

NHSBT Board Meeting in Public 26 September 2023

Corneal Transplant Patient Journey

Janet is a 55-year-old married lady working for the NHS East Midlands Ambulance Service for 30 years. She was diagnosed with Glaucoma in 2018. The diagnosis came as a shock as she had no history of eye disease.

Janet's condition worsened over time, and it became difficult to treat and cytomegalovirus (CMV) was eventually diagnosed. Her vision worsened affecting her independence and ability to work. She spoke to her surgeon about her worsening mental and physical distress who asked her to call the secretary to 'get booked in' and she was listed for a transplant in 2021.

The expectations and process were unclear from the transplanting hospital, and she waited for over 2 years for her transplant. During this time her mental and physical health was affected as she became increasingly anxious and dependent. It was difficult for Janet to leave her home as she was unable to see / judge distance / spaces. Workplace adjustments were made for her, and she was able to work from home, however it became increasingly difficult to spend time on her PC / online.

Janet eventually had her transplant in February 2023 but her postoperative recovery was not straight forward. She suffered immediate sight loss in both eyes and was in severe pain. In order to manage the pain, she was hospitalised and strong pain relief was administered as she was unable to sleep. She developed Bullous Keratopathy and it took approximately 3 weeks for the symptoms to settle and sight restoration to begin, however she still suffered from photosensitivity, needing to wear dark glasses.

Janette is seen regularly by her specialist team and her mental, physical and sight health is improving. She is waiting for her vision to settle before having an eye test for prescription glasses and she is back at work. Looking forward the expectation is that her vision will be better than pre-transplant with no physical symptoms, in good mental health and completely independent.

Despite her difficult recovery Janette is hugely grateful to her donor and their family, however when she requested information regarding her donor at a follow up appointment, so she could write and say thank you, she was told 'not to worry about that' and subsequently she felt unable to ask again.

Reflections and learning

- Informed consent should include more about what the transplantation involves / possible side effects / implications.
- More information should be provided regarding how the transplant waiting list works / is prioritised / allocation / expected waiting times / fairness.
- Consideration should be given to the psychological impact of having someone else's cells / tissue implanted – acceptance.
- Anecdotal evidence from donor families is that a thank you from the recipient is truly appreciated and more should be done to educate transplanting centers about the ability to write to donor families.

Author

Louise Hubner; Head of Education and Professional Development, OTDT.

Responsible Director

Anthony Clarkson – Director of Organ Donation and Transplantation