

Dementia Family Caregiver Wellness Guide

A rough and tumble practical DIY guide to being the best caregiver you can be

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One Day Mindfulness Millionaire: A light-hearted primer for the uninitiated.

Abhilash Desai and Faith Galliano Desai

Book available at store.bookbaby.com

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Each of us literally chooses, by his way of attending to things, what sort of a universe he shall appear to himself to inhabit.

- William James

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A Blessing for Caregivers

May the love in your soul guide you,
May the courage within you overcome fears about caregiving
May the heart within you conquer the pain involved in caregiving

May you be given the best education and training
To overcome challenges in this journey

May you have the commitment to care with compassion,
To learn from failures, to be patient
And be the best caregiver you can be

May you have great respect for yourself
May you show growing compassion and patience towards yourself
As you come to realize how much
The wellbeing of (name of the person needing care) depends on you.

May you have the wisdom to hear
The unspoken gratitude (name of the person needing care) has for you

And above all, may you be given the wonderful gift
Of meeting the beauty that is within you

May you be blessed, and may you find life
Enriched by your efforts of caregiving.

Adapted from John O'Donohue's poems

Introduction

Most family caregivers of persons living with dementia experience a lot of stress, burnout, and depression. Anxiety, fear, worries, sadness, grief, guilt, anger, resentment and despair become new family members in the home for many caregivers – especially if they do not have adequate support from family, friends and community including healthcare professionals.

It is often the case that the caregivers need more help and support than the person with dementia. It is common to see that the person with dementia scores higher on a 0-10 scale of “are you okay” (10 being totally okay / fine) compared to their family caregiver.

LOSILDA is the elephant in the room of caregivers that no one talks about.

LOSILDA = Loneliness, Social isolation, Living daily alone.

It is time all of us especially healthcare professionals make caregiver wellness as much of a priority as the wellness of persons with dementia. In fact, caregiver wellness may be the single greatest determinant of wellness of the person with dementia.

Our hope with this eBook is to provide education and guidance on all the things we can do to reduce caregiver burden, caregiver stress and promote healing, wellness and even joy in care-partnering and living the best life possible for both, the caregivers and their loved ones with dementia.

Three Pillars of Dementia Caregiver / Care Partner Wellness

1. At least one more family / friend is helping them on a daily basis with “grunt” work – scheduling appointments, transportation, filling paper work, accompanying the caregiver during a visit to explain / clarify / recall what was said during the visit with the healthcare provider, etc. Typically, this is a son or a daughter or a grandson or a granddaughter helping the parent / grandparent whose partner / spouse has dementia. Just physical presence of another person (ideally someone who is eternally positive and calm) in the house will do the trick. Audio – video recording last five minutes of a visit with the PCP / dementia expert where the physician / APP (advanced practice professional such as a nurse practitioner or a physician assistant) summarizes the care plan is recommended. This is in addition to care plan and recommendations given on a paper / document. Hiring a geriatric care manager may be considered if financially feasible to help with this kind of support.
2. Respite: Caregivers / Care Partners need breaks every day for a few hours ideally.
3. Easy access to experts: In many situations, dementia experts can quickly identify root cause and suggest corrections and solutions that are easy and practical. Telemedicine and Telepsychiatry is already revolutionizing access of caregivers / care partners to expert guidance.

Supporting Caregiver Wellbeing: Five Key Areas

If caregivers are well, they are able to interact with the person with dementia in positive ways. Healthcare professionals can provide education and skills training in the following areas to promote caregiver wellness.

1. Mindfulness: It is important for family and friend caregivers to approach their loved one with dementia in a mindful way. Mindfulness means that the caregiver is paying attention to the loved one non-judgmentally. Mindfulness is a journey and memory of past negative interactions with the person with dementia and worries about the future make it very difficult for the caregiver to be in the present with the loved one. Non-judgmental presence by the caregiver helps the person with dementia to feel secure and valued. Being present also allows the caregiver to become aware of numerous small positive interactions and experiences with the loved one that they can cherish. I encourage family members to engage in mindfulness training.
2. Validation: It is important for the caregivers to validate the experiences and feelings of the person with dementia. Authentic (sincere) validation helps the loved one recognize that they are being heard and understood and not ignored. Caregiver burnout is the most common reason for failures on the part of the caregivers to provide validation. I encourage caregivers to track their own level of burnout and take steps to prevent it and address it head on.
3. Trust: It is important for caregivers to trust the perspectives of the person with dementia. Persons with dementia have brilliant perspectives and all of us (not just family caregivers) need to recognize that and allow them to lead us as often as being led in their journey to live well with dementia. Negative cultural stereotypes (e.g., persons with dementia don't know what is going on so there is no reason to listen to them) is the key reason caregivers (both family and professional) fail to inquire their point of view or learn to listen to and see the creative ways the person with dementia is navigating challenges and seeking happiness.
4. Embracing imperfection: There are no road maps, only general guidelines that other caregivers and healthcare professionals can provide to the caregivers. Caregiving is complex, ever changing in its rules, and impossible to perfect. Caregivers need to be kind to themselves and not let their "numerous mistakes" and "frequent errors" get in the way of living and caring for self and loved one with kindness and forgiveness.
5. Sense of humor: It is not uncommon for the caregiver's sense of humor to be the first casualty of stress related to caring for their loved one with dementia. It is crucial for the caregiver to appreciate the tremendous value a healthy sense of humor has in living well with dementia. Healthy sense of humor is the strongest expression of spiritually defeating dementia.

Caregiver Dementia Questionnaire- CDQ-9 screening tool description

1. Do you forget that TRACing is counterproductive?
2. Do you forget that BITEing is counterproductive?
3. Do you forget that your loved one has dementia?
4. Do you repeat the same mistakes?
5. Do you forget to take time to maintain your health?
6. Do you forget what you have learned in support groups and caregiver education and training workshops?
7. Do you get confused about how to cope, what to say?
8. Do you have emotional outbursts?
9. Do you forget to give yourself a break?

TRACing = Testing, Reasoning, Arguing, Correcting

BITEing = Blaming, Insisting on reality, Taking symptoms personally, Expecting unrealistically

Resource Book: *Travelers to Unimaginable Lands*. Stories of dementia, caregiver, and the human brain. Dasha Kiper. Psychologist. We often provide education and training to family caregivers so that they can minimize TRACing and BITEing in their interactions with their loved one with dementia. This book beautifully and with great compassion illustrates just how hard it is for family caregivers to actually do that in day to day living.

Scored like PHQ-9 used for depression; 0-3 points for each. Max score 27.
5-12 mild; 13-20 moderate; 21-27 severe

Rx:

normalize (most caregivers develop mild caregiver dementia)

empathize

expand / improve utilization of their support network

respite

support group

individual counseling

bibliotherapy - Dasha Kiper's book

mindfulness skills training

creative engagement (e.g., journaling, Improv, poems, art)

other practical help

family interventions

participate in dementia friendly community programs like Memory Cafes

Caregiver Dementia 100% reversible but if not addressed, can leave serious negative effects on mental, spiritual and physical health. Reversing *caregiver dementia* is key to reducing AAD.

Note: I have made up this term *Caregiver Dementia*. No research to support this.

Caregiver Dementia Questionnaire – 9 CDQ-9

Name of the caregiver / care partner of the person living with dementia:
Date:

Over the past two weeks, how often:

#	Behavior	Not at all	Several days	More than half days	Nearly every day
1	Do you forget that TRACing is counterproductive?	0	1	2	3
2	Do you forget that BITEing is counterproductive?	0	1	2	3
3	Do you forget that your loved one has dementia?	0	1	2	3
4	Do you repeat the same mistakes?	0	1	2	3
5	Do you forget to take time to maintain your health?	0	1	2	3
6	Do you forget what you have learned in support groups and caregiver education and training workshops?	0	1	2	3
7	Do you get confused about how to cope, what to say?	0	1	2	3
8	Do you have emotional outbursts?	0	1	2	3
9	Do you forget to give yourself a break?	0	1	2	3

Score 0 + + +
Total score (max 27):

TRACing: Testing, Reasoning, Arguing, Correcting the person living with dementia.
BITEing: Blaming, Insisting on Reality, Taking things personally, Expecting unrealistically

Interpretation:

Mild Caregiver Dementia: 5-12

Moderate Caregiver Dementia: 13-20

Severe Caregiver Dementia: 21-27

Source: Abhilash Desai MD. Geriatric Psychiatrist. Dr.abhilashdesai@icloud.com

Note: This tool has NOT been researched / systematically studied. Dr. Desai has made up the term *Caregiver Dementia*. There is no research to support this concept.

Don't TRAC: Test Reason Argue Correct

A common cause of agitation is when family members (especially spouses and children) test their loved one with dementia, try to reason with them, argue with them or correct them.

