

Trust Board Meeting in Public: Wednesday 17th January 2018

TB2018.04

Title	Patient Story of Mr PF and Mrs SM
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Status	For information and learning
History	Patient Stories are presented to the Trust Board or the Quality Committee.

Board Lead(s)	Mrs Sam Foster, Chief Nurse			
Key purpose	Strategy	Assurance	Policy	Performance

Executive Summary

1. This paper relates to the patient story of Mr PF and Mrs SM, who had a shared experience of being treated with peritoneal dialysis (PD) by the Renal Unit of the Oxford University Hospitals NHS Foundation Trust (OUH).
2. Their combined story highlights the following:
 - The long term, life-changing and isolating impact of peritoneal dialysis therapy and the importance of emotional and practical support, which cannot be underestimated. This enabled Mr PF and Mrs SM to cope with living with renal failure and PD therapy.
 - The importance of patient involvement and patient education in enabling them to manage their dialysis therapy, prevent infections and have a good quality of life.

3. This story was related to the Patient and Public Involvement Manager and the Advanced Nurse Practitioner/Unit Manager of the Peritoneal Dialysis Unit at the Churchill Hospital in Oxford. This took place at a pre-arranged meeting held in the Renal Unit of the Great Western Hospitals NHS Foundation Trust in Swindon on the 28th December 2018.

4. Conclusion

This patient perspective highlights the importance of **supportive friendship, in order** to cope with the impact of long term renal failure and dialysis therapy. This is in addition to strong patient involvement, patient education and refresher courses. This can equip patients with the skills to work alongside nurses in managing their own condition and therapy. It also helps patients to understand the processes that can cause infections and the importance of hand hygiene and cleanliness in order to prevent infections.

5. Recommendation

The Trust Board is asked to reflect on the aspects highlighted in this patient perspective and the potential learning that can be gained.

1. Purpose

- 1.1. The purpose of this story is to relate the stories of Mr PF and Mrs SM; about their shared experience of peritoneal dialysis and the positive impact of the group refresher course, a patient education session that they both attended and which led to the establishment of their friendly and supportive relationship.

2. Background

- 2.1. Mr PF began peritoneal dialysis¹ (PD) in 2015. Six months after starting PD he developed peritonitis (an inflammation of the peritoneum; the tissue that lines the inner wall of the abdomen) as a result of an exit site infection (where the PD tube exits the body). This led to peritonitis in December 2015 and he remained in the hospital for a week, and was treated and the infection resolved, following an operation to remove his PD catheter.
- 2.2. Mr PF ceased PD for 6 weeks and a new PD catheter was later inserted in early 2016. Mr PF's PD is Continuous Ambulatory Peritoneal Dialysis (CAPD) or what is referred to as the 'bag system'.
- 2.3. Mr PF manages his own dialysis 4 times a day for 30 minutes each cycle, so it takes is time consuming in his normal day.
- 2.4. Mrs SM is 48 years old and started PD in June 2017. She explained that she also has diabetes and did not realise how ill she was when she started PD. She started on CAPD (the bag system).
- 2.5. In October 2017, she was told she had the option of using a PD machine. The machine and bag system are both effective for dialysis, the difference is that the machine dialysis can be done overnight whilst the patient is sleeping. A patient would prepare the dialysis machine (Automated Peritoneal Dialysis) before the night and when ready to sleep attach themselves to the machine. In the morning they then disconnect themselves from the machine and remove the dialysis connections and fluid. Mrs SM tried the machine overnight and decided that the machine PD suited her better. Mrs SM felt that this was a better option, because she can then plan her day without having to interrupt it by dialysing.
- 2.6. Patients on PD are taught how to do their own dialysis at home. They are also taught the importance of hand hygiene, cleaning the exit wound before and after dialysis and when taking a shower (not a bath), as well as the importance of having a clean environment at home to prevent infections from occurring.
- 2.7. Building on the lessons drawn from the high rates of infection from PD peritonitis, the Advanced Nurse Practitioner implemented a refresher course with individual patients. This improved peritonitis rates significantly, and following the success of the individual programme it was decided to implement group refresher training as this would be an ideal opportunity for PD patients to meet with other patients on PD to provide group support for those that wished to engage with it.
- 2.8. Working with the PD specialist nurses in Swindon, a group refresher course was organised with a group of 12 PD patients, and this was led by a PD specialist

¹ The PD dialysis process involves PD solution fluid (dialysate) being connected to a tube which is inserted into the peritoneal cavity around the stomach. The fluid circulates, absorbing waste products from the body. It is then removed and replaced with fresh fluid.

nurses in Swindon. It was an opportunity for the Renal Team to reinforce the key messages of infection prevention, emphasising the importance of hand washing and hygiene and keeping the exit site clean, as well as discussion about microorganisms. Group members could have a refreshment and chat to share their experiences of the self-management of PD and its side effects, including 'drain pain'² (pain on the fluid exiting), having difficulty sleeping and the management of diet and bowel movements.

