

**healthwatch**

# Herefordshire Patient Cancer journey stories

June 2023



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Herefordshire

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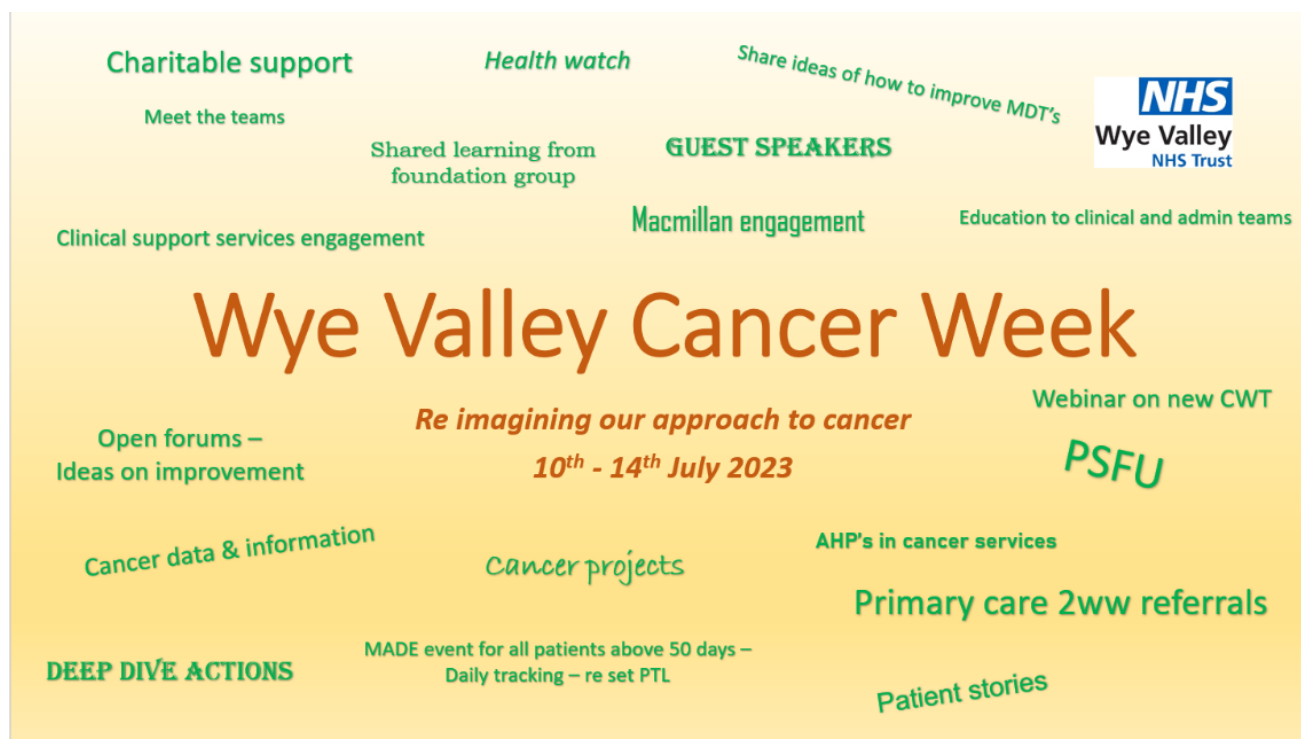
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# Context, appreciations.

## Context

Healthwatch Herefordshire carried out this project in partnership with Wye Valley Trust to gather the views and experiences of Herefordshire people that have experienced Cancer treatment in Herefordshire.

We aimed to compile a small collection of stories to offer an authentic patient experience at Wye Valley Cancer Week 10<sup>th</sup> –14<sup>th</sup> 2023.



Practitioners and clinicians from across cancer care pathways will see the stories and learn about the service and improvements from the patients' perspective. The aim is to 'reimagine our approach to cancer'.

Healthwatch arranged to meet people with cancer in person at a public venue or have a telephone or online conversation. In two cases we met support groups and recorded reflections of more than one person.

We asked people to tell us:

1. Your description of your experiences of cancer care in Herefordshire.
2. What were the most valuable parts of cancer care you/your relative received?
3. What could have been better?
4. Are there any future improvements to cancer services in Herefordshire you would like to propose?

We have presented the stories as they were related to us in their entirety for practitioners to read and gain an insight into real patient thoughts, emotions, ideas, and needs as they choose to tell them.

After each story, we suggested some learning and reflections that Healthwatch feel were highlighted by the patients. There may be other aspects that WVT practitioners can gain from the stories too.

We look forward to hearing WVT practitioner views and learning and the difference the patient stories have made.

We wish to emphasise here that while patients shared some glitches and issues overwhelmingly patients appreciated the kindness and expertise of the NHS and voluntary support services and wish to thank services for their care and support and for saving lives.

Thank you to the participants in the survey for sharing your stories.

## Demographics

20 people shared their experiences of living with cancer or related their experience of cancer as a carer of somebody living with cancer (3) or of somebody that had died of cancer (2).

Cancers included Primary and secondary breast cancer, brain tumours, Myeloma, Mesothelioma, Prostate cancer, and Lymphoma.

Responses were from people aged in between their 30s and 80s.

They were a mix of male (5) and female (15). People lived in postcodes distributed across Herefordshire.

# Wye Valley Trust service comments

# Patient Story 1

## Case Study MS4

Healthwatch Representative:	<b>Mary Simpson</b>
Date collected:	<b>29.03.2023</b>
Key theme/service area:	<b>Delays in Cancer diagnosis</b>

### CONTEXT:

While we were collecting stories this enquiry came through to Healthwatch and we felt that it was relevant to this project.

### IMPACT OF WHAT HAPPENED:

I was referred to WVT following blood in a stool sample, and I had been told I was on a two-week urgent potential cancer pathway. My assumption was that I'd have a scan of some sort within a fortnight.

Instead, I was called up by a nurse at WVT hospital and had a short conversation followed by being informed that it would be best if I saw a consultant. The earliest appointment was in 8 weeks' time.

I felt alarmed about this and full of anxiety as I had been experiencing increasing symptoms indicative of bowel or colorectal or bladder cancer.

I was left wondering:

- Why this would be?
- Are appointments delayed for all patients because of capacity issues?
- Would the two weeks mean a call within two weeks not an appointment?
- Would the call have determined a less urgent need to be seen?
- Is 8 weeks unlikely to make a significant difference to a patient if they do have colorectal cancer?

- Is there somebody I can call to talk through the rationale for this decision because a potential cancer diagnosis leads to an anxious wait.
- Are there alternative places I can choose to go (other than private) that would have an earlier appointment?

Not having any of this information has left me unable to decide whether this is a dangerous situation or whether I should consider getting a private appointment.

Healthwatch contacted PALS WVT who offered to call me to have a better conversation/ improved communication. Finally, through PALS an earlier appointment was organised.

### OUTCOMES/FURTHER LEARNING POSSIBILITIES:

The way in which GP referrals are handled by the specialists is important so that patients understand the rationale for decision-making.

In this case, the specialists listened to the symptoms and decided that cancer was unlikely and categorised the patient as less urgent. Because the GP had put the referral in as an urgent two-week pathway, this had made the patient anxious to be seen at an early date.

When the patient called the hospital and was distressed about the 8-week wait the limited hospital communication left the patient with lots of questions and fears.

All of the television and NHS advice is to catch cancer early and patients' fear of delays is natural. There is also a great deal of television time given to publicising delays and subsequent dangers for cancer patients.

As a result, hospitals and GPs will need to coordinate their actions and the ways that they communicate. They will need to explain to patients the way that they triage for cancer and weigh up the most urgent cases for the earliest appointments.

**CONSENT FOR SHARING STORY ANNONYMOUSLY? YES or ~~NO~~ (circle)**

**CONSENT FOR FUTURE CONTACT? ~~YES~~ or NO  
(circle)**

# Patient story 2

## Case Study MS12

Healthwatch Representative:	<b>Mary Simpson</b>
Date collected:	<b>30.05.2023</b>
Key theme/service area:	<b>Primary Breast Cancer</b>

### CONTEXT:

This is a 62-year-old woman who prior to this was generally healthy.

A routine breast scan indicated an anomaly which prompted an invite to attend the Worcester cancer unit.

The patient received health care in Worcester, Hereford, and Cheltenham.

They had a lumpectomy, radiotherapy, and hormone treatment and recently Lymphoedema treatment.

### IMPACT OF WHAT HAPPENED:

#### **Worcester clinic**

I went for a routine breast scan in Herefordshire (Kington) and was called back at the end of 2022 to attend a clinic in Worcester. I then was told about a diagnosis of breast cancer on November 9<sup>th</sup>, 2022, in Hereford Hospital.

The directions and administration to get me to the clinic were all fine. Luckily, I can drive and cope with the distance and I had taken some bereavement unpaid leave so didn't need to take time off work.

The staff were extremely kind, and I was accompanied at all times by a health professional. It felt a little odd being handed over to another person to travel the next corridor for the next procedure – like a pampered relay baton.



I was told it was very likely to be cancer by its shape and the doctor took a sample to be tested. I was asked how much I wanted to know, and I asked for total transparency. I was just about to ask my elderly freshly bereaved mum to live with me so I needed to know how serious this might be.

I got a bit emotional – not about the cancer but about my mum and they took me to a side room to have two nurses come to answer my questions and bought me a cup of tea.

They answered all of my questions well. The only criticism I can give is that they used the abbreviation MDT which I thought many people wouldn't understand as a multidisciplinary team. Apart from that, I couldn't fault their care.

They checked my family history. I have two grans that had cancer and had their breasts removed, an aunt similarly all of whom lived to old age. My cousin died a few years ago of breast cancer in her fifties.

### **Hereford diagnosis**

I took my husband with me to see Mr. Das. He explained that I had grade 3 cancer, it had been caught early, was small and may not have spread and a lumpectomy was recommended followed by radiotherapy. They were to send off a sample afterwards to a place in Los Angeles to ascertain the cancer type and the sort of treatment likely to be best. That would indicate whether chemotherapy was needed.

Mr. Das explained the surgical procedure to me and my husband. He was clear and sensitive.

It was quite a short appointment, and I was handed over to a nurse to get any other questions answered. I was told it would likely be a fortnight for my operation.

They gave me an A5 blue file with loads of information which I read later. They talked through who my cancer care nurse was and gave contact details. It was good but a bit overwhelming and difficult to figure out which phone numbers to use later. I often got it wrong, but the receptionists were good at signposting to the right one for your enquiry. They explained they'd call occasionally to check I was ok and answer any questions. It was very reassuring.

### **Lumpectomy**

About 3 weeks later I was asked to attend Hereford Hospital in the morning but in the end, my operation was about 4.30! It was a long day.

I had my preop and had a staple put in to mark where my cancer was. I never like the breast squashing scans which are uncomfortable and having it twice before and after the staple was put in wasn't nice, but all the clinicians were kind and efficient.

Family is not allowed to wait with you and as we knew nothing of when the operation was to be it was a worrying wait for them. I was able to send messages by mobile up to a point.

From the waiting room, I was transferred to a room and asked to remove my clothes except for pants and wear a hospital-thin robe. The room was way too cold to be underdressed and I remained there reading my Kindle for hours using my coat as a blanket.

