# Guiding an Improved Dementia Experience (GUIDE)

EDUCATION AND SUPPORT RESOURCES

## 3

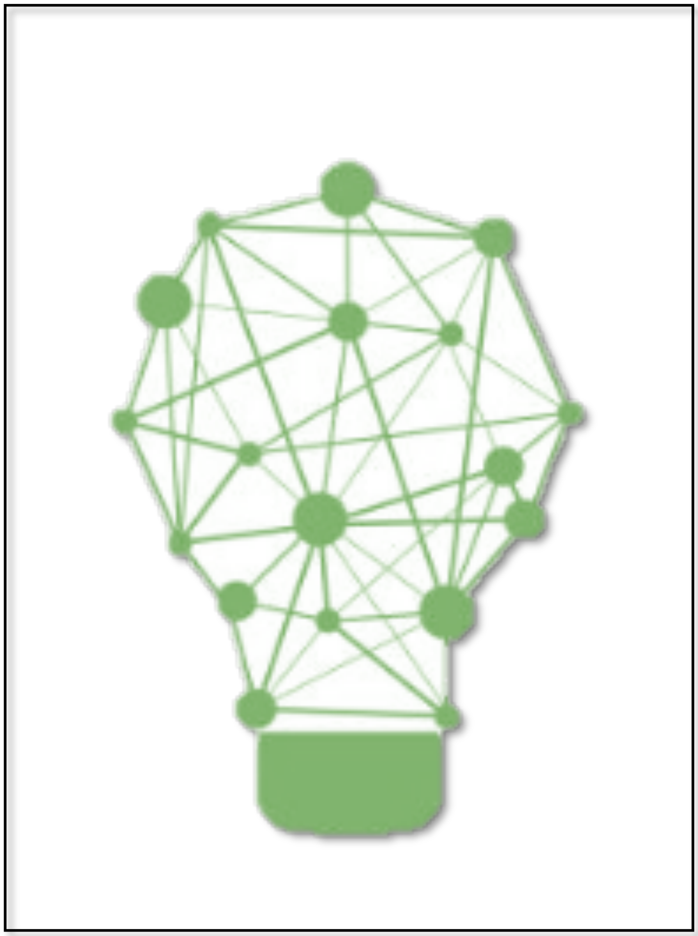
## Techniques and tips for everyday tasks

Caregiver health and wellness

Community resources

BAPTIST HEALTH

# Table of Contents



# Caregiving Tips

## Lifting and Moving

As dementia progresses, your loved one will need help moving to and from the bed, bath, chair or wheelchair. They may also need help after a fall. To help, you have to lift and move (transfer) your loved one.

### General Tips

- **Take your time**; accidents can happen when you rush.
- **Be safe**. Make sure that neither you nor your loved one wears shoes that may slip off or slide on the floor. Clear the pathway of obstacles and loose rugs. Use **assistive devices** (canes, walkers, grab bars . . .) to reduce the risk of injury.
- **Consider a transfer belt**. A transfer belt looks like a wide canvas belt with a buckle. It gives you a sturdy place to hold onto instead of belt loops, which can break. To use: 1. Put the belt around the waist. The tag of the belt should face your loved one's stomach. 2. Buckle the belt. 3. Pull the blet snugly but not too tightly. You should still be able to fit four fingers between the belt and your loved one's body. 3. Shorten the length of the belt if necessary.
- **Consider a swivel car seat cushion.** The cushion looks like a rotating tray and is cushioned with padded fabric. It helps get your loved one in and out of cars.
- Your GUIDE support team or an occupational therapist can also help to educate on the **safest techniques** for transfers and lifts.
- Consider a **back brace** or support if you begin to have discomfort.

### Communicating during lifts and transfers

- Always speak in a **calm and reassuring tone**. Tell your loved one what you are going to do before each step.
- **Make quick eye contact** without staring. As you start lifting and transferring, your voice will naturally fall below your loved one's hearing level. Speak louder without shouting.
- **Are they able to help you?** Ask, "Which side of your body is feeling stronger today?". Use that side to help you.
- **Use signals: Verbal signals** can be a simple work or two. Repeat them as often as needed. Never use an angry or inpatient tone. **Visual guidance**: Use

different colors to help your loved one see where he or she is going. **Use body language or hand signals** to guide. Yor touch should be firm but gentle. Pat your loved one's hand or arm during the transfer to give an extra feeling of security. Encourage them to touch the surface of where they are going. It will let your loved one know he or she will be safe.

## Dressing

Dressing can be a very personal action learned at an early age. However, dressing can become a challenge especially as the disease progresses over time.

### Common Dressing Challenges

- Dresses incorrectly (undergarments over street clothes, legs into shirt sleeves)
- Dresses in clothing, which is not suitable for outside activity or weather
- Dresses or changes clothes only when reminded
- Takes clothes out of the dirty laundry and wears them
- Does not change undergarments regularly
- Unable to use zippers, buttons, laces . . .
- Wears the same outfit for multiple days
- Unable to select clothing

### Recognize Dementia Causes

- Changes in memory
- Changes in the ability to reason and make decisions
- Changes in the ability to focus and pay attention
- Changes in the ability to communicate
- Embarrassment about (un)dressing in front of another person
- Confusion about instructions
- Too many distractions
- Room is too cold or hot, lighting is too dark . . .
- Depression
- Arthritis

### Other Possible Causes

Physical illness, mediation side effects, vision impairment, weak balance . . .

### Plan Ahead and Keep it Super Simple

Provide furniture to sit on while dressing
Declutter to avoid distractions

### Choosing Clothes

**If your loved one can still choose their clothes**, make it easy. Remove clothes that are not in season or are not work regularly. Too many choices may cause frustration. Help your love done make decisions without sounding "bossy". Example: Dad, we are going for a walk in the park. I know you want to look your best but it would be awful if your "Sunday best" got mud on it during the walk. It would be Ok if your jeans got muddy. Do you want this pair of jeans with pockets or do you want that pair of jeans without pockets?

**If they can no longer choose their clothes**, lay them out in dressing order. Make sure they are right-side out. Lay light-colored clothing on a dark blanket (or vice versa) so that your love done can see them more easily.

Add an extra half hour or hour to the amount of time you've scheduled for your love done to dress.

### Pick Your Battles

If your loved one chooses clothing that does not match or are not according to your taste, decide how important it really is. The key is that they feel comfortable.

### Think Outside of the Box

Does your loved one refuse to change clothes? He or she may have lost the sense of time. They may not realize that a day or two has passed. When shopping consider buying two identical sets of clothes. Dress your loved one in one set while you wash the other.

