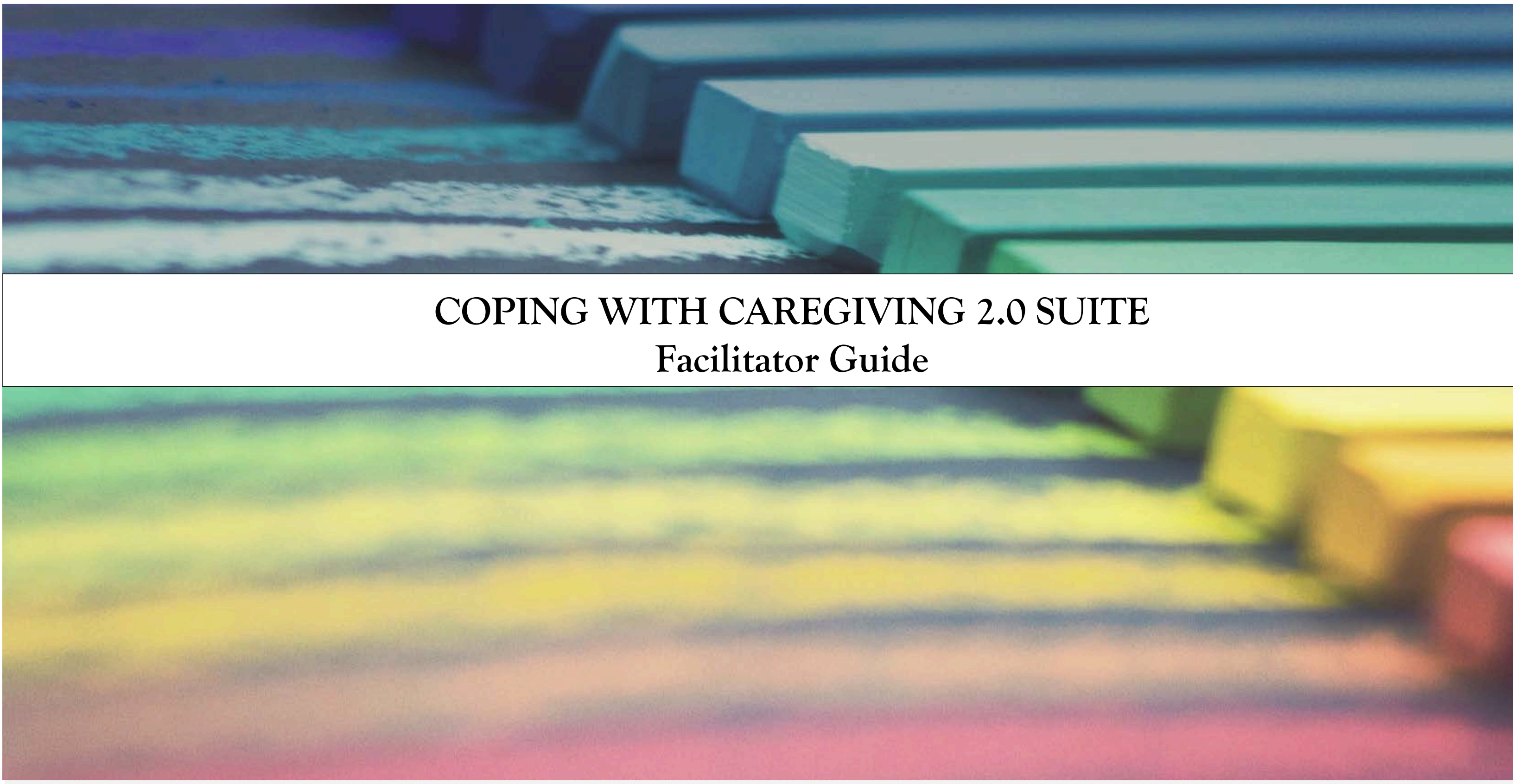


COPING WITH CAREGIVING 2.0 SUITE

Facilitator Guide

- Bouncing Back -

- Being Heard -

- Strategies for Stress -

- Coping with Frustration -

- All By Myself -

- Dealing with the Blues -

- Filling the Well -

- Challenging Behaviors I -

- Challenging Behaviors II -

Dolores Gallagher Thompson, PhD
Ann Choryan Bilbrey, PhD

OPTIMAL AGING CENTER

This book is not a substitute for continuing education, professional supervision, or for seeking advice from a trained professional. The authors disclaim responsibility for any adverse effects arising from the application of the information contained within this workbook. Optimal Aging Center provides additional training on the use of this workbook for mental health professionals. More information can be obtained at http://www.optimalagingcenter.com/.

2nd Edition 2023

Table of Contents

About this Manual

Session Summary Page

First page of each Session is a summary provided for the Facilitator's use. It is not intended to be shared with the participants. It is a quick orientation to the material about to be presented. It contains the aim, handouts, main points, activities, and action plan options.

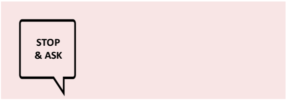
Considerations

This section offers additional information on the content on that slide. They can offer background, special issues, or pointers that can help facilitators to deliver the specific information on that slide.

Material

This is the content to be delivered. You may use your own words as long and the content is conveyed. The material is more accessible to the participant if it is not just read.

Stop & Ask



The Stop & Ask graphic contains brief questions to help the facilitators engage the participants. When you see this - pause and ask the question(s)

Activities


ACTIVITY-Directions

ACTIVITY-Do it

ACTIVITY-Process

The Activities are how the caregivers will learn the skills associated with improved well-being. These purple boxes help the facilitator to be aware when the material is part of an activity. The first box contains the directions for running the exercise for the facilitator. The second box is the material intended to be used with the participants. The third box contains the process question that will follow the exercise. Every exercise will not always have all three boxes.

Time Management

Asks & Activities are an opportunity to engage the participants. Some Asks will require engagement of all participants, other will ask for a volunteer. Activities should promote engagement in all participants. It is essential to the success of this workshop that it is not heavily lecture oriented. The facilitator should be familiar enough with the content and the planned Asks & Activities so time can be managed well. A good goal is to anticipate a third of the time in the workshop to be participative. In a 90 min workshop, facilitators should plan for at least 30 mins spent actively engaging participants in the material through Asks & Activities.

Length of Sessions

The length of the sessions are intended to be 90 mins but can last as long as 120 mins depending on the amount of participant engagement, number of participants, and experience of the facilitator with the content. If the attendance exceeds 6, the sessions will take more time to thoroughly engage all the participants. For facilitators with limited experience running highly structured workshops such as this, more time will be needed to adequately address both didactic and experiential components embedded in this workshop. If the facilitator finds the session is running consistently less that 90 mins the first place is to examine the engagement level of your participants, then make sure that all the material content is being covered, including the development of a personalize action plan at the end of the session.

Notes for Facilitators

You can look in the content of each session for specific facilitator content regarding that section. Look for **FACILITATORS:** ***note*** to access these notes. Additional information can be found under the Considerations section located at the beginning of each slide's page.

How the CWC 2.0 Suite Works

This program is designed to be delivered remotely via a telehealth platform. Offering a unique flexibility, these modules can be delivered either individually or they can be combined to create customized program to best fit the needs of the agency and their caregivers. Therefore, content and overall program length are variable depending on the number of modules selected. There are 8 topics, covered in 9 sessions. Each module is self-contained, including a mini-lecture on the topic along with group discussion, in-session practice, and development of action plans to integrate new skills.

Coping with Caregiving 2.0 Module Descriptions

Bouncing Back. This module explores the concept of resilience in caregiving, including tools to refocus on the positives in caregiver's life and the creation of a care map which will examine their current support team.
Being Heard. The focus is on communication, exploring empathy as the foundation, how memory loss affects communicating, and explores strategies to ask friends and family for help.
Strategies for Stress. With a focus on stress management, this module begins by exploring stress and caregiving including recognizing unique stress patterns and concludes by teaching two relaxation skills.
Coping with Frustration. This module emphasizes that frustration, and anger, are understandable emotions but they interfere with successful caregiving. Exploring first negative emotions and then concluding with strategies for management.
All By Myself. The focus in this module is on the loneliness and social isolation. The module discusses the difference between isolation and loneliness, finding support in today's world, and how to keep the person you are caring for safe.

Dealing with the Blues. This module's focus is on mood management. Discussion begins with the effects of caregiving on mood, then covered are strategies to manage mood more effectively for both the caregiver and the care recipient.
Filling the Well. Caregivers rarely devote time in their schedule to attend to their own self-care needs. This module explores caregiver burnout, self-care needs, and strategies for including self-care in their day.

Practical Notes

Combining Modules

Each module is prepared as a self-contained unit. If you choose to create a program by included multiple modules you may wish to include the ground rules and introduction only in the first module, removing the following slides from subsequent modules:

Slide 2: Ground Rules
Slide 3: Introduction

Adding a Contact/Agency Slide

A contact or agency slide can be added to the end of the slide. This is highly recommended if you are planning to share the slide set.

Contact with Participants

Registration > Welcome Email > Evaluation Survey

Registration
In addition to whichever is required for your agency. You may want to collect:
Relationship for who they are caring for [daughter/son vs spouse]
Care Recipient's Diagnosis
Length of time as caregiver [new vs experience]
It will help to inform type of information you will offer in session.

Welcome Email
Sent 24 hours in advance of Zoom Meeting. Contains:
Welcome, Zoom Meeting Info, Tech Contact Info, Handout PDFs, [PPT PDF]

Evaluation Survey
Sent immediately following completion of program. Should be brief, no more than 7-10 questions.

Dedicated Website Page

Handouts & PDF of PPT available anytime
If you use an open link - Anyone can access – may skip registering in class.

Better to use a private to participant link only. A link shared only with participants – encourages registration.

Sharing the PPT

If you use actual ppt slides, it will require either they have a version of the software or some type of work around. Too much work required from the caregivers means they won't look at it.
Instead create a PDF version
PDF (for Mac)

- Save As CWC 2.0.X PDF
- Remove housekeeping slides (Slides 2 & 3)
- May add contact slide for agency
- View > Handout Master > 3 Slides
- Deselect Date & Time
- Header CWC 2.0 Title
- Footer Agency Name & Email
- Close Master
- Print to PDF: in Layout select Handouts (3 Slides) from drop down
- Compress PDF Various free programs available [smallpdf.com]
- Example provided

When/How to Share PDF

- With Reminder Email
  - They can print and make notes the day of
- As a download upon completion of Evaluation Survey:
  - It can be used as an incitement to complete your survey

Bouncing Back

The following is the facilitator's summary of the module:

COPING WITH CAREGIVING 2.0 SUITE

Bouncing Back

Aim of Module

To increase caregiver perception of well-being by increasing observance of positives in their lives. To create an illustration of their care team allowing the caregiver to manage their team more effectively.

Handouts – CWC2.0.1 HO

All handouts are available in electronic format in a PDF.
OAC: Three Paths
Atlas: CareMap
Atlas CareMap-Ask Yourself

Three Main Points

1. The ability to bounce back from a crisis is something you can work on and make better.
2. Rewiring your brain to look for the positive can increase your sense of well-being.
3. Identifying your care team will help you to:
    appreciate what is working well
    plan for future difficulties
    manage the people involved
    identify missing people and services
    communicate with everyone

→ ***FACILITATORS:*** *Plan that the CareMap topic will utilize 2/3 of the session time.*
Forms are not required - pen and paper can be substituted.

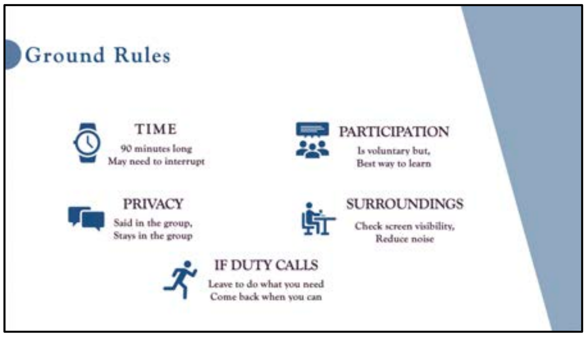
Activities

Activity 1: Three Paths to Happiness
Activity 2: Atlas CareMap
Activity 3: Action Plan

Action Plan

Choice of 2:
    Three Paths
    Refining Your Care Map

Slide 2 Ground Rules



Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*
- → *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

Slide 3 Introductions

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression.*
- → *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*
- → *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today’s Topics

Today’s Topics

Defining Bouncing Back

Finding Balance in your Day

Your Support Team

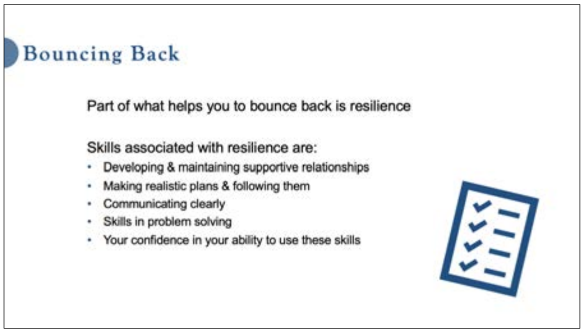
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

Today we will be talking about bouncing back or resilience.
We will be doing an activity to show you a way to shift how you view the world to a more positive view.
Finally, we’ll be taking you through a step-by-step process to help you visualize your support team.

Slide 5 Bouncing Back



Bouncing Back

Part of what helps you to bounce back is resilience

Skills associated with resilience are:
- Developing & maintaining supportive relationships
- Making realistic plans & following them
- Communicating clearly
- Skills in problem solving
- Your confidence in your ability to use these skills

Considerations

→ *Stress the practice, as most benefits of this program will be seen through the integration of the skills into the CG’s life.*

Material

Resilience is the ability to bounce back from life’s challenges. Research shows that there are many things that make up resilience. Some of these factors you may already feel confident in, some you may not.

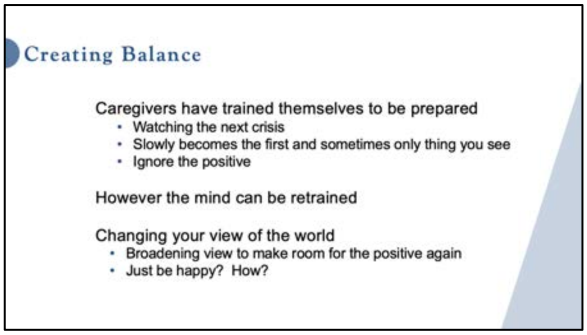
Factors associated with resilience are:
- The ability to develop and maintain supportive relationships
- Making realistic plans and following them
- The ability to communicate clearly
- Skills in problem solving
- Your confidence in your ability to use these skills

Your confidence in your ability to use these skills are important. Higher your confidence > more likely to use these skills when a crisis occurs. Confidence is created whenever you are successful in using your new skills.

Slide 6 Creating Balance

Considerations

- → *Grief is significant for some CGs. If this comes up, acknowledge it as a source of negativity in their life. Noting that the path of grief is rarely straight as it wanders through denial, anger, guilt, sadness and eventually acceptance. For some CGs grief can be a constant companion. Noting that much like the disease itself, they'll have good and bad days.*



Creating Balance

Caregivers have trained themselves to be prepared
- Watching the next crisis
- Slowly becomes the first and sometimes only thing you see
- Ignore the positive

However the mind can be retrained

Changing your view of the world
- Broadening view to make room for the positive again
- Just be happy? How?

Material

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 CGs experience, CGs train themselves to be vigilant—always alert to respond to the next crisis. 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.

STOP & ASK

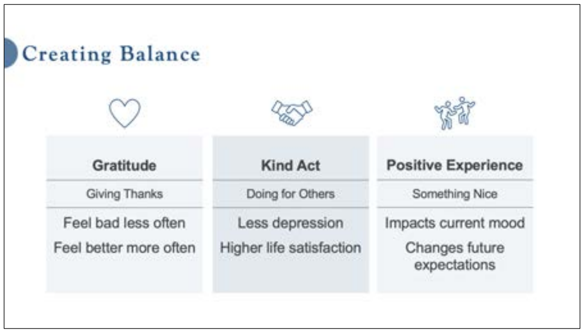
Have you noticed this happen to you?
Do you find it hard to see the positive in your life?

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

Slide 7 Creating Balance

Considerations

- → *Some CGs will already be doing a gratitude journal. Mention that this is similar but different. Encourage them to share if it has helped them.*
- → *Ask them how it has help?*
- → *What have they notice being different?*
- → *After a time was it easier to do?*



Creating Balance

Gratitude	Kind Act	Positive Experience
Giving Thanks	Doing for Others	Something Nice
Feel bad less often Feel better more often	Less depression Higher life satisfaction	Impacts current mood Changes future expectations

Material

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.
- People who express gratitude on a regular basis report feeling bad less often and feeling better more often.

A Kind Act: Defined as doing something for others

- 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.

Positive Experience: Defined as experiencing something nice

- What research tells us is that reflecting on past positive experiences can influence current mood. It can assist in building positive expectations for the future.

So, what is one simple thing you can do to help yourself start noticing the positive in your life again?

Slide 8 Three Paths to Happiness

Three Paths to Happiness

Two minutes a day for 21 days in a row

Write down 3 things:

- ✓ A Gratitude
  - something you give thanks for
- ✓ A Kind Act
  - something nice you’ve done for someone
- ✓ A Positive Experience
  - something good that has happened to you

Review at the end of each week

Considerations

→ *Not everyone enjoys journaling, but in this instance writing it down is part of the process. The ability to review and reflect on forgotten positive occurrences that happen over the week is part of the process that makes it easier to see the positives the next week. You can always ask people if they remember what they had for lunch a week ago last Tuesday. Many will not be able to – use that to reinforce the importance of using writing as a tool to increase their memory of these events that they usually overlook.*

→ *They do not need to write a novel. All that is needed is a word or two that will remind them of the event. Example: writing down ‘held door’ to remember that someone held the door for them. They should give no more than a few minutes a day to this task*

→ *This should be done every day for 21 days to see the change in broadening viewpoint.*

Material

Every day write down something you are grateful for, a positive experience you’ve had that day, and a kind act you’ve done or received.

Journaling these items serves two purposes:

- It focuses your attention on the positives in your life. In essence, it trains your brain to notice the good things around you.

- It acts as a memory aid. You can go back and see exactly what good you've done or experienced.

Tips for Success
- Pick a time - you'll need 2 mins of uninterrupted time to do your journaling, ideally the same time every day.
- Create a reminder
    - Writing before breakfast? Set an alarm and do your writing before cooking breakfast.
    - Write before going to sleep? Put your journal and pen next to your bed.
- 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.

Activity: Three Paths to Happiness

ACTIVITY-Do it

Write down one thing you are grateful for, one kind act, and one positive experience. You don't need to write down everything that happened. A word or short phrase is all that is needed to remember the event.

→ *FACILITATORS: Give the participants 2 mins to write down from yesterday.*

ACTIVITY-Process

STOP & ASK

How it was for you?
Did you find any one category harder?

→ *FACILITATORS: Reassure folks that many find it difficult the beginning but over time it becomes easier.*

First day is now done! Remember that to retrain your brain to look for and recognize the positives that are happening in your life, you need to do this activity for 2 mins every day for 21 days. Now let's look at another factor important for resilience when things get tough.

Slide 9 Looking at Your Support Team

Considerations

→ *There are CGs who will tell you that this won't help them because they do it all themselves. They have no one that helps. This exercise can be very valuable for them since it may help them to realize that there might be support that they are unaware of that they can take advantage of.*

Looking at Your Support Team

Important for bouncing back
- Ability to develop & maintain supportive relationships
- Without relationships you are at risk for isolation

Atlas CareMap
- Identify who is part of your care team
- Drawing your family's care ecosystem

Material

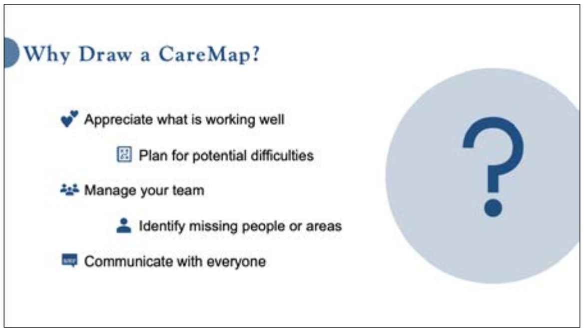
One of the most important factors for resilience, especially for CGs, is the ability to develop and maintain supportive relationships. These relationships can consist of close friends and family, medical professionals, even neighbors and structured groups like this workshop or a CG support group. CGs, especially those that care for people over a long time, are at risk for isolation.
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 Dr. Rajiv Mehta (raa-jeev meh-taa) and his team at the Atlas of Caregiving, is a drawing of a family's care ecosystem.
Simply it shows who is caring for whom, and how.

Slide 10 Why draw a CareMap?

Considerations

→ *One way to help a CG feel more in control is to help them get a clear picture of their current situation.*

→ *For those that are reluctant, remind them that before you can fix something you have to know what parts need fixing first. Drawing out the network can help them to easily see what needs work.*



Why Draw a CareMap?

- Appreciate what is working well
- Plan for potential difficulties
- Manage your team
- Identify missing people or areas
- Communicate with everyone

Material

An Atlas CareMap is a diagram of relationships, connections, and interactions. It illustrates the often-invisible threads that bind us to others: both those who we are closest to, and those who we may have only a passing relationship with.

The Atlas CareMap shows relationships of care:
- Any sort of relationship you have with another person where you give or receive help, support, or advice.
- They can be with family, friends, coworkers, neighbors, and even pets.

Creating your own Atlas CareMap will help you take notice of these relationships.

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.

Slide 11 Looking at Your Support Team

Looking at Your Support Team

ACTORS

People
Pets
Professionals
Places

LINKS

Arrows that connect
Who cares for whom
Frequency of care

PLACEMENT

How far away
they live

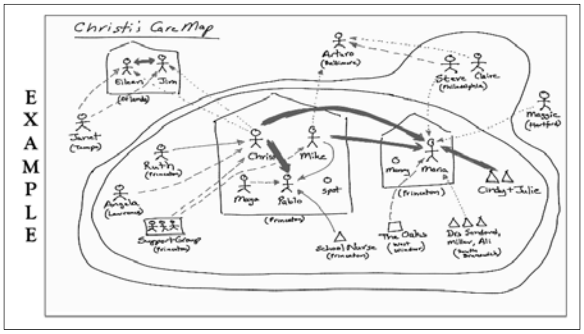
Considerations

→ *Some may look confused or worried at this point. You can reassure them that you will be working with them step by step and they can ask questions during the process.*

Material

An Atlas CareMap is composed of:
- "Actors" - people, pets, professionals, and places, shown using different symbols
- "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.

Slide 12 Example



Considerations

→ *Some may look confused or worried at this point. You can reassure them that you will be working with them step by step and they can ask questions during the process.*

Material

This is an example of what a CareMap looks like.
- Note it looks a little messy and that's ok. First drafts usually are very messy as you work to figure out where everyone belongs.

Christi's Atlas CareMap shows the many caring relations that exist within her family. You'll note that Christi and Mike family are spread out in different parts of the US.

In NJ, Christi & Mike care for Mike's mother Maria, who has dementia and lives next door. You can see that her pet Manny lives with her.

Several other relatives and professionals also care for Maria.
- The Oaks - Drs Sandoval, Miller, & Ali - Cindy & Julie

Christi and Mike also care for a son, Pablo, who has diabetes.
- You can also see the school nurse cares for him as well.

Mike and his brother, Steve (in Philadelphia) also care for their father Arturo (in Baltimore), while Christi and her sister Janet, support her parents, Eileen and Jim (in Orlando).

Two nearby friends, (Ruth & Angela) and a local support group provide support to Christi and Mike.

The people who live nearby are in the middle, while those far away are on the edges.

Arrows of different sorts show how frequently someone provides support, with the heavier arrows showing frequent care.

Rarely does a situation stay the same - a CareMap shows a situation at a point in time.
- People often redraw their maps as things change.

Slide 13 Handout

Atlas CareMap Worksheet

Who cares for you or supports you?

Your name: ______________

Who else is in your household?

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'?

Considerations

- → *Starting with this slide please encourage people to pull out a pen and paper (or use the blank CareMap) and follow along to create their own CareMap.*
- → *After you explain what is on the slide give people 2-3 minute to fill in their information.*
- → *HANDOUT Atlas: CareMap*

Activity: CareMap

ACTIVITY

→ *FACILITATOR: Over the next 9 slides the CG will be creating a draft of their CareMap.*

Material

This is the worksheet of the two forms.
It will be helpful to think about who will be on it.
You don't need to use the form - a pen & a few sheets of paper will be fine.
We are going to step through the worksheet part by part so please get the pen and paper or worksheet now.

Slide 14 Step by Step Creation of CareMap

Atlas CareMap Step By Step

Who lives with you?
Put their names here.
Pets too!

Who do you care for, & who else cares for them?
Enter the names of the people you care for
Enter the names of those who live with them
Enter the names of whoever else cares for them

Who cares for or supports you?
Put the names down of those that give you emotional support or provide time so you can get stuff done.

Considerations

→ *Starting with slide 14 please encourage people to pull out a pen and paper (or use the blank CareMap) and follow along to create their own CareMap.*

→ *After you explain what is on the slide give people 2-3 minute to fill in their information.*

Material

It will be helpful to think about who will be on it.
You don't need to use the form - a pen & a few sheets of paper will be fine.
So, let's get started.

→ *FACILTATORS: After you explain each step give people 1 minute to fill in their information.*

Step 1: Identify Key Actors

- For this exercise, it is best if you limit yourself to a few people, beginning with those that come to mind first.
- Later, you'll find it much easier to add more people and details.

Who lives with you?

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

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
- Enter the names of those who live with them, leave blank if live with you or live alone
- 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, includes those who help in ways that allow you the time to take care of your caregiving responsibilities including providing you with physical or emotional support
- Enter their names.

Slides 15 Blank CareMap

Atlas CareMap of ____________, Date ____________

Actors: people 🯅 groups of people professionals △ pets ○ facilities & services ☐
Links: frequently ➡ daily ⟶ weekly - - -→ occasionally · · · · ·→

ATLAS OF CAREGIVING

Considerations

→ *The legend has been increased in size to make it easier to see on the screen. The form is blank in the center.*

Material

- The legend has been enlarged.

- The actors People (stick person); groups of people (3 stick figures); professionals (triangle); pets (circle); facilities & services (square).
- The links: Frequently (think arrow); daily (thin arrow); weekly (dashed arrow); occasionally (dotted arrow).

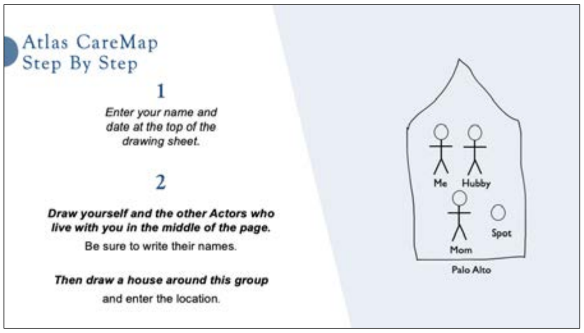
Slide 16 Atlas CareMap Step by Step

Considerations

→ ***Helpful Hint:*** *Add names & locations of Actors under symbols.*

→ *You can customize the location and names to match your location and CGs*

→ *FACILITATORS: After you explain this step give people 2 minutes to fill in their information.*



Atlas CareMap
Step By Step

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.

Material

1. Enter your name and date at the top of the drawing sheet. ***[Optional]***
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.

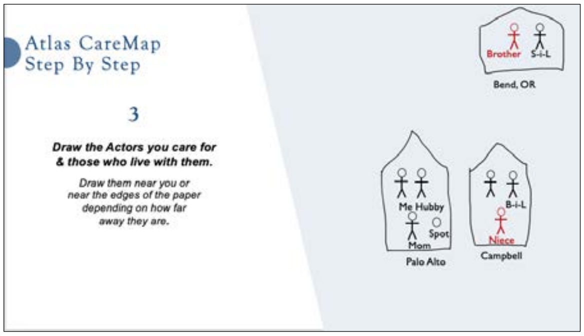
Slide 17 Atlas CareMap Step by Step

Considerations

→ *On the light blue is an example of what adding the new information looks like.*

→ *The new information is in red.*

→ *Helpful Hint Draw yourself in the middle, and then use space on the page to represent geographical distance.*



Atlas CareMap
Step By Step

3

Draw the Actors you care for & those who live with them.

Draw them near you or near the edges of the paper depending on how far away they are.

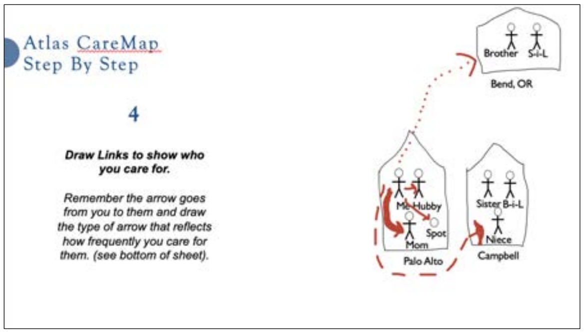
Material

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.

Slide 18 Atlas CareMap Step by Step

Material

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).



Atlas CareMap
Step By Step

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).

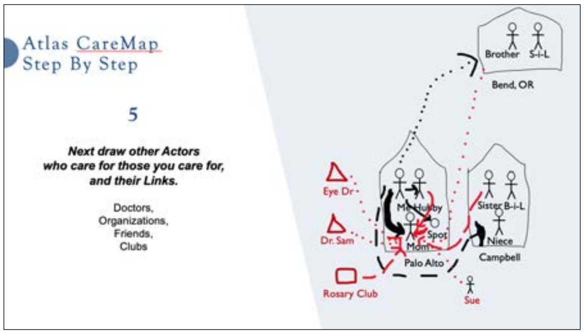
Slide 19 Atlas CareMap Step by Step

Considerations

→ ***Helpful Hint*** *- If caregiving is mutual (person A cares for person B, and vice versa), draw two separate Links if space permits to make it obvious.*

Material

5. Next draw other Actors who care for those you care for, and their Links.



Atlas CareMap
Step By Step

5

Next draw other Actors who care for those you care for, and their Links.

Doctors,
Organizations,
Friends,
Clubs

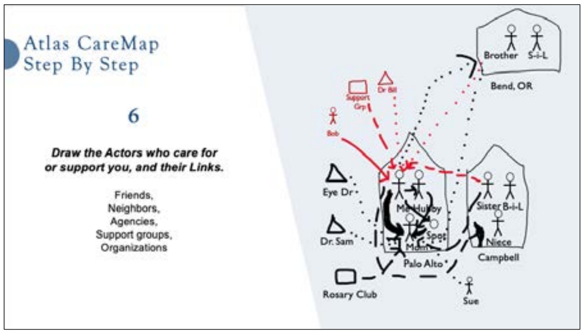
Slide 20 Atlas CareMap Step by Step

Considerations

→ *Encourage CGs to think broadly here.*

Material

6. Draw the Actors who care for or support you, and their Links.



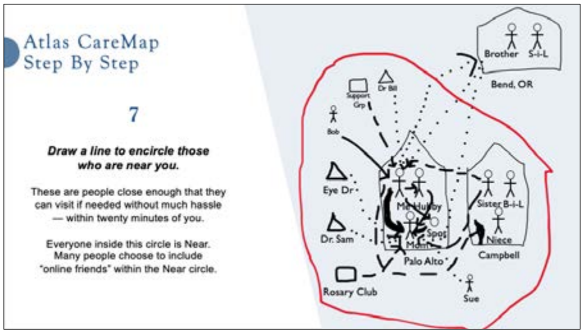
Atlas CareMap
Step By Step

6

Draw the Actors who care for or support you, and their Links.

Friends,
Neighbors,
Agencies,
Support groups,
Organizations

Slide 21 Atlas CareMap Step by Step



Atlas CareMap
Step By Step

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 — within twenty minutes of you.

Everyone inside this circle is Near. Many people choose to include "online friends" within the Near circle.

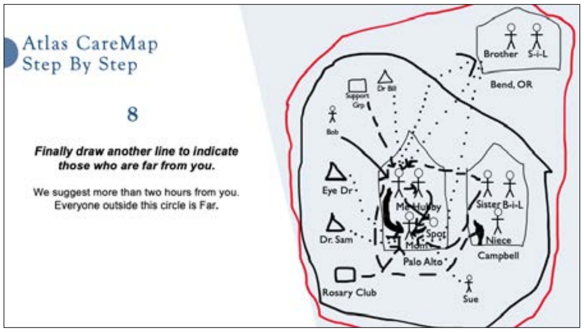
Considerations

→ *These are folks who you can depend on to respond quickly*

Material

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.

Slide 22 Atlas CareMap Step by Step



Atlas CareMap
Step By Step

8

Finally draw another line to indicate those who are far from you.

We suggest more than two hours from you. Everyone outside this circle is Far.

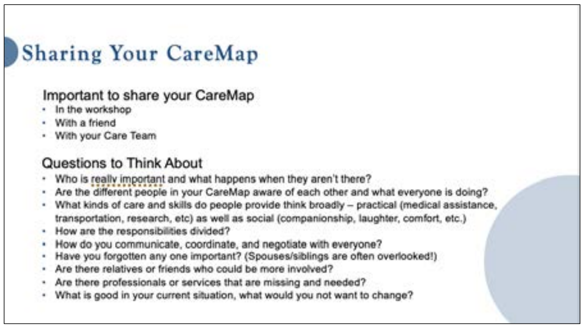
Considerations

→ *Very helpful for long distance CGs.*

Materials

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.

Slide 23 Sharing Your CareMap



Sharing Your CareMap

Important to share your CareMap
- In the workshop
- With a friend
- With your Care Team

Questions to Think About
- Who is really important and what happens when they aren't there?
- Are the different people in your CareMap aware of each other and what everyone is doing?
- What kinds of care and skills do people provide think broadly – practical (medical assistance, transportation, research, etc) as well as social (companionship, laughter, comfort, etc.)
- How are the responsibilities divided?
- How do you communicate, coordinate, and negotiate with everyone?
- Have you forgotten any one 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?

Considerations

→ *Helpful Hint - Your Atlas CareMap will likely be messy the first time you draw it. Don't worry about it.*

→ *HANDOUT Atlas CareMap-Ask Yourself*

→ *For More info atlasofcaregiving.com/caremap/*

Material

There are two things to remember as you look at the first draft of your CareMap. **One**, drawing a CareMap is a learning process. You are discovering who is in your network and where they belong. Some people are just where they need to be, and some may need adjusting once you have a complete picture in your mind of who is in your care network. **Two**, this is just a moment in time. Situations rarely stay the same for a long period of time. It is good to periodically review your CareMap to see what has changed. Depending on the amount of change you may need to redraw it to reflect your current situation more accurately.

Step 3: Sharing Your Atlas CareMap
- 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.
- 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.

ACTIVITY-Process

STOP & ASK

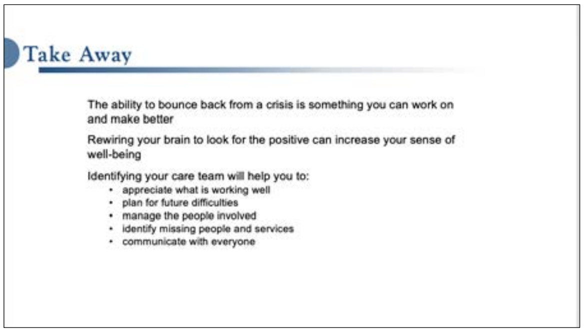
Take a moment and look at your CareMap.
What do you see?
Is there anything that jumps out at you?

→ *FACILITATORS: Allow the participants to share the insight they have gained during this first look at their care map then proceed to the reflection.*

Your CareMap is a tool you can use to figure out the ins and outs of your support network. You can use the following questions to reflect on the information your CareMap may have brought to light.
- Who is indispensable, and what happens when they're not available?
- Are the different people in your Atlas CareMap aware of each other?
- What are the different kinds of care and skills people provide? Think broadly, including practical as well as social.
- How are responsibilities divided amongst the different people?
- How do you communicate, coordinate, and negotiate issues with everyone?
- Have you forgotten anyone important?
- 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?

