

The Scars You Can't See are the Hardest to Heal

Hosted by **Blood & Marrow Transplant Information Network**



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Meet The Speakers



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The Scars You Can't See are
the Hardest to Heal:
*Coping with the
Impact of GVHD*

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Who We Are

- **Psychosocial Oncology at Christiana Care in Newark, DE addresses the intersection of the physical, social, psychological, and behavioral aspects of cancer trajectory for both patients and caregivers**
 - Coping and emotional reactions to cancer diagnosis, treatment, and survivorship
 - Health behavior change/prevention (sleep, lifestyle, smoking, etc.)
 - Communication with care team and loved ones in the context of cancer
 - Behavioral and psychiatric issues related to cancer and cancer treatment

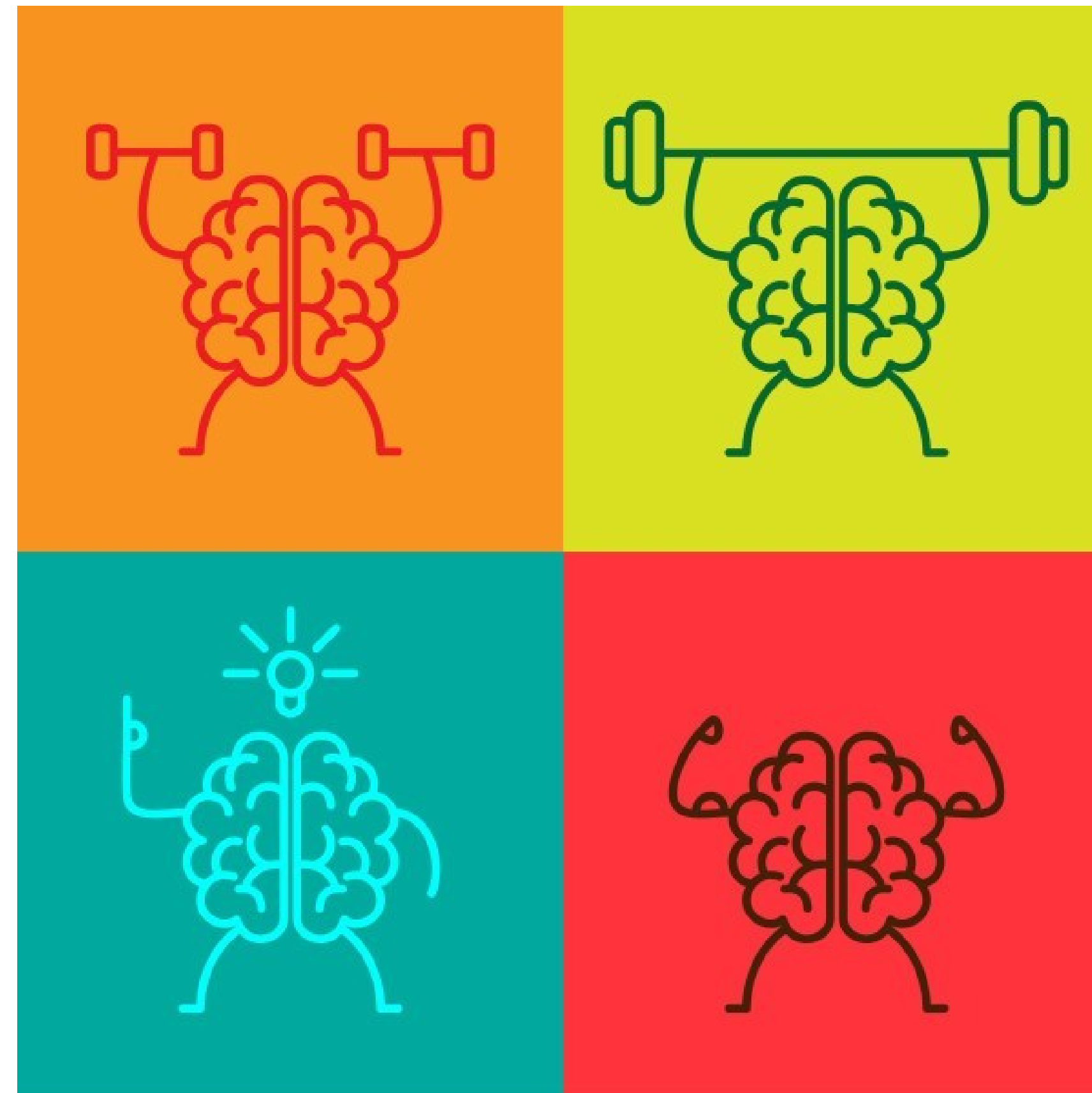




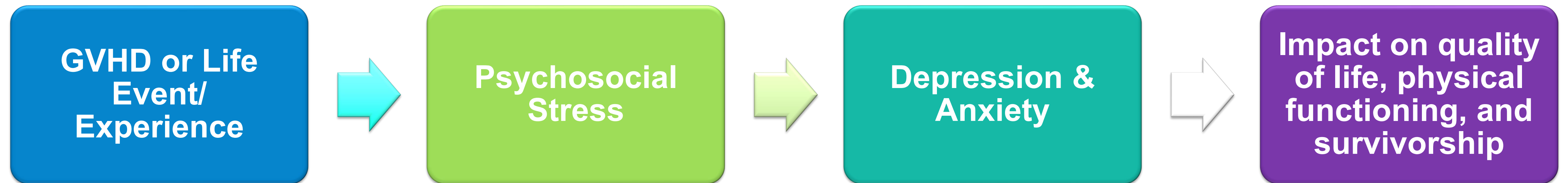
Objectives

- Learn psychotherapy tools that can be used to manage symptoms of GVHD
- Define Acceptance and Commitment Therapy (ACT) from other psychotherapies
- Apply several ACT therapy-based skills to your own experience
- Determine how to navigate additional psychosocial resources to help manage side effects/symptoms of transplant/GVHD

