



**Alzheimer's &
Dementia Services**
of Memphis, Inc.

CareLines

WWW.ADSMEMPHIS.ORG

SEPTEMBER 2020

ADS ONLINE SUPPORT GROUPS

We are pleased to share that we are now scheduling Support Groups online:

*First Wednesday of the month
September 2, 12:30
and*

*Third Thursday of the month
September 17, 3:00*

Join meetings from your computer, tablet or smartphone.

<https://global.gotomeeting.com/join/303620541>

You can also dial in using your phone.

US: +1 (872) 240-3212
Access Code: 303-620-541

New to GoToMeeting? Get the app now and be ready when your first meeting starts:

<https://global.gotomeeting.com/install/303620541>

*For questions, please call Adina
901-372-4585*

or email:

asamberg@adsmemphis.org

CareLines is partially supported by the Aging Commission of the Mid-South.

10 Requests From An Alzheimer's Patient

Please be patient with me.
I am the helpless victim of a brain disease.

Talk to me.

Even though I cannot always answer.

Be kind to me.

Each day of my life is a desperate struggle.

Consider my feelings.

They are still very much alive within me.

Treat me with dignity and respect.

As I would have gladly treated you.

Remember my past.

For I was once a healthy vibrant person.

Remember my present.

For I am still living.

Remember my future.

Though it may seem bleak to you.

Pray for me.

For I am a person who lingers in the mists of time and eternity.

Love me.

And the gifts of love you give will be a blessing forever.....

-Anonymous-



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Guilt: One of The Worst Emotions of All

Guilt may be the most annoying of the seven emotions of Alzheimer's caregiving. It's right up there with resentment, worry, fear, anger, loneliness and grief.

Guilt usually stems, ironically, from caring so much. We want the best for the person living with Alzheimer's. We want things to go well. We want them to be safe, happy, involved, free of pain and worry. Our intentions are good. We are good! But inherent in those lofty aspirations is the nagging feeling of never quite being good enough.

Guilt can come in so many forms:

- **Guilt for what I'm not doing.** I should be entertaining her more ... I should cook healthier meals ... I ought to get us both exercising
- **Guilt for what I am doing.** I feel bad when I take my husband to the day center, but I really need a break ... I shouldn't rush Mom through her shower like that ... I ought to be able to handle this without whining -- after all I love this person!
- **Guilt for being away.** Long-distance caregivers feel their cash and phone support isn't enough. Those who use respite care are pricked with feelings of insufficiency for not being there 24/7 (even though the person with dementia doesn't seem to mind).
- **Guilt for being happy or well.** "I'm in a good mood today -- oh wait, I shouldn't be, because my partner has Alzheimer's." ... "Why am I the healthy one and he's in such terrible shape?"

There's no end to opportunities for guilt in the realm of Alzheimer's caregiving. You cannot ignore this persistent emotion, whispering in your ear no matter what you do or don't do. You can't will it away. Guilt simply is.

Occasionally guilt can be a productive emotion. Call it "good guilt" -- the nagging voice in our heads that causes us to examine our behavior and decide whether a change is in order.

If you feel guilty because you were impatient with your loved one, for example, it's like a little poke reminding you to try harder or take a deep breath next time.

Unfortunately most of what eats us alive is what I call "bad guilt."

Bad guilt makes you feel bad about a situation that you can't help, such as when your loved one has to move to a rehab. Bad guilt makes you feel bad about a situation that may actually be helpful and positive for you, such as hiring home care so there are more hands on deck.

Bad guilt causes us to beat ourselves up for reasons that are unrealistic and counterproductive — not to mention that all that stewing and self-flagellation wastes precious mental energy.

