



Social Distancing, COVID - 19, Dementia and IDD

Kathleen M. Bishop, Ph.D. NTG Steering Committee Member, Co-chair of the NTG Education and Training Committee

(C)Thru Rose Colored Glasses, Dr. Kathie Bishop

From our cats
to your house
During our
isolation with
plenty of time
to think:

We've done the math; we can't
afford the dog!

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Caregivers are essential to our healing!

- ▶ Quote of the Week

- ▶ “One person’s visitor is another’s critical caregiver. We will inevitably learn much from our national experience with COVID-19. I hope one of the enduring lessons will be a heightened understanding of the critical role that caregivers provide for people living with Alzheimer’s.”

–*Phil Gutis, reporter, Being Patient contributor and early-onset Alzheimer's patient*

- ▶ *My addition* - And the heightened awareness of the importance of the physical environment to influence function and behavior. We can reimagine the environment during this crisis.

Social Distancing:

- ▶ What is it and why?

Social Distancing = Social Isolation to most older adults especially those with cognitive challenges due to disease or lifelong disability



Most of the challenges in dealing with patients and loved ones with Alzheimer's lies in the disruption to routines, for example, the closures of facilities that would normally allow social interaction.



"There may be caregivers who used to rely, for example, on adult day cares," Ballester said. "So instead of being able to have their loved ones participate in adult day care, they have to do activities at home."



The Alzheimer's Association says to keep the flow of information simple and not overwhelming.

COVID - 19 and IDD

<https://thehill.com/opinion/civil-rights/491039-people-who-have-been-overlooked-during-covid-19-adults-with-disabilities>

- ▶ More than six million Americans have been diagnosed as having Intellectual Disabilities
- ▶ Many adults with IDD rely daily on the assistance of others for their basic needs to be met
- ▶ Social distancing may not just be inconvenient or lonely, but could actually eliminate their sources of basic care, like food, transportation, assistance with hygiene, or critical emotional support.

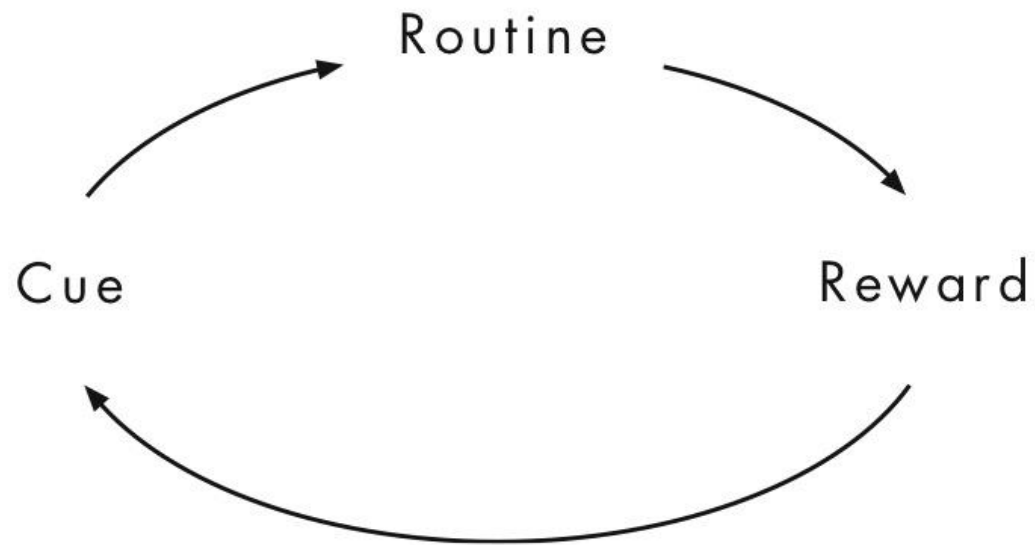
What has happened to my life <https://www.alzheimer-europe.org/Policy/Our-opinion-on/Wellbeing-of-people-with-dementia-during-COVID-19-pandemic>

- ▶ COVID - 19 has
 - ▶ Disrupted routines and habits
 - ▶ Increased fear and confusion
 - ▶ Likely changed caregivers, change in clothing of caregivers
 - ▶ location of activities, and rhythm of the day, week
 - ▶ time has changed meaning especially for people with dementia who rely on the routines to function
 - ▶ Lack of stimulation or over-stimulation
 - ▶ Inability to connect with those still remembered or important

The importance of habits and routines

Why do we have habits? Are there some habits that may now be perceived differently?

