

Person Centered Goal Discovery for People Living with Dementia

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Part of the National Alzheimer's and Dementia Resource Center webinar series sponsored by the Administration for Community Living. In collaboration with the National Center on Advancing Person Centered Practices and Systems (NCAPPS).

Learning Objectives

- At the end of this webinar, participants will:
 - Describe the differences between the foundational concepts of “important to” and “important for” in person centered practices in the context of supporting people living with dementia in the community.
 - Identify one process to capture and record a person’s unique communication and the way supporters can use a better understanding of behavior to provide effective supports that align with individual and family goals.
 - Recognize the purpose of discovery, management and everyday learning tools to identify effective person-centered approaches for people living with dementia.

Core Principles

- We honor the spectrum of the dementia journey
- We recognize people and families as experts
 - Content experts – the person, families, loved ones, direct supporters
 - Process experts – systems and services professionals
- We strive for balance, all the time, between what is ***important to*** the person and what is ***important for*** the person
- There is no such thing as “zero risk” – we seek balance between risks we can support and those we cannot, continuously

Important To

Elements that contribute to the person feeling happy, satisfied, fulfilled, comforted and content, including:

- People to be with (or not), and relationships
- Culture
- Identity
- Purpose and meaning
- Status and control
- Belongings
- Things to do, places to go (or not)
- Rituals and routines
- Rhythm and pace of life

Important To

- Quality of life ~ as defined by the person
- How the person communicates and can be listened to/heard
 - What people say with words
 - What people say with actions and behavior
- When words and behavior conflict, we must pay attention to behavior, and we must explore “why?”

Important For (part one)

Issues of health and well-being

- Prevention of injury or illness
- Treatment of injury or illness
- Promotion of wellness within the person's interests

Issues of safety

- In the environment, where the person lives and spends time
- Free from fear, anxiety, all-consuming worry
- Physical and emotional well-being

Important For (part two)

- What others see as necessary to help the person:
 - Feel and be valued in their community
 - Be a contributing member of their community

Important To and For are Connected

- **They influence each other**
 - Without coercion, almost no one does those things that are important for, unless they are connected to something that is important to.
- **Achieving balance is dynamic - there are always trade offs**
 - Between the important to elements, and
 - Between important to and important for
- Recognize that the scales may tip heavily one way (TO) or the other (FOR) depending upon circumstance (e.g., critical illness)

Communication as a Tool for Discovery

- When we listen differently, people communicate differently
 - Communication may become more complex
 - People may communicate more
 - Some people who previously only used behavior, may begin to use words
- Supporters respond differently
 - Actions and behavior previously seen as curious or problematic, are now understood to mean something
 - Supporters have guidance, and options to try when unsure

Insights on Culture and Communication



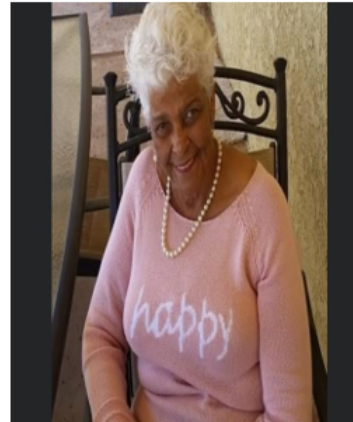
Challenging Our Assumptions

- Elias Rodriguez, RN works as the Community Life Director at Rowntree Gardens Senior Living Community, a continuing care retirement community in Orange County
- Rowntree's Memory Care Team recently earned gold certification in the Montessori Inspired Lifestyle from the Center for Applied Research in Dementia

Paulina's One Page Description

What Others Like and Admire about Paulina

- ✓ Family relationships are her anchor.
- ✓ Her sense of style!
- ✓ **She's a great storyteller – she loves to tell you all about her grandchildren.**
- ✓ **She has a fantastic memory for recipes.**
- ✓ **Her green thumb and her garden.**



What is Important to Paulina

- ✓ Family, family, family, including...
- ✓ Sharing stories about her daughter who died.
- ✓ Always being dressed nicely.
- ✓ Knowing she is being helpful.
- ✓ **Storytelling – about her family, her escapades, her life in the Foreign Service.**
- ✓ Cooking and baking – she loves being in charge in her kitchen.

Best Supports for Paulina

- ✓ It helps if you and she only do one thing at a time (ask one request, then wait...).
- ✓ Give her time to figure out what you have asked her to do. Don't immediately ask a second or third time.
- ✓ **If she's really upset, sometimes you can help her re-focus by asking about one of her grandchildren, or a "how do I cook xxx food?"**
- ✓ Help her stop when she is tired. She is accustomed to being busy and may need you to model sitting down, putting your feet up, taking a break.
- ✓ On the other hand, be ready to walk when she is!

People Who Support Paulina Best...

- ✓ Are flexible and can move from activity to the next
- ✓ **Are okay with waiting. It can take her a while to think through and then act what you have asked her to do.**
- ✓ Are creative and can help her re-focus when she's getting upset or agitated. Or...
- ✓ Are comfortable working through the agitation – doing what works in the moment.

