

This Guide is designed for caregivers who support people with memory challenges.
Caregivers include spouses, partners, adult children, parents, siblings, and other friends or family members. A similar Guide is available for professional and paraprofessional staff. A companion Self-Care Guide is also available for the person being supported.



Comprehensive Services on Aging (COPSA) has been providing compassionate and sensitive mental health care to the elderly and their caregivers since its inception in 1975. At the Memory Disorders Clinic, a team of dementia specialists diagnoses and treats people with memory disorders and the behavioral problems that often accompany them. COPSA offers training to doctors, nurses, social workers and other health-care professionals who work with older adults, as well as to caregivers and community members.

Care2Caregivers provides peer counseling, education, support and referrals through a toll-free help line. Trained professionals, who have also been family caregivers, are available to support caregivers at **800-424-2494**.

Funding for this project and the COPSA Institute for Alzheimer's Disease and Related Disorders is provided by The State of New Jersey Department of Human Services, NJ Division of Aging Services.

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# Caregiving

Caregivers support the health needs of a family member or someone significant in their lives. This may be something you took on willingly or it may be a responsibility that landed on you. Either way, to provide good care to someone else, you need to care for yourself. You need energy and attention to cope with the many tasks, demands, and challenges that you face.

This Guide to Caregiver Self-Care will help you attend to your own health and well-being. Self-care refers to activities and practices that you can do on a regular basis to reduce stress and to look after yourself so you can stay well.

Using this Guide, you will explore what you already do now, including your daily routines, habits, and activities. You will think about what else you can do or can learn to do, which may include identifying the supports you need to improve your self-care and life balance. This Guide reviews simple practices for taking care of yourself, which will increase your ability to provide support,

boost your quality of life and safety, and improve how

you feel every day.

"My mother thought she was in her late 40s and couldn't understand that it was my brother's 50th birthday. She insisted he was her brother, not her son!"

Caregivers often do a wonderful job providing care and support while wearing many hats and doing many different tasks. As a caregiver, you fill in for what the person can no longer do independently. They may need your help all day, every day. It may be up to you to get them connected to other supports and services they need. With all this going on, caregivers often fall short in extending the same care to themselves.

The person you are supporting may seem different. When the person loses the connection to your shared history, it can be like caring for a stranger. It's common to think, "This is not the person she was," or "She is not my wife anymore, but I still have to care for her," or "He doesn't seem like my father anymore." These feelings come on top of the physical demands of caregiving, and it may be hard for you to grieve the person you have lost because you have so much to do all day and all week.

Caregiving doesn't happen in a vacuum. You have other commitments, such as work, children or grandchildren, and maybe you have your own health or relationship issues to manage. It's hard to find the time

and the energy to look after everything and everyone.

"In the beginning, I was just helping my aunt remember to take her medicine and pay her bills. Now, just a few years later, someone has to help her get dressed and go to the bathroom. We have to be sure she eats and drinks enough water. We can't leave her alone, because she's not safe walking."

As a person's condition worsens, their world shrinks. It gets harder for them to do anything outside the home, such as attending a day program, religious services, or community events. Family gatherings can be overwhelming for them. As a result, you also may get out less, especially if you do not have additional help. People may stop visiting when the person you support doesn't remember them or has trouble communicating. You may be so busy giving help that you don't realize you feel mentally and physically exhausted. Getting worn down can create or worsen your own health problems.

The person you are caring for may need your help for a long time. Their symptoms may become more challenging. As they can do less for themselves, they will need more help from you. This makes it extra

important for you, as the caregiver, to remember to make it a habit to check in with yourself and to take care of your own needs.

"My father wakes up in the middle of the night and starts to pack his bag. He tries to leave the house because he doesn't know me, his family, or his home of 45 years. I feel sad. He seems so lost."

# Self-Care for Well-Being

We focus on self-care in this Guide because you are important! Self-care is a set of planned and deliberate actions that you take daily or weekly to manage your stress and to create and re-create a feeling of peace and contentment. We have included activities that you can easily add to your daily routines and habits. Strengthening your self-care skills, habits, and routines will help you get well, feel well, and stay well.

Well-being includes having a positive sense of self, and being healthy physically, emotionally, and socially. Your health habits, the things you do and the choices you make each day, can help you improve your sense of well-being. Some health habits that can enhance your well-being include: sleep and rest, active involvement in productive activity, nourishing yourself with good food and thoughts, moving more, moving with awareness, and making positive connections with people you care about.

While there is a lot you can do on your own, self-care also requires support from others. It can be helpful to reach out to your circle of supporters, both personal and professional, to help lighten your load.

It's never too early and never too late to pay attention to your self-care. You can start wherever you are with whatever you can do. Even though the person you are supporting may not have a favorable diagnosis, it is still possible for you to maintain a sense of well-being as you journey through the illness together.

### How do I find the time for self-care?

Some self-care can be done in small moments of time, even while you are caring for your family member. Even one minute can make a difference. As you go through each day, look for times that you can do something for yourself. You will find lots of ideas here. This Guide may even remind you of things you did in the past that can help you now.

This Guide provides you with a simple process for self-care. We encourage you to try the activities included here. Check out the tips and use the pieces that work best for you.

Our breathing is always there. No matter what our thoughts, emotions, and perceptions may be, our breathing stays with us like a faithful friend.

