

Supporting Our Caregivers In Alzheimer's Disease and Related Dementias (ADRD) Learning Study



S.O.C.I.A.L

A 6-week program designed to reduce stress for caregivers of
persons living with dementia

MEET THE RESEARCH & CLINICAL TEAM

We are a team at the Center for Health Outcomes and Interdisciplinary Research (CHOIR) and Center for Aging and Serious Illness (CASI) at Massachusetts General Hospital. We are passionate about improving the well-being of caregivers!



Dr. Christine Ritchie, MD, MSPH
Role: Multiple Principal Investigator



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Role: Study Coordinator



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Role: Study Coordinator

We are here to help!



We're here to help with:

- Scheduling the group sessions and assessments
- Addressing issues or challenges you might face attending group sessions

Role:	Study Coordinators
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MSW, LICSW

I'm here to help with:

- Facilitating group sessions
- Learning and practicing Mindfulness and Self-Compassion skills!

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INTRODUCTION

Thank you for participating in the Supporting Our Caregivers In Alzheimer Disease and Related Dementias (ADRD) Learning program! This program was designed to help caregivers of persons living with dementia decrease their stress and improve their well-being. Caring for a person with dementia can be hard. SOCIAL can help.

What will the SOCIAL Program do?

In this program we will teach you skills to manage stress related to being a caregiver of an individual with dementia. We will focus primarily on managing stress associated with your loved one's behavioral and mood symptoms. By successfully managing stress, you will increase your well-being and your loved one's quality of life. Over the course of this 6-week program you will learn how to:

1	Quickly identify and/or anticipate stress triggers.
2	Use mindfulness exercises to regulate emotions and act with awareness.
3	Use strategies to successfully respond to or avoid challenging behaviors through trigger identification.
4	Practice responding to challenging behaviors through problem-solving scenarios.
5	Learn and practice self-compassion and compassion towards others.

By the end of the program, you will be able to better manage your loved one's behavioral symptoms by first regulating your own emotions and then implementing behavioral management skills.

As a result of this program, we hope that you will experience reduced stress and increased well-being.

We hope that your loved one will experience a reduction in behavioral symptoms and increased well-being.

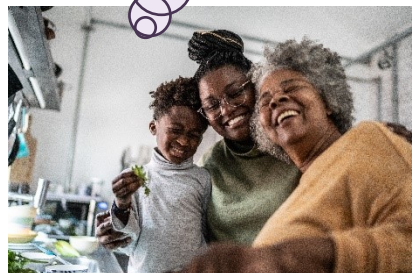
Being a caregiver is BOTH rewarding and difficult



I feel alone as few people understand some of the stressful parts of caregiving



I feel a need to learn tools to support myself and my loved ones



LOGISTICS

WHAT ARE THE PROGRAM MATERIALS?

- This manual
- For your convenience, you can access most skills and audio recordings at the SOCIAL study website: www.social1studymgh.com

WHAT ARE THE PROGRAM EXPECTATIONS?

- **Join 5 minutes before the scheduled session time.**
- Participate in the entire session and **keep your camera on.**
- If you need to attend to your loved one or need to turn your camera off, just please let the group know.
- **Be open to the different perspectives and** experiences of other caregivers.
- **Complete home practice** exercises daily to gain the most from the program! We will send you daily reminders to support you in practicing the skills learned. Please let us know if you don't want to receive them.
- **Let the clinician/facilitator know if you need to miss a session.** If you miss a session, please review the content you missed and plan to come 20-30 minutes before the next session. The clinician will review the material with you.

We are excited to spend the next 6 weeks together learning skills to decrease stress and increase your wellbeing.

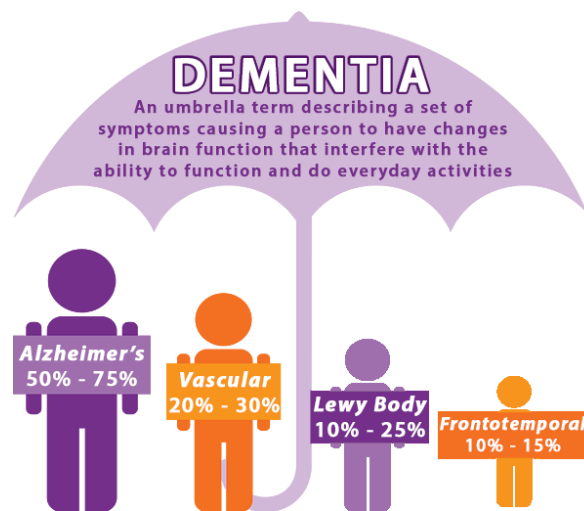
Any questions? Please reach out!

SESSION SCHEDULE

SESSION	SKILLS	DATE
1	Getting to Know Your Stress Response	
2	Introduction to Mindfulness	
3	The Skill of Compassion and Managing Challenging Behaviors	
4	The Skill of Self-Compassion While Caregiving	
5	Communication Skills with Persons with Dementia	
6	Putting It All Together	

****Please call our study team if you are unable to attend a session at 617-726-9623 or 617-726-1279 or email socialstudymgh@mgb.org****

A NOTE ABOUT DEMENTIA



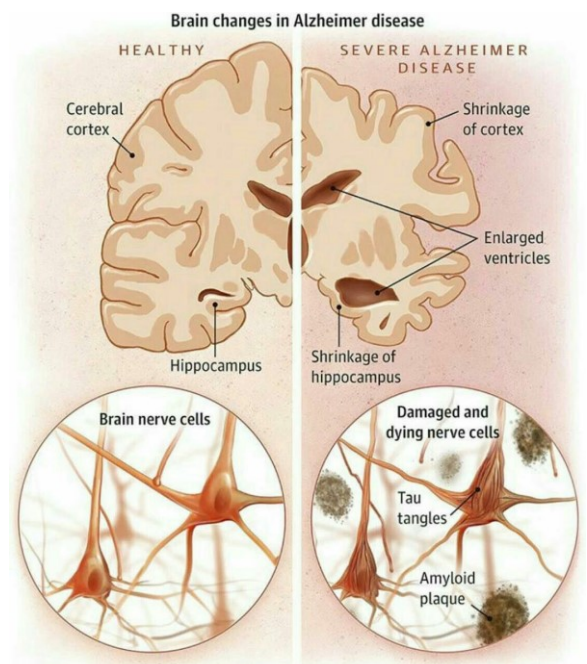
Graphic taken from: <https://www.alztennessee.org/info/related-dementias/dementia-the-basics>

Dementia is a disease of the brain.

Dementia is a progressive brain disease where nerve cells become damaged and die. It usually starts in the hippocampus, which is the area of the brain in charge of memories.

As the disease progresses, it affects many parts of the brain; not just parts involved in memory, but also language, movement, and behavior.

Learning about how the brain changes in dementia can help decrease the stress and confusion that may come from seeing your care recipient have difficulty with daily tasks or have behavior changes.



Graphic taken from [Alzheimer Disease | Dementia and Cognitive Impairment JAMA Network](https://jamanetwork.com/journals/jama/fullarticle/22471) found at <https://jamanetwork.com/journals/jama/fullarticle/22471>

Dementia and Its Effects on Different Parts of the Brain

Persons living with dementia often have different behavioral symptoms, depending on the type and stage of their particular dementia.

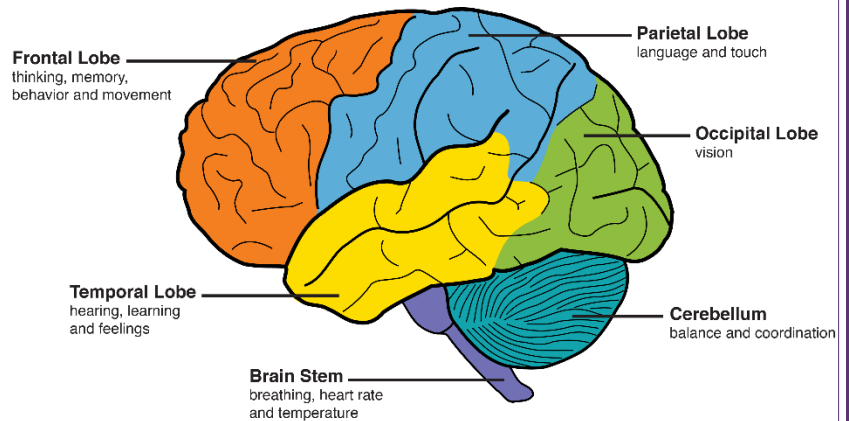
The kind of symptoms a person has depends on which part of the brain is affected by the disease process.

How the brain is affected and the symptoms someone has usually changes as the disease progresses to involve different parts of the brain.

Different types of dementia tend to affect certain parts of the brain. For example, the part of the brain that is important for forming new memories is usually affected early on in Alzheimer's Dementia, which is why short-term memory loss is often one of the first symptoms of AD. In Lewy Body Dementia, visual hallucinations and sleep changes may be more prominent at the beginning.

Common symptoms in dementia include difficulties with communication, planning and organization, navigation, personality changes, and psychiatric symptoms such as depression, anxiety, delusions and hallucinations—often because the parts of the brain that help with these tasks are affected.

During our sessions together, we will talk about these symptoms and how MASC can support you in navigating them.



SESSION 1

Getting to Know Your Stress Response



In Session 1 we will:

1. **Check-In:** Get to know each other
2. **Learn:** The stress spiral
3. **Design:** Your stress spiral
4. **Skill Practice:** Deep Breathing
5. **Discuss:** Goals for the program
6. **Learning Summary**
7. **Home Practice**

Check-In: Get to know each other

- Introductions
- Give an example of a frustrating or challenging aspect of being a caregiver of someone with dementia.



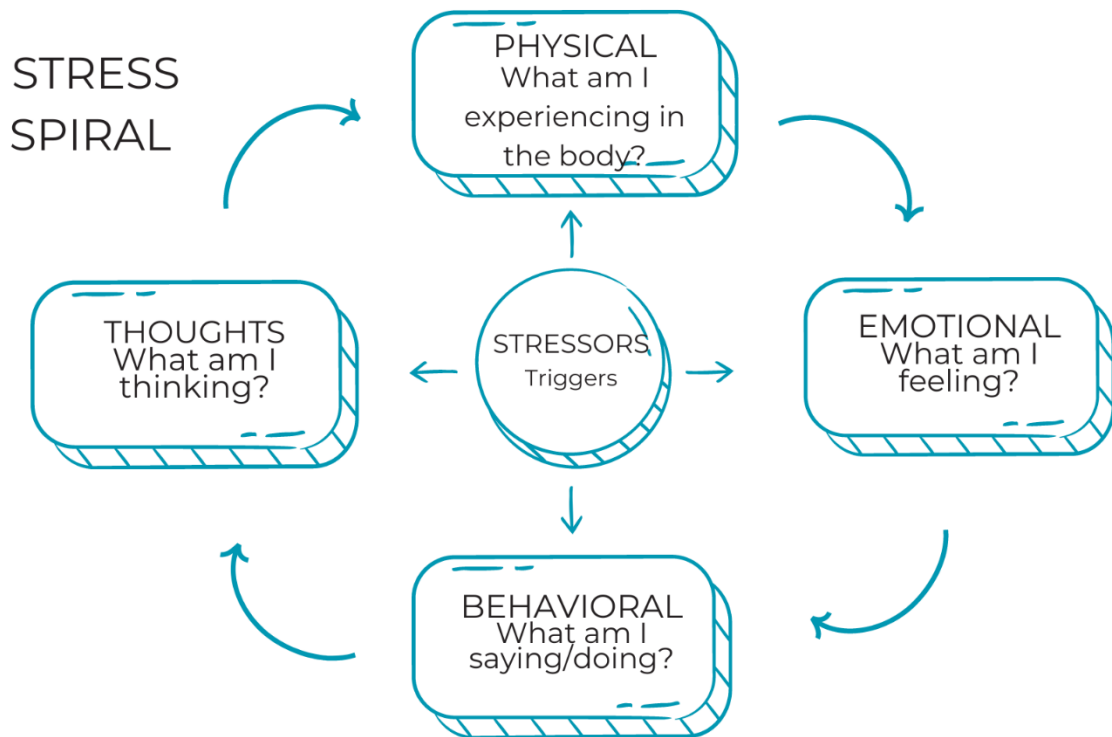
NOTE: Throughout this manual, we will be using the word "care recipient" and "loved one" to refer to the person with dementia you provide care to.

Learn: The stress spiral

Being a caregiver is rewarding but can be stressful at times. Stressors automatically trigger thoughts, behaviors, and emotions. These are often unpleasant and unhelpful, feeding off each other like a snowball.

