

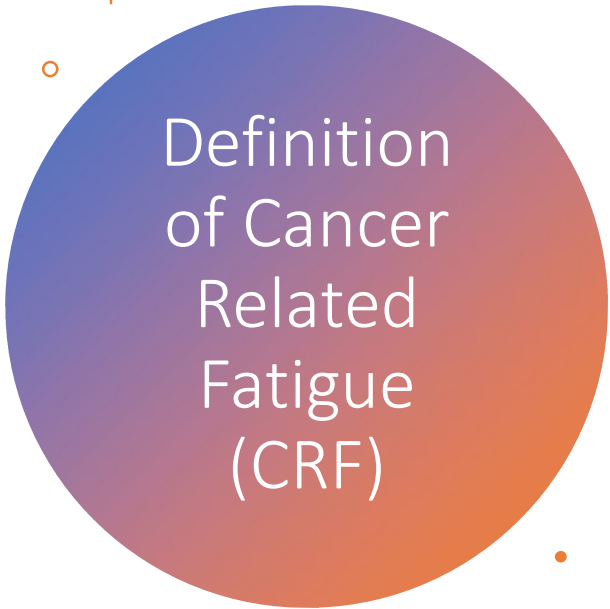
Waldenstrom
Macroglobulinemia
and Fatigue

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Definition
of Cancer
Related
Fatigue
(CRF)

- “CRF is a multifaceted, subjective, physiological state characterized by persistent, overwhelming exhaustion and a decreased capacity for physical and mental work.”

-(Mustian, et al, 2007)

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NCCN Definition

- “CRF is a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion, related to cancer treatment, that is not proportional to recent activity and interferes with usual functioning.”

-National Comprehensive Cancer Network (2018)

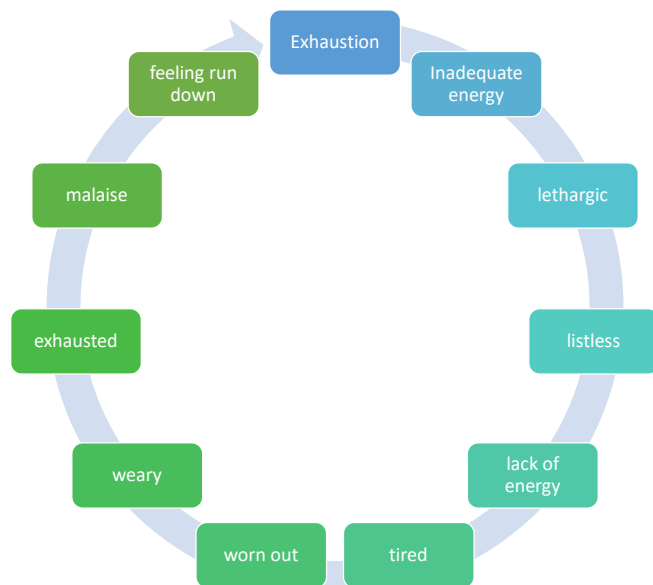
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Cancer (WM) related fatigue...

- Is long lasting
- Does not diminish after a good night's sleep or a restful half hour break
- Is different from the tiredness related to everyday stress
- Feels all encompassing
- Can be difficult to explain to family and friends who are not living with WM

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What are other ways to describe cancer related fatigue?



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Patients
have
described
CRF (Cancer
Related
Fatigue) as
being...

Feeling tired or weak

Feeling like your arms and legs are heavy

Not wanting to do things

Not being able to concentrate

Feeling irritable

Feeling slowed down

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Pervasiveness
of CRF

In the majority of studies, 30% to 60% of patients
report moderate to severe fatigue during treatment.
-(Bower, 2014)

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What Causes WM Related Fatigue?

