



Life After Transplant: Cultivating Resilience and Growing from Trauma

Celebrating a Second Chance at Life
Survivorship Symposium

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Stephanie Davidson PsyD

Westlake Village Counseling
Center

Life After Transplant: Cultivating Resilience and Growing from Trauma

Stephanie L. Davidson, Psy.D.
Health Psychologist

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Learning Objectives

- The incidence, type and duration of emotional challenges survivors face after transplant.
- An understanding of what resilience and emotional growth after transplant means.
- Strategies for growing resilience after emotional and physical struggles.
- The benefits of professional counseling, when to ask for help and where to find it.

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Emotional Challenges Faced after Transplant

- Distress
- Anxiety
- Depression
- Post-traumatic Stress Disorder

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Distress Following Transplant

- Distress is the MOST common, yet under-reported, side effect of treatment
- Distress ranges from feelings of vulnerability, sadness and anger – to problems such as severe depression, anxiety, panic and post traumatic stress
- Unaddressed, these symptoms will decrease the quality of your life
- Distress can be addressed effectively

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Common Signs of Distress

- Crying often
- Feeling “under the weather”
- Tense or jittery
- Change in eating or sleep habits
- Avoiding people or things that remind you of cancer
- Needing a lot of reassurance
- Withdrawal from people and activities
- Overreacting to situations
- Feeling irritable and moody

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Understanding Anxiety

- Restlessness
- Impending sense of danger
- Easily fatigued
- Difficulty concentrating
- Irritability
- Muscle tension
- Uncontrolled worry
- Sleep problems
- Increased startle response

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Understanding Depression

- Hopelessness
- Helplessness
- Guilt
- Loss of interest
- Changes in sleep
- Sadness/irritability
- Problems with memory/concentration

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Common Symptoms of Trauma Exposure

Emotional	Mental	Behavioral	Physical
Loneliness	Loss of concentration	Withdrawal from others	Aches/pains
Fear/Anxiety/Panic	Disorientation/confusion	Impulsive behavior	Fatigue/tiredness
Anger/frustration	Memory loss	Aggression	Racing heart
Mood swings	Obsessive thoughts	Crying	Nausea/vomiting
Sadness	Distractibility	Being argumentative	Shakiness/trembling
Hopelessness	Indecisiveness	Changes in sleep	Headaches
Helplessness	Thoughts about death/dying	Changes in appetite	Numbness/tingling
Feeling numb	Racing thoughts	Easily startled	Diarrhea
Nightmares		Increased drug/alcohol use	Hot flashes
Lack of confidence			

(Tedeschi & Moore, 2016)

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Post-traumatic Stress Disorder (PTSD) Symptoms

Intrusive Symptoms	Avoidance Symptoms	Negative Thoughts/Mood	Arousal/Activity
Pervasive/intrusive memories	Avoidance of trauma-related thoughts, memories and feelings	Trauma-related memory problems	Irritability/anger/aggressive
Nightmares	Avoidance of reminders of the event	Negative beliefs	Reckless behavior
Flashbacks/dissociation		Persistent blaming	Being on guard
Extreme distress)		Negative/distressing emotions	Easily startled
Increased physiological reactions		Loss of interest/pleasure	Concentration problems
		Feeling disconnected	Difficulty falling/maintaining sleep
		Lack of positive emotions	

(DSM-5, 2013; Tedeschi & Moore, 2016)

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Risk Factors for PTSD

- 6 months post HCT 18.9% of patients experienced clinically significant PTSD symptoms
- Lower financial/education status
- History of mental illness
- Physical injury
- Having seen people hurt/maimed or killed
- Feeling a sense of helplessness/horror/fear
- Little or no support
- Managing other difficult stressors

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Protective Factors for PTSD

- Support groups
- Relying on family or friends
- Low levels of guilt, shame, embarrassment
- Natural optimism
- Sense of humor
- Having more life experience
- Successful experiences with difficult life events
- Effective coping strategies

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Periods of Vulnerability

- Ongoing
 - Tests/Scans/Appointments
 - Anniversaries
- Transitions
 - Between treatment phases/off of treatment
 - Life changes (career, life insurance, family planning)
- New events
 - Others diagnosed
 - Loss of others in the transplant community
 - New symptoms/health problems or recurrence

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Defining Resilience vs. Post-traumatic Growth

- Resilience:
 - The ability to recover/bounce back from difficulties
- Post-traumatic Growth:
 - Moving from a struggle to bounce back to finding personal growth
 - Challenges personal beliefs
 - Endurance through psychological struggle

