Trust Board Meeting in Public: Wednesday 12 July 2017
TB2017.61

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Executive Summary

1. The purpose of this paper is to relate the story of Mr and Mrs A, who participated in the National Living Donor Kidney Sharing Scheme so that Mr A could receive a living donor kidney transplant. This story is accompanied by a recording of the interview with Mr and Mrs A.

2. This story provides an important opportunity to:
   - highlight the high quality of care;
   - highlight the compassionate excellence shown by nurses, doctors and other staff;
   - show the importance of small things that can make a significant difference to the patient’s experience of care;
   - ensure that the Trust hears the important lessons about the patient and carer experience, particularly in relation to management of post-operative constipation, pain and sickness.

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 and Mrs A, who participated in the National Living Donor Kidney Sharing Scheme so that Mr A could receive a kidney transplant.

1.2 The paper is accompanied by an audio recording of discussions with Mr and Mrs A.

2. Background

2.1 This story was produced by the Patient Experience Team in partnership with Mr and Mrs A, who were interviewed at their home in Oxford.

2.2 Mr and Mrs A wanted to share their story to highlight their positive experience of care and ensure that those responsible were recognised. In addition, the story provides an opportunity to publicise the National Living Donor Kidney Sharing Scheme. The Trust is extremely grateful to Mr and Mrs A for taking the time to share their story.

3. Mr and Mrs A’s story

3.1 In 2005, Mr A’s mother, who was aged 63, was found to have high blood pressure, which after tests was identified as being caused by Autosomal Dominant Polycystic Kidney Disease. This is a serious hereditary condition, which can start causing symptoms in adulthood. Mr A and his sister were told they had a 50-50 chance of also having the disease. They were tested and both siblings were found to have the disease. At time of diagnosis Mr A showed no symptoms.

3.2 From 2005 until the transplant in 2016, Mr A was under the care of Dr M “who is outstanding” and who advised that within 10 to 15 years Mr A would need either a kidney transplant or dialysis. Over the next 10 years, Mr A had regular appointments with Dr M, first annually, then twice annually. By 2016 the sessions were changed to every month.

3.3 In 2015, Dr M discussed donor options with Mr A and advised that a good match was needed because of his young age (he was 45 at this time) to ensure prolonged kidney function. Family members were tested but a satisfactory match was not found. In 2016 Mr A and his wife were registered by the Renal Team on the National Living Donor Kidney Sharing Scheme. This would allow Mrs A to donate to an anonymous match so that Mr A could receive a kidney from the best donor. For Mrs A there was no question about taking part in the scheme: “I didn’t even think about it, I knew I would do it. My family doesn’t work without him (her husband)”.

3.4 Mrs A undertook a range of tests, including an ultrasound of her chest, X-rays, computed tomography (CT) scan, scans with contrast (a special dye), and a

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1 Since January 2012, the National Living Donor Kidney Sharing Schemes (NLDKSS) is the collective term used to describe the schemes in which donated kidneys are ‘shared’ across the UK. See http://www.odt.nhs.uk/donation/living-donation/national-living-donor-kidney-sharing-scheme/ for more details.

2 Autosomal dominant polycystic kidney disease (ADPKD) is a multisystemic and progressive disorder characterised by cyst formation and enlargement in the kidney and other organs (e.g., liver, pancreas, spleen). Up to 50% of patients with ADPKD require a kidney transplant by 60 years of age.

3 It is also standard practice some months being added to the Living Donor scheme and also to the ‘Cadaver’ scheme, from which patients can receive organs via the NHS Organ Donor register.
glomerular filtration rate (GFR)\textsuperscript{4} test in order to make sure her kidney filtration rate was good enough. She was identified as being able to donate, as all her results were optimal.

3.5 During this time, both Mr and Mrs A were allocated to different specialist nurses, whom they saw separately. Mr A was given Nurse S, who was a Recipient Nurse Specialist and Mrs A was allocated Nurse H, who was a Donor Nurse Specialist.

3.6 Mr and Mrs A could not give high enough praise for each nurse, who supported them throughout the process from the initial tests through to the operation, recovery and beyond.

3.7 They also praised the thorough ethical process of consent for the donor. The Donor Nurse Specialist supported Mrs A throughout the process, to make sure that Mrs A was well enough to donate, definitely wanted to donate, and was not under any pressure to do so (even though she was desperate to donate). There was an additional check, during which both Mr and Mrs A were interviewed by a lay person (who used to be a clinical lead), to ensure they were certain of what they were doing and that ethically there was no apparent coercion.

3.8 In early 2016, Mr A’s test results started to identify that his kidneys were failing and unable to clear his body of urea as well as maintain a healthy level of haemoglobin production, another vital function of the kidneys. He was also feeling unwell, tired, sick and sleeping most afternoons. He had to get up carefully otherwise he would risk fainting.

3.9 He was given a dose of iron and a drug called Erythropoietin\textsuperscript{5}, which is a synthetic version of an enzyme found in bone marrow, instrumental in the creation of vital oxygen carrying haemoglobin. This is self-administered subcutaneously on a weekly basis. It allowed Mr A to continue working and even cycling regularly; exercise is recommended for patients with kidney disease if possible. In August 2016, the Erythropoietin medication was stopped as his haemoglobin levels had temporarily reached normal levels.

