

POST-OP LIVER TRANSPLANT PATIENT GUIDE





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CONGRATULATIONS ON YOUR NEW LIVER!

This manual is for you and your caregiver(s). Please become familiar with this information, as it will serve as a guide and resource over the coming months. Please understand that this is simply a guide, and your transplant surgeon will decide your specific plan of care.

DISCHARGE FROM TRANSPLANT CLINIC

TRANSPLANT CLINIC

The UK Transplant Clinic is located on the third floor, Wing D of the Kentucky Clinic.

Visits will be twice weekly for four to six weeks after discharge. You will then have weekly visits for the next two months.

Arrive at the Transplant Clinic between 7 -7:30 a.m. You will have blood drawn for tests that will measure your liver function, kidney function, blood count, and cyclosporine or Prograf® levels.

Always bring your medication to the clinic.

Do not take any medications until your labs have been drawn. Once the labs have been drawn, you may take your medications and go to the cafeteria for breakfast.

Please be prepared to spend all morning in the Transplant Center. You may want to bring reading material or another quiet activity to help pass the time.

We will call you between 4 -6 p.m. on the day of your clinic appointment if any changes need to be made in your medications. We must be able to contact you or leave a message. Please know how to retrieve messages on your answering machine or cellphone.

You must notify the transplant team if your phone numbers change so that we may contact you if your medication changes.

DISCHARGE FROM THE TRANSPLANT CLINIC

After three months, your transplant surgeons will return you to the care of your family physician or GI specialist, except for issues directly related to your transplant. You are required to have a primary care physician. The correct and up-to-date physician information must be on file with our transplant team.

Your family physician or GI specialist will take care of your regular medical needs, including stomach medicine, blood pressure checks, blood sugar medicine, chronic pain management issues and thyroid issues.

The transplant team will continue to monitor your lab results on a regular basis. You can have your blood work done in a local laboratory or at the Transplant Clinic by appointment only.

You will be given physician lab orders for your blood testing to be performed locally.

It is your responsibility to make sure that the Transplant Center receives the results of your blood work on a regular basis. Lab results can be faxed to **859-257-3644**.

Your family doctor may contact the Transplant Center to ask questions or seek advice about your care after surgery.

DISCHARGE FROM TRANSPLANT CLINIC

PROTECTING YOUR NEW LIVER

WEAR YOUR MASK

It is important to wear a mask. This is critical immediately after liver transplantation.

- You should wear a mask everywhere outside of your home for the first three months after your surgery.
- If you are treated for rejection, you may be asked to start wearing your mask again.

INCISION CARE

Once you are feeling strong enough, you will be allowed to shower.

- Use soap and water and wash right over the wound and staples.
- After you shower, replace the dressings that cover any open wounds.
- The incision may itch, feel numb, and be bruised and/or sore.
- Staples are generally removed in clinic two to three weeks after your surgery.

HANDWASHING

Frequent handwashing by you and your family is the most effective way to prevent infection. Use antibacterial soap or alcohol-based hand sanitizer.

PLANTS AND YARDWORK

Avoid live plants and do not touch the soil for three months after your transplant. Houseplants do not have to be removed from your home, but they should not be in your immediate living or sleeping areas.

- After three months, you must wear gloves and a mask when disturbing the soil.
- Mowing grass, including riding lawnmowers and using a weed eater, is not recommended until six months after transplant.

SEXUAL ACTIVITY

Once you feel strong enough, you may resume sexual activity.

- Be careful not to become pregnant or cause someone else to become pregnant following your transplant. The effects of anti-rejection medications on the fetuses are still unknown.
- It is important to always practice safe sex to avoid the risk of sexually transmitted diseases.

PROTECTING YOUR NEW LIVER

NUTRITION

HEALTHY EATING

Eat a healthy, low-fat diet with lots of fruits and vegetables. You may eat fresh fruits and vegetables, but be sure to wash all produce thoroughly. Do not eat raw fish. All meats should be cooked to a minimum of medium well. Avoid grapefruit and grapefruit juice completely.

WEIGHT GAIN

Weight gain is a very common problem after transplantation.