A nurse came to take blood pressure and fit tight socks etc and the surgeon came in later. I asked how deep my cancer was. I was concerned re radiotherapy and potential lung damage. He said he didn't know. He explained the operation and when it would happen.

The anaesthetist arrived. He talked me through what would happen and checked my temperature as I had a slight cold. He said he would send me home if it was too high because having a general anaesthetic is like having ten rounds in a boxing match! He was a bit hyper-jolly and full-on, to be honest. My temperature was fine, so it went ahead.

I was wheeled into a tiny room off the operating theatre with cupboards each side. It looked like a galley kitchen but super bright. The anaesthetist had two assistants who ooh'd and aah'd at his proficiency finding a vein. He put a tube in my hand and heart monitors on my chest. They put a mask over my face and he injected the anaesthetic and I was asked to count to ten. I think I reached 4...

I became aware I was in another room and Mr. Das was beside me. I wasn't really fully conscious, but I heard him say the operation was successful, and in answer to my question the cancer was deep in my breast. He headed off. I know there was an operation after me, but it did seem a bit too soon to give me information when I was still woozy and couldn't ask questions. I was pleased to have my question answered though!

I was wheeled to a women's post-operative ward and told I'd be there for the night. I had no overnight bag as it was in the boot of the car, and I'd been told it was unlikely I'd stay overnight since I was going in in the morning. Doh!

I feel like all of this was entirely predictable and could have been communicated better. However, the hospital provided all I needed which wasn't much.

### **Ward care**

It mostly went smoothly in the ward I gradually came to and expected to feel sick after general anaesthetic but didn't. I had suggested I might be as my dad and sister suffered badly after general anaesthetic so they may have given me something to counter this. Anyhow after a while, I was offered and ate a scrambled egg on toast which was tasty.

I was able to call home to say I would stay overnight. I also braved a look at my breast which had dressings on but was mostly, and a little surprisingly, intact. A nurse gave me some morphine for pain relief. The pain wasn't too bad actually.

The night on the ward was ok I slept a bit. We were woken by the last lady operated on who returned to the ward at some point noisily. The most difficult aspect apart from ambient noise was the light. Although they were dimmed, I found it too light to sleep soundly.

In the night I called the nurse for help to go to the loo but was alarmed to be told I wouldn't be able to and had to use a bedpan. Sure enough, my legs were like lead which begs the question of how I could have possibly gone home.

The nurse assumed I knew how to use a bed pan and I asked her to explain how to go about it. I had to ask her to pull the curtain around and leave me (I couldn't go when she was standing there though I was desperate) I felt very exposed. It felt very like it would spill and afterwards, I had to ask her to give me a tissue to wipe myself. Weird that she wouldn't do that are you supposed to air dry?

In the morning I was able to walk to the loo and they gave me a little hygiene pack to clean my teeth and have a wash.

Talking to the other women on the ward in the morning once I had recovered a bit was interesting. Several had had breast operations but there were hip and knee operations too. Nobody seemed to know when they'd go home. Everyone ordered lunch. I had

soup, which was again fine, but they all complained that their fish and chips were inedible – fish and chips too hard and overcooked.

Eventually, a nurse came around to check the dressings and explain how I was to look after my wound going forward. I was given lots of leaflets to add to my blue file. I called my husband to pick me up.

### **After care**

It felt very lonely caring for my wound myself. I knew I had to be careful not to let it get infected. I was told that the large dressing could come off after a few days and the strips along the two cuts would just fall off.

Removing the big dressing in my first bath caused some anxiety but I coped. I had some sterile dressings I had taken from my parents' house when Dad died in October, and they were really useful to place in the bra to cushion the breast and stop the wound from rubbing on the bra material.

The strips didn't fall off themselves and were removed by a nurse some weeks later when I went in for a check-up.

True to their promise I received phone calls from nurses to check how it was going and answer any questions I had. This made me feel well cared for and was very reassuring.

I had a long letter in which I was asked all sorts of questions about what concerned me. I sort of felt that this was too soon for me. I couldn't honestly say it was affecting my mental health or what my anxieties would be. When you are first diagnosed you just want it removed and hope that it will stay away. When or if it returns is when you might need much greater input in my opinion. I guess it depends on how you react to it.

Eventually, I did fill it, as I thought I ought to, and received another call with more leaflets and information. All good.

I had an appointment to check my breast before the radiotherapy to check the scar and if I might need reconstructive surgery.

Mr. Das introduced a student asking if it was ok for him to attend. I agreed as I recognise people have to learn but can't say I was comfortable. It would have felt difficult to say no. He asked me to take off my top behind the curtain and he was going to do an ultrasound.

But before that, he asked me to stand while he and the student looked at my breasts from across the examination bay to see if I needed any corrective surgery. He said 'it is a little more pert than the other one but that is usual', and I agreed I didn't need any plastic surgery. I found this excruciating – like having your breasts judged. I didn't know whether I was screaming or laughing inside – a bit of both. Believe me, there is nothing pert about my 62-year-old breasts!

Up against a cancer diagnosis these feelings are pathetic I realise, but for a woman who has not had children and few partners, this exposure was difficult. That said, though the young student looked embarrassed, Mr. Das was very professional and handled the situation well. And I'll live.

A nurse then spent time explaining the results of the sample sent to Los Angeles. The cancer is a result of too much Oestrogen and from the data of others with my type of cancer there is no advantage in having Chemotherapy so only radiotherapy was recommended. I would also be prescribed a hormone suppressant pill to lower Oestrogen.

I was told that there had been a minute amount of cancer cells detected in my armpit node but not significant enough to warrant further node removal. The hope is that radiotherapy will kill the cells and Oestrogen suppressing tablets will further prevent cancer from taking hold elsewhere.

### **Covid test**

I had to have a covid test before my radiotherapy but not before my operation which seemed odd especially since I did tell them I had a cold before my operation – on the phone.

I was sent an appointment to have a Covid test in Brecon as I was deemed to be in Powys (which I am not).

3 or 4 days before my operation I dutifully drove to a car park in Brecon and waited for an ambulance to arrive. There followed a 20-minute wait for them to get their computer to cope with my Herefordshire address. Then a quick and easy test and back home. All ok but, how you would cope without a car I don't know.

### **Radiotherapy**

Preparation for radiotherapy – I had to go to Cheltenham to see if I needed to have a mould made that would lift my breast up so that radiotherapy could target the breast

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more easily. Mum insisted on coming with me and sat in a freezing waiting room with a sliding door letting in wafts of icy air on hunched and shivering waiting, patients, and relatives.

I didn't need the mould so; they went on to put me in the radiotherapy machine and mark me up for treatment. This involved lying on my back with my arms overhead in stirrups naked to the waist while a male and female nurse drew on my chest, midriff, and sides. Moving the machine around me with light lines going across me and drawing some more marks while carrying out mathematical sums verifying each other's calculations.

I was asked to take deep breaths which pull the heart aside and raise the chest for radiotherapy. A kind of dress rehearsal ensued. They then took an x-ray to make sure the dots were lined up properly and the heart was away from the treatment area. Once satisfied they tattooed the mark on my midriff and two sides to be able to line me up later.

The male nurse failed to do the tattoos correctly for two of the three dots and took another go.

It wasn't too bad. The worst bit was feeling so very exposed. Whenever you have a breast scan it is just women. I wasn't that comfortable with the mounting number of male staff seeing my breasts. They might be used to it, but I am not.

My radiotherapy happened later once my scar tissue had mended. The first was to be in the Cheltenham Oncology unit and the rest in Hereford Hospital however the radiotherapy machine in Hereford was serviced and not up and running so they were all in Cheltenham. They were five days following with a weekend in the middle.

The journey is long from where I live on the Welsh borders, but they were considerate in making the appointment times later in the mornings to give me time to get there and not through rush hour traffic.

It did take up most of the day though by the time I was treated and had some lunch to settle before the drive back. I am used to driving longer distances I don't know how an older person would cope or somebody using public transport. Or someone with a less understanding employer.

The lido car park was very convenient for the hospital and not far to walk and the main waiting room was warm with a good coffee machine and tuck shop close by.

It was noticeable that Cheltenham insisted on social distancing and masks, but Hereford Hospital didn't.

The treatment was done with great precision and efficiency as well as kindness. I hated the exposure and the thought that I was damaging perfectly healthy breast cells as well as any remaining cancer cells.

I hated the thought that damage might occur to my lungs which might cause me problems down the road as happened to my dad and aunt. They said they'd do everything to avoid damage but couldn't guarantee it.

My breast became tender and as predicted became sore a bit like sunburn, a stinging sensation or like you have a bruise. I was told to use moisturising cream morning and night and was lucky that I didn't get any broken or blistered skin in the weeks that followed.

Following the operation, I had numbness under my arm and to the side of my breast. As the nerves recovered somewhat feeling began to return. Following radiotherapy, the numbness increased again. Three months later feeling is returning again though not completely.

My breast hurts a bit but is perfectly bearable. Worse is the little voice saying is it just knitting together or is it cancer returning? I don't fret over this but there is no denying it is there and will be for a while. However, you just get on. What else can you do?

### **Aftercare**

The nurses have continued to call periodically and talk through symptoms and give advice.

I have had a few appointments with Yeleni. I am trying Auricular acupuncture with hypnotherapy for menopausal symptoms and to encourage healthy eating. Not sure I am convinced that the therapy is effective, but I have felt calmer. I have found them beneficial as they encourage me to take some time for myself as I come to terms with a hell of a year – Dad dying, becoming a carer for Mum in our home and this cancer diagnosis.

## **Medication**

I was prescribed Anastrozole tablets to suppress the Oestrogen. I must take one pill a day for 5 years. I was alarmed to read about the side effects of this drug and the number of side effects that are 'very common' and 'common' particularly.

I have experienced some of the side effects but not as severely as I have read others do for which I am grateful.

I am much more menopausal than usual, foggy brain, emotional, hot flushes and my limbs are achy, and I get fatigued easily.

All of which are manageable and better than the cancer spreading. I am hopeful that the treatments work and that I continue to do well.

## **Lymphoedema**

I have developed Lymphoedema. I had read all about it so it was not a surprise though I had hoped I wouldn't get it.

On a recent check-up, Mr Das confirmed it and also took a biopsy from a persistently large lymph node in my armpit. I hope it does not turn up anything 'sinister'.

The nurse gave me a compression bra and referred me to Yeleni where I received manual Lymphoedema draining treatment and training.

## **Overall**

I have felt well cared for by all of the staff and experts dealing with me. The caring gentle compassionate attitudes of all the healthcare practitioners have been wonderful.

I have watched endless newscasts of the troubles that the NHS is having, and I know that the system is under strain with a lack of staff and resources. However, my personal experience of services has not demonstrated huge waits and less quality of care or long waiting times. I feel very fortunate.

I am extremely grateful for the expertise and kindness shown and the conscientious practitioners that I have met.

I particularly commend the scanning service without which my cancer would not have been found and treated at an early stage and the behind-the-scenes staff that look through all the samples that indicate cancer.



## OUTCOMES/FURTHER LEARNING POSSIBILITIES:

This patient found the wrap-around care for primary breast cancer from discovering cancer to treatment has been quick and professional.

