



JAMES L WEST
CENTER *for* DEMENTIA CARE

Reducing Care Partner Stress and Compassion Fatigue

James L. West Center for Dementia Care



Jaime Cobb Tinsley, certified Alzheimer's Educator and Montessori Dementia Care Professional is the Vice President of Dementia & Caregiver Education at James L. West Center for Dementia Care. She earned a degree in Integrated Marketing Communication at Abilene Christian University and has been working with persons with dementia and their families for over 15 years. Since Jaime has been at the West Center, she has developed and implemented a variety of innovative programs that focus on enhancing the quality of life for families living with Alzheimer's disease and related dementias. Jaime also leads collaborative models of training for current and future healthcare workers. These programs have been proven beneficial for professional and lay care partners. Jaime is a Certified Independent Positive Approach to Care™ Trainer, a Master Trainer for Dementia Live®, Compassionate Touch™ programs, Dealing with Dementia, and the Stress-Busting Program for Family Caregivers™.



Course Objectives:

- ▶ Explain the signs of compassion fatigue and burnout
- ▶ Define the symptoms and effects of long-term stress on a person's well-being.
- ▶ Illustrate a “stress profile” and its benefits to precede burnout
- ▶ Describe self-care and support tips that have shown to reduce stress levels
- ▶ Discover practical and proven ways to build resilience and increase coping skills in caregiving

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Perfect Caregiver Wanted

“Wanted: Full Time Caregiver

Must have unlimited stamina, be energetic, alert and attentive, friendly and caring, totally understanding and forever patient. Must be willing to always subordinate own needs to those of the patient and have few if any other commitments. Must know how to handle any situation. Background degree in psychology or human relations preferred, plus basic nursing skills, basic knowledge of medications and their interactions as well as side effects. Must be prepared to work for no pay and expect little, if any, appreciation of above abilities from the patient.”

by Wayne Lavengood, LCSW, MFCC



What is Compassion Fatigue and Burnout?

- ▶ **Compassion Fatigue:** A combination of physical, emotional, and spiritual exhaustion associated with internalizing and being impacted by the emotions and experiences of those who are suffering and whom we provide care.
- ▶ **Burnout:** A state of emotional and physical exhaustion caused by excessive and prolonged stress. It occurs when you feel overwhelmed and unable to meet demands.



Who develops Burnout and Compassion Fatigue?

- ▶ Anyone can, but professional and family caregivers are at high risk. Especially if the person they are caring for is terminal.
- ▶ We are taking care of someone who is getting progressively worse and is experiencing a steady decline.





