

Riding the Emotional Roller Coaster of Survival



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Celebrating a Second Chance at Life Survivorship Symposium

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Learning Objectives

Identify common psychosocial challenges after transplant and CAR T-cell therapy

Distinguish between normal adjustment post treatment and determining when to seek outside support

Develop strategies and resources to manage psychosocial challenges after transplant or CAR T-cell therapy

Outline

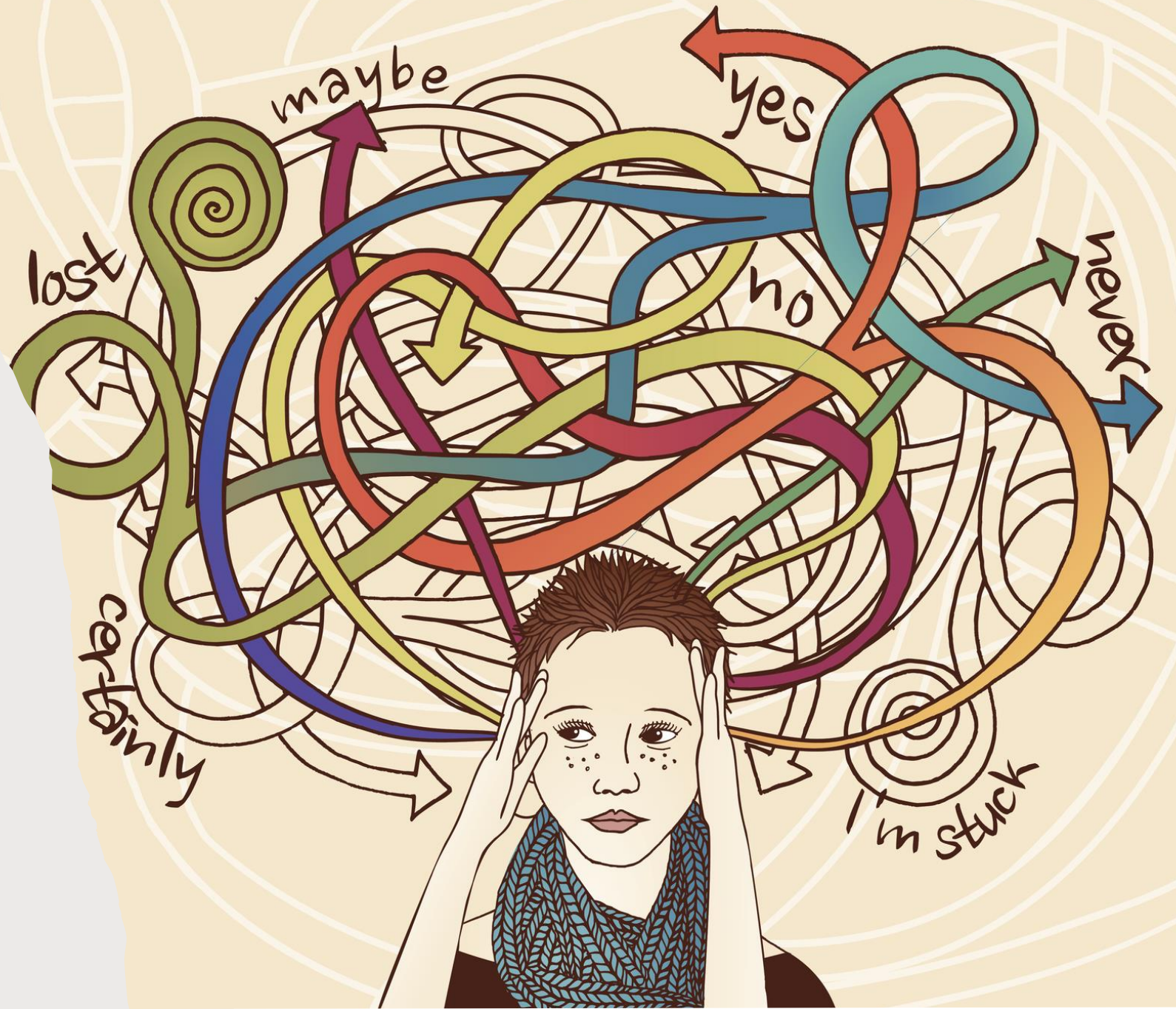
Psychosocial
challenges

Strategies for
adjustment

When to seek
support

Resources

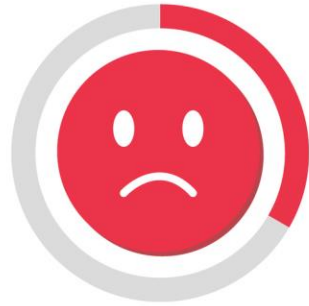
Psychosocial Challenges



Impact of Transplant & CAR-T

- Daily activities, work
- Family, friends, social network
- Intimate relationships, sexuality
- Transportation, mobility
- Leisure activities
- Self-care
- Household chores
- Finances
- Lifestyle
- Symptoms and side effects
- Shared decision making