→ *FACILITATORS: Depending on the time you have left you may want to pick one or two of the questions and have a discussion with the participants.*

Slide 24 Take Away



Take Away

The ability to bounce back from a crisis is something you can work on and make better

Rewiring your brain to look for the positive can increase your sense of well-being

Identifying your care team will help you to:
- appreciate what is working well
- plan for future difficulties
- manage the people involved
- identify missing people and services
- communicate with everyone

Considerations

→ *This is the end of module summary. If you have time, you can encourage your caregivers to offer what they believe the 'take away' was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*

STOP & ASK

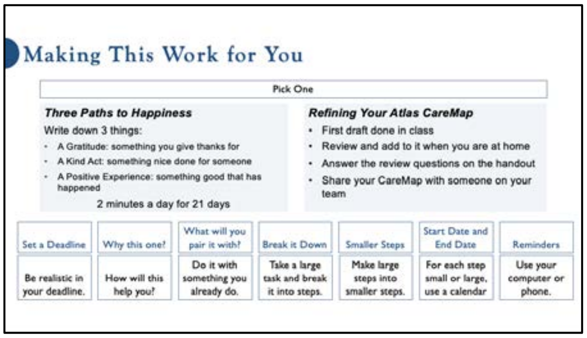
Thinking back over today's session, what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points as included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:

- Resilience is something you can work on and make better.
- Rewiring your brain to look for the positive can increase your sense of well-being.
- 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

Slide 25 Making This Work for You



Making This Work for You

Pick One

Three Paths to Happiness

Write down 3 things:
- A Gratitude: something you give thanks for
- A Kind Act: something nice done for someone
- A Positive Experience: something good that has happened

2 minutes a day for 21 days

Refining Your Atlas CareMap
- First draft done in class
- Review and add to it when you are at home
- Answer the review questions on the handout
- Share your CareMap with someone on your team

Set a Deadline	Why this one?	What will you pair it with?	Break it Down	Smaller Steps	Start Date and End Date	Reminders
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take a large task and break it into steps.	Make large steps into smaller steps.	For each step small or large, use a calendar	Use your computer or phone.

Considerations

→ *The Action Plan is the most important part.*

→ *Encourage them to pull out their pen and paper.*

→ *Remind CGs that to get the most out of this workshop they need to use the skills taught – not just hear about them.*

→ *Use the boxes along the bottom to assist in the creation of the action plan.*

Material

Activity: Action Plan

ACTIVITY-Directions

→ *FACILITATORS: Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you must do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
    - Have the CGs choose either Three Paths to Happiness or Refining the Atlas CareMap.

1. Set a deadline – *Be realistic*
    - I will start the Three Paths tomorrow and for the next 21 days I will journal a gratitude, kind act, positive experience.

2. Why chose this one? - *The more personal the better*
    - I need more positive in my life, my sister said I was a drag to talk to because all I talk about is the bad things that are happening.
3. What will you pair it with? – *Do it with something you already do*
    - I will do it before I read every night before bed

- Optional: Break it down – *Take a large task and break it into steps*
    - I will find the notebook & pen right after the workshop today
    - I will place it on my nightstand, on top of my book
    - I will start tonight before bed
    - I will journal for 21 days

4. Reminders – *Computer, phone, calendar*
    - I will set an alarm on the phone to remind me at 9pm every night
5. Problem-solving – *Pending*

→ *FACILITATORS: You may want to ask if your participants anticipate any issues and what their plan is for it.*

→ *FACILITATORS: Depending on the amount of time left in the session you can talk with the CGs about their action plans: what did they choose, why did they choose, what barriers do they think they might run into, what is their plan to work around any issues? If you are right on time? Share the resource website, answer any remaining questions, and thank them for coming to the workshop. If you have more workshops scheduled? Use this time to remind your CGs when the next workshop is offered.*

Being Heard

The following is the facilitator's summary of the module:

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Being Heard

Aim of Module

The aim of this module is twofold:

- To develop empathy and provide strategies to enhance communication between caregiver and care recipient
- To encourage concise and clear communication when requesting assistance from family and friends

Handouts – CWC2.0.2 HO

All handouts are available in electronic format in a PDF.
FCA: Saying 'Yes' to Offers of Help.pdf
Women's Alz Movement: Essential Dos and Don'ts
FCA: Holding a Family Meeting.pdf

Three Main Points

1. Empathy is a skill we work on throughout our lifetime.
2. Caregivers need to shift expectations rather than depend on the person they are caring for to change how they communicate.
3. Clear and concise information combined with flexibility can give a better outcome when speaking with family and friends

Activities

Experiencing Empathy

Action Plan

Choice of 2:
Practice Your Empathy
Reaching Out to Family or Friend

→ *FACILITATORS: Forms are not required - pen and paper can be substituted.*

Please note: This module is presented in a dementia-centric manner. Examples and references all involve dementia or issues likely to effect CGs caring for someone living with dementia.

Slide 2 Ground Rules

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*
- → *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*

Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

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 program 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.

Slide 3 Introductions

Considerations

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

- *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*
- *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*
- *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

- Name, Title, brief statement of how you work with caregivers
- Have your co-facilitator introduce themselves
- Introduce your tech person (especially if they shut off their video)
- Introduce any guest that may be observing

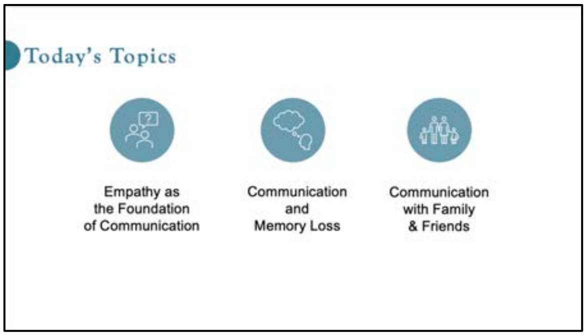
Have Caregivers Introduce Themselves:

- Please unmute and introduce yourself when I call out your name
- Tell us your name, who you are caring for, and if you know it, their diagnosis
- And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today’s Topics



Today’s Topics

Empathy as the Foundation of Communication

Communication and Memory Loss

Communication with Family & Friends

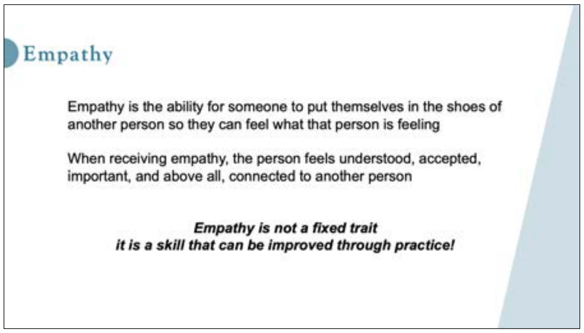
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

- Today we will be talking about empathy as the foundation of communication
- Then we’ll discuss how memory loss affects communication and offer some strategies on effective ways to communicate with the person you are caring for
- Our final topic will be tips and strategies on getting help from family and friends

Slide 5 Empathy



Empathy

Empathy is the ability for someone to put themselves in the shoes of another person so they can feel what that person is feeling

When receiving empathy, the person feels understood, accepted, important, and above all, connected to another person

Empathy is not a fixed trait
it is a skill that can be improved through practice!

Considerations

→ *By defining empathy right away we provide a foundation for further discussion*

→ *Emphasize the fact that practicing empathy allows it to grow and improve*

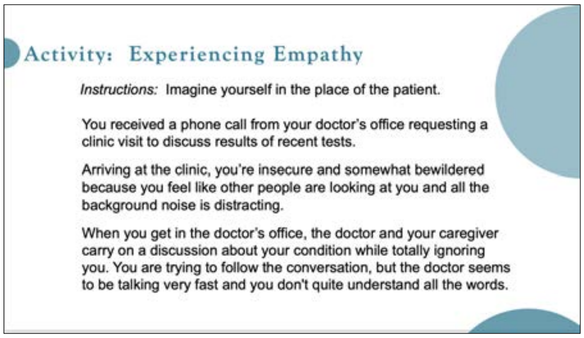
Material

Empathy is the ability for someone to put themselves in the shoes of another person so they can feel what that person is feeling. Memory Loss can make someone lose the feeling of being connected to others and some will react with agitation, some by withdrawing. Empathy helps caregivers connect and can help care recipients to feel understood and safe. When receiving empathy, the person feels understood, accepted, important, and above all, connected to another person. Empathy is not a fixed trait it is a skill that is improved through practice!

Slide 6: Experiencing Empathy

Considerations

- → *Practice reading the scenario until you can read it fluently and quickly. You want to give the impression of ease and that, of course, they should understand what you are saying.*
- → *Discussion is on next slide*



Activity: Experiencing Empathy

Instructions: Imagine yourself in the place of the patient.

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.

Material

Activity: Experiencing Empathy

ACTIVITY-Directions

- → ***FACILITATORS:** Participants are to imagine themselves in the place of the patient as the facilitator reads the scenario. There will be two discussion points following the scenario: First Reaction and then Points to Consider.*

ACTIVITY-Do it

Instructions for caregivers

- Imagine yourself in the place of the patient.
- 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.

You hear:
"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 stretches of 30 diurnal courses. Expression commiseration. There is a nonexistence of resolution to propound."

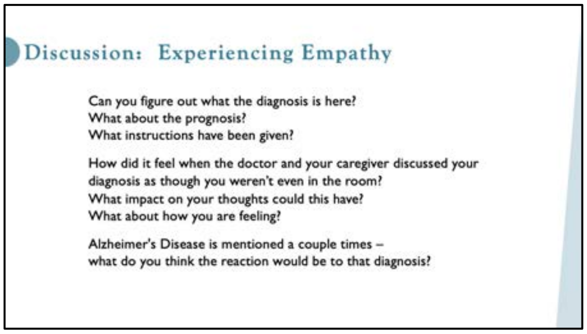
- → ***FACILITATORS:** It is very important to practice saying this out loud multiple times. It should flow smoothly, and you should say it quickly. If you are uncertain on how to pronounce any of the words, google can help – just type in the word and pronunciation and you should get a link. Even experience facilitators will practice this each time out loud in preparation for a workshop.*

Slide 7 Discussion-Experiencing Empathy

Considerations

→ *It is important to review the questions before to tell them what you said.*

→ *Asking the caregivers to place themselves even for a moment in the shoes of someone who is have difficulties following verbal communication can encourage empathy and compassion for the person they are caring for.*



Discussion: Experiencing Empathy

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?

Material

ACTIVITY-Process

→ *FACILIATORS: Note that most medical information is delivered verbally. The foreign words will help to simulate what listening to a conversation might feel like when you don't understand many of the words. Also, the increased speed can simulate the reduce processing speed some people may experience with progression of their disease.*

Ask:

Can you figure out what the diagnosis is here? (*most say they were confused*)
What about the future or the prognosis? (*same*)
What instructions have been given? (*same*)

→ *FACILITATORS: You will now switch from the information available to the feeling engendered during the discussion*

Ask:

How did it feel when the doctor and your caregiver were discussing your diagnosis as though you weren't even in the room? (*most say upset, angry*)
What impact on your thoughts could this have? (*lead to suspicion, paranoia*)
What about how you are feeling? (*angry, suspicious, persecuted*)
Alzheimer's Disease is mentioned a couple times – what do you think the reaction would be to that word? (*scary, disbelief, confusion*)

→ *FACILITATORS: Many caregivers are curious about what you actually said.*

What you said:

Looks like dementia, probably Alzheimer's. Progression will likely be slow, there is no urgency at this time. I'll give you a prescription for Aricept, give him a pill at bedtime for a month, then start 2 pills at night. I recommend you find a support group. An ID bracelet will be helpful in case they wander and get lost. My nurse will make you an appointment in 6 months. I'm sorry. There is no cure.

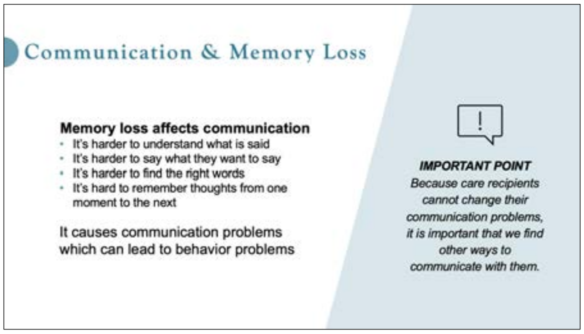
Summary

- 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.

Slide 8 Communication & Memory Loss

Considerations

→ *You may have a caregiver who is struggling with communicating not because of a lack of skill or understanding but because they are still in denial over the diagnosis. They will be trying to continue the patterns of communication that worked in the past. But reason and logic are not effective with someone who can't remember the foundation that the logic is built on or the rules that reason depends on. For these individuals, a referral to a counselor or a support group can be helpful.*



Communication & Memory Loss

Memory loss affects communication

- It's harder to understand what is said
- It's harder to say what they want to say
- It's harder to find the right words
- It's hard to remember thoughts from one moment to the next

It causes communication problems which can lead to behavior problems

IMPORTANT POINT

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

Material

- 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 the person we are caring for's behavior to match our expectations.
- There is a need to go with the flow of how things are now and be open to change at any time.
- 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 several 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. Added to this is when we are frustrated, we do not communicate effectively, which can result in further frustration and more problems.

IMPORTANT POINT

Because the people we care for can't change their communication problems, it is important that we find other ways to communicate with them

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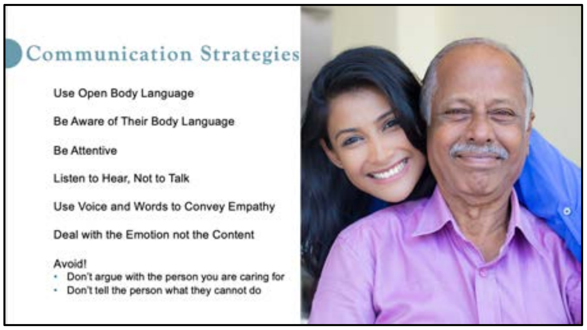
Slide 9 Communication Strategies



Communication Strategies

Use Open Body Language

Be Aware of Their Body Language

Be Attentive

Listen to Hear, Not to Talk

Use Voice and Words to Convey Empathy

Deal with the Emotion not the Content

Avoid!
- Don't argue with the person you are caring for
- Don't tell the person what they cannot do

Considerations

→ *There is a lot of information to share. Pacing and examples will help.*

Material

Let's jump right in with some tips or strategies that you can use.

Use Open Body Language. Non-verbal communication, like body language, conveys as much information as verbal language – sometimes conveying even more. If your body language says one thing (*crossed arms/frown)* and your words say another (*I'm fine)*, 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, drop your shoulders, smile

Watch the other person's body language for clues. Put yourself in their shoes. Much of what they use to anchor themselves is missing: who they are, who you are, where they are, or what they were doing. How scary is that? Watch and learn their signs that indicate they are scared. Let that guide you on how to interact. On the other hand, there are some individuals with memory loss who 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 the emotion. “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.”

We’ve talked some about how to communication with a person with memory loss, let now switch to getting help from family and friends.

Slide 10 Getting Help from Family & Friends

Considerations

→ *Not all families are the same. There are pattens of communication that have built up over decades. When things are very contentious a referral for a family meeting regarding the care plan may be helpful.*

→ ***HANDOUT**: FCA: Saying ‘Yes’ to Offers of Help.pdf*

→ ***HANDOUT**: Women's Alz Movement: Essential Dos and Don’ts*

Getting Help from Friends and Family

Prepare
- Examine your needs
- Who are you going to ask?

Ask
- State the **problem**
- Use **'I' Statements**
- Don't be afraid to **negotiate**
  - **Break it down** into smaller chunks
  - Be **persistent yet flexible**
  - **Don't give up!**
- Use **facts**
- Give **specific details**

Follow Through
- **Confirm** before event
- **Prepare** emergency info

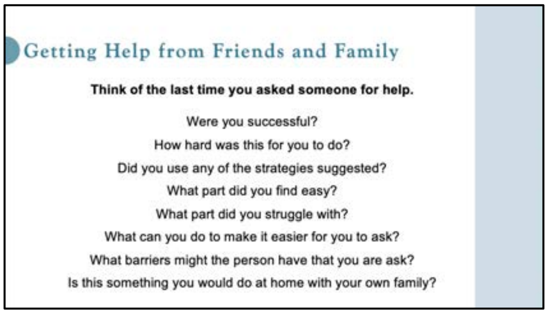
Material

- Family can either be tremendous support or a source of conflict, many times they are 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.
- Barriers exist, 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 some may feel ill-equipped to help because they don’t know how to handle situations or crisis if it should happen.
- On the other hand, sometimes people are over committed, being gracious now may open an opportunity for assistance at a later date.
- It all comes back to knowing who you are talking to. And knowing what you need help with. Many times, when people offer, caregivers aren’t ready with a task or need. The tips can assist you in clearly communicating your needs.

Examine your needs. What do you need? Make a list.
What exactly is the problem you are trying to address? Be brief-1 or 2 sentences.
Describe your thoughts and feelings clearly, so the other person can understand your point of view. But don’t ramble – be concise.
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 you may need to take 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 they cannot, ask if a different time or another task is possible and begin to negotiate. Be aware that what you are asking for may not be possible.
Be persistent and flexible. Maybe you won't get exactly what you asked for, but you will get something that will be helpful.
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.

Slide 11 Getting Help from Friends and Family



Getting Help from Friends and Family

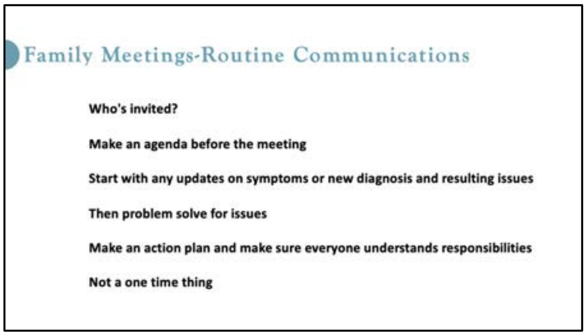
Think of the last time you asked someone for help.

Were you successful?
How hard was this for you to do?
Did you use any of the strategies suggested?
What part did you find easy?
What part did you struggle with?
What can you do to make it easier for you to ask?
What barriers might the person have that you are ask?
Is this something you would do at home with your own family?

Material

- Think of the last time you asked someone for help.
- Were you successful?
- How hard was this for you to do?
- Did you use any of the strategies suggested?
- What part did you find easy?
- What part did you struggle with?
- What can you do to make it easier for you to ask?
- What barriers might the person have that you are ask?
- Is this something you would do at home with your own family?

Slide 12 Family Meetings-Routine Communications



Family Meetings-Routine Communications

Who's invited?

Make an agenda before the meeting

Start with any updates on symptoms or new diagnosis and resulting issues

Then problem solve for issues

Make an action plan and make sure everyone understands responsibilities

Not a one time thing

Material

Who's invited?

- Decide who should attend
- If not available decide who will send a summary

Make an agenda before the meeting

- Done before the meeting and sent to who is coming so they can add to the agenda
- see handout FCA: Family Meeting for an example of an agenda

Start with any updates on symptoms/new diagnosis and resulting issues

- Can be a doctor's report or an update on daily functioning
- Note changing needs or developing issues
- It is good to make a list but do not move to problem solving until they are all introduced

Then problem solve for issues

- Use the list generated
- Note what solution was decided on, who is responsible for it

Make an action plan and make sure everyone understands responsibilities

- State the problem
- Outline the action steps that will be taken to address the problem,
- ID the person who is responsible for it
- Dates of when they will have it done by

Not a one-time thing

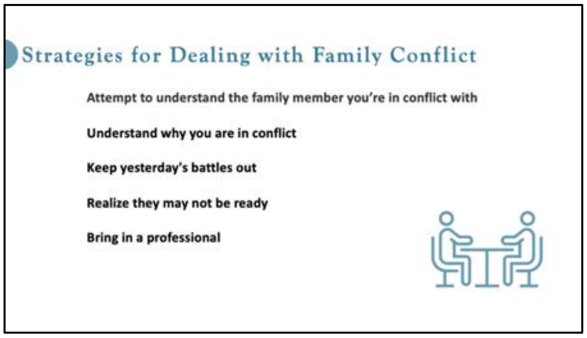
- To encourage communication, should have regular family meetings

---

Slide 13 Strategies for Dealing with Family Conflict

Material

When caring for someone with a chronic illness or memory issue, families are most successful when they work together and have a united plan of action. However**,** that does not always happen. For one reason or another a family may experience conflict which can disrupt the care plan.



Strategies for Dealing with Family Conflict

Attempt to understand the family member you're in conflict with

Understand why you are in conflict

Keep yesterday's battles out

Realize they may not be ready

Bring in a professional

The following strategies can help you to deal with conflicts that may arise during the caregiving journey.

Attempt to understand the family member you're in conflict with.

- Put yourself in the family member's shoes and think about why they are feeling or doing what is creating the conflict.
- Try to avoid treating them as you have in the past.
- Showing empathy does not mean that you agree with the other person, and it does not mean that you have to accept what they are saying. It simply means that you acknowledge the issue and any frustration that goes with it, in order to suggest a reasonable course of action to deal with the situation. By doing this in a calm and reasonable way we can often diffuse a conflict situation and get the other party to work with us to achieve what we are looking for.

Understand why you are in conflict.

- What are their expectations? How does what you (or your CR) need/want conflict with it?
- Describe in detail you or your CR's needs and wants. Be able to clearly state why.
- Use supporting examples, reports, doctor statements, expert information

Keep yesterday's battles out.

- Recognize that family histories and old patterns of coping can surface as family members deal with caregiving situations.
- Included in these histories are old patterns or roles of how each individual reacted or coped with stressful situations.

→ ***FACILITATORS:*** *You can use the following example if you have time and there is a need to illustrate.*

An example of old patterns is a CG who when they were young did not handle stress well. Now they are the CG, yet the family treats them like everything they say is just a stress exaggeration and ignoring the fact that since that time the CG has learn more effective methods of coping. Now this old pattern of functioning won't work as the CG is the one who communicates her parent's needs with other family members. This requires a new pattern of interaction between family members. This new pattern of interaction requires all family members to change how they view the CG.

Realize they may not be ready

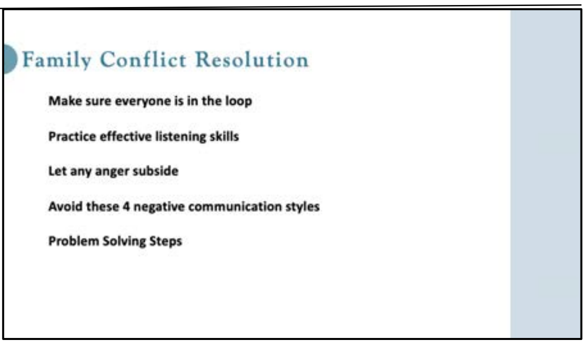
- They may not be able to come to terms with what is happening to the care receiver for many reasons.
- Past conflicts, sibling rivalries, or estranged relationships play a role in the person's ability to cope emotionally.
- Sometimes instead of coping with the situation they withdraw and appear as if they don't care.
- Keep in mind that denial is often used as a defense mechanism for lots of reasons including fear, the reality that things aren't going to be the same, or realization they could lose a loved one. Giving the individual in denial time to adjust will help. Insisting or arguing will only drive the individual away. How much time you give your family members depends on their personality, upbringing, resiliency and relationship with the care receiver.

Bring in a professional

- It often helps to invite a neutral outside facilitator to attend
- Who? Social workers, case managers, ministers, discharge planners, psychotherapists can either mediate or refer you to someone who can

We have discussed numerous strategies family members can use to address family conflict. Keep in mind that if one strategy doesn't work you can always try a different one.
The most important fact to keep in mind is the family will be most successful when they work together to care for the care receiver and have a united plan of action.

Slide 14 Family Conflict Resolution



Family Conflict Resolution

Make sure everyone is in the loop

Practice effective listening skills

Let any anger subside

Avoid these 4 negative communication styles

Problem Solving Steps

Material

The following are strategies the caregiver can keep in mind as they communicate with family members:

Make sure everyone is in the loop, especially those far away before the family meeting

- Decisions require accurate information.
- Use pertinent examples when discussing changes
- Don't assume everyone knows about changes in symptoms or diagnosis even if they regularly speak with the CR

Practice effective listening skills

- Don't interrupt, if you're worried about forgetting what you wanted to say bring a pen and paper and write it down.
- Allow whoever is speaking to finish, then paraphrase what you understood. Allow them the time to correct any misunderstandings.
- Save your opinion till it is your time to speak. Be respectful.

Let any anger subside

- When people are angry, the functional part of our brains goes offline, and it truly makes it hard to have a reasonable discussion with effective solutions.
- Try talking in a calm tone but if that doesn't work, take a 20m break.
- If you try to resolve a conflict while people are angry and lashing out, such attempts may fail or even worsen the situation further.
- Remember, the goal here is not to win an argument but to find a healthy and mutually beneficial resolution.

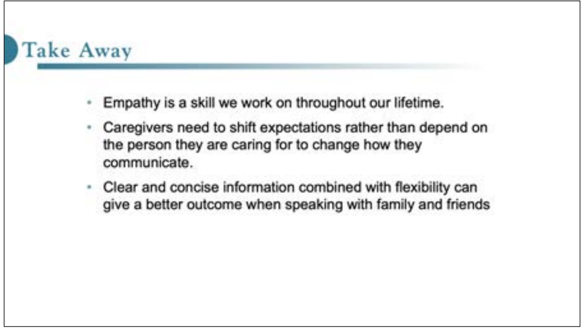
Avoid these 4 negative communication styles

- These four negative communication styles can make problems worse - criticism, contempt, defensiveness and stonewalling
- Criticism: attacks the character or personality of another. While it is normal to have complaints about another's specific actions, it is very different to put them down as a person because of those actions. Criticism negatively focuses on the person's intentions and character.
- Contempt: portrays disgust and a lack of respect for the other person through body language, such as eye rolling or sneering, or by name calling, sarcasm and cutting remarks.
- Defensiveness: is a seemingly understandable reaction that individuals take to criticism and contempt; however, it often escalates the conflict. When we are defensive, we tend to stop listening to the other's viewpoint and communication is shut down.
- Stonewalling: is withdrawing from communication and refusing to engage in discussion. Conflict resolution is impossible without communication!

Problem Solving Steps

- Identify the specific problem and who is involved.
- Answer the question, "What do each of us really want or need?"
- Brainstorm as many alternatives as possible without evaluating any of them.
- Evaluate the alternatives by talking about and/or listing the pros and cons.
- Select the best alternative(s) for the two of you based on what each person is willing to do (make I-statements, listen well to each other).
- Decide who will do what, when and how in the plan.

Slide 15 Take Away



Take Away

- Empathy is a skill we work on throughout our lifetime.
- Caregivers need to shift expectations 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

Considerations

→ *This is the end of module summary. If you have time, you can encourage your caregivers to offer what they believe the 'take away' was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*

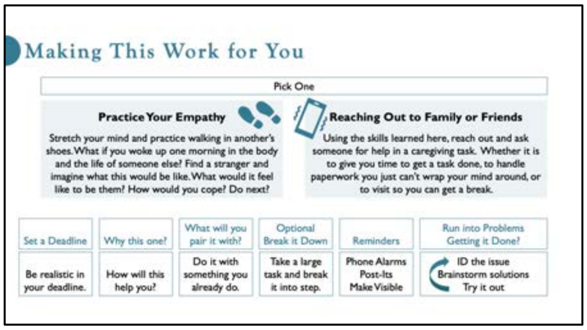
STOP & ASK

Thinking back over today's session, what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points as included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:
- Empathy is a skill we work on throughout our lifetime.
- Caregivers need to shift expectations 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 asking for help from family and friends

Slide 16 Making This Work for You



Making This Work for You

Pick One

Practice Your Empathy

Stretch your mind and practice walking in another's shoes. What if you woke up one morning in the body and the life of someone else? Find a stranger and imagine what this would be like. What would it feel like to be them? How would you cope? Do next?

Reaching Out to Family or Friends

Using the skills learned here, reach out and ask someone for help in a caregiving task. Whether it is to give you time to get a task done, to handle paperwork you just can't wrap your mind around, or to visit so you can get a break.

Set a Deadline	Why this one?	What will you pair it with?	Optional Break it Down	Reminders	Run into Problems Getting it Done?
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take a large task and break it into step.	Phone Alarms Post-Its Make Visible	ID the issue Brainstorm solutions Try it out

Considerations

→ *The Action Plan is perhaps the most important part of this session.*

→ *Encourage the caregivers to* ***pull out their pen and paper*** *and create an action plan right there.*

→ *Use the boxes along the bottom to assist in the creation of the action plan.*

Material

Activity: Action Plan

ACTIVITY-Directions

→ ***FACILITATORS:*** *Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you have to do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
    - Have the caregivers choose either *Practicing Your Empathy* or *Reaching Out to Family or Friends*

1. Set a deadline – *Be realistic*
    - For the week, every day I will try to 'walk in someone's shoes.'

2. Why chose this one? - *The more personal the better*
    - I have been struggling with being nice to people.

3. What will you pair it with? – *Do it with something you already do*
    - When I go for my walk, I can use my imagination on the people I see

4. Optional: Break it down – *Take a large task and break it into steps*
    - Don’t need to break this one down

5. Reminders – *Computer, phone, calendar*
    - I will set a reminder on the phone and a Post It note on the door to remind me

6. Problem-solving – *Pending*

→ *FACILITATORS: You may want to ask if participant anticipate any issues and plan for it.*

→ *FACILITATORS, depending on the amount of time left in the session you can talk with the CGs about their action plans: what did they choose, why did they choose, what barriers do they think they might run into, what is their plan to work around any issues? If you are right on time? Share the resource website, answer any remaining questions, and thank them for coming to the workshop. If you have more workshops scheduled? Use this time to remind your CGs when the next workshop is offered.*

Strategies for Stress

The following is the facilitator's summary of the module: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Strategies for Stress

Aim of Module

To educate the participant on stress and the effects of stress
To offer two evidence-based stress reduction skills

Handouts – CWC2.0.3 HO

All handouts are available in electronic format in a PDF.
OAC: Mapping Your Stress
OAC: Mindful Breathing
OAC: Visualization Guide

Three Main Points

1. Stress & Caregiving
2. Recognizing Stress
3. Relaxation Skills

Activities

Mapping Stress
Deep Breathing
Visualization

Action Plan

Choice of 2:
- Daily Practice of Deep Breathing
- Daily Practice of Visualization

→ ***FACILITATORS:*** *Forms are not required - pen and paper can be substituted.*

Slide 2 Ground Rules

Building Community

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Considerations

→ *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*

→ *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*

→ *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

Slide 3 Introductions

Considerations

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*
- → *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*
- → *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today's Topics

Material

Today's Topic is all about stress.

- We'll start with how caregiving can lead to additional stress in your life.
- Then look at your own unique stress reactions.
- Finally, we explore two different relaxation skills you can use.

Today's Topics

Stress & Caregiving

Recognizing Stress

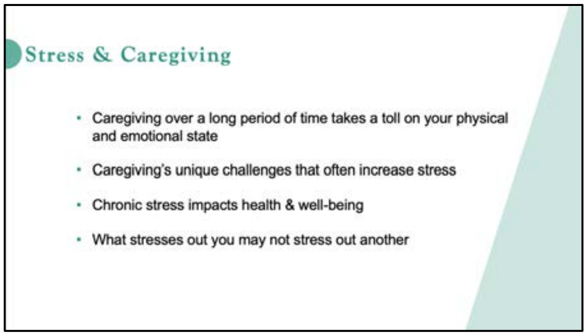
Relaxation Skills

Slide 5 Stress & Caregiving

Considerations

→ Important note here is that everyone reacts to stress in unique ways

→ Once they 'map' their own stress reaction they will have a clue as to when to use the relaxation skills to the best benefit.



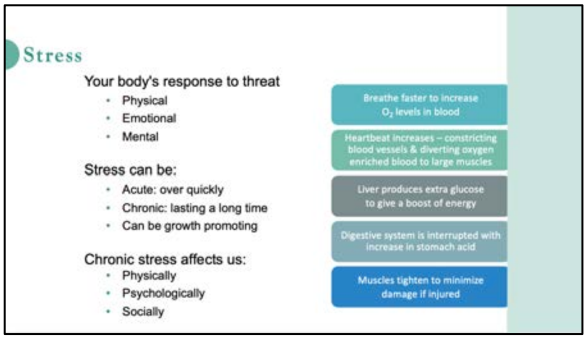
Stress & Caregiving

- Caregiving over a long period of time takes a toll on your physical and emotional state
- Caregiving's unique challenges that often increase stress
- Chronic stress impacts health & well-being
- What stresses out you may not stress out another

Material

- Caring for another person for a long period of time can take a toll on your physical and emotional state.
- Research has shown that CGs face unique challenges that often increase stress.
- Whether it is the length of time caregiving, huge range of tasks performed from addressing increasing complex medical needs to daily personal tasks like bathing and toileting to the sometimes awkward and confusing role changes that happen when you need to provide care for the person you always considered as the person who cared for you.
- When stress is excessive and extended, it can become very damaging. This chronic stress 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.

Slide 6 Stress



Stress

Your body's response to threat
- Physical
- Emotional
- Mental

Stress can be:
- Acute: over quickly
- Chronic: lasting a long time
- Can be growth promoting

Chronic stress affects us:
- Physically
- Psychologically
- Socially

Breathe faster to increase O_2 levels in blood

Heartbeat increases – constricting blood vessels & diverting oxygen enriched blood to large muscles

Liver produces extra glucose to give a boost of energy

Digestive system is interrupted with increase in stomach acid

Muscles tighten to minimize damage if injured

Considerations

→ *Knowing you're stressed is very important. This realization helps the CG to take a problem seriously, you must know you have an issue first.*

Material

Stress is a primitive biological response to threat. Any perceived threat - physical, emotional, or mental - starts a cascading effect, which happens very quickly, so let's go step by step.

- Threat is perceived, hormones are released, ultimately releasing the hormones adrenaline and cortisol.
- In response to these hormones, you breathe faster to increase oxygen levels in blood and your heartbeat increases, blood vessels constrict and diverts that oxygen enriched blood to the 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, a gland in your brain, the hypothalamus, sends a message to return your system to normal.

Acute Stress is over quickly – think of an almost accident. You're on the highway, you see an accident happen in front of you, time seems to slow as your body reacts, you are able to avoid accident, you pull over, and you calm down after a moment or two.

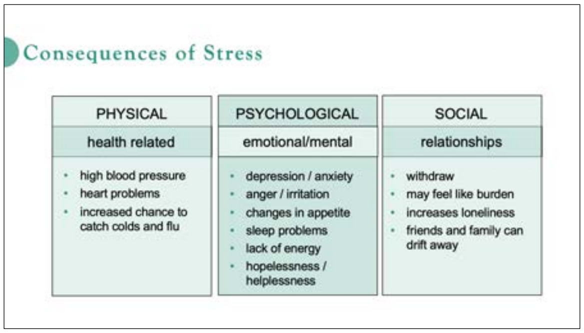
Well Managed Stress can help to make you stronger. When you need to handle a difficult, challenging, or stressful situation, stress signals the body to give you an added boost. Whether the situation is seeking information about a diagnosis or providing a physical boost in times of emergency like during 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 which will in turn increase your sense of competence to handle difficult situations. Most caregivers experience a mix of both the positive and negative effects of stress. Today we are focusing on the negative since that is what tends to cause the problems.

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 dealing with chronic stress important?

Research has shown us that a person who is chronically stress and is not managing their stress is affected throughout their system in very specific ways.

Slide 7 Consequence of Stress



Consequences of Stress

PHYSICAL	PSYCHOLOGICAL	SOCIAL
health related	emotional/mental	relationships
• high blood pressure • heart problems • increased chance to catch colds and flu	• depression / anxiety • anger / irritation • changes in appetite • sleep problems • lack of energy • hopelessness / helplessness	• withdraw • may feel like burden • increases loneliness • friends and family can drift away

Considerations

→ *Stress effects people throughout their whole system. The idea here is not to scare them but make them aware of how pervasive the effects of stress are.*

Material

Unmanaged Chronic stress has consequences. It can take away from your quality of life by lowering your ability to experience pleasure or a sense of accomplishment. This can affect your ability to provide the best care you can.

