



Supporting
People with Dementia during
COVID-19 and Beyond

**Being Curious
&
Being the Change**



SONYA BARSNESS

I am a revisionary gerontologist with nearly 25 years of professional experience in aging. My mission is to create better ways of supporting each other as we grow older and grow with dementia.



KAREN STOBBE

Both of my parents had Alzheimer's disease and my mom lived with us for 11 years. I have been devoting my work to helping professionals and families find ways that they and those they care for can have a better quality of life.



SONYA BARSNESS CONSULTING

www.sbcgerontology.com



www.in-themoment.net

SURVEY

How has COVID-19 changed your behavior?

Please provide a short answer in the Questions tab of your webinar's control panel.

Before the
Pandemic


During the
Pandemic

After the
Pandemic

Person-Centered





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▼ Being Curious
&
Being the Change



Meet the person with
dementia where they are.

(Being Curious)

Change OUR “behavior”, rather than try to change the “behavior” of the person with dementia.



(Being the Change)



Dementia is a shift in how
the person experiences the
world around them.

- Dr. Allen G. Power



People living with dementia are just trying to make sense of their world.

Just like we are.



Curiosity cu·ri·os·i·ty

- A Strong desire to know or learn something.
- Curiosity is the urge you feel to know more about something.
- Anything curious, strange, rare, or novel.

You are walking down
the sidewalk in a
small town and see a
sign in the window
that says...



...You go in the store.

A car pulls up
next to you

You're curious

So you edge up to see the
driver.

A smiling couple is waving
at you and laughing!



Charles has been peeing by the back door.

Maisie has been hiding her wallet.

Sam eats things with his fork that you would normally eat with your hands and uses his hands to eat things he should use a fork.

Nadine will turn off the TV in the middle of a program.

Sandra pushes her husband out of the bed. She tells him to get out.

Here are some
'behaviors' or
actions of persons
living with
dementia:



We can say that all these 'behaviors' happen
because the people who did them
have some type of dementia.
That's the reason and no more to think about.

Period.

Just forget it. Nothing you can do.

Maybe...if it is their dementia that is causing this, and dementia is a medical condition then we should seek out a medical answer?



Like medication?



Don't those actions
make you curious?

What could be the reasons? The Why?

- Health: Physical & Emotional
- Communication: Both of Ours
- The Task at Hand
- The Environment
- Unmet Needs
- Life Story
- You
- Dementia

The Environment

- Environment too large
- Excessive stimulation
- No orientation information or cues
- Poor sensory environment
- Too much clutter
- Unstructured environment
- Unfamiliar environment

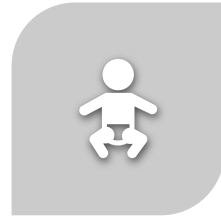
The Task at Hand

- Task unfamiliar
- Task too complicated
- Too many steps combined
- Task not modified for increasing impairments

Communication: Both of Ours

- Be aware of your approach – you set the tone
- Use your nonverbal skills, body language, facial expressions, vocal characteristics
- Respond to the emotional content
- Be patient

Unmet Needs of the Person



IDENTITY:

HAVING A HISTORY,
PERSONHOOD,
WELL-KNOWN



CONNECTEDNESS:

BELONGING,
ENGAGED, INVOLVED



SECURITY:

SAFETY, DIGNITY,
RESPECT, FREEDOM
FROM ANXIETY



AUTONOMY:

CHOICE, FREEDOM,
SELF-DETERMINATION



MEANING:

HOPE, VALUE,
PURPOSE



GROWTH:

DEVELOPING,
EVOLVING,
ENRICHMENT



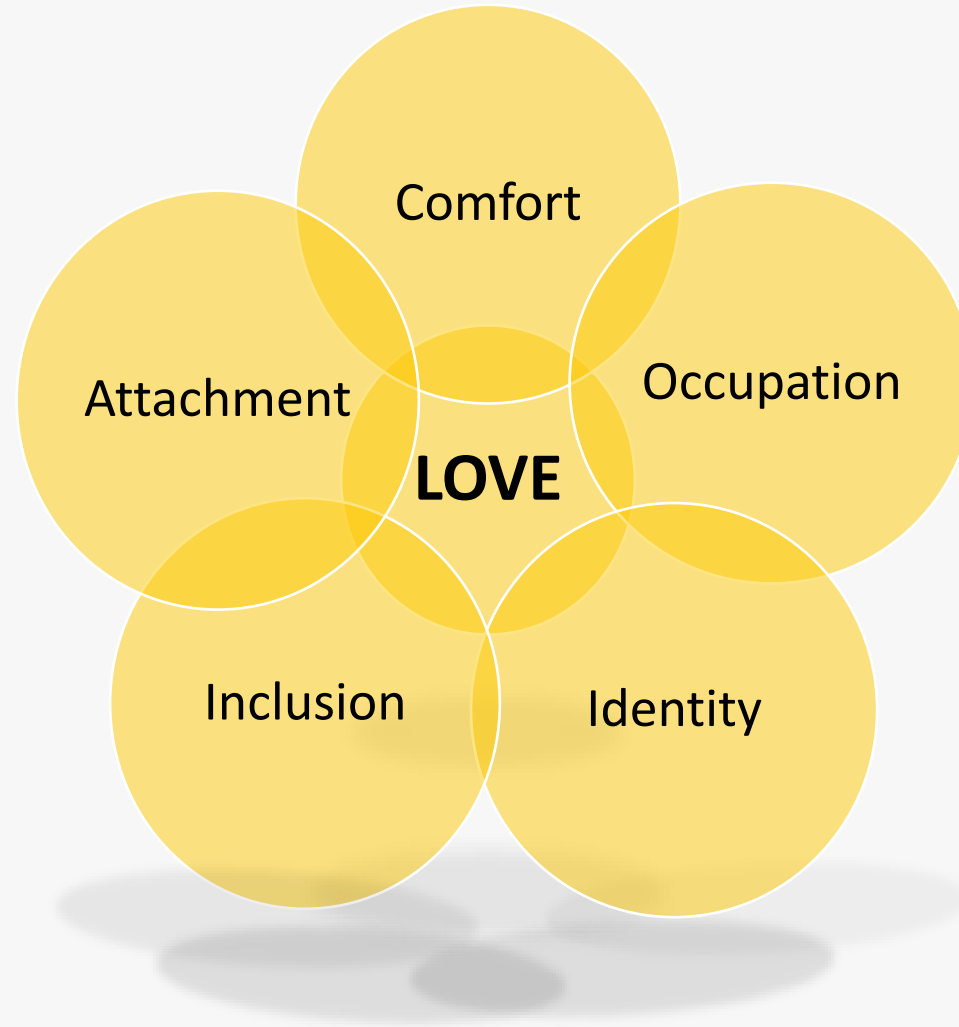
JOY:

HAPPINESS,
PLEASURE, DELIGHT,
CONTENTMENT



**THE EDEN
ALTERNATIVE**
WWW.EDENALT.ORG

Unmet Needs of the Person



Tom Kitwood

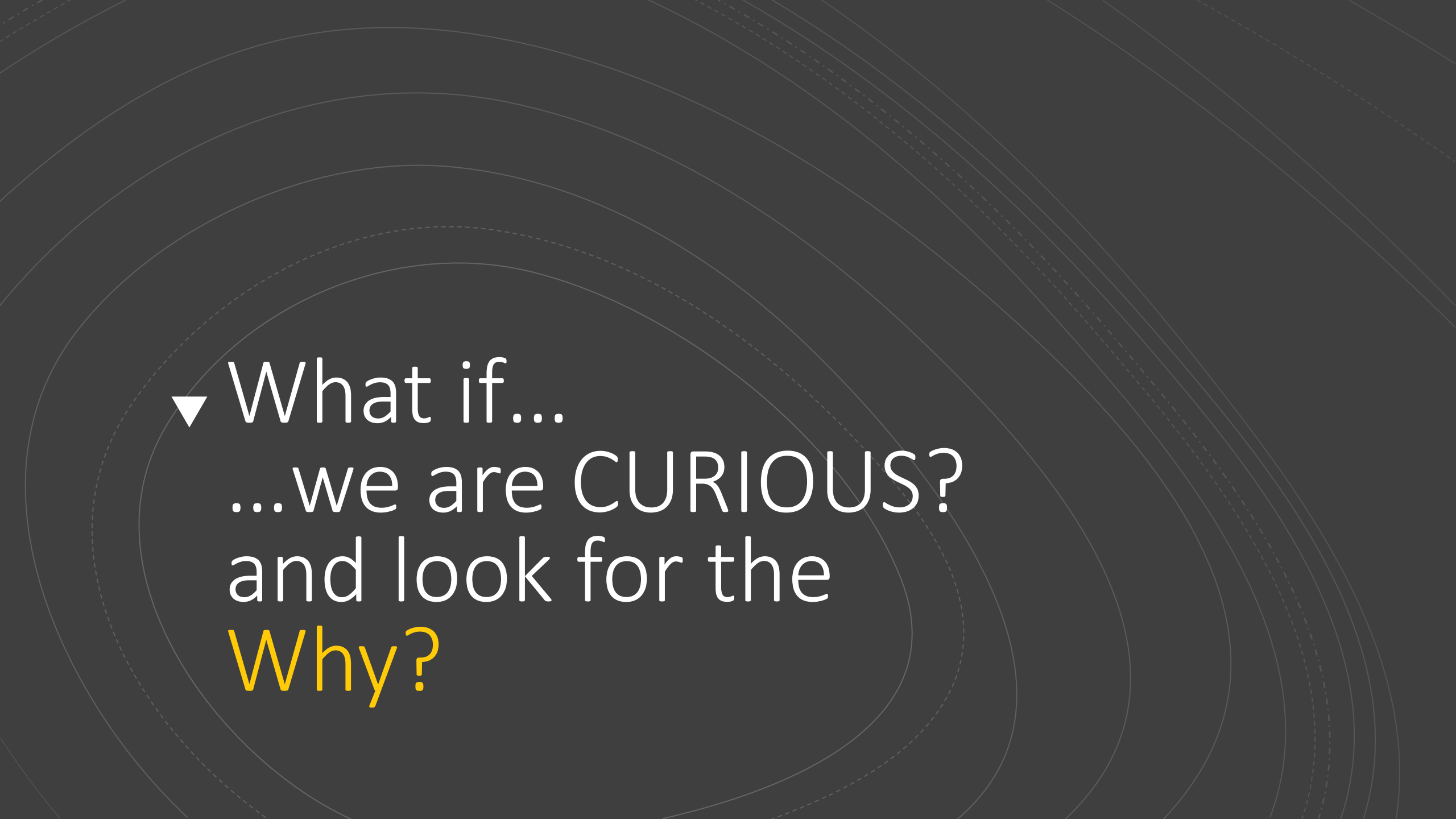
Their Life Story

- Who is this person?
- What events, occupations, relationships – moments have shaped their behaviors and their communication skills?
- Did they have any trauma in their life?
- Fears? Joys? Pet peeves?
- What parts of *who they were* tell you *who they are now*?

You

Dementia

As the disease progresses it may show some of the symptoms of dementia and those may be the reasons for some actions and reactions.

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▼ What if...
...we are CURIOUS?
and look for the
Why?

Charles has been peeing by the back door.

WHY?

Charles has been peeing by the back door.

COMMUNICATION

WHY?

Might not be any cues as to where the bathroom is



CHANGING OUR BEHAVIOR

Simple sign can help. Drawing a picture of a toilet with an arrow, a sign on the door, can be helpful.

Charles has been peeing by the back door.

ENVIRONMENT

WHY?

His roommate is in the bathroom for long amount of times and he doesn't know what else to do.