- Illness related knowledge
- Emotions, giving meaning to life
- and more.





-
- Anxiety
 - Sadness
 - Isolation
 - Fear
 - Depression
 - Anger
 - Joy
 - Grief
 - PTSD
 - Gratitude

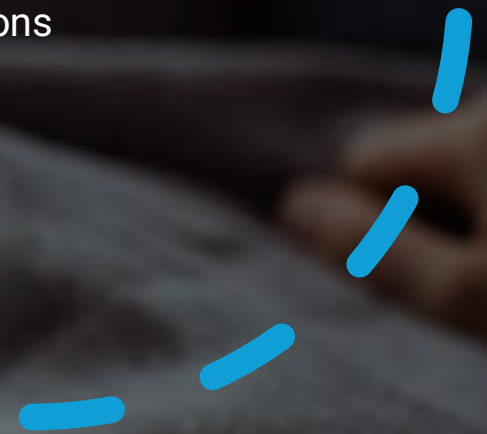
What is Anxiety?

- Emotional signs:
 - Fear, uneasiness, dread
- Physical signs:
 - Increased heart rate
 - Sweating
 - Restlessness
 - Irritability
 - Difficulty concentrating
 - Feeling keyed up or on edge



What is Depression?

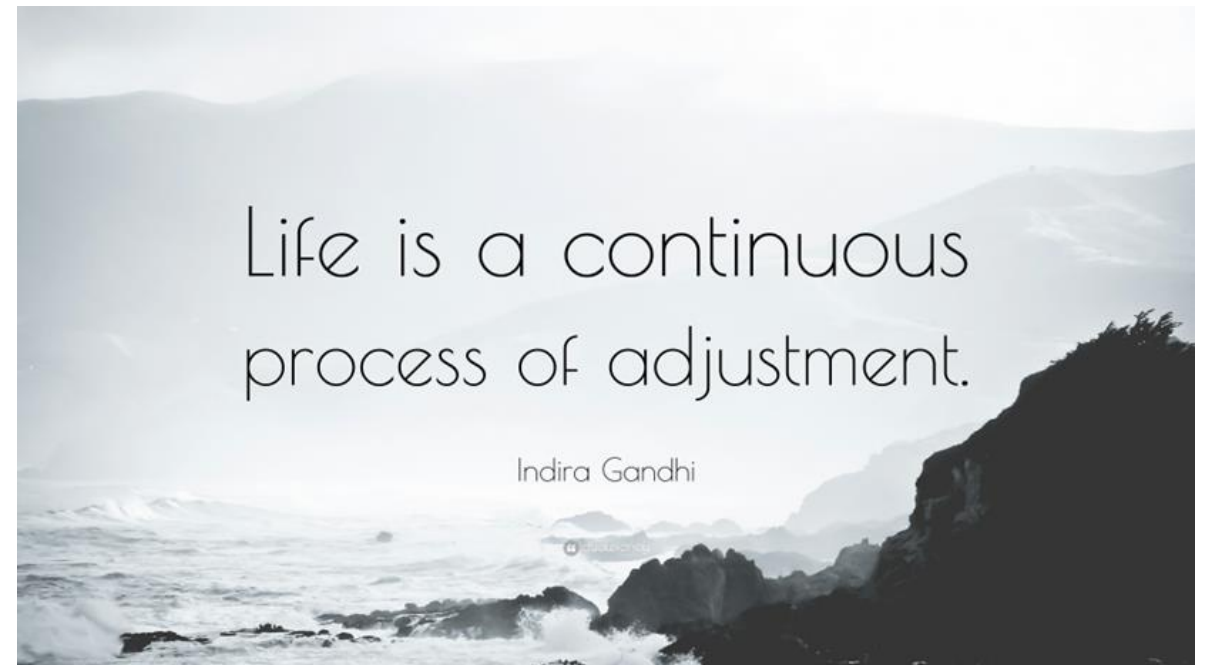
- Emotional signs:
 - Feeling sad or having a depressed mood
 - Feeling worthless or guilty
- Physical signs:
 - Loss of interest or pleasure in activities once enjoyed
 - Changes in appetite
 - Trouble sleeping or sleeping too much
 - Loss of energy or increased fatigue
 - Increase in purposeless physical activity (e.g., inability to sit still, pacing, handwringing) or slowed movements or speech (these actions must be severe enough to be observable by others)
 - Difficulty thinking, concentrating or making decisions



