



Caregiver Support

Caregivers of dementia patients are one of our greatest resources. Dementia caregivers are required to have patience when their last nerve is gone; to show strength for two, when they barely have strength for the next step; to always understand, while never being understood; and to live an increasingly lonely life while their life partner, or parent daily slips away from them. If you are a dementia caregiver you do not have to suffer on your own, organizations and educational materials are available over the phone or Internet. The following pages are meant to help you cope with your loved ones changing behavior, manage your own stress, and provide resources to help you survive the *36-hour day*.

Behavior Tips

Anger/Frustration

Your loved one is experiencing many changes that can cause anger or frustration. Memory is often a problem and forgetting how to do what were once simple tasks can be very difficult for your loved one to deal with. He or she may even take this frustration out on you. Don't take it personally. Try to be understanding and a good listener. When this happens give your loved ones some space and time to themselves. Also try to give short, simple instructions to avoid frustrating your loved one.

Communication Problems

Your loved one's brain is slowing down and this can affect the way he/she talks and understands language. Your loved one may slur his/her words or even whisper. If this happens repeat what was said and don't be afraid to ask your loved one to repeat herself/himself.

Your loved one may forget certain words, the meaning of words, or even make up words. Often caregivers come to know the made up words and what they mean, others correct the loved one. Always give your loved one time to get his/her meaning across. Do whatever works best without causing anger or frustration.

Delusions/Hallucinations

Your loved one may think they are something or someone other than they are. It is all right for them to do this if it does not put them or others at risk for injury. Sometimes caregivers correct the loved one. Do whatever works best without causing anger or frustration.



Your loved one may also see or hear people or objects that are not there. He or she may often stare into space like they are seeing something. Don't be afraid to ask about what is there. They may be remembering the past and talking about their past may be very helpful to them.

Depression

You may notice that your loved one isn't participating in his/her usual activities. Depression is very common in dementia patients and can be treated. Make sure you let your healthcare provider know if you think your loved one is depressed.

Resistance to Care

No one wants to depend on others for help, especially if they have always taken care of themselves. Also as the dementia progresses your loved one may not be able to understand what you are doing and they can become frightened causing resistance. Don't push your loved one to do something they seem uncomfortable about. Come back later and try again sometimes that it is all it takes.

Suspicious/Paranoid Behavior

This can be very difficult to handle. Often your loved one will accuse you of stealing items because he/she can't remember where they left them. When you find the item be sure to tell them where you found it "Here is your watch, you left it on the table." They may also accuse you of inappropriate behavior such as being unfaithful. Try not to take this personally and be caring and supportive not angry.

Sundowner's Syndrome

This happens when your loved one gets his/her days and nights mixed up. Wandering often happens at night and sleep problems can also happen. Making sure your loved one gets outside for fresh air and sunshine can help reduce the frequency of this behavior and improve sleep patterns.

Verbal and Physical Aggression

Your loved one may use curse words. Often ignoring this behavior will put a stop to it. If your loved one becomes violent you should remove yourself from the situation and give them time to "cool off." Try not to respond as this may make things worse.

your loved one about names, dates, and places may help him/her. Finding out all about your loved one's dementia is a good way of not feeling helpless.



Common Signs of Stress Include:

- Depression
- Headache
- Stomachache
- Difficulty sleeping
- Irritable or moody
- Gets sick easier
- Cries easily
- Can't concentrate
- Gain weight or lose weight

What can I Do about Stress?

Take care of yourself. Staying in good health is important. Eat well-balanced meals and get regular exercise. Exercising is very helpful in reducing stress. Be sure to check with your healthcare provider about starting an exercise program that is right for you. Get enough sleep. If you are up with your loved one at night try to get frequent naps to make up for this. Do things for yourself that make you feel good like taking a long tub bath or reading a good book. Explore available opportunities for respite or day care for your loved one.

Keep a positive attitude. Keep focused on the good things like what your loved one can still do. Mom used to play card games all the time and now she can't remember how. Instead think Mom used to play card games and now she plays solitaire with only a little help from me.

Laughter is the best medicine. There may be many bad days as a caregiver but there will also be many good ones. Don't forget to smile or laugh at yourself or even at your situation. Laughter can help you to feel less frustrated and more in control.

Keep yourself educated and up to date. Find out as much as you can about your loved one's condition. Use some of the resources we have listed here or talk with your healthcare provider or clergy. Don't hesitate to educate others in your family, friends or congregation about dementia and its effect on you and your loved one. This can help others to feel more comfortable with your loved one. Go to support groups and share your experiences. Learning from each other is very helpful. Remember knowledge is power.

Don't be afraid to ask for help. Don't be embarrassed to ask for help. Caregiving is not





an easy job. If you get the help you need then you can better help your loved one. There are services available in your community take advantage of them. Contact the Columbia County Senior Services Center for more information.

