

# CARING WITH PRESENCE

A MINDFUL APPROACH TO CARING FOR SOMEONE LIVING  
WITH DEMENTIA

JANUARY 25, 2023

---

**MICHELLE BARCLAY, MA**

THE BARCLAY GROUP, LLC



# SPONSORED BY

---



CATHOLIC CHARITIES  
HAWAI'I  
CIRCLE OF CARE FOR DEMENTIA



HALE KŪ'IKE



The Barclay  
Group

# ACKNOWLEDGEMENTS & DISCLOSURES

---

- Presence Care Project



- Michigan Alzheimer's Disease Center



- Health Partners



- Ray Dolby Brain Health Center



# INTENTIONS

---

# OBJECTIVES



Understand mindfulness and its benefits for dementia care partners



Learn ways to bring awareness, connection, love & compassion to daily life



Discover mindful habits that can lower stress and enhance well-being



Practice new skills that you can continue to use at home

# Invitations



being curious



give yourself this time to be here



in real time, observe what is occurring with an attitude of curiosity & kindness



decide what you need to remain present



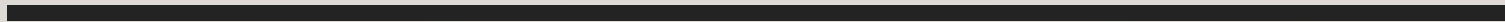
take care of yourself



humor and kindness toward what comes up



permission to let go of note taking and just be







# Welcome & Arrival Practice

“WHEN I AM CONSTANTLY RUNNING,  
THERE IS NO TIME FOR BEING. WHEN  
THERE IS NO TIME FOR BEING, THERE IS  
NO TIME FOR LISTENING.”

---

- MADELEINE L'ENGLE



# Intentional & Attentional Awareness

WHAT QUALITIES WOULD YOU LIKE TO CULTIVATE?

---



Open Chat to Attendees





# Mindful Check-In

## Sitting With Intentions

“I CAN BE A CARE-PARTNER WITH YOU, COMMUNICATING MY TRUE FEELINGS, MY TRUE NEEDS, SO THAT YOU CAN WALK ALONGSIDE ME, ADJUSTING AND COMPENSATING FOR THESE EXPRESSED NEEDS AS WE FACE THIS STRUGGLE TOGETHER.”

---

- CHRISTINE BRYDEN



# WHAT IS MINDFULNESS?

---

Mindfulness means paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.

Jon Kabat-Zinn



*Photo credit: Michelle Barclay 2016*

# MINDFULNESS IS:

---

- A practice and a way of being in a wise relationship with the moment and in our lives
- About becoming less reactive and more intentionally present
- A willingness to modify our perspective
- Fostered by “assuming a stance of an impartial witness to your own experience.”
- Observing our impulses and ultimately, having the skillful means to respond thoughtfully to life as it unfolds – moment by moment





# CULTIVATING MINDFULNESS

---



Cultivating mindfulness is training the mind to develop greater awareness of the present moment, including current physical sensations, thoughts and feelings, with a spirit of curiosity, wonder and friendliness.


# MINDFULNESS MEDITATION

---

- A tool to train our brains.
- A practice of learning to notice when the mind has wandered, and gently bringing it back to the present moment, usually by focusing on something that's happening in the present, like our breathing.
- It's simple, yet absolutely challenging!







# Mindful Check-In Presence Practice

“LIFE IS ALL A MEMORY, EXCEPT FOR THE  
ONE PRESENT MOMENT THAT GOES BY  
YOU SO QUICKLY, YOU HARDLY CATCH  
IT GOING.”

---

- TENNESSEE WILLIAMS



# HOW IS MINDFULNESS HELPFUL FOR CARE PARTNERS?

---

- Living with a brain disease is **unexpected**, often **unpredictable** and **frustrating**, and very **stressful**.
- Most care partners experience chronic physical and/or emotional stress, which **weakens their immune system** and leads premature aging of cells (telomeres) and dis-ease.
- Most care partners are concerned about maintaining their own **health and well-being**.
- Many care partners experience **depression** and other mood changes that can make **caregiving more difficult**.





