

# Living Well after Treatment: Coping with Fatigue



**Erin Costanzo PhD**

Professor, Department of Psychiatry,  
University of Wisconsin School of  
Medicine and Public Health

**Celebrating a Second Chance at Life  
Survivorship Symposium**

April 27 – May 3, 2024

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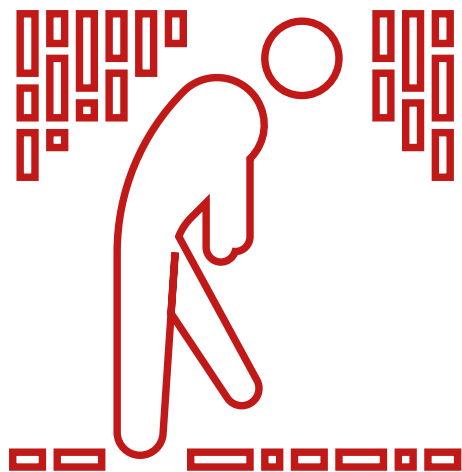
# LIVING WELL AFTER TREATMENT: COPING WITH FATIGUE

DR. ERIN COSTANZO

UW SCHOOL OF MEDICINE AND PUBLIC HEALTH

CARBONE CANCER CENTER





# AGENDA

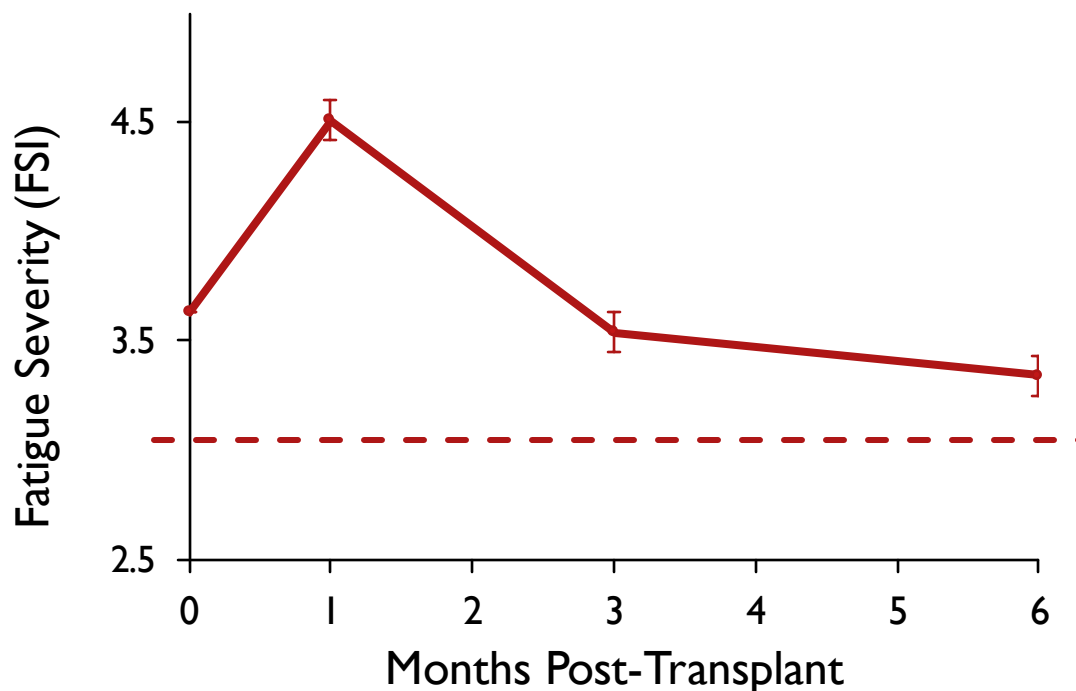
## Energy management strategies

- Prioritizing
- Pacing
- Increasing activity

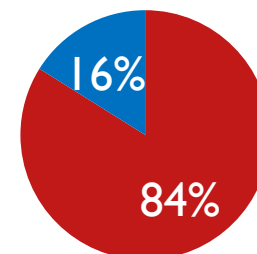
## Fatigue “ingredients” and strategies to help

- Treatment-related effects
- Medications
- Sleep
- Circadian rhythms
- Psychological stress and mood

