

**Spotlight****“It All Falls on Me”****Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction**

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Martin Simmons is a retired sales manager taking care of his wife who has Alzheimer’s disease and other chronic conditions.\* He finds managing his wife’s medications very difficult:

*I’ve been researching to try to find out what all these medications are for. I know one is for thyroid, and another one for blood pressure, but I’m not sure about all of them. A couple of times I have gone to her doctor and said, “She’s been dizzy these last couple of weeks. When she gets up every day, she’s dizzy.” So I said, “Could it be the [medication name]?” And he said, “No it’s not the [medication]. It doesn’t have that side effect.” Then I was listening to a commercial, and it said [medication] might make you dizzy, so I said to myself, “Probably that’s what’s doing it.” So, I stopped giving it every day and just gave it every other day, and the dizziness stopped. I try to coordinate with the doctor, but the doctor’s not very hands-on.*

Mr. Simmons is not alone. He was one of several family caregivers who participated in a series of discussion groups organized by the United Hospital Fund’s Families and Health Care Project who described medication management as challenging.

\* All family caregiver names and other personal information in this report have been changed.

The AARP Public Policy Institute contracted with the United Hospital Fund to conduct these discussion groups as part of a larger initiative known as the *Home Alone Alliance*<sup>SM</sup>. This initiative seeks to bring together partners from public, private, and nonprofit sectors to strive for sweeping cultural change in addressing the needs of family caregivers. One way this will be accomplished is through the development of instructional tools and resources to help family caregivers gain the skills and confidence to perform complex medical/nursing tasks.

Before developing a series of *Home Alone Alliance*<sup>SM</sup> instructional videos to fill the gap in this area, the AARP Public Policy Institute wanted to ground the work in the perspectives of family caregivers. The discussion groups were designed to hear directly from family caregivers about their experiences with two common and challenging tasks—managing medications and doing wound care—and to ask

For more information on this article, please visit [www.aarp.org/ppi](http://www.aarp.org/ppi). For more information on United Hospital Fund, Families and Health Care Project, please visit [www.uhfnyc.org/initiatives/family-caregiving](http://www.uhfnyc.org/initiatives/family-caregiving).



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them about what they would like to see in terms of video training for these tasks. This report describes the themes of the discussions and puts this effort into a larger perspective. It offers several ways to meet family caregivers' needs for information and support, with the ultimate goal of improving outcomes for their family members and themselves.

### **“Home Alone”: The Starting Point**

The immediate impetus for this project was the publication of a joint AARP Public Policy Institute-United Hospital Fund report in December 2012 called “Home Alone: Family Caregivers Providing Complex Chronic Care.”\*\* This report was based on a nationally representative survey of family caregivers who provided “medical/nursing tasks” such as managing medication, wound care, operating equipment, and other tasks. Almost half (46 percent) of the family caregivers reported doing one or more of these tasks. Despite frequent contact with hospitals, emergency departments, and doctor’s offices, family caregivers were seldom adequately prepared by health care professionals to take on these challenging tasks.

In addition to these tasks, they also reported providing help with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), and often served as the patient’s primary care coordinators; they had little or no help at home. Not surprisingly, these family caregivers reported high levels of anxiety and stress. Subsequent analyses of three subgroups (employed caregivers, spousal caregivers, and caregivers of people with cognitive or behavioral conditions) showed that these groups were doing the same tasks as the full survey sample and were especially stressed.

While the findings confirmed what many professionals and family caregivers knew firsthand, others who believe that family caregiving is mostly personal care and household chores were

surprised and shocked. Some action was clearly needed. Starting in March 2015, United Hospital Fund conducted a series of activities over nine months in order to guide AARP PPI’s development of instructional videos intended to better train family caregivers to manage complex medical/nursing tasks and to provide teaching tools to health care professionals. Better training is one way to help reduce the stress associated with challenging caregiving tasks.

Videos can be an important vehicle for instructing family caregivers. They are easy to access and use, can be reviewed many times, and offer both visual and spoken information. But understanding the target audience, developing the appropriate content, and creating engaging videos are critical to their effectiveness.

Many caregiver videos available today focus on stress reduction and other aspects of self-care, managing personal care and household chores, family dynamics, financial matters, and similar topics; all are important, but these videos do not address the kinds of challenges documented in “Home Alone.” A United Hospital Fund review of current training materials found relatively few that addressed medical/nursing tasks—and then only in generic ways; some simply featured adaptations of training intended for nursing students or paid home health aides. They used idealized care settings and healthy volunteers acting as care recipients. Some used plastic dummies to represent body parts. These videos did not acknowledge the emotional component of providing care that may be painful, embarrassing, or stressful to a family member, not a “patient.” The videos did not reflect adult learning theory, which values the learner’s prior experiences, addresses the learner’s goals, and incorporates different learning styles.

To narrow the topics for the first series of videos, United Hospital Fund discussed the possibilities with the AARP PPI advisory group. Medication management was a unanimous recommendation, with wound care a close second. Other areas, such as mobility, were recommended for future video development. The advisory group also reviewed a

\*\* S. Reinhard, C. Levine, and S. Samis, Home Alone: Family Caregivers Providing Complex Chronic Care (Washington DC: AARP Public Policy Institute and the United Hospital Fund, October 2012) <http://www.aarp.org/homealone> and <http://www.uhfnyc.org/publications/880853>.

discussion guide prepared by United Hospital Fund (Appendix I).

## Preparing for the Discussion Groups

### Literature Review

United Hospital Fund reviewed literature on video instruction for patients and caregivers to identify relevant themes for this project. Very few articles or reports specifically addressed the needs of family caregivers; most assumed that a patient, nursing student, or home care aide was the primary audience. When the video was apparently aimed at the caregiver, that person was seldom seen or heard. With the guidance of Felise Milan, MD, an expert in adult learning theory and communication techniques at Einstein Medical College in the Bronx, United Hospital Fund also reviewed articles on topics related to adult learning theory, instructional videos, and principles of teaching procedures.