CHANGING OUR BEHAVIOR

Check on Charles' roommate and make sure he is okay.

Make another bathroom available for Charles.

Label it with signs and set an alarm for you to check to see if he needs to use the bathroom.

Charles has been peeing by the back door.

LIFE STORY

WHY?

Charles was a dairy farmer and always checked on his goats and cows first thing in the morning and also went to the bathroom while he was in the fields.



CHANGING OUR BEHAVIOR

Find Charles early in the morning and say you would like to join him in checking on things – then encourage him to use the bathroom before you go...

Maisie has been hiding her wallet. Then she accuses people around her of stealing it.

WHY?

Maisie has been hiding her wallet.

Then she accuses people around her of stealing it.

COMMUNICATION

WHY?

Maisie could be communicating that she does not trust people around her, is afraid, that she is anxious about losing it, etc. She accuses people of stealing it because she is making sense of the fact that she cannot remember where she put it.



CHANGING OUR BEHAVIOR

Express concern for her lost wallet. Offer to find it. Help her find a safe place for it, even if she will not remember it.

Maisie has been hiding her wallet.

Then she accuses people around her of stealing it.

UNMET NEEDS

WHY?

Maisie is lacking a sense of security. Maybe she does not know who has been going in and out of her room.



CHANGING OUR BEHAVIOR

Identify yourself to Maisie all the time. Spend time with her and get to know her. When she makes accusations respond to her emotional need of anxiety and insecurity.

Maisie has been hiding her wallet.

Then she accuses people around her of stealing it.

LIFE STORY

WHY?

Maisie grew up with eight sisters. She always had to hide her stuff.



CHANGING OUR BEHAVIOR

Respond to the emotion. Assure her you will help her find it. Share your regret that it is gone and indicate that you will try to get to the bottom of it.



Sandra does not want to stay in her room (you are trying to keep people in their rooms because of COVID-19).

ENVIRONMENT, UNMET NEEDS, LIFE STORY, COMMUNICATION, ETC.

WHY?

Sandra is bored in her room. It is confusing to her that some people (team members) are walking around outside the room and she is not allowed to be with them. Sandra is not a person that is content to be alone. Sandra is picking up everyone's anxiety. She wants to see what is happening.