Habits Loop Habits are encoded in the structures of our brain and save us a lot of effort because we don't have to relearn everything we do.



Routines and habits

- ▶ Routines are essential for functioning; we all need them for healthy survival especially in congregate settings or unfamiliar surroundings
- ▶ "habit loop"
 - ▶ Cue or trigger
 - ▶ Brain goes into automatic mode
 - ▶ Behavior occurs
 - ▶ Becomes routine as part of ongoing behavior
 - ▶ To create a new routine need to determine the purpose of the routine that is being
 - ▶ Adults on Autism Spectrum and adults with Down syndrome are likely affected by change in routines even more so than others
 - ▶ How are habits rewarded?

Habits and routines allow us to function without thinking of every movement and activity.

- ▶ Habits originally labeled as obsessive compulsive, non-compliant, tactile defensive, etc. may now be encouraged when over a lifetime discouraged by caregivers.
- ▶ Greetings and salutations may now be frightening
- ▶ ADLs including eating, dressing, bathing, hygiene, all essential for health, the location and who assists have likely changed
- ▶ Habits are usually part of long-term memory, used most often in middle and later stages of ADRD to function
- ▶ We are all grieving our former lives, contacts, ability to touch each other or be together, people with dementia feel it all around them but can't understand

Benefits of Routines in Dementia

- ▶ **Maintains Functions:** Practicing an activity regularly, whether it's a physical or mental task, may increase the likelihood of that ability remaining.
- ▶ **Reduces Anxiety:** The predictability of a routine can decrease anxiety. The person with dementia may feel more comfortable and confident if he knows what to expect.
- ▶ **Decreases Caregiver Stress:** Routines can lessen the stress for those caring for people with dementia by making the day more organized and possibly decreasing the chance of challenging behaviors.
- ▶ **Allows for Some Independence:** Activities that have been practiced regularly, such as daily folding the laundry, can increase self-esteem and confidence because the person can perform it independently. Especially in the earlier stages of dementia when people are more likely to be aware of cognitive deficits, independence in a task can be an encouragement to them.

Have the common objects used every day changed? Can we replicate to minimize confusion? How different are the objects?



<https://www.bing.com/videos/search?q=habit+and+routine+for+adults+with+Intellectual+and+Developmental+Disabilities&qpv=habit+and+routine+for+adults+with+Intellectual+and+Developmental+Disabilities&FORM=VDRE>

Habits videos

- ▶ <https://www.theworldcounts.com/happiness/the-importance-of-good-habits>
- ▶ **Habits are very important**
- ▶ Habits shape your life far more than you probably realize. Habits are very strong. In fact, our brains cling to them at the exclusion of all else - including common sense.
- ▶ *More than 40 percent of the actions you perform each day aren't actual decisions, but habits.*
- ▶ **Habits works through the habit loop**
- ▶ **Cue / trigger:** A location, a time of day, certain people, an emotional state,
- ▶ **Routine:** Watching TV, smoking a cigarette, eating chocolate, biting your nails
- ▶ **Reward:** The pleasure chemicals released in the brain because of the routine.

Meaning of Time



We often tell time by our activity of the moment, where the sun is in the sky, or what is happening around us.