- This is usually the result of increased appetite from steroid medications.
- Eliminating nearly all fat or fatty and fried foods from your regular meals will help control this problem as well as your cholesterol.
- You may need to see a dietary specialist if weight gain becomes severe.

WEIGHT LOSS

Weight loss is also common after transplant. Some people experience a loss of appetite.

- Medications and general weakness may cause loss of appetite.
- Eating five or six small meals daily rather than three large meals is often helpful.

DIETARY SPECIALIST

You may need to see a dietary specialist if weight loss becomes severe.

- Special diets are usually not needed after transplant.
- Occasionally, patients have problems controlling their blood sugar due to steroid medications. The transplant team will review any special dietary changes that you may need to make.



PROTECTING YOUR NEW LIVER CAREGIVING RESPONSIBILITIES

You must have at least one caregiver to help you after transplant. The caregiver(s) must:

- Be present at the hospital prior to your discharge. The transplant nurse coordinators will provide education to you and the caregiver.
- Stay with you 24 hours a day, seven days a week for four to six weeks after surgery. If you live more than an hour away from the Transplant Center, you and your caregiver must stay in Lexington during this time.
- Provide transportation to the Transplant Clinic twice a week and as needed.
- Perform general errands such as grocery shopping, picking up medicine from the pharmacy, laundry, transportation to the clinic for unscheduled appointments, emergency department visits and anything else that is needed.

- Ensure that you take all medications as prescribed, including insulin injections, if needed.
- Check and record your blood pressure, blood glucose levels as needed, temperature and weight daily.
- Assist with meal preparation, bathing, dressing and wound care, if needed.
- Encourage you to drink fluids and eat healthfully to avoid dehydration.
- Encourage and assist you with minimal daily exercise.
- Make sure you wear your mask.
- Notify the transplant team in case of emergency.

POST-OP LIVER TRANSPLANT DO'S AND DON'TS

THINGS YOU MUST DO

Protect your health.

- Wear your mask.
- Wash your hands often.
- Take your medications as directed.
- Walk at least every four hours.
- Drink two to three liters of fluid every day.
- Use an incentive spirometer (blow bottle) every four hours.

Know your numbers.

- Take and record your blood pressure four times a day.
- Take and record your temperature every morning and every night.
- Weigh yourself every morning and record the results.
- Check your blood sugar as directed.

Be active in your care.

- Keep all of your doctor's appointments.
- Make appointments with the front desk for labs only.
- Ask questions and keep notes.

THINGS TO AVOID

Avoid these activities.

- Do not drive until your physician says it is OK.
- Avoid swimming in public pools, lakes, rivers or oceans for at least six months.
- Avoid climbing multiple steps (more than two) until directed otherwise.
- Do not lift anything heavier than a gallon of milk until otherwise instructed.
- Do not use alcohol, cigarettes or illegal drugs.

Avoid these situations.

- Avoid direct sunlight. Wear long sleeves, a hat and sunblock with at least SPF 25.
- Avoid large crowds of people for three months.
- Avoid anyone with an illness you could catch. This includes colds, fevers and sore throats.
- Avoid anyone who has had a live vaccination for a minimum of two weeks after that person received the vaccine.
- Avoid using hair color or permanents for three months.
- Avoid strong chemicals and toxic fumes for three months.

Avoid these medical mistakes.

- Do not take any over-the-counter medication without your doctor's approval.
- Do not adjust or change your medications unless instructed to do so. **5**



POST-OP LIVER TRANSPLANT GUIDELINES FOR LIVING WITH YOUR NEW ORGAN

PHYSICAL ACTIVITY

Be patient with yourself. Regain your strength through a gentle, gradual increase in the physical activity you do each day.

- For the first month, do not lift anything heavier than a gallon of milk.
- Begin increasing your activity by walking.
- Over time, you may begin other exercise if your doctor says it is OK. Examples are jogging, playing golf or riding a bicycle.
- Avoid contact sports. These include contact boxing, martial arts, football, and hockey.

DENTAL CARE

Good oral hygiene is a must.

