

CLL SOCIETY

Smart Patients Get Smart Care™

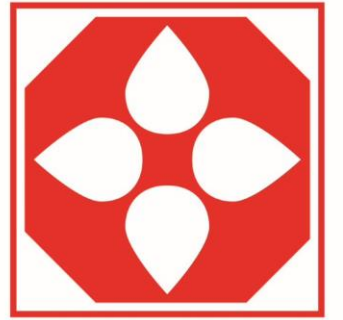
A Psychological Perspective: Dealing with the CLL Emotional Roller Coaster

July 22, 2019

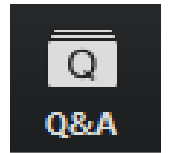
Housekeeping Notes

Welcome to the CLL Society Webinar!
The presentation will start momentarily

- Please direct your questions to CLL Society faculty or staff using the Q&A function (located at the bottom of your screen) at any time throughout the presentation
- You will receive a short email survey after the webinar. Your response will help CLL Society plan future webinars.
- The webinar is being recorded and all recorded webinars and the presentation slides will be available on our website via the Support Groups/Education page on cclsociety.org.



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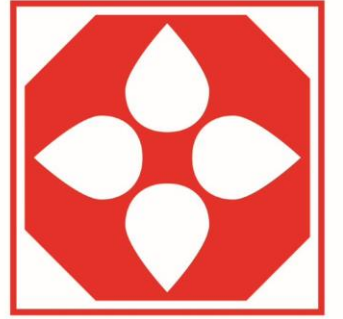
Question and Answer

Welcome
Feel free to ask the host and panelists questions

Type your question here

Send anonymously

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Speakers

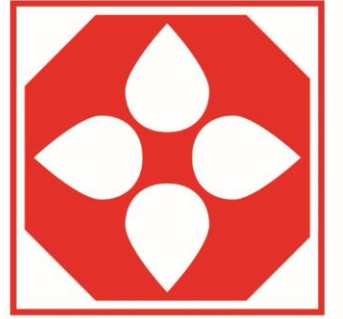
Moderator: Brian Koffman, MDCM, DCFP,
FCFP, DABFP, MSEd

Executive Vice President and Chief Medical
Officer, CLL Society



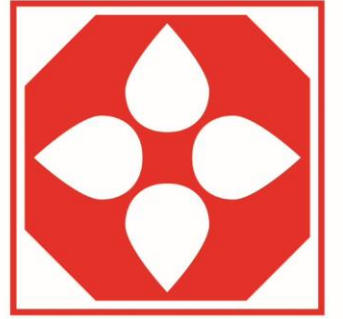
Speaker: Alison Brown, PhD

Coordinator, Psychologist
Center for Wellness & Wellbeing at Santa
Monica College



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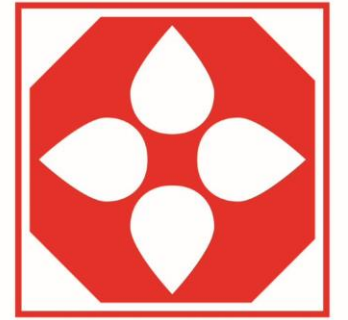
Introduction



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- Diagnosed with CLL in August 2016
- Symptoms at time of diagnosis included swollen lymph nodes, autoimmune hemolytic anemia (AHA) and high lymphocyte count
- Treated the AHA in Sept 2016 with Rituxan
- Entered CLL clinical trial beginning July 2017 and was treated with Gazyva and Chlorambucil
- Watch and wait since January 2018

Polling Question



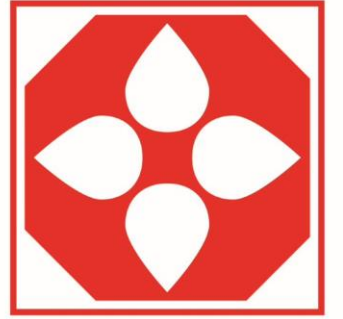
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What is your treatment status?

