### TRANSITION TO HOME AFTER YOUR TRANSPLANT SURGERY



## **CONGRATULATIONS!**

#### NOW IS THE TIME FOR YOU TO BEGIN TO PREPARE FOR DISCHARGE TO HOME

**OBJECTIVES FOR THIS CLASS** 

- PLANNING FOR DISCHARGE
- WHEN TO CALL YOUR TRANSPLANT TEAM
- OUTPATIENT LAB WORK
- OUTPATIENT VISITS
- MEDICATIONS
- TRANSPLANT BIOPSIES



## PREPARING FOR DISCHARGE

#### Coordinating your discharge

The inpatient and outpatient teams work together to assure for a smooth transition to home.

A few important points to remember:

- The inpatient team assesses your readiness for discharge daily

   ask your team when you may be ready to go home— call your
   family to let them know.
- The Transplant Nurse Coordinator (TNC) assigned to you will call your family to schedule the medication teaching on the day of discharge
- Write your questions down so that these may be answered by the team.

# DAY OF DISCHARGE

**Day of discharge** – your TNC WILL schedule a time for the teaching session – generally this will be scheduled for late morning on the day of discharge

Please **prepare for the co-pays** – **prior to the discharge day**, call the pharmacy to arrange for payment.

The **pharmacy prepares a bag** and includes:

- Your medications with a patient education medication sheet for every medication
- Pill box, pill cutter
- B/P cuff
- Thermometer
- Water bottle
- Peak flow meter lung transplant patients only

Please purchase a bathroom scale if you do not already have one

## **MEDICATION TIPS**

#### Taking your medications after transplant

You will be taking anti-rejection medications for the rest of your life.

- You must take them at **the same time every day** and **never miss** taking these medications.
- Make sure that you never take your morning medications on an empty stomach. Nausea and/or vomiting are common side effects of these medications. Food in your stomach will decrease the occurrence of this side effect.
- If you are **nauseated or vomiting** and cannot keep your medications in your stomach... **call us immediately**.
- You must check with the transplant team before taking any over the counter medications, vitamins or herbal medications.
- You cannot drink any alcohol.
- For medications that are twice a day you must take them every twelve hours, usually at 8am and 8pm.

## **MEDICATION TIPS**

- Keep a copy of your medication list with you at all times
- Follow your medication list for the dosage of the medication. DO NOT take the dose written on the medication bottle.
- Notify your transplant office before taking any medications prescribed by anyone other than your transplant doctor.
- Do not take ibuprofen products
- Notify your transplant office immediately if you have any problems obtaining medications

# **ANTI-REJECTION MEDICATIONS**

Your anti-rejection medications will be some combination of the following medications:

Neoral/gengraf (cyclosporine) Prograf/Envarsus (tacrolimus) Prednisone Cellcept (mycophenolate mofetil) Rapamune (sirolimus) Imuran (azathioprine)

All medications have two names, a generic name (in parenthesis above) and a brand name. Usually the brand names are easier to pronounce and to spell but you must become familiar with both names.

# **ANTI-REJECTION MEDICATIONS**

Your transplant nurse coordinator will go over your medications with you on the day of discharge

**Common side effects from your anti-rejection medications include:** 

- Tremors of hands
- Hair loss
- Excessive hair growth
- Elevated blood sugar
- Elevated blood pressure
- Burning feeling on the bottom of your feet
- Metallic taste in your mouth
- Blurry vision

We can provide you with an updated medication list when ever needed.

# MANAGING YOUR MEDICATIONS

- Manage your medication refills do not wait until you have are down to the last few pills or have none.
- Many medications require prior authorization, we ask for 7 10 business days to obtain authorization for refill prescriptions.
- Temple hospital pharmacy number is 215-707- 4528.
- For mail order pharmacy we will give you the prescription to send in, we do not call large mail order pharmacies.

Note: Avoid emails sent to a transplant nurse coordinator are not able to be access by anyone other than that specific coordinator. The same is true for the TNC cell phone. This causes delays in care and potential patient safety concerns.

All patients are highly encouraged to use MyTempleHealth contact the transplant team for routine questions. Please let us know if you you need assistance enrolling in MyTempleHealth.

## **OUTPATIENT LAB WORK**

Weekly labs are obtained for the first 2-3 months or longer following discharge. Please follow these instructions:

- Your blood must be drawn at 8:00AM every Monday at either a Labcorp, Quest or Temple Outpatient lab. If for any reason the lab is closed on a Monday, please have labs drawn on Tuesday.
- If your transplant team requires more frequent labs, your Transplant Nurse Coordinator will go over this with you.
- Do not take your morning medication until <u>after</u> your blood work has been drawn.
- You may have breakfast before your blood work.



