

# Viewer's Guide

## **“Bob, I’m Really Busy”:**

The Impact of Impersonal Care  
on the Well-being of Persons  
Living With Dementia



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# **“Bob, I’m Really Busy”:**

## **The Impact of Impersonal Care on the Well-being of Persons Living With Dementia**

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### Summary of the Five Scenarios

1. Man (Bob) unable to get out of bed in middle of night; expresses need to go to the bathroom. Aide tries to reason with him.
2. Man (Bob) with walker wants to go home and tries to go out of alarmed door.
3. Man (Steve) is eating with hands. Aide takes over feeding him.
4. Woman is being wheeled to shower, expresses need to use bathroom. Is ignored and has accident.
5. Woman “shops” (collects stuff) from around the residence. Aide reprimands her.

### Suggestions

- View each scenario at least twice; the first time just get an overall sense of what’s happening. With the second view, pay attention to what’s actually said and done, and to each person’s words, tone of voice, and body language.
- With each scenario be prepared to discuss these three basic points:
  - 1) If you were the resident in these scenes, how would you feel?
  - 2) Describe all the ways in which the aide’s words and actions are poor responses to the resident’s needs.
  - 3) What would be better actions and responses that could lead to more positive outcomes?

### Things to Discuss:

- How might the outcomes have changed if the aides had really listened to the residents and tried to figure out the underlying problem, and even better, solved the problem?
- How might knowing the resident as an individual – his or her life story, preferences, routines, likes and dislikes – have helped in each of these scenarios?
- How might the aides have used techniques like distraction, gentle touch, invitations, and cueing a person who is having trouble with a task?

# Notes for Facilitators: Things to Notice

## Scene 1: Bob is trying to get out of bed

- Bob says, “Help. Please, somebody help.” He is expressing distress. We don’t know why yet.
- In comes the aide (we’ll call her Susan). She flicks on the light, which may be disconcerting by itself, but calls him by name and asks not unkindly, “Bob, what’s wrong?”
- Bob says, “I gotta get outa here.” It’s not clear if he means the bed or the facility.
- Susan says, “It’s the middle of the night. We need to lie down and go to sleep.” Note that she ignores his words, does not seek clarification, and uses condescending language. (“We” need to go to sleep, clearly means only Bob, whom she is treating like a child.)
- Bob says, “I need to go home.” The main message of these five words is *always*, “I am uncomfortable where I am.”
- Susan says, “You *are* home. You live *here* now.” She ignores the discomfort behind the words and his perceived reality. She tries to reason with him, but reasoning never works when heightened emotion is involved.
- Bob says, “No, this isn’t home,” which basically means, “You are not helping me.” He’s right.
- Continuing to ignore him, Susan says, “It’s the middle of the night. We’re going to wake everybody up.” There’s that “we” and condescension again. Furthermore, she is refusing to see he HAS a problem and essentially tells him instead that he IS a problem.
- Bob says, “Can’t you help me? I’ve got to go to the bathroom.” Here, finally, is a clearly expressed need, but it is ignored.
- Susan says, “You just went to the bathroom a little while ago. Time to sleep now.” Susan clearly has not experienced the middle of the night urges to urinate that are common to many older adults (certainly not just those with dementia). Furthermore, she is insensitive to the fact that when someone thinks he has to urinate, sleep does not come easily.
- Bob says, “I might have an accident.” He does not want to be embarrassed by potential incontinence or create a greater problem (needing perhaps to change clothes and bedding). One of the tragedies of dementia is that people who are assisting them often think they are incapable of normal human feelings. In reality, they remain capable of the whole range of emotions, and are particularly sensitive to being shamed.
- Susan’s final response in this scenario is one that might get her fired if she were heard saying it: “Bob, I’m really busy. I’ll be back in the morning, and we’ll clean you up if we need to, okay?” With that, she walks away and turns out the light. In other words, she is saying, if you urinate in your bed, you can stay that way for the rest of the night and we’ll deal with it in the morning – or more likely, the aides on the next shift will deal with it.

There are, of course, health and sanitation issues here (discomfort, possible skin breakdown from lying in urine, etc.) but the main issue we're focusing on is Susan's verbal and non-verbal responses. It would be fairly easy to create extenuating circumstances for Susan. Perhaps she is the only aide on duty during the night and someone in her care is gravely ill. Perhaps this is the sixth time in an hour that Bob has called for help. But in that case, it should be even clearer that her responses are not working. What might she do instead to provide Bob with the care and comfort he needs?