We call this the “**Stress Spiral.**”

*A **stressor or trigger** can be defined as a situation, behavior and/or experience that automatically activates the stress spiral for us.*

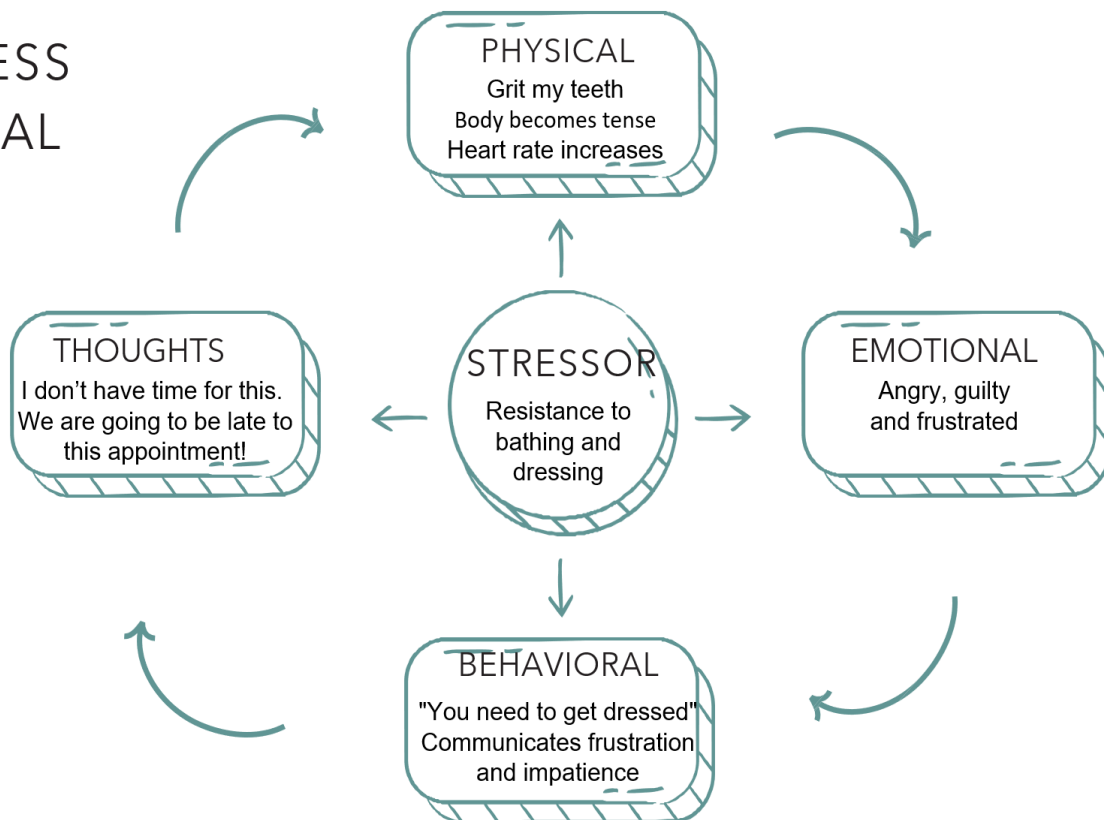


EXAMPLE

There are multiple triggers and stressors that caregivers of persons with dementia face. **In this program, we will focus primarily on stress associated with changes in behavior, personality, and moods of the person with dementia.** The skills you learn will apply to all stressors. See below.

Example: You have an appointment, and you want your loved one to get in the shower and get dressed.

STRESS SPIRAL



Let's identify dementia behaviors and stressors (triggers)

Below are some behaviors that people living with dementia may present as part of their medical diagnosis. These challenging behaviors, moods or personality changes can trigger a stress spiral. **Circle and add all that apply to you.**

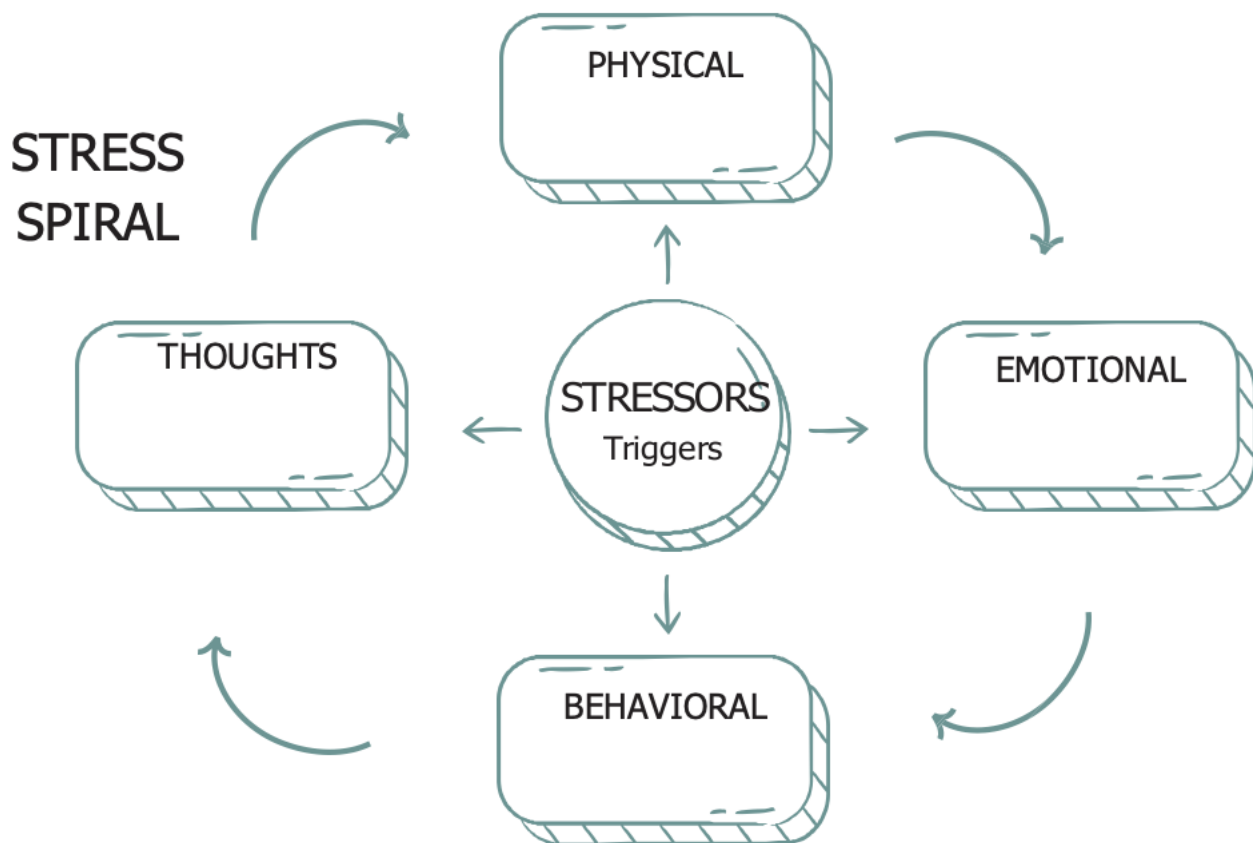
Loved one's behavior	Description of the stressor and trigger
Agitation/aggression	Resistant and refusing help from others (arguing, cursing, screaming, throwing objects)
Anxiety/worry	Signs of nervousness such as pacing, crying, moaning
Apathy	Seems less interested in usual activities or plans
Appetite	Changes in amount of food or different food preferences
Delusions	Having false beliefs, such as thinking that others plan on harming them
Depressed Mood	Seems sad or says he/she is depressed
Disinhibition	Acting impulsively, such as talking to strangers
Fear of separation	Gets upset when a specific caregiver is not present
Elation/euphoria	Appears to feel too good or acting excessively happy

Continuation: identify dementia behaviors and stressors

Care recipient's behavior	Description of additional stressors and triggers
Nighttime behaviors	Awake at night, rises too early, or takes excessive naps
Wandering	Looks for someone or something that is not there, following or shadowing people or caregiver
Hoarding, collecting, rummaging	Searches, takes, or hides items
Socially inappropriate behavior	Loss of normal judgement (not following social rules)
Repetitive questions or activities	Repetitive comments or behaviors
Distressing Beliefs	Hearing, seeing or sensing things that are not there
Irritability	Being impatient or cranky
Write other behaviors you see	

Design: Your stress spiral

Create your own stress spiral. In the bubble labeled stressors and triggers, write down a trigger (a behavior, mood or personality change that your loved one with AD/DRD exhibits) followed by your emotional, physical, and behavioral reactions. Use the table below to help you identify emotions, physical sensations, thoughts, and behaviors. Refer to page 14-15 for more details on [DEMENTIA BEHAVIORS AND STRESSORS \(TRIGGERS\)](#).



Discover your individual stress profile

We all react to stress differently. Some people get irritable, and others want to be alone. **Our reactions to stress are automatic and we do not choose them.** Our reactions are our “individual stress profiles”.

Think about a time when your care recipient exhibited a challenging behavior. **Please add/circle the emotional, physiological, behavioral, and cognitive reactions *that you experience* when stressed.**

Table 1. Reactions to Stress

PHYSICAL:

- Headache, jaw tension, teeth grinding, muscle tightness
- Appetite changes (increase/decrease)
- Pain (neck, shoulder, back)
- Increased heart rate, blood pressure
- Nausea, digestive problem
- Sleep problems
- _____
- _____

EMOTIONAL:

- Irritability
- Sadness
- Regret
- Guilt
- Shame
- Anxiety
- Depression
- Lack of enjoyment
- _____
- _____

BEHAVIORAL:

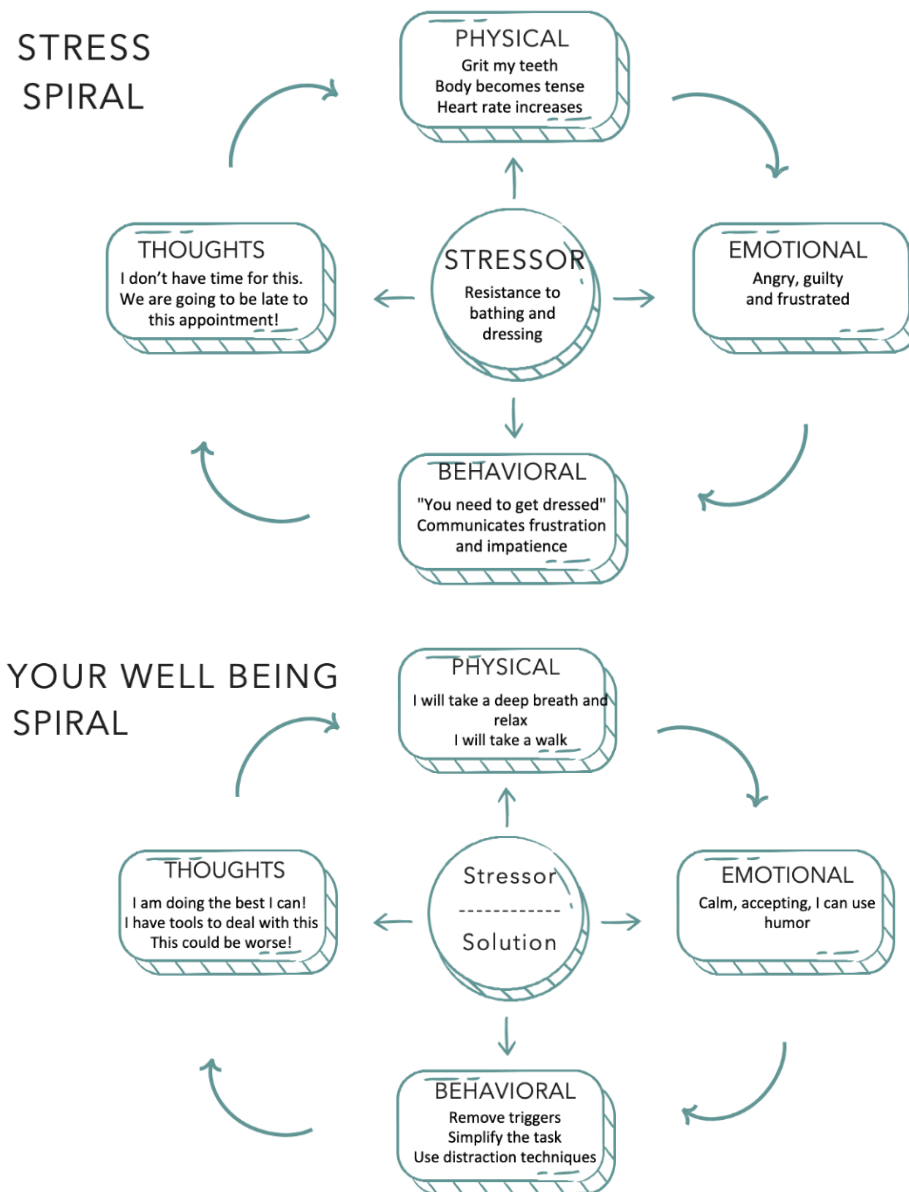
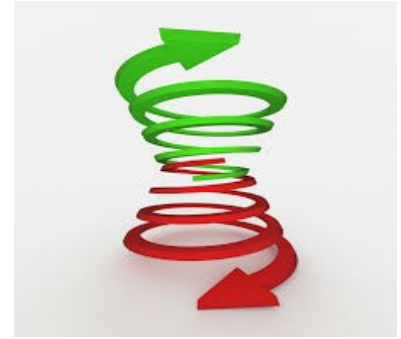
- Repeating myself
- Short tempered response
- Low frustration threshold
- Crying spells and isolation
- Lack of engagement in pleasurable activities
- Difficulty paying attention
- Confusion
- Forgetfulness

COGNITIVE/ THOUGHTS

- Negative thoughts about self
- Negative thoughts about others
- Negative thoughts about the future
- Rumination (thinking over and over about something, usually negative)
- _____

Stress to the wellbeing spiral

By understanding the stress spiral, you are learning to recognize situations (triggers and behaviors) that make you feel stressed and upset. Throughout this program, you will learn skills to move from the **stress spiral** toward a **well-being spiral**.





