Create a Wellness Plan

Have a plan in place for your emotional health so you know what to do if you feel upset:

Build Your Team: Write down the names and phone numbers of the family and friends that you can lean on when times are tough.

Know Your Triggers: Know what make you feel stressed and know what coping tools you will use to help.

Home Planning: Planning for what life will be like once you get home can be both inspirational and practical since you will have new guidelines after transplant.

Educate Yourself: Learning about transplant, what to expect, and the recovery timeline can reduce fear. Knowledge is power!

Resources for Your Emotional Well-being

NAMI (Mental Health Support): **nami.org**
FMLA (Family Medical Leave Act): **dol.gov**
Peer-to-peer support groups: **mendedhearts.org**
Professional Counselor or Social Worker: **https://www.psychologytoday.com/us/therapists**

Financial Assistance

https://mygooddays.org/
https://rxoutreach.org
https://copays.org
https://www.healthwellfoundation.org
https:/www.needymeds.org
https:/medicineassistancetool.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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Mental and Emotional Support During the Transplant Journey

The Mended Hearts, Inc.

Discussion Guide for Patients & Caregivers

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

Managing the Emotional Journey

The Emotional Heart

This guide is about the big feelings and worries that heart transplant patients and their caregivers have. It is totally normal to feel stressed, scared, or sad. Your feelings are an important part of your healing. When you feel better emotionally, your body heals better too.

Dealing With the Wait

Waiting for a new heart is very hard. You might feel sick and worried about what might happen. Being prepared helps you feel stronger:

- It's normal to feel sad or hopeless if your health is getting worse. Talk to your doctors, social worker, or psychologist. They can help.
- Talk openly with your family and friends about how you feel and what you need. This helps strengthen your support system.
- Fill out forms that explain your wishes. These include a Health Care Directive (Living Will), which tells doctors what care you want, and a Power of Attorney (POA), which lets someone you trust make decisions if you can't.

Financial Concerns

Worrying About Money: If you are working, being sick might affect your ability to work. Here are ways to plan ahead:

- Talk to your job's HR department to learn about your work benefits.
- Think about applying for Social Security Disability income.
- Check the financial resources in this guide.
- Research ways to raise money for your care, like using websites such as GoFundMe.

After the Transplant

Getting a new heart is an amazing gift, but recovery is a big challenge for your mind and body.

- **First Weeks**: After surgery, you may feel happy and thankful, but also confused or weak. Give yourself time to adjust.
- **Take It Easy**: Everyone heals at their own pace. Don't compare yourself to others. Full recovery can take about a year, so be patient with yourself.
- **New Challenges:** You might have some strange feelings because of new medications:
  - **Steroid Side Effects**: Strong medicines called steroids can cause mood swings, depression, or anxiety. Tell your care team right away if this happens.
  - **Brain Fog:** Sometimes you may feel confused or have trouble focusing or remembering things. This is usually temporary, but tell your transplant team if it doesn't go away.
- **Flashbacks (PTSD):** Being very sick in the hospital can be scary. Some people have nightmares or flashbacks afterward. If this happens often, talk to a doctor — they can help.

Big Feelings

These feelings are common after a heart transplant, and they are okay to talk about:

- **Feeling Guilty:** You might feel "survivor's guilt" - feeling bad that you got a new heart when others did not. This is a very common and normal feeling.
- **Feeling Alone:** It can feel like no one understands what you went through. This feeling of loneliness or isolation is why support groups are so important.
- **Worry About the New Heart:** It's normal to worry that your body might reject the new heart. If this worry never goes away, you need to talk to a counselor about it.

Everyday Tools for Managing Stress

You can manage stress by doing these small things:

1. **Deep Breathing:** When you feel worried, stop. Take five slow, deep breaths. This calms your body down.
2. **Keep a Schedule:** Go to sleep, wake up, and eat at the same times each day. This helps you feel safe and less confused. If you're in the hospital, make your own schedule and include activities you enjoy.
3. **Gentle Movement:** Follow your transplant team's advice about exercise. Gentle walking can boost your mood and help you get stronger for recovery after transplant.
4. **Be Thankful:** Write down or think about things you are thankful for each day. You can also write in a journal or draw to get feelings out.
5. **Time Off for Helpers:** Caregivers need time to themselves! They must schedule breaks and ask for help. Caregiver burnout (getting totally worn out) is real.