JFSCOMPASS

TOP TEN CAREGIVER ISSUES

Strategies for Managing Common Caregiving Issues in Dementia

INTRODUCTION:

Caring for an individual with dementia poses challenges because of the progressive cognitive decline that makes it increasingly difficult for them to remember, think rationally, communicate with others, and manage their lives independently. For all the issues to be discussed, it is important to keep basic communication principles in mind:

- **Set a positive mood** for interaction with a ready smile and a calm demeanor. They may feel confused, anxious, or unsure of themselves.
- **Get their attention;** limit distractions and maintain eye contact. State your message clearly using brief sentences; use names instead of pronouns. Break down activities into simple steps and one at a times.
- **Ask simple questions** that don't rely on memory. Use visual cues when possible, showing the red shirt and the blue shirt as choices.
- **Listen patiently** for the meaning and feeling that underlie words; it's okay to suggest words if they are struggling
- **Have realistic expectations;** their brain may remember things incorrectly. Avoid trying to convince them they are wrong.
- **Maintain your sense of humor.**

It is important to remember that there are many factors that impact the usefulness of the strategies offered below; what works one day may not work the next day (and vice versa). So be patient with yourself and your care recipient. Caring for people with dementia requires flexibility, creativity, and humor. May you be blessed in abundance!

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1. SAFETY CONCERNS: FINANCES MEDICATIONS, DRIVING

A person's ability to manage finances, mediations, and driving may decline early in the course of dementia. Periodic monitoring will help you know when intervention is necessary. However, because of impaired insight often present in dementia, addressing these concerns may threaten the person's autonomy and lead to distress in the relationship. The following are suggestions for navigating these challenges.

FINANCES:

What Happens:

Changes in judgement, decision-making, and reasoning skill are common in dementia, and may put life savings at risk. Older adults are often targeted for scams and are especially vulnerable in the early stages of dementia before it is clear the person needs supervision. Many families hesitate to become involved because it can be perceived as disrespectful.

Why It Is Important:

It is important to safeguard finances for ongoing care. To step in also requires takin on the responsibility of another's financial affairs. It is important to do for your loved one what they cannot do for themselves – make wise choices that protect their financial security. It can be done respectfully if you keep in mind what they at their best would have wanted for themselves. It is important to not let their role as your spouse, parent or sibling blind you to their limitations.

What You Can Do:

- Ensure Durable Power of Attorney (POA) is drafted and registered with the courthouse.
- Review bills and he checkbook monthly: Are there errors in the checkbook register? Missing checks? Are there late notices or late payment charges?
- Consider having bills automatically paid and the statement sent to you if they are confused and believe it still needs to be paid.
- Speak to your banker about putting a trusted individual on banking accounts (Personal Agency accounts protect your credit) so you can ensure that their funds are protected.
- Consider a low balance checking account; limit access to large amounts of cash.
- Alert credit bureau to freeze credit applications in the person's name.
- Register phone for the DO NOT CALL list: 1-888-382-1222 or www.DONOTCALL.gov
- Have mail re-directed to a post office box so you can screen what is received
- Write solicitors to remove the name and address from their mailing list.
- Provide a pre-paid credit card with a limited balance that will not jeopardize credit if lost.

MEDICATIONS:

What Happens:
At times the issue is forgetting to take medications or forgetting they've already been taken and taking them again. It can also be a matter of poor judgement – "I don't really need this anymore" or "if one is good, maybe more is better," which can be dangerous. Lack of a routine or changes in an existing routine may increase risk of errors.

Why It Is Important:
By missing doses, untreated illnesses may worsen; by taking meds too often they can unintentionally overdose putting them at risk of worsened cognition, illness or death.

What You Can Do:

- Take medications (or a detailed current list) with you to **every** doctor visit including dose, frequency of use; include over-the-counter medications and supplements, inhalers, eye drops. **Ask the doctor at every visit to be sure it is correct.**
- Simplify medication regimen; ask doctor for once daily dosing when possible. Ask if there are blood levels that may help clarify compliance.
- Assist in establishing a routine and have a system for monitoring medication use.
  Ask pharmacist if refills are requested on time and to call you if not.
  Do a pill count; does the number left in the bottle match the date filled?
  Help fill a weekly pillbox (or check it if they have filled it) and review it regularly.
  Call daily to remind them to "take meds for Monday" (they may forget the day)
  Automated pill delivery system can be purchased that notify caregiver if medications are missed.
  Enlist others to help monitor such as home health agency, parish nurse, etc.
- When it is clear the person cannot manage their medications.
  Keep medications out of reach, out of sight, or locked up
  Have a limited number of "as needed" medications available

DRIVING: cars, lawn mowers, tractors, etc.