Physically. If stress lasts for a long time, it can lead to many health problems. This can make CGs at risk for stress-related conditions such as:

- High blood pressure
- Heart problems
- Increased susceptibility to colds and flu

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

- Depression and/or Anxiety
- Changes in appetite
- Lack of energy
- Anger and/or Irritability
- Sleep problems
- Hopelessness/Helplessness

Socially. Caregiving often challenges friendships and relationships. As the stress builds up, some CGs:

- Feel like they are a burden
- Refuse assistance when offered
- Isolate themselves which increases loneliness
- Are 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.

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.

Slide 8 Your Stress Signs

Your Stress Signs

Everyone reacts to stress differently

Need to know your signs so you know when to react
- Think about a recent stressful experience
- Scan your body – where are you experiencing that stress?
- Use the handout to learn what your stress signs are

Over the next week
Pay attention to your stress signs

☐ 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

☐ Sadness
☐ Apathy
☐ Anxiety, worry
☐ Irritable
☐ Anger
☐ Trouble concentrating
☐ Drinking too much
☐ Smoking

Considerations

→ *Many caregivers have been living stressed for so long they no longer are aware they are stress – even if their body is registering stress.*

Material

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

Activity: Mapping Your Stress

ACTIVITY-Do it

STOP & ASK

How do **you** know you are stressed?
How do you typically handle your stress?

Let's do an exercise to help identify how you experience stress in your body. On the screen is a list of areas in the body commonly affected by stress. You can also find these lists in your packet as a handout.

- Do you remember the last time you were stressed?
- Where do you experience that stress in your body? Is your jaw clenched? Do you feel tension in your shoulders and neck? Does your stomach get upset?

Check off everything that your body does when you are under stressed.

People can also react emotionally to chronic stress. 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 and note your reactions. Over the next week, pay attention when you are feeling stressed. See if you can find your own pattern and map the stress.

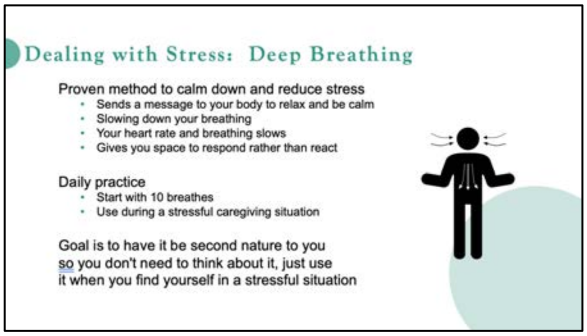
If you know the first place you experience stress is tension in your shoulders followed by irritability and a headache then you will have a map that will help you, unlike the example of our poor frog, know when to get out of the water. Next, we will teach you two quick and easy skills to help you to manage your stress that you can use at any time.

Slide 9 Deep Breathing

Considerations

→ *You may run into disbelief that something so simple as breathing can help something so overwhelming as chronic stress. Encourage them to try it out. You can also tell them that deep breathing interferes with the first step in the body's stress response – you can't breathe slow and fast at the same time, sends a different signal to the brain.*

→ *We highly recommend you use this practice in your own life. Then you can illustrate its use with a personal example, if needed.*



Dealing with Stress: Deep Breathing

Proven method to calm down and reduce stress
- Sends a message to your body to relax and be calm
- Slowing down your breathing
- Your heart rate and breathing slows
- Gives you space to respond rather than react

Daily practice
- Start with 10 breathes
- Use during a stressful caregiving situation

Goal is to have it be second nature to you
so you don't need to think about it, just use
it when you find yourself in a stressful situation

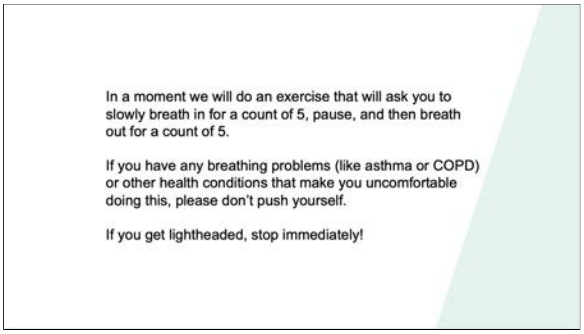
Material

- Research has shown us that deep breathing is one of the best ways to lower stress. Regular breathing is 'automatic' but deep breathing gives you an opportunity to control the breath cycle to reduce your stress. 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 hormones are released into the body. In a moment, we will try this out in session. But first, to become something that you use in a crisis moment you need to practice it while you are calm until it becomes second nature to you.
- So, we recommend a daily practice of taking 10 slow deep breaths – it should take no longer than 1 minute. The more you practice when you are calm, the more comfortable you are with the skill. The more comfortable you are with the skill, the more likely you will be to use it when you are stressed.

Slide 10 Caution

Considerations

→ *DO NOT SKIP. If someone knows they have a breathing issue – you can encourage them to just observe their breath - do not go deep but focus their mind on how it feels. Some can't do that. Encourage them to try to relax each muscle they note is tense until the next activity. We will offer an alternative in a moment for people who cannot do the deep breathing.*



In a moment we will do an exercise that will ask you to slowly breath in for a count of 5, pause, and then breath out for a count of 5.

If you have any breathing problems (like asthma or COPD) or other health conditions that make you uncomfortable doing this, please don't push yourself.

If you get lightheaded, stop immediately!

Material

- If you have any breathing problems (like asthma) or other health conditions that make you uncomfortable doing this, please don't push yourself.

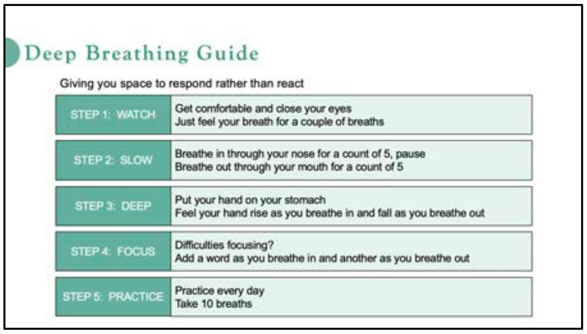
- We will be offering an alternative in a moment.
- If you find the deep breathing too difficult, please just sit comfortably and observe your breath as we do this exercise with the rest of the group.

Slide 11 Deep Breathing Guide

Considerations

→ *If someone gets lightheaded remind them to stop and breathe normally*

→ *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.*



Deep Breathing Guide

Giving you space to respond rather than react

STEP 1: WATCH	Get comfortable and close your eyes Just feel your breath for a couple of breaths
STEP 2: SLOW	Breathe in through your nose for a count of 5, pause Breathe out through your mouth for a count of 5
STEP 3: DEEP	Put your hand on your stomach Feel your hand rise as you breathe in and fall as you breathe out
STEP 4: FOCUS	Difficulties focusing? Add a word as you breathe in and another as you breathe out
STEP 5: PRACTICE	Practice every day Take 10 breaths

Material

Activity: Deep Breathing

ACTIVITY-Directions

→ *FACILITATORS: Explain the 5 steps, Do 10 deep breaths, Ask the Process Questions*

EXPLAIN IT: While it seems simple, there are a few steps to deep breathing which we will review with you now. After we review the steps, we will take ten breaths together**.**

- **In the first step**, you will get comfortable and take one or two breaths just to observe where your breathing is in that moment.
- **In the second step,** we will deliberately attempt to slow down our breathing to a count of 5 for each inhale and each exhale with a small pause at each beginning and end.
- **The third step** is for those of you who are not certain you are breathing deep. We invite you to place a hand on your abdomen – notice when you breathe, does your abdomen rise when you inhale? Then contract or sink when you exhale? That is a good sign that you are using your diaphragm to help your lungs open up to allow for a deep breath.
- **The fourth step** is for those having trouble with the counting, you'll notice we offer an option to replace the numbers with a word or phrase.
- **Finally, in the firth step** we want to talk about the importance of creating a daily practice. This practice will be very important if you want to integrate this very valuable tool into your life. It is important to become so comfortable that you don't need to think of the process when you need to use it. Through practice it will become second nature and you'll be able to do it without thinking about the steps.

ACTIVITY-Do it

→

→ *FACILITATORS: your voice should be slow and measured as you talk them through this activity. The pause is length of one count.*

DO IT: Ok so let take 10 breaths together. If you run out of breath before I finish counting that's ok. With practice, you will be able to breath deep enough to make the count of 5. Until then, just consciously slow your breathing. If you become lightheaded while doing this exercise – stop and return to breathing normally.

BEGIN: Sit comfortably in a chair and close your eyes. Your feet should be flat on the floor and arms should be supported in comfortable manner. Try to sit so your shoulders are over your hips. If closing your eyes is difficult for you, you can pick a place on the wall to stare at during this exercise. Notice your breathing, just observe your own breath for a couple of breaths.
(Pause for 2 breaths)
Now we are going to ask you to slow down your breathing to help you relax. To slow down, do a slow inhale through the nose, for a silent count of 5. Then do a slow exhale through the mouth, for the same count.

Breathe In, 2, 3, 4, 5, pause	- Breathe Out, 2, 3, 4, 5, pause,	(repeat 4 more times)
Breathe In, 2, 3, 4, 5,	- Breathe Out, 2, 3, 4, 5,	(repeat 1 more time)
Breathe In,	- Breathe Out,	(repeat 3 more times)

When you're ready open your eyes and come back to the room.

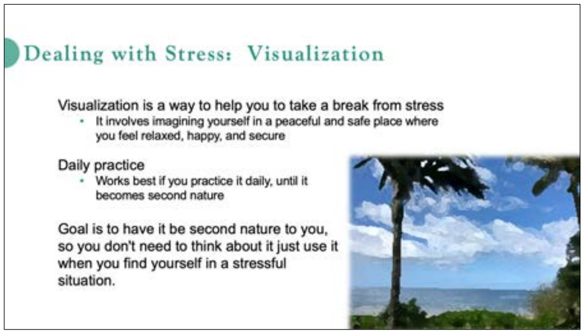
ACTIVITY-Process

STOP & ASK

What was this experience like for you?
Do you feel less stressed? Note any physical change?
Can you think of a specific event when this technique might have been helpful during a stressful caregiving situation?

It will be important to practice this tool until you become comfortable with its use. The more you practice, the more comfortable you'll become, the more comfortable you are with it, the more likely you are to use it. The goal is for you to feel comfortable enough that when you experience a stressful moment during your caregiving you will naturally take 10 breaths. It's a brief 'time out' from the situation causing you the stress.

Slide 12 Visualization



Dealing with Stress: Visualization

Visualization is a way to help you to take a break from stress

- It involves imagining yourself in a peaceful and safe place where you feel relaxed, happy, and secure

Daily practice

- Works best if you practice it daily, until it becomes second nature

Goal is to have it be second nature to you, so you don't need to think about it just use it when you find yourself in a stressful situation.

Considerations

→ *Although this isn't as portable, rarely is there any push back from it.*

→ *People will want to follow a script to guide them.*

Material

Visualization, sometimes called guided imagery, is another way to help you to take a break from stress. It involves the step-by-step method of imagining yourself in a peaceful and safe place where you feel relaxed, happy, and secure. It can be combined with the deep breathing or a progressive muscle relaxation technique where you start at the top of your head and consciously relax each muscle in your body. The aim is to associate the peaceful calm feeling with the image in your head. Eventually your brain will use the image as a signal that it is time to be calm and relaxed. Like the deep breathing, daily practice is the key for success. Best used in an uninterrupted moment, which may be hard to find. Some CGs have found that doing their visualization exercise just before bed can be helpful.

Activity: Visualization

ACTIVITY-Directions

→ *FACILITATORS: begin with this following prep for the participant. Much like the previous activity, keep you voice slow and measured. It is good to have a clock with a second hand handy as the participant needs the full 30 secs after each new addition to fully populate their imagery.*

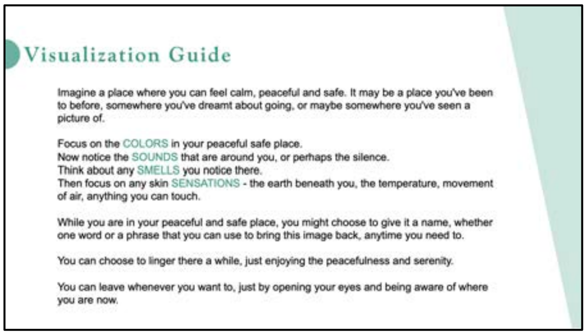
PREP: Do you have a place that sounds like this? Take a moment and pick one out to work with for this exercise. It could be someplace you've been to, or someplace you image that can bring you peace and calm. Close your eyes for a moment and pick a place to try out the next activity on. We will ask you to imagine the details in this place. The colors around you, the sounds you might hear if you were there, what you might smell, even the sensations you might experience like a warm breeze on your skin – the more detail you can think of the more alive the image will feel and the more you will feel immersed in it, experiencing all the relaxation you can draw from it. One last thing, there are long pauses where the I won't be talking, which will give you time to fill in your image or just experience it. I will let everyone know when the end of the activity is, so just enjoy the place where you are. Everyone ready?

→ ***FACILITATORS: Mute all participants for this exercise.***

Slide 13 Visualization Guide

Considerations

- → *Make your voice slow and measured - enunciate clearly.*
- → *Pause for 30 seconds after each period/section.*
- → *Find a watch/stopwatch, measure the pause in seconds. It will seem like forever to you until you get accustomed to the exercise.*



Visualization Guide

Imagine a place where you can feel calm, peaceful and safe. It may be a place you've been to before, somewhere you've dreamt about going, or maybe somewhere you've seen a picture of.

Focus on the COLORS in your peaceful safe place.
Now notice the SOUNDS that are around you, or perhaps the silence.
Think about any SMELLS you notice there.
Then focus on any skin SENSATIONS - the earth beneath you, the temperature, movement of air, anything you can touch.

While you are in your peaceful and safe place, you might choose to give it a name, whether one word or a phrase that you can use to bring this image back, anytime you need to.

You can choose to linger there a while, just enjoying the peacefulness and serenity.

You can leave whenever you want to, just by opening your eyes and being aware of where you are now.

Material

Activity: Visualization

ACTIVITY-Do it

Sit comfortably in a chair and close your eyes. Become aware of your breath, the tension in your body. With each breath out, release the tension. [PAUSE 30 secs]

Imagine a place where you can feel calm, peaceful, and safe. It may be a place you've been to before, somewhere you've dreamt about going, or maybe somewhere you've seen a picture of. [PAUSE 30s]

Focus on the COLORS in your peaceful safe place. [PAUSE 30s]
Notice the SOUNDS that are around you, or perhaps the silence. [PAUSE 30s]
Think about any SMELLS you notice there. [PAUSE 30s]
Then focus on any skin SENSATIONS - the earth beneath you, the temperature, movement of air, anything you can touch. [PAUSE 30s]

While you are in your peaceful & safe place, you might choose to give it a name, a word, or a phrase that you can use to bring this image back, anytime you need to. [PAUSE 30s]
You can linger there a while, just enjoying the peacefulness and serenity. [PAUSE 30s]
You can leave whenever you want to, just by opening your eyes and being aware of where you are now. [PAUSE 30s].

When you’re ready, open your eyes and come back to the room.

ACTIVITY-Process

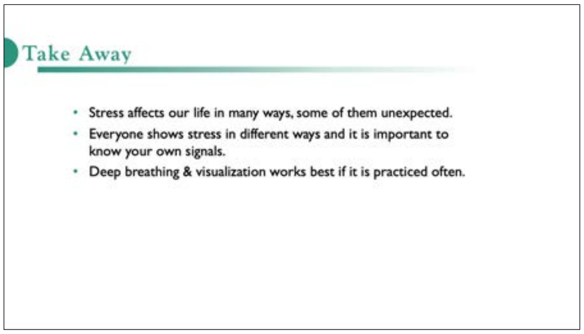
STOP & ASK

What was this experience like for you?
Do you feel less stressed? Note any physical change?
When do you think you will practice this? How do you see yourself using it?

Daily practice is very important. With daily practice you are training your brain to connect that feeling of relaxation to the image in your brain so that eventually whenever you think of that image? You brain uses it as a cue that it is time to relax.

That takes time and effort on your part – by practicing the same visualization every day you will soon be able to use your image to tell your mind and body to relax.

Slide 14 Take Away



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.
- Deep breathing & visualization works best if it is practiced often.

Considerations

→ This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the 'take away' was from this session.

Material

→ *FACILITATORS: If there is time do the stop & ask.*

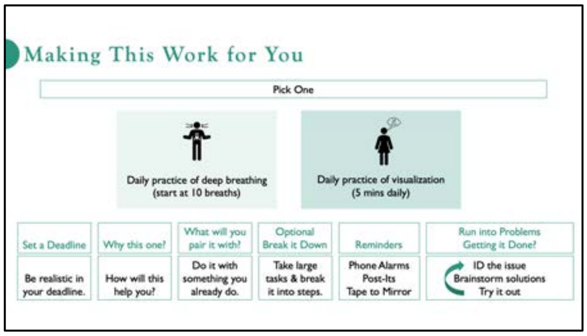
STOP & ASK

Thinking back over today's session,
what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:
- Stress affects people's lives in many ways, some of them can be unexpected.
- Everyone shows stress in different ways, and it is important to know your own signals.
- Deep breathing & visualization works best if it is practiced often.

Slide 15 Making This Work for You



Making This Work for You

Pick One

Daily practice of deep breathing (start at 10 breaths)

Daily practice of visualization (5 mins daily)

Set a Deadline	Why this one?	What will you pair it with?	Optional Break it Down	Reminders	Run into Problems Getting it Done?
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take large tasks & break it into steps.	Phone Alarms Post-Its Tape to Mirror	ID the issue Brainstorm solutions Try it out

Considerations

→ *The Action Plan is the most important part.*

→ *Encourage them to pull out their pen and paper.*

→ *Remind CGs that to get the most out of this workshop they need to use the skills taught – not just hear about them.*

→ *Use the boxes along the bottom to assist in the creation of the action plan.*

Material

Activity: Action Plan

ACTIVITY-Directions

→ ***FACILITATOR:*** *Explain what an Action Plan is, and that we will it at the end of each session (The INTRO). Then have the participant pull out a pen and paper and walk them through the creation of their own unique Action Plan (Do It). There are no process questions for this activity. That will be handled during the Check In which starts next week.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. Much like an exercise class, the benefits come from the doing not the watching. If you sit on the couch and watch the exercise program, you don't get the same benefit as if you got up and did the exercise along with.

What is in an Action Plan?

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.

2. **Why choose this one?:** knowing why can help to push you when the going gets tough – the more important the reason is to you, the better it is. For example – if you are doing this because it is part of the workshop versus you've been very irritable lately and snapping at everyone because you are feeling stressed out. You can see that the second is a stronger motivation because it is personal and as such has more push to it than the first.

3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up. Breaking it down can also help because plans work better when you know the steps you need to do for the task. We recommend adding a **start date/end date** for each step make you accountable.

4. **Reminders:** what reminders will you use? Reminders can come in many different formats – electronic like alerts or alarms on your smart phone or computer, you can have your electronic personal assistant (Alexa, Google or phone ones like Siri or Cortana) remind you or you like more old school methods like post it notes, written daily task lists, or physical reminders like a string tied around your finger. One good example is a mug with the word BREATHE on it to use when you drink your morning coffee reminding you to take a minute and do 10 deep breaths.

5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is (is it lack of time? Lack of desire? Problems with the task itself?), brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

-

- People do better when they limit the number of changes they are trying to make.
    - Pick between either Deep Breathing or **Visualization**

1. Set a deadline – *be realistic*
    - When are you going to start your new daily practice? Later today? Tomorrow?
    - Example: I will start practice tonight.
2. Why this one?
    - I am so stressed my stomach is upset all the time.
3. What will you pair it with?
    - It is best to do it with something you already do
    - Example: I will do it right before bed.

- Optional - Break it down
    - Is this new task complicated enough? Maybe not deep breathing but if you plan to do the visualization – do you need to record the script? Find one you like on You Tube?
    - Example:
        - I plan to look through the CG-TLC and listen to the visualizations after this session.
        - I'll copy the URL to my smart phone, so it is all ready for tonight and I'll make sure my phone charger is nearby, so I don't run out of battery.

4. Reminders – computer, phone, calendar
    - How will you remind yourself to do your new daily practice?
    - I'll set a phone alarm for 10:30 (right after the news so I'll remember)
5. Problem-solving
    - Do you anticipate any barriers? Anything you can do ahead of time to avoid them?
        - If I don't like the one I chose? I'll make note of others that might work as I go through them.
    - When will you plan to check with yourself to make sure you are on track?
        - I make a note on my calendar to check in on Friday (halfway through the week)

Coping with Frustration

The following is the facilitator's summary of the module:

COPING WITH CAREGIVING 2.0 SUITE

Coping with Frustration

Aim of Module

To normalize caregiver's emotions of frustration and anger experienced during caregiving.
To provide strategies caregivers can practice at home when frustration or anger become overwhelming.

Handouts – CWC2.0.4 HO

All handouts are available in electronic format in a PDF.
OAC Anger Mapping
OAC S.T.O.P.

Four Main Points

1. Both positive and negative emotions are a normal part of caregiving.
2. Emotions are one part how you feel, one part how your body reacts, one part how you behave.
3. There are different ways to proceed dependent on how angry you are.
4. Stop, Take ten breaths, Observe, and Proceed can help to give you space to respond rather than react when you are angry.

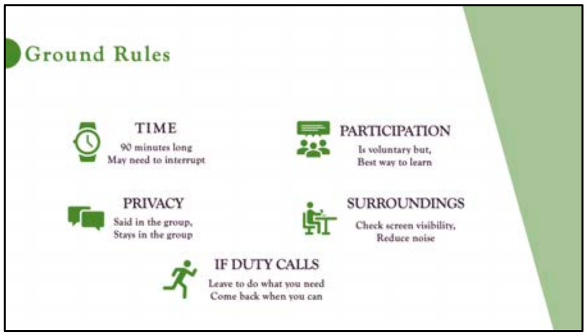
Activities	**Action Plan**
How Do You Know?	Choice of 3:
10 Breaths	Practice Daily 10 Breaths
	Becoming Aware of Self-Talk
	S.T.O.P

→ ***FACILITATORS:*** *Forms are not required - pen and paper can be substituted.*

Slide 2 Ground Rules

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*
- → *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*



Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

Slide 3 Introductions

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*
- → *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*
- → *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today's Topics


Today's Topics

Negative Emotions

Recognizing Intensity

Strategies for Managing

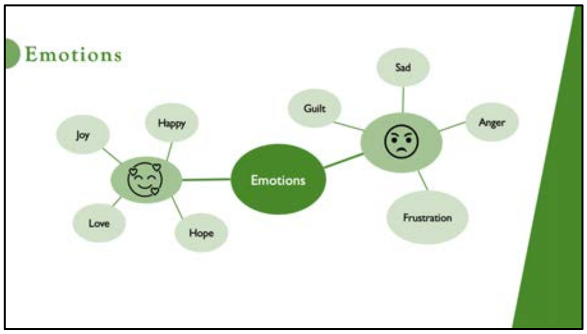
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

- Today's Topic is about coping with frustration and anger. We'll start with discuss exactly what are these negative emotions. Then talk about the range of intensity and why knowing where you are in the range is important. Then we will explore different strategies to use as your respond.

Slide 5 Positive & Negative Emotions


Emotions

Sad

Guilt

Anger

Joy

Happy

Emotions

Love

Hope

Frustration

Considerations

→ *Do not equate negative with bad or positive with good. Good and bad imply judgement and a participant who comes to you frustrated may turn that into the thought that they are bad. Emotion exists – how a person acts on the emotion can be helpful or harmful. Example: Anger can spur a person to hit someone, it can also spur a person to correct a misjustice that they have experienced.*

→ *The goal over the next few slides is in part to separate having an emotion and reacting to the emotion. It is almost impossible to stop a feeling. However, it is much easier to modify how you react when experiencing that feeling.*

→ *For those that struggle separating emotion and behavior. I feel… is an emotion. I [action word (do, yell, etc.)] … is the reaction. It can be more complicated than this, but this is an easy shortcut.*

Material

Positive emotions are those emotions we typically find pleasure in experiencing, feelings like joy or happiness, love, or hope. On the other hand, negative emotions are those emotions we do not find pleasurable to experience. These are feelings like sadness or guilt, anger, or frustration. **Neither side is 'good' or 'bad.'** Emotions serve a purpose - they can urge us to take action. For example – Anger can spur a person to hit or even kill someone. Anger can also provide the drive for a person to correct a misjustice that they have experienced.

STOP & ASK

How could emotions urge you to take action while caregiving?

→ ***FACILITATORS:*** *The answers do not have to come from personal experience. Ask "how could" not "how did."*

Emotions can also influence the decisions we make. For example, we may decide not to participate in an activity if we are feeling sad.

STOP & ASK

How could emotions influence your decisions while caregiving?

→ ***FACILITATORS:*** *The answers do not have to come from personal experience.*

There is a difference between how we feel about something (emotion) and what we do with that feeling (reaction).

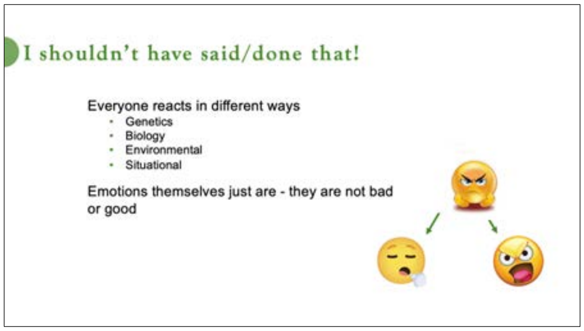
Slide 6 I shouldn't have

Considerations

→ *At times, having examples ready to illustrate the different ways can assist in understanding*

Material

- It is important to remember that everyone reacts emotionally to events in different ways. There are a number of factors that encourage us to react in one way or another.



I shouldn't have said/done that!

Everyone reacts in different ways
- Genetics
- Biology
- Environmental
- Situational

Emotions themselves just are - they are not bad or good

Genetics: your genes may influence how sensitive you are to emotional information

Biology: specifically, how responsive your limbic and autonomic nervous systems (ANS) are
    - Limbic system: categories emotional experiences as pleasant or unpleasant
    - ANS: regulates physical response (pulse, blood pressure, breathing) to emotional cues

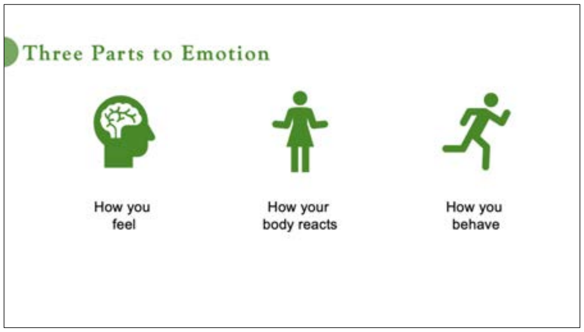
Environmentally: how responsive you are to the environment - how bright the lights are, did you get enough sleep, how hot or cold is it

Situational factors: is the situation dangerous, has it happened before (responses change over time you might not react the 1st time but the 5th time? The 10th time?)

Not only does the factors change from person to person, but they can also change for the same person from situation to situation.

It's important to note that most emotions come and go – if you feel stuck in the same negative emotion for a long time and find it effects your ability to do the things you normally do then you may want to seek some extra help.

Slide 7 Three Parts to Emotion



Three Parts to Emotion

How you feel

How your body reacts

How you behave

Considerations

→ *Emotions just are, but how we react to that emotion is something we can change.*

Material

There are three different parts to how someone experiences an emotion.

The first is how you feel the emotion, an example is I feel angry.
The second is how your body reacts to the emotion – my fists are clenched, my brow is scrunched, shoulders are tense, etc.
And finally, how you behave in response to the emotion – I yell, some people may cry, some people may kick or punch. Your body can serve as an early warning sign to clue you in to what emotion you are experiencing.

Our target is not to change the fact you feel an emotion but how you behave in reaction to that emotion

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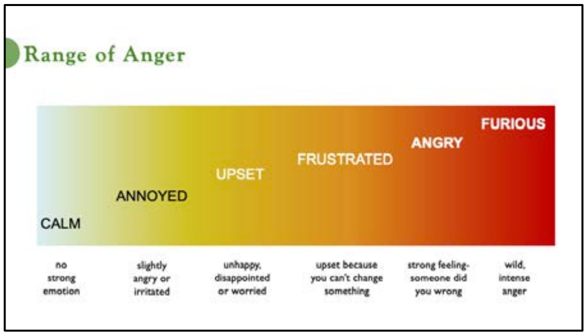
Slide 8 Range of Anger



Range of Anger

CALM – no strong emotion

ANNOYED – slightly angry or irritated

UPSET – unhappy, disappointed or worried

FRUSTRATED – upset because you can't change something

ANGRY – strong feeling- someone did you wrong

FURIOUS – wild, intense anger

Considerations

→ *Not every CG is aware of the emotions they are experiencing. If they appear to struggle, they may need a referral to a therapist to learn to identify and work with the feelings they are experiencing.*

Material

Although CGs do experience other negative emotions such as sadness, guilt, and blame. Today our focus is on frustration and how it turns into anger that interferes with your ability to provide care. As you get towards the right side, the more primitive the emotion is and the easier it is to slip into uncharacteristic behaviors. We discuss the range of anger, because once you are experiencing furious it is hard to reason yourself out of it. Where you are in the range will also help you to decide which is the best method to use to return to calm.

Let's description the emotions in the range:

- Calm – being free of strong emotion
- Annoyed – feeling slightly angry or irritated
- Upset – feeling unhappy, disappointed, or worried
- Frustrated – feeling distress due to inability to change or achieve something
- Angry - strong feeling experienced when you feel someone has done you wrong
- Furious - feeling of wild, intense anger

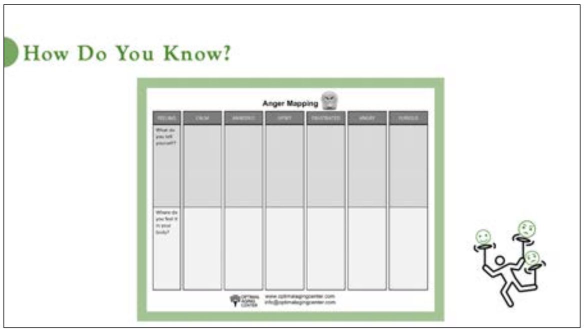
So how do you know where you are in this range?

Slide 9 How Do You Know?

Considerations

→ *Offering an example of the self-talk in each category can be helpful but be wary, this is a discovery process and if you supply them with an answer too early, they may not personalize it.*

→ *Some CGs will find it easy to be aware of what they are thinking in the 'heat' of the moment, others will need assistance.*



How Do You Know?

Anger Mapping

Material

Activity: How Do You Know?

Some people just know. For those that don't your body can give you a clue.

ACTIVITY-Directions

We will not ask you to share this information, it is private and only for you use. For many of you, you may not have ever been asked to think about your emotions in this way and it may prove difficult. We ask that you stick with it as this information is very important for you as it can help you figure out the best strategy to manage your response to emotions in this range.

ACTIVITY-Do it

Everyone should have a copy of the handout. If not, you can use a pen and paper and following along with what is on the screen.

We all tell ourselves things when we experience strong emotions.

- When we are calm, we might say something like: "Life is good right now."
- We note that in our body our shoulders are relaxed, our breathing is measured, neither fast nor slow, we may be smiling.

On the other hand, when we are furious

- We may say something: ”I’m so angry, I hate being a CG.”
- The body feels tight and tense, fists are clenched, face may feel hot, may be scowling.

Look at the form in your packet titled Anger Mapping. You’ll note there are emotions across the top, and on the left, there are two separate categories – what do you tell yourself and where do you feel it in your body. Today we are going to start with furious and we are going to give you 2 mins to write down where do you feel it in your body first. (Pause for 2m). Now that you’ve got that down we want you to think about what you tend to tell yourself when you are furious. We’ll give you 2 mins to write that down. (Pause for 2m).

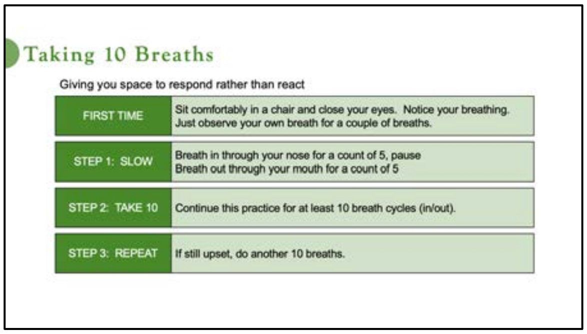
→ ***FACILITATORS:*** *walk them through filling out furious, frustrated, annoyed, and finally calm giving them a few minutes for each one.*

What we are thinking and what our bodies tell us are both clues to where we are in the range of anger.

Slide 10 Taking 10 Deep Breaths

Considerations

→ *If people have a medical issue with deep breath, they can just observe their breathing – if it is fast then return the breath to normal pace by adding a slight pause between the inhale and exhale. Or they can just start noting things about the breath itself. Is the air hot or cool? How does it feel in the throat? In the lungs? Can they trace the path of the breath?*



Taking 10 Breaths

Giving you space to respond rather than react

FIRST TIME	Sit comfortably in a chair and close your eyes. Notice your breathing. Just observe your own breath for a couple of breaths.
STEP 1: SLOW	Breath in through your nose for a count of 5, pause Breath out through your mouth for a count of 5
STEP 2: TAKE 10	Continue this practice for at least 10 breath cycles (in/out).
STEP 3: REPEAT	If still upset, do another 10 breaths.

Material

Like stress where we first taught this, many of the emotions experienced in this range can be perceived as a threat to our brains, which will in turn, trigger the fight or flight response. If you remember the first response you perceive is faster breathing. The same skill we taught you to slow your breathing, works well here. Taking 10 deep breaths tells your mind and body to stand down and is the foundation of allowing for a response instead of a reaction. It calms the mind and body and gives you the space to remember the disease and its contribution.

Activity: 10 Breaths

ACTIVITY-Directions

First Time: Sit comfortably in a chair and close your eyes. Notice your breathing, just observe your own breath for a couple of breaths.

Step 1: To slow down your breathing 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).

Step 2: Continue this practice for at least 10 breath cycles (in/out).

Step 3: If you are still upset, do another 10 breaths.

ACTIVITY-Do it

→ *FACILTATORS: Walk them through the 10 breaths.*

BEGIN: Sit comfortably in a chair and close your eyes. Your feet should be flat on the floor and arms should be supported in comfortable manner. Try to sit so your shoulders are over your hips. If closing your eyes is difficult for you, you can pick a place on the wall to stare at during this exercise. Notice your breathing, just observe your own breath for a couple of breaths.
(Pause for 2 breaths)
Now we are going to ask you to slow down your breathing to help you relax. To slow down, do a slow inhale through the nose, for a silent count of 5. Then do a slow exhale through the mouth, for the same count.

Breathe In, 2, 3, 4, 5, pause	- Breathe Out, 2, 3, 4, 5, pause,	(repeat 4 more times)
Breathe In, 2, 3, 4, 5,	- Breathe Out, 2, 3, 4, 5,	(repeat 1 more time)
Breathe In,	- Breathe Out,	(repeat 3 more times)

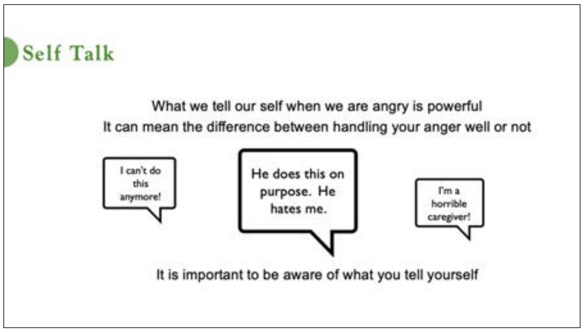
When you're ready open your eyes and come back to the room.

