

Heart 2 Heart

*Stories from Patients with
Left Ventricular Assist Devices*

Edited by

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Lake Michigan Sunset

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Dedication

Hope. Anticipation. Fear. Excitement. Anger. A sense of purpose. Denial. Joy. Boredom. Gratitude. Love of family. Contemplating death. The will to live. Acceptance. Life comes into sharper focus in times of personal challenge. In these pages, women and men with severe heart failure whose lives have been forever altered by the experience of living first with advanced heart failure and then a ventricular assist device (VAD) share their emotional stories.

This remarkable therapy allows us to cheat death, sometimes for many years, in patients previously at the precipice. For most patients, quality of life on a VAD is remarkably good. However, complications – stroke, life-threatening infections, gastrointestinal bleeding and the need for heart pump replacement - remain all too common. Their capacity to adjust to these changing life circumstances, to accept the restored opportunities afforded by VAD therapy along with the emotional burden of knowing that any day could bring tragedy, is testament to the amazing resilience and adaptability that makes us human.

As a cardiologist working with patients with advanced heart failure, I have been privileged to bear witness to the spirit of those who have pioneered the first two decades of widely-available ventricular assist device therapy, sharing in their joys and disappointments, their challenges and their triumphs. These reflections open that experience to a much wider audience. In 2016, to receive a ventricular assist device remains an uncommon experience; the emotional lives of those who do so are universal.

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Foreword

From a very basic scientific description, heart failure is the inability of the heart to pump blood commensurate with the needs of the body. The causes of heart failure are varied, stemming from something as common as a heart attack to something less common, such as a genetic defect in the muscle of the heart.

This simplistic scientific description of heart failure ignores the staggering toll of human limitations and suffering caused by heart failure as it progresses from its earliest stages to more advanced states. In its worst form, heart failure causes painful swelling of the body, extreme fatigue, chest pains, dizziness and extreme shortness of breath with little or no activity. These symptoms prevent participation in even the simplest activities of daily living such as bathing, brushing one's teeth or dressing. For some, sleeping in an upright position in a chair helps prevent their lungs from drowning in their own fluids.

Why is it important to understand the human suffering caused from heart failure? In the upcoming pages of this book you are going to hear stories from patients and families about their experiences and decisions to accept one treatment option for heart failure.

The treatment, a left ventricular assist device or LVAD, is an artificial heart pump that is attached to the heart through a major surgical operation that takes over the pumping action of the left side of the heart to relieve the symptoms of heart failure. Over the past 30 years, LVADs have moved from being a rarity to now becoming the most common forms of treatment for severe advanced cases of heart failure for those that are eligible and choose to accept this treatment.

For the very late stages of heart failure, scientific evidence strongly suggests that LVADs provide survival benefit and an improvement in one's quality of life. Technological improvements in LVADs have reduced their size from that of a grapefruit to that of a plum. In fact, LVADs have now become more common than heart transplantation because of the scarce limitations in heart donors. Many wonder at the marvels of man being able to create a machine that to some extent, replicates the exquisite human function of the heart. However, the story

is not so simple. LVADs, despite all the marvels and benefits they possess, have an ugly side to them and are associated with a host of complications including stroke, bleeding, infection and blood clots forming in the heart pump that may occur in some patients at a not too infrequent rate.

The stories in this book describe the difficult dilemma that patients face in trying to decide to accept a life-altering therapy that relieves the unimaginable suffering of advanced stages of heart failure, but for some may cause a series of dreadful or potentially deadly complications.

After reading these stories, one should marvel not at the life-saving technology of the LVAD, but at the strength and the capacity of our patients to endure. The stories describe the human spirit at its greatest when facing both the joys that LVAD therapy can bring and its darkest hours. These stories are about patients making a choice between life and death. All of these patients are brave, both in life and as they approach death.

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Preface

In the spring of 1996, as a graduate student at University of Michigan's School of Social Work, I was in my second semester at University Hospital in the Heart and Lung Transplant Programs. My preceptor thought it would be 'very interesting' for me to organize a group of patients and teach them leadership skills in order to better facilitate the patient run support groups that she had started throughout Michigan. Her suggestion was based on my former work experience as an Advertising Manager and Director of Sales for a large publishing company. Plus, she thought I should take a class in 'group therapy.' To be honest, I wasn't very interested in groups for reasons too numerous to list here. However, under her influence, I signed up for the class and extended an invitation to the group leaders she provided.

On our first meeting, I quickly learned that these individuals already had leadership skills; they were experts in their own illness and treatments. They immediately challenged me to help them put on a conference to include all transplant patients in Michigan. Their vision was a statewide affair with speakers from many areas of health care: insurance companies, legislators, doctors and more. After several months of planning, the conference was successfully held with over 500 patients and their families in attendance.

During one of the presentations, a pre-transplant lung patient stood up and shared that she wasn't sure her life was worth putting her family through the expense, both emotional and financial, to have a transplant. She was in tears as all those present heard her breath-shortened plea. That's when Pat, a heart recipient, stood up. Pat was a regular member of our support group and had quite a way with words. She asked all who thought this woman was 'worth it' to stand in support. The entire assembly rose to their feet and applauded, including the panel of speakers who were presenting at that moment.

I can't tell you how moved I was by this demonstration of sharing and support. It was sincere and heartfelt. In that brief question, this woman had told her story, one of suffering and fear about the future. Also in that moment, she received support from many others who'd likely felt like her at one time or another. And now through this conference, they were sharing and learning from

not only the ‘experts,’ but from each other. For me, that conference was the inspiration for this book and the catalyst for many other programs developed in support of heart transplants, and eventually LVAD patients and their families at University of Michigan Hospital.

During my twenty-one years as a professional social worker, I have learned much about the benefits of peer-to-peer support. The group that I helped facilitate during my internship still endures as a resource for new patients, those waiting and those who have undergone LVAD or heart transplant surgeries. Our ‘Peer Visitors’ are mentors, trained to meet with other patients, either in the hospital or out. Each year two large social events are hosted by social work so that patients can connect or reconnect with others and share their experiences. A newsletter of patient events is published each quarter to keep the patients and their families informed of the heart transplant and LVAD happenings. And, once each year, with each patient’s permission, a directory is published and given to every patient in our program so that they may ‘resource’ one another by phone, letter or email. These activities are self-supported by an annual hockey game fundraiser.

The power of shared experiences is well documented in literature on story telling. The stories told in this book contain personal accounts of high points, low points and turning points of emotionally charged events. They have helped make meaning out of suffering and setbacks not only for their writers, but also for those of us who read them. This book is a culmination of efforts that will hopefully help inform future patients in their decision making about having and living with an LVAD. And, more importantly, encourage them to share their experience; to tell their story to a doctor, nurse, social worker, family member and each other.

Ruth Halben, B.A., M.S.W.

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Francis D. Pagani, M.D., Ph.D. Surgical Director of Heart Transplantation and Director of the Center for Circulatory Support at University of Michigan, without whom there would be no LVAD program and consequently I would not have returned to the University of Michigan, nor would I have seen an actual heart transplant. You are, of course, a very accomplished surgeon. But many may not know that you were the inspiration for a 15-year-old hockey fundraiser, for which many other professionals have learned the joy of skating in order to support it as well. Thank you for the opportunity of a lifetime to work with you as you built this world class LVAD program. Thank you for your contribution to this book; for your much needed travel support over these many years; and finally for your recognition and support of the role of social work and understanding the importance of social support in all of its many facets.

And lastly but never least, the **patients** and **their caregivers**, not just those who have bravely shared their stories here but those who also shared them, privately, with me. Thank you.