What Happens:
One of the most challenging aspects of dementia is the impaired insight that is characteristic of the illness. Individuals may retain reasonably good social skills, leading other to overestimate their abilities. Because of decline in executive function (The part of the brain used for decision making and weighing risks of a decision), individuals may genuinely believe their decisions are good ("Why shouldn't I drive? – I've never had an accident!") yet altered judgement, slow reaction times, or confused thinking can result in tragedy. The challenge is to honor the individual's wishes as much as possible without jeopardizing anyone's safety.

Why It Is Important:
Driving often has great symbolic importance and is intertwined with a person's sense of self-worth and independence. Insurance companies are increasingly refusing to cover damages so there may be financial as well as moral implications given the risks to life and property.

What You Can Do:

- Ask the health care provider to recommend a formal driving evaluation with a road test or to notify the state department of motor vehicles of concerns
- Have MD write a prescription that says: "You must retire from driving."
- Leave discussion to the doctors so you can be the support person – "I'm so sorry but we have to do what the doctor recommends. I'd be upset too."
- Blame necessity of stopping on health problems such as vision, heart disease, or arthritis
- Have a plan in place for alternative transportation: begin to share driving responsibilities for grocery shopping, doctor visits, rides to church in advance
- Limit access to a vehicle. Some strategies:
  Out of sight out of mind: Sell the car, "loan" it to a family member, put it in a garage
  For those who need the comfort of seeing the vehicle, disable it by removing the battery, disconnecting cables, removing the distributor cap, have a blank key make.
  Let the insurance run out (do this only if you are clear they will not be driving)
  Be aware that they can be "resourceful" by calling a repairman or buying a new car!
- You cannot rely on rational arguments; offering a moral argument (that you know they would not want to put others at risk) may work, but sometimes the tough decision must be made against their wishes.

2. INCONTINENENCE: BOWEL OR BLADDER

What Happens:

Urinary incontinence can occur as a result of infections, confusion, medications, disease progression, and many other causes. Some with dementia forget how to undress themselves or how to find and use the bathroom.

Why It Is Important:

This is a quality of life issue for both the individual with dementia and for the caregiver any may help delay or avoid nursing home placement.

What You Can Do:

- Address reversible causes of the problem
  Urinary tract infection (UTI's), are often asymptomatic in dementia though may present with urinary frequency, pulling at crotch, pain, fever, foul-smelling urine, pacing, irritability, confusion. This is a very common cause of agitation or abrupt cognitive decline so call MD to request a urinalysis.
  Medications may contribute
    Diuretics (water pills) increase urine production; consider timing of dose (try to take before noon)
    Narcotics, tranquilizers, sleeping pills, antihistamines, etc. may sedate and limit recognition of need to go or initiative to get there and may cause a dry mouth which leads to excessive fluid intake; consider hard candy or gum
  Bladder spasms are common, especially in elderly women and may respond to meds
    Detrol (tolterodine) and Ditropan (oxybutynin) and similar meds that keep the bladder from contracting but may worsen confusion, so monitor to determine if the benefits outweigh the risks

- Other strategies to consider:
  Safety issues: Ensure good lighting, grab bars, and non-slip bathroom rugs.
  Keep the bladder empty as much as possible
  Schedule bathroom visits every 2 hours while they are awake and take them to void anytime, they awaken at night
  Limit afternoon/evening liquids (especially tea, coffee, cola, Mountain Dew)
  Place a photo of a toilet on the door to the bathroom
  Be alert to their cues of needing to go and guide them there, watching for tugging on clothes, feeling in crotch, pacing, asking to go home
  Consider a bedside commode at night
  Consider a contrasting color for the toilet seat to make it easy to see
  Use simple-to-remove clothing with elastic waistbands, not zippers or buttons. Consider skirts (easy to pull up)
  Be there to provide instructions including visual and verbal cues
- Strategies to deal with incontinence that occurs:
  Document when and where accidents happen to see if there is a pattern
  Carry a change of clothes (including socks and shoes), diaper wipes, and a plastic bag (for soiled clothes) with you wherever you go; leave one set in the trunk
  Put a rubber sheet over the mattress with an additional pad that can easily be removed without stripping the whole bed
  Learn about products such as disposable underwear, heavy pads, inserts; brands differ so shop around to find the right fit. Bigger is not always more absorbent
  Keep skin clean and dry, and moisturized if necessary
  Barrier creams like zinc oxide, A and D ointment, Balmex, Desitin, Vaseline may help
- For additional help, call 1-800-BLADDER: Help for Incontinent People