You may find yourself feeling burdened, bogged down in difficult emotions, or scattered by your many responsibilities. At these times, you can pay attention to your breathing.

This will help you to collect your thoughts and anchor your mind.

If you take time for self-care, by taking small "pause" breaks, eating well, moving more, and improving your sleep, you will feel less stressed. When you pay attention to your own physical and emotional needs, you feel better and you are better able to support others.

"Try pausing right before and right after undertaking a new action, even something simple like putting a key in a lock to open a door. Such pauses take a brief moment, yet they have the effect of decompressing time and centering you."

— David Steindl-Rast

check-in

# Pause

# Taking breaks during the day, even a few seconds at a time, is the first step in self-care. We call this Pause.

Pausing means being fully aware of the present moment, without judging what should or should not be happening. As a caregiver, you may find yourself in the middle of a situation that you don't like but can't change. You may feel trapped and angry.

Even in the midst of difficult feelings, like anger about that situation, you can choose to pause and pay attention, on purpose, to the present moment, with a loving awareness. Pausing, and being aware of the situation and your response to it, can help break the cycle of frustration and anger.

This may sound difficult and be challenging at first, but with practice, it becomes easier and more natural. Over time, practicing Pause can help you spend less time feeling annoyed. You may find you are more loving and forgiving of yourself. The moment of pause lets you choose responses that make you feel more comfortable and, as an added benefit, the person you are supporting may stay calmer.

When we stop and observe our interactions with others, and when we stop and observe our interactions with ourselves, it gives us space to be non-judgmental. A brief pause helps you accept the person you are supporting for who they are, and where they are, in their life journey.

To pause, you simply **stop**. **Stop** what you are doing. **Stop** what you are thinking. **Stop** before you react to the situation.

**Check in** with how you are feeling in your body. **Concentrate** on your senses. **Notice what you see, hear, smell, taste, or touch.** 

**Feel your feelings.** Are you angry? Frustrated? Sad? Do you feel guilty or helpless? You don't have to do anything with those feelings—just say "hello" to them and allow them to be.

A pause can help you learn that your mind sometimes tells you stories about not doing enough, about a difficult future, or about wishing for a different past. Of course, you do benefit from planning for the future and you can learn from the past. However, you also benefit from spending mental time in the present, where your life is actually happening. Learn the difference between the direct here-and-now that you're feeling through your senses of touch, taste, sight, sound, and smell, and the stories you tell yourself about what's going on.

The next time you find yourself getting angry or upset with others, try a pause and notice how you feel. Notice how different it is to provide support when you take time to be really aware of this moment. What happens?

Self-care includes a regular practice of pausing and being aware in the moment. This practice will help you gradually become more aware of a space where you can choose how to focus your attention, leading to less distress and a greater sense of ease and well-being right now.

Many caregivers who pause and take time to be more aware say that it improves their relationship with the person they support. When the caregiver is calm and less reactive to repetitive or disruptive behaviors, the person they are supporting tends to be calmer also. Both have more positive day-to-day experiences. This strengthens the relationship.

## Self-Care Activity: Pause & Breathe

This activity takes 1 to 3 minutes. There are three steps to the activity:

## 1 Check in

Sit quietly. Stay upright and awake through the practice. Relax. If you want, you can try closing your eyes.

Become aware of the feelings in your body.

- What do you feel? Notice what it's like to sit. Pay attention to how your clothes sit on your skin. Feel your muscles and joints from the inside of your body.
- > You don't need to change anything, just become aware.

## 2 Focus on the Breath

Now, become aware of your breathing.

- Notice the sensations of your breath coming in and going out. You don't need to change your breath at all. Just be aware of breathing.
- Make your breath the focus of your attention.
- Your mind may wander. That's fine. When you notice you are thinking or worrying, just shift your focus back to your breathing.
- ➤ Some people like to say something to themselves as they breathe in or breathe out, like "calm" or "peace" or "Breathing in, I know that I am breathing in. Breathing out, I know that I am breathing out."

# 3 Proceed (with awareness)

Before you end your short pause, refocus on how your body feels.

- Notice your body as a whole.
- Have any sensations changed?
- Don't worry about what you're thinking or if you're doing this correctly.
- Thank yourself for making time to pause.

As you move back into your daily activities, take some of your fresh awareness and your appreciation with you.

### Self-Care Tips: Pause

You can do a formal practice at specific times during the day. Many people find early morning and right before bed are good times for a pause practice.

**Try to build Pause into your daily routines, habits, and activities.** You can add informal practices by focusing on body sensations, breath, and awareness as you walk, eat, or do your everyday activities or chores.

- Pause and smell dinner cooking.
- Notice the feeling of the soft, warm towels as they come out of the dryer.
- Take a moment to really see the sunbeams through the window, the bright moon in the middle of the night, or raindrops streaming down the pane.

## Remember how important it is to pause during a stressful situation.

- Pause while you are waiting for the person you are supporting to complete a task that seems to be taking forever.
- ➤ Be aware of the sensations in your body when the person is asking the same question for what feels like the 50th time in the last 10 minutes.
- Notice how the seat of the car feels when you are sitting in a traffic jam.
- Pay attention to your breathing for a few moments before cleaning up a big mess or doing a difficult task.

Find ways that you can make your practice a part of your caregiving and your other daily activities without taking any extra time to do it.