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(continued from page 2) **Guilt: One of the Worst Emotions of All**



- **Beware of the "red flag words":** Ought to, should, could have, always, never. Ban them from your vocabulary; they're warnings that you're setting the bar too high. When you hear yourself saying, "I should..." flick your forefinger against your wrist as a reminder. "Always" and "never" are toxic because they set us up for future guilt: "I'll never put you in a home." "I'll always be here." Don't promise things you can't be 100 percent certain of -- most things in life!
- **Don't discount yourself.** Ironically, selfless people (the dominant caregiver personality) tend to feel proportionately more guilt. Because they work so hard aspiring to an ideal of doing things for others, they tend to ignore the inconvenient reality that they have to look after themselves all the more. They may even forget that they, too, deserve extras and shortcuts and breaks. When they finally get around to a slow bath or a lunch with friends, it feels as alien as it does great. Trust your needs, your perceptions, your value in this situation.
- **Aim to be a B+ caregiver.** Straight A's are for grad students and crazoids, not mere mortals with houses to keep, relationships to tend, jobs to do, and sanity to uphold. No caregiver anticipates every fall or prevents every bed sore. Tempers boil. Germs sneak in. Bills slip through unpaid. In other words, life happens. No matter how much you love the person or feel you "owe" him or her, you'll all be happier if you lower your standards to the level of real life. By aiming for the B, you'll achieve good marks consistently, and occasionally surprise yourself with an A, rather than constantly feeling like you're missing the mark.
- **Remind yourself of your true goals.** Ideally, you should be striving to give your loved one a secure life free of worry or pain, while maintaining your own quality of life and health. Don't beat yourself up over the small stuff.
- **Steer clear of comparisons.** We feel guilt when we feel that we're falling short of some imagined ideal. Where do those ideas come from? Often, from our own heads. We compare ourselves to someone else, without stopping to calculate what their stress levels or support situation is like, without allowing that every case is different. It doesn't matter if Nancy Reagan seemed like a saint over her husband's disease but all you want to do is cry and complain. Were you inside their house, seeing what went on? All that matters is you and yours, and how to make your hard situation as easy as you can.
- **See it as a sign of strength, not weakness, to enlist help.** Strong, smart people know that Alzheimer's care is not a task for the isolated and solitary. The more you can delegate and share, the better life feels.
- **Get the doctor's (or a therapist's) ten cents.** There's nothing like hearing from a neutral third party, "No, you have nothing to feel guilty about in that situation." Often we don't believe the obvious unless we hear it from a trusted, neutral source.

Adapted from article by Paula Spencer Scott, alzheimersreadingroom.com

A Caregiver's Bill of Rights

The right to have balance between caring for my loved one and caring for myself.

This includes asking for extra help when needed so I can best maintain routines and plans for myself while on this caregiving journey.

The right to receive a financial break or tax credit for caring full-time for my loved one.

The right to work for an employer who understands caregivers.

I have the right to work for an employer who will provide me with the employee assistance to maintain my work performance and productivity, my own health and wellness, and support for my loved one without fear of reprisal or dismissal.

The right to expect legislators to acknowledge the valuable service I perform and to enact policies that support those with the illness or disability as well as family caregivers.

The right to expect that my loved one's medical advisors recognize my critical role.

I should expect that these health care professionals will communicate with me without violating my loved one's privacy rights so I can best care for my loved one. Especially when it comes to transitions of care, I become a critical player in helping my loved one -- the patient -- transition from hospital to home or other facility and to maintain their health, medication compliance, and other aspects of care that will decrease hospital readmissions.

The right to easily find resources that will help me in my caregiving journey.

Whether these services are provided by public or private organizations, I should know where to turn to get the help and the education needed.

The right to not take on the financial burden of caregiving all by myself.

I should not have to put my financial future at risk to care for my loved one today.

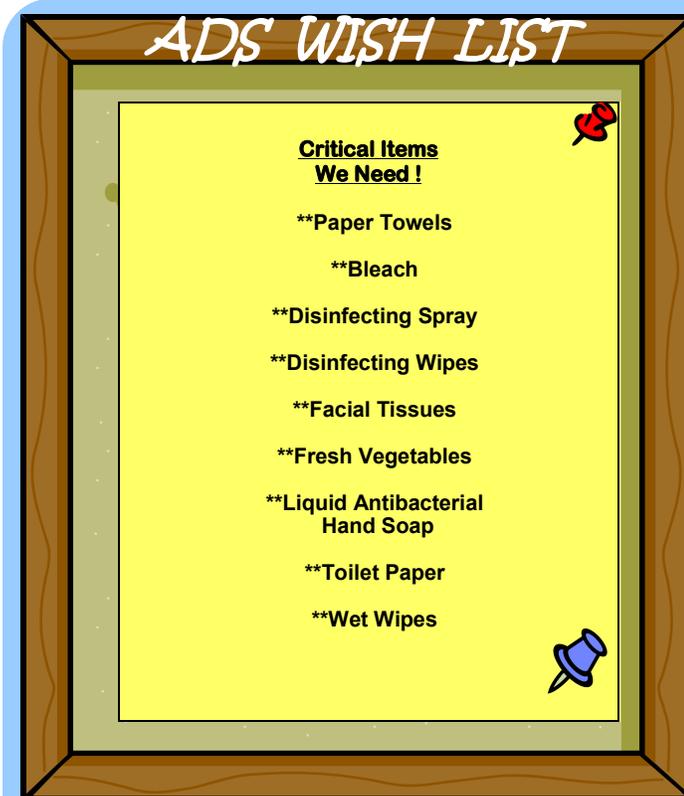
The right to make choices to help reduce my stress levels, without feeling guilt that I am focusing on myself at times rather than solely on my loved one.

