

# Frequently Asked Questions

## By LVAD Patients

1) **Can you go swimming with a VAD?**

Currently none of the VAD's we implant at the University of Michigan will allow you to submerge under water.

2) **Can you shower with a VAD?**

You are able to shower when you get permission from your surgeon. You will have to protect the external VAD equipment and driveline site as directed by your VAD coordinator.

3) **Can I be sexually active with a VAD?**

Yes, you may resume sexual activity once you have recovered from your surgery.

4) **Can I drive a car with a VAD?**

Your surgeon or cardiologist will discuss this with you at your three-month return visit. They will be looking at your post op recovery and any alarm or equipment issues. They may set limitations on where you can drive.

5) **Can I ever be alone (without a caregiver)?**

Our surgeons and cardiologist prefer you have strong caregiver support, especially in the early post-operative period (first three months). This will be reassessed three to six month after your implant, looking at how well you have recovered and can respond to emergency situations (trouble shooting alarms).

**6) How long do we have to do the driveline dressing change?**

The driveline always requires a sterile dressing over the site. You or your caregiver will start out having to change it daily for approximately three months then you should be transitioned to a weekly change, as long as there are no issues with the site.

**7) Do I have to carry all this VAD equipment with me everywhere I go?**

Because your VAD is a life sustaining device it is imperative that you always have your back up controller and fully charged batteries with you at all times.

**8) Who will help me troubleshoot VAD equipment issues?**

Your VAD team has someone on call 24 7 to assist with medical as well as equipment emergencies. Make sure you and your caregivers always have the on-call number available.

**9) Will my local EMS and Fire Department know anything about my VAD?**

Your VAD team notifies your local emergency room and first responders when you are discharged home from the hospital. The VAD team answers questions and provides education material; however, it is always a good idea to visit them yourself. Seeing a real patient and equipment is always helpful.

**10) How long do these heart pumps last?**

That is a complicated question with a lot of different variables that your surgeon will go over with you before your implant. These devices are meant to either bridge you to a heart transplant (if you are a candidate) or extend your life and improve your heart failure symptoms. There are patients out over ten years with VAD's.

# Psychosocial Factors of Left Ventricular Assist Device (LVAD) Candidate Selection and Success

*“Patient selection for left ventricular assist device (LVAD) therapy is the most important process in obtaining a successful outcome ... additional areas of focus and assessment that can impact adversely on LVAD outcomes include the degree of family and psychosocial support and preoperative neurologic function.”*

- Aaronson, M.D., Patel, M.D., Pagani, M.D., 2002

## **Social Support**

Candidates for LVAD implantation at University of Michigan are required to have a plan for twenty-four-hour supervision by trained caregiver(s). The caregiving plan must be sustainable for a minimum of 3 months post hospital discharge. There is the potential for 24-hour supervision indefinitely if there are post-operative complications. This plan may consist of a single caregiver or a combination of more than one person, but all must be stable adults, eighteen and older.

The quality of the support system relationships (i.e. primary caregiver, immediate family members, extended family, friends and community) are assessed by the clinical social worker. The patient and identified caregivers' level of stress and coping (strengths or weakness) are considered. Personality characteristics and sense of maturity are also important.

One aspect of support provided by the caregiver(s) is transportation, as the implanted patient is restricted from driving for a minimum of three months. Other aspects of practical support include attendance at clinic appointments or testing, daily or weekly driveline dressing changes, and assistance with medication organization and with equipment.

Emotional support is another necessary part of caring for someone with an LVAD. Both the patient and the caregiver(s) are making a major adjustment to lifestyle and role changes. Coping with these changes can bring about anxious or depressed responses in either the caregiver or the patient.

## **Other Psychosocial Indicators**

### *Financial*

Patients need to have the financial means to be successful with an LVAD, including adequate insurance. Both Medicare and Medicaid cover LVAD surgery. Supplies and medications for the long-term management of the LVAD are often covered, though copays vary depending on insurance coverage.