Skill Practice: Deep Breathing

Stress triggers rapid and shallow breathing. This type of breathing puts us on the stress spiral. Deep breathing involves consciously slowing down the rate of our breathing by taking deep and slow breaths. This type of breathing helps us move toward the well-being spiral.

DEEP BREATHING EXERCISE – HOW TO DO IT

1. Sit or lay in a comfortable position.
2. Become aware of your breath.
3. Try to take a deep and slow breath in, then exhale slowly.
 - a. Many people find it helpful to breathe in for the count of 4, hold, then release for the count of 4, pause, then repeat.



When does this help?

- Deep breathing works well when you are feeling upset, anxious, or overwhelmed.
- Begin with 2-3 minutes a day and increase as the exercise becomes easier.
- Practice conscious breathing before, during or after a stressful caregiving situation.

Discuss: Goals for the program

Why set goals? Goals are like destinations. They keep us focused and prevent us from getting distracted or discouraged.

Where do I want to be at the end of this 6-week program?

- How do I want to support my care-recipient?
- How do I want to react to my care-recipient's behaviors or personality?
- How do I want to react toward myself during challenging times?

My goal:

On a scale of 0-10 how confident am I that I will achieve my goal?



Not Confident

Extremely Confident

Why did you choose this number and not a lower one? Why did you choose this number and not a higher one?


My revised goal:

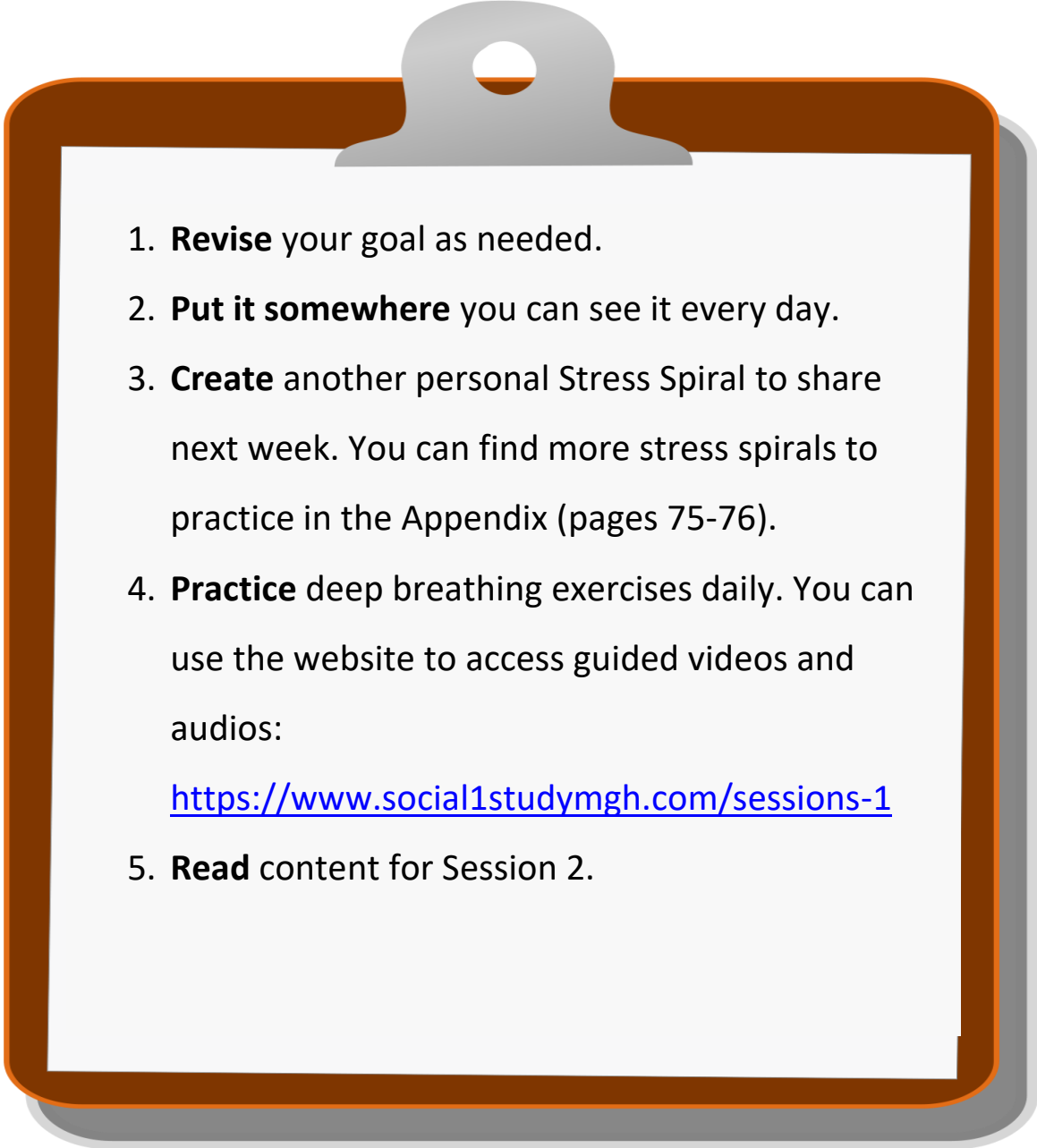
Learning Summary



- Today, we learned that the behaviors, moods, or personality changes of our loved one with dementia can trigger negative thoughts, unhelpful behaviors, unpleasant emotions and physical sensations that feed off each other and cause a stress spiral.
- We also learned the skill of deep breathing, which can help move from the stress spiral toward the well-being spiral.

NEW MASC SKILLS:

Tool:	Summary:	When to use:	When will I use it specifically (e.g., situations, times)?
Deep Breathing 	Breathe deeply and slowly	Use every day, especially when you feel tense or nervous. Notice how you feel before and after deep breathing.	

- 
1. **Revise** your goal as needed.
 2. **Put it somewhere** you can see it every day.
 3. **Create** another personal Stress Spiral to share next week. You can find more stress spirals to practice in the Appendix (pages 75-76).
 4. **Practice** deep breathing exercises daily. You can use the website to access guided videos and audios:
<https://www.social1studymgh.com/sessions-1>
 5. **Read** content for Session 2.

PRACTICE BREATHING EXERCISE & WRITE DOWN ANY QUESTIONS FOR YOUR CLINICIAN!



Breathe by Nina Heyen

Inhale deeply.

Fill your lungs with joy!

Let your body expand and grow roots deep into the earth.

Let your soul widen and stretch into the sky and beyond.

Let your mind drift away to glimpse the realm unnamed.

Breathe in the light that nourishes you and sustains you.

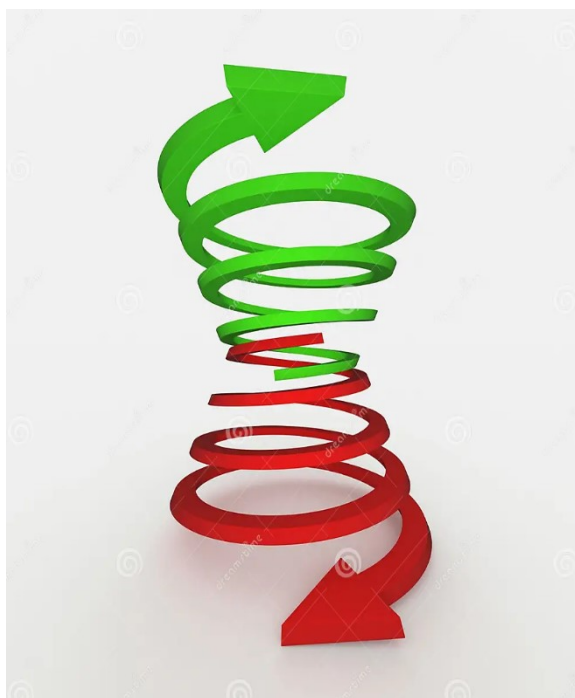
Then let it go,

gently joining the rise and the fall of the universe.



SESSION 2

Introduction to Mindfulness



In Session 2, we will:

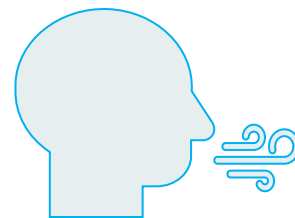
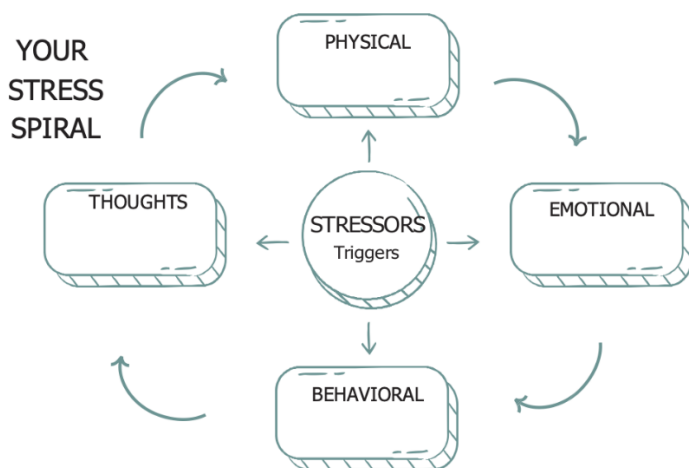
1. **Check-In:** Share with the group
2. **Review:** The Stress Spiral
3. **Learn:** Introduction to Mindfulness
4. **Skill Practice:** The Mindful Stop
5. **Discuss:** Linking the Stress Spiral and the Mindful Stop
6. **Learning Summary**
7. **Home Practice**

Check-In: Share with the group

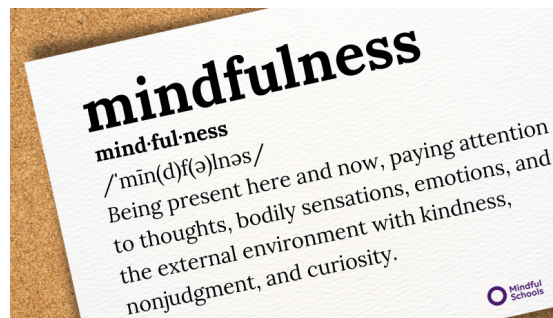
Share with the group any ways that you were able to incorporate something from last week's session.

- Were you able to practice deep breathing? What was your experience?
- Did you create another stress spiral? Did you revisit your program goal?

Review: The Stress Spiral



Learn: Introduction to Mindfulness



- Mindfulness is a practice of intentionally and non-judgmentally paying attention to our experiences:
 - Pay attention to what we see, hear, taste, smell, and touch (external experiences).
 - Notice our thoughts, emotions, reactions, and physical sensations (internal experiences).
 - Be **CURIOUS** about our experiences using mindfulness skills.

WHEN CAN YOU USE IT?

- You can use it any time!
- It is particularly useful when you are interacting with your care recipient, as a way to better respond to and manage tough situations.
- Mindfulness is like a muscle. The more you use it, the easier it becomes.



Mindfulness helps you:

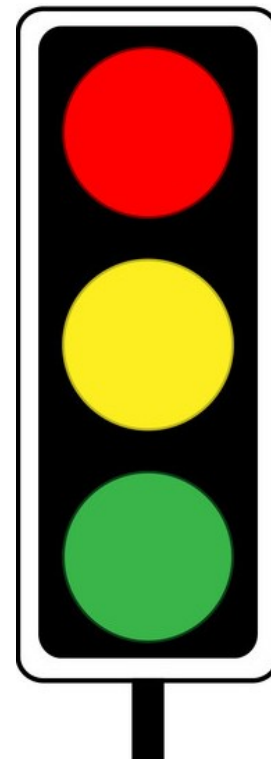
- Tolerate challenging emotions (stress, anxiety, grief, panic).
- Accept things that you can't change (like your loved one's dementia symptoms and changes).
 - It helps you regulate your emotions and physiology (e.g., decrease stress) so that you can utilize behavioral management strategies that we will teach you to support your loved one.
 - Become a detective. Use curiosity to develop your loved one's stress spiral. With this knowledge in hand, you will be best equipped to help them.

How can you use mindfulness?

- An easy way to practice mindfulness is with the **Mindful Stop** below.
- The figure below represents the 3 steps of mindfulness.

- **OBSERVE:**
- **DESCRIBE:**
- **ACT WITH AWARENESS:**

*In this program, you will learn to identify useful skills to **act with awareness** when dealing with stressful situations.*



Skill Practice: The Mindful Stop

OBSERVE

Notice what you are feeling and thinking in this moment.

Observe what is happening in your body with curiosity.

"I notice that my heart and mind are racing."

- *"I feel tense and wound up."*
- *"I am having a thought that I can't keep going like this."*

DESCRIBE:

Use words to describe and validate your thoughts and feelings **without judgement.**

Remember: Thoughts are not facts.