M
Co

Health

Defining Adjustment



Strategies for Adjustment



Mental Health



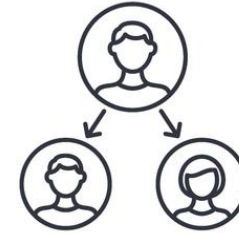
EATING WELL



GET ENOUGH SLEEP



MANAGE STRESS



BE SOCIABLE



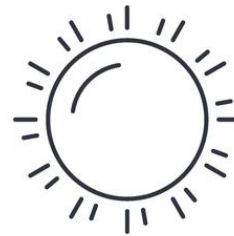
HAVING FUN



ACTIVITY AND EXERCISE



AVOID ALCOHOL, SMOKING AND DRUGS



GET PLENTY OF SUNLIGHT



PRACTICING HEALTH THINKING



TAKING CARE OF YOUR BODY



DIGITAL DETOX



HELPING OTHERS



SLOWING DOWN



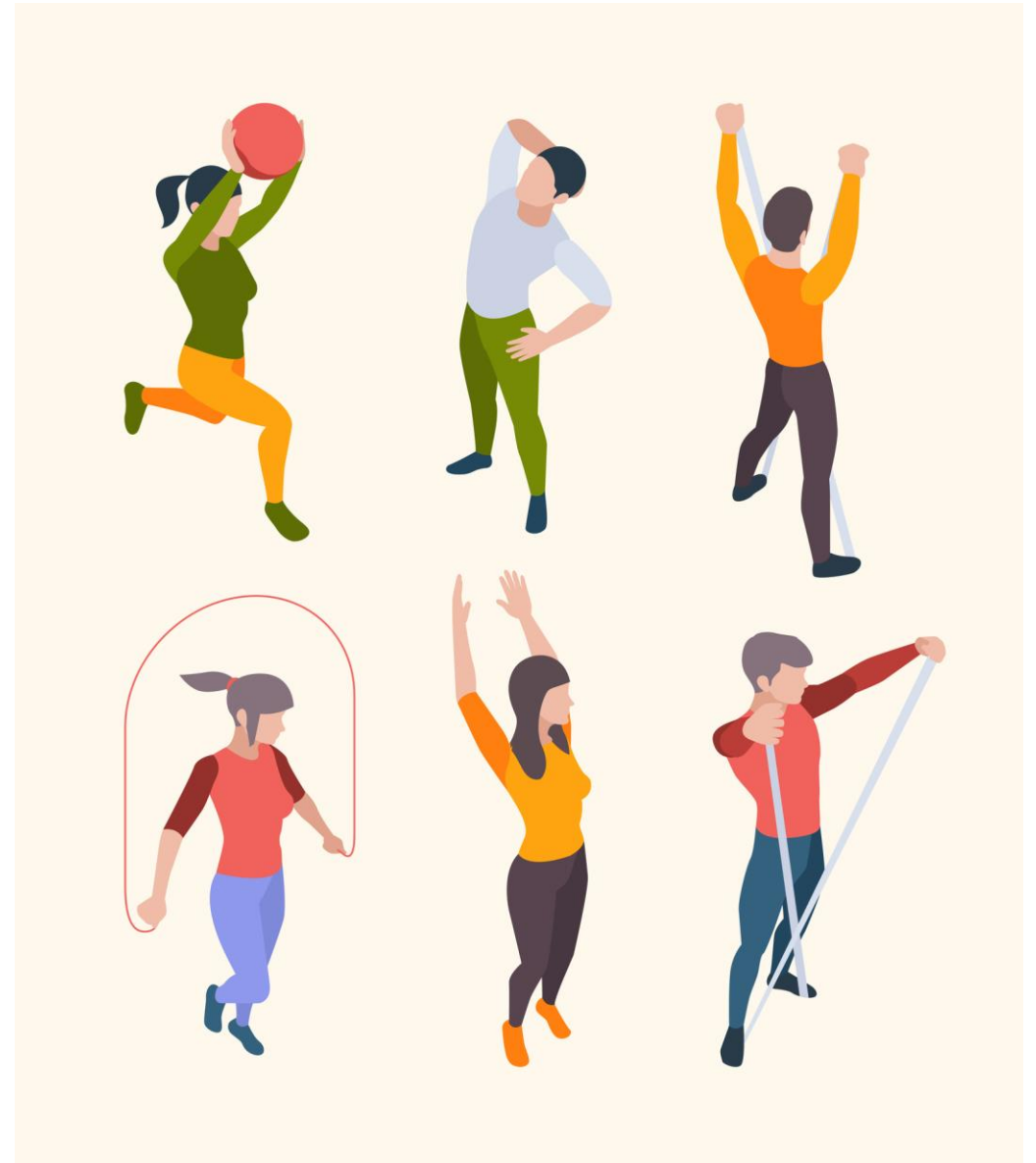
SOLVING PROBLEMS



ASK FOR HELP

Behavior Strategies

- Physical exercise
- Spend time outside
- Schedule social activities
- Join a support group
- Learn a new hobby



