

#### Duke Dementia Family Support Program

### Caregiver Connections An Educational Webinar Series with the Experts

The presentation will begin shortly.

dukefamilysupport.org 919-660-7510



# Behavioral Changes in Dementia

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#### Overview of talk

**Definition** 

**Examples** 

Why do these occur?

General principles to guide management

Nonpharmacologic management strategies

Medications

Putting it all together: Role Play



## Behavioral (neuropsychiatric) symptoms of dementia

Common and troubling

~75% of persons with dementia experience these

symptoms

Prevalence

as disease advances

Behaviors functional impairment

Can accelerate or lead to nursing home placement

#### What are they?

anxiety, apathy, depression, disinhibition

sleep disturbances

anger, agitation, verbal and physical aggression

restlessness including pacing, wandering

psychotic symptoms

- delusions
- hallucinations

#### A break in reality testing

#### Psychotic symptoms

- the experience is not consistent with reality
- usually feels very real to that person
- Auditory and visual hallucinations
- Common paranoid delusions
  - suspicions or accusations that personal objects are stolen
  - spouse is unfaithful
  - they are being watched or home is invaded

#### Why do these happen?

Dementia damages the brain



The person cannot make sense of what he sees and hears



Feeling lost, anxious, worried, vulnerable, helpless

# The afternoon is so challenging!

#### Sundowning

- Behaviors peak in late afternoon/ early evening
- Afternoon fatigue
- related to a disturbed circadian rhythm
- risk factors include disturbed sleep and poor light exposure

### General guidelines

Is the behavior harmful to that person or others?

Is the behavior making life intolerable for those who care for him?

If harmful  $\rightarrow$  it needs to stop

If not dangerous  $\rightarrow$  maybe the behavior can be easier to tolerate if you take a break

**CAREGIVER RESPITE!** 

# Detective: you know them best

Identify ANY underlying cause that you can adjust

 many people with dementia struggle to recognize their own unmet need → therefore unable to effectively communicate what they need

# Detective: any patterns/triggers?

Are they sleeping well at night?

Are there any new medications? Even over the counter meds?

Is there a new infection?

Is there untreated pain?

Are they having regular bowel movements?

Is there a sensory impairment? Is their vision and hearing ok?

Has there been a sudden change in environment?

#### Management: Safety first!

Remove weapons from the home

Locks, baby monitors, stove switches, pressure sensitive bed mats

Door chimes, alarms, motion detectors, medical bracelets

Project Lifesaver!

Crisis resources

Feeling unsafe? get help, call 911.





Protecting those who wander, and bringing peace of mind to families, caregivers and the community.

# MGMT: routine, structure, support

Create a supportive environment

Structured, familiar routines

- Go to bed, get up same time
- Start your day in similar fashion
- Exercising outside is usually best in the AM hours
- Shower on certain days of the week

Goal to avoid alcohol, coffee in afternoon/evening hours

Minimize clutter

Add personal touches

 Have photos on display, comforting items nearby, favorite music playing

#### MGMT:

(I know its difficult but)

Stay calm

### Provide calm, reassuring responses when loved one seems anxious

#### Validation therapy

- Developed in the 1960s (Naomi Feil)
- Instead of constantly correcting patients with dementia, why don't we validate their feelings and emotions?
- Empathy
- Acceptance
- Respect

#### Validation therapy in action:

"it's not me, it's not him, it's the disease"

- Listen
- Repeat what they have said so they know you have heard it
- Acknowledge feelings
- Emotional well being > factual accuracy
- Arguing/convincing → everyone upset and frustrated

#### MGMT: rechannel

Is there a way the behavior can continue in a safe way?

Turn restlessness into an active, simple task

Dusting, stacking books, folding laundry

Person is occupied and also may feel useful

#### MGMT:

Anything they love? redirect, distract





redirect their attention from distressing thoughts/behaviors to a different activity



Choose an activity that is meaningful for the person or involves sensory stimulation



Listen to music. Have a snack. Go for a walk. Play with the dog.



