

# Life After Transplant

Addressing emotional  
challenges in post-  
transplant survivorship

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# *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

**BMT  
SCT**

### **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

# *Life after transplant:*

## **Post-transplant distress is common**

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- 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.**



# *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

Mood issues can be caused or made worse by:

- Medication and treatment side effects
- Stress (financial, issues with relationships, etc.)
- History of trauma

### **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



**TALK TO YOUR DOCTOR  
AND GET SUPPORT!**

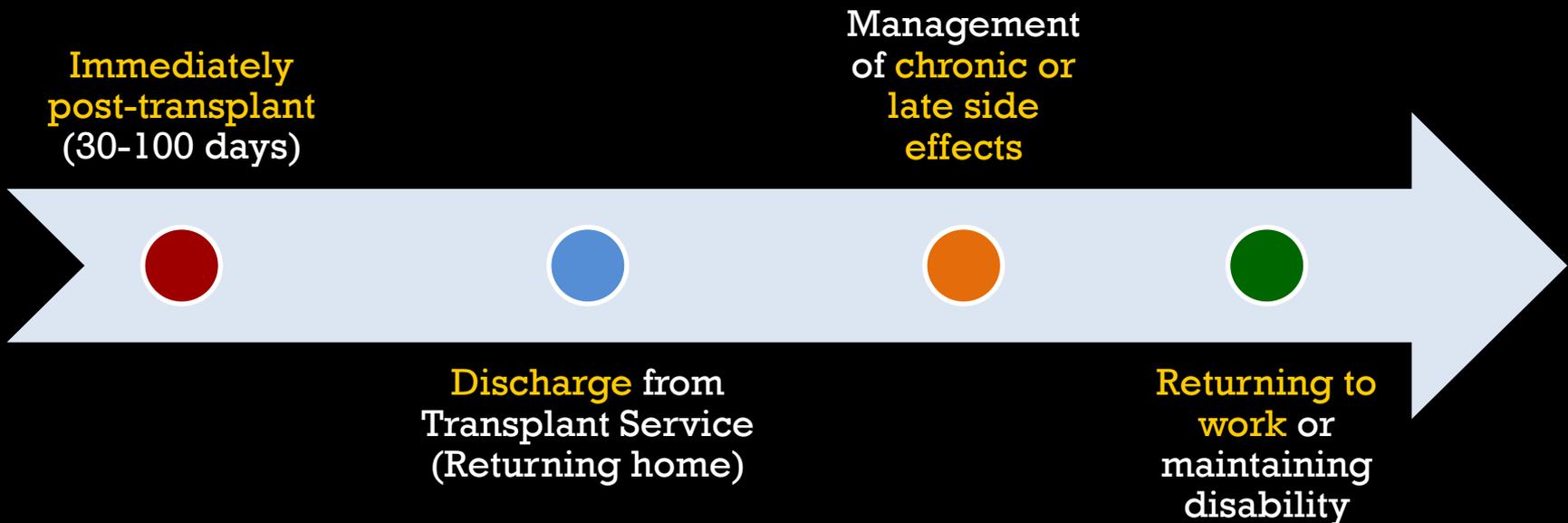
# *Life after transplant:*

## Time points for distress after transplant

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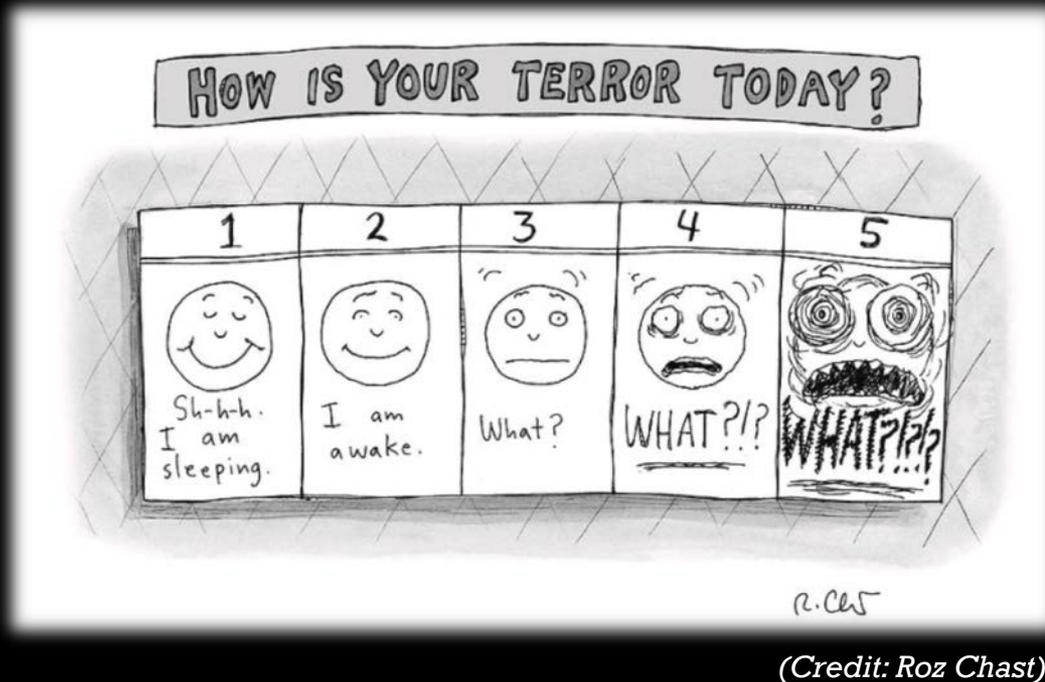
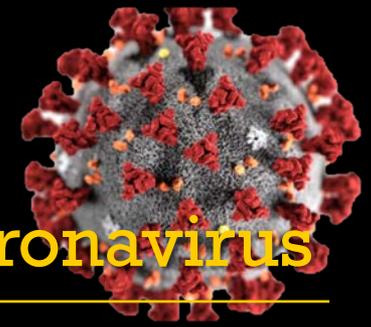
Distress can arise at any point on the transplant treatment trajectory.

Common times for distress to arise include:



# Life after transplant:

## Post-transplant distress in the time of coronavirus



*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.*

- **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**

# *Life after transplant:*

## **Addressing distress: *What can I do?***

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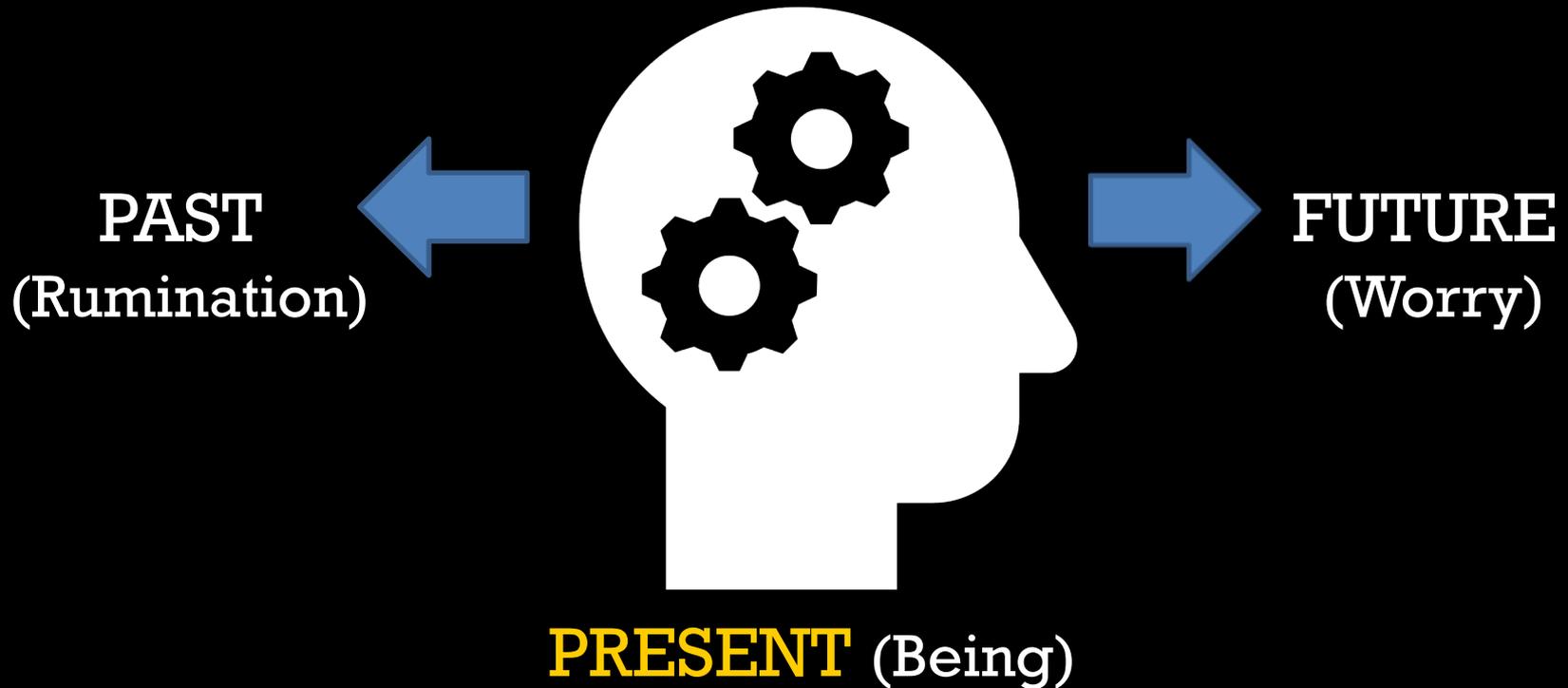
- Find **counseling support**
  - Cognitive behavioral therapy (CBT), Acceptance and Commitment Therapy (ACT), problem-solving therapy, behavioral activation, exposure therapy
- Seek **peer support** from other transplant survivors
- Maintain connection with **other social networks**
- Engage in **exercise/physical therapy**
- **Give back** or **pay it forward**
- Consider a **medication evaluation**



# *Life after transplant:*

## **Mindfulness as a tool for coping with distress**

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

*(Jon Kabat-Zinn, 1994)*

# *Life after transplant:*

## **Mindfulness as a tool for coping with distress**

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“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

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- *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

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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

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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



**Renate:** Diagnosed with Burkitt's lymphoma in 2009. Later diagnosed with leukemia. Allogeneic transplant in 2012.

See this and other stories of transplant survivors at [www.anthonynolan.org/patients-and-families/real-stories](http://www.anthonynolan.org/patients-and-families/real-stories).

“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.’”

**Thank you.**



# *Resources:*

## Mindfulness and related resources

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### 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  
<https://www.therapistaid.com/worksheets/mindfulness-exercises.pdf>

### Relaxation techniques

- Free guided progressive muscle relaxation (audio)  
<https://www.helpguide.org/meditations/progressive-muscle-relaxation-meditation.htm>
- Brief relaxation exercises  
<https://www.therapistaid.com/worksheets/relaxation-techniques.pdf>
- Deep breathing exercise  
<https://www.therapistaid.com/worksheets/deep-breathing-worksheet.pdf>

# *Resources:*

## Mindfulness and related resources

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### Gratitude practices

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

### 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

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### Mindful movement

- Mindful walking exercises  
[https://d10k7k7mywg42z.cloudfront.net/assets/5e9f524d76ed7f05900007cd/Mindful\\_Walking\\_Final.pdf](https://d10k7k7mywg42z.cloudfront.net/assets/5e9f524d76ed7f05900007cd/Mindful_Walking_Final.pdf)
- Walking meditation exercise (Tara Brach)  
<https://www.tarabrach.com/wp-content/uploads/pdf/Walking-Meditation-Instructions.pdf>
- Mindful stretching guide  
<https://uhs.berkeley.edu/sites/default/files/wellness-mindfulstretchingguide.pdf>