

Queen Elizabeth Hospital Birmingham

Heart and Lung Transplant Support Group

Saturday 17th May, 2025

Topics discussed during the meeting

Virtual Support Group

Following much anticipation, the first scheduled virtual support group will be held on Thursday 17th June. You will receive a text invite to this group in due course, following which you can email the team, to be sent a link.

If you do not receive a text invite please get in touch using the patient support group email

qe.hltx.group@uhb.nhs.uk

This support group offers a safe and supportive environment for patients at all stages of their heart or lung transplant journey — whether preparing for transplant or living post-transplant. It is a space to share experiences, offer mutual support, and receive information and guidance from peers and professionals. With this in mind, by joining the online support group, you acknowledge accept the group expectations, laid out in the QEHB Heart Lung transplant support group disclaimer. You can find the disclaimer attached to this webpage.

Save the Date

The list of upcoming group meetings has been updated on the main page of the QE Heart Lung Transplant support group webpage. You will receive notification for each group following its predecessor.

i.e. notification for June's group will come following May's group. Notification for July's group will come following Junes.

Change in Clinic letters

Due to the increasing workload on our secretary, patients past their first year after transplant will no longer receive a nurse letter following their clinic visit

This is due to the large volume of letters that are currently generated per week and the pressure this puts on our admin team. We feel this time is better focussed on more direct tasks such as responding to voicemail messages and other administrative duties

Patients will still receive a clinic call from a nurse to inform them of medication changes and any other advise given during the appointment, but this will not be reiterated in a letter

Patients will continue to receive appointment letters to confirm upcoming appointments

Exceptions to this will be patients who have memory issues or where there is a language barrier. If you feel you still need to receive a letter confirming your medication changes please discuss this with the team at your next clinic visit.

Writing to your donor family

Letters to donor families are initially shared through Transplant nurses, to Donor Care nurses. If you have a letter for your donor family, please pass it on to the transplant nurse at your next clinic visit.

The transplant nurse you give your letter to will proof read the letter, then forward it on to the donor care team. On receipt of your letter, the donor care team will contact your donors family and ask if they would like to receive the letter. If they do, the donor care team will forward it on to them.

If your donor family write back, they will first pass it on to the donor care team, will your forward it to the transplant nurses. We will then inform you, you have a letter.

If you have already sent a letter and have not heard back, please ask a transplant nurse to chase this for you. We can then get in touch with the donor care team.

Sadly, not all patients will get a reply.

For more information please search 'writing to your donor family' and visit the NHSBT website

Navigating Emotions post Transplant

Darren, a Heart transplant recipient and qualified psychotherapist and counsellor, shared a touching and informative presentation Navigating the Emotions most commonly experienced post Transplant which generated an engaging discussion amongst the group.

You can view Darrens presentation in the attachments on the support group webpage which also include details of how to contact him.

British Transplant Games

This years British Transplant Games take place in Oxford from Friday 31st July to 3rd August.

Paul, Andy and Imran shared their experiences on the games with the group alongside Martin who is the volunteer Birmingham group manager.

The games are open to all patients, families and supporters. The variety of games are accommodating of all levels of fitness. You do not have to partake in the games to attend the events. Supporters are encouraged.

For more info please contact Martin on;

Smartmartg26@gmail.com

Or visit;

www.britishtransplantgames.co.uk

Introduction to food safety post transplant

Magdalena, the trusts cardiothoracic specialist dietician shared some advise on food safety post transplant which generated a healthy group discussion.

The team plan to work on some resources focused on this information over the next 12 months.

If you need guidance on food safety after your transplant, please visits the following links;

<https://www.nhsbt.nhs.uk/organ-transplantation/resources/food-safety-advice-after-a-heart-or-lung-transplant>

<https://www.bda.uk.com/resource/fat.html>

Patient Resources

A 'transplant counselling talk' video is in the final stages of editing and will be shared with patients on the waiting list or being referred for transplant within the next couple of months. This video has been created as an indepth review of what to expect going in to transplantation.

The team are also working on an array of information leaflets, booklets and advice sheets which we hope to roll out over the next 12 months.

These leaflets will include topics such as 'What to expect during your assessment admission' and 'I'm on the waiting list, now what'. The plan is for this information to encompass the entire transplant pathway and so will also include an expansion of the resources provided to you during your discharge talk.

The team are also working on some specific resources focussed on children of patients undergoing transplant.

To generate such resources takes an incredible amount of time and commitment from not only the transplant team but the trust communications and resources team as well as our charities team who are kindly sponsoring this work. With this in mind, please do not be discouraged if you do not see or have access to these resources sooner than 12 months times.

Existing Resources and support

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.

ITU visits

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 outpatient appointment please email a request to ge.hltx.group@uhb.nhs.uk

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.



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

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.