Cancer-related fatigue can be brought on by a combination of things:

1. Cancer (WM) itself

2. Side effects of cancer treatments like chemotherapy and immunotherapy

3. Depression or anxiety associated with having a chronic illness

4. All of the above

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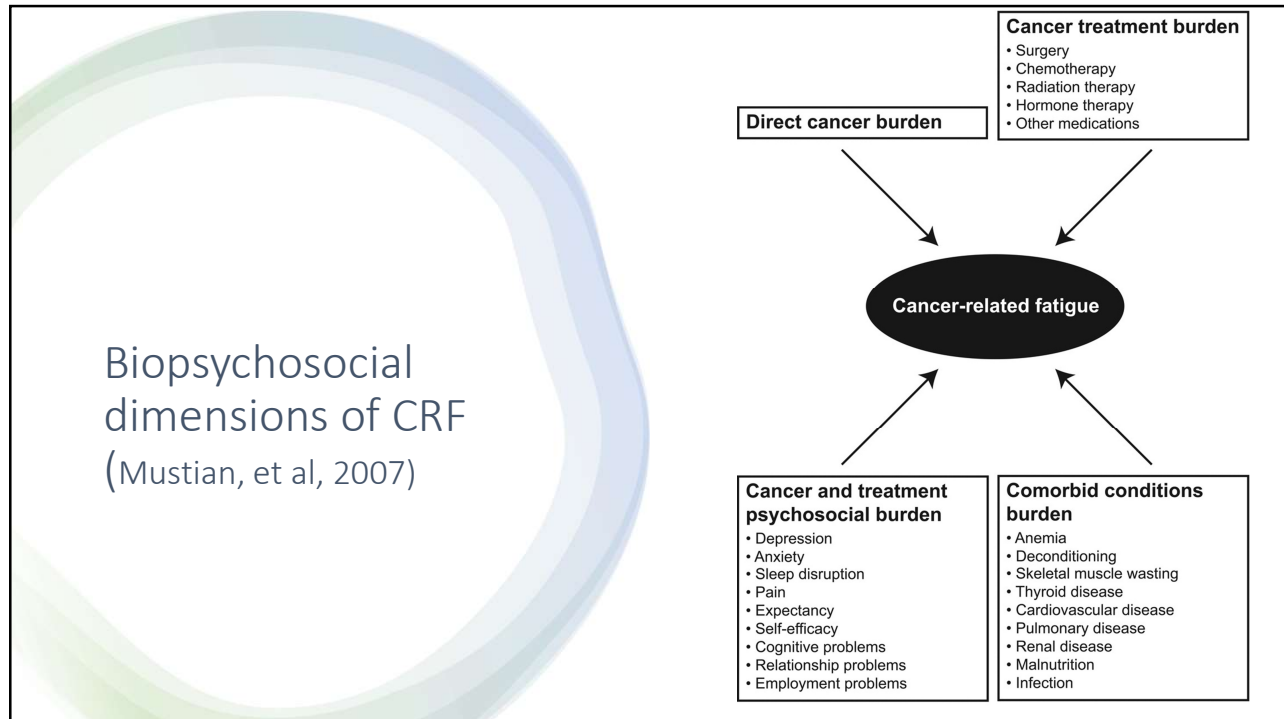


