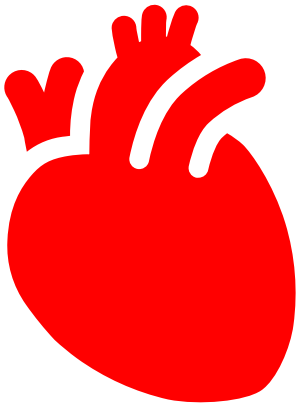
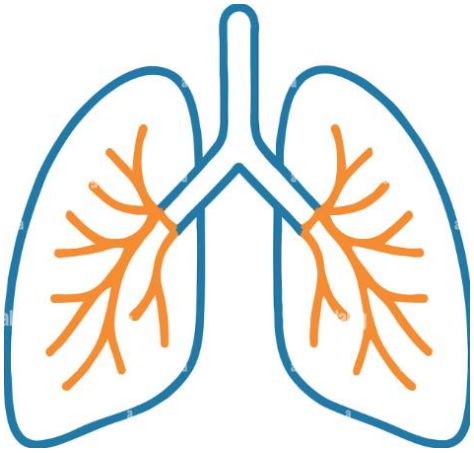
A RELATIVE'S VIEW OF TRANSPLANT

BASED ON LUNG TRANSPLANT

AT

WYTHENSHAWE HOSPITAL





Brandon Alexander Feb 2026
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Areas Covered in This Presentation

- What I observed
- How it makes you feel as a relative
- Discussions with loved ones
- Hints and Tips

- Pre transplant
- Getting the call
- Pre going to theatre
- Anaesthetic Room
- The wait during operation
- CTCCU(ICU)
- Jim Quick
- Going Home
- Clinic visits

- The aim of this presentation is to pass on my experiences. I can make it as graphic or reserved as you want

- Your normal presentations seem to cover specific areas I would like to give you an overall view

- If there are areas you don't want to cover or if I am going over what you already know let me know

- If there are other areas you would rather cover if I know about it I will talk about them

- I am not a medical professional so forgive me for using layman non medical terms

EVERYONES JOURNEY IS DIFFERENT ONE SCENARIO DOESN'T FIT ALL

Pre Transplant

- Keep positive
    - The transplant call will come
    - What will you do when your well
    - Just think when you are better you wont….. I will be able to…..
- Even though as a relative you feel sad, worried, emotional it's your job to stay positive and keep the 'transplatee' motivated
- Although you might not want to it is important to discuss what if's
- You can offer opinions, discuss concerns but it's their decision to make. Once that decision is made give them full support and encouragement
- Discuss who do you want to know and to be kept updated
- **Hint / Tip:** Create a message group so you are not going over the same message multiple times

- Eating and exercise
    - It's possible that eating and doing exercise becomes more difficult.
    - **Hint / Tip:** out of all the things advised before transplant I can't emphasise enough how important exercise is
- What to have packed ready to go
    - You will be in a hospital gown for a while before you need your own PJ's / Nightgown.
    - First things used post-op would-be body cream, toothpaste, hair brush, dressing gown
    - You are asked to shower on arrival to hospital so you could take shower gel but not necessary.
- **Hint / Tip:**
    - Relative have an over night bag packed as well.
    - Practice lip reading and hand gestures

Getting The Call

- It’s strange when the call comes as it’s expected but unexpected
- Exciting the wait is over but also nervous
- It will be a Transplant Coordinator

- No need to rush
- Take time to absorb; it's what you have been waiting for!
- It is a step closer to your road to better health
- **Hint / Tip:** no need to tell your relatives / friends at this point you will have time when at the hospital

- Remember there is no rush stick to speed limits
- Talk about what you are going to do when you recover
- Know what route you are going to take
- If it takes longer than expected don’t panic. There is time

- When you arrive at the hospital go via the door at the side of the clinic and press the buzzer for Jim Quick

