

BRIGHT:
Building
Resilience &
Inner Strength
for Caregivers of
Persons with
Memory Loss



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<http://www.optimalagingcenter.com/>

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Preface

BRIGHT is an interactive, online 4-week workshop for caregivers of persons with memory loss. The workshop was developed to enhance existing coping skills, teach new ones, and acknowledge the depth and breadth of each caregiver's inner strengths. In BRIGHT, caregivers will: create a care map & gain a clearer understanding of their care network, learn new stress and coping skills, and discover new strategies for communicating with the family, with the person with memory loss, & with medical professionals. Designed as a psychoeducational workshop, it is not intended to be a therapy group, although some caregivers report receiving positive benefits with participation.

How to Use This Workbook

BRIGHT consists of four core learning modules. Each module is 90-minutes long and is presented weekly for four consecutive weeks with a small group of caregiver participants (6-8). It is structured for delivery through an online video conferencing program. Thus, the manual has been adapted for online learners. In each module, a *Did You Know box* (shaded) contains additional basic facts on the topic not necessarily covered in the sessions. The *On The Plus Side* (shaded) focuses on the positive aspect of caregiving as reported by caregivers. The *Important!* (unshaded) box reviews vital information that is covered in each session. This material is best used as a psychoeducational workshop guided by a mental health professional or a trained facilitator.

Welcome

This workshop is for caregivers who care for individuals with memory loss. No matter what your relationship is to the individual with memory loss (spouse, children, significant other, or friend), all are welcome. This group will meet for four sessions. Please note the time and day of these meetings on your calendar. Out of respect for all participants we will start and end right on time.

Group Rules

Time: Since there is a lot of information to share and a limited amount of time (90 min), from time to time we may need to move the session along even though it might be nice to keep talking.

Privacy: Anything of a personal nature that is mentioned in group should be treated as private and should not be repeated outside of group.

Surroundings: Please make sure others in your environment cannot see or hear you or what goes on in each session. Limit distracting background noise as much as you can.

Voluntary Participation: Participation in the group is voluntary. You can decide to take part or not take part in any activity, but we do encourage you to participate as much as you can. We have learned that the best way to learn is to join in!

Key Point

In our work with caregivers, we have found that many types of memory loss disorders from Mild Cognitive Impairment to dementias like Alzheimer's Disease or Vascular Dementia can share certain concerns and issues which can become problematic for caregivers. For this workshop we use the term *Memory Loss Disorder* as a comprehensive phrase referring to all diagnosis which affect the memory in the person you are caring for.

Module 1: Managing the Stress of Caregiving



Stress and Caregiving

Caring for another person for a long period of time can take a toll on your physical and emotional state. Research has shown that caregivers face unique challenges that often increase stress. When stress is excessive and extended, it can become very damaging. Over time, it can impact your health and well-being. Since you're caring for someone at home right now, it is especially important for you to pay attention to your physical and emotional health. While this workshop can't take away all the challenges of caregiving, you can take steps to manage stressful situations in a way that is healthier for you.

What is stress?

Stress is a biological response to threat. Any threat, physical, emotional, or mental, starts a cascading effect. Hormones go crazy, ultimately releasing the hormones adrenaline and cortisol. In response to these hormones, you breathe faster to increase O₂ levels in blood and your heartbeat increases, which constricts blood vessels and diverts that oxygen enriched blood to large muscles. As a result, your blood pressure rises, and the liver produces extra glucose to give you a boost of energy. Your digestive system is also interrupted, and your muscles tighten to minimize damage in case of injury. When the perceived threat is over, your hypothalamus sends a message to return your system to normal.

Did You Know?

- 59% of caregivers report emotional stress as high or very high
- 38% of caregivers indicate physical stress as high or very high
- 41% of caregivers state they are the only provider of care

2019 Alzheimer's Disease Facts & Figures

Chronic stress occurs when your system believes it is under constant threat and it never gets the message to stand down and return to normal. Why is this important? Research has shown us that a person who is chronically stressed is affected throughout their system in very specific ways.



Consequences of Chronic Stress

The consequences of chronic stress take away from your quality of life by lowering your ability to experience pleasure or a sense of accomplishment. This, in turn, affects your ability to provide optimal care for the person you are caring for.

Physically. If stress lasts for a long time, it can lead to many health problems. Since caregiving can be a prolonged stressor, caregivers are at risk for stress-related conditions such as: high blood pressure, heart problems, or increased susceptibility to colds and flu.

Psychologically. When left untreated, chronic stress can affect a caregiver's emotional and mental state. Caregivers with untreated chronic stress are at a higher risk for the following

conditions: depression, anxiety, anger, irritability, changes in appetite, sleep problems, lack of energy, hopelessness, or helplessness.

Socially. Caregiving often challenges friendships and relationships. As the stress builds up, some caregivers: may feel like they are a burden, refuse assistance when offered, isolate themselves which increases loneliness and can be alone in caring because friends and family have drifted away.

While these consequences may seem inevitable, there are tools you can use to prevent or address many of these issues resulting from chronic stress.

On the Plus Side

Stress is not all bad. When you need to handle a difficult, challenging, or stressful situation, stress signals the body to give you an added boost. Whether the situation is seeking information about a diagnosis or providing a physical boost in times of emergency like during a fall, stress can provide the push to act. Stress can often help you lead to growth as well. Pushing you to do more than perhaps you would have done normally.

Recognizing Stress

Like the proverbial frog in a pot of water slowly heating that doesn't realize the water has started to boil, chronic stress creeps up on you until stress becomes your new normal. The first step in reducing stress is to know when you are experiencing it.

Stress Signs in the Body. Stress can show up in the body sometimes in unexpected ways. It is important for you to recognize your unique signs in your body.

Activity. Let's do an exercise to help identify how you experience stress in your body. On the handout called Mapping Your Stress is a list of areas in the body commonly affected by stress. Think about a recent stressful experience. Really think about it – put yourself in that place again. Freeze that moment. Scan your body – where are you experiencing that stress? Is your jaw clenched? Can you feel tension in your shoulders and neck? Check the box wherever you are feeling stress in your body in response to this experience.

Stress Signs in the Mind. People also react emotionally to chronic stress in many ways. They may find themselves anxious, be easily irritated or angered, or even find themselves acting out of character. Much like the previous activity, review the list on the handout and note your reactions. Over the next week, pay attention when you are feeling stressed. See if you can find the pattern and map the stress. If you know the first place you experience stress is tension in your shoulders followed by irritability and a headache then you will have a map that will help you, unlike the example of our poor frog, know when to get out of the water.

Mindful Breathing

Research has shown us that mindful breathing is one of the best ways to lower stress. While regular breathing is "automatic" but mindful breathing gives you an opportunity to control the breath cycle for your betterment. By slowing down your breath you send a message to your body

to relax and be calm. Your heart rate and breathing slows, blood pressure and oxygen use decreases, and less stress hormone is released into the body. In a moment we will do an exercise that will ask you to slowly breath in for a count of 5, and then breath out for a count of 5.