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The 5 Gifts of Trauma Resilience

- New possibilities
- Increased strength
- More meaningful relationships
- Greater appreciation
- Spiritual development

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(Tedeschi & Moore, 2016)

New Life Paths and Possibilities

- Making small or large changes associated with your experience
- New set of priorities
- Adjustments to doors that may have closed
- Focus on what would be most satisfying and important when setting new goals
- Know that you may experience some grief

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Increased Personal Strength

- Strength to handle challenges
- Helpful to acknowledge the strength
- Look at your self-reliance, better problem-solving or significant changes made in your life.
- Honor your ability to make room for and tolerate difficult emotions.
- Acceptance can bring a strong sense of strength and resilience.

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Improved or More Meaningful Relationships

- Learn to find and accept support
- Thinking of others as a part of your team
- Learning to accept our own limitations and vulnerabilities
- Increase in empathy and compassion
- There will be people who were or are unable to support you and you can forgive those people
- Explore deeper and more meaningful relationships

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Greater Appreciation of Life

- A greater understanding and acknowledgement of what they have.
- Appreciation of everyday experiences
- Focus on a sense of how precious life can be which may change priorities
- Recognition of the fortune that comes with being alive.
- Gratitude and ability to savor the daily enjoyment
- Perspective on taking risks may change

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Spiritual Change or Development

- A change in the meaning and purpose in life
- Struggle to figure out how to fit what has happened into existing beliefs
- Previous struggles may now seem trivial/unimportant.
- Focus is on finding your own truth for how to live life well
- Changes in spiritual understanding
- Help from others
- Deep examining of yourself and your ideas

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Things to Keep in Mind about Resilience

- Growth can be uncomfortable and may take time.
- Goal is focus on leaning into this change
- You may have to explore a number of life experiences
- Look for signs that you are changing
- Look at how your life has changed related to family, work and other social relationships

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Coping Mechanisms that Work

- Meditation
- Deep breathing/relaxation
- Humor/laughter
- Reading/watching tv/go to the movies/listen to music
- Take a bath/shower
- Engage in spiritual activities
- Be creative
- Talk with friends/family
- Hobbies
- Exercise
- Take a nap

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Social Support

- Find people who can support you
- Find others who are easy to be with
- Find others who can be with you on good days and bad
- Find a people who understand that their role is often passive
- Find others who have faith in your ability to understand your journey
- They are comfortable with the idea that the endpoint may not be clear
- They can provide feedback on things you may not see while still trusting your own process

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Active Coping Strategies

- Accept that the problem exists
- Take action to get rid of the problem
- Look for advice and information
- Adopt a new perspective: make the most of a bad situation
- Become aware of your feelings and express how you feel to others

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Avoidant Coping

- Deny the problem exists
- Withdraw from social life
- Avoid the problem with alcohol or drugs (the use of prescribed drugs to help actively cope, is different)
- Blame yourself for the problem and criticize yourself

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When to Seek Professional Counseling

- The impact of your symptoms interferes with love, work and play
- You find it challenging to move forward with what is meaningful to you
- You have thoughts about suicide or self-harm
- When symptoms interfere with medical care

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Types of Professional Help

- Therapist - talk therapy to assist with trauma-related symptoms
- Psychiatrist - medication to manage trauma-related symptoms
- Medical Team - referral for mental health assistance
- Support Group – run by a professional provider to offer support

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Where to Find Professional Help

- Contact your medical center for a referral
- BMT InfoNet Mental Health Directory (bmtinfonet.org/mh-directory)
- Reach out to your insurance company
- State and local psychological associations
- Psychology Today

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Recommended Reading

- Renton, J. (2015). *Upside: the new science of post-traumatic growth*. New York: Touchstone.
- Tedeschi, R. G. & Moore, B. A. (2016). *The posttraumatic growth workbook*. Oakland, CA: New Harbinger Publications, Inc..
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- Dembeck, L. (2020). Post-traumatic stress symptoms after hematopoietic stem cell transplantation. *Hematology Advisor*, <https://www.hematologyadvisor.com/home/conference-coverage/asco-2020/assessing-likelihood-ptsd-patients-receiving-hematopoietic-stem-cell-transplantation/>

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Questions?



Stephanie Davidson PsyD

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bmtinfonet.org ♦ help@bmtinfonet.org ♦ 847-433-3313



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