Liver Transplant Handbook

Revised August 2017
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This handbook is dedicated to those who make organ transplant possible – the donors & their families.
Contacting the Liver Transplant Team

A Post-Transplant Coordinator (Coordinator) is my contact person for the Liver Transplant Team after I am discharged.

When should I call my Coordinator?

1. When something doesn’t feel right.

2. When there are symptoms of REJECTION, including:
   - Fever (Temp over 100°F)
   - Fatigue
   - Itching throughout my body
   - Yellow skin or eyes (jaundice)
   - Pain over my liver transplant site
   - New swelling of my arms or legs
   - Gained 3 pounds or more in 1 day
   - Trouble breathing
   - Dark yellow or brown urine
   - Increasing bilirubin or LFT levels

3. When there are symptoms of INFECTION, including:
   - Fever (100°F or higher)
   - Shivering
   - Fatigue
   - Confusion
   - Swelling, redness, or green/yellow leakage from incision site
   - Burning feeling while urinating
   - Cloudy or bad smelling urine
   - Cough (dry or wet)
   - Bloody or green mucus
   - Shortness of breath
   - Nausea
   - Vomiting
   - Diarrhea
   - Loss of appetite
   - Weight loss
   - Blood in stool

4. Or if I am having any of the following issues:
   - A medication reaction.
   - I missed a medication dose.
   - Cannot pay for my medications.
   - Get a new prescription or dosage from my doctor.
   - A positive pregnancy test.
   - Had unprotected sex.
   - Gained more than 3 pounds in 24 hours.
   - Heart rate greater than 100 or less than 55 beats per minute when resting.
   - Systolic (top #) blood pressure that is greater than 150 or less than 100.
   - Diastolic (bottom #) blood pressure that is greater than 100 or less than 60.

Call 911 or go to the closest hospital immediately if I have:
- difficulty breathing, heavy bleeding, chest pain, seizures, one-sided weakness, slurred speech, facial droop, or hit my head after falling
My Coordinator will call to tell me about:

- Changes to my medication regimen (frequent)
- Unexpected lab values
- Scheduling follow-up appointments
- Concerns from the Transplant Team

I must program the following numbers into my cell phone & share them with my Health Buddy:

<table>
<thead>
<tr>
<th>Post-Transplant Liver Office</th>
<th>(410) 614-2989</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denise Burrell-Diggs, RN, MSN</td>
<td>Fax (410) 614-8741</td>
</tr>
<tr>
<td>Liver Transplant Coordinator</td>
<td>Call 8 AM – 4:30 PM</td>
</tr>
<tr>
<td>Lauren Boyer, CRNP</td>
<td>Monday-Friday</td>
</tr>
<tr>
<td>Post-Transplant Nurse Practitioner</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>On-Call Liver Transplant Coordinator</th>
<th>(443) 478-0723</th>
</tr>
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<tbody>
<tr>
<td>For URGENT attention after business hours, weekends, &amp; holidays</td>
<td></td>
</tr>
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</table>

My follow-up labs will be drawn at:

- on Mondays & Thursdays before 9 AM
- & at Express Testing the morning of clinic visits

<table>
<thead>
<tr>
<th>Transplant Pharmacist</th>
<th>1 (888) 264-0393</th>
</tr>
</thead>
<tbody>
<tr>
<td>Select “Store 5” then “Transplant”</td>
<td>Call 8:30 AM – 5:00 PM</td>
</tr>
<tr>
<td>Monday-Friday</td>
<td></td>
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<table>
<thead>
<tr>
<th>Home Care Coordinator</th>
<th>(410) 955-5870</th>
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<table>
<thead>
<tr>
<th>Social Workers</th>
<th>Jason Wheatley (410) 955-5427</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nicole Shah (443) 287-7154</td>
<td></td>
</tr>
</tbody>
</table>
**Blood Work Schedule**

<table>
<thead>
<tr>
<th>Schedule</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge - 2 months</td>
<td>Twice a week (Mondays &amp; Thursdays)</td>
</tr>
<tr>
<td>3 months - 4 months</td>
<td>Once a week</td>
</tr>
<tr>
<td>5 months - 6 months</td>
<td>Every other week</td>
</tr>
<tr>
<td>After 6 months – rest of my life</td>
<td>Once a month</td>
</tr>
</tbody>
</table>

I may go to a Labcorps, Quest Diagnostics or Johns Hopkins Outpatient Lab location close to my home. Lab results can take 2 days to process & post in my MyChart account. My Coordinator may call me about any unexpected results.