If you have any breathing problems (like asthma) or other health conditions that make you uncomfortable doing this, please don't push yourself. We are confident that one of the other options in our resource section will be helpful. We encourage you to explore that on your own this week. If you find the breathing exercise too difficult, please just sit comfortably and think of a positive experience from your past as we do this exercise with the rest of the group.

Step 1: Sit comfortably in a chair and close your eyes. Begin to notice your breathing, just observe your own breath for a couple of breaths.

Note: Your feet should be flat on the floor and arms should be supported in comfortable manner. If closing your eyes is difficult for you, you can pick a place on the wall to stare at during this exercise.

Step 2: Now we are going to ask you to slow down your breathing making it more mindful so it can work for you, to help you relax. To slow down do a slow inhale through the nose, for a silent count of 5 (can be shorter or longer depending on your comfort level). Then do a slow exhale through the mouth, for a silent count of 5 (can be shorter or longer depending on your comfort level).

More Options: *There are many techniques for doing this. You can try different ones till you find on that works for you. Find more options at www.optimalagingcenter.com/bright*

Step 3: As you breath, place one hand on your abdomen and feel it expand gently as you inhale and pull in or contract slightly as you exhale. It's good to do this a few times and see how it feels.

Note: Diaphragmatic breathing (abdomen expanding on inhale) encourages the beneficial trade of incoming oxygen for outgoing carbon dioxide. This type of breathing slows the heartbeat and can lower or stabilize blood pressure.

Step 4: If you are having difficulties focusing, you can add a word or phrase, that you say to yourself, as you inhale and exhale. A simple one is, "I am breathing in/ I am breathing out." Some people use a word that means something to them like "peace" or "amen" or a phrase like: "I am thankful" (on the inhale) "for being alive" (on the exhale).

Step 5: Continue this practice for at least 5 breath cycles (in/out) and gradually increase to 10 breaths at a time. The goal is for you to feel comfortable doing this and for the breathing to calm your body and your mind. It's your "time-out" from stress!

IMPORTANT

If you feel dizzy or light-headed during this exercise – **STOP** and breath normally.

Tips for Effectiveness

If you are not accustomed to mindful breathing it can feel unnatural and awkward in the beginning. Here is a set of tips gathered from other participants who have successfully added mindful breathing to manage stress:

- Deliberately & consciously slow your breathing
 - Focus on breathing in slowly and then exhaling the breath equally as slowly
- Add it to your daily routine
 - The more you practice, the more natural it feels and the more likely you will use it when you need it. We recommend trying this breathing pattern when you are in a stressful caregiving situation this week. You may be surprised to find that the situation is likely to be easier to manage after this exercise compared to before.
- Focus on the breathing
 - If thoughts are overwhelming? Concentrate on your breath. How does it feel on the back of your throat? Warm? Cool? Can you feel your lungs expanding with each breath?

If You are Unable to Practice This Method of Mindful Breathing:
Alternatives can be found at www.optimalagingcenter.com/bright
Please select one you can do and complete the Relaxation Diary using that method.

Calibrating Stress Rating

1. Think of a moment when you are not at all stressed – vividly picture it in your mind. Select two words to remind you and write that next to Not at All Stressed.
2. Now think of a moment when you were terribly stressed and select a word for that. Place it next to Terribly Stressed.
3. Now think of something in the middle, select a word and place it next to Moderately stressed.

This means every time you do a stress rating you remind yourself of your personalized stress rating scale so you accurately ranking your stress level.

1 = Not at all stressed _____

5 = Moderately stressed _____

10 = Terribly stressed _____



Power of Balance

The foundation of resilience is seeing the world as place you want to be part of. If your view of the world is only negative, it makes bouncing back from crisis that much harder. As you know, caregiving is not an easy task. On top of the grief most caregivers experience, caregivers train themselves to be vigilant—always alert to respond to the next crisis. Did he touch the stove? Then I need to make sure he shut off the burner to not burn down the house. Was that the door opening? Did Mom walk out? I need to check so she doesn't wander off and get lost. But this constant vigilance comes at a cost. People who train themselves to look for what could go wrong, may find it difficult to see or experience the positive—what is going right, even if it is right in front of them.

Caregiving & Grief

The saddest thing about memory loss disorders is they gradually take away the person you know. As this happens, you may experience different phases of grieving; denial, anger, guilt, sadness and acceptance. This rarely happens neatly. Much like the disease itself, you'll have good and bad days. Support groups can be helpful and are an important part of self-care for many caregivers.

Finding the Silver Lining

The brain works significantly better when a person is positive in their general outlook, versus negative, neutral or stressed. However, just saying be happy doesn't work. People need an active method to change their focus to include the positive, while still remaining aware of and responding to the negatives that are part of caregiving for someone with memory loss. By broadening your

view to include the positive in your lives you make room for opportunities to observe the silver linings in your world.

Predicting Happiness

The three greatest predictors of happiness are:

- Optimism or the belief your behavior will eventually matter
- Social connection or having people in your life you can depend on
- How we perceive stress - whether as a challenge or as a threat

Writing down three things that you are grateful for each night can actually rewire your brain to scan the world first for the positive and then for the negative. Rewiring the brain can be done in as little as 2 min a day for 21 days in a row.

Power of Balance

Research shows that the following three topics heavily influence a person's sense of well-being and happiness.

Gratitude: the act of giving thanks can have a remarkable impact on a person's well-being. Gratitude can Helps us to focus on the good things that are there in the situation and encourages us to feel positive emotions.

A Kind Act: people who volunteer or do kind acts for others on a consistent basis tend to have better psychological well-being, including fewer depressive symptoms and higher life-satisfaction.

This seems to be especially true in older individuals. Kind acts help you feel good about yourself and others. It also reminds you to take care of yourself.

Acts of Forgiveness: the act of forgiving improves your mood. Holding on to anger, hurt, or disappointment really hurts the person who can't let go.

What is one simple thing you can do to feel happier?

Every day write down something you are grateful for, a kind act you've done or received, and an act of forgiveness.

Journaling these items serves two purposes:

1. *It focuses your attention on the positives in your life.* In essence it trains your brain to notice the good things around you.
2. *It acts as a memory aid.* You can go back and see exactly what good you've done or experienced.

Tips for Success

1. Pick a time
 - Aim for 2 minutes of uninterrupted time to do your journaling, ideally the same time every day.
2. Create a reminder
 - Writing before breakfast? Set an alarm and spend a couple of minutes writing before doing breakfast.
 - Write before going to sleep? Put your journal and pen next to your bed.
3. Find your medium
 - Whether you use a book or computer program, get one you really like. Enjoying writing will help you stick to the habit.

