Southern Health and Social Care Trust

Quality Care - for you, with you

19 February 2018 **Our Ref:** Personal Information redacted by USI

Private & Confidential

Patient 13
Personal information redacted by USI

Dear Patient 13

The Southern Health and Social Care Trust received a urology referral from your GP. There was a delay in the processing of this GP referral.

When the Trust identified this delay it commissioned a Serious Adverse Incident (SAI) review. The purpose of the SAI review is to establish what happened, why it happened, impact if any on patients and what learning could be obtained. In order to have a degree of independence and integrity, the SAI review is chaired by senior doctor not directly involved in the patient's care.

An integral part of this SAI review is to engage and inform those patients included in the review. To this end The Trust would encourage your participation in the SAI review whilst fully understanding and respecting if you choose not to participate.

Patient 13 if your preference is to wait until the SAI review is completed I will write to you again to offer the sharing of the draft report and provide you with an opportunity to comment on the report.

However should you wish to take up this opportunity or require additional information please contact Mrs Trudy Reid on Personal information redacted by USI

Yours sincerely,

EA Gishkori

Mrs Esther Gishkori
Director of Acute Services

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Mr Haynes said that my G.P. possibly hit the wrong button on his computer and sent my referral through to urology C.A.H as routine. I was taking aback by this comment and asked him was it my G.P's fault for the delay? He said it was v. easily to make that mistake on a computer. I asked him if I hadnt have went back to my GP in early January 2017 to find out what was the delay in urology contacting me when did he think I would have been called by urology he didnt answer but ther seem to have oncology expertise as "I have had a good oncological outcome from this treatment"

page 11 mr Dawsons Report

Mr Haynes told me after I asked him did the delay in my diagnosis have an adverse outcome on the extent of my operation, was it possible that the prostrate or left kidney could have been saved if I had been seen by urology in July 2016 his response seemed to indicate that he had expertise in bladder cancer pathology, stating that although there was a delay in my referal in July 2016 until Jan 2017 "the ultimate treatment which (I) He required with a radical cystoprostatecomy and nephroureterectomy would have been recommended at the pont of initial referral"

Page 12 mr Dawsons' Report

After my Diagnosis in november 1995 with muscle wasting disease with a face rash, Dermatomyositis, I was treated in Quinhouse, RVH on atleast 3 occasions, staying from 10-14 days at a time, Mr Victor Patterson and Mr Michael Watt, neurologists, treatment involved steroids and Cyclophosphamide 150mgs, taken orally which increases considerably the risk of bladder cancer, even after 15-20yrs since last administered. I asked Mr Haynes was this a possible reason for my bladder Cancer diagnosis he said he wasnt sure because he didnt

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Dear Dr Hackett

This Personal information year old gentleman was admitted to Ward 2 South on 1.10.96. As you know, he has had a history of frequency, nocturia and dysuria, associated with haematuria for some time now. Previous flexible cystoscopy showed a lesion in the bladder. This was a booked admission for transurethral resection of this bladder lesion. However, at cystoscopy, the bladder was entirely normal. Multiple biopsies were taken. As you know, he has a history of dermatomyositis and has been on **Cyclophosphamide.** Histology showed some atypia with granulomatous inflammation. It was unsure whether this was related to the Cyclophosphamide therapy or not. He was discharged home on 3.10.96 to be reviewed at the out-patient clinic on 19.11.96. We will keep you informed on his progress.

Yours sincerely

- 12 May 97 – Letter from Mr O'Brien. "Further to previous correspondence pertaining to this gentleman, I write belatedly to confirm that I reviewed him on 19 November of last year, finding him to remain very well indeed. I have arranged to review him again in 6 months' time"
- 14 Aug 97 – Letter from Dr J Hamill, SHO to Mr O'Brien

I reviewed this gentleman at Mr O'Brien's clinic today. He has been remaining quite well until approximately 2 weeks ago when he developed symptoms of frequency, haematuria and dysuria. He also tells me that he noted his urine to be cloudy. He was commenced on Trimethoprim by your goodself which appears to have had some effect. He has no other symptoms, but I do note he is on Cyclophosphamide. Today I will be checking a routine FBP, U&E and his MSU. I have told him if his symptoms do not settle within the next few days to return to your good self. We will review him in 2 weeks.