Slide 11 Self Talk

Considerations

→ *We are meaner to ourselves then we would ever be to someone else. Remind people that they can tear themselves down or build themselves up. It is in what they tell themselves.*

→ *Many times, until they step back and listen, they really don't know what they are telling themselves.*



Self Talk

What we tell our self when we are angry is powerful
It can mean the difference between handling your anger well or not

I can't do this anymore!

He does this on purpose. He hates me.

I'm a horrible caregiver!

It is important to be aware of what you tell yourself

Material

In our minds there is usually a running commentary on our actions. For some it may sound like someone from our childhood – supporting us, criticizing us, or even mocking us. That voice can remind us of our standards, or it can very mean. Many times, we routinely are meaner to ourselves than we would ever be to another. Those voices have been a part of who we are since childhood and for many, have become part of the background – listen to but not consciously heard. We want you to become aware of them again and take back control of you tell yourself.

Activity: Self Talk

ACTIVITY-Directions

These statements are common responses CGs may tell themselves. Let's spend a moment and rewrite this internal script.

→ ***FACILITATORS:*** *Walk them through what else they could say.*

ACTIVITY-Do it

Scenario 1:

Suzie is on a time schedule to get to an important appointment on time. Her husband with moderate stage dementia being incredibly difficult. She finds herself feeling incredibly frustrated and tells herself, "I just can't do this anymore."

STOP & ASK

What do you think happened next?
What else could someone tell themselves in this situation?
Would that change what happens next?

→ ***FACILIATATORS:*** *Have the participants answers the questions.*

What happened?
- Seeking out the negative result – they didn't make the appt/ yelling/ etc.

What else could she tell herself?
- Alternative: This is tough right now, but I can do this.

The change?
- Suzie takes 10 deep breaths and pushes through with more patience.

Scenario 2:

Betty and Robert have been married a long time. Early in their marriage after a series of heated arguments, they decided that it wouldn't be fair for Robert to use Betty's Mom in an argument. Despite this agreement that has kept peace in their marriage for the last 40 years, all of a sudden, Robert who has been recently diagnosed with Lewy Body Dementia, is using her mom in arguments. Betty thinks: "He is doing this on purpose. He knows it makes me so angry."

STOP & ASK

What do you think happened next?
What else could someone tell themselves in this situation?
Would that change what happens next?

→ ***FACILIATATORS:*** *Have the participants answers the questions.*

What happened?

- Seeking out the negative result – they argue more, and they are getting worse

What else could she tell herself?

- Alternative: It's the disease causing his behavior, it isn't his fault.

The change?

- Betty doesn't respond to the comments and the arguments aren't quite as hurtful.

ACTIVITY-Process

STOP & ASK

Is this something you have ever done?
Is it something you see yourself doing? Why or why not?

Start small. First listen for the self-talk. What does it say? If it is not supportive – replace it with something more positive. Remember that negative self-talk can push your emotions up the range and positive self-talk can calm and give you some space. Caregiving is a hard job. Support is important – including your own for you.

Slide 12 STOP

STOP

S Stop
T Take 10 Breaths
O Observe: What's happening in me?
P Proceed Differently

Considerations

→ *There is a fine distinction between these two. Reacting uses the emotion and is usually immediate. Responding uses reason and requires an assessment of the situation.*

Material

Sometimes it just happens, despite all the precautions you put in place. You find yourself in a moment when you are reacting rather than responding. When you find yourself getting angry one method you can use to calm yourself down is S.T.O.P.

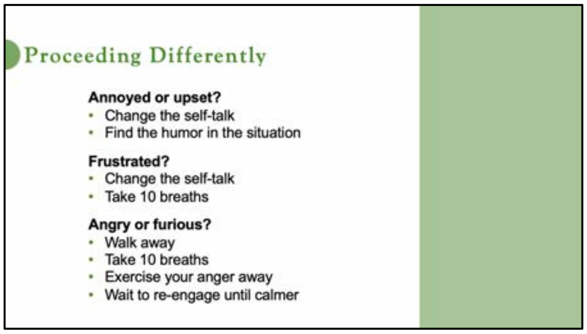
S stands for Stop	T is Take 10 breaths
O is Observe	P is Proceed Differently

- **Stop** means exactly what you think it does – stop whatever it is you are doing in that moment. If you were about to say or do something – don't.
- **Take 10 breaths** means right after you stop you take a minute, do 10 slow breaths – physically you are sending a signal to your body to stand down.

- **Observe** gives you the space to actually see what is happening so you can respond rather than react. It gives you time to observe what you are saying to yourself and time to craft another response. Because you've done the work of earlier – noting what you tend to tell yourself and practice telling yourself more positive statements it will be easier in the moment to tell yourself something like *No he isn't doing this on purpose - It is the disease making him say that*.
- **Proceed Differently** means to move forward using the new information. We will talk about this more in a moment.

If you find yourself angry or frustrated and reacting emotionally often, making a small card with the STOP info on it to refer to can be helpful.

Slide 13 Proceeding Differently



Proceeding Differently

Annoyed or upset?
- Change the self-talk
- Find the humor in the situation

Frustrated?
- Change the self-talk
- Take 10 breaths

Angry or furious?
- Walk away
- Take 10 breaths
- Exercise your anger away
- Wait to re-engage until calmer

Considerations

→ *Knowing where the CG is on the range of the emotion can allow them to tailor the response. It requires a certain level of psychological self-awareness. Some CGs will be more aware, some less, and a few will totally lack this awareness. They may need additional assistance.*

Material

Know where you are in the range of emotion is important for knowing how to respond. Are you annoyed or upset? Frustrated? Angry or furious?

If you are **annoyed or upset,** you can:
- Change the self-talk
- Find the humor in the situation – humor has more power than you think it has to defuse a situation like this. Humor can help you reframe problems that might otherwise seem overwhelming.

STOP & ASK

Have you ever used humor to defuse a situation?
What about in a caregiving situation?

If you are **frustrated,** you can:
- Change the self-talk
- Take 10 breaths

If you are **angry or furious,** you can:
- Walk away – take yourself away from what is making you angry
- Take 10 breaths – you will probably need more than one set

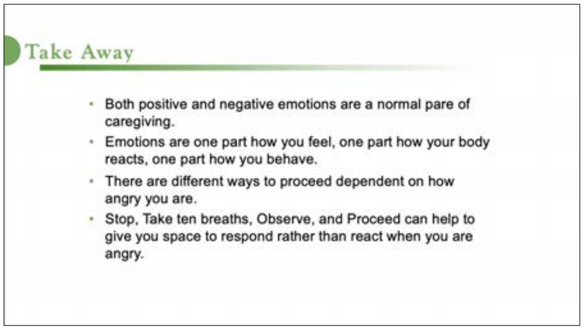
- Exercise your anger away – some people describe this type of anger as spiky energy that won't let them calm down. Exercise (like vigorous housekeeping) can be effective
- Wait to re-engage until calmer – this is very important! Do not re-engage while still angry. As you calm down watch for negative self-talk that is feeding the anger.

Reminder Filling out the Anger Mapping form can help you find the clues needed to know where you are on the range.

Slide 14 Take Away

Considerations

→ *This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the 'take away' was from this session.*



Take Away

- Both positive and negative emotions are a normal pare of caregiving.
- Emotions are one part how you feel, one part how your body reacts, one part how you behave.
- There are different ways to proceed dependent on how angry you are.
- Stop, Take ten breaths, Observe, and Proceed can help to give you space to respond rather than react when you are angry.

Material

→ *FACILITATORS: If there is time do the stop & ask.*

STOP & ASK

Thinking back over today's session,
what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:
- Both positive and negative emotions are a normal part of caregiving.
- Emotions are one part how you feel, one part how your body reacts, one part how you act.
- There are different ways to proceed dependent on how angry you are.
- Stop, Take ten breaths, Observe, and Proceed can help to give you space to respond rather than react when you are angry.

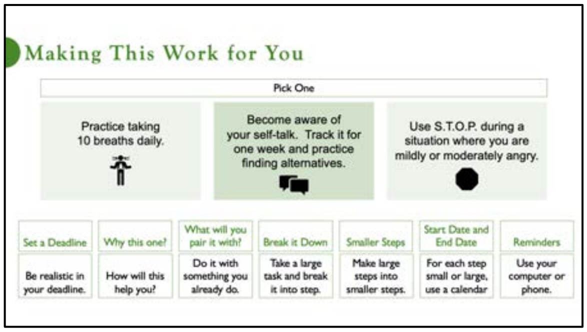
Slide 15 Making This Work for You

Considerations

→ *The Action Plan is the most important part.*

→ *Encourage the CGs to **pull out their pen and paper** and create an action plan right there.*

→ *Use the boxes along the bottom to assist in the creation of the action plan.*



Making This Work for You

Pick One

Practice taking 10 breaths daily.

Become aware of your self-talk. Track it for one week and practice finding alternatives.

Use S.T.O.P. during a situation where you are mildly or moderately angry.

Set a Deadline	Why this one?	What will you pair it with?	Break it Down	Smaller Steps	Start Date and End Date	Reminders
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take a large task and break it into step.	Make large steps into smaller steps.	For each step small or large, use a calendar	Use your computer or phone.

Material

Activity: Action Plan

ACTIVITY-Directions

→ ***FACILITATOR:** Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you must do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
    - Have the CGs choose either 10 breaths, self-talk, or using S.T.O.P.
    - This example: Self-talk

1. Set a deadline – *Be realistic*
    - By next Tuesday (one week) I will have practice becoming aware of my self-talk 5 times.

2. Why chose this one? - The more personal the better
    - I always feel exhausted, and I'm scared I will mess up something important.

3. What will you pair it with? – Do it with something you already do
    - After an outburst, I usually sit at the kitchen table to calm down so I will do it then.

- Optional: Break it down – Take a large task and break it into steps
    - I will keep my notebook visible, so I see it and remember to do it.
    - I will write the instructions in red on one of the pages

4. Reminders – *Computer, phone, calendar*
    - I'll write STOP on the white board in the kitchen
    - I'll also make a reminder in my phone to reminding in the morning to work on it

5. Problem-solving - *Pending*

→ ***FACILITATORS:*** *You may want to ask if participant anticipate any issues and plan for it*

All By Myself

The following is the facilitator's summary of the module:

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All By Myself

Aim of Module

To address the isolation experienced by caregivers during the pandemic by examining available online support.

Handouts – CWC2.0.5 HO

All handouts are available in electronic format in a PDF.
ALZ San Diego: 9 cognitively stimulating activities you can do at home
GeriPal: Staying Connected: Things to Do

Three Main Points

1. Staying socially connected is important to staying healthy, happy, and keep your mind sharp.
2. Support Groups come in many shapes and sizes and can help you feel less alone and serve as sources of practical advice.
3. Matching explanations to their level of understanding and making health related tasks part of the daily routine can both help to keep the person you are caring for safe and healthy.

Activities

No Activities

Action Plan

Choice of 2:
- Pick one activity from Staying Connected Handout
- Find a Support Group or Message Board to try out

→ ***FACILITATORS:*** *Forms are not required - pen and paper can be substituted.*

Slide 2 Ground Rules

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*
- → *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*

Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

Slide 3 Introductions

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

Considerations

→ *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*

→ *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*

→ *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*

→ *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

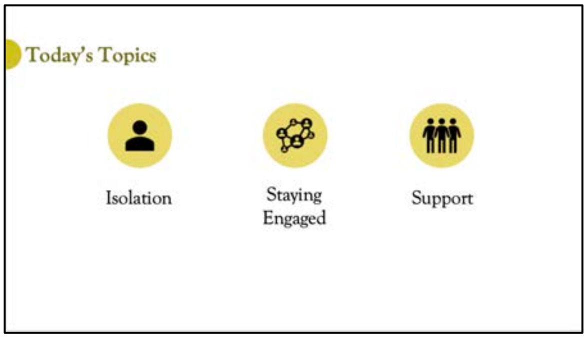
Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today’s Topics



Today’s Topics

Isolation

Staying Engaged

Support

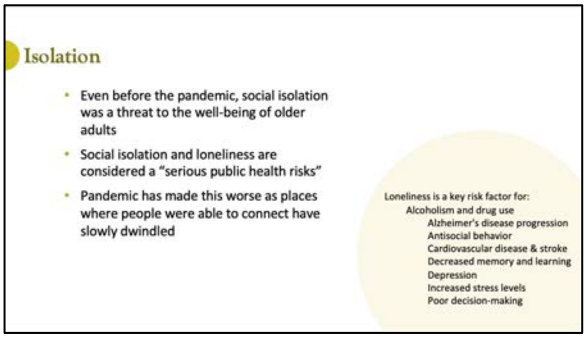
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

- Today we are going to talk about isolations, loneliness, and how it can share the same space as caregiving.
- Then we’ll discuss ways to stay engaged with the outside world.
- Finally, we’ll talk about different ways to find support online.

Slide 5 Isolation



Isolation

- Even before the pandemic, social isolation was a threat to the well-being of older adults
- Social isolation and loneliness are considered a “serious public health risks”
- Pandemic has made this worse as places where people were able to connect have slowly dwindled

Loneliness is a key risk factor for:
Alcoholism and drug use
Alzheimer’s disease progression
Antisocial behavior
Cardiovascular disease & stroke
Decreased memory and learning
Depression
Increased stress levels
Poor decision-making

Considerations

→ *More and more caregivers are reporting distress as the pandemic stretches on. Due to fear of transmitting the COVID-19, support systems including respite have closed and many caregivers are reporting feeling more isolated than ever.*

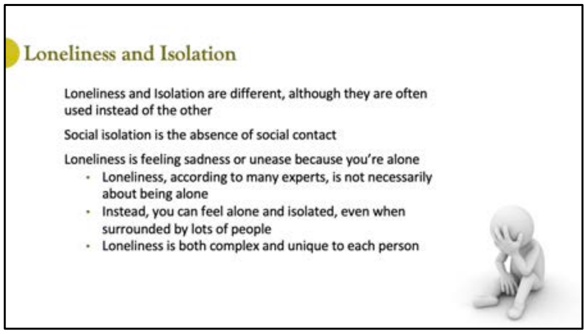
Material

We’ve known for a long time that social isolation is a threat to the well-being of most people.
And this never-ending pandemic has made it much worse as many of the places we used to go to connect with others are not available anymore or severely restricted.
So how is social isolation a threat? Mostly because it leads to loneliness.

Why is this important? Loneliness is a key risk factor for:
With Increased Stress Levels there is a higher risk for Cardiovascular disease & stroke

- Depression
- Alcoholism and drug use
- Without added stimulation dementia can progress more quickly for the person being caring for
- We can also see decreased memory, learning, and poor decision-making
- If the loneliness lasts long enough? We forget how to politely interact with one other, leading to antisocial behavior. “Get off my lawn!”

Slide 6 Loneliness & Isolation



Loneliness and Isolation

Loneliness and Isolation are different, although they are often used instead of the other

Social isolation is the absence of social contact

Loneliness is feeling sadness or unease because you're alone

- Loneliness, according to many experts, is not necessarily about being alone
- Instead, you can feel alone and isolated, even when surrounded by lots of people
- Loneliness is both complex and unique to each person

Considerations

→ *Social isolation is quantitative (number of contacts); isolation is qualitative (feeling).*

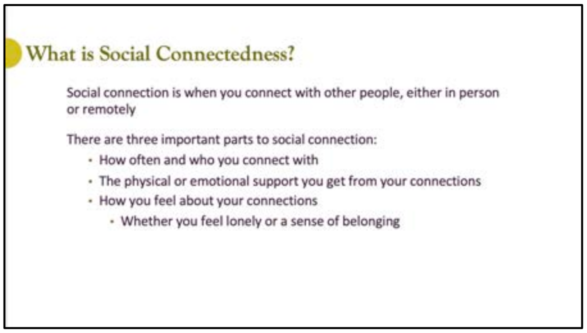
Material

Let's talk a moment about loneliness and isolation. Loneliness and Isolation are different, although people will sometimes use these words interchangeably.

- Social isolation is the **absence of social contact** – the number of people in your life is lacking.
- Loneliness is **feeling** sadness or unease because you're alone.

One does not automatically lead to the other. We all know people who appear to be very comfortable with limited interaction with other people. Many call them introverts. They have one or two close friends, and they are happy. We also know people who report feeling alone in the middle of a crowd surrounded by people. So, loneliness is not necessarily about being alone - It's about feeling alone. Loneliness is both complex and unique to each person. Social connections are one way to address loneliness.

Slide 7 What is Social Connectedness?



What is Social Connectedness?

Social connection is when you connect with other people, either in person or remotely

There are three important parts to social connection:

- How often and who you connect with
- The physical or emotional support you get from your connections
- How you feel about your connections
  - Whether you feel lonely or a sense of belonging

Material

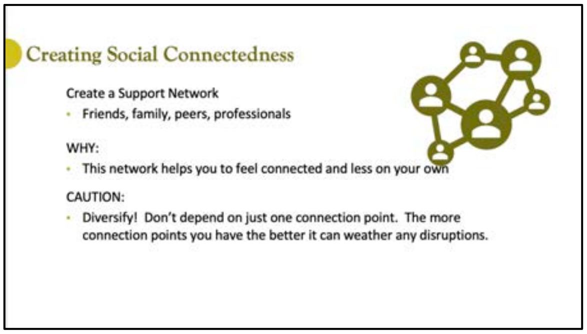
- Social connections are one way to address loneliness.

- Social connection is when you connect with other people, either in person or remotely

- There are three important parts to social connection:
  - **How often** and **who** you connect with
  - The **physical or emotional support** you get from your connections
  - **How you feel about your connections** - whether you feel lonely or a sense of belonging

The key to addressing loneliness for many people is feeling socially connected and being happy with those connections. There are many ways to feel connected to others.

Slide 8 Creating Social Connectedness



Creating Social Connectedness

Create a Support Network
- Friends, family, peers, professionals

WHY:
- This network helps you to feel connected and less on your own

CAUTION:
- Diversify! Don't depend on just one connection point. The more connection points you have the better it can weather any disruptions.

Material

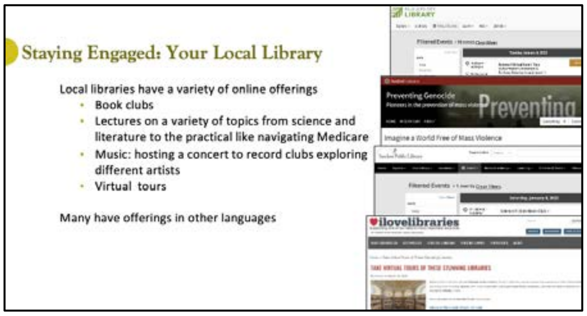
The best way to foster social connectedness is to create a large support network with many connection points. These points can be to friends, family members, other caregivers, or through professionals.

We know for many of you, caregiving has seriously limited your network.
Today we will we be looking at ways on the internet to increase your contacts so that you feel connected to others and less isolated even if you can't get out of the house.
The more connection points you have, the better it can weather any disruptions.

We'll be looking at a variety of ways you can reach out online, such as virtual support groups, message boards, helplines, and social media. We will also talk about where you can find each of these online.
It is important to remember that you can reach out in many ways to be connected – both in person and online

We have two handouts which describe many of these programs in greater detail but here's a quick introduction.

Slide 9 Staying Engaged: Your Local Library



Staying Engaged: Your Local Library

Local libraries have a variety of online offerings
- Book clubs
- Lectures on a variety of topics from science and literature to the practical like navigating Medicare
- Music: hosting a concert to record clubs exploring different artists
- Virtual tours

Many have offerings in other languages

Material

Let's take a closer look at a few of these options.
Local libraries have a variety of online offerings
- Virtual Book clubs
- Lectures on a variety of topics from science and literature to the practical like navigating Medicare
- For those of you who love music: Some libraries host concerts or offer record clubs to explore different artists

Some offer virtual tours and if libraries are your thing? There are even virtual tours of beautiful libraries.

Slide 10 Staying Engaged: Senior Planet & Well Connected

Staying Engaged: Senior Planet & Well Connected

Senior Planet by AARP

For more information:
https://seniorplanet.org/locations/palo-alto/events/

Well Connected by Covia

To download catalog or to check it out:
https://covia.org/programs/well-connected/

Televisit (not-for-profit)

For more information:
http://www.televisit.org/

Material

I would like to bring to your attention to two web sites you can use to stay connected.

Senior Planet offered by AARP offers different courses, programs, and activities. If you are struggling with keeping up with new technology? They offer OATS or Older Adults Technology Services which offers classes in technology to keep you in the know as the tech advances.

Well Connected is a service offered by Covia. It is a free virtual community that offers phone and online activities for people 60 and older. They offer discussion groups, games, laughter, and lectures all designed to create a community and to help you stay connected. You can download their catalog from the url on the screen.

There is another site not on the screen called Televisit. It is a not-for-profit organization that connects older adults to each other through their participation in interactive group activities from the convenience and comfort of home. This is a subscription-based program (~$15 monthly) which requires no technical skill to access programs. http://www.televisit.org TeleVisit Program Features: They call – so no need to remember; Only press a single button on the tablet to join a session; Notifications to family members if client does not attend a session, or facilitator believes that client may not be safe

Slide 11 Virtual Tours

Staying Engaged: Virtual Tours

Come and tour places you've never thought you would get a chance to see!

- Grab a friend and go for a tour each from your own computer
- https://teambuilding.com/blog/virtual-tours

Material

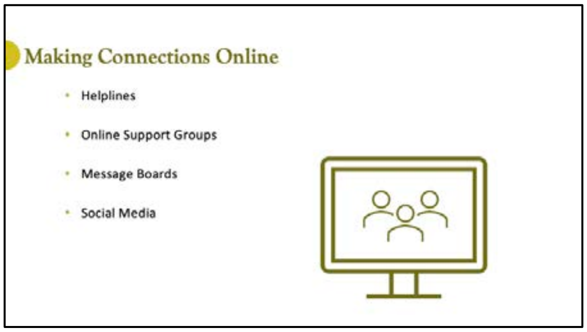
One unforeseen benefit of the pandemic has been the accelerated development of virtual tours from many tourist spots. For many of us a trip to Paris to see the Louvre or to the Vatican to view one of their many museums, may have been outside of our budget but now you can do a virtual tour from the comfort of your own home. Or perhaps you would prefer to wander some of the wonder national parks or landscapes of our world? Even the some of the most famous Zoos and Aquariums have gotten into the act and offer virtual tours.

Family and friends are using these tours to connect: they select a site, do the tour from their own home, then meet on Zoom to discuss their favorite parts.

Slide 12 Making Connections Online

Material

Over the next few slides, we will be exploring different ways to connect online.
From helplines to online support groups, to message boards and social media – each offer different methods to make connecting and finding support possible for you



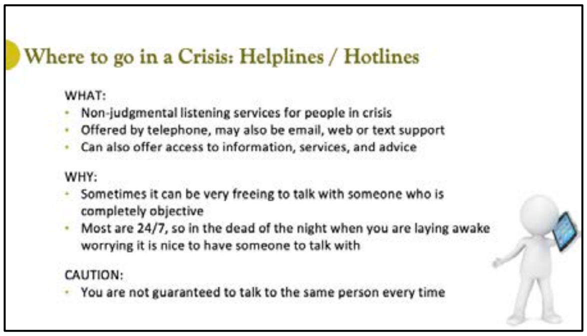
Making Connections Online

- Helplines
- Online Support Groups
- Message Boards
- Social Media

Slide 13 Where to go in a Crisis: Helplines / Hotlines

Material

Let's start with where you can go in a crisis. A helpline is a special telephone service that people can call to get advice about a particular subject.



Where to go in a Crisis: Helplines / Hotlines

WHAT:
- Non-judgmental listening services for people in crisis
- Offered by telephone, may also be email, web or text support
- Can also offer access to information, services, and advice

WHY:
- Sometimes it can be very freeing to talk with someone who is completely objective
- Most are 24/7, so in the dead of the night when you are laying awake worrying it is nice to have someone to talk with

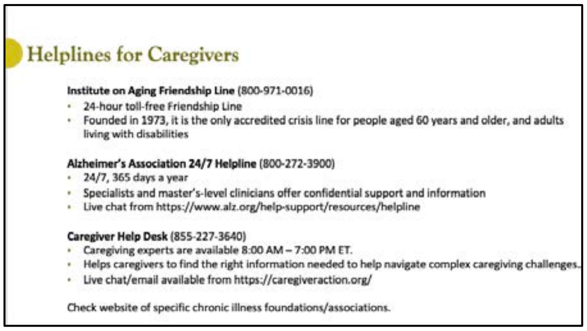
CAUTION:
- You are not guaranteed to talk to the same person every time

What are they?
- Non-judgmental listening services for people in crisis
- Offered by telephone, may also be email, web, or text support
- Can also offer information, services, and advice

Why should you consider using a helpline?
- Sometimes it can be very freeing to talk with someone who is completely objective
- Most are 24/7, so in the dead of the night when you are lying awake worrying it is nice to have someone to talk with

CAUTION: You are not guaranteed to talk to the same person every time so if you connect with someone you may not be able to, or it may be difficult to chat with them again.

Slide 14 Helplines for Caregivers



Helplines for Caregivers

Institute on Aging Friendship Line (800-971-0016)

- 24-hour toll-free Friendship Line
- Founded in 1973, it is the only accredited crisis line for people aged 60 years and older, and adults living with disabilities

Alzheimer's Association 24/7 Helpline (800-272-3900)

- 24/7, 365 days a year
- Specialists and master's-level clinicians offer confidential support and information
- Live chat from https://www.alz.org/help-support/resources/helpline

Caregiver Help Desk (855-227-3640)

- Caregiving experts are available 8:00 AM – 7:00 PM ET.
- Helps caregivers to find the right information needed to help navigate complex caregiving challenges.
- Live chat/email available from https://caregiveraction.org/

Check website of specific chronic illness foundations/associations.

Material

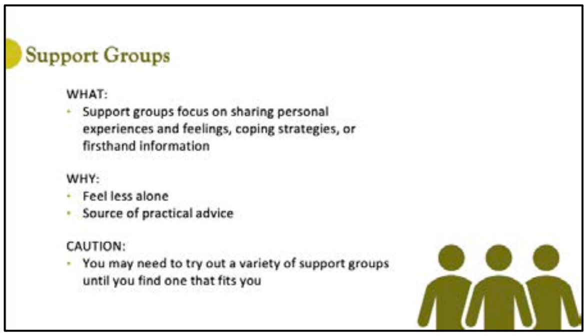
Friendship Line California (800-971-0016)
- 24-hour toll-free Friendship Line
- Founded in 1973, it is the only accredited crisis line in the country for people aged 60 years and older, and adults living with disabilities

Alzheimer's Association 24/7 Helpline (800-272-3900)
- 24/7, 365 days a year
- Specialists and master's-level clinicians offer confidential support and information to people living with the disease, CGs, families and the public
- live chat from https://www.alz.org/help-support/resources/helpline available from 7a-7p(CST) M-F

Caregiver Help Desk (855-227-3640)
- Caregiving experts are available 8:00 AM – 7:00 PM ET.
- Hosted by Caregiver Action Network and staffed by caregiving experts, helps CGs to find the right information needed to help navigate complex caregiving challenges.
- Live chat/email available from https://caregiveraction.org/

Check website of specific chronic illness foundations/associations. Many have some type of help line available.

Slide 15 Support Groups



Support Groups

WHAT:
- Support groups focus on sharing personal experiences and feelings, coping strategies, or firsthand information

WHY:
- Feel less alone
- Source of practical advice

CAUTION:
- You may need to try out a variety of support groups until you find one that fits you

Material

As a CG I'm sure you've heard a lot about support groups. Support groups are one way to connect with others in a similar situation like yours. They are not for everyone. But some people find them every helpful.

What are they?
- Support groups focus on sharing personal experiences and feelings, coping strategies, or firsthand information

Why do people keep recommending them?

- People who attend support group report feeling less alone.
- They can be a source of practical advice – many time the members 'have been there and done that' and can share what worked and what didn't

CAUTION: You may need to try out a variety of support groups until you find one that fits you since there are many kinds of support groups to consider
- **Condition-specific groups:** Parkinson Disease group vs Alzheimer's Disease group
- **Groups targeting different kinds of CGs:** spouses, children, men, women, etc.
- **Peer-led support groups:** led by a caregiver or someone who may have been a caregiver
- **Groups led by a trained facilitator:** led by someone trained to lead support groups

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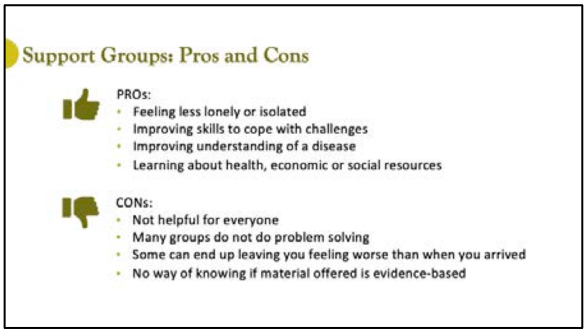
Slide 16 Support Groups: Pros & Cons



Support Groups: Pros and Cons

PROs:
- Feeling less lonely or isolated
- Improving skills to cope with challenges
- Improving understanding of a disease
- Learning about health, economic or social resources

CONs:
- Not helpful for everyone
- Many groups do not do problem solving
- Some can end up leaving you feeling worse than when you arrived
- No way of knowing if material offered is evidence-based

Material

In general, there are a lot of positives to joining a support group where you feel comfortable sharing**,**

Pros include:
- Feeling less lonely or isolated
- Improving skills to cope with challenges
- Improving understanding of a disease
- Learning about health, economic or social resources

But not everyone benefits from a support group. Some may find that :
- While support groups can benefit most people that attend, they are not helpful for all
- Many groups do not do problem solving, leaving members to apply new information by themselves
- Some groups without active moderation can fall into rant session leaving members feeling worse than when they arrived
- You don't know if the information shared has any evidence behind it

Slide 17 Finding One That Fits

Finding a Group That Fits

- Understand the Format
- Manage Expectations
- Cost Involved
- Don't Have to Stay
- Keep an Open Mind

Material

If a support group sounds like it might be doable but how do you find one that fits?

Find out what the format is.

- Does the group have a facilitator / trained leader / peer led?
- Ask about the group's confidentiality policy – should encourage a level of privacy where what's said in the group stays in the group.
- Know the difference between a virtual support group and an in-person support group
  - Both have a meeting date and time and certain frequency they meet (weekly/monthly)
  - In person meets at a location you go to.
  - Virtual meets on the computer through a teleconference program like Zoom or Skype

Mayo Clinic notes there are specific benefits to virtual groups which include:

- More frequent or flexible participation
- Opportunities for those without local face-to-face support groups
- A degree of privacy or anonymity

Manage Expectations.

- Friends don't magically appear – you must work at it. Be prepared to introduce yourself, be friendly, reach out to offer support and be open to accepting support in return.

Know that most groups are free to join.

Be wary if they charge. Ask why there is a fee. Some reasons why groups charge:

- Pay the facilitator or site.
- To encourage group stability – people value what they pay for, so they show up
- And there may be other reasons

Don't feel obligated to stay with a group if it doesn't feel right for you.

- You can always leave a group, but it is good to come a few times/stay for a week online to get a feel for what the group is like.

Keep an open mind.

- The important thing is to find a space where you can share stories, feelings, and advice with people who can relate, without judgment. Knowing that you are not alone can make a world of difference.

Slide 18 Where to Find a Support Group

Material

Family Caregiver Alliance offers an unmoderated email list style support for families, partners, and other CGs who want a safe place to discuss the stresses, challenges, and rewards of providing care for adults with disorders such as Alzheimer’s, stroke, brain injury, and other chronic debilitating health conditions. They also offer an online support group for lesbian, gay, bisexual, and transgender CGs of adults with chronic health problems to discuss the unique issues of caring for their loved ones. https://www.caregiver.org/connecting-caregivers/support-groups/

Where to Find a Support Group

Family Caregiver Alliance offers an emailing list style support for caregivers caring for persons with all types of chronic illnesses
https://www.caregiver.org/connecting-caregivers/support-groups/

Well Spouse Association open for all chronic illnesses https://wellspouse.org/

Looking for something local and in-person?

- Check out the major organizations for the illness of the person you are caring for

American Heart Association https://www.stroke.org/en/stroke-support-group-finder
Michael J Fox Foundation https://www.michaeljfox.org/news/support-groups
Alzheimer’s Association https://www.alz.org/events/event_search
Lewy Body Dementia Association https://www.lbda.org/local-support-groups/

Find your local **Area on Aging**. https://www.n4a.org/

Well Spouse Association org for spousal CGs across all chronic illnesses. Although the groups are member-based, the website has many free resources https://wellspouse.org/

Looking for something local and in-person (some of these also offer virtual support groups)?
- Look at your local hospital and/or major health center
- Local Area on Aging may offer support groups. https://www.n4a.org/
- Check out the major organizations for the illness of the person you are caring for. Many will have local chapters

Many offer both online and in-person groups depending on where you live: four examples follow.

American Heart Association
- for cardiovascular diseases offers a searchable database of support groups https://www.stroke.org/en/stroke-support-group-finder

Michael J Fox Foundation
- for Parkinson Disease has a support group page that lists available online groups. https://www.michaeljfox.org/news/support-groups

Alzheimer’s Association
- offers a searchable database of support groups, supports research, and offers great information via website https://www.alz.org/events/event_search

Lewy Body Dementia Association
- LBDA raises awareness, supports patients, families and CGs and promotes scientific advancements. They offer a support-group-locator tool to help you find local group. https://www.lbda.org/local-support-groups/

Slide 19 Online Message Boards

Online Message Boards

WHAT:
- Online message boards serves the same goals of a support group without the structure of attending a once a week ‘event’
- Available 24/7 you post your question or share an answer on your schedule

WHY:
- Along with feeling less alone & being a source of practical advice online message boards are available when you need them

CAUTION:
- You don’t know who is offering the advice so make sure you verify the information before you use it!

Material

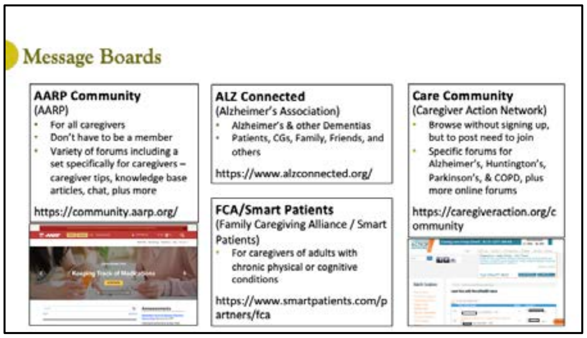
A message board is an online discussion site where people can hold conversations in the form of posted messages.

What are online message boards?
- Online message boards serve the same goals of a support group without the structure of attending a once a week ‘event’
  - Available 24/7, you post your question or share an answer on your schedule

Why should you consider an online message board?
- Along with feeling less alone & being a source of practical advice online message boards are available when you need them

CAUTION:
- You don’t know who is offering the advice so verify the information before you use it!

Slide 20 Message Boards



Message Boards

AARP Community
(AARP)
- For all caregivers
- Don’t have to be a member
- Variety of forums including a set specifically for caregivers – caregiver tips, knowledge base articles, chat, plus more

https://community.aarp.org/

ALZ Connected
(Alzheimer’s Association)
- Alzheimer’s & other Dementias
- Patients, CGs, Family, Friends, and others

https://www.alzconnected.org/

FCA/Smart Patients
(Family Caregiving Alliance / Smart Patients)
- For caregivers of adults with chronic physical or cognitive conditions

https://www.smartpatients.com/partners/fca

Care Community
(Caregiver Action Network)
- Browse without signing up, but to post need to join
- Specific forums for Alzheimer’s, Huntington’s, Parkinson’s, & COPD, plus more online forums

https://caregiveraction.org/community

Material

AARP Online Community (AARP)
https://community.aarp.org
- For all CGs
- Don’t have to be an AARP member or be over the age of 50 to use
- They offer a variety of forums including a set specifically for CGs with CG tips, knowledge base articles, chat, plus more

ALZ Connected (Alzheimer’s Association) https://www.alzconnected.org/
- free online community
- Alzheimer’s and other Dementias
- People with the disease, CGs, Family members, Friends, Individuals who have lost someone to Alzheimer’s

Smart Patients (Family Caregiving Alliance / Smart Patients)
https://www.smartpatients.com/partners/fca

- For CGs of adults with chronic physical or cognitive conditions such as Alzheimer’s, stroke, Parkinson’s, and other illnesses

Care Community (Caregiver Action Network) https://caregiveraction.org/community
- browse without signing up, however if you wish to post or comment you will need to
- various specific forums for Alzheimer’s, Huntington’s, Parkinson’s, & COPD, plus more general online forums

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Slide 21 Social Media-Facebook

Material

Facebook is a website which allows users, who sign-up for free profiles, to connect online with friends, work colleagues or people they don’t know. It allows users to share pictures, music, videos, and articles, as well as their own thoughts and opinions with however many people they like.