Social Determinants of CRF

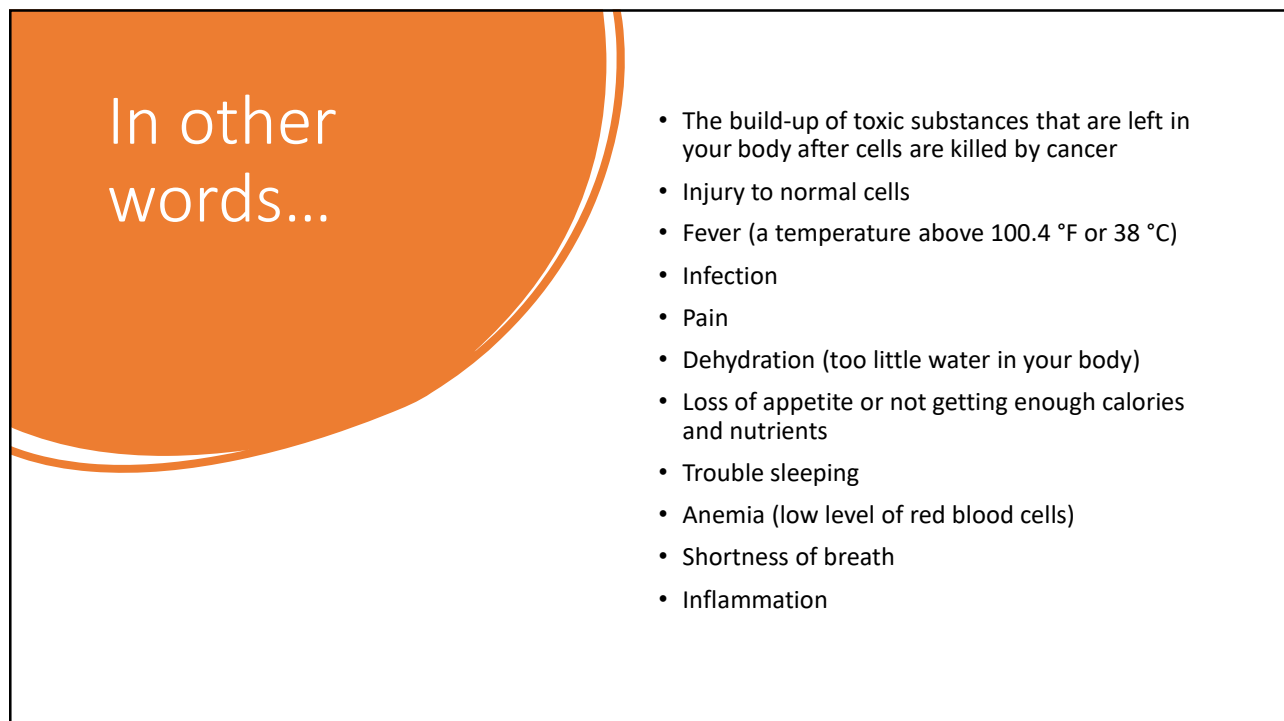
- “Marital status and income have been linked to cancer-related fatigue in some reports, with unmarried patients who have a lower household income reporting higher levels of fatigue. This suggests that contextual factors (e.g., absence of partner who can provide instrumental and emotional support) may influence the experience of this symptom.”

-(Bower, 2014)

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Risk Factors

- Genetic Factors
- History of or current levels of depression
- Treatment modality dependent
- Sleep disturbance or pre-existing sleep dysregulation
- Increased body mass index or pre-cancer inactivity
- History of trauma
- Difficulty coping
- Isolation and low levels of social support

-(Bower, 2014)

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What should I tell my health care provider about my fatigue?

1. Do you feel well in the morning when you wake up?
2. Does the fatigue progress through the day?
3. Do you nap unexpectedly or use excessive amounts of stimulants (e.g. caffeine) to complete your daily activities?
4. Does your fatigue come on gradually or abruptly?
5. Is it a daily occurrence or intermittent/periodic?
6. What makes it better?
7. What makes it worse?
8. How has your life changed because of the fatigue?
9. Is the fatigue mental or physical? Or both?
10. Be specific (e.g. "I was so tired I could not work for 3 days.")

