



Expectations and Responsibilities of Transplant Patient and Caregiver

The transplant patient and caregiver should plan to dedicate a substantial amount of time to the process of receiving and recuperating from a transplant at the Medical University of South Carolina (MUSC). This serious undertaking requires both the patient and caregiver to understand fully the impact of this process on their time and energy commitments. To learn more about transplants, patients and caregivers can access the website of the United Network for Organ Sharing (UNOS) at <http://www.unos.org>. Should you have specific questions, you can call UNOS at 888-893-6361. The mailing address is PO Box 2484, Richmond, Virginia 23218.

Both patient and caregiver should expect to spend the following amount of time for each type of transplant in the Charleston area:

- **LIVER - 4 nights to 2 weeks in the hospital and 1-3 months locally.**

Caregivers must stay with the patient during the entire time at MUSC and locally.

Prior to Listing

The patient must designate both a primary and secondary (backup) caregiver, with telephone numbers, prior to listing. Caregivers must be able to drive and have a valid driver's license and reliable vehicle. They will meet with the transplant social worker who will discuss their roles in the transplant process and determine whether the designated caregivers will be able to fulfill their roles. Caregivers must be healthy enough to provide physical assistance, if needed. To encourage a healthy lifestyle for the patient, the caregiver should not smoke. (Patients can be disqualified from receiving a transplant if they smoke.) **Your social worker must meet with your caregivers and receive contact from your secondary caregiver that they are willing and able to perform as a caregiver for the transplant event. As this is a formal plan, should any changes occur in your caregiver support you must contact your social worker with the updates. You also must have reliable transportation for the entire event.**

It is recommended patients have a valid Power of Attorney for Healthcare or a Living Will with MUSC. Caregivers need to be aware of these documents and know the patient's wishes as specified in them. Should the patient be unable to make decisions, the caregiver will need to make them based on the patient's wishes. For this reason, the patient caregiver must be present at the hospital during the day while the patient is in the

Intensive Care Unit (ICU) and available by telephone overnight. After release from the ICU and prior to release from the hospital, the caregiver must stay in the hospital room with the patient to receive caregiver training. Once released from the hospital, the caregiver will need to monitor medical devices and equipment, and assist the patient in bathing, dressing, changing dressings, and taking medications. The caregiver will also need to prepare meals for the patient and ensure that the patient is achieving adequate caloric intake. Because patients will not be allowed to drive for 6 to 8 weeks, as determined by the surgeon, the caregiver will need to provide all transportation for clinic and therapy appointments and accompany the patient to all appointments.

Considerations for Caregivers

Potential caregivers should ask themselves:

- 1) Will I *be able* to take off work for up to 3 months?
- 2) Can I *afford* to take off work without pay for this length of time, or do I *have enough accumulated leave* to cover the longest length of time that might be required?
- 3) If the patient lives alone, will I be able to provide extended care and support *beyond the 3-month hospital/local recuperation period* when they return home?
- 4) Do I *have prior obligations*, such as caring for dependent children, an elderly parent, pets, etc.?
- 5) Can I provide the *full range of support to the transplant patient*, from minimal assistance and supervision to physically supporting the patient, if needed? You maybe asked to managing temporary feeding tubes, insulin, and drains if needed.
- 6) Can I manage the stress of caring for a loved one and being away from home for an extended period of time?
- 7) ***Can I track up to 25 pills daily? This caregiver responsibility is of utmost importance.*** While patients ultimately need to be responsible for their own medications, the amount of medications and frequency of dosage changes in the early post-transplant stages can be overwhelming. The caregiver needs to ensure that medications are taken in the correct dosage at the appropriate time. Because medications are adjusted after nearly every laboratory visit, we strongly suggest that the caregiver use a pillbox to track the patient's medications.
- 8) ***Paid caregivers are not acceptable and insurance will not pay for them.***

Behavioral Medicine

We want all of our patients and caregivers to have as much support as we can provide during this very stressful time. You and your caregiver may be asked to meet with our psychologist in order to increase that support. If they require you complete a formal program they will discuss this at your appointment. In addition you may also be required to have follow up appointments for coping, mental health issues or substance abuse.

Providing documentation from your provider must be requested by the patient and sent to MUSC to confirm your participation.

Hospital Stay

When an organ is located, you must be ready to go to Charleston when directed. This could be at a moment's notice or several hours after we first contact you. Please also be aware that you could be sent home without being transplanted if the organ is of poor quality. We suggest you prepack suitcases with clothes and toiletries and a box with all needed food staples to begin your relocation. You also must have the funds available to pay for parking, food, medications and lodging. The patient will be brought to the hospital and undergo surgery, usually within a few hours to a day. Liver transplanted patients will be moved to the ICU after surgery for a brief stay. Once stable they will go to 6E Main Hospital for their continued recovery.

