

Dementia is Stressful

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She didn't want to come to the doctor's office. It was already a struggle to get her in the car.

Now she refuses to have her vitals checked. She is yelling profanities at the nurse and demanding to go home.

Why can't she understand that this is for her own good? We are just trying to help her!



Objectives

Recognize Stressors

Unexpected behaviors often relate to unexpected or confusing stressors

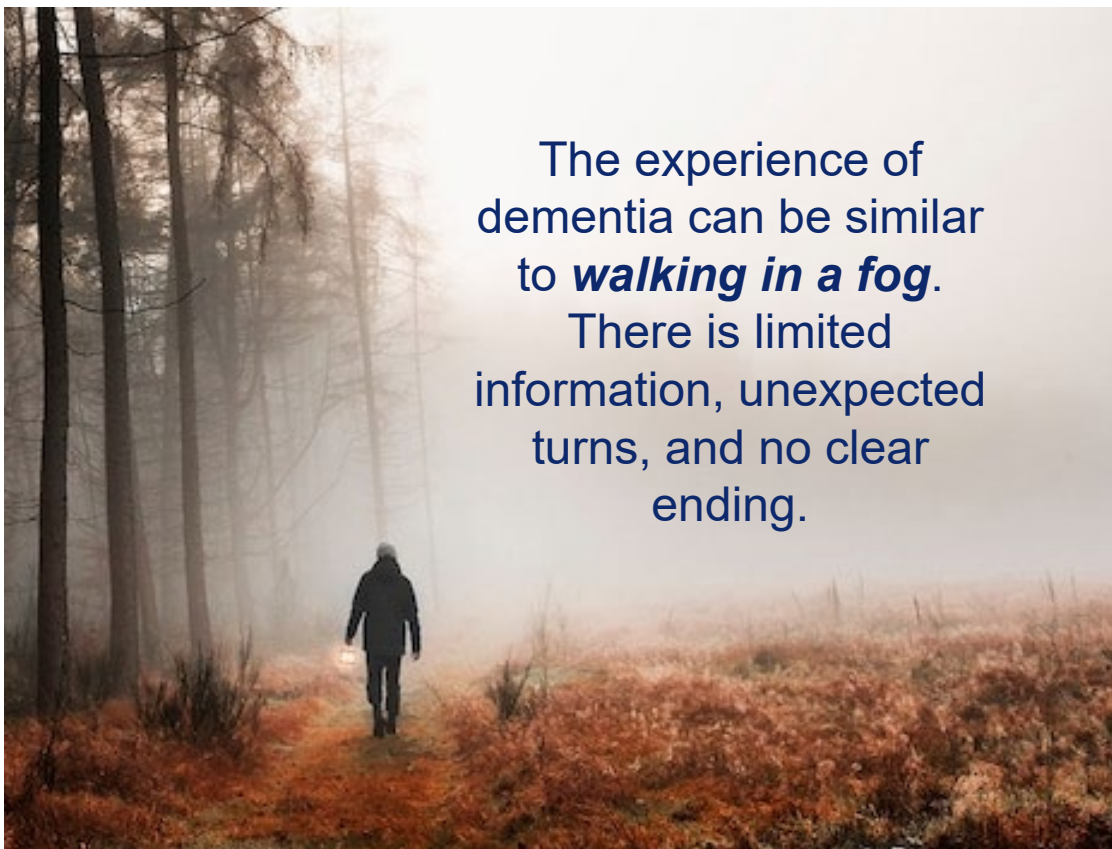
Address Physical Needs

Stress is not just psychological, is there a physical change that we can address?

Change the Environment

When we can't change the behavior, we change the trigger or the response.

“Why Can’t She Understand?”



The experience of dementia can be similar to ***walking in a fog***.

There is limited information, unexpected turns, and no clear ending.

Anosognosia

A neurological condition in which the patient is unaware of their symptom or condition.