# CARE PARTNER PARACHUTES

---

It's not the load that breaks you  
down. It's the way you carry it.

Lena Horne



5

# WAYS MINDFULNESS SUPPORTS CARE PARTNERS

**CARING WITH PRESENCE**

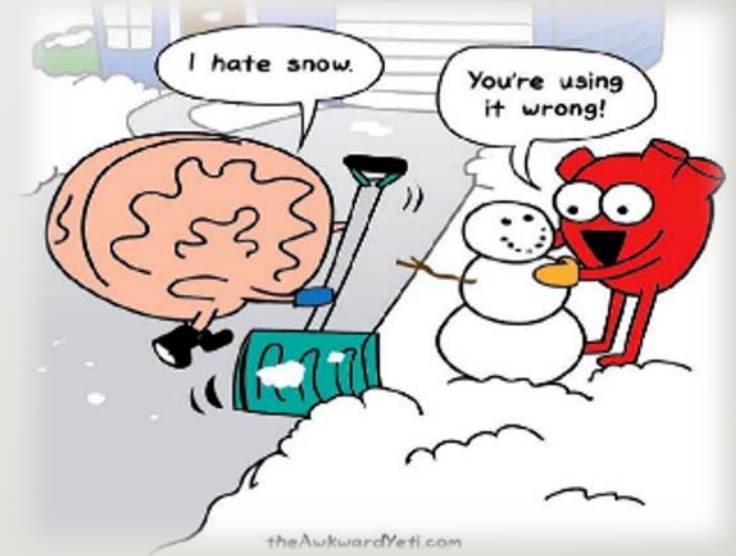
---





1

## EXPERIENCE STRESS DIFFERENTLY



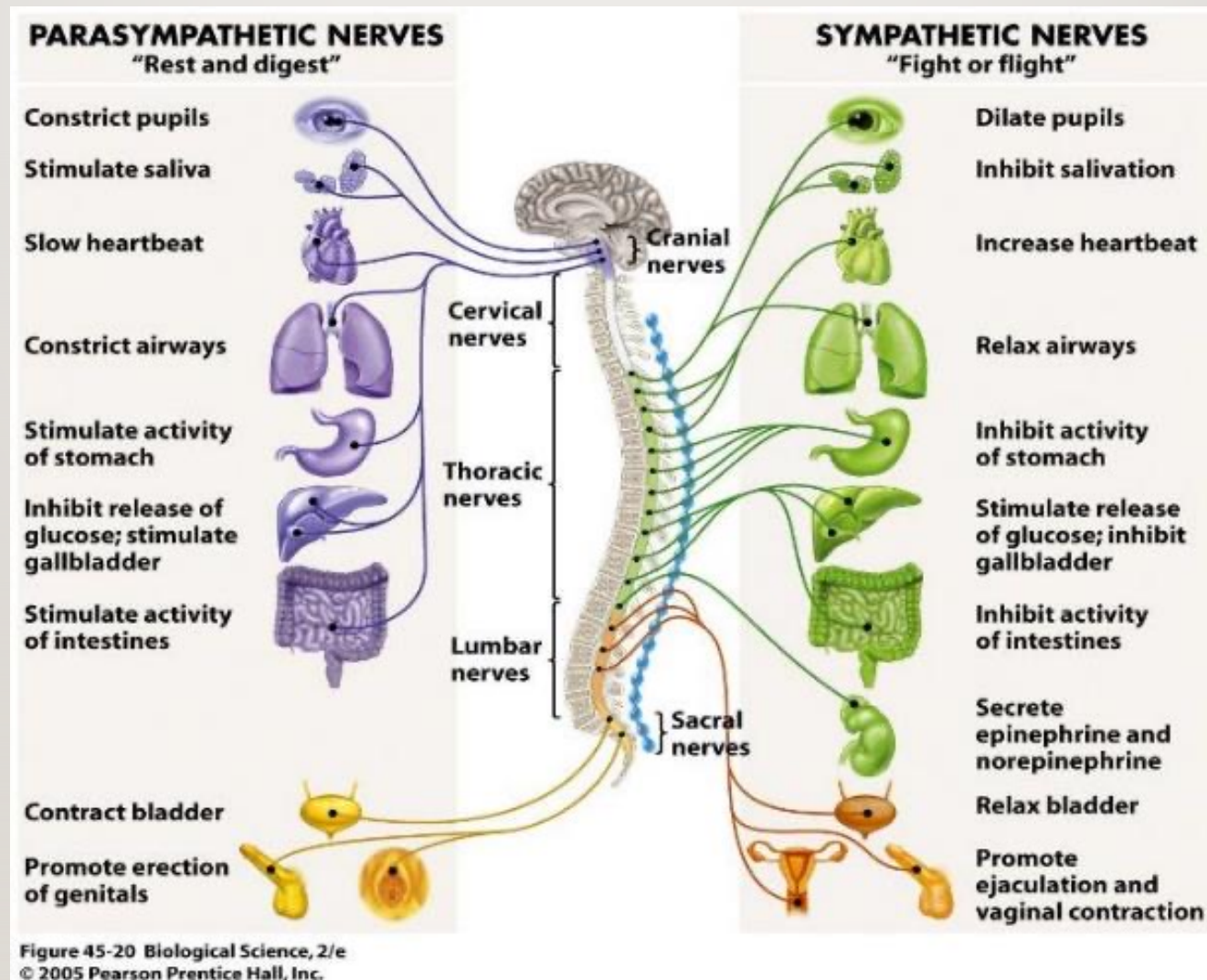
---

MINDFULNESS PRACTICE SUPPORTS CARE PARTNERS IN UNDERSTANDING THE COMPLEXITY OF THEIR STRESSORS AND FROM THIS AWARENESS, KNOW HOW TO APPLY THIS KNOWLEDGE TO IMPROVE THEIR HEALTH & WELL-BEING.

# STRESS REDUCTION



→  
Mindfulness





# KNOWING YOU'VE BEEN HIJACKED

---



***“The emotional brain responds to an event more quickly than the thinking brain.” - Daniel Goldman, Ph.D.***

- Strong and sudden emotional reaction
- Say or do something insensitive, hurtful, counter to our intentions
- The after-effect lingers & we do not recover easily
- It taints our behavior, mood and decisions beyond the time of the interaction







# Mindful Check-In

## Awareness of Embodied Stress

ONE VERY IMPORTANT DOMAIN OF OUR LIVES  
AND EXPERIENCE THAT WE TEND TO MISS,  