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Pharmacologic Interventions

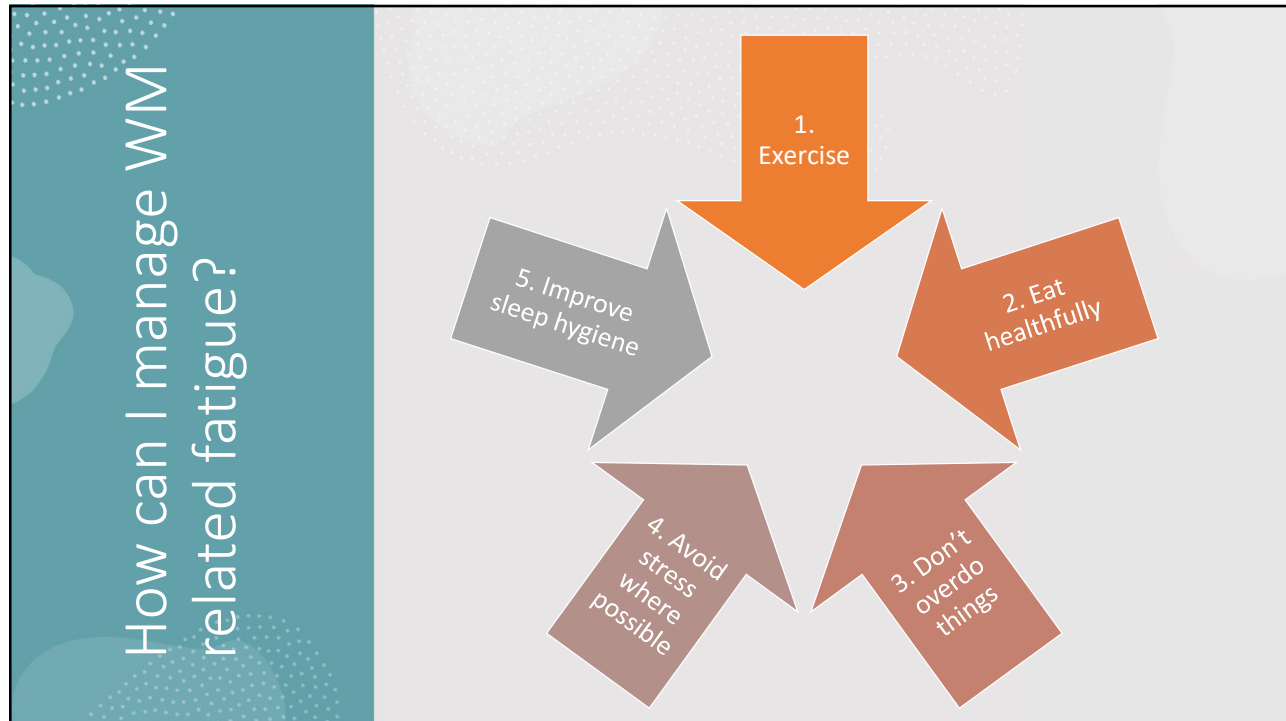
- Corticosteroids (e.g. dexamethasone, prednisone)
- Psychostimulants (e.g. Ritalin, Adderall)
- Hematopoietic growth factors
- Anti-depressants
- Treat underlying medical condition
- Always consult with your physician or health care provider

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Non-pharmacologic Interventions for managing CRF

- Physical activity
- Yoga
- Exercise rehabilitation
- OT/PT
- Massage therapy
- Mindfulness Based Stress Reduction (MBSR)
- Psychoeducation
- Restorative therapy
- Cognitive Behavioral Therapy
- Bright white light therapy
- Nutritional consultation

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“How can I exercise when I’m so tired?”

Do	Do your best to keep doing your current level of activity. Doing some physical activity for 3 to 5 hours a week may help cancer-related fatigue.
Walk	Walk daily, if your healthcare provider says it’s safe for you.
Think about	Think about starting an exercise program that’s appropriate for your treatment. Yoga or gentle stretching exercises may be helpful to include as part of an exercise program.

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OT/PT Interventions

- OTs help to improve activities of daily living (e.g. getting dressed, taking a shower, or cooking a meal.)
- Can help you plan your activities so you're able to do as many physical activities as possible without getting too tired.
- Can also suggest ways that you can save energy and help you practice using special equipment.
- PTs help improve your ability to move by helping you build your strength and balance. They can also help you develop a safe exercise plan that works for you.
- OTs and PTs can help you stay motivated and set goals. They can also help you keep track of your energy level and make changes to your exercise plan as needed.