Amnesia

A neurological condition in which the patient is unable to remember

What Can Stress Look Like?

Anxiety

Restlessness or Pacing

Shadowing or Following Everywhere

Suspicion or Paranoia

Delusions or Hallucinations

Stubbornness and Resistance

Wandering

Verbal or Physical Aggression



Learn More About Their World

Recognize Stressors

Unexpected behaviors often relate to unexpected or confusing stressors

What just happened?

Did somebody new enter the room?

Was there a loud or unexpected sound?

Is the conversation confusing?

Did this remind them of something?

Is the light too bright?

Is this a difficult task?

Learn More About Their World

Recognize Stressors

Behavior can be a reaction to many things, here are the common triggers

Pain or discomfort

Fear or frustration

Loss of control or autonomy

New people or places

Confusing conversation or tasks

Overstimulation or under-stimulation

Lack of information

“It’s just a doctor’s visit!”

Focus on the
Feelings, not
on the **Facts**

You and I can get
stressed by
unreal situations
as well.



Why Does This Happen?

Examples of Behavior Change



“He is seeing people and strangers entering the house.”

- Protective of their property and family
- Saw shadows or flickering lights
- Things around the house are rearranged
- Assumed there was danger
- It doesn't make sense
- Brain filled in the missing spots

Why Does This Happen?

Examples of Behavior Change



“She wakes up at 2am every night and gets ready, wandering outside!”

- They're used to a schedule; they want to be on time and held accountable
- They don't think they are at home
- They think it is daytime
- They want to be independent, in control
- Sundowning when tired

Why Does This Happen?

Examples of Behavior Change



“He is refusing all medications!”

- Anosognosia, don't think they need help
- Loss of autonomy
 - Will they put me in a home? Tell me not to drive?
 - Fearful of something wrong
- Don't understand medical conversation
- Know they will be tested and questioned
 - They may not remember what was said, but they remember the experience!

Why Does This Happen?

Examples of Behavior Change



“She keeps following me around, even to the bathroom. I can’t get any work done.”

- You are the lighthouse when they are lost
- Every second is a brand-new experience for them
- When you are not there, it is as if you don’t exist, and that can be a loss of control
 - The opposite of object permanence.
- They might not recognize or know anything else

How is Dementia Stressful?

Recognize Stressors

Understanding their world is the first step

Address Physical Needs

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Is There Something Physical Changing?