### Identification of Videos on Medication Management or Wound Care to Show at Discussion Groups

United Hospital Fund staff reviewed many videos to identify those that addressed medication management or wound care. Most of the videos were aimed at patients or at student nurses or aides. During the discussion groups, we showed clips from three or four of these videos, including videos in Spanish and Chinese for those audiences. These clips served not only to stimulate discussion about the video content and presentation style but also to elicit from the participants what they felt was inaccurate, missing, or unrealistic.

### Outreach to Community-based Organizations (CBOs) to Recruit Participants for Discussion Groups

To identify a diverse group of family caregivers, United Hospital Fund contacted several CBOs and one medical center for recruitment. These groups recruited participants and hosted the sessions:

- Alzheimer's Association, New York City chapter (mid-Manhattan); now CaringKind
- Sunnyside Community Services Caregiver Support (Queens), Spanish-speaking family caregivers
- Chinatown NORC (Naturally Occurring Retirement Community)/Visiting Nurse Service of New York (lower Manhattan), Chinese-speaking caregivers
- Montefiore Medical Center Caregiver Resource Center (Bronx)

Other CBOs were contacted, and staff members were eager to participate but were unable to recruit enough participants for a group session. The family caregivers from those groups who responded positively were combined into two groups held at United Hospital Fund offices.

United Hospital Fund created a fact sheet for each CBO, which the agency staff could then distribute to potential participants. (A sample fact sheet is included in Appendix II.) The participants were offered a stipend of \$40 to thank them for their participation, and refreshments appropriate to the hour were provided. Each session lasted 90 minutes; in all the sessions, participants stayed longer to talk to each other, United Hospital Fund staff, or the moderator.

### Implementation of Discussion Groups

Six groups involving 33 participants (20 women, 13 men) were held. Most participants were caring for a parent or spouse, although several were caring for or had cared for more than one person. One was caring for a friend, another for a partner. Two caregivers brought their family members with them (a mother and a husband), and both participated in the discussions. One caregiver brought her mother's home care aide, a distant cousin, with her. The groups ranged in size from three to eight. Participants' ages were not obtained, but they ranged from young adult to over 65. They were all caring for adults, including several whose family members were in their late 90s or over 100. Ethnicity was not recorded (except for the Spanish- and Chinese-speaking groups); among the others, an estimated two-thirds were Latino or African-American. Socioeconomic status was also not recorded; none of the participants spoke about severe financial constraints.

Two of the groups—Spanish-speaking and Chinese-speaking caregivers—were conducted in the participants' preferred languages. Notably,

### Moderators, Consultant, and Staff

**Ann Wyatt** moderated three English-language discussion groups. She is a social worker and consultant to the New York City chapter of the Alzheimer's Association (now CaringKind) who has worked with United Hospital Fund on many projects involving family caregivers.

**Guillermina Altomonte** moderated the Spanish-language discussion group as well as one of the English-language groups. She is a PhD candidate in sociology at The New School in New York and a former journalist in her native Chile. She has extensive experience interviewing caregivers for her dissertation.

**Carol Levine**, director of United Hospital Fund's Families and Health Care Project, co-moderated the Chinatown NORC/VNSNY group, with **Hing Lin Sit** (known as Helen), and **Maggie Ng** of the Chinatown NORC and Visiting Nurse Service of New York. Carol's comments and questions were translated by Helen and Maggie, and the participants' responses were translated into English. A few of the participants responded partly in English and partly in Chinese, and these comments had to be fully translated into Chinese for the rest of the group.

**Felise Milan, MD**, professor of clinical medicine at Einstein College of Medicine, was a consultant to the project on adult learning theory and communication skills. She is director of the Clinical Skills Center, and she teaches first- and second-year medical students in the Introduction to Clinical Medicine programs. Her academic interests include teaching communication skills, psychosocial and behavioral medicine, and complementary/alternative medicine. She attended one discussion group as an observer.

**Deborah Halper**, United Hospital Fund vice-president for education and program, supervised the activities. **Carol Levine** was assisted by **Kristina Ramos-Callan**, program manager, who coordinated all the groups, audiotaped the sessions, prepared the consent forms and stipend receipts, and prepared summaries of the discussions.

the Chinese-speaking group was the largest (eight participants, five of them men), and the Spanish-speaking group had seven participants.

All discussions were audio-recorded, with participants' written consent.

### Themes of Family Caregiver Discussion Groups

At the outset of this project, we anticipated that the discussions would focus on the specific tasks involved in managing medication and doing wound care—the “how-to’s” of these tasks. While these aspects of caregiving did emerge, family caregivers were more interested—even eager—to tell their personal stories. These stories painted a picture of failures of health care providers to give participants basic information about caring for their family member or friend, even when the caregivers asked, and demonstrated how caregivers had to find their own way to learn the complicated and often frightening jobs they were doing.

While most recent research and policy attention has been focused on the risky transition from hospital to home, primarily in the context of reducing avoidable hospital readmissions, most of the participants' stories revolved around care in the community. Community providers included primary care physicians, home care nurses and aides, and pharmacists. A few participants mentioned hospital staff (physician specialists in the case of life-threatening illnesses) and nurses as an initial source of information. The following themes were articulated by participants in all the groups, to a greater or lesser degree.

#### Theme 1: Emotional Impact of Caregiving

Emotional responses to caregiving (sometimes related to the task, often to the whole experience) were common in all the groups. The emotions included sadness because of the family member's declining health and well-being, frustration in trying and failing to get appropriate information from health care professionals, fear of making a mistake in medications, anxiety about managing all the aspects of care, isolation from friends and family, and anger at feeling abandoned by doctors. The emotions ranged from annoyance to existential despair.