3.10 Prior to this, Mr A was introduced to the pre-dialysis team where he was briefed on the dialysis process and asked to choose a preferred dialysis method. This is standard practice with renal patients approaching kidney failure, regardless of transplant likelihood. This is because preparing for dialysis can take a number of months as there is surgery required. The family received a pre-dialysis visit, during which the dialysis team came to their home to discuss the dialysis options, should a transplant kidney not become available in time. Mrs A said she found this extremely hard as it “really brought home the reality of the situation.” However, they both praised the team, who discussed the different options and how dialysis at home would work.

3.11 When Mr and Mrs A were on holiday with their extended family, in July 2016 on the west coast of France, the call came through that a kidney match had been found. They were delighted and there were “lots of tears and it really made the holiday”. However, in early August they then got the very disappointing news that the match

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\textsuperscript{4} A glomerular filtration rate (GFR) study is a test that uses radioactive materials or tracers (radiopharmaceuticals) and a computer to see how well the kidneys are working. Glomeruli are tiny filters in the kidney that remove waste products from the blood.

\textsuperscript{5} Erythropoietin also known as EPO, hematopoietin, or hemopoietin, is a glycoprotein hormone that controls erythropoiesis, or red blood cell production. It is a cytokine (protein signaling molecule) for erythrocyte (red blood cell) precursors in the bone marrow. Human EPO has a molecular weight of 34 kDa.
was no longer viable. Due to patient confidentiality they could not be told the reason why. “This was devastating. We were both really upset as we had been really geared up for it. The team was incredibly supportive. They explained that the transplant was not really urgent. This made the whole process so much better and able to cope with”.

3.12 In early October, there was another Living Donor Kidney Matching Run (LDKMR)\(^6\) and Mr and Mrs A were again matched. At the beginning of November were told that the operation would take place on 21\(^{st}\) November 2016. Mr and Mrs A found this to be both stressful and exciting due to the very short notice that had been given. Mrs A had to go through more tests to make sure she was still fit to be a donor.

3.13 Mrs A described her concerns about their four year old son. Although she knew he was happy and would be looked after by her parents whilst they were in hospital, the fact that both she and her husband would be having serious operations naturally made her feel anxious.

“I was particularly concerned about J (her son) and the thought of us both being under general at the same time. The surgeon was incredibly reassuring, as she explained how the day would work and she said I would probably wake up before my husband went in for his operation which meant we wouldn’t be under anaesthetic at the same time. She even said there was every likelihood that we saw each other after my operation and before he went in for his.”

3.14 On the day of the operation, Mrs A remembers the kindness and professionalism of all staff. Nurse N was with her until she went to sleep, holding her hand. This was both supportive and also to provide the opportunity for her to change her mind about donating, even at this late stage; it was taken as a kind and supportive gesture. Equally supportive and professional was the anaesthetist.

”The anaesthetist was delightful, kind and professional. I remember because the cannula was difficult to get in and he gently asked everyone to be quiet so he could fully concentrate.” Mrs A

“I was also so pleased that after the operation when I was back on the ward that I was able to see R (her husband) before he went for his operation. I was particularly touched that the anaesthetist, who treated my husband as well as me, came to see me and told me that R was in recovery and that his operation had gone really well. He didn’t need to do this but it made such a difference. When R came out, the nurses made sure he went past my room, so that we could wave at each other through the door.” Mrs A

\(^6\) Living Donor Kidney Matching Runs (LDKMR) are performed 4 times per year, in January, April, July and October. All donors and recipients who are registered in the NLDKSS (National Living Donor Kidney Sharing Scheme) and entered into the LDKMR are eligible for inclusion. Each LDKMR identifies paired/pooled exchanges and altruistic donor chains in optimal combinations (see LDKMR matching process), which are reported to transplant centres on the matching run report.
Mr and Mrs A in recovery the day after the operation

“Everyone worked so hard, still had the time, though we could see they were working beyond their shifts and constantly going the extra mile.” Mr A

3.15 Mr A described how he felt immediately better when he woke up. He didn’t feel sick and had a clear head. This is because when he went into surgery his creatinine level was 760 and when he came out it was 132, which is a huge difference and demonstrates much improved kidney function.

3.16 Both patients identified things that happened post-operatively that could have been improved. Mr A had severe and extremely painful constipation which went on for several days and caused great discomfort and pain. He did not feel this was taken seriously enough by medical and nursing staff and feels it should have been managed better.

3.17 The Deputy Matron for the area acknowledged that post-operative constipation is common and can be very painful. She outlined the process for managing pain and constipation after an operation. Mr A was on a Patient Controlled Analgesia (PCA) and Tramadol, and was given Lactulose\(^7\) and Senna\(^8\). He was also encouraged to drink water and mobilise. Three days post-operation, it was evident that these treatments had not been effective and he requested a Glycerol suppository.