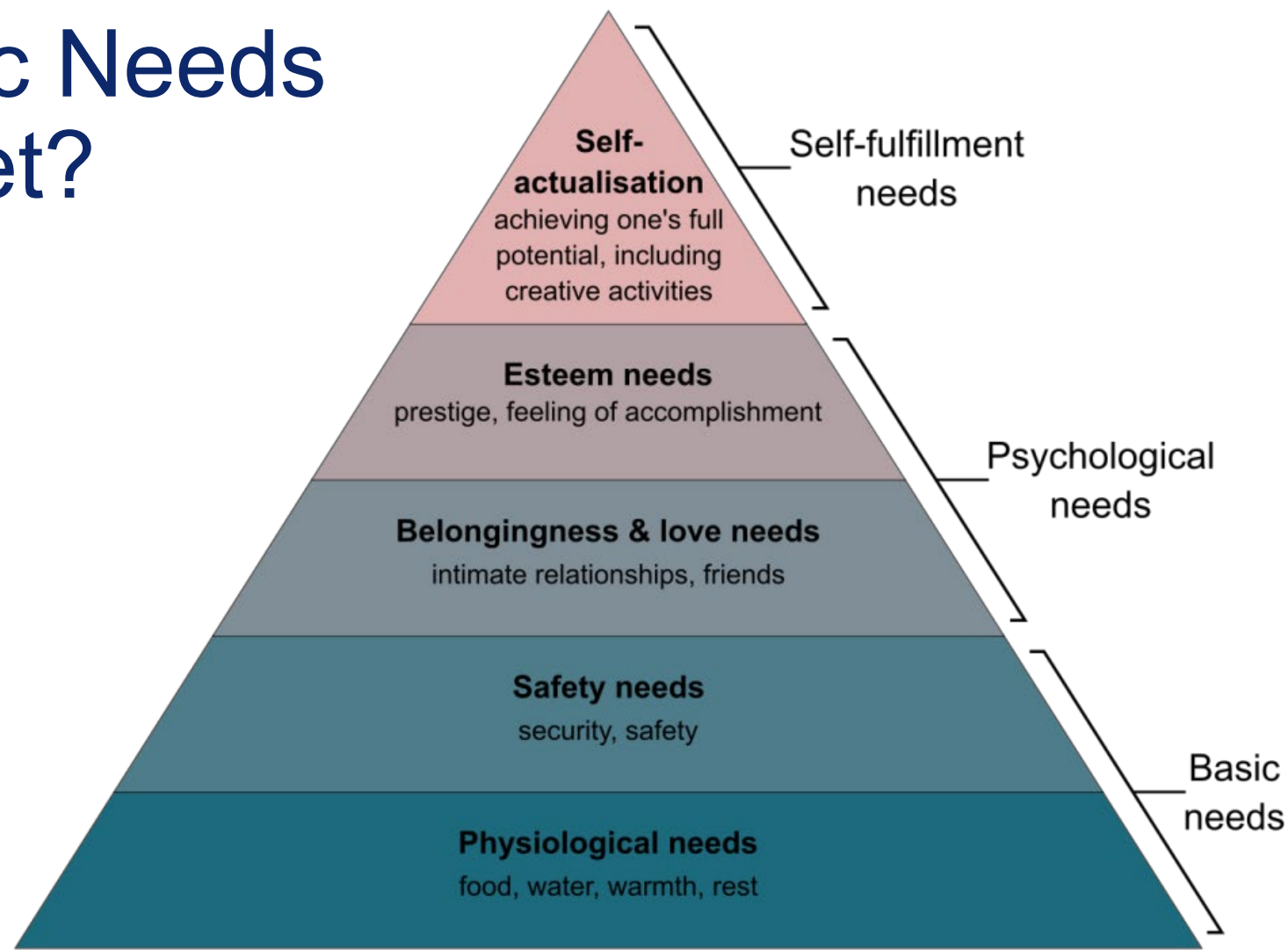
Address Physical Needs

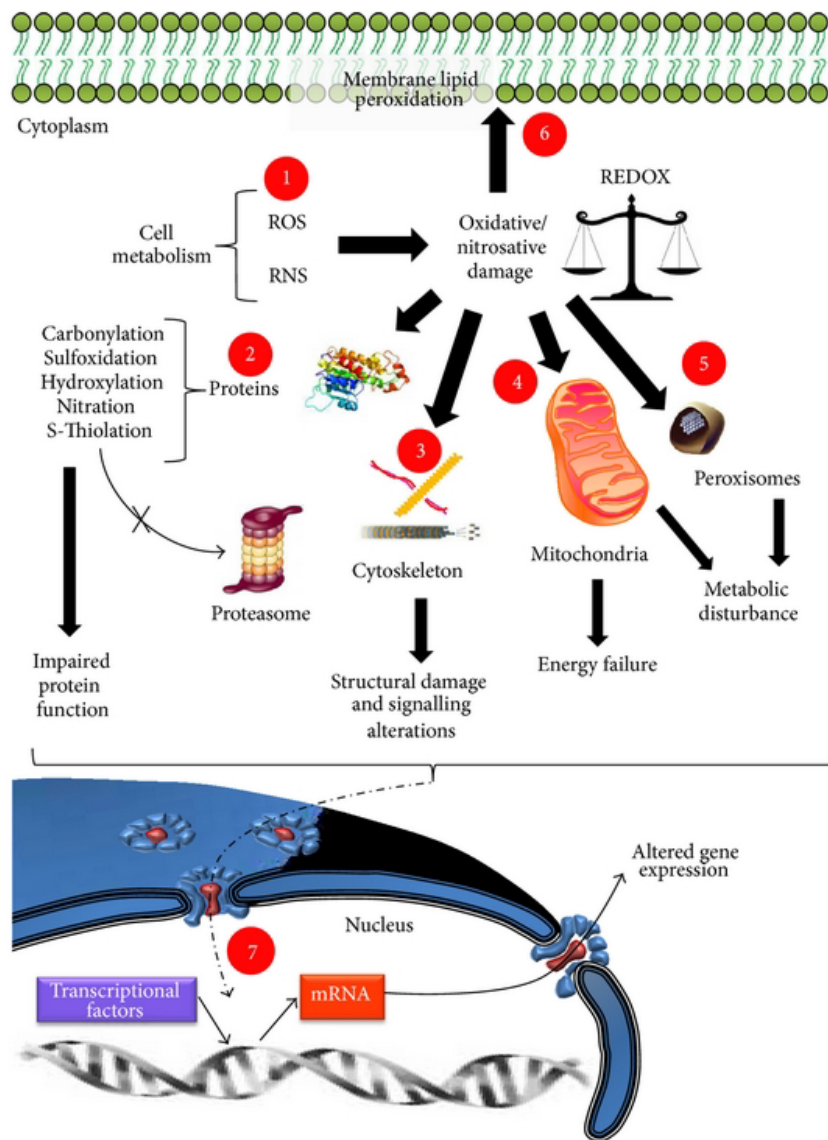
Stress is not just psychological, is there a physical change that we can address?

Is the water too hot or cold?
Are they comfortable in their clothes?
Does their stomach hurt?
Did they not sleep well?
Is something bothering them?
Have they eaten?
Have they taken their meds?

Are Their Basic Needs Being Met?

Often stress results from the brain not getting enough of its basic energy needs met!





Neurodegeneration is Stressful on the Brain

Neurodegenerative diseases cause a breakdown of brain cells. This causes actual physical and chemical stress on the brain.

The brain is sick.

Why Does This Happen?

Examples of Behavior Change



“He is refusing to shower or wash-up!”

- Showers are very stimulating
 - A lot of wetness, smells, touch, temperature change at once
 - Soap or water may get in eye or hair, uncomfortable
- The order of hygiene can be confusing
- Humiliating and embarrassing to need help with this
- Clothes are comfortable and warm, why change
 - Will sometimes wear layers of clothes or inappropriate clothing
- Shaving, toilet wiping is intimate and painful if done incorrectly

Why Does This Happen?

Examples of Behavior Change



“She keeps pocketing all of her meds in her mouth!”

- Do the pills taste bad? Cause upset stomach?
- Are you hungry and prefer to eat food? Are you thirsty?
- Is the food too warm? Too smelly? Not flavorful?
 - Taste and smell change with dementia
- Do we need to cut up the food or use utensils together?

How is Dementia Stressful?

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Change the Environment

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Change the External Environment

Adjust
temperature and
lighting in the
house

Remove clutter
and extra lights
that cause
shadows

Dissolve pills in
food or water

Prioritize activities
and responsibilities
to daytime, before
sundown-ing

Surround them with
familiar faces and
environments as
much as possible

Ensure proper
sleep cycles and
regular meals and
water

Change the Internal Environment

Consider
probiotics or
prebiotics to help
with digestion

Do they need
constipation
medications or pain
pills for comfort?

