

Trust Board Meeting in Public: Wednesday 11 November 2015
TB2015.124

Title	Patient Story
--------------	----------------------

Status	For information
History	Patient stories are regularly presented to Trust Board and Quality Committee

Board Lead(s)	Ms Catherine Stoddart, Chief Nurse			
Key purpose	Strategy	Assurance	Policy	Performance

Executive Summary

1.	The purpose of this paper is to tell the recent story of a patient 'G', who was treated for Leukaemia at the Children's Hospital of the Oxford University Hospitals NHS Foundation Trust (OUHFT).
2.	This story provides an important opportunity to: <ul style="list-style-type: none">• Recognise good practice especially in relation to communication, medical and nursing expertise and compassion.• Recognise the high value patients and carers place on their relationship with staff.• Reflect on the value of providing information and context how a department is run, of managing patient and carer expectations and showing flexibility.• Raise awareness of the importance of preserving patient privacy and dignity and ensuring patient consent.• Raise awareness of the negative impact on patients and carers when experiencing organisational or system issues that are perceived to be unnecessary or avoidable.
3.	Recommendation The Trust Board is asked to read and reflect on the patient story and acknowledge the learning.

Patient story

1. Purpose

- 1.1 The purpose of this paper is to tell the recent story of 16 year old patient 'G' who was treated for Acute Myeloid Leukaemia (AML)¹ at the Children's Hospital during 2015. The story includes the perspective of the patient and his parents.

2. Background

- 2.1 The Patient Experience Team produced this story through an hour long conversation with G and his mother at their home in Oxford, followed by emails from his mother and father. The staff perspective was obtained through conversations with the Sister for the ward on which he was cared for and through email correspondence with the consultants whose care G was under.

- 2.2 This story portrays the positive impact on patients and carers of excellent care and full communication, including the "little things" that make a difference and demonstrate compassion and "going the extra mile".

"I had a lot of confidence in all the nurses and doctors." (G)

"We felt there was a high level of expertise and compassion throughout" (G's mother)

- 2.3 While all staff were praised, one nurse and one consultant were singled out by G and his parents who felt that these individuals showed particular warmth towards G and communicated fully at every point. This story shows the difference it makes when a patient feels supported and "seen" as an individual throughout his journey.

- 2.4 The story also shows that there is a negative impact on patients where there is incomplete communication and a perceived lack of flexibility around care or organisational arrangements.

- 2.5 The presentation of patient stories gives an opportunity to represent real life examples of the Trust's values in action, both from a positive and negative standpoint. This story gives Trust staff an opportunity to reflect on clinical and non-clinical work with patients and their families; and the critical role we all play in supporting healthcare to run smoothly.

3. Mr G's story

Diagnosis and treatment

- 3.1 G had had a virus with "flu-like" symptoms for a few weeks in December 2014 and his leg had swollen up. A few days before Christmas, he visited his GP who took blood tests. Later that day the family were phoned to say that the blood tests were abnormal and that he needed to attend as an urgent patient at the Children's Hospital where he was diagnosed on Christmas Eve

¹ Acute myeloid Leukaemia (AML) is the most common form of Leukaemia and affects myeloid cells