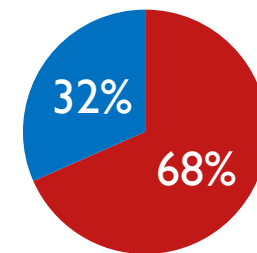
# FATIGUE IS A PROBLEM DURING EARLY RECOVERY



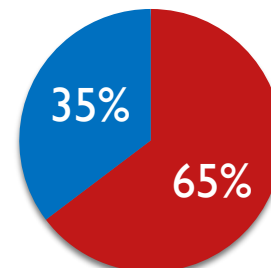
1 month



3 months

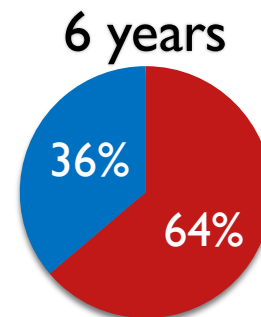
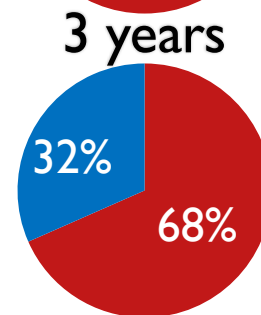
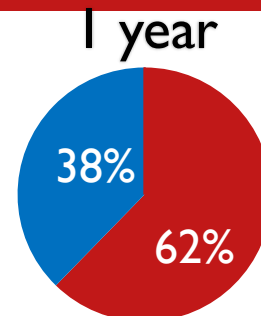
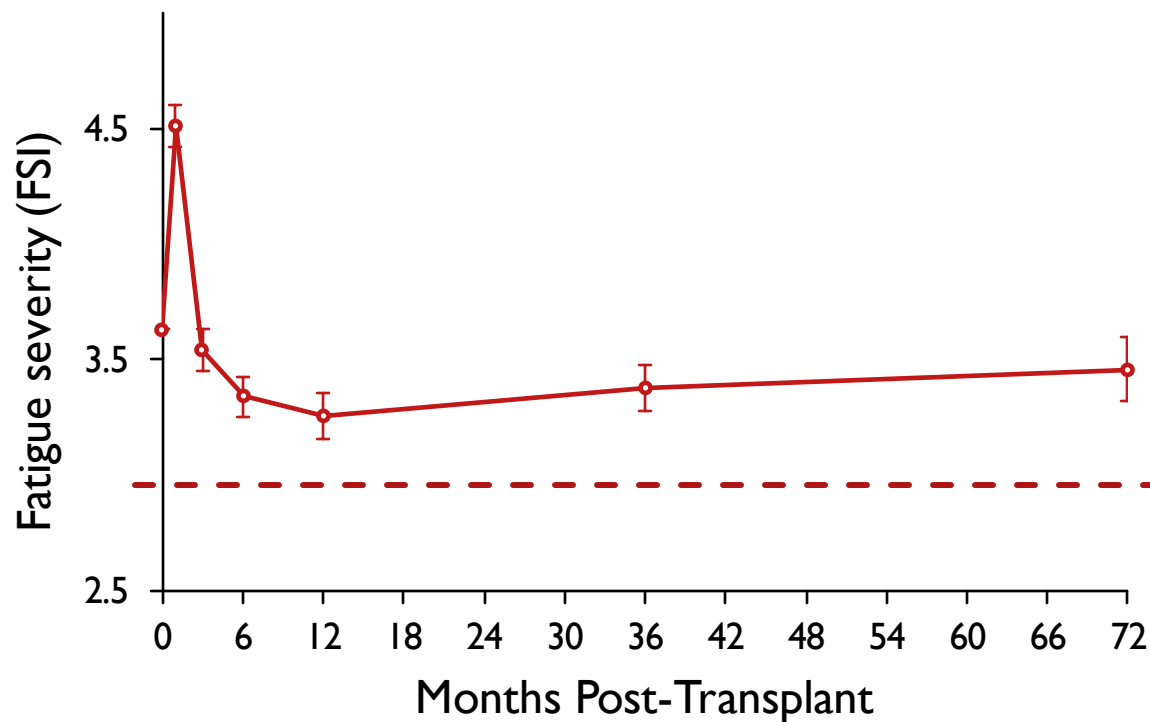


6 months



■ High fatigue  
■ Normal fatigue

# FATIGUE CAN BE A PROBLEM FOR MANY YEARS



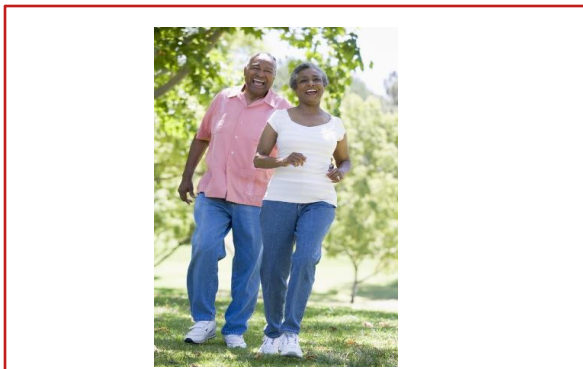
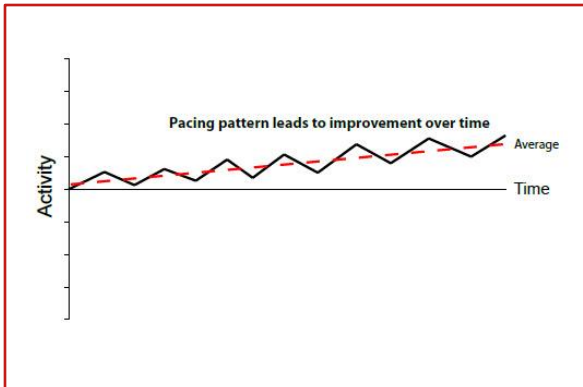
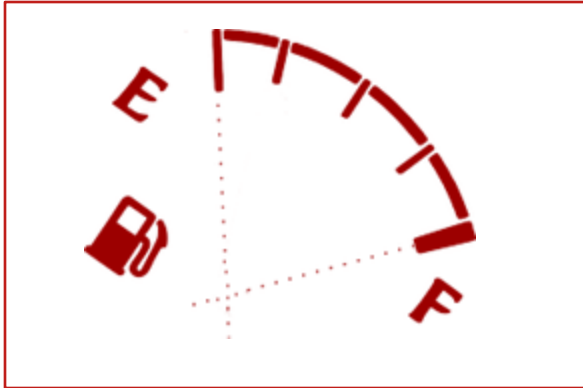
■ High fatigue  
■ Normal fatigue

# ENERGY MANAGEMENT STRATEGIES

Prioritizing

Pacing

Increasing activity



# HOW FULL IS YOUR ENERGY TANK?

- In the past, you probably had a full “tank of gas” to get through each day. You were able to do many activities in a single day.
- After HCT and CAR T, most people have less gas in their tank and do not have the fuel available to do all of the activities they normally would.



