



Caring for the Caregiver

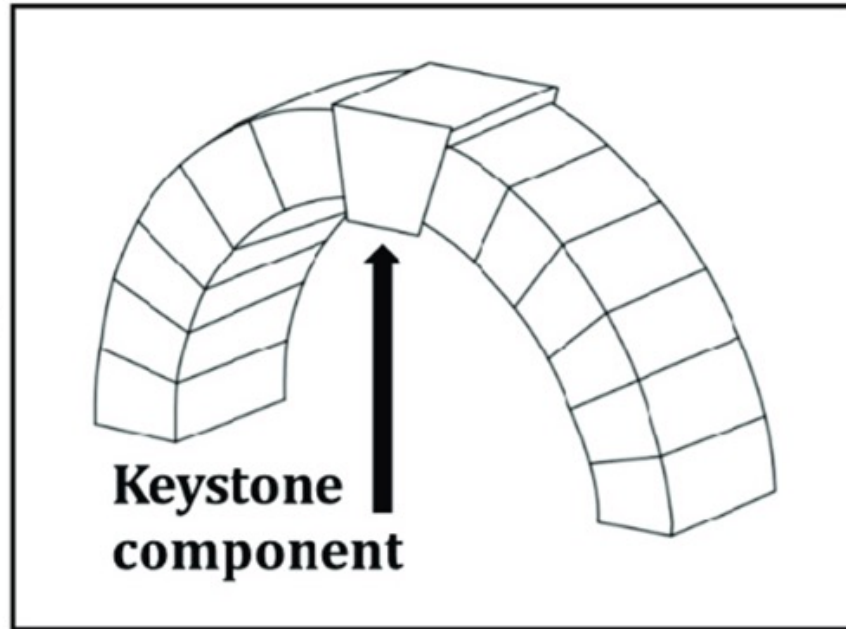
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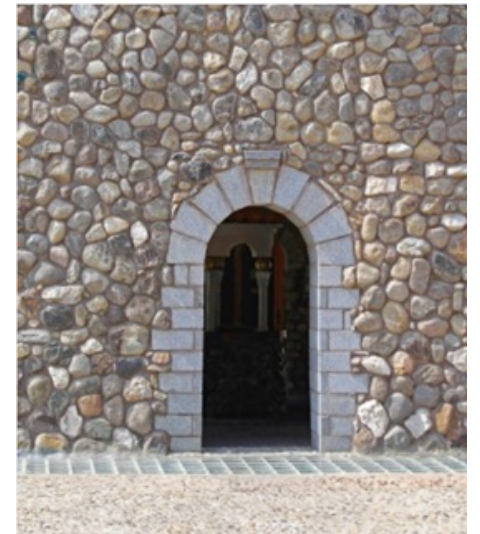
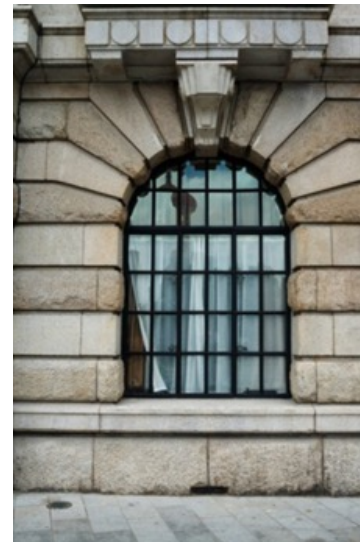


You Are the Keystone!



- A keystone holds an arch together
- If it is removed, the structure will fall

- The keystone will allow the arch to hold weight from above, as well
- A keystone cannot be replaced by just any stone—it is special in size, shape, and other features



Caregiving: TCB

- ...with responsibilities being added on over time
- ...atop what you had before
-and, all the while experiencing a protracted (lengthy, ongoing) period of loss and grief.
- But, caregiving is also taking care of YOU



Caregiving & Burnout

- Caregiving affects
 - Sleep
 - Work performance
 - Personal health (physical, mental)
 - Your relationships with others
 - Decision making & reasoning speed & accuracy
 - Mood, Appetite → Nutrition → Strength
 - Your healthcare partner's well-being: emotions, behavior, safety



What Caregiving Burnout Looks Like

Burnout looks different in different people, but there are some common signs that many with burnout experience. A caregiver with burnout might feel:

- Extremely tired, even when they sleep well
- Easily flustered or frustrated
- Quick to anger
- Forgetful or foggy
- Uninterested in engaging with people or activities they used to enjoy
- Anxious or depressed
- Hopeless or helpless

At its extreme, burnout can also leave caregivers indifferent or hostile to the person they care for or put them at risk for hurting themselves or others.