- a. Never been in treatment; only watch and wait
- b. Currently in active treatment
- c. Less than 1 year post-treatment
- d. More than 1 year post-treatment

Watch and wait? Wait for what?

- Congratulations. You have the “Good Cancer”
- Living with uncertainty
- Lack of control
- Negativity bias
- Increase in stress levels

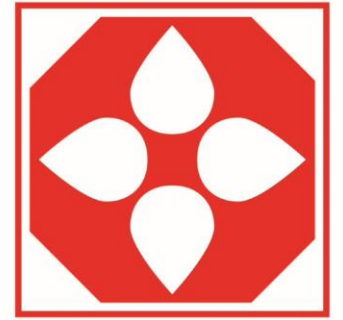
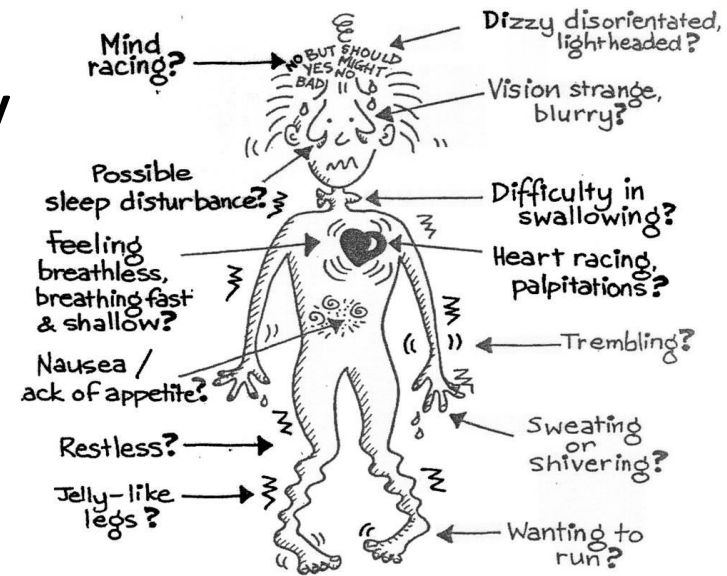


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Dealing with uncertainty

- Feeling helpless
- We often try to establish control
- Often we do this by worrying... a lot
- Worrying can be both helpful and harmful

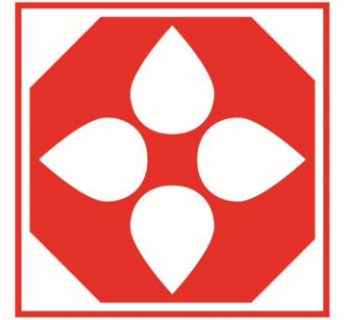


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- “If you have fear of some pain or suffering, you should examine whether there is anything you can do about it. If you can, there is no need to worry about it; if you cannot do anything, then there is also no need to worry.” ~14th Dalai Lama quote
- “...grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference.”
~ Serenity Prayer

We also try to fill in the blanks with Cognitive Distortions (aka unhelpful thinking styles)

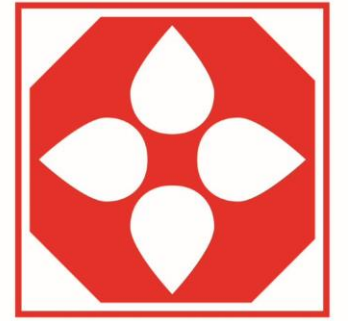
- All or Nothing Thinking
- Overgeneralizing
- Mental Filter
- Discounting the Positive
- Jumping to Conclusions: Mind Reading/Fortune Telling
- Magnification (Catastrophizing) or Minimization
- Emotional Reasoning
- Should/Must Statements
- Labeling
- Blame