Behaviors Continued

- Self-monitoring
- Prioritize your tasks
- Break tasks into smaller steps
- Ask for help
- Concentrate your efforts on things you can control



Important & Urgent	Urgent & Not important
Not urgent & Not important	Important & Not Urgent

Manage Stress

One helpful way to think about life events is to divide them into things that are largely controllable and those that are uncontrollable

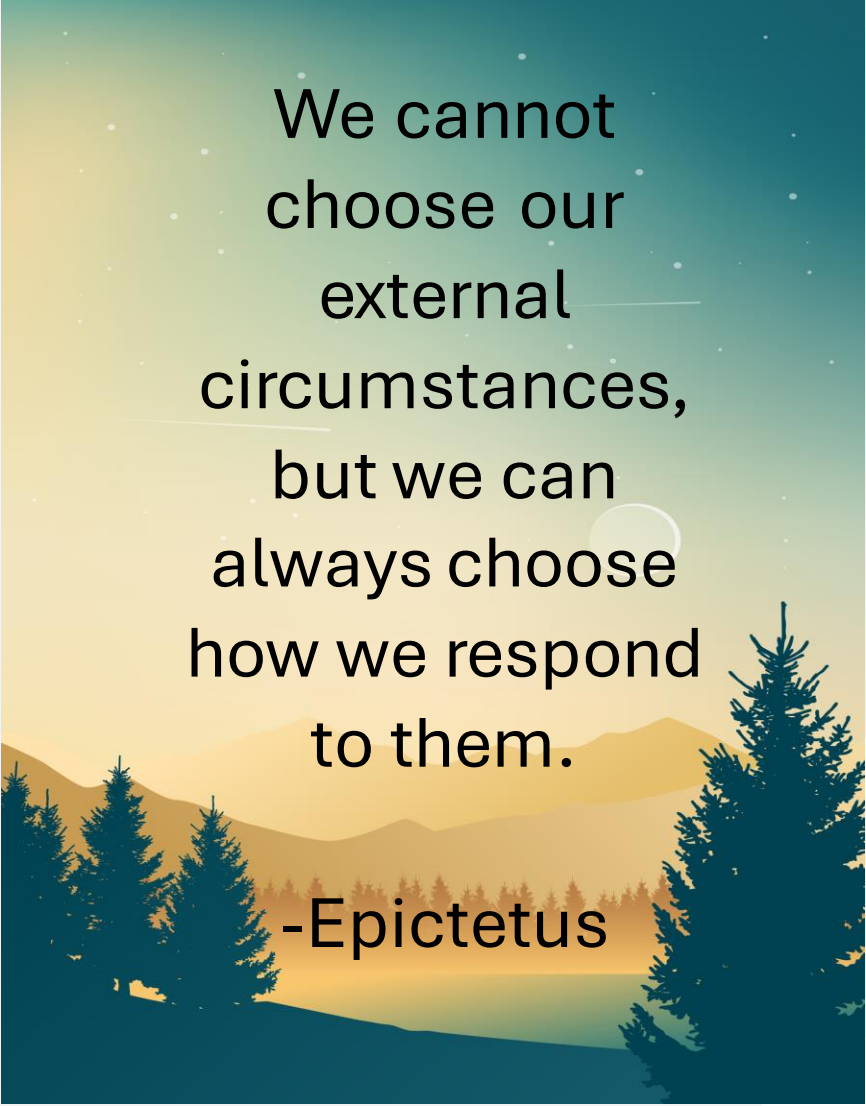
- Controllable → problem-focused coping
- Uncontrollable → emotion-focused coping (Means you deal with the emotions the stressor brought up, since you can't change the situation itself)