3. BATHING RESISTANCE

What Happens:

With dementia, people may forget how to turn on the water and may not ask for help out of embarrassment, poor judgement, or not realizing the need to bathe. The sense of smell declines with Alzheimer's so they may truly be unaware and may be insulted if you comment on body odor. Some people develop hypersensitivity to water touching their skin, the sound of water running, or temperature changes, so consider trying a bath that's already drawn if they refuse a shower (or vice versa). Bathing is an intimate process; for some, having help may feel embarrassing, especially if provided by a stranger or someone of the opposite sex.

Why It Is Important:

Families often worry about the risk of infections and odor associated with poor hygiene and the person may be stigmatized for being less clean. When incontinence is a problem, not bathing becomes an even bigger concern.

What You Can Do:

- Frequency: aim for a twice a week, though the genital region should be washed daily if possible. A sponge bath is an alternative, using a warm wet washcloth, or cleaning them with a warm washcloth after they have toileted.

- Honor their preferences; try to be flexible and adjust to the person's routine such as their preferred time of day to bathe, whether they prefer bath or shower, and soap or bath gel,
- Safety and Environment
  Set water heater below 120 degrees to minimize risk of burns
  Have temperature adjusted, room warmed up and everything ready before you bring them into the room
  Be sure the person feels safe and comfortable
  Have tub and grab rails available and non-skid mat on the floor
  Consider a shower chair, though it may be too new and scary, so consider introducing it very early while they can understand what it is and accept it
  Consider using a handheld shower head and starting at their fee, which are less sensitive than the head; consider washing hair another day or in the sink
  Give verbal instructions and/or model what needs to be done. Let them help as much as they want to
  If agitated, walk away and try later
  Preserve dignity by using towels to keep person covered
  It is possible to wash someone with their clothes on, but it takes ingenuity
  Consider getting into the shower with them

4. SLEEP DISTURBANCE

What Happens:

Circadian rhythms may be disrupted by damage occurring in the brain; in addition, changes in routine can lead to agitation that may impair sleep. Pain, hunger, acute or chronic illness, sleep apnea, medications, depression, restless leg syndrome, caffeine, or other factors may contribute. If a person with dementia awakens at night, they may be disoriented, afraid, or need to use the bathroom. Dreams may be confused with reality; dementia medications may cause nightmares, especially if taken at night. With normal aging, there is a decrease I the overall amount of sleep necessary (6-7 hours/24 hours); daytime napping if > 30 minutes will borrow from that.

Why It Is Important:

Lack of sleep can cause poor general health and can increase the risk of confusion and hallucinations. Tired caregivers may lose much needed patience and become more easily frustrated. An exhausted caregiver may also be less attentive to safety issues such as wandering, fire hazards, medications, and their own health will also suffer.

What You Can Do:

- Sleep hygiene:
  Maintain a consistent bedtime routine with a bathroom ritual of toileting, brushing teeth, washing (only if that does not stress or agitate them)
  Consider a cup of chamomile or Sleepy time tea or warm milk. Avoid sleep aids that contain diphenhydramine which can worsen confusion (Benadryl, Tylenol PM, Advil PM, Sominex, Sleep-Eze, and others)
  If medication is needed, low-dose trazadone is preferable to Ambien or benzodiazepines such as lorazepam/Ativan, alprazolam/Xanax, etc.
  Read, say prayers, or listen to music but do NOT watch night-time news

Make sure the person gets plenty of exercise during the day (to their ability)
Limit caffeine and alcohol intake, particularly after 3 pm
Avoid nicotine, chocolate, or foods that can cause reflux: fried foods, dairy
Pursue treatment of pain, illness, and depression
Consider a "white noise" machine

- Create a safe path to the bathroom for night-time voiding; consider motion-activated lights near the floor. Shadows or glare can lead to misperceptions and increase fear. Mirrors can sometimes be upsetting if the image in the mirror is not recognized so cover it if needed.