Issues for learning include:

- Be aware of abbreviations or technical terms when communicating to patients.
- Sensibilities around male practitioners treating females that are not used to exposure. Is this aspect discussed with patients especially those with ethnic religious sensibilities?
- Care with requesting the presence of training staff. A patient will be reluctant to withhold consent in front of the student.
- Good collaboration between Worcester, Cheltenham, and Hereford but travel requirements for patients is challenging.
- Covid tests – If Covid tests are necessary try to limit patient travel time.
- Covid safeguards – Consistency between hospitals is not there with regard to masks and tests.
- Temperature of waiting rooms and preop rooms could be raised or patients remain dressed for longer or advised to bring a fleece.
- Operation times. Advise patient of likely whole day wait and to hang on to night bag even if overnight stay thought unlikely.
- Don't assume everyone knows how to use a bedpan and offer a tissue to wipe.
- Consider offering some dressings to go home with.
- Clarify telephone numbers on one sheet.

CONSENT FOR SHARING STORY ANNONYMOUSLY? YES ~~or~~ NO (circle)

CONSENT FOR FUTURE CONTACT? YES ~~or~~ NO  
(circle)

# Patient Story 3

## Case study MS14

Healthwatch Representative:	Mary Simpson
Date collected:	16.06.2023
Key theme/service area:	Cancer Care

### CONTEXT:

A 55-year-old woman was diagnosed with a brain tumour and treated in Birmingham QE and Hereford.

They have suffered a small amount of brain damage but have recovered. After being paralysed completely down one side they can now walk and move about.

We met and spoke with her and her dad her carer. He had previously/simultaneously been caring for his wife before she died of cancer in 2020.

This account is mainly made by the daughter with some input by her dad.

### IMPACT OF WHAT HAPPENED:

#### Diagnosis

#### (Dad)

My wife had a form of myelitis discovered in rheumatology. It affected their lungs and took a long time to diagnose because it's so rare. Finally, it was discovered by a junior doctor.

The junior doctor looked at their fingernails and eyelids and could pinpoint it. It was called plumber's disease. I suppose a junior doctor was familiar with fresh knowledge and had just studied it perhaps.

When we were told about the diagnosis the practitioner said I can look after you for the next five years. That indicated to us that my wife was not going to live very long. In fact, she lived for six years from 2014 to 2020. Not the best way to be told.

Towards the end of my wife's life, my daughter became ill and was receiving treatment. I am now my daughter's carer.

## **Diagnosis (Daughter)**

In the beginning, Dad called an ambulance because I was paralysed and was initially put in a stroke ward at Hereford Hospital. I liked all the nurses and doctors there.

## **Stroke ward**

Because most people that get strokes are elderly the people on the ward were mostly elderly whereas I was in my early 50s.

I was in a ward with older ladies. I found that you were spoken to in a certain way like a child. Some doctors are not able to switch if you are cognitively aware or not. This can be patronising.

I suppose they think that your brain has been affected. They are so busy they don't individualise their approach.

They did a scan and I had to do exercises. I was fairly sure I had not had a stroke and I kept saying so. I went home.

## **Home care and readmission**

I did the exercises but, I was getting worse.

Doctor Charlotte Jones at the surgery sent me to A&E where they thought I had had another stroke. They did another scan and realised that I had a brain tumour.

## **Queen Elizabeth Hospital, Birmingham (QE)**

I was taken to the QE in Birmingham.

Once I arrived at the QE in Birmingham a man yelled, she is here for a brain biopsy and I yelled back no she is not!

Altogether I stayed for 111 days. I had a lovely room in the neurology ward with a lovely view while my mum was in palliative care.

My brother was present from Exeter by phone while they told us about the CT scans as this was during Covid. They explained it all. They were going to do nothing for a couple of months. I think information was needed at that point.

I was happy with all the team. There were lots of Navy or army nurses they were very calm and very good. Military nurses are the best.

You know straight away if you will respect and like a doctor. Ones like Durant and Phillips.

You can also recognise the difference in staff at the QE they behave differently with different doctors if they respect them or not. With a respected Dr it's a bit like captains on deck and everybody responds better.

You are more open and communicate better with someone you trust. Others have an idiotic attitude. Some have no bedside manner. The surgeons need nurses to communicate properly with patients.

### **Brain Biopsy**

I had a brain tumour. At the QE they told me this required a brain biopsy. I formed the impression that they all wanted to do it because they all have new equipment computer-based and they were all eager to be the ones to carry out the brain biopsy. I felt very pressured. I felt it was not about me, but it was about who got to do the surgery.

They were very dismissive of me and what I was going through. It wasn't about me. It was just nil by mouth need a biopsy. At this point I had total left-side paralysis I needed two nurses to go to the toilet this was in June 2020 during the pandemic I was very alone. I was so vulnerable. I couldn't have visitors.

Then a nurse told me they can't do anything without my consent. This gave me back my power. I formed the impression that all the male surgeons didn't treat women very well. I felt like a piece of meat.

This went on for a long time. They kept bringing me more and more senior doctors to persuade me. As they get more senior, they get called Mr. Eventually they said they would try a lumbar puncture but with no success.

They tried a CT scan and a nuclear scan, but they just couldn't diagnose it.

I was told there are two possibilities for my brain tumour a really bad one or lymphoma. A 50:50 chance of either. They could try a special chemotherapy matrix created by one of the doctors there if it was lymphoma. If it was not lymphoma this would kill me. The only way to know was by a brain biopsy but I was scared of the chop shop surgeons they just seemed too gung-ho it didn't feel like it was about me. Finally, I met a female surgeon who was wonderful very gentle, and explained things to me.

### **Bone Marrow Biopsy**

They tried a bone marrow biopsy which was horrific you could hear the bone-crunching but I could get through it because I had that relationship with the staff.

The Doctor who invented the matrix I called matrix man or Mr. Frankenstein. I was having my bone biopsy and he walked in and said this won't work you have to have the brain biopsy.

I asked what the risk of brain surgery was. He said the operation might kill you but if not, we could hit the optic nerve and you'd be blind if not, if we hit motor functions you might be paralysed and then you might be blind and paralysed.

The other staff stood with their mouths open until one of the men there said this isn't the time and asked if I still wanted to continue my procedure.

Later on, after I had my stem cell transplant in Birmingham doctor 'Frankenstein' came to my ward to do the rounds I said to him thank you for inventing the matrix brew, and I showed him I could move. He said I am so pleased. I felt he did not behave well but his matrix saved my life, and I don't hold that grudge I have to give credit where it is due.

### **Chaplains**

The bone biopsy didn't work and the staff who had witnessed that behaviour must have told someone because someone came in with a sister and offered me access to the chaplains Maureen and David.

I couldn't have any visitors but felt I could say anything to them they were really good. From then on, every time I went to the QE Maureen came in and said hello. I really want to praise the chaplains they were fantastic.

I was dealing with all this alone and my mum was dying at home. They helped a lot.

## **Mum's Palliative care**

(dad)

My wife was in and out of hospital for nigh on six years. At that time, I could go in whenever I liked. I saw the doctor as helpful.

When my wife had a lung flush I asked why. They gave me an explanation I felt as a carer I could ask and get the answers that I needed. We built good trust with the doctor.

The only thing we weren't that happy about was that he pestered her to have a lung flush to help her to breathe near the end and it didn't really do any good.

It took a long time for her to wake up from the anaesthetic. They didn't find anything, and she went downhill fast.

Once my wife started to go downhill, we felt they lost interest a little bit they thought the lung flush might help with the breathing but eventually, she couldn't breathe unaided. They did a walk test, and a monitor, and the physio said yes you need oxygen so she had oxygen at home.

## **Breath test**

(Daughter)

One of the breath tests is very scary you have to cut off your breath you have a mask on and they shut off the air and you can't breathe. They say 'Keep going nearly there', then you can breathe. You are shut in a room it's not good.

They are looking at your blood oxygen levels.

Mum hated it, I Didn't realise how bad it was until I had to have it.

## **PICC lines**

(Dad)

I noticed that for some of the procedures, it feels like some of the doctors are not as good as the nurses who do things all the time like putting PICC lines in.

I was in the RAF in Singapore in the 50s and I equate it to pilots having to keep their wings they have to put in a certain number of hours even though they spend most of their time these days doing admin.

Sometimes it feels like the doctors have to have a go every now and again to remember how to do things but because they're not very good at it you feel it is better for the patient to ask someone who does it all the time.

### **(Daughter)**

Some of the staff just are not very good at putting lines in I found that often the Philippine nurses were very good at finding a vein. One nurse had three goes on mum.

She was in agony I do wonder why they use that nurse at all if this is what happens.

After a while, you begin to know who is good at PICC lines. A stupid doctor at Worcestershire suggested that I had had so many PICC lines that they should try putting in a Tunnelled Dialysis Catheter instead.

It seemed like a good idea as my arm was so full of scars from PICC lines but it was horrific.

I went to the QE to have it put in. It is put in my top right upper chest, and they push a long tube in. I was very distressed I screamed and shouted. When they took it out the doctor commented and said they really didn't know why that much had to go in. I kept it at home for a while...

It was not very successful because I could not sleep on my paralysed side on the left and now, I could not sleep on my right side, so I had to sleep on my back.

Added to this nobody had seen it before they were even nervous to take the end off, they always struggled with it. Herefordshire and Worcestershire didn't know how to use it. It was much more invasive.

In fact, somebody put another catheter in my arm again because they could not use it which defeats the purpose.

Eventually, a phlebotomist came in and said his wife worked in a different department as a renal nurse and he said she'll do it. She came and she was so gentle, and it was so simple. She taught me to do it and on occasion, I was able to tell nurses.

From then on if any of the staff were nervous I said no to prevent the tugging the same nurse took the time to do it gently.

On another occasion, I couldn't get transport within seven hours as I had been in touch with someone who had COVID.

On this occasion I refused to let a nurse take out my infected cannula I asked for someone who knew how to do it as she said she had been taught but she had never done it before. The next day the same nurse did a prick test on my finger and did it really hard and left a bad bruise. A doctor confirmed that the prick test should not have left such a bruise.

While there that time I taught a night nurse how to take bloods because I had watched it happen so many times and she did it perfectly.

Later on, haematology wanted to keep it in mainly. I had to ask for it to come out and I was able to do that once my bloods reached the magic level.

They wanted to do another bone marrow biopsy to see if it had done its job. That is standard procedure. They kept saying that is a standard procedure we have all been trained. But I refused and insisted that they find another way.

Doctor Skibbe in Worcester was wonderful and told the registrar to take it out. Doctor Nori is also wonderful. I was so relieved to get it out.

## **Staff**

On the Herefordshire ward, the managing doctor seemed to cause havoc every time he came on the ward, he really should have left the nurses to organise things.

I found it best to be direct and ask who I wanted and to get someone who knows how to use the catheter. I grew annoyed when they said they didn't know how to use it and suggested putting new lines in. I said either use it or take it out.

I was very lucky because the renal nurse came in every morning to do the bloods.

One day she had one day off, and the doctor freaked out and said he'd have to have a cannula put in I refused and I was so touched that the renal nurse came in on her day off to help me.

With the bad, there are angels that really care about the patients and enjoy what they are doing and this restores your faith.

