

Graft-versus-Host Disease Caregivers are Survivors, Too!

Celebrating a Second Chance at Life Survivorship Symposium

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Michelle M. Bishop PhD
Coping with Cancer & Caregiving, LLC

Learning Objectives

- To understand the unique challenges of living with chronic GVHD (cGVHD)
- To describe the impact of cGVHD on the quality of life of family members, both as caregivers and as fellow “survivors”
- To discuss the importance of self-care and other coping strategies to maintain health and good quality of life along the way

Chronic Graft-versus-Host Disease

- Most common complication of allogeneic transplant
- 40-60% of allogeneic transplant survivors will experience
- Donor immune cells perceive patient's organs and tissues as "foreign"
- Can affect many different organs
- Can be disabling and distressing

Chronic GVHD (cGVHD)

- Can range from mild to moderate to severe (15%)
- Usually starts within first year, but sometimes much later
- Typically require treatment for 3-5 years (15% of patients much longer)
- Treated with medications that themselves have difficult side effects
- Survived (even cured of) cancer but now have new disease

Unique Aspects of Chronic GVHD

- New condition
- Unexpected
- Rare
- Chronic
- Unpredictable
- Can be serious and quite stressful



The cGVHD “Road”

- Unplanned trip that comes after the rough road of cancer and transplant
- Unpredictable twists and turns
- Unclear end point
- Road that patients and caregivers are on together



GVHD Family Caregivers

- Spouses/partners, parents, adult children, siblings, friends
- Provide physical, practical, emotional, social care and support
- May not identify as caregivers
- Professional vs informal
- Direct and indirect impact



GVHD Care Roles – Similar to BMT, “plus”

- Provider of “hands on” care
- Medical manager & monitor
- Patient advocate & liaison
- Driver, cook
- Home and financial manager
- Communicator with family & friends
- Protector
- “Cheerleader”



Family Caregivers are Survivors, too!

- Definition of cancer survivor
 - An individual is considered a “survivor” from the time of diagnosis through the balance of life
 - Because friends, family members, and caregivers are also affected by cancer, they are included in this definition, as well

- *GVHD Survivors*
 - *Includes family caregivers who are impacted by cGVHD*



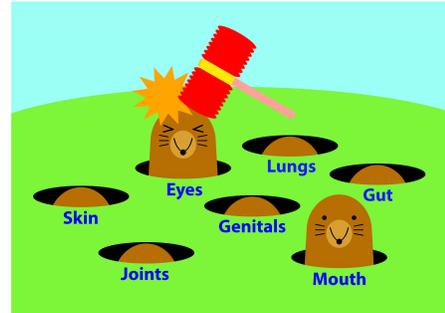
Three Experiences

- Patient experience
- Family caregiver experience
- Patient-family caregiver experience



What Both Survivors & Caregivers Say

- “I had no idea this could happen”
- “It’s like a game of ‘Whac-a-Mole’”
- “It’s always something”
- “It’s an emotional and physical roller coaster”
- “It’s the gift that keeps on giving”
- “No one gets it”



Physical Impact of cGVHD

- Patients
 - Fatigue, pain, disability, sleep issues, cognitive issues
- Family caregivers
 - Fatigue/exhaustion, sleep problems, cognitive issues
 - Don't have time to exercise, take care of self
 - Own needs may go to bottom of pile

Psychological Impact of cGVHD

- Patients and family caregivers
 - Shock, uncertainty, fear of the unknown
 - Managing cGVHD can take up a lot of time and “bandwidth”
 - Loss & grief -- sense of self/identity/former life/imagined future
 - Worries about the future, finances
- Family caregivers
 - Sense of responsibility, feelings of guilt, concealment of feelings
 - Distress as high as survivors, often higher