3. The story

- 3.1 The group refresher course was first organised in June 2016, and following this the PD/Renal Unit Team noticed a significant decrease of infection rates and PD peritonitis. This group refresher course is now being planned on a regular basis following the patient feedback and the clinical improvements in infection rates.
- 3.2 It was during one of these refresher courses that Mrs SM met Mr PF in June 2017. She learned that Mr PF had recently lost his wife, in February 2017. Mrs SM felt that Mr PF needed someone to talk to and support him in dealing with the loss of his wife, as well as dealing with the issues of the PD treatment. As a PD patient herself, Mrs SM is aware of the impact of PD on depression and mental health, and the need for emotional support from other people who understand the experience, without judgement and guilt.
- 3.3 Mr PF and Mrs SM chatted lengthily at the refresher course, which marked the beginning of a supportive and friendly relationship.
- 3.4 They are now in regular contact with each other, have had dinners out together and spent this Christmas together. They got to know each other better and found that they both share similar interests in art and find that this support has been conducive to enabling their mutual wellbeing and morale.
- 3.5 They coordinate schedules, so that when they attend the refresher course or have a hospital visit they can go together; Mrs SM usually drives them.
- 3.6 Both Mr PF and Mrs SM agreed that PD is an isolating experience and it can take control over your life because of the need to undertake it every day on a long term basis. There are lots of implications that impact on their lives, including the time allocated to dialyse, ensuring that they are confident to undertake the PD correctly, the stocks required and ensuring there are enough supplies.
- 3.7 Both found the support system that they established very important, including working alongside the support of clinical staff. This helped them to cope with the side effects of PD and living with PD.

"We found the support in each other because we were able to talk to each other with the knowledge that we were talking to someone who could listen and understand what we are going through, without explaining what PD is about, why you have it and feeling

² Drain pain is what patients can experience at the end of draining out all of the PD fluid from the abdomen. It is especially noticeable on APD (overnight PD). It can be due to constipation, migration of the catheter and a particular APD machine, although often there is no obvious cause. The team work with patients to ensure that they are pain free including using a different type of APD machine if they are unable to resolve the pain. Women refer to it as really bad period pain, and men tend to experience rectal pain.

guilty about taking up somebody's time or making someone feel bored about your story." (Mrs SM)

3.8 The supportive friendship is mutually beneficial.

"I was in a very bad shape when I first started PD. I had mental health problems, was not eating well and not sleeping well, but in talking to Mr PF, he helped me to get back on my feet again and enjoy a quality of life that PD can allow." (Mrs SM)

"Mrs SM provided a listening ear when we first met, when I was grieving the death of my wife, and we could both talk about the horrifying feeling of being alone." (Mr PF)

3.9 Although they recognise the limitations of PD, both are positively looking forward to the future.

3.9.1 Mr PF is scheduled to start using the PD machine on the 15th January 2018, having understood the benefits of undergoing dialysis overnight instead of 4 times a day. This was recommended as his renal condition continued to decline.

3.9.2 Mrs SM is waiting for the final tests to be completed before she is accepted onto the kidney and pancreas transplant list.

3.9.3 Mr PF is looking forward to celebrating his 80th birthday in February 2018.

4 Conclusion

4.1 When asked about what they would like to recommend, Mr PF and Mrs SM's experience highlighted the following:

4.2 The support provided by staff to patients through the patient education/refresher course and the infection prevention learning is imperative and really important for information, knowledge and networking as a patient support group.

4.3 The involvement of patients in the self-management of their PD is essential in improving their quality of life, and gaining confidence in controlling their lives.

5 Recommendation

The Trust Board is asked to note the contents of the patients' perspective and acknowledge the benefits of combining patient education and support networks.

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28 December 2017