First Step...



- To become aware of your stress response and reactions:
 - Learn to recognize your response in action
 - Identify triggers, times of day, and reason behind stress response

A scenic landscape with mountains, trees, and a sunset sky. The sky transitions from a warm orange at the horizon to a deep teal at the top. Silhouettes of evergreen trees are visible in the foreground and middle ground. The overall mood is peaceful and contemplative.

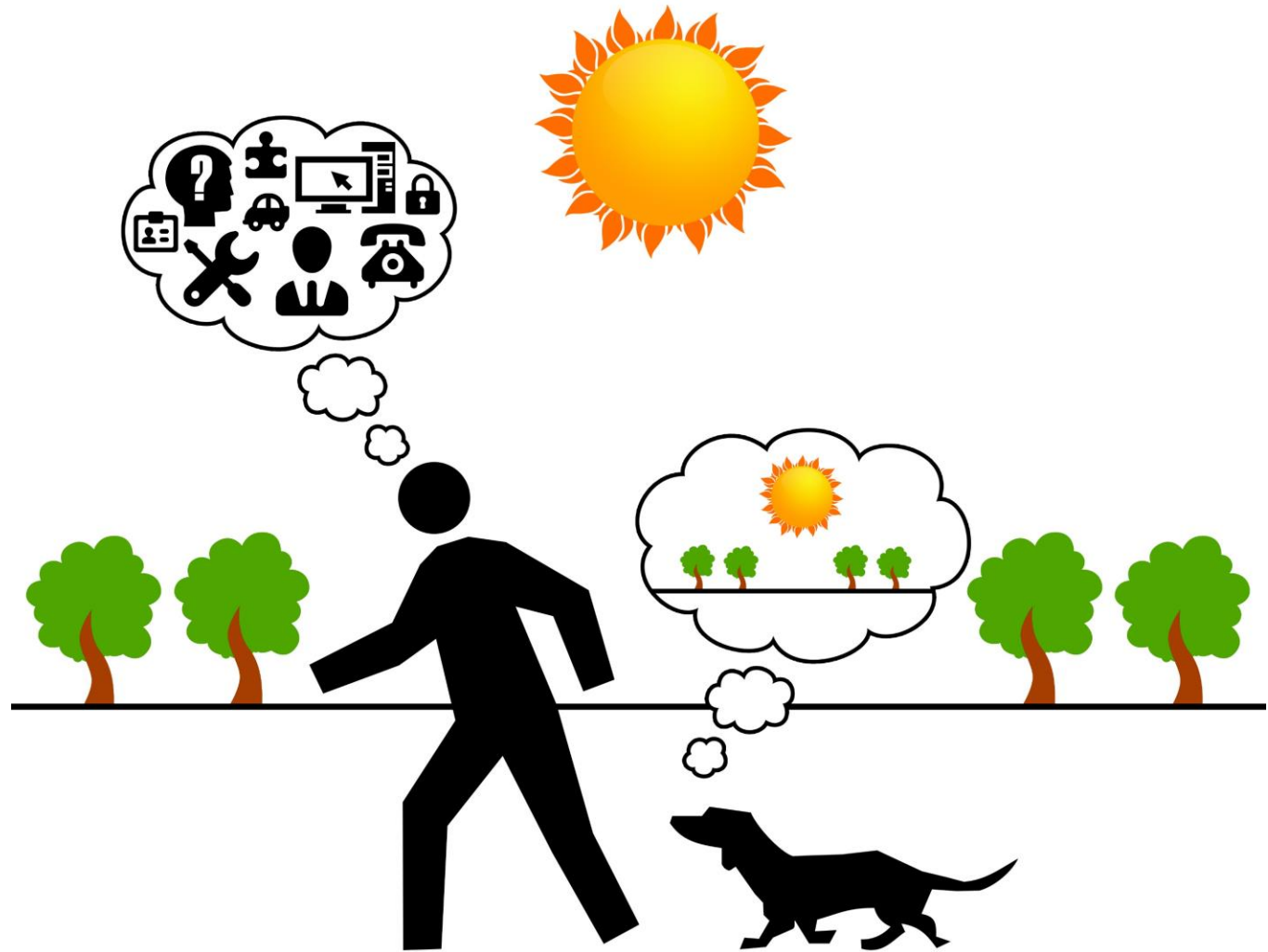
We cannot
choose our
external
circumstances,
but we can
always choose
how we respond
to them.