As a patient, you need to work out who are the good ones.



I also observed that all the senior staff are white and British and junior staff are from the Philippines and India and are very good practically but perhaps their English stops them from reaching senior posts. The admin managers seem to be useless practically.

The QE uses a lot of bank nurses to care for you especially through the night to take you to the toilet or change sheets. On one night I experienced one bank nurse just upped and left because she couldn't hack it.

There were a lot of male nurses in the neurological ward a lot of them were young black men and were most lovely gentlemanly proper nurses very polite.

One I remember was called Moses. They would build great relationships and help you through bad times especially when you couldn't go to the loo. I always felt safe with the male nurses they were all utterly professional.

The physios are fantastic. There was a small amount of brain damage so they explained that I had to retrain my brain so that other nerves could pick up the task of helping me to move and walk.

There was an army gym that I used to get me to walk again. When I was back on the ward it was so boring, I was always very keen to do physio.

Macmillan Renton staff are wonderful.

### **(Dad)**

When COVID left I could visit more, and I could see the improvement.

### **(Daughter)**

#### **Transfer and transport**

I must mention the drivers who were fantastic with transport to and from the hospital. From Hereford to the QE, it was two hours journey you have to book ahead they were dead chatty.

#### **Disruptive/ antisocial patients**

On the ward where I had stem cell treatment, there was a lady who was very awkward she was disruptive she kept all of us up late at night talking through the night she was very noisily talking to her husband on her iPad and using her iPad and then she would sleep in during the day. She took up a lot of nurses' time.

That Lady was just an irritant and I had to request from the nurses that the woman was sorted. Everyone on the ward was ill and all of them were upset by her.

The nurse said we can't have everyone in their own room but they did move her to a private room. It shouldn't be the patient that complains I feel the nurses should have realised what was happening. It's a shame when one person spoils it.

Once I was mobile, I helped others. You have got to understand the system. I would have a laugh. I discovered I had a voice and I used to be very vocal. I told the doctors off if they had a go at the nurses.

I had a spell in ICU with pneumonia. A group of doctors used to come in with their laptops on stands on wheels. I told them they looked like a boy band. I felt the nurses looked a bit nervous the next time they came in I played Backstreet Boys and they laughed then.

They all come in wearing suits I think they need to take it down a peg. It's very hierarchical.

Months later back on the ward, a lady remembered it. It can be very boring on the ward.

### **Hospital Radio**

I also want to mention hospital radio which is free. When you are on the wards you are stuck there, you're fed up and bored and you keep thinking about things that you should not. You stick on the radio which is run by volunteers, and it occupies you and is so cheerful and entertaining. I want to give a shout-out to them.

### **Stem Cell treatment**

I should have had a private ward when I had my stem cell transplant.

Because I arrived and there was an hour's delay the sister had had to rejig the beds so I couldn't have a private room. I was therefore on the ward which wasn't ideal because everybody was looking at me as the stem cells went in.

I had another chemo to kill the bone marrow before the stem cells went back in. He told me that it was like setting a nuclear bomb in my body and that my hair my eyelashes everything would go. I was very sick. In fact, I had four lots of chemotherapy before the stem cells went back in.

I also realised that as long as the doctor put something on your notes it happens. I asked for a liquid food that I had seen my mum having called Ensure because I couldn't eat. I asked the doctor he put it on my notes, and it happened.

## **Discharge**

There was a sister at Worcester who knew Mum was dying and that I wanted to get home. I was cross because discharge was taking too long. When the pharmacist came around, they said it was not them because they haven't had the order yet. They order the drugs after the ward tells them. It felt like the world was not in a rush to get you out.

It turned out that the junior doctor needed some guidance to know the order in which to carry out the admin and discharge different people.

Eventually, after quite a lot of persuasion, the senior nurse sorted it and told him which people were able to leave today so he needed to sort that admin first. I had to stand in reception and refuse to go until they sorted it.

The sister was horrible and wouldn't speak to me her whole attitude was bad. But I thought I don't care I want to see my mum. The pharmacy sorted it quickly then.

## **Haematology**

I have to go to haematology and the problem with Clinical Nurse Specialists (CNS) is that they work half days, so continuity is not good and therefore communication.

I find the reception staff at Haematology are a bit severe.

The doctors are good but overworked when you go for your three monthly appointments.

## **Fred Bulmer ward and Covid**

Previously I was in Fred Bulmer ward because I'd had COVID before the vaccine I was there for 90 days. I had to go to the discharge lounge at Fred Bulmer because I had had COVID. That's when I had to be flushed every week.

My bloods were getting better and better. I had to have infusions when my red blood counts got low.

If I could go to Worcester, I didn't like the ward but it was much quicker than QE. Fred Bulmer was the quickest I was in and out very quickly.

When I had COVID injections I always had a 24-hour to 48-hour bad reaction. I developed shingles.

### **Continuing outpatient care**

I go to Haematology every three months I email the GP and they e-mail back two days before I have to go. Belmont medical practice is wonderful they know the system and can work the system.

I take a bag with me that says what bloods are wanted so that when I go for my appointment later at the hospital, they already have the results of the blood tests.

At one point I used to have lots of pills very complicated working out when to have them some four hours apart some two hours apart etc. I was out of it, so I relied on Dad.

### **Overall reflections**

On the whole, I know I have mentioned lots of areas that were difficult, but they were very good. They saved my life.

The QE is excellent. Worcester is a poor cousin without the facilities. Hereford has nice people and is better now. They are smaller so you get the same nurses which is nice.

The QE has lots of bank nurses.

I liked that the QE took the lead as they are the experienced doctors some of the best doctors. I like that Worcestershire and Herefordshire followed their expertise. It mostly worked well except if there were procedures that they didn't know about.

Staff are always following up because of shifts and they don't always hand over well. They can be short staffed and there is a lot of firefighting.

Macmillan help is a game changer once you get remission you are left thinking what do we do now Macmillan helps at this stage especially.

### **(Dad)**

I have a new daughter now she swears more and has a different personality!

Macmillan are a wonderful gateway to support groups; it's good to talk to other carers. The social side especially benefits.

We found McMillan in the waiting room but it would have been nice if someone had said to seek them out.

### **(Daughter)**

The All Cancer Support group in Hereford is good. It is important to meet younger people with cancer I was 55 my mum was 86 when we were diagnosed.

Yeleni is good too. I enjoyed the complimentary therapy.

I did the whole Halo course, I met nice people and I use the toning suite.

They really are wonderful people they save your life it is wonderful the things they do.

Once you are through all the procedures afterward you feel a bit lost.

Macmillan fills that gap they are a gateway to getting your life back on track there needs to be more funding there and for Yeleni too. You just want to be back to being a normal person again.

And then of course there are the unpaid carers like my dad without whom we could not remain independent.

## **OUTCOMES/FURTHER LEARNING POSSIBILITIES:**

### **Diagnosis**

There may be some learning around the diagnosis and the early assumption that the individual had a stroke. As the woman was in her 50's perhaps other possibilities could have been considered.

In the case of the Mum, it was suggested that a junior doctor with more recent training may have noted their diagnosis earlier so updating training may be a learning possibility.

### **Communication regarding life-changing procedures**

From the patient's perspective, their situation and the prospective procedure were terrifying. They did not want it and they wanted to understand if there were other options. During Covid, they were alone and vulnerable physically and mentally.

The patient had choices that they were not given initially as the hospital felt it was the only possible course of action to save the patient's life.

The communication around this does not appear to have been good or planned or person-centred.

The way in which they had the risks related to them in the middle of a bone biopsy was not professional.

Communication upon diagnosis of potentially life-changing procedures could be handled in a more professional, sensitive fashion and include choices.

Health practitioners need to recognise the imbalance of power when patients are at their most vulnerable and inform them that their consent matters and that they have choices.

In this case, a nurse did this, but it isn't clear whether this is routine practice.

Health professionals must remember that they are used to the environment. Patients that have not had life-long conditions are not.

### **Training to use different PICC lines**

There seems to be an issue of one hospital using a more advanced technique or technology without checking if practitioners in their partner hospitals have the expertise to use them.

This raises both a system issue and a training issue.

### **Specialist or generic roles**

This story relates a system in which staff are trained generally to carry out procedures (such as putting in Cannulas and PICCS) but some staff are much better at carrying them out (painlessly) than others.

This raises the question as to whether a practitioner whose job is not routinely involved in this activity should defer to a local expert and stick to their area of expertise in turn. Or whether more regular update training might be facilitated.

Patients recognise that staff must practice improving but a patient in the hospital for a long time will notice differences in finesse. The difference is mentally and physically draining. A more consistent experience is the aspiration.

Many patients will not be as proactive as this patient in asking for particular staff.

The experience of the nurse allegedly inflicting pain on purpose when rejected by the patient is unacceptable.

### **Hierarchy, attitudes, staff race and gender diversity, teamwork**

The patient notes issues that relate to a very hierarchical way of working. They felt that junior staff were not always valued by senior staff and that better teamwork would improve the smooth running of hospitals.

Some of the symbols of status such as suit-wearing were questioned. This can be intimidating for some patients.

The patient noted and praised the staff of a diverse workforce of both races and genders. They also observed that the higher echelons tend to be white and often male.

This raises a challenge for HR (NHS) to work to increase diversity evenly at all levels.

They observed managers with less practical organisational acumen not working in harmony with ward staff and causing tensions when they come onto the ward. Can more attention to this aspect be included in training and learning opportunities in the NHS?

In the example of ward discharge the ward staff can assist junior doctors to prioritise their admin with relative ease – if they communicate well together. This will assist patients eager to get home as well as release beds on the wards quicker.

With a few notable exceptions, the attitudes and expertise of staff at all levels were highly praised. The particular extraordinary commitment of a nurse from Haematology coming in on a day off was particularly moving to hear as well as the night staff in the QE.

### **Support, organisations, personnel, and volunteers**

This patient emphasises the value of support staff and volunteers and voluntary organisations to positive mental well-being in and out of the hospital and to their ongoing journey.

The Chaplains and hospital radio are highlighted and Macmillan, Yeleni and the All Cancer Support group.

Bringing them to the patient's notice consistently is suggested.

### **End-of-life procedures**

The family suggests that consideration be given to the overall benefits of late-life clinical procedures.

The last lung flush appears to have caused a lot of unnecessary and ultimately unfruitful discomfort to a Mum and the end of her life.

### **Coordination between Primary and Secondary health services**

In this example, the patient relates good coordination in particular for ongoing blood tests and visits to Haematology.

### **CONSENT FOR SHARING STORY ANNONYMOUSLY? YES NO (circle)**

The patient recognises that their story may be identifiable and is still happy to give permission for it to be used.

### **CONSENT FOR FUTURE CONTACT? YES NO (circle)**



# Patient story 4

## Case study MS13

Healthwatch Representative:	<b>Mary Simpson</b>
Date collected:	<b>02.06.23</b>
Key theme/service area:	<b>Cancer Care</b>

### CONTEXT:

The patient was diagnosed with Myeloma in 2006 by a visit to the GP. This is bone marrow cancer.

They received rapid treatment involving the removal of stem cells, chemotherapy, and replacement of stem cells. At the time the process was a trial and medication required authorisation calls to the USA. Care was in Hereford, Cheltenham, Bristol, and Bath.