Some patients receive disability benefits either from an employer paid policy or by qualifying for Social Security Disability. Some patients are able to return to their former employment and some are not, depending on the type of work they were engaged in.

### *Mental Health*

Stable mental health is very important for both the patient and their caregiver(s). Treatment history, willingness to engage in treatment currently, and recent or history of suicidal ideation are considered as they can impact patient compliance

### *Coping Style*

Dealing with major illness and treatment is difficult. Consequently, it is important to develop positive coping strategies. Concerning patterns that impact medical care will be addressed, but would not necessarily be considered a contraindication to LVAD candidacy.

### *Violence*

Domestic violence or other legal issues are considered as they could interfere with one's ability to comply with medical treatment.

### *Substance Abuse*

Smoking and alcohol are not absolute contraindications in destination LVAD implantation, however, if the patient is being considered for heart transplantation, these substances are strictly prohibited and six months of

abstinence is monitored with random urine screening. The use of illegal drugs is an absolute contraindication for both LVAD implantation and heart transplantation. Of note, certain over the counter medications may be contraindicated as well. One's history of treatment for substance use and abuse is assessed. The impact of substance abuse could be life threatening.

### *Cognitive Function*

Patients presenting with neurocognitive deficits will be referred for neurocognitive testing and recommendations for patient teaching.

### *Health Literacy and Compliance*

Patients and their caregivers must have the ability to correctly identify and manage medications, as well as VAD equipment and alarms. They must also possess the ability to manage multiple appointments and follow medical and social work recommendations. Knowledge of a healthy diet is also important. Patients and their caregivers are required to review our Success Contract, which specifically outlines the practical side of LVAD management.

## **Cultural and Spiritual Considerations**

Specific cultural, religious, or spiritual practices that may interfere with care should be shared with your social worker or medical provider (for example, a Jehovah's Witness who does not wish to receive blood transfusions).

### *Advanced Directives*

Living wills and durable powers of attorney should be considered but are not required. An unmarried adult with no adult children should especially consider appointing a surrogate decision maker.

### *Institutional Support*

The University of Michigan LVAD Program has two full time clinical social workers who possess Masters Degrees in social work and have combined experience exceeding 25 years. Their role consists of initial psychosocial assessment of the patient and the primary caregiver. They also provide ongoing assessment and support of the patient and family through these resources:

- *Outpatient Clinic visits*
- *Inpatient visits*

- *Peer Visitors*: patients who have undergone LVAD implant, and(or) their caregivers, and have completed specialized training by the social work staff to enable them to meet with new patients in order to orient and support them through their LVAD experience
- *Psychiatric referrals* for identified needs
- *Monthly Support Group* for Pre and Post LVAD and Transplant Patients and their Families with speakers on specific treatment related topics
- *Quarterly Newsletter* aimed at keeping patients and their caregiver(s) apprised of U-M LVAD patient activities
- *Winter and Summer Social Events*: the purpose of which is to connect patients with their peers as well as recognize them and their caregiver(s) for their courage
- *Limited Financial Resources*: to help meet the occasional transportation, lodging or meal needs for qualified patients

### **Online Resources**

[www.thoratec.com](http://www.thoratec.com)

[www.mylvad.com](http://www.mylvad.com)

[www.hearthope.com](http://www.hearthope.com)

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# About this Book

In participation with Learning Design and Publishing, this initiative is based on the principle that public universities have a responsibility to share the knowledge and resources they create with the public they serve.

Based on literature of the storytelling process, this project has provided an avenue for patients who underwent LVAD implants to share their uniquely individual stories with others.

Twenty-five patients who underwent LVAD implants between July 1998 and February 2015 were recruited to share their stories of living with an LVAD. Written invitations to 25 patients resulted in submission of 17 manuscripts. Participants were required to sign a Transfer of Copyright Contract, giving the Medical School permission to publish their work.

