Life After Transplant
Addressing emotional challenges in post-transplant survivorship

Ailey Armstrong, MSW, LICSW
Seattle Cancer Care Alliance
Life after transplant:
Transplant’s impact on quality of life

Physical Well Being
- Strength/Stamina
- Functional Activity
- Visual Disturbance/Vision Loss
- Cataracts
- Infertility
- Coping with Chronic GVHD
- Nutrition

Psychological Well Being
- Anxiety
- Fear of Recurrence
- Depression
- Changed Priorities
- Changed Sense of Normalcy
- Second Chance
- Coping with Survival

Social Well Being
- Appearance
- Financial Burden
- Roles and Relationships
- Affection/Sexual Function
- Caregiver Burden
- Leisure Activities
- Return to Work

Spiritual Well Being
- Meaning of Illness
- Strengthened Belief
- Hope
- Changes to Religiosity
- Inner Strength
- Uncertainty
- Transcendence

Psychological Issues of Stem Cell Transplant (Seminars in Oncology Nursing, 2009, Cooke et al.)
Life after transplant:

Post-transplant distress is common

- In 2007 study of long-term hematopoietic stem cell transplant (HSCT) survivors, 43% reported clinically significant global psychological distress.

- One in four were identified as having clinically significant symptoms of anxiety and depression.

- HSCT survivors also reported persistent concerns re: cognitive impairment and loneliness while in the presence of others.

- Prior studies by same authors determined that approximately 5-13% of HSCT survivors have PTSD.

*Psychological Distress in Long-Term Survivors of Hematopoietic Stem Cell Transplantation (Psycho-Oncology, 2007, Rusiewicz et al.)*
Life after transplant:
Post-transplant distress—What am I feeling?

**ANXIETY**
- Excessive worry that is difficult to control
- Restlessness; feeling on edge
- Easily fatigued
- Difficulty concentrating
- Irritability
- Sleep disturbances
- Muscle tension

**DEPRESSION**
- Feeling down, depressed, or hopeless
- Loss of interest or pleasure in doing things
- Eating and/or sleeping much less or much more
- Feeling bad about oneself; worthlessness
- Overall fatigue
- Difficulty concentrating
- Slowed thoughts/movement
- Thoughts of self-harm or being better off dead

**POST-TRAUMATIC STRESS DISORDER**
- Intrusive memories, nightmares, flashbacks
- Avoidance of trauma-related thoughts, memories, external reminders
- Negative thoughts or blame for self/others
- Feeling isolated
- Difficulty experiencing positive affect
- Hypervigilance
- Aggression; risky or destructive behavior
- Difficulty concentrating or sleeping

Mood issues can be caused or made worse by:
- Medication and treatment side effects
- Stress (financial, issues with relationships, etc.)
- History of trauma

STOP TALK TO YOUR DOCTOR AND GET SUPPORT!
Life after transplant:
Time points for distress after transplant

Distress can arise at any point on the transplant treatment trajectory.
Common times for distress to arise include:

- Immediately post-transplant (30-100 days)
- Discharge from Transplant Service (Returning home)
- Management of chronic or late side effects
- Returning to work or maintaining disability
Life after transplant: Post-transplant distress in the time of coronavirus

• Fear due to increased risks of infection
• Grief over losses
• Greater isolation from family/friends
• Increased financial/job-related stress
• More demands on caregivers
• Heightened sense of uncertainty about the future
• Pandemic fatigue

Some transplant survivors report feeling better able to cope with the restrictions and precautions associated with COVID-19 due to their experiences during the transplant process.
Life after transplant: 
Addressing distress: What can I do?

• Find counseling support
  • Cognitive behavioral therapy (CBT), Acceptance and Commitment Therapy (ACT), problem-solving therapy, behavioral activation, exposure therapy

• Seek peer support from other transplant survivors

• Maintain connection with other social networks

• Engage in exercise/physical therapy

• Give back or pay it forward

• Consider a medication evaluation
Life after transplant:
Mindfulness as a tool for coping with distress

PAST (Rumination)  ↯  FUTURE (Worry)

PRESENT (Being)

“Mindfulness means paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.”

(Jon Kabat-Zinn, 1994)
“Mindfulness is a set of psychological skills for effective living that involves paying attention with openness, curiosity, kindness, and flexibility.”