## Eating

Is your loved one refusing to eat? Does he or she hold food in the mouth (pocket) without swallowing? Or scream when eating? Or even spit out the food?

### Common Eating Challenges

- Lost or gained 5-10 pounds a month, eats or drinks more/less than usual
- Screams when food or drink is in the mouth; spits it out
- Refuses to eat or drink; afraid of being poisoned

- Does not touch what is on the plate
- Pockets food
- Chokes frequently or drools while eating – usually in the later stages

**Recognize Dementia Causes**

- Boredom, confusion, depression, grief, social withdrawal, tiredness
- Changes in memory affecting the ability to chew and swallow; use utensils
- Changes in communication skills
- Changes in the ability to focus
- Changes in the senses
- Feels overwhelmed by the amount of food on the plate
- Taste or texture of the food being served
- Changes in eating routines, eating styles
- Too many distractions
- Embarrassment or humiliation when scolded for not eating, forgetting how to eat, forgetting table manners

**Keep It Simple**

**Keep the table setting simple** otherwise your loved one may have a hard time seeing and understanding what is on the table. He or she may no longer recognize common everyday items and their purposes anymore.

Make it easier to enjoy foods normally eaten with a fork or spoon. Turn them into foods that can be **eaten using fingers**. Slice food thinly or pu them into wrap.

**If a utensil is needed, give only one** – a spoon is generally best.

**Limit food choices** to two items.

**Keep in Mind Lifelong Routines**

- If your loved one has never been a big eater, serve food every couple of hours instead of three large meals a day.
- If your loved one always skipped breakfast, give a banana and beverage instead of a full breakfast. Follow up with another food and beverage about an hour later.

**Think Outside of the Box**

**Make it easier for your loved one to eat and drink “on the go”.** If your loved one paces a lot – even during mealtimes – make eating easier. Put a beverage and a plate of sliced fruits or vegetable sticks in the rooms where they pace.
**Consider enrolling in a community meals on wheels** program. Sandwiches can be made with any leftovers.

**Constipation can be a common reason for appetite suppression**. This may be the reason your loved one is refusing to eat. Has it been more than 3 days since a bowel movement? Have they been rubbing the lower back or abdomen? Do they appear to be in pain (straining) or making faces when using the toilet. Has there been a recent change in medication?

Most people experience a lack of appetite and weight loss but some types of dementia cause an **increase in appetite and weight gain**. Changes in the brain may have affected your loved one’s ability to tell when he or she is full. Memory loss may also have caused them to forget that they have just eaten. Or they may be bored or depressed. Consider cutting back on portions or using child locks on cabinets. If more than 5-10 pounds are gained in a month, discuss with you GUIDE support team.

**Progression of Disease**
**As dementia worsens, some pocket food, drool when eating, or lose their appetite completely**. All of these behaviors are related to the disease. Your loved one is not in control of these behaviors. They may have many underlying causes.

**Be sure to maintain good oral health** – check for cavities, denture issues or gum disease. This too may become more challenging over time.

**Spitting out food may be a sign of displeasure** – too salty, too spice, too hot, too cold, to sweet or sour. Tastes as texture preferences change as we age. Be patient. Sometimes it is trial and error.

**Anorexia can occur in late-stage dementia**. Changes in the brain can lessen one’s appetite. These changes can also impact your loved one’s ability to swallow. This can result in drooling or aspiration (when food particles track into the lungs instead of the esophagus). Softer foods and smaller foods may help.

Feeding tubes are often discussed at this stage. Feeding tubes for dementia have not been proven to improve quality or quantity of life. Your loved will likely still aspirate. They may experience bloating or infections.

Anorexia related to dementia is a part of the disease, it is not a failure of you as a caregiver or your loved one as a patient. At this stage, consider comfort foods as a pleasure for your love done and bonding experience and consider your preparedness planning – would hospice be an option to improve quality of life at this time?

## Bathing

As dementia progresses, bathing and personal hygiene may become a challenge. During the middle stages of the disease, your loved one may need to be reminded – and reminded – about bath time and how to bathe In the later stage, you may need to assume responsibility during bath time.

### Common Bathing Challenges

- Does not use soap or wash full body when bathing
- Not using toothpaste when brushing teeth
- Looks unwashed or messy; has noticeable body odor
- Insists he or she has already bathed or does not need to bathe
- Afraid of bathing, shampooing, brushing teeth . . .
- Bathes or brushes teeth only when reminded
- Unable to test water level and temperature
- Refuses to get into the tub or shower; Refuses to shampoo

### Recognize Dementia Causes

- Changes in the ability to reason and make decisions
- Changes in the ability to focus and pay attention
- Changes in communication skills
- Changes in senses, ability to understand signals
- Anger or frustration about the loss of independence
- Memory loss
- Depression

### Other Causes

- Embarrassment about being naked in front of another person
- Physical impairment or illness such as arthritis, dizziness, vision/hearing deficits
- Fear of falling or slipping

**Plan Ahead**

Make bath time and personal hygiene safer

- Declutter the space
- Provide furniture for your loved one to sit in while dressing and undressing
- Explain step-by-step what you are going to do
- Use hand-held showerheads, grab bars, rubber non-slip mats, shower benches/chairs, transfer benches and non-slip rugs

Your loved one may be frightened by the sound of the bathroom fan or the water filling or draining from the tub.

- If the bathroom gets foggy, leave the door open
- Wait until you have filled the tub to bring him or her in
- Wait until he or she leaves to drain the tub
- Add an extra half hour to the amount of time you have budgeted for bathing

If your loved one forgets how to bathe or brush teeth

- Consider a prop doll to show step-by-step instructions

**Pick Your Battles**

Bathing two or three times a week is usually all that is needed. Forcing a daily bath out of habit may cause agitation. Dementia may cause your loved one to lose sense of time. It may not be clear that it has been days since the last bath. However, if there is a strong odor that does not go away, phone the GUIDE team. There may be a medication or a medical issue that is causing the odor.

**Think Outside the Box**

**Create a routine.** Write bath day on the calendar and/or tape a “Today is Bath Day” on the bathroom mirror. Consider a talking alarm clock to set audio reminders or announce bath time. It may take you out of the argument if your loved one argues with the clock instead.

**Make bath time an event to look forward to.** If your loved one used to sing songs in the shower, play those songs as you get the bathroom ready. Toss the bath towel or robe into the dryer before bath time. The heat may be comforting while he or she waits to get in or gets out of the shower. Put rubber ducks or other soft toys in the tub. If his or her hands are busy, they may be less likely to hit during the bath. Consider adding aromatherapy to the routine, if he or he does not have sensitivity to products with a scent.

