

Trust Board Meeting in Public Wednesday 10 May 2017

TB2017.43

Title	Mr W – a Patient Perspective
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Status	For information
History	Patient perspectives are regularly presented to the Trust Board and the Quality Committee

Board Lead(s)	Mr Andrew MacCallum, Interim Chief Nurse			
Key purpose	Strategy	Assurance	Policy	Performance

Executive Summary

1.	The purpose of this paper is to relate the story of Mr W who has been treated for cancer at Oxford University Hospitals Foundation Trust (OUHFT) since 2003 for Nodal Marginal Zone Lymphoma.
2.	This story provides an important opportunity to: <ul style="list-style-type: none">• highlight the high quality of care delivered over a fourteen-year period;• ensure that the Trust hears the important lessons about the patient and carer experience, particularly in relation to travel, environment, pharmacy and staff.
3.	Recommendation The Trust Board is asked to reflect on the patient story and the learning.

Patient story

1. Purpose

- 1.1 The purpose of this paper is to relate the story of Mr W who has been treated for Nodal Marginal Zone Lymphoma¹ and Follicular Lymphoma² since 2003. During this time he received two stem cell transplants.

2. Background

- 2.1 This story was produced by the Patient Experience Team and the Communications Team (Community and Liaison) in partnership with Mr W.
- 2.2 The main purpose of this story is to highlight the experience of receiving treatment for cancer over a long period of time, as well as outlining the impact on the individual and on his spouse.
- 2.3 Mr W is currently in remission having had a second stem cell transplant. He wanted to talk to us in order that the Trust can improve the experience of patients.
- 2.4 The Trust is extremely grateful to Mr W for taking the time to share his story so fully.

3. Mr W's story

- 3.1 Mr W was referred by his GP to Oxford University Hospitals NHS Foundation Trust (OUHFT) in 2003, aged 52, after feeling unwell for some time and the emergence of a lump in his neck. On the same day as seeing his GP, he had an x-ray at the Horton General Hospital (HGH), followed by a CT scan a couple of days later, and within a week had a biopsy taken. About 2 weeks afterwards he received the diagnosis of Nodal Marginal Zone Lymphoma.
- 3.2 He received a six month course of chemotherapy (Chlorambucil³) resulting in the tumours responding and followed by a period of remission for 2.5 years. Further treatment was provided at the Brodey Centre in the Horton General Hospital (HGH) which resulted in a further year of remission. When the cancer returned, he was given a chemotherapy drug called R-CHOP⁴. This drug was much stronger than previous treatments and left him feeling quite unwell. He lost his hair for the first time and was also unable to work for some time and later took early retirement as a result:

¹ Nodal marginal zone lymphoma is a type of non-Hodgkin lymphoma. It develops from abnormal B-lymphocytes – the lymphoma cells. (B-lymphocytes are white blood cells that fight infection.) The lymphoma cells build up in lymph nodes.

² Follicular lymphoma is the commonest single type of low-grade non-Hodgkin lymphoma. It is a slow-growing lymphoma that develops from B lymphocytes (B cells). It is called 'follicular' lymphoma because the abnormal lymphocytes often collect in lymph nodes in clumps that are known as 'follicles'.

³ Chlorambucil is a chemotherapy drug used to treat different cancers, including chronic lymphocytic leukaemia (CLL), low-grade non-Hodgkin lymphoma, Hodgkin lymphoma and Waldenstrom's macroglobulinaemia.

⁴ R-CHOP is named after the initials of the drugs used in the treatment. The drugs are: R – rituximab (Mabthera®), C – cyclophosphamide, H – doxorubicin (hydroxydaunomycin), O – vincristine (Oncovin®), P – prednisolone (a steroid).

“this was the worst of all the treatments. I was extremely tired and there was a lot of other side effects”.

However, the treatment was successful and he was then put on a two year maintenance programme which involved going into the Brodey Centre at the HGH once every three months for a Rituximab infusion.

