue's 'troublesome' brain tumour could not be attempted, she would only have weeks left and not months. In fact, the neurosurgeon said two days later that surgery was not possible. It would be far too risky and he could not possibly cure the tumour, which would only grow again. Once we saw Sue's latest scan on the neurosurgeon's screen, it was obvious what the problems are - even to a non-medical person.

Sue has since had radiotherapy to her spine tumour, and this has produced no side effects at all so far, so we hope that it was successful. Her problems of mobility, mental ability and dexterity have continued to worsen, but she is still in no pain. She tires very easily.

We are now in the situation that Sue will not be seeing her consultant again, nor receive any more immunotherapy. She will continue to have any necessary drugs, but these will now be provided by her GP or the local hospice. She is now a patient receiving palliative care.

From the occupational therapist of the hospice, we have received a great deal of equipment to help us through the next phase, and we are sure this will help, particularly when Sue is established in a comfortable downstairs bedroom. The view out of the window into the garden is a joy at this time of the year.

Sue still hopes that the background amount of immunotherapy will still be working, and that the steroid dose will be reducing the inflammation - although this also negates the effect of the immunotherapy. She refuses to give up, and is still planning changes in the garden, the continuation of her long-distance walk and future concerts.

### ***Update 39 - 6 July 2017***

Over the last two weeks, Sue's health has not changed too much.

Sue's right arm and hand are not functioning at all, but her ability to 'walk' with my help (me holding both arms and walking backwards) has not noticeably changed. Her mental abilities do seem to have deteriorated slightly and she feels disorientated, often not quite absorbing the conversation.

Ten days ago, Sue had another minor seizure in the middle of the night, but the paramedics did not consider that she need to be in hospital. We visited the local hospice on the following day, and all sorts of local facilities suddenly started to go into action, including the GP, who came to visit Sue at lunchtime. He was very helpful, but unpromisingly considered that Sue's prognosis of weeks is likely to mean only a few weeks. Sue is still hoping to prove all the medics to be wrong.

The downstairs 'bedroom' is still not being used, as I can get Sue upstairs, which she prefers.

Overall, Sue seems to be in quite good health, still with no pain, although she is quiet. She sleeps about 12 hours each night and dozes during the day.

Highlights for Sue have been to go to watch an orchestral rehearsal and stay for tea, and to attend Wednesday lunchtime concerts, in which she has been heavily involved.

### ***Update 40 - 20 July 2017***

Sue has significantly improved in the last 10 days. Mobility in her right arm and hand have meant that she can now hold many objects. Her right leg has gained strength, and better balance has meant that she has managed to get around the house a small amount, although with caution. The medical opinion is that the high dose of steroids has suddenly started to work in reducing the oedema (a build-up of fluid around the tumour) and the inflammation into her brain. Although this has taken a long time to work, it is not a cure for the tumour, which we are disturbingly assured will continue to grow, and the end result is inevitable.

Sue has not been at all happy about taking steroids, as the side effects are not pleasant for her, and so she has asked her GP to prescribe a decreasing dose. She hopes to reduce the side effects, but retain the beneficial effects. The GP was not confident that this is wise, but agreed.

Otherwise, Sue continues to be in reasonable health, with no pain. She still sleeps a great deal, as she tires easily.

### ***Update 41 - 4 August 2017***

Progress of Sue's physical mobility continued for another week after the last update, and then reached a plateau. She has possibly regressed a little since then, but has continued to be able to walk cautiously around the house. She cannot manage the stairs by herself yet. Her right hand and arm are continuing to be much better.

Fatigue is now a problem. Her daytime snoozing is becoming longer, and she is still sleeping about 12 hours each night.

The position of her brain tumour is in the left frontal lobe, which is a very large section dealing with movement on her right, problem solving, reasoning/judgement/decision-making, some memory, language, impulse control and social behaviour (amongst other things). It is easy to see why Sue is tired, if these functions are under stress.

Sue is now on 50% of the initial standard steroid dose. Consequently, the water retention is starting to subside in her cheeks, stomach and left ankle.

We went to see her cancer consultant yesterday, who was amazed to see her looking so much better than he expected! Much to our surprise and contrary to the GP's recommendation, he has instructed Sue to reduce the steroid dose yet again. He thinks the weakness in her legs is caused by the steroid dose, so he will expect the improvement in physical mobility to continue, as the dose is reduced.

Six weeks ago, the consultant made it clear that he did not need to see Sue again. He has now changed his mind, and is now considering that the immunotherapy has triggered Sue's own immune system into more action by itself - although the last dose of immunotherapy was over 11 weeks ago.

### ***Update 42 - 18 August 2017***

This update is mainly 'no news is good news'.