-Epictetus

Second step...

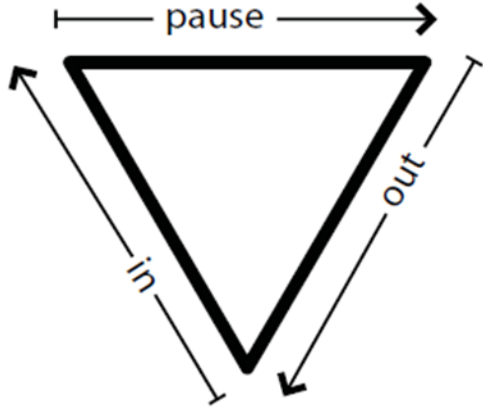
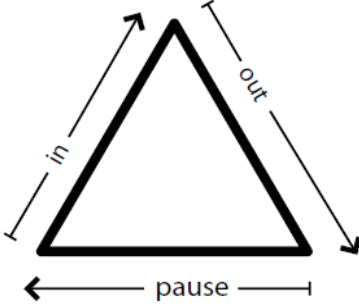
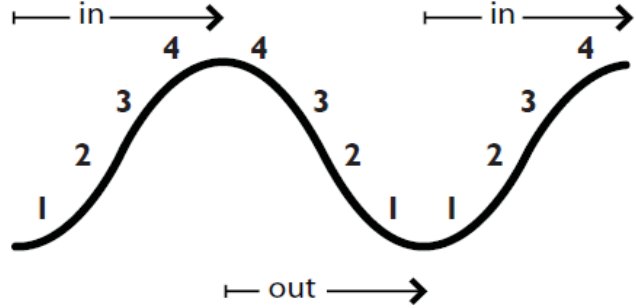
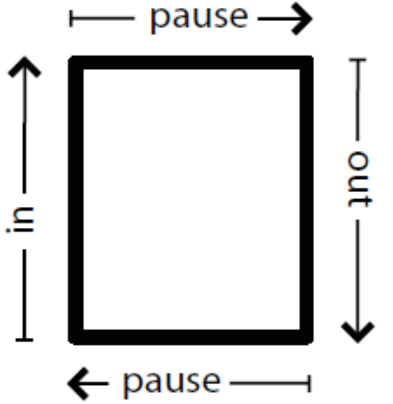
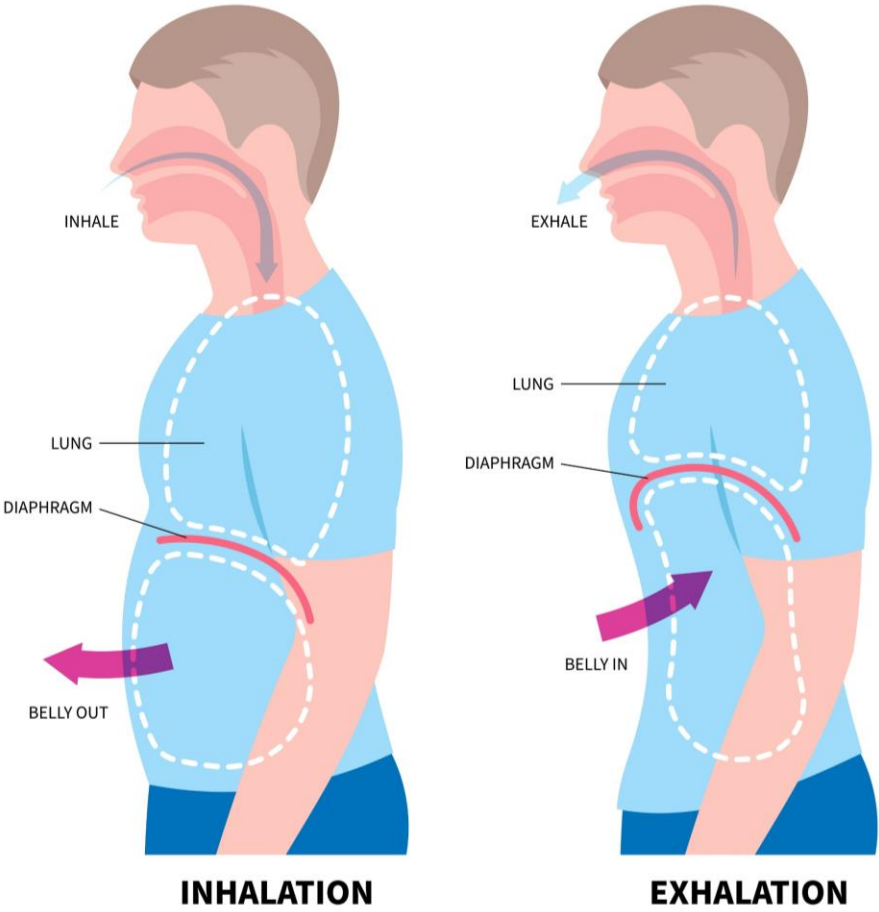
Understand that you have a choice in
how you respond