Social Media - Facebook

WHAT:
- Facebook has many private support groups, some have been around for years
- Providing support & advice, many caregivers find them very helpful

WHY:
- Facebook is a media that many are already familiar with

CAUTION:
- There is no guarantee of privacy on Facebook. While thes groups do make an effort to protect their members, the very nature of Facebook can at times work against them.

Private groups are Facebook code for groups which require members to join individual groups and posts can only be viewed by members of the group. This means what you post will not show to your Facebook friends unless they are also members of the group.

What are private Facebook groups?
- Facebook has many private support groups, some have been around for years
- Providing support & advice these groups, many CGs find them very helpful

Why should you consider one?
- Facebook is a media that many are already familiar with and some of these groups have been around for a very long time so they should have people with a lot of experience in them

CAUTION:
- There is no guarantee of privacy on Facebook. While these groups do try to protect their members, the very nature of Facebook can at times work against them

Slide 22 Facebook Caregiver Groups for All Caregivers

Facebook Caregiver Groups for All Caregivers

Caregiver Nation
For family caregivers to share information, empathy, understanding, and resources to support caregivers.
https://www.facebook.com/groups/122999778390804

Working Daughter
This is for women who are balancing caring for an aging parent with their career.
https://www.facebook.com/groups/workingdaughter/

Caregiver Space Community
Offers a variety of private Facebook groups. Group by specific caregiver type, these private Facebook groups are part of Caregiver Space.org and open to any caregiver.
https://thecaregiverspace.org/

Considerations

→ *If a caregiver is unfamiliar with Facebook the following URL provides step-by-step instructions with illustrations. Written for someone new to Facebook these instructions are simple and easy to use. (https://www.facebook.com/help/345121355559712/)*

Material

Caregiver Nation

This is a group for family CGs. They share information, understanding, empathy, and resources so that CGs never feel alone or unsupported in their efforts.

→ *https://www.facebook.com/groups/122999778390804*

Working Daughter

This is for women who are balancing caring for an aging parent with their career. They promote community, support, and encouragement. They encourage you to share questions and advice.

→ *https://www.facebook.com/groups/workingdaughter/*

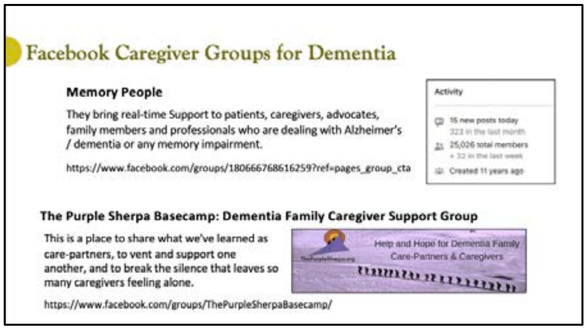
The Caregiver Space Community offers a variety of private Facebook groups

These private Facebook groups are part of Caregiver Space.org and open to any CG providing care and are specific.

→ *https://thecaregiverspace.org/*

They offer groups for:
Spousal Care Caring for a romantic partner or ex.
Eldercare Caring for seniors **Caregiving**
Parents Caring for child or grandchild
Young Caregivers CGs under 35
Long-Term Care Caregiving lasting years
After Caregiving Post caregiving
Caregiving Sons Men’s group
Caregiving Daughters Women’s group
Spousal Care: 20s, 30s, & 40s Young people caregiving for a romantic partner
LGBTQIAP+ Caregivers For sharing issues specific to the LGBTIAP+ community

Slide 23 Facebook Caregiver Groups for Dementia



Facebook Caregiver Groups for Dementia

Memory People

They bring real-time Support to patients, caregivers, advocates, family members and professionals who are dealing with Alzheimer's / dementia or any memory impairment.

https://www.facebook.com/groups/180666768616259?ref=pages_group_cta

Activity
15 new posts today
323 in the last month
25,026 total members
+ 32 in the last week
Created 11 years ago

The Purple Sherpa Basecamp: Dementia Family Caregiver Support Group

This is a place to share what we've learned as care-partners, to vent and support one another, and to break the silence that leaves so many caregivers feeling alone.

https://www.facebook.com/groups/ThePurpleSherpaBasecamp/

Material

Memory People

They bring real-time Support to patients, CGs, advocates, family members and professionals who are dealing with Alzheimer's/dementia or any memory impairment.

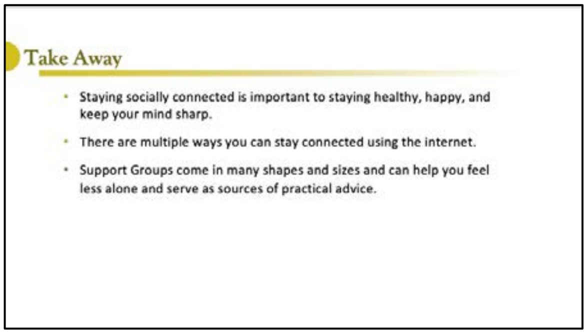
→ *https://www.facebook.com/groups/180666768616259*

The Purple Sherpa Basecamp: Dementia Family Caregiver Support Group

This is a place to share what we've learned as care-partners, to vent and support one another, and to break the silence that leaves so many CGs feeling alone.

→ *https://www.facebook.com/groups/ThePurpleSherpaBasecamp/*

Slide 24 Take Away



Take Away

- Staying socially connected is important to staying healthy, happy, and keep your mind sharp.
- There are multiple ways you can stay connected using the internet.
- Support Groups come in many shapes and sizes and can help you feel less alone and serve as sources of practical advice.

Considerations

→ *This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the 'take away' was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*

STOP & ASK

Thinking back over today's session,
what are the important points you will take away with you?

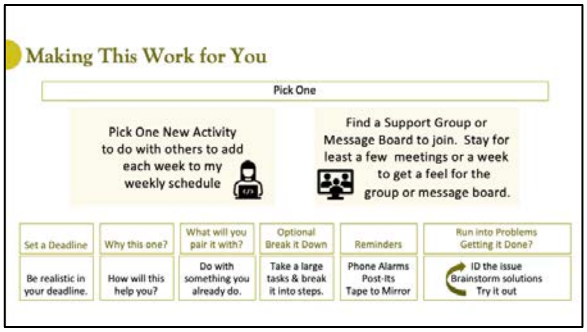
→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:
- Staying socially connected is important to staying healthy, happy, and keep your mind sharp.
- There are multiple ways you can stay connected using the internet.
- Support Groups come in many shapes and sizes and can help you feel less alone and serve as sources of practical advice.

Slide 25 Making This Work for You

Considerations

- → *The Action Plan is the most important part.*
- → *Encourage the CGs to **pull out their pen and paper** and create an action plan right there.*
- → *Use the boxes along the bottom to assist in the creation of the action plan.*



Making This Work for You

Pick One

Pick One New Activity to do with others to add each week to my weekly schedule

Find a Support Group or Message Board to join. Stay for least a few meetings or a week to get a feel for the group or message board.

Set a Deadline	Why this one?	What will you pair it with?	Optional Break it Down	Reminders	Run into Problems Getting it Done?
Be realistic in your deadline.	How will this help you?	Do with something you already do.	Take a large tasks & break it into steps.	Phone Alarms Post-Its Tape to Mirror	ID the issue Brainstorm solutions Try it out

Material

Activity: Action Plan

ACTIVITY-Directions

- → ***FACILITATOR:** Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you must do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
  - Have the CGs choose either added a new activity to do with others, or find a support group or message board
  - This example: explore one of the message boards

1. Set a deadline – *Be realistic*
   - By next Wednesday I will have signed up and looked at 2 forums.
   - By the end of the month, I will have tried out commenting on a message and posted one of my own.
2. Why chose this one? - The more personal the better
   - I feel like I have no one to ask specific caregiving questions to.

3. What will you pair it with? – Do it with something you already do
   - I check my email right after breakfast every morning so I will work on it then.

- Optional: Break it down – Take a large task and break it into steps
  - I will download the pdf of the slide set, so I have all of the URLS to find the sites
  - I will set aside 15minutes a day to look at the different sites
  - At the end of the week, I will choose one to try out.

4. Reminders – *Computer, phone, calendar*
   - I will put a note on my calendar to remind me.
   - I'll also make a couple of reminders in my phone to remind in the morning to work on it

5. Problem-solving – *Pending*

→ ***FACILITATORS:*** *You may want to ask if participant anticipate any issues and plan for it.*

Dealing with the Blues

The following is the facilitator's summary of the module:

COPING WITH CAREGIVING 2.0 SUITE

Dealing with the Blues

Aim of Module

To introduce caregivers to a behavioral activation tool to manage mood.

Handouts – CWC2.0.6 HO

All handouts are available in electronic format in a PDF.
OAC Positive Activities Log (PAL)

Four Main Points

1. Depressive symptoms are common during caregiving. Taking the time to enjoy yourself will help you feel less stressed and a better caregiver.
2. Scheduling and then doing positive activities can help to manage mood.
3. 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.
4. 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.

Activities

Making a List

Action Plan

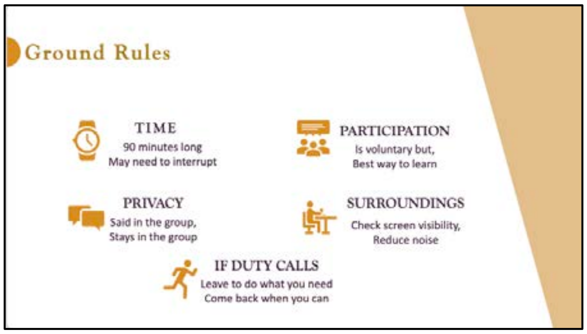
Choice of 1:
Positive Activity Log Positive Activities

→ ***FACILITATORS:** Forms are not required - pen and paper can be substituted.*

Slide 2 Ground Rules

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*
- → *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*



Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

Slide 3 Introductions

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

Considerations

→ *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*

→ *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*

→ *Not all care recipients have a diagnosis, or even if it is in the chart has the caregiver been informed.*

→ *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today’s Topics

Today’s Topics

Caregiving & Your Mood

Positive Activities

Going Forward

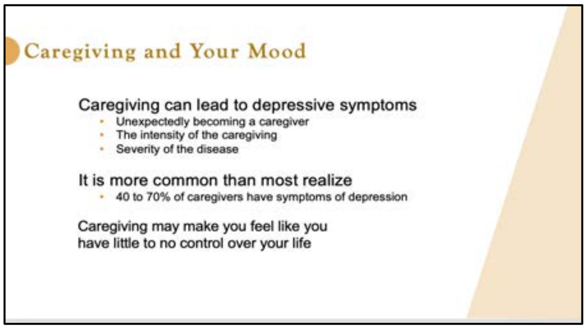
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

- Today’s topic is on managing your mood.
- We’ll start with how caregiving can influence mood
- Then we’ll introduce a tool you can use to help lift your spirits when you are feeling down
- Then follow up with how to practice this tool over the upcoming weeks to get the most benefits from it.

Slide 5 Caregiving & Your Mood



Caregiving and Your Mood

Caregiving can lead to depressive symptoms
- Unexpectedly becoming a caregiver
- The intensity of the caregiving
- Severity of the disease

It is more common than most realize
- 40 to 70% of caregivers have symptoms of depression

Caregiving may make you feel like you
have little to no control over your life

Considerations

→ *Having depressive symptoms versus being depressed are very different. If a CG is clinically depressed cg will need more than this program to address the need. A referral to professional help is needed.*

→ *If a CG mentions they are thinking of harming themself or another – follow emergency protocol.*

Material

STOP & ASK

Sometimes as a caregiver you may experience some uncomfortable moods. Has this happened to you? Do you end up feeling down, or anxious? Frustrated sometimes?

→ ***FACILITATORS:** Remember to normalize this experience.*

These feelings are a normal part of caregiving, and many caregivers find good ways to cope. But sometimes you may need a little something extra to boost your spirits, so today we will be focusing on those times when you are feeling down and offering a tool that has proven to be helpful to other caregivers.

There are many reasons why caregiving may lead to experiencing depressive symptoms and other uncomfortable moods.

- *Unexpectedly becoming a CG.* For many CGs, 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 can become all consuming.* Caring for another can mean long hours, high levels of stress, less sleep, and more family conflict. All of this can add up leading to feelings of being overwhelmed.
- *Severity of the person's illness*. The more severe the disorder, the more CGs reported depressive symptoms and other negative emotions.

In caregiving, experiencing depressive symptoms is more common than you may realize. Research shows that between 40 to 70% of CGs have some symptoms of depression. Many people who have these symptoms either fail to recognize them or may be too embarrassed to seek help.

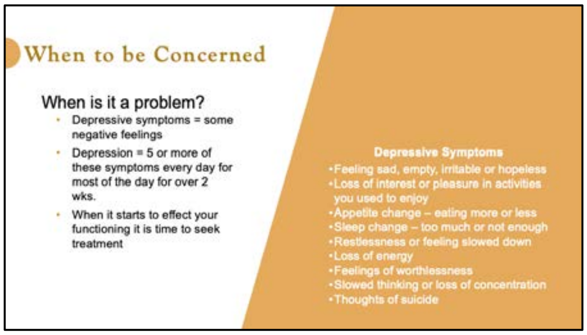
Slide 6 When to be Concerned

Considerations

→ *There are a variety of hotlines that are available for folks to use. The national suicide hotline is 988. It is available 24/7, including holidays. Translators are available for any language.*

→ *I always recommend that the facilitator calls the hotline before doing this module, so they can speak from a place of knowledge when they*

→ *decide whether a recommendation during the module is warranted.*



When to be Concerned

When is it a problem?

- Depressive symptoms = some negative feelings
- Depression = 5 or more of these symptoms every day for most of the day for over 2 wks.
- When it starts to effect your functioning it is time to seek treatment

Depressive Symptoms

- Feeling sad, empty, irritable or hopeless
- Loss of interest or pleasure in activities you used to enjoy
- Appetite change – eating more or 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

Material

So, what are these depressive symptoms?

- You may feel sad, empty, irritable, or hopeless
- You may find yourself having a loss of interest or just gaining no pleasure in activities you used to enjoy
- Your appetite can change – you may find yourself eating more or eating less
- Your sleep may change – too much or not enough
- You may feel restlessness or the opposite - feeling slowed down
- You may experience a loss of energy
- Feelings of worthlessness
- Slowed thinking or finding it very hard to concentrate
- Or you have thoughts of harming yourself

STOP & ASK

You may want to take a moment and look at the list on the screen. Do you recognize many of these? You don't have to share with the group, but it is important to keep in mind as we continue our discussion.

There is a difference between have some symptoms and have a depressive disorder. 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, psychotherapy, or a combination of these. If you are feeling depressed, please reach out for help.

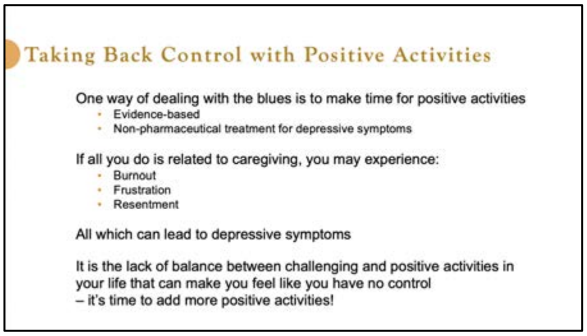
There's nothing wrong with you for seeking help – in fact, it's likely to make you a better CG in the long run. Untreated depression rarely gets better on its own, so getting help will be good for both you and the person you are caring for.

Slide 7 Taking Back Control with Positive Activities

Considerations

→ *We tend to see CGs when things are going bad – therefore we talk about the bad a lot as we normalize these experiences and help the CG to find solutions.*

→ *There are good things about caregiving. CGs report a sense of accomplishment. They learn / practice new skills which can help to keep their brain active and strong. They report that giving back to the person they are caring for can provide a sense of purpose to their lives. They report an increase in confidence in the ability to handle problems, sometime referred to as self-efficacy. So, it's not all bad!*



Taking Back Control with Positive Activities

One way of dealing with the blues is to make time for positive activities
- Evidence-based
- Non-pharmaceutical treatment for depressive symptoms

If all you do is related to caregiving, you may experience:
- Burnout
- Frustration
- Resentment

All which can lead to depressive symptoms

It is the lack of balance between challenging and positive activities in your life that can make you feel like you have no control
– it's time to add more positive activities!

Material

- 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.
- Although being a CG is time consuming, it is important that you make time to do activities that add something positive to your day. If all your activities are limited to your caregiving responsibilities, you may begin to feel burned out, frustrated, and even resentful. This can lead to depressive symptoms.
- You may say to yourself "What's the use?" or, "It seems like there's nothing I can do to make things better."
- When you notice that you are starting to have these types of feeling – it's time to add positive activities into your day.

Slide 8 What are Positive Activities?

What are Positive Activities?

They are activities which give you a sense of pleasure, meaning, or purpose

- They can be big or small
- Require some planning as they must be scheduled
- Be done alone or with others
- Can be brief lasting only a few moments or take all day

Examples:

- Reading
- Going for a walk
- Listening to music
- Helping a neighbor
- Doing a kind act
- Meeting a friend
- Being creative
- Taking a hike
- Gardening
- Watching children play
- Shopping
- Planning a trip
- Trying out a new recipe
- Watching a sunset
- Baking
- Listening to the bird sing
- Doing a puzzle
- Visiting a museum
- Volunteering
- Being needed
- Playing a game
- Yoga
- Smiling at a neighbor
- Being creative

Considerations

→ *You might get some push back that something so 'simple' can make a difference. It does and your confidence in presentation will go a long way in convincing the CGs to give it a try.*

→ *One of the most common depressive symptoms – apathy or lack of interest in doing things – is an issue with this intervention. If it comes up, acknowledge it. "I have no energy" or "I can't think*

→ *of anything to do" are both identifiers to this. For these people –* ***just do it*** *becomes a good mantra. Plan it, schedule it, do it – whether you feel like it or not until you start to feel better.*

→ *Keep the activities simple and problem-solve if issues arise. If it is a walk around the block – walk them through what they need to do. Sneakers by the door – makes them easier to find but also, it's a reminder to go and walk. Walking with a buddy can help. So can setting an alarm.*

Material

Positive Activities are activities which give you a sense of pleasure, meaning, or purpose.

They can be big or small

- Example Going to see a play with friends or having a cup of coffee in the morning to start your day

Scheduling is important – so there is some planning involved.

- If the object here is to 'take back some control of your day' you can't just pick stuff out of the day that happened. To count you must schedule it, then do it.

Positive Activities can be done alone or with others

- Positive activities don't require others to be successful, although having others along can enhance some activities. However, including others can also complicate things. Will your friend show up? Are they as excited about doing this as you are? Does having them along mean you are more likely to do the activity? As you can see – there are pros and cons to having others involved.

Can be brief lasting only a few moments or take all day

- The power is in the scheduling and doing – the length of the event is not as important as whether you actually do it
- To start, we are going to encourage you to make the activities small and easy to do. The larger the plan, the more places the plan can fail. So, in the beginning – keep it simple and easy. As you gain experience and your mood is better, adding more complicated plans can help to keep better mood as you anticipate the activity.

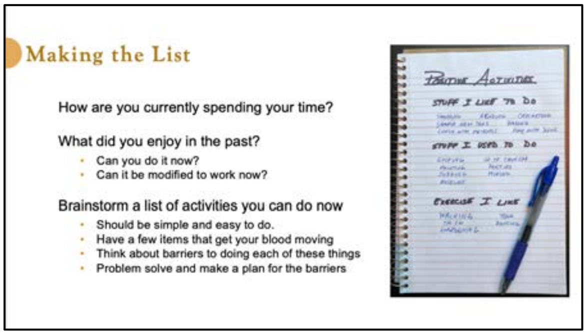
- Some examples of Positive Activities might be reading, going for a walk, listening to music, or helping out at your place of worship. More examples that caregivers report helpful are on the screen.

Slide 9 Making the List

Considerations

→ *You will walk them through this step by step. Make sure they have pen & paper available before you begin.*

→ *You can use return to slide 31 in between to spark their memory*



Making the List

How are you currently spending your time?

What did you enjoy in the past?

- Can you do it now?
- Can it be modified to work now?

Brainstorm a list of activities you can do now

- Should be simple and easy to do.
- Have a few items that get your blood moving
- Think about barriers to doing each of these things
- Problem solve and make a plan for the barriers

Material

Activity: Making a List

ACTIVITY-Directions

→ ***FACILITATORS:*** *Encourage the participants to pull out a pen and a piece a paper to write on as you will be walking them through the process of brainstorming a master list of 15-20 activities that they think will provide a sense of pleasure, meaning or purpose. Encourage them to not use their caregiving tasks for this exercise, even though they might fit the criteria. After you give them the instructions for the step they are on, flip back to S31 so they can use the list to spark thoughts on what might work for them. They give them at least 2 – 5 mins to think of 5 to 7 positive activities for each step. Note: the exercise step will follow on the next slide (S33).*

ACTIVITY-Do it

We are going to make our master list of Positive Activities now. This is the list you will draw your Positive Activities from later when it is time to schedule them. Please make sure you have a paper and pen handy. (wait a moment for the CGs to return) Ok let's get started.

Step 1 Write down your current Positive Activities

What are you doing right now that you enjoy? What do you find meaning or purpose from? **Example** This can be anything from a morning coffee, evening walk, reading, etc.

Try to keep most of your activities simple or small. Things you can do with little planning, or things that won't take a long time to do. Try to think of things that you don't need a lot of preparation for. The easier it is for you to do right now the more likely it is that you will actually do them – especially if you are feeling down.

→ ***FACILITATORS:*** *flip back to S8 and give the CGs 2-5 minutes to write down some current activities.*

Step 2 What did you enjoy in the past?

When you are thinking about this, ask yourself: Can you do it now? Why did you stop do it?

Or can it be modified to work now?
Example A CG I worked with used to like to hike and take pictures of the wildlife, but he couldn't be gone all day and taking Dad with was impractical.
Modification He put up a bird feeder and now takes pictures of the local wildlife in his backyard. Bonus - now the backyard is full of birds and his dad likes to watch the birds too.

How to do this
1) Identify what made it enjoyable
2) Find a way to keep the enjoyable part by:
    what is stopping you?
    problem solve and make a plan

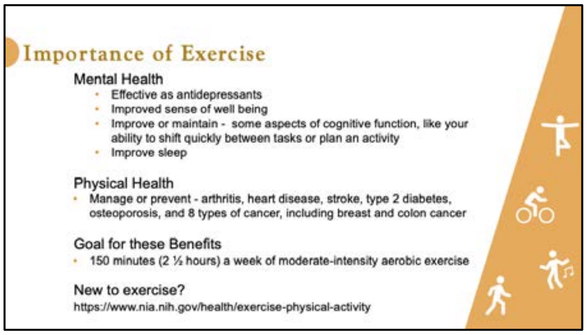
→ ***FACILITATORS:*** *flip back to S8 and give the CGs 2-5 minutes to write down some current activities.*

STOP & ASK

Do you have any past activities that you think might work?
How would you modify them?
or
Briefly share some of their favorite activities off their list.

Your aim in this exercise is to brainstorm a list of 15-20 activities you can do now
- Preferably these positive activities should be simple and easy to do.
- If you haven't quite got 15-20 activities on your list, don't worry we have one more category of activities for you to think about.

Slide 10 Importance of Staying Active



Importance of Exercise

Mental Health
- Effective as antidepressants
- Improved sense of well being
- Improve or maintain - some aspects of cognitive function, like your ability to shift quickly between tasks or plan an activity
- Improve sleep

Physical Health
- Manage or prevent - arthritis, heart disease, stroke, type 2 diabetes, osteoporosis, and 8 types of cancer, including breast and colon cancer

Goal for these Benefits
- 150 minutes (2 ½ hours) a week of moderate-intensity aerobic exercise

New to exercise?
https://www.nia.nih.gov/health/exercise-physical-activity

Considerations

→ *Addition of exercise for someone who is not active needs a clear recommendation that they talk to their doctor before exercising so they can do so safely.*
→ *There are more complicated ways to measure moderate intensity aerobic exercise using heart rate or activity trackers. You can find those at:*
→ *https://www.mayoclinic.org/healthy-lifestyle/fitness/in-depth/exercise-intensity/art-20046887*
→ *National Institute on Aging has a wonderful website for those over the age of 50 interested in adding exercise to the life. www.nia.nih.gov/exrcise-physical-activity*

Material

We are going to encourage that you add some way of staying physically active to your positive activity list. Staying physically active has many benefits for a healthy life.
It effects your:

Mental Health

- Research has shown it can be as effective as antidepressants for treatment of depression and maintenance of a healthy mood
- People who regularly exercise report an improved sense of well being
- It has been shown to improve or maintain some aspects of cognitive function, like your ability to shift quickly between tasks or plan an activity
- And not unexpectedly, exercise helps to improve sleep

Physical Health

- It can manage or prevent - arthritis, heart disease, stroke, type 2 diabetes, osteoporosis, and 8 types of cancer, including breast and colon cancer

So, what marathon do you need to run to get these types of benefits?

It's not really that bad. The target for these benefits is 150 minutes (2 ½ hours) a week of moderate-intensity aerobic exercise.

- Which is about 30 minutes per day for 5 out of 7 days
- 30 minutes can be broken up – it doesn't have to all occur at once
- ANY movement is better than none at all

Moderate-intensity aerobic exercise means any activity that gets your heart pumping. A simple way to tell what moderate intensity means for you is that you can still talk but you can't sing.

New to exercise? The National Institutes on Aging has a wonderful website
- URL is on screen

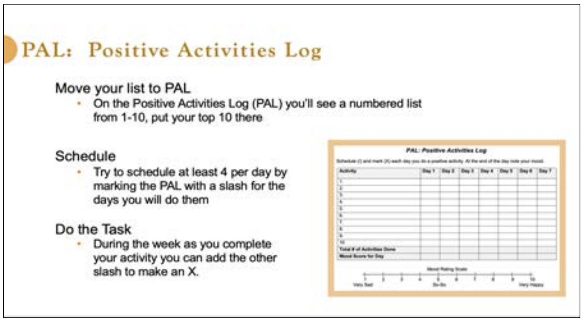
Bottom line for your health - schedule in some activities that you enjoy get your blood moving.

Slide 11 Positive Activities Log

Considerations

→ *The easiest way to keep track using the form is to schedule with a / and mark complete with a X.*

→ *If they are using a calendar schedule with a title and check mark next to it or strike through when it is complete should be sufficient.*



PAL: Positive Activities Log

Move your list to PAL
- On the Positive Activities Log (PAL) you'll see a numbered list from 1-10, put your top 10 there

Schedule
- Try to schedule at least 4 per day by marking the PAL with a slash for the days you will do them

Do the Task
- During the week as you complete your activity you can add the other slash to make an X.

Material

Activity: Scheduling the Positive Activities

ACTIVITY-Directions

→ ***FACILITATORS:*** *This is the one time we really encourage people to use the form. But if they don't have it? They can use a calendar or a planner to schedule in the activity. They should either have the form or a calendar handy along with a pen.*

→ ***FACILITATORS:*** *Before you start, review the form with the participants.*

- To the left is a place to put the Positive Activities you will be scheduling.
- Across the top is a weekly schedule (have them write tomorrow's date or name under Day 1).
- At the bottom of the grid is two lines. One is for totaling up the number of activities completed that you scheduled and the other is a place to record your mood at the end of the day. The rating scale from 1 (very sad) to 10 (very happy) is at the bottom of the form.

ACTIVITY-Do it

Step 1: Using the Positive Activities List

- Pick 10 things from your Activity List that you are likely to do next week.
    - If you are working with a calendar – mark these 10 activities.

→ ***FACILITATORS:*** *Give them 3 minutes to select the 10 activities from the list they just made, remind them to keep these first activities simple and easy to do.*

Step 2: Scheduling your List of Positive Activities

Now that you have a list of your favorite 10, it is time to put it into action.

- On the PAL you'll see a numbered list from 1-10. Move your list to PAL. Order doesn't matter.
- To schedule, mark the PAL with a slash for the days you will do them over the next week.
    - Repeats are ok – coffee every morning, evening walk most nights
    - On a calendar you are going to schedule by writing it in.
- The **goal** is 4 Positive Activities a day.

→ ***FACILITATORS:*** *Give them 10 minutes to transfer and schedule the activities.*

During the week, it's good to pick a time in the evening or early the next morning where you can sit down and fill in the form.

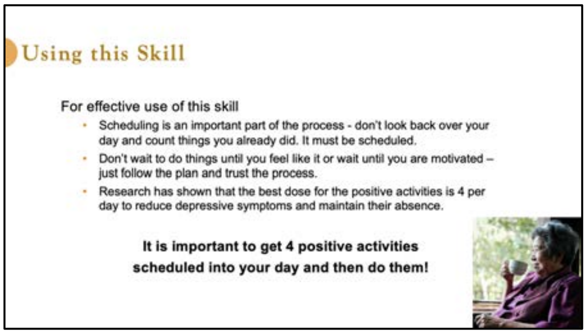
Step 3: Every night mark which activities you completed

- During the week as you complete your activity you can add the other slash to make an X.
    - On the calendar you can strike it through or check mark it.
- At the end of the day total up the number of activities you completed and enter that on its line near of the bottom of the grid. Then rate your mood for the day, from 1-10 and enter that on its line.

Slide 12 Using this Skill

Consideration

→ *Four is the number of positive activities that is the goal to work towards. Some of the CGs you work with will be able to integrate four with no problem but for those that are overwhelmed or who are experiencing apathy they may struggle adding one. It is important to meet the CG where they are.*



Using this Skill

For effective use of this skill

- Scheduling is an important part of the process - don't look back over your day and count things you already did. It must 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.
- Research has shown that the best dose for the positive activities is 4 per day to reduce depressive symptoms and maintain their absence.

It is important to get 4 positive activities scheduled into your day and then do them!

Material

When people are feeling down, 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 must 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 it's time to problem solve why you are having trouble.
- Maybe finding an exercise buddy to help encourage you or change the day/time might be easier options for 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.

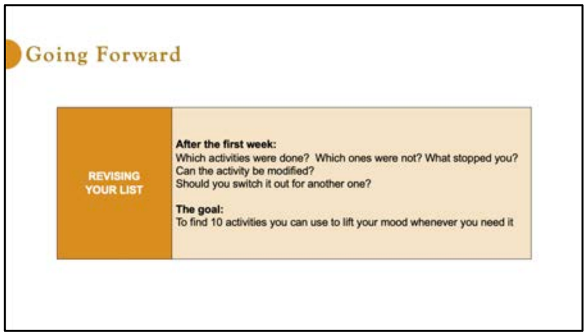
If you are not feeling down right now, this is a good thing to prepare for since most of us have down days every now and then. Know which positive activities work for you can prove very helpful in the future.

If it's difficult to do 4? Are the activities you're choosing require too much effort/planning? – Try to find some smaller ones. Start with a few and grow into 4 a day.

STOP & ASK

Is this something you are willing to try? Does it sound doable?

Slide 13 Revising Your List



Going Forward

REVISING YOUR LIST

After the first week:
Which activities were done? Which ones were not? What stopped you?
Can the activity be modified?
Should you switch it out for another one?

The goal:
To find 10 activities you can use to lift your mood whenever you need it

Consideration

→ *Encourage participants who are not currently feeling down to think of the future. It is good to do the work now and be prepared with a list of 10 solid pick me up type of activities.*

Material

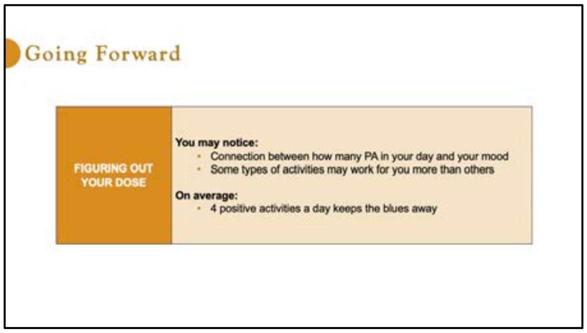
After you have completed a week of scheduled activities it is time to review your list.

- 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. Most people will work on this list for a few weeks.

Slide 14 Figuring Out Your Dose



Going Forward

FIGURING OUT YOUR DOSE

You may notice:
- Connection between how many PA in your day and your mood
- Some types of activities may work for you more than others

On average:
- 4 positive activities a day keeps the blues away

Consideration

→ *Some will see the connection between what activities they are doing and how it effects their mood. Some will not. If someone is very interested and still struggling, encourage them to reach out to a mental health professional proficient in behavioral activation.*

Material

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.

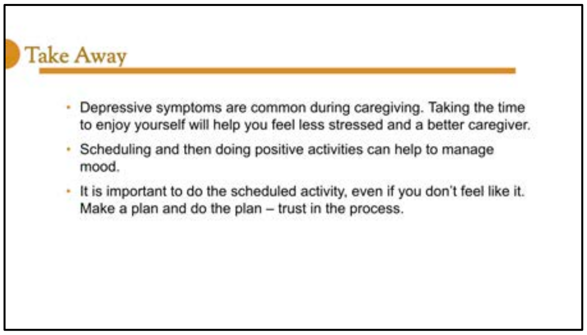
It is important to note those activities when they happen since they may provide an extra boost when you need it most.

  - An example may be when a friend visits after you’ve been alone for a long time. Your mood may respond more positively.

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.

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.

Slide 15 Take Away



Take Away

- Depressive symptoms are common during caregiving. Taking the time to enjoy yourself will help you feel less stressed and a better caregiver.
- Scheduling and then doing positive activities can help to manage 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.

Considerations

→ *This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the ‘take away’ was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*

STOP & ASK

Thinking back over today’s session,
what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today’s session.*

To summarize, the Take Aways we hope you will take with you today are that:
- Depressive symptoms are common during caregiving.
- Scheduling and then doing positive activities can help to manage 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 CG.

Slide 16 Making This Work for You

Considerations

→ *The Action Plan is the most important part.*
→ *Encourage the CGs to pull out their pen and paper.*
→ *Use the boxes along the bottom to assist in the creation of the action plan.*

Making This Work for You

Positive Activities

- Create a list of positive activities
- Schedule 4 Positive Activities each day
- Do the activities as scheduled
- At the end of each day note your mood rating for that day
- Each week, revise your list until you have a solid 10 you can depend on
- Add activities to your schedule whenever you are feeling down or notice you are getting very irritable

Set a Deadline	Why this one?	What will you pair it with?	Optional Break it Down	Reminders	Run into Problems Getting it Done?
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take large tasks & break it into steps.	Phone Alarms Post-Its Tape to Mirror	ID the issue Brainstorm solutions Try it out

Material

Activity: Action Plan

ACTIVITY-Directions

→ ***FACILITATOR:*** *Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you must do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
  - No choosing on this one – everyone does Positive Activities.