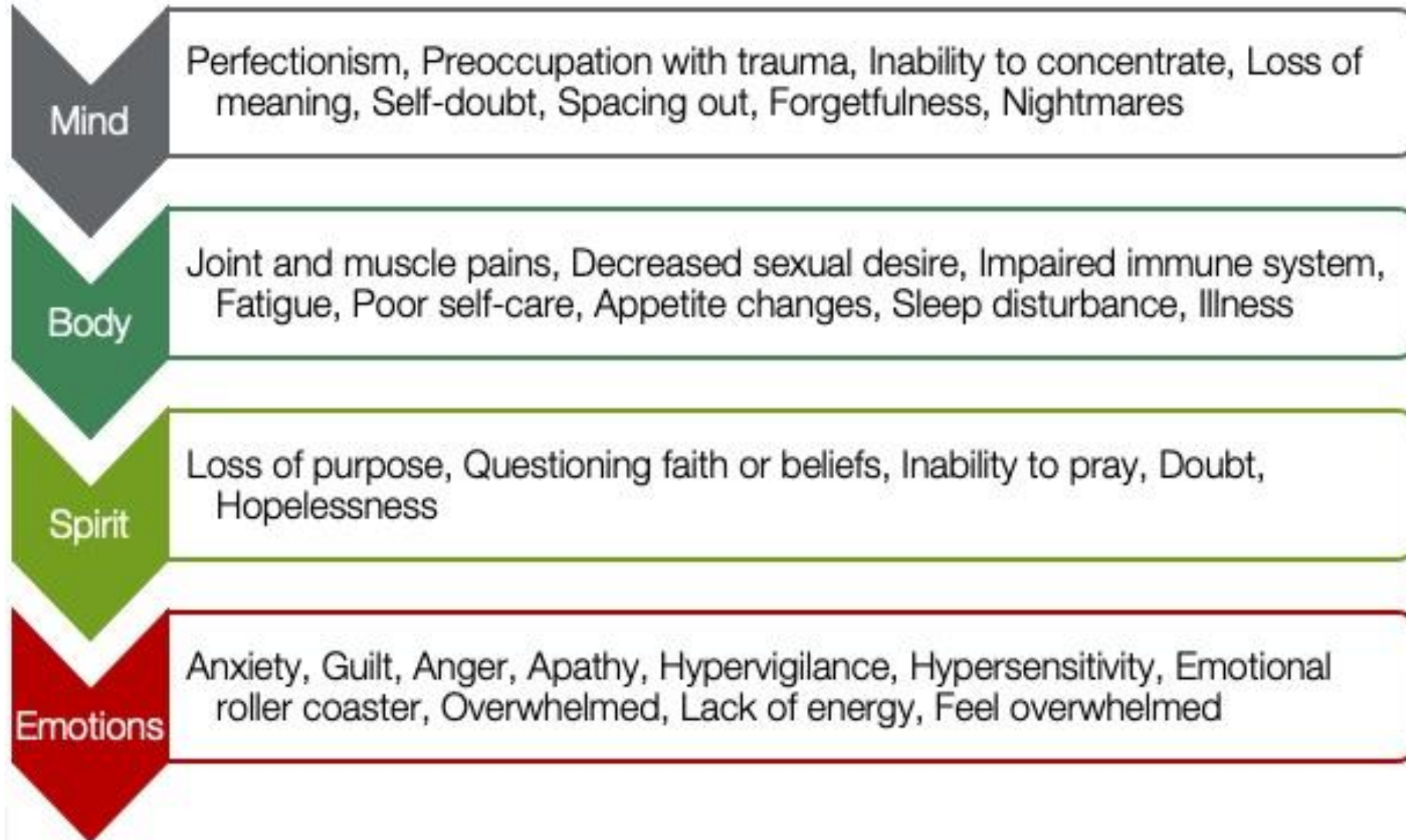
Dementia Affects on Care Partners

- ▶ As the disease continues to destroy brain cells, patients increasingly depend on care partners for assistance.
- ▶ Dementia is not a typical disease model.
- ▶ Care partners for people with dementia are particularly vulnerable to burnout and fatigue due to the long process of decline.
- ▶ Dementia is a progressively worsening terminal disease, but the rate of progression from mild to advanced dementia varies widely from 3 to 20 years.
- ▶ Care partners feel grief and loss, not unlike a death in the family; except that instead of being sudden, it's spread out over years with multiple losses. (Ambiguous Grief and Anticipatory Grief)



What Are the Signs and Symptoms of Compassion Fatigue?

Kathy Pillow-Price, EdD



Are you suffering from Compassion Fatigue and/or Burnout?

- ▶ Do you feel unappreciated?
- ▶ Do you feel like your self-worth is determined by how others perceive you?
- ▶ Do you get anxious around conflict?
- ▶ Have you experienced feelings of hopelessness?
- ▶ Do you have problems separating your personal life from caregiving?
- ▶ Do you have problems sleeping?
- ▶ Do you often feel “used up” at the end of the day?
- ▶ Is your stress affecting your emotional and/or physical health?

Did you answer yes to most of these questions?

If you sense that you are experiencing compassion fatigue, you probably are.



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Caregiver Stress

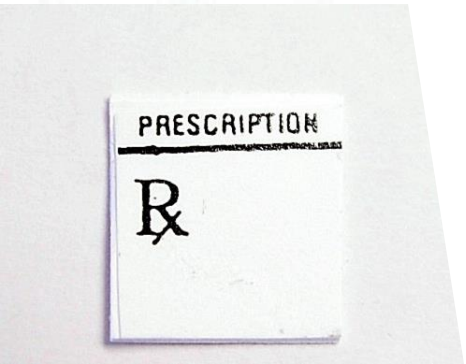


- ▶ Caregiver stress is defined as the emotional and physical strain of caring for someone in need of help.
- ▶ 75% of caregivers who report feeling very strained emotionally, physically or financially are women.
- ▶ Caregivers are often referred to as “the hidden patient”.

Caregiver Stress Statistics

A UCLA Study found the following about care partners:

- ▶ 41% of women care partners and 54% of men care partners are coping by using alcohol
- ▶ 51% of care partners admit to “overusing” prescription medications
- ▶ 16% start to smoke again after sometimes years off nicotine
- ▶ 72% are overweight



