

Riding the Emotional Roller Coaster of BMT Survivorship

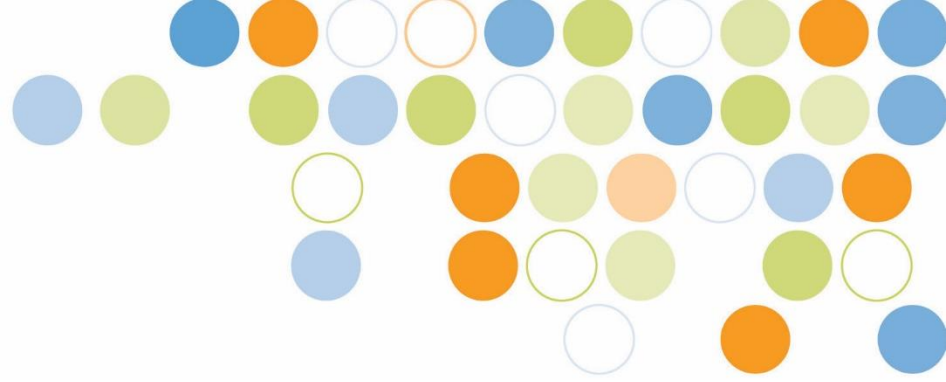
Celebrating a Second Chance at Life
Survivorship Symposium

July 11-17, 2020



**Katie Schoeppner, MSW,
LICSW**

Be The Match®

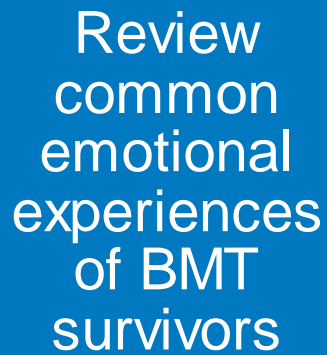


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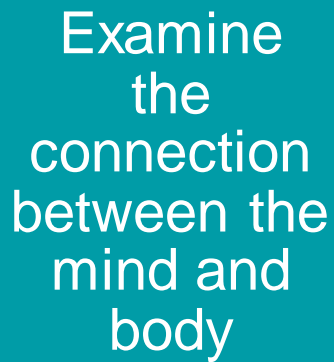
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Today we will...

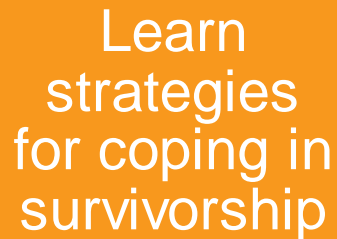
Review
common
emotional
experiences
of BMT
survivors



Examine
the
connection
between the
mind and
body



Learn
strategies
for coping in
survivorship



Leave time
for
questions



A bit about me:

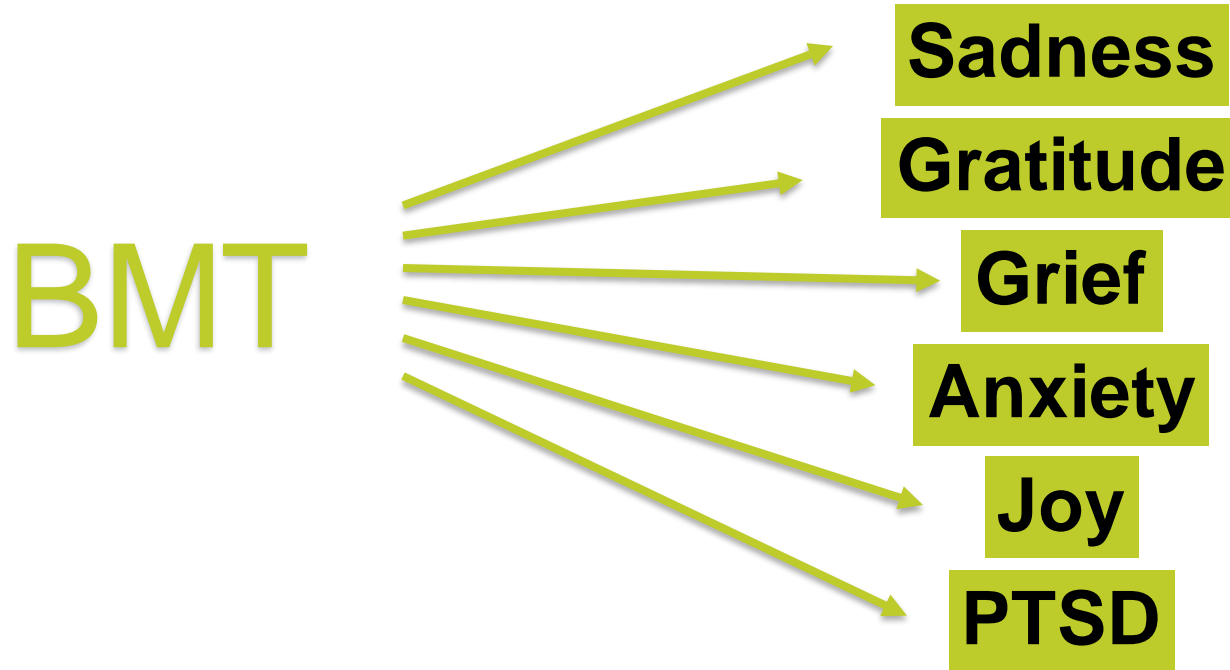
- I am not a transplant survivor
- I am a licensed clinical social worker and provide individual and group counseling to BMT patients and families
- I've worked with BMT patients since 2008, both in a transplant center and at Be The Match
- I am passionate about improving quality of life for patients after transplant



Life after transplant may mean...