Mind/Body Connection



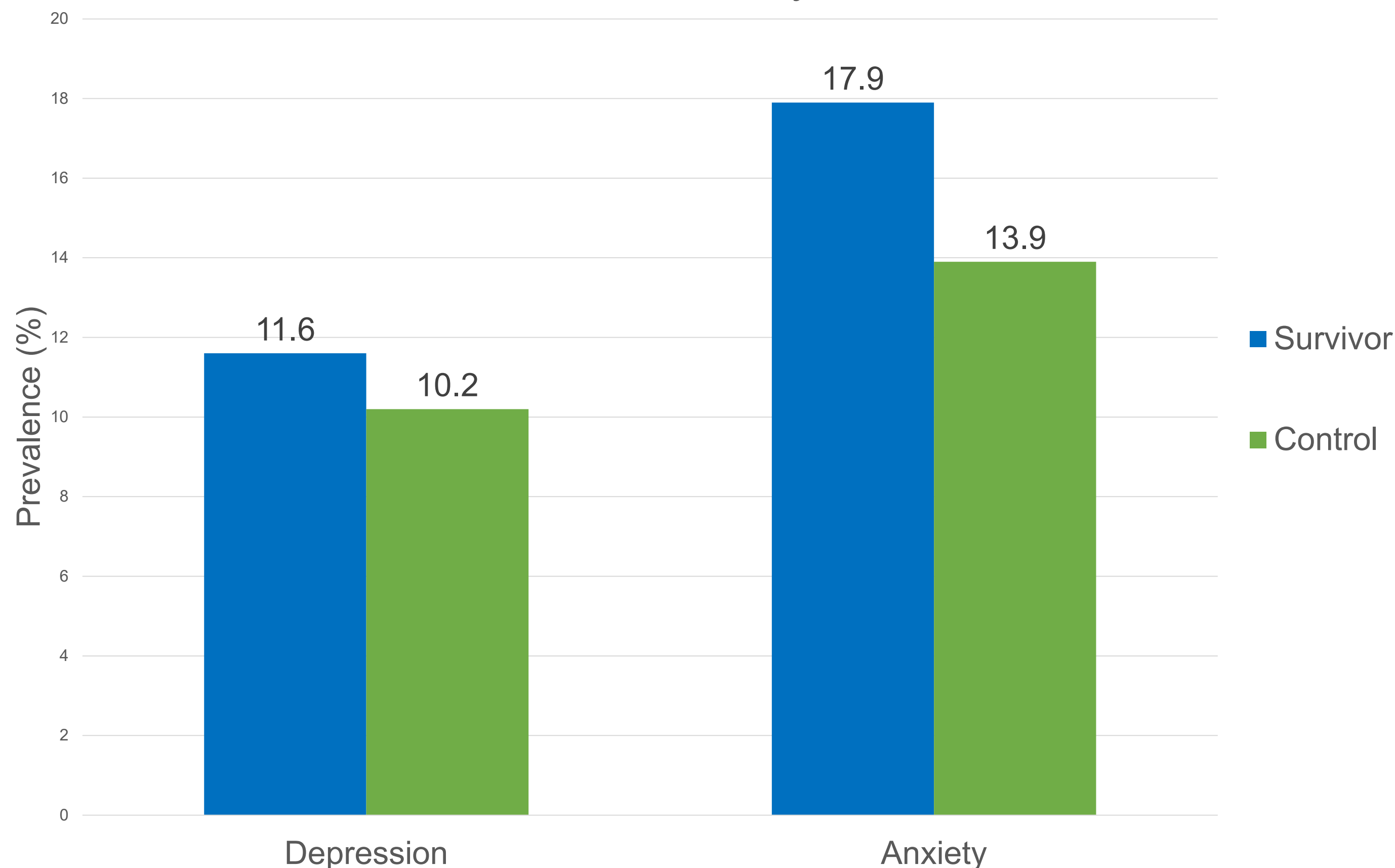
Psychosocial Burden



(El-Jawahari et al., 2018)

Increased Risk for Anxiety and Depression in Survivors

Rates of Depression and Anxiety in Long-Term Cancer Survivors vs. Healthy Controls

