



A Study Guide for Home Care Workers

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

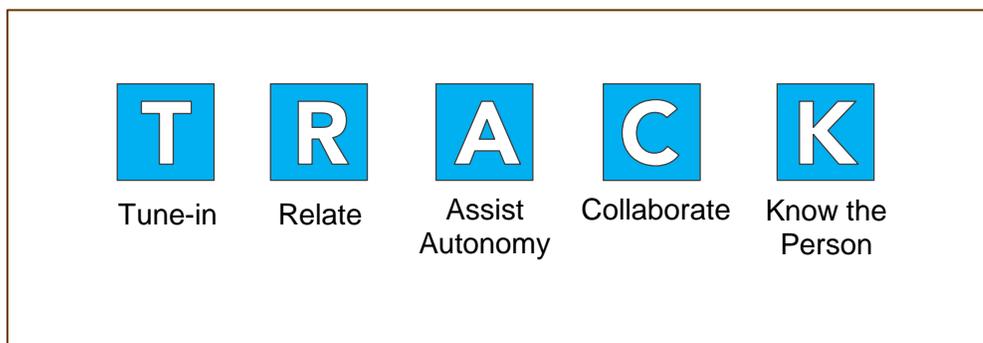
Assist Autonomy

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.



Mabel's story

Marcia had been helping out her home care client, Mabel, a woman with severe arthritis, for months now. Marcia used to squeeze out the toothpaste for Mabel and help her pick out her clothes, but she always waited for Mabel to brush her own teeth and button her own blouse. It took a while but she felt it was important.

Then Mabel's services were cut back and Marcia found herself pressed for time. To get things done faster with Mabel, and so Marcia could get to her next client, Marcia started just doing things for Mabel. She brushed Mabel's teeth for her and started dressing her and buttoning up her blouses for her and it took half the time. Mabel didn't really like it at first, but she accepted, saying "It's OK, I know you have a lot to do and I don't want to be a bother." Marcia was getting more done in less time.

A few months later Marcia had to take a day off for jury duty and Donna, one of the other home care workers, covered for her. Donna used to care for Mabel before Marcia started. When Marcia saw Donna at a staff meeting, Donna told her she was really surprised at how much Mabel had gone downhill in terms of her capabilities. She mentioned how Mabel used to be able to take care of most of her own grooming. Now she can barely hold on to the toothbrush and she can't button a single button.



Questions

1. Have you ever struggled with balancing being "person-centered" with the desire to get tasks done? Provide some examples?
2. List some ways that Marcia might help maintain Mabel's autonomy and abilities when pressed for time?
3. Was Marcia following TRACK? What did Marcia miss? How did this affect Mabel?

What Donna did

Marcia worried that her own actions had contributed to Mabel's decline. Did she help Mabel too much? Did she stop Mabel from doing the few things she could do by herself just because she wanted things to go faster? Marcia decided to ask Donna. Donna had some advice. Donna suggested finding smarter ways to use time – for example, Donna put the tooth paste on the toothbrush for Mabel because that was hard for her. While Mabel brushed her teeth, Marcia could go make the bed, open the curtains, or prepare her morning pills. She could do the same thing while Mabel was buttoning her shirt. Marcia also realized that it was important to Mabel to select her own clothes and added that back into their routine. Marcia also realized that her focus on getting the tasks done had gotten in the way of relating to Mabel and learning more about her. She began to find ways to engage in conversations and ask questions of Mabel as she worked on some of these other tasks. Over time, Marcia noted that Mabel began to regain some of her abilities and that their relationship improved.

Question

1. What are some other things Marcia might have done to support Mabel's autonomy while still getting her tasks accomplished?

Lottie's story



Lottie is unable to take care of all of her ADLs so has caregivers who come to her home every day to help her get up, do some light housekeeping and prepare meals. She quickly became a person the homecare workers wanted to avoid.

She had frequent requests of her caregivers that went beyond their job responsibilities, and when they explained this to her she got angry. When they tried to meet some of her requests, it seemed as if

nothing was ever right. She complained, had frequent requests for food, and kept changing her mind about what she wanted. The homecare workers were frustrated over the extended time they spent that made it difficult to get to their other clients on time. She had also gained a lot of weight, which made her physical care difficult. As a result, turnover in homecare workers was quite high.