Time locates us in the context of the moment and expectations for behavior, dress, and functioning



Concept of time for most of us is based on the day of the week, our activities, and everyday activities



Normally seasonal and weather related


Concerns for Social Distancing, COVID-19, ID, and Dementia

Habits, Routines and Behavior

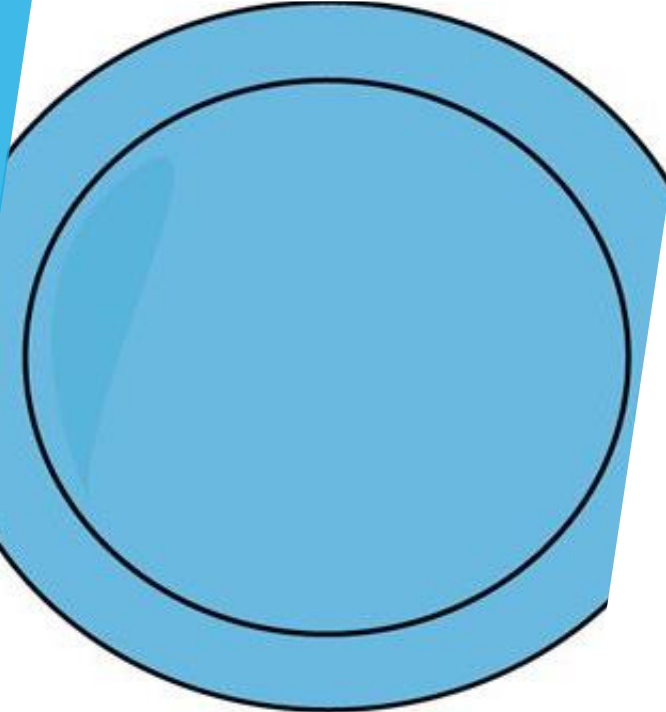
- ▶
- ▶ What is the normal routine for weekdays?
- ▶ What is the normal routine for weekends?
- ▶ What has changed?
- ▶ Specifically how have routines changed?
- ▶ What “inappropriate” behaviors are you observing?
- ▶ What was the function of the routines and how can you replicate or replace?
- ▶ What changes have you made you want to carry over to our new normalcy, our new imagining?



With dementia in a different time and place, Do the objects
around support that time?
Do we expect too much?



What are the challenges in the environment, the new routine?

- ▶ What do I choose?
 - ▶ How do I use these objects?
 - ▶ What choices do I have other than to run away, refuse to eat?
 - ▶ Are these choices different every day?
 - ▶ Is my cognitive loss showing?
 - ▶ How can I pretend I am okay or do I want to pretend at all?
- 





What do I do with these objects?
How do I use them?

Sensory Processing, IDD, and Dementia

What is it and what can we do?

Sensory Processing

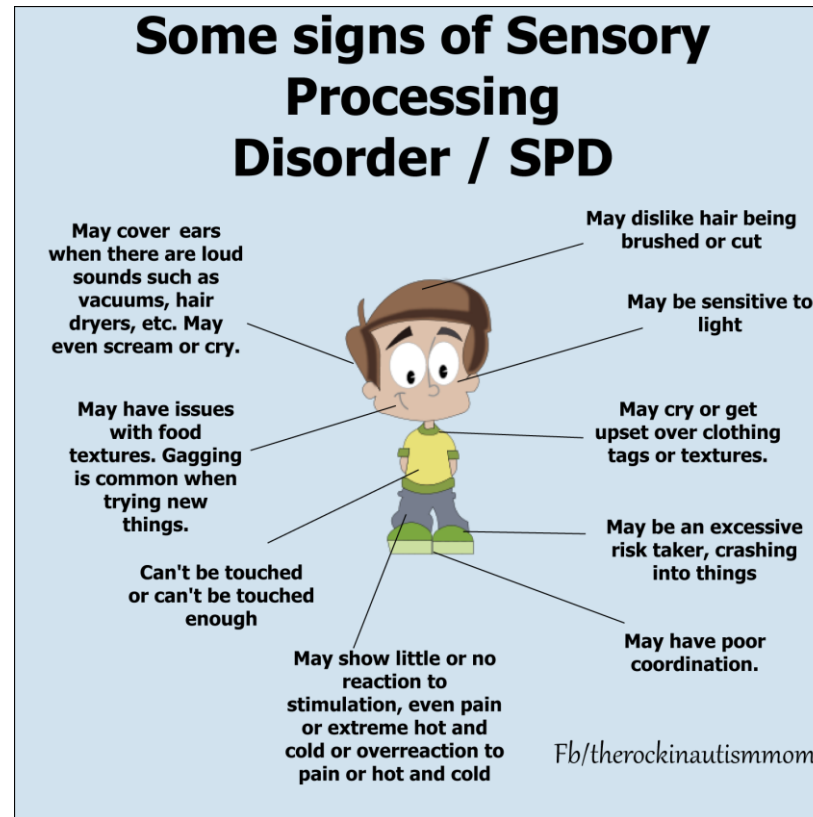
- ▶ The ability to use all 8 of our senses together-
 - ▶ Vision
 - ▶ Auditory/hearing
 - ▶ Tactile/touch
 - ▶ Smell/taste
 - ▶ Vestibular (balance)
 - ▶ Proprioceptor (location in space)
 - ▶ Interoception (inner sense of our organs - sense of hunger, thirst, hot, cold)