With repeated practice, you will be more aware of, and comfortable with, your feelings and the sensations in your body. You will learn to be more gentle with yourself. A moment's pause can give you a whole new outlook on life.

Remember: It's all about returning your attention again and again to the present. Be aware of the moment. Don't judge your feelings. Be kind to yourself.

# Breathe

When you pause, you focus on your breath, but you don't change it. Now, we are adding a different kind of attention to your breath. This new practice will help you relax, so you feel calmer and less stressed.

Have you noticed that when you are calm and peaceful, you breathe differently from when you are nervous or afraid?

The breath responds to the mind. The amazing thing, which you may not know, is that the mind also responds to the breath! You can change the state of your mind and body by controlling your breathing.

You may have heard of the "flight or fight" response. When you are frightened or stressed, your body wants to either escape or attack the source of the problem. Your body's energy changes. This can be helpful in an emergency. However, when this happens over and over every day, your body can wear down. You get tense. You feel tired. You may be short-tempered. You may catch a cold or worsen another health problem.

Your body also has a relaxation response, sometimes called "rest and digest." At these times, your body and mind are calm. The world feels like a safe place and you feel content.

By learning to control your breath, you can influence your feelings and affect your body. Adjusting your breathing in certain ways when you pause helps you feel calm. Once you feel more calm, you can re-focus. This becomes especially important in difficult situations, such as when you are surrounded by disorder and chaos.

To relax, you can change your breathing so that your upper belly and lower ribs come outward as you breathe in and go inward as you breathe out. This happens when you use the large breathing muscle in the middle of your body to move the air in and out of your lungs. This is different from breathing mainly into your upper chest, which tends to make you feel more anxious.

## Self-Care Activity: Breathing

### **Controlling your breathing is a good self-care practice.**

This activity will help you breathe so your upper belly and lower ribs come outward as you breathe in and go inward as you breathe out. This is the way you were born breathing. It is the best way to breathe as you go through your day.

During this breathing practice, you will take deep, full, slow breaths, so you can relax into the "rest and digest" mode. Breathing in this way can help balance your nervous system, calm your mind, and help boost the oxygen in your blood.

To do this activity, sit straight up in a comfortable chair. It's best to sit on a firm surface, not on a very soft chair or couch.

Once you learn this breathing practice, you can try it on your own in other positions—lying down on your back, lying down on your front, sitting on the floor, or standing. The important thing is to take a few minutes to pause and breathe. Make it a habit. Over time, you will learn what works best for you.

"Breathing is your seatbelt in everyday life—it keeps you safe here in the present moment. If you know how to breathe, how to sit calmly and quietly, then you have your seatbelt and you're always safe."

- Thich Nhat Hanh

## **Breathing** While Sitting

# Sit up straight with your feet on the floor.

- Place your right hand on your upper belly, just above your belly button, with your thumb at your breastbone.
- Place your left hand on your upper chest.

#### Breathe slowly and deeply through your nose. Breathe in. Breathe out.

- Notice that your upper belly comes out when you breathe in and goes in when you breathe out. Your upper hand on your chest stays still.
- Lengthen your exhale. Let your breath out more slowly and more deeply. Don't force it. Be sure you are still comfortable and relaxed.
- Count the time it takes you to breathe in. Count the time to breathe out.
  - When "in" and "out" times are equal, this is one-to-one breathing.
  - Once you feel comfortable with one-to-one breathing, try slowing down when you breathe out. You can let your exhale be up to twice as long as your inhale. This is called two-to-one breath.
  - Counting your breath occupies your mind. By counting and making your out-breath longer and more complete, you are able to calm your body and mind.

#### Breathe without a break or pause.

Reduce and gradually let go of any pause at the end of the inhale or the exhale. Let every inhale flow into the exhale. Let every exhale flow into the inhale. There should be no pause or break. Let the breath flow. If you need to pause between breaths, see if you can shorten the pause.

#### Smooth the breath.

If your mind is agitated, your breath is uneven or jerky. Imagine your breath as a flowing stream. Smoothing it out will help calm your mind.

#### Quiet the breath.

Gradually make your breath as silent as you can at this time.

After you understand how to breathe like this, you can let your hands rest on your thighs with your palms facing down. Continue to breathe this way.

### Self-Care Tips: Breathe

As you go through your day, pause now and then to experience how you are breathing. During your pause, notice what's happening around you, check in with yourself and add a short breathing exercise. Then proceed, with awareness, to your daily activities.

When you check in, just **feel where you are breathing.** Is your chest moving? Concentrate for a moment on breathing into your upper belly.

If you notice you are breathing quickly, slow your breath down by letting your breath out more slowly. **Smooth and quiet your breathing.** 

When you feel stressed or angry, or just want to relax, **pay attention to the timing of your breath.** Count as you breathe in. Count as you breathe out. Without forcing, let your lungs empty more slowly and completely. Allow your "out" breath to become up to two times longer than your "in" breath. This will help your body and mind to become more relaxed and calm.

If the person you support is agitated or is not feeling well, your calmness may help them. It can surely help you. **Try asking them to breathe with you.** Together, count the inhale and exhale out loud, softly and gently.

We encourage you to **try breathing practices.** Be patient and kind with yourself. Like most things, you will get better with practice. You will probably find that the benefits will increase with time.