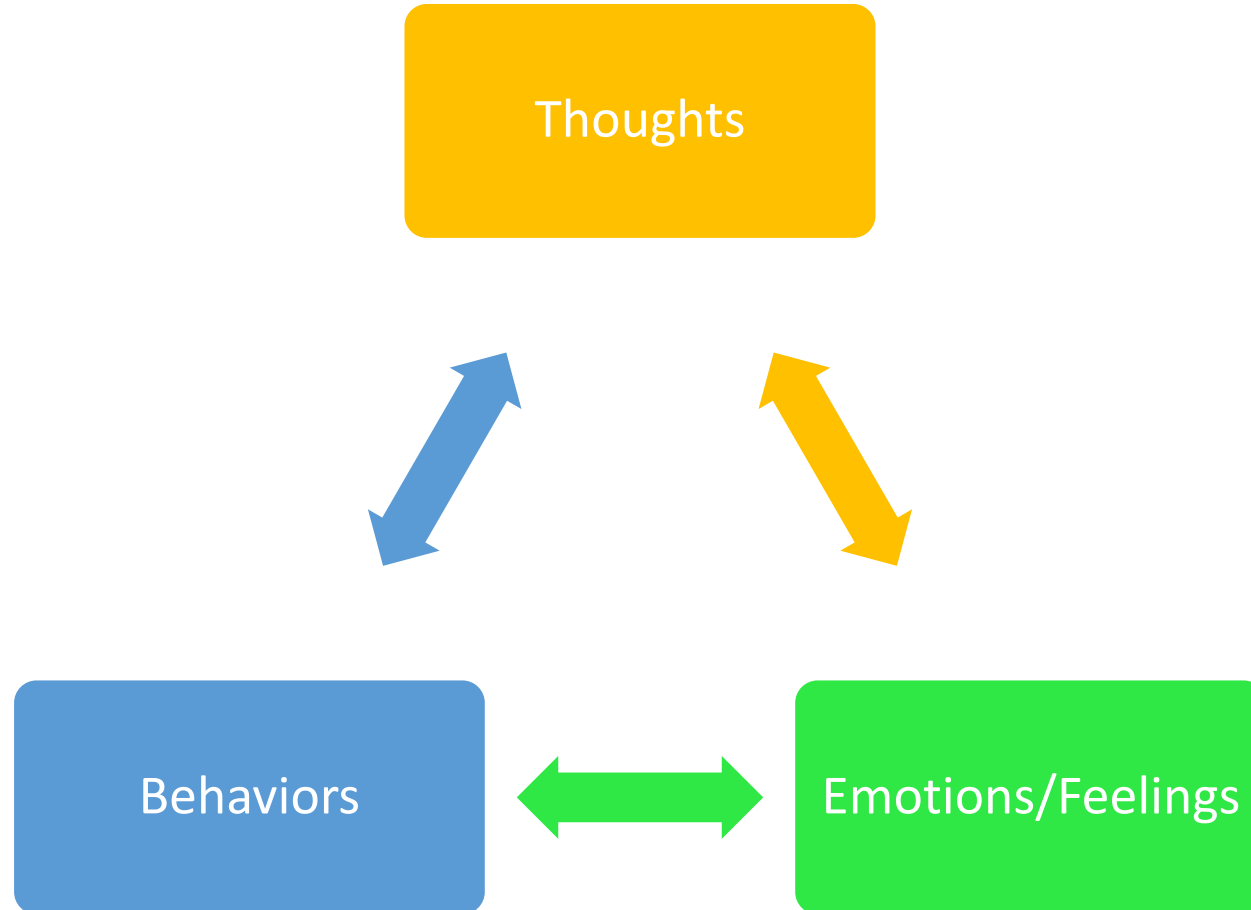
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(David D. Burns, MD, <https://feelinggood.com>)

Relationship between thoughts, moods, and behaviors



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THOUGHTS are **NOT** FACTS PRACTICE

When you put some space between you and your reaction, it changes your relationship to your thoughts—you can watch them come and go instead of treating them as facts.