The process of sensory processing

- ▶ Occurs in brain, Central Nervous System
- ▶ Brain automatically receives sensory information and pays attention to the meaningful information, ordinarily filters out information not needed, automatic and subconscious usually
 - ▶ Allows us to interact with the physical and social environment
 - ▶ Interrupted by lack of habits and routines
 - ▶ Diseases such as Alzheimer's disease and related dementias cause disruption
 - ▶ May be dysfunction over a lifetime
 - ▶ Makes it possible to move through the environment, feel safe and comfortable
 - ▶ Without consistent routine it is like pulling the rug out of sensory processing

- ▶ **Resource: *Out of Sync Child* by Carol Stock Kranowitz**

Sensory processing Disorder (SPD)



The Seven Senses and Sensory Integration



Auditory



Visual



Taste



Tactile



Smell



Vestibular



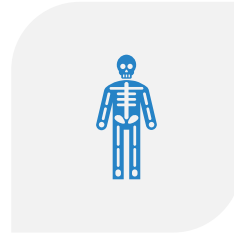
Proprioceptor

Seven Senses

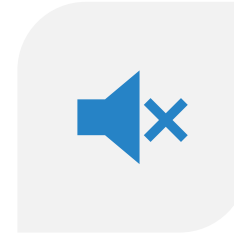
- ▶ All work together to help each individual function and respond “appropriately” to the environment.
- ▶ Need to be able to discriminate, modulate, and integrate the senses (All steps of sensory processing).
- ▶ Likelihood of Preferred Sense(s) for learning, taking in information from the environment



Dementia and Sensory Processing



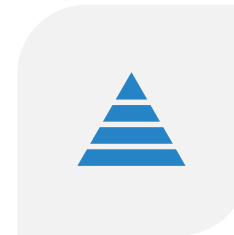
STUDIES CONDUCTED ON
PROPRIOCEPTOR/VESTIBULA
R SYSTEMS AND ADRD



MEANING DEAF



MEANING BLIND



NEED FOR STRUCTURE AND
ROUTINE



Sensory impairments and Dementia

The Eight senses

Sensory Impairments and aging: Visual Impairments

- ▶ Central Vision impairment - cataracts, stroke
- ▶ Peripheral vision impairment - Glaucoma, Retinitis Pigmentosa



*Degree of side (peripheral) vision loss varies based upon severity of disease



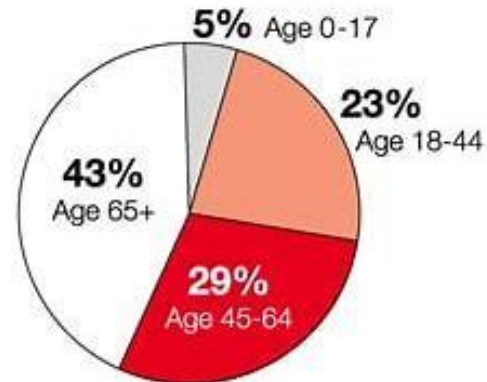
Auditory impairments

- ▶ By age 75 1 in 2.5 persons has a significant hearing impairment
- ▶ Correlation with ADRD diagnosis
- ▶ Can also be ‘meaning deaf’

II. Types of Hearing Loss

- 1. **Conductive hearing loss:** Hearing losses caused by damage or obstruction to the outer or middle ear that prevents transfer of sound to the inner ear.
 - a. Some conductive hearing loss is temporary.
- 2. **Sensorineural hearing loss:** Hearing loss caused by damage to the inner ear or the auditory nerve.