**Be alert for unexpected issues**

Dementia may affect how the brain is sensing water pressure. The water may feel like stings to your loved one. Consider a bath.

Rinsing hair may worsen feelings or dizziness or increase the fear of water getting into the eyes. Consider no-rinse shower caps or no-rinse shampoo.

Skin may hurt when you rub the towel vigorously. Try patting instead.

Unsteadiness or a worsening ability to hear instructions may be related to ear wax build-up. Use ear wax removal kits instead of cotton swabs.

Sounds from water or the fan may be louder to your loved one if they have a hearing aid. If the hearing aid volume is set too high, it may be picking up routine background sounds as much louder than they actually are. Readjust the setting.

# Navigating Tough Topics

## Sex

Your role has changed from partner to caregiver. Your sexual relationship may also change as dementia progresses. You may want to continue the sexual relationship you have had with your partner. Or you may no longer feel that bond because of the changes in your lives. Either way, it is okay.

There are many types of sexual closeness: hugging, cuddling, touching and intercourse.  It is okay for you and your loved one to be sexually close in all of these ways. **Make sure that both of you are comfortable.** If your loved one is scared or in pain, change or stop what you are doing. If you become scared or in pain, tell your loved one to stop.

**Your interest in sexual activities with you loved one may change.**

- Your sexual relationship may be stronger than before. Touching may be a stronger way to communicate than words.
- Or you may wish to be sexually close with your loved one but not have the desire. Your role is changing from partner to caregiver. You may feel too exhausted. You may find that dementia has negatively affected your loved one's sexual abilities.
- Or you may no longer feel the need to be sexually close with your loved one. You may feel you can no longer enjoy sex as you may now be helping with bathing and toileting difficulties.
- You may decide to sleep apart from your loved one. It is okay if you feel more comfortable sleeping in another room. If necessary, use a room monitor so you can hear movements in your loved one's room.
- If you have less sexual needs, do not feel guilty. Caregivers of people with dementia often have these feelings. Discuss with your doctor or therapist. Consider attending a support group. Keep in mind, there is no right or wrong answer. There is no single solution.
- Your loved one may be confused, frustrated, jealous or even agitated by your reduced sexual interest. Reassure your loved one that you still love him or her. Find other ways to be intimate without intercourse. If your loved one still has

good language skills, encourage him or her to talk it over with a doctor, therapist, support group or close friend.

- Your loved one may have an increased desire for sexual activities. If you want to enjoy the increase, that is okay. If you do not, that is okay too. Keep in mind that your loved one's memory has changed. They may not remember having sex a few minutes earlier. Or, their language skills may be affected, which impacts their ability to express the need for closeness, touch, comfort, warmth and security. You can say no. Show or talk about other ways to be physically intimate without intercourse.

- Your loved one may continue to have sex but without showing much interest. You may feel guilty because you cannot tell. Watch for non-verbal signs of interest. Stop if you see any signs of unwillingness.

- Your loved one may begin to act in ways that are sexually inappropriate. See the chapter on Inappropriate Sexual Behaviors in booklet one.

## Sex and Residential Care Facilities

If your loved one is moving to a residential care facility, ask about the residents' romantic and sexual relationship policies. This may be an uncomfortable subject for many but this is a common consideration for facilities.

**What happens if your loved one develops a romance – even a sexual relationship – with another resident who consents?**

If you are a spouse or long-term partner, this is one of the most challenging dementia caregiving issues you may face. As the dementia progresses, your loved one may no longer recognize you and may not remember you are his or her spouse.

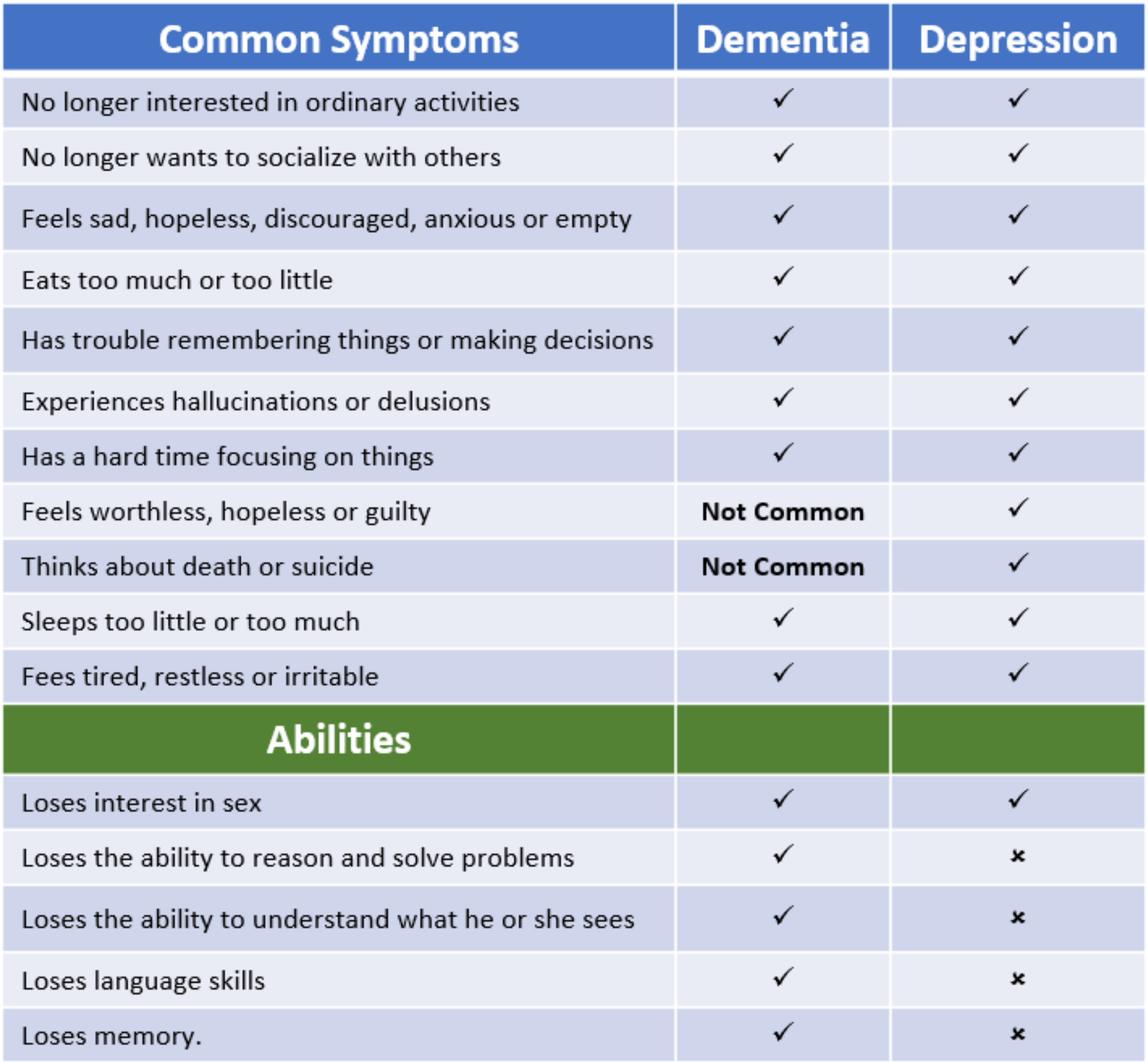
As they adjust to life in the facility, they may be drawn to another resident. Would you want the facility to stop the relationship no matter what? Or would you accept – perhaps encourage – that relationship because the dementia has changed your loved one so much? There is no easy or right answer to this very personal question. If you are faced with this decision, talk with your family, friends, clergy, support group or the GUIDE team.