Sue has been reasonably stable over the last two weeks. She is still able to walk cautiously where the floor is level. Her most noticeable problem is fatigue, and she is starting to sleep even more. The fatigue seems to be caused by mental, rather than physical, effort.

Sue's steroid dose is still being slowly reduced, with no apparent positive or negative effect.

### ***Update 43 - 1 September 2017***

Sue has continued to be reasonably stable again since the last update, although possibly not quite so steady on her feet. The amount of her fatigue has not altered. She is now on 25% of the initial standard steroid dose.

A new complication arose a week ago, when Sue started to have an exceptionally distended abdomen. It is uncomfortable, rather than painful, but also seems to be associated with discomfort around her right shoulder-blade. A doctor visited Sue last Sunday (Bank Holiday) at 11.00pm, and decided that it was gas (not liquid) retention, but did not know the cause. A hastily-organised appointment to see her consultant resulted in requesting a body scan to see what is happening with all Sue's various body tumours, which were last scanned four months ago. The consultant considers the distension to be caused by liquid (not gas) retention, but also does not know the cause.

## ***Update 44 - 15 September 2017***

Sue has had another seizure, which necessitated an ambulance call-out, but not a hospital visit. It was assumed that it was caused by her brain tumour, and her anti-seizure medication has since been increased.

Sue also had a body scan, which was analysed by her consultant about two hours later, although we have not heard the radiologist's official report. The consultant considered that Sue's distended abdomen (which hasn't altered) was being caused by a new tumour on Sue's right adrenal gland, together with the further enlargement of the tumour on her left adrenal gland (each kidney has an adrenal gland on its side). Additionally, there is a new tumour in her abdomen, probably in a lymph node.

The consultant is considering the possibility of Sue going back onto some form of immunotherapy, but we have not heard his decision yet. He also decreased Sue's steroid dose even further. It's a careful balancing act with the various medications.

In the meantime, suddenly (since Sue's recent seizure) the Macmillan Nurse has started to visit again, and the District Nurse team is now actively involved.

Sue is still feels about the same as she has for the last few weeks, and is trying to do a little more in the kitchen.

## ***Update 45 - 29 September 2017***

About a week ago, two areas of Sue's distended abdomen started to be painful on occasions. We have been told that this is part of the continuing progress of her tumours. A non-steroid gel is providing good relief from the pain, when necessary.

Sue's consultant telephoned last week to let her know that he had decided to put her back on the same immunotherapy drug as before, and she had a treatment of it earlier this week. Her steroid dose has been reduced yet again. Her consultant hopes that the immunotherapy will improve the various tumours.

Perhaps it is a useful time to explain briefly what happens with immunotherapy, which boosts the body's natural way of dealing with a tumour. The body normally creates inflammation around a tumour, in order to fight it, and this inflammation is increased by immunotherapy. The current problem is that Sue's brain tumour's inflammation became out of control, so a vast dose of steroid was given to reduce the inflammation. Sue's return to immunotherapy now creates a predicament, as she is still on a certain amount of steroid, which counteracts the effect of the immunotherapy. This explains why it has been necessary to reduce the steroid dose progressively. Ideally, Sue should not be taking a steroid of any sort, so this is a careful balancing act.

Sue has recently had problems with coordination (we assume being caused by her brain tumour) when playing music, but has now embarked on a regime of playing at least the piano every day, and sometimes other instruments as well.

## ***Update 46 - 14 October 2017***

Sue had been reasonably stable over the last two weeks, continuing to play at the least the piano every day, with coordination improving each time as her practising progressed. She had recently been trying to shorten her nightly sleep routine, which was for about 12 hours. Although she had reduced this to about 11 hours, she then needed more daytime sleep.

We saw the consultant again yesterday, with him agreeing to continue the immunotherapy course, and decreasing the steroid dose yet again. The full report of the body scan of five weeks ago revealed that the two adrenal gland tumours are roughly 50mm (2″) and 70mm (2.5″) diameter, and the pancreas tumour is about 50mm (2″) diameter. There are also a few small abdominal lymph node tumours, each being about 6mm (1/4″) diameter. These account for some of Sue′s distended abdomen, together with effects from the steroid. As it has been five months [actually four months - see next update] since Sue had a head scan, the consultant was going to organise another full body and head scan around the beginning of December.

However, only 30 minutes after leaving the consultant, and 3 miles from the hospital, Sue had another major seizure in the car on the way home. We immediately returned to the hospital, where her 1-hour seizure was controlled with drugs - increasing the steroid dose massively again, together with other drug increases. Having already spent one night in hospital, she is awaiting a head scan tomorrow and then for the results to be analysed. Sue is rather weak from this new ordeal.