IGNORE, ABUSE OR LOSE CONTROL OF AS A  
RESULT OF BEING IN THE AUTOMATIC PILOT  
MODE IS OUR OWN BODY.”

---

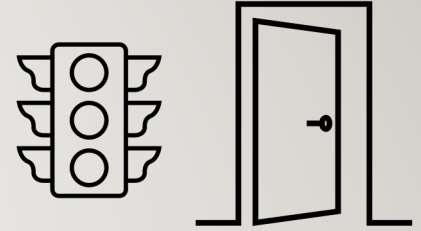
- JON KABAT ZINN



2

## CLARIFY NEEDS

---



MINDFULNESS PRACTICE HELPS CARE PARTNERS BE **HIGHLY ATTUNED** TO THEIR PARTNER AND **AWARE** OF THEIR PARTNER'S NEEDS, AS DIFFERENTIATED FROM THEIR OWN.





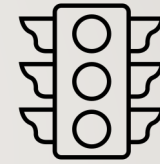
# STOP Practice



- 
- STOP
  - Take a Breath (or 3)
  - Observe what's happening
  - Proceed (and praise)



## SANDY: “LITTLE STOPS”



---

*“The other thing was the little STOP sign, and I laminated that on a stone and I carry that in my pocket. And then every time I needed it, it was in my pocket and I would feel it, and I went through the four steps, and that was a huge game 3 changer, too. My husband is now living in a memory care facility and I’m able to go back and visit him again, and I always stop in the door and greet him so that before I’m right there in his face. And I just do it naturally. So just approach someone slowly, I guess, is the key.” – Sandy K.*