Paulina's Communication Chart

When this is happening...	And Paulina does this...	We think it means....	And we should.....
Anytime	She's pulling at her clothing – as if to take it off or, as if it's irritating her	She's hot; the fabric is bothering her; she's itchy	Help her take off the offending clothing (always have extras/options with you); if you're someplace where she can't take off her clothes, try getting to a restroom where you can go into a stall with her to remove clothes (she always wears sleeveless tops with layers over top).
Paulina is telling you a story about her life	She uses nonsense words; or she says things that seem uncertain ("then the Prime Minister brought us blueberries!")	She probably doesn't remember the right word for what she wants to say – but it seems right to her; there is a kernel of truth in what she's saying and she's telling it the way she remembers it now	Do not correct her unless she asks for the right word – her tone and inflection are accurate even if her words are not. Just go with it.... ask her for more details. She's a great storyteller.
You've asked Paulina to 'do' something (put on a coat, take medication, put a tissue in the wastebasket.....any task)	She refuses your request, and/or says "no, no, no", or refuses and calls you a nasty name	She doesn't want to do what you've asked; She may be confused by the request (but can't say those words)	Stop. Suggest something else that's related (e.g., instead of putting on her coat, ask if she'll hold your coat while you put it on) – she may imitate you

Communication Chart

This is happening...	The person does this...	We think it means...	And we should do....

Communication Chart, first set of information

	The person does this...		
	<p data-bbox="691 568 819 644">#1</p> <ul data-bbox="562 649 904 915" style="list-style-type: none"><li data-bbox="562 649 904 743">• Observable action<li data-bbox="562 761 904 915">• What do you see? Hear? Feel?		

Communication Chart, second set

This is happening...	The person does this...		
<p>#2</p> <ul style="list-style-type: none">• What is going on around the person?• What just happened? What is taking place in the environment?			

Communication Chart, third set

This is happening...	The person does this...	We think it means....	
		<p data-bbox="1108 591 1238 668">#3</p> <ul data-bbox="981 696 1329 1139" style="list-style-type: none"><li data-bbox="981 696 1329 853">• What is the person trying to tell us?<li data-bbox="981 868 1329 1139">• What do we think the actions or behavior mean?	

Communication Chart, fourth set

This is happening...	The person does this...	We think it means....	And we should do...
			<p data-bbox="1522 592 1653 668">#4</p> <ul data-bbox="1396 696 1787 1025" style="list-style-type: none"><li data-bbox="1396 696 1746 801">• How should we respond?<li data-bbox="1396 811 1787 1025">• What does the person need us to do at this moment?

Communication Chart Sequence

This is happening...	The person does this...	We think it means....	And we should do...
<p>#2</p> <ul style="list-style-type: none">• What is going on around the person?• What just happened? What is taking place in the environment?	<p>#1</p> <ul style="list-style-type: none">• Observable action• What do you see? Hear? Feel?	<p>#3</p> <ul style="list-style-type: none">• What is the person trying to tell us?• What do the actions or behavior mean?	<p>#4</p> <ul style="list-style-type: none">• How should we respond?• What does the person need us to do at this moment?

John's One Page Description

What People Like and Admire About Me:

- Very thoughtful
- Dedicated to family
- Great sense of humor
- Deep and independent thinker
- PhD in Physics
- Great storyteller
- Great sense of humor
- Loves good food
- I always do what interests me
- Artist



What's Important to Me:

- I feel listened to and understood
- I have enough alone time
- I understand what is happening, no surprises
- Predictable routine
- Politeness and manners
- Engage in deep, meaningful conversations
- My things are organized
- I make my coffee in the morning

Supports I Need to be Happy, Healthy and Safe

- Try playing classical music on the radio: 99.5 FM
- Help me exit social situations that I don't like (stern facial expression, or by asking the person to leave me alone.)
- Listen to the stories about my life.
- Give me plenty of notice before coming to my apartment.
- Talk through things that are worrying me, however minor it may appear.
- Make sure my meds are up to date
- Keep Dr. phone numbers readily available
- Remind me to drink water several times a day

People Who Support Me Best

- Be gentle and quiet
- Do not direct me to do anything
- Don't be overenthusiastic (e.g. no high fives).
- Curious disposition
- Enjoy quiet and deep conversation
- Patient with things that worry me

JT's Communication Chart

What is happening?	JT does this...	We think it means...	And JT wants us to...
Someone remains in his space, is too forward, or too talkative after he asked nicely to leave him alone.	Gives you or someone else a stern look or yells.	He is telling you/us that he needs to be left alone (expressed sometimes as anger).	VERY RESPECTFULLY help him leave the situation. Ask if he wants to go for a walk, wants something to eat, sit somewhere else.

Key Takeaways

- Good person centered practice means *continually* striving for balance
- All behavior is communication – our role is to listen/observe and try and understand what the person is telling us
- When we honor someone’s communication and culture, and listen well, people will communicate more, and possibly, in new and different ways
- “A person with dementia is not *giving you a hard time*, they are *having a hard time*” (Teepa Snow)

Selected Resources

- Bowers, H., Bailey, G., Sanderson, H., Easterbrook, L., & Macadam, A. (2007). Practicalities and possibilities: Person centered thinking with older people. <https://www.ndti.org.uk/assets/files/PCPOPweb3.pdf>
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Thank you for joining us today!

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