

# Everyday Choices

*ethics and decision-making in home care and community nursing*



## Study Guide

# Everyday Choices: *Study Guide*

## INTRODUCTION

Visiting nurses and others who work in home care and community settings often play complex roles in the lives of their patients. In such situations, nurses may confront personal and ethical dilemmas that challenge their sense of themselves and their professional responsibilities.

This video follows a single case, focusing on the relationship between a young RN, who is employed by a regional Visiting Nurse Association, and just one of the many patients on her case load. In dealing with Gerardo, Allison encounters a number of issues that concern her, as well as others that may occur to viewers of the film.

The video is not meant to provide answers to the issues it raises. It recognizes that in most cases there *are* no easy answers. Rather, by allowing viewers to share to some extent in Allison's experiences, it invites them to explore and discuss their own responses to these questions.

## BACKGROUND

Allison is a Registered Nurse who has been working for the Visiting Nurse Association of the Pioneer Valley, located in Springfield, Massachusetts, for only a few years – since graduating from nursing school. She is simultaneously working on a graduate nursing degree at a nearby university. She has chosen to work in home care because she values direct, ongoing patient contact, and because she prefers to work in the community rather than in a hospital environment.



Gerardo, as indicated in the film, is a 75-year-old gentleman who immigrated to the United States from Spain as a young adult. He was married and has two daughters, one of whom

lives nearby. His wife died several years ago. He also has a grandson who was primarily raised by Gerardo and his wife, and whom Gerardo sometimes refers to as his son. The grandson also lives nearby. Gerardo receives Visiting Nurse services twice daily, to care for a variety of health problems, the most important of which are high blood pressure and diabetes. He is also receiving medication for depression.

Gerardo lives in a public housing project with his sole companion, his dog, Linda. Although he has been receiving housekeeping services from another agency, he has sometimes refused to allow the home health aide into his apartment (or simply not been there when she arrives). Other



tenants in his building have complained about cockroaches and odors, because of his inadequate housekeeping and failure to take proper care of Linda. Gerardo has been threatened with eviction, but a recent lease termination was put on hold after Allison and her supervisor promised to work with him to make sure that he accepted housekeeping services, and also to arrange for a second neuropsychological evaluation to determine his competence.

To date, Gerardo has been considered to be legally competent to make his own decisions – or, at least, no one has taken the initiative to have him declared legally *incompetent*. He is clearly experiencing some form of progressive dementia, however. He has problems with short-term memory (cannot remember what medications to take or which ones he has already taken, for example) and has limited understanding of his medical problems. His long-term memories are a sometimes entertaining mix of the (probably) real and the fabulous or at least improbable. Most important for purposes of the film is his conviction that his past and present health problems have been caused by a person he sometimes describes as a witch or a devil, or as a "midget man," who has put some kind of a curse on him. He frequently talks about ways he would like to take revenge on this person.

Gerardo values his independence and has several times refused suggestions that he consider alternative living arrangements. This is further complicated by the fact that there are few if any options where he would be able to keep Linda, who at this point is his primary, and much loved, companion.

He has two cars, and drives regularly to fast food outlets, to visit a friend he refers to as "the French Lady," and to his night-shift job as a security guard at a car dealership. To the extent of his mental abilities, he appears to be a careful (though very slow) driver. However he has very poor reaction times, cannot remember directions to places he does not habitually visit, and sometimes seems unaware of other drivers.

## SUMMARY OF THE VIDEO

*Everyday Choices* begins during Allison's daily visit to check Gerardo's blood sugar and blood pressure, deal with his pills, and deliver his insulin. In an interview, she discusses the fact that his living independently poses risks both to himself and to others, and wonders whether she ought to be helping him to maintain his independence or should be



pressing for him to move to a safer environment.

The manager of Gerardo's housing project indicates that a notice of lease termination (eviction) was issued to Gerardo because of complaints by other

tenants. Denise Perlaky, the VNA's Geriatric Resource Coordinator, describes how she and Allison were able to persuade the Housing Authority to hold off on the eviction.

