



## Heart Transplant & VAD Patient Resource Guide

# Welcome to Ochsner's Advanced Heart Failure, VAD, and Transplant Team

Your Ochsner care team consists of specially trained professionals from several different disciplines. We work together to ensure you receive the best care possible.

Your team includes Master's-degree prepared social workers who will help you, your loved ones, and any other caregivers prepare for the next step in your care journey. This guide is designed to help you prepare for VAD and/or transplant.



## How to Reach Your Transplant and VAD Team

Ochsner Heart Failure and Transplant Department..... 504-842-4721 (8:00 am - 5:00 pm)

After hours and weekends - Ochsner Main Hospital..... 504-842-3000

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# Tips for Preparing for Transplant or VAD

Preparing for transplant or VAD can be overwhelming. These practical tips can help you prepare in all the ways that contribute to the progress of your treatment plan.

## Medical Tips



**Be available by phone at ALL times. You don't want to miss important calls.**

- **Be sure your VAD/Transplant Team has all phone numbers and ways to contact you!** Inform your team of any new phone numbers or addresses immediately.
- Notify your VAD/Transplant team of new health issues or symptoms or travel plans as soon as they occur
- Keep ALL scheduled medical appointments.
- Follow medical, diet, and exercise recommendations.
- Remain as active and healthy as possible before surgery. This will make recovery easier.
- No alcohol, tobacco, vaping, or illegal drugs allowed. This includes medications not prescribed to you.
- All patients are referred to Palliative Care to discuss goals of care and help with symptom management.

## Practical Tips

- **Select a caregiving team.** All caregivers must be over 18 years old.

**Transplant patients** will need **at least two individuals** who have the time, health, and flexibility to be reliable caregivers.



**VAD patients** must have **one caregiver** available to learn how to change dressings properly before the patient leaves the hospital.

## Personal Tips

- **Organize your personal affairs.** Consider
  - an Advance Directive so family, caregivers and providers know your wishes
  - a will, for peace of mind
  - sharing important information with your loved ones
- **Fill out work-related forms** like Family Medical Leave Act (FMLA) paperwork (for both the patient and caregivers). Contact the Health Information Management office at 504-842-0534 for help.
- **Make a care plan** for children under 18, other dependents, and pets.

- **Have a transportation plan** for when you get the call or need to get to Ochsner. Know
  - who will drive you to Ochsner
  - the driving route
  - traffic conditions that could impact getting there on time
- **Pack a bag.** Prepare now for any hospital stays. Include
  - all insurance cards
  - list of medications and at least one day's worth of medication
  - personal items such as cell phone and charger, eye glasses, personal hygiene items, reading materials, and several changes of clothes. Please bring items that will make your stay more comfortable.



## Emotional Tips



Your Ochsner VAD/Transplant Team should be the main source of information about your care and the VAD/transplant process.

Information from social media or TV is often wrong. Popular media and social media are frequently full of misinformation and false beliefs about how the process actually works.

- **Talk to your VAD/Transplant Team about how you are feeling.** Be sure to raise any concerns with them. They can help you cope with emotions about your upcoming surgery. They can also offer resources and support.
- Websites you may find helpful: [www.SRTR.org](http://www.SRTR.org) and [www.heartmate.com](http://www.heartmate.com) are dedicated to transplant and VAD candidates, patients, and loved ones.

## Educational Tips

- Transplant and VAD are lifelong commitments. The more you learn about transplant and VAD and what to expect, the more control you have over your experience.
- **Read educational material.** Life after transplant or VAD will have its challenges. You must commit to learning how to live with a transplant or VAD.
- **Join a support group** in person (monthly or every other month at Ochsner) or online.



## Financial Tips

- Transplant and VAD out-of-pocket expenses include
  - co-pays for monthly medications and medical supplies
  - hospital bills
  - co-pays for clinic visits
  - procedures and lab work
  - food and housing (for those who live outside the New Orleans area)
  - transportation and gas
  - other unexpected expenses



You must have insurance. Discuss potential changes in your insurance plan with the VAD/Transplant Team BEFORE you change plans or lose coverage.

*Note: Not all insurance plans are accepted at Ochsner Medical Center - New Orleans.*

- **Make a realistic financial plan.** Talk to your VAD/Transplant Team and your loved ones about your financial situation. Your VAD/Transplant Financial Coordinator or VAD/Transplant Social Worker can help.
- **Share concerns with your social worker.** You may be concerned about loss of income, unemployment, increase in medical bills and monthly medication co-pays, cost of living expenses, etc. Your social worker can help you work through these.
- **Plan ahead.** If you anticipate financial difficulties, **begin fundraising immediately.** See fundraising tips and resources on page 10. If you have questions about fundraising, speak with your VAD/Transplant Financial Coordinator or VAD/Transplant Social Worker.