Hospital Admission / Pre-Going to Theatre

- Greeted by the Transplant Coordinator
- Allocated a bed on Jim Quick
- Dependant on time of day you could start to let people know but there is no guarantee it will happen at this stage.
- Shower and shave
- Nurses do various checks
- You may go for an X-ray
- You get updates about retrieval
- Visits from anaesthetist, surgeons who go over the various operation scenarios
- Told if donor organs are suitable and if it is going ahead

- **Hints / Tips**
- You are waiting for a few hours but I feel it went quicker than expected
- Plenty of time to ask any questions
- There may be other post transplant patients who may talk to you
- It's absolutely normal to feel apprehensive during the wait. Think of the positives. They have done this lots of times and they are experts.
- If you want pictures of old / new organ, ask the Transplant Coordinator if it is possible.

Anaesthetic Room

- Your relative can escort you when you are taken to theatre. The Transplant Coordinator goes with you.
- Relative waits outside the pre theatre room (Anaesthetic Room)
- When ready relative is allowed in. This is emotional.
    - You may have been the main carer for years and now you are handing over to the medical team.
    - You have a moment to say what you want to each other.

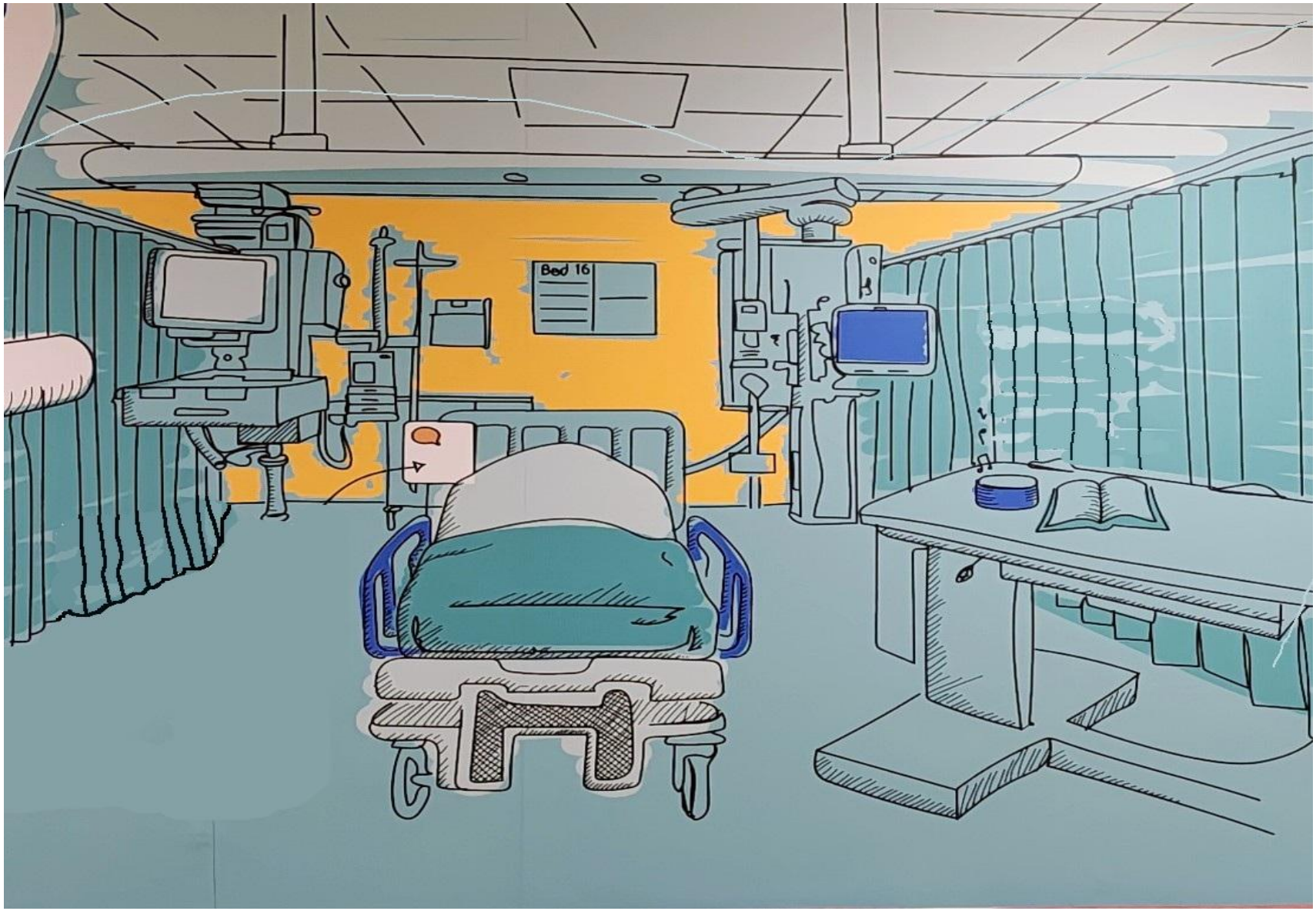
- **Hint Tip.**
    - This is the point where the phycologist may have told you “have you thought about what you may say”
    - This is a point for the relative to stay strong
    - Wait until you leave the room before you show emotion