None of the videos we found recognized this

*I'm the only one taking care of my wife [who has advanced cancer]. I'm with her 24 hours a day, 365 days a year. When she goes to that dark side, because of the chemo—it totally wipes her out—and says she wants to end her life, it all falls on me to bring her back. There's no other person—a daughter, a son, uncle or aunt, somebody else who can talk to her. I just wish we had more of a family around us; it would make things a lot easier. My wife would have the benefit of different opinions, different people talking to her. She only comes to me, and I have to be everything to her, and sometimes I run out of things to say. There are times when I'm happy, when my wife is sad, where I feel guilty that I'm happy and she's sad. When I come back from a little exercise, a little biking, feeling good, I have to adjust my mood according to hers so I have to bring myself down. I haven't wanted to be happy, because when she's not happy, I don't want to be happy. It affects me a lot.*

—George

*He's been in the hospital about 18 times over the past two years. Leaving the hospital the first time was particularly scary because he came home with drains from his wounds. They had to be cleaned frequently. I had a few lessons in the hospital, but I wasn't prepared for doing it myself when we came home. I knew the procedure, but nothing prepared me for seeing his open wound and having to clean it. I was scared, really scared.*

—Jackie (caring for her husband who has cancer)

important component of the experience of learning to do medication management or wound care—or caregiving in general. People whose heightened emotional state is not recognized are less able to pay close attention to instruction and are more likely to forget what they have been taught. This is well recognized in the case of patients who cannot remember hospital instructions but is less well studied in the case of family caregivers.

Caregivers' stories were powerful and compelling, not just in the content but in the manner of narration. For many, it was the first opportunity to

tell their stories to a group of peers and attentive outsiders. In each group, caregivers listened carefully to each other as they spoke, offered support (and tissues, in the case of one caregiver who began to weep), and generally created an atmosphere of compassion and consolation. Many thanked United Hospital Fund staff for organizing the group, even though we were the beneficiaries of their knowledge and experience.

It is important for health care professionals to understand and acknowledge the emotional aspect of caregiving—not just in the videos but in everyday practice. It is not possible to provide long-term and in-depth emotional support to family caregivers in the context of ordinary medical, nursing, or home care practice. But it is essential to acknowledge at the outset of an encounter that the caregiver has complicated and often conflicting feelings about his or her responsibilities. The first quote on the left illustrates a caregiver's overwhelming sense of isolation; the second conveys the anxiety that accompanies learning a new task.

*I found a better way to sort the medications than putting them into a pill box. I put each dose into a small baggie, label the baggie by what the pill is for, when it has to be taken, and so on. Then I put the small baggies into a big baggie for each medication. That way, the doses are always available and easy to take with you. It's a lot easier than a calendar or medication chart. I've told a lot of other caregivers about this, and they all think it works really well.*

—Amanda (caring for partner)

*I'm a college student, and I have to organize my life around my caregiving responsibilities. There are a lot of doctor appointments, especially for my mother and grandfather. I keep a color-coded calendar: one color for my mother's oncologist, another color for my grandfather's cardiologist, and still another for their primary care physician.*

—Tamara (caring for mother, grandmother, and grandfather)

**Theme 2: Caregivers' Resourcefulness**

At the same time, many family caregivers demonstrated how resourceful they had become out of necessity—and how they solved problems that no one had warned them about. They did this in different ways: finding alternate sources of information, trying out different ways of organizing and administering medications, and finding ways to cajole their family member into taking the medications.

**Theme 3: Problems with Medication Management**

Not surprisingly, several aspects of medication management arose in the discussions. While they are all related, for the purposes of the report, we have divided them into three themes: lack of information, family members' resistance to taking medications, and confusion about similar-looking pills.

*She had to get her medicine through a PICC line [peripherally inserted central catheter], and I had to clean it, put in the new medication, and repeat the process the next day. Then they changed the medication, and that meant the whole process had to be changed. A lady called to say, 'You've done this before, and it's the same thing.' But it wasn't. It was a much more complicated system. I was able to figure it out, but I don't think anyone else who wasn't used to putting equipment together would have been able to do it. They should have sent someone to show me how to do it, not just leave it to a lady on the phone.*

—Paul (caring for friend with multiple conditions)

**Theme 3A: Lack of information about medications**

Family caregivers in these groups looked to the person's doctors for information about medications. Many reported that doctors did not give them adequate information about changes in medications, including potential side effects. Even when caregivers reported a side effect, doctors often did not seem concerned. These caregivers had to find alternate sources of information—pharmacists, the Internet, package inserts—and adjust the dose themselves or even discontinue the drug. This theme was present in all groups, although

caregivers whose very ill family members were being treated by specialist teams were more likely to get information.

*I used to work in a hospital. That's where I learned to administer all sorts of pills. When mom was in the hospital, I noticed that whenever the nurse turned around, mom would spit the pill out. It was at that point I knew that I had to stand there and watch her swallow just to make sure she actually took the medication.*

—Artie

**Theme 3B: Family members' resistance to taking medications**

Resistance to taking medications was a common theme—perhaps influenced by a video shown during the session that depicted a frustrated granddaughter trying to get her grandmother to take her pills. But even before the video was shown, many caregivers reported difficulties getting their family member to take the medications as prescribed.

**Theme 3C: Confusion about similar-looking pills**

One of the specific issues related to medication management mentioned by a few family caregivers was the difficulty in making sure that the right pills were in the right slot in the pill box, because these medications were similar in shape, size, or color.

When one caregiver offered a tip on how he or she did something, other participants said that they would try that as well. Although the moderators probed for caregivers' ideas on what would help them, their answers were general, rather than

*It would be better if someone could show me how to make sure the pills I give my father are the right ones, because he has so many medications and all the pills look similar. They are all white, but some are bigger, some are smaller. I need a better way to tell them apart.*

—May

specific: “More information,” “someone to watch me do it,” “don’t ignore me.”

#### **Theme 4: Lack of Training on Wound Care**

Although fewer caregivers reported doing wound care, those that did reported some of the most serious lapses in training—for example, no training at all, one-time demonstration, failure to address infection control, and prevention of pressure sores. Some nurses came to the home and did the wound care but didn’t train the family; other nurses did show the family what to do at least once or twice.