# Mindful Practice:

## ‘Before Meeting’ or Doorway Practice

Entering with intention, awareness & compassion



- 1. Begin with STOP
- 2. When ready, connect with compassionate intention for yourself and the person(s) on the other side of the door
- *Such as....*
- May I be patient / May we be patient
- May I be calm / May we be calm
- May I be kind / May we be kind



3

## INTEGRATE SELF CARE



*"I can't sleep. I think I'll get up and solve all my problems."*

---

MINDFULNESS PRACTICE  
SUPPORTS CARE PARTNERS  
IN RECOGNIZING HOW &  
WHEN TO PROVIDE CARE  
FOR THEMSELVES.



## CAROL: “TAKE CARE OF YOURSELF”

---

*“It does reinforce for me the importance of caring for yourself, and that, you know, you need to put your own, as they tell you on the airlines, put your oxygen mask on first is so important, and do not ever minimize that value. Because you taking care of yourself, which we’re not always great at, is the most important thing you can do. Because if something happens to you, then that person you’re caring for is really going to be in a tough spot. And there just aren’t that many resources out there that provide so much support for the person giving the care and give you that space to feel that you’re worthy of that. Even though, you know, you don’t have Alzheimer’s, or in the broad scheme of things, between you and your partner, you’re ok. Gosh, you’re perfect. But there is so much care of self that really allows you to continue being a caregiver and allows you to continue caring for the rest of your family, which is as important as anything else.” - Carol D.*





# Know Your Refuges

- REFUGE: WHATEVER BRINGS YOU BACK TO YOUR GROUNDED, SECURE, SAFE, CENTERED SELF
- BRINGS ATTENTION TO THE MOMENT (“IN THE ZONE”)
- EYE OF THE STORM
- INVESTMENT IN RESILIENCE
- MINDFULNESS IS A REFUGE AND CREATES ACCESS TO OTHER REFUGES

*WHAT ARE YOUR REFUGES?*

*HOW MIGHT YOU BRING REFUGE PRACTICE INTO YOUR DAILY ROUTINE?*



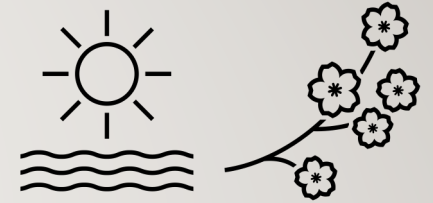
Open Chat to Attendees



4

## BALANCE THE NEGATIVITY BIAS

---



MINDFULNESS SUPPORTS  
CARE PARTNERS IN  
SPENDING TIME ***TAKING IN  
THE GOOD AND  
CULTIVATING GRATITUDE.***





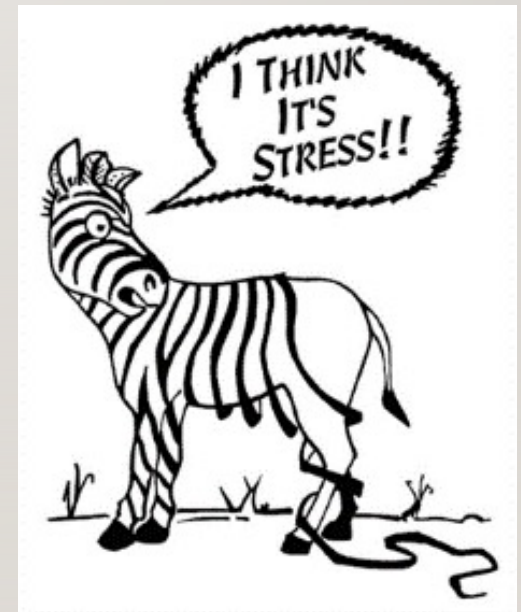
# THE BRAIN'S NEGATIVITY BIAS

---

Our mind is wired to focus on what's wrong, or what could go wrong (survival instinct).