Remember: Rewiring the brain can be done in as little as 2 min a day for 21 days in a row.

Take Away

- Stress affects our life in many ways, some of them unexpected.
- Everyone shows stress in different ways and it is important to know your own signals and pay attention to them.
- Mindful breathing works best if it is practiced often.
- Rewiring your brain to look for the positives in your caregiving situation can increase your sense of well-being.
- Specific practices can help you rewire your brain, if you do them regularly

Home Practice: Making It Work for You

Skill 1: Relaxation Diary/Mindful Breathing

- For 7 days, once a day practice your mindful breathing
- Start with 5 breaths and gradually work up to 10 breaths
- Do a stress rating before and after each practice.
- Use this technique particularly when you are stressed over caregiving.

Skill 2: Power of Balance

Write down 3 things:

- *A Gratitude: something you give thanks for*
- *A Kind Act: something nice done for someone or for yourself*
- *An Act of Forgiveness: clearing the slate*
- *Review at the end of each week*

Need More Information?

More information and resources to explore these topics can be found at www.optimalagingcenter.com/bright

Practice Records/Handouts

Practice Record 1.1: Mapping Stress

Mapping Your Unique Stress Response

Stress in the Body

- Headache
- Jaw clenching
- Grinding teeth
- Trembling of lips, hands
- Neck ache, back pain
- Tension
- Dizziness
- Faintness
- Ringing, or buzzing
- Blushing, sweating
- Cold/sweaty hands, feet
- Clenched fists
- Dry mouth
- Goose bumps
- Heartburn
- Stomach pain, nausea
- Difficulty breathing
- Frequent sighing
- Chest pain
- Palpitations, rapid pulse
- Other: unique to you:

Physical Stress: Let's do an exercise to help identify how you experience stress in your body. In the box next to this text is a list of areas in the body commonly affected by stress. Think about a recent stressful experience. Really think about it – put yourself in that place again. Freeze that moment. Scan your body – where are you experiencing that stress? Is your jaw clenched? Can you feel tension in your shoulders and neck? Check the box wherever you are feeling stress in your body in response to this experience.

Mental Stress: Review the list in the box and note your reactions. Over the next week, pay attention when you are feeling stressed. See if you can find the pattern and map the stress. If you know the first place you experience stress is tension in your shoulders followed by irritability and a headache then you will have a map that will help you, unlike the example of our poor frog, know when to get out of the water.

Stress in the Mind

- Sadness
- Apathy
- Anxiety, worry
- Irritable
- Anger
- Trouble concentrating
- Drinking too much
- Smoking
- Other: unique to you

Relaxation Diary: Stress Evaluation

Please rate your stress level from 1 to 10 in this moment: _____



- 1 = Not at all stressed _____
- 5 = Moderately stressed _____
- 10 = Terribly stressed _____

DATE	STRESS	COMMENTS (why I felt this way, etc.)
	Before: _____ After: _____	
	Before: _____ After: _____	
	Before: _____ After: _____	
	Before: _____ After: _____	
	Before: _____ After: _____	
	Before: _____ After: _____	
	Before: _____ After: _____	

Activity: Mindful Breathing



Stress Rating Before Exercise

Please rate your stress level from 1 to 10 in this moment: _____

1 = Not at all stressed _____

5 = Moderately stressed _____

10 = Terribly stressed _____

Instructions for Mindful Breathing (do at least 10 breaths)

- Find a comfortable seat
- Take a deep slow breath in through your nose for a count of 5
- Feel your abdomen expand as you do this
- Breathe out slowly through your mouth for a count of 5
- Breathe in again, making every breath slow and steady and exactly like the one before it

If You are Unable to Practice This Method of Mindful Breathing:

Alternatives can be found at www.optimalagingcenter.com/bright Please select one you can do and complete the Relaxation Diary using that method.

Stress Rating After Exercise

How would you rate your stress level now? _____

Questions to Explore

1. Did your level of stress change?
2. What was this experience like for you?
3. Can you think of a specific event when this technique might have been helpful during a stressful caregiving situation?

Power of Balance

Gratitude

<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	

Kind Act

<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	

Act of Forgiveness

<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	

Module 2: When Caregiving Affects Your Mood

Check In

Power of Balance (7 days): Is everyone journaling? Is it getting easier to find things to note in each category? Has anyone reviewed what they've written at the end of the week? What did you notice?

Relaxation Diary: Did you work on your mindful breathing all week? If not, what prevented you from doing it? Are there ways to work around it? If you did, did it change your level of tension? What was this experience like for you? Can you think of a specific event when this technique might have been helpful during a stressful caregiving situation?



Caregiving and Your Mood

There are many reasons why caregiving for someone with a memory loss disorder may lead to a caregiver experiencing depressive symptoms.

- *Unexpectedly becoming a caregiver.* For many caregivers, providing care was not what they expected. Whether it is a retirement derailed or trying to care for a parent while caring for children, the added responsibility and destruction of long-awaited plans can take a toll.
- *Caregiving for someone with memory loss can be all consuming.* Caring for someone with memory loss can mean long hours, higher levels of stress, less sleep, and more family conflict. In addition, many dementia-related symptoms (wandering, agitation, aggression, non-cooperation, etc.) make for difficult days and nights and may make it harder to receive help. All of this adds up leading to feelings of being overwhelmed.
- *Severity of the memory loss disorder.* The more severe the memory loss disorder, the more caregivers reported depressive symptoms and other negative emotions.

What are Depressive Symptoms?

In caregiving, depression is more common than you may realize. Caregiving research indicates that between 40 to 70% of caregivers have symptoms of depression. Many people who have these symptoms either fail to recognize them or are too embarrassed to seek help. Some may feel like a failure or fear people judging them. Everyone has negative feelings that come and go, but when you experience 5 or more of these symptoms every day for most of the day for over two weeks it is important to seek treatment from your primary care physician or a mental health professional. Depression can be treated very effectively with either medication, psychological therapy, or a combination of these.

If you are feeling depressed, please reach out for help. There's nothing wrong with you for seeking help – in fact, it's

Depressive Symptoms

- Feeling sad, empty, irritable or hopeless
- Loss of interest or no pleasure in activities you used to enjoy
- Appetite change – eating more or eating less
- Sleep change – too much or not enough
- Restlessness or feeling slowed down
- Loss of energy
- Feelings of worthlessness
- Slowed thinking or loss of concentration
- Thoughts of suicide

likely to make you a better caregiver in the long run. Untreated depression rarely gets better on its own, so getting help will be good for both you and your care recipient.

Dealing with the Blues

Decades of research show that one effective way to manage your mood is to take control of your life. Many times, caregiving is not an activity we ever planned to take on; we come to it by necessity. At times, it can make our lives feel a bit out of control, or at least it may feel like you have little to no control. One very effective way of dealing with this is to make time in your schedule for positive activities.