### ***Update 47 - 28 October 2017***

Since Sue's last update, the emphasis has changed from abdomen to brain tumour(s).

Sue's stay in hospital lasted for 5 days and nights while she waited for a head scan and the effects of high drug levels to wear off. Since then, she has returned to her previous stable situation.

The head scan showed that the original brain tumour has grown in comparison with about four months previously (the last update mentioned five months, but this was wrong), although it is now well-defined with no associated swelling nor inflammation. There is also a new brain tumour, also on the left, about 6mm (1/4") diameter, further back and lower.

Although Sue missed an immunotherapy treatment whilst in hospital, she has returned to the course and now received the next dose.

For those who do not see Sue regularly, you may remember that she started to lose her hair after whole brain radiotherapy treatment in January (nine months ago). That hair loss continued until about two-thirds had gone, then new growth started to appear slowly. She now has a full head of hair about 50mm (2") long, roughly the same colour, but in tight curls, rather than her original straight hair.

### ***Update 48 - 10 November 2017***

Sue has been reasonably stable in the last two weeks.

Unfortunately, Sue had a minor seizure five days ago. She quickly recovered and it did not justify calling paramedics, although it made her very tired for a few days. Sue's balance and walking are rather unstable at the moment, which the hospice physiotherapist considers are caused by her brain tumour(s), rather than anything else.

Sue still continues to think positively and is playing more of the piano and oboe. She is playing oboe and recorder in a quartet with friends as I send this.

### ***Update 49 - 24 November 2017***

A day after the last update, Sue started to lose a little control of her previously-good left leg. Sue then saw her consultant, had a body scan and the next immunotherapy dose during the following week, just before the deterioration rapidly worsened.

We now know that, over the course of nearly ten weeks, the substantial tumours on Sue's two adrenal glands have grown by about 50% and 70%, and the pancreatic tumour has grown by almost 40% - all three having previously been about the size of a tangerine. There are also various other very small body tumours. Happily, none of these body tumours seem to be causing Sue any problems, other than putting on more weight and distension around her abdomen.

The real problem over the last two weeks has been the very rapid deterioration of Sue's physical ability, together with more minor seizures last Sunday morning. In conjunction with the superb Macmillan Nurse and paramedics, it was decided to apply for Sue's immediate admission to a hospice, which was achieved within a couple of hours.

The hospice is now assessing Sue's situation and, once more, increased the steroid dose to a maximum in an attempt to reduce any oedema (a build-up of fluid) and inflammation around her brain tumour(s). This has been reasonably successful so far, but Sue is still disorientated. She has lost the use of her right side, and her left leg is now very weak, although her left hand and arm are still strong. She is also able to move her head and eat.

Sue is not in any pain and is not unhappy - accepting everything that is done for her. She is tired much of the time and has her eyes closed, as I suspect it's easier for her.

At the moment, we have no idea what happens from now, so we wait to see what the drugs do and what care facilities can be put in place elsewhere.

### ***Update 50 - 8 December 2017***

Two days after the last update, Sue spent one day mostly asleep whilst in the hospice. On the following day, she was intent on discharging herself to go home, which was not at all realistic. Happily, she did not pursue this ambition and had two more sleepy days.

Over the last six to nine months, Sue has been determined to achieve her 70th birthday on the 30th November. Unfortunately, she did not really wake up on the day. The hospice doctor thought she may have had yet another seizure during the night or a bleed in her brain. After that, she was mostly 'asleep', but did communicate occasionally with a squeeze of her hand when asked questions. This change in Sue's health halted all consideration of moving from the hospice to a nursing home.

Because she was 'asleep', food and liquid could not be risked by mouth. An attempted drip of saline hydration failed to be absorbed. She did have some pain towards the end and pain-killers were administered to her, but only in small doses.

After nine complete days of peaceful sleep, Sue passed away early this afternoon.

Thanks must be given to the unfailingly kind and helpful staff at the Royal Worcestershire Hospital, The Primrose Hospice in Bromsgrove, Sue's Macmillan Nurse and the absolutely exemplary attention to Sue's needs at St Richard's Hospice in Worcester, where she spent her final days.

I will notify recipients of these progress emails separately concerning Sue's funeral arrangements, which she had substantially organised in advance, as you might expect. For interest, these progress emails were sent to 101 recipients, mainly in the UK, but also to many friends elsewhere in the world.

*Carrot juice is considered to be a safe way of creating an alkaline environment in the body. It is thought that cancer thrives in an acid environment, and making that environment to be alkaline will inhibit cancer.
Carrot juice, yoga and reiki are not part of the official line of attack by the UK medical professionals. However, the medics have all been very kind, saying that all can be utilised, as they won't do any harm.