If you're stuck on a negative thought, ask yourself:

1

Is it true?

Often the answer is, "Well, yes." This is the brain initially reacting—the autopilot you live with and believe is you.

2

Is it **absolutely** true?

Is this thought 100% accurate? Can you see the thought in a different way?

3

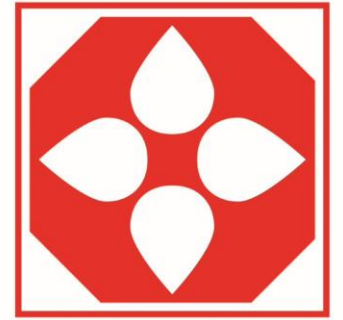
How does this thought make me feel?

Notice any storylines you're holding onto, and name your feelings: *sad, angry, jealous, hurt*.

4

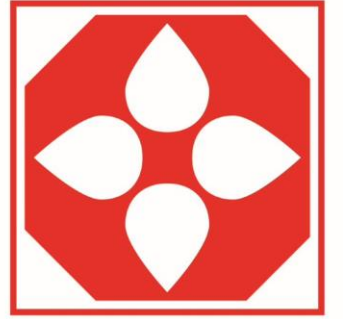
What would things be like if I didn't hold this belief?

Imagine possible benefits to your relationships, energy levels, and motivation.



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Polling Question

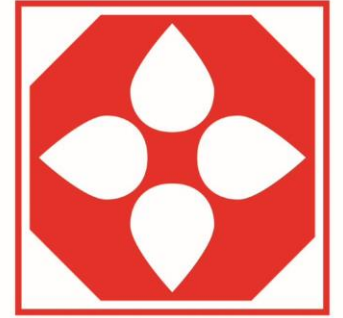


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Which interferes most with your daily functioning?

- a. Emotional symptoms
- b. Physical symptoms
- c. Both emotional and physical symptoms
- d. Neither

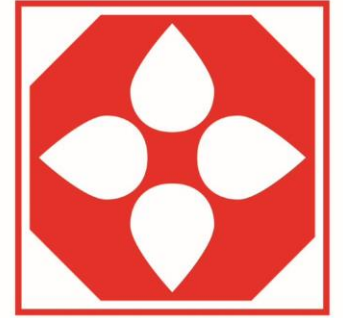
Definition of Stress



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- What is stress?
 - Stress is what arises when something we care about is at stake (from “How to Make Stress Work for You”, an online Great Courses class taught by Kimberlee Bethany Bonura, PhD)
 - The body’s response to a challenging event
 - External stressors
 - Threat or perceived threat to your physical safety (e.g., illness)
 - Internal stressors
 - Threat is in your internal world (e.g., worrying about the illness)
- Stress is often influenced by individual perception (e.g., traffic can be perceived as stressful for some but not for others)
- How do you know that you are stressed?

Symptoms/Signals of Stress



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Physical Symptoms of Stress

- Indigestion
- Fatigue
- Rapid heartbeat, chest pain
- Nervousness, shaking, sweating
- Insomnia
- Muscle tension
- Changes in appetite (over / under eating)
- Headaches

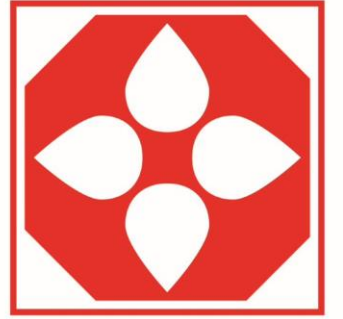
Cognitive Symptoms of Stress

- Scattered attention
- Loss of perspective
- Obsessive thinking

Emotional Symptoms of Stress

- Anger
- Impatience
- Irritability
- Anxiety
- Depression

Polling Question



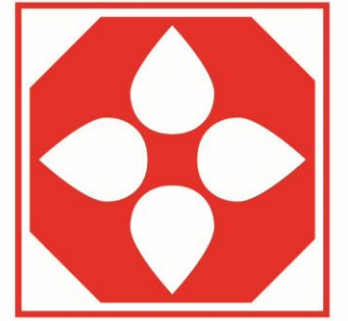
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What is your predominant emotional symptom related to having a CLL diagnosis?

