

Boston Children's Hospital Pediatric Transplant Center

Caring for Your Child After a Transplant



Boston Children's Hospital
Pediatric Transplant Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



Healthcare goals

- The healthcare team will set specific goals for your child after talking about them with your family.
- Your family will understand clear health goals.
- Your child's and your family's preferences will be part of the plan.

Focus of this class:

- Helping you understand the information you need to care for your child safely at home.
- Going through topics, including post-transplant rejection, infection, when/who to call, nutrition, the care plan and transplant medications.
- We won't be talking about your child's medications/doses/timing in this class. Your child's nurse and pharmacist will talk with you each shift about medication.
- You'll take a 15-question survey on the day you leave the hospital to check your understanding of how to care for your child.

Before leaving the hospital, you must clearly understand some key things.

- The reason for giving each medication
- How to give medications, including when to give them, how much to give and what signs to watch out for
- How to work out financial issues when getting medications and refills

We encourage you to:

- Set alarms for medication prep
- Know how to draw up medications (if applicable) in syringes
- Identify each drug your child takes

The “teach-back” method

- Teach-back means that we’ll ask you to explain or “teach” what you have just learned to someone else.
- It may seem like you’re being “quizzed” in this class, but the teach-back method is a very helpful learning tool.
- Teach-back is a proven way of making sure that a healthcare team has explained the necessary information in a way that you can understand.
- We make sure that you understand the information by asking you to re-state it in your own words.

Topics for class

- Preventing infections
- Preventing rejection
- Medications
- Fluid needs
- Daily routine
- Returning to school and physical activity
- Clinic follow-ups and blood tests
- Who to call for questions after leaving the hospital
- Reasons to call the transplant clinic after leaving the hospital
- Food safety and sun safety

Infection control



- Wash hands very well (everyone).
- Avoid sick friends or family members.
- Don't let sick people visit your home.
- Avoid crowds.
- Don't drink well water. Filtered, bottle and city water is usually OK.
- Check with your transplant team about new pets.
- Don't clean a litter box or bird cage.
- Don't visit farms or petting zoos until team approves.
- Avoid dead or decaying plants or leaves, compost piles, soil aerosols (like mulching), bird or animal droppings.
- Household members and close contacts should be up to date on routine vaccines, including the seasonal flu and COVID-19 vaccines.
- Your transplant and ID teams will talk with you about vaccine recommendations after the transplant.

Keep germs away by:

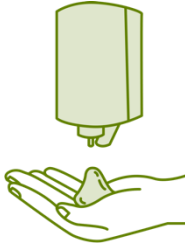
- Giving your child regular baths or showers.
- Washing cuts with warm, soapy water.
- Flossing and brushing your child's teeth every day.
 - Wait to see the dentist for 6 months after the transplant. Then go every 6 months.
 - Contact your transplant program to find out if your child needs antibiotics before going to the dentist.
- Keeping hands and fingernails clean.
- Using Purell or other hand sanitizer often in between hand-washings.
- Making sure siblings (brothers/sisters), caregivers and all family members have up-to-date immunizations.

Your child's immune system is weakened because of the medicine that is given to keep rejection from happening.

Hand washing steps:



1. Wet hands



2. Use soap



3. Scrub backs of hands, wrists, between fingers, under fingernails (20 seconds)



4. Rinse



5. Towel dry



6. Turn off taps with towel

Avoid crowds after the transplant for:



Heart: 8 –12 weeks

Lung: 3 – 6 months

Liver/intestine: 6 weeks

Kidney: 6 weeks

*These are the **least** amounts of time. You may want to avoid crowded areas longer if there are a lot of viruses in your community.*

You should stay away from crowded areas because of the risk of germs.

- School
- Church
- Malls
- Parties



All family members and visitors to your home:

Should wash their hands and/or use Purell (or other hand sanitizer) often.



Your child will have regular tests to look for infections after the transplant. Some of these infections include:

- EBV (Epstein-Barr virus)
- CMV (Cytomegalovirus)
- BK virus (Human polyomavirus)

EBV can lead to a serious condition called PTLD (post-transplant lymphoproliferative disease). PTLD can affect the lymph glands anywhere in the body, or organs like the spleen or the liver.



Renal transplant guidelines

- Talk to the transplant team about when to return to work or school.
- Ask team about swimming guidelines.
- Wash all fruits and veggies very well. Follow all instructions for safe food cooking and storage. Heat cold cuts until they're steaming.