*Alison: With my mom having amputations and lots of medications, I go to the pharmacy all the time. But I had never seen the wound-care aisle—the first aid aisle. So, I was wandering around and just found it. While she was in the hospital after having her surgeries, I would watch the nurses. They wouldn’t say, ‘Hey, come over here, let me show you how to do it,’ but I would just watch them. After watching what materials they used, I went to the pharmacy and bought those same things. I learned to buy the bandages, the wound washes, and I just bought anything that I thought would help her. She’s got a dresser full of that stuff now, but I had to just watch.*

*Moderator: But no one actually showed you? Or supervised you the first time you did it?*

*Alison: No. They didn’t say, ‘I’m going to teach you how to do this.’ I just watched.*

#### **Theme 5: Cultural and Language Differences**

We expected to hear more about how culture and language differences affected communication with health care professionals. These caregivers did not dwell on these differences, perhaps because they had found ways to work around them. Other family caregivers without ties to a CBO might have responded differently.

They did report specific cultural attitudes and practices, however. Many Chinese caregivers reported using traditional medicines as well as those prescribed by doctors. They described the different oils, ointments, and herbs that they use.

*When I came back from a trip to Hong Kong, my skin was very itchy. It bled when I scratched. None of the ointments doctors prescribed did any good. My mother said, ‘Try white vinegar. Dilute it in a gallon of water. It will help.’ And I used it on my skin for a few days and the itching started to go away. I continued to use it every time I took a shower, and everything cleared up.*

*[To moderator] You should try it on one hand, you will see the difference!*

–Chen

When the moderator asked whether their regular doctors ask about these medications, caregivers said no, and they don’t offer the information to doctors.

A Latino caregiver mentioned a reluctance to go to doctors as a cultural factor, and also the stigma associated with dementia.

The Spanish and Chinese caregivers wanted translations in the videos if the speaker used English. The Chinese caregivers differed on whether the video should be in Cantonese, Mandarin, or Fujianese, or all three.

*A lot of people [with signs of dementia] don’t want to go to the doctor. There is a lot of stigma associated with dementia. People will say, ‘La loca [the crazy lady].’ We need to talk more about this in our community.*

–Teresa

#### **Theme 6: Lack of Coordination among Health Care Professionals**

Only the group of caregivers caring for family members in advanced stages of illness (cancer, liver transplants) reported that the care was provided by a team, led by a specialist. For the other caregivers, community doctors were their primary contacts with the health care system. Nurses were involved in hospital care, and some came to the home a few times after discharge, but they were not seen as major sources of information about medications. Some caregivers reported

very quick training from nurses on wound care. Pharmacists were a valued source of information for those who had an ongoing relationship with them. Several of the Chinese-speaking caregivers mentioned home care aides but sometimes called them “nurses,” though they clearly were aides because they were limited in what they could do. Because nearly all the participants were recruited through a community-based agency, they had contact with an agency social worker. But in the discussion of medication management and wound

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*He was previously at another hospital where they said he had cirrhosis. I wasn't satisfied, and so I encouraged him to find a new doctor at a hospital closer to home. There they discovered he was very sick, and needed a liver transplant.*

–Barbara (caregiver for her husband)

*Every so often I get a phone call from a social worker at [a national advocacy organization] asking if I need anything. But when I tell her what I need, she doesn't do anything.*

–Sharon

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care, there was only one mention of a social worker—and even then it was not clear that the person was actually a social worker or the reason for his or her call.

These themes were similar to those expressed in focus groups conducted by Project ACHIEVE, an ongoing, PCORI (Patient-Centered Outcome Research Institute)-funded national study of patient and family caregiver experiences in transitions, mainly from hospital to home.

### **Family Caregiver Responses to Video Clips**

In general, most family caregivers had not considered videos as a potential source of information. They liked the idea of videos but seemed unsure about whether they would actually seek them out. Some didn't even use computers, while others were very familiar with Google and YouTube. A few cited Google as their first approach to getting information that they didn't get from a

health care provider. One man said he asked his daughter to find information on Google.

Because these caregivers had little or no experience in learning through video instruction, and the video clips were short, these responses should be seen as suggestive, not definitive. Caregiver responses depended on the type of message and the context. When the information was technical (showing how to remove a bandage safely), they preferred clinicians as presenters. For a problem such as dealing with refusal to take medications, they liked a more informal home setting. Several commented that the videos showing conversations with patients in the doctor's office were unrealistic because doctors don't spend that much time with a patient. Many specifically wanted caregivers to be in the picture, not just the clinician and the patient.

Whether or not they liked the video, many commented that they had learned something. After viewing a video showing a strategy for eliciting cooperation in taking medications by pointing to a letter from a doctor that the patient liked, one caregiver said, “I'm going to try that. It would probably work better than what I am doing now.” She had been raising the specter of hospitalization if the person didn't take the medicine. Another caregiver said, after viewing a video about wound care, “I could just cry, knowing that this information was available to me and nobody told me about it.” Other caregivers valued the experience of seeing

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*This is serious stuff. Cartoons are silly.*

–Lily

*I don't have time to be entertained. I just want the information.*

–Jackie

information that they already had in a visual format. Most liked videos that had graphics or bullet points reinforcing the spoken information. Some studies have found, however, that this kind of additional material can be distracting.

These caregivers definitely wanted printed material to accompany the videos. They didn't specify the format or whether it should be a printout of the same information or additional information. They saw videos as one piece of an overall approach to learning, not the only aspect. (As a follow-up activity, United Hospital Fund is preparing one-page supplements to the videos.)

Videos with cartoon characters were generally not popular, and several caregivers felt that attempts at humor fell flat.

On the other hand, they liked a video that showed wound care via animated graphics rather than via demonstration on a plastic dummy.

### **Principles of Adult Learning Theory**

Teaching adults is different from teaching children and different from teaching professionals or paraprofessionals. (See Appendix III for a selected bibliography.) Adult learning theory is based on a set of assumptions about how adults learn best. It originated in Europe in the 1950s and was popularized in the 1970s in the United States by Malcolm Knowles, who identified six principles of adult learning:

- Adults are internally motivated and self-directed.
- Adults bring life experiences and knowledge to the learning experience.
- Adults are goal oriented.
- Adults are relevancy oriented.

***Caregivers deserve respect for the daunting challenges they undertake and for the contributions they make to their family member, community, and the health care system.***

- Adults are practical.
- Adult learners like to be respected.