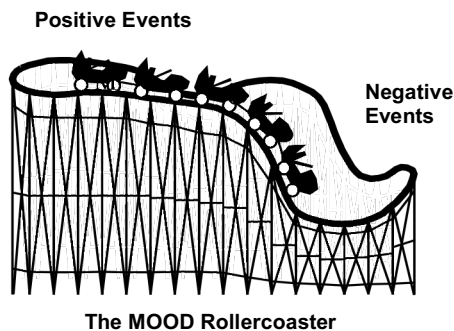
On the Plus Side Caregivers report some positives:

- A sense of accomplishment
- Learn and practice new skills
- Giving back to the person they are caring for
- Increase a sense of self-efficacy
- Increase in activities sees benefits to increased health



Positive Activities

Although being a caregiver is time consuming, it is important that you make time to do activities you enjoy. If all your activities are limited to your caregiving responsibilities, you may begin to feel burned out, frustrated, and even resentful and this can lead to depressive symptoms.



For example, negative emotions such as sadness can develop when there are too few positive events in your day. The lack of balance between challenging and positive events in your life can make you feel like you have no control. You may say to yourself “What’s the use?” or, “It seems like there’s nothing I can do to make things better.” However, you can feel better by making sure your day has a few positive activities. The addition of positive activities will help with the following: how you manage your mood, how you spend your time, and your overall outlook on life.

What counts as Positive Activities?

Positive Activities don’t have to be big activities that require a lot of planning - they can be small activities that you do on your own, with friends, or with your care recipients. Examples might be reading, going for a walk, listening to music, or helping out at your place of worship. Even though these activities may be brief, taking this time out for yourself is important for your well-being.

Adding Positive Activities to your Day

Begin with some questions:

- How are you and the person you are caring for currently spending your time?
- Identify potential positive activities that you are not doing now by asking yourself:
- What did I enjoy in the past?
- Can it still be done now?
- If not, how could it be modified to become more doable now?

Adapting Past Positive Activities

There are probably a few activities that you used to enjoy but maybe for health reasons, or time commitment reasons, you don't think they are doable right now. Whether it might be attending a movie or caring for a large garden, there are ways to adapt a past activity and make it doable now. A first step is to identify what made it enjoyable. The second is to find a way to keep the enjoyable part of the activity. If watching a movie at the theater isn't possible then an adaptation may be to watch a shorter movie at home on your TV .

Making the List

- Think about and then write down a "Top 10" list to get started
- This first list should consist of activities that are simple and easy to do.
- Make sure you have a few items that get your blood moving, like a walk.
- Think about barriers to doing each of these things
- Try to problem solve and devise a plan around the barriers

Examples of possible positive activities

- Listening to music
- Baking or cooking
- Reading
- Having coffee or tea with friends
- Helping someone
- Solving a problem, puzzle, or crossword
- Having peace and quiet
- Going for a walk

Scheduling your List of Positive Activities

Now that you have a list of 10 positive activities, it is time to put it into action. On the Positive Activities Log (PAL) you'll see a numbered list from 1-10. Move your list to PAL. For the next 7 days you will schedule when you will be doing each activity. Try to schedule at least 4 per day by marking the PAL with a slash for the days you will do them. During the week as you complete your activity you can add the other slash to make an X.

When people are depressed, they rarely feel like doing anything. When we first started talking about positive activities, we talked about how taking control of your schedule could help to manage your mood. To do this effectively, you need to have a plan and follow it. Scheduling is an important part of the process - don't look back over your day and count things you already did. It has to be scheduled. Don't wait to do things until you feel like it or wait until you are motivated – just follow the plan and trust the process. If you scheduled a walk on Tuesday, then on Tuesday you walk. Now if you find that following the plan is difficult? For example, you just can't get out there and walk. Then find an exercise buddy to help encourage you – the idea is to problem solve around the barrier. Research has shown that the best dose for the positive activities is 4 per day to reduce depressive symptoms and maintain their absence. The important thing is to get 4 positive activities scheduled into your day and to do them.

Figuring Out Your Dose of Positive Activities

Over time you may notice that there is a connection between the number of positive activities you schedule then complete, and your mood score. There will be times when your mood may respond more to a certain type of activity rather than the sheer number of activities. It is important to note those activities when they happen since they may provide an extra boost when you need it most. An example may be when a friend visits after you've been alone for a long time. This type of activity may end up being so important it becomes largely responsible for increasing your mood despite other things happening or not happening in the day.

Key Point: 4 positive activities a day keeps the blues away!

Revising Your List of Positive Activities

After you have completed a week of scheduled activities it is time to review your list. Which activities were you able to complete? Which ones were never done? Can you figure out what the barrier was that prevented you from doing that activity? Is there a way to modify that activity so it is more likely to be completed? Take off the activities on the list that you would be less likely to complete next week and add others that you would like to schedule. This list of activities is an ever-evolving list. Every week you'll review it and either modify or remove the activities you didn't do until you have a solid list of 10 go to activities that work for you.

Summary of Steps for Adding Positive Activities to Your Life

STEP 1: Identify specific activities or situations associated with positive mood which can be added into your day.

STEP 2: Schedule, do, and track these positive activities every day and notice if there really is an association between mood and activities.

STEP 3: Revise or modify this "list" based on your changing needs and observations about what works and what doesn't work.



Memory Loss and Depression

For many people with memory loss, depression especially at the beginning of a cognitive decline, is common. Scheduling positive activities works for these individuals as well, but they will need a bit more help. Scheduling positive activities that you and the person you are caring for with memory loss can do together can be very helpful. They can help reduce depressive symptoms such as irritability, anger, sadness, etc. Whether it is watching a movie you both enjoy, taking a walk together, or finding a small task your care recipient can do to help while you do household chores, such as taking the plates to the table while you get dinner, these activities promote a positive connection with the person you are caring for. We realize it may be challenging to develop a list of shared positive activities, but we encourage you to give it a try. If it's too much for now, come back to it at a later time.

Creating a Shared List of Positive Activities

Much like the list you made for yourself we encourage you to make one for your care recipient with her or his input, if possible. Start slowly with one or two activities a day until you can build up to 4. Be flexible as some days will be good and other not so much. On the bad days, or when the person you are caring for is in a bad mood or uncooperative, keep it very simple. Aerobic exercise, like a brisk walk, has been shown to be very helpful on many levels. It can help memory, improve sleep, improve physical health and quality of life for both the person with memory loss and the caregiver.

The focus here is on figuring out what activities could be enjoyable for both of you, scheduling them in, and then actually doing them. In our experience this technique improves mood in both caregivers and the persons they are caring for. It does take trial and error to figure this out, however, so please be patient with yourself and the person you are caring for. We consider this an “optional” exercise that may or may not be appropriate for you right now. But we wanted to share these observations so that when you are ready, you will have some guidance for how to proceed as well as simple recording form to use.