- Visit your dentist once every six months.
- Get any infection treated right away. If you take immunosuppressive medicines, a minor dental infection can be very serious.
- When you have any dental work, you must have a short course of oral antibiotics. Your dentist will arrange for antibiotic therapy before dental work and follow American Heart Association guidelines.

IMMUNIZATIONS

You may only get killed-virus immunizations (shots). You may not get any live or weakened virus vaccine. These include mumps, measles, rubella, chicken pox, shingles and oral polio.

- You may get a flu shot six months after transplant.
- Family members should get a flu shot right away.
- You and your family must avoid the nasal flu vaccine.

ALCOHOLIC BEVERAGES

Alcohol is a toxin that will harm your transplant. One drink is too many.

- People who choose to use alcohol after surgery will not be considered for a second transplant if needed.

SMOKING

Stop smoking and tobacco use.

- The blood vessels in transplanted organs harden faster. Smoking and other tobacco makes this problem even worse.

POST-OP LIVER TRANSPLANT CONTACTING THE TRANSPLANT TEAM

The transplant team is in the office Monday through Friday 8 a.m. – 5 p.m.

The main liver transplant number is

859-323-8500 or **888-808-3212** (toll-free).

Please be aware that the transplant nurse coordinators work in the clinic every Tuesday and Friday.

You will be directed to leave a voicemail when your nurse is unavailable. Expect this to happen frequently. Leave a message and your call will be returned as soon as possible.

FOR EMERGENCIES

Call the 24-hour UK Answering Service at 859-323-6667. Follow these steps:

- You or your family will call 859-323-6667. You do not need to dial the area code if you are calling from Lexington.
- Your call will be answered by a UK Operator. Tell the operator that you need to speak with the on-call liver transplant nurse coordinator.

Call the emergency contact right away if you have any of the following:

- Temperature greater than 100.5° F.
- Systolic (top number) of blood pressure greater than 180 or less than 100.

- Diastolic (bottom number) of blood pressure greater than 100.
- Significantly increased or new drainage from your wound.
- Vomiting, diarrhea or constipation lasting more than two to three days.
- Pain that is not relieved by your pain medicine.
- Bright red blood in your urine or stool.
- New onset of weakness.

Do not use the emergency contact for non-emergency questions. Please direct non-emergency-related questions to your transplant nurse coordinator during normal business hours. The transplant nurse coordinators will return your routine calls within 24 hours or during the next business day.

PRESCRIPTIONS

It is your responsibility to notify the transplant team seven to 10 days prior to running out of medications.

Many insurance companies need to have preauthorization. Requests must be made to your coordinator during regular business hours.

Prescription refills are never an emergency, and the pager should not be used.

POST-OP LIVER TRANSPLANT POSSIBLE COMPLICATIONS

Most patients do well after transplantation, however, some can develop complications resulting in long hospital stays and even death. Possible complications include:

PRIMARY NONFUNCTION

A serious, rare condition in which the transplanted organ did not start working immediately after surgery. It can be caused by multiple factors.

BLEEDING

As with any surgery, there is a risk of bleeding. It is possible that after surgery, bleeding may still occur and you may have to return to the operating room.

REJECTION

This term is used to describe how your body responds to anything it recognizes as “foreign.” Your body will not recognize the new organ as being part of you. Anti-rejection medication will help your body accept the new organ. rejection is the easiest problem to treat and can happen any time after your transplant.

- Rejection has no symptoms, although some patients experience discomfort in the abdomen, as well as a slight fever.
- Lab tests will become abnormal. If this occurs you may need a biopsy.
- You may need to be admitted to the hospital for treatment.

- When you are discharged, you may have medication changes and require more frequent follow-up – labs and clinic visits, etc.

INFECTIONS

Anti-rejection medication reduces your body’s ability to fight infections, so you should stay away from people who have colds, flu or any other contagious illnesses.

Viral – Two common viral infections are cytomegalovirus (CMV) and the herpes virus (HSV). Most people have been exposed to these viruses during normal daily activities. With anti-rejection medication the viruses can become reactivated and cause significant illnesses that may require treatment. Medicine is available to treat these infections. If the infection is severe, you may require a period of hospitalization to receive this medicine intravenously.