The patient has made a full recovery and still receives regular check-ups.

### IMPACT OF WHAT HAPPENED:

#### Diagnosis

In 2006 I began to feel weak and tired. At first, I thought it was just fatigue from building our house. I was a fit man but felt weak and had pain in my shoulder, arms, and bones.

I went to my doctor in Kington, and he took some blood tests.

I was asked to come in and told I had Myeloma. I was diagnosed with bone marrow cancer. The GP was a very experienced doctor. I reckon the GP knew. The average GP will see one case in 10 years, so I feel I was very lucky to be diagnosed so quickly. Within a fortnight I was in and having treatment.

#### Myeloma UK

According to Myeloma UK an online help group it can take a long time to get diagnosed. They provide lots of information and leaflets aimed at groups and individuals.

Patients in myeloma UK have asked for literature to go to GPS and they do lots of information days because getting diagnosed quickly is so important.

### **Quality of care**

I was treated by Doctor Robinson and Doctor Willoughby both of whom have left now they were both excellent and they put me in touch with Myeloma UK.

I had a specialist nurse who was also excellent in telling me how things would progress.

### **Family**

My wife was very distressed and went to pieces. After crying all weekend, I sat her down and told her she would have to be the project manager of our building and so she pulled herself together and set too. It was very challenging for her but in a way a good distraction.

### **Treatment**

My treatment was a trial from the UK or the USA I was given the USA trial which was very vigorous steroids chemotherapy and thalidomide.

Every time I had a prescription, I had to wait for them to contact the USA and get authorization. The science was fascinating, and it was all explained to me.

I had chemotherapy by tablet I had to take 40 all at once and all three of the medications once a week. I was told that the first day it will make me feel marginally better and the second will be worse and I'd feel really weak and tired. By the end of the week by Friday I started to feel OK and then had to take the next lot of tablets.

Every month I would go to see the doctors and I could see that the paraproteins were going down in the third session they brought it down to 0.

At this point, all my stem cells were taken. I went to Bristol for a number of visits to have my stem cells taken. I was plugged into a machine, and I stayed in Bristol. The blood transfusion centre was very helpful in saying where we could stay, and they froze my stem cells ready for a later stem cell transplant.

At this stage, I was given a big blast of chemo to kill the bone marrow and I went to Bath where I was isolated for a month because I had no immunity. I wasn't allowed visitors, but I could call my wife.

Then after that the blood transfusion put the stem cells back in and I was nursed back to health again.

My mouth and throat were full of ulcers as the chemo kills fast-growing cells. I was on morphine, and I couldn't eat. I had a lot of tomato soup!

The nurses checked my bone marrow was replenishing and I was allowed visitors occasionally. I gradually got better.

### **Home Recovery**

We finished the house before I went in for stem cell replacement so I could recover in my new home.

I gradually built myself back up. I had to take 35 tonnes of soil in a Barrow to flower beds gradually and that was my recuperation.

### **Care and support comments**

I feel that all the doctors explained it so well. I can't praise the Renton unit enough they were all excellent. Phillipa who gave the infusion of Zometa for osteoporosis to fill up again was also excellent.

My para protein is still at 0. But I do three monthly appointments for checkups. I have lived for 17 years since that time.

It is a miracle really what they can do. I was told that just a few years earlier they would have been telling me sorry there is nothing we can do you are going to die.

The nurse offered my wife the chance to ring her too and doctors took time to ask her how she was coping. We always felt we could just ring up Cheltenham out of hours too.

### **Support group**

Phillipa when she came set up a group locally for purely Herefordshire people and ran it for two years with fundraisers and quizzes etc. This got people to talk and hear about new treatments. After a couple of years, the hospital considered that it wasn't the best use of Phillipa's time.

We tried to keep it going but we couldn't. Her contacts could get people coming that we couldn't. myeloma UK advised us, but we couldn't get people to come that were relevant to us. Yeleni did come. The Hospice came too. We found that it didn't work without health professional input. Numbers dwindled.

I would have liked this support group when I was first diagnosed there is one in Worcester and Gloucester, but you can't very easily travel when you're being treated.

### **Continuing home health care and Covid**

I was given Zometa once a month and in 2017 that was stopped. I had checks on my kidneys the medication has side effects. They found that one of my kidneys was dead and they removed it.

I still get seen once every three months. During COVID I still was able to go to the surgery and they send my bloods a fortnight before I visit for my checkup in the hospital. They call to say everything ok.

I am considered vulnerable so during COVID we got food parcels as we didn't want to go out of the house - stopping the food parcels was actually quite difficult!

With COVID immunisation I was first in line and the GPs were really on the ball at Ewyas Harold and Peterchurch.

I had a pre-diabetic course too.

### **Suggested improvements**

Having the support group for two hours a month made all the difference and was good for partners and carers as well.

I feel that some might struggle if they had financial problems or were working with having to stay in Bristol and to travel to see your partner in treatment that takes such a long time.

I am very pleased with the way I was treated and grateful for the advances in research that have kept me alive.

## **OUTCOMES/FURTHER LEARNING POSSIBILITIES:**

### **Excellent care and coordination between Primary and Secondary services**

This patient felt that their care was excellent, and the hospital and GP surgery worked well together during treatment and since.

### **Enabling a consistent support Group**

The benefit of a support group with medical professional input was important to his recovery and also supported his wife. Losing the input of the medical professional was detrimental and led to the group stopping.

It may be too difficult to rely on patients to run their own support groups unaided. With cancer patients, this can also lead to the collapse of support groups if the active members or leaders are ill or have relapses.

### **Health inequalities**

The patient was able to afford stays in Bristol and travel, but financial barriers could exist for other patients.

### **Speedy diagnosis and GP education**

Providing GP surgeries with information about rarer cancers such as Myeloma is suggested as the speedy diagnosis has benefitted this patient and contributed to his survival.

### **Consideration of Partner/ carer impact**

The impact on partners and family is very apparent in this experience.

### **Positive transparent communication**

This patient appreciated full transparent explanations and information about his treatment and the science behind his treatment. Not all patients seek such transparency, but it is important to give the patient that choice.

### **Ongoing care**

This patient appreciated the ongoing checks and finds them reassuring.

CONSENT FOR SHARING STORY ANNONYMOUSLY? YES or ~~NO~~ (circle)

CONSENT FOR FUTURE CONTACT? YES or ~~NO~~  
(circle)

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# Patient story 5

## Case study MS16

Healthwatch Representative:	<b>Mary Simpson</b>
Date collected:	<b>200623</b>
Key theme/service area:	<b>Cancer Care</b>

### CONTEXT:

I met this person at the Hereford Breast Cancer Group and she agreed to share her story. She had previously filled out a survey about her experiences and this is that transcript.

### IMPACT OF WHAT HAPPENED:

I might get a bit swearsy below, sorry if that offends you but I'm also taking this opportunity to write down my experience, for myself, and it includes a bit of swearing to express myself. I know it's not big or clever!

### Questions

1. When did you find out you had breast cancer? What year and what was your age?  
July 2021, I was 51.
2. How did you find out you had breast cancer? Did you have a lump or other symptom and then visit the doctor, or was it found during a routine examination or screening mammogram?

I noticed a lump. I am an F cup and was kind of wiggling myself around in my bra on the sofa, trying to get comfortable when I suddenly felt a lump deep in my right breast. It was late on a Friday night, so the next day I had a proper feel, and had to wait till Monday to call my GP.

I saw him the day after and then was put through to see a consultant on the two-week wait protocol. I hadn't done a self-exam in months, if not for longer than a year, and I really kick myself about that. I have no idea how long the lump had been there, but it was sizeable enough that if I had done a self-exam, I would have felt it.

### 3. Who was with you when you were given the diagnosis?

When I went to the hospital to see the consultant (I was alone – COVID), he did an ultrasound and said he saw something “sinister”. He used that exact word, which I will never forget. I went straight off for a mammogram, and when he'd got the image, he asked me if I wanted to know what he had seen. I said yes. He showed me the mammogram and the spiky lump, saying again that it looked sinister. He told me then that what we really want to see is a nice round lump.

My lump had about a quarter nice and smooth, and the rest was very spiky and misshapen. So, he said he thought it was breast cancer. He would confirm with the biopsy. If it was breast cancer, he would do a lumpectomy and I'd have radiotherapy. At this point I noticed the Macmillan Nurse in the room. I was looking at the image thinking ooo how interesting, then realised, wait, I've got breast cancer?

Looking back, this process was dreadful. It was managed really badly. The GP told me I would see the consultant and have tests to rule out BC. No one told me that I would get the first indication that very day. I expected to have tests and then wait for the results. So, to come out of that first appointment being 90% sure I had breast cancer, and to be told so flippantly was really harsh. A massive shock.

After he told me, he ushered me out with a breast care nurse, and it didn't hit me until she gave me her business card, her name on the front, and the green and yellow Macmillan on the back. Fuck, I'm a cancer patient.

I gibbered on to her for a while, I remember not making any sense and walking out in a daze. And there was my husband, waiting outside the hospital and smiling, and I had to tell him. As if it is not hard enough to hear it on your own, then you have to tell your husband ten minutes later.

The consultant was supposed to call me two weeks later on a Friday with the biopsy results, but the call never came. That was a very long weekend.

By noon on the following Monday, I was losing my mind, and called the breast nurse. She said they didn't usually give the results over the phone, and that the consultant had gone on holiday.

I did really well not to lose my shit at that point. I persuaded her to tell me, and it was then she said I was positive for an Oestrogen receptor, and they were waiting to find out about others.

I had no idea what she meant, except that I definitely had breast cancer. So, a long answer, as being given the diagnosis was not very straightforward. And fairly badly handled all around, looking back.

4. How did you feel on hearing the diagnosis?

In shock. As soon as the consultant said the word "sinister", I was in a panic. I could feel my heart constrict. Disbelief. Partly because I was not expecting to hear that first initial diagnosis, and it was all so fast. One minute I'm healthy, and the next I have a Macmillan Nurse assigned to me.

I felt like I'd been battered around the head with a cricket bat. You know Tom and Jerry cartoons where the cat is hit with a frying pan so hard, he vibrates and has a ringing in his ears – movement stops and sound slows down. I kind of felt like that. Or perhaps like a rabbit in the headlights of the biggest juggernaut, with my rabbit toes already crushed under the tyre. And it came in waves, circles. Disbelief, shock, panic. I only cried once, two days later. It took that long to sink in.

5. How did your family and friends react to the news? Was there anyone specifically who offered you support?

Big mix of reactions but all very supportive. Cards, presents, messages of strength. My sister-in-law was especially supportive at the beginning, but she had had colon cancer 20 years ago so knew exactly what the early days were like.

She sent me a book while I was waiting for the results, for example, as she knew I'd need some distraction while waiting. She sent me a hamper full of delicious food when I came out of hospital. We'd never been chatty or close, but she rang me a few times in the early days because she also knew how difficult it is mentally.

The least useful reactions were "My aunt/sister/friend died of that" and "Breast cancer is a good one to get as there are so many treatments, you will be fine".



