

DUKE DEMENTIA FAMILY SUPPORT PROGRAM

Caregiver Connections

An Educational Webinar Series With The Experts

**The presentation will begin shortly.
Thank you for your patience!**

dukefamilysupport.org

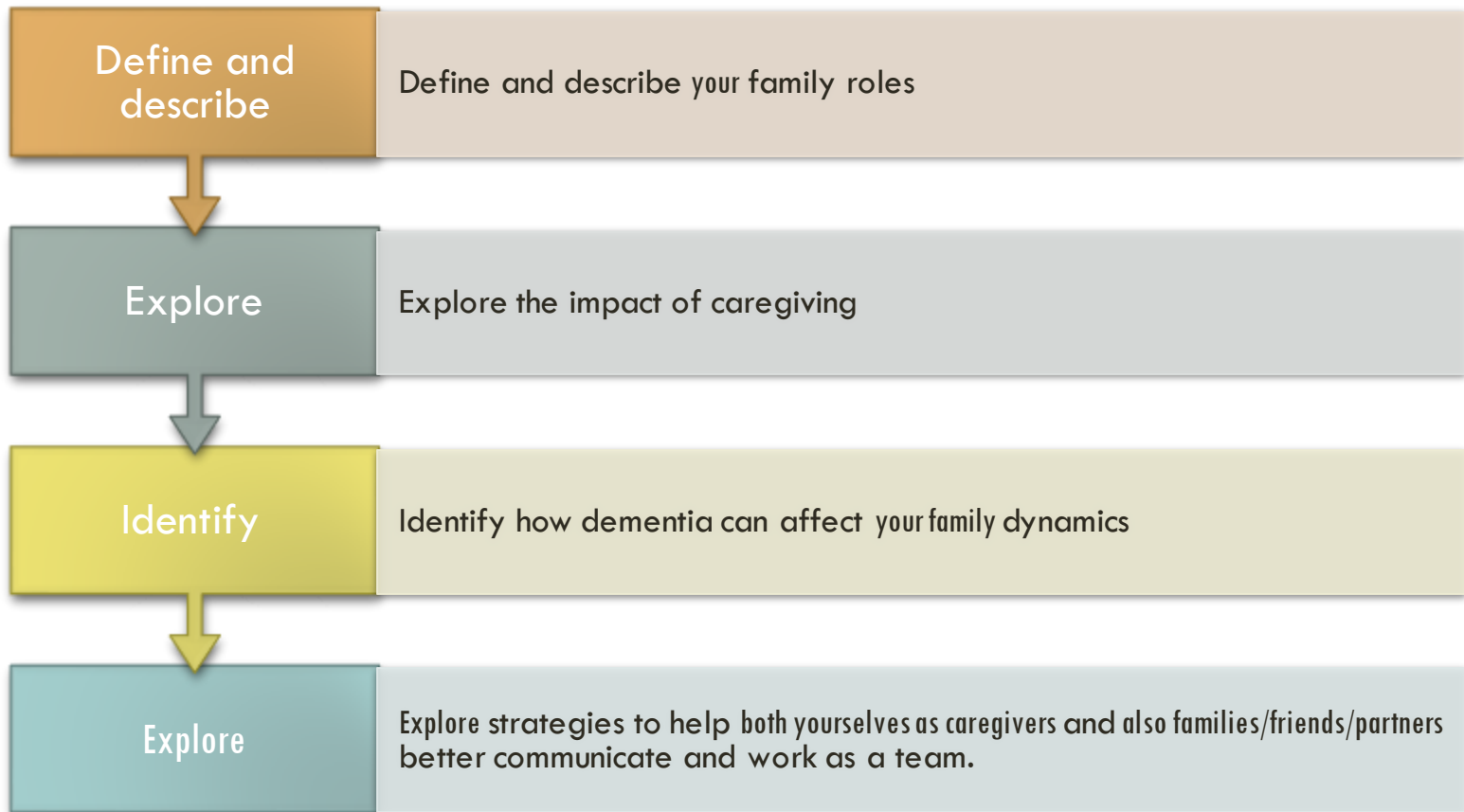
919-660-7510

FAMILY DYNAMICS

And Negotiating Difficult Behaviors
Presented by Linda Mockler, LMSW



OBJECTIVES



DEMENTIA'S RIPPLE EFFECT

A close-up photograph of a single water droplet suspended in mid-air just above a pool of water. The droplet is perfectly spherical and reflects light. Below it, the water surface is disturbed, creating a series of concentric, overlapping ripples that spread outwards from the point of impact. The background is a soft, out-of-focus blue, suggesting a sky or a large body of water.