1. Set a deadline – *Be realistic*
   - I will start adding Positive Activities to my schedule tomorrow and continue adding them until I have 10 solid activities I know work for me.
2. Why chose this one? - The more personal the better
   - I've been feeling down and irritable lately – I am snapping at everyone.
3. What will you pair it with? – Do it with something you already do
   - I will check the schedule every morning with my morning coffee

- Optional: Break it down – Take a large task and break it into steps

→ ***FACILITATORS:*** *This will greatly depend on the activities chosen. Offer to walk people through the breakdown process.*

4. Reminders – *Computer, phone, calendar*
   - I'll put a Post It note on my bathroom mirror to remind myself why I am doing this
   - I'll set my form right next to my coffee maker, so I see it when I get my coffee.
5. Problem-solving – *Pending*

→ ***FACILITATORS:*** *You may want to ask if participant anticipate any issues and plan for it.*

Filling the Well

The following is the facilitator's summary of the module:

COPING WITH CAREGIVING 2.0 SUITE

Filling the Well

Aim of Module

To address the issue of self-care and provide caregivers with insight into their own level of self-care

Handouts – CWC2.0.7 HO

All handouts are available in electronic format in a PDF.
NIH: A Good Night's Sleep
OAC: Self Care Checklist
NIA: Exercise & Physical Activity: Your Everyday Guide

Four Main Points

1. Caregivers are at an increased risk for certain health concerns and burnout.
2. Self-Care is a deliberate action you take that improves your physical, mental, or emotional well-being.
3. Understanding what keeps you from doing self-care can help you to increase the amount of self-care you do.
4. Prioritizing addressing health concerns, finding support, practicing self-compassion, and adding laughter is a good start on adding self-care to my day.

Activities

Self-Care Check List

Action Plan

Choice of 2:
    Identify Areas of Self-Care
    Practice Top 3

→ ***FACILITATORS:*** *Forms are not required - pen and paper can be substituted.*

Slide 2 Ground Rules

Considerations

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*
- → *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*

Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

Slide 3 Introductions

Considerations

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

- → *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*
- → *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*
- → *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*
- → *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today’s Topics

Today’s Topics

Caregiver Burnout

Self-Care

Tips & Strategies

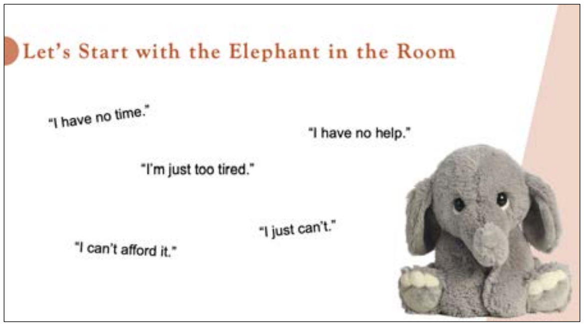
Considerations

- → *This slide should be a quick introduction of what this session will cover.*

Material

Today’s topic is self-care. We’ll start by exploring burnout, and why this can be an issue. Then we’ll talk about self-care with a focus on different tips and strategies you can use to help you get some self-care into your life.

Slide 5 Elephant in the Room



Let’s Start with the Elephant in the Room

“I have no time.”

“I have no help.”

“I’m just too tired.”

“I just can’t.”

“I can’t afford it.”

Considerations

- → *Almost without fail when the topic of self-care comes up there is at least one CG who will say one of these phrases. And it’s all true – time, money, energy - they are all at a premium. By stating this upfront, we are letting CGs know that no matter how important this is we realize what we are asking them to do is very hard and even if it may*
- → *provide relief, it can seem huge trying to add themselves onto the long to-do list. Our job it to make sure they know that by doing so it makes the rest easier to do.*

Material

We know these are real concerns – the job of caring for another person day in and day out can be overwhelming. It can seem impossible to fit one more thing into your schedule. But it’s important to find small, doable ways to keep yourself healthy. Ask yourself, what will happen to the person you are caring for, if you burnout from all the stress of caregiving? You are here today because either you noted you needed help, or someone you know recommended that you attend. Try to keep an open mind to the suggestions offered here and focus on the small doable things you can do. Sometimes it doesn’t matter how much you do but just that you are doing something for you.

Slide 6 Caregiving & Well-being

Considerations

→ *Not every CG will find themselves with every issue. And if you get a very vocal CG who is very early in the disease progression or someone who is very negative and appears on the edge of burnout, they may shut down everyone else. Redirecting the conversation by calling on someone else to contribute by name can be helpful.*

Caregiving &Well-being

Love
Commitment
Giving Back
Very Rewarding

Worry
Exhaustion
Continuous Care
Inadequate Resources

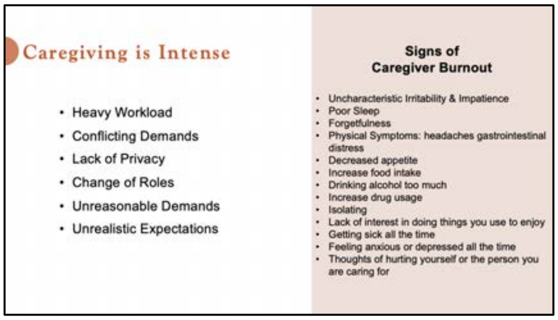
Material

Caregiving is a balancing act between the ups and downs. On one side you have the positives. Caregiving is an opportunity for you to give back to a someone who cares for you, a spouse, a parent, or a dear friend whom you love. Many find it very rewarding. But on the other side the need for continuous care with, at times, inadequate resources can be a source of constant worry and stress. Because of these stressors and other like them CG are at an increased risk for burnout.

Slide 7 Caregiving is Intense

Material

Around 1 in 4 caregivers experience burnout. Why does this happen?



Caregiving is Intense

- Heavy Workload
- Conflicting Demands
- Lack of Privacy
- Change of Roles
- Unreasonable Demands
- Unrealistic Expectations

Signs of Caregiver Burnout

- Uncharacteristic Irritability & Impatience
- Poor Sleep
- Forgetfulness
- Physical Symptoms: headaches gastrointestinal distress
- Decreased appetite
- Increase food intake
- Drinking alcohol too much
- Increase drug usage
- Isolating
- Lack of interest in doing things you use to enjoy
- Getting sick all the time
- Feeling anxious or depressed all the time
- Thoughts of hurting yourself or the person you are caring for

Heavy workload

- Most chronic illnesses are progressive meaning they get worse over time, increasing in intensity as the disease progresses.

Conflicting demands

- There are not enough hours in the day to get everything done for everybody. Balancing the needs of the person you are caring for, coworkers and employers, family members, and your own needs.

Lack of privacy

- On demand 24/7 means there is little time to be alone.

Change of roles

- CGs move from child or spouse to CG, changing how to relate to the person, and grieving for the lost relationship.

Unreasonable demands

- Can be placed upon a CG by other family members or the person being cared for.

Unrealistic expectations

- About the effect caregiving efforts will have on loved ones with progressive diseases such as Parkinson's or Alzheimer’s

STOP & ASK

In a moment we will examine the signs of caregiver burnout. As we review these signs you may recognize a few happening in your own lives. You are not required to share your past or current experiences with burnout. We realize this may be difficult. However, if you are comfortable and wish to share your experiences please do so.

→ *FACILITATORS: It is important to normalize these experiences. Almost all caregivers experience some of these symptoms during their caregiving journey.*

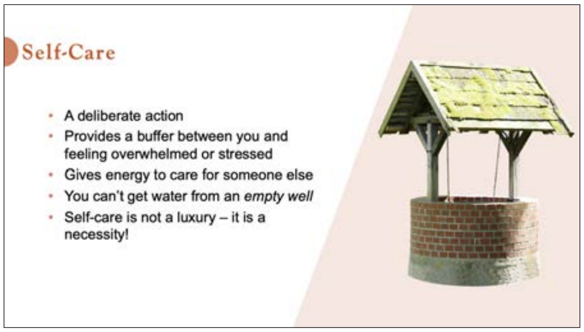
Signs of CG burnout

- Uncharacteristic Irritability & Impatience
- Forgetfulness
- Decreased appetite or Increase food intake
- No interest in doing things you use to enjoy
- Getting sick all the time
- Poor Sleep
- Headaches / gastrointestinal distress
- Isolating
- Feeling anxious/depressed all the time
- Thoughts of hurting yourself or the person you are caring for
- Drinking alcohol too much & Increase drug usage – this includes OTC or prescription drugs

But CG burnout is not inevitable. The proper use of self-care and respite can go a long way to addressing these symptoms.

Slide 8 Self-Care

Material



Self-Care

- A deliberate action
- Provides a buffer between you and feeling overwhelmed or stressed
- Gives energy to care for someone else
- You can't get water from an *empty well*
- Self-care is not a luxury – it is a necessity!

Self-Care is defined as a deliberate action you take that improves your physical, mental, or emotional well-being. This does not mean that you are putting you needs over anyone else's – it simply means you are relaxing and recovering to perform at the best of your ability when you are needed.

Self-Care can lessen the effects of things you normally would find overwhelming or stressing, like the signs of burnout we talked about on the last slide. Certain acts of self-care provide you more energy than they take to do. Exercise is a good example of this. As you know, your energy is not infinite, once it's gone it takes time to refill. Proper nutrition, a good night sleep, exercising your body or mind all provide you with a boost to your energy levels, in essence filling the well with more energy than it takes to do these things.

Much like the airline attendants who encourage you to put your own mask on first, taking care of you first means you'll have the energy to take care of everyone else you are responsible for. Self-care comes in many different forms so let's look at that next.

Slide 9 Four Areas of Self-Care

Considerations

→ *By splitting self-care into four areas, we offer a more approachable way of thinking of self-care.*

Material

Four Areas of Self- Care

Physical	Mental
care for your body	exercising your mind
Schedule a doctor appt Take a daily walk Try chair yoga Eat more veggies	Listen to a pod cast Do a puzzle or play a game Use your non-dominant hand Draw a map of your neighborhood
Spiritual	**Social**
meaningful action	reaching out to others
Say a prayer Spend time in nature Help someone else Mediation	Call a friend Unfriend a negative person on Facebook Join a support group Greet a neighbor on your walk

Many CGs find there are several areas of self-care that probably have been neglected to some extent, as you progressed in the caregiving journey – physical, mental, spiritual, and social.

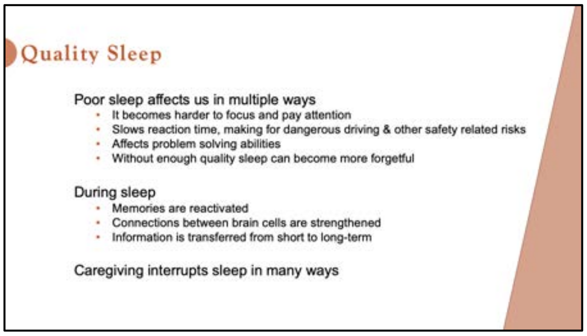
Physical: Care for your body. As a CG you may find yourself neglecting your physical well-being. There is a tendency to push it off, thinking "I will do it later." However, caregiving can take years and neglecting your health over a long stretch of time is not beneficial for you and may in fact impact your ability to provide optimal care. Ask yourself, when was my last physical or dental check-up? How am I sleeping? Am I eating well or depending on take out and fast food? Am I exercising?

Mental: Exercising your mind. Your brain is a muscle that needs to be exercised like any other muscle. If you are feeling fuzzy, finding it hard to think and you have addressed the physical (sleep, eating and exercising), then it’s time to stretch your mind. Whether you are learning something new or challenging yourself with a puzzle, your brain develops new pathways allowing it to adapt and change.

Spiritual: Doing what is meaningful for you. Spirituality is a broad concept with room for many perspectives. In general, it includes a sense of connection to something bigger than ourselves and typically involves a search for meaning in life. Spirituality is a personal practice that is meaningful and kindles a sense of sacredness and belonging. Spiritual self-care is any practice that gives you that connection and reduces feelings of isolation and loneliness.

Social: Reach out to others. Social self-care is all about nurturing relationships. Whether is spending quality time with friends, developing new friends, or meeting new people, these people should uplift and support you. Social self-care also means letting go of those individuals who flood your life with self-doubt and negativity when you can. In Facebook, look for the 3 dots at the upper right corner, click on it and select hide post (see fewer post like this), Snooze the author for 30 days, or unfollow them (you’ll stop seeing their posts but still stay friends.

Slide 10 Quality Sleep



Quality Sleep

Poor sleep affects us in multiple ways
- It becomes harder to focus and pay attention
- Slows reaction time, making for dangerous driving & other safety related risks
- Affects problem solving abilities
- Without enough quality sleep can become more forgetful

During sleep
- Memories are reactivated
- Connections between brain cells are strengthened
- Information is transferred from short to long-term

Caregiving interrupts sleep in many ways

Considerations

→ *76% of CGs reported poor sleep quality, and the proportion is considerably higher for female CGs compared to male CGs.*

Material

For many of us we have been burning the candle at both ends for a long time. And as a result, our sleep quality has slowly declined over time.

However poor sleep affects us in multiple ways
- It becomes harder to focus and pay attention
- Slows reaction time, making for dangerous driving & other safety related risks
- Affects problem solving abilities
- Without enough quality sleep we can become more forgetful
- Affects mood, leading to irritability, depression, and increase anxiety
- Chronic sleep deprivation increases the risk of high blood pressure, heart disease, obesity, and diabetes

Many people think that sleep is a waste of precious time they could be using to do important things. However, sleep is important and serves a purpose. During sleep

- Memories are reactivated and consolidated, making it easier to recall them
- Connections between brain cells are strengthened
- Information is transferred from short to long-term memory

Caregiving also interrupts sleep in many ways

- Stress, worry, and anxiety can delay falling asleep or may wake you early
- Person you are caring for may wake in the night and need help
- Depressive symptoms can include sleep disturbances

STOP & ASK

How much sleep do you think you need?
How much are you actually getting?

Slide 11 How Much Sleep Do You Need?

Considerations

→ *This slide directly addresses the myth that we don't need 7-8 hr. sleep a night for optimal results.*

→ *Get through this slide quickly*

How Much Sleep do You Need?

SLEEPFOUNDATION.ORG | SLEEP.ORG

Material

How much sleep do you need?

- A persistent myth exists that as we age, we need less sleep. This is not true.
- By age 18 the recommended amount of sleep is 7-9 hours.
- This numbers only slightly decrease as we age. For those over the age of 65, the recommended sleep is for 7-8 hours.

Sleep needs are individual, and we've all heard how people can not only survive but thrive on less than 5 hours a night. It is important to note this is **less than 5%** of the general population and that most people are walking around sleep deprived.

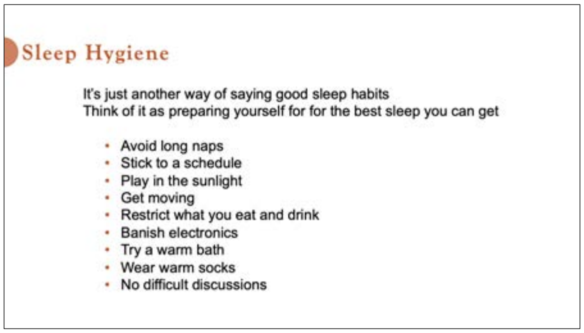
So how do you know you are sleep deprived?

You may be experiencing the following symptoms

- Feeling drowsy during the day
- Routinely falling asleep within only 5 minutes of lying down in bed for the night
- Experiencing "microsleeps," which are very brief episodes of sleep while being awake

So how do you increase the amount of sleep you are getting?

Slide 12 Sleep Hygiene



Sleep Hygiene

It's just another way of saying good sleep habits
Think of it as preparing yourself for for the best sleep you can get

- Avoid long naps
- Stick to a schedule
- Play in the sunlight
- Get moving
- Restrict what you eat and drink
- Banish electronics
- Try a warm bath
- Wear warm socks
- No difficult discussions

Considerations

→ *Sleep hygiene is the first step to addressing sleep problem but if sleep hygiene is insufficient, a recommendation to a physician or a psychologist who specializes in sleep.*

Material

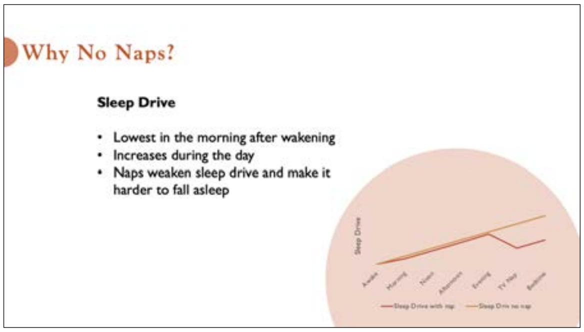
Sleep hygiene describes the things we do that can make it easier to get the number of hours of sleep you need as well as improve the quality of that sleep. If you are already getting a solid 8 hours of sleep, you wake up feeling refreshed and rested, then your sleep hygiene is sufficient for your needs. But if you are struggling with getting enough good quality sleep so you wake up the next morning feeling rested than the first step is looking at your sleep hygiene and seeing if any of these items can improve your sleep.

Avoid long naps: Limit napping to 30 min in the early afternoon.
Stick to a schedule: Get up at the same time every day, seven days a week.
Get some sunlight: Expose yourself to sunlight during the day, which helps set your body clock.
Get moving: Regular physical activity promotes good sleep.
Restrict what you eat & drink: Avoid caffeine after lunch; don't eat/drink for 3 hrs before bed.
Banish electronics: Bedroom is for sleeping or sex, not watching TV, reading, playing games.
Try a warm bath, warm socks
- A regular bath may be beneficial two to three hours before bedtime.
- Wearing socks to keep feet warm can also help you fall asleep more easily.

No difficult discussions: Keep it peaceful before bedtime. No arguing/discussing touchy topics.

If you try these for 3-4 weeks and see no improvement, then it is good to reach out to a mental health provider who specializes in sleep to help you.

Slide 13 Why No Naps?



Why No Naps?

Sleep Drive

- Lowest in the morning after wakening
- Increases during the day
- Naps weaken sleep drive and make it harder to fall asleep

Considerations

→ *This is important for the care recipient as well as the CG. If they sleep all day, they will be up all night.*

Material

Sleep Drive tracks how much you need to sleep over a 24-hour period.

- Your sleep drive is lowest in the morning when you wake up, and gradually increases as the day progresses.
- Napping reduces sleep drive by recharging the energy reserve.
- Longer naps reduce the sleep drive more than shorter ones.
- Napping close to bedtime (even briefly dozing off while watching TV) weakens your sleep drive just when it is most needed.
- Basically, the longer the time that has elapsed since you last slept, the stronger the sleep drive becomes, and the easier it will be to fall asleep.
- In some ways the sleep drive is similar to hunger and napping to snacking. Naps spoil your sleep drive like appetite may be ruined by snacking close to dinner

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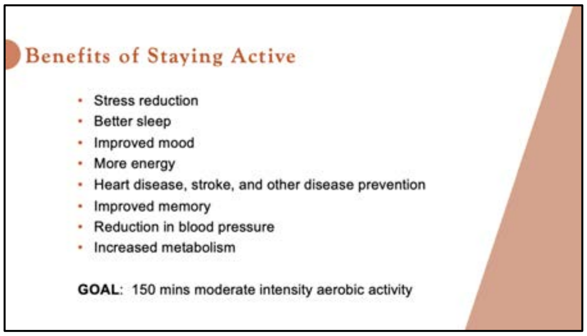
Slide 14 Benefits of Staying Active



Benefits of Staying Active

- Stress reduction
- Better sleep
- Improved mood
- More energy
- Heart disease, stroke, and other disease prevention
- Improved memory
- Reduction in blood pressure
- Increased metabolism

GOAL: 150 mins moderate intensity aerobic activity

Considerations

→ *Exercise is mentioned multiple places throughout the modules as it is beneficial for multiple issues.*

-

Material

One way to take care of yourself – physically, mentally, and emotionally – is to exercise regularly. Even though it may sometimes be hard to find the time, just 30 minutes of physical activity a day can help you maintain a healthy weight, reduce stress, and improve your overall health and well-being.

Exercising regularly has many positive health benefits, including:

- Stress reduction	- Better sleep
- Improved mood	- Better weight management
- Increased energy levels	- Improved memory
- Reduction in blood pressure	- Increased metabolism
- Heart disease, stroke, and other disease prevention	

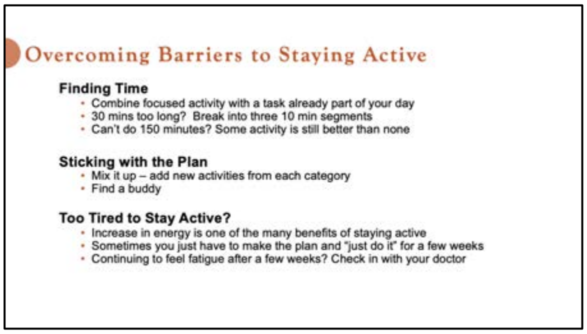
The goal to get these benefits is 150 mins of moderate intensity aerobic activity over the course of a week, so 30 mins daily for 5 of the 7 days will do it!

Slide 15 Overcoming Barriers

Considerations

→ *Can't have a conversation about adding something to their schedule without discussing the barriers.*

→ *These are recommendations, if you have extra time in the module, you can ask the CGs themselves to offer workarounds.*



Overcoming Barriers to Staying Active

Finding Time

- Combine focused activity with a task already part of your day
- 30 mins too long? Break into three 10 min segments
- Can't do 150 minutes? Some activity is still better than none

Sticking with the Plan

- Mix it up – add new activities from each category
- Find a buddy

Too Tired to Stay Active?

- Increase in energy is one of the many benefits of staying active
- Sometimes you just have to make the plan and "just do it" for a few weeks
- Continuing to feel fatigue after a few weeks? Check in with your doctor

Material

Finding Time

- Combine exercise with a task already part of your day
- 30 mins too long? Break into three 10 min segments
- Can't do 150 minutes? Some activity is still better than none

Sticking with the Plan

- Mix it up – add new exercises from each category
- Find a buddy

Too Tired to Exercise

- An increase in energy is one of the many benefits of exercise
- Sometimes you just must make the plan and "just do it" for a few weeks
- Continuing to feel fatigue after a few weeks? Check in with your doctor

Make it a priority

- This is one of the best things you can do for your overall health – physical, psychological, & cognitive health

Make it easy

- Do it first thing in the morning before you get busy, join a gym close by, walk the stairs instead of the escalator etc.

Make it fun!

- Do a Zumba class, do something you enjoy! Laugh
- Mark it on your calendar

STOP & ASK

What are some of the things that have helped you to stay active in your day-to-day life?

→ *FACILITATORS: Don't forget to mention to check in with their doctor if they haven't exercised in a while. Even if they have a disability, most doctors can offer modifications or work arounds so that they can still get the benefits from staying active.*

Slide 16 Self-Care Check List

Self-Care Check List

When you are trying to start a new habit it is good to write down your intentions and post them where you can see them every day

- ✓ Write down what you want to do
- ✓ Then check it off when the task is done

Self-Care Check List: Building Your Reserve

Considerations

→ *The form isn't required, though writing it down is recommended.*

Material

Activity: Self-Care Check List

ACTIVITY-Directions

There is a form in your packet called the Self-Care Check List. This can be used in two different ways depending on where you feel comfortable. Up on the slide you'll see one way. If you want to add different types of self-care into your day, then making a list and checking off when you've completed the task is a good way to go about it. But if you are not sure, then more exploration may be needed. This form can also be used to discover what you are currently doing, and which types of self-care you tend to use.

ACTIVITY-Do it

Remember, if you feel like you've got self-care covered and overall, you are not feeling overwhelmed – then just continue with what you are doing. But if you noticed that lately things seem to be weighing more on you and you noted that you are experienced more signs of burnout – then it is time to increase your self-care.

How to increase the amount of self-care you are doing.
Step 1: Let's take a moment and identify what you currently do for self-care. Think about the four different areas – what do you do to take care of your physical body? Exercise your mind? Embrace a connection to the spiritual? Stay connected socially? Go ahead and write those in.

Step 2: What area needs more work? Is there one (or more) area you've neglected in the past year or two? What self-care items would work for you to fill that area?

When you are trying to add a new habit, it is good to write down your intentions and post them where you can see them every day.

- Write down what you want to do
- Then check it off when the task is done

One aspect of self-care we haven't discussed is respite. Respite is a short-term break from caregiving. It can be for a few hours one afternoon, or for several days. Care can be provided from another family member, a friend, or something more structured like an adult care center or a brief stay at a residential facility. The Caregiving TLC website has a respite locator for North Carolina available. (We'll show you how to access it at the end of this session.)

Step 3: We realize that most people can't work on all four areas at once, but we encourage you to select at least one area to focus on and work on in the weeks and months ahead. Writing it down can help you later. If you notice you are starting to experience more and more of the signs of burnout you can pull out your list and add more self-care into your life.

ACTIVITY-Process

STOP & ASK

What self-care are you doing now?
What are you thinking of adding to your day-to-day life that will help?

Slide 17 What Stops You from Self-Care

Considerations

→ *Adapted from FCA Identifying Personal Barriers https://www.CG.org/taking-care-you-self-care-family-CGs*

What Stops You From Self-Care?

Identify attitude or beliefs

Negative Self-Talk

Material

Activity: What Stops You?

ACTIVITY-Directions

→ *FACILITATORS: Provide the introduction & ask the questions to lead to a discussion.*

ACTIVITY-Do it

Many times, attitudes and beliefs we hold can stand in the way of caring for yourself. Whether or not taking care of yourself is a lifelong pattern, or you find that taking care of others an easier option here are two things you can do to help you understand what is stopping you.

IDENTIFY:
The first is identifying what attitudes and beliefs you have about self-care

- Do you think you are being selfish if you put your needs first?
- Do you feel guilty if you take time for yourself?

- Do you feel inadequate if you ask for help?

Lack of time or energy can make getting that time away particularly challenging. You may even feel guilty or selfish for paying attention to your own needs. What you need to know is this: in fact, practicing self-care allows the CG to remain more balanced, focused, and effective, which helps everyone involved.

STOP & ASK

What beliefs do you hold about self-care?
Do you feel guilty if you decide to take some time for yourself?
How do you think this would get in the way of you doing self-care?

NEGATIVE SELF-TALK

Negative self-talk is the negative stuff we tell ourselves. Many times, we are meaner to ourselves then we would ever be to someone else. Can you image telling your best friend some of things we routinely tell ourselves? Stuff like "I'm so stupid!" or "You're just lazy." Let's look at what negative self-talk looks like.

Scene 1:

Sally has been trying to become more active by adding an evening walk, but it rarely seems to work. She decides to walk after dinner but as she is getting ready, she looks in the mirror. She thinks to herself: "I look horrible – there is no way I'm going out!"

STOP & ASK

What do you think happened? (Did this caregiver go for her walk?)

What could she tell herself to influence her decision?

- *There are two ways to attack this statement:*
    - *1. Address the "horrible"*
    - *2. Address the "not going out." Both might work – it'll depend on the caregiver.*
- *Have the participants try to reframe both side of the negative self-talk before asking them how the new statement might change her behavior (go for the walk rather than staying home).*
- *Encourage the caregivers to recognize the power in the self-talk to encourage or discourage.*
- *Help the caregivers to recognize they have agency – encourage them to brainstorm the alternatives.*

Scene 2:

Anna decided to steal a few moments and enjoy catching up with her friends on Facebook. As she scrolls through her feed, she sees that an ex-co-worker has posted. She feels a sense a dread as she sees her name because every time her ex-co-worker posts she get so upset at what she writes. Anna finds herself thinking: "If I unfriend her, she'll get mad at me. I'm such a coward."

STOP & ASK

What do you think happened? Did this end up being self-care or did the experience end up adding to her stress?
What could she do to remedy this? What could she tell herself to help her to

- *Encourage the caregivers to recognize the power in the self-talk to encourage or discourage.*
- *Help the caregivers to recognize they have agency – encourage them to brainstorm the alternatives.*
-
- *The goal here is to get the participants to recognize that by telling herself she is a "coward" it limits the options she has to deal with the situation. She can hide the post, which will limit her seeing post like this, Snooze the author for 30 days, or unfollow them so she'll stop seeing their posts but still stay friends.*

Slide 18 If Lost – Start Here

if lost
start here

1. Address Your Health Issues
2. Find a Support Group
3. Practice Self-Compassion
4. Laugh

Considerations

→ *We present a lot of information in the module. This is a shortcut for the CG so they can get started right away.*

Material

If you find yourself overwhelmed by all the choices presented in this module, then start with these four.

1. **Address your own health issues.** Make a doctor's appointment, get the physical, get a flu shot, update your glasses prescription, whatever you need to do to be healthy. No matter how much juggling it takes to get to these appointments, they are important. Someone depends on you to be healthy. If you are up to date on your medical appointments, then are you eating well? Sleeping well? Pick one thing at a time to change.

2. **Develop a support network**. Whether you use a best friend or a structured support group, find somewhere to safely share your worries and concerns. There are many support groups online now due to the pandemic. Check your local hospital, one of the Foundations that support the chronic illness of the person you are caring for, or Facebook.

3. **Self-compassion is essential.** Self-compassion means being kind to yourself by giving yourself credit for the tough work of caregiving, ignoring your harsh inner critic, and allowing yourself time to take care of yourself, even if it's just a few minutes a day. Forgive yourself—often. You cannot be a perfect CG, all day, every day

4. **Laugh.** Find ways to keep your sense of humor. Watch comedies, share jokes with friends. Research shows that even pretend laughter if done often and long enough turns into real laughter.

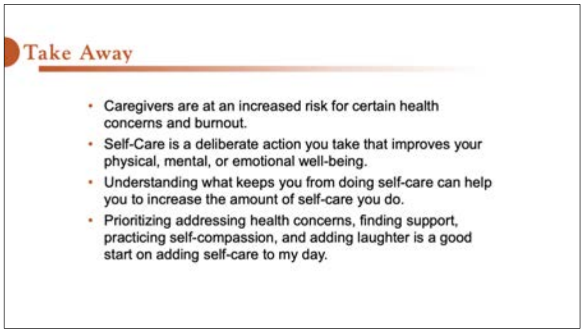
Slide 19 Take Away

Considerations

→ *This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the 'take away' was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*



Take Away

- Caregivers are at an increased risk for certain health concerns and burnout.
- Self-Care is a deliberate action you take that improves your physical, mental, or emotional well-being.
- Understanding what keeps you from doing self-care can help you to increase the amount of self-care you do.
- Prioritizing addressing health concerns, finding support, practicing self-compassion, and adding laughter is a good start on adding self-care to my day.

STOP & ASK

Thinking back over today's session,
what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:

- CGs are at an increased risk for certain health concerns and burnout.
- Self-Care is a deliberate action you take that improves your physical, mental, or emotional well-being.
- Understanding what keeps you from doing self-care can help you to increase the amount of self-care you do.
- Prioritizing addressing health concerns, finding support, practicing self-compassion, and adding laughter is a good start on adding self-care to my day.

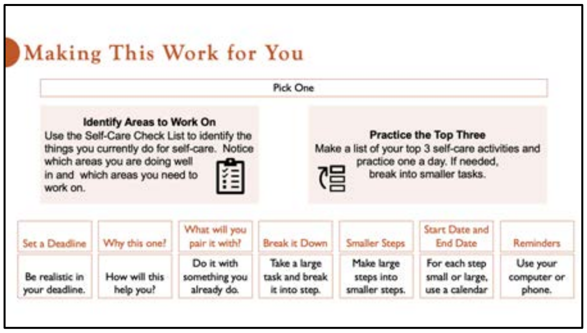
Slide 20 Making This Work for You

Considerations

→ *The Action Plan is perhaps the most important part of this session.*

→ *Encourage the CGs to **pull out their pen and paper** and create an action plan right there.*

→ *Use the boxes along the bottom to assist in the creation of the action plans*



Making This Work for You

Pick One

Identify Areas to Work On
Use the Self-Care Check List to identify the things you currently do for self-care. Notice which areas you are doing well in and which areas you need to work on.

Practice the Top Three
Make a list of your top 3 self-care activities and practice one a day. If needed, break into smaller tasks.

Set a Deadline	Why this one?	What will you pair it with?	Break it Down	Smaller Steps	Start Date and End Date	Reminders
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take a large task and break it into step.	Make large steps into smaller steps.	For each step small or large, use a calendar	Use your computer or phone.

Material

Activity 2: Action Plan

ACTIVITY-Directions

→ *FACILITATOR: Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you must do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
  - Have the CGs choose either ID Self-Care areas to Work On or Practice Top Three
  - This example: My top three are to read more, work on my sleep habits, & attend my worship service more often. (Only illustrating one of these)

1. Set a deadline – *Be realistic*

- My sleep will be more on track within 1 month. I will be in bed by 10:30p and ready for sleep by 11:00p

2. Why chose this one? - The more personal the better
   - I always feel exhausted, and I'm scared I will mess up something important.
3. What will you pair it with? – Do it with something you already do
   - I'm setting up a bedtime routine that will start at 10pm with the news.

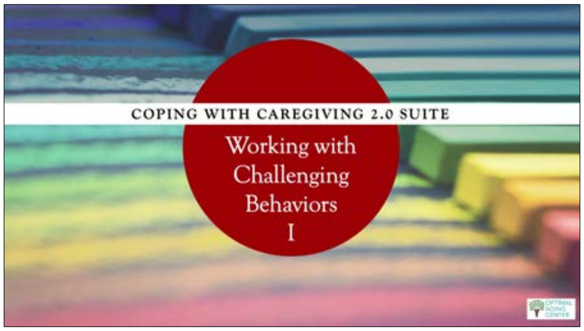
- Optional: Break it down – Take a large task and break it into steps
  - I'm working on my bedtime routine, morning wake up, and no caffeine after 2p
  - Write out my routine with a time schedule
  - Set my morning alarm
  - After my first pot of coffee is done, I'll prep a de-caf pot

4. Reminders – *Computer, phone, calendar*
   - I'll put a Post It note on my bathroom mirror to remind myself why I am doing this
   - I'll set my phone with an alarm 15m after my alarm to remind myself to get out of bed.
5. Problem-solving – *Pending*

→ ***FACILITATORS:*** *You may want to ask if participant anticipate any issues and plan for it.*

Challenging Behaviors I

The following is the facilitator's summary of the module:



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Working with Challenging Behaviors I

Aim of Module

To be able to identify the three parts of behaviors and recognize these parts in challenging behaviors.

Handouts – CWC2.0.8 HO

All handouts are available in electronic format in a PDF.
OAC: The BDA

Three Main Points

1. Challenging behaviors have a large effect on caregivers and the people they care for.
2. Behavior has three parts what happens before the behavior, the behavior itself, and the reactions to the behavior after.
3. The only things you as a caregiver have control over are triggers and reactions

Activities

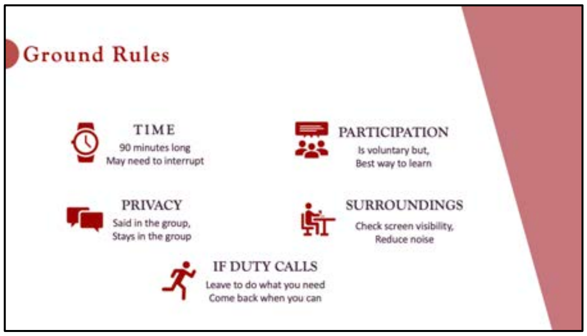
No activities in this module

Homework

Practice recognizing the three parts of behavior and bring in a challenging behavior you are struggling with.

→ ***FACILITATORS:*** *Forms are not required - pen and paper can be substituted.*

Slide 2 Ground Rules



Ground Rules

TIME
90 minutes long
May need to interrupt

PARTICIPATION
Is voluntary but,
Best way to learn

PRIVACY
Said in the group,
Stays in the group

SURROUNDINGS
Check screen visibility,
Reduce noise

IF DUTY CALLS
Leave to do what you need
Come back when you can

Considerations

→ *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*

→ *Review of the use of the chat feature is appropriate at this time. If you prefer questions being submitted through the chat feature now is a good time to mention it.*

→ *We usually mention who the tech person is and how they can contact this person either via chat in session or via email if they can't access Zoom.*

Material

Time. This session is 90 minutes long. Since we respect your time, we will start right at ________ and end at _______. Due to the amount of material we need to cover and the limited amount of time we have, I apologize in advance however I may need to interrupt you to keep us on track.

Privacy. To make this a safe place for everyone to share, we follow Las Vegas rules – what is said in the group, stays in the group. Please don't share the stories you hear outside of this session.

Surroundings. Please check your screen visibility if you are in a public place. Your mute button looks like a little microphone and is in your tool bar. If you click on it and a line appears across it, then no one can hear you or any noise happening by you. If you want to talk, just click on it again – the bar will be no longer across the microphone - and we can hear you if you speak. It is good to be muted until you want to say something.