# USING ENERGY WISELY

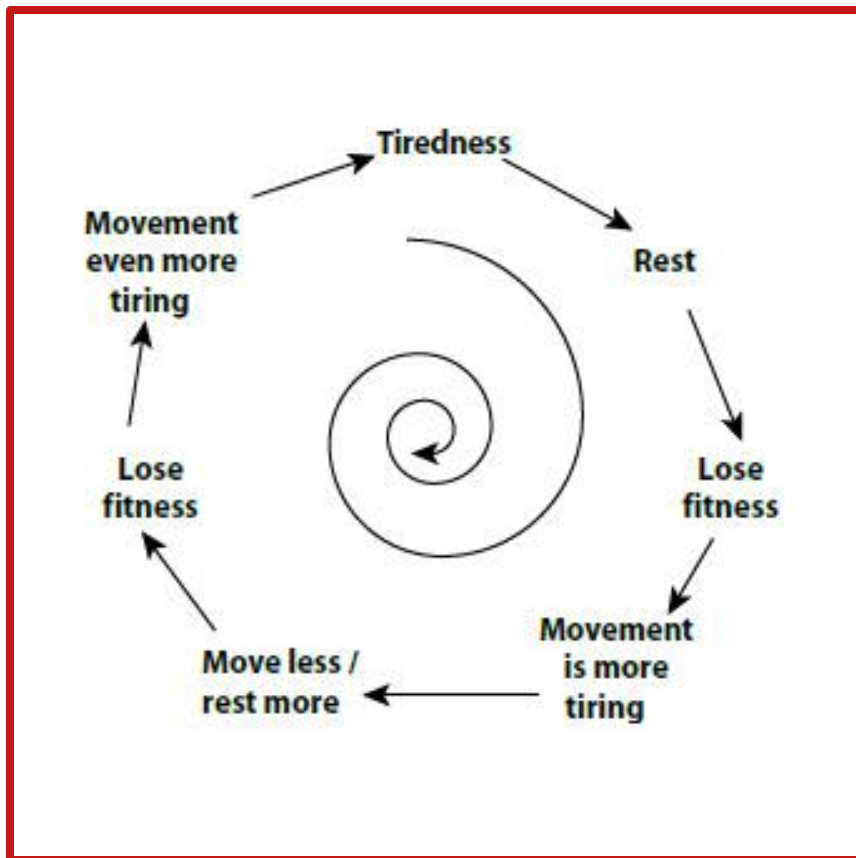
- **What are the MOST IMPORTANT tasks I want to accomplish today?**
  - It is best to choose just 2-3 things.  
When your fuel increases, you can add more.
  - Consider doing your highest priority and/or most energy consuming activities during your **PEAK ENERGY** time.



# USING ENERGY WISELY

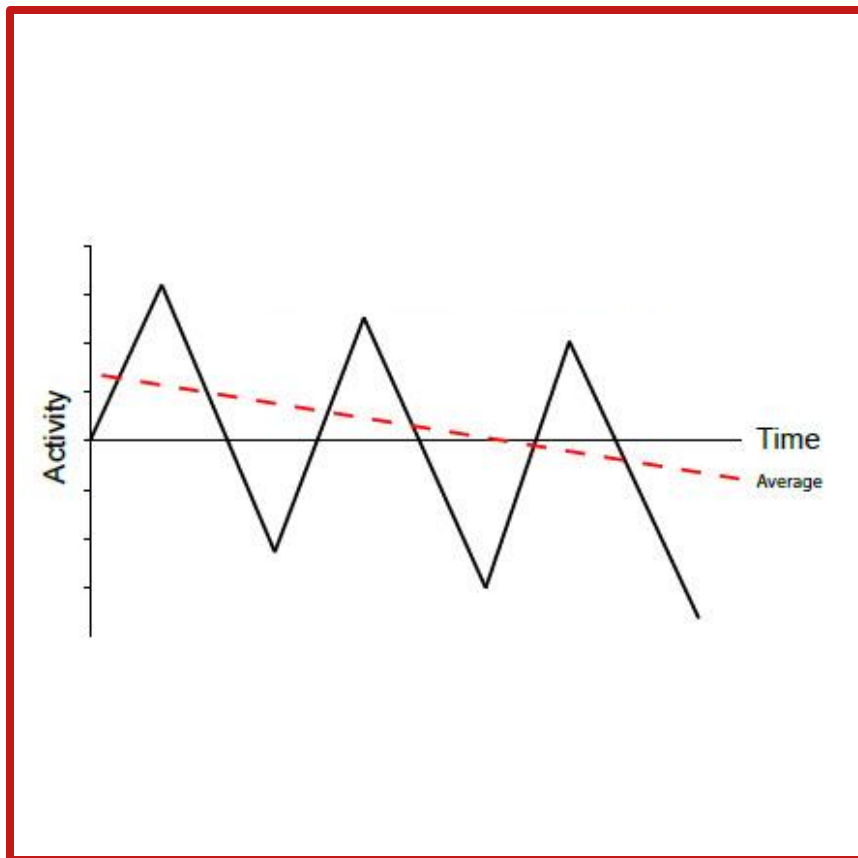
- What can I **DELEGATE** (ask someone else to do) or **TRIAGE** (wait until later, or don't do it at all)?
- Where can I **TAKE A SHORTCUT** or do something an easier way?

# UNDERACTIVITY CYCLE



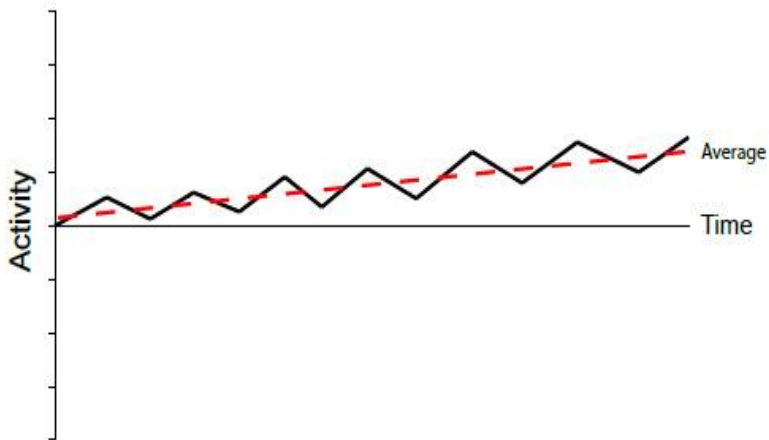
- Some people spend a lot of time resting. This approach makes sense in the short term but comes with unintended consequences.
- Extended resting makes you less fit. This means that it takes less and less activity to make you feel tired.
- Doing nothing can lead to boredom and depression, which can make fatigue worse.

# BOOM-BUST CYCLE



- Other people choose to be very active and to battle through the fatigue. This approach also makes sense, but it can also be counterproductive.
- Some people find that they push themselves too hard and end up suffering. They can be laid low for several hours or days following over-exertion.

# PACING



- Pacing is a skill that enables you to consistently carry out activities without causing extra fatigue.
- Pacing means spending just enough time on an activity to get the most out of it, without pushing yourself so far that you end up too more tired.
- Over time, pacing enables you to do more.