5. COOKING SAFETY, WEIGHT LOSS AND NUTRITION

What Happens:

People with dementia may forget to eat (or gain weight by forgetting the already ate) or may lose their appetite or interest in food as their sense of smell declines. At later stages, they may not know what to do with food or how to use utensils. Aspiration of food or difficulty swallowing can lead to choking spells that is frightening; they may avoid eating to keep it form happening again. Similarly, thirst may decline, and some people avoid drinking fluids to keep from having to urinate as frequently, especially if incontinence is a problem.

Why It Is Important:

Weight loss affects general health and may lead to dehydration, poor wound healing, and increase susceptibility to infection. Weight loss in someone with cognitive impairment who lives alone may indicate the need for additional supervision; each year, we see patients who undergo expensive, invasive evaluations for weight loss because they are forgetting to eat. In later stages of dementia, weight loss may necessitate discussions of artificial hydration and nutrition, although feeding tubes are generally not recommended.

What You Can Do:

- Environment: Make mealtimes pleasant. Keep things simple and minimize clutter on the table
  Give one food at a time if they appear overwhelmed and serve smaller amounts if they complain about too much food
  Use adaptive equipment such as a plate with dividers or colorful plates to help those with perceptual impairment. Straws may help with fluid intake
- Strategies to encourage eating
  Make sure they are hungry (try to fit schedule to their appetite)
  Serve their favorite foods
  Sweet taste buds provide strongest flavor; offer fruit, carrots, sweet potatoes
  Have frequent, small meals (no need to hold out for a big one)
  It is OK to eat the same things several days in a row
  Eat *with* the person to model for them (it may minimize frustration)
  Consider having finger foods like nuts or dried fruit left out for snacks
- Safety
  Eventually all persons with dementia will gradually lose their skills to prepare food

Stoves can be adapted with timing or shut off switches or unplugged
Smoke detectors and fire extinguisher should be in all cooking areas
Check the temperature of the food to be sure it is not too hot (or cold)
If choking frequently, consider a swallow study but do not pursue a PEG feeding tube unless they have a reversible problem
Learn to do the Heimlich maneuver
Size of bites matters; cut up foods ahead of time
Consistency of food may be important. Thicken foods by adding cornstarch or gelatin if necessary
Monitor hydration; be creative and offer soup, grapes, oranges, pineapple, popsicles
Consider protein supplements and/or multivitamin
Consider Hospice referral at later stages

- Consider the person's goals of care an honor their wishes

6. SHARING BAD NEWS

What Happens:

With dementia there is increased difficulty retaining new information and often a distortion of past events. For highly emotional events, the person may either ask repeatedly about it or they may forget it altogether. At times, people believe they are living in a previous era (from recent to their own childhood), recalling or looking for people who were alive during those times. They may ask to "go home" and are likely referring to the home they lived in at that time.

Why It Is Important:

Sharing bad news is not easy but when they look for someone who died many years ago and are repeatedly told the person is dead, it can be devastation for all concerned. It can be painful for caregivers to explain an emotionally charged event repeatedly and can be a new loss to a person with dementia every time they hear it explained again. It is better to be kind and honor that they are living in a mental place that may look different from your reality for reasons we don't fully understand.

What You Can Do:

- Caregivers need to take time to experience their own grief and accept that their loved one with dementia may grieve very differently or not at all.
- There is no right answer about taking a demented person to a funeral
  If you take them, be prepared with a plan to allow them to leave if needed
  Consider going to the gravesite after the funeral for a private goodbye
  It generally is not effective to go to a gravesite to prove someone is dead reasoning is impaired and it may antagonize the person
- People have a right to know bad news and grieve losses. However, once you have told them and it is clear they cannot retain it, it is important and respectful to stop telling them. The rational part of the brain is impaired, and they cannot enter your reality. Honor that
- Strategies for dealing with questions regarding a deceased relative ("Where's Mamma?"). It may help to redirect the person:
  "I don't know; what do you think?"
  "No, I haven't seen ___, have you? Tell me about her."

