Pediatric Heart Transplant

Discharge Information

Time to go Home

• You will be able to leave the hospital once your child is eating and drinking or on a tube feeding schedule that you can manage at home
• Babies must be gaining weight
• Parents must have attended teaching with the transplant coordinator and the pharmacist
• Parents must be able to demonstrate that they can draw up all the medications and give them to their child
Emotions

• After transplant it is normal for your child to be more emotional than before
• They may have temper tantrums or nightmares
• If this does not stop within 6 months further treatment might be necessary

Emotions

• It is normal for you to feel overwhelmed, excited, depressed and tired after transplant
• It is wonderful that your child’s life has been saved but there is so much to learn and do
Food - Nutrition

- You want to prepare heart healthy meals and snacks for your child
- The transplant dietitian will see you in the hospital and in the clinic, she will teach you about healthy choices

Physical Activity

- Because of denervation your child must warm up before brisk physical activity
- Your child can participate in sports, dance and fitness activities
Denervation

- The nerves to the heart are cut at the time of transplant
- This means the heart does not get the same messages about speeding up and slowing down

Medic Alert

- Please get a Medic Alert bracelet, it may save your life
- Fill out the forms to get one, not just one from the drug store as these have little information on them
Pets

• Your child must not handle animal waste products (pee and poo)
• Some pets are better than others for carrying germs

Return to School

• Your child can return to school 3 months after the transplant
• No contact sports until checking with the doctor, it might be 3-6 months
• Can go to daycare after 3 months, but we prefer a dayhome as there are less kids and less exposure to germs
At School

- Talk to the principal, teacher and school nurse before your child goes back to school
- Ask them to let you know if there is any disease going around at school
- Chicken pox can be bad after transplant and your child might need special antibodies to stop them from catching it, let us know right away if your child has been in contact with someone with chicken pox

Vaccines or Immunization

- Vaccines can protect your child against common illnesses
- We ask that you and your child get the flu shot every year
- For vaccines at school, your child can only receive killed vaccines, not the live vaccines
- Common live vaccines are: measles, mumps, rubella, chicken pox
Travelling

- You can go on holidays, just let us know where you are
- Avoid large crowds for the first 3-6 months
- Do not travel outside of Canada for one year

Dental Health

- Make sure your dentist knows your child has had a heart transplant
- Heart transplant patients need antibiotics before any invasive procedure like aggressive dental cleaning
Teenagers Beware!

- Cannot drive for 3-6 months
- No smoking
- Avoid alcohol
- Protect yourself from pregnancy and disease

Early Problems after Transplant

- Wound Healing – check the incision every day to make sure there is no redness, swelling or pus.
- High Blood Pressure – this is common after transplant and your child may need to be on medication. We will do a blood pressure in clinic but you might be asked to do it at home too.
Early Problems 2

• Heart Rate Problems – sometimes children need a pacemaker after transplant but this is not common and will be done before you leave the hospital.
• Fluid Build Up – Surgery can cause you to retain water, steroids can also help you to retain water. Some children need a water pill to help them get rid of water early after transplant.

Rejection

• This is what happens when your immune system attacks the new heart
• The immune system will recognize that the heart does not have the same DNA as you and will try to get rid of it like a bacteria or virus
Symptoms of Rejection

• Higher or lower resting heart rate than normal
• Lower blood pressure than normal
• Sudden weight gain
• Nausea, vomiting, upset stomach
• Low energy, tired
• Dizzy
• Short of breath
• fever

Looking for Rejection

• A heart biopsy is the true diagnosis of rejection
• 5-6 very small pieces are taken from the heart and examined under a microscope and with special stains to look for rejection
• This is done 4 times the first year, then every year for 5 years
• After 5 years the chance of rejection goes very low (6%) as long as you take your meds
Treating Rejection

• There is a scale that measures rejection
• The scale goes from 0-4
• For a 1-2 grade of rejection, your doctor might just increase the dose of your Tacrolimus or Cellcept
• A grade 3-4 rejection would require IV medication for a few days.

Infection

• Number 1 complication after transplant
• Same symptoms as rejection but instead of attacking your heart the immune system is attacking the bacteria or virus
Looking for Infection

- There could be blood tests, urine tests, sputum tests, and x-rays to find the infection

Treating Infection

- Antibiotics
- Anti-Viral
- Anti-Fungal
Preventing Infection

Wash Your Hands!
- Use soap and warm water
- Scrub for 20 seconds
- Sing ABC song

Preventing Infection 2

Do not touch poo!
Medicine

- Parents usually give medication to their child until they are 12-14, then teach the child to look after their medication with supervision.
- Usually start with liquid but once school age easier to take pills.

Managing Medication

Have a routine
Stick to it
Managing Medication 2

Take medicine on time
Within 45 minutes of scheduled time

Take Meds on Time

- 1.5 h off regularly scheduled time, rejection rate 1.2%
- 2.5 h off time = 14.3% rejection
- 4.3 h off time = 22.2% rejection

More Variability = More Rejection
Vomiting Meds

- If the infant vomits within 10 minutes give whole dose over (wait ½ hr to let tummy settle)
- Otherwise do not re-give meds as you may end up double dosing.

Absorption of tacrolimus at steady-state in kidney transplant patients

Day 3
Week 3
Month 3

Do Not Eat Grapefruit

- Avoid grapefruit, pomelo and starfruit
- Look for grapefruit extracts in other preparations
- 5 Alive

Kidney Damage

- Drink water – for 10kg child=1000ml/day, 15kg=1250ml/day, 20kg=1500ml/day
- Void 5-6 times per day
- Urine should be nearly colourless and odourless, if not drink more.
Diabetes

- Unusual in young children but more common in teens and adults
- If diabetes runs in your family this is more likely
- Both prednisone and tacrolimus contribute to this problem

Blood Pressure

- Lower salt in your diet
- Regular physical activity
- May need medication
Low Blood Count

- Cellcept, Septra and Valganciclovir can lower the white blood cell count below normal
- This will increase your risk of infection

Cancer

- Regular blood work to monitor
- Regular clinic visits
- Avoid sunburn
PTLD

- PTLD – post transplant lymphoproliferative disease is a type of blood cancer that is common in transplant patients
- It seems to be linked to the Epstein Barr virus (EBV)
- Decreasing anti-rejection drugs is the first defense
- Sometimes chemotherapy is needed.
- This happens in 7-10% of children

Problem?

Call us!