It is important for family members to take a deep breath and go back to minimizing TRACing.

Don't:

- Test: avoid asking questions that require memory such as "what did you do today, what did you eat."
- Reason: avoid trying to reason with them and trying to use logic to get them to change their beliefs or behavior based on their perception of reality
- Argue: avoid going back and forth stating your point and perspective again and again
- Correct: avoid correcting them

We have seen agitation escalate to verbal abuse and even paranoia and physical aggression if the family caregiver continues to TRAC.

It is very difficult not to TRAC so family caregivers need lot of support and guidance in their efforts to master this important communication skill. In many situations, individual counseling is needed for family caregivers to tackle the trauma, grief, guilt, fear, and shame they are struggling to cope with.

Don't BITE: Blame, Insist on Reality, Take things personally, Expect unrealistically

A common cause of agitation is when family members (especially spouses and children) start either blaming the person with dementia or themselves about mistakes or setbacks; when family members insist on reality, take what the person with dementia says in anger, personally; and when family members have unrealistic expectations from their loved one with dementia.

It is important for family members to take a deep breath and go back to minimizing BITEing.

Don't:

- Blame: avoid blaming the person with dementia (e.g., "you make me feel bad about myself") or oneself (e.g., "see what you did, you are the reason she is unhappy").
- Insist on reality: avoid trying to insist that the loved one with dementia live in reality, especially your (family caregiver's) reality
- Take things personally: avoid believing every negative statement and accusation your loved one with dementia makes regarding you (e.g., "you are a terrible daughter for leaving me here" [meaning in the assisted living community])
- Expect unrealistically: avoid unrealistic expectations (e.g., the loved one with dementia will be reasonable or grateful for all the sacrifices you – the family caregiver – have made).

We have seen agitation escalate to verbal abuse and even paranoia and physical aggression if the family caregiver continues to BITE

It is very difficult not to BITE so family caregivers need lot of support and guidance in their efforts to master this important communication skill. In many situations, individual counseling is needed for family caregivers to tackle the trauma, grief, guilt, fear, and shame they are struggling to cope with.

T-A-DA method of managing agitation

Dr. Joseph Flaherty, geriatrician at Saint Louis University School of Medicine has a YouTube video on this. Please check it out. Although he describes this method to manage agitation in the context of delirium in the hospital setting, all the principles apply also to management of agitation in individuals with dementia.

T-A-DA is an acronym. It stands for:

T: Tolerate - increase your tolerance for negative behaviors of the loved one with dementia as often times, they are transient [like bad weather] and pass on their own).

A: Anticipate – anticipate the unmet needs and triggers so that agitation can be aborted. For example, anticipate that they will get agitated if not toileted frequently, if they don't drink adequately throughout the day, if they get constipated or are in pain. Best to see all agitation as a way of communication of unmet needs (biological needs like hunger; psychological needs like having a choice; social needs like companionship; spiritual needs like having a purpose).

DA: Don't Agitate. TRAC and BITE mentioned in earlier sections are common ways that family caregivers can worsen agitation. Other ways they can worsen agitation is by ignoring the persistent negative behaviors of the person with dementia (aka not investigating and meeting their unmet needs), and giving them psychiatric medications when the agitation is due to dehydration or pain or constipation or other biopsychosocial needs.

Mission Impossible

As we mentioned earlier, most family caregivers struggle to understand the negative emotions, statements, behaviors, verbal and physical abuse and paranoia expressed by their loved one with dementia. Family caregivers have told us that our suggestions on “Don’t TRAC” and “Don’t BITE” are “Mission Impossible” and that we are having unrealistic expectations from the family caregivers and we (my wife and I) are doing the same thing that we are telling them (the family caregivers) to stop doing. We are having unrealistic expectations from family caregivers.

We acknowledge everything that the family caregivers are saying and agree that it often is “Mission Impossible.” Both of us have been family caregivers to our elderly parents (one of them had vascular dementia) and it indeed was “Mission Impossible” at times.

With lot of support, guidance, role-playing (I take the role of the family caregiver and the family caregiver takes the role of their loved one with dementia), Improv, creative and compassionate engagement and communication, and time, we do feel that many family caregivers are able to dramatically reduce TRAC and BITE behaviors, increase T-A-DA approaches and will see amazing results in terms of not only reduction in agitation but even increase in frequency, duration and intensity of joyful and happy moments.

GLAD meditation
Gratitude Love Amazement Dialogue

Hello, and welcome to GLAD Meditation.

GLAD is an acronym for Gratitude, Love, Amazement, Dialogue.

This meditation will help you find moments of calm, strengthen your resilience and help you reconnect with gratitude, love, and amazement.

Instructions (are an invitation, you don't have to do it)

In this meditation you will be mindfully (with your heart) reading (in your mind) the five statements written below several times over a few minutes. In between each reading, you will bring one hand to your chest and another on your belly and take a few silent mindful breaths – watching your hands move with your chest and your belly. You will go back and forth between mindful reading and mindful breathing. During this meditation, your mind is likely to wander into the land of thinking. This is okay. No need to get upset. This is what our mind does. When you notice that your mind has wandered, gently bring it back to the meditation and begin again. Do this meditation for at least 3 minutes.

Get into a comfortable position. Gently close your eyes. Keeping eyes open and gaze directed downwards to a specific spot is fine.

Let's begin.

Dear ___ (name of your loved one)

Thank you for being in my life

I love you

You are amazing

Let's chat



STOP SMILE GO

S = Stop everything you are doing and close your eyes

T = Take 10 slow deep belly breaths with exhalation longer than inhalation

O = Observe your chest and belly moving

P = Pause - go back to regular breathing

SMILE - give a big smile to the universe. fake smile is totally okay

G = Express Gratitude to your breath - hello Breath, my old friend. Thank you for relaxing me again

O = Open your eyes and get back to what you were doing



Belly breath = Diaphragmatic breathing = belly comes out during inhalation and goes in during exhalation

Okay to breathe in through the nose and breathe out through the mouth

Remind yourself that by the end of this mind body exercise, your stress hormones (eg, cortisol) will have come down dramatically, heart rate would also slow down, blood pressure will come down, immune function and insulin signaling will have improved and prefrontal cortex (our CEO of the brain) will have strengthened

Do this once every hour on easy days. More often or longer on challenging days. Caregiving is stressful. You will be amazed at the power of even one-minute can bring you much needed momentary calm.

Count 10 breaths with fingers or count in your mind

Inspired by Zev Schuman-Olivier MD - STOP ACHE GO
Center for Mindfulness and Compassion <https://www.chacmc.org/stopacheho>

From Burnout to Joy in Caregiving – DIY Workshop

Four Session Workshop

In each workshop, you will be doing short meditations 5 minutes or more and discussion with yourself (CPR – contemplation, pondering, reflection) for a total time of at least 10 min per session. This DIY (do it yourself) workshop will provide you with skills of what to do to prevent burnout and improve your capacity to experience moments of joy. I hope you make your mental health a top priority and make such meditations and discussions (with yourself, your family, friends, pet, God, nature) a daily habit. We need to move from knowledge to skills to practice. This can also be workshop led by a mindfulness meditation teacher 😊. Feel free to increase the time to suit your needs.

Session One: *Don't* Meditations and discussion (10 min)

Session Two: *Gratitude* Meditations and discussion (10 min)

Session Three: Review of a research paper by Dr. Herbert Benson and his team on positive gene activity changes after 20 minutes of relaxation response, a short simple *ABC* meditation and discussion (10 min)

Session Four: *Compassion* (self-compassion and compassion for others) meditations and discussion (10 min)

Basic Meditation Instructions

We will be doing one short meditation (5 minutes or more) in each session. You can use the timer on your phone to mind the time. To get ready for the meditation, get into a comfortable position. Gently close your eyes. Keeping eyes open and looking down at a fixed spot is also fine. Do a quick body scan and shake lose any tension in your shoulder, neck, back and other muscle groups.

When possible, try to synchronize the words with your breath. Such synchronization strengthens our prefrontal cortex – part of the brain that helps us not be overwhelmed by our emotions. Feel free to modify the phrases to suit the needs of your heart.

Your mind is likely to wander, generally into the land of thinking (self-talk, inner chatter), worrying, planning, rehashing negative events, and having imaginary conversations. No need to be upset. That is what our minds do. When you notice that you have lost track, gently bring your awareness back to your breath and begin again.

After each meditation, gently bring your awareness to your surroundings and smile. Say in your mind, “cheers. You just completed a wonderful meditation.”