The impact of dementia can be extensive. This illness impacts a person's ability to communicate, care for themselves, relate to the external world, and affects relationships with family, friends and community.

ALZHEIMER'S DISEASE

Alzheimer's disease is a brain disorder that impacts memory, thinking and language skills, and the ability to carry out the simplest tasks.

It is the most common form of dementia

It is a chronic, progressive, degenerative disorder

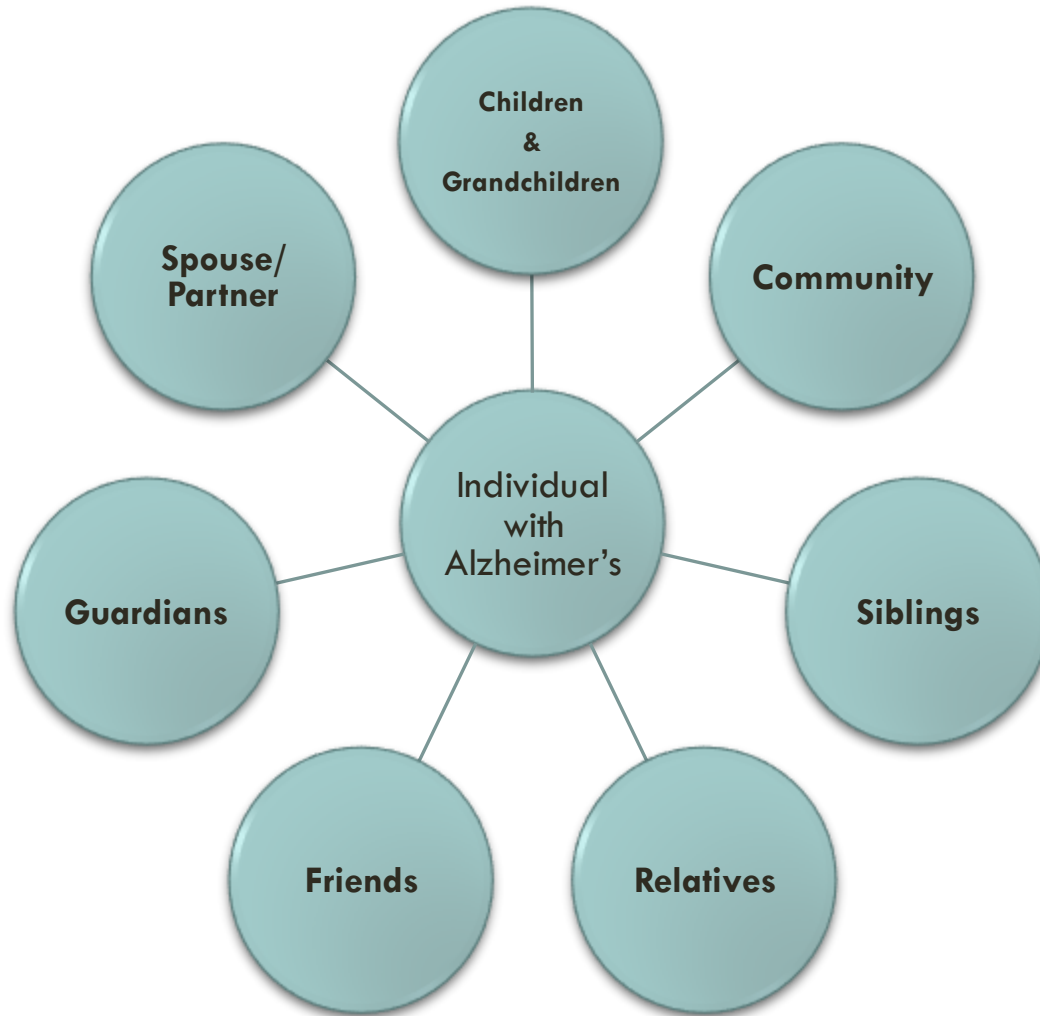
There are two types – young onset and late onset

CAREGIVING

More than 11.2 million Americans provide unpaid care for people with Alzheimer's Disease and other Dementia-related illnesses