Bacterial – Wound infections can occur after transplantation. These will most often require antibiotics. Occasionally, they may require additional operations.

Fungal – Fungal and yeast infections may occur. Medicine and good hygiene will help prevent infections. Fungal infections of the lungs can be very serious and may be contracted by inhaling dust or mold.

DEPENDENCE ON VENTILATOR

Dependence on ventilator (breathing machine), from pre-existing lung problems or pneumonia.

POOR NUTRITION

Poor nutrition from the inability to eat.

NEUROLOGICAL SIDE EFFECTS

These can range from mild confusion to seizures and stroke.

KIDNEY DYSFUNCTION

Kidney and failure requires dialysis. n.

BILE DUCT PROBLEMS

This at may require you to go home with drains and tubes. Additional instructions will be given when you are discharged.

BLOOD SUPPLY

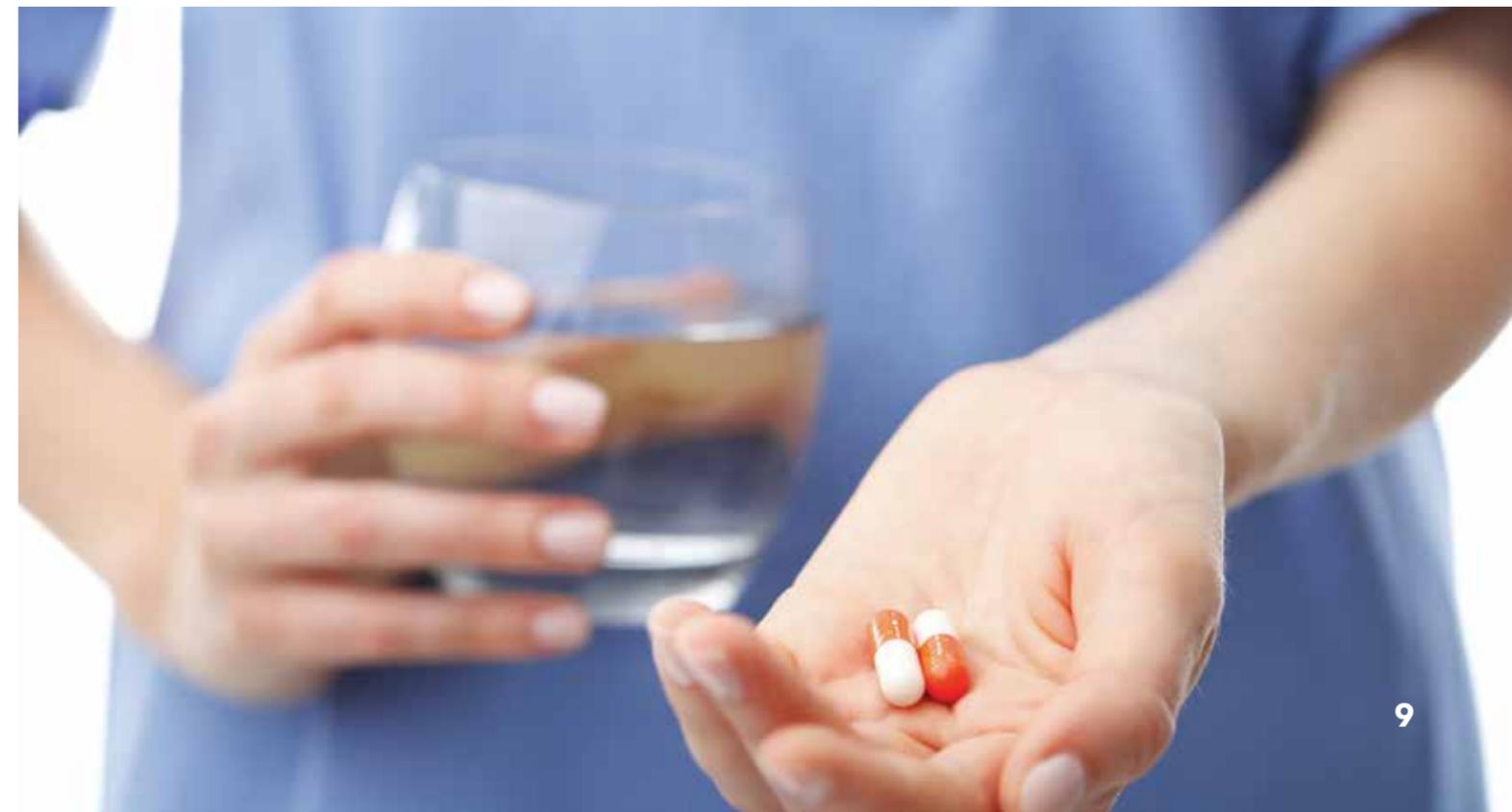
Blood supply to your new organ may become compromised after surgery, requiring an additional operation.