"She's not here right now" or "I'm not sure when she'll be back."
It may help to turn the discussion to memories: What were they known for? Famous for cookies? Jokes? Hugs? It may be helpful for you to know about the person who died and what they meant to the person with dementia
It may help to ask them to do something that gets their mind off the topic

7. WANDERING OR GETTING LOST

What Happens:
Many with dementia have a need to be in constant motion and if not occupied with activities or monitored closely, may wander to placate the need to be active. Becoming disoriented in familiar places, even in the early stages, is common and can be worse with certain medications. If a person is afraid, bored, restless, in pain, stressed, or delusional they may "wander off" to get away. They may need to go to the bathroom, or they may be lonely and want company. Some may become overwhelmed with too much commotion (noise, crowds, loud TV). Others may be responding to environmental stimulus such as an exit sign, people leaving or waving goodbye; they may have had an argument and want to get away from it. Some may believe they are still going to work or having to pick up the children from school and others have a lifelong pattern of being on the go.

Why It Is Important:
Wandering can pose major safety concerns. They may go hungry, freeze, or develop illness with lack of shelter. They may also be afraid of other and vulnerable to exploitation.

What You Can Do:

- Keep them involved: folding laundry, simple art projects, washing non-breakable dishes; background music might be soothing
- Consider adult day programs which provide socialization and a break for caregivers
- Safety Precautions:
  Put away essential items like their coat or purse that might prompt departure
  Register with the Safe Return program of the Alzheimer's Association
  Have a bracelet, necklace or other identification such as provided by Medic-Alert
  Tell neighbors so they can provide an informal "community watch"
  Put childproof knob covers on doors; consider door and window alarms
  Be aware that at night when caregivers are sleeping is a high-risk time so consider a baby monitor, bells on the door, or sleep in the same room
  Simple lock placed out of the line of sight may deter wandering
  Consider a home monitoring system to watch over them if they are alone
  All caregivers should have identification in their wallets instructing emergency responders that they are responsible for another person's care in the event they are incapacitated
- In case of wandering:
  People tend to walk in a straight line until their path is disrupted by a physical barrier or a distraction such as a noise
  Notify police and neighbors
  Have recent pictures ready for identification: with and without dentures.

Have an unwashed item of clothing the person has worn and put it in a plastic bag to preserve the person's scent for search dogs (hope you never use it)

8. PLACEMENT

What Happens:

Placement may occur when it becomes impossible to provide care and safety for a person at home. It can result from one or more safety concerns such as missing medications, losing weight, causing fires, inability to access help in an emergency, or vulnerability to scams. For some there may be no family close by, or the person may have rejected previous caregiving efforts and a crisis triggers placement. At

later stage dementia, the physical challenges of care such as help with bathing, toileting, feeding, or walking, may trigger placement. It can also result from a caregiver's health problems, compassion fatigue, or death.

Why It Is Important:

Deciding when to make this transition is among the hardest decisions faced by families, particularly if the person being placed is resentful. It requires review of financial resources and supports which can trigger family conflict. For caregivers, it can conjure feeling of failure and guilt as they struggle to accept that they may need to make decisions that are unpopular but necessary in the face of declining insight and judgment caused by dementia. It may help to ask oneself how they would have decided when they were at their best; most people would not have wanted a spouse's or their children's health to be negatively impacted by caring for them. Realistic expectations are important; while a love on may not get the same care they received at home, they will be in a safe environment where their needs will be met by a staff of many, freeing the family to resume the role of loving child or spouse rather than exhausted caregiver.

What You Can Do:

- If considering placement:
  Explore options in advance so you do not have to make this decision in a crisis. Be aware of the person's wishes as well as your own limitations for caregiving
  Consider safety concerns and which can be managed outside a facility setting such as finances, medications, nutrition, fire hazards, ability to access help in an emergency, getting lost, driving, falls
  Have a family meeting to discuss financial resources and triggers for placement.
  Is there an alternative intervention that may help, such as in-home help, Meals on Wheels, short term respite, help of other family members, financial reimbursement for time spent, medications monitoring, etc.
  Be aware of resources in the area. Eldercare lawyers can provide legal advice about how best to use financial resources and deal with Medicaid eligibility
  Department of Social Services knows of local resources for in-home care, placement
  Hospital discharge planners or facility social workers can be a resource
  Alzheimer's Association publishes lists about local resources including in-home agencies, short-term respite options, long-term care facilities, support groups, etc.
  Council on Aging can provide additional services and information

There are many web-based resources with links on our website: www.JFSDelaware.org/COMPASS.