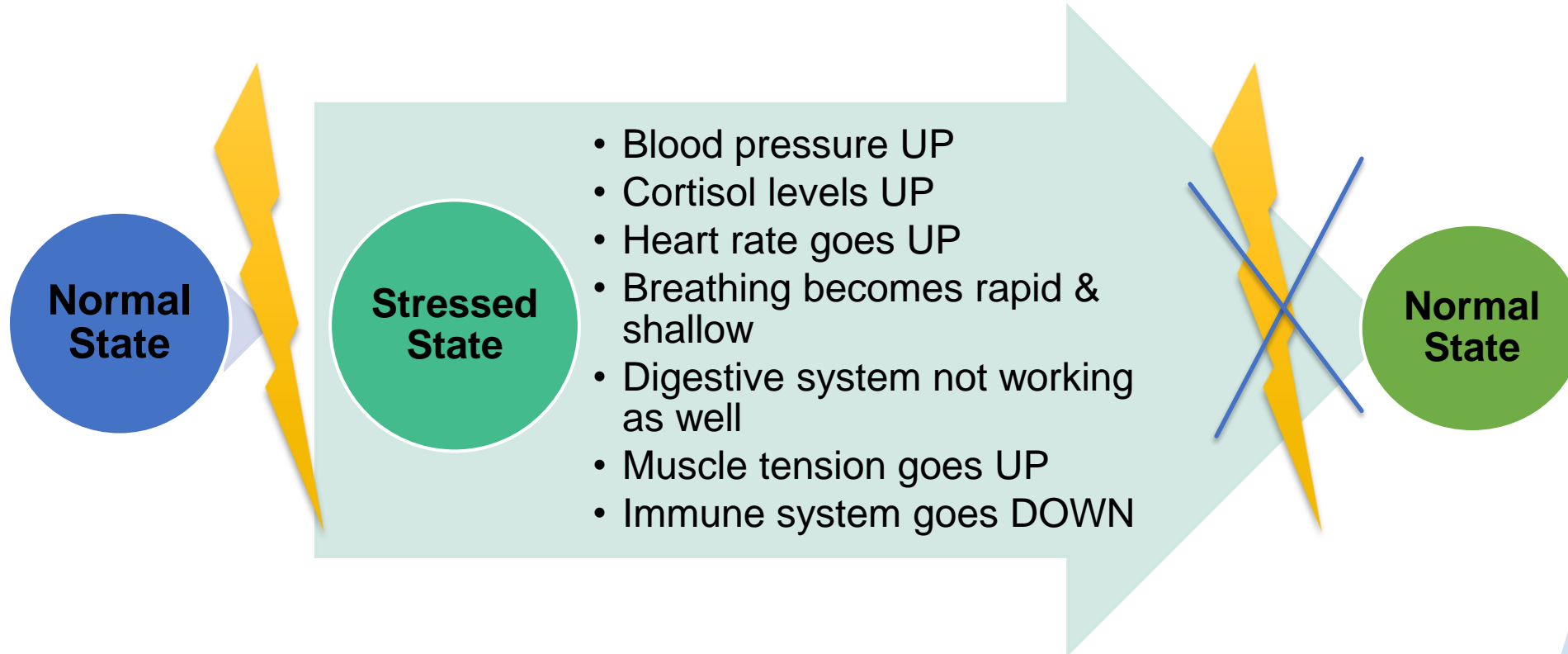
Defining Stress



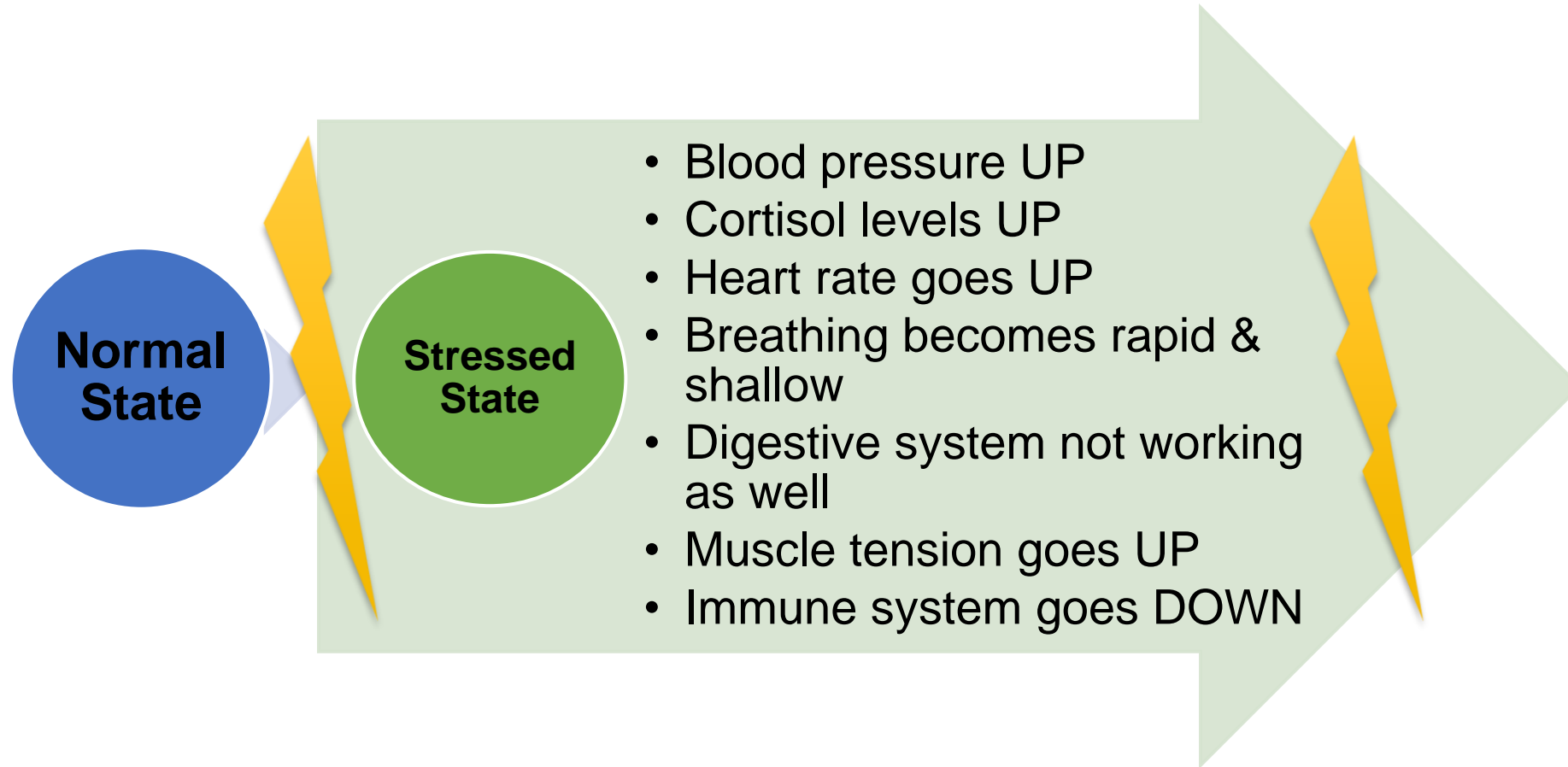
- Feeling troubled or threatened by life.
- How your body responds, mentally, emotionally, physically, to any kind of change, demand or event.
- A normal feeling/response but long-term stress contributes to a range of health problems.