## Depression in the Care Recipient

Does your loved one refuse to leave the house? Do they often speak of dying? Have they been feeling extremely sad for more than two weeks?

Your loved one may be experiencing depression. It can be difficult to tell if someone with dementia also has depression. Difficulty in finding the right words makes it even harder to express feeling. Additionally, the symptoms of depression may come and go and may be less severe at times.

Many symptoms of dementia are similar to the symptoms of depression.



| Common Symptoms | Dementia | Depression |
|---|---|---|
| No longer interested in ordinary activities | ✓ | ✓ |
| No longer wants to socialize with others | ✓ | ✓ |
| Feels sad, hopeless, discouraged, anxious or empty | ✓ | ✓ |
| Eats too much or too little | ✓ | ✓ |
| Has trouble remembering things or making decisions | ✓ | ✓ |
| Experiences hallucinations or delusions | ✓ | ✓ |
| Has a hard time focusing on things | ✓ | ✓ |
| Feels worthless, hopeless or guilty | **Not Common** | ✓ |
| Thinks about death or suicide | **Not Common** | ✓ |
| Sleeps too little or too much | ✓ | ✓ |
| Fees tired, restless or irritable | ✓ | ✓ |
| **Abilities** | | |
| Loses interest in sex | ✓ | ✓ |
| Loses the ability to reason and solve problems | ✓ | ✗ |
| Loses the ability to understand what he or she sees | ✓ | ✗ |
| Loses language skills | ✓ | ✗ |
| Loses memory. | ✓ | ✗ |

## Next Steps

- If your loved one is showing signs of wanting to commit suicide, call 911.
- See the doctor and talk to your GUIDE team if your loved has some of the symptoms listed above for more than two weeks. They use drugs or alcohol to feel better. Or they begin to think or talk about not wanting to "be here" anymore. They can assess for signs of depression or other medical problems, which may present the same way.

## Grief in the Care Recipient

Your loved one will continue to experience grief just like those without dementia. They may not be able to understand their grief or talk about it with others. It may be expressed as fear, agitation, restlessness, distress or suspicion.

**Grieving loss that will come.** Dementia is a progressive disease. There will be many losses during the disease including independence and the ability to do many previously enjoyable things. Thinking about these losses before they occur is called **anticipatory grief.**

**Strategies to Help**

- Reassure: The road ahead will be long but you will be there to listen and help. Remind them that is okay to feel scared, frustrated or angry. It is okay to want to cry.

- Help regain some control: Encourage discussing how your loved one would like to live with dementia from now on. Explain that you would like their help now so you can make the best decisions on their behalf in the future. Ask your loved one what activities they enjoy or wish to do and plan them now. Ask what types of adjustments you should make at each ability level. As painful as it may be, ask them for help in planning financial, legal and end of life matters. Most importantly, help your loved one focus on what they can still do.

- Encourage your loved one to participate in a support group or one-on-on counseling with a therapist.

**Grieving the loss of a loved one from the past.** It is not unusual for your loved one to repeatedly ask for someone who died a long time ago. They may have lost the sense of time. Telling your loved one that the person died a long time ago will cause pain and confusion. Look for the emotion behind your loved one's need for the deceased: Example: "You seem angry, yelling for Mom. Please tell me why you are angry." If he says, "Your Mother didn't put supper on the table", give him a quick snack. Ask him to help set the table.

**Grieving the loss of a loved who has recently died.** First, decide whether to share the news with your loved one of someone else's death. Remember, your loved one is a different person now. At one time, they would have "needed or wanted to know" and had "the right to know". Your loved one's needs are different now and they are basic.

- If you share the news, keep it simple. For example, "Mom has died." Avoid words that may have another meaning such as lost or passed. Your loved one may get confused and think they are literally lost and want to look for them.

- Avoid sharing details of the death, as the disease progresses, these details may not help them understand the reality of the death.

- If they keep asking about the death, support them through the changes. Share your own feelings of loss. Help them remember the deceased without emphasizing that the death was recent. Example: "I miss Mom, too. She was such a good piano player. Let's have a concert now. I will play her favorite song on the piano. You can be the conductor."

- Look at the emotions or reasons behind your loved one's focus on the deceased. Just because they have dementia, it does not mean the emotions or feelings are gone. What they may have difficulty with is expressing those emotions verbally. They may show grief by becoming agitated or restless, They may feel "lost", "cut off" or that "something is not right". They may feel confused because someone close if "missing". To stay connected keep favorite items nearby (photos, blankets, toys . . .). Play favorite music or television programming. Serve favorite foods and drinks.

- Your loved one may have confusion over time and circumstance, and may not understand who has died. Example: His wife just died. Though his mother died several years ago, he may think it was she who just died.

## Depression in the Caregiver

Do you feel hopeless? Are you more irritable or impatient than usual? Have you lost interest in thongs you used to enjoy? Have you been feeling extremely sad for more than two weeks?

You may be experiencing depression. Some people say “depressed” when they mean “very sad”. Feeling very sad when your loved one was diagnosed with dementia is expected. Feeling very sad as you and your loved one face the daily struggle of dementia is expected. Life has handed you a monumental challenge. Feling sad and even angry is a normal reaction.