Who has hearing loss?



Source:
<http://ihcrp.georgetown.edu/agingsociety/pdfs/hearing.pdf>



Hearing Loss can appear as a type of dementia



Sensory overload

Smell, Taste, and the Environment



Differing degrees of sensitivity.



Age-associated changes?



Too much or too little



Can be the underlying cause for refusing to eat or “inappropriate behaviors”



Medications and taste, smell

Tactile Sense and Environment



First developed, last lost



Differing degrees of sensitivity



Environments can have too much tactile information or not enough to meet each person's needs



Probably underrecognized as underlying cause for many “behaviors”

Tactile Defensiveness:
Inability to interpret appropriately the affective meaning of touch within the context of the situation. May be a disorder of modulation or regulation of tactile sensory input.

- ▶ Characterized by the following behaviors:
 - ▶ Avoidance of touch, hugs.
 - ▶ Avoidance of textures, preference for certain clothing (refusing to wear anything else)
 - ▶ Avoidance of activities or places where there are many people and possibilities of touch
 - ▶ Avoidance of baths, daily living tasks, hair care, etc.
 - ▶ Avoidance of dental care
 - ▶ Responding with withdrawal aggression to light touch
 - ▶ Increased stress when close to people
 - ▶ Pulling away or aggression to light touch

Tactile Defensiveness

- ▶ Characterized by:
 - ▶ Extreme need for personal space (rocking?)
 - ▶ Distractibility
 - ▶ Increased levels of activity
 - ▶ May be a result of poor tactile discrimination such as not knowing how many times touched, degree of touch, or being able to recognize the shapes of objects.
 - ▶ Increase or decrease with age?

What it
looks like

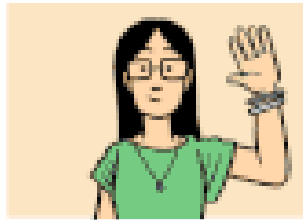


What it
feels like

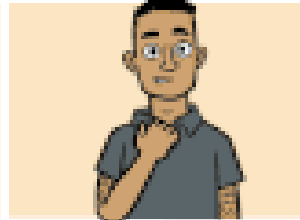


Example of tactile defensiveness - It may look harmless to you but especially frightening to the person with dementia.

ALTERNATIVES TO HANDSHAKES, HUGS, HIGH FIVES AND HONGI



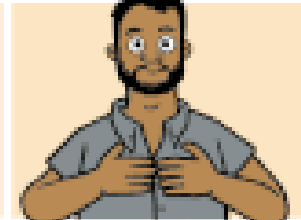
THE WAVE



THE HAND ON HEART



NAMASTE



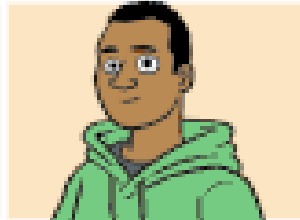
NZSL: HOW ARE YOU?



THE 'HI-BROWS'



THE 'ALL GOOD' NOD



THE 'EAST COAST WAVE'



THE 'WHAT A WORLD EH?'

Options for hugs and touching

Movement and the Environment:

To be able to move freely throughout our environment is often taken for granted.




We use all our senses to move throughout our environment. If any one is faulty or integration of information is not possible, it is likely that mobility will be affected.



The right to move throughout our environment freely is a basic right.

Vestibular System Works closely with the Proprioceptor System

Whenever the head moves through space you are using the vestibular system. This works closely with the Proprioception system.