This includes the right to take a break -- for a few minutes, a few hours, or a few days. Seeking respite is essential to my ability to continue caring for my loved one.

The right to expect my close circle of friends and family to understand my caregiving role and to support me in any way they can.

This includes the right to expect that I can reach out to others so I do not feel alone. I can expect that my spouse, my adult children, my siblings, my coworkers, and my close friends will lift me up when I am down and help keep me going on this caregiving journey.

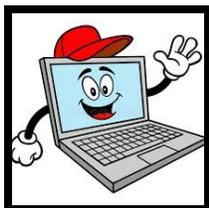
The right to expect "life, liberty, and the pursuit of happiness" even while so much of my time, energy, and attention is going to care for my loved one.



Online and Telephone Support Options for Caregivers.

For virtual community events and support:

- ◆ See front page for info about ADS online Support Groups
- ◆ Call 901-372-4585 to talk to an ADS Social Worker on the phone
- ◆ alzfdn.org
- ◆ alztennessee.org
or call 24/7 Helpline: 800-259-4283



Tips for the Month of September

◆ Watch your loved one's body language. If a situation becomes combative, stop and back up. We cannot control another person no matter how close we are. We can, however, change the activity. Offer a favorite food or suggest a dance or a hug as a pleasant distraction.

◆ If your loved one is fearful of having a shampoo in the shower, doing it at the sink or going to the beauty parlor may work. You might want to consider a dry shampoo for a while.

◆ Sometimes your loved one also needs the companionship and stimulation of other people. If appropriate, invite family or friends over for frequent visits. Don't forget the companionship she can find at day care. Neither one of you should be deprived of social contact.

◆ When leaving your loved one in the care of another person or at day care, make sure you advise them of any unusual words or terms he uses to express his needs or concerns. Tell the interim caregiver the words your loved one used to communicate the need to use the bathroom. Tell the person the words you use to comfort and reassure your loved one.

◆ Keep a fidgeter busy. String some common everyday items together on a short cord and knot the end. Use an empty spool of thread, plastic spoons or measuring cups with holes in them, or any safe objects you think might keep her attention for a while.

◆ It is a lot easier to be honest and free to discuss what you are experiencing with all your family. After all, the whole family is affected by anything that happens to one of its members. There are excellent books available for children and teens explaining AD in a loving way they can understand and relate to.

◆ Wincing when chewing, tenderness when someone touches his mouth or side of his face, and bad breath could indicate a tooth or gum problem in your loved one.

Adapted from: Lyn Roche, *Coping with Caring*, Elder Books, 1996.

Alzheimer's/Dementia Home Safety Checklist

The general checklist below can help you to provide a safe home environment for a loved one with Alzheimer's disease or another dementia related disorder.