Allison reminds Gerardo that he has an appointment that day with a neuropsychologist. This will be Gerardo's second appointment with Dr. Clionski, but he does not remember having been there before. He says that he wants to drive, rather than take the taxi Allison has arranged. In her interview, Allison discusses her fears about his driving, and about his job as a security guard, and wonders whether she should be doing something more concrete to intervene. She also mentions that, as part of helping him maintain his independence, she sometimes has to remind him to feed Linda, and to take her outside. (In the film, we see a brief shot showing urine-soaked newspapers in Gerardo's hallway, after he has forgotten to take her outside.)

At the office of Dr. Mitchell Clionski, we see the neuropsychologist administering portions of a standard mental competency test and then telling Gerardo that he should not be driving a car. Gerardo protests that he has been driving for 40 years with no accidents, but Dr. Clionski says that his driving is a danger to himself and to others, and that he has so noted in a report to Gerardo's doctor. We next see Gerardo visiting his primary physician, Dr. Jeff Scavron, who works at a neighborhood clinic near the housing project, and who also raises issues about Gerardo's driving and his job. Despite Gerardo's obvious rapport with Dr. Scavron, the message does not seem to be getting through.

Allison and Denise meet informally with Sylvia Wilson, the VNA's Clinical Supervisor. Denise points out that Gerardo's family have so far not been willing to take any steps to interfere with his driving. She says that VNA staff could pressure him to take a road test, but wonders whether he might pass it. She also questions whether this is the nurse's responsibility, in a situation where family members are not willing to take the initiative.

Allison has asked for a chance to discuss her concerns about Gerardo at the VNA's monthly ethics rounds. In the course of this meeting, various participants raise issues about both the legal and the ethical responsibilities of VNA staff, and of the organization itself, *vis-a-vis* the neuropsychologist, the primary physician, and other parties involved. They also discuss the possibility that a family meeting might be arranged to try to get the grandson to take a more active role.

In an informal staff discussion with Allison and Denise following ethics rounds, Sylvia notes that Allison's close involvement with this patient might be problematic, in part because changes in circumstances might mean that she would no longer see him. Shortly after this meeting, Allison is laid off as part of a major staff reduction at the VNA.

Following a third interview, Dr. Clionski, the neuropsychologist, says that he feels Gerardo is no longer capable of making his own decisions, but that as a consultant there is nothing he can do to act on this conclusion – it is something best dealt with by the family or by "one of the public agencies" who could seek a guardianship arrangement.

We next see Allison, on her own time, visiting Gerardo in a nursing home, where he has ended up following minor surgery. (At this point he is no longer on the VNA's caseload.) We learn that, even though Gerardo has been refusing his insulin and blood pressure medications, the nursing home has not taken steps to deal with the guardianship issue. Transferred to a rest home, Gerardo leaves, without his medication, and stays with the "French Lady" until he is hospitalized again, this time for liver cancer.



Allison accompanies Gerardo's daughter, Nancy, to the hospital, where Gerardo is unconscious following surgery. Allison comforts Nancy, who feels she has made the wrong decision in authorizing surgery. Allison says she regrets that Gerardo will die this way, in the hospital, and comments that she "can't do this job and not be attached...I care about all my patients...That's a big part of it to me."

## NOTES FOR DISCUSSION LEADERS

Before discussing some of the more specific questions raised below, it may be worthwhile to spend a little time airing viewers' general reactions to the video. What do they feel about Allison, Gerardo, and the others in the film? Do they understand what is going on in all the scenes? Do they feel the issues are clearly presented?

**It may also be interesting to ask viewers what *they* think are the major issues or questions raised by the film: If they were in Allison's position, what problems would they be focusing on?** Since the suggested questions below are probably far more than can be dealt with in a single session, knowing what's on the minds of audience members may be helpful in guiding the discussion.

## QUESTIONS FOR DISCUSSION

Allison knows that independence is very important to Gerardo, and that driving and working are an important part of his self-image. She also knows that his increasing dementia makes these activities potentially hazardous both for him and for others. A similar issue, though perhaps less critical, is the fact that his independent lifestyle may be creating problems for others in his building.