Session One:

Don't Meditations

Don't overreact

Don't take things personally

Don't sweat small stuff

It's all small stuff

Don't overreact

Don't take things personally

Don't sweat small stuff

It's all small stuff

Don't overreact

Don't take things personally

Don't sweat small stuff

It's all small stuff

Please do this first thing in the morning for at least a minute and sprinkle it in rest of your day. Feel free to add your own *Don'ts* (e.g., *Don't Overthink Don't Be Hard On Yourself Don't Be Hard On Others, Don't Overtry*). Let's get out of our own way my friend. Life is short. Smile of and on throughout today (as a message to self not to take life too seriously) - no reason smile is the best gift you can give yourself. Sad smile okay.

Discussion / CPR: What are the *Don'ts* and *Do's* (e.g., *Do Exercise* [to reach the level recommended by NIH – see info below] *Do Science-based Stress Management* [see info below]) that you have found helpful in managing your stress and strengthening emotional resilience? Please share your experience with this meditation and the phrases.

Session Two:

Gratitude Meditations

Let's listen to this 5-minute YouTube video by Father David Steindl-Rast on importance of cultivating gratitude

- "A Grateful Day" With Brother David Steindl-Rast https://www.youtube.com/watch?v=zSt7k_q_qRU

Now, let's do a short gratitude meditation.

In your mind, give your thankfulness to different people who are important in your life. Be as specific as possible and start from your immediate family (one person at a time) and move to friends, pets, larger circle of family and friends, work colleagues and individuals who have inspired you.

Discussion: Please share your experience watching the video and doing this meditation. Would you say that you have Gratitude Deficit Disorder (significant struggles to be grateful for what you have)? Let's discuss some barriers (e.g., unaddressed grief and trauma) to being grateful?

Session Three:

Review of a research paper by Dr. Herbert Benson and his team on positive gene activity changes after 20 minutes of relaxation response.

Research paper: Bhasin et al. Relaxation Response Induces Temporal Transcriptome Changes in Energy Metabolism, Insulin Secretion and Inflammatory Pathways. *PLOS One*. May 2013.

Available free on the internet (not providing the link intentionally as the link is several lines long). This is not the link to the study but summary of the study:

<https://www.sciencedaily.com/releases/2013/05/130501193204.htm>

ABC Meditation: Attentive Breath Counting. Breathing in, say One. Breathing out, say Two. Breathing in, say Three. And so on until you reach Ten. Then start again from one. Do this for at least two minutes.

Discussion: Please share your reaction to the findings of the paper discussed. Please share your practices / habits that you think would count as *Relaxation Response* (e.g., meditation, yoga, prayers).

Session Four: Final Session: Compassion Meditations

Self-compassion Mantra meditation: This meditation involves intentionally slowing the thoughts down and repeating out loud or in one's mind statements that reflect self-compassion. For example: "today I will show caring, understanding, and kindness to myself. I will be less judgmental to myself. I will encourage myself often. I will not be afraid to acknowledge my mistakes and weaknesses. I will accept them without being hard on myself." WISPing with a timer! Wallowing in Self-Pity (WISP aka Pity Party) is a normal and healthy expression of our emotional reaction to unfairness of life. The key is to use a timer so that the amount of WISPing matches the context and we do not spend too much time WISPing. Perhaps 10 minutes per day?

Compassion for others meditation:

Look at your loved one with dementia (or visualize them as vividly as is possible using all your senses as if they are sitting right next to you).

Breathing in, say: I take in your pain

Breathing out, say: I send relief (or peace)

Discussion: Please share your experience with these meditations. Would you say that you have weak Self-Compassion mindset (you are too hard on yourself, you are not your own best friend)? Are there family members or friends or colleagues you find difficult to have compassion for?

Recommended Resources

- (1) Why Health Professionals Should Cultivate Gratitude
https://greatergood.berkeley.edu/article/item/why_health_professionals_should_cultivate_gratitude
- (2) Book: *One Day Mindfulness Millionaire: Living Mindfully – A light-hearted primer for the uninitiated*. Abhilash Desai and Faith Galliano Desai. (eBook available).
<https://store.bookbaby.com/book/one-day-mindfulness-millionaire>
- (3) Free high-quality apps
 - a. Healthy Minds Program from the University of Wisconsin - Madison
 - b. Cleveland Clinic Wellness (ccw) Mindful Moments
 - c. UCLA Mindful
 - d. PTSD Coach by Veterans Administration
 - e. CBT-i Coach (CBT-insomnia) by Veterans Administration
- (4) Book: *Why Zebras Don't Get Ulcers*. By Robert Sapolsky.
- (5) Book: *Micro-trauma: A psychoanalytic understanding of cumulative psychic injury*. Margaret Crastnopol.
- (6) Book: *The Age of Overwhelm*. Laura van Dernoot Lipsky
- (7) How to Awaken Compassion at Work
https://greatergood.berkeley.edu/article/item/how_to_awaken_compassion_at_work
- (8) Can Compassion Training Help Physicians Avoid Burnout?
https://greatergood.berkeley.edu/article/item/can_compassion_training_help_physicians_avoid_burnout
- (9) Measuring Compassion in the Body
https://greatergood.berkeley.edu/article/item/measuring_compassion_in_the_body
- (10) The Compassion Paradox Faced by Healthcare Workers
https://greatergood.berkeley.edu/article/item/the_compassion_paradox_faced_by_health_care_workers
- (11) Can Empathy Protect You from Burnout?
https://greatergood.berkeley.edu/article/item/can_empathy_protect_you_from_burnout
- (12) Book: *Awe – The new science of everyday wonder and how it can transform your life*. Dacher Keltner. Must read.

A Mindful Way to Becoming A Wise Caregiver

Wisdom is the state of highly developed knowledge, understanding, and insight into human nature and the nature of reality.* Wisdom can also be considered as the judicious application of knowledge.

Neurobiologically, wisdom is an executive function that involves integration of rational thought processes, memory as well as utilization of emotions and body sensations as sources of information.

Mindfulness provides an opportunity to observe our habitual thoughts and perceptions, our automatic ways to reacting, and the narratives/scripts that run through our minds. At the same time, mindfulness gives us sufficient distance from what we observe that we are not swept away or drowned in our own thoughts, negative emotions, and habits. Through such observation, we can become more familiar with the nature of our mind and nature of reality.

Mindfulness provides energy to analyze and reflect on difficult and uncertain situations and issues related to the meaning and conduct of life. Mindfulness enables us to develop increasing comfort with uncertainty.

Mindfulness increases our awareness that the moments when there is synergy between mind and character are spiritually transformative.

Mindfulness allows us to see events and phenomena from different perspectives, a key characteristic of wise individuals.

Mindfulness helps us recognize the strong impact of culture on values and beliefs, another key characteristic of wise individuals.

Finally, mindfulness teaches us that, after all is said and done, our knowledge is limited, and that is okay. We can still make it if we have love.

*Ute Kunzmann. Wisdom: A Royal Road to Personality Growth. Chapter 20. *The Cambridge Handbook of Successful Aging*. (2019.)

Quotes and Resources on Wisdom

Rather than letting our negativity get the better of us, we could acknowledge that right now we feel like a piece of shit and not be squeamish about taking a good look.

- Pema Chodron

I learned a long time ago that the wisest thing I can do is be on my own side, be an advocate for myself and others like me.

- Maya Angelou

What's fair aint' necessarily right.

- Toni Morrison

The art of being wise is the art of knowing what to overlook.

- William James

Life is too important to be taken seriously.

- Oscar Wilde

Life isn't about finding yourself. Life is about creating yourself.

- George Bernard Shaw

Everything that irritates us about others can lead us to an understanding of ourselves.

- Carl Jung

Resources

1. Bailey and Rehman. Don't underestimate the power of self-reflection. *Harvard Business Review*. March 4, 2022.
2. Meeks and Jeste. Neurobiology of wisdom: A review of literature. *Arch Gen Psychiatry* 2009; 66(4):355-365.
3. Ute Kunzmann. Wisdom: A Royal Road to Personality Growth. Chapter 20. *The Cambridge Handbook of Successful Aging*. (2019.)

Cultivating the Habit of Mindful Reflection

Bottom line: A habit of mindful reflection (on your own [self-reflection] AND in a group (spiritual group / community) can separate extraordinary living from mediocre living.