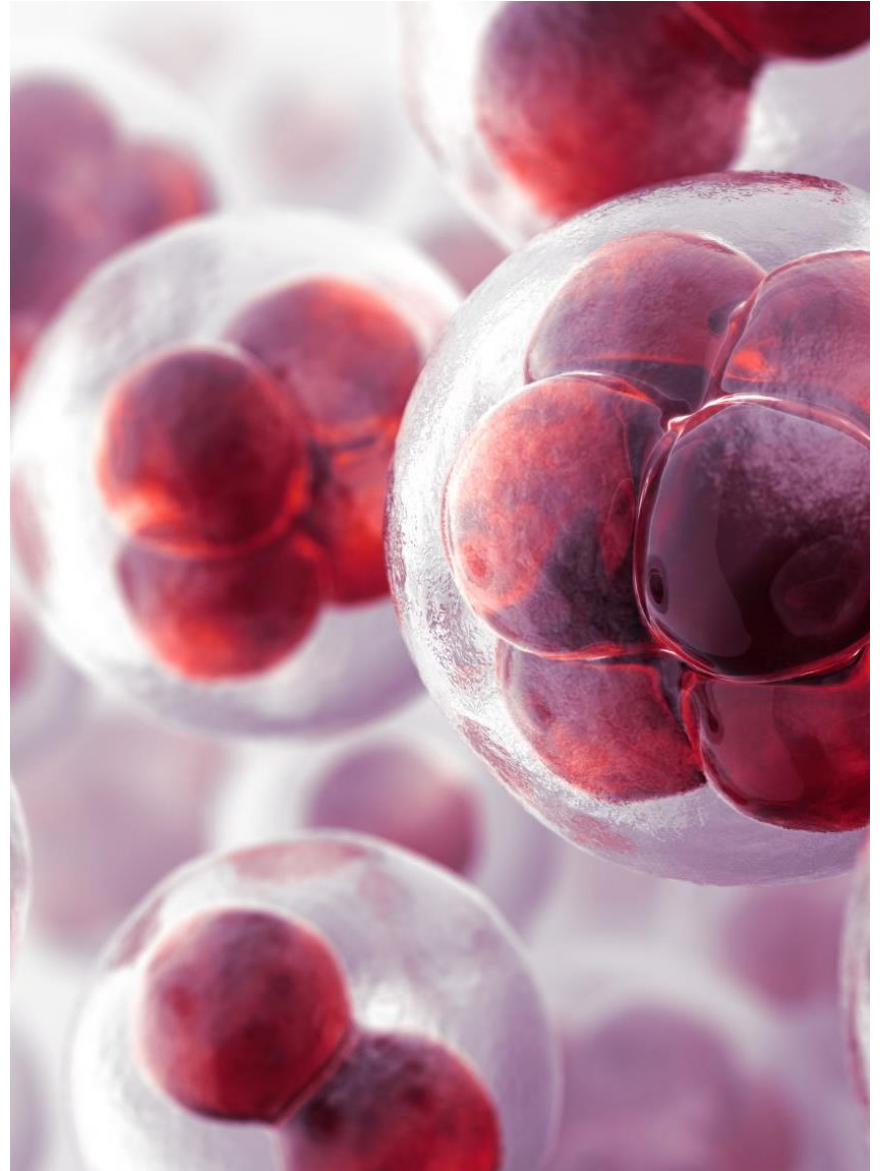
2020 – Caregivers of those with dementia provided 15.3 billions hours of unpaid care which equates to \$256.7 billion

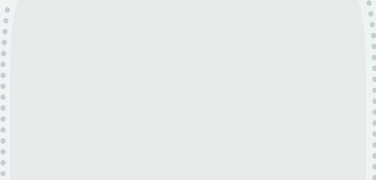
WHO'S IN THE FAMILY?




FAMILY & DISEASE PROGRESSION

It is important to note that not only the individual shows changes as the disease progresses. The family system can also go through a variety of changes as the disease evolves.





What
Contributes
to Family
Dynamics



History of the Parents


Birth order

Role in the Family

Life events (illnesses, deaths, divorce)

Trauma, disorders

Ways the family members are taught to communicate



Stressors
within the
Family

Financial pressures

Addictions

Discord within the parental relationship

Abuse

Inability to communicate

Vying for
attention



Family System

How does the family function?