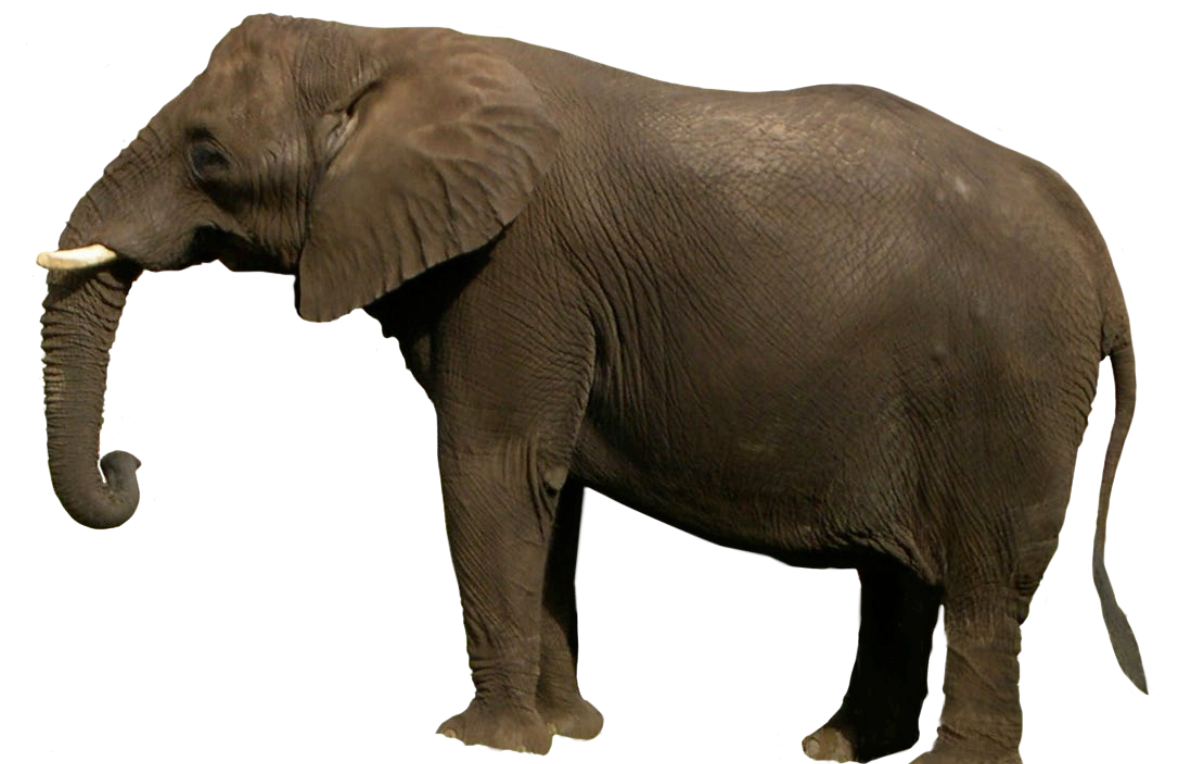


- Major Depression rates among 2+ year survivors are 11% higher than general population
- Anxiety Disorder rates are 27% higher than general population
- No differences in rates of distress between survivors and their **caregivers**

(Mitchell et al., 2013)

Fear of Cancer Recurrence

- Fear or worry that cancer could return or progress in survivors who have been treated for a cure
 - Adjustment to fear of cancer recurrence can be more difficult than adjustment to cancer
- ***GVHD symptoms as triggers for fear of cancer recurrence***
- Many negative impacts, including:
 - Impact on quality of life, intrusive thoughts, body checking
 - Less satisfaction with healthcare
 - Healthcare costs/medical utilization



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**Despite high rates of distress related to transplant,
50% or fewer individuals with distress seek
mental health care.**



Common Psychosocial Concerns & Treatments

- **Diagnoses:**

- Generalized Anxiety Disorder
- Major Depressive Disorder
- Post-Traumatic Stress Disorder
- Panic Disorders
- Substance Use Disorders

- **Treatments:**

- Medication management
- **Psychotherapy:**
 - Cognitive Behavioral Therapy (and specialized variations), Mindfulness-based, Narrative Therapy, Group support
 - **Acceptance & Commitment Therapy (ACT)**



Brief exercise





What is Acceptance and Commitment Therapy (ACT)?

Broadly, psychological flexibility is at the heart of healthy emotional functioning.

- **Acept** that which is, and what cannot be changed.
- **Commit** to moving forward in a manner that is in accordance with our values.
- **Take** action.

Goal = be fully present and open to our experiences so we can take actions guided by our values.



Core Principles of ACT

Acceptance

Cognitive
defusion

Being present

Self as context

Values

Committed
action



Core Principles

Acceptance

- Gently holding whatever arises
- Active choice against avoiding our emotions so we can be in the present moment
- What it's NOT: a passive, self-defeating stance

Cognitive Defusion

- Stepping back from thoughts and creating distance
- Altering the way we interact with our thoughts and thought processes
- THOUGHTS do not necessarily equal TRUTH



