

Honored to be  
Rebekah's  
Mom..and  
Caregiver





# 10 Tips for Effective Caregiving from Mended Hearts *Heartguide*

(With additional comments by  
Rebekah's Mom)

## Source: Mended Hearts HeartGuide

- ***Tips for Caregivers***

When you are caring for a loved one, whether in the hospital or at home, caring for yourself is often your last priority. However, it is important to create a balance between caring for others and yourself. You may not feel that caring for yourself is a priority, but it is imperative that you try. The best gift you can give your loved one is to also care for yourself.

### **For the Caregiver- Remember to:**

- **Communicate** how you are feeling
- **Allow** time to grieve the lack of normal
- **Reflect** on the journey—in writing
- **Educate** yourself about the disease
- **Get** involved in your loved one's care
- **Involve** others who can help
- **Visit** with other MHI/MLH members
- **Eat** right
- **Rest**—get sleep and take breaks

# And I would add...

- Make the most of the time you have.....hours in the hospital can be boring and also tense – **but make the best of it and enjoy having each other.** Rebekah liked to have visitors with no expectations of her - She just liked having someone sitting beside her regardless of her being awake or asleep, whether she wanted to be talkative or silent– I cherish those times when there was no agenda.
- Caregiving is about the patient’s mental health and **yours...challenge them to do what they may not want to do and but take care of yourself too.**
- **We never said “no” if she wanted to try** – At the same time if she knew her limitations and we picked her up when she needed the help. **Don’t overprotect.**
- **Encourage them to give of themselves to others & they will feel more self worth.** Rebekah found “her place” in reaching out to others from her hospital bed or when home meeting for coffee --she liked connecting with others. She knew she had made a difference in others lives and knew she must have accomplished what she was here to do if the Lord was taking her home. We were overwhelmed by those we met for the first time following her death & all that they shared.

# Rebekah's story in VERY brief form

- She was first diagnosed at 5 months with multiple Congenital Heart Defects (TGA, Atrial & Ventricular Septal Defects and her Patent Ductus did not close). Due to all these combined she quickly developed Pulmonary Hypertension which eventually destroys the lungs.
- Rebekah had 2 palliative surgeries, one at 8 months and another at 5 which was open heart and considered to be her only hope of living past 10. She was home in 11 days, with great but not normal O2 stats.
- I am terrible about pictures at certain times so I am sharing a picture of Mallory...Sharing it as it brings back memories of Rebekah looking the same at 8 months and while bigger again at 5 years old .



- Until 17 she took no prescriptions and had only the restrictions she placed on herself – she could do nothing aerobic. At 17 she went on a drug – aimed at controlling the PH –Tracleer. Because of the FDA X for pregnancy before going on the Tracleer, Rebekah had eggs harvested & frozen & after she married her first husband her cousin volunteered & successfully carried Rebekah’s son Gavin who was born in March 2008 – Rebekah was 23.



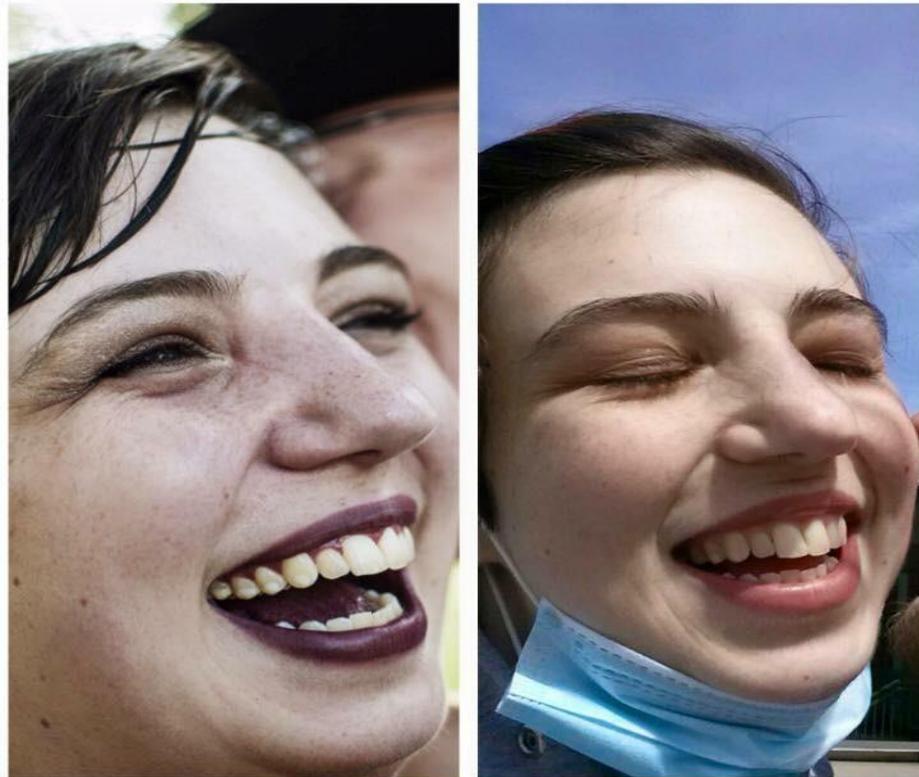
- Sadly, her first marriage did not work out and Rebekah divorced in 2011 .. Shortly after she started dating a high school friend -- they fell in love and she married Jay in September 2013 -she also gained a step-son whom she adored, Jonathan.
- In her late 20's due to multiple bouts of Congestive Heart Failure there were ER visits and many stays here at the Ross --Several different drugs aimed at controlling the PH were tried but none worked well enough to keep the CHF from progressing.