Mindfulness



MINDFUL, OR MIND FULL?

Breathing Techniques





Relaxation & Meditation

- Progressive Muscle Relaxation
- Body Scan
- Autogenic Training
- Mindfulness meditation
- Mental imagery or visualization

Writing

- Figure out the best way to get the words out
- Think about making writing part of your daily routine
- Write what's on your mind, not just a list of the day's events
- You don't have to limit your journal to words on paper
- Just do it!



Situation: Woke up feeling so fatigued

Thinking
Differently

- Unhelpful thought:
 - “I’ve been dealing with this for months. It will never get better.”
- Reaction:
 - Helplessness, depression, no motivation
 - Staying in bed all day
 - Not answering phone calls, avoiding friends and family
 - Not eating
- Does this thought involve one of these common traps?
 - Focusing only on the negative, not on the positive
 - Thinking only one way or the other (black or white)
 - Coming to general conclusion based a single event
 - Thinking the worst will happen, no matter the odds
- Is there a more helpful or supportive way to think?



Ask for Support



Asking for Help: Mantras

- “Every person, including the most successful people I can think of, have benefited from help at some point in their life.”
- “I have the right to ask for help and deserve to have my needs met.”
- “There are times in everyone’s life when we give help, and there are times when we accept help so that we can give it back again later.”
- “Asking for help isn’t comfortable AND I can do it anyway.”
- “Asking for help recognizes that someone has a skill, strength, or resource that I could learn from, borrow, or lean on at this time.”
- “I encourage others to accept help; I’m allowed to do the same.”
- “Other people may have it worse than me AND I’m also allowed to ask for/deserve support.”
- “Even though I might be able to get through this alone, I don’t have to.”





DEAR WOMAN Skill

D = Describe what is wanted (what is your intention for the conversation, or what do you want the end result to be?)

E = Encourage others to help ("You can help me by...")

A = Ask for what is wanted ("I want...")

R = Reinforce others ("It is helpful when you.....")

W = Willingness to tolerate not always getting it my way

O = Observe what is going on inside and around me

M = Mindfully present in the current moment

A = Appear confident

N = Negotiate with others



When to seek outside support

Persistent symptoms of:

- Experiencing lack of interest or pleasure in daily activities
- Mood changes
- Isolation/withdrawal
- Hopelessness

Suicidal or Homicidal Ideation



Resources



988 Lifeline

What Happens When You Call The 988 Lifeline?