Depression is more than feeling very sad at a sad situation. Depression is an **overwhelming** feeling of sadness. You may feel lifeless and empty. You may feel no joy and no longer look forward. Making decisions may become hard, even simple chores may become nearly impossible to finish.

| Common Symptoms of Depression |
|---|
| No longer interested in ordinary activities |
| No longer wanting to socialize with other people |
| Feeling sad, hopeless, discouraged, anxious or empty for a long time |
| Eating too much or too little |
| Has frequent aches or pains that do not respond to treatment |
| Has trouble remembering or making decisions |
| Experiences hallucinations or delusions |
| Has a hard time focusing in tasks |
| Thinks about death or suicide |
| Sleeps too little or too much |
| Feels tired, restless or irritable |
| Loses interest in sex |
| May use alcohol or drugs to cope and feel better |

If you have these feelings, you are at risk for depression. Depression is not a choice. It is a medical condition that requires support and treatment. If you think you are experiencing dementia symptoms, discuss it with your provider as soon as possible. **If you are thinking of suicide or harming another person, call 911 or the local emergency number to get help now.**

If diagnosed with depression, you can work together with your provider to find a treatment plan. Note: Many symptoms of depression are similar to dementia. **Avoid jumping to the conclusion that you have dementia.**

Your provider will assess any medical problems, which might mimic or cause the same symptoms as depression. If depression is diagnosed, there are three common types of treatments.

**Cognitive Behavioral Therapy.** This means changing the way you do certain things or changing the way you behave in certain situations. You also change the way you think about yourself and your circumstances. Example: You often take the blame for whatever goes wrong. You therapist may suggest that you stop and consider if you truly have responsibility for what has happened.

**Talking with a therapist or participating in a support group.** This means sharing your thoughts and feelings with others who are in similar situations. You may find that you are like many people who are dealing with life's challenges.

**Medications.** Antidepressants work in different ways for different people. You may have to try several different types or doses before finding one that works for you. If you do not feel better after the length of time your provider recommends, discuss it with them again. It may take several months to find an effective medication and/or therapist. Be patient with yourself and your loved one.

## Grief in the Caregiver

Do you miss your loved one even when he or she is alive? Do you worry about how the next disease will affect your loved one? Do you have a hard time enjoying the good times with your loved one because you fear what lies ahead?

You may be experiencing what is called “anticipatory grief”. You can think of it as pre-grieving. You know there will be loss in your life but it has not happened yet. Loss is a main feature of dementia. Loss of memory, independence, communication and personality unfolds over the months and years. No two people are the same. You and tour loved one will experience and grieve this experience in your own way.

**Common loss felt by caregivers**

- Relationships: family, friends and colleagues
- Money or lifestyle taken for granted
- Personal dignity
- Hopes and dreams
- Planned future
- Independence
- Intimacy, sex
- Privacy
- Control

You can think of dementia as a series of losses. It can be as painful as grieving an actual death because it seems to go on and on. Ongoing grief can lead to depression, if it is not treated.

**Watch for these common signs of grief**

**The Physical:** Loss of concentration, numbness, headaches, body aches, crying, shakiness, dizziness, sensitivity to noise, sleeping problems, eating problems, breathing difficulty, tightness in the throat and chest, restlessness

**The Emotional**: Shock, denial, regret, sadness, guilt, anxiety, despair, panic, loneliness, self-pity, resentment, anger, feelings of abandonment, mood swings.

**The Social Signs:** Acting angry, hostile irritable or short-tempered; withdrawing from usual social activities; avoiding family and friends; loss of interest in personal appearance; increased use of tobacco, alcohol, prescribed medications or drugs.

**The Spiritual Signs:** Feeling anguish; feeling spiritually empty; feeling uncertain in previous beliefs such as life after death; asking “Why him/her?, Why me?, How could this happen? Why did this happen?";being angry with God; questioning priorities.

## Strategies to Help

- Accept your feelings as typical for a dementia caregiver. Grief is a natural human emotion.
- Take care of yourself; grief can lead to depression. Don't wait. Seek help now.
- Practice living in the moment. Try not to worry abut what will happen next. Enjoy the times when you feel connected to your love done. Take a deep breath and find joy in the moment.

## Getting the Appropriate Help

Find a therapist who is trained in anticipatory grief. The therapist can help you and your loved one:

- Deal with wishes that you could have prevented the dementia.
- Deal with unresolved issues about your relationship before the diagnosis.
- Prepare you both for changes in the roles of your current relationship.
- Find peace in not having all the answers.
- Accept and adapt to significant life changes.
- Address the inability to find closure when no death has occurred.
- Address your family and friends' inability to recognize you and your loved one's need to grieve though no death has occurred.
- Cope with the desire for your loved one to live as long as possible and the confusing desire for their suffering to end.
- Deal with your concern about failing if you ask for help or can no longer look after your loved one anymore.
- Address the guilt of enjoying things that your loved one now has difficulty with.
- Deal with the unrealistic expectations that you may place on yourself.

Ask your GUIDE care team, other caregivers or look to The Alzheimer's Association for help to find a qualified therapist.

## Grief and Loss after Caregiving

Bereavement – or the process of grieving a loss – is an expected outcome to the death of a loved one. This grief helps work through the pain and adjust to life without the deceased. It means learning to live with the loss. Everyone grieves differently.

Even if your loved one was not enrolled in a local Hospice program, you can reach out for their community-provided bereavement services and resources. These services may help you or other friends and family cope with the deep sorrow of loss.

# Caregiver Wellness

## Caring for Yourself

Do you often say "I am fine" even when you do not feel fine? Do you focus on your loved one's needs and ignore your own? Do you feel guilty when you take the time to care for yourself? Has feeling tired and worried become your new normal?

**Here are six strategies for taking better care of yourself:**

- Think about why you do not take better care of yourself.
- Begin thinking in a different way about taking better care of yourself.
- Set goals for taking better care of yourself.
- Solve problems that block you from taking better care of yourself.
- Ask your care team to do their part so that you have time to take better care of yourself.

**Think about why you do not take better care of yourself.**

The answer may be obvious to you. You have no time. Your loved one needs all your attention. Look more closely at that answer.

- Do you feel guilty because you are healthy and your loved one is not?
- Do you believe you are indestructible and don't need to worry about yourself?
- Are you worried others may think you are selfish or uncaring if you take time?
- Are you afraid others may tell you to put your loved one in a residential facility?

**Ask this second question. Why do I think this way?**

Did someone tell you that your family's needs always come first?
Are you assuming your family's needs come first because it has always been so?
Have you often been the one to take care of others at the expense of your needs?

**Begin thinking in a different way about taking better care of yourself.**

Consider these examples if you have identified at least one belief that holds you back from taking care of yourself. **Examples: Old way:** I do not have time to see my doctor about my headaches. **New way:** I must take care of the headaches so I feel up to caring for Mom. **Old way**: I cannot take the time for my book club/exercise class/walk/yoga/gardening. It is not fair for me to have fun while Dad is suffering. **New way:** My book club/exercise class/walk/yoga/gardening help reduce my stress. Dad will sense that calm. **Old way**: If I take this time to myself, my husband will think I do not love him as much. **New way**: My husband knows I love him. I show it to him every day with what I do. He loves me, too, and would want me to take some time to enjoy myself."

