

Queen Elizabeth Hospital Birmingham

Heart and Lung Transplant Support Group

Virtual session

Wednesday 23rd July, 2025

Topics discussed during the meeting

Review of patient support group webpage and ongoing work with Charities to create more patient resources

Reminder 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 via the Facebook page or visit the link under 'other websites' on the main page.

Patient Story

Andy and Donna shared their Transplant journey over the last 31 years.

In 1994, at age 25, Andy underwent his first transplant, 12 years later he developed chronic rejection and in 2006, at age 37, he was listed for and underwent a second (or 're-do') heart transplant. Following his second transplant Andy suffered with progressive kidney failure, and in 2014, at age 45, he underwent a Kidney transplant. Andy and Donna shared the trials and tribulations they suffered along their journey while reflecting their positive approach to the challenges they faced.

Andy is now living in Australia with his family and continues to make the most of his time while also promoting organ donation and the gift of life. To help maintain his physical and mental health, Andy has accessed various support groups that are available to him locally.

A true inspiration to us all.

Charities work in resources for children

Kate from charities joined us to talk about the ongoing work going in to creating some resources for the children of patients going through transplant.

We will base this on a resource the charities team currently provide for the children of cancer patients. This is a care package that can be catered for a range of different ages. It will include information sheets, activities and diagrams in different formats based on each age range (example pictures below).

In order for us to make this as helpful as possible, we need your feedback. Please complete the questionnaire on the main page under 'other websites' by 15th August

Once we have decided what the contents of the box should be, we will need to focus on fundraising. Each box costs £40 to make. The transplant team are planning a charitable walk to raise funds for this. We hope to share more details of this at the next group.



Psychology

Unfortunately due to a jam packed agenda and lots of enlightening discussion, our session with Steph, the new transplant psychologist, was cut short.

For the half an hour we did have, Steph led a session focussed on coping on the waiting list and managing uncertainty. This was guided by feedback and input from attendees.

Next time Steph attends a session we will aim for her to be the only speaker, so we don't run out of time.

Save the Date

Next virtual session will be **Monday 18th August, 5-7pm.**

Agenda

A Lung transplant recipient will share the journey just shy of reaching the 10th Birthday!

Clemmie Fraiser, a Lung transplant consultant will discuss some of the common infection transplant patients can be susceptible to.

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