Normal Stress & Relaxation Response



Long-term Stress & Relaxation Response



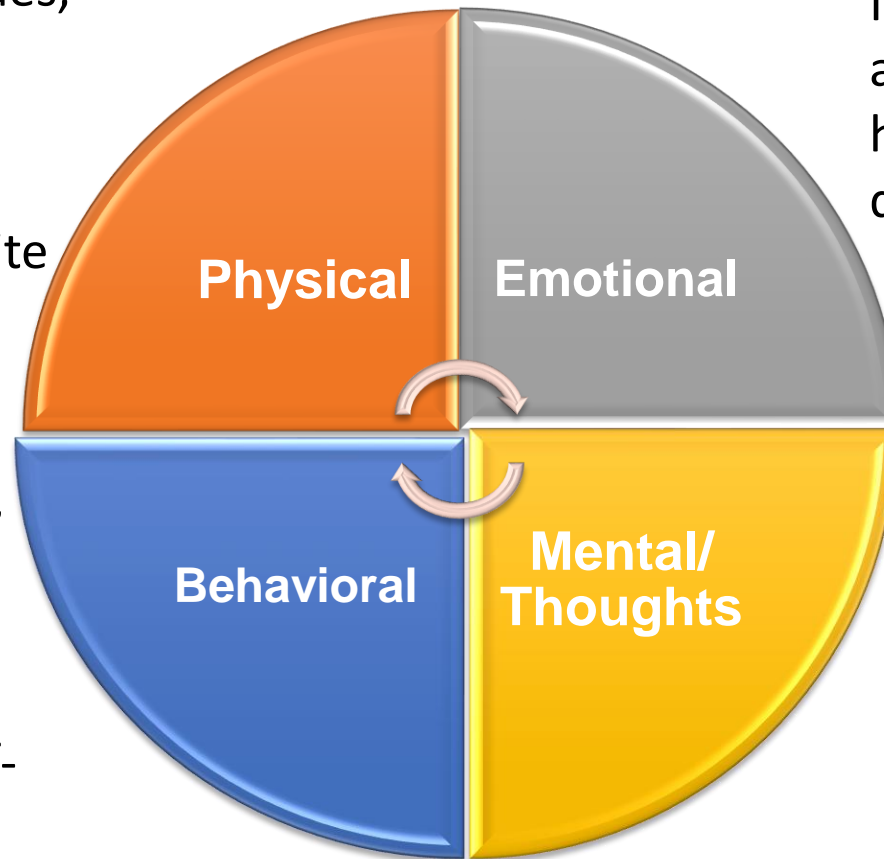
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Effects of Long-Term Stress

Sleeplessness, digestive issues, fatigue, muscle aches, sweating, pain (physical/emotional), increased/decreased appetite

Social & inward withdrawal, blaming, self-medicating, reacting with anger, nail biting, ignoring personal hygiene, deviating from self-care routines.



Increased anger, guilt, sadness, anxiety, denial, resentment, hopelessness, self-doubt, difficulty concentrating

Increased thoughts of worry, anxiety, forgetfulness, confusion, sadness, lack of focus, rumination and overthinking, Loss of interest in work or play



Know your personal “stress profile”

How do you define stress?
What causes you stress?
What are your warning signs?

Understanding your triggers and stress symptoms will help you from running into a wall and take timely action using a positive coping strategy.

Ask Yourself:

- ▶ When I am stressed, I typically think thoughts like:
 - ▶ *“This is too hard; Nothing will ever change; I am not good enough”*
- ▶ When I am stressed, this is what I notice in my body: (physical)
 - ▶ *Tension headaches, stomach pain, fatigue*
- ▶ When I am stressed, this is how I tend to react/ behave:
 - ▶ *Withdraw inward and disconnect; lash out on others; have no happiness or joy in the day*



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When the health and well-being of a care partner is threatened, the care receiver is in jeopardy.



No matter how hard I try,
I cannot give everyone
around me what I do not
have myself.



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What is Resilience?

- ▶ The capacity to recover quickly from difficulties
- ▶ Toughness
- ▶ The ability to adjust easily to adversity or change
- ▶ The ability to return to its original shape and size after being compressed



Personal Resilience & Stress Management

- ▶ The ability to maintain well-being and effective functioning in the face of high levels of disruption.
- ▶ Adapting well in the face of adversity, trauma, threats, and stress
- ▶ Bouncing back from difficulties with family, relationships, health, work, home, finances, etc.