**Set goals for taking better care of yourself.**
What goals should you set? Keep them short – about 5 words. Look at your answers in the checklist at the end of this section. Which ones scored 3s, 4s or 5s? **Example:** In doing the checklist, you could not remember what you ate for supper last night. Perhaps the goal would be: Eat 2-3 nutritious meals every day.

To reach each goal, break it down into smaller steps. **Example:** Think of reasons you have not been eating nutritious meals. Is it because you feel you cannot spare even 15 minutes to cook or eat? Perhaps a small step would be: "Buy same-day cooked foods from deli."

Set a date for reaching each goal and smaller step. **Example**: Goal of eating 2-3 nutritious meals every day by the end of 3 months. The smaller step of buying deli food should be easier, so maybe start this weekend.

**Solve problems that block you from taking better care of yourself.**
As you try to set goals and take smaller steps, you may run into obstacles that block you from achieving them. Solve these problems now instead of letting them grow bigger. **Example: Problem:** I am too tired to exercise in the evening. **Solution:** I will walk for 15 minutes every morning while my husband is still asleep and before I get too tired. I will ask a neighbor or other care team member to come to my house in case my husband wakes up while I am exercising.

Ask your care team to do their part so that you have time to take better care of yourself. As the team captain, you can never do all of the work. Look at the entire team standing behind you. Think about ways the team can free up time you need to take better care of yourself. If you are not sure, just ask the care team for help.

# Checklist: How Well Do I Take Care of Myself

**I exercise on a regular basis.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I make and keep preventative and necessary medical, dental and vision appointments.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I have a job or regular volunteer activity that I like.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I do not use tobacco.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I do not abuse alcohol or drugs.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I sleep at least 6-8 hours each night.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I have a hobby or recreational activity that I enjoy and spend time doing.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I eat at least one person 2-3 nutritious meals a day.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I have at least one person I can tell all my problems and successes.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I take time to do things that are important to me (church, spend time alone, garden, read, spend time with friends and/or family).**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I have an easy time sleeping at night.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

**I have personal goals and am taking steps to achieve them.**
1=almost always. 2=frequently 3=sometimes 4=rarely 5=never

Circle the number that shows how you currently feel. **Total the score: ____.**
**Total Score of 12-24**: I am doing a great job of taking care of myself.
**Total Score of 25-36**: I am good at taking care of myself, but I can improve.
**Total Score of 37-48**: I am at moderate risk for having personal health problems.
**Total Score of 49-60**. I am at high-risk for personal health problems.

## Managing Stress

You probably already know that you have too much stress in your life. But did you know that the stress of caregiving can harm your health? If your health fails, you will not be able to continue caring for your loved one. In fact, you may find yourself needing someone to look after you.

### Causes of Caregiver Stress

**Emotional demands** caring for your loved one. Your loved one need a high level of physical and emotional care.

**Conflicting demands.** You feel pulled in different directions by your own needs and the needs of many others (your love done who has dementia, your spouse or partner, children, other family members, employers, colleagues . . . ).

**Uncertainty of roles.** The role you play in your loved one's life will change. Sometimes the role will go back and forth between what was and what is. This is hard. An adult daughter finds herself telling her mother what to do. A spouse will be more of a parent than a partner. This shifting of roles can be uncomfortable. It may also cause hard feelings on all sides of the relationship.

**Workload**. There is just too much to do.

**Conflicting policies and procedures of insurance companies.** These can prevent the care team from doing what is appropriate. These conflicts also prevent you from receiving the services you need and want.

**Navigating the healthcare system.** Multiple appointments with multiple providers including office visits, laboratory orders and pharmacy pick-ups, arranging transportation to and from the clinics and wait- times, which can be challenging all on their own.

**Lack of Privacy.** You cannot find time to be alone. Your loved one may be at a stage when he or she cannot be left alone. There may be people going in and out of your home all of the time to assist with caregiving.

## Signs of Stress

**Physical:** Fatigue (tiredness), headaches, skin irritations, frequent infections, breathlessness, tight muscles, muscle twitches.

**Emotional:** Irritability, depression, loss of confidence, fussiness, apprehension (fear of something bad happening), alienation (withdrawal from a social group or activity), apathy (loss of interest, enthusiasm or concern).

**Mental:** Worrying, making hasty decisions, impaired judgement, muddled thinking, nightmares, negativity, indecision.

**Behavioral:** Insomnia (unable to get to sleep or stay asleep), accident-prone (tend to have more than the average number of accidents), loss of appetite, over-eating, loss of sex drive, drinking more, smoking more, restlessness.

## Stress and Your Body

Your body responds to stressful situations by releasing certain types of hormones. As the level of "stress hormones" increases, it can affect different organs. These hormones can impact your heart, stomach, liver and even our emotions. Replacing unhealthy coping strategies with healthy stress management is the key to maintaining your health. It will help your body process these hormones and minimize risk.

## Healthy versus Unhealthy Stress Management

You may feel you are already managing your stress. If you are easing your stress with unhealthy strategies, they may cause more harm than good.

- Are you calming yourself by drinking more alcohol than usual?
- Are you taking more medications than you are prescribed? Or taking another person's medications?
- Are you eating more "comfort foods", high in sugar, fats or carbohydrates?
- Do you lose hours watching television programs or movies frequently?
- Do you have "pity parties" all the time?
- Are you yelling at the people around you about anything and everything?
- Do you feel like a victim and blame other people for whatever is wrong?

## Strategies for Healthy Stress Management

1. **Recognize the signs of stress**.

2. **Ask yourself, “What causes or drives my stress**?” **Examples**: My family creates stress for me because they often criticize how I look after Mom. I create stress for myself because I cannot say no to anyone even though I am overwhelmed.

3. **Recognize what you can change. Let go of what you cannot.** The things you can change are the ones you have control over. Since you have no control over what other people think, say or do, let it in and let it go out. What you can control is your own response. Avoid arguing. Acknowledge the feeling and opinion. What you chose to do after that acknowledgement is solely within our control. Their words have no power over you. **Example:** Thanks, Aunt Edna, for sharing your opinion of how I am caring for Mom. Would you come over at noon tomorrow to prepare his lunch while I run to the store?”

4. **Take action.** Find our peace. These are some recommendations: Music, Stretching, Meditation, Adding fun activities back into your life (popping popcorn and watching a favorite movie on the couch; talking on the phone to a good friend; listening to music from your teenage years; going to plays, picnics or community events; walking in the park, going for ice cream; baking a cake; driving a scenic highway; gardening). Make it a commitment to try each or another at least twice. Find the ones that work best for you. The most important thing is to **practice** them daily – not just when stressful events occur.