Liver and bowel transplant guidelines

- Ask the transplant team about swimming.
- Follow all guidelines for food safety as well as safety giving food/formula by a G-tube or J-tube.
- Wash hands well after touching animals. Avoid stray animals or animals that look ill.
- Don't go inside barns.



Lung transplant guidelines

- Wash fruits and vegetables well.
- Don't swim in ponds or lakes.
- Don't play or dig in a garden.
- Don't go to petting zoos or farms.



Heart transplant guidelines

- Talk with the transplant team about when to go back to school.
- Speak with the team about when the mask precautions can stop.
- Don't get new pets for 6 months.
- Don't swim in ponds or lakes.
- Don't go to water parks.
- Don't travel for 6 months. After that, you must have any travel approved by the team.



How do I protect my child?

- Make sure to give *all* medicines *every day*.
- Give medication to prevent infections (Valcyte, Mepron, Bactrim).
- Tell the transplant team about any signs of infections. They may order tests.
- Give medications as prescribed. The transplant team may add or change the medicine plan, depending on test results and/or your child's symptoms.

Sexual activity

- Your child has a higher risk of sexually transmitted diseases (STDs) if they're sexually active.
- Medicine to keep transplant rejection from happening weakens the immune system.
- This means that the body has less immune protection to fight STDs.
- There should be no sexual activity for at least 6 weeks after the transplant.
- Your child should **always practice safe sex**.
- Your child should talk with their transplant team if they decide to start family planning. Their medication may need to be changed.

Infection control

Q&A

Any questions?

Rejection



What is rejection and what do you do about it?

Transplant rejection happens when transplanted tissue is rejected by your child's immune system. Acute rejection is common after a transplant while your child's immune system recovers. There may or may not be physical or obvious symptoms. We do regular blood tests to check for signs of rejection and to adjust immunosuppression when this happens.

Don't panic when you hear the word "rejection."
It doesn't mean your child will need a new organ!

Here's what we may do if your child has a transplant rejection:

- Check blood tests before clinic visits
- Possibly admit your child if blood tests aren't normal
- Give extra fluids in the hospital
- Do blood tests every morning to check on any changes
- Do a biopsy of the transplanted organ
- Give other medicine or treatments
- Talk about medication changes

Signs of an infection or rejection



Kidney

- A fever
- Urinating (peeing) less often
- Flu-like symptoms: aches, tiredness, sore throat
- Abdominal (belly) pain, back pain, pain with urinating
- Sudden weight gain, puffiness
- Higher blood pressure
- Pain over the new organ
- Redness or pus from an incision



Liver

- Sometimes no symptoms
- A fever
- Abdominal (belly) pain or discomfort
- Higher liver function tests (blood test)
- Redness or pus from an incision
- Urinating (peeing) less often
- Pain with urinating

Signs of an infection or rejection



Intestinal

- A fever
- Higher stool (poop) or ostomy output
- Lower stool or ostomy output
- Nausea/vomiting
- Not wanting to eat
- Abdominal (belly) pain
- Redness or pus from an incision
- Urinating (peeing) less often
- Pain with urinating



Lung

- A fever
- Having trouble breathing
- Less home PFTs or home spirometry
- Lower blood oxygen levels
- Coughing
- Upper respiratory symptoms
- Redness or pus from an incision



Heart

- Might not be any symptoms
- A fever
- Coughing, fast breathing
- Irritability (being fussy or cranky)
- Belly pain, nausea, vomiting/throwing up, not wanting to eat
- Fatigue (feeling tired and weak), not able to do normal daily activities

Medicines that prevent rejection weaken the immune system.

- Immunosuppression medicines help keep rejection from happening.
- Immunosuppression medicine weakens the body's ability to fight infections.
- Your child's immunosuppression levels are constantly checked. Doses of medications may change a lot in the first few months or years after the transplant.
- Your child will be prescribed medicine to keep different kinds of infections from happening. **Don't skip doses or run out of medicine.**
- Call the transplant team if you have any problems with medications or prescriptions.
 - Call your pharmacy early for refills so you don't run out.

Rejection

Q&A

Any questions?

