

A Study Guide for Memory Care Communities

Let's Get Real: Being Person-Centered in a Task Oriented World

This study guide serves as a supplement to the course *Let's Get Real*. The guide provides an opportunity to talk about real situations and how TRACK can be used to make sure that the *task* of care be accomplished in a person-centered way.



Making Oregon Vital for Elders (MOVE) developed this training on behalf of Oregon Department of Human Services – Aging and People with Disabilities. Funding for this project was provided by a grant from the Oregon Quality Care Fund.



Review

In **Person-Centered Care** (PCC), a resident's preferences or past patterns of living is the basis for planning and providing support. PCC is not a task that is added on to a caregiver's already busy schedule, but an approach to care that balances quality of care (tasks performed) with the resident's quality of life. Quality of life means supporting the whole person. By this we mean recognizing and respecting each person's uniqueness, knowing and acting according to the person's preferences, facilitating decisions and honoring choices, and sustaining independence and dignity.

TRACK

TRACK is a self-reflection tool that serves as a reminder in the course of care. It can be used to

Tune-in

Relate

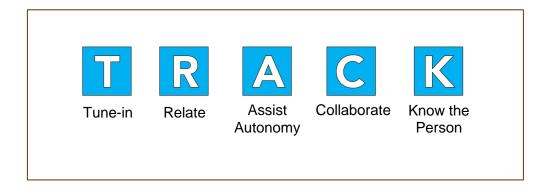
Assist Autonomy

Collaborate

Know the person

Applying **TRACK** everyday

The stories presented in this guide are based on real experiences in many different kinds of settings. Read the story and then discuss how **TRACK** can help you figure out how to help the person in a way that will be important to them and provide the care they need.



Lottie's story



Lottie moved into the memory care unit because she was unable to take care of herself. She quickly became a person the staff wanted to avoid. Her language skills had declined, so it was difficult to understand what she wanted. Most of the staff just knew what she didn't want because she would yell at them and say "no, no, no!" She would yell at them to get out, but then would be calling them to come and help. The staff were frustrated over the

extended time they spent in her room that prevented them from tending to other resident's needs. The only way to calm her down seemed to be to give her food and then she would let them know she wanted more. She gained a lot of weight which made her physical care difficult.

When Sarah came to work at the community, she was assigned to Lottie. One day Pedro, another caregiver in the community, was surprised when Sarah talked about how much she liked Lottie. He was sure she had the resident's name wrong. But sure enough, he saw the two talking and laughing together. Then he realized that Lottie seemed much more pleasant – he even saw her smile at another resident when she came out of her room. He wasn't sure what was more surprising, her smile or that she had come out of her room.

- 1. What sort of care issues have you noticed cause us to avoid residents and why?
- 2. What do you think Sarah knew about Lottie that the rest of the staff did not?
- 3. If you were Pedro, what questions would you ask Sarah?

What Sarah did

Pedro asked Sarah how she managed to develop a positive relationship with Lottie. Sarah said that Lottie was really frustrated when she felt out of control. Sarah said that she paid attention to what Lottie seemed to be saying in addition to her gestures and facial expressions and then anticipated those things when she was there to provide care. She also learned the things she did that would cause Lottie distressed. She also kept checking in with Lottie to make sure she was doing things the way Lottie wanted, asking "is this right or do you want it different?" before Lottie had a chance to complain. Sarah also looked around the room at the family photos and the quilt hanging on the wall and asked Lottie about them. She found out that Lottie had been an expert quilter and used to win ribbons for her quilts at the State Fair. She had also raised five sons. Sarah had two sons and started talking to Lottie about raising boys. Sometimes Lottie would respond by laughing at Sarah's stories. Sarah brought Lottie scraps of cloth. Sometimes she would cut squares, and sometimes Sarah would give her a large needle and thread, and Lottie would sew pieces together.

The staff noticed that Lottie began to lose some excess weight and her blood sugars improved – once she didn't feel out of control, she obsessed less about food.

- 1. What are some experiences you have had in building a relationship with a person whose behaviors were difficult to understand?
- 2. How can the rest of the staff learn from Sarah?
- 3. How can the staff continue to support Lottie and help her improve her quality of life?

What the staff did

The rest of the staff began greeting Lottie by name. The activity director helped her assemble her quilting squares. The staff would encourage Lottie to use her walker more by talking to her about their children while they walked alongside her.

The staff began to use this approach with other residents – they asked more questions about how they wanted things done and began to focus more on the cues in residents' rooms so that they could get to know them better. Staff began to share this information and were soon amazed by what they learned.

- 1. How could this approach work in your community or care home?
- 2. What parts of TRACK can be seen in this scenario?

Ginny's story, 1

Tania tries to be person-centered and respect what the elder wants, but a lot of the elders she works with have a hard time expressing what they want – but they don't have such a hard time expressing what they don't want.

