

Fear of Retaliation Video Script - Barbara

Background Only

Barbara is a woman with COPD (chronic obstructive pulmonary disease). Physically, she clears her throat fairly often and sometimes pauses to catch her breath or coughs lightly. She uses a nasal cannula and oxygen to help her lung function. Barbara has a small apartment within a CBRF where she has lived for the last 3 years. As her COPD gets worse, she finds it more and more difficult to walk even short distances or care for herself and her surroundings. As a result, Barbara has become anxious and depressed.

B=Barbara

IM=Interviewer Mike

IM: Good morning, Barbara. Thank you for agreeing to this interview.

B: You're welcome. I hope I can be helpful.

IM: I'm sure you can. As we talked about earlier, I'd like to learn a little more about how it feels to be cared for by others.

B: Well, in some ways, it's very nice. The caregivers here are usually very responsive and have been good to me. But they're also very busy and have many others to help so they're not always available.

IM: You said "in some ways" it's very nice. Is there a reverse side to that?

B: Oh...I guess the worst thing is the waiting. I'm always waiting for someone—to help me get dressed or push my wheel chair to the activity room. I love to knit, you know? I'm working on a knitting project with some other ladies and really enjoy it. But you have no idea what it feels like to be forced to wait on someone else to help you when you're used to doing things for yourself.

IM: I imagine it's very hard. What other kinds of help do you get?

B: The nurses bring my meds to me every day. I don't like taking so many medications so sometimes I refuse to take one or two. I don't think it makes a difference really.

IM: What happens when you refuse your medication?

B: One day last month, the nurse told me that if I didn't take my medication, I could get even sicker. When I started to cry, she told me she didn't want to see any tears. She said she was leaving for a while to give me some time to think about that. I felt like a 2 year-old being given a time out.

IM: What happened after that?

B: I've lived here long enough to know about the resident council. It's a place to talk to other residents and get help when something seems wrong.

When I first came here, I never wanted to cause any trouble or make more work for the staff. But I know now that this is MY home and the caregivers are here to help me with what I need.

So, I went to the next resident council meeting and told them about the incident with the medication and how the nurse treated me.

IM: How did it turn out?

B: The other residents encouraged me to speak to our administrator—her name is Beth-- so I did. Beth made the nurse who scolded me come and apologize. The nurse told me she was feeling very stressed that day. She said she was sorry for treating me like a child.

The administrator also made sure I got an appointment to see my doctor about my medications. He actually agreed that I didn't need one of the meds. He also went over the purpose for all the others. I felt better about taking my meds after that...but I still refuse them once in a while. It's about the only thing I have any control over.

IM: Is there anything else you'd like to share?

B: I just want caregivers...the CNAs and the nurses...to remember that they're here to do a job like anyplace else. It's like I'm their customer. If they thought of me that way, I think they would understand what I mean. I worked in retail for over 20 years. I didn't always like my customers, but I needed to be polite and professional if I wanted to keep my job. I had to leave my personal problems at the front door.

Don't get me wrong...most of the staff here are really helpful. But they have so many demands on their time. If I can understand that, then they should be able to understand my point of view also.

IM: Thank you very much, Barbara.

B: You're welcome. Thank you for the chance to vent a little.