The Congestive Heart Failure eventually started to affect other things – and on February 19, 2014 when Dr. Daniels found she was in serious organ failure –he had her life-flighted from the Ross Heart Hosp to the Cleveland Clinic where she was stabilized and spent 6 weeks on IV Epinephrine waiting for a heart and lungs from the same donor to come.



Rebekah had a heart /double lung transplant on March 28, 2014 – she did very well and was walking (not far) 3 days later! Before very cyanotic and after very pink!!!



- Rebekah had a few infections but overall did very well- for 18 months
- There were no signs of any rejection until late July 2015 when she started have breathing issues and other signs of what turned out to be Severe Chronic Rejection of her donated lungs -- She went on 24/7 O2 & eventually a BiPap.



- Her health deteriorated quickly, she was in and out of the Cleveland Clinic 5 times and on December 18<sup>th</sup> she was told she was not a candidate for a 2<sup>nd</sup> Lung transplant because they did not know why the rejection was so severe and happening so quickly.
- We moved her to Kobacker House Hospice here in Columbus on December 24<sup>th</sup> and she passed away December 28<sup>th</sup>, 2015 .



# And so my topic: End of Life Caregiving

- **Not an expert in end of life caregiving by any means** –much of my job was made easier for me by Rebekah herself – she had given things lots of thought.
- **Because of the Chronic Rejection she was going down hill so quickly Rebekah said she knew it was coming long before the final news came** – she had spent 3 months preparing her son, Gavin, giving up custody to her ex-husband, helping Gavin transition as well as doing other things to ease things for her family.
- For Rebekah **all the legal paperwork had been in place** as far as Durable Power of Attorney, Living Will and other legal formalities from before her Heart/Lung Transplant. I was the person listed on all of it.
- When the “NO HOPE” news came we cried with her and as we usually did following each new prognosis's/ or change in care we took a **few days to “mourn” before telling “the world”** --during this time we discussed what **palliative care meant and it’s implications, and we found out what Rebekah wanted.**

- **Over the course of the 3 days it also became clear that we were not going to have her a long period of time**— Rebekah’s breathing was getting much too labored and it was very obvious that the BiPap machine was keeping her alive and that she was in a lot of pain. She could not be off of the BiPap long and when off it she found it extremely hard to talk at more than a whisper due to lack of breath. Accomplished at sign language she taught us a few key things so she did not have to talk to make her immediate needs known.
- So we sat beside her and when she could Rebekah talked about what she wanted - **we were there to love and support her and make sure her wishes were followed. After so many years of battling for her the hardest thing for me was to let go of the hope and let her lead the way ..**
- **Her decisions meant we had to go against doctor’s advice** to move her to Columbus and to a place she was familiar with and wanted to go to...that was the Kobacker House. Once there **we enforced her desire** to have limited visitors, so she could spend most of her time with immediate family, most of all she did not want for Gavin and her step son to see her so dependent on the BiPap . Most of the time she opted for O2 only.
- When she felt as though she had said goodbye to all those she wanted to and had had enough time alone with her husband and the boys **she herself made the decision that she wanted O2 and painkillers only and choose to have no other drugs, no more BiPap, no more pain** –with great agony I called the nurse.

- From the time she arrived at Kobacker **a family member was always with her**, and shortly after the “no more” decision on the 26th she slipped into a coma and passed away 36 hours later and in her husbands arms.
- We arrived about 5 minutes after she had passed and when walking into her room were overwhelmed with a **sense of peace**. **All her battles to live were over**, she knew where she was headed and **we knew she had lived as much of a life as she had the strength to-she had died on her own terms**.
- We made sure she had the **funeral that she wanted**. She gave specific instructions – they were followed and very much a testimony to her, it was **beautiful...and so good to see how far she reached and meet those she knew through all her pursuits many shared from how she had touched them – and we had no idea**.
- **My/ Our caregiving was/ is still not over though --We have “orders” as far as taking care of her own family – and are working closely with her husband and ex-husband to make sure the boys loved and supported**.
- **She expressed her desire that certain of her efforts related to being a CHD kid and ACHD adult continue**, and we (and several of her friends) will be doing that on her behalf. That is why I agreed to continue to be a part of this session on caregiving.

# In summary....Caring for Rebekah at the end of her life amounted to:

- Accepting the prognosis
- Listening to her wishes
- Being supportive
- Accepting that Hospice was needed
- Being strong enough to protect her
- Fulfilling her wishes
- Releasing her to go
- And now doing all I can to make sure her legacy lives on

# Additional Websites

- Mended Hearts new “Heart Guide” has a Caregivers section – download the app by searching for Mended Hearts Heart Guide at the app store.
- Caregiver Action Network – [www.caregiveraction.org](http://www.caregiveraction.org)
- National Alliance for Caregiving -[www.caregiving.org](http://www.caregiving.org)
- National Family Caregivers Association – [www.nfcacares.org](http://www.nfcacares.org)
- Hospice Of Central Ohio - [www.hospiceofcentralohio.org](http://www.hospiceofcentralohio.org)