- 3.3** For 18 months, Mr W was in remission, but then the cancer returned. The only option going forward now was a stem cell transplant and Mr W was given the option of having a transplant using his own cells or a donor's. He decided to use his own and these were harvested at the Blood Transfusion Unit at the John Radcliffe Hospital (JRH). Before having the stem cell transplant he had another type of chemotherapy treatment called RICE⁵. A biopsy was undertaken and it was found that he had low grade Follicular Lymphoma for which there is not a cure. Because the cancer was not fully under control, he needed to have another type of chemotherapy called Fludarabin following which he could then have the stem cell transplant.
- 3.4** The stem cell transplant was undertaken at the Churchill Hospital (CH) but he contracted an infection and was unconscious for two weeks. At one point his wife was called in the middle of night by the consultant because there was concern *“that I wouldn't make it”*. However, thankfully, Mr W made a full recovery and was in remission again for five years until 2011 when he relapsed. The only option at this stage was another stem cell transplant, this time using donor cells. His brother was tested to see if he was a match, and he was. It was explained to Mr W that there was a 70% success rate, a 30% failure rate and a 10% mortality rate.
- 3.5** Again Mr W had to have a further six months of chemotherapy (Bendamustine⁶) to control the lymphoma before the stem cell transplant could take place. He finally had his second transplant in January 2016 and had a good recovery apart from having to manage Graft versus Host Disease⁷. The Graft versus Host Disease is currently being managed with steroids (Prednisolone) and he has recently had the good news that his stems cells have changed 100% to that of his donor. These cells are now 'fighting' his lymphoma; the best result possible. From Mr W's perspective, the transplant has been a success.
- 3.6** Mr W had nothing but praise for the treatment he received. However, having been treated for a number of years, he wanted to highlight a few areas where he feels that the patient experience could be improved in a number of ways.

3.7 Follow up treatments

- 3.7.1** Because Mr W had already been treated at the Churchill Hospital (CH) (for example, this was where he went for the major surgery) this meant

⁵ RICE is the name of a combination of cancer drugs for non-Hodgkin lymphoma or Hodgkin lymphoma that has come back after previous treatment. It is the ICE chemotherapy combination with the drug rituximab. Most people who have this type of chemotherapy will also have a stem cell transplant. RICE is made up of the drugs **R** – Rituximab (Mabthera), a type of biological therapy called a monoclonal antibody, **I** – Ifosfamide, **C** – Carboplatin, **E** – Etoposide.

⁶ Bendamustine (Levact®) is a chemotherapy drug. It is used to treat chronic lymphocytic leukaemia (CLL), non-Hodgkin lymphoma (NHL) and myeloma.

⁷ GVHD means the graft reacts against the host. The graft is the donated marrow or stem cells. The host is the person receiving the transplant. GVHD can cause diarrhoea, skin rashes and liver damage.

that there seemed to be an automatic assumption that follow-up treatments would also be done at the Oxford hospitals. Mr W asked his nurse co-ordinator to see if the follow up treatments could be done at the HGH and this resulted in many of the treatments being transferred made it much easier for Mr W and his wife to attend.

- 3.7.2 Another time when unnecessary travel was avoided was when he had a skin rash due to GVHD and the nurse asked him to come down to the CH to get it checked⁸. However, Mr W asked if he could take a photo and email it which was done, the diagnosis was made, and the 50 mile round trip avoided.