## Asking for Help

Is it hard to ask for help, even though you know you need it? Do you feel that if you ask for help people may think you do not know what you are doing?

**Do you believe you are the only person capable of taking care of your loved one?** You are the best person to care for your loved one. However, other members of the care team can do a good or even a great job. Give them a chance for short periods of time. You can try for longer times once you are more comfortable.

**Do you believe it is just easier to do it yourself?** It may be easier to do things yourself in the beginning. However, caregiving is a long-term responsibility. With the care team shouldering some of the tasks, you will have time to handle new challenges or take better care of yourself.

**Do you believe that if someone else helps, you will not get the credit you deserve?** You may not realize how much other people know and appreciate the role you play. Asking for help does not reduce the role you play as care team captain, it only increases the amount of support your loved one receives.

**Do you believe or fear you will be rejected if you ask for help and that you will become angry?** Some care team members cannot help when you ask. They may have valid reasons for not helping. Do not take it personally. Give them the benefit of the doubt. Take a dep breath and go down the list to the next care team member. Many team members want to help but may not know how. You will not know their answer until you ask.

**Do you believe that people should know what you need and that you should not have to ask them?** You are not a mind reader who knows how willing others are to help you. In the same way, other people are not mind readers who know what you do and do not need. Some people see you doing a good job and assume you do not need help. Even those who see your struggles may have no idea how to help. Tell them.

**Do you believe that no one will help you no matter what you say or do?** You may not have family members or friends close by that can help you. You may have been turned down when ou have asked for help. Never give up! Make finding help an important part of your role as the care team captain. Be creative. Be bold. Be assertive.

**Remember** the care team is made up of more than medical professionals and other service providers. The care team includes you, family, friends, clergy, neighbors . . .

**Assertive Communication**

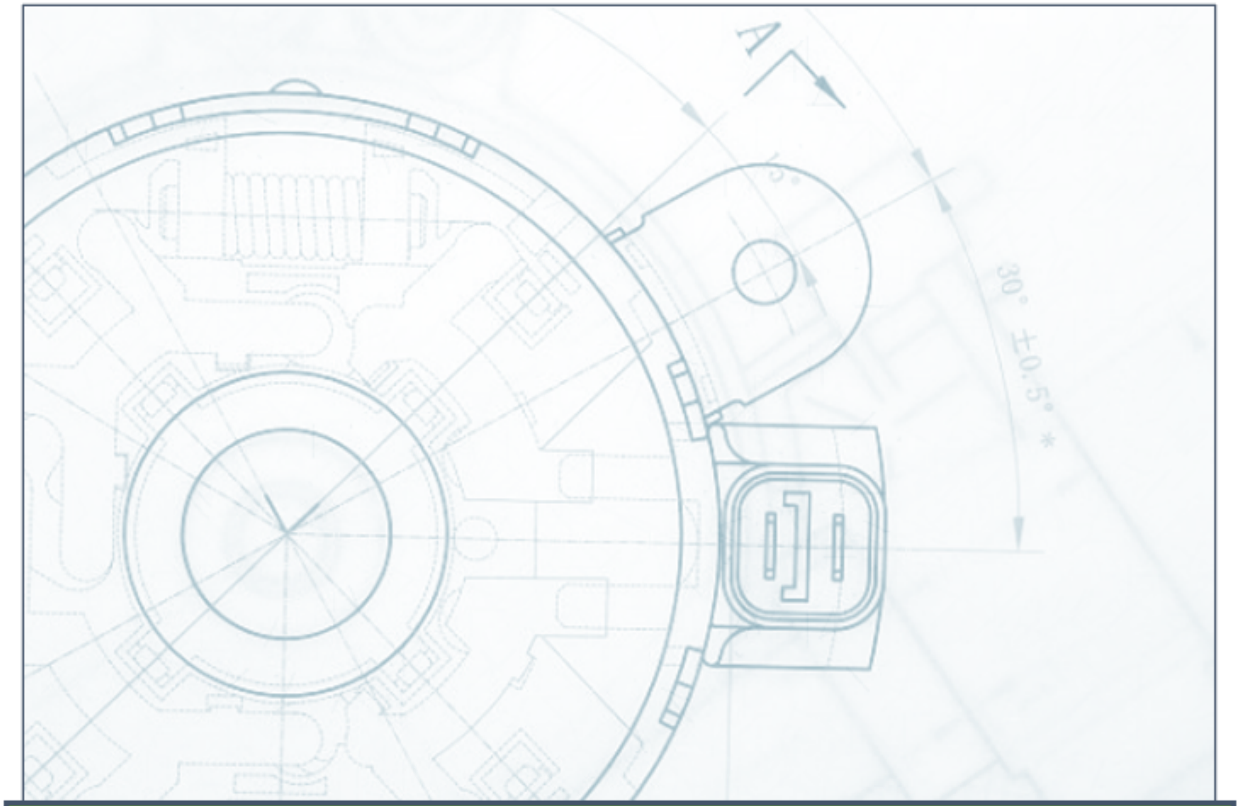
Some people think assertive communication is being bossy or loud. Instead, it is open, honest and direct and is based on mutual respect. You are not begging or blaming. You are telling him or her the help you need and why. You also respect what the other person has to say even though you may not agree with it. Being assertive is not the same as being passive or passive-aggressive or aggressive.

**Passive Communication**: I know you are too busy to help your dad, Cousin Mike. Do what you can. I am already taking care of Uncle Ali 24/7, so I have no worries.

**Aggressive Communication**: You are the most selfish man I have ever met, Cousin Mike. You do not even help your own dad. Here I am, working my fingers to the bone looking after him without any help from you. Who cares about your finals anyway? It is not like anyone would hire such a selfish person.

**Passive-Aggressive Communication:** Kelly, I cannot believe Cousin Mike! He said that he is very busy and cannot even spare 15 minutes to look after his father while I take a break. Of course, I had to say, 'Yes, I understand, Cousin. What else could I have said'.

**Assertive Communication:** I need help looking after your Dad, Cousin Mike. I know and respect that you are busy with finals. We should discuss how we can work together. Let's talk more about it over lunch on Saturday at noon. **Or, once the relationship is established.** Uncle Mike, I need you to sit with your dad this Saturday for one hour. The time is flexible from noon until 5PM. What time works best for you?



# Resources

# Tips for Taking Care

**Don't focus on the worst things that can happen.** **Example**: You may have been thinking: Caregiving is so exhausting, it is going to kill me. Try thinking this instead. Caregiving is very hard but I have overcome bog problems before. I will overcome them this time too.