# OUTPATIENT LAB WORK

#### YOUR TRANSPLANT LABS INCLUDE:

- Complete blood count w/differential (CBC)
- Comprehensive metabolic panel (CMP)
- Tacrolimus level (Prograf or Envarsus)
- Before you are discharged you will be give lab slips specific to you.
- Each time you have blood work drawn show the lab slips to the blood draw technician but do not let them keep it.
- If the lab needs a paper copy of the orders they must make a copy of the paperwork.
- When the year expires, contact us and we will send you lab slips for the next year.
- All patients are highly encouraged to use MyTempleHealth to track your lab results. If you need assistance enrolling in MyTempleHealth, please let us know and we will have someone assist you.
- Your TNC will call you on the telephone if your labs are abnormal and make any adjustments to your medications.

# **CONTACTING THE TRANSPLANT OFFICE**

Your calls are important to us and throughout the day patient calls are handled and triaged. Please follow these guidelines when contacting the lung transplant office.

Routine calls – every attempt is made to return the call that day or within 24 hours – please do not email individual TNC.

Examples of routine calls handled during office hours:

- Prescription refills
- Rescheduling appointments
- Questions about medications
- Oxygen equipment



### **SICK CALLS**

There is a transplant nurse coordinator on call 24/7 and handles illness that arise after business hours, weekends and holidays

#### WHEN TO CALL YOUR TRANSPLANT TEAM

Call if you experience any of the following:

- Fever of 100.4
- New shortness of breath or increased from baseline
- Worsening mucus or change in color
- GI symptoms persistent vomiting or diarrhea
- A drop in peak flow value of 20% from your baseline over 3-4 days

# PLEASE DO NOT CALL THE ON CALL NURSE FOR ROUTINE QUESTIONS.

### SICK CALLS

The Transplant Nurse Coordinator cannot handle emergencies on the phone, call 911 or go to the closest ER and have them call us, do not wait for a return call.

Any questions regarding home services following discharge such as visiting nurse, home health aide, oxygen equipment, please call the case manager arranging for these services.

Contact Numbers: Lung transplant office – 215-707-1722 Heart transplant office – 215-707-6066 Kidney transplant office – 215-707-8889 Liver transplant office – 215-707-8889

# **CONTACTING THE TRANSPLANT OFFICE**

A few important considerations in contacting your transplant office:

- Avoid emails sent to a transplant nurse coordinator are not able to be access by anyone other than that specific coordinator.
- The same is true for the TNC cell phone. This causes delays in care and potential patient safety concerns.
- All patients are highly encouraged to use MyTempleHealth contact the transplant team for routine questions. Please let us know if you need assistance enrolling in MyTempleHealth.



### **GENERAL PRECAUTIONS**

- It is recommended that you not acquire new pets after transplant
- If you already have pets, do not provide direct pet care including emptying the cat litter box
- Always wash your hands following any contact with your pet
- Abstain from alcoholic beverages and from smoking
- Do not drive for at least 8 weeks after transplant and until you are cleared to drive by your transplant cardiologist or surgeon
- You may sit in the front passenger seat of the car if there is an airbag and you are 8 weeks or more since your transplant surgery.

## **GENERAL PRECAUTIONS**

- Always use your seatbelt
- Do not eat raw foods/avoid salad bars and buffets
- No heavy lifting
- No exposure to indoor construction or renovations
- No birds, exotic animals including reptiles



## **IMMUNOSUPPRESSION PRECAUTIONS**

- Wear mask when you leave your home including the hospital.
- Frequent hand washing
- Do not clean cat litter box
- Do not fly in airplanes for the first 6 months
- No saunas and swimming pools for the first 6 months
- Avoid nail salons do not use acrylic nails

# DAILY HOME MONITORING

Record daily temperature, blood pressure, heart rate, and weight in your log book every morning and evening

- Record your highest peak flow meter result
- Record blood sugar results as directed
- Call transplant office if:
  - Temperature is greater than 100.4
  - Cough or shortness of breath
  - Nausea, vomiting or diarrhea
  - A drop in peak flow value of 20% from your baseline over 3-4 days (lung transplant only)

# **GENERAL HEALTH MAINTENANCE**

Schedule all annual health screenings

- Update flu shot annually and pneumonia vaccines as indicated
- Do not take live vaccines
- Avoid sun exposure and apply sunscreen daily using SPF of 30 or greater

#### Maintain your hydration / nutrition

- Drink 6-8 eight (8) ounce glasses of fluid daily
- Eat small and frequent meals
- Do not lie down immediately after eating

## **SEXUAL ACTIVITY**

- You may resume sexual activity when you feel ready
- Women of child-bearing years must use contraception
- The effects of many medicines on fetal growth are unknown
- Erectile dysfunction is common after transplant; please discuss with your PCP your treatment options



## **OUTPATIENT BIOPSIES**

- Biopsies following transplant are done to look for rejection.
- Your transplant team will review with you the specific schedule for biopsies.
- The outpatient transplant team will arrange for the biopsy.



# **TEMPLE HEALTH**