Approaches for Thriving With Chronic Graft versus Host Disease
GVHD is not rare. Up to 70 percent of transplant recipients develop acute GVHD, which crops up within the first few months of treatment, and 40 percent get chronic GVHD, the form that appears more than 100 days post-transplant. As the name implies, the chronic condition can last for years — or a lifetime — and its symptoms range from mildly annoying to disabling. (Fred Hutch/SCCA)

“It can be frustrating for patients who find themselves cured of their primary disease but are now living with a chronic illness with a profound impact on their quality of life — it is like trading one disease for another,” Dr. Mary Flowers said.

Patients with chronic GVHD usually require treatment for three to five years.

Approximately 15 percent require treatment for a longer period of time and, in rare cases, may need life-long immunosuppressive drugs. (BMT InfoNet)
But There is Hope!!!

Gains are being made in the development of new medications and treatments. One is even being given proactively to help lessen/prevent symptoms, especially with those that have transplants that aren’t as matched. (Abatacept)

https://www.nccn.org/home/news/newsdetails?NewsId=3054&fbclid=IwAR2HRrEMaDjQEu5PgY2z6xVdxzqsBv-HNsjCoDxUKmDDZK0gjKmEMIjrQKog
Education is Key in Coping

Stay connected with groups that keep up to date on the latest treatments
Learn From Your Fellow Survivors

There is no “one size fits all answer”

We need to have a realistic view of what coping is. It takes time for the body to heal, so it takes time for the soul.

You have survived a “personal earthquake”, which required an increased tolerance for the unknown as you walk with exhaustion, consistent pressure, grief, loss of identity, relationship changes, loss of control, and cGVHD can cause distressing symptoms that can make you feel discouraged.

To find how to live the best version of you, making the best of what your body can do, finding ways to cope, minimizing emotional distress, finding ways to reconnect with the world around you, and establishing a renewed sense of meaning and purpose in your life.

It is walking in balance with persistence, patience, hope, and acceptance.
Set Realistic Expectations

What is your new norm?

Reclaim areas of importance in your life while allowing for flexibility and creativity

Understand that everyone that loves you walks this journey with you. You all may cope differently but work together as a team to support each other.

Know when to ask for help

Learn to say no
Discover what time of day your body is at its peak and try to schedule what you need to do during these times.

Allow yourself breaks.

Prioritize.

Break bigger tasks into smaller tasks.

Become your own author in life.

Discover what brings you meaning, joy and hope.
Tips From David

Find ways to stimulate your brain (learn a language, crosswords, etc.)

Look for positives Find ways to be social, even on the transplant floor

Exercise

High Quality Foods instead of junk food

When able, get involved (He helps others going through the journey now

Accept life will never be the same, it is different, but increase the quality of life

Fatigue is no joke, get the rest you require and it helps you get more done

Consider counseling

Consider talking with someone who has been through it, peer mentors are available through nbmtLINK

15 years
Jen recommends keeping a list of the gains you make so you have something to reference when you feel discouraged.

Jen learned how to adapt with the changes she noticed with herself.

Walking around the office once an hour and resting her eyes from the computer were important once she was strong enough to return to work. She also modified her time in the office.


Jen shares how important it was to see this recovery as a marathon and not a sprint.
He viewed his transplant as a “recall to life”

He and his wife were a team that had an attitude of “whatever it takes to fight this” together

A strong support team

Chose a project to distract himself

He attends support groups, senior groups, and stays active.

His wife and he enjoy walking together and participate with an app, www.charitymiles.org. Large corporations will donate to charities of your choice by the level of walking you do.
Tips From Rhonda

- As a runner, she shares that she sees the transplant journey like a marathon and not a sprint. She framed her experience to be a mile she had to frame her brain to run 26 times, (instead of looking at the marathon as a whole 26 miles at once).
- Everyday she asked herself, what can I do to make myself physically stronger, mentally stronger/more positive, spiritually stronger, and socially stronger. She believes 80% of this fight was psychological. Envision your goal.
- She also recommends being informed of medications, symptom concerns, etc.
- Keep your eye on the prize, your second chance at life.
- Change negative mindsets. Remember, you are not a burden, you are a blessing.
- Learn to ask questions and speak up for yourself.
It is hard to keep up with others socially. However, you need support. She chose to blog. This also allowed her to control what she shared.

She had someone that was her liaison to control her social agenda. They arranged visits when she was up to it but also informed others when she was not up to visitors.

It helps to have someone taking care of the financial aspects of this situation. This person can assist with negotiating, payment plans, etc.

Spiritually, she found that she had to figure out what this was in her life. What is my connection? For her, this went beyond a belief of a doctrine, this involved a belief that I can and will continue.

Be at peace with your choices.

She shared several losses. She took time to review options every time she faced a loss. You can’t always choose what happens to you, but you can choose how you handle it. Fighting for your life takes enormous courage and you need to will yourself out of bed every day.
Communicate with Your Health Team

Develop a system to stay organized

Communicate clearly and honestly with your providers

Keep a running list of symptoms, health status changes, and new questions and ask how they can be treated

Be a strong advocate for yourself

Have a medical coordinator for your care

Copy other healthcare providers on emails

Use the whole health care team

Consider attending conferences

Don’t give up
You can’t stop the waves, but you can learn to surf.

Joseph Goldstein
Questions?

Feel free to type your questions in the chat box below. We will answer as many as we can today.
Thank you for joining us today. If we can support you further, please reach out to

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