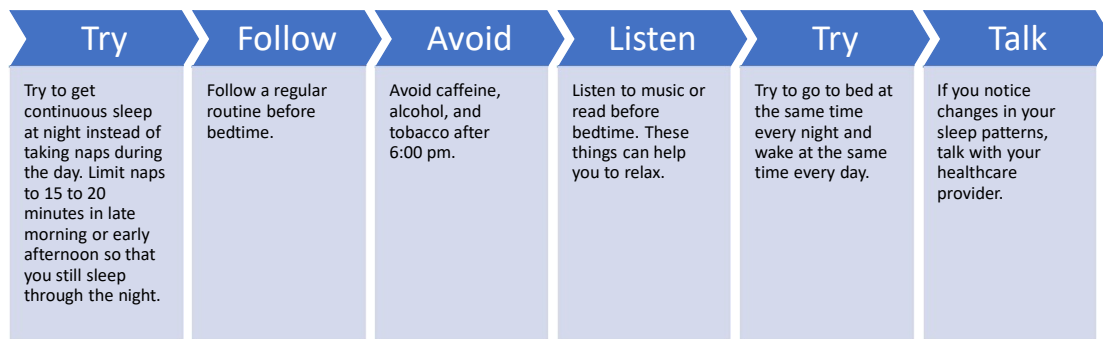
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Research has shown that spending time in nature can offer physical and mental health benefits. Simply taking a short walk in a park, admiring your garden, watching birds in your backyard, or sitting near a lake may be restorative, especially when you're feeling overwhelmed and tired.

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Does how I sleep matter?



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Additional sleep hygiene recommendations

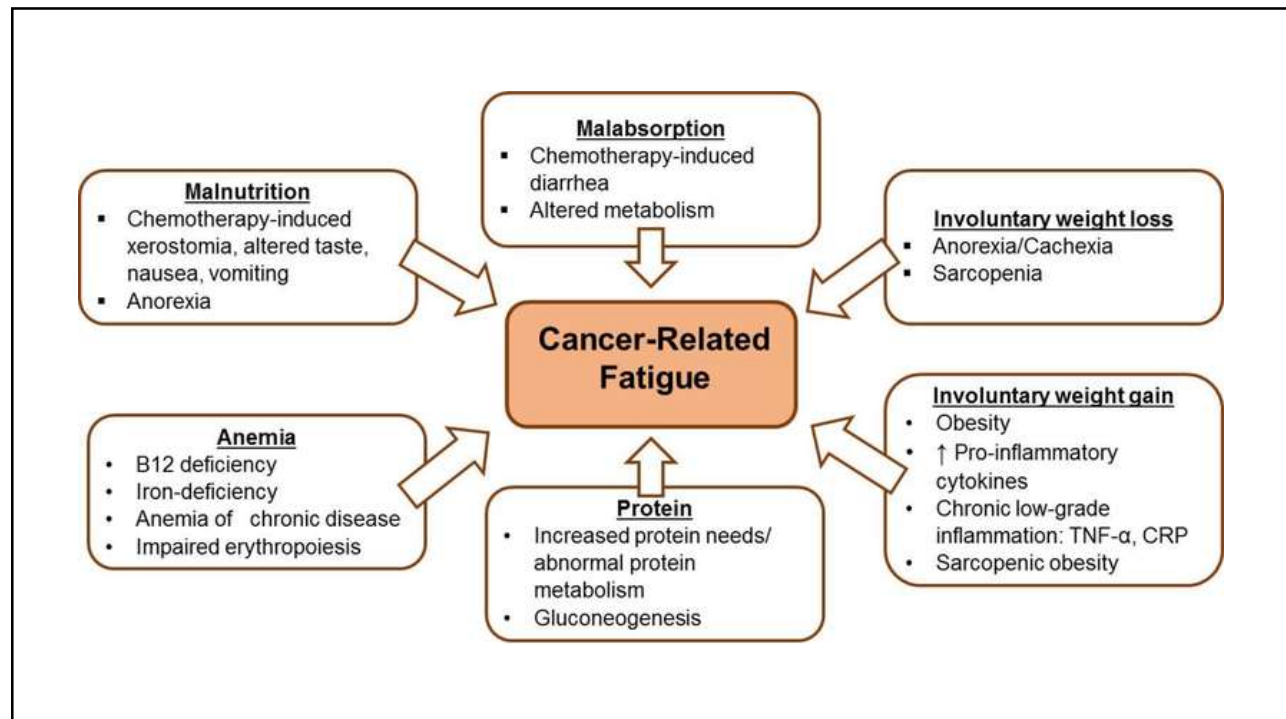
Limit	Limit use of electronics (e.g. phone, TV) to no more than 1 hour before bedtime.
Set	Set limits on work obligations before bed.
Ensure	Ensure room is at a comfortable temperature.
Use	Use bedroom only for sleep or intimate activity.
Try	Try meditation or prayer during periods of wakefulness in the night.
Go	Go to another room if you have been awake for more than 20 minutes.

