The Truth Behind Caregiving

• 75% are concerned about their health.
• 61% suffer from high emotional stress.
• 53% experience strain regarding family issues.
• 43% experience high physical stress.
• 33% report symptoms of depression.
• Caregivers of a person living with a neurodegenerative disease are more likely to have high levels of stress hormones, reduced immune function, increased hypertension and coronary heart disease.

I feel like I am in quicksand and can’t find solid ground.
“I struggle to adjust and adapt to so many changes. I feel so angry. Frustrated. Everything is such an endeavor.

I keep reminding myself to go slow, stay calm, and take it easy.

I am not doing so great in this role. I want to run away.”
Acceptance is not liking it, agreeing with it, or giving in. It's letting go of the need to control it, and making peace with what is.

I find calm when I stop trying so hard to make things different.

Making Room for Acceptance

• Accept that a diagnosis, with all its implications, will have a profound impact on your marriage, relationship, or friendship.
• Accept that you will not be perfect and you will get angry.
• Accept that everything changes.
The opposite of acceptance is resistance.

Resistance creates suffering.

Acceptance eases it.

Employ Empathy

The practice of understanding another person's experience from their perspective.
I kept trying to imagine what it was like to be in John’s shoes, slowing, and surely losing abilities, self-esteem, status, and self-confidence.

When I was feeling frustrated I would tell myself, ‘if he could, he would’.

**Empathy sees**

*Human Emotional Needs*

- Need to feel respected.
- Need to have choice and control.
- Need to feel that life has purpose.
- Need to feel needed.

“I am Sylvia. I was Sylvia before I was diagnosed, and I am still Sylvia after being diagnosed. I am still the same person – treat me the same way. Talk to me the same way. Include me in the conversation as you would before.”
• See the person first, not his or her disease.

• Treat like an adult at all times and under all circumstances.

Study found:
People frequently react with agitation, anger, or they become withdrawn.

Empathy sees

Need to feel respected.

Need to have choice and control.

Need to feel that life has purpose.

Need to feel needed.
### What is the person hearing?

#### No Choice or Control

<table>
<thead>
<tr>
<th>Sentence</th>
<th>An offering of choice and control</th>
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<tbody>
<tr>
<td>Let's get your robe on.</td>
<td></td>
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<tr>
<td>I'll cut that up for you.</td>
<td></td>
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<tr>
<td>I'll bet you’d like the television on.</td>
<td></td>
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<tr>
<td>I’ll take care of that.</td>
<td></td>
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</tbody>
</table>

#### No choice are control

<table>
<thead>
<tr>
<th>Sentence</th>
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<tbody>
<tr>
<td>You need to take your medications.</td>
<td></td>
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<tr>
<td>Why don’t you sit over there.</td>
<td></td>
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<tr>
<td>You don’t really want to go do you?</td>
<td></td>
</tr>
<tr>
<td>No, not like that.</td>
<td></td>
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</tbody>
</table>
• Ask.
• Offer choices, all day, everyday.
• Include in decisions every day.
• Adopt a “no wrong way” spirit.

This has been our most delightful visit with my mother in years, not because she changed, but because we did.

Daughter

Empathy sees

Need to feel respected.
Need to have choice and control.
Need to feel that life has purpose.
Need to feel needed.
• Recognize and support the need to contribute.
• Focus on strengths and abilities.
• Avoid assuming the person is incompetent—these beliefs will influence your attitude & your behaviors.
• Encourage often.
• Praise often.

The person living with dementia is not unhappy or upset simply because of their disease or me.

They are living with unwanted dependency and loss.

They need to feel useful, respected and loved.

Most distress arises when an emotional need is threatened.
Feeling shamed or humiliated; a loss of dignity and/or respect.

Being told what to do; a loss of control or choice.

No reason to get up in the morning; a loss of a meaningful and purpose-filled life.

Care partners who ‘overcome’ recognize that it is not the actual situation that causes excess anger or stress and limits their ability to cope.

It is their thoughts.

Mindfulness Based Caring
Mindfulness is **Not**

- panacea or a cure for every ill
- a religion
- a state of bliss
- an empty mind
- controlling the mind
- mind control
- something to harass yourself about
- an assurance that you will always be happy, well, safe, and stress-free.

> Mindfulness means paying attention in a particular way; On purpose, in the present moment, and non-judgmentally.”

Jon Kabat-Zinn
Mindfulness is simply
being aware of what is happening right
now without wishing it were different.
Enjoying the pleasant without
holding on when it changes.
(which it will)
Being with the unpleasant without
fearing it will always be this way.
(which it won’t)

– James Baraz

In order to change negative feelings,
we first have to notice them.

To be in relationship with what
you’re going through, to hold it,
and, in some sense to befriend it, is
where the healing lies.

Jon Kabat-Zinn
Mindfulness **is**

- being aware of our pattern to become entangled in our stories, lost in our incessant thinking and doing.

50% of the time we are lost in our thinking

**What’s the Problem?**

The tendency to think about what is NOT happening comes with an emotional cost.
“Some terrible things have happened in my life, some of which have actually happened.”

~Mark Twain

Mindfulness is

- observing our impulses and feelings in order to skillfully respond moment by moment.

Mindfulness is

- the practice of creating space (pause) between the stimulus and our response.

Respond | React
A Mindful Difference
Mindfulness **IS**

- focused attention on the ‘now’
  (many ways)

3 Everyday Mindfulness Practices

*Joyful awakening*
S.T.O.P and Pause Practice

Stop
Take a Breath
Observe
Pause and thoughtfully respond

Self-Compassion Break

1. This is a moment of suffering

2. Suffering is a part of life- I’m not alone.
   
   Put your hands over your heart, feel the warmth of your hands and the gentle touch of your hands on your chest.

3. May I give myself the compassion that I need.

   This practice can be used any time of day or night.
I'm able to recognize that caregiving is now the major chapter in my life.

My future holds other chapters. But for now, I'm being remade and reformed by my role of caregiving into a gentler, more compassionate, more patient, kinder person.