Caregiving Tips

- 1.** For loved ones who enjoy watching TV get a remote with large buttons or label the buttons with something to help them remember how to turn the TV on and move through the channels.
- 2.** You may want to remove or raise the mirrors in your home. These can often be confusing to your loved ones because they may not recognize themselves and get fearful of this strange person.
- 3.** If your loved one can read words or recognize pictures of objects, placing them around your home can be very helpful. If you use words instead of pictures keep it short with no more than 3 words per card.
- 4.** Offer choices whenever possible. For example in getting dressed ask your loved one to choose between 2 articles of clothes such as shirts or pants. Get rid of clothes that are too small, big or not worn anymore to avoid confusion.
- 5.** If your loved one can still tell time use large numbered clocks and watches. Also use large print calendars.
- 6.** Make sure your phone is easy to use. Large buttons work best. If your loved one can't answer the phone and you have an answering machine turn down the ringer and turn down the volume on the answering machine. If the answering machine goes off it can trigger fear as your loved one may think there is someone in the house.

Communication Dos and Don'ts

- Be calm and supportive. Dementia patients pick up on strong emotions.
- Move and speak slowly. You could scare your loved one with quick movements.
- Keep your promises. Always do what you say you are going to do.
- Maintain eye contact. Looking at your loved one helps them to feel connected to you.
- Use a low, even, soft tone of voice. A loud or angry tone may cause agitation.
- Use familiar words. Use short simple words that can be easily understood.
- Use visual cues like pointing, waving or smiling to get the message across.



- Use touch. This can be very calming.
- Don't argue with your loved one.
- Don't give too many choices, as this can be very confusing.
- Don't rush your loved one this could cause anger or aggression.
- Be direct. Say, "Come and sit down" instead of "Would you like to sit down."
- Do not come from behind the person, this may frighten them.

Home Activities

Providing activities to keep your loved one happy and distracted can be very useful. You can do things you need to while your loved one is busy with their activity. Doing things together is also very important. Doing activities together makes your loved one feel useful and needed.

When deciding what types of activities to do you should focus on what your loved one is able to do. You should include activities that your loved one enjoyed in the past. Plan short activities that won't lose his/her attention span. Assist your loved one as needed but allow them to be as independent as possible. Develop a schedule and stick to it, a routine is very comforting to the dementia patient.

Here are some examples of activities that can be done inside and outside your home:

Exercise

Dancing or movement to music
Walking
Swimming or other water activities
Chair or bed exercises

Music

Cassette tapes, CDs or records
Videos of dance instruction
Singing
Listening to the radio with or without headphones

Games

Sorting and separating objects
Memory games like concentration
Alphabet or category games
Simple jigsaw puzzles



Simple trivia or news events

Arts and Crafts

Non-toxic clay
Collages
Painting with water colors
Finger-painting
Stringing beads or other objects

Reminiscing

Scrapbooks and photo albums
Recalling historical events with pictures
Talking about past happy events
Participate in reminiscence groups

Pet Therapy

Holding and touching animals
Watching a hamster or gerbil in its cage
Watching birds or squirrels at a feeder
Listening to a canary or parakeet
Watching fish in an aquarium

Spiritual Activities

Attending services
Singing hymns or Christmas carols
Listening to someone read from the Bible

Gardening

Planting in inside containers
Planting outside in containers or the ground
Arranging cut flowers
Picking flowers outside

Home Safety

Providing a safe environment is important for you and your loved one. This may sound easy but sometimes things get overlooked. What may not be unsafe for us may be for your loved one. Please keep in mind that as the dementia progresses you may need to add extra safety measures.





1. Oven and stove-This is a fire hazard if you are not at home with your loved one. If possible remove the knobs on the stove. If they cannot be removed try placing covers over them. Contact an electrician to see what else can be done for safety.

2. Fire alarms and extinguishers-Check regularly to make sure your alarms are in good working order. You should have an extinguisher in the kitchen and know how to use it. Extinguishers should be serviced twice a year, call your local fire department for help.

3. Doors-This is especially important if your loved one wanders. You can add a bolt lock or regular lock that needs a key to be opened. Put the lock at the top of the door out of reach. Keep the key with you at all times. If you having sliding glass doors, there are special locks that can be used to keep them secure.

4. Medications and chemicals-Keep these items hidden or under lock and key.

5. Car keys-If your loved one still insists on driving keep the car keys hidden or locked up.

6. Stairs-If your loved one has troubling walking, stairs may be a hazard. Make sure there are rails available. As the dementia progresses you may need to think about furniture and sleeping arrangements especially if you live in a two-story home.

7. Night lights-Keeping areas well lit will reduce accidents and falls. Place lights in the kitchen, hallways and bathroom. If you live in a two-story home keep lights by the staircase.

8. Floors-If you have hardwood or tile floors you may want to add rugs or mats that will stay in place. You can also purchase non-skid slippers or socks for your loved one. Be careful that your carpet doesn't lift up at the corners.

9. Matches and lighters-If your loved one smokes make sure you are there to supervise and keep matches and lighters locked away.

10. Bathroom-There are many items that can be purchased to make the bathroom safe-rails, handles, elevated toilet seat, shower chair, and detachable shower head. Buy no-tear shampoo.



