Resources for Your Emotional Well-being

- **Hospital Social Workers:** They offer emotional support, practical guidance, and can connect you to community resources.
- **Psychologists/Psychiatrists:** Counseling can help manage stress, anxiety, or depression.
- **Pre- and Post- Transplant Coordinators:** These team members can guide you through the process and answer your questions.
- **Caregiver Support Groups**: Connecting with others who understand your experience can be incredibly powerful. Ask us about local Mended Hearts groups!
- **Your Personal Network:** Don't hesitate to ask family and friends for specific help – whether it's an errand, a meal, or just a listening ear.
- **The Caregiver Action Network:** www.caregiveraction.org

Contact Us

If you would like to receive support or need more information, please contact us at:

The Mended Hearts, Inc.
1579 US Highway 19 S
Leesburg, GA 31763
1-888-HEART99

www.mendedhearts.org

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Caregiver Support and Resources on the Transplant Journey

The Mended Hearts, Inc.

Discussion Guide for Patients & Caregivers

This discussion guide is part of the EMPOWERTRANSPLANT™ educational series.

Caring for the Caregiver

Your Vital Role

Facing a heart transplant is a major journey, not just for the patient, but for their loved ones also. As a caregiver, your role is essential. This guide will show you what to expect, remind you how important you are, and point you to support. You're a key part of this, and we're with you every step of the way.

Understanding the Critical Part You Play

Your support makes a big difference in your loved one's journey. You become their:

Advocate: You may help speak up for them, ask questions, and make sure the medical team understands their needs.
Care Coordinator: You may be the main care organizer - handling appointments, medications, and rides.
Emotional Anchor: Your comfort, support, and being someone to talk to, can help them feel less stressed and anxious.
Information Hub: You may keep friends and family informed and help plan visits.

Navigating the Journey

The heart transplant process involves several phases:

Evaluation
Waitlist
Transplant Surgery
Recovery & Rehabilitation

These phases are discussed in detail in the Discussion Guide: *An Introduction to the Heart Transplant Journey*

Communicating for Support

Communicate Clearly: Talk openly with the medical team and your loved one.

- Ask questions of your loved one's medical team.
- Work together with your loved one to develop a written list of questions.
- Acknowledge that this experience is challenging for everyone.
- Connect with a trusted friend or family member who isn't as emotionally involved.

Stay Organized: Tracking medications, appointments, and instructions makes it easier to share information clearly.
Ask For Practical Help: Acknowledging and accepting that you need help can be difficult. Make a list of possible ways friends and family can help and LET THEM!

- Bring a meal
- Buy groceries
- Pick up the kids
- Clean the house
- Sit with the patient
- Run an errand

Self-care Helps Avoid Burnout

It's completely normal to experience a wide range of emotions – stress, fear, hope, exhaustion. Please know you're not alone, and your feelings are valid.
When you're burned out, it's harder to care for others and it can harm your own health.
Some signs of burnout:

- Feeling overwhelmed
- Routinely feeling exhausted
- Losing interest in the things you used to enjoy
- Becoming easily irritated or angry
- Frequent headaches or other physical problems

Ways to Prioritize your Self-care

Physical: Get enough sleep, eat well, and try to incorporate light activity.

Mental: Find moments for hobbies or relaxation.

Emotional: Acknowledge your feelings and seek help when you need it.

Helpful Tips:

- Keep a notebook for important information such as medical contacts, medications, appointments.
- Track the patient's medications, diet or physical activity when they are unable.
- Spend time together and with others not focused on medical issues.
- Keep healthy snacks handy for those times when you or others need something to munch on.