- *"I am juggling a lot right now."*
- *"I am getting frustrated."*
- *"I feel angry that my loved one has dementia."*

ACT WITH AWARENESS:

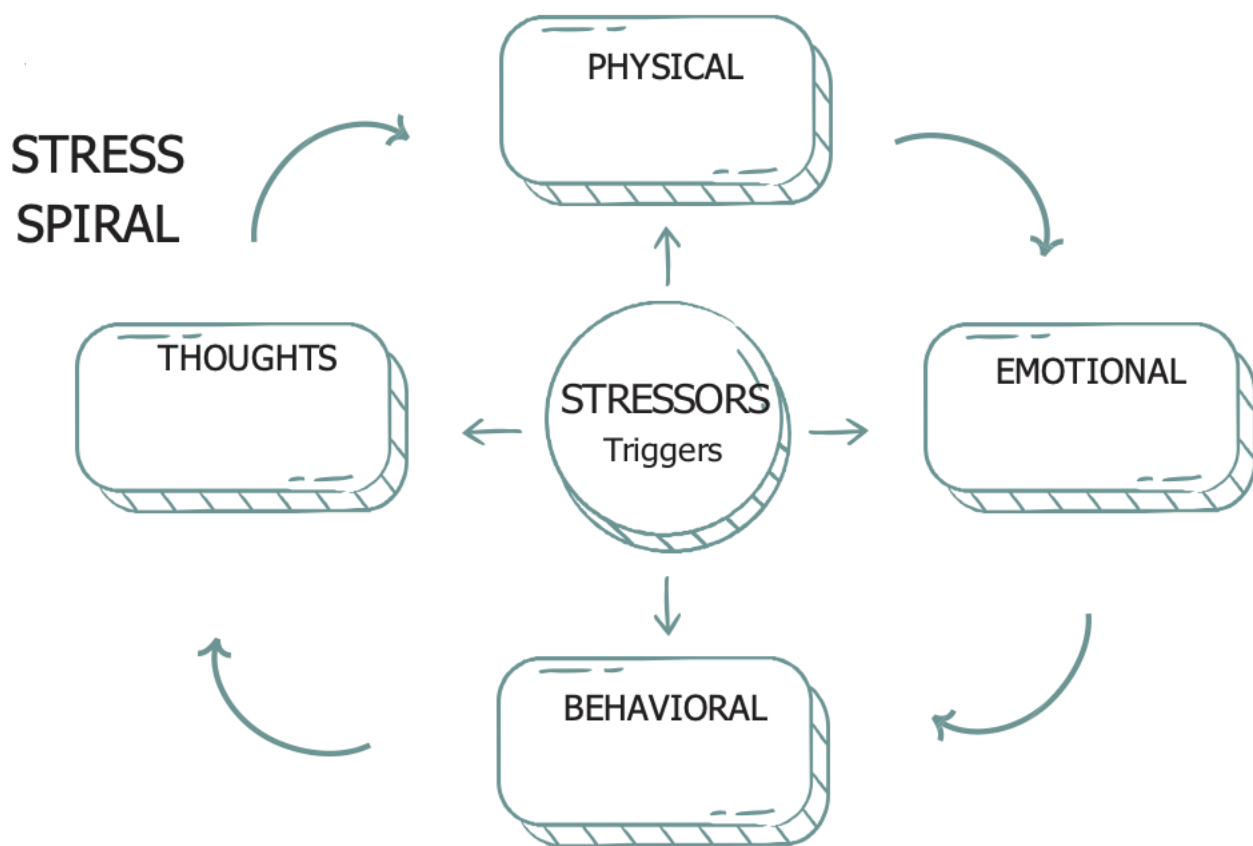
Choose to engage in a way that is going to help you get off the stress spiral and use the best behavioral skills to manage the situation.

- *"I will use deep breathing instead of reacting."*
- *"I will walk out of the room and return to revisit this later."*
- *"I will ask for help and try to avoid rushing through on autopilot."*

Discuss: The Mindful Stop and Your Stress Spiral

EXERCISE:

1. Think about a recent situation where your loved one with dementia was having challenging behaviors.
2. Briefly write down what happened using the stress spiral:



Now imagine that you could go back and use **Mindful Stop**.

Complete the exercise below.

MINDFUL STOP

OBSERVE

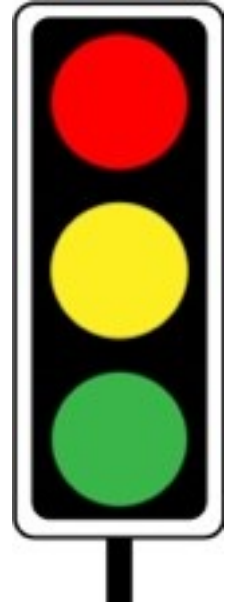
- I notice the thought that ...
- I notice the emotion of ...
- I notice in my body the sensation of ...
- I notice an urge to ...

DESCRIBE:

- I am experiencing the feeling of ...
- I notice that I am having a negative thought about myself/my care recipient...
- This situation is bringing up emotions of...

ACT WITH AWARENESS:

- I can take a minute to take a deep breath to calm my mind and body.
- I will allow this unpleasant thought to be here and use deep breathing instead of reacting to it.
- I will walk away and try again in a few minutes.



Learning Summary



- Practice the skills learned so far to support your loved one.
- Understanding your loved one's **stress spiral** will help you intervene in ways that are helpful to:

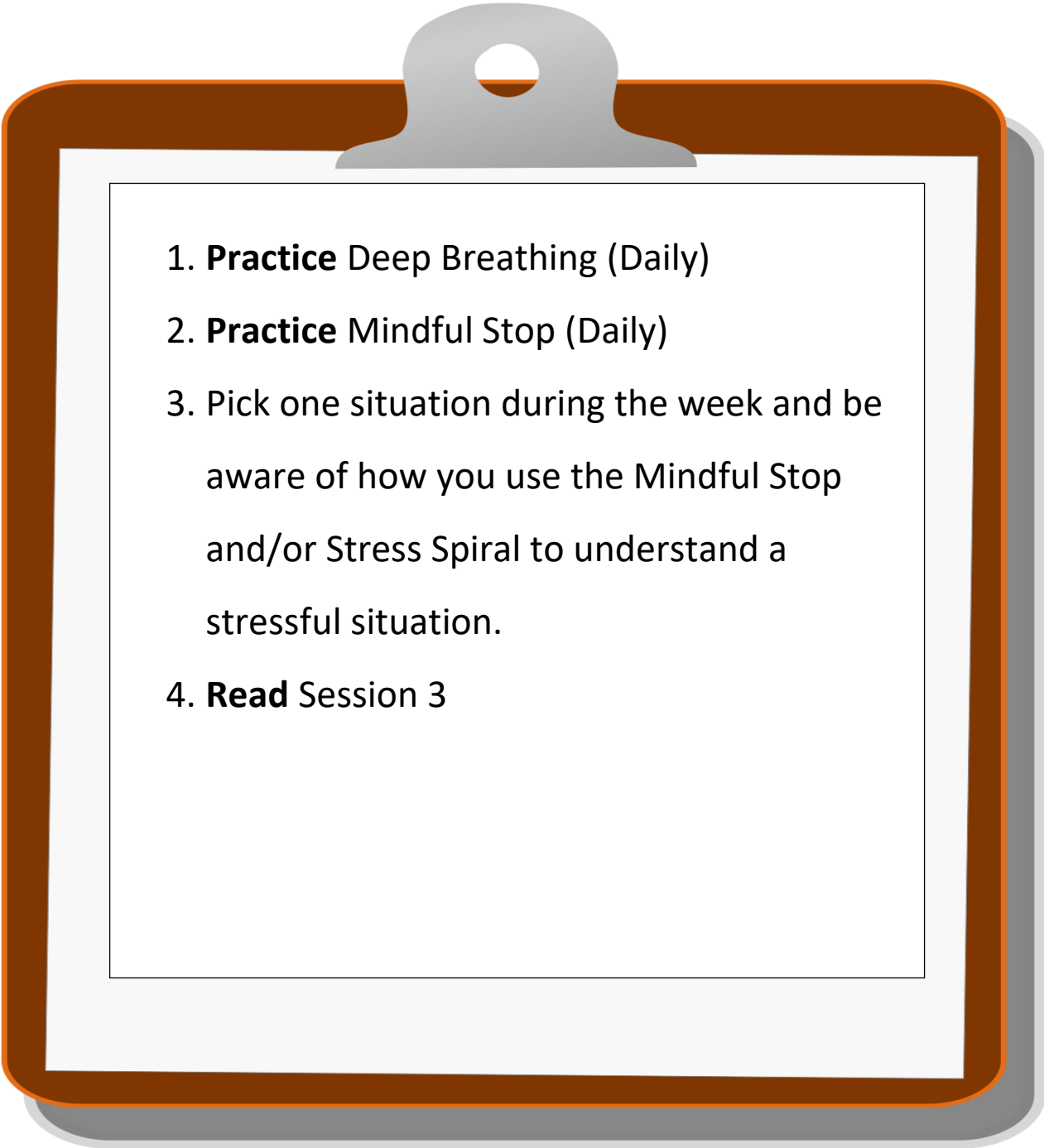
1) Remove the stress trigger

2) Practice deep breathing yourself or with your care recipient to calm the body/mind

3) Use skills in the Mindful Stop: **Observe**, **Describe**, **Act with Awareness**

NEW MASC SKILLS:

Tool:	Summary:	When to use:	When and why will / use it?
Mindful Stop 	Observe what is happening in your mind and body with curiosity .	Choose to engage in a way that is going to help you get off of the stress spiral.	
Stress Spiral 	Become aware of unhelpful thoughts and stress that keeps us in the stress spiral.	Whenever you feel anxious or frustrated with your loved one's behavior.	

- 
1. **Practice** Deep Breathing (Daily)
 2. **Practice** Mindful Stop (Daily)
 3. Pick one situation during the week and be aware of how you use the Mindful Stop and/or Stress Spiral to understand a stressful situation.
 4. **Read** Session 3

REFLECT & WRITE DOWN ANY QUESTIONS FOR YOUR CLINICIAN!

Do Not Ask Me to Remember

Do not ask me to remember.
Don't try to make me understand.
Let me rest and know you're with me.
Kiss my cheek and hold my hand.

I'm confused beyond your concept.
I am sad and sick and lost.
All I know is that I need you
To be with me at all cost.

Do not lose your patience with me.
Do not scold or curse or cry.
I can't help the way I'm acting.
Can't be different 'though I try.

Just remember that I need you,
That the best of me is gone.
Please don't fail to stand beside me,
Love me 'til my life is done.



SESSION 3

The Skill of Compassion and Managing Challenging Behaviors



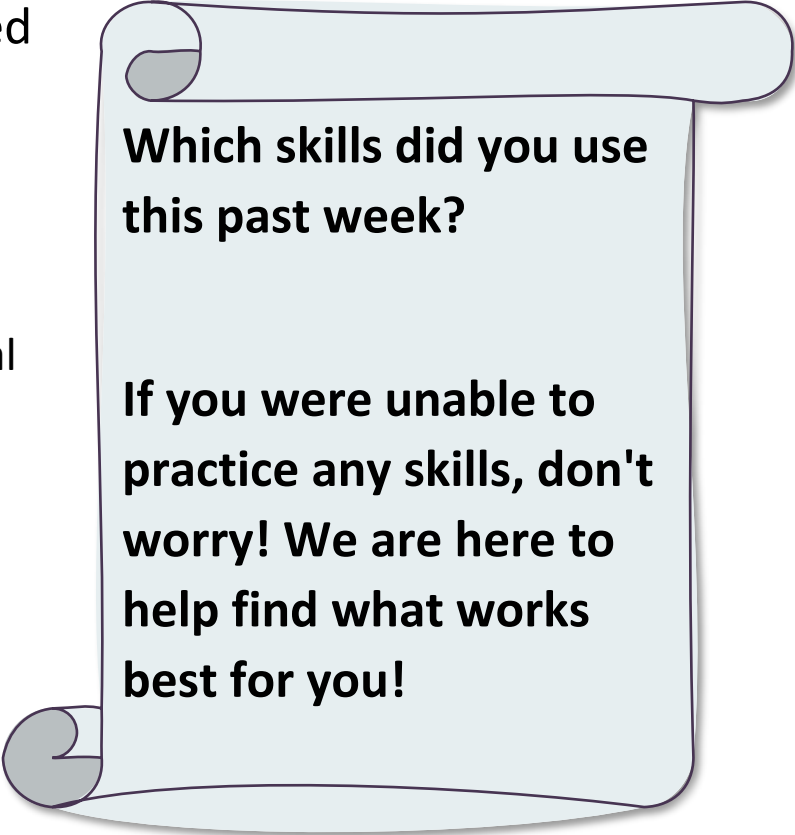
In Session 3, we will:

- **Check-In:** Skills you reviewed
- **Learn:** The Skill of Compassion
- **Design:** Stress Spiral and Mindful Stop
- **Skill Practice:** Loving Kindness Exercise
- **Discuss:** Strategies to Manage Challenging Behaviors
- **Learning Summary**
- **Home Practice**

Check-In: Skills you reviewed

In sessions 1 and 2, we have learned the following skills:

- Deep breathing
- Your personal Stress Spiral
- Mindful Stop Technique



Which skills did you use this past week?

If you were unable to practice any skills, don't worry! We are here to help find what works best for you!

Learn: The Skill of Compassion

Compassion is showing kindness to others when they don't meet expectations, when they make mistakes or when they suffer.