## Spiritual Tips

- Life-threatening illness followed by a second chance at a healthy life may bring up spiritual questions. It can create both growth and challenges in your spiritual beliefs.
- **Spiritual guidance and counseling may be helpful.** Your religious/spiritual leader or hospital chaplain can talk with you about your spiritual needs.
- If you would like to see a hospital chaplain, please ask your nurse or social worker to contact Ochsner's Spiritual Care Department.



*Kate and Laurance Eustis Interdenominational Chapel at Ochsner Medical Center - New Orleans*

# Building a Support System

Your support system and caregivers are critical before, during, and after transplant or VAD.

As with any major health concern or treatment, you will need help. **You must have support to go through the transplant or VAD process.**

What does “support” or “caregiver support” mean?

- **Physical support** once you have left the hospital
- **Emotional support** when you feel discouraged or are experiencing complications
- **Spiritual support** when needed
- **Assistance with practical needs** (groceries, meals, transportation, etc.)

## Identifying Your Primary Caregiver

**You will need to identify one person as your primary caregiver to help you during and after transplant or VAD.** Your primary caregiver will interact with your healthcare team to ensure continuity. This person will stay aware of your needs, problems, medications, etc. Your primary caregiver MUST be available to learn how to best support you. Your VAD/Transplant Team will teach your caregiver specific skills and practices that will help you recover successfully.

**For VAD patients**, your VAD/Transplant Team will teach your primary caregiver to change dressings. Your primary caregiver will change dressings while you are in the hospital and at home.

In addition to a primary caregiver, **transplant patients** will also need to identify a backup caregiver. This should be someone who can step into the primary caregiver role, if your primary caregiver is unable to be with you for any reason. **You must enlist a backup caregiver before we can place you on the transplant list.**

## Mental Health

Your mental health plays an important role in your physical recovery. **Please reach out to one of your VAD/Transplant social workers at any time if you experience depression, anxiety, or other mental health stressors.**

CaringBridge ([www.caringbridge.org](http://www.caringbridge.org)) is a free, nonprofit web service that connects family and friends. Through it you can share information and gain support during a health care crisis, treatment, and recovery. This may also be a useful tool to help communicate your fundraising efforts.

In addition, your social worker will provide you with the schedule for support groups at Ochsner.

# For Caregivers: Preparing Yourself for the Role

A caregiver must be

- in good health (physically and mentally able to serve as caregiver)
- available 24/7 for an extended amount of time
- able to provide transportation at any given moment
- 18 years or older

Caregivers are the main source of physical and emotional support for the transplant or VAD patient. Being a full-time caregiver can be both mentally and physically exhausting. As a caregiver, it is important to consider your own needs.



## Physical Health

Taking good care of yourself is very important.

- **Pack your own medications** when coming to the hospital with the transplant or VAD patient.
- **Attend necessary medical appointments.** Your physical health is just as important as that of the patient.

## Mental Health

- **Avoid burnout by taking time for yourself.** Take a daily walk, listen to your favorite music, talk to supportive family and friends, maintain activities or hobbies you enjoy.
- **Arrange back-up caregivers** to relieve you so you have time away. Be sure to inform the VAD/Transplant Team when you will be stepping away to handle personal care and responsibilities. Tell the team who will be the backup caregiver.
- **Attend necessary mental health appointments.** Your mental health is just as important as that of the patient.

## Living Arrangements

- **Where will you stay** while the patient is hospitalized? One caregiver is encouraged to stay with the patient in the hospital room, subject to the medical team and ICU restrictions.
- **Back at home**, who will get your mail and watch your house? Who will take care of your children or other loved ones who depend on you? Who will take care of pets?
- **If you forget items at home**, who will bring them to you?

## Support

- A variety of **caregiver support groups** can be found online. Ochsner offers a caregiver support group on the second Wednesday of every month.
- **Make friends** with people who have served as transplant or VAD caregivers.
- **Keep in touch** with friends and social groups. Arrange for back-up caregivers to relieve you while you take time off.