Social Impact of cGVHD

- Patients and family caregivers
 - Patient’s fatigue, restrictions, or immunological vulnerability make it difficult to do things
 - Hard to make or keep plans – don’t know how patient will feel
 - Friends and family may not understand
 - Others may stop helping and/or inviting
- Caregivers
 - May lose touch with own friends
 - Often experience more loneliness than survivors

Relationship Impact of cGVHD

- Hard to see loved-one suffer
- Pain, fatigue, skin changes, weight loss, low sex drive, genital changes affect physical touch and intimacy
- Patient/caregiver roles can change interpersonal dynamics
- Hard to know when to push and when to let go
- Can be hard to stay cheerful when you are scared and tired

Risk of burnout or “breakdown”



It's a Marathon, not Sprint

- Can be a long road
- How does one learn to live with GVHD and adjust to the ongoing journey?
- What can one do to keep going and have a good quality of life?



Roadmap to Resilience

- Information/expectations
- Build a support crew
- Work together as a team
- Vehicle (and driver) maintenance (self-care)
- Recognize the need to pull over sometimes (both for respite and to check out the view)



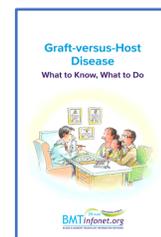
Information/Expectations

- Whole new road
- Seek GVHD-specific resources
- Develop realistic expectations
- Learn from others



cGVHD & Caregiver Resources

- GVHD alliance.org
 - BMT InfoNet
 - The National Bone Marrow Transplant Link (nbmtLINK)
 - BeTheMatch
 - Meredith Cowden Foundation
- Written and online materials
- Webinars, online presentations, podcasts
- Searchable directories
- Peer to peer support



Peer-to-Peer Information & Support

- Invaluable
 - No substitute for talking with someone who “gets it”
 - May have valuable tips and tricks they have learned
 - Helps to decrease sense of isolation
 - Easy to access - can connect by phone or computer/internet
- Resources
 - Online GVHD Caregiver Support Groups (BMT InfoNet)
 - Caring Connections (BMT InfoNet), Peer Support on Call (nbmtLINK), Peer Connect (Be The Match)
 - Facebook groups

Build a Pit Crew

- Find others who “get it”
- Create a cGVHD medical team
- Let family and friends know you still need help
- Consider “outsourcing” if you can
- GVHD landscape is different but many tools still apply
 - e.g., caringbridge.com, myline.org, lotshelpinghands.com, mealtrain.com



Challenges to Getting Support

- Support system may not understand cGVHD road or “marathon”
- Can be hard to ask for help...and to keep asking
- Support system may fatigue
- Help is not always helpful

Ways to Manage Help

- Try putting cGVHD in a framework others might understand (e.g., MS)
- Point them to GVHD information resources
- Be ready with a list when people ask “can I do anything?”
- Be clear: “This would really be helpful”
- Try to tap multiple sources of support
- Build in ongoing support for the long haul

Work Together as a Team

- You are both on this road together
- Try to communicate openly and clearly
- Encourage patient independence and practice letting go
- Find new ways to do old things
- Engage in creative problem solving together
- Engage in things that remind you of who you are

Self-Care is Critical

- Patient's, family's, and your own well-being is dependent on you



Put Your Oxygen Mask on First



If you do not care for yourself, you will not be able to provide the quality and quantity of care you want for your loved-one

Try to Keep Some Charge in Your Battery



Barriers to Self-Care

- Self-care is hard!
 - *"I feel selfish thinking of my own needs"*
 - *"I don't have time"*
 - *"If I don't do it, it won't get done"*
 - *"I don't want to bother other people"*
 - *"I shouldn't need to take a break. I'm strong"*



What is Self-Care?