Core Principles

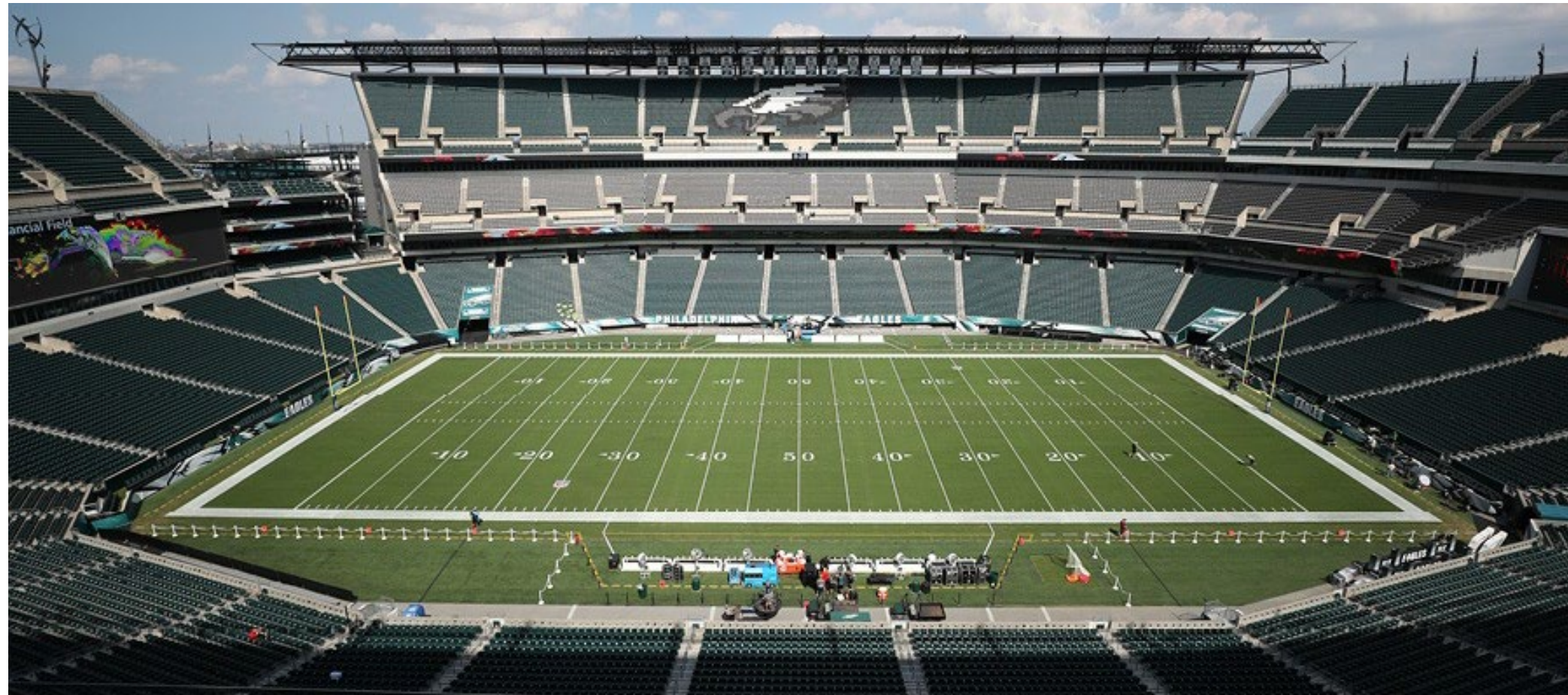
Being Present/Mindful

- Non-judgmental, present-focused awareness
- Not focused on the past or future
- Encourages an open approach to all experiences



Core Principles

Self as Context



- “The arena where life happens”
- In contrast - self as *content* (thoughts, feelings, physical symptoms, sensations)
- Self as the experiencer of life vs. the stories we tell about our lives



Core Principles

Values

- Personal, freely chosen
- A roadmap for guiding our behaviors
- Cannot be permanently achieved
- *If no one knew I was doing this, would it still be important to me?*

Committed Action

- “Walking the walk”
- Personal commitment for behavior change
- The goals/actions driven by our values



Physical wellbeing

What kind of values do you have regarding your physical wellbeing? How do you want to look after yourself?

Marriage / couple / intimate relations

*What kind of husband/wife/partner do you want to be?
What quality of relationship do you want to be a part of?*

Citizenship / community

What kind of environment do you want to be a part of? How do you want to contribute to your community?

Parenting

*What sort of parent do you want to be?
What qualities do you want your children to see in you?*

Spirituality

What kind of relationship do you want with God / nature / the Earth?

Friendships / social relationships

*What sort of friend do you want to be?
What friendships is it important to cultivate?
How would you like to act towards your friends?*