# HOW TO PACE

## *“I don’t know how long to do an activity”*

- Choose an activity – e.g. sitting, walking, preparing a meal
- Measure the length of time you are comfortably able to do this. Do this at least three separate times – on good days and bad days
- Take the average of these times, then subtract a fifth

# HOW TO PACE

***“I got so involved I lost track of time”***

- Good pacing means knowing when to stop and take a break.
- Place a clock in full view, or set an alarm to go off.
- Taking a break is a wise move to allow you to gradually build up your stamina.

# HOW TO PACE

## ***“I don’t know how long to break for or what to do”***

- To make the most of a break it is important to change your position and body posture and do something that engages you. It’s less helpful to just stop and do nothing.
- Walk around, do some stretching exercises, put on the radio.
- Some activities will require shorter breaks, others will require longer breaks.

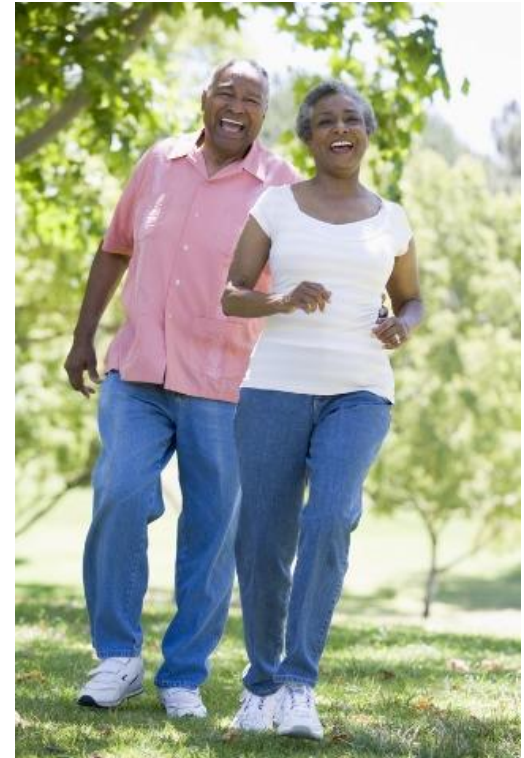
## ***“I make decisions based on how I’m feeling at the time”***

- This is often part of the boom/bust over-exertion cycle – doing more on good days and then suffering the consequences.

# INCREASING ACTIVITY

**Set small goals** to gradually increase your activity level. When you achieve the goal, consider whether you are ready to set another small goal. Example goals:

- Add in a walk around the block
- Increase your daily step count by a few hundred steps
- Try to move about when talking on the phone
- When watching TV, stand and walk in place during commercials.





# INCREASING ACTIVITY

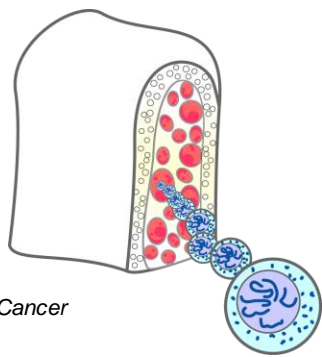
- One of the best ways to make sure your activity is productive is to use a pedometer or activity tracker.
- Start by wearing your activity tracker or pedometer for 1-2 weeks. Write your daily step or activity count on a calendar or in a notebook.
- **General Step-Increase Guidelines:** Approximately 10% each week, or each time you make an adjustment.

<5000

- +200 steps/day
- Each Week

>5000

- + 500 steps/day
- Each week



National Cancer  
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# FATIGUE INGREDIENTS AND STRATEGIES TO HELP