Intensive Care Unit

Liver transplants will take place in:

- 1) Main Hospital, 171 Ashley Avenue, for liver, kidney, or pancreas transplants.

After surgery, the patient will be taken to the ICU. Both ICU waiting rooms can accommodate up to two people overnight while the patient is in ICU. Both buildings also offer shower facilities for caregivers and family.

Each waiting room has a Guest Relations Desk to provide the patient's caregiver and family with information on resources within the area. Guest Relations can reserve a hotel room at reduced MUSC rates or direct the caregiver and family to other resources. While MUSC has no laundry facility on site, for example, Guest Relations can direct you to a local commercial Laundromat. ***For Guest Relations, dial 843-792-3122.***

Hope House

Hope House is another lodging option for the caregiver and family members (but no children under 18) while the patient is in ICU. Owned and operated by the Presbyterian Church, Hope House offers rooms on a first-come, first-served basis at a charge of \$5 per night. Hope House is located about 10 minutes from MUSC in Mount Pleasant, just across the Cooper River near Shem Creek. If interested in staying at Hope House, the caregiver or family member should ask your transplant nurse coordinator to contact the inpatient transplant social worker. The social worker will contact Hope House staff to find out if a room is available and, if so, give them your name and phone number and fill out the referral document for you to take with you. <http://www.mppc.net/496052.ihtml>

Release from Intensive Care

Upon release from ICU, the patient will be moved to a regular room on Floor 6E of the Main Hospital. At this point, the caregiver will stay with the patient and begin learning about post-transplant care. Upon release from the hospital, the caretaker will be expected to administer medications, bathe and dress the patient, change dressings, and prepare the patient's meals, ensuring adequate nutrition. The caregiver will drive and accompany the patient to all clinic and therapy appointments. While at Main Hospital have cafeterias, the caregiver may want to have a selection of food to eat while tending the patient in the hospital and, of course, all necessary toiletries.

Clinic Follow-up Visits

Patients released from the hospital after transplant are required to make all clinic appointments, accompanied by caregivers, as required. *The importance of making all clinic visits and adhering to all medical instructions cannot be stressed enough.* Clinic visits are important to monitor the patient for ongoing adjustments to medication until stabilized and to ensure that any changes in the patient's progress are addressed immediately. For this reason, the patient must be within reasonable proximity to the hospital for the recuperation period immediately following discharge. **Plan for 7:30am appointment for lab work.**

Release to Hotel or Home (If Local)

As listed above, the patient and caregiver will be required to relocate to Charleston for a length of time depending on which organ is transplanted and the speed of recovery. A patient living within 45 miles of Charleston may be released to recuperate at home as long as the caregiver can drive the patient to all clinic and therapy appointments. Patients not living within the 45-mile distance must relocate to Charleston for the entire period designated for each organ or longer, if necessary.

The need for out-of-town patients to remain close to the hospital for post-transplant care and these patients will now be responsible for securing and paying for their lodging needs. Depending on the length of stay, these costs could easily exceed \$2000. We are aware that this change could cause a hardship and have worked with the hospital's patient guest services department to ensure that they will be available to help patients and caregivers locate local lodging options and negotiate a medical rate. Your bedside nurse can assist you in speaking with a representative during the admission for transplant. Please note, the guest service staffs are only helping find lodging options, they will not make the reservation or pay for the costs – these are the responsibilities of the patient and/or caregiver. A list may be obtained by them; however, the list is subject to change. ***For Guest Relations, dial 843-792-3122.***

Many restaurants will deliver meals to your hotel room. For those who do not, Charleston has several restaurant delivery services such as Charleston Restaurant

Runners and Quick Foxes. **East Cooper Meals on Wheels** may be able to deliver to the hotel you choose. If you are interested please let your social worker know.

On occasion it may be required to go to a rehab stay locally after discharge. If a patient has other conditions the transplant surgery may make it so they are not functionally able to be discharged to the hotel. Resources **are limited** in these cases and the caregiver still needs to be present to help manage the patient's illness.

Returning Home

Based on how well the patient does during recovery period, he or she still may need 24/7 assistance from the caregiver. However, if the patient's condition permits, it may be okay for the caregiver to leave the patient for brief periods. **For local patients**, caregivers must commit to stay with the patient in the hospital and also when they return home until the patient is independent to be alone. Please do not plan to work or manage other house hold responsibilities while being a caregiver as it is often too difficult to do both. Once you are home and recovered remember that **Thanking the Donor** family is a great way to express your gratitude. Your social worker can give you more information if needed.

Planning Your Out-of-Pocket Costs

Lodging: You need to budget \$100 plus per night for lodging based on your particular organ's requirement as to how much total you will be responsible. Your insurance may cover the expense for lodging after a transplant; be sure to inquire.