- with AML. He was 15 at the time and in his GCSE year at a local Oxford school.
- 3.2 G and his parents felt that the communication throughout the investigations and diagnosis was “excellent”, they felt fully informed and that their questions were answered throughout. One issue G raised was that he was told he had leukaemia but not told that he had cancer. It was only a few days after diagnosis that G asked his parents “do I have cancer?” This was not a criticism but rather a comment.
- 3.3 One of the first things G’s mother noticed was that the Consultant made a “huge effort” to ensure that G had the right chemotherapy drugs so that he could start treatment straight away over Christmas. The drug company closed at 4pm on Christmas Eve and this meant that urgent telephone calls were made to ensure that the treatment was available. In discussion for this story with the Sister, she recalled out that another young person had been admitted just after G, also with AML, but there was not enough beds available in the hospital for him. So the Consultant was also arranging for this patient to be transferred to Bristol that evening. G’s mother said she was very grateful to the consultant for staying late on Christmas Eve to ensure G’s treatment could start as soon as possible. *“I am sure she would have expected to have gone home earlier on Christmas Eve”* (G’s mother).
- 3.4 After the first round of chemotherapy G had a bone marrow test and lumbar puncture and, at that point, it was decided that he would benefit from a bone marrow transplant to prevent the leukaemia from recurring. He received the bone marrow transplant at Bristol Children’s Hospital after receiving further chemotherapy in Oxford.
- 3.5 G’s parents were very impressed by the Consultant who was caring for G as she used a FLOW test to explore the state of the disease². The consultant identified that G’s blood did not have the usual chromosome markers³ which indicate the response of the disease to treatment. G and his parents felt the consultant explained to them very well that the absence of markers makes it more difficult to give a definite indication of the progression of the disease. Therefore, the consultant used the protocol which has been used for acute lymphoblastic leukaemia (ALL)⁴ and is to be used routinely in AML.
- 3.6 G’s flow test showed that although the chemotherapy had killed off the leukaemia to a large extent, it had not killed it off enough and would be a risk that it would recur after his treatment had finished. G’s mother felt that this flexibility to use a protocol that was not yet being widely used for AML patients was due to the experience of the consultant.

Waiting times and managing expectations

² Flow cytometry is a method by which the surface markers on the patients leukaemia cells, specific to their leukaemia, can be seen, so that even small numbers of remaining leukaemic cells (blasts) can be detected

³ Markers are changes to the chromosomes inside the cells specific for the patients individual leukaemia' -

⁴ Acute myeloid leukaemia (AML) affects myeloid cells and Acute lymphoblastic leukaemia (ALL) affects lymphoid cells.

- 3.7 The key issue that G and his mother had concerns about was the waiting times, but they were also grateful when nurses utilised opportunities for flexibility.
- 3.8 G needed a general anaesthetic on a number of occasions and was asked to come to the hospital at 7.30am after being nil by mouth from 6am. The first time he attended at 7.30am he wasn't seen until 12 noon which meant a long wait in a waiting area which was quite noisy due to the number of young children also attending. It was particularly difficult because he had had trouble getting to sleep early and was usually only falling asleep at around 2am. His mother said it was really hard waking him up for a 7.30am appointment. Then he arrived and had to wait for several hours feeling extremely exhausted.
- 3.9 After a few visits they realised that the children's lists are organised by age so that the youngest is seen first. As G was 15 years old at the time he was usually last on the list so seen later in the day.
- "It would have been really helpful to have had our expectations managed so that we were aware that it would be a long wait." (G's mother).*
- 3.10 At some point, G's mother asked if they could come in later. After a few appointments, they were told they could come in at 10am, which was much better, and they appreciated this flexibility. The Sister explained that if possible they do try to be flexible with arrival times. However, in the beginning stages of the illness, there are a lot of tests that need to take place (to check platelets and other factors), so it is important that people arrive early. It is also the case that some patients live quite a long way away so there would be potentially more issues with traffic and parking if they arrived later. Once the team realised that G lived nearby in Oxford and would be able to get to the hospital in half an hour, it was possible to be more flexible.
- 3.11 G's mother noticed that in a side room near the waiting area there were some beds that often weren't being used. At one point she asked a nurse if G could lie down on one of these beds while he was waiting and this was arranged. At another time, a nurse said it wasn't possible. G's mother said she felt she had to be proactive in asking for these things and that some nurses showed more flexibility and were particularly proactive in looking for solutions. The Sister explained that often these beds are empty as people are due to return from surgery, but said that they do try to allow outpatients to use them if possible.
- 3.12 G and his mother noticed that sometimes communication between departments meant that there seemed to be a level of disorganisation that they found hard to understand. An example was a recent experience when G came in for one of his regular echocardiograms ('echo')⁵ appointments a couple of weeks ago. He was asked to go to the Children's Hospital and wait on the ward until the echo registrar was ready to see him. The reason for this is that patients who have recently had chemotherapy may be neutropenic and it is not advisable for them to wait in a busy outpatients' clinic where

⁵ Echocardiogram, often referred to as a cardiac echo or simply an echo, is a sonogram of the heart.

there is a risk of picking up an infection.⁶ The plan was that he would be called down from the Children's Hospital when the echo registrar was available to see him.