The habit involves the following 7 steps:

1. Setting a time aside dailyish for mindful reflection
2. Setting the intention to learn about oneself, others, and all aspects of life and living.
3. Engaging in a 5-minute mindfulness exercise (e.g., the GRACE exercise described below)
4. Engage in positive affirmations as honest reflection requires courage – repeat one or more of the following statements (at least 10 times with slow breathing in between) such as “I am fearless I am strong I have the courage to reflect honestly. I will be thoughtful. I will be deliberate. I will be self-effacing. Failures, mistakes, frustrations are growth opportunities. I will set realistic expectations. I will press myself. I will become a neutral observer”
5. Looking back on the day to reflect on your behavior and its effects / consequences on yourself and others and on Mother Earth. Feel free to journal, type notes / dictate in the phone, or talk to yourself in a pleasant spot – and reflect as honestly as is possible. What went well, what did not, and so on. If you are not sure what to reflect on, consider the following: smart decisions, dumb decisions, meaningful interactions, meaningless interactions, amazing accomplishments, abject failure, brilliant judgment calls, lapses in judgment, right on the money assumptions, wrongful assumptions, events prior to panic attack, how happiness and stress manifest in your body. Reflect on a poem or quotes that stop you in your tracks. Just about anything that is deeply felt is grist for the reflection mill 😊. Try to identify the *what and the why* behind the emotions. Can I see the same event from a different perspective?
6. Do the GRACE mindful exercise again to give your brain a chance to integrate information without your conscious intent.
7. When the time set aside is up, take a deep breath, smile and go back to living life.

Namaste

GRACE – A mindfulness exercise

Mindfulness is living in our senses as opposed to being on autopilot.

G: Gather your attention and place it in a sensory activity (e.g., sensation of breathing – chest and belly going up and down, sound of your breathing, air going in and out, temperature of the air coming in vs going out, the “touch spots” of your body against the chair)

R: Relax into this activity (e.g., by relaxing your muscles [forehead, jaw, shoulder, limbs, back], exhaling longer than inhalation (when you inhale, sympathetic activity goes up, when you exhale, parasympathetic activity – vagus nerve activity goes up and heart rate and blood pressure and stress hormones come down), smile (fake smile is okay)

A: Adjust your posture so that you are alert (e.g., straightening the spine) and comfortable (in sitting or standing position – feel free to wiggle and adjust)

C: Count your breaths (counting can help you anchor your attention so that it wanders away less) – e.g., breathing in, say in your mind “One”, breathing out “Two” and so on till you reach “Ten”, then begin again from “One.” If you lose count, don’t be upset. That is what our minds do. When you realize that you have lost count or have gone beyond “Ten,” gently begin from “One.” Do this exercise for at least one minute (or three rounds of counting till 10) several times a day. On difficult days, do it for 5 minutes several times a day or even longer.

E: Enjoy being in your senses (and taking a break from TNT channel in your mind – Thinking N Thinking channel – the inner chatter – the inner critic)!

Modifications:

- Do it with other sensory activities (e.g., watching your child play, while eating, bathing, washing dishes, brushing your teeth, going for a run and just about any sensory activity).
- Modify how you count to suit your needs. Count with your fingers to make it more physical. Modify C to mean Continue keeping your attention in the sensory activity. No need to count. Each time your mind wanders, gently bring it back to the sensory activity.
- Mindful Reflection: Do it before engaging in reflection (develop a regular reflection practice – reflect on what surprised you / shocked you [it may help you identify unrealistic expectations], reflect on your failures [it will help you improve as long as you do it self-compassionately] and successes, reflect on your frustrations [it may help you become more patient]). E of GRACE here stands for Ego Unburdening reflection and Ego Bruising reflection ☺. Reflect on the poem. – *Why are you searching for me elsewhere?*

Namaste

PROSAC – Science-based Stress Reduction

Informed by the teachings of Dr. Robert Sapolsky – his book *Why Zebras Don't Get Ulcers* is to me the best book to understand the harms of chronic stress and we should all strive to do better with stress management.

P: *Physical activity* – aerobic, strength training and stretching

R: *Relaxation exercises* (includes meditation practice), *Rest* (includes sleep), *Reducing / Removing exposure to stressors*

O: *Outlets for frustration**

S: *Social biome* that is wise, calm and friendly

A: *Acceptance* (of the situation) and deciding to be Proactive in a wise manner (includes seeking professional help if needed)

C: *Cognitive tricks* – positive reappraisal/reframing, switching locus of control (from inner to outer), inventing/finding meaning in negative events, adopting a different perspective, dropping the narratives completely.

*Right kind (e.g., benign outlet for frustration)

*Right amount (dailyish)

*Right mix (tailored to your own unique strengths and needs)

Namaste

Validation Education and Skills Coaching

Caregivers often experience invalidation of their experiences. Invalidating interpersonal environment is neurotoxic.

Invalidating environment is the tendency of others to discount, negate, and/or respond erratically and inappropriately to subjective negative emotional experiences of an individual (caregiver in the context of this book). The caregiver's experiences are trivialized, punished, ignored, dismissed, gaslighted, and/or attributed to them being "sensitive, overreactive" and/or that the caregiver is "not motivated to improve, not motivated to be positive, not motivated to use their coping skills" and so on.

Such toxic interpersonal environments worsen the caregiver's emotional dysregulation and undermine their sense of agency (confidence in managing hardships of life) and self-worth.

Many individuals in caregiver's social circles (e.g., some family members, some so called friends) and occasionally, healthcare professionals, unknowingly are part of the caregiver's invalidating interpersonal environment.

Validation education and validation skills coaching (VESC) of these individuals who are part of the caregiver support network (social biome) is needed in such situations.

VESC is an antidote to the poison of invalidating interpersonal environment. The goal of VESC is to increase validation from the others and at the same time increase the individual's skills for emotional regulation, skills for self-validation, and skills to reduce exposure to invalidating responses from others.

Validation = "Your feelings, thoughts, and actions make sense and are understandable to me in this particular situation."

Other statements: "I am sorry that I have trivialized your pain in the past"

VESC also requires learning to be nonjudgmental, and developing other mindfulness skills (besides nonjudgmental attitude).

Resources:

1. Dialectical Behavior Therapy - DBT skills manual for adolescents. Jill Rathus and Alec Miller. Under stress, we all act like adolescents!
2. DBT for Dummies.

Namaste

Overcoming Despair

Many dementia family caregivers often go through periods of deep hopelessness, demoralization and despair. The following quotes may help them overcome despair.

Just as despair can come to one another only from other human beings, hope, too, can be given to one only by other human beings.

- Elie Wiesel.

Suggestion: Find a mentor / spiritual advisor / a wise elder who can give you hope.

We have to use our intelligence, our insight in order to transform our suffering.

- Thich Nhat Hanh (TNH).

Suggestion: Remind yourself of this.

Anger, hate, despair and fear are born from wrong perceptions. We should try to clear misunderstandings, bring right understanding.

- TNH.

Suggestion: Spend time to improve your understanding of your despair.

The most difficult times for many of us are the ones we give ourselves.

- Pema Chodron.

Suggestion: Stop giving yourself a hard time. Take care of your broken heart.

Even after all this time, the sun never says to the earth, "You owe me." Look what happens with a love like that. It lights the whole sky.

- Hafez.

Suggestion: See yourself as the sun, the light you wish to see in the world.

There is a part within us that is always fearless, incredibly strong, full of love, patience, kindness, listens deeply, speaks lovingly, is full of optimism, calm and insight. Let's remind each other of this and through togetherness, meditation, poems, music, Improv, and being in nature, experience its presence and power and allow it to transform our suffering, our despair.



Best App: Healthy Minds Program

Details: Created by Dr. Richard Davidson and his team. It involves training your mind in meditation and mindfulness. It is free but requires you to sign in with your email. Blue square icon with hm in it. By Healthy Minds Innovations, Inc.

Relationship Building Communication Techniques

Relationship building communication approaches are an essential skill for all family caregivers as well as healthcare professionals. Many persons having dementia (PhD) are looking to be part of warm loving relationships when they express wish to “go home” and relationship building communication approaches are key to making PhDs feel emotionally secure. “Agitation” in PhDs is also frequently related to feelings of insecurity, loneliness, lack of feeling connected and feeling “lost” (in the interpersonal world). Helping family caregivers develop skills for relationship building communication techniques will not only improve the wellbeing of the PhD but also the wellbeing of the family caregivers themselves.

There are at least six key relationship-building communication techniques that all care-partners / caregivers (family and professional) of PhDs should become familiar with and utilize in their daily interactions with the PhD.

Reflective listening: This technique involves making eye contact, adjusting body posture (e.g., leaning forward, avoiding hands folded across one’s chest), and providing nonverbal and verbal encouragement for PhD to express themselves (e.g. nodding, stating verbal continuers [e.g. “I see,” “Go on,” “Sounds like...”]). It is important to avoid expressing judgment, getting distracted, or redirecting the PhD. Repeating what the PhD has stated and seeking clarification is also important. *Humanitude training* may facilitate development of this skill.

Elicit storyline: Positive (e.g. joy) as well as negative emotions (e.g. anger) are embedded in stories that are unique to each PhD. A PhD’s narrative can be brought out through use of open-ended questions and continuers (e.g., “tell me more,” “what next?”). Understanding the PhD’s narrative is essential to seeing the PhD as a unique person.

