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

Define and describe
Define and describe your family roles

Explore
Explore the impact of caregiving

Identify
Identify how dementia can affect your family dynamics

Explore
Explore strategies to help both yourselves as caregivers and also families/friends/partners better communicate and work as a team.
DEMENTIA’S RIPPLE EFFECT

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.
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?

- Individual with Alzheimer's
- Spouse/Partner
- Children & Grandchildren
- Community
- Guardians
- Siblings
- Friends
- Relatives
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.
<table>
<thead>
<tr>
<th>What Contributes to Family Dynamics</th>
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<tbody>
<tr>
<td>History of the Parents</td>
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<tr>
<td>Birth order</td>
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<tr>
<td>Role in the Family</td>
</tr>
<tr>
<td>Life events (illnesses, deaths, divorce)</td>
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<td>Trauma, disorders</td>
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<td>Ways the family members are taught to communicate</td>
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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
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
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
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?

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

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 can include:
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
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!
## Home Safety Check

### 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 trip hazard and not 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.
- Do not overload outlets or extension cords with too many appliances.
- Install ground-fault circuit interrupter (GFCI) electrical receptacles in kitchens 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.

### 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 reduce 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 near sinks and bath tubs.

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

### Halls and Entryways
- Make sure that all windows and doors to the outside are closed 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.

### Basements/Laundry Room
- Clean the clothes dryer’s lint trap after each use.
- Make sure you never run the dryer when no one is home.
- 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.
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?
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Thank you for joining us today!

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