Ginny had dementia and couldn't speak very well. Shower days were especially challenging because no matter how hard Tania tried to comfort her, she screamed and tried to walk out of the shower stall. It took forever to bathe her. Ginny was always slapping at her with her wet, soapy hands and everyone was exhausted and frustrated by the end of the shower.

All the caregivers would like to honor Ginny's wishes not to take a shower, but they need to find a way to keep her clean for health and sanitary reasons.

- 1. How might getting to know Ginny better help accomplish the task of keeping her clean while making it a more pleasant experience for everyone?
- 2. How might Tania collaborate with others in this situation?



What the staff did

One day Molly, one of the housekeepers, told Tania that she often sees Ginny watching cat videos on her tablet. "Maybe you can get her in the shower if you entertain her with pictures of cats," she suggested. Tania had never thought of that! So at the next team meeting she brought it up and everybody thought it was worth a shot. They printed out some cute pictures of kittens and decorated the bathroom and shower area. Margaret, the director, said she had a waterproof case she could bring in.

So the next time it was shower day, they put Ginny's tablet into the case and brought it into the shower. At first Ginny didn't want to go in, of course. But once they started the cat videos, she quieted down and Ginny walked right into the shower without her normal signs of anxiety. Having the videos to watch really helped keep her calm. They got her shower done in half the time. Later that day Tania went to Molly and thanked her for the idea to entertain Ginny with cats on shower day – it made a huge difference!

- 1. What parts of TRACK can be seen in this scenario?
- Think of a time when information offered by staff other than direct caregivers helped improve a resident's experience.

Ginny's story, 2

In memory care, figuring out what someone *does* want is often harder than figuring out what someone *doesn't want*.



One day Tania overheard a conversation between Ginny and her daughter. Ginny's daughter was going through an old photo album with her mom and she said, "Look, Mom, you were so pretty! You never did leave the house without your hair up and your makeup on." This got Tania thinking since none of the caregivers ever spent much time on Ginny's hair. It was long, so they all just combed it and kept it pulled back in a rubber band to keep it out of the way. Also Tania realized she and the other caregivers never applied Ginny's makeup. One evening, as Tania was leaning over Ginny to reposition her in bed, Tania noticed that Ginny was focusing on her sparkly earrings. So she asked her: "You like my earrings?" Ginny nodded, then she reached for her braid and caressed it with her hand. And Tania said, "Would you like me to braid your hair some time?" Ginny cracked a big smile.

The next day, when Tania got Ginny up and dressed for the day she said, "Ginny, your daughter is coming today, let's get you looking pretty for her visit!" Ginny perked up. Tania helped her over to the closet and watched which items her eyes focused on. While looking in her eyes for any negative reaction Tania said, 'Ginny I'm going to look in your drawer for some makeup. She handed her a brush and Ginny raised it to her ear and awkwardly brushed in short strokes while Tania looked in her drawer. Tania finished brushing her hair then braided her hair into a French braid and wrapped the long braid around in front so Ginny could stroke it. Tania put on a little lipstick and blush to Ginny's cheekbones. As Tania put on her makeup, she told Ginny "You are going to look so pretty today when your daughter comes!" Ginny just beamed. Then Ginny reached out her hand and picked up an earring. She had a little trouble getting it up to her ear, so Tania helped her put on the earrings and a matching necklace.

Ginny looked into the mirror and her eyes were focused and clear. She smiled at herself, which Tania never saw her do before, and she looked up at Tania's reflection smiling back at her.

When Ginny's daughter came that day, the daughter looked so surprised and happy. "Mom, you look lovely today!" she said, and Ginny beamed.

Questions

- 1. What examples do you have of figuring out what someone wanted and could provide it in a way that brought pleasure to the person?
- 2. What can staff learn from Tania?
- 3. What parts of TRACK can be seen in this scenario?

What the staff did

The staff began to routinely put Ginny's hair up and made sure she was wearing lipstick before she went out of her room. She seemed to feel a lot better about herself and she no longer seemed so distant and unhappy.

The staff really learned from Ginny that even when people can't speak, they can still communicate what they want — and it's up to all of us to pay attention, to watch their expressions and listen to all the information around us that will help us know what makes that elder happy.

9

Ben's story



Sometimes families unknowingly make it harder to focus on what the elder wants. Everybody thinks they know what's best for the elder — but sometimes it's all about family's expectations, not what their elder family member really needs or wants.

Ben used to be an insurance salesman who wore a suit and tie to work and he was always on the go. Then his wife died and Ben's memory began to fail. It became difficult for Ben to take care of himself. His daughter and son live on the other side of the country, but even with cognitive decline, Ben had made it clear that he did not want to leave his community. So Ben's children found a memory care unit, not far from where he used to live, where he could get the care he needed.

