The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Paediatric Heart Transplant Study Day

18/06/2024

Zdenka Reinhardt

No conflict of interest relevant to this presentation

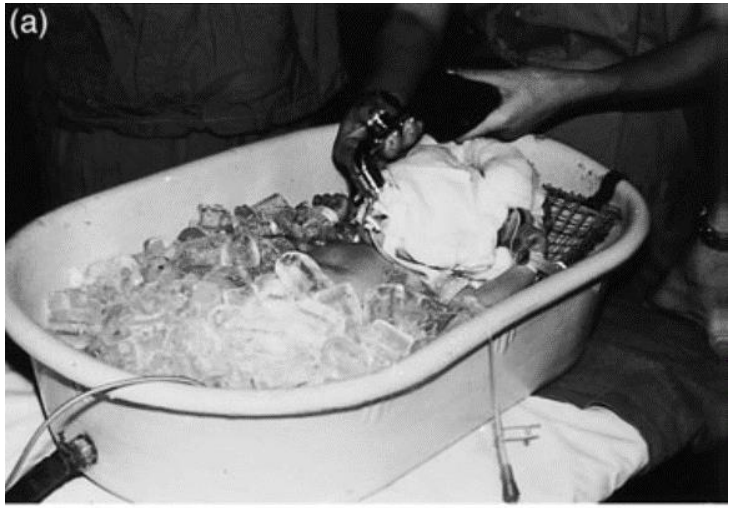
Content

- History of Heart Transplant
- Freeman Data
- National Data
- Freeman Strength
- Future

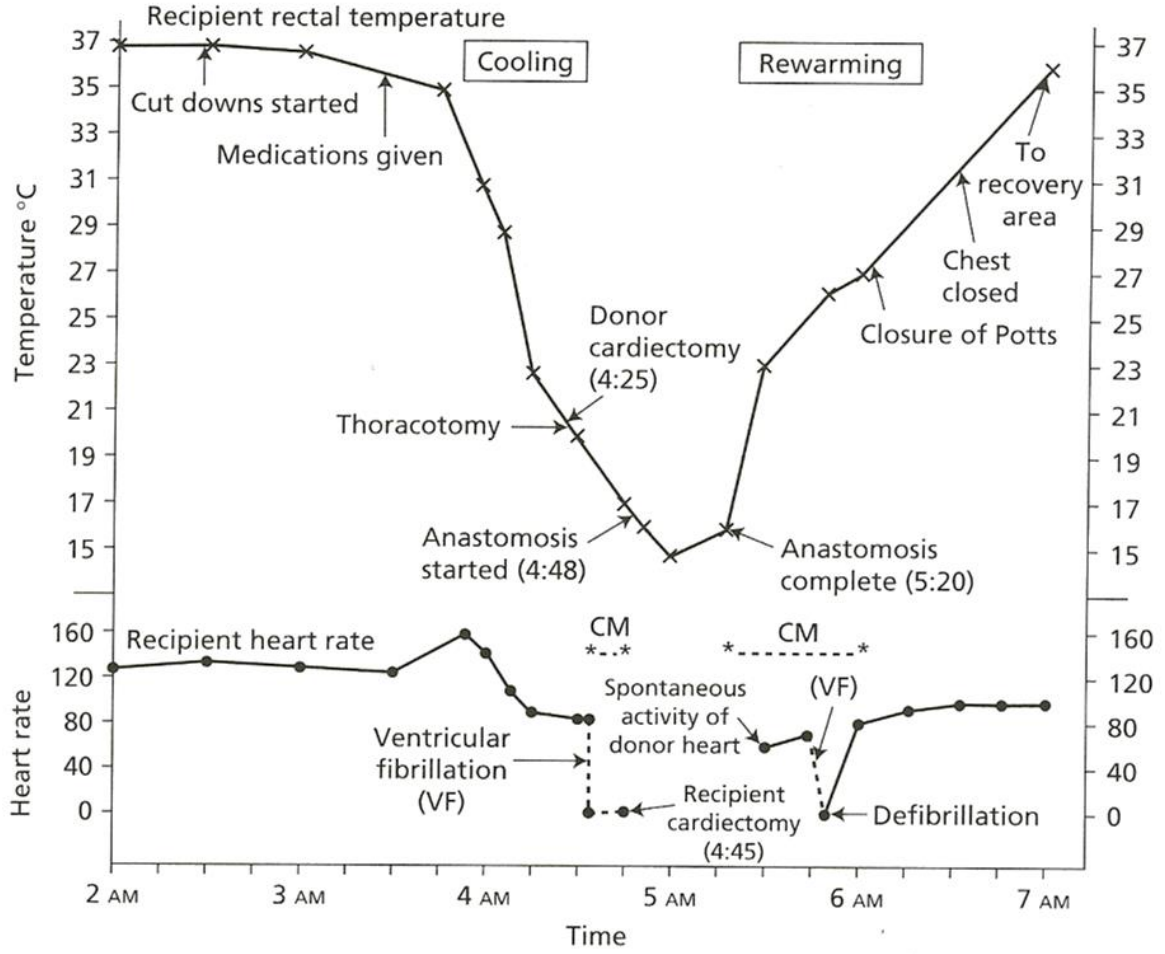
3rd December 1967

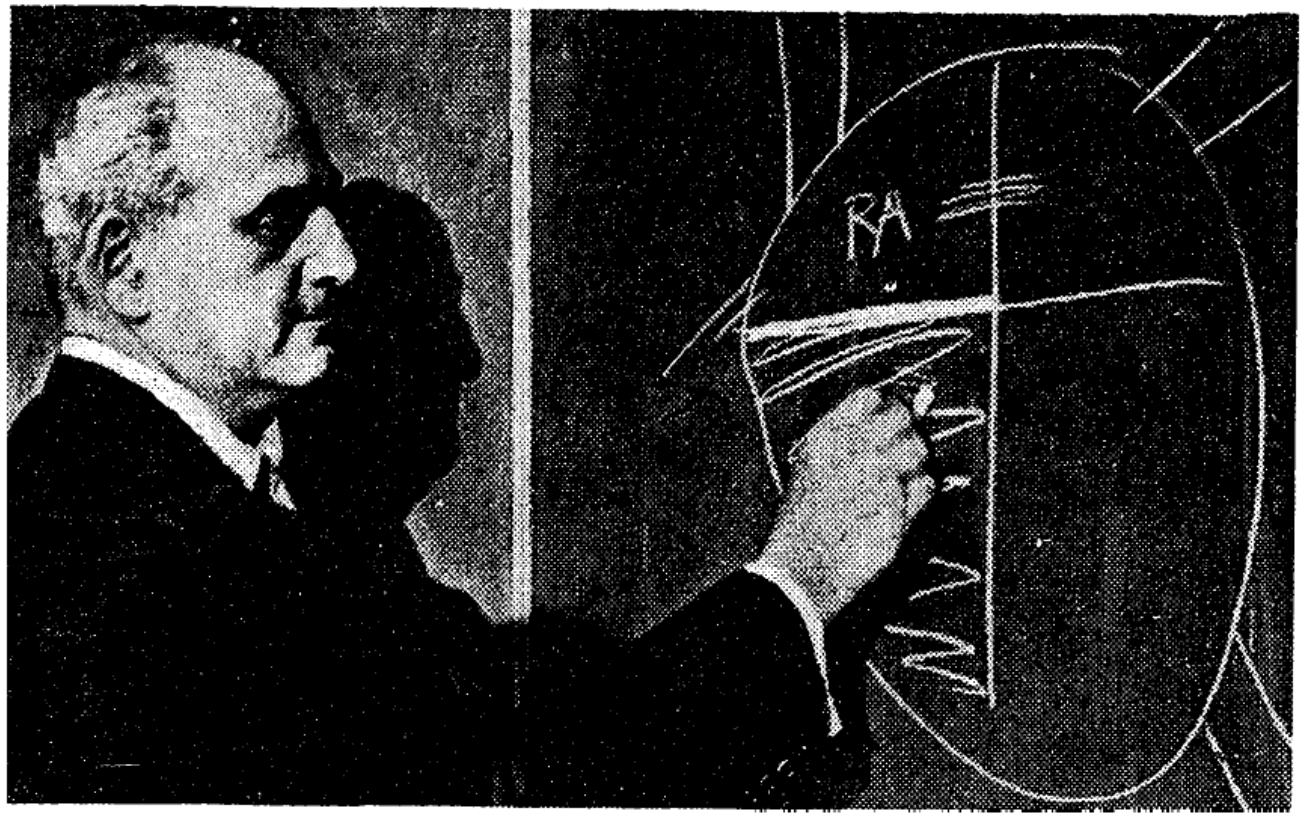
- An iconic image of which inspired a generation to do medicine, as it was one of the great medical advancement of twentieth century

- Photo of CB shaking hand with LW


(a)


(b)


Recipient rectal temperature
Cooling
Rewarming
Cut downs started
Medications given
To recovery area
Chest closed
Closure of Potts
Donor cardiectomy (4:25)
Thoracotomy
Anastomosis started (4:48)
Anastomosis complete (5:20)
Temperature °C
37
35
33
31
29
27
25
23
21
19
17
15
Recipient heart rate
CM
CM
Spontaneous activity of donor heart
(VF)
Ventricular fibrillation (VF)
Recipient cardiectomy (4:45)
Defibrillation
Heart rate
160
120
80
40
0
2 AM
3 AM
4 AM
5 AM
6 AM
7 AM
Time



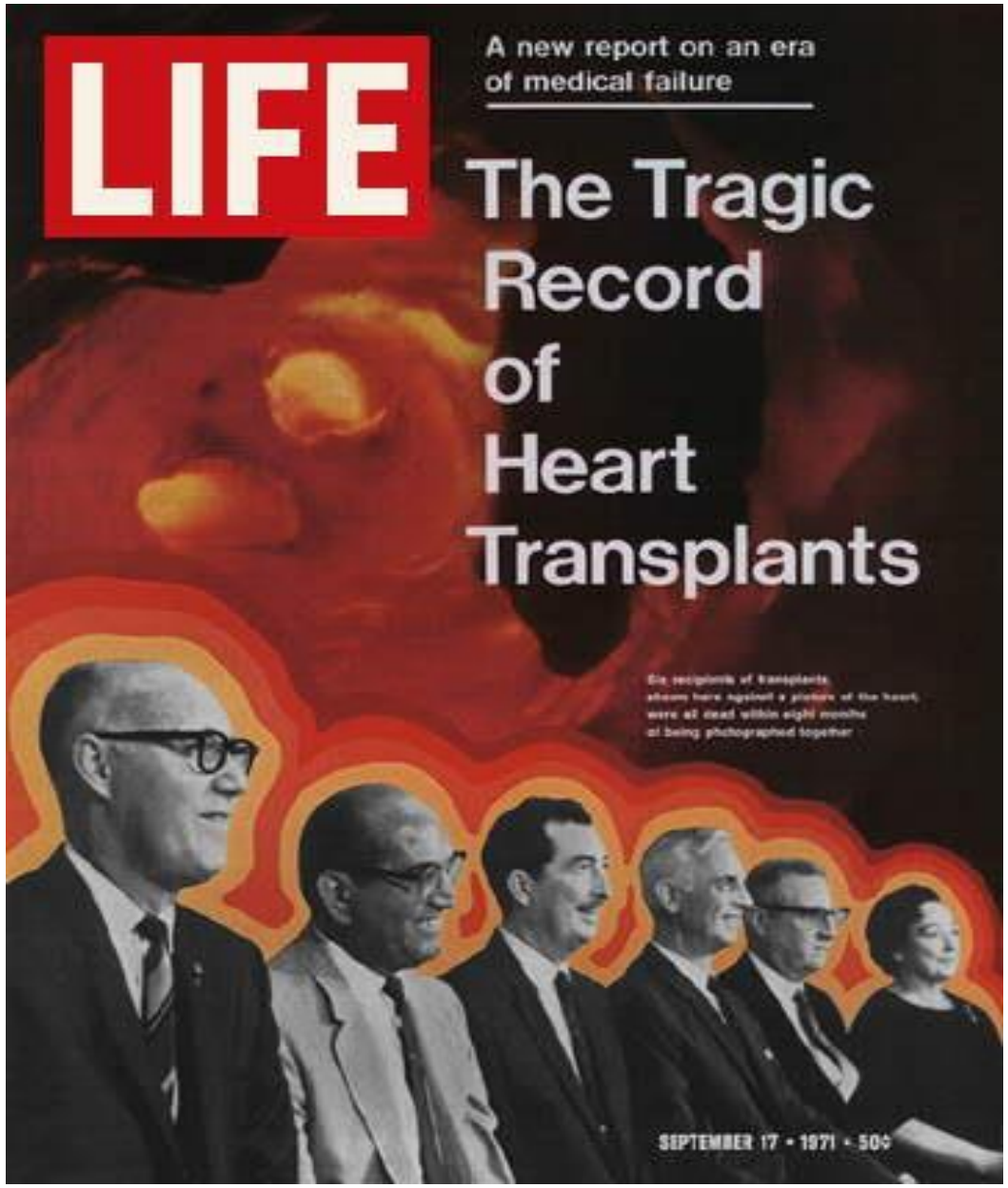
The New York Times

THE 'HEROIC' ATTEMPT FAILS: Dr. Adrian Kantrowitz, cardiac surgeon who headed the 22-member team that sought to transplant a heart to save an infant, describes his operating technique at Maimonides Medical Center. The baby died after the operation.

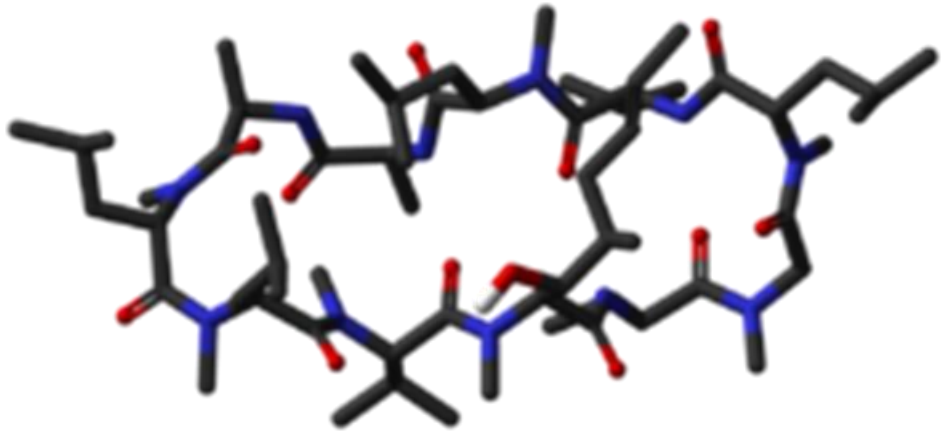
Heart Transplant Fails to Save Baby

Continued From Page 1, Col.

defect "incompatible with life. by the left side of the heart Such a condition is "lethal," he added. A respirator and an incubator into which almost 10[illegible] part by part to the stumps of the original heart of the living baby. Four main steps were required to implant the donor


LIFE
A new report on an era of medical failure
The Tragic Record of Heart Transplants
SEPTEMBER 17 • 1971 • 50¢

CICLOSPORIN



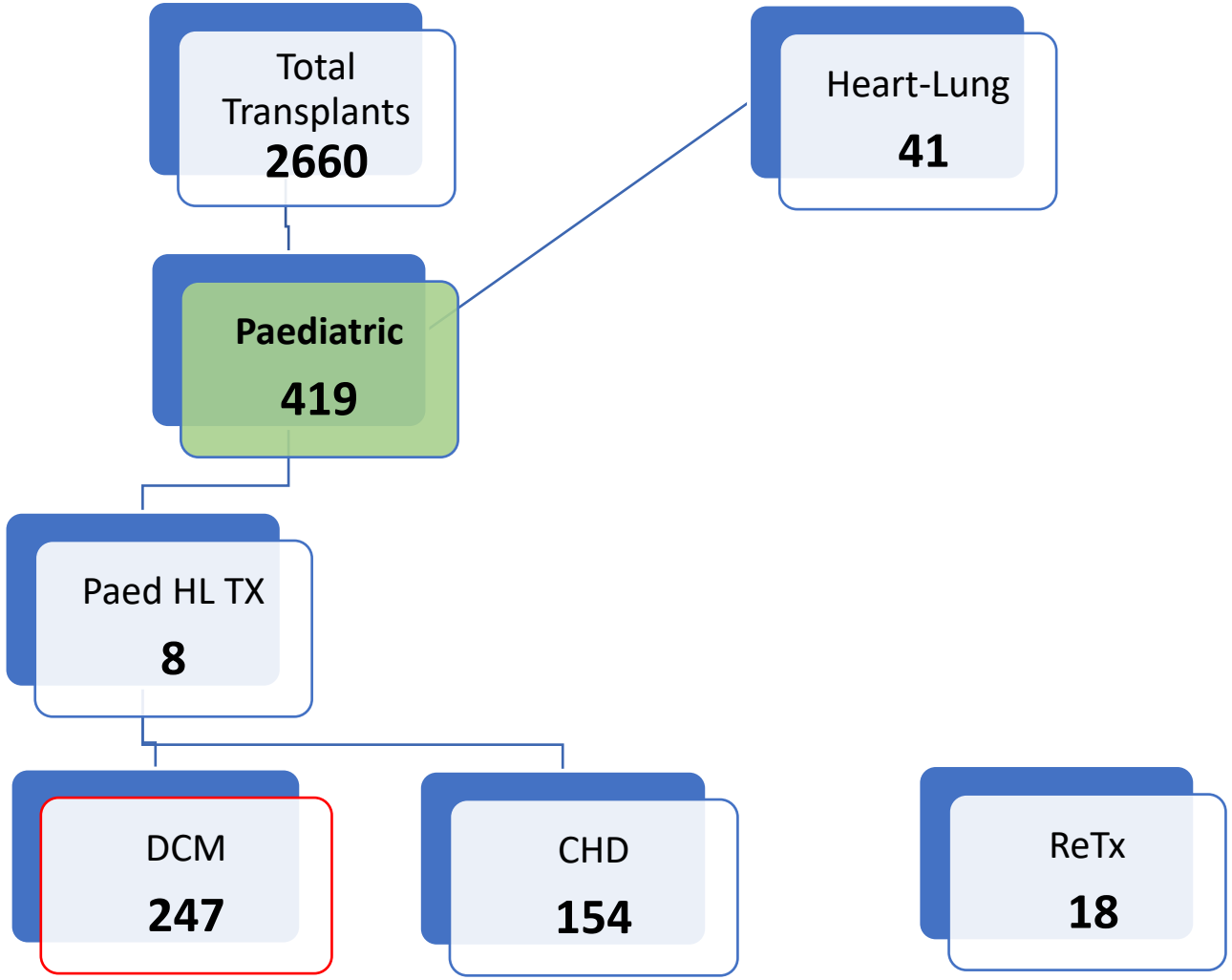
Kaylee Davidson

UK 1st successful infant Heart Transplant:1987


Female Toilet
Fire exit

Freeman Paediatric Heart Transplant

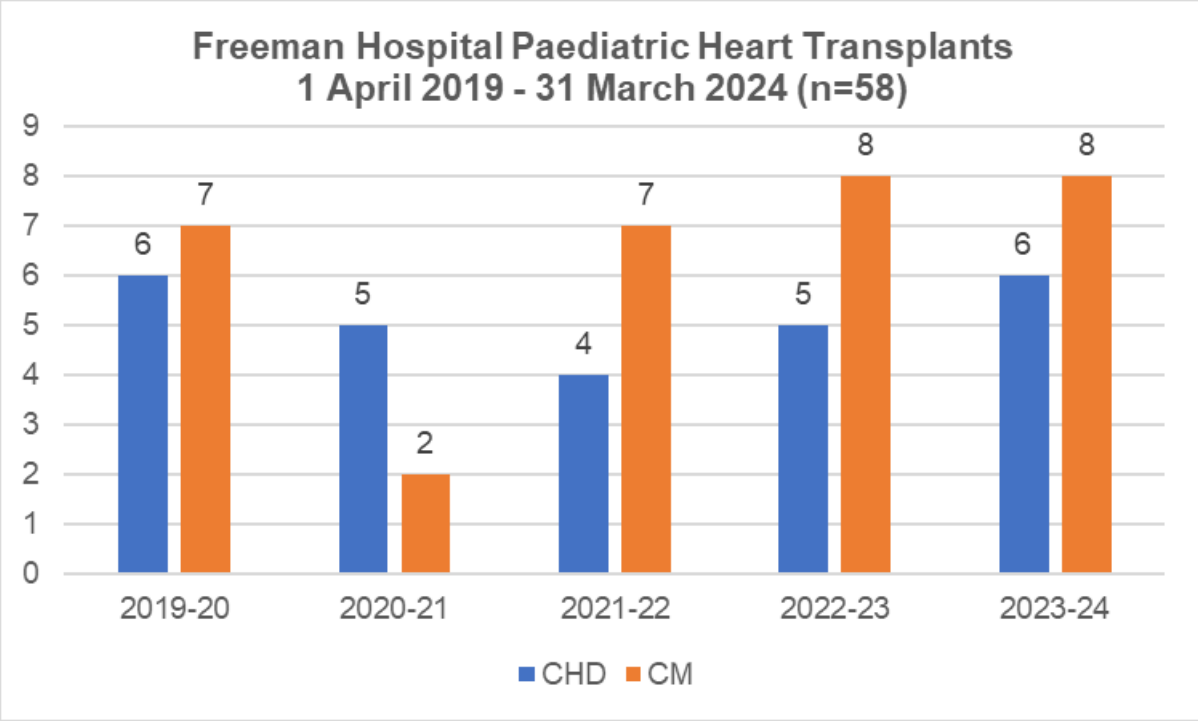
1985-2023


Total Transplants
2660
Heart-Lung
41
Paediatric
419
Paed HL TX
8
DCM
247
CHD
154
ReTx
18

Freeman Hospital Paediatric Transplants

The Newcastle upon Tyne Hospitals NHS Foundation Trust

1 April 2019 – 31 March 2024



58 hearts

-26 congenital

-32 non-congenital

Year	2019	2020	2021	2022	2023
Assessments	9	10	6	9	10
Transplants	3	1	1	0	0

5 double lungs

Background

Historical

- First infant heart transplant
- Started ABOi transplant
- Paediatric Heartware
- First UK Paediatric Recovery on VAD
- OCS transplant into children
- UK largest ACHD transplant programme
- UK only ACHD VAD programme
- Re-do and bail out surgery from all UK units