- ◆ Exterior doors have secure, safety-proof locks.
- ◆ Rugs/carpet edges are safely secured.
- ◆ Throw rugs have been removed.
- ◆ Problem floor/wall coverings have been removed or replaced (e.g., dark rugs confused for holes; patterned designs that are causing irritation).
- ◆ Furniture is arranged to allow for safe walkways and pathways.
- ◆ Other walkways/pathways through the house are clear of obstacles and free of clutter.
- ◆ Furniture being used for support while ambulating is stable and secure.
- ◆ Glare from lighting or sunlight has been reduced as much as possible.
- ◆ Lighting is adequate and even in all the accessible areas of your home and special lighting has been added where needed (e.g., night lights in halls and bathrooms).
- ◆ Colored stickers have been applied to large windows and sliding glass doors.
- ◆ Poisonous plants have been removed.
- ◆ Steps/stairs have:
 - Railings that run the entire length.
 - Railings along both sides.
 - Clearly visible edges (apply a slip-resistant strip in a contrasting color to the edges if needed).
- ◆ Guns or firearms have been removed OR secured and disabled.
- ◆ Alcohol is locked up.
- ◆ Electric outlets are covered (if not in use). Lamp, extension and phone cords are located away from walking paths.
- ◆ Access to garage, basement, and any other unsafe areas is restricted.
- ◆ Access to computers or other electronics is secured or restricted (if needed).
- ◆ Valuable or irreplaceable items have been secured or removed (safety precaution in case your loved one hides or hoards belongings).





Summer Fun at ADS



“*Friends*” at Dorothy Place and at Kennedy Park enjoyed special days of summer activity fun!

Dorothy’s Place celebrated “Christmas in July,” which included decorating a Christmas tree and ornaments and playing Christmas Jingo, on a fun, but unusually warm holiday day. Everyone enjoyed musical entertainment, by Double D Band, courtesy of Creative Aging.

Kennedy Park enjoyed a fun and beautiful day outdoors, finding shells in the sand, blowing bubbles and playing with the parachute. A fun cookout lunch included grilled hotdogs, potato salad, coleslaw, fresh watermelon and a refreshing cup of lemonade. The afternoon was topped off with musical entertainment by Heart Memphis Duo, courtesy of Creative Aging.

The “*Friends*” had a blast! One “*Friend*” commented, “We should do this every Friday!”

We’re all looking forward to Spirit Week in September. Follow the schedule below for “*Friends*” to come dressed in wild and crazy garments, but dress their best for the prom on Friday!

ADS SPIRIT WEEK

September 14th—September 18th

Monday, September 14th — HAT DAY

Tuesday, September 15th — PAJAMA DAY

Wednesday, September 16th — SPORTS FAN DAY

Thursday, September 17th —WACKY TACKY DAY

Friday, September 18th —PROM DAY

Prom day will include a variety of contests, with lots of winners. Musical entertainment, courtesy of Creative Aging, will be provided by David Virone at Dorothy’s Place, and by Double D Band at Kennedy Park. Looking forward to a fun day and a fun week!



What to Do About Loss of Inhibition and Problem Behaviors

As dementia slowly robs self-awareness, the person may become less inhibited, losing both the memory of how he or she once behaved as well as a sense of social norms. It's as if an internal filter on what's polite behavior or not is turned off. Examples: Undressing in public, saying inappropriate things (rude comments, cursing), staring at strangers, making inappropriate sexual advances, masturbating in public.

Tips for Dealing with these Behaviors:

- Know that some behaviors aren't what they look like. People with dementia who are losing language skills often express themselves with actions. For example, someone who unzips his pants may need to use the restroom. A person who disrobes may be hot. Someone who hurls a stream of foul language may feel stressed.
- Notice what else is going on when a behavior occurs; something about the environment may be triggering a reaction in the form of this inappropriate behavior. Pay attention to the noise level, who's present, the time of day, whether the person has eaten or used the bathroom. Jot down this information if an odd behavior happens more than once.
- Ignore these behaviors where possible. Reacting to them —especially with outrage or disapproval— may only upset the person.
- React with calm reassurance. The person may be acting out because he or she feels uncomfortable, insecure, or overwhelmed by noise (such as in a public place).
- Try reacting to sexual behaviors counter intuitively by providing extra touching and affection. Rub the hands or shoulders, smile, hug. The person may be expressing a (nonsexual) need for affection and human contact.
- Distract by changing the scene (moving to another room, going outside), or the activity.
- Take strangers aside and explain, "Please excuse Mother; she has dementia and isn't fully aware of her actions." (Some people make up small cards they can silently pass to wait staff, store clerks, and others that explain the same message. **We at ADS have these cards; please feel free to ask for some**).
- For chronic undressing, try difficult-to-remove clothing, such as challenging fasteners (like small buttons) or tops that zip or button in back.
- Don't try to reason the person into proper behavior: "We don't do that in public!" or "Mind your manners!" The person with dementia cannot follow that line of logic.



Adapted from article at www.caring.com