When Sarah was assigned to Lottie, things began to change. The home care nurse was surprised to learn that Sarah actually liked Lottie. He was sure she had the client's name wrong. But sure enough, at his next home visit, he saw the two talking and laughing together. He realized that Lottie seemed much more pleasant, and the weekend caregivers were not turning over so frequently

Questions

1. What sort of care issues have you noticed cause us to avoid clients or make us want to avoid conversations with them
2. Why do you think these things happen?
3. What experiences have you had where you have wanted to avoid a client
4. What do you think Sarah knew about Lottie that the rest of the home care workers did not?
5. If you were another of Lottie's caregivers, what questions would you ask Sarah?

What Sarah did

The nurse asked Sarah how she managed to develop a positive relationship with Lottie. Sarah said that Lottie was really frustrated because she had lost her independence. Sarah said that she paid attention to what Lottie requested and then anticipated those things when she was there to provide care. 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 house 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 asking Lottie for pointers, which Sarah found helpful. Lottie even began telling funny stories about her kids when they were small.

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.

Questions

1. What are some experiences you have had in building a relationship with a demanding person who is difficult to be around?
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

Sarah told her manager about the importance of quilting for Lottie. Together, they arranged for Lottie to go to a quilting class at the senior center. Sarah was able to use their mutual interest in craft shows to encourage Lottie to use her walker more.

Ginny's story



Ginny lived at home with her husband, her primary care taker but he had requested assistance with bathing Ginny as that had become more difficult for him. Ginny had a past stroke that resulted in some physical and cognitive limitations and she couldn't speak very well. Sometimes Ginny had a hard time expressing what she wanted but it was often very clear what she didn't want.

Shower days were especially challenging because no matter how hard Tania tried to comfort her, she screamed and stiffened throughout the whole shower. 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.

Tania wanted to honor Ginny's wishes not to take a shower, but they she needed to find a way to keep her clean for health and sanitary reasons.

One day Molly, one of Tania's granddaughters was visiting. Molly and Ginny were watching cat videos and giggling. When it came time for Ginny's shower, Tania decided to put the tablet in a plastic waterproof bag to keep Molly entertained in the shower room. What she didn't expect was that Ginny also continued to watch the cat videos during her shower and was much calmer while Tania assisted her! Having the videos to watch really helped keep her calm. They got her shower done in half the time. From then on Tania always played cat videos during shower time!

Questions

1. What parts of TRACK can be seen in this scenario?
2. Think of a time when knowing an elders preferences has helped make necessary tasks more comfortable?
3. Think of a time when information offered by other family members or friends helped improve an elder's experience.

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 had a stroke that made it hard for him to take care of himself. His daughter and son live on the other side of the country and Ben declined to go live with either of them. So they arranged for Natasha, a home care worker, to come in the morning and again at night to provide the assistance he needed to get up, get a shower, and get to bed. They also provided breakfast and dinner and he received meals on wheels. He could use the bathroom on his own after they installed the proper supports.

Ben's daughter visited a couple of times a year, and she always had a laundry list of "reminders" for the home workers about what she wanted done for her 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 home care manager that it was important for Ben to get up at 8am 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. Ben told the manager that his kids still expected him to be like he was when they were in high school.

The thing is, Ben now likes to sleep in until at least 9:30 a.m. or 10 a.m. He has *no* desire to wear dress pants. He says they're too hard for him to zip and all he really wants to wear are his drawstring sweat pants and a sweatshirt. He doesn't like to read much anymore – he'd rather watch sports on TV. He does enjoy his walks and goes on one with Natasha most days right after lunch. One day Ben saw the International Beard Competition on TV and decided he wanted to grow a beard (he'd never had one).

When his daughter came to visit 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. She was *livid*. She immediately called Natasha and went into a tirade about how she thought they were supposed to be a "person-centered" agency and instead they were letting her father languish here. She said the home care workers obviously weren'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, “I can see you are very concerned about your father”. She then asked the daughter, “have you asked your father what *he* wants?” The daughter was silent. 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.

She hung up and walked back down to her father’s room. The two of them had a long talk. There were tears and arguments. Later that afternoon, Ben’s daughter called Natasha and told her the “To-Do List for Ben” had only one item on it: “Whatever makes him happy.”

Questions

1. How did Natasha support person-centered care when family members wanted something else?
2. What could the agency 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?