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**Clinic Visit Schedule**

<table>
<thead>
<tr>
<th>Schedule</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge - 1 month</td>
<td>Once a week</td>
</tr>
<tr>
<td>2 - 3 months</td>
<td>Every 2 - 4 weeks</td>
</tr>
<tr>
<td>4 months - 1 year</td>
<td>Every 1 - 4 months</td>
</tr>
<tr>
<td>After 1 year – rest of my life</td>
<td>Every 6 - 12 months</td>
</tr>
</tbody>
</table>

The date, time & location of my first clinic visit will be listed in my MyChart account & on my discharge papers. On the day of clinic visits, **I must come 1 hour before my appointment to have bloodwork drawn at Express Testing**, located on the 1st floor of the Johns Hopkins Outpatient Center (JHOC). Arrive to my clinic visit ON TIME. During clinic visits, a physical exam & review of recent lab results & log entries will be done. Any remaining drains or staples may be removed. Changes to my medication regimen may occur during any clinic visit.

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**Bring to ALL clinic visits:**

yellow bag with pill bottles, 7 day pill box, logs, & medication list
Living with My Transplant

As a lifetime caregiver of my donated liver, I will need to:

- Have healthy habits like eating balanced meals & staying active.
- Follow the **strategies to prevent infection**. *(See pages 7-12)*
- Follow my medication regimen. I **must** take my anti-rejection medications or I will lose my liver.
- Report any **falls**, or symptoms of **rejection, infection**, or **bleeding** to my Coordinator.
- **Always** call my Coordinator if I have a question or concern. **Never** think to myself: “I don’t want to bother my Coordinator with this problem.”
- Go to all routine lab tests & clinic visits. My body can begin to reject the donated organ & the labs may be the only sign.
- Contact my Coordinator before taking any medications—prescribed or over-the-counter—**NOT** listed on my medication list.
- Check my blood pressure & heart rate **before** taking my blood pressure & heart medications.
- Stay hydrated. Drink 2 liters per day of water or zero/low calorie, non-caffeinated drinks.
- Follow food safety advice or I could get a food-related infection. *(See page 10)*
- Do not drink alcohol or take illegal drugs.
- Tell my doctors, dentist & pharmacist that I received a transplant & share my new medication regimen.
- Always communicate any changes in health, financial, or living situations with my Coordinator or my Social Worker.

**Questions:**
Avoiding Infection after Transplant

Infections are the #1 cause of readmission after transplant. Why?
For the rest of my life, I will be on anti-rejection medications that LOWER my immune system. Because of this, it will be EASIER to get an infection.

I must prevent infections & call my Coordinator at the earliest sign of infection. I must check my temperature & incision EVERY DAY. I will write the results in my “Daily Vital Signs Log” which I will bring to clinic. (See Logs section)

HOW TO PREVENT INFECTION FOR THE REST OF MY LIFE

- Wash my hands with soap & warm water after I enter the house, use the bathroom & before I eat. Visitors & anyone who lives with me should do the same.

- Use hand sanitizer only if my hands are NOT visibly dirty. Carry a bottle of hand sanitizer when I will be away from home.

- Follow food safety guidelines when purchasing & preparing food. (See page 10)

- Get the flu shot every year!

- Avoid being around anyone who has diarrhea, cold or flu-like symptoms.
 Wear a face mask inside a hospital, clinic, or lab. Replace face mask when dirty.