# Planning for VAD or Transplant Surgery



**IMPORTANT: Your VAD/Transplant Team will give you specific instructions to ensure you are as healthy as possible before VAD or transplant. If you do not follow these instructions, you may no longer be able to get a transplant, a VAD, or both.**

Carefully follow your VAD/Transplant Team instructions about

- diet
- exercise
- fluid restrictions
- medications
- follow-up appointments
- abstaining from substance use

## Substance Use Testing

Before VAD or transplant surgery, you may be randomly tested for substance use. This includes tobacco, vaping, and alcohol. **If you test positive for substances that are not allowed, you may not be able to get a transplant or VAD.**

## Finances

Getting a transplant or VAD requires time and a financial commitment. **Have a financial plan to afford post-VAD and post-transplant expenses.** See fundraising resources on page 10.

## Transportation

Make a plan with family, friends, and other support system members to **ensure adequate transportation arrangements for ALL appointments before AND after transplant or VAD.** Raise funds to afford the costs of gas, ride shares, cab fare, or bus tickets if necessary. See fundraising resources on page 10.

## Housing

**Transplant patients:** If you live within 60 minutes of Ochsner Medical Center, you and your caregiver may need to stay at Brent House Hotel. **Your caregiver must be with you 24/7 during this time.**

**VAD patients** are discharged to their home community with follow-up medical care Ochsner Medical Center.

# Ochsner Hotel Accommodations

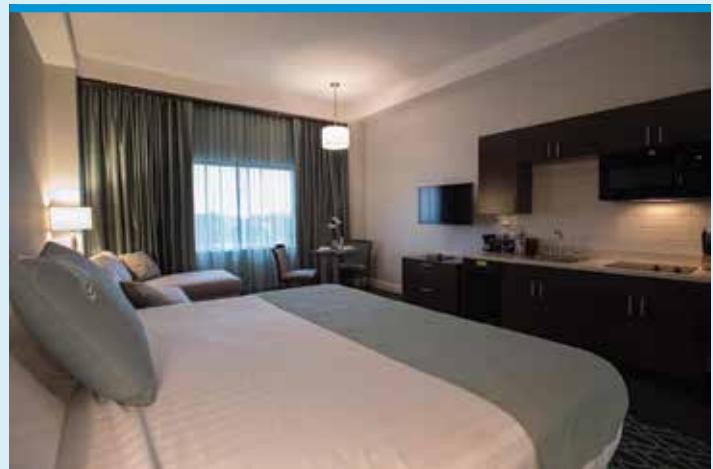
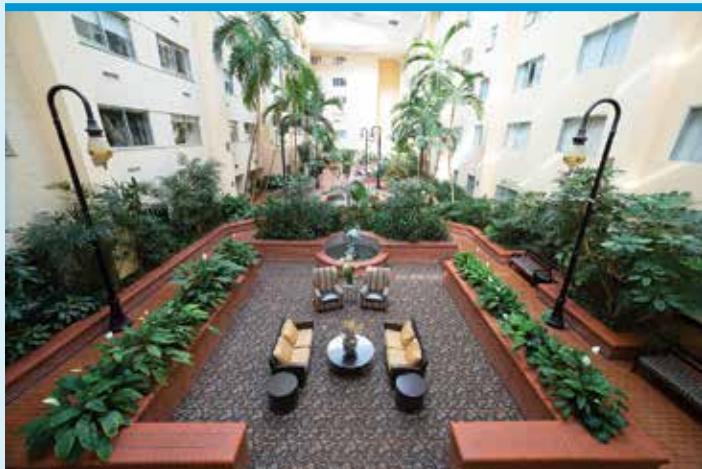
The Brent House Hotel is located on the campus of Ochsner Medical Center-New Orleans. Consider it your home away from home with convenient, comfortable, and affordable accommodations. Patients pay based on a sliding-fee scale unless your insurance has a lodging benefit.

The Brent House Hotel offers:

- Well-appointed rooms and suites
- Extended stay rooms with kitchenettes
- Outdoor heated pool and 24-hour fitness center
- Free covered self-parking and valet parking
- Restaurant and coffee shop
- Complimentary Wi-Fi throughout our guest rooms and facilities
- Close to the airport, French Quarter, Superdome and downtown New Orleans



For more information visit [www.brenthouse.com](http://www.brenthouse.com).