Contemporary

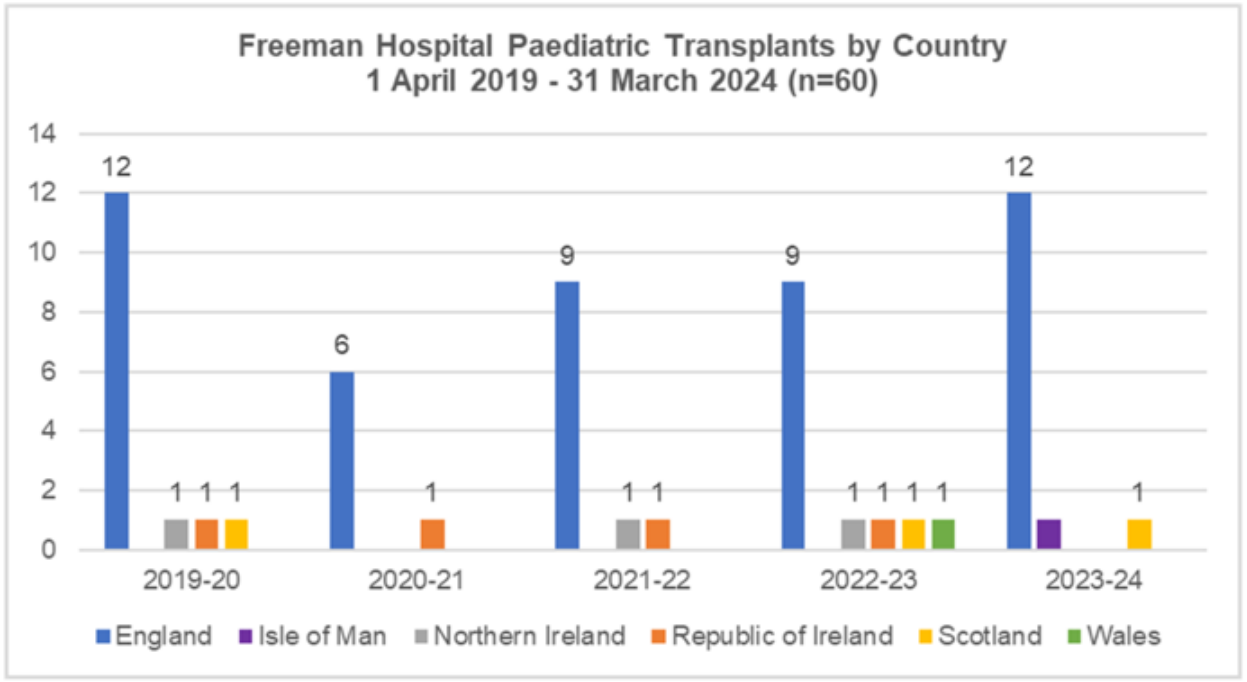
- Percutaneous ECMO in children (cardiac/ respiratory)
- Percutaneous mechanical support in children to transplant (1st and only UK unit)
- Changed Heartware to Heartmate 3 in children (first UK unit)
- Transplant review in children- case complexity exceeds other paediatric transplant units
- National recognition as Advanced Heart Failure unit – particularly for Congenital Heart Disease

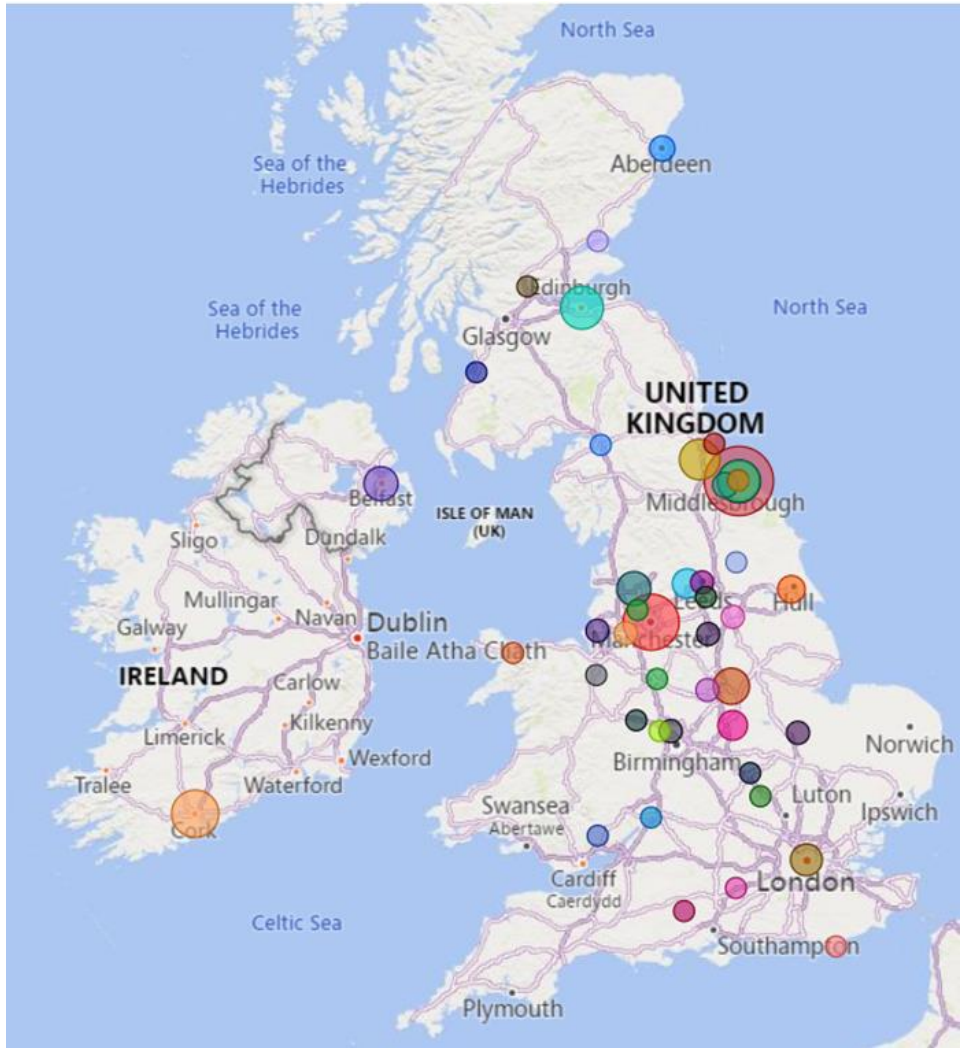
Referral Area

The Newcastle upon Tyne Hospitals NHS Foundation Trust

The Freeman hospital accepts referrals from all around the UK (approx. pop 66.97 Million people, 2022)

- **181** Paediatric heart referrals
- 44 Lung assessments





National Paediatric Heart Transplant data

NHSBT

Figure 15.1 Number of paediatric patients on the heart transplant list at 31 March each year, by urgency status

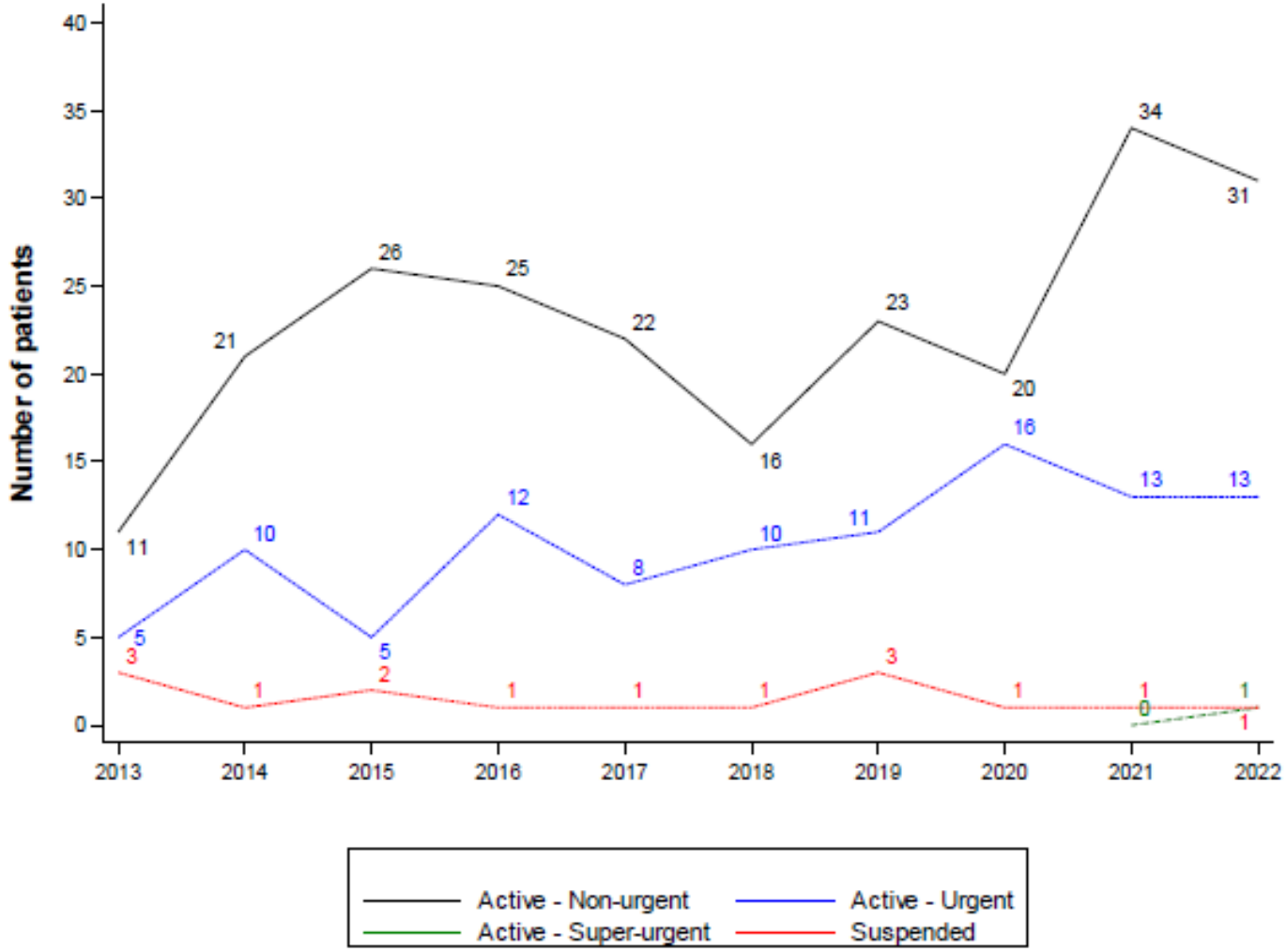


Figure 15.2 Number of paediatric patients on the active heart transplant list at 31 March 2022, by centre and urgency

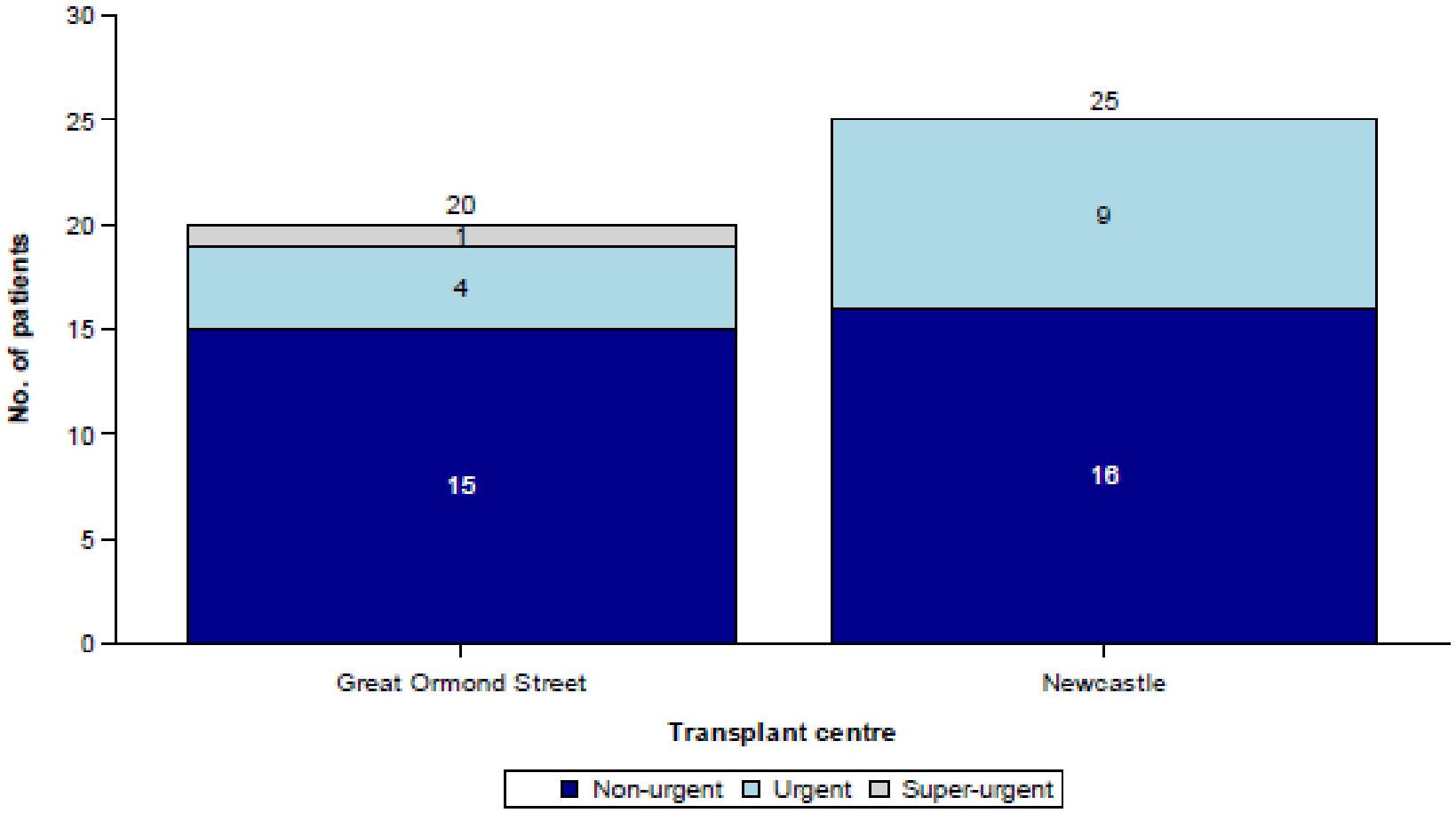
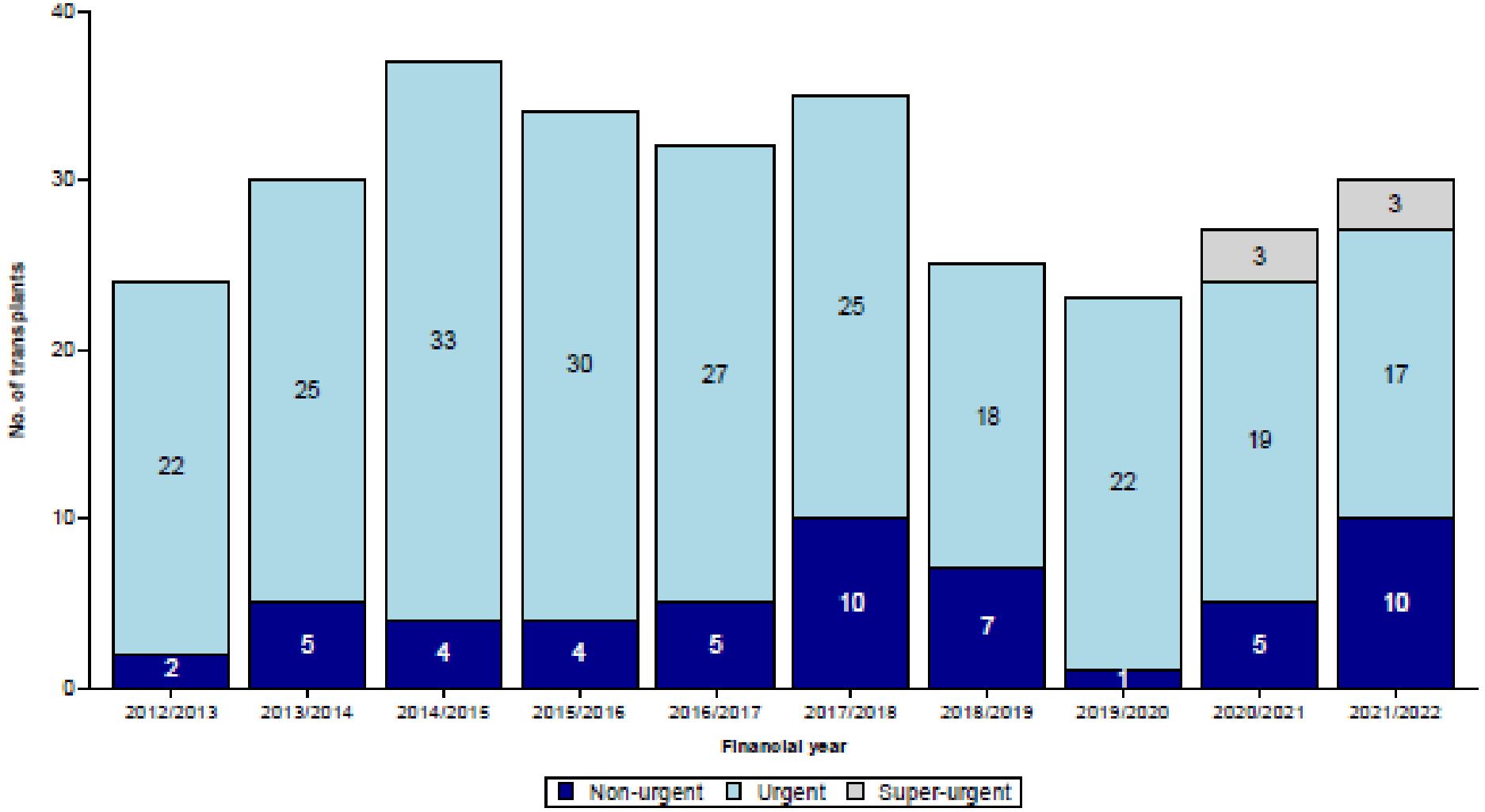


Table 15.2 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency at registration and centre, 1 April 2018 to 31 March 2021

Transplant centre	Number registered	Number transplanted	Waiting time (days) Median	95% Confidence interval
Non-urgent at initial registration				
Great Ormond Street	37	17	762	404 - 1120
Newcastle[1]	25	9	-	-
UK	**62**	**26**	**762**	**364 - 1160**
Urgent at initial registration				
Great Ormond Street	27	18	276	42 - 510
Newcastle	47	24	191	84 - 298
UK	**74**	**42**	**193**	**53 - 333**

[1] Median and 95% confidence intervals could not be calculated due to low transplant rate

Figure 17.4 Number of paediatric heart transplants in the UK, by financial year and urgency status, 1 April 2012 to 31 March 2022



Freeman Strengths: WORKING TOGETHER

- Only combined adult and paediatric programmes – joint working, **learning from each other**
- Complex congenital heart disease transplant – paediatric and adult (including heart lung/liver)
- Paediatric mechanical circulatory support and respiratory ECMO expertise
- A new generation of adult & paediatric consultant transplant surgeons ready to take heart, lung and heart and lung Tx forward
- Organ perfusion research (development of paediatric ex-vivo cannula)
- Multi-organ Institute of Transplantation (Paediatric to Adult Transition)

Future

XVIVO: Lead Louise Kenny

- Hypothermic organ perfusion technology
- 35 long distance DBD cases in Australia (including 5 children)
- 12 hour transit time with good myocardial function- French group!
- Permission obtained for use in children DBD
- Pushing towards DCD in the next year….

Opportunities

- Increase Paediatric Donors (organ perfusion, long range DBD, DCD)
- National Centre for Congenital Heart Disease: (Adults and Paediatrics)
- VAD for single ventricles
- VAD < 5 kg children
- VAD to recovery (including after high risk surgery)
- Patient and family engagement to develop a paediatric transplant information website

Acknowledgement to my colleagues, patients and their families

Thank you

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NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Pre-Transplant Process

Stephanie Dunn Transplant Coordinator

Healthcare at its best
with people at our heart

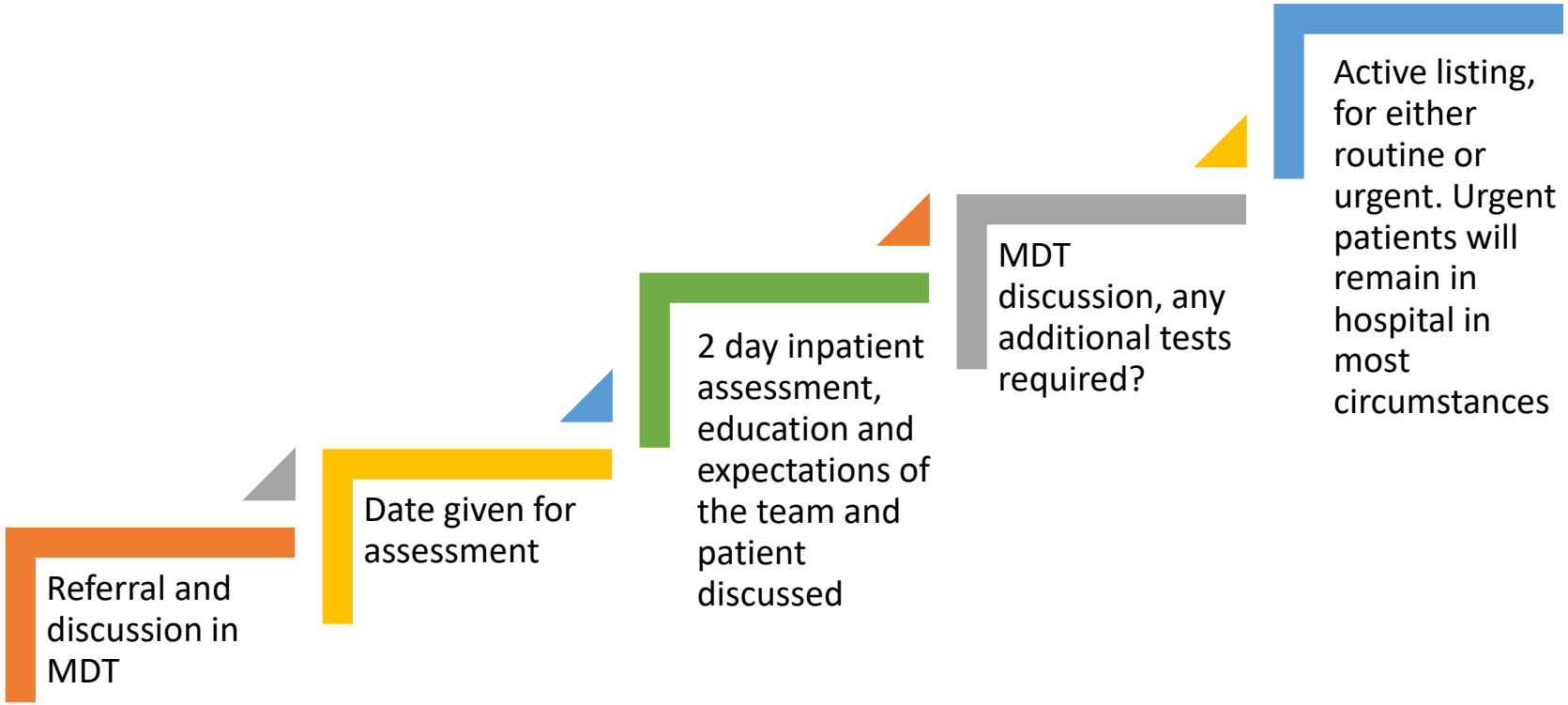
Referral Process

- Acute admission – can be a patient we have previously assessed or a new presenting patient.
- Usually a critical situation, with a higher risk patient due to acute nature of admission.
- Less time to prepare the family and child, usually involving bridge to transplant with VAD/ECMO, inotropes.
- Planned admission – Usually discussed in an MDT prior to a date being given to ensure they are suitable for assessment. Would have several tests done over 2 days.

Tests

- Bloods including HLA for tissue typing and titres
- Chest X-Ray (radiology images requested from local centre)
- ECHO
- 6 minute walk test
- Psychology and social review
- Dental review
- Neck and groin dopplers
- ECG (24 hour possibly required)

The process of assessment



Education: why is it so important?

Education: knowledge and consent

- Knowledge

-Wide variety of patients, different backgrounds, level of education, denial, acceptance and dedication to information.

- Different diseases, information often depends on the disease, patient age, potential bridge to transplant and HLA results if available

- Consent

-What are they signing up for?

- How much does the patient know?
- Dule signing?
- Average adult takes in around 20% of the education provided at the time of assessment

Education

Parent

- Full education, discussed in a story like method, from the process of listing to discharge.
- Risks of transplant, bleeding, infection, rejection, PGD, renal failure, ECMO, 10% mortality rate, higher if more complex anatomy/previous surgery which could lead to complications.