“I was in excruciating pain. I didn’t feel listened to and the Lactulose and Senna just were not working. I had to demand an enema.” Mr A

3.18 The Deputy Matron first of all asked that her apologies were passed onto Mr A for what he went through and she also wished to thank him for providing such a clear and honest account of the impact this pain had on his experience. She said that Mr A’s constipation was managed in the usual way but more should have been done proactively to both reduce the pain experienced and to ensure communication of actions take. His experience highlights the importance of keeping patients informed

\(^7\) Lactulose is a laxative taken to treat constipation.

\(^8\) Senna is a natural laxative made from the leaves and fruit of the senna plant. It is used to treat constipation.
as to what steps are being taken, the process for proactively preventing constipation (or similar pain), and reducing pre-operative pain experienced where possible.

3.19 Similarly, Mrs A felt very sick after her operation and asked many times for an anti-sickness pill but did not receive one. She felt this could have been managed better so that she felt less nauseous. If she had not been administered an anti-sickness medication and been able to eat and drink adequately, then that may have delayed her discharge. This feedback was acknowledged as very valuable to highlight the importance to staff of understanding and acknowledging the impact of delays in being offered, and receiving, medication on the patient experience.

3.20 The experiences of Mr and Mrs A have been fed back to the team to inform learning and improvement. The Deputy Matron will ensure that nursing and medical staff understand the impact on patients when post-operative pain and sickness are not proactively managed.

3.21 The Deputy Matron will raise the issues highlighted in the story at the Divisional Clinical Governance meeting in July, particularly in terms of post-operative pain and constipation management. Feedback provided in the story will also be inputted into the directorate’s monthly Quality Report, and the proactive management of post-operative pain and sickness will be identified as a clear learning point for all staff.

3.22 After two days Mrs A was able to go home and after a week Mr A was able to be discharged too. Both of them spent the next few weeks and the Christmas period recovering from the operations with support from their family.

3.23 In mid-February 2017 Mr A started feeling unwell; he had a high temperature and contacted the Renal Unit. He had his blood pressure, temperature and weight checked. It was found that he had gained eight kilograms in one week. His body was ‘attacking’ the kidney. He spent another week on Wytham Ward, where he received anti-rejection drugs and steroids. This was a real set back and a difficult and worrying time for him and his family. Again they felt supported throughout. “The staff were so
brilliant, even though these were dark days, I was terrified that I was rejecting the kidney and worried about how this would affect our new life.” Mr A.

3.24 Both Mr and Mrs A have shown great improvement since the transplant. Mr A’s appetite returned, he is no longer sleeping during the day, and is exercising and feeling stronger; he has been cycling 40 miles a week and increasing this gradually. Mrs A did her first 5 kilometre run in February 2017 and did a 10 kilometre run a few weeks ago in May 2017.

The family on holiday, six months post operation

3.25 As well as the “amazing care, treatment and support” they received, a number of other factors contributed to their positive experience:

- Patient View: an online portal set up for renal patients allowing them to self-manage their care.9

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9 [https://www.patientview.org/#/PatientView](https://www.patientview.org/#/PatientView) shows your latest test results, letters and medicines, plus info about diagnosis and treatment. Set up alerts, monitor symptoms and download your records. You can view PatientView from anywhere you want and share your information with anyone you want.
The phlebotomists were so cheerful and friendly; going the extra mile by carrying out home visits. A separate team of Phlebotomists would even make home visits to take bloods for monitoring the Erythropoietin and iron levels.

- Medicines were sent to Mr and Mrs A’s home rather than them having to travel to collect them\(^\text{10}\)

- “A multitude of smaller things too numerous to list”. Two examples: (1) the Nursing Assistant on the recovery ward was incredibly kind immediately after her operation, helping Mrs A out of her chair and also asking if she could get to the toilet to wash. Since Mrs A could not manage this the Nursing Assistant got her a bowl of water and helped her wash her face, and then found her hairbrush so she could comb her hair. (2) Mr A observed attention to detail in the caregiving from all staff, from the Ward Sister to the staff administering medication or serving food.

- Wytham Ward offered a comfortable, private environment for recovery from surgery.

4. Learning

4.1 Mr and Mrs A would like their positive comments to be shared to praise the staff involved in their care and treatment. They also wish for the constructive comments to be viewed as ways to improve an already very good service.

5. Conclusion

5.1 This story highlights:

\(^{10}\) Via a service run by Healthcare At Home: [https://hah.co.uk/](https://hah.co.uk/)
• excellent compassionate care, delivered over a prolonged period;
• the importance of fully supporting patients and their families when they are going through difficult and complex treatment pathways;
• the importance of ensuring that options of receiving treatment and medicines at home, wherever possible, and the positive impact this can have;
• the importance of ensuring that patient needs are listened to and adequately met post-surgery but also proactively discussed as a potential issue that may arise during pre-operative discussions.
• the improved patient experience when staff exhibit kindness as well as professionalism.

5.2 The story is accompanied by an audio recording of the interview with Mr and Mrs A. This can be accessed here.11

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

Executive Lead:
Andrew MacCallum, Interim Chief Nurse

Authors:
Rachel Taylor, Public Engagement Manager
Olivia Galloway, Patient Experience Project Manager

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