

Names have been changed to respect patient anonymity

***Stephen = Patient**

**** Sarah = Carer**

PATIENT STORY

***Stephen**

Patient experience at Bradford Teaching Hospitals NHS Trust from January 2022 to December 2022

Compiled by **Sarah - Wife/Carer

Background

We retired in the summer of 2009. We both had a busy and active retirement until November 2021 when Stephen started to have various symptoms and felt unwell. Over Christmas and New Year he became very unwell. I eventually managed to speak with our GP on 11th January and within 45 minutes he was in the surgery. He was referred to the Trust with suspected lung cancer with metastases and one week later on 18th January Stephen had his first scan. With all the negative press about the NHS we were very impressed and grateful for such swift action.

During the last twelve months Stephen has had several appointments and investigations at Bradford Royal Infirmary (BRI), St Luke's Hospital (SLH) and Eccleshill Community Hospital. The overall experience has been interesting and mixed. I must emphasise that the care he has received at all three hospitals has been very good. The problems have been the non-patient friendly administration systems, communication and physical access to the care.

Examples

18th January - Scan at BRI Radiology Department.

Positive:

As stated above this was arranged very quickly. Later that evening we received a telephone call from a nurse in the Respiratory team informing us that the scan was negative for cancer. We really appreciated this call. She went on to say that the team had requested a head scan (at the time Stephen was very confused) as well as lungs but this had not been done and suggested we speak to our General Practitioner (GP).

Negative:

On 13th January we received a telephone call to arrange the scan on 18th. A letter was received confirming the appointment with instructions to access the Department via the MRI/CT door near Ear Nose and Throat (ENT). As we knew parking would be a problem we arranged a lift and were dropped off by this door but we could not get in. Stephen was in too much pain to walk to the ENT or main entrance and too confused for me to leave him on his own whilst I went in search of a wheelchair and there was no one around to help. Fortunately a member of staff came out of the door. We explained what had happened and she let us in. When we showed the letter to

Radiology staff they were surprised that we had been sent these instructions as the MRI/CT door had not been in use since the beginning of Covid.

30th January - CT scan at BRI Radiology Department.

Positive:

On 21st January we spoke with our GP who arranged blood tests and sent a referral for a head scan. Again we were contacted very quickly and an appointment was arranged for Sunday, 30th January. This time I confirmed the access arrangements in case a letter gave different instructions.

Negative:

The letter said to report to reception in Radiology but this isn't staffed at weekends. When we arrived in the Department there were other patients sitting in the waiting area who didn't know where to go and there was no one around to ask. Fortunately we knew the way and could help.

17th February - Eccleshill Community Hospital.

Positive:

Following blood test results our GP telephoned on 4th February and told us that Stephen had suspected Myeloma. We were obviously worried but an appointment was arranged for 17th February. Again we were impressed by how little time we had to wait. The staff at the hospital were very kind. We saw the Speciality Doctor and we cannot thank him enough for his care and attention. He spent over an hour with Stephen. The following day he rang me to say that although Myeloma could cause some pain he didn't think it was the cause of the severe pain that Stephen was suffering nor most of his other symptoms. He had the result of Stephen's head scan and told us there were two infarcts but there were other worrying symptoms and with our permission he would arrange further tests, namely:-

- MRI of spine and CT of pelvis.
- Bone marrow biopsy.
- Gastroscopy and Colonoscopy (Stephen had lost 2 stones in weight).
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Negative:

We received a telephone call the day after to say there had been a cancellation for an MRI and CT the following day, Saturday 19th. We were amazed but on the Saturday morning the confirmation letter gave different times and instructions. When I telephoned the number on the letter to check the times a recorded message said the Department was closed at weekends. Fortunately I managed to contact the Department via switchboard to check the times but other patients may not have known to do this.

3rd March - Telephone Appointment with the Speciality Doctor.

Positive:

Between 17th February and 3rd March the Speciality Doctor had telephoned several times to check how Stephen was. He told us that the MRI of the spine showed deterioration in several vertebrae and a possible fracture - no wonder Stephen was in so much pain. The report on the CT scan of pelvis had not been received, but because of the result of the MRI he was going to arrange a DEXA scan. Also the bone marrow biopsy would be arranged soon.

Negative:

The biopsy letter just gave a date, time and venue - The Meadows at Eccleshill Community Hospital. I rang to check how long the appointment would take and whether we needed to do Lateral Flow tests. I was told "no" because Stephen would have a PCR test two days before. I am glad I rang because the PCR test appointment had not been arranged.

28th March - Bone Marrow Biopsy at the Meadows.

Positive:

Stephen was in extreme pain and very confused. The staff were very kind. The registrar advised postponing the biopsy and rebooked this the following week. She had the result of the pelvic CT scan and could confirm a fracture as well as damage to several vertebrae and was surprised we hadn't been contacted about this. She prescribed morphine to be taken when needed but definitely one hour before the biopsy appointment.

Negative:

I had to collect the prescription from Rowlands Pharmacy ENT at BRI. Not easy. Nowhere to park nearby. Stephen couldn't walk from the Smith Lane car park and wasn't well enough to be left on his own in the car so I drove home, arranged for a friend to stay with him and another friend to drive me to the hospital and wait for me. I waited 45 minutes in Rowlands for the prescription to be filled - not good for patients who are very unwell. I cannot understand why the Pharmacy is not situated with the shops in the main reception area. This would be far more accessible and convenient for patients.