Patient

- Aimed at patients age along with the wishes of the parents.
- Can help explain what a transplant is and why they would need it.
- Often do not give a great deal of detail regarding risk/ complications.
- Encourage some type of education just to be inclusive of the child.

Education……what do we say?

- Why we transplant, life expectancy and quality of life. It's a treatment not a "fix".
- Timing of transplant listing.
- Waiting on the list, follow up whilst on the list, dual centre approach, regular bloods, repeat tests.
- The waiting time, how this can impact on daily life, going on holiday, keeping healthy.
- Communication, what we need to know, any changes, any abx, hospital admissions, new diagnosis of other health problems.
- Expected waiting times, the difference between routine and urgent listing and their waiting times.
- Getting "the call" if at home, getting into the hospital, time frames, managing expectations, communicating with your child, transport.
- Arrival at the hospital, what to expect, tests, consent, who you will meet and the wait.

Education…….The operation

- What if the organ isn't suitable for transplant? Getting home, managing expectations
- Moving to theatre, can the parents come to theatre with the patient? Pre-med, meeting the team.
- Getting put to sleep, pain control and time of operation

The risk

- Kidneys
- Clotting/bleeding
- Primary Graft Dysfunction
- Infection
- Rejection

10% mortality risk in the first 12 months following transplant.

Post Transplant…….

Helpful Pre-Transplant information

- We are working on a new online education tool, with some interactive elements and child friendly information.
- [Home - Organ transplantation - NHS Blood and Transplant (nhsbt.nhs.uk)]

https://i2-prod.gazettelive.co.uk/incoming/article28322260.ece/ALTERNATES/s615/0_JS319941791.jpg

What we need from other centres

- Regular updates, change in circumstances, medical, social and psychological.
- Dental check prior to assessment, time for treatment can often be very long.
- Psychology support locally is required.
- Early referral to help prepare the family for assessment, transplant and future care.
- Realistic expectations from local centres.
- If in doubt, ask.
- Check HLA, help with direction of care.

Pre-Transplant useful Information

Useful contacts

Heart transplant Coordinator contacts:

Alison Davidson – 0191 2139543

Stephanie Dunn – 0191 2139647

Philip Seeley – 0191 2139641

Katherine Doherty – 0191244266

Office - 01912137736

Address

Cardiothoracic Transplant Coordinators Office

Level 4, Institute of Transplant

Freeman Hospital

High Heaton

Newcastle Upon Tyne

NE7 7QN

Email: CT-TX@nhs.net

Useful pre-transplant information

CXR	Social update
Bloods – HLA	Psychology update
Dopplers of neck and groin	6 minute walk test
ECG (possibly 24 hour)	Dietician/ dental report
Up to date images sent to us (CT/Angio/MRI)	

Useful links

Home - Organ transplantation - NHS Blood and Transplant (nhsbt.nhs.uk)

The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Bridging- The waiting game

Transplant Nurse Study day

June 2024

Claire McGraith – Children's Heart Failure and Ventricular Assist Device (VAD) Nurse Specialist

Healthcare at its best
with people at our heart

Aims

Overview of VAD's

Co-morbidity and complications

Waiting times

Family

Active transplant list (2014-2023)

Figure 9.1 Number of paediatric patients on the heart transplant list at 31 March each year, by urgency status

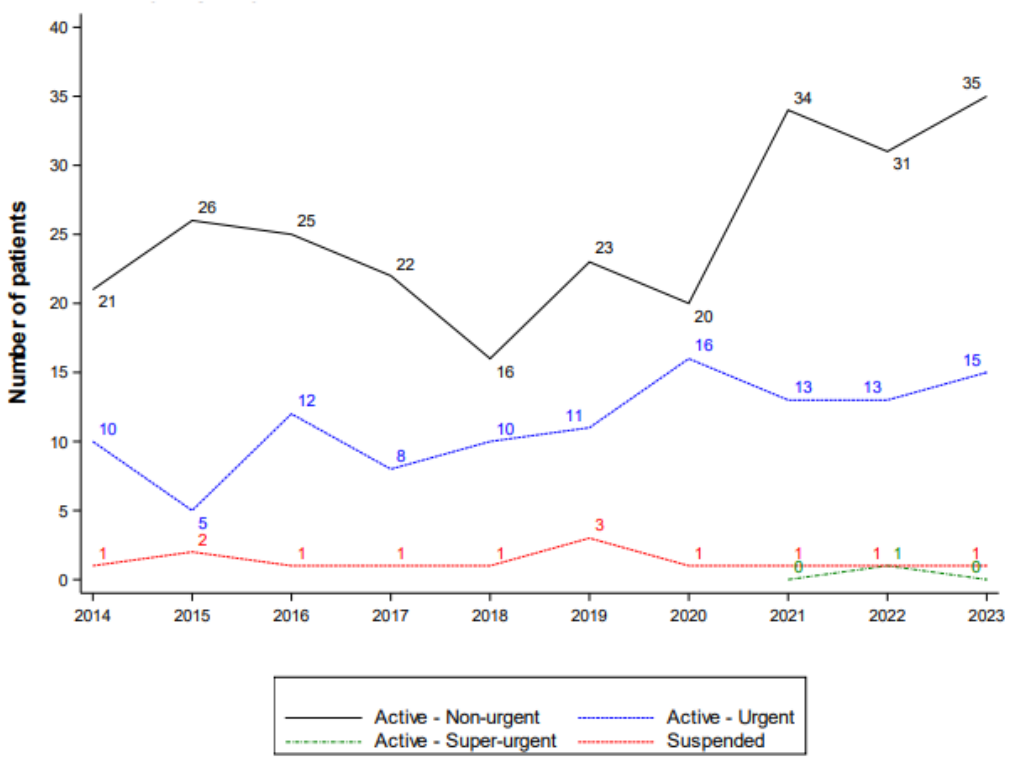


Table 15.2 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency at registration and centre, 1 April 2014 to 31 March 2017

Transplant centre	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Overall			
Great Ormond Street Hospital	70	199	153 - 245
Newcastle	82	106	59 - 153
UK	**152**	**154**	**114 - 194**
Non-urgent at initial registration			
Great Ormond Street Hospital	32	662	202 - 1122
Newcastle	21	176	65 - 287
UK	**53**	**427**	**112 - 742**
Urgent at initial registration			
Great Ormond Street Hospital	38	105	67 - 143
Newcastle	61	77	6 - 148
UK	**99**	**102**	**58 - 146**

Table 9.2 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency at registration and centre, 1 April 2019 to 31 March 2022

Transplant centre	Number registered	Number transplanted	Waiting time (days) Median	95% Confidence interval
Non-urgent at initial registration				
Great Ormond Street[1]	24	9	-	-
Newcastle[1]	24	7	-	-
UK[1]	**48**	**16**	**-**	**-**
Urgent at initial registration				
Great Ormond Street	30	21	237	100 - 374
Newcastle	43	24	191	106 - 276
UK	**73**	**45**	**193**	**128 - 258**

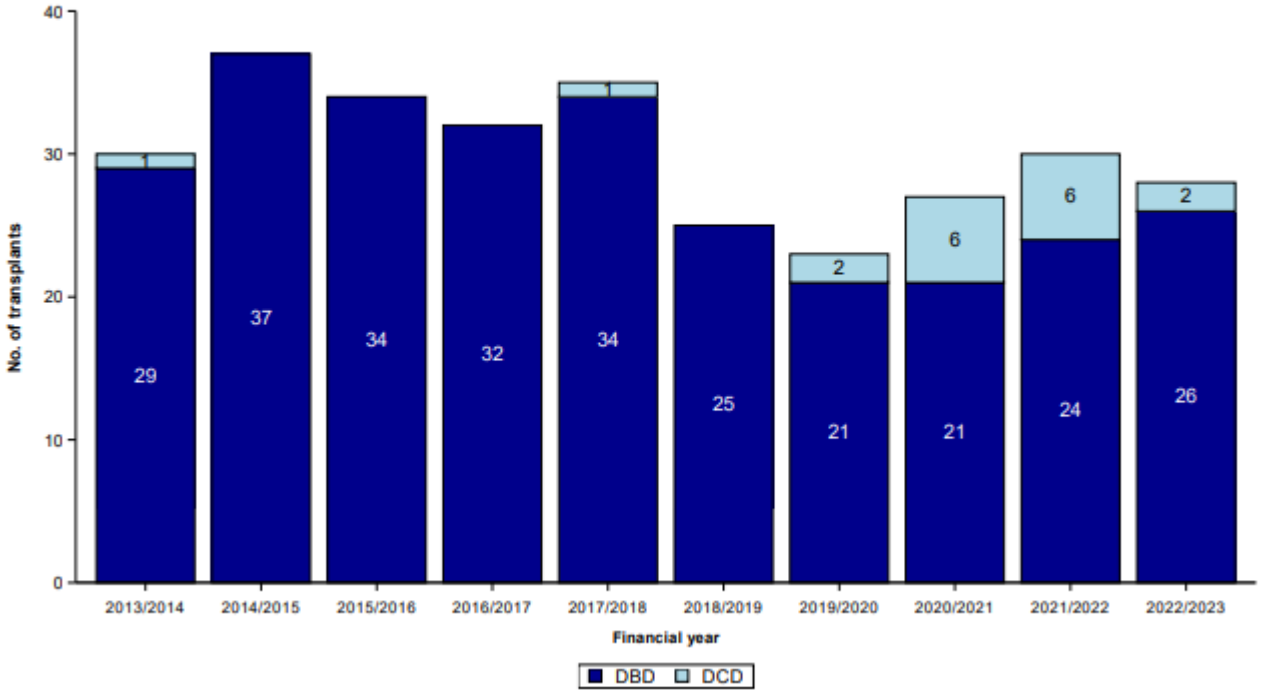
[1] Median and 95% confidence intervals could not be calculated due to low transplant rate

Where do our VAD referrals come from?

Why do patients need a VAD?

47% were mechanically supported on VAD

Figure 11.1 Number of paediatric heart transplants in the UK, by financial year and donor type, 1 April 2013 to 31 March 2023



What types of VAD are available?

Short term VAD

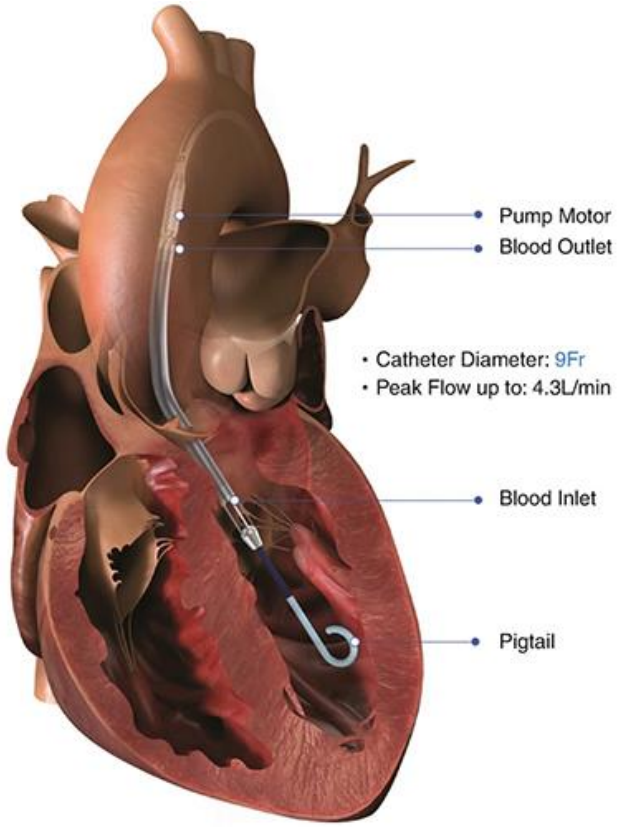
Impella

Support for up to 30 days

Percutaneous/surgical cut-down access

Minimal inflammatory response

Super - urgent listing



Short - medium term VAD

Levitronix (Centrimag)

Short- and medium-term VAD

Continuous flow pump

No oxygenator

Berlin Heart cannulae

Sternotomy and CPB

Stimulates inflammation

Once inflammatory response settles and anticoagulants – change to BH Ventricles

Urgent listing

Long term VAD

Berlin Heart EXCOR

Age age/size

Pulsatile flow

Remain in hospital

Independence

Urgent listing

EXCOR Components

Driving Units

Excor mobile

Blood Pumps

10 ml
25 ml
30 ml
50 ml
60 ml

60 ml
80 ml

Children Infants

Adults

Cannulae

Arterial Cannulae
Diameter from 5 to 12 mn

Atrial Cannulae
Diameter from 5 to 12 mn

Apex Cannulae
Diameter from 5 to 12 mn

Arterial Cannulae
nominal size 12 mm

Atrial Cannulae
nominal size 12 mm

Apex Cannulae

Long term VAD

Heartmate 3

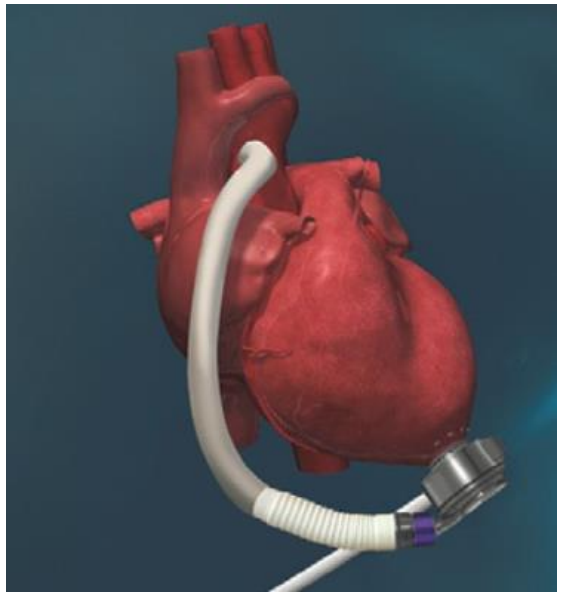
From Approx. 35kgs

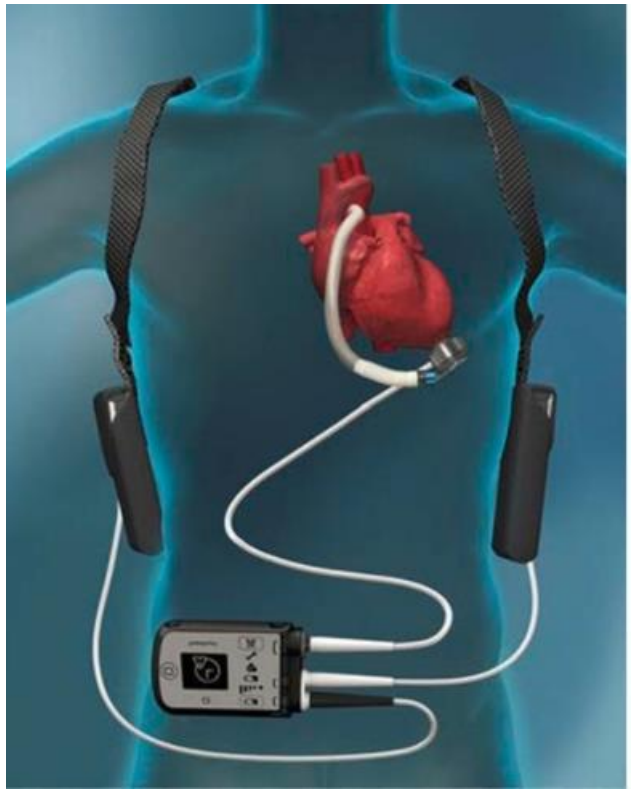
One size fits all

2.5l/min

Discharge home

Routine listing





Co-morbidity and complications

Dialysis

Line sepsis

Arrhythmia

Drug complications

Thromboembolic stroke

NEC/laparotomy

Tracheostomy

Cannula site/driveline infection

RV Failure

Delayed physical development

Intracerebral haemorrhage

Thromboembolism to bowel

Feeding problems

Chest re-opening

Effects on the family

Disruption

Displacement

Separation

Stress

Change

Psychological distress (anxiety/depression)

Loss and Grief

Cabin fever / institutionalisation

Practical strain

Trauma

Uncertainty

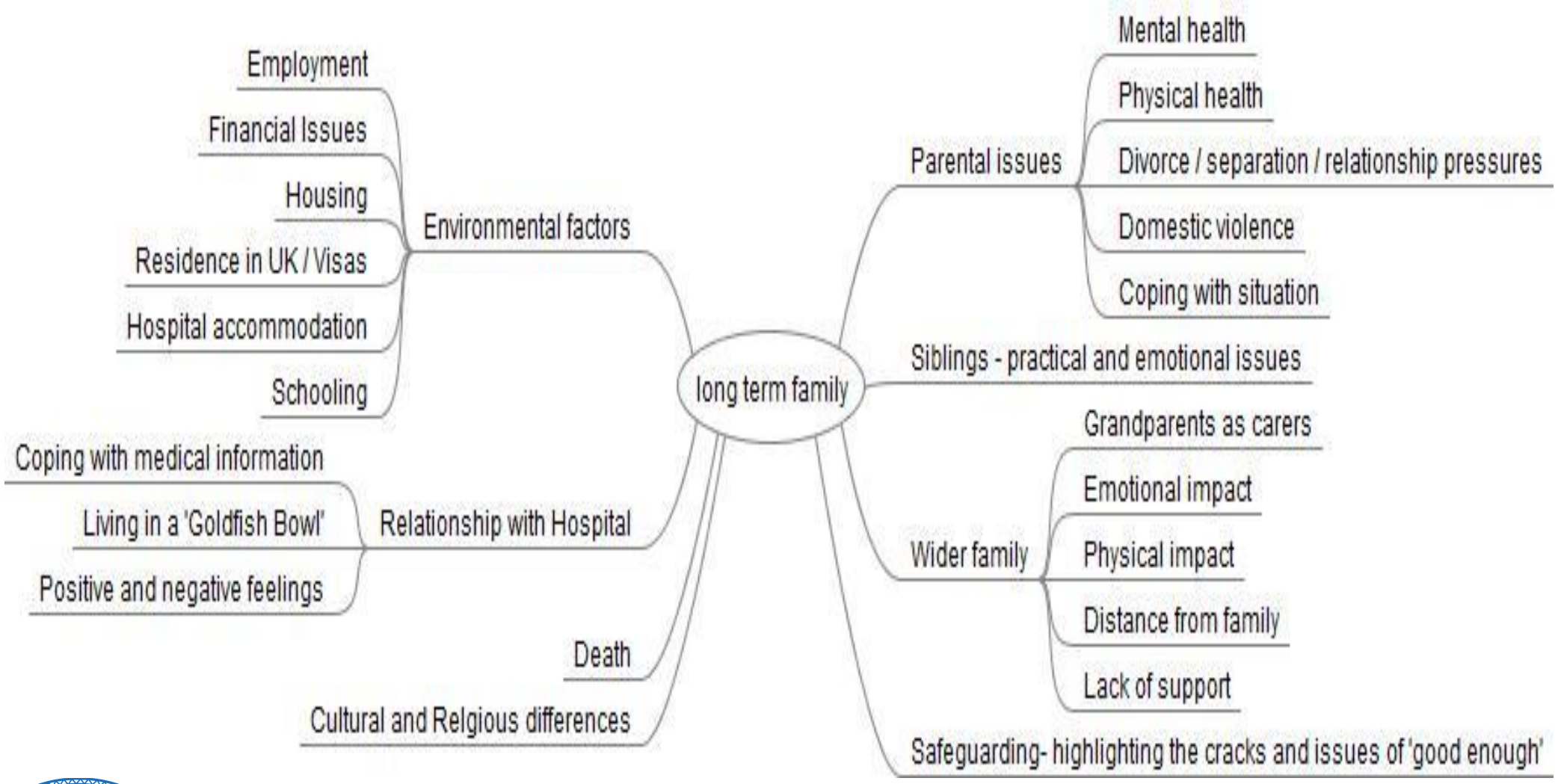
Hope for the future

Denial

Overwhelmed by responsibility of VAD related cares

Beaverment

Financial hardship


long term family
Environmental factors
Employment
Financial Issues
Housing
Residence in UK / Visas
Hospital accommodation
Schooling
Relationship with Hospital
Coping with medical information
Living in a 'Goldfish Bowl'
Positive and negative feelings
Death
Cultural and Relgious differences
Parental issues
Mental health
Physical health
Divorce / separation / relationship pressures
Domestic violence
Coping with situation
Siblings - practical and emotional issues
Wider family
Grandparents as carers
Emotional impact
Physical impact
Distance from family
Lack of support
Safeguarding- highlighting the cracks and issues of 'good enough'


VIVAVIDEO

Conclusion

- Established practice but constantly changing
- Vulnerable group- especially as support times are increasing leading to higher morbidity
- Important to get the care as good as we possibly can
- Goal of mechanical support is not just to bridge but to optimise the patient prior to transplant
- Impacts whole family
- Long waiting times

Any questions

Claire McGraith
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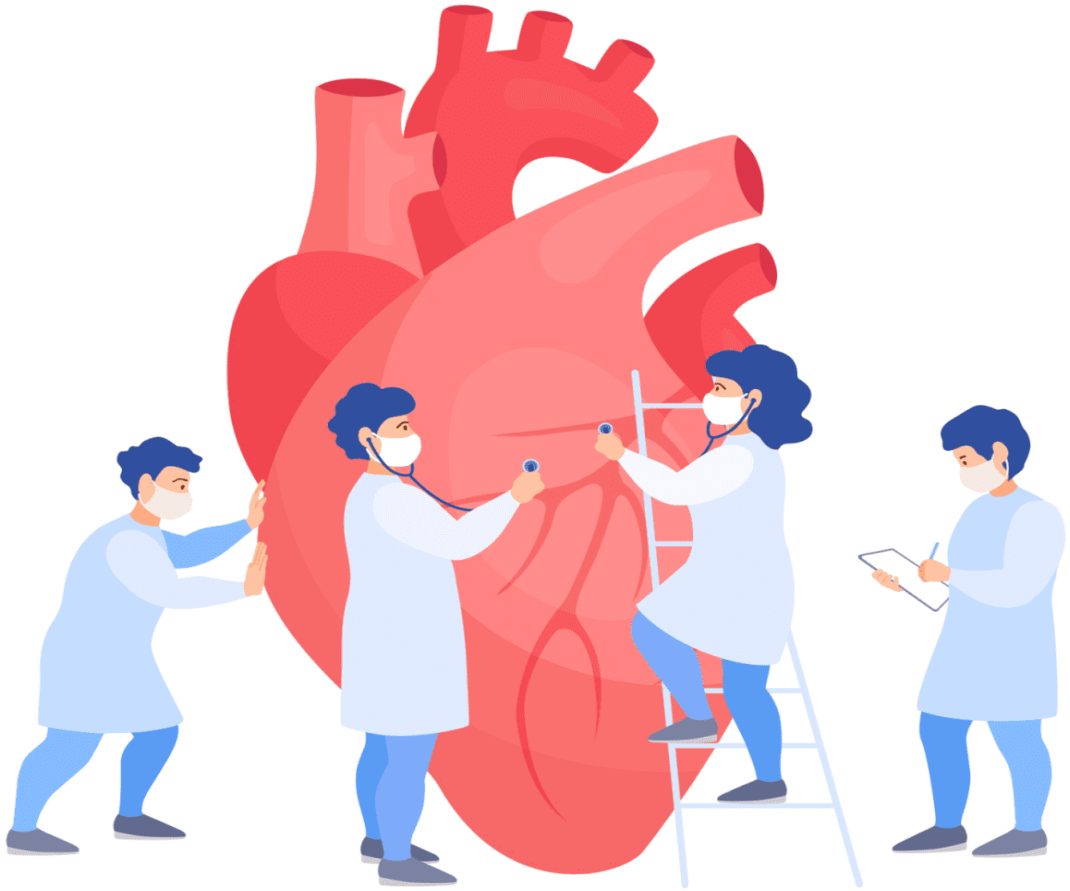
0191 2448961

Paediatric Heart Transplantation

Thirty Days Post Transplant

Iember Ajanaku
Paediatric Heart Failure and Transplantation Fellow
Freeman Hospital, Newcastle upon Tyne
18/06/2024

NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust



…Heart transplant – delivered by the MDT…

Healthcare at its best
with people at our heart

Return from Theatre / PICU

Heart transplant – size, ABO, Rhesus, CMV, EBV match/mismatch

Post operative TOE – ventricular function, anastomoses, pericardial effusion

May return on ECMO – primary graft failure/chest open – size mismatch, bleeding

I&V, drains in situ – mediastinal, pleural

Inotrope/milrinone/vasopressor support, iNO, blood pressure control, pacing wires, blood products

Renal – fluid management, renal replacement therapy

Peri transplant immunosuppression – ciclosporin, azathioprine, rATG/basiliximab, methylprednisolone

Surgical prophylaxis – infection concerns pre op, open chest

Anticoagulation – ECMO/dialysis/stents/vascular thrombosis

PICU

Respiratory support wean - I&V -> NIV -> SVIA, need for tracheostomy/bronchial stents, removal of drains

Haemodynamics – wean of vasopressor & inotropes/milrinone, monitor for acute rejection/post op complications – clinical/ECG/echocardiogram/HLAs/cardiac biopsy, BP control, pacing wires, stents

Renal function – pre-transplant concerns/peri-transplant complications/medications

Immunosuppression: ciclosporin, steroids - methylprednisolone/prednisolone, rATG/basiliximab, azathioprine/MMF

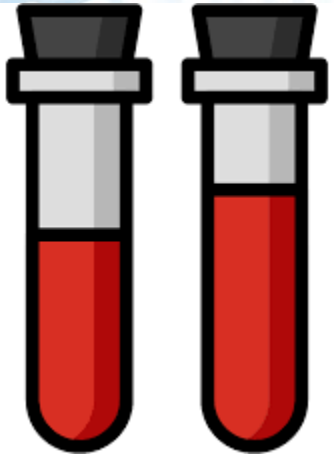
Antihypertensives

Diuretics

Infection prophylaxis – acyclovir, co-trimoxazole

Electrolytes

PICU



Bloods:

Ciclosporin trough levels, U&Es, CRP, LFTs, bone profile, Mg, FBC.