*"I've lived through some terrible things in my life, some of which have actually happened."*

~Mark Twain



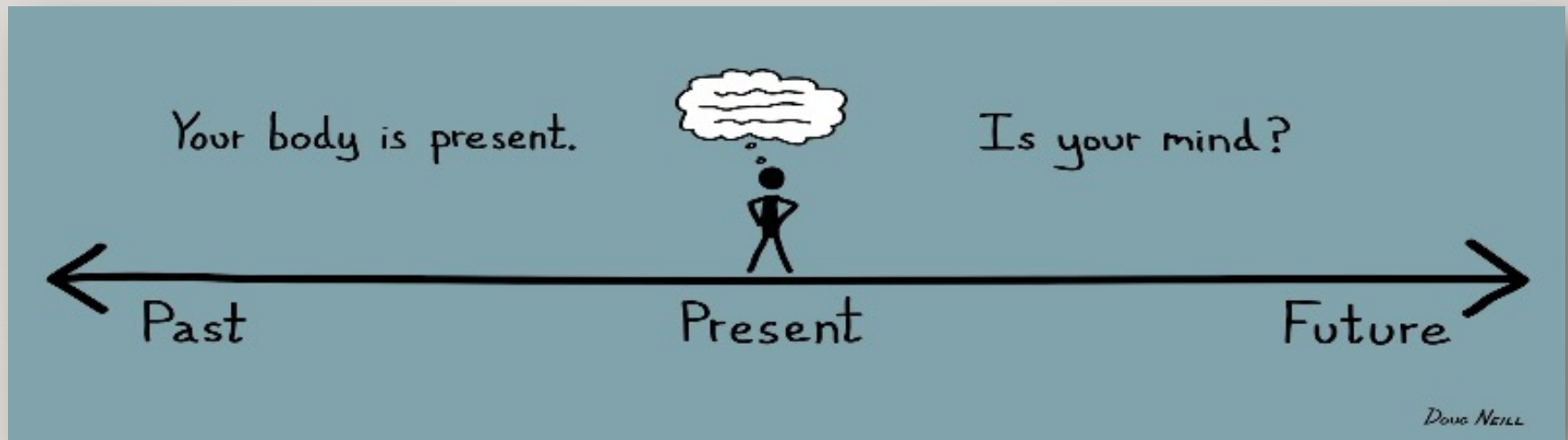
# THE “MINDLESS” BRAIN

AUTOPILOT + NEGATIVITY BIAS = DIS-EASE



Our minds are developed to think and plan for us, so they wander around a lot.

- Harvard Study<sup>1</sup>: 47% of our waking time is spent NOT paying attention to the present moment – “lost in thought”.
- Where your mind wanders impacts your happiness and wellbeing<sup>2</sup>.



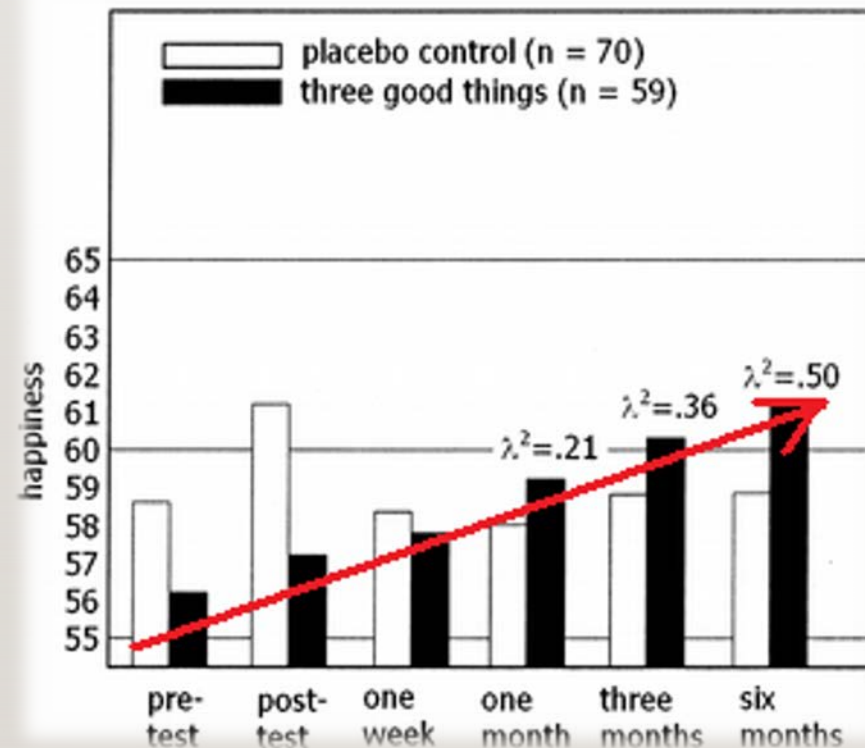
1. Killingsworth & Gilbert, 2010. 2. Seli, Carriere et al., 2018.