Participation. Finally, I saved the most important for last. Research has shown us that those that engage and participate gain the most. This includes the Action Plan we will discuss with you at the end of this session. If you just listen, but don't actually practice what we share with you, you won't get the benefit. Sort of like just watching an exercise video instead of getting up and doing it.

If Duty Calls. If you are attending from home, and the person you are caring for needs you, please feel comfortable attending to their needs. There is no need to announce that you need to leave, please do what you need and join us when you are able.

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 program 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.

Slide 3 Introductions

Introductions

Your Name

Who you are caring for and their diagnosis

One thing you hope to learn today

Considerations

→ *While this slide is provided with each module, if multiple modules are combined the review of this material is usually only required at the first meeting.*

→ *It is good to write a few notes that identify the caregiver by name on screen, preferred name, who they are caring for and relation to them, and the diagnosis. If they share it is good to note stage of disease progression. In addition to this information, we use a simple form created in Excel that allows us to track attendance in multiple module programs.*

→ *Not all care recipients have a diagnosis, or even if it has been written in a chart has the caregiver been informed.*

→ *It is up to the facilitator to single out each caregiver and have them introduce themselves. We highly recommend that the number of caregivers are limited to no more than 12. Once you get over 8 or so you might want to drop the last question in the introduction.*

Material

Introduce Facilitator(s)

Name, Title, brief statement of how you work with caregivers
Have your co-facilitator introduce themselves
Introduce your tech person (especially if they shut off their video)
Introduce any guest that may be observing

Have Caregivers Introduce Themselves:

Please unmute and introduce yourself when I call out your name
Tell us your name, who you are caring for, and if you know it, their diagnosis
And finally, tell us one thing you hope to learn today

STOP & ASK

Have CGs Introduce Themselves:
We'd like each person to say, in a minute or two, your first name, who you are caring for, what their main problems are, and what you hope to get from this workshop. We'll go around the group, so everyone has a chance. Let's get started!

Slide 4 Today’s Topics

Today’s Topics

Challenging Behaviors

Anatomy of Behavior

Step by Step Examples

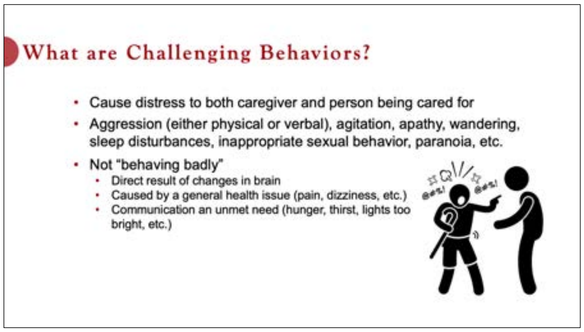
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

- The is the first session of a two-part module focused on working with Challenging Behaviors.
- We will start today by talking about challenging behaviors.
- Then we’ll break down the challenging behavior into three parts.
- Most of our session will be learning how to recognize these three parts by using multiple examples.

Slide 5 What are Challenging Behaviors?



What are Challenging Behaviors?

- Cause distress to both caregiver and person being cared for
- Aggression (either physical or verbal), agitation, apathy, wandering, sleep disturbances, inappropriate sexual behavior, paranoia, etc.
- Not “behaving badly”
  - Direct result of changes in brain
  - Caused by a general health issue (pain, dizziness, etc.)
  - Communication an unmet need (hunger, thirst, lights too bright, etc.)

Considerations

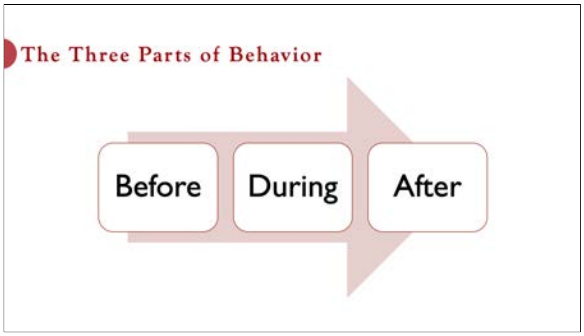
→ *The important aspect to stress here is the intention behind these behaviors. The care recipient is rarely “seeking attention” or “doing it on purpose.” Usually, it is an attempt to communicate with the only tools they have.*

Material

- One of the more difficult jobs a caregiver has is managing the behavioral symptoms of the disease sometimes called challenging behaviors.
- Challenging behaviors are a catch all phrase, as many behaviors can be clumped under this name.
- Some examples of challenging behaviors are aggressive behavior, wandering, apathy, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.
- But the one thing they all have in common is they cause distress to the both the caregiver and the person they are caring for.
- It is important to remember that in many cases the behavior is a direct result of the changes happening in the brain during the progression of the disease.
- Many experts believe that these challenging behaviors are an attempt to communicate a need or a way to say something isn’t quite right .
- In many instances, it is important to remind yourself that it isn’t the person doing this behavior to upset you.

- This may allow for a measure of calm when you respond.

Slide 6 Three Parts of Behavior



The Three Parts of Behavior

Before

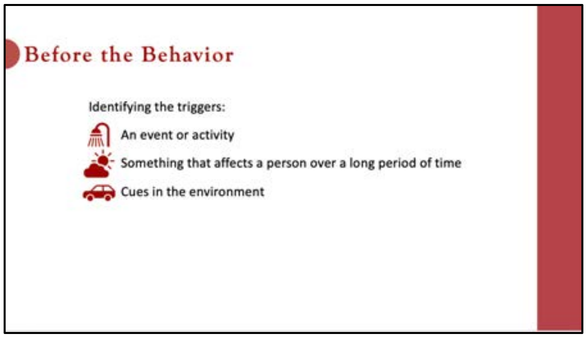
During

After

Material

- The first step in identifying the purpose of someone’s behavior is to pay attention to what happens before and after the behavior.
- Something is always taking place before and after the behavior.
- Sometimes what happens before the behavior can be referred to as a “trigger.”
- What happens after the behavior as a “reaction.”

Slide 7 Before the Behavior



Before the Behavior

Identifying the triggers:

- An event or activity
- Something that affects a person over a long period of time
- Cues in the environment

Material

To understand the purpose of the behavior, it is important to pay attention to what is happening immediately before the behavior happens. What is occurring *before* the behavior is called a **“trigger.”**

Triggers could be any of the following:

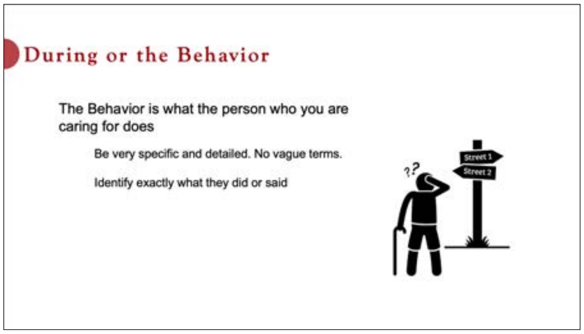
- An **event** or **activity**, such as *noise* or a *demand* that is being placed on the person (e.g., bathing)
- **General things** that affect a person for a long period of time (e.g., time of day, season, and/or physical illness)
- **Cues** in the environment, such as keys to the car or the presence of another person

Slide 8 During or the Behavior

Material

The Behavior is what the person who you are caring for does

- Be very specific and detailed. No vague terms.
- Identify exactly what they did or said



During or the Behavior

The Behavior is what the person who you are caring for does

Be very specific and detailed. No vague terms.

Identify exactly what they did or said

Slide 9 After the Behavior

Material

Reactions occur immediately after the behavior. Reactions include:

- What you do, how you feel
- What the person who you are caring for does.
- In other words, what happens after the behavior?

After the Behavior

Reactions occur immediately after the behavior

Reactions include:
What you do, how you feel
What the person who you are caring for does

In other words, what happens after the behavior?

It is very important to pay attention to reactions Depending on how you react, you may increase or decrease the problem behavior

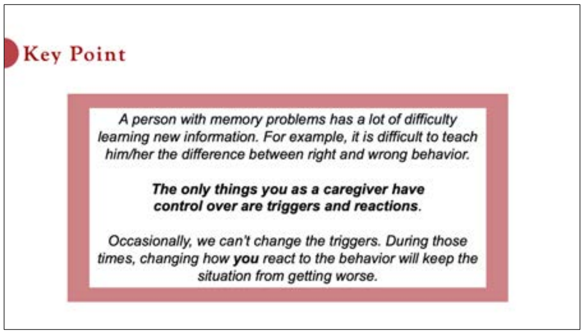
It is very important to pay attention to reactions. Depending on how you react, you may increase or decrease the problem behavior.

Slide 10 Key Point

Material

A person with memory problems has a lot of difficulty learning new information. For example, it is difficult to teach him/her the difference between right and wrong behavior.

The only things you as a caregiver have control over are triggers and reactions.



Key Point

A person with memory problems has a lot of difficulty learning new information. For example, it is difficult to teach him/her the difference between right and wrong behavior.

The only things you as a caregiver have control over are triggers and reactions.

*Occasionally, we can't change the triggers. During those times, changing how **you** react to the behavior will keep the situation from getting worse.*

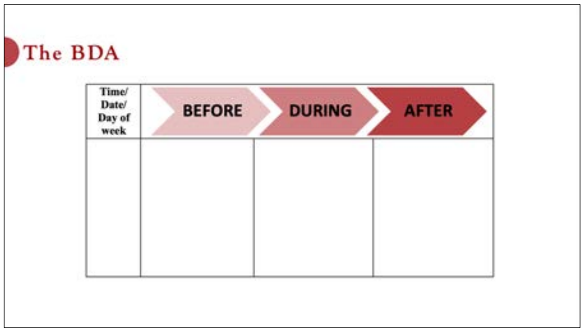
Occasionally, we can’t change the triggers. During those times, changing how **you** react to the behavior will keep the situation from getting worse.

Slide 11 The BDA

Material

It is helpful to think about the different phases of behavior as a **BDA** for short.

We will be applying the BDA in the following examples using a simple form to understand what occurs before and after a difficult behavior happens.



The BDA

Time/ Date/ Day of week	BEFORE	DURING	AFTER

In the first column you will write the date or the day of the week, the time when the difficult behavior occurred.

For the next three columns:

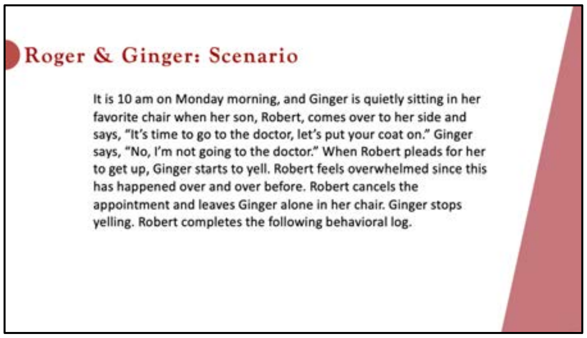
- In the center column, you will be describing the behavior that occurred.
- In the BEFORE column, you will list what happened right before the behavior.
    - This could be an event, activity, timing, or cue in the environment just before the difficult behavior occurred.
- The last column is for what happened directly following the behavior, including your reaction to the behavior.

Slide 12 Roger & Ginger Scenario

Material

Read the scenario:

It is 10 am on Monday morning, and Ginger is quietly sitting in her favorite chair when her son, Robert, comes over to her side and says, "It's time to go to the doctor, let's put your coat on." Ginger says, "No, I'm not going to the doctor." When Robert pleads for her to get up, Ginger starts to yell. Robert cancels the appointment and leaves Ginger alone in her chair. Ginger stops yelling. Robert completes the following behavioral log.



Roger & Ginger: Scenario

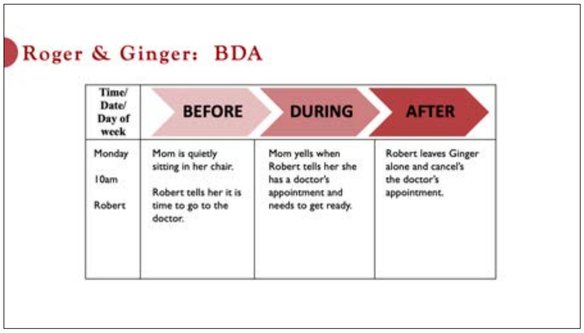
It is 10 am on Monday morning, and Ginger is quietly sitting in her favorite chair when her son, Robert, comes over to her side and says, "It's time to go to the doctor, let's put your coat on." Ginger says, "No, I'm not going to the doctor." When Robert pleads for her to get up, Ginger starts to yell. Robert feels overwhelmed since this has happened over and over before. Robert cancels the appointment and leaves Ginger alone in her chair. Ginger stops yelling. Robert completes the following behavioral log.

Ok, now let's start filling out the BDA.

Slide 13 Roger & Ginger BDA

Considerations

→ *The BDA will fill in on each click on the screen*



Roger & Ginger: BDA

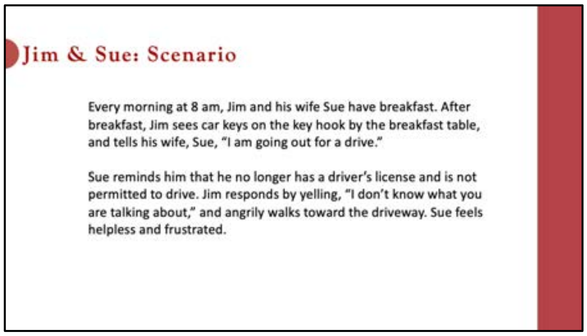
Time/ Date/ Day of week	BEFORE	DURING	AFTER
Monday 10am Robert	Mom is quietly sitting in her chair. Robert tells her it is time to go to the doctor.	Mom yells when Robert tells her she has a doctor's appointment and needs to get ready.	Robert leaves Ginger alone and cancel's the doctor's appointment.

Material

1. The first step is to fill out the first column date, time and day of the week.
    - Monday, 10am, Robert
2. Next, what was the difficult behavior?
    - Ginger yelled, refused to go to the doctor.
3. What happened just BEFORE (Trigger) Ginger started yelling?
    - Let's see, before she started yelling, she was sitting quietly and then Robert came in and told her it was time to go to the doctor.
4. What was the reaction to Ginger's yelling and refusal to go the doctor?
    - Robert left Ginger alone and cancelled the appointment.

Slide 14 Jim & Sue Scenario

Material



Jim & Sue: Scenario

Every morning at 8 am, Jim and his wife Sue have breakfast. After breakfast, Jim sees car keys on the key hook by the breakfast table, and tells his wife, Sue, "I am going out for a drive."

Sue reminds him that he no longer has a driver's license and is not permitted to drive. Jim responds by yelling, "I don't know what you are talking about," and angrily walks toward the driveway. Sue feels helpless and frustrated.

Read the Scenario:

Every morning at 8 am, Jim and his wife Sue have breakfast. After breakfast, Jim sees car keys on the key hook by the breakfast table, and tells his wife, Sue, "I am going out for a drive."

Sue reminds him that he no longer has a driver's license and is not permitted to drive. Jim responds by yelling, "I don't know what you are talking about," and angrily walks toward the driveway. Sue feels helpless and frustrated.

Slide 15 Jim & Sue BDA

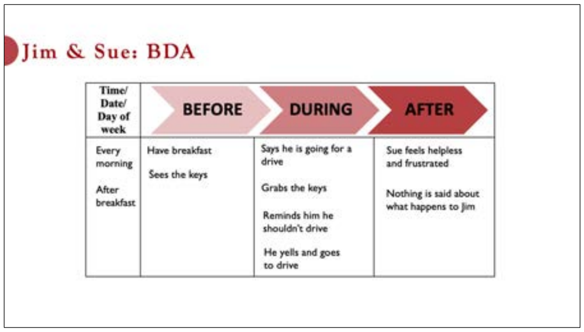
Considerations

→ *The BDA will fill in on each click on the screen*

Material

Let's walk through the steps together.

1. The first step is to fill out the first three columns date, time and who.
    - Every morning, After breakfast.
2. Next, what was the difficult behavior?
    - Says he is going for a drive & grabs the keys
    - Sue reminds him he shouldn't drive
    - He yells and goes to drive
3. So, what happened just BEFORE (Trigger)?
    - They have breakfast
    - After breakfast
4. What was the reaction to the difficult behavior?
    - Sue feels helpless and frustrated
    - We don't know what happened to Jim



Jim & Sue: BDA

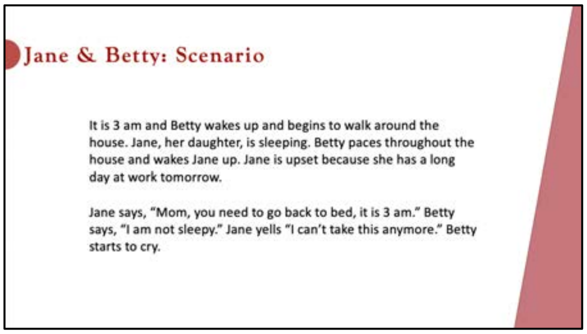
Time/ Date/ Day of week	BEFORE	DURING	AFTER
Every morning After breakfast	Have breakfast Sees the keys	Says he is going for a drive Grabs the keys Reminds him he shouldn't drive He yells and goes to drive	Sue feels helpless and frustrated Nothing is said about what happens to Jim

Slide 16 Jane & Betty Scenario

Material

Read the scenario.

Let set the scene:
Jane is concerned with Betty's wandering at night. Some nights she tries to make tea and leaves the burner on. A couple of nights ago she made it as far as the porch.



Jane & Betty: Scenario

It is 3 am and Betty wakes up and begins to walk around the house. Jane, her daughter, is sleeping. Betty paces throughout the house and wakes Jane up. Jane is upset because she has a long day at work tomorrow.

Jane says, "Mom, you need to go back to bed, it is 3 am." Betty says, "I am not sleepy." Jane yells "I can't take this anymore." Betty starts to cry.

The scenario:
It is 3 am and Betty wakes up and begins to walk around the house. Jane, her daughter, is sleeping. Betty paces throughout the house and wakes Jane up. Jane is upset because she has a long day at work tomorrow.
Jane says, "Mom, you need to go back to bed, it is 3 am." Betty says, "I am not sleepy." Jane yells "I can't take this anymore." Betty starts to cry.

Slide 17 Jane & Betty BDA

Considerations

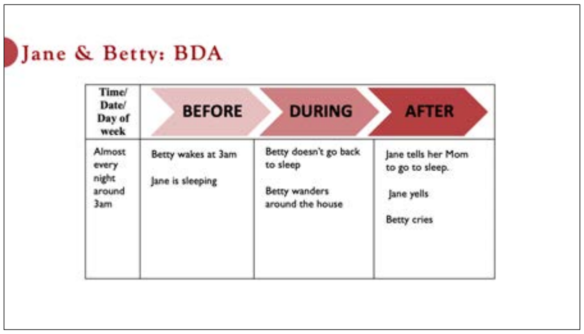
→ *The BDA will fill in on each click on the screen*

Material

Let the caregivers provide the answers.

Let's walk through the steps together.

1. The first step is to fill out the first three columns date, time and who.
    - Almost every night around 3am
2. Next, what was the difficult behavior?
    - Betty doesn't go back to sleep
    - Betty wanders around the house
3. So, what happened just BEFORE (Trigger)?
    - Betty wakes at 3am
    - Jane is sleeping
4. What was the reaction to the difficult behavior?
    - Jane tells her Mom to go to sleep.
    - Jane yells
    - Betty cries



Jane & Betty: BDA

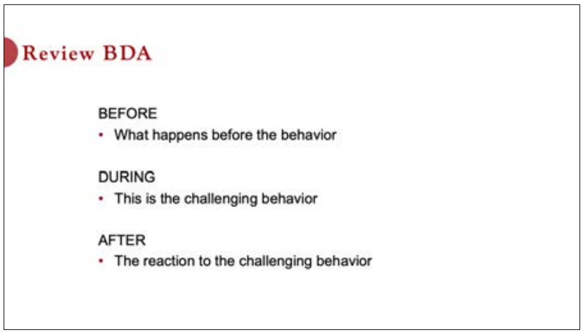
Time/ Date/ Day of week	BEFORE	DURING	AFTER
Almost every night around 3am	Betty wakes at 3am Jane is sleeping	Betty doesn't go back to sleep Betty wanders around the house	Jane tells her Mom to go to sleep. Jane yells Betty cries

Slide 18 Review BDA

Material

BEFORE

- What happens before the behavior
- Triggers could be any of the following:
    - An event or activity, such as *noise* or a *demand* that is being placed on the person (e.g., bathing)
    - General things that affect a person for a long period of time (e.g., time of day, season, and/or physical illness)
    - Cues in the environment, such as keys to the car or the presence of another person



Review BDA

BEFORE
- What happens before the behavior

DURING
- This is the challenging behavior

AFTER
- The reaction to the challenging behavior

DURING

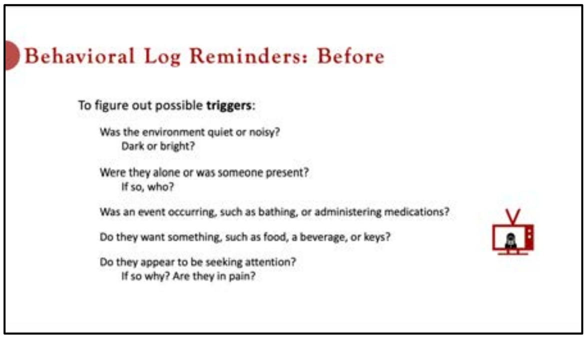
- The Behavior is what the person who you are caring for does
    - Be very specific and detailed. No vague terms.
    - Identify exactly what they did or said

AFTER
- Reactions occur immediately after the behavior.
- Reactions include:
  - What you do, how you feel
  - What the person who you are caring for does.
  - In other words, what happens after the behavior?

Slide 19 Behavioral Log Reminders: Before

Material

To figure out possible **triggers**:
- Was the environment quiet or noisy?
- Dark or bright?
- Were they alone or was someone present?
- If so, who?
- Was an event occurring, such as bathing, or administering medications?
- Do they want something, such as food, a beverage, or keys?
- Do they appear to be seeking attention?
- If so, why? Are they in pain?



Behavioral Log Reminders: Before

To figure out possible **triggers**:

Was the environment quiet or noisy?
  Dark or bright?

Were they alone or was someone present?
  If so, who?

Was an event occurring, such as bathing, or administering medications?

Do they want something, such as food, a beverage, or keys?

Do they appear to be seeking attention?
  If so why? Are they in pain?

Slide 20 Behavioral Log Reminders: After

Material

To figure out your **reaction**:
- Did you stop the event?
- Such as bathing, administering medications
- What kind of feelings did you experience?
- Did your level of stress increase or decrease?
- What did you actually do?

Behavioral Log Reminders: After

To figure out your **reaction**:

Did you stop the event?
  Such as bathing, administering medications

What kind of feelings did you experience?
  Did your level of stress increase or decrease?

What did you actually do?

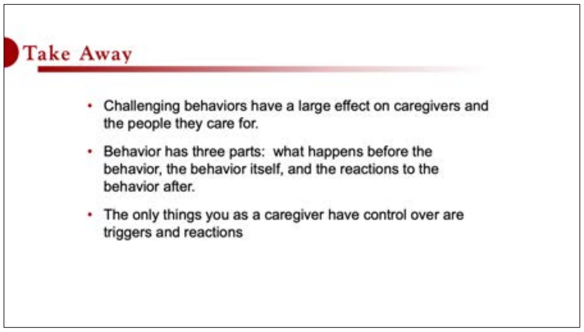
Slide 21 Take Away

Considerations

→ *This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the 'take away' was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*


Take Away

- Challenging behaviors have a large effect on caregivers and the people they care for.
- Behavior has three parts: what happens before the behavior, the behavior itself, and the reactions to the behavior after.
- The only things you as a caregiver have control over are triggers and reactions

STOP & ASK

Thinking back over today's session, what are the important points you will take away with you?

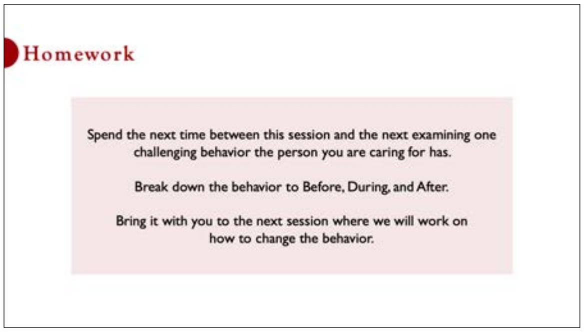
→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:
- Challenging behaviors have a large effect on caregivers and the people they care for.
- Behavior has three parts what happens before the behavior, the behavior itself, and the reactions to the behavior after.
- The only things you as a caregiver have control over are triggers and reactions

Slide 22 Homework

Material

- Spend the next time between this session and the next examining one.
- challenging behavior the person you are caring for has.
- Break down the behavior to Before, During, and After.
- Bring it with you to the next session where we will work on how to change the behavior.


Homework

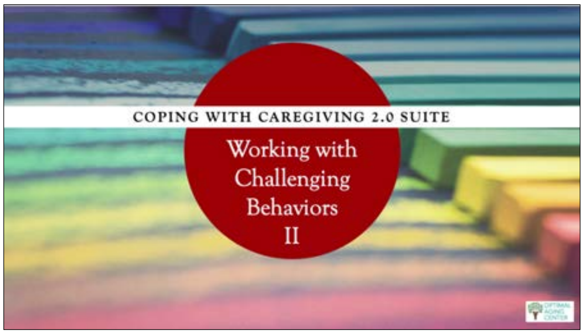
Spend the next time between this session and the next examining one challenging behavior the person you are caring for has.

Break down the behavior to Before, During, and After.

Bring it with you to the next session where we will work on how to change the behavior.

Challenging Behaviors II

The following is the facilitator's summary of the module:



Aim of Module

To use the BDA to work with a challenging behavior to cause less distress.

Handouts – CWC2.0.9 HO

All handouts are available in electronic format in a PDF.
OAC: Behavioral Log
OAC: Behavioral Log Reminders

Four Main Points

1. It is important to rule out medical conditions by speaking with their doctor as a possible change of the challenging behavior, especially if the behavior is new and onset was sudden.
2. The only things you as a caregiver have control over are triggers and reactions.
3. It is important to keep track of what happened to your proposed strategies, so you have a record of what worked AND what didn't.
4. Problem solving is a process of trial and error. Be flexible, patient and creative! Give yourself the gift of time, and permission to fail.

Activities

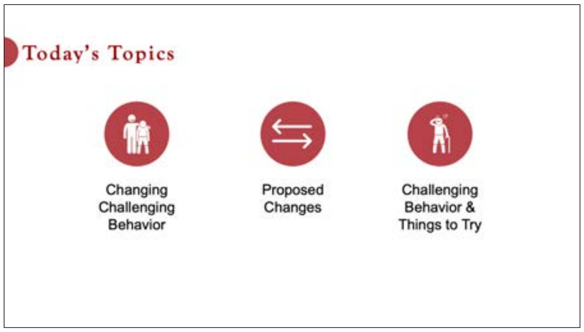
BDA

Action Plan

Choice of 2:
Use 2 or 3 strategies to modify the challenging behavior
Practice recognizing the part of a challenging behavior

→ ***FACILITATORS:*** *Forms are not required - pen and paper can be substituted.*

Slide 2 Today's Topics


Today's Topics

Changing Challenging Behavior

Proposed Changes

Challenging Behavior & Things to Try

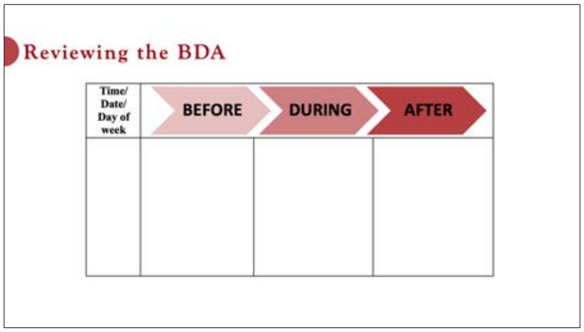
Considerations

→ *This slide should be a quick introduction of what this session will cover.*

Material

- Welcome to the second part of Challenging Behaviors.
- Today we will be discussing how to use the BDA to guide how to change these behaviors and how to propose and follow through on these changes.
- Then we will look at different challenging behaviors and some proposed changes other caregivers have found useful.

Slide 3 Reviewing the BDA


Reviewing the BDA

Time/ Date/ Day of week	BEFORE	DURING	AFTER

Material

Review last sessions material:

- As we covered in the last session, it is helpful to think about the different phases of behavior as **BDA** for short.
- In the first column you will write the date or the day of the week, the time when the difficult behavior occurred.
- For the next three columns:
    - In the center column, you will be describing the behavior that occurred.
    - In the BEFORE column, you will list what happened right before the behavior.
    - This could be an event, activity, timing, or cue in the environment just before the difficult behavior occurred.
- The last column is for what happened directly following the behavior, including your reaction to the behavior.

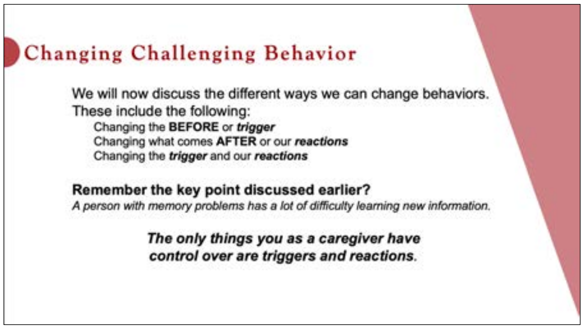
Slide 4 Changing Challenging Behavior

Material

We will now discuss the different ways we can change behaviors.

These include the following
- Changing the BEFORE or trigger
- Changing what comes AFTER or our reactions
- Changing the ***trigger*** and our ***reactions***

Remember the key point discussed earlier?
A person with memory problems has a lot of difficulty learning new information.
The only things you as a caregiver have control over are triggers and reactions.



Changing Challenging Behavior

We will now discuss the different ways we can change behaviors.
These include the following:
  Changing the **BEFORE** or ***trigger***
  Changing what comes **AFTER** or our ***reactions***
  Changing the ***trigger*** and our ***reactions***

Remember the key point discussed earlier?
A person with memory problems has a lot of difficulty learning new information.

The only things you as a caregiver have control over are triggers and reactions.

Slide 5 Rule Outs

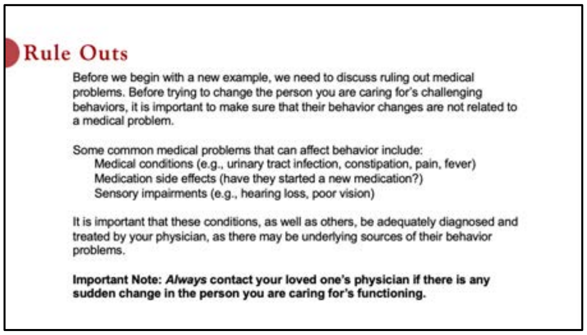
Material

Before we begin with a new example, we need to discuss ruling out medical problems.
Before trying to change the person, you are caring for's challenging behaviors, it is important to make sure that their behavior changes are not related to a medical problem.

Some common medical problems that can affect behavior include:
- Medical conditions (e.g., urinary tract infection, constipation, pain, fever)
- Medication side effects (have they started a new medication?)
- Sensory impairments (e.g., hearing loss, poor vision)

It is important that these conditions, as well as others, be adequately diagnosed and treated by your physician, as there may be underlying sources of their behavior problems.

Important Note: *Always* contact your loved one's physician if there is any sudden change in the person you are caring for's functioning.



Rule Outs

Before we begin with a new example, we need to discuss ruling out medical problems. Before trying to change the person you are caring for's challenging behaviors, it is important to make sure that their behavior changes are not related to a medical problem.

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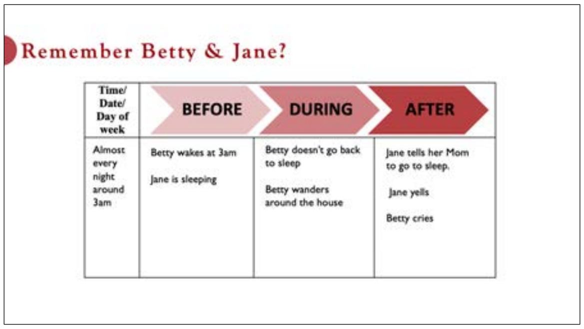
  Sensory impairments (e.g., hearing loss, poor vision)

It is important that these conditions, as well as others, be adequately diagnosed and treated by your physician, as there may be underlying sources of their behavior problems.

Important Note: *Always* contact your loved one's physician if there is any sudden change in the person you are caring for's functioning.

Slide 6 Remember Betty & Jane?



Remember Betty & Jane?

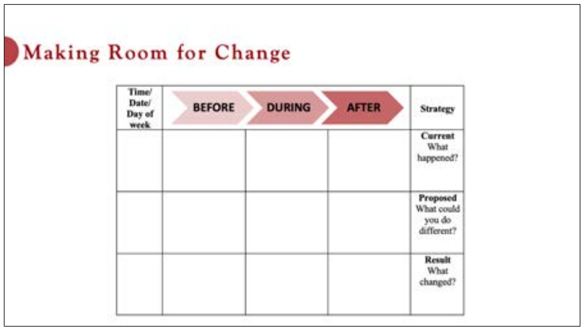
Time/ Date/ Day of week	BEFORE	DURING	AFTER
Almost every night around 3am	Betty wakes at 3am Jane is sleeping	Betty doesn't go back to sleep Betty wanders around the house	Jane tells her Mom to go to sleep. Jane yells Betty cries

Material

- Remember Betty & Jane?
- It is 3 am and Betty wakes up and begins to walk around the house. Jane, her daughter, is sleeping. Betty paces throughout the house and wakes Jane up. Jane is upset because she has a long day at work tomorrow. Jane says, "Mom, you need to go back to bed, it is 3 am." Betty says, "I am not sleepy." Jane yells "I can't take this anymore." Betty starts to cry.

As you can see, we have mapped out the behavior.
- Time/Date/Day of the week Almost every night around 3am
- During Betty doesn't go back to sleep. Betty wanders around the house
- Before Betty wakes at 3am. Jane is sleeping.
- After Jane tells her Mom to go to sleep. Jane yells. Betty cries.

Slide 7 Making Room for Change



Making Room for Change

Time/ Date/ Day of week	BEFORE	DURING	AFTER	Strategy
				Current What happened?
				Proposed What could you do different?
				Result What changed?

Material

There is a lot to keep track of here so it may be helpful to use the form below called the **Behavioral Log.**

Parts of this log should look familiar to you, but we've added an extra column.

The column labeled 'Strategy' adds new rows. Notice it has Current, Proposed, and Result headings.
  - The Current row describes the difficult behavior you are concerned about.
  - The Proposed row is the place to describe your strategy to change either the **BEFORE** or **AFTER**.
  - The Result row gives you a place to write what the result was for the proposed strategy.
    - What happened when you used it? What was the outcome?

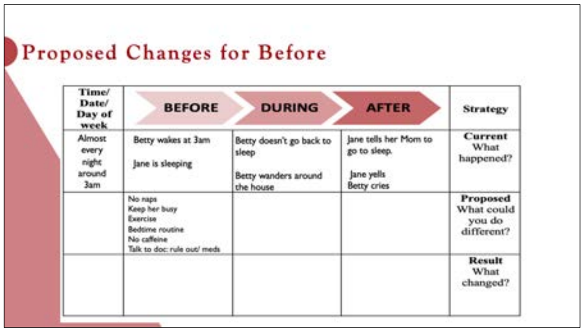
There will be times when you will need to sleuth your way through, trying many strategies to change a difficult behavior. Now that you've seen what a Behavioral Log looks like, let's use it to organize Jane's new strategies.

Slide 8 Proposed Changes for Before

Material

What are some of the *proposed changes* Jane can do during the Before?