 Wear a face mask & gloves while gardening or digging in the dirt.

 Do not scoop cat litter, clean a bird cage, or change diapers if possible.

 Before swimming in lakes or oceans, check online for water quality or safety advisories.

 Avoid cruises.

 **For the Next 3 Months**

 Avoid INDOOR public areas AT BUSY TIMES (grocery stores, places of worship, gyms, malls, theaters & restaurants). If *unavoidable*, I must wear a face mask & frequently wash my hands.

 **For the Next 6 Months**

 Avoid digging in soil or gardening.

 Avoid swimming in UNTREATED water (lakes/ocean).

 **For the Next Year**

 Avoid traveling internationally. If travel is necessary, I must inform my Coordinator & wear a face mask & frequently wash my hands while traveling.

 **I must notify my Coordinator if I have any of these symptoms:**

 - Fever (100°F or higher)
 - Shivering
 - Fatigue
 - Confusion
 - Swelling, redness, or green/yellow leakage from incision site
 - Burning feeling while urinating
 - Cloudy or bad smelling urine
 - Cough (dry or wet)
 - Bloody or green mucus
 - Shortness of breath
 - Nausea
 - Vomiting
 - Diarrhea
 - Loss of appetite
 - Weight loss
 - Blood in stool
**Immunizations**

An immunization or vaccine is typically a shot that is given to prevent future illness.

**Since I am at a higher risk of infection, I must:**

- Stay up to date with all my recommended immunizations.
- Get the flu shot every autumn.
- Get the pneumonia shot every 5 years.
- Wait at least 2 months after transplant before getting any immunizations.
- Gather my vaccination history & create a written record.

**To protect me from infection, anyone I live with must:**

- Get the flu shot every autumn.
- Receive any vaccines recommended by their doctor or pediatrician.
- Call my Coordinator with questions about immunizations for me or my children.

**Immunizations safe for transplant recipients (inactivated/killed/subunit/conjugate)**

- Haemophilus influenzae type B (HiB), hepatitis A, hepatitis B series, human papilloma virus (HPV), polio (injection), influenza (injection), meningococcal, pneumococcal (pneumonia), & Tdap (tetanus, diphtheria, pertussis)

**Immunizations to avoid after transplant (live or attenuated)**

- MMR (measles, mumps, rubella), FluMist (nasal influenza vaccine), chickenpox (varicella), shingles (zoster), & BCG
**Nutrition & Food Safety Considerations**

To help my wound(s) heal & prevent high blood sugar, I should eat balanced, high protein meals & snacks. *(See page 24 for recommendations.)* **Avoid** grapefruit & grapefruit juice which can affect my tacrolimus level. Talk to my Transplant Team about taking Vitamin D & a daily multivitamin. A Transplant Dietitian will meet with me to discuss meal options & food safety guidelines.

As a transplant recipient, it is important that my family & I **follow food safety guidelines when purchasing, handling & preparing food:**

<table>
<thead>
<tr>
<th>Drink treated or filtered water. Annually test well water for contaminants.</th>
<th>Wash hands for 20 seconds before preparing &amp; eating food. Use warm soapy water.</th>
<th>Rinse all fruits &amp; vegetables under running water.</th>
<th>Refrigerate or freeze perishable foods within 2 hours of buying, peeling, cutting, or cooking.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separate cooked &amp; raw foods. Use cleaned or separate cutting boards &amp; knives.</td>
<td>Use a food thermometer. <strong>Cook</strong> internal temperature of meat to at least 165°F (well done) &amp; seafood to 145°F.</td>
<td>Use a food thermometer. <strong>Cook</strong> internal temperature of meat to at least 165°F (well done) &amp; seafood to 145°F.</td>
<td>Throw away refrigerated leftovers after 3 days.</td>
</tr>
</tbody>
</table>