Others –

CD3 counts

Isohaemagglutinins for ABO mismatch

HLAs

Nutrition – enteral/NG/PN

Sedation wean

Physiotherapy

Medications at the time of transplant

Immunosuppression

Induction Therapy

ATG

OR

Basilixumab

Calcineurin Inhibitors

Ciclosporin

OR

Tacrolimus

Cell Inhibitor

Azathioprine

OR

Mycophenolate Mofetil

Steroids

Methylprednisolone

Weaning Prednisolone

Medications at the time of transplant

- **Pre-operative**:
  - **Ciclosporin** 4 mg/kg orally, dose reduced to 2 mg/kg if eGFR 60-90 and omitted if eGFR <60
  - **Azathioprine** 4 mg/kg orally, dose reduced or withheld if WCC or platelet is significantly reduced
  - **Anti-thymocyte globulin (rATG)** 2.5mg/kg IV
    OR Basiliximab (Simulect) 10 mg IV (<35kg) or 20 mg IV (>35 kg)

- **Intra-Operative:**
  - Methyl prednisolone 15 mg/kg IV (max dose 500 mg)

Medications at the time of transplant

Post-Operative:

- **Anti-thymocyte globulin (rATG)** Check CD3 count daily for up to 7 days post transplant, dose given if CD3 >0.05x10^9/l

  OR Basiliximab (Simulect) on the 4th postoperative day
- **Ciclosporin** 1 mg/kg IV over 6 hours every 12 hours, conversion to oral is typically at 3x IV dose
- **Azathioprine** 2 mg/kg daily, aim WCC 4-6 x 10^9/l
- **Methylprednisolone** 3 mg/kg 8 hourly (max dose 125 mg), THREE doses are given
- **Prednisolone maintenance** – protocol differs for different ages, and if there are episodes of rejection

Medications at the time of transplant

Long Term Immunosuppression:

- CNIs (Ciclosporin or Tacrolimus) + metabolic inhibitor (azathioprine or mycophenolate mofetil) unless contraindications
- Steroids given in those with episodes of rejection
- Sirolimus may be used as an adjuvant or substitute for CNIs in poor renal function, CAV, PTLD

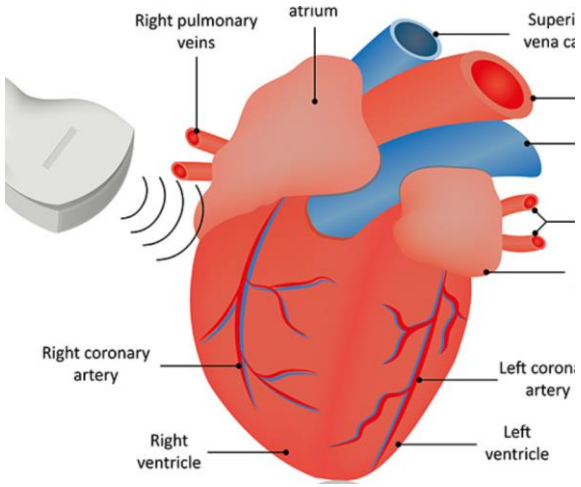
Medications at the time of Transplant

- Infection prophylaxis – aciclovir, co-trimoxazole
- Chlorhexidine mouthwash
- Antihypertensive medications
- Diuretics
- Electrolyte replacement
- Pravastatin in patients > 5 years old
- Anticoagulation – heparin / warfarin / tinzaparin / rivaroxaban / aspirin

Monitoring

- Monitoring for post-transplant complications mainly rejection, infection and renal dysfunction in the 1st 30 days post-transplant.

1. Clinical
2. ECG - arrhythmias
3. Echocardiogram – ventricular function, valvular regurgitation, pericardial effusion
4. Bloods including HLAs
5. Cardiac biopsy
6. Others - isohaemagglutinins, CMV PCR, EBV PCR



Cardiac biopsy

Not routinely done in very young patients <2 years old due to risks of the procedure

15 - 20kg will have 1 biopsy

>20kg will have 2 biopsies

Gold standard for diagnosis of rejection is by biopsy, however also commonly diagnosed by ECHO findings

Usually done within first 3 weeks post-transplant for suitable patients

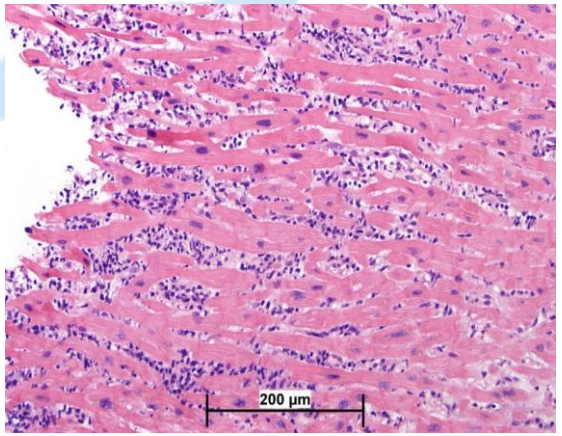
Symptoms - Non-specific/infection/heart failure: fever, tiredness, feeling unwell or irritable, shortness of breath, fluid retention, decreased urine output, abdominal pain, arrhythmia/ECHO changes/effusions

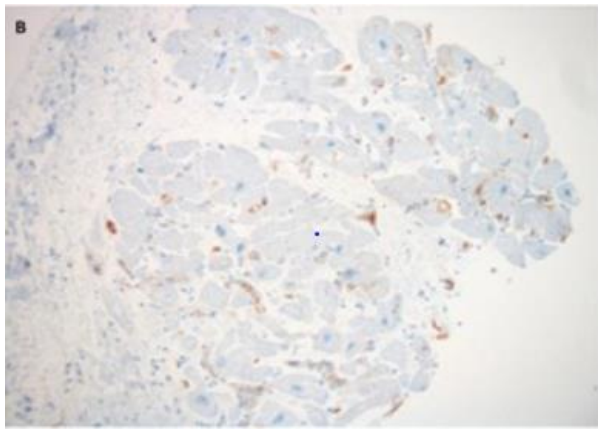
Treatment - IV steroids 10mg/kg once a day for 3 days then high dose oral steroids

Close monitoring and protective isolation during this period

Grading of acute rejection (ISHLT)

ISHLT ACR grading	AMR grading:
0 - No rejection	0 - Negative histologic and immunopathologic findings
1 R, mild - Interstitial and/or perivascular infiltrate with up to one focus of myocyte damage	1 - Presence of positive histologic and immunopathologic findings
2 R, moderate - Two or more foci of infiltrates with associated myocyte damage.	2 - Presence of both histologic and immunopathologic findings
3 R, severe - Diffuse infiltrate with multifocal myocyte damage, with or without edema, hemorrhage, or vasculitis	3 - Presence of severe histologic plus immunopathologic findings





Ward 23

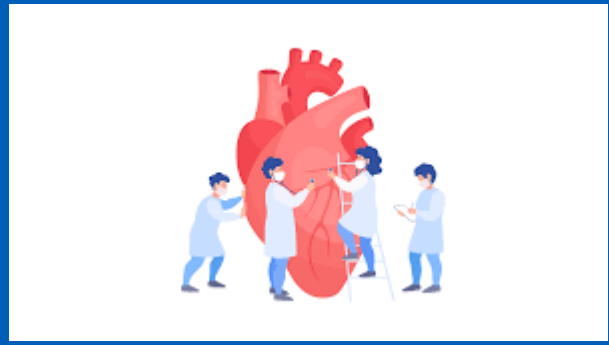
- Normalising the patient as much as possible for discharge -
  - Wean any respiratory support and discontinue if possible
  - Discontinue milrinone, 2nd biopsy, remove pacing wires, adjust antihypertensive medications – reduce number of medications/dose, wean diuretics
  - Commence pravastatin in >5 years if CK is within normal
  - Optimise nutrition
  - Change to oral medications
  - Long term access for home where needed
- Rehabilitation
- Education of patients and family
- Discharge planning - follow up with other specialties for comorbidities, local teams
- Continued vigilance re rejection


obrigado
Dank U
Merci
mahalo
Köszi
спасибо
Grazie
Thank you
mauruuru
Takk
Gracias
Dziękuję
Děkuju
danke
Kiitos

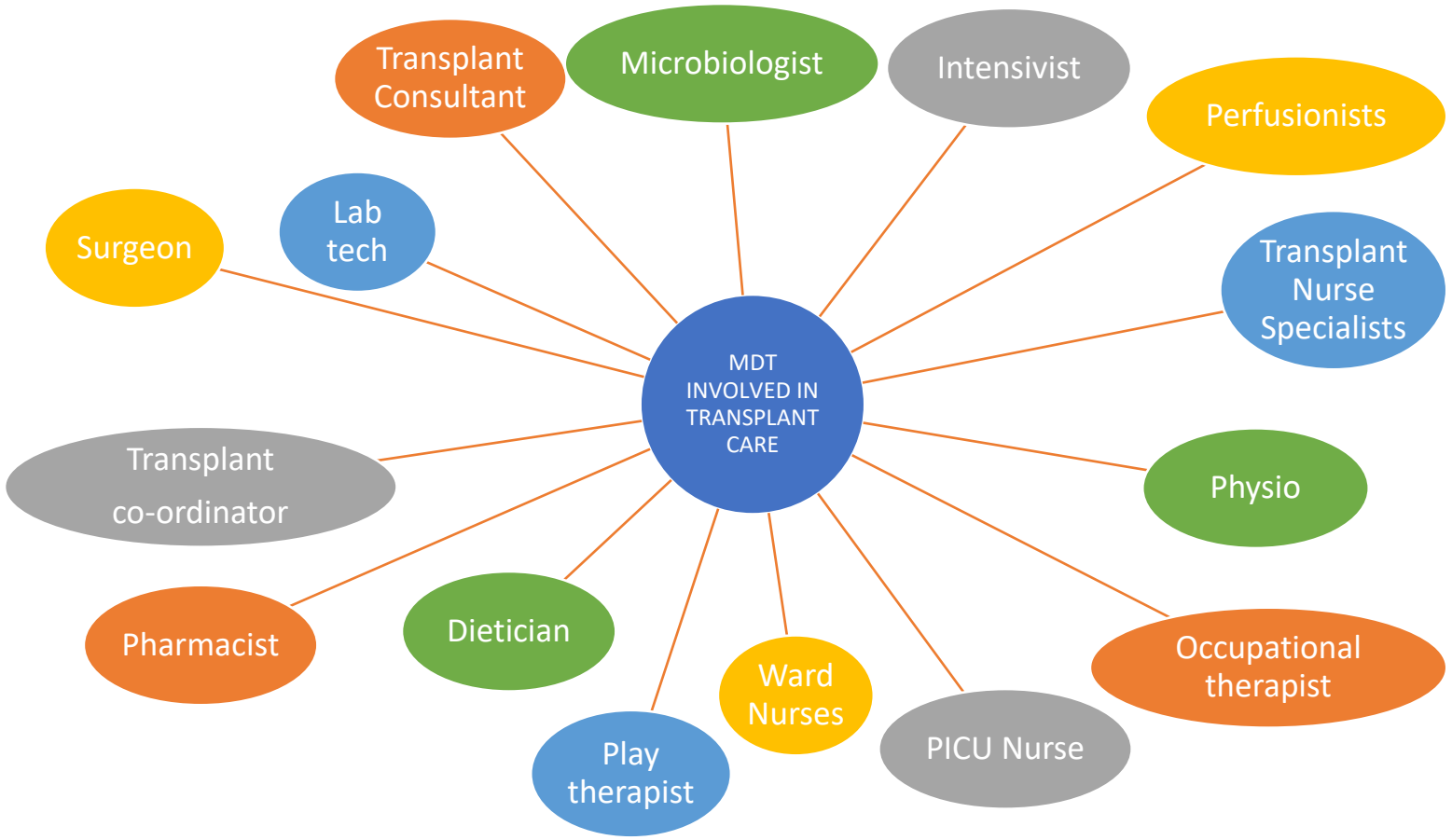
The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Initial 30 days Post Heart Tx

Nursing Considerations



Antonia Philp –
Transplant Specialist Nurse


MDT INVOLVED IN TRANSPLANT CARE
Transplant Consultant
Microbiologist
Intensivist
Perfusionists
Surgeon
Lab tech
Transplant Nurse Specialists
Transplant co-ordinator
Physio
Pharmacist
Dietician
Ward Nurses
Occupational therapist
Play therapist
PICU Nurse

What is the role of the Transplant specialist nurse?

- Supports the patient and their family.
- Link for PICU / ward staff and Doctors regarding all Transplant issues and about blood levels and dosages of Immunosuppression
- Assessment of competency around medication administration and teaching for families
- Liaise with the MDT to help support the family during the hospital admission
- Communication with and education of other healthcare professionals, teams and nursery /school
- Leads discharge planning and coordination of training of the family
- Responsible for ongoing training after discharge
- Provide telephone helpline post discharge

Post Transplant Journey

PICU

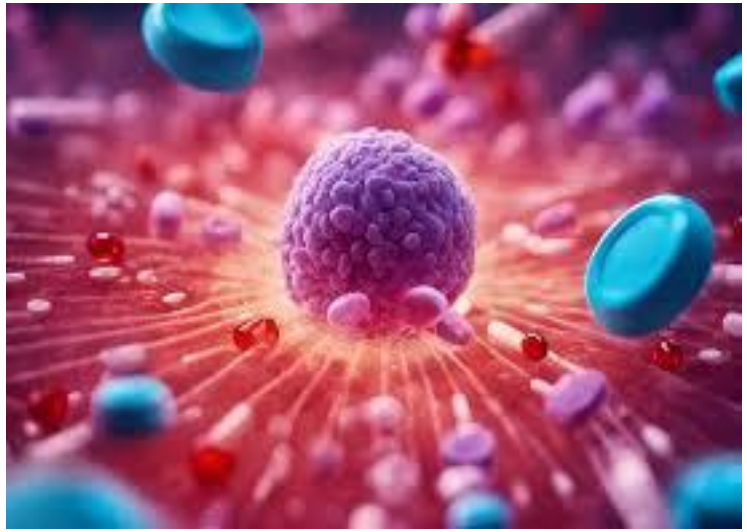
- Variable length of stay and level of support required

HDU / WARD

- Focus on rehabilitation and education
- Discharge planning meetings
- Home from home stay at Scott house pre discharge
- Average length of stay in hospital 4-6 weeks but can be very much longer

Immunosuppressants

- Ciclosporin
- Tacrolimus
- Sirolimus
- Azathioprine
- Mycophenolate mofetil
- Prednisolone



Ciclosporin

- First line immunosuppressant post transplant as available intravenously.
- Given IV until patient is absorbing. Administered over 4 hours
- When the patient is converted to oral Ciclosporin the dose is always given twice a day, 12 hours apart (ideally 8am and 8pm)
- Levels should be taken as trough (i.e. before the next dose)
- When giving IV or NG ciclosporin it must be given by a PVC free giving set
- Please note that IV ciclosporin dose is not the same as oral dose

Tacrolimus

- Second line if ciclosporin is not appropriate.
- Tacrolimus also comes in IV form but our unit tends to not use IV.
- The dose is always given twice a day, 12 hours apart (ideally 8am and 8pm)
- Always ensure the same brand is prescribed
- Check for interactions – ask the ward pharmacist
- Specialist manufactures have different bioavailability
- Generally we use Prograf which comes in strengths of 500 microgram, 1mg & 5mg
- Advagraf can be used in non - compliance / issues with levels

Azathioprine

- Generally all patients start on Azathioprine post transplant once tolerating enteral diet
- Works on the B cells and T cells.
- Azathioprine is cytotoxic
- Also available in oral suspension 50mg/5ml
- Injections where possible should be made in pharmacy
- Tablets should not be crushed or halved – use liquid instead

Mycophenolate Mofetil

- Classed as an antimetabolite working by interfering with how white cells reproduce and function.
- Patients who are unable to tolerate azathioprine use MMF
- MMF is used in combination with other drugs in desensitization therapy for high HLA's
- There is potential to be changed to myfortic to reduce gastric side effects

Sirolimus

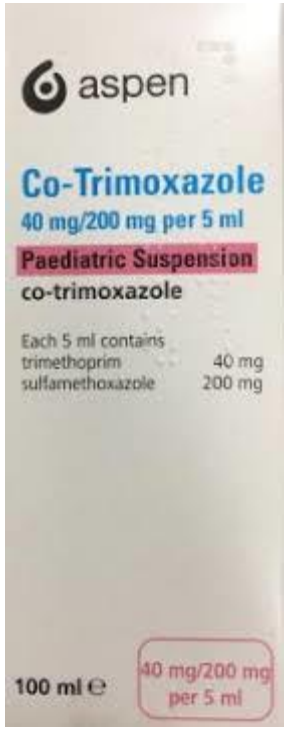
- Also an immunosuppressant
- Allows the reduction of ciclosporin/tacrolimus required if patients have poor renal function
- Potentially prevents worsening coronary artery disease
- Always give in the morning
- Oral solution should be stored in the fridge
- Clearance may be reduced in poor renal function
- Not to be given with patients allergic to peanuts and soya.

Steroids

- We have different regimes depending upon the age of the child.
- Young children (less than 5) don't get steroids routinely as this can affect their growth
- High dose of IV Methylprednisalone is given as treatment for rejection
- May change depending on rejection and renal function
- Always should be given in the morning.

Antivirals / Antibacterials

- Aciclovir should always be given for at least 3 months post heart transplant to prevent viral infection
- If over 2yrs – 400mg TDS, under 2yrs 200mg TDS, or if under 1yrs 100mg TDS but dose should be reduced in poor renal function
- Co-Trimoxazole is also given alongside Aciclovir for prevention of bacterial infections.
- Chlorhexidine mouth wash – 5mls-10mls twice a day to prevent mouth infections (alcohol free is available)



Bloods

- **Ciclosporin level -**
  - this needs to be taken pre the morning dose (trough level) and goes in an EDTA bottle.
  - We ask that the transplant team are informed if patient has any vomiting or diarroah and if any repeat dosages have been given.
  - Do not take the level from any line that has had Ciclosporin administered through it
  - Order test just before the Ciclosporin level is taken and not the evening before, and please get to labs as soon as you can.

- **Tacrolimus Level -**
  - this needs to be taken pre the morning dose (trough level) and goes in an EDTA bottle.
  - We ask that the transplant team know if patient has any vomiting or diarroah and if any repeat dosages have been given.
  - Order test just before the Tacrolimus level is taken and not the evening before, and please get to labs as soon as you can.

Isolation

- Patients should have limited contacts immediately post transplant as patients require protective isolation.
- Initially the patient should have their cubicle **door closed** which is usually for around 1 week or until biopsy results are known.
- When **door closed** the only visitors allowed are the Parents
- Once **door open** the patient is allowed parents and siblings **plus 4 nominated family/friends**.
- Full visiting policy for ward and home is available from the Transplant team.

Rehabilitation

- Comorbidities
- Education

  - patient and family
- Physiotherapy / Occupational therapy
- Lines / Feeding tubes etc.
- Early discharge planning
- Phased discharge
- Local teams essential

Physiotherapy post Transplant

Initiate movement asap to get the new heart pumping → What was the patients previous baseline → How can they manage in their own environment → Advice is given around app ropriate exercise and activities

Boredom is not allowed!