Explore the PhD’s perspective (point of view): When another person understands our perspective, we feel heard. Specific questions can help elicit PhD’s perspective (e.g. what is your opinion? How do you feel about the care you are getting? Is anyone bothering you? How are they bothering you?).

Validate PhD’s experiences: When our experiences are validated, healing occurs. Validation can be done by genuinely felt and expressed statements such as, “I would also feel scared if I was in a strange place...I would feel sad too if my family was not with me.” Giving advice, opinion and correcting or interrupting the PhD is avoided. Gentle touch is important.

Mirroring: This technique involves mirroring PhD’s emotions such as a smile or sadness. Mirroring conveys to the person that we understand their emotional state.

Touch: Gentle touch can promote bonding through release of oxytocin (and other mechanisms) and help build trust in relationship.

Case Example: When do I go home?

Ms. G has been very upset, anxious, and tearful almost every day from the day a few weeks ago when she was admitted to a secure memory-care unit of an assisted living community. She has been repeatedly stating “when do I go home.... did I do something to be here...just kill me...” Staff listens to Ms. G using reflective listening skills mentioned above (e.g., “sounds like you are unhappy here”). Staff then make efforts to bring out the PhD’s narrative (e.g., where would you like to go? Tell me more about your home?). Staff then try to explore Ms. G’s perspective (e.g., “what is worrying you? What would you like us to do? If you could have anything, what would you want? Why is it so terrible over here?) and validate her feelings of abandonment and loneliness. Staff also mirrors PhD’s sadness and frequently holds PhD’s hands.

Relationship building communication approaches over time will give Ms. G a sense that staff care, that they understand her perspective and this will help Ms. G slowly but surely feel less anxious and lonely. Ms. G will feel part of several loving relationships with different staff members.

Resources:

1. Abhilash Desai and George Grossberg. Chapter 13 “Psychosocial Spiritual Wellness Care plan for persons with dementia” of the book titled *Psychiatric Consultation in Long-Term Care: A guide for healthcare professionals* by Cambridge University Press, 2017.
2. Boissy et al. Communication skills training of physicians improves patient satisfaction. *Journal of General Internal Medicine* 2016; 31(7):755-761).
3. Humanitude International. <https://humanitudesingapore.com>

Namaste

STEPS: Support system / Staff Training Education Praise and Support

STEPS is a comprehensive approach to improving quality of care provided by family members (patient's support system) and professional caregivers (e.g., staff to our long-term care residents). It involves three components:

1. **Education and Training:** Two key areas:
 - a. Understanding and implementing SPPEICE – Strengths-based Personalized Psychosocial Environmental Initiatives and Creative Engagement*. Goals of this training: Improved wellbeing of residents using SPPEICE and Reduced use of psychotropic medications.
 - b. Mindfulness training. Goals of this training: Improved skills to provide care with mindfulness (with awareness and compassion) and Increased Joy at work (besides reduced burnout)
2. **Praise:** This includes case-based in-time praise for specific behavior of the family caregiver / staff that lead to specific positive outcome. Sharing success stories routinely during clinical encounters and informal meetings and at other times is one of the many ways to praise family caregiver / staff regularly.
3. **Support:** This includes direct one-on-one emotional support by healthcare team to family caregivers / staff as caregiving is hard and mistakes are a norm. This includes helping family caregivers / staff be more self-compassionate and less hard on themselves / more forgiving towards themselves.

*SPPEICE – detailed information available in chapter 13 – *Psychosocial Spiritual Wellness Care Plan* in my book: *Psychiatric Consultation in Long-Term Care: A Guide for Healthcare Professionals* 2nd Edition. Cambridge University Press 2017.

Two essential trainings:

1. DICE – Describe Investigate Create Evaluate. www.diceapproach.com
2. Mindful Care-Partnering (see page 21)

ABCD of Family Caregiver Spiritual Assessment

A = Ask. Ask permission to inquire about caregiver's spirituality. Explain that spirituality is an important factor in wellness, resilience and healing. Involve other family members whenever feasible.

B = Beliefs. Inquire about their spiritual beliefs so that you can better understand them.

C = Community. Inquire about whether the caregiver is part of a spiritual community (Sangha).

D = Daily practice. Discuss what daily spiritual practices can be continued and new ones added to promote wellness, resilience and healing.

Common spiritual practices and rituals

- Prayers
- Meditation (Healthy Minds Program – Best app for learning to meditate and understanding mindfulness)
- Reading religious scriptures and spiritual books (including audio books)
- Attending church, mosque, temple events and events and gatherings of other spiritual communities
- Volunteering
- Yoga, Tai Chi, Qi Gong
- Spending time with nature
- Listening to spiritual / religious podcasts
- Singing religious / spiritual songs and dancing to it
- Gratitude and Awe – based practices and rituals

Suggested reading:

1. Sulmasy DP. Physicians, Spirituality, and Compassionate Patient Care. NEJM 2024.

Tomorrow will bring good news: Dementia Friendly Hospitals

A stab went through her
so sharp that my patient
sobbed and clutched
at her belly.
“Just sleep,
tomorrow will bring good news,”
she kept repeating
like a mantra,
coordinating the words
with her breath.
She slept fitfully.
When she woke,
pale light of morning
was slanting
through her window.
She felt
as sick and achy
as if she had
not slept at all.
Her tummy
was still tied
in a knot.
“Just breathe slowly,
today will bring good news,”
She kept repeating
like a mantra.



This is my patient’s daughter. My 69-year-old patient with mild dementia was in the ICU for cardiac arrhythmia. She recovered beautifully to the surprise of all of us and was discharged home. I was teaching the daughter mantra meditation and mindful breathing.

Many individuals with dementia come out of the ICU in more advanced stage due to brain injury caused by underlying medical issues that required ICU plus trauma of being in a hospital and ICU - especially if the hospital doesn’t have HELP program and dementia friendly hospital practices. They often need to be discharged to a nursing home rather than home and may never return home 😞

HELP - Hospital Elder Life Program: For Delirium prevention through the American Geriatrics Society

Top 5 dementia friendly hospital practices:

- routine consult with dementia team - dementia physician / nurse practitioner expert (e.g., consultant psychiatrist) plus at least one of the following: chaplain, nurse, social worker, neuropsychologist, occupational therapist (addressing ageism and dementia-ism being a top priority)
- one to one with a trained staff
- supportive family educated and involved as much as the family can
- individualized strengths based routine bio-psychosocial spiritual culturally appropriate care plan that includes early mobilization with intensive physical therapy, continuous daily meaningful activities schedule and night time sleep enhancement
- close collaboration with Hospitalist team and HELP program team to prevent delirium, falls, pain, constipation, dehydration, de-conditioning and frailty

Resources for Family Caregivers for the Management of Agitation Associated with Dementia (AAD)

To assess for medical conditions causing agitation including medication-induced agitation:

Saint Alphonsus Memory Center
Boise Nampa Eagle
Telehealth appointment available
No referral needed. Self-referral accepted.
208-302-5400 Boise
208-302-6000 Nampa Eagle

Primary care provider of the person with dementia can also do this assessment.

Individual counseling (for family caregiver) and guidance regarding behavior management strategies

Laura LaForte LCSW
206-953-3708
<https://www.lafortetherapy.com/>

Connection Club Adult Daycare
Dick Eardley Boise senior center
208-608-7578

Dementia and Creativity Sessions
Erika Shaver-Nelson, MA
208-724-4754

Family education on Behavior Management Strategies
Family Caregiver Alliance Website: Behavior Management Strategies
High quality videos and quick reads: <https://www.caregiver.org/caregiver-resources/caring-for-another/behavior-management-strategies/?via=caregiver-resources,caring-for-another>

Telephone support and guidance of community resources

- 988 suicide and crisis line
- 211 Idaho care line
- 800-898-9626 Alzheimer Association 24/7 helpline

Case Management Respite Education regarding Dementia
Community Care Program
Regarding dementia
208-898-9626

Ccp@a3ssa.com
www.a3ssa.com

Family caregiver wellness and resilience education and training
Powerful tools for Caregivers workshop
<https://www.agingstrong.org/powerful-tools-for-caregivers>
208-947-4283

Family support and respite
Family Caregiver Navigator
<https://caregivernavigator.org/>
208-426-5899

Family assistance for community resources (e.g., transportation)
Saint Alphonsus Community Health Worker program
208-367-4482

Websites

The DICE approach online training program. <https://diceapproach.com/>

International cognitive therapy stimulation (CST) center
Saint Louis University's Geriatric Education Program offers CST
<https://www.slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/cognitive-stimulation-therapy.php>

Music and Memory Program. <https://musicandmemory.org/>

Book for patients and their families

1. Mayo Clinic on Alzheimer's Disease and Other Dementias. 2020. Jonathan Graff-Radford MD, Angela Lunde MA.
2. Mayo Clinic: Day to Day Living with Dementia. A Mayo Clinic Guide for offering care and support. Angela M. Lunde, M.A.
3. Agitation associated with Dementia management. eBook by Abhilash Desai MD. Available upon email request.
4. STAR-C VA Manual for Challenging Behavioral Management Strategies

Citation: Karlin, B. E., Teri, L., McGee, J. S., et al (2017c). STAR-VA Intervention for Managing Challenging Behaviors in VA Community Living Center Residents with Dementia: Manual for STAR-VA Behavioral Coordinators and Nurse Champions. Washington, DC: U.S. Department of Veterans Affairs
https://www.mentalhealth.va.gov/healthcare-providers/docs/STAR-VA_Manual.pdf

Arts on Prescription for Dementia Care: Resources

Book

Creative Care. A revolutionary approach to dementia and elder care. Anne Basting. 2020.
Excellent book to improve emotional and spiritual wellbeing of individuals with all stages of dementia through creative expression and engagement.