Make breathing practice a habit. Add it to your daily routine. Practice during your caregiving activities. You can start your day with a few minutes of focusing on your breathing to help you start the day feeling calm. You can end the day with a breathing practice to relax as you fall asleep.

# Nourish Yourself

### Nourishing yourself with good food and thoughts will help you be a more effective caregiver.

Make sure you take time during the day to eat. This will fuel your body and mind and give you the energy you need to get through your many tasks.

### Think about fueling your body:

- Do you know what foods make you feel well?
- Do you take time to prepare and eat healthy foods that give you energy?
- Do you gobble food mindlessly or pay attention to what you're eating?
- Do you enjoy an occasional self-indulgence as part of your self-care?

Mealtimes change when the person you are supporting changes. Eating habits, preferences, and abilities change as the person's condition worsens. Any meal can become a challenge. It may be hard for you to have a pleasant, relaxed, and healthy meal. Make adjustments as needed, like serving simple finger foods, but don't neglect yourself.

Staying hydrated is especially important for both of you. As people age, they may not notice when they're thirsty. Without enough water, someone may become dizzy, confused, or even develop a urinary tract infection. In general, experts recommend 6-8 cups of water a day. Many people prefer drinks with some flavor. Decaf or herbal teas with fruity flavors can be a good healthy choice.

### Think about fueling your mind:

- ➤ What positive thoughts fill your mind with good feelings?
- What thoughts help you feel strong?
- ➤ What is going right?
- What do you appreciate right now?

It's easy to notice what's going wrong—with you, with the person you are supporting, with the world around you. Focus on what's going well and what you're grateful for. This takes a little work but has a big payoff.

### Self-Care Activity: Nourish Your Body

**Eating is something we do everyday.** We all have powerful habits attached to our eating patterns. This activity helps you slow down the process and pay greater attention to what fuels your mind and body.

Pause before you eat. Sit still for a moment.

Notice your sensations. What do you smell? How does the chair feel under your body? Pay attention to the floor under your feet. Check in with yourself. You might try closing your eyes and noticing how you feel right now. Are you hungry? Tired?

**Breathe.** Before you begin, take a few slow deep breaths.

As you proceed with your meal or snack, increase your awareness.

- Pay attention to the smells and flavors of what you are eating. See the colors on your plate. Feel the texture of the food—is it soft or crunchy?
- Notice how your focus shifts.
- Observe how your sensations change as you eat.

Pause again after you eat. Sit still for a moment.

**Check in with yourself.** What is different about how you feel right now? How does your body feel? What thoughts and feelings do you have?

**Pay attention to how you are feeling.** Don't judge it as good or bad, just be aware. Listen to your thoughts. Are you being kind to yourself?

**Breathe.** After you are done, take a few slow deep breaths. This is time to rest and digest.

As you proceed with your day, **give thanks** for a moment's pause. Appreciate the food that fuels your body and gives you the energy you need. **Applaud yourself** for taking the time you need for nourishment.

### Self-Care Activity: Nourish Your Mind

Many people dwell on the negative — what went wrong, what they want but don't have. You may find it hard to let go of a nasty remark from the person you are supporting, even though you know it's part of their condition. Thinking about these sorts of negatives over and over can contribute to a bad mood or even long-term depression. This activity helps you focus specifically on the positive.

This activity takes just a few minutes of quiet time. Decide if you are going to spend three minutes or five minutes. Set a timer, if you wish. If you can't find five minutes, even one minute can help.

"My husband picks up on my energy, and if my energy is positive, it's easier to care for him."

— Melissa Meltzer Warehall

# Start with a pause and a breath. Calm your mind and body.

Begin by thinking of something that went right in the last 24 hours. This can be something simple and obvious. For example, water came out of the faucet when you turned it on this morning. Did you see a beautiful garden as you were driving or riding by on the bus? Did you treat yourself to fresh strawberries? Did you and the person you are supporting finish that tricky jigsaw puzzle? Was there a funny comic strip in the newspaper?

Now, think of something you did well recently. Maybe you stayed patient in a difficult situation. Maybe you made someone laugh. Maybe you made yourself a delicious meal. Maybe you remembered to pause and breathe.

# Repeat. Think of as many positive gifts and strengths as you can in the time you set aside.

You can do this activity silently, in your thoughts, or you can do it as a writing activity. Some people like to keep a small notebook where they can list what they feel grateful for. When they are feeling down, they go back and read what they wrote earlier.

### Self-Care Tips: Nourish Yourself

Focus on nourishing yourself and taking the time to fuel your mind and body. You need to be strong to deal with the responsibilities of caregiving. Feed yourself well, with good food and positive thoughts. Add pauses and breathing into your daily routines to feed and refresh your mind and body.

**Take time to notice your physical surroundings** and check in with your emotions as you go through each day. Notice when you are hungry or thirsty. Be kind to yourself by eating good nutritious food when you need it. You will feel better and have more energy for your caregiving activities.

If you find it's hard to focus on your own nourishment, **consider** eating your own meal at a separate time from the person you are supporting.

**Notice what, when, and how you eat.** What makes you feel good? Notice what gives you energy in the morning. See if you can repeat those experiences the next day.

Be especially sure that you **nourish yourself at stressful times.** For example, if you spend the whole day at the hospital with the person you are supporting, take breaks to eat at the hospital cafeteria. Nourish yourself while waiting in the cafeteria line—pause, breathe, find a positive thought.