**Avoid:**
- Unpasteurized: milk, fruit or vegetable juice/cider
- Cheeses made with **unpasteurized** milk
- **Raw or undercooked:** eggs, meat, poultry, seafood, pâtés, tofu, & sprouts
- Food from self-serve salad bars or buffets
- Food past its “Use By” or expiration date
Cytomegalovirus (CMV) & Epstein-Barr Virus (EBV)

CMV & EBV are common viruses that infect people of all ages by direct contact with an infected person’s bodily fluids. Over half of adults by age 40 have been infected with CMV and/or EBV. Once CMV or EBV is in a person’s body, it stays there for life & can reactivate in organ recipients with weakened immune systems due to lifetime anti-rejection medications. An active CMV infection can raise my risk of organ rejection. An EBV infection can raise my risk of developing post-transplant lymphoproliferative disorders (PTLD).

I must notify my Coordinator if I have these symptoms of CMV or EBV:

- Cold-like symptoms
- Inflamed throat
- Swollen lymph nodes in the neck
- Diarrhea
- Rash
- Fever & chills
- Fatigue
- Nausea & vomiting
- Shortness of breath
- Chest pain

Before I am discharged, I will know the CMV & EBV status of the donor & myself & will discuss my risk for active CMV and/or EBV infection. If I was negative (-) for CMV & EBV before transplant & the donor was positive (+), my risk for developing problems associated with CMV & EBV is high. The Transplant Infectious Disease team will determine which anti-viral medications I should be on & for how long to prevent active infection of either virus. My viral count will be followed while my immune system is severely weakened by the anti-rejection medications.

I was (    ) for CMV & (    ) for EBV before transplant.

The DONOR was (    ) for CMV & (    ) for EBV.

Therefore, I am at _________ risk for active CMV infection & _________ risk for active EBV infection.
Anti-Infection Medications

Bactrim
generic: sulfamethoxazole/trimethoprim

- “B” for anti-BIOTIC or anti-BACTERIAL
- Prevents bacterial infections, e.g. pneumonia
- Take for 1 year after transplant, once daily
- Some SIDE EFFECTS:
  - High potassium levels
  - Low blood counts
  - Easier to sunburn
- Wear sunscreen on areas exposed to direct sunlight

Valcyte
generic: valganciclovir

- “V” for anti-VIRAL
- Protects against cytomegalovirus (CMV) or to prevent viral flare-ups
- Take for 3 to 6 months after transplant, once daily
- Some SIDE EFFECTS:
  - Loose stools
  - Upset stomach
  - Low blood counts

Diflucan
generic: fluconazole

- Anti-FUNGAL
- Prevents infections of the blood, mouth, throat, esophagus, abdomen, lungs, & other organs
- Take for 6 weeks after transplant, once daily
- Some SIDE EFFECTS:
  - Upset stomach
  - Change in taste
  - Can affect my tacrolimus levels
Organ Rejection

Organ rejection occurs when my immune system attacks the “foreign” donated organ & the organ becomes damaged. Anti-rejection medications weaken or block these attacks. I may or may not have symptoms of rejection. The only way to prevent rejection is to take my anti-rejection medications & have my bloodwork drawn as scheduled, though rejection can still happen even if I take my medications.

I must notify my Coordinator if I have any of these symptoms:
- Fever (Temp over 100°F)
- Fatigue
- Itching throughout my body
- Yellow skin or eyes (jaundice)
- Pain over my liver transplant site
- New swelling of my arms or legs
- Gained 3 pounds or more in 1 day
- Trouble breathing
- Dark yellow or brown urine
- Increasing bilirubin or LFT levels

Kidney & liver recipients should report any of these symptoms:
- Less urine output than usual
- Tenderness over my kidney transplant
- Swelling of my hands or feet
- Fever
- Sudden weight gain
- Trouble breathing
- Blood in my urine

If I have any of these symptoms, the Transplant Team may order additional bloodwork, an ultrasound of my organ & adjust my anti-rejection dosages. An organ biopsy may be requested for further diagnosis. The Transplant Team will select the appropriate therapy to stop & reverse the organ rejection. Typically these therapies require inpatient admission, potentially continuing as outpatient treatment.