Treatment-related effects

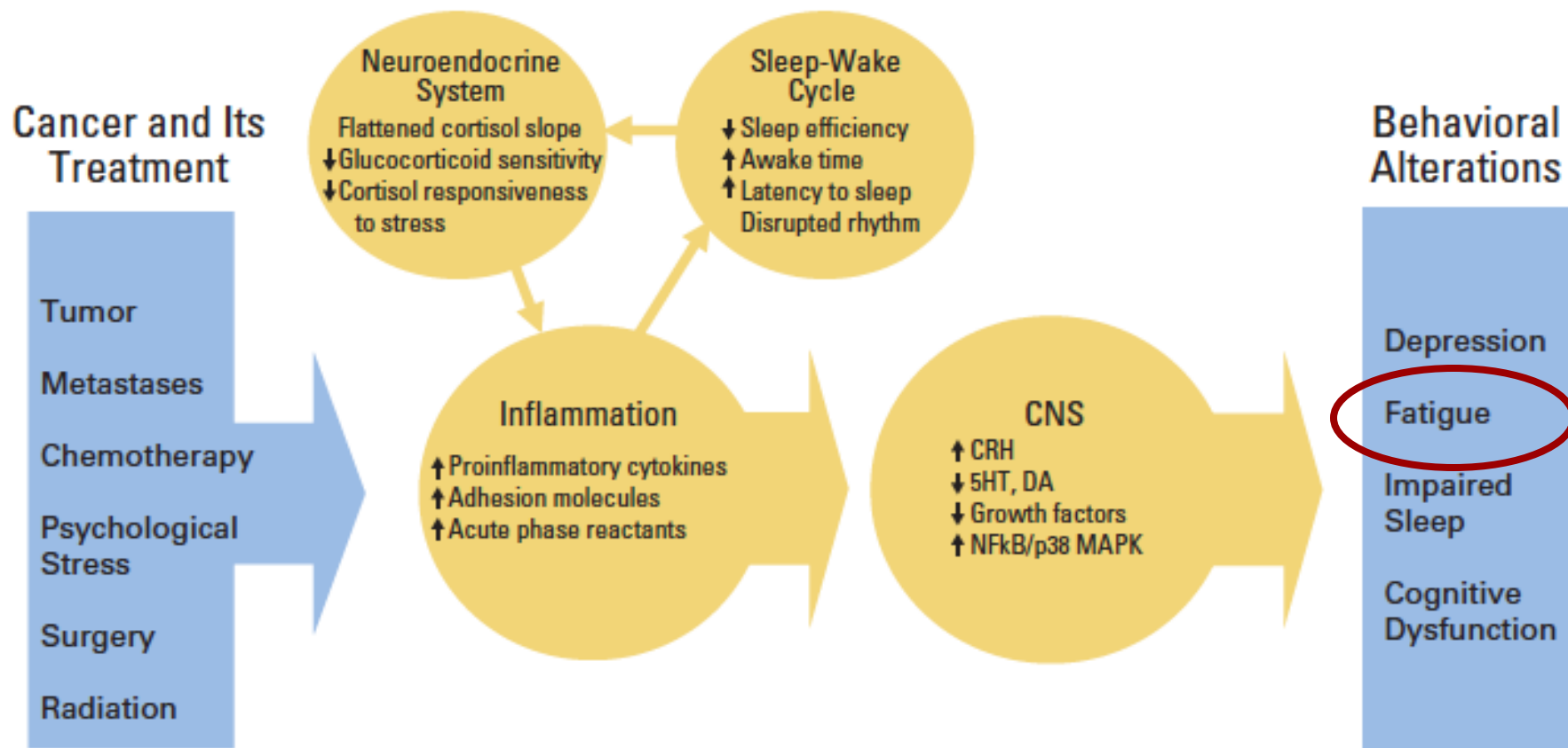
Medications

Sleep

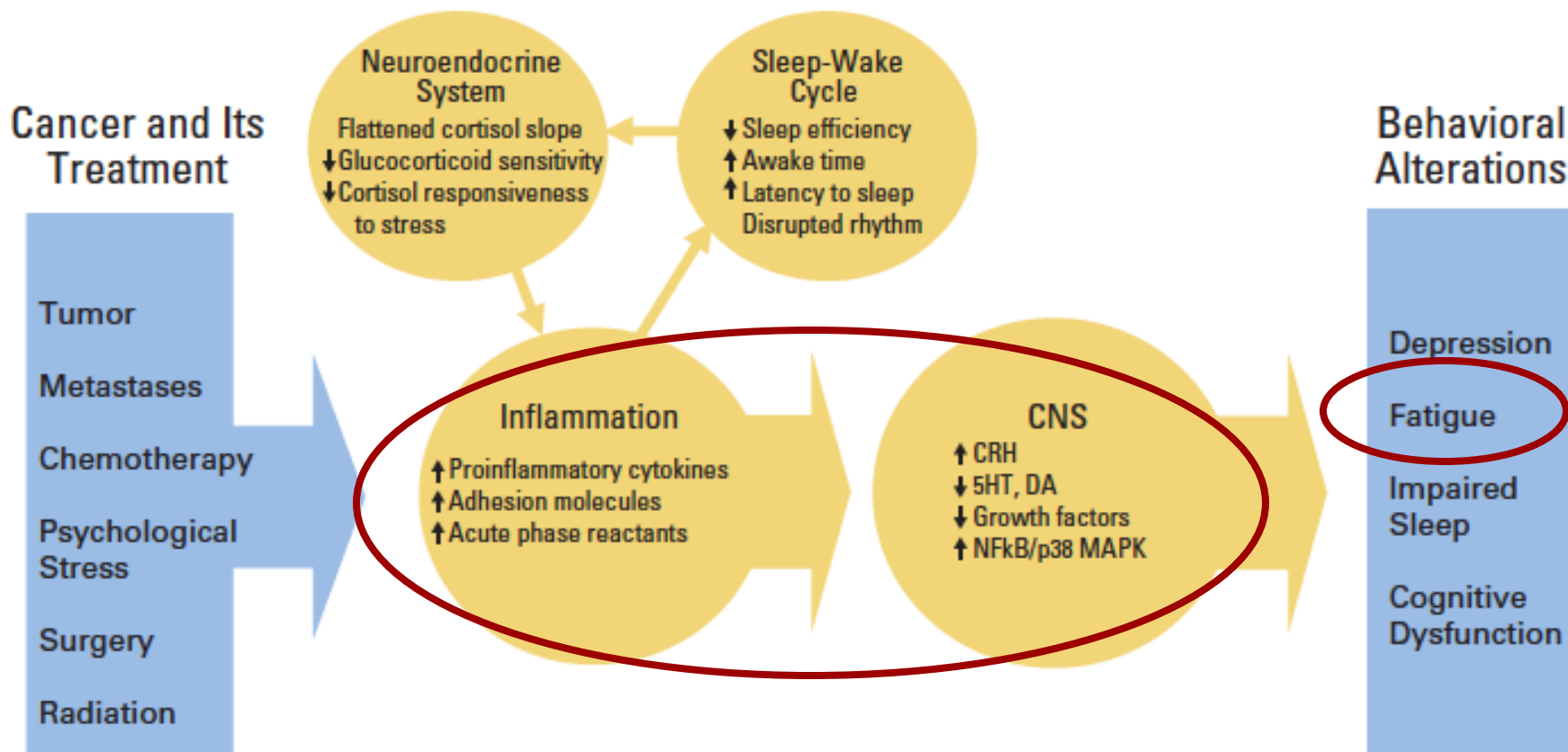
Circadian rhythms

Psychological stress and mood

# FATIGUE IS MULTIFACTORIAL (COMPLICATED!)



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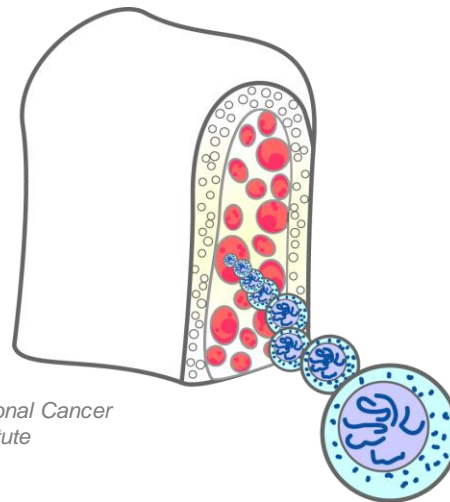


# TREATMENT COMPLICATIONS

- Not enough blood cells
- Dehydration
- Insufficient nutrition
- Graft-versus-host disease
- Lung problems
- Thyroid problems
- Sleep apnea