In the **SOCIAL** program, compassion has 2 components:

1. **Perspective taking.** This means being able to “put yourself in the other person’s shoes” when they make mistakes or hurt you, and trying to understand their perspectives, circumstances, and feelings.
2. **Compassionate Behaviors.** This means choosing to engage in behaviors or actions that are aimed at relieving the suffering of the other person.



HOW DOES COMPASSION HELP:

- Using compassion when others experience life challenges helps us move out of the stress spiral and experience a greater sense of well-being.
- When we are compassionate, we build closer connections with other people.

HOW YOU CAN USE COMPASSION:

- When you are feeling angry, notice you are judging because of your loved one's dementia behaviors, or when you feel disconnected from your loved one, use the **Loving Kindness Exercise**.

Skill Practice: Loving Kindness Exercise

Lovingkindness meditation, even brief, naturally nurtures compassion and an open heart radiates kindness to others and the world.

This is a simple GUIDE. You can go through it slowly and stop and practice at your own rhythm. Sit comfortably with your back straight.

- 1) Take a breath to become present in your body. Take your time.
- 2) Imagine yourself in a peaceful place where you are relaxed. Imagine being filled with a warm light of love surrounding you and imagine it is wrapping you in a blanket of love and compassion.
- 3) Now put this lovingkindness and warmth that you are receiving into words. Adapt the words so they reflect your personal wishes and situation. Here's one example:

May (insert name of person here) be held in lovingkindness.

May (name) be happy.

May (name) be connected and calm.

May their heart know peace.

Repeat the wishes at least three times, out loud or in your mind. Savor them. Take your time. Feel their ability to warm and open the heart.

Discuss: What is an example of a challenging behavior where you struggle to find compassion?

IDENTIFY COMMON STRESS TRIGGERS FOR CARE RECIPIENT

Last week, we talked about behavioral symptoms in your loved one that are triggering YOUR OWN stress response. Below is a chart of potential triggers for YOUR LOVED ONE's challenging behaviors and a chart with strategies to use. **Circle** the triggers you have already identified and underline additional triggers that you think might apply:

Potential Medical Triggers

- A flare of an underlying medical condition
- Pain, poor sleep, dehydration, constipation, urinary tract infection
- Medications (e.g., sleep aids or antihistamines)
- Progression of the disease

Potential Caregiver Triggers

- Complex communication (multiple steps)
- Threatening/belittling tones (reacting critically or harshly)
- Mismatch of dementia stage and caregiver expectations

Potential Environmental Triggers

- Too much/too little stimulation
- Poor lighting or lack of exposure to natural light
- No cues/signs to guide person
- Lack of activity or structure

Other Triggers You Observed

Circle the strategies that you can employ to manage challenging behaviors and **underline** the potential strategies that you can try with your loved one during challenging times.

Potential Medical Strategies

- Check to see if there is any indication of a new medical problem (fever, shortness of breath, elevated heart rate, change in bowel or bladder habits)
- Treat pain
- Optimize hearing and vision

Potential Caregiver Options

- Deep breathing
- Mindful awareness
- Optimize communication:
 - Set a positive tone
 - Keep tasks/directions simple (one step)
 - Show what you mean
 - Don't confront directly

Environmental Solutions

- Create a daily schedule that includes exercise
- Reduce clutter, noise or too many people at one time
- Remove dangerous objects or things that could cause falls
- Use labeling or visual cues
- Avoid sudden changes to the environment
- Get natural light

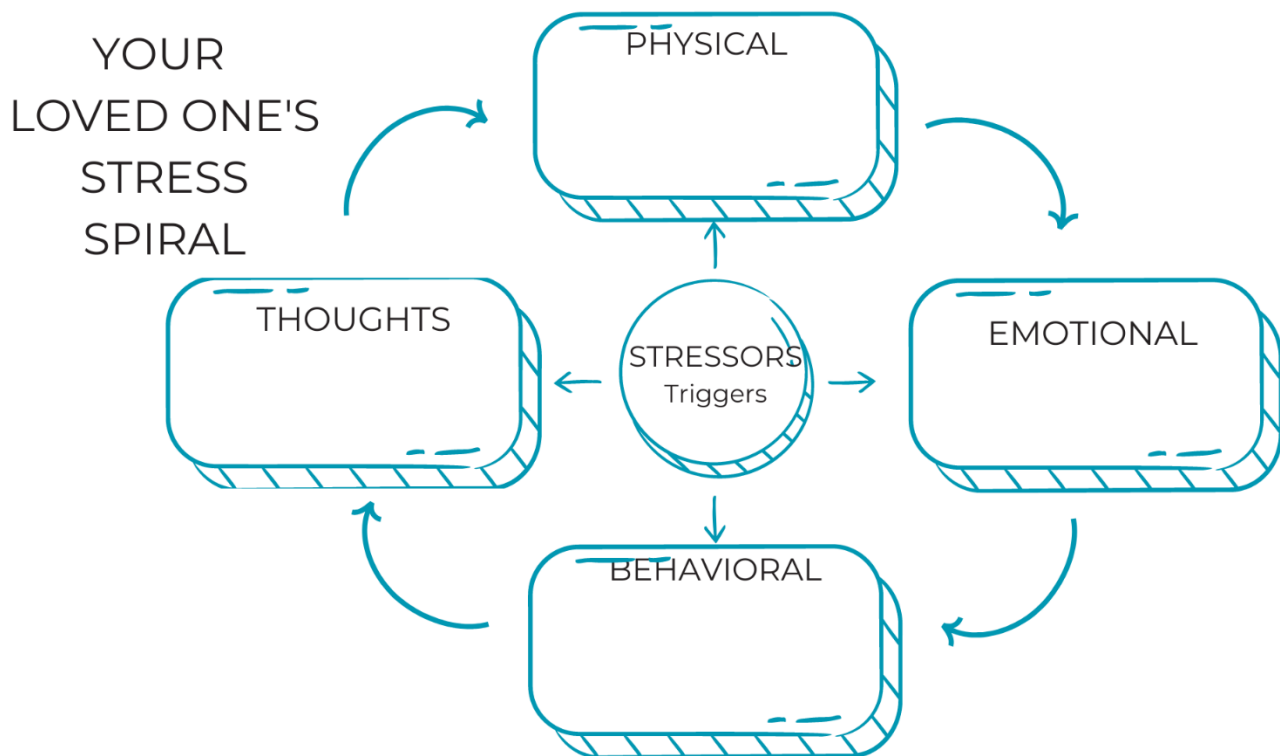
Others:

List other strategies you have used:

- _____
- _____
- _____

Design: Stress Spiral and Mindful Stop

Now that you have identified your care recipient's triggers, complete their personal stress spiral to understand their reaction to stressful situations. This exercise can help you build compassion for your care recipient.

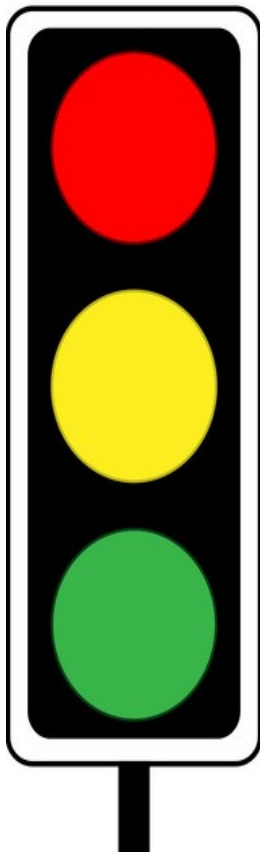


PUTTING IT ALL TOGETHER

Now imagine that you could use mindfulness using the Mindful Stop to support your care recipient as they experience their own stress spiral.

Let's design this together as a group!

Group Example Trigger: _____



PERVE

I notice my loved one _____

when _____

CRIBE

They are responding by _____

which is _____

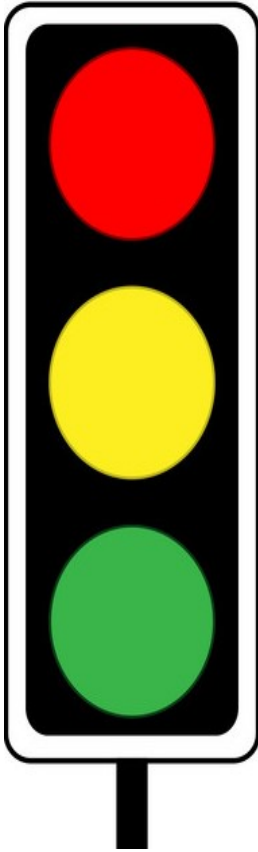
ACT WITH AWARENESS

I can _____

and respond by _____

NOW TRY ONE ON YOUR OWN!

TRIGGER: _____



I notice my loved one _____

PERVE
when _____

CRIBE
They are responding by _____

which is _____


ACT WITH AWARENESS

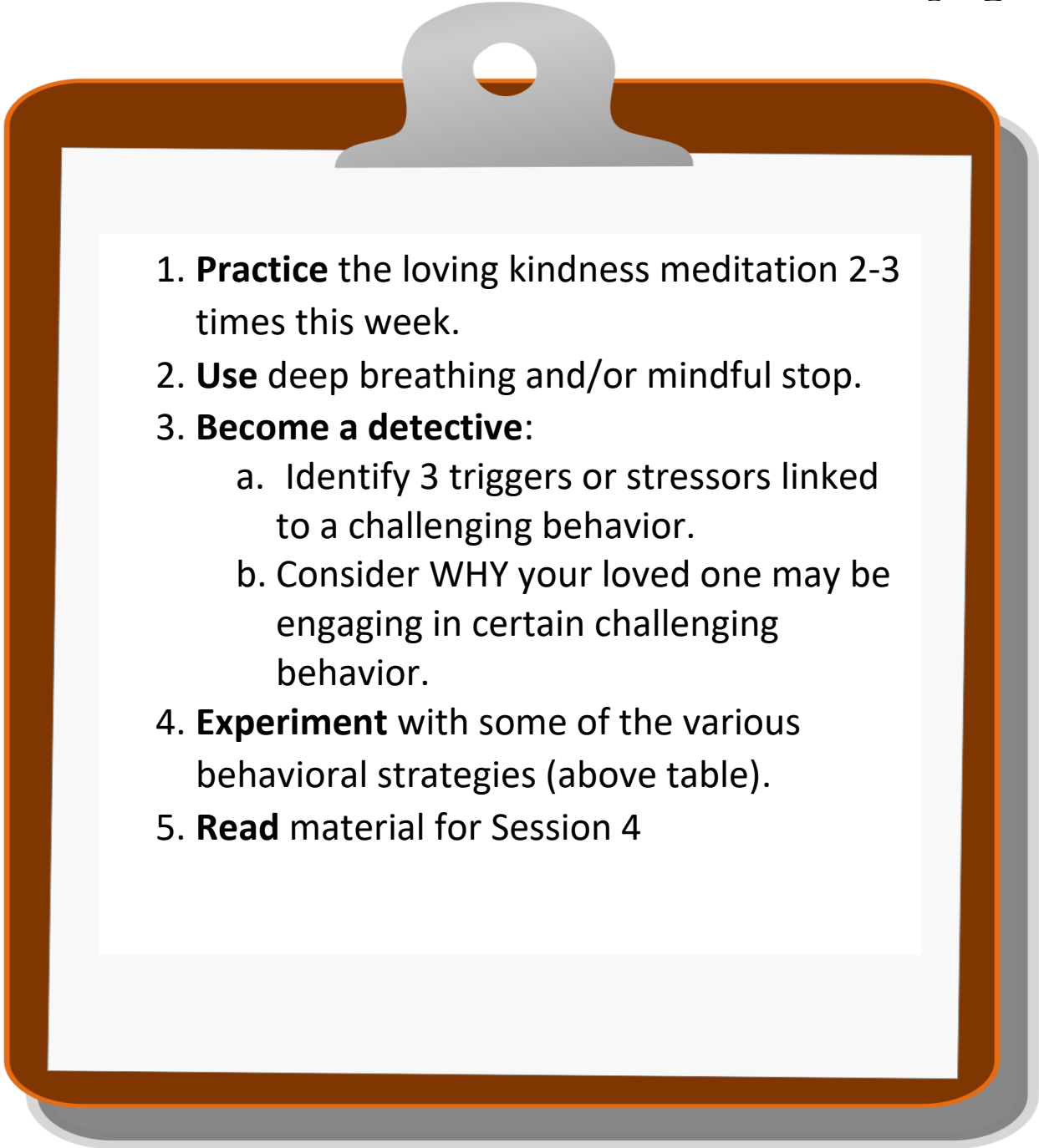
I can _____

and respond by _____

Learning Summary

- This session, we learned about compassion and created **a stress spiral for your loved one's stressors.**
- Just like your personal **stress spiral** gets triggered by a stressor, your loved one's challenging behavior or mood are also triggered by a stressor.
- Mindfulness and compassion can help support your loved one during their stress spiral and better respond to their behaviors.
- Practice the Loving Kindness Meditation for home practice.

Tool:	Summary:	When to use:	When and why will I use it?
Compassion 	Compassion will help you cope with difficult behaviors coming from your loved one with dementia.	Use whenever you are sad, frustrated, or angry. Use when you notice negative feelings toward others.	
Loving Kindness Meditation (Part 1)	This loving kindness meditation helps us cultivate compassion for others	When you wake up or are heading to sleep. When you need a compassion break.	