Cellular Rejection (CR): when my immune system uses T-cells to attack the donated organ. Medications given to reverse cellular rejection may include thymoglobulin & IV steroids (methylprednisolone), followed by an oral steroid taper.

Antibody-Mediated Rejection (AMR): when my immune system uses antibodies to attack the donated organ. Treatment of AMR may include plasmapheresis & intravenous immunoglobulin (IVIG). The plasmapheresis process removes antibodies from my blood. The IVIG replaces the good antibodies that fight infection & teaches my immune system not to make the bad antibodies that hurt my transplant.
Anti-Rejection Medications

**Prograf**
generic: tacrolimus

- Lifetime anti-rejection medication
- Blood levels will be checked to make sure my dose is appropriate
- Avoid grapefruit & grapefruit juice
- Some SIDE EFFECTS:
  - Tremors
  - Increased blood sugar
  - Kidney damage
- Take twice daily at 8 AM & 8 PM
  - On lab days take AM dose after bloodwork is drawn

**CellCept**
generic: mycophenolate mofetil

- Anti-rejection medication taken for 3 months after transplant
  - Exception: lifetime medication for combined liver & kidney recipients
- Magnesium, calcium, or iron-containing tablets I am prescribed must be taken 1 hour **before** or 2 hours **after** CellCept dose
- Some SIDE EFFECTS:
  - Loose stools
  - Upset stomach
  - Vomiting
- Take twice daily unless instructed otherwise by the Transplant Team

**Prednisone**

- Anti-rejection medication taken for one year after transplant
  - Exception: lifetime medication for combined liver & kidney recipients
- Will be tapered down gradually—my Coordinator will tell me how & when
- Some SIDE EFFECTS:
  - Increased blood sugar
  - Weight gain
  - Mood changes
  - Delayed incision healing
- Take once daily unless instructed otherwise by the Transplant Team
Taking Care of My Incision & Drain

I can expect to feel some numbness over the incision & occasional pain during the healing process. The staples will be removed when fully healed. This typically takes 3-4 weeks after surgery. Showering—NOT bathing or swimming—is okay while I have drains & my incision is healing. Be careful not to scrub the incision. If leaking occurs, I can place a sterile dressing over the incision.

If I go home with a drain, the Transplant Team will give me an opportunity to measure & describe the color & consistency of the drainage. With the supplies provided, I will measure & record the volume, color, & consistency of drainage in my “Drain Care Log” (See Logs section). I will bring the log to my first clinic visit.

I must notify my Coordinator if I have:
- a temperature of 100° F or higher
- a sudden gush of fluid from the incision
- increased drainage output
- bright red drainage that is new
- changes in drainage color or consistency
- redness, tenderness, swelling, or pus along the incision or around the drain insertion site(s)

Activity Considerations

Every day, I will increase my physical activity or I risk returning to the hospital.

I must:
- Move at least every 2 hours during the day.
- Avoid lifting more than 10 pounds (or items heavier than a full gallon of milk) for 8 weeks after surgery.
- Not drive for 4-6 weeks after the date of surgery or while taking narcotic pain medications. Discuss driving & returning to work at my clinic visits.

If I require additional rehabilitation or home care after discharge, a Social Worker will discuss rehabilitation options with me & my family. A Home Care Coordinator will arrange medical equipment, home rehabilitation, & skilled nursing visits as needed.
Taking Care of My Teeth & Gums

A lot of germs live in the mouth; therefore, **keeping my teeth & gums clean prevents infection**. Dental cleanings do not need to be delayed after my transplant.

I will:
- Alert the dentist about my transplant & share my medication regimen.
- If I can, wait at least 6 months to have any major dental work done.
- Take antibiotics prescribed by my dentist.

Herbal Supplements

Avoid consuming herbal supplements due to limited information regarding harmful interactions with anti-rejection medicines. The Transplant Team does not recommend over-the-counter probiotics; however, yogurt is okay. Herbal teas are okay.

