

Becoming a Caregiver - My personal Journey

What AML taught me about caring
for the person I love...



My caregiving journey

Dangerously low platelets led to Steve's AML diagnosis

Eight months of intensive chemotherapy

Allogenic transplant was February, 2023

A marathon, not a sprint

My role changed at every stage



Learning to Advocate

- Advocacy is a learned skill
- Learn enough to ask informed questions
- Write questions before appointments
- Organize information so you can find it
- Keep test results and medications organized
- Report changes to the care team
- Ask for help when needed
- Know who to call after hours



Caring for the Relationship

- Find moments of normalcy
- Talk about more than cancer
- Laugh when you can
- Make time for each other

You are still a team.



Your circle of support

- Family and friends
- Your medical team
- Caregiver Support groups (local *and* social media)
- Neighbors and co-workers
- Your faith community

*You can't do this alone ...
... and you shouldn't !!*



Caring for yourself without guilt

- Exercise (even if it's just a walk)
- Eat well and make time for rest
- Keep your medical appointments
- Accept help and take a break
- *Your Needs matter too!*



Grief, fear, and hope

- You may grieve the life you expected
- This was the hardest journey of my life
- Hope and fear can exist together
- You do not have to be strong every minute
- Find one or two people with whom you can be completely honest
- Life gets better as time goes on



Recovery is a new chapter

- Treatment ending does not mean life feels normal
- The caregiver may stay in “crisis mode” long after the crisis.
- Recovery can be uneven.
- Celebrate milestones — even the small ones.
- Give yourself time to recover too.



What I want you to remember...

You do not have to be perfect.

Ask for help before you are depleted.

Take care of yourself, too.

Find moments of joy

Take one day at a time

Hold on to hope....

*“A good caregiver is not a perfect caregiver. They are a **present** caregiver.”*

— Pat