Food: The caregiver will need money for 3 meals a day during the patient's inpatient stay, and money for both caregiver and patient once released to the local hotel.

Transportation: The caregiver will need funds for gas for clinic appointments while in Charleston and, after returning home, for follow-up clinic visits to Charleston. You must provide your own reliable transportation.

Parking: The daily parking rate at MUSC for inpatients is \$6 per day and, for outpatients, \$3 per day. However, for long-term inpatients, after 2 weeks in the hospital, your social worker can assess your financial need for a parking waiver. If you are inpatient longer than 30 days, you may be eligible to purchase a parking pass for \$84 a month inpatient parking pass. Your social worker will assist you with this.

Prescription Assistance Program /Copays for Medication: MUSC has a Prescription Assistance Program that can help with copays. The patient may qualify for free or low-cost medicine. Contact the Patient Advocate, Rutledge Tower, Suite 106, 135 Rutledge Avenue. The office is open Monday through Friday from 8am to 4:30pm and is on the first floor of Rutledge Tower across from the Blood Draw at the rear of the waiting area. Call Becca Peters at 843-876-8440 or Karen Muckenfuss at 843-876-8936 for information on documentation to bring with you.

Medicaid Recipients: Ask your social worker about specific benefits associated with Medicaid. Travel, lodging, and meal expenses may be reimbursable under Medicaid. If you do not receive Medicaid and think you may be eligible, visit the South Carolina Medicaid website, www.SCDHHS.gov. Medicaid patients can download forms for reimbursable expenses at: <https://memberinfo.logisticare.com/Downloads.aspx>

Fundraising: We encourage fundraising to offset out-of-pocket expenses. Below are the websites of three organizations that can help guide you with fundraising.

<http://www.helphopelive.org/>

<http://www.transplants.org>

<http://cota.org/> (for children)

Help Hope Live is a nonprofit organization that helps patients and families raise funds to meet out-of-pocket expenses by providing fundraising guidance, customized materials, free web pages, tax deductibility, and fiscal accountability for donors. Funds raised will not jeopardize Medicaid status. Since 1982, the organization has helped more than 6,200 patients raise more than \$87.6 million. Go to the website to fill out the online application form. For questions, call 800-642-8399.

Transplants.org is the website for the National Foundation for Transplants (NFT). NFT is also a nonprofit organization that offers fundraising guidance and grants for transplant candidates and recipients. For questions, call 800-489-3863.

COTA.org is the website for the Children's Organ Transplant Association (COTA). Since 1985, COTA has been helping children and young adults, including those over 21 who need a transplant due to a genetic disease such as Cystic Fibrosis or Sickle Cell Anemia, with fundraising assistance and family support. COTA will organize and train volunteers, plan events and activities, work with local media, provide web-based resources, and find multiple sources of funding. For questions, call 800-366-2682.

Contributions from Individuals and Organizations

The state provides **a resource** option for you in your community should you need help with expenses and other resources. You may be able to obtain help by **calling 2-1-1** on any phone.

Family members, friends, and organizations with which you are affiliated may ask how they can help in lieu of or in addition to contributing to a nonprofit transplant fund in your name, if you establish one. You might suggest that they help by contributing gas cards or a meal card to use at the MUSC cafeteria.

Gas Cards: Many gas stations sell gift cards to which you can add money as needed during your stay in Charleston. Discounted gas cards may also be bought online. Your

contributors might want to purchase these for your stay in Charleston or to use driving to and from Charleston.

MUSC cafeteria gift cards and meal tickets: The MUSC cafeteria provides two ways for contributors to donate meals during your stay in the hospital or during visits: a meal gift card or meal tickets.

The meal gift card has several advantages. First, the card can be purchased in any amount and food purchases are deducted in the exact amount, just like cash. Anyone can use the card; no name is attached to the card. Cafeteria gift cards can be purchased from Joann, 843-792-9655 or Maureen, 843-792-4558 in Room H109 across from the cafeteria between Subway and the Pizza concession from 8:30am to 4:00pm.

Meal tickets are another option when a group of people (such as a church group) will be visiting MUSC and a set amount is to be given to each member of the group. The group's name can be printed on the tickets, as well. They are purchased in set amounts, such as \$1, \$5, etc., and are surrendered to the cashier for payment of the food purchased. No change is given, so that if a meal were to cost \$5.75, then a \$5 and \$1 ticket would be surrendered with no change returned. Meal tickets can be purchased from Deborah, 843-792-4559, in Room 110B Children's Hospital, located to the right beyond the Children's Hospital Gift Shop, and to the right of the aquarium toward Office Supply.