- Play team
- Clown doctors
- Daily activities planned
- Motivation through daily routines
- Schooling
- Music group
- Playroom booked out for transplant patient and their family when allowed , sensory room

Social workers

- Meet at time of assessment
- Identify any issues with housing / ability to keep up with mortgage payments / rental payment if parent is not working for a while
- Supporting letters for charitable funds
- Sibling support such as Rainbow trust, helping sort out school places as families often temporarily relocate
- Applying for assylum
- Contacting employers
- Psychological referrals
- A friendly face

Early Psychosocial needs

- History of the heart failure condition
- Sudden onset/congenital
- Impact of shock and grief
- Initial psychological trauma care
- Relocation/disorientation
- Lack of usual support
- Practical issues – finance, accommodation, other sibs, PR, safeguarding

After Transplant Psychosocial

- Time to process
- PTSD
- Parenting/resuming normal life
- Picking up the pieces of life eg work, siblings, friendships
- Living with ‘on going’ threat
- Education, work, finances, travel, relationships, re-evaluating goals and beliefs

General information

- Transplant patients should be isolated in a cubicle where possible. This can be discussed in certain circumstances.
- Bottled water should be used (only in hospital) or from the filtered fonts within hospitals
- Baths should be ran and left to stand for 10 minutes prior to use. (only in hospital)
- Transplant patients are **not to have grapefruit** as it affects absorption of medication, this includes soft drinks such as Lilt.
- Patients will be isolated after discharge until 12 weeks post transplant (not discharge).
- Visitors to the house should be limited until this time.
- Patients can return to school after 12 weeks.
- Home schooling should be arranged prior to discharge.
- Transport to clinic can be arranged during the first 12 weeks but will no longer be available after 12 weeks post transplant

Scott House home from home

- Family accommodation
- Transplant flat
- Open spaces to allow families to socialise
- Washing / drying facilities
- Support and interaction from staff members

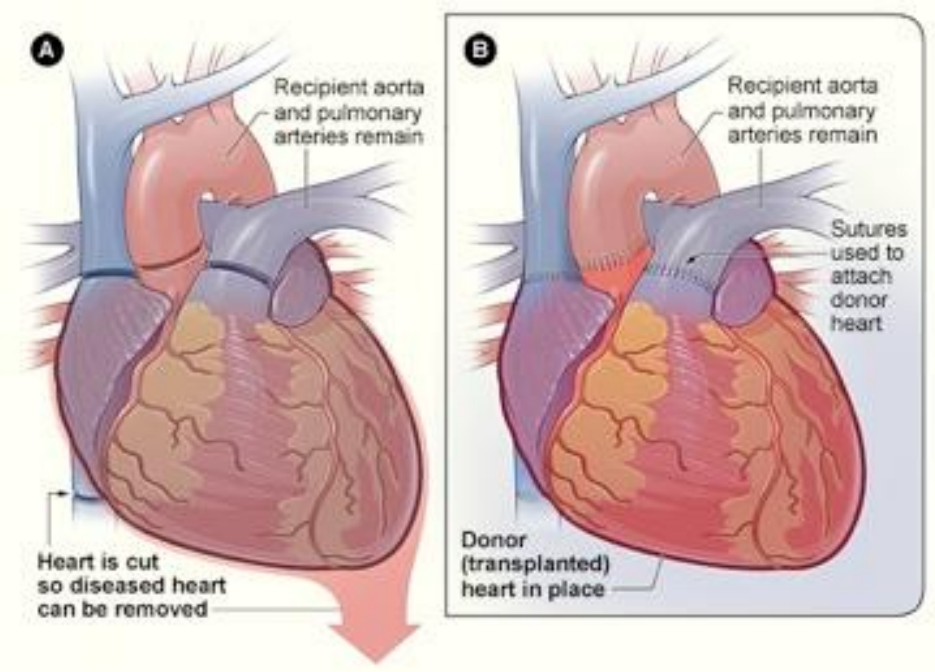
The Sick Children's Trust
We're here, so families can be together

CHUF
Children's Heart Unit Fund


Cubicle 3

Thank you for listening. Please feel free to ask any questions in the Teams chat.

Paediatric Cardiac Transplantation Complications & Long-term Outcomes



Abbas Khushnood

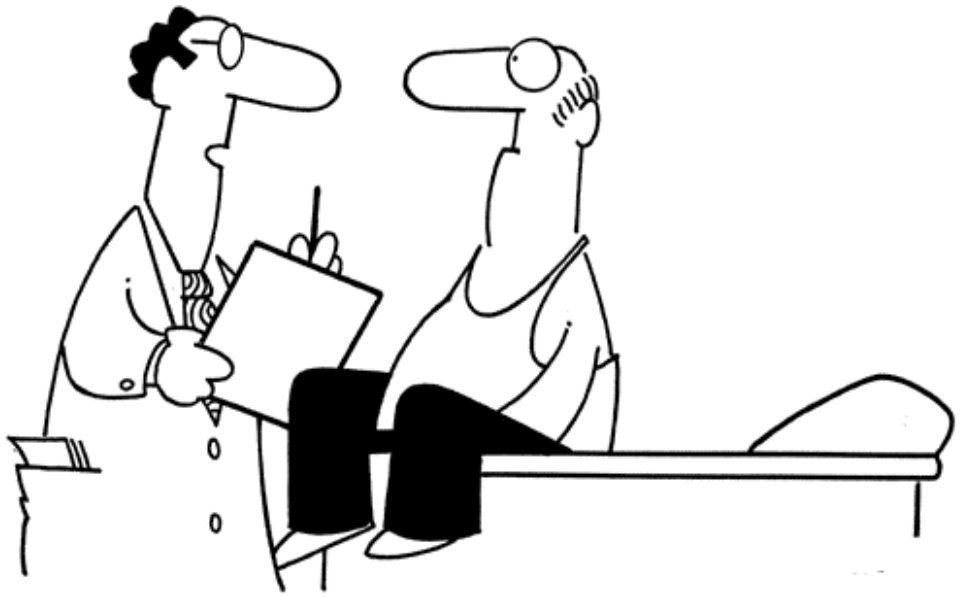
Consultant Paediatric Cardiologist

& Transplant Physician

Freeman Hospital, Newcastle

18.06.24

No disclosures



**"The good news is, you have a healthy heart.
The bad news is, it's in someone else's chest right now."**

Post-transplant course

Survival & Complications

Cardiac: Rejection/Infection/CAV/PTLD

Non-cardiac: Renal/Hypertension/Diabetes

Compliance & Transition

Re-transplantation

Transplant Journey

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Pre-Transplant Period

(Assessment)

- Planned vs. Acute

Transplantation ⟷ MCS - VAD

Post-Transplant Period

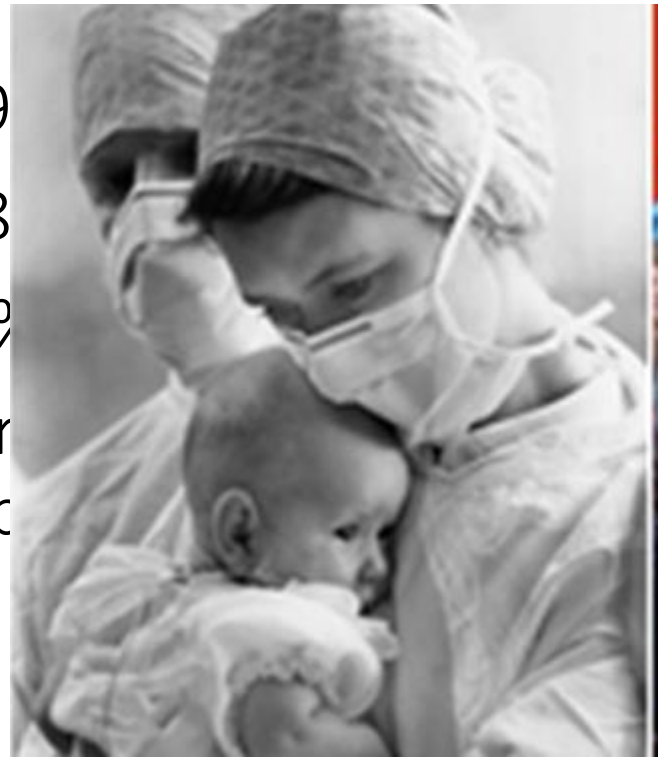
- Immediate
- Pre-discharge/Meds
- Clinics
- Surveillance
- Complications
- Transition

Survival

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Average heart 15-20 years

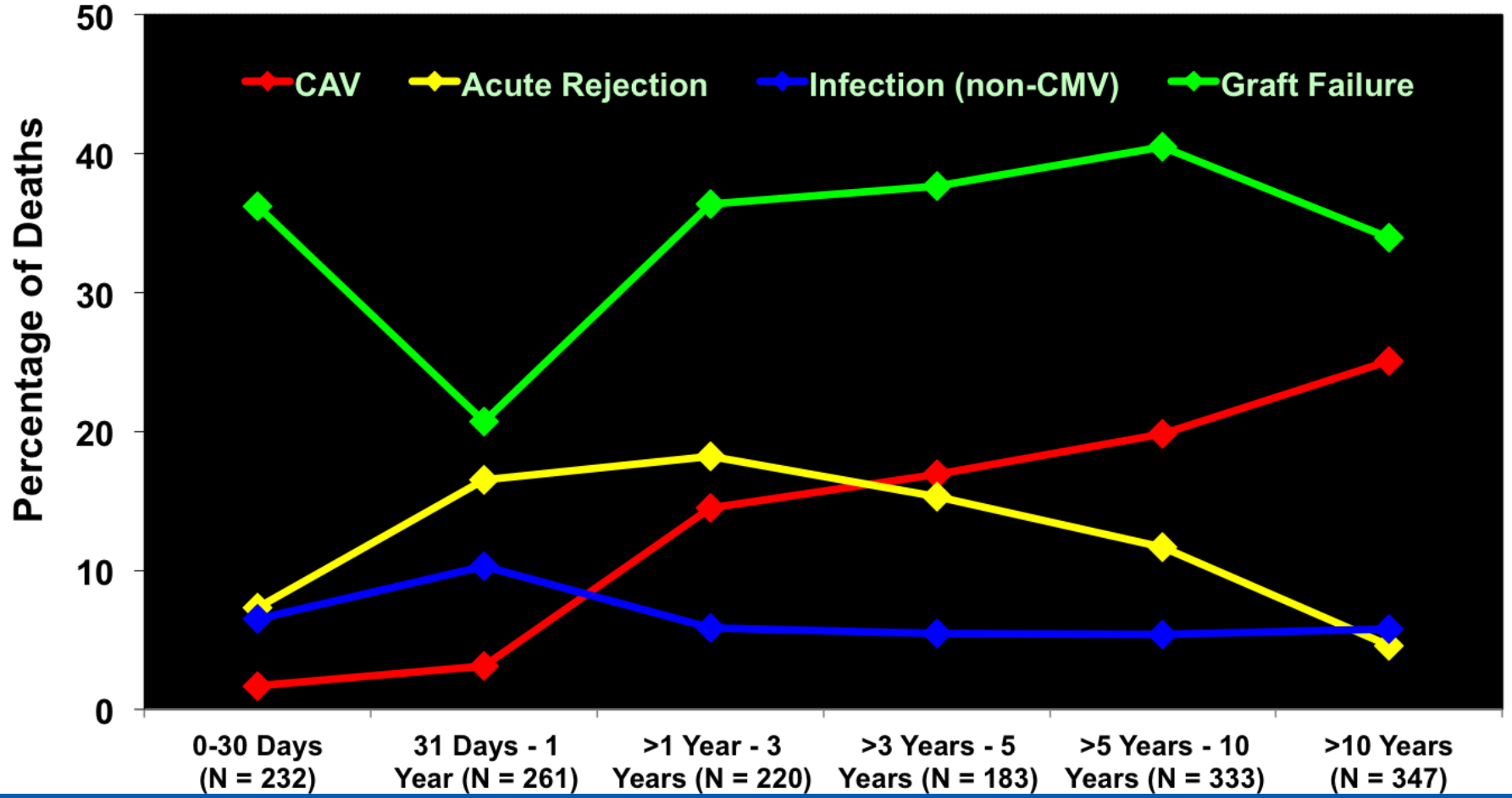
- 85-9
- 75-8
- >70%
- Impr
  recip



Kaplan-Meier Survival Conditional on Survival to 1 Year
(Transplants: January 1982 – June 2016)

JHLT. 2018 Oct; 37(10): 1155-1206

Complications



JHLT. 2015 Oct; 34(10): 1233-1243

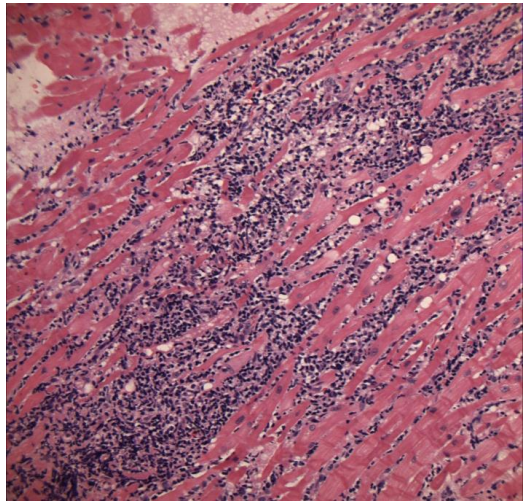
Rejection

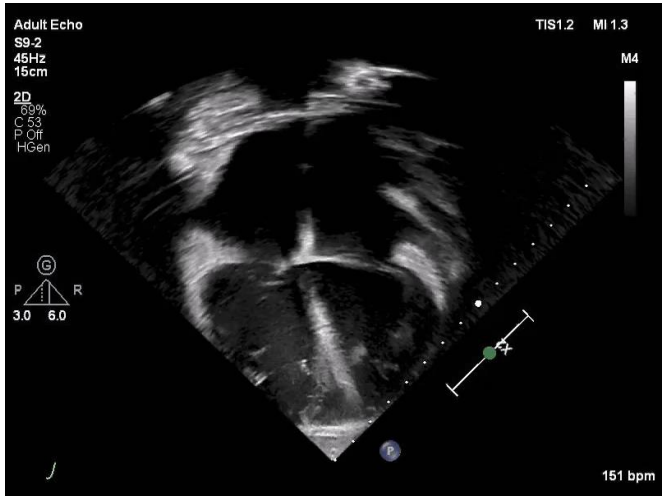
The Newcastle upon Tyne Hospitals NHS Foundation Trust

- Malaise, Fever, Arrhythmia, Collapse
- Echo: Thickened walls. Decreased FS/EF, new MR, effusions
- Antibodies
- Imaging
- Biomarkers

Acute

Chronic





Dipchand AI, Kirk R, Edwards LB, et al. The Registry of the International Society for Heart and Lung Transplantation: Sixteenth Official Pediatric Heart Transplantation Report--2013; focus theme: age. J Heart Lung Transplant 013;32:979-88.

Graft Rejection

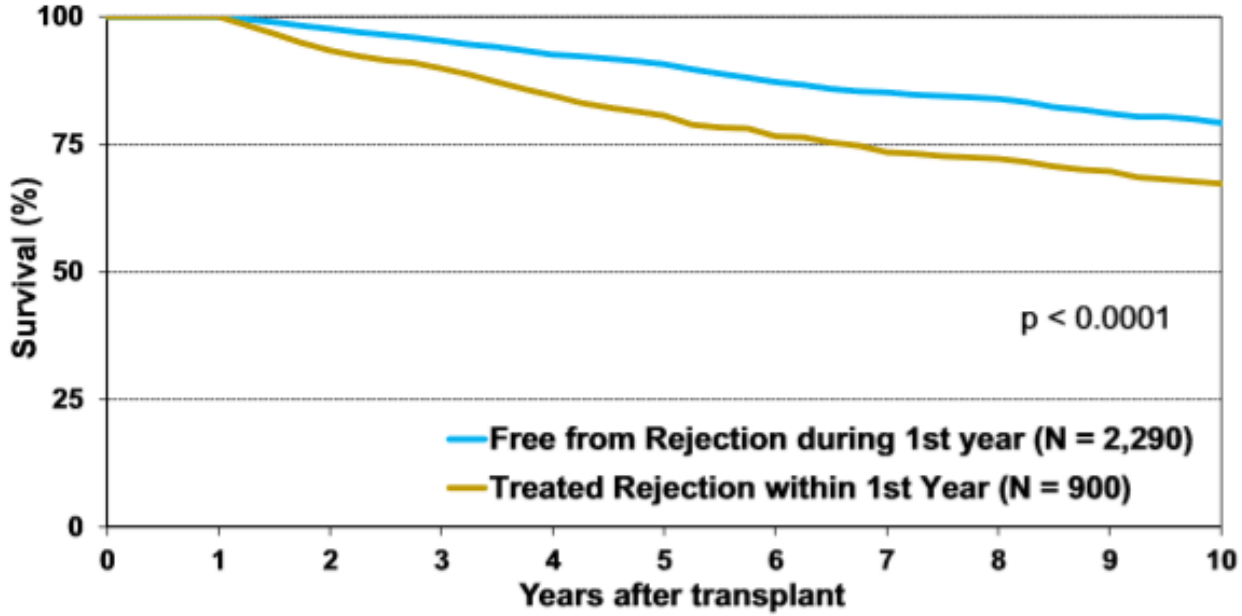
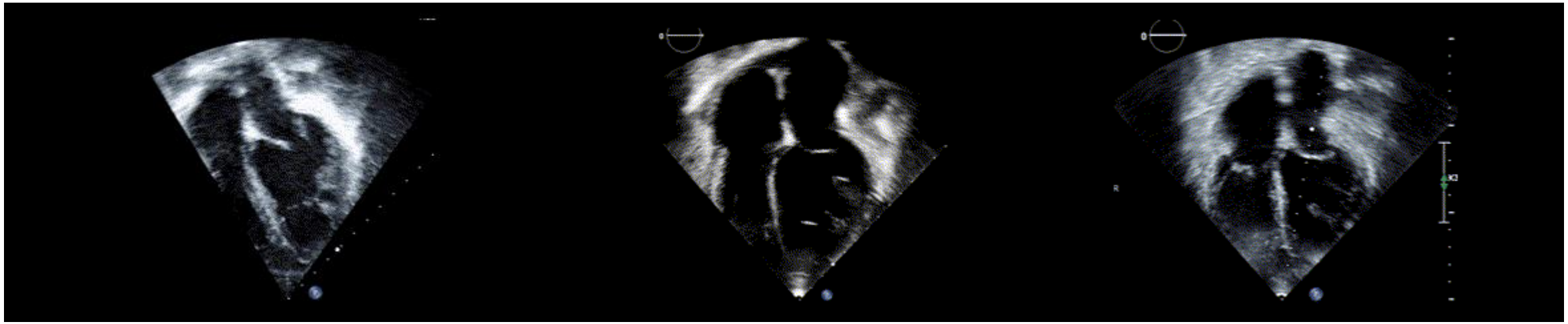


Figure 14 Kaplan–Meier survival based on treated rejection within the first year, conditional on survival to 1 year (1-year follow-ups: July 2004 to June 2015). Treated rejection—recipient was reported to: (1) have at least 1 acute rejection episode that was treated with an anti-rejection agent; or (2) have been hospitalized for rejection. No rejection—recipient had: (1) no acute rejection episodes; and (2) was reported either as not hospitalized for rejection or did not receive anti-rejection agents.

Endomyocardial Biopsy

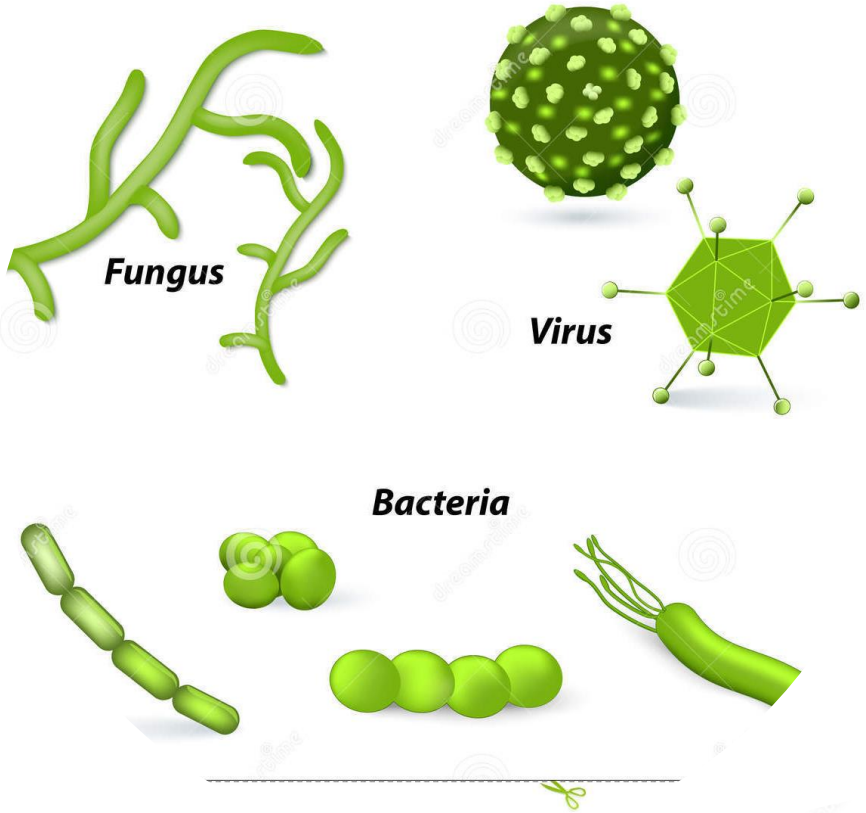
Rossano et al. ISHLT 20th Pediatric Heart Transplant Report

Acute Graft Rejection



PTx 6 yrs → Rejection → Post Rx

Infection



Usual ‘routine’ infections

Unusual ‘pathogens’

Try not to treat ‘blind’

Prophylaxis for ‘other’ surgery

Dipchand AI, Kirk R, Edwards LB, et al. The Registry of the International Society for Heart and Lung Transplantation: Sixteenth Official Pediatric Heart Transplantation Report--2013; focus theme: age. J Heart Lung Transplant 013;32:979-88.