Increased Risk of Death for Care Partners

- ▶ Care partner spouses between the ages of 66 and 96, who are experiencing mental and emotional strain, have a 68% higher risk of dying than people the same age who are not caregivers.
- ▶ According to sharecare.com, adult children, have a 63% higher risk of dying over the course of caregiving for 4 or more years.

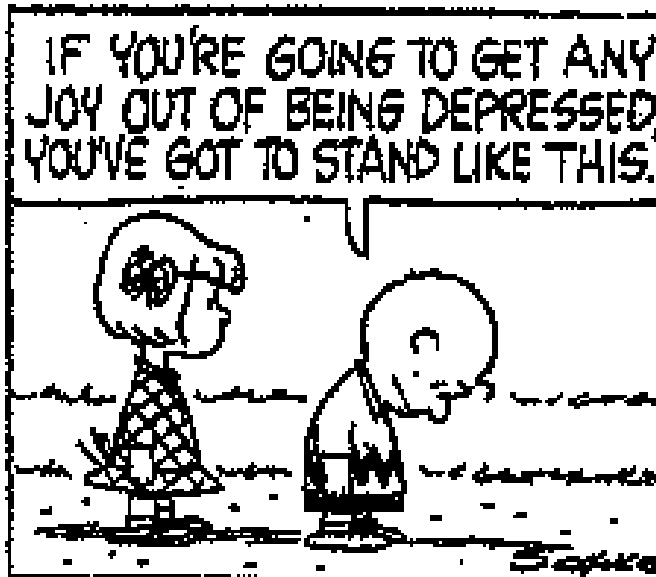
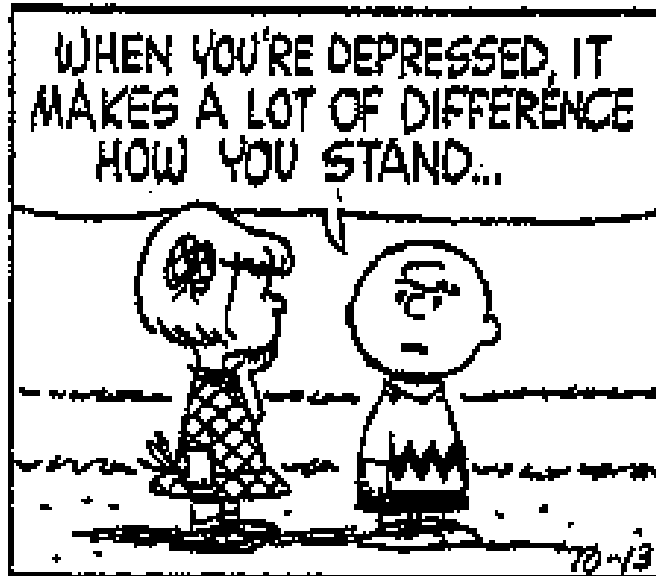
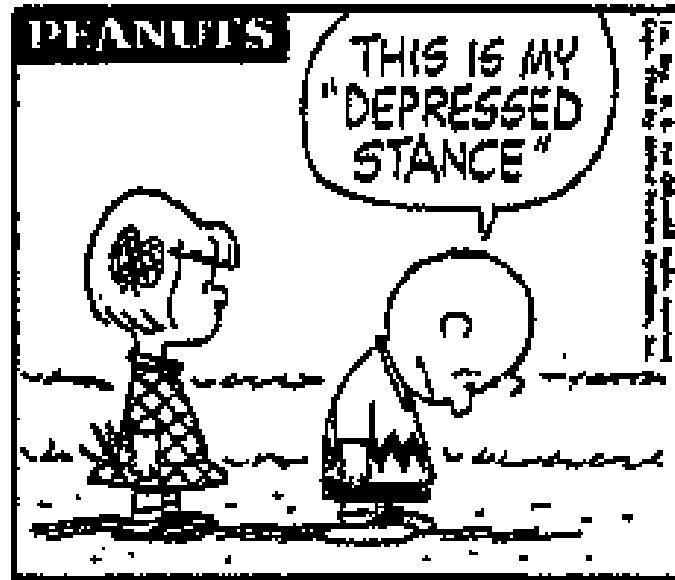


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PEANUTS®

By Charles M. Schulz



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MENTAL

AWARENESS
ADAPTABILITY
DECISION-MAKING
POSITIVE THINKING



PHYSICAL

ENDURANCE
NUTRITION
RECOVERY
STRENGTH



SOCIAL

FAMILY
COMMUNICATIONS
CONNECTEDNESS
SOCIAL SUPPORT
TEAMWORK



SPIRITUAL

CORE VALUES
PERSEVERANCE
PERSPECTIVE
PURPOSE

Resilience Provides Balance to Life



Best Support Tips

- Accept your own limits: ask for and accept help
- Create a support team
- Get organized, prioritize, establish a routine
- Make your own health your first priority
- Whether you feel like you need a break or not, schedule some personal time, organize it, and stick to your schedule.
- *Carefully guard any time you do manage to set aside. It is a non-negotiable.*



(Your Name) Caregiving Inc.

VP of Caregiving Inc.
(trusted sounding board)

Day/Night shift care
partner

Doctor & Pharmacist

Hospice Care partners

Cooking & Cleaning

Legal/Financial
paperwork/research

To be a successful care partner you must take care of yourself so you can take care of others.