- What are Allison's responsibilities as Gerardo's visiting nurse? In fact, does she have *any* responsibilities beyond those directly related to his healthcare?
- Is she fulfilling her responsibility to advocate for her patient by supporting the activities and living situation she knows he prizes.
- To what extent is Allison contributing to Gerardo's risky behavior (as opposed to simply tolerating it)? Do you feel she would have some responsibility if, for example, he were to injure a pedestrian, or start a fire in his apartment, or have a diabetic crisis while at work?
- Allison and Denise have intervened to prevent Gerardo's eviction from public housing. Do you feel this was appropriate on their part? Having done so, what responsibility do they have for whatever consequences may follow? If Gerardo had been evicted, what housing options do you think would have been available for him? (Note: apparently living with a family member was *not* an option at that time.)
- Is there a difference in Allison's responsibility with regard to situations in which she might be viewed as *abetting* Gerardo's behavior (making it possible for him to live alone in his apartment) versus situations in which she simply fails to *intervene* in his behavior (driving and working)?

- Allison wonders whether she should "do something more drastic to completely ensure that he's not driving – something to his car, or something with his license..." And, later, she says about his working, "I don't know if I should try to pursue that with his employer..." What are the "more drastic" steps you imagine Allison might take? What would you consider doing if you were in her place?
- What are the ethical issues she would need to consider? Might speaking with Gerardo's employer, or reporting him to the licensing authorities, raise issues of patient confidentiality? What ethical concerns (not to mention legal risks) might be involved in a decision to do "something to his car?"

Allison mentions that, as part of promoting Gerardo's independence, she sometimes has to help him with caring for his dog, Linda: "If I remind him to feed her, or take her out for a walk, and maybe put the leash on her and as I'm leaving sort of lead him by the hand down with me, that's not that much extra. That's part of caring for him and making sure that he's happy..."

- Do you think that helping with such things as pet care is normally part of a Visiting Nurse's responsibilities? Does it help to establish an effective therapeutic relationship between Allison and Gerardo? In Allison's place would you provide this kind of help?
- Denise talks about the heavy workload that VNA nurses carry. Do you think Allison has time to give this kind of personal attention to all patients? If not, how do you think a nurse should decide which patients should receive extra help or attention?
- During a prior hospitalization, Allison knew that Linda was alone in Gerardo's apartment, unfed and un-walked. She wondered whether she should take the dog home or arrange some kind of temporary place for her. What would you have done? What are the values and/or problems in doing something good but "extra" (supererogatory) for a patient?
- Discuss your view of the professional role of the Visiting Nurse in the context of the various activities you see Allison carrying out in the course of the video.



At an earlier appointment, Dr. Clionski performed a variety of tests to evaluate Gerardo's mental abilities. On this visit, he advises Gerardo that he should not be driving, and says that he will be writing this advice in his report to Gerardo's doctors. Dr. Scavron, Gerardo's primary physician, also advises against driving. Yet neither doctor directly raises the question of overall mental competence – and neither takes any action to force the issue. Denise Perlaky notes that Gerardo's family are unwilling to interfere with his driving. Speaking about the possibility of a road test, she asks, "Who's going to take him down there? He needs cueing to get to places. Certainly that's not the nurse's role, but whose role is it when the family won't do it?"



- As long as Gerardo is legally competent, he has the right to make his own decisions about where to live, whether to drive, whether and where to work. Based on what you have seen and heard in this film, do you feel that Gerardo is capable of making his own decisions about his health and life? Why or why not? Do you think it is the nurse's responsibility to respect his decisions.
- Do you know what the criteria are for assessing patients' decision-making capacity? Do you know how someone can be declared legally incompetent? Who should, or can, take the initiative? (Criteria for competence are generally consistent from state to state, but there may be some variations.)
- If someone is not legally competent, a guardian must be appointed to make decisions for them. Often this is a family member, but in this case the family were unwilling. What do you know about guardianship procedures in your area? Why do you think the various parties involved did not take the step of seeking guardianship for Gerardo? Note that in a later discussion, Denise says "Nobody wants to address it because it's so expensive." Do you know what costs are involved in guardianship proceedings? Who bears those costs?
- In this film there are a number of individuals or organizations who *might* have addressed the guardianship issue: Gerardo's family members, Allison (or any of the other nursing staff who work with him), the VNA as an organization, Dr. Clionski, Dr. Scavron, the nursing home where Gerardo stays after his first surgery, or the hospital where he has both surgeries. Given that the family were unwilling to act, what do you think the various professionals and organizations should have done? If you can imagine yourself in Allison's position, what do you think you would have done?