(Russ Harris, ACT Made Simple, 2019)

• Acknowledges and accepts “what is” rather than focusing on “shoulds” or “what ifs”

• Creates space to observe thoughts as transitory and fluctuating, and to experience ourselves as separate from our thoughts

• Helps us to become more flexible in our thinking, allowing us to notice both the negative and the positive aspects of our experience and to make room for new possibilities
Life after transplant:
Three simple mindfulness exercises

• If you have 5 minutes: Be present with your thoughts
  • Find a quiet place to sit comfortably and set a timer for 5 minutes.
  • Close/lower your eyes; focus on the physical sensations of your breath.
  • Notice when your mind wanders. Label the thoughts: Thinking, judging, worrying, etc. (If you notice your mind wandering, you’re doing it right!)
  • Bring your attention back to your breath.

• If you have 2 minutes: Notice your five senses
  • Bringing your awareness to the present moment, notice and label what you SEE, HEAR, SMELL, FEEL, and TASTE. Be as specific as possible.

• If you have 1 minute or less: Box breathing
  • Breathe in for 4 counts, hold for 4 counts, breathe out for 4 counts, hold for 4 counts. Repeat.
Life after transplant:
Other mindful practices to try

Any activity that allows us to bring deliberate and focused attention to our experience in a way that is open and curious can be an opportunity for mindfulness.

See Resource slides at end of presentation for more links to resources for these practices.
Life after transplant:  
Post-traumatic growth

Post-traumatic growth is “positive change experienced as a result of the struggle with a major life crisis or a traumatic event.”

- New opportunities
- Positive change in relationships
- Increased sense of one’s own strength
- Greater appreciation for life in general
- Deepening of spiritual life

From UNC-Charlotte Post-Traumatic Growth Research Group (https://ptgi.uncc.edu/what-is-ptg/)
“Returning to yoga has been wonderful. There was a long time where I didn’t want to go near it, but my husband pushed me because he knew that once I got going things would improve. And he was right.

I’m not quite where I was and I probably never will be; my body feels different now. It’s what they call the ‘new normal’: it feels different, responds differently. But I’ve got used to it and it’s great.

‘Once I started feeling better, I thought about all the things I wanted to do. With a transplant you have new hope, but you never know how long it could last. So we went on a pilgrimage in Spain – the Camino Inglés.

We called it a gratitude walk: being thankful that I’m alive, thankful to my donor, thankful to everyone who is on the donor list and giving me the opportunity to be here today.”


See this and other stories of transplant survivors at www.anthonynolan.org/patients-and-families/real-stories.
Thank you.
Resources:

Mindfulness and related resources

Mindfulness and mindfulness meditation

• Free guided mindfulness meditations (via UCLA Mindful Research Center)
  https://www.uclahealth.org/marc/mindful-meditations

• Free online Mindfulness-Based Stress Reduction course
  https://palousemindfulness.com/

• Brief mindfulness exercises

Relaxation techniques

• Free guided progressive muscle relaxation (audio)
  https://www.helpguide.org/meditations/progressive-muscle-relaxation-meditation.htm

• Brief relaxation exercises

• Deep breathing exercise
  https://www.therapistaid.com/worksheets/deep-breathing-worksheet.pdf
Resources:
Mindfulness and related resources

Gratitude practices
- Gratitude journal (Why gratitude practice matters, plus tools to get started)
  https://positivepsychology.com/gratitude-journal-pdf/
- Brief gratitude exercises

Self-compassion practices
- Self-compassion (What it is, why it’s important, plus many free tools)
  https://self-compassion.org/
- More free self-compassion tools (audio and written practices)
  https://chrisgermer.com/meditations/

Journaling
- Journaling for anxiety, depression, and stress (Why and how, plus tools)
  https://positivepsychology.com/benefits-of-journaling
Resources:
Mindfulness and related resources

Mindful movement

- Mindful walking exercises
  https://d10k7k7mywg42z.cloudfront.net/assets/5e9f524d76ed7f05900007cd/Mindful_Walking_Final.pdf

- Walking meditation exercise (Tara Brach)

- Mindful stretching guide
  https://uhs.berkeley.edu/sites/default/files/wellness-mindfulstretchingguide.pdf