DEVELOPMENT OF TUMORS

If you have had liver cancer, you will require additional testing after transplantation.

MOOD CHANGES

(depression, crying spells, irritability, difficulty sleeping, night sweats or memory loss). Your caregiver and transplant team will help you through this difficult period. Please let your transplant team know if you have been experiencing any of these issues for more than a week.



POST-OP LIVER TRANSPLANT

POST-OP LIVER TRANSPLANT

Taking your medications correctly is the most important thing you can do to prevent rejection of your liver transplant. Never skip a dose or change your dose unless you are instructed to do so. Here are some general medication rules for liver transplant patients:

- Always contact the transplant team before starting any new medications, whether over-the-counter or prescription.
- Store all medications at room temperature unless otherwise indicated on the medication container.
- Do not store medication in the bathroom medicine cabinet. Always keep medications in their prescription bottles or your weekly pill box.
- Please protect these medications from children.
- When flying, keep your medications in your carry-on. Airline regulations require you to keep all medication in the original pill bottles or they will be thrown away.
- Make taking your medications a part of your daily routine, just like eating and sleeping.
- While you are in the hospital, the transplant pharmacist will teach you about your medications.
- Always bring your pill bottles to every clinic visit.

MEDICATION RESOURCES

Genetech, the makers of Cellcept® and Valcyte® www.cellcept.com
www.valcyte.com

RxAssist, patient assistance program
www.rxassist.org

Rx Outreach, patient assistance program
www.rxoutreach.com

Pfizer, the makers of Rapamune®
www.rapamune.com

Partnership for Prescription Assistance
www.pparx.org

Transplant Experience
www.transplantexperience.com

MyMedSchedule
www.mymedschedule.com

Abbott, the makers of Gengraf®
www.abbott.com

Astellas, the makers of Prograf®
www.us.astellas.com www.prograf.com

Novartis, the makers of Neoral® and Myfortic® www.novartis.com
www.myfortic.com

POST-OP LIVER TRANSPLANT

TRANSPLANT MEDICINES

TACROLIMUS (PROGRAF)

Type of drug: Anti-rejection

How often to take: Every 12 hours

Possible side effects:

- Decreased Liver function: We will closely check your Liver function with lab tests. Keep to the correct dose to minimize the risk.
- Tremor of hands: This usually stops as the dosage is reduced. A new onset of tremor may indicate the level is too high.
- Increased blood pressure: We will use medications to keep your blood pressure under control.
- Headache.
- High blood sugar: We will closely check your blood sugar with lab tests.
- Flushing of the skin.

What to do if you miss a dose: If you remember it within six hours, go ahead and take it. If you remember after six hours, **do not** make up for the missed dose. Take your next dose at the regular time and get back on schedule. **Never take a double dose.** If you miss two or more doses, call your transplant nurse coordinator.

If your body cannot handle tacrolimus, we may replace it with cyclosporine (Neoral® or Gengraf®).

Do not eat grapefruit or drink grapefruit juice while taking this medicine.

MYCOPHENOLATE MOFETIL (CELLCEPT)/ MYCOPHENOLIC ACID (MYFORTIC)

Type of drug: Anti-rejection

How often to take: Every 12 hours

Possible side effects:

- Decreased blood counts: We will follow your labs closely and adjust this medicine as needed.
- Dizziness or Drowsiness.
- Nausea, vomiting or diarrhea.
- Insomnia.
- Mood changes.