My mum is 86 and has Alzheimer's so we (my brother and I) agreed that it would not benefit any of us to tell her. I am not 100% happy with that decision, but with her being so forgetful, I really felt like I could not cope if she kept forgetting and I had to tell her again and again. And she would find it stressful. I live 5 hours from her, so it has been easy enough to keep it from her.

6. Was there support that you felt you needed from those around you but didn't get?

I sometimes feel like I could use a little more pampering, a little more actual sympathy, a little more talking about how I felt.

That sounds quite odd but many people would just give moral support – “you are strong, you can do this” – “we are all thinking of you” – yes, that is all great but did not match up to how vulnerable and terrified I was feeling, or help to fill that emotional hole.

I felt like I still had to face it all on my own. I still feel the hardest part is mental – the thoughts of “will it spread, will it come back, were my lymph nodes really clear, how long will I live” .... Etc etc – having someone tell you you look great with no hair, or they are impressed at how well you have coped, just reiterates the fact that I've done it alone – but then, is there any other way?

What could others have done to bear some of the burden? I am not really sure.

7. Do you have any specific memories or tips you would like to share about letting family and friends know your diagnosis?

Not really. I did most of it over the phone. I always feel that you need to break bad news gently and work up to it a little, so I'd say I found a lump, went to get it checked, and by then they've already worked it out.

8. Did anyone's reaction surprise you?

Only the “least useful” reactions I mentioned in no.5 above. And I was surprised by my book club – we are about 10 ladies, and I'm probably the youngest.

I announced it in the group WhatsApp and three of them contacted me directly to say they'd had it, and to offer support. I never knew.

Same with my husband's theatre group. He told them all immediately and three women from there contacted me directly and offered their stories.

9. What was your diagnosis? Stage, grade, lobular, ductal.... any details you can remember would be useful.

I was told not to worry about stages. I don't know why.

Primary breast cancer, ER+, 2.8mm, grade 3, clear lymph nodes, curative approach.

When the consultant said 'curative approach' I thought that sounded really positive until I realised much later (i.e. 2-3 months later) that there are really only two options.

10. What treatments were you offered? What treatments did you have and in what order?

I was told I would have surgery to have the tumour removed. I didn't know what surgery until the actual day.

I thought it would be a lumpectomy, but I had a mammoplasty. I found that quite bizarre, that I didn't know what surgery I was having until the anaesthetist turned up to have a pre-op chat.

The results from the surgery were that the margins were not clear, but the lymph nodes were, and I was borderline for chemo. They did an Oncotype test and I had a high score, 38, so then I had chemo, and am in the very last week (as of March 11<sup>th</sup>).

Because the margins were not clear, and there was DCIS (*Ductal Carcinoma In Situ*) detected, I was offered a re-excision, a mastectomy, or a mastectomy with reconstruction.

I definitely didn't want recon, but it was still a very difficult decision to make, I had to push to get information which would help me, but I finally chose a re-excision, which is scheduled for April 5<sup>th</sup> 2022.

11. Were you given options on which treatments to have and were you given the chance to be involved in your treatment plan?

Yes, as above. I had been leaning towards a mastectomy, but right at the last moment they told me that I had clips put in, so they know exactly where the margins and DCIS (Ductal carcinoma in situ) is.

That had been a concern – how does he know where to re-excise? In addition, each time I mentioned mastectomy, the first thing the clinical staff would talk about was a prosthesis.

I found this very odd, with lots of concern about me having two matching boobs, and looking nice (for who? So when I go out in society people aren't shocked at my appearance? – to hell with "people") when that was the least of my worries.

12. How long did you stay in hospital following your surgery? Were you sent home with drains? How often were you seen after surgery? Was a breast care nurse or district nurse involved?

I stayed for two nights as I felt so crappy. I had one drain. The consultant saw me that night, and again the next morning (Saturday). I went home on Sunday with the drain. Then the breast nurses rang me on Monday, and I went in for dressing to be removed/changed on Wednesday. No complications.

13. Do you have any specific memories or tips you would like to share about the recovery from surgery?

14. How did you feel about having chemotherapy? What was your experience of chemotherapy? What side effects did you have?

I was devastated when I heard that chemo was being recommended. Cried all weekend. Much more upset than at diagnosis.

Maybe this was when it hit home that I'd really got cancer. I was kind of in denial up to that point. I was just having some surgery and it was nothing much really. But chemo is the big guns. If you need chemo, you really have got cancer, the shit is really hitting the fan. Suddenly it was all too real.

I thought I'd got away with it. But no, I'm going to have to go through the worst of the cancer treatments. It was an awful shock. I was terrified, both for the treatment itself and for what it meant in terms of the bigger picture.

Was my situation, my diagnosis, actually really really bad? What were the actual chances of recurrence? What is my prognosis?

I still don't know as I specifically asked not to be told my prognosis, as I can't deal with it.

I still don't have the answers to these questions, and I am still terrified at the thought of why I needed chemo.

15. Do you have any specific memories or tips you would like to share about having chemotherapy?

16. Did you lose your hair? How did you feel about losing your hair? Did you use scarves or have a wig? Were you offered financial support to buy these items? Yes, I lost all my hair, and not just the hair on my head – my eyelashes, and eyebrows are mostly gone. As is my underarm hair, my nasal hair, and pubic hair. And the hair on my face, which feels very odd to lose that slight fluff.

The process of losing the hair was pretty upsetting, but once it was all gone (I shaved it off after a week of it falling out), I didn't mind so much.

17. Do you have any specific memories or tips you would like to share about losing your hair?

18. Did you have radiotherapy? What was this like?  
It is in the plan, after the next surgery.

19. Did you work through your breast cancer treatments?

20. Did you go back to work once all treatments had finished?

21. Were there things you felt you couldn't do during your breast cancer treatments?  
I think an easier question would be what I could do – with cancer, chemo, and COVID, it meant I was basically self-isolating for the best part of a year.

22. Did you have a breast reconstruction, or do you use a prosthetic?  
No, I did not want either of these. I was willing to be uniboob if needed.

I was not prepared to pretend to have two boobs or boobs of the same size just to look right or nice for other people, as the nurses seemed to be recommending.

23. Did you join any support groups, either in person or online?  
I joined the support group at my local hospital.

## OUTCOMES/FURTHER LEARNING POSSIBILITIES:

Further learning possibilities from this patient story include:

- Advise all patients to be accompanied to appointments for cancer checks in case bad news is revealed.
- Give patients support when hearing for the first time that they are likely to have cancer and recognise that there will be other notable firsts along the journey e.g., the margins not clear, cancer found in lymph nodes, chemo is needed, secondary cancer detected. Each of these stages may be more shocking for the patient than the first diagnosis as the realisation of severity dawns. Staff to be aware that there are different stages of shock that may occur at different stages of that patient's journey.
- Delays of biopsy results are made worse by expected times to hear not being realistic or adhered to.
- It is important that patients understand what surgery they will be having before the day of the operation.
- When offered choices e.g., Mastectomy, re-excision, or mastectomy with reconstruction patients need all of the information to make the decision without having to push for it.
- Staff to understand that for many women the appearance of the breast afterwards is not an important immediate concern compared to removing the cancer. Early talk of reconstruction may not feel appropriate to the patient.
- Weighing up how much information to give is difficult. Here the patient does not want to be told a likely prognosis (this may not be something that can be predicted anyway), but they do want lots of information to be able to make choices about different treatments.

Lack of information can cause more anxiety for some, and more information can cause more for others. It is important to understand what the patient and carer wants and to personalise levels of transparency.

There will be times when explicit information and permissions are necessary when full information should be offered e.g. what sort of operation is to take place or what chemotherapy chemicals are to be used and their side effects.

CONSENT FOR SHARING STORY ANNONYMOUSLY? YES ~~or~~ NO (circle)

CONSENT FOR FUTURE CONTACT? YES ~~or~~ NO (circle)

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# Patient stories (group)

## 6

### Case Study MS11

Healthwatch Representative:	<b>Mary Simpson</b>
Date collected:	<b>05.04.2023</b>
Key theme/service area:	<b>Secondary breast cancer care</b>

### CONTEXT:

These stories were collected in a secondary breast cancer support group. The main issue expressed was that there was no breast cancer nurse for secondary cancer in Herefordshire.

There are 180 secondary breast cancer patients in Herefordshire.

One of the women started the support group because there was nothing for women with secondary breast cancer.

We heard from 8 women.

### IMPACT OF WHAT HAPPENED:

#### **Secondary Breast cancer care compared to primary Breast cancer care**

When I was diagnosed with primary breast cancer it felt like I was wrapped in a cloak of love. We were given a blue folder and loads of information a breast care nurse as keyworker and the offer of other support.

But for secondary breast cancer there is nothing. No breast cancer nurse for secondary cancer.

The women in the group felt it would be a real benefit to have a Key worker that could do call-backs and so on.

Someone who could also tell you about symptoms of 2ary breast cancer. This would be useful for women with primary breast cancer too.

### **Living with secondary breast cancer**

With Primary cancer, it is all about looking at your diet and lifestyle. A lot of us cleaned up our diets and improved our exercise but to be honest I exercised and ate well before I got cancer. I don't feel it made a difference. If you are going to get cancer you are going to get it.

With secondary cancer, you sometimes must exercise less. Recognise your limitations. My hip hurt less when I shortened my walk distances. Walking helps but I can do too much now the cancer is in my hip bones.

Being given percentages of likelihood return or how long you may live. It is all individual. They can't really tell you. We are all different. Our secondary cancers are in different places and develop at different speeds. We take medication and it works for a while then when it stops, we try another. You ask how long this or that medication will work. At first, I got the longest estimate. Then I found it was best to ask for the average.

Once I was told between 6 months and ten years!

### **Living with cancer and the BRCA2 gene variant**

Two years after primary breast cancer I discovered that I had secondary cancer and probably had it when I had been diagnosed with primary breast cancer in fact.

I was tested and found out I had the BRCA2 gene variant. I had both breasts removed and so did my sister who tested positive for it too. At some point, my daughters will have the test but for now, we are coming to terms with my diagnosis.

### **Benefits of Secondary Breast Cancer support group**

It has made a huge difference to me being able to talk about my diagnosis with women that understand.

I went to the primary breast cancer support group, and it was a bit difficult. With a primary diagnosis, you are still quite hopeful. The meeting is all about being healthy. You hope it won't progress. I found the jokey black humour a bit much.

I felt people with primary breast cancer could get experience that might help them to identify symptoms of secondary cancer – what to look out for – from us women with secondary cancer but I couldn't really see what was in it for us.

That's why this group has been good. We are all different but many of the issues are common and we can support each other with the uncertainty.

I feel it would be good to have something for the husbands too. They don't really have anyone to talk to about it. They have to be positive with us.

It is individual yes, but I don't want to involve mine I tell them very little. I heard about the Halo cancer rehab programme £20 for 10 sessions here.

In terms of the secondary care group, it's hard to get the hospital staff involved. Sharon was great but she's gone. The next one has not contacted us yet it's difficult for us to keep continuity when new staff have to get involved again.

In Macmillan Allison left and the replacement has not contacted us yet.

Years ago, Lindsey set up her own charity Haven 15 years ago, we would have gone to Haven. They held classes and had therapies and you could just walk in and have advice. They were in the town centre.