Infection

Table I. Types and number of severe infections in the infant and older heart transplant recipients groups during the observation period of the study

	Infant recipients	Older recipients
Pneumonia	23	1
Bacteremia	2	1
Viral respiratory infection	5	0
Gastroenteritis	3	3
Sinusitis	5	0
Parvovirus	3	1
Osteomyelitis	2	0
Others	6	3
Total	49	9

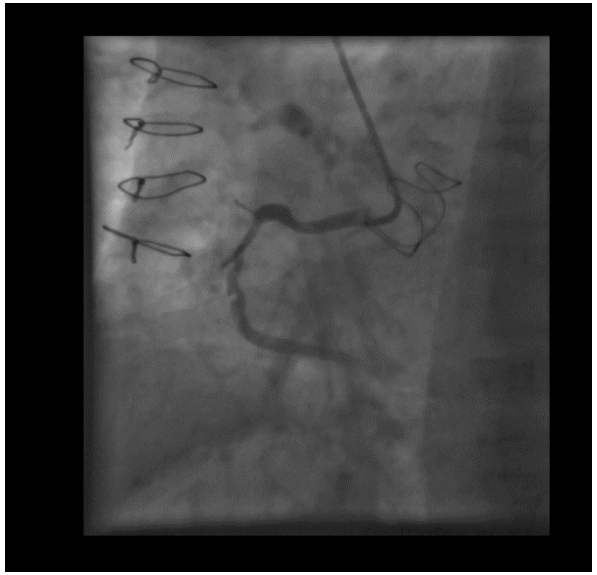
Table II. Types of chronic/recurrent infections and numbers of years with chronic/recurrent infections in the infant and older heart transplant recipients groups during the observation period of the study

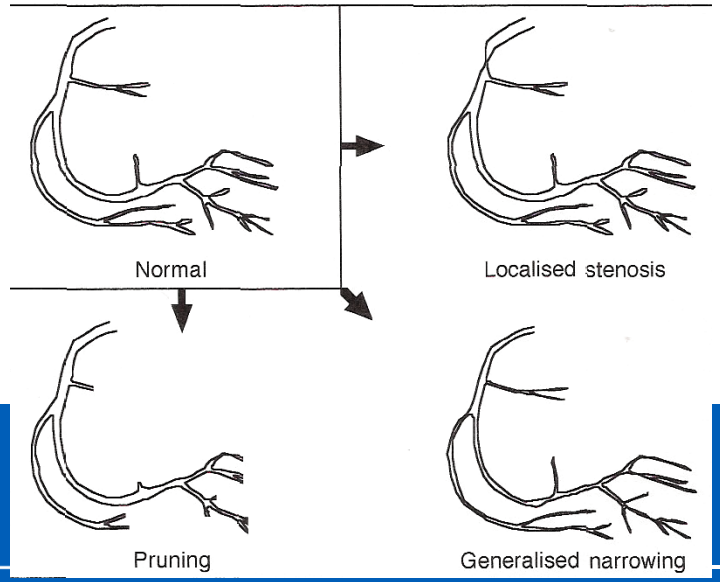
	Infant recipients	Older recipients
Sinusitis	34	4
Otitis media	14	2
Otitis externa	2	1
Tonsillitis	3	1
Pneumonia	18	0
Urinary tract infection	1	4
Verruca/molluscum	23	6
Others	7	1
Total	102	19

doi:10.1016/j.jpeds.2007.10.018

Coronary Allograft Vasculopathy (CAV)

- Inflammatory response to immune or nonimmune-mediated endothelial damage
- Characterized by the release of inflammatory cytokines, upregulation of cell-surface adhesion molecules, and the subsequent binding of leukocytes
- Once induced, vascular smooth muscle cells proliferate and migrate from the media to form a neointima





Causes of CAV

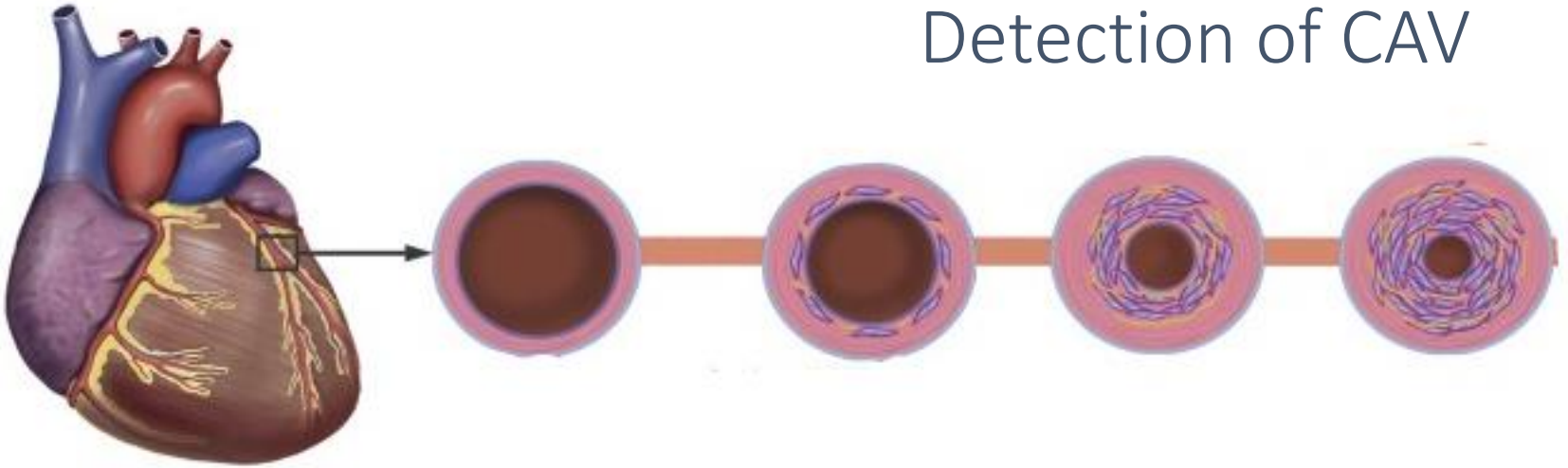
Injury before/at transplantation

- Donor risk factors
- Explosive brain death v anoxia
- Age of donor
- Smoking

Injury after transplantation

- Rejection
- Hyperlipidaemia
- CMV

Detection of CAV



DENERVATION - 'NO' ANGINA/CHEST PAIN

SURVEILLANCE

ANATOMICAL - ANGIOGRAPHY/CT/MRI/IVUS

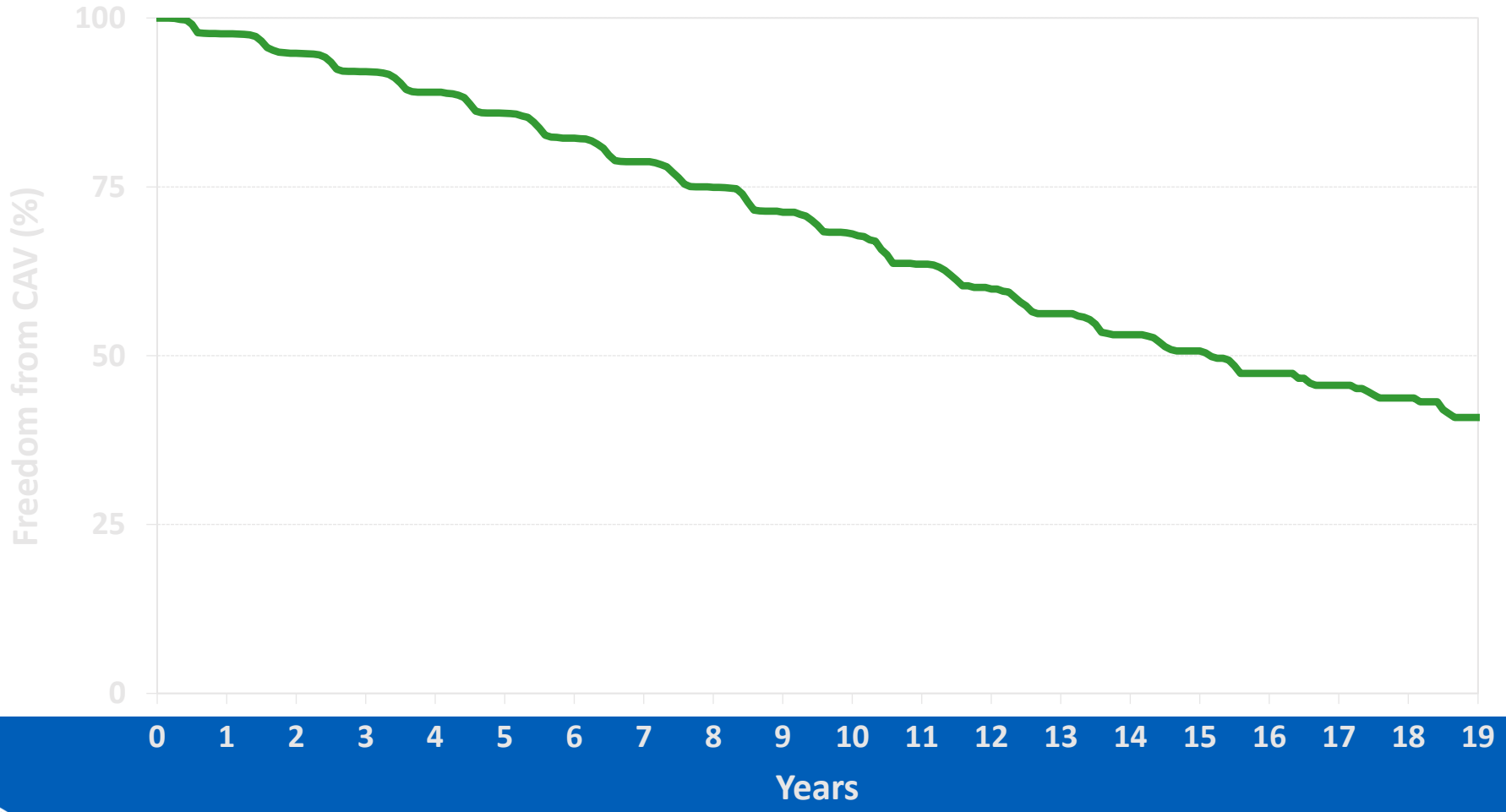
FUNCTIONAL - PERFUSION

STRESS RADIONUCLIDE IMAGING

STRESS ECHO

Freedom from Cardiac Allograft Vasculopathy

(Transplants: January 1994 – June 2016)



Prevention/treatment of CAV

Better preservation? (live donors)

Immunosuppression

- Mycophenolate mofetil
- Sirolimus/everolimus
- Cyclosporin/tacrolimus

Statins

PCI

Retransplant

Post-Transplant Lymphoproliferative Disorder (PTLD) - Malignancy

- Abnormal proliferation of lymphomatous tissue induced by immunosuppression
- Usually B cell
- Usually EBV driven (pre-transplant EBV -ve risky)
- Spectrum from hyperplasia to high grade malignancy

Webber SA, Naftel DC, Fricker FJ, et al. Lymphoproliferative disorders after paediatric heart transplantation: a multi-institutional study. Lancet 2006;367:233-9.
Schubert S, Renner C, Hammer M, et al. Relationship of immunosuppression to Epstein-Barr viral load and lymphoproliferative disease in pediatric heart transplant patients. J Heart Lung Transplant 2008;27:100-5.

Management of PTLD

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Reduce immunosuppression

- Stop azathioprine (? MMF)
- Gradually reduce Ciclo/tacro
- ? Increase steroids

→ Monitor graft function and rejection status

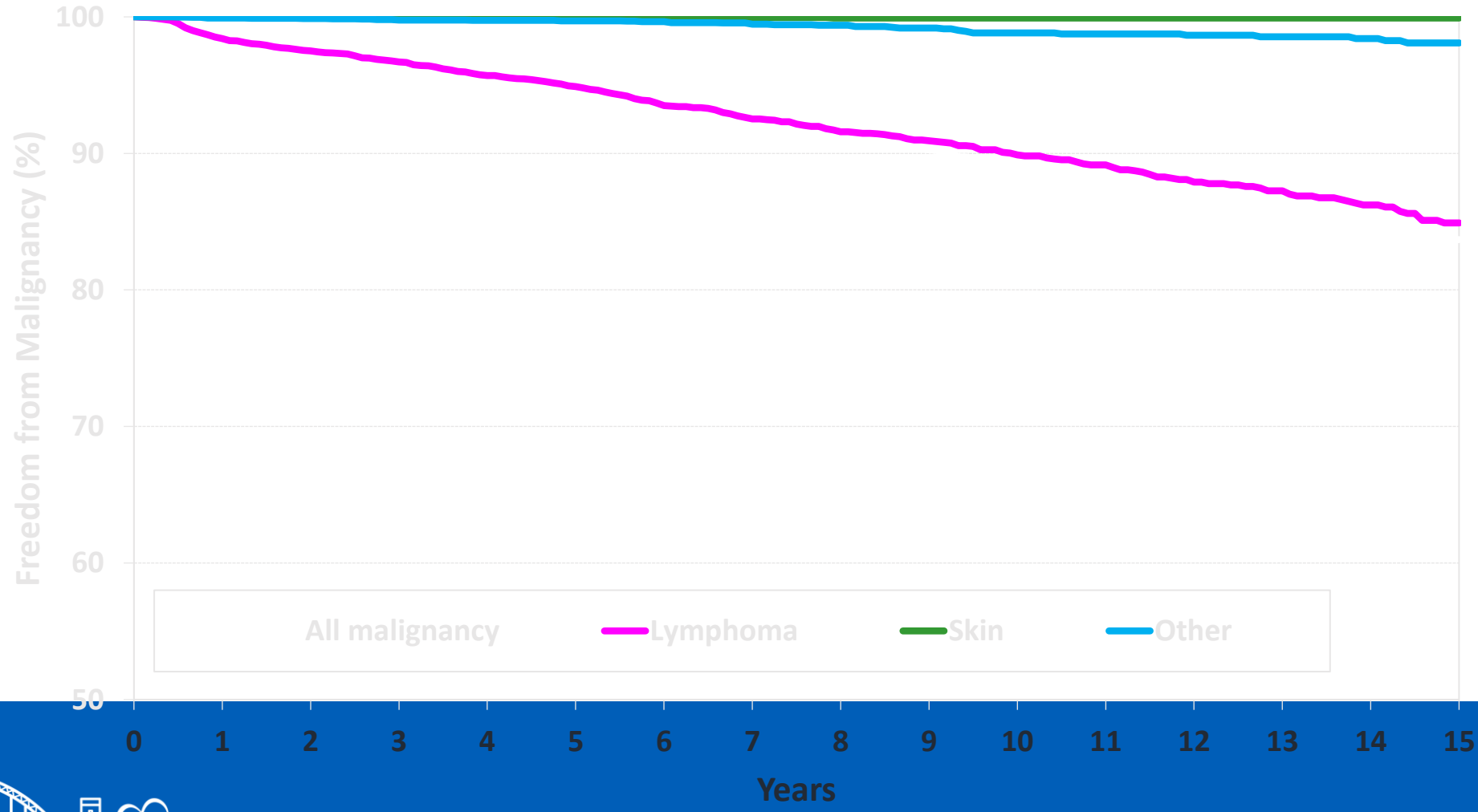
Monitor disease size and extent

Rituximab
(CD20 +ve cells)

Chemotherapy

Dipchand AI, Kirk R, Edwards LB, et al. The Registry of the International Society for Heart and Lung Transplantation: Sixteenth Official Pediatric Heart Transplantation Report--2013; focus theme: age. J Heart Lung Transplant 2013;32:979-8
Webber SA, Naftel DC, Fricker FJ, et al. Lymphoproliferative disorders after paediatric heart transplantation: a multi-institutional study. Lancet 2006;367:233-9.

Freedom from Malignancy (Transplants: January 1994 - June 2016)

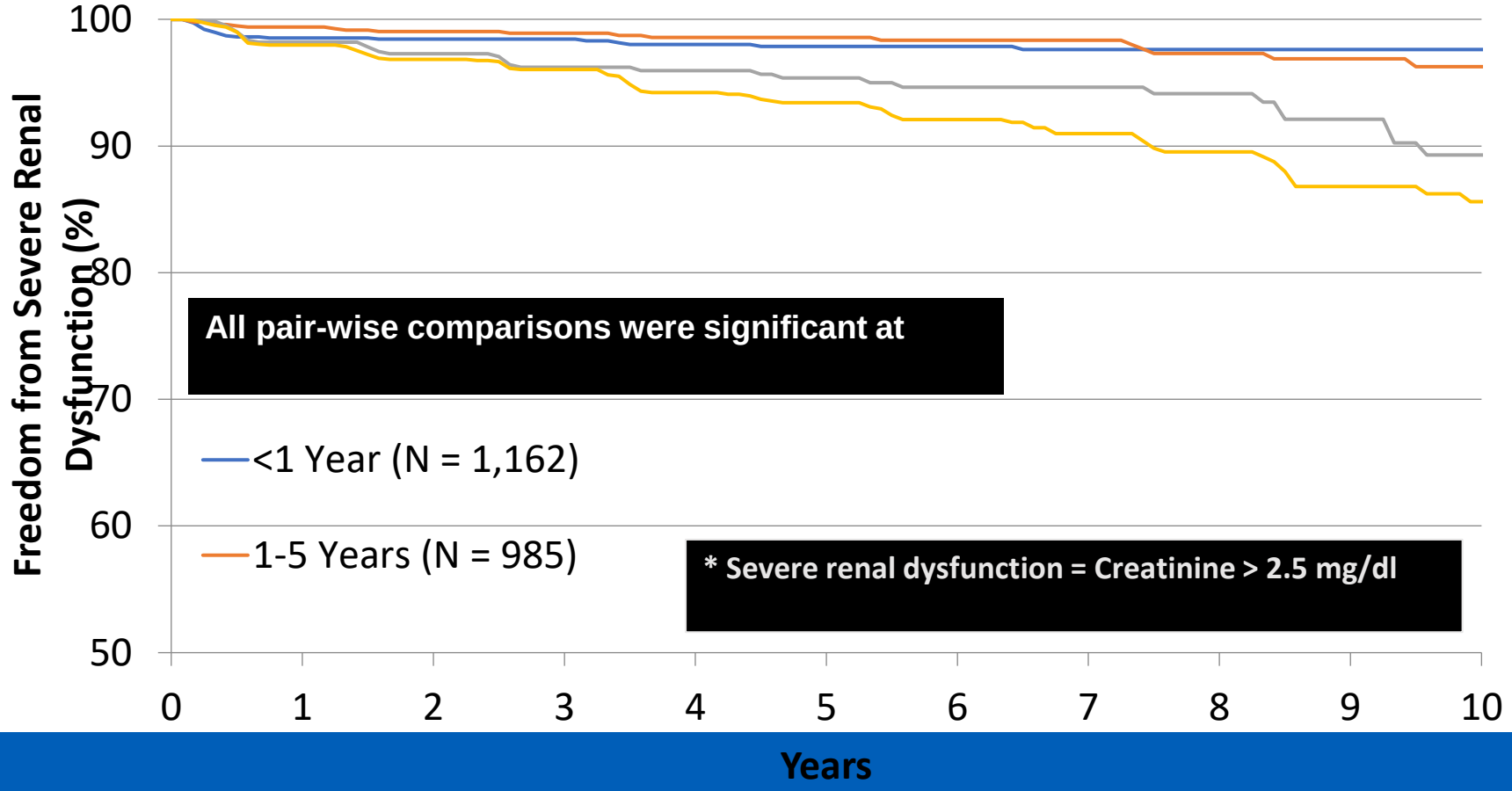


ISHLT • INTERNATIONAL SOCIETY FOR HEART AND LUNG TRANSPLANTATION
2018
JHLT. 2018 Oct; 37(10): 1155-1206

Kidney dysfunction

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Freedom from Severe Renal Dysfunction* by Age Group (Transplants: January 2004 – June 2016)



Healthcare at its best with people at our heart

ISHLT 2018
ISHLT • INTERNATIONAL SOCIETY FOR HEART AND LUNG TRANSPLANTATION

JHLT. 2018 Oct; 37(10): 1155-1206

CARDIOTHORACIC TRANSPLANTATION|_VOLUME 147, ISSUE 1, P456-461.E1, JANUARY 01, 2014

Combined heart-kidney transplant improves post-transplant survival compared with isolated heart transplant in recipients with reduced glomerular filtration rate: Analysis of 593 combined heart-kidney transplants from the United Network Organ Sharing Database

Tara Karamlou, MD , Karl F. Welke, MD D. Michael McMullan, MD James M. Mudd, MD Matthew S. Slater, MD Howard K. Song, MD

PEDIATRIC TRANSPLANTATION
The Official Journal of the International Pediatric Transplant Association

ORIGINAL ARTICLE

Long-term outcomes of simultaneous heart and kidney transplantation in pediatric recipients

Weng, PL, Alejos, JC, Halnon, N, Zhang, Q, Reed, EF, Tsai Chambers, E.

ELSEVIER CrossMark

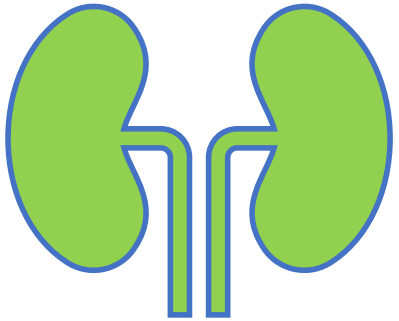
Combined Heart and Kidney Transplantation: A 23-Year Experience

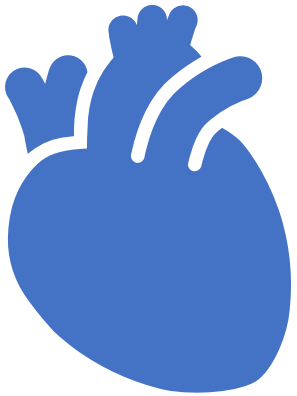
M. Awad[a,d], L.S.C. Czer[a,d,*], F. Esmailian[b,d], S. Jordan[c,d], M.A. De Robertis[b], J. Mirocha[e], J. Patel[a,d], D.H. Chang[a,d], M. Kittleson[a,d], D. Ramzy[b,d], F. Arabia[b,d], J.S. Chung[b,d], J.L. Cohen[d], A. Trento[b,d], and J.A. Kobashigawa[a,d]

[a]Division of Cardiology and [b]Division of Cardiothoracic Surgery, Cedars-Sinai Heart Institute, Los Angeles, California; [c]Division of Pediatric Nephrology, [d]Multiorgan Transplant Program, and [e]Section of Biostatistics and Department of Surgery, Cedars-Sinai Medical Center, Los Angeles, California

Combined heart and kidney transplant

- Relatively uncommon compared to HTx alone, becoming more common
- Efforts made to identify who would benefit based on pre-transplant eGFR
- It is possible in pts who had previous heart or kidney transplants despite sensitisation
- No worse or maybe even lower rates of rejection compared to HTx





Post-transplant Hypertension

Increased cardiovascular morbidity

↓ Up to 90%

Graft dysfunction

Ventricular hypertrophy
Arterial stiffness
Sympathetic denervation
Graft vascular disease
Complications (rejection)
Nephrotoxicity

Ca channel blocker – Amlodipine
ACE inhibitor – Enalapril
Direct vasodilator – Hydralazine
Alpha blockers – Prazocin
Beta blockers - Propranolol

Post-transplant Diabetes

Pre-transplant morbidity
(Chronic heart failure)

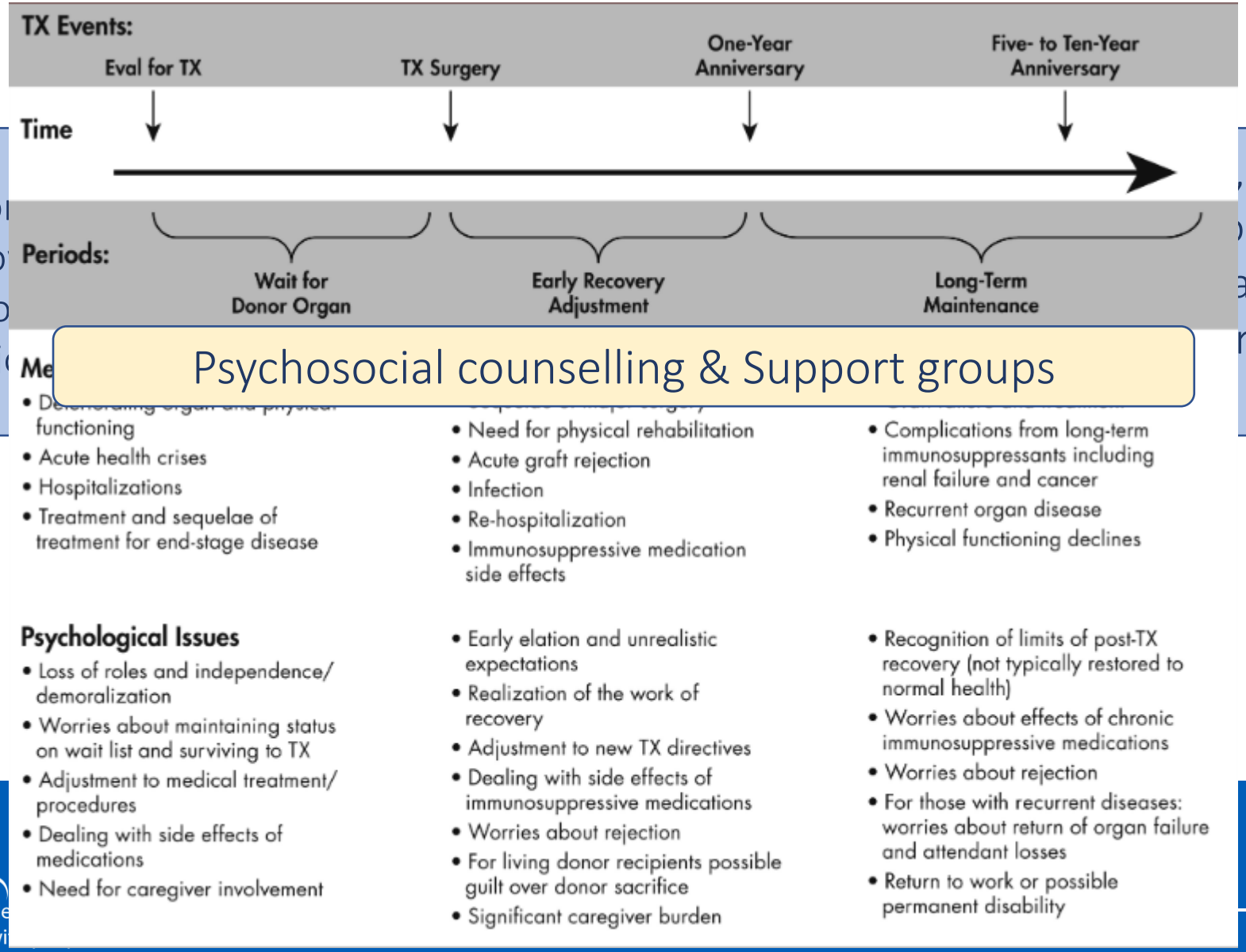
Post-transplant morbidity
(pancreatic injury)