## ACTION ITEMS:

- Tell your doctors about your fatigue
- Ask whether tests / evaluations should be done



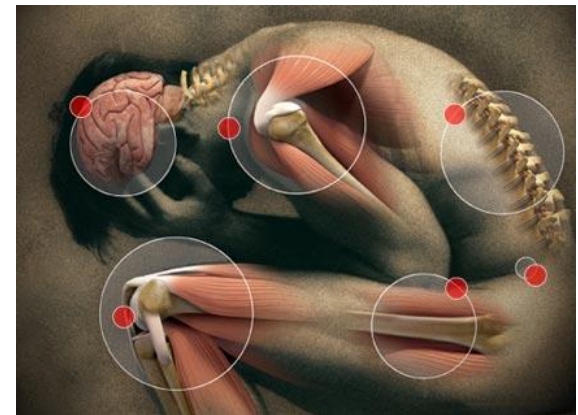
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# INFLAMMATION

- Cytokine release syndrome
- Immune effector cell neurotoxicity syndrome (ICANS)
- Graft-versus-host disease
- Infection
- Effects of conditioning radiation and chemotherapy

## ACTION ITEMS:

- Tell your doctors about your fatigue
- Ask whether tests / evaluations should be done



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# MEDICATION AND NUTRITION

## Medication

- Treating post-HCT and CAR T complications
- Bupropion
- Stimulant medication



## Nutrition

- ❑ American Cancer Society guidelines for nutrition
- ❑ Get enough calories and protein
- ❑ Consider working with a dietitian



# POLYPHARMACY

- Anti-nausea medications
- Pain medications
- Sleep medications
- Anxiety medications
- Allergy medications
- Muscle relaxants
- Blood pressure medications
- Alcohol

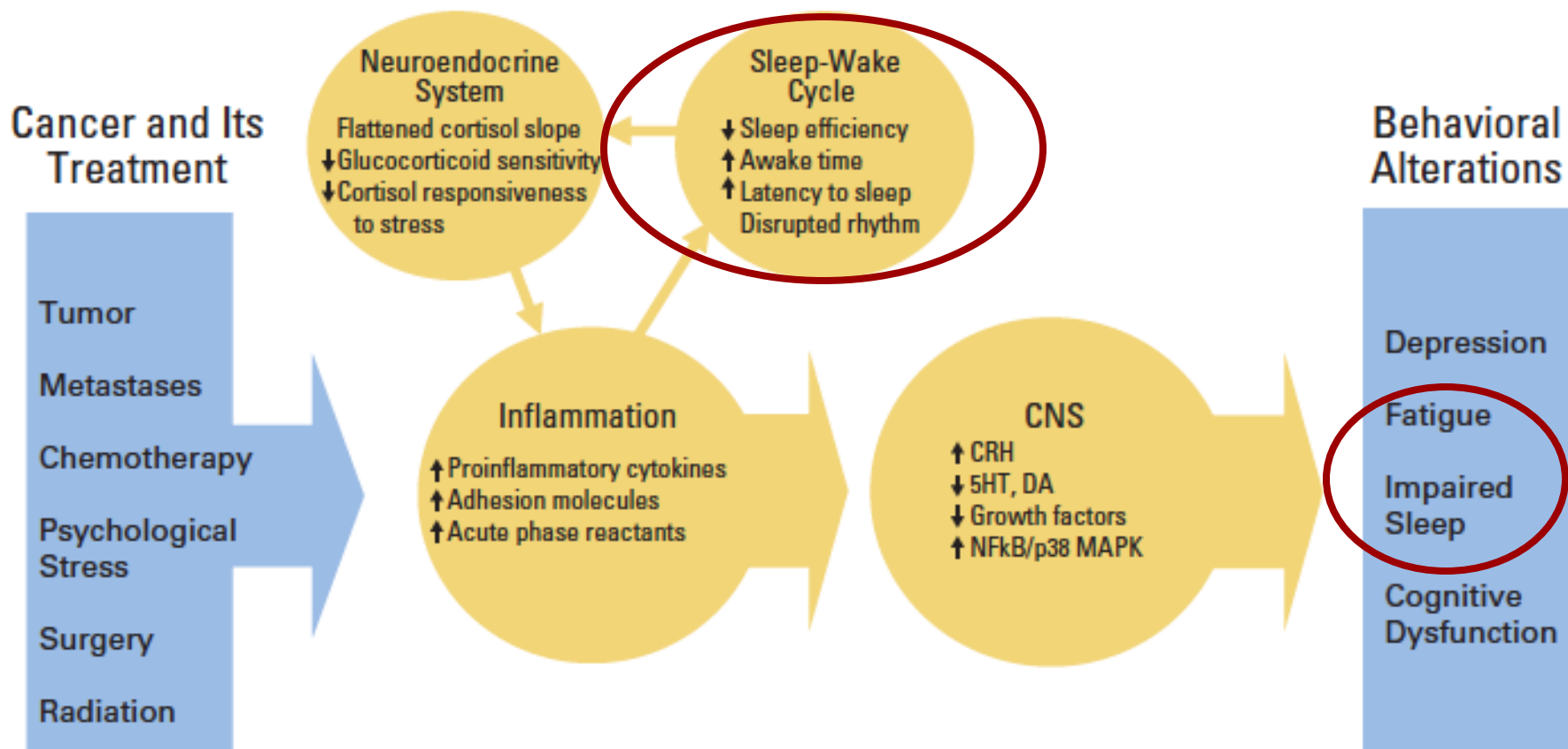
## **ACTION ITEMS:**

- Ask your pharmacist or doctor to review your medications
- Avoid or minimize alcohol use





# FATIGUE IS MULTIFACTORIAL (COMPLICATED!)



# SLEEP: SELF-MANAGEMENT STRATEGIES

- Select a standard wake-up time
- Do not use screens directly before bedtime
- Give yourself time to let go of the day each evening
- Go to bed when you are sleepy
- Get out of bed when you are unable to sleep
- Take naps in the late morning or mid-day
- Keep naps to no more than 60 minutes