Consider your "diet" of news, information, conversations, and energy that you take in every day. Are they nourishing? Do they give you energy and a positive attitude or lifestyle? What are you "feeding" yourself right now?

Notice what helps you relax in the evening and make it a regular habit.

**Focus on what is strong in you.** Think of a short phrase that is a positive reflection of you or of something you do well. When you feel down or stressed, silently repeat this phrase to yourself.

#### Laugh.

Make happiness a habit. Notice what is going right. Appreciate the small gifts in life. Fuel your mind with nourishing thoughts.



Moving is important for self-care, for health, and for stress relief. Keep your body moving. Pay attention to your movements. Movement can be calming and build your physical strength so you can fulfill your caregiver role.

Caregiving can be stressful. Supporting someone with memory challenges can be emotionally draining. It can be physically exhausting, too. You may have times when you just can't take another step or do another thing.

It may seem strange but moving can make you less tired. Moving gets your blood flowing and helps you breathe more deeply. People who are active during the day often sleep better. Better sleep means less fatigue.

Moving includes exercising on purpose. But moving also means using all your body parts. During the day, you move your head, neck, shoulders, hands, wrists, chest, hips, legs, and feet. Some parts of your body get moved more than others. You can add some extra movements while sitting or standing. This will help keep all your joints flexible.

Movement tells your brain to stay alert. Over time, moving your body helps you stay healthy and fight off illness. Moving with awareness can reduce stress and improve concentration. Energetic movement and very slow movement can both help reduce depression and anxiety.

Moving more means keeping active. Remind yourself to stand for a while each hour instead of sitting all day. Remember to move around instead of simply standing still. Put some energy into your physical chores!

To move with awareness, notice the sensations of your body as you go from sitting to standing and from standing to walking. Notice what you are doing as you move about. Pay attention to how it feels when you bend to pick something up or when you reach for something in the kitchen cabinet

### Self-Care Activity: Move

This activity is a series of 8 gentle stretches. Do these slowly with awareness. Let your breath flow. Let the movement follow the breath. You can slow yourself down and focus your concentration by doing each move 3 to 5 times. Listen to your body and only do what feels comfortable. Doing the whole series should take about 10 minutes.

You can do most of these sitting or standing. If you have balance problems, you may want to sit or, if you stand, stay near a chair or a wall.

# 1 Head up and down

- ➤ Breathe in as you bring your face upward and look up. Stay comfortable. Lengthen your neck. Don't tip your head too far back.
- Breathe out as you lengthen your neck, and bring your chin toward your chest, looking downward.
- > Repeat this up and down head movement 3 to 5 times.

# 2 Head sideways

- > Breathe in. Sit tall and bring your shoulders down and back.
- As you breathe out, tip your head to the right. Move your ear toward your shoulder. Face forward, not up or down.
- > Breathe in, lengthen as you move your head back to upright.
- Breathe out and tip your head to the left, stretching gently.
- Breathe in as you move your head back to upright.
- Repeat this sideways head movement 3 to 5 times.

# 3 Turning head

- > Breathe in. Lengthen your neck. Keep your body facing forward.
- > As you breathe out, turn your head so you are facing to your right.
- Breathe in as you turn your head back to facing forwards.
- Breathe out as you turn your head to the left.
- Breathe in as you turn your head back to facing forwards.
- Repeat this head-turning movement 3 to 5 times.

# 4 Neck rolls

- Breathe out as you bring your chin toward your chest.
- As you breathe in, swoop your head up towards your left shoulder.
- Breathe out as you move your head down to center.
- Breathe in as you move your head up to your right shoulder.
- Repeat these neck rolls 3 to 5 times, gently swinging side to side.

# 5 Turtle stretch

- Sit with a straight back, looking forward.
- As you breathe in, gently slide your chin forward, sticking your head and neck out like a turtle poking out of its shell.
- As you breathe out, gently slide your head back to stretch the back of your neck. Try not to tip your head forward or back—keep your eyes focused straight ahead. Some people find it helpful to put a finger on their chin when they are learning this stretch.
- Repeat this turtle stretch for your neck 3 to 5 times.

# 6 Shoulder Rotations

- Sit or stand with a straight back, looking forward.
- As you breathe in, roll your shoulders backwards and up towards your ears.
- As you breathe out, roll your shoulders forward and downwards.
- Repeat this forward shoulder roll 3 to 5 times.
- Next, reverse direction. As you breathe out, roll your shoulders forward and up, breathe in while rolling them back and downwards.
- Repeat this backward shoulder roll 3 to 5 times.

# 7 Overhead stretch

- > Sit with a straight back, looking forward.
- As you breathe in, slowly raise both arms out to your sides, palms down. At shoulder height, turn your palms up, continue to breathe in and stretch up.
- As you breathe out, slowly lower your arms, turning palms down at shoulder height, until they are back at your sides.
- Repeat this overhead stretch 3 to 5 times.

## 8 Side bends

- Sit with a straight back, looking forward.
- As you breathe in, slowly raise both arms over your head. If you can, interlace your fingers. Keep your arms and hands up.
- > As you breathe out, slowly bend to the left.
- Breathe in as you come back up to center.
- As you breathe out, slowly bend to the right.
- Repeat these side bends 3 to 5 times.