No naps
Keep her busy
No caffeine
Talk to doc: rule out/ meds
Exercise
Bedtime routine



Proposed Changes for Before

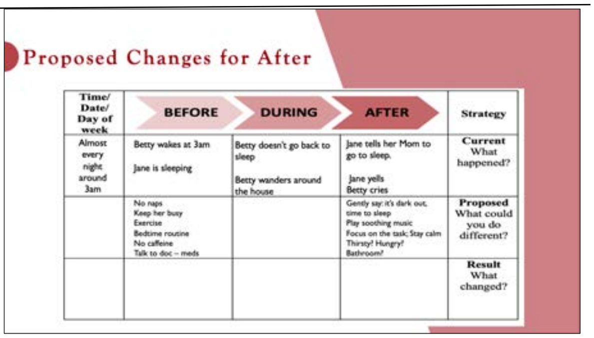
Time/ Date/ Day of week	BEFORE	DURING	AFTER	Strategy
Almost every night around 3am	Betty wakes at 3am Jane is sleeping	Betty doesn't go back to sleep Betty wanders around the house	Jane tells her Mom to go to sleep. Jane yells Betty cries	**Current** What happened?
	No naps Keep her busy Exercise Bedtime routine No caffeine Talk to doc: rule out/ meds			**Proposed** What could you do different?
				Result What changed?

Slide 9 Proposed Changes for After

Material

What are some of the *proposed changes* Jane can do during the After?

- Gently say: it's dark out, time to sleep
- Play soothing music
- Focus on the task; Stay calm
- Thirsty? Hungry? Bathroom?



Proposed Changes for After

Time/ Date/ Day of week	BEFORE	DURING	AFTER	Strategy
Almost every night around 3am	Betty wakes at 3am Jane is sleeping	Betty doesn't go back to sleep Betty wanders around the house	Jane tells her Mom to go to sleep. Jane yells Betty cries	**Current** What happened?
	No naps Keep her busy Exercise Bedtime routine No caffeine Talk to doc – meds		Gently say: it's dark out, time to sleep Play soothing music Focus on the task; Stay calm Thirsty? Hungry? Bathroom?	**Proposed** What could you do different?
				Result What changed?

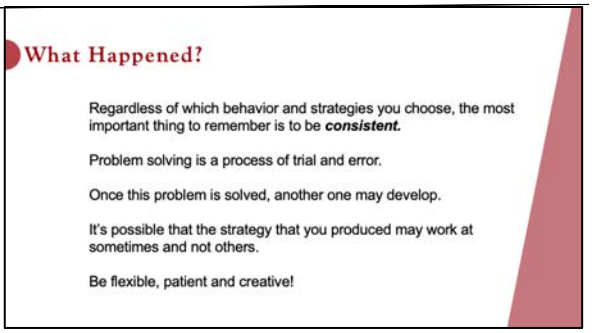
Walk through the changes made – do the caregivers think they would work? Are there other suggestions they would make?

Point out there was no attempt to use logic or reasoning. Why?

- A person with memory problems has a lot of difficulty learning new information or remembering the steps needed to make logic work.

The only things you as a caregiver have control over are triggers and reactions.

Slide 10 What Happened?



What Happened?

Regardless of which behavior and strategies you choose, the most important thing to remember is to be ***consistent.***

Problem solving is a process of trial and error.

Once this problem is solved, another one may develop.

It's possible that the strategy that you produced may work at sometimes and not others.

Be flexible, patient and creative!

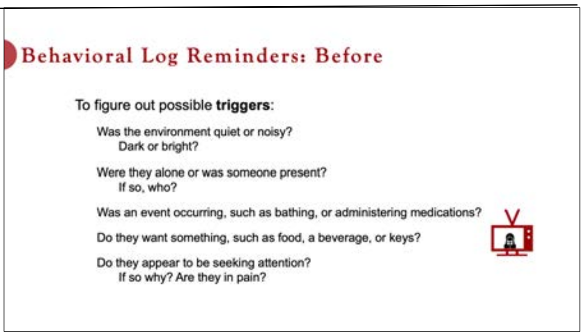
Material

Regardless of which behavior and strategies you choose the most important thing to remember is to be **consistent.**

Problem solving is a process of trial and error. Once this problem is solved, another one may develop.

It’s possible that the strategy that you came up with may work at sometimes and not others. Be flexible, patient, and creative!

Slide 11 Behavioral Log Reminders Before



Behavioral Log Reminders: Before

To figure out possible **triggers**:
- Was the environment quiet or noisy?
  - Dark or bright?
- Were they alone or was someone present?
  - If so, who?
- Was an event occurring, such as bathing, or administering medications?
- Do they want something, such as food, a beverage, or keys?
- Do they appear to be seeking attention?
  - If so why? Are they in pain?

Material

To figure out possible **triggers**:
- Was the environment quiet or noisy?
- Dark or bright?
- Were they alone or was someone present?
- If so, who?
- Was an event occurring, such as bathing, or administering medications?
- Do they want something, such as food, a beverage, or keys?
- Do they appear to be seeking attention?
- If so, why? Are they in pain?

Slide 12 Behavioral Log Reminders After

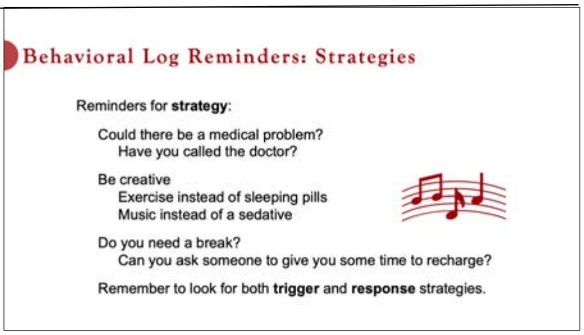
Behavioral Log Reminders: After

To figure out your **reaction**:
- Did you stop the event?
  - Such as bathing, administering medications
- What kind of feelings did you experience?
  - Did your level of stress increase or decrease?
- What did you actually do?

Material

To figure out your **reaction**:
- Did you stop the event?
- Such as bathing, administering medications
- What kind of feelings did you experience?
- Did your level of stress increase or decrease?
- What did you actually do?

Slide 13 Behavioral Log Reminders Strategies



Behavioral Log Reminders: Strategies

Reminders for **strategy**:

Could there be a medical problem?
Have you called the doctor?

Be creative
Exercise instead of sleeping pills
Music instead of a sedative

Do you need a break?
Can you ask someone to give you some time to recharge?

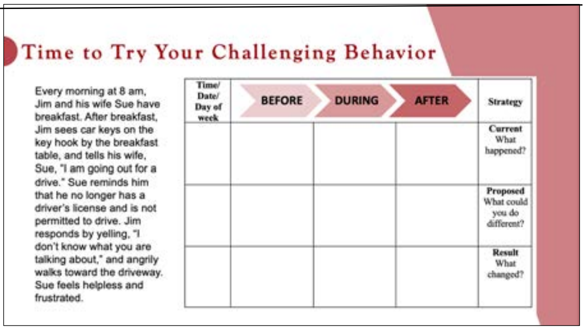
Remember to look for both **trigger** and **response** strategies.

Material

Reminders for **strategy**:

- Could there be a medical problem?
    - Have you called the doctor?
- Be creative
    - Exercise instead of sleeping pills
    - Music instead of a sedative
- Do you need a break?
    - Can you ask someone to give you some time to recharge?
- Remember to look for both **trigger** and **response** strategies.
-
- Consistently use these strategies and complete the behavior log to find out if the behavior has changed.
- You may feel that you can "mentally" keep track of whether the behavior has changed, however many find the log helpful, so they don't have to remember the fine points of what they've tried.
- Problem solving is a process of trial and error.
- Once this problem is solved, another one may develop.
- It's possible that the strategy that you came up with may work at sometimes and not others.
    - Be flexible, patient and creative! Give yourself the gift of time, and permission to fail.

Slide 14 Time to Try



Time to Try Your Challenging Behavior

Every morning at 8 am, Jim and his wife Sue have breakfast. After breakfast, Jim sees car keys on the key hook by the breakfast table, and tells his wife, Sue, "I am going out for a drive." Sue reminds him that he no longer has a driver's license and is not permitted to drive. Jim responds by yelling, "I don't know what you are talking about," and angrily walks toward the driveway. Sue feels helpless and frustrated.

Time/ Date/ Day of week	BEFORE	DURING	AFTER	Strategy
				Current What happened?
				Proposed What could you do different?
				Result What changed?

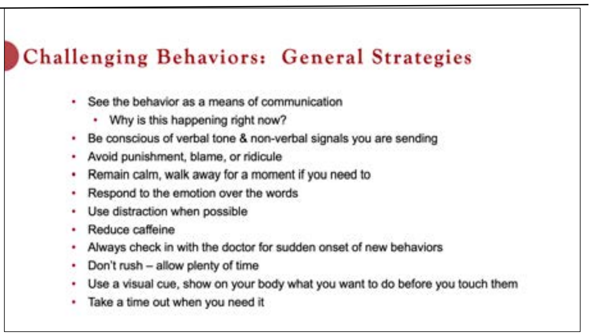
Material

Remind your caregivers that the last sessions homework was to bring a challenging behavior that they were struggling with.

If they did not bring one, have them work on Jim & Sue.

→ ***FACILITATORS:*** *The activity is they fill out the current and proposed rows.* ***Give them 10 mins****, then check in. Ask if someone was willing to share.*

Slide 15 Challenging Behaviors General Strategies



Challenging Behaviors: General Strategies

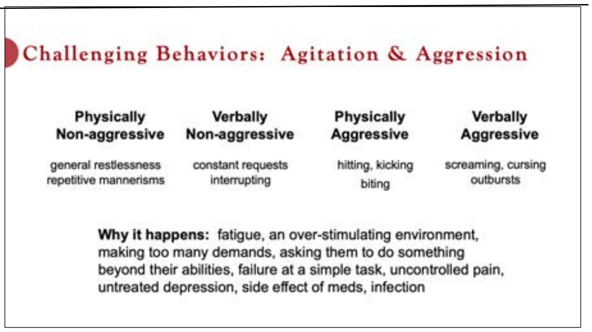
- See the behavior as a means of communication
  - Why is this happening right now?
- Be conscious of verbal tone & non-verbal signals you are sending
- Avoid punishment, blame, or ridicule
- Remain calm, walk away for a moment if you need to
- Respond to the emotion over the words
- Use distraction when possible
- Reduce caffeine
- Always check in with the doctor for sudden onset of new behaviors
- Don't rush – allow plenty of time
- Use a visual cue, show on your body what you want to do before you touch them
- Take a time out when you need it

Material

- - See the behavior as a means of communication.
- Why is this happening right now?
- - Be conscious of verbal tone & non-verbal signals
- you are sending
- - Remain calm, walk away for a moment if you
- need to
- - Respond to the emotion over the words
- - Use distraction when possible
- - Take a time out when you need it
- - Always check in with the doctor for sudden onset of new behaviors
- - Use a visual cue, show on your body what you want to do before you touch them
- Reduce caffeine
- Don't rush – allow plenty of time
- Avoid punishment, blame, or ridicule

Over the next couple of slides, we are going to examine different challenging behaviors and what other caregivers have found helpful.

Slide 16 Challenging Behaviors Agitation & Aggression



Challenging Behaviors: Agitation & Aggression

Physically Non-aggressive	Verbally Non-aggressive	Physically Aggressive	Verbally Aggressive
general restlessness repetitive mannerisms	constant requests interrupting	hitting, kicking biting	screaming, cursing outbursts

Why it happens: fatigue, an over-stimulating environment, making too many demands, asking them to do something beyond their abilities, failure at a simple task, uncontrolled pain, untreated depression, side effect of meds, infection

Material

These four types of behavioral classifications are from the International Psychogeriatric Association.

Physically Non-aggressive
Example restlessness, repetitive mannerisms

Physically Aggressive
Example hitting, kicking, biting

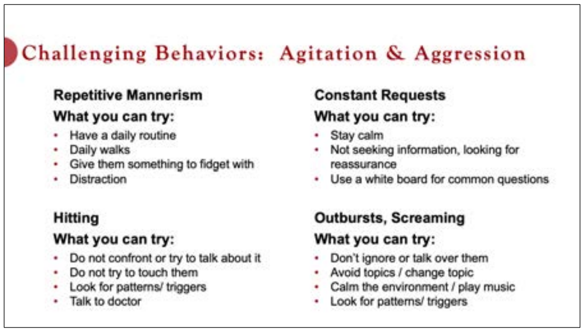
Verbally Non-aggressive
Example constant requests interrupting

Verbally Aggressive
Example screaming, cursing, outbursts

Why it happens

Fatigue
An over-stimulating environment
Making too many demands
Asking them to do something
Beyond their abilities
Failure at a simple task
Uncontrolled pain
Untreated depression
Side effect of meds
Infection

Slide 17 Challenging Behaviors Agitation & Aggression



Challenging Behaviors: Agitation & Aggression

Repetitive Mannerism
What you can try:
- Have a daily routine
- Daily walks
- Give them something to fidget with
- Distraction

Constant Requests
What you can try:
- Stay calm
- Not seeking information, looking for reassurance
- Use a white board for common questions

Hitting
What you can try:
- Do not confront or try to talk about it
- Do not try to touch them
- Look for patterns/ triggers
- Talk to doctor

Outbursts, Screaming
What you can try:
- Don't ignore or talk over them
- Avoid topics / change topic
- Calm the environment / play music
- Look for patterns/ triggers

Material

Repetitive Mannerism: What you can try

Have a daily routine
Daily walks
Give them something to fidget with
Distraction

Constant Requests: What you can try

Stay calm
Not seeking information, looking for reassurance
Use a white board for common questions

Hitting: **What you can try**

Do not confront or try to talk about it
Do not try to touch them
Look for patterns/ triggers
Talk to doctor

Outbursts, Screaming: **What you can try**

Don't ignore or talk over them
Avoid topics / change topic
Calm the environment / play music
Look for patterns/ triggers

Slide 18 Challenging Behaviors Wandering

Challenging Behaviors: Wandering

What it is: Shadowing, repeated looking for cg, aimlessly walking, repeated attempts to leave the house, usually a combo of disorientation and restlessness

Why it happens: an attempt to leave, following someone out the door, bored or lack of stimulation, restlessness due to meds

What you can try:
- Keep coats/keys/purse out of sight
- Have a safe place and time to walk
- ID bracelet/dog tags
- Escape proof the house
- Exercise
- Redirect wandering to a new activity
- Reduce noise and confusion
- Keep a recent photo handy in case

Material

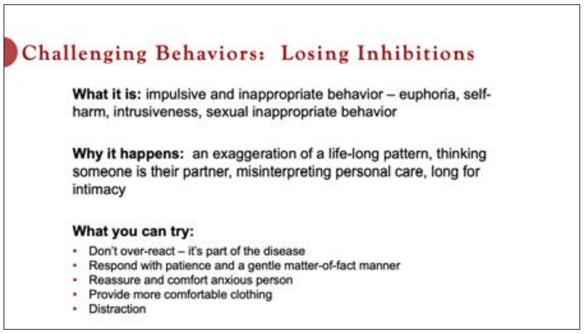
What it is: Shadowing, repeated looking for cg, aimlessly walking, repeated attempts to leave the house, usually a combo of disorientation and restlessness

Why it happens an attempt to leave, following someone out the door, bored or lack of stimulation, restlessness due to meds

What you can try:

Keep coats/keys/purse out of sight
Have a safe place and time to walk
ID bracelet/dog tags
Escape proof the house
Exercise
Redirect wandering to a new activity
Reduce noise and confusion
Keep a recent photo handy in case

Slide 19 Challenging Behaviors Losing Inhibitions



Challenging Behaviors: Losing Inhibitions

What it is: impulsive and inappropriate behavior – euphoria, self-harm, intrusiveness, sexual inappropriate behavior

Why it happens: an exaggeration of a life-long pattern, thinking someone is their partner, misinterpreting personal care, long for intimacy

What you can try:

- Don't over-react – it's part of the disease
- Respond with patience and a gentle matter-of-fact manner
- Reassure and comfort anxious person
- Provide more comfortable clothing
- Distraction

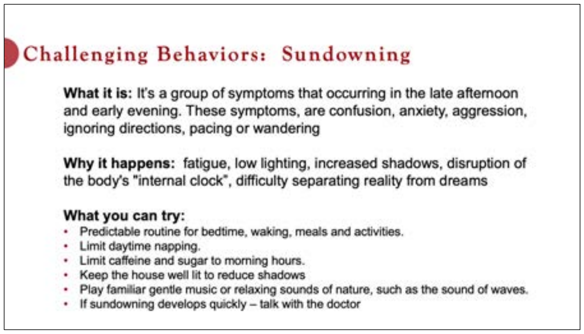
Material

What it is: impulsive and inappropriate behavior – euphoria, self-harm, intrusiveness, sexual inappropriate behavior

Why it happens an exaggeration of a life-long pattern, thinking someone is their partner, misinterpreting personal care, long for intimacy

What you can try: Respond with patience and a gentle matter-of-fact manner
Don't over-react – it's part of the disease
Provide more comfortable clothing
Reassure and comfort anxious person
Distraction

Slide 20 Challenging Behaviors Sundowning



Challenging Behaviors: Sundowning

What it is: It's a group of symptoms that occurring in the late afternoon and early evening. These symptoms, are confusion, anxiety, aggression, ignoring directions, pacing or wandering

Why it happens: fatigue, low lighting, increased shadows, disruption of the body's "internal clock", difficulty separating reality from dreams

What you can try:

- Predictable routine for bedtime, waking, meals and activities.
- Limit daytime napping.
- Limit caffeine and sugar to morning hours.
- Keep the house well lit to reduce shadows
- Play familiar gentle music or relaxing sounds of nature, such as the sound of waves.
- If sundowning develops quickly – talk with the doctor

Material

What it is: It's a group of symptoms that occurring in the late afternoon and early evening. These symptoms, are confusion, anxiety, aggression, ignoring directions, pacing or wandering

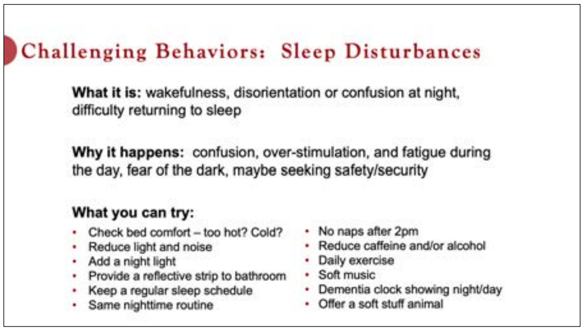
Why it happens fatigue, low lighting, increased shadows, disruption of the body's "internal clock", difficulty separating reality from dreams

What you can try

Predictable routine for bedtime, waking, meals and activities
Limit daytime napping
Limit caffeine and sugar to morning hours
Keep the house well-lit to reduce shadows
Play familiar gentle music or relaxing sounds of nature, such as the sound of waves

If sundowning develops quickly – talk with the doctor

Slide 21 Challenging Behaviors Sleep Disturbances



Challenging Behaviors: Sleep Disturbances

What it is: wakefulness, disorientation or confusion at night, difficulty returning to sleep

Why it happens: confusion, over-stimulation, and fatigue during the day, fear of the dark, maybe seeking safety/security

What you can try:

- Check bed comfort – too hot? Cold?
- Reduce light and noise
- Add a night light
- Provide a reflective strip to bathroom
- Keep a regular sleep schedule
- Same nighttime routine
- No naps after 2pm
- Reduce caffeine and/or alcohol
- Daily exercise
- Soft music
- Dementia clock showing night/day
- Offer a soft stuff animal

Material

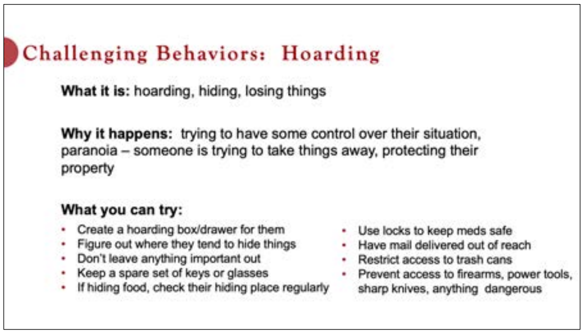
What it is: wakefulness, disorientation or confusion at night, difficulty returning to sleep

Why it happens confusion, over-stimulation, and fatigue during the day, fear of the dark, maybe seeking safety/security

What you can try:

Check bed comfort – too hot? Cold?
Soft music
Daily exercise
Add a night light
Keep a regular sleep schedule
No naps after 2pm
Dementia clock showing night/day
Reduce light and noise
Provide a reflective strip to bathroom
Same nighttime routine
Reduce caffeine and/or alcohol
Offer a soft stuff animal

Slide 22 Challenging Behaviors Hoarding



Challenging Behaviors: Hoarding

What it is: hoarding, hiding, losing things

Why it happens: trying to have some control over their situation, paranoia – someone is trying to take things away, protecting their property

What you can try:

- Create a hoarding box/drawer for them
- Figure out where they tend to hide things
- Don't leave anything important out
- Keep a spare set of keys or glasses
- If hiding food, check their hiding place regularly
- Use locks to keep meds safe
- Have mail delivered out of reach
- Restrict access to trash cans
- Prevent access to firearms, power tools, sharp knives, anything dangerous

Material

What it is: hoarding, hiding, losing things

Why it happens trying to have some control over their situation, paranoia – someone is trying to take things away, protecting their property

What you can try:

Create a hoarding box/drawer for them
Figure out where they tend to hide things
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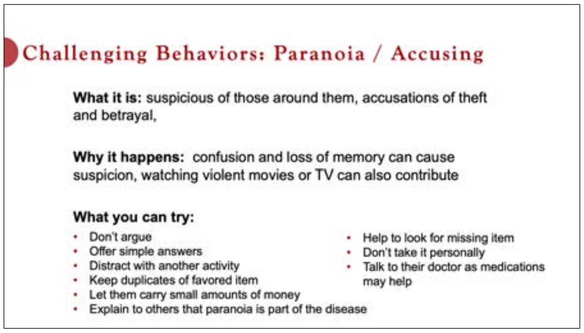
Restrict access to trash cans
If hiding food, check their hiding place regularly
Prevent access to firearms, power tools, sharp knives, anything dangerous

Slide 23 Challenging Behaviors Paranoia / Accusing


Challenging Behaviors: Paranoia / Accusing

What it is: suspicious of those around them, accusations of theft and betrayal,

Why it happens: confusion and loss of memory can cause suspicion, watching violent movies or TV can also contribute

What you can try:
- Don't argue
- Offer simple answers
- Distract with another activity
- Keep duplicates of favored item
- Let them carry small amounts of money
- Explain to others that paranoia is part of the disease
- Help to look for missing item
- Don't take it personally
- Talk to their doctor as medications may help

Material

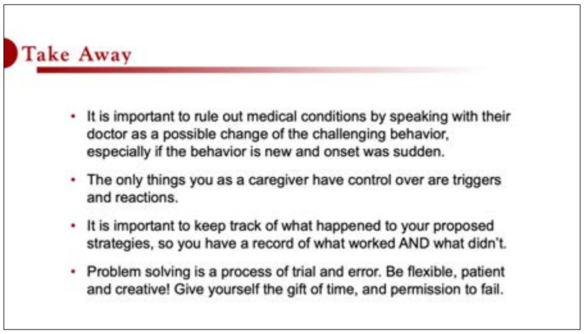
What it is: suspicious of those around them, accusations of theft and betrayal

Why it happens confusion and loss of memory can cause suspicion, watching violent movies or TV can also contribute

What you can try:

Don't argue
Offer simple answers
Distract with another activity
Keep duplicates of favored item
Let them carry small amounts of money
Talk to doctor as medications may help
Help to look for missing item
Don't take it personally
Explain that paranoia is part of the disease

Slide 24 Take Away


Take Away

- It is important to rule out medical conditions by speaking with their doctor as a possible change of the challenging behavior, especially if the behavior is new and onset was sudden.
- The only things you as a caregiver have control over are triggers and reactions.
- It is important to keep track of what happened to your proposed strategies, so you have a record of what worked AND what didn't.
- Problem solving is a process of trial and error. Be flexible, patient and creative! Give yourself the gift of time, and permission to fail.

Considerations

→ *This is the end of module summary. If you have time, you can encourage your CGs to offer what they believe the 'take away' was from this session.*

Material

→ *FACILITATORS: If there is time do the stop & ask.*

STOP & ASK

Thinking back over today's session,
what are the important points you will take away with you?

→ *FACILITATORS: If not mentioned, make sure these points are included in the Take Aways from today's session.*

To summarize, the Take Aways we hope you will take with you today are that:
- It is important to rule out medical conditions by speaking with their doctor as a possible change of the challenging behavior, especially if the behavior is new and onset was sudden.
- The only things you as a caregiver have control over are triggers and reactions.

- It is important to keep track of what happened to your proposed strategies, so you have a record of what worked AND what didn't.
- Problem solving is a process of trial and error. Be flexible, patient, and creative! Give yourself the gift of time, and permission to fail.

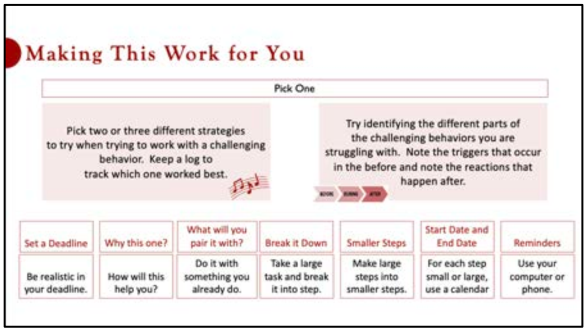
Slide 25 Making This Work for You

Considerations

→ *The Action Plan is perhaps the most important part of this session.*

→ *Encourage the caregivers to **pull out their pen and paper** and create an action plan right there.*

→ *Use the boxes along the bottom to assist in the creation of the action plan.*



Making This Work for You

Pick One

Pick two or three different strategies to try when trying to work with a challenging behavior. Keep a log to track which one worked best.

Try identifying the different parts of the challenging behaviors you are struggling with. Note the triggers that occur in the before and note the reactions that happen after.

Set a Deadline	Why this one?	What will you pair it with?	Break it Down	Smaller Steps	Start Date and End Date	Reminders
Be realistic in your deadline.	How will this help you?	Do it with something you already do.	Take a large task and break it into step.	Make large steps into smaller steps.	For each step small or large, use a calendar	Use your computer or phone.

Material

Activity: Action Plan

ACTIVITY-Directions

FACILITATOR: *Briefly define the steps.*

INTRO: At the end of each session after our review we will work together to create an Action Plan whose purpose is to help you to figure out how you plan to use the skills and tools we explored today in session. To get the benefit from these tools, you must do your part and practice them at home.

The Action Plan has 5 Steps

1. **Set a Deadline:** this is a deadline for when you will start and finish this goal. It is important to be realistic when you think about your deadlines.
2. **Why choose this one?:** The more personal you can make it the more likely it is to push you to complete your goal
3. **What will you pair it with?:** research tells us that piggybacking a new task onto something you already do routinely and consistently is a great way to jumpstart something new. It becomes an automatic reminder to do the new task.

OPTIONAL Break it down: Sometimes the skills and tools we teach can be complicated. At that time, you have the option to break it down into many different steps and just deal with each step as it's turn comes up.

4. **Reminders:** what reminders will you use? Be creative!
5. **Problem Solving:** One of the important parts of any goal making is the problem solving. When you just can't seem to get it done it is important to sit down, figure out what the

issue is, brainstorm some solutions, and try out the one most likely to succeed. If it does succeed and you are able to do the task – great! If not, then go back to your brainstormed list of solutions and try a new until you find what works.

ACTIVITY-Do it

Everyone should have paper and pen. Let's go through creating your own personal action plan step-by-step. As we go through these, write it down on your paper. A written plan has more weight than one you keep in your mind.

- People do better when they limit the number of changes they are trying to make.
    - Have the caregivers choose either *Try out 2 or 3 proposed strategies* or *Identify parts of behavior*

1. Set a deadline – *Be realistic*
    - Next time Mama won't sleep I will try playing some soft music and leaving a night light on

2. Why chose this one? - *The more personal the better*
    - I always feel exhausted, and I'm scared I will mess up something important

3. What will you pair it with? – *Do it with something you already do*
    - Nothing to pair it with

- Optional: Break it down – Take a large task and break it into steps
    - I will pick out some of Mama's favorite music and have it ready for her
    - I will find a soft night light with a pretty pink light since it is her favorite color
    - I will pick 10 songs and load them into a player
    - I will order the night light and figure out the best place for it in her room

4. Reminders – *Computer, phone, calendar*
    - I will post a reminder of my plan next to my nightstand, so I see it when Mama wakes me.

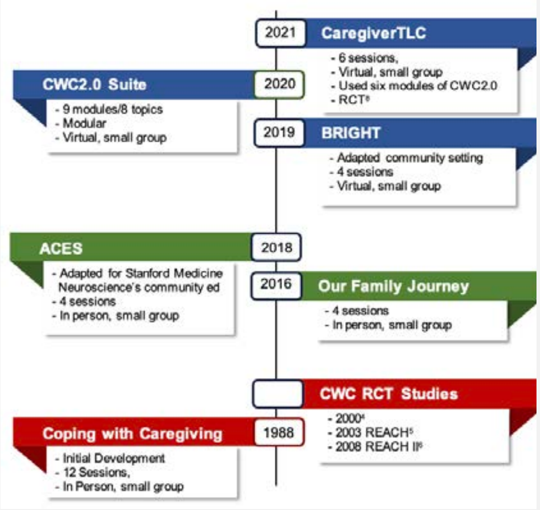
5. Problem-solving - *Pending*

FACILITATORS: *You may want to ask if participant anticipate any issues and plan for it.*

History

CWC2.0 Suite is an update version of the Coping with Caregiving program developed by Dolores Gallagher Thompson PhD, ABPP and her colleagues. The first version of the Coping with Caregiving program is an evidence-based face-to face workshop for caregivers of person living with dementia (PLWD). It is theoretically rooted in two sources: Pearlin's model of primary and secondary stressors as sources of caregiver distress[1] and Beck's cognitive-behavioral model for treating depression[2]. Caregiving is a complex experience and surveys showed that 50-75% of caregivers report symptoms of depression. The original workshop was developed in 1985 and first evaluated in a pilot study in 1988[3]. Results of the first RCT were published in 2000[4]. Subsequently, Dr. Gallagher-Thompson was invited to participate in the first set of the REACH studies: Resources to Enhance Alzheimer's Caregivers' Health (REACH I). That 2nd RCT used the CWC program with Caucasian/ White and Latino/Hispanic caregivers, with very positive results for both groups, compared to a minimal support condition[5].

CWC Development Timeline



Note: This timeline tracks the development of CWC. Blue titles are virtual programs. Green titles are face-to-face programs. Red titles are the initial CWC.

Following the success of REACH I which ran six unique interventions in six separate sites in the US, REACH II was designed incorporating the best features of the successful REACH I programs. The following CWC elements were included in the REACH II multi-component program: home practice was incorporated and was referred to as an *Action Plan*; skills such as controlled breathing were kept to reduce caregiver anxiety; and material on increasing positive activities and challenging unhelpful negative thinking were retained. New material included a Risk Appraisal at the outset to determine which topics would be most helpful to each caregiver. The Risk Appraisal included an assessment of safety in the home, adequacy of the support network, and encouragement for caregiver to take care of their health. REACH II was a 5-site multi-ethnic, multi-racial study of over 600 caregivers of PLWD, done in English and Spanish. Results indicated significant improvement for White/Caucasian and Latino/Hispanic caregivers on an omnibus measure of distress. African American/Black caregivers were less responsive to the program[6].

The Coping with Caregiving program was developed to meet the psychological needs of depressed family caregivers of PLWD. By offering what was essentially cognitive-behavioral therapy in an educational format, the stigma associated with help-seeking for mental health services was reduced. Caregivers were willing to say they were "distressed" and come to a workshop that encouraged them to learn skills to manage depression. It was the first psychoeducational program in the US that was carefully researched and implemented in a variety of settings, with caregivers of diverse ethnic and socio-cultural backgrounds. The original CWC was developed when few services existed that were tailored to caregivers' specific needs. Due to a strong need for culturally appropriate services for Hispanic/Latino caregivers in the state of California, CWC went through several iterations to adapt it for cultural relevance. Similar positive effects on depression and caregiving stress were found in RCTs where CWC was compared to other active programs[4,5,7]. With CWC's success, further adaptations and appropriate modifications in language, format, and examples were developed and studied with other culturally and linguistically diverse groups including Chinese American caregivers, Vietnamese American caregivers, and Farsi-speaking Persian caregivers. There are several programs which have been developed using CWC and the program's core components. A few of the most recent are described in the following text.

Initial CWC Program (1988)
Length: 12 sessions held on consecutive weeks, 2hr duration each session
Intervention Style: Delivered face-to-face in a small group format: 8- 12 caregivers of PLWD who met specific criteria for acceptance of significant symptoms of depression
Topics: Teach a set of cognitive-behavioral skills to improve mood, including identify/add positive activities into daily life, skills for questioning unhelpful negative thoughts about caregiving, developing more adaptive ways to think about their situation and ways to manage problem behaviors of their care recipient.
Materials: Participant workbook and Leader workbook.

Active Caregiving: Empowering Skills (ACES)

ACES is a face-to-face workshop for caregivers of persons with memory loss. In ACES, CWC was modified to include some positive psychology features. Caregivers learn about resilience, stress and stress management, behavioral activation for mood stabilization, tools for changing challenging care recipient behaviors, communication with individual with dementia, family, & providers, and tools for happiness while caregiving such as positive thinking, gratitude and forgiveness. This adaptation was based on caregiver feedback as well as advances in the field of caregiving research.

ACES Program (2018)
Length: Eight-hour workshop: divided into four 2-hr sessions, offered over a 4-wk period
Intervention Style: Delivered face-to-face in a small group format
Topics: Stress, mood, communication, & challenging behaviors
Materials: Participant Packet, & Handouts

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

BRIGHT is an interactive, online workshop for caregivers of persons with memory loss. It was developed to enhance existing coping skills, teach new ones, and acknowledge the depth and breadth of each caregiver's inner strengths. Built using the ACES program as a base and adapted for delivery virtually using a teleconferencing technology. In BRIGHT, caregivers create a care

BRIGHT Program (2019)
Length: Six-hour workshop: divided into four 90-minute sessions, offered over a 4-week period
Intervention Style: Delivered remotely via a teleconference platform
Topics: Resilience, stress, mood, & communication
Materials: Workbook, PPTs, & Handouts

map gaining a clearer understanding of their care network. They learn new skills for coping with stress, and practice new strategies for communicating with the family, with the person with memory loss, & with medical professionals.

CWC2.0 Suite

CWC2.0 is an evidence-informed module-based program that is delivered virtually. It consists of 9 modules that cover 8 topics. Each topic is designed as an independent workshop. Dependent on the needs, the modules can be combined to form short workshops. Each module has 1 topic with 3 sub-topics; each session starts with an agenda, skills are taught through an interactive combination of information, exercises, and discussion, topic is summarized at the end of the session; and an individual Action Plan is created to integrate skills into the caregiver's daily life.

CWC2.0 Suite Program (2020)

Length: Nine modules: 90-minutes each, can be combined into short workshops or used independently
Intervention Style: Delivered remotely via a teleconference platform
Topics: Resilience, communication, stress, frustration, isolation, mood, self-care, care-recipient challenging behaviors
Materials: Facilitator's Guide, PPTs, & Handouts; Companion Website with caregiver materials & resource links sorted by topics

CaregiverTLC

CaregiverTLC is an evidence-based workshop created from CWC2.0. The CaregiverTLC program broaden application of the CWC2.0 from a dementia/memory loss focus to one encompassing physical chronic illness. The caregiver issues are similar: stress, frustration, depressive symptoms, lack of self-care, need for a larger support network, and issues with loneliness/isolation. The psychoeducation and skills from the CWC2.0 program were paired with new examples appropriate for those caring for those with physical chronic illnesses, including memory loss. CaregiverTLC was created during the pandemic and thus followed the CWC2.0 format as a virtual program. It has been evaluated in an RCT[8] compared to a waiting list control with strong positive results. Caregivers learn about stress and stress management, behavioral activation for mood stabilization, resilience and their support team, self-care, frustration and anger management, how to reduce isolation and stay socially connected while staying primarily at home. The Workshop uses CWC2.0 modules but adds a check in at the beginning of each session to review home practice of the action plan and problem-solve any obstacles encountered.

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