- Caregiver burden: (Dr. Sollman's definition): a multi-faceted strain that affects the energy, mood, thoughts, behavior, health, etc of someone in a *direct or indirect* care giving role
 - This accumulates over time, AND ebbs and flows depending on many factors
 - We are not usually aware of this as it is growing very slowly within us
- Contributors to caregiver burden, aside from the obvious:
 - Level of perceived disability or dependency of your loved one
 - And their INSIGHT
 - Emotional health of your partner and / or yourself
 - How much one identified as a caregiver prior to this specific relationship role
 - Sacrifices made to or by virtue of being in the caregiving role
 - Appreciation, Acknowledgement, Gratitude cups' fulfillment
 - Basic Need for Love and Support cup fulfillment
 - FEAR, GRIEF, LOSS
 - UNSPOKEN CONVERSATIONS

The Most Important Question

- When faced with caregiver burnout, sometimes extremely difficult decisions have to be made
 - Do I go away for the weekend to recharge my batteries?
 - Do I leave the house and call our son to come step in?
 - Do I keep my loved one safe by bringing in outside nursing care, even though they said they don't want strangers to ever be in our home?
- “What is most important in our relationship?”
- Every decision affects you just as much as it affects the other party, even though you'll be inclined to feel you are the perpetrator of hurt
- If you are not *at your best*, your care partner will do worse

Relationships Are a System

- As humans, our emotions and behaviors are affected by our environment and those around us
- The people in your sphere affect your mood, energy, attitude
- Medicine can help your loved one's status to some extent, but learning tricks to distract, redirect, and impose a positive environment can as well
- This requires you to be your best
- This is not something you can do 12-24 hours a day. Think of it as a job
- Caregiving is NOT the same as raising children

- When you are not *at your best*, your partner will do worse
 - When you are fatigued, you will cut corners, drop balls, make mistakes
 - You will be also be less adept at problem solving, anticipating, explaining
 - SO much of dementia care is figuring out new ways to do things!
- When you are rejuvenated, you will “have space” for fun
- As complex humans, our emotions naturally mirror our environment, including and especially of people around you.
 - Sensing or even receiving your stress/negativity will make them more irritable, stressed, or depressed. This is especially true for individuals whose verbal reasoning or conversation skills have declined.

Preventing Burnout: The Practical Tips

- Physical care: Eat well, sleep, exercise, avoid alcohol and marijuana
- Constantly evaluate your energy, emotions, physical health/needs: feed these
- Learn & practice strategies for relaxation and regrouping (focus today).
Set a time and post a sign.
- Regularly check on the 'health' of your positive relationships: feed these. Others may take a step back, awaiting your invitation.
- Constantly identify resources and supports, and ways to streamline life.
 - Home organization aids
 - Grocery delivery
 - Caregiving grants

Language for Easier Interactions

- Direct—don't ask—and *be specific*:
 - “Please run the vacuum *right now*.”
- Language to remind one that their behavior impacts you and them:
 - “I need help to have dinner ready ASAP. Please do xyz.”
 - “I am tired, please help me by xyz...”
- Restate or redirect, don't remind or point out forgetfulness or errors.
 - Not “You forgot,” or “remember that I asked?” but rather, “Would you please...”
- Know when to use “we” versus “you”

Quick Tips For Self-Care

- **Get good sleep.** Be on a sleep schedule as much as possible. Have a routine to “train” your brain that it is time to sleep. Melatonin is great.
- **Exercise.** This helps your sleep, your stress, your focus and mental clarity,
- **Support & therapy.** As a sounding board, to help you problem solve...
- **Better living through chemistry!** Sometimes, medication is the easiest solution to help with stress and other emotional burdens. Alcohol and marijuana, on the other hand, are not. They WILL make it worse over time.
- **Comedy breaks.** Decompress with 5 minutes of dogs learning to howl or kittens falling over each other on YouTube
- **Meditation, Mindfulness.** This gets its own page!

Preventing Burnout: The Emotional Tips

- Have outlets and create positive things to rejuvenate yourself
- Process “baggage” (pre-existing hurts, unmet needs) that existed before your role change
- Trauma, Grief and Loss: normalize humans talking about humanity
 - Do NOT fall into the habit of hiding, keeping secrets, pretending everything is “normal”
 - Speak about what you are losing, or what you fear about losing
 - You will need to learn to “fill your cup” in other ways
 - Process the traumatic experiences associated with your situation. Nothing is “normal,” but there are many people who can relate.