## Scene 2: Bob tries to leave the residential care setting

- Bob is walking along with his walker, finds a door to the outside and sets off a piercing alarm when he opens it. An aide named Chris comes running up, and says, "Bob, stop! Let's go; I have to turn off the alarm." He reaches over Bob and does so.
- Bob says, "I have to get home." It seems to be a repeat of the previous night's scenario. As noted above, the main message of these five words is *always*, "I am uncomfortable where I am." Chris, however, is focused only on getting everyone into the dining room for lunch. He says, in spite of Bob's protests to the contrary, "Bob, this is where you live. . . Yes, I know where your room is, right down the hallway. Let's go to lunch now."
- Again Bob expresses his discomfort by saying, "I have to go home," and again, Chris ignores Bob's need in favor of his own agenda: "This IS your home. We have 27 other people I have to take care of. We're going to lunch."
- They argue a bit longer and finally, Bob says, "I'm not that hungry. You go ahead." When Chris turns away toward the dining room, Bob continues down the hall, and says under his breath, "I was right. There is another door." He moves purposefully toward a set of double doors that are partially disguised with paint as a bookcase, but that have two narrow windows in them, where people seem to be working in an office.
- Suddenly, Chris is beside him again, claiming against reality, "Bob, there's no other door." Bob says, "Yes, I can see it." Chris answers, "All right, all that's out there are nurses and CNAs. You're not going to be able to do anything out there." Now Chris is clearly losing patience in his body language and tone of voice. He pushes the door release repeatedly and says, "Look. You can bang on it all you want. Nothing's going to happen. All you're going to hear is the alarm every single time. You can sit here all day and do it. It's not going to open up. Just come with me and have lunch. Please."
- When Bob still hesitates, Chris says, "Bob, I'm getting really aggravated right now." Bob answers, "You think *you're* aggravated?" Chris answers, "Yes, I am aggravated, and I can tell you're aggravated, too. Let's have lunch and not be aggravated. Does that make sense?"
- Bob responds – ***and this is the key to the whole set of scenarios – "Why don't you just listen to me once in a while?"***
- Chris protests that he's trying to listen, but Bob tells him he's not doing a very good job. Chris asks, "What do you want me to do?" Bob responds with something about

not being “blocked” all the time, but Chris again ignores him, pushing on the door a few more times (a loud and disconcerting action) and saying, “Bob, look it’s locked. It’s time for lunch. That’s how I’m trying to help you.” Once again, Chris has effectively told Bob that it is only Chris’s agenda that matters.

- Finally Bob relents, saying “I don’t understand this place at all.” Chris, walking ahead of Bob says, “I’m sorry you don’t.” (But he doesn’t sound sorry.) “Sometimes I don’t either.”

### Scene 3: Steve is eating with his fingers

- The scene opens with resident Steve eating a meal of chicken, mashed potatoes and beans with his fingers. Chris comes over, and says, “Steve, Steve, let’s put a bib on you.” Steve protests that he doesn’t wear “those things.” Chris insists: “Look how you’re eating.” Against Steve’s continued protests, Chris puts the clothing protector on anyway saying, “You’re going to have dietary going into a fit if they see your clothes when you’re done eating.” (Putting aside the fact that it is Steve’s aides or family more likely to be upset seeing food spilled on his clothes, the point is that Chris is treating Steve like a toddler.)
- As Chris reaches for Steve’s fork, he sees another aide seated at the table. She is off camera for most of this scene, but he begins by rudely asking her, “What are you doing here? Don’t you have work to do?” Her words are unclear (not helped by the fact that she is chewing gum), but for the rest of the scene, Chris does not talk with Steve except once to say, “Don’t eat a bone. Can you put your hand down (as he pushes it away)?”
- Here’s what is happening in the rest of the scene. Chris and the off-screen aide carry on a conversation about last night’s activities, which although not totally clear, seems to have involved a lot of drinking. (“Last night is a blur.”) It is also apparently the cause of today’s exhaustion, and probably why he says, “I don’t have any patience right now.” In the midst of their conversation he also takes a brief personal call on his cell phone. Through all this Chris stands and absent mindedly feeds Steve, without actually looking at him. Steve continues to eat his chicken with his hands, but accepts with only slight surprise the bites of food that Chris shoves toward his mouth.
- The many, many things wrong with this scene should be obvious, but first and foremost is Chris’s assumption that because Steve was eating with his fingers, he needed to be hand fed. There is no indication that giving Steve food precut into bite-sized pieces and cueing him with a fork in his hand might be all that’s needed. Hand feeding a person can be very embarrassing for the person, and needs to be done tenderly and sensitively. It is also generally needed only at the end of life or for a limited time after a traumatic illness. Steve seemed to have a hearty appetite and be able to manage perfectly well on his own, even if he wasn’t very neat or mannerly.