- 
1. **Practice** the loving kindness meditation 2-3 times this week.
 2. **Use** deep breathing and/or mindful stop.
 3. **Become a detective:**
 - a. Identify 3 triggers or stressors linked to a challenging behavior.
 - b. Consider WHY your loved one may be engaging in certain challenging behavior.
 4. **Experiment** with some of the various behavioral strategies (above table).
 5. **Read** material for Session 4

LOVINGKINDNESS PRACTICE

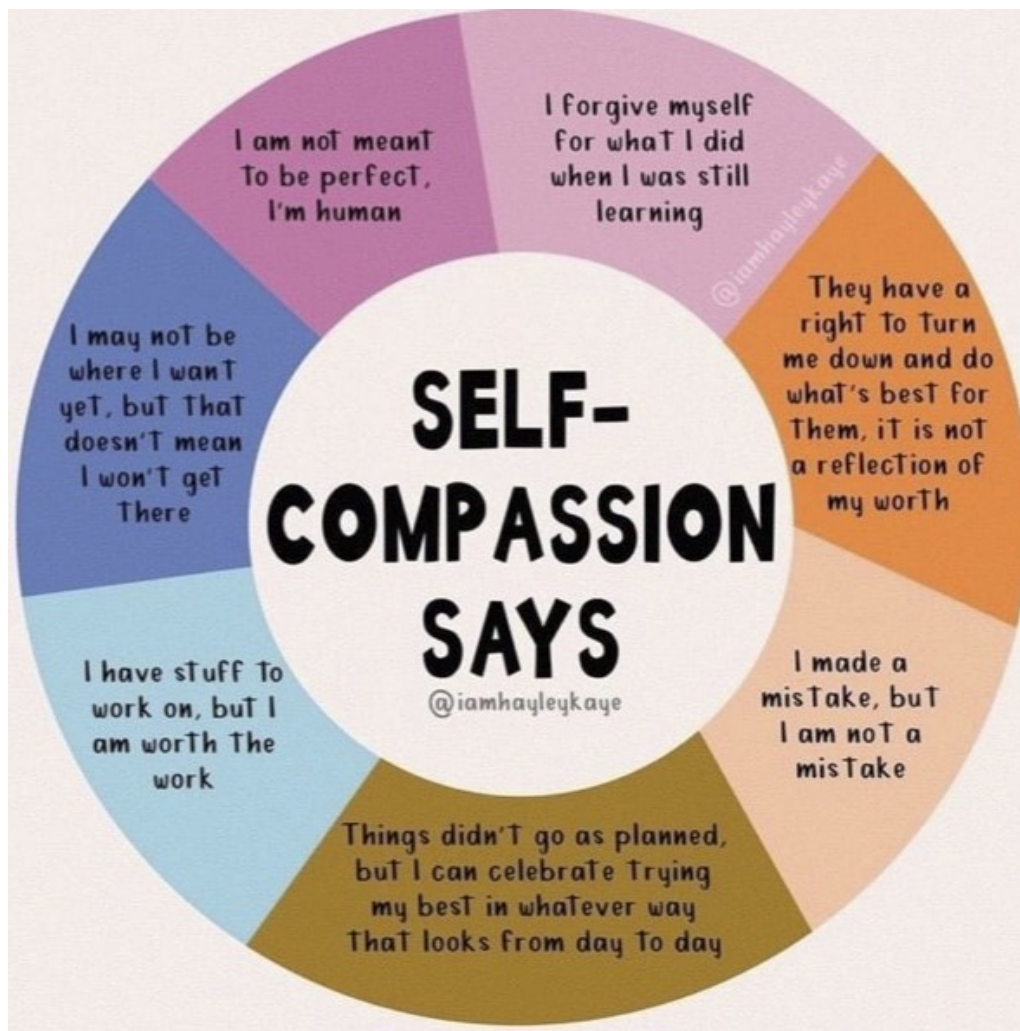
MAY YOU BE SAFE
MAY YOU BE HAPPY
MAY YOU BE HEALTHY
MAY YOU LIVE WITH EASE

Sharon Salzberg 



SESSION 4

The Skill of Self-Compassion While Caregiving

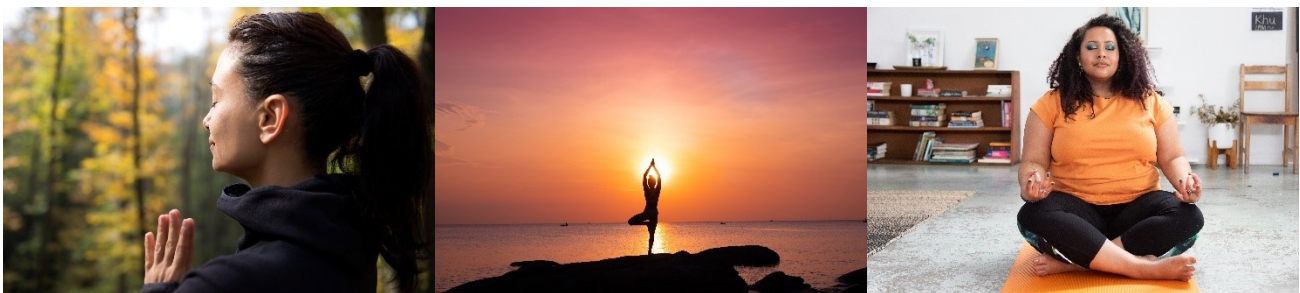


In Session 4, we will:

- **Check-In:** Goal Check in
- **Review:** Loving Kindness Meditation
- **Learn:** The Skill of Self-Compassion
- **Skill Practice:** Self-Compassion Break
- **Learning Summary**
- **Home Practice**

Check-In: Your goals and the program

What were your goals in session 1? Are you meeting them? Do they need to be adjusted?



Review: Loving Kindness Meditation

Let's begin with a short loving kindness meditation. We will practice sending compassion to our ourselves and then expand it to our care recipient, then the world (see Appendix for written script).

Learn: The Skill of Self-Compassion

WHAT IS IT?

- Self-compassion is showing kindness to yourself. It builds on the skill of compassion we discussed last week.
- Self-compassion refers to the tendency to be understanding and caring towards oneself rather than being harsh or critical.
- Self-compassion is necessary in the context of caregiving because it allows you to acknowledge the difficulties of your role all while comforting yourself.

The MASC program skill, self-compassion, has 3 components:

- **Self-kindness rather than self-judgement** – this means accepting that we are imperfect, we fail, and we can't always get what we want or work for.
- **Common humanity rather than isolation** – this means understanding that we are not failing or suffering alone. At any moment in time there are millions of others who are going through similar situations. Suffering, failing and being imperfect are shared by all humans.
- **Self-compassionate behaviors** – doing kind things for yourself.



BENEFITS OF SELF COMPASSION

SELF COMPASSION AS A TOOL

- Self-compassion is not simply doing things you enjoy, it is thoughtful engagement in meaningful activities focused on YOU.
- Self-compassion is a practice -- a way to soothe yourself, to be affectionate with yourself, to give yourself generosity etc.
- For caregivers, it is about being kind to themselves when they experience negative emotions associated with their care recipient's behavioral symptoms.



SELF COMPASSION CAN MOVE YOU ON THE WELL-BEING SPIRAL

- Being hard on ourselves puts us further onto the stress spiral.
- When we are kind and gentle with ourselves, when we experience life challenges, or we fail at something, we more easily move out of the stress spiral and experience a greater sense of well-being.
- When we recognize that failing and suffering is a part of the human experience, we feel more connected with others and the world.
- We can move out of the stress spiral and experience a sense of well-being.

HOW YOU CAN USE SELF COMPASSION:

- When you feel a great deal of guilt, or when you have constant thoughts about how you could have done better for your loved one.

Practice self-compassion using the [Self-Compassion Break](#) recording on the website to develop self-kindness and connection with others.

Skill Practice: Self-Compassion Break

This is a quick exercise you can use whenever you need a little self-compassion. Maybe you're getting frustrated with your loved one and feeling overwhelmed. This exercise will help you extend kindness to yourself when you need it most.

Call to mind a particularly difficult situation you're dealing with right now.

- Breathe, see if you can feel stress or emotional discomfort in your body.

Be mindful of the thoughts, emotions and sensations that are coming up for you.

- Try saying to yourself: “This is a moment of difficulty” or “This is stressful.” Notice and accept these feelings for a moment without trying to push them away.

Take a moment to acknowledge that you're not alone. Think of all the caregivers around the world who are experiencing similar frustrations right now and everyone who has come before you.

- Try saying “Other people feel this way” or “I'm not alone.”



Now place your hands over your heart. Feel the warmth and gentle touch of your hands on your chest or a soothing place that feels right for you.

- Say to yourself: “May I be kind to myself.”

Ask yourself, what do I need to hear right now to express kindness to myself? Is there a phrase that speaks to you?

You may come up with your own or try the following:

- May I give myself the compassion that I need.
- May I learn to accept myself as I am.
- I forgive myself for getting frustrated with my loved ones; I am human.
- I am doing the best I can in this moment.
- This too, will pass.

SELF COMPASSION: FRUSTRATION

- Frustration is a common emotion among caregivers.
- It is human to be frustrated with challenging behaviors, especially when we cannot change the behavior easily (or at all!).

*When you are interacting with your loved one and the strategies to help them do not work the way you hoped, you can practice self-compassion with the **Mindful Stop**.*

Example of using the Mindful Stop when you are frustrated because you are repeating the same request over and over:

OBSERVE –

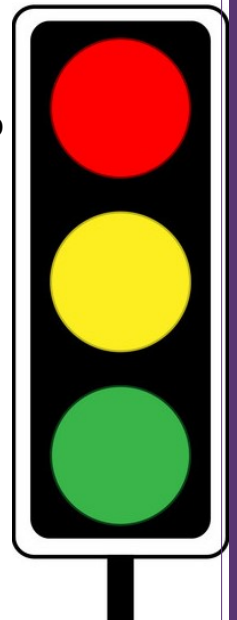
- “I notice the feeling of tension in my body.”
- “I am repeating myself over and over with no changes.”
- “I notice the thought that my loved one won’t do what they need to do.”

DESCRIBE

- “I am experiencing the feeling of guilt, and this is OK.”
- “I am frustrated and losing my patience.”
- “I am feeling sad and angry and alone.”

ACT WITH AWARENESS AND SELF COMPASSION

- I can remind myself that I am doing the best I can.
- I can remind myself that caregiving is hard.
- I am going to ensure my loved one is safe and take time to drink a tea.
- I am going to switch gears and ____ (take my care recipient for a walk (turn on music, give them a task).





Learning Summary

This session we discussed self-compassion and how being kind to yourself can help you take care of yourself.

- We learned about the Self Compassion break.
- Using the mindful stop and incorporating self-compassion can be a tool to use when we are feeling overwhelmed and frustrated.

NEW MASC SKILLS:

Tool:	Summary:	When to use:	When and why will / use it?
Self-Compassion 	Self-Compassion will help you cope with difficult thoughts and feelings by being kinder to yourself.	Use whenever you are down on yourself or notice negative “self-talk”.	

- 
1. **Practice** some of your new skills!
 - a. Self-compassion break
 - b. Loving kindness meditation
 - c. Deep breathing
 - d. Mindful Stop

 2. **Continue** your detective work surrounding triggers for your care recipient's stress spiral (see Session 3)

 3. **Read** material for Session 5

My Caregiving Friend,
When I was lost, you showed the way.
When I was frightened, you calmed my fear away.
You made me laugh when I wanted to cry.
I fail do often and you tell me: "Just try."
You are my friend, and I forgot your name.
I called for help and it was you: who came.
The time is short and soon, I must go.
There one thing left for you to know.
The sun and rain help to make the garden grow.
The garden grew well, now winter threatens snow.
And so, I leave with a final, loving refrain,
You are the sunshine, - I am the rain.

- Tim Brennan

REFLECT & WRITE DOWN ANY QUESTIONS FOR YOUR CLINICIAN!



SESSION 5

Communication Skills with Persons with Dementia



In Session 5, we will:

- **Check-In:** Self-Compassion Break
- **Learn:** Communication Strategies
- **Skill Practice:** Problem Solving Scenarios
- **Discuss:** Approaches for Challenging Behaviors
- **Learning Summary**
- **Home Practice**

In Sessions 1-4 we have learned...

- Self-compassion break
- Loving kindness meditation
- Deep breathing
- Stress spiral
- Mindful Stop

Check-In: Self-Compassion Break

What did you do for a self-compassion break?



Any challenges practicing or engaging in the skills discussed so far?



Learn: Communication Strategies

The brain of your loved one is changing because of dementia. It is helpful to adjust the way you previously used to communicate with your loved one, while also supporting them in maintaining their dignity.

This means that you will need to develop and employ new communication strategies as the disease progresses. It is easier to use these skills when you are in a calm state.

The program skills you learned so far ([Deep breathing](#); [Mindful Stop](#); [Compassion](#); [Self-compassion](#)) will help calm you down so that you can better use communication skills to be effective with your care recipient.



COMMON BEHAVIORS AND STRATEGIES

Below, we present a list of communication strategies to use, organized by dementia stage. **Circle** your loved one's behaviors from the list below and reflect on strategies you already use. **Add** other strategies that work.