Websites

1. TimeSlips (<https://www.timeslips.org>) creative storytelling. Online training course available. At least one long-term care staff should be trained in *TimeSlips*
2. Center for Arts in Medicine. <https://arts.ufl.edu/sites/creating-healthy-communities/resources/arts-on-prescription-a-field-guide-for-us-communities/>
3. American Medical Association. How Improv is helping patients with Alzheimer's disease. <https://www.ama-assn.org/delivering-care/public-health/how-improv-helping-patients-alzheimers-disease>
4. Improv artists Karen Stobbe and Mondy Carter TedMed video. Using Improv to improve life with Alzheimer's. https://www.youtube.com/watch?v=GciWltvLo_s



Resources for Dementia Training

Free

1. Health Resources and Service Administration HRSA Dementia modules (free):
<https://bhw.hrsa.gov/alzheimers-dementia-training>
2. Johns Hopkins. Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies. <https://www.coursera.org/learn/dementia-care> 18 hours to complete.
3. Dementia Training Australia. Includes modules on behavior change, pain management, medication management. <https://dta.com.au>
4. REACH certified caregiver support coaches.
https://www.caregiver.va.gov/REACH_VA_Program.asp

Not Free: Certification available

1. Alzheimer's Association Dementia Training (not free). Provides a certificate.
<https://www.alz.org/professionals/professional-providers/dementia-care-training-certification>
2. Certified Dementia Practitioner. National Council on Certified Dementia Practitioner
<https://www.nccdp.org/cdp/>
3. National Certification Board for Alzheimer's Care
<https://ncbac.net>
4. American Health Care Association – AHCA
<https://educate.ahcancal.org/CARESprogram>
5. Dementia Care Specialists. Crisis Prevention Institute
<https://www.crisisprevention.com/Our-Programs/Dementia-Care-Specialists>

Dementia Bibliotherapy: Books recommended to improve lives of individuals with Alzheimer's and other dementias and their family members, friends and carepartners

Mayo Clinic on Alzheimer's Disease and Other Dementias. Jonathan Graff-Radford MD, Angela Lunde MA. 2020. Mayo Clinic Press. Excellent first book for individuals with mild memory problems who are worried that they may have dementia and family members of individuals with dementia. High-quality, relatively easy to understand information of complex topics as well as many practical tips and guidance to get early accurate diagnosis and live well.

Day-to-Day: Living with Dementia: A Mayo Clinic guide for offering care and support. Angela M. Lunde, M.A., offers essential caregiving guidance, including practical tips and resources, techniques for working through difficult emotions, and strategies for managing common dementia-related challenges.

Improving Brain Health. eBook. Free. Saint Alphonsus Memory Center.
<https://www.saintalphonsus.org/specialty/memory-center/resources>

Navigating Dementia: A workbook for family caregivers. Free. Awesome book. A must for all family caregivers. <https://healthtools.dhw.idaho.gov/collections/brain-health-alzheimer-s-and-dementias>

When your aging parent needs help: A geriatrician's step-by-step guide to memory loss, resistance, safety worries, and more. Leslie Kernisan, MD, MPH and Paula Spencer Scott. 2021

Travelers to Unimaginable Lands. Stories of Dementia, the Caregiver, and the Human Brain. Dasha Kiper

Living with Memory Loss: A Basic Guide by University of Washington Memory and Brain Wellness Center. This essential resource is downloadable (for free) from their website under the Resources tab, either the full handbook, or separate chapters. Excellent for patients with mild to moderate dementia and their family members.

Before I Forget: Love, Hope, and Acceptance In Our Fight Against Alzheimer's. B. Smith & Dan Gasby. Excellent resource to promote positive approach to living with dementia.

The Alzheimer's Solution: A breakthrough program to prevent and reverse the symptoms of cognitive decline at every age. Dean & Ayesha Sherzai, M.D. Codirectors of the Brain Health and Alzheimer's Prevention Program at Loma Linda University Medical Center. Useful for patients with mild dementia who wish to slow down cognitive decline.

The Spectrum of Hope: An optimistic and new approach to Alzheimer's Disease and other Dementias 2017, by Gayatri Devi MD, neurologist and the Director of the New York Memory and Healthy Aging Services. Many cases with remarkably positive outcomes are discussed.

Excellent for patients with mild dementia and their family members to learn about ways to slow cognitive decline.

Seven Steps to Manage Your Memory by Andrew Budson and Maureen O'Connor. Oxford University Press, 2017. Excellent resource to differentiate normal memory loss from memory decline due to dementia and many cases with positive outcomes are shared. Excellent for patients with mild dementia

Aging Together: Dementia, Friendships and Flourishing Communities. By Susan McFadden and John T. McFadden. Johns Hopkins Press. 2011. Excellent book to improve emotional and spiritual wellbeing of patients in all stages of dementia and their loved ones and improve community understanding and support.

Dementia-Friendly Communities. Why we need them and how we can create them. Susan H. McFadden. Jessica Kingsley Publishers. 2020. Excellent book to understand what “dementia friendly” means and to improve community and understanding and support. Best first resource to begin to create dementia friendly communities in your community.

Creative Care. A revolutionary approach to dementia and elder care. Anne Basting. 2020. Excellent book to improve emotional and spiritual wellbeing of individuals with all stages of dementia through creative expression and engagement.

On Vanishing: Mortality, Dementia, and What It Means to Disappear. Lynn Casteel Harper. 2020. New York, NY: Catapult.

Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End. Tia Powell. 2019. New York, NY: Avery.

Dancing with Elephants: Mindfulness Training for Those Living with Dementia, Chronic Illness, or an Aging Brain (How to Die Smiling). Jarem Sawatsky. 2017. Toronto, ON: Red Canoe Press.

In Love: A Memoir of Love and Loss. Amy Bloom. A poignant book about a wife's journey in assisting her husband with dementia to receive Medical Aid in Dying / Euthanasia.

My Father's Brain: Life in the Shadow of Alzheimer's. Sandeep Jauhar. 2023. A beautifully written book about a son's journey in helping his father and family will well with dementia. The author was featured on NPR's *Fresh Air* by Terry Gross. Awesome interview (available on Podcast)

With the End in Mind: Dying, Death and Wisdom in the Age of Denial. Kathryn Mannix

How to prevent Dementia. An expert's guide to long-term brain health. Dr. Richard Restak 2023.

Dr. Desai Books and Podcasts

1. *Psychiatric Consultation in Long-term Care: A guide for healthcare professionals.* Abhilash Desai and George Grossberg. 2nd Edition. Cambridge University Press. 2017. It has info on STAR model to safely address AAD.
 - a. Chapter 3: Dementias / Neurocognitive disorders
 - b. Chapter 12: Psychiatric aspects of rational deprescribing
 - c. Chapter 13: Psychosocial spiritual wellness care plan
2. *One Day Mindfulness Millionaire – Living Mindfully: A lighthearted primer for the uninitiated.* Abhilash Desai MD and Faith Galliano Desai PhD.
<https://store.bookbaby.com/book/one-day-mindfulness-millionaire>
3. *Overcoming Anxiety, Depression and Anger.* Non-pharmacological interventions to manage stress, anxiety, depression and anger. eBook available upon email request.
4. *Mindfulness and Meditation.* eBook available upon email request.
5. *Fearless Strong Patient Kind - Short meditations to manage stress and become resilient.* eBook available upon email request.
6. *Agitation associated with Dementia (AAD) management without antipsychotics.* eBook available upon email request.
7. *Dementia Prevention.* eBook available upon email request.
8. *Dementia Medical Poems.* eBook available upon email request.
9. GeriPal podcast. Alex Smith and Eric Widera. Transforming the culture of dementia care: Anne Basting, Ab Desai, Susan McFadden, and Judy Long. Dec 2, 2022. Must hear
10. Saint Alphonsus Wellcast. Ageism: Combating common myths surrounding aging. 7/27/2023.
11. Saint Alphonsus Wellcast: Unlocking the mind: exploring modifiable risk factors for dementia. 6/15/2023.