What to do if you miss a dose: If you remember it within six hours, go ahead and take it. If you remember after six hours, **do not** make up for the missed dose. Take your next dose at the regular time and get back on schedule. **Never take a double dose.**

PREDNISONE

Type of drug: Anti-rejection, steroid

How often to take: Once a day in the morning

Possible side effects:

- Salt and water retention: This may make your ankles puffy.
- Stomach ulcers: Always take this medicine with food. You will take medicine to prevent ulcers until we reduce your dose.
- Weight gain: This may be from storing

extra fluid or extra fat. A common problem is “moon face.” Weight gain in the face is a common problem with steroids. This improves as your steroid dose is lowered.

- Increased appetite: You may have to “push yourself away from the table” to avoid weight gain.
- Muscle weakness: Be careful when you get out of chairs or climb stairs until you get your strength back. Continue to walk and exercise to keep your strength.
- Blurred vision: This improves as your steroid dose is lowered. Do not get new glasses right after your transplant. Your vision will change over the next six months. You may also develop cataracts. Have an ophthalmologist check your eyes regularly.
- Sleep problems.
- Slow wound healing.
- Mood swings: You may feel happy one minute and depressed the next. You should feel like your normal self again when your steroid dose is lower.
- Increased risk for infection.
- High blood sugar: Tell your doctor if you have any sign of high blood sugar, such as increased thirst or tiredness. You may need to start on insulin if your blood sugar stays high.
- Osteoporosis or low bone density: This medicine can make your bones brittle. You should have your family doctor check this every year. You may need to take a medicine to treat osteoporosis.

What to do you if you miss a dose: If you remember it within 12 hours, take

it right away. If you remember after 12 hours, **do not** make up for the missed dose. Take your next dose at the regular time and get back on schedule. **Never take a double dose.**

Do not stop this medicine unless the transplant team says it is OK.

SULFAMETHOXAZOLE/TRI-METHOPRIM (BACTRIM, SEPTRA, COTRIM)

Type of drug: Antibiotic (to prevent infection)

How often to take: Once a day in the morning

Possible side effects:

- Nausea, vomiting, belly cramps or diarrhea: If you have these, take the medicine with food.
- Skin rash or itching: If you have these, call your doctor right away.
- Sensitivity to light: Always wear sunscreen when outdoors.

What to do you if you miss a dose: If you remember it within 12 hours, take it right away. If you remember after 12 hours, **do not** make up for the missed dose. Take your next dose at the regular time and get back on schedule. **Never take a double dose.**

If you are allergic to sulfa drugs, we will use dapsone instead.

ACYCLOVIR

Type of drug: Anti-viral drug (to prevent viral infections)

How often to take: Three times a day

Possible side effects:

- Decreased blood counts: We will follow your labs closely and adjust this medication as needed.
- Nausea: If nausea occurs, take your dose with a meal or snack.
- Tremors and neurological side effects: Let us know if you develop tremors or confusion. The dose may need to be reduced or the drug stopped.

What to do if you miss a dose: Resume taking the medication with the next scheduled dose. Do not take a double dose. Some patients are at a high risk for a virus called CMV. In that case, we will use another drug called valganciclovir (Valcyte). It has similar side effects and is given once or twice a day.

FLUCONAZOLE (DIFLUCAN)

Type of drug: Anti-fungal (to prevent fungal infection)

How often to take: Once a day in the morning

Possible side effects:

- Upset stomach.
- Change in sense of taste.
- Headache.
- Dizziness.

What to do if you miss a dose: If you remember it within 12 hours, take it right away. If you remember after 12 hours, **do not** make up for the missed dose. Take your next dose at the regular time and get back on schedule. **Never take a double dose.**

DOCUSATE (DOSS)

Type of drug: Stool softener

How to take: Two times a day as needed

Possible side effects:

- Upset stomach.
- Cramping.
- Diarrhea: If you have diarrhea, do not take.