As an open system where communication is easy and feelings are expressed; strong connections to others outside of the family encouraged and nourished

As a closed system where the family does not communicate and feelings are not expressed; outside relationships are not part of the family system

BOWEN'S FAMILY SYSTEMS THEORY

Dr. Bowen postulated that the human family is a living system

This means that individual members and the group as a whole influence one another's functioning in many ways.

The development of each family member as a person, their resulting health and happiness, and the quality of their connection (and interactions) with each other in the family unit are affected by this interdependence

Individuals and families vary greatly in their ability to develop in ways that contribute to the betterment of themselves, their families, and their society. There are many factors impacting the individual and family abilities to act in the best interest of yourself, your family, and your society, and balance all of them at the same time. The way your families regulated emotions, tensions and anxieties, will inform how you think, feel, act, and interact.

FAMILY ROLES

Families are organized around roles, rules, rituals, and boundaries. This structure assists in the understanding of the family and the function of its members.

Hero

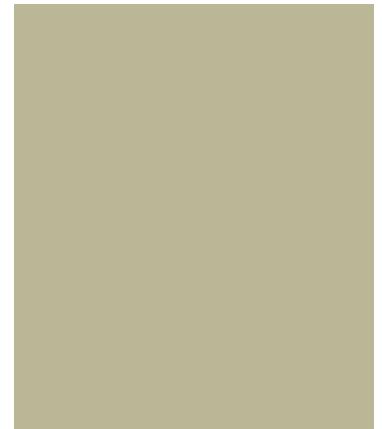
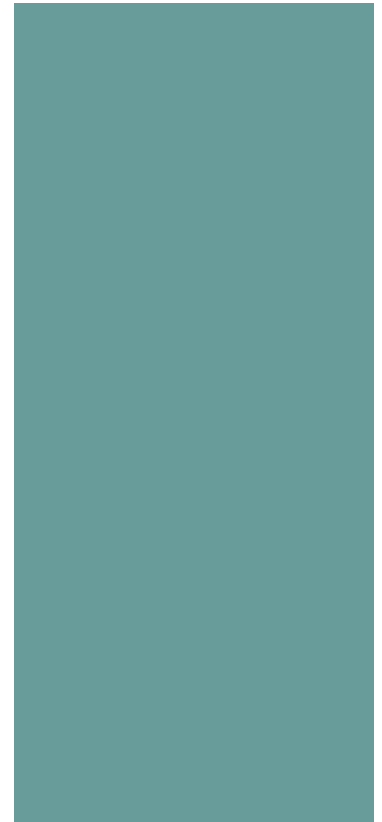
Rescuer

Power Broker

Scapegoat

Lost Child

Clown



HOMEOSTASIS

The concept of homeostasis involves family members acting to maintain the typical organization and functioning of their system – whether positive or harmful to everyone. There is resistance to change.

What happens when roles inevitably shift due to someone developing Alzheimer's disease?

What is this experience like for everyone?

How will each role react?

How can your family restructure the family system?

ROLE TRANSITIONS AND COMMON THEMES THAT MAY ARISE

When transitioning to the care partner role at any time, identities and relationships shift.



COMMON CHANGES THAT MAY AFFECT FAMILY DYNAMICS

Roles can
reverse

Increase in
guilt

A shift in
priorities

Changes in
emotions

A growth in
uncertainty

Disagreements
increase

ASPECTS OF LOSS

Child Role

Relationships

Vicarious
losses

Independence

“I had no
choice”

ANTICIPATORY GRIEF



FAMILY MEETINGS

Arrange the best time and place for everyone involved

Assure that everyone is heard

Highlight shared values when differences occur

Facilitate respect and caring

Involve all members in decision making

Create an Action Plan

Ensure your loved one is involved in every step of the process as long as they are able

HOW TO ORGANIZE AND HOLD A FAMILY CARE MEETING

If you are interested in watching a 9- minute video about how to organize and hold a family care meeting just follow this link:

<https://attendee.gotowebinar.com/recording/4128588503813606914>



TALKING WITH CHILDREN ABOUT ALZHEIMER'S

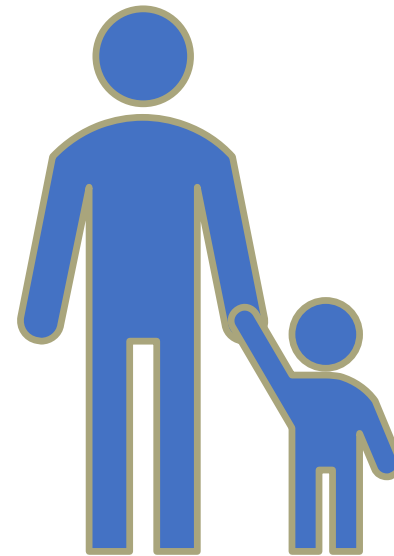
Assess their reactions

Some things to look for if they are having a difficult time: aggression, withdrawal, depression