Movement can often be therapeutic or even necessary for function.

Proprioception System and Movement

Gives us a sense of where we are in space and is part of motor planning. Allows us to sequence and time activities.



Suggestions to heighten the use of this sense system include:

Strong touch and hugs when appropriate.

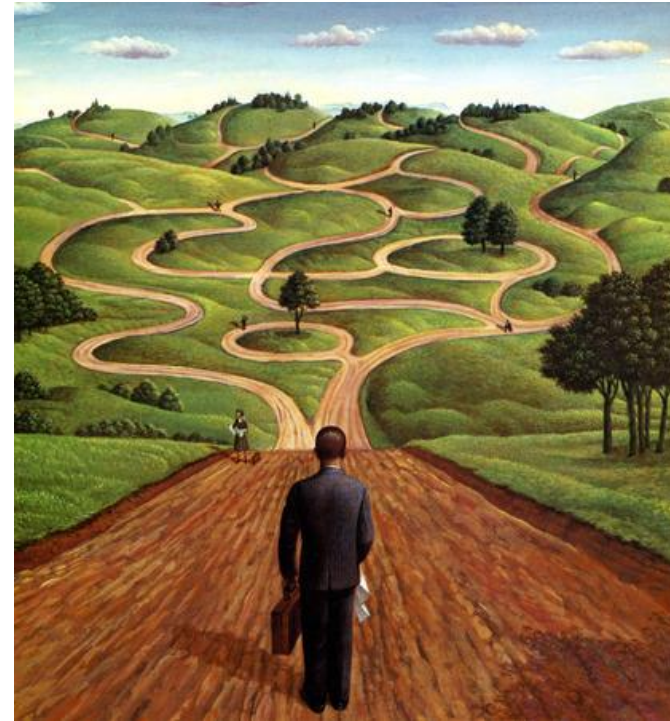
Weighted vests and blankets. (If appropriate, may not be if arthritis or other age-associated conditions are the problem. Each suggestion needs to be adapted to the individual).

Proprioceptive Dysfunction*

□ Sensory Seeking Behaviors

- seeks out jumping, bumping, and crashing activities
- bites or sucks on fingers and/or frequently cracks his/her knuckles
- loves to be tightly wrapped in many or weighted blankets, especially at bedtime
- grinds his/her teeth throughout the day
- chews on pens, straws, shirt sleeves etc.

Proprioceptive Dysfunction



Lost in space and time
Where are we? Who are we? How do we find our way to
safety?

Room designed for
sensory experiences
for adults with
dementia
Does this work?





Redesigning our environments during COVID - 19

What can we do? Personal Space

- ▶ Reinterpret social distancing as an opportunity for development of territory and personal space
 - ▶ **Personal space** describes the immediate **space** surrounding a **person**, **territory** refers to the area which a person may "lay claim to" and defend against others.
 - ▶ 1. Introduce the concept of personal space. **Sit or stand in a place that is unusually close to one of your students, without touching the student.** After a minute of sitting or standing there while the class wonders what you are doing, ask the student how he or she feels about your location. <https://www.nationalgeographic.org/activity/define-your-personal-territory>
 - ▶ Territory - the material space and objects we claim as our own. Look around where you are sitting now and you will have marked territory by your personal objects, body position, and where you have located in space.

Personal space: Types of personal space (Proxemics)

- ▶ Types of personal space defined by the use of space around us
 - ▶ Intimate Space
 - ▶ Personal Space
 - ▶ Social Space (1.2 - 3.0 ft.)
 - ▶ Public space (3+ ft.)

Types (cont.)