Medications



Medications

Immunosuppression – some medicines that keep rejection from happening:

- Prograf (Tacrolimus)
- Rapamune (Sirolimus)
- Cellcept (Mycophenolate Mofetil)
- Imuran (Azathioprine)
- Prednisone

Some medicines that keep rejection from happening:

- Mepron (Atovoquone)
- Bactrim
- Valcyte (Valganciclovir)

Blood pressure medicines:

- Norvasc (Amlodipine)

Dietary Supplements:

- Sodium chloride
- K-Phos
- Calcium
- Iron
- Magnesium
- Sodium bicarbonate

Can we skip medicine?

 **NO**

Important notes about medications:

- Never stop giving medications or change doses without talking to the transplant team.
- Give each medicine at the same time every day.
- Talk to the transplant team about what to do if your child vomits (throws up) after taking their medication.
- Don't give any over-the-counter medicine unless you check with the transplant team.
- Don't give your child Motrin, ibuprofen, Advil or any NSAIDs (nonsteroidal anti-inflammatory drugs like aspirin, naproxen and others).
- If you miss a dose of medicine, call the transplant team.

Medications

Q&A

Any questions?

Daily fluid (drinks)



Daily fluid amounts *may look like this:*

I/O Sheet
 Date: 1 / 1 / 2019
 Fluid Min/Max 30 oz. or 900 ml's (cc's) per day
 Daily Weight _____
 Am Temperature _____ PM Temperature _____
 AM Blood Pressure _____ PM Blood Pressure _____

Time	Intake	Comment
8AM	4 oz. juice 4 oz.	breakfast
10AM	3 oz. 7 oz.	
12Noon	4 oz. milk 11 oz.	
2PM	8 oz. ice cream 19 oz.	
4:30PM	2 oz. popsicle 21 oz.	
7PM	6 oz. milk 27 oz.	dinner
9:30PM	4 oz. water 31 oz.	bedtime

Running totals

End of day totals



Keep track of how much fluid your child gets in a day. Bring your log to the clinic visit.

Did your child meet the fluid requirement for today?
 What is the fluid requirement?

Daily fluid

Q&A

Any questions?

Food & sun safety



Why is food safety important?

- Immunosuppressant medications can make your child more likely to get an illness or infection.
- Certain foods can carry bacteria or other germs that can cause food poisoning.

How can I keep food safe from bacteria?

- Keep your hands and surfaces (counters, tables) clean.
- Separate raw meat, poultry, seafood and eggs from other foods.
- Cook foods to the right temperature.
- Keep foods cold by refrigerating them right away.

Your child can't eat:

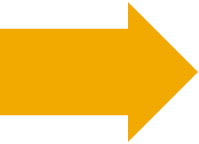
- Grapefruit
- Raw or undercooked meat, fish or poultry
- Raw sushi (cooked sushi is generally OK)
- Unpasteurized cheeses (feta, brie, bleu, Gorgonzola)
- Unpasteurized milk, cider, honey or eggnog
- Raw bean sprouts
- Raw eggs or raw cookie dough

Avoid fountain drinks and other drinks from machine dispensers when possible.





**Heat lunch meat until
it's steaming.**



**Wash fruit and vegetables well.
Your child may ask that you peel
all fruits and vegetables before
eating.**

4 steps to food safety

Clean

Separate

Cook

Chill



Cooking temperature

USDA-FDA recommended safe minimum internal temperatures



Beef, pork, veal, lamb
steaks, roasts and chops

145°F

(with 3-minute rest time)



Fish

145°F



Beef, pork, veal, lamb
ground

160°F



Egg dishes

160°F



Turkey, chicken and duck
(whole, pieces and ground)

165°F

- Cook foods to a safe internal temperature.
- Use a food thermometer to test the internal temperature.
- Keep hot foods hot and cold foods cold.
- Store foods in refrigerator when done serving. Don't leave them on the counter.

Food Storage

“Sell-by” date: Buy the product before this date. Throw it away after this date.






“Best if used by” date: This is a recommended date for best flavor or quality.

“Use-by” date: This is the last date recommended to use for best quality.

