

Queen Elizabeth Hospital Birmingham

Heart and Lung Transplant Support Group

Virtual session

Monday August 18th, 2025

Topics discussed during the meeting

Review of patient support group webpage

Patient Group feedback – please direct towards support group email address
(qe.hltx.group@uhb.nhs.uk)

Plans to create QR code to give anonymous feedback

There will be a suggestion box at next group in September (face to face @ QE)

Reminders

Organ donation awareness week runs from 22nd to 28th September.

The Heart and Lung Transplant team will have a stand in the main atrium on **Wednesday 24th September from 9am till 5pm**. If you want to get involved please contact Jan Lockett through facebook group or email (qe.hltx.group@uhb.nhs.uk).

If you have children or grandchildren that have been part of your transplant journey please follow the below link or QR code to give feedback of what resources we could develop, to support them through your, and their, transplant journey!



bit.ly/transplantsupportboxes

Patient Story

Eileen shared her story, 7 years post Lung transplant.

Eileen was originally listed in 2018 for COPD. She waited around 12 months for her transplant.

She reflected on the 'chaos' of receiving 'the call' and stumbling in to the hospital and delirium on ITU such as fear, anxiety and even thoughts that 'the doctors were trying to kill her', a feeling that is very common whilst being weaned off the anaesthetic medication.

Eileen remembered the pain she felt in her chest and encouraged the use of analgesia, recalled the physio team being at her bed side on day 1 ready to get her up and moving.

Meds education, steroids, the increased appetite and weight gain and some early issues with reflux for which she needed a small procedure to repair.

Eileen shared the letter she sent to her donors family around a year after her transplant. Unfortunately, Eileen didn't hear back from them but felt reassured that she had passed on her gratitude.

This led to a discussion about writing to donors..

It is always encouraged to write to your donors family, though there is no set time frame in which you should do so, nor is there a set script of what you should write, sometimes a brief 'thank you' will suffice.

Donor families are looked after by the 'donor care team' and receive open ended support after donation. They receive a certificate summarising the lives their loved one saved and a gold 'badge of honor'.

More information can be found through the links below.

After this, Jan shared her experience of meeting her donors family. This doesn't happen as needs both parties to be willing but would be supported by both the transplant team and donor care team.

Infections in Transplant patients by Dr Clemmie Fraiser

Clemmie is a respiratory consultant specialising in transplant and complex Infection with sub specialist interest in Fungal lung disease and mycobacterium. She spends 2 out of 7 days with the Transplant team. She shared an insightful presentation discussing common infections patient can be prone to, post Heart and Lung Transplant.

COVID advise – call transplant team for advise about your immunosuppression

Contact GP or call 111 to self refer for anti viral treatment (first line anti viral is Sotrovimab but can differ in locations).

Shingles vaccine 'Shinrix' will be available from 1st September. Contact your GP for more info

More information on immunisation against infectious disease can be found at [Immunisation against infectious disease - GOV.UK](#) (link saved under 'other websites'). You can encourage your GP's to refer to the 'Green Book'.

Clemmie's full presentation has been saved to 'downloads'

Save the date

The next group will be held on Sunday 27th September, 2 till 4pm at the QE in the Education Centre on the 1st floor. It is accessible through the stairs and lift in the main entrance.

On the agenda

Another inspiring patient will share the journey with us

Guest speaker will be a member of the west midlands Specialist Nurses in Organ Donation.

Your feedback is paramount in the ongoing planning and structure of this group. If there is a particular topic you feel will be of value, or if you have any feedback on what has or hasn't worked well please let the team know by emailing;

qe.hltx.group@uhb.nhs.uk

Reminder; this email address is NOT for medical queries or prescriptions.

Please continue to use uhb.hltx@uhb.nhs.uk or contact the transplant office on 0121 371 8824 for all other general enquiries