These principles echo many of the themes in the caregiver discussion groups. “Patient and family engagement” has become a mantra for culture change in the health care system. True patient and family engagement, however, has to start with the professional's willingness to meet caregivers at their current level of understanding and capabilities. And if these principles were to be updated, the final one —“Adult learners like to be respected”—would be “*should* be respected.” Caregivers deserve respect for the daunting challenges they undertake and for the contributions they make to their family member, community, and the health care system.

The participants in the discussion groups exhibited all of these characteristics: They were self-directed and motivated by the desire to take good care of their ill family members; there were no external rewards or incentives. They had a lot of life experiences and knowledge that could have been utilized but generally wasn't known or incorporated. They were goal oriented and wanted information that was directly relevant to their situations. They looked for practical advice, not theory. Finally, they wanted to be respected but often felt that they were ignored.

These principles were developed with classroom or one-on-one learning in mind, not video instruction. But they can be applied to videos, as suggested in the following list of do's and don'ts. And they can also be used as general guides to communication with family caregivers.

## Do's and Don'ts for Caregiver Instructional Videos

The following recommendations are based not only on the basic themes articulated by the discussion group participants but also by a review of relevant literature (see Appendix III) and by the suggestions of Dr. Felise Milan, consultant to United Hospital Fund. These recommendations serve as a foundation for all future instructional videos that will be developed under the *Home Alone Alliance*.

### Do's for Video Development

**Do respect the family caregiver's close relationship with the person needing care by acknowledging the emotional impact of caregiving.** The caregiver's relationship with the person requiring care is different from that of a professional or paraprofessional. A professional has expertise about accomplishing the task, but the caregiver has expertise about the person and how he or she responds to being cared for as well as the limitations of the home environment. Learning is a partnership; the professional is learning about the patient, caregiver, and the home, while the caregiver is learning how to do the job better.

**Do incorporate principles of successful teaching of psychomotor or technical skills, which usually require both hands-on observation and feedback.** See Appendix III for references.

- Begin by laying out the learning objectives and the knowledge that the caregiver will attain.
- Stimulate recall of prior learning. Information is more likely to be transferred from short- to long-term memory (and therefore remembered) when it is attached to a schema and/or a bundle of information the learner already knows. (See item c below.) Using cues for retrieval can also assist with this.
- Research has shown that learning proceeds more easily if a large list is divided into chunks of about five to seven items and each chunk is mastered before the next chunk is taken on.
- Move from very simple to increasingly more complex information or tasks.

- For novice learners, the procedure should be broken down into its most basic tasks, and each step should have a discrete beginning and end.
- Demonstrating the whole procedure, followed by the discrete parts—then followed again with the whole procedure—has been shown to be effective.

**Do relate the task to a more commonly performed activity.** This demystifies the task and puts it in a familiar framework. Where appropriate, relate the task to something the caregiver already knows—for example, making sure all the needed supplies are organized in an easily accessible place, as one would do in the kitchen or garage.

**Do provide basic instruction as well as tips for adapting these techniques to the patient's specific need and environment.** For example, a caregiver may have to clean a different type of wound or recognize a range of medication side effects. This prepares the caregiver to be able to adapt the procedure, as needed, or ask for further instructions.

**Do encourage caregivers to make sure they have (or know who to ask for) the following key pieces of information on medications:**

- What are the two names of the medicine (brand and generic)?
- Why was it prescribed for your family member? Medicines often have more than one use.
- What are the dosing intervals, and what other information is relevant to dosing? An example would be to take a pill with food or during a certain period after eating breakfast. (Some caregivers may be confused by the common phrase “on an empty stomach,” so that should be explained by referring to a time period.)
- What are common side effects with this medication? What else should the caregiver look out for?
- What are important reasons the person should not be taking a particular medication? For example, allergies or drug interactions.
- Are there harmful effects to stopping the medicine? Does the dosing need to be tapered off?

- Whom should I call if I have questions? Alternatives to physicians include home care nurse and pharmacist.
- What are different ways to keep track of medications?

**Do identify the source for the clinical information.**

It is important to ensure that the video comes with backing from a reputable clinical source (professional organization, university, medical center, etc.) as well as AARP. The Internet is full of dubious information. Some disclaimer suggesting further discussions with the patient's health care provider will also be appropriate.

**Do offer authoritative resources for more information.**

This could be websites, publications, or other sources. The printed material accompanying the video could include a guide to identifying reliable sources for information—for example, avoiding products sales pitches, promises of quick cures, and the like. Studies of videos on YouTube show that viewers watch videos that are produced by individuals (often with inaccurate information) more often than those produced by credible organizations.

**Do build trust between instructor and caregiver by acknowledging that some tasks are difficult for a variety of reasons.**

**Do show the family caregiver doing the task, with an instructor providing supervision.** Videos showing only the instructor don't give the caregiver confidence that he or she can learn the task too.

**Do make sure the title of the video is easily understood and relevant to the topic.**

**Do keep the video short.** If the task is simple or the message straightforward, try to keep the video to about two to five minutes. More complicated tasks can be divided into segments of three to five minutes or into separate videos. Give the viewer time to absorb the procedure before moving on to the next step.

**Do choose the professional speaker carefully.** It should be someone who is comfortable demonstrating the tasks but who also has an engaging and friendly, but not effusive, manner.

**Do keep language simple and explain any technical terms.**

**Do organize the content in segments that can be readily learned.** This helps prevent "cognitive overload" and loss of concentration, which occurs when too much material is being presented too quickly.

**Do make sure the professional speaks clearly and at a normal rate of speech.** Older caregivers may not be able to follow very rapid speech patterns.

**Do use bullets or graphics selectively to reinforce the spoken presentation.**

**Do, where appropriate, choose a home setting rather than a clinic or doctor's office.** Procedures or management skills that are going to be used at home should be demonstrated in a home setting.

**Do keep the background and format simple to allow for viewing on mobile devices.**

**Do use closed-captioning for the hearing impaired.**

**Do consider multiple variations in different languages or add translations to reach specific groups.**

### **Don'ts for Video Development**

**Don't ignore the patient in focusing on the caregiver.**

Both are important; caregivers will be alert to depictions of treating the patient roughly or insensitively.

