

Discussion Guide for Thin Edge of Dignity Video

Background:

About a year ago the manager of our Oregon Department of Human Services, Aging and People with Disabilities State Unit on Aging heard Dr. Richard “Dick” Weinman read from a series of essays that he had written about what it was like for him to live in an assisted living facility (ALF). What she heard Dr. Weinman say was similar to what she had heard many individuals say about living in a long-term care-setting. However, Dr. Weinman has a unique gift as a powerful communicator and shares his message with great eloquence.

When viewing this video, we hope you pay close attention and think about the various settings we work within and about what types of person-centered practices might be put into place to better accommodate older adults and people with disabilities.

Discussion Questions:

1. What was your response and biggest take-away from the video? What did you like and not like?
2. Dr. Weinman had an active life prior to a debilitating accident, which made his children feel he could not live at home alone. He had no say as to where he would live.
 - How do Dick’s experiences fit with the person-centered principles of:
 - An individual’s wishes, values, and beliefs are considered and respected;
 - An individual is listened to and their needs and concerns are addressed;
 - An individual should receive the information and training they need in order to make informed decisions. With a person-centered system, even in acute situations, individual choice and preferences should drive the planning process.
 - What would you have done in this situation?
 - How could the situation have been handled differently to be more in line with person-centered principles?
 - How do these types of situations affect the entire family? What does it do to their relationships?

- Does it sound like this family had previous conversations about what Dick's preferences might be if a situation like this should occur?
3. Has your family had these important conversations? If you not, what is keeping you from having these conversations?
 4. When admitted, Dick became #108, which is his room number, this is how staff refer to him. Further, the ALF calls him Richard as opposed to his preference to be called Dick. How would this make you feel?
 - If a person-centered system is designed, scheduled and delivered to meet the needs and preferences of the individual, not the service provider. What could this ALF be doing instead?
 - Dick mentions a couple of other specific adjustments he's made in order to meet the facility schedule or way of doing things. What are they?
 - What simple things help him to maintain his physical and emotional independence so he doesn't have to rely on others?
 - What are the barriers to being able to implement person-centered approach?
 5. Dr. Weinman was always actively engaged in life prior to his accident; he volunteered at schools, lectured, enjoyed visiting with friends, etc. He still enjoys going out with friends, but the ALF is on a strict time schedule for meals and other activities which he refers to as the "Synchronization of Time." He worries that when he goes out with friends, or spends time volunteering, the bus won't pick him up in time for the ALF staff to have time to get him ready for the evening meal. Or if he should go out in the evening, he worries that he won't make it back in time for his shower, since showers seem to take place only in the evenings.
 - If a person-centered system is committed to excellence and quality improvement, what are some ways that this facility can work with Dick to meet his needs? What barriers exist for the facility to overcome?
 - Do you think things can be changed to be more person-centered in Oregon's long-term care system? What do you think is the first step?
 - Dick has to compromise on who he is in order to live at this facility How do you think this is affecting him, his morale, his self-image, etc.?

6. Consider the issues surrounding Activities of Daily Living or ADLs. Dick talked showering and how it makes one feel vulnerable and uncomfortable. He also talked about going to the bathroom and how it can be a degrading experience when you cannot do it yourself or you have to sit on the toilet until someone comes to help you up.
 - How does hearing Dick talk about these activities make you feel?
 - What would it be like if it was you or your loved one “in his shoes”?
 - How would you begin to talk with your caregivers about this?
7. Dick mentioned that for someone who had a rich active and social life like he did prior to his accident, activities in the ALF are minimal.
 - Think about your own life. What would it be like to have your social activities curtailed and not be able to get around to see your friends without assistance from another person?
 - What are some of the activities he mentions that the group does?
 - Do these activities sound like things you would want to do?
8. During the video, Dick talks about the fact that people often sit together at meals with the same group of residents, and when someone isn't there for a meal, because of HIPPA laws, the staff from the setting is not allowed to tell the other residents what is happening or why their friends are not at the meal.
 - It concerns Dick that he can't know what is happening to these people that he cares about and sees every day. Not knowing what is happening can also cause him some stress. He says, personally, that he would like his friends to be able to know if something is happening with him. What do you think about this? How would this make you feel if you couldn't know what was happening to someone you saw on a daily basis?
9. Another thing that Dick mentioned during the video is that those who are cognitively impaired will close themselves off, stay in their rooms and will not engage.
 - Why do you think that happens? What could be done to change that?
10. What Dick saw in the memory care community where his wife lived was no different than what he has experienced in the ALF.

- What do you think about that?
- Have you had any experiences with either kind of facility? If so, what were they?

11. What do you think about Dick's idea that when a new resident moves in there would be a "welcome wagon" type of group to help mentor and get the new person oriented to their new home?

12. Is there anything else you would like to discuss about this video?