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Over 20 years of direct oncology patient
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setting

Here to help you with resources and
emotional support

Survivors are our best teachers

- There is no “one size fits all answer” and it is often a highly emotional experience
- “I thought this transplant was supposed to make me better”
- We need to have a realistic view of what coping is. It takes time for the body 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

Living and thriving with cGvHD

- 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.
- Attend conferences and network as you look for solutions

Living and thriving with cGVHD

Get nbmtLINK's cGVHD book



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





Tips from Jen...

- ▶ 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 recommends the video, *The New Normal*, made by nbmtLINK. Visit our website, www.nbmtlink.org.
- ▶ Jen shares how important it was to see this recovery as a marathon and not a sprint.



Tips from Meredith...

- ▶ 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

Tips from Lew...



- ▶ 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.



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 on the lower part of your screen. We will answer as many as we can in our session today.

Thank you for joining us today. If we can be of any further support, please reach out to us at jennifergillette@nbmtlink.org.

Thank you to our speakers, our sponsors, and our partners. You make everything we do possible.