- 3.13 As soon as they arrived were called down but they were waiting in the waiting room for some time and wondered what had happened. They did not want to ask at reception as there was a long queue and only one receptionist and did not want to bother her. After 45 minutes G's mother say the nurse who does weight and height who said the registrar had been down but had not been able to find them. G and his mother were then allowed to wait in the echo room. By the time the doctor did the echo they had been waiting for over an hour.
- 3.14 The family praised the expertise of the registrars who did the echo, particularly one registrar who seemed very experienced and was very quick which was very much appreciated by G and his mother.
- 3.15 The Consultant who manages the echo clinic explained that for some reason the registrar on this occasion had not been able to find the patient and then he was called to care for another patient. Generally, the appointment slots are offered in such a way as they tie in with other appointments in order to prevent several visits to the hospital. That means that these are not clinic slots but ad hoc slots. The registrar can be bleeped for other emergencies during this slot, so there may be delays, as happened in this case.

Communication and person-centred care

- 3.16 G and his mother praised the nursing and medical staff. One nurse in particular was praised:

"We have to mention (nurse's name) – every time she saw G, she looked as if it had made her day" (G's mother).

G was complimentary about the nurses – *"they were all really friendly and I could have a chat and joke with all of them".*

- 3.17 The consultant whose care they were under was highly praised.

"She explained everything really well, she was really approachable and always really positive. When she explained that G needed a bone marrow transplant – at first we were in shock – but she was very positive and explained it really well." (G's mother)

"(Consultant name) is a hugely impressive clinician and human being. When your own child is facing a life-threatening illness the relationship with the Consultant is key to coping, and patient care - and she does that brilliantly." (G's father)

- 3.18 G noticed that the nurses and doctors always asked him if he had any questions

⁶ Neutropenia is a low level of neutrophils, a type of white blood cell. Neutrophils fight infection by destroying harmful bacteria and fungi or yeast that invade the body. Some level of neutropenia occurs in about half of people with cancer who are receiving chemotherapy. It is a common side effect in people presenting with or receiving treatment for leukaemia.

"I didn't usually have any questions because everything had been explained to me really well, but even so I was glad that they asked me if I wanted to ask anything else.

"There was never a time when I asked something and they couldn't explain it to me" (G)

- 3.19 G and his mother were touched that one of the consultants had heard that G liked a particular pasta dish from Waitrose and she went to her local store to buy it for him.

Ensuring privacy and dignity and consent

- 3.20 G's father described an incident that was quite distressing for the family. At one stage, after his fourth round of chemotherapy, G suffered from very low platelet levels which resulted in "copious nosebleeds" (G's father). This was dealt with by giving him more platelets.⁷ There was one occasion when his nose simply would not stop bleeding so a decision was made to have him reviewed by the appropriate doctor in the Ear Nose Throat Department (ENT) and they decided that they would pack the nose to stop the bleeding. The doctor was accompanied by several trainee doctors and G and his parents' permission was not asked regarding the observers which increased the distress of an already very difficult situation:

"This is a pretty distressing and upsetting procedure for G (and his parents). The doctor turned up with a whole team of people. G - and we - felt that having lots of doctors in the room at the time was not helpful. Accepting that other doctors need to learn by observing, there did seem to be a lot of people in the room (3 or 4 observers?). No-one asked if we minded and perhaps we should have objected" (G's father).

- 3.21 G's father was also concerned that this could increase the risk of infection although he noted that all the doctors had plastic aprons on.