# SLEEP: EVALUATION, TREATMENT, RESOURCES

- Sleep study to evaluate for sleep disorders
- Cognitive-Behavior Therapy for Insomnia (CBT-I)
- Short-term medication



**CBT-i Coach** 12+

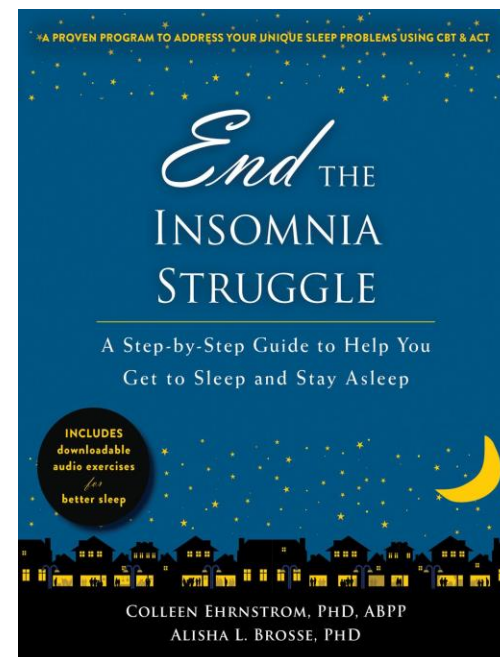
US Department of Veterans Affairs (VA)

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# CIRCADIAN RHYTHMS

- Your **circadian rhythm** regulates the timing of when you are awake and when you are asleep, and when you are active and when you are resting. It can be thought of as your body’s “clock”.
- Circadian rhythms are disrupted after transplant and cellular therapy due to:
  - Being in the hospital
  - Disrupted daily routines
  - Emotional distress
  - Medication/Treatment
  - Decreased activity level



# DISRUPTED CIRCADIAN RHYTHMS

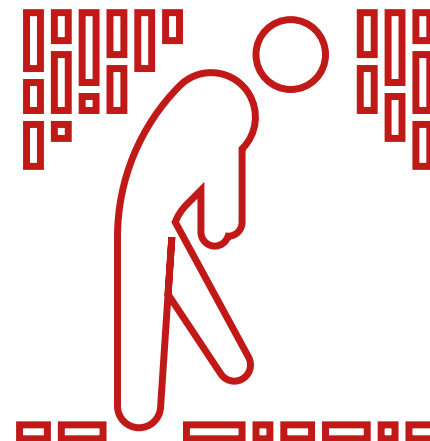
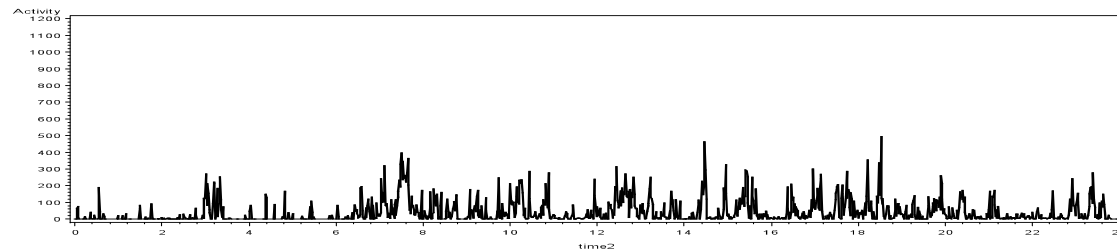
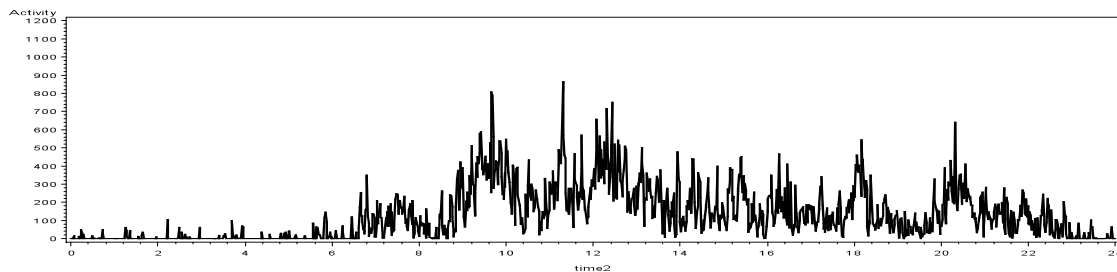
Transplant and cellular therapy