Let go of the small stuff and set priorities. Learn to delegate and allow others to help you.



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Learn to Breathe

Slow, Deep, Abdominal Breathing

- Slow, deep breathing exercises have been shown to:
 - Lower blood pressure and heart rate
 - Increase heart rate variability, a sign of cardiovascular health
 - Create a sense of calm
- These exercises work well for managing anxiety, insomnia, and fatigue, they are free, can be done anywhere at any time, and anyone can learn them.
- Sigh Breath
 - Take in a deep breath (suck in all the air you can)
 - Exhale fully pushing all the air out of your body with a “sigh”
 - Relax and repeat
- 4 x 4 breathing exercise
 - Breathe in through nose for a count of 4
 - Hold breath for a count of 4
 - Release breath for a count of 4
 - Relax for a count of 4 and repeat



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Eat Your Stress Away

Robyn Berzin, MD says “we need to learn how to use food to lower inflammatory stress in the body. The typical response today is to “reward” our stressed-out nervous systems with sugar and fat, a learned behavior reinforced by the prevalence of nutrient-poor, calorie dense foods around us.

Instead, we need to teach people which types of foods to eat to hydrate the body, lower oxidative stress, and give cells more energy.

This style of eating is what we teach at my medical practice, where we advocate for a diet high in greens, lean protein, and healthy fat, and low in sugar, processed carbs, and chemically preserved foods.”

The Stress Epidemic and the Search for the Modern Cure | HuffPost Life



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Meet The 'MIND' Diet

(It Slashes Alzheimer's Risk By 35%)

The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) Diet is proof that noshing your way to brain benefits doesn't have to involve following a strict regimen.



At least three servings of whole grains a day



A salad and one other vegetable a day



A glass of wine a day



A serving of nuts a day



Beans every other day



Poultry and berries at least twice a week



Fish at least once a week



Limit unhealthy-brain foods, especially butter (less than one tablespoon a day), cheese, and fast or fried food

Source: Rush University Medical Center
Alzheimer's & Dementia: The Journal of the Alzheimer's Association

YAHOO! HEALTH

Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND)

- Hybrid of Mediterranean & DASH Diet
- All 3 diets found to reduce risk of cardiovascular conditions
- MIND showed those who had high adherence reduced AD risk as much as 53% & those who had a moderate adherence still benefitted at 35% reduced risk.

Easy to follow - 15 Dietary components

10 brain healthy food groups

- Green leafy vegetables
- Nuts
- Beans
- Fish
- Olive Oil

Other Vegetables

Berries

Whole Grains

Poultry

Wine

5 unhealthy groups to limit

- Butter/Stick Margarine
- Cheese
- Red Meats

Sweets/Pastries

Fried/Fast Foods



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Use Movement for Stress Relief

“The body is an excellent tool for channeling stress through movements like yoga, running, and tai chi.”

- Robyn Berzin, MD

Movement is one of the greatest, reliable, and safest ways of managing stress.

[The Stress Epidemic and the Search for the Modern Cure | HuffPost Life](#)



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Using Music to Relax

- ▶ Emotions and memories are tied to music - music influences our emotions!
- ▶ Each person gives their own meaning to music or has different responses to music
 - ▶ Select music that you find relaxing, peaceful and soothing for the purpose of relieving stress
- ▶ Get comfortable - have a nice space to listen
- ▶ Give your at least ½ hour for dedicated relaxation time
 - ▶ Remove distractions and possible interruptions
- ▶ Have it on in the background to create a relaxing atmosphere
- ▶ Use music several times a week as either a pause in stressful situation, or as “preventative” on non stressful situations for long lasting benefits



Benefits of Art to De-stress

No artistic ability is necessary!

All you need is 20 minutes 😊

- Most of the studies done have people drawing or coloring for about 20 minutes.
- Drawing and coloring may be helpful for stress as the act itself brings us to the present moment—it can be an exercise in mindfulness.
- Art is a form of self-care. Regular devotion to a hobby that brings happiness, satisfaction.
- A positive outlet to “get lost” in; or become engrossed. It’s akin to meditation.
- Helps take you mind off things for a moment. It is hard to ruminate on your problems when you are creating.
- Improves cognitive ability and can increase self-esteem.



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Thoughts & Perceptions to Reduce Stress

- Negative or distorted thinking damages confidence, harms performance and paralyzes mental skills.
- Distorted and negative thoughts turn into beliefs and cause real damage if we let them.

“I can’t believe I just said that I am so stupid”

“I can’t do anything right”

“I’m not getting any better at this”

“This is too hard”

“There is no way this will work”

“The greater part of our happiness or misery depends upon our dispositions, and not upon our circumstances.”

– Martha Washington



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Two Arrows - A Buddhist Metaphor

“If you get struck by an arrow, do you then shoot another arrow into yourself?” - Buddha

- ▶ Arrow #1 represents pain/negative events. Pain is part of life and will happen to all of us. Whether it's a minor pain (e.g., another doctor's visit, a boring task) or major pain (e.g., a diagnosis, the loss of a loved one). It's inevitable; we will all face painful events that we cannot escape.
- ▶ Arrow #2 represents suffering. Suffering is the result of how we react to the pain. We may react to the pain in ways that create suffering for ourselves. For example, we may condemn ourselves, complain, point the finger, or over-analyze. By doing this, we make the pain even worse.
- ▶ While the first arrow is inevitable, the second one optional.