Fourteen males and three females with ages ranging from 21 years to 72 years at time of implant submitted manuscripts. Ten are Caucasian, four are Asian and three are African American. One story was submitted by the family of their deceased sister. Copy was submitted in handwritten and typed formats, in both electronic and hard copy forms. Nine of the participants eventually underwent heart transplants, four are destination patients, one participant is still waiting for transplant, one was explanted and one destination patient is deceased.

The manuscripts were edited and published by Learning Design and Publishing, a unit within the University of Michigan Health Information Technology and Services department. *Heart 2 Heart* is available for purchase from Amazon in both paperback and electronic formats.

Select stories will be available online from Open Michigan, a University collaborative committed to open content and supporting the use, redistribution, and adaptation of educational materials. Once published, this collection of stories will also be shared with new pre LVAD candidates as a method of preparation for their own surgeries. Thank you.



# Department Events

At the University of Michigan Center for Circulatory Support, LVAD patients discover a warm environment where they and their families are supported through excellent health care. Here are some examples of recent events and materials the Center for Circulatory Support provided for LVAD and Transplant patients and their families.



Annual Patient Picnic, a partially catered gathering where patients share their favorite dishes and experiences. One of two events at which new LVAD and Transplant patients are recognized with Olympic-type medals. Caregivers are recognized with their own lapel pin (see photo).

Family Directory  
2016

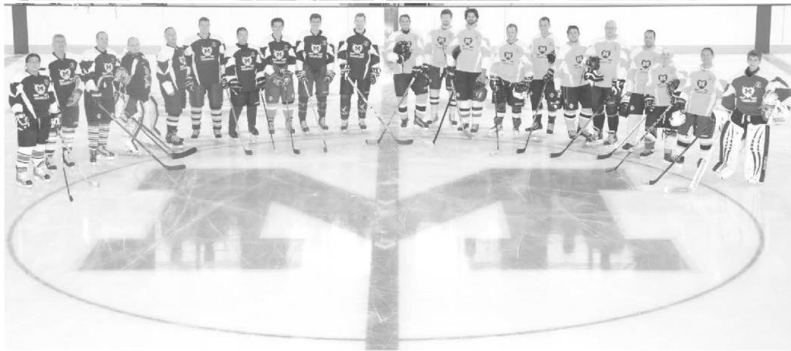


Annual Patient Directory which includes those LVAD and Transplant patients wishing to share their personal contact information with other patients. It is distributed to all patients for the benefit of communication when face-to-face contact is not possible

Caregivers Pin, created to honor the role that caregivers play in the lives of their loved ones and in our programs.



# Hearts on Ice



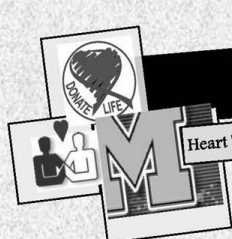
*From all of us at  
University of Michigan  
Hearts on Ice,  
Thank You!*

Hearts on Ice, our annual fundraiser, supports all of our patient programming

Annual Holiday  
Happening, a catered  
event where patients again  
gather to share their  
experiences. The second  
of two events at which  
new LVAD and  
Transplant recipients and  
their caregivers are  
recognized with the  
patient medal and  
caregiver lapel pin.



Patient Medal Presentation  
for LVAD and Transplant  
patients; Todd Koelling,  
M.D., one of our ten heart  
failure and transplant  
cardiologists making this  
presentation



# A CHANGE OF HEART

Heart Transplant and VAD Patient and Family Newsletter

Summer 2016

## Caregivers Recognized

For those who find themselves in the role of Caregiver, you are among 43.5 million in the United States today whose life may have changed, perhaps dramatically. It can mean a tremendous number of new responsibilities along with the emotional components of providing support and reassurance. And you share one very important thing: the service you provide, usually without benefit of professional training enables your loved one to remain at home or, in the case of transplant and LVAD consideration, actually give them the chance to live.