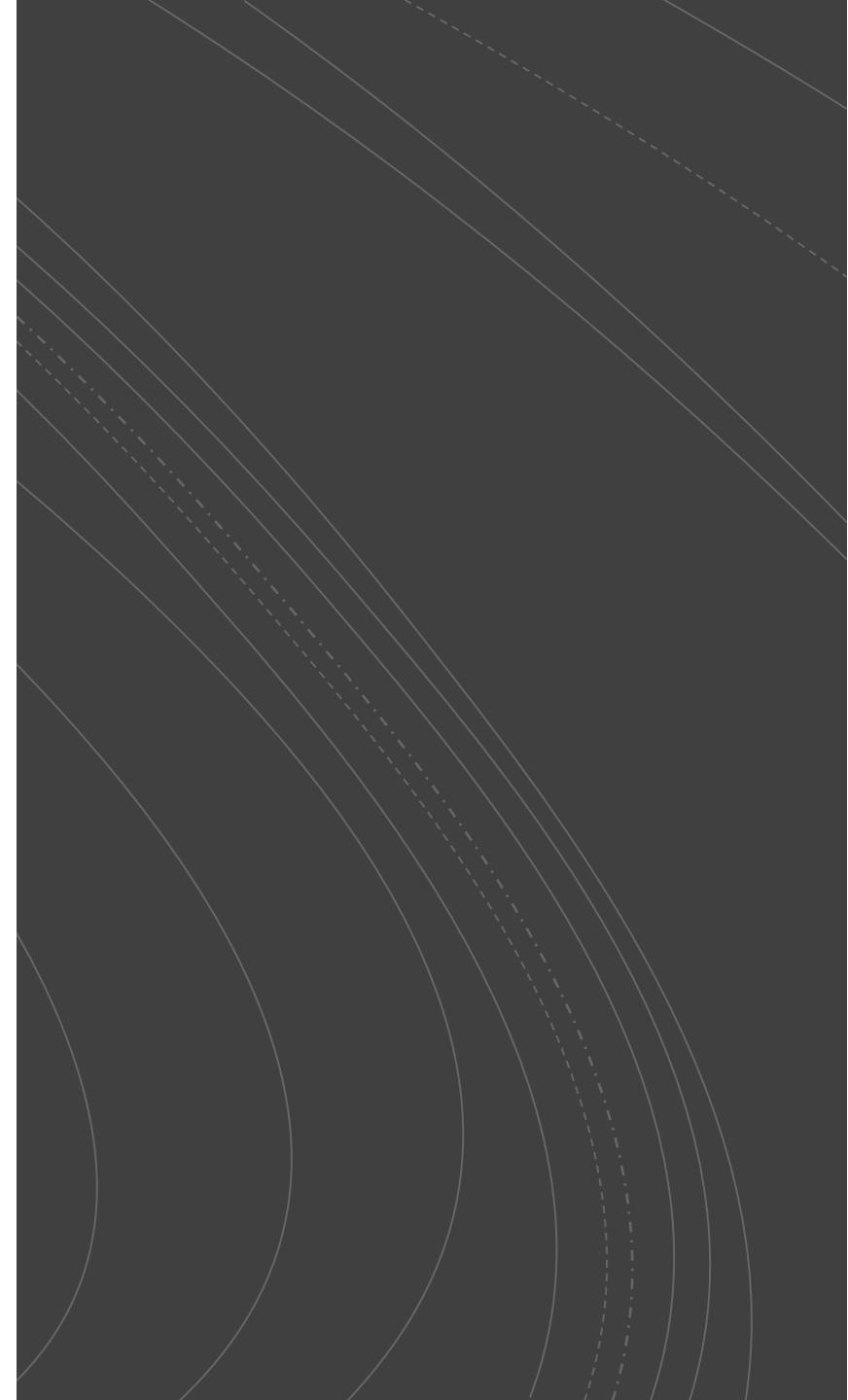
CHANGING OUR BEHAVIOR



Go with the
flow.

How do we use the strengths
and gifts of people with
dementia in this moment?

What gives
people with
dementia
joy and flow?



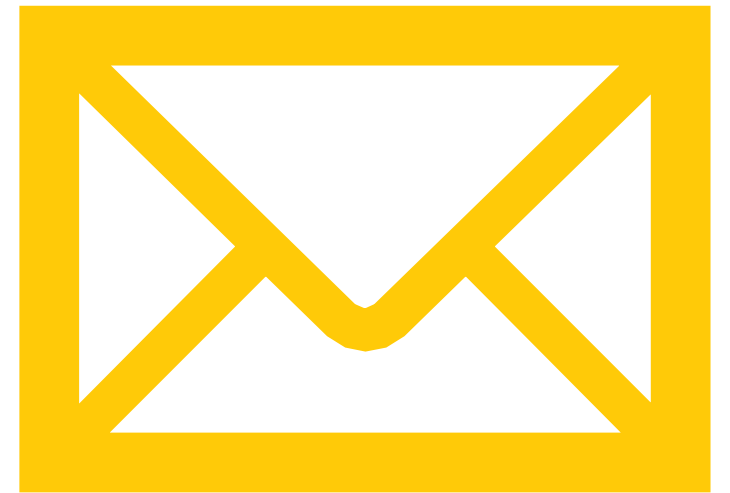
*Thank you.
We appreciate your time
and the work you do.*



Keep in touch!

sonya@sbcgerontology.com

kstobbe1@gmail.com



SUMMARY

Be curious about **WHY** people with dementia are acting the way they are (don't assume that this is just "because of their dementia")

We have to **change OUR behavior** rather than change the behavior of the person with dementia

Person-centeredness is the foundation of HOW we support people with dementia and we can always come back to this foundation