Find age-appropriate strategies:

How to help: play therapy, books for children about dementia, encouraging questions

Pin-point and schedule activities they and their family member can continue to do together



Understanding Behaviors

Due to the very nature of dementia-related illnesses, the ability to communicate with language, can be impacted leading to what often is labelled as “problematic behavior.”

What we need to identify is the unmet need.

Agitation and Aggression

Due to the loss of cognitive functions many people with dementia struggle to recognize their own unmet need, therefore unable to effectively communicate what they need.

Agitation and behaviors that appear aggressive may be a reaction to physical pain or psychosis.

We as care partners must look past the behaviors to help identify the source of the person's distress.

What is the Source of Distress?

Physical Needs	Social Needs	Psychological Needs
Physical pain	Loneliness	Mental health concerns
Inadequate sleep	Boredom	Others taking over
Medication side effects	Poor communication	Loss of independence
Overstimulating environment	Wanting to hide the illness	Experience of being ignored or disrespected
Poor eyesight or hearing	Lack of trust in professionals	Misperceptions of others' intentions
Loss of inhibitions		Fearful of unfamiliar places
Lack of judgement or self-control		Hallucinations or delusions

How to Respond

Approach slowly
and to their
dominant side

Keep your hands
down

Get on their level

Speak slowly in a
soft tone

Try to identify
the immediate
cause

Rule out physical
pain

Focus on
feelings, not facts

Listen and restate
what they are
saying

Give positive
feedback and
encouragement

Avoid getting
upset – Take a
break!

Redirect to an
activity – PLAY
MUSIC!

Ensure safety

Music

Strengthens social interactions

Improves mood

Improves sleep patterns

Soothes during challenging activities

Reduces wandering

**NEEDS TO BE
THE PERSON'S
PREFERRED
CHOICE**

Sundowning



Sundowning can include:

SUNDOWNING CAUSES



CHANGE IN INTERNAL CLOCK



EXHAUSTION



INACTIVITY AND NAPPING



ANXIETY



LACK OF LIGHT



MEDICATION SIDE EFFECTS



DEPRESSION

Coping with Sundowning

01

Reduce noise, clutter, or the number of people in the room

02

Redirect a person with a pleasurable activity, a snack, or favorite object

03

Make early evening a quiet time of day

04

Close the curtains or blinds at dusk to minimize shadows

05

Manage caffeine intake

06

Stay active during daytime hours

SUPPORT FOR THE CAREGIVER

Possible resources to reduce the stress of long-term caregiving include:

- Respite care
- Support groups
- Education
- Increased understanding
- Counseling & psychotherapy

Self-care is crucial!

HOW TO BE A CARE PARTNER FROM AFAR



Get organized

Collect and coordinate all medical information, insurance claims, legal documents, etc.



Continuously reassess your loved one's needs

Develop a baseline of your loved one's overall health and functioning



Regularly check in with both family members and your loved one



Be in the medical care loop



Utilize technology to stay in touch



Enjoy your time together!

GENERAL

- Make sure the numerals for your address are clearly visible from the street.
- Keep important phone numbers – including police, fire, poison control and emergency services near the telephone, and be sure to write in large, easy-to-read print.
- Water leaks can cause serious damage to your home and your health – identify the cause of any leak and fix it promptly.
- Have your gutters and downspouts checked once a year to ensure they are clean and free of obstructions.
- Set your water heater no hotter than 120 degrees Fahrenheit.
- Keep low coffee tables, magazine racks, footrests and plants out of walkways.
- Remove old throw rugs and install a non-slip pad.

ELECTRICAL SAFETY

- Do not place cords where they can be a tripping hazard and never place cords under rugs or carpets.
- Do not drape cords over space heaters, radiators or other hot surfaces.
- If possible, avoid using extension cords.
- Use safety plugs to cover unused electrical outlets.
- Never overload outlets, and do not use extension cords or power strips.
- Install ground-fault circuit interrupter (GFCI) electrical receptacles in kitchen and bathrooms.