In early stages of dementia:

Common problems	Strategies to Use
Unable to find the right word or substituting words	<ul style="list-style-type: none">• Wait• "Would you like help with that word?"• Ask yes/no questions• Acknowledge frustration
Loses train of thought	<ul style="list-style-type: none">• Repeat the last couple of words (as long as this is not irritating)• Avoid sarcastic or belittling remarks
Slowing of thinking and language processes	<ul style="list-style-type: none">• Speak more slowly (but not as to a child)• Pause more• Use simpler and shorter sentences
Reduced comprehension	<ul style="list-style-type: none">• Repeat using different words• Use visual cues

As Dementia Progresses, common behaviors are:

Common problems	Strategies to Use
Care recipient uses fewer words	<ul style="list-style-type: none"> • Ask questions that can be answered with a YES or NO
Makes sounds not words	<ul style="list-style-type: none"> • This may be due to brain damage and your care recipient may not be able to stop making sounds • Determine if the sounds are related to your care recipient being distressed or bored
Confabulation	<ul style="list-style-type: none"> • Sometimes people with dementia make up facts and stories to fill in their memory gaps • This is a common way for the brain to respond to the damage it is experiencing from dementia • Acknowledge the story and don't try to correct

When you don't understand what your care recipient is saying

- Let them know you are listening and acknowledge them
- Pay attention to your tone of voice (be aware of your stress spiral)
- **Say** "Thank you for sharing that with me", "That is interesting!"

When your care recipient doesn't understand what you are saying

- Speak slowly and deliberately and keep sentences short.
- Show what you are asking your care recipient to do.
- Focus on the one thing you can understand.

Skill Practice: Problem Solving Scenarios

1. Reflect on a recent situation when your loved one exhibited challenging behaviors/mood.

2. Were you able to use any of the skills learned in the SOCIAL program? If so, which ones?

3. What, if anything, remains challenging about this situation for you? What might you try next time?

We will use this information and work as a group to identify additional opportunities to intervene.

LET'S REVIEW THE SKILLS WE LEARNED

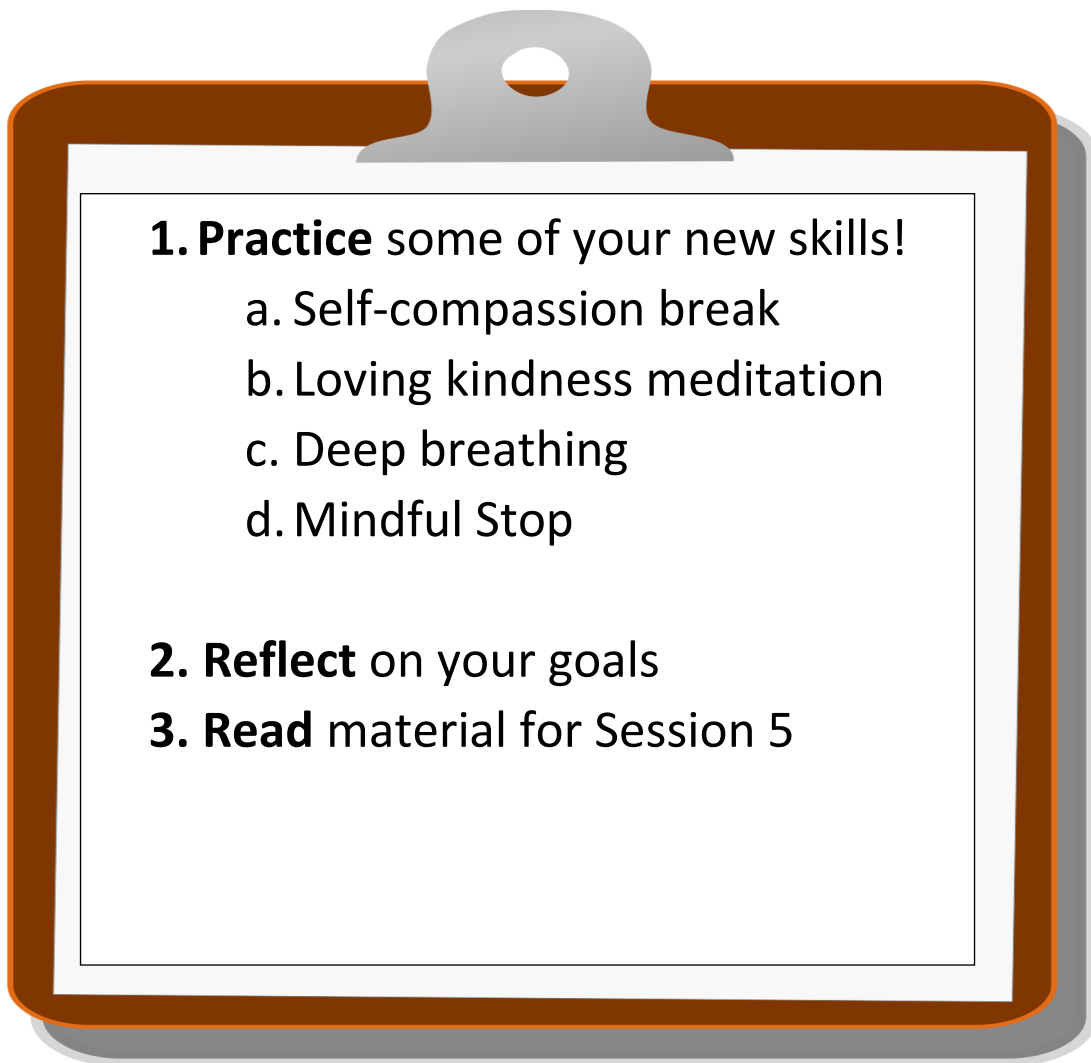
SKILL	Summary/Definition	When to use	My experience with this skill
Deep Breathing	Breathe slowly and don't try to force it.	You are feeling upset, frustrated, anxious or overwhelmed	
Stress Spiral	Map out stressors and identify the thoughts, behaviors, emotions and physical sensations	Recognize your thought spiral and change your thought pattern.	
Mindful Stop	Observe, Describe, Act with Awareness	Use this to get out of the stress spiral	
Loving Kindness Meditation	A meditation to give yourself compassion	Daily when you need kindness	
Self-Compassion Break	A skill to take a moment for yourself	When you feel guilt or feel you could have done better	
Behavior Triggers	Know common trigger stress for caregivers and their loved ones	Use this to fill out the stress spiral	
Communication examples	Strategies on how to respond to difficult behaviors	Use when you are Acting with Awareness in the Mindful Stop	

Learning Summary

- In this session, we learned about common behaviors of people living with dementia and possible strategies to use.
- We reviewed the mindfulness and self-compassion skills.
- The group discussed difficult real-life scenarios and strategies that have worked for us and others.

Rx

Home Practice



1. Practice some of your new skills!

- a. Self-compassion break
- b. Loving kindness meditation
- c. Deep breathing
- d. Mindful Stop

2. Reflect on your goals

3. Read material for Session 5

MIRACLE OF MORNING

By Amanda Gorman

I thought I'd awaken to a world in mourning.
Heavy clouds crowding, a society storming.
But there's something different on this golden morning.
Something magical in the sunlight, wide and warming.

While we might feel small, separate, and all alone,
Our people have never been more tightly tethered,
Because the question isn't if we will weather this unknown,
But how we will weather this unknown together.

So on this meaningful morn, we mourn and we mend.
Like light, we can't be broken, even when we bend.

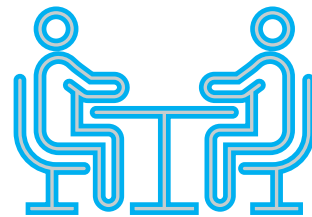
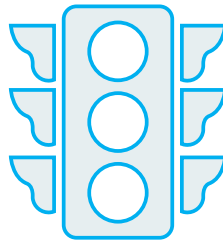
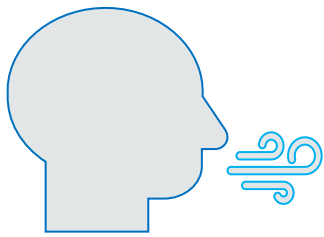
As one, we will defeat both despair and disease.
We stand with healthcare heroes and all employees.
We ignite not in the light, but in lack thereof,
For it is in loss that we truly learn to love.
In this chaos, we will discover clarity.
In suffering, we must find solidarity.

For it's our grief that gives us our gratitude,
Shows us how to find hope, if we ever shall lose it.
So don't ignore the pain. Give it purpose. Use it.
Read children's books, dance alone to DJ music.
Know that this distance will make our hearts grow fonder.
From a wave of woes our world will emerge stronger.

We'll observe how the burdens braved by humankind,
Are also those moments that make us humans, kind;
Let each dawn find us courageous, brought closer;
Heeding the light before the fight is over.
When this ends, we'll smile sweetly, finally seeing,
In testing times, we became the best of beings.

SESSION 6

Putting It All Together



In Session 6, we will:

- **Check-In:** Share with the group
- **Discuss:** Continuing to use skills
- **Skill Practice:** Stress Spiral, Mindful Stop, and Problem-Solving Scenarios
- **Reflect:** Your goals and the program
- **Learning Summary** Taking tools into real life
- **Home Practice**

Check-In:

- 1) Looking back, which program skills do you feel has been the most effective for you in your caregiving?
- 2) How do you feel like you will be able to continue using these skills after the program is over?



Skill Practice: Problem Solving Scenarios

Reflect on a recent situation when your loved one exhibited challenging behaviors/mood.

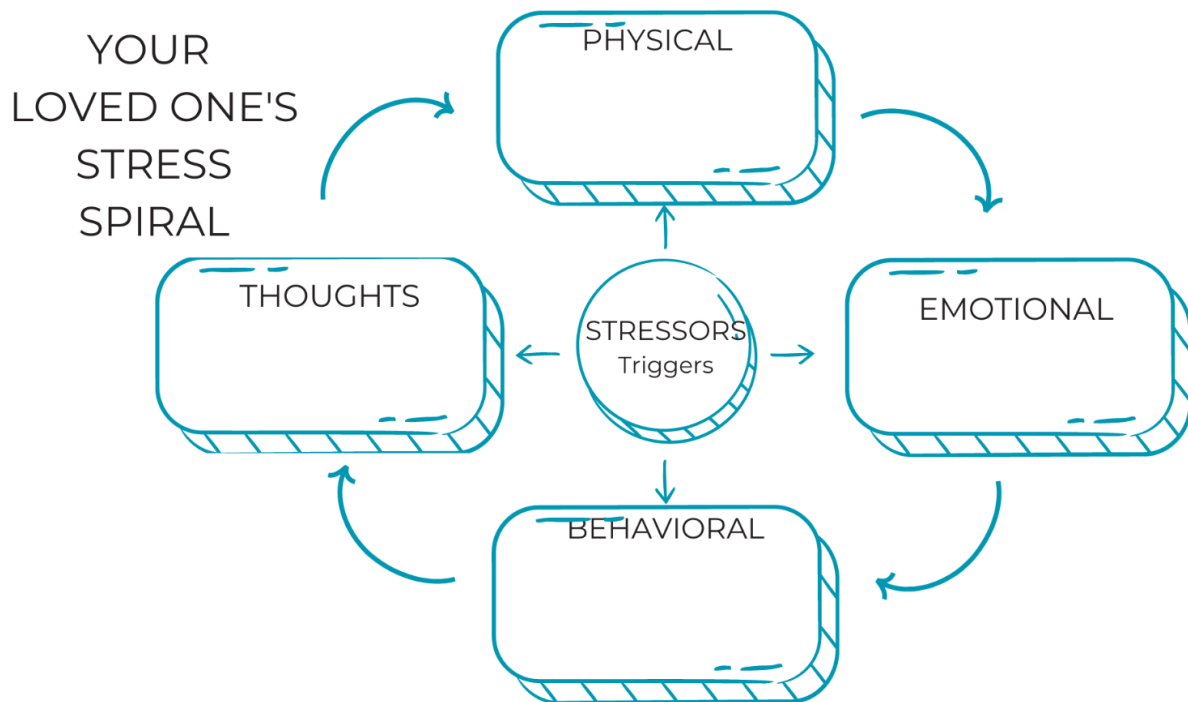
Were you able to use any of the skills learned in the SOCIAL program? If so, which ones?

What, if anything, remains challenging about this situation for you?
What might you try next time?

We will use this information and work as a group to identify additional opportunities to intervene.

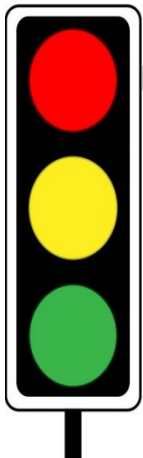
Skill Review: Stress Spiral and Mindful Stop

Think of a challenging behavior that occurred and how you used the stress spiral to change and share it with the group!



OBSERVE

MINDFUL STOP



RED

I notice my loved one _____

They are responding by _____

GREEN

I can respond by _____

Reflect: Your goals and the program

Reflect on your participation in the program.

What were your goals? Did you meet them?








What goals do you want to take forward?

What parts would you like to take with you?

What could we do to support you continuing using these tools?

Learning Review Taking tools into real life

Let's come up with a plan for how and why to keep practicing these skills moving forward.