Take Away

- Depressive symptoms are common during caregiving.
- Scheduling and then doing an array of everyday positive activities can help to improve mood.
- It is important to do the scheduled activity, even if you don't feel like it. Make a plan and do the plan – trust in the process.
- Taking the time to enjoy yourself will help you feel less stressed and a better caregiver.
- Doing Positive Activities together with the person being cared for can help to manage their mood as well. However, it may take time and a trial-and-error process to get this to happen on a regular basis.

Home Practice: Making It Work for You

Positive Activity Log

- *If not done in class, schedule your Positive Activities each day and then do them.*
- *At the end of each day note your mood rating for that day and the number of activities you completed.*

Shared Positive Activities

- *Identify and schedule Positive Activities that you and the person you are caring for would enjoy doing together each day and then do them.*
- *At the end of each day note your mood rating for that day and the number of activities you completed.*

Need More Information?

More information and resources to explore these topics can be found at

www.optimalagingcenter.com/bright

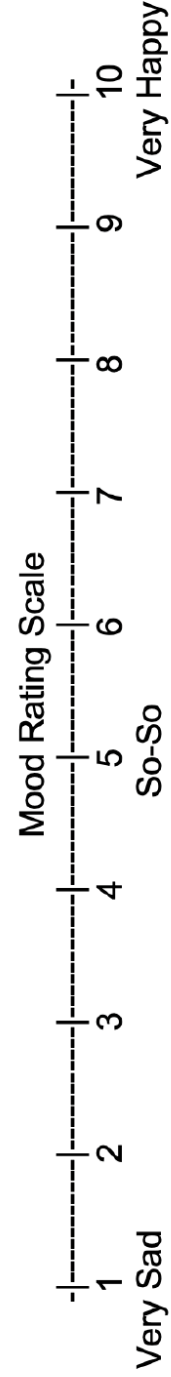
Practice Records/Handouts

Practice Record 2.1: Pleasant Activities Log

PAL: Positive Activities Log

Schedule (/) and mark (X) each day you do a positive activity. At the end of the day note your mood.

Activity	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							
9.							
10							
Total # of Activities Done							
Mood Score for Day							



Module 3: Resilience and Caregiving

Check In

Positive Activity Log: Did you do the activities you scheduled? If not, what happened? What do you need to do to make sure there are positive activities in your daily schedule? How can you adapt your schedule? What did you notice as you did your positive activities?

Shared Positive Activities: Did you do the activities you scheduled? If not, what happened? If you did, was there any change?

Power of Balance (14 days): Is everyone journaling? Is it getting easier to find things to note in each category? Has anyone reviewed what they've written at the end of the week? What did you notice?

Relaxation Diary: Did you work on your mindful breathing all week? If not, what prevented you from doing it? Are there ways to work around it? If you did, did it change your level of tension? What was this experience like for you? Can you think of a specific event when this technique might have been helpful during a stressful caregiving situation?



Recognizing Your Inner Strengths

Resilience is the ability to bounce back from life's challenges. Research shows that there are many inner strengths that make up resilience. Some of these strengths you may already feel confident in, some you may not. As you will experience over the course of this workshop, *all inner strengths* can be further developed through practice. Factors associated with resilience are:

- The ability to develop and maintain supportive relationships
- Making realistic plans and following them
- The ability to communicate clearly
- Skills in problem solving
- Your confidence in your ability to use these strengths

Your confidence in your ability to use your strengths is important; since the higher your confidence is, the more likely it is that you will use your strengths when challenges happen. Confidence is created whenever you are successful using your inner strengths.



Examining Your Support Team

One of the most important factors for resilience, especially for caregivers, is the ability to develop and maintain supportive relationships. These relationships can consist of close friends and family, medical professionals, even neighbors and structured groups like this workshop or a caregiver support group. Caregivers, especially those that care for people over a long time, are at risk for isolation.

Creating Your Atlas CareMap

It is important to identify who is part of your care team. To do that we will be using an Atlas CareMap. The Atlas CareMap, developed by Rajiv Mehta and his team at the Atlas of Caregiving, is a drawing of a family's care ecosystem. It shows who is caring for whom, and how. This can

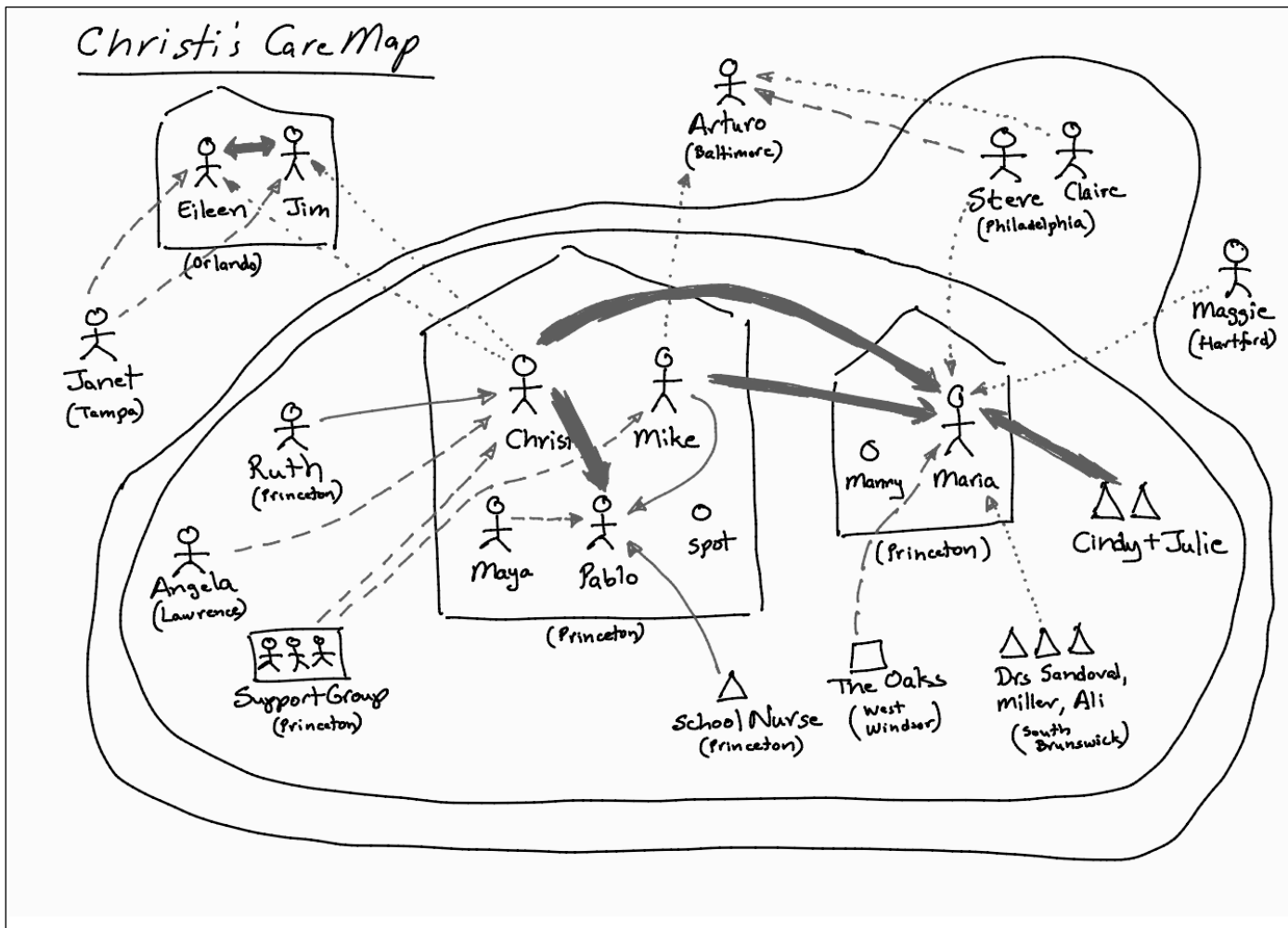
better help you to appreciate what is working well, plan for potential difficulties, manage the many people involved, identify missing people and services, and communicate with everyone.