- Replenishing and protecting physical, emotional, social, spiritual energy
- Ongoing practice of maintenance & monitoring



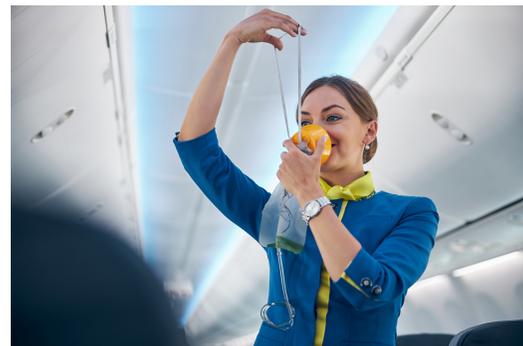
Maintenance Model

- Keep mind, body, spirit strong
- Keep batteries charged
- Reduce wear and tear
- Work smarter not harder
- Get regular check ups/tune ups



Lots of Ways to Recharge

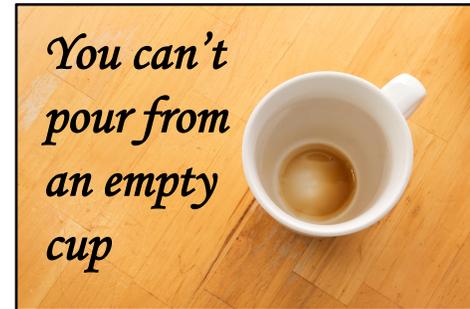
- Movement, stretching, exercise
- Nutrition, hydration, rest
- Relaxation techniques
- Time with friends
- Time alone
- Time outdoors
- Prayer/meditation/mindfulness



What is your oxygen?

Prioritize & Protect Your Energy

- Do it first thing or schedule it in
- Advocate for yourself
- If others are draining, it is okay to say no
- Keep your own medical appointments including preventive care
- Be mindful of unhealthy coping (smoking, alcohol, emotional eating)



Check Your Dashboard Daily



Medical Support

- Signs of burnout
 - Feeling down, depressed, overwhelmed
 - Irritability or crying spells
 - Finding it difficult to concentrate
 - Back pain, headaches, stomach aches
 - Weight changes
 - Using more medications, alcohol, caffeine
 - Neglecting your own physical needs
 - Withdrawing from people



Talk to your doctor if you experience prolonged symptoms of depression or anxiety

Counseling Support

- Individual counseling
 - Transplant center or community-based
 - BMT InfoNet directory of providers
 - Insurance often covers; Employee Assist. Prog.
- BeTheMatch.org
 - Patient and Caregiver Emotional Support (PACES program)
 - Spiritual support services
- Couples/family counseling



Flexibility & Adaptability

- Mental preparation, social & emotional support, self-care helps
- Can feel like constantly “rerouting”
- Take each day as it comes
- Control what you can and practice letting go
- Use self-compassion, gentleness, and humor
- Stop & get out of the car periodically



Pull Over Periodically

- Take a break (respite)
 - You both need to “unplug”
 - Take a break from the medical
 - Take a break from each other
 - Do something that helps you to feel “normal”



Acknowledge & Process Feelings/Loss

- Acknowledge emotional roller coaster
 - Fear/Hope
 - Frustration/Relief
 - Sadness/Joy
- Process feelings, loss, change
 - Writing, journaling, documenting
 - Art, music, photography
 - Talking/sharing with others
- Grieve what used to be, accept what is, and move forward to what will be



Stop, Get Out of the Car, Look Around

- Reflect on perspective & meaning
 - Take stock, notice progress, see how far you have come
 - Remember why you are doing this
 - Give yourself (a lot of!) credit
- Consider a gratitude diary
- What grounds you?



Reflect on Gifts and Growth

- Gifts of caregiving – rewarding, purposeful
- Appreciation of life & more time
- Increased personal strength
- Feeling closer to loved-ones
- Stronger faith
- Making new connections
- Giving back & helping others



In Summary

- GVHD can be a long & crazy road
- Caregivers along for the ride
(and often in the driver's seat)
- One can build resilience for the journey to be able to care for their loved-one and maintain a good quality of life





QUESTIONS?



Michelle Bishop PhD
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