Survivorship Post-Transplant

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Psychological Effects

- Emotional highs and lows after transplant are common and should be expected.
- BMTs can trigger several emotion reactions, including:
  - Joy
  - Gratitude
  - Sadness
  - Grief
  - Anxiety
  - PTSD
- However, sometimes feelings of anxiety, worry or feeling down persists or get in the way of activities of everyday life.
Psychological Effects

After receiving a transplant and throughout survivorship, some people may experience long-term psychological effects.

These effects include, but are not limited to:

- Depression
- Anxiety
- PTSD
Some survivors experience depression or symptoms of depression following a transplant.

A clinical diagnosis of depression includes:

- Ongoing sad moods and/or loss of interest in activities that were once enjoyable.
- Isolation or withdrawal
- Irritability
- Trouble carrying out day-to-day activities
- Feeling guilty, hopeless, helpless or worthless
- Thoughts of hurting or that your family would be better off without you
- Typically, a diagnosis of depression occurs when symptoms persist for at least two weeks

Especially difficult when there’s an expectation of how you should respond, or that you “should be happy” in survivorship.

- Experiencing symptoms or depression or sadness seems “wrong”, which makes it more difficult to cope.

Depression
Anxiety

- There are feelings of anxiety that are caused by the common worries encountered in day-to-day life, as well as undergoing a stem cell transplant.

- Worries may include:
  - Transplant effectiveness and outcome
  - Recovery process
  - Fear of recurrence or relapsing when in survivorship
  - Financial stressors associated with transplant
  - Caregiver stressors

- Anxiety disorder, on the other hand, includes intrusive thoughts, extreme worry, fear, and dread following a transplant.

- When suffering from anxiety disorder, it is difficult to pull yourself out of an “anxious state of mind”.

- Symptoms of anxiety disorder make it difficult to perform daily life tasks.
In some cases, anxiety can be so pronounced after going through a very difficult experience that post-traumatic stress disorder, or PTSD, develops.

Some of the symptoms of PTSD include:
- Bad dreams or nightmares
- Scary thoughts
- Reliving your experience over and over
- Feeling emotionally numb, guilty, depressed or worried
- Feeling easily startled, tense or “on edge”

These symptoms may come early in your recovery or later.

Typically, PTSD is diagnosed if the symptoms last at least a month.

If untreated, PTSD may affect your relationships and your ability to function at home, school or work.
Ways To Cope

- **Medical**
  - Rule out a medical basis for your symptoms by discussing with your healthcare providers

- **Grace**
  - Give yourself some grace

- **You’re Not Alone**
  - Know that you’re not alone and normalize asking for help
  - There is no right or wrong way to feel and there is no shame in needing help.

- **Talk it out**
  - Talk about your feelings and fears with your family and friends

- **Acknowledge**
  - Acknowledge the uncertainties of survivorship and choose to focus on what you can control
Ways To Cope

- Stay in the present
- Talk with others who have received a transplant
- Try to implement relaxation exercises throughout the day
- Journal what you’re feeling
- Reconnect with your physical body through yoga, meditation, deep breathing, or exercise.
- Talk with your healthcare team about professional counseling and/or medication, if needed
Advocating For Yourself During Survivorship

- Talk with your healthcare provider about your survivorship care plan, as well as late and long-term side effects, and how they will be managed.
  - Follow-up appointment expectations
  - What to expect during survivorship
- Talk to your oncologist about your risk for relapse or disease progression and the signs and/or symptoms that may indicate a relapse or disease progression.
- Discuss returning to work with your healthcare provider
Advocating For Yourself During Survivorship

- Discuss ways to engage in healthy behaviors during survivorship:
  - Other disease screenings
  - Immunizations
  - Diet and exercise
  - Sexual health
- Address and discuss mental health symptoms
- Inquire about survivorship clinics and how you can connect with these resources
Thriving During Survivorship

- Give yourself grace
- Acceptance and gratitude
- Make lifestyle changes to improve your overall health and well-being, such as making good food choices or starting an exercise program
- Create a self-care plan that will nourish your spirit, soul, and body.
- Reconnect with family, friends, and activities that were postponed during treatment
- Find a hobby that can help occupy your mind, as well as teach you a new skill.
- Connect with other cancer and transplant survivors.
- Find meaning from your experience
LLS Resources

- Publications
  - Survivorship Workbook
  - Side-effect management booklets

- Support resources
  - FSG
  - Peer to peer support
  - LLS Community
  - Podcasts
  - PearlPoint Nutrition Services

- Connect with an Information Specialist
References

- www.lls.org

- American Cancer Society
  https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/emotional-mood-changes/depression.html

- Cancer.gov

- Be The Match