An Atlas CareMap is composed of:

- “Actors” (people, pets, professionals, and places, shown using different symbols), and
- “Links” (arrows that connect them showing who cares for whom, with different types of lines indicating how frequently the care is provided).
- Placement of Actors corresponds to how far away they live.

An Example

Christi’s Atlas CareMap shows the many caring relations that exist within her family, who are spread out in different parts of the US. In Princeton, NJ, Christi and Mike care for Mike’s mother Maria, who has dementia and lives next door. Several other relatives and professionals also care for Maria. Christi and Mike also care for a son, Pablo, who has diabetes. Mike and his brother (in Philadelphia) also care for their father Arturo (in Baltimore), while Christi and her sister support her parents, Eileen and Jim (in Orlando). Two nearby friends and a local support group provide support to Christi and Mike.



Identify Key Actors

Before you begin drawing your Atlas CareMap, it's helpful to think about who will be on it. For this exercise, it is best if you limit yourself to a few people, beginning with those that come to mind first. Later on, you'll find it much easier to add more people and details.

Use the Practice Record 3.1 Atlas CareMap to answer the questions below:

Who lives with you?

Enter their names in the appropriate section. Don't forget your pets!

Who else is in your household?

Whom do you care for?

a.

If 'a' does not live with you, who else is in their household?

Who else cares for 'a'?

Whom do you care for, and who else cares for them?

Enter the names of the people you care for (limit yourself to only one or two for now). Then enter the names of those who live with them (leave blank if they live with you or live alone).

In the section below, enter the names of whoever else cares for them. Limit yourself to a few people for now.

Who cares for or supports you?

These could be people who directly care for you (including providing you with emotional support), or those who help in ways that allow you the time to take care of your caregiving responsibilities. Enter their names.

ATLAS OF CAREGIVING

Atlas CareMap Worksheet

Who cares for you or supports you?

Draw an Atlas CareMap

Using the Practice Record 3.1 Atlas CareMap when following the next instructions.

1. Enter your name and date at the top of the drawing sheet.
2. Draw yourself and the other Actors who live with you in the middle of the page. Be sure to write their names. Then draw a house around this group and enter the location.
3. Draw the Actors you care for, if they are not already on the Atlas CareMap, and those who live with them. Remember to draw them near you or near the edges of the paper depending on how far away they are.
4. Draw Links to show who you care for. Remember the arrow goes from you to them and draw the type of arrow that reflects how frequently you care for them. (see bottom of sheet).
5. Next draw other Actors who care for those you care for, and their Links.
6. Draw the Actors who care for or support you, and their Links.
7. Draw a line to encircle those who are "Near" you. These are people close enough that they can visit if needed without much hassle (e.g., within twenty minutes of you). Everyone inside this circle is Near. Many people choose to include "online friends" (such as Facebook groups) within the Near circle.
8. Finally draw another line to indicate those who are "Far" from you — more than two hours from you. Everyone outside this circle is Far.

Helpful Hints

- Add names & locations of Actors under symbols.
- Draw yourself in the middle, and then use space on the page to represent **geographical distance**: if someone is nearby draw them near; if they are far away draw them near the paper's edges.
- Link arrows from caregivers to care recipients. Use different types of lines to represent frequency of care provided (see bottom of sheet).
- If caregiving is mutual (person A cares for person B, and vice versa), draw two separate Links if space permits to make it obvious.

Your Atlas CareMap will likely be messy the first time you draw it. Don't worry about it.

Reflect on Your Atlas CareMap

Just the process of drawing your Atlas CareMap may have given you a new perspective on your situation. However, taking the time to reflect on your map may offer some key insights for future planning.

Take a moment and think about your Atlas CareMap and the people in it, then try to answer the following questions:

- Who is indispensable, and what happens when they're not available?
- Are the different people in your Atlas CareMap aware of each other's involvement?
- What are the different kinds of care and skills people provide? Think broadly, including practical (medical assistance, transportation, research, etc.) as well as social (companionship, laughter, comfort, etc.).
- How are responsibilities divided amongst the different people?
- How do you communicate, coordinate, and negotiate issues with everyone?
- Have you forgotten anyone important? (spouses/siblings are often overlooked!)
- Are there relatives or friends who could be more involved?
- Are there professionals or services that are missing and needed?
- What is good in your current situation, what would you not want to change?

Sharing Your Atlas CareMap

An important step in this process is finding a partner and sharing your Atlas CareMap. Whether you hold your CareMap up to the camera and share it with workshop or find someone closer to home to share it with – explaining what you diagramed can help to clarify in your mind your situation or even help you to remember additional actors you may have forgotten to add.

For more information about the Atlas CareMap go to the Atlas of Caregiving website:

<https://atlasofcaregiving.com/caremap/>

This link will also be available on www.optimalagingcenter.com/bright

Take Away

Identifying your care team will help you to:

- appreciate what is working well
- plan for potential difficulties

- manage the people involved
- identify missing people and services
- communicate with everyone

Identifying your unmet care needs is the first step that you have to do, so that then you can begin to think and plan for how to get these needs met.

Home Practice: Making It Work in Your Life

Skill 1: Further Develop your CareMap

- *First draft done in class*
- *Review and add to it when you are at home*
- *Optionally you can transfer your draft to your computer via Atlas CareMap at <https://atlascaresmap.org/>*

Skill 2: Reflect on CareMap

- Reflect on the questions discussed in session and found on page 15 of your workbook.
- Figure out what your unmet needs are and begin to think about how to get them met.