PAIN MEDICATION

Pain medications will be prescribed for a short while after transplant. If you were taking pain medications for chronic pain before transplant, contact your local physician for new prescriptions to continue these medications. The transplant team will prescribe pain medications related to the transplant surgery only.

OTHER MEDICINES

Other medications may be prescribed for you after your transplant. Common drugs include antibiotics, blood pressure medication and insulin. However, not all patients will need these medications.

Disclaimer: This list does not have all medicines and side effects. Only use this information as a guide. It is not a formal drug reference. Please call the Transplant Center for more information.

POST-OP LIVER TRANSPLANT SERVICES

ATM

There is an ATM on the first floor of Pavilion H, near the Registration Desk. There is another ATM near the elevators on the ground floor of Pavilion A.

BUSES AND CABS

Lextran bus schedules are available at the Information Desks. Taxi cab service is available by calling 859-231-8294.

DINING OPTIONS

(hours may change)

- **Chandler Dining** is on the first floor of Pavilion A. It is open 22 hours a day, closing only 5-6 a.m. and 10-11 a.m.
- **Courtyard Café** is on the ground floor of Pavilion A, near the auditorium. It is open Monday – Friday, 7 a.m. – 3 p.m.
- **Vending area** is on the first floor in Pavilion H, near the cafeteria. It is open 24 hours a day, seven days a week.

DON AND CATHY JACOBS HEALTH EDUCATION CENTER

This resource center is open to patients and visitors. The staff can help you find health information you can trust. There is also internet with printing and fax machine. It is on the first floor of Pavilion A, near the bridge to the garage. It is open Monday – Friday, 9 a.m. – 4:30 p.m. For information, please call **859-323-7808**.

GIFT SHOPS

Our gift shops sell various personal care items, reading materials, candy and gifts. One gift shop is in the Pavilion H lobby, across from the Information Desk. A second gift shop is on the first floor of Pavilion A. Both are open Monday – Friday, 10 a.m. – 6 p.m., Saturday, 10:30 a.m. – 6 p.m., and Sunday, 1 – 5 p.m.

MAIL

A post office is on the ground floor of Pavilion H in Room M63. It is open Monday – Friday, 8 a.m. – 4:30 p.m. Mail slots are located at the main elevator on each floor.

NEWSPAPERS

You can buy newspapers from a vending machine beside the ATM near the Registration Desk in Pavilion H.

PARKING

Garages:

- The Kentucky Clinic Garage is located at 140 Huguelet Ave.
- The UK HealthCare Garage is located at 110 Transcript Ave.

Parking fee: There is a fee for parking. Please note the rates posted as you enter the garage. Parking is free on weekends and at certain hours of the day. You may

buy extended-stay parking passes in the parking office. It is on Level A of the UK HealthCare Garage. Once you buy seven-day passes two weeks in a row, parking in the garage is free for the rest of your visit. You may call the parking office at **859-257-1000** or **800-333-8874**.

Shuttle from garage to hospital: Free shuttle service provides door-to-door service from the garage to the hospital. Shuttles leave from Level A of the garage every three to five minutes. There is an ambassador in the parking garage

6 a.m. – 11 p.m. daily to answer questions and help patients and visitors onto the shuttles, which are wheelchair accessible. Passengers who have a hard time walking may be dropped off in the passenger drop-off and pickup areas. These are on each floor of the garage near the elevators. The Transplant Clinic is located on the third floor of the Kentucky Clinic, Wing D.

Concourse bridge: Instead of the shuttle, you may walk across the bridge from Level C of the main garage. Golf cart service is available.

PASTORAL SERVICES

A chaplain is here 24 hours a day, seven days a week. You can call the chaplain at **859-323-5301**. There is a sanctuary on the first floor of Pavilion H in Room H-122. In Pavilion A, the non-denominational Myra Leigh Tobin Chapel is conveniently located on the ground floor.

TOBACCO FREE

The UK HealthCare campus is tobacco free. You may buy nicotine replacement products in the gift shops.





NEED INFO HEADLINE HERE

888-808-3212



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