- 16 Oct 97 – Letter from Urology Registrar

The above named gentleman who suffers from dermatomyositis and is on regular doses of Cyclophosphamide was reviewed in the urology outpatients today. He still continues to have nocturia and terminal haematuria with a burning sensation. On his last visit in July 1997 he was commenced on Trimethoprim 200mgs and Cimetdine 400 mg tablets, twice daily. Unfortunately this treatment has not helped him. He also has been on long term treatment with Cyclophoshamide. Suspect he might have ongoing symptoms due to urothelial toxicity caused by Cyclophosphamide. After discussing this with Mr O'Brien I am putting him on Mesna 400mgs once daily orally for a period of 3 months and we have checked his MSSU today and his name has been transferred from flexible cystoscopy list to the rigid cystoscopy list. We will keep you informed.

Yours sincerely

- 26 Nov 97 – Letter from Dr Patterson. "he still complains of the bladder symptoms"
- 3 Feb 98 – Letter from Urology Registrar. Patient 13 s recent urine culture indicates a urinary tract infection with coliforms"

- 17 May 99 – Letter from Mr O'Brien

Further to Mr Thompson's letter of 3 February 1998, I write to advise you that Patient 13 was subsequently reviewed in May of last year, and again in June of last year. As you will recall, we believe that Patient 13 has had a Cyclophosphamide induced cystitis. Generally speaking, his lower urinary tract symptoms have improved since discontinuing the Cyclophosphamide and since being managed with MESNA. At review in May of last year, Patient 13 had by then discontinued the MENSA as well as the Cyclophasphamide. Whilst he no longer had any nocturia, and had decreasing diurnal urinary frequency, he still did have occasional frank haematuria, this was confirmed by urinary microscopy in May of last year, when it was also noted that he had minimal pyuria and bactiuria. However, urinary culture was negative. When I reviewed him on 16 June of last year, I advised him that we should have him readmitted for cystoscopy under general anaesthesia at some time in the future. I have not been able to arrange his admission to date but I will arrange to do so in due course.

- 26 Jan 01 – Letter from Mr Wilson, Consultant Urologist

Patient 13 is on the waiting list for cystoscopy and bladder biopsies. He gives a history of Dermatomyositis and was on Cyclophosphamide in April 1996. The then had frank haematuria associated with dysuria. Patient 13 tells me he had a cystoscopy and his bladder appeared normal but biopsies showed atypia. He stopped taking Cyclophosphamide and he has been well since then with no further blood. Urinalysis today was clear.

I do not think Patient 13 requires a cystoscopy at this stage and I have discharged him back to your care.

- 28 Jul 16 – GP referral to Urology. Marked as Routine

Reason for Referral/ History of Presenting Complaint

Description: .

Comment: Episode of single haematuria 4 wks ago, no associated flank pain, nil since.
No other urinary symptoms.
Normal cystoscopy in 1996 for haematuria in context of dermatomyositis.
o/e abdo snt, prostate enlarged, nodule right lobe

- 23 Jan 17 – Letter from Southern Care and Social Care Trust informing Claimant of Haematuria Clinic Appointment on 31st January 2017
- 31 Jan 17 – Letter from Urology

Finally I would like to say that Mr John Keane, urologist, B.C.H. was and is a great Doctor and I will be forever grateful to him and his Team. The young female nurse who drew where the stoma was to be fitted on my stomach drew it V near my belly button hence after my op and to this very day because of the indent of the belly button this causes the stoma bag to leak very often, I feel that if it had been drew 2-3cms further away from belly button I wouldnt be having this problem which causes so much anxiety for me.

Also on march 2017 my wife and I attended C.A.H Thorndale unit to discuss and find out what my prognosis was, Mr Glackin, Urologist, CAH told us the terrible news, I was speechless I then asked mr Glackin how long had it been in my body (the cancer) he replied - " 2 weeks, 2 months, 2 years I dont know" and shrugged his shoulders, we both broke down in tears at his Coldness I asked him had cyclophosphamide been a reason for my cancer and he turned and faced his Computer and didnt reply.

The urologists and neurologists comment in mr Dawsons Report that I had bladder problems before commencing Cyclophosphamide this is true broadly speaking, but my bladder problems pre cyclophosphamide were being caused by the onset of Dermatomyositis, a muscle wasting disease, where I was lossing bladder strength and continually thinking I was wetting myself. post cyclophosphamide and during its administration it was more painful passing water and more frequent passing urine and very small amounts being passed, waking me out of my sleep 2-3 times a night, I feel that I had different Symptons Pre + Post, Present taking cyclophosphamide

yours Sincerely

[redacted] Patient 13

Southern Health and Social Care Trust

Acute Governance

Patient 13

Armagh Community Hospital

25th November 2020

PRESENT: Mr Mark Haynes Consultant Urologist

Patient 13

Mrs Carly Connolly

Mr Haynes welcomed Patient 13 and advised the meeting today was for him so that he could ask questions about his care.