Skill 3: Share your CareMap

- Share your CareMap with at least one person in your Care Network.

Need More Information?

More information and resources to explore these topics can be found at www.optimalagingcenter.com/bright

Practice Records/Handouts

Practice Record 1.1a: Atlas CareMap



Who cares for you or supports you?

Who else is in your household?

Your name: _____

Whom do you care for? a.	b.
If 'a' does not live with you, who else is in their household?	If 'b' does not live with you, who else is in their household?
Who else cares for 'a'?	Who else cares for 'b'?



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Atlas CareMap of _____ Date _____ Practice Record 1.1b: Atlas CareMap

- Actors: people  groups of people  professionals  pets  facilities & services 
- Links: frequently  daily  weekly  occasionally 

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Module 4: Healthy Communication

Check In

Atlas CareMap: Did you do the activities you scheduled? If not, what happened? How can you adapt your activities or schedule?

Positive Activity Log: Did you do the activities you scheduled? If not, what happened? How can you adapt your activities or schedule?

Shared Positive Activities: Did you do the activities you scheduled? Are there different activities you can do? If you did, was there any change?

Power of Balance (21 days): Is everyone still journaling? This was our last week for this task. Have you noticed any changes – small or large?

Mindful Breathing: Did you continue to set aside some time each day to do your mindful breathing? Were you able to use mindful breathing when in the midst of a stressful caregiving situation? The more you can practice this skill and learn how to calm yourself, the more you'll use it when you are stressed from caregiving.



Empathy: The Foundation of Communication

Many people believe that empathy is the foundation for all good communication.

Sometimes we just want someone to understand what we are going through. In that moment, we don't want solutions, we just want someone to be there for us, to listen and care. In a nutshell, empathy is the ability for someone to figuratively put themselves in the shoes of another person so they can feel what that person is feeling. Empathy is about understanding and accepting without judgement. When receiving empathy, the person feels understood, accepted, important, and above all, connected to another person. People do not do well, either physically or emotionally, when they feel isolated. Empathy from another person breaks that sense of feeling disconnected from everyone.

As persons with memory loss loses parts of their memory, they lose the feeling of being connected to others. Some people react with agitation and some react by withdrawing. Caregiver empathy helps caregivers connect with their loved ones. In addition, it helps care recipients with memory loss to feel understood and safe. We know through research that empathy is not a fixed trait, it is a skill that can be improved. Like any skill, empathy requires practice. Here are some techniques that will help you develop empathy toward the person you are caring for.

Activity: Experiencing Empathy

Introduction: Many memory loss disorders involve a general slowing of the ability to understand verbal language, one of the main ways we communicate important medical information. The following exercise is an example of what it can feel like to want to understand something important but find it difficult.

Instructions: Participants are to imagine themselves in the place of the patient as the facilitator reads the scenario. There will be a discussion following the scenario.

Scenario: You received a phone call from your doctor's office requesting a clinic visit to discuss results of recent tests. Arriving at the clinic, you're insecure and somewhat bewildered because

you feel like other people are looking at you and all the background noise is distracting. When you get in the doctor's office, the doctor and your caregiver carry on a discussion about your condition while totally ignoring you. You are trying to follow the conversation, but the doctor seems to be talking very fast and you don't quite understand all the words.

"Well, the consummation connote dementia, practicably Alzheimer's blazon. There's no expeditiously percipient progress, but exigency is no medicament for Alzheimer's. I'll pharmacon Aricept for pother. Inguritate one bolus qhs for a singular stretch of 30 diurnal courses then inguritate 2 bolus qhs. You might endeavor to acquire formation of stanchion to frequent. I cede a practitioner vigilance bangle contingent upon irretrievability. My RN will make an observation of duration to resume in six stretch of 30 diurnal courses. Expression commiseration. There is a nonexistence of resolution to propound."

Discussion

- Can you figure out what the diagnosis is here?
- What about the prognosis?
- What instructions have been given?
- How did it feel when the doctor and your caregiver discussed your diagnosis as though you weren't even in the room?
- What impact on your thoughts could this have?
- What about how you are feeling?
- Alzheimer's Disease is mentioned a couple times - what do you think the reaction would be to that diagnosis?

Summary

This exercise was designed to help you place yourself in the shoes of the person you are caring for. The memory loss disorder itself provides a filter that the person who is living with the disorder must negotiate each time they reach out to the world. It is important to allow yourself to imagine her or his experience. This increases empathy, which in turn feeds increased compassion and patience.



Communication and Memory Loss

It is important to remember that what we say, how we say it, what we do not say, and our body language all convey meaningful messages to others. There are times when what we say is in direct opposition to what our body's say. For those closest to us the messages we send – both verbal and non-verbal – set the stage for feeling safe and cared for. In addition to the signals we send out, we have gotten used to responding in a set way to those we have lived with and loved for a long time.

A key factor to keep in mind for the person experiencing memory loss is that they will not be communicating in the way they used to. We need to be mindful of shifting our expectations to fit the current circumstances, and not try to change our care recipient's behaviors to match our expectations. We need to go with the flow of how things are now and where your care recipient is in the present moment and be open to change at any time. This can be very challenging, we

admit. However, once you come to terms with this reality, you can make life so much easier for all concerned.

Communicating with someone with memory problems can be challenging. At times you may feel as if you have to jump over many hurdles or have to walk on eggshells. Memory loss affects communication in a number of ways:

- It affects one's ability to understand what is said
- It limits the ability to express what he or she wants to say.
- It leads to problems finding the right words, as well as an inability to remember thoughts from one moment to the next.
- It causes communication problems which can lead to behavior problems.

Increased behavior problems can be frustrating and increase caregiver stress. When we are frustrated, we do not communicate effectively, which can result in further frustration and more problems.

IMPORTANT POINT

Because care recipients cannot change their communication problems, it is important that we find other ways to communicate with them.

Communication Tips

When your care recipient cannot understand what is being said, or find the words to express thoughts, it can be frustrating and embarrassing for everyone involved. Here are some things to consider when you are communicating with a person that has memory loss.

Use Open Body Language.

Non-verbal communication like body language conveys as much information as verbal language – sometimes conveying even more than verbal language. If your body language says one thing and your words say another, people tend to trust what your body says over your words.

- Turn towards the person you are speaking to
- Don't be too far away
- If the person you are talking with is seated, you should sit, too
- Relax your body- uncross your arms and legs

Watch the other person's body language for clues. Put yourself in the care recipient's shoes. Much of what persons with memory loss use to anchor themselves is missing, they may not know who they are, who you are, where they are, or what they were doing. How scary would that be? Watch and learn their signs that indicate they are scared. Let that guide you on how to interact. On the other hand, some individuals with memory loss live in the moment and express whatever emotion is most important to them in that moment, which could be joy and happiness.