**Don't oversimplify complicated tasks.** Acknowledge it may take time to get it right and that it is important to follow the steps in order.

**Don't start in the middle of the task; start at the beginning.**

**Don't use condescending language.** While instructors may not intend to be condescending, they may use language that suggests that the task is so easy to learn that questions are either unnecessary or signs of inattention.

**Don't clutter the video with extraneous information or visuals.**

**Don't try to be funny.** Humor may arise out of the situation but don't force it.

**Don't be overly enthusiastic or cheerful.** Chances are, the caregiver doesn't share those feelings.

### AARP's Future Plans

The Do's and Don'ts proved immensely useful in the development of the story lines and content of the first series of videos. The initial series focuses on medication management. Specific topics include:

- Guide to Giving Injections
- Beyond Pills: Eye Drops, Patches, and Suppositories
- Conversations with the Pharmacist (Spanish)
- Overcoming Challenges: Medication and Dementia
- Shoebox of Bottles: Understanding and Organizing Complex Medication Routines

Additional series will focus on such topics as wound care, preventing pressure ulcers, and mobility, among others. In addition to instructing family caregivers how to perform complex medical/nursing tasks, these videos will be used to enhance the curriculum in nursing schools and professional development for current nurses across the country.

A collaboration with the *American Journal of Nursing* will produce a special supplement to their monthly journal. It will highlight these videos while offering professional nurses and students' instruction into how they can use this material to improve the instruction that is given to families performing medical/nursing tasks.

The videos and other related tools will live on AARP's website ([www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone)). The benefit of this placement is that family caregivers will have access to tools and resources that speak to their needs across the spectrum.

Two of the desired outcomes of the *Home Alone Alliance* are (1) to decrease the stress of the family caregiver by empowering them through instruction, and (2) increase the knowledge of health care professionals, specifically nurses, in how to instruct family caregivers. This first series of videos along with accompanying tools is the first in a series of efforts to change the field so that family caregivers no longer feel "home alone."

## Appendix I: Moderator's Guide for Discussion Groups for United Hospital Fund/AARP PPI Video Development Project

*NOTE: This guide assumes that all participants will have experience in either medication management or wound care. If only one or two have experiences in wound care, then the main focus will have to be on medication management. We will try to get this information ahead of the session, but it may be incomplete.*

### Welcome

Thank you for coming. My name is [MODERATOR TO FILL IN], and I will be your moderator today. Speaking for myself and the United Hospital Fund staff, we all appreciate your willingness to share your experiences and ideas, and we look forward to talking with you.

### Describe the Project Very Briefly

This discussion group has been brought together by the United Hospital Fund, working with AARP Public Policy Institute. The United Hospital Fund is an independent nonprofit health services research organization. It is not affiliated with any hospital, health care provider, or drug company. I'm sure you know about AARP and its many activities on behalf of older adults, but you may not know that AARP has taken on family caregiving as a major issue.

AARP's Public Policy Institute is developing a series of videos to help train family caregivers to do some of the tasks that research has shown to be most challenging—managing multiple medications of different types and doing wound care. The purpose of this discussion is to hear your perspectives on these topics. We want to know what you think is important for us to tell the people who will actually make the videos.

### Some Housekeeping Information

- Location of bathroom
- Refreshments—help yourself at any time.

### Ground Rules for Our Discussion

- We have some ground rules for the group today:

- We'd like you to write your first name—or any name you choose—on a name tag. Your name tag makes it easier for other people to refer to your comments when they want to add to what you have said.
- There are no right or wrong answers.
- We have several topics to cover, so we will not be able to talk about every aspect of your experience.
- We want to give everyone an opportunity to talk about each topic, so try to be brief.
- I may sometimes need to stop you so we can get back on target and get through all of our topics.
- To make it easier for us to listen and not take too many notes, this discussion is being audio taped, to make it easier for us to listen and not take too many notes. We are conducting several discussion groups and will use the recordings to summarize caregivers' perspectives on this topic. We will not disclose your identity to anyone or attribute the recorded comments to you in any way.
- Since we are taping, we all need to speak up, one person at a time.
- The discussion in this group is confidential. Please do not share what you hear in this conversation with others.
- Any questions?

Most people enjoy these groups as an opportunity to talk with others about experiences they have shared. Please relax and be as open as possible.

### Let's Get Started

Introductions: First, I'd like to go around the room and ask each of you to give the name you have chosen for your name tag. Please tell us a little about yourself and the person you are taking care of.

Probe for:

- relationship
- how long individual has been a caregiver
- whether caregiver is employed

- age of patient
- condition of the patient
- what kinds of medical/nursing tasks are part of care
- anything else caregiver wants to be sure we know

Elapsed time: 20 minutes

Most of the time when you are asked questions, it is about the person you are caring for. For the purposes of this group, though, we will ask you to focus on your experiences as a caregiver. In other words, tell us how you felt and how you were treated, not what happened to the patient—unless it's because you didn't get appropriate information or training.

*Note: The probes in the following sections are suggestions and may be modified as the group progresses. It is important, however, to get to the questions about the videos.*

### Medication Management

Let's talk about medications first. Nearly every family caregiver has to deal with many medications. Sometimes they have to be given at different times of the day and have different side effects. Think back to a time when you had to learn about new medications or a new way of administering a medication (for example, injection or an IV infusion). It might have been during a hospital discharge, an ER visit, or a doctor's office. You can write down a few notes if that will help.

PAUSE

Probe:

- What information did you receive about giving this medication? What kind? Instruction sheets?
- Did someone ask you to repeat the information to make sure that the instructions were clear? Who showed you?
- Was the instruction realistic? For example, did it meet your needs in a way that was easy for you to understand and get access to?
- What was helpful?