The 2nd Arrow

- Consider the painful/negative experience (1st arrow)
- Stop and think about what you are thinking!
 - What did you *think and do* that created additional pain or negative outcome on top of the initial negative event? What kind of thoughts and actions may have caused you to fire a second arrow on top of the first one?
- Ask yourself: What can I do right now, to stop firing more arrows?
 - You may decide to focus on your breath to move away from negative thoughts.
 - You may also simply stop doing what you are doing, take a pause and some time to reflect.
 - Make it a habit to use the two-arrows metaphor when you notice that you are suffering.



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The 2nd Arrow and Distortions in Thinking

Suffering = Distorted thinking or twisted thoughts. Distorted patterns of thought that cause us to view reality inaccurately (misinterpreted a situation); usually in negative ways.

2nd arrow - Negative attitudes, thoughts, reactions and emotions are caused by thought patterns that distorted or twisted.

▶ Distorted thoughts can turn our perceptions to:

- one-sided
- inaccurate
- unfair
- false
- bitter

▶ These distorted thought patterns can cause:

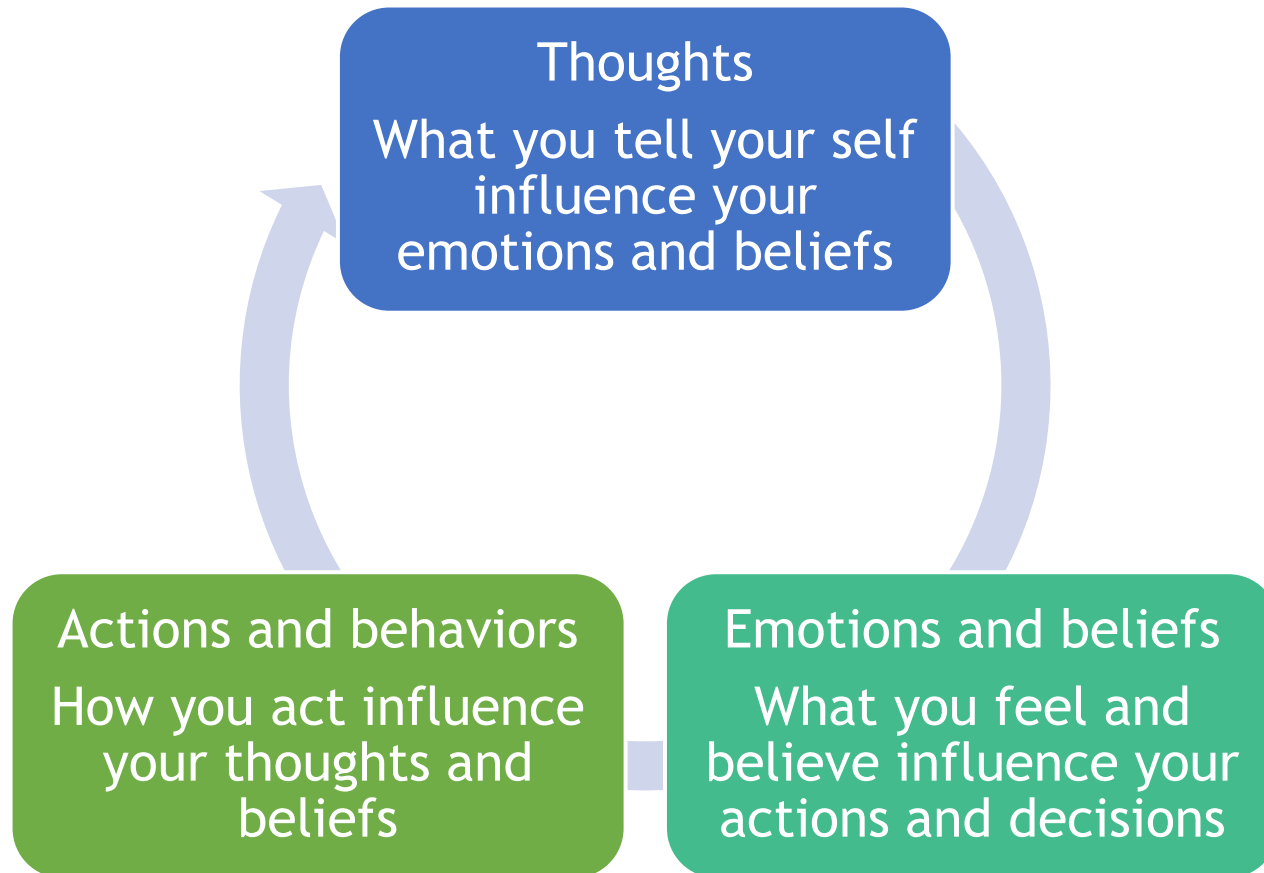
- depression
- anxiety
- self-criticism
- low self-esteem
- hopelessness



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When you change your thoughts, you change how you feel, and you will change your actions!