First, you'll hear an automated message featuring additional options while your call is routed to your local 988 Lifeline network crisis center.

We'll play you a little music while we connect you to a skilled, trained crisis worker.

A trained crisis worker at your local center will answer the phone.

This person will listen to you, understand how your problem is affecting you, provide support, and get you the help you need.

988 Lifeline Center calls are free and confidential, and we're available 24/7.





Utilize Your Transplant Team

- Who is on your team?
 - Social Worker, Psychologist, Nurse, Doctor, Dietitian
- How can your team support you?
- Utilize your team for referrals to outside support/programming
 - These referrals may include home health (physical therapy/ occupational therapy), counseling, financial resources, beauty/image resources, support groups, local programming

How to find a therapist



Contact your insurance



Inquire about cost/sliding scale fees



Verify licensure and certifications



Other factors to consider

Setting: In Person Vs. Virtual
Availability-Session Limit
Cultural Background
Expertise in specific concern

BMT InfoNet's Directory of Mental Health Providers

BmtInfonet.org/mh-directory

- Search for social workers, psychologists, and other counselors who have experience working with patients who:
 - have gone through transplant
 - had CAR T-Cell Therapy
 - are dealing with GVHD
- You can search by
 - experience (transplant, CAR T-cell therapy, or GVHD)
 - age of clients accepted
 - states in which they can provide service
 - mental health provider's name



Peer Support



National Support Groups

- Patients and caregivers
- Disease specific, educational, support group counseling
- Virtual

Local groups/programming

- Virtual/in person options
- Support groups specific to hospital
- Programming through local organizations
 - Art programs, exercise programs, dance, cooking classes, support groups, meditation

Peer Support Resources

- **American Cancer Society** (cancer.org) connects patients, survivors, and caregivers through online community (Cancer Survivors Network)
- **BMT InfoNet** (bmtinfonet.org) offers one-on-one peer support GVHD support groups, and educational workshops \.
- **NMDP** (nmdp.org) offers telephone counseling, one-on-one support, support groups, educational work shops and caregiver support. (nmdp.org)
- **CancerCare** ([cancercare.org](https://cancer.org)) provides educational resources and virtual support groups for patients and caregivers.



Peer Support Resources cont'd



- **Imerman Angels** (imermanangels.org/find-mentor-angel) matches cancer patients and caregivers with a mentor who has gone through a similar cancer experience.
- **International Myeloma Foundation** (myeloma.org/support-groups) lists local in-person myeloma support groups
- **Leukemia and Lymphoma Society** (lls.org/support-resources/support-groups) One-on-one support and support groups for patients with leukemia, lymphoma and other blood cancers.
- **Multiple Myeloma Research Foundation** (themmrf.org/support/) Connects patients with either one on one mentors or support groups.



Breathe2Relax
Health & Fitness



Insight Timer–Meditate...
Meditation for Sleep & Anxiety



YouTube: Watch, Listen...
Videos, Music and Live Streams



UCLA Mindful
Meditations for well-being



Mindfulness Coach
Health & Fitness

Free Mindfulness & Relaxation Applications (Apps)

Wigs Boutiques, Beauty workshops

- **American Cancer Society** has wigs available for purchase at [tlcdirect.org](https://www.tlcdirect.org).
- **Hope Scarves** (hopescarves.org/request-hope-scarf) and **Courage for the Soul** (courageforthesoul.com/request-a-scarf-for-yourself) provide free scarves to cancer patients in treatment.
- **Look Good, Feel Better** (lookgoodfeelbetter.org/virtual-workshops) offers free virtual workshops for women undergoing cancer treatment on how to deal with appearance-related side effects.
- **Stay Beautiful Foundation** (thestaybeautifulfoundation.org) offers free beauty boxes for women going through cancer treatment.
- **Wigs & Wishes** (wigsandwishes.org/request-a-wig.php) provides free wigs in partnership with local salons. The first step is to look on the organization's website for a partner salon near you and schedule a wig consultation. If you cannot find a salon in your area, contact wigs@wigsandwishes.org to request assistance.

Questions?



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Let Us Know How We Can Help You



Visit our website: bmtinfonet.org

Email us: help@bmtinfonet.org

Phone: 888-597-7674 or 847-433-3313

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