Recreation

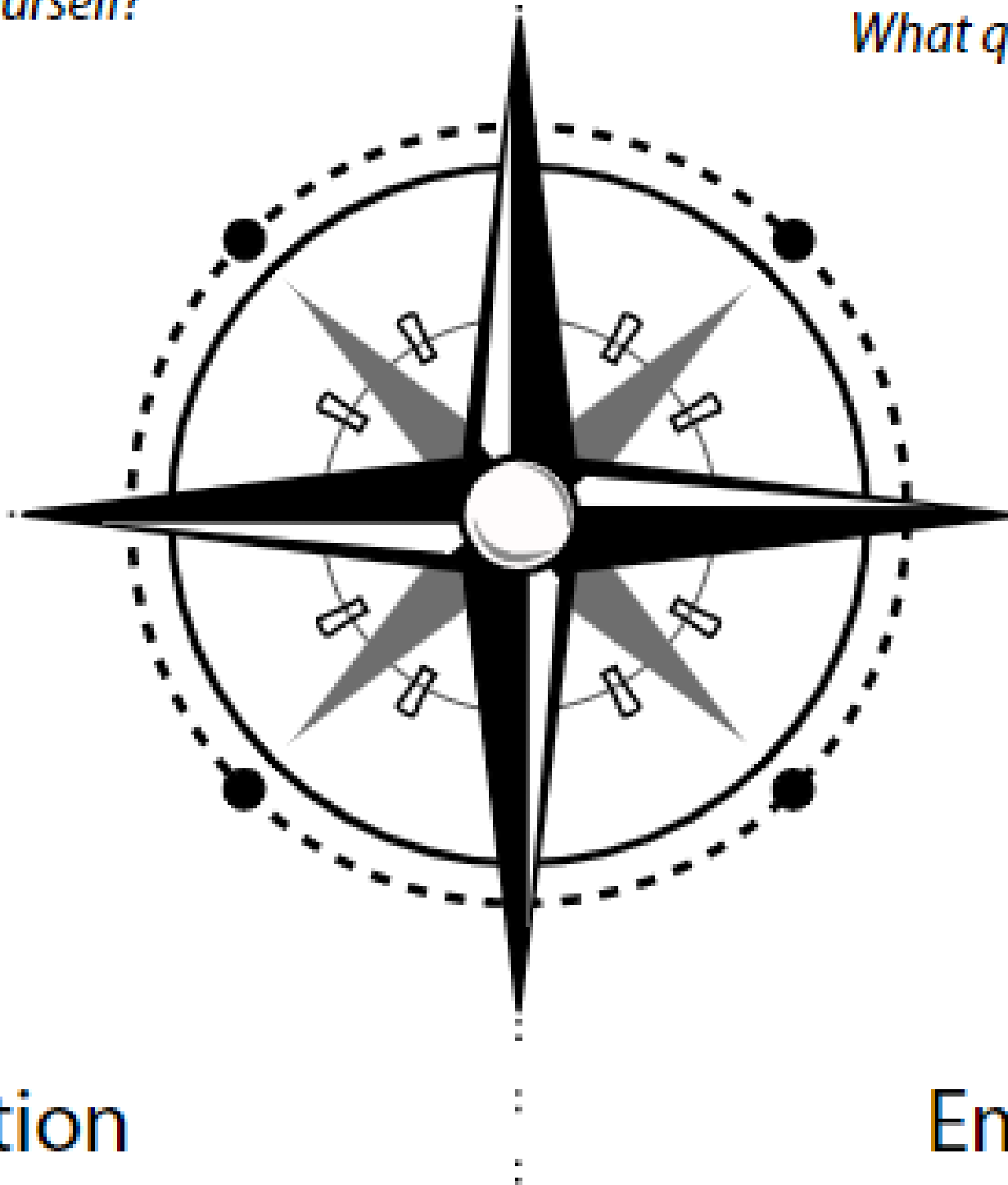
*How would you like to enjoy yourself?
What relaxes you? When are you most playful?*

Employment

*What kind of work is valuable to you?
What qualities do you want to bring as an employee?
What kind of work relationships would you like to build?*

Education / training / personal growth

*How would you like to grow?
What kind of skills would you like to develop?
What would you like to know more about?*