Hidden Thoughts, Unspoken Secrets of our Mind

- It is very important to get to know our inner voices, thoughts, worries, hopes, and strength of 'faith'
- These silently guide our emotions, thoughts, reactions/behaviors (not just to our loved ones, but towards ourselves and within ourselves)...
 - Concept of what guides "reactivity"
- This is an uncomfortable process that may require supportive guidance or care— from a counselor, a friend who has been through this, a support group.
- The more we talk about the "dirty" "embarrassing" and "ugly" thoughts and aspects of care giving, the healthier we can be, and the better caregivers we can be

- Automatic thoughts: thoughts that are almost reflexive, but unconscious (not directly verbalized), which affect our mood, decisions, behaviors. These are formed over time through experience, sometimes using faulty logic, and sometimes using over-generalization. But either we're unaware of the faulty logic or the "math" makes sense in our mind.
 - For example: life teaches us If A, then B; and If B then C.....and our mind jumps to "If A then C."
 - Real life example: P doesn't help me with the *** when they are able to. Therefore, P doesn't respect me.
 - -As an automatic thought, you won't go through this phrase in your head, but it might become an emotion that "dings" or "pings" you just so when you need help but your partner doesn't offer to help. Over time, what is the effect on you?
 - We need to ID and then work through the logic of our automatic thoughts.
 - The best way to do this is to listen for those "pings" or "dings" and ask questions

Let's Learn: Excerpts from Handouts

- Skills for maintaining health
- Skills for improving the moment
 - Distress Tolerance
 - Meditation, Mindfulness
 - Mood Improving Strategies
- PLEASE REVIEW AND PRACTICE THESE REGULARLY

On meditation and mindfulness:

- Your heart rate, breathing rate, muscular/physical tension, stress hormones not only affect how your body feels, but how well your mind works. Chronically, they also contribute to fatigue and *burnout*.
- Learn to change these
 - Learn to control your breath
 - Learn to control your physical tension
 - Learn to reset your mood

Controlling Your Breath & Heartrate:

- Let's practice
- There are wonderful exercises for controlling breathing: search Google and YouTube for “breathing exercises” or “controlled breathing”
- These take daily practice at a time that you are less stressed. (You don't practice for a 100-yard-dash track event by jumping into a 100-yard-dash).
- Some types of yoga teach relaxation and breathing. Hop on YouTube and give it a try! Other exercises, such as Tai Chi, can also have the same effect.

Controlling Your Physical Tension

- Progressive Muscle Relaxation: let's practice
 - Add breathing in as you do this
 - This exercise can be done in short spurts or in longer breaks
 - Through practice over time, you can just focus on one muscle group in a moment to achieve relaxation

Resetting Your Mood

- Exercise: Sit with a half-smile
 - Sit in a relaxed position
 - In a quiet room if possible
 - Imagine yourself in a peaceful and comfortable environment, if it helps.
- Practice this regularly

Guided Meditations

- Guided meditation involves either listening to a narrator walk you through a meditation, or creating your own.
- Many available online—use for yourself or your loved one
- My recommendation:
 - Pick the most comfortable and relaxing scene you can think of.
 - Develop it with information involving your five senses: what do you see, smell, feel, hear? Walk through the five senses while taking deep, cleansing breaths.
 - Practice this while not stressed.
- See handout

On meditation and mindfulness:

Savor The Moment...

- Mindfulness is a practice of learning to **be present in the moment**. When our relaxation time is very limited, this is especially important.
- Practice eating a piece of chocolate mindfully:
 - What does it look like in your hand?
 - What does it smell like?
 - How does it feel, look, and sound as it breaks in your fingertips?
 - Put a small piece on the very tip of your tongue. What sensation do you experience?
Put a small piece at the very back of your tongue. What sensation is there?

Now let those pieces melt, and swoosh them around in your mouth.
What does it taste like now?

Take a deep breath in as you taste it. How does smell enhance the flavor?



Other Skills (see handouts)

- Distress tolerance skills
- Changing the moment: Build your activity list

Show yourself loving kindness

- Don't beat yourself up over a less-than-ideal or BAD day. Commit to believing tomorrow is a blank slate.
- When things go wrong: Acknowledge no one gave you the instruction manual/playbook, and you're not going to have all the answers. Try to figure out what could have been done differently or what you might try next time. Who can you ask for guidance?
- Take perspective:
 - Was anyone lost or hospitalized?
 - Was the home burned down?
 - Does everyone have all of their fingers and toes?
 - Was anyone injured, starved, or irreparably harmed?
 - If you weren't caregiving, what would the situation be for your loved one?



To request a digital copy of handouts:

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