- a. Fear and/or anxiety
- b. Depression and/or loneliness
- c. Anger
- d. Grief
- e. I frequently feel most or all of these emotional symptoms
- f. Other

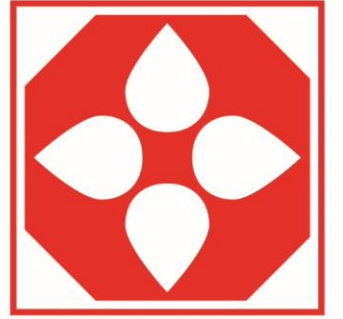
Thinking about the Past or Future

- Pulls us away from the “here and now.”
- Often creates or increases anxiety or depression....Why???
- Practicing mindfulness can help us cultivate present moment awareness



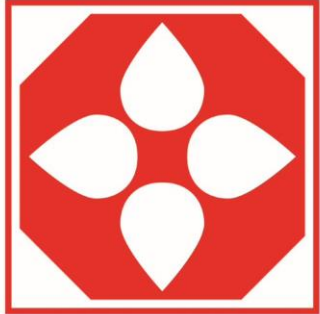
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What is Mindfulness?



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- Mindfulness is the practice of becoming more fully aware of the present moment (using all of our senses) rather than dwelling in the past or projecting into the future.
- Mindfulness is cultivated by paying attention in a sustained and particular way: on purpose, in the present moment, and non-judgmentally (J. Kabat-Zinn, Full Catastrophe Living).
- There are both formal (e.g., meditation) and informal ways to practice (e.g., bringing awareness to everyday activities) .