3.8 Transport issues:

- 3.8.1 Parking at the Churchill Hospital (CH) can be very difficult and access to get in and out of Headington means that Mr W and his wife have to leave at 6am to make sure they are in time for a 9am appointment. If it is mid-morning, his wife usually gets parked just in time to attend his clinic appointment. It is extremely important to Mr W that his wife is at all the appointments as she can ask questions and often remembers more of what is said than he does. It is very helpful and much appreciated that parking is free for cancer patients attending multiple appointments/clinics.
- 3.8.2 The Energy Project Engagement Officer responded that there are several ongoing initiatives to improve parking. The Trust Management team is working towards the implementation of new systems and processes at the Headington hospital sites which will build on measures already taken over the past 12 months, aiming to greatly improve access and parking for patients. These include Automatic Number Plate Recognition (ANPR) and additional security measures to ensure that parking spaces are not taken by members of the public who are not using hospital services or visiting. The Trust is working to have these new systems in place by the end of summer 2017.
- 3.8.3 There is no public transport from Brackley (and environs) to Oxford, so, without his wife driving him, Mr W cannot access the CH for the weekly/fortnightly checkups and treatment. He would also be concerned about travelling on public transport when he is undergoing chemotherapy and following the transplants when his immune system is compromised.
- 3.8.4 When Mr W was in the CH for a month after his operation in an isolation room, his wife visited every day, which would not have happened if she could not drive. He had very little other human contact for his month's stay as he had had a stem cell transplant. Without his wife's visits, he would not have recovered so well. The cost of travelling from Brackley to Oxford is not insubstantial and Mr W was concerned that other patients may not be able to fund the transport.

3.9 Facilities at the Churchill Hospital and Horton General Hospital

- 3.9.1 The CH Chemotherapy Day Centre is uninviting compared to the HGH Brodey Centre. Mr W and his wife are very comfortable at the Brodey Centre. On occasions he also feels that nurses at the CH Day Centre

⁸ GVHD means the graft reacts against the host. The graft is the donated marrow or stem cells. The host is the person receiving the transplant. GVHD can cause diarrhoea, skin rashes and liver damage.

spend a lot of time conversing at the main desk when they could be treating and talking to patients. He finds the nurses at the Brodey Centre warmer, friendlier, and more personal. Here, although teams are busy, patients feel more cared for.

- 3.9.2 Mr W made the point that family members are not well catered for at all at the CH Day Centre so it can be really tiring for them to be there all day and then have a long drive home. With treatment at the HGH it is possible for his wife to drop him off in the morning and then pick him up later but with the distance involved with the Oxford hospitals, this is not practical.
- 3.9.3 Maggie's Centre is a great resource, but the CH Day Centre would be hugely improved for family members if they had a kitchenette where they could go and talk to each other over the kettle, for example.
- 3.9.4 The food at the CH is not as appetising as at the Brodey Centre and during his months stay at the Churchill, his wife had to bring him food most days, otherwise he would not have eaten sufficiently.
- 3.9.5 The Sister for Oncology DTU has provided some context for comparisons between the two units: when comparing the Brodey Centre and the Churchill DTU side by side they are very different. The Brodey Centre is a small unit where there may only be four patients at a time with two or three nurses on duty, and the centre may see 16 to 20 patients per day. In contrast, the DTU has lower patient to nurse ratio with a total of 16 to 18 nurses caring for between 80 and 100 patients per day.
- 3.9.6 Regarding nurses holding conversations on the unit, the Sister explained that, due to its layout, a large number of patients in the DTU will be facing the nurses' station and nurses hold hourly handover meetings here as they do not have a meeting facility. These 'mini handovers' ensure that each team member is aware of the complex information required to safely treat each patient. This is particularly useful when members of staff are going on or returning from breaks, or starting and finishing shifts.
- 3.9.7 In terms of available facilities and the environment, the DTU has been relocated to a smaller location and the team has invested time and charitable funds into art work to display and wallpaper to improve the space as the windows are too high to see out of. In its previous location, the unit had more facilities for food and drink but in the current location there is no space to introduce a kitchenette. There is a comprehensive drinks and food trolley (including soup, sandwiches and fruit pots) available for patients, as well as snack boxes for those who are there for long periods, and there is a donations-based tea, coffee and biscuits station for visitors and patients. Patients are also encouraged prior to coming into the unit to bring in any food they would like from home.
- 3.9.8 The Sister commented that patient feedback is generally very positive about the unit but it is understandable that patients would find the smaller and quieter Brodey centre a more pleasant environment.

