

Queen Elizabeth Hospital Birmingham

Heart and Lung Transplant Support Group

Saturday 8th Feb, 2025

Mission and Vision Statement

- * To create a non judgemental, fair and respectful group to support mental health and well being for patients pre and post Heart and Lung Transplant*
- * To speak honestly and encourage positive thinking by learning from each others knowledge and experience*
- * To acknowledge the good and bad, be open, patient, understanding and above all else, kind.*

Transplant Ambassadors

Lungs; Andy, Mike, Paul

Hearts; Darren, Jan, Sarah

Updates on existing topics/ resources

Psychology

Part time psychologist in post (3 days a week). Currently only capacity to support in patients (on urgent heart waiting list, in patients on intensive care or wards pre and post transplant) though discussions on going about out patient clinics. Continue to recruit for a second psychologist (would be 2 days a week to equate to one full time role) with focus on support for out patients.

Transplant Centre

Transplant centre now open. In old QE site. Unfortunately no diagnostic recourses (ECHO, Lung function, xray machines). Currently only able to use for appointments with no tests (bloods and go). Hopeful there will be scope to improve this in future.

Scope to work with physios/ dieticians, utilise 'therapies suite' for exercise/ dietetics programmes and clinics.

Work in progress

Patient and family accommodation

On site accommodation for patients/ family- Nuffield House (chargeable, £30-40, no children) 0121 371 4524

Bottles cottages- charity funded apartments, bookable through transplant nurses, total 8 cottages to cover whole hospital, subject to availability

Military or ex -military personnel charity accommodation available free of charge for your family. This is called Fisher House. Please contact the welfare team on 0121 472 6748, they will request your service number.

Current Resources

The following video is an informative guide for patients that outlines the heart and lung transplant assessment process and what investigations take place over the course of the three-night hospital stay.
<https://archive.uhb.nhs.uk/heart-and-lung-transplant-assessment-process-videos.htm>

You can also access the NHS transplant society information area for organ transplantation at <https://www.nhsbt.nhs.uk/organ-transplantation/>. This information will help prepare you for your assessment and the process of waiting, receiving and recovering from a transplant.

Ongoing work with education team to create a 'counselling talk' video to refer back to pre and post transplant. Watch this space

Topics of discussion during meeting;

Support Donor families receive- Donor families are supported by a donor care team pre and post donation. Not all families chose to receive letters from recipients, we are not informed of this information but can reach out to donor care teams at your request if you have not heard back from a letter you are sent. All families receive a certificate, with a brief summary of each organ that was donated, i.e 'Heart was donated to 54yo male, Lungs were donated to 33yo female'. All family members receive a gold 'I do' donation badge to be worn as a 'badge of honour' . This will be picked up as a topic for one of our upcoming teams meetings.

Writing to your donor family- support in this process can be found via the following link
<https://www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-your-donors-family/>

Or by searching 'NHSBT writing to your donor family'. You can also discuss this with the nurse you see at your next clinic appointment if you need advise.

Information shared of 'discharge talk' prior to going home following a transplant. Discussion on foods, activities, procedures transplant recipients should avoid. Plans to expand 'post transplant advise' handouts with more up to date information. These will be accessible to all patients, not just those newly transplanted.

Visit to ITU post transplant- if this is something you or your family are interested in the ITU team are happy to accommodate. Please speak to the coordinator you see at your outpatient appointment. These visits will require forward planning and an escort with either a transplant or ITU nurse. With this in mind, visits cannot be arranged on the day of clinic. If you would like to arrange this for your next out patient appointment please email a request to ge.hltx.group@uhb.nhs.uk

Further discussion on topics such as updated resources and educational videos for patients and their families including children as well as link work between recipients and donor families. This is something we plan to look in to more over the next few months.

Upcoming projects

Newsletter

Scope to create a 'Transplant Newsletter' that patients can 'subscribe' to.

To include patients experiences- good and bad.

Informative/ resource for education- 'what is CMV'.

Meet the Team 'interviews'.

Counselling Programme

Darren, a post Heart transplant recipient and qualified councillor is setting up a counselling programme. This will be over a 6-12 week period.

A note from Darren;

This therapeutic group for transplant patients will aim to provide emotional support, coping strategies with the opportunity to share experiences in a safe environment, where you can connect with patients alike facing similar challenges, fostering a sense of belonging.

“Hope is the best heartbeat of the soul” – Michelle Horst

If this is something you are interested in, please email ge.hltx.group@uhb.nhs.uk for more information or how to enrol on to the course. There will be limited number of places for each course. Once the first course has completed, there will be opportunity to attend future groups.

Opportunities for you to be involved

As this is a start up group, there will be lots of opportunities for more of you to get involved. The areas we need your help are as follows

- Face to face support for patients in hospital on the urgent transplant waiting list
- Face to face support for patients in hospital, recovering post transplant
- Over the phone support for patient waiting for transplant
- Over the phone support for patients struggling, post transplant
- Over the phone support for care givers and loved ones of patients

If you are interested in offering any of the above types of support please let us know by emailing ge.hltx.group@uhb.nhs.uk . We will then be in touch to discuss this in a little more detail.

Future Meetings

Meetings will be held monthly via Microsoft teams and every 4 months face to face.

To allow time for planning, the first teams meeting will be early April.

Face to face meetings will be held in the months of May, September, January

All meetings will be held on Saturday afternoons.

Meetings will include group discussion and break out rooms for Heart/ Lung, Pre/ post

Future Topics and guests for discussion

Psychology

Physiotherapy

Nutrition (weight loss)

Nutrition (weight gain)

Donor family support

Mental rehab

Preparing/ supporting children for transplant

Mindfulness

An agenda will be put together for the next 12 months worth of meeting which will be shared with you in due course.

The next meeting will be via Microsoft teams on the 12th April at 2-4pm.

You will receive a text notification with an invite in due course.

If you have any questions related to the patient group please email ge.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.