Dementia Physician Experts in Idaho

Eastern Idaho

Scott Christensen MD, Geriatrician
Intermountain Medical Clinic
1951 Bench Road, Suite B Pocatello, ID 83201
Phone: (208) 238-1000
Dr. Christensen can do telemedicine visits

Northern Idaho

Susan Melchiore MD, Geriatrician
One Site for Seniors
296 W. Sunset Ave, #14-15
CDA, ID 83815
Phone: 208-967-4771
Dr. Melchiore can do telemedicine visits

Central Idaho

Jennifer Lewis MD, Geriatrician
211 Forest Street McCall Idaho.
Phone: 208-634-2225
Dr. Lewis can do telemedicine visits.

Southwest Idaho

Kara Kuntz MD, Geriatrician and team
Saint Alphonsus Memory Center,
Boise, Eagle, Nampa
Phone: 208-302-5400; 208-302-6000
Memory Center team can do telemedicine visits

The Healing Power of Mindful Care-Partnering

Are you (like us) a caregiver struggling with the responsibilities and stress of caregiving? Have you wondered how on earth do some caregivers find the role of caregiving a blessing? Are you amazed at how some caregivers tend to their responsibilities effortlessly and continue to be cheerful day in and day out? Yes, these remarkable individuals do exist, and, we have had the good fortune to have met them in our professional life (as a psychiatrist [AKD] treating patients from ages 5 and up, and child and adolescent psychologist [FDG]) as well as in our personal life. We have been looking for a path towards becoming better caregivers for some time now.

This long essay is aimed at helping caregivers (family [e.g., parents, siblings] and professional [e.g., staff in nursing homes]) of persons having dementia (PHD) improve their capacity for compassion, creativity during caregiving, effectiveness of their efforts, and at the same time improve caregiver's own sense of wellbeing. Caregivers work hard to improve quality of life of PHDs but often experience frustration, helplessness, hopelessness, stress, and burnout. We have discovered that an approach that blends mindfulness with the concept of care-partnering can not only improve our skills in improving wellness and positive experiences of PHDs but also prevent burnout and promote our emotional and spiritual growth. For many caregivers, mindful care-partnering comes naturally, without any knowledge or training. For the rest of us, focus and effort in developing skills of mindful care-partnering are necessary.

Mindfulness is bringing one's awareness to the present moment, with intention, to whatever one is experiencing (e.g., feelings, sensations, thoughts) with an attitude of kindness and curiosity. It is a skill and as such, can be developed much more easily than generally recognized. Mindfulness is an excellent way to become familiar with the workings on one's mind and minds of others (especially of PHD). Intimate familiarity with the workings of one's own mind and that of others opens up doors of healing and wellness that have otherwise remained obstinately closed.

Mindfulness is paying attention in a particular way – on purpose, in the present moment, and nonjudgmentally.

- Jon Kabat Zinn

Care-partnering includes all traditional aspects of caring for another person (e.g., helping them with daily activities) but also involves awareness of the PHD's capacity to partner and collaborate with caregivers and the unique gifts caregivers receive from PHDs as well as from the very act of caring. Care-partnering also goes a step further in recognizing that the PHD is the expert in how best to have her/his needs met and thus, **it is crucial to be led by the PHD** at least as often as leading the PHD towards safety, better ways of adapting to life's challenges and positive experiences.

Henceforth, all caregivers will be called care-partners.

Mindful Care-Partnering

It is easier to understand mindful care-partnering by understanding three common aspects of unmindful care-partnering. These are: autopilot, auto-reaction and premature cognitive commitments.

Autopilot

As you (the care-partner) embark on mindful care-partnering, you will quickly notice that your mind wanders to many different places/situations as you go through the task at hand (say for example, taking a walk with the PHD). It is typical for our minds to jump from paying attention to the task at hand to having imaginary conversations, plans, worries, replaying memories, and a host of other thoughts. One can say that our mind keeps wandering into the land of thoughts and thinking. You may finish the walk and may not be able to remember what areas of the park you walked and what conversation you have had with the PHD. This happens automatically because it is a natural tendency of our brain to go on autopilot. Autopilot requires much less energy and intentional activity takes up much more energy so given a choice, brain will always switch to autopilot to conserve energy (a strategy that improved survival of our hunter-gatherer ancestors). Mindful care-partnering involves gently bringing your wandering mind to the present moment, becoming aware that you are walking with the PHD, that you are holding their hand, and becoming aware of the green landscape around you. Mindfulness in such situations involves catching oneself having these thoughts, minimizing or withholding any negative judgment or criticism for being distracted and intentionally bringing our focus back to the present. You can be certain that your mind will wander again, and you can once again bring your mind gently to the present. Being present with the PHD in such a way will improve sense of value the PHD has for herself/himself and improve PHD's sense of connectedness with you. Improved sense of one's value and sense of connectedness are two most basic requirements for any significant and sustained healing and wellness to occur.

The faculty of voluntarily bringing back a wandering attention over and over again is the very root of judgment, character, and will. No one is compos sui if he have it not. An education which should improve this faculty would be the education par excellence.

– William James (*Principles of Psychology* 1950; p.424) Note: *Compos Sui* meanings *master of oneself*

Auto-reaction

As you become aware of your emotions during care-partnering, you will notice that you often react automatically from emotion first rather than pause, reflect and then respond. Once again, the brain under strong emotions (especially negative emotions such as fear or anger) will tend to respond immediately based on perceived threat. Brain's initially perception of threat involves a part of the brain called amygdala and amygdala is biased towards over-reacting (guided by the goal of increasing survival). By being mindful of our brain's (specifically amygdala's) tendency to over-react, you can develop skills to inhibit the immediate auto-reaction, pause and reflect taking in any additional information our senses are registering and contrasting the event with any past experience with similar events we may have, attempting to see from the point of view of the PHD, and then responding. Your pre-frontal lobe plays a key

role in mediating all these actions (inhibiting auto-reaction, pausing, reflecting, responding). Depending on the situation, all these actions may take only a few seconds or several minutes or even longer.

Premature Cognitive Commitments (PCC)

Our brains are programmed to come to quick conclusions based on minimal information (because such function provided survival advantage). Such conclusions are key examples of premature cognitive commitments (PCCs) (a term coined by Dr. Ellen Langer, psychologist in her book *Mindfulness*). Judgmental thinking is typically based on PCCs. This tendency of our brain is valuable in emergency situations but can be counter-productive and at times even destructive in day-to-day situations involving caring. As you become more aware of your thoughts and feelings during caring, you will be able to catch yourself in such acts of prematurely committing to an understanding of what is going on (especially challenging behaviors). For example, the PHD is having an anger outburst and you quickly decide that this is “manipulative, attention seeking behavior” or that the PHD is “just being mean”. Many PCCs involve harsh judgment about ourselves (e.g., “I am a terrible caregiver”) or catastrophic predictions (e.g., “this resident with dementia is going to tear down the place”). PCC will push you to react as if this conclusion was absolutely correct and there was no alternative explanation for the behavior or alternative future scenarios (especially positive ones). PCC will further increase intensity of negative emotions that triggered them in the first place. Auto-reaction and PCCs by care-partners often make the behavior of the PHD worse. Mindful care-partnering will slowly but surely help you become aware of how often our PCCs are incorrect. As you learn to pause, take in the context, get to know the narrative of the PHD (how the PHD got to this point), your understanding of challenging behaviors will become more nuanced, what needs to be done to address the challenging situation will become clearer, and your success in addressing the challenging behavior will greatly improve.

Benefits of Mindful Care-Partnering

As you delve into this practice of mindful care-partnering, you will become aware of your fears, expectations, and judgments and how those color how you relate to the PHD. Mindful care-partnering will also help you see the situation from PHD’s point of view. Mindful care-partnering is all about honoring relationships, connectedness, and a sense of belonging. Your relationship with PHD may feel chaotic or different from the ideal you want. You may find yourself drifting through life on “autopilot,” constantly worrying about the future or feeling upset (guilty, resentful) about the past instead of living in the here and now. This method of caring teaches you to stay “in the present” and stay connected with the PHD as well as yourself in kinder and softer ways.