# 9 End with a pause

- Pause, notice what's around you, and check in with yourself.
- Take a moment to recognize how you feel before you proceed back to your everyday activities.
- Applaud yourself for taking a movement break.

### Self-Care Activities: Move with awareness

Moving with awareness means paying attention to your **body.** Notice how it feels when your body is moving, stretching, or breathing. Notice how your body feels when you are resting and relaxed. Moving with awareness can be included as you exercise and as you go about your everyday activities. You can make mindful movement a part of any activity in your day: laundry, cooking, cleaning, shopping, walking, exercising, or caregiving activities.

### Standing Up and Sitting Down

We move from sitting to standing and from standing to sitting many times during the day. Explore what it is like to bring awareness to this body activity. Notice the feelings you have when you are sitting. Move with gentleness as you focus on what it's like to go from sitting to standing. Pay attention to the sensations in your muscles and bones. Focus on your balance as you rise or sit. Once you are standing, pause and breathe before starting your next task.

### **Washing Dishes**

As you do the dishes, pay attention to the sounds and feel of the water. Notice how you move your hands to soap and rinse the dishes. Be aware of your gentleness in placing the dishes in the rack, drying them, or putting them away. When you are done, pause and breathe before starting your next task.

### Folding Laundry

Focus your awareness on the feeling and texture of the clothes or towels. Feel their warmth or coolness. Are they rough or smooth? Heavy or light? Pay attention to how it feels to pick up each item. Notice how you lift and turn your arms and hands as you fold each piece. Notice if your mind tells "stories" about laundry, such as "Someone should be helping," or "I have other things I should be doing." Gently return to the direct experience of the item in your hands. Just be in the moment, doing what you are doing.

Be curious about how your body feels. Move with kindness and gentleness. Appreciate what is right with your body in any given moment.

### Self-Care Tips: Move

Once you learn the series of stretches described in this Guide, you can do one or more throughout the day. Many people like to do the whole series in the morning. Others find these stretches relaxing before bed. Some people stretch when they wake up and again before they go to sleep.

Before starting any exercise, it's a good idea to check with a doctor or physical therapist. If you have joint pain or other medical problems,

they can advise you about how to adjust the stretching routine.

"Walk your dog three times a day, whether or not you have a dog."

— Old saying

Notes on stretching: Don't worry if you hear crunching noises in your neck (these are normal). However, you should not feel any pain or strong discomfort. If you do, skip the stretch that bothers you. If you feel dizzy, take a break until you feel normal. Drink some water. When you go back to

the stretches, let your breath flow at a pace that comes naturally.

### Fitting in movement:

- Involve the person you are supporting in some way. Play music and move together. Try music they like or enjoyed in the past. If they are in a chair, have them tap or clap and move their feet and legs.
- ➤ Pause regularly during the day. Check in with how your body and mind are feeling. Proceed with the day remaining aware of your movement.
- ➤ Don't forget the importance of moving throughout the day, even when you are in a tough situation. You can always fit in a small stretch.
- Try a few side bends while you are waiting for the microwave or teakettle to finish. Enjoy a turtle stretch in the line at the supermarket.

# Sleep

Caregivers often find their sleep is disturbed, since people with memory loss often have changes in their sleep patterns. Sleep has many important benefits for memory, mood, energy, and overall physical health. You probably know that too little sleep makes kids tired and cranky, but it makes adults tired and cranky, too!

During the night, sleep helps you store and organize your memories and any new learning. Your body heals during sleep. Too little sleep can make you more likely to get sick or to develop heart disease or some other serious problem. Sleep is important for safety, too, and

may help you to avoid accidents, such as those caused by drowsy driving.

"A good laugh and a long sleep are two of the best cures for anything."

— Irish Proverb

In addition to sleep, learn how to recharge during the day by building in times for rest and relaxation. Many people have a natural low-energy point in the afternoon. Use that time to rest or do a one-minute refresher such as stretching. Plan to do your less mentally challenging chores at these low points, like folding laundry, instead of brainwork, like paying bills.

### Self-Care Activity: Sleep

Use your breathing practice sitting up before you get in bed or after you lie down. This will help you relax into a restful sleep.

- > Sit straight in a chair or lie in your bed on your back.
- Put your left hand on your heart and your right hand on your belly.
- > Breathe out through your mouth with a "whoosh" or a deep sigh.
- ➤ Breathe slowly and deeply into your belly. Notice the movement under your right hand as you breathe in and out.
- Imagine the air traveling from your nose to your toes and back again.
- Count as you breathe in. Count as you breathe out. Slowly lengthen your out-breath so it is longer than your in-breath.

### Self-Care Tips: Sleep

Sleep and rest are important for your health. However, caring for someone else can make it hard to get the sleep you need. Many caregivers who have tried the activities in this Guide have said that their sleep has dramatically improved after they start using these practices regularly. They find it easier to go to sleep, stay asleep, or return to sleep after being awakened in the night.

A sleep mask is a practical tool. Many people have difficulties getting or staying asleep, or even resting during the day.

- A sleep mask may be helpful by blocking out the light when you are taking a quick rest or when you go to bed at night.
- A good night's sleep is good for both your body and mind. The sleep mask can remind you to take a moment for yourself from time to time.
- When you pause during the day, you can wear the sleep mask for a few minutes. This will allow you to focus inward and remove distractions.