Product	Refrigerator (40 °F)	Freezer (0 °F)
Eggs		
Fresh, in shell	3 to 5 weeks	Don't freeze
Hard cooked	1 week	Don't freeze well
Liquid Pasteurized Eggs, Egg Substitutes		
Opened	3 days	Don't freeze well
Unopened	10 days	1 year
Deli and Vacuum-Packed Products		
Egg, chicken, ham, tuna, & macaroni salads	3 to 5 days	Don't freeze well
Hot Dogs		
Opened package	1 week	1 to 2 months
Unopened package	2 weeks	1 to 2 months
Luncheon Meat		
Opened package	3 to 5 days	1 to 2 months
Unopened package	2 weeks	1 to 2 months
Bacon & Sausage		
Bacon	7 days	1 month
Sausage, raw—from chicken, turkey, pork, beef	1 to 2 days	1 to 2 months

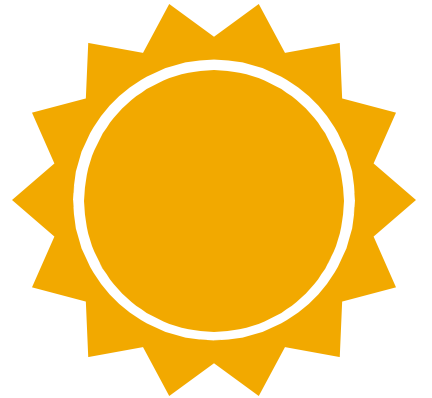
Hamburger and Other Ground Meats		
Hamburger, ground beef, turkey, veal, pork, lamb, & mixtures of them	1 to 2 days	3 to 4 months
Fresh Beef, Veal, Lamb, Pork		
Steaks	3 to 5 days	6 to 12 months
Chops	3 to 5 days	4 to 6 months
Roasts	3 to 5 days	4 to 12 months
Fresh Poultry		
Chicken or turkey, whole	1 to 2 days	1 year
Chicken or turkey, pieces	1 to 2 days	9 months
Seafood		
Lean fish (flounder, haddock, halibut, etc.)	1 to 2 days	6 to 8 months
Fatty fish (salmon, tuna, etc.)	1 to 2 days	2 to 3 months
Leftovers		
Cooked meat or poultry	3 to 4 days	2 to 6 months
Chicken nuggets, patties	3 to 4 days	1 to 3 months
Pizza	3 to 4 days	1 to 2 months

Foods to eat/avoid

Food groups	Foods to eat	Foods not to eat
 Vegetables	<ul style="list-style-type: none">Washed fresh vegetables, lettuce and salads	<ul style="list-style-type: none">Unwashed fresh vegetables, lettuce and salads
 Fruits	<ul style="list-style-type: none">Washed fresh fruits with thin skinsThick-skinned fruits, like oranges, melon and kiwi	<ul style="list-style-type: none">Unwashed fresh fruitsUnpasteurized apple cider
 Meat, poultry and seafood	<ul style="list-style-type: none">Meats, poultry and seafood cooked to safe internal temperaturesHot dogs, lunch and deli meats heated to steaming hot before eating (temperature should be 165°F/73.8°C)Canned pâté or meat spread	<ul style="list-style-type: none">Raw or undercooked meat poultry or seafoodHot dogs, lunch and deli meats that are not heatedUnpasteurized pâtés or meat spreads
 Milk and milk products	<ul style="list-style-type: none">Pasteurized milkHard cheese, processed and pasteurized cheeses (cheddar, mozzarella, cream cheese)	<ul style="list-style-type: none">Unpasteurized milkSoft cheeses and unpasteurized cheeses (feta, brie, Camembert, bleu, Gorgonzola, queso fresco)
 Eggs	<ul style="list-style-type: none">Pasteurized eggs and egg products	<ul style="list-style-type: none">Foods with raw eggs
Other	<ul style="list-style-type: none">Cooked sprouts	<ul style="list-style-type: none">Raw alfalfa and bean sproutsUnpasteurized honey

Sun safety

- Transplant medications raise the risk of skin cancer. Your child should always use sunscreen with SPF 30 or higher.
- Your child should wear a hat and sunglasses and cover up.
- Sun exposure is strongest between 10:00 a.m. and 3:00 p.m. Be extra careful during this time.
- Your child should have regular skin checks.
- Tell the doctor about any new or changing moles or freckles.



Food & sun safety

Q&A

Any questions?

Daily routine



A daily routine might include:

- Wake up.
- Check weight if your transplant team asked you to. Do this at the same time every day – first thing in the morning after using the bathroom and before eating or drinking anything.
- Take blood pressure if your transplant team asked you to.
- Write down weight and blood pressure.
- Give breakfast and medicine at the same time every day.

Recording daily information

Bring this to your clinic visits

Date	Weight	Blood pressure morning	Temp morning	Blood pressure evening	Temp evening	Fluids for the day

Daily routine

Q&A

Any questions?