MIND or
Mediterranean Diet
to reduce oxidative
stress on the brain

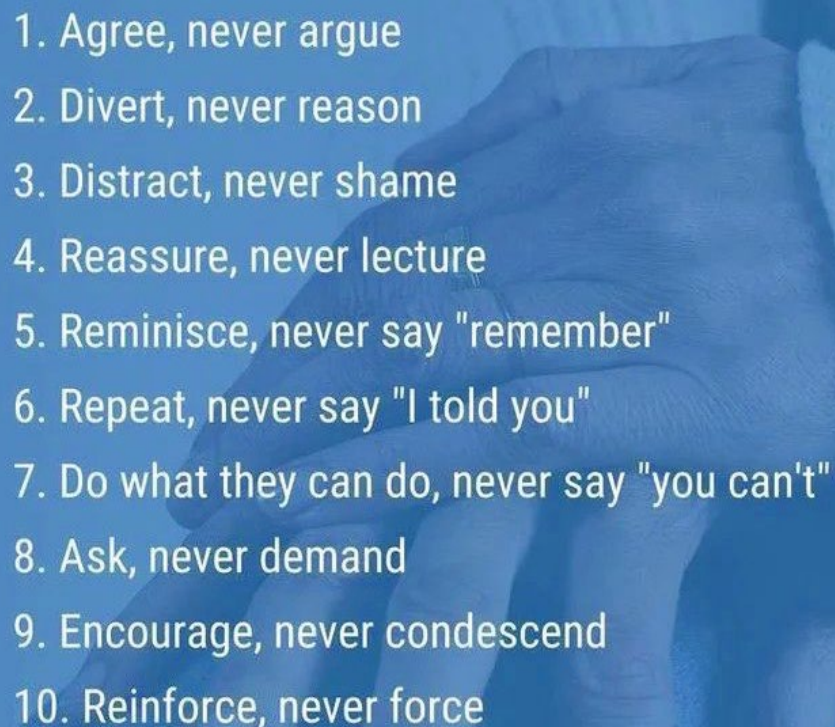
Nuts, berries, fruits,
leafy vegetables,
water, low sugar
and low processing

Regular primary
care visits to
address chronic
medical conditions.

Do we need hearing
aides or visual
aides to reduce
confusion?

Dementia-Friendly Language and Communication

LIVING WITH DEMENTIA

- 
1. Agree, never argue
 2. Divert, never reason
 3. Distract, never shame
 4. Reassure, never lecture
 5. Reminisce, never say "remember"
 6. Repeat, never say "I told you"
 7. Do what they can do, never say "you can't"
 8. Ask, never demand
 9. Encourage, never condescend
 10. Reinforce, never force

- Understand their world and put yourself in their shoes to better relate
- Try not to emphasize weakness or inability
 - *You get to be a passenger!*
- Focus on finding a common ground
 - *I also like my food cut up, let me help you*
- Reassure, reorient, redirect, repeat, RESPECT
 - *I love how you care about my safety, let's check together to make sure we are safe*
 - *Did you want more cookies? Maybe we can go to the store after I finish these dishes, could you help me?*

Summary

Recognize Stressors

Unexpected behaviors often relate to unexpected or confusing stressors

Address Physical Needs

Stress is not just psychological, is there a physical change that we can address?

Change the Environment

When we can't change the behavior, we change the trigger or the response.

Know When You Need Help

- In general, most dementias are progressive. But we have **medications that lessen the burden**:
 - Insomnia, hypersomnolence
 - Appetite suppression, appetite promotion
 - Apathy, depression, mania, anxiety
- Other times we need emergency services. **Please call 911** if there is ever:
 - Danger to self or others
 - Concern for inability to support your loved one successfully at home, i.e., “failure to thrive”
- There are many organizations to provide skills and support to help you succeed as a caregiver


alz.org

- Alzheimer’s Navigator
- Community Resource Finder
- ALZConnected
- Alzheimer’s and Dementia Caregiver Center
- Safety Center


alz.org/findus

- Support groups, education programs and more available in communities nationwide


800.272.3900

- 24/7 Helpline – Available all day every day


training.alz.org

- Free online education programs available at training.alz.org



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