# Transplant and VAD Surgery: What to Expect

| Question  | VAD   | Transplant   |
|---|---|--|
| <b>How long will I be in the Intensive Care Unit (ICU) after surgery?</b>   | 1-2 weeks (may be longer if complications occur)  | 3-5 days (may be longer if complications occur)  |
| <b>How long will I be in the hospital after surgery?</b>  | 3-6 weeks total (may be longer if complications occur)  | 2-3 weeks total (may be longer if complications occur)   |
| <b>How long will I need a caregiver?</b><br><br><i>You will <u>NOT</u> be discharged from the hospital until you AND your caregiver are fully educated and knowledgeable about necessary medical information.</i> | <p><i>In the hospital, your caregiver must be available during regular business hours</i> to learn about the VAD and the driveline dressing change. The first dressing change takes place 48 hours after chest closure.</p> <p><i>Only ONE caregiver will be trained to do the driveline dressing change. This person needs to be present for every dressing change.</i> Please coordinate with your bedside nurse.</p> <p>Your caregiver will be responsible for assisting you with dressing changes for the life of your VAD.</p> | <p>About 8-10 weeks after surgery</p> <p><i>Your caregiver must be available during regular business hours while you are in the hospital</i> to learn about your medication regimen and precautions you should take post-transplant to keep you safe.</p> <p>Your caregiver will also need to be with you 24/7 for 4-6 weeks after hospital discharge.</p> |
| <b>Will my caregiver and I need to stay locally after being discharged from the hospital?</b>   | <p>No, you will be able to return to your own home after hospital discharge.</p> <p><i>A caregiver should be with you at home for the first 24-48 hours after discharge while you are recovering.</i></p>   | <p>If you live more than 60 minutes from Ochsner, you AND your caregiver may have to stay <u>locally</u> for 4-6 weeks after hospital discharge.</p>   |

| Question   | VAD   | Transplant   |
|--|---|--|
| <p><b>What will my Ochsner outpatient follow up appointments be?</b></p> <p><i>You will not be able to drive for 8 to 10 weeks, or until your doctor says it's safe. You must have a caregiver you can drive you to all your follow-up appointments.</i></p> | <p>1st month: weekly</p> <p>2nd month: every other week</p> <p>Life of VAD: monthly for the first year (subject to change per MD)</p>   | <p>1st month: weekly</p> <p>2nd month: every other week</p> <p>1st year: monthly (subject to change per MD)</p>                                |
| <p><b>When can I return to work?</b></p>   | <p>About 6 months after surgery, depending on your type of work. Returning to work will be discussed at clinic visits.</p> <p><i>Before your surgery, make a plan for going back to work.</i></p> | <p>About 6 months after surgery, depending on your type of work.</p> <p><i>Before your transplant, make a plan for going back to work.</i></p> |
| <p><b>Will my disability status change?</b></p>  | <p>You may no longer be considered disabled after you recover from your VAD surgery.</p>  | <p>One year after transplant – possibly sooner – you will no longer be considered disabled.</p>  |

# Fundraising Resources

Raising money is often a major effort that requires the assistance of your family, friends, or community.

We recommend that you work with a group of volunteers to help you. Your church, mosque, synagogue, temple, or other spiritual community can help you with fundraising. Other non-profit groups may be able to help too.



- **Involve your community.**

Reach out to friends, family, colleagues, and local businesses to raise awareness and donations.

- **Consider holding events.**

For example, organize parties, races, supper plates, or bake sales to raise funds and spread awareness about organ donation.

If your insurance plan does not fully cover transplant or VAD, fundraising can help to offset additional expenses.



Even if you have insurance, you will still have miscellaneous expenses not covered by insurance. For example, transportation to and from medical appointments – gas, rideshare costs, etc.

## National Transplant Resources

The agencies listed below may provide guidance and/or sponsor your efforts. They will not provide direct ongoing financial aid. This is not a comprehensive list. You may find other organizations that can also provide fundraising support.

- Help HOPE Live ..... 800-642-8399 | [helphopelive.org](http://helphopelive.org)
- American Transplant Foundation ..... [www.americantransplantfoundation.org](http://www.americantransplantfoundation.org)
- Health Well Foundation ..... 800-675-8416 | [www.healthwellfoundation.org](http://www.healthwellfoundation.org)
- The Equity in Heart Transplant Project ..... [theequityinhearttransplantproject.org](http://theequityinhearttransplantproject.org)
- Children's Organ Transplant Association (children only) ..... 800-366-2682 | [cota.org](http://cota.org)
- UNOS Network For Organ Sharing ..... 888-894-6361 | [unos.org](http://unos.org)

## Online Fundraising Platforms

**Be aware of how these work.** Online platforms may collect fees from the money donated.

- GoFundMe ..... [www.gofundme.com](http://www.gofundme.com)
- Spotfund ..... [www.spotfund.com](http://www.spotfund.com)

## Notes











1-866-OCHSNER | [ochsner.org](http://ochsner.org)