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How we eat makes a difference with CRF

- Eat small, well-balanced meals and snacks throughout the day.
- Aim to drink 8 to 10 (8-ounce) glasses of water every day.
- Talking with a clinical dietitian or nutritionist may also be helpful. Your healthcare provider can give you a referral to meet with a clinical dietitian.
- Dietary patterns that reduce inflammation, such as the Mediterranean diet and other plant-based diets, appear tolerable to cancer survivors and may reduce fatigue (Englis, et al, 2019)
- Supplementation with ginseng, ginger, or probiotics may improve cancer survivors' energy levels. (Englis, et al, 2019)
- Increased protein intake may help preserve lean mass and body composition. (Englis, et al, 2019)

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Emotional and Psychological Manifestations of CRF

Depression and anxiety

Hopelessness or negative outcome expectancies

Cognitive symptoms (e.g. impaired memory, inability to concentrate)

Reduction in ability to participate in leisure activities

Reduced capacity to sustain meaningful relationships and activities with their families

Feeling demoralized or discouraged about dependency on others

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Depression Signs/Symptoms

Pervasive feelings of worthlessness, hopelessness, or negative mood for more than 2 weeks

Changes in eating (e.g. lack of appetite, under/overeating)

Changes in sleep (e.g. too much/too little)

Withdrawal from friends/family

Finding little or no pleasure in activities that were once enjoyable

Cognitive changes (e.g. loss of focus, short term memory, inability to concentrate)

Suicidal or homicidal thoughts

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Psychosocial Interventions for Stress Management

Progressive Muscle Relaxation

MBSR (Mindfulness Based Stress Reduction)

Yoga

Hypnosis

Cognitive Behavioral Therapy


Counseling

Biofeedback

Support Groups/On-line support

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Bright White Therapy

- Light box with fluorescent light (10,000 lux)
 - At-home use
 - Traditionally used for mood disturbances and sleep disorders
 - Stimulates hypothalamus which regulates circadian rhythms
 - Morning use of 30-90 minutes
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Cognitive Behavioral Therapy

- Therapy focusing on the link between thoughts, feelings, and associated behaviors
- Cognitive strategies (e.g. reframing, finding evidence, facts vs. opinion, challenging dysfunctional thought patterns)
- Behavioral strategies (e.g. education re: behaviorally based stress reduction techniques)

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What are other things I can do?

- Track when you feel energized and when you feel exhausted. Use that log to help you expend your energy when it makes the most sense.
- Consider scheduling your exercise, errands, and appointments for the time of day when you are least tired.
- Ask for help from others, especially when you're feeling low energy.
- It's normal to feel fatigued from WM. Being realistic about your energy levels can provide a sense of empowerment and help you feel more encouraged throughout the week.
- When you're not feeling up to a task, try not to be too hard on yourself.

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Spoon Theory

- Coined by Christine Miserandino in 2003 in her essay "The Spoon Theory."
- Spoons represent finite amounts of energy we each have throughout the day.
- Each spoon is delegated to a specific activity.
- Selective energy rationing

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Take Aways

- CRF is real and pervasive.
- The causes are multifactorial and not pinpointed to one specific cause.
- In some cases, the cause is unknown.
- CRF impacts the majority of cancer patients undergoing treatment and/or post-treatment.
- Management is often multi-layered.
- Three-tiered approach: exercise, cognitive-behavioral strategies, nutritional focus for best results
- Engage your provider.

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