Physical activity & returning to school



Physical activity

- Talk to the transplant team about sports and gym recommendations.
- Walking is great exercise. Check with the transplant team and the physical therapy team.
- No lifting, pulling or pushing more than 10 pounds.
- Limit over-the-head exercises for 6 – 8 weeks.
- No swimming until the team says it's OK.
- No driving until the team says it's OK.



Back to school

- Your transplant team will tell you when your child can go back to school, work or daycare.
- Your team will give you a school note for absences and restrictions, like gym or sports.
- With your permission, the team can be in touch with the school about your child's medicines, blood pressure checks at school, immunizations, tutoring needs or any other matters.



Physical activity & returning to school

Q&A

Any questions?

Transplant Clinic follow-up



- **Don't** give your child's anti-rejection medication at home on the morning of your clinic appointment.
- Be sure to **bring** your child's anti-rejection medicine with you to the hospital on the morning of the appointment.
- **First:** Go to the outpatient blood drawing lab (Fegan 1) to get blood drawn before your appointment.
 - Tell the lab you have a "timed level ordered."
- Give your child's medicine right away after their blood is drawn in the lab.



Next: Go to clinic to see your transplant team.

Clinic days and locations

Clinic	Days	Location
Renal Clinic	Tuesday and Friday	<i>Fegan 5</i>
Liver/Intestine Clinic	Monday	<i>Fegan 3</i>
Lung Clinic	Wednesday or Thursday (alt weeks)	<i>Fegan 10</i>
Heart Clinic	Tuesday, Wednesday and Thursday	<i>Fegan 2</i>
Outpatient Cardiac Cath	Monday and Thursday	<i>6th Floor Hale Building</i>

Transplant clinic follow-up

Q&A

Any questions?

Calling the Transplant Team



Call anytime

Kidney Transplant

Someone is available day and night.

Routine business hours:

8:30 a.m.– 4:30 p.m.

Main office:

(617) 355-7636

Fax:

(617) 730-0342

Nights/weekends/holidays:

Call (617) 355-6000 and ask to speak to the kidney transplant fellow on call.

Liver and Bowel Transplant

Someone is available day and night.

Routine business hours:

8:30 a.m.– 4:30 p.m.

Main office:

(617) 355-4837

Fax:

(617) 734-0316

Nights/weekends/holidays:

Call (617) 355-6363 and ask to speak to the hepatology fellow on call.

Call anytime

Lung Transplant

Someone is available day and night.

Routine business hours:

8:30 a.m.– 4:30 p.m.

Main office:

(617) 355-6681

Fax:

(617) 730-0097

Nights/weekends/holidays:

Call (617) 355-6363 and ask the page operator to page beeper #0025 **or** dial (617) 355-6000 and ask to page the pulmonary fellow on call.

Heart Transplant

Someone is available day and night.

Routine business hours:

8:30 a.m.– 4:30 p.m.

Main office:

(617) 355-6329

Fax:

(617) 734-9930

Nights/weekends/holidays:

Call (617) 355-6363 and ask the page operator to page the heart transplant cardiologist on call.

When to call or go to the ED:

- Fever higher than 100.5°F/38°C
- A lot of vomiting (throwing up) or diarrhea
- Sore throat or flu-like symptoms
- **Abdominal** (belly) pain or back pain
- Unusual headaches, dizziness, weakness or muscle cramps
- Trouble **urinating** (peeing) or bloody **urine** (pee)
- Not able to take medicines or keep medicine down
- Pain, redness or drainage from a transplant incision
- Signs of infection or rejection
- Trouble breathing or chest pain:
Go to the nearest Emergency Room

ALWAYS CALL 911 in a medical emergency

Be sure to call the transplant team if you go to your child's pediatrician for any illness.

Call your transplant team if you have problems with:

- Equipment and supplies
- Filling prescriptions
- Keeping follow-up appointments

Be sure to refill prescriptions 1 week before medications run out.



Calling the Transplant Team

Q&A

Any questions?

Your transplant guide



- Please keep your guidebook close by, especially for the first few months after the transplant. It has information on every topic about your child's recovery and care.
- Keep your child's medication schedule that the hospital pharmacist gave you in an easy-to-find place.
- **Bring your child's updated medication list with you to your clinic visits or whenever your child is admitted to the hospital.**
- Put the phone numbers for the transplant team **in your cell phone before you leave the hospital during this visit.** Add them to your speed dial at home if you have another phone.

Final questions and review

You can complete a caregiver survey on the day you leave the hospital.

Thank you for your participation!