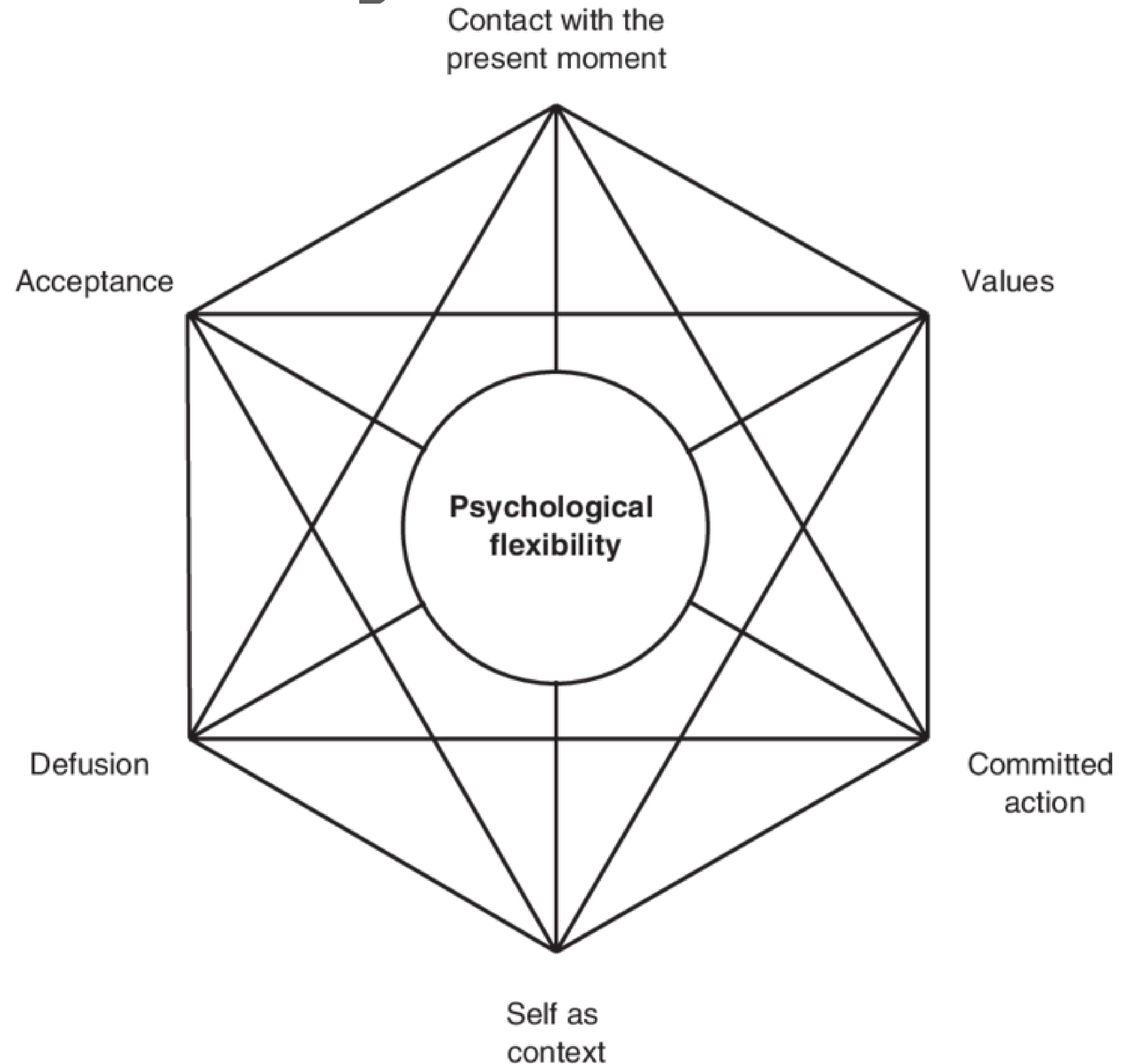


“Walking the walk”



In summary...

- **Psychological flexibility** is at the heart of healthy emotional functioning
- We can achieve that through active participation in these core skills





Finding Additional Support



Support Resources

BMT InfoNet: 888-597-7674, 847-433-3313

- Coping with the Stress of GVHD bmtinfonet.org/coping-stress-gvhd
- Caring Connections Peer Support Program bmtinfonet.org/caring-connection
- GVHD support groups: email help@bmtinfonet.org
- BMT InfoNet Mental Health Provider Directory. bmtinfonet.org/mh-directory

BeTheMatch: 888-999-6743

- Counseling www.BeTheMatch.org/Counseling

Leukemia Lymphoma Society: 800-955-4572

- Support Groups, Caregiver and Peer Support Programs lls.org/support-resources

Imerman Angels: 866-463-7626

- Peer/Caregiver One-on-One Support/Mentorship imermanangels.org/get-support.
- Good list of additional support resources here: imermanangels.org/cancer-partner-resources

Cancer Support Community: 888-793-9355

- Support Helpline, Virtual/In-Person Support Groups cancersupportcommunity.org/cancer-support-helpline



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Questions?



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