29th March - DEXA Scan at St Luke's Radiology Department.

Positive:

Staff very kind and efficient.

Negative:

The appointment letter didn't mention a blood test was needed. Stephen had blood tests for his haematology review just before the DEXA scan. If we had known one was needed for the osteoporosis check we could have arranged that at the same time.

4th April - Bone Marrow Biopsy at The Meadows.

Positive:

Before leaving the hospital last week I made sure that a PCR test had been booked for 2nd April. The scan was done on 4th as planned. Staff were very kind and caring.

20th April - Dual Procedure Gastroenterology Department at BRI.

Positive:

A telephone appointment took place two weeks before to check medical history and explain the procedure. An appointment was arranged for a PCR test on 17th April and instructions given for collection of preparation medication. On the 20th staff were very kind and caring. We were given both a verbal and written report before we left so we knew the diagnosis. We were told that tissues samples had been taken and polyps removed and that the results would take 6-8 weeks.

Negative:

The confirmation letter included a map of St Luke's Hospital and instructions to drive to building number 10 and to ring the mobile number on the letter for the PCR test. I thought this strange as I knew there was a testing station at SLH having taken Stephen there twice before but as the 17th was Easter Sunday maybe there was a different system. We followed the instructions which turned out to be wrong so went to the testing station. No one could explain the information we had been sent.

The preparation medication had to be collected from BRI before 14th April. I was told to go to the Duke of York entrance; ring the Gastroenterology Department then someone would come down and give me the package. I had to wait there and not go to the Department. I rang before driving down to make sure someone would be available but was left waiting outside for 40 minutes. The security officer on duty at the door was no help.

The arrangements assumed that patients could drive to SLH for a PCR test and get to BRI to pick up the package. If Stephen had been living on his own he wouldn't have been well enough to do this.

It is now 15th January 2023 and we have still not received the biopsy results from 20th April, nor has our GP, but as Stephen has regained the weight he lost then it is reasonably safe to assume that there was nothing serious.

Continuing Care

Stephen has had several blood tests and telephone reviews. He was diagnosed with osteoporosis after the DEXA scan and has been receiving treatment. Haematology reviews continue but they have been with different doctors - we haven't spoken with the Speciality Doctor recently. Stephen remains very unwell - a different person from 12 months ago. Our GP subsequently referred him to a neurologist who made arrangements for MRI scans.

25th October - MRI Scans - Unit outside SLH Radiology Department.

Positive:

This was an evening appointment. We were very impressed with the two staff on duty - sorry don't know their names. We explained that earlier scans had not been a good experience and Stephen was somewhat apprehensive today. The staff had been kind before but Stephen was in pain and confused at the time and when his hearing aids were removed he could not understand what people were saying and what was happening. The staff at today's appointment understood and were very kind. They gave him a break between the two scans and explained before asking him to remove his hearing aids.

Negative:

The staff said the consultant would receive the results within two weeks but we have still not been contacted by neurology and I have not been able to contact the neurology secretaries.

General Information

- An assumption has been made that all patients have a smartphone or another way of accessing the internet. Stephen frequently receives texts asking him to click on a link to view an appointment. We have a laptop and a desk top computer but from choice do not have smartphones. Also as well as texts he receives emails asking him to click on a link to view letters but in order to view anything patients have to register with the DrDoctor website which is a third party website. When an email is sent is it not possible to send letters as an attachment? Like many people we are dubious about any third party websites.
- Stephen has bilateral hearing aids but still has problems hearing and cannot hold a conversation on a mobile. I have explained this numerous times to staff and asked that all telephone appointments be on the landline. We can turn up the volume and use the speaker. This also means I can help if Stephen is too unwell to engage with the conversation. However, every time someone rings they use the mobile. I have been told the mobile number is the number of choice for the Trust and can't be removed from the patient record. (We should mention that the service from Audiology staff at BRI is excellent).
- Over use of answer phones. It is very difficult contacting departments. Some numbers connect directly with a recorded message without even ringing.
- We have on two occasions received copies of letters sent to our GP saying a haematology review could not take place because Stephen hadn't arranged blood tests or completed a questionnaire. I immediately contacted the hospital on each occasion to say we knew nothing of these appointments. After the last review we were told it would be 6 months before the next then a few days later received an appt for the following month. I obviously contacted the hospital - this appointment letter was a mistake.
- As Stephen has been so ill I have had to accompany him to all appointments. Whilst sitting in the waiting areas I have heard other patients/carers experiencing similar communication problems - mistakes with appointments, being sent to the wrong venue, confusion over instructions. I have been able to sort out the various issues for Stephen but how would an elderly, vulnerable patient living on their own manage.

In conclusion

As I said at the beginning the care for Stephen has been very good and was arranged very quickly when needed. We knew that Stephen was ill but hadn't realised how many conditions he had and how his quality of life would change, but we will be eternally grateful that the Speciality Doctor took the trouble to explore all avenues even though he said they were not in his area of expertise. If he hadn't been so thorough we may still have been trying to obtain definitive diagnoses. It is just neurology which is awaited

Sarah

15th January 2023