**Let go of things that cannot be undone.** **Example**: Your loved one has been focused on complaining about how a doctor spoke to her and what she should have said. Encourage her to write down how she will handle the conversation differently next time. Then, encourage her to forget what happened and focus on what she can do now.

**Stick to a routine.** This applies not just to your loved one but also to you. Even if you do  not have to go anywhere, get out of bed, eat breakfast and get dressed every morning. Many caregivers say that keeping daily routines reduces a sense of depression.

**Connect with others.** Caregiving can make you feel alone and you may not even realize it. Call a friend or join a support group. Even a small amount of interaction with others can make a big difference.

## Focusing on Positive Thoughts

Be careful how you talk to yourself. You would never allow someone to speak to you the way your mind may speak to you. When you hear negative self-directed thoughts, fight back. Stop them immediately. Replace them with something positive or change them in a positive way.

**Example**: Negative: I am so stupid. **Positive**: I make mistakes but usually I do OK. Negative: I will never be able to do this right. **Positive**: I am learning and will get the hand of it soon if I keep trying.

**Monitor your loved one's self talk too.** **Example**: You loved one says: I do not want to leave the house again. I am worried people will treat me differently because of my dementia. **Encourage them to say**: I am still me. I am still the same person. I just do or say things in a different way. My true friends are the ones who will be worried if they do not get to see me anymore.

**Practice Positive Thinking**
Do more than say kinder things to yourself. Think more positively about what goes on around you. The next time you feel hurt or angry, take a stop back. Think through the event. Try these steps to positive thinking.

**Step I: Identify the situation.**
What just happened? What events led to the situation.

**Step II: What were your thoughts in that situation.**
Recognize unhealthy thoughts. Watch for "all or nothing" thinking, "awfulizing" thinking and "focusing on the negatives".

**All or nothing** (ought, must, should). **Example**: I must get Uncle Lou to behave when we go out. What if he undresses in public? I will be so embarrassed that I will never be able to go out into public again.

**Awfulizing** (awful, terrible, horrible). **Example**: What if Uncle Lou undresses in public? It will be horrible. Family Services may take him away because I am a terrible caregiver.

**Negative Thinking.** **Example**: You leave a message for your Cousin Anne asking her to call you about Uncle Lou. She does not call. You find yourself thinking negatively. What doesn't she call back? She just does not care about Uncle Lou or me.

**Step III: How did you feel in that situation?**
Describe your feelings and reactions.

**Step IV: What is a different way of thinking about the situation?**
**Come up with positive solutions and act on them.** Example: Try calling Cousin Anne again. You may find out she did not receive your original message.

You may have thought of an experience as horrible. Now, try to think of it as merely unpleasant. **Example**: I wonder what Cousin Anne did not call me back. Perhaps she did not get my message. This is an important step. It may be hard at first. The more you use it, the easier it will become. Use more positive thoughts instead of “all or nothing” or “awfulizing”.

**Remember: Just because a negative thought comes into your mind, it does not mean that it is true.**

**Step V: Match milder emotions to your milder thoughts.**
**Example:** Instead of feeling devastated that Cousin Anne did not call you back, you might feel only disappointed.

## Dealing with Negative Emotions

Do you feel guilty after yelling at your loved one? Do you resent your loved one foe making you feel guilty? You may also feel other negative emotions: anger, fear, frustration, helplessness, guilt, jealousy, loneliness, sadness . . . **It is natural to feel these negative emotions. Your emotions are a part of who you are.** Deal with your negative emotions instead of letting them block you from taking better care of yourself.

### Step I: Take responsibility for dealing with your negative emotions.

No one else had control over your emotions. No one else can change them.

### Step II: Identify the source of your negative emotions.

Is it an unmet need that you have? Is it the feeling you do not have what it takes to be a caregiver? What kinds of challenges block you from taking better care of yourself?

### Step III: Watch out for the “hooks”.

Hooks are things other people say or do to manipulate you. The “hooks” are used to make you react in a certain way, to get you “off center”, to use you. Create a plan for dealing with these hooks.

## Common hooks

### Guilt/shame

If you really cared for . . . , you would . . .
That’s OK. I will manage by myself somehow.

### Blaming

You told me to . . . , I did it, and now look at what has happened.

It is all your fault.

**Scapegoating**
If you had not . . . , everything would be OK.

**Lack of empathy**
You just do not know what I am going through.
You do not understand.

**Advice Seeking**
I am at my wits' end. What should I do?
What would you do if you were in my place?

**Getting you to take sides**
How could he have done this to me?
You agree with me, don't you?

**Step IV: Let the care team know that you have these negative emotions.**
Let them know how difficult things are for you. Ask them to "step to the plate" so that you have time to better care for yourself.

## Choosing Professional Care Service Providers

Your GUIDE Care Team can assist with the identification, assessment and engagement of professional care service providers. This may include Adult Day Services, In-home Care Services, Palliative Care Services, Residential Care Facilities, and/or Hospice Services.

## Resources and Contact Information

This section does not intend to endorse or recommend any particular resource. Please talk with your GUIDE Care Team about specific needs, which may better tailor your resource needs.

**Baptist Health System Patient Internet Site:** www.baptistjax.com – **FINAL**

**Caregiver Training Videos in multiple languages:** www.uclahealth.org/medical-services/geriatrics/dementia/caregiver-education/caregiver-training-videos

**Alzheimers.gov**.

**Alzheimer’s Association: www.alz.org.**

**Alzheimer's Foundation or America: www.alzfdn.org.**

**Alzheimer's Disease Education and Referral Center (ADEAR): www.nia.nih.gov/alzheimers.**

**AARP’s Home Alone Alliance. www.aarp.org/ppi/initiatives/home-alone-alliance.**

**Department of Veterans Affairs Caregiver Support. www.caregiver.va.gov.**

**Family Caregiver Alliance. www.Caregiver.org**

**National Association of Area Agencies on Aging: www.n4a.org.**

**National Caregivers Library: www.caregiverslibrary.org.**

**National Institute on Aging: www.nia.nih.gov/health.**

**National Council on Aging: www.benefitscheckup.org.**

**MedicAlert + Alzheimer’s Association Safe Return: 1-888-572-8566.**

**National Academy of Elder Law Attorneys: www.naela.org.**

**National Center for Assisted Living: www.ahcancal.org/ncall.**

**National Clearinghouse for Long Term Care Information: www.longtermcare.gov.**

**National Hospice and Palliative Care Organization: www.nhpco.org.**

**Smart Patients. www.smartpatients.com.**