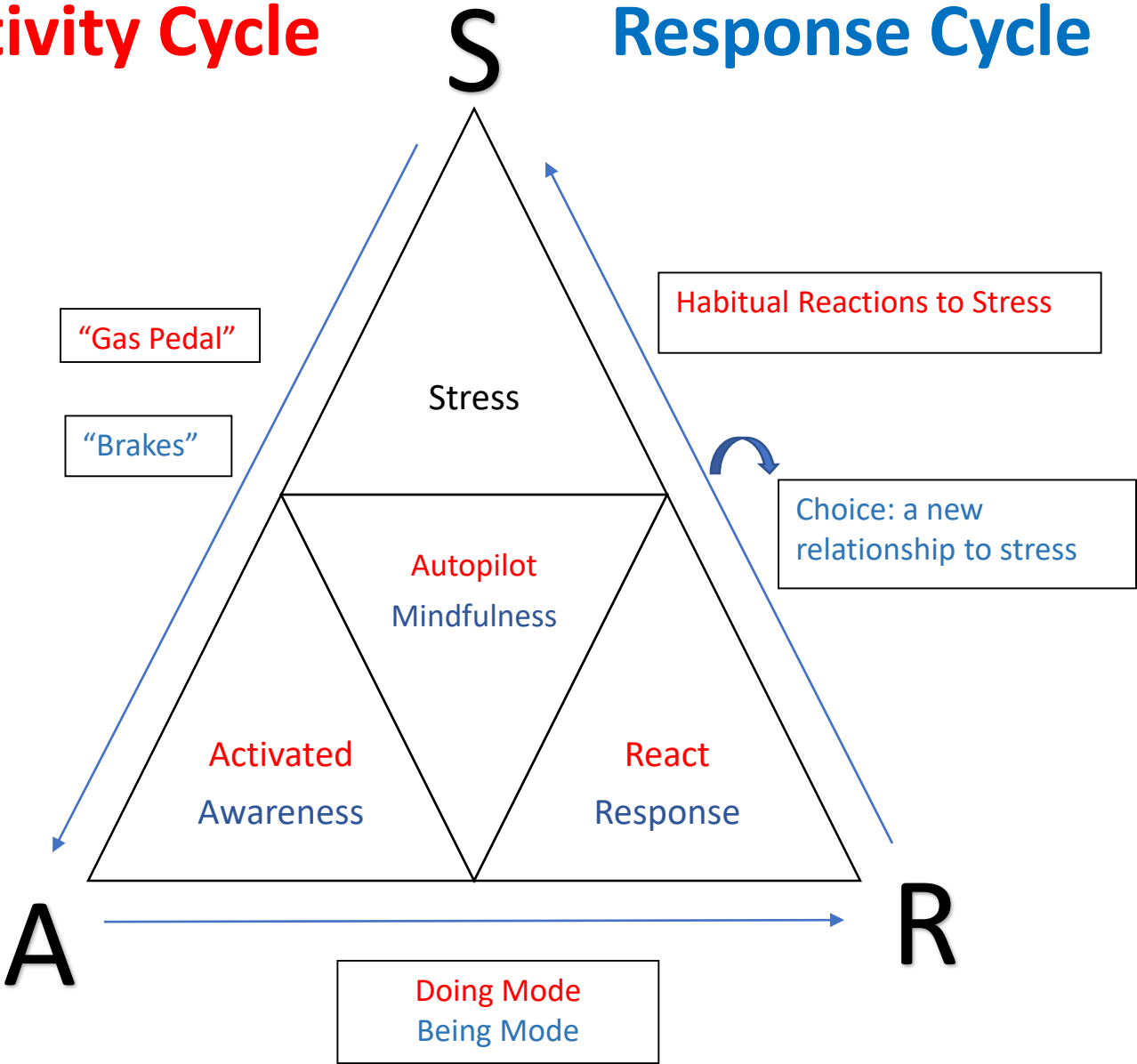
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“Between stimulus and response there is a space. In that space lies our freedom and power to choose our response. In those choices lie our growth and our happiness.”

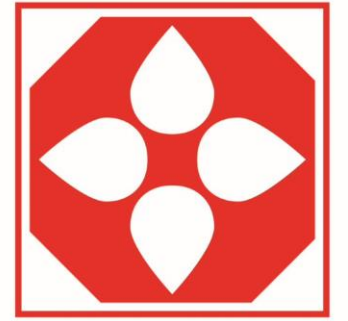
~Victor Frankl, Austrian neurologist and psychiatrist, Holocaust survivor, author of “Man’s Search for Meaning”

Reactivity Cycle

Response Cycle



Depression vs. Sadness



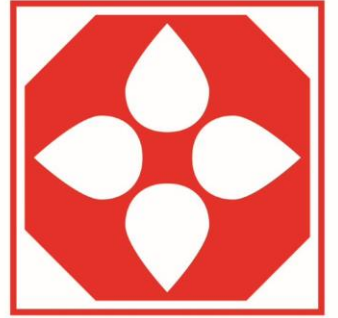
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- Feelings of sadness, or feeling “blue” from time to time is normal.
 - Occur in reaction to life struggles, setbacks, loss, or disappointments.
 - Temporary and often do not significantly impact daily functioning or activity.
- Depression: feelings of despair or emptiness do not seem to go away, or make it difficult to complete daily tasks.

Common Signs of Depression

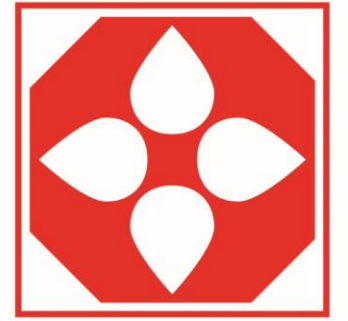
- Feelings of helplessness and hopelessness
- Loss of interest in daily activities
- Appetite or weight changes
- Sleep changes
- Anger or irritability
- Loss of energy
- Social Isolation
- Self-loathing
- Reckless behavior
- Concentration problems
- Unexplained aches and pains
- Thoughts of death and dying

* These can be normal to have, but when they have become overwhelming, or do not seem to be getting better, it may be time to seek help.