Ben's daughter visited a couple of times a year, and she always had a laundry list of "reminders" for memory care unit staff about what they want done for their dad – she wanted to preserve his dignity by maintaining the way he dressed and the activities he pursued throughout his working life. She told the staff that it is important for Ben to get up at 8 a.m. every day and go for

a walk, make sure he reads all his magazine subscriptions they get him, make sure he wears his button down shirt and slacks, that he be kept clean-shaven and his hair is kept short.

The thing is, Ben is now happier if they wait to wake him until at least 9:30 a.m. or 10 a.m. If they wake him earlier, he tends to growl at the other residents and then falls asleep during breakfast. They also lay him down for a nap mid-afternoon when his eyelids start to droop. His legs are stiff and putting on his slacks causes pain and when they did put them on, he would grimace, tugging at the waist saying "off, off". When they dress him in his drawstring sweat pants and a sweatshirt he appears comfortable. He gets frustrated when he tries to read as his eyesight is poor and he has difficulty tracking. He would quickly toss magazines on the floor saying "no good". The staff noticed that his eyes would light up when sports were on TV and he would pump his fist saying "yes, yes" when a score was made, so they now turn his TV to the sports channel. He does enjoy his walks with one of the caregivers most days right after lunch. When caregivers attempted to help Ben shave he would grab the razer and toss it aside saying 'no' and point to the male caregiver's beard and smile.

One day the daughter came to visit. When she arrived she found her dad lying in bed at 2:30 in the afternoon, wearing sweats, with a week's worth of beard. She saw the pile of unopened magazines in the corner and ESPN was blaring on the TV.

His daughter was *livid*. She confronted Natasha and went into a tirade about how she thought this was supposed to be a "person-centered" memory care and instead they were letting her father languish here. She said the center obviously wasn't taking care of him well and they weren't giving him enough mental stimulation. All this before she even said "hello" to her dad.

Natasha calmly listened to Ben's daughter finish her litany of complaints before she spoke. The first thing she asked the daughter was, "Have you asked your father what *he* wants?" The daughter looked confused. Finally she said "He's my dad and I know what's best for him."

Very respectfully, Natasha explained that person-centered care isn't about what everyone else wants for the elder, it's about how the elder wants to live his or her life right now. Not how they used to be or how we would like them to be. She said that elders need to have the ability to make their own decisions about how they want to live

even if they cannot express them in words. She also talked about expressions of distress and how they had learned to interpret his gestures, facial expressions and vocalizations. She talked about the regular walks and various activities he participated in most days.

The daughter got up from the desk and walked back down to her father's room. Natasha went with her and engaged Ben in conversation about the game on TV. It was clear to the daughter that the two had a good rapport. Natasha gave Ben's daughter a handout on how to talk with someone with dementia and showed her where various "kits" were that would help her have quality time with her father. That day she chose one kit full of sports memorabilia and the next she used one that had a photos of old cars. Ben talked about the cars he drove when he was a salesman. On the last day of her visit, Ben's daughter handed Natasha a piece of paper. At the top it said "To-Do List for Ben" and there was only one item on it. It said: "Whatever makes him happy."

- 1. How did Natasha support person-centered care when family members wanted something else?
- 2. What could the staff have done to prevent the "blow up" with Ben's daughter?
- 3. How was TRACK used to support Ben?
- 4. What are some ways you have helped family learn about person-centered care?

Jodi's story

Jodi had a lot of sadness every afternoon. Although her husband never visited because he was living in another care setting, she would often angrily call out his name in the afternoon. She would also shout at an imaginary woman in her bed. She also seemed worried about her looks and would point to her breasts in the shower room and repeat "flats." Her wedding photo sat on her bedside stand. She used to be a beautiful voluptuous woman.

For her birthday her daughter gave Jodi a leopard print push up bra. Jodi cracked a

huge smile and they couldn't get it out of her hands! At first the staff were reluctant to put it on her thinking it didn't suit her, but her daughter insisted. The daughter explained that since getting dementia, her mother had become paranoid that her father was having an affair and had become very fixated on her own appearance hoping to attract her husband's attention. As soon as they put Jodi's new bra on, her demeanor changed instantly. She felt beautiful again and had had a twinkle in her eye the staff had never seen before.

Question

- 1. How was TRACK used to support Jodi?
- 2. Think about a time when you witnessed an elder rediscover their sense of personhood. Why is it important to know what gives elders their sense of identity?

One day, the leopard print bra was in the laundry when they got Jodi dressed for the day. That afternoon Jodi was distraught about her husband again. She looked tiny and hunched over in her chair. Susan, the housekeeper rubbed her shoulder to

console her and realized that she did not have on her bra. Susan found it in the clean laundry and asked a caregiver to help her put her bra on and her demeanor instantly improved again.

- 1. Think about a time when an elder was showing signs of distress. How did tuning in help you identify how to respond?
- 5. Whose responsibility is it to support each resident's sense of identity?