3.10 Communicating with patients

- 3.10.1 Mr W feels that the printed reports sent to his house are not necessary and are expensive to produce and post. He thinks that there should be an option for patients and GPs to receive this information digitally.
- 3.10.2 Mr W's comments are in line with aims of the Trust's Go Digital project and our "ambitious plans to accelerate the opportunities that digital technology offers, in line with the ambition of the NHS to be 'paper-free' and for patient records to be held electronically and accessible across different systems"⁹. Mr W's comments will be fed back to this Go Digital Project Team.

3.11 Pharmacy

- 3.11.1 The waiting times for medication are lengthy and this is particularly difficult after a long day in a clinic or receiving treatment. Mr W has waited up to two hours (and once five hours on leaving the Haematology Ward) for his medicines. After a long session of chemotherapy and for him and his wife (who has also been there with him all the time and is waiting to drive him home) this length of wait is very difficult.
- 3.11.2 The Lead Pharmacy Operational Service Manager (OSM) has commented that 'to take out' (TTOs) drugs turnaround times are monitored for outpatients and inpatients. The target turnaround for inpatients is 90% of TTOs dispensed within 90 minutes, and this was achieved in March. For outpatients, the target is 90% within 30 minutes and this was 70% achieved in March, so it is acknowledged that there is more work to be done. The Pharmacy team carries out a local survey on a monthly basis to gather and analyse feedback from outpatients regarding the service they receive, including waiting times.
- 3.11.3 The OSM commented that drug prescriptions for cancer patients are often quite complex and must go through several checks, including clinical screening, to ensure they are clinically correct, including the correct dose, and suitable for the patient before being dispensed and then accurately checked before being safely released, which may lead to longer waiting times. The OSM also described that some medicines in the day treatment areas, for example for anti-sickness drugs, can be prescribed and supplied within the units to reduce the need for patients to visit pharmacy.
- 3.11.4 The Cancer Consultant Pharmacist for the Trust has fed back that a recent patient survey carried out based on services provided at the Cancer Centre satellite pharmacy and the Day Treatment Unit (DTU) pharmacy showed a high level of satisfaction from patients, and this included questions about waiting times. A significant amount of work has been carried out to streamline the cancer pharmacy service in terms of patients' waiting for their prescriptions and being able to access them closer to where they are being treated. For example, there is a satellite pharmacy within the Cancer Centre at the Churchill Hospital, which means patients who are seen as outpatients or within the DTU can avoid

⁹ <http://www.ouh.nhs.uk/working-for-us/go-digital/default.aspx>

making the one kilometre trip to main pharmacy. The cancer DTUs at the Churchill and Horton have 'near patient' dispensing and a clinical pharmacy service with pharmacists and pharmacy technicians available. This service was shortlisted for a Health Service Journal award, in July 2013, when the Trust piloted the service for the Oncology DTU, and was subsequently rolled out to Haematology services and to the HGH. The changes in the service has improved patient experience, reduced medicines wastage and workloads for nurses, and shortened waiting times.¹⁰ The service is also provided to chemotherapy patients on the Haematology and Oncology wards.

3.12 Staff

3.12.1 Mr W feels that staff have all been exemplary; the nurse co-ordinator is wonderful and he has nothing but praise for all the consultants involved in his care and the HGH staff. Mr W said:

"I have nothing but admiration and praise for the staff I have encountered over the last 14 years in Banbury and Oxford. Without their dedication and professionalism I wouldn't be here and I can't speak highly enough of them"

3.13 Learning

3.13.1 Mr W would like his constructive comments to be viewed as ways to improve an already good service.

4. Conclusion

4.1 This story highlights:

- excellent compassionate care, delivered over a prolonged period;
- issues for patients and carers travelling long distances and the importance of ensuring that care is delivered close to home wherever possible;
- the importance of avoiding lengthy waits for prescriptions particularly after a long day receiving chemotherapy treatment or spending time in a clinic;
- the improved patient and carer experience when a treatment environment is welcoming and the staff warm and friendly.

5. Recommendation

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

Andrew MacCallum
Interim Chief Nurse

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¹⁰ <https://awards.hsj.co.uk/>

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