Regular meditation practice (e.g., 30-minute Breath Awareness Meditation early in the morning before starting one’s day; at least a few minutes of Breath Awareness Meditation when experiencing strong negative emotions [e.g., anger]) and mindfulness practices throughout the day (e.g., mindful eating, mindful walking) has been shown to dramatically improve one’s sense of wellbeing and inner strength in just eight weeks of daily practice. Yoga, Tai Chi and Qi Gong are other mindfulness-based practices (often called mind-body practices) that promote

psychological and spiritual wellness and make us more effective care- partners. Meditation and mindfulness practices increase our emotional and spiritual resilience (emotional and spiritual bank-balance) and lower our risk for burnout, depression and persistent anxiety. Every time we engage in meditation and mindfulness practices, we are depositing money in our emotional and spiritual bank! As we build this bank balance, hassles of daily life will seem mere annoyances rather than “terrible” events, and we will bounce back from traumatic events faster and without becoming demoralized. We will be less likely to dwell in self-pity or resentment and more likely to be aware of many things we can still be grateful for. We will find improved capacity to be patient, to see silver lining in clouds and make lemonade from lemons that life gives us (again and again). We will be able to make ourselves do things we don’t want to do (e.g., regularly exercising, eating healthy foods, having a good sleep routine, taking time to enjoy simple things in life [HYGGE {Danish art of contentment, comfort and connection}]) and we will also be able to more easily restrain ourselves from doing things we should not (e.g., putting self or others down under the influence of strong negative emotions). Meditation and mindfulness practices will help us laugh at our foibles with light-hearted spontaneity and avoid taking life too seriously. We will be able to let go of materialistic attachments and move towards a simpler and easier life where awareness of being alive and surrounded by love will be enough reason to be happy.

From Knowledge to Skills to Practice

Mindful care-partnering challenges you to examine your expectations. Your fears may motivate you to try and direct the PHD in certain ways and often will blind you to what is truly in their best interests. PHDs have their own trajectories, beliefs, ideas, and opinions, often different from ours, and what we think theirs should be. When you challenge yourself to pay attention to the present moment and see caring as collaboration, an artistic endeavor, you gain opportunities to truly see PHDs, to understand and appreciate them, and solve problems with them rather than for them.

Everyone has times where inner musings (inner chatter, conversation with oneself in our minds) take over, but this means we lose opportunities to connect with the PHD by being blind to the present moment. The key is in paying attention to the small things, like a child, fully embodying every moment, as opposed to life being a movie in our minds or trying to match it to our expectations.

You can think of mindful care-partnering as an opportunity to get to know yourself better and to accelerate your own psychological and spiritual growth. A moment of mindful care-partnering may allow you to catch yourself and realize an opportunity to change direction. When you pay attention to the present you may recognize that some thoughts or fears are not based in reality and liberate yourself to a more productive course of action.

As with most skills, mindful care-partnering takes time and practice. Even small changes are profoundly healing and transformative. Some examples of small steps are being aware of your breath, the feeling of your hands, or your own body language, the feel of PHD’s hand in yours. The simplest method of becoming mindful is to get connected with our senses. Bring your

awareness to your breathing, for example, in the belly or the nostrils, to focus on one thing at one time. Practicing this at a moment of tranquility, and drawing on this experience when a conflict happens, will help you respond mindfully to the conflict instead of reacting emotionally, and find better ways of dealing with it.

Instead of preparing for situations in the future, or using a cookbook approach, mindful care-partnering asks that you trust yourself to be aware of the next moment and find a solution when that moment comes. The goal is not to eliminate chaos and negative feelings; these are a natural part of life filled with caring responsibilities. The goal is to be kind and curious when those moments arise.

It is crucial to give yourself credit for the little moments of success and accept yourself and others with all the imperfections. Choosing to engage in mindful care-partnering is empowering yourself to be present for the challenges and successes.

Source:

One Day Mindfulness Millionaire: Living Mindfully - A Primer for the Uninitiated. Book by Abhilash Desai and Faith Galliano Desai. Available as eBook.

Holistic Dementia Care Medicine: 11 Domains

#	Type	Description
1	Psychoeducation	Improve brain health literacy and address incorrect understanding and unrealistic expectations from psychiatric medications
2	Medical evaluation and workup	Identify and correct reversible medical (e.g., pain, dehydration, hearing and vision deficits, dental problems) causes of neuropsychiatric symptoms
3	De-prescribing	Identify and de-prescribe medications causing neuropsychiatric problems and medications that are unnecessary
4	STEPS	Support system (family and professional care partners) Training Empowerment Praise Support to improve healing and therapeutic approaches and prevent or discontinue counter therapeutic approaches and interventions
5	Nidotherapy	Improve physical environment and engagement with outdoors and nature (includes occupational therapy assessment)
6	Lifestyle medicine	Improve brain healthy lifestyle (diet, exercise, socialization, sleep, meditation, mind-body exercises, cognitive stimulation)
7	PERMA	Positive emotions, Engagement, Relationships, Meaning, Accomplishment (positive psychology science-based interventions)
8	Emotional regulation skills training	To prevent and reduce dysregulated emotional states in the person with dementia and their care partners
9	ACT	Acceptance Commitment Therapy – for the person with dementia and their care partners to accept the need for holistic approach and commit to it.
10	DEIBA	Diversity, Equity, Inclusion, Belonging, Anti-Ableism Includes Anti-Ageism and Anti-Dementiaism Includes addressing social determinants of health and bolstering community resources
11	Peer-led interventions	Peer-led and peer-supported interventions including support groups and advocacy groups

Key Resources:

1. Saint Alphonsus Memory Center, Boise, Idaho. <https://www.saintalphonsus.org/specialty/memory-center/>
2. The DICE Approach. <https://diceapproach.com>
3. ABC Dementia - Community Dementia Education. <https://community.abcdementia.org>
4. Laura LaForte Therapy. <https://www.lafortetherapy.com>
5. University of Pennsylvania Positive Psychology Center. <https://ppc.sas.upenn.edu/learn-more/perma-theory-well-being-and-perma-workshops>
6. Stanford Lifestyle Medicine.

Mindfulness: A personal journey of a physician **Abhilash Desai**

I met Mindfulness around two decades ago. One of my new colleagues, a wonderful nurse practitioner, introduced me to Mindfulness, specifically the writings of Pema Chodron, a Buddhist teacher. I had just moved to a new city in a new state, and in a new job as a psychiatrist. I also knew that I needed to make a certain number of RVUs (Relative Value Units – translates into certain number of patients to be seen per day) so that I can have the income I wanted to not only try to ensure a good life for my lovely wife and my wonderful son, but also to send money to my loving parents in India. I was also going through personal health challenges. As a result, I was experiencing lot of existential angst. I felt my emotional state was dire, and I was desperate for a way out. I knew intellectually that I had a lot of things to be grateful for, but my day to day experience was that of heart ache, sadness, anger, resentment, guilt, shame, disappointment in myself, fear of disappointing my family, and dread of the future.

I started reading and listening to Pema Chodron as one final attempt to help myself before I sought professional help. Pema Chodron's teachings had an amazing effect on me from day one. I was so desperate that I did just about anything and everything she suggested, and adopted her perspectives on what causes suffering. Slowly but surely, I started experiencing periods of calm, self-confidence and hope. Most importantly, my relationship with myself started improving rapidly. I started giving myself a break and my self-compassion improved quite a bit. I began to understand what I was going through, and possible root causes of my angst. One of Pema Chodron's quotes that I kept going to again and again for spiritual nourishment and strength is as follows:

Only to the extent that we expose ourselves over and over to annihilation can that which is indestructible in us be found. – Pema Chodron

Soon the universe of Mindfulness introduced me to the one and only, Thich Nhat Hanh. I started devouring his books and teachings and deepened my practice of Mindfulness. One of his short poems speaks directly to my soul. He had written this poem right after he heard about the bombing of Ben Tre during the Vietnam war, and the comment made by an American military man, "We had to destroy the town in order to save it."

For Warmth by Thich Nhat Hanh

*I hold my face between my hands.
No, I am not crying.
I hold my face between my hands
to keep my loneliness warm —
two hands protecting,
two hands nourishing,
two hands to prevent*

*my soul from leaving me
in anger.*

Since then, Mindfulness and Meditation (I call them MnMs ☺) have become my friends whom I visit every day and hang out with them as much as I can. Without MnMs, I would not have come out of the Pandemic tragedy spiritually stronger. Heck, I would not have survived, let alone overcome Moral Injury that I experienced during the Pandemic (one of the most heart wrenching experiences in my life, the aftermath of which I am still experiencing in the background). MnMs have helped me notice and experience so much of the beauty and joy that life has to offer. My favorite poet John O'Donohue shares such beauty and joy in his poems. Here is one of the many of his poems that stops me in my tracks every time I mindfully read it.

*"You have traveled too fast over false ground;
Now your soul has come to take you back.*

*Take refuge in your senses, open up
To all the small miracles you rushed through.*

*Become inclined to watch the way of rain
When it falls slow and free.*

*Imitate the habit of twilight,
Taking time to open the well of color
That fostered the brightness of day.*

*Draw alongside the silence of stone
Until its calmness can claim you."
— John O'Donohue*

Namaste