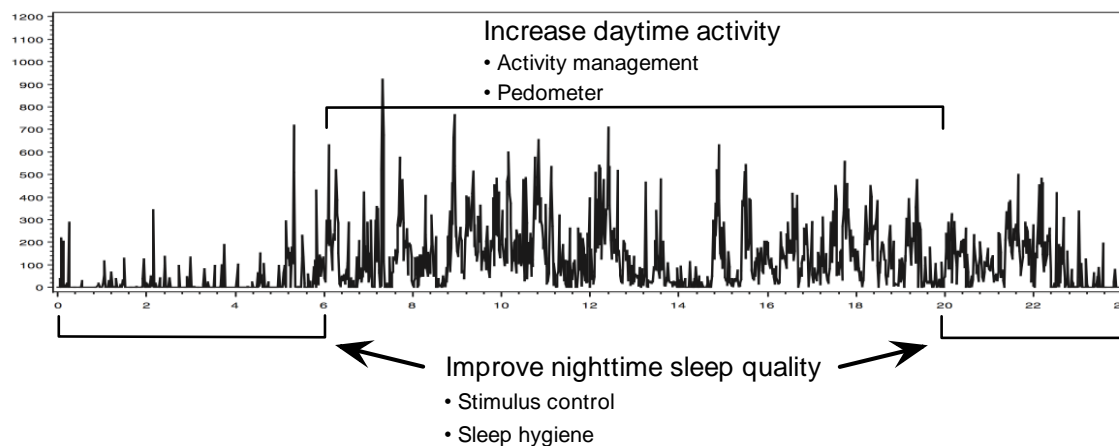
Disrupted circadian rhythm



Fatigue



# CIRCADIAN RHYTHMS: SELF-MANAGEMENT STRATEGIES



# CIRCADIAN RHYTHMS: BRIGHT LIGHT THERAPY

## Choosing a light box:

- Intensity: 10,000+ lux
- Larger is more effective

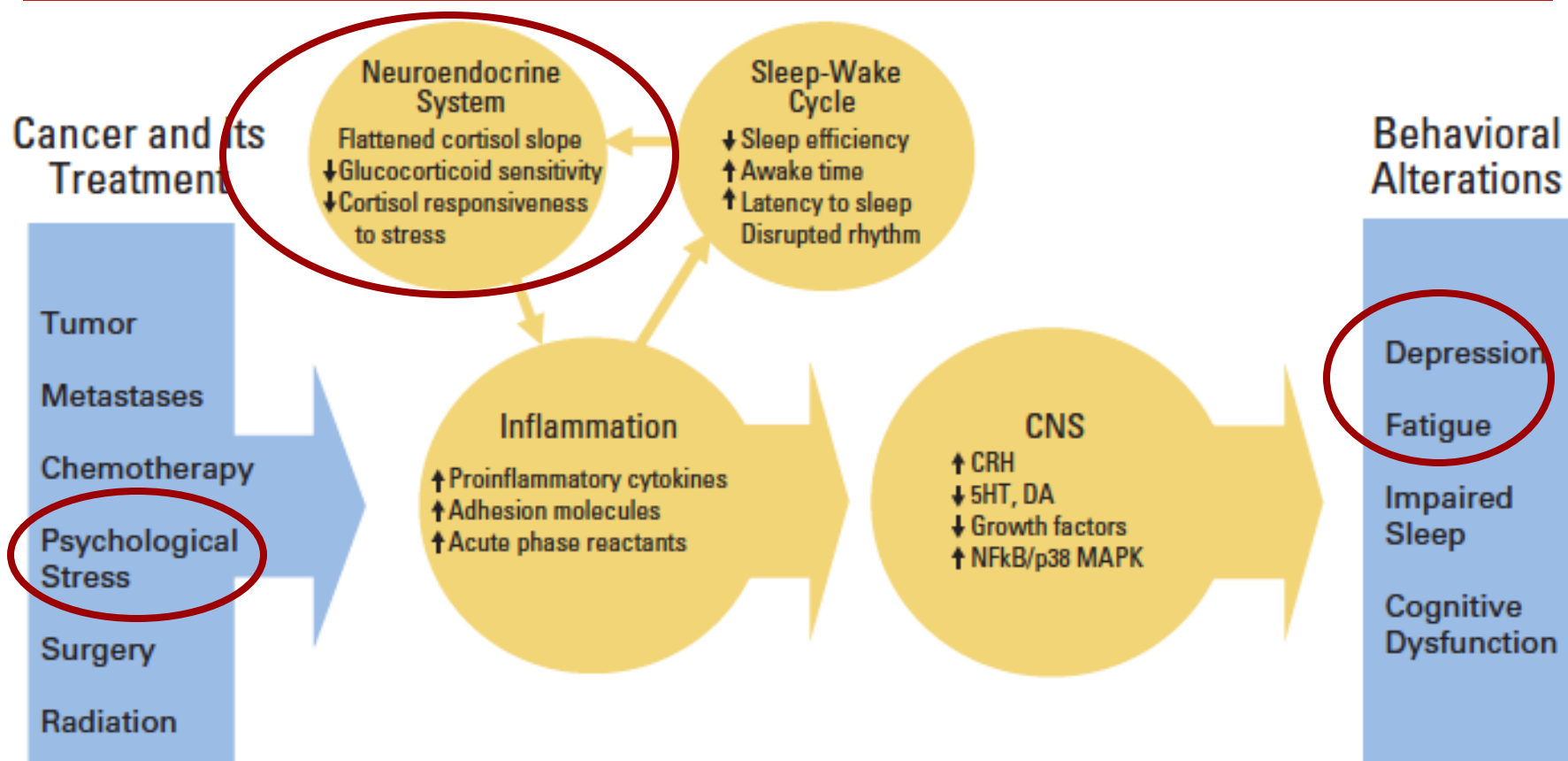
## Using your light box:

- 20-30 minutes close to wake time
- Additional dose mid-day if tolerated



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# FATIGUE IS MULTIFACTORIAL (COMPLICATED!)





# PSYCHOLOGICAL STRESS AND MOOD: SELF MANAGEMENT STRATEGIES

- Regular physical activity
- Prioritize sleep
- Connection and support
- Mindfulness and mind-body practices
- Give painful emotions, thoughts, and memories “room to breathe”
- Do activities that give you a sense of meaning and purpose



# PSYCHOLOGICAL STRESS AND MOOD: WHEN TO GET HELP

- Feeling overwhelmed or unable to cope with anxiety or mood changes
- Anxiety or mood changes are getting in the way of things that are important to you
- Treatment situations provoke anxiety that is difficult to manage
- Weather or climate change?

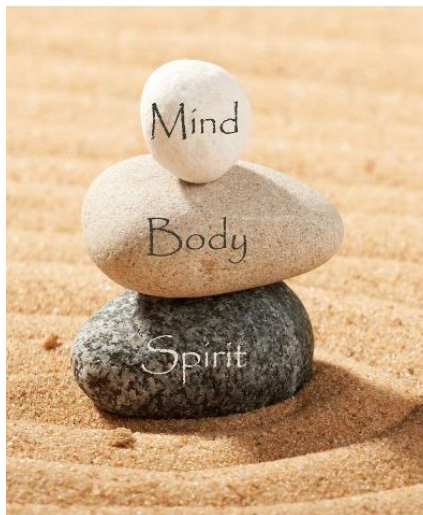
## WHO CAN HELP?

- Hematology/oncology team
- Primary care doctor
- Psychologist
- Social worker, counselor, and therapist
- Psychiatrist





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**QUESTIONS?**



**Carbone Cancer Center**  
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# Questions?



**Erin Costanzo PhD**

Professor, Department of  
Psychiatry, University of  
Wisconsin School of Medicine  
and Public Health

# Let Us Know How We Can Help You



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