The primary breast cancer group meets every month still which is really good and supportive, and they also support the secondary group because they have plenty of funds and they help where they can.

We could do with a base and a notice board as I don't use social media.

### **Cancer and travel insurance**

Going on holiday and gaining insurance suddenly became an issue. The amount I was quoted initially was £800 for a week which was ridiculous.

I was advised by somebody in the support group and was able to get a reasonable quote just by entering my medication. <https://www.insurancewith.com> Going for a week in the warmer weather has done me a lot of good.

### **Diagnosis of secondary breast cancer**

I went to my three-month check-up blissfully unaware that I had secondary breast cancer. Luckily, I took my relative in with me.



The doctor told me that my scan revealed metastatic cancer in my hip, lung, and heart and just began listing all the places it was. I was utterly shaken. I was so glad I had somebody with me. I probably would have taken my husband if I had known. It didn't seem right that I wasn't prepared for this. I think they should have suggested I bring somebody with me.

I face lots of complications with where my cancers are. It is very complex. Trying to administer all the medication and scans and check-ups is hard.

There is no GP staff now. For six months I couldn't get an appointment at the medical centre I had to go to A&E. I had 4 1/2 litres in my lung cavity.

A & E is phenomenal. This was how I got a secondary breast cancer diagnosis. The respiratory ward nurse told me I had secondary breast cancer.

### **Breast Cancer scans and results**

One of the most difficult times is waiting for scan results. I know you can download your scans on the NHS app, but someone needs to look at it first before you are allowed to see it. I like to see mine. It is the most anxious time, waiting.

Waiting to have a scan is also hard - I waited 4 weeks for a scan.

It can also cause anxiety seeing different people. Explaining your story again and again.

A while ago a mobile unit a portable scanning unit at Hereford gave results in a week it was around the middle of last year.

MRI takes longer. In the hospital, results were quick because I was an inpatient.

MRU (Magnetic resonance urography), coordination is difficult.

### **General experience of doctors.**

The women had some good experiences with some doctors and negative about others.

The women commented that one Dr was very blunt and 'on the spectrum'. Some liked the honesty and brevity and others struggled with it. Some women didn't want to know the details and others did.

Most people felt it was OK to have trainees as doctors talked to them because they have to get the experience.

### **Ongoing/ Outpatient experience**

I find that I am chasing my own care. I have to be on at my oncologist Daniel all the time I have to navigate my own health care all the time.

Having to navigate your own journey and feeling that you have to remind people of procedures for example an echocardiogram can be difficult.

Also, when do they mention help at the Hospice and counseling? It seems to be a bit random who was referred, and when. I heard from the breast care support group.

The Hospice told me about clinical trials and other services and planning for the end of life.

It is 90% about facing the emotional side. I find I am a bit detached. When people talk about the future, I know I may not be here.

It is upsetting when you think you may not be there for something your kids talk about but then I try to stand back and let them help themselves more, be more independent. It pleases me to see they can solve problems themselves. I know they will cope without me.

Recently the 24-hour line at Cheltenham just has a continual ring and nobody picks up. This is the line at Cheltenham the helpline that you have to call if you have any side effects, and you can't get through.

For example, I had lots of mouth sores after chemotherapy. The lady on the phone had a heavy accent and I couldn't understand I thought why were you on the end of the phone?

I go through breast care nurses, Kaija Assirati is good from Macmillan.

The telephone system now has a waiting system that implements a queue.

Overall access and consistency is the important bit.

## **Patient and clinical trials.**

Make Seconds Count has someone you can call about clinical trials.

There is a question of what stage they mention the possibility of trials it seems to be a bit random.

There are issues with the coordination of services and consistency and choices.

A private appointment I had gave me more information on alternatives.

## **OUTCOMES/FURTHER LEARNING POSSIBILITIES:**

### **A need for a Herefordshire Secondary breast cancer nurse**

The impression that we gathered was that the experience of care for secondary breast cancer in Herefordshire was of reduced support in comparison with primary breast cancer.

There was a feeling almost akin to abandonment or of being a lost cause. A feeling that, now their cancer has spread they were not worth the time and money to treat, care for, or support.

Kaija Assirati, a primary breast cancer nurse, and Sharon a Macmillan nurse came to the secondary breast cancer support group to explain that the issue was that in Herefordshire there is no funding for a dedicated secondary breast cancer care nurse.

Kaija explained she is in the process of building a business case for one. It is seen as good practice and there is one in Worcestershire. The business case would be made to have a secondary care nurse as it is the national standard that Herefordshire should have one. [current best practice.pdf \(breastcancer.org\)](#)

The group was encouraged to send their experiences to Kaija or to Healthwatch Herefordshire who can collect and pass on their experiences to evidence patient views regarding need. Healthwatch has also asked the question and will raise it in Wye Valley Trust's Cancer Week in July 2023.

### **Learning for improved care**

There is a difficult balancing act to keep patients positive and giving realistic prognoses. Many times, cancer returns but many times it does not, and each patient is different. On top of this, some patients want to know the unvarnished truth and others prefer not to.

Given these difficulties, it is hard for practitioners to provide the information patients want but from the above comments we can learn that:

- It is important to consider the support needs of patients who are coming to an appointment that is going to deliver the bad news of metastatic cancer. They want to be advised to bring a supporting person with them.
- Patients whose breast cancer becomes secondary breast cancer are asking for the same kind of wrap-around care that they receive with a primary breast cancer diagnosis.
- Because of the complexities and individual issues arising depending on where the cancer has spread women need tailored advice and information.
- Women are able to say what degree of detail they wish to receive.
- Some women wish to see a chosen consultant at this stage of their cancer if they are not happy with the sensitivity or style shown by an individual.
- Delays to receive results of scans are the most anxious time for patients.
- Patients value consistency in relaying information and choices including support options (hospice, support groups, Macmillan, Halo, Yeleni, web and paper-based) and potential clinical trial choices.
- Coordination between Primary and Secondary care is important and medical practices vary in terms of the ease with which patients can make and manage their appointments to have blood tests prior to planned hospital appointments.
- Most patients would prefer the practitioners to be able to share their medical records so that they don't have to repeat themselves and could be confident about their coordinated care.
- Anything that can ease the burden on patients to navigate the system themselves or drive the process or administer their own care would be welcomed by patients. This becomes increasingly difficult as they grow older or more unwell, especially for patients without family or supportive carers.
- The support and information needs of spouses/ relatives/ children of cancer patients is an area flagged up as an unmet need.
- Practical information like holiday insurance, as well as medical needs, are useful to patients.
- These patients felt that the secondary cancer support group was a great benefit to them and being able to invite Macmillan/NHS experts periodically was very useful.
- A notice board and base were desired by people that do not do social media.

CONSENT FOR SHARING STORY ANNONYMOUSLY? YES ~~or~~ NO (circle)

CONSENT FOR FUTURE CONTACT? YES ~~or~~ NO

(circle) The group has agreed that we can return to hear more of their views.

# Patient stories (group)

## 7

### Case Study MS15 Group

Healthwatch Representative:	<b>Mary Simpson</b>
Date collected:	<b>20/06/2023</b>
Key theme/service area:	<b>Cancer care</b>

### CONTEXT:

I visited the Ross Cancer Support Group and they shared their stories and how they felt about aspects of their cancer journeys and health care.

There were 7 people present, a mix of cancer patients and carers.

Cancers included Prostate Cancer, Lymphoma, brain tumour and Mesothelioma.

Several people present had lost their spouses to cancer.

### IMPACT OF WHAT HAPPENED:

#### Diagnosis

I have always experienced excellent service.

Getting that first appointment is the difficult thing.

I had a six month wait.

Once you get a diagnosis the delay is over.

I agree you can't complain once you're in. It is getting that diagnosis that is important.

The difficulty during COVID and since is that I can't see how they can possibly diagnose you over the telephone.

With lymphoma, I was monitored, and a heart operation was triggered.

My blood test threw up a low blood count by the following week they were treating me it was all very good and quick.

Recently my husband died. His diagnosis was very difficult he had a biopsy in Gloucestershire, and they couldn't decide what cancer it was and they waited. We had to wait to see the results. Mesothelioma from exposure to asbestos 30 years ago was the issue with my husband. He only learned about it 3 1/2 months before he died. We just had to wait so long for results. We were told it was either that or small cell carcinoma and, in the wait, we felt abandoned. Gloucester lab couldn't decide which and they sent the sample to Bristol specialists which was another two weeks. Really, we would have liked more support in the interim.

The question we would like to ask is that if cancer manifests like that could the test reveal it earlier on? Why does it take two weeks to test for?

My husband had worked in the building trade I knew he had worked with asbestos so surely that second test could have been done simultaneously or at least quicker rather than wait for the results of the first one even if it was a more common cancer.

Can they do anything to help with rapid cancer? His cancer journey was three months from start to finish and he died. Is there anything that can be done while you are waiting a month for results?

Ref this patient who lost his life last month – this is intelligence from the support group leader:

- Patient was incredibly sick with vomiting when their wife came to our meeting and emailed to say he was worse afterward.
- I contacted the Dietician at Renton Unit, on her behalf, to see if they could help or advise her.
- Because he was under the Glos NHS and had not had a definite diagnosis, they were unable to do anything to help.
- He was already waiting for the Dietician to get in touch from Gloucester but was on a waiting list.
- In the meantime, he was getting sicker and sicker with vomiting and not even able to hold down the huge number of tablets that they had prescribed for him.
- He was therefore getting dehydrated and losing weight rapidly. – You can imagine how desperate X and her family must have been, and she now has to

live with those memories and those feelings of helplessness. There did not seem to be anyone that could advise or support them.

- He was then eventually sent to hospital and sadly died.

My husband had Lymphoma in Jan 2019 – there were delays in him being able to see a doctor for a few months so that he could be referred to a specialist. He was losing weight, vomiting, and getting weaker every day, but the receptionists were still not booking him to see a doctor. He saw a nurse who was very unpleasant, and she has since been dismissed. Once in the system, they were exceptional and couldn't be faulted.

### **Diagnosis is ongoing...**

He was due to be signed off, after being monitored by the specialist nurse for 3 years, before Christmas and was seen by Dr Jack for his final consultation. He referred him for an MRI to be sure and the Radiologist picked something up. He was then referred for a PET scan and was told that the Lymphoma was back in the same place.

He then needed surgery to remove the lymph sac so that they could conduct a biopsy. He was then told 5 weeks later that it was not Lymphoma, and that after the scar has healed, he would see him again and refer him for another PET scan to see what is going on. That's where we are now.

He's had 2 separate bouts of vomiting and I'm not sure quite what is going on. His operation involved taking out the node from behind the small intestine (and under the stomach) exactly at the same place as before.

Not sure if this helps but it can all be so complicated for some patients.

### **Feedback system**

Speaking in a very practical sense about Herefordshire Hospital. I always come back and fill in the feedback form saying it was very good. But the form will not accept it, it won't go through! If you can get that changed it would be good.

### **GP and Pharmacy experience**

Getting an appointment through your doctor is gold dust or you just can't see one. Bizarrely with Taurus it's dead easy to get a doctor.

I used to call every morning at 8:00 I now ring at 10 and I explain clearly and calmly, and they generally will do anything that I ask for on that day. It's a question of being polite and clear and staff being taught how to triage better, I think.