- If someone is placed:
  Continue to advocate for their needs; regular involvement; regular remains important
  Allow for an adjustment period of several months. Disorientations may be triggered and takes time to resolve
  Visiting in the first few days may be a dilemma
    Be flexible – If you visit and it is clearly upsetting, consider decreasing visits in the first few weeks if staff feels appropriate. Check with staff to see how your loved one is doing after you leave; don't take it personally if your visits upset them for it will likely be temporary.

    Try to schedule your visit before a meal or planned activity at the facility so the person will be called in and can leave you to go somewhere rather than you leaving them
    Sometimes providing reminders of home can help the person feel more comfortable and sometimes they can be confusing because they are alert enough to know they are not at home
  Advocate for least restrictive level of care that can ensure trust
  Have an outlet to deal with complicated emotions that may come up such as:
    Ambivalence or guilt – "Was this the right choice?"
    Anger of other family members who disagree with the decision.
  If worried the person is being mistreated, address the concern immediately
    Talk to the director of nursing, head administrator, direct care staff, social worker, or ombudsman who oversees facilities
    Do speak up about concerns but in a way that is respectful and doesn't engender resentment for your loved one
  Recognize the many responsibilities and limitations of paid staff and let them know you appreciate what they do. A good book is Life in the Land of Alzheimer's.

9. BEHAVIORS, HALLUCINATIONS, DELUSIONS, PARANOIA

Hallucination delusions, and paranoia are distressing problems that are often associated with dementia. Examples include seeing things that others don't, thinking that dreams or what they use on TV is real, the belief that others are stealing from them, the idea home is not really home, being confused by the image in the mirror, or not believing people are who they say they are. Sometimes this thinking is harmless and even pleasant, however it can sometimes be a source of great suffering.

What Happens:

These behaviors occur when individuals with dementia cannot make sense of what is occurring. For some, there are triggers such as shadows or misinterpreting sounds and this may be worse if no one is around to reassure them. Other factors which can cause these behaviors are changes in routine, new caregivers, poor sleep, pain, excessive alcohol intake, history of psychiatric illness, or conflict in the family. Urinary tract infections are often asymptomatic in this populations and behavioral change (such as agitation) may be the only symptom.

Why It Is Important:

Remember that all behavior is an effort to communicate, so seek first to understand. They may feel unsafe and be at greater risk of wandering or becoming hostile, agitated, or threatening to protect themselves. A quick and compassionate response is important to alleviate their suffering and yours as well.

What You Can Do:

- Address safety concerns by removing or securing items that could be used as weapons (especially guns and ammunition), maintaining good lighting to minimize shadows
- Behavior has a purpose; use compassionate curiosity to try to understand it
- Provide calm reassurance to convey that you care

- Don remind them that they just asked the same question
- Sympathize with their upset feeling and use distractions to change the subject
- Avoid confrontation but be firm in not tolerating threats to your safety. If there is danger, call 911 or the mobile crisis team I your area.
- Check with the doctor for treatable causes such as pain, infection or medication side effects
- Have hearing and vision evaluated and treated
- Try to accommodate the behavior, not control it and pick you battles
- Sexual behaviors may be confused seeking of affection; redirection may be effective
- Keep in mid that it is better to be kind that to be right
- Reduce caffeine, sugar, and junk food
- Avoid crowds where they may feel less comfortable
- Simplicity and maintaining a routine can help
- If the hallucination or delusion is non-distressing, no intervention is needed
- Medical intervention may become necessary if the person becomes aggressive
  Consider medications such as dementia medications, antidepressants, trazadone, or antipsychotics if the person is threatening others or if distress is affecting quality of life. Psychiatric evaluation or hospitalization may be necessary

10. END OF LIFE ISSUES

In a person with dementia, the average life expectancy is 8-10 years from diagnosis less for some more for others; this affords a golden opportunity for forethought and planning of important issues that arise at life's end. While there is no single "right" way to do things, discussion and discernment in advance can help families facilitate the type of care most hoped for by the individual with dementia involving issues such as artificial nutrition, life support, advance directives, hospice, organ donation, autopsy, and who would like to speak for them if they are unable to do so for themselves.