Anti-rejection medications
Usually 3-6 months

Increased infection
Renal dysfunction
Microvascular disease
Graft disease
Long-term Cx of Diabetes

Psychological/Well-being

Emotio
highs/lo
pre/po
transplant j



Adherence/Compliance

- Ciclosporine, Tacrolimus
- Prednisolone
- Azathioprine/MMF
- Sirolimus
- Statins
- IV Ig

Pediatric Heart Retransplants

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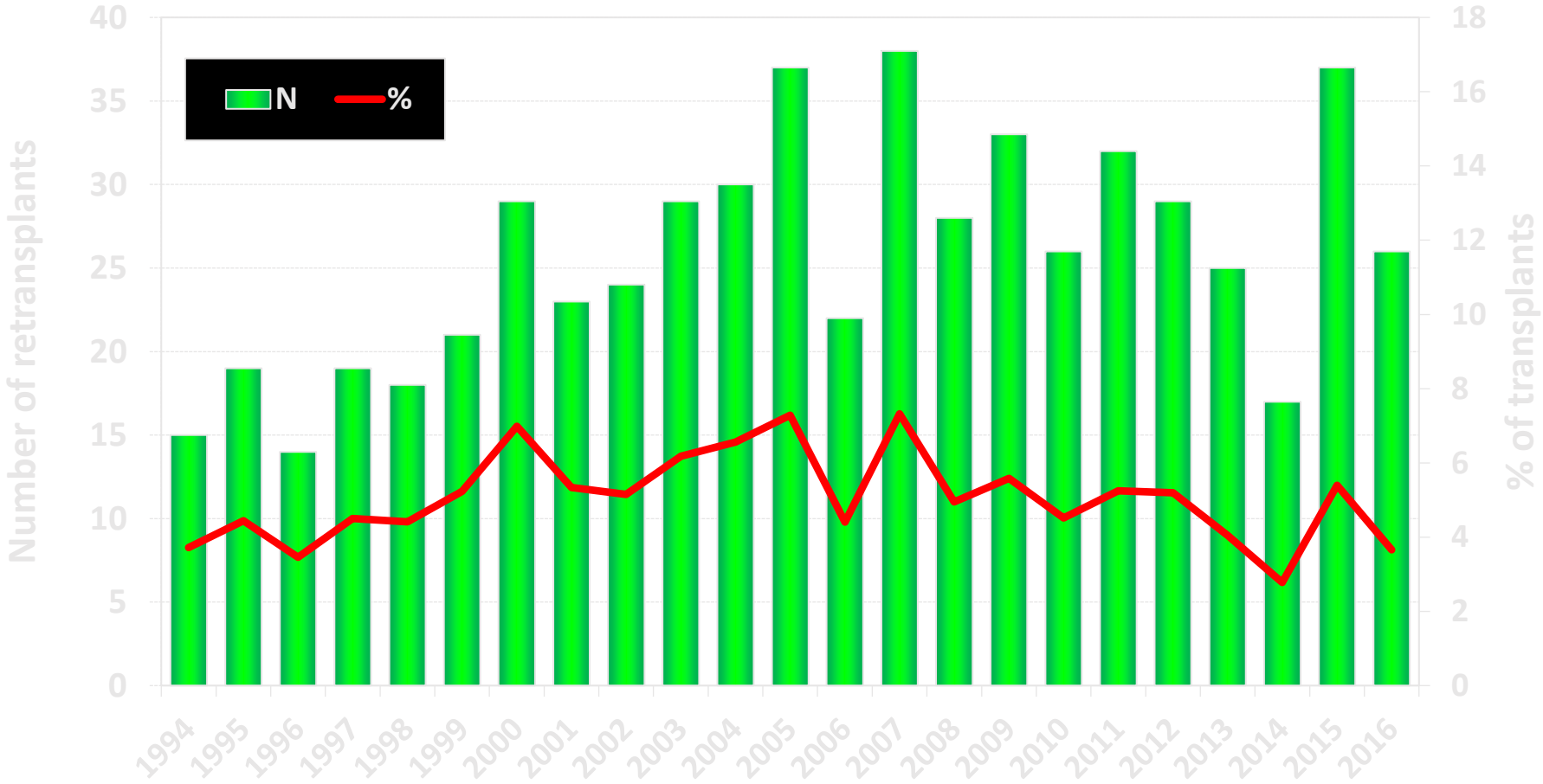
NHS Foundation Trust



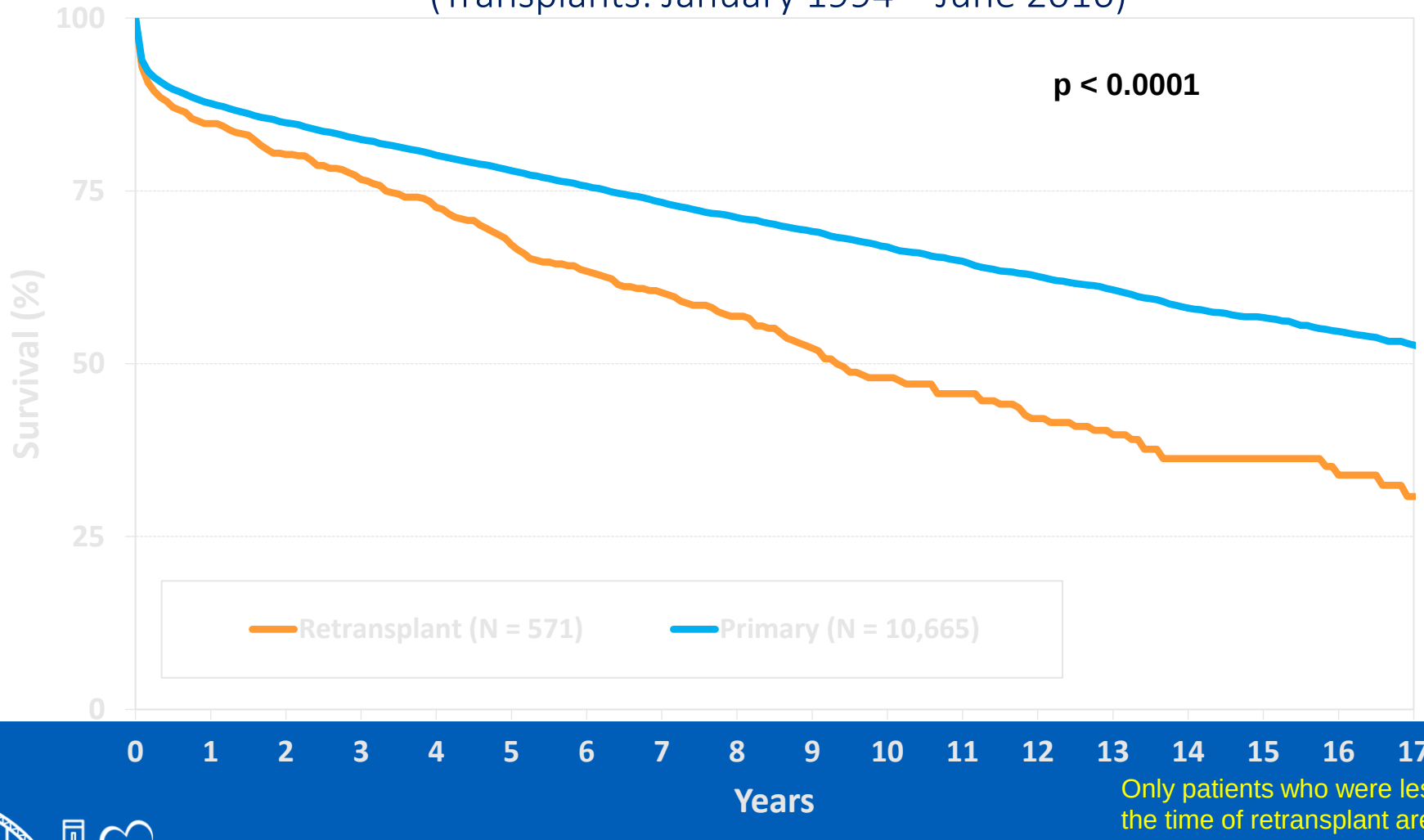
Year of retransplant

Only patients who were less than 18 years old at the time of retransplant are included.

Pediatric Heart Retransplants

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Kaplan-Meier Survival Rates for Primary and Retransplants
(Transplants: January 1994 – June 2016)



Only patients who were less than 18 years old at the time of retransplant are included.

Healthcare at its best with people at our heart

ISHLT • INTERNATIONAL SOCIETY FOR HEART AND LUNG TRANSPLANTATION

2018

JHLT. 2018 Oct; 37(10): 1155-1206

Transition: Adolescent to Adult service

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NHS Foundation Trust

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with people at our heart

Transition challenges

Paediatric transplant team – 'unable to give up' ☺ (long extended relationship)

Adult transplant team – less experience managing old paediatric patient

Parent issues – interdependence, over protection,

Young adult issues – dependence on parents, paeds. team; chrono vs. develop age

Other issues – financial, employment, independent living etc.

Factors favouring a smooth transition:

- *Start talking about transition at an appropriate time*
- *Transition clinical nurse specialist involvement*
- *General practitioners involvement*
- *Structured transition programme*
- *Joint appointments with paediatric cardiologist and ACHD specialist*
- *Good communication skills*
- *Increasing patients' self advocacy and knowledge on their disease*
- *Psychologist involvement*
- *High technology support*
- *Publicity campaigns on media*

Staged Approach (from 12-14yrs to 18yrs

Examples

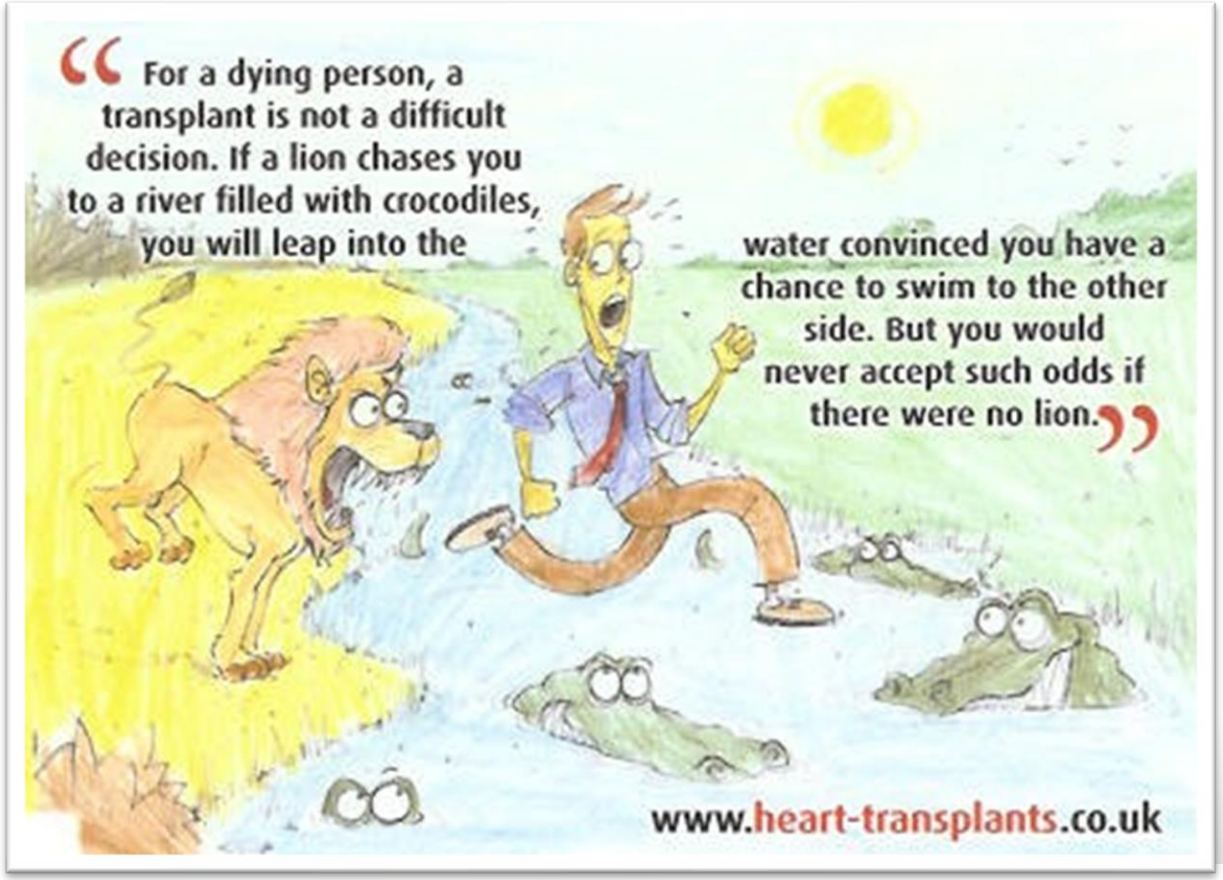
Case 1: Reduced appetite, SOB, lethargy, fluid overload, weight gain (rejection)

Case 2: CXR – lung congestion, effusions; ECG – arrhythmia – heart block (rejection)

Case 3: Temperature/fever; weight loss, GI symptoms (infection – EBV, CMV)

Case 4: hypotension, tachycardia, oedema, organomegaly (graft failure)

Case 5: not sure – adherence, non-compliance, not normal for the patient



MDT, Communication & Education

Thank you for listening!

Questions?

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Family Education

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with people at our heart

What is education?

The act or process of imparting or acquiring particular knowledge or skills

Training is practical education (learning to do) or practice, usually under supervision.

What do we want to achieve?

To empower with the knowledge and skills to :

- Care for the child safely at home
- Adhere to a medical regime to avoid complications
- To recognise complications early
- Foster independence in the young person
- Work with teams of professionals

Why is health literacy important?

People with low health literacy:

- are more likely to die younger
- are more likely to have long-term conditions
- miss appointments more often
- find it hard to take medication correctly
- feel worried and angry
- struggle to look after their own health effectively

How to improve health literacy

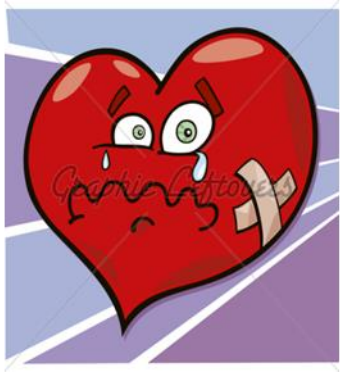
- Share clearer health information.
- Speak and write in ways that make it easier for children and carers to understand.
- Write in a clear way, the average adult UK reading age is only 9-11 years.
- Use as little medical jargon as possible. Talk about health using everyday words.
- Check with patients if we've explained clearly

Who should be educated?

- The child's primary carers
- The child
- Extended family or friends
- Teams working in partnership

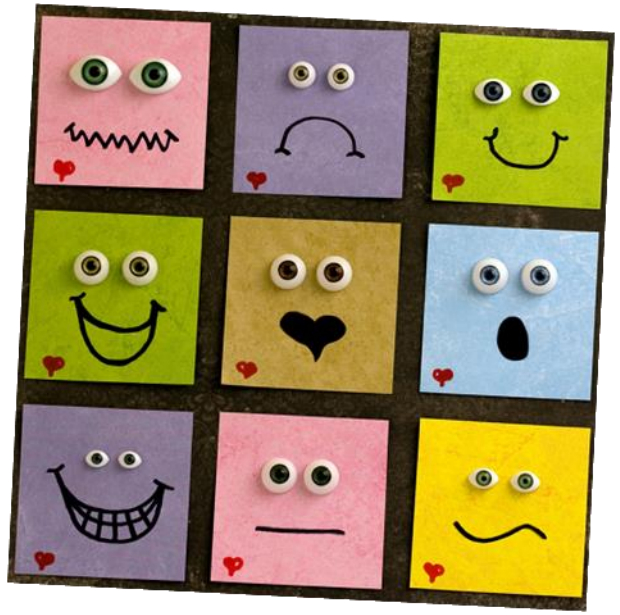
Knowledge and skills

- General understanding of transplant issues and ongoing follow up
- Medicines management, diary, side effects, ordering issues, adherence
- Rejection
- Infection



Knowledge and skills

- PTLD
- Long term complications
- Psychological problems
- Lifestyle issues
- Other medical and special needs



Who are the educators?

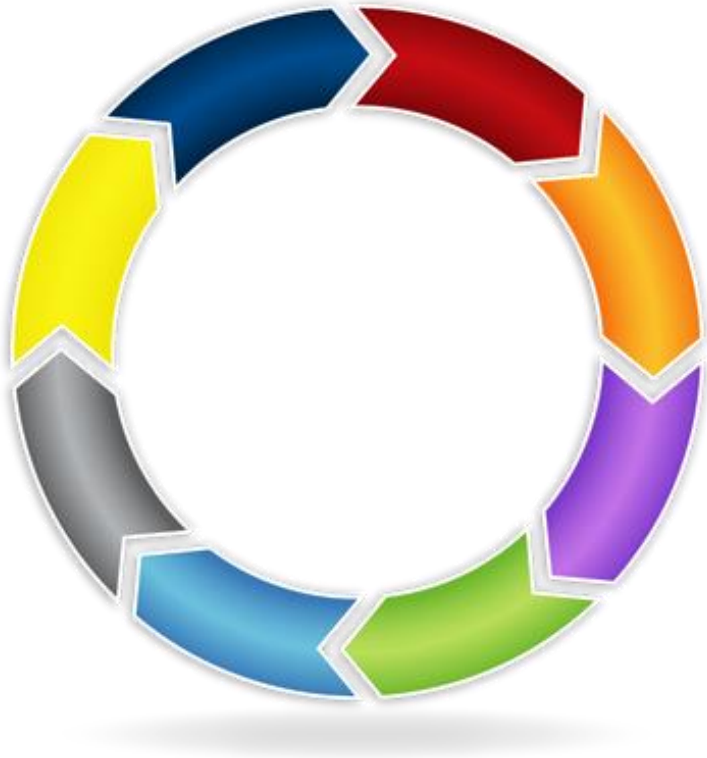
Transplant Specialist Nurse

- Leads coordination of training and discharge planning
- Assessment of competency
- Alternative strategies
- Communication with and education of other professionals
- Responsible for ongoing training after discharge

Other Educators

A lifelong commitment

- Initial post-transplant needs
- Ongoing and changing needs
- Young people and independence
- Expert patient



Early

- MDT responsible for meeting practical training needs
- Specialist nurse provides in depth education to ensure safe care at home
- Multiple educational sessions pre discharge
- Provides specialist resource to community teams

Medium term

- Specialist nurse introduces more in depth knowledge over time
- Age specific eg sexual health
- Encourages active engagement in own care
- Recaps carers knowledge

Transition

- Assessment of current knowledge by specialist nurse
- Impart depth of knowledge in structured sessions
- Reassess & recap
- Aiming for independent management of own care

Barriers to learning

- Communication barriers
- Learning difficulties / disability
- Sensory impairment
- Poorly supported families
- Lack of motivation
- Culture
- Geographical factors

Long distance learning

- Majority of patients live outside of Newcastle area
- Many only reviewed in Newcastle twice per year
- Challenging to provide face to face education
- Planning required
- Needs active engagement of patient and family
- Time consuming
- Can have advantages

Assessment of learning & understanding

- Targeted questions
- Change in behaviour
- Teachback to assess understanding

Management Strategies

- Traditional methods and technological advances internet, texting, apps, skype
- Local services and support groups
- New initiatives
- Person specific

New initiatives

- Young person's clinic
  - Aimed at 16–18-year-olds
  - In partnership with adult transplant service
- Structured education package for young people
- How to assess learning
- Transition of responsibility to young person
- New educational website under development

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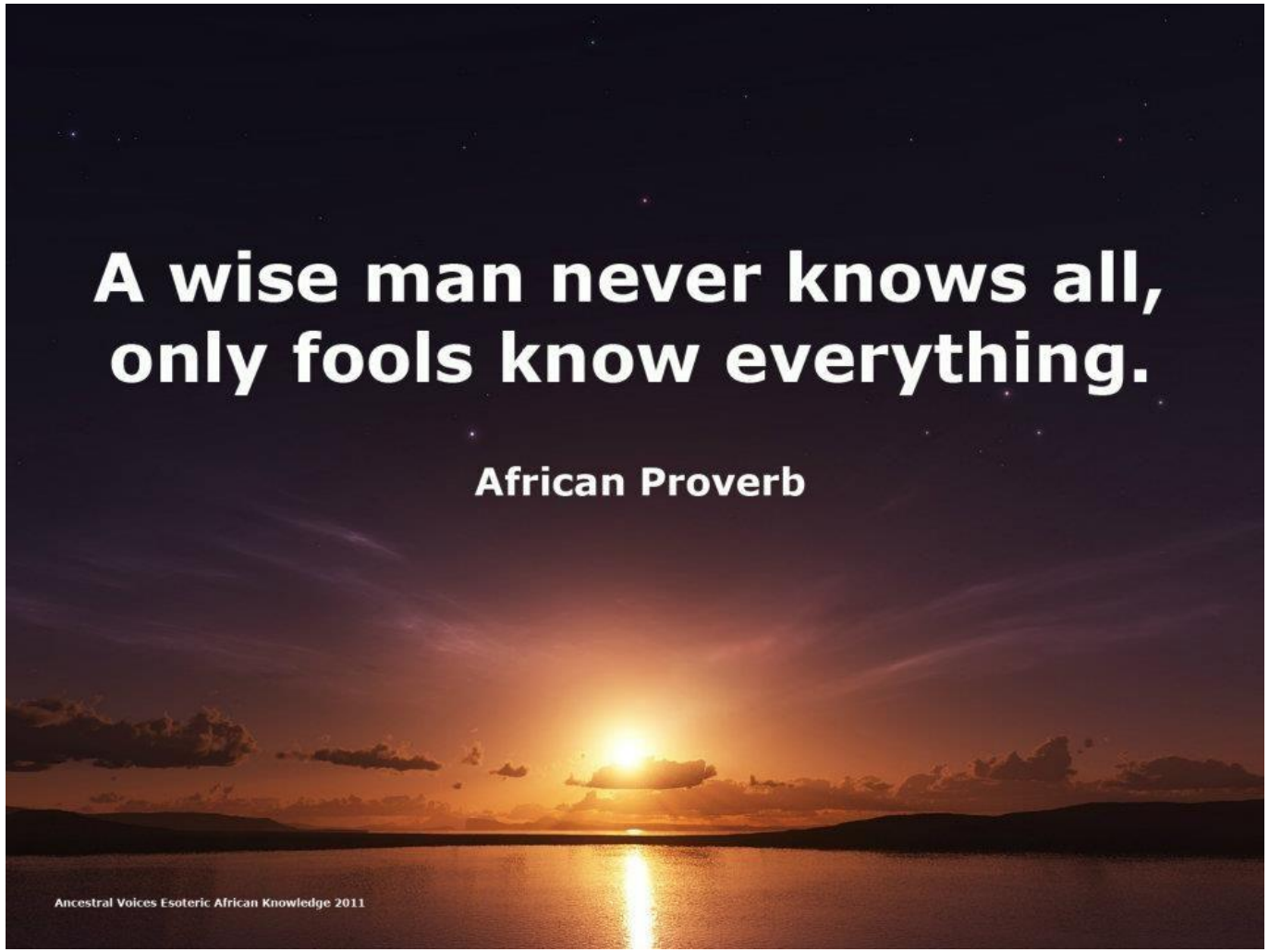
Never too young to learn!