It's a case of educating patients as well for example it's actually quite good to see the nurses sometimes.

It seems to me that the doctors are spending too long with insurance forms and doing admin.

It seems to me that pharmacists are very useful for example with medication reviews.

When getting regular blood tests every three months you need to book your blood test at least a week before you go to the hospital. I don't understand why you can't book the second one after your first appointment that makes sense to me, but it doesn't seem to be possible. It would also decrease the number of calls that the surgery had to handle.

I had a training Doctor Who appeared to be on the ball. I am willing to talk to any doctor but if you see a junior doctor, they will go off to check with my doctor anyway so why not just give me an appointment with my doctor?

I agree the beginning stage is the most difficult I spoke to Claire Davis about prostate cancer she is very knowledgeable.

I prefer to go up and ask face-to-face. Phoning is more difficult. My surgery is Pendeen.

In Alton St you can phone and ask them to call you back there is a new phone system now.

In 2015 I was diagnosed with lymphoma. My doctor is at Alton St. I'd say it has improved gradually concerning my blood tests.

I'm being organised so that I could have them before I go for my hospital appointments, but some consistency is needed between the surgeries.

You have to know the system.

## **Hospital Delays**

If you cannot refer to the correct consultant this causes delays.

It's a really depressing problem when it should have started in December then January then there was a test then we had to wait five weeks and then you have another test, and you have to wait another five weeks and then you have to have yet another appointment to hear that the test is OK why can't they just phone you and tell you.

It can take six weeks to talk to an oncologist it gets you really down. This has been hanging over us for a year you can't go on holiday or anything you just have to wait, and you don't know when you'll hear from them.

One of the unnecessary delays is 1 consultant sending a letter to another consultant it can take six weeks each time why does it take so long to get from A to B? Sometimes it's just to tell each other that your results are OK they could have phoned you to say it was OK straight away.

We understand that the system allows time for the meeting of the multidisciplinary team to decide on treatment and time to tell you, but it shouldn't have to take that amount of time.

I have seen different teams meeting to discuss different patients they all look at the statistics together I know that takes time.

I just remembered something else, regarding the shortage of consultants now at Hereford in Haematology. Dr. Fraser Jack is covering (on secondment) for 12 months, and Mr. Costa has only recently come and I'm not sure for how long.

I understand there will be several diagnostic centres soon that might help I have heard.

### **Medication and understanding your treatment and side effects**

I was given Vincristine medication (chemotherapy) and I could not feel the end of my fingers and toes I was straight away put on another medication and sent down. Nobody had mentioned this might happen with chemotherapy you don't know what you are getting.

After a few weeks, you get a letter that tells you what you were having and what the effects are with the summary.

Seven years ago, you didn't get anything like that.

I get it now, it's a bit worrying in a letter, and you get a discharge summary but it's important.

### **Information sharing between hospitals and GP**

The crazy thing is each of the hospitals can't necessarily see each other's scans – the QE, Cheltenham, Hereford, Gloucestershire. They don't seem to talk to each other you would think that they did but their computer systems are all different.

The GP in Gloucestershire where I had most treatment had my notes. But I had one hospitalisation in Hereford it was a nightmare. I had photocopied the discharge summary and taken it to the GP in Gloucestershire when the paramedics came and took me to Hereford because there was a queue in Gloucester.

Hereford was smaller but they had a bed for me. I'd kept a file of all the consultations, and they photocopied it and asked me questions about it. They said well done for keeping it but what if I hadn't?

It's a lot better in Hereford now.

### **Finding beds**

I went in as an emergency to A&E dosed up. They were debating whether to give me an operation and rang around and finally got a bed and I was in a ward.

I was moved around a bit.

Hereford has to borrow beds. I think that's a problem. The haematology side of Hereford is brilliant except they don't have any beds. I spent a lot of time in corridors and on the edge of wards. Is there any way that they can have urgent beds for haematology patients?

### **Macmillan Renton unit**

The Macmillan Renton unit is really excellent I was really anxious. People there are really friendly I found them really helpful.

### **Communication**

You are not always given a choice but if you were how do you make that decision?

You're often not told the long-term effects of staying on hormone therapy I wasn't.

With prescribed medication you can read the packets and the information inside, with chemotherapy you have no idea what you're being given, and the long-term side effects and I don't think I was ever told.

With pelvic radiation, they didn't tell you about the long-term effects in the past, but I think they do now.

*Were you asked the level of information you wanted to know? Were you asked how transparent you wanted them to be?* Two people said no. Others said yes.

Communication is what is lacking.

You only need to know what you need to know but what you need to know changes.

They just need to talk to you like you have a brain. I have experienced the French and Irish systems and communication is so much different. It's better. You are given the reason for things it's still a bit of talking down to you but at least you know what is happening and why.

I found the Cheltenham phone line 24/7 very good. (*Two people present agreed that it was answered consistently*).

My haematology appointments were changed from Cheltenham to Worcester. Afterward, I had to call the line because I was violently sick, I was told to take two anti-nausea tablets and another in four hours' time I had very specific individual advice. When I had to ring Worcester, they gave me only general advice but not specific because they have different computer systems later on it worked better, I think they sorted the computer glitches out.

Communication is always the issue.

Phone support suited me I found that with any issues I could talk to them, and they did respond, and the specialist called me too. With my incontinence with my treatment, I didn't want to travel I needed to stay at home.

I had my radiotherapy in Cheltenham. All checkups were through the specialist. They did give me medication for the bowels etc and told me to get in touch. They gave me enough information to know what to expect. The hormones they do tell you about, but you don't really expect all the side effects. It's a bit of a shock when you have them.

My specialist said the likely prognosis is two years, I can give you 5 years with new drugs, hopefully, it can be 20 if new drugs are found in those years.

I felt five years – OK – I have been living 6 so far. When I got my diagnosis, they said you have had this a long time since 1986 when you had hot sweats, etc, and were given antibiotics. This had been picked up in Hereford, but they did not tell me in those days.

I use the patient gateway and was able to see my information.

The GP never contacted me until two months after diagnosis.

I was told that within three months the GP will get in contact to invite you to see them. This was last September but they haven't. It makes you feel they don't care.

### **Support and signposting**

I was told about support services like Yeleni and Cancer Support Group but at the time I didn't want to travel with the side effects for example incontinence, so I stayed at home. Quite isolating.

I knew about Ross's support group too and I needed support after that.

Yeleni has been very good when my husband was frustrated and tense, they calmed him down and helped him with side effects. I found out at the hospital and at the support group about Yeleni they're brilliant people the first lot of acupuncture did work for my husband.

The best support, the most important support is the support of family and carers.

In Cheltenham, they have a great lymphoma group, and they refer people to Yeleni. I think we want a Maggie's, and they want a Yeleni in Cheltenham! I belong to the lymphoma group as well.

### **Home care – end-of-life care**

My husband had a terminal brain tumour and was supported by 27 different agencies he came home to die.

Initially, the air mattress didn't work, or the compressor and the ambulance people didn't want to lift him into bed. There was very poor communication about that and the slip sheets etc. They didn't know how to use them he had home care. It would be useful for these services to share experiences.

Day Hospice can be very important to give the carer a day out.

My spouse would agree with that. It's important that the carer has support and very important that they have a break.

### **Covid**

I had treatment all through COVID. Hereford was very good it only stopped about a month ago using masks.

COVID well I went with it that was an experience. I had three ambulance trips, and the second the doc told me I had it I was sent home and then two days I was back in again.

*Several had caught COVID and were very ill and in hospital. Some people had initially tested negative but when they arrived at the hospital had to be wheel chaired in and quickly deteriorated.*

### **Difficulties for employed patients.**

It can be difficult for employed people who have to go for treatment over and over and not many employers understand. This can be very worrying for them and not having money can be difficult.

It is mentally exhausting.

Macmillan is very good at pointing you in the right direction. We, men, are not very good at asking for help.

Maggie's were brilliant They came to this group, and I got a lower rate of allowance up to 2014 I used to fill in forms I didn't want to ask. But they helped me.

### **Treatment cost**

*Re: prostate cancer. The patients were astounded at how much tablets cost one of them said one of their tablets cost £150 per tablet and they had read the chemotherapy was over 1000 pounds each time. They found this hard to believe.*

## **OUTCOMES/FURTHER LEARNING POSSIBILITIES:**

This group of carers and patients suggested the following future improvements and learning points:

### **Suggested Future improvements**

1. Could Haematology have urgent beds of their own
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2. Make systems talk to each other so you can see your scans or if that is impossible have a folder to take everywhere.
3. What if they implanted a chip with all your information on it? (Not everyone agreed with that!) Perhaps a bracelet with a chip in?
4. The most important thing is speeding up delays.
5. GP should contact you after diagnosis if that is what you are told.
6. Bringing down the barriers between the counties is important in cancer care.

### **Other learning possibilities**

1. 24/7 post-chemotherapy Phone line: tailored responses as opposed to generic advice are ideal so record sharing is important. It is important that the phone line operative has clear diction without a strong accent.
2. It would be useful to be able to explain to patients why test results take a long time. Understanding reasons for test delays might help patients to feel less anxious e.g., if cancer cells need to be cultured to measure speed of growth for example.
3. Can tests be done simultaneously when identifying which cancer a patient has especially when a patient is deteriorating fast?
4. What support could be available for sick patients and carers whilst waiting for results?
5. Is there a reason for delays in a dietician's advice for nauseous cancer patients? Is this something that written information might help?
6. Can anything help with rapid cancer? Is there anything that can be done while you are waiting a month for results to slow down cancer progression?
7. Does the hospital feedback form allow the patient to fill it out and say good or very good? (Patient experienced a digital glitch preventing him from filling out the form).
8. Could there be a better system at GP surgeries for patients that need regular blood tests before their ongoing regular Hospital appointments to make appointment booking less difficult? E.g., being able to book the next appointment at the previous appointment.
9. Explanation for other delays would also help patients to understand the rationale for time delays e.g., time to have Multidisciplinary team discussions, Consultant to consultant communication, and GP consultation.
10. Patients said that when they are awaiting results to say their tests are ok, they are comfortable with having a phone call to relay this information to speed up the process.
11. There is concern that there is a shortage of consultants in Haematology. Is this patient fear founded?

12. Are there going to be Diagnostic Centres and if so, what are the likely benefits?  
Patients would be interested to hear about this.
13. Detailed discharge information was thought to be a very good thing but some patients that sought transparency (not all do) wanted staff to explain risks and side effects before treatment (short and long term). Also, people wanted to know possible choices and enough information to be able to make those choices. E.g., Chemotherapy, Hormone therapy, and radiotherapy.
14. Patients appreciated being asked what level of transparency they would like and recognised that not every patient wants every detail. Two people said they had not been asked. All the rest had.
15. Address training/skills issues in home end-of-life care regarding lifting and handling and the use of slip sheets.
16. For employed patients it is useful to flag up at an early stage how to access financial help when work income loss is likely.

**CONSENT FOR SHARING STORY ANNONYMOUSLY? YES ~~or~~ NO (circle)**

**CONSENT FOR FUTURE CONTACT? YES ~~or~~ NO  
(circle)**







# healthwatch

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