### Here are some tips for better sleep:

- Naps may be helpful for you and for the person you care for. If you find that naps make it easier for both of you to get through the day, build them in. Try limiting nap time to 20-30 minutes.
- You probably know that caffeine can keep someone awake, so it's often best to quit drinking caffeinated drinks by 2 o'clock in the afternoon. Experiment to see what works best for you and for the person you support.
- Keep a small notepad and pen nearby. Instead of worrying about what you have to do tomorrow, write it down to get it out of your mind!
- ➤ If you wake up in the night and are having trouble going back to sleep, pause and breathe. **Think thoughts that nourish your mind.** You may find it helpful to get up and move through the stretches described earlier.

If you are trying all the tips discussed here and it is still hard for you to get the sleep you need, it's time to reach out and get help. The person you are supporting may need a medication adjustment to reduce problem nighttime behaviors. Talk with their medical team. It's also a good idea to consult with your own medical providers about your situation.

# Creating Self-Care Moments

Caregiving can be very rewarding. Caregiving can also be very draining. You are experiencing many changes and demands in your life. While you may have little or no control over your situation, you may be able to control how you react physically, mentally and emotionally. By changing how you react, the situation still occurs but you may feel less stressed.

Over time, the person you are supporting will change. Your relationship will change, and the sources of your stress will change. When you learn to take care of yourself by following some of the suggestions in this Guide, it can help ease your journey through the many phases of caregiving.

**Every caregiver's situation is unique.** It's up to you to decide what works best for you in different stressful situations. Consider the self-care skills you have learned from this Guide:

#### Pause and Breathe

There's great value in just stopping for a minute, noticing what's around you, and checking in with yourself. This reminds you how it feels to step off the endless treadmill of doing.

Controlling your breathing can help you feel calm. This will help you regain a sense of control and stability when either you or the person you are supporting is having a bad day or a difficult moment.

After you pause and breathe, move back to your day with awareness.

#### Here are some ways pausing and breathing can help you with stress:

- You relax.
- You are more aware of how you feel and what you need.
- You don't react as quickly to a bad situation when you pause.
- You may become more aware of how others feel.
- You may feel more kind and caring towards both yourself and others.

### Nourish yourself

Eating well nourishes your body. Your mind also needs nourishment through the many things you enjoy doing. Find ways to feed your whole self. It's important to find the right balance that works for you.

#### Move

For many people, moving more can help reduce stress. Moving your body can create positive changes in your body and your brain. It can calm and energize you and help you feel more in control. This may help your sleep and will boost your health over time.

### Sleep

Getting enough sleep and rest are critical for your health. Your body needs this time to heal from the busyness of the day and from all that you do to care for the person you are supporting. Your mind needs to recharge, too.

### Putting it all together

Once you recognize that you are beginning to feel overwhelmed, using these skills can help you manage the stress and chaos better.

- What other self-care skills and activities do you do?
- What things can you practice or add to your day that will help build strong self-care habits and routines?

Often, we can fit in self-care activities to the day as we go along. This Guide includes many tips that will help you add self-care to your week and boost your well-being. Remember, even a minute to pause and breathe pays off.

Some self-care activities require some planning. You may want to try to schedule some things that will nourish and refresh you. Use the chart on the next page to think through what you want to do for yourself.

## Self-Care Activity: Planning Moments

- > Some categories of self-care activities are listed in the left-hand column. Add other things that will nourish you in the blank rows at the bottom.
- Note specific times you can work on the activities you choose.

| When I could do this | Who could holp                   |
|----------------------|----------------------------------|
| (days and times)     | Who could help make this happen? |
|                      | A                                |
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### Self-Care Activity: Creating Self-Care Moments

#### This activity involves using Caregiver Affirmations.

Begin by focusing on your breath. Breathe fully, smoothly, and evenly. Say one or more of these affirmations to yourself as you breathe. If you prefer, you can recite your favorite affirmations quietly, out loud with emotion and conviction, while seated or lying down, anytime, anywhere. You might try writing one or more on a note for your wallet, or post it where you can see it—on your mirror or refrigerator, or over your kitchen sink.

An affirmation is a positive statement of emotional support or encouragement. It helps you replace negative thoughts. Repeating positive affirmations can improve your mood and boost your confidence.

- ➤ I am finding strength, energy, and patience.
- ➤ I support my health.
- ➤ I forgive myself when I make a mistake.
- ➤ I accept that I will have difficult days from time to time.
- ➤ I am finding ways to improve my situation.
- Even when there is chaos around me, I reach for calmness.
- I reach out to others to help me carry the load.
- I pay attention to and listen to what my body needs.
- ➤ I am doing the best I can.
- When I truly care for myself, I can help others.

| Other positive statements I can say to myself: |      |  |
|--|------|--|
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### Self-Care Tips: Creating Self-Care Moments

See if you can fit in a 10-minute early morning stretch.

**Is the person you are supporting able to move about?** Maybe you can take a walk together, stretch, or move to music.

Music is often helpful for people with memory loss and good for you, too. It can be calming in the early evening, when people with memory challenges may experience confusion or anxiety. During the day, music can get you both moving or change your thoughts. Playing music from when the person was young can be especially powerful and helpful.

Take a short break with coffee or tea in your favorite mug. Sit down for lunch instead of eating over the sink or on the run. Plan your time so you don't end up skipping a meal altogether.

