Queen Elizabeth Hospital Birmingham

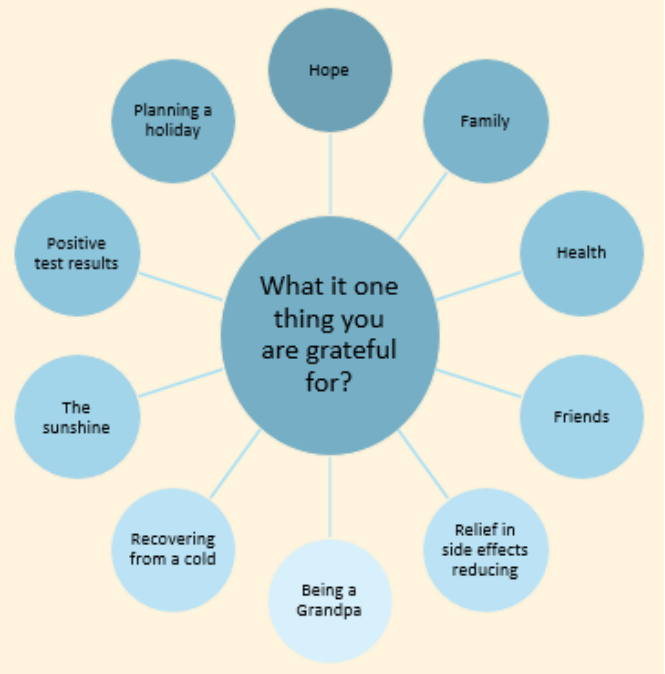
Heart and Lung Transplant Support Group

Virtual session

Thursday 16th October 2025

This months sessions was led by Darren, a post heart transplant recipient and one of the patient support groups ambassadors.

The sessions was started with some ice breakers. We created polls to open the floor up for discussion and see how people were feeling.



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

Specialist Nurse in Organ Donation (SNOD) What do they do and how are donor families supported?

Natalie, a SNOD based on the midlands gave a presentation on what the role of the SNOD involves and what support donor families get at the time of and after donation.

SNOD's are based throughout the country and manage areas of hospitals based on regions. Natalie covers the Midlands. They are based at the QE but have to travel around hospitals depending on where donors are.

There isn't much awareness or understanding of the process of organ donation in non transplant hospital and so SNOD's role also includes educating intensive care units about how and when to consider donation.

Organ donation is considered when a patient declared brain dead or where the team looking after them agree that they are not going to recover from the event that has brought them to the ITU.

The donor stays on ITU and the donation operation happens in that hospital.

One donor can save up to 9 lives.

To be an organ donor, a patient must be ventilated and in either ITU or an Emergency department. To be a tissue donor, a patient can also be on a ward or a hospice.

Before a patient can become a donor, their next of kin must give consent. This is the case whether a patient is registered as an organ donor or not. The message of organ donation is to ensure your loved ones know what your wishes are, so they do not have to make that difficult decision, on their own.

Before a SNOD approaches a family, the doctors and nurses looking after them will start the conversation of end of life care, and ask for their thoughts on organ donation and then their consent to refer their loved one to the organ donation team.

The SNOD then spends time with the family, learning about their loved one to work out if they are suitable to become a donor and to provide the family with reassurance that the person taking the lead in donation 'knows' them.

The SNOD can provide hand prints, hair locks and quality time in the bed space before donation plans are made. Families are given time to rest and are not rushed in making a decision. There is time for more family to visit and if needs be, faith leaders can attend to bless or baptise the patient.

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After donation the family receive an 'outcome letter' with a list of the organs that were donated and a brief summary of who too, i.e, 'Lungs were donated to a 63yo man', 'Heart was donated to a 40yo man'

Families are signposted to the 'donor care services' who can chase recipient outcomes if letters are not sent. They provide memory cards on donors birthdays and anniversary of death. There is also an annual memorial service that takes place in different areas of the UK each year.

Questions

Why are there fewer heart and lung transplants compared to liver and kidney transplant?

Kidneys are and livers are easier to maintain during the process of donation. Unfortunately there is more that can go wrong with Hearts and Lungs and the recovery is more complex because of the size of the operation. With that in mind we are much more selective in choosing appropriate donors.

However, technology advanced all the time. There are now perfusion machines that can 'recruit' organs or give us more time to test the quality of organs. For Hearts the 'OCS' programme has been running for more than 8 years. For Lungs the 'EVLP' programme is in the early stages of trials having been established in America and parts of Europe for many years,

Why isn't there more publication for organ donation, during organ donation awareness week and throughout the rest of the year?

Funding is a huge barrier in NHSBT's ability to publicise at a national level. A lot of this years campaigning has been on social media as it is easier/ more cost effective, to spread the message this way.

Can you donate If you have/ have had cancer?

Cancer within the last 5 years is usually a vito for donation but it is always better to have the conversation, than not!

Interactive session: What do I know now, that I wish I'd known before?

- 'Acute Rejection' doesn't have to be scary. 'Acute' just means it is happening now, but can, and will, be treated. More than 50% of patients experience some form of rejection in their first year post transplant.
- Hallucinations and confusion on intensive care or very common. Patients can recite or report a whole range of behaviours, that to them at the time, feel truly real. This can range from thinking your on a boat, not a hospital bed, thinking a face mask is a hat, or thinking the doctors are trying to harm them. This usually only lasts a couple of days but can occasionally take weeks to resolve. Theres nothing we can do to speed this long, just listen, acknowledge what the patient thinks is happening and reassure them that you understand and that everything is going to be ok.
- Unfortunately, there isn't much 'psychological care' for families during the recovery period. If you have questions or need support, ask to speak to the coordinators. One of the most useful tools we have is the peer support we have generated from this group. There are *always* families, patients, loved ones, that are willing to offer support, that have been where you are and can share in your worries.
- There are pro's and con's to immunosuppression and it is often a balancing act with side effects vs keeping your organs protected.
- Pain relief and nerve blocks on intensive care can make it harder to take deep breaths. This is a normal side effect of those medications and doesn't mean my new heart/ lungs aren't working.
- ITU and the medication you receive can alter your sleeping pattern, making your hearing feel off or give you blurred vision. It can be difficult to distinguish between day and night. Mindfulness exercise can help relax you and aid your sleep.
- Learning 'the little things' your spouse or loved one normally takes care of so that when they are in hospital you know what to do. Ranging from, managing the finances, to switching their hearing aids on/off!!
- Everyone's journey is different and sometimes things don't go 'to plan'. Try not to compare your wait or recovery to others.

Save the date

The next group will be held via teams on Tuesday 18th November between 5 and 7pm. Steph, the transplant psychologist will be leading a session on 'donor and survivors guilt' as well normalising the anxieties and fears families experience.

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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;

ge.hltx.group@uhb.nhs.uk

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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