Allison takes Gerardo's case to the VNA's Ethics Committee for discussion. Ethics Committees of this type are a fairly recent innovation. Though not specifically identified in the video, the participants in the Committee meeting include several members of the VNA's staff and administration including its Director, an attorney, a clergyman, and representatives of the community. Ethicist Molly Noonan, who leads the discussion, is an outside consultant.

- Do you have any experience with ethics committees? Based on your experiences, or on what you have seen in this video, what do you think about how useful they might be? (Keep in mind, of course, that the video only shows a small portion of a much longer discussion.)
- What do you think is the purpose of this meeting: sharing information, clarifying issues, providing emotional support, making decisions, avoiding legal liability, or...?
- What are the advantages of sharing concerns like these with people who have different experiences and perspectives? Do you feel that this meeting is helpful to Allison? To what extent might it be helpful to others on the VNA staff.

Following the Ethics Committee meeting, Allison meets informally with Denise and Sylvia, who are her superiors at the VNA. In response to her comment that she sometimes feels "in quite a difficult situation in terms of having such influence over him," Sylvia says, "That can be problematic... we have to be careful with that. Sometimes supervisors have to step in and say you need to move back a little bit and look at what's happening."

- What do you think Sylvia means here? What kinds of problems is she referring to?
- Do you feel that Allison is over-involved with this patient? What practical or ethical risks may arise from excessive involvement or attachment? Do you think Allison would be more or less effective in caring for Gerardo if she were less involved?
- Denise also says: "Maybe he does have to go into a nursing home, and then you're not there anymore... because he's no longer on VNA service..." This speaks to a broader issue about continuity of care for patients who may be receiving services from a continually shifting array of public and private agencies. How much do you know about the various agencies who may be responsible for patients living at home in your area? How do they handle the issue of continuity of care?
- In general, what do you think is the appropriate or ideal level of attachment or involvement for a nurse working with patients in the community?

- Soon after this discussion we learn that Allison has been laid off. If continuity of care is important to patients, what responsibility does the VNA have toward its clients? How does an agency like this weigh such responsibilities against its budgetary realities?

After his third meeting with Gerardo, Dr. Clionski, the neuropsychologist, concludes that he is no longer able to make his own decisions – i.e., no longer competent. "As his nurse," he says, "I'm not sure that Allison can do very much except advise him, unless she wants to personally go out on a limb and say that this is something that should be turned over for guardianship."

- What could Allison, or the VNA, do about the guardianship issue? How does anyone go about initiating such procedures? Is Dr. Clionski correct that Allison would be going "out on a limb?"
- Dr. Clionski also says that "We go to great lengths in our society to ensure personal freedom...Until that person does something really horrendous... there's nothing you can do." Discuss your feelings about freedom, independence, and responsibility in the context of what you have learned about Gerardo. What are, or should be, the limits of personal freedom in a case like this?
- Allison has learned that Gerardo has been refusing to have his blood pressure checked or to take his insulin while at the nursing home – clearly placing his health and even his life at risk. Does this signal a further decrease in his level of competence? Should it trigger a more aggressive effort toward guardianship? Should the nursing home staff have forced him to take his medications?
- As long as he is considered competent, Gerardo is free to refuse medical treatment, including his insulin. Yet it is well known that the blood sugar "highs" and "lows" of uncontrolled diabetes themselves can cause mental confusion. Taking this into account, would nursing home staff be ethically justified in forcing him to take his insulin? Would they be legally permitted to do so?

In the final scenes of the video we see Allison accompanying Gerardo's daughter to the hospital to visit him, and comforting her when she is upset over her fear that she made the wrong decision in allowing his cancer surgery?

- Nurses working in home care may often develop ongoing relationships with other members of their clients' families. What do you think are the risks and benefits of such relationships? Does Allison's concern for Nancy interfere with, or complement, her primary responsibility toward Gerardo?
- Since Allison has been laid off, she actually no longer has any "official" responsibility toward Gerardo or Nancy, though she obviously feels a strong connection. What responsibility do you think a nurse has toward *former* patients?



As the film closes, Allison says "I can't do this job and not be attached. I don't really think anybody can. He was a special one to me, but I care about all my patients. I mean, I really get to know all of them – that's a big part of it to me..."

- Discuss this statement in relation to your understanding of the professional role of the nurse, and of your own experiences in dealing with patients. To what extent is detachment possible or desirable? When does attachment become a problem?