Find something enjoyable you can do together now.

On a nice day, you can take a ride in the car to a beautiful place. You can also get some library books of peaceful scenes to share together when the weather is bad.

Look at old photos to remind yourself and the person you are supporting about more enjoyable days in the past.

Reach out to important people in your life. This can help you to manage during tough times. Share your concerns or feelings with people who care about you and are willing to listen. As the old saying goes, "A burden shared is a burden halved."

"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver."

— Rosalyn Carter

### **Flexibility**

Regular self-care helps you manage the demands of caregiving, so you do not become exhausted. This involves flexibility. Think of an elastic band. "Healthy" elastic bands can stretch and recover their shape. Overused elastic bands are "unhealthy" and break when they are stretched too much. Good self-care helps give you the strength you need to face stressful situations and to bounce back.

"[The ability to bounce back | comes from deep within us and from support outside us...It comes from analyzing how we process grief and from simply accepting that grief... I learned that when life pulls you under, you can kick against the bottom, break the surface, and breathe again."

> —Sheryl Sandberg, Option B

#### Here are some tips to consider for thriving (instead of just surviving):

- Notice what goes well. Focus on what is going well, even if you think it is very small. What we focus on expands.
- Stay connected with people who provide support and acceptance. Sharing helps.
- Take care of your physical and mental health needs. Learn from your experiences by thinking about how you managed stress, crisis, and loss in the past.
- Make every day meaningful by doing things that give you a sense of accomplishment and purpose. Remind yourself of these and cherish your strengths.
- Remain hopeful.

There is no roadmap for the caregiver journey, but it's like any trip. To stay safe and to appreciate your travel, you need to pause. Make sure you pause, breathe, move, and nourish your body and mind. At the end of the day, remind yourself of where you've been and all that you have done.

# Resources

This Guide is designed for caregivers. Separate Guides are available to use with the individual you are supporting and for professional and paraprofessional staff.

We have created a video that goes with this Guide to Caregiver Self-Care. The video leads you through the activities in this Guide. Many people have said that actually seeing the breathing and stretching exercises is especially helpful. The video can be used with and by anyone, as it does not specifically mention caregivers or memory loss.

To watch the video, go to <a href="http://care2caregivers.com/">http://care2caregivers.com/</a>

#### Here are some resources for more information:

Pause and Breathe

- To learn more about focused awareness, the website www.mindful.org includes many short readings and practice suggestions.
- There are many videos and recordings online. You may enjoy using peaceful music and guided exercises as you pause and breathe.

#### Some of our favorite online resources are:

- ➤ Jon Kabat Zinn, *The Breathing Space* (3:48 min.) on YouTube
- NJ Center for Mindful Awareness: http://www.mindfulawarenessnj.com/
- UCLA Mindful Awareness Research Center: https://www.uclahealth.org/marc/
- Some people use free apps to pause, breathe, and relax, such as *Insight Timer* or *Stop, Breathe & Think*.

### Nourish Yourself

- Information on healthy eating:
  - https://www.choosemyplate.gov/
  - https://www.hsph.harvard.edu/nutritionsource/healthyeating-plate/
- > Why it's important to drink water:
  - https://www.health.harvard.edu/staying-healthy/theimportance-of-staying-hydrated
- The description of gratitude for water coming out of your faucet comes from a 5-minute video from Brother David Steindl-Rast on YouTube. It's worth watching!

### Move

➤ Simple at-home exercise ideas: https://go4life.nia.nih.gov/

### Sleep

- You can find lots of information at www.sleep.org such as "Why caregivers should focus on better sleep"
- > For tips on falling asleep, search for these articles on www.mindful.org
  - 5 steps to wind down and fall asleep
  - 3 mindful things to do before you fall asleep
- ➤ These sites offer some specific sleep exercises:
  - Jennifer Piercy on Insight Timer (https://insighttimer.com)
  - Search for "best breathing exercises for sleep" on https://www.tuck.com

# References

The personal statements at the beginning of the Guide are based on the combined experiences of many caregivers. When the quote is from an identified person or a publication, the source is listed here.

The "seatbelt" quote comes from Thich Nhat Hanh, Peace Is Every Breath: A Practice for Our Busy Lives.

The quote from Melissa Meltzer Warehall is from a story titled <u>"From Gloom to Gratitude"</u> on National Public Radio (May 5, 2019)

"Happiness is a habit" comes from Juanita Nolan.

The definition of "affirmation" is based on the one from www.mindtools.com

The "move" self-care activity and controlled breathing are adapted from and used with permission of the Himalayan Yoga Teacher Training Program.

We also drew on these publications for inspiration and reference:

- ➤ Alidina, S. (2015). *The mindful way through stress*. Guilford Press.
- Garafano, J., Jr., & Celano, C. (2011, January). Journaling—A wellness tool. This booklet is available from www.cspnj.org
- Kabat-Zinn, J. (2016). Mindfulness for beginners: Reclaiming the present moment and your life. Louisville, CO: Sounds True Publishing.
- ➤ Neff, K. Self-compassion. (www.self-compassion.org)
- Sandberg, S., & Grant, A. (2017). Option B: Facing adversity, building resilience, and finding joy. Knopf.
- Verni, K. (2015). Happiness the mindful way: A practical guide. London, England: Penguin Random House.
- Walker, M. (2018). Why we sleep. Scribner.