	SKILL	When I will use it	Why I will use it
	Deep Breathing		
	Stress Spiral		
	Mindful Stop		
	Loving Kindness Meditation		
	Self-Compassion Break		
	Behavior Triggers		
	Communication Examples		

CONGRATULATIONS!

*YOU HAVE GRADUATED FROM THE SOCIAL SKILLS PROGRAM.
WE HOPE YOU HAVE ENJOYED THE PROGRAM AND LEARNED
NEW SKILLS TO MANAGE STRESS RELATED TO BEING A
CAREGIVER OF A LOVED ONE WITH DEMENTIA.*

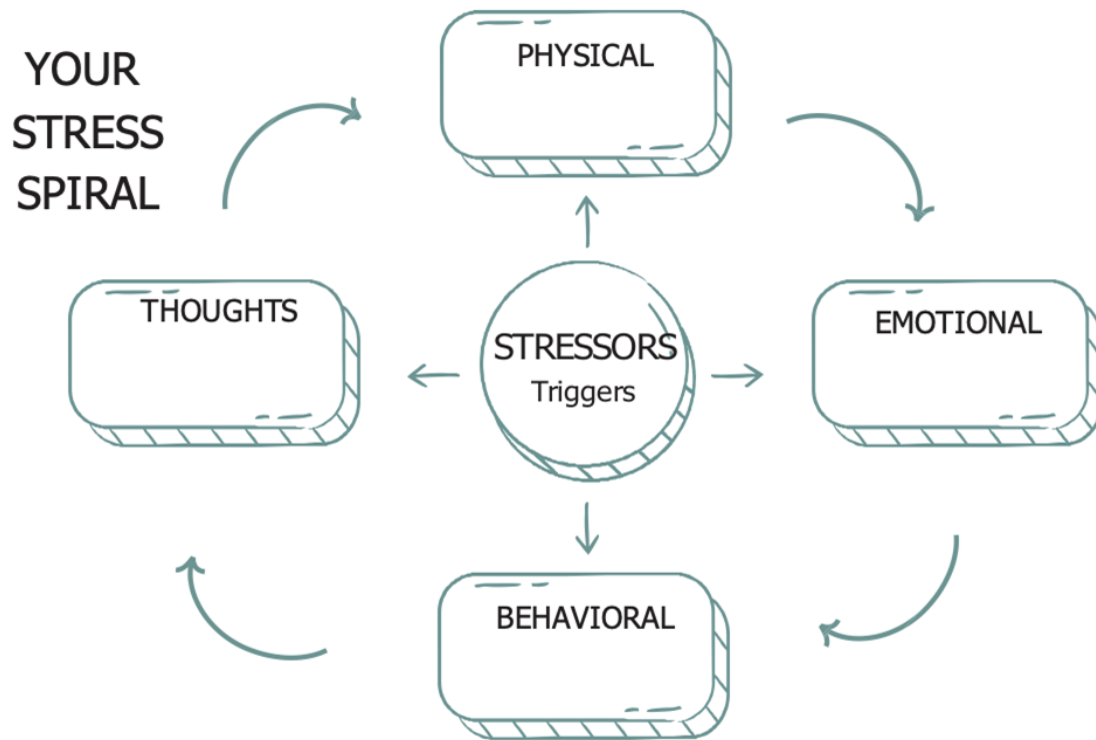


**REMEMBER, YOU CAN ALWAYS VISIT THE SOCIAL WEBSITE TO
PRACTICE MASC SKILLS**

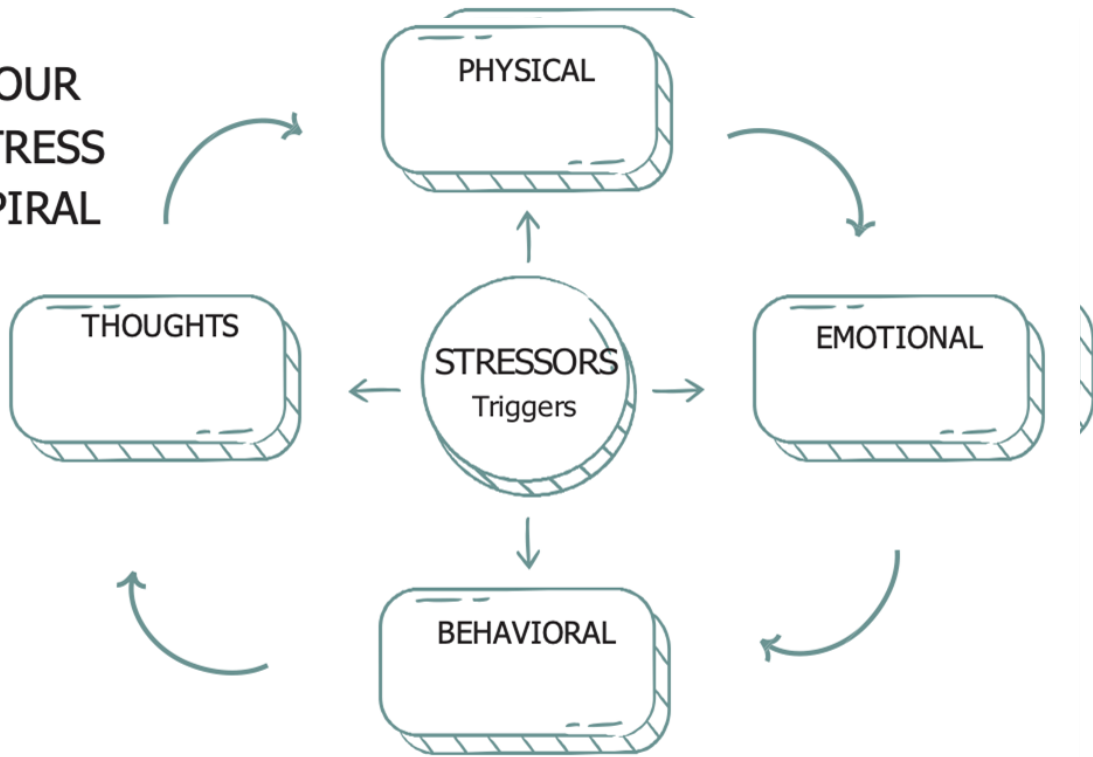
<https://www.social1studymgh.com/sessions-1>

APPENDIX

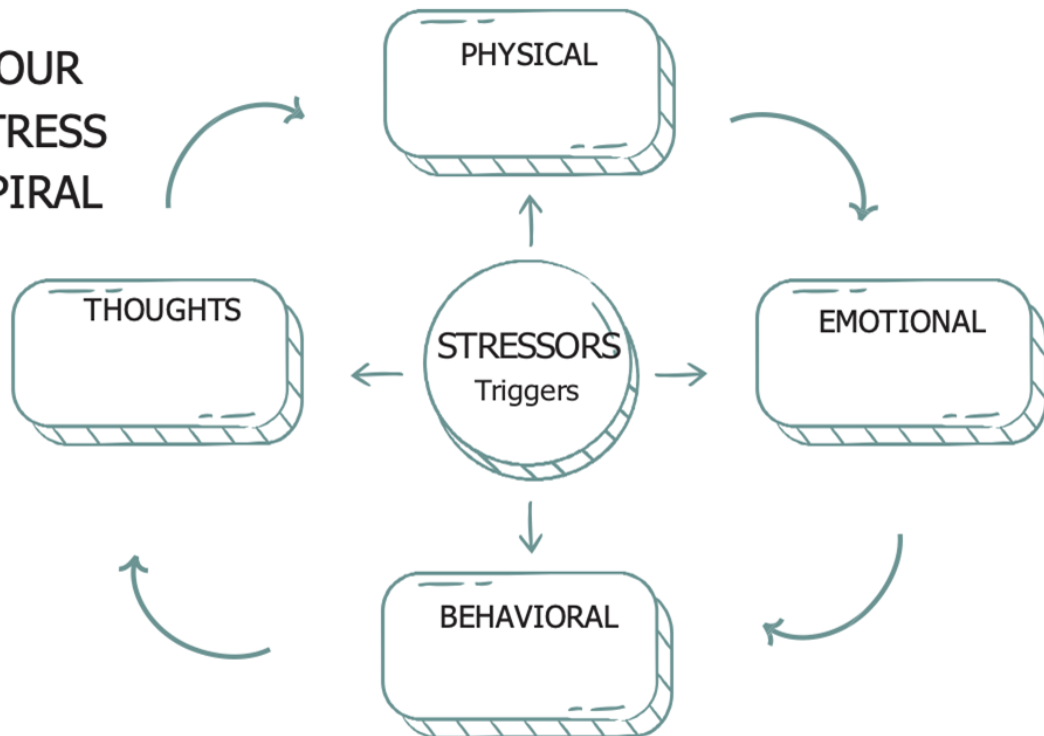
Extra Worksheets



YOUR
STRESS
SPIRAL



YOUR
STRESS
SPIRAL



Deep Breathing Exercise

Sit in a comfortable position, with your feet flat on the floor and your back straight. Note the level of tension you are feeling. Then place one hand on your chest and the other hand on your abdomen.

Inhale slowly and deeply through your nose into the "bottom" of your lungs--in other words, send the air as low down as you can. If you are breathing from your abdomen, your hand should actually rise. Your chest should move only slightly, while your stomach expands.

When you have taken in a full breath, pause for a moment and then exhale slowly through your nose or mouth, depending on your preference. As you exhale feel your abdomen contract. As you exhale, allow your whole body to just let go (you might visualize your arms and legs going loose and limp like a rag doll).

Be aware of the natural short pause after exhaling and before beginning a new breath – this is a moment of maximum relaxation the entire body is at rest.

Do five slow, full abdominal breaths. Try to keep your breathing smooth and regular, without gulping in a big breath or letting your breath out all at once.

Remember to pause briefly at the end of each inhalation.

Breathe in 1, 2, 3, breathe out 3, 2, 1 Pause

Breathe in 1, 2, 3, breathe out 3, 2, 1

Breathe in 1, 2, 3, breathe out 3, 2, 1

Breathe in 1, 2, 3, breathe out 3, 2, 1

Keep doing this for a few minutes on your own.

Skill Practice: Loving Kindness Exercise

Lovingkindness meditation, even brief, naturally nurtures compassion and an open heart radiates kindness to others and the world.

This is a simple GUIDE. You can go through it slowly and stop and practice at your own rhythm. Sit comfortably with your back straight.

- 1) Take a breath to become present in your body. Take your time.
- 2) Imagine yourself in a peaceful place where you are relaxed. Imagine being filled with a warm light of love surrounding you and imagine it is wrapping you in a blanket of love and compassion.
- 3) Now put this lovingkindness and warmth that you are receiving into words. Adapt the words so they reflect your personal wishes and situation. Here's one example:

May (insert name of person here) be held in lovingkindness.

May (name) be happy.

May (name) be connected and calm.

May their heart know peace.

Repeat the wishes at least three times, out loud or in your mind. Savor them. Take your time. Feel their ability to warm and open the heart.

Other Metta phrases

- *May I be filled with lovingkindness.*
- *May I be safe from inner and outer dangers.*
- *May I be well in body and mind.*
- *May I be at ease and happy.*
- *May I be peaceful, happy, and light in body and in mind.*
- *May I be safe and free from accidents.*
- *May I be free from anger, unwholesome state of mind like fear and worries.*
- *May I know to look at myself with the eyes of understanding and love.*
- *May I be able to recognize and touch the seeds of joy and happiness in myself.*
- *May I learn how to nourish myself with joy each day.*
- *May I be able to live fresh, solid, and free.*
- *May I not fall into the state of indifference or be caught in the extremes of attachment or aversion.*

For Others

- *May he or she be peaceful and light in his or her body and mind.*
- *May he/she be safe and free from accidents.*
- *May she be free from anger, unwholesome state of mind like fear and worries.*
- *May she know to look at herself with the eyes of understanding and love.*
- *May all beings be peaceful and light in their body and mind.*
- *May all beings be safe and free from accidents.*

Skill Practice: Loving Kindness Exercise extend to others

You can also expand your loving kindness out to others, it is the same process as above, but you imagine

- A loved one, sending love to them
- A person you are neutral about
- A person you don't like
- Your community
- The world

Skill Practice: Self-Compassion Break

This is a quick exercise you can use whenever you need a little self-compassion. Maybe you're getting frustrated with your loved one and feeling overwhelmed. This exercise will help you extend kindness to yourself when you need it most.

Call to mind a particularly difficult situation you're dealing with right now.

- Breathe, see if you can feel stress or emotional discomfort in your body.

Be mindful of the thoughts, emotions and sensations that are coming up.

- Try saying to yourself: “This is a moment of difficulty” or “This is stressful.” Notice and accept these feelings for a moment without trying to push them away.

Take a moment to acknowledge that you're not alone. Think of all the caregivers around the world who are experiencing similar frustrations right now and everyone who has come before you.



- Try saying “Other people feel this way” or “I’m not alone.”

Now place your hands over your heart. Feel the warmth and gentle touch of your hands on your chest or a soothing place that feels right for you.

- Say to yourself: “am worthy of love and kindness

Ask yourself, what do I need to hear right now to express kindness to myself? Is there a phrase that speaks to you?

You may come up with your own or try the following:

- I am worthy of love and kindness
- I wish happiness for myself
- I forgive myself for getting frustrated with my loved ones; I am human.
- I am doing the best I can in this moment.
- This too, will pass.