## Scene 4: A resident goes “shopping,” collecting things that are not hers

- In this scene, a resident (we'll call her Margaret) is pushing her wheelchair down the hall and into various rooms, collecting anything she finds appealing and placing it on her wheelchair. Within a short time she accumulates a large envelope taken from an in-house mailbox, a lei, a visor, a feathery item she wears as a bracelet, (all of these from an activity director's office), various supplies taken from a file cabinet loaded with nightgowns, gloves, wipes, etc., and a teddy bear taken from another resident's room.
- As she exits the resident's room, an aide stops her, saying, “Where'd you get that stuff?” Margaret says, “I found it. It's mine. It's nice.” The aide says, “I'm going to have to take it. It's not yours.” Margaret says, “No! It's mine. I like it. I want it.” The aide persists, “I'm sorry. All this stuff has to go; it's not yours,” and begins picking it all up. Margaret is at first angry, insisting it's hers and trying to pull it away from the aide and hits her on the arm when she keeps trying to take it away. The aide says, “You took it from other people's rooms.” Margaret says, “Give me that back!” The aide unfeelingly answers, “It's not yours,” and keeps picking it all up. Margaret says, “But I like it. I want it.” The aide keeps saying, “No,” and finally walks away with all of it while Margaret starts to cry.
- People with dementia frequently “go shopping” in other people's spaces, looking for interesting things. It's a phase, and not everyone goes through it. (Some people go rummaging through other people's things without taking anything. They are looking for something specific, but can't often tell you what it is.) There are many ways to deal with it, in part by keeping an eye on the person and giving her (usually a woman) some safe places to do her shopping. Some residences have “stations” where women can pick up hats, shawls, jewelry and perhaps other items of clothing. Others might have a kitchen-like area or fashion or decorating magazines for the taking.
- In this scene the aide did almost everything wrong. (On the positive side, she didn't react to Margaret hitting her and she never raised her voice.) She accused Margaret of taking things that weren't hers. (Once they reach a certain stage, many people living with dementia don't have a sense that anything they see is not “theirs.” Plus, you've told them over and over that this is their home now. Whatever is in one's home is theirs, right? And the room with the teddy bear had a welcome wreath on the door. Isn't that another reason to believe the teddy bear could be hers?) The aide gave Margaret no options except to give all her collection back, and she forcefully took it all away. She didn't distract her with food or drink or something more interesting to hold or another activity. Nor did she try to comfort Margaret or admire anything that really was one of Margaret's belongings.

## Scene 5: A woman is taken to be bathed against her will

This is really two brief scenes: 1) A resident (Nancy) is wheeled down a hallway wrapped in sheets and taken into what is supposed to be a bathing room where we only hear the action, and 2) the actor playing the resident describes how she felt playing that role.

- In spite of what has been a 20-year attempt on the part of several advocates for more humane bathing practices in residential care settings, the opening scene – in which a protesting woman is being wheeled down the hall where all can see her wrapped only in sheets – is still all too common.
- The discussion of how to make bathing a pleasurable experience that maintains the comfort and dignity of the resident being bathed is definitely worth having. There are many resources to help you brainstorm solutions if your residence has not yet introduced person-centered bathing practices.
- The primary purpose of these scenarios, however, is to find solutions to bad communication practices. Two things happen in these two scenes.
- One is that Nancy is obviously uncomfortable and frightened by the prospect of bathing. By completely ignoring her protests, the aide is heightening her fear and likely creating fear of bathing for anyone within hearing (which could be everyone in the building). There is no reasoning with fear. The first response must be to calm the person. What will calm her? It varies by individual, but certainly stopping to listen and acknowledge the fear is the first step.
- The second thing happening is that the shower chair Nancy is being pushed down the hall in – as she says in her evaluation of the scene – “feels like a toilet.” That type of shower chair *does* have a sort of toilet seat so that the resident’s private parts (perineal area) can be more easily washed. As any aide can tell you, the seat in combination with the running water of the shower often stimulates people to urinate (and sometimes defecate). The idea of asking a person to wait until after her shower to go to the bathroom is unrealistic and unfair to any resident (especially female residents who often have bladder control problems anyway). When the aide tells Nancy to wait until after her shower to use the bathroom and she is unable to do so, the aide embarrasses her further by saying, “Oh, look what you did.” Nancy is not only ignored when her request to use the bathroom is denied, but is then blamed when she couldn’t “hold it.”
- In her after-the-scene interview, Nancy was articulate in her outrage that her discomfort was ignored. She really did find the shower chair uncomfortable and she could readily understand the fear a person who has about to be showered against her will might feel. She said she felt like an object, just part of the aide’s job duties that had to be performed at a certain time. “I am a person. I should be listened to. I should be honored in some way. Ask my permission to do certain things.”