# RESTORING EQUILIBRIUM

## ONE STRATEGY: 3 GOOD THINGS



Seligman, Steen, Park, & Peterson, 2005



## LIZ: “NOTICING & APPRECIATING THE GOOD”

---

*“Yeah, I think that the fact that the sessions start with meditation and mindfulness and appreciation for the small things... I’m really fortunate, I have four grandchildren that are the ages 6, 4, 3, and 2. And they have such joy with such little things. I mean, they can make a mundane watching of a bird or a butterfly just an exciting thing or blowing bubbles. They find such joy in little things, and I think, as adults, we lose that. So, the idea that we stop and we’re mindful of the small things and try to find peace and calmness... The meditation and mindfulness of this program has been very helpful.” - Liz F.*





# Cultivating Gratitude



- One to Three things you are grateful for today
  - Small or large
  - Person, Thing, Experience
- ***PAUSE: Notice How you feel.***
- ....add the 'because'
- I am grateful for \_\_\_\_\_ because \_\_\_\_\_.
- ***Notice how you feel now. Did adding the because change anything?***



Open Chat to Attendees



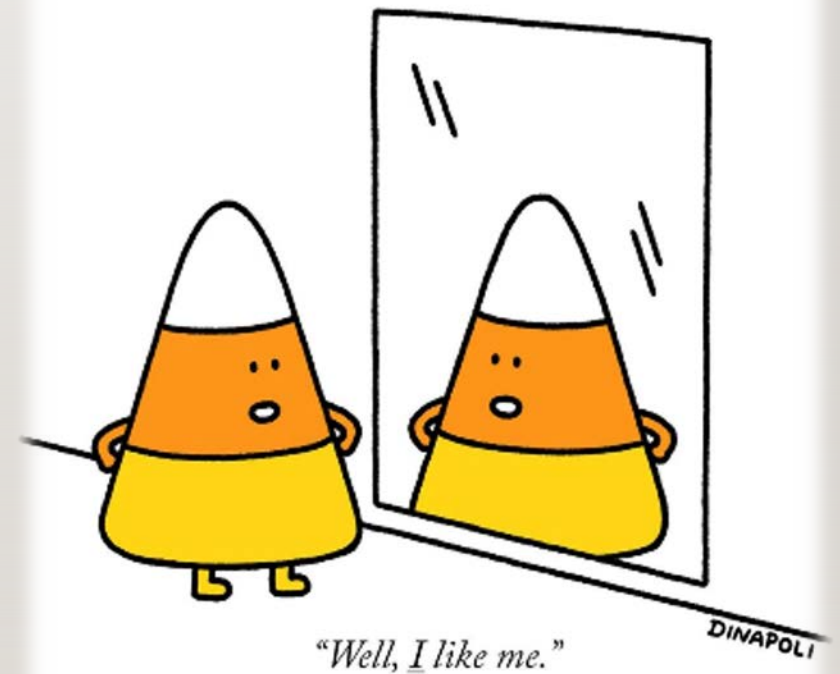
5



## CULTIVATE KINDNESS, PATIENCE & COMPASSION

---

MINDFUL CARE PARTNERS  
ARE **KIND AND  
COMPASSIONATE** WITH  
THEMSELVES, ESPECIALLY  
WHEN THEY MAKE MISTAKES  
OR ARE STRUGGLING WITH A  
CHALLENGE.



