

Additional Resources for Hard Call: The Electronic Heart Episode One

<u>Rise Above Heart Failure:</u> Are you or a loved one experiencing heart failure and looking for help? The American Heart Association offers free, multilingual and downloadable resources regarding the symptoms, treatment and causes of heart failure as well as tips to living better. The site also provides links to community events and an online support network.

Call the American Heart Association 24/7 for information on heart health and support groups at 1-800-242-8721.

<u>MyHealthFinder- Heart Health:</u> Looking for resources on how to stay healthy? The US Department of Health and Human Service's Heart Health page offers tips on reducing risks of heart disease, healthy eating suggestions and conversation starters if you or a loved one have heart disease.

To learn more about heart failure, heart transplants and left ventricular assist devices (LVADs):

- <u>CDC Fact Sheets- Heart Failure:</u> Looking for facts and statistics about heart failure? The CDC has a brief fact sheet detailing prevalence, prognosis, cost and risk factors for Heart Failure.
- Heart Failure- Overview: MedlinePlus (from the National Library of Medicine) provides basic information
 regarding causes, symptoms, treatment and prognosis of heart failure. Similar information is also be found in this
 PubMed Health article, from the National Heart Lung and Blood Institute (part of the US National Institutes of
 Health).
- <u>Cleveland Clinic: LVAD:</u> The Cleveland Clinic provides a good example of the type of information provided by most hospitals about LVADs, emphasizing how they work, possible good outcomes, selection criteria, and mentioning complications very briefly while noting that "special precautions are taken to reduce risks".
- <u>VAD Patient Selection Criteria:</u> The University of Wisconsin Madison web site, like that of the Cleveland Clinic, describes differences in selection criteria for Bridge-to-Transplant Candidates and Destination Therapy candidates, and emphasizes stories of positive patient outcomes.
- <u>LVAD Patient Stories:</u> This promotional blog post from the University of Michigan includes several remarkable
 patient stories all very positive about receiving an LVAD, including the longest living LVAD recipient in the US.
- How Organ Allocation Works: This brief information sheet from the Organ Procurement and Transplantation
 Network of the US Department of Health and Human Services explains how organs are distributed, which
 patients receive priority for organs, and the challenges of transplantation transport.



• <u>TedMed</u> has a wonderful talk from O.H Frazier, Chief of Cardiopulmonary Transplantation at the Texas Heart Institute, describing the history and development of heart assist devices, including the VAD. There is an emphasis on the remarkable fact that modern LVADs do not produce a pulse. More heart health related content from TedTalks can be found here.

To delve deeper into the decision whether or not to receive an LVAD:

- <u>Deciding Together: An LVAD Decision Aid:</u> This Youtube channel gives more balanced information to help patients
 decide whether or not to receive an LVAD, using materials developed under a grant from PCORI, the Patient
 Centered Outcomes Research Institute. There are four videos: Considering an LVAD, the Caregiver's Perspective,
 LVAD Surgery and Recovery, and Life with an LVAD.
- The Device Kept Him Alive, but was the Pain and Suffering Worth It? In this Washington Post article, Kristen Kostick and Jennifer Bluemental-Barby of Baylor's Center of Ethics and Health Policy follow the story of Beverly and Robert in their journey through a LVAD transplant and end stage heart failure. Through their humanizing struggles with mortality, Beverly and Robert weigh the difficult decision of prolonging life.
- Managing our Mortality: Why Some Terminally III Choose Death: While technology such as the LVAD makes it
 possible for terminally ill patient to prolong their lives, some may choose not to. Rachel Roubein of The Atlantic
 follows the story of Jim Reales, a patient who chose against receiving an LVAD.
- Ethical Challenges with the Left Ventricular Assist Device as a Destination Therapy. Philosophy, Ethics, and Humanities in Medicine. 2008; 3:20. By Aaron G Rizzieri Ph.D., Joseph L. Verheijde Ph.D, MBA, Mohamed Y. Rady M.D., and Joan L. McGregor Ph.D. A nuanced view of how LVAD transplantations can significantly alter end-of-life trajectories for patients undergoing destination therapy. The article emphasizes the importance of direct participation of multidisciplinary care teams and palliative care specialists, and accurate and complete counseling and informed consent for patients.