FIRE SAFETY

- Have a plan for escape in case of a home fire that all occupants understand, making special considerations for small children and older home occupants.
- Have an ABC-rated fire extinguisher on every floor of the house, especially in or near the kitchen.
- Be sure that everyone in the house knows how to properly operate fire extinguishers.
- Have your furnace checked once a year.
- Have your chimney and flue inspected once a year.
- Never leave a space heater, halogen lamp or open flame unattended. Do not keep any of these items close to curtains or other flammable materials.
- Make sure that all lamps and fixtures are equipped with bulbs having wattage equal to or less than the manufacturer's suggestion.

SMOKE AND CARBON MONOXIDE DETECTORS

- Have an operating smoke and/or carbon monoxide detector on each floor of your home.
- Check batteries twice a year (when daylight savings time changes) and replace as needed.
- If anyone in your home is hearing impaired, be sure that the smoke detectors in your home alert using lights or vibrations, as well as sound.

KITCHEN

- Be sure to have sturdy step stools and ladders on hand. Do not use a chair to reach high surfaces of your home.
- Store flammable items away from your stove top or range:
 - Do not place rags or towels near the oven handle.
 - Store plastic utensils and pot holders away from hot surfaces.
- Do not wear loose fitting clothing while cooking.
- Turn pot handles away from the front of the stove.
- Unplug all portable and countertop appliances that are not in use.
- Make sure that the kitchen is well-lit.
- Clean all spills immediately to avoid slips and the spread of water.
- Store flammable cleaning products and other chemicals from floors and sinks.
- Keep anything poisonous secure and out of reach of children.
- Use the exhaust fan when cooking to avoid moisture build up.

HALLS AND ENTRYWAYS

- Make sure that all windows and doors to the outside close and lock securely.
- Keep keys to internal door locks close to the door and easily accessible.
- Keep hallways clear for easy passage in case of an emergency.
- Place locks where all members of the household can reach and use them.
- Be sure that any walkways to the house are free of tripping hazards.
- Widen doorways to accommodate household members who use a walker or wheelchair.

STAIRS

- Stairs should be well-lit with switches at both the top and bottom of a stairway.
- Do not store anything on the steps – even temporarily.
- Do not place loose area rugs at the top or bottom of stairways.
- Install handrails on both sides of any stairway.

BATHROOMS

- Keep electric devices away from bathtubs and sinks.
- Keep towels and washcloths away from heaters.
- Install grab bars in bathrooms and elsewhere as needed.
- Install and/or use the exhaust fan when bathing to help prevent mold and moisture build up.
- Install a non-slip mat or textured adhesive strips on the floor of your shower or bathtub.
- Modify your toilets, sinks and bathtubs as needed to make them easier and safer to use.
- Keep first aid supplies well stocked and easily accessible.

BEDROOMS

- Have a lamp or light switch with a dimmer feature that you can easily reach from bed.
- Keep hot plates, space heaters and other hot appliances away from bed.
- Keep a phone near the bed.
- Never place anything on top of a plugged-in electric blanket.
- Place nightlights in bedrooms and hallways to guide you in the dark.

BASEMENT/LAUNDRY ROOM

- Clean the clothes dryer's lint trap after each use.
- Make sure you never run the dryer when no one is home.
- Do not leave clutter on the floor – it is both a fire and a tripping hazard.
- Make sure the dryer vents outside with metal duct and unobstructed air flow.
- Make sure water heaters, furnaces and space heaters that produce carbon monoxide vent outside.

HOME SAFETY CHECK

Ways to safeguard your loved one in the home



QUESTIONS? |

AFA RESOURCES AND SUPPORT

AFA's National Toll-free Helpline – **NOW 7 DAYS A WEEK 9am-9pm EST**

Professional Trainings offering Continuing Education Credits!!

AFA's TEAL ROOM!

AFA's Educating America Tour

National Virtual Memory Screening Program

Care Connection monthly webinar

Support Groups Onsite

Alzheimer's Today Magazine

AFA's Education & Resource Center in New York City

Telephone Caregiver Support Groups

www.alzfdn.org

866-232-8484

THANK YOU!!!

Additional Questions?

Contact Linda Mockler

lmockler@alzfdn.org

Or Melpo Voulieris

mvoulieris@alzfdn.org

866-232-8484



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Thank you for joining us today!

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