Prescription Refills

I should always have a week’s supply of medications. If I do not have refills left on my prescription, have lost my medications, or cannot pay for my medicines, I must call my Coordinator during business hours or the On-Call Liver Transplant Coordinator after hours, weekends, or holidays. The Transplant Pharmacists will discuss preferred pharmacy options with me & counsel me on all my medications before I am discharged.

International Travel

Certain countries & modes of travel significantly increase my risk for infection. The Johns Hopkins Travel Health program can provide vaccines, medicines & offer prevention advice for malaria, travelers’ diarrhea & other serious infections found in other countries. Please note that full immunity may take several months to develop after receiving a vaccination.

I must:
- Avoid traveling internationally in the first year after transplant.
- Avoid cruises for the rest of my life.
- Notify my Coordinator if I plan to travel internationally or will be on a plane.
- Wear a face mask & frequently wash my hands in airports & on planes.
Sexual Relations/ Safer Sex/ Contraception

The Transplant Team believes that I may be physically able to resume sexual activity when I can easily walk up a flight of stairs. Avoid any position that causes pain or puts strain on my incision. **If I am not in a committed, single-partner relationship, I should follow safer sex practices**, including the use of a barrier such as condoms to prevent sexually transmitted infections during oral, vaginal & anal sex.

**Male & female** transplant recipients must consult with their Coordinator before trying to have a child. The health of a male recipient’s sperm may be affected by the anti-rejection medications. For female recipients, the anti-rejection medications increase the risk of pregnancy loss in the first trimester, birth defects in the developing baby, & delivering a baby with low birth weight. Additionally, the risk of rejection increases if pregnant. Discuss the **best methods of contraception** with my Transplant Team.

**I must notify my Coordinator if I have:**
- a positive (+) pregnancy test
- unprotected sex

Skin Cancer Risk

The anti-rejection medications triple my risk for skin cancer. **To reduce this risk,** I should wear SPF 30+ sunscreen on areas of my body exposed to direct sunlight, along with loose pants, long-sleeved shirts, & a wide-brimmed hat. It is better that I avoid being in direct sun from 11 AM - 3 PM. The Transplant Team will arrange a skin cancer screening with a dermatologist 6 months from my transplant.
When to Contact a Social Worker

After I am discharged, I may feel burdened, stressed or anxious by the various responsibilities & costs that come with having a transplant. The Transplant Team asks that I wait 2 months from transplant before returning to work, potentially creating a financial burden on my family & me.

To thrive after my transplant, I should rely on the help & support of friends & family. When there is a need for additional support, I should contact my Liver Transplant Team’s Social Worker, either Jason Wheatley at (410) 955-5427 or Nicole Shah at (443) 287-7154.

Concerns that can be addressed include:

- difficulty adjusting to the responsibilities of managing my transplant
- inability to pay my medical bills or to fund daily needs
- lack reliable transportation to & from my appointments
- anxiety, depression, or other mental health issues
Potential Complications

Blood Pressure (Low or High)

Recurrent Liver Disease

Cancer

High Cholesterol

Diabetes
Blood Pressure (Low or High)

The Transplant Team will work with my primary care physician or cardiologist to select the best blood pressure & heart medications. Low or high blood pressure can damage my donated organ & increases my risk for strokes & heart attacks.

I will be provided a blood pressure monitor so I can measure my blood pressure & heart rate twice a day before taking blood pressure & heart medications. I will record these measurements in my “Daily Vital Signs Log” & bring the log to clinic visits. (See Logs section)

I must notify my Coordinator if:
- Heart rate is greater than 100 or less than 55 beats per minute while resting.
- Systolic (top #) blood pressure reading is greater than 150 or less than 100.
- Diastolic (bottom #) blood pressure reading is greater than 100 or less than 60.
- I feel dizzy or light-headed when I make sudden changes in position.
- Blood pressure cuff is not working properly.