More Ways to Avoid the 2nd Arrow

- We have the power to control our thoughts, emotions and behaviors!
- Actively reflect on your strengths, accomplishments, and successes - DAILY!
 - Write them down
 - Share them with others
 - It takes daily discipline and time to change thought patterns.
- Keep track of your positives every day for a week. What does this record tell you?
 - What are your accomplishments & strengths
- Every time you or someone else does something positive, praise yourself or the person.
 - Will this praise increase or decrease the positive behavior?





Avoiding the 2nd Arrow

- Don't say anything to yourself that you would not say to anyone else
- Send a thank you note and practice gratitude
- Identify areas of change
- Surround yourself with positive people
- Work on your spiritual needs - focus on your values
- Remember why you care
- The goal is progress not perfection.
- We don't have to go through this alone - talk to trusted people who can help us "see" different perspectives and challenge distorted thought patterns.

Why are you?

Why do you get up in the morning?

What keeps you awake at night?

When are you most alive?

What does being successful mean to you?

How might you apply your gifts to a pursuit that is of deep interest to you and helps others?

What can you do to make a difference in one person's life, today?

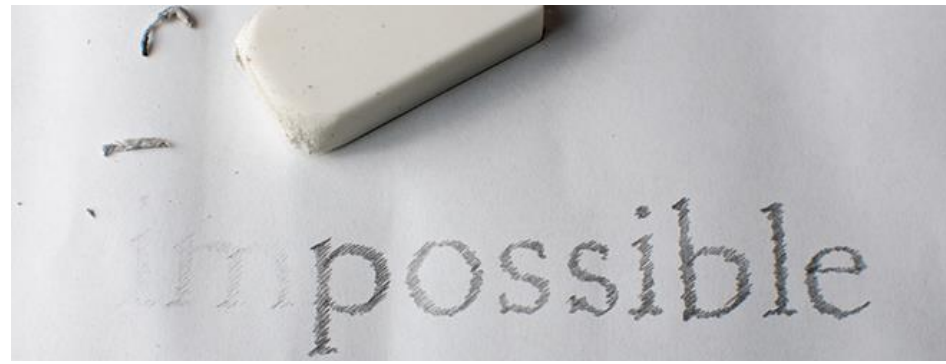
If you say yes to living purposefully, what do you say no to?

If you met an older version of yourself, what sage advice would they give you



Purpose Reflection Activity

Mantra/Identity Statement



- Recite a personalized identity statement that emphasizes a positive quality and specifies something you want to become in five seconds, such as *“I am confident and passionate,”* or *“I’m consistently excellent every day as a care partner, wife, and mother.”* *“I can do anything for a little while.”*
- **“A hard moment does not mean a hard rest of the day”**
- **“This will not last forever.”**
- **“I am resilient!”**
- **“This, too, shall pass.”**
- **“I can ride this out and not let it get me down.”**
- **“May there be joy in this day, may I bring joy to others.”**
- **“I am choosing grace in this moment.”**



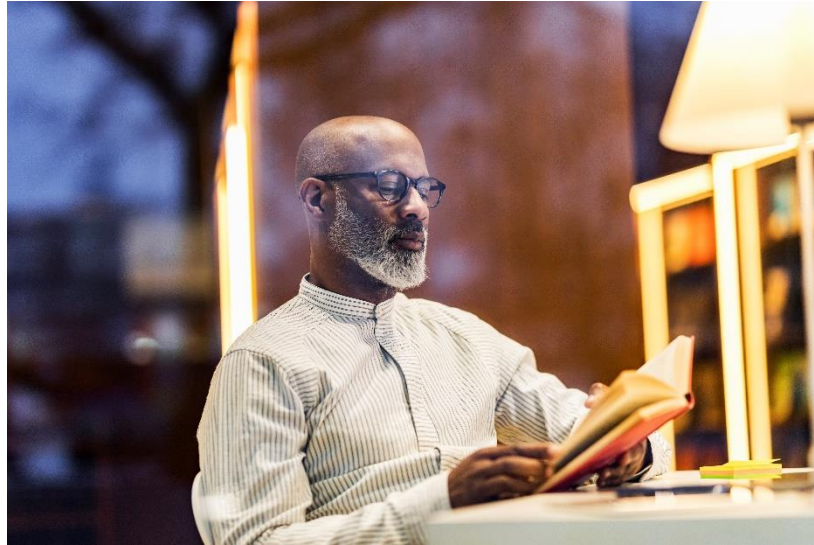
Helping Others Be Resilient

- ▶ **Affirmation:** Notice and point out another's resilience. They may not even realize it. It will help them build their own awareness so they can continue to develop it.
- ▶ **Environment:** ensure reminders and reinforcements by encouraging others rather than pointing out errors, encourage rather than discourage
- ▶ **Support:** provide assistance in areas where others may be lacking
- ▶ **Role Model:** others see how you deal with challenges, bring a positive attitude and strong set of problem-solving skills to help others do the same



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James L. West Center for Dementia Care

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James L. West is a faith inspired, not-for-profit organization serving persons impacted by dementia. As a trusted expert, we provide personalized, innovative care and support for families, as well as specialized education for caregivers, healthcare professionals and the community at large.

Residential & Respite Care
West Center Day Program
Dementia & Caregiver Education

www.jameslwest.org
www.jameslwestLEARN.org

817-877-1199



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