- What was missing? Is there anything that you wish you had been taught that you were not taught?
- What was the hardest part of learning to manage your family member's medications?
- How do your health care providers provide training and resources for you?
- How do you get general information about managing medications?
- Have you ever used caregiver training videos? If so, where do you find them, and how helpful are they?
- What do you think are the most important points a video on medications should cover?
- Would you watch a video on a computer, a smartphone, or TV?
- Where would you go to find a video on medication management? An organization website? YouTube? Somewhere else?

Now I'm going to show you a short clip from an existing video. I'd like to get your quick reaction. What do you think of it? What parts were done well? What could be improved? What would you have preferred that they covered?

Elapsed time: 30 minutes

### Wound Care

Not as many family caregivers do wound care as manage medications. But for those who do, it can be a challenging and upsetting task. Let's go through the same process as we did with medications. Think back to a time when you had to clean and dress a wound—for example, after surgery, or for a chronic condition such as diabetes, or taking care of a colostomy.

Again, write down a few ideas if it helps.

PAUSE

Probe:

- Were you given a choice about whether to do this kind of care?
- What was the hardest part of learning to do wound care?

- Did you receive any information about how to keep the wound clean and free from infection?
- Did you receive any information about supplies you would need?
- Did someone demonstrate how to take care of the wound? How many times?
- Did anyone watch you to make sure you were doing everything correctly?
- Who showed you?
- Was the instruction realistic? For example, what did it say about what to do if your family member was in pain or complained about the treatment?
- What was helpful?
- What was missing? Is there anything that you wish you had been taught that you were not taught?
- Where do you get general information about wound care?
- What do you think are the most important points a video on wound care should cover?
- Would you watch a video on a computer, a smartphone, or TV?
- Where would you watch a video? What device would you use (a computer, a smartphone, or TV)?

- Where would you go to find a video on wound care? An organization website? YouTube? Somewhere else?

Elapsed time: 30 minutes

### Some Final Questions

We've focused on the content of videos today. I want to close our discussion by asking you what other kinds of information and training you would like to recommend as part of the caregiver learning process.

- Written instructions to accompany the videos?
- Diagrams or other visual aids?
- More hands-on training by nurses?
- Anything else?

Elapsed time: 20 minutes

Thank you for coming. You have been a great group, and your comments will be very helpful as the project moves forward. I hope everything goes well for you and your family in the future. If there's anything else you'd like to tell us, please send a follow-up e-mail or phone call.

## Appendix II: Fact Sheet Sample

### Are You a Family Caregiver Who Manages Medications or Does Wound Care?

*Join us to share your experiences and offer advice for an important project.*

#### Sponsor

The Families and Health Care Project at United Hospital Fund\* is working with the AARP Public Policy Institute on a project that will develop a series of videos to help meet family caregivers' training needs to perform tasks like medication management and wound care. United Hospital Fund is not affiliated with any hospital, health care provider, drug company, or other commercial organization.

#### When, Where, and More Details

- Monday, May 4, from 5:30 to 7 p.m.
- Offices of Alzheimer's Association New York City chapter, 360 Lexington Avenue, 3rd floor
- Refreshments will be served.
- You will receive \$40 as a thank-you for your participation.
- A professional moderator will lead the discussion.
- Everything you say will be confidential and will not be shared with anyone outside the project team.

#### Who Should Attend

We are looking for family caregivers who are performing or have recently performed **either or both** of these hands-on caregiving tasks:

- **Medication management** that is complicated because of the number of medications (pills, liquids, or ointments), the timing for taking them, or the way they have to be administered (by injection, IV infusion, nebulizer, or other methods)
- **Wound care**, such as post-surgery care, colostomy care, or prevention and treatment of pressure sores/ulcers

We want to know about your real-world experiences: how you learned to do what you do, how you felt about taking on this responsibility, and how videos might play a role in learning and remembering what to do.

#### For More Information and to Sign Up

Contact Kristina Ramos-Callan, program manager, United Hospital Fund.\*

\*United Hospital Fund is an independent nonprofit organization working to build a more effective healthcare system for every New Yorker.

### Appendix III: Selected Bibliography

#### Adult Learning Theory

Knowles, Malcolm S., Elwood F. Horton III, and Richard A. Swanson. *The Adult Learner: The Definitive Classic in Adult Education and Human Resource Development*. 8<sup>th</sup> ed. New York: Routledge Publishing Company, 2015.

This edition of a pioneering class has been updated to include chapters on neuroscience and andragogy (the science of how adults learn as opposed to pedagogy, the science of teaching), and information technology and learning.

Lorenzi, Gayle, Barbara Schreiner, Joachim Osther, and Marilyn Boardman. "Application of Adult-Learning Principles to Patient Instructions: A Usability Study for an Exenatide Once-Weekly Injection Device." *Clinical Diabetes* 28 (2010): 157–162.

People with type 2 diabetes were able to learn to do a weekly injection after being trained with a PIU (patient instruction for use) kit that incorporated adult learning theory principles to decrease the burden of learning. The device instructions laid out the steps needed to prepare and administer a dose, a small flip-book format helped learning focus on each instructional step, and a coli-bound design was used to keep pages flat during use. Line drawing, a simple color palette, and abundant use of white space decreased visual clutter.

Mayer, Richard E. *Multimedia Learning*. 2<sup>nd</sup> ed. Cambridge University Press, 2009.

A classic study of applying principles of cognition and engagement to multimedia. The 12 Principles of Multimedia Learning are available from the University of Hartford Faculty Center for Learning Development at [http://hartford.edu/academics/faculty/fcld/data/documentation/technology/presentation/powerpoint/12\\_principles\\_multimedia.pdf](http://hartford.edu/academics/faculty/fcld/data/documentation/technology/presentation/powerpoint/12_principles_multimedia.pdf).

Van Merriënboer, Jeroen J. G., and John Sweller. "Cognitive Load Theory in Health Professional Education: Design Principles and Strategies." *Medical Education* 44 (2010): 85–93.

Although designed for professional education, the principles can be applied to nonprofessional training. Design principles stress minimizing cognitive load (the amount of information a learner, especially a novice, can incorporate) and also minimizing extraneous load imposed by instructional procedures that may be confusing or inchoate.