Call 911 or go to the closest hospital immediately if I have:
- difficulty breathing, heavy bleeding, chest pain, seizures, one-sided weakness, slurred speech, facial droop, or hit my head after falling

High LDL Cholesterol

My body needs some cholesterol to work properly; but, if I have too much in my blood—specifically low-density lipoprotein or LDL—it can stick to the walls of my arteries creating plaque. If this plaque continues building up, it can narrow, block or harden my arteries increasing my risk for heart attack, stroke & heart disease.

Foods high in fat & cholesterol along with a family history of high cholesterol contribute to high LDL cholesterol levels. I may be able to control my LDL cholesterol level with healthy meals & an active lifestyle. If changes in my food choices & lifestyle do not lower my cholesterol, a cholesterol-lowering medication may be needed. The Transplant Dietitian is available to discuss low cholesterol meal choices.
**Recurrent Liver Disease**

The Transplant Team will inform me if my liver disease can recur in my transplanted liver. They will monitor my lab results to determine if I have any signs of recurrent disease. If I have unexpected lab results, they will consider multiple causes & order tests before making a diagnosis & ordering treatment.

**Cancer**

Some people require a liver transplant because of liver cancer. Those persons are screened very carefully before transplant to be sure the cancer has not spread outside of the liver. They will be screened every three months for the first year after transplant to check for signs of recurrent cancer. I should have regular screenings to check for signs of other types of cancer, including skin, breast, cervical & prostate cancer.

**Diabetes**

The anti-rejection drugs tacrolimus & prednisone can raise my blood sugars, increasing my risk of developing post-transplant diabetes. If I am currently diabetic & my blood sugars have been controlled with pills, this regimen will be put off for the next several months. My blood sugars will be controlled by a combination of insulin, smarter food choices, & a physically-active lifestyle.

While in the hospital, all transplant patients are ordered short-acting insulin for meals & bedtime. My nurse will use a SLIDING SCALE & my finger-stick blood sugar to determine my CORRECTIONAL insulin dose. A NUTRITIONAL dose of short-acting insulin may be ordered for additional sugar control at mealtimes. LONG-ACTING insulin may be ordered to help control my blood sugars throughout the next day.

If insulin is needed after discharge, I will:

- Be taught how to select correct insulin doses & use an insulin pen. I will practice these skills during my hospital stay.
- Be provided & taught how to use a glucometer & lancets to check my blood sugar.
- Record blood sugar readings & insulin doses in the “Blood Sugar & Insulin Log” & bring this log to clinic visits. *(See Logs section)*
- Carry candies at all times in case of low blood sugar.
I must notify my Coordinator if I have:

- blood sugars are consistently above 200 or less than 80.
- Have any of the following signs & symptoms of low or high blood sugar:

Low Blood Sugar
(Hypoglycemia)

Causes
You might get low blood sugar (also called hypoglycemia) if you:

- Take certain medicines and eat too few carbohydrates or skip or delay a meal (Talk with your diabetes care team to see if this applies to you)
- Take too much insulin or diabetes pills
- Are more active than usual

Signs and Symptoms
Here’s what may happen when your blood sugar is low:

- Shaky
- Fast heartbeat
- Sweaty
- Dizzy or shaky
- Anxious
- Hungry
- Blurry vision
- Weak or tired
- Headache
- Nervous or upset

If low blood sugar is not treated, it can cause you to pass out. You may even die.
High Blood Sugar
(Hyperglycemia)

Causes
Over time, too much sugar in your blood can cause serious health problems. High blood sugar (also called hyperglycemia) can occur if you:

- Skip a dose of insulin or diabetes pills
- Eat more than usual
- Are less active than usual
- Are under stress or are sick

What to do about high blood sugar
The best way to avoid high blood sugar is to follow your diabetes care plan. Call your diabetes care team if your blood sugar is higher than your goal for 3 days in a row or as suggested by your diabetes care team.