*More inside, see 'pages 4 & 5.'*

The "Change of Heart" newsletter is yours to enjoy with your fellow heart transplant and VAD patients. It provides a place to share your special moments, suggestions, and ideas. Your stories are important to all of us, such as meeting your donor family, special events (weddings, births, anniversaries, new jobs), special talents, and important bits of information that can benefit all of us. Send your stories, ideas or comments to:

Ruth Halben, LMSW (734) 763-9788 rhalben@umich.edu  
 Erin Spangler, LMSW (734) 615-7625 espangle@umich.edu  
 Rebecca Congdon, LMSW (734) 764-6205 rikera@umich.edu

*If you prefer not to receive our communications, please contact Ruth, Erin or Rebecca.*

Michigan Patients Waiting for a Transplant as of	
Heart	132
Lung	86
Liver	387
Kidney	2899
Kidney/Pancreas	60
Pancreas	23
Intestine	1
Other Organ Combos	45
<b>TOTAL</b>	<b>3582</b>

In 2015,  
the generosity of  
Michigan's 285 organ donors  
resulted in more than



Patient Newsletter, published quarterly to keep both LVAD and Transplant patients informed of upcoming events and happenings of the program



Peer Mentor of the Year, Tom Zasadny and his wife, Geri. Tom was honored by the U-M Transplant Center for 20 years of service as a Peer Visitor

Patient Medals, as mentioned, these are awarded to LVAD and Transplant patients in recognition of their courage and bravery at two annual social events



# About the Editor

Ruth Halben is the fourth of eight children. She has owned a construction business, been a 911 dispatcher and managed a medical practice. In 1991 she left her job as a director of advertising for an ABC Broadcasting owned newspaper, to return to school and finish a long sought after degree. To that point, all of her education was in advertising, marketing and management from various schools of business. Upon entering the University of Michigan – Flint, 18 of her 121 credits would transfer. When asked what area of study she would pursue, her response was, ‘I want to help people.’ She was advised that psychology was a broad field she might want to explore.

Nearing the end of her psychology degree, she enrolled in an introductory social work class. She completed her studies with honors in 1995 and earned a B.A. with psychology and social work emphasis and a minor in Health Care Education. She interned for one year at a hospice. That fall, she began her studies at University of Michigan – Ann Arbor in the School of Social Work. While completing her Master of Social Work degree in 1996 with a Certification in Aging Studies, she also completed an internship at University of Michigan Hospital in the Heart and Lung Transplant Programs.

In January 1997, she began her professional social work career at Lapeer County Health Department Home Care Division working as a clinical social worker until December 1998. The first six months of that time were combined with a part time, temporary appointment to the Heart Transplant Program at U-M.

From May 1997 to September 1997, she collaborated with her former preceptor, Oliva Kuester, MSW on a presentation of their work on the impact of groups on patient self-care at the Society for Transplant Social workers in September 1997.

Since July 1998, Ruth has been a permanent employee of the University of Michigan Hospital in the heart transplant program and is now primarily an LVAD social worker, one of the first in this specialty area in the country. She

has presented several times to the Society for Transplant Social Workers as well as given other health care related talks. Twice nominated for the Beverly Jean Howard Award for Excellence in Social Work, she has developed several social support programs, including this book, as fundamental components of her practice.

Ruth has been a field instructor for the University of Michigan School of Social Work and continues to work as a host for the School of Language, Science and Arts in the Health Science Scholars Program.

She has also worked as a home care and hospice social worker as well as provided consulting services on the social work role in home care and hospice. She has served on many boards and volunteers with the American Red Cross.

Ruth is the proud mother of three married children, grandmother to eight and great grandmother to four with another on the way. The Panda is her favorite endangered species, representative of her daughter Andrea who died of Cystic Fibrosis at the age of 15 in 1987. Ruth is an avid Michigan fan and works as an Event Staff Usher for Michigan Football and Basketball.

Go Blue!