Healthcare at its best
with people at our heart


A wise man never knows all,
only fools know everything.
African Proverb
Ancestral Voices Esoteric African Knowledge 2011

Thank you for your attention!

Paediatric Cardiac Transplantation what, when and how?

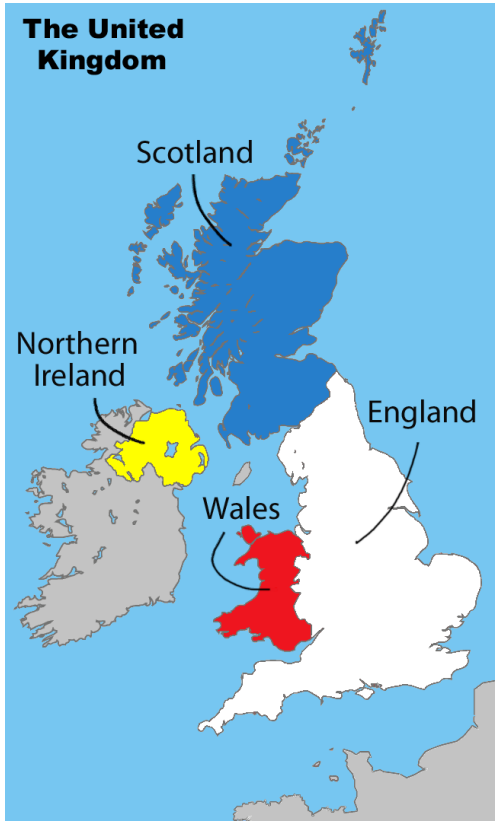
Shared Care

Terry Hewitt
Paediatric Transplant Specialist Nurse
Freeman Hospital, Newcastle upon Tyne

Transplant Shared Care

- Assessment
- Pre & peri-operatively
- Post transplant

- 126 patients currently being followed up
- 71 patients on shared care regime
- 13 centres share care
- Patient criteria
- Shared care protocol



Shared Care Patients

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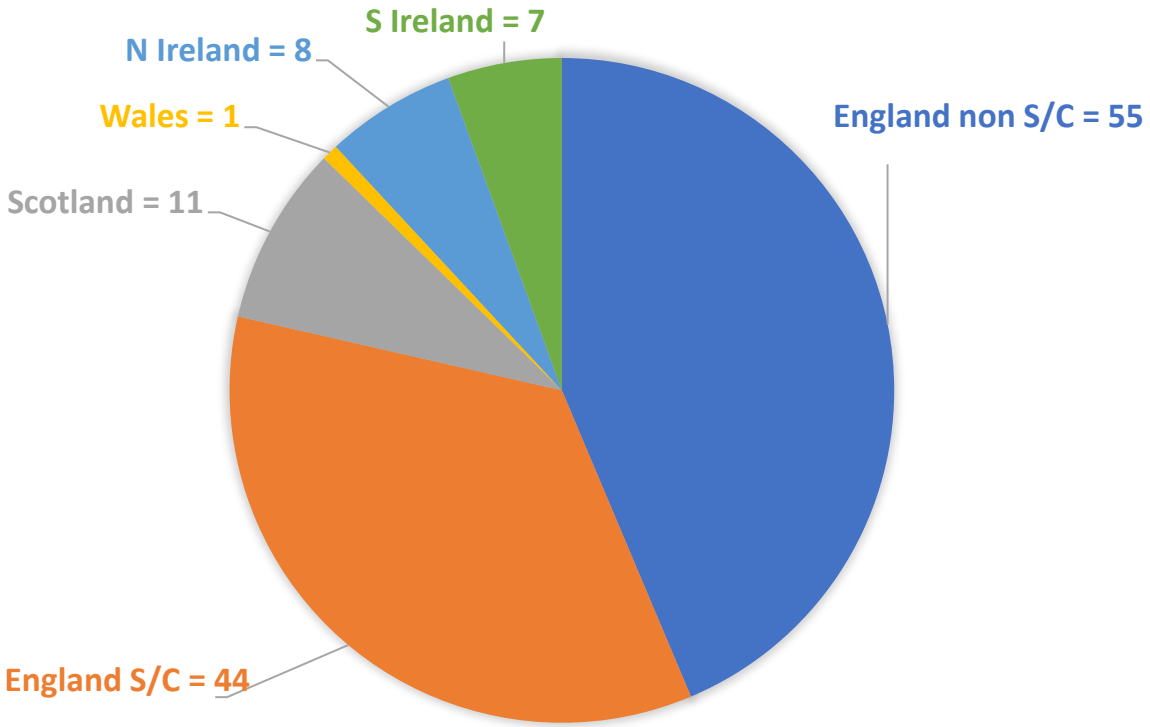
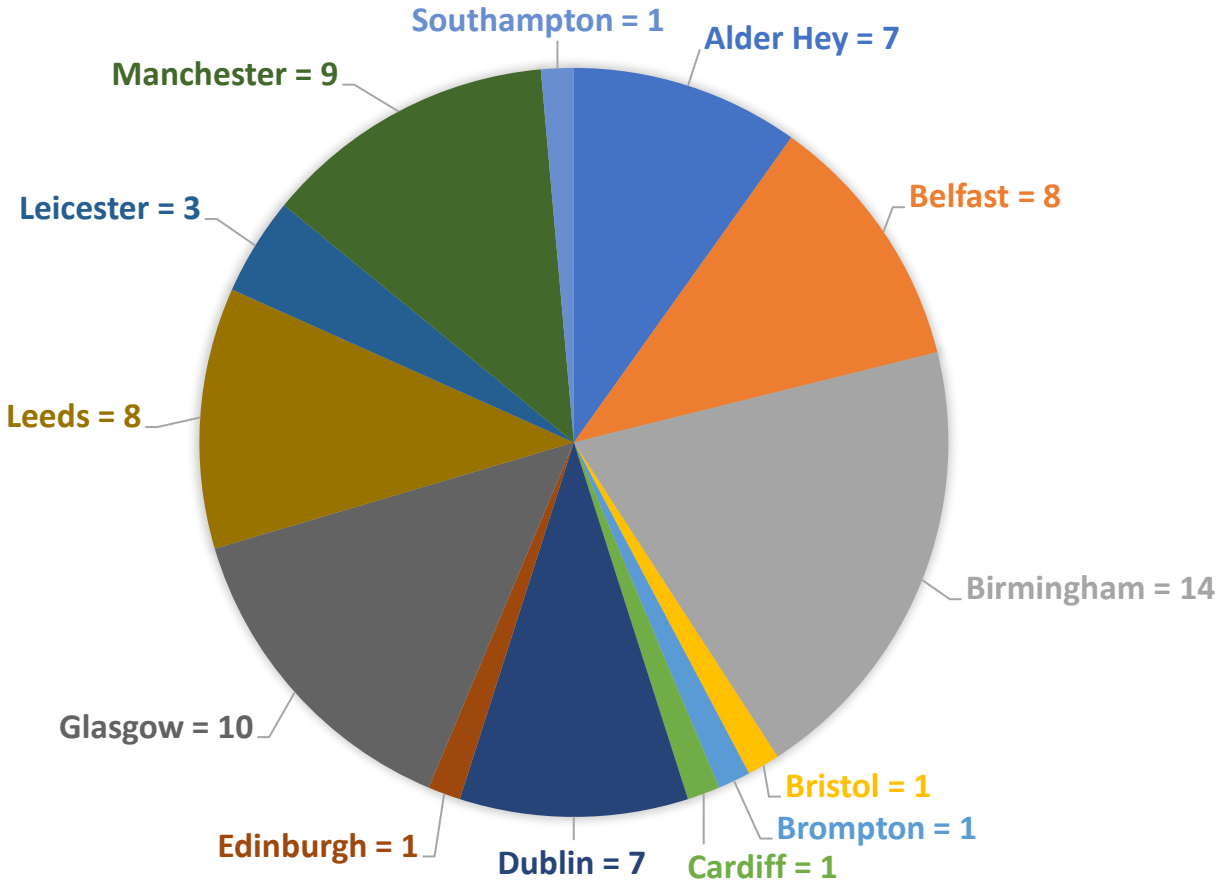
All patients by origin





Transplant Shared Care

- Formalised and robust
- Requires joint participation of local (both primary care and referring cardiology teams) and specialist (transplant) teams in the planned delivery of care.
- Promotes and supports continuity of care.

Shared Care Principles

- Safe
- Protocols
- Agreed standards of care
- Clearly defined roles & responsibilities
- Patient centred, whole person care
- Individualised
- Co-ordinated care
- Timely and effective communication
- Partnership working

Shared Care Benefits

- Convenient
- Continuity of care
- Immediate and effective care
- Open/rapid ward access
- Open/rapid clinic access
- Familiarity
- Support
    - local GP
    - local cardiology team (nursing & medical)
    - liaison nurses
- Education and training
- More efficient use of specialist resources

Transplant Shared Care

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Time Post-Transplant	Routine	Freeman	Local
0-3 Months	Weekly	All At FRH	
3-6 Months	Fortnightly	3 (Alt)	3 (Alt)
6-12 Months	Monthly	3 (Alt)	3 (Alt)
1-2 years	6 Weekly	4 or 5 (Alt)	4 or 5 (Alt)
2-3years	8 Weekly	3 (Alt)	3 (Alt)
> 3 years	12 weeks with interim bloods	2 (Alt)	2 (Alt) (+4 bloods)

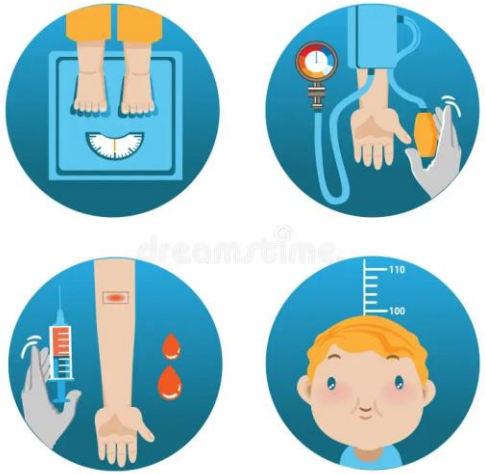
Local Team Responsibilities

- Availability
    - regular outpatient assessment
    - urgent / emergency appointments

- Routine investigations including blood tests / Monitor immunosuppressant drug levels
- Adjust general medications as necessary
- Be aware of drug interactions / medication side effects
- Be aware of post transplant complications / identify complications early
- Communication

Clinical Assessment

History - non specific symptoms
cardiac symptoms
drug compliance
psychological issues
lifestyle including exercise tolerance



Examination- temperature / heart rate / blood pressure / weight
JVP (in older patients)
gallop rhythm
murmurs
enlarged tonsils
lymphadenopathy
hepatosplenomegaly
skin lesions

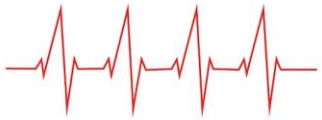
Routine Investigations

Ciclosporin / Tacrolimus/ Sirolimus levels	Trough levels. EDTA tube Interpretation and dosing by transplant centre
Full Blood Count -	Deranged secondary to medication Azathioprine / MMF / Sirolimus
Urea and Electrolytes – Bone profile	Renal impairment, electrolyte disturbance secondary to medication Ciclosporin / Tacrolimus
Liver Function Tests -	Deranged secondary to medication Azathioprine / MMF

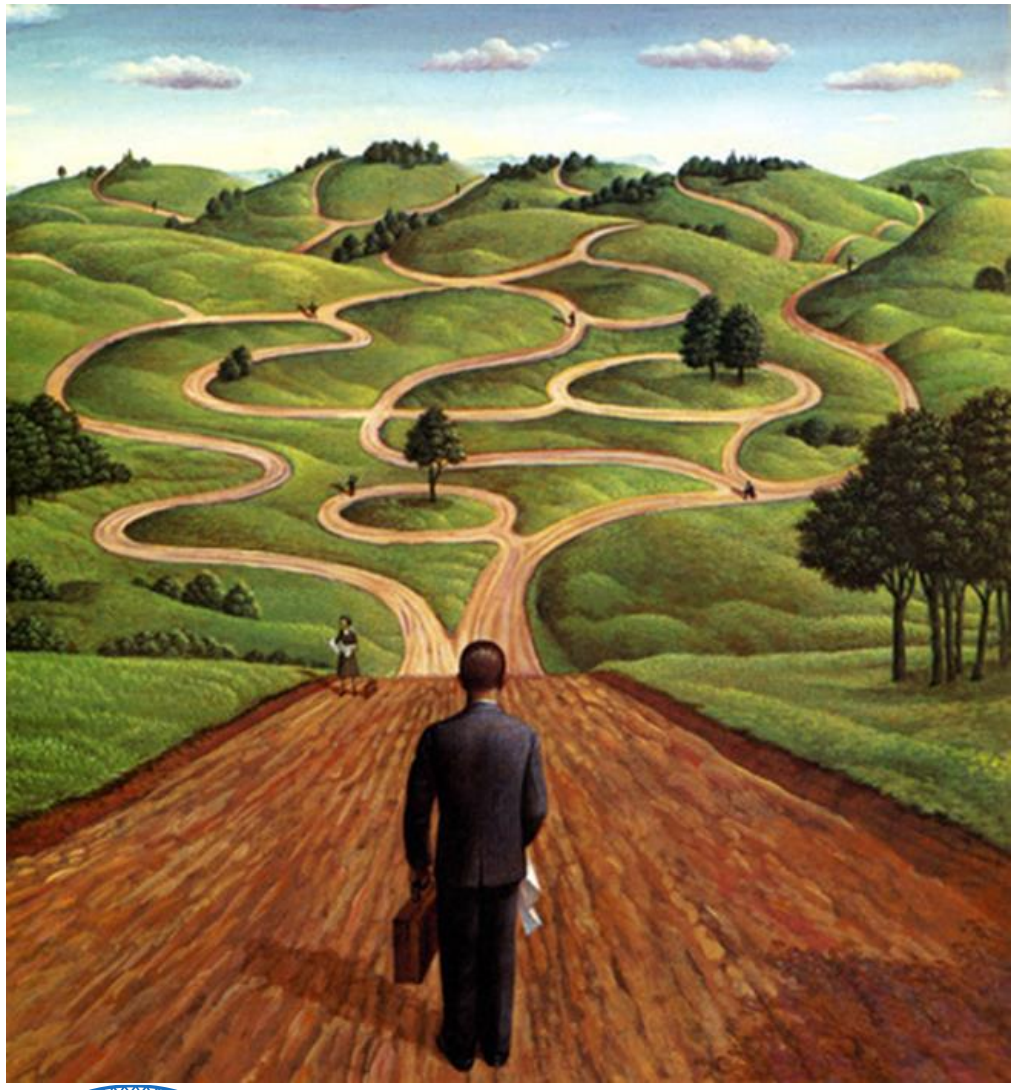
Glucose - Hyperglycaemia secondary to medication -Tacrolimus

Lipids - Hyperlipidaemia/ secondary to medication - Sirolimus

Ecg - Summed voltage decrease in acute rejection. Assess rate and rhythm especially PR interval. Bradycardia may indicate new onset heart block

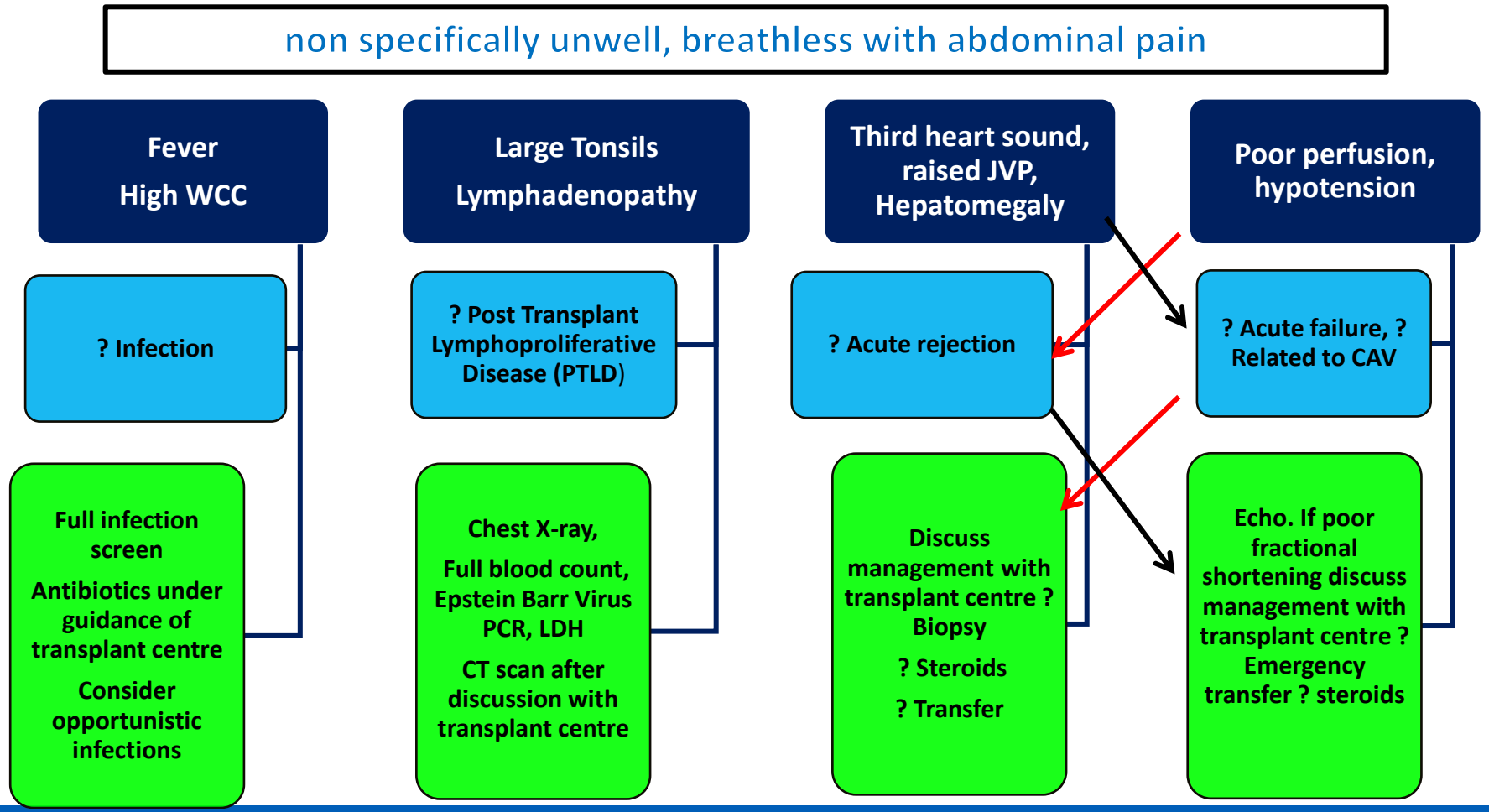


Echo - Assessment of cardiac function Clues to rejection - Decreased ventricular function, increased wall thickness, pericardial effusion and mitral regurgitation can indicate rejection




Rejection
Vasculopathy
Hypertension
PTLD
Anaemia
Infection
Renal Dysfunction
Hyperlipidaemia
Neutropenia
Psychological Issues

Acute presentation scenario



We are here to help

Please please do not be scared to contact the team at Freeman Hospital

Monday to Friday 9-5 contact Nurse Specialists

- 0191 2139412
- 0191 2448185
- 0191 2139909
- 0191 2139144

Evenings and weekends contact ward 23

- 0191 2137023

Conclusions

Meticulous follow-up of paediatric cardiac transplant recipients is of paramount importance to their medium and long term wellbeing

Well planned and organised shared care arrangements provide an excellent model of care

Local teams must be aware of the potential problems that these young people may develop

Robust communication links between the partners in shared care arrangements are vital.


Thank you
for listening

Frankie Lord

Cardiac Presentation

Before Frankie Was Born

- 20 Week Scan – HLHS Diagnosis
- 24 Week Scan – Possible Intact Atrial Septum
- 28 Week Scan – Confirmed Intact Atrial Septum
- 60% Chance of Survival (Surgical Route)

Before Stage One

- Recovering well from IAS stent surgery
- Preparing for the Norwood Procedure
- 70- 80% Chance of Survival to 1 year

Before Stage Two

- Preparing for the Glenn
- >90% Chance of Survival

Something Was Not Right

- At 17 Months old, Frankie was Diagnosed with Heart Failure-
- Positively Still Working together with the same approach

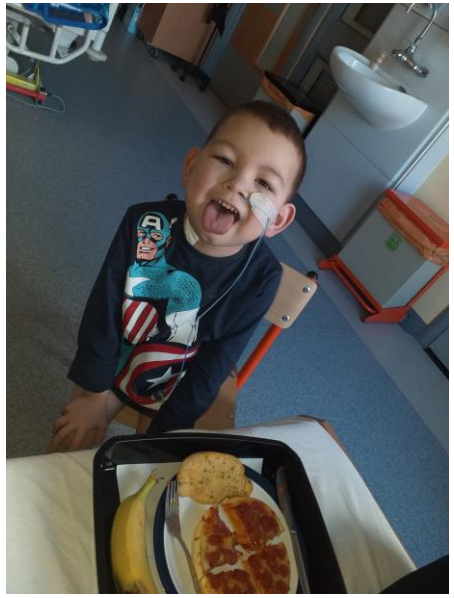
Frankie Needed a Heart Transplant

- Tests found Frankie was eligible for Organ Transplant
- Transplant Talks Began
- 80% Chance of Survival
- Finding the balance but still hoping and praying.

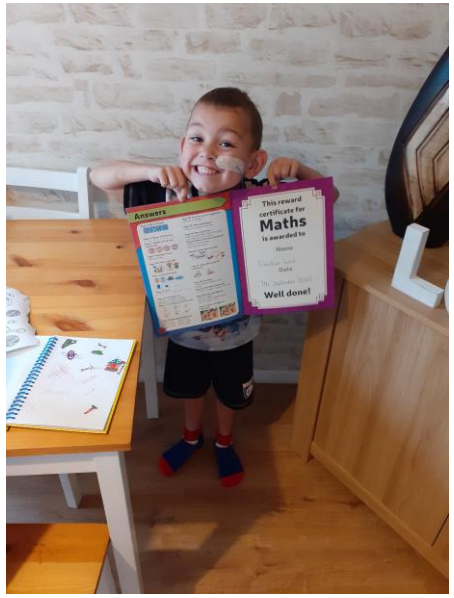
Post Heart Transplant Photos

Frankie Now Needs a New Kidney

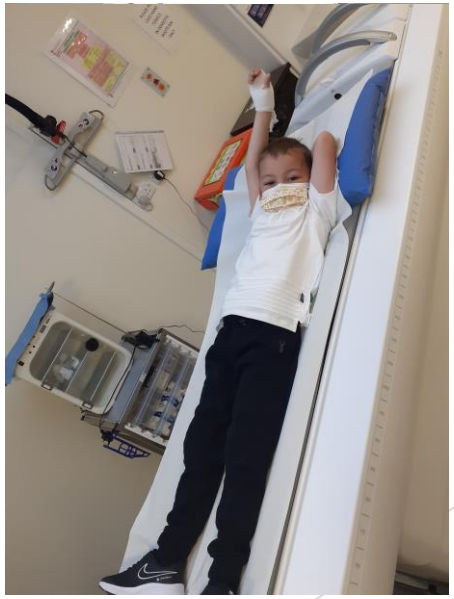
- Diagnosed with End Stage Chronic Kidney Failure
- Haemodialysis 3 Times Per Week
- Placed on the transplant waiting list once again- for a kidney this time



Kidney Transplant



COVID-19 Pandemic



Heart Transplant Rejection

Frankie Now

Being Frankie's Mam