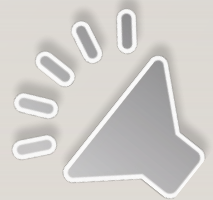




## CAROL: “TREAT YOURSELF WITH KINDNESS, PATIENCE & COMPASSION”

---

*“Tell yourself what an incredible job you’re doing, just as you would tell a friend who is manage all the things that you’re trying to manage. We’re always, I think, by our nature more critical of our own- of ourselves and we all know that in our hearts that we won’t have all the answers but we’re still going to proceed as best we can.” - Carol D.*





# Mindful Check-In Appreciation Practice



“SIMPLY GIVE TO YOURSELVES THAT  
WHICH YOU NEED – WHICH IS LOVE  
AND APPRECIATION WITHOUT  
JUDGMENT.”

---

- René Gaudette

**One gift or strength?**



**Open Chat to Attendees**



# REASONS TO PRACTICE

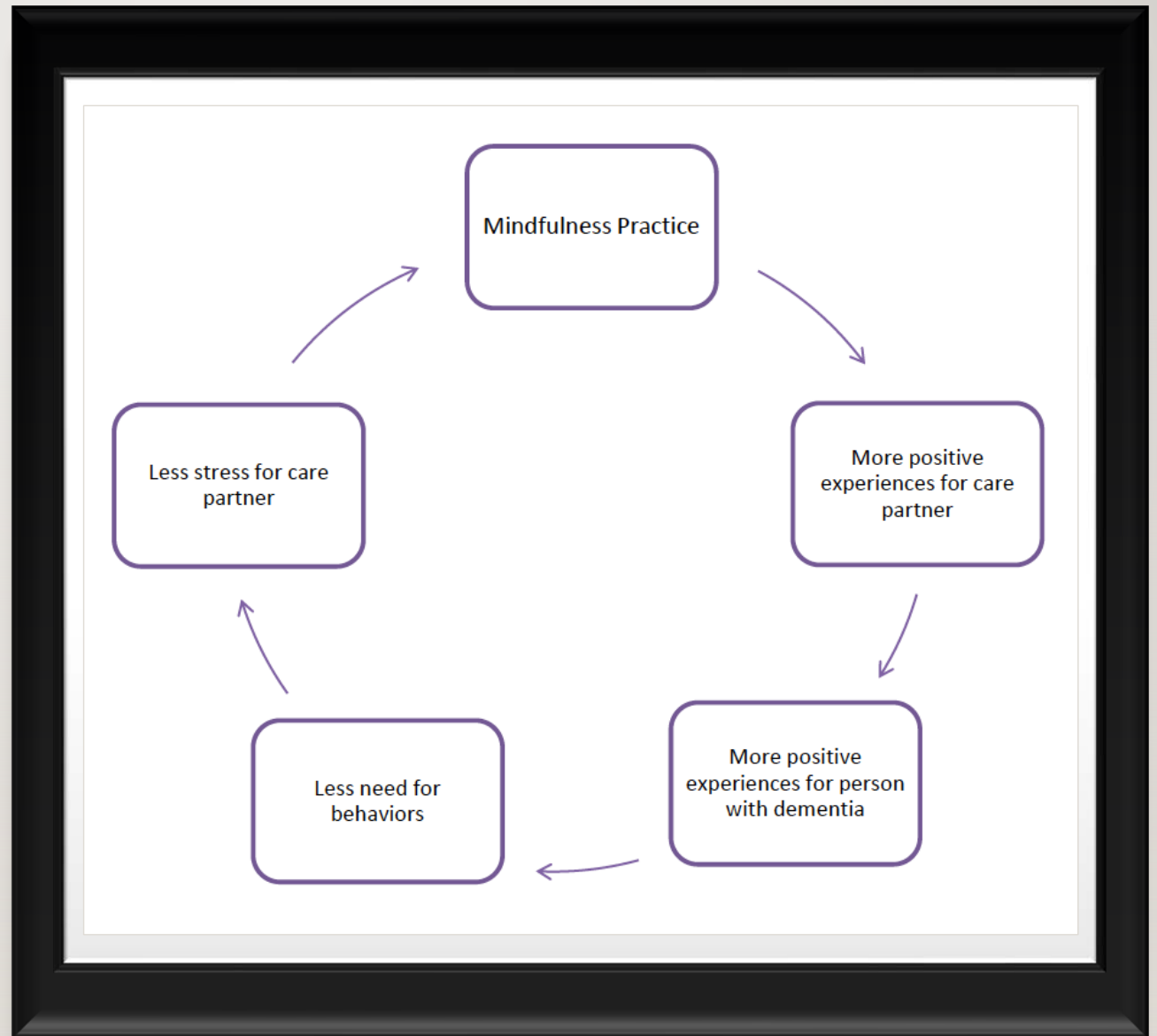
---



- To **reduce stress** and improve your mental & physical health
- To increase your sense of **self-efficacy** as a care partner
- To improve the **well-being** of the person in your care
- To decrease the frequency of challenging behavioral symptoms of Alzheimer's disease or other related dementias

# INFLUENCE OF MINDFULNESS PRACTICE

---





# JOAN: “MINDFULNESS & DEMENTIA”

---

*“When you start to notice changes in behavior with somebody you’ve been living with for a very long time, you have certain expectations about how that interaction and that relationship is going to work. And when you start to see changes that don’t fit with the person that you’ve known all those years (for instance, not initiating as many things as they have in the past, of joint kinds of things, or reacting in an upset and angry way which is out of character for them), you know, it causes you to feel angry and not valued by that person, and so you have that initial reaction. And what mindfulness does is gives you a sense to – you have a choice about how do you respond. Are you going to respond to those new behaviors, or are you going to stop and observe and take some time to reflect and start to figure out what’s going on and see how that might change what’s happening? And that’s a whole process, that doesn’t take place in a day.” – Joan B.*