Aromatherapy can be very calming- some people are soothed by lemon balm or lavender

#### MGMT:

meet them in their reality

#### Little white lies can be OK

#### Therapeutic fibbing

- In an ideal world, we would always be able to tell the truth
- In dementia: sometimes the truth can cause more harm than good
- Meet them in their reality, don't force them into ours
- A compassionate way to reduce suffering

#### MGMT: Medications

Always target good sleep at night first!

Cognitive enhancer

Antidepressants

#### Antipsychotics

- start low, titrate slowly with ongoing assessment
- 2005: black box warning
- REXULTI (Brexpiprazole)- FDA approval for agitation in setting of dementia 2023

Anticonvulsants/ mood stabilizers: rarely used

Review of Management Strategies

#### Safety first!

Supportive environment with routine, structure

Stay calm: validate feelings and emotions

Rechannel

Redirect / divert / distract

Meet them in their reality

Medications

### Putting it all together

ROLE PLAY.
Scene 1

# Challenge: belief that things are being stolen

Scene: PLWD is upset that the housekeeper Sally is stealing things from her

Scene 1. Take one.

Stolen things

#### PLWD:

She stole all my sweaters again!

#### Caregiver:

Are you crazy? that's not possible. Sally would never do that!

Scene 1. Take two.

Stolen things

Stay calm: validate

Meet them in their reality

#### **PLWD:**

She stole all my sweaters again!

#### Caregiver:

Oh goodness, ok. Can I help you look for them?

### Scene 1. Take three.

#### Stolen things

Stay calm: validate

Redirect / divert / distract

Meet them in their reality

#### **PLWD:**

She stole all my sweaters again!

#### **Caregiver:**

Oh goodness ok. I'm pretty hungry, can we eat an early dinner and then we can look for them together?

#### Scene 2

# Challenge: wandering, leaving the home

Scene: husband is attempting to leave home to go to work

Scene 2. Take one.

Wandering

#### PLWD:

I need to go to work now. I'm already late.

#### **Caregiver:**

What do you mean? You don't have a job. You retired 20 years ago. And remember, you have Alzheimer's now. Stop trying to go out.

Scene 2. Take two.

Wandering

Meet them in their reality
Redirect / divert / distract

#### PLWD:

I need to go to work now. I'm already late.

#### **Caregiver:**

That's right, I almost forgot. Well, we can't have you going off without a good breakfast.

### Scene 2. Take three.

#### Wandering

Meet them in their reality
Redirect / divert / distract

#### PLWD:

I need to go to work now. I'm already late.

#### **Caregiver:**

That's right, I almost forgot. Let's get your jacket. It's chilly out today. And let's make sure your lunch is packed. Here, I'll help.

Scene 3

Challenge: believing deceased family members are alive, pacing

Scene: PLWD is pacing anxiously

Scene 3. Take one.

Believing deceased family members are alive

#### PLWD(pacing around anxiously):

Mom and Dad are coming to visit

#### **Caregiver:**

What? That cant be. They died 30 years ago

Scene 3. Take two.

Believing deceased family members are alive

Rechannel

#### PLWD(pacing anxiously):

Mom and Dad are coming to visit

#### **Caregiver:**

Oh good, that sounds lovely. Let's get things tidy for them.

Scene 3. Take three.

Believing deceased family members are alive

Stay calm: validate

Redirect / divert / distract

#### PLWD(pacing anxiously):

Mom and Dad are coming to visit

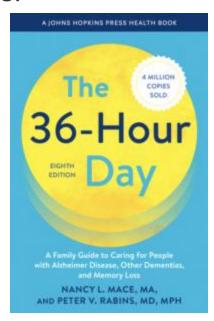
#### **Caregiver:**

Oh I know how much you love them, can you share with me some of your favorite photos?

#### References

#### **The 36-Hour Day, 8th Edition**

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**Dukefamilysupport.org** 

projectlifesaver@durhamsheriff.org

www.alz.org

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Thank you for joining us today!

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