The Wait

- This is a long wait for the relative. It could be 12hrs
- You will probably want to stay but if you live near you would be more comfortable at home.
- You are likely to get a couple of updates from the Transplant Coordinator. These help to reassure you as an anxious relative.
- Once the operation is over and the patient is moved to ICU the relative will get a call from the nurse on the ward.
- At this point dependant on the time of day, it would be up to the nurse in charge to allow a visit or wait until visiting time

- **Hint / Tips**
- If waiting away from home remember drinks and snacks. Dependant on time of the day shops at the hospital could be closed.
- There are few rooms for family on CTCCU (ICU). Maybe day room on Jim Quick.
- The New Start charity have donated bungalows where the relative may be able stay if they live too far away.
- The patient will be asleep post the operation so unless you want visual reassurance other than from the nurse. You may want to wait until visiting time. (ICU is a very busy area).

CTCCU (ICU)



CTCCU (ICU) Cont.

- It can be overwhelming especially if you have never been in an ICU before
- The patient will have a breathing tube, drains, various intravenous lines .
- There are a lot of beeps and alarms
- Patient could be asleep for a few days
- It's possible that their arms and legs will swell
- It's possible that upon removal of the breathing tube a tracheostomy has to be performed.
- Physio will start. (Salt)? Team swallow / talk review.
- Dependent on length of stay a diary will be started for the patient
- At this point do you want me to explain further more graphic details.

- **Hints / Tips**
- It's not called ICU it is CTCCU which makes a difference when trying to find it.
- You will see patients come in and out in a very short time while your relative is still there. The ward is also used for other heart operations not as big as a transplant.
- For access you have to be let in either by the reception or notifying the ward. You are taken to a waiting room that you cannot access the ward corridor from without the door being opened for you
- Relative to let the team know you have special dietary requirements. If not previously mentioned.

- **Hints / Tips**
- It is normally 2 people per bed for visiting so you may have to wait and take turns
- If they are treating your relative you will be asked to go to the waiting room
- The relative may be asked about the patient likes, job etc
- You could bring in a few pictures of family and a favourite blanket etc.
- Long visiting times; relative should take sometime out for themselves
- Relative will see things and remember things the patient will not they may need to be your memory

Jim Quick / Going Home/ Clinic Visits

- Once you move to Jim Quick its another emotional step as you are well on the mend.
- From a relative point of view they get to see you doing much more for yourself and able to do things you were unable to do before.
- More physio, learning about medication and important information about looking after your health once you are home.
- Now on Jim Quick you will want more of your own belongings.

- Before you go home physio will assess your mobility and may suggest aids for home.
- The pharmacist will go over your medication. It is a good idea to have your relative / carer there at the time
- You will be sent home with a supply of medication.
- **Hint / Tip**
  - The ward / pharmacist / physio etc are only a phone call away if you need advice.