G's father spoke to their Consultant about it, who then contacted the doctor involved and ensured that in future only doctors directly involved with treating G would go into his room (cubicle). The Consultant confirmed that she did speak to the doctor involved explaining that the levels of anxiety and distress a teenager (even though he may be over 6 foot tall and look like an adult) and his parents may experience are significant:

"It is hard enough having to cope with cancer and its treatment without also having to go through a particularly difficult and unpleasant lifesaving procedure." (G's Consultant)

"I appreciated our Consultant intervened and the follow up visit was with only one doctor" (G's father)

The OUHFT Privacy and Dignity Policy is currently being finalised and will include a section on consent for observation.

Other issues

⁷ Nose bleeds are a result of low platelets which is not uncommon in AML patients. However, G wasn't responding well to platelet transfusions and he had very sore, swollen mucosa in his nose which is vulnerable to bleeding.

- 3.22 G was being treated when the new Electronic Patient Records (EPR)⁸ system was introduced. This system means that staff have to log in and scan the patient's wrist band before administering drugs. It has been introduced across OUHFT and is widely used throughout the NHS as it offers increased safety in the administration of medication.

However, both G and his mother noticed that this meant it was taking a lot longer for medicines to be given out as two nurses were needed to administer medication.

"The new system seemed to take the nurses away from treating patients and meant they had to focus more time on administration. Everything seemed to take much longer" (G's mother)

The Sister reiterated this view that the new system does take longer, however, it particularly affected G because the system was introduced while he was being treated so the staff were learning how to use it and system glitches were being ironed out.

- 3.23 G and his mother often experienced delays in leaving hospital due to the time required for medication to be dispensed from Pharmacy. There have been reduction in delays for getting medication for outpatients as patients or carers can now email in advance to request medication, a facility that G's parents use.

- 3.24 G thought the availability of a large screen in his room, the consoles and games, and the Teenage Room were all good facilities. However, there was an initial problem when G arrived during Christmas 2014 as it was not possible to get access to Wi-Fi for a week as the play workers were away and were the only people who had the code. The play workers were also needed to find the various leads and PS3 controllers. This issue is now resolved due to Trust wide open access to Wi-Fi.

"I'd like to empathise that we weren't complaining about this. I wouldn't expect them all to be there over Christmas, it was just unfortunate timing, since we were rather traumatised and in need of any distractions available" (G's mother)

- 3.25 G missed his GCSE year and did not take any exams this year. However, he is now catching up and has had tutors at home since September. He will be returning into Year 12 with his peer group after half term. He is taking English and Maths GCSE in November and further GCSEs in June. At the same time, he is starting his 'A' levels courses in History, Maths and Physics.

4. Conclusion

- 4.1 There is an opportunity for learning from the following positive aspects of G's care:
- 4.1.1. Many of the nurses and doctors went the extra mile to ensure that G received good treatment. This was noticed and appreciated by G and his mother.

⁸ The hospital's Electronic Patient Record system enables storage of more in-depth clinical information about our patients, and allows paper records to be dispensed with.

4.1.2. G and his parents were given opportunities to be involved in his care and felt fully informed.

4.1.3. The overall impression was that most of the doctors and nurses could not do enough to ensure that G received the best treatment and was made as comfortable as possible.

4.1.4. The trust and confidence that G and his parents had in key staff was very important to them.

4.2 In addition, there were some aspects of care that could be improved:

4.2.1 The importance of preserving privacy and dignity at all times and of ensuring consent for trainee doctors to be present, but especially during already distressing circumstances.

4.2.2 Sometimes a combination of a lack of communication and hospital systems (which are in place for patient safety), led to G's comfort being compromised. Such as, administration of medicines, long waits for discharge, fasting and waiting in the waiting area for longer than necessary and waiting in the outpatients' area for the echo doctor.

4.2.3 There were times where increased flexibility in arrangements was possible but these were not always actively pursued by the team, rather G's mother felt she had to be proactive in asking for this, rather than it being offered automatically.

5. Recommendation

5.1. The Trust Board is asked to read and reflect on the patient story and acknowledge the learning.

Catherine Stoddart

Chief Nurse

November 2015

Report prepared by:

Rachel Taylor

Public Engagement Manager