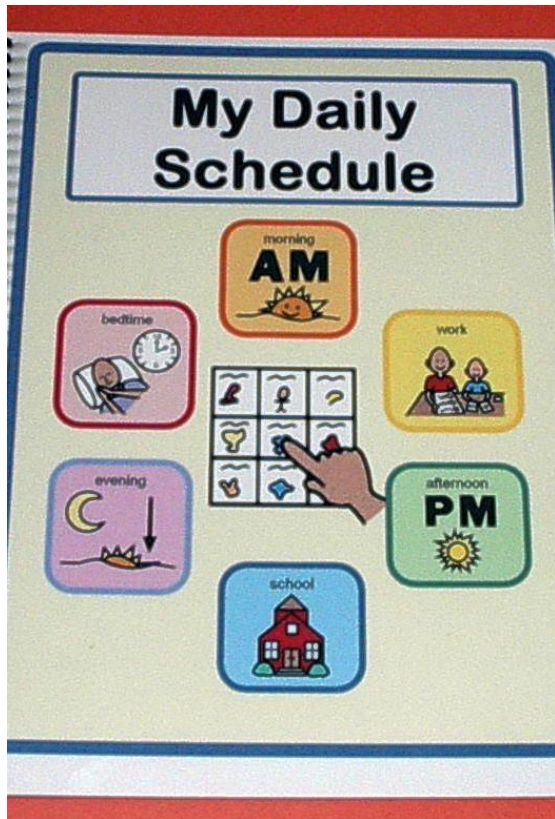
- ▶ PROXEMICS (space):
 - ▶ Personal space - relationships, culture, personal preferences, context:
 - ▶ Distance: intimate, personal, social, public
 - ▶ Territoriality - physical space & items claimed as own:
 - ▶ Primary territory - your very own (clothes, bedroom, car...)
 - ▶ Secondary territory - associated with you (desk at school)
 - ▶ Public territory - claimed only temporarily (space at the beach)
 - ▶ Levels of invasion:
 - ▶ Violation - smth. personal used without permission
 - ▶ Invasion - a claimed public territory used by someone else
 - ▶ Contamination - evidence of territory used is left behind (trash)

Proprioception System and Movement

- ▶ Suggestions (Continued):
 - ▶ Opportunities to touch textures and objects.
 - ▶ Controlled spaces with lots of cueing.
 - ▶ Clearly identified beginnings and endings of space.



Environmental Supports



- ▶ Visual Schedules
 - ▶ Daily
 - ▶ Task specific (e.g., task lists)
- ▶ Visual Supports
 - ▶ Clarity
 - ▶ Instruction
 - ▶ Organization, left to right, able to visualize completion

There is a fake village with fake shops and restaurants that is actually a care home for elderly dementia sufferers in the Netherlands.



Many nursing homes in Germany have fake bus stops to collect residents with dementia who try to leave.

Weird World



for



Outside sitting area inside



Technology as part of
the solution, create
spaces for quiet
individual connections



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Colors and furniture to create private spaces



- ▶ Take a photo, that will help you see the environment and find simple changes
- ▶ See the environment from a different perspective
- ▶ Do it together
- ▶ Reuse some of the space used for programs in different ways

(c)Thru Rose Colored Glasses; Dr. Kathie Bishop

Suggestions and activities

<https://www.firstcoastnews.com/article/news/health/coronavirus/impacts-of-social-distancing-on-those-living-with-alzheimers-dementia/77-f5082a82-89e4-4b0a-aa15-ea8789eed5a0>



ZOOM, SKYPE AND WEB RADIO
TO PROMOTE SOCIAL CONTACT
AND FACE-TO-FACE SUPPORT,



APPS AND ONLINE VIDEOS (E.G.
FOR PRACTICAL ADVICE,
COUNSELLING, CHAIR
EXERCISES, YOGA AND KEEP FIT,
COGNITIVE STIMULATION AND
INFORMATION)



FACILITATE CONTACT WITH
RELATIVES AND CLOSE FRIENDS
OF THE PERSON WITH DEMENTIA
VIA PHONE AND ONLINE
COMMUNICATION, FACETIME,



IT IS NOT EASY, BUT IT IS
POSSIBLE TO VISUALIZE A NEW
WORLD



Questions/Comments?

- ▶ I hope that I have added to your wisdom and compassion today to help you make a difference for others.
- ▶ Please ask if I can help.
- ▶ bisbur1@earthlink.net