


The Psychosocial Aspects of Dealing with Chronic GVHD

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Who Am I???

- Blood and Marrow Transplant Program at Northside Hospital
 - Dedicated Program Psychologist
- In Bone Marrow Transplant for over 20 years

Emotions related to cGVHD

- Start with frustration, because transplant process long enough

Why me?

Why now?

How much long will this go on?

Emotions related to cGVHD

- Angry – Why Me? (also a spiritual component)
- Sad – I thought things were getting better.
- Scared – Will I be okay?
- Acceptance: avoid guilt/blaming. Truth is 40-50% of patients get GVHD.

Coming to Terms with cGVHD

- Important to understand what GVHD is and what the treatment are for your specific issue (eyes vs skin).
- Understanding will help with emotional and physical symptoms. (depression, GI sx)
- Understanding and asking if it will go away?
- Understanding and asking will it come back?

Coming to Terms with cGVHD

- Important to get treatment
- GVHD left untreated can lead to:
 - Decrease in QOL
 - Decrease in physical functioning
 - Increase in cGVHD symptoms
- Understand that patients want to be done with BMT process, but can't ignore cGVHD.

Feeling Alone with cGVHD

- Feel more removed from BMT program due to less frequent visits
- Hard to find people who understand what you are dealing with
- Hard to understand yourself what the future holds.

Dealing with cGVHD

- Build support system: Friends and Family
- Support Groups: many online group options specific to BMT and GVHD
- Change in relationships: Intimacy, might need treatment to help with mood or physical symptoms impacting intimacy

Dealing with cGVHD

- Practical Problems:
 - Finances: medical bills, not returning to work
 - Being unable to care for children or parents
 - Delay in returning to role preBMT.

Chronic GVHD Feels Uncertain

- Patients feel Stuck!
- When will it End?
- Important to Keep Positive Attitude!
- Same energy when diagnosed with cancer:
Still Fight for Life!

Coping with cGVHD

- Build that Support System
- Find Purpose (volunteer, help others)
- Seek activities you can do that increase QOL
- Stay present and mindful daily
- Healthy habits (diet, exercise, sleep)
- Be compliant with your cGVHD treatments

Coping with cGVHD

- Reach out with symptoms
- Reach out to find ways to deal with physical complaints
- Reach out to find ways to deal with emotional complaints
- Let your team help you with what can be helped.
- Be **PATIENT** with yourself and others.