- 11. Water heaters**-Turn down your water heater temperature to avoid burns.
- 12. Furniture**-make sure the bed is not too high. Keep rooms free of clutter. The neater the environment the less chance of an accident.
- 13. Appliances**-Only keep out the appliances your loved one can use safely. Be sure to keep your blow dryer, hot curlers or curling iron out of reach. Keep your clothes iron out of reach as well.
- 14. Food**-Throw out food that is bad. Your loved one may eat it and get sick.
- 15. Kitchen utensils**-If your loved one has trouble using knives and forks you may want to purchase plastic ware and paper plates.

Respite Care Services

Columbia County Senior Services has a variety of ways that a family caregiver can receive needed respite from the stress of caring for a dementia patient. To access this service call Senior Services at 386-755-0264 or 386-752-8235 and ask for a case manager. The case manager can discuss your needs with you and perform the assessment that is necessary to determine if you are eligible for available grants that provide respite services.

The **Alzheimer's Disease Initiative Grant** and the **Community Care for the Elderly Grant** are designed to give family caregivers a regular break from constant care and supervision. Care is provided for a certain number of hours per week based on funding availability and eligibility.

The **Family CareGiver Support Grant** is designed to give episodes of respite care of a longer duration but for one time only. For example, if you need someone to look after your loved one while you go to the hospital or if you need a vacation, we can provide up to 14 days of 24 hour consecutive care as long as funds are available.

Funds are also available from the **Alzheimer's Fund** at Columbia County Senior Services to provide services and needed equipment for dementia patients and their families. The funds have been raised through the annual "Stroll Down Marion" event sponsored by the **Columbia County Alzheimer's Coalition**.

Respite funds are also available through the **Mid-Florida Area Agency on Aging** to provide a respite worker in cases where you want to attend an educational or caregiver support program. You can call 1-800-262-2243 and ask for information on the Family caregiver Education and Support Program.

If you are not eligible for respite services provided through state or federal grants, respite care can be provided by **Extended family Services**, a fee for service program of Columbia County Senior Services.

Support Groups

There are many reasons to join a support group.

- To benefit from the experiences of others who have been in your shoes. Dementia and memory loss can create many problems for the loved one in your life. Talking about these problems at support groups with others who have faced the same situations can get you suggestions and tips on how to solve your problems.
- It gives you an opportunity to talk about your feelings instead of keeping them all bottled up inside. It is helpful to talk to other people who will not judge you for your frustrations. This can be a big comfort to you.
- A support group is a safe place to bring up issues that make you uncomfortable. You can say anything without feeling guilty.
- This is an excellent way to learn more about dementia, research about dementia, new treatments, resources in your community, and legal issues.

Ten Steps for Being a Compassionate Caregiver

By Pam Haisman RN

- 1.** Although I do not fully understand the memory loss disease process a person has, I need to remember that my loved one deserves dignity and respect.
- 2.** I need to remember that most persons with dementia are aware of this present moment. Even though they will often not retain the memory of the encounter, they will



retain the emotions and feelings that accompanied this moment with me. Therefore let me leave them with good feelings.

3. I need to have a sense of humor when talking or taking care of my loved one with dementia, because laughter helps put things in a more positive perspective.

4. I need to remember that my loved one is not being difficult or forgetful on purpose; rather the disease may distort his/her memory, behavior, and personality. I should never take this personally.

5. Because I understand that my loved one will often tell me the same story or joke over and over again, I need to be sensitive and a good listener.

6. Many people with dementia live in the past. Let me be compassionate by never arguing or trying to convince them they are not in the past.

7. I need to focus on and enjoy what my loved one can do on this day, and not complain about what they cannot do anymore.

8. I can best be a compassionate caregiver by being there for my loved one on good days and bad.

9. I understand that dementia patients can be an overwhelming emotional burden for people like me.

10. I need to be aware of my own feelings and know when to seek help and support.

Ten Steps for Healthcare Professionals For Being a Compassionate Caregiver

By Pam Haisman RN

1. Although I may not fully understand the memory loss disease process a person has, I need to remember that this person deserves dignity and respect.

2. I need to remember that that most persons with dementia are aware of this present moment. Even though they will often not retain the memory of the encounter, they will retain the emotions and feelings that accompanied this moment with me. Therefore let me





leave them with good feelings.

3. I need to have a sense of humor when talking with persons with dementia, because laughter helps put things in a more positive perspective.

4. I need to remember that this person is not being difficult or forgetful on purpose; rather the disease may distort his/her memory, behavior, and personality.

5. Because I understand that the person with dementia will often tell the same story or joke over and over again, I need to be sensitive to his/her memory loss.

6. Many persons with dementia recall the past with vivid detail. Let me be compassionate by never arguing or trying to convince them they are not in the past.

7. I need to focus on and enjoy what each individual person with dementia can do on this day, and not complain about what they cannot achieve.

8. I can best be a compassionate caregiver by joining the journey through validation and distraction techniques of compassionate communication.

9. I understand persons with dementia are often an overwhelming emotional burden for family members. It is compassionate to ask the family how they are doing and refer them to support groups.

10. I need to be aware of my own feelings and know when to seek help and support.