# RECAP: PRACTICES FOR TOOLBOX

---

- Formal Practice: dedicate time every day to sit and focus attention on the present moment (guided meditations)
  - Awareness of Breath
  - Awareness of Body
- Informal or Micro Practices
  - STOP
  - Before Meeting
  - 3 Good Things
  - Gratitude
  - Self-appreciation practice



**What is one practice you will try?**



**Open Chat to Attendees**



# THIS IS A PRACTICE, NOT A PERFECT

---

*“It really works. I mean, you don’t think it does at first. There’s no way to do it right or wrong, or good or bad, it’s a process, and it will always be a process. And you really learn only after doing it many, many times how powerful and helpful a tool it is. And it’s always a process, it’s always a learning, you know, it’s not ‘oh, I’m now a master at mindfulness.’” - Bobbie T.*



“She was Zen five minutes ago.”

# PRACTICING FORWARD

---

- Experience small doses
  - Read, listen, practice at home or in your community
- Take a class (MBSR or MBDC)
  - **8 weeks is really just the beginning of developing a new skill for life**
- Experience a mini-retreat
  - ½ day facilitated time for mindfulness practice







# MINDFULNESS RESOURCES

---

## **Presence Care**

[www.presencecareproject.com](http://www.presencecareproject.com)

## **Apps**

The Mindfulness App

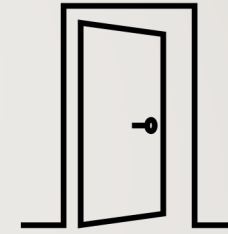
<http://themindfulnessapp.com/>

Insight Timer

<https://insighttimer.com/>



# MINDFUL CLOSING



---

*“Remember that caregiving is as hard as anything you’ve ever done. Whatever happens – and we know all the unpredictable, alarming things that can – the most valuable response is your steady, calm, and caring presence.”*

- Olivia Ames Hoblitzelle