- Once home you will go back for clinic visits (weekly at first)
- You will be asked to keep a record of taking your medication and various stats. (you are given a book to record this)
- **Hint / Tip**
  - At home relative / carer assist with the medication (two heads are better than one)

Clinic Visits / Home blood Tests

- The clinic is the same place where you have had your pre transplant appointments.
- You will be normally be asked to attend by 9am
- Check in at the office you will be asked what time you took your meds the night before.
- **Hint / Tip**
  - Do not take your meds until your bloods have been taken
  - In the waiting room you will get the opportunity to chat with other transplantees (not everyone will want to talk)

- The clinic appointments change from as simple as just blood test to including further test such as lung function , x ray, biopsy etc
- You might see the dietitian or the pharmacist, if you want to ask questions but not seeing them ask (best before you attend appointment)
- You will be called later that day or the next day for any changes to meds
- **Hint / Tip**
  - Remember to take your meds with you
  - You could be there for a while you may want to take a drink and snacks

- As you progress you may be able to take blood samples at home and send them to the hospital by post.
- These blood tests are for checking the amount of anti rejection meds you need. You will be advised by phone if any changes are required.

You can have someone attend clinic with you; a second pair of ears helps as you may be given information

Medication Tips

Medications		Morning	Afternoon	Evening	Night
Immunosuppression					
Tacrolimus (Prograf)	CNI	2.5mg			2.5mg
Azathioprine	CCI			HELD	
Prednisolone	Steroid	15 mg			
Infection prevention					
Valganciclovir	Antiviral	450mg			450mg
Itraconazole	Antifungal	200 mg			200mg
Co-trimoxazole	Antibiotic	480mg, Mon, Wed, Fri			
Other					
Calcium/vit D	Bone health	One			One
	Protects stomach	30mg			
	relief	On			
	retions				

Medications		Supplier	Picture	Morning	Afternoon	Evening	Night
Immunosuppression							
Tacrolimus (Prograf)	CNI	H		2.0mg			2.0mg
Azathioprine	CCI	H				HELD	
Prednisolone	Steroid	D		15 mg			
Infection prevention							
Valganciclovir	Antiviral	H		450mg			450mg
Itraconazole	Antifungal	H		200 mg			200mg
Co-trimoxazole	Antibiotic	H		480mg, Mon, Wed, Fri			
Other							
Calcium/vit D	Bone health	D		One			

Medication	From	Strength	Unit	Dose Per Day	Unit	No. of Tabs Per Dose	Current Total	Remaining Days
Tacrolimus (Prograf)	H	1	mg	4	mg	4	336	84
Tacrolimus (Prograf)	H	0.5	mg	0	mg	0	115	115
Azathioprine	H	25	mg	25		1	28	28
Prednisolone	D	5	mg	15	mg	3	62	20.67
Valganciclovir	H	450	mg	900	mg	2	37	18.5
Itraconazole	H	100	mg	400	mg	4	164	41
Co-trimoxazole	H	480	mg	205.71	mg	0.4285625	9	21.0004375
Calcium/vit D	D	1	ea	1	ea	1	63	63
Lansoprazole	D	30	mg	30	mg	1	41	
Lid	H	1	ea			1	29	

Letter to Donor Family

- You may want to thank your donor family (its not compulsory)
- The transplantee or any of their family can write to the donor family
- There are some guidelines: Nothing that could identify the transplantee. You can use your first name.
- Leave the envelope open
- On a separate sheet you will need to put Name DOB hospital where the transplant performed and date. (This is not passed to donor family)

- There is no time scale; do it when you are ready
- As well as your thank you what do you want to say? Some ideas are
- What organ you received, how your health was prior to the transplant, how it has improved and what you can do now that you couldn't before

- There is help available
- The Social Worker Team have examples of letters
- There is a pamphlet with information

- You can hand the letter to the Transplant Coordinator, the Social Worker or send to Donor Family Care Dept.

The letter is a very personal thing you write what you want to say remember the donor family's feelings

Thank you for listening

Questions / Comments / Discussions