What Happens:

Dementia leads to gradual inability to communicate wishes to loved ones and results in increased dependence on others for care as one nears the end of life. Planning can help you honor the person's wishes and inform decision-making should a crisis arise.

Why It Is Important:

Caregivers will likely face decisions that will affect the person's health, financial state, and emotional well-being. Knowing what they want gives the caregiver the best chance of honoring those preferences if realistically possible. Autopsy is especially important to discuss in advance since it can clarify diagnosis and help younger generations manage their own risk factors and further research for a cure.

What You Can Do:

- Obtain Advance Directives including living will, healthcare and durable powers of attorney
- Consider Do Not Resuscitate and /or MOST Form and have it available
- Discuss artificial hydration, nutrition and life support machines
  IV fluids may add discomfort if given when person is dying but can be life sustaining if the problem faced is reversible
- Be clear about goals of care – is life extension or quality of life the priority? Making the "right" choice is very personal with no clear guidelines. Consult trusted friends, mentors, physicians, and/or clergy
- Autopsy may facilitate confirmation of specific diagnosis for family: paperwork must be done in advance unless death occurs in the hospital
- Learn about available resources: support groups, in-home care, hospice, educational programs in the community

10 Symptoms of Caregiver Stress

Adapted from Alzheimer's Association website (www.alz.org)

If you experience any of these signs of stress on a regular basis, make time to talk to your doctor.

1. Denial about the disease and its effect on the person who's been diagnosed. *I know Mom is going to get better."*

2. Anger at the person with Alzheimer's or others, anger that no cure exists or anger that people don't understand what's going on. *"If he asks me that question one more time, I'll scream."*

3. Social withdrawal from friends and activities that once brought pleasure. *"I don't care about getting together with the neighbors anymore."*

4. Anxiety about facing another day and what the future holds. *"What happens when he needs more care than I can provide?"*

5. Depression that begins to break your spirit and affects your ability to cope. *"I don't care anymore."*

6. Exhaustion that makes it nearly impossible to complete necessary daily tasks. "*I'm too tired for this."*

7. Sleeplessness caused by a never-ending list of concerns. *"What if she wanders out of the house or falls and hurts herself?""*

8. Irritability that leads to moodiness and triggers negative responses and actions. *"Leave me alone!"*

9. Lack of concentration that makes it difficult to perform familiar tasks. *"I was so busy, I forgot we had an appointment."*

10. Health problems that begin to take their toll, both mentally and physically. *"I can't remember the last time I felt good."*

The Benefits of a Caregiver Support Group

By Allen Jesson

You and your parent are in the unique position of doing something that has not been done before in the history of the world. Are you aware that your parent is among the first generation to live en masse into later life? In all previous generations, most people died before they reached later life. They died from disease, warfare, childbirth, famine, and other hardships. However, most people born into your parents' generation have survived to become older adults. The flip side of that story is that you are part of the first generation to experience caregiving as a normal part of midlife. Not only that, but you are providing care for longer than every generation prior to yours and are caring for parents who are frailer. Your parents might have provided care for their aging parents for months, or maybe a few years, but your generation provides caregiving to aging parent for an average of 17 years! Many of you will care for four parents or mores, if you assist in your in-laws and stepparents as well as your own parents. In the past, most people died of their first physical crisis which might have been a heart attack, stroke or cancer.

Now many people survive the first incident, often for many years, but not completely recovered, and not with the same health and vigor they had before the crisis. They need a little help from you. Here's where a support group becomes important. Since no one in a previous generation has experienced this, you have a few options for advice. You are the leading edge. You do not have a model from earlier generations of how to choose between attending your son's baseball game or visiting your chronically ill mother. Your friends, neighbors and co-workers might not know what criteria to consider when you're faced with making heartbreaking decisions about money, time, and energy. And you certainly were not raised knowing how to say no to mom or dad.

A group whose participants are currently facing the same issues as you are can provide support in a way nothing else can. Another advantage of discussing aging issues with a peer group is that you become a better, more knowledgeable caregiver. By drawing on the experiences of other participants, you have information on how to cope with events even before they happen. Most participants will say at some point: Thank goodness I knew what to do or had heard of that before. It's reassuring to know that you are not the only one who resents the burden of caregiving while fearing the end of it. Another great reason to find a peer support group is to share your hard-earned knowledge with others who may be floundering. You may be able to guide someone through the process of takin the car keys or moving their parent out of the home they've lived in for the last 70 years. Become a better caregiver. Attend your local peer support group.