Patient 13 thanked Mr Haynes for meeting with him today and asked what he know.

Mr Haynes advised he was on the review panel advising he was not the chair of the review but was a panel member and provided a urology expert opinion. Mr Haynes advised Patient 13 he has kept an eye on his care and progress over this period of time.

Patient 13 advised he is more than happy with the care he has received from Mr Keane and Mr John.

Mr Haynes advised Mr Keane will be moving on now to new employment.

Patient 13 advised he would be a big loss.

Mr Haynes advised he has worked with Mr Keane after Mr Keane's father retired and agreed he would be a big loss.

Patient 13 described his time in 1995/1996 when he developed muscle disease dermatomyositis; he was treated by Mr Watt in Quinn House in Belfast. Dr Watt prescribed the drug cyclophosphamide, which he did not know at the time could potentially lead to bladder cancer. Patient 13 advised he is aware there was a delay in referral to Thorndale, that he attended his GP as he was passing blood in his urine, he explained that he had his PSA checked regularly, and this was good. GP advised him to come back. At this appointment his GP asked if he had received word from anyone from the hospital to which Patient 13 advised he had not. His GP followed up and by the Friday he had received a letter.

Mr Haynes advised these are 2 issues: 1. Cyclophosphamide and 2. The process. Mr Haynes advised the SAI process recognised the delay; Patient 13 was initially referred in July 2016 due to blood in his urine, which is an indicator for suspect cancer. The cancer pathway is a red flag referral. Mr Haynes advised that when cases are reviewed and when something has gone wrong there is generally always more than one thing that has gone wrong in the care.

Mr Haynes advised Patient 13 his GP referral was intended to be a red flag referral, however it was mistakenly sent as a routine referral. Mr Haynes advised there are fail safe mechanisms in place, all referral letters received by the Trust are triaged by consultants to ensure they have the correct urgency assigned to them. In Patient 13 's situation he had blood in his your urine and although it was sent as routine referral it should have been triaged and upgraded to a red flag. Unfortunately triage did not take place in his case.

Patient 13 advised he was seen within 2 weeks once the error was identified.

Mr Haynes advised that when errors happen in health care there is usually more than one thing that goes wrong. Mr Haynes used the Swiss cheese model to demonstrate how multiple errors can happen and reflected Patient 13 's case.

Patient 13 advised he was not aware the GP mistakenly sent the referral as routine. The GP has since left the practice. Patient 13 advised all the doctors in the practice were very good and would not fault them.

Mr Haynes advised it was not intentional explaining there is a drop down menu on the system for selecting referral type; if you inevitably press the arrow it may select the wrong referral type.

Patient 13 asked would it have made a difference, the letter he received advised it would not as he was now 2 years free of bladder cancer. Would the delay have made a difference to the situation he is in now, explaining this has been life changing for him.

Mr Haynes advised with bladder cancer we would look at 2 factors, 1 the outcome, the prospect of survival. 2. What treatment you required. Mr Haynes advised that although his name was not attached to the letter he was involved in the wording referring to cancer survival. Mr Haynes explained that with some cancers there is very clear evidence that delay in symptoms can reduce the chance of long term survival. With bladder cancer time is important. The letter received recognised the referral made by the GP in June /July and identified the delay did Patient 13 at risk. However because some time has passed since treatment and Patient 13 was still her today reflects a good outcome. In most cases bladder cancer would re-occur within the first year of treatment. It is now 3 years on since treatment and Patient 13 has had no re-occurrence, advising he is lucky. At that point of treatment Patient 13 had a 2 year survival rate 50/50, however if he had been treated earlier the survival rate would have been 60/50. Fortunately the delay has not impacted him as he has had no re-occurrence at this stage down the line.

Patient 13 asked about treatment/surgery, would it have been different if treated earlier.

Mr Haynes advised what is known about bladder cancer is that if invasive it can be aggressive from the outset. The location of the cancer was always going to be invasive and Patient 13 was going to require a bag even if seen earlier. Mr Haynes advised Patient 13 he had cancer cells and either way the best treatment was the operation. When bladder cancer develops there is a further risk of cancer aggression if treatment is delayed.