- Touch can be powerful: it can show that someone cares, it can connect them to another person and allow them not to feel so isolated.

Be attentive.

There is so much in this world that distracts.

- If they allow, make eye contact.
- Shut off the TV, put away the phone.

Listen to hear, not to talk.

Too many times in our busy lives we take the shortcut of listening so we can reply. Listen for the emotion and seek to understand what has contributed to it.

- Allow yourself to listen as if your only job is to understand.
- Focus on understanding their unique experience.

Use your voice and words to convey empathy.

- Emotions can be contagious, monitor the sound of your voice.
 - Lower your vocal register, speak slower and in a calm soothing tone.
- Verbalize your understanding.
 - Identify and label emotions. “You sound sad.” or “You look happy when you talk about your sister.”
- Don’t counter an emotion with a fact, just acknowledge it.
 - This is not the time to be “right.” If they say, “I feel scared to go to the doctor,” don’t say, “The doctor won’t hurt you.” Acknowledge their fear by saying, “I know, sometimes going to the doctor is scary.”

Deal with the emotion not the content.

- What can you do to help them feel less scared? Less worried? Less agitated?
- Identify what soothes them and offer it. Hold their hand, bring their favorite blanket, bring a favorite snack.

Adapted for use from

<http://www.caregiverstress.com/geriatric-professional-resources/professionaldevelopment/clinical-empathy-a-key-tool-for-client-care>

What to avoid!

- Don’t argue with your care recipient.
- Don’t tell the person what he or she cannot do. Instead of saying, “You can’t go outside,” try, “Let’s sit down and read the paper together.”



Getting Help from Family

Family can either be a tremendous support or a source of conflict, many times they can be both. Effective communication can help your family and friends to understand what your needs are in this moment. Knowing who you are speaking to, and how much information they need to make a decision can help you to know what you can expect when you ask. It can also inform you how much information you will need to share to get their help. At times, barriers such as whether the person you are asking is worried about being “trapped” by volunteering to help (if they help you this time will you always expect their help?), and even whether they feel ill-equipped to help because they don’t know how to handle any situations or crisis if it should happen. On the other hand, sometimes people are over committed and are not available to help, being gracious now may open an opportunity for assistance at a later date. It all comes back to knowing who you are talking to. The tips presented next can assist you in clearly communicating your needs.

Tips for Better Communication with Family and Friends

Examine your needs. What do you want, and what are your feelings about the situation?

What exactly is the problem? Formulate this in one or two sentences.

Describe your thoughts and feelings clearly, so the other person can understand your point of view.

Be persistent and flexible. Maybe you won't get exactly what you asked for, but you will get something that will be helpful.

Avoid substituting opinions for facts. Try to use "I statements" frequently.

Give detailed information. For example: taking care of Mom for two hours involves feeding her a snack, turning the radio to her favorite station, and taking her to the bathroom.

Break it down into smaller parts. It's usually easier for people to say yes to a little request than to a big one!

Listen to whether the listener can fulfill the request. If he or she cannot do the request, ask if a different time or request is possible and begin to negotiate. Be aware that what you are asking for may not be possible – be willing to be flexible.

If you are at an impasse, take a break. Go back to the discussion at a future time. For example, agree to think about it and talk again tomorrow afternoon.

If appropriate, offer to do the task with the person. For example, sit together with Mom for two hours first before your brother does it alone so that he can learn what is involved and feel more confident.

DON'T GIVE UP! It may take many attempts before things change.

Activity: Practice Effective Communication Skills

We are going to ask for 2 volunteers to role-play a specific situation in which you are trying to ask for help or respite from a family member or friend and he or she is reluctant to agree. After 5 minutes, we will have two more volunteers jump in and continue the conversation so that you all can practice your effective communication skills. Afterwards, we will discuss your thoughts and reactions to this exercise. Please try to make this situation as realistic as possible for you. Try to be aware of how to be effective in your approach.

Role-Playing Situation

You are in need of a “break” (to go shopping, go to the dentist, pay bills, etc.), so that you can get things done without your care recipient coming along and distracting you. You want to ask your sister (brother, son, daughter, whoever is appropriate) to come over and be with your care recipient for 4 hours while you go out. Your relative usually doesn’t agree when you’ve asked for this kind of help in the past, or usually says yes and then cancels at the last minute. This time you really want a solid “yes”.

Questions to Consider

- How hard was this for you to do?
- What part did you find easy?
- What part did you struggle with?
- Is this something you would do at home with your own family?



Communication with Healthcare Professionals

It may seem like attempting to be heard during a short visit with your doctor is impossible. You may be surprised to hear that lack of time with patients is the number one complaint of many doctors as well as patients. Here are some tips that will help you use your precious time with the doctor more effectively. Some of them you may already be doing, if not the first 3 are key to improving communication. Please read the list over and think about which ones you can start using at the next visit.

Talking with Your Healthcare Professional

- Make a list of questions and bring it with you to the appointment so as to maximize use of time.
- Be clear when you speak with the health care provider. Try not to ramble.
- If you have access to an online service send your questions to the doctor before your visit

Other Issues to Consider

- If you have a lot of things to talk about, or expect that you'll need additional time, try requesting a longer appointment so the provider can allow enough time to meet with you (some practices allow for a consultation appointment).
- Educate yourself about your care recipient's disease or disability.
- Learn the routine at your provider's office so you can make the system work for you, not against you. For example, do they prefer a phone call, emails or prefer you use their web service like MyHealth Online? Ask who should you talk to if your main provider is not available? What is the arrangement for after-hours questions?
- Recognize that not all questions have answers; sometimes you just have to "muddle through."
- Appreciate what the providers are doing to help and say thank you from time to time.

Take Away

- Empathy is a skill we develop throughout our lifetime.
- Caregivers need to shift expectations and the ways they communicate, rather than depend on the person they are caring for to change how they communicate.

- Clear and concise information combined with flexibility can give a better outcome when speaking with family and friends.
- It is better to plan ahead and make a list so that you can get concerns addressed when speaking with healthcare providers.
- Improving communication is an ongoing process; be open to feedback so you can use it to improve your skills.

Final Words

Over the past four weeks we have worked together to encourage the use of caregiving skills. But like any skills, they require practice and use to make them part of your life. If you remember the first time you sat behind the wheel of a car, you probably recall that there were so many steps to remember, that it could feel a bit overwhelming. But with practice and experience, over time you eventually got to the point where driving became relatively simple and automatic. This is true of the skills we taught during this workshop. Go home and practice them until they become part of your life. So, when you need them, they will be right there ready for use. Continue with the positive activities and self-care so that when you need to depend on your ability to bounce back from a crisis, those reserves will be there for you as well.

Congratulations on completing the BRIGHT workshop!

We've asked you to do a lot of hard work over the past 4 weeks. It is our hope you will find the information and tools helpful on your journey as a caregiver.