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easterseals
Delaware & Maryland's Eastern Shore

RESPITE VOUCHER PROGRAM

Take a Break through Easterseals Respite Grants

Respite grant funding is available!

While caregiving is rewarding, it requires an immense amount of time and energy and often leads to caregiver burnout. By providing a temporary break in caregiving, respite allows you to relax a bit, clear your mind and/or attend to other family needs. Respite helps to keep family caregivers physically and emotionally healthy by reducing the likelihood of depression, anxiety, and isolation.

Through Easterseals respite services, caregivers can receive a voucher to be used to pay for the care of your loved one while you take a break. It could be a date night with your significant other; lunch with a good friend; or sitting outside reading a book. A friend, a neighbor, or an agency may provide the care. The respite provider cannot live in the same household as the care recipient and must be at least 18 years of age.

See back for additional eligibility requirements.

All Abilities. Limitless Possibilities.

resources@esdel.org | 1-302-221-2087

Respite Grant Eligibility Requirements for Delaware Residents

RELATIVE RESPITE

Funds are available to grandparents (or other non-parent relatives) who are:

Age 55 or older and caring for a child 17 or younger,

responsible for a majority of the child's care,

related to the child by blood, marriage, or adoption.

Partially funded by the Division of Services for Aging and Adults with Physical Disabilities through the National Family Caregiver Support Program, Title III-E of the Older Americans Act.

"Caregiving has us managing two lives and balancing both."
– THECAREGIVERSPACE.ORG

LIFESPAN RESPITE

Lifespan Respite funds are available to individuals providing unpaid care to a loved one of any age or disability, including:

a senior who is unable to stay alone,

an adult with a disability,

or a child with special needs.

Partially funded by the Division of Services for Aging and Adults with Physical Disabilities through the National Family Caregiver Support Program, Title III-E of the Older Americans Act.

DELAWARE HEALTH AND SOCIAL SERVICES
Division of Services for Aging and Adults with Physical Disabilities

CHILD + ADOLESCENT CAREGIVER RESPITE

Funding is available if you provide care to a child under 18 with a behavioral health challenge who is eligible for the Division of Prevention and Behavioral Health services.

Funding may also be available for children who do not yet qualify for services through DDDS.

Funded by the Department of Services for Children, Youth and Their Families, Division of Prevention and Behavioral Health Services and the Substance Abuse and Mental Health Service Administration System of Care grant.

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FTD Support Group

DE – Wilmington

Christ United Methodist Church
6 N. Clifton Street
Wilmington, DE

Last Friday of the month, 12 p.m.

Carol Lovett
302-345-4932

Dear JFS COMPASS Caregiver,

We highly recommend this support group, led by Carol Lovett, a former caregiver, herself, and social worker. Although the group is sponsored by AFTD, the group is attended by caregivers of individuals with different types of dementia, including Alzheimer's, vascular, etc., in addition to FTD.

During Covid-19, the group is meeting by phone teleconference a couple of Fridays per month. Please contact Carol for details, at carol.b.lovett@gmail.com, or the phone number to the left, or let us know if you would be interested in having Carol contact you to tell you about the group.

This group is led by an AFTD affiliated leader who has participated in additional FTD training. Note: Before attending your first group, please contact your facilitator to affirm the date and time, as both are subject to change.

"From Carol Lovett: We have been meeting since 2005. Our support group is sponsored by AFTD; however, members of the support group are care partners for individuals with a variety of diagnoses, including Alzheimer's, FTD and its subtypes, Parkinson's, Lewy Body, ALS, etc. All are welcome. We feel the key to being comfortable in a support group is hearing your story in the group for validation and support.

Our caregivers are youthful in spirit and vary in chronological age. Among the members who attend the support group meetings are current care partners and widows and widowers. I am a widow and cared for my husband for more than 10 years. There is an amazing amount of support and information in the room and we firmly believe that support is the best medicine in a journey that can become lonely.

We meet on the last Friday of the month in the Christ United Methodist Church on Clifton Ave, just off Kirkwood highway, next to BJ's and behind the PNC bank. Potential members can contact me or simply show up."