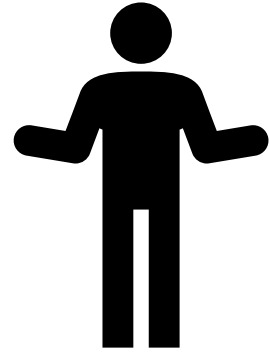
- Living with painful and uncomfortable physical symptoms
- Living with anxiety
- Living with fatigue
- Living with mobility issues
- Living with uncertainty
- Living with GVHD

Emotional Reactions to BMT





Mind Body Connection



Anxiety
Depression
Happiness

Symptoms
Fatigue
Energy

The Trouble with Steroids

**They are a
double
edged
sword!**

The Good

Lifesaving

Better appetite

Higher energy

Symptom relief

The Bad

Osteoporosis

Swelling

Weight gain

Infection risk

Other Consequences of Steroid Use

Mood lability

Anxiety symptoms

Cognitive impairments

Agitation

Lethargy

Insomnia

Hypomania

Irritability

Tearfulness

Delirium

Depressive symptoms

Psychosis

ASSESSMENT

Rule out the Medical

1. Talk to your doctor about any symptoms you are having or that others have noticed
2. Get medical help for the physical symptoms post-transplant
3. If you are on prednisone or other corticosteroids, be sure to discuss issues with mood

Physical Signs of Emotional Distress

- Increased heart rate
- Muscle tension
- Headaches
- Sleep disturbances
- Easily tearful

Psychological Signs of Emotional Distress

- Racing thoughts
- Uncontrollable worry
- Lack of interest in previously enjoyable activities
- Flashbacks
- Feeling more emotionally raw and vulnerable
- Isolation

Determine the best way to get help

- There are a lot of ways to manage emotional distress related to survivorship
- No “one size fits all approach”
- Consider what has worked in the past and what fits into your lifestyle



STRATEGIES FOR LIVING WELL POST-TRANSPLANT

Give Yourself Grace

- Grief is a normal reaction to BMT and the impact it has on life
- Allow yourself the time and space to grieve
- Be gentle with yourself

Communication

Doctor



- Write down your concerns and prioritize your top questions
- Ask the question of “at what point should I be concerned about this?”
- Send a message through online medical portal

Family/Friends



- Be open and honest about your symptoms
- Know that difficult emotions are normal and that they are okay
- Ask your friends and family for what you need in terms of support

Professional Support

What can a therapist of counselor offer?

- A good outlet for processing emotions
- A perspective from the outside
- New tools and strategies for coping
- Identification of mental health disorders

Tips for Finding a Therapist

Make sure they are in your insurance network

Ask about sliding scale fees

Confirm licensure and certifications

Focus on connection

When to Seek Professional Help

Substance
abuse

Suicidal or
homicidal
thoughts

Lack of joy or
interest in day
to day activities

Extreme high
and low
feelings

Increased
difficulty in
coping with
challenges

Withdrawal or
isolation

Peer Support

- Social support helps mitigate the stress that can occur in survivorship
- Connection with other people can provide emotional relief
- Other patients may have ideas for dealing with post-transplant issues

Relaxation Techniques

Simple Self Care:

- Shower or bath
- Reading
- Quiet moments
- Be in nature
- Massage or gentle touch

Yoga

Balance

Gentle stretching

Grounding

Meditation

Breathing

Personal reflection

Mantras

Breathing Exercise



Expressive Strategies



Acceptance and Gratitude

*“My body needs this [prednisone] now
but it doesn’t mean it will be forever.”*

*“You can’t always control the cards you were dealt
but you can control how you play.”*

Cognitive Restructuring

All or nothing thinking

- Thinking in extremes; you are either a success or a failure
- Being unable to see the “gray” in situations

Overgeneralizing

- Something or someone is always this way
- Allowing upsetting events to affect unrelated situations

Jumping to conclusions

- Making interpretations without actual evidence
- Interpretations are often negative

Use a Thought Log

Event

I woke up to yet another new rash and feeling so fatigued.

Negative Thought

I've been dealing with this for months. This will never get better.

Reaction

Hopelessness, depression, lack of motivation

Alternate Thought

This is really hard. I've gotten through hard things before and I will get better.

Arguments For:

- I have been dealing with complications for months.
- I just have a bad feeling.

“I’ll never feel better”

Arguments Against:

- My doctor told me to expect things to get better over time.
- There are new treatments I haven’t yet tried.
- I’m doing everything my doctor has recommended.

Conclusion: This thought is not supported by the evidence

BMT and Emotional Health

There is hope!!

Emotional side effects of BMT can be difficult to cope with

There are many ways to address emotional challenges

Seek the help and support that you need

Find the tools that work and use them

RESOURCES



Get Support

- BMTInfoNet <https://www.bmtinfonet.org/>
- NBMTLink <https://www.nbmtlink.org/>
- Be The Match <https://bethematch.org/one-on-one>

Patient Support Center

- The Be The Match *Patient Support Center* provides support, information and resources for patients, caregivers and families before, during and **after** transplant.
- We offer:
 - ✓ Telephone counseling and one-on-one support
 - ✓ Financial grants
 - ✓ Support groups and telephone workshops
 - ✓ Caregiver support

CALL: 1 (888) 999-6743
Monday-Friday, 8 a.m.-5 p.m. CST
EMAIL: patientinfo@nmdp.org



Questions?



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