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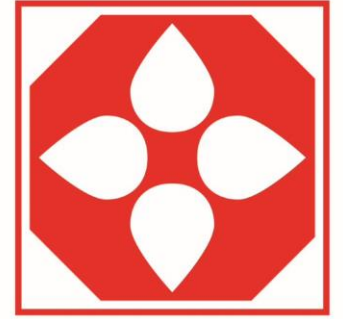


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Have you shared your diagnosis with others outside of your immediate family or social circle?

- a. Yes, on social media
- b. Yes, with acquaintances and/or coworkers
- c. Nobody outside of my immediate family (and medical team)
- d. Nobody other than family and closest friends (and medical team)
- e. I have not shared my diagnosis with my immediate family or social circle

Make Time for Self-Care

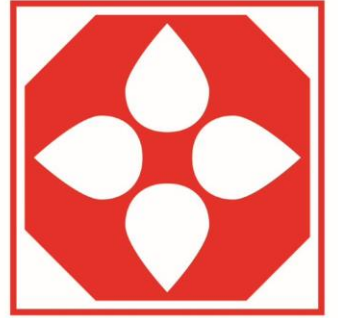


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- Physical Self-Care: Move your body, eat a healthy diet, sleep
- Psychological Self-Care: Make time away from demands, write in a journal, say no to extra responsibilities, be curious, engage in relaxation activities
- Emotional Self-Care: Connect with others whose company you enjoy, express your feelings, laugh, cry, be of service, play with children or animals,, love yourself
- Spiritual Self-Care: Spend time in nature, find spiritual connection or community, be open to not knowing, meditate, engage in artistic activity, have experiences of awe, make meaning from the difficult periods
- Professional Self-Care: take time to connect with coworkers, take time for breaks, balance your workload, set limits, identify projects or tasks that are exciting/rewarding, start a peer support group or outing, volunteer, develop interests outside of work

(Self-Care & Revitalization Worksheet, J. Eric Gentry, PhD)

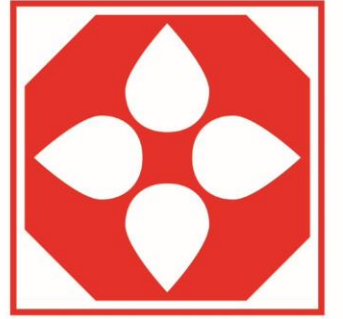
Additional Coping Strategies



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- Practice Self-Compassion:
 - 1) Self-Kindness vs Self-Judgment; 2) Common Humanity vs. Isolation, and 3) Mindfulness vs. Over-identification (K. Neff, <https://self-compassion.org/>)
- Practice Gratitude (<https://greatergood.berkeley.edu/topic/gratitude>)
- Increase your social support
- Seek psychological and/or psychiatric support if symptoms are:
 - significantly and negatively affecting thinking, emotional state, and behavior over time
 - disrupting ability to carry out daily activities and engage in satisfying relationships

Resources



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- Books:
 - *Full Catastrophe Living: Using the Wisdom of Your Mind to Face Stress, Pain, and Illness* (Revised Edition, 2013) by Jon Kabat-Zinn
 - *Self-Compassion: Stop Beating Yourself Up and Leave Insecurity Behind* (2011) by Kristin Neff, Ph.D.
 - *How to Live Well with Chronic Pain and Illness: A Mindful Guide* (2015) by Toni Bernhard
- Meditation apps, such as Calm and Insight Timer
- Feel free to email me with questions about this presentation at brown_alison@smc.edu