Support Groups

These groups were established by volunteers to help those waiting transplant/donation as well as those who have been through transplant/donation to cope with the process and share questions that only someone who has experienced the process could answer.

Charleston

Charleston Transplant Support Group

Contact: Carol Dolida

Phone: 843-552-4038

Email: charlestontransplant@gmail.com

Meets at: Springhill Suites, 98 Ripley Point, Charleston, SC 29407

When: Last Tuesday of every month at 2-4pm.

Columbia

Second Chance Transplant Support Group

Contact: Steve Ford

Phone: 803-394-2364

Email: secondchance430@gmail.com

Meets at: Holland Avenue Baptist Church
801 12th Street, Cayce, SC 29033

When: Third Tuesday of each month at 4-5pm

Greenville

SC Greenville Transplant Donor Support Group

Contact: Heather Breña

Phone: 864-360-2550

Email: greenvilletransplant@gmail.com

Meets at: Greenville Memorial Hospital
701 Grove Road Conference center room 1
Greenville, South Carolina 29605

When: Last Tuesday of the Month @ 6-7pm

Facebook : SC Greenville Transplant Donor Support Group

Myrtle Beach

Grand Strand Transplant Support Group

Contact: Anthony Kostecki

Phone: 843-274-1820

Email : anthonykostecki@aol.com

Meets at: Coastal Grand Mall Healthfinders
2000 Coastal Grand Mall Circle
Myrtle Beach, SC 29577

When: Meets last Monday of every Month 1:30pm -4:00pm

Medical University sponsored programs

You can find announcement for upcoming events and new information at the Transplant Center's Facebook page:

MUSC TRANSPLANT CENTER

Charleston Lung Transplant Support Group at MUSC

Support for lung transplant patients.

Contact: Nancy Holbach

Phone: 843-792-5092

Email: holbach@musc.edu

Meets at: ART Auditorium
Courtenay Drive, Charleston

When: Second Tuesday of each month at 11:30am-1:30pm.

Facebook: Charleston Lung Transplant

Group type: closed group for Lung patients and their caregivers

Carolina's Medical Center Sponsored programs

Charlotte, North Carolina

The New Hearts

Support for heart transplant patients.

Contact: Cherie Cone, MSW

Phone: 704-355-8092

Meets at: Carolinas Medical Center, Main Hospital, Dining Room #2
1001 Blythe Boulevard
Charlotte, NC

When: 4 times a year with a annual picnic. Call Ms. Cone for more details.

Kidney Support Group

2nd Tuesday each month 6:30pm-8pm at Carolinas Medical Center, 1000 Blythe Blvd.,
3rd floor, Dining Room #2

Liver

Central Carolina Liver Association meets the 2nd Tuesday each month from 7:00pm-
8:30pm at Carolinas Medical Center, 1000 Blythe Blvd., 3rd Floor, Tower Dining Room.

Apartments

Some patients may need larger living quarters to accommodate more people or may want full-sized kitchens. Such accommodations within the Charleston area include:

Short term, furnished apartment/condominium rentals

(\$1,500 and up, depending on the number of bedrooms and time of year.)

Capital One Real Estate	843 452-2228
Bee Street Lofts (new)	697-2225 (Christina Edmonds)
Carolina One Real Estate	843 884-1800 (Hillary)
Fred Holland Realty	843 670-3521

ACRS (upscale) 843 747-2194 (Will rent apartment and set up furniture)
2 BR Edgewater Plantation, Long Point, Mount Pleasant \$2,215
2 BR Westcott Plantation, Summerville \$1,985

Temporary Housing Unlimited 800 528-0139/ 843 766-9022 (Will rent apartment & set up furniture)
\$2,050 furnished 2 BR Atlantic Community, North Charleston
\$2,350 furnished 2 BR Bell Hall \$ 1,950 furnished 1 BR 2nd floor Belle Hall

Joan Schultz, Private Condos 843 345-0662
2 BR house on Society St \$2, 500
1 BR Tides handicapped apt \$2,000

Northwind Apartments 888-329-2790
2561 Fassit Rd, North Charleston, near airport, could be noisy
Fully furnished \$1,050 a month

Veterans Program

Shelly Grey 843 789-7855/843 577-5011
 Make reservations through MUSC Guest Relations

Open Arms

There are two apartment complexes in the area that will donate a free furnished apartment for patients and their families. The complex normally has a waiting list. Contact the social worker to inquire about these apartments.

NOTES:

#1 Caregiver: _____ **Relationship** _____ **#** _____

#2 Caregiver: _____ **Relationship** _____ **#** _____

Your social worker _____ Kay Moore, LMSW 843-792-9207
 Email mooreeu@musc.edu

Your Coordinator: _____

Items you must follow up on:

1 _____

2 _____