Signs & Symptoms
Here’s what may happen when your blood sugar is high:

- Very thirsty
- Needing to pass urine more often than usual
- Dry skin
- Very hungry
- Sleepy
- Blurry vision
- Infections or injuries heal more slowly than usual
Logs

Daily Vital Signs Log

Drain Care Log

Blood Sugar & Insulin Log

Bring Logs to Clinic Visits
**DAILY VITAL SIGNS LOG**

Check Vital Signs *before* taking medications

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**I must notify my Coordinator if:**

**BLOOD PRESSURE:** Systolic reading (top number) is greater than 150 or less than 100.

Diastolic reading (bottom number) is greater than 100 or less than 60.

I feel dizzy or light-headed when I make sudden changes in position.

**HEART RATE:** Greater than 100 or less than 55 beats per minute at rest.

**TEMPERATURE:** Greater than 100° F.

**WEIGHT:** Gained more than 3 pounds in 24 hours.
# DAILY VITAL SIGNS LOG

Check Vital Signs *before* taking medications

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# DAILY VITAL SIGNS LOG

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I feel dizzy or light-headed when I make sudden changes in position.

**HEART RATE:** Greater than 100 or less than 55 beats per minute at rest.

**TEMPERATURE:** Greater than 100° F.

**WEIGHT:** Gained more than 3 pounds in 24 hours.
# DRAIN CARE LOG

Empty drains TWICE A DAY & when fully inflated or filled. Strip tubing if clots are present.

<table>
<thead>
<tr>
<th>DATE/ TIME</th>
<th>DRAIN #</th>
<th>DRAINAGE AMOUNT (ml)</th>
<th>DRAINAGE Clear, Pink-tinged, Pink, Red, Dark Red? Thin or Thick?</th>
<th>DRAIN INSERTION SITE DRESSING CHANGED?</th>
<th>UNUSUAL OBSERVATIONS @ the DRAIN INSERTION SITE Redness, Drainage, or Swelling?</th>
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**I must notify my Coordinator if I have:**

- Increased drainage; bright red drainage that is new; temperature of 100° F or higher; or
- redness, tenderness, swelling, or pus at the insertion site.
DRAIN CARE LOG

Empty drains TWICE A DAY & when fully inflated or filled. Strip tubing if clots are present.

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Increased drainage; bright red drainage that is new; temperature of 100° F or higher; or redness, tenderness, swelling, or pus at the insertion site.
BLOOD SUGAR & INSULIN LOG

Check blood sugar within 30 minutes **before** eating my meal & going to bed.
Inject insulin within 30 minutes **after** eating my meal.

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<tr>
<th>Date</th>
<th>Before Breakfast Sugar</th>
<th>Insulin Amount &amp; Type</th>
<th>Before Lunch Sugar</th>
<th>Insulin Amount &amp; Type</th>
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- **BEFORE** meals check blood sugar & record results in log. Bring log to clinic.
- Administer insulin **AFTER** meals.
- Carry some candies **at all times** in case of low blood sugar.
- If blood sugars are consistently above 200 or less than 80, call my Coordinator.
- If sugar is greater than 350, call my Coordinator.
- If I have cold sweats, confusion, nausea, or vomiting, check my blood sugar.
- If my sugar is less than 70, drink juice or eat 6 crackers. Recheck sugar in 15 minutes. Repeat until sugar is greater than 80. Call my Coordinator.
BLOOD SUGAR & INSULIN LOG

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- **BEFORE** meals check blood sugar & record results in log. Bring log to clinic.
- Administer insulin **AFTER** meals.
- Carry some candies at all times in case of low blood sugar.
- If blood sugars are consistently above 200 or less than 80, call my Coordinator.
- If sugar is greater than 350, call my Coordinator.
- If I have cold sweats, confusion, nausea, or vomiting, check my blood sugar.
- If my sugar is less than 70, drink juice or eat 6 crackers. Recheck sugar in 15 minutes. Repeat until sugar is greater than 80. Call my Coordinator.