#### Training for Technical Skills

Aggarwal, Rajesh, Teodor P. Grantcharov, and Ara Darzi. "Framework for Systematic Training and Assessment of Technical Skills." *Journal of the American College of Surgeons* 204, no. 4 (2007): 697–705.

Although the framework is intended for a surgical audience, the authors say that the task-based techniques can be used as a model for instructing people who do not have medical training. They stress fragmenting the procedure into its constituent parts with a defined beginning and end to each part.

Buscombe, Charlotte. "Using Gagne's Theory to Teach Procedural Skills." *The Clinical Teacher* 10 (2013): 302–307.

The author uses the nine points described by Robert Gagne to design lesson plans and teach procedural skills in small group settings. Gagne's model is based on the information-processing model of mental events that occur when adults are presented with various stimuli.

National Guidelines for Educating EMS Instructors. 2002. *Module 17: Teaching Psychomotor Skills*.

Intended for EMS (Emergency Management Staff) learners, this teaching module outlines the cognitive, psychomotor, and affective goals involved in teaching the skills, action, muscle movement, and manual manipulation that are crucial to EMS practitioners (and family caregivers). The affective goals include valuing the need for students to practice until they attain mastery.

### Studies of Video Instruction

Chen, H. M., Z. A. Hu, X. L. Zheng, et al. "Effectiveness of YouTube as a Source of Medical Information on Heart Transplantation." *Interactive Journal of Medical Research* 2, no. 2 (2013): e28.

YouTube videos on heart transplantation provide a substantial amount of information; however, it is time-consuming to find high-quality videos.

Madathil, Kapil Chalil, A. Joy Rivera-Rodriguez, Joel S. Greenstein, and Anand K. Gramopadhye. "Healthcare Information on YouTube: A Systematic Review." *Health Informatics Journal* 21, no.3 (September 2015): 173–194.

The authors analyzed the peer-reviewed literature on health information available through YouTube and found that videos from government organizations and professional associations provide trustworthy and high-quality information, but the platform is also used as a medium for promoting unscientific therapies and unapproved drugs. Interventions need to be designed to enable consumers to critically assimilate the information posted on YouTube.

McAlister, Robert. "Conference Proceedings: Use of Instructor-Produced YouTube Videos to Supplement Manual Skills Training in Occupational Therapy Education." *American Journal of Occupational Therapy* 68, no. S2 (2014): S68–S72.

Videos improved the quality of a course in clinical manual assessment, increased students' level of engagement and learning, and boosted confidence in their manual skills.

Rittberg, Rebekah, Tharindri Dissanaayake, and Steven J. Katz. "A Qualitative Analysis of Methotrexate Self-Injection Education Videos on YouTube." *Clinical Rheumatology* 35, no. 5 (May 2016): 1329–1333.

This study demonstrates that a minority of videos are useful for teaching methotrexate (MTX) injection and that video quality does not correlate with video views—that is, patients do not differentiate between useful and misleading videos. While web video may be an additional educational tool available, clinicians need to

be familiar with specific resources to help guide and educate their patients to ensure best outcomes.

Salina, Loris, Carlo Ruffinengo, Lorenza Garrino, et al. "Effectiveness of an Educational Video as an Instrument to Refresh and Reinforce the Learning of a Nursing Technique: A Randomized Controlled Trial." *Perspectives in Medical Education* 1 (2012): 67–75.

The authors found that nursing students who had seen a video about moving an uncooperative patient were better able to apply the technique than those who had only read up on the technique.

Wellbourne, Dustin J., and Will J. Grant. "Science Communication on YouTube: Factors That Affect Channel and Video Popularity." *PUS (Public Understanding of Science)* 25, no. 6 (August 2016): 706–718. First published on February 19, 2015.

A content analysis of 390 videos from 39 YouTube channels found that while professionally generated content is superior, user-generated content was significantly more popular. Videos that had consistent science communicators were more popular than those without a regular communicator.

Wittenberg-Lyles, Elaine, Debra Parker Oliver, George Demiris, et al. "YouTube as a Tool for Pain Management with Informal Caregivers of Cancer Patients: A Systematic Review." *Journal of Pain and Symptom Management*. Online April 2, 2014. [http://www.jpsmjjournal.com/article/S0885-3924\(14\)00227-9/pdf](http://www.jpsmjjournal.com/article/S0885-3924(14)00227-9/pdf).

Most videos on pain management were directed toward a clinical audience, and the authors recommend future research to determine if the platform is feasible and beneficial as a support tool for oncology caregivers.

### Advice on Creating Instructional Videos

O'Rourke, Jennifer. "How to Videos—10 Tips to Making More Effective Training Videos." Videomaker.com. 2012.

<https://www.videomaker.com/videonews/2012/10/how-to-videos-10-tips-to-making-more-effective-training-videos>.

Stresses using a script, keeping it succinct, ensuring good audio, and employing simple graphics.

Pratt, Ellis. "The Ideal Length for Instructional Screencast Videos." *Cherryleaf Blog for Technical Authors & Content Strategists*. Posted November 14, 2014. <https://www.cherryleaf.com/blog/2013/11/the-ideal-length-for-instructional-screencast-videos/>.

Points out that shorter videos are better for getting people to watch the whole thing; the longer the video, the fewer people will watch it. After a certain point, engagement average flattens out; viewers tend to skip the parts they find boring and take a second look at the parts that are interesting or confusing.

Swarts, Jason. "New Modes of Help: Best Practices for Instructional Video." *Technical Communication* 59, no. 3 (2012): 195–206.

Stresses application of good printed instructions to video introduction that frames lesson to be learned; spends more time doing AND explaining rather than doing or explaining alone; content should be easy to locate and access, understand and utilize, and engaging and reassuring.

Vest, Jeremy. "Six Steps to Creating High Quality Video Training." *Learning Solutions Magazine*. 2009.

Covers basic step in production; stresses keeping videos simple to access and easy to watch. Offering quizzes or tests after the video helps learners complete the learning cycles. Recommends a limit of 10 minutes for a video. <http://www.learningsolutionsmag.com/articles/185/six-steps-to-creating-high-quality-video-training>.

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